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## Dementia

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Second edition

### What is Japan Health Policy NOW?

Created in 2015 by Health and Global Policy Institute (HGPI), **Japan Health Policy NOW (JHPN)** is the only centralized platform in the world on Japanese health policy available in both Japanese and English.

As the world's attention turns to Japan, one of the world's fastest ageing countries, there is increasing interest in Japanese health policy and a growing need to share information on Japan's health policy with the world. JHPN is committed to addressing this need by delivering factual information about the Japanese health system, Japanese health policy stories of interest, recent Japanese health policy news, and a resource list for those who want to learn more about Japanese health policy. For more information, please see [www.Japanhpn.org](http://www.Japanhpn.org).

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## Dementia Policy in Japan

As average life expectancies grow longer, it becomes increasingly necessary for society to face issues that arise in aging populations. Dementia is a representative example of these issues. An estimated 46,086,000 people live with dementia worldwide today and their number is projected to increase to 74,070,000 people by 2030. Early-onset dementia must also be addressed.

Currently, there are no drugs for directly treating the primary diseases causing dementia such as Alzheimer's disease. The development of new drugs alone, however, is insufficient. Society must be reconstructed in a way that enables people to effectively cope with the urgent issue of dementia on a global scale.

# 1.1

## Past changes in Japan's Dementia Policy

### ➤ **2000: The Long-term Care Insurance Act comes into effect**

After its enactment in 1997, the Long-term Care Insurance Act came into effect in 2000. It aimed to create a system for enabling society as a whole to provide long-term care to elderly people. Before this law came into effect, the societal expectation in Japan was that elder care should be provided within the household, particularly by women. Factors such as increased workforce participation for women and declining numbers of multi-generation households resulted in a shortage of caregivers. This resulted in greater calls for socialized care. Meanwhile, there was a shift from the previous “sochi” or “placement” system of elder welfare. Under this system, care was provided according to predetermined budgets decided by local governments. After the shift, elderly people began to be perceived as proactive rights holders and as “parties to contracts.” Greater emphasis began to be placed on their independence and rights. For more details, refer to the “Long-term Care Insurance Act” section on JHPN.

### ➤ **2004: The Japanese terminology for “Dementia” is changed**

The Ministry of Health, Labour and Welfare (MHLW) formed the Committee for Examining Affairs Concerning the Term “Chiho” in 2004. The Committee identified three problems with the term “chiho”: that it is a derogative that causes feelings of contempt, that it does not accurately portray the state of the person being described, and that it obstructs early detection and early diagnosis<sup>1</sup>. The Committee then conducted a wide-ranging public opinion survey and other research and revised the term for dementia to “ninchisho,” meaning “cognitive disorder.” When revising the term, they also took the opportunity to create plans for promoting the correct understanding of dementia and for upholding the rights of people with dementia.

### ➤ **2008: The Emergency Project for Improvement of Medical Care and Quality of Life for People with Dementia report is released**

The Emergency Project for Improvement of Medical Care and Quality of Life for Persons with Dementia began in 2008 to promote future measures for dementia more effectively. It released a report that identified early diagnosis as a key starting point for promoting appropriate measures for dementia and named it a basic principle for dementia policy. It identified five specific action items: (1) Accurately understand the condition of the person with dementia, (2) Accelerate research and development, (3) Promote early diagnosis and the provision of appropriate healthcare, (4) Normalize appropriate care and support for people with dementia and their families, and (5) Implement measures for early-onset dementia.

### ➤ **2012: The direction of future dementia measures is specified**

Based on the aforementioned Emergency Project report, a proposal entitled the “Future Direction

<sup>1</sup> MHLW “The future direction of Dementia Measures” <http://www.mhlw.go.jp/stf/shingi/2r9852000002fv2e-att/2r9852000002fv5j.pdf> (Accessed: July 2, 2018)

of Policies on Dementia” was prepared to re-examine past dementia policy and propose the foundation of policy to come. It was presented by the Dementia Measures Investigation Project team which was established by the Team for Investigating the Creation of a New Regional Mental Healthcare System in 2010 to deepen discussion on dementia measures and recreate the path for dementia treatment. In the past, admission to a nursing home or hospital was considered an inevitable step in dementia treatment. Hospitalization was the final step in a care path in which people were moved from their home to a group home and then into a nursing home, general hospital, or psychiatric hospital. This team set out to recreate that pathway by rebuilding society so that the rights of people with dementia are respected and so that those people can continue living in familiar spaces and communities. The new care pathway would provide appropriate care according to the condition of the person receiving it. The plan also specified a goal to encourage efforts to research the promotion of such a policy<sup>2</sup>.

➤ **2012: The Five-Year Plan for the Promotion of Dementia Measures (Orange Plan) is enacted**

Based on 2012’s Future Direction of Policies on Dementia, the Five-Year Plan for the Promotion of Dementia Measures (the Orange Plan) was developed that same year. The Orange Plan consisted of seven pillars: (1) Create a standardized dementia care pathway and make it widespread, (2) Promote early diagnosis and intervention, (3) Improve community-based healthcare services to provide daily support, (4) Develop long-term care services that support daily living, (5) Strengthen support for daily living and family support in communities, (6) Reinforce measures for early-onset dementia, and (7) Accelerate the development of human resources for providing healthcare and long-term care.

➤ **2013: The G8 Dementia Summit is held**

The first G8 Dementia Summit was held in the United Kingdom in December 2013. In addition to representatives from every G8 nation, the European Commission, the World Health Organization (WHO), and Organization for Economic Co-operation and Development (OECD), the Senior Vice Minister of Health, Labour and Welfare from Japan also participated. He explained population aging in Japan, the then-current situation surrounding dementia, and the Orange Plan. The Summit agreed on the necessity of a new, international approach in which issues related to aging such as dementia research and accelerating research are pursued as a common goal for every nation instead of letting these efforts be shouldered by a single nation.

➤ **2014: The Global Dementia Legacy Event Japan is held**

In response to the G8 Dementia Summit, the Global Dementia Legacy Event Japan was held in Tokyo in November 2014 with the theme of planning a new care and prevention model. HGPI supported this event and HGPI Chairman Kiyoshi Kurokawa participated by giving a speech. A new strategy consisting of three pillars was announced after the event. Those pillars were: (1) Construct a circular medical system that offers seamless service dependent on the condition of the person receiving healthcare, in which healthcare and long-term care services coordinate organically and in which early diagnosis and prevention are promoted, (2) Create a holistic, cross-ministerial strategy for building dementia-friendly communities, and (3) Promote policies that emphasize the perspectives of people with dementia and their families.

Together with this event, HGPI and the OECD held the Taking Action on Dementia: Opportunities for Social Investment – A G7 Global Dementia Legacy Event Private Sector Side Meeting. This meeting provided an opportunity for the private and public sector to discuss private sector-led strategies and approaches for addressing various issues related to dementia using social

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<sup>2</sup> MHLW “The future direction of Dementia Measures” <http://www.mhlw.go.jp/stf/shingi/2r9852000002fv2e-att/2r9852000002fv5i.pdf> (Accessed: July 2, 2018)

investment.

