Proposal on Achieving Better Communication Between Healthcare Providers and Beneficiaries

Building a Flat Healthcare System That Draws Upon Both Sides of Healthcare Equally

Introduction

Listening to the Voices of Those Most Affected to Build a Flat Healthcare System That Draws Upon Both Sides of Healthcare Equally

Non-communicable diseases (NCDs) cause approximately 71% of all deaths worldwide,[1] making the implementation of effective measures for NCDs an urgent issue facing society. Until the 1950s,[2] the leading causes of death in Japan were infectious diseases, but NCDs such as cancer and stroke currently cause around 82% of deaths in Japan,[3] making NCD countermeasures a significant issue for Japan as well. For many infectious diseases, people receive treatment provided by medical staff while symptoms are present and can return to their normal everyday lives once they fully recover. However, managing NCDs requires long-term lifestyle changes, similar to chronic diseases. Healthcare and daily living become inseparable and must be kept in balance by people living with NCDs (PLWNCDs) over the long term. To uphold their roles in society, to live with a sense of purpose, and to achieve lifelong dreams and other aspirations, PLWNCDs must work with medical staff[4] as partners while maintaining harmony between daily living and their disease. These conditions do not apply only to PLWNCDs; they also apply to people with various chronic diseases such as intractable diseases or long-term infectious diseases such as HIV/AIDs. The 2016 Comprehensive Survey of Living Conditions[5] conducted by the Ministry of Health, Labour and Welfare (MHLW) found that 390.2 out of every 1000 people in Japan regularly visit healthcare institutions for some disease. If an increasing number of diseases can be controlled by advances in medicine while population aging advances and daily routines for the general population continue to shift, it is likely that the number of people who can lead normal everyday lives while receiving long-term care will continue to increase. In response to this situation, we met with PLWNCDs, people living with various chronic diseases, and stakeholders involved in healthcare to examine methods for constructing sustainable healthcare and social systems and to identify measures needed to develop those systems further.

"Nothing about us without us" was used as a slogan to represent the feelings of people with disabilities during the creation of the Convention on the Rights of Persons with Disabilities and is a well-known phrase made famous by its use in many fields of activism. These words communicate the fact that the people directly affected by an issue understand the problems facing them better than

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[1] World Health Organization (2018), "Noncommunicable diseases country profiles 2018"
https://apps.who.int/iris/handle/10665/274512 Last retrieved June 25, 2020.

[2] Ministry of Health, Labour and Welfare (MHLW). *White Paper on the Labour Economy 2014*. pp.11
https://www.mhlw.go.jp/wp/hakusyo/kousei/14/dl/1-01.pdf Last retrieved July 17, 2020.

[3] World Health Organization (2018), "Noncommunicable diseases country profiles 2018"

[4] Refers to all people engaged in providing healthcare.

[5] MHLW. "2016 Comprehensive Survey of Living Conditions." https://www.mhlw.go.jp/toukei/saikin/hw/k-tyosa/k-tyosa16/dl/06.pdf Last retrieved June 25, 2020.

anyone else. These words emphasize empowerment[6] and aim to restore rights to the people affected by an issue who were previously only treated as the target of protection so they can be placed in positions of equal importance to those held by other stakeholders playing critical roles in the policy formulation and implementation processes. This slogan also applies to people living with diseases, who are the direct recipients of and parties most affected by healthcare.

Taking an overhead look at the situation in Japan, where parties on the supply side of healthcare are considered to have the most direct and significant influence when formulating healthcare policy and building healthcare systems, active efforts to reform the healthcare system are advancing with a focus on healthcare providers. In addition to these supply-side reform efforts, however, we anticipate that demand-side reform which focuses on people on the receiving side of healthcare (namely, people with diseases and the people close to them) will be needed to successfully create a better healthcare system that improves quality of life (QOL) for every member of the public. We also look forward to the reinforcement of efforts promoting cooperation among people receiving healthcare and healthcare providers. In the previous era, healthcare policy was shaped and advanced by a few specific stakeholders. Moving forward, if we do not transition to an era in which those developments are driven by numerous unspecified stakeholders, it is likely that maintaining sustainable healthcare and social systems will be difficult because the public – which supports the healthcare system through health insurance premiums and labor – will grow less engaged in healthcare policy in the medium-to long-term. In addition to people with diseases, members of the wider public are also among the parties most affected by healthcare policy and systems, so from the perspective of using resources effectively, systems that make full use of the inherent power of the public to engage in promoting health and medicine must be designed.

With that backdrop, our "Proposal on Achieving better Communication between Healthcare Providers and Beneficiaries" clarifies the status of and issues facing cooperation in clinical settings[7] between people receiving healthcare and medical staff. It also provides recommendations for overcoming those issues and for promoting cooperation. During the creation of this proposal, Coronavirus Disease 2019 (COVID-19) began to spread rapidly around the world, giving many members of the public the opportunity to see that their cooperation is essential to sustain healthcare services. With the deepest gratitude to everyone working in healthcare, we will cooperate with various stakeholders including the public to keep the content of this proposal up-to-date and relevant to the current situation as we continue working towards achieving a flat healthcare system that draws

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[6] Empowerment: Drawing out the inherent potential of or inspiring an individual or group by granting them authority or enhancing their capacity to act.

[7] Refers to settings in which people receiving healthcare receive medical examinations or treatment.

out the abilities of parties on both sides of healthcare in an equal manner.

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1   Introduction

1.1 Introducing Health and Global Policy Institute

Health and Global Policy Institute (HGPI) is a Tokyo-based independent and non-profit health policy think tank established in 2004. In its capacity as a neutral think-tank, HGPI involves stakeholders from wide-ranging fields of expertise to provide policy options to the public to successfully create citizen-focused healthcare policies. Looking to the future, HGPI produces novel ideas and values from a standpoint that offers a wide perspective. It aims to realize a healthy and fair society while holding fast to its independence to avoid being bound to the specific interests of political parties and other organizations. HGPI intends for its policy options to be effective not only in Japan, but also in the wider world, and in this vein the institute is very active in creating policies for resolving global health challenges.

1.2 Introducing NCD Alliance Japan[8]

NCD Alliance Japan is a collaborative platform operated by HGPI for engaging civil society and promoting countermeasures for NCDs such as cancers, cardiovascular diseases (CVDs), diabetes, chronic respiratory diseases, and mental and neurological disorders. NCD Alliance is a collaborative platform bringing together over 2000 civil society organizations and academic institutions in more than 170 countries, and NCD Alliance Japan has operated as its Japanese branch since 2013. We became a full member of the NCD Alliance on January 17, 2019. Through three key activities, which are formulating policy proposals, supporting PLWNCDs and other parties most affected by NCDs, and conducting survey research, NCD Alliance Japan aims to unite PLWNCDs and other parties most affected by NCDs with multi-stakeholders in industry, government, academia, and civil society from Japan and abroad to contribute to solving issues in the field of NCDs.

1.3 Defining NCDs

According to the World Health Organization (WHO), the term "noncommunicable diseases" refers to chronic diseases such as cancer, diabetes, cardiovascular diseases (CVDs), chronic respiratory diseases, and mental and neurological disorders. These diseases tend to occur due to genetic, physiological, environmental, and behavioral factors and can be caused or worsened by an unhealthy diet, a lack of exercise, smoking, or excessive alcohol use. According to WHO statistics, NCDs are the cause of 82% of deaths in Japan and 71% of deaths worldwide,[9] making the establishment of NCD countermeasures an urgent issue.

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[8] NCD Alliance Japan uses the abbreviation "NCD" with the express permission of National Clinical Database (NCD), which is a registered trademark.
[9] World Health Organization (2018), "Noncommunicable diseases country profiles 2018"

2   Executive summary

Looking to 2040, when rapid demographic change caused by a falling birthrate and population aging will result in significant healthcare supply shortages, the Japanese government has begun implementing comprehensive reforms of the healthcare provision system called the Trinity Reforms of Healthcare Policy. These reforms include the Regional Medical Initiative, measures against the uneven distribution of doctors, and work style reform for doctors and other medical professionals. However, many stakeholders from each domain have voiced their apprehension or disagreement towards these revolutionary reforms, slowing their implementation. One of the causes for that delay is insufficient involvement of patients and other parties on the receiving side of healthcare services. Although recognition towards the importance of involving patients and other affected parties in the healthcare policy formulation process has grown in recent years, these efforts have not advanced to the point that the people on the receiving side of healthcare services have the most direct and substantial influence on the healthcare policy formulation process.

In response, NCD Alliance Japan has created this proposal so that future health policy in Japan can create a flat healthcare system that allows parties on both sides of healthcare to participate while making full use of their abilities. Our workshops and hearings demonstrated that cooperation from both of those parties is absolutely essential to build a flat healthcare system. Among the three types of cooperation that will be necessary to successfully create a flat healthcare system, we have placed a particular focus on cooperation within clinical settings, which many patients and other affected parties recognize as a significant challenge. To identify current issues and factors that obstruct cooperation within clinical settings, we conducted a public opinion survey and series of in-depth interviews[10] exploring that theme.

Our public opinion survey showed that over 90% of respondents said they want their opinions and preferences to be taken into account when making decisions concerning the direction of treatment and when selecting medicines. However, less than 30% of respondents were accustomed to independently participating in healthcare, about 40% of respondents were dependent on the situation, and the remaining group, which was over 30% of respondents, said that they could not proactively participate in healthcare. This result shows that there is a mismatch in the will to participate and the real-world circumstances surrounding cooperation during important decision-making opportunities such as when deciding the direction of treatments or when selecting medicines. Three factors obstructing cooperation were identified in our in-depth interviews: a lack of empowerment for patients and other affected parties, shortcomings from partners during

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[10] One-on-one interviews conducted with a member of the survey target group and the interviewer.

opportunities to cooperate, and insufficient preparation of the environment.

To overcome these three hurdles, to foster cooperation in clinical settings, and to successfully create a flat healthcare system that draws equally upon the abilities of both those providing healthcare and those receiving it, NCD Alliance Japan has generated examples of concrete actions to be taken by each stakeholder from the following four perspectives.

Four perspectives for successfully creating a flat healthcare system

Perspective 1: Empower people receiving healthcare

(1) Provide health education that includes information on diseases and health, how to select the right healthcare institutions and the best times to visit them, how to make the most out of visits to healthcare institutions, and other such information.

(2) Verify and support trustworthy medical information websites so people can access accurate medical information.

(3) Promote the development of decision aids and other decision-making guides as well as the effective use of existing tools.

Perspective 2: Emphasize communication when training medical staff

(1) Implement education and training programs that emphasize communication and Shared Decision Making (SDM) in educational processes for all disciplines.

(2) Train family doctors and general practitioners and promote their placement in every region.

Perspective 3: Build systems to support decision-making among people receiving healthcare for topics related to health and healthcare

(1) Establish counselling support systems within healthcare institutions.

(2) Gather evidence and create quality standards to promote the effective use of peer support.

(3) Make effective use of information technology (IT) to share information between people receiving healthcare and medical staff.

Perspective 4: Establish cooperative systems for the entire life course

(1) Achieve team-based medicine that includes the people receiving healthcare on treatment teams.

(2) Build a framework for collecting feedback from people receiving healthcare.

(3) Construct a platform for promoting cooperation.

Examples of specific actions for each stakeholder to take

Members of the public (including patients and other parties most affected) should:

- ✓ Use trustworthy sites when looking up medical information.
- ✓ Think about their preferred types of healthcare and future lifestyles before developing diseases and create opportunities to communicate those preferences to family members and supporters.
- ✓ Make time to think about how to select the most fitting healthcare institutions and visit times and how to make the most of those visits. Use decision-making guides and similar tools when doing so.
- ✓ Find family doctors with whom they can share their healthcare preferences and desired future lifestyles.
- ✓ Develop an interest in building networks and forming communities among people receiving healthcare and seek decision-making support for topics related to health or healthcare.
- ✓ Cooperate with academia, medical staff, and the Government in efforts to build evidence for effective types of peer support, such as by participating in verification studies or helping to identify best practices.
- ✓ Proactively engage in reviewing decision-making processes for health and healthcare and providing feedback to medical staff when such opportunities arise.
- ✓ Be conscious of consulting healthcare specialists other than physicians.

The Government should:

- ✓ Implement educational programs at elementary and middle schools that teach students about topics like how to select and use healthcare institutions or the best methods of communicating with medical staff in addition to providing them with information on diseases, healthy lifestyle habits, and similar knowledge.
- ✓ Engage in efforts to promote health education and provide accurate medical information so members of the public can access information on and think about decision-making for topics related to healthcare and health before developing diseases.
- ✓ Help disseminate decision aids and other decision-making guides that foster cooperation between medical staff and people receiving healthcare.
- ✓ Establish systems to support decision-making among people receiving healthcare with multidisciplinary cooperation, starting with family doctors and general practitioners.
- ✓ While cooperating with healthcare institutions and insurers, examine the best methods for providing information to the public on healthcare institutions that provide family doctor services.
- ✓ Recognize the need for communication between people receiving healthcare and medical staff and SDM in clinical settings and provide leadership in efforts to provide training on

communication and SDM to all medical staff.

- ✓ Provide financial assistance for developing programs and constructing guidelines that effectively teach communication and SDM methods.
- ✓ Establish consultation offices within healthcare institutions where patient supporters, such as their family members, can receive counseling.
- ✓ Examine the best way to evaluate and reward healthcare institutions that implement consultation support services for people receiving outpatient care, such as by requiring users to make small payments for those services.
- ✓ Consider methods of reforming consultation support services within healthcare institutions to standardize the quality of such services, such as by requiring all parties responsible for providing counselling services within healthcare institutions to undergo training or by defining indicators to use as conditions to qualify for the Patient Support System Improvement Premium. An example of one such indicator might be the ratio of the number of consultations to the total number of hospitalized patients.
- ✓ Acknowledge and reward effective efforts to provide peer support consultations undertaken by municipalities.
- ✓ While collaborating with the private sector, promote research and development on products and services that promote cooperation between people receiving healthcare and medical staff such as treatment apps or tools for online medical examinations and information sharing.
- ✓ Conduct user satisfaction surveys for all healthcare institutions and utilize user feedback when building healthcare provision systems.
- ✓ Establish a platform that promotes cooperation by creating networks among related parties or by providing matching support.
- ✓ Establish a framework for evaluating and verifying products and services provided by the private sector that satisfy the needs of the public.

Medical staff should:
- ✓ Conduct training within healthcare institutions using decision aids and other decision-making guides and tools developed by academic societies.
- ✓ Consider requiring communication training programs to be included in educational programs for specialist doctors.
- ✓ Proactively participate in training programs on communication and SDM.
- ✓ Reinforce healthcare institutions' systems that provide on-site consultation support to people receiving healthcare.
- ✓ Examine how to make effective use of consultation support systems for people receiving healthcare and their supporters, such as their family members.

