

Increasing Public Participation for Better Healthcare System Reform

Policy Recommendations for those that do and do not go to the hospital, and everyone who supports the delivery of safe medical care

Health and Global Policy Institute Rebalancing Innovation and Sustainability Project

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Background

The social security system is foundational to society’s ability to provide the public with stable, secure lives and opportunities to seek happiness. Within that system, the healthcare system in particular plays a central role as social infrastructure that provides ready and affordable access to the highest standards of medical care in the world to all residents of Japan, including members of vulnerable social groups. However, the development of the healthcare system is premised on the assumption of continuous economic growth and expansion, and this premise is likely false. The working-age population, which funds the healthcare system, is shrinking due to accelerating population aging and a declining birthrate. Furthermore, as society ages and the working-age population continues to shrink, it is expected that the cost of healthcare will continue to grow. These changes in society threaten the sustainability of the healthcare system.

The Coronavirus Disease 2019 (COVID-19) pandemic has made various issues related to the healthcare system clear to the public. These include issues related to the fragility of Japan’s society and economy, the limits of healthcare financing, regional disparities in the provision of healthcare, and the disparate provision of services at each healthcare institution. The pandemic has driven society to reexamine its values and its structure, as well as the lifestyles and working styles enjoyed by the public. This presents an opportunity to once again reexamine Japan’s healthcare system and work to ensure that realize that the issues of the system affect every member of society.

To that end, from November to December 2020, the Health and Global Policy Institute (HGPI) conducted a public opinion survey and series of focus groups and interviews to gauge public opinion about health system policy (with results published in a separate research report, “Healthcare System Reform and the Value of Healthcare: Public

¹ Health and Global Policy Institute, “Healthcare System Reform and the Value of Healthcare Public Opinion Research on the Views of Citizens and Patients” May 2021

Opinion Research on the Views of Citizens and Patients”). The key takeaways from that research included points such as, “The public does not necessarily feel the need to increase healthcare system financing,” “The public does not necessarily feel the need to increase healthcare system financing,” and “People do not seem to feel ownership over the system, or that they are a stakeholder in its policies.”¹ The results suggest a need to do more to foster a sense of ownership over the healthcare system among the public in order to achieve the reforms that are needed to truly ensure system sustainability. The recommendations that follow suggest how various sectors in society can contribute to effort to foster a sense ownership among the public and thereby improve the healthcare system policymaking process.

In order to achieve a truly strong and sustainable healthcare system it is important that there be widespread participation in and understanding of healthcare policy discussions. The time has come for a national conversation on the healthcare system based on the realization that it is something that impacts everyone’s life. The public should begin to think about and discuss what aspects of the healthcare system it wants to fund, and whether it would be willing to give up healthcare access or innovation to reduce payments.

These policy recommendations are aimed at developing a discourse on healthcare policy for those who regularly visit healthcare institutions, those who do not, and everyone who is directly or indirectly involved in the provision of safe medical care. The recommendations ask all members of society to consider what kind of healthcare system they want to have ten to twenty years from now.

Discussions on the reform of Japan's healthcare system have been advancing at the Government level through the National Council on Social Security Reform, which operates according to the Social Security Reform Program Act of 2013. That Council outlined measures to strengthen social support for the working-age population in its *Guidelines for Reforming Social Security for All Generations* published in December 2020. The proposals in those guidelines would have some impact on curbing healthcare costs, but further policies are needed. Those reforms must be undertaken while listening closely to the voices of the public. In HGPI's *2019 Survey on Healthcare in Japan*, 79.6% of respondents stated that they wanted their opinions reflected in the healthcare policy formulation process while 66.3% of respondents expressed dissatisfaction toward the degree to which public opinion is reflected in that process. Furthermore, the 2020 Public Opinion Research, suggested that some in the public feel there are few opportunities to express one's opinion about healthcare policy and that the public is going along with what has already been decided about healthcare policy without having the opportunity to express opinions on the design of policies. It is hard to say that the public feels that decisions in healthcare policy are being made with their consent.

