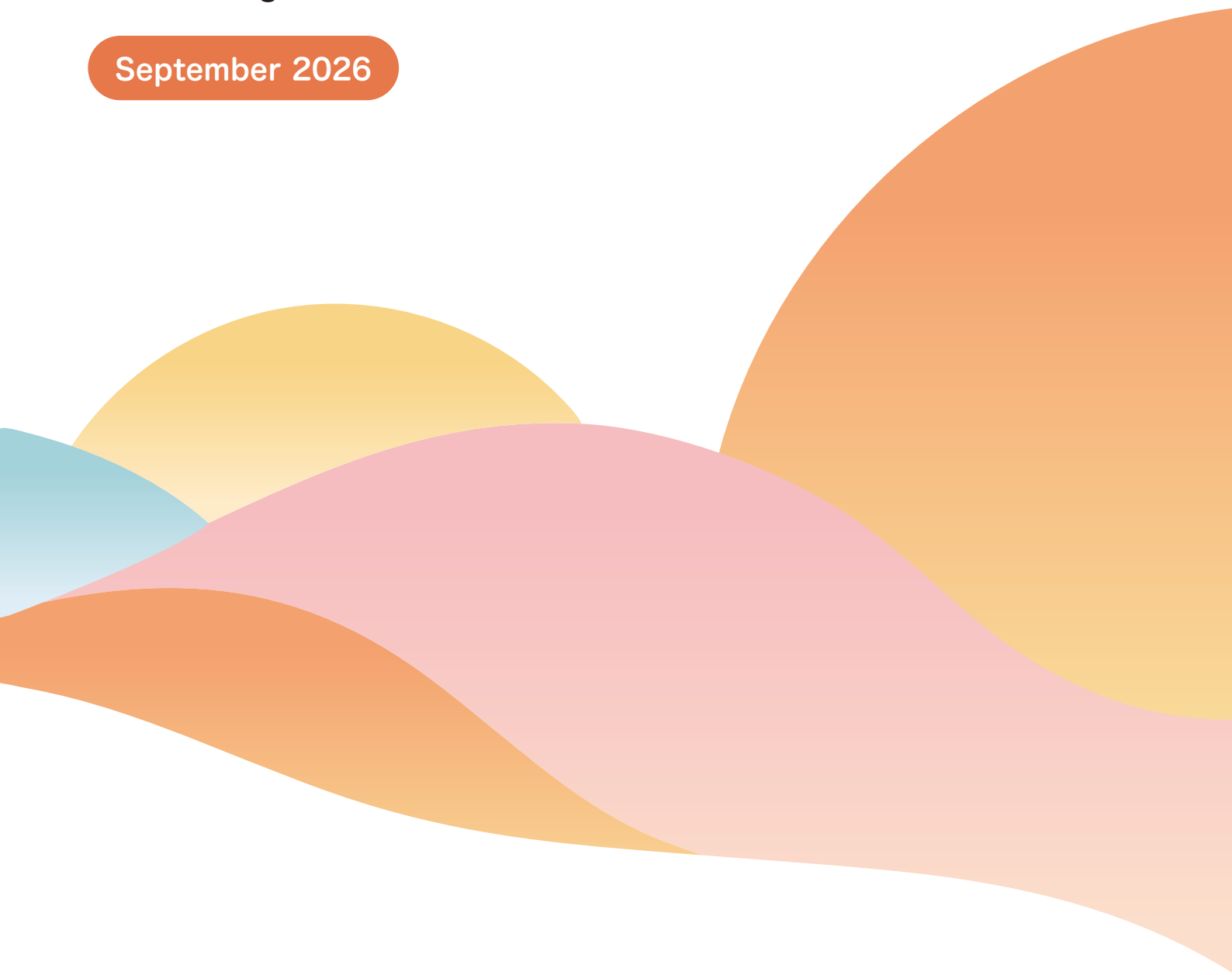


Health and Global Policy Institute (HGPI) Intractable & Rare Diseases Project
Policy Recommendations

Driving Progress in Intractable and Rare Disease Policy Through Patient and Public Voices:

Towards Redesigning Healthcare Delivery Systems
Across Diagnosis

September 2026



Introduction

Intractable and rare diseases are a particularly important area among health policy issues. For many of these conditions, underlying mechanisms of onset have yet to be elucidated, and definitive treatments have yet to be established. Furthermore, many intractable diseases require prolonged medical interventions, placing substantial physical and psychological burdens on patients. As of April 2025, the Government of Japan recognizes 348 conditions as “designated intractable diseases,”¹⁾ which impact an estimated minimum of 1.1 million people.²⁾ Since the presentation of the “Outline of Intractable Disease Measures” in 1972, Japan has advanced its measures for intractable and rare diseases by promoting R&D, developing healthcare systems, and providing patient support (primarily through healthcare subsidies). Later, the Act on Medical Care for Patients with Intractable Diseases was enacted in 2014, setting a direction for efforts to drive progress in healthcare and enhance the social environment.

Despite these advances, people living with intractable and rare diseases face many lingering challenges on the path to receiving a diagnosis and appropriate medical care. For example, because many intractable and rare diseases share early symptoms with other conditions, such as fatigue, they are often mistaken for common illnesses or mental health issues. Other challenges shared by patients and other people living with intractable and rare diseases include not knowing which department to visit for treatment or feeling that their symptoms were misunderstood, even after an examination.

Domestic measures for intractable and rare diseases aim to “Secure a system that allows for accurate diagnosis as early as possible while securing opportunities for people to receive appropriate treatment after diagnosis at accessible healthcare facilities.” In addition, in May 2025, the World Health Organization (WHO) adopted its first-ever resolution on these conditions, titled “Rare diseases: a global health priority for equity and inclusion.” It describes global priority actions that include strengthening health systems (particularly in primary healthcare), leveraging digital technologies, and promoting the involvement of patients and other affected parties. However, the characteristics of this field make it difficult to completely eliminate the uneven distribution of medical resources or expertise. Even if the number of medical facilities and specialists were increased across Japan, mounting an adequate response for every disease would remain a challenge. While keeping such structural limitations in mind, we must build a health system that ensures all patients and others living with an intractable or rare disease can receive the care they need.

The Health and Global Policy Institute (HGPI) Intractable & Rare Diseases Project was established to increase societal interest in intractable and rare diseases and to drive progress through more effective and organic measures in this area, and we have outlined the policy direction society should pursue for these conditions over the medium to long term. With this objective in mind, along with a bird’s-eye view of the health system and domestic policy trends, these recommendations further refine our focus on the healthcare system for intractable and rare diseases. Through desk research, individual interviews with related parties, and discussions among experts from industry, government, academia, and civil society, we have worked to grasp the current state of the healthcare delivery system for intractable and rare diseases from the perspectives of patients, affected parties, and citizens and set a direction for necessary measures to ensure that patients and other affected parties can continue receiving healthcare with peace of mind.

1) Ministry of Health, Labour and Welfare (MHLW). Designated Intractable Diseases. Retrieved August 3, 2026, from <https://www.mhlw.go.jp/stf/seisakunitsuite/bunya/0000084783.html>.

2) FY2024 Public Health Administration Report. Number of Certified Recipients of Specific Medical Expenses (Designated Intractable Diseases) by Age Group and Target Disease.

Chapter 1

The Voices of Patients and Other People Living with Intractable and Rare Diseases

We held individual interviews with patients and other people living with intractable and rare diseases to grasp the current state of healthcare delivery for these conditions, then compiled their comments. Through our interviews, it became clear that patients, family members, and caregivers encounter various challenges at each stage from the time they notice physical or mental symptoms, to when they visit clinics or specialized medical facilities, to when they can receive ongoing healthcare in the community. Working independently, we then divided the journey experienced by patients and other affected parties into phases and arranged their statements accordingly.

Phase
1

From first noticing discomfort to undergoing an examination at a clinic

Phase
2

From undergoing an initial examination at a clinic to arriving at a specialized medical facility

Phase
3

From undergoing an examination at a specialized medical facility to finding a primary care physician

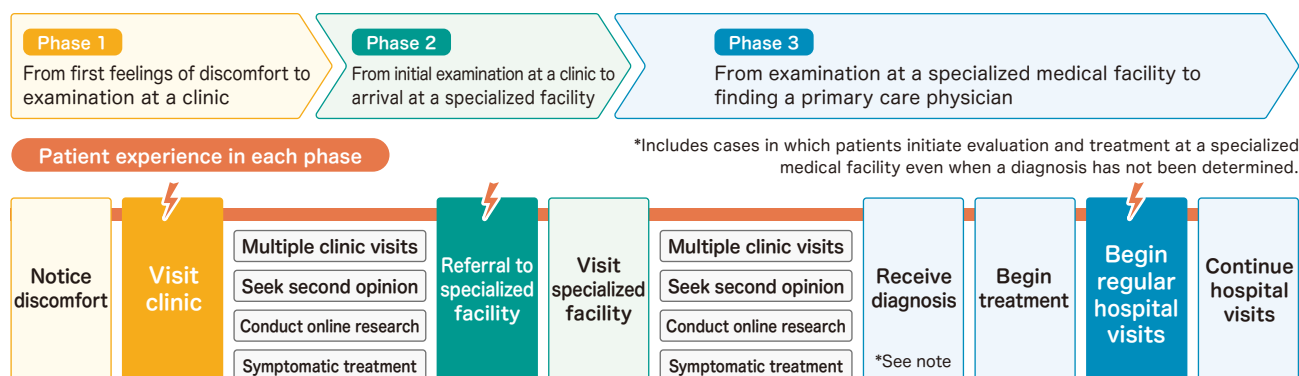


Fig. 1: The journey for patients and other people living with intractable and rare diseases

The objective of these interviews was to examine the healthcare delivery system from the perspectives of patients and other affected parties. Another key issue for these parties is the period between an examination at a specialized medical facility and finding a primary care physician, which occurs between Phases 2 and 3. However, there are major roles for physicians, healthcare institutions, the private sector, and research institutions to play in ensuring that diagnoses provided at specialized medical facilities are rapid and accurate, as well as in advancing diagnostic technology. Many patients and other affected parties are also currently going without clear diagnoses. Given these circumstances, these recommendations focus on the healthcare delivery system regardless of diagnostic status, and were not compiled with the assumption that patients and other affected parties have received a definitive diagnosis. While the development and performance evaluation of diagnostic technology generally fall outside the scope of this document, access to diagnostic support and healthcare system implementation is included. Experts in this area are already advancing discussions on these topics, and we look forward to future developments.