✓ Conduct user satisfaction surveys targeting people receiving healthcare and, based on the results, establish on-site systems at healthcare institutions for exploring ways to improve care.

✓ Promote the use of online medical examinations, tools for sharing information between people receiving healthcare and medical staff, and treatment apps.

The private sector (including companies and organizations) should:

✓ Promote awareness-building and educational programs for improving health literacy among employees and make efforts to implement working-style reform and help employees manage their health.

✓ Advance research and development on products and tools that promote cooperation between people receiving healthcare and medical staff, such as treatment apps and tools for online medical examinations and information sharing.

✓ Advance research and development on products and services for efficiently collecting feedback from people receiving healthcare.

3   Steps towards the creation of a flat healthcare system

3.1 The current situation surrounding healthcare policy in Japan

Japan's national health insurance system covers every citizen so they can access the necessary healthcare services while shouldering a certain portion of the burden and this system has received recognition from the international community. Maintaining a high standard of public health has led to average life expectancies that are among the longest in the world; the average life expectancies in Japan are 87.32 years for women and 81.25 years for men.[11] However, Japan is currently facing a wide range of serious issues, including rapid demographic change caused by a shrinking birthrate, population aging, and population decline; obstacles to economic growth, segmentation of the middle class, and transformation of regional communities; and changes to the disease structure that has expanded the need for healthcare and long-term care, increasing prices accompanying advances in healthcare technology, and heavy workloads for physicians.

To respond to these various issues accompanying these changes in society, the Japanese Government has initiated the Trinity Reforms of Healthcare Policy with its sights set on 2040. These reforms include the Regional Medical Initiative, work-style reform for doctors and medical professionals, and measures against the uneven distribution of doctors, all of which are reforms targeting the supply side of healthcare. However, there have been many voices of uncertainty or disagreement to these systemic reforms from various stakeholders, with a significant gap in opinions among regions. One factor that may currently be slowing the implementation of these reforms is insufficient involvement from people receiving healthcare. Although recognition towards the importance of involving patients and other affected parties in the healthcare policy formulation process has grown in recent years, these efforts have not advanced to the point that the people on the receiving side of healthcare services have the most direct and substantial influence on the healthcare policy creation process. In addition to creating more opportunities for people receiving healthcare to be involved in that process, it is necessary to emphasize the active involvement of every citizen, who are the parties most affected by healthcare, in efforts to promote health or by educating them on how to make effective use of healthcare institutions and pharmacies.

3.2 The need to construct the flat healthcare system we envision

Based on this background, NCD Alliance Japan believes future healthcare policy in Japan must create a flat healthcare system that allows for equal participation from both the supplying and receiving sides of healthcare. In this document, we define a "flat healthcare system" as one in which (1) necessary knowledge and information is shared among each stakeholder, (2) all citizens, including

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[11] MHLW. Abridged Life Tables for 2018.https://www.mhlw.go.jp/toukei/saikin/hw/life/life18/dl/life18-15.pdf. Last retrieved June 25, 2020.

patients, healthcare beneficiaries, and medical staff can participate voluntarily and with peace of mind, and (3) improving daily living, quality of life (QOL), and satisfaction levels is emphasized alongside treating diseases, and is (4) operated as a sustainable healthcare system in an effective, efficient manner.

Compared to the current healthcare system, a flat healthcare system allows healthcare providers and recipients to have equal relationships, and their abilities are drawn upon equally. This difference is illustrated in Figure 1. In past workshops and hearings conducted by NCD Alliance Japan, participants pointed out that it is absolutely essential to draw out the powers of both healthcare providers and healthcare recipients to the greatest extent possible in this manner and allow both parties to participate in healthcare under the basis of mutual cooperation.
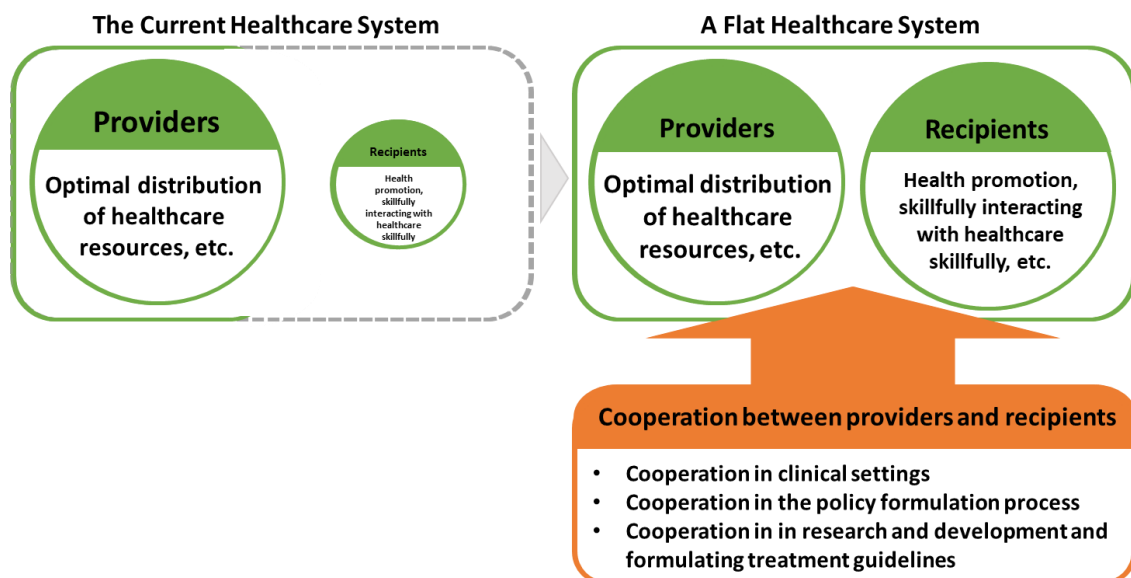
Figure 1: Illustration of a flat healthcare system

3.3 Defining "cooperation" and examining three settings in which people on both sides of healthcare can cooperate

Cooperation between healthcare providers and beneficiaries is a crucial element for successfully building a flat healthcare system. NCD Alliance Japan defines "cooperation" as "A state in which stakeholders including patients and other parties most affected can collaborate in a manner that surpasses the boundaries of roles by sharing the latest knowledge, information, or opinions with each other continuously and while being aware of each other's roles with the goal of improving QOL for

people receiving healthcare or to uphold their dignity and rights."[12] Additionally, we believe that cooperation of this sort exists in the three settings described below.

(1) Cooperation in clinical settings
"Cooperation in clinical settings" mainly refers to cooperation that takes place in healthcare institutions during which physicians, nurses, and other medical staff and patients or other healthcare beneficiaries communicate or engage in decision-making. Also, that mutual cooperation must not only take place at predetermined times; it must take place continuously and at every step in the entire patient journey,[13] starting with the detection of a disease to diagnosis, treatment, and daily living after treatment.

(2) Cooperation in the policy formulation process
"Cooperation in the policy formulation process" is cooperation with the goal of influencing the Government's policy decision-making process conducted through actions undertaken by members of civil society or cooperation between citizens and the Government or the legislation in the policy formulation process. This cooperation is not limited to voting, but also includes participation in Government activities. Examples of those activities include participating in deliberation councils established by government agencies, making policy proposals, and cooperating with survey activities and their publication.

(3) Cooperation in research and development and establishing treatment guidelines
This type of cooperation occurs when citizens cooperate with researchers, private corporations, and similar parties in medical research or clinical trials. Specifically, in medical research or clinical trials, we believe this includes situations in which patients and other citizens are study participants, when researchers share information or knowledge gained from the results of studies with society, and when patients and citizens form partnerships with researchers and are involved in planning, designing, managing, and evaluating research as well as disseminating the results.[14]

3.4 Why we have focused on cooperation in clinical settings
Among the three settings described above, it became clear over the course of the workshops and hearings conducted by NCD Alliance Japan in the past that many patients and related parties were particularly aware of problems in clinical settings related to communication with medical staff or

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[12] Both definitions from NCD Alliance Japan.
[13] The series of events that take place in the life of a person receiving healthcare including detecting a disease, diagnosis, treatment, and daily living thereafter.
[14] Japan Agency for Medical Research and Development, 2019. *Patient and Public Involvement (PPI) Guidebook*, pp.7. https://www.amed.go.jp/ppi/guidebook.html. Last retrieved July 17, 2020.

support for decision-making on health and medical treatment. Furthermore, many PLWNCDs require treatment that spans long periods of time, regular visits to healthcare facilities, and treatments using pharmaceuticals or that require diet management, and they must balance these treatments with the activities of day-to-day life, such as employment or hobbies. Longer treatment times mean PLWNCDs must work harder to maintain relationships with medical staff compared to people whose diseases require treatments that end after relatively short periods. Therefore, we can say cooperation in clinical settings is essential. The progression of NCDs can be greatly affected by individual daily routines, so awareness and acceptance towards treatment from PLWNCDs is essential. By completing processes in which medical staff and people receiving healthcare make joint decisions concerning treatment plans, it improves medication adherence and behavioral change, helps services to be provided in a more effective and efficient manner, and improves treatment outcomes. For these reasons, this proposal focuses on cooperation in clinical settings.

3.5 Eight requirements for cooperation in clinical settings

Defining cooperation in clinical settings as, "A state in which both people receiving healthcare and medical staff can reach consensus on treatment plans and are able to alter those plans after people receiving healthcare discuss how they want to live their lives, their desired future lifestyles, and their needs and desires towards their purpose in life with medical staff." This proposal identifies eight items we consider absolutely essential for cooperation in clinical settings. Based on this definition and these elements, this proposal will provide recommendations for successfully achieving a flat healthcare system based on surveys and analyses of the current situation surrounding cooperation between people receiving healthcare and medical staff and factors obstructing cooperation.

● **People receiving healthcare should have:**

（1）The ability to think about how they want to live their lives, their desired future lifestyles, and their own needs and desires towards their purpose in life.

（2）The ability to tell their families and supporters how they want to live their lives, their desired future lifestyles, and their needs and desires towards their purpose in life.

（3）The ability to communicate how they want to live their lives, their desired future lifestyles, and their needs and desires towards their purpose in life to medical staff.

● **Medical staff should have:**

（4）Awareness towards the need to ask people receiving healthcare to share how they want to live their lives, their desired future lifestyles, and their needs and desires towards their purpose in life.

（5）The ability to listen to people receiving healthcare when they share how they want to live their

lives, their desired future lifestyles, and their needs and desires towards their purpose in life.

（6）The ability to form treatment plans based on how people receiving healthcare want to live their lives, their desired future lifestyles, and their needs and desires towards their purpose in life.

● **Requirements for both parties:**

（7）After people receiving healthcare consent to treatment plans through interacting with medical staff, they must be able to decide on a treatment plan together with medical staff.

（8）It must be possible for people receiving healthcare and medical staff to have regular conversations about updating treatment plans in accordance to changes in the patient's life plan or feelings.

4 Surveys

4.1 Overview of the two surveys conducted

To grasp the situation surrounding cooperation between people receiving healthcare and medical staff in clinical settings when formulating this proposal, we conducted one quantitative survey and one qualitative survey with the goal of clarifying the obstructing factors to cooperation on both the supplying and receiving sides of healthcare. Details on these surveys are given in Figure 2. In the first survey, the main purpose was to grasp the situation surrounding cooperation between people receiving healthcare and medical staff. To do that, we conducted a nationwide public opinion survey of 1,000 men and women age 20 and over. In the second survey, we conducted in-depth interviews with three people representing the parties most affected with the main goal of identifying factors obstructing cooperation between people receiving healthcare and medical staff and the backgrounds to those factors. The interviewer was a cultural anthropologist and obstructive factors and their backgrounds were collected by observing psychological or behavioral patterns that interview subjects may not have been particularly aware of themselves.

As such, this study used a mixed method using a quantitative survey and a qualitative survey. The complementary nature of the two surveys allowed us to get a clear view of the situation surrounding cooperation between people receiving healthcare and medical staff and factors obstructing that cooperation from multiple perspectives.

Type		Overview
Quantitative survey	Public opinion survey	Nationwide online survey of 1,000 men and women
Qualitative survey	In-depth interviews	Unstructured interviews with three patients or related parties; three interviews per subject

Figure 2: Overview of surveys conducted as part of this study

4.2 Overview of both surveys and their results

Overviews for each survey and their results are detailed below. Information for the public opinion survey is provided first and information for the in-depth interviews is provided second, followed by our observations on the results of both surveys.

Survey 1: Public opinion survey

(1) **Survey overview**

An internet-based public opinion survey was administered to 1,000 males and females over 20 years of age throughout Japan during March 2020. The breakdown of respondent demographics is shown in Figure 3. Respondents were selected by region, age, and sex in ratios in that correspond to the demographics of the total population of Japan. The survey was administered only to those who gave informed consent after being provided an explanation of the survey's objectives. The survey was self-administered and a serial number was given to each respondent to ensure anonymity.

Survey Overview | Figure 3

- Survey Period: March 2020

- Method: Online survey

- Respondents: 1,000 nationally representative males and females aged 20 and above, selected from the monitor panel of the research firm that conducted the survey

- Number of valid responses: 1,000

- Breakdown of respondent demographics

Region		Age group		Sex	
Hokkaido - Tohoku	11.1 %	20s	13.3 %	Male	49.7%
Kanto	34.5 %	30s	15.5 %	Female	50.3%
Chubu	17.9 %	40s	19.7 %		
Kinki	16.4 %	50s	17.0 %	Medical history	
Chugoku - Shikoku	8.8 %	60s	18.2 %	Present	97.0%
Kyushu - Okinawa	11.3 %	70s	16.3 %	Absent	3.0%

Source: Health and Global Policy Institute, "Public Opinion Survey on Cooperation between Providers and Recipients in Healthcare."

(2) **Survey results**

Key findings of the public opinion survey

The public opinion survey was conducted with the goal of clarifying the general situation surrounding cooperation between people receiving healthcare and medical staff. Its key findings are described below.

✓ **92.9% of respondents said they want treatment plans or medicines to be selected according to their opinions, preferences, daily routines, and desired future lifestyles.**

✓ **When asked about their ability to communicate symptoms to physicians when receiving medical examinations at hospitals, 79.0% of respondents said they can communicate such information. However, only 28.6% said they always do so, 38.0% only do so sometimes, and 33.4% never or almost never communicate such information.**

✓ **Compared to respondents with family doctors, fewer than half of respondents without family doctors said they always tell medical staff their opinions, preferences, daily routines, and desires towards future lifestyles when selecting treatment plans or medicines.**

✓ **When asked why they could not always tell medical staff their opinions, preferences, daily routines, and desired future lifestyles, the most common responses were "The doctor doesn't ask" (44.0%), followed by "I don't possess medical knowledge" (38.9%).**

✓ **Over 61.5% of respondents said that physicians are the easiest people to talk to among health workers.**

✓ **70.0% of respondents said that they did not have a clear idea what their desired future lifestyle would be if they developed a disease before they had a disease.**

✓ **Over 72.5% of respondents said they had not told their families or loved ones what their desired future lifestyle would be if they developed a disease before they had a disease.**

Survey results

● **Respondent attributes**

  ✓ **Past medical history**

    When asked about their medical history, 63.3% of all respondents had no past illnesses. Among the options provided by the survey, the next most common response was "Other" (14.5%), followed by "Respiratory disease" (7.1%), "Mental disorder" (6.1%), and "Diabetes" (5.5%) (Figure 4).

