

Center for Cancer Control  
and Information Services

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# Organization

President:

Tomomitsu Hotta

Director:

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Division of Cancer Information Service

Chief: Tomoko Takayama

Information Development Research Section

Communication Research Section

Evaluation Research Section

Division of Surveillance

Chief: Hiroshi Nishimoto

Epidemiology and Statistics Section

Population-based Cancer Registry Section

Hospital-based Cancer Registry Section

Cancer Care Statistics Section

Economics Section

Division of Medical Support and Partnership

Chief: Masashi Kato

Medical Support and Partnership Section

Pathology Consultation Section

Radiology Consultation Section

Outreach Radiation Oncology and Physics Section

Cancer Control Educations and Trainings Section

Division of Cancer Survivorship Research

Chief: Miyako Takahashi

Division of Health Services Research

Chief: Takahiro Higashi

Division of Tobacco Policy Research

Chief: Yumiko Mochizuki-Kobayashi

Division of Task Force for National Cancer Registry

Chief: Hiroshi Nishimoto



# Activities of the Divisions

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## DIVISION OF CANCER INFORMATION SERVICE

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### Introduction

The mission of the Cancer Information Services (CIS) is to provide credible information about cancer. In the National Cancer Information Network, the CIS plays an important role in disseminating cancer-related information directly to a wide range of audience, including patients, caregivers, health professionals, policy makers, researchers, advocates, the news media and other stakeholders. The information we disseminate, are made available over the internet, distributed in brochure formats, and through a range of both public and closed forums and symposiums throughout Japan. Our dissemination channels also include the 409 designated cancer care hospitals and their respective cancer information and support teams. One of our key mandates is to provide all patients and their loved ones, with the means to access comprehensive cancer-related information at the point of need, and with appropriate context. Over the past year, our key delivery channel “ganjoho.jp” has undergone its third major make-over, with the intent to allow users to reach the information they require more quickly via enhanced contextual navigation aids. For those who are unable to navigate the net, we have also compiled a more comprehensive all-in-one handbook for cancer patients and their families: “Guidebook for Cancer Patients”, and a sister publication for working patients “Working With Cancer – a comprehensive FAQ” – in our never ending effort to ensure widest reach for essential information requested by patients over the years. In the last few years, we have also greatly expanded existing partnering agreements with the health insurers and pharmaceutical companies, which have committed to providing additional venues for the dissemination of our many publications intended for the public at large.

### Line of service

#### Information Development Research Section

The Information Development Research Section has exerted efforts to provide reliable, evidence-based cancer information to patients, their families, citizens, healthcare professionals, researchers, and policy makers. Evidence databases such as clinical practice guidelines and research findings are continuously sourced, assessed, and edited, ensuring that the information is presented in a manner consistent with how the users digest and process the information. As part of continually providing reliable information in an easily understood format, cancer information contents are developed by translating based on the latest treatment guidelines, and evaluated by domain experts (for accuracy) and by editorial review teams (professional writers as well as patients for clarity and usability). Information is disseminated through various media formats, including the website “Cancer Information Service <http://ganjoho.jp/>”, a wide range of patient education brochures, flyers and handbooks that contain comprehensive cancer information to help empower patients and families throughout the continuum of cancer survivorship. To make the brochures more widely available, we have introduced a publication ordering system, to cater to increasing demand from hospitals, clinics and even regional governments. More than 0.9 million brochures were ordered from 490 organizations in FY2014. The Section also helps direct health care providers by providing access to an extensive library of articles on cancer treatment and supportive information that have undergone the CIS peer reviews, as well as other cancer information sources that are of interest to health care professionals.

## Communication Research Section

The Communication Research Section is in charge of supporting the smooth operation of cancer information services among the Cancer Information & Support Centers (CISCs) in designated cancer hospitals (409 locations around the nation). The Section handles developing training materials and provides basic and advanced level trainings for the CISCs staffs. To provide quality education program, the Section operates the “CISC-expert panel” which consists of 11 supporters with variety of professionals and regional backgrounds, and they check if the program is effective throughout the year.

## Evaluation Research Section

In order to disseminate reliable cancer information to the public, the Evaluation Research Section is in charge of supporting the smooth operation of cancer information services and of encouraging the collaboration among relevant stakeholders, such as the support groups, and prefectural government units responsible for planning and managing their respective regional cancer programs. The Section helps to manage the regional trainings and networking forums for the CISCs staffs, in addition to seminars for the public and local health care workers. The Section also prepares and manages the collaborative work with the “Patient-civil panel” which consists of 100 supporters with a variety of experiences with cancer and different regional backgrounds from throughout Japan, and provides mutual educational forums for media professionals. The Section also operates the hotline “Cancer Information Support Center” which helps to provide cancer information

to the public and professionals through telephone.

## Research activities

In our division, three sections jointly conduct research activities.

To ensure timely dissemination of accurate and pertinent information on cancer, and to more effectively support decision-making by patients, their families and the general public, we conduct extensive surveys to better gauge what type of information is needed, how it needs to be delivered in order to make a timely impact, and which stakeholders in the community need to be part of the delivery/dissemination network. Increasingly, we are also involving with regional community stakeholders, (patients, caregivers, health practitioners, and municipal governments), to help to compile more regionally pertinent set of information, in the effort to improve our community outreach efforts.

