



Research News

Alzheimer's disease public-private partnerships: Update 2017

Heather M. Snyder^{a,*}, William R. Perlman^b, Robert Egge^c, Maria C. Carrillo^a^aMedical & Scientific Relations Division, Alzheimer's Association, Chicago, IL, USA^bIndependent Science Writer, Califon, NJ, USA^cPublic Policy and Advocacy Division, Alzheimer's Association, Washington, DC, USA**Abstract**

Introduction: The National Plan to Address Alzheimer's Disease stresses the need for public-private partnerships to be coordinated and cooperative to accelerate the state of research and reach the ultimate goal of preventing and effectively treating Alzheimer's disease by the year 2025.

Methods: The Alzheimer's Association, in collaboration with the International Alzheimer's disease Research Funder Consortium, compiles this annually updated compendium to centralize this inventory of partnerships in an effort to synergize these activities.

Results: This article reflects the 2017 landscape of nonprofit organizations who engage in public-private partnerships to promote and support dementia research.

Discussion: The private-public partnerships in the Alzheimer's disease community continue to increase, addressing much needed complex challenges in the field.

Keywords:

Alzheimer's disease; Collaborations; Private-public partnerships; Public policy; International efforts; Neuroscience

1. Introduction

There are greater than five million Americans living with Alzheimer's dementia and more than 35 million people worldwide [1], and without a way to stop or slow the progression, there will be nearly a tripling of individuals affected by 2050 (13.8 million) [1]. The urgency to develop an intervention to stop or slow the progression of Alzheimer's disease (AD) [2,3] is driving collaborations both within and between federal/governmental agencies, industrial/for-profit organizations, and nonprofit entities. Since 2013, the Alzheimer's Association has taken the lead on working with the global nonprofit community to compile and publish compendium on the landscape of the changing landscape of private-public partnerships between these organizations and other stakeholders [4]. This compendium of global and regional private-public partnerships between governmental/federal entities, industrial/for-profit organizations, and nonprofit organizations invested in the

AD research landscape was updated in 2014 [5]. Given the continuing growth of the landscape, the compendium requires update of the rapidly growing number of organizations involved, their varied goals, and their relationships with one another. The following sections include the mission statements of 25 nonprofit/charity organizations and their collaborative partnerships with governmental, global, and industrial entities, with an emphasis on the nature of collaborative efforts (i.e., improving clinical trials, obtaining and sharing data, supporting individuals with dementia and caregivers, and research funding).

2. Organizations included, mission statements and public web sites

There are 25 nonprofit organizations represented in the following sections with their mission summaries.

2.1. Accelerate cure/treatments for AD

<http://www.act-ad.org/>.

Accelerate cure/treatments for AD (ACT-AD) supports accelerating research into transformational therapies to

*Corresponding author. Tel.: (312) 335-5184; Fax: 866875-2533.
E-mail address: hsnyder@alz.org

better treat and potentially slow, halt, or reverse the progression of AD.

2.2. Alzheimer Argentina

<http://www.alzheimer.org.ar>.

The goals of this organization are the performance of basic research in field of AD and related areas, as well as the training of researchers and technicians in the same discipline, either by direct or indirect means owned by the Association or by third parties.

2.3. Alzheimer Europe

<http://www.alzheimer-europe.org>.

Alzheimer Europe sees its mission as “changing perceptions, practice, and policy to improve the quality of life of people with dementia and their carers”. The Organization aims to achieve this mission by providing a voice to people with dementia and their carers, making dementia a European priority, promoting a rights-based approach to dementia, supporting dementia research, and strengthening the European dementia movement.

2.4. Alzheimer Forschung Initiative e.V.

<http://www.alzheimer-forschung.de>.

This Initiative drives innovative national and border-crossing research and promotes awareness of AD as well.

2.5. Alzheimer Nederland

<http://www.alzheimer-nederland.nl/>.

The mission of Alzheimer Nederland is to prevent and cure dementia. As long as dementia is still a progressive and fatal disease, Alzheimer Nederland strives to improve the quality of life of people with dementia and their (family) caregivers. The three stated aims of Alzheimer Nederland are to invest in research to bring about solutions to the problem, improve quality of life through better care and delivery of support services, and mobilize financial support for the fight against dementia.

2.6. Alzheimer Society of Canada

<http://www.alzheimer.ca/en>.

The Alzheimer Society of Canada identifies, develops, and facilitates national priorities that enable its members to effectively alleviate the personal and social consequences of AD and other dementias, promotes research, and leads the search for a cure.

2.7. Alzheimer's Association

<https://www.alz.org/>.

The Alzheimer's Association aims to eliminate AD through the advancement of research, providing and

enhancing care and support for all affected, and reducing the risk of dementia through the promotion of brain health.

2.8. Dementia Australia Research Foundation (formerly Alzheimer's Australia Dementia Research Foundation)

<http://www.dementiaresearchfoundation.org.au/>.