Medical History | **Figure 4** |

Q: Please select all items that apply to your personal medical history.

(March, 2020, n=1,000)
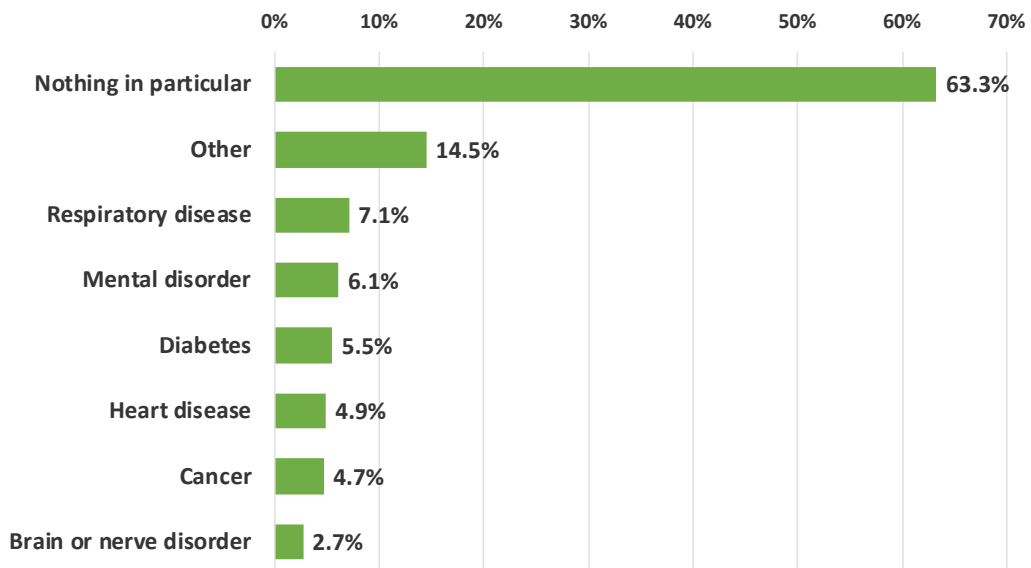
Nothing in particular	63.3%
Other	14.5%
Respiratory disease	7.1%
Mental disorder	6.1%
Diabetes	5.5%
Heart disease	4.9%
Cancer	4.7%
Brain or nerve disorder	2.7%

Source: Health and Global Policy Institute, "Public Opinion Survey on Cooperation between Providers and Recipients in Healthcare."

✓ **Family doctors**

We asked respondents if they had a family doctor. The most popular response was "No, but there is a hospital or clinic I visit frequently" (40.9%), followed by "I do" (31.9%), and "I do not" (27.2%) (Figure 5).

Presence of family doctor	Figure 5

Q: Do you have a family doctor*?

(March, 2020, n=1,000)

40.9%	31.9%	27.2%

■ **No, but there is a hospital or clinic I visit frequently** ■ I do ■ I do not

* A family doctor is a close and trusted physician one can consult on any topic concerning health and depend upon for references to specialist healthcare institutions when necessary.

Source: Health and Global Policy Institute, "Public Opinion Survey on Cooperation between Providers and Recipients in Healthcare."

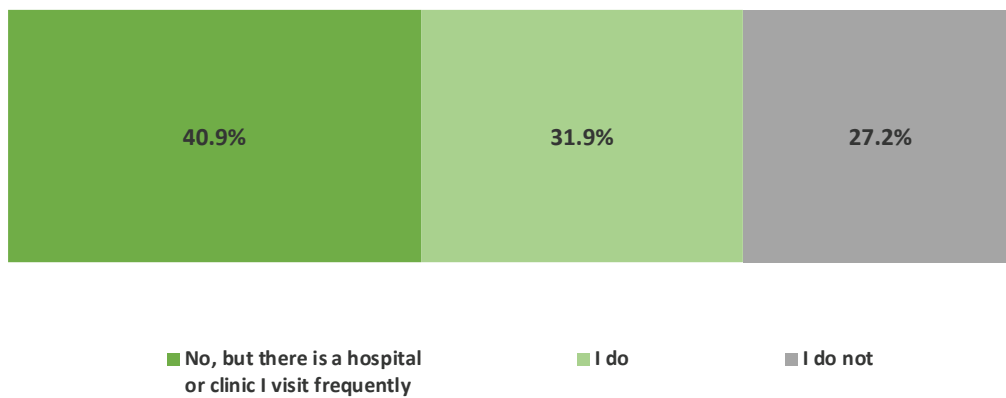- **Desire to cooperate and current situations surrounding cooperation**
    - ✓ **Desire to cooperate when selecting treatment plans or medicines**

        Our survey asked, "When selecting treatment plans or medicines, do you want selections to be made according to your opinions, preferences, daily routines, and desired future lifestyle?" Most respondents (92.9%) either said they wanted to make selections based on those factors (48.7%) or that they somewhat wanted to make selections based on those factors (44.2%) (Figure 6).
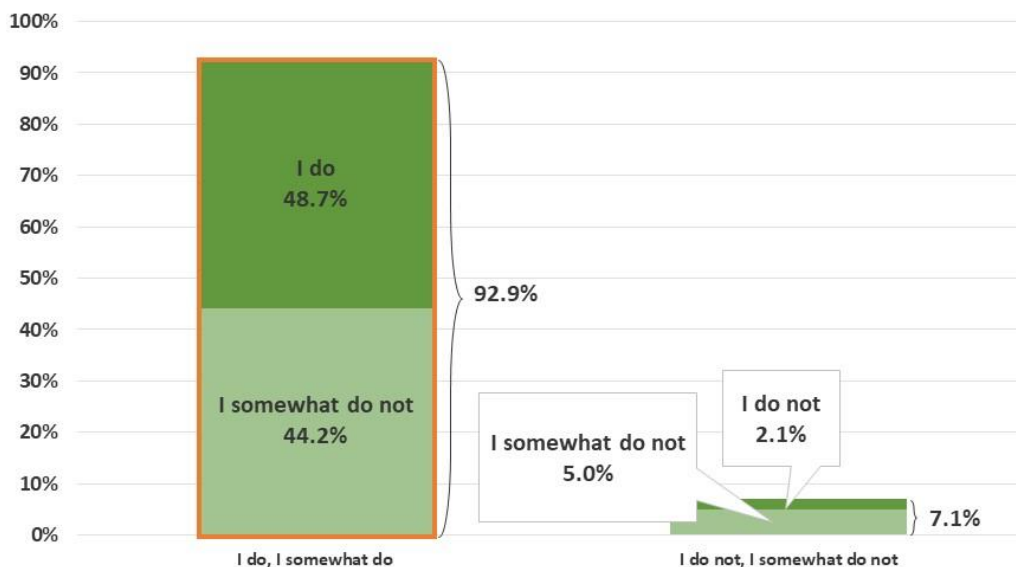
Preferences when deciding treatment plans or medicines

Q: When selecting treatment plans or medicines, do you want selections to be made according to your opinions, preferences, daily routines, and desired future lifestyle?

(March, 2020, n=1,000)

Source: Health and Global Policy Institute, "Public Opinion Survey on Cooperation between Providers and Recipients in Healthcare."

✓ **Communication during medical examinations (1): Can you communicate your symptoms to physicians?**

We asked "Can you communicate your symptoms to physicians when receiving medical examinations at hospitals?" Most respondents (79.0%) said that they can always tell physicians about their symptoms, while 14.6% of respondents selected "I sometimes can," 5.6% chose "I can't communicate them very well," and 0.8% responded "I cannot communicate them" (Figure 7).

Communication during medical examinations (1)

Figure 7

Q: Can you communicate your symptoms to physicians when receiving medical examinations at hospitals?

(March, 2020, n=1,000)

I always can	79.0%
I sometimes can	14.6%
I can't communicate them very well	5.6%
I cannot communicate them	0.8%

Source: Health and Global Policy Institute, "Public Opinion Survey on Cooperation between Providers and Recipients in Healthcare."

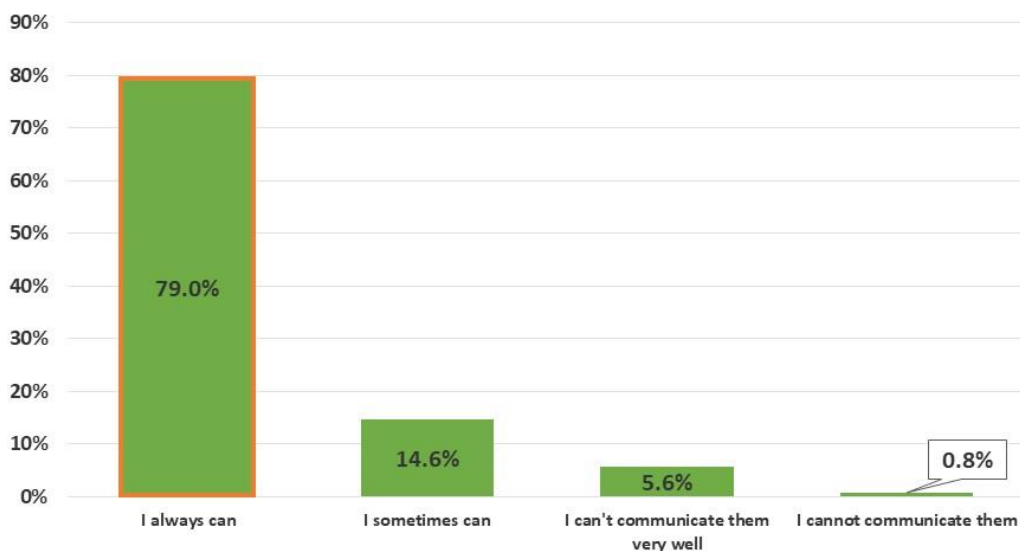✓ **Communication during medical examinations (2): Can you share your opinions or preferences with medical staff?**

The most common response to "Are you able to talk to physicians about your opinions, preferences, daily routines, and desired future lifestyle when selecting treatment plans or medicines during medical examinations at hospitals?" was "Sometimes," which was selected by 38.0% of all respondents. It was followed by "Always" (28.6%), "Not very often" (27.3%), and "Never" (6.1%) (Figure 8).

Communication during medical examinations (2)	Figure 8

Q: Are you able to talk to physicians about your opinions, preferences, daily routines, and desired future lifestyle when selecting treatment plans or medicines during medical examinations at hospitals?

(March, 2020, n=1,000)
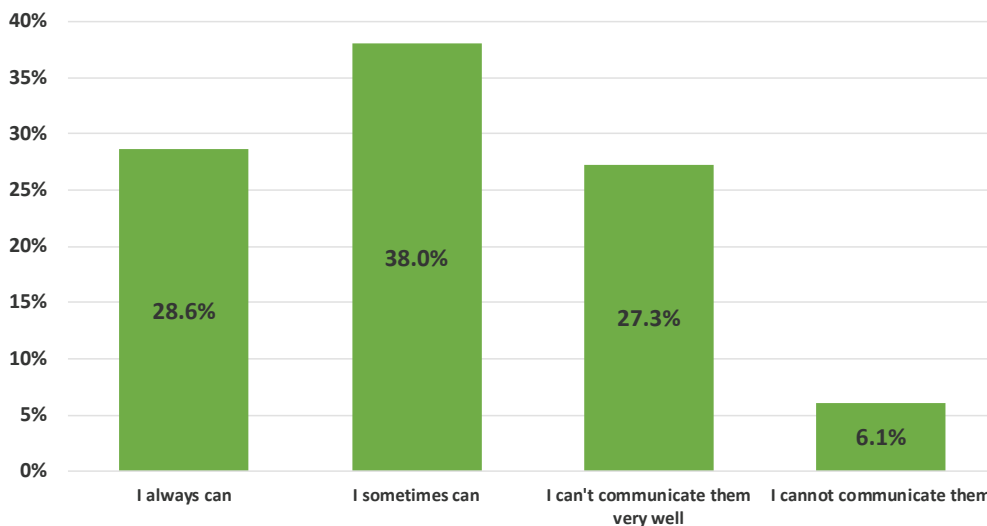
*For example, "I want to avoid medicines that cause drowsiness due to my job," "I want to continue working or pursuing my hobbies, so I want to consider treatment plans that involve few hospital visits," or "I want to try a surgery that wasn't in our original treatment plan."

Source: Health and Global Policy Institute, "Public Opinion Survey on Cooperation between Providers and Recipients in Healthcare."

✓ **Communication during medical examinations (3): Differences among people with and without family doctors, regular hospitals, and regular clinics**

We compared respondents by their ability to share their opinions, preferences, routines, or desired future lifestyle with physicians with whether or not they had family doctors, regular hospitals, or regular clinics. Among people always share, 41.4% had family doctors, 24.7% had hospitals or clinics they visit frequently, and 19.5% did not have family doctors (Figure 9).

