

Policy Forum

Countrywide strategic plans on Alzheimer's disease: Developing the framework for the international battle against Alzheimer's disease

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Abstract

As the world's population ages, countries must prepare for the significant impact Alzheimer's disease will have on their health systems, their economies, and their citizens. In anticipation of major global demographic changes, many countries in the G-20 since 2000 have begun to develop and enact plans to address Alzheimer's disease as a national priority. However, even with nearly half of these participating countries having plans in place, there has been little research done to quantify the value of enacting a countrywide plan on this disease. In this review, we summarize recent national plans (from the year 2000 and beyond) and any results stemming from their respective recommendations and activities.

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1. Introduction

With life expectancies anticipated to increase significantly across developed and developing nations alike, one of the most important global issues of this century will be how to manage the health and socioeconomic impact of Alzheimer's disease (AD). An estimated 35.6 million people worldwide were living with dementia in 2010, and this number is projected to nearly double every 20 years, to 65.7 million in 2030, and to 115.4 million in 2050, at an enormous cost to society [1]. Developing countries are expected to be the hardest hit, as the numbers of elderly individuals increase exponentially, rising by as much as 140% compared with approximately 51% in developed countries by 2030 [2]. The worldwide costs of dementia will also soar, exceeding 1% of global Gross Domestic Product in 2010, or US\$604 billion [3].

The worldwide response to the growing threat of dementing disorders is a patchwork of comprehensive and limited programs and both funded and unfunded mandates. Only a few

countries—France, Australia, The Netherlands, Norway, Scotland, the Republic of Korea, the United Kingdom, and the United States—have made dementia a national priority. Other countries have also begun to propose national plans aimed at halting the progression of disease, providing adequate care and treatment for patients and caregivers, and implementing prevention strategies for individuals at elevated risk of dementing disease. The focus and scope of these plans vary depending on the socioeconomic and cultural profiles of the countries, yet there have been no meaningful systematic reviews or evaluations of differing national plans that may aid health policy formulators and decision makers in the design of new plans or the refinement of existing plans. We began to address this deficiency in the literature by examining national plans in G-20 countries that have been established to develop and coordinate research, treatment, and prevention programs aimed at controlling the pandemic of dementing illnesses.

2. What comprises a “National Plan?”

For the purposes of this article, a “national plan” (hereinafter a “plan”) is defined as societal recognition expressed either

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by the government alone or in combination with a national advocacy community that national health policy changes are needed to care and treat individuals afflicted with dementia, prevent or mitigate future cases of illness, and provide support to patients' caregivers. These plans differ in their origin; some have been developed by government agencies and key government figures, whereas others have been developed and promoted by advocacy organizations such as a country's Alzheimer's advocacy patient group (e.g., the Alzheimer's Association). Many plans represent partnerships between governments and advocacy organizations.

At the center of all the national plans are several recurring themes: increased awareness, early diagnosis, access to care, improved support services, patient-centered care delivery, research, and improved support for caregivers. The plans differ in terms of effectiveness in creating or effecting policy changes. We considered the organization that initiated the planning process, as well as the extent of government departmental involvement, to see how influential these components were to the success of a plan.

The comprehensiveness of plans was evaluated across five general categories: (1) call-to-action, meaning a public declaration; (2) government/key stakeholder engagement both in creating and implementing the plan; (3) allocation of resources to support those government programs; (4) provision of funding to accomplish the goals of the programs (i.e., deployment of resources); and (5) measurement of outcomes and effectiveness after programs have been put in place (Fig. 1).

3. Brief summaries of national plans

3.1. European Union

In September 2008, the Competitiveness Council of the European Union (EU) recommended a European initiative that would mobilize member states to promote research and the training of specialists to treat neurodegenerative diseases, particularly AD [4]. In 2009, the European Commission (EC; the executive arm of the EU) adopted a proposal to tackle AD and other neurodegenerative diseases, calling for a coordinated focus on prevention, diagnosis, treatment, and care efforts and joint programming of research efforts. In March 2010, the Joint Program Initiative, led by the EC and EU member states, proposed bringing together medical researchers from across Europe to make research more efficient and avoid duplication of work. The ultimate goal of the Joint Programming Initiative on Combating Neurodegenerative Diseases (JPND) is to accelerate progress in understanding the causes of these debilitating conditions and better enable early diagnosis, the development of new treatments and prevention, and the provision of more effective medical and social care to improve the quality of life for patients and caregivers. Although the program is primarily focused on research, there are components of the plan that touch on other needs arising from AD. The plan seeks to incorporate

