

# **Dementia Innovation Readiness Index**

G7 Progress Report

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**Summer 2018**

In April 2017, the Global Coalition on Aging (GCOA) and Alzheimer's Disease International (ADI) published the Dementia Innovation Readiness Index. The Index was the first-ever effort to analyze the readiness of different countries to integrate innovative dementia solutions into their healthcare systems and policy frameworks. Since the Index's publication, several countries that were analyzed have taken steps forward to support innovation readiness in dementia, yet others have failed to make any measurable progress. This progress report provides updates on the changes that have occurred across G7 countries to foster innovation readiness since the publication of the original findings.

The Index reports on 10 factors that support or enable dementia innovation readiness:

- 1) Strategy & Commitment
- 2) Government Funding
- 3) Education & Workforce
- 4) Early Detection & Diagnosis
- 5) Regulatory Environment
- 6) Access to Care
- 7) Prevention & Risk Reduction
- 8) Business Environment
- 9) Care Standards
- 10) Built Environment

GCOA and ADI would like to thank their members and the following individuals for their contributions to this progress report:

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## ***Table of Contents***

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|                             |    |
|-----------------------------|----|
| Strategy & Commitment       | 4  |
| Government Funding          | 6  |
| Education & Workforce       | 8  |
| Early Detection & Diagnosis | 10 |
| Regulatory Environment      | 12 |
| Access to Care              | 14 |
| Prevention & Risk Reduction | 16 |
| Business Environment        | 18 |
| Care Standards              | 20 |
| Built Environment           | 22 |
| Conclusion                  | 24 |
| Sources                     | 27 |

# Strategy & Commitment

A national plan and commitment to addressing dementia is considered by the broad range of experts who contributed to the Index to be the top driver of innovation within a country. The presence, implementation, and monitoring of a national dementia plan aligns national leadership, signals commitment to the advocacy community as well as the public and the private sector, and holds the government accountable to a set of specific goals and milestones in research and care delivery.

## Notable Progress:

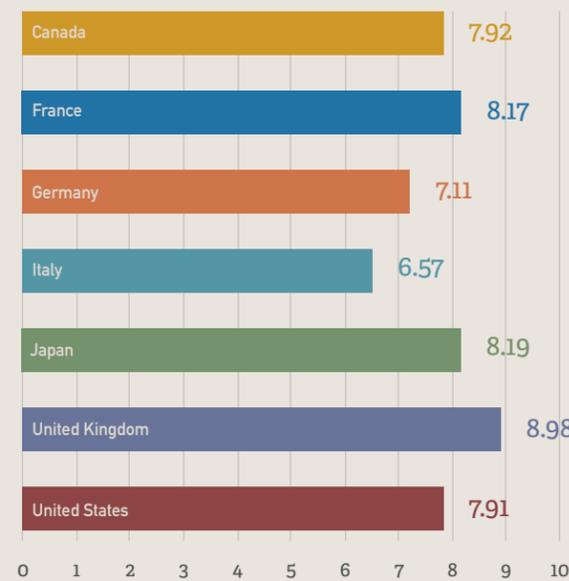
### 1) Canada takes steps to create a national dementia plan.

The Canadian Parliament officially passed legislation directing the Minister of Health to develop and enact a national dementia plan.<sup>1</sup> The plan will build upon Canada’s national dementia strategy, which had been developed by Alzheimer’s Society Canada but was never officially adopted by the government. The new plan will help to create opportunities for dementia innovation at the highest levels of government.

### 2) Ontario funds implementation of regional dementia strategy.

The provincial government announced that it will commit \$100 million to implement its province-wide dementia strategy. The strategy prioritizes increasing community-based care, caregiver support, and education for healthcare providers.<sup>2</sup>

## 2017 Index Scores:



### 3) The U.S. Department of Health and Human Services (HHS) establishes leadership on caregiving issues.

In October 2017, HHS hosted the National Research Summit on Care, Services, and Support for Persons with Dementia and Their Caregivers. The first-of-its-kind summit convened key public and private sector stakeholders to set research priorities to build and scale innovative, evidence-based care programs in the U.S.<sup>3</sup> Following the summit, the U.S. Congress and President Donald Trump passed into law the RAISE Family Caregivers Act, directing HHS to create a national family caregiver strategy.

### 4) Italy continues to update and build upon its national plan.

The group responsible for monitoring Italy’s dementia plan has published two new documents, including a

plan to develop systems that will track information about dementia, as well as guidelines for improved diagnostic and care pathways for people with dementia and their families. However, the plan has yet to be fully funded, delaying implementation and therefore impact in Italian society and health systems.

