

Cancer Registry in Japan

Second edition



Japanese Association of
Cancer Registries

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THE FUTURE OF POPULATION-BASED CANCER REGISTRIES

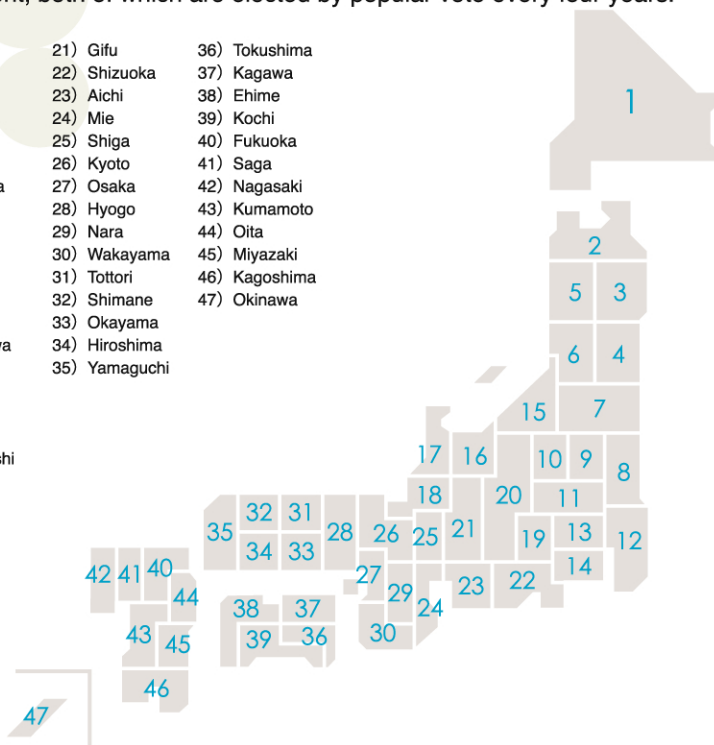
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About Japan

Prefectures: Administrative units in Japan

Japan is divided into forty-seven administrative units called prefectures. Each of the forty-seven prefectures has a governor and a prefectural government, both of which are elected by popular vote every four years.

- | | | |
|---------------|---------------|---------------|
| 1) Hokkaido | 21) Gifu | 36) Tokushima |
| 2) Aomori | 22) Shizuoka | 37) Kagawa |
| 3) Iwate | 23) Aichi | 38) Ehime |
| 4) Miyagi | 24) Mie | 39) Kochi |
| 5) Akita | 25) Shiga | 40) Fukuoka |
| 6) Yamagata | 26) Kyoto | 41) Saga |
| 7) Fukushima | 27) Osaka | 42) Nagasaki |
| 8) Ibaraki | 28) Hyogo | 43) Kumamoto |
| 9) Tochigi | 29) Nara | 44) Oita |
| 10) Gunma | 30) Wakayama | 45) Miyazaki |
| 11) Saitama | 31) Tottori | 46) Kagoshima |
| 12) Chiba | 32) Shimane | 47) Okinawa |
| 13) Tokyo | 33) Okayama | |
| 14) Kanagawa | 34) Hiroshima | |
| 15) Niigata | 35) Yamaguchi | |
| 16) Toyama | | |
| 17) Ishikawa | | |
| 18) Fukui | | |
| 19) Yamanashi | | |
| 20) Nagano | | |



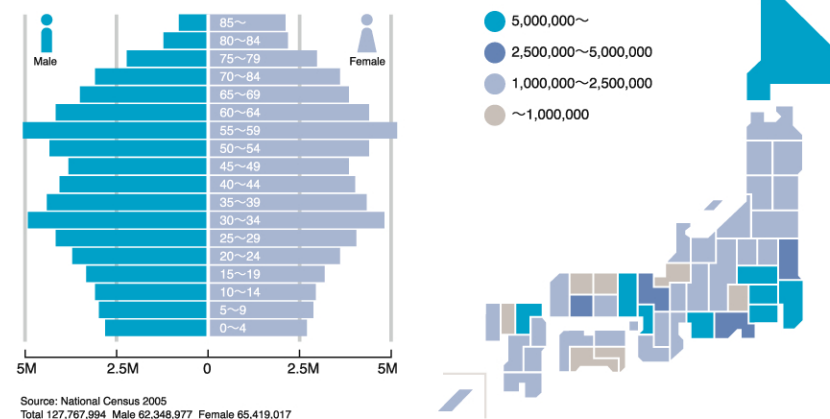
Administrative units in Japan

Population

Japan had a total population of 128 million in 2005, which was the tenth largest in the world. Recently, declining birth and mortality rates have led to a dramatic shift in the population demographics; Japan is experiencing rapid population aging. In 2005, the population of elderly citizens, those aged 65 years or more, made up about 21% of the total population.

