

# Healthcare System Reform and the Value of Healthcare

## Public Opinion Research on the Views of Citizens and Patients

Health and Global Policy Institute

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## I. Introduction

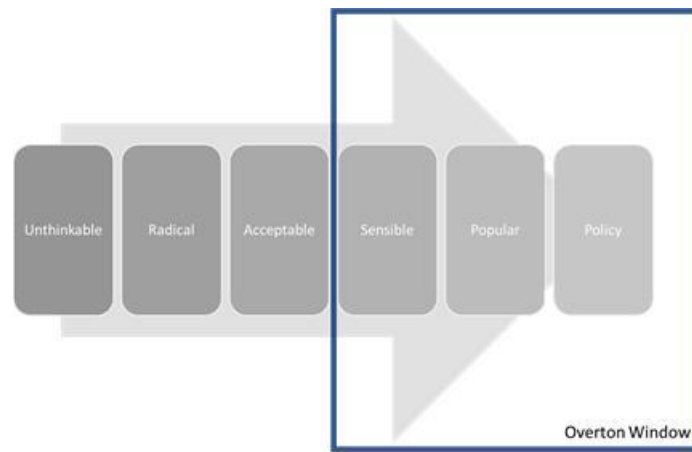
Since the achievement of universal health coverage in 1961, the Japanese health system has supported the growth of the one of the healthiest and longest living populations in the world. However, the sustainability of that healthcare system is now being called into question due to demographic and epidemiologic changes, and the development of innovative but sometimes expensive pharmaceuticals and health technology. The Japanese population is aging, with 28.4% of the population over the age of 65 as of October 2019. That is the highest degree of population aging worldwide. Alongside population aging, total national healthcare expenditure as a proportion of GDP has grown. In 1965, shortly after Japan achieved universal health coverage, that ratio was 3.32%. By FY2018, it had increased to 7.91%. Meanwhile, the working age population is shrinking, as is the ability of that population to continue funding the system. When universal health coverage was achieved, there were approximately 12 people in the workforce for every dependent person. Now, that number is approaching 2 to 1, and it is expected to shrink further in the future.

Likewise, in recent decades, the proportion of income paid to social security by the public has outpaced income growth – since 1990, that figure has grown approximately 7%, while average household income has increased just 1%. The biggest portions of social security costs (120 trillion yen in 2019) are pension (approximately 57 trillion yen) and healthcare (approximately 40 trillion yen). Healthcare costs are covered by insurance fees (accounting for approximately half of the healthcare system’s income), as well as taxes, debt in the form of bonds, and capital assets. As costs rise, Japan has very few choices it can select to ensure health system sustainability – it can either attempt to lower costs, or increase income via insurance payments, tax increases, or debt. In recent decades, Japan has primarily dealt with rising costs through increases to insurance fees and additional debt – for instance, income from the issuance of Government bonds has increased almost six-fold since 1990 (from 5.6 trillion yen to 32.6 trillion yen in 2020) while income from tax sources has increased just 1.15-fold (from 60.6 trillion yen to 70.1 trillion yen in 2020). Increasingly, Japan is asking for its healthcare costs to be covered by the shrinking workforce of today and the shrunken workforce of tomorrow. It is this issue that is calling the sustainability of the healthcare system into question – without drastic action on the system’s finances, it is hard to see how it could possibly continue to be sustainable with its current level of quality and access.

Fixing this problem is going to require serious policy reform – but is that even possible? Sustainability is a long-standing issue that has been debated in the policymaking community for many years, but those discussions have yet to generate definitive solutions. A fix may not be politically feasible. In addition to a sluggish economy, wage growth is a problem in Japan. “Even though your income isn’t going up, and it feels like your family is working hard to make ends meet, we must ask you and your children to pay more” is not a message that can necessarily win votes. The idea that we need more funding for the healthcare system in order to maintain its current levels of quality and access into the future may be *sensible*, but it cannot be said to be *popular*.

However, to move forward on this issue, that must be changed. To ensure health system sustainability, we must foster political leadership. And to do that, we must move the idea that more funding is needed from being something that the policymaking community is merely willing to discuss, to something that the public will actively support in an election.

When considering the relative political popularity of an idea, it can be useful to consider that idea in comparison to other ideas along a spectrum of acceptability (see the figure on the following page). On one side of the spectrum, we have ideas that are unthinkable. On the other side of the spectrum, we have ideas that are so popular that politicians have no choice but to work toward making them into policy. Over the course of a political debate, an idea might move further toward one end of the spectrum or the other as social norms change. As society changes its thinking and an idea moves closer to popularity or policy, there is likely a point where it becomes acceptable enough to enter the political discourse. At that point, we might say that it has entered what is often called the “Overton Window” – the range of politically feasible ideas within our spectrum of acceptability. The primary challenge of health system sustainability is how to move the issue of health system financing further along the spectrum and into the Overton Window so that discussions on it can begin.



In order to make a start at tackling that issue, over the course of FY2020, Health and Global Policy Institute’s (HGPI) Rebalancing Innovation and Sustainability project undertook a series of research initiatives aimed at trying to discover where various issues related to health system sustainability lied in relation to the Overton Window. To achieve that, we conducted a national opinion poll, focus groups, and interviews with patient advocates and patient support group leaders to try and understand the following research questions:

1. Is it palatable to the public to increase the amount of funding available to the healthcare system?
2. How does the public feel about the fairness of healthcare system funding? (Who should pay?)
3. Does the public feel that they are getting value for money in terms of the access to healthcare and quality of healthcare that the system provides?
4. What are public expectations toward quality improvements and innovation?
5. How does the public feel about participating in healthcare policy?

In other words, we wanted to know, is it possible, in the public’s view, to increase the financial resources available to the healthcare system? And if not, where should we cut? To find answers to these questions and hints for how to draw the public into the decision-making process for building a sustainable healthcare system, we conducted research to measure public opinion.

Detailed results from each of our research initiatives are presented in this report. Through our research and our activities this year, we developed five key takeaways about the current health policy discourse and identified two key issues that must be addressed to promote public discourse toward achieving the necessary reforms.

### Key Takeaways

1. The public does not necessarily feel the need to increase healthcare system financing. Rather, many seem to feel that they are already paying too much into the system without receiving any real benefits at all, especially those who do not regularly use healthcare services.
2. The public is probably ready to support more progressive funding schemes for the healthcare system. Many expressed support for the idea that those with the means to pay more, should pay more.
3. People tended to be more supportive of increased health system financing if it would lead to quality improvements, as opposed to maintaining or improving healthcare access.
4. On hopes for innovation, respondents had higher expectations toward overall quality improvements for commonly-used pharmaceuticals and medical devices compared to the development of pharmaceuticals and medical devices that would treat severe diseases affecting smaller groups of patients. Comparatively high expectations were expressed for other technological innovations, such as online medical consultations.
5. People do not seem to feel ownership over the system, or that they are a stakeholder in its policies.

Overall, the main message that we received from the research is that increased financing is still largely unthinkable to the extent that it might affect the respondents themselves, while cost reductions are starting to seem acceptable or sensible. It is felt that there is a disconnect between the value that the healthcare system is providing to society and

the extent that people feel that value in their own lives. From these perspectives, HGPI will deepen discussions on the two key issues described below and synthesize our findings into a separate proposal.

### **Key issues**

1. Members of the public do not recognize themselves as participants in healthcare policy.

Within the current healthcare system, it is difficult to gauge how much each person is paying through insurance premiums and out-of-pocket payments and how insurance premiums and taxes are being used. These issues make it harder for infrequent users to become interested in the healthcare system and healthcare policy. Communication and education must be undertaken on the role of the social security system, the role of the healthcare system, and methods for members of the public to get involved in policy.

2. It is difficult for patients and related parties to participate in decision-making forums. Even when they do, it is difficult for them to speak up.

To better participate in healthcare policy, individuals with a strong sense of ownership over healthcare policy must be equipped with broad knowledge of public health. However, money, time constraints, and other hurdles can make it difficult for people to deepen their knowledge of the healthcare system enough to effectively serve as advocates in decision-making fora. While efforts are being made to broaden policy committee member diversity within the Government, issues remain related to the relative influence of each party within official opinion exchanges involving patient representatives and other stakeholders.



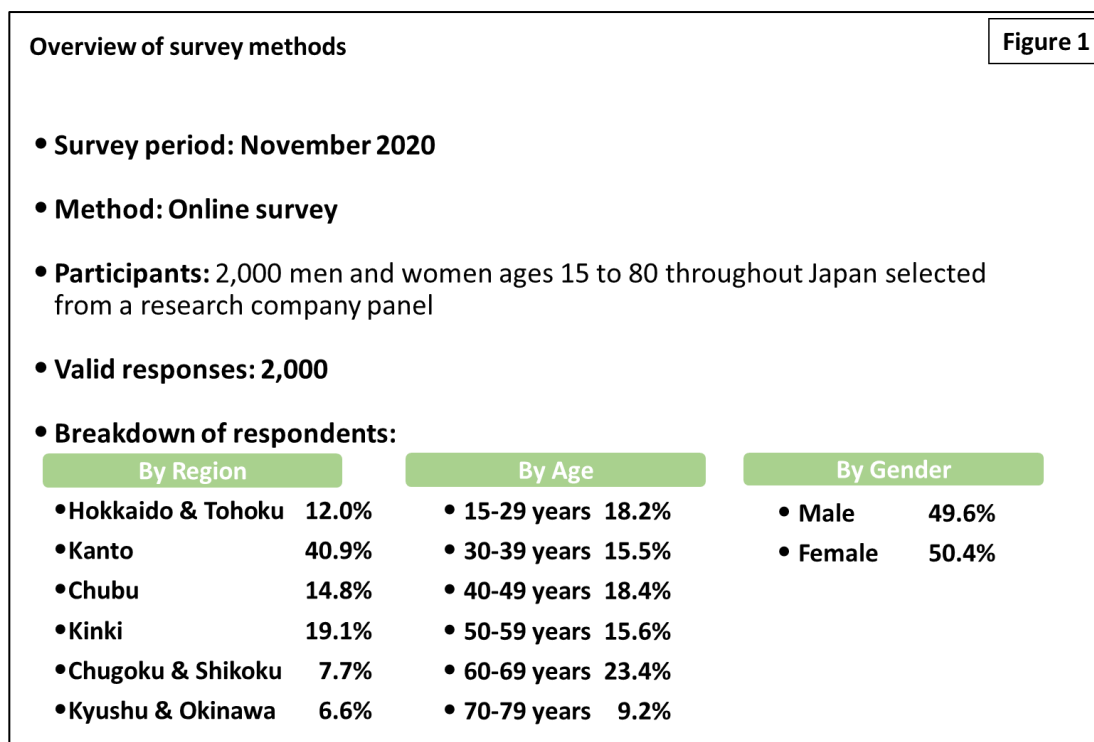
## II. Overview of Research

HGPI conducted an internet-based public opinion survey during November 2020 of 2,000 men and women ages 15 to 80 throughout Japan selected from a panel managed by a collaborating research firm to be representative of the population profile of Japan by age, gender, and region. The breakdown of respondent demographics is shown in Figure 1.