### 5) Japan creates new goals for its national dementia plan, “New Orange Plan.”

The 2017 updates to Japan’s national dementia plan include new goals to train 10,000 doctors certified to play a key role of dementia diagnosis in the community coordinating with primary care doctors and 12 million “dementia supporters” with good knowledge and understanding of dementia by 2020.<sup>4</sup> Japan continues to lead the G7 countries in public engagement for dementia support within local communities.

## Call to Action:

### German government must prioritize creation and implementation of a National Plan.

The German government has extended the work of its National Alliance for People with Dementia. The Alliance, which is working to set a framework for a national plan in Germany, was set to end in September 2018. Its extension signals Germany’s interest in developing a formalized national plan. The Alliance’s membership comprises government, healthcare providers, and advocacy organizations. Germany must support the Alliance and its efforts to build a national dementia plan as it is now the only G7 country without a national dementia plan adopted or in progress.

**“Germany is now the only G7 country without a national plan. We have to act now to set in place a comprehensive plan to make sure that Germany is prepared for innovation and cooperation in the field of dementia.”**

**Sabine Jansen**  
Executive Director, Deutsche Alzheimer Gesellschaft

## World Dementia Council establishes four areas of focus.

By setting these goals, the World Dementia Council is setting an international framework for countries to work from as they develop innovative models to address Alzheimer’s disease and related dementias.

### Awareness

Raising awareness to promote early diagnosis

### Care

Promoting innovations in care to improve quality of life for people with dementia, their carers, and the women who are disproportionately affected by the condition

### Risk Reduction

Reducing risk by promoting lifestyle interventions that will lower the overall disease burden

### Research

Encouraging collaborative research, including shared research initiatives

The World Dementia Council was launched in 2014 as a response to the G7 Dementia Summit. It works parallel to intergovernmental organizations to achieve the goal of introducing the first disease-modifying treatment for Alzheimer’s disease and related dementias by 2025.<sup>5</sup>

# Government Funding

Government funding enables dementia innovation by advancing scientific understanding of the condition. Funding for dementia research, in general, is on the rise. But the increased investment is still not in congruity with the need: Health systems are facing increasing costs for long-term care for people with dementia. Failure to invest in research that supports innovations and systems that ensure dignified care for those with dementia could lead to a higher cost in the future as global economies face aging populations and the absence of effective treatments.

## Notable Progress:

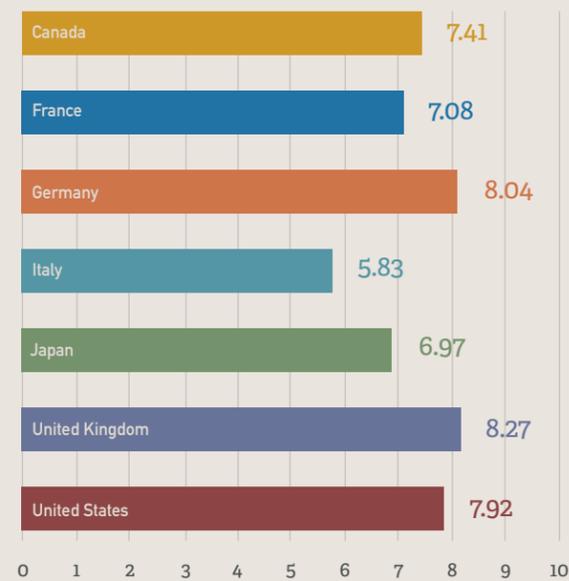
### 1) The U.S. increases its Alzheimer's and dementia research budget.

In 2017, the U.S. Congress passed a \$400 million increase for Alzheimer's research funding at the National Institutes of Health.<sup>6</sup> Again in 2018, the NIH received an increase of \$414 million, raising the total Alzheimer's disease research budget to \$1.8 billion.<sup>7</sup>

### 2) Japan works to create public-private partnerships for dementia research.

The Health and Global Policy Institute and the Japanese government's Agency for Medical Research and Development are working to create public-private partnerships funded jointly by the public and the private sectors.<sup>8</sup> Japan is finalizing the focus, structure, and funding model of these partnerships.

## 2017 Index Scores:



### 3) The UK increases funding for public-private partnerships and aging issues.

The UK Medical Research Council, one of the government's national research funding agencies, allocated £40 million for the UK Dementia Research Institute (UK DRI) to construct its hub building at University College London (UCL). The new hub will be connected to the UCL Institute of Neurology and will incorporate space for public engagement, emphasizing collaboration and openness in the effort to prevent, diagnose, and treat dementia. The Dementia Research Institute (DRI) is a research program funded by the government, Alzheimer's Research UK, and the Alzheimer's Society.

