

# Development of a New Tool for Better Social Recognition of Cancer Information and Support Activities Under the National Cancer Control Policy in Japan

Tomoko Takayama, PhD; Chikako Yamaki, PhD; Masayo Hayakawa, PhD; Takahiro Higashi, MD, PhD; Yasushi Toh, MD, PhD, FACS; Fumihiko Wakao, MD

## ABSTRACT

Under the recent trend of an increasing number of cancer survivors, there is a need to devise measures for visualization of medical care and public health programs related to cancer control, which will enable better overview of the activities at hospitals and local communities and allow various stakeholders to share the information about such activities. The aim of this study was to propose a new tool for proper implementation of cancer information and support programs provided under the national cancer control policy in Japan. Considering 5 elements reported by Handler et al (macro context, mission, structural capacity, processes, and outcomes), we conducted the focus group discussions to confirm the goals of activities of Cancer Information and Support Centers. Eventually, 2 final goals ("reduction in the number of patients/families having difficulties related to cancer" and "being able to live at ease even after diagnosis of cancer") were identified, accompanied by 5 semifinal goals and 16 prerequisite conditions needed to achieve the final goals, as well as the necessary states and the activity indicators corresponding to them. This tool was utilized by 180 (42.7%) of 422 cancer care hospitals designated by the government of Japan (designated cancer care hospitals [DCCHs]) in 2016 and by 336 (77.1%) of 436 DCCHs in 2018, which were the data at 6 months and 3 years after introduction of the tool, respectively. Thus, the tool for evaluating the Cancer Information and Support Centers' activity presented here is expected to stimulate the stakeholders involved in providing supports in various fields of each local community, to share the final goals, to evaluate the status of their achievement, and to further advance their own activities.

**KEY WORDS:** activity indicator, cancer information and support activity, framework, national cancer control, visualization

**Author Affiliations:** Division of Cancer Information Service (Drs Takayama, Yamaki, and Hayakawa) and Division of Health Services Research (Dr Higashi), Center for Cancer Control and Information Services, National Cancer Center, Tokyo, Japan; National Hospital Organization Kyusyu Cancer Center, Fukuoka, Japan (Dr Toh); and Center for Cancer Control and Information Services, National Cancer Center, Tokyo, Japan (Dr Wakao).

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The survival rates of patients with cancer have been improving<sup>1</sup> and cancer survivors are increasingly able to live their lives outside medical facilities. While living in local communities, each patient and his or her family members are required to deal with anxieties and concerns, including physical<sup>2,3</sup> and social issues<sup>4-6</sup> related to treatment and care.<sup>7-9</sup> As the environments surrounding health care change,

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**Correspondence:** Tomoko Takayama, PhD, Division of Cancer Information Service, Center for Cancer Control and Information Services, National Cancer Center, 5-1-1, Tsukiji, Chuo-ku, Tokyo 104-0045, Japan ([totakaya@ncc.go.jp](mailto:totakaya@ncc.go.jp)).

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it is more essential for patients and their families to get reliable cancer information,<sup>10,11</sup> to make decisions by themselves, and, if necessary, to be connected to adequate care and support.<sup>12</sup> At the same time, it becomes increasingly important to arrange and improve the system of medical care and public health, in order for patients and their families to be supported in a holistic manner at both the medical facilities and the local communities.<sup>13–19</sup>

In countermeasures against cancer in Japan, the Cancer Information and Support Centers (CISCs), which any citizens (not confined to sick individuals) could access freely, were founded in 2006, in response to the voices from patients with cancer. They were expected to provide reliable and accurate information about cancer and also support to persons seeking counseling.<sup>20</sup> In this way, the places that provide counseling in local communities have been set up at 436 hospitals in Japan as of 2019 under the governmental policy, playing a central role in cancer treatment and care across the country. When new medical care and public health programs are introduced, it is necessary to comprehensively visualize them so that the information about the activities can be shared by various stakeholders including hospital and public health practitioners with different standpoints.<sup>21</sup> Furthermore, under the recent trend of increasingly complex systems of medical care and public health, it is essential for all stakeholders to utilize a uniform framework for continuous assessment and improvement of them.<sup>22</sup>

