



Partnership for Health System  
Sustainability and Resilience

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# Policy Recommendations on Addressing Regional Disparities in Breast Cancer Care

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# Table of Contents



<b>I . Executive Summary</b>	<b>1</b>
1. Background and Objectives	2
2. Current Regional Disparities in Breast Cancer Medical Care	2
3. Challenges and Proposed Measures for Addressing Regional Disparities in Breast Cancer Care	2
<b>II . Introduction</b>	<b>5</b>
<b>III . Current Regional Disparities in Breast Cancer Medical Care</b>	<b>7</b>
<b>IV . An In-Depth Analysis of Regional Disparities in Breast Cancer Care and Proposed Measures</b>	<b>10</b>
1. Establishing a Sustainable Healthcare Delivery System Adapted to Regional Realities	12
【Current Situation and Challenges】	12
【Recommendations for Addressing the current Challenges】	17
2. Visualization and Improvement of Healthcare Quality through Data Utilization (Ensuring the PDCA Cycle)	22
【Current Situation and Challenges】	22
【Recommendations for Solving these Issues】	24
3. Patient Engagement and Social/Economic Comprehensive Support	27
【Current Situation and Challenges】	27
【Proposals for Addressing the Identified Issues】	30
<b>V. Case Study</b>	<b>33</b>
Cancer Care PDCA Initiatives by Okinawa Prefecture Cancer Care Coordination Council	34
<b>VI. Acknowledgments</b>	<b>36</b>
<b>VII. References</b>	<b>37</b>

# I . Executive Summary



## 1. Background and Objectives

Cancer is currently one of the leading causes of death in Japan, making it a priority area for research and countermeasures across various medical fields. While the delivery of cancer care has been promoted through measures like the hub hospital system<sup>i</sup> to ensure "equalization" (i.e., providing standardized specialized care nationwide to eliminate disparities in medical technologies<sup>ii</sup>), challenges related to disparities in access to care and care quality persist.

Breast cancer, though dependent on the stage at detection, generally has a higher five-year survival rate compared to other cancers. Factors such as the high number of female patients, the relatively early onset with the first peak in the 40s, the significant number of patients in the Adolescent and Young Adult (AYA)<sup>iii</sup> generation, the complexity of treatment, and the rapid advancements in treatment options demand advanced medical expertise, capacity and knowledge, including the adoption and appropriate implementation of the latest treatments and team-based care.

This report focuses on addressing regional disparities in breast cancer care by analyzing issues in Japan's current healthcare system and identifying the challenges unique to breast cancer. It proposes policy measures that not only address for breast cancer but that are generalizable to other types of cancer, and that address healthcare disparities.

## 2. Current Regional Disparities in Breast Cancer Medical Care

To identify the challenges in regional disparities in breast cancer care, we conducted both qualitative and quantitative surveys. Qualitative surveys involved interviews and literature reviews targeting healthcare professionals, breast cancer patients, and policymakers, and included evaluations of indicators used in quantitative studies. Quantitative surveys, informed by qualitative findings, identified indicators to capture regional disparities. Data were collected from various public statistics and measured at the prefectural level.

The results revealed regional disparities in breast cancer care across four domains:

1. Multidisciplinary treatment based on the latest evidence.
2. Emerging advanced medical care (e.g., personalized medicine, clinical trials).
3. Treatment options and medical support associated with breast cancer care (e.g., fertility preservation, appearance care, breast reconstruction).
4. Social support, including employment-related support for breast cancer patients.

## 3. Challenges and Proposed Measures for Addressing Regional Disparities in Breast Cancer Care

To address regional disparities in breast cancer care, discussions among experts centered on three key perspectives: Sustainable healthcare delivery systems, Implementation of the PDCA cycle<sup>iv</sup> for quality improvement, and Patient participation and comprehensive support.

<sup>i</sup> The Hub Hospital System is a system in which hospitals serving as hubs for cancer care (designated as "Cancer Care Coordination Hub Hospitals") are appointed by the Minister of Health, Labour and Welfare based on specific criteria, to ensure high-quality cancer care is available nationwide.

<sup>ii</sup> This system is defined in the "Report of the Study Group on Promoting Equalization of Cancer Medical Standards," which was established in 2004 as an advisory panel to the Minister of Health, Labour and Welfare. The report, chaired by Dr. Tadao Kakizoe, then President of the National Cancer Center, aimed to examine the factors contributing to regional disparities in cancer care and propose concrete measures for their resolution. The definition appears in the "Introduction" section of the report.

<sup>iii</sup> AYA Generation: The acronym for Adolescent and Young Adult, referring primarily to individuals from adolescence (around age 15) to their 30s. Among this age group, especially in their 30s, breast cancer is the most common type of cancer in terms of incidence rate (percentage of total cancers).

<sup>iv</sup> PDCA Cycle: A systematic method for achieving goals and improving or streamlining processes through a repeated sequence of four steps: Plan (planning) → Do (execution) → Check (evaluation) → Action (improvement).

## 1. Sustainable Healthcare Delivery Systems Adapted to Regional Needs

A sustainable healthcare delivery system tailored to regional needs is essential for breast cancer care. This includes periodically updating the functional differentiation and coordination of healthcare services in response to regional changes and advancing the allocation and training of specialized personnel. However, the current system is not fully optimized for regional needs, with issues such as shortages of specialists, geographical inequities, and inadequate medical education systems.

Effective breast cancer care requires close collaboration and coordination across facilities and specialties to provide appropriate care and support based on patient precarious conditions. However, many prefectures lack well-structured regional coordination systems and role-sharing frameworks, including non-hub hospitals and medical associations supporting local care.

Proposals to Address These Challenges:

### 1. Accelerating Functional Differentiation and Coordination among Medical Facilities ("Hub-and-Spoke Model"):

The national government should provide a general vision, that will help prefectures and Prefectural Cancer Treatment Coordination Councils to lead discussions to centralize certain functions and build close cooperation among institutions tailored to regional needs.

### 2. Leveraging Digital Technologies:

Digital solutions such as telemedicine and workflow efficiency enhancements should be promoted through financial incentives provided by the national and prefectural governments to address geographical and personnel limitations.

### 3. Advancing Systematic Initiatives for Specialist Personnel Deployment and Task Sharing:

Policies supporting the training and employment of diverse specialists involved in breast cancer care should be promoted, including discussions on efficient role-sharing to facilitate effective team-based care.

### 4. Creating Environments for Learning and Applying Specialized Knowledge:

Collaborative efforts among the government, professional organizations, and academic societies should establish well-organized and practical training programs, supported by ICT, to ensure knowledge acquisition and provide opportunities for personnel to utilize and be recognized for their expertise.

## 2. Visualization and Improvement of Medical Quality through Data Utilization (PDCA Cycle)

Improving healthcare quality requires collecting objective data, evaluating and publishing quality research based on the collected data, and creating a framework for continuous improvement through monitoring temporal changes and comparative assessments (PDCA cycle). However, indicators for assessing the quality of breast cancer care, such as Quality Indicators (QI), and data utilization are not yet adequately and sufficiently developed. Similarly, hospital-based cancer registries, mandated by national guidelines, are underutilized for hospital policy development or PDCA cycles in less than half of the prefectural councils.

Proposals for Addressing Data Utilization Challenges:

### 1. Ensuring early Execution of PDCA Cycles Based on Data:

Strengthen systems to analyze and improve the quality of breast cancer care using objective data across national, prefectural, and institutional levels.

### 2. Building a Foundation for Objective and Comparable Data Utilization:

Enhance database integration to leverage existing high-quality data sources (e.g., National Clinical Database) for assessing and improving cancer care quality.

v Hub-and-Spokes Model:

A transportation method where cargo is centralized at a large hub (such as an airport) and then distributed to various points (spokes). This term is commonly used in logistics and information technology fields (as defined by the Japan Transport and Logistics Glossary).

In the context of this document, the concept of establishing a "Hub-and-Spokes Network" is based on the following two points:

- **Centralizing resources and expertise at hub hospitals:** To ensure efficient use of specialized personnel and maintain the quality of care, resources, expertise, and patients (case numbers) are centralized at a central hospital (hub).
- **Leveraging online technology:** Through the use of online technologies, collaborating hospitals and other facilities (spokes) are connected to the central hospital (hub), enabling the provision of quality-assured medical care to patients in remote areas and bridging access disparities.

### 3. Patient Participation and Comprehensive Social and Economic Support

Achieving quality patient-centered breast cancer care requires shared decision-making between patients and healthcare providers. However, the plethora of information about diseases, treatments, and available support makes it difficult for patients to fully understand their options and make value-based decisions. The use of resources such as second opinions, cancer counseling centers, and peer supporters is insufficient. Moreover, economic support from the government and local municipalities for fertility preservation, appearance care, and breast reconstruction, as well as corporate support for balancing treatment and work, remains inadequate. These factors, coupled with gender-based employment disparities and societal norms, highlight the need for multidimensional support and interdisciplinary collaboration.

To enable patients to actively receive treatment and other support according to their individual conditions, this report makes the following proposals:

**1. Enhancing the frequency and quality of communication between patients and healthcare providers through maximum use of existing resources:**

By combining consultation services, introducing online consultations, and strengthening the promotion of consultation services, improve the efficiency of existing resources to enhance communication between patients and healthcare providers. This will support patients in actively receiving treatment and other necessary care and support based on their specific conditions.

**2. Promoting discussions aimed at rectifying regional disparities and strengthening access to social and economic support:**

Visualize existing supporting frameworks, such as national support systems or region-specific subsidies, to ensure that individuals receive the necessary support at the right time based on the stage of the disease or life course. Additionally, discuss potential improvements ("raising the baseline") for support systems where disparities exist due to patients' attributes, such as geographical location, workplace characteristics, employment type, or age etc.

**3. Fostering public understanding of regional healthcare systems and coordination:**

Expand and reinforce educational opportunities, such as public seminars, to help patients actively learn about their health and medical care. Encourage meaningful consultations with healthcare professionals and enable informed choices of healthcare institutions. Furthermore, ensure clear and accessible information is made available regarding the local breast cancer care delivery system.

Today, it is imperative for healthcare providers to deliver medical care, and support that meet the diverse needs of patients in a sustainable manner. To address regional disparities in breast cancer care, it is essential not only to optimize healthcare resources and continuously improve the quality of care through measures such as functional differentiation, enhanced collaboration across regions, and the establishment of data infrastructure and PDCA cycle frameworks, but also to simultaneously strengthen support systems. This can be achieved by improving patients' access to information and healthcare environments through initiatives like information disclosure. It is strongly hoped that this proposal will contribute to further advancing patient-centered care and establishing breast cancer or cancer care as a whole in the future.

## II . Introduction





Cancer is a disease that currently affects one in two people in Japan and is one of the leading causes of death. As such, addressing regional disparities in medical care has been highlighted as a critical issue requiring the concerted efforts of not only the national and local governments but also healthcare professionals, researchers, and other stakeholders.

Efforts to standardize cancer care have progressed, centering on the establishment of Cancer Care Coordination Hub Hospitals. However, disparities in the quality of care between regions and medical institutions remain an ongoing concern.

Amid this situation, various policies and research initiatives have been implemented in cancer care, but the current conditions and challenges vary depending on the type of cancer. This report focuses on breast cancer, aiming to identify issues related to regional disparities and propose policy measures for their resolution. Breast cancer was chosen as the theme because it is the most common type of cancer among Japanese women, and as detailed below, the characteristics of its patients and treatments demand diverse and multifaceted efforts to ensure standardization and reduce care disparities.

