

**Health and Global Policy Institute (HGPI) Patient and Public Involvement (PPI) Support Project**  
**Necessary Steps for Promoting PPI in Policy Making**  
**Second Advisory Board Meeting**  
**Event Report**

**Meeting background**

Under its stated mission of “Achieving citizen-centered health policy,” Health and Global Policy Institute (HGPI) has generated policy recommendations and engaged in a number of activities to promote patient and public involvement (PPI) in the health policy development process. In recent years, PPI in the administrative meetings where policies are created has expanded beyond ministries and agencies at the national Government to the local level at municipal governments. At the same time, a number of new issues have emerged. For example, too few people are willing to serve as patient and citizen committee members and committees thus tend to rely on the same people to serve repeatedly. Given these circumstances, starting in FY2023, the HGPI Patient and Public Involvement (PPI) Support Project has been working to encourage broader participation among patients and citizens in the policy development process. To advance this project, we have brought together representatives from industry, Government, academia, and civil society to form a multi-stakeholder advisory board. At our first advisory board meeting, our discussion examined the purpose of PPI in policy formulation and the necessary roles, qualities, and other characteristics of patient and citizen committee members. Our second meeting looked back on past discussions and hearings and examined how to best structure the policy development process to reflect diverse voices from patients and citizens, the support needed for patient and citizen committee members, and the necessary measures to secure adequate human resources for PPI.

**Minutes****■ Diversifying opportunities for PPI in the policy formulation process and past developments in democracy**

Citizens have had increasing opportunities to take part in the policy formulation process in recent years. In the past, the main methods for citizens to participate were to express their opinions in demonstrations and similar activities or to petition authorities on an individual basis. Recently, processes like public hearings and public comments have made it possible to gather a wide range of opinions. It is also becoming common for citizens to participate in administrative meetings as committee members. Administrative meetings come in a variety of forms at both the central Government and local governments and include councils and other central meetings as well as sectional meetings like subcommittees. There are also a variety of purposes such meetings are held as well as for having citizens participate in them, so it will be necessary to promote effective PPI that is tailored to each type of meeting.

In its final stage, an ideal democracy would not be a place where the leading actor in PPI is the government. Rather, it would be a place where citizens are the driving force behind PPI with the government providing support. Citizens are randomly selected to participate in some systems like the jury system or in certain municipal-level initiatives, and these could be viewed as steps in the evolution of a citizen-centered policy formulation process. However, from a citizen’s point of view, suddenly taking part in government meetings and taking charge of decision-making is no easy task.

The popularization of online video streaming services also means that more meetings are being broadcasted live for public viewing. While this practice is invaluable in terms of transparency for the proceedings, it can prevent free, lively discussions in which participants go beyond merely stating the opinions of the organizations or interests groups to which they are affiliated. While keeping such challenges in mind, expectations are high for efforts to identify necessary initiatives for effectively implementing PPI in meetings and the future creation of a policy formulation process which is citizen-centered and supported by the government.

**■ Achieving fair and effective PPI in meetings**

One objective of PPI is to communicate the heretofore unrecognized issues and needs of patients and citizens to policy. This can be considered a social model-based approach to identifying solutions to the problems patients and citizens face in society over the course of daily life. Given the diversity in values related to daily life, however, it can

be difficult to tell if the opinions expressed by patient and citizen committee members are universal. Rather than seeking substantive justice by assessing the content of statements and their results, we should seek procedural justice by evaluating patient and citizen committee member participation using an impartial process. More specifically, it is desirable that there are multiple patient and citizen committee members, for committee members to have set term limits, for committee members to be selected via random sampling or other highly impartial selection methods, and for committee members to be selected through third-party organizations.

