Center for Cancer Control and Information Services
Preface

The Center for Cancer Control & Information Services (CIS) is a nationally funded program established in 2006, as an essential part of NCC’s extramural activities.

The mission statement of the CIS is as follows: "The Center for cancer control and information services provides information needed to promote comprehensive and systematic cancer control program in Japan. In collaboration with designated cancer care hospitals, Ministry of Health Labour and Welfare and other relevant Ministries, the Center plays a central role to plan, manage and evaluate nation-wide 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.”

Since its inception, the CIS has been providing comprehensive, scientifically based, unbiased information to patients, their families, and the general public about all aspects of living with cancer, via its homepage (http://ganjoho.jp) as well as other dissemination channels. The CIS also provides physicians and other health professionals, with up-to-date information on early detection, diagnosis, treatment, care, cancer research, clinical trials and cancer statistics, via our various information channels and professional training programs.

To ensure that we remain relevant to the needs and perspectives of patients, their families, healthcare professionals, and the general public, we are committed to facilitating the participation of all of these stakeholders in shaping both what information we provide, and how this is delivered. In formulating our key publications, we have sought active input from our on-going nationwide panel of cancer patients as well as specialist review boards. The CIS Advisory Board, representing both healthcare professionals and patient advocacy organizations, has also been proactive in helping the CIS prioritize its efforts. We will firmly grasp, every opportunity to improve our services and appreciate your continued support.

Takamasa Kayama, M.D., Ph.D.
Director, Center for Cancer Control and Information Services
Activities of the Divisions
CANCER INFORMATION SERVICE DIVISION

Fumihiko Wakao, Kiyotaka Watanabe, Tomoko Takayama, Seiichiro Yamamoto, Akiko Uraikubo, Maki Hirano, Teruo Ito, Yumiko Yamazaki, Chikako Yamak, Eriko Tao, Nozomu Suzuki, Yuri Mizota (joint), Mika Takai, Tamaki Kumagai

Introduction

The mission of the Cancer Information Services is to provide credible information about cancer. In the National Cancer Information Network, the Cancer Information Service Division plays an important role in disseminating cancer-related information directly to our audiences, including patients and their families, the public at large, healthcare professionals, policy makers and researchers. Our dissemination channels also include the 388 designated cancer care hospitals throughout Japan and their respective cancer information & support teams. Currently, multi-channel cancer information services are provided through the internet, brochures, lectures, and public meetings. One of our key mandates is to provide all patients and their dear ones the means to access comprehensive cancer-related information, at the point of need, and with appropriate context. The Spring 2011 launch of a cancer information handbook for patients, the “Kanja Hikkei”, represented an important step in this direction. Over 80,000 copies have been disseminated among healthcare professionals, with a view to making this the lingua franca between the cancer patients, their physicians and other healthcare professionals.

Line of Service

Cancer Information Development Research Section

The Cancer Information Development 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. Information is disseminated through various media formats, including the website “Cancer Information Service http://ganjoho.jp/”, a wide range of patients education brochures and more recently, the handbook (“Kanja-Hikkei”) that contains comprehensive cancer information to help empower patients throughout the continuum of cancer survivorship. The Section also helps direct health care providers to access an extensive library of cancer treatment and supportive information that have undergone CIS peer reviews, as well as other cancer information sources that are of interest to health care professionals.

Communication Research Section

In order to disseminate reliable cancer information, the Communication Research Section is in charge of supporting the smooth operation of cancer information services and of encouraging collaboration among relevant stakeholders, such as the cancer information & counseling centers in designated cancer hospitals (388 locations around the nation), support groups, patient advocate groups, prefectural government units responsible for planning and managing their respective regional cancer programs, and other information specialists like public libraries. The Section also handles large volumes of inquiries to cancer information services, prepares and manages collaborative work with a “Patient-civil panel” which consists of 100 supporters of various cancer experience and regional background from throughout Japan, and provides mutual educational forums for media professionals.