Communication during medical examinations (3)

Figure 9

Q: Are you able to talk about or express your opinions, preferences, daily routines, and desired future lifestyle when selecting treatment plans or medicines with physicians during medical examinations at hospitals?
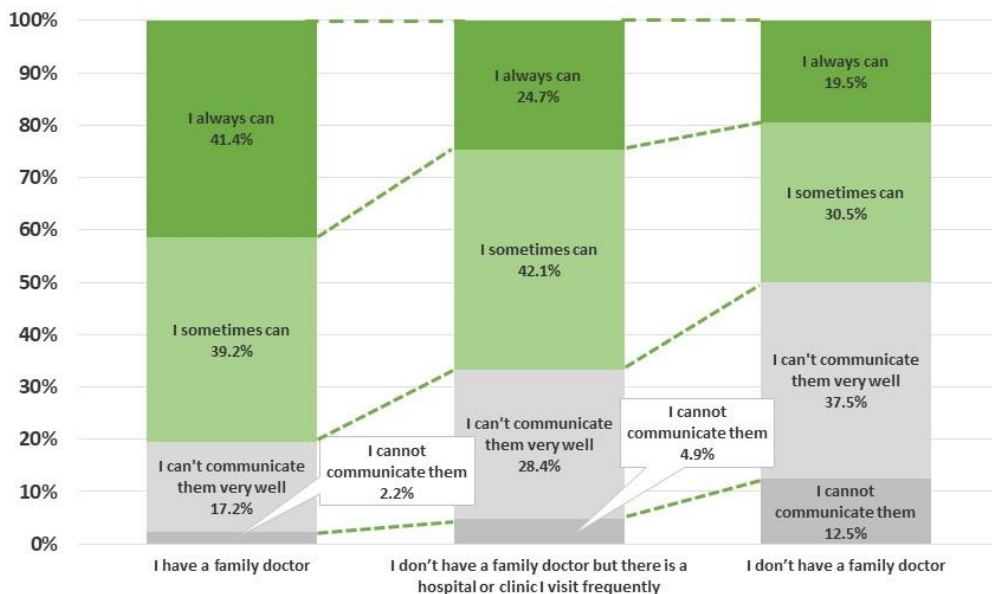
(March, 2020, n=1,000)

	I have a family doctor	I don't have a family doctor but there is a hospital or clinic I visit frequently	I don't have a family doctor
I always can	41.4%	24.7%	19.5%
I sometimes can	39.2%	42.1%	30.5%
I can't communicate them very well	17.2%	28.4%	37.5%
I cannot communicate them	2.2%	4.9%	12.5%

Source: Health and Global Policy Institute, "Public Opinion Survey on Cooperation between Providers and Recipients in Healthcare."

✓ **Willingness to reflect patients' opinions and preferences in treatment plans among medical staff**

We asked survey participants if medical staff ask them about their opinions, preferences, daily routines, and desired future lifestyles and reflect that information in treatment plans. We then compared those responses to responses about having family doctors, regular hospitals, or regular clinics. Over one-third (35.4%) of respondents with family doctors felt medical staff always ask for their preferences and incorporate them into treatment plans compared to 16.9% of people with regular hospitals or clinics and 12.9% of people without family doctors (Figure 10).

Willingness to reflect patients' opinions and preferences in treatment plans among medical staff | **Figure 10**

Q: Do you feel health workers such as physicians or nurses ask for or about your opinions, preferences, daily routines, and desired future lifestyle and then reflect or incorporate that information into treatment plans?

(March, 2020, n=1,000)
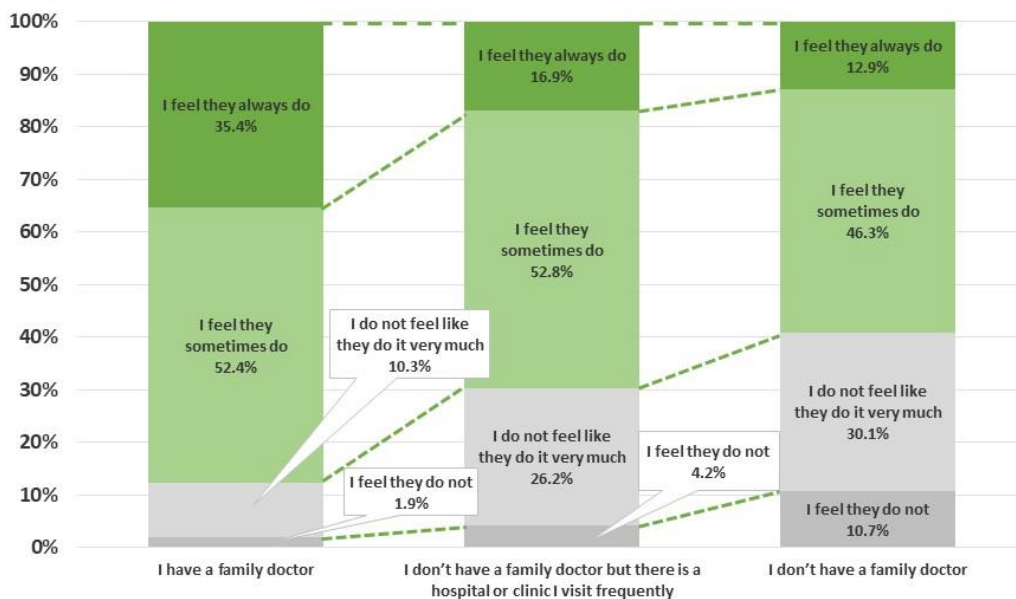
Source: Health and Global Policy Institute, "Public Opinion Survey on Cooperation between Providers and Recipients in Healthcare."

- **Factors preventing cooperation**
  - ✓ **Reasons for difficulties expressing opinions and preferences to physicians**
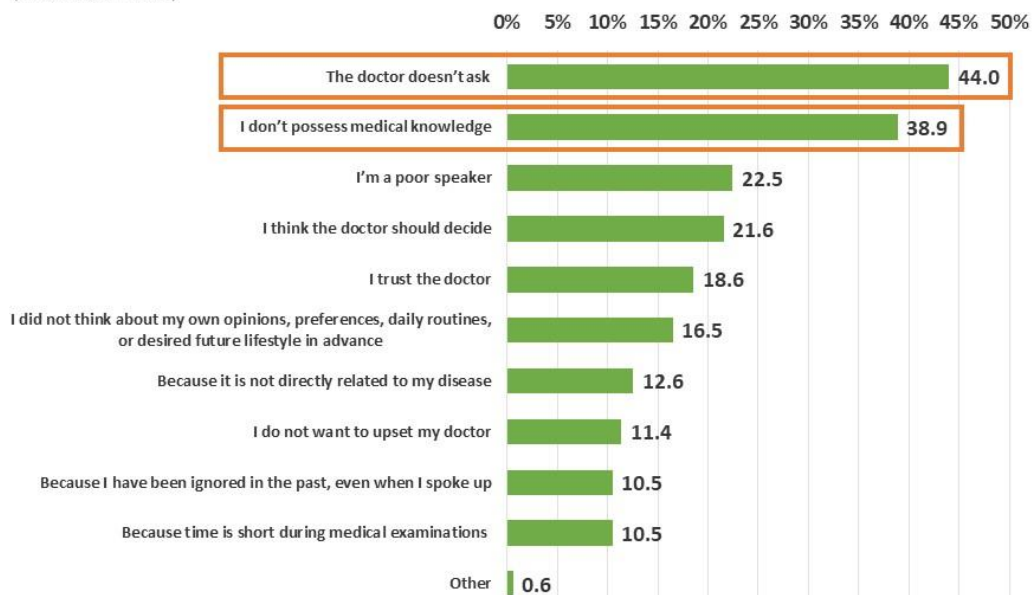
    The 334 participants who responded that they could not share or could only sometimes share their own opinions, preferences, daily routines, or desired future lifestyles with physicians were asked to identify the reasons they were unable to always do so. The most frequently-selected reason was "The doctor doesn't ask," which was selected by 44.0% of participants. It was followed by, "I do not possess medical knowledge" (38.9%) and "I'm a poor speaker" (22.5%) (Figure 11).

Reasons for difficulties expressing opinions and preferences to physicians — Figure 11

Q: Why can you not talk about or share your opinions, preferences, daily routines, and desired future lifestyle with physicians when selecting treatment plans or medicines? Select all that apply.

(March, 2020, n=1,000)

Reason	%
The doctor doesn't ask	44.0
I don't possess medical knowledge	38.9
I'm a poor speaker	22.5
I think the doctor should decide	21.6
I trust the doctor	18.6
I did not think about my own opinions, preferences, daily routines, or desired future lifestyle in advance	16.5
Because it is not directly related to my disease	12.6
I do not want to upset my doctor	11.4
Because I have been ignored in the past, even when I spoke up	10.5
Because time is short during medical examinations	10.5
Other	0.6

Source: Health and Global Policy Institute, "Public Opinion Survey on Cooperation between Providers and Recipients in Healthcare."

✓ **The easiest health worker to share opinions and preferences with**

We asked participants to identify which healthcare worker is easiest for people receiving healthcare to share their own thoughts or preferences with. The most popular response was physicians, who were chosen by 61.5% of respondents. The next most common response was nurses (17.0%), and the third most commonly-selected response was that there are no members of medical staff that are easy to talk to, which was selected by 14.5% of all respondents (Figure 12).

The easiest health worker to share opinions and preferences with	Figure 12

Q: When you receive healthcare*, who is the easiest health worker to share your opinions, preferences, daily routines, and desired future lifestyle with?

(March, 2020, n=1,000)
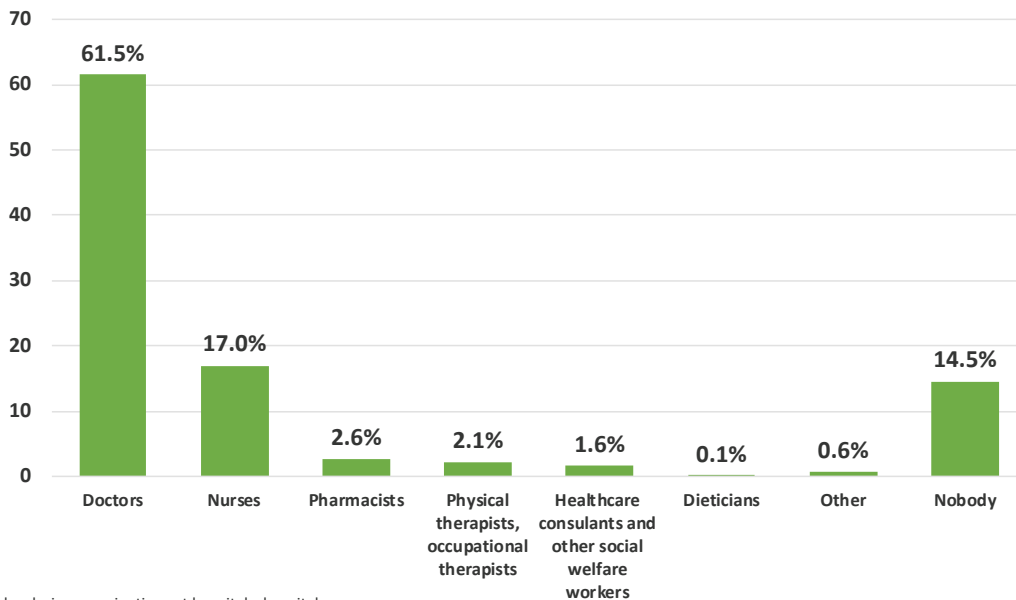
* Includes during examinations at hospitals, hospital check-in, and rehabilitation

Source: Health and Global Policy Institute, "Public Opinion Survey on Cooperation between Providers and Recipients in Healthcare."

✓ **The current degree of cooperation between patients and medical staff**

We asked respondents to what degree they thought cooperation generally takes place in healthcare on a scale of 0% to 100%, with 0% representing no cooperation and 100% representing full cooperation. The average score given by people with family doctors was 62.8%; people with regular hospitals or clinics gave an average score of 55.6%; and people without family doctors assigned an average score of 52.8% (Figure 13).

The current degree of cooperation between patients and medical staff	Figure 13

Q: This survey defines cooperation between medical staff and people receiving healthcare as the process of determining treatment plans that both parties agree upon and accept after people receiving healthcare share their symptoms, opinions, preferences, daily routines, and desired future lifestyles with medical staff. Please share your opinion on this topic. Generally speaking, to what degree do you think cooperation between medical staff and people receiving healthcare takes place in Japan? Please assign the degree of cooperation a score of 0% to 100%, with 0% representing no cooperation and 100% representing full cooperation.

(March, 2020, n=1,000)
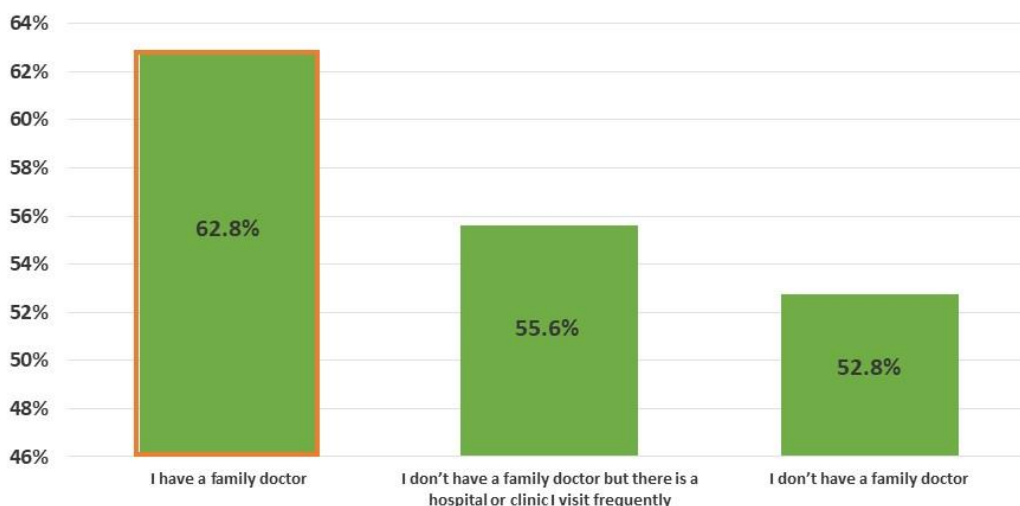
Source: Health and Global Policy Institute, "Public Opinion Survey on Cooperation between Providers and Recipients in Healthcare."

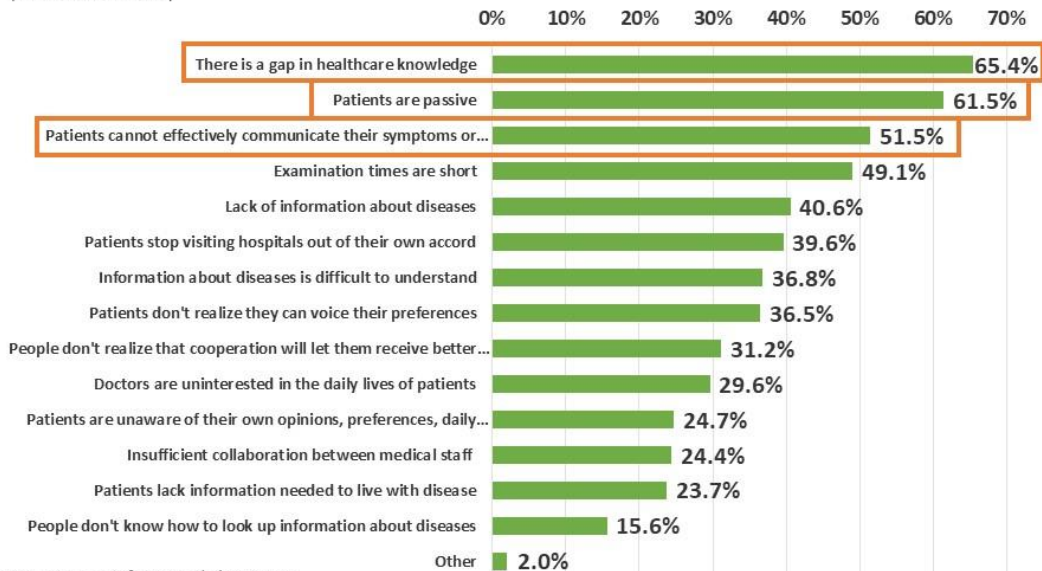## Issues preventing cooperation between patients and medical staff

When asked to identify general issues preventing cooperation, the most commonly-selected response was "There is a gap in medical knowledge," which almost two-thirds (65.4%) of respondents selected. It was followed by "Patients are passive," (61.5%) and "Patients cannot effectively communicate their own symptoms or preferences (referring to their opinions, preferences, daily routines, and desired future lifestyles)" (51.5%) (Figure 14).

