

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

**Purpose of the event**

Health and Global Policy Institute (HGPI) has offered policy recommendations and taken a number of other activities to promote patient and public involvement (PPI) in policy development process, under our stated mission of “Achieving citizen-centered health policy.” Recently, initiatives for PPI in processes of health policy development are now being advanced at both the national Government and local level at councils. However, new issues have been recognized consequently, which include lack of the diversities in and the number of individuals who desire to be involved. Based on our recognition of these issues, our PPI Support Project this year aims to promote the involvement of diverse patient and public representatives into policy development process. In the 1st advisory board meeting, advisory board members from industries, government officials, academia and civil society discussed the purpose and meaningfulness of PPI in policy development and roles that is required to patient and public representatives in governmental discussion committee.

**Summary of the discussion****■ The significance of patient and public involvement (PPI) in Government meetings**

Examining past trends in democracy, it is safe to say that society has gradually transitioned from a representative democracy, in which policies are determined by public representatives elected through electoral systems, to a participatory democracy, in which citizens work with governments to create policies through demonstrations and other forms of opposition. In this context, we can view government meetings as opportunities for citizens to collaborate in policy-making.

Unlike public comments, hearings, and other opportunities during which citizens can participate in the policy-making process, government meetings are characterized by their potential for two-way communication and for gathering stakeholders with different ideas for discussions. These elements have significant impacts on policy making. Specifically, these meetings provide opportunities to: (1) collect opinions (when government representatives are unsure of what kind of bill to draft, they can solicit and collect committee member opinions); (2) receive approval (for bills proposed by the government that are deliberated upon and approved); (3) address conflicts of interest (when participants who disagree on certain issues discuss their differences and reconcile their interests); and (4) display legitimacy (of the policy formulation process, which is legitimized to outside parties by the fact that key issues have been thoroughly discussed and that conclusions have been reached).

In healthcare policy, traditionally, it has been rare for patients/citizens to participate in policy-making bodies as committee members, and policies have mainly been created by stakeholders on the side of healthcare providers. There are times this process does not produce policies that are acceptable to patients and citizens, so patient/citizen committee members have been joining many meetings in recent years. As stakeholders representing healthcare beneficiaries and taxpayers, patient/citizen committee members are invaluable for their ability to help prevent discussions from veering in directions that do not align with the interests of those most affected by health policy and to introduce the specific needs of such parties as matters of policy. In fulfilling such roles, they are contributing to the formulation of fair, effective healthcare policies that are based on the needs of patients and citizens.

**■ Is representativeness required of patient/citizen committee members?**

As patient/citizen committee members who participate in government meetings are considered to be representatives of patients and citizens, they must be mentally prepared to represent specific groups of stakeholders. As advocates overseas have pointed out, when doing so, they must recognize the importance of “Saying ‘We’ and not ‘I’” to speak for others. Then, before participating in meetings, they must obtain a grasp of the real needs of many patients and citizens over the course of their daily activities (such as consultation support activities).

However, when someone is working to represent the interests of patients and citizens, it has been pointed out that it can sometimes be unclear exactly whose interests they are meant to represent, and that it is practically impossible for individual committee members to represent the opinions of every patient and citizen. This means patient/citizen committee members must be aware that their own opinions may be biased. In fact, there have been examples in which the findings of large-scale government surveys differed from those of hearings conducted with patients and their families by patient/citizen committee members. Because of this, it is particularly important for patient/citizen committee members to understand the needs of citizens who are unable to speak up for themselves or who are living with diseases.

Considering these circumstances from the perspectives of political thought and democracy, there is a difference between patient/citizen committee members who participate in government meetings and legislators, whose legitimacy as representatives is reinforced by the electoral system. Patient/citizen committee members do not necessarily need to serve as representatives of specific stakeholders, but they do need to help crystallize and generalize problems and needs from the perspectives of patients and citizens and then deliver that information at meetings. They do not need to serve as representatives of specific groups or organizations in order to be involved. However, representing larger groups or organizations makes it possible for them to crystallize the needs of more people, so it can be a positive factor if patient/citizen committee members represent groups or organizations.

Other important efforts will be building understanding toward the difficulty of representing the voices of patients and citizens among patient/citizen committee members, government representatives, and other committee members, and encouraging the involvement of multiple patient/citizen committee members in each meeting. Being proactive about accepting patient/citizen committee members from different age groups and from various backgrounds and setting suitable terms of office to prevent committees from becoming overly reliant on the same individuals for each meeting will help ensure diversity among patient/citizen committee members while expanding representativeness. Efforts must also be devoted to specifying whose interests they are representing by clearly documenting, in advance, the purposes of meetings and criteria for selecting patient/citizen committee members. As local governments are experiencing great difficulties in recruiting patient/citizen committee members and are over-reliant on specific patient/citizen committee members, the government also has a major role in helping to plan and administer meetings.

#### ■ **Enabling patient/citizen committee members to speak effectively at meetings**

A broad variety of specialists participate in government meetings, so those who wish to make effective statements at such meetings must possess a certain degree of knowledge, understand the purpose of the meetings, and have communication skills.

In the field of medicine, there is said to be a great amount of information asymmetry among those who provide healthcare and the patients and citizens who receive it. Given this context, for people from both sides to be able to take part in discussions, they must first possess basic knowledge about healthcare to serve as a common language. Depending on the meeting, there are also times it is best for patient/citizen committee members to have a detailed understanding of topics like the process of pharmaceutical development or the rules surrounding the pharmaceutical industry.

Furthermore, holding discussions with stakeholders in different positions requires communication ability and cooperation. Participants must understand each other and work together, even when they are approaching a subject from different positions and do not see eye-to-eye. At the same time, when encountering conflicts of opinion with other stakeholders, it is also important for participants to be able to express the reasons for their disagreement or to bravely and calmly speak up about the real needs of patients and citizens. Other important skills include presentation ability and the ability to express oneself effectively, such as by providing remarks that respect the subjective voices (the narratives) of affected parties or that are logical, all while keeping the discussion process in mind. It is also important for participants to come into meetings with an understanding of government meeting processes. In addition to understanding policy and government meetings themselves, this means having the ability to convey one's thoughts or to raise discussion points in a concise manner when time is limited and knowing how to present reference materials.

While patient/citizen committee members are not the only participants who require these skills, learning them can pose a heavy burden, especially in a field where there is a great amount of information asymmetry like the field of healthcare. Rather than leaving this acquisition of skills up to the efforts of patient/citizen committee members, overcoming this issue will also require devoted efforts from government representatives and other committee members.

■ **Handling social networks when gathering opinions**

On the topic of handling social networks when aggregating opinions, social networks allow people with shared senses of value or opinions to gather, which carries the risk of bias. It can also be difficult to rely on individual influencers to represent the opinions of society as a whole. Social networks can foster biased opinions, as well. This occurs due to the filter bubble problem, in which social network users only see the information that they want to see. There is also the framing effect, in which the impression given off by information changes according to how it is conveyed, which can influence decision-making. Social networks also contain comments that are made with the intent to manipulate or offend, so opinions from social networks should be handled with caution and not be directly applied during policy making. At the same time, people can use social networks to grasp the true feelings of the general public and to encounter different opinions, which means social networks can be useful tools for grasping diversity in society as a whole.

## **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: Tuesday, October 3, 2023; from 17:30 to 19:30

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”