日本医療政策機構(HGPI)患者当事者支援プロジェクト

Health and Global Policy Institute (HGPI) Meaningful Involvement Promotion Project



「みんなの患者・当事者フォーラム2025

一緒につくる、これからの医療」報告書

"The Patient and Citizen Lived Experience Forum 2025" Report

2025年5月17日(土) Saturday, May 17, 2025



開催趣旨

日本医療政策機構では、2004年の設立以来、「市民主体の医療政策の実現」をミッションに掲げ、医療提供者、研究者、企業関係者、行政・立法関係者、そして患者・当事者を含むマルチステークホルダーの議論に基づく政策提言活動や、医療政策の政策形成過程における患者・当事者参画の支援等を行ってきました。

近年では、患者・当事者としての経験の価値が広く認識され、患者・当事者の参画が推進されています。歴史的には「Nothing about us without us(私たち抜きに私たちのことを決めないで)」を掛け声とした世界的な障がい者運動に始まり、2024年5月には世界保健総会で社会参加(social participation)に関する決議が承認されるなど、国際社会でも医療政策の形成過程における患者・当事者参画が推進されています。

国内でも、2006年にがん対策基本法が成立して以来、国や都道府県では、保健医療計画策定等を協議する場で患者委員等が参画し、患者・当事者の視点や経験を施策に反映していくことの重要性が高まっています。実際に、2019年に当機構が実施した世論調査「日本の医療・医療制度に関する満足度調査」では、医療政策策定プロセスにおいて約8割が「自分の声を医療政策に反映させたい」と回答しています。

一方で、2023年に当機構が実施した世論調査では、現在の医療及び医療制度の満足度に関する質問の中で、最も満足度の低い項目として患者・当事者参画に関する項目である「制度決定プロセスの公正さ」(37.2%)、「医療制度のわかりやすさ」(36.2%)、「制度決定への市民参加の度合い」(33.2%)が挙げられています。また、当機構が独自に実施したヒアリングによると、国や都道府県、市町村からは「患者・当事者委員を公募しても応募数が少ない」、「患者・当事者、市民の本音を聞くことができている実感が薄い」といった新たな課題に直面していることもわかりました。患者・当事者参画を支える環境が整ってきた反面、折角の理念や制度が十分に生かされていない側面があります。この状況を乗り越え、多様な経験や背景を持つ患者・当事者が医療政策形成過程に参画することで、医療政策に大きく影響を受ける患者・当事者の声が反映された政策の実現に繋がるはずです。

そこで、当機構では「みんなの患者・当事者フォーラム2025 ~一緒につくる、これからの医療~」と題して、患者・当事者参画に関わりたいという希望をお持ちの皆さまに全国からお集まりいただく機会を設けます。これまでの経験は全く問いません。患者・当事者参画を始める糸口となるような交流の場を目指して、本フォーラムではプログラム1「トークセッション "みんなで進める患者・当事者参画の第一歩"」、プログラム2「チャレンジングワークショップ "参画の一歩を踏み出そう!"」の2つを実施します。プログラム1では、既に多くの参画経験を持つ患者・当事者のほか、実際に都道原県における循環器病対策推進計画の策定に携わった行政担当者や、これから医療政策に自らの声を届けていきたいと考えている患者・当事者らをお招きし、それぞれの立場から患者・当事者参画の実際をお話いただきます。なかでも、患者・当事者の方には、会議体という場に代表として参画するまでに至ったこれまでの歩みや経験、教訓についても共有いただきます。医療政策における患者・当事者参画の意義と可能性を改めて皆さまと共有しながら、参画の場面や道筋を具体的に想像できるようなプログラムを目指しています。プログラム2では、医療政策に関わる身近なテーマについて、少数で自由に意見交換をする場を設けます。参画の場面が少し想像できた段階で、新たにこの場で出会った人々と協働しながら、それぞれの思いや視点を共有いただくことで、医療政策形成過程への参画を行うための一歩に繋がる時間を目指しています。

Explanatory introduction

Health and Global Policy Institute (HGPI) has operated under the stated mission of "Achieving citizen-centered health policy" since its establishment in 2004. In pursuit of this mission, HGPI has engaged in policy advocacy based on multi-stakeholder discussions that involve healthcare providers, researchers, industry representatives, representatives of the government and legislation, and patients and other people with lived experience of health concerns. HGPI has also supported the meaningful involvement of people with lived experience in the health policy formulation process.

