

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



ISSUE 1 : Understanding toward the significance of patient involvement is insufficient

➤ The need to formulate concepts and guiding principles

- I think it is important to promote understanding toward the significance of patient involvement among chairpersons and members of expert committees. Chairpersons should be given summaries and explanations of guiding principles in advance so they can actively watch over and support patient advocate committee members and help them feel comfortable speaking up. Although I think one role of a chairperson is ensuring impartiality, on the other hand, it might be good to conduct training or make other preparations in advance so the opinions of patient advocate committee members can be drawn out.
- Guiding principles detailing the significance of participation from patients and other affected parties in health policy discussions should be put in writing. The National Institute for Health and Care Excellence (NICE) in the U.K. has published guidelines on developing principles and processes. Presenting those principles in advance will make it easier for participating committee members to understand the system's purpose and concepts. While just establishing principles may not necessarily be enough to move forward, I think they are valuable for sharing the general direction.

➤ Methods of deepening understanding among chairpersons

- The most significant aspect of citizen participation on deliberation councils is that it delivers the voices of the most affected parties. For example, I think having a man who has no experience with child rearing talk about child rearing will never result in good policy. I also want organizers to understand this.
- Committee chairpersons should be educated. I think that depending on their capacities, there may be times they pay consideration to minority committee members, such as in seating arrangements or speaking order, and there may be times they do not. Problems with chairpersons should be considered together with those for patient advocate committee members.
- The chairperson of a meeting or committee is an important presence. At certain meetings, people have been so traumatized by something said to them that they could no longer speak up at all. I am currently participating on another Ministry of Health, Labour and Welfare (MHLW) committee. I am strongly encouraging chairperson training there, as well. Chairpersons think what they are doing is okay, and we need them to notice when that is not the case.
- People tend to shy away from becoming chairpersons for clinical research and ethics review committees due to the heavy workloads. Given current circumstances, in which someone has to plead before someone takes up the role, there are few incentives for receiving training as a committee chair. In the U.K., someone cannot serve as the chairperson of an institutional review board (IRB) without completing IRB chairperson training. There are also forums for committee chairs to gather and exchange information. In Japan, rather than training, I think we should first create forums where committee chairs can discover solutions for better management.
- The need for peer review has also been pointed out at the Clinical Review Board (CRB), and committee chairs are beginning to sit in on other committee meetings.
- Chairperson training is not only a matter that involves health policy and social security at ministries and agencies, so it would be good to propose introducing it as a rule for all committees.
- Both top-down and bottom-up approaches are necessary. In addition to bottom-up solutions, I would like for the recommendations to make clear mention of the role of top management.

➤ **Expand education on public health and foster understanding among the public**

- From the perspective of the public, there is a need to visualize the limited perspectives of those in the field of healthcare and create opportunities for education. Because processes are out of view, decisions end up being made through political pressure. Instead of saying, “It is useless, nothing will change anyway,” we must create an atmosphere in which various discussions can be held. Public health education for citizens is also lacking. I think allowing the public to learn about and develop an interest in Japan’s social security, health insurance, and healthcare systems (including the universal health insurance system and the process of setting medical fees by teaching these things in school and in similar settings) will lead to the creation of such opportunities and start a movement for patient and citizen involvement.

➤ **Items related to understanding among patients**

- I feel there are two recent trends in negative reactions to patient involvement. The first is that some people feel rejected and do not want to participate as long as there is no law in place because of bad experiences with patient or citizen organizations they had in the past. I think that it will be difficult to meet them halfway without providing some sort of allowance. The second is that some people have said they do not like it because only certain patients stand out. However, I notice those people tend to not seem willing to take the time to be introspective and think about what sort of education they have received, or about what they can do. Many people seem to think there is nobody that will pay attention to them when they hear “patient involvement,” which frustrates them. In the future, I expect a variety of opinions will emerge from patients.
- I understand the increase in the number of dissatisfied people among patients pointed out earlier is not occurring due to the advance of PPI, but is something that tends to occur in non-profit organizations. For example, when the Basic Act on Cancer Control was enacted in 2006, it received lots of coverage in the media. Broadcasters then received a flood of complaints from other patient groups who said, “Why did you feature that patient group?” There are certain people whose standards for value become based on reputation in place of the profits such organizations do not pursue.
- Recently, a patient group has come to me for advice. As momentum for promoting PPI continues to grow, so do the number of requests for interviews and surveys from companies and organizations who approach them from out of the blue. Some are concerned that patient groups are feeling they are being taken advantage of. It will be a setback for PPI if patient groups start rejecting it, we must be careful.