Evaluation Research Section

In order to meet our mandate, to continually provide reliable information in an easily understood format, the Section evaluates the credibility of cancer-related information to be disseminated through “ganjoho.jp” (Cancer Information Services). Treatment guidelines are evaluated using the AGREE (Appraisal of Guidelines for Research & Evaluation) instrument and accumulated as evidence repositories. This Section plays a role as the editorial office of cancer information services.
Research Activities

Cancer Information Development Section
To ensure timely dissemination of accurate and pertinent information on cancer, and to more effectively support decision-making by patients, their families and citizens, we conduct extensive surveys to better gauge what type of information is needed, how it needs to be delivered in order to make timely impact, and which stakeholders in the community need to be part of the delivery/dissemination network. Increasingly, we are also involving regional community stakeholders, patients and care providers, in helping to compile more regionally pertinent sets of information, in the effort to improve our community outreach efforts.

Communication Research Section
To overcome the disparities of cancer related information all over Japan and to contribute to building better cancer information and support systems, this Section 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.

Evaluation Research Section
In collaboration with the Japan Public Health Center-based Prospective Study and other epidemiological and clinical studies, the association of various risk/prognostic factors and cancer have been evaluated. A statistical contribution is being performed for therapeutic development. A new cohort is being established for breast cancer patients, to investigate the effect of lifestyle factors and alternative medicine on their QOL and prognosis. Health communication research using a social marketing method is being conducted in order to fill the gap between practice and evidence of cancer prevention and cancer screening. As for the educational contribution, an e-learning system for clinical research methodology has been established for anyone involved in clinical research.

Published Papers
Introduction

The Surveillance Division is in charge of providing credible cancer statistics to patients and their families, 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. A 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 the 45 prefectural registries in practical terms and the other 2 prefectures in planning terms, by disseminating up-to-date information through websites and mailing lists; by setting up a Q&A service; by holding a one day seminar in May for administrative officers who were new to their post; and organizing 2-day educational workshops for cancer registrars and administrative officers, a total of 105 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 covered a total of 10 prefectures.

Standardization of the population-based cancer registry has rapidly advanced: 41 registries out of 45 use the standard registry items. Thirty-one registries had introduced the SDS as of December 2011. Introduction is in progress in five registries and 4 are planning to introduce it in 2012. The self-check software on security control in cancer registration, and security educational materials for new workers were developed by the division and are ready for practical use.

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 388 designated cancer care hospitals (DCCHs) and over 100 other hospitals in 2011.

In collaboration with other relevant parties, the division develops data standards for HCR, modifies datasets, and distributes the standardized software "Hos-CanR", which is used in about 250 hospitals. In 2011, individual records for 484,771 cancer cases diagnosed in 2009 were collected from 370 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 8 cities in which about 800 registrars participated. Furthermore, the Division performed site visits to 31 DCCHs in 2011.

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 2006 were estimated based on the data from 32 cancer registries. 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. The Division realized a national survey of cancer registries in Japan. The results were effectively utilized to figure out the latest situation in population-based cancer registration in Japan and to promote cancer control.

Quality Indicators
Ensuring quality of cancer care is an important aspect of cancer control. We have developed quality indicators for 5 major cancers in Japan and palliative care. To enable timely feedback, these quality indicators focus on the process of care rather than outcomes. We now are pilot testing the feasibility of these quality indicators in a real practice setting. At the same time, we determined the priority of quality indicators by an expert panel. The high-priority indicators can be incorporated into a future national quality measurement system.

Cancer Statistics
International comparisons of time trends in cancer mortality and screening rate were conducted based on the WHO mortality and OECD database. The population attributable fraction of mortality was estimated for various risk factors among the Japanese population. Cancer mortality was projected according to different scenarios of smoking prevalence among Japanese males. The association between lung cancer mortality and long-term exposure to ambient air pollution was examined by a prospective cohort study.