From first noticing discomfort to undergoing an examination at a clinic

Overview

Participants shared experiences in which they noticed physical or mental discomfort and, due to the difficulty of deciding which clinic or department to visit on their own, ended up selecting a healthcare facility based on proximity. While many intractable and rare diseases have symptoms that impact the entire body, patients and other affected parties tend to choose an internist or department of internal medicine for the initial visit. These visits sometimes conclude with further monitoring for low-grade fever or other general symptoms. Some participants noted that even when information on specialized medical facilities is available online, it is only accessible to people who can look it up themselves. They expressed a desire for this information to also be conveyed directly by physicians, government public health nurses, and other parties who are certain to come into contact with patients or those close to them.

Voices of Patients and Other People Living with Intractable and Rare Diseases



"I did not know which healthcare facility was right, so I just visited one that was in my neighborhood."



"Even when information on a specialized medical facility is provided online, it is meaningless because that information can only be accessed by people who can look it up. That information must also be delivered to people who know nothing at all. I think that it should be conveyed by people who are certain to come into contact with people with intractable diseases, like physicians or government public health nurses."



"Among intractable diseases, quite a few are systemic diseases, but people tend to opt for general internal medicine for their initial visit. For example, when experiencing a kidney problem, not many people would immediately visit a nephrologist or urologist. So, they receive a comprehensive checkup and are guided to a specialized department, where they might be given a diagnosis. If asked if local internists are providing proper diagnoses, I must admit I think that is not the case. Since many patients present with low-grade fevers, the doctor says it is a common cold, and most examinations end with them telling the patient to wait and see how they progress. I agree that it is difficult for people to know which local healthcare facility they should visit."

Phase 2

From undergoing an initial examination at a clinic to arriving at a specialized medical facility

Overview

Participants spoke about experiences in which they were told “We do not know how to treat that here” after an examination at a clinic due to the limited number of specialists, or in which they did not receive explanations about which services were offered by a medical facility to which they were referred. There are also times when patients must undergo examinations at multiple medical facilities and have the same tests taken multiple times when the cause of their symptoms is unclear. Some interview participants expressed a desire for greater data-sharing among healthcare institutions. On the other hand, the time to reach a diagnosis has shortened in recent years due to factors like diseases becoming more well-known among physicians. In addition to training more medical specialists, participants also highlighted the need to facilitate patient access to specialized medical facilities, including through online medical consultations. Finally, while some respondents did not know where to go to receive support from Intractable Disease Medical Coordinators or what kinds of support they provide, others spoke about experiences in which coordinators helped to connect them with specialized medical facilities.

Voices of Patients and Other People Living with Intractable and Rare Diseases



“Very few physicians specialize in intractable and rare diseases, so there were times when I was told ‘We do not know how to treat that here’ when I visited a local medical facility.”



“When one visits many different hospitals because their underlying condition is unclear, they sometimes have to undergo the same test multiple times. Hospitals should share test data with each other.”



“When referring patients to specialized medical facilities, I wish primary care physicians would give careful explanations on what those facilities treat so that patients could understand the reasons for their referral.”



“I do not know how to get in touch with an Intractable Disease Medical Coordinator or where to find them. I have heard of them, but I do not know what they can do for me, so I have not considered going to see one.”



“Although the population of Japan is shrinking and there are fewer hospitals and healthcare professionals, I think advances in technology will create more opportunities to diagnose intractable and rare diseases. Training medical specialists takes many years, so instead of training specialists, I think it might be better to focus on improving access to specialists.”



“I feel like the time to reach a diagnosis has shortened significantly in recent years. In the past, it was not uncommon for people to wait a decade for a diagnosis, but recently, many people receive a diagnosis in the same year that symptoms emerge. I think this is due to knowledge regarding intractable and rare diseases becoming more widespread among physicians, and because the number of therapeutics has increased.”



“Patients do not all live in urban centers, nor do they all have immediate access to a specialist, so I think we need a system that allows patients across the country to consult specialists through online consultations.”



“It is especially easy to get lost when trying to find the right hospital for intractable neurological diseases. When there is an Intractable Disease Medical Coordinator available, there are times when they can give guidance on which hospital is best to visit.”

From undergoing an examination at a specialized medical facility to finding a primary care physician

Overview

One person was told the name of the condition they had been diagnosed with, but not that it was an intractable disease, and that they only found out by looking it up on their own. Others spoke about feelings of intense anxiety over the lack of a clear future outlook due to lack of access to information regarding disease details, necessary treatment, or how the disease might progress with continued treatment. We also heard about the reassurance that comes from having someone close to confide in, or who can act as an intermediary for issues that are difficult to convey directly to a doctor. In addition, patients and other affected parties are sometimes recommended to transition to care at a local medical facility after their conditions stabilize, but they cannot see the degree to which information on their condition is shared between their primary care physician and the specialist. Some expressed the desire for information on systems or healthcare facilities to be provided by people who are in contact with patients and other affected parties through the renewal of benefits certification or other such processes. These people include officials or public health nurses serving at prefectural governments and in designated cities (namely, cities designated by government ordinance, core cities, cities operating public health centers by government ordinance, and special wards).

Voices of Patients and Other People Living with Intractable and Rare Diseases



"When the doctor told me the name of the condition I had been diagnosed with, they did not tell me that it was an intractable disease. I did my best to commit the name to memory and was able to look it up on my phone after paying at the desk. That was when I first learned about my condition. I thought, 'What? An intractable disease? A designated intractable disease?'"



"When I first learned about my disease, I had no information about it whatsoever – I did not know what type of disease it was, what type of treatment would be necessary, or what would happen to my body as treatment progressed. I was unable to envision or plan for my future. It made me realize just how anxious people can become when they have no information about the future. It would have been nice to have someone to talk to during that period."



"When I was first diagnosed, a nurse took the time to listen to me carefully"



"I think it is necessary to have an intermediary who can tell the doctor the things that are difficult to say to them directly. This isn't limited to transferring hospitals, because there are people who are unable to build trusting relationships with doctors over the course of daily life. There are also times when patients themselves do not know how far to go into detail with their questions. It would be good to have someone who could tell them outright when a question is not something to ask a doctor."



"Among patients with intractable diseases, some make regular visits to university hospitals for decades. Recognizing this burden, recently, some doctors are telling patients to visit local hospitals or, for those with mild symptoms, to see their primary care physicians. I think that as a system, healthcare should be arranged in tiers, but patients have no way of knowing how much information about their condition is being shared between their primary care physician and specialist."



"It is extremely common for patients to mention positive interactions with pharmacists. If there is even a slight change in a prescription, a pharmacist might ask, 'Your prescription changed, did something happen?' If the dose has been decreased, they might say, 'You've been given less,' or they might check and ask, 'Are you feeling better now?' When I ask about something I don't understand, the pharmacist checks thoroughly. One time they said, 'Can I check on that, and call you later?' when they could not find an answer immediately. Then, they made sure to call me a few days later, after receiving an answer from the pharmaceutical company. Having someone close by can be a source of peace of mind for patients and those around them."



"People have various opportunities to interact with staff or public health nurses at prefectural governments, designated city governments, or public health centers, such as when they renew their certification for benefits. I would like such staff members to take those interactions as opportunities to keep visitors up-to-date on items like systems or hospitals."

Several limitations apply to these interview findings. The interviews focused on patient experiences surrounding the process of noticing symptoms and reaching a diagnosis, with many comments being reflections on events from several years ago. As responses are based on participant recall, there were challenges in accurately grasping circumstances during the specified timeframes.

In the area of intractable and rare diseases, it can be difficult for people to recognize challenges encountered on the path to diagnosis when they are experiencing that journey in real time. During the period when the cause of their symptoms is still unclear, people are unlikely to arrive at the conclusion that they may have an intractable or rare disease, and they may also have difficulty grasping the full picture of the challenges in front of them. Therefore, holding retrospective interviews may offer significant insights into these challenges.

Chapter 2

The Current State of the Healthcare Delivery System for Intractable and Rare Diseases

To further clarify the state of the healthcare delivery system for intractable and rare diseases from multiple angles based on the voices of patients and other affected parties, we organized issues currently facing that system through desk research and discussions with experts from industry, government, academia, and civil society.

