

Future Direction and Outlook

Short-term

1-3 years

Building a collaborative model and developing an institutional environment

- Establishing a collaboration model and collection and dissemination of information on community hematologists
- Strengthening the institutional environment for home-based care
- Establishing an operational system for hematological malignancy gene panel testing
- Systematic review of medical service fees to support collaborative systems

Medium-term

3-5 years

Nationwide expansion of healthcare DX and multidisciplinary collaboration

- Developing an electronic information sharing platform
- Nationwide dissemination of multidisciplinary team-based medicine and collaboration between hospital and community pharmacists
- Full-scale adoption of ePROs and real-world data

Long-term

around 2040

Establishing a sustainable healthcare ecosystem

- Deepening the lifecycle approach
- Continuous policy dialogue through multi-stakeholder collaboration
- Establishing international competitiveness

Expectations for Each Stakeholder

National Government (MHLW, and others)

- Developing systematic medical service fee evaluation frameworks
- Ensuring the financial sustainability of advanced medical care

Prefectural Governments

- Reflecting blood disorder measures in medical plans
- Promoting the development of regional acceptance systems for follow-up patients

Prefectural Medical Associations

- Aggregating and publishing information on Community Hematologists
- Piloting and evaluating collaborative systems in model areas

Related Academic Societies & Medical Organizations

- Organizing medical care for centralization and equalization
- Developing disease-specific follow-up guides

Healthcare Institutions

- Implementing community-based multi-attending physician systems
- Establishing systems for multidisciplinary team medicine and home-based blood transfusion

Patient Organizations

- Promoting PPI and peer support
- Participating in awareness campaigns and reflecting the perspectives of patients and those affected in policy

Employers & Occupational Health Doctors

- Establishing support systems for balancing treatment and work tailored to blood disorder characteristics
- Promoting flexible work arrangements

Industry

- Developing collaboration tools and digital infrastructure
- Promoting drug development for rare disorders and strengthening domestic manufacturing capacity

Blood disorder care in Japan has achieved world-leading standards in treatment outcomes through the efforts of generations of healthcare professionals and researchers.

Building on these achievements, we call on all stakeholders to work together toward realizing "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."

About the Blood Disorders Project

This project established an advisory board comprising diverse stakeholders, through which ongoing constructive discussions were held. We sincerely hope that these recommendations will serve as a starting point for constructive dialogue to further advance blood disorder policy, and that through collaboration among stakeholders, they will contribute to the realization of a sustainable healthcare ecosystem centered on patients and those affected.

About Health and Global Policy Institute

Health and Global Policy Institute (HGPI) is a non-profit, independent and non-partisan think tank established in 2004, dedicated to advancing citizen-centered health policy. Independent of any particular political party or organization, we bring together a broad range of stakeholders and present society with effective policy options to realize citizen-centered healthcare. Looking ahead to the future, we continue to propose innovative new ideas and values from a wide range of perspectives to build a fair and healthy society. Since its establishment, HGPI has remained at the forefront of identifying themes that were not yet receiving sufficient attention and ensuring their adoption as policy issues in areas such as women's health, cancer control, dementia, antimicrobial resistance (AMR), regenerative medicine, and global health. By ensuring such themes are reflected in the formulation of legal systems and national strategies as well as in global policy discussions, HGPI contributes to concrete policy progress. These sustained efforts have earned recognition from domestic and international policy stakeholders and organizations. We will continue participating in global dialogues in our capacity as a health policy think-tank from Japan. We continue to present effective health policy options and advance efforts to address health and medical challenges, not only in Japan, but on a global scale.



Click here for the full report

<https://hgpi.org/en/research/ncd-bd-20260413.html>



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Building a Healthcare Ecosystem Centered on Patients and Those Affected



Policy Recommendations in the Field of Blood Disorders

Toward a society where all patients with blood disorders can continue to live with peace of mind, on their own terms, in their own communities

Innovations such as molecularly targeted agents and CAR-T cell therapy have made long-term survival a reality for many blood disorders that were once considered to have poor prognosis. At the same time, as many of these disorders are transitioning into chronic conditions requiring long-term management, patients across a wide range of life stages – from children to the elderly – face distinct challenges related to growth and development, education, employment, and multimorbidity. Looking ahead to 2040, the simultaneous increase in elderly patients and the decline in the working-age population are expected to make it increasingly difficult for the current system, which is centered on specialized medical institutions, to meet patient needs. The financial and time burdens associated with long-distance commuting to hospitals are also significant. A structural transformation is urgently needed from the standpoint of both patient QOL and the sustainability of the healthcare delivery system.

