

Research News

## Alzheimer's disease public-private partnerships: A landscape of the global nonprofit community

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With the prevalence of dementia expected to exceed 115 million worldwide by 2050 [1], stakeholders across all sectors of society recognize the need for an aggressive, coordinated, and global response. Similar challenges have been faced in the past and provide models for how to mount an effective response today. In the mid-1950s and early 1960s, patient advocacy organizations, pharmaceutical companies, and public health agencies came together to provide polio vaccine to 400 million children, reducing the incidence of this dreaded disease by 90% in the United States [2]. More than 20 years later, polio was again the target in the creation of the world's largest public-private partnership, the Global Polio Eradication Initiative, spearheaded by national governments from around the world, the World Health Organization (WHO), Rotary International, the U.S. Centers for Disease Control (CDC), and the United Nations Children's Fund (UNICEF). Key partners included the Bill and Melinda Gates Foundation and many pharmaceutical companies. Between 1988 and 2012, polio cases had decreased by over 99% [3].

Alzheimer's disease (AD) represents a problem that, like polio in the 1950s, is too big for any one entity to address. The National Plan to Address Alzheimer's Disease [4] recognized the enormity of the challenge and the need for building coordinated partnerships with multiple stakeholders. Indeed, public-private partnerships have played an important role in the global effort related to AD, as exemplified by the Alzheimer's Disease Neuroimaging Initiative (ADNI), and subsequently, Worldwide ADNI [5]. Since its inception, ADNI has represented a true public-private partnership, with initial

public support in the form of \$480 million in grants from the National Institute on Aging (NIA) and other National Institutes of Health (NIH) institutes and an additional \$49 million in private support donated to the Foundation for the NIH (FNIH) from nonprofit organizations/foundations and pharmaceutical companies. Drawing on the expertise of a wide range of stakeholders, the ADNI franchise has encouraged global collaboration and leveraged funding to enable groundbreaking research. The result has been significant progress toward defining the progression of AD and developing, standardizing, and validating various biomarkers of AD and other dementias [5].

In Europe, public-private partnerships have been used to underwrite the costs of building hospitals and delivering care to individuals with dementia [6]. In the United States and Europe, partnerships have been created in precompetitive space to facilitate data sharing and expedite drug discovery [7]. In 2005, NIH established a Public-Private Partnership program; in Europe, the European Union and European Federation of Pharmaceutical Industries and Associations established the Innovative Medicines Initiative (IMI) [8]. Recent initiatives have been launched to globally align AD public-private partnerships, such as Worldwide ADNI and the IMI/Critical Path Institute (both described below), with the goal of an international integration of efforts.

In the United States, the National Plan to Address Alzheimer's Disease established coordinating research with international public and private entities as one of its strategies to prevent and effectively treat AD by 2025. This paper represents an initial inventory—with the expectation to be updated annually—of public-private partnerships of nonprofit organizations invested in AD research worldwide and is an ongoing effort to reflect the landscape of these collaborations. The hope is that this will be a potential tool to align global efforts, reduce duplication of efforts, and create platforms for new alliances among nonprofit organizations.

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## 1. Accelerate Cure/Treatments for Alzheimer's Disease coalition

### 1.1. Mission

With a coalition of more than 50 nonprofit organizations, Accelerate Cure/Treatments for Alzheimer's Disease (ACT-AD) works to accelerate research into transformational therapies to better treat and potentially slow, halt, or reverse the progression of AD.

### 1.2. Partners

ACT-AD members include organizations that represent patients, providers, caregivers, consumers, older Americans, employers, and health-care industries. ACT-AD receives support from several pharmaceutical companies and has worked with the U.S. Food and Drug Administration (FDA) on several projects.

### 1.3. Projects

ACT-AD has convened five meetings on topics relevant to AD clinical trials, convened a 12-member expert panel to assess the status of biomarker research and explore means of using biomarkers effectively in drug development, and organized symposia at national AD meetings with the goal of expediting drug development by advancing consensus among regulatory agencies about requirements for clinical trials of disease-modifying therapies.

## 2. Alzheimer's Association

### 2.1. Mission

The mission of the Alzheimer's Association is to eliminate AD through the advancement of research, to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health.

### 2.2. Partners

The Alzheimer's Association partners with NIH, FNIH, and other foundations and nonprofit organizations, pharmaceutical companies and other corporations, regulatory agencies, academic institutions, and other international organizations.

### 2.3. Projects

The Alzheimer's Association established the Alzheimer's Association Research Roundtable, a consortium of scientists from industry that meets regularly to explore a wide range of topics related to AD drug development. Other public-private partnerships established by the association include the Everyday Technologies for Alzheimer's Care (ETAC) program, the Animal Model Consortium, the Global Biomarkers Standardization Consortium (GBSC), the Common Alzheimer's Disease Research Ontology (CADRO), and the

MedicAlert® + Alzheimer's Safe Return® program. In addition, the association is a major funder of ADNI and a partner in the International Alzheimer's Disease Research Portfolio (IADRP), the Coalition Against Major Diseases (CAMD), and several projects of the Biomarkers Consortium, including the Placebo Database Project.