The value of the lived experiences of patients and other affected parties has been the subject of growing recognition in recent years, and progress has been made in efforts to advance the meaningful involvement of these parties. Building on the historic momentum of the global disability movement, which advanced under the slogan of "Nothing about us without us," a number of movements around the world aiming to encourage involvement from those with lived experience in the health policy formulation process have advanced around the world. For example, a resolution on social participation was approved at the World Health Assembly in May 2024.

In Japan, since the enactment of the Cancer Control Act in 2006, it has become more important for the national Government and local governments to include patient advocate committee members and related parties in discussions during the formulation of health and medical care plans to ensure the perspectives and experiences of those most affected are reflected in measures. In fact, in a public opinion survey conducted by HGPI in 2019 titled the "Survey on Healthcare in Japan," approx. 80% of respondents said they want their opinions reflected in health policy during the health policy creation process.

On the other hand, in a public opinion survey on satisfaction with healthcare and the healthcare system in Japan conducted by HGPI in 2023, satisfaction was lowest for items related to meaningful participation, namely, "Fairness of decision-making processes" (37.2%), "Ease of understanding of the healthcare system" (36.2%), and "Extent of citizen participation in decision-making" (33.2%). Interviews conducted independently by HGPI have also found that national, prefectural, and municipal authorities face a number of new challenges in this area. These challenges include low applicant numbers even when conducting open recruitment for patient advocate committee members, or that they feel they are not hearing the true feelings of people with lived experience and citizens. There has been progress in establishing a supportive environment for meaningful involvement, but despite the considerable efforts that have been devoted to developing underlying concepts and systems, they remain underutilized. Overcoming this situation and achieving meaningful involvement for people with lived experience with diverse experiences and backgrounds in the health policy formulation process is certain to open the path to policies that reflect the voices of those who are most impacted by health policy: patients and those close to them.

In response to this need, HGPI established "The Patient and Citizen Lived Experience Forum 2025" to create an opportunity to bring together everyone who wishes to take part in meaningful involvement from throughout Japan. It requires no prior experience whatsoever. This forum will offer two programs that aim to foster interactions that serve as a starting point for meaningful involvement. Program 1 is titled, "Talk Session — 'The First Step Toward Meaningful Involvement: Moving Forward Together'" and Program 2 is "Level Up Workshop — 'Let's Take Our First Step Toward Involvement!" In addition to people who have already built a wealth of experience in meaningful involvement as patient advocates, Program 1 also includes government officials who have real-world experience in formulating Plans for the Promotion of Cardiovascular Disease (CVD) Control for local governments as well as people with lived experience who would like to deliver their own voices to health policy in the future. From their respective positions, they will discuss the realities of meaningful involvement. The stories of those with lived experience will include past steps that led to their involvement as representatives in government committees as well as their past experiences and lessons learned. By having them share, we hope Program 1 helps everyone take a new look at the significance and potential of meaningful involvement in health policy with fresh eyes as well as envision specific opportunities for and paths to meaningful involvement. In Program 2, participants will form small groups where they can freely exchange opinions on health policy-related themes that are close to them. After participants can envision opportunities for involvement, we hope sharing thoughts and perspectives and by collaborating with new people who they meet today leads them to the next step toward meaningful involvement in the health policy formulation process.

プログラム

日時: 2025年5月17日(土) 12:00-16:30

会場: Global Business Hub Tokyo

(東京都千代田区大手町1-9-2 大手町フィナンシャルシティ グランキューブ3階)

形式: 対面

主催: 特定非営利活動法人 日本医療政策機構

12:00-13:00 懇親会(自由参加)

開会挨拶 13:00-13:05 開会挨拶

河野 結 (日本医療政策機構 マネージャー)

13:05-15:10 プログラム1「トークセッション"みんなで進める患者・当事者参画の第一歩"」

アイスブレイク・趣旨説明

パネルトーク1:参画事例について聞いてみよう!