The Dementia Australia Research Foundation is the research arm of Dementia Australia which funds Australia's talented new and early career dementia researchers. The Foundation supports research into the causes of all forms of dementia as well as strategies to reduce dementia risk, provide accurate and timely diagnoses and improve treatment and care options for people living with dementia. The stated objectives of the Foundation are to support innovative Australian research that offers the best hope of defeating dementia, work with people with dementia to ensure that research reflects their concerns, and disseminate information about the progress of dementia research.

2.9. Alzheimer's Disease International

<http://www.alz.co.uk/>.

Alzheimer's Disease International (ADI) is a federation of 85 national AD associations, which aims to exchange information, support emerging associations, and advocate for AD and dementia at the global level.

2.10. Alzheimer's Drug Discovery Foundation

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

The Alzheimer's Drug Discovery Foundation (ADDF) aims to rapidly accelerate the discovery of drugs to prevent, treat, and cure AD.

2.11. Alzheimer's Research UK

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

Alzheimer's Research UK, the largest dedicated funder of dementia research in the UK, supports fundamental and clinical research toward a world free from the fear, harm, and heartbreak of dementia. Alzheimer's Research UK also plays a central role in campaigning and energizing a movement across society to support, fund, and take part in dementia research.

2.12. Alzheimer's Society (United Kingdom)

<http://www.alzheimers.org.uk/>.

The Society's vision is a world without dementia. Their mission is to change the face of dementia research, demonstrate best practice in dementia care and support, provide the best advice and support to anyone dealing with dementia, and influence the state and society to enable those affected by dementia to live as they wish to live. These goals are intended to mobilize people to reduce the impact of dementia on lives today and create a world without dementia tomorrow.

2.13. American Federation for Aging Research

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

The American Federation for Aging Research is a national nonprofit organization whose mission is to support and advance healthy aging through biomedical research.

2.14. Brain Canada

<http://www.braincanada.ca/>.

Brain Canada is dedicated to increasing the scale and scope of funding to accelerate the pace of Canadian brain research, creating a collective commitment to brain research across the public, private, and voluntary sectors and delivering transformative, original, and outstanding research programs.

2.15. BrightFocus Foundation

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

BrightFocus drives innovative research worldwide and promotes awareness of AD, macular degeneration, and glaucoma.

2.16. Coalition Against Major Disease

<https://www.c-path.org/programs/camd/>.

The Coalition Against Major Diseases (CAMD) is a consortium aimed at creating new Drug Development Tools, data standards, integrated standardized databases, and methods that can be applied during the development process of new treatments for cognitive decline and dementia of AD. CAMD is one of fourteen consortia of the Critical Path Institute (C-Path), a nonprofit organization that is dedicated to accelerating drug development by delivering on the mission outlined by the U.S. Food and Drug Administration's (FDA's) critical path.

2.17. Cure Alzheimer's Fund

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

The goal of the Cure Alzheimer's fund is to fund research with the highest probability of preventing, slowing, or reversing AD.

2.18. Deutsche Alzheimer Gesellschaft e.V. Selbsthilfe Demenz

<http://www.deutsche-alzheimer.de>.

The stated mission of this Germany-based organization is to improve the life of people with dementia and their caregivers.

2.19. Fondation Plan Alzheimer

<http://www.fondation-alzheimer.org>.

The primary mission of the Foundation is to drive world-class research into AD and other related diseases in France.

The Foundation aims to foster national and international research collaborations in basic, clinical, and social sciences; expand the network of public and private researchers in France; forge partnerships with industry to reduce treatment development times.

2.20. Foundation for the National Institutes of Health

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

The Foundation for National Institutes of Health (FNIH) was established by Congress in 1990 as a 501(c)(3) public charity. The Foundation began its work in 1996 to facilitate groundbreaking research at the National Institutes of Health (NIH) and worldwide. As an independent nonprofit organization, the Foundation accomplished this by raising private funds and creating public-private partnerships to support the mission of the NIH: conducting scientific research to extend healthy life and to reduce the burdens of illness and disability.

2.21. National Biomedical Research Ethics Council

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

The goal of the National Biomedical Research Ethics Council (NBREC) is to establish a single, central, national institutional review board for neurodegenerative diseases and other chronic conditions that will both guarantee the protection of human volunteers in clinical trials and that will also increase the efficiency of initiating large multicenter clinical trials—with the larger goal of accelerating the development of novel therapeutics for devastating chronic diseases.

2.22. The Alzheimer Foundation Czech Republic

<http://www.alzheimernf.cz>.

The Alzheimer Foundation was established in 2011 to support research into AD and other neurodegenerative or vascular diseases of the brain that lead to cognitive impairment and dementia. The Foundation also aims to improve the quality of patient care.

2.23. The New York Academy of Sciences Alzheimer's Disease and Dementia Initiative

<http://www.nyas.org/WhatWeDo/Alzheimers.aspx>.

