

The Health and Global Policy Institute (HGPI) Platform Project for Patient and Public Involvement

Policy Recommendations – Further Promoting Patient and Public Involvement in the Policy-Making Process

Steps for Achieving Healthcare Policies That Are Truly Centered on Patients and Citizens

July 2022

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Introduction

Introducing 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.

Introducing NCD Alliance Japan¹

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.

Defining 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.²

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

² World Health Organization (2018), “Noncommunicable diseases country profiles 2018”

Policy Recommendations – Further Promoting Patient and Public Involvement in the Policy-Making Process

Executive summary

Since its establishment in 2004, Health and Global Policy Institute (HGPI) has operated with the mission of serving in its capacity as a neutral think tank to involve stakeholders from wide-ranging fields of expertise to provide policy options to the public and successfully create citizen-focused healthcare policies. This concept is assigned great value in every HGPI project, and in almost every opportunity for discussion that we create, patients and other affected parties in the disease area in question participate alongside representatives of industry, the Government, the legislature, and academia. After identifying policy issues and considering next steps through fair and equal discussions with multi-stakeholders representing industry, Government, academia, and civil society, we work to synthesize our discussions into policy recommendations and publicize them.

Alongside various changes in the environment surrounding healthcare in recent years, the medical community as a whole has started expanding patient and public involvement (PPI) in many aspects of conducting research and formulating policy to achieve better healthcare. For example, regarding PPI in the field of medical research and clinical trials, the Japan Agency for Medical Research and Development (AMED) conducted the Survey of Trends in PPI in Clinical Research according to the Plan for Promotion of Medical Research and Development enacted by the Headquarters for Healthcare and Medical Strategy Promotion in 2014. That survey identified the need to promote PPI, and AMED created “The Patient and Public Involvement Guidebook: First Steps for Collaboration Among Patients and Researchers.”

From the perspective of the policy-making process, there was momentum for involving those most affected by policies in policy creation in fields like community development and environmental problems earlier than in health policy. In the field of disability welfare policy, which is close to health policy, during the process of creating the Convention on the Rights of Persons with Disabilities (CRPD), which was adopted by the United Nations in 2006, many people living with disabilities around the world got involved under the slogan, “Nothing About Us Without Us.” This development influenced many policy fields. In recent years, there have been many cases in which involving people with disabilities in such forums became mandatory, and there have been many academic studies conducted on the methods and effects of their involvement. In health policy, PPI has also started to take root in various disease areas like dementia and mental disorders, and is mainly represented by the Basic Act on Cancer Control of 2008 and the Basic Act on Cardiovascular Disease Measures of 2018. Discussions that led to the enactment of these laws started with the voices of patients and, after they were enacted, patients and citizens have been involved as

members of councils and other discussion forums for drafting plans. Also in recent years, some countries and regions have started developing laws that not only aim to respond to certain diseases, but to also uphold patients' rights. In Japan, the Parliamentary Association for the Enactment of the Basic Act on Medical Care was established in 2019 with the objective of enacting a basic act for medical care that is centered on upholding the rights of patients.

However, patients and citizens who have participated in study groups and committees hosted by the national and local governments have pointed out various issues. These include both operational issues, such as not being able to participate completely, as well as issues related to participants themselves. For example, some people are unable to fully express their own opinions even when presented with the opportunity to do so.

Given this backdrop, in FY2021, HGPI brought together opinion leaders in this field from industry, Government, academia, and civil society to hold two advisory board meetings and to conduct individual hearings with committee members to examine concrete next steps for more effective PPI in policy-making forums.

As pointed out at the advisory board meetings for this project, there are still many issues to be addressed for PPI in the field of health policy. These are not only issues that lie with policy decision-makers in the government or legislature; there are many cases in which there are issues among the patients and citizens who participate, as well. There are also points of improvement among industry and academia, who are collaborating parties in policy creation. The following policy recommendations were compiled by the secretariat at HGPI with the aim of further promoting PPI in health policy and are based on discussions held at our advisory board meetings and individual hearings conducted for this project in FY2021 as well as on past HGPI activities.