ISSUE 2 : The shortage of specialized knowledge

- One development after the first Advisory Board meeting regarding educational contents was that applications for “Research for Developing a Standard Educational Program for Patient and Public Involvement in Cancer Research” are being accepted for the FY2022 Health and Labour Sciences Research Grants. It seems the MHLW has begun to consider educational programs in earnest.
- I think patients do not need specialized knowledge. No matter how much they study, there is no way they can surpass academics and experts. Instead, I think we should tell them that it is okay to have a general, life-sized perspective, and that it is okay for them to speak from perspectives without specialized knowledge. To make solutions more persuasive, instead of having a person speak individually, I think one possible method would be to provide support by conducting surveys using the internet and other tools to compile and present the opinions of many people at places like

committee meetings.

- Regarding learning opportunities, there are systems that prevent patients from actively participating in the pharmaceutical industry. For example, there are regulations placed on advertising by the Pharmaceutical Affairs Law. Patients are trapped in frameworks in which they can only receive information from healthcare professionals, which prevents them from taking active roles in healthcare. Stringent efforts should be made to improve this situation, given current circumstances in which patients can see so much information aimed at healthcare professionals using social networks and other tools.
- It is best if people who serve on committees have a certain degree of knowledge, but it is not necessary for them to be experts on health policy or the social security system like academics and bureaucrats are. I think it is enough if they know how bureaucrats and politicians who create policies work, as well as understand the decision-making process. They should know things like what sorts of schedules are followed in policy-making, which players are involved, and how those players interact. Once they know how decisions are made and understand those processes, they will know who they should talk to and when, and serve as interpreters. If training functions are to be built, it would be good if users could also acquire this know-how at the same time. It is difficult to learn systematically if you can only hear about past experiences from senior staff. We are currently at work on a textbook for helping people learn the 5W1H of policymaking (namely, who makes policy, what they aim to achieve or for what purpose, where discussions are held, how they work, etc.).
- Depending on the discussion venue, there are different demands placed on patient advocate committee members in terms of information and abilities, so I feel it is difficult to cover all these many items together.
- If patient advocate committee members do not possess a basic understanding of healthcare, it is difficult for them to communicate from the perspectives of patients.
- Citizens need opportunities to acquire basic knowledge on healthcare and public health. This is the greatest source of confusion, as we learned painfully from COVID-19 countermeasures. This point is so important it should be our first recommendation.
- Both patients and healthcare professionals must strive to use a common language. Those on the patient side must work to acquire a certain degree of specialized knowledge to speak that common language, while healthcare professionals must strive to convey specialized terms in a general, easy-to-understand manner to create that common language.

ISSUE 3 : The shortage of know-how and other knowledge

- I thought conducting interviews and creating content for passing down know-how was a good idea. I think it would also be good to share information through Q&As.
- It can be difficult to speak in direct terms in a limited amount of time. The message, “It is okay if you are not the best at speaking” must be communicated, and an environment in which people feel relaxed and comfortable enough to talk must be created.
- I think patient advocate committee members will find it reassuring just to be seated together at committee meetings and other meetings. Seating arrangements require consideration.
- There was discussion that meetings are run in an old-fashioned manner, and that it would be better to outsource meeting logistics to private companies and organizations that can run them using more modern methods. Government officials are not professionals in meeting logistics. Sometimes, private companies contracted to manage Government

meetings are also old-fashioned, so some inventive thinking is needed to draft specifications. If that is something HGPI can handle, it may be good to have them do so.