### 4) Ontario regional government provides \$100 million in funding to the Ontario Brain Institute (OBI) over the next five years.

The OBI is a research center that focuses on neuroscience. Its Ontario Neurodegenerative Disease Research Initiative aims to advance innovations that improve diagnosis, treatment, and care for people with neurodegenerative diseases. In addition to its research, OBI's leadership helps to shape and advance Ontario's regional dementia strategy.

## Call to Action:

### Italy, Canada, France, and Germany must prioritize increased funding for dementia research.

Since the original Index was published in 2017, the U.S. has drastically increased its dementia research budget, and the UK and Japan have bolstered their public-private partnerships. These efforts scratch the surface of what is needed eradicate dementia or even ameliorate its effects on individuals and families, and the remaining G7 countries must follow suit both by increasing the amount of funding provided by their governments and by exploring new mechanisms through which to deploy funding. France, specifically, should explore new ways to fund support for people with dementia and training for caregivers. Given France's recent announcement that it will no longer reimburse the symptomatic treatments that are available, the government should prioritize funding the discovery and delivery of other innovations in prevention, treatment, and care.

### Non-profit investment increasing: Billionaire Bill Gates and AARP make unprecedented investments in the U.K.-based Dementia Discovery Fund (DDF).

Gates has contributed \$50 million to the DDF, in addition to \$50 million to start-up companies researching Alzheimer's disease and related dementias.<sup>9</sup>

AARP has invested another \$60 million in the DDF, in recognition of AARP's 60th anniversary. This investment is the first disease-specific investment made by AARP and signals the organization's commitment to innovative solutions to Alzheimer's disease and related dementias.<sup>10</sup>

DDF, which was formed in collaboration with the U.K. Department of Health and £10 million in public funding, is a venture fund that advances research on promising compounds to discover and develop new therapies for dementia.

## Education & Workforce

A country's education and workforce is an opportunity to improve upon the pipeline of health and care providers for people with dementia. And building a workforce competently trained in dementia research is one of the key challenges to promoting innovations in dementia. When countries prioritize training their scientific and healthcare workforce to be fluent in issues surrounding dementia, they increase the ability of those workers to successfully investigate, manage, treat – and one day prevent – dementia.

### Notable Progress:

#### 1) Germany and Sri Lanka sign an agreement to increase foreign recruitment of geriatric nurses to Germany.<sup>11</sup>

The agreement aims to kick off training in 2018.

Trainees will receive German language training as well as professional training in geriatric care.

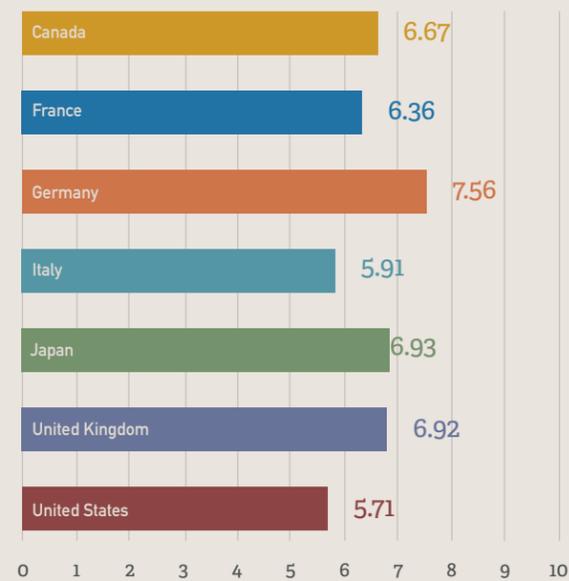
#### 2) Japan plans to recruit 10,000 foreign interns to join its nursing care sector over the next 3 years.

The effort is a response to the country's shortage of eldercare nurses. The first cohort of 300 trainees arrived from Vietnam at the end of 2017.<sup>12</sup>

#### 3) Canadian universities recruit students for geriatric medicine.

Researchers conducted interviews and developed a podcast to help prospective students better understand what a career pathway in geriatrics

### 2017 Index Scores:



entails.<sup>13</sup> Training and developing specialists requires a robust educational pipeline, and more candidates in the field are needed across the G7 countries.