One way that the public can participate in the policymaking process is through voting. In the past, there was a time in Japan in which each party fielded three to five candidates for elections. This created competition within each party. Candidates were incentivized to listened to voters’ opinions and worked to win public understanding for their own ideas and policies, helping to ensure that the voices of the people were reflected in policy through the election process. However, since the introduction of the single-seat constituency system, which was created to bolster the

¹ Health and Global Policy Institute, “Healthcare System Reform and the Value of Healthcare Public Opinion Research on the Views of Citizens and Patients” May 2021

ability of the party in power and the upper echelons of political parties in general to enact policies, the choices presented to the public have narrowed. Of course, there are processes for formulating individual policies between elections, but the influence of some organizations that used to consolidate public opinion have declined, weakening the influence of the public on policymaking. Furthermore, the development of social networking services (SNS) and similar technologies in recent years have helped to increase the visibility of individual citizens' opinions about specific policies. There have even been cases in Japan in which policies have been decided in reaction to the opinions of individuals without input from other relevant organizations and parties. Due to these reasons and other issues, it is thought that there are currently no effective methods or opportunities for the public to participate in discussions on healthcare system reform.

It is crucial that society work to eliminate the hurdles that prevent public participation in policy discussions and build a healthcare system that is acceptable to the people of today and the people of tomorrow. To that end, we propose the following three recommendations: (1) increase opportunities to communicate with the public about the current circumstances facing Japan's healthcare system in a clear, straightforward manner; (2) listen to the public; and (3) hold transparent policy discussions and make decisions in view of the public.

Recommendations

Recommendation 1: Increase opportunities to communicate with the public about the current circumstances facing Japan's healthcare system in a clear, straightforward manner.

Current situation and issues:

Population aging, a declining birthrate, and a shrinking working-age population severely threaten the sustainability of the healthcare system. Funding problems may make it difficult to provide everyone with the healthcare they need, when they need it, in the future. Currently, the main funding sources for the healthcare system are public spending, social insurance premiums, and out-of-pocket payments from users at healthcare institutions. **Payments from the current working population do not fully cover the costs of healthcare. There are financial shortfalls which are being covered by national bonds. In other words, the costs of healthcare are being shifted onto members the future generations who do not yet have a say in healthcare system decision making** (In FY2021, social security expenditures totaled 35.8 trillion-yen, tax revenue was 57.4 trillion yen, and outstanding long-term national debt was 1,019 trillion yen (180% of GDP¹)). Views on the healthcare system are shaped by a person's health status, age, occupation, income, household conditions, living environment, and other factors. Opinions on who should bear the cost burden for healthcare vary accordingly. In addition, healthcare is a very specialized field. Not every user of the healthcare system definitely understands what the current issues are related to healthcare system inefficiencies, or issues related to the structure of the system. All of this can make it difficult to hold public discussions on healthcare policy.

It is thought that, partly for these reasons, public opinion research undertaken by HGPI in 2020 suggested that the public does not feel that information about the facts of the healthcare system (healthcare demand, information on

¹ https://www.mof.go.jp/budget/budger_workflow/budget/fy2021/seifuan2021/04.pdf

¹ Health and Global Policy Institute, "Healthcare System Reform and the Value of Healthcare Public Opinion Research on the Views of Citizens and Patients" May 2021

the provision of healthcare, healthcare financing, and so on) is reaching them. Possibly as a result of that, many responded that they did not feel there is a need to increase payments in order to maintain or improve the system in the future. Furthermore, research also suggested that people do not feel they are receiving adequate value for money related to the amounts they are paying for healthcare.

Over the past six decades, the Japanese public has enjoyed Universal Health Coverage (UHC), which has allowed every member of society to receive appropriate and affordable healthcare. The healthcare system has succeeded for so long that it may now be difficult for members of the public to understand the real merits of the system. Furthermore, a hesitancy to have public discussions about taxes and other financial issues has made it difficult to discuss reforms that could improve healthcare efficiency or adjust payments and costs to ensure the future sustainability of the healthcare system.

Proposed Solution:

All parties involved in healthcare policy, including politicians, Government institutions, academia, the media, healthcare providers, and insurers, should continuously communicate, in a clear and simple manner, information regarding topics like the current structure of the Japanese healthcare system, the difficulty of sustaining it, and policies for solving issues related to financing. This could help more people obtain the fundamental knowledge and understanding needed to participate in public discussions and decision-making.