Tokyo prefecture, the capital of Japan, has the highest total population at 12.6 million. Among the prefectures that have implemented a population-based cancer registry, Kanagawa prefecture has the largest population (8.8 million), followed by Osaka (8.8 million), and Aichi (7.3 million). On the other hand, prefectures with less than 1 million people have also implemented cancer registries: Yamanashi (0.9 million), Saga (0.9 million), Fukui (0.8 million), Tokushima (0.8 million), Kochi (0.8 million), Shimane (0.7 million), and Tottori (0.6 million).

The proportion of elderly citizens varies by prefecture: Shimane is the highest (27%) and Okinawa is the lowest (16%). Generally, prefectures with large populations (metropolitan areas) have a low proportion of elderly citizens.

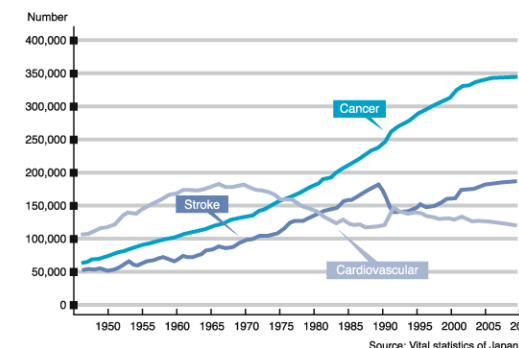


Source: National Census 2005
Total 127,767,994 Male 62,348,977 Female 65,419,017

Population in Japan and population size in each prefecture

Cause of death

The disease structure in Japan has changed with the development of society and the aging population after World War II. Lifestyle-related diseases have replaced infectious diseases as the leading cause of death, and cancer has been the leading cause of death since 1981.



Number of deaths (3 major causes) in Japan

History of the cancer registry

The Japanese cancer registration system has a long history spanning over 50 years; the first population-based cancer registry was established in Miyagi prefecture in 1951.

In 1945, Hiroshima and Nagasaki became the first cities in the history of humanity to experience atomic bombing. In the years following the bombing, a higher incidence of leukemia was observed in these cities.

As a result, the Hiroshima and Nagasaki City Medical Associations started tumor registries in the 1950s with support from the Atomic Bomb Casualty Commission (ABCC). Since then, the importance of cancer registration has been gradually recognized by most of the prefectures.

1951

A population-based cancer registry was first started in Miyagi prefecture covering residents in the prefecture in 1951. First regional cancer incidence rates in Japan were reported in 1954.

1957-59

In Hiroshima (1957) and Nagasaki (1958), Tumor registries were implemented to cover residents in Hiroshima city and Nagasaki city by the local medical associations in cooperation with the Atomic Bomb Casualty Commission (ABCC, which is now the Radiation Effects Research Foundation).

1960's

In 1962, Aichi and Osaka Prefectures started cancer registries.

1970's

Kanagawa Prefecture (1970), Tottori Prefecture (1971), Hokkaido Prefecture (1972), Kochi Prefecture (1973), Yamagata Prefecture (1974) and Chiba Prefecture (1975) started cancer registries.

1975

Research Group for population-based cancer registries with support from Ministry of Health, Labour and Welfare was organized. (PIs: I. Fujimoto, S. Fukuma, A. Hanai, A. Oshima and H. Tsukuma).

1980's

Up until 1983, when the Health and Medical Service Law for the Aged came into effect, the number of population-based cancer registries existed in 14 prefectures. After the law, the number of registries sharply increased.

2010

Population-based cancer registries are conducted in 38 prefectures and 1 city.

2000's

The Japan Cancer Surveillance Research Group was involved in the 3rd-term Comprehensive Ten-Year Strategy for Cancer Control from 2004.

1990's

Japanese Association of Cancer Registries (JACR) was founded .

Population-based cancer registry and supporting laws

Supporting legislation

In Japan, the reporting of cancer cases to the population-based cancer registries is not a mandatory task for medical institutions. However, there is a legislative basis that supports the operation of a cancer registry.

Population-based cancer registration was officially described for the first time by the Health Promotion Law (2003), but it was defined only as a voluntary task. The Health Promotion Law stipulates that national and local governments must strive to ascertain the conditions for the onset of lifestyle-related diseases (Article 16) in order to clarify the correlation between the lifestyles of Japanese citizens and lifestyle-related diseases such as cancer and cardiovascular disease.

