

# National Strategy for Recruitment and Retention in Alzheimer's Disease Clinical Research

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## Strategy Update

Melissa McGowan, MHS, CHES, NIA

Heather Snyder, Ph.D., Alzheimer's Association

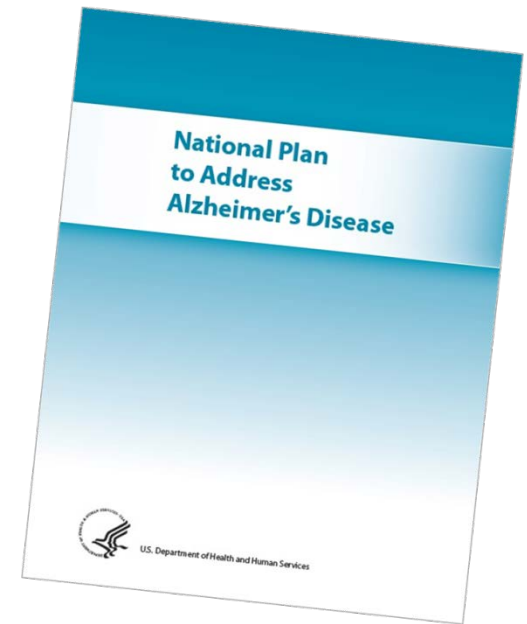
October 13, 2017



# National Plan to Address Alzheimer's Disease

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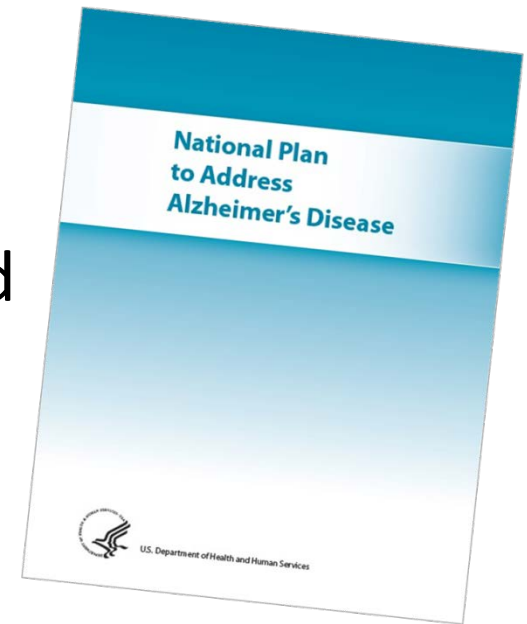
- The National Alzheimer's Project Act was into law in 2011, and resulted in the National Plan to Address Alzheimer's Disease.
- The National Plan sets research goal "to prevent and treat Alzheimer's by 2025."



# National Plan to Address Alzheimer's Disease

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- Specifically, the plan seeks to
  1. Increase enrollment in clinical trials and other clinical research through community, national, and international research, and
  2. Monitor and identify strategies to increase enrollment of racial and ethnic minorities in Alzheimer's disease studies.



# Need for Research Participants

- Today, 150 ongoing trials listed in [clinicaltrials.gov](http://clinicaltrials.gov) are seeking 70,000 volunteers
- 10 times that number will need to be screened

**ALZHEIMER'S RESEARCH NEEDS YOU!**

The number of older Americans 65+ with Alzheimer's disease is rapidly growing

Year	Number of Older Americans 65+ with Alzheimer's Disease
2014	6.0 MILLION
2050	13.6 MILLION

**GOOD NEWS** IMPORTANT ALZHEIMER'S RESEARCH IS MOVING FORWARD

**BUT WE NEED YOUR HELP**

More than **150** Alzheimer's and related clinical trials in the U.S. are looking for volunteers

At least **70,000** people with Alzheimer's, healthy volunteers, and caregivers are urgently needed

**1** volunteer at a time is what it takes

**YOU** COULD BE THAT VOLUNTEER

**YOU CAN MAKE A DIFFERENCE**

**Join Us!** TAKE THE FIRST STEP TODAY

Call 1-800-438-4380  
Go to [www.nia.nih.gov/alzheimers/volunteer](http://www.nia.nih.gov/alzheimers/volunteer)

Alzheimer's Disease Education & Referral Center  
NIH National Institute on Aging  
Follow us on Twitter: @Alzheimers\_NIH

\*Hogart L.E., Wilner J., Cohen P.S., Ryan D.R. Alzheimer disease in the United States (2010-2050) estimated using the 2010 census. *Neurology*. 2013;80(9):1778-1783.



# National Recruitment Strategy for Recruitment and Participation in Alzheimer's Clinical Research

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To engage broad segments of the public in the Alzheimer's and related dementias research enterprise, with a particular focus on underrepresented communities, so that studies can successfully and more quickly enroll and retain individuals in studies to better understand and eventually cure these disorders.



# Strategic Planning

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- Alzheimer's Association hosted stakeholder meeting at AAIC 2016 in Toronto
- NIA hosted a larger stakeholder meeting in Bethesda, MD, December 2016
- Steering Committee of volunteers established, January 2017
- *Alzheimer's & Dementia* hosted a webinar on development of the strategy, February 2017
- Topic leaders for strategy working groups identified, February 2017
- Working groups begin discussing and drafting strategy, March 2017
- NIA hosts meeting of working groups to discuss strategy drafts, April 2017



# Steering Committee

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- Paul Aisen, M.D.
- Vicky Cahan
- Maria Carillo, Ph.D.
- Meryl Comer
- Susan De Santi, Ph.D.
- John Dwyer, J. D.
- Zaven Khachaturian, Ph.D.
- Jessica Langbaum, Ph.D.
- Laurie Ryan, Ph.D.
- Nina Silverberg, Ph.D.
- Heather Snyder, Ph.D.
- Eliezer Masliah, M.D.
- George Vradenburg, J.D.