小澤 裕 (静岡県 健康福祉部 医療局 疾病対策課 がん対策班 主査)

福原 斉 (一般社団法人 心臓弁膜症ネットワーク 代表理事)

山家 京子 (NPO法人 つばめの会 代表)

聞き手:平家 穂乃佳 (日本医療政策機構 シニアアソシエイト)

パネルトーク2:いろんなひとの参画経験について聞いてみよう!

奥野 真由 (埼玉 IBD の会(炎症性腸疾患患者会) 代表)

櫻井 公恵 (NPO法人 GISTERS 副理事長)

宿野部 武志(一般社団法人 ピーペック 代表理事)

山田 悠平 (一般社団法人 精神障害当事者会ポルケ 代表理事)

聞き手:山下織江(日本医療政策機構 アソシエイト)

15:10-15:25 休憩

15:25-16:25 プログラム2「チャレンジングワークショップ "参画の一歩を踏み出そう!"|

趣旨説明

グループワーク

16:25-16:30 閉会

Program

Date & Time: Saturday, May 17, 2025; 12:00-16:30

Venue: Global Business Hub Tokyo

(3F, Otemachi Financial City Grand Cube, 1-9-2 Otemachi, Chiyoda-ku, Tokyo)

Format: In-person only

Host: Health and Global Policy Institute (HGPI)

12:00-13:00 Networking Session (Optional)

13:00-13:05 Opening Remarks

Yui Kohno (Manager , HGPI)

13:05-15:10 Program1: Talk Session

"The First Step Toward Meaningful Involvement: Moving Forward Together"

Ice Break • Explanatory Introduction

Panel Talk 1: Listening to Real Examples of Involvement

Yutaka Ozawa (Assistant Section Chief, Cancer Control Group, Disease Control Division,

Medical Bureau, Health and Welfare Department, Shizuoka Prefecture)

Hitoshi Fukuhara (Representative Director, Heart Valve Voice)

Kyoko Yamauchi (Representative, Swallow Association)

Facilitator: Honoka Hiraka (Senior Associate, HGPI)

Panel Talk 2: Diverse Experiences from the Field

Mayu Okuno (President, Saitama IBD Association)

Kimie Sakurai (Vice Chair, NPO GISTERS)

Takeshi Shukunobe (President and CEO, PPeCC)

Yuhei Yamada (Representative Director, Porque,

the Organization of Persons with Psychosocial Disabilities)

Facilitator: Orie Yamashita (Associate, HGPI)

15:10-15:25 Break

15:25-16:25 **Program 2: Challenging Workshop**

"Let's Take Our First Step Toward Involvement!"

Explanatory Introduction

Group work

16:25-16:30 **Closing**

開会挨拶

日本医療政策機構は2004年に設立された非営利・独立・超党派の医療政策シンクタンクであり、設立以来「市民主体の医療政策の実現」をミッションに掲げて活動してきた。多様なステークホルダーの意見を丁寧に集約し、中立的な立場から政策提言を行ってきた。その中で、患者・当事者が政策形成過程に関わることの重要性についても、継続的に発信してきた。

近年では、疾患横断的な視点を持ちながら、患者・当事者が政策形成過程に持続的・効果的に参画することを支援する活動にも力を入れている。患者・当事者向けのワークショップの開催や、自治体職員同士の意見交換の場の創出、情報・交流ウェブサイト「みんなの患者・当事者プラットフォーム(J-PEP: Japan's Patient Expert Platform)」の運営など、さまざまな取り組みを展開している。

本日は、全国から患者・当事者の方々だけでなく、行政、アカデミア、企業など、さまざまな立場の皆さま、50名以上の方々にお集まりいただいた。このように多様な視点が交わる場だからこそ、より実りある議論が生まれると考えている。

患者・当事者が政策形成過程に参画することで、そこから生まれる制度への理解・共感につながり、 それがより良い医療の実現を後押しするものとなる。本フォーラムが、その歩みを支える一助となる ことを期待している。



河野 結 (日本医療政策機構 マネージャー)



プログラム1「トークセッション"みんなで進める患者・当事者参画の第一歩"|

パネルトーク1:参画事例について聞いてみよう!

