

**MILKEN  
INSTITUTE**  
CENTER FOR  
THE FUTURE OF AGING

# Alliance to Improve Dementia Care

General Member Meeting

Wednesday, June 2<sup>nd</sup>, 2021

# Agenda

|                     |   |
|---------------------|---|
| 12:00 – 12:05 PM ET | <b>Opening Remarks + Welcome New Members</b><br>Nora Super, Executive Director, Alliance to Improve Dementia Care; Senior Director, Milken Institute Center for the Future of Aging   |
| 12:05 – 12:25 PM ET | <b>Resource Highlight: Dementia-Friendly America (DFA) Evaluation Guide</b><br>Meredith Hanley, Director, Community Capacity Building, National Association of Area Agencies on Aging (n4a)<br>(Presentation + Q&A)   |
| 12:25 – 12:45 PM ET | <b>Resource Highlight: Best Practice Caregiving</b><br>Orion Bell, President & CEO, Benjamin Rose Institute on Aging<br>David M. Bass, PhD, Senior Vice President & Senior Research Scientist, Center for Research and Education, Benjamin Rose Institute on Aging<br>Kathleen Kelly, Executive Director, Family Caregiver Alliance<br>Mike Simmons, President & CEO, Bridge Builder Strategies<br>(Presentation + Q&A) |
| 12:45 – 12:50 PM ET | <b>Alliance Updates: Future of Health Summit Programming + Upcoming Items</b><br>Diane Ty, Director, Alliance to Improve Dementia Care; Director, Milken Institute Center for the Future of Aging<br>Raj Ahuja, Associate Director, Alliance to Improve Dementia Care; Associate Director, Milken Institute Center for the Future of Aging  |
| 12:50 – 1:00 PM ET  | <b>Open Dialogue: Member Questions and Connections</b>  |