To overcome disparities of cancer related information all over Japan and to contribute to build better cancer information and support systems, our division conducts a portfolio of research in wide ranging areas such as the identification of underserved populations, building a cross functional network of community care providers, defining the activities of cancer information centers, developing innovative educational programs and training methods that help accelerate best practice adoption among cancer information counselors. In 2014, we started to examine the barriers of health professionals’ usage of information for people with visual impairments.

## List of papers published in 2014

### Journal

1. Nakanotani T, Akechi T, Takayama T, Karato A, Kikuuchi Y, Okamoto N, Katayama K, Yokoo M, Ogawa A. Characteristics of elderly cancer patients’ concerns and their quality of life in Japan: a Web-based survey. *Jpn J Clin Oncol*, 44:448-455, 2014
2. Yokoo M, Akechi T, Takayama T, Karato A, Kikuuchi Y, Okamoto N, Katayama K, Nakanotani T, Ogawa A. Comprehensive assessment of cancer patients’ concerns and the association with quality of life. *Jpn J Clin Oncol*, 44:670-676, 2014

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## DIVISION OF SURVEILLANCE

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**Hiroshi Nishimoto, Koichi B. Ishikawa, Akiko Shibata, Kota Katanoda, Tomohiro Matsuda, Kumiko Saika, Megumi Hori, Yoshiko Emori, Kaori Nakano, Mariko Niino, Masako Sato**

### Introduction

The Division of Surveillance is in charge of providing credible cancer statistics to patients and their families, the public, healthcare professionals, policy makers and researchers. The Division also collects accurate and useful information on cancer statistics at the national level. We promote the standardization of hospital-based cancer registries in designated cancer care hospitals and population-based cancer registries in prefectures. The data are collected from both hospital-based and population-based cancer registries, analyzed to calculate accurate cancer statistics and disseminated throughout Japan. Newly incorporated economics section will augment epidemiologic data with economic information crucial for formulation of future policy.

### Routine activities

#### Population-based Cancer Registries

The Division has continuously exerted efforts to develop a reliable cancer surveillance system in Japan, which is stated as a key element in the Cancer Control Act. The Division supports all these 47 registries, by disseminating up-to-date information through websites and mailing lists; by setting up a Q&A service; by holding 2-day educational workshops for cancer registrars and administrative officers in charge of cancer control newly assigned to their post in May, with a total of 72 participants; and organizing 2-day advanced educational workshops with a total of 118 participants in December. The Division also provided site visiting as part of training for the Standard Database System (SDS), for promoting the protection of personal information, and for cancer registry start-up preparation. This activity supported a total of 17 prefectures this year. 41

registries had introduced the SDS as of January 2015. Introduction is in progress in one registry. The self-check software on security control in cancer registration, and security educational materials for new workers were updated and provided by the Division. In accordance with the Act on Promotion of Cancer Registry enacted in 2013, the Division participated in preparations for establishment of the National Cancer Registry Data Center. Specifically, the preparation activities included advice for the Ministry of Health, Labour and Welfare, forming the materials and data for discussion, development of the National Cancer Registry System, checking the data of the current regional cancer registries, and visiting prefectures for explanation of the act.

#### Hospital-based Cancer Registries

Since a hospital-based cancer registry (HCR) is essential to evaluate cancer care in each hospital and also to achieve high completeness of population-based cancer registries, it should be established urgently for cancer control. The Division plays an important role as a driving force for the standardization and quality improvement of HCRs, which has been performed at 397 designated cancer care hospitals (DCCHs) and over other 300 hospitals in 2013. In collaboration with other relevant parties, the Division develops data standards for HCR, modifies datasets, and distributes the standardized software "Hos-CanR PLUS" which is used in about 800 hospitals. In 2014, individual records for 313,377 cancer cases diagnosed in 2012 were collected from 397 DCCHs. To improve the data quality, the Division devised an education program for cancer registrars through holding three one-week-long workshops for experts in Tokyo per year and 2-day workshops for beginners twice a year at 12 cities in which about 1,500 registrars participated. Furthermore, the

Division performed site visits to 33 DCCHs in 2013.  
Cancer Statistics

The Division is in charge of providing information on cancer statistics. The updated data of cancer mortality, incidence, survival, and prevalence, the secular trends of cancer mortality and incidence, and the framework of cancer control in Japan have been published both on the web site and in the book titled "Cancer Statistics in Japan."

## Research activities

### Population-based Cancer Registries

The national cancer incidences in 2008 and 2009 were estimated based on the data from 37 and 31 cancer registries, respectively. The number of prefectures that have met the data quality standards increased since last year. The incidence data were then analyzed in detail by cancer site. The study results were published in an international journal. The cancer incidence data have been used in a couple of research analyses; the results are presented at conferences both in Japan and abroad.

### Cancer Statistics

International comparisons of cancer burden and survival rate were conducted based on the WHO mortality, GLOBOCAN, and cancer registry database. Updated trend analysis of cancer incidence and mortality in Japan was conducted. Descriptive analysis was also conducted for myelodysplastic syndrome in Japan. Tobacco control situations were analyzed in three East Asian countries, Japan, China and the Republic of Korea, and the association between environmental tobacco smoke and stroke was examined.

### Economic studies on cancer care

A nation-wide database of inpatient and outpatient clinical practice is constructed with DPC-survey compliant data from over 1,000 hospitals. Using this data, we published a data book on the use of pharmaceuticals related to chemotherapy. Findings from this database and other information related to utilization of services are linked with population estimates to form future forecasts of supply and demand in cancer care.