Moreover, on introducing new programs, keeping the budget under control is an annoying issue of priority, not only in Japan but also in other countries.<sup>23,24</sup> In such circumstances, those programs are often incorporated as only a supplement to the existing system and are forced to rely on the resources and functions already possessed by individual medical facilities and local communities. As a result, they produce many obstacles to the implementation of the stakeholders' activities such as provision of cancer information and counseling at a uniform level throughout the country. This situation is also observed in the case of the CISCs. Therefore, it is now required that the CISCs with various situations share the same tool in pursuing the nationwide cancer information and support program.<sup>21,22</sup>

Thus, this study was undertaken to develop and provide a new tool for evaluating the CISCs' activities toward the same goals of the national cancer control program in Japan. This tool will be expected to work for better social recognition (visualization) of cancer information and support activities under the program and to encourage the society to improve the program itself.

## Methods

The activities of the CISCs were arranged by adopting the structure/process/outcome model of Donabedian<sup>25</sup> as the theoretical framework. During the process of preparing for them, the situations faced by the CISCs were viewed and analyzed from the viewpoint of 5 elements of framework components reported by Handler et al<sup>21</sup>: macro context, mission, structural capacity, processes, and outcomes. Focus group discussions were conducted to reconfirm the goals of activities at CISCs. Then, the activity indicators were outlined, classified as the outcomes, process, and structures with examples of activity indicators and their corresponding anticancer policy in Japan.

### *Macro context*

The CISC was founded in Japan in 2006 reflecting the voices of patients with cancer in those days, saying: "We wish we can obtain reliable information about cancer in each community or at each hospital across the country." Such voices prompted the adoption of the national policy called Action Plan 2005 for Promotion of Cancer Control.<sup>20</sup> Consequently, the social requests to the CISCs are composed of (1) providing information about cancer and places where the patients and citizens can reach information and support desired, (2) allowing patients and citizens to make the appropriate decisions on the basis of correct information, and (3) making these services easily accessible across the country.

### *Structural capacity*

Handler et al<sup>21</sup> defined structural capacity as "resources and relationships needed for implementation of important public health processes," such as information/organizational resources, physical/human resources, and financial resources. In Japan, 47 prefectures, differing markedly from each other in terms of area and population size, are instructed to make and execute their own action plans to promote anticancer measures on the basis of Basic Plan to Promote Cancer Control Programs by the Ministry of Health, Labour and Welfare of Japan. In all prefectures, 436 hospitals designated by the Ministry of Health, Labour and Welfare (designated cancer care hospitals: DCCHs) provide primarily specialized cancer care and information and support to patients and citizens.<sup>26</sup> The levels of budgets required extensively vary among DCCHs. Of these, 51 are registered as prefectural DCCHs playing the roles of coordinator and core facility for interfacility cooperation for cancer care in a given prefecture; these hospitals

periodically receive opportunities to share information about nationwide open issues.<sup>27,28</sup>

Under such backgrounds, the nationwide activities related to cancer counseling have been advanced in 2 directions since 2006. The first is the so-called top-down advances, based on the standards prepared by the Ministry of Health, Labour and Welfare (DCCH Arrangement Guideline<sup>29</sup>); the guideline specifies the prerequisite conditions for each DCCH, such as the number of counselors and the range of counseling services to be provided. The other is the bottom-up approach that arises from clinical frontlines of the CISC in medical facilities and local communities, reflecting the users' needs.

