

# Arizona Alzheimer's Registry: Strategy and Outcomes

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## ABSTRACT

**Background:** The Arizona Alzheimer's Consortium (AAC) created the Arizona Alzheimer's Registry, a screening and referral process for people interested in participating in Alzheimer's disease (AD)-related research. The goals of the Registry were to increase awareness of AD research and accelerate enrollment into AAC research studies.

**Methods:** Participation was by open invitation to adults 18 and older. Those interested provided consent and completed a written questionnaire. A subset of participants underwent an initial telephone cognitive assessment. Referral to AAC sites was based on medical history, telephone cognitive assessment, and research interests.

**Results:** 2263 people contacted the Registry, 1257 consented and 1182 underwent an initial cognitive screening. Earned media (38.7%) was the most effective recruitment strategy. Participants had a mean age of 68.1 (SD 10.6), 97% were Caucasian, had 15.2 (SD 2.7) mean years of education, and 60% were female. 30% reported a family history of dementia and 70% normal cognition. 301 were referred to AAC sites.

**Conclusion:** An infrastructure and process to screen and refer a high volume of potential research participants was created and allowed the Registry to increase awareness about AD research opportunities, enroll a large number of people into this statewide Registry, and refer hundreds of potential participants to AAC sites. The established infrastructure and experiences gained from the Registry will serve as the prototype for the web-based Alzheimer's Prevention Registry ([www.endalznow.org](http://www.endalznow.org)), a national registry focusing on AD prevention research.

## INTRODUCTION

### Arizona Alzheimer's Consortium (AAC)

- A statewide Alzheimer's disease (AD) research consortium funded by the National Institute on Aging (NIA) and the state of Arizona.
- Institutions include:
  - Arizona State University
  - Banner Alzheimer's Institute
  - Banner Sun Health Research Institute
  - Barrow Neurological Institute
  - Mayo Clinic Arizona
  - Translational Genomics Research Institute
  - University of Arizona

### Arizona Alzheimer's Registry (Registry)

- Devised in 2006 by the AAC to facilitate enrollment into current and future AD clinical trials

## METHODS

### Registry Goals

- Increase awareness of research in the fields of dementia and AD
- Expedite enrollment into clinical trials
- Enhance research within the AAC

## Enrollment

- Participation was by open invitation to adults over 18 with a target audience of 50 and older.
- Participants were recruited with a multimedia campaign.
- Interested volunteers received a welcome packet including:
  - Informed Consent
  - Questionnaire
- After returning the completed consent and questionnaire, participants were contacted by telephone for a verbal review of the consent form and telephone assessment.

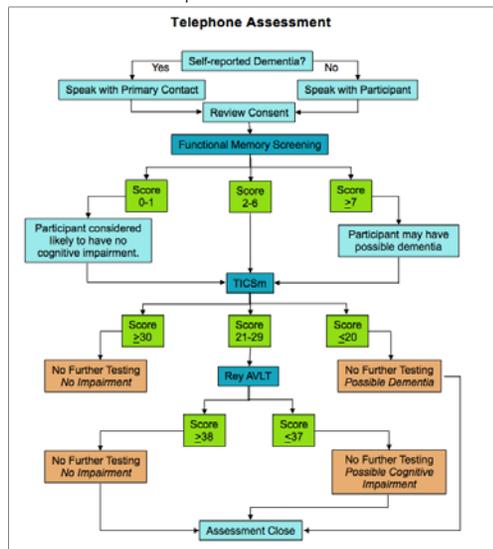


Figure 1: Sequence of telephone assessment components. TICS = Telephone Interview Cognitive Screen modified; AVLT = Auditory Verbal Learning Test.

