Center for Cancer Control and Information Services

#### Preface

The Center for Cancer Control and Information Services (CIS) is a nationally funded program established in 2006 as an essential part of NCC's extramural activities. The Task Force for the National Cancer Registry was newly established in January 2015. Then the CIS consisted of six Divisions and one Task Force.

The mission statement of the CIS is as follows: "The Center for Cancer Control and Information Services provides information needed to promote a comprehensive and systematic cancer control program in Japan." In collaboration with designated cancer care hospitals, the Ministry of Health, Labour and Welfare and other relevant ministries, the Center plays a central role to plan, manage and evaluate nationwide cancer control programs, through promotion of specialized, multidisciplinary and comprehensive cancer research, coordination of training and information dissemination, and support of prevention, diagnosis, treatment of cancer, rehabilitation from cancer and the continuing care of cancer patients and their families.

One of our key mandates is to provide all patients and their loved ones the means to access comprehensive cancer-related information at the point of need, and with appropriate context including websites such as "ganjoho. jp". An important step in this direction followed with publications for patients with cancer diagnosis, revision of a cancer information handbook for patients with cancer named "Guidebook for cancer patients", and a publication for workers named "Prescription for cancer survivors."

The CIS promotes 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. In addition, the CIS has continuously made efforts to develop a reliable cancer surveillance system in Japan, which is stated as a key element in the Cancer Control Act. In 2015, the Act on Promotion of Cancer Registries was also implemented.

The CIS is also building partnerships with Designated Cancer Care Hospitals to support all health-allied professionals concerned with cancer control in Japan in a pathology consultation service, a radiology consultation service, a cancer image reference database, a radiotherapy case service and the promotion of medical education programs for cancer control.

The CIS aims to research activities and advocacies based on four pillars: Monitoring and Evaluation, Development and Research of Practical Programs, Public Education and Information Services, and Promoting Policy and Networking.

Fumihiko Wakao, M.D., Director, Center for Cancer Control and Information Services



# Activities of the Divisions

# **DIVISION OF CANCER INFORMATION SERVICE (DCIS)**

Tomoko Takayama, Masayo Hayakawa, Haruto Ikeyama, Chikako Yamaki, Ayako Ishikawa, Akiko Urakubo, Satoko Matsumoto, Yuki Nakatani, Yuko Ogo, Yoshimi Ishibashi, Tomoko Ono, Masayo Sakurai, Eimi Sawai, Tomoko Matsuzawa, Yukako Urata, Sachiko Kawaguchi, Ayumi Kishimoto, Satoru Takizawa, Sanae Nemoto, Hitomi Yamashita, Kaori Shioda, Jun Nakamachi

# Lines of service

We have continued to enhance and update "Ganjoho.jp", the nation's trusted source of cancer information with 1,500 new pages (159,601 pages as of the end of CY2015), and annual usage is now at 31.9 million PV. Our library of patient education publications has added two new titles, and 6 of the existing 87 titles in circulation have now been updated. Contents by cancer type and regional cancer information resources have also been updated extensively. All of our patient education publications, in either booklet or pamphlet formats, are available for free downloads online and hard copies are disseminated via a bulk order printing scheme, which has made it more cost effective for cancer care facilities and related healthcare providers of all sizes. These publications are now available via 795 facilities nationwide, with over 1 million copies distributed nationwide in the course of CY2015 alone, an 11% increase over the previous year.

Division of Cancer Information Service (DCIS) continues to act as a hub that brings together the over 2,000 specialists that man the 424 Cancer Information & Support Centers (CISCs) deployed nationwide, with a bi-annual conference for prefectural CISC leadership, where we seek not only to allow the practitioners to share the latest set of best practices but also, starting in 2015, we have belatedly begun the process of better assessing our effectiveness on a more systematic basis.

The DCIS Contact Center, now in its 5th year of operation, has accommodated 2,870 calls during the calendar year, with monthly call volumes that have experienced a 46% increase over the last CY, and are fielding an increasing number of calls from patients with rare forms of cancer.

# **Research activities**

As part of our efforts to reduce the disparity of cancer information access, pilot research programs are on-going in the following areas: 1) Assessing the nature of cancer information access for patients with visual impairments and hearing disabilities, 2) Multi-modal cancer information delivery models for patients with visual impairments, 3) Use of radio broadcast dramas to encourage patients and families with lower net literacy to make use of manned cancer information resources. Further research will aim to determine both efficacy and cost effectiveness of such delivery and dissemination models, as an integral part of the broader efforts to reduce cancer disparity.