### **Processes**

As a key process of cancer information and support activities, we referred to the contents of core values for high-quality services proposed by the International Cancer Information Service Group<sup>30</sup> that have been utilized as the guide for the basic attitude of counselors at the CISCs nationwide. The core values include respect for the service user's sense of values and culture, right for making informed choices, provision of anonymous services, protection of privacy, and support for patient-doctor/health professional relationship. They additionally provide guidance on the points to achieve these values, that is, information based on latest scientific evidence, a system for collection of such information, the viewpoint of education, and service user's assessment.<sup>31</sup>

### **Outcomes**

Outcomes that show the final destination were discussed on the basis of the Basic Plan to Promote Cancer Control Programs. The second-term Basic Plan, which was started in 2012, set the following 3 overall goals: "reduction in deaths from cancer," "alleviation of pain of all cancer patients and their family members and maintaining/improving the quality of their lives," and "establishment of a society that would allow people to live at ease even after diagnosis of cancer."<sup>32</sup> Of these goals, the latter 2 are considered to be closely related to the cancer information and support activities. Therefore, the focus group discussions were undertaken over these 2 goals.

### **Focus group discussion to achieve the ideal cancer information and support activities**

The focus group discussion consisted of 10 members appointed from the prefectural DCCHs on the basis of recommendations or voluntary candidacy, taking

the regional background, affiliation, and specialty into consideration. It included 4 members from cancer-center hospitals, 4 from university hospitals, and 2 from public hospitals (2 physicians, 4 nurses, and 4 social workers). From January to May 2015, 3 sessions of discussions (about 3 hours per session) were held to accomplish a tool for better social recognition (visualization) of cancer information and support activities (Table 1), with examples of activities to satisfy the prerequisite conditions to achieve the final goals (Table 2). Those were approved at the meeting of the Information and Support Service Panel (ISSP) comprising members from 51 prefectural DCCHs nationwide in June 2015. Furthermore, to measure the utilization status of this tool in each prefecture, the same ISSP conducted a questionnaire survey 6 months later (March 2016) and 3 years later (December 2018).

All the data were anonymized. An ethical approval was judged not to be required by the Medical Ethical Committee of the National Cancer Center (6000-014). According to the ethical guidelines for medical and health research involving human subjects in Japan, ethical committee approval was not needed for this type of study.

## **Results**

### **Mission and goals of cancer information and support activities**

Prior to establishment of a tool for better social recognition (visualization) of cancer information and support activities, the mission of the CISCs was discussed by the focus group from 4 viewpoints: (1) targets of activities, (2) similarities and features of the hospital functions, (3) provision of support from a "neutral standpoint," and (4) living without anxiety even after diagnosis of cancer. The major arguments were summarized (see Supplemental Digital Content Appendix 1, available at <http://links.lww.com/JPHMP/A648>) in the view that the CISC aims at "serving as the mediator of reliable cancer-related information from a neutral standpoint to all those who need it and empowering them to make their own informed choices and to take some actions."

### **Setting the outcomes, processes with activity indicators, and structures which correspond to the anticancer policy in Japan**

Taking the mission of the CISCs into account, the focus group discussions were held over the ideal states experienced by patients, family members, and citizens after diagnosis of cancer (see Supplemental