**Table 1. Population-based Cancer Registries from Prefectural Registries**

Year of Diagnosis	Prefectures	Number of New Cancer Cases
2011	40 (14 for estimation and 39 for inter-regional comparison)	851,537

**Table 2. Population-based Cancer Registries from Prefectural Registries**

Year of Diagnosis	Applied Hospitals	Number of New Cancer Cases
2010	387	548,979
2011	395	584,120
2012	397	613,377

## List of papers published in 2014

### Journal

1. Katanoda K, Kamo K, Saika K, Matsuda T, Shibata A, Matsuda A, Nishino Y, Hattori M, Soda M, Ioka A, Sobue T, Nishimoto H. Shortterm projection of cancer incidence in Japan using an age-period interaction model with spline smoothing. *Jpn J Clin Oncol*, 44:36-41, 2014
2. Higashi T, Nakamura F, Shibata A, Emori Y, Nishimoto H. The national database of hospital-based cancer registries: a nationwide infrastructure to support evidence-based cancer care and cancer control policy in Japan. *Jpn J Clin Oncol*, 44:2-8, 2014
3. Iwanaga M, Chiang C-J, Soda M, Lai M-S, Yang Y-W, Miyazaki Y, Matsuo K, Matsuda T, Sobue T. Incidence of lymphoplasmacytic lymphoma/Waldenstrom's macroglobulinaemia in Japan and Taiwan population-based cancer registries, 1996-2003. *Int J Cancer*, 134:174-180, 2014
4. Katanoda K, Kamo K, Hori M, Tsugane S. Estimated prevalence of thyroid cancer in Fukushima prior to the Fukushima Daiichi nuclear disaster. *BMJ[Internet]*, 2014
5. Matsuda A, Yamaoka K, Tango T, Matsuda T, Nishimoto H. Effectiveness of psychoeducational support on quality of life in early-stage breast cancer patients: a systematic review and meta-analysis of randomized controlled trials. *Qual Life Res*, 23:21-30, 2014
6. Matsuda A, Katanoda K. Five-year relative survival rate of ovarian cancer in the USA, Europe and Japan. *Jpn J Clin Oncol*, 44:196, 2014
7. Katanoda K, Matsuda T. Five-year relative survival rate of liver cancer in the USA, Europe and Japan. *Jpn J Clin Oncol*, 44:302-303, 2014
8. Matsuda T, Matsuda A. Five-year relative survival rate of pancreas cancer in the USA, Europe and Japan. *Jpn J Clin Oncol*, 44:398-399, 2014
9. Chihara D, Ito H, Matsuda T, Shibata A, Katsumi A, Nakamura S, Tomotaka S, Morton LM, Weisenburger DD, Matsuo K. Differences in incidence and trends of haematological malignancies in Japan and the United States. *Br J Haematol*, 164:536-545, 2014
10. Matsuda A, Matsuda T, Shibata A, Katanoda K, Sobue T, Nishimoto H. Cancer incidence and incidence rates in Japan in 2008: a study of 25 population-based cancer registries for the Monitoring of Cancer Incidence in Japan (MCIJ) project. *Jpn J Clin Oncol*, 44:388-396, 2014
11. Katanoda K, Jiang Y, Park S, Lim MK, Qiao Y-L, Inoue M. Tobacco control challenges in East Asia: proposals for change in the world's largest epidemic region. *Tob Control*, 23:359-368, 2014
12. Tamaki T, Dong Y, Ohno Y, Sobue T, Nishimoto H, Shibata A. The burden of rare cancer in Japan: application of the RARECARE definition. *Cancer Epidemiol*, 38:490-495, 2014
13. Chihara D, Ito H, Katanoda K, Shibata A, Matsuda T, Sobue T, Matsuo K. Incidence of myelodysplastic syndrome in Japan. *J Epidemiol*, 24:469-473, 2014
14. Katanoda K, Matsuda T. Five-year relative survival rate of breast cancer in the USA, Europe and Japan. *Jpn J Clin Oncol*, 44:611, 2014
15. Katanoda K. The dynamics of cancer burden in Asia. *Ann Transl Med*, 2:67, 2014
16. Matsuda T, Hori M. Five-year relative survival rate of bladder cancer in the USA, Europe and Japan. *Jpn J Clin Oncol*, 44:776, 2014
17. Hori M, Katanoda K. Five-year relative survival rate of skin cancer in the USA, Europe and Japan. *Jpn J Clin Oncol*, 44:881, 2014
18. Nishino Y, Tsuji I, Tanaka H, Nakayama T, Nakatsuka H, Ito H, Suzuki T, Katanoda K, Sobue T, Tominaga S. Stroke mortality associated with environmental tobacco smoke among never-smoking Japanese women: a prospective cohort study. *Prev Med*, 67:41-45, 2014
19. Yako-Suketomo H, Katanoda K, Sobue T, Imai H. Practical use of cancer control promoters in municipalities in Japan. *Asian Pac J Cancer Prev*, 15:8239-8244, 2014
20. Saika K, Matsuda T, Sobue T. Incidence rate of thyroid cancer by histological type in Japan. *Jpn J Clin Oncol*, 44:1131-1132, 2014
21. Ito Y, Miyashiro I, Ito H, Hosono S, Chihara D, Nakata-Yamada K, Nakayama M, Matsuzaka M, Hattori M, Sugiyama H, Oze I, Tanaka R, Nomura E, Nishino Y, Matsuda T, Ioka A, Tsukuma H, Nakayama T. Long-term survival and conditional survival of cancer patients in Japan using population-based cancer registry data. *Cancer Sci*, 105:1480-1486, 2014
22. Allemani C, Weir HK, Carreira H, Harewood R, Spika D, Wang X-S, Bannon F, Ahn JV, Johnson CJ, Bonaventure A, Marcos-Gragera R, Stiller C, Azevedo E Silva G, Chen W-Q, Ogunbiyi OJ, Rachet B, Soeberg MJ, You H, Matsuda T, Bielska-Lasota M, Storm H, Tucker TC, Coleman MP. Global surveillance of cancer survival 1995-2009: analysis of individual data for 25 676 887 patients from 279 populationbased registries in 67 countries (CONCORD-2). *Lancet*, 385:977-1010, 2014
23. Katanoda K, Matsuda T. Five-year relative survival rate of testis cancer in the USA, Europe and Japan. *Jpn J Clin Oncol*, 44:1248, 2014

