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Health and Global Policy Institute (HGPI) Patient and Public Involvement (PPI)

Support Project Policy Recommendations

Promoting PPI in the Policymaking Process

Background of these recommendations

For two decades, Health and Global Policy Institute (HGPI) has pursued its mission of “Achieving citizen-centered health policies by bringing broad stakeholders together in its capacity as an independent think-tank to generate policy options for society.” HGPI creates opportunities for patients, citizens, and other multi-stakeholders to come together for discussion-based policy advocacy activities that aim to advance policies in various areas in health and medicine. We view the proactive involvement of patients and citizens in the policy formulation process as a key theme for achieving “citizen-centered health policy,” and have engaged in various activities to encourage such involvement.

Initiatives in which citizens affected by policies take part in the policymaking process were pioneered in areas like infrastructure development and policies for people living with disabilities. However, we have recently started to see similar examples in the field of healthcare, where activities to promote patient and public involvement (PPI) in the health policy formulation process have been advancing. For example, the voices of the parties most affected were the starting point for discussions that led to the enactment of the Cancer Control Act in 2006. That act obligates the Ministry of Health, Labour and Welfare (MHLW) and prefectural governments to include members with lived experience such as cancer patients, their families, or the bereaved on Cancer Control Promotion Councils. The inclusion of this requirement in the Cancer Control Act helped to establish a framework for ongoing PPI in the policy formulation process even after it came into effect. Similar initiatives inspired by such efforts for cancer control have also been launched in areas such as cardiovascular diseases (CVDs), intractable diseases, allergic diseases, and hepatitis and have contributed to the development of policies based on the needs of patients and citizens.

As we can see, a legal basis for PPI in the policy formulation process has been established, particularly for administrative bodies, where patients and citizens can serve as committee members. However, there are sometimes shortages of people willing to participate in policy making in their capacity as patients and citizens, so further efforts must be taken for more effective PPI in such settings. Some local governments have conducted open recruitment for patient and citizen committee members, but these efforts sometimes fail to attract applicants. Furthermore, even when patient and citizen committee members participate in meetings, they may have trouble following discussions on technical topics, or they may be unable to offer comments. From the perspective of encouraging a democratic policymaking process, as well, it will be important to address these issues and encourage PPI in policymaking. There are also high expectations that establishing a policymaking process that enables patients and citizens to more actively engage in PPI will lead to the creation of more democratic health policies.

Recognizing this, in FY2021, HGPI formed an advisory board of experts with experience serving as patient and citizen committee members and other specialists in this area for discussions on promoting PPI in health policy. Based on the findings of those efforts and with cooperation from broad stakeholders including patients and citizens, administrative officials, and academics, who participated in our interviews and other activities, we compiled the “Guidance on PPI in Health Policymaking” in March 2024. In hopes of seeing PPI implemented in the policymaking process as described in that Guidance, these recommendations summarize specific initiatives that must be taken, especially by central ministries and agencies as well as by local governments.

Policy recommendations

Patients and citizens possess valuable viewpoints that other stakeholders lack, and their knowledge and lived experience is a form of expertise. Their voices should be given adequate consideration in the health policy formulation process. The following recommendations outline necessary future actions for promoting the fair implementation of PPI in that process.

Recommendation 1: Reserve more than two seats for patient and citizen members so government committees can deliver a diversity of patient and citizen voices to policy.

The input of patient and citizen committee members in policy deliberations is critical to shaping policies based on the voices of those they most affect. Some committees currently have only one patient and citizen member, but it is practically impossible for one person to represent the broad range of patient and citizen voices. Furthermore, the expectations placed on those individuals as representatives of many patients and citizens result in significant psychological burdens. Addressing this will require establishing quotas for the inclusion of multiple patient and citizen members at every committee with PPI to gather the widest possible range of voices and to reduce the burden on patient and citizen committee members.

Recommendation 2: Ensure equal opportunities for involvement in government committees by establishing terms of office for committee members and by disclosing selection criteria for patient and citizen committee members in advance.

At certain administrative bodies, some committee members—including patient and citizen committee members—have been serving in their roles for many years. This has led to concerns that opportunities for participation in deliberation bodies may be unequal, or that current circumstances may result in bias in opinions gathered through committee members. Furthermore, some may distrust the appointment process if the criteria for selecting committee members are unclear, especially for patient and citizen committee members. To provide fair opportunities for participation in administrative bodies, terms of office should be defined for committee members, selection criteria for patient and citizen committee members should be disclosed in clear terms, and highly transparent selection processes should be adopted.

Recommendation 3: Enable patient and citizen committee members to effectively participate on government committees by establishing a comprehensive support framework.

Government committees on health policy include experts who serve on the provider side of healthcare, such as healthcare providers and researchers whose field of specialty is the healthcare system. In general, it is recognized that there is information asymmetry between those who provide healthcare and those who receive it. To enable both of these parties to be able to take part in effective discussions at government committees, steps must be taken to compensate for this information asymmetry and to establish a common language. Achieving this will place heavy burdens on patients and citizens, who are not healthcare specialists, so they must be provided with sufficient educational support, such as through explanations provided prior to committee meetings. In addition to efforts to ensure they are well-informed before meetings, patient and citizen committee members also require comprehensive support that includes providing reasonable accommodations toward the burdens they shoulder by attending meetings while living with diseases or disabilities, by establishing an environment that helps them offer comments during meetings, and by providing them with feedback after they finish their term of appointment to improve future PPI.

Recommendation 4: Draw upon a variety of PPI methods to overcome the limitations of government committees in gathering a broad range of patient and citizen voices.

