

Recruiting Older Adults into Research (ROAR) Toolkit Overview and User Guide



Overview: Recruiting Older Adults into Research

Our best hope to find new ways to treat, prevent or cure health conditions is through research. Advances in longevity, comfort and quality of life are due to research, such as better treatments for cancer or drugs like penicillin. However, there is still an urgent need for adults of all ages and health levels to participate in research to address some of our biggest health challenges, such as Alzheimer's disease and related dementias.

Other than money, the biggest barrier to research on Alzheimer's disease is recruiting research volunteers¹. In recent years, Alzheimer's research has focused on people with signs and symptoms of dementia. However, beginning in 2014, several new large research studies will begin to recruit volunteers who have no signs of dementia. This means that researchers have a growing need for volunteers both with and without signs of dementia.

What is ROAR?

The Administration for Community Living (ACL), Centers for Disease Control and Prevention (CDC) and the National Institute on Aging (NIA) at NIH have joined together with researchers on a project called "Recruiting Older Adults into Research" or ROAR. ROAR aims to help the Aging Services and Public Health networks to share information about participating in research with older adults and caregivers, including those of diverse ethnic and racial backgrounds, starting with information about Alzheimer's disease research. Our goal is to improve older adults' knowledge of research and offer an easy action step for them to participate. To do so, ROAR is working with research registry partners, such as ResearchMatch, the Alzheimer's Prevention Registry, and the Alzheimer's Association's TrialMatch.

The ROAR team has developed this Toolkit with information designed to help seniors and their caregivers learn why their research participation is important, the benefits of research participation, and how to find research participation opportunities in their areas.

¹ Pharmaceutical Research and Manufacturers Association (PhRMA), <http://www.phrma.org/sites/default/files/Alzheimer%27s%202013.pdf>

The Toolkit includes:

1. A **User Guide** which discusses ideas for Aging Network and Public Health staff to consider in advance of and while sharing ROAR information.
2. **Frequently Asked Questions** which offer additional background and supporting information for presenters and staff who may get questions from audiences.
3. **Sample Social Media Messages** which agencies and organizations can use in their social media channels, newsletters, websites, or other communications channels.
4. **2 PowerPoint Presentations** (a short and a long version) which offer space for local customization and information at a basic level to older adults, caregivers or both. Talking points targeted to an older adult audience accompany each slide.
5. **2 Flyers** which offer space for local customization and information at a basic level to older adults, caregivers or both.

The National Institute on Aging, the Centers for Disease Control and Prevention and the Administration for Community Living have reviewed the information in the slides and accompanying materials.

ROAR Toolkit User Guide

This User Guide is intended to help Aging Network and Public Health staff members plan how and when to share information on participating in research with their older adult clients. It includes three (3) sections:

- Local initiatives and resources
- Why, Who, When, What and Where to share ROAR information and materials
- Final considerations

Local initiatives and resources

There are research participation opportunities available in communities across the country (e.g., internet-based surveys) as well as research studies located in and/or targeting people in urban, suburban and rural settings. However, opportunities vary by location. Learning more about the specific needs and resources in your area may help you find:

- Specific studies, locations or recruitment needs
- Potential partners to host presentations or other events
- Possible speakers specializing in research recruitment and/or related topics
- Other resources and/or referral sources

The Powerpoint Presentations and Flyers included in the ROAR Toolkit have space that you can customize with local information. Connect with the contacts below in your community to discuss specific needs and resources:

- A. ResearchMatch receives funding from the National Institutes of Health to work with research organizations across the country. Each of these organizations has a Community Liaison who are responsible for working with researchers (not necessarily Alzheimer's/dementia-specific), as well as doing outreach to local communities. The ResearchMatch Community Liaison may be a good first contact to discuss plans on how to share research participation information with the older adults and caregivers in your community. Contact information for your local Community Liaison is available at info@researchmatch.org or 1-866-321-0259.

- B. The National Institute on Aging funds research at 27 Alzheimer’s Disease Centers located in major medical institutions across the country. For a list of locations and contacts, go to <http://www.nia.nih.gov/alzheimers/alzheimers-disease-research-centers>. Additionally, other academic research centers may serve as Alzheimer’s Disease Cooperative Study sites, as indicated at <http://www.adcs.org/Research/ClinicalSite.aspx>.
- C. Many other institutions and groups in your state or local area, such as State Alzheimer’s Disease Taskforces, universities, local Alzheimer’s Association chapters and other Alzheimer’s disease advocacy organizations may also be doing important Alzheimer’s disease/dementia research. These locations may be especially important if you are not near a ResearchMatch, Alzheimer’s Disease Center or Alzheimer’s Disease Cooperative Study site. If you’re not sure where to start, consider contacting your State Aging or Public Health agency.