パネルトークから得られた知見

- 医療政策への参画において意見を述べる際は、国・都道府県・市町村といった行政規模の違いを踏まえ、場面に応じた対応が重要である。例えば意見交換では、要望ではなく提案の形で、地域特性 や相手の立場に寄り添った形で伝えることが効果的である。
- 患者・当事者が会議体に参画する際は、自分の考えをよく練り、焦らず時間をかけて準備をすることが大切である。同時に、多様な他者の異なる意見にも耳を傾け、自分の立場だけに偏らないようを心掛けることも重要である。そのうえで、自身の立場から伝えるべきことを見極めて発言をする姿勢が求められる。
- 行政の会議体では合意を目指す場も多く、譲れない部分を意識しつつも、落としどころを探る姿勢が求められる。限られた時間で明確に、機会を逃さずに伝えることが必要である。
- 医療政策への参画では、すぐに成果が見えるとは限らないからこそ、会議体では議事録に残るように意識して継続的に関わることが重要である。また、人とのつながりによって自らの新たな経験や意見につながっていくので、多様な人々とのつながりを大切にすることが、医療政策への参画を継続し広げていく力になる。

登壇者



● 小澤 裕。 (静岡県 健康福祉部 医療局 疾病対策課 がん対策班 主査)



福原 斉 (一般社団法人 心臓弁膜症 ネットワーク 代表理事)



山家 京子 (NPO法人 つばめの会 代表)



プログラム1「トークセッション"みんなで進める患者・当事者参画の第一歩"|

パネルトーク2:いろんなひとの参画経験について聞いてみよう!

パネルトークから得られた知見

- 参画に至るきっかけは、病気・障害との向き合うなかでの変化や、患者・当事者会との出会い、さらには身近な課題へ問題意識を持ったことなど、様々である。いずれにしても、患者・当事者としての「経験」がベースとなり、自分自身の行動へとつながっている。
- 行政・企業・研究者など異なる立場の人々と対話と相互理解を深めるプロセスの中で、自らの経験や声が社会に届いているという実感を得ることができ、それが次なる参画への動機づけとなっている。
- 本来は「一個人」として参画していても、「患者代表」として認識される場面がある。だからこそ、 自分の思いに加え、仲間の声を集めて言語化する姿勢と工夫が求められる。
- 患者・当事者参画を持続可能なものにするには、安心して声を届けられる場づくり、治療や仕事と両立できる柔軟な仕組み、参画経験のある仲間とのつながりが重要である。

登壇者



奥野 真由 (埼玉 IBD の会 (炎症性腸疾患患者会) 代表)



櫻井 公恵 (NPO法人 GISTERS 副理事長)



宿野部 武志 (一般社団法人 ピーペック 代表理事)



山田 悠平 (一般社団法人 精神障害 当事者会ポルケ 代表理事)



プログラム2「チャレンジングワークショップ"参画の一歩を踏み出そう!"

参加者が少人数のグループに分かれ、自己紹介を含む30秒スピーチと、医療政策の患者当事者参画に関する意見交換を行った。グループワークでは、今回のグランドルールである「(1) よく聴いてよく話すこと」「(2) 否定せず、受け止めること」「(3) 時間を意識すること」を大切にしながら進行した。

30秒スピーチでは、それぞれがどのような立場や経験を持ち、何を伝えたいのかを簡潔に表現し、限られた時間の中でもお互いの背景が共有された。

意見交換では、これまでに参画した医療政策に関する会議や、会社や地域の会議など、さまざまな場面で「意見を伝える側」「運営する側」として関わった経験を振り返りながら、各人が自分の思いや立場を言葉にした。日常の中で感じている課題や、これまで気づかなかった他者の視点を織り交ぜることで、活発な対話となった。参加者それぞれが異なる経験や専門性を持っているからこそ、単なる情報交換にとどまらず、「患者・当事者として、また市民として、どう医療政策に関わっていけるか」を考えるきっかけとなるような時間となった。

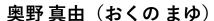








登壇者プロフィール(敬称略・順不同)