### Characteristics of Breast Cancer Care

- **Age of Onset:** The peak onset ages for breast cancer are in the 40s and 60s. Women in their 40s and 50s, who often hold significant roles in both family and society, account for approximately 37%<sup>4</sup> of all breast cancer cases. Additionally, patients in the AYA (Adolescent and Young Adult) generation make up about 4%<sup>1</sup> of cases. Challenges related to balancing treatment with life stage responsibilities require treatment plans to be tailored to patient preferences.
- **Diverse Treatment Methods:** Breast cancer care involves various treatment options, including surgical treatments, drug therapies such as molecular targeted drugs and hormone therapies, radiation therapy, fertility preservation<sup>vi</sup>, and breast reconstruction surgery. Multidisciplinary teams with expertise in these fields are essential for delivering care.
- **Advances in Treatment:** Rapid progress in treatments, including personalized medicine, necessitates the selection of therapies tailored to the individual patient's background and condition.
- **Genetic Insights:** Advances in understanding the genetic causes of breast cancer and the development of new treatments have led to the recognition of some cases as hereditary conditions (e.g., Hereditary Breast and Ovarian Cancer Syndrome).
- **Early Detection and Prognosis:** Breast cancer tends to occur at a relatively younger age compared to other cancers. When detected early, the prognosis is favorable, underlining the importance of survivorship support.

Healthcare disparities refer to any inequalities faced by individuals in accessing medical services or the quality of care they receive. The Basic Law on Cancer Control includes as one of its fundamental principles the goal of ensuring that "cancer patients, regardless of their place of residence, can equally receive appropriate cancer care based on scientific evidence" (Article 2, Paragraph 2). Similarly, the Fourth Basic Plan for Cancer Control, initiated in 2023, sets forth the overarching objective of "promoting cancer countermeasures that leave no one behind and aiming for the elimination of cancer across the entire population." Addressing healthcare disparities in cancer care is recognized as a pertinent and critical issue. In general, disparities in healthcare standards can be observed at various levels, such as between regional blocs, prefectures, secondary medical care zones, institutions, and across socioeconomic factors like race, gender, or occupation. While it goes without saying that all such disparities require investigation and adequate effort that results in resolution, this report focuses on disparities in breast cancer care, analyzing differences at the regional level (primarily by prefecture), which serves as the main site for healthcare delivery.

It should be noted that early detection is crucial in breast cancer, and secondary prevention measures such as screenings and diagnostic testing remain high-priority policy issues. However, this report focuses on the domain of breast cancer care starting from confirmed diagnosis onwards.

vi **Fertility:** The ability to conceive and bear children, which depends not only on sperm and eggs but also on sexual function, reproductive organs, and endocrine functions. Cancer treatments, such as chemotherapy, radiation therapy, and surgical procedures, can have side effects that impact these functions, potentially leading to a decrease or loss of fertility.

# III . Current Regional Disparities in Breast Cancer Medical Care



To identify the challenges related to regional disparities in breast cancer care for this report, we conducted qualitative and quantitative surveys. Based on these findings, discussions with experts were held to consider measures to address and resolve these disparities.

#### **Qualitative Survey:**

Interviews were conducted with healthcare professionals (including physicians and nurses involved in breast cancer care), breast cancer patients, and policymakers. These interviews aimed to identify the challenges of regional disparities in breast cancer care, potential solutions, and to evaluate the indicators used in the quantitative survey. A literature review was also performed to evaluate the current situation, identify issues, and explore potential solutions.

#### **Quantitative Survey:**

Building on the findings of the qualitative survey, specific indicators were identified to assess regional disparities. Data were collected from various statistical and publicly available sources and measured at the prefectural level. These results served as reference values for understanding regional disparities.

By considering the results of the qualitative and quantitative surveys and the discussions with experts, this report confirms the existence of outcome disparities in regional breast cancer care. Furthermore, it identifies four key areas in which disparities in provided medical care and support are most pronounced. The next chapter will delve deeper into the challenges underlying these disparities and propose measures to address them.

#### **<Outcome>**

The measurement results of both the age-adjusted mortality rate and the 5-year survival rate revealed disparities among prefectures. Regarding the age-adjusted mortality rate (under 75 years old), while it is heavily influenced by incidence and therefore not appropriate to view solely as an outcome of the medical care provided, disparities exist among prefectures, with a gap of more than twofold between the maximum value (13.6%) and the minimum value (5.4%)<sup>1</sup>.

As for the 5-year survival rate, differences in the types and numbers of cooperating facilities in regional surveys, the distribution of disease stages, and other patient background factors suggest that an analysis excluding these variables would be desirable to accurately evaluate disparities in the quality of medical care provided by medical institutions. However, available stage-specific data reveal that the 5-year survival rate for breast cancer tends to show greater disparities and variability among prefectures as the disease progresses. For Stage I, the maximum rate is 100%, while the minimum is 95.8%, showing a difference of 4.2 percentage points. From Stage II onward, the gap between the maximum and minimum values widens further. For Stage II, the maximum value is 97.6% and the minimum is 81.1%, a difference of 16.5 percentage points. For Stage III, the maximum value is 89.3% and the minimum is 65.1%, a difference of 24.2 percentage points. For Stage IV, the maximum value is 54.4%, and the minimum is 17.2%, showing a gap of 37.2 percentage points, which is nearly threefold<sup>1</sup>.

#### **<Key Areas Where Regional Disparities Are Considered to Exist>**

##### **Pertinent evidence-based multidisciplinary treatment**

Discrepancies in the implementation rates of standard treatments for breast cancer exist across facilities and regions. For example, the Quality Indicator (QI) defined by the Cancer Registry Subcommittee of the Prefectural Cancer Care Coordination Hub Hospitals Liaison Council specifies "radiotherapy for high-risk recurrence after mastectomy (excluding T3N0 or cases with four or more lymph node metastases)." The implementation rate for this standard treatment is approximately 78%<sup>vii</sup>, highlighting differences in implementation rates across facilities<sup>1</sup>. Furthermore, research indicates that patients treated at non-designated hospitals have significantly lower rates of standard treatment implementation compared to those treated at designated hospitals<sup>2</sup>.

vii The simple aggregated implementation rate from the QI survey is 41.9%; however, this report adopts an estimated implementation rate calculated based on the reasons for non-implementation. In the estimation, cases where the reason was "patient preference" or "performed at another hospital" were treated as equivalent to implemented cases and reflected in the implementation rate. On the other hand, reports citing "unknown reason" or adherence to the facility's own guidelines were deemed not valid reasons and were excluded from the implementation rate calculation.

### **Emerging Advanced Medical Care (Personalized Medicine, Clinical Research, and Trials)**

Regional disparities exist in the healthcare provision system and implementation rates of cancer genome medicine. Existing research suggests regional differences in the proposal, implementation, and treatment completion rates of cancer gene panel testing<sup>1</sup>. Significant regional disparities were also observed in related process indicators, such as the "number of BRCA tests<sup>viii</sup> performed" and the "calculation of cancer patient counseling management fees for obtaining consent for genetic testing." Furthermore, there is a notable imbalance in human resources, as several there is currently no certified genetic counsellor in several prefectures.

### **Treatment Options and Medical Support Associated with Breast Cancer Care (Fertility Preservation, Appearance Care, and Breast Reconstruction)**

Regional disparities exist in the availability and implementation of fertility preservation, appearance care, and breast reconstruction. Breast reconstruction can be broadly categorized into autologous tissue reconstruction and artificial implant reconstruction. However, autologous tissue reconstruction is performed less frequently than artificial implants, and the number of facilities capable of performing such procedures is limited. Even for artificial implant surgeries, which are more commonly performed, they can only be carried out at facilities certified by the Japan Breast Oncoplastic Surgery Society.

The certification requirements for such facilities include having both a full-time<sup>ix</sup> breast surgeon and a plastic surgeon (either part-time or full-time)<sup>1</sup>, effectively limiting the number of facilities capable of performing these surgeries. According to data from the National Database (NDB) open data, surgeries for both autologous tissue and artificial implants are concentrated solely to urban areas<sup>2</sup>.

Furthermore, in the national program promoting research on fertility preservation therapy for pediatric and AYA generation cancer patients, some prefectures have only one certified facility for fertility preservation, indicating significant regional disparities relating to access to such services<sup>3</sup>.

### **Social Support for Breast Cancer Patients, Including Employment**

Many breast cancer patients are of working age and often face socio-economic challenges, including employment-related issues. During the initiation or continuation of treatment, some patients are forced to resign or take a leave of absence. The ease of continuing employment (and the adequacy of related support) is likely influenced by the size of the employer and the employment type. For example, large companies, which are more prevalent in urban areas, tend to offer relatively robust support systems for employees dealing with illness. In contrast, small and medium-sized enterprises, more common in rural areas, may lack the resources to provide comparable support for employees with personal health challenges. Additionally, prior research<sup>1</sup> has highlighted that employment type itself can affect a patient's ability to continue treatment or make treatment choices. Women are more likely to be employed in non-regular positions or belong to low-income groups, a trend that is even more pronounced in rural areas. These factors may contribute to geographical healthcare disparities for breast cancer patients in this context.

viii **BRCA Test:** A test that examines the information in the BRCA (Breast CAncer) genes present from birth, conducted through a blood sample. If a pathogenic mutation is found in either the BRCA1 or BRCA2 gene, the individual is diagnosed with Hereditary Breast and Ovarian Cancer (HBOC).

ix In the certification requirements for No. 3, breast surgeons are not included as part of the responsible physician composition.

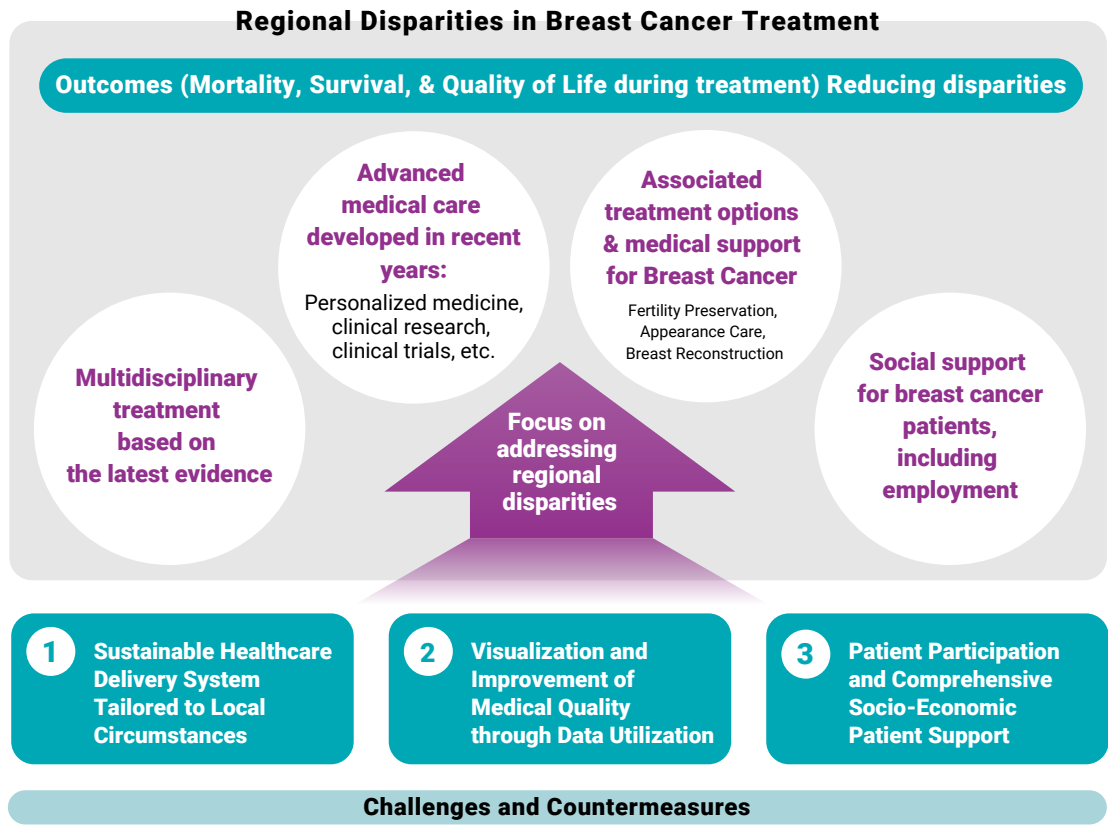
# IV . An In-Depth Analysis of Regional Disparities in Breast Cancer Care and Proposed Measures