# Nurturing professionals

The specialist cancer counselors who staff the nationwide network of CISC's undergo both online training (eLearning curriculums delivered via a site we operate) and on-site group training sessions. A newly introduced certification scheme has now made it possible for cancer counselors in hospitals outside the fold of the MHW-Designation (nationally orchestrated regional cancer center designation) schemes to undergo the same set of fundamental training, and to receive certifications. This potentially opens an avenue for cancer information counselors to be deployed at upwards of 300 prefecture-designated cancer care hospitals, above and beyond and 440 nationally designated locations.

DCIS has spearheaded efforts to encourage regional networking of CISC professionals, so that a more frequent and more pertinent mix of skill enhancing opportunities are made available to a broader set of professionals in this still nascent field. During 2015, various workshops and public education forums were conducted in cities as far afield as Nagasaki, Shimane, Mie and Fukuoka.

Our media education initiatives are now in their eighth year, with four theme conferences held during 2015, and we have stepped up our initiatives to raise public awareness of the ongoing challenges of cancer survivorship, by focusing on "Working with Cancer" in conjunction with related national initiatives to ensure more cancer patients can return to their workplace.

# **Future prospects**

DCIS remains committed to our stated aims of bringing more accurate and reliable information to

# List of papers published in 2015

#### Journal

 Seki Y, Takayama T, Yamaki C. Evaluating the Cancer Information Service - a qualitative study of evaluation criteria for the telephone service in Japan. Journal of Saitama University. Faculty of Education, 64:145-154, 2015 patients, families, caregivers, as well as healthcare practitioners, in a context-sensitive manner. Towards this goal, our initiatives will focus not only on enhancing the set of information disseminated via our various channels, but also on enhancing delivery channels to cater to the needs of those patients and families for whom self-service channels are either inaccessible, or do not adequately meet their unique set of needs and circumstances. Raising awareness of the services provided at CISCs, and making them more accessible, particularly in regions were cancer stigma still runs high, are among our priorities in ensuring that cancer information dissemination helps drive reduction of cancer health disparities.

# **DIVISION OF SURVEILLANCE**

Hiroshi Nishimoto, Koichi B. Ishikawa, Akiko Shibata, Kota Katanoda, Tomohiro Matsuda, Kumiko Saika, Megumi Hori, Ayako Okuyama, 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. The newly incorporated economics section will augment epidemiologic data with economic information crucial for formulation of future policy.

#### **Routine activities**

#### 1) 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 who were new to their post in May; and organizing 2-day advanced educational workshops, attended by over 120 participants, in December. The Division also provided site visiting as part of the 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. Forty-two registries had introduced the SDS as of January 2015. The self-check software on security control in cancer registration and security educational materials for new workers were updated and provided by the division. According to 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 giving explanations about the act.

#### 2) 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 were performed at 409 designated cancer care hospitals (DCCHs) and over 300 other hospitals in 2014. 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 2015, individual records for 656,272 cancer cases diagnosed in 2013 were collected from 409 DCCHs. To improve the data quality, the Division devised an education program for cancer registrars through holding four one-weeklong workshops for experts in Tokyo per year, and conducted the primary cancer registrar examination for certifying over 800 registrars.

#### 3) 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 website and in the book titled "Cancer Statistics in Japan".

# **Research activities**

#### 1) Population-based Cancer Registries

The national cancer incidences in 2012 were estimated based on the data from 47 cancer registries, covering all prefectures. The prefectures that meet the data quality standards increased since last year. The incidence data were then analyzed in detail by the 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.

#### 2) 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 strokes was examined.

#### 3) Economic studies on cancer care

A nationwide database of inpatient and outpatient clinical practice was 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.

# Education

Our activities of extramural education were executed as mentioned above.

# **Future prospects**

We will start the National Cancer Registry (NCR) in the National Cancer Center (NCC), which will be implemented in January 2016, based on the activities of the project team.

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

| Year of Diagnosis | Prefectures  | Number of New Cancer Cases |
|-------------------|--|----------------------------|
| 2011 40           | 0 (14 for estimation and 39 for inter-regional comparison) | 851,537                    |
| 2012 47           | 7 (28 for estimation and 47 for inter-regional comparison) | 865,238                    |

#### Table 2. Cancer Patients Data from Hospital-based Cancer Registries at Designated Cancer Care Hospitals

| Year of Diagnosis | Applied Hospitals | Number of New Cancer Cases |
|-------------------|-------------------|----------------------------|
| 2010              | 387               | 548,979                    |
| 2011              | 395               | 584,120                    |
| 2012              | 397               | 613,377                    |
| 2013              | 409               | 656,272                    |