Only a few people can participate in government meetings, and this imposes limitations when attempting to gather a diversity of patient and citizen voices. Some people also experience hurdles to involvement due to mobility, visual, or hearing impairments. While being considerate toward the physical environment to ensure that everyone can participate, it is also necessary to use PPI methods other than meetings, such as public comments, public hearings, workshops, and surveys. Taking into account their strengths and weaknesses, each method should be fully utilized to compensate for the limited representativeness resulting from the small number of patient and citizen committee members. Providing more opportunities for various parties to participate can help build experience with PPI and even elevate interest in the policymaking process among patients and citizens. In order to gather a diversity of patient and citizen voices and to increase public interest in the policymaking process, a variety

of PPI methods should be used effectively and in a manner that reflects the characteristics of themes and topics at hand, as well as the circumstances of each person who wants to participate.

Recommendation 5: Secure human resources for PPI in the policymaking process by identifying the necessary qualities for taking part in government meetings and developing a training system based on an integrated curriculum.

PPI in government committees is expanding in central ministries and agencies as well as in local governments. However, open recruitment for patient and public committee members by these administrative bodies sometimes fails to attract applications, especially at local governments. Securing human resources to serve as patient and citizen committee members has become an urgent issue. In addition, depending on the goals of a meeting body or the agenda, there may be certain conditions that patient and citizen committee members must meet. This means that potential participants must not only be willing to participate, but also meet these requirements. Educational and awareness-raising activities must be undertaken to generate interest in PPI in policymaking among many patients and citizens, as well as to train those who meet the necessary criteria. There are already several good examples of programs offered by private organizations and similar parties that provide patients and citizens with the training they need, but from the perspectives of patients and citizens, it can be difficult to know which course to take or to see a full picture of the necessary skills and requirements. An integrated curriculum that covers all of the necessary competencies and training for patient and citizen committee members must be designed and a training system based on that integrated curriculum must be established.

Recommendation 6: Develop guidelines on implementing PPI to provide a foundation for fair involvement in the policymaking process.

How to implement PPI in the policy formulation process and which specific methods of PPI to introduce must be considered in terms of factors like individual policy issues and the characteristics of the region in question. This means that the most effective methods for PPI may be highly situational. While allowing for a certain degree of freedom, guidelines on conditions where PPI is mandatory, methods of introducing PPI, and other necessary information must be formulated to ensure PPI can be implemented uniformly in the areas where it is needed. Guidelines on promoting fair citizen involvement have already been created in other fields. For example, the Ministry of Land, Infrastructure, Transport and Tourism (MLIT) compiled the “Guidelines for Public Participation in the Road Planning Process in the Conceptual Stage”¹ in 2005, and certain local governments have passed ordinances on citizen participation. While harmonizing with such guidelines, it will be necessary to compile guidance on promoting PPI in the health and welfare policy formulation process for use throughout Japan and to encourage the implementation of fair PPI based on that guidance.

¹ MLIT Road Bureau. “Guidelines for Public Participation in the Road Planning Process in the Conceptual Stage.” Retrieved April 2, 2024, from <https://www.mlit.go.jp/road/pi/2guide/guide.pdf>.

Acknowledgements

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About the authors

About Health and Global Policy Institute

Health and Global Policy Institute (HGPI) is a non-profit, independent, non-partisan health policy think tank established in 2004. In its capacity as a neutral think-tank, HGPI involves stakeholders from wide-ranging fields of expertise to provide policy options to the public to successfully create citizen-focused healthcare policies. Looking to the future, HGPI produces novel ideas and values from a standpoint that offers a wide perspective. It aims to realize a healthy and fair society while holding fast to its independence to avoid being bound to the specific interests of political parties and other organizations. HGPI intends for its policy options to be effective not only in Japan, but also in the wider world, and in this vein the institute will continue to be very active in creating policies for resolving global health challenges. HGPI's activities have received global recognition. It was ranked second in the "Domestic Health Policy Think Tanks" category and third in the "Global Health Policy Think Tanks" category in the Global Go To Think Tank Index Report presented by the University of Pennsylvania (as of January 2021, the most recent report)

About NCD Alliance Japan²

NCD Alliance Japan is a collaborative civil society platform operated by Health and Global Policy Institute (HGPI) for advancing countermeasures for prominent NCDs such as cancer, CVDs, diabetes, chronic respiratory diseases, and mental and neurological disorders. Since 2013, NCD Alliance Japan has served as the Japanese branch of NCD Alliance, a collaborative platform bringing together over 2000 civil society and academic organizations in more than 170 countries. NCD Alliance Japan became a full member of NCD Alliance on January 17, 2019. Through activities in the three fields of policy proposals, support for people living with NCDs, and survey research, NCD Alliance Japan aims to unite people living with NCDs and multi-stakeholders in industry, Government, academia, and civil society from Japan and overseas to contribute to addressing NCD-related issues.

About NCDs

According to the World Health Organization (WHO), the term "non-communicable diseases" or NCDs refers to chronic diseases such as cancer, diabetes, CVDs, chronic respiratory diseases, and mental and neurological disorders. These diseases tend to occur due to genetic, physiological, environmental, and behavioral factors and can be caused or exacerbated by unhealthy diet, physical inactivity, smoking, or excessive alcohol consumption. According to WHO statistics, NCDs are the cause of 71% of deaths worldwide and 82% of deaths in Japan,³ making NCDs an urgent issue.

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² NCD Alliance Japan uses the abbreviation "NCD" with the express permission of National Clinical Database (NCD), which is a registered trademark

³ World Health Organization (2018), "Noncommunicable diseases country profiles 2018"

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