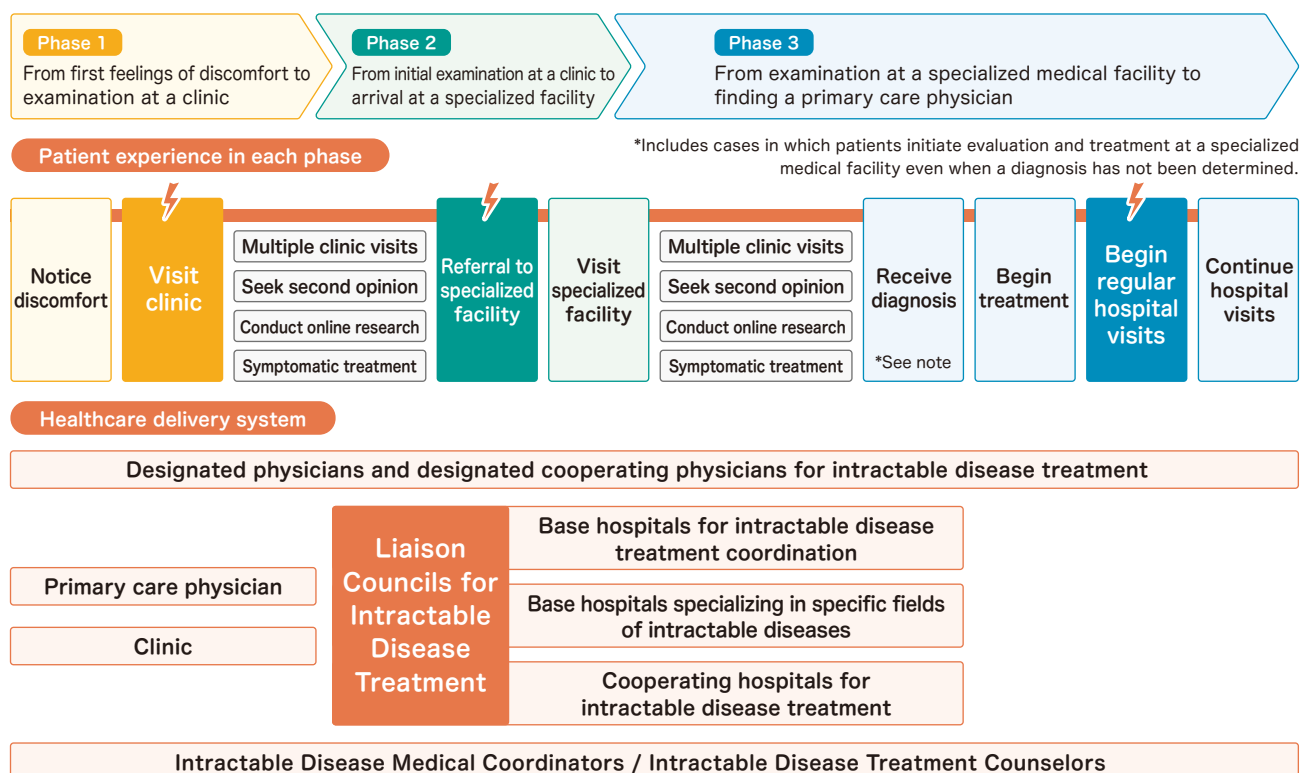


Fig 2: The journey for patients and other people living with intractable and rare diseases and overview of the healthcare delivery system for intractable and rare diseases

From first noticing discomfort to undergoing an examination at a clinic

Selecting the clinic or department for a medical examination

- In principle, patients and other affected parties in Japan have the freedom to visit any healthcare institution they wish, so hurdles to receiving a medical examination are low. Furthermore, Japan has a highly-developed healthcare system centered on clinics, with 105,207 clinics nationwide (which equates to approx. 84 facilities per 100,000 people).³⁾ On the other hand, having the freedom to choose which healthcare institution to visit also means that it is up to the patient or affected party to determine which clinic or department is right for them.
- It is difficult to determine the appropriate clinic or department to visit based on one's symptoms. For example, a patient with nail dystrophy experienced delays in visiting a dermatologist because they were unaware that nails are part of the skin.
- There are also many people without regular primary care physicians. Some people have family members or friends who are healthcare professionals, or know people through bodies like patient advocacy groups and who can provide advice such as, "You should probably go to this department for those symptoms." However, many people have no such network. As a result, whether or not an individual arrives at the appropriate clinic can be influenced by their environment or situation.
- Patients and other affected parties often do not consider the possibility that their condition is an intractable or rare disease from the outset. There are limits to how much can reasonably be expected of patients and other affected parties, or to which a healthcare system can be designed with the assumption that they will be able to select the right clinic or department to visit on their own.

Gathering information on clinics or departments to visit for medical examinations

- The first action that many patients and other affected parties take when they notice discomfort or symptoms is to look up information using the internet, and the national Government has been expanding the amount of available information. The system for looking up medical facilities was previously operated separately by each prefecture, but has now been integrated into Healthcare Information Online (Navi), a nationwide system operated by the Ministry of Health, Labour and Welfare (MHLW).⁴⁾ This system provides a centralized resource where users can look up items such as medical specialties or conditions treated at each healthcare institution nationwide. This system has made it easier for patients and other affected parties who live near prefectural borders to look up information. The system is expected to help eliminate information disparities caused by place of residence.
- On the other hand, recognition toward this system itself is insufficient, and the very act of searching for this information is difficult for citizens who are unfamiliar with healthcare or the health system. The Healthcare Information Online (Navi) system provides a mechanism for presenting residents with information on health services or functions as reported by healthcare institutions, focusing on items like their medical departments or diseases they handle. This means that it does not include certain information that patients and other affected parties may be looking for, such as the clinic or department they should visit based on their symptoms, or the treatment or referral processes they are likely to experience after a medical examination.
- In recent years, more people are using AI to look up information, and information resources are growing more diverse to include internet searches, social networks, and user review sites. However, many intractable and rare diseases have early symptoms commonly seen across many conditions, such as fever or fatigue. People also often think their symptoms are simply the result of changes due to aging or psychological distress. From appearances, it is particularly difficult to distinguish conditions such as autoimmune diseases or neuromuscular diseases (which are among the most common designated intractable diseases by number of patients) by initial symptoms. When it is difficult for the person in question or those around them to notice abnormalities, it is even more difficult for them to gather information.
- Clinics and specialties are limited in depopulated areas or remote regions and islands, and people living in some regions may have no access to certain specialties at all. This limits their options for attending a medical examination, even if they are able to obtain information using the internet or other such means. Even if their symptoms suggest that they may have an intractable or rare disease, selecting an appropriate medical facility is even more difficult than it is for people living in urban areas.

3) MHLW. Overview of the FY2024 Survey of Medical Facilities (by Operational Status) and Hospital Reports. Retrieved August 3, 2026, from <https://www.mhlw.go.jp/toukei/saikin/hw/iryosd/24/>.

4) MHLW. Healthcare Information Online (Navi). Retrieved August 3, 2026, from <https://www.iryuu.teikyouseido.mhlw.go.jp/znk-web/juminkanja/S2300/initialize>.

Phase 2

From undergoing an initial examination at a clinic to arriving at a specialized medical facility

Recognizing conditions at clinics and making referrals to specialized medical facilities

- The initial symptoms of intractable and rare diseases are often common ones, such as fever or fatigue. This not only causes patients and other affected parties to overlook the possibility of an intractable and rare disease, but it can also cause healthcare professionals to do the same. This can sometimes make it difficult for clinics to determine the extent of testing and monitoring needed, or to determine when and to which specialized medical facility to refer patients.
- The aforementioned challenges result in prolonged periods of symptomatic treatment or monitoring. Additionally, when physicians see patients with conditions they consider to be outside their specialty, they sometimes end consultations without performing thorough examinations. It is not uncommon for medical history or changes in symptoms to play a crucial role in the diagnosis of intractable and rare diseases, so failing to provide appropriate care or referrals carries the risk of delaying diagnosis.
- Additionally, when symptoms span multiple departments, it becomes more difficult to decide where to direct a referral. For example, symptoms like lower back pain, joint pain, muscle pain, and numbness are often treated in orthopedics or other departments specializing in the affected area, so even when a systemic disease may be present, physicians sometimes do not consider referring patients to specialized medical facilities that treat intractable or rare diseases, departments of rheumatology, connective tissue disorder clinics, or other such departments of internal medicine. There is a need to establish systems for comprehensively viewing symptoms across multiple departments to guide patients to specialized medical facilities when necessary, as well as to share information and educate healthcare professionals in a cross-departmental manner at academic conferences and similar events.

Providing information about the path to diagnosis

- During the period between attending a medical examination at a clinic and visiting a specialized medical facility, patients and other affected parties are likely to have anxious thoughts like, “Will I be okay to go on like this?” or “I wonder how far testing has advanced.” Their wishes to arrive at a diagnosis quickly or concern that they will not be told about their future outlook sometimes causes them to seek examinations at multiple clinics, specialized medical facilities, or departments. This can cause testing data or clinical information to become scattered. Additionally, the foundation for healthcare institutions to share clinical information with each other is underdeveloped, which sometimes results in redundant testing. This not only causes undue physical and psychological burdens for patients and those close to them, but it can also cause unnecessary healthcare expenditures and other issues that prevent the efficient use of medical resources.
- There are also cases in which people living with intractable and rare diseases are only able to obtain a diagnosis after being monitored for a certain period of time. There are times when it is desirable for patients to be monitored continuously at the same healthcare institution, and it is not always that delays in diagnosis occur simply because the diagnosis has yet to be determined. However, patients and other affected parties are not sufficiently informed about this aspect of monitoring. Even if clinics and specialized medical facilities require time to diagnose a condition, patients and other affected parties can easily feel neglected when a medium- to long-term outlook is not provided.

Consultation support prior to diagnosis or periods without a clear diagnosis

- It is difficult for physicians serving at clinics to be the sole parties responsible for supporting patients and other affected parties who do not yet have a clear diagnosis. However, an adequate support system for this period has yet to be established, and Intractable Disease Consultation Support Centers receive many inquiries asking which healthcare facility to visit next when a clear diagnosis cannot be reached.
- In addition to handling procedures for the Intractable Disease Medical Expenses Subsidy System, prefectural governments and government-designated cities are taking advantage of opportunities (such as when people enroll in programs or renew their certification) to provide guidance and services including consultations from public health nurses and other professionals, online consultations, and home visits. Additionally, Intractable Disease Consultation Support Centers operated by prefectural governments and designated cities are providing consultation support to patients, their family members, or other related parties. However, in many cases, support from public agencies is designed primarily for patients and families who have already received a diagnosis. There are cases in which patients or other affected parties cannot make use of these services while they are still waiting for a diagnosis, as well as cases in which systems providing continuous support starting from the period prior to diagnosis are underdeveloped.