Focus group interviews were conducted with 18 individuals selected from the 2,000 respondents to the aforementioned survey. Participants were separated into groups of three by age and arranged to avoid gender bias. There were two groups each for ages 10-30, ages 40-50, and ages 60-70. Interviews were then conducted online.

Interviews with patients and representatives of patient support groups (hereafter “patient advocates”) were conducted online or face-to-face with nine people from eight organizations while paying consideration to ensure diverse representation for various disease areas.

In recent years, there has been a decline in the efficacy of traditional survey methods due to factors such as decreased response rates for mail-in surveys or in-person interviews and expansions in survey restrictions, which has led to higher expectations for internet surveys. However, the conduction of a survey on the internet introduces a fixed sampling bias in that it selects only for respondents who can use the internet, and hence have a certain level of education, as internet literacy is generally correlated with education level.<sup>1 2 3 4 5</sup> It is important to take this limitation into account when interpreting the results of this survey. Furthermore, income level and disease history may be other potential sources of bias, as this project was not able to ensure that our population was representative of the general population of Japan related to these factors.

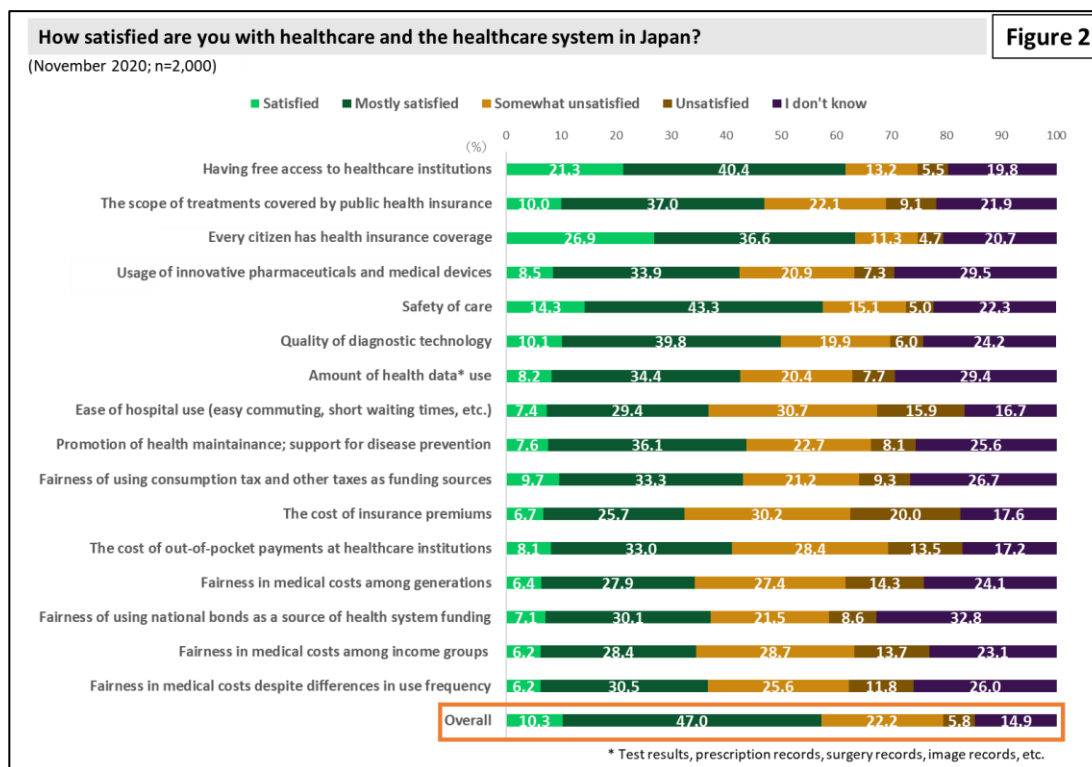


<sup>1</sup> Smith MA, Leigh B, 1997, Virtual subjects: Using the Internet as an alternative source of subjects and research environment. Behav Res Meth Instrum Comput, 29, 496–505.  
<sup>2</sup> Osomi N, Maeda T, 2007, Problems with online surveys - Observations from experimental investigations (Part 1) (From members). Japan Association for Public Opinion and Research Newsletter Yoron, 100, 58-70.  
<sup>3</sup> Osomi N, Maeda T, 2008, Problems with online surveys - Observations from experimental investigations (Part 2) (From members). Japan Association for Public Opinion and Research Newsletter Yoron, 101, 79-94.  
<sup>4</sup> Miura A, Kobayashi T, 2015, Monitors are not monitored: How satisficing among online survey monitors can distort empirical findings. Japanese Journal of Social Psychology, 31, 1–12.  
<sup>5</sup> Hanibuchi N, Muranaka A, Ando M, 2015, Challenges of Data Collection through Internet Research: Analysis of “Frivolous” Responses, Response Time, and Geographical Pattern. E-journal GEO, 10 (1), 81-98.

### III. Survey Results

#### 1. Public Opinion Survey on the Healthcare System

##### (1) Satisfaction toward healthcare and the healthcare system



- More than half (57.3%) of respondents reported that they were satisfied with healthcare and the healthcare system in Japan. The popularity of options like “Every citizen has health insurance coverage” and “Safety of care” showed that satisfaction toward access and quality tended to be high. Conversely, satisfaction was low toward the cost of insurance premiums and the equity of healthcare payments.

#### Related comments from patient advocate and focus group interviews:

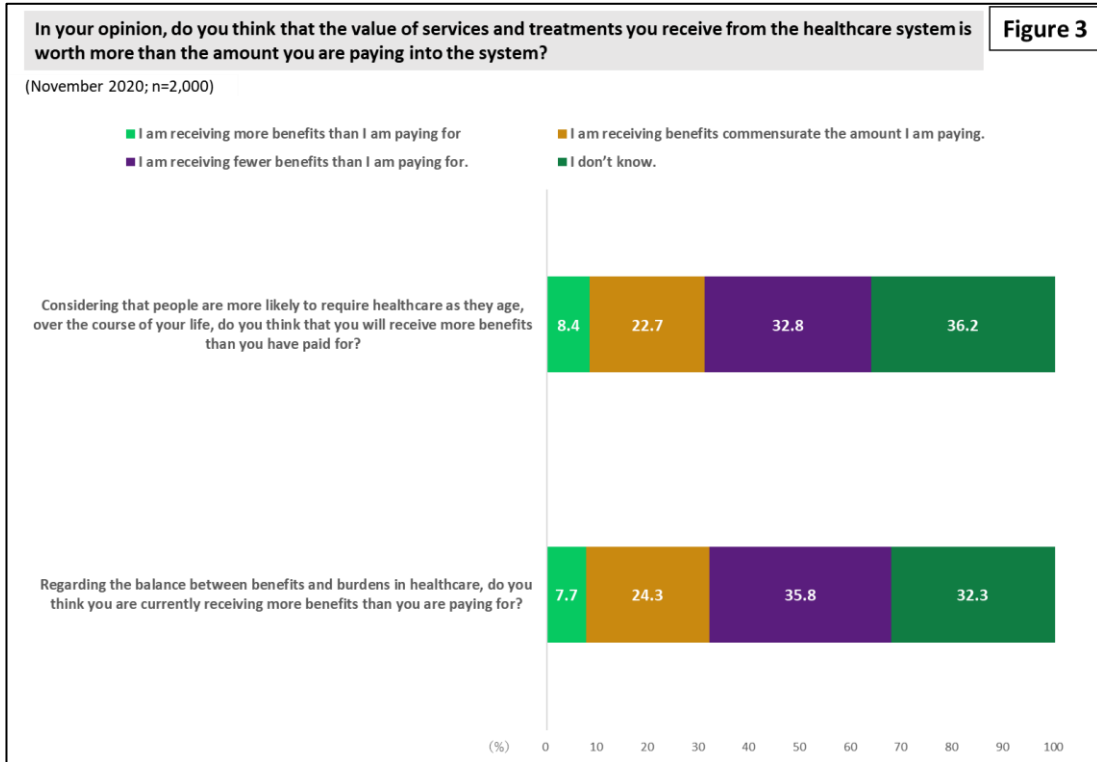
Japan is noted for its National Health Insurance system worldwide, especially in terms of access to safe and high-quality care. Some respondents thought that high satisfaction toward these aspects accurately reflected the characteristics and strengths of Japan’s healthcare system.

- ✓ “Thinking of the level of benefits offered by Japan’s healthcare system compared to healthcare systems in other countries, it is no surprise satisfaction was high, particularly toward safety and free access.” (Patient advocate)
- Patient advocates felt that the amount of people who selected “I don’t know” reflected insufficiencies in the amount of information communicated about the system to the public, and the public’s understanding of what is communicated.
- ✓ “I do think it is a problem that so many people selected, ‘I don’t know.’ It could be a sign of how little the public understands the system.” (Patient advocate)
- ✓ “The fact that many people said, ‘I don’t know’ on topics like national bonds and health data suggests that efforts to disseminate information on these topics have been lacking.” (Patient advocate)

**(2) Results related to healthcare system financing**

**Key takeaway 1: The public does not necessarily feel the need to increase healthcare system financing**

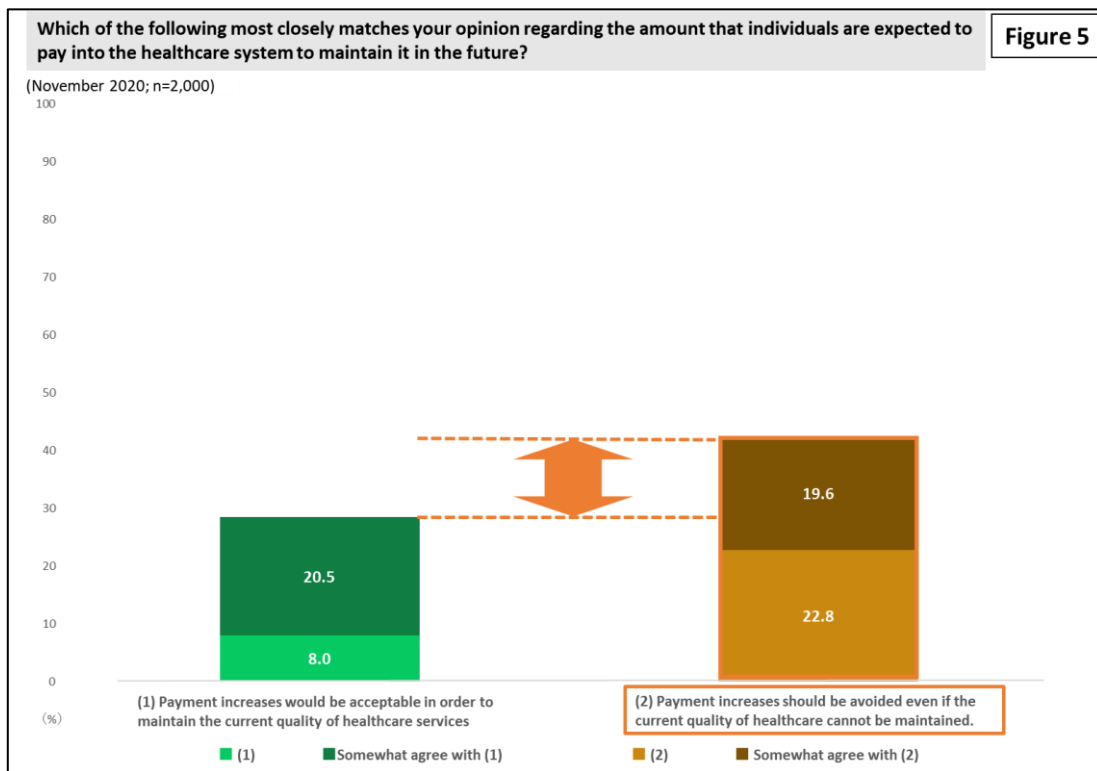
Members of the public who are not currently receiving healthcare services especially seem to feel that they are not receiving a commensurate value from the amount of money that they are paying into the system.