---

---

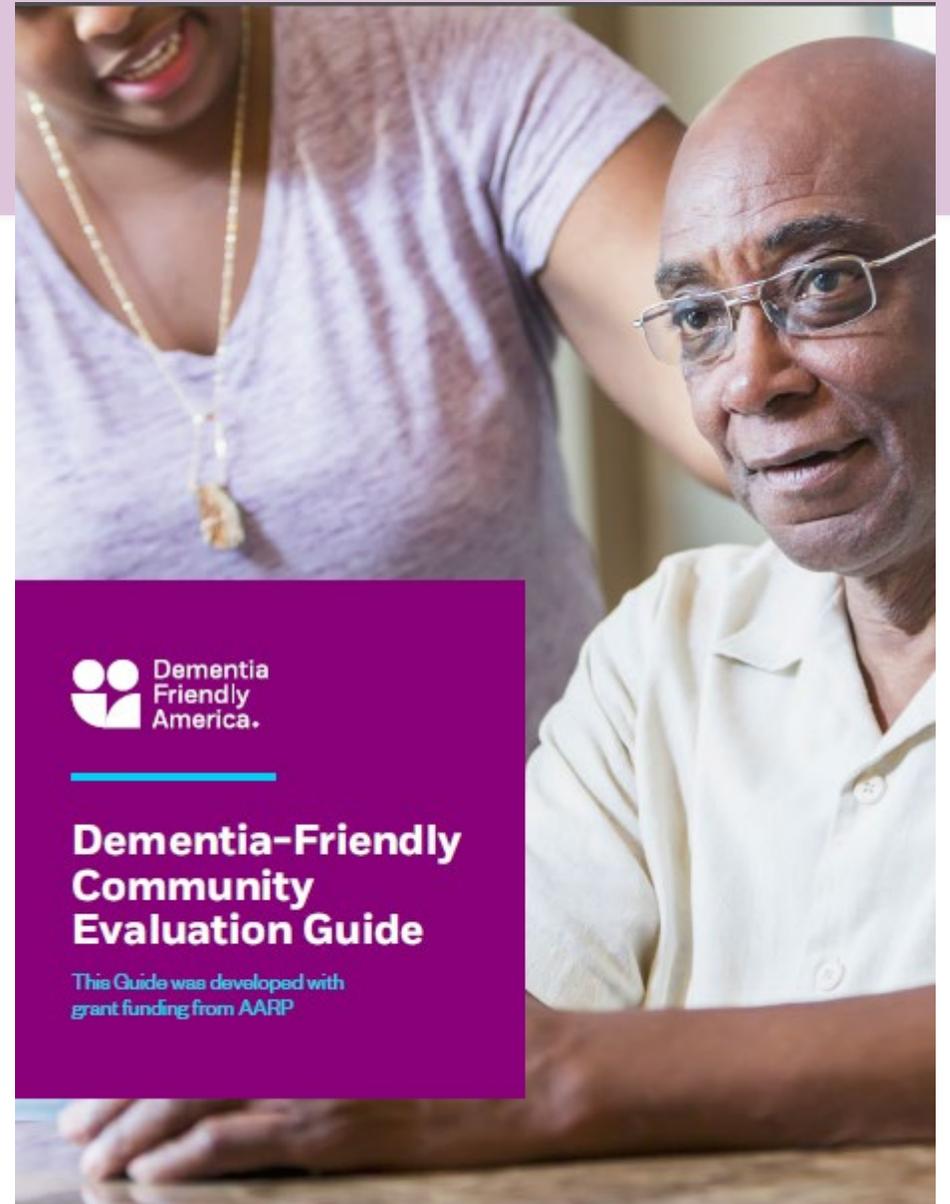
# Welcome New Alliance Members

- **Ellen Flaherty**, PhD, Director, Dartmouth Centers for Health & Aging, Geisel School of Medicine, Dartmouth College
- **Don Smith**, President & CEO, Texas Healthy at Home
- **Mary Ann Spanos**, Director, Office for the Aging, Chautauqua County Government
- **Nancy Wilson**, Associate Professor, Department of Medicine-Geriatrics, Huffington Center on Aging, Baylor College of Medicine



# Dementia-Friendly Community Evaluation Guide

*Developed with funding from AARP*



# Dementia Friendly America

- Dementia Friendly America (DFA) launched in 2015
- Goal is to ensure that communities and individuals across the U.S. are equipped to support people living with dementia and their caregivers.
- Two primary initiatives within DFA:
  - Dementia friendly communities (community-wide impact)
  - Dementia Friends (individual-focused impact)
- Modelled after Minnesota's ACT on Alzheimer's
- National Association of Area Agencies on Aging is fiscal agent and program administrator for DFA.
- Guided by a National Council of 35+ national leading organizations
- [www.dfamerica.org](http://www.dfamerica.org) and [www.dementiafriendsusa.org](http://www.dementiafriendsusa.org)



# Challenges and Opportunities Related to Evaluation

- Grassroots nature of DFA communities meant a one size-fits-all evaluation approach was not possible
- Many community efforts are low-budget and/or volunteer driven - capacity?
- International DFCs also have limited guidance on evaluation
- Dedicated stakeholders
- Some have received foundation or federal grants (e.g. ADPI or GWEP) and have evaluation requirements; are situated with university partners; or have a strong community lead with evaluation
- There is a lot of interest from communities: how can we do more with evaluating our work.
- Committed stakeholders willing to share their time and expertise with us (16+ reviewers)

# Process: Literature Review and Feedback from Stakeholders

- Worked with consultant from ACT on Alzheimer's
- Literature review of dementia-friendly, age-friendly, and dementia inclusive evaluations (2018-present).
  - Descriptive
  - How communities were formed
  - Barriers and challenges
  - Reported outputs, not outcomes
    - Numbers of participants in awareness raising activities
    - Numbers of initiatives offered by a community

# Feedback – Individuals Leading Dementia-Friendly Efforts

- Keep it simple.
- Provide examples of dementia-friendly activities.
- Include measurement methods other than tools.
- Sample evaluation plan.