The New York Academy of Sciences has a three-pronged mission; (1) to advance scientific research and knowledge, (2) to support scientific literacy, and (3) to promote the resolution of society's global challenges through science-based solutions.

2.24. UsAgainstAlzheimer's

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

UsAgainstAlzheimer's (UsA2) is a relentless force committed to ending Alzheimer's by 2020. Driven by the suffering of millions of families, UsA2 presses for greater

urgency from government, industry, and the scientific community in the quest for an AD cure.

2.25. Weston Brain Institute

<http://www.westonbraininstitute.ca>.

The Weston Brain Institute supports high-risk, high-reward translational research projects to accelerate the development of therapeutics for neurodegenerative diseases of aging. This is accomplished by leveraging world-class business and scientific expertise and driving innovation in funding processes to provide broad support to researchers.

3. Partnerships

Partnerships between and among the 25 listed organizations are with multiple stakeholders, including with governmental agencies, nonprofit organizations, industry, and/or a combination of these stakeholders. An outline of different partnerships by type of stakeholders and priority areas of consortium/collaborative efforts is provided in the following section (Table 1 and 2).

Table 1
Alzheimer's disease public-private partnerships: collaborations

Organization name	Collaborates with governmental agencies	Collaborates internationally	Collaborates with industry	Collaborates with other nonprofits
Accelerate Cure/Treatments for Alzheimer's Disease	X		X	X
Alzheimer Argentina	X	X		X
Alzheimer Europe	X	X	X	X
Alzheimer Forschung Initiative e.V.	X	X		X
Alzheimer Nederland	X	X	X	X
Alzheimer Society of Canada	X		X	X
Alzheimer's Association	X	X	X	X
Alzheimer's Australia Dementia Research Foundation			X	X
Alzheimer's Disease International	X	X	X	X
Alzheimer's Drug Discovery Foundation	X	X	X	X
Alzheimer's research UK	X	X	X	X
Alzheimer's Society (United Kingdom)	X	X	X	X
American Federation for Aging Research	X	X		X
Brain Canada	X	X	X	X
BrightFocus Foundation		X		X
Critical Path Institute	X		X	X
Cure Alzheimer's Fund	X	X		X
Deutsche Alzheimer Gesellschaft e.V. Selbsthilfe Demenz	X			X
Fondation Plan Alzheimer	X	X	X	X
Foundation for the National Institutes of Health	X	X	X	X
National Biomedical Research Ethics Council			X	X
The Alzheimer Foundation	X		X	X
The New York Academy of Sciences Alzheimer's Disease and Dementia Initiative			X	X
UsAgainstAlzheimer's	X	X	X	X
Weston Brain Institute	X	X		X

NOTE. X indicates organization participates in activities, resources, and/or other aspects to support collaborations with the named stakeholders; boxes that do not have an X indicate the organization does not participate in those collaborations.

3.1. Collaborations with governmental agencies

- ACT-AD interacts directly with representatives of the U.S. FDA through regular meetings and opportunities for formal regulatory comment on policies affecting drug development and patient access to treatments. ACT-AD advocates before the Office of Management and Budget, the U.S. Department of Health and Human Services, and the U.S. Congress in favor of adequate levels of appropriated and collected (user fees) funding. In 2016, ACT-AD became a sponsor of the Alzheimer's Disease Neuroimaging Initiative 3.
- Alzheimer Argentina engages with three governmental/federal entities throughout Argentina to advance and fund research initiatives at the following institutions: Center of Neuropsychiatry and Behavioural Neurology, as well as the Instituto Lanari, School of Medicine of the University of Buenos Aires, and the Programa de atención medica integral–Instituto Nacional de Servicios Sociales para Jubilados y Pensionado.
- The Alzheimer Society of Canada collaborates with the Canadian Institutes for Health Research and the

Table 2
Alzheimer's disease public-private partnerships: activities

Organization name	Improving clinical trials	Obtaining and sharing data	Supporting individuals with AD/dementia and caregivers	Funding research
Accelerate Cure/Treatments for Alzheimer's Disease	X		X	
Alzheimer Argentina	X	X	X	X
Alzheimer Europe	X	X	X	
Alzheimer Forschung Initiative e.V.	X	X	X	X
Alzheimer Nederland	X	X	X	X
Alzheimer Society of Canada	X	X	X	X
Alzheimer's Association	X	X	X	X
Alzheimer's Australia Dementia Research Foundation	X	X		X
Alzheimer's Disease International	X		X	
Alzheimer's Drug Discovery Foundation	X			X
Alzheimer's research UK	X		X	X
Alzheimer's Society (United Kingdom)	X	X	X	X
American Federation for Aging Research				X
Brain Canada		X	X	X
BrightFocus Foundation	X		X	X
Critical Path Institute	X	X	X	
Cure Alzheimer's Fund	X	X	X	X
Deutsche Alzheimer Gesellschaft e.V. Selbsthilfe Demenz	X		X	
Fondation Plan Alzheimer	X	X	X	X
Foundation for the National Institutes of Health		X		X
National Biomedical Research Ethics Council	X		X	
The Alzheimer Foundation (Czech Republic)			X	X
The New York Academy of Sciences Alzheimer's Disease and Dementia Initiative			X	
UsAgainstAlzheimer's	X	X	X	
Weston Brain Institute	X	X		X

NOTE. X indicates organization participates in activities, resources, and/or other aspects to support named activities and/or priorities; boxes that do not have an X indicate the organization does not participate in those activities.

federally funded Canadian Consortium for Neurodegeneration in Aging and Canadian Longitudinal Study on Aging.

