



# Promoting Research Participation as a Part of Healthy Aging



# Learning Objectives for Today's Presentation

- The **need for various types of research** on Alzheimer's and other dementias
- **Initiatives & resources** of the NIA, CDC, ACL relating to Alzheimer's disease and dementia
- **Materials** developed to help aging services and public health networks educate older adults and family caregivers on how research participation can be a part of healthy aging
- Ways that HCBS organizations & professionals can **promote these federally-funded resources** to their constituents
- **Lessons learned** by aging services and public health agencies in sharing research participation messages

# Top 8 Reasons why promoting research participation makes sense for HCBS professionals

1. Can **empower** older adults and caregivers with dementia, including Alzheimer's or other conditions
2. Provides a **civic engagement** opportunity for people of all health levels
3. Moves toward medical & HCBS **integration**
4. Offers opportunities to **build relationships** with partners, including those in medical and research disciplines
5. Helps build the research base to **improve practice & care**
6. Part of **core Information & Assistance/Referral** role
7. Keeps you & your organization on the "**cutting edge**" of science & practice
8. Potential **funding stream**

# Interest in Alzheimer's / dementia & research

- ACL (Aging Services Network)
  - Provide information, referrals & support to individuals & caregivers on Alzheimer's & dementia (I & A, ADSSP, Family Caregiver programs), as well as HCBS
  - Move toward healthy aging, prevention & evidence-based programs
  - Funds 24/7 National Alzheimer's Call Center (800-272-3900 or [www.alz.org](http://www.alz.org)) & manages [www.alzheimers.gov](http://www.alzheimers.gov)
- CDC (Public Health network)
  - Healthy Brain Roadmap
  - Many state public health departments involved in state Alzheimer's Plans and other state activities

# Aging and Public Health: Potential Channels

## **Aging Services**

- Information & Assistance Hotlines
- Health & Wellness Programs at Senior Centers & Nutrition Sites
- Caregiver Support groups
- Respite
- Aging & Disability Resource Centers
- Care Coordination, In-home Chore & Homemaker Programs
- Senior Transportation & Home Delivered Meal Programs

## **Public Health**

- Community coalitions
- Public health centers & clinics
- State/Local plans
- Educational programs
- Community health workers

# Reaching Underrepresented Populations

## **Aging Services**

- 11,304,795 Total Clients
- 2,879,521 Registered Services Clients
- 25% of registered services clients are racial/ethnic minority
- 29.5% registered services clients below poverty
- 37% rural
- Survey of Caregiver Program participants found 60% caring for someone with dementia

## **Public Health**

Survey of state health departments:

- 84% of agencies support health disparities or minority health initiatives
- almost three-fourths work to address rural health issues
- approximately three-fourths provide financial support to primary care providers in their state

# Interest in Alzheimer's / dementia & research

- NIH (Researcher Network)
  - NIA is lead Federal agency for Alzheimer's research
  - NIH: Approximately \$500 million in support for Alzheimer's research grants
  - Funds 27 NIA-funded Alzheimer's Disease Centers
  - Funds Alzheimer's Disease Education & Referral (ADEAR) Center (800-438-4380 or <http://www.nia.nih.gov/alzheimers>)



# Recruiting Older Adults into Research (ROAR)

## Background





Engage **older adults** about  
research participation

(starting with  
**Alzheimer's** research)

