

Health and Global Policy Institute (HGPI) Dementia Policy Project
Building a Research and Development System Together With People Living with
Dementia and Their Families to Drive Parallel Progress in Creating an Inclusive
Society and Advancing R&D
Policy Recommendations

Background to these policy recommendations

In its capacity as a non-profit, independent, non-partisan health policy think-tank, Health and Global Policy Institute (HGPI) views all issues related to population aging starting with dementia as health policy issues on the global level and has made ongoing efforts from this position. In July 2022, we presented comprehensive policy recommendations titled “The Future of Dementia Policy 2022: Deepening Dementia Policies Centered on People Living with Dementia and their Families to Lead Global Society.” In those recommendations, we provided suggestions regarding Japan’s path forward for further reinforcing measures for dementia in the international community from the four perspectives of the social environment, care, research, and political leadership. In particular, in its role as the country where population aging has advanced the most, there are high expectations for Japan to provide leadership to the international community in generating innovations that are based on the needs of people living with dementia and their families.

In the field of dementia, R&D is broad and spans 1) reducing the risk of developing dementia; 2) early diagnosis; 3) treatment, starting with disease-modifying pharmaceuticals; 4) long-term care and caregiving, and 5) products and services. Studies in these areas are characterized by the fact they sometimes require long-term participation to grasp changes in cognitive function among participants or that they may require cooperation from members of the general public who do not have dementia symptoms. This is why it will be necessary to establish a research system that facilitates involvement from people living with dementia, their families, and the general public. Given this need, that system should incorporate perspectives other than those of researchers and do so from the planning stages of research. Initiatives like this are currently advancing around the world in the form of Patient and Public Involvement (PPI). Some involve the parties most affected in R&D from the planning and design stages to ensure research initiatives are rooted in their needs or to identify methods of disseminating information about research initiatives that participants will find easy to understand. Efforts to encourage PPI have been gaining momentum in Japan, particularly in the field of oncology. In the field of dementia, anticipation is high for the establishment of a system that drives progress in R&D by bringing together people living with dementia, their families, and the general public as well as researchers and industry. In addition to research, in Japan and overseas, there have been advances in similar efforts from industry when working to develop products and services, and anticipation is also high for further progress in such efforts.

In addition to identifying the ideal methods of planning and designing R&D programs, promoting PPI in R&D will also require an examination of how to construct a system for providing and receiving information. Current efforts to disseminate information are centered around universities and research institutions, or they are parts of

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individual research projects. Expectations are high for the establishment of a more comprehensive system for disseminating information that can serve as a one-stop information resource for anyone who is interested in research, including people living with dementia, their families, and members of the general public.

Given this backdrop, activities from the HGPI Dementia Policy Project in FY2022 have emphasized the importance of establishing a platform for collaboration among industry, Government, academia, and civil society with the objective of creating an R&D system that is advanced together with people living with dementia and their families. In Japan, expectations are particularly high for civil society organizations to play central roles in advancing efforts to establish a system for collaboration that is agile and neutral. Based on these circumstances, we offer the following recommendations.

Recommendations

To achieve innovations in dementia that are based on the needs of people living with dementia, their families, and citizens, a collaborative platform centered on civil society should be established.

Anticipated features for the collaborative platform

1. Features that promote Patient and Public Involvement (PPI) and PPI-centered development

Collaborating with people living with dementia, their families, and citizens from the planning stages of R&D will be an essential step in promoting R&D and generating innovations that are based on their needs in a stable manner. Their perspectives must be incorporated to identify research topics that are based on the needs of the parties most affected, research designs that allow participants to feel that their participation is significant, and methods of communicating and explaining information in ways that are easy for participants to understand. Initiatives such as these are currently being advanced as forms of PPI and PPI-centered development, and expectations are high for further progress. However, before people living with dementia, their families, and citizens can get involved in R&D, it is important to attract their interest in involvement, to enhance their understanding of R&D, and to inform them of R&D initiatives they can participate in. The collaborative platform should provide information on which R&D initiatives these parties can participate in and serve as a link between them and researchers or industry.