*“The guide emphasizes that communities should focus on just a few goals so we do not get overwhelmed by trying to do everything.”*

*Action Team Lead*

# Feedback – Experts in Evaluation

- Provide a framework that offers enough information so that you do not need to be an evaluator to conduct an evaluation.
- Reinforce the benefits to evaluating outcomes:
  - Evidence of success and challenges in creating community change.
  - Motivate stakeholders to invest time and resources.
  - Help communities recognize their own abilities to bring about change.
  - Have information to celebrate, make adjustments and communicate lessons learned.

*“It maps the key outputs, outcomes and tools to each of the major goals. I think it will be a helpful tool for communities.” Evaluator*

# Living Well with Dementia Survey

- Polled people living with dementia and community partners about what it means to live well with dementia and the outcomes a person with dementia values in a dementia-friendly community.
- Asked them to share feedback and prioritize their goals:
  1. Being able to do things that you enjoy and want to keep doing.
  2. Continuing relationships with people who are important to you.
  3. Being able to communicate with others and feeling understood.
  4. Feeling safe.
  5. Feeling valued and respected by others.
  6. Keeping physically active.
  7. Feeling able to have a laugh with other people.
  8. Having a sense of purpose.
  9. Minimizing loneliness or isolation.
  10. Being able to learn new things.

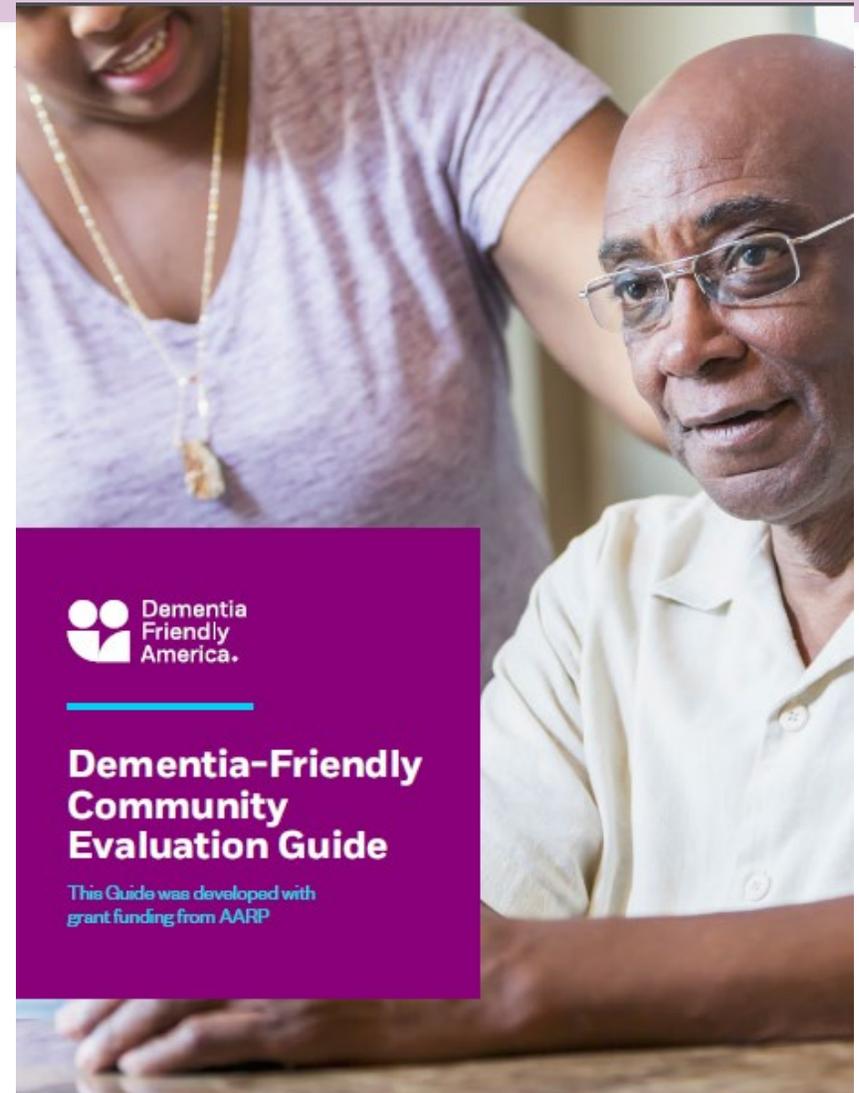
*"I believe these will help slow the progress of my dementia."*