Systems for consultations among clinics and specialized medical facilities

- Base hospitals for intractable disease treatment coordination, base hospitals specializing in specific fields of intractable diseases, cooperating hospitals for intractable disease treatment, and Intractable Disease Consultation Support Centers not only provide treatment and support for patients and other affected parties, but they are also responsible for responding to inquiries from local healthcare institutions and community supporters and providing advice on and arranging referrals to appropriate departments or specialized medical facilities. However, not all physicians serving in clinics are aware of these consultation providers or make full use of their services.
- In addition to public consultation services, physicians often contact specialists they know directly for consultations. However, consultations among physicians that occur prior to patient referral are not currently included in the medical service fee schedule. This means consultations via phone or email are only possible through the goodwill of physicians serving at specialized medical facilities. This can create psychological hurdles for physicians at clinics. Furthermore, physicians may hesitate to request assistance from individuals with whom they are not acquainted. In this manner, the personal relationships among physicians can also influence consultations.
- The Remote Collaborative Treatment Premium covers cases in which primary care physicians help patients and other affected parties work with specialists to receive remote treatment for intractable diseases or epilepsy. However, the distribution of that premium's reimbursement between the two healthcare institutions depends on their mutual agreement. The fact that this distribution is undefined encumbers efforts to further strengthen collaboration among healthcare institutions.
- In addition, the specialists required for consultations and referrals are few in number, and are unevenly distributed among regions. For example, for neurological diseases (which represent some of the most common intractable and rare diseases), the national average number of physicians specializing in neurological internal medicine is 4.2 per 100,000 people. This figure ranges from a high of 9.5 in Kyoto Prefecture to a low of 2.0 in Aomori Prefecture, demonstrating a more than fourfold difference across prefectures.⁵⁾
- Base hospitals for intractable disease treatment coordination and other such facilities are designated independently by each prefecture, leading to major regional differences in the number of healthcare institutions, arrangements for collaboration, and utilization methods. This also creates disparities in channels for consultation and collaboration among clinics and specialized medical facilities as well as in the availability of and awareness of consultation services.

The role and status of Intractable Disease Medical Coordinators

- Intractable Disease Medical Coordinators serve as community facilitators in intractable disease healthcare delivery systems, with duties that include providing treatment support to patients and other affected parties, making arrangements for collaboration among healthcare institutions, and supporting access to specialized healthcare. Since the enactment of the Act on Medical Care for Patients with Intractable Diseases, the number of intractable diseases has increased and diagnostic technology has advanced. Accordingly, the roles of Intractable Disease Medical Coordinators have expanded. They are now required to handle a wider range of consultations, including those for rare or hereditary diseases. In addition to enabling smooth connections to appropriate healthcare for patients and other affected parties, their roles are vital for ensuring the effective use of limited specialized medical resources.
- On the other hand, circumstances surrounding Intractable Disease Medical Coordinator placement differ by prefecture in aspects such as full-time or part-time status, the appointment to concurrent positions, and job types. Hospitals are not required to have Intractable Disease Medical Coordinators to be eligible for designation as base hospitals for intractable disease treatment coordination, nor is their placement included in the medical service fee schedule. In other words, their roles and deployment vary significantly from region to region.
- Prefectures select hospitals to serve as core hospitals and then assign them Intractable Disease Medical Coordinators. This system means that even if someone with knowledge and experience is placed in this position, there are cases in which their position is not maintained after personnel transfers or changes in core hospital status.

5) MHLW. 2024 Statistics on Physicians, Dentists, and Pharmacists. Statistics on Physicians, Dentists, and Pharmacists/2024 Statistics on Physicians, Dentists, and Pharmacists: Physicians. Retrieved August 3, 2026, from https://www.e-stat.go.jp/stat-search/files?page=1&query=%E5%B0%82%E9%96%80%E5%8C%BB%E3%80%80%E9%83%BD%E9%81%93%E5%BA%9C%E7%9C%8C%E3%80%80%E7%AC%AC42%E8%A1%A8&layout=dataset&stat_infid=000040383794.

Phase 3

From undergoing an examination at a specialized medical facility to finding a primary care physician

Receiving adequate explanations and information about the outlook for treatment at diagnosis

- Sufficient information is not being provided at diagnosis. Some people have spoken of experiences in which they were told the name of their condition but not about its status as an intractable disease, and only found out after looking it up on their own. Due to time constraints and other restrictions, information provided at examinations sometimes does not fully cover details of the disease, the necessary treatments, or the expected course for those who undergo continued treatment. This makes it difficult for patients and other affected parties to predict what daily life will be like during long-term treatment.

The division of duties between specialized medical facilities and primary care physicians

- Many intractable and rare diseases require the patient to undergo long-term treatment or recuperation, and once symptoms have stabilized, specialized medical facilities and local healthcare institutions must continue providing treatment with a clear division of duties. However, there is a significant degree of variation in symptoms, progression, and necessary treatments from one intractable or rare disease to another, making it difficult to define uniform roles for specialized medical facilities and primary care physicians.
- The difficulty of defining the division of duties can lead to concerns among patients and other affected parties that they may not receive adequate care from physicians outside of specialized medical facilities. Furthermore, it is sometimes unclear which healthcare institution is responsible for managing the overall health and treatment plans of patients who regularly visit multiple facilities due to multiple diseases or complications.
- At the same time, physicians in the community experience concern as to whether they can make the necessary decisions or provide the necessary management for diseases that involve a high degree of expertise. In addition to the limited nature of knowledge and experience treating these diseases, there is deep-rooted uncertainty about how to interact with patients and other affected parties living with diseases without established cures, or how to support them during long-term management. This results in cases in which physicians determine that treatment will be difficult because the condition lies outside of their specialty.
- Because the number of patients is small, it is also difficult for physicians serving in local clinics to accumulate experience treating people living with intractable and rare diseases. It is unrealistic to expect all primary care physicians to have the capacity to provide specialized treatments. Furthermore, treatments that involve the use of expensive pharmaceuticals can also create burdens for small-scale healthcare institutions. This is due to challenges like managing pharmaceuticals or establishing systems for their continuous administration.

Handling healthcare in areas other than intractable and rare diseases

- When a person with an intractable or rare disease becomes ill due to unrelated causes and requires emergency transport or hospitalization, finding a medical facility that will admit them can be difficult. Healthcare facilities with limited experience in managing patients and other parties with intractable and rare diseases may be uncertain about the characteristics of their condition or how it should be managed, which sometimes makes them hesitant to accept such patients.
- Additionally, patients may not always be accepted at base hospitals for intractable disease treatment coordination or similar facilities. While these base hospitals have systems in place to provide diagnoses and specialized treatment, they are not intended for the provision of emergency or general care on a regular basis. In particular, it is even more difficult for patients and other affected parties whose symptoms have stabilized after diagnosis and are primarily being treated at community healthcare institutions to find a hospital if they suddenly need hospitalization or emergency care.
- For patients and other affected parties who find it difficult to make regular hospital visits due to the progression of symptoms, continuing to receive necessary medical care can be a significant challenge. When their condition is not the result of an acute change, they are ineligible for emergency transport. Also, people who are under age 40, or who are over 40 with conditions that are not considered “specified diseases” under the Long-Term Care Insurance system, cannot receive support for hospital visits provided through that system. These issues result in cases in which people who require treatment are unable to receive the care they need because they cannot secure a means of transport to and from a healthcare institution.
- Examining the ratio of people who are certified for specific healthcare expenses for designated intractable diseases and who are 75 years of age and older by fiscal year, we find an increase from 23.0% (216,539 people) at the end of FY2015 to 28.7% (322,137 people) at the end of FY2024.⁶⁾ As patients and other affected parties grow older, and as diagnostic technologies become more sophisticated, not only will more treatments be provided for intractable and rare diseases themselves, there is likely to be even greater demand for emergency, general, in-home, and long-term care services. However, Japan has yet to establish adequate collaborative systems in which healthcare, long-term care, and social welfare organizations share information on patients and other affected parties to provide seamless support.

6) Intractable Disease Information Center. Number of people certified for specific healthcare expenses (Designated intractable diseases). Retrieved August 4, 2026, from <https://www.nanbyou.or.jp/entry/5354>.

Chapter 3

Recommendations on Redesigning the Healthcare Delivery System Surrounding Intractable and Rare Diseases

Based on the voices of patients and other people living with intractable and rare diseases as well as the current state of the healthcare delivery system surrounding these conditions, we offer the following recommendations for redesigning that system. These recommendations span the period across diagnosis and are based on the perspectives of patients, affected parties, and citizens. The journey that patients and other affected parties experience is cohesive, and issues that have been identified within each phase are related to one another. Given this interconnectedness, we organized our recommendations in a manner that cuts across phases, and have identified which phases are related to each of our recommendations.