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## DIVISION OF MEDICAL SUPPORT AND PARTNERSHIP

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Masashi Kato, Yasuaki Arai, Jun Itami, Nobuyoshi Hiraoka, Yoshinori Makino, Miki Hosoya, Yoko Nakazawa, Kanako Kono, Saho Wada, Tadakazu Shimoda, Hiroaki Onaya, Toshiyuki Minemura, Takashi Hanada, Yuki Aono, Saran Yoshida, Naotoshi Atoda, Naoya Ikeno, Ryoji Kushima, Hiroko Suketomo, Megumi Fukuda, Ritsuko Chinda, Yuri Yamauchi, Hiromi Nakamura, Toshiko Sakaguchi, Shiho Hirai, Hiroyo Ohchi, Ito Chisako, Sasaki Erina

### Introduction

The Division builds partnership with the Designated Cancer Care Hospitals to support all health-allied professionals concerned with for cancer control in Japan. The Medical Support and Partnership Section (MSPS) plays a unique role in supporting the Designated Cancer Care Hospitals in Japan. The Pathology Consultation Section (PCS) makes effort to perform human pathology research based on histology of tumor cells and tumor-stromal cells to improve diagnostic pathology of the tumors. The Radiology Consultation Section (RCS) provides a consultation service and a cancer image reference database (NCC-CIR). A radiology consultation service is aimed at the improvement of the quality of diagnosis based on medical images. The NCC-CIR is a web-based reference database system of images of neoplasms for physicians, radiologists, and pathologists providing medical diagnostic images and information together with the pathology. The Outreach Radiation Oncology and Physics Section (ORPS) provides the following support programs for designated regional cancer centers and institutions participating in clinical trials. The Cancer Control Education and Training Section (CCET) plays a central role in the planning, management and evaluation of specialized and multidisciplinary training programs for physicians and other health professionals as trainers of each designated cancer care hospital, to promote a comprehensive and systematic cancer control program in Japan.

### Routine activities

#### A. Networking among Designated Cancer Care Hospitals

The MSPS held the Designated Cancer Care Hospitals Liaison-council and the Palliative Care

Committee (a subsidiary organization) to enhance partnership for cancer control in Japan. The designated cancer care hospitals are important partners with the NCC to promote comprehensive cancer control in Japan.

#### B. Pathology consultation service

The PCS received 478 cases requested for specialist's second opinion regarding histopathological diagnosis in 2014. There are 82 consultants having been registered, many of them are highly recognized experts in specialty disciplines. One of them assigned as consultant examines the slides and rapidly sends back the report of opinion to each client. Most of the clients expressed satisfaction with the contents of the report and this consultation system. We also selected typical or educational cases from accumulated archives and constructed referential database.

#### C. Radiology consultation service

74 consultation reports have been put together for requests mainly from the Kanto and Kyushu regions at the RCS. Hepato-biliary-pancreatic, musculoskeletal, and lung lesions were the common subjects. Consultation with a specialist was the most frequent reason 37.9% for consultation. The client radiologists have evaluated 314 (91.0%) of the 345 consultation reports as being useful for the presence of clinical impact on the final radiological diagnoses.

#### D. NCC-CIR

The average number of effective accesses to this site was almost the same as that in 2013, about 100,000 per month. Cases with cancers who underwent musculoskeletal malignancies (n=4), head and neck cancers (n=2), urological malignancies (n=2), liver cancers (n=2), and other

cancers have been published, resulting in the total provision of 300 cases.

#### **E. Radiotherapy case service**

Mailed dosimetry and on-site dosimetry were performed in 129 institutions and 12 institutions, respectively at the ORPS. All data of the institutions were within the permissible limit.

### **Research activities**

#### **A. Evaluate changes in Palliative Care by Cancer Control Program**

To evaluate the changes of palliative care induced by the Basic Plan to Promote Cancer Control Program in Japan, an interview survey and a questionnaire survey are conducted at the MSPS.

#### **B. Develop a peer review method to implement a PDCA cycle in among the Designated Cancer Care Hospitals**

The MSPS developed a guide and a manual for carrying out peer review about palliative care.

#### **C. Support for clinical trials**

The RCS is currently trying to reconstruct the consultation system to make it more suitable for supporting central radiological review in clinical trials.

#### **D. Develop the IMRT quality control support program**

The ORPS were developing enforcement of the on-site dosimetry regarding the output dose

of Intensity Modulated Radiotherapy (IMRT) in 2 institutions (designated regional cancer centers).