Other members of such committees are people like representatives of professional associations and members of academia. In addition to a gap in organizational capacity between members of such organizations and patient and citizen committee members, who are participating as individuals, there is also information asymmetry regarding healthcare among healthcare professionals and patients. Patients may also face additional burdens when participating in such meetings due to health conditions. Given these challenges, patient and citizen committee members must be supported so they can participate effectively. Secretariats that operate meetings, chairpersons, and other committee members should be considerate toward patient and citizen committee members to make it easier for them to speak. Doing so might include addressing information asymmetry (such as providing advance explanations and training) or making reasonable accommodations for illnesses or disabilities. As the specific purpose of PPI is to identify the needs of patients and citizens, it is vital for the opinions of laypersons which are not based on specialized medical knowledge to be heard. This means it is necessary to establish an environment where patients and citizens who do not possess such knowledge can take part in discussions. Such support carries the risk of creating bias in statements from patient and citizen committee members, so support should be provided by a neutral third party. It would be a good idea to recruit people with past experience serving as patient and citizen committee members or working with government agencies to provide accompaniment and support.

Due to the heavy burdens that come with participating in government meetings and because their opinions are as valuable as the other experts, patient and citizen committee members should also be provided with fair compensation. From a research ethics perspective, researchers have traditionally been hesitant to provide subjects with financial compensation to avoid conflicts of interest, but after a shift in recent years, little or no compensation is starting to be viewed as a form of exploitation. As long as there is no unfair inducement, in a general sense, fair compensation may help secure participation from patient and citizen committee members and should be provided.

In addition to before and during meetings, patient and citizen committee members also require support after meetings. Rather than allowing their involvement to end with the meeting they joined, to ensure they can participate effectively in the future, it is important to follow up with them afterwards. A system has been introduced for providing committee members with feedback based on their attendance history and comments at ethics committee meetings. Expectations are high for such initiatives to be used as a point of reference when providing follow-up evaluations to participants.

#### ■ **Leveraging diverse participation opportunities to broaden the scope of PPI**

As discussed above, there are a variety of methods that patients and citizens can use to give input on health policy, such as by participating in meetings of various scales at the central Government or local governments, or through public hearings and public comments. There are also opportunities for community members to meet with government officials at meetings hosted by the government like hearings and town halls.

Subcommittees, individual hearings, and other such processes make it possible to collect a broad range of opinions from patients and citizens that could not be gathered in just a few meetings. Taking part in these processes also provides patients and citizens with opportunities that are similar to on-the-job training (OJT). Given the difficulty of taking part in large government meetings, it is unrealistic to expect people to be able to do so without a certain amount of experience. Building initial experience participating in smaller-scale meetings, hearings, and other processes is likely to help participants grow accustomed to such settings and motivate them to participate in the future.

#### ■ **Building systems for training patients and citizens and disseminating information to promote PPI**

While patient and citizen committee members must be provided with training and explanations for each meeting

they attend and steps must be taken to create an environment that allows them to participate without specialized knowledge or experience, there are also a number of items that all patient and citizen committee members should learn in advance. It will be important to prepare a complete set of necessary knowledge and to create an environment that ensures anyone can undergo training to acquire that knowledge for free and in an easily accessible form, such as through e-learning. Expectations are also high for the establishment of a system that utilizes records of participation in said comprehensive training as well as individual experiences to facilitate matching among patients and citizens and the government.

In addition to establishing that system, actions must be taken to encourage more patients and citizens to participate. Many of those who have experienced a disease want to use their experiences to help others with the same disease. However, many people do not know that patients and citizens participate in various fields like pharmaceutical development, medical research, and health policy. In many cases, it is minor incidents of chance that encourage people to get involved. Effective methods of reaching out to potentially interested patients and citizens should be examined. These might include, for example, placing leaflets about participating in health policy at health institutions visited often by people who have experienced health concerns. Effective methods of helping patients and citizens actually want to participate might include portraying PPI as an opportunity to contribute to society, sharing concrete past examples of what led people to get involved, and sharing the fruits of their participation.