## 3. Alzheimer's Australia

### 3.1. Mission

Alzheimer's Australia provides support and advocacy for Australians living with dementia and their caregivers, and it supports research aimed at better understanding all forms of dementia, developing new interventions and treatments, and rapidly translating relevant research into better dementia care.

### 3.2. Partners

Alzheimer's Australia participates in several public-private dementia research partnerships with the Australian government, residential aged care providers, philanthropic organizations, private aged care organizations, research centers, and industry partners.

### 3.3. Projects

Alzheimer's Australia partners with the National Health and Medical Research Council (NHMRC) and several other care organizations in the Partnership Centre on Dealing with Cognitive and Related Functional Decline in Older People, which brings research and clinicians together with consumer and industry organizations for research programs aimed at effecting system change in areas such as hospital dementia services, clinical guideline development, and appropriate medication management. The National Quality Dementia Care Initiative is Alzheimer's Australia's flagship research translation program to drive nationwide improvements in dementia care. The Australian Government established Dementia Collaborative Research Centers in 2005 to coordinate research and translate findings into an accessible form for policy-makers and service providers. Alzheimer's Australia is a member of each center along with other research centers and industrial partners.

## 4. Alzheimer's Disease International

### 4.1. Mission

A confederation of 80 national Alzheimer's associations, Alzheimer's Disease International (ADI) was founded to facilitate the sharing and exchange of information, resources, and skills among national Alzheimer's organizations seeking to improve the quality of life for people with dementia and their families, raise awareness, and advocate on their behalf in the main international policy bodies.

#### 4.2. Partners

In addition to the 80-member organizations, ADI partners with WHO and the United Nations as well as other international umbrella organizations such as HelpAge International, International Federation of Aging (IFA) and International Psychogeriatric Association (IPA).

#### 4.3. Projects

ADI conducts population-based research about the worldwide prevalence of AD as well as risk factors and family support available in lower- and middle-income countries. In 1998, ADI created the 10/66 Dementia Research Group to gather data about the 66% of people with dementia living in low- and middle-income countries, where less than 10% of the population-based research has been performed.

### 5. Alzheimer's Drug Discovery Foundation

#### 5.1. Mission

The mission of the Alzheimer's Drug Discovery Foundation (ADDF) is to rapidly accelerate the discovery of drugs to prevent, treat, and cure AD, related dementias, and cognitive aging by providing seed funding to academic centers and biotechnology companies.

#### 5.2. Partners

ADDF develops collaborations with scientists, foundations, industry partners, and contract research organizations.

#### 5.3. Projects

ADDF has established a program called ADDF ACCESS to connect scientists with the collaborators and tools needed for drug discovery and a Biotechnology Development Program to support programs dedicated to AD drug discovery and clinical development. In addition, ADDF has several other partnerships: the ADDF/Belfer ApoE Therapeutics Innovation Program to accelerate development of therapies that target ApoE; the ADDF/New York Academy of Sciences Challenge Grant to accelerate drug development for AD and dementia; the ADDF/NIH collaboration to provide support for grants scored but not funded by NIA and the National Institute of Neurological Disorders and Stroke (NINDS) that fall within ADDF's funding priorities; the ADDF/Association for Frontotemporal Degeneration (FTD) Partnership to Accelerate Drug Discovery for FTD; the ADDF/Lewy Body Dementia Association Biomarker Research Program; and the Collaborative CNS Screening Initiative (CCSI), a partnership with the Beyond Batten Disease Foundation and the Multiple Sclerosis Society to establish a central repository of chemical compounds known to have significant central nervous system (CNS) activity.

### 6. Alzheimer Nederland

#### 6.1. Mission

Alzheimer Nederland (Alzheimer's Society in the Netherlands) aims to prevent or cure dementia; to improve the quality of life for patients and caregivers; and to mobilize society, citizens, caregivers, and patients in the fight against dementia.

#### 6.2. Partners

Alzheimer Nederland partners with AD research centers throughout the Netherlands; medical university hospitals; insurance and other industry partners; and the Ministry of Health, Welfare, and Sports and other national organizations of health research and development. It is also involved with the European Union's Joint Programme–Neurodegenerative Disease Research (JPND).

#### 6.3. Projects

In 2011, Alzheimer Nederland co-initiated a public-private partnership called Deltaplan Dementia, the national plan of the Netherlands, to build scientific research and health-care delivery for people with dementia. In April 2013, Deltaplan Dementia was launched with the ministry announcing a grant of €32.5 million for a scientific programme for the next 4 years. Alzheimer Nederland will invest an additional €12.5 million.