Why, Who, When, What and Where

Once you have learned more about the specific needs and resources in your community, you can determine how to best share the information to increase research participation awareness and action.

A. Why & Who?

You may be interested in sharing ROAR information with older adults and caregivers for various reasons, including:

- Allowing older adults to play an active role in their health care.
- Providing older adults and caregivers with specific actions they can take to fight Alzheimer’s disease/dementia or other health problems.
- Introducing older adults and caregivers to information sources and health programs available in their communities.
- Offering older adults and caregiver ways to make a difference for future generations.

Therefore, you will need to consider your audience. Your target audience may include:

- Older adults: both with and without health problems.
- Caregivers.

- People who are under-represented in research studies and/or those who are at especially high risk: This may include people who are African-American or Hispanic, as well as those who have certain conditions, such as Down Syndrome.

Note: Consider whether your potential audience members travel on a regular basis and may be willing and interested in participating in research studies in other areas of the country.

Finally, as with other types of presentations, similar advice applies:

- Be sensitive to the fears and hopes of your audience;
- Establish a positive atmosphere and focus on the community engagement aspects of joining others in the fight against Alzheimer's disease and other dementias;
- Use easy, simple language;
- Speak clearly, free of other distractions;
- Illustrate steps, give examples; and
- Answer questions as you are comfortable, using the talking points, frequently asked questions, and federal resources that accompany ROAR materials, and always let others know when you don't know an answer (you can offer to get back to them).

B. When?

Depending on your target audience, you may wish to consider the best timing to share research participation information, including ROAR materials. Think about sharing information:

- In times that are **not emotionally charged** (e.g., not in time of crisis)
- When **relationship** is established (e.g., ongoing care coordinator or caregiver support facilitator)
- When **educational materials** are presented and/or other types of benefits counseling are being done (e.g., presentations at senior centers or congregate dining programs)

C. What and Where?

Some ideas for what and where to share ROAR information and materials include:

1. For Aging Network services:
 - Create a referral protocol and provide training for staff answering Information & Assistance or Aging & Disability Resource Center Hotlines;
 - Give presentations at or post flyers with Health & Wellness Programs at Senior Centers & Nutrition Sites;
 - Hand out information to Senior Transportation & Home Delivered Meal Program participants;
 - Include information on research participation opportunities when providing Options Counseling, as well as when conducting Assessment; or Care Coordination for Respite, In-home Chore, Homemaker and/or other supportive service programs;
 - Provide presentations or share flyers with Caregiver Support group members.

2. For Public Health Network services:
 - Create opportunities to convene coalitions and partners, such as the aging services network and local researchers, to develop strategies to increase participation;
 - Include information about research participation opportunities and referrals to local experts at public health centers and clinics;
 - Incorporate strategies to increase participation in research in state and local plans and community assessments;
 - Provide presentations or share flyers with participants in educational programs;
 - Provide information about participation opportunities and referrals to local experts on your social media and Internet sites;
 - Develop opportunities to engage community health workers in providing information about research participation opportunities.

Consider what communications methods your potential audience members prefer. Both telephone and internet communication options are available, so don't let lack of internet access or savvy be a barrier.

Final considerations

Once you have learned about Local Resources and Initiatives and developed a plan for how you will share research participation information and messages in your community, here are some additional steps to consider taking:

- Customize any ROAR materials with local information, as appropriate and feel free to adapt the materials to the needs of your audience. For example, you can add or remove slides from the slide deck or change the order of the slides, or adapt the flyers. Let us know what works!
- Add www.researchmatch.org/roar or other local research participation information to the links listed on your organization's website.
- Look for opportunities to coordinate with other programs within your organizations. For example, if you have a computer lab available, you might offer to help audience members go to www.researchmatch.org/roar as a part of your computer lab assistance or instruction.
- Manage your own and your audience's expectations. Inquiring about potential research opportunities is only a starting point.
 - Research studies are carefully designed to get the best, most usable results. As such, they may need to screen as many as 10 people just to find 1 who meets the eligibility criteria and will ultimately end up being a part of that research study. Those 9 people who put themselves forth for consideration are very important and deeply appreciated.
 - Even if there are no research studies currently recruiting in your area, populating research registries is critical. For example, the Alzheimer's Prevention Registry frequently sends informational emails to keep registry members on stand-by, ready to get engaged as new research studies begin.