## List of papers published in 2015

#### Journal

- Saika K, Machii R. Five-year relative survival rate of brain and other nervous system cancer in the USA, Europe and Japan. Jpn J Clin Oncol, 45:313-314, 2015
- Machii R, Saika K. Morphological distribution of esophageal cancer from Cancer Incidence in Five Continents Vol. X. Jpn J Clin Oncol, 45:506-507, 2015
- Saika K, Matsuda T. Morphological distribution of ovarian cancer from Cancer Incidence in Five Continents Vol. X. Jpn J Clin Oncol, 45:793, 2015
- Matsuda T, Machii R. Morphological distribution of lung cancer from Cancer Incidence in Five Continents Vol. X. Jpn J Clin Oncol, 45:404, 2015
- Tanaka H, Matsuda T. Arrival of a new era in Japan with the establishment of the Cancer Registration Promotion Act. Eur J Cancer Prev, 24:542-543, 2015
- Niino M, Matsuda T. Morphological distribution of bladder cancer from Cancer Incidence in Five Continents Vol. X. Jpn J Clin Oncol, 45:999, 2015
- Matsuda T, Sobue T. Recent trends in population-based cancer registries in Japan: the Act on Promotion of Cancer Registries and drastic changes in the historical registry. Int J Clin Oncol, 20:11-20, 2015
- Matsuda T, Niino M. Morphological distribution of testis cancer from Cancer Incidence in Five Continents Vol. X. Jpn J Clin Oncol, 45:894, 2015
- Matsuda T, Hori M. Five-year relative survival rate of kidney and renal pelvis cancer in the USA, Europe and Japan. Jpn J Clin Oncol, 45:136, 2015
- Katanoda K, Hori M, Matsuda T, Shibata A, Nishino Y, Hattori M, Soda M, Ioka A, Sobue T, Nishimoto H. An updated report on the trends in cancer incidence and mortality in Japan, 1958-2013. Jpn J Clin Oncol, 45:390-401, 2015
- 11. Hori M, Matsuda T, Shibata A, Katanoda K, Sobue T, Nishimoto H, Japan Cancer Surveillance Research Group. Cancer incidence and incidence rates in Japan in 2009: a study of 32 population-based cancer registries for the Monitoring of Cancer Incidence in Japan (MCIJ) project. Jpn J Clin Oncol, 45:884-891, 2015
- 12. Chihara D, Ito H, Izutsu K, Hattori M, Nishino Y, Ioka A, Matsuda T, Ito Y. Advance and stagnation in the treatment of patients with lymphoma and myeloma: Analysis using population-based cancer registry data in Japan from 1993 to 2006. Int J Cancer, 137:1217-1223, 2015

- 13.Allemani C, Weir HK, Carreira H, Harewood R, Spika D, Wang XS, Bannon F, Ahn JV, Johnson CJ, Bonaventure A, Marcos-Gragera R, Stiller C, Azevedo e Silva G, Chen WQ, Ogunbiyi OJ, Rachet B, Soeberg MJ, You H, Matsuda T, Bielska-Lasota M, Storm H, Tucker TC, Coleman MP, CONCORD Working Group. Global surveillance of cancer survival 1995-2009: analysis of individual data for 25,676,887 patients from 279 population-based registries in 67 countries (CONCORD-2). Lancet, 385:977-1010, 2015
- 14. Nagai K, Hayashi K, Yasui T, Katanoda K, Iso H, Kiyohara Y, Wakatsuki A, Kubota T, Mizunuma H. Disease history and risk of comorbidity in women's life course: a comprehensive analysis of the Japan Nurses' Health Study baseline survey. BMJ Open, 5:e006360, 2015
- Katanoda K, Hori M. Morphological distribution for cancer of the central nervous system from Cancer Incidence in Five Continents Vol. X. Jpn J Clin Oncol, 45:1096, 2015
- Katanoda K, Hori M. Morphological distribution of liver cancer from Cancer Incidence in Five Continents Vol. X. Jpn J Clin Oncol, 45:607, 2015
- Hori M, Katanoda K. Morphological distribution of thyroid cancer from Cancer Incidence in Five Continents Vol. X. Jpn J Clin Oncol, 45:1182, 2015
- Hori M, Katanoda K. Morphological distribution of cervical and corpus uteri cancer from Cancer Incidence in Five Continents Vol. X. Jpn J Clin Oncol, 45:697, 2015
- Hori M, Katanoda K. Five-year relative survival rate of lymphoma in the USA, Europe and Japan. Jpn J Clin Oncol, 45:233-234, 2015
- 20. Nojiri T, Hosoda H, Tokudome T, Miura K, Ishikane S, Otani K, Kishimoto I, Shintani Y, Inoue M, Kimura T, Sawabata N, Minami M, Nakagiri T, Funaki S, Takeuchi Y, Maeda H, Kidoya H, Kiyonari H, Shioi G, Arai Y, Hasegawa T, Takakura N, Hori M, Ohno Y, Miyazato M, Mochizuki N, Okumura M, Kangawa K. Atrial natriuretic peptide prevents cancer metastasis through vascular endothelial cells. Proc Natl Acad Sci U S A, 112:4086-4091, 2015
- 21. Tanaka N, Ohno Y, Hori M, Utada M, Ito K, Suzuki T, Furukawa F. Predicting Preoperative Hemodynamic Changes Using the Visual Analog Scale. J Perianesth Nurs, 30:460-467, 2015

