

Health and Global Policy Institute (HGPI) Meaningful Involvement Promotion Project
National Local Government Conference
“Reflecting on Involvement of People with Lived Experience in Prefectural Healthcare Planning Processes
– To Promote Meaningful Involvement in Prefectures and Municipalities”
Discussion points

Purpose of this conference

In recent years, there has been broad recognition of the value of the experiences of people with lived experience of health concern as well as of the importance of involving such parties in policy and hearing their experiences. There have been a number of movements that aim to encourage involvement from those with lived experience around the world. Historically, these include the global disability movement, which advanced under the slogan of “Nothing about us without us.” More recently, there was a resolution on social participation approved at the World Health Assembly in 2024. As these examples show, opportunities for real involvement for people with lived experience have emerged in a wide variety of settings.

Turning our attention to involvement for affected parties in Japan’s health policy formulation process, we find there has been a long history of participation in areas such as AIDS, disabilities, and cancer control. For example, the Cancer Control Act, which was enacted in 2006 and began from the voices of people living with cancer and those close to them, obligated the Ministry of Health, Labour and Welfare (MHLW) to include members with lived experience such as cancer patients, their families, or the bereaved on Cancer Control Promotion Councils. This encouraged broader movements aiming to see the inclusion of people with lived experience in councils and other government committees. This momentum also carried over to plans that span specific conditions like allergic diseases and cardiovascular diseases (CVDs), encompass various diseases, or that target specific regions, such as Medical Care Plans or Health Promotion Plans.

However, a variety of lingering issues remain to be addressed for achieving the meaningful involvement of affected parties in health policy and for the significance of that involvement to fully manifest. For example, while opportunities for meaningful involvement have increased, there has not been a corresponding and natural increase in the number of participants, resulting in shortages. As a matter of fact, when local governments have open recruitment for people with lived experience to apply to serve on councils, the number of applicants is often limited. Depending on the local government or the disease in question, there may be smaller communities or few affected parties, which are also factors that lead to few applications. There are also times when those that do participate miss opportunities to offer comments because they feel nervous or uncomfortable. Some have voiced concern about the representativeness of those who are selected to participate, or question their capacity to convey the voices of a wide range of affected parties. It is also important for governments to be eager to hear the voices of a wide range of people with lived experience using methods that do not rely on government committees, such as public comments or public hearings. However, which mechanism for supporting meaningful involvement for affected parties is best can vary among local governments, and there is great variance in the status of such initiatives by locale. It is precisely because there has been a broad expansion in opportunities for meaningful involvement across diseases and regions that expectations are now high for each local government to implement measures for more effective involvement that take local circumstances into account.

With this backdrop, Health and Global Policy Institute (HGPI) hosted a National Local Government Conference aiming to further promote the meaningful involvement of people with lived experience in local governments. Our discussions were not confined to specific disease areas and allowed local government officials and experts to share initiatives and best practices for meaningful involvement as well as noteworthy issues in this area. The keynote speeches shared global trends in involvement for people with lived experiences and introduced relevant domestic and international discussions on and implementation of meaningful involvement. This was followed by an opinion exchange session after which each local government shared specific initiatives and lessons learned regarding meaningful involvement. Drawing on past experiences with the formulation and revision processes for healthcare-related plans, participants took part in a forthright and active discussion. This summary of discussion points from that conference has been prepared by HGPI in its capacity as an independent health policy think-tank and describes issues related to meaningful involvement in local government policy processes, necessary actions to address those issues, and innovative examples of meaningful involvement.

Challenges and Necessary Actions for Advancing Meaningful Involvement in Municipalities and Prefectures

1. Ensuring fair selection of patient advocate committee members for involvement in government committees

In some regions or disease areas, there are cases in which specific individuals continuously serve as patient advocate committee members in government committees for many years. While there are some situations in which this is unavoidable (such as when there is an extremely small number of applicants), there are cases in which opinions reflected in overall discussions at government committees become biased toward the perspectives of certain individuals or groups, or when absences increase due to factors like aging. Furthermore, government committees often look to patient advocate committee members to represent the positions of people with lived experience, but methods to ensure adequate representativeness have yet to be established. Given the current environment, below, we have compiled measures and innovative examples of methods that each local government can use for the fairer selection of patient advocate committee members for government committees.

1-1. Establishing appropriate terms of appointment for committee members according to circumstances in the region or disease area

Establishing terms of appointment for committee members will provide fairer access to participation opportunities, prevent membership from becoming fixed, and enable committees to reflect the opinions of a broader range of people with lived experience. If these appointments are too short, however, there may be cases in which new appointees will be replaced before they can become fully accustomed to the discussions, which may become an obstacle to effective involvement. It will be necessary to give careful consideration before setting terms of appointment.