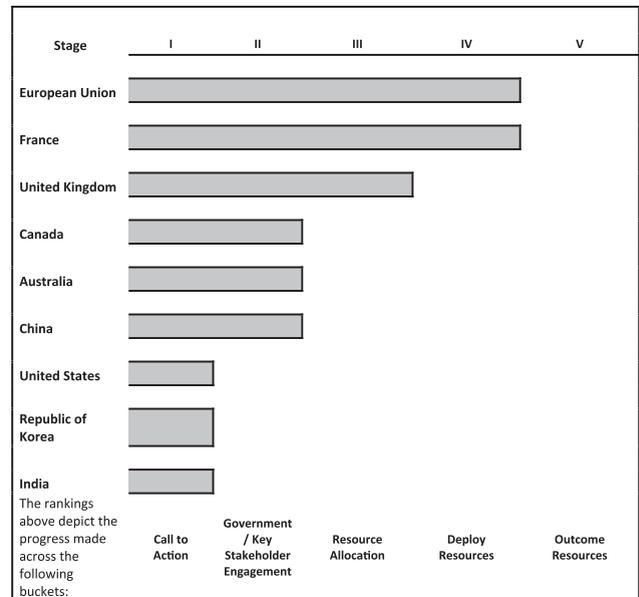


Fig. 1. Progress of national plans.

a “dementia dimension” into health promotion activities or to produce recommendations on a “healthy brain lifestyle” for citizens. The Commission will also help to develop early, accurate diagnosis tools that will promote the best use of existing treatments. In support of patients and their caregivers, the EC wants to promote common policies on the rights, autonomy, and dignity of patients. Caring for people whose cognitive abilities are becoming affected by dementia raises difficult questions, over which laws and practices vary widely throughout the EU.

Twenty-three countries are participating in the JPND effort (Table 1). In January 2011, 12 member states provisionally agreed to participate, with a total funding commitment of 7 million euros; an additional 7 member states had pending agreements [5]. In May 2011, JPND launched its first major activity, a joint transnational call between 20 countries (including Canada) to establish collaborative research projects for optimization of biomarkers and harmonization of their use. Total funding for this program is more than 15 million euros for all participating countries.

Table 1
States participating in EU Joint Programme—Neurodegenerative Disease Research (JPND)

Albania	Netherlands
Belgium	Norway
Czech Republic	Poland
Denmark	Portugal
Finland	Slovak Republic
France	Slovenia
Germany	Spain
Greece	Sweden
Hungary	Switzerland
Ireland	Turkey
Italy	United Kingdom
Luxembourg	

3.2. France

France today has what is possibly the world's model for a national plan. France started this effort in 1998, and by 2001, more than 186 forums had taken place across the country, with more than 13,000 "forumists" participating from different professions. This led to France's first National Plan for Alzheimer's, which was launched in 2001. In 2004, the Minister of Health unveiled his Alzheimer's Plan that would last until 2007. In conjunction with the release of the 2004 National Plan, France launched national policies for the elderly population in 2003 (*vieillesse et solidarités*) and a plan for the oldest old in 2006 (*plan de solidarité-grand âge 2007–2012*). These policies were aimed at giving elderly people the choice to stay at home and improving residential care by increasing the workforce and adapting hospitals to care for patients with AD. Funding for these programs was jointly provided by Caisse nationale de solidarité pour l'autonomie (CSNA; national health insurance) and local governments. Money and other support for the elderly population have also been allocated by these plans, and multiple initiatives have been put into place to benefit this population.