In the “Notice from the Director of the Health Service Bureau of the Ministry of Health, Labour and Welfare” issued on Jan. 8, 2004, population-based cancer registry tasks were specified as corresponding to “improving public health,” an exception as provided in the Private Information Protection Law (Article 16, restriction by the purpose of utilization; Article 23, restriction of provision to a third party). The “Guidelines for the Appropriate Handling of Personal Information by Medical and Care-related Enterprises” drafted on Dec. 24, 2004 confirmed the policy.

The Cancer Control Act was approved in 2006 and the Basic Plan to Promote Cancer Control Program was completed in 2007, in which cancer registration is recognized as a central component of cancer control. One development that is an expected outcome of the Plan is mandatory hospital-based registries in designated cancer care hospitals.

Some prefectures have ordinances related to the protection of personal information at the local level that override national laws such as the Health Promotion Law. These laws have made it difficult for registries to operate.

Protection over-ride

Without a sufficient legal basis for cancer registration in Japan, population-based cancer registries protect personal information by voluntarily drafting guidelines and code to protect information so as to avoid omissions in routine tasks such as the collection and management of personal information.

The handling of personal information in population-based cancer registry operations is based on the “Guidelines to Protect Information in Population-based Cancer Registries.” These guidelines draw upon the “International Association of Cancer Registries’ Guidelines on Confidentiality in Cancer Registries” published in 1996 and revised in 2005.

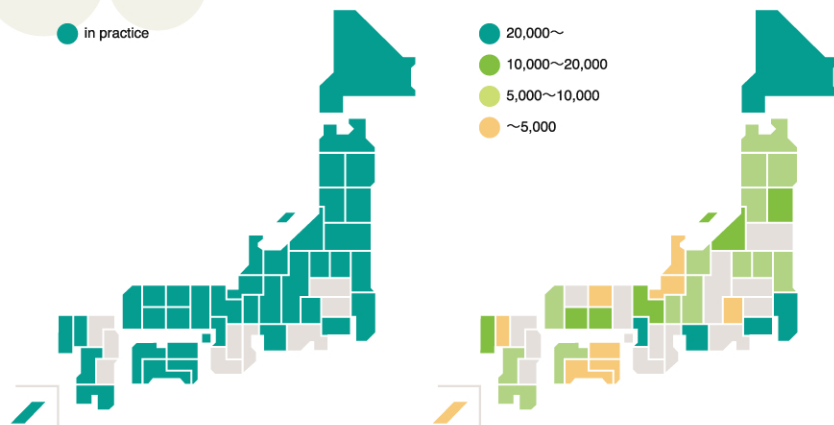
According to the guidelines, the registries must strictly carry out operations so as to avoid infringing upon individual rights or interests due to the loss, leakage, or other mishandling of personal information. For example, collected data are kept under lock and key in a room that prohibits access to unauthorized personnel, and computers containing sensitive data are isolated from external access. Also, tabulated results and study results using cancer registries are not published in a way that allows identification of individuals.

Contents	Date	Laws, notice, guideline, etc.
Status of the population-based cancer registry (population-based cancer registry is not epidemiological research but a municipal work)	June 17, 2002 December 28, 2004 amendment June 29, 2005 partly amended	Ethics Guidelines of the Epidemiological Study (Ministry of Education, Culture, Sports, Science and Technology)
Promotion of population-based cancer registry by the national and local (prefectural) government	August 2, 2002 promulgation July 26, 2005 amendment May 1, 2006 enforcement	Health Promotion Law Art. 16 (Ascertainment of trends of lifestyle-related diseases)
	June 23, 2006 promulgation April 1, 2007 enforcement	Cancer Control Act Art. 17 (2) (Improvement of collection and provision of data regarding cancer treatment)
	June 15, 2006	Cancer Control Act Supplementary provision 16
Reporting to the population-based cancer registry without prior informed consent of the individual is an exception to Privation Information Protection Law's Art.16 (Restriction by the purpose of utilization) and Art. 23 (Restriction of provision to a third party)	January 8, 2004	Notice No. 0108003, January 8, 2004 (Director of the Health Service Bureau of the Ministry of Health, Labour and Welfare)
	December 24, 2004	Guidelines for the Appropriate Handling of Personal Information by Medical and Care-related Enterprises (Ministry of Health, Labour and Welfare)
		Prefectural ordinances allowing the registry to obtain the personal information of cancer patients

Current Status of Cancer Registries in Japan

Implementation of cancer registries

As of October 2010, 38 prefectures and 1 city have implemented population-based cancer registries. Of the 38 prefectures, 3 (Fukushima, Nagano, and Shimane) started their cancer registry in 2010.