- One can learn what kinds of patients there are many of by listening to tens of thousands of telephone consultations. It is important to understand patients' actual circumstances through surveys and similar means.
- Interviews are not held to recruit committee members, they are for encouraging involvement. This perspective seems to be somewhat mistaken, so I would like for it to be clarified.
- It is said the three steps we aim to achieve in PPI are (1) participation, (2) engagement, and (3) involvement. When patients at NPO Kanja Speaker Bank ("Patient Speaker Bank") speak to pharmaceutical companies or other parties, they gain a sense of accomplishment. This is because they are not bottling up their experiences, but are using them to give back to society. While building on that foundation, I think we need the perspective of gradually elevating PPI in society.
- There is no push from regulatory authorities in Japan to provide patient participation mechanisms that listen to the voices of patients. In Europe, in particular, quotas are set for research, publications, insurance coverage, and pharmaceutical prices to force these sorts of pushes. (While they did cause some confusion, they have provided patients with opportunities to unite.)
- Right now, PPI is highly undervalued. Even though physicians are paid, in many cases, patients are unpaid volunteers. Even in MHLW research and other initiatives, patients can only be research collaborators, and even if they voice their opinions at places like meetings, they do so as volunteers. PPI has not been embedded into the system from the ground up. We must learn from various fields, like the jury system, and integrate PPI as a system.
- When pharmaceutical companies and other parties submit requests to NPO Kanja Speaker Bank, there is always a fee. Such initiatives should be operated as businesses, and not only done in the spirit of volunteerism. The parties should be equal. In fact, there are many patients who are forced to bear financial burdens. I think we require proactive efforts in society to see they are paid back.

ISSUE 4 : The shortage of patient advocate committee members

➤ Representation

- When I spoke at a symposium on PPI, I was asked, "How do you guarantee representation?" many times. At this meeting, we are mostly speaking about representation at bodies like deliberation councils or review meetings. The Cancer Control Act states that "Councils must include representatives of people with cancer or living or bereaved family members," but it is difficult to say that these parties are being represented, even when the person involved is doing their best to represent them. What does it mean to represent someone, in the first place? This is difficult to answer. To ensure representation, diversity is crucial. Increased diversity leads to increased representation. I would like to emphasize that making efforts to increase diversity when training patient advocate committee members and gathering broad opinions from patients and their families through surveys and research are equally important.
- I think there is an inherent mismatch within patient representation. For example, even if someone is participating as a representative of physicians, that person's opinions might vary according to their background or the organizations to which they belong. I think it is important for patients to be able to view circumstances from a bird's-eye view to a certain extent, to be able to speak in an easy-to-understand manner, and to focus on specific points rather than just expressing opinions related to their own interests. I hope we can train patients who can do these things while maintaining the perspectives of patients.

➤ **Patient advocate committee member selection**

- I am opposed to leaving committee member selection up to third parties. If they are third parties, how can they pick the right people? Won't that result in a lack of democratic legitimacy? Candidates for important committees on policy should be selected by ministries and agencies, and the responsibility for making final decisions should rest with the Minister, who possesses democratic legitimacy. However, there are three things that private third-party organizations can handle. The first is training committee member candidates. The second is providing information during the selection process at the administration, or on the candidates. The administration cannot complete the selection process if they do not know the candidates. Third, they can work together with the administration to function as a third-party evaluator of the Minister's (or ministry's) selections.
- On the topic of committee member selection, a situation in which a Government agency handpicks a committee member from a black box is, after all, something that should be avoided. When that happens, we do not even know why that person was picked. In society, there are two aspects to justice: the substantive aspect and the procedural aspect. In modern society, where there are diverse values, it is impossible for substantive justice to be consolidated. In fact, in modern society and this discussion, the important aspect is procedural justice, so in the modern era, we should pursue justice within processes that lead to results.
- What is important is ensuring transparency in the process. Committee member selection is a particularly powerful form of authority, so how to make the decision-making process transparent will be an extremely important topic in society in the future. The National Institute for Health and Care Excellence (NICE) accepts committee member applications from the general public through its website. It may be good for Japan to formulate committee member selection guidelines at ministries and agencies and, after setting certain criteria, to recruit committee members from the public. I think it may be good to consider such aspects of procedural justice and transparency while designing the society of the future.
- Guidelines for council member selection already exist, so it would be good to propose having committee member selection guidelines appended to them. For example, they might recommend providing committee chair training or making the reasons for committee member selection public. It might also be possible to provide information on open recruitment for certain committee members. It would be good to recommend content that should be included.
- I think it will be good to have open recruitment of committee members, but selection criteria are important. Past experience shows that people who say they want to serve on committees are not always the best fit. There is also the question of accountability toward those who are not selected. Since educational content is not currently consolidated, there is also the issue of who will be responsible for consolidating it. I think one reason public institutions cannot select people is because they cannot be accountable to those who are not selected.
- I think open recruitment for committee members is possible, but because there are various types of committees, like roundtables, review meetings, and deliberation councils, it will be difficult to discuss them all at once. When selecting committee members through open recruitment, I think it will be difficult for Government offices to decide whether to conduct interviews or not. In addition to applying the expertise of its members to policy, another function of councils is to aggregate opinions by holding discussions and making real decisions on policy plans at Government offices. To aggregate opinions effectively, I think representatives of organizations being addressed must also be included.
- In reality, it can be exhausting to respond to people who are not selected during open recruitment when they ask why. From the perspective of continuity, when actually using open recruitment, it will be best if the people who are not