2. Features that provide suitable support and easy access to information regarding research programs to all participants

Making information more accessible for people living with dementia, their families, and citizens will be vital for encouraging their involvement in research programs. It will also be important to have a consultation and support system that helps people understand which studies they can participate in, or that address their questions or concerns during their involvement. There are examples of such systems in other countries, such as Trial Match in the U.S. and Join Dementia Research in the U.K. These systems widely consolidate and disseminate information regarding research programs and provide points of contact for people to access information regarding research. Researchers and patient advocacy organizations are also collaborating to construct a consultation system that combines telephone, e-mail, and (when necessary) in-person consultations. Attempts to consolidate information and provide other services regarding dementia research programs have also begun in Japan. While utilizing existing networks and initiatives, expectations are high for the creation of a collaborative platform that consolidates comprehensive information and disseminates it from a neutral position, and that provides support to those who get involved.

Features related to gathering and disseminating information are generally provided over the internet. From both the perspective of the digital divide and for better peace of mind for participants, it will also be necessary to provide information on research and consultation support for research participants at the community level. Having access to a variety of information and support regarding involvement in research from both specialists and

other familiar faces as well as over the internet will provide great comfort for people living with dementia and their families who feel uncertain about participation. Reinforcing cooperation among frameworks provided by the Integrated Community Care System and those conducting R&D will also be important for enhancing support provided at the community level.

3. “Participant first” and “Family first” features that provide access to care through research program participation

There are various factors that motivate people living with dementia and their families to participate in research programs, such as their expectations toward cutting-edge treatments or their will to contribute to future generations. However, they can be provided with even greater benefits if participating in research programs also allows them to access consultation support, peer support, and other forms of care. It would also be highly significant if people living with dementia and their families could be guided to the care that best meets their needs when they apply for a research program but are deemed ineligible, or after a program they participated in has ended. Other efforts to facilitate involvement will also be important, such as by enabling the people conducting research projects to share information so applicants can be introduced to suitable research programs when they are unable to participate in a study, or by creating opportunities for participants to communicate with each other. Expectations are high for the collaborative platform to serve as a gateway to involvement in such research programs and for it to pave the way to care through features that place people with dementia and their families first.

4. Features that enable two-way feedback among participants and researchers after research programs are concluded and that create communities that last

Rather than viewing people who participate in research programs as passive “subjects,” it is vital that they are perceived as partners who support the research goals and take part in identifying issues for research to target. The findings and outcomes of research are not only important to researchers and companies; they are also important to people living with dementia, their families, and the general public. It is important to share the findings of research with participants, who are partners in research, in a manner that is easy for them to understand. It would be ideal if feedback from participants is gathered and utilized in a manner that it can be applied during the design of future phases or similar studies. Collecting and disseminating the opinions of past participants will benefit researchers and companies as well as provide a valuable source of information for those who will participate in research in the future. Other countries are now taking the first steps in similar initiatives, and expectations are high for the collaborative platform to have features that allow for mutual feedback and to function as a community even after such research programs are completed.

5. Features that allow opinions on and evaluations of innovations that have been introduced to be accumulated and utilized to contribute to further improvements

Another significant factor for the innovations achieved through the steps above will be to utilize real-world data and survey results (such as those that demonstrate their effectiveness and safety in real-world clinical practice or

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on the costs of healthcare and long-term care) to gather user opinions and third-party evaluation after they have been implemented in society. Gathering such information is likely to enable future innovations that reflect the needs of people living with dementia, their families, and citizens, and to benefit related parties by encouraging continued involvement in the platform. Although this perspective was not explored in-depth during our discussions this fiscal year, it is likely to be an important perspective when creating a virtuous cycle that will start with the establishment of a collaborative platform.

Acknowledgement

HGPI created this recommendation as part of our Dementia Policy Project activity in FY2022 entitled “Building an R&D System Together with People Living With Dementia and Their Families – Driving Parallel Progress on an Inclusive Society and in R&D.” We are deeply grateful for the expert advice of our Roundtable Discussion members, and Symposium Speakers.

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