- Excluding those who selected “I don't know,” most respondents felt that they are receiving fewer benefits than they are paying for.



- Over two-thirds of respondents (67.6%) want to maintain the current healthcare system and levels of financing as much as possible.



- **42.4% of respondents felt that the amount they pay for healthcare should not be increased even if current healthcare quality standards cannot be maintained. More respondents were opposed to increasing costs than lowering benefit levels.**

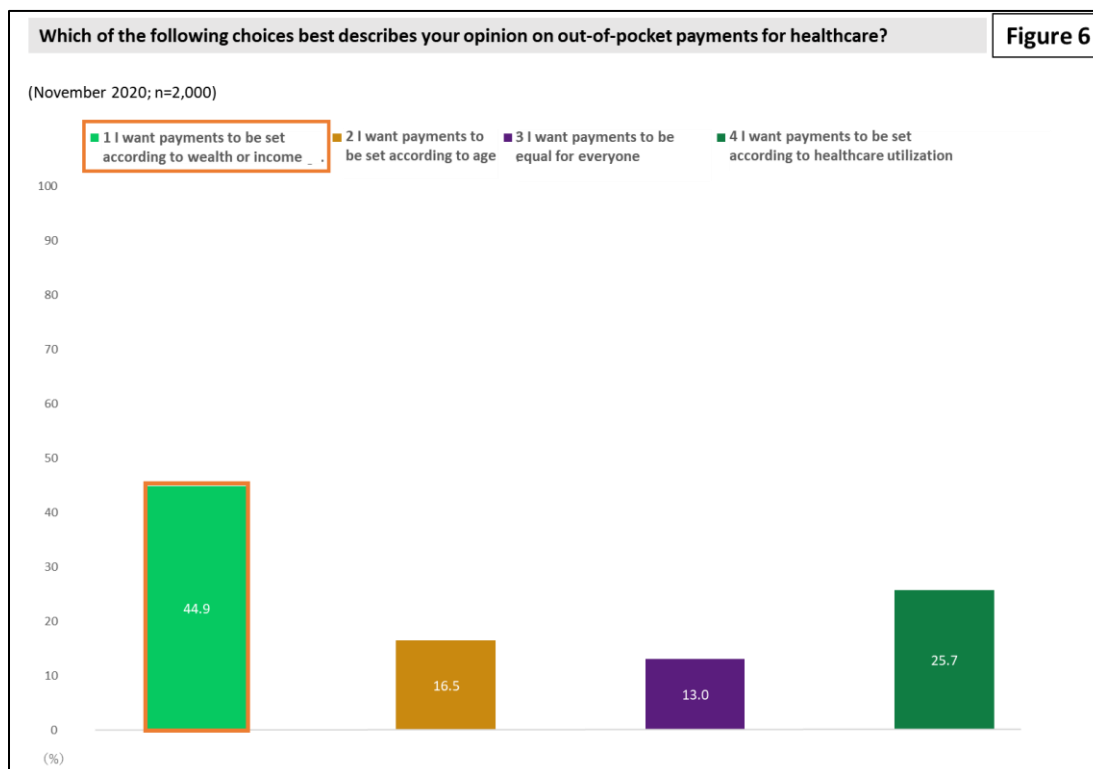
**Related comments from patient advocate and focus group interviews concerning these three questions:**

Responses may have been influenced by past experiences with medical visit frequency and disease severity

- ✓ “I only see a doctor a few times a year, like when I catch a cold. When I do go to the doctor, the bill is never large enough to make me want to question whether or not it is fair. I don’t think healthcare is expensive, which makes me think that the benefits I’m receiving probably do match what I am paying in.” (Female, 30s, Tokyo, full-time employee, household income: ¥4-6 MM)
- ✓ “I’m single and young, so I don’t visit the doctor very often. I have almost no medical expenses. It feels like my insurance premiums are just being taken out of my pay each month for nothing. The benefits don’t match the cost.” (Female, 20s, Tokyo, civil servant, household income: ¥4-6 MM)
- ✓ “I have been visiting the hospital regularly to receive blood pressure and cholesterol medications, and I’ve had various tests done. Looking at my current state of good health, I think I am getting sufficient benefits from what I’m paying.” (Female, 60s, Tokyo, part-time employee, household income: ¥4-6 MM)

**Key takeaway 2: The public is probably ready to support more progressive funding schemes for the healthcare system The public generally supports progressive funding schemes**

When asked questions related to who should and should not shoulder the burden of healthcare payments, most respondents supported the idea that people with the means to pay more, should pay more.



- The highest proportion of respondents said, “I want payments to be set according to wealth and income” (44.9%). “I want payments to be set according to healthcare utilization” was also relatively popular (25.7%).

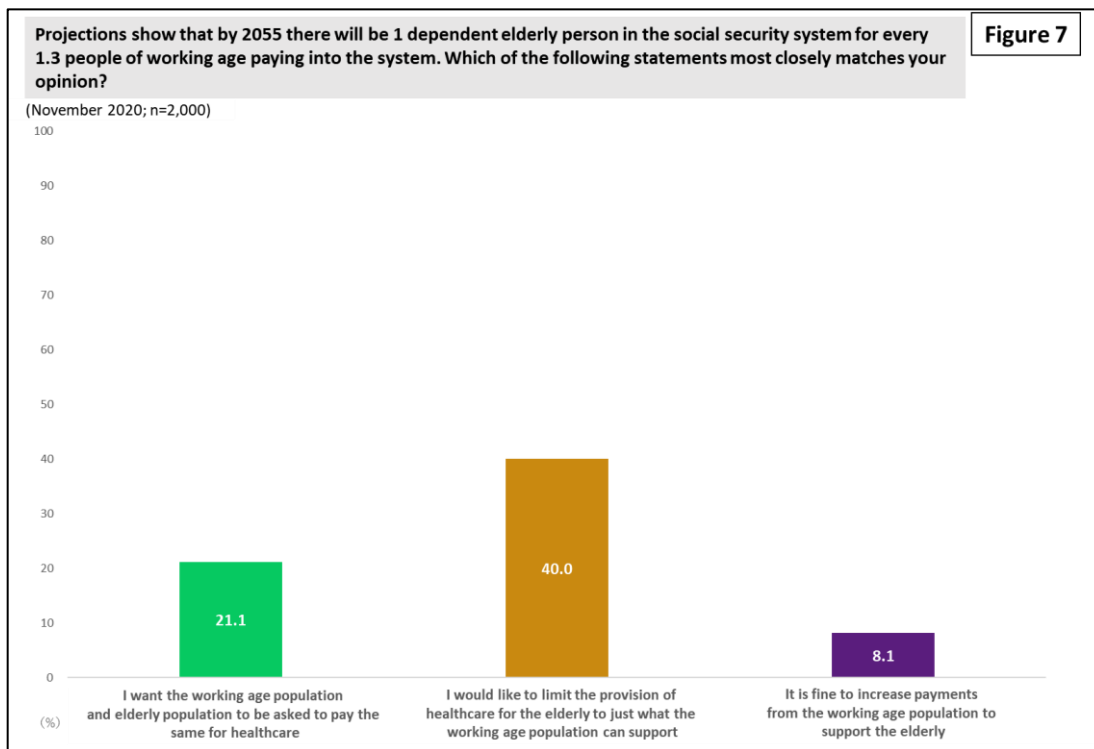
**Related comments from patient advocate and focus group interviews:**

Some respondents thought that steps should be taken to maintain healthcare access for people with high medical care needs or low incomes.

- ✓ “When I selected ‘I want payments to be set according to wealth and income,’ I was thinking about the people who have to visit the hospital regularly for long periods of time.” (Male, 30s, Tokyo, full-time employee, household income: ¥2-4 MM)
- ✓ “I think that every person should have access to the bare minimum of healthcare services, and that out-of-pocket payments should be set according to their income or wealth.” (Female, 20s, Tokyo, part-time employee, household income: ¥4-6 MM)

Many respondents supported progressive funding schemes because they felt the amount that infrequent users pay into the system is unfair. In response to this, many patient advocates expressed concern about the perceived lack of understanding toward the function of social security and the healthcare system as a means of sharing risk.

- ✓ “It is unfair that people have to pay into the system even if you don’t use it.” (Female, 50s, Tokyo, part-time employee, household income: ¥10-12 MM)
- ✓ “I think the amount of support for progressive funding schemes shows how tight household finances are. It also perhaps shows a lack of awareness toward the fact that anyone can develop a disease at any time.” (Patient and patient advocate)



- The most popular response was, “I would like to limit the provision of healthcare for the elderly to just what the working age population can support.” (40.0%).

