



Recruitment of ADC Participants

Virginia Buckles, PhD

Research Associate Professor of
Neurology



Changes in Motivation - 20 years

Then	Now
Motivations	Motivations: '03 survey
Altruism ("want to help; if not for us, then for our children")	Altruism ("Want to help") - 62%
Expert diagnosis	Seek knowledge/info – 22%
Caregiver needs	More caregiver resources available
Access to drug trials when no therapy existed	Treatments available thru PCPs

Current Barriers to Recruitment

- More demanding protocols in frequency and duration
 - ADNI
 - » Controls/MCI, every 6 m for 3 y
 - » AD, every 6 m for 2 y
 - Weekly or biweekly visits for some clinical trials
- Higher risk clinical trials
 - Vaccine study
 - Other immunotherapy protocols
 - Secretase inhibitors
 - Gene therapy (e.g., nerve growth factor)
- More invasive or demanding procedures (PET, LP, infusions)
- Tighter eligibility criteria for entry (e.g., metal objects for MRI; blood thinners for LP)



Key factors in Washington University Recruitment Success

1. Cohort of dedicated research participants (not patients) from whom recruitment for other studies and clinical trials occurs.
2. Staff dedicated to both the research and the participants
3. Efficiency in entry requirements: tradeoff between the numbers enrolling and what they agree to do (MRI, PET, LP) (more 'Bang for the Buck')
4. Director support

1. Cohort Development and Care

- Establish supportive relationship with participants (customer service)
 - Nurses and social workers available for limited consultation and problem solving, willing to help if at all possible
 - Careful about participation burden and treatment by outside investigators (investigator orientation)
- Provide individual and group feedback and news
 - At end of individual clinical assessment
 - In quarterly newsletters
 - At annual participants meeting
- Provide whatever will make participation easier
 - Lunches
 - Taxi cabs, gas money
 - In-home assessments
- Maintain contact in between annual assessments (6 month 'check-up' phone calls)
- Create expectation of extended participation at entry
 - agreement at entry to participate in demanding protocols (LP, MRI, PET) and other studies as they come up
 - More 'Bang for the Buck'
- "We need them, they don't need us"

2. *Staff Development and Care*

- Professional and dedicated staff
 - 80% of clinical assessments are performed by physicians (important to some participants, they have a choice)
 - Nurses are all masters' prepared with interests in research, many hold faculty rank
 - Extensive training (not expected to be independent for ~ 1 year, physicians or nurses)
 - Only hire nice people



3. Efficiency - WU ADRC Recruitment Policy (8/1/04)

- Limited capacity for clinical assessments, can't afford participants who won't entertain possibility of participating in all procedures
- All new enrollees commit "up front" to:
 - Longitudinal participation
 - Genetic studies
 - Imaging (MRI; fMRI; PET)
 - LP for CSF analysis

4. *Director Support*

- Creates an infrastructure and environment that supports recruitment
 - ‘Customer service’ attitude is rewarded
 - Necessary resources are provided (time, personnel, etc.)
- Regular and direct involvement with staff on recruitment is critical

Challenges

- Emphasis on diversity
- Representativeness of sample (anyone who would agree to all this isn't normal)

Ralphs-UCLA Alzheimer Disease Center Collaboration: A Partnership for Care





- Premier regional pharmacies
- Broad patient/customer base
- A preferred partner for UCLA

Ralphs/UCLA ADRC Partnership Benefits

- Enhanced value for both partners
- Improved range of services for Ralph's customers
- Ready referral to UCLA ADRC
- Increased recruitment to UCLA treatment discovery programs
- Progress toward breakthrough treatments

Ralphs/UCLA ADRC Partnership in Action

- Provide referral information to all customers receiving FDA approved anti-dementia therapies
 - Aricept (donepezil)
 - Razadyne (galantamine)
 - Exelon (rivastigmine)
 - Namenda (memantine)

Ralphs/UCLA ADRC Partnership in Action

- Provide referral information to all customers requesting memory screens
- Provide referral information on in-house displays
- Consider putting together a team for the Alzheimer's Association Memory Walk (October)
- Consider UCLA ADRC for corporate support programs