With so many critical research studies beginning and in process, researchers hope potential volunteers will keep coming forward until they find a study that is a good mutual fit.

Resources

- *Video:* Why Participate in Clinical Research? (ResearchMatch)
<http://youtu.be/-Fo5OB--TYc>
- *Tip Sheet:* Clinical Trials and Older People (National Institute on Aging):
<http://www.nia.nih.gov/health/publication/clinical-trials-and-older-people>
- *Website:* NIH Clinical Research Trials & You:
<http://www.nih.gov/health/clinicaltrials/>
- For any questions or more information about Alzheimer's research studies and clinical trials, visit www.nia.nih.gov/alzheimers/clinical-trials. Or, contact the NIA Alzheimer's Disease Education and Referral (ADEAR) Center at 1-800-438-4380 (toll-free) or adear@nia.nih.gov.

Thank You!

On behalf of the Administration for Community Living (ACL), Centers for Disease Control and Prevention (CDC) and National Institute on Aging (NIA) at NIH, the ROAR team thanks you for your efforts to increase awareness of older adult research participation opportunities.

Frequently Asked Questions (FAQs) About Participating in Research

How do I know which studies are safe to participate in?

Clinical trials can involve risks. Safety measures are in place to protect you while participating in research. All research studies have federal, state and institution rules. Researchers are required by law to explain the details of their study to you. Before you decide to volunteer for a research study, you need to know as much as possible about it (purpose, duration, required procedures, risks, potential benefits). So ask questions until you feel comfortable and safe participating. You have the right to stop being in a research study at any time.

Other safeguards, such as Institutional Review Boards and Data and Safety Monitoring Committees, work to ensure that participants are safe and not exposed to unnecessary risk or harm during the course of a study. If it is determined that an intervention is not effective or is harming participants, the trial will be stopped. If you have any questions, you should ask the study staff at any time, including after you have consented to participate.

Can I still see my regular doctor if I participate in a research study?

Yes. You should continue to see your regular doctor. You may want to provide information about the research to your doctor.

Will researchers coordinate with or give information to my regular doctor?

How a researcher works with your doctor will depend on the study, so you should ask. You can also ask the researcher for information about the research and any findings about your health to take with you to your doctor. If a health issue happens to you during the study, researchers will, with your permission (or at your request), tell your doctor.

Will research participation affect my Medicare, Medicaid or other benefits?

No, it will not affect your health insurance. Under the Affordable Care Act, health insurance carriers are required to cover the routine costs of people taking part in clinical

trials and cannot drop or limit coverage because a person chooses to take part in a clinical trial.

However, if you do not already have long term care and life insurance, it is possible that if you apply, you will be asked whether you know certain information about your health. It is a good idea to make these arrangements prior to research participation.

If I take medications does that keep me from participating in a trial or study?

It depends on the medication and what is needed for the study. Talk to the research team to find out.

How much time does it take to participate in a research study?

All research study times are different— some studies can be completed in a single visit or a few visits, others can last for months or years. Some research studies may have regular visits; others may allow you to report by phone or complete a survey. Read the description of the study and ask the research team to make sure you understand the time required.

What if I change my mind?

You can always change your mind. If you are participating in a study, you can drop out at any time for any reason. The research team may ask you why you have decided to stop so that they can learn better ways to keep people in studies or to figure out if people are leaving a study for the same reasons.

Is there a cost?

Most research is paid for by federal or sometimes state governments, or by research foundations or private organizations. If there are any costs, the research team must tell you up front.

Will I get paid?

Some studies do pay participants for their time or other costs like transportation. Any form of payment will be explained by the research team.

Who will have right to use or view my personal information?

The research team and possibly other researchers will have access to your data, depending on the study. Any data that is shared cannot contain information that would identify you. The study team will provide details of how study data will be shared and used, and ask for your permission to share it. Some information may be shared widely, but always only with permission from you and only after removing your personally identifiable information.

Do I have to have computer/internet access or an email address to sign up for a registry?

For online registries and matching services like ResearchMatch or the Alzheimer's Prevention Registry, you must have an email address to sign up because that is how you will be contacted by researchers. If you don't have access to a computer or the internet at home, you can often go to a public library or senior center to use publicly available computers.

Other services, like the Alzheimer's Association's TrialMatch, can sign you up by phone and send you information by postal mail. You can also call the NIH Alzheimer's Disease Information and Referral Center at 1-800-438-4380 to get information on Alzheimer's studies in your area.

How often will I be asked to participate in research studies?