- Alzheimer's Association works with multiple federal entities. The Association is a voting member on the Steering committee of the Accelerating Medicines Partnership, a collaboration including the NIH and several pharma partners. In addition, the Alzheimer's Association co-led the development of the Common Alzheimer's disease Research Ontology [6] and the International Alzheimer's Disease Research Portfolio [7] with the National Institute on Aging (NIA), and has worked closely with the team to develop the updated ontology to include Alzheimer's and Alzheimer's related dementias to be launched in spring 2018. The Alzheimer's Association has also been partnered with the Centers for Disease Control and Prevention since 2005 under the Health Brain Initiative.
- Alzheimer Europe actively participates in a number of projects funded by the Innovative Medicines Initiative where the organization represents the views of national Alzheimer associations, of people with dementia and

their carers, participates in the discussion of ethical issues raised by the research, and contributes to or leads the dissemination activities of these projects toward the wider dementia community. In 2016, Alzheimer Europe was involved with Innovative Medicines Initiative projects including PharmaCog, European Medical Information Framework, European Prevention of Alzheimer's Dementia, Amyloid imaging to prevent Alzheimer's disease, Real World Outcomes across the AD spectrum for better care: Multi-modal Data Access Platform, and the Model Organism Protein Expression Database. All Innovative Medicines Initiative projects are private-public partnerships involving funding from the European Commission and the European Federation of Pharmaceutical Industries and Associations with the participation of academia, companies, small and medium size enterprises, nonprofit organizations (and regulators and payers such as the National Institute for Health and Care Excellence and European Medicines Agency in an advisory capacity).

- The Alzheimer Forschung Initiative e.V. engages in private-public partnerships with governmental/federal

entities including Alzheimer Society Düsseldorf, Intercultural dementia network Düsseldorf, and Integration office Düsseldorf.

- The ADDF's annual Drug Discovery for Neurodegeneration Conference is an Educational Course on Translating Research into Drugs supported through a cooperative grant from NIA and the National Institute of Neurological Disorders and Stroke.
- Both CAMD and the FNIH have entered into private-public partnerships with governmental agencies, a host of large global pharmaceutical companies, and long lists of associations and foundations to facilitate essential AD-related research.
- Brain Canada is engaged in private-public partnerships with government/federal entities including the Government of Canada through Health Canada and the NIH to advance Canadian-based researchers working in brain science, including dementia.
- Global CEO Initiative on Alzheimer's Disease (CEOi) convenes the Lausanne Conference and the Lausanne Dialogues, in partnership with the Organisation for Economic Co-operation and Development, the Swiss government, and ADI, to advance global alignment on, among other matters, regulatory and payer issues.
- The Fondation Plan Alzheimer collaborated with the French Ministry of Research and of Health, the Agence Nationale de la Recherche, the Institut National de la Santé et de la Recherche Médicale, the Commissariat à l'Énergie Atomique, the Caisse National de Solidarité pour l'Autonomie, and the Alliance for life and health sciences to support research programs and call for grants in the field of AD and related disorders. The Fondation is a member of the research steering committee of the National Plan for Neurodegenerative diseases and is an active member of the Global Joint Programming Initiative on Neurodegenerative diseases and AD in particular. The Fondation also collaborated with the European Commission for the support of Joint Programming Initiative on Neurodegenerative diseases.
- Alzheimer's Society (UK), Alzheimer's Research UK, and the Medical Research Council are founding partners of the UK Dementia Research Institute. The UK Dementia Research Institute is a £250m investment to create a national Institute, which will bring together world-leading expertise in biomedical, care, public health, and translational dementia research. Alzheimer's Research UK is a member of the Coalition against Major Diseases, with a range of governmental, industry, nonprofit, and regulatory organizations.

3.2. Global collaborations

- ADI leads a number of partnerships with its member organizations including Alzheimer Europe, Alzheimer

Ibero-America, the Non-communicable Disease Alliance, and the Global Alzheimer's and Dementia Action Alliance to facilitate global communication and engagement. An example, in 2015, the Alzheimer's Association convened the first Ibero-America Alzheimer's Research Symposium and ADI provided leadership in engaging Alzheimer Ibero-America, providing introductions to government officials and engaged multiple stakeholders in this global discussion.

