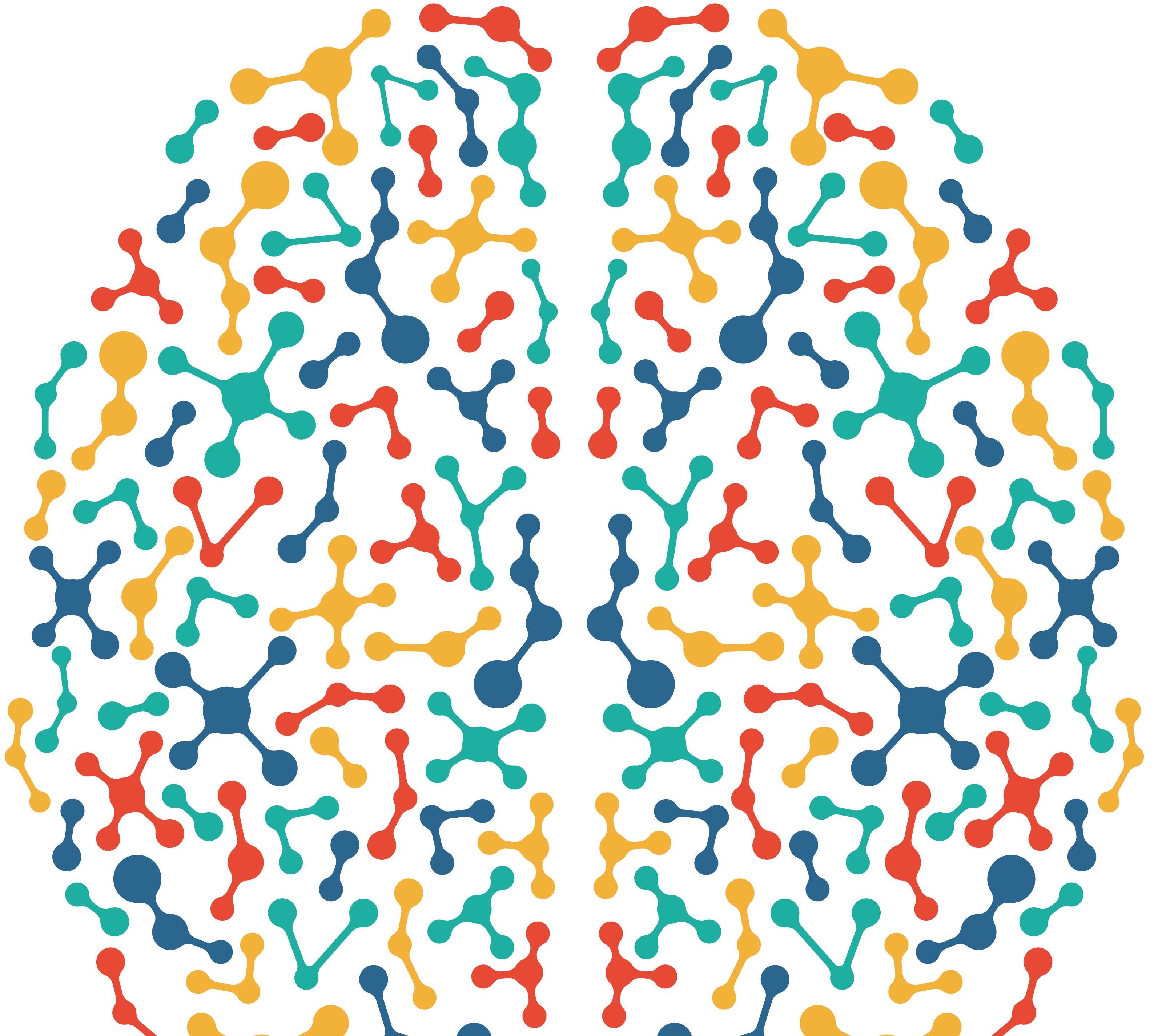
Health and Global Policy Institute (HGPI) Dementia Policy Project Policy Recommendations

Dementia Prevention Initiatives for Achieving a Dementia-Friendly and Inclusive Society

March,2024



Policy Recommendations

Recommendation 1

Envision a broader meaning for “policy beneficiaries” than the people covered by general dementia policies and endeavor to provide information.