*Respondent living with dementia*

# Results of Literature Review, Feedback, Survey = Evaluation Guide

- Updated language, dementia-friendly activities.
- Aligns with DFA Community Toolkit.
- Multiple audiences (DFA communities, evaluators, community sector/ organization).
- Provides an evaluation framework that is useful, practical and adaptable at any stage of a dementia-friendly effort.
- Not all communities have the capacity to conduct an evaluation of all activities but can identify 1 – 2 activities to evaluate.
- Contains common outcomes and measurement methods but communities have the flexibility to choose what they evaluate.
- Evaluation is an ongoing process, just like the work of creating a dementia friendly community.

Ti



# Overview of Evaluation Guide

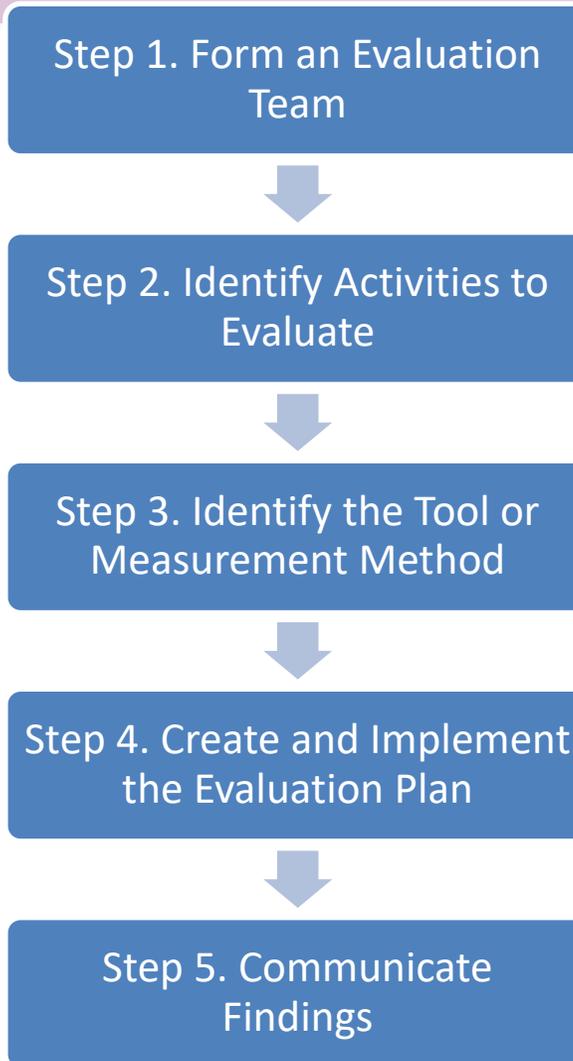
## **Principles of Dementia-Friendly Communities**

Include and involve people living with dementia in the community effort.

Establish and maintain a team that works collaboratively to create change.



# Creating a Plan: Five Steps



# Dementia-Friendly Community Goals

- Increase awareness and understanding of dementia and of people living with dementia.
- Increase awareness and understanding of brain health and risk reduction.
- Collaborate with public, private, nonprofit and health care sectors.
- Address the changing needs of people with dementia and care partners.
- Create social, cultural and business environments that are inclusive.
- Improve the physical environment in public places and systems.