Deliver message through  
**trusted networks**

Help **accelerate**  
scientific **discovery**

# Objective: Low cost, high impact

**Utilize existing networks  
& resources**

**Easy action step**

**Measurable impact**

## Why This Project?

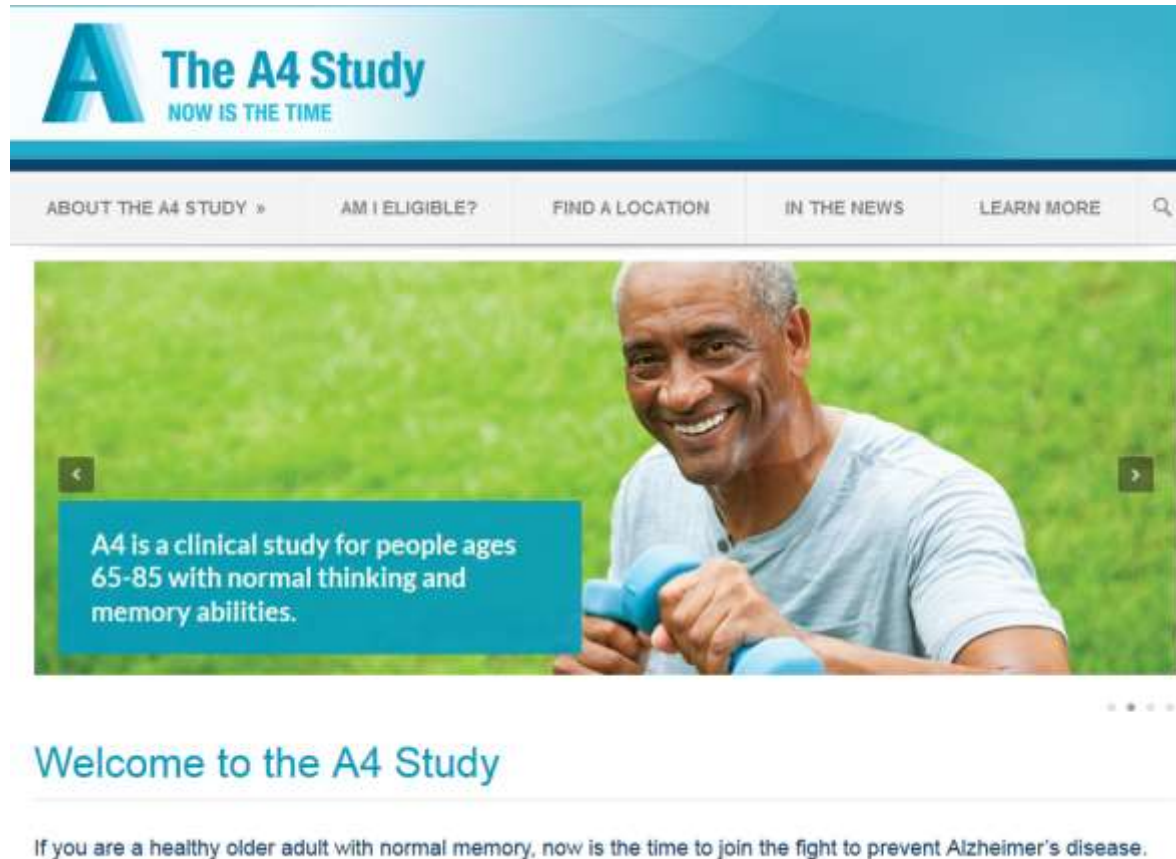
U.S. National Plan to Address Alzheimer's top goal:  
**Prevent and effectively treat the disease by 2025**



Major push to conduct research to test emerging  
prevention and treatment strategies

Collaboration among government agencies to support efforts

# Currently Enrolling!



The A4 Study  
NOW IS THE TIME

ABOUT THE A4 STUDY » AM I ELIGIBLE? FIND A LOCATION IN THE NEWS LEARN MORE 🔍

A4 is a clinical study for people ages 65-85 with normal thinking and memory abilities.

Welcome to the A4 Study

If you are a healthy older adult with normal memory, now is the time to join the fight to prevent Alzheimer's disease.

The screenshot shows the top section of the A4 Study website. At the top is a blue header with the logo 'The A4 Study' and the tagline 'NOW IS THE TIME'. Below the header is a navigation bar with links: 'ABOUT THE A4 STUDY »', 'AM I ELIGIBLE?', 'FIND A LOCATION', 'IN THE NEWS', 'LEARN MORE', and a search icon. The main content area features a large image of a smiling man in a light blue shirt lifting blue dumbbells. A teal text box is overlaid on the image with the text: 'A4 is a clinical study for people ages 65-85 with normal thinking and memory abilities.' Below the image is the heading 'Welcome to the A4 Study' and a sub-headline: 'If you are a healthy older adult with normal memory, now is the time to join the fight to prevent Alzheimer's disease.'