➤ **2015: The Comprehensive Strategy to Accelerate Dementia Measures (the New Orange Plan) is announced**

In January 2015, a new plan based on the strategy announced after the Global Dementia Legacy Event Japan called the New Orange Plan was unveiled. The New Orange Plan was created after a wide-ranging survey was conducted to collect stories and opinions from people with dementia, their families, and other related parties. It emphasizes the perspectives of people with dementia and their families. Although the New Orange Plan is effective until 2025, its numerical targets and other targets will be reviewed every three years. A unique feature of the New Orange Plan is that it is not driven by efforts from the MHLW alone, but that it involves multiple government agencies, including the Cabinet Secretariat; the Cabinet Office; the National Police Agency; the Financial Service Agency; the Consumer Affairs Agency; the Ministry of Internal Affairs and Communication (MIC); the Ministry of Justice (MOJ); the Ministry of Education, Culture, Sports, Science and Technology (MEXT); the Ministry of Agriculture, Forestry and Fisheries (MAFF); the Ministry of Economy, Trade and Industry (METI); and the Ministry of Land, Infrastructure, Transport and Tourism (MLIT).

# 1.2

## The New Orange Plan

The The New Orange Plan is based on the utilization of Integrated Community Care Systems. It aims to promote the development of dementia-friendly communities and to improve the living environments of people with dementia by enabling them to continue living in familiar spaces and environments as long as possible. It consists of seven pillars: six measure provisions and one principle provision. The principal provision is to “Prioritize the perspectives of people with dementia and their families.” Each provision is linked to specific systems. These pillars and measures are as follows.

➤ **Raise awareness and promote understanding of dementia**

This pillar aims to raise awareness of dementia so that society as a whole can remember that dementia is a common disease.

✓ Example 1: The Dementia Supporters training program

This program trains Dementia Supporters who possess accurate knowledge and understanding of dementia so that they can aid people with dementia and their families in communities and workplaces.

The Dementia Supporters training program aims to train 12 million Dementia Supporters by 2020.

➤ **Provide healthcare and long-term care services in a timely and appropriate manner as the person receiving care progresses through the stages of dementia**

This pillar aims to provide healthcare and long-term care services that can collaborate effectively and provide timely and appropriate services for each stage of dementia progression. This pillar is for replacing the system which responded to the Behavioral and Psychological Symptoms of Dementia (BPSD) and physical complications of dementia with hospitalization in medical institutions and nursing homes with a system that consistently provides appropriate services at suitable facilities with a specific focus on early diagnosis and prevention.

✓ Example 1: Training primary care doctors to improve their capabilities for responding to dementia

For people receiving healthcare, primary care doctors are reliable first points of contact for medical issues and are sources of advice on health concerns<sup>3</sup>. They can introduce people to more specialized medical centers when necessary. Prefectures and designated cities have implemented training programs for primary care doctors (who will specialize in various fields in the future) in order to improve their ability to respond to dementia and so that they can become mediators between people seeking healthcare and medical specialists.

This initiative aims to train 75,000 primary care doctors by 2020.

✓ Example 2: Training dementia support doctors

These doctors exist between primary care doctors and doctors specializing in dementia. This training project began in 2005 in hopes that these dementia support doctors can become drivers of regional cooperation. The training course is similar to the course for training primary care doctors and is centered on prefectures and designated cities. Dementia support doctors are not primary care doctors. The aim of the program is to train dementia support doctors who can be leaders in regional coordination efforts involving dementia specialists and specialized medical institutions.

This initiative aims to train 10,000 dementia support doctors by 2020.

<sup>3</sup> Japan Medical Association 「かかりつけ医を持ちましょう」 <https://www.med.or.jp/people/kakari/> (Accessed : July, 10, 2018)

✓ **Example 3: Establishing medical centers for dementia**

These medical institutions will be bases for the dementia medical provider system within communities. They will provide differential diagnoses and other diagnoses. Dependent on their function, their number of hospital beds, and the doctors working there, these centers are divided into three categories: Basic, Community, and Clinical. All three types will have medical facilities for providing comprehensive examinations related to differential diagnosis. This initiative aims to establish 500 medical centers for dementia with at least one center in all secondary medical areas.

✓ **Example 4: Establishing the Initial-phase Intensive Support Team system**

These teams consist of several specialized professionals including doctors and nurses. They support independent living by visiting people with dementia and people who are suspected of dementia (upon family request) to assess their condition and provide comprehensive and concentrated initial support to the families. This initial-phase support is provided for approximately six months. This system has been established in every municipality as of 2018.

✓ **Example 5: Establishing dementia care pathways**

Dementia care pathways show which services are appropriate to provide according to the condition of the person with dementia. Every municipality is responsible for establishing such pathways. This initiative aims to understand local resources to build seamless support frameworks and cross-occupational, coordinated frameworks that take both the stage to which the condition has progressed and the disease timeline into account.

✓ **Example 6: Training community dementia support promoters**

Because community dementia support promoters fulfill a central role in efforts to construct healthcare and long-term care support networks, improve dementia response capabilities, and provide advisory support, they have been established in each municipality. To become a promoter, one must be a medical or welfare professional or have one's level of knowledge and experience recognized by the municipality as equal to a professional.

➤ **Reinforce measures for early-onset dementia**

In addition to the issues that are common among elderly people with dementia, people with early-onset dementia face hurdles in maintaining employment and daily living as well as providing support for their children. To provide people with early-onset dementia with support that is more well-suited to them, counseling service counters for people with early-onset dementia and their families were established in every prefecture. Support for the families of people with early-onset dementia, their care workers, and the companies that employ them is essential.

✓ **Example 1: Establishing the national early-onset dementia call center was established and training early-onset dementia coordinators**

✓ **Example 2: Publishing and distributing handbooks and guidebooks on early-onset dementia**

➤ **Support dementia caregivers**

Because providing direct support for dementia caregivers will improve the quality of life for people with dementia, the physical and mental burdens placed on the people providing care to people with dementia must be reduced.

✓ **Example 1: Holding events called "Alzheimer Cafés"**

These café-based events have been set up all over the country to provide places for people

with dementia and their families to share information and exchange opinions with the community, their supporters, and specialists. Although they are mainly held by community comprehensive care centers, in some cases, they are held by local NPOs and private enterprises that have started initiatives in elder support.

➤ **Build communities that are friendly to elderly people, including those with dementia**

Communities that are friendly to elderly people including people with dementia can be promoted by establishing systems to provide support for daily living as a soft goal and by constructing comfortable environments to live in as a hard goal. Fulfilling these goals will make it easier for the people receiving support to participate in employment and in society.