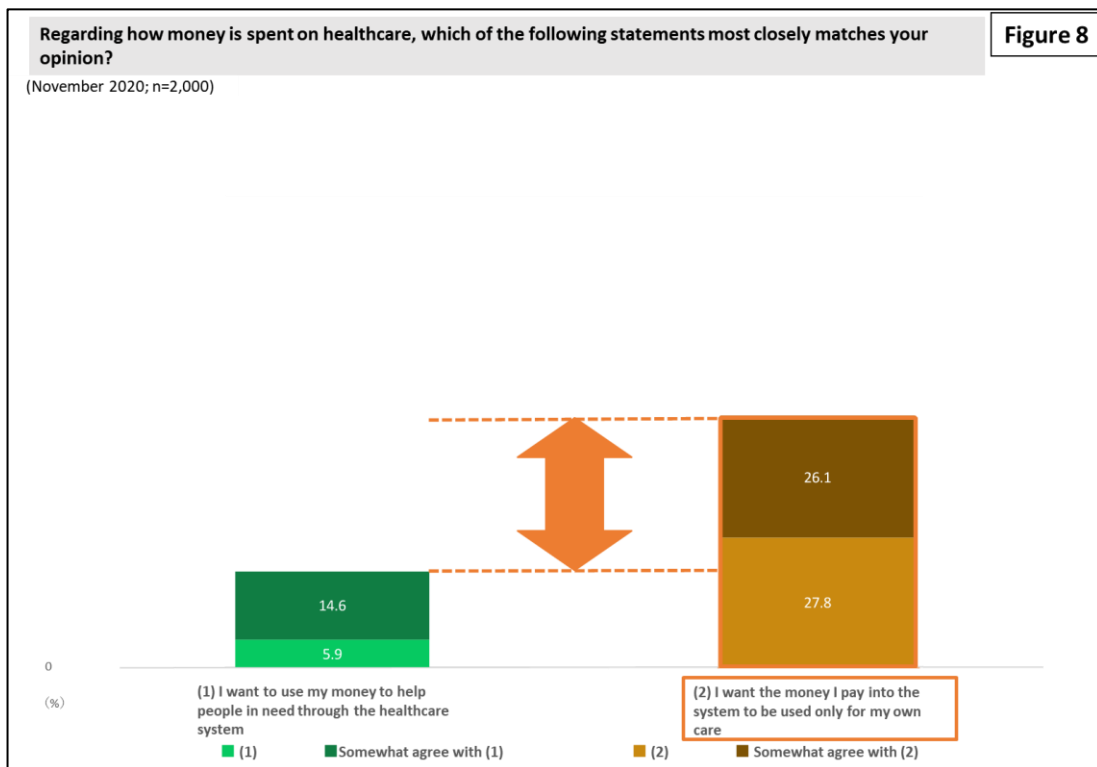
#### Related comments from patient advocate and focus group interviews:

Many respondents stated that they tried to answer while thinking about their parents, or what their own situation would be as they grew older, concluding that unfair to increase the financial burden placed on elderly people in the future. There were high hopes expressed for efforts to improve the efficiency of the healthcare system.

- ✓ “(If the burden on elderly people is increased) I feel it will come back to haunt me or my parents in the future.” (Female, 30s, Tokyo, full-time employee, household income: ¥4-5 MM)
- ✓ “The working population doesn’t have the money. Money is too tight to increase out-of-pocket payments. I will be elderly in 2055, and the working-age population will be smaller then. The system should stop paying for unnecessary services and goods, like pain relief patches.” (Male, 40s, Nagasaki Prefecture, full-time employee, household income: ¥8-10 MM)
- ✓ “The payments that we expect from the working-age population in the future should be kept similar to how they are now. The system should be redesigned so that the costs can be passed on more to those who need healthcare, while lowering payments for those who don't.” (Male, 40s, Kanagawa Prefecture, full-time employee, household income: ¥6-8 MM)

Some respondents expressed the opinion that an environment that allows able-bodied elderly people to work should be created, and that payments should be increased for elderly people with incomes or property.

- ✓ “Some elderly people have money. If they do, they should have to pay according to the same standards as everyone else.” (Female, 10s, Tokyo, university student, household income: ¥14-16 MM)
- ✓ “The age of mandatory retirement should be eliminated. Elderly people who can work, should work. And those people should be asked to pay their fair share into the healthcare system.” (Male, 50s, Kanagawa Prefecture, full-time employee, household income: ¥6-8 MM)



- The most popular response was, “I want to the money I pay into the system to be used only for my own care” (53.9%).

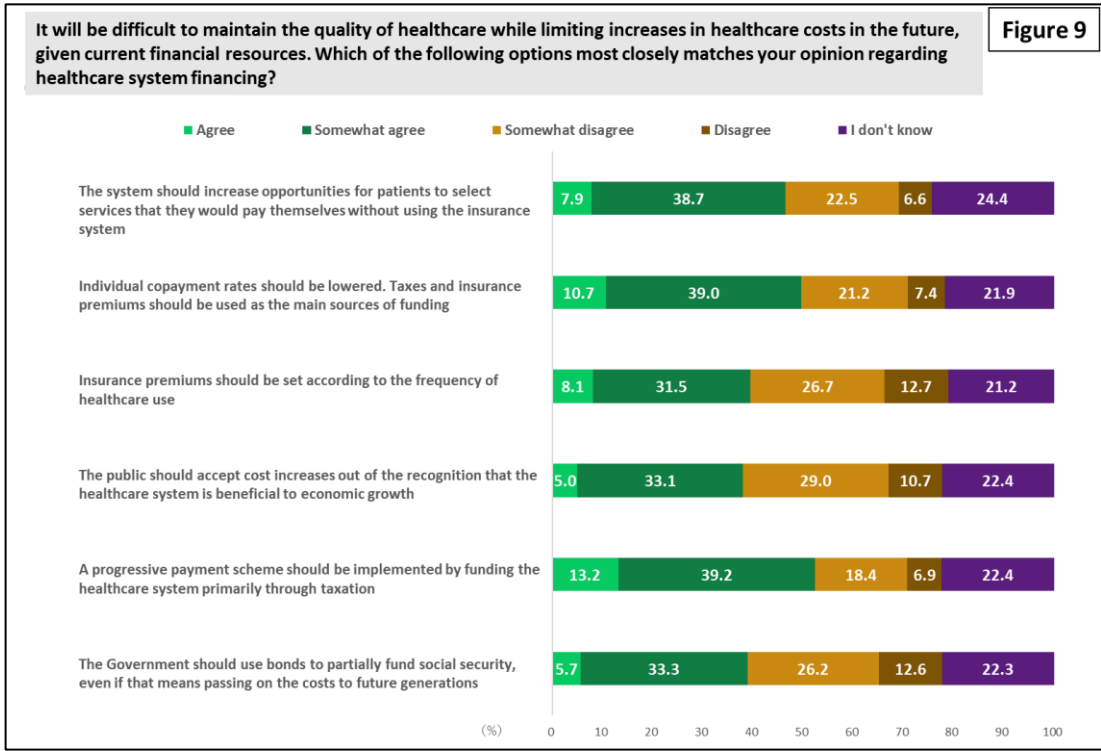
**Related comments from patient advocate and focus group interviews:**

Among those who selected, “I want the money I pay into the healthcare system to be use for those in need,” some emphasized their belief in the healthcare system as a social safety net

- ✓ “I think the basic principle of insurance is that everyone shares the burden of payment to help those in need.” (Female, 50s, Tokyo, business owner, household income: ¥10-12 MM)
- ✓ “It depends on how you define who is ‘in need.’ I support the use of the nation’s financial resources to support people and diseases that can only be treated with high-cost treatments.” (Male, 40s, Kanagawa Prefecture, full-time employee, household income: ¥6-8 MM)

Among those who selected, “I want to use my money on myself,” some expressed the belief that individuals should help themselves in times of trouble, without relying on social support. Patient advocates expressed concerned over the possibility that there is low awareness of the importance of social support.

- ✓ “A certain degree of self-help is necessary. That’s capitalism.” (Male, 50s, Kanagawa Prefecture, full-time employee, household income: ¥6-8 MM)
- ✓ “I don’t want to spend so much on other people.” (Female, 70s, Hyogo Prefecture, homemaker, household income: ¥4-6 MM)
- ✓ “People perhaps are not thinking about the fact that the money they pay now is being invested in the care they may receive in the future.” (Patient advocate)
- ✓ “It is possible that too few people recognize that they are helping those in need by paying into the healthcare system. There is not much transparency in the way that insurance premiums and taxes are used.” (Patient advocate)



- When asked how to make up for shortcomings in health system finances, “The system should increase opportunities for patients to select services that they would pay themselves without using the insurance system,” “Individual copayment rates should be lowered. Taxes and insurance premiums should be used as the main sources of funding,” and “A progressive payment scheme should be implemented by funding the healthcare system primarily through taxation,” were selected by 46.6%, 49.7%, and 52.4% of respondents, respectively. If we exclude people who answered, “I don’t know,” each one of these selections was favored by the majority of respondents. Respondents were split on whether they supported policy to “Insurance premiums should be set according to the frequency of healthcare use,” “The public should accept cost increases out of the recognition that the healthcare system is beneficial to economic growth,” and “The Government should use bonds to partially fund social security, even if that means passing on the costs to future generations.”

**Related comments from patient advocate and focus group interviews:**

Many respondents were aware of issues related to the use of Government bonds as a source of social security funding. Some stated that they felt the use of bonds was unavoidable due to issues like the COVID-19 pandemic and the declining birthrate, while others did not view Government bonds as a problem.

- ✓ “Is it really okay to secure financial resources by issuing Government bonds?” (Male, 40s, Kanagawa Prefecture, full-time employee, household income: ¥6-8 MM)
- ✓ Despite all the debate about raising the consumption tax, it feels it will be difficult to improve the situation given the current state of the economy. I don’t think Government bonds can fix things.” (Female, 30s, Tokyo, full-time employee, household income: ¥4-6 MM)
- ✓ “Are bonds really debt? We need to reduce the financial burden currently being placed on the public right now.” (Male, 50s, Kanagawa Prefecture, full-time employee, household income: ¥6-8 MM)

Some respondents were supportive of self-financed healthcare out of concern about the limitations of public health insurance finances, and the belief that it might provide access to a greater range of healthcare options. Others expressed the belief that promoting self-financed healthcare might increase disparity.