### **Clinical trials**

In Japan Clinical Oncology Group (JCOG1008, JCOG1208, JCOG1303) and Japanese Radiation Oncology Study Group (JROSG12-1), the ORPS performed the on-site dosimetry regarding the output dose of IMRT in 10 institutions.

### **Education**

The CCET provides and evaluates various oncology professional training programs about up-to-date information on early detection, diagnosis, treatment, nursing care, cancer research, clinical trials and cancer statistics for physicians, nurses, pharmacists, cancer information (CI) specialists, technologists and cancer registrars. The CCET also provides multidisciplinary training programs for Palliative Care Teams and Chemotherapy Teams. (Table 1)

### **Future prospects**

The MSPS conduct a needs assessment survey about the support for medical service of the Designated Cancer Care Hospitals, and search a support system to meet the need. All sections will continue to be involved in our routine activities and education.

**Table 1. Training programs conducted during April 2013 - March 2015**

Category of Education and Training program	Titles of Education and Training program	Number of participants (April 2013 - March 2014)	Number of participants (April 2014 - March 2015)
Oncology nursing education	Continuing education and development of oncology nursing workshop for trainers	44	74
	Continuing education and development of oncology nursing workshop for trainers-Follow up	11	60
	Oncology nursing seminar for trainers	362	505
	Oncology nursing on the job training for trainers	6	-
	Oncology nursing on the job training for trainers-Follow up	6	-
	Certified Nurse Follow up Program	38	51
	End-of-life nursing education program for trainers	76	84
	CI specialist education	CI Specialist Education Program -Basic course 1	680
CI Specialist Education Program -Basic course 2		658	633
CI Specialist Education Program -Basic course 3		339	338
CI Specialist Education Program -Upskill course		-	92
CI Specialist Education Program for trainers		52	188
CI Specialist Education Program for trainers-Follow up		98	30
Hospital-based cancer registrar training	Training program for instructors of hospital-based cancer registrars	10	20
	Continuous training program for instructors of hospital-based cancer registrars	9	6
	Supplementary training program for instructors of hospital-based cancer registrars	93	96
	Basic training program for hospital-based cancer registrars	1,442	1,582
	Supplementary training program for hospital-based cancer registrars of basic course completion	770	1,079
	Advanced training program for hospital-based cancer registrars	155	155
	Introduction program for implementation of hospital-based cancer registry	70	72
	Basic training programs on population-based cancer registry for population-based cancer registrars and administrative officers in charge of cancer control	294	191
Technologist education	Trainer training for oncologic radiology technologists	15	-
	Trainer training for oncologic laboratory medical technologists	5	-
Pharmacist education	Seminar for pharmacists of dispensing neoplastic agents to be trainers	71	58
	On the job training for pharmacists of dispensing neoplastic agents to be trainers	19	24
Palliative care physicians education	Palliative care education meeting for trainers	53	62
Psycho-oncologists education	Psycho-oncology education meeting for trainers	53	27
Palliative care team education	Palliative care team workshops for consultation-Basic course	73	45
	Palliative care team workshops for trainers	34	38
Chemotherapy team education	Chemotherapy team workshops to introduce a new drug safety	64	32
	Chemotherapy team workshops for regional trainers	-	24
Prefectural official education	Cancer control seminars and workshops	110	77
<b>Total</b>		<b>5,710</b>	<b>6,267</b>

## List of papers published in 2014

### Journal

1. Iwao Y, Ojima H, Onaya H, Sakamoto Y, Kishi Y, Nara S, Esaki M, Mizuguchi Y, Ushigome M, Asahina D, Hiraoka N, Shimada K, Kosuge T, Kanai Y. Early venous return in hepatic angiomyolipoma due to an intratumoral structure resembling an arteriovenous fistula. *Hepatol Res*, 44:700-706, 2014
2. Sato Y, Ojima H, Onaya H, Mori T, Hiraoka N, Kishi Y, Nara S, Esaki M, Shimada K, Kosuge T, Sugihara K, Kanai Y. Histopathological characteristics of hypervascular cholangiocellular carcinoma as an early stage of cholangiocellular carcinoma. *Hepatol Res*, 44:1119-1129, 2014
3. Imura C, Morita T, Kato M, Akizuki N, Kinoshita H, Shirahige Y, Suzuki S, Takebayashi T, Yoshihara R, Eguchi K. How and why did a regional palliative care program lead to changes in a region? A qualitative analysis of the Japan OPTIM study. *J Pain Symptom Manage*, 47:849-859, 2014
4. Kuno H, Onaya H, Fujii S, Ojiri H, Otani K, Satake M. Primary staging of laryngeal and hypopharyngeal cancer: CT, MR imaging and dual-energy CT. *Eur J Radiol*, 83:e23-35, 2014
5. Kuno H, Onaya H. A case of oropharyngeal squamous cell carcinoma with nasopharyngeal extension via the levator veli palatini muscle. *Jpn J Clin Oncol*, 44:195, 2014
6. Nakazawa Y, Kizawa Y, Hashizume T, Morita T, Sasahara T, Miyashita M. One-year followup of an educational intervention for palliative care consultation teams. *Jpn J Clin Oncol*, 44:172-179, 2014
7. Hirooka K, Miyashita M, Morita T, Ichikawa T, Yoshida S, Akizuki N, Akiyama M, Shirahige Y, Eguchi K. Regional medical professionals' confidence in providing palliative care, associated difficulties and availability of specialized palliative care services in Japan. *Jpn J Clin Oncol*, 44:249-256, 2014
8. Yoshida S, Shimizu K, Kobayashi M, Inoguchi H, Oshima Y, Dotani C, Nakahara R, Takahashi T, Kato M. Barriers of healthcare providers against end-of-life discussions with pediatric cancer patients. *Jpn J Clin Oncol*, 44:729-735, 2014
9. Kono K, Tamashiro DAA, Alarcon VB. Inhibition of RHO-ROCK signaling enhances ICM and suppresses TE characteristics through activation of Hippo signaling in the mouse blastocyst. *Dev Biol*, 394:142-155, 2014
10. Yoshida S, Amano K, Ohta H, Kusuki S, Morita T, Ogata A, Hirai K. A comprehensive study of the distressing experiences and support needs of parents of children with intractable cancer. *Jpn J Clin Oncol*, 44:1181-1188, 2014