1-2. Adopting flexible appointment methods to ensure patient advocate committee members are well-suited to the purpose of the government committee

The Cancer Control Act and a number of other laws obligate governments to include representatives of the perspectives of affected parties (i.e., as patient advocate committee members) at meetings where local government plans are discussed. However, in general, each government committee only has one to three seats for patient advocate committee members. This limits the capacity of such committees to comprehensively examine diverse opinions as well as the ability of such members to speak as representatives. In recent years, membership rates in patient advocacy organizations have been on the decline, so there are also limits when attempting to select committee members through such organizations or to ensure representativeness by aggregating the opinions of their members. Within that context, a number of local governments have adopted flexible interpretations of “representatives of the perspectives of affected parties” to suit the purposes of committees, and are considering how to structure committees so diverse opinions from people with lived experiences related to said purpose can be suitably reflected.

Example 1: Taking diversity in diseases, age groups, etc. into account and appointing multiple committee members

There is diversity among patients and other people with lived experience of health concerns. For example, a prefectural government’s Plan for the Promotion of Cancer Control impacts all generations of residents who live with cancer. This includes patients for all types of cancer including lung cancer, stomach cancer, and breast cancer, as well as their families or their bereaved family members. It is for this reason that some governing bodies are now working to appoint multiple patient advocate committee members to reflect the opinions of as many people with different attributes as possible. However, covering every attribute is unrealistic; even committee members representing the positions of healthcare providers do not cover all specialties and occupations. It is necessary to keep in mind that patient advocate committee members also do not necessarily need to cover every attribute.

Example 2: Inviting committee members from other regions

In some cases, when a region lacks suitable patient advocate committee members (due to a lack of related

organizations or willing applicants, for example), they sometimes invite people from other regions to participate. Among prefectural councils, there are several cases in which people from related organizations are invited to serve as patient advocate committee members even when they are not local residents. For example, this is practiced at the Okinawa Prefecture Cancer Control Promotion Council.

Example 3: Adopting a broader range of conditions for people to be defined as “patients” or “affected parties”

People with lived experience are sometimes appointed to government committees regardless of affiliation with patient advocacy organizations or presence of a disease or disability. For example, when recruiting members, the Nara Prefecture Cancer Control Promotion Council does not include “be a patient” among its eligibility requirements. Instead, it requires applicants to “possess a wide range of knowledge and interest in cancer control.” There are also examples in which supporters or others who have regular and long-term everyday interactions with many patients or affected parties serve as committee members to represent the opinions of those with lived experience. This type of involvement is likely to be effective for gathering a broad range of opinions. On the other hand, the opinions of supporters and citizens with limited experience as patients or affected parties do not always match those of people with lived experience, so it is desirable that their input is supplemented with the perspectives of people with lived experience.

1-3. Publicly presenting information regarding the appointment process and requirements for patient advocate committee members in advance and ensuring fair appointments

There are various methods used to select patient advocate committee members. They include open recruitment, nominations from related organizations (the Social Welfare Council, patient advocacy organizations, etc.), or referrals from other committee members. Regardless of method, it is important to ensure fairness by being clear about the selection process and criteria (application requirements for open recruitment, selection methods, etc.) in advance. This will make it possible to avoid placing excessive focus on where someone lives, if they have experience as a patient or affected party, or similar criteria while ensuring appointments that are fair and flexible while also being well-suited to conditions in the region or the purpose of the government committee.

2. Methods of operating government committees that facilitate discussion participation for patient advocate committee members

There are inherent aspects of government committee meetings that can make it difficult for patient advocate committee members to offer comments. Such committees often involve a number of experts in healthcare or policy, but patient advocate committee members are not necessarily experts in these fields. This can result in asymmetries of knowledge or information between them and other participants. In fact, many examples have been shared in which patient advocate committee members could not fully understand discussions and were unable to offer comments. Although patient advocate committee members are sometimes unable to offer comments (despite wanting to), decisions made at government committees are sometimes formally deemed to have been approved by all members. In other words, there may be discrepancies between decisions made by government committees and substantive discussions or the state of consensus. Government personnel who manage such committees should provide patient advocate committee members with adequate support.

2-1. Providing sufficient pre- and post-meeting explanations and follow-ups

Government committee meetings begin with members sharing a specific social issue. Participants then share views on that issue from their various positions, and discussions are held on realizing better policies. Knowledge and information asymmetries between patient advocate committee members and people like experts in healthcare or policy must be addressed to help patient advocate committee members understand specific social issues and policies and participate in discussions. Information and explanations provided in advance are essential in achieving this. Even when people with lived experience have obtained adequate knowledge and information in advance, there are still cases when offering comments at meetings creates psychological burdens for them. Therefore, it is also important to provide psychological support.