Specific actions for each stakeholder:

Politicians, the Government ministries and agencies, academia (including pharmacoeconomics specialists, healthcare policy specialists, and so on), the media, healthcare providers (healthcare industry organizations), and insurers should all:

- Work to build a foundation for healthy public discussion on ways to evenly distributing costs associated with establishing a sustainable healthcare system, including restricted access or higher payments, by thoroughly and clearly communicating information related to the following topics to the public:
 - ✧ The current situation facing Japan’s healthcare system, including its strengths and areas where improvement is needed.
 - ✧ The fact that the healthcare system is important to the public’s lives and should be protected.
 - ✧ The situation surrounding shortages of the financial resources required to support the healthcare system.
 - ✧ The fact that continued reform efforts to further optimize the healthcare system will be necessary.
 - ✧ What will happen in the future if the current situation is not handled.
- Engage in educational and awareness-building efforts and promote the implementation of compulsory educational for all generations on the social security system to supplement currently inadequate educational initiatives on this topic.
- ✓ Academics should:
 - Improve public understanding using methods such as those described below to expand the range of policy

¹ Health and Global Policy Institute, “Healthcare System Reform and the Value of Healthcare Public Opinion Research on the Views of Citizens and Patients” May 2021

options being debated and facilitate effective communication among all stakeholders including the public, politicians, and Government organizations:

- ✧ Proactively propose policy options that would be difficult for politicians or Government organizations to present.
 - ✧ Provide data on the validity, feasibility, etc. of policy proposals before and after elections and discussions in the Diet.
 - ✧ Analyze and share data on the balance between healthcare supply and demand for each region. (Specifically, deliver data that can form the basis for building an efficient healthcare provision system in each region. To do so, academics should work to generate estimates of healthcare demand in each region using the National Database of Health Insurance Claims and Specific Health Checkups of Japan (NDB). Following that, it will be important to identify current and future supply and demand gaps in regional healthcare provision systems using those estimates.)
 - ✧ Present data on the impact that shifting to over-the-counter versions of specific pharmaceuticals will have on individuals' healthcare payments, healthcare-seeking behaviors, and so on.
- ✓ The media should:
- Build an environment in which it is difficult for fake news and conspiracies to spread by promoting coolheaded, logical, and scientific discussions among members of the public using the following methods:
 - ✧ Avoid presenting information that triggers feelings of condemnation, criticism, fear, etc. and incite an emotional response from society with the aim of increasing viewership.
 - ✧ Consider the following topics with academics and Government organizations:
 - How to conduct fact-checking
 - How fact-checking should be incentivized (Indicators to evaluate media performance other than viewership ratings, etc.)
- ✓ Healthcare providers (and healthcare industry organizations) should:
- Strive to disseminate clear, straightforward information based on professional knowledge, clinical perspectives, and connections with members of the community to promote constructive discussions that are based on feasible ideas.
- ✓ Insurers should:
- Take the following actions to drive proactive public involvement in discussions on healthcare policy reform:
 - ✧ Utilize professional knowledge and direct access to insurance enrollees to develop and provide easy-to-understand information to the public.
 - ✧ Take advantage of being in the position of one of the few parties that can set insurance premiums by actively participating in discussions on medical service fees and working to coordinate opinions among the public, healthcare providers, and other stakeholders.
 - Proactively communicate with the public about effective healthcare resource utilization, how to make choices about treatment plans, and other matters.
- ✓ In addition to the above, academics, the media, healthcare providers (and healthcare industry organizations),

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and insurers should:

- Work together to utilize social networks or other new communication tools to create a new verification and evaluation system for information presented by the media.

✓ The public should:

- Work to understand the current Japanese medical system (pros/cons)
- Engage in practices that can help reduce healthcare costs, including finding a family doctor, or using telemedicine services. (Examples of these consultation services include hotlines like the pediatric emergency care hotline at #8000, which provides after-hours consultations for sick children, or the Emergency Relief Center at #7199, which provides after-hours consultations on sudden illnesses.)
- Help healthcare reform discussions to advance in a constructive manner by:
 - ✧ Understanding and accepting that certain aspects of the current healthcare system will grow more inconvenient and that we might all be required to share in that inconvenience for the system to continue to be maintained.
 - ✧ Understand that major policy reforms require continuous debate, that policy reforms can cause problems for certain groups in society, and which groups those are.