In 2008, President Nicolas Sarkozy announced the "National Plan for Alzheimer and Related Diseases 2008–2012," with a budget of 1.6 billion euros in new expenditures over 5 years. The plan was the first to develop a comprehensive approach for fighting the disease, integrating research, care, and support, and, most importantly, developing synergies for the improvement of the quality of life for patients and their relatives [6]. France's commitment marked a paradigm shift at the policy level, placing the patient and caregiver at the center of delivery and care. The plan called for strengthening home support, increasing specialized professionals in AD, and providing case managers for support and guidance after diagnosis. In addition, the plan proposed new structures and processes to provide more adequate care. Some of these include the development and diversification of respite care services and the creation of 11,000 day care facilities and 5600 temporary residential care places, adding to an existing capacity of 7000 and 3600, respectively.

France has completely integrated AD into its system of care, with plans for reimbursement and the creation of separate units of health care for the elderly population (Personalized Autonomy Allocation and Plan for the Oldest Elderly). To increase awareness, France has set up help lines and a Web site [7], conducted regional conferences, and announced a national declaration and public awareness campaign. To enhance early diagnosis and provide personalized care pathways for patients and their families, coordination centers were established to provide a single point of contact and help track the management of patients from the disclosure of a diagnosis through treatment and long-term care. To improve access of care, an experimental flat-fee payment system is used with private practice health care professionals. The

special needs of AD patients are addressed by newly created "case managers" in gerontology, who are trained using a special curriculum. In addition to expanded day care and temporary housing facilities, 120 specialized cognitive behavioral units for people with AD have been established within the rehabilitation services network. Finally, to enhance research efforts, France has deployed resources for research project grants, created a Foundation for International Scientific Cooperation to stimulate and coordinate scientific research, and supported development of clinical research on AD and improvement of nonpharmacological drug interventions. All told, France has allotted about 1.6 billion euros for these efforts. With integrated support at all levels of the government, France has made progress on all fronts, according to a roundtable organized in February 2011 [8].

3.3. United Kingdom

"Living Well with Dementia" is the 5-year plan launched by the U.K. Department of Health in February 2009 [9], with an allocation of £150 million for the first 2 years. Originally introduced in 2007, the plan was envisioned as a partnership between the National Health Service (NHS), local authorities, and key stakeholders. It was further developed after gathering input from more than 4000 individuals at 50 stakeholder events. An implementation plan was published in July 2009 [10] and updated in September 2010 [11]. The plan is not prescriptive, but outlines how the Department of Health will support national and regional implementation of the strategy. It also includes a timeline that indicates the expected progress over 5 years.

The Plan focuses on three areas: improved awareness, earlier diagnosis and intervention, and higher quality of care. Within these three overall thematic areas, 17 key objectives were established. Documents published by the Department of Health emphasize the government's commitment to putting patients and the public first and adapting the program to local needs and resources, with accountability at the local level as well.

With regard to the goal of increasing awareness, the government announced "Living Well with Dementia," a national campaign that seeks to inform individuals of the benefits of timely diagnosis and care of dementing illnesses, promote the prevention of dementia, and reduce social exclusion and discrimination. In terms of changes to available services, the plan proposes that people with dementia have access to a pathway of care that delivers rapid and competent specialist assessments; accurate diagnoses that are sensitively communicated to the person with dementia and their caregivers; and treatment, care, and support provided after the diagnosis.

To assist AD patients, the Department of Health will provide support at both the national and regional levels to all those involved in delivering the necessary implementation of the national strategy by establishing a well-organized framework

and empowering local leadership. To ensure patient-centered care, the United Kingdom is considering provision of housing support, housing-related services, and telecare to support people with dementia and their caregivers; improving end-of-life care for people with dementia; and creating an informed and effective workforce for people with dementia. For caregivers, the United Kingdom has created a separate strategy in which caregivers are to be provided a needs assessment and an agreed support plan that includes good quality, personalized breaks. Children caring for parents with AD are given particular priority within the caregiver strategy.

The Plan used an outcome-focused approach in developing its dementia strategy. To this end, the Department is working with partner organizations, including the Alzheimer's Society, to identify key outcomes and specific evidence-based statements that will incentivize industry partners to invest in research and development of AD therapies. A National Clinical Director for Dementia was appointed, and dementia was identified as an area requiring increased emphasis in the NHS Operating Framework for 2010/2011. In addition, the NHS National Quality Board was established and tasked with identifying ways of improving the quality of dementia care.