Economic Studies on Cancer Care
Containing the costs and improving the efficiency of cancer care, while ensuring patient access to required services is an important issue in ageing society. A database on the costs and revenues related to cancer surgery in NCC hospital is developed and analysis on the data for the fiscal year 2010 showed differing levels of performance and profitability among specialties and procedures. For analysis on accessibility to care, DPC survey data are used to capture major cancer treatment facilities and are visualized with GIS to calculate the coverage of the population categorized by driving-time.

<table>
<thead>
<tr>
<th>Year of Diagnosis</th>
<th>Prefectures</th>
<th>Number of New Cancer Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006</td>
<td>32 (15 for estimation)</td>
<td>664,398</td>
</tr>
<tr>
<td>2007</td>
<td>33 (21 for estimation)</td>
<td>Work in progress</td>
</tr>
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</table>

Table 1. Cancer Incidence Data from Population-based Cancer Registries

<table>
<thead>
<tr>
<th>Year of Diagnosis</th>
<th>Applied Hospitals</th>
<th>Number of New Cancer Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008</td>
<td>357</td>
<td>426,753</td>
</tr>
<tr>
<td>2009</td>
<td>370</td>
<td>484,771</td>
</tr>
</tbody>
</table>
Published Papers


Introduction
The Division builds partnership with Designated Cancer Care Hospitals to support all health allied professionals concerned with cancer control in Japan. The Medical Support and Partnership Section (MSPS) was established in 2011, and plays a unique role in suggesting the cancer control policy in Japan. The Pathology Consultation Section strives to perform human pathology research based on the histology of tumor cells and tumor-stromal cells to improve diagnostic pathology of the tumors. The Diagnostic Radiology Section (DRS) 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 mailed and on-site dosimetry for monitoring the output for radiotherapy beams and a radiotherapy case review for three-dimensional or more complicated radiotherapy plans. The Cancer Control Educations and Trainings Section (CCET) produces or plans and operates several training programs in the clinical and cancer registry disciplines to provide leadership base for the promotion of a certain level of cancer treatment programs and epidemiological Surveillance. To correct medical inequality in the provision of cancer care throughout Japan, the CCET organizes a number of special training programs for physicians, nurses, pharmacists, cancer information (CI) specialists, other health professionals and cancer registries staff personnel of Designated Cancer Care Hospitals in all parts of the country.

Routine Activities
A. Networking among designated cancer care hospitals
The MSPS formed a network among the designated cancer care hospitals to build partnership for cancer control in Japan. The designated cancer care hospitals are important partners with the NCC to promote comprehensive cancer control; implementing the cancer registry, providing cancer information services, and training oncology professionals, as well as strengthening clinical performance in Japan. Currently, mailing lists have been prepared to allow participants to share their practices or other information among the participating hospitals.

B. Pathology consultation service
The pathology slides of lesions arising in various sites have been submitted from clients. Eighty-five consultant pathologists who are specialists in various fields are registered, and one pathologist, who was assigned as the consultant, examined the slides and rapidly sent back the report of his or her opinion to each client. Most of the clients expressed satisfaction with the contents of the report and this consultation system. “Pathological diagnosis for soft part pleomorphic sarcoma" has been published as the Geka-byouri-shindan-no-tebiki.

C. Radiology consultation service
Ninety-six consultation reports have been put together for requests mainly from the Kanto and Kyushu region. Hepato-biliary-pancreatic, musculoskeletal, and head-and-neck lesions were the common subjects. Consultation with a specialist was the most frequent reason 46/96 (47.9%) for consultation. The client radiologists have evaluated 194 (85.1%) of the 288 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 2010, about 100000 per month. Nine cases with adenoma-related lesions of the uterine cervix, pharyngeal cancers, glioblastoma, and neuroendocrine carcinomas with 22 virtual slides have been published, resulting in the total provision of 210 cases.
E. Radiotherapy case reviews

Mailed dosimetry and on-site dosimetry were performed in 23 institutions and 10 institutions, respectively. All data of the institutions were within the permissible limit. In clinical trials, radiotherapy case reviews were performed in 152 institutions.