# **DIVISION OF MEDICAL SUPPORT AND PARTNERSHIP**

Masashi Kato, Yasuaki Arai, Jun Itami, Nobuyoshi Hiraoka, Hironobu Hashimoto, Miki Hosoya, Toshiyuki Minemura, Yoko Nakazawa, Hiroaki Onaya, Takashi Hanada, Yuichi Matsuyama, Saran Yoshida, Hideaki Kobayashi, Naotoshi Atoda, Chieko Nagashima, Ryoji Kushima, Risa Hiranuma, Yoshiko Yamaya, Hiroyo Ohchi, Hiromi Nakamura, Shiho Hirai, Ritsuko Chinda, Mayumi Kobayashi

# Introduction

The Division builds partnerships with Designated Cancer Care Hospitals to support all health-allied professionals concerned with cancer control in Japan. The Medical Support and Partnership Section (MSPS) plays a unique role in supporting Designated Cancer Care Hospitals in Japan. The Pathology Consultation Section (PCS) makes efforts to perform human pathology research based on the histology of tumor cells and tumorstromal 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 aims 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 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**

# 1) 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 partnerships for cancer control, and the PDCA cycle Forum to improve the quality of cancer care in Japan. The designated cancer care hospitals are important partners with the National Cancer Center (NCC) to promote comprehensive cancer control in Japan.

# 2) Pathology consultation service

The PCS received 466 cases requesting a specialist's second opinion regarding histopathological diagnosis in 2015. There are 86 consultants registered, many of them highly recognized experts in specialty disciplines. One of them assigned as a consultant examines the slides and quickly sends back their opinion report 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 a referential database.

# 3) Radiology consultation service

Twenty-nine consultation reports have been put together for requests mainly from the Kanto and Kyushu regions. Hepato-biliary-pancreatic and musculoskeletal lesions were the common subjects. Consultation with a specialist was the most frequent reason (37.9%) for consultation. The client radiologists have evaluated 451 (91.1%) of the 570 consultation reports as being useful for the presence of a clinical impact on the final radiological diagnoses.

# 4) NCC-CIR

The average number of effective accesses to this site was almost the same as that in 2014, about 100,000 per month. Cases with cancers who underwent urological malignancies (n=1) have been published, resulting in the total provision of 301 cases.

## 5) Radiotherapy case service

Mailed dosimetry and on-site dosimetry were performed in 116 institutions and 17 institutions, respectively, at the ORPS. All data of the institutions were within the permissible limit.

# **Research activities**

1) Develop a method to implement a PDCA cycle among the Designated Cancer Care Hospitals

The MSPS developed a method for carrying out a peer review about palliative care and examined how to implement the PDCA cycle continuously.

2) Develop the IMRT quality control support program

The ORPS were developing enforcement of the mailed dosimetry regarding the output dose of Intensity Modulated Radiotherapy (IMRT) in two institutions (designated regional cancer centers).

# **Clinical trials**

1) The on-site dosimetry regarding the output dose of IMRT

In the Japan Clinical Oncology Group (JCOG1008, JCOG1208, JCOG1303) and the Japanese Radiation Oncology Study Group (JROSG12-1), the ORPS performed on-site dosimetry regarding the output dose of IMRT in 14 institutions.

#### 2) Support for clinical trials

To support a central radiological review in clinical trials, we have provided a system for receiving and sending DICOM imaging data between participating multi-centers and the review board since September 2014. It has been already used by some clinical trials.