#### 4) The UK is considering ways to boost caregiving as a desirable career field.

The effort is aimed at meeting the needs of the growing older population, including many people living with dementia. Policy changes promoting the impactful and valuable work of the caregiving field will lead to more effective recruitment of skilled caregivers and better care across the country.

#### 5) The UK National Institute for Health Research launched a new website for early career researchers (ECR).

The website, [www.dementiaresearcher.nihr.ac.uk](http://www.dementiaresearcher.nihr.ac.uk), provides support, resources, and an online community for early career researchers. It offers an

approachable entry point for ECR users to learn about job opportunities, grants, and events, and even provides learning through podcasts about dementia.<sup>14</sup>

### Call to Action:

#### Canada, France, Italy, and the US must follow German and Japanese innovative recruitment models.

As the number of people with dementia grows, countries must adapt innovative workforce development strategies to develop a skilled workforce able to treat and provide care for people with dementia. By prioritizing the recruitment and training of foreign workers, Germany and Japan have set a framework that other countries can replicate to address workforce challenges.

#### “Supporting the professional development of early career researchers helps to ensure that the next generation will continue to build upon the legacy of dementia innovation in the UK.”

**Professor Martin Rossor**

National Director for Dementia Research,  
National Institute of Health Research (NIHR)

## Early Detection & Diagnosis

Early detection and diagnosis is needed in G7 countries as greater understanding of the progression of dementia points to the need for early intervention. Improving diagnostic tools would help countries to prepare for innovations in dementia, for example, by creating more opportunities to participate in clinical trials. But challenges, such as delays in access to specialists or insufficient training for general practitioners to screen and diagnose high risk patients, have slowed the identification of people at the earliest stages of their condition.

### Notable Progress:

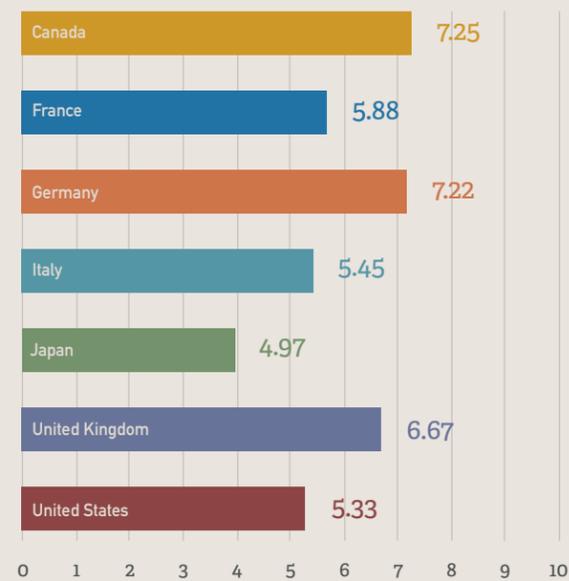
#### 1) German researchers publish the cost of diagnosing dementia.

By providing solid evidence to the cost of diagnosis, this study makes the case for a reimbursement system that aligns doctors, patients, and payers to incentivize diagnosis of dementia.<sup>15</sup>

#### 2) Japanese researchers develop a new screening tool to help paramedical and first-line physicians detect mild cognitive impairment.

The Tokyo Cognitive Assessment for MCI is a useful way for providers and paraprofessionals to provide screenings in the clinic and the community as well as encourage referrals to specialists for diagnosis.<sup>16</sup>

### 2017 Index Scores:



#### 3) Japanese study on dementia care workers uncovers new opportunities for professional education.

A survey of 117 care providers for older adults found a need for increased professional education. Survey respondents were most interested in learning about “non-pharmacological treatments for behavioral and psychological symptoms of dementia, workshops and mentor-based programs, and formal certification incentives.”<sup>17</sup>

### Call to Action:

#### G7 countries must continue to increase training for general practitioners, standardize diagnosis incentives, and improve monitoring systems.

Many general practitioners remain undertrained in how to recognize and refer suspected cases of dementia. Countries must act now to improve the training of general practitioners and normalize diagnostic standards. By increasing training, general practitioners would be better equipped to detect early signs of dementia. And by updating reimbursement rates, payers could ensure that healthcare providers are incentivized to promote early detection and diagnosis. Finally, it is essential for G7 countries to improve their monitoring systems – a recent OECD report revealed that 40% of OECD countries, including the G7, do not monitor diagnosis.

The Organisation for Economic Co-Operation and Development releases new report on dementia diagnosis and care.<sup>18</sup>

Key findings include:

Fewer than 40% of countries have national diagnosis rates.