**TABLE 1**  
**Identified Outcomes, Processes, and Structures and Their Corresponding Anticancer Policies for CISCs**

Outcome		Process		Structure	Anticancer Policy	
Final Goal	Semifinal Goal	Prerequisite Condition	Necessary State	Activity Indicator	System Indicator	Details of Arrangement Guideline <sup>a</sup>
1. Reduction in the number of patients/families having difficulties related to cancer	1.1. Reliable person/chance of consultation available (close support)	1.1.1. Increase in the number of people aware of the availability of places for counseling	<ul style="list-style-type: none"> <li>Easily accessible place/entrance for counseling available</li> <li>Counselors with expertise in various areas available</li> <li>Multiple places for counseling available</li> </ul>	[Survey of citizens/patients] Percentage of responses indicating "Having place for consultation"	Number of privacy-protected rooms Number of telephone lines Presence/absence of direct telephone lines Number of counselors No. of full-time/single-role/multiple-role counselors No. of counselors who have received training No. of counselors in each specialty Presence/absence of a sign board, "Cancer Information and Support Center" Status of library installation for patients and family members	A sign board saying, "Cancer Information and Support Center" should be posted. Active PR3 should be undertaken for CISC. A system should be established that is capable of responding to the request of counseling, etc, from patients with cancer inside/outside the hospital, their family members, regional inhabitants, medical facilities, and so on
		1.1.2. Increase in the number of people aware of the roles of the CISC	<ul style="list-style-type: none"> <li>Informed about the roles of the CISC in an easily understandable manner</li> </ul>			
		1.1.3. Isolation of patients avoided	<ul style="list-style-type: none"> <li>More people aware of the presence of information/support</li> <li>More people guided to contact the appropriate counseling desk</li> <li>Information on CISC disseminated inside/outside the hospital</li> </ul>	Number of counseling cases arranged by the attending physician Degree of awareness about CISC, frequency of past utilization	Status of PR about the role as core hospital	A system should be established to disseminate the information to patients with cancer and family members from the attending physician and others.

(continues)

**TABLE 1**  
**Identified Outcomes, Processes, and Structures and Their Corresponding Anticancer Policies for CISCs (Continued)**

Outcome		Process			Structure		Anticancer Policy
Final Goal	Semifinal Goal	Prerequisite Condition	Necessary State	Activity Indicator	System Indicator	Details of Arrangement Guideline <sup>a</sup>	
		1.1.4. Communication among patients possible	<ul style="list-style-type: none"> <li>Meeting place available for stakeholders</li> <li>Manage patient salons or help in their management</li> <li>Support patient group activities</li> </ul>	Frequency of patient salon meetings Number of counseling cases guided to peer support function	[Survey of patients/service users] Degree of awareness about the presence of patient groups	Presence/absence of attempts at establishing a system for linkage and collaboration with patient groups having sufficient experience about information/support activities	Active involvement is needed in the attempt at establishing a system of linkage and collaboration with patient groups having sufficient experience about information/support activities. Scope of work in CISC (support patient activities, such as support group activities managed jointly by health care professionals and patient organizations or the like, periodical holding of patient salons, etc)
1.2. Patient able to resolve problem to live in one's own way		1.2.1. Having the perspective of living after cancer diagnosis 1.2.2. More methods for resolving/dealing with problems 1.2.3. Less problems or matters of concern	<ul style="list-style-type: none"> <li>Quality of counseling ensured</li> <li>Sharing of information about open issues and about the methods for resolving them possible among counselors or CISCs</li> </ul>	Number of counselors that have received training	[Survey of patients/service users] Percentage of responses indicating: "I am leading a fully normal life"	Number of counselors who have received training Status of securing the PDCA cycle (inside the hospital)	Two (full-time/single-role) counselors who have undergone "CISC counselor training/basic training" are allocated. Discussion is held at meetings of the prefectural council, etc, to secure a system for collaboration, including sharing of information and role allocation among prefectural core hospitals, regional core hospitals, specific field core hospitals, and DCCCHs. A system for feedback from counseling-seeking individuals is arranged. Scope of work in CISC (Supply of general information through, health care counseling about ATL)

(continues)