The policy recommendations are presented from three perspectives:

Perspective 1: Establishing an environment for PPI

Perspective 2: Participation in the policy-making process

Perspective 3: Following up on policy implementation

Based on these three perspectives, we will identify next steps for further promoting PPI in health policy in the future.

Perspective 1: Establishing an environment for PPI

Discover and educate patient advocate leaders on a continuous basis and provide support for their activities to prevent the burdens of that role from becoming concentrated on certain individuals

A challenge facing many disease areas is that people who can serve as patient advocate leaders are limited to a certain few, which places heavy burdens on them. To ensure continuous activities for patient advocate leaders in each disease area, various people of different genders, ages, and locations must be identified and trained. This is also necessary to ensure active participation from diverse patient advocate leaders. To achieve a policy-making process that is based on sound democracy, it will be essential to ensure there are opportunities for people who are minorities and in vulnerable positions to express their opinions. In the context of health policy, this refers to patients and other healthcare beneficiaries. In addition to financial support for activities, support can take many forms, such as providing forums, opportunities, and information. It will be necessary for stakeholders other than patients and affected parties to consider which forms of support are feasible for them to provide within their respective restrictions and to provide support after matching it to the needs of patients and other affected parties.

Secure educational opportunities to provide the necessary knowledge and grounding while promoting PPI in the policy-making process

To participate in the policy-making process and engage in effective activities, in addition to specific knowledge regarding the policy field in question, people must also know about policy-making itself. Furthermore, to be able to collaborate with other stakeholders, they must also deepen their knowledge regarding other people or organizations. This may include the structure and culture of those organizations. In addition, they will need to have positive attitudes toward active collaboration and cooperation. In many cases, patients and citizens do not have this knowledge and background from the start of their activities, so when there are opportunities for PPI, they must be provided with opportunities to acquire this knowledge in advance. To prevent PPI from becoming a mere formality, patients and citizens engaged in it must show a willingness to learn, and each stakeholder must share the knowledge and information they possess to work toward achieving a sound policy-making process.

➤ **The roles of the national Government, local governments, and the Diet**

Provide opportunities for people to obtain basic knowledge regarding the policy-making process or legal systems related to social security and to deepen their understanding regarding how the national Government, local governments, and Diet are organized or operate.

➤ **The role of industry**

Make the information (mechanisms, characteristics, etc.) regarding pharmaceuticals and medical devices held by industry or each company transparent to the greatest extent possible and publicize said information in easy-to-understand formats, such as on websites.

➤ **The roles of academia and think tanks**

Publicize information regarding the latest medical evidence in the disease area in question and policies or examples from other countries using language that can be easily understood among people who are not specialists.

➤ **The roles of patient advocacy organizations**

Demonstrate a clear willingness to collaborate with people who can participate as new patient advocate leaders, members of the general public, and other stakeholders, and publicize the content of activities in an easy-to-understand manner.

➤ **The role of the media**

While emphasizing scientific evidence, convey information regarding the latest medical expertise and policies in various disease areas and be proactive about establishing opportunities for the stakeholders mentioned above to broadly publicize their activities.

Create opportunities for patient advocacy organizations from different disease areas to collaborate and interact

By disease area, there is significant variation in scale of activities and amount of experience possessed by patients and other affected parties. This means opportunities must be provided for patient advocate organizations from different disease areas to interact. Doing so will enable patient advocate leaders in disease areas with smaller pools of experience to learn from the experiences of those in areas where more progress has been made. It will also be necessary to build an environment in which patients and other affected parties who might not belong to advocacy organizations can participate in those interactions, as well as to secure opportunities for everyone to engage in PPI according to their own circumstances.

Refer to activities undertaken for PPI in fields of policy other than health policy, and adopt and disseminate practices found to be more effective

As mentioned above, PPI in the policy-making process has been implemented in various fields adjacent to the field of health policy, like community development, environmental issues, and disability welfare. Many of these areas have long histories of PPI, and the effectiveness of the

methods used in their activities has been verified in academic terms in many areas. We must refer to examples from policy fields other than health policy and actively adopt their practices to pursue effective PPI.