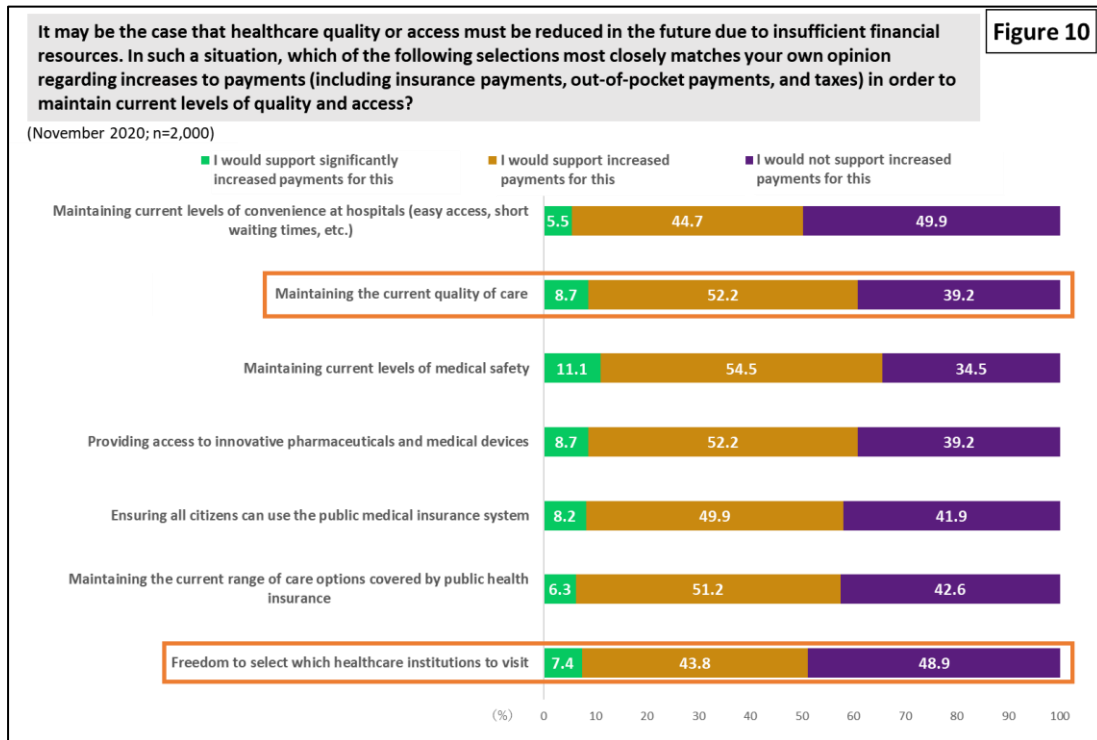
- ✓ “I think it is getting extremely difficult to finance public health insurance. It would be better if people bought private insurance for additional partial coverage and to access more options.” (Female, 50s, Tokyo, business owner, household income: ¥10-12 MM)
- ✓ “Self-financed healthcare could lead to a situation where people with money would be able to access care, but those without money wouldn’t. That would only increase disparity.” (Female, 30s, Saitama Prefecture, full-time employee, household income: ¥8-10 MM)



### (3) Results on healthcare system quality and access

**Key takeaway 3: People tended to be more supportive of increased health system financing if it would lead to quality improvements, as opposed to maintaining or improving healthcare access.**

People tended to be more supportive of policies that increase health system financing if it meant maintaining or improving quality, as opposed to access.

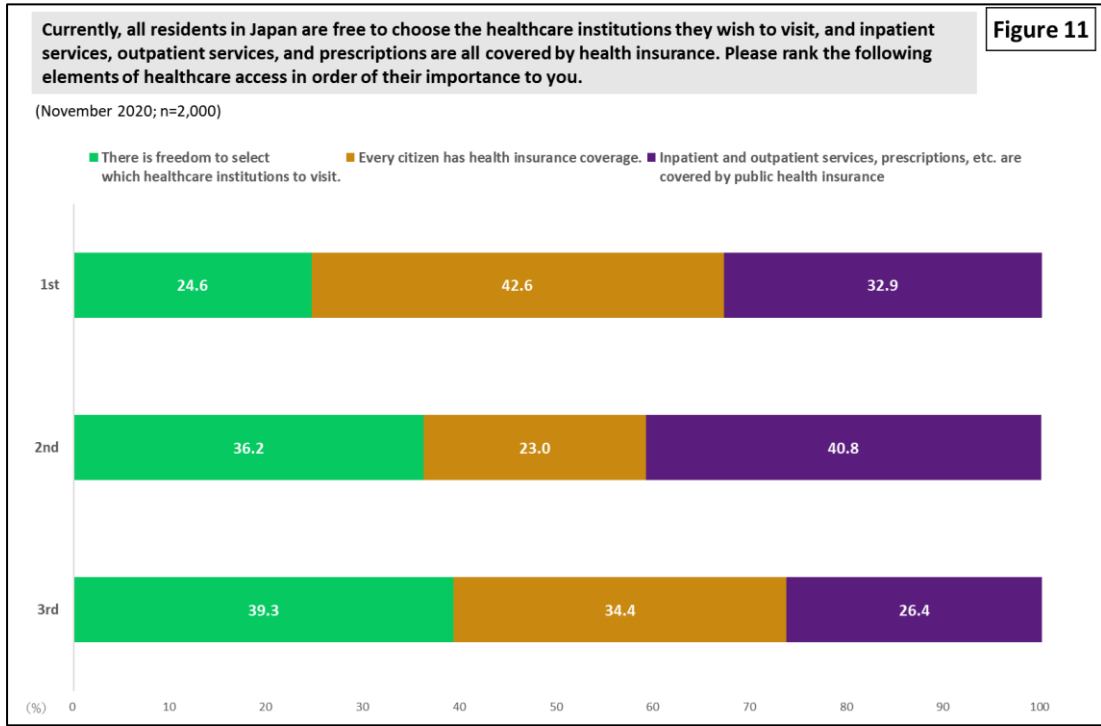


- While a significant proportion of respondents supported the use of financial resources for safety, quality, and innovation, around half of respondents said they would not support cost increases to maintain or improve healthcare access, or increase the convenience of healthcare facilities.

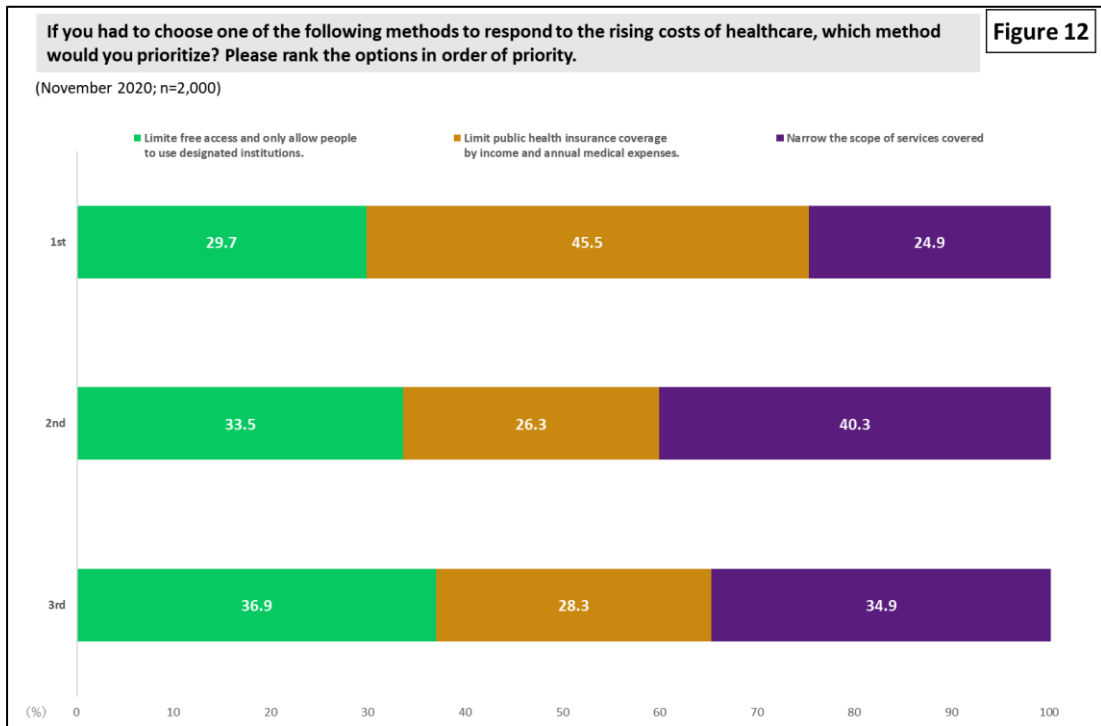
#### Related comments from patient advocate and focus group interviews:

Patient advocates expressed the desire to see a healthcare system that maintains consideration for minority groups, given that one’s medical history and treatment status can impact feelings about whether payments and benefits are fair. That said, we did not find any difference in this question’s results according to variables related to medical history or treatment status. More research may be needed to explore this idea further in the future.

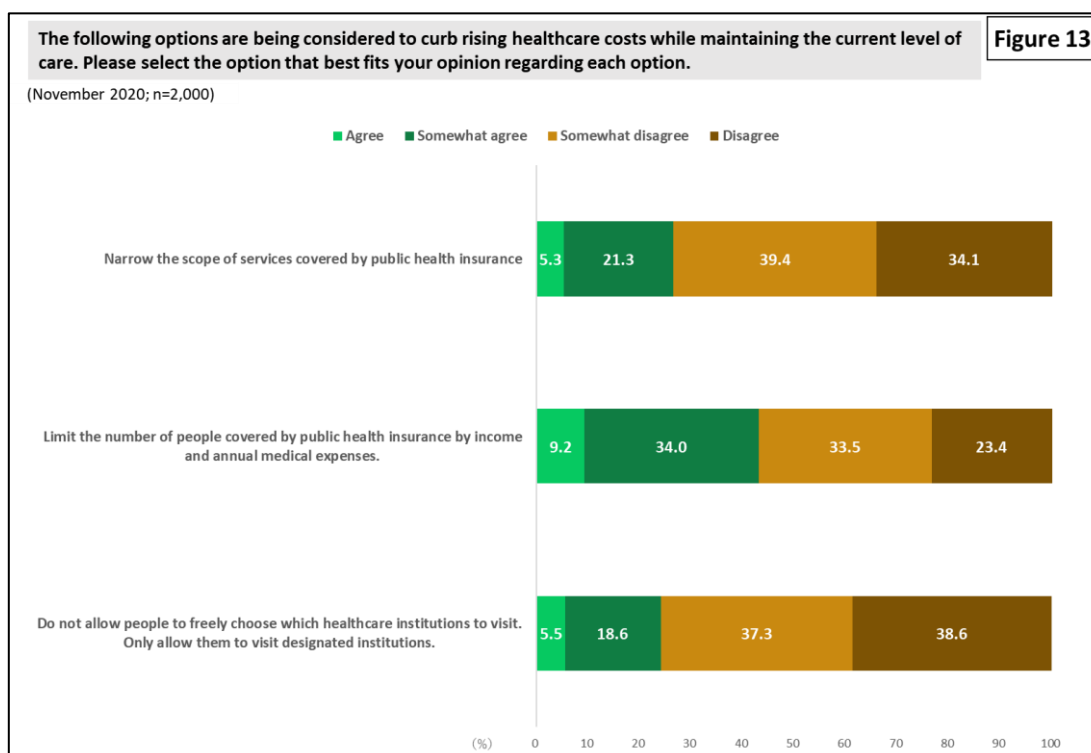
- ✓ “I think people’s answers change according to how much experience they have with healthcare. I can see how those who have not experienced hardships associated with convenience and access would be more inclined to focus on things like safety. The COVID-19 pandemic has made people question if they have any underlying diseases, and when a natural disaster or similar event occurs, it boosts advocacy. The question is how to communicate information regarding the healthcare system to the public.” (Patient advocate)
- ✓ “Concerning measures to restrict free access, there are aspects to the issue that people will not understand without firsthand experience.” (Patient advocate)



- When asked what aspect of healthcare access they put the most value on, the highest proportion of respondents (42.6%) said they value the fact that all citizens have public health insurance coverage.



- When asked what cuts to access might be acceptable to control costs if they were forced to make a choice, the most popular answer was to limit the number of people covered by public health insurance based on factors like income or annual medical expenses.