Increasing Number of Blood Disorder Patients

Increase in Prevalence per Disease

Multiple myeloma, leukemia, malignant lymphoma
Prevalence (2020→2050 projection)

~30% increase each

Key Figures

Increase in Elderly Patients

Projected new cases in patients aged 65 and over (2010→2040 projection)

~1.7-fold increase

Structural Challenges in Healthcare Delivery

Enormous Hospitalization Costs

Leukemia and Malignant Lymphoma inpatient medical costs

~370 billion yen/year

Uneven Distribution of Hematologists

Hematologists working in hospitals

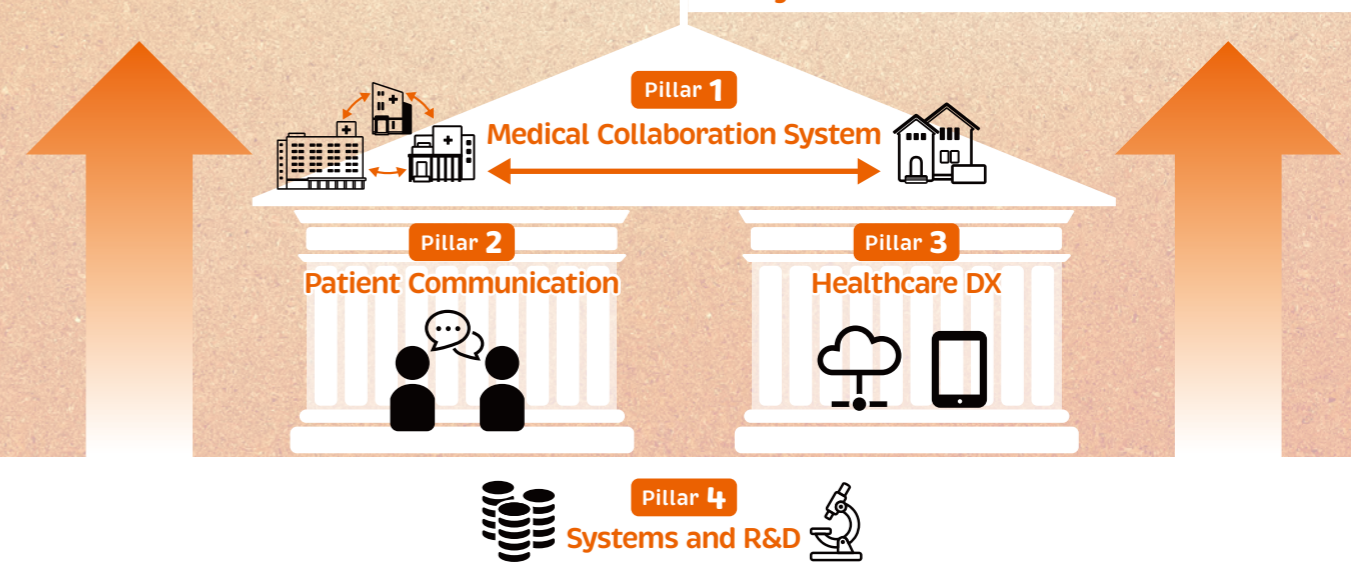
97.5%

*Increase in prevalence: Nguyen et al. 2023 (2020→2050 projection, male values. Malignant lymphoma women +71.6%, all cancers +13.1%) / Increase in elderly patients: Narimatsu et al. 2020 (2010→2040 projection) / Medical costs: calculated from National Medical Care Expenditures in FY2022 / Number of hematologists: Calculated from the Overview of Statistics on Physicians, Dentists, and Pharmacists 2024

In light of this context,

a total of **ten policy recommendations** across **four pillars** are proposed, which HGPI aims to realize through multi-stakeholder collaboration among government, academic societies, healthcare institutions, patient organizations, and industry.

Building a Patient-Centered Healthcare Ecosystem



Please see the following page for an overview of each recommendation, and please refer to the full report for details. ▶▶▶▶

10 Policy Recommendations

for Building a Healthcare Ecosystem Centered on Patients and Those Affected

Pillar 1 Building a Multi-Layered Medical Collaboration System

With an eye toward increasingly long-term treatment, it is important to organize advanced care where 'centralization' is effective and continuous care where 'equalization' is desirable, and to build a multi-layered collaboration system that supports patients throughout the community.