- The Alzheimer Forschung Initiative e.V. also collaborates with the BrightFocus Foundation, LECMA-Vaincre Alzheimer, and Alzheimer Netherlands.
- In addition to collaboration with the Alzheimer Forschung Initiative e.V. and LECMA-Vaincre Alzheimer, Alzheimer Nederland engages in private-public partnerships with Alzheimer's Society UK and Fonds Psychische Gezondheid.
- The Alzheimer's Association has multiple global collaborations with diverse stakeholders, including the Global Biomarkers Standardization Consortium to develop standards for biomarker studies used in research and clinical care through Worldwide Alzheimer's Disease Neuroimaging Initiative to convene ADNI-related efforts from around the world for the continued communication and harmonization of collected data. In addition, the Alzheimer's Association convenes the largest meeting of dementia researchers through the Alzheimer's Association International Conference (alz.org/AAIC) representing more than 5000 participants and 70 countries as a platform to exchange information on the latest in Alzheimer's and dementia research.
- The Alzheimer's Association, in collaboration with NIA and Alzheimer's Research UK, convenes the International Alzheimer's disease Research Funder Consortium of more than 30 funding organizations (private, government, and nonprofit) from over 10 countries to enable communication and collaborative efforts to advance and leverage future investments in dementia research. As a result of these discussions, there has been an increased cross-collaboration of efforts, including funding programs, among members.
- CAMD works with global companies and academic institutions to advance the regulatory science required by the U.S. Food and Drug Administration (FDA) and European Medicine Agency (EMA) to develop Drug Development Tools and disease progression models.

3.3. Collaborations to improve clinical trials

- Join Dementia Research is a service provided by Alzheimer's Research UK, Alzheimer's Society (UK), and the National Institute for Health Research for people to register their interest in becoming participants in

research studies. The platform allows researchers to identify potential participants to screen and contact them and run feasibility tests for future studies.

- The Alzheimer's Association provides collaborative funding for Anti-Amyloid Treatment in Asymptomatic Alzheimer's Disease/Longitudinal Evaluation of Amyloid Risk and Neurodegeneration, Dominantly Inherited Alzheimer Network Trial, and the Alzheimer's Prevention Initiative Generation Study. These investments provide and leverage infrastructure support across funding organizations—including NIH, pharma, and other nonprofit organizations—to advance important clinical trials, add emerging biomarkers and tools to these studies, and to provide exchange of information.
- The Collaboration for Alzheimer's Prevention is co-led by the Alzheimer's Association and FBRI to synergize ongoing and new prevention efforts in AD, facilitate comparative data and assessment efforts through collection and analysis, and lead data sharing initiatives among these teams with the global scientific community. Current members of Collaboration for Alzheimer's Prevention include the Dominantly Inherited Alzheimer's Network Trials Unit, the TOMMORROW trial, the Anti-Amyloid Asymptomatic in Alzheimer's study, and the Alzheimer's Prevention Initiative.
- The Alzheimer's Association partners with EmergingMed and the Association's nationwide network across the United States to offer TrialMatch as a clinical study matching service for individuals to identify trials in their local community and beyond.
- Global Alzheimer's Platform (GAP) Foundation: GAP, a 501(c)(3) partnering with industry and other foundations, is establishing a standing global trial-ready platform to drive quality, efficiency, and innovation in AD clinical trials, seeking to reduce clinical testing cycles by up to 2 years and to achieve more uniformity in trial populations by building large, well-characterized clinical trial cohorts and an adaptive proof-of-concept trial mechanism. Partners of GAP-Net, a global network of optimized clinical trial sites, are top-performing, respected academic and private commercial institutions that share the goal of streamlining clinical research and development for AD.
- In 2016, NBREC and Schulman entered into a public-private partnership to further extend and enhance Schulman's central institutional review board (IRB) review of trials focusing on neurodegenerative diseases. The alliance will provide highly customized review support services to study sponsors, participating research institutions, principal investigators, and project staff. All IRBs provide board members sufficiently qualified to review the research that comes before it. The unique feature of the alliance is that the IRB will now be reinforced by internationally recognized key

opinion leaders via the provision of a focused review of the science itself. NBREC is working actively with many nonprofit advocacy and academic research groups including the Alzheimer's Association, ADDF, and the Canadian Consortium for Neurodegeneration in Aging. In addition, NBREC in partnership with Schulman's IRB is advising several AD clinical research cooperative groups including the Alzheimer's Therapeutic Research Institute, the Alzheimer's Diseases Cooperative Study, and the GAP on models, approaches, and best practices for development of centralized ethics review for clinical research.