Recommendation 2: Listen to the public.

Current situation and issues:

The various existing channels and platforms for gathering the opinions of the public are not operating effectively.

In particular, Japan is seeing a weakening in the capacity of intermediate organizations (industry organizations, patient advocate organizations, etc.), which used to play central roles in delivering the voices of the public to the Government by gathering and disseminating opinions, to operate like they used to. Furthermore, there are few cases of the methods used by the Government to gather opinions, such as public comment initiatives or public opinion exchanges, actually leading to significant policy changes. There are also issues with the way that public opinions are gathered. For example, it can be hard for people to know where to make submissions, and the process of submitting comments can be difficult. Even when opinions are submitted, policy does not usually change as a result. In such cases, it is hard to see the value of expressing an opinion.

In principle, the public also has the opportunity to express opinions about policy through various Government committees, but it is often the case that participation in these meetings is limited to those who have personal connections to Government officials. It cannot be said that such participants represent the complete opinions of the public.

These reasons and other issues are thought to be behind results from 2020 HGPI public opinion research showing that many members of the public feel that they have never been asked about their opinion, despite wanting to participate in policy discussions if possible. Another comment often heard from focus group participants in this research was the statement that some felt they only realized they actually had an opinion about health policy once they were given the opportunity to express their opinion. This result suggests that just increasing the opportunities

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the public has to impact policy could itself help to foster ownership over the healthcare system.

With growth in the popularity of social networks in recent years, there have been cases in which sudden policy changes have been made in response to debate on SNS that was subsequently covered widely in the traditional press. Social networks provide an opportunity for public policy debate, but they can also be a breeding ground for populist ideas in particular. It is important to carefully consider policy debates on social networks with that in mind.

Proposed Solution:

Create further platforms and opportunities for the public and policymakers to communicate. These platforms should give the public and opportunity to submit opinions on policy and foster the sense that the views of the public are actually reaching decisionmakers.

Specific actions for each stakeholder to take

- ✓ Politicians should:
 - Work to represent the voices of the people by listening to the public using new and various methods of communication such as SNS sites to ensure that policies will gain public support. Use new platforms that allow businesses, policy makers, and lawmakers to discuss rules for the coming era or that allow for the voices of the public to be gathered while engaging in bilateral communication with politicians.
- ✓ Government ministries and agencies should:
 - Listen to the public using SNS sites and other tools so that policy discussions can be held that are convincing to the public and that take the needs of the public into account alongside expert perspectives and long-term outlooks.
 - Increase feelings of significance and participation when the public expresses opinions on policy proposals or participates in policy discussions by actively publicizing good examples of when voices from the public have been reflected in policymaking.
 - Share best practices among Government agencies and build a system to continuously identify best practices to increase the number of cases in which public opinion is reflected in policy.
 - Referring to examples from overseas, invest financial and human resources, knowledge, and other resources into the creation of a framework for reflecting patient voices in policy that is tailor-made for Japan. For instance:
 - ✧ In the United States, there are frameworks like the FDA Patient Representative Program for reflecting the voices of patients in decision-making during the inspection process for pharmaceuticals and other health technology.
 - ✧ In the United Kingdom, there are frameworks like the Patient and Public Involvement Programme for reflecting the voices of patients and the public during decision-making in medical research, clinical trials, and health policy.
 - ✧ In Thailand, opportunities for opinion exchanges involving patient organizations and health ministry representatives are provided several times every year.

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- ✓ Academics should:
 - Train health economic and health policy specialists while cooperating with other stakeholders on the creation of a framework for reflecting patient voices in policy that is tailor-made for Japan.
 - Use big data to gather information representing the opinions of the public to analyze public attitudes and behavior toward healthcare system use.
- ✓ The media, healthcare providers (and healthcare industry organizations), and insurers should:
 - Use new communication methods like social networking as one means to understand and analyze public opinion. Additionally, insurers should proactively engage in bilateral communication with the insured (in other words, the public).
- ✓ Patient organizations should:
 - Refer to efforts from abroad to develop multi-partnerships that allow for opinions and statements that cut across disease fields to be shared and discussions from the perspective of public health to be held. The goal of doing so is to establish grassroots advocacy for reflecting perspectives gathered from the voices of patients and from the individual, firsthand experiences of Storytellers in Japan's healthcare system, which is used by everyone.