selected can be provided with convincing reasons for not being picked.

- Regarding accountability toward people who are not selected during open recruitment, at the national level, it is not necessary to provide an explanation to each individual. Instead, we should perceive it as accountability toward society. To that end, making visible guidelines and presenting selection criteria in clear terms will lead to procedural justice. In other words, there is social significance in publicly presenting guidelines. Doing so will help ensure accountability toward unsuccessful applicants.

➤ **Provide mechanisms and educational opportunities for upholding diversity with a broader scope**

- It is not very feasible to have a scope that includes training patient advocates to serve in review meetings or on other such committees, or the development of a human resource bank. There are many methods for influencing policy, and joining a committee or similar body is only one part of that. There are many ways people can get involved, like collecting signatures, providing input to individual legislators or administrative officials, or conducting hearings with government agencies. If organizations with vast amounts of resources, like those representing industry, can train advocates, it will strengthen the voices of those on the provider side. This might distort the policy process. To ensure users' voices are heard, having systems to support patient-side advocacy capacity building will be important. If resources are limited when doing so, I think that it may be necessary to gather them at some place and manage them in a collective manner, but if we are talking about a human resources bank for helping people become patient advocate committee members, there may be fewer people who can commit to that degree. Therefore, I think it is better to define a scope that supports a broader variety of activities.
- Instead of having a group that only consists of people who have willingly registered to serve as committee members, it is important to have diverse participants. For example, parents' opinions on children's COVID-19 vaccines were split depending on whether or not they had a disease. While having people attend a five- or ten-session course to learn about healthcare may present high hurdles, there are many people who will want to participate and share their opinions if it is a field they are highly interested in. We need to create a process to help more people build interest that can serve as a gateway for that.
- The lack of patient advocate committee members is a direct result of insufficient public health education for citizens. I think that increasing the number of people interested in healthcare will be a key element in finding people who can voice their opinions. PPI is premised on participation from citizens, not only patients. I think the problem is that in society today, very few people want to go so far as to pay fees and study healthcare on their days off. But, becoming a patient is something that happens suddenly. It is important to possess a certain level of knowledge when that happens. That is why I think it is a key element. People must be educated from childhood so that knowledge on healthcare can, to a certain degree, become common knowledge. Adults should be provided with educational opportunities as part of the benefits packages at their companies so they can deepen their knowledge of healthcare and long-term care and to help prevent them from leaving the workforce to provide long-term care.
- Since incorporating the promotion of PPI into policy would make it a formality, I would like policy recommendations that help more people take an interest in healthcare.
- Committee members cannot be trained overnight, so the first priority is to return to the starting point and build a platform for patients and affected parties.
- People on the side of healthcare are happy to collaborate with patient groups to make healthcare better together. However, it is quite difficult to talk to organizations that only seek to criticize.

- Instead of taking excessive measures to gather committee members, I think it would be meaningful if we could first build a platform for patients and affected parties and bring together existing patient groups. Then, patient advocate committee members could be trained from within that organization, or requests for help could be made to COML or other organizations.

■ Overview

Date and time: Thursday, January 27, 2022; from 18:00 to 19:30

Venue: Online using 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)

Tepei 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))