Issues preventing cooperation between patients and medical staff | **Figure 14**

Q: Generally speaking, which issues do you believe obstruct the process in which people receiving healthcare share their symptoms and preferences* to medical staff to decide treatment plans both parties agree upon and accept? Please select all that apply.

(March, 2020, n=1,000)

There is a gap in healthcare knowledge	65.4%
Patients are passive	61.5%
Patients cannot effectively communicate their symptoms or...	51.5%
Examination times are short	49.1%
Lack of information about diseases	40.6%
Patients stop visiting hospitals out of their own accord	39.6%
Information about diseases is difficult to understand	36.8%
Patients don't realize they can voice their preferences	36.5%
People don't realize that cooperation will let them receive better...	31.2%
Doctors are uninterested in the daily lives of patients	29.6%
Patients are unaware of their own opinions, preferences, daily...	24.7%
Insufficient collaboration between medical staff	24.4%
Patients lack information needed to live with disease	23.7%
People don't know how to look up information about diseases	15.6%
Other	2.0%

* Refers to opinions, preferences, daily routines, and desired future lifestyles.

Source: Health and Global Policy Institute, "Public Opinion Survey on Cooperation between Providers and Recipients in Healthcare."

✓ **Desired future lifestyles (1): Did you have a clear awareness of what kind of life you wanted to lead before you developed a disease?**
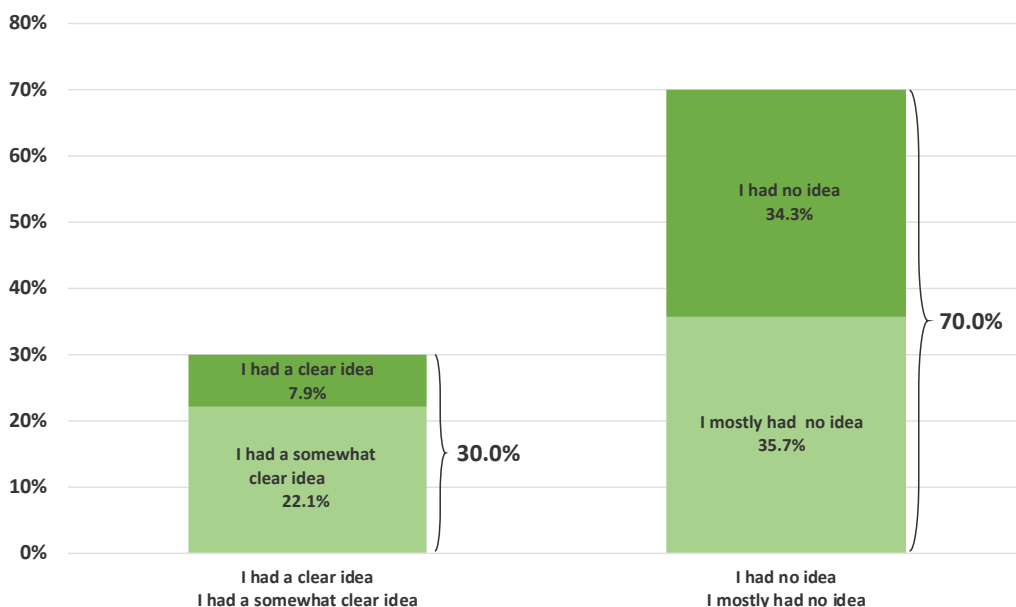
We asked the 367 respondents with medical histories if they had a clear idea of what their desired future lifestyle would be before developing a disease. The most popular response was, "I mostly had no idea" which was selected by 35.7% of respondents, followed by "I had no idea" which was selected by 34.3% of respondents, for a total of 70.0% (Figure 15).

Desired future lifestyles (1)　　　　　　　　　　　　　　　　　　　　　　| **Figure 15** |

Q: Before developing a disease, did you have a clear idea of what your desired future lifestyle would be if you developed a disease?

(March, 2020, n=1,000)

Source: Health and Global Policy Institute, "Public Opinion Survey on Cooperation between Providers and Recipients in Healthcare."

✓ **Desired future lifestyles (2): Did you tell your family or other people close to you what your desired future lifestyle would be if you developed a disease?**

We asked the 367 respondents with a medical history if they told their families or other people close to them what their desired future lifestyle with a disease would be before developing a disease. A total of 72.5% of responses were negative; the most commonly-selected answer was "I did not," which was selected by 40.6% of respondents, followed by "I mostly did not," which was selected by 31.9% (Figure 16).

Desired future lifestyles (2)	Figure 16

Q: Before developing a disease, did you tell your family or other people close to you what your desired future lifestyle would be if you developed a disease?

(March, 2020, n=1,000)
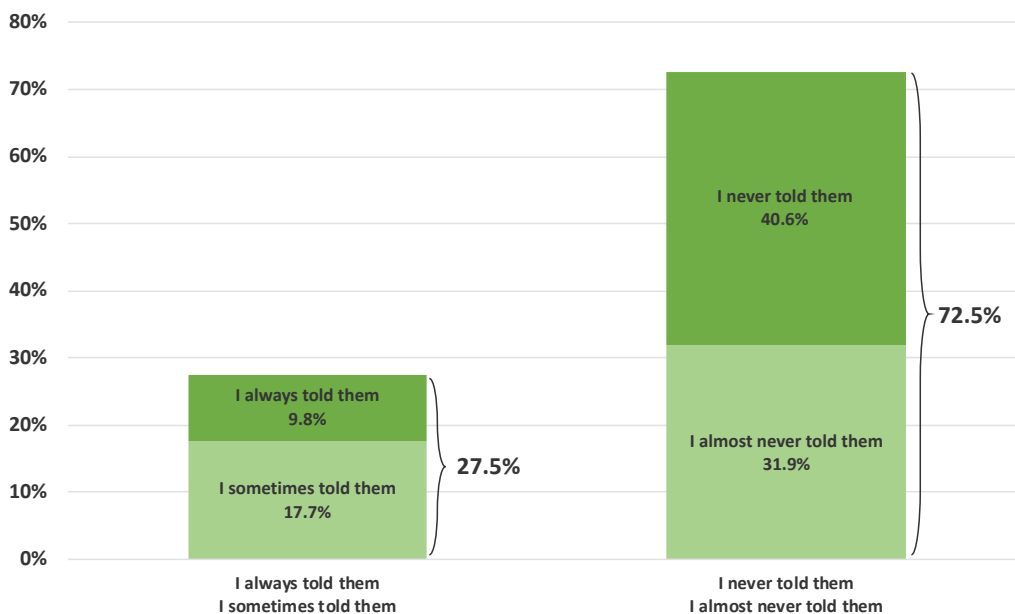
Source: Health and Global Policy Institute, "Public Opinion Survey on Cooperation between Providers and Recipients in Healthcare."

Commentary

- **Desire to cooperate and the current situation surrounding cooperation**
  - ✓ Our survey revealed that 92.9% of respondents want their opinions, preferences, daily routines, and desired future lifestyles taken into account when selecting treatment plans and medicines. However, 28.6% of respondents said that they always communicate their own thoughts and preferences in real-world interactions with physicians while 79.0% of respondents said they can always communicate their symptoms to medical staff, so there was a significant gap among those who always talk about their preferences and those who feel confident towards communicating their own symptoms.

  - ✓ Meanwhile, the ratio of respondents who said they always share their opinions and preferences and who had family doctors was twice as high as those without family doctors. Furthermore, the ratio of people with family doctors who felt that medical staff such as physicians and nurses listen to their opinions and preferences and incorporate them into treatment plans was approximately three times higher than people without family doctors. We believe there is a tendency for people with family doctors to build relationships of trust with health workers such as physicians and nurses, which helps create an environment in which it is easier for them to regularly talk to medical staff about illness and health. Accordingly, this allows them to engage in good communication with medical staff, making it easier for medical staff to grasp their opinions, feelings, and other preferences and to incorporate those preferences into treatment plans. We find it likely that this results in higher levels of satisfaction towards treatment among that patient group because their treatment plans reflect their opinions and preferences.

- **Factors preventing cooperation**
  - ✓ When asked about the reasons they could not share their opinions and preferences with physicians, the top three reasons selected by respondents were all items that applied to people receiving healthcare. The fact that the most popular reason selected was "The doctor doesn't ask" reveals that people receiving healthcare are over-reliant on explanations from medical staff in clinical settings, so this passive stance results in a significant obstacle to cooperation. The second most commonly-selected response was "I don't possess medical knowledge." People receiving healthcare must independently participate in healthcare as experts on their own bodies. We believe that insufficient medical knowledge was frequently selected as an obstacle to cooperation because many people do not fully recognize the need to participate in healthcare. Finally, the third most frequent response was, "I am a poor speaker," which revealed that a lack of communication

skills among people receiving healthcare acts as an obstacle to cooperation.

✓ Physicians were chosen as the easiest health worker to talk to. We think this was because people have high expectations towards physicians and because physicians are the professionals most closely involved in medical examinations. Patients and other healthcare beneficiaries who have not experienced hospitalizations or rehabilitation programs have not had opportunities to interact with medical staff from various disciplines, so a more detailed study to address this point is required.

✓ The fact that people with family doctors rated the degree of general cooperation in clinical settings ten points higher than people without family doctors suggests that having a family doctor is beneficial to cooperation. Furthermore, looking at general factors that prevent cooperation, the top three reasons respondents felt that cooperation cannot be achieved were that people receiving healthcare do not possess the same degree of medical expertise as physicians, that patients are passive, and that people receiving healthcare do not possess sufficient communication skills. Just like when we examined the reasons people were unable to communicate their opinions to physicians, these responses highlighted the fact that a significant hurdle to cooperation is a lack of preparedness among people receiving healthcare.

✓ Few respondents said they had been aware of what their desired future lifestyle would be if they developed a disease before developing one. Similarly, few respondents told those close to them about those preferences. These responses made it clear just how difficult it is for members of the public to be proactive about their health during the transitional ME-BYO[15] stage.

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[15] A state when people experience minor symptoms that do not qualify as the onset of a disease.

Survey 2: In-depth interviews

(1) **Survey overview**

With the goal of identifying factors preventing cooperation between people receiving healthcare and medical staff in the decision-making process in clinical settings as well as the backgrounds of those issues, a cultural anthropologist conducted in-depth interviews with three people receiving healthcare in March 2020. An overview of the interview subjects is shown in Figure 17. The cultural anthropologist conducting the interviews encouraged natural and free conversations within the context of each interview subject's situation and then collected data.

Name	Age	Sex	Relationship to patient	Disease
Mr. A	40s	Male	Self	Cancer
Ms. B	30s	Female	Parent	Tuberous sclerosis complex
Ms. C	30s	Female	Self	Narcolepsy type 1

Figure 17: In-depth interview subjects

(2) **Survey results**

Key points of in-depth interview results

The interviews identified eight factors preventing cooperation between people receiving healthcare and medical staff in the decision-making process in clinical settings. We have arranged those eight obstructing factors according to requirements described in section 3.5, "Eight requirements for cooperation in clinical settings," as shown below. Items that were not identified during this survey have been removed.

Subject	Requirement for cooperation	#	Factors preventing cooperation
People receiving healthcare	**The ability to think about one's own opinions and preferences**	**1**	**Lack of preparation in terms of desired future lifestyles and hopes and needs towards purpose in life before developing diseases**
		2	**Lack of information or knowledge concerning effects of treatment on daily living**
	The ability to communicate one's own opinions and preferences	**3**	**Unable to verbalize thoughts, worries, or concerns in an effective manner**
		4	**Psychological hurdles towards opinion-sharing with medical staff**
Medical staff	**After asking for opinions and preferences from people receiving healthcare, the ability to produce treatment plans based on that information**	**5**	**Insufficient communication skills among medical staff**
The environment	**The ability to provide treatment by multidisciplinary teams that include people receiving healthcare**	**6**	**Medical staff face time restrictions and heavy workloads**
		7	**Team healthcare systems do not include people receiving healthcare and peer support systems involving parties like patient associations have not been established**

	The capacity for regularly revisions to decision-making processes after discussions between people receiving healthcare and medical staff have been held	8	Lack of opportunities to revise decision-making processes or to provide feedback to medical staff

Survey results

Factors preventing cooperation related to people receiving healthcare

- ✓ **Lack of preparation in terms of desired future lifestyles and hopes and needs towards purpose in life before developing diseases**

The psychological shock people experience when first developing a disease or the suffering or pain accompanying symptoms can be so severe there are times when they cannot spare the time or the energy to devote to identifying the lives they want to live, their desired future lifestyles, or their desires and needs towards a purpose in life. Therefore, it is advantageous if people receiving healthcare think about these topics in advance, and the fact that many people do not do so was identified as one factor that obstructs cooperation between people receiving healthcare and medical staff.

Mr. A

"Based on what my attending physician told me, I felt that I had to have surgery immediately. I did not have time to think about my own wishes or my future living situation. Therefore, I felt that it would have been better if I had knowledge about cancer before developing symptoms, or instead of knowledge about cancer, it would have been good to know stories from people who had cancer."

- ✓ **Lack of information or knowledge concerning effects of treatment on daily living**

In addition to evidence based on medical science, knowledge concerning the effects of treatment on daily living or troubles faced in daily living during the process of balancing treatment and everyday living is beneficial to people receiving healthcare. Another issue identified was a lack of such knowledge during decision-making. However, it is sometimes difficult for people to access these types of information, and even if they can, it can be difficult for them to form an accurate mental image of daily life during and after treatment. Additionally, there may be scenarios when people require welfare services in addition to healthcare, particularly when there are comorbid physical or psychological disorders, but there have been cases when people could not obtain detailed information on welfare services at healthcare institutions.

Ms. B

"I could find information on topics related to medical science like objective clinical symptoms, the conditions for a confirmed diagnosis, disease progression, and treatment methods, but I could not find anything that gave me insight on everyday living, such as the real-world circumstances related to how children with this disease are living their everyday lives.