# Education

The CCET provides and evaluates various oncology professional training programs about upto-date information on early detection, diagnosis, treatment, nursing care, clinical trials and cancer statistics for physicians, nurses, pharmacists, cancer information (CI) specialists and cancer registrars. The CCET provides multidisciplinary training programs for Palliative Care Teams and Chemotherapy Teams. In order to develop leaders in each prefecture, CCET holds leadership training programs for skilled physicians, nurses, pharmacists and CI specialists. (Table 1, 2)

## **Future prospects**

The MSPS searches a support system to meet the needs of the Designated Cancer Care hospitals. All sections will continue to be involved in our routine activities and education.

| Category of Education and<br>Training Program   | Titles of Education and Training Program   | Number of participants |                         |       |
|---|--|------------------------|-------------------------|-------|
|   |  | Leaders in prefecture  | Leaders in<br>institute | Other |
| Oncology nursing education  | Continuing education and development of oncology<br>nursing workshop for trainers  |                        | 54                      |       |
|   | Continuing education and development of oncology<br>nursing workshop for trainers - Follow-up  |                        | 60                      |       |
|   | Continuing education and development of oncology nursing workshop for trainers in prefecture   | 20                     |                         |       |
|   | Oncology nursing seminar for trainers  |                        | 422                     |       |
|   | Certified Nurse Follow-up Program  |                        | 51                      |       |
|   | End-of-life nursing education workshop for trainers  |                        | 84                      |       |
|   | CI Specialist Education Program - Basic course 1   |                        |                         | 624   |
|   | CI Specialist Education Program - Basic course 2   |                        |                         | 635   |
|   | CI Specialist Education Program - Basic course 3   |                        |                         | 338   |
| CI specialist education   | CI Specialist Education Program for trainers   | 188                    |                         |       |
|   | CI Specialist Education Program for trainers - Follow-up   | 30                     |                         |       |
|   | CI Specialist Education Program - Skill-up course  |                        |                         | 92    |
|   | Training program for instructors of hospital-based cancer registrars   | 20                     |                         |       |
|   | Continuous training program for instructors of hospital-<br>based cancer registrars  | 6                      |                         |       |
|   | Supplementary training program for instructors of hospital-<br>based cancer registrars   | 96                     |                         |       |
| Hospital-based cancer<br>egistrar training  | Basic training program for hospital-based cancer<br>registrars   |                        |                         | 1,582 |
| egistial training   | Supplementary training program for hospital-based cancer registrars of basic course completion   |                        |                         | 1,079 |
|   | Advanced training program for hospital-based cancer registrars   |                        |                         | 156   |
|   | Introduction program for implementation of hospital-based cancer registry  |                        |                         | 72    |
| Training for population-<br>based cancer registrars and<br>administrative officers in<br>charge of cancer control | Basic training programs on population-based cancer registry for population-based cancer registrars and administrative officers in charge of cancer control |                        |                         | 191   |
|   | Seminar for pharmacists of dispensing neoplastic agents to be trainers   |                        | 58                      |       |
| Pharmacist education  | On-the-job training for pharmacists of dispensing neoplastic agents to be trainers   |                        | 24                      |       |
| Palliative care physicians education  | Palliative care education meeting for trainers   | 62                     |                         |       |
| Psycho-oncologists education  | Psycho-oncology education meeting for trainers   | 27                     |                         |       |
| Palliative care team education  | Palliative care team workshops for consultation - Basic course   |                        | 46                      |       |
|   | Palliative care team workshops for trainers  | 38                     |                         |       |
| Chemotherapy team education   | Chemotherapy team workshops to introduce new drug safety   |                        | 32                      |       |
|   | Chemotherapy care team workshops for trainers  | 24                     |                         |       |
| Training for administrative<br>officers in charge of cancer<br>control  |  |                        |                         | 77    |
| Total   |  | 511                    | 831                     | 4,846 |