This depends on you and the types of studies you may be interested in. It will also depend on whether you are a match for researchers who need you for their studies. If you feel that you are getting contacted too many times, or decide not to participate any longer you can always say you are not interested or remove yourself from the registry.

I have tried to participate in research studies before but didn't get contacted to participate. Should I try again?

Yes, please keep trying! Not being selected for a study can be disappointing. It's important to remember the decision is not personal. No matter what is being researched, all studies have rules about who can participate in a study. So, there is a chance that studies might not be available in the right place at the right time for you. However, you can make yourself available to many more kinds of studies that may be local or national by joining a registry or matching service, like ResearchMatch. Some studies may be simple, like a survey, and can be done anywhere.

I'm already in a study; can I also sign up for another study or join a registry?

Being in more than one drug or intervention research study at the same time, or even at different times, may increase the risks to you. It may also affect the results of the studies. Check with the researchers involved in each study before agreeing to participate in a second study. You can join as many registries as you wish.

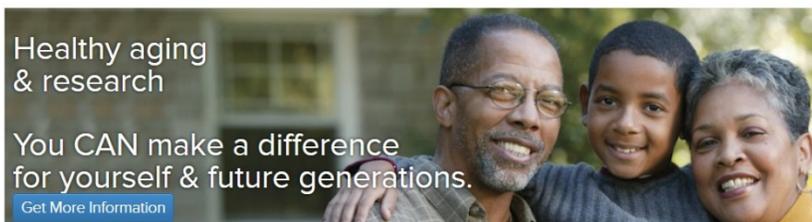
SAMPLE Social Media Messages

Use the following messages or feel free to adapt or customize them for your social media channels, email alerts, or newsletters.

Facebook or Newsletter blurbs

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 are needed for clinical trials and studies to treat, prevent or cure health conditions. One easy way is to join ResearchMatch, a service to match you with research you may be eligible for. Go to www.researchmatch.org/roar to learn more.

Did you know there is an urgent need for adults of all ages and health levels to participate in research? Our best hope to find new ways to treat, prevent or cure health conditions is through research. You can help by joining ResearchMatch, a service to match you with trials and studies you may be eligible for. Go to www.researchmatch.org/roar to learn more.



How can participating in research be part of healthy aging for you? You can learn more about your health, get regular monitoring from health professionals, and help future generations. Consider joining ResearchMatch, a service to match you with trials and studies you may be eligible for. Go to www.researchmatch.org/roar to learn more.

Discoveries from research led to the medicines and treatments we take for granted today. How can you help discover new treatments for dementia, cancer, heart disease? Consider participating in a research study. Sign up with ResearchMatch, a service to

match you with trials and studies you may be eligible for. Go to www.researchmatch.org/roar to learn more.

Join in to make a difference! Many clinical trials and studies are going on now that are urgently looking for people of all kinds, including older adults. Can you help? Sign up with ResearchMatch, a service to match you with trials and studies you may be eligible for. Go to www.researchmatch.org/roar to learn more.

Join your family, neighbors and friends participating in research to make a difference for yourself and future generations. Learn about research opportunities by signing up with ResearchMatch at www.researchmatch.org/roar.

Consider participating in research as part of your healthy aging plan! Learn about research opportunities by signing up with ResearchMatch at www.researchmatch.org/roar.

Worried about Alzheimer's, heart disease, cancer? You can help find the answers to treating, preventing or curing these diseases by participating in research. People of all kinds, including older adults, are needed for studies and trials going on now. Learn about research opportunities by signing up with ResearchMatch at www.researchmatch.org/roar.

All of the progress that's been made in medical treatments has occurred because people have stepped up to the plate and participated in clinical trials. Check out this video: Why participate in clinical research? <http://youtu.be/-Fo5OB--TYc> . Learn about research opportunities by signing up with ResearchMatch at www.researchmatch.org/roar.

Tweets

How can participating in research be part of healthy aging for you? Learn more at www.researchmatch.org/roar #GetMatched

Research studies are urgently looking for people of all kinds, including older adults. Can you help? Learn more at www.researchmatch.org/roar.

ROAR! Research, aging, and public health collaborate to recruit older adults into research - <http://1.usa.gov/1nhxcBp>

Calling all baby boomers to participate in research studies to help you & future generations! #GetMatched at www.researchmatch.org/roar

Join your family, neighbors and friends participating in research to make a difference! Sign up with ResearchMatch www.researchmatch.org/roar.

You can help find the answers to treating, preventing or curing diseases by participating in research. #GetMatched at www.researchmatch.org/roar

Make participating in research part of your healthy aging plan! Learn more by signing up with ResearchMatch at www.researchmatch.org/roar.