This report explores the regional disparities in breast cancer care outlined in the previous chapter and provides detailed challenges and proposed solutions based on the following three key perspectives:

- 1. **Establishing a Sustainable Healthcare Delivery System Adapted to Regional Realities**  
(This includes functional differentiation in breast cancer care, intra-regional and inter-regional coordination, and securing professionals for breast cancer care.)
- 2. **Visualizing and Improving Healthcare Quality through Data Utilization**  
(Ensuring the PDCA cycle is effectively implemented.)
- 3. **Patient Participation and Comprehensive Social and Economic Support for Patients**

**Regional Disparities in Breast Cancer and key points for improvement**



## 1. Establishing a Sustainable Healthcare Delivery System Adapted to Regional Realities

To address regional disparities in breast cancer care, it is essential to continuously update the framework for appropriate functional differentiation and coordination of medical services based on regional needs. Furthermore, establishing an appropriate healthcare delivery system must be integrated with the allocation and development of medical personnel. This section discusses the challenges and provides recommendations related to these aspects.

### [Current Situation and Challenges]

#### Non-Optimal Nationwide Equalization and Centralization of Breast Cancer Care Functions

To improve the quality of breast cancer care, it is essential necessary not only for individual hospitals and regions to strive for quality improvement and collaboration but also to identify the functions that need to be equalized and centralized. The healthcare delivery system must be optimized based on the realities of each region and the nation as a whole. The government has worked to enhance the quality and equalization of cancer care by establishing Cancer Care Coordination Hub Hospitals. However, the Fourth Basic Plan for Cancer Control<sup>5</sup> highlights centralization, considering the advancement of cancer care and population decline, alongside the goal of equalizing cancer care systems. There is ample evidence suggesting that facilities and physicians with higher patient and case volumes deliver higher-quality care. In breast cancer care, it is considered essential to promote a certain degree of centralization of regional healthcare functions, led by Prefectural Cancer Treatment Coordination Councils, to ensure high-quality care. A study by Hattori et al., using regional cancer registry data, examined the direction of cancer care centralization and its potential effect on reducing mortality rates. The study concluded that centralizing cancer treatment to facilities with high case volumes, such as designated hub hospitals, could improve survival rates and reduce mortality<sup>1</sup>. However, disparities in the centralization of cases to specialized facilities and physicians within regional hub hospitals appear to exist across prefectures. Addressing these disparities requires targeted effort to balance the centralization process across regions.

A study by Yuri Ito and colleagues, focusing on understanding the actual conditions of cancer treatment at Cancer Care Coordination Hub Hospitals, revealed significant variation in the proportion of patients treated at these hub hospitals depending on the prefecture and diagnosed type of cancer. In regions with a large number of medical institutions, the proportion of patients treated at hub hospitals tended to be lower, highlighting regional differences in centralization practices. For example, an indicator reflecting the proportion of patients receiving treatment at specialized facilities is the coverage rate of facilities participating in hospital-based cancer registries. This rate measures the percentage of initial treatment cases registered at facilities that conduct hospital-based cancer registries, including nationally designated hub hospitals, prefectural hospitals, and pediatric cancer hub hospitals, relative to the number of breast cancer patients in the region<sup>1</sup>. In 2018, the highest coverage rate was 89.3% in Tottori Prefecture, while the lowest was 35.3% in Miyazaki Prefecture, showing an approximately 2.5-fold difference between regions<sup>2</sup>. Additionally, an analysis of 2020 hospital-based cancer registry data comparing the number of breast cancer cases treated at prefectural hub hospitals revealed significant regional differences, even among prefectures with similar numbers of breast cancer patients. For example, in Ehime Prefecture (1,081 patients), 362 cases were treated at hub hospitals, whereas in Okinawa Prefecture (1,081 patients), only 92 cases were treated. Similarly, in Yamagata Prefecture (709 patients), 233 cases were treated at hub hospitals, whereas in Oita Prefecture (788 patients), only 109 cases were treated. These findings suggest considerable variation in the centralization of cases to hub hospitals across regions. It is noteworthy, however, that a higher number of cases treated at hub hospitals does not necessarily represent the optimal form of regional healthcare, as the division of roles among medical institutions varies by region<sup>x</sup>.

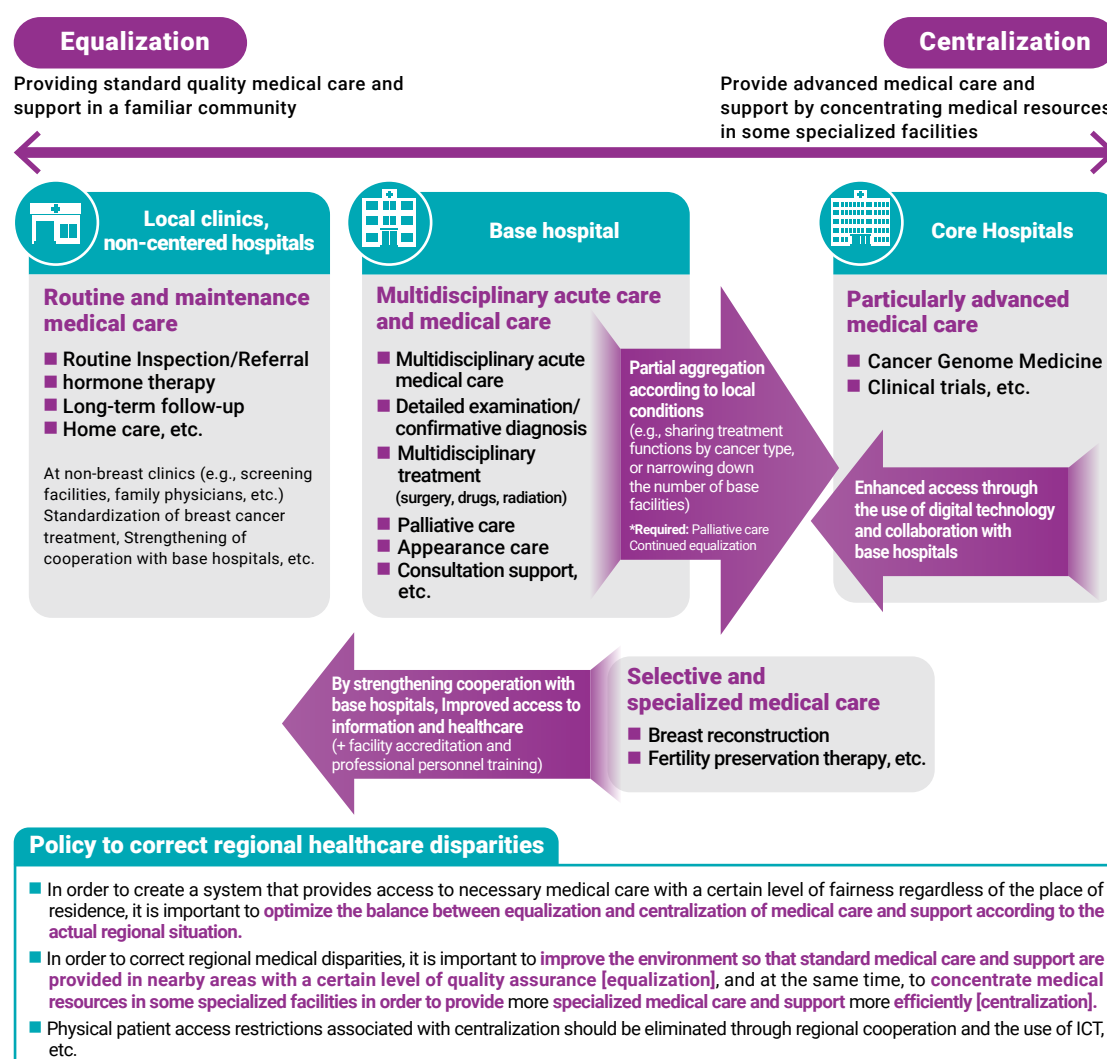
Additionally, the number of cases handled per specialist involved in breast cancer care suggests regional differences in the degree of centralization. Using data from the number of specialists in nationally designated hub hospitals in each prefecture (breast surgery specialists and cancer drug therapy specialists, as reported in the 2023 status report) and the number of breast cancer patients treated at those hospitals (hospital-based

x In Okinawa Prefecture, breast cancer diagnosis and treatment are frequently conducted at breast specialty clinics. According to the 2022 Okinawa Prefecture Hospital-Based Cancer Registry Report, two of the top five facilities for breast cancer registrations were clinics: Naha West Clinic with 335 cases, Nakagami Hospital with 268 cases, Naha City Hospital with 174 cases, Urasoe General Hospital with 154 cases, and Makabi Branch of Naha West Clinic with 140 cases.

cancer registry cases of all breast cancer stages diagnosed in 2022), the average number of cases per specialist was estimated. Among prefectural cancer care coordination hub hospitals of the same designation, the highest average was observed in Shiga Prefecture, with 83.5 cases per specialist, while the lowest was in Oita Prefecture, with just 3 cases per specialist, showing a large discrepancy of approximately 27 times. In rural areas, where the absolute number of physicians is lower than in urban areas, many cases are concentrated among a small number of physicians at hub hospitals, or the available human resources, such as breast surgeons, as well as cases, may be dispersed among small hospitals or other institutions. When cases are dispersed and numbers are low, issues such as costs and difficulty in securing personnel may hinder the introduction of advanced medical equipment or the provision of high-level treatments. This makes it challenging to establish an efficient regional healthcare delivery system, potentially leading to a decline in the quality of care. However, it should also be noted that facilities other than hub hospitals may play a central role in regional breast cancer care, handling a significant number of cases, which could impact the interpretation of the number of cases per specialist.

Although the division of roles among facilities varies by region, the significant disparities in centralization (number of cases per facility or physician) highlight the need to reconsider the minimum number of cases required for hub hospitals to fulfill their intended role of providing high-quality cancer care. Furthermore, in cases where non-hub facilities play a central role in breast cancer care, it is crucial to establish guidelines for the necessary number of cases at such facilities. Based on this, efforts should focus on achieving regionally appropriate and adequate centralization and role-sharing to address local needs effectively.

### Example of organization of equalization/intensification functions in breast cancer treatment (Current status and directional thinking for each function)





While the centralization of medical functions is critical for the efficient delivery of high-quality healthcare, it also presents challenges. For instance, access issues related to centralized medical systems, such as genome medicine and clinical trials, have become evident due to the limited number of facilities capable of providing such care. In practice, geographical conditions significantly affect access to medication and treatment availability (particularly for unapproved medication) for patients who have undergone gene panel testing<sup>10</sup>. Clinical trials associated with cancer genome medicine tend to be concentrated in large medical institutions or specific research facilities. As a result, patients who undergo panel testing at local medical institutions and identify treatment targets (available only through clinical trials) often face difficulties accessing these trials if the implementing hospital is located far away. Physical, logistical, and financial burdens can lead some patients to forgo treatment altogether. Addressing such geographical and physical barriers to cutting-edge medical care is a critical issue in advancing the centralization of healthcare services.