**TABLE 1**

**Identified Outcomes, Processes, and Structures and Their Corresponding Anticancer Policies for CISCs (Continued)**

Outcome		Process			Structure		Anticancer Policy
Final Goal	Semifinal Goal	Prerequisite Condition	Necessary State	Activity Indicator	System Indicator	Details of Arrangement	Guideline <sup>a</sup>
1.3. Patients able to decide at one's own initiative	1.3.1. Able to make well-informed choices 1.3.2. Access available to information needed for making decisions 1.3.3. Good communication with health care providers	<ul style="list-style-type: none"> <li>Quality of counseling ensured</li> <li>Smooth linkage to health care seen</li> </ul>	Number of counselors who have received training [Prefectural DCCH] Number of counselors in a prefecture invited to attend/who have attended the training	[Survey of patients/service users] Percentage of responses indicating: "I am leading a fully normal life"	Number of counselors who have received training Status of establishment/participation of or in collaboration system and place of discussion (panel, etc) within a prefecture Presence/absence of a mutual assessment system in a prefecture Status of the collaboration system, including sharing of information related to information/support activities and role allocation	Two (full-time/single-role) counselors who have undergone "CISC counselor training/basic training" are allocated.	
	1.3.4. Fair/neutral places for consultation secured		<ul style="list-style-type: none"> <li>Clearly state and ensure that everyone can seek counseling</li> <li>Clearly state and ensure that anonymous counseling is possible</li> <li>System for protection and appropriate handling of personal information in place</li> </ul>	Number of anonymous counseling cases	[Survey of patients/service users] Percentage of responses indicating: "It is fair/neutral"		

(continues)

**TABLE 1**  
**Identified Outcomes, Processes, and Structures and Their Corresponding Anticancer Policies for CISCs (Continued)**

Outcome		Process			Structure	Anticancer Policy
Final Goal	Semifinal Goal	Prerequisite Condition	Necessary State	Activity Indicator	System Indicator	Details of Arrangement Guideline <sup>a</sup>
1.4. Increase in health care professionals able to make appropriate actions (viewed from patient/family/citizen)	1.4.1. Able to receive sufficient explanation/information 1.4.2. Easier to express concern/anxiety about treatment and other matters	<ul style="list-style-type: none"> <li>• Patient/family can reach the counseling desk smoothly.</li> <li>Flow/system for this purpose ensured (from inside/outside the hospital and in the local community)</li> </ul>	Number of counseling cases arranged by in-hospital health care professionals Degree of awareness about CISC, frequency of past utilization Number of counseling cases referred from in-hospital health care professionals Number of counseling cases referred from out-of-hospital health care professionals	[Survey of health care professionals] Degree of awareness about CISC, frequency of past utilization	Number of counselors No. of full-time/single-role/multiple-role counselors No. of counselors who have received training No. of counselors in each specialty	A system should be established to disseminate the information to patients with cancer and family members from the attending physician and others.
2. Able to live at ease even after diagnosis of cancer	2.1. The ability to deal with cancer is cultivated in the society	2.1.1. Ability to receive social support	<ul style="list-style-type: none"> <li>• PR activity provided</li> </ul>	Number/percentage of citizens who have contacted the CISC Number of cases of counseling provided to patients without identification number	Status of active PR about CISC	Scope of work in CISC (PR/dissemination activity)

(continues)

**TABLE 1**  
**Identified Outcomes, Processes, and Structures and Their Corresponding Anticancer Policies for CISCs (Continued)**

Outcome		Process		Structure		Anticancer Policy	
Final Goal	Semifinal Goal	Prerequisite Condition	Necessary State	Activity Indicator	System Indicator	Details of Arrangement Guideline <sup>a</sup>	
		2.1.2. Place for acquisition/exchange of information secured	<ul style="list-style-type: none"> <li>• Able to dispatch new information about anticancer measures and treatment</li> </ul>	Number of seminars for patients/citizens (total of seminars held inside and outside the hospital)  Number of seminars for health care professionals (total number of seminars held inside and outside the hospital)	[Survey of service users]  Percentage of responses indicating: "I have obtained new information" or "I have understood it more deeply"	Status of establishment/participation of or in a collaboration system and place of discussion (panel, etc) within a prefecture  Presence/absence of a mutual assessment system in a prefecture	A system should be established that is capable of responding to requests for counseling, etc, from patients with cancer inside/outside the hospital, their family members, regional inhabitants, medical facilities, and so on.
		2.1.3. Regional network established	<ul style="list-style-type: none"> <li>• Periodic dissemination of information about the CISC conducted in the local community</li> </ul>	Number of seminars held outside the hospital  Number of cases for counseling provided to health care professionals outside the hospital	[Survey of citizens]  Degree of awareness about CISC	Number of telephone lines  Presence/absence of direct telephone lines  Number of meetings within the networks	If designated as a member of a group affiliated with the DCCHs, a system should be established for providing information/support services through linkage and collaboration.