Physicians run the risk of being undertrained, with an average of just 12 hours of dementia training.

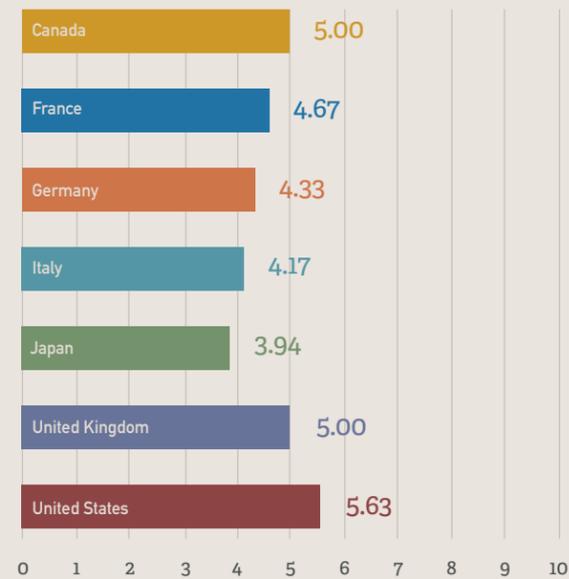
Most people with dementia living in residential care settings are not in a facility that is optimized for people with dementia.

Innovative residential care models, such as “dementia villages”, can potentially serve as best practice models in OECD countries that should be made more widely accessible.

# Regulatory Environment

Leaders in the regulatory environment across G7 countries should work to enable innovation by developing up-to-date guidance documents and using accelerated review processes for new, impactful therapeutic candidates. Without any breakthroughs in the science behind dementia pathologies, new approaches to innovation need to be tested, and guidance must be clarified to ensure pathways for new scientific findings.

2017 Index Scores:



## Notable Progress:

### 1) The FDA issues draft guidance to encourage new approaches to research.

The guidance focuses on early Alzheimer’s disease and clarifies how the administration will consider whether new treatments have a meaningful impact. It suggests that cognitive measures could be a singular endpoint for drug developers, calls for the development of new surrogate biomarkers, and encourages patient involvement in the regulatory process. Updating the regulatory guidance for Alzheimer’s disease helps move the FDA in line with the latest scientific understanding of the disease and provides global leadership to the regulatory community.

### 2) The EMA adopts new guidance documents.

The new guidance reflects the latest science surrounding early and prodromal Alzheimer’s disease. It suggests that for patients in the early stages of the disease, a treatment that meets an endpoint that is a composite of both cognition and function could be approved. It also articulates how biomarkers could be used in the drug development process.<sup>19</sup>

## Call to Action:

Countries’ regulatory bodies must adapt and issue updated guidance as new learnings about the complexities of dementia are revealed.

Regulatory guidance documents play a key role in the drug development process by articulating what a government will look for when evaluating the impact of a potential treatment. The FDA and the EMA have shown leadership by adopting regulatory guidance reflecting the latest scientific understanding of dementia – Health Canada and the PMDA should do the same.

**“By issuing a revised guidance document, the FDA has shown its leadership in and commitment to patient engagement and regulatory science that promotes innovation.”**

George Vradenburg

Chairman, UsAgainstAlzheimer’s

## Access to Care

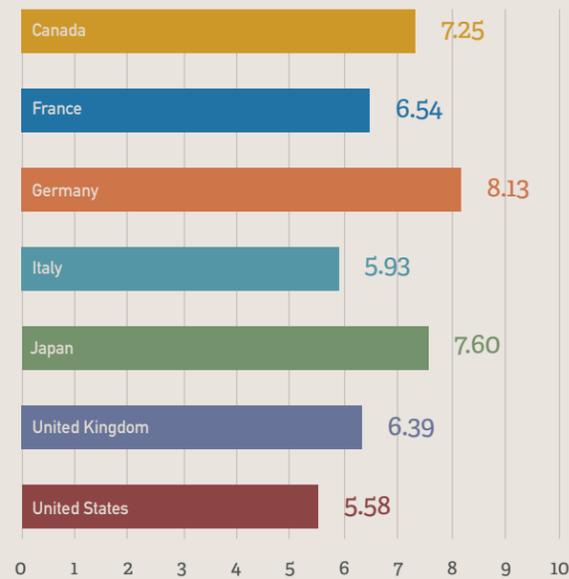
Access to care has not notably improved in any of the G7 countries. As researchers work to develop innovative treatments for dementia, it is critical that governments enable care systems that are designed and optimized to help individuals access new treatments as they become available. In all countries evaluated, lengthy wait times for advanced diagnostics and specialist consultation persist as challenges. Further, care systems should promote continuity of care as a critical component of high-quality care, particularly for those living with dementia.