#### **Lack of Regional Coordination Systems and Frameworks Between Hub Hospitals and Other Facilities**

In breast cancer treatment, local care is often required for long-term hormone therapy after intensive treatment, as well as for medium- to long-term follow-up after remission. Additionally, treatment options associated with breast cancer care—such as breast reconstruction and reproductive medicine (fertility preservation)—require integrated and interdisciplinary collaboration not only between cancer treatment facilities but also with relevant specialties and dedicated facilities. However, in the current cancer care system, including breast cancer, smooth coordination among prefectural administrations, cancer treatment coordination councils, and non-specialized hospitals within the region is not always achieved. Geographical access to specialized facilities capable of providing breast reconstruction or fertility preservation often poses a challenge. Moreover, in cases where integrated and interdisciplinary coordination is not well-established, patients may receive limited information about available treatment and care options.

**Transition and Coordination Between Medical Institutions:** There are regional disparities in the coordination between hospitals providing acute-phase treatment and local facilities offering continued care. For example, some clinics accept only patients referred from specific major hospitals, and inter-facility coordination often depends on personal relationships between physicians. These variations lead to disparities in patients' transition experiences.

**Breast Reconstruction Surgery:** Collaboration between breast surgeons and plastic surgeons is essential for breast reconstruction surgery. Additionally, the Ministry of Health, Labour and Welfare (MHLW) has established requirements for facilities that can perform breast reconstruction. As a result, in some regions, breast reconstruction cannot be carried out within the area. This requires inter-departmental or inter-facility collaboration, sometimes even across regions. However, for medical procedures that require collaboration across departments, facilities, or even regions, it is often the case that such information is not adequately communicated from physicians to patients. For example, breast surgeons may not adequately inform patients about breast reconstruction procedures, which fall under the field of plastic surgery. In rural areas facing depopulation, not only is access to capable facilities limited, but patients often receive insufficient information, thereby further restricting their options<sup>12</sup>.

**Fertility Preservation Therapy:** Efforts are underway in each prefecture to establish the "Cancer and Reproductive Medicine Network," aimed at fostering collaboration between cancer treatment physicians, reproductive medicine specialists, and administrative bodies. However, some prefectures are still not able to coordinate in a sufficient and effective manner between the cancer care and reproductive medicine sectors, thus highlighting the importance of equalizing regional collaboration<sup>15</sup>.

These challenges can be attributed to a lack of properly structured regional coordination frameworks comprising of both hub and non-hub facilities, as well as inter-departmental collaboration. Regarding regional healthcare delivery systems, prefectural healthcare plans call for the establishment of forums where related medical professionals, including regional medical associations, dental institutions, and pharmacies, can discuss strategies. However, while the national guidelines for system development state that "those responsible for cancer care in the region, administrative bodies, patient organizations, and other related entities should actively participate," they do not specify concrete roles or activities expected in regional

coordination. As a result, the adequacy of collaboration systems with non-hub medical institutions varies by region and type of medical support. It is also presumed that the dissemination of initiatives such as the Basic Plan to Promote Cancer Control and related measures has not fully reached all stakeholders, limiting their impact.

### **Shortage and Geographic Imbalance of Personnel Responsible for Breast Cancer Care**

Establishing a robust healthcare delivery system requires the training and allocation of specialized personnel to support medical services. The government has been promoting the development of cancer care professionals through the "Next-Generation Cancer Professional Training Plan" (Cancer Pro). However, the shortage of specialists, including surgeons, and the uneven distribution of personnel across regions and medical departments remain critical issues. These disparities between regions and institutions are widening rather than improving. As a result, challenges have emerged, such as fewer cancer gene panel tests being conducted in regions with a smaller number of cancer drug therapy specialists, thereby underlining the effects of these imbalances.

In Japan, there is a shortage of specialists available for breast cancer care, including breast surgeons, cancer drug therapy specialists, radiation oncologists, hereditary tumor specialists, and palliative care specialists, with significant regional disparities. Quantitative analysis conducted for this report revealed that the number of breast surgeons per 1,000 breast cancer patients varies by approximately fourfold between prefectures (highest: Kyoto, 37.08; lowest: Aomori, 9.12). Similarly, the number of cancer drug therapy specialists per 1,000 cancer patients varies by approximately fivefold (highest: Tokyo, 3.28; lowest: Akita, 0.62), and the number of radiation oncologists varies by approximately sixfold (highest: Kyoto, 2.78; lowest: Miyazaki, 0.48)<sup>1</sup>. For hereditary tumor specialists and palliative care specialists, the nationwide allocation remains insufficient. Several prefectures have no hereditary tumor specialists at all. In Tokyo, there are 1.5 hereditary tumor specialists per 1,000 cancer patients, but in more than half of the prefectures, this figure is below 0.5, indicating a nationwide shortage and an uneven distribution. Furthermore, it has been reported that more than half of the palliative care teams and palliative care wards at hub hospitals lack a dedicated palliative care specialist, highlighting the deficient allocation of these professionals.

Furthermore, there is no clear prospect for improvement regarding the shortage and geographic maldistribution of specialist physicians. Like other surgical societies, the Japan Breast Cancer Society has seen a declining trend in membership in recent years<sup>xi</sup>. Some physicians are working nearly 3,000 hours of overtime annually. To achieve work style reform for physicians and enable efficient and effective team-based care, measures such as task-sharing and task-shifting with doctor's assistants, medical clerks, and nurses must be advanced. This is particularly important as the majority of younger breast surgeons are women, who often face life events such as maternity leave and childcare, requiring even greater efforts to promote work style reform. However, according to the "Survey on Work Styles of Physicians and Others Working in Hospitals (2020)" conducted by the MHLW, 27% of the 3,155 hospitals that participated in the survey had not implemented task-shifting for tasks such as inputting medical certificates. Additionally, more than half of the medical corporations, which account for 65% of the hospitals surveyed, did not employ physician administrative assistants. The MHLW is discussing nationwide measures to address issues such as the geographical maldistribution of physicians and the imbalance between hospital and clinic employment. Alongside comprehensive and fundamental measures at the national level, it is necessary to hold region-specific discussions among stakeholders to address regional realities, including physician allocation, the design of clinic and hospital networks, and the ideal form of hospital-clinic collaboration, to steadily advance these efforts.

In addition to specialists, nurses and pharmacists with specialized qualifications who play a central role in medical care also face an absolute shortage and significant geographical discrepancies. As of December 2023, there are fewer than 400 certified breast cancer nurses nationwide. On a prefectural basis, 42 are located in Tokyo and 31 in Kanagawa, indicating a concentration in metropolitan areas. In contrast, 35 prefectures have fewer than 10 certified breast cancer nurses, highlighting a significant disparity between urban and rural areas. Similarly, for other specialized roles in cancer care—including certified oncology nurses

<sup>xi</sup> According to the Japanese Breast Cancer Society's website, the number of members peaked in 2015 and has been declining since then, with a notable decrease in new memberships among young physicians.

involved in cancer nursing (including breast cancer), certified oncology chemotherapy nurses, certified oncology radiation therapy nurses, as well as oncology pharmacists, certified oncology drug therapy pharmacists, and certified outpatient oncology treatment pharmacists—there are substantial disparities in the number of certified professionals across prefectures, mirroring the trends observed for nurses.

It has also been noted that the specialized skills of certified nurses are not being fully maximized within their regions. During the 83rd Cancer Control Promotion Council (2022), the utility of highly specialized nurses was highlighted in scenarios such as decision-making support and psychosocial support in cancer genome medicine, as well as continuous care for side effects during and after treatment for AYA generation cancer patients. However, many certified nurses remain focused on routine clinical practice at their affiliated medical institutions. Mechanisms to leverage these nurses as community resources—such as accompanying home-visit nursing services or providing consultations to regional nurses—have not yet become widely established.

In recent years, with advancements in cancer genome medicine, the importance of genetic counselors has substantially increased. These professionals play a key role in risk assessment, consideration of genetic testing, post-test explanations, psychosocial support during treatment and care, and follow-up for blood relatives. According to the Breast Cancer Treatment Guidelines, 5–10% of breast cancer cases are considered hereditary. Evaluating the possibility of hereditary breast cancer in patients with a history of breast cancer and providing genetic testing and counseling are crucial for secondary cancer prevention.

However, as of March 2024, there are only 387 certified genetic counselors nationwide<sup>xii</sup>, and they are heavily concentrated in metropolitan areas such as Tokyo. Many prefectures lack certified counselors, resulting in significant regional disparities, in comparison with other specialized professions.

In cases of early-stage breast cancer with relatively favorable long-term prognoses, support for balancing work and treatment, as well as assistance with returning to work, is essential from a survivorship perspective. Professionals such as appearance care training graduates and work-life balance support coordinators play key roles in these situations. However, there are significant regional disparities in the number of such professionals. For example, the number of appearance care training graduates ranges from a minimum of 5 in the least-populated prefecture to a maximum of 266 in the most populous prefecture. Similarly, for work-life balance support coordinators, the ratio per 100,000 population varies significantly, from 33.8 in Tottori Prefecture to 9.5 in Saitama Prefecture, a difference of approximately 3.6 times. From the perspective of balancing treatment and employment, it is necessary to establish consultation systems that provide adequate and continuous support for employment. However, medical institutions often report that it is difficult to hire personnel who do not directly contribute to securing medical reimbursements, further complicating efforts to enhance support systems.

### **Regional Disparities in Systems for Training Professionals in Breast Cancer Care**

To ensure an adequate supply of healthcare professionals in breast cancer care in the future and to address disparities in medical resources across prefectures, it is essential to reinforce and expand education systems for training specialized medical personnel. However, regional disparities exist even in the education systems at universities, which serve as the primary training institutions for specialists. According to the report by Ishioka et al., (year) more than half of university hospitals lack specific medical courses for training radiation oncologists and palliative care specialists. While the Ministry of Education, Culture, Sports, Science, and Technology has promoted the "Cancer Professional Training Plan" since 2007, aiming to develop cancer specialists, including cancer drug therapy specialists, the number of oncology departments established at universities remains insufficient. Additionally, many hospitals in rural areas rely on a single breast surgeon to manage breast cancer treatment, thus making it difficult to internally sustain personnel training within the hospital. Historically, medical departments played a significant role in personnel deployment and education. However, since the introduction of the new clinical training system, the functions of medical departments have evolved, mandating a reexamination of how physician education systems in rural areas should be designed and structured.

<sup>xii</sup> The source document, the Certified Genetic Counselor Registry, lists 388 individuals. However, during the verification process, information for one individual was missing. Therefore, this report adopts the count of 387, based on the verifiable data.

For certified nurses, limited educational facilities and the lack of incentives are also considered factors hindering an increase in qualified personnel. Obtaining certification often requires nurses to take leave or resign from their positions to enroll in training programs. Furthermore, after obtaining certification, additional allowances are rarely provided, resulting in a mismatch between the effort required to earn the qualification and the rewards received. Additionally, during the expert meetings held for this report, it was noted that hospital nurses often undergo departmental or ward rotations every few years. This means that even after obtaining certification, nurses may not always work in environments where they can consistently apply their specialized skills. This rigid career path, where nurses are valued primarily as generalists, was highlighted as another challenge.