Example 1: Providing explanations tailored to the needs of individual patient advocate committee members in advance

Depending on factors like their personal experiences, there is a significant degree of variation in the information and preparation that patient advocate committee members would like in advance. In addition to the need to share the purpose of a government committee and explain main agenda items to all committee members, it is also important to provide sufficient explanations of technical terms to patient advocate committee members as well as what is expected of them. This should be done in a format that is aligned with the needs and expectations of each committee member. There are examples in which new patient advocate committee members were able to actively participate in discussions and make effective statements from their very first meeting because they were provided with thorough explanations from the chair or government personnel in advance.

Example 2: Providing psychological support after meetings

Many patient advocate committee members feel psychological burdens toward participating in meetings. In particular, some have reported that they feel unsure that their comments are appropriate or that they are contributing to discussions overall if they receive a tepid response from the chair or other participants. When this happens, it can make them hesitant toward offering comments at future meetings. However, many patient advocate committee members report better psychological safety when offering comments and higher motivation if government personnel, in their capacity as steering committee members, express appreciation and provide ample feedback after meetings. It is desirable that practices in which government personnel and other staff provide positive psychological support both before and after meetings become more widespread.

2-2. Operating government committee meetings so patient advocate committee members can participate in discussions and offer comments more easily

Regardless of the presence of support before and after meetings, there are some situations in which patient advocate committee members cannot effectively participate in discussions. As previously discussed, to prevent their lack of comments from being taken as agreement, it is important for the chair or the steering committee to call on patient advocate committee members when the time is right and encourage them to share their thoughts. When doing so, it is good to begin by first asking the patient advocate committee member if they have an opinion. It is also desirable that technical terms are avoided in favor of plain language so all participants including patient advocate committee members can maintain an accurate understanding of discussions.

3. Utilizing various methods to collect and aggregate opinions from a vast range of people with lived experience of health concerns

Several laws related to meaningful involvement specify “people representing the positions of patients and other affected parties” must be included on specific government committees (such as deliberation councils or joint committees) as patient advocate committee members. On the other hand, there are few examples in which best practices and methods for meaningful involvement from a diverse range of affected parties (such as hearings or interviews) are even mentioned. While government committees are one avenue for effectively promoting meaningful involvement, there are physical limitations on how many people can participate and on how long they can speak. As such, it will be necessary to collect and aggregate the opinions of a diversity of people with lived experience through a variety of administrative procedures that utilize methods that can complement government committees, such as hearings and interviews.

3-1. Establishing government committees centered on people with lived experience

Only a limited number of people can participate in multi-stakeholder deliberation councils or joint committees, so the number of seats for people with lived experience is also limited. In addition, meetings of such groups are often open, and are sometimes streamed online. This means the timing of comments or the behaviors of committee members can have a significant impact, which can make patient advocate committee members more nervous about offering comments. Given the legal limitations placed on deliberation councils or joint committees, it may be effective to establish additional working groups centered on people with lived experience so the opinions from a greater number of them can be aggregated. In addition to contributing to greater variety in opportunities for meaningful involvement, having additional working groups would also

provide participants with practice opportunities before formally participating in deliberation councils or joint committees.

Example 1: Securing participation opportunities through opinion exchange sessions

Working groups centered on people with lived experience have been established under several local governments. However, establishing working groups is very difficult for some local governments, and they face significant budgetary or operational burdens or limitations. In Shizuoka Prefecture, the Cancer Control Promotion Council has become a forum for opinion exchange. They also hold only one meeting. These changes have made meetings easier to hold while securing opportunities to collect opinions from a greater number of people with lived experience.

3-2. Making effective use of hearings, surveys, and public comments

For government committees that are working groups or opinion exchange meetings, it is unavoidable that the number of seats for people with lived experience is limited. Effective and widely-used methods of compensating for such limitations on government committees and ensuring opinions are gathered from a diversity of affected parties include hearings, questionnaires, and public comments. However, unlike participation in government committees where members' names are publicly disclosed in advance, these methods often allow people to respond anonymously, so care should be taken to ensure they are used appropriately.

4. Building cooperative relationships with a wide range of people with lived experience of health concerns

Recently, there has been growing recognition of the importance of meaningful involvement in the policy formulation process, and participation opportunities are increasing. However, certain regions or disease areas face shortages in people with lived experience who would like to be involved in such efforts. There have been a number of cases in which open recruitment of patient advocate committee members or calls for public comments were met with an extremely small number of responses or even no applicants at all. The original purpose of meaningful involvement is to provide ways for people with lived experience and the government to work toward sharing the same social issues and collaborating to generate better policies. However, they sometimes develop confrontational relationships in which instead of cooperating with one another, patients and affected parties make requests while those on the government side respond to those requests. These confrontational relationships are especially common in the initial stages, when new forms of involvement are introduced. This can sometimes cause those on the government side to view the involvement of people with lived experience as burdensome. It is urgent that we create an environment for continuously fostering more people with lived experience who will take part in generating better policies, especially people who view health policy issues as a personal concern and who will collaborate with the government and other affected parties.