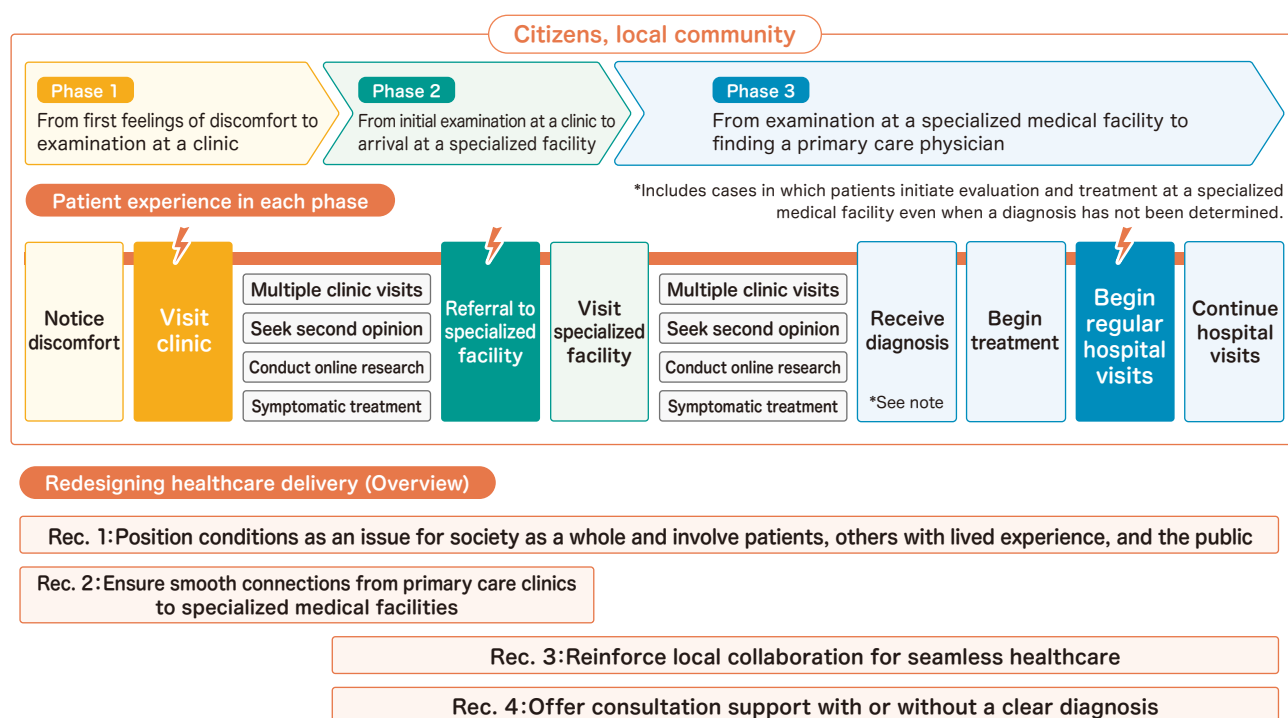


Fig. 3: The journey from the perspectives of patients and other affected parties and how our recommendations correspond to each phase

column

“Rare is common”—The EURORDIS strategy for raising public awareness of rare diseases in Europe

Centered on EURORDIS–Rare Diseases Europe, several public awareness campaigns are being conducted in Europe emphasizing that although each rare disease is uncommon, they collectively impact many people. While these efforts tended to focus on rarity in the past, current campaigns stress the fact that rare diseases are an issue that concerns everyone. In the European Union (EU), a rare disease is defined as a condition affecting “not more than five persons per 10,000” (approx. 1 in 2,000 people), with over 6,000 conditions recognized. Overall, it is estimated that these conditions impact 30 million people in Europe and 300 million people globally.

Recognizing the prevalence of rare diseases, EURORDIS and its partners have stated, “There are 30 million people living with a rare disease in Europe, and 300 million worldwide. But while each rare condition is uncommon ... that means someone you know—a friend, colleague, or neighbour—could be living with one,” and they are working to raise awareness of rare diseases as an issue for all of society. This concept is also reflected in specific campaigns like the “Rare is common” campaign in 2019 and the “#30millionreasons” campaign in 2021. Rather than focusing on individual diseases, the latter campaign emphasized the collective impact of these conditions on 30 million people in Europe. Then, for Rare Disease Day 2025, EURORDIS worked to raise public awareness that rare diseases are more common than people realize under the theme, “More Than You Can Imagine.”

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Position intractable and rare diseases as an issue for society as a whole and spur progress in relevant policies through collaboration that involves patients, others with lived experience, and the public

Adopt a fresh perspective that intractable and rare diseases are a deeply relevant issue for society and advance activities to raise awareness

- The conventional view of intractable and rare diseases has been that they deserve societal support because of their rarity. While individual intractable and rare diseases affect relatively few people, their collective impact on the population is significant. Moving forward, we must transition from awareness-raising activities that emphasize the rarity of intractable and rare diseases to activities that are centered on the view that these conditions are immediate health concerns that can impact anyone.
- The national Government should clearly position awareness-raising and education as key elements of intractable and rare disease measures in policies such as the Act on Medical Care for Patients with Intractable Diseases or the Basic Plan for Intractable Disease Measures. At the same time, municipal governments and related parties should work together to advance activities that increase societal understanding in an ongoing manner. As of the end of FY2024, approximately 1.1 million people in Japan had been certified for specific healthcare expenses for designated intractable diseases.²⁾ This equates to about 1 in every 110 people in Japan. Additionally, Intractable Disease Support Centers have been established in every prefecture, so a foundation for collaboration among parties such as patient advocacy organizations and relevant academic societies is already in place. Reinforcing the roles of Intractable Disease Support Centers as consultation and collaboration hubs and making further proactive use of their networks may be effective when advancing nationwide efforts to raise awareness of these conditions.
- It must be noted that the number of patients with designated intractable diseases does not directly represent the overall scale of intractable and rare diseases in Japan. In addition to those with mild symptoms and who are ineligible for healthcare subsidies, there are also likely to be people living with diseases that are not included among designated intractable diseases or diseases that have yet to be diagnosed. Considering these factors, intractable and rare diseases may actually affect a greater number of people.
- At the same time, when positioning intractable and rare diseases as an immediate issue for society, care must be taken to avoid reducing visibility for issues for individual diseases. Progress must be made in initiatives to spread awareness throughout society as well as those for addressing specific challenges in intractable and rare diseases such as the difficulty of diagnosis, access to specialized healthcare, and prolonged treatment periods.

Furthermore, in response to advocacy efforts from EURORDIS and other parties, in December 2021, the United Nations General Assembly (UNGA) adopted a resolution recognizing the approximately 300 million people living with rare diseases and their families around the world. There is now growing global awareness that rare diseases are not merely a minority concern, but are a health issue that requires action from society as a whole.

Meanwhile, a set of policy recommendations for Europe titled the “Rare 2030 Foresight Study” positioned rare diseases as a society-wide challenge while highlighting the need to sustain efforts to overcome the difficulty of diagnosis, to secure access to specialized care, and to address other concerns specific to rare diseases. This underscores the importance of striking a balance between efforts to broaden understanding throughout society and those addressing the challenges specific to rare diseases.

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Promoting understanding of intractable and rare diseases while expanding opportunities for people to learn how to utilize healthcare services

- Because the early symptoms of intractable and rare diseases are often common ones like fever or fatigue, it is difficult for patients and other affected parties to recognize that they may have such a disease. This means the judgment needed to not overlook changes in physical condition, the ability to seek appropriate medical care, and the practical knowledge to accurately describe symptoms during a medical examination, including how they have changed over time, are all more important than the expertise to identify specific diseases. These capacities are a fundamental form of knowledge that should be acquired by everyone, and not only in relation to intractable and rare diseases.
- However, people in Japan do not always have ample opportunities to systematically learn about subjects like how the healthcare system is structured, how to receive medical examinations based on one's symptoms, or how to utilize healthcare services. Through education provided in schools, communities, and workplaces, people must be provided with continuous opportunities to acquire the knowledge or judgment they need to think about their own health and to receive appropriate healthcare.
- Parties such as the national Government, municipalities, academic societies, medical associations, and patient advocacy organizations should collaborate to create opportunities for people to learn how to utilize healthcare services during compulsory education as well as in communities and workplaces. While making full use of existing educational initiatives (such as cancer education), these efforts should include sharing the experiences of patients and other affected parties with society and securing opportunities to deepen understanding of various diseases and daily life during long-term treatment.

Systemically promoting meaningful involvement of patients and other affected parties in the field of intractable and rare diseases

- Meaningful involvement in systems for patients and other affected parties should be more clearly positioned when the Act on Medical Care for Patients with Intractable Diseases and corresponding Basic Plan are revised in the future, and steps should be taken to secure opportunities for that involvement. Article 32 of the Act on Medical Care for Patients with Intractable Diseases states that patients living with intractable diseases and other affected parties must be included on regional councils for intractable disease measures. Meanwhile, the Basic Plan calls for the involvement of a broad range of stakeholders, including those most affected. However, local governments are only obligated to endeavor to establish regional councils for intractable disease measures. Also, regions vary in whether they have established these councils, how active their councils are, and whether or not they involve patients and other affected parties.
- The significance of reflecting the perspectives of patients and other affected parties in health policy has gained widespread recognition around the world. A resolution on social participation was approved at the 77th World Health Assembly in 2024, and the meaningful involvement of patients and other affected parties was a key element of the first-ever resolution on rare diseases adopted at the 78th World Health Assembly in 2025.
- Given these developments, in the field of intractable and rare diseases, meaningful involvement for patients and other affected parties should be expanded in the policy formulation and healthcare delivery system planning and evaluation processes. Since the enactment of the Cancer Control Act in 2006, Japan has formally implemented meaningful involvement for patients and other affected parties in many disease policies. Then, the 2026 revision of the Guidelines for the Development of Core Hospitals for Coordinated Cancer Care, etc. included a new stipulation obligating prefectural governments to include organizations like patient advocacy groups on joint councils for coordinated cancer care. As these examples show, there is growing recognition of the importance of meaningful involvement for patients and other affected parties in discussions on the healthcare delivery system. Similar steps should be taken in the field of intractable and rare diseases, including the promotion of meaningful involvement in discussions on the healthcare delivery system at forums such as prefectural Liaison Councils for Intractable Disease Treatment. Mechanisms for fully reflecting the opinions of patients and other affected parties in policy formulation and community healthcare must also be established.
- Continuous and meaningful involvement from patients and other affected parties should be systematically implemented in research, as well. As the development of diagnostic technology or treatment methods and R&D in areas like genomic medicine are closely linked to treatment and daily life for patients and other people living with intractable and rare diseases, further efforts to encourage meaningful involvement in this field are eagerly anticipated. The perspectives of patients, affected parties, and citizens must be reflected in each step of research (including selecting research topics, formulating research plans, providing information to research participants, and applying research findings for public benefit), and mechanisms that ensure R&D can be advanced with collaboration among patients, affected parties, and researchers must be developed.
- Meaningful involvement for patients and other affected parties should not be limited to policy, healthcare, and research; it should also be part of each stage of designing, evaluating, and improving services and information infrastructure. For example, while public agencies and many organizations provide systems to look up information, there are calls from patients and other affected parties for a centralized information platform that would allow users to determine which department to visit or where to seek advice based on their own symptoms, or to learn about the course of treatment or referral process they may experience. When developing information platforms, AI and other cutting-edge technologies should be utilized and the perspectives of patients, affected parties, and citizens should be reflected in the design, evaluation, and improvement processes.