<http://a4study.org/>

# Urgent Need for Research Participants

- ~150 Alzheimer's and MCI trials currently recruiting
- Seeking 70,000+ participants
- Will likely need to screen at least 5-10 people for every participant enrolled in a trial
- Pharmaceutical Research and Manufacturers Association: Recruiting and retaining clinical trial participants is *“currently the greatest obstacle to developing new Alzheimer's treatments.”* From <http://www.phrma.org/sites/default/files/Alzheimer%27s%202013.pdf>

# Alzheimer's Disease

More than 5 million Americans are living with Alzheimer's disease

Alzheimer's disease is the 6<sup>th</sup> leading cause of death and the 2<sup>nd</sup> most feared disease in the U.S.

Costs of caring for people with dementia in the U.S. in 2010 were between \$159 billion to \$215 billion with numbers anticipated to rise in coming years.

Delaying dementia by 5 years would reduce projected Medicare dementia costs by nearly 50%.

# Challenges to Recruitment for Alzheimer's Trials

- Participation of a study partner/caregiver often required
- Issue of consent/assent for people with dementia
- Studies likely to involve invasive procedures
- Barriers for older adults (e.g., co-morbidities)
- Barriers for under-represented communities (e.g., mistrust)
- Reluctance of primary care physicians to diagnose cognitive impairment (in the absence of treatment)
- Reluctance of PCPs to refer patients to research

# Research Participation

## Positive attitude

- Only 16% of Americans report that they or a family member have participated in research
- However, 76% feel that clinical research is very important and would be very or somewhat likely to participate in a trial

## Need more information

- Lack of information a top-cited barrier to participation in research
- After physicians, federal government considered second most responsible to educate the public about clinical trials



# Collaboration with Registries

Finding  
solutions,  
advancing  
health.



**ResearchMatch.org**

# Collaboration with Registries



## HOW THE ALZHEIMER'S PREVENTION REGISTRY WORKS



1. SIGN UP to help end Alzheimer's
2. RECEIVE EMAILS about prevention study opportunities and research news
3. PARTICIPATE in studies you choose and qualify for

### Crucial Help for Alzheimer's Prevention Research

Any research endeavor is limited by the ability to enlist support from people willing to take part in the study process. Eighty percent of research studies fail to meet their initial recruiting goals and are delayed as a result. With Alzheimer's prevention research at a turning point, thousands of people will be needed for research studies designed to help us stop this terrible disease.



GET THE LATEST ALZHEIMER'S NEWS AND RESEARCH

JOIN **0 41768** OTHERS

→ Enter your email here

→ Zip/Postal Code

Year of Birth

Sign up now ▶

Your privacy is extremely important!  
We promise to protect it — [learn more](#).