埼玉 IBDの会(炎症性腸疾患患者会) 代表

1993年生まれ。2004年指定難病のクローン病診断。2016年から埼玉IBDに入会し、以降スタッフとして活動。2024年より現職。

患者会活動を開始した頃から、医療・福祉関係の勉強会やイベント等に参加。そこで出会ったひとづてに患者としての経験を話す機会をいただく。以降、製薬企業や保健所主催のイベント等での登壇、メディア出演等を行っています。

小澤 裕(おざわ ゆたか)

静岡県 健康福祉部 医療局 疾病対策課 がん対策班 主査

静岡県に薬剤師職として入職し、主に衛生分野での保健所勤務、県庁勤務等を経験してきました。 薬剤師・薬局施策に関わることが多かったですが、2023年度から疾病対策課がん対策班に異動し、循 環器病対策とがん対策を担当しています。

各種会議(県循環器病対策推進協議会、県がん対策推進協議会等)の運営や各種計画(県保健医療計画、県循環器病対策推進計画、県がん対策推進計画)の策定等に携わっています。

櫻井 公恵 (さくらい きみえ)

NPO法人 GISTERS 副理事長

2004年、配偶者が38歳で希少がんのGIST(消化管間質腫瘍)に罹患しました。2006年に任意団体として活動をスタートしたGISTERSは2012年に法人化し、新薬の早期承認を求める要望活動やSNSの運営・セミナー開催などの患者支援活動を行ってきました。また一方、中小企業経営者であることから2014年に厚生労働省「がん患者・経験者の就労支援のあり方に関する検討会」構成員を拝命いたしました。

宿野部 武志(しゅくのべ たけし)

一般社団法人 ピーペック 代表理事

3歳時に慢性腎炎に罹患。18歳時に慢性腎不全により血液透析を開始。2010年に自身の疾患領域である腎臓病分野で起業。2019年より疾患横断型の患者支援団体である一般社団法人ピーペックを設立し病気をもつ人の"こえ"を医療・社会に届ける活動を続けてきました。行政機関における参画経験としては、中医協での意見発表(2022年1月21日)、内閣府規制改革推進会議医療・介護・感染症対策WG出席(2023年2月~2024年6月)。また、現在日本製薬工業協会患者団体アドバイザリーボードメンバー、東京科学大学病院治験等審査委員会委員等を務めています。他の疾患の方や企業・行政・アカデミアの方と協働しており、患者市民参画の輪を誰もが身近に感じながら共により良い医療を創っていけたらと思っています。

福原 斉(ふくはら ひとし)

一般社団法人 心臓弁膜症ネットワーク 代表理事

心臓弁膜症に関する全国組織の患者会を心臓弁膜症を持つ仲間と2019年に設立し、国内外の当事者と支援者と共に心臓弁膜症をもつひとの今とこれからをよくする活動に注力してきました。2019年NCD Alliance主催の「Our Views, Our Voicesワークショップ」に参加し、同年日本でも患者や当事者のアドボカシー能力の強化を目的としたワークショップのピアトレーナーを務めました。循環器病対策基本法や都道府県での推進計画において議員や自治体に要望書を提出する活動も行いました。

登壇者プロフィール(敬称略・順不同)

山田 悠平(やまだ ゆうへい)

一般社団法人 精神障害当事者会ポルケ 代表理事

初めて精神科医療を受診して20年近くが経とうしています。精神科病院の入院経験からピアサポート活動に出会い、精神障害領域の当事者活動に関わりもちはじめました。医療を経験した中での様々な課題感を共有する中で、「社会の課題」として解決することを目指すようになりました。近年では、障害者権利条約の国内審査の過程の中で、パラレルレポート作成の取り組みなどにも取り組んできました。条約のスローガン「私たち抜きに私たちを決めないで」を自分たちからも切り拓くような運動を頑張りたいです。

山家 京子(やまうち きょうこ)

NPO法人 つばめの会 代表

摂食嚥下に問題のある乳幼児、胃ろうや鼻チューブなどの経管栄養を使う乳幼児、極端な偏食・少食・拒食のある乳幼児を育てる親の会を13年前に設立しました。低出生体重児・基礎疾患がある・発達障害の子どもなど疾患に限らず似た問題に悩む保護者のピアサポートをしています。また医療者向けに啓発活動や教育活動を行っています。