Ralphs/UCLA ADRC Partnership in Action

- Provide training to pharmacists on how to do the MMSE or other screen
- Conduct memory screening days in the stores (e.g., during Alzheimer's month)
- Provide faculty for community lectures sponsored by Ralphs

- Begin March 2006
- Reassess at 6 month intervals with meeting and opportunity for feedback from each partner
- Consider means of enhancing/adjusting partnership to further increase value





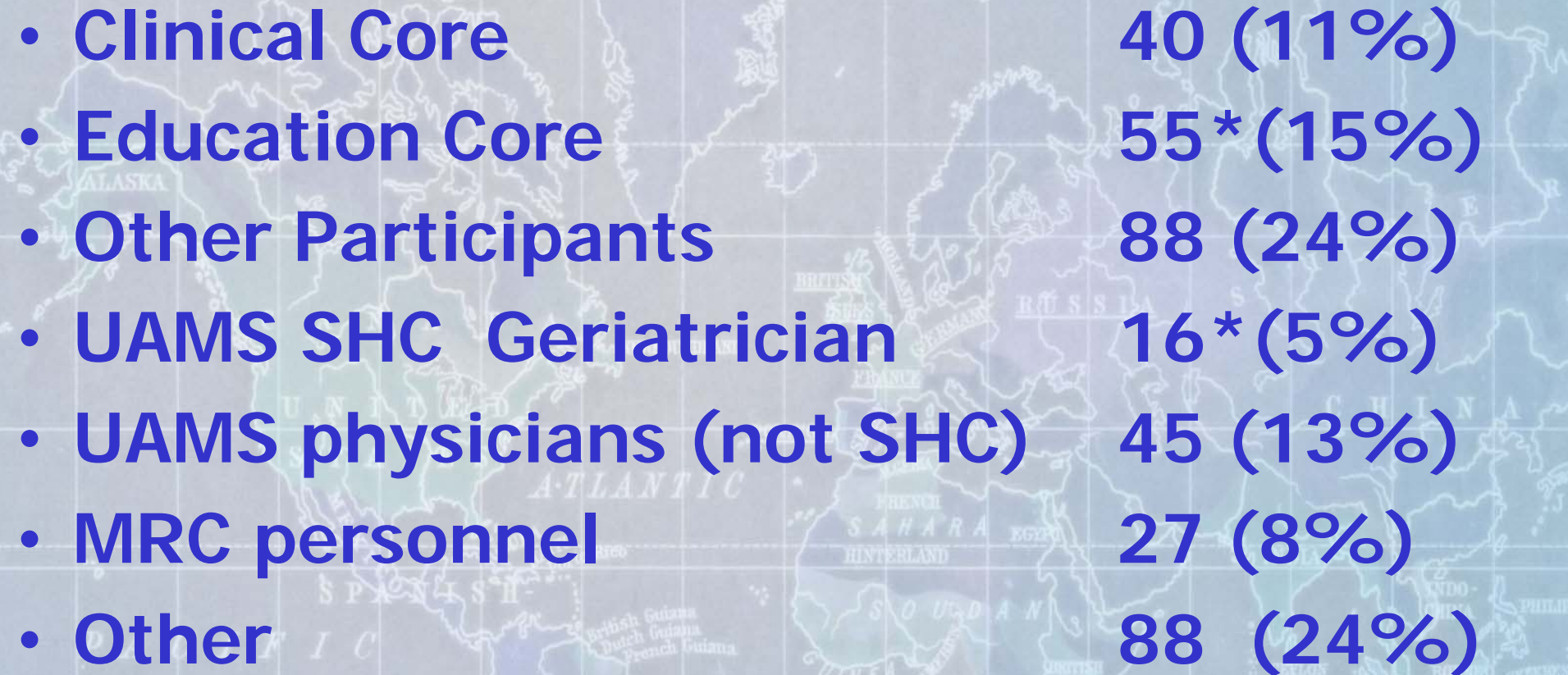
Arkansas Alzheimer's Disease Center

Recruitment Experience

Referrals Profile

- 350 Arkansas participants
- 6 out of state participants
- 36% rural
- 64% urban
- 30% African American
- 70% Caucasian

Methods of Referral

A faint world map is visible in the background of the slide, showing continents and oceans in light blue and green tones.