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## DIVISION OF CANCER SURVIVORSHIP RESEARCH

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Miyako Takahashi, Makiko Tomita, Makiko Tazaki, Kyoko Onozawa

### Introduction

The Division of Cancer Survivorship was established in April 2013. Our mission is to enhance the quality of life of people with cancer and their caregivers, and to promote social awareness in Japan about cancer survivorship issues.

### Routine activities

As for academic research, we mainly deal with various psychosocial issues experienced by cancer survivors and their caregivers during and after treatments such as employment, interpersonal relationships, sexuality and fertility, prejudice against cancer, and life-style modifications. In particular, we examine the influence of the Japanese socio-cultural background on living with and through cancer, and try to propose countermeasures based on the research findings.

As for activities to promote social awareness toward cancer survivorship, we plan and implement educational programs for the general public as well as healthcare providers.

In addition to the above mentioned activities, Dr. Miyako Takahashi, Division Chief, served as a member of “Cancer and Work” council organized by the Ministry of Health, Labour and Welfare in 2014.

### Research activities

The research projects we conducted in 2014 include “cancer and work”, “psychosocial impact of appearance change among male cancer survivors”, “pediatric cancer survivors’ sexual development”, “father-child communication when mother has cancer”, and so on. As for research on cancer and work, we published “Cancer and Work Q&A 2nd edition”, which is now available on Cancer

Information Service website.

This year, we conducted keynote lectures, symposium presentations, and oral presentations in 13 academic meetings. Also, we published 4 articles in English, 10 articles, 1 edited book, and 4 chapters in co-authored book in Japanese.

### Education

As for education for healthcare providers in 2014, we delivered lectures in 3 universities for medical and nursing students, 3 lectures for advanced nursing courses, 2 lectures for the Tokyo Metropolitan Medical Association, 6 lectures for prefectural governments, and 22 lectures for medical institutions nationwide.

As for promoting social awareness of cancer survivorship, we planned and implemented 2 lecture series, “Community Center Café” and “Gotochi (Local) Café”, which were open to the public. These café programs were held in a relaxed atmosphere with a cup of tea, consist of a lecture that takes up various cancer survivorship topics followed by a small group discussion by participants. It provided participants an opportunity to learn about cancer survivorship issues as well as exchange views each other. In 2014, we held The Community Center Café 6 times with 300 participants in total in the Tsukishima Community Center in Chuo ward, where National Cancer Center is located. The Gotochi (Local) Café, the other café program, has the same structure as the Community Center Cafe, but was co-sponsored by our division and healthcare providers in prefectures outside of Tokyo, and focused on high priority survivorship issues within the local community. In 2014, we held the Gotochi Café 4 times in Okinawa, Miyagi, Hokkaido, and Nara, and 200 people participated.

## List of papers published in 2014

### Journal

1. Saito N, Takahashi M, Sairenchi T, Muto T. The impact of breast cancer on employment among Japanese women. *J Occup Health*, 56:49-55, 2014
2. Takahashi M. Psychosocial distress among young breast cancer survivors: implications for healthcare providers. *Breast Cancer*, 21:664-669, 2014

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## DIVISION OF HEALTH SERVICES RESEARCH

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### Introduction

In order to establish an evaluation system for health systems and health policy performance in cancer care in Japan, the Division of Health Services Research primarily focused on the following research projects in 2014.

### Routine activities

#### i. Establishing a clinical database by linking hospital-based cancer registry and DPC / insurance claims data

As a first step in monitoring the quality of cancer care and ensuring equitable access to care in Japan, the division developed a large clinical database that linked hospital-based cancer registry data with DPC / insurance claims data obtained from designated cancer care hospitals throughout Japan. The Division distributed free encryption software designed to support different file formats used by various hospitals, which allowed multiple data sources to be synthesized smoothly into a single database. The database contains de-identified information on all procedures, tests, and prescriptions given to patients with major cancers who were diagnosed in 2011 from 182 hospitals across the country. We used the database to calculate 13 quality indicators (QIs) among 206 QIs that were previously developed by an expert panel led by Dr. Sobue Tomotaka, professor of Medicine at Osaka University, which ask if certain types of tests, procedures, or prescriptions were given to a specified set of patients, such as the proportion of stage III colorectal cancer patients that received adjuvant chemotherapy within 8 weeks of surgery. Results of the QI scores were fed back to participating hospitals through an interactive website that allows hospitals to compare its performance to other hospitals. We expect the hospitals to use the results for future quality

improvements.

We also began collecting data of patients who were diagnosed with cancer in 2012 for all cancer types, and have finished creating a database containing DPC data of 232 hospitals. The data is currently being analyzed for QI measurement. We also plan to improve our quality metrics so that results are more relevant and meaningful for hospitals, and hope that the initiative will be sustainable.