<http://www.endalznow.org/>

# Collaboration with Registries



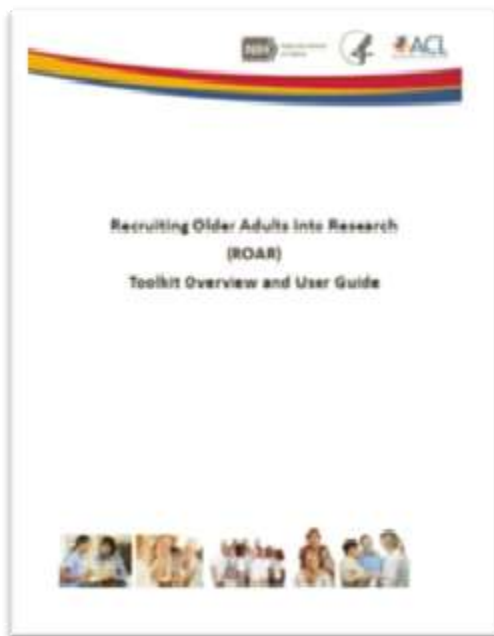
## How to use TrialMatch

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- |               |   |
|---------------|---|
| <b>Step 1</b> | Access <a href="#">TrialMatch</a> at the top of this page or call our toll-free number, 1-800-272-3900, 7 a.m.-8:30 p.m. CT, Monday-Friday.   |
| <b>Step 2</b> | Complete a brief questionnaire, either online or over the phone, to create a profile.   |
| <b>Step 3</b> | The Alzheimer's Association will compare your unique profile to its comprehensive, continually updated clinical trial database.               |
| <b>Step 4</b> | With your permission, a TrialMatch specialist will contact you to provide a list of trials that match your specific eligibility and criteria. |
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[alz.org/trialmatch](http://alz.org/trialmatch)

# Recruiting Older Adults into Research – ROAR (ACL-NIH-CDC)



▶ Available Fall 2014

▶ Contact  
[watsonjl@nia.nih.gov](mailto:watsonjl@nia.nih.gov)



# Overview of Topics

- Why research is important to healthy aging
- What you need to know about research studies
- How YOU can make a difference for yourself and future generations by participating





# Research Studies Need *All Kinds* of People – Including YOU!



**Men and women**



**Of all ages**



**Of different racial  
and ethnic  
backgrounds**



**Who are healthy or  
who have health  
problems**

# Benefits of volunteering for research

**Help** others, including future generations of your family who may be at risk



**Learn more** about your health conditions from experts



Get **information** about support groups and resources in your community



Receive **regular monitoring** by health professionals



# Join in to make a difference

There are many research studies going on right now that are urgently looking for volunteers.



*Can you help?*



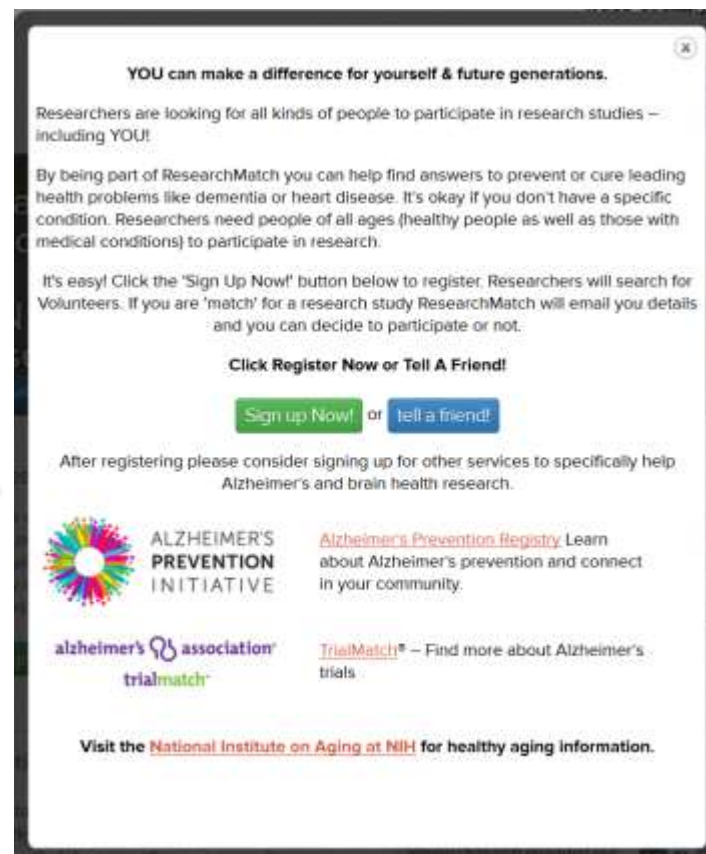
# One *easy* way to make a difference

## Sign up with a research registry or matching service.

- You will be contacted when studies are looking for people like you.
- You can learn more about a study and decide if you would like to participate.
- It's always **your choice** whether or not to take part in a study.
- Your information will remain confidential.



