Health and Global Policy Institute

Blood Disorders Project

Policy Recommendations in the Field of Blood Disorders

Building a Healthcare Ecosystem Centered on Patients and Those Affected

HGPI Health and Global Policy Institute

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1. Background and Purpose

1.1 A Turning Point in Blood Disorder Care: From "Curative Medicine" to "Medicine that Supports Living with Illness"

Blood disorder care is now at a historic turning point. Years of dedication by medical professionals and researchers, together with remarkable advances in molecular biology and immunology, have made long-term survival a reality for many blood disorders that were once considered to have poor prognosis.

The introduction of groundbreaking innovations, including tyrosine kinase inhibitors (TKIs) and other molecularly targeted agents, bispecific antibodies, and chimeric antigen receptor T-cell (CAR-T) therapy dramatically transformed the way blood disorder treatment is conducted. For example, patients with chronic myeloid leukemia (CML) can now "live a normal life while taking medication", and treatment-free remission (TFR) has emerged as a new treatment goal. Prognoses for multiple myeloma (MM) and some malignant lymphomas have also improved significantly due to the advent of new treatments. In particular, CAR-T cell therapy is being established as a curative treatment option for relapsed or refractory diffuse large B-cell lymphoma.

Advances in hematopoietic stem cell transplantation technology and supportive care have also been remarkable, and the number of long-term post-transplantation survivors continues to grow steadily. The increasing number of patients with acute leukemia who have undergone remission through intense chemotherapy and transplantation and have reintegrated into society is a definite and direct result of medical progress.

These outcomes have been achieved through the collaboration of many stakeholders: specialized medical institutions providing advanced care, academic societies and researchers promoting clinical research, and patient organizations providing support. Japan's blood disorder care maintains a world-class standard in treatment outcomes, and we can strive for further development on this foundation.

Today's achievements in improved treatment outcomes simultaneously bring new challenges and opportunities. As many blood disorders are changing their nature from "conditions that require intensive treatment in the acute stage" to "chronic conditions to be managed over the long term", the healthcare delivery system is also required to evolve in response to this change.

The traditional healthcare delivery system was designed around acute inpatient treatment and has achieved great success in "curative medicine". Now, building on that success, there is an expectation of further development towards "medicine that supports living with illness", supporting patients in co-existing with their disorder.

Now that long-term survival is possible, it is important to create a system that improves patients' quality of life (QOL), supports social participation, and enhances psychological and social support. This represents a qualitative shift in medical care and a great opportunity for blood disorder care to progress to its next stage.

1.2 The Current State of Blood Disorder Care as Revealed by Data

When considering the future direction of blood disorder care, it is important to accurately grasp the current situation based on data. Various statistics clearly show that blood disorders are an area that requires intensive investment of medical resources due to their disease characteristics.

Medical Resource Allocation

According to the Ministry of Health, Labour and Welfare's (MHLW) "National Medical Care Expenditures in FY2022", medical costs for blood disorders have reached a considerable scale.

- Medical treatment costs for leukemia (hospitalization): 173.6 billion yen (100.7 billion yen for men, 72.8 billion yen for women)
- Medical treatment costs for malignant lymphoma (hospitalization): 192.8 billion yen (106.0 billion yen for men, 86.8 billion yen for women)

In addition, according to a survey by the National Federation of Health Insurance Societies, the estimated average length of stay per hospitalization for leukemia is 44.54 days for men and 43.34 days for women, and the medical costs per hospitalization are approximately 4.7 million yen (men). These figures reflect that blood disorders require a high level of expertise and intensive supportive care (such as sterile room management, blood transfusion).

Dedicated Efforts at Specialized Medical Institutions

According to the MHLW's "Statistics on Physicians, Dentists, and Pharmacists, 2024", 97.5% of doctors in the field of hematology work in hospitals, and only 2.5% work in clinics. This shows the dedicated efforts of hematologists at the forefront of advanced medical care.
The centralized structure of specialized medical institutions has played a crucial role in providing high-quality care to patients requiring advanced treatment. At the same time, reducing the burden on specialists and building a more sustainable system are also important themes for the future.

1.3 Patient Challenges by Life Stage

Blood disorders occur across a wide range of age groups, from children to the elderly, and there are unique challenges specific to each life stage.

Pediatric and Adolescent (0-14 years)

Treatment during the developmental period affects physical growth, academic continuity, and psychosocial development. It is important to establish in-hospital schooling, support for returning to school, and long-term follow-up systems. In addition, the financial and psychological burden on families (especially parents) accompanying this age group is also significant.

AYA (Adolescent and Young Adult) Generation (15-39 years old)

Since disease onset occurs during important life events such as education, employment, romance, marriage, pregnancy, and childbirth, treatment has a particularly large impact on life

planning. Chemotherapy and hematopoietic stem cell transplantation can affect fertility (the ability to become pregnant), making information provision on fertility preservation before treatment and decision-making support critical. In addition to supporting the balance of treatment with work and study, supporting new employment after treatment is also a challenge. Therefore, it is necessary to develop a comprehensive support system for social reintegration, addressing post-transplant complications such as graft-versus-host disease (GVHD) and barriers to social insurance enrollment.

Middle-Aged (40-64 years old)

These patients are of working age, and balancing treatment with employment is a major challenge. Leave of absence and return-to-work support, promotion of workplace understanding, and reduction of economic burden are essential. In addition, as they are also the child-rearing generation, support that considers the impact on the family is also necessary.

Elderly (65 years of age and older)

Age-related challenges such as cognitive decline, multimorbidity, frailty, and decreased activities of daily living (ADL) affect treatment choices and daily life during therapy. It is important to evaluate the person's decision-making capacity, coordinate with family members and caregivers, and practice advance care planning (ACP).
Enhancement of medical professionals' education, information provision systems, and consultation support systems tailored to each life stage is required.

1.4 Structural Changes in Demand for 2040

An epidemiological study by Narimatsu et al. (2020) used data from the Kanagawa Cancer Registry and future population estimates to estimate the number of new cases of blood cancers (leukemia, malignant lymphoma, and multiple myeloma). The results project an approximately 38% increase (1970 cases → 2712 cases) in new cases of blood cancers in Kanagawa Prefecture from 2010 to 2040. Particularly for patients aged 65 and over, with an index value of 100 in 2010, projections for 2040 show leukemia at 169, malignant lymphoma at 167, and multiple myeloma at 169, all representing approximately 70% increases. Meanwhile, leukemia patients under age 40, who are candidates for myeloablative transplantation, are expected to decrease to 67% of 2010 levels by 2040, suggesting a structural change in patient demographics. The study confirmed that this trend is common nationwide and also confirmed similar trends in the three prefectures of Yamagata, Osaka, and Nagasaki, and predicted a faster increase rate in urban areas (Kanagawa and Osaka).
In addition, a long-term projection study by Nguyen et al. (2023) estimated the 5-year prevalence of patients across all 22 cancer types through 2050, demonstrating relatively high increase rates in the blood cancer field compared to other cancer types. From 2020 to 2050, the five-year prevalence among men is estimated to increase by 32.3% (65,400 → 86,500) for malignant lymphoma, 34.2% (22,400 → 30,100) for leukemia, and 35.2% (12,400 → 16,800) for multiple myeloma. In women, the increase in malignant lymphoma is particularly high at 71.6% (61,000 → 104,600). Notably, these increases significantly exceed the total cancer prevalence average increase rate (13.1%), thereby highlighting the growing demand for healthcare in the field of blood disorders compared to other cancer types.
Furthermore, as aging progresses, the need for care of blood disorders common among the elderly, such as myelodysplastic syndromes, is expected to increase in particular. In addition, improved survival rates due to advancements in treatment technologies are a structural factor driving further increases in the number of surviving patients and pushing up demand for long-term follow-up and supportive care. On the other hand, it has been pointed out that specific measures to address the 2040 challenge in blood disorders have not been sufficiently examined as concrete policies even at the prefectural level. Consideration of issues pertaining to all cancers is just beginning, and responses to challenges unique to blood cancers are still in development.

1.5 Developing a Sustainable Healthcare Delivery System

National Direction for the New Regional Healthcare Vision

In December 2024, the MHLW announced the "Summary of the Study Group on New Regional Healthcare Vision" indicating the direction for restructuring the healthcare delivery system with an eye toward 2040. Demand for acute care (surgeries and other procedures requiring significant medical resources) is expected to decline toward 2040, and as the decline in the occupancy rate of acute beds is expected to have an impact on the management of healthcare institutions, there is a need to build a system that provides acute care and emergency care while consolidating a certain number of cases and doctors.

This direction of centralization and reorganization of acute care beds is closely related to the healthcare delivery system for blood disorders. At the same time, it is necessary to maintain the functions of specialized medical institutions responsible for advanced treatments such as hematopoietic stem cell transplantation and CAR-T therapy, while simultaneously strengthening cooperation with local primary care doctors. Establishing a healthcare delivery system that simultaneously achieves both centralization and equalization in the blood disorder field has become an urgent issue.

National Direction on Cancer Care Delivery

As indicated in the previous section, the number of blood cancer patients is expected to increase significantly toward 2040. In light of this situation, the MHLW published the "Summary of Equalization and Centralization of the Cancer Care Delivery System for 2040" in August 2025. This report sets a direction for building a sustainable cancer care delivery system as the working-age population declines and the elderly population increases.

The report presented the basic idea of maintaining a high-quality care delivery system through 'centralization' for advanced medical technologies, while promoting 'equalization' for widely established medical practices. Particularly noteworthy is the statement that cancer prevention, supportive care and palliative care, and long-term follow-up of low-risk cancer survivors should be provided in as many clinics and hospitals as possible, along with the explicit recognition of the importance of the role of primary care doctors.

Directions of Centralization and Equalization in the Field of Blood Disorders

In the field of blood disorders, it will be possible to build a more convenient healthcare delivery system for patients by advancing centralization of advanced treatments (hematopoietic stem cell transplantation, CAR-T therapy, intensive chemotherapy, and other treatments) at specialized medical institutions, while enhancing regional delivery systems for areas requiring equalization (blood transfusion, prescription and management of oral anticancer medications, follow-up during stable periods, supportive care, and other areas).

For elderly patients in particular, access to specialized medical institutions is a significant burden. Cases have been reported of elderly patients with myelodysplastic syndromes who require regular blood transfusions driving themselves to distant hospitals every week. Establishing systems that allow patients to receive supportive care such as blood transfusions in their local area is an urgent issue. According to Nguyen et al. (2023), by 2050 patients aged 75-84 will be the largest age group among prevalent cancer patients, making it urgent to establish comprehensive care systems that consider the multimorbidity and frailty characteristic of elderly patients. To continue providing high-quality care while responding to this increase in demand, it is essential to improve the efficiency of healthcare delivery and clarify the division of roles.

Structural Challenges Associated with Promoting Centralization

Many structural challenges have been identified in promoting centralization. With the progress of doctors' work style reforms, reports suggest that it is becoming increasingly difficult to dispatch doctors from university hospitals to regional core hospitals. This has led to a situation where university hospitals are forced to absorb regional medical care while regional healthcare

institutions are becoming exhausted. It has also been observed that the vertical structure of hospital departments by medical specialty makes it difficult to flexibly increase the number of beds in the hematology department.
For example, when a policy was considered to consolidate facilities for total-body irradiation, which is essential for hematopoietic stem cell transplantation, it was pointed out that many transplantation-certified facilities would no longer be able to perform irradiation at their own hospitals, putting the continuation of transplantation medicine itself at risk. This led to a need for careful consideration. This shows that careful system design that reflects the realities on the ground is necessary to balance centralization and equalization.

In light of these challenges, there are significant opportunities for further development in blood disorder medicine. Below are three opportunities for building a sustainable system.

Establishment of a Regional Collaboration Model

In the solid tumor field, collaboration between specialized medical institutions and local healthcare institutions using the "Regional Collaboration Critical Pathway for Cancer" is advancing. Although there is no provision to exclude blood cancer in the national system, it has been pointed out that the development of the regional cooperation critical pathways for blood cancer currently lags behind the five major cancers in each prefecture.
This situation shows room for future development. Blood disorders have different characteristics from solid cancers, including long-term chemotherapy cycles and repeated cycles of remission and follow-up. Development of new collaborative models suited to these characteristics is expected, with discussions drawing on the knowledge of healthcare institutions and regions undertaking pioneering efforts.

Comprehensive Care Through Multidisciplinary Collaboration

In blood disorder care, a doctor-centered medical care system has been established, but expectations for team-based medicine that utilizes the expertise of pharmacists, nurses, clinical laboratory technicians, medical social workers (MSWs), and others are increasing.
There are a wide range of areas in which multidisciplinary collaboration can provide more fulfilling patient support, including medication management for molecularly targeted agents, side effect monitoring, psychological support, and social reintegration support. The development of a system that allows each specialist to maximize their abilities will contribute to reducing the burden on doctors, while also providing an opportunity for patients to receive more comprehensive care.

Development of Home-based and Community Healthcare

Advanced initiatives are emerging in various regions throughout the country in home-based and community healthcare. Efforts are being made to expand patient options, such as the promotion of home-based blood transfusions by the NPO Hemato-Homecare Network and the establishment of specialized clinics specializing in blood disorders.
A survey targeting patients with blood disorders conducted by Adachi et al. (2014) demonstrated that more than 90% of patients want to see a hematologist, they also want to reduce their physical burden (84%), secure time for themselves (79%), and reduce their family burden (73%). Creating a system that balances "ensuring specialist expertise" and "improving access" is the key to meeting the needs of patients.