# Activities

- Implement the Dementia Friends program.
- Dementia-friendly business and organization training.
- Dementia training for first responders.
- Creation of a directory of private, public and nonprofit resources and services available in the community (print or online) accessible to people of different cultures, languages and educational levels.
- Dementia-friendly faith services and choirs.
- Distributing a dementia-friendly environment checklist.

# Measurement Methods and Tools

- Tools created by researchers
- Surveys/questionnaires created by the evaluation team
- Examine existing data
- Conduct an inventory of programs
- Hold focus groups or individual interviews
- Observation or visual assessment

Appendix C: Table of Tools to Measure Common Outcomes

| Outcomes                   | Tool   | Intended Audience                  |
|----------------------------|--|------------------------------------|
| Attitude, Knowledge        | <a href="#">Measuring the Impact of Dementia-friendly Education and Training Sessions: A Toolkit</a> <sup>32</sup> | General public                     |
| Attitude                   | <a href="#">Dementia Attitudes Scale (DAS)</a> <sup>33</sup>   | General public                     |
| Competence                 | <a href="#">Caregiving Competence Scale</a> <sup>34</sup>  | Care partner                       |
| Well Being                 | <a href="#">Perceived Change Scale</a> <sup>35</sup>   | Care partner                       |
| Burden                     | <a href="#">Zarit Burden</a> <sup>36</sup>   | Care partner                       |
| Loneliness                 | <a href="#">UCLA Loneliness Scale</a> <sup>37</sup>  | Person with dementia, Care partner |
| Loneliness                 | <a href="#">Campaign to End Loneliness Measurement Tool</a> <sup>38</sup>  | Person with dementia, Care partner |
| Personal Gain              | <a href="#">Personal Gain Scale</a> <sup>39</sup>  | Care partner                       |
| Quality of Life            | <a href="#">Quality of Life in Alzheimer's Disease (QoL-AD)</a> <sup>39</sup>                                      | Person with dementia, Care partner |
| Social Engagement, Support | <a href="#">Lubben Social Network Scale</a> <sup>40</sup>  | Person with dementia, Care partner |
| Social Isolation           | <a href="#">The Friendship Scale</a> <sup>41</sup>   | Person with dementia, Care partner |
| Stigma                     | <a href="#">Affiliate Stigma Scale</a> <sup>42</sup>   | Care partner                       |

# Evaluation Plan Template

## Appendix A: Evaluation Plan (Template)

| Goal  | Activity  | Target Audience  | Outputs  | Outcome                                     | Tool or Method   |
|---|---|--|--|---|--|
| Increase awareness and understanding of people living with dementia.  | Work with schools to raise awareness in younger people about dementia.                      | High school students   | Number of students in Health 101 attend one class session about dementia | Improved attitude                           | Survey before and after class using Dementia Attitudes Scale (DAS)   |
| Increase awareness and understanding of people living with dementia.  | Hold a Dementia Friends Information Session.  | Community members  | Number of participants   | Increased knowledge<br>Increased confidence | Survey before and after session using Administration for Community Living's Brief Tool for Dementia-Friendly Education and Training Sessions |
| Address the changing needs of people with dementia and care partners. | Provide post-diagnostic support services for persons with dementia and their care partners. | Persons recently diagnosed with dementia and their care partners | Number of families   | Increase in knowledge and support           | Interview about needs met, questions answered and referrals/connections made.  |

# DFA's Future Evaluation Goals

- This is Evaluation Guide 1.0. As we hear feedback and insights, we will refine. There will likely be an Evaluation Guide 2.0!
- We'd love to engage in collaborative evaluation projects & are actively seeking out funding opportunities.
- Longer-term goal is that the Evaluation Guide can be used by DFA for national evaluation efforts

# Thank you!

Meredith Hanley,  
Director, Community Capacity Building  
National Association of Area Agencies on Aging

- Download the Evaluation Guide:  
<https://www.dfamerica.org/evaluation>
- For more information: [mhanley@n4a.org](mailto:mhanley@n4a.org)