4-1. Providing information in a thorough manner and devising methods of disseminating information tailored to its main target audience

Publicly disclosing information on policies or the processes by which they are formulated is a necessary step for advancing meaningful involvement, and it must be done thoroughly. Effectively disseminating information may also have the potential to encourage meaningful involvement. When disseminating information, it is important to have its main target audience in mind and to work to transmit it in a format that will make it easy to reach that audience and for its members to respond.

Example 1: The effects and efforts of gathering public comments as an integrated part of Medical Care Plans

In recent years, some local governments (mainly prefectural governments) have been incorporating multiple healthcare-related plans (Basic Plans for the Promotion of Cancer Control, Prefectural Plans for the Promotion of CVD Countermeasures, etc.) into regional Medical Care Plans to formulate them in an integrated manner. In many cases, public comments are gathered in an integrated manner, and they only apply to the combined tentative Medical Care Plan. When this occurs, it may be difficult for affected parties to view the combined tentative Medical Care Plan as something that impacts them directly, like a person living with cancer might view a Basic Plan for the Promotion of Cancer Control. In fact, regarding the number of public comments

submitted, one tentative Medical Care Plan that integrated multiple plans did receive a certain number of submissions, but it received fewer submissions regarding cancer control compared to when comments were gathered for just the Basic Plan for the Promotion of Cancer Control in the past. While formulating Medical Care Plans and related plans in an integrated manner is effective for reducing the workloads associated with various tasks at local governments, focused efforts must be devoted to gathering public comments separately for each disease area.

4-2. Utilizing a variety of procedures and related initiatives to build cooperative relationships with a wide range of people with lived experience

Making the most of various procedures to create participation opportunities for many affected parties can lead to opportunities for prospective patients advocate committee members to gain experience for future deliberation councils, joint committees, and other government committees. In particular, ample communication with and support for those who have little experience taking part in such meetings can help cultivate future collaborative relationships.

It is also effective to collaborate with related projects within local governments that involve people with lived experience and who are interested in policy or social issues. For example, people who serve as peer supporters and welfare commissioners and have lived experience of health concerns have insights as healthcare recipients as well as providers of support. They also have points of contact with many patients and other affected parties. Such people are likely to be interested in meaningful involvement.

Example 1: Using a peer supporter training program to recruit patient advocate committee members

The Mie Prefecture Cancer Control Promotion Council cooperates with a peer supporter training program to scout and recruit patient advocate committee member candidates. Peer supporters are provided with explanations on cancer policy and some of those trained through the project are appointed to the deliberation council as patient advocate committee members.

4-3. Engaging in multi-stakeholder collaboration to educate people with lived experience and to establish a social infrastructure that supports meaningful involvement

In addition to building collaborative relationships through existing opportunities for involvement, over the long term, it will also be important to establish a framework for maintaining growth in the number of people with lived experience involved in the policy formulation process. In addition to the government, initiatives for meaningful involvement (including Patient and Public Involvement, or PPI) are being undertaken by various groups including patient advocate groups, academic societies, health facilities, and civil society groups. These multi-stakeholders should collaborate to expand the base of parties engaged in meaningful involvement.

Expectations are also high for the creation of a system for compiling and visualizing information on people with lived experience and who are interested in involvement, and efforts to quantify the knowledge, skills, and experience they need for involvement are currently underway. In the future, we hope to see the creation of a social infrastructure based on a system that centralizes relevant information and that local governments will be able to use to search for people with lived experience who are suitable for their objectives.

Example 1: Collaborating with multi-stakeholders to encourage meaningful involvement

Recent years have seen an increasing number of parties such as patient advocacy groups, academic societies, and health facilities engaged in initiatives related to meaningful involvement. For example, in addition to their usual researcher-centered events, academic societies have also been hosting programs on involvement for patients and citizens. Collaborating with relevant initiatives like those programs will facilitate effective connections with people with lived experience who are interested in policy issues and involvement for specific diseases as well as expand meaningful involvement in the policy formulation process. For example, in Tokyo, having a civil society group inform the public about a public comment period increased submissions and created opportunities to reflect diverse opinions in policy.

Example 2: Identifying and visualizing necessary personal qualities for meaningful involvement

The Japan Agency for Medical Research and Development (AMED) is working to identify the qualities that patients and citizens must possess to participate in medical research in the field of oncology, and is developing an educational program to foster those qualities. Furthermore, Health and Global Policy Institute (HGPI) is working to systematize and present the knowledge and skills needed to participate in the health policy formulation process and to collaborate with a wide variety of related parties, and is visualizing participants' history of completing relevant training courses.

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