### Notable Progress:

#### 1) Canada increases investment in home care.

Over the next 10 years, the Canadian government will invest \$6 billion to improve access to home-based care when it is the most appropriate setting.<sup>20</sup>

### 2017 Index Scores:



#### 2) The UK opens its first emergency department specifically for older adults.

Located at Norfolk and Norwich University Hospital, the department will specialize in emergency care for people over 80.<sup>21</sup>

### Call to Action:

#### Governments and other stakeholders must work to address gaps in the care pathway.

People with dementia in G7 countries have reported being uncertain of the “next step” after diagnosis. Government, payers, and providers must work to ensure that these gaps are filled so that people can access treatment and care. Best practices in other disease areas, such as the patient navigation model in cancer, should be studied and replicated to develop a more cohesive care pathway.

**“One of the challenges that still needs to be addressed in Italy is a lack of services for people with dementia that are standardized and of high quality. Furthermore, some of our paid caregivers do not receive adequate training for people with dementia.”**

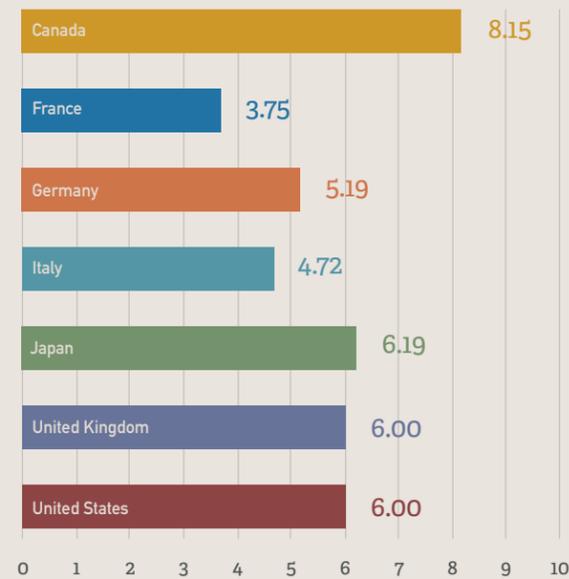
Mario Possenti

Secretary, Federazione Alzheimer Italia

## Prevention & Risk Reduction

Prevention and risk reduction efforts remain stagnant in G7 countries. Raising awareness of dementia and the steps everyone can take to reduce the risk would have an impact on the overall burden of the disease. But the current lack of public awareness of dementia presents two primary issues: There is no collective urgency demanding that governments act to enable innovative treatments for Alzheimer's disease and related dementias, and people with dementia are less likely to participate in the drug development process, for example by participating in clinical trials.

### 2017 Index Scores:



### Notable Progress:

1) The UK's advocacy and research organizations provide a model for raising awareness of dementia.

Alzheimer's Research UK re-launched the #ShareTheOrange social media campaign to raise awareness of dementia. The campaign first launched in 2016 and was revitalized in 2018 by a short film featuring actor Bryan Cranston.<sup>22</sup> At the same time, the Alzheimer's Society of the UK developed a televised campaign to be "united against dementia". The TV spot debuted in April 2018. It aims to show dementia as an issue that crosses boundaries of age, race, and views on Brexit.<sup>23</sup>

### Call to Action:

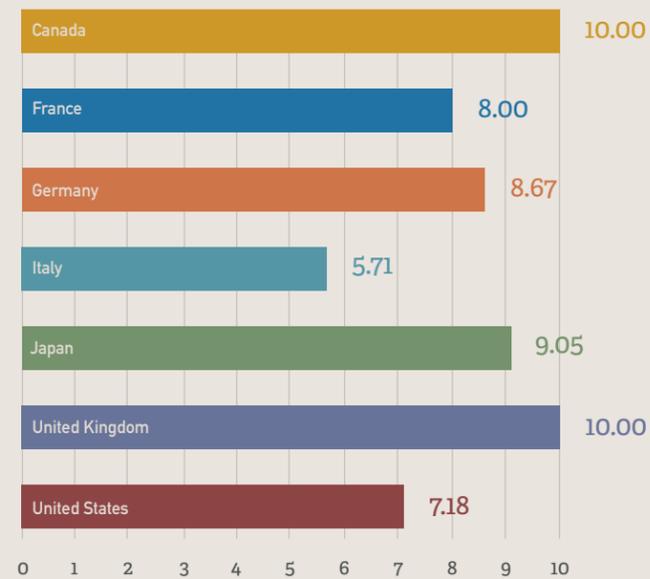
**Governments and advocacy organizations must continue working together to raise awareness of dementia prevention.**

Research released in 2017 found that up to one third of dementia cases could be prevented through modifying lifestyle factors.<sup>24</sup> As dementia prevalence forecasts grow increasingly grim, countries must take action now to prevent a looming crisis.