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Build a healthcare delivery system with smooth connections from primary care clinics to specialized medical facilities that provides patients and other people living with intractable and rare diseases with appropriate care early on

Developing the environment to ensure physicians can notice when an intractable and rare disease may be present and can refer patients to specialized medical facilities

- For patients and other affected parties to receive appropriate healthcare, it is important for the physician that provides their initial examination to notice when an intractable and rare disease may be present, and to then refer them to a suitable specialized medical facility. However, it is unrealistic to expect every physician to possess specialized knowledge on various intractable and rare diseases. What is important is for them to keep in mind that an intractable and rare disease may be present when a condition is difficult to diagnose, and to have the judgment to refer patients and other affected parties to specialized medical facilities when it is difficult to provide treatment with only their own expertise. Instead of being overly-reliant on the information-gathering capacity and other abilities of patients and other affected parties, it will be vital to foster an environment where they can be guided to specialized medical facilities as necessary, regardless of which local healthcare institution they visit first.
- To foster such an environment, the national Government, relevant academic societies, and healthcare institutions should incorporate a cross-specialty perspective on symptoms into clinical training and specialist certification systems. They should also foster the clinical capacity needed to guide people to the specialized medical facilities that are right for them. Education must be expanded so physicians are prepared to consider intractable and rare diseases based on knowledge regarding specific diseases, as well as on symptoms that are common for many diseases, such as fatigue, pain, and muscle weakness.
- Continuous opportunities should be secured for physicians to learn about intractable and rare diseases after graduation or during lifelong education, and mechanisms for the continuous development of practical clinical skills should be expanded to enable physicians to respond appropriately to cases that are difficult to diagnose and to refer patients to specialized medical facilities when necessary.

Establishing systems that make it easier for physicians in clinics to consult physicians in specialized medical facilities

- Facilities such as local core hospitals or base hospitals for intractable disease treatment coordination should expand functions that allow for consultations with specialists, along with systems that allow clinics and other local healthcare institutions to consult specialists, such as through online consultations. As part of these efforts, proactive consideration must be given to appropriately evaluating efforts from both healthcare institutions that seek consultations as well as institutions providing consultations, such as through the medical service fee mechanism or financial support schemes.
- Another potential option may be to develop online consultation services at specialized medical facilities (such as base hospitals for intractable disease treatment coordination) to provide local healthcare institutions with continuous access to consultations from specialists in multiple departments on predetermined days and times. In addition to making it possible for physicians serving in clinics to consult with specialists when necessary, such services would also foster ongoing collaboration between specialized and local medical facilities, enabling them to share their expertise more widely.
- The healthcare information infrastructure should be developed to facilitate remote consultations by allowing users to share images, test results, and medical records in a secure environment. A mechanism should also be established so that insights gained through these consultations can be shared with healthcare and research institutions on a continuous basis and so that care quality can be elevated. The benefits of a specialist consultation system will extend beyond support for individual patients; its presence will also help make the healthcare delivery system for intractable and rare diseases a “learning health system,” or a mechanism for continuous learning and improvement.

Further promoting the use of diagnostic support systems and genomic medicine

- While strengthening the Initiative on Rare and Undiagnosed Diseases (IRUD) and other existing systems for diagnostic support, society should fully leverage efforts from Genomic Medicine Japan (GeMJ), which was launched in March 2026. These efforts include those aiming to utilize whole-genome analysis findings to benefit patients, to promote precision medicine, and to develop and operate an information infrastructure. Through these initiatives, we must build a system that ensures patients and other people living with intractable and rare diseases throughout Japan can benefit equally from advances in genomic medicine.
- Collaborative systems should be reinforced to facilitate referrals and consultations from local healthcare institutions to specialized facilities involved in IRUD and genomic medicine while reflecting circumstances and disease characteristics for patients and other affected parties. Despite progress in the environment surrounding diagnosis (such as the inclusion of multigene panel testing in health insurance coverage), access to whole-exome and whole-genome sequencing and other advanced forms of genomic analysis remains inconsistent in routine clinical care across Japan. Such tests are currently conducted under research frameworks or as part of other initiatives at specialized medical facilities. Japan must establish a system that provides patients and other affected parties with specialized diagnostic support in a timely manner, regardless of their place of residence or their attending physician's knowledge and experience.
- Research in and the adoption of AI utilizing clinical or genomic data and other diagnostic support technologies should be advanced to improve diagnostic accuracy and shorten times to diagnosis. However, AI should be used as a tool to complement physicians' diagnostic and decision-making abilities. Determining diagnoses and treatment plans should ultimately be the responsibility of physicians.
- While advancing efforts to benefit individual patients by applying genomic information obtained through whole-genome sequencing and other related clinical information to diagnosis and treatment, efforts must also be made to promote the appropriate use of said information in other areas like research and drug discovery. Steps should also be taken to ensure transparency (for items such as who is using said information and for what purpose, or how the results of such efforts will be used to benefit the patients and others who provided their information), and mechanisms for safe and fair data use should be developed.
- When promoting genomic medicine, access to suitable genetic counseling and support services must be provided, as findings from genetic testing and whole-genome sequencing can affect both the person tested and their blood relatives. Furthermore, when using genomic information, there should also be continuous and integrated efforts to address Ethical, Legal, and Social Issues (ELSI) as well as to ensure transparency and trust through the meaningful involvement of patients and citizens.

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Phase 2

Phase 3

Reinforce local systems for collaboration to ensure patients and other people living with intractable and rare diseases can receive reliable, continuous care

Clarifying how roles are to be divided among specialized medical facilities and primary care physicians, and reinforcing local systems for collaboration

- Working together, the national Government, prefectural governments, and academic societies should outline the respective roles of specialized medical facilities and primary care physicians based on disease characteristics and patient conditions. They should then define the division of duties and set basic principles for collaboration to ensure continuous care can be delivered in communities. For example, primary care physicians could be assigned routine care when a patient's condition is stable, while making use of systems for consulting specialists as necessary. Meanwhile, specialized medical facilities would regularly review and evaluate treatment plans. In this manner, it will be necessary to clearly define the respective roles of each party.
- Prefectural governments should collaborate with parties such as base hospitals for intractable disease treatment coordination and medical associations to create an environment that facilitates participation from local clinics in intractable disease healthcare delivery networks. Collaboration among local healthcare institutions and specialized medical facilities through activities like information sharing, training, and case reviews must be encouraged, and systems that support continuous care delivered through region-wide engagement must be built.
- The national Government and prefectural governments should develop frameworks to enable specialized medical facilities, local healthcare institutions (including primary care physicians), and emergency medical facilities to smoothly share medical information on patients and other parties living with intractable and rare diseases when needed. Such information should include treatment plans and emergency response protocols. It will be necessary to implement such arrangements to enable healthcare institutions to grasp disease characteristics, treatment histories, and emergency response protocols in a timely manner so that they can admit patients with intractable and rare diseases and provide care with confidence.
- In addition to clearly defining the division of roles, collaborative systems should be established in advance among specialized medical facilities, local healthcare institutions, and emergency medical facilities to ensure patients and other affected parties can be provided with cohesive and appropriate care when a patient's condition deteriorates or undergoes an acute change, or when the progression of symptoms makes outpatient visits difficult. Each region should develop systems to maintain continuous care through clearly outlined collaboration arrangements that cover admission procedures for acute changes, methods for consulting with specialized medical facilities, and transitions to home visits or inpatient care.

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Phase 2

Phase 3

Develop consultation support systems to guarantee patients and other people living with intractable and rare diseases get the support they need, regardless of where they live or whether they have a diagnosis

Expand systems providing explanations and consultation support to patients and other people living with intractable and rare diseases

- The national Government and prefectural governments should create systems that allow patients, affected parties, and healthcare professionals to continuously share information on treatment plans and future prospects regardless of whether they have a diagnosis. The foundation of treatment should be informing patients and other affected parties not only of the name of their condition, but all of the information that is currently available, the outlook for diagnosis, and the treatment plan moving forward. Even when a clear diagnosis is unavailable, providing thorough explanation on items like reasons for follow-up observation and the outlook for future treatment will be important for building mutual understanding with patients and those close to them.
- Systems should be equipped to provide continuous consultation support and explanations with multi-disciplinary collaboration among professionals including physicians, nurses, pharmacists, social workers, Intractable Disease Medical Coordinators, and Intractable Disease Consultation Support Center staff. Accomplishing this will require implementing institutional and operational measures that ensure multi-disciplinary teams can make full use of expertise in their respective fields to provide support, including setting aside time blocks outside of routine medical care for providing explanations and consultations.

Develop systems providing seamless consultation support from before diagnosis

- The national Government, prefectural governments, and local governments should respond carefully to consultation requests from patients and other parties living with intractable and rare diseases as well as their families, regardless of whether they have a diagnosis. After doing so, they should determine how to best structure consultation support systems that work closely with affected parties to guide them to the health, medical, and welfare services they need, and develop those systems. Starting with the Intractable Disease Medical Expenses Subsidy System, many systems require users to have a clear diagnosis. Given the fact that it is difficult for patients and other affected parties to access support before obtaining a diagnosis, we must build a system that allows for consultations sought before diagnosis to be fully heard and that connects people to suitable care and support.
- As the administrative bodies that are closest to residents, it is particularly important for designated cities to ensure that no one is denied support solely because they lack a diagnosis. In addition to providing certification and renewal for the Intractable Disease Medical Expenses Subsidy System, they should be responsive to consultations from patients, affected parties, and their families, provide continuous counseling support from public health nurses and other professionals, and develop systems that connect people to relevant organizations (such as healthcare institutions, Intractable Disease Consultation Support Centers, and welfare services) when necessary.