1.6 History of This Project and Purpose of These Policy Recommendations

Phase 1 (FY2024) Outcomes

In FY2024, Health and Global Policy Institute (HGPI) conducted Phase 1 of the Blood Disorders Control Promotion Project, through which multi-stakeholder discussions across industry, academia, and civil society were conducted to organize the current situation and challenges of blood disorder countermeasures.
Experts from various backgrounds, including hematologists, home-visiting physicians, pharmacists, and patient organization representatives, were represented in the advisory board and

engaged in constructive discussions. The results were compiled as "Discussion Paper: Current Challenges and Prospects in Promoting Control of Blood Disorders", organizing future directions from the following four perspectives:

1. Structural Issues in the Healthcare Delivery System
2. Issues in Community Transition and Healthcare Coordination
3. Structural Barriers to Delivering Patient-centered Care and Enhancing Quality of Life
4. Issues in R&D and Institutional Support

Phase 2 (FY2025) Challenges

In Phase 2 of FY2025, specific policy recommendations based on the understanding of challenges organized in Phase 1 have been formulated. Moreover, additional interviews were conducted to carefully gather perspectives from the field, and effective recommendations have been developed based on the knowledge of healthcare institutions and organizations that are undertaking advanced initiatives.
These policy recommendations summarize the results of these discussions and present a concrete path for the further development of blood disorder care.

Purpose of these Policy Recommendations

These policy recommendations were developed with the following objectives:

- To present concrete policy recommendations for the promotion of blood disorder countermeasures
- To indicate a direction for building a healthcare ecosystem that supports patients and those affected to "live on their own terms"
- To clarify the necessary actions that relevant stakeholders (including governments, healthcare providers, patient organizations) should undertake together

We hope that these policy recommendations will serve as an opportunity for constructive discussions toward the advancement of blood disorder care and contribute to the realization of a sustainable healthcare ecosystem centered on patients and those affected.

Definition of Key Terms

The following terms are defined and used throughout this document as specified below.

- **Specialized medical institutions**
  Healthcare institutions where hematologists are full-time at university hospitals, cancer treatment collaboration base hospitals, and other similar institutions, and provide advanced medical care such as hematopoietic stem cell transplantation and CAR-T therapy.
- **Local healthcare institutions**
  Healthcare institutions that provide continuous care in the patient's living area, such as hematology clinics, general internal medicine clinics, and home-based care support clinics.
- **Related academic societies**
  Societies related to the field of hematology, such as the Japanese Society of Hematology, Japanese Society for Transplantation and Cellular Therapy, The Japan Society of Transfusion Medicine and Cell Therapy, The Japanese Society of Pediatric Hematology/Oncology, The Japanese Society of Lymphoma Research, Japanese Society of Medical Oncology, and the Japanese Society of Pharmaceutical Oncology.
- **Community Hematologist (CH)**
  A doctor who is responsible for the ongoing follow-up of patients with blood disorders in a local healthcare institution. This includes doctors who are qualified as hematologists or engaged in the treatment of blood disorders in cooperation with specialized medical institutions.

2. Policy Recommendations in the Field of Blood Disorders

Pillars	Recommendations
Pillar 1 Building a Multi-Layered Medical Collaboration System	**Recommendation 1-1** Clarify the division of roles between highly specialized care and ongoing follow-up care, and develop an optimal healthcare delivery system tailored to each patient's condition.
	Recommendation 1-2 Build a system that allows patients to continue treatment with peace of mind through collaboration between specialized medical institutions and local healthcare institutions.
	Recommendation 1-3 Promote home-based blood transfusions and home-based chemotherapy to create an environment where patients can receive care with peace of mind within their own communities.
	Recommendation 1-4 Build a system for comprehensive patient support by promoting multidisciplinary team-based medicine that leverages diverse professional expertise and by strengthening coordination functions.
Pillar 2 Patient-Centered Medical Communication and Support	**Recommendation 2-1** Establish a decision-making support environment so that patients can make informed treatment choices based on sufficient information.
	Recommendation 2-2 Strengthen consultation support systems and promote peer support to reduce patients' psychological and social burden.
Pillar 3 Healthcare DX and Information Sharing	**Recommendation 3-1** Establish a system that allows for efficient sharing of clinical information between specialized medical institutions and local healthcare institutions.
	Recommendation 3-2 Establish a system that enables patients to track and understand their treatment progress and engage in two-way information sharing with their healthcare providers.
Pillar 4 Institutional Support and R&D	**Recommendation 4-1** Establish an institutional framework based on the characteristics of blood disorders to ensure a sustainable healthcare delivery system and equitable patient cost-sharing.
	Recommendation 4-2 Enhance international competitiveness in the field of hematology by strengthening clinical research and clinical trial infrastructure and building an innovation ecosystem.

Overview of Recommendations

Based on the challenges identified in Phase 1, the following four pillars and ten recommendations are presented for building a patient-centered healthcare delivery system in the field of blood disorders. These recommendations are interrelated and are expected to have a greater impact if promoted in an integrated manner. In particular, Pillar 1, "Building a Multi-Layered Medical Collaboration System," forms the foundation for the other three pillars, and is expected to be a priority area. The structure is one in which the collaborative system (Pillar 1) is supported by patient-centered communication (Pillar 2) and healthcare DX (Pillar 3), while institutional support (Pillar 4) ensures the sustainability of these elements and underpins the entire system.
In addition, each recommendation is structured to analyze the current situation and challenges, the specific content of the recommendations, and the expected actions and effects for each implementing entity, with the aim of effective policy implementation.
The field of hematology has been actively incorporating perspectives of patients and those affected and has been at the forefront of innovative efforts in Japanese healthcare. We hope these recommendations will contribute to building a sustainable ecosystem where all patients can achieve a high quality of both medical care and life.

*It should be noted that this document focuses on challenges unique to blood disorders, while also presenting specific implementation methods from the perspective of patients with blood disorders for broader healthcare issues, including cancer treatment (shared decision-making, peer support, healthcare DX).

Pillar 1

Building a Multi-Layered Medical Collaboration System

The healthcare delivery system in the field of hematology faces structural challenges such as the concentration of patients at specialized medical institutions and the underdeveloped state of cooperation with local healthcare institutions. According to the "Statistics on Physicians, Dentists, and Pharmacists, 2024" (MHLW, 2024), 97.5% of doctors specialized in hematology work in hospitals, while only 2.5% work in clinics. Compared to the same survey in 2022, although the proportion of clinics has shown a slight increase, compared to other fields such as cardiology and gastroenterology, the proportion in hospital settings remains significantly high.
On the other hand, recent advances in treatment technology have led to the transition of many blood disorders that were once considered difficult to achieve remission into disorders that can be managed over the long term. This change is promoting a shift towards a comprehensive approach that supports patients in "living with their disease." This pillar sets out four recommendations for building a multi-layered medical collaboration system that simultaneously achieves centralization of advanced care and the equalization of continuous care.

Recommendation 1-1

Clarify the division of roles between highly specialized care and ongoing follow-up care, and develop an optimal healthcare delivery system tailored to each patient's condition

Current Situation and Challenges

Since blood disorder care requires high levels of specialization, most of it is concentrated at specialized medical institutions. Currently, the division of roles between advanced care and continuous follow-up is still in development, and many patients, including those in stable phases, are treated at specialized medical institutions.

The "Summary of Equalization and Centralization of the Cancer Care Delivery System for 2040" (MHLW, 2025) indicates the direction for restructuring the medical supply system toward 2040, when a sharp decline in the working-age population will overlap with a peak in the elderly population. In the field of blood disorders, it is expected that medical function differentiation will advance to organizing advanced care in which "centralization" is effective and continuous care where "equalization" is desirable.

Diseases such as CML and MM, in which patients continue long-term treatment while working and managing family life, are increasing. For these patients, access to continuous care in their own community is thought to contribute to improved QOL.

When promoting centralization, it is important to consider the economic and time burden of patients (so-called financial toxicity and time toxicity). According to Nishide et al. (2012), 47% of patients with blood cancer incurred round trip costs of 10,000 yen or more, and a report by Terada et al. (2017) found a decline in outpatient visit continuation rates among pediatric acute lymphoblastic leukemia patients after age 19. Among CML patients who tend to have prolonged treatment, cases of going to the hospital across prefectures by bullet train have been reported, and support is especially needed for the cost of accompaniment, transportation, and living expenses for caregivers of pediatric patients.

In addition, it is necessary to pay attention to the unique challenges of Japan's healthcare system when promoting centralization. Compared to academic healthcare institutions (such as university hospitals) in other countries, there is a shortage of medical staff, rigid allocation of beds within hospitals due to vertical departmental structures, difficulty of regional dispatch due to work-style reforms, and changes in the choice of doctors' medical department, all of which make it difficult to directly apply a European-style center model. It is necessary to advance centralization and equalization simultaneously.

It is also crucial to note that there are structural dilemmas in the allocation of medical resources. While individual doctors face the problem of overwork, working hour restrictions under work style reforms impose additional constraints. Clinics need to be managed, and university hospitals may lose medical reimbursements by dispatching doctors to the community. It has been pointed out that without formal efforts by the government to engage academia (such as academic societies), the appropriate allocation of medical resources will not progress.

Beyond these issues, the need for a model in which specialized cancer clinics in the community serve as a mediator between hospitals and home-based care has also been highlighted. As hospitals undergo structural reorganization and reformation, there is a structural challenge that about 98% of hematology specialists work in hospitals. Therefore, it is crucial to act promptly in preparing alternative care settings when hospital functions are reduced.

Recommendations

1-1-1. Organize advanced care where the centralization of hematopoietic stem cell transplantation and CAR-T therapy is effective, and advance functional centralization at specialized medical institutions

The following advanced treatments are expected to benefit from centralization at specialized medical institutions in terms of improving medical quality and safety. The specific target medical procedures should ideally be organized through expert review by academic societies.

- Hematopoietic stem cell transplantation (allogeneic and autologous), CAR-T therapy
- Intensive chemotherapy in the acute phase (such as induction therapy, consolidation therapy)
- Expert panel for hematological malignancy gene panel testing
- Management of severe cases with complex complications

1-1-2. Organize continuous care where equalization is desirable, such as follow-up during stable periods and long-term prescription management of oral anticancer medications, and establish a regional delivery system

The following type of medical care is expected to reduce the burden of outpatient visits and improve patient QOL by establishing delivery systems at regional healthcare institutions. Specific target treatments should ideally be organized through expert review by academic societies.

- Follow-up during the stable period (regular blood tests, disease assessment)
- Long-term prescription management of oral anticancer medications such as TKIs
- Supportive care (blood transfusion, infection prevention and treatment, nutritional management)
- Long-term follow-up after transplantation (management of late complications)

1-1-3. Examine disease-specific, stage-specific division-of-roles models, and clarify the timing of regional transition

Examining disease-specific, stage-specific division-of-roles models (such as acuteness, treatment intensity, follow-up period) is beneficial. For example, organizing benchmarks for timing of regional transition, such as 'after achieving deep molecular remission' for CML, and 'during the follow-up period after achieving complete remission' for malignant lymphoma, is expected to promote smooth collaboration.

1-1-4. Establish a system for accepting post-treatment follow-up patients throughout the community

It has been pointed out that there is a need for initiatives to address the situation in which patients requiring post-treatment follow-up are sometimes turned away by local healthcare institutions solely due to a history of blood disorders. It is expected that a system will be created to support follow-up patients locally by promoting a deeper level of understanding of blood disorders among general physicians and family doctors and by applying the collaborative guidelines for surgical cancers. In addition, it is necessary to deal with the financial toxicity (transportation and accommodation costs) and time toxicity associated with centralization. In particular, supporting the expenses for caregivers of pediatric patients including accompaniment costs, transportation costs, and living expenses, should be considered.

Expected Actions and Effects (by implementing entity)

Implementing Entity	Expected Actions	Expected Effects
National Government (MHLW)	Presenting the basic concept of role division, promoting functional differentiation in the medical service fee system (Recommendations 1-1-1, 1-1-2). Examining support measures for financial and time toxicity associated with centralization (Recommendation 1-1-4).	Efficient allocation of medical resources and improved patient access
Related Academic Societies	Arrangement of advanced medical care for effective intensification (Recommendation 1-1-1). Arrangement of continuous care where equalization is desirable (Recommendation 1-1-2). Examining disease-specific/stage-specific division-of-roles models, and clarifying the guidelines for regional transition (Recommendation 1-1-3).	Dissemination of standard division-of-roles models and promotion of evidence-based regional transitions
Prefectural Governments	Organizing institutional roles of healthcare institutions according to local conditions, reflecting in medical plans and other administrative plans (Recommendations 1-1-1, 1-1-2). Promoting the development of a regional acceptance system for follow-up patients (Recommendation 1-1-4).	Development of seamless healthcare delivery systems in the region
Specialized Medical Institutions	Promoting collaboration with local healthcare institutions and providing educational support (Recommendations 1-1-2, 1-1-4). Providing information on the timing of regional transitions (Recommendation 1-1-3).	Improved ability to respond to new and acute-phase patients, and smooth regional transition for follow-up patients

Recommendation 1-2

Build a system that allows patients to continue treatment with peace of mind through collaboration between specialized medical institutions and local healthcare institutions

Current Situation and Challenges

The Regional Collaboration Critical Pathway in cancer care is being developed mainly for the five major cancers (stomach, colorectal, lung, liver, and breast cancer), with all prefectures having established pathways for these five cancers. Blood cancers are not excluded in the national system, but in practice they are slower to develop than the five major cancers. In recent years, pioneering initiatives have begun in some regions, such as the Kanagawa Prefectural Cancer Center (a regional collaborative care plan for G-CSF subcutaneous injection in malignant lymphoma) and the Osaka International Cancer Center (a demonstration project for blood cancer collaboration using regional healthcare DX), but they have not yet spread nationwide.