| Category of Education and<br>Training Program   |  | Number of participants   |                         |       |
|---|--|--------------------------|-------------------------|-------|
|   | Titles of Education and Training Program   | Leaders in<br>prefecture | Leaders in<br>institute | Other |
|   | Continuing education and development of oncology nursing workshop for trainers                           |                          | 40                      |       |
|   | Continuing education and development of oncology nursing workshop for trainers - Follow-up               |                          | 47                      |       |
| Dncology nursing education  | Continuing education and development of oncology nursing workshop for trainers in prefecture             | 23                       |                         |       |
|   | Continuing education and development of oncology nursing workshop for trainers in prefecture - Follow-up | 13                       |                         |       |
|   | Oncology nursing seminar for trainers  |                          | 376                     |       |
|   | Certified Nurse Follow-up Program  |                          | 34                      |       |
|   | CI Specialist Education Program - Basic course 1 & 2   |                          |                         | 1,086 |
|   | CI Specialist Education Program - Basic course 3   |                          |                         | 557   |
| CI specialist education   | CI Specialist Education Program - Continuous course  |                          |                         | 191   |
| specialist education  | CI Specialist Education Program for trainers   | 93                       |                         |       |
|   | CI Specialist Education Program for trainers - Follow-up   | 81                       |                         |       |
|   | CI Specialist Education Program - Skill-up course  |                          | 180                     | 8     |
|   | Training program for instructors of hospital-based cancer registrars                                     | 6                        |                         |       |
|   | Continuous training program for instructors of hospital-<br>based cancer registrars                      | 6                        |                         |       |
|   | Supplementary training program for instructors of hospital-<br>based cancer registrars                   | 101                      |                         |       |
|   | Certification for primary cancer registrars  |                          |                         | 854   |
| lospital-based cancer registrar<br>aining   | Supplementary training program for certified primary cancer registrars                                   |                          |                         | 1,110 |
| annig   | Advanced training program and certification for intermediate cancer registrars                           |                          |                         | 150   |
|   | Supplementary training program for certified intermediate cancer registrars                              |                          |                         | 401   |
|   | Introduction program for implementation of hospital-based cancer registry                                |                          |                         | 111   |
|   | Supplementary education program for the new datasets and rules of hospital-based cancer registries       |                          |                         | 568   |
| Fraining for population-<br>based cancer registrars and<br>administrative officers in charge<br>of cancer control | Basic training programs on population-based cancer   |                          |                         | 211   |
| Pharmacist education  | Oncology pharmacist workshops for trainers   | 32                       |                         |       |
| Palliative care team education  | Palliative care team workshops for trainers  | 45                       |                         |       |
| Chemotherapy team education   | Chemotherapy team workshops to introduce new drug  |                          | 28                      |       |
|   | Chemotherapy care team workshops for trainers  | 28                       |                         |       |
| Surgical pathology education  | Seminar for diagnostic tumor surgical pathology  |                          |                         | 107   |
| raining for administrative<br>fficers in charge of cancer   |  |                          |                         | 93    |
| control   |  |                          |                         |       |
| Total   |  | 428                      | 705                     | 5,44  |

# List of papers published in 2015

# Journal

 Mori M, Shimizu C, Ogawa A, Okusaka T, Yoshida S, Morita T. A National Survey to Systematically Identify Factors Associated With Oncologists' Attitudes Toward End-of-Life Discussions: What Determines Timing of End-of-Life Discussions? Oncologist, 20:1304-1311, 2015

# **DIVISION OF CANCER SURVIVORSHIP RESEARCH**

Miyako Takahashi, Miyako Tsuchiya, Makiko Tomita, Makiko Tazaki, Kyoko Onozawa, Kayoko Horikawa

# Introduction

The Division of Cancer Survivorship Research 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 treatment such as employment, interpersonal relationships, sexuality and fertility, prejudice against cancer, life-style modifications, and unmet needs. In particular, we examine the influence of the Japanese socio-cultural background on living with, through, and beyond 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 listed in the education section 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 the "Coexistence of Treatment and Work" council organized by the Ministry of Health, Labour and Welfare, and contributed in creating guidelines for business people.

#### **Research activities**

The research projects we conducted in 2015 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", "the effect of providing written, personalized information", and so on. As for research on cancer and work, we revealed that about 40% of patients who stopped working decided to do so before initial treatment began, and that information and support needs among patients change across the passage of time since diagnosis. Also, we developed an intervention program for business people to promote their awareness in supporting employees with cancer.

This year, we conducted six keynote lectures, seven symposium presentations, and eight oral presentations in academic meetings. Also, we published three articles in English, six articles, and four chapters in a co-authored book in Japanese.

# Education

As for education for healthcare providers and citizens in 2015, we delivered 22 lectures in answer to requests from universities, academic organizations, national and local governments, and medical institutions nationwide.

As for promoting social awareness of cancer survivorship, we planned and implemented three lecture series, "Community Center Café", "Gotochi (Local) Café", and "Cancer Survivorship Open Seminar", which were open to the public. These café and seminar programs were held in a relaxed atmosphere with refreshments, and consisted of a lecture that takes up various cancer survivorship topics followed by a small group discussion by participants. It provided participants with an opportunity to learn about cancer survivorship issues as well as exchange views with each other. In 2015, we held The Community Center Café 2 times with 100 participants in total in the Tsukishima Community Center in Chuo Ward, where the National Cancer Center is located. The Gotochi (Local) Café, the other café program, has the same structure as the Community Center Café, 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 2015, we held the Gotochi Café twice in Kanazawa and Nagoya, and 100 people participated. The "Cancer Survivorship Open Seminar", held in the National Cancer Center Tsukiji campus, was newly started in 2015. It is a lecture series by researchers and focuses more on academic aspects of survivorship research. In 2015, we held the seminar three times on "dental-medical collaboration", "employment issues after cancer", and "cancer information". About 300 people participated.