2021年から厚生科学審議会 (医薬品医療機器制度部会) の委員を務めています。



Opening Remarks

HGPI is a non-profit, independent, non-partisan health policy think tank that has actively pursued its stated mission of "Achieving citizen-centered health policy" since its establishment in 2004. HGPI carefully synthesizes the opinions of diverse stakeholders to generate policy recommendations from a neutral standpoint. Over the course of its activities, HGPI has continuously advocated for the importance of ensuring that patients and others with lived experience of health concerns are involved in the policymaking process.

With a cross-cutting perspective that spans disease areas, HGPI's focus in recent years has also included supporting continuous and effective involvement for people with lived experience of health conditions in the policy formulation process. HGPI's various initiatives for meaningful involvement include hosting workshops for people with lived experience, providing opportunities for local government officials to exchange opinions, and operating "Japan's Patient Expert Platform (J-PEP)," a website for information and interaction.

Today, we are joined by over 50 people from all over Japan. In addition to people with lived experience, they represent various positions including government, academia, and industry. I think having such diverse points of view intersect at this forum will make our discussions all the more productive.

Involvement from people with lived experience in the policy formulation process will bring about better understanding and support for systems built by that process, which will in turn lead to better healthcare. I have high expectations that this forum will help support such developments.



Yui Kohno (Manager, HGPI)



"The First Step Toward Meaningful Involvement: Moving Forward Together"

Panel Talk 1: Listening to Real Examples of Involvement

Knowledge acquired during panel discussion

- When sharing opinions during health policy participation, it is important for participants to appropriately shape their responses in a manner that takes the differences in scale among national, prefectural, and municipal administrative bodies into account. For example, when sharing one's opinions, it is more effective to express thoughts as proposals rather than as requests and to be accommodating for local characteristics or the other parties' positions.
- When people with lived experience take part in government committees, it is important that they carefully
 organize their thoughts and take time to prepare without rushing. It is also important for them to lend an ear
 to the voices of many other people with different opinions and do their best to avoid being biased toward
 their own position. In addition, they must be ready and willing to offer comments after carefully identifying
 what they can convey from their own position.
- There are many cases in which the aim of government committee meetings is to reach consensus. This
 requires an awareness of items that are non-negotiable and a willingness to accept compromise. Participants
 must be able to convey their thoughts clearly in limited amounts of time and without missing opportunities
 to offer comments.
- It is precisely because efforts to be involved in health policy do not immediately generate results that it is
 important to recognize the need to participate in meetings on a continuous basis and leave one's mark in the
 meeting minutes. Also, because connecting with people can help participants have new experiences or shape
 new opinions, fostering connections with a diverse range of people is great for maintaining and expanding
 involvement in health policy.

Panelists



Yutaka Ozawa
(Assistant Section Chief,
Cancer Control Group,
Disease Control Division,
Medical Bureau, Health and Welfare
Department, Shizuoka Prefecture)



Hitoshi Fukuhara
(Representative Director,
Heart Valve Voice)



Kyoko Yamauchi (Representative, Swallow Association)



"The First Step Toward Meaningful Involvement: Moving Forward Together"

Panel Talk 2: Diverse Experiences from the Field

Knowledge acquired during panel discussion

- There are many reasons why people with lived experience decide to get involved. For example, how they
 approach their disease or disorder may have changed; they may have met a patient advocacy organization; or
 they may have become aware of an issue that is close to them. Regardless of reason, their involvement is
 based on their lived experiences as patients or affected parties, and that is what leads them to take action.
- Over the course of the process of deepening conversations and mutual understanding with people in government, industry, research, or other different positions, people with lived experience can directly feel that their experiences or voices are reaching society, and this is a source of motivation that encourages them to participate again at the next opportunity for involvement.
- Even when a person with lived experience is participating as an individual, they are still somewhat aware that
 they are acting as a patient representative. This is why in addition to expressing their own thoughts, they
 must be willing and able to gather the voices of their peers and put them into words.
- Important aspects for sustainable involvement for people with lived experience are spaces where they can deliver their voices with peace of mind, systems that provide flexibility to manage treatment and employment, and connections with partners who have experience in meaningful involvement.