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

- 1 Centralize advanced care such as hematopoietic stem cell transplantation and CAR-T therapy at specialized medical institutions
- 2 Establish a regional delivery system for follow-up during stable periods and oral anticancer medication management
- 3 Examine disease-specific, stage-specific division-of-roles models, and clarify the timing of regional transition
- 4 Establish a system for accepting post-treatment follow-up patients throughout the community

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

- 1 Establish a community-based "multi-attending physician system", while also ensuring access to specialists through online consultations and other means
- 2 Develop integrated guidelines covering regional transition and follow-up for each disease and disease stage



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

- 1 Establish a home-based blood transfusion delivery system targeting patients with limited mobility and elderly patients
- 2 Establish a home-based chemotherapy delivery system for subcutaneous injection preparations, oral anticancer medications, and similar medications
- 3 Enhance the capacity of local healthcare institutions through training programs for home-based blood transfusion and home-based chemotherapy
- 4 Examine appropriate medical service fee evaluations for home-based blood transfusion and home-based chemotherapy

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

- 1 Establish a multidisciplinary collaboration system for nurses, pharmacists, MSWs, registered dietitians, rehabilitation professionals, clinical psychologists, and others
- 2 Promote the training and placement of coordinator positions such as HCTCs, and strengthen the bridging function for advanced medical care
- 3 Promote collaboration between hospital and community pharmacists through a three-tier structure of hospital pharmacy departments, specialized medical institution-affiliated pharmacies, and family pharmacies
- 4 Promote the development of multidisciplinary human resources responsible for community collaboration in blood disorders, and strengthen the bridging functions
- 5 Enhance medical service fee evaluations for multidisciplinary team medicine, coordination functions, and collaboration between hospital and community pharmacists

Pillar 2 Patient-Centered Medical Communication and Support

Bridge the awareness gap between doctors and patients, implement shared decision-making (SDM) so that patients can make treatment decisions aligned with their values, and support the integration of treatment with social life.

Recommendation 2-1

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

- 1 Develop comprehensive patient information materials
- 2 Use patient-reported outcomes (PROs) in clinical practice
- 3 Create an environment for SDM practice and promote active patient participation
- 4 Promote advance care planning (ACP)
- 5 Enhance pre-treatment information provision and decision-making support regarding fertility preservation for AYA generation patients

Recommendation 2-2

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

- 1 Strengthen the capabilities of cancer consultation support centers and raise awareness of them
- 2 Enhance support for balancing treatment with work and social life
- 3 Strengthen cooperation with patient organizations and promote the training of peer supporters and ensure opportunities for them to be active
- 4 Provide continuous support and consultation regarding future life planning (e.g. pregnancy, childbirth, employment) for AYA generation patients during and after treatment
- 5 Promote patient and public involvement (PPI) in R&D and policy-making processes
- 6 Promote awareness campaigns on blood disorders through collaboration among academic societies, patient organizations, companies, and government

Pillar 3 Healthcare DX and Information Sharing

Advance healthcare DX infrastructure by breaking away from reliance on conventional tools, and position blood disorders as a model field that reflects their unique characteristics.

Recommendation 3-1

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

- 1 Standardize the minimum common data set to be shared, and promote the disclosure of information on healthcare institutions available for collaboration
- 2 Ensure consistency with the National Cancer Registry and hematologic disease registries, and promote data linkage
- 3 Establish an electronic medical information sharing platform and promote information exchange through D to D tools and among home care teams
- 4 Establish disease-specific referral letter templates and support the creation of medical information summaries using AI
- 5 Examine medical service fee incentives to promote the use of IT-based information sharing



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

- 1 Establish a standard format for patient treatment summaries and progress records
- 2 Utilize digital tools such as ePRO to promote two-way information sharing between patients and healthcare providers



Pillar 4 Institutional Support and R&D

Develop a medical service fee system that ensures the sustainability of the ecosystem, and strengthen the R&D foundation, including measures to address drug loss and operational systems for panel testing.

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

- 1 Develop systematic medical service fee evaluations based on the characteristics of blood disorders
- 2 Develop a revenue structure in which healthcare institutions do not suffer losses from advanced medical care such as CAR-T therapy
- 3 Assess the current state of local rules regarding insurance coverage and promote nationwide uniform operation
- 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
- 5 Promote the rationalization of regulations in line with actual treatment conditions, expand outpatient treatment, and improve patient convenience

Recommendation 4-2

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

- 1 Train research personnel such as clinical research coordinators (CRCs) and secure research support staff
- 2 Promote early participation in international collaborative clinical trials and advance investigator-initiated trials, especially in the field of rare disorders
- 3 Promote the usage of cancer registries and other registries for research, and strengthen the financial foundation of registries essential for long-term follow-up
- 4 Address the drug loss problem, and develop operational systems for hematological malignancy gene panel testing, including reviewing the base hospital system
- 5 Promote the development of domestic manufacturing bases for regenerative medicine products such as CAR-T cell therapy

[Glossary]

QOL : Quality of Life
SDM : Shared Decision-Making
PPI : Patient and Public Involvement

ePRO : Electronic Patient-Reported Outcome
HCTC : Hematopoietic Cell Transplant Coordinator
CRC : Clinical Research Coordinator

MSW : Medical Social Worker

For details on each recommendation (current situation and challenges, expected actions and effects by implementing entity), please refer to the full report.