➤ **Promote the research and development of prevention, diagnosis, cures, rehabilitation models, and care models for dementia and disseminate the results**

Elucidating the causes of dementia and the mechanisms of BPSD will promote research and development on prevention, diagnosis, cures, rehabilitation models, and care models for dementia.

➤ **Prioritize the perspectives of people with dementia and their families**

In all the initiatives listed above, the perspectives of people with dementia and their families are to be prioritized. To this end, people with dementia and their families have participated in meetings on dementia held by the national government and local governments in recent years. In addition, opportunities for people with dementia and their families to be involved in community-building activities have increased in several regions. One example of these activities are special conferences where people with dementia discuss experiences and challenges together with other people with dementia.



## Activities related to dementia measures undertaken by the Health and Global Policy Institute

In the recent years, HGPI has focused on research and advocacy for dementia measures. As the country in which population aging has advanced the most, dementia is a critical issue for Japan. Countries that will soon face population aging will face the issues that Japan is currently facing. We believe that in order to build a society that enables better living with dementia, it is crucial for multi-stakeholders to collaborate in building a platform in each field to seek solutions to issues related to aging. We are moving forward in a central role as a driver of global cooperation and we are working to deepen bonds with people with dementia and their families.

# 2.1 The Research Project on the Construction and Use of a Model for an International Public-Private Partnership (PPP) in Dementia Research

### ➤ Research Summary

This research was conducted with support from Japan Agency for Medical Research and Development (AMED) through the joint participation of HGPI Chairman Kiyoshi Kurokawa as research and development representative and co-researchers HGPI Vice-Chairman Hiroaki Yoshida and Yoshiki Niimi, Assistant Professor of Fujita Health University, School of Medicine.

This research program aims to propose the best possible method for establishing an International Public-Private Partnership (PPP) that will promote dementia research in an effective and efficient manner and incorporate their methods into a concrete framework in Japan. It also aims to spread Japan's knowledge so that international initiatives can be included in frameworks created abroad when they are proposed to related government agencies and international organizations.

### ➤ Research Research on projects and organizations related to dementia that make use of the PPP model in Japan and abroad

We conducted a survey of research projects and organizations related to dementia that make use of the PPP model. The survey also included representative organizations that are making progress in research on the formation of PPPs.

### ✓ Dementia research programs around the world – Large-scale, multi-institutional joint studies and partnerships

Abbreviation	WW-ADNI	DIAN	A4 study
Official Name	World Wide Alzheimer's Disease Neuroimaging Initiative	Dominantly Inherited Alzheimer Network	Anti-Amyloid Treatment in Asymptomatic Alzheimer's study
Year of Establishment	2003	2008	2014
Management	Alzheimer's Association	Washington University School of Medicine	Alzheimer's Therapeutic Research Institute
Collaborated organizations	25 companies, 150 academic organizations, Foundation for the National Institutes of Health The National Institute on Aging	The National Institute on Aging	The National Institute on Ageing, Eli Lilly and Company, Philanthropic institutions
Aims	To help define the rate of progression of mild cognitive impairment and Alzheimer's disease To develop improved methods for identifying the appropriate patient populations to participate in clinical trials. To standardize the methods used for conducting imaging scans and gathering and testing fluid samples	To find solutions to treat or prevent Dominantly Inherited Alzheimer's Disease (A rare form of Alzheimer's), and potentially, all forms of Alzheimer's	To test whether a new investigational treatment, called solanezumab, an anti-amyloid antibody, can slow memory loss caused by Alzheimer's disease

✓ **Dementia research programs around the world – Large-scale study-funding organizations**

Abbreviation	IMI	EPAD	DPUK	GAP
<b>Official Name</b>	Innovative Medicines Initiative	European Prevention of Alzheimer Dementia Consortium	The MRC Dementias Platform UK	Global Alzheimer's Platform Foundation
<b>Year of Establishment</b>	2008	2015	2014	2013
<b>Management</b>	The European Union, represented by the European Commission and the European Federation for Pharmaceutical Industries and Associations	Dr. Serge Van der Geyten	Randall Bateman, Charles F., Joanne Knight	John Dwyer
<b>Collaborated organizations</b>	Janssen Pharmaceutical, Eisai Pharma, Bayer Pharma...etc	35 organisations including European Union, EFPIA companies and Universities, and research organisations	the National Institute on Aging (NIA), the National Institute of Bioimaging and Bioengineering (NIBIB), Araclon Biotech, Cambridge Cognition, MedImmune, the global biologics research & development arm of AstraZeneca, GlaxoSmithKline, Invicro, Ixico, Janssen Pharmaceuticals, in collaboration with Johnson & Johnson Innovation, SomaLogic.	Janssen, Eli Lilly and Company, Roche, Lundbeck
<b>Aims</b>	To develop next generation vaccine, medicine, treatments	To improve the understanding of the early stages of Alzheimer's disease and deliver new preventative treatments	To help define the rate of progression of mild cognitive impairment and Alzheimer's disease To develop improved methods for identifying the appropriate patient populations to participate in clinical trials. To standardize the methods used for conducting imaging scans and gathering and testing fluid samples	To speed up the delivery of innovative therapies to those afflicted with Alzheimer's by reducing the time and cost of Alzheimer's disease (AD) clinical trials.

Abbreviation	AMP	IADRP	GAAN
<b>Official Name</b>	Accelerating Medicine Partnership	International Alzheimer's and Related Dementias Research Portfolio	Global Alzheimer's Association Interactive Network
<b>Year of Establishment</b>	2014	2010	2010
<b>Management</b>	Maria C. Freire	NIH, the National Institute on Ageing, and the Alzheimer's Association	USC Laboratory of Neuro Imaging, USC Mark and Mary Stevens Neuroimaging and Informatics institute, Keck School of Medicine of USC
<b>Collaborated organizations</b>	Food and Drug Administration (FDA), National Institutes of Health (NIH), AbbVie, Biogen, Bristol-Myers Squibb, GlaxoSmithKline, Johnson & Johnson, Eli Lilly and Company, Merck, Pfizer, Sanofi, Takeda Pharmaceutical Company, Alzheimer's Association, Alzheimer's Drug Discovery, American Diabetes Association	40 organizations from 10 countries including, Administration on Ageing, CDC, Alzheimer's Association, BrightFocus Foundation, Canadian Institute of Health Research, Alzheimer's Research UK	24 organizations including, Alzheimer's Association, DIAN, Aibl, ADNI, I-ADNI, CAMD
<b>Aims</b>	To transform the current model for developing new diagnostics and treatments by jointly identifying and validating promising biological targets for therapeutics	Enable public and private funders of Alzheimer's research to coordinate research planning, leverage resources, avoid duplication of funding efforts and identify new opportunities in promising areas of growth.	Promotes big data sharing among a federated, global network of data partners who are studying Alzheimer's disease and other dementias. To address the need to coordinate and leverage existing resources to advance research into the root causes of the disease, improve diagnostics and discover novel therapeutics, and find better ways to deliver care.