From the perspective of institutions providing education for specialized certifications, significant disparities in academic ability among trainees with diverse nursing education backgrounds have increasingly burdened dedicated instructors. Additionally, challenges such as declining enrollment and difficulties in securing dedicated teaching staff have led to a rise in the suspension of educational programs, making it increasingly difficult to maintain a suitable and proper educational environment. Moreover, beyond the initial qualification process, a scarcity of learning opportunities for knowledge development post-certification has also been highlighted. For instance, current breast cancer specialists are required to renew their certification every five years; however, updating and developing their knowledge during the renewal period largely relies on individual efforts. In many rural hospitals, where a single physician often manages breast cancer care, it is challenging to engage in mutual verification of treatment practices within the medical team. As a result, there are concerns that treatments are not always based on the latest and most relevant evidence, thereby contributing to regional disparities in care.

### **[Recommendations for Addressing the current Challenges]**

In the above sections, issues were identified concerning the functional differentiation and centralization of breast cancer care within regions, the coordination frameworks between hub hospitals and other facilities, the shortage and geographic maldistribution of personnel in breast cancer care, and the challenges in the educational systems for human resource development. To address these challenges, the following five measures are proposed:

#### **1. Accelerating Functional Differentiation and Coordination Among Medical Facilities (Development of a "Hub-and-Spokes" Network)**

To prepare for the future advancement of cancer care and population decline, we propose the optimization and differentiation of healthcare functions while creating an organic network to maximize the use of limited human resources. Stakeholders at the national, prefectural, and medical institution levels should demonstrate leadership from their respective positions to discuss and formulate plans for centralization that align with regional realities.

In breast cancer care, for example, advanced and specialized medical institutions or hub hospitals with comprehensive functions could focus on tasks such as advanced diagnostics, definitive diagnosis, surgery, radiation therapy, drug therapy (including chemotherapy and molecular-targeted therapy), fertility preservation, breast reconstruction, cancer genome medicine, clinical trials, and social care such as employment support. Meanwhile, local clinics could handle long-term follow-up treatments, including regular check-ups and hormone therapy.

To achieve the above, the following actions are expected from the key stakeholders:

National Government (MHLW)	To ensure both the quality of healthcare in each region (addressing regional disparities) and a sustainable healthcare delivery system, discussions should be conducted with a certain level of specificity, such as by cancer type for high-incidence cancers. These discussions should aim to establish a clear direction regarding the functions that should be centralized and equalized.
	Based on the above direction, efforts should be made to ensure that discussions on the differentiation and coordination of healthcare delivery functions proceed accordingly in each prefecture, taking into account regional circumstances. This includes establishing necessary financial resources (e.g., medical fees, grants) and refining various systems. For example: <ul style="list-style-type: none"> <li>■ <b>Incentive Allocation:</b> Consider allowing hospitals that achieve functional centralization with a certain number of cases and a high referral patient ratio to claim medical fees for outpatient or inpatient services, providing incentives. This may involve revising the requirements and points for cancer hub hospital add-ons.</li> <li>■ <b>Promotion of Telemedicine:</b> Institutionalize and encourage, and accelerate the use of telemedicine for online medical coordination, online consultations, and decentralized clinical trials (linked to Recommendation 3).</li> </ul>
	Consider establishing a system for regional coordination, led by prefectural councils and medical associations, to facilitate the sharing of medical information between hub hospitals and clinics through digital technology. This could include the development of inter-facility and interdisciplinary information-sharing systems based on electronic medical records, as outlined in the development guidelines.
	Establish an effective platform to discuss the challenges of functional differentiation and coordination systems among medical institutions within each region, as well as national directions. This platform should also facilitate the sharing of best practices, leveraging the Prefectural Cancer Care Coordination Hub Hospitals Liaison Council for maximum impact.
	For medical functions that require cross-prefectural coordination, such as cancer genome medicine and clinical trials, the national government should take the lead in formulating guidelines for collaboration.
Academic Society	Present a framework for regional coordination in breast cancer care, including directions for role-sharing. For instance, outline specific roles and actions for each type of medical institution, such as conducting routine tests at local clinics while scheduling periodic visits to hub hospitals every few months. This should include the development of a regional care pathway guidance document led by academic societies, specifying standard schedules and responsibilities for coordinated care.
Prefecture	Include in the Prefectural Cancer Control Promotion Plan a provision stating that "the council will take the lead in considering case volume standards for facilities handling breast cancer, based on the circumstances of each secondary medical area, and promote discussions on role-sharing among medical institutions, such as hub hospitals, as well as the allocation and development plans for specialized medical personnel." Additionally, establish specific achievement indicators to evaluate and manage the progress of the plan.
Prefecture/Council	Analyze the treatment performance data of each medical institution based on the cancer type to consider case volume standards for facilities playing central roles. Use these findings to accelerate discussions on the centralization of treatment functions, role-sharing (with effective measures), and regional coordination frameworks. These discussions should include not only hub hospitals but also medical associations and non-hub institutions, such as clinics specializing in breast cancer care, other specialties, and primary care physicians, to comprehensively address functional and role-sharing arrangements.

## 2. Leveraging Digital Technology to Address Geographic Access Constraints and the Shortage/ Maldistribution of Specialists

It is proposed to use telemedicine and online consultations among healthcare providers to reduce disparities in geographic access for patients, while also sharing expertise and specialized human resources to establish an efficient regional specialist medical system. For clinical trials, the promotion of decentralized clinical trials (DCTs) that do not rely on patient visits should be pursued to encourage proactive collaboration among medical institutions, increase patient engagement, and expand opportunities for clinical trial participation. As a foundational step to advance these initiatives, it is essential to promote the digitization of patient information required for inter-hospital coordination, focusing on the "three documents and six pieces of information." Efforts should also be made to reduce the operational burden in regional and inter-facility collaboration.

The following actions are expected from key stakeholders to realize the above initiatives:

<b>National Government (MHLW)</b>	To accelerate online and remote medical coordination as well as the use of digital technology for operational efficiency in the field of oncology, consider revising incentives such as enhancing medical fees related to such services in order to increase the revenue of healthcare institutions and reviewing the hub hospital system.
	Promote research and technological development support (e.g., research projects and grant programs), as well as the formulation and dissemination of guidelines and examples of their application, to ensure the implementation of digital initiatives in cancer care. These initiatives include the development of information-sharing platforms driven by medical DX, collaboration between local governments, healthcare institutions, and long-term care providers, and the secondary use of data. These efforts aim to address regional disparities and evaluate the clinical feasibility of digitalization, while considering policy integration into a sustainable healthcare delivery system.
<b>National Government (MHLW/Ministry of Education, Culture, Sports, Science and Technology, MEXT)</b>	To enable the practical implementation of medical DX, establish guidelines for training plans and systems for ICT personnel. Additionally, advance measures such as securing financial resources for personnel development and deployment, as well as facilitating the placement of such personnel.
<b>National Government (MHLW)/Health care facilities/healthcare industry</b>	<p>To promote the adoption of online consultations, electronic patient information sharing, AI-driven operational efficiency (e.g., automation of document creation), and the online implementation of DCTs/clinical trials, discussions should be held among stakeholders to address regulatory barriers and devise solutions, fostering collaboration.</p> <p>In addition, to accelerate the practical application of electronic patient information sharing in the field of oncology, model projects should be conducted, for example, employing the electronic medical record information-sharing service set to begin operation in 2025. These initiatives should aim to verify the utility of such services and also address the following practical issues:</p> <ul style="list-style-type: none"> <li>■ Defining standardized data formats for information sharing required for breast cancer care</li> <li>■ Establishing the framework for an information-sharing online platform</li> <li>■ Determining the scope of information disclosure to patients, including informed consent and patient summaries (especially for patients who have not been informed)</li> </ul> <p>The findings should be examined, the challenges and solutions discussed, and the results made publicly available to inform a wide range of regions and medical institutions.</p>
<b>Prefecture/Council</b>	In regional coordination, actively discuss the ICT transformation and explore strategies for the efficient sharing and the use of medical resources, including patient information and human resources (e.g., providing specialized healthcare through regional online consultations). Additionally, encourage discussions on specific human resource training plans, including the number of personnel required and the necessary skills, to meet the needs of the field in the context of ICT adoption.



### 3. Promoting Systematic Discussions on Accelerating the Allocation and Task-Sharing of Specialized Cancer Personnel

To enable diverse healthcare professionals supporting breast cancer care to efficiently and effectively provide team-based care, it is proposed to advance systematic discussions on defining the required personnel and role-sharing for breast cancer care in each region. This should include specific qualifications and a clear framework for allocating tasks among medical professionals.

The following actions are expected from key stakeholders to realize the above initiatives:

<b>National Government (MHLW)</b>	For the shortage of personnel, particularly nurses and pharmacists with specialized knowledge in cancer care, it is proposed to advance discussions on revising incentive structures, such as the criteria for hub hospital designation and medical reimbursements, to promote an increase in qualified professionals and their employment. For example, setting guidelines for the patient-to-cancer nursing specialist ratio in outpatient settings could be considered as a part of this initiative.
<b>Academic Society</b>	Regarding specific skills training, we propose to not only include lectures and group training sessions but also evaluate practical experience in clinical settings. Additionally, training regulations should be regularly reviewed to ensure that undergoing training does not impose an excessive burden on healthcare staff.
<b>Prefecture</b>	Visualize the number of specialized professionals and the status of task-sharing at each facility, and advance discussions on regional personnel allocation, role-sharing, education, and the centralization of services based on these conditions. This should include strategies for securing and optimizing human resources.

### 4. Creating an Environment that Facilitates Learning and Utilizing Expertise and Skills in Cancer Care

To train and secure specialized medical personnel for cancer care, it is essential for all necessary stakeholders to collaborate in initiating and advancing systemic discussions. Additionally, to minimize geographical and time constraints in acquiring qualifications and knowledge, it is proposed to leverage ICT and other tools to revise training methods and improve access to education.

The following actions are expected from key stakeholders to realize the above initiatives:

<b>National Government (MHLW/MEXT)</b>	Based on future projections of physician supply and demand, it is essential to assess the current situation regarding workforce development in the region. Following this, discussions should be actively conducted with relevant stakeholders, including professional associations and academic societies, on the necessary personnel (including job types), the methods for training (including national certification), the appropriate setting of medical fees when placing specialists in cancer care, and the development of specific schedules and plans for implementation. This should be considered in relation to the basic plan and hub hospital system.
<b>National Government (MHLW)/Prefecture</b>	In each region, to ensure the adequate supply of specialized healthcare personnel, we suggest the consideration of providing financial support for education, such as grants and subsidies, particularly for professions with significant supply-demand gaps. Additionally, the distribution and activity status of personnel after acquiring specialization should be visualized to promote the effective administration of expertise within the region.
<b>Academic Society</b>	Utilize QI indicators to monitor the implementation rate of standard treatments by physicians with specialist qualifications. For physicians with low compliance rates, conduct root cause analysis and require reports on improvement measures. If necessary, mandate training participation to actively intervene in the process of understanding and improving the situation. (For example: Strengthening the use of NCD/QI by the Japan Breast Cancer Society).

<b>Professional organizations</b>	To lower the barriers to obtaining specialist qualifications, particularly for nursing and pharmacy staff, it is proposed to enable qualification acquisition and maintenance through a combination of practical experience in the field and online learning (e.g., developing curricula that prioritize the evaluation of clinical competencies over course completion). Additionally, provide specific examples of the use of various specializations and career path options to support the development of diverse professional roles.
	To ensure that high-quality breast cancer care can be practiced even in regions and facilities with a shortage of specialized healthcare personnel, it is proposed to create a widely accessible manual that can be used in clinical settings.
<b>Healthcare institutions/Council</b>	To facilitate smooth collaboration between non-hub hospitals (such as clinics specializing in breast care, other medical departments, and primary care physicians) and hub hospitals, it is proposed to cooperate with local medical associations to provide regular training opportunities for knowledge development and refinement. Additionally, clearly define regional healthcare institutions based on their functions and promote the acquisition of knowledge and skills by non-specialist physicians to strengthen collaboration.