### 7. Alzheimer's Research United Kingdom

#### 7.1. Mission

Alzheimer's Research United Kingdom (ARUK), the largest dedicated funder of dementia research in the United Kingdom, supports research toward a world free of dementia, from basic research through clinical studies.

#### 7.2. Partners

ARUK is represented in several research and advocacy efforts and is developing new funding partnerships with the pharmaceutical industry, other national and international charity funders, and government/public agencies. The latter include the Canadian Institutes for Health Research and the Chief Scientist Office in Scotland.

#### 7.3. Projects

ARUK participates in the Prime Minister's Dementia Challenge Research Champion's Group, the Dementia Research Funders Forum, the Evington Initiative, and the Dementia Action Alliance. Other partnerships are in development.

## 8. Alzheimer's Society, United Kingdom

### 8.1. Mission

Alzheimer's Society, United Kingdom (Alzheimer's Society UK) is the largest care and research charity in the United Kingdom. Alzheimer's Society UK looks to lead the fight against all forms of dementia through research, campaigning, and influencing policy and to be the foremost people of contact for people with dementia in the United Kingdom, providing care services, support, and information for those affected by the condition. In 2012, the society invested over £5 million (US \$8 million) in research, with a further £3 million being added by funding partners.

### 8.2. Partners

Alzheimer's Society UK works with the government and charity funders of research across the sector, including the U.K. government on the Prime Minister's Challenge on Dementia Research, and across U.K. business through the Evington Initiative. In addition, they are exploring the opportunity for international collaboration.

### 8.3. Projects

The society works with other research funders to develop specific research projects, notably with ARUK and the Medical Research Council, to support brain banking for dementia research and with the British Heart Foundation and Stroke Association to advance research into vascular dementia. Working with the James Lind Alliance, Alzheimer's Society UK is completing a large research prioritization exercise, taking into account the priorities of clinicians, practitioners, and patients (expected to be published in June 2013).

## 9. Brain Canada

### 9.1. Mission

Brain Canada is a national charitable organization with the goal of funding research aimed at unlocking the mystery of the brain to develop diagnostics, treatments, and ultimately cures for brain disorders.

### 9.2. Partners

Brain Canada partners with private sources, foundations, and other organizations devoted to neuroscience and brain health through the Canada Brain Research Fund (CBRF), a public-private partnership established by the Canadian government with a commitment of up to \$100 million in matching funds.

### 9.3. Projects

CBRF supports three main programs: the Multi-Investigator Research Initiative, Research Training Awards,

and Platform Support Grants. CBRF also supports several major partnerships such as the Brain Canada–Chagnon Family Interventions for the Prevention of Alzheimer Disease and Related Disorders program.

## 10. BrightFocus Foundation

### 10.1. Mission

Formerly the American Health Assistance Foundation, BrightFocus is committed to advancing knowledge that saves mind and sight through support for health research and public education.

### 10.2. Partners

BrightFocus partners with other philanthropic organizations and with the Biomed Central publication, *Molecular Neurodegeneration*.

### 10.3. Projects

BrightFocus Foundation, along with the U.S. Against Alzheimer's and the Geoffrey Beene Gives Back Alzheimer's Initiative, has convened the 21st Century Brain Trust to fund studies aimed at promoting mobile health technologies. BrightFocus has also partnered with the ADDF to support a clinical trial, and with LEAD (Leaders Against Alzheimer's Disease) and other organizations on advocacy and education campaigns.

## 11. Critical Path Institute

### 11.1. Mission

The Critical Path Institute (C-Path) was created to support implementation of the FDA Critical Path Initiative. C-Path and its partners work to establish the scientific basis for new standards, tools (including biomarkers and clinical outcome assessment measures), and disease models and to contribute to best-practice and FDA guidance documents that affect drug development. The overall goal is to accelerate the development and review of medical products by the advancement of drug development tools through a formal regulatory path.

### 11.2. Partners

C-Path serves as a neutral third party orchestrating the sharing of data and knowledge among industry, global regulatory agencies, patient advocacy groups, research foundations, government funding agencies, academia, scientific associations, and consultant groups.

### 11.3. Projects

AD consortia include CAMD and the Patient-Reported Outcome (PRO) Consortium. CAMD is working to accelerate the development of therapies for AD and Parkinson's

disease (PD) through the qualification of new tools and streamlining regulatory review. These new tools include a harmonized set of data standards, a database incorporating clinical trials data from industry sponsors and trials, disease progression models, and qualification of biomarkers. PRO is developing self-report measures for use as clinical trial endpoints that assess complex activities of daily living and interpersonal function in individuals with mild cognitive impairment (MCI) due to AD.