✓ **Dementia research programs in Japan – Large-scale, multi-institutional joint studies, partnerships, and large-scale study-funding organizations**

Abbreviation	J-ADNI	IROOP	ORANGE Registry
Official Name	Japanese-Alzheimer's Disease Neuroimaging Initiative	Integrated Registry Of Orange Plan	Organized Registration for the Assessment of dementia on Nation-wide General consortium toward Effective treatment in Japan
Year of Establishment	2007	2016	2015
Management	University of Tokyo	National Center of Neurology and Psychiatry (NCNP), Japan Agency for Medical Research and Development	National Center for Geriatrics and Gerontology, National Center of Neurology and Psychiatry (NCNP), Tokyo dementia care research and training center, Ministry of Health, Labor and Welfare
Collaborated organizations	30 academic organizations	National Center for Geriatrics and Gerontology, Yokohama Brain and Spine Center, Osaka City University Faculty of Medicine	30 academic organizations
Aims	To conduct joint clinical studies with other facilities to develop criteria for evaluating the efficacy of AD drugs. To track healthy elderly patients, MCI patients, and early AD patients for two to three years.	To clarify symptoms that appear before the onset of dementia and to elucidate risk factors by improving lifestyles, habits, etc. To promote clinical research and clinical trials for the development of drugs expected to improve cognitive function.	To establish appropriate care methods for dementia by collecting information on people in various stages of health including: Healthy, Preclinical stage, MCI, Mild dementia, Moderate dementia, and Advanced dementia.

This research identified that the essential element of an effective PPP is clarity in organizational values, mission, and goals.

Furthermore, those interviewed commented on the strong need for Japan to be involved in international research collaborations including those using the PPP model. To achieve this, it is important to strengthen the basic foundations of clinical trial research in Japan, including the practices by which participants and workers who can collaborate internationally are recruited. It is also crucial to secure stable funding streams to make all of this possible.

➤ **Collection of case studies on dementia research and research promotion efforts led by PPPs**

In a study of fields that can be expected to be promoted by a PPP excluding drug discovery, we conducted interviews and other surveys with care service providers and related services, local governments, town planning experts, robotics experts, and IoT researchers. We also conducted a survey of precedent cases of research promoted by PPPs on topics other than dementia and used them as references for modeling the construction of a dementia PPP.

✓ **Challenges facing stakeholders undertaking advanced efforts in areas related to dementia and their needs**

Stakeholder	Challenges and needs
People with dementia and their families	<ul style="list-style-type: none"> <li>• There is a lack of support other than public services.</li> <li>• There is a lack of understanding towards people with dementia from industry.</li> <li>• These stakeholders require a society designed to respond to people with dementia and that is comfortable for the entire aging population.</li> <li>• These stakeholders desire for more recognition to be paid to the fact that people with dementia are capable of supporting society rather than unilaterally receiving support.</li> </ul>
Medical and care service providers	<ul style="list-style-type: none"> <li>• Proven services and technologies should be adopted.</li> <li>• These stakeholders require technologies that reduce the burden on caregivers.</li> </ul>
Companies and academia involved in clinical trials and clinical research	<ul style="list-style-type: none"> <li>• These stakeholders need longer research periods, larger sample sizes, and generous funding to collect evidence and develop medicines needed for dementia treatment.</li> <li>• These stakeholders need clinical research funding due to the fact that preclinical trial tests and medicines are exempt from health insurance.</li> <li>• These stakeholders face difficulties recruiting participants in preclinical trials and need for recruitment to not only be conducted in clinics.</li> <li>• These stakeholders need standardization in test procedures and diagnostic standards.</li> <li>• These stakeholders lack the infrastructure needed to give integrated support during large-scale multi-institutional joint studies.</li> </ul>
Companies providing technology and services that promote and improve care	<ul style="list-style-type: none"> <li>• Clearly presenting evidence of effects is difficult, and the cost effectiveness of doing so is low.</li> <li>• Reputable private services with verified effectiveness need to be promoted and disseminated.</li> <li>• Investments in private services and research plans commensurate with their societal achievements are needed.</li> <li>• There is a lack of communication between research institutes and those in the field (such as at care facilities).</li> </ul>
Self-governing bodies that implement progressive initiatives	<ul style="list-style-type: none"> <li>• It is difficult for lateral initiatives undertaken by local governments and NPOs to overcome regional boundaries.</li> <li>• Collaboration between communities, social networks, and healthcare institutions is necessary.</li> <li>• Data collected by the private sector must be utilized effectively.</li> </ul>
As a whole	<ul style="list-style-type: none"> <li>• All stakeholders require a clear vision and mission to be shared among the various stakeholders.</li> <li>• All stakeholders require neutral management that involves outside professionals while keeping conflicts of interest under consideration.</li> <li>• All stakeholders face difficulty covering the security and operational maintenance costs of maintaining a registry with just annual public research grants.</li> </ul>

✓ **Suggestions for the PPP mechanism in Japan**

Classification	Suggestions for PPP mechanism
Visions, missions, and values	<ul style="list-style-type: none"> <li>• Clear goals must be set. These goals and the methods for achieving them should be differentiated from other efforts to avoid difficulties when fundraising.</li> <li>• It is necessary to be transparent and independent so that the decision-making process regarding project implementation and fund provider intent can be explained clearly.</li> </ul>
Business model	<ul style="list-style-type: none"> <li>• To build a sustainable business model, it is necessary to involve fund-providing entities that can eventually fund the model. It is possible that initial investments can be made by the government and organizations like foundations.</li> <li>• Continuously promoting the construction of evidence-based scientific programs is of the utmost importance.</li> </ul>
Administrative structure	<ul style="list-style-type: none"> <li>• Strong fundraising and communications team are required.</li> <li>• As dementia has issues related to multiple fields (such as treatment, the transition from care facilities to housing, and mobility), multi-stakeholders should be involved in planning the PPP. It will then be necessary that continuous efforts are made to create a unified sense of purpose among participants.</li> <li>• To develop the next generation of human resources, it is necessary to involve multiple generations.</li> <li>• It is important to decide how to enable people with dementia and their families to actively participate in decision-making.</li> </ul>
Publicity campaigns	<ul style="list-style-type: none"> <li>• Collaboration between the public and private sectors is required to raise awareness and educate the general public.</li> <li>• Publicity campaigns with messages based on scientific knowledge are important in promoting the correct understanding of dementia within society.</li> </ul>
Collaboration with other organizations	<ul style="list-style-type: none"> <li>• Organizations such as private insurance companies have conducted various investigations and research initiatives. A system that enables the government to make use of their research findings would be useful.</li> <li>• Evidence collected in each field should be shared as much as possible so that it may be utilized.</li> </ul>
Institutional design	<ul style="list-style-type: none"> <li>• There is no definite answer or system for formulating PPPs and long-term care systems. PPPs should be designed to enable consideration of the culture of each country and region from the bottom up through discussions between multi-stakeholders.</li> <li>• As for the medical and nursing fields, the private sector is easily influenced by changes in government systems. Therefore, a system that enables the private sector to collaborate with the government during the institutional design stage is necessary.</li> </ul>

Interviews identified the need for a PPP to facilitate knowledge sharing within the research community and to assess new technology. Also, interviews highlighted the importance of having a clear shared vision and mission within the PPP and of promoting transparency and impartiality in project management.