- The Patient-Centered Outcomes Research Institute funds the Alzheimer's & Dementia Patient- & Caregiver-Powered Network, a partnership of UsA2, the Mayo Clinic, the University of Florida, and the Brain Health Registry at the University of California, San Francisco. Alzheimer's & Dementia Patient- & Caregiver-Powered Network aims to connect patients, caregivers, and researchers focused on developing, conducting, and disseminating patient-centered dementia research; enroll large numbers of individuals at risk for/manifesting Alzheimer's or dementia and caregivers in a network to facilitate patient-focused studies; recruit, characterize, retain, and enroll these individuals in trials through novel web-based registries; develop specific means to increase outreach to and enrollment of minority populations; and test a computable patient phenotype for early risk of AD.
- The Alzheimer's & Dementia Disparities Engagement Network (ADDEN) is an initiative of UsAgainstAlzheimer's, partially funded by PCORI. ADDEN is engaged in activities (e.g., webinars, panel discussions, and a national Summit focusing on disparities) to build and bring together a broad network of diverse researchers, patients, caregivers, health professionals, and community-based organizations for knowledge sharing around barriers, facilitators and priorities in Alzheimer's and brain health research.
- The Weston Brain Institute and the ADDF have partnered to support the Program to Accelerate Clinical Trials.
- The Coalition Against Major Diseases (CAMD) advances the regulatory science required by the US Food and Drug Administration (FDA) and European Medicine Agency (EMA) to achieve acceptance as Drug Development Tools that enable the delivery of innovative treatments, includes multiple non-profit entities as members including Alzheimer's Research UK and the Alzheimer's Association.

3.4. Collaborations to obtain and share data

- Global Alzheimer's Association Interaction Network (gaain.org) provides federated network to access

research data, sophisticated analytical tools, and computational power to analyze data from over 400,000 clinical records globally. CAMD, ADNI, AMP-AD and other large initiatives are partners of GAAIN.

- CAMD continues to work with industry partners and the Clinical Data Interchange Standards Consortium to maintain and link a Unified Clinical Trial Database for AD and enable data sharing. Global Alzheimer's Association Interaction Network uses Clinical Data Interchange Standards Consortium standards for clinical trial record information.
- The FNIH convenes the ADNI Private Public Partnership Scientific Board, including pharma, nonprofit, and governmental stakeholders of the ADNI initiative. The Alzheimer's Association and ADDF are partners of the ADNI Private Public Partnership Scientific Board, and ACT-AD is also represented. In addition, the FNIH Biomarkers Consortium convenes to advance efforts to evaluate and validate biomarkers of disease progression. Data and outcomes as a result of ADNI and FNIH Biomarkers Consortium efforts are shared with the global scientific community as free access.
- CEOi and Optum Labs have launched Project Insights: Big Data Research Initiative to Fight Alzheimer's Disease, linking industry, academia, and government to accelerate research.
- AD PACE is a patient-/caregiver-led collaboration that is in the process of being launched by UsAgainstAlzheimer's to build a standing platform to deliver to regulators and payers new insights into the treatment and health outcomes preferred by those living with Alzheimer's and their caregivers. AD PACE will conduct a wide-ranging, scientifically rigorous study to confirm *what matters most* to those across the breadth of the lived-experience with this disease. Part of AD PACE, the A-LIST is an online community providing insights into the patient and caregiver experience, the outcomes most meaningful to them, and priorities for access to care, services, treatment and clinical research.

3.5. Collaborations with industry

- The Alzheimer's Association has formed partnerships with the Alzheimer's Association Research Roundtable and the Alzheimer's Association Business Consortium, an entity which convenes small biotech/start-up organizations to come together in a precompetitive space to share ideas, opportunities, and leverage one another's knowledge.
- The ADDF has formed a partnership with Pfizer Centers for Therapeutic Innovation, which works with specific universities in the United States to support small molecule projects. ADDF helps to fund projects in

collaboration with Pfizer Centers for Therapeutic Innovation, leveraging Pfizer's expertise and funding. The Alzheimer Society of Canada has also engaged in a public-private partnership with Pfizer. ADI supports awareness and educational projects through collaborations with roughly 15 corporate partners.

- Alzheimer's Research UK established a network of Drug Discovery Institutes at University College London, University of Cambridge, and University of Oxford. The Institutes collaborate with a range of pharmaceutical companies on targets of common interest. In addition, Alzheimer's Research UK is a partner of the Dementia Discovery Fund together with the UK Department of Health and several industry partners and led by SV Life sciences.
- The Alzheimer's Society (UK), among others, is part of the Neurodegeneration Medicines Acceleration Programme, a consortium working together with the pharmaceutical industry to invest in stalled existing projects and accelerating the development of medicines.
- ADDF established the ADDF ACCESS program to provide scientists with a virtual network of contract research organizations, consultants, and educational resources for drug development. ADDF has partnered with a number of contract research organizations within this network to provide discounted pricing and consultation for the scientific community.
- Alzheimer's Research UK established, together with the Medical Research Council Technology, Eisai and Eli Lilly, the Dementia Consortium to target validation.
- Brain Canada is engaged in private-public partnerships with several pharmaceutical companies, such as Eli Lilly and Atuka Inc. to fund and support Canadian-based dementia researchers.
- CAMD collaborates with 11 industry partners to advance the regulatory science required to develop Drug Development Tools that can be used by industry and academia.
- UsA2 convenes the CEOi coalition with over 15 corporate members and partnerships globally with public authorities.
- Five pharmaceutical companies are members of the board of trustees of the Fondation Plan Alzheimer and participated in the creation and initial funding of the foundation.
- Early-stage drug discovery research initiatives.