Perspective 2: Participation in the policy-making process

Utilize opportunities for expressing diverse opinions to build recognition of issues among a greater number of patients and citizens

The first step in enacting or improving policies is to make the Government or Diet aware that a policy response is required to resolve a current issue facing society or in how our systems currently operate. To do so, patients and citizens must be proactive about expressing those issues and heighten interest among the general public and policymakers. Such movements can also start from efforts in industry or academia, so it will be necessary for patients and citizens to use various channels to communicate the issues they feel are relevant. At the same time, it is also safe to say that for sustainable PPI, it will be important for other stakeholders to be aware that patients and citizens are a type of specialist, to treat them with respect when interacting with them, and to provide them with adequate compensation for the time and expertise they contribute.

➤ **The roles of the national Government and local governments**

Instead of only allowing certain patients or advocacy organization representatives to participate in forums for expressing opinions, secure opportunities to enable as many patients and citizens as possible to express their opinions using methods like personal interviews or hearings, surveys, and workshops.

➤ **The role of the Diet**

In their capacity as Diet members, members of the Diet should engage in communication with many patients and citizens and actively deliver the opinions they gather to the national and local governments.

➤ **The role of industry**

In addition to fulfilling the role of industry, stay up-to-date on the issues faced by patients and citizens as users and utilize that information when issuing policy recommendations from companies or business groups.

➤ **The role of academia**

Based on the concept of PPI in medical and clinical research, always include the perspectives of patients and citizens when setting research topics or issuing policy recommendations.

➤ **The role of the media**

When presenting information related to healthcare, incorporate the perspectives of

patients and citizens in addition to those of the Government, industry, and academia.

Make the necessary considerations to ensure patients and citizens with insufficient specialized knowledge can participate in discussions

Even if the aforementioned educational opportunities are provided, there are many cases when patients and citizens who participate in policy-making forums have less experience and knowledge than other stakeholders regarding activities in the disease area. This means other participants and meeting organizers must ensure these patients and citizens have chances to fully comprehend the content of discussions and to have their questions answered to ensure they can participate on truly equal terms.

Participating in policy decision-making does not only mean participating in discussion forums. Public comments during the formulation of laws, regulations, and all types of government plans provide another important opportunity for patients and other affected parties who do not participate in discussions as committee members to present specific policy recommendations. The administration should take steps to ensure various opportunities for participation like public comments and, whenever possible, disclose what actions were taken in response to comments received.

- **The roles of the national Government and local governments**
Reexamine how to best operate meetings to prevent PPI from becoming a formality, such as by providing explanations on meeting content in advance or by establishing guidelines or assessment criteria for meeting operations.
- **The roles of industry and academia**
Use language that is easy to understand for patient and citizen committee members in attendance and show a willingness to cooperate.
- **The roles of patient advocacy organizations**
Avoid placing oversized burdens on patient and citizen committee members who participate in discussions, such as by creating support opportunities like reading through meeting reference materials together in advance; or by creating support systems that help them adequately express their opinions, such for creating reference materials.

Patient and citizen committee members who join discussions must channel society-wide issues in addition to communicating their own issues, and organize and communicate those issues in a

manner other stakeholders can understand

While cooperation from other stakeholders is required to engage patient and citizen committee members, patient and citizen committee members must also make sure they are communicating their thoughts to other stakeholders in a manner that is easy to understand. The direction of discussions must be set by allocating a limited amount of time for each person's comments, which demands sophisticated organizational skills. Speakers must keep to their allotted time during discussions, prepare their own issues and main points, and communicate those points in a logical manner. These conditions are the same for patient and citizen committee members, whose contributions to discussions should not be limited to their personal experiences. In addition to those personal thoughts, they must also serve as representatives for patients and citizens and cover general issues as much as possible. This means they must determine the priority of items and prepare their points in advance so those points can be communicated in a manner other stakeholders can comprehend. Discussion forums can be utilized to gain understanding from other stakeholders and encourage collaboration if patient and citizen committee members maintain a sense of calm and present their points logically while sometimes expressing their emotions.