# Focus of Working Groups

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- National efforts – Chaired by Jason Karlawish, M.D.
- Capacity-building – Chaired by Pierre Tariot, M.D.
- Local and diverse recruitment efforts – Chaired by Laura Baker, Ph.D.





# National Efforts Working Group

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- Chair – Jason Karlawish, M.D.

## Working Group Members:

- Malaz A. Boustani, M.D., MPH
- Vicky Cahan
- Maria Carrillo, Ph.D.
- Joshua Chodosh, M.D., MSHS, FACP
- Josh Grill, Ph.D.
- Amy Jordan, Ph.D.
- Rachel L. Nosheny, Ph.D.
- Itzhak Yanovitzky, Ph.D.

## Goal:

*To empower people from diverse communities to participate in research*



# Local and Diverse Recruitment Efforts Working Group

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- Chair – Laura Baker, Ph.D.

## Working Group Members:

- Debra Buchwald, M.D.
- Debra Clark-Jones
- Gina Green-Harris, M.B.A.
- Jonathan Jackson, Ph.D.
- Olivia Mastry, J.D., MPH
- Stephanie Monroe, J.D.
- Jason Resendez
- Nina Silverberg, Ph.D.
- Heather Snyder, Ph.D.

## Goal:

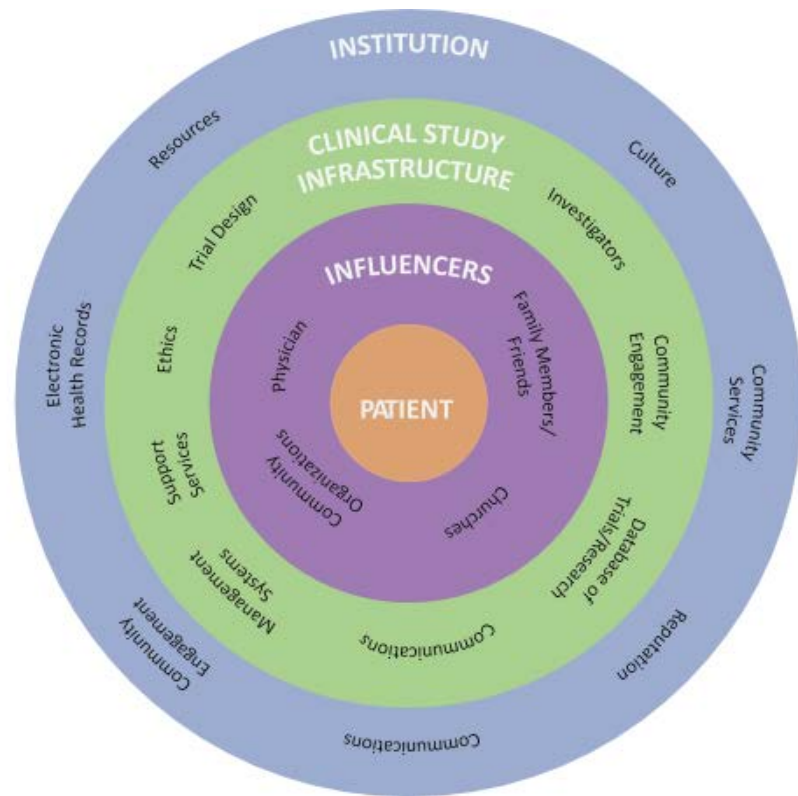
*To increase recruitment and retention of participants into Alzheimer's and dementia research at the local level, with particular focus on inclusivity and diversity with regard to age, race, ethnicity, sex, education, income, geography (rural/urban), and cognitive status (asymptomatic, MCI, AD/related dementias).*

# Local and Diverse Recruitment Efforts Working Group

- Chair – Laura Baker, Ph.D.

## Working Group Members:

- Debra Buchwald, M.D.
- Debra Clark-Jones
- Gina Green-Harris, M.B.A.
- Jonathan Jackson, Ph.D.
- Olivia Mastry, J.D., MPH
- Stephanie Monroe, J.D.
- Jason Resendez
- Nina Silverberg, Ph.D.
- Heather Snyder, Ph.D.



# Capacity Building Working Group

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- Chair – Pierre Tariot, M.D.

## Working Group Members:

- Jeffrey Burns, M.D., M.S.
- Keith Fargo, Ph.D.
- Lynn Hughes, B.Med.Sci., Ph.D., PMP
- Jamie Roberts, MPH, MA, CCRP
- Laurie Ryan, Ph.D.
- Stephen Salloway, M.D., M.S.
- Chris Van Dyck, M.D.

## Goal:

*To create the capacity to increase enrollment for an ever-growing portfolio of Alzheimer's disease and related dementias studies.*



# Timeline and Next Steps

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- Finalize and combined drafts into one integrated document – November 2017

**\*\*Solicit public comment on integrated document\*\***

- Currently considering options for public comment
- Date TBD

- Release final national recruitment strategy in early 2018



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**Thank you!**