- A high proportion of respondents opposed the placement of restrictions on choices about which medical facility to visit (75.9%), and the limitation of what treatments the health insurance system covers (73.5%).

**Related comments from patient advocate and focus group interviews on these three questions:**

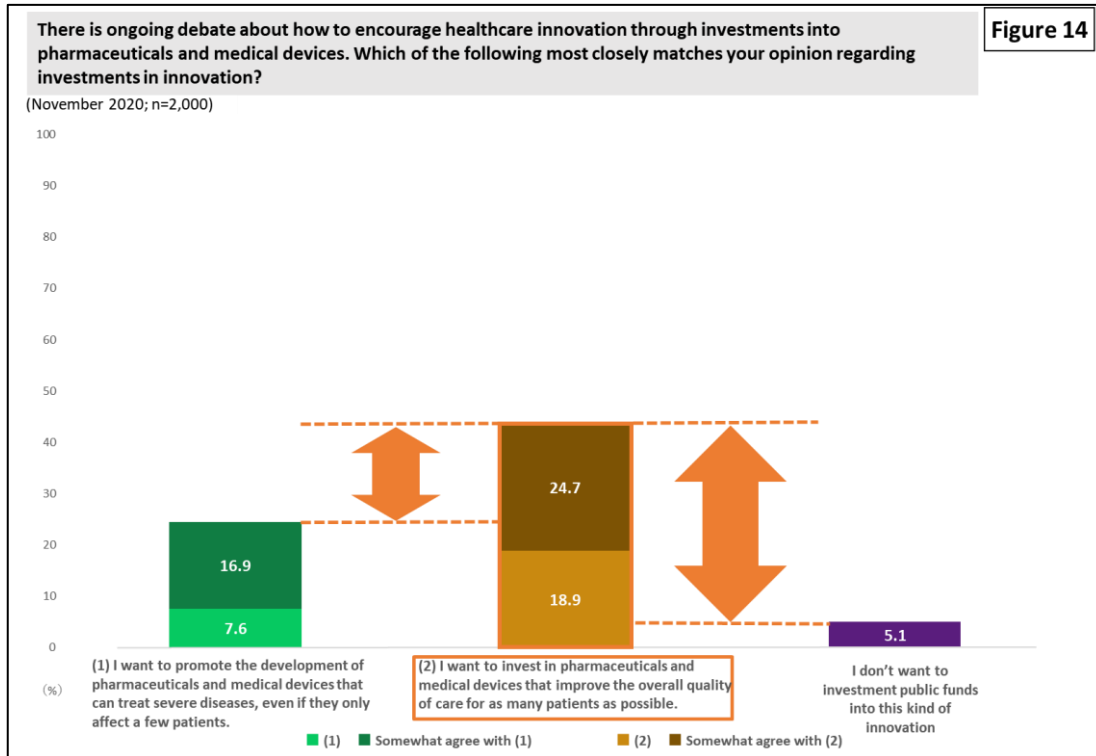
Reasons respondents stated for their opposition to limitations on choices about where to seek medical care included the desire to seek care from doctors that the respondent is most familiar with, the desire to seek second opinions freely, matters of convenience, and the desire to preserve a sense of competition among hospitals and physicians. Those in support of restrictions cited the need to efficient distribute resources.

- ✓ “In rural areas, it is especially inconvenient if you cannot choose your own doctor freely.” (Female, 40s, Nagasaki Prefecture, full-time employee, household income: ¥8-10 MM)
- ✓ “To put it bluntly, I’m worried about errors. I would be in trouble if my designated healthcare institution was low quality. When I want a second opinion, I don’t want to be refused or hear that it will cost money.” (Male, 50s, Kanagawa Prefecture, full-time employee, household income: ¥6-8 MM)
- ✓ “I think one way to design the system would be to provide primary care at a designated hospital and then allow people to sift through different options to select secondary or specialized care providers. I’ve lived in the United Kingdom, and that was the kind of system they had. Using that system was extremely stressful, but in terms of healthcare finances, I think it is much less costly than the Japanese system.” (Male, 40s, Kanagawa Prefecture, full-time employee, household income: ¥6-8 MM)
- ✓ “From the perspective of someone with a severe disease, I think free access to healthcare facilities is important. People need to be able to find the doctor that is right for them. That is why I’m opposed to placing restrictions on access, if it can be avoided. If we must have restrictions, it should only be after establishing a referral system that would allow people to see the specialists they need.” (Patient advocate)

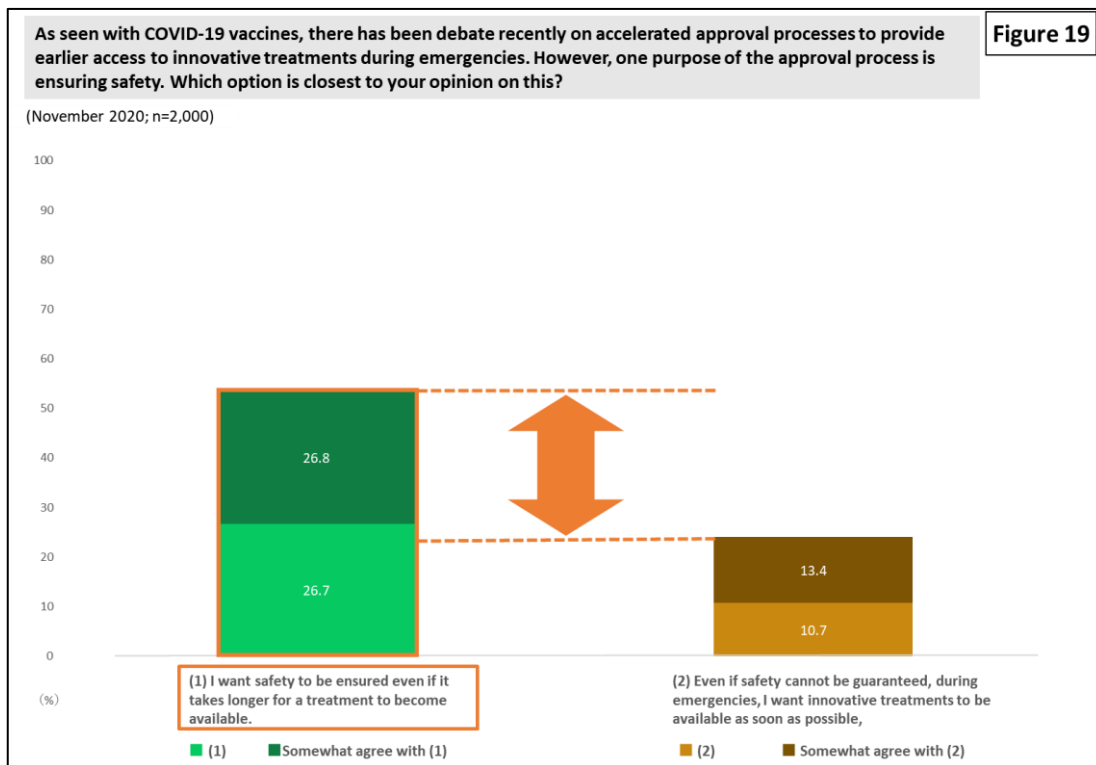
**(4) Results on investing into innovation**

**Key takeaway 4: There were higher expectations toward overall quality improvements than for improvements targeting specific diseases. Expectations were expressed for technological innovations.**

On innovation, respondents had higher expectations toward overall quality improvements for commonly-used pharmaceuticals and medical devices compared to the development of treatments for diseases that affect smaller groups of patients. There were also comparatively high expectations for technological innovations.



- Fewer respondents (24.5%) supported innovation in treatments for severe diseases that affect smaller groups of patients than those who supported innovation for common diseases that affect a large number of people (43.6%).

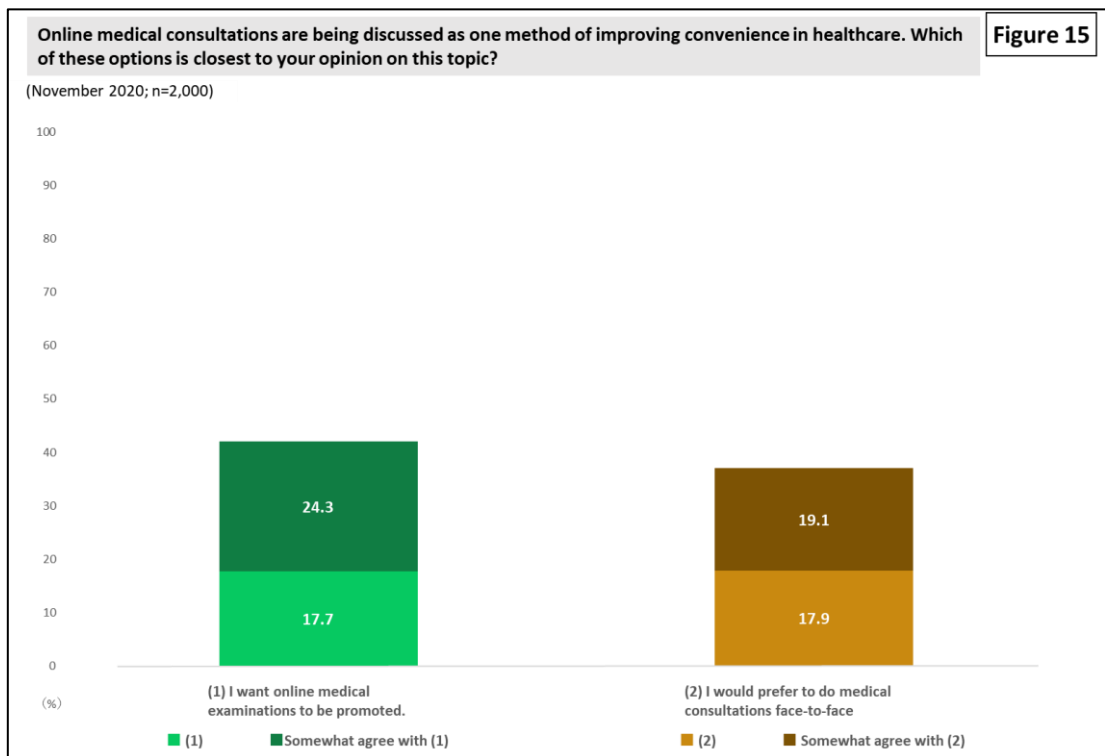


- When introducing innovative treatments, more respondents (53.5%) said they wanted to emphasize safety compared to those who wanted to emphasize accelerated approvals, even during times of emergency (24.1%).

**Related comments from patient advocate and focus group interviews about these two questions:**

Respondents supported innovation in treatments for common diseases that affect large patient groups for reasons such as higher cost-effectiveness. That said, respondents also expressed concern for those with severe diseases. Patient advocates expressed the view that it may be difficult for members of the public to understand the importance of innovation for rare diseases without firsthand experience.