## 2. Visualization and Improvement of Healthcare Quality through Data Utilization (Ensuring the PDCA Cycle)

The second underlying factor contributing to regional disparities in breast cancer care is the lack of a system that evaluates the quality of care based on data and connects that evaluation to improving the quality of the healthcare provided (the PDCA cycle). This section also addresses the challenges related to the data implementation environment necessary to implement and evaluate these improvements.

### [Current Situation and Challenges]

#### Lack of appropriate Systems and Platforms for Running the PDCA Cycle to Evaluate the Quality of Breast Cancer Care

To evaluate and improve the quality of healthcare in regions and medical institutions, it is essential to establish objective and appropriate indicators, visualize the current state of healthcare delivery, and create systems for running the PDCA cycle. This involves reviewing the indicators regularly and considering appropriate measures at each level—national, regional, and institutional—to ensure the continuous improvement of care.

At the national level, the 4th Cancer Control Promotion Plan has established a logic model with specific evaluation indicators for cancer prevention, cancer care, and living with cancer. These include individual output measures, intermediate outcomes, field outcomes, and final outcomes, which are used to evaluate policies. However, some of these indicators (e.g., postoperative mortality rate and standard treatment implementation rate) lack target values. As a result, it remains unclear how these indicators will be reflected and implemented in cancer medical policy, particularly in terms of strategies to address regional disparities.

At the regional level, there are disparities in the implementation of the PDCA cycle for cancer care. In fact, differences between regions have been pointed out in terms of the review systems for the "Prefectural Cancer Control Promotion Plans" and the quality of the plans themselves. According to the Cancer Control White Paper (2022) compiled by the Cancer Control Comprehensive Organization, for example, Nara Prefecture planned to hold 19 meetings (including subcommittees) with approximately 90 stakeholders to develop its prefectural plan. In contrast, Niigata Prefecture planned only one meeting with a membership of 16 people. These differences in the "number of participants," "number of meetings," and the presence or absence of "subcommittees" clearly indicate disparities between prefectures.

At the facility level, quality improvement initiatives in healthcare often use Quality Indicators (QI) to directly or indirectly reflect patient health outcomes, which serve as evaluation metrics for medical institutions. In the field of breast cancer care, QI setting and implementation have advanced through initiatives such as the QI research project by the Cancer Registration Division of the Prefectural Cancer Care Coordination Hub Hospitals Liaison Council and the Japan Breast Cancer Society's development of "QI in Breast Cancer Care." However, the public disclosure of QI data and its use in facility-based improvement efforts rely largely on individual institutional efforts. Opportunities for inter-organizational information sharing are limited, so the sharing of accumulated knowledge regarding data measurement and utilization has not yet been achieved.

In the guidelines for the development of cancer care hub hospitals, the national government specifies that "Prefectural Coordination Councils should share, analyze, evaluate, and publish data from in-hospital cancer registries, cancer care, palliative care, counseling support, and other services from hub hospitals within the prefecture. Based on this, each prefecture should collaborate and create and implement specific plans to improve the quality of cancer care across the entire prefecture, actively using Quality Indicators (QI). Additionally, the government should work to promote the collection and utilization of cancer-related information within the prefecture, including supporting in-hospital cancer registry personnel." However, according to the "In-Hospital Cancer Registry Status Survey Report (2022)" by the National Cancer Center, more than half of the 863 facilities participating in the survey reported that they were unable to utilize in-hospital cancer registry data for their hospital's policies. The same report also revealed significant disparities between types of facilities in the establishment of committees to evaluate operational challenges and the use of in-hospital cancer registries (e.g., cancer care hub hospitals (87.5%) vs. prefecture-recommended hospitals

(48.8%)). There are significant regional and facility-based disparities in the utilization and systems for cancer care data. This indicates that a foundational data infrastructure for analyzing the quality of cancer care and conducting self and inter-facility comparisons has not yet been adequately established.

According to the results of the pre-survey conducted at the 2023 Prefectural Cancer Care Coordination Hub Hospitals PDCA Cycle Forum, among 29 hub hospitals, only slightly more than half of the prefectures had achieved the initial design of the PDCA cycle, which includes identifying issues in cancer care, setting common goals, and developing action plans. Additionally, in more than half of the prefectures, the progress of the PDCA cycle was not adequately monitored or evaluated. Therefore, it can be said that a system that is sufficient in the evaluation of care quality through the PDCA cycle has not yet been fully developed.

In a study on cancer care evaluation indicators conducted by Fujii et al., it was pointed out that, particularly for process evaluation, there is a limited amount of cancer-specific data linked to Diagnosis Procedure Combination (DPC) data, and there is a lack of nationwide comparative information. These issues highlight the challenges of limited available data and the high workload at the frontline, making it difficult to continuously implement indicator measurement and quality evaluation in cancer care. To evaluate and improve the quality of healthcare in a sustainable manner, it is crucial to design indicators and data registration tasks that minimize the burden on healthcare providers.

Finally, it is imperative to mention the evaluation of healthcare quality from the patient's perspective. For individual cancer patients, understanding which medical institutions in their region provide care, the background of the patients receiving care there, the type of medical care offered, and the patient's experience with the care is crucial for making informed decisions about treatment options. For instance, in Ehime Prefecture, the Cancer Care Coordination Council's website ("Cancer Support Site Ehime") compiles and presents data such as the number of patients, treatments, the medical staff structure (including specialists and specialized nurses), and various initiatives at hub hospitals and prefecture-designated cancer care hospitals. This information serves as an important resource for patients when choosing a hospital for treatment. However, based on a review of publicly available information, similar data is not commonly found on other prefectures' websites or cancer care coordination council sites, where most information is limited to basic hospital names and contact details. Given that many patients today rely on publicly available information from the internet for decision-making, it is crucial for the regional healthcare system and the roles of medical institutions to be clearly specified and outlined. This will assist patients in making informed choices about healthcare institutions, and ultimately, the right treatment options. It is desirable for such information to be comprehensively published, regardless of the patient's region.

### **Lack of an Established Data Implementation Environment for Evaluating Healthcare Quality**

In order to evaluate and improve the quality of healthcare over time, it is essential to build databases and combine existing data to extract new insights in breast cancer care. This is crucial for improving healthcare quality. However, in the current data utilization environment, there is a lack of data sources for evaluating the quality of patient care, limitations on the use of data, insufficient skills and human resources, and in some cases, a lack of progress in the digitization of medical records, which results in the ineffective use of data.

For example, the National Cancer Registry, which registers information on all cancers diagnosed in Japan, and in-hospital cancer registries at specialized cancer care institutions such as hub hospitals, are expected to enable more thought-through evaluations of the medical processes and outcomes for individual patients when cross-referenced with public databases such as DPC, NDB, and databases like NCD, which were built under the leadership of academic societies. These databases offer comprehensive and accurate data on cancer incidence and mortality. However, currently, the linking and analysis of the National Cancer Registry (or in-hospital cancer registry) with other public healthcare databases is still an ongoing issue for discussion at the national level and has not yet been realized. While NCD excels in comprehensiveness of registration and the richness of information on treatment details and risk factors, particularly for surgeries. However, when it comes to tracking prognostic information, collaboration with other databases is a critical issue to ensure both efficient data collection and the quality of the data. Collaborating with other databases remains a significant

issue. Additionally, challenges in the employment of these databases have been specifically indicated. For example, public databases like NDB (excluding open data), DPC, and cancer registry databases require lengthy and complicated application procedures, and the strict constraints on their usage have been identified as barriers in national forums for promoting data utilization. While discussions on promoting the use of these public databases have progressed alongside the ongoing debates on medical DX, further improvements in the implementation and employment environment, are still needed while taking into account the needs of healthcare providers. Furthermore, the shortage of personnel capable of administrating these data is also a concern. For instance, in-house cancer registry information analysis is primarily handled by in-house cancer registry practitioners. However, there are frequent reports from the field that the lack of skills in using analysis tools, along with being overburdened and handling multiple roles, makes it difficult to find time for skill and knowledge development and data analysis itself.

Additionally, the "current status report" that the government requests from each hub hospital regarding their medical system, activities, and progress can serve as data to understand the current state. However, this report was designed primarily for the purpose of hospital designation, not for improving the quality of care. For example, due to ambiguous definitions of the reporting items, there is variability in the data across facilities. Many questions are framed in a yes/no format, with many facilities answering "yes," which leads to limited differentiation. As such, the current reporting format is not particularly helpful for continuous benchmarking in the region or for improving the quality of cancer care through PDCA cycle activities.

### **[Recommendations for Solving these Issues]**

In addressing these issues, we identified a scarcity of systems and platforms for running the PDCA cycle to evaluate the quality of breast cancer care, as well as the underdeveloped data utilization environment for evaluating healthcare quality. To correct regional disparities in breast cancer care, it is essential to accurately assess the quality of care over time and work towards continuous improvement based on data and evidence. Particularly in the treatment of recurrent breast cancer, which is highly complex, building Real World Data (RWD), generating Real World Evidence (RWE), and creating progressive systems to improve patient quality of life (QOL) and healthcare economic efficiency are urgent and noteworthy tasks. To establish a system for running the quality evaluation cycle and build a data infrastructure, the following two measures are proposed.

#### **1. Ensuring the Feasibility of the PDCA Cycle for Regional Healthcare Based on Evidence-Based Data**

To improve the quality of breast cancer care, it is crucial to analyze the current state of cancer care at each level—medical institutions, prefectures, and the national level—based on objective data, and to continuously implement the PDCA cycle. It is recommended to establish a forum for discussing the status and challenges of data usage, as well as to strengthen initiatives that assess the appropriate role distribution among regional healthcare institutions, evaluate progress, and address any issues based on the actual circumstances.

The following actions are expected from key stakeholders to achieve the above initiatives:

<b>National Government (MHLW)/National Cancer Center · Council (National level)/Academic Society</b>	Establish a forum to discuss measures addressing regional disparities in cancer care, such as variations in the implementation rate of standard treatments. Additionally, utilize the logic model of the Cancer Control Promotion Plan to specifically design objective improvement goals for the quality of cancer care and regularly review them at appropriate intervals.
	In the process of these discussions, the Japan Breast Cancer Society will take the lead (with other relevant academic societies for cancers other than breast cancer) in establishing national standards for evaluating the quality of breast cancer care, such as QI indicators, and defining how these standards will be implemented. Additionally, active information distribution will be promoted, starting with facilities and regions that agree, encouraging discussions on cancer control and the healthcare delivery system at the national and prefectural levels. Furthermore, patient and citizen representatives will be actively involved in the development of indicators, improvement initiatives, and information disclosure strategies, ensuring that the perspectives of patients are reflected in these efforts.
	Regular forums will be established to discuss the usage status and challenges of various data sources, such as NCD, NDB, and cancer registry data, and to share best practices. These forums will serve as platforms for stakeholders to share awareness and exchange opinions on the visualization of healthcare and quality improvement based on data. Furthermore, efforts to improve care quality will be made accessible not only to participating institutions but also to a broader range of facilities. Special attention will be given to activating quality improvement initiatives even in small-scale facilities where systems for QI measurement and other frameworks have not yet been established.
	Personnel and teams will be dispatched to each region to support data analysis by cancer type (or medical specialty), provide best practices, and offer advice on data management and dissemination to promote the effective use of data. For example, regarding the QI indicators set by the Japan Breast Cancer Society, discussions will be held to explore whether these can be applied at the regional level to address regional disparities in breast cancer care.
<b>Prefecture/Council</b>	Responsible individuals from key cancer care facilities within each prefecture will be gathered to set indicators and visualize data at the disease-specific (cancer type) level. This will be used to facilitate discussions on the division of roles, collaboration, and improvements in the quality of care. The progress of the established indicators will be reviewed regularly. Additionally, the incorporation of new indicators, such as those set by the Japan Breast Cancer Society or national authorities, will be accounted for accordingly.
	The treatment data from each medical institution will be organized and compiled, providing patients with accessible and clear information about the treatment options, systems, and case volumes available at different facilities within the prefecture for breast cancer care. This information will be made publicly available to help patients make informed decisions about where to seek treatment and which options to choose. In addition, the content of the information shared will be designed to be easily accessible and understandable for patients and the public, with input from stakeholders actively incorporated into the process.
<b>Health care institutions</b>	The performance data related to breast cancer care (such as the number of patients by age group, treatment types, QI indicators, and their measurement results) will be made publicly available.