Underlying this is the complexity of the disease course peculiar to blood disorders. While solid tumors often follow a relatively linear course, blood disorders often have a diverse and non-linear course, including prolonged chemotherapy, repeated cycles of remission and follow-up, and long-term follow-up after transplantation. These disease characteristics are factors that are difficult to address within the existing regional collaboration framework for critical pathways.

In addition, the number of hematology specialists is small compared to other internal medicine subspecialties (such as cardiology, gastroenterology), and regional disparities are also pronounced. Based on specialist search data from the Japanese Society of Hematology and population estimates from the Statistics Bureau of the Ministry of Internal Affairs and Communications (as of October 1, 2023), the national average number of hematology specialists working in hospitals per 100,000 population is 2.34. However, there is a gap of approximately 4.7 times between Kyoto Prefecture (5.17), which is the highest, and Aomori Prefecture (1.10), which is the lowest. According to the "Statistics on Physicians, Dentists, and Pharmacists, 2024" (MHLW, 2024), 97.5% of hematology specialists work in hospitals, while only 2.5% work in clinics. In other words, it is extremely rare for hematologists to practice in clinics in rural areas, and depending on the region, collaboration between the hematologist at a core hospital and home-visiting physicians and general practitioners may be the practical model.

This uneven distribution of doctors also affects access to advanced medical care, and there are also disparities in the per-population number of CAR-T therapy and allogeneic transplants between areas with many and few doctors. When building a collaborative system, it is essential to design flexibly based on the actual medical resources in each region.

In a questionnaire survey of patients with blood disorders by Adachi et al. (2014), 72% of patients cited "severing their relationship with their primary care doctor" as a concern about transitioning to community medical care. Many blood disorders have an uncertain prognosis, with repeated cycles of remission and relapse, and patients have continued treatment over a long period in a relationship of trust with their specialists. Against this background, many patients feel psychological anxiety when transitioning to a community medical institution. In addition, from the perspective of the burden of outpatient visits, in a study by Terada et al. (2017) investigating outpatient attendance in pediatric patients with acute lymphoblastic leukemia, self-interruption of outpatient visits was reported, suggesting that long-term commuting from distant places may be a barrier to the continuation of treatment. In order for patients to continue treatment with peace of mind, it is necessary to build a system that promotes cooperation with local healthcare institutions while maintaining relationships with specialists.

In promoting community collaboration, it is essential to build a system in which hospitals, local healthcare institutions, and patients and their families all benefit (WIN-WIN-WIN). For example, regarding the community transition of blood transfusions: hospitals have management advantages (optimization of bed occupancy rate, shorter outpatient waiting times); local healthcare institutions can get early intervention and opportunities to attract patients; and patients and families can reduce the burden of hospital visits and caregiving. A survey by Kozai & Motomura (2025) of patients who transitioned to home blood transfusion reported that patients were worried about blood transfusions at home before the transition, but improvements in patient QOL were reported after the actual transition, indicating that home blood transfusion can be a beneficial option for patients when the appropriate system is in place. On the other hand, there are complex issues regarding the community transition of chemotherapy, such as the profitability of hospitals, maintaining the motivation of doctors, and the procurement of medication by local healthcare institutions, countermeasures against exposure, and securing backup beds. In promoting community collaboration, it is necessary to clarify the merits and challenges of each medical procedure for all three parties, and to design a system that does not put pressure on hospital management, allows local healthcare institutions to participate in a sustainable manner, and improves patient QOL.

In some regions, pioneering efforts for such collaboration have already begun. In some areas, a system has been established in which university hospitals and community hospitals closely exchange information through regular web conferences to share patient status and treatment plans, and in some areas, hematology clinics established in collaboration with large hospitals have achieved both a reduction in outpatient burden and the provision of specialized care. In addition, there are cases in which successful experience of community collaboration in other disease areas, for example, establishing a system for accepting patients at local healthcare institutions by disseminating accurate knowledge through on-site training, has been applied to these efforts, showing that the dissemination of knowledge and the promotion of understanding of blood disorders are key to the success or failure of equalization. Going forward, it will be necessary to build models that can be implemented in a wide range of regions with institutional support such as medical service fee adjustments, while referring to these good examples.

Recommendations

1-2-1. Establish a community-based "multi-attending physician system", in which a specialist in hematology at a specialized medical institution and a family doctor at a local medical institution both serve as co-attending physicians for the same patient, while also ensuring access to specialists through online consultations and other means

Establish a system in which the attending physician of a specialized medical institution and the family doctor of a local medical institution both serve as attending physicians. Having specialists handle advanced medical care and professional judgment, while family doctors handle day-to-day health management and QOL monitoring, enables collaboration that draws on the strengths of each.

In addition, as an operational model of "concurrent consultation" (a combination of regular hospital outpatient visits and home medical care in between), a pattern combining specialist outpatient visits once every three months with management by a home-visiting physician in between has been reported as a practical example. Developing a medical service fee system that allows chemotherapy to be performed at community clinics is also expected. The following elements can be considered as specific components of the operational model:

- Continuing specialist follow-up through regular specialist outpatient visits (approximately 1 to 4 times per year)
- Routine medical care and prescriptions handled by the family doctor
- Clarification of emergency visit and hospitalization routes in case of changes in patient condition (backup system)
- Ensuring access to specialists through remote consultations and online medical consultations

As a concrete way of operating the multi-attending physician system, it is considered effective to use various types of online medical consultations. Current types include doctor-to-patient (D to P), "D to P with D" in which specialists participate online in the presence of family doctors, and teleconsultation between doctors (D to D), all of which have great potential for use in community collaboration for blood disorders. For example, in the "D to P with D" scheme, the three parties can share treatment plans at the same time by having the specialist participate online while the patient sees the family doctor. In addition, a form where patients undergo testing at a community medical institution while receiving online medical treatment from a specialist, and a system in which family doctors can immediately receive advice on professional matters through online case consultations between doctors, are also effective. Flexible use according to the patient's condition and local circumstances is expected.

In order to improve the efficiency of the collaboration process, digital tools such as doctor to doctor collaboration platforms that allow doctors to directly indicate their availability to accept patients to each other are also being developed. These are expected to improve the efficiency of the conventional referral process through the regional coordination office, and will be described in detail in Recommendation 3-1.

1-2-2. Develop comprehensive guidelines for regional transition and follow-up guides for each disease and disease stage, and build a collaborative foundation that allows patients to transition with peace of mind

Organize guidelines for regional transition for each disease and stage so that both patients and medical professionals can share the prospects for transition. Specifically, it is desirable to develop the following collaborative infrastructure in an integrated manner.

- Formulation and operation of disease-specific follow-up guides
- Collection and dissemination of information on community hematologists
- Disclosure of information on healthcare institutions that can be collaborated with (such as treatable disorders,

testing system)
- Formulation of standard formats for collaborative care pathways
- Establishment of response procedures in the event of adverse events (such as criteria for contacting specialized medical institutions, criteria for determining emergency visits)

Disorders and stages that may be prioritized for regional transition include: CML (patients in stable phase on TKIs), malignant lymphoma (patients in the follow-up period after complete remission), post-hematopoietic stem cell transplantation (patients in the long-term follow-up period), and myelodysplastic syndrome (MDS)/myeloproliferative neoplasms (MPN) in the elderly (patients mainly on supportive care). In order to verify the effectiveness of such a collaborative foundation, conducting pilot projects that select model areas is also considered beneficial.

When transitioning to the community, it is crucial to carefully explain to patients that the relationship with their specialist will continue, providing them with a sense of security. It is expected that psychological anxiety will be reduced through face-to-face meetings before the transition (tripartite meetings with the specialist, family doctor, and patient) and regular follow-up at specialist outpatient clinics after the transition.

The development of multidisciplinary human resources who will be responsible for community collaboration will be described in detail in Recommendation 1-4.

Expected Actions and Effects (by implementing entity)

Implementing Entity	Expected Actions	Expected Effects
National Government (MHLW)	Examining medical service fee evaluations for effective collaborative models (Recommendation 1-2-1). Collecting and disseminating good practices (Recommendation 1-2-2).	Creation of incentives to promote collaboration and effective nationwide dissemination
Related Academic Societies	Examining operational guidelines for collaborative models (Recommendation 1-2-1). Formulating disease-specific follow-up guides and organizing guidelines for regional transitions (Recommendation 1-2-2).	Dissemination of standard collaborative frameworks and establishment of evidence-based collaborative models
Prefectural Medical Association	Coordinating regional collaborative systems (Recommendation 1-2-1). Collecting and disseminating information on Community Hematologists (Recommendation 1-2-2). Piloting collaborative systems in model areas (Recommendation 1-2-2).	Development of collaborative networks in the region and the development of practical knowledge
Specialized Medical Institutions	Promoting collaboration and providing educational support for local healthcare institutions (Recommendation 1-2-1). Practicing collaboration using online medical consultations (Recommendation 1-2-1). Explaining and providing psychological support to patients during community transition (Recommendation 1-2-2).	Improved peace of mind for patients and smooth transition
Industry	Supporting the development of collaborative tools (See Recommendation 1-2-1 → Recommendation 3-1). Disease awareness activities.	Development of a sustainable collaboration system

Recommendation 1-3

Promote home-based blood transfusions and home-based chemotherapy to create an environment where patients can receive care with peace of mind within their own communities

Current Situation and Challenges

Home blood transfusions can not only improve patients' quality of life but also contribute to reducing healthcare costs. According to some estimates, compared to inpatient blood transfusion, home blood transfusion could lead to a reduction of more than 30,000 yen in medical costs. Although medical costs increase compared to outpatient blood transfusions, considering the reduction in waiting times and reduced leave from work for patients and families, overall social costs may also be reduced. In this way, home blood transfusion is expected to simultaneously improve patient QOL and achieve medical economic rationality.

A survey of patients with blood disorders by Adachi et al. (2014) found that the top expectations for home medical care were "reducing physical burden" (84%) and "securing time for oneself" (79%). The desire to continue home blood transfusions is high, at 53.5% for red blood cells and 53.9% for platelets. On the other hand, concerns about home medical care included "response to emergencies" (76%) and "separation from the attending doctor" (72%), thus indicating that ensuring safety and a sense of security regarding collaboration are challenges. There is a need to establish systems that can provide safe, high-quality home medical care while meeting patient needs.

Regarding home blood transfusions, efforts by individual doctors and healthcare institutions are increasing in various regions, and awareness that blood transfusions can be administered at home is increasing. However, there are several structural barriers to wider adoption. On the hospital side, the perception that blood transfusions are performed in inpatient or outpatient settings is deeply ingrained, and many cases do not progress to referrals to home care institutions. On the home care side, in addition to the psychological barrier of risks such as anaphylactic shock, there are operational constraints such as red blood cell transfusions requiring approximately 2 hours while the reimbursable time per home-visit nursing session is limited to 60 minutes, and the complexity of procuring and managing blood products, resulting in limited numbers of healthcare institutions able to perform them. Reimbursement in the fee schedule is also not considered sufficient, and insufficient economic incentives for taking on home blood transfusions are also pointed out.

In promoting home blood transfusions, it is also necessary to pay attention to the ethical challenge of making appropriate judgments about continuing transfusions. There is currently no consensus on how to balance maintaining QOL with avoiding overtreatment in cases where transfusions become less effective as the disease progresses, and further consideration by specialists is required.

Regarding other home-based drug administration, there are also institutional challenges in expanding indications for existing medications. For example, self-injection of granulocyte colony-stimulating factor (G-CSF) preparations at home is not permitted in Japan, lagging behind other countries. When it comes to new medications, companies can drive approval applications themselves, but for expanding indications for existing medications, companies have limited incentives, and it is necessary to establish mechanisms to promote indication expansions that contribute to advancing home-based care.

Recommendations

1-3-1. Establish a home-based blood transfusion delivery system targeting patients with limited mobility and elderly patients

Establish a home blood transfusion delivery system targeting patients who have difficulty commuting, elderly patients with a high commuting burden, and similar cases. Standardize safe implementation procedures by referring to the "Guidelines for Home-based Red Blood Cell Transfusion" developed by The Japan Society of Transfusion Medicine and Cell Therapy and training videos on home blood transfusion procedures and implementation guidelines established by the NPO Hemato-Homecare Network.

For widespread adoption of home blood transfusions, a two-fold approach is needed: raising awareness on the hospital side and establishing implementation systems on the home care side. Disseminating research findings on the utility and safety of home blood transfusions is also important.

Through this system development, simultaneously achieving patient QOL improvement and medical economic rationality is expected.

1-3-2. Establish a home-based chemotherapy delivery system for subcutaneous injection preparations, oral anticancer medications, and similar medications

For medications that can be administered at home, such as subcutaneous injection preparations and oral anticancer medications, establish home-based chemotherapy delivery systems. It is desirable to organize eligibility criteria based on patient condition

and medication characteristics. Additionally, self-injection of G-CSF preparations, used to reduce chemotherapy-induced neutropenia, is currently not permitted in Japan, lagging behind other countries. Advancing institutional consideration toward legalizing G-CSF self-injection has the potential to simultaneously reduce outpatient visit frequency during chemotherapy, reduce burden on patients and families, and improve resource efficiency at healthcare institutions.