"(No matter where I went,) I could not obtain information on welfare in my city. Our hospital services a wide area, but the social workers there did not know about welfare for people with disabilities in the region we live in (because it is not within the scope of healthcare). I first learned of the existence of employment support offices for people with disabilities from other parents raising children with disabilities. My child is under ten years old and I do not know where and how children with disabilities live after they grow up, which is one source of concern for me."

✓ **Unable to verbalize thoughts, worries, or concerns in an effective manner**

There are aspects of verbalizing one's own thoughts and worries that people receiving healthcare find difficult. Our interviews mentioned examples of times medical staff helped people receiving healthcare verbalize their thoughts by working more closely with them.

Ms. C

"I can't identify problems on my own, but there are problems in my daily life. I am certain that there are some sorts of problems, but I just cannot figure out what they are. So, there are often times that I can't look for a goal, or when I don't know where to go.

"(My family doctor) recommended I write things down, like in an itemized list, and that I bring that list to the medical examination. The medical staff worked more closely with me and that also made it easier for me to talk."

✓ **Psychological hurdles towards opinion-sharing with medical staff**

Another factor mentioned during the in-depth interviews was that people receiving healthcare may face psychological hurdles that prevent them from communicating their own thoughts to medical staff. In our interviews, there were some cases in which people receiving healthcare wanted to share their thoughts with medical staff, but they thought doing so would increase the burden placed on medical staff, so they withheld from speaking.

Ms. C

"I don't know the best way to share (my own opinions or preferences), and I worry that I will be causing trouble for the medical staff, or in other words, because an answer might not become clear during the time I have with the doctor, I sometimes worry that I will be causing trouble for the doctor."

- **Factors related to medical staff**
  - ✓ **Insufficient communication skills among medical staff**

One reason medical staff cannot get people receiving healthcare to sufficiently express their needs or preferences mentioned during the interviews was a lack of communication skills among medical staff.

Mr. A

"I want both physicians and nurses to talk to patients more. I have things to say that I want them to hear. While there are some patients who can speak up and share their thoughts without hesitation, there are some people who cannot. Medical staff who can always approach disease while skillfully drawing out patients' opinions or their way of thinking are ideal."

- **Factors related to the environment**
  - ✓ **Medical staff have limited time and heavy workloads**

Generally speaking, increasing the number of patients assigned to each health worker shortens the amount of time they have for one-on-one communication. When physicians have limited time to conduct medical examinations, it may result in situations when people receiving healthcare are not able to communicate their individual opinions, desires, and needs, or may cause them to hesitate when they have the opportunity to do so.

Mr. A

"The nurse told me if I was in pain, then do not hesitate to say so. But watching the nurse work, it seemed like they were shorthanded or they were too busy, so in the end, I could not bring myself to say anything."

- ✓ **Team healthcare systems do not include people receiving healthcare and peer support systems involving parties like patient associations have not been established**

Another factor identified during interviews was when information provided by people receiving healthcare is not shared among medical staff, which prevents treatment teams from functioning effectively as teams. It was also pointed out that people receiving healthcare feel alienated if they are not included on treatment teams. Another necessity that was mentioned was the need for peer support in which people receiving healthcare can hear first-hand accounts from people in similar situations or receive psychological support through patient associations.

Cases in which treatment teams did not function effectively as teams

Ms. B

"(Over three years, our attending physician frequently) changed, and every time they changed, I told a different doctor the same story. Although I could tell they were handing over my child's treatment carefully, looking back on those times, I was discouraged because I did not have anyone to share and sympathize with. Although everything is handed over in the medical record, . . . I realized that it is difficult to continue staying at a hospital where the organization is constantly shifting."

Ms. C

"My doctor always changes, and every time, they ask the same questions – "How are you doing?" – and I give them the same replies. Although maybe it would actually be better if I explained in detail, when I think that my doctor will just change again, I am left with the strong feeling that there is no point in sharing in the first place."

Mr. A

"Because each patient is assigned an attending physician, a nurse, a pharmacist, and a dietician, I can see they are providing team treatment. But, when I could not eat properly and asked the nurse to substitute the rice for noodles, the nurse said, "Okay, I'll tell the dietician to do that," but I was still served rice every day for two or three days."

Cases in which the people receiving healthcare were not included on treatment teams

Mr. A

"An attending physician, a nurse, a pharmacist, and a dietician are all present and I could see that they provide treatment to the same patient as a team, I felt that the patient exists outside of the circle of team medicine."

Ms. B

"I think feelings of unity and motivation among treatment teams change depending on whether or not they feel the presence of the person receiving treatment as a member of the team."

Cases in which people felt peer support systems such as those including patient organizations were necessary

Ms. C

"Although there are (events for people affected by intractable diseases to meet called) Nanbyo Cafes and similar events, they are relatively unknown or are difficult to attend. I think it would be nice if there were places for patients to drop in for a chat during hospital visits or similar times."

Mr. A

"(At patient associations or events,) there are many participants who enthusiastically talk about their own experiences, and I was able to openly share the types of stories I usually cannot share and hear other people's stories. Because I was the only person receiving treatment during my treatment experience, I thought I was the only one who was going through hard, painful, or stressful times. Many of the people who come to events like that are good people, and there were many people who I completely fit with in terms of motivation or feelings, so the sense that I was not alone grew stronger and stronger."

✓ **Lack of opportunities to revise decision-making processes or to provide feedback to medical staff**

Clinical settings, particularly the inside of examination rooms, can easily make people receiving healthcare feel psychological pressure. Therefore, even when they feel medical staff are being thoughtful or understanding of their issues during communication, it can be difficult for them to put their feelings in order or to attain the peace of mind needed to actually communicate those feelings. This difficulty was identified as an obstacle to cooperation. As described above, we believe this is related to the fact that medical staff are overworked and have limited time to spend with each patient.

Ms. C

"There are people who can understand what medical staff told them if they take the time to think carefully and go over it in their head, but cannot speak well during the actual conversation."

Mr. A

"When you are discharged after completing treatment and only visit the hospital once every six months, you do not have any chances to talk to the nurses working in the ward where you were hospitalized. You might only get to talk to your attending physician once every six months, and only at predetermined times, and you can tell they are busy just by looking. . . . I always think it would be nice if there were healthcare meetings or something similar to provide patients opportunities to give feedback (after treatments are completed) within the hospital, not necessarily during medical examinations and similar times."

4.3 Observations on the results of both surveys

Conducting the two surveys described in the previous sections allowed us to obtain a clear picture of the general situation surrounding cooperation between people receiving healthcare and medical staff as well as factors preventing cooperation. Below, we have collected our observations based on the results of the two surveys.

(1) The current situation surrounding cooperation in clinical settings

The results of the public opinion survey revealed that over 90% of respondents wanted their opinions or preferences taken into account when selecting treatment plans or medicines. On the other hand, when asked about their ability to communicate these opinions or preferences to medical staff, their behaviour patterns fell into one of three patterns: taking initiative and engaging, waiting for the right situation to engage, or not engaging out of their own initiative. Fewer than 30% of respondents said they regularly take initiative and engage, about 40% of respondents were dependent on the situation if they engaged or not, while the remaining group, over 30%, was unable to take initiative and engage. Even though selecting treatment plans and medicines are important opportunities for people receiving healthcare to engage in decision-making, there was a split in their behaviour patterns, and based on that fact, we can say there is an apparent mismatch between their desire for cooperation and real-world circumstances surrounding cooperation.

(2) Factors preventing cooperation between people receiving healthcare and medical staff in the decision-making process in clinical settings

The results of the in-depth interviews revealed eight obstructing factors that prevent cooperation between people receiving healthcare and medical staff in clinical settings. Categorizing those obstruction factors by their causes reveals insufficiencies in three areas: insufficient empowerment of people receiving healthcare, insufficient cooperation skills from partners, and insufficient preparation of the environment.

"Insufficient empowerment of people receiving healthcare" originates from the inability of people receiving healthcare to determine or communicate their opinions and preferences when interacting with medical staff. When someone develops a disease and is undergoing one test or treatment after another, it is often the case that the time constraints and psychological burdens accompanying those continuous tests and treatments leave them no room to consider their desired future lifestyle. Therefore, it is desirable that people think about what kind of life they want to lead in the event they develop a disease and prepare in advance. However, the results of the public opinion survey showed that only 30% of respondents had actually thought about their desired future lifestyles before developing a disease, so it is likely that many people were engaged in decision-making during

treatment without having made advance preparations before developing any symptoms. Additionally, insufficient information or knowledge about the effects of treatment on daily living was a significant obstacle that prevented people receiving healthcare from engaging in the act of thinking. Lacking information and knowledge on topics like how to choose the best treatment plan for one's own beliefs or lifestyle among a number of options or how to balance treatment and everyday living in the future makes it more difficult for people receiving healthcare to think about their own opinions or preferences.

A lack of health literacy or knowledge concerning diseases and healthcare is another reason people are unable to communicate their opinions or preferences. Past studies have shown that Japanese people tend to possess a lower degree of health literacy than people from other countries.[16] It is absolutely essential to improve health literacy to overcome the issues identified by the in-depth interviews, namely insufficient verbal skills, psychological hurdles people feel when trying to communicate their thoughts to physicians, and the fact that "patients are passive" (which was named as a factor obstructing cooperation by 61.5% of public opinion survey respondents). Measures to empower people receiving healthcare that draw out and boost the inherent latent abilities possessed by individuals and organizations are needed to improve health literacy. These measures include implementing health education, popularizing tools to support decision-making in healthcare or for communicating with medical staff, and establishing systems to provide accurate information about diseases and health.

The second obstructing factor, "insufficient cooperation skills from partners," refers to insufficient communication skills among medical staff, who are partners in decision-making, or to the absence of partners who are easy to consult. A paradigm shift is currently underway in which the relationship between medical staff and people receiving healthcare is starting to be based on informed consent[17] rather than paternalism.[18] Awareness and behavior among healthcare providers are changing to allow people receiving healthcare and medical staff to engage in Shared Decision Making (SDM),[19] in which people receiving healthcare share decision-making duties with medical staff. However, people receiving healthcare currently feel there is a substantial gap between ideals and reality when it comes

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[16] Kazuhiro Nakayama, Wakako Osaka, Taisuke Togari, Hirono Ishikawa, Yuki Yonekura, Ai Sekido & Masayoshi Matsumoto (2015), "Comprehensive health literacy in Japan is lower than in Europe: a validated Japanese-language assessment of health literacy"

[17] A concept in which patients agree with and provide voluntary consent to treatments after having received satisfactory explanations (including written explanations) from health workers.

[18] Paternalism: An attitude in which people in stronger positions (medical staff) interfere or intervene beyond the desires and preferences of people in weaker positions (people receiving healthcare), believing that it is for the weaker party's own good.

[19] The act of making decisions in healthcare by sharing information and holding conversations between healthcare recipients and medical staff.

to communication with medical staff. That gap was visible in the results of the public opinion survey and in-depth interviews. Furthermore, according to hearings conducted by NCD Alliance Japan with medical staff and organizations providing support to people receiving healthcare, even when medical staff believe they sufficiently explained treatment plans, their patients are unable to understand technical terminology used in such explanations, causing some patients to be left with the impression that they did not receive a sufficient explanation. We believe that medical staff can be more effective partners in cooperation and that cooperation with people receiving healthcare will be accelerated if training that provides specific communication methods and readiness or education that emphasizes SDM is implemented into the training processes for every discipline. Also, the ratio of respondents in the public opinion survey who said they feel that medical staff incorporate the opinions and preferences of patients in treatment plans was 59.9% among people without family doctors and 87.8% for people with family doctors. This result demonstrates that the presence of a trustworthy partner is absolutely essential for cooperation.

Factors related to "insufficient preparation of the environment," the third obstacle to cooperation, include lack of time among medical staff, insufficient team medicine systems, patients focusing their expectations only on physicians or their roles, and lack of opportunities to review decision-making processes and provide feedback to medical staff. In our interviews, there were cases when interview subjects thought that there are times when the opinions of people receiving healthcare are not shared among treatment teams if they tell them to medical staff other than physicians. In addition to team treatment systems, we also understood that patient associations or peer supporters play significant roles in supporting people receiving healthcare. It was also pointed out that one reason physicians face time constraints is because they are relied up upon to play multiple roles in providing care. This is another reason it is necessary to establish team treatment systems that include people receiving healthcare on treatment teams. To improve feedback for medical staff, first it is necessary to prepare opportunities for feedback at appropriate times because there are few opportunities to do so. Also, when people receiving healthcare obtain a sufficient understanding of the explanations they are given, it is important for health workers to confirm and review whether or not healthcare recipients had opinions or thoughts that they wanted to communicate but were unable to. Additionally, we believe that these types of opportunities to provide feedback will allow healthcare providers to notice new issues related to communication or care systems. In this manner, in addition to changes in awareness among people receiving healthcare and medical staff, it is necessary to implement significant reforms to the care environment itself including systems that promote cooperation to achieve cooperation in clinical settings and to ensure systems promoting cooperation are sustainable.

5   Four perspectives for achieving a flat healthcare system and examples of specific actions for each stakeholder to take

Our study identified three issues preventing cooperation in clinical settings: insufficient empowerment of people receiving healthcare, insufficient cooperation skills from partners, and insufficient preparation of the environment. To solve these three issues, to promote cooperation in clinical settings, and to achieve the creation of a flat healthcare system, we have compiled a list of specific actions for each stakeholder to take from the four perspectives described below.

Perspective 1: Empower people receiving healthcare

Perspective 2: Emphasize communication when training medical staff

Perspective 3: Build systems to support decision-making among people receiving healthcare for topics related to health and healthcare

Perspective 4: Establish cooperative systems for the entire life course

5.1 Perspective 1: Empower people receiving healthcare

(1) Provide health education that includes information on diseases and health, how to select the right healthcare institutions and the best times to visit them, how to make the most out of visits to healthcare institutions, and other such information.

For people receiving healthcare to be able to communicate their opinions and preferences with medical staff and engage in decision-making in a manner that they can consent to, it is important for every person receiving healthcare to improve their health literacy before developing diseases.

Health education within the school education process is important for improving health literacy. In recent years, in the field of cancer, the third-term Basic Plan to Promote Cancer Control Programs (FY2017-FY2022) which was formulated according to the Cancer Control Act states, "After grasping nationwide implementation status for cancer education programs, the Government will establish systems to deploy counsellors and make efforts to improve cancer education according to the situations in each region." As a result, new educational measures were added to curriculum guidelines for both junior and senior high schools to be implemented in FY2021 and FY2022. Furthermore, the new curriculum guidelines for elementary schools to be implemented in FY2020 also now address cancer. A report published by the Ministry of Education, Culture, Sports, Science and Technology (MEXT) Investigation Committee for Cancer Education (established March 2015)[20] stated, "Cancer education must not only intend to address cancer as a separate topic from other

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[20] MEXT, 2015. "Report on the State of Cancer Education in Schools."
https://www.mext.go.jp/a_menu/kenko/hoken/__icsFiles/afieldfile/2016/04/22/1369993_1_1.pdf. Last retrieved July 17, 2020.

diseases. Rather, it must enhance health education by addressing topics related to cancer that will be beneficial for preventing various other diseases and encourage the establishment of desirable lifestyle habits."