---

---

# Milken Institute Future of Health Summit - Programming

[Tuesday, June 22, 10:30-11:30 AM ET](#)

## ***“COVID-19 and the Future of Aging”***

### **Panelists:**

- Richard Ashworth, President and CEO, Tivity Health
- Lauren Dunning, Director, Center for the Future of Aging, Milken Institute
- Trent Stamp, CEO, The Eisner Foundation
- Fernando Torres-Gil, Director, UCLA Center for Policy Research on Aging

**Moderator:** Richard Eisenberg, Managing Editor, Next Avenue

[Tuesday, June 22, 1:30-2:30 PM ET](#)

## ***“Bringing Health Home: The New Frontiers of Technology and Aging”***

### **Panelists:**

- Joseph Coughlin, Director, Massachusetts Institute of Technology AgeLab
- Kelly Cronin, Deputy Administrator, Center for Innovation and Partnership, Administration for Community Living, US Department of Health and Human Services
- Jeff Huber, CEO, Home Instead, Inc.
- Daniel Knecht, Vice President, Health Strategy and Innovation, CVS Health

**Moderator:** Bertha Coombs, Reporter, CNBC

---

---

# Milken Institute Future of Health Summit - Programming

[Tuesday, June 22, 4:30-5:30 PM ET](#)

***“The COVID Long Haulers: Facing the Cognitive and Physical Consequences”***

**Panelists:**

- Nisreen Alwan, PhD, Associate Professor in Public Health, University of Southampton
- David Putrino, PhD, Director, Rehabilitation Innovation, Icahn School of Medicine at Mount Sinai
- Heather Snyder, PhD, Vice President, Medical & Scientific Relations, Alzheimer’s Association

**Moderator:** Liz Cooney, General Assignment Reporter, STAT News

[Tuesday, June 22, 4:30-5:30 PM ET](#)

***“Dementia: Addressing the Stigma of America's Most Feared Diagnosis”***

**Panelists:**

- Malaz Boustani, MD, Richard M. Fairbanks Professor of Aging Research, Center for Health Innovation and Implementation Science, Indiana University
- Karin Hellsvik, Head of Patient Advocacy and External Communications, Alzheimer’s Disease, Biogen
- Sarah Lenz Lock, JD, Senior Vice President, Policy & Brain Health, AARP; Executive Director, Global Council on Brain Health
- Lauren Miller Rogen, Actress, Screenwriter, Co-Founder, HFC

**Moderator:** Nora Super, Executive Director, Alliance to Improve Dementia Care; Senior Director, Milken Institute Center for the Future of Aging

# Milken Institute Future of Health Summit - Programming

[Wednesday, June 23, 12:00-2:00 PM ET](#)

## Center for the Future of Aging Advisory Board Meeting (Invite Only)

### Panelists (TBD):

- Bob Casey, United States Senator, Pennsylvania; Chairman, Special Committee on Aging, United States Senate
- Nanette Cocero, PhD, Global President, Vaccines, Pfizer

**Moderator:** Paul Irving, Chairman, Center for the Future of Aging, Milken Institute; Distinguished Scholar in Residence, Davis School of Gerontology, USC

[Wednesday, June 23, 3:00-4:00 PM ET](#)