In March 2010, the All-Party Parliamentary Group on Dementia published an examination of the progress made in implementing the strategy, particularly with regard to funding. They found that two-thirds of the primary care trusts assigned to implement the plan were unable to document whether or how the money had been spent [12].

3.4. Australia

In 2006, the Australian Health Ministers published a National Framework for Action on Dementia (2006–2010), which provides a structure to bring together strategies from all the states and territories. The Framework identified five key priority areas: care and support, access and equity, information and education, research, and workforce and training [13]. The Framework was developed with a working group of officials from all jurisdictions as well as after consultation with consumers, caregivers, industry, and professional organizations. It builds on previous initiatives in Australia, including the National Action Plan for Dementia Care (1992–1997) and a budget measure in 2005 that made dementia a national health priority, with an infusion of an extra \$321 million over 4 years [14]. The 2006 plan included a commitment from the Australian Government for \$2.3 billion annually to support people with dementia, their caregivers, and their families, as well as other funding for a national cross-cultural dementia network, a dementia training package for aboriginal people and Torres Strait Islanders, and a range of research and workforce training initiatives.

There is strong advocacy by the national organization, Alzheimer's Australia. This group focuses on increased awareness about the disease as well as established resources, support groups, and a hotline for patients. To increase awareness, Alzheimer's Australia has developed brochures and

messaging for people with AD and their families to support them after diagnosis. The *National Dementia Helpline and Referral Service* provides a first point of contact for dementia information, support, and other health community services staffed by trained and experienced advisors. For patients who go into home care, Dementia and Memory Community Centers are managed in each state and territory. People with dementia and their families and caregivers can choose whether they receive care in the community or in a residential facility, with options to help them tailor a consumer-directed service package to best meet their needs.

3.5. Republic of Korea

South Korea has one of the world's fastest aging populations, with 9% of the population >65 years of age. In 2008, the government of Korea proclaimed dementia to be a national health care priority, increased national health insurance payments by 4% to raise money for long-term care of the elderly, and declared a "War on Dementia" [15,16]. The Korea Plan, developed by the Ministry of Health and Welfare, with the involvement of the Alzheimer's Association of Korea and neuropsychologist, psychiatrist, and nursing organizations, aims to increase early diagnosis, expand the training of dementia specialists, and ease caregiver burden by making long-term care insurance more accessible and by expanding outreach services. One innovative program in South Korea aims to train thousands of people, including children, to recognize symptoms and provide care for people with dementia [17].

3.6. United States of America

Although the United States has no true national plan at this time, it has a long history of governmental and private programs to deal with aging and dementia. In 1974, the National Institutes of Health established the National Institute on Aging (NIA). Not long after, in 1980, several family support groups in partnership with the NIA founded the Alzheimer's Association, which to this day remains the largest AD advocacy group in the world. The increased attention on AD resulted in the creation of the NIA's Office of Alzheimer's Disease Research in 1985, which coordinated all U.S. federal research investments in AD until 1995 [18]. Through the efforts of this Office, the NIA began funding a network of Alzheimer's Disease Research Centers in 1984 as a means of enhancing and translating research on AD into better treatments. In 1991, the NIA in collaboration with the University of California, San Diego, formed the Alzheimer's Disease Cooperative Study to advance drug development for AD. Other programs funded by NIA include the Alzheimer's Disease Education and Referral Center; the National Alzheimer's Coordinating Center, which coordinates data collection for Alzheimer's Disease Centers collaborative projects; and the National Cell Repository for Alzheimer's Disease.

The early elements of a coordinated, national plan emerged in 2011, when the U.S. Congress passed and

President Barack Obama signed the National Alzheimer's Project Act, which will create a coordinated national strategy to deal with the Alzheimer's crisis. The plan aims to accelerate the development of treatments, promote early diagnosis, coordinate the care and treatment of individuals with AD, and coordinate with international organizations in the fight against AD. At this point, however, no funds have been allocated to implement the plan.

3.7. Canada

Canada's response to the Alzheimer's crisis initiated at the provincial level. Ontario led the way with its 1999–2004 Alzheimer Strategy, and followed that with 10 by 20: Ontario action plan for dementia, released in 2010 [19]. British Columbia, Manitoba, Saskatchewan, Newfoundland, and Labrador have also developed dementia-specific programs. However, as of 2011, Canada had no national Alzheimer's plan.