In the past, dementia policies mainly focused on people living with dementia, people who are at high risk of developing dementia (such as those with MCI), their family members, and caregivers. However, as previously discussed, the term “prevention” has a broad meaning, so measures for prevention could be perceived as targeting almost all citizens. This means there is an extremely broad range of needs among individuals, including latent needs of which people may not be aware. As it is difficult to package all needs under the term “dementia prevention,” needs must be subdivided when considering prevention.

In particular, in cases where a person is unaware of their own needs, expectations are high for efforts to provide them with sufficient materials for decision-making, including future predictions generated using big data and other tools. Furthermore, to help people living with health concerns but who have not adopted new behaviors access the support they may need, it will be necessary to approach them in an ongoing manner while respecting their autonomy and while utilizing an incentive model.

Recommendation 2

Make preparations in the social environment utilizing the voices and experiences of people living with dementia, their families, and related parties.

Recognizing dementia as “a social issue that affects approximately 7 million people in Japan” results in shortsighted ideas that overemphasize reducing the number of people with dementia. On the other hand, if we are thorough about compiling the current experiences of people living with dementia and their families, rather than only pursuing prevention that focuses on the onset of dementia, it will become possible to promote understanding throughout society, establish a social environment with more robust consultation systems for after dementia onset, and make multilayered preparations that include changing attitudes among individuals and in society.

It is safe to say that the voices of people living with dementia and their families are even more important in tertiary prevention, which aims to delay the progression of dementia. Expectations are high for R&D that focuses from the outset on the needs of each individual and factors that reduce QOL over the course of daily life to realize “research, etc. that contributes to the creation of an inclusive society” as described in Article 20, Paragraph 3 of the Dementia Basic Act.

Recommendation 3

Promote industry-government-academia collaboration from the development stage to ensure quality.

It will be important to continue advancing industry-government-academia collaboration to ensure products and services that claim to contribute to delaying the progression of dementia are of sufficient quality. In March 2023, the Ministry of Economy, Trade and Industry (METI) and six academic societies related to dementia compiled and presented “Recommendations on the Development and Expansion of Private Sector Services Related to Dementia Prevention.” While these were recommendations and not “guidelines,” they have set a direction to a certain extent by providing a point of reference for companies to use when developing and expanding services (based on non-pharmaceutical approaches) related to dementia prevention.

There are no evidence-based standards for interventions in the areas of prevention and health promotion similar to clinical practice guidelines in healthcare. While service providers have a high degree of freedom in these areas to develop programs that are tailored to the needs of individuals or groups, it is crucial that products and services which claim to promote better health are proven to be valid and reliable. Shaping a market where quality is assured will require establishing a system with continuous collaboration among industry, government, and academia. One area where collaboration needs to be promoted is during the development stage, and there are high expectations for political support for that collaboration. Establishing a system to certify and commemorate industry-academia collaboration from the stages of planning and development and that meets certain standards will allow consumers and users to be able to use new products and services with peace of mind. Another area that requires promotion is efforts to further improve products and services through post-marketing follow-up surveys and effects assessments. In the coming era, it is likely that consumer expectations for prevention and health promotion will shift toward more personalized products and services that fit their individual needs, physical and mental characteristics, and daily lives. This transformation may be further accelerated through digital technologies like Information and Communications Technology (ICT) and AI. This means that in the future, in addition to evidence generated through effects assessments on groups, we will also require “personal evidence,” where more emphasis is placed on evaluating effects for individuals. Linking these efforts to a results-based payment system described in the following recommendation will allow us to envision the creation of more flexible value assessments and systems.

Recommendation 4

Encourage private sector participation by implementing frameworks for evaluation and payment that elevate quality.