1-3-3. Develop training programs for home-based blood transfusion and home-based chemotherapy, and enhance the response capacity of local healthcare institutions

In order to increase the number of healthcare institutions providing home-based blood care, the following initiatives are beneficial.

- Developing training programs for home-based blood transfusion and home-based chemotherapy (including use of online materials and platforms, such as YouTube)
- Guidance and mentoring by healthcare institutions undertaking pioneering efforts
- Clarifying emergency backup systems (such as collaboration agreements with specialized medical institutions)

1-3-4. Examine appropriate medical service fee evaluations for home-based blood transfusion and home-based chemotherapy

Examine appropriate medical service fee evaluations for home blood transfusion and home-based chemotherapy. It has been pointed out that the current system has limited incentives for home-based blood disorder treatment, and it is expected that the number of implementing healthcare institutions will expand through appropriate evaluation.

Expected Actions and Effects (by implementing entity)

Implementing Entity	Expected Actions	Expected Effects
National Government (MHLW)	Examining medical service fee evaluations for home blood transfusion and home-based chemotherapy (Recommendation 1-3-4). Cooperation with home medical care promotion measures, and examining mechanisms to promote indication approvals for existing medications such as G-CSF home self-injection (Recommendation 1-3-2).	Creation of incentives for home-based blood care and expansion of patient choices
Related Academic Societies	Formulating safety standards for home-based blood transfusion and home-based chemotherapy (Recommendations 1-3-1, 1-3-2). Disseminating and updating the "Guidelines for Home Red Blood Cell Transfusion" (Recommendation 1-3-1). Disseminating research findings on the usefulness and safety of home blood transfusions (Recommendation 1-3-1). Developing training programs (Recommendation 1-3-3).	Widespread adoption of safe and high-quality home-based blood care, accumulation and standardization of evidence for home blood transfusion
Specialized Medical Institutions	Strengthening cooperation with local healthcare institutions, establishing an emergency backup system (Recommendation 1-3-3). Raising awareness within hospitals about the usefulness of home blood transfusions (Recommendation 1-3-1).	Realization of a safe home medical care environment
Others (NPO Hemato-Homecare Network, and others)	Disseminating standard protocols, education and awareness-raising activities using training videos (Recommendations 1-3-1, 1-3-3). Promoting guidance and mentoring by healthcare institutions engaged in advanced initiatives (Recommendation 1-3-3).	Sharing and horizontal expansion of practical knowledge

Recommendation 1-4

Build a system for comprehensive patient support by promoting multidisciplinary team-based medicine that leverages diverse professional expertise and by strengthening coordination functions

Current Situation and Challenges

The treatment and care of patients with blood disorders involves a wide range of needs, from diagnosis and treatment to long-term follow-up and social reintegration support. In order to provide such comprehensive care, it is essential to promote team medicine involving multidisciplinary collaboration, centered on doctors.

At specialized medical institutions, a system is being established in which nurses, pharmacists, clinical laboratory technicians, MSWs, registered dietitians, rehabilitation professionals, clinical psychologists, and other professionals work together to provide care. On the other hand, regarding hematopoietic cell transplant coordinators (HCTCs), while the number has increased from the first 13 certifications in Japan in 2013 to 174 as of 2023, they are not placed at all of the approximately 200 transplant-accredited facilities nationwide, and employment issues and work styles for HCTCs have also been cited as challenges (Kanemoto, 2023). In addition, roles and work content are left to the circumstances of each facility and the functions of each HCTC, and positions are not clearly defined (Okita, 2022). In other words, the current situation is that the placement of professional coordinator positions such as HCTC is insufficient, making it necessary to promote their training and placement. Furthermore, with the introduction of hematological malignancy gene panel testing, demand for certified genetic counselors responsible for genetic counseling is increasing. However, due to difficulty of task shifting from qualification requirements, securing human resources has not kept pace (see Recommendation 4-2).

Among the areas of multidisciplinary collaboration, developing a medication support system led by pharmacists is one noteworthy challenge. As treatment with molecularly targeted agents such as TKIs continues to be prolonged, maintaining medication adherence is key to treatment success. However, the information sharing system between the pharmacy departments of specialized medical institutions and community pharmacies is not sufficiently established. At specialized facilities with high in-hospital prescription rates, factors that hinder collaboration have been pointed out, such as the severance of relationships with family pharmacies including community partner pharmacies, the formalization of tracing reports, and the attitude among community pharmacies that cancer is handled at specialized facilities. It is necessary to strengthen collaboration between hospital pharmacists and community pharmacists and to build a system that supports patients' medication throughout the community.

In order to promote such multidisciplinary collaboration and coordination functions in a sustainable manner, appropriate medical service fee evaluation is essential. However, in the current situation, evaluation of multidisciplinary team medicine is limited, and since advanced medical coordination is difficult to link to revenue,healthcare institutions have to secure their own personnel. In addition, the involvement of community pharmacists in patients taking oral anticancer medications (such as TKIs used for CML) for a long period has not been fully evaluated in medical service fees, as tracing reports primarily target patients receiving treatment with injectable medications.

Recommendations

1-4-1. Establish a multidisciplinary collaboration system for nurses, pharmacists, MSWs, registered dietitians, rehabilitation professionals, clinical psychologists, and others

Establish a multidisciplinary collaboration system for nurses, pharmacists, MSWs, registered dietitians, rehabilitation professionals, clinical psychologists, and others, to evaluate and consult on patients' quality of life while compensating for doctors' time constraints. Specifically, promote the establishment of a collaborative system based on the following division of roles:

- **Nurses**
  Symptom management, patient education, transition support
- **Pharmacists**
  Medication guidance, side effect monitoring
- **MSWs**
  Medical expense consultation, social reintegration support, employment support
- **Registered dietitians**
  Nutritional management, dietary guidance
- **Rehabilitation professionals**
  Physical function maintenance and recovery support
- **Clinical psychologists**
  Psychological support

Mechanisms to support cooperation, such as regular conferences,

information sharing via electronic medical records, and the development of multidisciplinary manuals, will also be established.

1-4-2. Promote the training and placement of coordinator positions such as hematopoietic cell transplant coordinators (HCTCs), and strengthen the bridging function for advanced medical care

Promote the training and placement of coordinator positions such as HCTCs and cancer consultation support workers. Securing human resources who serve as bridges between patients and medical teams, as the hub of multidisciplinary collaboration, is essential. In addition to HCTCs, there is an urgent need to place and train specialists responsible for coordinating advanced medical care such as CAR-T therapy. The development of an adequate institutional foundation for the sustainable operation of coordinator positions is described in Recommendation 1-4-5.

1-4-3. Promote collaboration through a three-tier structure of hospital pharmacy departments, specialized medical institution-affiliated pharmacies, and family pharmacies, and build a system to support patients' long-term medication throughout the community

Build a three-tier collaborative system with: hospital pharmacy departments at the center; specialized medical institution-affiliated pharmacies that can respond to specialized pharmaceutical management for cancer, in coordination with related organizations; and family pharmacies including community partner pharmacies that can respond in an integrated and continuous manner in coordination with healthcare institutions at admission and discharge and with community pharmacies for home medical care. This distributes inventory risk for high-cost medications while ensuring patient convenience and enhancing continuity of medication support:

- **Hospital pharmacy departments**
  Treatment planning, provision of side effect information, pharmaceutical management for highly specialized treatments
- **Specialized medical institution-affiliated pharmacies**
  Education and support for community pharmacies, handling of complex cases, securing inventory of high-cost cancer specialist medications, hub function for distributing to family pharmacies
- **Family pharmacies** (including community partner pharmacies)
  Day-to-day medication management, pharmaceutical responses for underlying disorders, side effect monitoring

Information sharing mechanisms will also be developed through substantive use of tracing reports, use of electronic medication notebooks, and pre-collection of side effect information through patient apps.

1-4-4. Promote the development of multidisciplinary human resources responsible for community collaboration in blood disorders, and strengthen the bridging function between specialized medical institutions and local healthcare institutions

In order to promote community collaboration in blood disorders, it is important to develop human resources who serve as bridges between specialized medical institutions and local healthcare institutions. Opportunities will be provided for hematology specialists, as well as general internists, general practitioners, home-visiting doctors, nurses, pharmacists, MSWs, and other multidisciplinary professionals to learn about the characteristics of blood disorders, the key points of long-term follow-up, and how to collaborate with local healthcare institutions.

Specifically, it is expected that a community collaboration perspective will be incorporated into the curricula of medical education, nursing education, and pharmacy education, and that content related to community collaboration in lifelong education programs provided by academic societies and professional organizations will also be enriched. In addition, efforts such as creating opportunities for on-the-job education through dialogue with actual patients regarding drug therapy for blood disorders, and establishing consultation systems that connect specialists with community professionals, are also beneficial.

1-4-5. Enhance medical service fee evaluations for the sustainable operation of multidisciplinary team medicine, coordination functions, and collaboration between hospital and community pharmacists

In order to promote multidisciplinary collaboration and coordination functions in a sustainable manner, the enhancement of medical service fee evaluation is essential. In particular, enhanced evaluation is expected in the following three areas:

- **Multidisciplinary Team Medicine**
  Enhancement of evaluations for multidisciplinary

conferences, multidisciplinary comprehensive patient support.

- **Placement and Operation of Coordinator Positions**
  For advanced medical coordinator positions such as HCTCs and CAR-T therapy coordinators, the current situation in which such positions are difficult to link to revenue and healthcare institutions must secure their own personnel means that evaluation of medical service fees for placement and operation is required.
- **Information Sharing Between Hospital and Community Pharmacists**
  Substantiating tracing reports, enhancing additions to information sharing, and evaluating the involvement of community pharmacy pharmacists in patients taking oral anticancer medications for a long period.

Expected Actions and Effects (by implementing entity)

Implementing Entity	Expected Actions	Expected Effects
National Government (MHLW)	Examining medical service fee evaluations for team medicine, coordinator positions, and collaboration between hospital and community pharmacists (Recommendation 1-4-5).	Creation of incentives to promote multidisciplinary collaboration
Related Academic Societies	Presenting team medicine models and formulating multidisciplinary collaboration guides (Recommendation 1-4-1). Promoting HCTC training and certification and clarifying positions and roles of coordinator positions (Recommendation 1-4-2). Examining protocols for collaboration between hospital and community pharmacists and standardizing information sharing items (Recommendation 1-4-3). Incorporating community collaboration into lifelong education programs (Recommendation 1-4-4).	Dissemination of effective collaboration models, establishment of collaborative frameworks, securing of coordinator personnel, and development of a sustainable operational foundation
Specialized Medical Institutions	Establishing a multidisciplinary team structure and collaborative system (Recommendation 1-4-1). Assignment of coordinator positions (Recommendation 1-4-2). Strengthening cooperation with community pharmacies (Recommendation 1-4-3). Education and support for local healthcare institutions (Recommendation 1-4-4).	Comprehensive patient support
Japan Pharmacists Association and Japan Hospital Pharmacists Association	Supporting the establishment of a system for collaboration between hospital and community pharmacists (Recommendation 1-4-3). Participating in the development of multidisciplinary human resources (Recommendation 1-4-4).	Improved response capacity of community pharmacies
Educational Institutions and Professional Organizations	Incorporating community collaboration perspectives into medical, nursing, and pharmacy education curricula, and creating opportunities for on-the-job education (Recommendation 1-4-4).	Sustainable development of human resources responsible for community collaboration

Pillar 2

Patient-Centered Medical Communication and Support

Patients with blood disorders often face various psychological and social burdens, including prolonged treatment, anxiety about recurrence, and difficulties in reintegration. In this pillar, two recommendations are made on enhancing decision-making support and consultation support systems so that patients can choose treatment and learn to live with the illness after obtaining sufficient information.

Recommendation 2-1

Establish a decision-making support environment so that patients can make informed treatment choices based on sufficient information

Current Situation and Challenges

In the treatment of blood disorders, there are often multiple treatment options. It is expected that medical care be provided based on the concept of shared decision-making (SDM) so that patients can choose treatment based on their own values and wishes. The following structural issues exist in the practice of SDM.

First, there is an awareness gap between doctors and patients. The importance of dialogue about factors other than clinical indicators, such as patients' QOL, social background, and values, is not fully recognized. Research has made clear that there is a gap in priorities between patients and doctors. An international survey of CML patients by Lang et al. (2025) shows that while doctors thought the patient's top priority was "survival," patients in reality placed more emphasis on "quality of life." This misalignment of perception leads to insufficient provision of information that is truly important to patients. This points out that the essence of the cognitive gap between doctors and patients is not a problem of "ability to communicate" but that medical professionals do not have sufficient awareness of "what to communicate (the content of communication)." Addressing these structural challenges of perception is a prerequisite for the realization of SDM in the true sense.

Second, there is insufficient information provided that is required for treatment selection. For example, there are six types of TKIs for CML, but many patients are not fully informed about medication selection at the time of initial presentation. While doctors are considerate that too many options will confuse patients, some patients say, "I was simply told this was the drug, without any explanation." In addition, patient materials produced by pharmaceutical companies sometimes omit parts related to medication selection. There is also a lack of presentation of long-term prognostic data, such as the rate of achieving treatment discontinuation (TFR), and further enhancing the provision of information to help patients make decisions with an eye on treatment goals is expected. In particular, for patients with blood disorders in the AYA generation (15-39 years), the impact of treatment on fertility is an important issue directly related to future life planning. While it is important to be fully informed about fertility preservation options (sperm freezing, egg freezing, and other options) before starting treatment such as chemotherapy, radiation therapy, or hematopoietic stem cell transplantation, in some cases this information is not adequately provided at the time of initial presentation. Furthermore, fertility preservation carries an economic burden, and while some municipalities have subsidy systems, they are insufficient nationwide. There is also a lack of information on access to facilities where fertility preservation can be performed and coordination with treatment schedules, making it difficult for patients to make timely decisions.