In 2010, the Alzheimer Society of Canada published a report entitled *Rising Tide: The Impact of Dementia on Canadian Society* [20], which aimed to document the impact of dementia on Canadian society and stimulate action by the federal government to invest in a national strategy. The report predicted that by 2038, 1.1 million Canadians (approximately 2.8% of the population) would have dementia and the total economic burden, including costs of informal care, would exceed \$872 billion. The report outlined and analyzed the economic impact of four intervention scenarios, ranging from increasing physical activity to implementing a system navigator approach to coordinate care and provide caregiver support. It went on to recommend a five-point comprehensive National Dementia Strategy: (1) accelerating investment in research; (2) supporting informal caregivers; (3) recognizing the importance of prevention; (4) integrating best practices in chronic disease prevention and management, community support, and community care; and (5) strengthening the dementia workforce across all levels of care.

Also in 2010, the Canadian Dementia Action Network, a nonprofit charitable organization dedicated to eradicating AD and related dementias, proposed a national initiative that would establish nine teams representing the nine components of an integrated comprehensive plan: basic research, brain banking, animal models, genetics research, clinical research, neuroimaging, translational research, formal clinical trials, and international and industry relations. The Canadian Dementia Action Network plan included budgets for each component, with an overall cost of \$50 million per year for a minimum of 5 years.

No governmental funds have been allocated to implement a national plan in Canada. However, over the past decade, the Canadian Institutes of Health Research has increased annual funding for dementia research to \$20 million (Canadian dollars) from \$4.5 million, and Alzheimer's Society Ontario is co-founder and lead funder (\$12 million) of the center for research in neurodegenerative diseases at the

University of Toronto. In addition, privately funded organizations have implemented programs to provide patient and caregiver support, such as Alzheimer's Society Ontario's First Link for newly diagnosed individuals and Safely Home, a program to find people with dementia who are lost and return them safely to their homes.

3.8. China

Although China has no national plan, the Chinese government listed dementia as a priority of disease prevention and treatment in mental health in a 10-year government plan announced in 2002. This plan spurred several initiatives to improve diagnosis and awareness around the disease. China Alzheimer's Project was launched in 2009 as a voluntary health organization focused on increasing public awareness about dementia, supporting patients and their families, and training professional caregivers.

China faces a serious threat from AD because of its large population and increasing life expectancy. By 2050, China's population aged 60 years or older is expected to reach 438 million, 33% of the total population [21]. The incidence of chronic diseases is also high in China. In one recent survey of elderly institutions in Chengdu, Sichuan Province, the incidence of chronic disorders was 87.1%, with nearly one-quarter of people suffering from more than three chronic diseases [22]. Moreover, although Chinese culture values family care of the elderly population, as a result of China's one-child policy, the Chinese family of the future is predicted to follow a "4:2:1 paradigm": four grandparents, two adult children, and one grandchild. As a result, although most patients are currently cared for at home by family caregivers, there will be a serious imbalance between those requiring care and those able to provide it. Training adequate numbers of home care workers would present a considerable challenge [23].

The burden of the disease is further complicated by poor public awareness, a low rate of medical diagnosis, and inadequate medical and nursing care services. According to the China Alzheimer's Project, China has a severe shortage of hospitals that can provide comprehensive diagnosis and treatment for AD patients, physicians with experience in managing patients with dementia, community health service centers with the ability to screen and provide specialized care for people with dementia, public nursing homes or hospitals that can provide services for people with dementia, and senior caregivers. These problems are exacerbated by a low level of public health education and miniscule investments in AD clinical research.

There is currently no national health insurance program or publicly funded safety net program for the elderly population in China [24]. The Chinese government implemented two programs in 2001: the "Star Light Program" and "Beloved and Care Engineering," which increased the number of senior centers and nursing homes for elderly individuals, primarily by encouraging private and foreign investors

to participate in the nursing home industry [25]. In 2005, Beijing adopted new measures that would provide government subsidies to nongovernmental institutions and encourage individuals to invest in care centers for the aged. More recently, Shanghai proposed what it calls the 90-7-3 plan, in which 90% of the elderly population will be cared for at home, 7% with visits to community centers, and 3% in nursing homes. This approach is expected to require an additional 5000 nursing beds each year [26].