Map of population-based cancer registries (October, 2010) and number of incidences* in each registration area.

*Calculated based on data from 32 cancer registries. The numbers are the newly diagnosed and registered cancer cases from 2004 and 2005.

Budget and staff

In many of the prefectures, the budgets and staff of population-based cancer registries may not be sufficient. Generally, local government subsidy is the main source of funding, corresponding to 80.2% of the total budget. The annual budget of registries varies from 2,600,000 JPY (about 28,000 USD) to 81,000,000 JPY (about 900,000 USD), including salaries for the registry staff. The total staff for all the 35 registries includes 5.6 full-time equivalent (FTE) medical doctors, 13.3 FTE medical related jobs (i.e. researchers, nurses), 9.6 FTE health information managers, and 84.2 FTE clerical jobs.

About JACR

Thirty-five prefectures, one research institute, and 22 patronage members (e.g., insurance or pharmaceutical companies) belong to the Japanese Association of Cancer Registries (JACR), the network of population-based cancer registries.

The JACR was founded in 1992 and aims to develop population-based cancer registries in Japan. The JACR holds an annual scientific meeting where members exchange information and the senior registrars provide education and training to members. The status of each registry is surveyed annually. On the web-site (<http://www.jacr.info/>), the standard methods of cancer registration are explained, publications can be downloaded, and members provide a description of their registry and staff members. Additionally, once a year, newsletters (semi-annually) and a monograph (annually) are sent to members.

The JACR was certified as an “incorporated nonprofit organization” in 2010. We are expected to encourage unity among the registries and make great strides in cancer registration in Japan.