Third, the support environment for implementing SDM is not in place. There is insufficient development and dissemination of support tools such as decision aid tools (Decision Aids) and plain language summaries (PLS) to help patients understand complex medical information and make decisions. Another issue is the development of a medical system that allows doctors to secure sufficient time for dialogue with patients. In the practice of SDM, it is important to have a thorough discussion about what the patient is aiming for and how far they can accept the treatment (financially and physically). For example, about 70% of CML patients are said to take medication for the rest of their lives, and the issue is how much medication to continue taking. Decision support based on patient values including the option to gradually reduce the amount and continue to take generic medication in

small doses is required.

Fourth, there is the challenge of decision support in the final stage of treatment. While blood disorders can be cured or long-term remission can be achieved when anticancer medications are effective, there are cases where the disease progresses rapidly. As the attending doctor devotes all efforts to treatment, the patient may not have time to spend quiet final moments with their family. In addition, if the patient wishes not to be a burden on their family, home care may conversely undermine the patient's wishes. The practice of advance care planning (ACP), which identifies patients' values and wishes early and provides medical care in line with them, is insufficient.

In order to address these issues and realize patient-centered medical care, it is necessary to create a multifaceted environment focused on developing the following: enhancing medical professional education, building a system for providing information from a neutral standpoint, developing decision support tools, establishing a system to systematically assess patient quality of life, and providing decision-making support in the final stage of life.

Recommendations

2-1-1. Develop comprehensive patient information materials for major blood disorders

Develop comprehensive information materials for major blood disorders that patients can refer to when making treatment choices. Specifically, these include:

- **Development and dissemination of decision support tools (Decision Aids) and plain language summaries (PLS)**
  Information such as the effects, side effects, and long-term prognosis of treatment is presented to patients in an easy-to-understand form. When there are multiple treatment options, it is essential to present the characteristics of each in a comparable and accessible manner.
- **Development of a medication selection guide for first-time patients**
  For first-time patients, explanatory materials including available drug options and their characteristics (efficacy, side effects, method of administration, TFR achievement rate, and other long-term prognostic data) will be developed. As patient materials produced by pharmaceutical companies sometimes omit parts related to medication selection, it is desirable for academic societies to promote the provision of comprehensive information from a neutral standpoint.
- **Visualization of long-term prognostic data**
  A system will be established to present data on long-term prognosis, such as TFR achievement rates, long-term survival rates, and incidence of late complications, to patients in an easy-to-understand format. Evidence-based information provision is imperative so that patients can approach treatment with a future outlook.

2-1-2. Use patient-reported outcomes (PROs) in clinical practice to better understand patient's conditions

Patient-reported outcomes (PROs) that evaluate patients' subjective symptoms and quality of life will be used in clinical practice. Specific ways to use them include:

- **Conducting regular QOL assessments**
  A comprehensive QOL assessment will be conducted about once a year to assess the patient's overall condition. According to Lang et al. (2025) and Hillis et al. (2023), "implementing tools" is cited as a concrete solution to bridge the gap in priorities between doctors and patients. For example, in Canada, simple written materials (3 to 5 questions) are distributed in clinic waiting rooms, and initiatives are being implemented to help patients navigate their individual situations.
- **Employment of ePRO (Electronic Patient-Reported Outcome)**
  A system will be built for patients to enter information about their side effects through an app and send it before consultations. By having pharmacists and nurses check it in advance and use it in pre-consultation interviews, it becomes possible to make suggestions to the doctor (such as "I have this symptom, so please consider this medication in my next prescription") and to serve as an alternative to phone follow-up.
- **Multidisciplinary collaboration through medical record sharing**
  By creating an environment where PRO data recorded at hospitals can be viewed at pharmacies and home-visit nursing stations, and sharing information with medical professionals, patient guidance and nursing quality can be improved. Regular collection and analysis of PROs allows for a more accurate understanding of the patient's condition and enables the provision of personalized care.

2-1-3. Create an environment for SDM practice and promote active patient participation

In order to practice SDM, it is essential to secure sufficient time for doctors and patients to communicate. It is desirable to create an environment for promoting SDM through medical service fee evaluation and the development of support systems by nurses, pharmacists, and others.

In addition, active patient participation will be promoted by providing support tools for patients to organize their concerns before consultations and distributing patient education materials in clinics and hospitals, so that patients can effectively communicate their situation and wishes during consultations. In particular, some patients feel that they should not speak up about side effects because they are receiving effective treatment (so-called "survivor guilt"). It is also important to promote patient education that makes clear that communicating QOL concerns and symptoms to the doctor is a legitimate right of patients, even when treatment is working.

2-1-4. Promote advance care planning (ACP) to provide care that aligns with patients' values and wishes

While blood disorders can be cured or have long-term remission when anticancer medications are effective, there are also cases where the disease progresses rapidly. As the attending doctor devotes all efforts to treatment, the patient may not have time to spend quiet final moments with their family.

In addition, if the patient wishes not to be a burden on their family, home care may conversely undermine the patient's wishes. It is important for a multidisciplinary team, including the attending doctor, to practice ACP from an early stage, confirm the patient's values and wishes, and provide medical care accordingly.

Early palliative care interventions and the introduction of ACP in patients with acute myeloid leukemia (AML) have been shown to lead to improved patient QOL (El-Jawahri et al., 2021). It has been reported that even when blood cancer patients spend their last days at home, QOL and end-of-life care comparable to other cancer types can be provided. Since transitioning to the community as a place to spend final days can be a WIN-WIN-WIN situation for all three parties (hospitals, communities, and patients), further promotion is expected.

2-1-5. Enhance information provision on fertility preservation and future life planning, and decision-making support for AYA generation patients

For patients with blood disorders of the AYA generation (15-39 years old), appropriate information will be provided before starting treatment on the side effects of treatment on fertility, fertility preservation options (sperm freezing, egg freezing, embryo freezing, and other options), facilities where these can be implemented, and financial support systems (such as municipal subsidy systems). A system for cooperation with obstetricians, gynecologists, and reproductive medicine specialists will be established, and a system allowing prompt referral to specialists when patients wish will be built. In addition, nationwide expansion of subsidy systems for fertility preservation and the collection and disclosure of information on implementing facilities will be promoted. Continuous consultation support regarding pregnancy and childbirth during and after treatment will be provided, and an environment will be created in which patients can approach treatment while planning for their future.

Expected Actions and Effects (by implementing entity)

Implementing Entity	Expected Actions	Expected Effects
National Government (MHLW)	Examining medical service fee evaluations for promoting SDM (Recommendation 2-1-3). Supporting the development of ePRO infrastructure (Recommendation 2-1-2). Cooperation with ACP promotion measures (Recommendation 2-1-4). Expanding nationwide subsidy systems for fertility preservation (Recommendation 2-1-5).	Promotion of SDM, PRO, and ACP use, and development of an institutional foundation to support future life planning for the AYA generation
Related Academic Societies	Developing comprehensive patient information materials and decision support tools for major disorders (Recommendation 2-1-1). Formulating medication selection guides for first-time patients (Recommendation 2-1-1). Examining guidelines for incorporating PROs into clinical practice (Recommendation 2-1-2). Organizing recommendations for ACP implementation (Recommendation 2-1-4).	Achievement of neutral and comprehensive information provision and dissemination of evidence-based SDM
Specialized Medical Institutions	Incorporating PROs into medical care and introducing ePRO systems (Recommendation 2-1-2). Developing a medical care system for SDM practice (Recommendation 2-1-3). Establishing an ACP implementation system with a multidisciplinary team (Recommendation 2-1-4). Providing information on fertility preservation to AYA generation patients and developing a system for collaboration with reproductive medicine specialists (Recommendation 2-1-5).	Accurate understanding of the patient's condition, promotion of personalized medicine, and improved patient satisfaction
Patient Organizations	Participating in patient education programs (Recommendation 2-1-3). Reflecting patient perspectives in PRO tool development (Recommendation 2-1-2). Collaborating with peer support for the AYA generation (Recommendation 2-1-5).	Promotion of patient empowerment
Pharmaceutical Companies	Supporting the preparation of information materials in collaboration with academic societies (Recommendation 2-1-1). Cooperating in the visualization of long-term prognostic data (Recommendation 2-1-1).	Provision of appropriate and neutral information to patients

Recommendation 2-2

Strengthen consultation support systems and promote peer support to reduce patients' psychological and social burden

Current Situation and Challenges

Patients with blood disorders often face various psychological and social burdens, including prolonged treatment, fear of recurrence, and difficulties in employment and finances. Cancer consultation support centers have been established at cancer treatment collaboration base hospitals and similar facilities, but their awareness and utilization rates are not considered sufficient.

In addition, the importance of "peer support" in which patients who have experienced the same disorder support each other is recognized, but organizational activities are still developing. As seen in the bone marrow bank movement, there is a history of collaboration between patients and medical professionals in the field of blood disorders, and it is expected that peer support will be promoted using this foundation. In recent years, the number of people who can take on the role of peer supporter has increased due to improved treatment outcomes and the expansion of treatment options beyond transplantation. At the same time, patients' treatment experiences and courses are diversifying, and the need for peer support that can understand and support those with different experiences is increasing.

On the other hand, while patient and public involvement (PPI) programs have been established at the academic level in other cancer fields (including breast cancer, gynecological cancer), in the field of hematology there are few examples of patient participation at the clinical trial stage, and the patient-public perspective is not adequately incorporated at the level of informed consent documents and guideline development. In particular, although long-term post-transplant follow-up and survivor support are areas where patient participation can be effective, there are few post-transplant patient associations at the national level, and there are not many opportunities for patients to participate in long-term follow-up research.

Furthermore, it has been pointed out that blood disorders, particularly rare complications such as GVHD, are not well known among the general public or in the media. This lack of awareness makes it difficult for patients to explain their disease and treatment course to the workplace and those around them, and in many cases, it is a barrier to social participation including employment. Although efforts are being made by pharmaceutical companies to raise awareness through press seminars for the media and dissemination of patient experiences, there are limits to establishing social recognition through individual efforts by individual stakeholders, given the rarity and difficulty of technical terminology. The implementation of systematic efforts on the policy side remains insufficient, and a public relations and awareness strategy coordinated by all relevant parties is required.

Recommendations

2-2-1. Enhance the capacity and awareness of cancer consultation support centers to address the unique needs of patients with blood disorders

In addition to raising awareness of cancer consultation support centers, the enhancement of functions that can respond to the unique needs of patients with blood disorders (such as long-term treatment, post-transplant care) will be promoted.

2-2-2. Enhance support for balancing treatment and work/social life so that patients with blood disorders can continue their work and social lives while continuing treatment

Support for balancing treatment with work and social life will be enhanced so that patients with blood disorders can continue their work and social lives while continuing treatment. Blood disorders have work-life balance challenges that differ from those associated with solid tumors. The cumulative impact of factors such as restrictions on attendance from the risk of infection during the neutropenic phase associated with chemotherapy, frequent hospitalization and frequent hospital visits for blood transfusions, chronic side effects (including fatigue, muscle spasms) associated with long-term use of oral anticancer medications such as TKIs, and work restrictions due to post-transplant GVHD and immunosuppressive conditions makes it difficult for patients to maintain stable employment, and repeated cycles of taking leave and returning to work are not uncommon. In addition, as mentioned in Section 1.3, in seeking new employment after treatment, sequelae such as GVHD and barriers to social insurance enrollment present ongoing challenges.

In order to respond to these challenges unique to blood disorders, it is beneficial to strengthen information linkage between occupational health doctors, attending doctors, and MSWs, raise employers' awareness of the characteristics of blood disorders (long-term treatment, risk of sudden changes, risk of infection, and other characteristics), and promote flexible work systems such as telework and staggered working hours. In addition, it is desirable to promote the use of the "Guidelines for Supporting the

Balance Between Medical Treatment and Working Life at Workplaces" (MHLW, 2024), as well as to gather and share specific cases of returning to work based on the characteristics of blood disorders.

2-2-3. Strengthen cooperation with patient organizations and promote the training of peer supporters and the securing of opportunities for their activities

Cooperation with patient organizations will be strengthened and peer support activities will be promoted. The training of peer supporters, securing opportunities for their activities, and building a system for coordination with healthcare institutions are beneficial.

The field of blood disorders has a history of collaboration between patients and medical professionals, such as the bone marrow bank movement. Promoting peer support and patient and public involvement (PPI) by building on these existing activities is expected to be well-received by academic societies and doctors. In addition, in order to support the ongoing activities of patient organizations, mechanisms for securing at least minimal activity funds (including transportation and accommodation costs) will be established, and support for drafting conflict of interest (COI) rules for patient organizations is also expected to be considered.

2-2-4. Provide continuous consultation support on fertility preservation and future life planning for AYA generation patients

During and after treatment, ongoing consultation support regarding pregnancy and childbirth will be provided. Information provision and psychological support on future family planning will be offered to both patients who underwent fertility preservation and those who did not. In addition, through peer support, a space will be provided where patients who have had similar experiences can exchange information and seek advice.

2-2-5. Promote patient and public involvement (PPI) in R&D and policy-making processes

Patient and public involvement (PPI) in research and development and policy-making processes will be promoted. Establishment of patient and public involvement programs at the level of the Japanese Society of Hematology and other academic societies, and patient participation in guideline revisions, are expected to lead to advancements in this field.