3.6. Collaborations to support patients and caregivers

- ACT-AD is a coalition of organizations representing people with AD, caregivers, consumers, older Americans, researchers, and women's health advocates.
- Alzheimer's Australia provides direct support to individuals living with dementia and their families or caregivers and engages in public policy.

- The ADI collaborates with the World Health Organization on global public policy and some caregiver services and has established a similar collaboration with the Pan American Health Organization for countries in the Americas. ADI is the worldwide federation of Alzheimer associations, which supports people with dementia and their families.
- The Alzheimer's Association offers information and direct support services for those affected by AD and related dementia. These programs include the community programs offered by more than 70 Alzheimer's Association chapters across the United States, the toll-free 24/7/365 helpline in multiple languages; the website (alz.org) with online resources and support related services. The Association partners with multiple national, state, and community agencies to provide resources to families.
- Alzheimer's Research UK and Alzheimer's Society works with Public Health England to pilot an extension of the dementia risk reduction component of the National Health Service Health Check to all 40- to 64-year olds.
- Deutsche Alzheimer Gesellschaft e.V. Selbsthilfe Demenz works in partnership with the Ministry of Health and Ministry for Family Affairs, Senior Citizens, Women and Youth in a "National alliance for people with dementia." In addition, this organization has entered into a contract with the German centre for neurodegenerative diseases concerning counseling and with a counseling agency of a private health insurance concerning education.
- The Alzheimer's Society (UK) provides leadership to Dementia Action Alliances across England. The Dementia Action Alliance was formed in October 2010 and is made up of more than 900 national and local organizations across the United Kingdom committed to transforming the quality of life for people living with dementia.
- UsA2 supports the Alzheimer's Disease Patient and Caregiver-Powered Research Network, a patient-powered research network funded by Patient-Centered Outcomes Research Institute. This network is guided by expert advisory councils, whose members include representatives of the NIA and FDA. The Alzheimer's Disease Patient and Caregiver Engagement is a patient- and caregiver-led initiative to develop a range of patient-focused drug development, patient preference tools, and resources to support AD drug development and regulatory and payment review. In collaboration with industry, academia and patient advocates, Alzheimer's Disease Patient and Caregiver Engagement will draw on a breadth of early investments by industry and nonprofit partners specific to engaging patients, caregivers, and at-risk individuals in the science of patient input.
- BrightFocus, ADF, C-Path, CURE Alzheimer's Fund and UsA2 collaborate as part of Leaders

Engaged on Alzheimer's Disease Coalition, with more than 90 member organizations. The coalition focuses on accelerating transformational progress in (1) care and support to enrich the quality of life of those living with dementia and their caregivers; (2) detection and diagnosis; and (3) research leading to prevention, effective treatment, and eventual cures. Leaders Engaged on Alzheimer's Disease Coalition members include patient advocacy organizations and health nonprofits, philanthropies and foundations, trade and professional associations, academic research and clinical institutions, home and residential care providers, and biotechnology and pharmaceutical companies.

3.7. Collaborations to fund research

- Alzheimer Argentina supports research and advanced scientific training in the life sciences at the Fundación Instituto Leloir.
- Alzheimer Nederland is a partner in the Dutch national plan, Deltaplan for Dementia, which is a nationwide public-private initiative. The national plan consists of three elements: prevention and cure of dementia, improving health care for people with dementia, and creating a dementia friendly society. Alzheimer Nederland funds research spanning four areas: origin of AD, diagnostics, prevention and treatment, and care and support. Also, Joint Programming Initiative on Neurodegenerative diseases projects are financially supported by Alzheimer Nederland. Within the research program of the Deltaplan for Dementia, one of the criteria for application is that researchers have to find public-private partnerships for co-funding of their research projects. Therefore, most of the research that is funded by Alzheimer Nederland within the Deltaplan Dementia has private-public partnerships of which some are with industry or for-profit entities.
- The Alzheimer's Association is the largest nonprofit funder of AD research in the world, funding over \$380 million to nearly 2500 scientific investigations since 1982. As of December, 2017, the Alzheimer's Association has more than \$110 million in active projects in 18 countries to over 400 investigations. The Association networks with the global scientific community of over 6000 individuals who provide peer-review activities. As a part of the Association's programs, there are several collaborative funding efforts to leverage investments and advance research. The Biomarkers Across Neurodegenerative Diseases initiative has been offered in two rounds, including Michael J. Fox Foundation for Parkinson's Research, Weston Brain Institute, and Alzheimer's Research UK (in the second

