The NCD Alliance Japan Platform Project for Patient and Public Involvement
First Advisory Board Meeting
Minutes

Systemic and Operational Challenges

The lack of transparency in the patient advocate committee member selection process

- I have seen cases in which the same person has served on a committee as a patient advocate for many years. It is questionable if that is an acceptable way to form committees at the national Government. The Cancer Control Act states Cancer Control Promotion Councils should have members who represent the perspectives of cancer patients and the family members of cancer patients both living and deceased. Since its enactment fifteen years ago, there has been increasing patient advocate involvement on those councils. However, there is no fixed process for member selection and their terms of appointment vary.
- In my personal experience, many of the committees I have participated on are established for set periods of time, usually about one year. I do not feel it is a problem if the same person continuously serves on a committee.

- For real patient involvement, it may be effective for a third-party organization like Health and Global Policy Institute (HGPI) to serve as a human resource bank for patient advocate committee member selection, similar to how the national Government outsources Medical Accident Investigation and Support Center operations to the Japan Medical Safety Research Organization. A program to ensure PPI of substance should be constructed at that human resource bank. Enacting a law called the Basic Medical Act will also make fiscal measures possible. It may be worthwhile to consider placing the selection of committee members outside of the authority of the administration. In theory, this could be achieved by specifying in that act which parties (for example, patients) should select council members. I think it will be important to enact the Basic Medical Act and to share the concepts that patient participation is important from the perspectives of public nature and democracy.
- One possibility is for the Ministry of Health, Labour and Welfare (MHLW) to draft guidelines on committee member selection. Although they would not be legally binding, it is likely such guidelines would be adopted for regular use during selection.

- Because there are various types of stakeholders, it may not be possible to specify only patients in writing.
- I think that will be difficult to achieve without big discussions.

- While it would be good if committee member selection could be outsourced, I think there is no way the MHLW will give up their authority to select people. On the other hand, it is likely that circumstances will change if the committee member selection process is conducted in open view. The situation could also be changed if, for example, committees just for selecting council members were established.

- While I think it would be good to advance efforts for PPI in Japan while referring to PPI guidelines created by the National Institute for Health and Care Excellence (NICE) in the U.K., it will be necessary to hold thorough discussions on guideline content because various educational programs are already being provided by several organizations.

Meeting organizers do not fully recognize the significance of patient involvement

- The opinions a council needs to hear can depend on the council in question. For example, they might need to hear from patients or people receiving long-term care, or from people in the acute or chronic phases of a disease. It is important to clearly state the purpose of each meeting and what they want to hear about.
- The root of the issue is a lack of coordination ability among meeting organizers. Because they do not know who to appoint as committee members and why, they pick whoever is there or who Diet members recommend. I think because they lack firm convictions and opinions, they make selections for no particular reason.

Steps are not being taken to ensure opinions are represented

- I have doubts about how opinions are gathered at meetings. It is a problem that the personal opinions and experiences of council members can greatly influence discussions.
- I think it is important for patient advocate committee members to always listen to stories from the people most affected in advance. For example, when the topic of discussion is postpartum care, they should talk to ordinary mothers.
- When speaking at deliberation councils and other meetings, I sometimes see patient advocate committee members speak from a victim’s perspective from beginning to end. That should not happen.

It is difficult for multiple patient advocates to participate

- The ministries and agencies that organize committees should give thorough lectures in advance. I think doing so would create a system that enables multiple patient advocate committee members to participate as teams and allow us to leave behind the current insider-based system.
- When patients participate at meetings hosted by private companies and other institutions, inexperienced people who are unsure of their ability to speak can participate alongside someone with experience. I think it would be good for meeting organizers to consider this and similar arrangements.