Abbreviations: ATL, adult T-cell leukemia; CISC, Cancer Information and Support Center; DCCH, designated cancer care hospital; PDCA, Plan-Do-Check-Act cycle; PR, public relations.  
<sup>a</sup> "Designated Cancer Care Hospital Arrangement Guideline" prepared by the Ministry of Health, Labour and Welfare.



**TABLE 2****Examples of Activities Corresponding to the “Prerequisite Conditions” for CISC Outcomes**

CISC Outcomes “Prerequisite conditions”	Examples of Activities
1.1.1. Increase in the number of people aware of the presence of places for counseling 1.1.2. Increase in the number of people aware about the roles of CISC	Cancer counseling desk is easy to find. Cancer counseling provided out of the hospitals. Place for peer support arranged (patient group, cancer salon, etc).
1.1.3. No isolation of patients	Written information about CISC delivered to individuals (card, leaflet, etc). PR given during each ward’s training courses inside the hospital Information added to homepage.
1.1.4. Communication among patients possible	Poster of patient salon exhibited. List of patient groups presented. Operation of patient groups supported.
1.2.1. Having perspective for living after diagnosed with cancer 1.2.2. Increase in problem resolving/dealing methods 1.2.3. Decrease in factors causing problems/concerns	Counselor training received In-hospital learning meetings attended. Case conference meeting held (within each center/prefecture). Prefectural DCCH Counselor training (periodical) provided. Open issues/resolving methods shared (within each center/prefecture). Shared open issues/methods for resolving them were reported to hospital executives, the prefectural panel, and the prefectural council.
1.3.1. Well-informed choice of treatment possible 1.3.2. Information necessary for decision accessible 1.3.3. Good communication with health care providers	Information improved/updated periodically on the basis of scientific evidence and reliable information. Quality assurance activities conducted periodically for better counseling. Conference with other units held inside/outside the hospital.
1.3.4. Place of fair/neutral counseling secured	Dealt with all service users in a fair manner. Faced all counseling-seeking individuals in a neutral manner. CISC’s rules about personal information handling were faithfully followed.
1.4.1. Sufficient explanation/information available 1.4.2. Easier to express concerns/anxiety about treatment and other matters	Responded to the request of counseling from health care professionals inside/outside the hospital (local community). Details of the counseling provided to health care professionals inside/outside the hospital and the actions taken were analyzed, and issues having potential for improvement were discussed. Issues having potential for improvement were reported to hospital executives, the prefectural panel, and the prefectural council.
2.1.1. Awareness of the availability of social support	Leaflets or the like on cancer were distributed. Announcement of events in PR journals, media, etc, was requested. Regional relay for life events was attended.
2.1.2. Place for acquisition/exchange of information secured	Agenda for council/panel meetings were shared. Seminars for patients and citizens (adopting new topics) were conducted. Seminars for in-hospital health care professionals (adopting new topics) were conducted.
2.1.3. Regional network established	Seminars and workshops meetings for regional health care professionals and job-finding support for practitioners were conducted. City/town/village government office governing the location of the hospital was visited. Other PR activities were undertaken.

Digital Content Appendix 2, available at <http://links.lww.com/JPHMP/A648>). Sixteen conditions necessary for the acquisition of the ideal states (prerequisite conditions in Table 1) and then 5 goals to achieve those conditions (semifinal goals in Table 1) were identified. These goals were integrated into 2 final “outcomes” that were “reduction in the number of patients/families having difficulties related to cancer” and “being able to live at ease even after diagnosis of cancer” (final goals in Table 1).