#### ii. Monitoring and Evaluation of National Cancer Control Programs

A clearly defined set of performance indicators to measure health policy performance in cancer care have never been developed in Japan. In order to develop such a system to monitor the performance of cancer control programs, the Division gathered a panel of experts including clinical specialists, patient representatives, biomedical and public health researchers, cancer information experts, and policy makers in early 2014. Using a modified Delphi method, we created a list of 91 performance indicators agreed upon by the expert panel and the Cancer Control Promotion Council to measure various outcomes and outputs of cancer control programs. We also conducted a series of group interviews by the panel and members of the Cancer Control Promotion Council to identify essential components of the three major goals of cancer control program.

1. Advancement of medicine
2. Provision to appropriate medical treatment
3. Disseminate cancer-related information to the public and provide help-desk for cancer patients
4. Addressing the economic burden of cancer and providing financial support
5. Mitigating the burden of family caregivers of cancer patients
6. Creating a society without discrimination and alienation against cancer patients

We broke these components into a series of questions to be asked to cancer patients and their families, and launched a patient experience survey to over 130 hospitals. The survey also included questions from the 91 performance measures. The Division is currently analyzing the results for reporting to the Cancer Control Promotion Council.

### **iii. Evidence Generation for Rare Cancer Policy**

The Basic Plan to Promote Cancer Control Programs indicates the need for provision of better medical services and support for rare cancer patients, yet its definition of rare cancer has not been identified. Essential data on patterns of care of rare cancer patients are also lacking, making it impossible for policymakers to implement appropriate and impactful cancer programs. In order to support the activities of policymakers by providing them with evidence, we conducted a survey to physicians in oncology-related academic societies to develop a definition of rare cancer in Japan, using epidemiological data of rare cancer patients from registry data. We are also analyzing patterns of care of rare cancer patients using registry data and administrative data.

### **iv. Search engine for finding cancer treatment hospitals**

Using hospital-based cancer registry data of 2,200,000 cancer patients who were registered between 2009 and 2012, we developed a search engine that could be used by counselors stationed at support centers in 46 Prefectural Designated Cancer Care Hospitals to provide information to cancer patients and their families in finding hospitals that have previous experience in treating

a specified type of cancer patients. We hope to continue this system by updating the registry data on an annual basis.

### **Research training and education**

The Division has had a continuous flow of physicians and graduate students for research trainings throughout the year. We mentored two graduate students: one pursuing a clinical doctorate and another from nursing-related doctorate program. Additionally, the Division accepted four medical students from the University of Tokyo for a clerkship in Public Health.

### **Future prospects**

The Division supports evidence-based policymaking and strives to improve the care of cancer patients by monitoring the performance of cancer policy and quality of care among cancer treatment centers across the country. In addition to the current activities, the Division is working to provide an information exchange platform for specialists and various stakeholders, designed to foster smooth communication and active exchange of ideas for cancer policy planning at the local government level. The Division will continue to endeavor towards making clinically relevant and evidence-based policy recommendations in order to help implement meaningful cancer control programs in Japan.

## List of papers published in 2014

### Journal

1. Higashi T, Nakamura F, Shibata A, Emori Y, Nishimoto H. The national database of hospital-based cancer registries: a nationwide infrastructure to support evidence-based cancer care and cancer control policy in Japan. *Jpn J Clin Oncol*, 44:2-8, 2014
2. Inohara T, Kohsaka S, Miyata H, Ueda I, Noma S, Suzuki M, Negishi K, Endo A, Nishi Y, Hayashida K, Maekawa Y, Kawamura A, Higashi T, Fukuda K. Appropriateness of coronary interventions in Japan by the US and Japanese standards. *Am Heart J*, 168:854-861 e811, 2014
3. Iwamoto M, Nakamura F, Higashi T. Estimated life expectancy and risk of death from cancer by quartiles in the older Japanese population: 2010 vital statistics. *Cancer Epidemiol*, 38:511-514, 2014
4. Inohara T, Kohsaka S, Miyata H, Ueda I, Ishikawa S, Ohki T, Nishi Y, Hayashida K, Maekawa Y, Kawamura A, Higashi T, Fukuda K. Appropriateness ratings of percutaneous coronary intervention in Japan and its association with the trend of noninvasive testing. *JACC Cardiovasc Interv*, 7:1000-1009, 2014
5. Ohura T, Higashi T, Ishizaki T, Nakayama T. Assessment of the validity and internal consistency of a performance evaluation tool based on the Japanese version of the modified barthel index for elderly people living at home. *J Phys Ther Sci*, 26:1971-1974, 2014
6. Nakamura F, Higashi T, Saruki N, Fukuhara S, Sobue T. Understanding by the general public of newspaper reports on publicly reported cancer survival in Japan: a randomized controlled trial. *Jpn J Clin Oncol*, 44:651-660, 2014
7. Okuyama A, Nakamura F, Higashi T. Prescription trends of prophylactic antiemetics for chemotherapy-induced nausea and vomiting in Japan. *Support Care Cancer*, 22:1789-1795, 2014
8. Ishiguro M, Higashi T, Watanabe T, Sugihara K. Changes in colorectal cancer care in Japan before and after guideline publication: a nationwide survey about D3 lymph node dissection and adjuvant chemotherapy. *J Am Coll Surg*, 218:969-977 e961, 2014

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## DIVISION OF TOBACCO POLICY RESEARCH

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Yumiko Mochizuki-Kobayashi, Tomoyasu Hirano, Yuriko Nishikawa

### Introduction

The death toll attributable to tobacco use is resulted from a manmade disaster worldwide, but many countries have successfully shown that it is avoidable with effective tobacco control regulations. Thus, to achieve the global standard level of tobacco policies, our missions are research activities and advocacies based on the following four pillars: 1. Monitoring and Evaluation, 2. Development and Research of Practical Programs, 3. Public Education and Information Services, and 4. Promoting Policy and Networking.