➤ **Collaboration with the World Dementia Council (WDC)**

Interviews with stakeholders revealed that they are highly interested in the role that Japan is expected to fill in the WDC and in other global policy planning endeavors. After sharing opinions with the WDC on this matter, the WDC decided to investigate the current situation of and future topics in each field it focuses on.

✓ **Suggestions and expectations for Japan from the WDC**

Category	Suggestions and expectations for Japan
Finance	<ul style="list-style-type: none"> <li>Japan only devotes 0.2% of its total research funding to dementia, making Japan's investment into dementia research the smallest among G7 countries. Therefore, Japan is expected to rapidly increase investments into dementia research. Japan is also expected to actively adopt a successful, revolutionary private and public collaboration model like the Dementia Discovery Fund (DDF).</li> </ul>
Integrated Drug Development	<ul style="list-style-type: none"> <li>Continuing with the Pharmaceutical and Medical Device Agency (PMDA) as the main constituent, the Japanese government should form partnerships with regulatory authorities in each Asian country and establish itself as a leader in the region.</li> <li>Furthermore, the MHLW and insurers should make concrete proposals for drug prices and the extent to which insurance should cover dementia drugs. Policy direction should be decided after consulting with other countries to examine which approaches should be taken (for example, to examine drug evaluation methods).</li> </ul>
Research, Open Science, and Data	<ul style="list-style-type: none"> <li>Japan should actively strengthen its partnerships with research centers in other countries. As one method for accomplishing this, AMED suggested participation in the EU Joint Programme – Neurodegenerative Disease Research (JPND). Furthermore, it is desirable that a platform for sharing various data is established.</li> </ul>
Care	<ul style="list-style-type: none"> <li>As a super aging society, Japan should share best practices for dementia care and its experience with the world. It has been brought up that there are no examples of policies that involve society like the New Orange Plan. Japan is also receiving attention for its utilization of ICT in treatments.</li> <li>The efforts of Dementia Friends in the UK are very highly praised. In order to contribute to the establishment and expansion of similar programs in other countries, it is important to promote the evaluation of similar programs in Japan.</li> </ul>
Risk Reduction	<ul style="list-style-type: none"> <li>Japan should follow risk reduction recommendations from the World Health Organization (WHO). In addition, since Japan is unique in that it has a super aging society, Japan should actively conduct research for identifying risk factors to delay the progression of dementia.</li> </ul>

These conversations allowed for opinions on the concept of the PPP model to be exchanged and they reaffirmed the need for Japan to actively contribute to the WDC. They also stressed the importance of long-term strategic efforts for effective drug discovery and the standardization of care and evaluation methods.

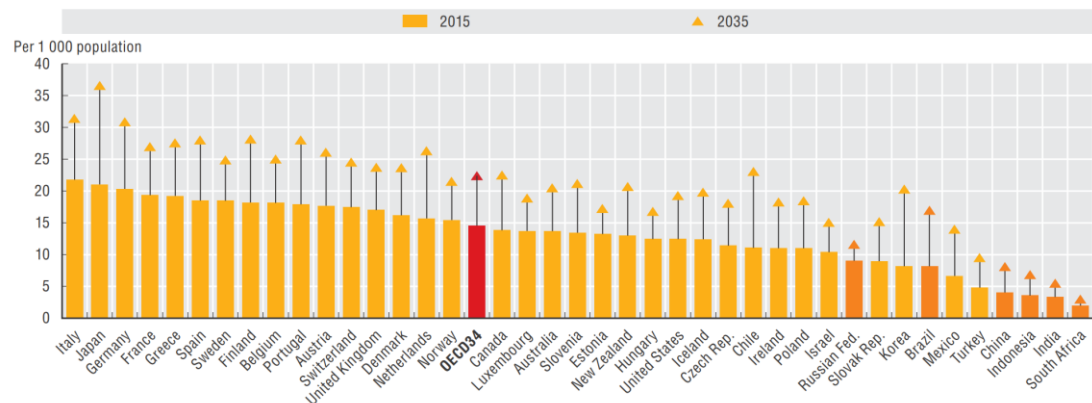
➤ **Multinational comparative analysis of the current state of PPPs for dementia**

A multinational comparative analysis was carried out to examine the current status of international PPPs for dementia research. It identified elements and functions required for cooperation between industry, government, and academia regarding dementia research in Japan.

✓ **The number of people with dementia**

According to the estimate for the number of people with dementia in member nations of the OECD reported in the OECD's Health at a Glance 2015, both the prevalence of dementia and its future rate of growth in Japan are high. Western Europe and the Nordic countries mostly had high levels of dementia among the OECD member states, and countries such as Chili, South Korea, and Brazil were projected to have high growth rates in the future.

**11.9. Estimated prevalence of dementia per 1 000 population, 2015 and 2035**



Source: OECD analysis of data from Prince et al. (2013) and the United Nations.

✓ **Dementia-related research and development funding**

Although funding for the Government Budget Appropriations or Outlays on Research and Development (GBAORD) in Japan is around the same as countries excluding the United States and the United Kingdom, the amount of funding for dementia and neurodegenerative disease-related research and development is very low.

**Public funding of research and development on neurodegenerative diseases (NDD) in G7 countries**

Million USD in purchasing power parity (PPP) terms

	Reference year	Funding for dementia R&D	Funding for NDD R&D	Health R&D budget (GBAORD)	R&D budget (GBAORD total)
Canada	2012/13	31	38	1,356	7,743
France	2012	55	170	1,338	17,997
Germany	2012	n/a	115	1,634	30,956
Japan	2012	21	40	1,657	35,273
United Kingdom	2011	49	75	2,736	12,982
United States	2012	625	1,671	33,924	143,737
Italy*	2011	n/a	6	1,209	11,708
<b>G7 area</b>		<b>781</b>	<b>2,115</b>	<b>43,854</b>	<b>260,396</b>