Led by rising social security expenditures due to factors like population aging and advances in medical technology, Japan’s national budget is increasing annually. This coupled with sluggish economic growth has made securing financial resources a lingering challenge. With further complications such as the declining birthrate and the COVID-19 pandemic, spending continues to rise while the Government steadily issues more and more bonds. Given these circumstances, fiscal consolidation has been a topic of discussion in Japan for many years. However, the history of health policy shows that systems or measures are difficult to pause or suspend once introduced, and some have noted that policies in the social security area are especially resilient. This inevitably results in discussions focusing on what methods can be used to improve cost-effectiveness rather than how to narrow down policies or measures. At the same time, it is extremely difficult to determine if policies have generated adequate results for the resources invested using ex-post policy evaluations. To begin with, the priority assigned to policy evaluations and the methods of conducting them are influenced by political and social contexts. Even if one attempts to calculate the benefits generated by a policy, debate becomes divided as to who gets to enjoy those benefits.

One tool for overcoming these challenges that has emerged in recent years is the Pay For Success (PFS) agreement. In PFS agreements, national Governments or local governments outsource projects to private companies, private companies design and carry out projects, and their financial compensation is adjusted based on how much conditions improve using predetermined performance indicators. Introducing this mechanism incentivizes private sector companies to produce results, which makes it more likely that they will implement projects of higher quality. As for the government side, adjusting payments according to results helps to ensure objectivity and transparency in the evaluation process as well as uphold accountability to the public. PFS agreements will also encourage private companies to develop new industries and attempt new business endeavors, and data and evidence accumulated over the course of their projects will contribute to disseminating evidence-based policy making (EBPM).

There are also Social Impact Bonds (SIBs), which are a mechanism used to secure financing for PFS agreements in advance through private equity from financial institutions and similar parties. In SIB agreements, governments reimburse private equity providers based on results. Private equity can also be utilized for projects where it is difficult to create projections for the benefits to society or that are difficult to implement with a local government’s own budget. SIB agreements also allow businesses to reduce risks that accompany carrying out projects because they can raise funds from investors. Expectations are high for the use of SIB agreements to attract a diverse range of participating businesses while incentivizing results. METI has taken the lead in introducing SIB agreements in the health sector, and has already launched a trial project for dementia prevention. Expectations are high for efforts that utilize this new form of public-private partnership and help build momentum for the more effective use of limited financial resources.

Recommendation 5

Adopt practices for risk reduction that lead to early detection, diagnosis, and intervention and coordinate with measures for other chronic diseases.

In addition to sending a false message about dementia to society, having the stated goal of “avoiding the onset of dementia” can also lead people to think little of risks that individuals cannot address on their own. Therefore, while encouraging individuals to alter behaviors related to modifiable dementia risk factors,[1] it will also be important to establish a social environment that facilitates early detection, diagnosis, and intervention in an integrated manner. While “early detection and early response” was mentioned often in many policy documents in the past, the recently-enacted Dementia Basic Act presents this concept as “early detection, diagnosis, and intervention” for the first time. There are forms of dementia that improve with treatment, such as where the underlying cause is idiopathic Normal Pressure Hydrocephalus (iNPH), so while encouraging activities that contribute to risk reduction, it will be important to recognize the signs of dementia early and to connect people to the healthcare and long-term care they need to maintain their current QOL. Disease-modifying pharmaceuticals that were recently launched target the early stages of dementia, so it has become all the more important to diagnose dementia during the period that was considered the primary prevention stage. In particular, there are high expectations for the creation of pathways from early detection to early diagnosis at the primary care level and the introduction of new blood, digital, and other biomarkers for early diagnosis. Responding to these changes in the treatment environment will require integrating the conventional approach to delaying and reducing the risk of dementia onset (primary prevention) with early detection, diagnosis, and intervention (secondary prevention).

Recently identified modifiable risk factors for dementia include those that are also associated with cardiovascular disease, diabetes, and other chronic diseases, such as high BMI, hypertension, and smoking. Therefore, instead of advancing dementia prevention measures in an isolated manner, they should be advanced as a part of broader chronic disease control programs. In addition to elevating public interest in initiatives for health promotion that include necessary actions for better living, incorporating dementia prevention in these programs may also prevent overcrowding in policies and programs in municipal level health services and help streamline both budgets and the use of human resources like public health nurses.