Clarify roles, increase placements, and strengthen training systems for Intractable Disease Medical Coordinators

- In addition to clarifying the roles expected of Intractable Disease Medical Coordinators, their placement and designation requirements for base hospitals for intractable disease treatment coordination and other such facilities should be specified. At the same time, steps should be taken to determine how to best fund coordination services and to develop systems that prevent any major support system disparities from emerging among regions.
- While utilizing educational programs offered by academic societies and other organizations and further developing standardized training systems, actions should be taken to foster an environment in which all Intractable Disease Medical Coordinators who wish to undergo training can do so in an ongoing manner. To prevent support systems from growing dependent on the knowledge or experience of any specific individual, systems that enable each region to provide high-quality, continuous support should be built and human resource development should be promoted.

Chapter 4

Initiatives for Expanding Consultation Support and Collaboration Systems in Intractable and Rare Diseases

Overview and Background

The framework for the healthcare delivery system for intractable diseases described by the Basic Plan for Intractable Disease Measures, formulated in accordance with the Act on Medical Care for Patients with Intractable Diseases, includes base hospitals for intractable disease treatment coordination, base hospitals specializing in specific fields of intractable diseases, and cooperating hospitals for intractable disease treatment. However, the designation of each medical facility is performed by prefectural governments, who also determine the conditions for designation. As a result, there are significant regional variations in the design of these systems, despite their common framework. Furthermore, while Intractable Disease Medical Coordinators are supposed to be placed at base hospitals for intractable disease treatment coordination, the methods used to place or utilize those coordinators vary according to local conditions in each prefecture.

In such circumstances, it will be crucial for regions to share initiatives and innovations to expand systems ensuring patients and other affected parties receive necessary healthcare in their communities. However, Japan does not yet have sufficient mechanisms needed for regions to share innovations or information on the circumstances behind them.

In response to this situation, we conducted a desk study to obtain an overview of systems in each prefecture, then interviewed representatives from three prefectures with noteworthy initiatives in consultation support or collaboration systems. The information we compiled is centered on the roles and placement of Intractable Disease Medical Coordinators, pre-diagnosis consultation support, and systems for collaboration with local healthcare institutions and related organizations. To serve as points of reference for other regions, we also compiled information on the systems underlying these items as well as special considerations given to how they are operated.

The three prefectures had the following items in common.



We found that they also face some common challenges. All three prefectures have found it difficult to reinforce collaboration among local clinics or primary care physicians and specialized medical facilities. In addition, they each use their own methods of placing or employing Intractable Disease Medical Coordinators. Our findings suggested that the institutional status of coordinators must be given further consideration to ensure that their roles can be carried out continuously and effectively.



Overview

The healthcare delivery system for intractable diseases in Fukuoka Prefecture is centered around one base hospital for intractable disease treatment coordination (Kyushu University Hospital) as well as 14 core cooperating hospitals for intractable disease treatment and 107 general hospitals. There are also three Intractable Disease Consultation Support Centers managed and operated by the prefectural government and ordinance-designated cities (the Fukuoka Prefecture, Fukuoka City, and Kitakyushu City centers). Certification for intractable disease benefits is held by 45,732 people in the prefecture.

Specific Initiatives and Supporting Organizational Innovations

Leveraging organizational capacity covering the entire prefecture

- An initiative called the Project for the Development of a Healthcare Delivery System for Intractable Diseases is being implemented by the Fukuoka Prefectural Liaison Council for Intractable Disease Treatment under appointment from Fukuoka Prefecture. The prefectural government has also designated Kyushu University Hospital as a base hospital for intractable disease treatment coordination, where it has also established a center called the “Undiagnosed or Undesignated Intractable Disease Consultation Support Center.” Appointed by the prefectural government, Kyushu University Hospital serves as a base hospital for intractable disease treatment coordination and is operating the aforementioned Center. While Intractable Disease Medical Coordinators have been placed at Kyushu University Hospital, they are employees of the prefecture. This arrangement enables them to respond to a broad range of consultations from people living with intractable diseases and local healthcare institutions in the prefecture, including those who are not patients at Kyushu University Hospital.

Expanding the consultation support system into pre-diagnosis

- Kyushu University Hospital's Undiagnosed or Undesignated Intractable Disease Consultation Support Center helps provide a seamless support system across diagnosis and into daily life during daily life with ongoing care by responding to consultations from patients who do not know which department to visit or who have yet to receive a diagnosis.
- The Undiagnosed or Undesignated Intractable Disease Consultation Support Center is staffed by nurses who are Kyushu University Hospital employees, so its staff work under a different arrangement from Intractable Disease Medical Coordinators, who are employed under the prefectural program.
- The Undiagnosed or Undesignated Intractable Disease Consultation Support Center works closely with the Intractable Disease Consultation Support Center. The Undiagnosed or Undesignated Intractable Disease Consultation Support Center collaborates directly with coordinators from the Intractable Disease Consultation Support Center to address consultations from patients with undiagnosed conditions.

Strengthening patient support systems with collaboration among the prefectural government, designated cities, and relevant organizations

- Three types of professionals provide support at the Fukuoka Prefecture Intractable Disease Consultation Support Center: Intractable Disease Support Staff, Intractable Disease Medical Coordinators, and Independent Support Staff for Specified Chronic Pediatric Diseases and Other Conditions. This arrangement makes it possible for the Center to provide people with continuous support throughout the life course, from patients with specified chronic pediatric diseases to adults with intractable diseases.
- There is collaboration among the Fukuoka Prefecture, Fukuoka City, and Kitakyushu City Intractable Disease Consultation Support Centers. While Fukuoka City has outsourced operations of its Intractable Disease Consultation Support Center to the prefectural government, Kitakyushu City operates its Center independently, so officials from Fukuoka Prefecture and Kitakyushu City are working to build face-to-face relationships through regular meetings held about once per month.

Promoting the creation of a network connecting local healthcare facilities and residents

- Awareness of the Undesignated Intractable Disease Consultation Support Center and the Intractable Disease Consultation Support Center is being raised through the local medical association, and efforts to build a system for appropriate consultations and referrals from local physicians in private practice are currently advancing.
- Other activities for raising awareness include distributing pamphlets to cooperating hospitals, holding public lectures for citizens, and publishing information in the prefectural newsletter. Also, during the medical expense benefits certification renewal period, Intractable Disease Consultation Support Center staff are visiting various public health centers throughout the prefecture to provide on-site consultations as well as to proactively reach out to patients.
- As for regional collaboration, Intractable Disease Medical Coordinators are participating in councils for intractable disease measures at each public health center, and an initiative to build a network with the local medical association and relevant organizations is underway.

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Overview

Osaka Prefecture has a healthcare delivery system centered on 14 base hospitals for intractable disease treatment coordination, 3 base hospitals specializing in specific fields of intractable diseases (namely, neurological and muscular disorders; specified pediatric intractable diseases; and cardiovascular and respiratory diseases), and 13 cooperating hospitals for intractable disease treatment. There is also an Intractable Disease Consultation Support Center. The Center is managed and operated by the Osaka Intractable Disease Association, a nonprofit organization (NPO) and patient advocacy organization appointed by the Osaka Prefectural Government. In Osaka Prefecture, 88,216 people are certified for specific healthcare expenses for designated intractable diseases.

Specific Initiatives and Supporting Organizational Innovations

Building a healthcare delivery system that makes the most of expertise for each disease group

- Appointed by the Osaka Prefectural Government, a facility called the Osaka Intractable Diseases Medical Information Center (located at the Osaka General Medical Center) is carrying out the Project for the Development of a Healthcare Delivery System for Intractable Diseases. In addition to its role as the base hospital for that project, the Center is also responsible for administrative duties for the prefecture's base hospitals, specialized base hospitals, and cooperating hospitals, as well as for hosting meetings and coordinating healthcare institutions.
- Osaka Prefecture has designated 14 base hospitals for intractable disease treatment coordination and has built a clinical system that makes the most of expertise in each disease group through its base hospitals specializing in specific fields of intractable diseases. The criteria for designating medical facilities for intractable diseases are left up to the discretion of prefectural governments, and Osaka Prefecture's criteria are based on regional expertise and clinical track records, including the number of patients with intractable and rare diseases a facility has seen.

Expanding consultation support systems that incorporate the perspectives of patients and other affected parties

- The patient support program is the responsibility of the Osaka Intractable Disease Support Consultation Center, and is operated under contract by the Osaka Intractable Disease Association. As program operations are being led by a patient group, its activities incorporate the perspective of patients and other affected parties. They include providing consultations or hosting lectures on daily life during ongoing care or employment.
- In addition to Intractable Disease Medical Coordinators, Certified Genetic Counselors and Employment Supporters for People Living With Intractable Diseases are also posted at the Osaka Intractable Diseases Medical Information Center, where they provide specialized consultations on topics like genetics or employment. The Center has established a system that can handle a wide variety of consultations, reflecting the expanded scope of diseases eligible for support and increased need for efforts for rare diseases and genetic disease after the enactment of the Act on Medical Care for Patients with Intractable Diseases.
- The Osaka Intractable Diseases Medical Information Center (located at the Osaka General Medical Center) is responsible for the healthcare delivery system, while the role of the Osaka Intractable Diseases Consultation Support Center is patient support. At the same time, the Osaka Intractable Disease Association (which has been contracted to operate the Osaka Intractable Disease Consultation Support Center) operates from a location adjacent to the Osaka General Medical Center, thus providing an environment that facilitates collaboration between a medical facility and a patient support group. This allows them to collaborate on support in situations where consultations about daily living reveal the need for medical intervention, or where medical consultations reveal the need for support in daily life.