## Referral

- Evaluation of medical history, cognitive status, and interests resulted in a referral to existing AAC studies or being held for future referral.
- In some cases, additional clinical assessment with the participant's primary care physician (PCP) was recommended, referral to specialty clinics, or for further evaluation under the Confirm sub-study.
- Participants who were referred to AAC research sites were then screened for eligibility and contacted by the receiving AAC.
- The number and type of trials enrolling at AAC sites fluctuated over time and included:
  - Non-intervention studies for people with and without memory problems
  - Treatment trials for people with a diagnosis of AD or Mild Cognitive Impairment (MCI)

## RESULTS

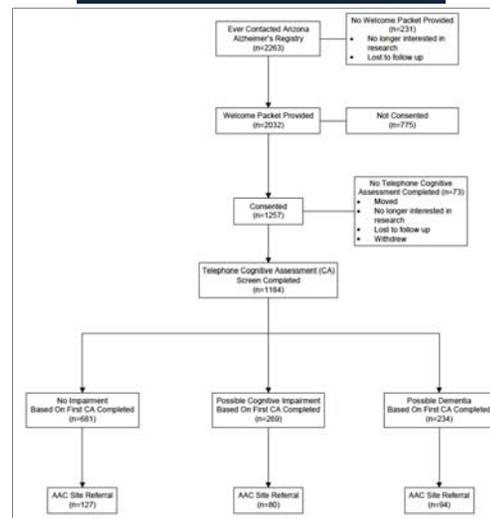


Figure 2: Registry consent diagram depicting the progress of volunteers through stages of participation.

Age	68.1 ± 10.6
Education	15.2 ± 2.7
Sex	Female 1168 (60.3) Male 770 (39.7)
Race	White 1485 (127.2) Other 19 (1.2) Asian 10 (0.7) Black or African American 9 (0.6) American Indian/ Alaska Native 4 (0.3)
Ethnic background	Non Hispanic 855 (94.0) Hispanic 55 (6.0)
Marital status	Married 1178 (69.9) Divorced 218 (13.8) Widowed 194 (12.1) Single 77 (4.8)
Living situation	Family/Spouse 955 (75.4) Alone 294 (23.2) Other 18 (1.5)
Self reported family history of dementia	Yes 68 (1.1) No or Missing 1582 (69.9)
Self reported memory status	Normal 1037 (61.2) Mild Memory Loss 483 (28.5) Significant Memory Loss 168 (9.9) Unknown 7 (0.4)
Self reported diagnosis	Alzheimer's Dementia 142 (60.3) Dementia, unspecified 36 (14.6) Mild Cognitive Impairment 22 (8.9) Other Dementia 40 (16.1)

Table 1: Registry participant demographics. Age and education are mean years ± standard deviation, all others are number and percent, n(%).

Referral to Registry	n (%)
Source	Newspaper article (earned) 716 (33.8)
	Direct mail (paid) 380 (16.8)
	Presentations/meeting 201 (8.9)
	Webinars 183 (7.2)
	Personal Contact 149 (6.6)
	Newspaper/mag article (earned) 128 (5.7)
	Unreported 95 (4.2)
	Internal corporate affiliate 94 (4.2)
	Health professional 78 (3.5)
	Newspaper advertising (paid) 49 (2.2)
	All Other 205 (9.1)
Source Categories	Earned Media 875 (39.7)
	Other 822 (35.8)
	Paid Advertising 471 (20.8)
	Health Related 237 (10.5)
	Unreported 95 (4.2)

Table 2: Referral source as reported by participant.

- 943 (75%) participants reported interest in participating in prevention studies
- 301 participants were referred to AAC sites.

## DISCUSSION and CONCLUSION

### Successes

- An infrastructure and process to screen and refer a high volume of potential research participants was created
- Increased awareness of AD research opportunities
- Enrolled a large number of people into this statewide Registry
- Referred hundreds of potential participants to AAC sites

### Enrollment

- Lengthy paper based questionnaire with postal mail return and telephone cognitive assessment
- Level of burden may have prohibited some volunteers from enrolling
- Modifications to the enrollment process that may alleviate enrollment barriers:
  - A simplified questionnaire with electronic completion
  - An optional telephone cognitive assessment
- Volunteers were self-selected and were not representative of the general population of Arizona:
  - future efforts should consider focused recruitment of these individuals

### Cognitive Assessment Findings

- The detection of possible, previously unrecognized cognitive disorders
  - Warranted further clinical work up before an appropriate research referral could be made.
  - Ambiguous telephone assessment findings created a referral dilemma.

### Referrals

- Research referral was dependent upon clinical trial availability.
- There were limited study opportunities for cognitively normal volunteers, who primarily were interested in prevention research.

### Future Directions

- The AAR serves as the model for the web-based Alzheimer's Prevention Registry ([www.endalznow.org](http://www.endalznow.org)), an online community and national registry focused on AD prevention research.

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