## Business Environment

When a country's business environment has amenable regulations – such as patent and intellectual property protection – drug developers have a greater incentive to invest in the high-cost research necessary to develop innovative medicines and diagnostics tools, and care providers are better equipped to deliver the highest-quality care models to those with dementia.

### 2017 Index Scores:



### Notable Progress:

#### 1) Japan strengthens free trade policies.

At the close of the 2018 World Economic Forum in Davos, the Japanese Economy Minister, Toshimitsu Motegi, announced his plan to sign the Comprehensive and Progressive Agreement for Trans-Pacific Partnership. This notes an important development in Japan's increased openness to international business and opportunities for further innovation and collaboration globally.<sup>25</sup>

### Call to Action:

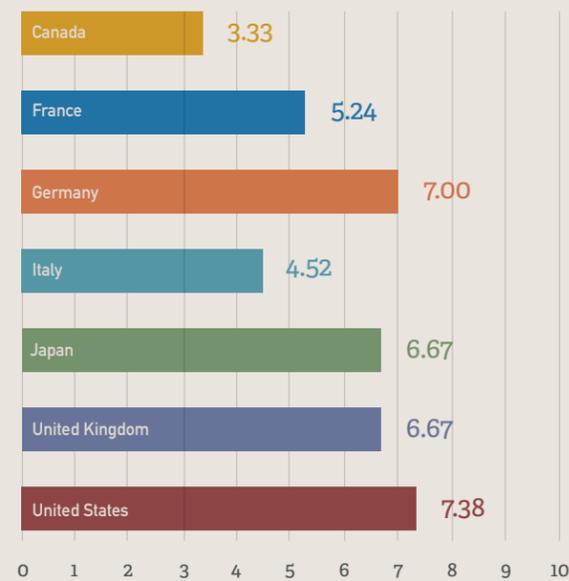
**G7 government leaders must continue to view the business community as valuable partners toward innovation.**

There have been minimal advances in G7 countries' business environments since the Index's publication. To encourage action, business leaders must demonstrate commitment to the treatment and prevention of dementia, as well as care for people with the disease. Government can help to drive business leadership, especially by creating tax incentives, encouraging public-private partnerships, and building innovative investment models.

## Care Standards

Care standards provide an opportunity for countries to develop a framework promoting higher quality care and innovating services. While more stringent care standards can improve the quality of life for people with dementia, gaps in the care pathway, a lack of funding for care research, and under-utilization of technology interventions have slowed innovation for the sector.

**2017 Index Scores:**



### Notable Progress:

1) The American Academy of Neurology and the American Psychiatric Association update quality measures for dementia care.

The updates included adding three new quality measures, which aim to 1) encourage healthcare providers to disclose diagnoses of dementia to people with the disease and their caregivers, 2) better assess pain that people with dementia experience, and 3) improve treatment and quality of life through pharmacological, behavioral, and lifestyle modifications.<sup>26 27</sup>

### Call to Action:

**G7 countries must continue to investigate innovative care services.**

Care delivery remains an under-investigated aspect of dementia research, and not enough evidence-based models for dementia care have been established. There must be greater attention given to establishing best practices in care – especially for those who are living alone or in rural areas.

**Researchers release a consensus paper on in-home care for people with dementia.**

A research team led by Johns Hopkins University and funded by the BrightFocus foundation outlined recommendations for home-based dementia care (HBDC). Researcher and policy experts from the U.S., France, Germany, and the Netherlands contributed to the report.<sup>28</sup>

1) “HBDC should be considered the nexus of new dementia models, from diagnosis to end of life in dementia

2) New payment models are needed to support HBDC and to reward integration of care

3) A diverse new workforce that spans the care continuum should be prepared urgently

4) New technologies to promote communications and monitor safety must be tested, integrated, and deployed