Compared to people who have experienced a disease, those with no such experience are less likely to be interested in healthcare and will require a different approach. Many people take an interest in healthcare after learning basic medical knowledge and after recognizing the fact that anyone can develop a disease. Other efforts to broadly inform the public about healthcare are also advancing, including those from companies that aim to build awareness among employees. Efforts must be made to help more people take an interest in healthcare through such activities.

## Acknowledgement

This report summarizes the discussions at the First Advisory Board Meeting, which was attended by the following Advisory Board members. We would like to express our deepest gratitude to all those who participated in this meeting. This report is a neutral summary compiled by HGPI in its capacity as an independent health policy think tank, and should not be taken to represent the views of any advisory board member, or any other organization to which they are affiliated.

### ■ Advisory Board Members (Titles omitted; in Japanese alphabetical order by last name, absent members included)

**Kyoko Ama** (Representative, Children and Healthcare Project; Fellow, HGPI)

**Shinsuke Amano** (Chair, The Japan Federation of Cancer Patient Groups; CEO, Group Nexus Japan)

**Etsuko Aruga** (Professor, Department of Palliative Medicine, Teikyo University School of Medicine)

**Naomi Sakurai** (President, Cancer Solutions Co., Ltd)

**Takeshi Shukunobe** (President and CEO, PPeCC)

**Kazuyuki Suzuki** (Senior Lead, Patient Engagement Group, Strategy & Execution, Novartis Pharma K.K.)

**Yasuhiro Sensho** (CEO, SENSHO-GUMI, Co., Ltd.; Former Director-General, MHLW)

**Teppe Maeda** (Lawyer, Maeda & Unosawa Law Offices; Representative, Medical Basic Act Community)

**Kaori Muto** (Professor, Department of Public Policy Studies, Institute of Medical Science, University of Tokyo)

**Akira Morita** (Representative Director, Next Generation Fundamental Policy Research Institute (NFI))

**Ikuko Yamaguchi** (Chief Director, Consumer Organization for Medicine and Law (COML))

**Risa Yamazaki** (Public Affairs Group, External Affairs Department, Chugai Pharmaceutical Co., LTD.)

### ■ Event Overview

Date and time: Friday, December 8, 2023; from 17:00 to 19:00

Venue: Hybrid format (Zoom conferencing system and in-person participation at the venue)

### **About Health and Global Policy Institute (HGPI)**

Health and Global Policy Institute (HGPI) is an independent, non-profit, 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 is very active in creating policies for resolving global health challenges.

### **About NCD Alliance Japan<sup>1</sup>**

NCD Alliance Japan is a collaborative platform operated by HGPI for engaging civil society and promoting countermeasures for non-communicable diseases (NCDs) including cancers, cardiovascular diseases (CVDs), diabetes, chronic respiratory diseases, and mental and neurological disorders. NCD Alliance is a collaborative platform bringing together over 2000 civil society organizations and academic institutions in more than 170 countries, and NCD Alliance Japan has operated as its Japanese branch since 2013. NCD Alliance Japan became a full member of the NCD Alliance on January 17, 2019. Through three key activities, which are formulating policy proposals, supporting people living with NCDs and other parties affected by NCDs, and conducting survey research, NCD Alliance Japan aims to unite those most impacted by NCDs with multi-stakeholders in industry, Government, academia, and civil society from Japan and abroad to contribute to solving issues in the field of NCDs.

### **About NCDs**

According to the World Health Organization (WHO), the term “non-communicable diseases” refers to chronic diseases including cancers, diabetes, cardiovascular diseases (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 worsened by unhealthy diets, insufficient exercise, smoking, or excessive alcohol use. According to WHO statistics, NCDs are the cause of 82% of deaths in Japan and 71% of deaths worldwide, making the establishment of NCD countermeasures an urgent issue.<sup>2</sup>

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<sup>1</sup> NCD Alliance Japan uses the abbreviation “NCD” with the express permission of National Clinical Database (NCD), which is a registered trademark.

<sup>2</sup> World Health Organization (2018), “Noncommunicable diseases country profiles 2018”