Annual Meeting



Website



Monograph

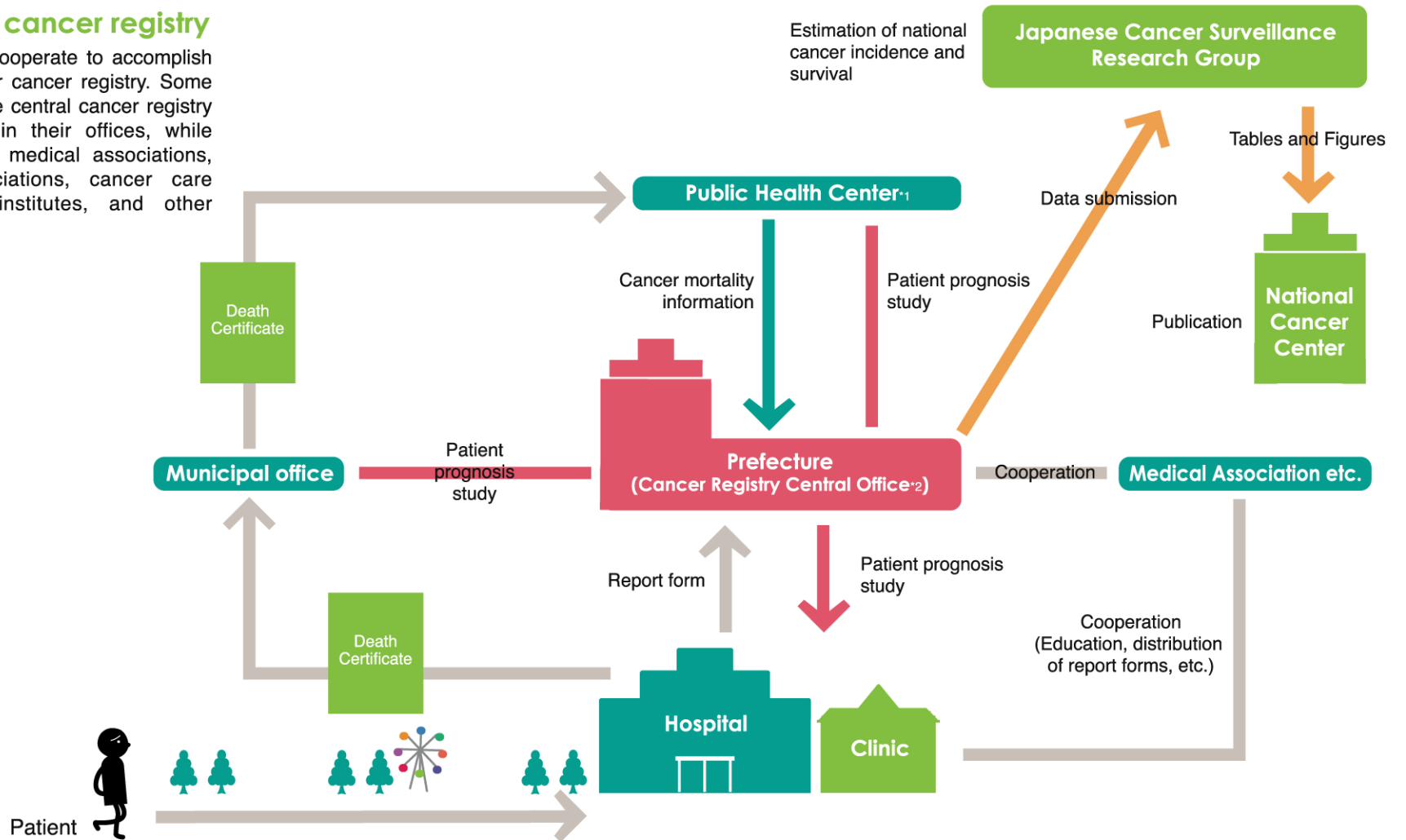


Newsletter

Registration procedures for cancer registries

Organization of cancer registry

Various organizations cooperate to accomplish the necessary tasks for cancer registry. Some prefectures do all of the central cancer registry tasks individually within their offices, while others cooperate with medical associations, health service associations, cancer care hospitals, research institutes, and other organizations.



Organization of cancer registry

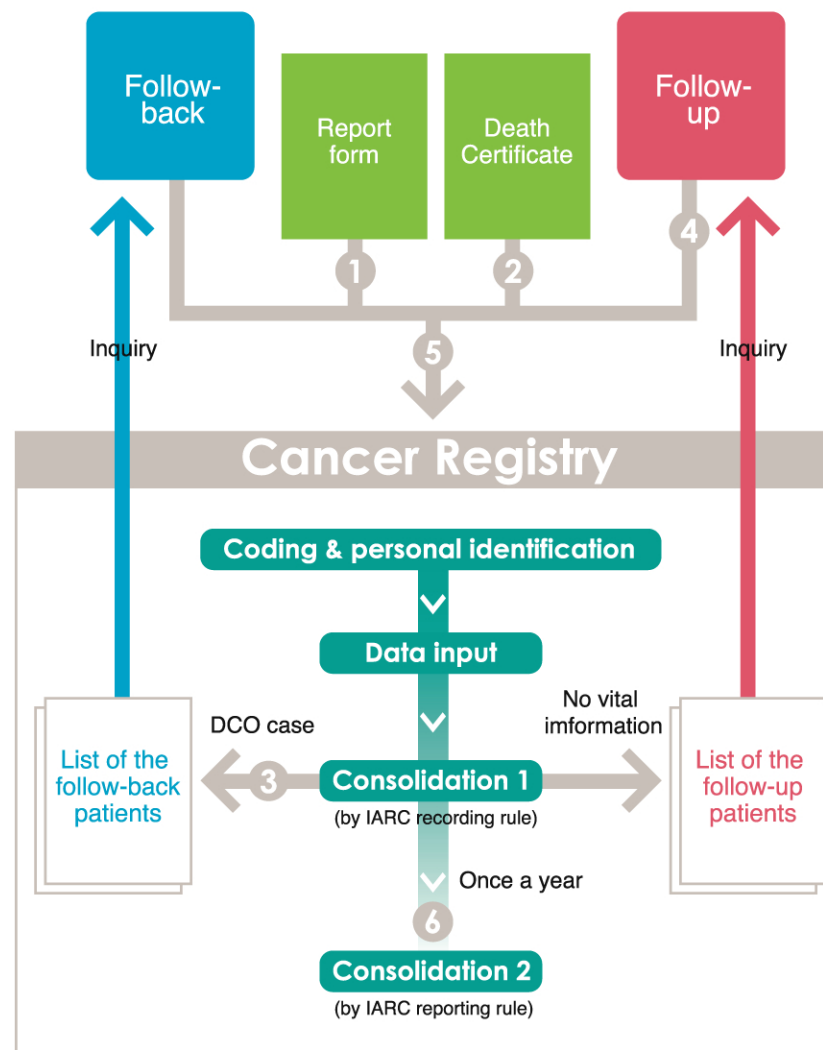
^{*1}The public health center is one of the official bodies that supports local residents' health and hygiene and was set up by the local prefectural government or a special administrative district according to the Community Health Law. Generally, the prefectural government, the public health center, and the central cancer registry play important roles and collaborate with each other within the cancer registry organization.