- ✓ “To begin, I would like to state that I believe all lives are equal, and that everyone’s life should be saved, if possible. However, given the current financial situation facing Japan, treating everyone may not be feasible, so we are faced with the question of who to treat. Treating more people and enabling them to live a normal life and work energizes the economy and creates a broader tax base, benefiting both Japan and society.” (Male, 20s, Tokyo, civil servant, household income: ¥4-6 MM)
- ✓ “If there is no treatment for a rare disease, the people with that disease have nowhere to turn for help. We can’t just leave them without care.” (Male, 60s, Osaka Prefecture, freelance employee, household income: ¥6-8 MM)
- ✓ “My elder brother died of amyotrophic lateral sclerosis (ALS), and I strongly feel that there is far too little work being done to develop medicines for rare diseases. I would like to eliminate situations in which there is no hope for treatment.” (Female, 50s, Tokyo, part-time employee, income: ¥10-12 MM)
- ✓ “Overall, I get the impression that most people thought, ‘Anything that benefits me as an individual is good; I want to see benefits from the system.’ I am worried that minority groups would be left behind (if we moved forward with policy based on this response). Figuring out how to change overall trends here is the issue.” (Patient advocate)
- ✓ “These responses may just be people expressing their desire to see money spent on things that are relevant to them.” (Patient advocate)



- There was a split in support for the greater promotion of online medical consultations over face-to-face consultations, which were selected by 42.0% and 37.0% of respondents, respectively.

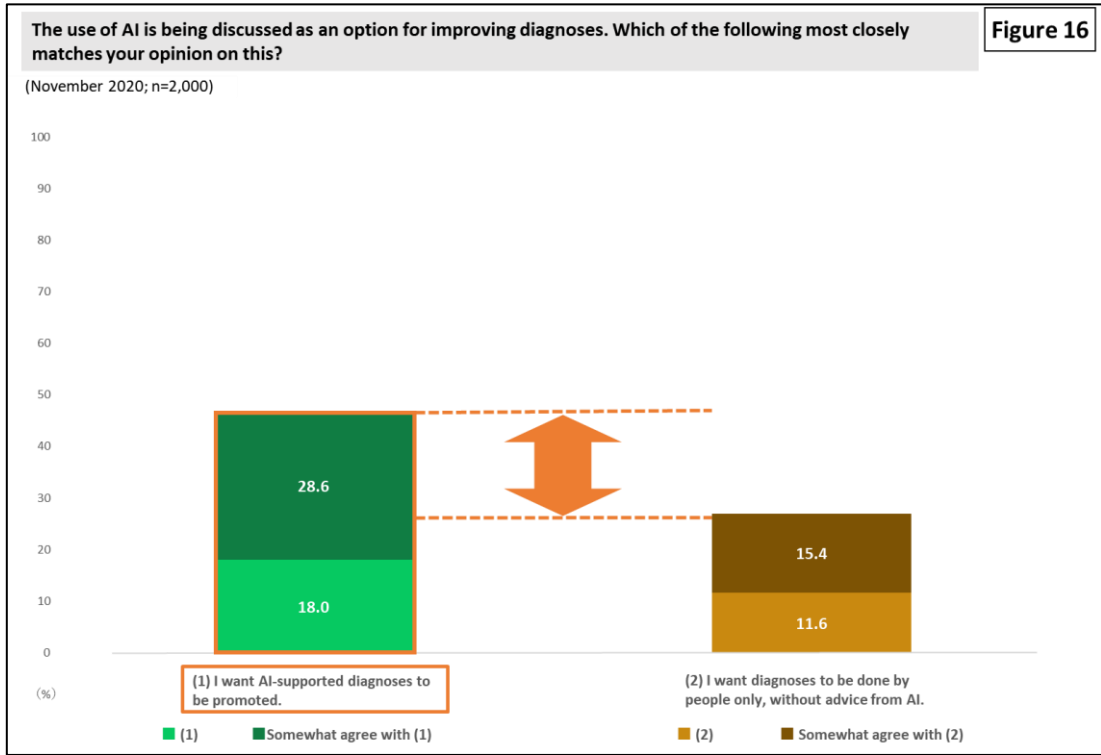
**Related comments from patient advocate and focus group interviews:**

Respondents supported the promotion of online medical consultations as a response to the COVID-19 pandemic and for reasons like convenience. Many respondents said that both online medical consultations and face-to-face consultations should be used as needed.

- ✓ Thinking of healthcare staff shortages or COVID-19 clusters in hospitals can make one feel apprehensive about going to the doctor. Also, online medical consultations will make providing treatment smoother for simple diseases without exposing anyone to the disease, so I support promoting online medical consultations. (Male, 30s, Tokyo, full-time employee, household income: ¥2-4 MM)
- ✓ I want examinations from certain specialists like dermatologists to be conducted face-to-face, so I want online consultations to be promoted while maintaining access to in-person treatment. (Female, 10s, Tokyo, university student, household income: ¥14-16 MM)

Those that preferred in-person medical consultations stated reasons such as the idea that it might be difficult to conduct examinations related in certain fields like dermatology, or that they thought they would feel greater peace of mind about their health from an in-person visit with their doctor.

- ✓ “I feel more relaxed when I can see my doctor in person. Online consultations have improved, though, so I don’t think they’re bad.” (Female, 70s, Hyogo Prefecture, homemaker, household income: ¥4-6 MM)



■ **More respondents supported the promotion of the use of AI in medical examinations (36.6%) compared to those who preferred that doctors rely on their own judgement without advice from AI (27.0%).**

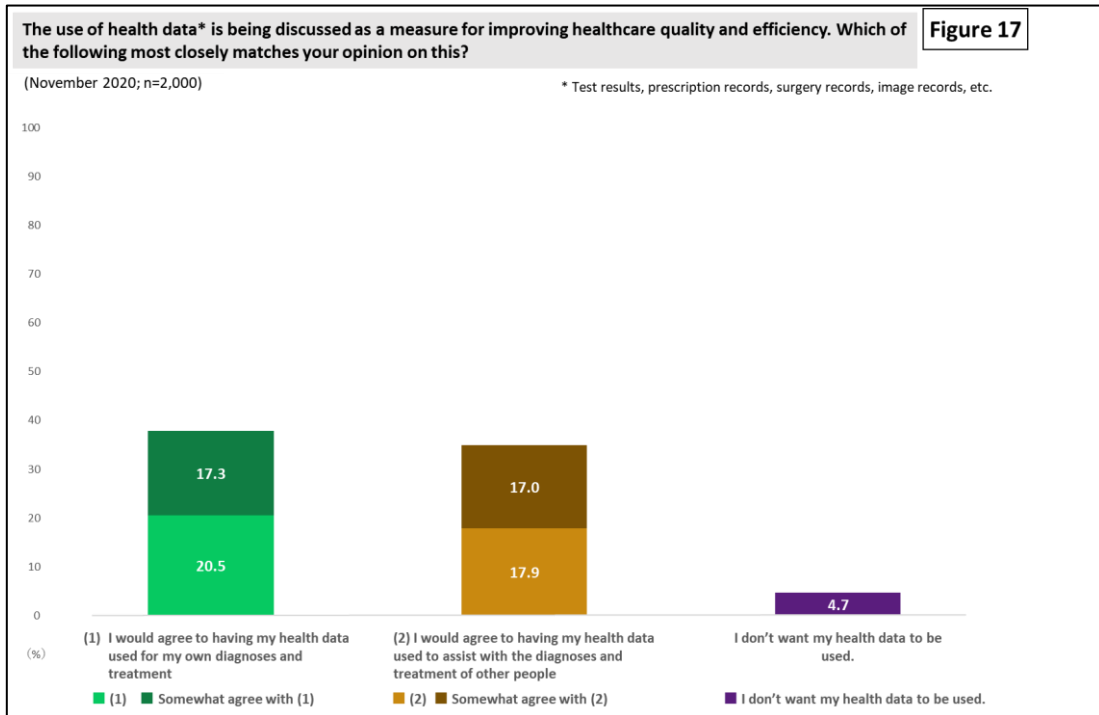
**Related comments from patient advocate and focus group interviews:**

Many supported the use of AI as a response to staffing shortages or the uneven regional distributions of physicians. Some stressed the need for further consideration about just what AI can and cannot help with.

- ✓ “Thinking of problems like the shortage in physicians, or to lower healthcare spending, I support the use of AI.” (Male, 20s, Tokyo, civil servant, household income: ¥4-6 MM)
- ✓ “In remote islands, advanced technology like only medical examinations is already being used. Healthcare cannot be provided by AI alone. We need to use it where appropriate.” (Female, 40s, Nagasaki Prefecture, full-time employee, household income: ¥8-10 MM)
- ✓ “I think we should use the right tool for the right job. Let AI handle what it can and let people do what AI cannot.” (Female, 30s, Saitama Prefecture, full-time employee, household income: ¥8-10 MM)

Those who opposed the use of AI to support diagnoses expressed distrust of AI.

- ✓ “I don’t think we can trust AI. Actually, I think the use of AI is fine if we are talking about the common cold or something like that, but if I had a really serious disease, I would like my diagnosis to be decided based on the experience of my doctor.” (Female, 10s, Tokyo, university student, household income: ¥14-16 MM)
- ✓ “I just cannot trust AI. I trust people. It’s great to see technological progress but I still only trust the judgement of people.” (Female, 70s, Hyogo Prefecture, homemaker, household income: ¥4-6 MM)



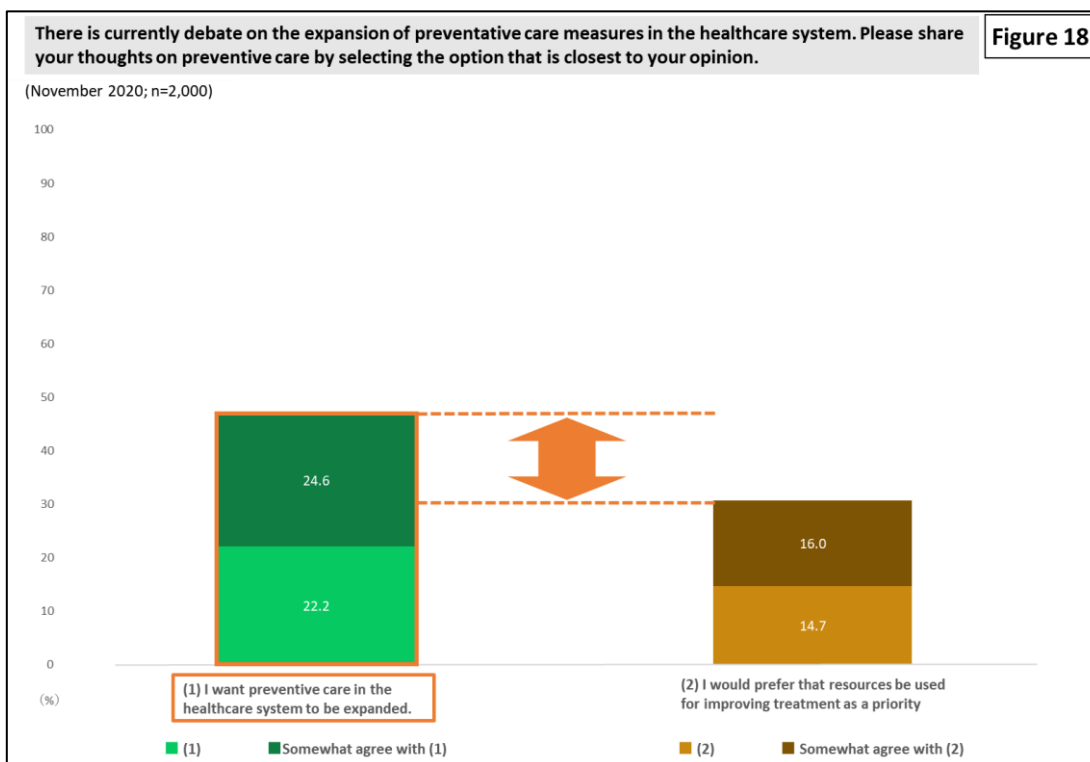
- The majority of respondents supported the greater use of healthcare data, with 37.8% supporting its use for healthcare in general, while another 37.8% said that they would agree to its use for their own benefit.