Continuously maintaining a consultation support system while drawing on many years of experience

- Even before the launch of its Project for the Development of a Healthcare Delivery System for Intractable Diseases, Osaka Prefecture had an Intractable Diseases Consultation Office. The Office was established in 1980 and became the Osaka Intractable Diseases Medical Information Center in 1993. Utilizing its experience in consultation support and vast store of information, that same facility has continued to build up a long history of serving as a support system in intractable disease measures following the enactment of the Act on Medical Care for Patients with Intractable Diseases and the launch of the Project for the Development of a Healthcare Delivery System for Intractable Diseases.
- Because the Osaka Intractable Diseases Medical Information Center has maintained its role as a consultation office for many years, it is well-known as a consultation provider among related institutions, as well as patients and other affected parties. Furthermore, as an organization, it possesses a wealth of experience and a long track record of responding to consultation requests. This has created a continuous consultation support system that does not rely on the personal experiences of any individual staff member.

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Overview

The healthcare delivery system in Nagasaki Prefecture revolves around one base hospital for intractable disease treatment coordination (Nagasaki University Hospital), 14 cooperating hospitals for intractable disease treatment, and 18 general hospitals. There is also one Intractable Disease Consultation Support Center. The Nagasaki Welfare Association for Single-Parent Households is responsible for its management and operation, a role it has been designated by the Nagasaki Prefectural Government. In Nagasaki Prefecture, 14,566 people are certified for specific healthcare expenses for designated intractable diseases.

Specific Initiatives and Supporting Organizational Innovations

Strengthening the system for collaboration between healthcare and the community by sharing information on a regular basis

- Appointed by the Nagasaki Prefectural Government, the Nagasaki University Intractable Disease Control Center is implementing the Project for the Development of a Healthcare Delivery System for Intractable Diseases. In addition to the Director and Deputy Director (both of whom are physicians), the Center has a nurse serving as Intractable Disease Medical Coordinator who is responsible for facilitating collaboration among healthcare institutions and providing consultation support.
- Once every two months, the Intractable Disease Medical Coordinators lead online roundtable discussions that bring together core hospitals as well as core collaborating hospitals, collaborating hospitals, and public health centers. The presence of a regular forum for information-sharing not only enables healthcare professionals to share information with each other, it also promotes collaboration among healthcare and community health and that includes public health centers. To create a system that facilitates early referrals to specialized medical facilities and supports long-term treatment in communities, they are currently considering the possibility of involving local clinics in the roundtable discussions in the future.
- Nagasaki Prefecture has made a clear division of roles between specialized medical facilities and clinics or other local medical facilities. After determining a diagnosis or treatment plan, based on the condition of the patient or other affected party or the disease characteristics, there are cases in which ongoing treatment is provided by Nagasaki University Hospital or at one of the core collaborating hospitals, and cases where it is provided in the community by a primary care physician, as part of routine care.
- Long-standing collaborative relationships between Nagasaki University Hospital and other healthcare institutions in the prefecture provide a foundation for a medical network for intractable diseases across Nagasaki Prefecture.

Monitoring real-world circumstances surrounding access to diagnosis in the community

- In FY2023, Nagasaki Prefecture conducted an independent study on how long it took patients to undergo examination at Nagasaki University Hospital after their initial consultation. It found that for intractable neurological diseases, timing to referral to a specialized medical facility varied by condition. For example, among conditions like Parkinson's disease or amyotrophic lateral sclerosis (ALS), there were cases in which referrals took one year or more.
- The time required for patients and other people living with intractable and rare diseases to receive a diagnosis can result in physical and mental burdens and affect when they initiate treatment, yet the processes leading up to diagnosis are only well-understood for a limited number of communities. Referring to the findings from their study, Nagasaki Prefecture built shared recognition of the need to strengthen collaboration with clinics and other local healthcare institutions so that patients can be connected to specialized medical facilities early on.

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Delivering Healthcare in Remote Islands Through Initiatives Using a Mobile Clinic and Telemedicine (Goto City, Nagasaki Prefecture)

In general, people residing on remote islands and isolated regions face challenges in accessing medical facilities, and those who live with intractable and rare diseases face even greater difficulties in accessing specialized medical facilities. Together with the Nagasaki Prefectural Government and Nagasaki University, Goto City is advancing a joint initiative to ensure healthcare access despite limited medical resources through the use of remote medical services based on a local 5G network. In this column, we will introduce two of Goto City's initiatives: one using a mobile clinic with a "Doctor to Patient with Nurse" (D to P with N) format; and one using telemedicine through a "Doctor to Patient with Doctor" (D to P with D) format.

The Doctor to Patient with Nurse (D to P with N) Mobile Clinic

- In this initiative, nurses visit locations near the homes of patients and other affected parties in vehicles equipped with information and communications technology (ICT) equipment for online medical consultations. This program was launched as a joint project by Goto City and Nagasaki University using grants from the Cabinet Office's "Digital Garden City Nation" initiative. As of the end of July 2026, the mobile clinic had been dispatched 955 times and was in use by 99 patients and other affected parties residing in Goto City.
- The intended users of the mobile clinic are people who have difficulties traveling to and from healthcare institutions. Over 40% of Goto City residents are senior citizens. In some areas, this rate increases to over 60%. Some residents have voluntarily returned their driver's licenses, and some have lost access to buses due to reductions in services, making it difficult for them to even visit a hospital. Goto City previously had a medical dispatch system for providing on-site care at various locations. However, due to the deterioration of the facilities used to provide these services and a growing number of patients and other affected parties who have difficulties traveling to and from healthcare institutions becoming unable to visit them, some locations were discontinued at the end of March 2026.
- Equipment in the mobile clinic vehicle includes an electronic stethoscope and blood pressure monitor, with the intent that nurses can use this equipment to gather information equivalent to that obtained during in-person consultations. The vehicle is also equipped with a system for providing patients with online nutritional guidance from national registered dietitians.
- Patients can be referred to specialized medical facilities when it is determined that they will require specialized care based on examination results. There have even been examples in which online consultations detected signs of Parkinson's disease among patients and other people with difficulties visiting clinics due to their remote locations. After making arrangements with their family members living off the island, these patients were referred to an outpatient neurology clinic held in Goto City twice per month.

Doctor to Patient with Doctor (D to P with D) Telemedicine Services

- This system links local healthcare institutions and the university hospital and is for patients and other affected parties who can physically visit healthcare institutions. In one example of an examination using this system, a patient's joint exam findings are captured with a high-resolution camera and projected as a holographic image in a consultation room at the university hospital for a physician to review. Based on this review, the physician at the university hospital can give the primary care physician advice on follow-up observation methods and alterations to the treatment plan. If the findings showed that the patient required care at a specialized medical facility, they would be referred from the core hospital on the island to the university hospital off the island.
- Goto City has only one full-time specialist in rheumatology and connective tissue disorders, and the island has no other physicians in the same field available for them to consult. Despite these circumstances, local physicians are able to collaborate with specialists at the university hospital via ICT. This system relieves local physicians of the burden of making decisions alone.
- However, in its current stage, this initiative is being implemented as a pilot study. Specialists at the university hospital are participating as part of the study, and only the local healthcare institutions are eligible for medical service fees. One challenge for maintaining and expanding this system for collaboration will be addressing inadequate compensation for specialists providing remote guidance.

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Conclusion

In these recommendations, we closely examined each stage of healthcare delivery, from when patients and other people living with intractable and rare diseases first notice physical or mental discomfort to when they can receive ongoing healthcare in the community. While recognizing that structural limitations prevent the complete elimination of disparities in medical resources and expertise, these recommendations set a direction for vital next steps to guarantee that patients and those close to them are guided to the healthcare they need.

However, living with an intractable or rare disease also means facing a long period of ongoing care. To enable people to continue living in their communities, they must be provided with seamless support that is tailored to every life stage and that extends beyond healthcare to encompass welfare, employment, and education. Support systems have been developed to a certain degree, but they currently fall short in adequately reaching patients and other affected parties. While Japan is home to an estimated minimum of 1.1 million people living with designated intractable diseases,⁷⁾ actual use of disability welfare services provided in accordance with the Act on Providing Comprehensive Support for the Daily Life and Life in Society of Persons with Disabilities is limited. Among primary types of disabilities, people living with intractable diseases account for approximately 0.5% of service users⁷⁾. Therefore, in addition to developing support systems, further challenges lie in the fact that the mechanisms for appropriately delivering necessary support to patients and other affected parties are not fully effective.

The backdrop to this issue is that support for intractable and rare diseases is provided through a number of different systems in healthcare, welfare, employment, and education in an arrangement that lacks suitable linking mechanisms. As a result, people risk disruptions in support when transitioning between these systems, especially between pediatric and adult services. Rather than considering systems in healthcare, welfare, employment, and education in isolation, for intractable and rare disease measures, we must shift to policies that support patients and other affected parties throughout the life course.

When advancing these discussions, we must also keep in mind that the term “intractable disease” has developed as a policy concept unique to Japan. In the international community, these conditions are generally classified as “rare diseases.” It is essential that we create societal consensus on the criteria for recognizing diseases as “intractable.” In particular, we must give careful consideration to how we define the requirements for them to become “designated intractable diseases” and how we should take disease severity into account. Additionally, advances in medical technology will not only lead to an increase in the number of diseases diagnosed as intractable and rare, but they may also help us better understand their pathogenesis and pathophysiology and bring about new treatments and medications. Given the limited nature of resources, our discussions must also examine the scope of public support and how to ensure that support reaches the people who need it.

It is our sincere hope that these recommendations contribute to making society a place where patients and other people living with intractable and rare diseases can receive care with peace of mind throughout their lives, while living in a manner that is true to themselves.

7) MHLW. Welfare and Long-Term Care Statistics. 4. Usage of Disability Welfare Services, etc. Retrieved August 10, 2026, from https://www.mhlw.go.jp/stf/seisakunitsuite/bunya/hukushi_kaigo/shougaishahukushi/toukei/index.html.

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