^{*2}The Cancer Registry Central Office is sometimes located in a research institute or prefectural cancer care hospital(s).

Registration procedures

Cancer registration is accomplished by the following 6 steps:

- 1 Information on cancer patients living in the prefecture is collected from medical institutions by mailing registry forms (paper or computer file format) or active registration.
- 2 Mortality information is obtained via public health centers (PHC). In order to use mortality information, each registry must complete the necessary procedures required for the use of the national vital statistics. Treating methods of data and available items in the death certificate are strictly prescribed by the Statistic Law.
- 3 Follow-back surveys are conducted in the medical institutions for death certificate only (DCO) cases. Currently, 16 prefectures perform follow-back surveys (Sep. 2009).
- 4 For prognostic information, the vital status of the person registered in the cancer registry is confirmed by referencing the residential registration data with the cooperation of PHC or local municipalities. Mortality information (via PHC) for a person whose cause of death is not cancer is used to supplement information regarding prognostic status. Furthermore, some registries obtain computer data regarding vital statistics (data with date of death, cause of death, birth date, and address code, but not name) with the permission of the national government and use it for the supplemental prognosis information. Currently, regular survival confirmation is being conducted by 21 prefectures (Sep. 2009).
- 5 Incidence, mortality, and prognostic information are concentrated in the cancer registry central office. Then, the information is organized, verified (individual identification), consolidated, and registered in the database. It takes about 3-4 years to complete all of these procedures.
- 6 Database information is compiled and utilized in the drafting of reports, for public relations, and the provision of registry information for research use.

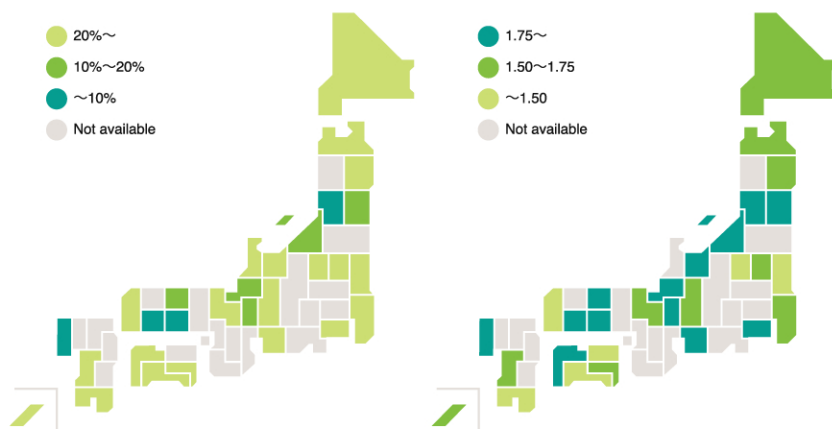


Flow of data consolidation in the cancer registry

Completeness and quality of registrations

Completeness

Although 38 prefectures have population-based cancer registries in Japan, not all registries have high degree of completeness in their incidence data. Out of a total of 30 registries, there are 12 with a DCO ratio of 25% or lower and 13 with an IM ratio of 1.75 or higher. Unfortunately, only one third of the registries conduct follow-backs as a result of being understaffed.



Completeness of data of 2005 incidence (Left: DCO, Right: IM ratio, Sep. 2009)

Quality of registries

The proportion of registered individuals with unknown age at diagnosis or unknown gender is low in most prefectures. The proportion of those with an unknown primary cancer site is also low. In terms of the histology code and extension of disease, however, the proportion of individuals with missing information is higher than the optimal level.

Monitoring of Cancer Incidence in Japan Project (MCIJ)

Collection of incidence data by the Japan Cancer Surveillance Research Group (JCSRG)

For use in monitoring national cancer trends, incidence data from the prefectural cancer registries are collected once a year as part of the Monitoring of Cancer Incidence in Japan Project (MCIJ) by the Japan Cancer Surveillance Research Group (JCSRG). Each population-based cancer registry is required to submit a minimum of 14 items (identification number, multiple primary, sex, birth date, date of diagnosis, date of death, primary site, histological code, basis of diagnosis, DCN, DCO, extension of disease, circumstance of cancer detection, last confirmation date).

The JCSRG extended the collection of incidence data from the 35 cancer registries (excluding the 3 registries that began cancer registries in 2010). In the 2009 questionnaire survey, all 35 registries indicated that data submission would be feasible.