# ResearchMatch



Go to:

[www.ResearchMatch.org/roar](http://www.ResearchMatch.org/roar)

You must have an **email address** to sign up.

You can call 1-866-321-0259 if you need help with online registration.

# ResearchMatch: Connects YOU to Researchers!

Research. Discovery. Hope.

Want a chance to make a difference?  
Here it is.



ResearchMatch is not about one condition, one institution, one partner or one research study...

We are a **NATION OF MANY** working together to make a difference now and in the future.



Ready to become a *volunteer*?

Joining ResearchMatch is free and only takes a few minutes. You may register yourself or someone else as their guardian or caretaker.

# How does RM work?

## Step 1:

Volunteer participant registers in a few minutes on ***ResearchMatch.org/ROAR*** and answers a few questions, with many of the health questions being optional.



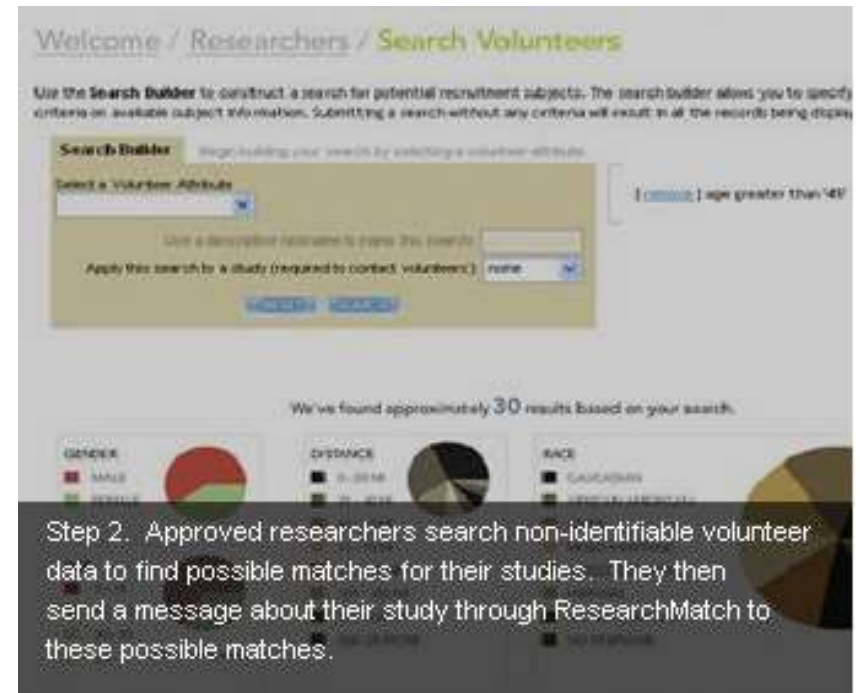
Step 1. Potential volunteers (or their parent/guardian/caretaker) complete a short registration form that asks some questions about who they are along with some optional health questions.

1 2 3 4 5

# How does RM work?

## Step 2:

Volunteer can rest assured that ***all personal health information is protected*** and the researchers cannot see it until volunteer decides to release it.



Welcome / Researchers / Search Volunteers

Use the Search Builder to construct a search for potential recruitment subjects. The search builder allows you to specify criteria on available subject information. Submitting a search without any criteria will result in all the records being displayed.

**Search Builder** Begin building your search by selecting a volunteer attribute.

Select a Volunteer Attribute: [dropdown menu]

Use a description reference to refine this search: [dropdown menu]

Apply this search to a study (required to contact volunteers): [dropdown menu]

[SEARCH] [RESET]

We've found approximately 30 results based on your search.

**GENDER**

- MALE
- FEMALE

**DISTANCE**

- 0-20 MI
- 20-50 MI
- 50-100 MI
- 100+ MI

**RACE**

- CAUCASIAN
- AFRICAN AMERICAN
- ASIAN
- HISPANIC
- OTHER

Step 2. Approved researchers search non-identifiable volunteer data to find possible matches for their studies. They then send a message about their study through ResearchMatch to these possible matches.