Recommendation 3: Hold transparent policy discussions and make decisions in view of the public.

Current situation and issues:

Insufficient and unclear communication to the public about topics like the social security and healthcare systems can make it difficult for the public to make informed decisions about these topics and erode the effectiveness of the democratic decision-making process. For example, insufficient communication to the public about the relative merits of raising taxes or increasing insurance payments has likely impacted the decisions made about how to finance the healthcare system up to this point. As a result of that insufficient communication, it is felt that the public now has less understanding and interest in matters related to health insurance payments in comparison to taxes, which is a topic of concern for many members of the public. **As a result, it has thus far been easier to increase insurance premiums as opposed to increasing taxes in order to pay for the system. This issue is fundamentally a problem of communication and the transparency of the policymaking process.**

HGPI's 2020 public opinion research suggested that the public is interested in the implementation of more progressive funding schemes for the healthcare system designed through a process of public discourse and decision-making. However, there currently exists fundamental issues that are preventing that kind of decision-making. For instance, although the COVID-19 decision-making process may have been exceptional in this regard, there were cases in which policy decisions were made solely behind closed doors, with not even meeting minutes made available to the public.

If improvements are not made to the transparency of the policymaking, it will be impossible to foster public understanding about health system sustainability and financing issues.

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Proposed Solution:

Which policy debates and decisions are acceptable to the public is determined by what options are presented to the public. In order to realize policy decisions that work to balance healthcare payments and benefits in such a way that is manageable for the current working population and put a stop to the trend of passing costs to future generations, it is important to increase the transparency of policymaking and help the public develop a sense of the risks and benefits of various policy options at both a micro and macro level.

Specific actions for each stakeholder to take

- ✓ Politicians should:
 - Demonstrate the decision-making process to the public by setting aside time for substantive policy discussions to advance policies that have public support.
 - Engage in comprehensive policy discussions and decision-making on healthcare and health insurance policy after clearly identifying the issues of each region based on data. This will enable the advancement of policies that are acceptable to the public and in-line with local conditions, including the balance between healthcare demand and supply in each region.
 - Revise related laws and regulations to create an environment in which local government officials, insurers, and other parties close to the public can participate in the policy decision-making process to shorten the gap between the public and policy decision-making and discussion processes.
- ✓ Government ministries and agencies should:
 - Promote efficient and open discussions on policies that are supported by the public through the following actions:
 - ✧ Utilize opportunities for cross-departmental or cross-ministerial discussions to consider comprehensive policies that span multiple jurisdictions (including areas like healthcare policy, health insurance policy, and prevention and treatment).
 - ✧ Distribute all council meetings and review meetings online via outlets like YouTube. Measures needed for effective online distribution should be taken in advance. These include ensuring audio or video is of sufficient quality or publishing or uploading related materials ahead of time.
 - Conduct a thorough analysis to identify issues that impede access to the NDB and other data held by the Government, make data more accessible to academia and the private sector, and encourage detailed private-sector discussions (for example, in various regions, fields, or healthcare institutions) on the gap between healthcare supply and demand.
 - Hold the following discussions in view of the public in order to build understanding toward the importance of maintaining good health:
 - ✧ Discussions on disseminating and reinforcing current mechanisms for incentivizing prevention (such as the Insurer Effort Support System).
 - ✧ Discussions on issues caused by the divide between prevention policy (which targets insurers) and treatment policy (which targets healthcare providers), and how to resolve those issues.
- ✓ Academics should:

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- Conduct comprehensive, cross-disciplinary examinations of the healthcare system by setting up opportunities for discussions across research fields (for example, on healthcare policy and health insurance policy) to promote transparent and efficient discussions on policies that have public support.
- ✓ The public should:
 - In order to ensure that discussions be held and decisions made on policies that have public support, demand the creation of an environment in which policy discussions and decisions are transparent through elections and the use of new communications tools.

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