## 2. Building an Objective and Comparable Data Utilization Infrastructure

It is recommended to make the quality of healthcare visible at the level of each medical institution, prefecture, and regional block, so that the temporal changes and improvements in the quality of care provided to patients can be assessed. This can be achieved by maximizing the use of existing data infrastructures.

The following actions are expected from key stakeholders to achieve the above initiatives:

<b>National Government (MHLW)</b>	To maximize the use of information from national databases, such as cancer registries, and existing academic society-led databases like NCD, it is necessary to advance legal and technical arrangements for linking and analyzing data across databases, as well as connecting prognostic information. Additionally, as available data expands, discussions should be conducted in a timely manner to review and extend indicators for improving healthcare quality (related to Recommendation 1).
	Along with the revision of the development guidelines, discussions should be conducted to review the current status report, taking into account the balance of facility input burdens, in order to ensure it contributes to the establishment of a PDCA cycle for improving the quality of healthcare. Based on this, the information should be made publicly available in a format that permits data analysis at the prefectural level or national level thereby allowing appropriate use in regional discussions such as those held by coordination councils.
	Participation in initiatives related to the visualization and improvement of healthcare quality, such as QI projects, should be made mandatory for cancer hub hospitals and other facilities. This will help enhance the comprehensiveness of national data collection and usage.

### 3. Patient Engagement and Social/Economic Comprehensive Support

Finally, the third background factor contributing to regional disparities is the challenges related to patient involvement in treatment and the structure of social and economic comprehensive support.

#### **[Current Situation and Challenges]**

##### **Challenges in Patient-Engaged Breast Cancer Care Communication**

In breast cancer care, where treatment options are diverse, it is essential for patients and healthcare providers to consult, collaborate, and make decisions together in order to achieve patient-centered, high-quality care. However, amidst the overwhelming amount of information regarding the disease, treatment options, and available support, it is not easy for patients to properly understand the necessary information and actively participate in deciding their treatment plan.

For example, some patients may not fully understand breast cancer, standard treatments, or their own condition, leading them to trust scientifically unsupported information and miss appropriate treatment opportunities. According to the "Public Opinion Survey on Cancer Control (FY 2023)," 26.2% of respondents stated they would seek information about cancer treatments and hospitals from sources other than the "Cancer Information Service<sup>xiii</sup>," such as the internet, Twitter, LINE, Facebook, Instagram, and other social media platforms. However, research by Ogasawara and associates has shown that a significant proportion of websites on the internet provide false information. Only about 10% of the cancer information available is deemed reliable, while approximately 40% contains falsified content, including expensive supplements and questionable treatments. To ensure that patients select accurate information and receive appropriate care, it is essential not only for healthcare providers to offer appropriate and sufficient information, but also to provide cancer education for the general public through platforms like compulsory education and other social settings.

Additionally, there are likely facility- and region-specific discrepancies in the quality of information provided by key sources for many patients, such as physicians, nurses, and consultation offices at hospitals and clinics. For example, due to differences in medical care systems at outpatient facilities and variations in explanations and information provided by primary doctors, some patients have reported not receiving sufficient information or any explanation at all regarding breast reconstruction during mastectomy.

In addition to scarcity of access to appropriate treatment, a lack of understanding and confidence from patients can also hinder efficient regional collaboration. For example, patients referred back to local clinics for continued care may become overly concerned about a perceived decline in the quality of treatment due to a reduction in the size of the hospital, leading them to return to the original hub hospital for follow-up care. To achieve adequate medical function differentiation and collaboration within regions, it is essential to provide decision-making support for patients regarding the selection of medical institutions based on their treatment needs, as well as improve patient communication and education.

When facing cancer, patients often encounter various concerns and issues related to the diagnosis, treatment, side effects, post-treatment life, finances, work, school, family and medical relationships, as well as doubts, worries, and anxiety during the treatment process. Therefore, it is crucial to have an environment where cancer patients can easily seek consultation. However, it has become clear that consultation services are not being fully utilized by patients, particularly when it comes to consultation locations. For instance, a study conducted by the Ministry of Health, Labour and Welfare's research group in 2014, titled "Research on the Development of Progress Management Indicators and Measurement Systems for Cancer Control," found that cancer consultation support centers were established as a mandatory requirement at all cancer treatment hub hospitals. Despite this, only 57% of patients surveyed at these hospitals reported being aware of the cancer consultation support centers. Similarly, a 2023 public opinion survey by the Cabinet Office on cancer control found that only 43% of respondents indicated they would seek information about cancer treatment and hospitals from a cancer consultation support center, suggesting that awareness of the centers, as well as understanding of their functions and roles, remains limited. Moreover, to deepen patients' understanding of

xiii "Cancer Information Service": A website managed by the National Cancer Center, providing scientifically accurate information about cancer. It is aimed at a broad audience, including patients, families, healthcare professionals, government officials, and researchers.

their illness and treatment, and to help them make more informed decisions, obtaining a second opinion from multiple doctors plays an important role. However, the "Patient Experience Survey for Fiscal Year 2018" revealed significant regional disparities in the implementation of second opinions, with the highest rate of second opinion consultation at 37% and the lowest at 10%. This indicates a substantial gap in the availability and practice of second opinions across different regions.

In addition, there are things that cancer patients may find difficult to discuss with family members, relatives, friends, or healthcare providers. However, there are instances where they may feel more comfortable expressing these concerns with others who are in a similar position. Therefore, peer supporters and patient groups, who understand and are able to empathize with the worries and anxieties of others based on their own experiences, play an important role in providing support by listening and engaging in thoughtful conversations. On the other hand, peer support is often managed by local governments, and as a result, there is variation in the scale and operations of these programs. Furthermore, with the diverse needs for support related to treatment, employment continuation, child-rearing, and childbirth, the availability of training opportunities for peer supporters to ensure the quality of their consultations is still insufficient. This includes a lack of adequate support and training provided by national and local governments, as well as private organizations.

### **Regional Differences in Treatment Options and Medical Support Related to Breast Cancer Treatment (Fertility Preservation, Appearance Care, and Breast Reconstruction)**

Breast cancer, primarily affecting women and with many young patients, requires survivorship support to address the losses associated with treatment. For example, fertility preservation therapies, such as freezing eggs, sperm, embryos, or ovarian tissue before cancer treatment, are important for preserving the possibility of having children in the future. Appearance care aims to help patients maintain a connection to their lifestyle and society, and motivation for treatment, by addressing changes in appearance caused by cancer or its treatments. Breast reconstruction surgery is performed to restore the breast as much as possible after the removal or alteration caused by breast cancer surgery.

Ideally, all breast cancer patients should be informed about and be aware of these treatment options and be able to access the necessary medical support without facing weighty challenges, should they choose to do so. However, in reality, there are regional disparities in access to these medical services and care. Specifically, fertility preservation and breast reconstruction are highly specialized treatments, and it is realistically difficult to expect that patients can receive these treatments locally, regardless of where they live. Moreover, there are concerns that, during cancer treatment, information regarding available treatment options, support, and facilities capable of providing care may not always be properly communicated to patients. This lack of information may restrict treatment options and thus result in disadvantaged and unequal treatment for patients.

Additionally, the financial burden of fertility preservation and appearance care, which are not covered by insurance, places a substantial burden on patients. To ensure that patients do not have to forgo these treatments due to financial reasons, support from local governments is expected from the patient's perspective. However, there are regional disparities in the costs and subsidies for these services. For example, fertility preservation treatments are typically self-pay, and the prices can vary depending on the region and facility. As for subsidies, some local governments offer financial assistance for counseling costs in cases where preservation is unsuccessful or for the storage fees of frozen specimens, but this support is not available in all regions. Similarly, for appearance care, there are regional differences in subsidy programs for the purchase of medical prostheses and the amount of financial assistance provided.

Additionally, because breast cancer has aspects of a hereditary disease, it is important to provide support and care not only for cancer patients but also for their families. Genetic testing is essential to determine whether relatives have a history of cancer. However, at present, only genetic testing for pathological mutations in BRCA1/2 in breast cancer patients is covered by insurance, and other genetic tests are not covered. Furthermore, when healthy relatives wish to undergo testing, they are required to bear the cost themselves.



While it is necessary to carefully consider the individuals who should be tested to avoid unnecessary testing, there seems to be room to further explore the appropriateness of testing in terms of preventive medicine, considering the effectiveness of early detection and prevention of breast cancer for those who have not yet developed the disease.

**Lack of support based on patients' socio-economic background (challenges in employment support in small and medium-sized enterprises, etc.)**

Cancer treatment involves significant financial burdens. Balancing cancer treatment with work (preventing job loss and supporting reemployment) is crucial not only for reducing financial stress but also for maintaining social connections and leading a fulfilling life. In breast cancer, a significant proportion of patients are young or in the working-age group, and a large percentage of them are women, many of whom are in non-regular employment. Therefore, employment support is particularly noteworthy in the context of breast cancer care.

According to research on work-life balance support for breast cancer patients, non-regular employees have a higher rate of job loss after diagnosis compared to regular employees. Additionally, some individuals are forced to adjust their treatment plans to accommodate their work schedules. In the current system of work-related sick leave support provided by companies, non-regular employees face more challenges than regular employees, such as fewer opportunities to use paid leave or participate in hourly leave systems. Furthermore, in small and medium-sized enterprises (SMEs), there are fewer systems in place to support extended sick leave beyond regular paid leave, and the maximum leave period is often shorter compared to large companies. As a result, whether a patient can access cancer-related work support largely depends on the size and policies of the company they are employed by. In particular, in rural areas in which many small businesses are prevalent, there are higher numbers of non-regular employees, leading to significant regional disparities in access to work support.

In a study by Sakamoto et al. on the work environment of cancer patients and the support provided by employers, it was found that only 18.4% of companies consulted experts (mainly social insurance labor consultants and industrial physicians) for assistance with handling cancer patient cases. The use of regional industrial health centers and consultation departments at medical institutions was almost nonexistent. Additionally, 18.9% of companies that did not consult experts cited the reason as "not knowing where to turn for advice," suggesting that there is an inadequate system that links employers and healthcare providers.

It has also become clear that there are regional disparities in the support systems for cancer patients' employment within the healthcare system. For example, for cancer patients, including those with breast cancer, coordinating communication between the working patients and their families, primary doctors, employers, and industrial physicians is crucial for balancing work and treatment. A key role in this is played by work-life balance coordinators. However, a survey of the distribution of these professionals by population per 100,000 people across prefectures revealed a nearly threefold difference between the highest and lowest regions. It has also been shown that patients facing employment and economic issues are more than three times as likely to experience depression compared to those without such issues. To prevent mental distress, it is essential to ensure work-life balance support for cancer patients without regional disparities.