Although all registries submitted data, some registries were missing some data items. Because few prefectures are conducting follow-up surveys at the present time, most of the missing items were data regarding follow-up, which is required to measure survival rates.

Data publication by the Center for Cancer Control and Information Services

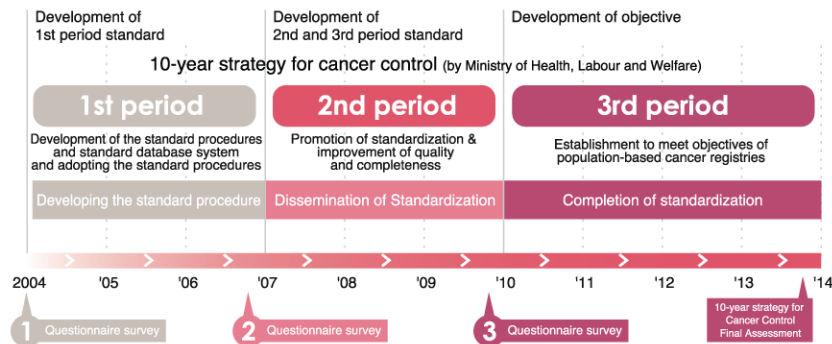
In October 2006, the Center for Cancer Control and Information Services (CIS) was established at the National Cancer Center. The Cancer Information Services and Surveillance Division belongs to the CIS. The tasks of the division are to improve the population- and hospital-based cancer registries and to collect data without personal identifiers from prefectures and hospitals.

Additionally the division is responsible for providing accurate and useful information. The JCSRG provides the division tables and figures on incidence data (estimation), mortality data, and survival data as results of the MCIJ project to the division. The division subsequently publishes these data in book form and on the CIS's website (<http://ganjoho.ncc.go.jp/professional/statistics/>).

Standardization of the cancer registry

Development of the cancer registry within 10 years

The JCSRG, which is composed of core members from the CIS's Population-based Cancer Registry Section and representatives from 9 population-based cancer registries, became involved in the 3rd-Term Comprehensive Ten-Year Strategy for Cancer Control (2004-13). Over a ten year period that began in 2004, the research activities of the group are mainly focused on the standardization of procedures for population-based cancer registries.



In the first period...

- The JCSRG established the objectives and standards to be achieved within 10 years in accordance with the following 8 items: legislative authorization, standard data content and format, data completeness, data timeliness, data quality, patient follow-up survey, annual reporting of registry data, and data use for epidemiological research.
- The JCSRG developed the standard registry system for the regional cancer registries.
- The JCSRG provided the standard registry system to cancer registries on request to improve the standardized registration procedure (input the data, identification method of individuals, consolidation, and statistics) through the training of local staff.
- Incidence data were collected from 15 population-based cancer registries and used to estimate the number of cancer incidences in Japan.

In the second period

- The JCSRG disseminated the standard registry system and standard cancer registration process.
- The JCSRG planned to call for data from all prefectures that have a cancer registry.
- The JCSRG provided training to prefectural registry staff.

In the third period

- The JCSRG plans to improve the completeness and quality of the data.
- The standardization will be completed.

Establishment of a standard procedure

The Steering Committee of the JCSRG established a standard procedure for cancer registry in Japan.

Standard items for cancer incidence case

25 standard items and codes for a classification of items.
Standard registry form includes 25 standard items.

Mortality information

Tumors that should be retrieved from a death certificate.
Items other than tumors that should be registered (for personal identification).
Code of items.
Procedures of follow-back for death certificate only cases.

Registration methods

Double entry is standard for entry of all data.

Rule of name in a database

Using Kanji, Japanese character such as 久子 for a first name, 広島 for a family name.
Level of Kanji. (Kanji has 3 levels for distinguishing between a new or old character. If a patient's name is not in the 3 levels, that Kanji is replaced by _ in the database.)

Personal identification

Standard method of personal identification uses the first name, family name, and birth date (year and month).
Different characters with the same meaning should be retrieved by computerized personal identification. (ex.) The standard registry system has a list of characters with the same pronunciation or meaning.

Multiple primary and rules for consolidation

Using modified IACR multiple primary.

Logic check

Using modified IACR logic check.

Survival study

Two methods of survival confirmation are acceptable.

- Reference to a district's municipal office is the most complete method.
- Confirmation should be also done by ascertaining all individuals dying of causes other than tumors in the prefecture.

Statistics of the prefectural cancer

Statistics that should be routinely included in a report for the comparison of cancer incidence rates between prefectures.