**Related comments from patient advocate and focus group interviews:**

The public likely supports the use of health data. However, some respondents expressed concern regarding personal information protection. Others stressed the need for greater efforts to disseminate accurate information regarding personal information protection and the benefits of using health data.

- ✓ “The more entries there are, the more accurate health data will be. That is good. As long as it’s deidentified and privacy can be protected.” (Male, 40s, Kanagawa Prefecture, full-time employee, household income: ¥6-10 MM)
- ✓ “If data is anonymized and steps are taken to protect personal information (I would support it). The more data entries there are, the more efficient the system will be.” (Male, 50s, Kanagawa Prefecture, full-time employee, household income: ¥6-10 MM)
- ✓ “I think people oppose the use of data because they do not see direct benefits from its use. I would like the Government to tell the public why data must be used and explain how personal information will be protected.” (Patient and patient advocate)





- **More respondents (46.8%) supported the expansion of preventive medicine within the healthcare system over efforts that would prioritize improving its ability to treat diseases after they have occurred.**

**Related comments from patient advocate and focus group interviews:**

While many respondents supported the expansion of preventive care to lower healthcare spending and improve QOL, others expressed doubt toward its effectiveness. Patient advocates emphasized the need to establish incentives for promoting preventive care.

- ✓ “I think it is best to prevent health issues. If something can be prevented, that seems like the least expensive solution.” (Female, 50s, Tokyo, part-time employee, household income: ¥10-12 MM)
- ✓ “Incentives promoting prevention should be provided to those who are neither sick nor exactly healthy. For example, healthy people could have access to discounts on examinations, like how car insurance is cheaper for safe drivers. While there’s no avoiding costs once someone has developed a disease, people should be rewarded for healthy habits before reaching that point.” (Patient and patient leader)

## 2. Results related to public participation in the policymaking process

### Key takeaway 5: People do not seem to feel ownership over the system, or that they are a stakeholder in its policies.

Members of the public do not seem to realize that they are stakeholders in healthcare policy, nor do they seem to possess a sense of ownership over it.

#### Findings from focus group interviews

- Not everyone covered by insurance is aware of their role as a stakeholder.
  - ✓ “I wouldn’t say at all that I am an active stakeholder in the healthcare system. I’m only listening to the policies that have already been decided. I’m not expressing my own opinions or desires at all. I really wonder if decisions are balanced. I mean it’s all fine as long as decisions are made such that everyone is paying into the system in a balanced way. I have the feeling that isn’t the case though. I’d like to have a bigger say in healthcare policy.” (Male, 70s, Osaka, unemployed, household income: ¥2-4 MM)
  - ✓ I think that members of the general public should participate in decision-making as a third party. I think that would help to make people’s lives just a bit better. (Male, 60s, Osaka Prefecture, freelance employee, household income: ¥6-8 MM)
- About two-thirds (67%) of focus group respondents stated that they want to participate in healthcare policy debates.

Reasons for wanting to participate:

  - ✓ “While issues in healthcare policy do not directly affect me at the moment, and I do not necessarily want to be a proactive participant, diseases can affect anyone at any time, so the topic is not completely unrelated to my life I think.” (Female, 30s, Tokyo, full-time employee, household income: ¥4-6 MM)
  - ✓ “As someone currently receiving long-term care, it directly concerns me. I’m interested in healthcare policy.” (Female, 40s, Nagasaki Prefecture, full-time employee, household income: ¥8-10 MM)
  - ✓ “I don’t know how to participate. If I can, I want to.” (Male, 40s, Tokyo, full-time employee, household income: ¥8-10 MM)
- To foster interest in healthcare policy among the uninterested people, focus groups stated that that more easy-to-understand information and education on healthcare and social systems needs to be provided. Many younger respondents wanted that information provided over social networks or through the medium of comics.
  - ✓ “I once heard that “People need 20 million yen for retirement.” If specific numbers like that were presented on TV about health system finances, I think more people would start to think about the topic.” (Male, 30s, Fukuoka Prefecture, full-time employee, household income: ¥4-6 MM)
  - ✓ “It is hard to say anything because there is no information available concerning how much it currently costs for what level of insurance. If someone were to present accurate information on that, I think people would understand.” (Male, 70s, Osaka, unemployed, household income: ¥2-4 MM)
  - ✓ “I think that working people will be interested in the topic in some form. I think if it is portrayed in a comic or TV drama, then children will also become interested in it.” (Female, 40s, Nagasaki Prefecture, full-time employee, household income: ¥8-10 MM)
  - ✓ “Education on the healthcare system should be provided in extracurricular classes at school.” (Female, 50s, Tokyo, business owner, household income: ¥10-12 MM)
- Respondents were asked to rate how much concerns about the healthcare system factored into their voting selections during national elections on a scale of zero to 100. At maximum, younger people in their 10s and 30s rated healthcare policy at 10 in terms of importance, while those in their 40s and 50s said 30, and those in their 60s and 70s at maximum said that healthcare policy was a 70 in terms of importance for them.
  - ✓ “It’s about 3% to 5%, because I am not currently undergoing treatment.” (Female, 10s, Tokyo, university student, household income: ¥14-16 MM)
  - ✓ “About 5%. There are many other issues that I tend to think about instead, like the economy, child-rearing, or education policy.” (Female, 30s, Saitama Prefecture, full-time employee, household income: ¥8-10 MM)
  - ✓ “30%. I probably didn’t think about it when I was younger, but given my age and the fact my parents are elderly, healthcare is now a major concern for me.” (Female, 50s, Tokyo, business owner, household income: ¥10-12 MM)

#### Findings on efforts to involve the public in policy discussions based on interviews with patient advocates

Mainly, patient advocates raised issues around opportunities for patients and members of civil society groups to participate in decision-making meetings, and issues related to public awareness about the healthcare system.

1. On participation in decision-making by members of patient and civil society groups
  - There is a lack of diversity among members of decision-making bodies at the Government level.

- ✓ “Most policy meetings are held with high-level people from academic societies, famous doctors, heads of hospitals, and then people like me. Most meetings are between people who are all in their 60s and 70s, with extremely few women. I wish there was a way to get more diverse opinions at these meetings from the younger generation and women in particular.” (patient advocate)
  - ✓ “There are far, far more service providers at policy meetings than users. There are proportionally very few patients, and very few patient family members. Among patients and their family members there is a diversity of thought. We should have policy meetings that include as many patients and family members as other groups, or at least have multiple seats for such people.” (patient advocate)
  - There are few opportunities for the public and members of the Government to communicate as equals, and few initiatives designed to gather public opinion. This differs depending on the disease area.
    - “I hope we can build mutual understanding through online townhalls and other opportunities for the Government to reach out to the public and gather opinions. That includes Twitter and other social networking services.” (patient advocate)
    - “Depending on the disease area and region, there are cases where patient opinions are better reflected in policy, such as with cancer. I think we should codify patient participation in policymaking in law.” (patient advocate)
  - There are few patient leaders with a broad-based view of public health that express opinions based on evidence.
    - “Many patient advocates are speaking in policy meetings emotionally, based on their own experiences.” (patient advocate)
    - “Only people who are comfortable financially are able to become patient advocates. A lot of learning and experience is needed about each disease area in order to become an advocate. Most people lose income when they get sick, and they have to pay medical fees. Most people don’t have the financial freedom to become advocates. We need a system that can support and foster patient advocates.” (patient advocate)
2. On public awareness of the healthcare system
- Healthcare is not a matter of concern for many members of the public
    - “Opinions about healthcare and the healthcare system are heavily influenced by individual experiences. Most people aren’t interested in healthcare or the healthcare system if they aren’t sick.” (patient advocate)
    - “Many people are passive in their approach to healthcare, and leave everything up to doctors when they get sick. I think we need to expand the amount that we teach in the education system about the social security system, the healthcare system, and how to manage your own healthcare. I think it’s important that we increase the amount that people care about the system” (patient advocate)
    - “In addition to education, I think that we need to consider behavioral science. How can we create incentives that make people understand that they are stakeholders in the system?” (patient advocate)

## IV. Conclusion

In spite of the fact that the healthcare system is financed by the public through national bonds and taxes, insurance premiums, and out-of-pocket payments, the results of this research suggested that the public does not feel a sense of ownership over decisions made on the distribution of the financial resources that they provide. The results also suggested a low awareness around topics such as how much citizens are paying for the healthcare system and what benefits they enjoy in exchange, which is knowledge needed to develop a sense of ownership over the healthcare system.

Healthcare system financing is a significant issue for Japan, and without serious efforts for reform, it will continue to be so in the future. Over the coming years, Japan will be asked to consider what kind of healthcare system it can create to best serve a population which is undergoing demographic and epidemiologic changes. This will also occur over a time span that is likely to see new health threats from global warming, and the emergence of new diseases and pandemics. Efforts to build the kind of healthcare system that can best respond to those challenges must be implemented and a willingness to pay for that system must be fostered among the public.

Our research started with an examination of healthcare policy, but the results suggest that even beyond healthcare, we may be seeing the emergence of governance issues in Japan's national policy in general. We live in a world where it is easier than ever for the Government to communicate with the public, and for the public to express its desires and see those desires reflected in policy. As society changes alongside the development of new technologies, it is likely that the Government will need to pay greater consideration to effectively engaging in new methods of communication and decision-making.

We hope that this research report and our continued work can help all stakeholders to come to common ground and understanding of the issues facing Japan's healthcare system and drive discussions on improving its sustainability. We will continue to use our platform to facilitate such understanding, and to develop fresh solutions to the new challenges that are approaching the healthcare system.



## V. Acknowledgements

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