# **Future prospects**

Cancer survivorship research and care practice is indispensable in creating a society in which we can live in peace after having cancer. Our Division will conduct research on various cancer survivorship issues and propose countermeasures for them. As the center of information dispatch and the personnel exchange of survivorship research and care in Japan, we plan to develop activities in cooperation with domestic and international researchers and practitioners.

# List of papers published in 2015

#### Journal

- Miyashita M, Ohno S, Kataoka A, Tokunaga E, Masuda N, Shien T, Kawabata K, Takahashi M. Unmet Information Needs and Quality of Life in Young Breast Cancer Survivors in Japan. Cancer Nurs, 38:E1-E11, 2015
- Okada H, Maru M, Maeda R, Iwasaki F, Nagasawa M, Takahashi M. Impact of childhood cancer on maternal employment in Japan. Cancer Nurs, 38:23-30, 2015

# **DIVISION OF HEALTH SERVICES RESEARCH**

Takahiro Higashi, Momoko Iwamoto, Izumi Inoue, Fumiaki Nakamura, Yoichiro Tsukada, Naoki Sakakibara, Rei Goto, Kaoru Konno, Kazumi Shimamura

# **Research activities**

The Division of Health Services Research conducts research that contributes to the improvement of the quality of cancer care in Japan through meaningful evaluation of health systems and health policy performance.

#### 1) Cancer registry-linked DPC database

As part of our ongoing initiative to monitor the quality of cancer care in Japan using a database of cancer registry-linked diagnosis procedure combination (DPC) data, we continued building the database for cancer patients diagnosed in 2013. 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 deidentified information on all procedures, tests, and prescriptions given to patients. We used the database to calculate 12 quality indicators (QIs) among 206 QIs that were previously developed by an expert panel led by Dr. Tomotaka Sobue, 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 eight weeks of surgery. Results of the QI scores were fed back to participating hospitals through an interactive website that allowed hospitals to compare its performance to other hospitals. A total of 182 hospitals participated in the first year we launched the program in 2013. This expanded to 232 hospitals in the following year and 297 hospitals in 2015.

# 2) Monitoring and Evaluation of National Cancer Control Programs

The Division conducted a national patient

experience survey and mailed out roughly 15,000 surveys to cancer patients throughout the country. The purpose of the survey was to measure the performance of the nation's Cancer Control Program through patient evaluations. Results of the survey along with measured outcomes of other performance indicators were put together into a 300-page final report describing the significance of the indicators and the methods used to measure them in detail. The reports were printed and distributed to various stakeholders and prefectural policymakers.

#### 3) Rare Cancer Policy

We conducted various analyses using cancer registry data and the cancer registry-linked DPC database to describe the distribution and patterns of care of rare cancer patients in Japan. We also surveyed clinicians concerning their opinions about the definition of "rare cancer" using epidemiological data, in order to create an agreeable and meaningful definition of the term. Findings from the analyses and survey were reported to the Ministry of Health, Labour, and Welfare's Commission Expert Group on Rare Cancer, and was used to further define rare cancer and discuss priority issues in Cancer Control Policy. The Division also hosted a symposium aiming to foster open discussion on the centralization of care for bone and soft-tissue tumors among clinicians who are daily engaged in the treatment of rare cancer patients. The Division has been assigned the administrative task of facilitating the Working Group for Rare Cancer Policy by the Ministry of Health, Labour, and Welfare in 2016.

## **Research training and Education**

The Division received a continuous flow of physicians and graduate students for research training in 2015. We mentored two graduate students: one pursuing a clinical doctorate and another from a nursing-related doctorate program. We accepted four medical students from The University of Tokyo for a clerkship in Public Health. The Division also established an Affiliate Graduate Program with The University of Tokyo's Department of Public Health/Health Policy, opening the doors to graduate school students who are interested in gaining hands-on public health training.