In this way, the final and semifinal goals that CISCs aimed at and the prerequisite conditions were arranged (Table 1). Furthermore, as “process,” the necessary states and activity indicators to satisfy the prerequisite conditions were also summarized. The latter was categorized into 2 parts: “measurement-related indicators” assessed through the activities of the CISCs and “survey-related indicators” assessed primarily through users such as patients, family members, citizens, and health care professionals. The requirements for “structure” (eg, man power size, etc) were also listed. Finally, the corresponding anticancer policies in Japan (DCCH Arrangement Guideline) corresponding to the structure/process/outcome framework were shown (Table 1).

To facilitate the utilization of this tool in individual medical facilities and local communities, examples of CISCs’ activities reported in the focus group discussions and meetings of the ISSP were summarized in Table 2.

### **Utilization status of the new tool in Japan**

In regard to utilization of the tool shown in Tables 1 and 2, the nationwide surveys were conducted by the ISSP at 9 months (March 2016) and 3 years (October 2018) after introduction. This tool was utilized by 180 hospitals (42.7%) out of 422 DCCHs as of 2016 in 19 of the 47 prefectures at 9 months and by 336 hospitals (77.1%) out of 436 DCCHs as of 2018 in 35 prefectures at 3 years (Table 3). Activity indicators unique to individual prefectures were intentionally added to some of the prerequisite conditions in 2 to 10 of 35 prefectures at 3 years.

### **Discussion**

There are at least 5 issues to be considered for improving the quality of cancer information and support activities. Visualization of activities shown in Tables 1 and 2 will be indispensable to overcome them.

The first issue pertains to the tendency that local stakeholders are difficult to be involved in a nationwide medical care and public health program. Therefore, it is important to establish good systems for

the service providers such as cancer counselors at the CISC equipped in each DCCH to readily participate in the Basic Plan to Promote Cancer Control Programs in Japan. For that purpose, all of the cancer counselors in Japan have been educated by the same training protocols and have both nationwide and local networks to constantly and readily exchange the information about problems in service provision and counseling. In this study, the focus group discussions prior to the ISSP included the cancer counselors who would be expected to serve as the actual users of the tool. Therefore, we believe that the tool shown in this study would reflect the actual impressions of clinical practitioners. Furthermore, practical examples included in this tool are thought to make it easier to position the activities already existing at individual facilities/prefectures and to encourage their voluntary use. This tool was adopted by 35 prefectures (about 3/4th of all prefectures) within 3 years and the activities unique to individual prefectures were added in about 1/4th of all prefectures after introduction, suggesting that this tool has been widely utilized by medical facilities in Japan.

The second issue is that providing reliable information and counseling about cancer involves various activities that should be properly and promptly adapted to changing users’ needs and environments. Corresponding to a wide variety of needs, many attempts have been made in the clinical practice. Ng and de Colombani<sup>33</sup> demonstrated that practice-based evidence derived from the program introduced into the society serves more effectively as a guide to the public health program. Such practice-based evidence will provide users with a good opportunity for facilitating the growth of the program. The tool shown here could help users foster a better program to achieve final and semifinal goals (Table 1) and to obtain new skills and practices without losing the directions of the national anticancer policy.

The third issue relates to the fact that stakeholders in charge of diverse cancer information and support activities are not only confined to medical professionals within hospitals but also encompass various relevant people and players, such as municipal personnel, citizens, and patient support groups. So that the needs of patients and counseling-seeking persons can be satisfied, linkage to various health care professions and services is indispensable. Furthermore, it is necessary that the goals of activities to be adopted are shared among the stakeholders and also that the stakeholders should be mutually aware of others’ activities. For these purposes, using the tool shown here would be useful.