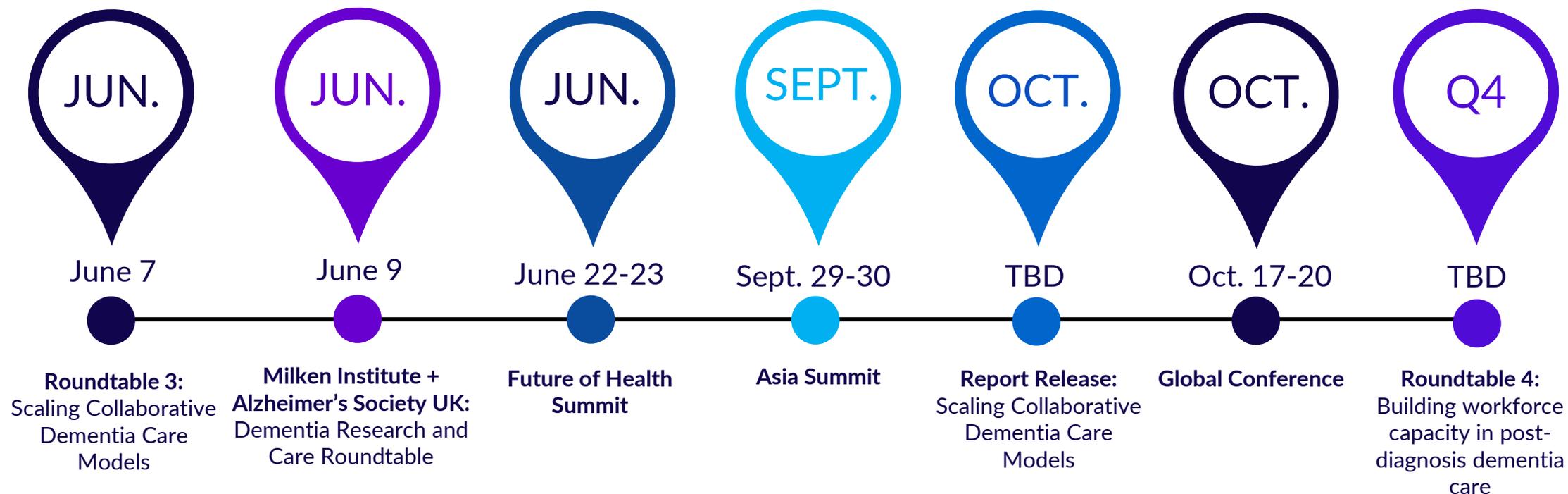
## *“It's the Life in Your Years: Reimagining Retirement for Longer, Healthier Lives”*

### Panelists:

- Kevin Crain, Managing Director, Head of Workplace Solutions Integration, Bank of America
- Linda Fried, Dean and DeLamar Professor of Public Health, Columbia University's Mailman School of Public Health
- Paul Irving, Chairman, Center for the Future of Aging, Milken Institute; Distinguished Scholar in Residence, Davis School of Gerontology, USC
- Bob Kerrey, Former US Senator, Nebraska

**Moderator (pending):** Sharon Epperson, Senior Personal Finance Correspondent, CNBC

# 2021 Important Dates



Alzheimer's Society UK, advising on roadmap for strategic investment in dementia care/research (January-December 2021)

# Open Dialogue



Questions? Interests? Open-ended items?

# Email us with any questions



**Nora Super**  
Executive Director, Alliance to Improve Dementia Care  
Senior Director, Center for the Future of Aging  
[nsuper@milkeninstitute.org](mailto:nsuper@milkeninstitute.org)



**Diane Ty**  
Director, Alliance to Improve Dementia Care  
Director, Center for the Future of Aging  
[dty@milkeninstitute.org](mailto:dty@milkeninstitute.org)



**Raj Ahuja**  
Associate Director, Center for the Future of Aging  
[rahuja@milkeninstitute.org](mailto:rahuja@milkeninstitute.org)



**Amy Fehir**  
Director, Business and Program Development, Milken Institute  
[afehir@milkeninstitute.org](mailto:afehir@milkeninstitute.org)



**Cara Levy**  
Senior Associate, Center for the Future of Aging  
[clevy@milkeninstitute.org](mailto:clevy@milkeninstitute.org)



**Mac McDermott**  
Associate, Center for the Future of Aging  
[mmcdermott@milkeninstitute.org](mailto:mmcdermott@milkeninstitute.org)



Follow our social media for updates on our work:

Twitter: @MIAging

LinkedIn/Facebook: Milken Institute Center for the  
Future of Aging