1 An epidemiological study on dementia risk presented by Professor Gill Livingston of University College London examined a number of modifiable risk factors for dementia and calculated population attributable fractions (PAFs) for each to show how many people in the population would not have developed dementia had those risks been absent. In addition to nine risk factors described in a 2017 paper such as smoking, depression, physical inactivity, and diabetes, a report published in 2020 titled, “Dementia prevention, intervention, and care: 2020 report of the Lancet Commission” added three new risk factors: traumatic brain injury, excessive alcohol consumption, and air pollution. This brought the total number of modifiable risk factors to 12, which account for around 40% of dementia cases worldwide.

For more details, please see HGPI Policy Column No. 18, “Considering the Importance of Global Efforts from Multi-Stakeholders for Issues in Dementia in Terms of Dementia Risk Factors” (https://hgpi.org/en/lecture/column-18.html).

Afterword

The Dementia Basic Act for an Inclusive Society (or, the Dementia Basic Act) came into effect on January 1, 2024 and included a section entitled “Prevention of Dementia, etc.” in Article 21. Stating that the Act will “enable willing participants to engage in appropriate and scientifically sound activities for dementia and mild cognitive impairment,” Article 21 envisions people who can make autonomous decisions. To mark the enactment of the Dementia Basic Act, HGPI arranged opportunities to discuss and examine the nature of dementia prevention. In December 2023, we held multi-stakeholder discussions at a public symposium titled, “Dementia Risk Reduction: How Society Should Face the Individualization of Risk.” Working independently, we then formulated policy recommendations based on those discussions and on other opinion exchanges with experts and representatives of civil society.

In health policy, the term “prevention” specifically refers to various actions taken from the primary to tertiary stages of prevention. When necessary, this term is also often used to discuss individual stages of prevention. In reality, however, many citizens may not understand what exactly “prevention” means when it is classified into primary, secondary, or tertiary stages. In many cases, citizens may take the term “prevention” to mean “not getting sick,” which means their understanding may be limited to primary prevention.

In dementia policy, the great amount of discussion devoted to the positioning and implications of “prevention” in the national Government’s 2019 National Framework for Promotion of Dementia Policies is still fresh in mind. During those discussions, it was pointed out that “Promoting dementia prevention will result in stigma toward the people who develop dementia because they failed to prevent it.” Studies being conducted around the world have revealed risks related to dementia onset that are linked to the individual, and this provides context for the growing focus on the topic of “primary dementia prevention and personal liability for prevention.” We should welcome the emergence of new evidence from research and recognize that it can contribute to better human health. However, we must also recognize that risks are not always factors that individuals can control on their own. In 2020, an epidemiological study published in The Lancet estimated that modifiable risk factors account for approximately 40% of dementia cases worldwide, and that those factors include environmental ones like social isolation, air pollution, and less education (Livingston et al., 2020). As such, we can say with some degree of certainty that the onset of dementia cannot be completely prevented by individuals on their own. Furthermore, discussions on health cannot overlook discussions on Social Determinants of Health (SDH). Even risk factors that are linked to individuals’ daily habits and behaviors may be subject to a great degree of influence from the social environment, meaning it may be difficult for individuals to modify these factors on their own. Human beings are, after all, social creatures. Delving deeper into the subject, we must also recognize that emphasizing the inability of an individual to control these factors due to SDH clashes with the idea of the individual as an entity that can exercise self-determination (Tamate, 2020, p. 173).

While primary prevention is an important aspect of dementia prevention, given the points described above, subsequent actions taken for secondary and tertiary prevention are also vital for maintaining and improving individual QOL. People must be provided with early detection, diagnosis, and intervention to ensure they can continue leading enriched lives even in the event they develop dementia, and this will require the steady implementation of efforts that aim to delay the progression of the condition. The judgmental statements that emerged in discussions on dementia prevention were made due to the latent stigma within those who offered criticism. Rather than avoiding discussions on prevention, settling this discussion will require the creation of a social environment in which people can say, “It is okay even if someone develops dementia.” In this debate, “prevention” mainly refers to “primary prevention,” but dementia prevention must be perceived as a seamless process spanning primary, secondary, and tertiary prevention. SDH is an important aspect of secondary and tertiary prevention, as well. After all, the social environment in which one lives has a significant impact on access to appropriate information, regular opportunities for checkups and examinations, and appropriate care that is tailored to one’s condition.