Panelists



Mayu Okuno (President, Saitama IBD Association)



Kimie Sakurai (Vice Chair, NPO GISTERS)



Takeshi Shukunobe (President and CEO, PPeCC)



Yuhei Yamada (Representative Director, Porque, the Organization of Persons with Psychosocial Disabilities)



Program 2: Challenging Workshop "Let's Take Our First Step Toward Involvement!"

Participants formed small groups where they gave 30-second speeches (including self-introductions) and exchanged opinions on meaningful involvement in health policy. Participants observed three ground rules while completing the group work: (1) listen and speak well; (2) accept what others are saying without contradicting them; and (3) be conscious of time.

Participants shared their backgrounds during the limited time available during their 30-second speeches, which included brief descriptions of their positions, experiences, and messages.

During the opinion exchange, each person shared their own thoughts and views while looking back on their experiences being involved in various settings, on both the side sharing opinions and the side conducting operations. These settings included past meetings on health policy that they had joined or meetings at companies or in communities. Discussions grew lively as participants weaved in issues they felt in daily life and new perspectives from others. As each participant had their own unique experiences and expertise, rather than just being a time to exchange information, these discussions became opportunities for participants to consider how they can take part in health policy as people with lived experience and as citizens.









Speaker Profiles (titles omitted; in no particular order)

Mayu Okuno

President, Saitama IBD Association

Ms. Mayu Okuno was born in 1993. In 2004, she was diagnosed with Crohn's disease, which is a designated intractable disease. She became a member of Saitama IBD in 2016, where she has served as a staff member. She assumed her current position in 2024.

Ms. Okuno has participated in study groups, events, and other gatherings related to healthcare and welfare since the start of her patient advocacy activities. Through the people she encountered at those events, she received opportunities to share her experiences as a patient. Since then, her activities have included speaking at events hosted by organizations like pharmaceutical companies and public health centers, or making media appearances.

Yutaka Ozawa

Assistant Section Chief, Cancer Control Group, Disease Control Division, Medical Bureau, Health and Welfare Department, Shizuoka Prefecture

Mr. Ozawa Yutaka joined the Shizuoka Prefectural Government as a pharmacist and has past experience serving at facilities like public health centers and prefectural offices, mainly in the field of sanitation. While he was often involved in measures related to pharmacists and pharmacies, he transferred to the Disease Control Division's Cancer Control Team in FY2023. There, he leads efforts for CVD and cancer control.

Mr. Ozawa is involved in operating various government committees (including Shizuoka Prefecture's Council for the Promotion of CVD Control and Council for the Promotion of Cancer Control) and formulating prefectural plans (including Shizuoka Prefecture's Medical Care Plan, Plan for the Promotion of CVD Control, and Plan for the Promotion of Cancer Control).

Kimie Sakurai

Vice Chair, NPO GISTERS

In 2004, Ms. Kimie Sakurai's spouse was diagnosed with a rare form of cancer called gastrointestinal stromal tumor (GIST) at age 38. GISTERS was established as a private organization in 2006 and incorporated in 2012. Its various activities for patient support have included requesting accelerated approval for new pharmaceuticals, operating social network accounts, and hosting seminars. In addition, in her capacity as a small business owner, Ms. Sakurai was appointed to the Ministry of Health, Labour and Welfare's Study Group on Ideal Employment Support for Cancer Patients and Survivors in 2014.

Takeshi Shukunobe

President and CEO, PPeCC

Mr. Takeshi Shukunobe developed chronic nephritis at age 3. He began hemodialysis at age 18, after developing chronic renal failure. He launched a business in the area of his own condition, kidney disease, in 2010. In 2019, he established PPeCC, Inc., which is an organization providing patient support across diseases that has been continuously delivering the voices of people living with health conditions to healthcare and society. His experience participating at government institutions includes presenting an opinion at the Central Social Insurance Medical Council on January 21, 2022 and participating in the Working Group on Healthcare, Long-term Care, and Infectious Disease Control at the Cabinet Office's Council for Regulatory Reform from February 2023 to June 2024. Currently, his other roles include Member, Patient Group Advisory Board, Japan Pharmaceutical Manufacturers Association; and Member, Clinical Trial Review Committee, Institute of Science Tokyo Hospital. Mr. Shukunobe works together with people living with other health conditions as well as representatives of industry, government, and academia, and would like to help build better healthcare with his partners while making the circle of meaningful involvement feel close at hand for everyone.