F. Promotion of medical education programs for cancer control

The CCET organizes medical training programs for allied oncology/hematology professionals to rectify medical inequality in the provision of cancer care throughout Japan as a part of our cancer control projects. The training programs are intended for Health Allied Professionals (physicians, pharmacists, nurses and technologists, CI specialists), for Palliative Care consultation and Chemotherapy teams, for counseling team members, and members of In-hospital cancer registries.

Research Activities

Suggestion for Cancer Control Policy

To suggest a policy for cancer control to the Japanese government, a mailed and web survey was conducted on the next Basic Plan to Promote Cancer Control Programs to the 377 designated cancer care hospitals. The oncology professionals' opinions were analyzed and used for further suggestions to the government.

Trend of Pathology Consultation Services

In 2011, the Pathology Consultation Section received histopathology slides of 364 cases for a specialist's second opinion regarding histopathological diagnosis. The number of consultation cases showed a 20% increase in comparison with the number in 2010.

Develop and Use of a Teleradiology System

The division is investigating methods to improve the way how we can send and receive digital imaging files more easily and more quickly using a teleradiology system. Case presentations with the NCC-CIR English version have almost doubled from 53 to 112.

Develop the RTPS Quality Control Support Program

The division is developing enforcement of "the Radiation Treatment Planning System (RTPS) quality control support program" to confirm the beam modeling data of the RTPS in 45 institutions. In clinical trials, we examine enforcement of the on-site dosimetry regarding the output dose of Intensity Modulated Radiotherapy (IMRT).

<table>
<thead>
<tr>
<th>Subjects and programs</th>
<th>Education and Training program title</th>
<th>No. of participants</th>
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<tbody>
<tr>
<td>Oncology nurses education</td>
<td>Continuing education and development of oncology nursing Workshop for trainers</td>
<td>102</td>
</tr>
<tr>
<td>CI specialists education</td>
<td>CI Specialist Education Program -Basic course 1</td>
<td>662</td>
</tr>
<tr>
<td>Hospital-based cancer registrars training</td>
<td>Basic training program for hospital-based cancer registrars</td>
<td>1592</td>
</tr>
<tr>
<td>Cancer registrars and administrative officers training</td>
<td>Basic training programs on a population-based cancer registry for cancer registrars and administrative officers</td>
<td>195</td>
</tr>
<tr>
<td>Technologists education</td>
<td>Trainer training for oncolgic radiology technologists</td>
<td>16</td>
</tr>
<tr>
<td>Palliative care physicians education</td>
<td>Palliative care education meeting for trainers</td>
<td>64</td>
</tr>
<tr>
<td>Psycho-oncologists education</td>
<td>Psycho-oncology education meeting for trainers</td>
<td>63</td>
</tr>
<tr>
<td>Palliative care team education</td>
<td>Palliative care team workshops for consultation</td>
<td>120</td>
</tr>
<tr>
<td>Chemotherapy Team education</td>
<td>Chemotherapy Team workshops to introduce safety aspects of new drugs</td>
<td>75</td>
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<tr>
<td></td>
<td>Site Visiting program on hospital-based cancer registries in national cancer center hospital</td>
<td>72</td>
</tr>
<tr>
<td></td>
<td>Site Visiting program on hospital-based cancer registries in national cancer center hospital</td>
<td>72</td>
</tr>
</tbody>
</table>

Table 1. Training programs conducted during April 2010-March 2011

In the hospital-based cancer registrars training section, we have operated a new program four times under the following title : “Supplementary training program for hospital-based cancer registrars who have completed an advanced course (UICC TNM-7)”
Published Papers