Certain meetings have become formalities

- There are times I have felt the direction of meetings at central Government ministries and agencies was decided in advance, or that it was a formality to listen to each participants’ opinions. These experiences make me feel that real discussions are not being held.
- When you look at the final versions of meeting reports, there are times when slight changes have been made to what was actually said. This can leave the impression that the discussion only went in the direction decided in advance.
- Healthcare must be democratic. The decision making process used to determine healthcare policy must also be democratic. If patient participation becomes a formality, then that participation will only be a form of venting.
- I do not think there are many meetings where a clear answer is possible. I have also heard of times when discussions went in the opposite direction.

There are significant regional disparities

- Another problem is that there are also great disparities among regions. I have been involved in a number of deliberation councils, and the ones hosted by municipalities outside of major cities are held outside of view from third parties like the media. This means there are no dissenting opinions voiced, which can lead to horrible situations.

- Because few members from the committee bank are from areas outside of major cities, in the future, it will be necessary to establish a local block for each region.

➢ **Compared to the private sector, there is little change in how meetings are operated**

- In Japan, once a method for doing something is adopted, it is difficult to change to a different method. That means people are still using the same methods as always, such as by having mountains of printed reference materials or by using fax machines to contact each other. Deliberation councils also went unchanged for twenty years, but were taken online in response to the Coronavirus Disease 2019 (COVID-19) pandemic. I would like for more people to be aware that it is acceptable to adopt new methods and be willing to work for improvement or to rethink things from step one.
- Deliberation councils that met in person went remote due to COVID-19 and it became possible for people to watch them on YouTube. We can say that having participation from various viewers is an extreme form of PPI. While doing so might create higher hurdles for committee members, having more people tune in makes for more lively discussions and can lead to civil participation in the true sense of the phrase. In the future, all deliberation councils should continue to be broadcast live on the internet.

■ Issues for training patient advocate committee members

The lack of sufficient programs to provide patient advocates the knowledge needed to participate in committee discussions on equal footing

- To help patients participate in assessment and planning as outlined in the third-term Basic Plan to Promote Cancer Control Programs, the Japan Agency for Medical Research and Development (AMED) began a research advocate training program. In the field of oncology, it is difficult for patient advocates participating on MHLW deliberation councils to speak as much as they want to without advanced knowledge on topics like genome medicine. These meetings require participants to acquire a certain level of knowledge and conform to certain rules of etiquette, so Japan should introduce training programs like ones currently being implemented overseas.
- Although the importance of providing educational programs for patient participation is clearly stated in the third-term Basic Plan to Promote Cancer Control Programs and the AMED guidebook, clear progress has yet to be made. Japan is lagging behind the rest of the world in this area. PPI began with Human Immunodeficiency Virus (HIV), an infectious disease. Now that we are experiencing COVID-19, we are given all the more reason to take the next step.

➢ **Unique know-how is necessary to issue statements at councils**

- Deliberation councils organized by the MHLW have many unique rules of etiquette to follow, and I feel they are structured in a way that prevents effective opinions from being expressed.
- I feel it is rather difficult for patients who are laypersons to express their opinions at deliberation councils. I would like it if organizers were more resourceful in helping people to speak up on the spot.
- When people speak as a patient advocate or witness on a committee, I think they must have both an effective narrative and logical reasoning. It is best to begin with the narrative, then develop it with logic based on data from sources like surveys. If there is no narrative, people will not listen at all. Simply telling stories with a victim mentality will result in

unrefined discussions, so I think it is necessary to educate committee members so they can share a narrative while staying logical.

- **There are no systems to build horizontal connections among patient advocate committee members and promote progress from the bottom up**

- I think it is important for patient advocates on committees to have horizontal connections that enable them to share concerns. They also need opportunities to study new information and improve their abilities by reviewing meeting minutes and examining each statement as a team so they can brush up their skills on a continuous basis.
- I feel that it will be important to listen to the stories of people who have served on committees as patient advocates in the past, to expand the foundation for building connections, and to promote progress from the bottom up.

■ Overview

Date and time: Tuesday, November 9, 2021; 18:00 to 19:30

Venue: Held online over the Zoom conferencing system

Host: Health and Global Policy Institute (HGPI)

■ Advisory Board Members

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)

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

Teppei 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)

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