## 12. FNIH

### 12.1. Mission

FNIH was formed to support the NIH in its mission to improve health by forming and facilitating public-private partnerships for biomedical research and training.

### 12.2. Partners

FNIH forms partnerships among different institutes and centers at NIH, regulatory agencies, the pharmaceutical industry, academia, advocacy organizations, patient groups, and individuals.

### 12.3. Projects

FNIH has formed several research consortia around topics related to AD. ADNI is an ongoing, longitudinal, multicenter study designed to develop clinical, imaging, genetic, and biochemical biomarkers for early detection and tracking of AD. After the first 5-year study, the project was extended by a Grand Opportunities (GO) grant and then renewed and expanded in ADNI-2. Funding for ADNI is provided by NIA, with current support from 23 pharmaceutical and biotechnical companies, 2 foundations, and 1 government entity. The FNIH-convened ADNI Private Partner Scientific Board (PPSB) is an independent, open, precompetitive forum for all private-sector partners in ADNI to encourage collaboration and sharing of information and to provide scientific and private-sector perspectives and expertise on issues related to ADNI. PPSB has undertaken several projects regarding amyloid- $\beta$  as a biomarker, genotyping analysis, collection of cerebrospinal fluid (CSF), and substudies aimed at developing positron emission tomography (PET) imaging ligands and a more sensitive cognitive measure for clinical trials. In addition, the FNIH Biomarkers Consortium has undertaken several AD-related projects, including the AD Targeted Plasma Proteomics Project, to qualify a multiplexed panel of known AD biomarkers using ADNI plasma samples; the ADNI CSF Proteomics Project to utilize ADNI CSF samples to assess multiplexed immunoassay and multiple reaction monitoring (MRM) mass spectrometry panels; the TSPO PET Radioligand Project to explore the 18-kD translocator protein (TSPO) as a biomarker of neuroinflammation; and the AD/MCI Placebo Database Analysis Project, which combines and analyzes placebo data from nu-

merous large clinical trials as a means of identifying reliable and sensitive cognitive and biomarker measures of disease progression.

## 13. The Global CEO Initiative on Alzheimer's Disease

### 13.1. Mission

The Global CEO Initiative on Alzheimer's Disease (CEO Initiative or CEOi) represents an acceptance of the invitation from public authorities, domestically and internationally, to the private sector to forge robust public-private partnerships to stop AD and dementia. The vision for the CEO Initiative is to become the leading business voice on AD and to have a profound effect in fiscal, social, and political matters as it works to "change the game" on AD.

### 13.2. Partners

The CEO Initiative partners with leaders from corporations across multiple industries and sectors, nonprofits, and the public sector.

### 13.3. Projects

The CEO Initiative has convened focused working groups co-led by industry and nonprofit leaders to craft an action-oriented, results-driven approach to achieving the important goal of preventing and treating AD and increasing the nation's research and development productivity by 2025: (1) developing a prioritized research agenda; (2) reducing the time cost and risk of drug development to improve productivity of research and development investments; (3) developing new investment models to support research, clinical care, and patient and caregiver support; and (4) raising public awareness, reducing stigma, and driving greater levels of patient and family engagement in clinical trials.

## 14. National Biomedical Research Ethics Council

### 14.1. Mission

The National Biomedical Research Ethics Council (NBREC) aims to improve human subject safety as well as increase the efficiency and speed of conducting large-scale, multicenter trials.

### 14.2. Partners

NBREC works with patient advocacy organizations, academia, and the private sector in consultation with representatives of the U.S. Federal Government.

### 14.3. Projects

NBREC seeks to establish a National Institutional Review Board for Neurodegenerative Disease (NIRB-ND) for

multicenter clinical trials to promote more efficient and effective human subject safety and research.

## 15. New York Academy of Sciences Alzheimer's Disease and Dementia Initiative

### 15.1. Mission

The mission of the New York Academy of Sciences Alzheimer's Disease and Dementia Initiative (NYAS ADDI) is to advance the diagnosis, treatment, and prevention of AD and dementia as a neutral convener.

### 15.2. Partners

The academy has assembled stakeholders from academia, industry, patient advocacy organizations, governmental organizations, and foundations to define priorities and develop actionable plans for progress in research, early development/translation, clinical trials, and facilitating the public-private interface.

### 15.3. Projects

The academy is advocating for improvements in the current AD and dementia landscape by developing a business case for co-investment in AD (with Research Triangle International), issuing seed funding for innovative biomarkers with ADDF, convening stakeholders at an industry-led AD

Summit and developing a research agenda with the CEO Initiative (CEOi), as described above, and conducting a scoping analysis with Humanitas Global Development to identify gaps in the current landscape. They are independently developing a roadmap for innovative clinical trial design.

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