Perspective 3: Following up on policy implementation

Continue working to ensure policies are implemented in the intended manner after they are finalized

The implementation phase that comes after a law has been enacted or a system has been established is an important part of the policy-making process. During this phase, patients and citizens must confirm that the finalized policy is being implemented or is functioning as originally intended. In the event a policy is not being implemented as originally intended, patients and citizens must actively approach the officials serving in the national and local governments who are responsible for its implementation. Monitoring politics and the Government is one of the key roles of both citizens and the Diet. In health policy, patients and affected parties must play central roles in that monitoring as they work to engage the general public.

- **The role of the Diet**

Check if finalized laws and systems are being implemented as originally intended, with the included perspective that they are based on the needs of patients and citizens who are affected by the policy in question.

- **The roles of academia and think tanks**

Assess policy implantation status and communicate findings to society. When doing so, include specific data.

- **The roles of patient advocacy organizations**

Conduct hearings and surveys regarding policy implementation status among patients and other affected parties belonging to and outside one's organization, then summarize and disseminate findings on the current status.

➤ **The role of the media**

Incorporate the viewpoints of patients and other affected parties when reporting on or assessing policy implementation status.

Patients and citizens must be actively involved in policy assessment to further improve policies

Opportunities for policy assessment are important for identifying future policy issues as well as for creating a virtuous circle in the policy-making process. It will be necessary for patients and citizens to cooperate with industry and academia and, in a continuous manner, communicate their opinions on changes patients and other affected parties experienced due to implemented policies and what points of improvement there are to address next. Patients and citizens who take part in the policy-making process in a specific policy area over the medium to long term will foster trusting relationships with other stakeholders, which will help them become recognized as key players in the policy-making process. This cycle will lead to collaboration among broad stakeholders in the policy-making process.

Advisory board**Advisory board members (titles omitted; in alphabetical order)**

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

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

Yoshiko Kobata (Director, CSR Promotion Office, General Affairs Bureau, Fuji Television Network, Inc.)

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

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

Special advisor (titles omitted)

Yuji Inokuchi (Vice-President, Japan Medical Association)

These recommendations were compiled by HGPI in its capacity as an independent health policy think tank based on discussions at meetings held for this project. They should not be taken to represent the opinions of any specific advisory board member or other related party, or to any organization to which they belong.

Advisory board meeting details

First meeting: Tuesday, November 9, 2021; from 18:00-19:30

Second meeting: Thursday, January 27, 2022; from 18:00-19:30

In light of the circumstances surrounding COVID-19, both meetings were held remotely with an online conferencing system.

Key discussion points from advisory board meetings

Discussions held at advisory board meetings examined the current situation surrounding PPI and future solutions with the goal of achieving more significant PPI. Key points from the meetings are summarized below.

- **Establish an environment in which all citizens can learn about social security systems including the healthcare system**

Based on experiences from the COVID-19 pandemic, it will be necessary for citizens to learn about

the structure of health insurance and healthcare services to foster broader recognition toward problems facing healthcare and social security in the context of healthcare as a social infrastructure. This can begin with topics close at hand, like health self-management or how to make the most out of visits to healthcare institutions. An environment must be created in which citizens are given opportunities to learn about these topics during school education and, for adults, through corporate benefits programs.

- **Make the policy-making process more transparent**

For patients and citizens, there are still many aspects of the policy-making process that are unclear. Steps must be taken to further expand live online broadcasting of meetings at the national and local governments that are open to the public. The policy-making process must also be made more transparent, such as by establishing guidelines for selecting patient and citizen committee members and making that selection process more visible.

- **Make the operations of meetings held by the administration subject to third-party assessment**

There are no uniform methods for operating government meetings and the level of PPI can vary depending on the discretion of meeting organizers. A mechanism is necessary that encourages improvement by having neutral third-parties conduct comprehensive assessments based on certain criteria and disclose their findings to the public. Such criteria might include confirming if diversity and neutrality were considered during committee member selection, or if steps are being taken to ensure transparency, such as by disclosing information like reference materials or minutes.