• Clinical Core	40 (11%)
• Education Core	55* (15%)
• Other Participants	88 (24%)
• UAMS SHC Geriatrician	16* (5%)
• UAMS physicians (not SHC)	45 (13%)
• MRC personnel	27 (8%)
• Other	88 (24%)

*majority AA recruitments

Methods of Referral

- Wide distribution of ADC materials through extensive state-wide rural networks
 - Area Health Education Centers
 - Arkansas Aging Initiative
 - 7 Rural Center's on Aging
 - 7 Rural Senior Health Clinics
- Speakers Bureau Development
 - Community Presentations
 - Over 120 over past 4 years
 - Mostly to predominantly AA communities

Methods of Referral

- Annual Family Information Day
- Mass Media and Printed Materials
 - Newspaper articles
 - Newsletter
 - Radio and television appearances
 - Webpage (averages ~3000 hits per month)
 - Brochures (over 5000 distributed)
 - "The UAMS Alzheimer's Disease Center"
 - "Autopsy: The Gift of Hope"
 - "What African Americans Should know about Memory Loss"
- AA Participant Referrals (receives 2 books of stamps per adjudicated participate)

African American Recruitment

- **African American Lay Educator**
 - Attends Church Series
 - Works unofficially in the lay community educating individuals regarding AD
 - Paid \$50 for every adjudicated referral
- **African American Community Outreach Advisory Committee**
 - Meets quarterly
 - Reviewed and gave suggestions for the "What African Americans Should Know about Memory Loss"

African American Recruitment

- **African American Church Series**
 - "Aging and Dementia"
 - 4-Week series
 - Average attendance 48
 - Yielded ~ 14 referrals each series
- **Physician Assistance**
 - Geriatrician at UAMS SHC devoted time to visit with AA individuals in the SHC waiting room
 - Meets with UAMS and other physicians and NP regarding ADC recruitment needs
 - ADC Neurologist met with local AA physicians to discuss project and recruitment

African American Recruitment

- Videotape Project
 - Recommendation from the AA Advisory Committee
 - "Participating in Research: A Legacy of Hope"
 - Shown by Advisory committee members in
 - Beauty parlors
 - Grocery stores
 - Festivals
- TV and Radio Interviews
 - Predominately AA stations
 - 14 interviews during the past 4 years

Lessons Learned

- African Americans distrust traditional medical centers staffed primarily by white personnel
- Our new Institute on Aging is intimidating to African Americans
- Must give something of value back to the AA community if we expect participation

Lessons Learned

- There may be a need to increase the gratuity for reimbursement
- Use older AA males, not younger females to recruit
- To emphasize health, normal aging and how to decrease risk for AD rather than the prevalence and symptoms of AD
- Efforts to recruit AAs may take several years to bear fruit.

A blue-tinted photograph of the Golden Gate Bridge in San Francisco, viewed from the water. The bridge's iconic towers and suspension cables are visible against a hazy sky. The water in the foreground is calm, and a small building is visible on the left side of the frame.

New Approaches to Dementia Heterogeneity

UCSF ADRC

- Who we want to recruit
- Experience with advertising
- Recruitment infrastructure

UCSF ADRC began in 4/04

5 year targets

- 100 Alzheimer's Disease
- 100 Mild Cognitive Impairment
- 75 Frontotemporal Lobar Degeneration
- 30 PSP/CBD
- 20 Creutzfeld-Jacob Disease
- 10 FTLD-ALS
- 100 Normal Controls

Hit or Miss

- Print ads
 - Daily Newspaper - Health Section
 - Sunday Paper
- Radio spot
 - Classical station
- TV news
 - Public relations
 - Patient participation

Are You a Healthy Adult?