In this manner, education that promotes desirable lifestyle habits for NCDs is advancing with cancer education as a starting point. However, curriculum guidelines make no mention of how to effectively use healthcare institutions or the ideal methods for communicating with medical staff, so there are many people who only learn how to use healthcare institutions or interact with medical staff when they notice something out of the ordinary with their body or mind or with the body or mind of a family member. There are countries in which education on decision-making in healthcare and similar topics is provided alongside education on diseases and daily lifestyle habits starting in elementary and middle school education. For example, in the U.S., the Center for Disease Control and Prevention (CDC) established the National Health Education Standards (NHES)[21] with the aim of improving health literacy among young people. Many states are starting to provide education on concepts like communicating with medical staff or decision-making in addition to diseases, daily lifestyle habits, and other such topics starting from the early years of elementary school based on the guidelines provided by the NHES. While referring to such examples from abroad, education on the effective use of healthcare institutions and similar topics should be implemented into educational curriculums at elementary and middle schools in Japan.

Looking to areas other than school education, educational opportunities should be provided to the public throughout the life course through measures like promoting health education among employees at each company and organization or providing lifetime education in each municipality. Before that can happen, however, the ability of members of the public to think about their own lives and deaths is an important perspective for improving health literacy among the public. Efforts should be made to increase awareness and deepen understanding towards life, death, and other philosophical topics.

(2) Verify and support trustworthy medical information websites so people can access accurate medical information.
The hearings we conducted as part of this study pointed out that because it has become possible to obtain vast amounts of information using the internet, there are cases in which people simply believe incorrect healthcare information they found online. This can result in them failing to take appropriate

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[21] CDC, "National Health Education Standards" https://www.cdc.gov/healthyschools/sher/standards/index.htm. Last retrieved July 3, 2020.

health seeking behavior. It will be necessary to establish an environment in which all people can obtain accurate medical information moving forward. The Ministry of Health, Labour and Welfare (MHLW) established the Roundtable on Promoting Skillful Interactions with Healthcare in FY2018, which presented the "Citizens Project Declaration on Protecting Lives and Healthcare."[22] Within that declaration, an example of a specific action for the Government to take was to verify and support trustworthy healthcare information websites. In the future, the concept behind this effort, the content of its activities, and other such information should be widely disseminated and its effects should be verified.

(3) Promote the development of decision aids and other decision-making guides as well as the effective use of existing tools.

Tools that teach people receiving healthcare specific methods for navigating the decision-making process in healthcare and enable smooth communication with medical staff should be developed and disseminated. In one example from the U.S., a campaign called "Ask Me 3"[23] simplified the questions people receiving healthcare should ask medical staff in the examination room down to three key questions (1. What is my main problem? 2. What do I need to do? 3. Why is it important for me to do this?). Posters, pamphlets, and other tools were then used to build awareness towards these three questions among people receiving healthcare. In Japan, an NPO called Consumer Organization for Medicine and Law (COML) created a pamphlet called the "New Ten Articles for Doctors,"[24] and academic societies in certain disease fields such as breast cancer and dementia have formulated decision-making guidelines. In the future, all academic societies and similar organizations in every disease field should consider developing decision-making guidelines and other tools. Then, those tools and decision-making guidelines should be distributed to or placed at all healthcare institutions to provide information to people receiving healthcare. At the same time, healthcare institutions should collaborate with related academic societies to conduct training for medical staff based on those tools or guidelines. Systems that provide appropriate decision-making support should be established moving forward.

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[22] MHLW, 2018. "The Protect Our Lives, Protect Our Healthcare! Citizens Project Declaration." https://www.mhlw.go.jp/content/10800000/000458856.pdf. Last retrieved June 25, 2020.

[23] Institute for Healthcare Improvement. "Ask Me 3: Good Questions for Your Good Health."

http://www.ihi.org/resources/Pages/Tools/Ask-Me-3-Good-Questions-for-Your-Good-Health.aspx. Last retrieved July 17, 2020.

[24] COML. "The New Ten Articles for Doctors." https://www.coml.gr.jp/shoseki-hanbai/10kajo.html. Last retrieved July 17, 2020.

Examples of specific actions to take for perspective 1:

Specific actions for each stakeholder to take for perspective 1 are described below.

Members of the public (including people receiving healthcare) should:

✓ Use trustworthy sites when looking up medical information.

✓ Think about their preferred types of healthcare and future lifestyles before developing diseases and create opportunities to communicate those preferences to family members and supporters.

✓ Make time to think about how to select the most fitting healthcare institutions and visit times and how to make the most of those visits. Use decision-making guides and similar tools when doing so.

The Government should:

✓ Implement educational programs at elementary and middle schools that teach students about topics like how to select and use healthcare institutions or the best methods of communicating with medical staff in addition to providing them with information on diseases, healthy lifestyle habits, and similar knowledge.

✓ Engage in efforts to promote health education and provide accurate medical information so members of the public can access information on and think about decision-making for topics related to healthcare and health before developing diseases.

✓ Help disseminate decision aids and other decision-making guides that foster cooperation between medical staff and people receiving healthcare.

Medical staff should:

✓ Conduct training within healthcare institutions using decision aids and other decision-making guides and tools developed by academic societies.

The private sector (including companies and organizations) should:

✓ Promote awareness-building and educational programs for improving health literacy among employees and make efforts to implement working-style reform and help employees manage their health.

5.2 Perspective 2: Emphasize communication when training medical staff

(1) Implement education and training programs that emphasize communication and Shared Decision Making (SDM) in educational processes for all disciplines.

While promoting awareness-building and educational support among people receiving healthcare, healthcare providers must be given training that emphasizes SDM or that teaches specific methods for communicating with people receiving healthcare and that develops attitudes for that purpose. Healthcare institutions provide care to patients based on multidisciplinary expert knowledge and experience possessed by each member of medical staff including nurses, pharmacists, clinical engineers, physical therapists, occupational therapists, social workers, and office staff. In order for each member of medical staff to be able to act as a partner in cooperation, education that meets the unique characteristics and roles of each discipline must be implemented within the training processes for each discipline.

One effort in the field of cancer undertaken to "research and develop support programs for improving QOL for patients in all disease fields" as part of the Third Term Comprehensive 10-Year Strategy for Cancer Program was the development of the SHARE-CST program.[25] The SHARE-CST program aims to help physicians obtain communication skills according to the SHARE mode and is was based on the "Study on Communication Between Patients and Physicians in Cancer Treatment" conducted by the National Cancer Center Japan Psycho-oncology Group. The SHARE-CST Program is conducted through communication skills training workshops that are jointly operated by the Japan Psycho-oncology Society and the Japanese Society for Palliative Medicine. These workshops aim to improve the quality of communication between patients and physicians during cancer treatment. Their emphasis on promoting cooperation in treatment is particularly noteworthy. Currently, participation in this program is voluntary, so participants tend to already possess a high degree of awareness towards the importance of communication. As such, it is difficult to reach the physicians who truly need training on communication. In the future, programs like the SHARE-CST Program should be developed for fields other than cancer. Participation in those programs or other such communication training programs should be required in the educational process for each medical discipline.

(2) Train family doctors and general practitioners and promote their placement in every region.

In the public opinion survey conducted as part of this study, people with family doctors indicated that they felt cooperation in clinical settings was being achieved to a higher degree compared to people without family doctors. The presence of family doctors and general practitioners who can respond to everyday medical needs is an important element for achieving cooperation, and measures to train

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[25] Japan Psycho-oncology Society. http://www.share-cst.jp/02.html. Last retrieved July 17, 2020.

general practitioners who can provide holistic, continuous care as family doctors or primary care physicians[26] as well as measures to ensure their placement in every region should be advanced. When doing so, it is important to clearly indicate cooperation as one of the priorities within the function and role of family doctors and to provide training or information to that end. The "Basic Policies on Economic and Fiscal Management and Reform 2020"[27] also mentions the placement of family doctors nationwide, saying "While promoting the differentiation of functions and cooperation between hospitals and clinics and taking the needs of the primary care functions into account, promote the use of family doctors, family dentists, and family pharmacists." Also, healthcare institutions providing the functions associated with family doctors are reimbursed in the medical service fee schedule through the Comprehensive Community Care Premium and other such premiums. Meanwhile, a public awareness survey conducted by the Japan Medical Association Research Institution[28] found that 43.5% of respondents did not have family doctors. Also, in a survey conducted by the National Federation of Health Insurance Societies,[29] 32.7% of respondents said that they do not have a doctor or healthcare institution they regularly visit for examinations, and 27.2% of all respondents said that they do not have family doctors. So, 30% to 40% of respondents in both surveys said they do not have family doctors or healthcare institutions they regularly visit. Among the reasons given, some said that they did not know how to find the right healthcare facilities, so at the same time as providing incentives to healthcare institutions, we believe it is also necessary to take measures to provide information to people receiving healthcare. In light of these issues, a new condition was added to the FY2020 revision of the medical service fee schedule which requires institutions providing family doctor services to engage in efforts to provide information about those services to patients through on-site bulletins and other notifications to qualify for premiums used to evaluate institutions providing family doctor services. To provide information to even more people in the future, each municipality or insurer should consider engaging in efforts to provide information about family doctor services in addition to the information already being provided within healthcare institutions. Furthermore, members of the general public including patients and other parties most affected should have family doctors with whom they can share their own preferences towards healthcare or their desired future lifestyles. They should also recognize the importance of effectively using information regarding health from their family doctor when making healthcare choices.

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[26] Physicians who can treat most health-related problems, build ongoing partnerships, and be responsible for providing care within the family and community framework.

[27] Basic Policies on Economic and Fiscal Management and Reform 2020. https://www5.cao.go.jp/keizai-shimon/kaigi/cabinet/2020/2020_basicpolicies_ja.pdf.   Last retrieved July 17, 2020.

[28] Japan Medical Association Research Institution, 2017. "The 6th Public Awareness Survey on Healthcare in Japan." https://www.jmari.med.or.jp/download/WP384.pdf. Last retrieved July 17, 2020.

[29] National Federation of Health Insurance Societies, 2017. "Survey on Public Awareness towards Healthcare and Health Insurance Systems." https://www.kenporen.com/include/press/2017/20170925_7.pdf. Last retrieved July 17, 2020.

Examples of specific actions to take for perspective 2:

Specific actions for each stakeholder to take for perspective 2 are described below.

Members of the public (including people receiving healthcare) should:

✓ Find family doctors with whom they can share their healthcare preferences and desired future lifestyles.

The Government should:

✓ Establish systems to support decision-making among people receiving healthcare with multidisciplinary cooperation, starting with family doctors and general practitioners.

✓ While cooperating with healthcare institutions and insurers, examine the best methods for providing information to the public on healthcare institutions that provide family doctor services.

✓ Recognize the need for communication between people receiving healthcare and medical staff and SDM in clinical settings and provide leadership in efforts to provide training on communication and SDM to all medical staff.

✓ Provide financial assistance for developing programs and constructing guidelines that effectively teach communication and SDM methods.

Medical staff should:

✓ Consider requiring communication training programs to be included in educational programs for specialist doctors.

✓ Proactively participate in training programs on communication and SDM.

5.3 Perspective 3: Build systems to support decision-making among people receiving healthcare for topics related to health and healthcare

(1) Establish counselling support systems within healthcare institutions.

Over the course of the decision-making process, people may experience changes in their relationships with other people. This can cause their psychological burden to increase, so systems that allow people receiving healthcare to receive decision-making support or consultation support must be established. One tool for decision-making support at healthcare institutions are the consultation offices established at every institution. When people receiving healthcare experience unease towards care or daily living, being able to access immediate counselling at the healthcare institutions they are commuting to or hospitalized in can help them gain peace of mind. The FY2012 revision of the medical service fee schedule added a new premium called the Patient Support System Improvement Premium. Healthcare institutions must establish consultation support offices that promote conversations between medical staff and patients to be eligible for the Patient Support System Improvement Premium. Since it was added, efforts to establish consultation offices within every institution have advanced. According to materials shared at the 377th General Meeting of the Central Social Insurance Medical Council,[30] approximately 4,700 healthcare institutions had applied for the Patient Support System Improvement Premium, and both the number of applications and the number of healthcare institutions applying for them is trending upwards. Furthermore, according a special study conducted to verify the effects of the FY2012 revision of the medical service fee schedule called the "Impact Study on Evaluations for Healthcare Safety Countermeasures or Patient Support Systems," [31] approximately 30% of the people who used consultation offices were undergoing outpatient treatment and the number of such consultations is trending upwards. The content of consultations provided to people receiving outpatient treatment covers many topics; in addition to treatment methods and psychological unease, users are able to receive consultation on topics like systems and support services that can be used to help them continue treatment. Therefore, it is necessary to link these services with public welfare or health and welfare institutions. However, the Patient Support System Improvement Premium is only disbursed when hospitalized people are provided support, and there is no medical fee reimbursement for healthcare institutions to receive when they provide consultation support services to people receiving outpatient treatment. Furthermore, according to expert hearings conducted for this proposal, the Patient Support System Improvement Premium does not provide enough funding to cover the costs associated with

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[30]　377th General Meeting of the Central Social Insurance Medical Council materials. https://www.mhlw.go.jp/file/05-Shingikai-12404000-Hokenkyoku-Iryouka/0000187304.pdf Last retrieved July 17, 2020.
[31] From materials shared at the38th Session of the Central Social Insurance Medical Council's Subcommittee on Verifying Medical Service Fee Revision Results. https://www.mhlw.go.jp/file/05-Shingikai-12404000-Hokenkyoku-Iryouka/0000025689.pdf Last retrieved July 17, 2020.

establishing consultation offices, including personnel expenses, so the current system places a significant burden on healthcare institutions. In the future, it will be necessary to consider the best way to reimburse healthcare institutions providing consultation support to people receiving outpatient treatment so that said systems can be built. For example, users of consultation support systems could be required to shoulder a small portion of the financial burden associated with providing support.