The fourth issue pertains to the significance of continuous measurement. Because it is often difficult to

**TABLE 3**  
**Utilization Status of the Tool for CISC in Japan**

CISC Outcomes "Prerequisite Conditions"	Number of Prefectures Utilize the Tool (Among 47 Prefectures)	
	March 2016 <sup>a</sup>	October 2018 <sup>b</sup>
	19 prefectures (40.4%) 180 hospitals (42.7%)	35 prefectures (74.5%) 336 hospitals (77.1%)
<b>Number of Prefectures That Have Added Unique Activities</b>		
1.1.1. Increase in the number of people aware of presence of places for counseling	...	4
1.1.2. Increase in the number of people aware about the roles of CISC		
1.1.3. No isolation of patients	...	10
1.1.4. Communication among patients possible	...	3
1.2.1. Having perspective for living after diagnosed with cancer	...	8
1.2.2. Increase in problem resolving/dealing methods		
1.2.3. Decrease in factors causing problems/concerns		
1.3.1. Well-informed choice of treatment possible	...	9
1.3.2. Information necessary for decision accessible		
1.3.3. Good communication with health care providers		
1.3.4. Place of fair/neutral counseling secured	...	6
1.4.1. Sufficient explanation/information available	...	2
1.4.2. Easier to express concerns/anxiety about treatment and other matters		
2.1.1. Awareness of the availability of social support	...	6
2.1.2. Place for acquisition/exchange of information secured	...	4
2.1.3. Regional network established	...	6

Abbreviation: CISC, Cancer Information and Support Center.

<sup>a</sup>The number of designated cancer care hospitals was 422 as of fiscal year 2015.

<sup>b</sup>The number of designated cancer care hospitals was 436 as of fiscal year 2018.

specify the scope of the cancer information and support activities, it is also difficult to measure and visualize it. If stakeholders rely merely upon some structural indicators, such as measurable man power size and number of users, true goals will be passed over. In this study, we presented a series of activity indicators that are measurable for the goals to be achieved by the CISCs. Paying attention to the entire framework, rather than to individual indicators, will make it easier for the stakeholders to understand the purpose of each activity and, as a result, be more likely to enable continuous and appropriate assessments. Particularly for the type of health care services in which visualization is difficult, construction of the system of presenting the framework of cancer information and support activities and facilitating its sharing among stakeholders will lead to achieving a higher quality of the activities.

Finally, much cost is required for sustainable improvement of medical quality.<sup>34,35</sup> However, by freely utilizing this tool, the local stakeholders could measure their activities with low cost. Furthermore, to know the activities of other prefectures and compare

them with their own will lead to quality improvement of their cancer information and support activities.

There are some limitations in this study. This study did not involve patients or prefecture government staff members in the focus group discussions. Stelfox and Straus<sup>36</sup> listed the method accompanied by the patients' viewpoints as one of the key steps for developing better indicators. Multifaceted discussions involving patients and prefecture government staffs are needed for further improvement of the tool shown in this study. They may be expected to stimulate addition of activity indicators and practical actions that would take us closer to the goals. Also, the activity status in the prefectures adopting the tool has not yet been sufficiently assessed. Analysis and discussion tailored to situations unique to a given prefecture may yield important suggestions on changing times (eg, at the occasion of policy change) in the future. This is a subject for the future.

In conclusion, we developed a new tool to evaluate the practical status of cancer information and support activities in Japan. Our attempt at encouraging social recognition (visualization) of the cancer information

## Implications for Policy & Practice

- It becomes increasingly important to arrange and improve the system of medical care and public health, in order for patients with cancer and their families to be supported in a holistic manner at both medical facilities and local communities.
- Implementation of policy and practice on the basis of evidence is ideal, but it often happens that medical care and public health programs start responding to public requirements in the real world without enough evidence and preparation. Such new programs should be introduced at a uniform level throughout the country in Japan.
- We developed a new tool to objectively evaluate the practical status of cancer information and support activities in Japan.
- The tool shown here provides an overview of the cancer information and support activities that would be useful for stakeholders to adopt. They should also share the goals of their own activities and be mutually aware of others'.
- Our attempt at encouraging social recognition (visualization) of the cancer information and support activities will eventually lead to establishing a better national anticancer policy.
- The processes mentioned in this study could also serve as a practical guide to facilitate continuous activity assessments in other countries.

and support activities will eventually lead to establishing a better national anticancer policy. The processes mentioned in this study could also serve as a practical guide to improve and facilitate continuous activity assessments in other countries.

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