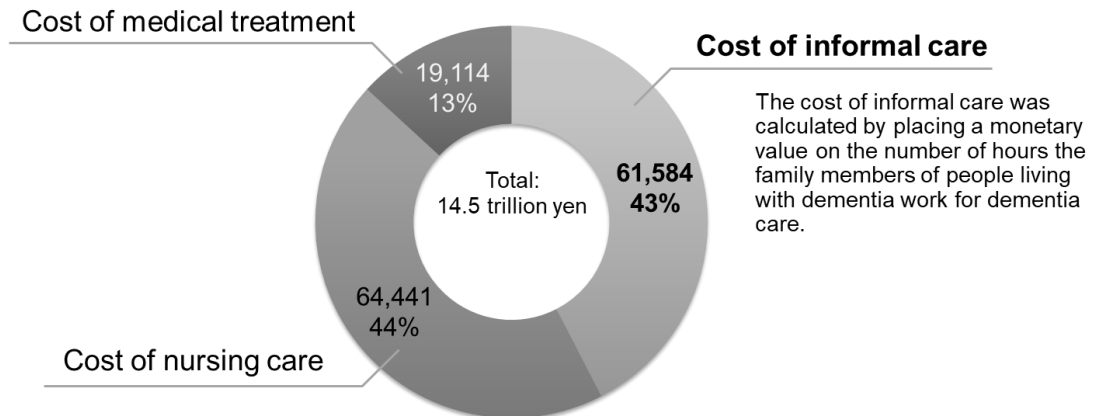
Source: OECD Health Policy Studies Addressing Dementia

✓ **Cost of Dementia in Japan**

The overall cost of dementia in Japan is 14.5 trillion yen (2014 estimation). The breakdown of costs reveals that the costs of nursing and informal care together account for a much larger proportion (87%) of total costs than medical treatment.

Regarding the dementia related cost ratio around the world, Asian countries have especially low medical costs, and Western countries often have high cost ratios for social centers.





Source: Sado et al., Report on results of Health Labor Sciences Research, 2015 "Research on the economic consequences to Japan"

**Costs of dementia in 2015 (US\$ billions), by Global Burden of Disease region classification. Costs in cost categories. Percentages of each GBD region class costs**

Cost sub-category	Direct medical costs		Direct social sector costs		Informal care costs	
GBD World region	US\$ (billions)	Per cent	US\$ (billions)	Per cent	US\$ (billions)	Per cent
Australasia	1.0	6.9%	7.1	50.3%	6.0	42.8%
Asia Pacific High Income	7.0	6.3%	56.4	51.3%	46.5	42.4%
Oceania	0.0	17.4%	0.0	8.6%	0.1	74.0%
Asia Central	0.3	29.6%	0.3	25.3%	0.5	45.1%
Asia East	2.2	5.2%	10.2	23.8%	30.5	71.0%
Asia South	0.5	10.7%	0.1	3.3%	3.8	86.0%
Asia Southeast	2.7	36.8%	1.3	18.2%	3.3	45.0%
Europe Central	2.8	18.8%	3.1	20.4%	9.1	60.8%
Europe Eastern	5.7	24.1%	4.9	20.7%	13.0	55.2%
Europe Western	50.8	19.3%	113.0	43.0%	98.9	37.6%
North America High Income	61.1	22.7%	115.5	43.0%	92.3	34.3%
Caribbean	0.8	21.3%	0.8	21.8%	2.0	56.9%
Latin America Andean	0.2	17.8%	0.4	32.6%	0.6	49.5%
Latin America Central	6.2	39.2%	5.5	34.3%	4.2	26.5%
Latin America Southern	2.8	27.8%	2.6	25.2%	4.8	47.0%
Latin America Tropical	5.7	36.8%	5.2	33.4%	4.7	29.9%
North Africa / Middle East	8.5	50.7%	1.2	7.2%	7.0	42.0%
Sub-Saharan Africa Central	0.1	28.5%	0.0	14.1%	0.2	57.3%
Sub-Saharan Africa East	0.3	20.8%	0.2	10.3%	1.0	68.9%
Sub-Saharan Africa Southern	0.4	16.4%	0.2	8.1%	1.7	75.6%
Sub-Saharan Africa West	0.2	22.8%	0.1	11.3%	0.5	66.0%
<b>Total</b>	<b>159.2</b>	<b>19.5%</b>	<b>327.9</b>	<b>40.1%</b>	<b>330.8</b>	<b>40.4%</b>

Source: World Alzheimer Report 2015

#### ✓ **Status Development status for national strategies and guidelines**

The United States signed the National Alzheimer's Project Act (NAPA) into law as a national project on Alzheimer's disease, while Britain and Japan have implemented policy measures as part of their national strategies. It is necessary for Japan to consider establishing basic laws in the future like the United States. Furthermore, Japan's guidelines on clinical trials are inadequate compared to Western countries, and therefore their improvement will be a goal for the future.



### Dementia-related national strategies and guidelines in Western countries and Japan

		United States	United Kingdom	Japan
<b>Dementia related national strategies</b>		The National Alzheimer's Project Act (NAPA)	Living well with dementia: A National Dementia Strategy	Comprehensive Strategy to Accelerate Dementia Measures (New Orange Plan)
<b>Guidance • Guidelines</b>	<b>Name</b>	Guidance for Industry, Alzheimer's Disease : Developing Drugs for the Treatment of Early Stage Disease	Draft guideline on the clinical investigation of medicines for the treatment of Alzheimer's disease and other dementias	Guideline on the clinical evaluation of medicines for the treatment of Alzheimer's Disease (AD)
	<b>Explanation</b>	The FDA's current approach covers areas such as: diagnostic methods for early-stage Alzheimer's disease patients who are participating in clinical trials; patient selection and diagnostic methods for patients for whom the disease has the possibility of progressing; directions for setting the endpoints of clinical trials; and directions for using biomarkers to measure treatment outcomes.	These guidelines aim to create new diagnostic criteria for AD, including early-stage and asymptomatic AD patients based on the results of impact assessments; select treatments based on outcomes for each stage of progress of AD; enable the effective use of biomarkers; and design trials to determine the long - term effectiveness and safety of dementia treatment drugs.	Currently being produced.

The results of this project emphasized the need for Japan to become involved in improving relevant guidance and guidelines for dementia. It also emphasized the importance of developing a registry framework for clinical trials in order to further advance global collaborations in dementia research.