- iteration) (alz.org/BAND). The Association, Weston Brain Institute, and Alzheimer's Research UK co-funded the MEchanisms of cellular death in NeuroDegeneration program (alz.org/MCDN). Other collaborative programs include the Alzheimer's Association co-funding with ADDF for the Alzheimer's Combination Therapy Opportunities (alz.org/ACTO) program, with Global Down Syndrome Foundation for investigator-initiated projects linking Down syndrome and AD research and with Brain Canada to increase Canadian researchers in this field.
- In addition, the Alzheimer's Association has partnered with the Tau Consortium to offer the Tau Pipeline Enabling Program (alz.org/t-pep) and with the Global Brain Health Institute (GBHI, gbhi.org) to provide pilot funding for Global Brain Health Leaders to advance skills, knowledge, activities, and general efforts to delay, prevent, and/or mitigate the impact of dementia worldwide.
 - The AADRF partners with organizations who have donated funds to support research projects, such as Resthaven Inc. and Plants Management Australia. The AADRF also partners with not-for-profit organizations who have donated funds to support research projects including the Yulgilbar Foundation, the Cromwell Property Group Fund, the Dementia Collaborative Research Centres, the Petersen Family Foundation, and the Sylvia and Charles Viertel Charitable Foundation.
 - ADDF co-funds the repurposing of research projects with Alzheimer's Society (UK), drug discovery and clinical trials for frontotemporal dementia with the Association for Frontotemporal Degeneration, and combination therapy trials with the Alzheimer's Association.
 - Alzheimer's Research UK, Alzheimer's Society (UK) collaborate with the Medical Research Council to support a network of UK brain banks for dementia research.
 - Alzheimer's Research UK serves as a member of several funder groups including the International Alzheimer's Disease Research Funder Consortium, Dementia Research Funders Forum (UK), Neurological Alliance, the UK Health Forum, and the Dementia Action Alliance.
 - The Alzheimer's Society (UK), in partnership with major UK heart and stroke charities (The Stroke Association and British Heart Foundation), has developed a funding initiative for vascular dementia. The Society also partners with researchers working on grant funding from the National Institute of Health Research to support delivery of care, patient involvement, and general dissemination of research findings.
 - American Federation for Aging Research partners with other funding agencies to support research on AD, in

particular, through American Federation for Aging Research Grants to junior faculty.

- Brain Canada is engaged in private-public partnerships to fund Canadian researchers with a very high number of nonprofit entities including the Weston Brain Institute Multi-Investigator Research Initiative, Alzheimer Society of Canada, and the Alzheimer's Association.
- The Cure Alzheimer's Fund engages in private-public partnerships with multiple organizations and academic institutions to support Alzheimer's Genome Project, the Whole-Genome Sequencing project, and other consortia exploring the role of genetics in AD pathology. In addition, Cure Alzheimer's Fund partners with Carlingkind NYC and UsAgainstAlzheimer's to support AD research.

4. Summary

As reflected in this compendium, the landscape of private-public partnerships in the AD and dementia space continues to grow as momentum continues globally to address this growing public health crisis. The collaborations and initiatives driven by the stakeholder groups represented in this compendium advance efforts to understand and address the complexity of AD, leverage funding opportunities and shared priorities across organizations, and ultimately synergize initiative activities to promote and support dementia research.

References

- [1] Alzheimer's Association. 2016 Alzheimer's disease facts and figures. *Alzheimers Dement* 2016;12:459–509.
- [2] G8 Dementia Summit Declaration, 2013. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/265869/2901668_G8_DementiaSummitDeclaration_acc.pdf. Accessed December 15, 2017.
- [3] The National Plan to Address Alzheimer's Disease. Published 2012. Available at: <https://www.nia.nih.gov/alzheimers/publication/2012-2013-alzheimersdisease-progress-report/national-plan-address-alzheimers>. Accessed December 15, 2017.
- [4] Snyder HM, Bain LJ, Egge R, Carrillo MC. Alzheimer's disease public-private partnerships: A landscape of the global nonprofit community. *Alzheimers Dement* 2013 Jul;9:466–71.
- [5] Snyder HM, Kim H, Bain LJ, Egge R, Carrillo MC. Alzheimer's disease public-private partnerships: update 2014. *Alzheimers Dement* 2014 Nov;10:873–80.
- [6] Refolo LM, Snyder H, Liggins C, Ryan L, Silverberg N, Petanceska S, et al. Common Alzheimer's Disease Research Ontology: National Institute on Aging and Alzheimer's Association collaborative project. *Alzheimers Dement* 2012;8:372–5.
- [7] Liggins C, Snyder HM, Silverberg N, Petanceska S, Refolo LM, Ryan L, et al. International Alzheimer's Disease Research Portfolio (IADRP) aims to capture global Alzheimer's disease research funding. *Alzheimers Dement* 2014;10:405–8.