3.9. India

India has no national program, but is included here because there has been substantial effort from the advocacy community. In 2010, the Alzheimer's and Related Disorder Society of India (ARDSI) held a national dementia summit in New Delhi, and released *The Dementia India Report 2010*, a study of the prevalence, impact, available services, and costs of dementia in India [27]. Formed in 1992, ARDSI is India's largest national voluntary organization dedicated to improving the care, support, and research of dementia. The report called on government and policy makers to develop a National Dementia Strategy that would recognize dementia as a public health priority. The report was prepared after a series of consultative meetings throughout India with health care professionals, policy makers, organizations involved in dementia care and research, as well as the Ministry of Social Justice and Empowerment. The group believes that ignorance and stigma around Alzheimer's are contributing to a general lack of knowledge and wishes to raise awareness, develop services, train family members and professionals, and undertake research. To achieve their main goals, the organization promotes a clear flow of public information through newspapers, magazines, radio, and television. According to the Society, this coverage should consist of general information about the disease, how it affects families, and what help is available. Although not a comprehensive change, two achievements in India have been the "Friends of ARDSI" campaign to raise public awareness of Alzheimer's and the "Dementia Care Fund" that offers practical, affordable help to patients with dementia, including clothes and medicines.

4. Discussion

In 2009 and 2010, Alzheimer's Disease International (ADI) published *World Alzheimer Reports*, which documented the global burden of AD and the efforts that have been made throughout the world to address this crisis [1,28]. Here, we have evaluated the established and developing policies with the goal of providing information that will better position governments, national medical systems, and societies to deal with the impending implications of AD.

The ADI analysis concluded that high-income (developed) countries have generally allocated resources for AD prevention and management to become an integrated part

of their health care system in the coming years, whereas lower- and middle-income (developing) countries tend to emphasize community-based efforts and educational campaigns. However, we found that there were many similarities in emphasis among plans across the economic spectrum.

The information gathered in this article resulted in the identification of five strategies that can be enacted at the national (and, in some instances, the regional) level so that Alzheimer's plans encompass the most relevant and supportive initiatives for patients. The strategies that were recognized as priorities in most national programs include increasing awareness about AD, a focus on early diagnosis, increasing the workforce of specialists and care providers, improving residential care, and putting patients and caregivers at the center of delivery and care. There are additional strategies that are laid out in one or two plans that we believe are important aspects of plans, and things to consider when the essential five strategies are in place. These strategies include research, increased access, patients' rights, improving day care, strengthening home support, improved end-of-life care, and coordinating with international organizations.

It is essential to note that funding must be provided for the implementation of all the recommendations laid out within Alzheimer's Plans. Plans that have the most success in implementation are those that plan for and budget resources. Furthermore, building on the five recurring strategies that we have laid out previously will be essential in the success of the adoption of a plan.

The prevalence and nature of AD present national leaders with challenges unlike the diseases of the past. National governments must now make substantial investments to address the prevention, support, and research needs of this disease, and couple these investments with sound policy and legislative initiatives. However, it is clear that governments cannot do this alone. Advocacy organizations such as ADI, the Alzheimer's Association, and ARDSI have provided leadership in developing many of the national plans. Indeed, public-private partnerships have proven to be essential in advancing initiatives, particularly when resources are limited. Care providers, researchers, physicians, pharmaceutical and biotechnology companies, and individuals with dementia and their families also play important roles in developing plans that are responsive to the individual country's needs.

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Did you know?

The screenshot shows the website for *Alzheimer's & Dementia*, the journal of the Alzheimer's Association. The page features a navigation menu on the left, a search bar at the top right, and a central content area. A prominent badge on the right side of the page states "Now Included on MEDLINE". Below this, the "Current Issue" is listed as "November 2008 | Vol. 8, No. 8". A "Featured Article" is highlighted, and a red circle with an arrow points to a "Change Alert" button in the "PROFILES" section. Other sections include "JOURNAL ACCESS" and "ABOUT THE ALZHEIMER'S ASSOCIATION".

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