# **Future prospects**

The Division supports evidence-based policymaking and strives to improve the care of cancer

#### List of papers published in 2015

#### Journal

- Inoue I, Higashi T, Iwamoto M, Heiney SP, Tamaki T, Osawa K, Inoue M, Shiraishi K, Kojima R, Matoba M. A national profile of the impact of parental cancer on their children in Japan. Cancer Epidemiol, 39:838-841, 2015
- Iwamoto M, Higashi T, Miura H, Kawaguchi T, Tanaka S, Yamashita I, Yoshimoto T, Yoshida S, Matoba M. Accuracy of using Diagnosis Procedure Combination administrative claims data for estimating the amount of opioid consumption among cancer patients in Japan. Jpn J Clin Oncol, 45:1036-1041, 2015

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 to make clinically relevant and evidence-based policy recommendations in order to help implement meaningful cancer control programs in Japan.

 Tsukada Y, Nakamura F, Iwamoto M, Nishimoto H, Emori Y, Terahara A, Higashi T. Are hospitals in Japan with larger patient volume treating younger and earlier-stage cancer patients? An analysis of hospital-based cancer registry data in Japan. Jpn J Clin Oncol, 45:719-726, 2015

# **DIVISION OF TOBACCO POLICY RESEARCH**

Yumiko Mochizuki-Kobayashi, Tomoyasu Hirano, Yuriko Nishikawa

# Introduction

The death toll attributable to tobacco use is a manmade disaster worldwide; however, many countries have successfully shown that such death toll is avoidable with effective tobacco control regulations. Thus, to achieve a global standard for tobacco policies, our missions are research activities and advocacies based on the following four pillars: Monitoring and Evaluation, Development and Research of Practical Programs, Public Education and Information Services, and Promoting Policies and Networking.

#### **Routine and research activities**

- Through government commissioned projects, we collected information about the implementation status of FCTC (Framework Convention on Tobacco Control) Parties. Analysis and evaluation were carried out by providing a study panel.
- We conducted participatory workshops with elementary school children on tobacco with respect to cancer education. Based on the results, we considered ways to continue

helping to promote the "Tobacco Free Kids Japan" program. In 2015, we carried out test programs in Hakodate, Tokyo, and Kumamoto and reported the results in the 9th Annual Meeting of the Japan Society for Tobacco Control.

- We carried out a test trial of the quitline service program, which was considered appropriate to Japan's situation. The results are based on the efficient dissemination of quitline, which prepares the activities of semi-autonomous scheme-building intended for the workplace by private sectors. We registered the trademark of quitline (Figure 1) and started a scheme that combined supervision for private companies with permission to use the trademark.
- Through providing information and planning assistance to various societies, non-governmental organizations, and prefectural government departments related to tobacco, and so forth, we carried out networking and capacity development. This year, we contributed to reports on policy proposals, such as those by the Science Council of Japan and the Tobacco Control Medical-Dental Research Network.



Figure 1. Quitline Logo, registered trademark of the National Cancer Center

# TASK FORCE FOR NATIONAL CANCER REGISTRY

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 the National Cancer Registry (NCR) in the National Cancer Center (NCC), which will be implemented in January 2016, according to the Act on Promotion of Cancer Registry enacted in December 2013, enacted by 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 47 prefectures

In collaboration with Fujitsu Ltd., the team developed the NCR-DBS at NCC. The 47 prefectures and the NCC, through the NCR-DBS server, were linked by a secured network (VPN), and the prefectures were equipped with client PCs. 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 the consistency of cancer statistics, the team developed the Pref-DBS replacing the SDS, and had a contract of use with the prefectures. Forty-two prefectures had introduced the Pref-DBS, and data migration is in progress. Ahead of the data migration, for an efficient procedure, the team verified the quality of cancer death data in seven prefectures.

 Development of the Electronic Cancer Reporting System (ECRS)

The team has developed the ECRS, by using an auto-encrypting PDF format, and released it on the website (ganjoho.jp) mainly for the clinics that do not conduct a hospital-based cancer registration. 4) Plan for the online data submission network

The team discussed the future plans for the online data submission network with the MHLW, for online data submission by the hospitals with the highest security.

5) Discussion on the government ordinance and the manuals

The team discussed the settlement of the government ordinance on the 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 the NCR

The team was in charge of development of the website, creation of a cancer registry PR movie, infographics, posters and a pamphlet on cancer registration for the public. In July, the team organized an educational workshop on the NCR for cancer registrars and administrative officers. The team supports all the 47 registries, by disseminating up-to-date information through websites and mailing lists, by setting up a Q&A service.

#### **Future prospects**

We will start the National Cancer Registry (NCR) in the National Cancer Center (NCC), which will be implemented in January 2016, based on the activities of the project team.