Hitoshi Fukuhara

Representative Director, Heart Valve Voice

In 2019, Mr. Hitoshi Fukuhara founded a national patient advocacy organization for valvular heart disease together with partners living with that condition, and their activities have since focused on improving the present and future for people living with valvular heart disease together with affected parties and supporters from Japan and overseas. In 2019, Mr. Fukuhara participated in the "Our Views, Our Voices" workshop hosted by NCD Alliance and served as a peer trainer for a workshop for strengthening advocacy capacity among patients and others with lived experience in Japan. His other activities include submitting requests to Diet members and local governments regarding the Basic Act on Stroke, Heart Disease, and Other CVDs to Extend Healthy Life Expectancies and prefectural plans for the promotion of CVD countermeasures.

Speaker Profiles (titles omitted; in no particular order)

Yuhei Yamada

Representative Director, Porque, the Organization of Persons with Psychosocial Disabilities

It has been almost two decades since Mr. Yuhei Yamada first began receiving psychiatric care. His initial encounter with peer support activities stems from his experiences being hospitalized in a psychiatric hospital, which also led to his involvement in patient advocacy activities in the area of psychiatric disorders. Over the course of sharing various challenges he encountered during his experiences with healthcare, he began to set his sights on addressing those that could be considered challenges for society. In recent years, he has also been involved in the process of investigating Japan's adherence to the Convention on the Rights of Persons with Disabilities, including the creation of parallel reports. Mr. Yamada would like to continue actively contributing to the movement to help people open new paths under the slogan of that Convention, "Nothing about us without us."

Kyoko Yamauchi

Representative, Swallow Association

Thirteen years ago, Ms. Kyoko Yamauchi established the Swallow Association for parents raising infants with feeding and swallowing disorders, infants who use feeding tubes (such as percutaneous endoscopic gastrostomy tubes or nasogastric tubes), or infants with extremely unbalanced diets, small appetites, or that will not eat. She is also engaged in peer support for parents who share similar issues and that is not limited to specific diseases. Those parents include those with babies with low birth weights, children with underlying medical conditions, and children with developmental disabilities. She is also engaged in awareness-raising and educational activities for healthcare professionals.

Ms. Yamauchi has also served as a member of the Pharmaceutical and Medical Device Systems Subcommittee of the Health Science Council since 2021.



日本医療政策機構について

日本医療政策機構(HGPI: Health and Global Policy Institute)は、2004 年に設立された非営利、独立、超党派の民間の医療政策シンクタンクです。市民主体の医療政策を実現すべく、中立的なシンクタンクとして、幅広いステークホルダーを結集し、社会に政策の選択肢を提供してまいります。特定の政党、団体の立場にとらわれず、独立性を堅持し、フェアで健やかな社会を実現するために、将来を見据えた幅広い観点から、新しいアイデアや価値観を提供します。日本国内はもとより、世界に向けても有効な医療政策の選択肢を提示し、地球規模の健康・医療課題を解決すべく、これからも皆様とともに活動してまいります。当機構の活動は国際的にも評価されており、米国ペンシルベニア大学のローダー・インスティテュート発表の「世界のシンクタンクランキング報告書」における「国内医療政策」部門で世界2位、「国際保健政策」部門で世界3位に選出されています(2021年1月時点(最新データ))。

About Health and Global Policy Institute

Health and Global Policy Institute (HGPI) is a non-profit, independent, 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 will continue to be very active in creating policies for resolving global health challenges. HGPI's activities have received global recognition. It was ranked second in the "Domestic Health Policy Think Tanks" category and third in the "Global Health Policy Think Tanks" category in the Global Go To Think Tank Index Report presented by the University of Pennsylvania (as of January 2021, the most recent report).

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協賛企業 (五十音順)

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