Research using the Areal Deprivation Index (ADI), which is a geographic statistical indicator summarizing the geographic concentration of poverty and deprivation, has been advancing to explore how patients' socio-economic backgrounds affect cancer outcomes. Studies have shown that areas with higher levels of deprivation, as indicated by the ADI, tend to have higher mortality rates, lower early diagnosis rates, fewer surgeries performed, and fewer opportunities to access specialized cancer care at designated hospitals. This suggests that, despite efforts to standardize cancer care quality, health disparities based on socio-economic backgrounds continue to exist between regions. To improve patient outcomes, it is crucial to not only provide support for the treatment received by individual patients but also consider approaches to address the broader socio-economic challenges, such as poverty and deprivation, that patients face.



### [Proposals for Addressing the Identified Issues]

In addressing the challenges, it has been identified that patients face difficulties in accessing appropriate healthcare or their preferred specialized care, due to concerns such as challenges in patient-participatory communication in breast cancer care, regional disparities in treatment options and medical support (e.g., fertility preservation, appearance care, breast reconstruction), and insufficient support based on patients' socio-economic backgrounds (e.g., employment support for workers in small and medium-sized enterprises). To overcome these challenges, we propose the following three measures:

#### 1. Maximizing the Use of Current Resources to Improve Communication Between Patients and Healthcare Providers

To enable patients to actively engage in their treatment and other forms of support based on their condition, we propose enhancing the functionality of consultation services by centralizing and promoting them. This can be achieved through online platforms, such as chatbots, offering online consultations, and expanding access to information in a one-stop format. Additionally, we recommend strengthening outpatient services (nurse consultations, pharmacist consultations) and reinforcing the role of primary care physicians in cancer care. This would facilitate the identification of patient concerns and treatment preferences, ensuring appropriate referral to specialists and facilities.

The following actions are expected from key stakeholders to achieve the above initiatives:

<b>National Government (MHLW)</b>	We propose evaluating the adequacy of consultation support at cancer support centers, including consultations for patients from other facilities, by assessing the number of counselors and other structural factors as part of a system enhancement added to the medical reimbursement system. Additionally, consideration should be given to revising the evaluation of the use of information communication technology (ICT) in medical reimbursements to ensure the strengthening of consultation support. Furthermore, it is important to review and strengthen the collaboration with patient organizations by supporting initiatives such as peer support for patient consultations and providing spaces for patient and family interaction within the centers, including revising base requirements accordingly.
	To accelerate treatment consultation support by nurses and pharmacists in outpatient settings, it is essential to consider introducing incentives such as additional reimbursement for the allocation of consultative personnel, strengthening the support system for these roles. This would encourage healthcare providers to improve the availability of specialized support staff and ameliorate the overall quality of care.
	In the guidelines for the system, it is important to consider how cancer consultation support centers and other relevant organizations can collaborate and publicly share information to actively involve patients in various patient groups. This would ensure that patients can effectively participate in and engage in these groups for support and information.
<b>Academic Society</b>	Collaborate with patient groups that are actively engaged in external activities and have high organizational credibility to promote the dissemination of information to patients. This can include hosting public lectures in collaboration with patient organizations and sharing information through patient organizations that are in partnership with academic societies.
<b>Prefecture</b>	For prefectures that have regional centralized consultation support centers such as hubs, promote further utilization of these centers, including enhancing their publicity and information linkage with various medical institutions. Additionally, in prefectures where such centers are not yet established, encourage the establishment of these centers.

<b>Hub hospital</b>	By centralizing various consultation support functions at the hub cancer consultation support center, it will be possible to provide diverse consultation services to each visiting patient. Effective use of resources such as the cancer information service and chatbots (related to Recommendation 3) will be promoted. Additionally, by accepting consultations from other facilities through online consultation support, we can ensure that consultation services are provided to a wide range of patients without limitations to access or time delays.
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## 2. Promotion of Discussions on Correcting Regional Disparities in Social and Economic Support and Strengthening Access

Considering that breast cancer has an earlier onset peak compared to other cancers and that it predominantly affects women, it is essential to provide support that aligns with disease stage and life course, including employment support, fertility preservation, appearance care, and breast reconstruction. To ensure that individuals receive the necessary support at the right time, we recommend promoting information sharing and collaboration between medical professionals, including occupational physicians, and between businesses and healthcare providers. Furthermore, from the perspective of ensuring that people facing socio-economic difficulties are not left behind, we suggest reviewing national and additional support measures, such as the augmentation of incentives for employment support in small and medium-sized enterprises, subsidies for self-payment costs, and support systems for younger generations regarding long-term care insurance.

The following actions are expected from key stakeholders to achieve the above initiatives:

<b>National Government (MHLW)</b>	<p>Discussing and reviewing the feasibility of the following national and additional support measures:</p> <ul style="list-style-type: none"> <li>■ Subsidies for self-payment costs related to fertility preservation and appearance care, which are not covered by public medical insurance, and public insurance coverage for these services, particularly aimed at younger patients.</li> <li>■ Expanding insurance coverage for genetic testing for healthy relatives of breast cancer patients.</li> <li>■ Establishing reimbursement for medical institutions for "guidance to prevent employee resignation" and "collaboration with employment agencies like Hello Work to promote reemployment."</li> <li>■ Strengthening incentives, including subsidies and certification, for employment support systems and measures to prevent resignation and promote reemployment for small and medium-sized enterprises and non-regular employees.</li> <li>■ Expanding support systems for balancing treatment and employment, inspired by existing child-rearing support frameworks, such as considerations for businesses in the context of child-rearing support.</li> </ul> <p>Additionally, from the perspective of addressing the socio-economic factors contributing to breast cancer medical disparities, we propose further promotion of women's empowerment through recurrent education, self-development opportunities and other initiatives.</p>
<b>National government (MHLW)/Prefecture</b>	At the national level, it is imperative to visualize the available socio-economic support systems across the country, including grant and subsidy options. At the prefectural level, efforts should be made to clearly organize and publicly disclose information about the socio-economic support available to patients, as well as how to access the aid available, in collaboration with municipalities within the prefecture.

### 3. Promoting Public Understanding of Local Healthcare Systems and Collaboration

It is recommended to actively provide learning opportunities for patients, such as citizen lectures, so they can take an active role in understanding their health and healthcare, and engage in meaningful consultations with healthcare professionals. Additionally, it is important to provide patients with clear information about the healthcare options available in their community, including which facilities offer specific treatments regardless of the stage or treatment phase. This should be done by organizing and clearly presenting the local healthcare system, and ensuring that patients can smoothly access the care they need. It is also recommended that local governments and councils take the lead in disseminating this information.

The following actions are expected from key stakeholders to achieve the above initiatives:

<b>Government (MHLW)</b>	Raise awareness to enhance knowledge about the basic structure of cancer care in Japan, such as what cancer centers are, and the variances in the medical institutions and specialists to consult with depending on the stage and condition of the disease.
<b>National Cancer Center</b>	A system should be developed that allows the automated provision of scientifically accurate and evidence-based information about cancer treatment, such as the information provided by the Cancer Information Service, through technologies like chatbots (AI). This would enable consultations and information sharing with patients and the public up to a certain point (related to recommendation 2).
<b>Prefecture/Council</b>	Collaborate with local municipalities, medical associations, etc., to compile and clearly communicate information about the local healthcare system, role distribution, the treatment status of breast cancer patients (including the age groups of patients visiting each medical institution, diagnosis, types of treatment, treatment records, etc.), and available consultation services.
<b>Academic Society/ Private sector/ Patient Association or Organization</b>	Provide transparent information through trustworthy media and organizations, and promote patient education and awareness, to enable each patient to make independent decisions about their treatment and healthcare facilities.

# V . Case Study



## Cancer Care PDCA Initiatives by Okinawa Prefecture Cancer Care Coordination Council

### ■ Background and Challenges

To trigger discussions regarding the improvement of the quality of cancer care and the healthcare delivery system in prefectures, it is essential to establish indicators related to the current state of breast cancer care, visualize them, and engage in discussions based on data-driven improvement strategies. However, in practice, the use of various data in prefecture-level discussions (such as visualizing the current situation, making decisions on improvement efforts, evaluation, and establishing a PDCA cycle for revisions) has not yet adequately advanced.

### ■ Initiatives

The Okinawa Prefecture Cancer Care Coordination Council is organized with the Cancer Center of the University of the Ryukyus Hospital as the secretariat and is composed of the prefecture's base hospitals and major medical institutions. It is structured with specialized committees (Medical Committee, Remote Islands & Rural Areas Committee, Pediatric & AYA Committee, Information Provision & Consultation Support Committee, and Benchmarking Committee) and a steering committee that oversees these specialized committees. The Okinawa Prefecture Cancer Care Coordination Council has been promoting the PDCA cycle using the logic model since the second half of 2009. As of 2024, the utilization (operation) is as follows: In the Okinawa Prefecture Council, each specialized committee takes the lead, using the logic model to define indicators for evaluating initiatives based on outcomes. Activities are set up to improve outcomes in each field. To manage the progress of these initiatives, the council has developed a regional cancer data collection (Council version) and widely disseminates the information. The Benchmarking Committee evaluates each indicator and presents the results to the specialized committees. Every three months, the specialized committees assess the progress and report to the council. The council manages overall progress and evaluates and improves the results. Through this cycle, Okinawa Prefecture's cancer measures are continuously evaluated and improved using the logic model. In addition, in Okinawa Prefecture's logic model, indicators are organized and centered upon for specific cancer types, such as "breast cancer."

In addition, the Okinawa Prefecture Council publishes treatment details, facility introductions, case number data, survival rates, and most of the indicator data used in the logic model for cancer patients on its website, "Uchina~Gan Net Ganjū," which is accessible to the public.

### ■ Results of the Efforts

The establishment of a PDCA system for progress management and evaluation improvement by each specialized subcommittee and the council has been successfully achieved, starting from the identification of improvement efforts, setting indicators, and measuring progress.

## Suggestions for Addressing Regional Disparities in Breast Cancer

### ■ Relevant Issues and Recommendations

#### 2. Visualization and Improvement of Healthcare Quality through Data Utilization

**Issue 1:** Lack of mechanisms or platforms for evaluation the quality of breast cancer care through the PDCA cycle

**Recommendation 1:** Ensuring the feasibility of executing the PDCA cycle based on data in local regions

### ■ Key points

- In the clinical cooperation councils involving cancer treatment base hospitals, indicators for specific cancer types, such as "breast cancer," have been organized and agreed upon, and evaluation indicators are also organized and publicly disclosed by cancer site. The "Benchmark Committee" (specialized committee) evaluates measures including healthcare quality and discusses improvements to policies, playing a key role in driving the PDCA cycle. Additionally, the committee promotes a unique healthcare provider survey conducted by the prefecture to assess clinical conditions (it is rare for prefectures/ councils to independently conduct healthcare provider surveys for cancer policy evaluation).
- The status of cancer type (disease)-specific responses in remote islands and rural areas is also discussed within the council, and information on treatment facilities is widely made available to patients.

## ■ Future Directions

- Under the delegation of authority from the prefectures and strong collaboration, facilities that exhibit strong leadership play a central role, aim to make it possible to strengthen efforts toward improving regional cancer care.
- In the Okinawa Prefecture Council, when the logic model was introduced, reports indicate that frequent workshops were held with ample time to ensure the understanding and dissemination of the model among stakeholders. During the data utilization phase, it was important to create environments where stakeholders could gain understanding and utilize the data by setting up opportunities for experts to share knowledge, expertise, and case studies related to data utilization.

# VI. Acknowledgments



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This policy recommendations were compiled by the project team for the "Proposal on Addressing Regional Disparities in Breast Cancer Care" based on interviews and literature review conducted, and it does not represent the views of the advisory board members, interviewees, or the organizations to which they belong.

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