### Projects and Research activities

- Through the government commissioned projects, we gathered comprehensive information on the implementation of FCTC (Framework Convention on Tobacco Control) for Japan to be reported to the convention secretariat. In addition, we analysed and evaluated the methods and contents of the report in consultation with the FCTC Study Panel.
- As a cancer education program, we developed participatory workshop curriculums on tobacco prevention for elementary school children and carried out a test pilot case in Hokkaido in collaboration with a local consortium. Based on the results, we accomplished a project framework with essential program modules to promote this innovative educational project, "Tobacco Free Kids Japan," to generate a tobacco free generation.
- In order to facilitate the government effort to promote cessation services, we carried out a test trial of quitline services that was considered appropriate to Japan's situation by the Quitline Expert Panel. With the results of the trial, we reached to a semi-autonomous scheme building intended for the workplaces by private sectors which would act in a mutually complementary manner with the existing government model based on core cancer hospitals.
- To examine possible conflict of interests with respect to the evidence based tobacco policy developments among academic societies, we carried out a survey on the interactions of individual researchers with research institutions such as universities, scientific societies and the private companies (pharmaceutical, medical device and tobacco industry). As a result of the study, most researchers in the field of public health did not recognize the conflict of interests might exist in their interactions with tobacco companies. To increase their awareness of this issue, we delivered the survey results overview as well as the FCTC Article5.3 guidelines to all respondents in commemoration of the 10th anniversary of FCTC.
- To support the Tobacco Free Olympic Games Tokyo 2020, we carried out an internet survey for residents in Tokyo with a result that majority of the respondents supported an opinion seeking regulation of penalties. Based on the results, we urged the Governor of Tokyo Metropolitan Government to implement tobacco control policies reflecting public opinions.
- As a member of the Tobacco Free Committee of the Japan Science Council, we contributed to the Tokyo Metropolitan Government to drafting and issuance of urgent proposals for tobacco control policies to realize the Tobacco Free Olympic Games 2020. Also, as a member of the Tobacco Risk Assessment Committee of the Ministry of Health, Labor and Welfare, we demonstrated the introduction of regulatory science to tobacco control and global trends of E-cigarette use, with proposals to possible regulatory framework in Japan.

- We organized various public education events at the WHO World No Tobacco Days and Science Agora of Japan Science and Technology Agency (JST) to educate people on tobacco and cancer, and also contributed to governments, schools and NGO/NPOs to develop policies and programs.

In addition, through providing information and planning assistance to the various communities, non-governmental organizations and prefectural governments with good results in networking and capacity building.

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## DIVISION OF TASK FORCE FOR NATIONAL CANCER REGISTRY

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Hiroshi Nishimoto, Naoyuki Sato, Tomohiro Matsuda, Akiko Shibata, Mariko Niino, Masako Sato (-March 2015), Rika Nabata (April 2015-), Yumi Nishikawa, Seiya Kondo

### Introduction

The Project team was in charge of development of National Cancer Registry (NCR) in the National Cancer Center (NCC) which will be launched in January 2016, as provided for by the act on promoting cancer registry enacted in December 2013, on consignment from the Ministry of Health, Labour and Welfare (MHLW).

### Routine activities

- 1) Development of the National Cancer Registry database system (NCR-DBS) and the network linking the NCC and the 47 prefectures

In collaboration with Fujitsu Ltd., the team developed the NCR-DBS at the NCC. The 47 prefectures and the NCR-DBS server of the NCC were linked by the secured network (VPN), and the prefectures were equipped with the client PC. The electronic system for automated coding of causes of death (Iris) was introduced in the NCC as a sub-system of the NCR-DBS.

- 2) Development of the Prefectural cancer registry database system (Pref-DBS) and data migration from the Standard Database System (SDS)

In order to maintain consistency of the cancer statistics, the team developed the Pref-DBS replacing the SDS, and had a contract of use with the prefectures. 42 prefectures had introduced the Pref-DBS, and the data migration is in progress. Ahead of the data migration, the team verified the quality of cancer death data in 7 prefectures for an efficient procedure.

- 3) Development of the Electronic Cancer Reporting System (E CRS)

The team has developed the ECRS and released on the web site (ganjoho.jp) mainly for the clinics which do not conduct a hospital-based cancer registration, by using auto-encrypting PDF format.

- 4) Plan for the online data submission network

The team discussed about a future plan for the online data submission network with the MHLW and the online data submission by the hospital with the highest security.

- 5) Discussion on the government ordinance and the manuals

The team discussed about the settlement of the government ordinance on NCR. The team developed several manuals for cancer reporting, data security and data use. These manuals were uploaded on the website.

- 6) Provision Information on NCR

The team was in charge of development of the website and creation of a cancer registry PR movie, infographics, posters and pamphlet on cancer registration for the public. The team supports all the 47 registries by disseminating up-to-date information through websites and mailing lists as well as by setting up a Q&A service.

### Future Prospects

NCR in the NCC will be launched in January 2016.