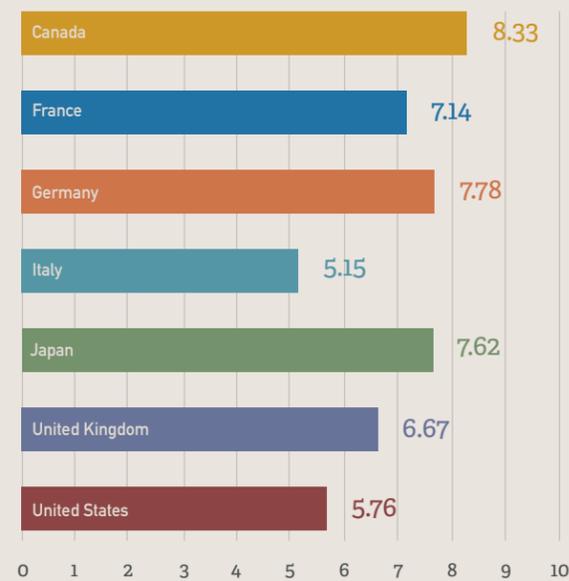
5) Targeted dissemination efforts for HBDC must be employed.”

Identifying best practices in care delivery was a key need articulated in the 2017 Dementia Innovation Readiness Index. The report is a positive step forward in this regard.

## Built Environment

The built environment impacts how people with dementia receive care, enroll in clinical trials, and navigate life in the community post-diagnosis. Governments, advocacy organizations, and the private sector must continue to develop dementia and age-friendly infrastructure to make sure that – as new treatments become available and care options for people with dementia improve – people with dementia are able to maintain independence and remain in communities safely and with a high quality of life.

### 2017 Index Scores:



### Notable Progress:

1) Japan enacts a new policy requiring that all drivers over 75 undergo a cognitive assessment when renewing their licenses.

As of December 2017, about 1.7 million older Japanese drivers had taken the assessment. Approximately 47,000 showed some symptoms of dementia, and 1,351 had their licenses revoked. Those who showed signs of dementia must periodically visit a doctor to re-evaluate their suitability to drive. This policy sets a model to ensure that people with dementia and others remain safe. Japan must take the next step by providing alternative transportation options for those who do not have a driver's license to ensure that they are able to access services. Further, the Japanese government must be cautious to ensure that the new policy does not lead to age-based discrimination.

2) The Global Alzheimer's Platform Foundation partners with Lyft to provide transportation to people enrolled in Alzheimer's clinical research in the US.

The partnership will kick off by providing transportation to participants in Eli Lilly's TRAILBLAZER-ALZ study. Removing the logistical barriers to clinical trials is critical to ensure that people with dementia can access new, innovative therapies.

3) Paris, France joins the World Health Organization's Global Network for Age-Friendly Cities.

As part of its commitment to become an age-friendly city, Paris's Mayor Anne Hidalgo released and is working to enact an age-friendly Paris plan titled, "2017-2021 Seniors in Paris."

### Call to Action:

**Governments must continue to prioritize and collaborate across the public and private sectors to develop a better built environment for those with dementia.**

As innovative treatments enter the market and allow for people with dementia to live in the community for longer, it is critical that G7 governments make sure they can do so safely. While all countries have shown some commitment to improving the built environment, either through specific policies or through fostering age and dementia-friendly communities on a local level, more action is needed to ensure the inclusion of those living with dementia.

## ***Conclusion***

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Since the publication of the G7 Dementia Innovation Readiness Index, in 2017 several countries have taken positive steps forward to enable innovation readiness in dementia. But more work must be done as the unprecedented trend of global aging increases dementia's burden. By monitoring progress and identifying bottlenecks, ADI and GCOA will continue to hold leaders accountable to fostering dementia innovation readiness.

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ADI is the international federation of 90 Alzheimer associations around the world, in official relations with the World Health Organization. ADI's vision is prevention, care and inclusion today, and cure tomorrow. ADI believes that the key to winning the fight against dementia lies in a unique combination of global solutions and local knowledge. As such, it works locally, by empowering Alzheimer associations to promote and offer care and support for persons with dementia and their care partners, while working globally to focus attention on dementia and campaign for policy change from governments. For more information, please visit [www.alz.co.uk](http://www.alz.co.uk).



The Global Coalition on Aging aims to reshape how global leaders approach and prepare for the 21st century's profound shift in population aging. GCOA uniquely brings together global corporations across industry sectors with common strategic interests in aging populations, a comprehensive and systemic understanding of aging, and an optimistic view of its impact. Through research, public policy analysis, advocacy, and strategic communications, GCOA is advancing innovative solutions and working to ensure global aging is a path to health, productivity and economic growth. For more information, visit [www.globalcoalitiononaging.com](http://www.globalcoalitiononaging.com).