➤ **Organizing meetings involving people with dementia and their families and representatives from government, academia, and the private sector**

An advisory board and an expert committee that brought together people with dementia and their families and representatives from industry, government, and academia was established in order to exchange opinions regarding the promotion of research by a PPP. (\*All affiliations are current at the time of writing)

## ✓ Expert Committee

Experts Committee
<b>Roles</b> Provide technical expertise, advice and guidance on the dementia research
<b>Members (Titles omitted):</b> <ul style="list-style-type: none"> <li>• <b>Haruhiko Akiyama</b> <i>Chair, the Board of Directors, Japan Society for Dementia Research</i></li> <li>• <b>Shuichi Awata</b> <i>Director of Research, Tokyo Metropolitan Institute of Gerontology</i></li> <li>• <b>Takeshi Iwatsubo</b> <i>Professor, Dept. of Neuropathology, Graduate School of Medicine, University of Tokyo</i></li> <li>• <b>Mitsuhiro Sado</b> <i>Lecturer, Department of Neuropsychiatry, School of Medicine, Keio University</i></li> <li>• <b>Takehito Tokuda</b> <i>President, Smart Aging Ltd./ Board member, NPO Dementia Friendship Club</i></li> <li>• <b>Satoko Hotta</b> <i>Professor, Division of Health and Social Service, International University of Health and Welfare Graduate School</i></li> <li>• <b>Shinsuke Muto</b> <i>President, Tetsuyu Institute Medical Corporation</i></li> <li>• <b>Tomofumi Yamamoto</b> <i>Patient /Editor Shukan Asahi Weekly Magazine</i></li> </ul>

## ✓ Advisory board

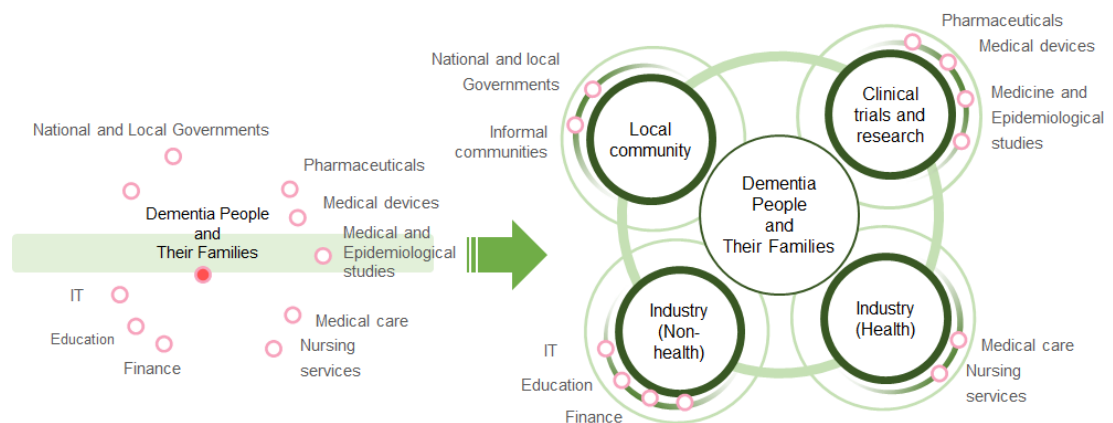
Advisory Board
<b>Roles</b> Provide advice and suggestions for the research based on the needs of researchers
<b>Members (Titles omitted):</b> <ul style="list-style-type: none"> <li>• <b>Hiroko Akiyama</b> <i>Professor, Institute of Gerontology, University of Tokyo</i></li> <li>• <b>Hiromichi Iwasa</b> <i>Chairman of the Board and CEO, Mitsui Fudosan Co., Ltd.</i></li> <li>• <b>Yoshiharu Otsuka</b> <i>Vice-President, The Japanese Red Cross Society</i></li> <li>• <b>Akira Kashima</b> <i>Chairman and Group Managing Partner, PwC Consulting LLC.</i></li> <li>• <b>Masaru Kitsuregawa</b> <i>Director General, National Institute of Informatics</i></li> <li>• <b>Hidehito Kotani</b> <i>President/CEO, Panasonic Healthcare Holdings Co., Ltd.</i></li> <li>• <b>Kunio Takami</b> <i>President, Alzheimer's Association Japan</i></li> <li>• <b>Yasutake Tango</b> <i>Chairman, Japan Tobacco Inc.</i></li> <li>• <b>Kenji Toba</b> <i>President, National Center for Geriatrics and Gerontology</i></li> <li>• <b>Haruo Naito</b> <i>Representative Corporate Officer and CEO, Eisai Co., Ltd.</i></li> <li>• <b>Ryozo Nagai</b> <i>President, Jichi Medical University</i></li> <li>• <b>Yasuchika Hasegawa</b> <i>Director, Chairman of the Board, Takeda Pharmaceutical Co., Ltd.</i></li> <li>• <b>Tatsuo Higuchi</b> <i>President, CEO &amp; Representative Director, Otsuka Holdings Co., Ltd.</i></li> <li>• <b>Yoshinori Hiroi</b> <i>Professor, Kokoro Research Center, Kyoto University</i></li> <li>• <b>Kazuko Fujita</b> <i>Co-Chair, Japan Dementia Working Group</i></li> <li>• <b>Hidehiro Mizusawa</b> <i>President, National Center of Neurology and Psychiatry</i></li> <li>• <b>Mitsuru Miyata</b> <i>Executive Leader Writer, Nikkei Business Publications, Inc.</i></li> <li>• <b>Teruji Yamamura</b> <i>President &amp; CEO, Duskin Co., Ltd.</i></li> <li>• <b>Yoshitake Yokokura</b> <i>President, Japan Medical association</i></li> <li>• <b>Danny Risberg</b> <i>CEO, Philips Electronics Japan Ltd.</i></li> <li>• <b>Patrik Jonsson</b> <i>President and General Manager, Eli Lilly Japan K.K.</i></li> </ul>

➤ **Proposals for the establishment of an international PPP model and policy**

Three key approaches that will enable Japan to demonstrate leadership in Asia as a society experiencing advanced aging have been identified. First, the PPP must provide a platform for data collection and assessment that can facilitate discussion among organizations from various sectors. Second, the PPP must also function as a high-quality dementia registry that can enable Japan's participation in large-scale international clinical trials. Last but not least, the PPP should function as an organization that can raise awareness of dementia among the public and thereby promote understanding and acceptance.

✓ **Stakeholders for promoting a PPP**

The promotion of a PPP for dementia policy will require not only cooperation between stakeholders and people with dementia and their families, but also mutual cooperation among stakeholders. Furthermore, people with dementia should not be positioned to only receive unilateral support; rather, we should aim to create a world in which those with dementia can also actively contribute to tackling the challenges dementia presents to society.



✓ **The ideal dementia PPP as suggested by this research**

Detailed below is a vision for the field of dementia and for society that the dementia PPP structure proposed by this research aims to create. In the future, we must present a vision and mission and create a PPP roadmap.

- In pursuit of an effective and efficient PPP

Ideally, in the future this PPP will:

- Develop research themes and activities based on the needs of people with dementia and their families.
- Appropriately prioritize research funding and activities based on an understanding of the issues surrounding dementia and evaluate the effects of research constantly.
- Enable all stakeholders to access and share data and knowledge from dementia research and related services.
- Encourage the private sector to invest actively in dementia policy and motivate further participation in this area.
- Actively adopt and utilize scientific and technical innovations for its work, including innovations related to ICT and robotics.

- Goals of the dementia PPP

The PPP should aim to:

- Solve latent social issues in Japan that are at the backdrop of dementia-related problems, including but not limited to issues related to low birthrates and an aging population; issues

that women face; and issues related to people leaving employment to care for family members. Multifaceted and systematic solutions should be developed.