2-2-6. Promote awareness campaigns on blood disorders through collaboration among academic societies, patient organizations, companies, and government

To address the awareness challenges described above, a systematic awareness strategy on blood disorders will be promoted through collaboration among academic societies, patient organizations, pharmaceutical companies, and government agencies. Specifically, the following are beneficial: ongoing media press seminars, promoting understanding of disorders through the dissemination of patient experiences, joint production of easy-to-understand awareness content (such as videos, websites) on blood disorders, and examining social recognition campaigns, such as "Blood Cancer Awareness Month." In particular, for rare complications such as GVHD, development of awareness methods including approaches for conveying specialized terminology in an easy-to-understand manner (such as using plain language) is expected.

Expected Actions and Effects (by implementing entity)

Implementing Entity	Expected Actions	Expected Effects
National Government (MHLW)	Cooperation with work-life balance support measures (Recommendation 2-2-2). Examining support for the activity foundation of patient organizations (Recommendation 2-2-3).	Establishment of an institutional foundation supporting the balance of treatment and social life
Related Academic Societies	Establishing PPI promotion systems and patient participation in guideline revisions (Recommendation 2-2-5). Cooperating in awareness campaigns on blood disorders (Recommendation 2-2-6).	Advancement of medical care that reflects the patient perspective and increased social recognition of the disorders
Specialized Medical Institutions (cancer treatment collaboration base hospitals)	Strengthening the capabilities and raising awareness of cancer consultation support centers (Recommendation 2-2-1). Providing ongoing consultation support on fertility and future life planning for AYA generation patients (Recommendation 2-2-4).	Enhanced support systems that address the unique needs of patients with blood disorders
Patient Organizations	Promoting peer support activities and training peer supporters (Recommendation 2-2-3). Providing spaces for information exchange and consultation for the AYA generation (Recommendation 2-2-4). Actively participating in PPI (Recommendation 2-2-5). Working on COI rule formulation (Recommendation 2-2-3).	Reflection of the perspective of those affected, mutual support among patients, and sustainability of activities
Industry (pharmaceutical companies, and others)	Implementing disease awareness activities for the media (such as press seminars) and supporting the dissemination of patient experiences (Recommendation 2-2-6).	Increased social awareness of blood disorders and rare complications
Employers and Occupational Health Doctors	Establishing systems to support the balance of treatment and work tailored to the characteristics of blood disorders, promoting flexible work arrangements, and strengthening information linkage with attending doctors and MSWs (Recommendation 2-2-2)	Promotion of social participation for patients

Pillar 3 Healthcare DX and Information Sharing

In order to effectively advance cooperation between specialized medical institutions and local healthcare institutions, it is essential to properly share medical information. In addition, patients themselves understanding their treatment progress and realizing two-way information sharing with medical professionals also contributes to improving the quality of treatment and empowering patients. Currently, much information sharing relies on paper and fax, and there is significant room for improvement in efficiency through the use of digital technology. In this pillar, two recommendations are made on developing an information sharing platform among medical professionals and creating a mechanism for patient-centered information sharing.

Recommendation 3-1

Establish a system that allows for efficient sharing of clinical information between specialized medical institutions and local healthcare institutions

Current Situation and Challenges

Sharing medical information is essential for cooperation between specialized medical institutions and local healthcare institutions, but at present, paper- and fax-based information sharing is mainstream, and efficiency is a challenge. In addition, the content and format of information sharing are not standardized, and each medical institution operates separately and independently.

In the field of blood disorders, there is a structural background that makes this problem particularly serious. Most doctors who practice hematology work in hospitals, and only a few hematologists work in clinics. For this reason, information sharing between different electronic medical record systems is inevitably required both between specialized medical institutions and between specialized medical institutions and local healthcare institutions. Blood disorders are also characterized by a large amount of information that needs to be shared, such as long-term treatment courses, frequent test data, and multi-drug therapy.

The absence of an established mechanism for information sharing among doctors is one of the structural issues hindering the promotion of community collaboration. It has been pointed out that the lack of economic incentives for efficient information sharing means "the system is not designed to benefit from sharing information through IT." Matsumoto (2022) points out that insufficient medical service fee evaluation for the use of regional medical information collaboration networks is a barrier to dissemination, and the importance of institutional incentive design is also supported academically. In addition, it has been reported that information sharing is "person-dependent" in that it relies on human relationships, medical offices, and academic backgrounds, and there is a risk that the collaboration system will collapse due to the transfer or retirement of a specific person or institution. There is a need to shift from person-dependent collaboration to collaboration supported by institutional and technological foundations.

On the other hand, blood disorders have the characteristic which makes it possible to grasp the patient's condition almost entirely with blood test data, and the information to be shared (including blood test results, symptoms, medication history) is relatively clear. This characteristic is suitable for building an electronic information sharing platform, suggesting that blood disorders may become a model area for information sharing.

The burden of creating referral letters is also cited as an issue. In the short term, developing common templates for each disease is considered effective, and in the medium to long term, automatically generating medical information summaries using AI technologies such as large language models (LLMs) is considered effective.

In addition, in the field of home-based care, information sharing among multidisciplinary teams such as home-visit clinics, pharmacies, and home-visit nursing stations is also an issue. Currently, in addition to informal collaboration using social media, multidisciplinary collaboration communication tools have been introduced at the municipal and medical association level in some regions, but there are regional disparities in the adoption status at the level of individual healthcare institutions and offices, and a nationally standardized system has not yet been established. In medical procedures such as home-based blood transfusions, it has been pointed out that the use of remote monitoring may shorten

the time spent accompanying blood transfusions and reduce the burden on medical personnel.

Recommendations

3-1-1. Standardize the minimum common data set to be shared in blood disorder collaboration, and promote the disclosure of information on collaborative healthcare institutions

Standardize the minimum common data set to be shared in blood disorder collaboration (including disease name, treatment history, current treatment content, precautions). This is expected to improve the efficiency and quality of information sharing.

At the same time, it is desirable to promote the collection and dissemination of information on Community Hematologists and the disclosure of information on collaborative healthcare institutions (including treatable disorders, testing systems), and to "visualize" potential collaboration partners. The development of such an information foundation supports the construction of the community collaboration system described in Recommendation 1-2 from a technical perspective.

3-1-2. Ensure consistency with existing systems such as the National Cancer Registry and the Japanese Society of Hematology Blood Disease Case Registry, and promote data linkage

Ensure consistency with existing data collection systems, such as the National Cancer Registry, the Japanese Society of Hematology Blood Disease Case Registry, and the Japanese Society for Hematopoietic and Immune Cell Therapy, and reduce the burden of duplicate entry. In particular, hematological malignancy gene panel testing requires test application from the time of initial detection and long-term follow-up input, and the input burden is higher than that of solid tumors. Reducing this burden through DX is directly linked to the spread of panel testing (see Recommendation 4-2). Creating an environment where researchers can easily use cancer registry data will also contribute to the promotion of research in the field of blood disorders.

3-1-3. Establish an electronic medical information sharing platform and promote doctor to doctor (D to D) collaboration tools and information sharing among home care teams

Establish a platform for electronic sharing of medical information between specialized medical institutions and local healthcare institutions. Cooperation with the national medical information platform and the use of regional medical information collaboration networks are approaches worth considering and implementing.

The use of digital tools to support collaboration between doctors (D to D) is also effective. A system has been developed that allows doctors to directly indicate their availability to accept patients, which may improve the conventional referral process through the regional coordination center, making it more efficient. The use of these tools is expected to shift from person-dependent collaboration to collaboration supported by institutional and technological foundations.

In addition, information sharing between multidisciplinary teams (including home-visit clinics, pharmacies, home-visit nursing stations) in the field of home medical care will be standardized, and the use of remote monitoring in home blood transfusions and similar procedures will be promoted.

3-1-4. Reduce the burden of creating referral letters by developing common disease-specific templates and supporting the creation of medical information summaries using AI

In the short term, common templates for referral letters for each blood disorder disease (such as Word files) will be developed so that the minimum necessary information can be shared efficiently. In the medium to long term, it is expected that AI will be introduced for creating medical information summaries using LLMs to automatically extract and summarize necessary information from electronic medical records.

3-1-5. Examine medical service fee incentive design to promote the use of IT for information sharing

In order to promote the use of IT for information sharing, the design of medical service fee incentives will be examined. Currently, the lack of economic benefits for electronic information sharing is a barrier to its development and expansion, and it is necessary to design a system that rewards healthcare institutions that actively promote IT use.

Expected Actions and Effects (by implementing entity)

Implementing Entity	Expected Actions	Expected Effects
National Government (MHLW, Digital Agency)	Establishing a national medical information platform (Recommendation 3-1-3). Examining medical service fee evaluations (Recommendation 3-1-5). Improving the research and utilization environment for cancer registry data (Recommendation 3-1-2).	Establishment of an electronic information sharing platform and creation of incentives for IT use
Related Academic Societies	Standardizing shared items and developing templates (Recommendations 3-1-1, 3-1-4). Promoting the disclosure of information on healthcare institutions that can share information on and collaborate with Community Hematologists (Recommendation 3-1-1). Ensuring consistency of data linkage (Recommendation 3-1-2).	Improvement of the efficiency and quality of information sharing, and visualization of collaboration partners
Healthcare Institutions	Using the information sharing platform and establishing a collaborative system (Recommendation 3-1-3). Promoting information sharing among home care teams (Recommendation 3-1-3).	Realization of efficient medical collaboration
Industry	Developing and providing D to D collaboration tools (Recommendation 3-1-3). Developing AI summary generation tools (Recommendation 3-1-4). Developing remote monitoring technology (Recommendation 3-1-3).	Realization of a highly convenient collaboration environment

Recommendation 3-2

Establish a system that enables patients to track and understand their treatment progress and engage in two-way information sharing with their healthcare providers

Current Situation and Challenges

Being able to monitor treatment progress and share information between healthcare institutions as needed is imperative for both improving care quality and empowering patients. However, at present, the system for patients to systematically manage and share their treatment information is inadequate.

The current medical system focuses on one-way information provision from doctors to patients, and there are limited opportunities for information feedback and consultation from patients to doctors. With limited consultation time, there are few means for patients to properly convey subjective information such as daily physical changes and the extent of side effects, and doctors have no choice but to make treatment decisions with limited information. In recent years, some initiatives using patient-reported outcomes (PROs) and ePROs have begun, but they have not led to institutionalized support.

In addition, since the treatment of blood disorders requires a high level of expertise, it is not easy for patients to correctly understand their medical conditions and treatment content, and to make appropriate treatment choices and manage their own health. The internet and social media are flooded with a huge amount of information, and it has been pointed out that patients are exposed to uncertain information that amplifies their anxiety. There is a need to strengthen systems to ensure access to reliable information.

There are also several implementation barriers to the adoption of digital tools. In recent years, QOL evaluation tools and apps (with functions such as symptom recording, medication management, and blood data sharing) for patients with blood disorders have been developed and demonstrated, and have received a certain level of positive evaluation from patients. However, it has been pointed out that the biggest bottleneck is healthcare professionals,who do not have the time to check app information in their busy clinical practice. When introducing digital tools, it is essential to incorporate them into the existing workflows of medical professionals and to clarify their use scenarios in the treatment process. In addition, the digital literacy gap among elderly patients is also an issue for widespread adoption, and it is imperative to develop analog alternatives (such as paper questionnaires) that can be accessed by all patients, including the elderly, in parallel with the introduction of digital tools.

Recommendations

3-2-1. Establish a standard format for patient treatment summaries and progress records to support patients in managing their own information

A standard format for treatment summaries and progress records will be developed so that patients can understand their own treatment progress. Referring to the model of the collaborative notebook used in surgical cancers, it is useful to examine a format suitable for blood disorders. Considering linkage with existing tools such as electronic medication notebooks, an environment will also be created that makes it easy for patients to share their information among healthcare institutions. It is also desirable to establish a portal that allows patients to easily access reliable disease and treatment information.

3-2-2. Utilize digital tools such as ePRO to promote two-way information sharing between patients and healthcare providers

Digital tools such as medication management apps and ePROs will be used to support patients in managing their own health and providing information feedback to healthcare providers. Specifically, a system can be built for patients to enter side effect information through an app and send it before consultations, so that pharmacists and nurses can check it in advance and use it in pre-consultation interviews.

When using ePRO and digital tools, it is essential to create an environment where the content recorded at hospitals can be viewed at pharmacies and home-visit nursing stations. By developing a nationally unified format and accumulating digital records, retrospective analysis also becomes possible, which will also lead to improvements in patients' own health management quality.

In addition, it is also important to develop analog alternatives such as paper-based simple questionnaires in parallel for cases where digital tools are difficult to use, such as for elderly patients.