To conclude, we would like once again consider the Dementia Basic Act. When contemplating dementia prevention in a dementia-friendly and inclusive society, we must take into account the fact that each of us is an individual capable of making independent decisions. The “willing participants” mentioned under “dementia prevention” in the Dementia Basic Act (Article 21, paragraph 1) are those who wish to participate voluntarily under this premise. However, we must not allow anyone to remain “unwilling” because they were unable to acquire sufficient information and subsequently miss opportunities for better health that they could have taken. At the same time, placing too much focus on ensuring nobody is left out may result in paternalistic measures that take away individual freedom of choice. Amidst the tension between these two extremes, initiatives for dementia prevention that are based on the Dementia Basic Act must respect the autonomy of people who can make decisions independently and for themselves. If someone is facing circumstances that hinder them from independently obtaining information, understanding it, and making decisions, rather than automatically providing some measure targeting that person, we need to prepare information so it can be used for decision-making and convey that information in a way that is easy to understand. This could be considered a “reasonable accommodation,” which is one measure for restoring equality outlined by the Convention on the Rights of Persons with Disabilities (Park, 2023, p. 178). We believe that introducing such accommodating processes will help bring about the “inclusive and vibrant society in which all citizens, including people with dementia, can live together harmoniously with mutual support and respect for each person’s personality and individuality while fully displaying their individuality and abilities” envisioned by the Dementia Basic Act.

Regarding the independent nature of these recommendations

These policy recommendations are based on discussions at meetings HGPI held for this project and has been compiled in HGPI's capacity as an independent health policy think-tank. It does not, in any capacity, represent the opinions of any participating expert, speaker, related party, or organization to which those parties are affiliated.

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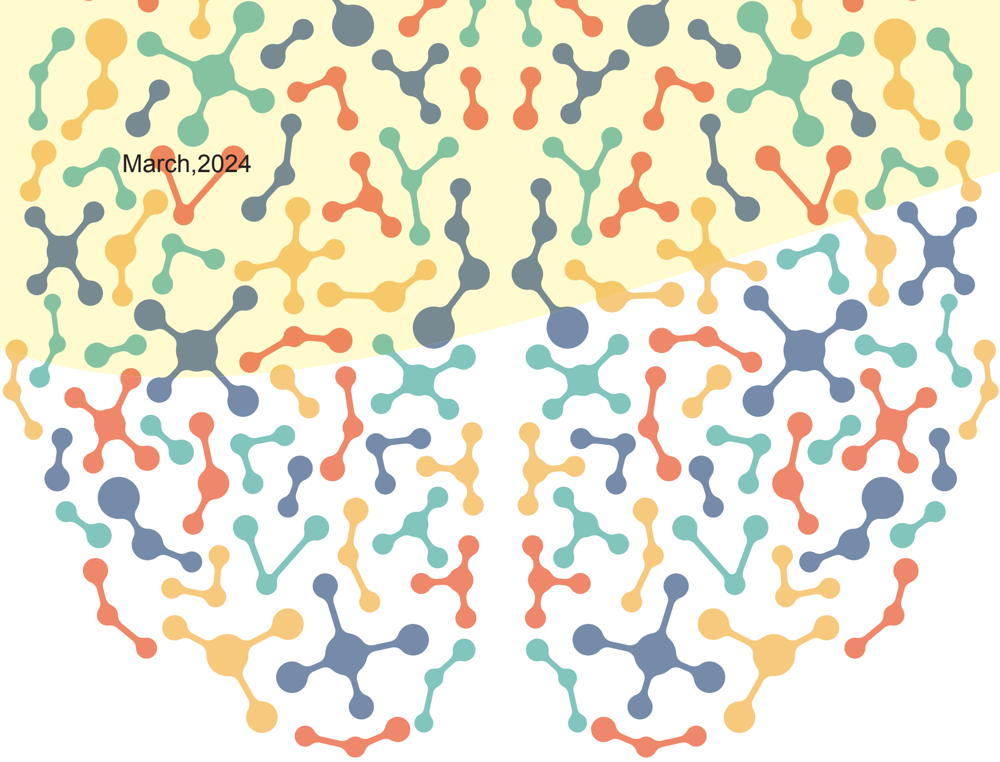

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