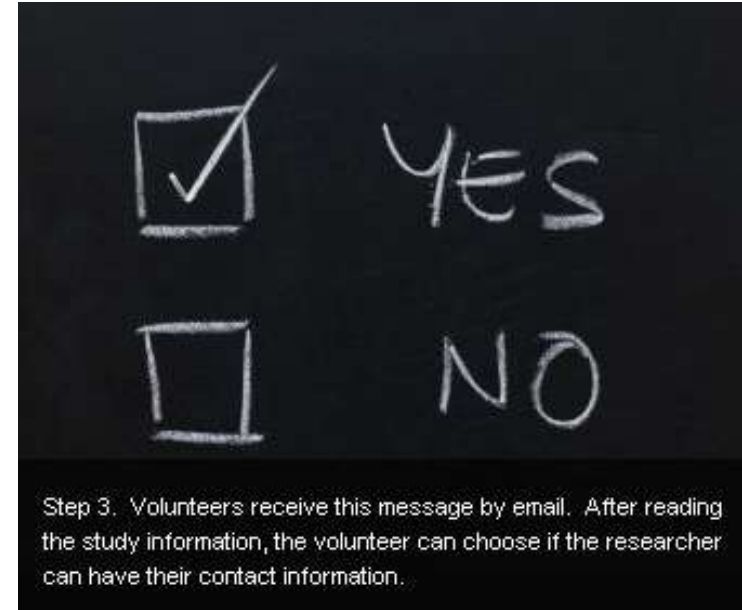
1 2 3 4 5

# How does it work?

## Step 3:

Volunteer *receives email message from researchmatch* and reads about the study.  
Volunteer decides to click

YES, I am interested or  
NO, thank you



1 2 3 4 5

# How does it work?

## Step 4:

Only if a Volunteer clicks, 'Yes, I am interested' a Researcher may contact the interested volunteer to share more about the study and the ***volunteer can decide whether to participate.***



Step 4. The researcher may then directly contact those volunteers who want to learn more about the study and the volunteer can decide whether or not to participate in the study.

- 1
- 2
- 3
- 4
- 5



# How does it work?

## Step 5:

Researchers and interested volunteers come together and make a difference by ensuring ***research studies are completed on time and contribute to great research together.***



Step 5. ResearchMatch has helped fulfill its mission to bring together the right volunteers with the right researchers.... An effort we all hope will find solutions today for a better tomorrow.

1 2 3 4 5



## **Resources in our community**

Placeholder here for any local registries, resources or research studies currently recruiting

**Join your family, neighbors and friends  
participating in research to make a difference  
for yourself and future generations!**



**Go to [www.ResearchMatch.org/roar](http://www.ResearchMatch.org/roar)  
or for help registering online call 1-866-321-0259**

## What's next with ROAR?

- Working to bring together Aging Services, Public Health, Alzheimer's Research Centers in selected areas/agencies who have expressed interest
- Testing out materials, strategy to get feedback (Summer 2014)
- Refining materials and strategy
- Wider dissemination, outreach (Fall 2014)
- Anyone can go to [www.ResearchMatch.org/roar](http://www.ResearchMatch.org/roar) for more information & to sign up!

## Take Away

- Talk with your clients/consumers about the importance of research participation, and share materials as available.
- Consider how these messages of research participation fit into your current work on healthy aging.
- Looks for ways to partner with other organizations and groups to share info.



# We want to help you get started!

## Ideas for local outreach

- Host a training in your computer lab (or partner with your library)
- Post [www.researchmatch.org/roar](http://www.researchmatch.org/roar) link on your social media
- Write an article for your local newspaper, newsletter or blog
- Ask your clients to write or blog about it
- Host an online webinar at your location presented by ResearchMatch and ROAR team
- Add ROAR flyers to your booth at a local health fair
- Have an idea? Let us know, we'd love to help!

# ROAR Federal Team

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