Expected Actions and Effects (by implementing entity)

Implementing Entity	Expected Actions	Expected Effects
National Government (MHLW)	Supporting the development of ePRO infrastructure (Recommendation 3-2-2). Promoting the development of a nationally unified format (Recommendation 3-2-2).	Establishment of an institutional foundation for two-way information sharing
Related Academic Societies	Formulating standard formats for patient treatment summaries (Recommendation 3-2-1). Developing and providing reliable disease information (Recommendation 3-2-1).	Promotion of patient information management
Patient Organizations	Promoting the use of tools from the patient's perspective, participating in patient education programs, reflecting patient perspectives in PRO tool development (Recommendation 3-2-2). Raising awareness of tool use (Recommendation 3-2-1).	Promotion of patient empowerment
Industry	Developing and providing digital tools such as ePRO apps and QOL evaluation tools (Recommendation 3-2-2).	Support of patient self-care and realization of two-way information linkage

Pillar 4

Institutional Support and R&D

The treatment of blood disorders can create financial burdens for both patients and the healthcare system due to characteristics such as prolonged hospitalization, expensive medication, and frequent blood transfusions. In order to make the collaborative systems and DX infrastructure indicated in Pillars 1 to 3 of this report effective, it is essential to develop the institutional foundation to support them. In addition, the field of hematology is located at the frontier of medicine, including regenerative medicine and genomic medicine. Strengthening the clinical research and trial infrastructure and building an innovation ecosystem can contribute to the development of medical care in Japan as a whole. In this pillar, two recommendations are made on developing institutions to ensure the sustainability of the healthcare delivery system and the fairness of patient burdens (Recommendation 4-1), and on strengthening the clinical research and trial infrastructure and building an innovation ecosystem (Recommendation 4-2).

Recommendation 4-1

Establish an institutional framework based on the characteristics of blood disorders to ensure a sustainable healthcare delivery system and equitable patient cost-sharing

Current Situation and Challenges

It has been pointed out that the current medical service fee and insurance system does not necessarily respond appropriately to the provision of medical care for blood disorders. This report proposes the establishment of specific collaborative systems in Pillar 1 (community collaboration and multidisciplinary collaboration), Pillar 2 (patient-centered communication), and Pillar 3 (healthcare DX and information sharing), and in order to achieve these goals, it is essential to design a system that is economically sustainable for each initiative.

Absence of economic incentive designs

The design of economic incentives through medical service fees greatly affects the healthcare delivery system. It is said that financial incentives were behind the spread of home medical care, and it has been pointed out that appropriate medical service fee evaluation is essential to expand blood disorder care in the community. Voices such as "principles alone will never lead to widespread adoption" and "the number of participants will not increase without economic incentives to make it financially viable" are common across all areas of community collaboration, multidisciplinary collaboration, and information sharing.

Crisis of management sustainability of advanced medical care

Regarding advanced medical care such as CAR-T cell therapy, it has been pointed out that there is a risk of a significant deficit in the event of serious adverse events under the DPC system, and in some cases hospital management is pressured to refrain from implementing it. Although the medical service fee system for autologous peripheral blood stem cell transplantation is applied by analogy to the medical service fee system for procedures related to CAR-T cell therapy, it has been pointed out that the costs of the medical provision system, such as the personnel and equipment necessary for implementation, are not covered by the current medical service fee. Specialized medical institutions responsible for advanced medical care are required to have a management-sustainable institutional design.

Regional differences in patient financial burden and institutional irrationality

There are also institutional challenges regarding the financial burden on patients. It has been pointed out that there are local rules in which the prescription period for the same disease varies by prefecture. It has been reported that the prescription period for CML treatment medications is only one month in some prefectures, while in other prefectures it is three months. This can result in a difference of up to approximately three times in the medical cost burden. A questionnaire survey conducted by CancerNet Japan in 2022 among CML patients (n=138) also indicated prefectural disparities in prescription periods from the patient's perspective, and correction of this problem is needed.

In addition, the increase in the copayment ceiling amount for the high-cost medical expense benefit system scheduled for August of 2026 will have a significant impact on patients with blood disorders who continue long-term treatment. It is also necessary to address structural issues in the system, such as the problem that the multiple-instance designation is reset when the insurer changes due to job change or retirement, and the reversal phenomenon in which payments increase due to the spread of generics that fall outside the scope of high-cost medical expenses.

Recommendations

4-1-1. Systematically develop medical service fee evaluations based on the characteristics of blood disorders, to support the establishment of collaborative systems such as community collaboration and multidisciplinary collaboration

In order to achieve the collaborative systems indicated in Pillars 1 to 3 of this report, it is essential to design a system that is economically sustainable for each initiative, and it is desirable that medical service fee evaluations be systematically developed in the following areas:

- **"Hematology Community Collaboration Guidance Fee (provisional name)"** (Pillar 1 related)
  Evaluation of cooperation between specialized medical institutions and local healthcare institutions (Recommendation 1-2)
- **"Home Blood Transfusion Service Fee (provisional name)"** (Pillar 1 related)
  Evaluation of home blood transfusion management (Recommendation 1-3) and oral anticancer medication management in the community (Recommendation 1-3)
- **"Long-term Blood Disorder Care Guidance and Service Fee (provisional name)"**(Pillar 1 related)
  Evaluation of multidisciplinary team medicine, placement and operation of coordinator positions, and information sharing between hospital and community pharmacists (Recommendation 1-4)
- **"Patient-Reported Outcome Utilization Premium (provisional name)"** (Pillar 2 related)
  Evaluation of long-term care support including PRO utilization and SDM practice (Recommendation 2-1)
- **"Medical Information Sharing Promotion Premium (provisional name)"** (Pillar 3 related)
  Incentive design to promote the use of IT for information sharing (Recommendation 3-1)

The specific design of medical service fees in each area is oriented in the recommendations for each pillar. Based on these recommendations, it is hoped that the National Government (MHLW and the Central Social Insurance Medical Council) will examine systematic medical service fee evaluations in accordance with the characteristics of blood disorders.

4-1-2. Develop a revenue structure in which healthcare institutions do not suffer losses from advanced medical care such as CAR-T therapy

A system design will be developed that does not cause losses to healthcare institutions responsible for advanced medical care such as CAR-T therapy. Specifically, the issues to be considered include reviewing the evaluation of advanced medical care in the DPC system, dealing with additional costs in the event of complications, and providing incentives to actively accept referrals from other hospitals.
In order to make the centralization of advanced medical care (Recommendation 1-1) effective, ensuring the management sustainability of the facilities responsible for centralization is essential.

4-1-3. Assess the actual situation of local rules regarding insurance coverage and promote nationwide uniform operation

Through review and payment organizations such as the Health Insurance Claims Review & Reimbursement Services and the Federation of National Health Insurance Associations, it is desirable to assess the actual situation of regional differences in medical service fees and insurance coverage (so-called local rules) and promote uniform operation based on scientific evidence. Specifically, it is desirable to conduct claims analysis and patient surveys. It is expected that standard monitoring tests for blood disorders will be operated uniformly nationwide. Promoting nationwide uniform operation through the use of online medical consultations is also considered an effective means of reducing the burden on patients.

4-1-4. Improve the operation of the high-cost medical expense benefit system to ensure stability and fairness in the financial burden of patients continuing long-term treatment

It is crucial to pay close attention to the impact of the increase in the copayment ceiling amount scheduled for August 2026 on patients with blood disorders continuing long-term treatment. The following structural issues in the system will need to be considered and addressed.

- Reset problem when changing jobs or retiring (multiple-instance designation is reset due to change of insurer)
- Reversal phenomenon due to the spread of generics (payments increase instead of being covered by high-cost medical expenses)
- Effectiveness of the annual maximum amount (the problem that it is set as high as 530,000 yen for the middle-income group)

It is desirable to create an environment where patients can continue long-term treatment with peace of mind.

4-1-5. Promote the rationalization of regulations in line with actual treatment conditions, expand outpatient treatment, and improve patient convenience

Rationalization of regulations in line with the actual treatment of blood disorders will be promoted. When a new treatment goal is created, such as treatment-free remission (TFR) in CML, it is beneficial to establish a system that quickly evaluates the monitoring tests needed to support it.

Another challenge is to remove institutional barriers to the expansion of outpatient care. For example, in the current situation outpatient treatment with central venous catheter placement is not permitted, and there is no reimbursement addition to the use of pumps in outpatient settings. These restrictions result in unnecessary hospitalization for continuously administered medications such as blinatumomab.

In some drug management areas, excessive regulation that is not based on risk-benefit assessment has been pointed out. Reviewing regulations based on scientific evidence is expected.

Expected Actions and Effects (by implementing entity)

Implementing Entity	Expected Actions	Expected Effects
National (MHLW, The Central Social Insurance Medical Council)	Systematic examination of medical service fees to support the collaborative system indicated in this document (Recommendation 4-1-1). Review of DPC evaluation of advanced medical care (Recommendation 4-1-2). Promotion of understanding the actual situation of local rules and optimization of operation (Recommendation 4-1-3). Examination of structural issues of the high-cost medical expense benefit system (Recommendation 4-1-4). Rationalization of regulations for the expansion of outpatient treatment (Recommendation 4-1-5).	Creation of incentives to promote collaboration, ensured institutional fairness, and sustainability of advanced medical care
Related Academic Societies	Presenting evidence necessary for the realization of each recommendation and submitting requests (Recommendations 4-1-1 to 4-1-5).	Science-based system design
Patient Organizations	Collecting and disseminating patient voices, cooperating in fact-finding surveys on the high-cost medical expense benefit system (Recommendations 4-1-3, 4-1-4).	Reflection of the perspective of those affected in policy
Health Insurance Claims Review & Reimbursement Services / Federation of National Health Insurance Associations	Optimization of review operations (Recommendation 4-1-3).	Development of nationwide uniform operation

Recommendation 4-2

Enhance international competitiveness in the field of hematology by strengthening clinical research and clinical trial infrastructure and building an innovation ecosystem

Current Situation and Challenges

The field of hematology is at the frontier of medicine, including regenerative medicine and genomic medicine, and innovative treatment and diagnostic technologies such as CAR-T cell therapy, hematological malignancy gene panel testing, and iPS cell therapy have emerged one after another. However, there are structural challenges at the layers of research and development infrastructure, data infrastructure, and regulatory and economic systems to deliver these innovations to patients, requiring comprehensive efforts to simultaneously ensure both research sustainability and equitable access to innovation.

Vulnerability of the research implementation system

The clinical research and clinical trial system in the field of hematology has challenges in terms of both human resources and institutional aspects. The shortage of research support personnel such as clinical research coordinators (CRCs), data managers, and biostatisticians is a chronic problem, and there is an urgent need to develop career paths that allow young researchers and clinicians to balance research and clinical practice.

In addition, it has been pointed out that the recent strengthening of conflict of interest (COI) regulations, promotion regulations, and advertising regulations has made it increasingly difficult to build long-term evidence through collaboration between multiple companies and doctors. A system is needed to promote clinical research through industry-academia collaboration while assuming appropriate COI management. For small pharmaceutical companies, there is also the issue that they do not have the resources (funds and human resources) to start development in Japan, and development cannot begin unless they are successfully matched with Japanese pharmaceutical companies.

The sustainability crisis of data infrastructure and registries

Serious issues have also been pointed out regarding the financial foundation of patient registries, which are essential for long-term follow-up of hematopoietic stem cell transplantation, CAR-T therapy, and similar treatments. Despite the fact that the government requires long-term follow-up of CAR-T therapy at implementing facilities, public funding for registry operations is extremely limited.

Although individual data such as the National Cancer Registry and society registries exist, it is difficult to connect and utilize them. The emotional factor of researchers not wanting to give up first-mover advantage and the complexity and cost of ethical procedures are barriers.

Drug lag, drug loss, and economic sustainability

The profitability of blood disorders is a challenge due to the dispersion of the number of disorders and the small number of patients. As the number of new medications increases and competition intensifies, it becomes commercially difficult to establish a viable business, making market entry challenging. In many cases, it is difficult for blood cancer drugs to expand their indications to cover solid tumors, and the narrow scope of application is a constraint on investment recovery.

There are concerns about the shift from "drug lag", the time lag in new drug approval, to "drug loss" where new medications are not introduced to the Japanese market at all, and it has been pointed out that 70% of regenerative medicine products have not been approved in Japan. The current situation where the manufacturing of regenerative medicine products such as CAR-T cell therapy is mainly dependent on other countries is also an issue from the perspectives of supply stability and international competitiveness.

In addition, it is worth noting that the current situation, where new drug development is led by Europe and the United States, and development and approval applications are judged by companies, makes it difficult to develop therapeutic medications for rare disorders when patients are concentrated in Japan.

The field of hematology is one of the pioneering areas where companion diagnostics and the simultaneous design of diagnosis and treatment are advancing, but there is a gap between the cost of developing, manufacturing, and operating tests and the insurance point value, which raises concerns about the sustainability of test provision.

Dissemination and operational challenges of hematological malignancy gene panel testing

Hematological malignancy gene panel testing (blood cancer panel test) is an important test that contributes to the advancement of personalized medicine. According to the documents submitted to the Central Social Insurance Medical Council at the time of HemeSight® approval (604th General Meeting, February 19, 2025), in tests conducted on patients with hematological malignancies, clinically useful genetic abnormalities with scientific evidence were confirmed in 74% of patients for diagnosis, 41% for prognosis prediction, and 12% for treatment selection. Overall,

clinically useful genetic abnormalities were detected in approximately 80% of patients, of which scientific evidence was confirmed in approximately 75% of patients. In addition, the turnaround time (TAT), the time required from receipt of the test to reporting the results, is also being shortened.

On the other hand, only about 150 facilities, approximately half, of the cancer genome core base hospitals and similar facilities have a track record of testing one year after insurance coverage. There are approximately 720 hematological malignancy treatment facilities that register at least one case of leukemia, malignant lymphoma, multiple myeloma, and other blood cancers in the in-hospital cancer registry (2023 data), but only 41% of them correspond to cancer genomic medicine, and only half of those have a track record of testing. As a result, only about one quarter of all facilities can provide testing. While awareness is high among hematologists at over 90%, the main factors hindering its spread are the operational system, such as strict facility requirements and the human resource burden associated with the operation of expert panels.