Other items that were raised on the topic of on-site consultation support offices is that there is a clear variation in the quality of consultation support and in the number of consultations provided among healthcare facilities. The Patient Support System Improvement Premium requires that people responsible for providing counselling are placed at on-site consultation support offices, but it allows for a wide range of acceptable disciplines. So, even people without professional healthcare qualifications such as those possessed by physicians, nurses, pharmacists, or social workers can be placed in charge of such offices if they meet certain requirements. Specifically, their past experience requirements are "One or more years of conducting tasks related to patient support," "Has provided 20 or more patient consultations," and "Possesses applicable experience conducting activities related to patient support (such as participating in workshops or having served as workshop instructors) in hospitals." They must also have 20 or more hours of training from organizations that meet standards[32] defined in the MHLW's "Operational and Training Program Creation Guidelines for Promoters of Dialogue in Healthcare."[33] The conditions to receive reimbursement listed in the medical service fee schedule say that it is preferable that such parties have completed the training required of qualified medical personnel,[34] but it is not a requirement. From the perspective of standardizing the quality of consultation support services in the future, measures to reform consultation support systems should be considered. Such reforms might include requiring all full-time employees responsible for providing those services to undergo training or defining new indicators to be used as conditions to qualify for premiums (such as the ratio of consultations provided to the number of patients hospitalized) to track the number of consultations provided more accurately.

In the field of cancer, the Basic Plan to Promote Cancer Control Programs that was established based

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[32] MHLW, 2018. Health Insurance Bureau, Health Care Division, "Notes on the Sending of Materials for Resolving Doubts, Item 7." https://www.mhlw.go.jp/file/06-Seisakujouhou-12400000-Hokenkyoku/0000136971.pdf. Last retrieved August 25, 2020.

[33] MHLW, 2013. HPB Notification No. 0110-2 from the Director of the General Affairs Division, Health Policy Bureau. "Operational and Training Program Creation Guidelines for Promoters of Dialogue in Healthcare – Developing a Culture of Explanation and Dialogue." https://www.mhlw.go.jp/topics/bukyoku/isei/i-anzen/hourei/dl/130110-2.pdf. Last retrieved August 25, 2020.

[34] MHLW, 2018. Health Insurance Bureau, Health Care Division, "Notes on the Sending of Materials for Resolving Doubts, Item 12." https://www.mhlw.go.jp/file/06-Seisakujouhou-12400000-Hokenkyoku/0000136971.pdf. Last retrieved August 25, 2020.

on the Cancer Control Act clearly positions the establishment of consultation systems as a priority policy. After the Comprehensive Cancer Consultation Project was established in 2011, Regional Consultation Centers have been established in 14 prefectures based on cooperation with healthcare institutions, so advancements in the creation of consultation systems have been made. Moving forward, systems that allow all PLWNCDs and their family members to receive consultation support must be established for every NCD including cancer.

(2) Gather evidence and create quality standards to promote the effective use of peer support.
Peer support occurs when people who have undergone treatment for a disease or disability provide psychological support to other people, including patients or their family members, based on their own experiences. In addition to sharing stories of their own experiences, they might also provide advice on topics like the best ways of selecting and visiting healthcare institutions and other facilities or how to use support systems. The people who provide peer support are not only on the receiving end of healthcare services, they also become providers of services supporting other people. This provides a clear example of cooperation and we anticipate further efforts to make effective use of peer support in the future. During the in-depth reviews conducted for this proposal, some interviewees shared examples of their psychological burden being lightened through peer support. There were also examples in which taking part in activities at patient organizations gave interviewees opportunities to consider the effects various treatment methods have on daily living. At the same time, there have been cases in which providing peer support resulted in greater psychological burden among supporters. In addition, the quality of peer support may vary, meaning there are times when peers cannot provide effective support, so there are lingering issues that must be addressed as efforts to popularize peer support are advanced.

In the field of cancer, the second-term Basic Plan to Promote Cancer Control Programs enacted in 2012 says "The Government, local public organizations, and other such organizations will promote cooperation involving both people with cancer and people who have experienced cancer and will make efforts to improve peer support, such as by implementing training programs to promote peer support." However, the FY2016 survey[35] conducted by the Ministry of Internal Affairs revealed that 7 of the 17 regions surveyed had not implemented peer support training programs. Furthermore, among the 38 core hospitals located within the 12 regions that had implemented peer support training programs, 10 of them had no records of peer supporter activities. Reasons for not doing so included, "The Government does not have a system to publicly certify peer supporters, making the

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[35] Ministry of Internal Affairs, 2016. "Recommendations Based on Results of Evaluation on Administration and Monitoring of Cancer Measures Focusing on Early Detection, Treatment, and Palliative Care." https://www.soumu.go.jp/menu_news/s-news/107650.html. Last retrieved July 15, 2020.

degree to which each organization's peer supporters can provide consultations unclear, so the current conditions do not allow us to accept peer supporters," or, "We do not have response guidelines for when trouble occurs between patients." In response, the MHLW is making efforts to improve this situation by preparing peer supporter training programs and training program content in a balanced manner through research projects and similar measures. In the future, to improve the situation surrounding the use of peer support in every disease field in addition to the field of cancer, it will be necessary to establish evidence through verification studies to identify and collect best practices and more effective methods of peer support. Furthermore, the quality of peer support should be standardized by creating training programs based on the aforementioned evidence and by evaluating and certifying peer supporters who have received sufficient training.

(3) Make effective use of information technology (IT) to share information between people receiving healthcare and medical staff.

Measures should be taken that promote the effective use of tools that help overcome issues related to lack of time during medical examinations or the psychological hurdles that people receiving healthcare may feel towards medical staff. Such tools include online medical examinations, treatment apps, and tools that allow for people receiving healthcare and medical staff to share information. One potential cause of psychological hurdles for people receiving healthcare is the unique atmosphere that exists within hospital examination rooms. If online medical examinations become more widespread, it will lower psychological burdens for people receiving healthcare and create opportunities for them to express their opinions and needs to medical staff. Interest towards online examinations is growing and, on April 10, 2020, it became possible for initial medical examinations to be provided online as a limited measure for responding to the spread of COVID-19. While referring to examples from abroad, it will be necessary to gather and build evidence for online examinations from the point of view of people receiving healthcare moving forward, such as by asking people who have used online medical examinations how they feel about the experience and what sorts of effects it had on them.

The effective use of tools for sharing information between people receiving healthcare and medical staff has the potential to serve as one method for overcoming the issue of short examination times. We heard about an example of one such tool during hearings we conducted with people with hemophilia. They told us about their use of a digital application that allowed them to record causes of concern they felt towards medical examinations together with their injection records, which were then shared with medical staff. They reported that the app made their examinations more efficient and created more time for communication. Programs such as those used in diagnosis or treatment that are added to medical devices were included within medical devices by the 2014 revision of the

Act on Securing Quality, Efficacy and Safety of Products Including Pharmaceuticals and Medical Devices. The development of treatment methods using such apps is advancing in certain fields like smoking cessation or high blood pressure, where they improve the efficiency of medical examinations. Behavior modification (such as changes in diet or exercise habits or prescription management) among PLWNCDs is an important tool for treating NCDs. Providing tools that allow people to receive detailed support even outside of examination hours can lead to healthcare provision that is more effective and more efficient. Moving forward, the development of treatment apps and tools that allow people receiving healthcare to share information with medical staff should be promoted through cooperation between the public and private sectors to benefit people in all disease fields.

Examples of specific actions to take for perspective 3:
Specific actions for each stakeholder to take for perspective 3 are described below.

Members of the public (including people receiving healthcare) should:
- ✓ Develop an interest in building networks and forming communities among people receiving healthcare and seek decision-making support for topics related to health or healthcare.
- ✓ Cooperate with academia, medical staff, and the Government in efforts to build evidence for effective types of peer support, such as by participating in verification studies or helping to identify best practices.

The Government should:
- ✓ Establish consultation offices within healthcare institutions where patient supporters, such as their family members, can receive counseling.
- ✓ Examine the best way to evaluate and reward healthcare institutions that implement consultation support services for people receiving outpatient care, such as by requiring users to make small payments for those services.
- ✓ Consider methods of reforming consultation support services within healthcare institutions to standardize the quality of such services, such as by requiring all parties responsible for providing counselling services within healthcare institutions to undergo training or by defining indicators to use as conditions to qualify for the Patient Support System Improvement Premium. An example of one such indicator might be the ratio of the number of consultations to the total number of hospitalized patients.
- ✓ Acknowledge and reward effective efforts to provide peer support consultations undertaken by municipalities.
- ✓ While collaborating with the private sector, promote research and development on products and services that promote cooperation between people receiving healthcare and medical staff

such as treatment apps or tools for online medical examinations and information sharing.

Medical staff should:

✓ Reinforce healthcare institutions' systems that provide on-site consultation support to people receiving healthcare.

✓ Examine how to make effective use of consultation support systems for people receiving healthcare and their supporters, such as their family members.

✓ Promote the use of online medical examinations, tools for sharing information between people receiving healthcare and medical staff, and treatment apps.

The private sector (including companies and organizations) should:

✓ Advance research and development on products and tools that promote cooperation between people receiving healthcare and medical staff, such as treatment apps and tools for online medical examinations and information sharing.

5.4 Perspective 4: Establish cooperative systems for the entire life course

(1) Achieve team-based medicine that includes the people receiving healthcare on treatment teams.

To support decision-making among people receiving healthcare while providing high-quality care, it is essential to achieve team-based medicine in which team members from each discipline share goals and information and cooperate and complement each other while making the most of their individual expertise. For example, at healthcare institutions with multiple medical departments, it is important to establish multidisciplinary conferences for sharing information concerning people receiving treatment on a ward basis that are begun by hospitalists,[36] whose multidisciplinary knowledge allows them to play central roles in multidisciplinary efforts.

As mentioned in Perspective 3, patient organizations or peer support programs can provide psychological support to people receiving healthcare, and have important roles to play as partners in cooperation. Some have reported that they have received effective advice or support for deciding treatment plans and for balancing treatment and employment from peers with the same troubles and experiences as themselves. Representatives of patient organizations or peer supporters should be allowed to function as members of treatment teams according to the situation and needs of the person receiving care.

(2) Build a framework for collecting feedback from people receiving healthcare.

Frameworks that allow for people receiving healthcare to give feedback, such as patient satisfaction surveys, are important to provide PLWNCDs who require treatment over long periods to be able to review and change treatment plans they previously agreed to at the appropriate times and in the appropriate settings. Although measures to collect feedback for medical staff from people receiving healthcare such as the MHLW's Project for Promotion of Evaluation and Publishment of Medical Care Quality or the survey projects conducted by the Japan Council for Quality Health Care gauge patient satisfaction levels and use them as an indicator for evaluating the quality of healthcare, their targets are limited to hospitals. Such measures should be expanded to target all healthcare institutions, including clinics. Also, if feedback from people receiving healthcare reaches medical staff providing primary care, it is likely to contribute to promoting the creation of systems for cooperation over the entire life course.

Furthermore, to evaluate and monitor the quality of healthcare services being provided at hospitals

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[36] General practitioners specializing in care for hospitalized patients.

or clinics by third-party organizations, systems should be established to provide incentives for those who provide higher-quality services. To ensure the public is being provided efficient, high-quality medicine and care in the U.K, for example, the Care Quality Commission (CQC) has established a framework to evaluate and monitor public and private hospitals, general practitioners (GPs), and welfare and long-term care institutions and for publicizing the results of their evaluations. It conducts these activities from the position of an independent public institution. The results of their evaluations are highly-transparent and useful for the public when selecting healthcare institutions or welfare and long-term care institutions. Furthermore, medical services provided by each physician are evaluated once per year by a reviewer using user feedback and other messages entered through the ePortfolio system.[37] In addition to medical and care services provided by medical staff, these evaluations also examine topics like bedside manner, if staff was considerate when interacting with patients, the administration system of the healthcare institution, and education and training systems for staff. Furthermore, there is a results-based reward system called the Quality and Outcomes Framework (QOF) which was implemented for primary care in the U.K. in 2004. This system provides medical service fee rewards to create incentives for GPs who strive to provide high-quality healthcare. A similar system is worth considering for Japan as well.

(3) Construct a platform for promoting cooperation.
To accelerate the social implementation of products and services promoting cooperation, it is important for stakeholders with an interest in this field to collaborate. Products and services that promote communication between people receiving healthcare and medical staff such as online medical examinations, tools for sharing information, and treatment apps should operate in a mutually compatible manner to provide seamless, one-stop service. Looking to one example from abroad, a major financial group in China called the Ping An Insurance (Group) Company of China, Ltd. independently developed an ecosystem centered on people receiving healthcare that provides healthcare in a seamless manner. They have developed various services based on the needs of people receiving healthcare which allow them to make appointments for medical examinations, access online examinations, and receive prescriptions. Their users can also purchase general pharmaceuticals or insurance. Based on guidance from each Ministry or municipal government, a platform should be built which can conduct matching for public-private partnerships and to match private companies and organizations with research institutions to promote the development of products and services and to ensure their mutual compatibility. Said platform would also promote the sharing and delivery of information for building networks among related parties. Furthermore, to ensure that the platform is a place where products, solutions, and systems for the issues facing

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[37] Digitized records

people receiving healthcare can be planned with an accurate understanding of those issues, people receiving healthcare should be involved in that platform.

Examples of specific actions to take for perspective 4:
Specific actions for each stakeholder to take for perspective 4 are described below.

Members of the public (including people receiving healthcare) should:
- ✓ Proactively engage in reviewing decision-making processes for health and healthcare and providing feedback to medical staff when such opportunities arise.
- ✓ Be conscious of consulting healthcare specialists other than physicians.

The Government should:
- ✓ Conduct user satisfaction surveys for all healthcare institutions and utilize user feedback when building healthcare provision systems.
- ✓ Establish a platform that promotes cooperation by creating networks among related parties or by providing matching support.
- ✓ Establish a framework for evaluating and verifying products and services provided by the private sector that satisfy the needs of the public.

Medical staff should:
- ✓ Conduct user satisfaction surveys targeting people receiving healthcare and, based on the results, establish on-site systems at healthcare institutions for exploring ways to improve care.

The private sector (including companies and organizations) should:
- ✓ Advance research and development on products and services for efficiently collecting feedback from people receiving healthcare.

6   Conclusion

6.1 The limitations of this study and topics to examine in future discussions

One limit of this study was that only certain groups of people could participate in the survey and in-depth interviews. Because this study analyzed and considered issues based on data obtained from people receiving healthcare, it does not provide sufficient consideration to issues facing medical staff or their causes. A follow-up survey from the perspectives of all disciplines involved in providing healthcare is needed, and should not only target physicians, but also nurses, physical therapists, occupational therapists, registered dietitians, and other such professionals. Furthermore, this survey has not been able to sufficiently survey or analyze cases when participants faced difficulties with decision-making for reasons such as dementia or old age. In addition to healthcare institutions, future studies should also take welfare facilities and other institutions providing long-term care into consideration. It is also necessary to examine support for decision-making among patients and other parties most affected, supporters such as family members, and medical staff.

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Japan Federation of Cancer Patient Groups

Cancer Parents

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