- **Ensure diversity among patient and citizen committee members instead of requiring them to represent their respective groups**

As with every stakeholder, having a limited number of patient and citizen committee members restricts the scope of representation at meetings. From the perspective of meeting involvement, steps must be taken to ensure diverse opinions are being expressed. This can be accomplished by gathering opinions before meetings are held, or by using other methods of PPI such as hearings, workshops, questionnaires, and public comments.

- **Arrange and provide the knowledge patients and citizens need to serve as committee members**

Educational content must be created so people can, in a systematic manner, acquire the knowledge they need to serve as patient and citizen committee members and to have constructive discussions. There are many cases in which gathering that information or knowledge depends on the ability of

the individual serving as a committee member. It will be necessary to establish resources where information and knowledge from each stakeholder is gathered and provided, from knowledge required of all patient and citizen committee members to the knowledge required for activities in a specific disease area.

NCD Alliance Japan seminars for patients and other affected parties

First seminar: Tuesday, December 7, 2021

“The Significance of Reflecting the Voices of Patients and Other Healthcare Beneficiaries in Policy”

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

Key points of the lecture

- Four ways citizens can get involved in reflecting the voices of affected parties in policy are submitting public comments, forming organizations, observing study groups and other meetings, and becoming members of study groups or other committees.
- Aspiring participants must process their lived experiences as individuals and engage in constructive opinion exchanges with broad stakeholders.
- Aspiring participants do not need to learn vast amounts of information from specialized fields like healthcare professionals and expert committee members do, and they should recognize the importance of speaking from the viewpoints of members of the general public.
- The most important action for a patient committee member to take is to listen closely to the voices of those most affected.

For details, please visit: <https://hgpi.org/en/events/ncd-20211207-1.html>.

Second seminar: Tuesday, February 22, 2021

“The Hospitals We Need in the Era of COVID-19: The Need for Wi-Fi in Hospital Rooms”

Mr. Shinsuke Kasai (Freelance Announcer; #Hospital Room Wi-Fi Council)

Key points of the lecture

- In-person visitations continue to be restricted or suspended to prevent the potential spread of COVID-19, but many patients say they are saved by the feelings they get from remote visitations. “Hospital room Wi-Fi” is becoming a new standard criteria when selecting a hospital.

- The current presumption that Wi-Fi is only a source of leisure for patients no longer applies in the era of COVID-19. Hospital room Wi-Fi is actually a lifeline.
- In September 2021, we conducted our first nationwide survey, “Every Room At This Hospital Has Wi-Fi! The Grand Survey.” We have presented in-room Wi-Fi introduction rates by prefecture and municipality and a list of hospitals where every room has Wi-Fi on our homepage, which has made an impact.
- Based on the nationwide survey mentioned above, Iwate Prefecture introduced free Wi-Fi in every room in all its prefectural hospitals. It is important to drive policy by involving multi-stakeholders, including the Government.

For details, please visit: <https://hgpi.org/en/events/ncd-20220222-1.html>

Acknowledgements

Over the course of planning and operating this project since its start at the beginning of FY2021, we have received input from many people representing industry, Government, academia, and civil society. In particular, we would like to express our deepest gratitude to the members of our advisory board, who provided expert advice and support for the objectives of these recommendations; to Dr. Yuji Inokuchi (Vice-President, Japan Medical Association), who served as special advisor to this project; and to the many experts who joined our hearings. Please note that, as a general rule, the affiliation and position listed for each participant reflects those at the time of advisory board meetings and that they may differ from current affiliations or positions.

Furthermore, in pursuit of its mission of “achieving citizen-centered healthcare policy,” HGPI collaborates with a wide variety of patients and other affected parties in many projects. These policy recommendations were, in large part, born from collaboration with those parties, and we at HGPI once again express our gratitude to all patients and other affected parties who worked with us.

Please note that these recommendations are a compilation of opinions shared at hearings and discussions held over the course of this project that were gathered by its author, HGPI. They should not be taken to represent the opinions of any specific participant or organization.

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