The structure of human resource shortages is particularly serious. There is a shortage of hematologists responsible for analyzing reports, certified genetic counselors handling genetic counseling that requires high qualifications, and clerical and co-medical personnel responsible for entering information before and after examinations. Public budget measures were taken to secure personnel to support the operation of solid cancer panel testing, which was introduced earlier, but similar measures were not taken for blood cancer panel testing, and healthcare institutions must secure their own personnel. In terms of medical service fees, the addition to the explanation of results is evaluated at the same level as the solid cancer panel, and in the field of hematological malignancies, there is a workload different from that of solid cancer, such as the application of testing from the initial presentation and continuing long-term follow-up data entry, but this difference is not reflected in the evaluation.

In terms of institutional aspects, specimen-only transfer from non-cancer-genomic-medicine-compliant hospitals to compliant hospitals is not permitted, and patients themselves must travel to compliant hospitals. For patients with acute blood disorders, travel may be difficult, and there are cases where testing opportunities are lost.

Furthermore, the cancer treatment collaboration base hospital system is designed primarily for the five major cancers. Even facilities with a high track record in blood cancer treatment may not receive base hospital designation if they have few solid cancer cases, resulting in a structural problem where they cannot receive genomic medicine facility designation. This issue was pointed out in multiple interviews.

In addition, ethical considerations specific to hematological malignancies are also a significant challenge. Issues different from solid cancers, such as the relationship between donor selection and germline mutations, exist, and the development of guidelines specific to hematological malignancies within the framework of the Genomic Medicine Promotion Act is required.

Recommendations

4-2-1. Develop research personnel such as clinical research coordinators (CRCs) and secure research support staff

In order to sustainably promote clinical research and clinical trials in the field of blood disorders, the following initiatives are required:

- Career path support for young researchers and clinicians (presenting models for balancing research and clinical practice)
- Promoting the training and placement of clinical research coordinators (CRCs)
- Securing research support staff (such as data managers, biostatisticians)

4-2-2. Promote early participation in international collaborative clinical trials and advance investigator-initiated trials, especially in the field of rare disorders

To resolve drug lag, Japan's participation in international collaborative clinical trials will be promoted from early stages (Phase I/II). In addition, ensuring appropriate infrastructure for late-stage (Phase III) clinical trials is also vital. For rare disorders such as AL amyloidosis and POEMS syndrome, promoting investigator-initiated trials and registry research is important. Streamlining clinical trials (considering introduction of single Institutional Review Board (IRB), simplification of documents, and promotion of decentralized clinical trials (DCTs)) will also be advanced simultaneously. Constructing systems to promote clinical research through industry-academia collaboration while assuming appropriate COI management, and strengthening matching functions to support the entry of small pharmaceutical companies into the Japanese market, are also issues worth considering.

4-2-3. Promote the usage of cancer registries for research, and strengthen the financial foundation of registries required for long-term follow-up

The research utilization of existing data collection systems, such as the National Cancer Registry, in-hospital cancer registries, the Japanese Society of Hematology Blood Disorder Case Registry, and the Japanese Society for Transplantation and Cellular Therapy registry, should be promoted. It is required to develop environments that enable the linked use of data and to rationalize ethical procedures.

For patient registries essential for long-term follow-up of hematopoietic stem cell transplantation and CAR-T therapy, expanding public funding is an urgent issue. Going forward, from the perspective of the development and reliability assurance of regenerative medicine as a whole, including iPS cell therapy, strengthening the financial foundation of registries is also crucial. Promoting patient and public involvement (PPI) in research and improving access to clinical trial information also contribute to enriching the data foundation (see Recommendation 2-2).

4-2-4. Address the drug loss problem, develop operational systems for hematological malignancy gene panel testing, and promote review of the base hospital system taking into account the characteristics of blood cancers

Regarding the way in which drug pricing systems appropriately evaluate innovation, international perspectives are required. In addition, reviewing the market expansion re-calculation rules taking into account the characteristics of regenerative medicine products is also an important issue. Furthermore, developing a pricing evaluation system that appropriately reflects the cost of test development, manufacturing, and operation is required.

For rare and intractable blood disorders with a high concentration of patients in Japan, considering strengthening the public framework that provides consistent support from the initial stage of research and development to approval and implementation is expected. In particular, for areas where it is difficult to commercialize privately led by the private sector due to the small number of patients and constraints on drug prices, strategic allocation of research funds, expansion of public-private partnership schemes, and the use of conditional early approval systems will be promoted.

Regarding hematological malignancy gene panel testing, the following institutional improvements are expected to promote its expansion.

- Public budget measures for securing staffing for panel testing
- Flexibility of facility requirements
- Review of specimen transfer systems (permitting specimen-only transfer from non-compliant hospitals)
- Review of medical service fee evaluations to reflect the workload differential from solid cancer panel testing
- Development of guidelines and enhancement of information provision systems for ethical issues specific to hematological malignancies (e.g., relationship between donor selection and germline mutations)

Regarding the cancer treatment collaboration base hospital system, a review of base designation criteria based on the medical performance of blood cancer treatment will be considered to ensure access to genomic medicine facilities.

4-2-5. Promote the development of domestic manufacturing bases for regenerative medicine products such as CAR-T cell therapy to ensure stable supply and international competitiveness

The development of domestic manufacturing bases will be promoted based on the following perspectives.

- **Ensuring stable supply for patients**
  reducing the risk of supply disruptions associated with dependence on overseas manufacturing
- **Reducing manufacturing costs**
  reducing international transportation costs, and streamlining and automating manufacturing processes
- **Strengthening international competitiveness**
  strengthening the competitiveness of the entire regenerative medicine industry through domestic development of contract development and manufacturing organizations (CDMOs)
- **Building a foundation for next-generation therapy**
  building an industrial base to support regenerative medicine as a whole with a vision for the practical application of iPS cell-derived cell therapy products

Development of domestic manufacturing bases using subsidies from the Ministry of Economy, Trade and Industry is underway, and acceleration is expected.

Expected Actions and Effects (by implementing entity)

Implementing Entity	Expected Actions	Expected Effects
National Government (MHLW, Ministry of Education, Culture, Sports, Science and Technology, Japan Agency for Medical Research and Development (AMED))	Supporting research funds and human resource development, including establishing a public framework to consistently support research and development from initial research to approval and implementation for rare and intractable blood disorders (Recommendation 4-2-1). Improving the clinical trial environment (Recommendation 4-2-2). Expanding public funding for registries (Recommendation 4-2-3). Public budget measures for panel testing staffing, flexibility of facility requirements, review of specimen transfer systems, review of base hospital systems (Recommendation 4-2-4). Establishing guidelines for ethical issues specific to hematological malignancies (Recommendation 4-2-4).	Strengthening of the research base, improvement of international competitiveness, promotion of drug discovery for rare disorders, and improvement of access to panel testing
National Government (Ministry of Economy, Trade and Industry)	Supporting CDMO development and promoting investment in manufacturing sites (Recommendation 4-2-5).	Strengthening of domestic manufacturing capacity and achievement of stable supply
Related Academic Societies	Career support programs and promoting PPI (Recommendation 4-2-1). Operating multi-center joint research (Recommendation 4-2-2). Promoting registry operation and data centralization (Recommendation 4-2-3). Improving the efficiency of expert panel operation (Recommendation 4-2-4).	Establishment of a sustainable research system
Japanese Society for Transplantation and Cellular Therapy	Registry Operation, development of data collection and analysis infrastructure (Recommendation 4-2-3).	Establishment of a long-term follow-up system
Patient Organizations	Participating in research (PPIs), clinical trial literacy improvement activities (see Recommendation 4-2-3 → Recommendation 2-2).	Reflection of patient perspectives into research
Industry (Pharmaceutical Companies)	Promoting industry-academia collaboration, establishing a public-private partnership model in the rare disorder field, participating in Japan from the early development stage (Recommendation 4-2-2). Investing in domestic manufacturing (Recommendation 4-2-5). Technological innovation and shortening turnaround times for panel testing (Recommendation 4-2-4). Participating in dialogue on innovation evaluation (Recommendation 4-2-4).	Rapid patient access to new medications and diagnostic technologies

3. Future Outlook

This report analyzes the structural challenges facing the field of blood disorders from four pillars and presents a total of ten specific policy recommendations. This chapter describes the future direction and medium- to long-term outlook for making these recommendations effective.

Realizing the Transition from "Curative Medicine" to "Medicine that Supports Living with Illness"

As mentioned in Chapter 1, advances in innovation including molecularly targeted agents are changing the nature of many blood disorders into long-term chronic diseases. At the same time, innovative treatments such as CAR-T cell therapy have reached a stage where cure itself is a realistic goal for some disorders, and blood disorder care is entering a major turning point in both chronic disease management and cure-oriented treatment. This change calls for the creation of a healthcare ecosystem that supports patients in living their lives with their illness, building on the success of acute-phase treatment. The goal of these policy recommendations is to facilitate the realization of the transformation to "medicine that supports living with illness" as a concrete system and structure.

Short-term Priorities

Building a Collaborative Model and Developing an Institutional Foundation

The first priority to actualize the recommendations is to establish a model for cooperation between specialized medical institutions and local healthcare institutions (Recommendations 1-1 and 1-2). It is necessary to develop a collaboration mechanism suitable for the characteristics of blood disorders, such as prolonged chemotherapy cycles, repeated remission and follow-up, and the presence of a risk of sudden change, referring to the knowledge of regional collaboration critical pathways in the field of solid tumors. Establishing a new role as a "Community Hematologist" and promoting the development of an institutional environment for home blood transfusion and home-based chemotherapy (Recommendation 1-3) will be key to simultaneously improving patient access and reducing the burden on specialized medical institutions.

At the same time, it is essential to promote the development of institutional infrastructure, such as developing an environment in which patients can choose treatment based on appropriate and adequate information (Recommendation 2-1), and establishing an operational system for hematological malignancy gene panel testing (Recommendation 4-2).

Medium-term Outlook

Enhancing Collaboration and Realizing Data-driven Healthcare through Healthcare DX

In the medium term, the progress of healthcare DX will greatly affect the effectiveness of the overall recommendations. With the development of electronic medical record information sharing services and national medical information platforms, establishing a system for real-time sharing of test data and treatment progress between specialized medical institutions and local healthcare institutions is becoming a reality in the field of blood disorders (Recommendation 3-1). A mechanism for patients to monitor their own treatment progress and share information with healthcare providers bidirectionally through ePRO (Recommendation 3-2) will improve the quality of shared decision-making (SDM) and provide technical support for patient-centered medical care.

In addition, the enrichment of registry data and the use of real-world data will contribute to the optimization of treatments and the acceleration of new drug development, as well as provide an essential evidence base for policymaking in the field of blood disorders. If the data infrastructure development (Recommendation 4-2) presented in this document is realized, it is expected that personalized medicine based on evidence from Japan will be further advanced.

Long-term Outlook

Preparing for the 2040 Challenge and Deepening the Lifecycle Approach

As future estimates show, the number of blood cancer patients is expected to increase significantly by 2040, both in terms of incidence and prevalence. The structural shift, especially in the form of a surge in elderly patients aged 65 and above and a decrease in younger patients under 40, will result in a qualitative shift in healthcare needs. It is necessary to deepen the lifecycle approach (Recommendations 1-4, 2-1, and 2-2) that addresses different issues for each age group, such as the increasing need for disorders such as myelodysplastic syndrome which is common in the elderly, the need for comprehensive care that takes into account multimorbidity and frailty, and fertility preservation and support for education and employment in patients of the AYA generation.

In order to respond to the increasing demand for medical care amid the sharp decline in the working-age population, it is necessary to simultaneously promote a multidisciplinary collaboration system (Recommendation 1-4) and improve operational efficiency through healthcare DX (Recommendations 3-1 and 3-2) to realize the optimal allocation of limited medical personnel.

Multi-stakeholder Collaboration and Ongoing Policy Dialogue

None of the ten recommendations made in this document can be realized by a single entity. It is essential for the government (MHLW, Ministry of Economy, Trade and Industry, Ministry of Education, Culture, Sports, Science and Technology, and other relevant ministries), academic societies and medical professional groups, healthcare institutions, patient organizations, and industry to collaborate and work together while leveraging their respective strengths. The multi-stakeholder dialogue framework established through Phase 1 (FY2024) and Phase 2 (FY2025) of this project will also play an important role in the implementation phase of the recommendations.

Going forward, it is desirable to establish a continuous cycle of regularly monitoring the progress of each recommendation, verifying results and issues, and updating the policy recommendations accordingly. In addition, regarding issues that could not be addressed in this document, such as the reflection of blood disorder measures in prefectural plans, creating an environment for smooth transition support, responses for blood disorder patients in the event of a disaster, and international human resource exchange and research collaboration, it is necessary to continue to deepen discussions for future consideration.

Conclusion

Blood disorder medical care has achieved world-leading standards in treatment outcomes through the efforts of generations of healthcare professionals and researchers. Building on these achievements, this report aims to realize a society in which all patients with blood disorders can continue to live with peace of mind, on their own terms, in their own communities. We sincerely hope that these recommendations will serve as a starting point for constructive discussions to further promote measures against blood disorders, and contribute to the realization of a sustainable medical ecosystem centered on patients and those affected, through the collaboration of all relevant parties.

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5. Acknowledgment

When formulating these policy recommendations, we received opinions from the experts listed below who participated on our Advisory Board. We express our deepest gratitude for their input. These policy recommendations are based on discussions and interviews HGPI held for this project and have been compiled in HGPI's capacity as an independent health policy think-tank. It does not, in any capacity, represent the opinions of any participating expert, speaker, related party, or organization to which those parties are affiliated.

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