The UCSF Memory and Aging Center needs healthy volunteers ages 45-85 with no memory problems to participate in a healthy aging study. Our study looks at cognition in healthy adults. Participation involves a neurological exam, emotions and memory testing and an MRI brain scan. A friend or family member must be willing to spend 3 hours with us.



Please call
(415) 476-8101
<http://memory.ucsf.edu>

UCSF

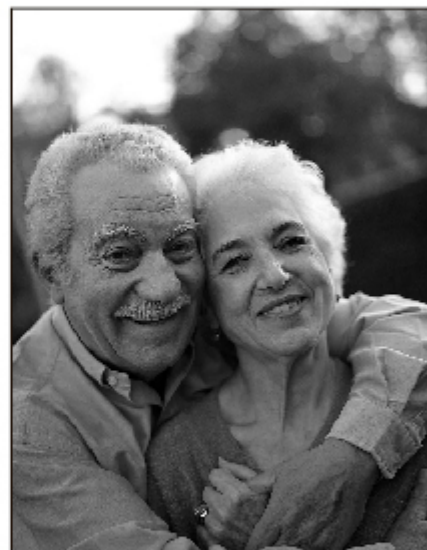


University of California
San Francisco

Does your loved one suffer from
ALZHEIMER'S DISEASE?

Are you interested in participating in research to help understand and treat this disease?

The **UCSF Memory and Aging Center** is currently seeking individuals with Alzheimer's disease to participate in observational studies and clinical trials, many of which investigate novel treatments. Participants must be willing to come to UCSF for study visits. Treatment and examinations are free of charge. The Memory and Aging Center is a NIH-designated Alzheimer's Disease Research Center.



For more information, please call
(415) 476-1681



MEMORY & AGING CENTER memory.ucsf.edu
350 Parnassus Avenue, Suite 706 San Francisco, CA 94117



- Nov 29, 2005 4:43 pm US/Pacific

- **UCSF Takes Aim At Alzheimer's**

- [Kim Mulvihill, M.D.](#)
Reporting

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- *(CBS 5)*

- Millions of Americans suffer from Alzheimer's, a degenerative and incurable brain disease.

A new experimental treatment is being tested in the Bay Area. The process targets a protein known as amyloid that gunks up the brain, and is thought to play an important role in Alzheimer's.

Researchers at UCSF are testing a new experimental treatment. An Antibody designed to clear amyloid from the brain. In animal studies, the antibody dramatically removed the buildup. It is now being tested in humans.

Dr. Adam Boxer heads up the trial at UCSF. He believes that the treatment will change the course of the disease.

"It's going to prevent some of the damage, some of the brain shrinkage that we see in this disease, some of the cognitive problems, memory, language navigational problems. It's going to help stabilize people over time," Dr. Boxer says.

Several drugs currently on the market treat symptoms of the disease. This experimental treatment aims at preventing the underlying damage.

Recruitment Sources

- 1. Clinic primary pipeline
- 2. Collaborators' cohorts
- 3. Letters to referring physicians
- 4. Partners
 - ADEAR
 - Alzheimer's Association
 - Family Caregiver Alliance
- 5. Advertising
 - Web
 - Print
 - Broadcast

'BEST CARE' Philosophy

- Clinical Services
 - UCSF
 - VA
 - Chinatown
- Collaborator's Cohorts
 - UC Berkeley Couples Study
- Consultation Services
 - Kaiser Permanente Members
 - Masonic Home Residents

ADRC

Cohort Research Teams

<u>Cohort</u>	<u>RA</u>	<u>MD</u>	<u>Cog</u>	<u>RN</u>	<u>Trials</u>
AD	Becky Weldon	Marilu Gorno - Tempini	Kate Rankin	Lea Ross	Huperzine Elan Myriad
CIND/ MCI	Katie Freeman	Howard Rosen	Julene Johnson	Lea Ross	none
FTLD	Victoria Beckman	Bill Seeley	Joel Kramer	Jennifer Merrilees	none