TOBACCO POLICY AND EDUCATION DIVISION

Yumiko Mochizuki-Kobayashi, Jun'ichi Adachi, Sayuri Takise

Introduction

Every year, tobacco kills more than five million people in the world and 200,000 in Japan. Without immediate action, the number of deaths will reach eight million by 2030. As the tobacco epidemic emerged from human activities and it could be also prevented by human efforts, it is called a "man-made disaster". On the contrary, collective efforts are being made globally to build a tobacco-free society for the next generation, and Japan should not be left behind. Thus, the mission of our Division is to advance tobacco control policy and its implementation with scientific evidence in order to end the tobacco epidemic in our lifetime. The Framework Convention on Tobacco Control (FCTC) entered into force in 2005 and Japan, as a Party to the FCTC, is obliged to implement its provisions and fulfill international responsibilities. The Health Promotion Act and Cancer Control Act as well as the recent political power shift positioned tobacco control as one of the highest priorities among health policies in Japan. Driven by such policy climate changes, our Division serves as a professional think-tank to evaluate tobacco policies and to develop strategies to curb the tobacco epidemic, building concrete partnerships with national and international organizations and institutions.

Knowledge Transfer on Tobacco and Cancer

As a party to the FCTC, Japan is obligated to implement each article. A smoke-free policy (article 8) and a tax policy (article 6) are two prioritized areas to curb the tobacco epidemic, but are the most controversial. The guidelines for article 8, which aims to protect the public from exposure to tobacco smoke, were the first to be implemented rigorously. As the Division is involved in policy development processes at national and local level, accurate and convincing scientific evidence to mobilize political will and obtain public support is essential to dispel emotional and doubtful messages among stakeholders. Regarding the smoke-free policy, we estimated the annual number of deaths from exposure to secondhand smoke in workplaces and homes at 6,800, combining lung cancer and ischemic heart disease. We also conducted a regulatory impact analysis comparing policy options on smoke-free policies. A complete smoke-free policy was found to be a highly cost effective option with the largest number of lives saved but an incomplete ban (with exemptions) was found to generate no significant health benefit, although it was frequently recommended and adopted by government committees in Japan. Regarding a tax policy, we have conducted a rigorous simulation study to support the highest price increase of cigarettes for political debates in the government. Either a gradual increase or a sudden increase in tobacco retail prices was proposed to generate a significant increase in tax revenue, but the sudden increase approach would be more beneficial as far as public health would be concerned, because of its greatest reduction in the smoking population. For the further development of a tobacco control policy, we need a more systematic roadmap as a policy recommendation tool with critical evidence that no policy maker could discard, as well as a precise advocacy plan to mobilize public support.

Stakeholder Analysis and Capacity Building for Programme Implementation

To increase the net resource for tobacco control, the roles of health professionals are essential but still potential. A questionnaire survey to prefectural pharmacist associations was conducted in collaboration with the Japan Pharmacist Association to investigate the current status of their interests in and knowledge on tobacco control and to develop a capacity-building curriculum as well as educational material for cessation services. Most of the pharmacists were involved in some form of tobacco control activities with varied counterparts such as local governments or other health professional organizations, but the quality and the contents of the activities were varied because of lack of standardized materials and access to the appropriate information.
Operational Studies on Tobacco Control

We have conducted workshop-type studies to gather intellectual knowledge and generate political will in order to develop operational work plans on tobacco control, through inviting key academic researchers and advocates as well as politicians. The main purpose of the meetings was to consolidate the best available evidence and to develop a practical roadmap which would lead researchers to the best route for generating the necessary study results for policy development. The next step will be to hold open discussions, inviting other committed stakeholders to operate the given work plans. The outcome of the study is to draft a concrete alternative legislation on tobacco control in Japan.

WHO Collaborating Centre for Reference on Smoking and Health

The National Cancer Center has been designated as a WHO Collaborating Centre (WHO-CC) for Reference on Smoking and Health since 1978 and our Division took over as Head of the WHO-CC since 2009. It has sponsored a series of tobacco control meetings, such as the “World No Tobacco Day (WNTD) Symposium”, annually with the Ministry of Health, Labour and Welfare, the “WHO Global Launch on the World No Tobacco Day - Gender and Tobacco” with WHO, and an international seminar entitled “Framework Convention on Tobacco Control” inviting the Head of the Secretariat of the Convention. It also helped the WHO Tobacco Free Initiative to develop WNTD 2011’s global campaigns and to launch a monograph on gender, women and tobacco.