- Take the initiative in creating global policy and serve as a hub for global research as a PPP based in the country with the highest proportion of elderly people in the population in the world. It should build links to the government's Asia Health and Human Well-Being Initiative.

✓ **The functions that Japan's PPP platform on dementia should have, and the course of action that it must take**

We will establish a PPP platform on Dementia so that Japan can successfully manage the social challenges brought about by long life expectancies among Japanese people and to demonstrate leadership in Asia as a country already experiencing population aging.

This platform shall:

1. Offer a space for stakeholders, including people with dementia and their families, to cooperate and conduct discussions, evaluations, and inspections of dementia-related issues using objective data.
2. Work to raise awareness and understanding of dementia in society, and to disseminate information internationally.
3. Prioritize the development and objective evaluation of new technologies relating to dementia care.
4. Strengthen the foundation for implementing clinical trials via various initiatives to promote international cooperation, such as by developing a registry or participating in large-scale, international clinical trials.

\*The contents of Section2.1 is based on the information as of March 2017 when we published our research results.

## 2.2 International Collaboration

### ➤ **The collaboration with the World Dementia Council (WDC)**

The WDC is an independent charity that is based in London and operates internationally. The Council comprises 24 members from all sectors of society around the globe, including HGPI Chairman Kiyoshi Kurokawa. The Council aims to improve dementia countermeasures through international advocacy, international leadership, and the building of global networks.

In addition, the WDC, together with HGPI, has conducted research on the current situation of dementia and the problems presented by dementia prevention as a partner in the “Research Project on the Construction and Use of a Model for International Public-Private Partnerships (PPP) in Dementia Research” joint research project which was conducted by HGPI with the support of AMED. It also gave its recommendations and suggestions for Japan.

Based on these achievements, the 12<sup>th</sup> meeting of the WDC was held in March 2018, co-sponsored by HGPI and WDC. During that meeting, members discussed which actions that need to be taken to accelerate progress and agreed to focus on four areas: awareness, research, care, and risk reduction. On the sidelines of the WDC12 meeting, a Japan-UK Dementia Conference was held. It was organized by HGPI together with WDC and media organizations from Japan and the United Kingdom (Nikkei and the Financial Times). During this conference, guests shared knowledge about dementia from Japan and the United Kingdom and had an in-depth discussion on how to create and make use of international Public-Private Partnerships (PPPs).

### ➤ **Research Proposal on Post Diagnosis Support in Scotland**

Early diagnosis and early response are considered important in dementia measures. Although this concept is described with various expressions, the situation is same for every country. However, it is not rare for the patients to become isolated and have their condition worsen due to the lack of appropriate post diagnosis support (PDS). Therefore, a research proposal was created with suggestions for Japan based on the policy in Scotland, which is the country with the most highly-developed PDS.

\*This investigation was held with the support from the Global Health Innovation Policy Program (GHIPP) by the National Graduate Institute for Policy Studies.

✓ Observation report of Scotland “[Alzheimer’s Scotland and the Link Worker System](#)”

## 2.3 Awareness-raising activities

### ➤ **“A Social Prescription for Dementia-Enabling Early Detection and Diagnoses through the Building of a Dementia-friendly Community”**

This white paper aims to fill the knowledge gap concerning dementia on various topics including evidence for supporting the early detection and early diagnosis, to investigate the current situation, and to offer opportunities for interested parties, health professionals, researchers engaged in the field of dementia, policymakers, and NGO personnel to further deepen their understanding of the importance of early detection and diagnosis.

### ➤ **Implementation of study groups featuring various subject of dementia**

#### ✓ **HGPI Breakfast Meeting**

- 57th Breakfast Meeting (March 8, 2016)
  - “Losing Marbles! - Experiences of Early Treatment for Dementia-“ Mr. Tomofumi Yamamoto (Member of the editor board of Asahi Weekly),
- The 62nd Breakfast Meeting (June 22, 2017)
  - “Building a Dementia-Friendly Community? Expectations for Japan’s National Dementia Strategy and the Role of Stakeholders” Mr. Yuto Tokuda (Director of Dementia Friendship Club NGO)
- The 64th Breakfast Meeting (October 27, 2017)
  - “Action Plan Towards a More Dementia Friendly Society -Making VR Dementia Experiences a Key Part of Integrated Community Care-“ Dr. Satoko Hotta (Professor, Graduate School of Health Management at Keio University), Mr. Tadamichi Shimogawara (President, Silverwood Co., Ltd., Japan)
- The 69th Breakfast Meeting (May 31, 2018)
  - “A World Young Leader in Dementia on the Current Issues and Topics in Dementia at the Global Level – What Does It Mean to Build Dementia-Friendly Communities?” Miharu Nakanishi (World Dementia Young Leaders (WDYL))

### ➤ **Diet Study Group on Dementia**

It is important to increase the number of diet members that have a strong interest in dementia and possess correct awareness and understanding of the current situation in order to implement further measures in the future in addition to the “Comprehensive Strategy to Accelerate Dementia Measures (New Orange Plan)”. HGPI supports the management of the Diet Study Group on Dementia, which is a voluntary, regular and non-partisan study group headed by House of Representatives member Hayato Suzuki.

- First session of the Diet Study Group on Dementia (February 27, 2018)
  - “The Current State of Dementia in Japan – Building a Dementia-friendly Society” Mr. Yuto Tokuda (Director of Dementia Friendship Club NGO)
  - “Community Support for People with Dementia and their Families” Mr. Takahiro Sugiyama (Vice-director of Alzheimer’s Association Japan – Director of Kanagawa branch)
- Second session of the Diet Study Group on Dementia (March 27, 2018)
  - “Listening to the Voices of People with Dementia” Mr. Tomofumi Yamato (Member of the editor board of Asahi Weekly)
- Third session of the Diet Study Group on Dementia (April 19, 2018)
  - “Event Report on the Nikkei Financial Times-hosted Japan-UK Dementia Conference” Ms. Yuko Shiozaki (Executive officer and Head of Special Programs Section)

- “Event Report on a Meeting of the World Dementia Council” (Dr. Kiyoshi Kurokawa (HGPI Chairman and member of the World Dementia Council))
- “The Future of Dementia Care” Dr. Yoshimasa Takase (President of Takase Clinic)
- Fourth session of the Diet Study Group on Dementia (May 31, 2018)
  - “Frontline Research on Alzheimer’s Disease and Dementia” Mr. Takeshi Iwatsubo (Professor at the Department of Neuropathology at the Graduate School of Medicine in the University of Tokyo)
- Fifth session of the Diet Study Group on Dementia (June 26, 2018)
  - “What I myself had dementia?” Mr. Takayuki Maeda (Psychiatric Social Workers, President of "Let's make Machida an open town" NPO; Member of the board of directors of Young onset dementia support center NPO; Member of the advisory board of Dementia friendship club NPO; Member of the board of directors of Japan dementia working group general incorporated association)

## Contributors:

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Note: The information above denotes titles and affiliations at the time of the first edition.