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Review

Politics of science: Progress toward prevention of the dementia–Alzheimer's syndrome

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ABSTRACT

There exist many challenges hampering the discovery and development of effective interventions to prevent dementia. Three major trends have now intersected to influence the emerging interest in disease modifying therapies that may delay or halt dementia. The three crucial factors shaping this current focus are: (1) the emergence of the longevity revolution and the impact of a aging society, (2) the effects of the US Federal investment in research in advancing knowledge about the neurobiology of aging and dementia, and (3) the problem of US legislators and health policy makers to balance the allocation of evermore scarce research funding resources. The purpose of this essay is to provide a survey of the politics of science and to describe efforts to correctly manage the high level of expectations of both the patient and research communities. The perspective offered reviews the history and evolution of the ideas to treat or prevent dementia and Alzheimer's disease as a national strategic goal. The aim is to evaluate the interplay between science and formulation of public policy for setting research priority. We use the history of developing US National Institute of Aging's extramural research programs on brain aging and Alzheimer's disease (Khachaturian, 2006; 2007) as an initial case study.

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1. Introduction

Recently the National Institutes of Health [NIH] released the highly anticipated recommendations, based on the opinion of some leading experts, the framework for a

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national research agenda for Alzheimer's disease [AD]. The NIH research schema for dementia, and other related chronic brain disorders, is touted to promote *bold* and *transformative* programs, which will foster *innovative* approaches and *collaborations* to speed discovery (National Institute on Aging, National Institutes of Health).

The prospective strategy for speeding the development of effective interventions for Alzheimer's and related dementias was developed at the *Alzheimer's Disease Research Summit 2015: Path to Treatment and Prevention* – convened by the National Institute on Aging (NIA), National Institutes of Health (NIH), U.S. Department of Health and Human Services [DHHS] in Bethesda, Maryland, February 9–10, 2015, as one of *legacy meetings* to follow-up the proceedings of the *G-8 (Group of 8) Summit on Dementia,* in December 2013, London, UK (Global Action Against Dementia). These recommendations call for a change in how the academic, biopharmaceutical and government sectors participating in Alzheimer's research and therapy generate share and use knowledge to propel the development of critically needed therapies.

Francis S. Collins, NIH Director, said, "Alzheimer's research is entering a new era in which creative approaches for detecting, measuring and analyzing a wide range of biomedical data sets are leading to new insights about the causes and course of the disease." He continued to say, "In these times of significant fiscal constraints, we need to work smarter, faster and more collaboratively. These recommendations underscore the importance of data sharing and multidisciplinary partnerships to a research community that looks to the NIH for guidance on the way forward."

The proposed *action plan* outlined new scientific approaches to address critical knowledge gaps and proposed: (a) ways to harness emerging technologies to accelerate treatments, (b) identify infrastructure needs, (c) partnerships necessary to successfully implement the new research agenda, (d) strategies to empower patients and engage citizens and (e) an array of overarching research themes that include:

- understand all aspects of healthy brain aging and cognitive resilience to inform strategies for Alzheimer's disease prevention;
- expand integrative, data-driven research approaches such as systems biology and systems pharmacology;
- develop computational tools and infrastructure in order to enable storage, integration and analysis of large-scale biological and other patient-relevant data;
- leverage the use of wearable sensors and other mobile health technologies to inform discovery science as well as research on Alzheimer's disease care;
- support and enable Open Science in basic, translational and clinical research;
- change the academic, publishing and funding incentives to promote collaborative, transparent and reproducible research;
- invest in the development of a new translational and data science workforce;
- engage citizens, caregivers and patients as equal partners in Alzheimer's disease research.

These recommendations will be considered by the National Council on Aging as well as the Advisory Council of NAPA[1] in updating the specific milestones of the *National Plan*, which has promulgated the strategic goal of finding *effective therapies to treat or prevent Alzheimer's disease and related dementias by 2025* (US Department of Health & Human Services).

The NIA/NIH Summit meeting represents the culmination of a series of research planning workshops/think-tank meetings organized by the Campaign to Prevent Alzheimer by 2020 [PAD2020] (Khachaturian and Khachaturian, 2009; Khachaturian et al., 2008, 2009a, 2009b, 2010, 2011), Alzheimer's Association (Alzheimer's Association Expert Advisory Group on NAPA, 2012; Fargo et al., 2014; Khachaturian et al., 2012), Organization for Economic Cooperation and Development [OECD] (OECD, 2013; OECD), G-8 Summit on Dementia[2] and others since 2009, preparing the ground work for a major initiative to address the global menace of dementia (Alzheimer's Study Group, 2007). The scientific community has fulfilled its responsibility, in outlining a comprehensive scientific agenda to attack the challenges of dementia. Now, the burden for action, i.e., implementation of the plan, is in the political arena; the ball is in the policy makers'/legislators' court. The open question is whether the *scientific roadmap* suggested by the NIA/NIH Summit–Alzheimer's Association and others will succeed in garnering more resources for R&D on dementia or whether the National Alzheimer Project Act (NAPA) production of a National Plan to Address Alzheimer will be translated into increased appropriations for research dollars.

There is no doubt that the array of recommendations for a potent scientific agenda to address the global challenge of dementia/Alzheimer's by the international scientific community will advance the prospect of discovering novel treatments or strategies for prevention. However, the ultimate objective of these recommendations, i.e., building-up the essential scientific knowledge for treatments, will not be attained without substantial increases of funds for research (Khachaturian et al., 2012).

The enormous public health dilemma of dementia cannot be solved without a solid commitment for a systematic increase of dollars for discovery – sustained for the next 10-years. Unfortunately the policy makers' choices to address this challenge are limited and problematic. One option for

[1] Public Law (PL 111–375), a.k.a., NAPA – enacted by Congress in 2011, mandated the formulation of a "national strategic plan" to mobilize research and development (R&D) resources, which would alter the catastrophic trajectory of an imminent public health crisis due to the exponential increases of people with the disease and explosive costs of health care. The overall strategic goal of the "national plan" is to promote the discovery and validation of wide arrays of new scientific knowledge and associated novel technologies, which would ameliorate the progression of not only Alzheimer's disease but also other chronic brain disorders due to degenerative processes. The ultimate aim of the "national plan" is to expand or develop the national scientific–technical capabilities, which would eventually enable the prevention of the onset of disabling symptoms within a decade. The strategic public health objective of the national plan is based on the premise that a modest delay of 5 years in the onset of symptoms will reduce the prevalence and health care cost of the disease by 50%.

[2] In December 2013, at the G8 Dementia Summit in the UK, G8 health ministers from G8 countries decided that the economic impact of Alzheimer's disease is a great weight on health care systems already crippled by dangerously shrinking budgets. This provided impetus and incentive to participating G8 Health Ministers, including Canada, to vow to find a cure or treatment for dementia in 12 years.