Items submitted to the JCSRG

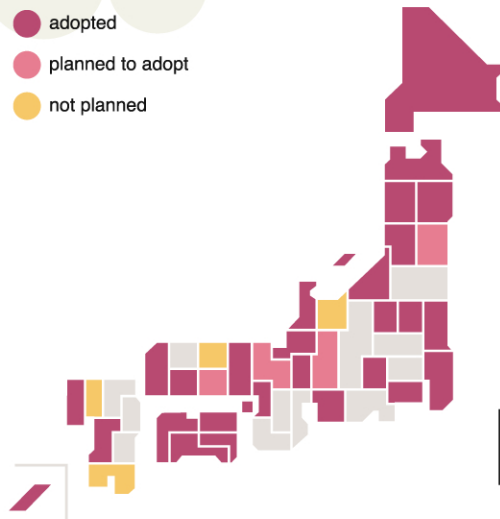
14 items submitted to the JCSRG for the MCIJ project.

Standard registry items and form

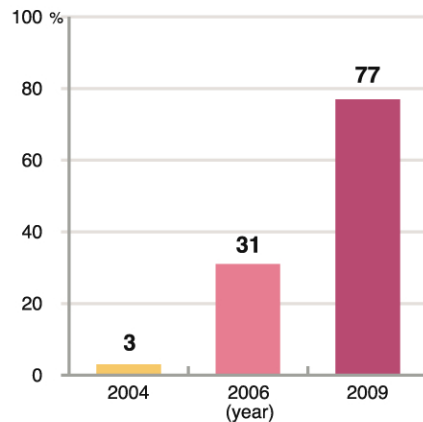
In 2004, the JCSRJ determined 25 standard items concerning the data that each registry must collect. In 2009, 27 prefectures had adopted the 25 standard items and 4 prefectures planned to adopt them in the future.

The standard registry form, which includes the 25 items, was developed in order to collect standardized information for the population-based cancer registry central office. Areas that adopt the 25 standard items mainly use the standard registry form.

- adopted
- planned to adopt
- not planned



Areas adopting the twenty-five standard items in 2009.



Proportion of registries adopting the twenty-five standard items in 2004, 2006, and 2009.

悪性新生物患者届出票 秘		事務局 使用欄	受付番号 受付年月日	使事 務務 欄局
医療機関 名称	1 Name of hospital	照会先所属 届出者		
貴院患者ID	2 Patient's ID number	性別	生年月日	
姓・名 (漢字)	3 Patient's name	4 Sex	5 Birth date	
診断時住所	6 Address of patient at diagnosis	0 西暦 1 明治 2 大正 3 昭和 4 平成	年 月 日	
診断名 部位	7 Diagnosis (newly, recurrence/in treatment, or possible cancer) 11 Primary site	12 Laterality 1 右 2 左 9 不明 3 両側 (原巣、腎芽腫、網膜芽腫) (例 胃U、肺S2、など)	病理診断名 詳細をお願いします	14 Histology (incl. behavior, grade)
診断情報	9 Date of conclusive diagnosis in the hospital 8 Date of initial diagnosis (required only recurrence/in treatment cases)	15 Basis of diagnosis 1 原発巣の組織診 2 転移巣の組織診 3 細胞診 4 免疫学的腫瘍マーカー (PSA, AFP, HCG, VMA, 免疫グロブリン高値) 5 臨床検査 6 臨床診断	患者の全経過を通じて、がんと診断する根拠となった検査に○(初回治療前の診断に限定しない)	
病期	13 Extension of disease	10 Circumstance of cancer detection 1 がん検診 2 健診・人間ドック 3 他疾患の経過観察中 4 剖検 9 自覚症状・その他・不明	初発の場合、病巣の拡がりか UICC/TNMのどちらか必ず記入 (地域がん登録では病巣の拡がり)を累計する。病巣の拡がりに記入がなければTNM分類やその他の情報からコード化する。)	
初回治療	16 Surgery of primary site 17 Laparoscopic/thoracoscopic surgery	20 Radiation therapy	21 Chemotherapy	
貴院における初回の一連の治療についてすべてご記入ください。	18 Endoscopic surgery 19 Result of surgery	22 Immunotherapy	23 Endocrine therapy	
再発では記載不要	20 Radiation therapy	24 Other treatment		
死亡年月日	25 Date of death			
オプション (自由記載欄)				

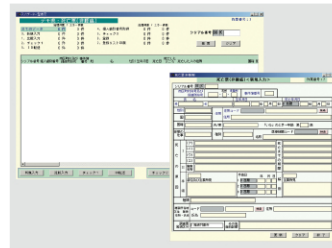
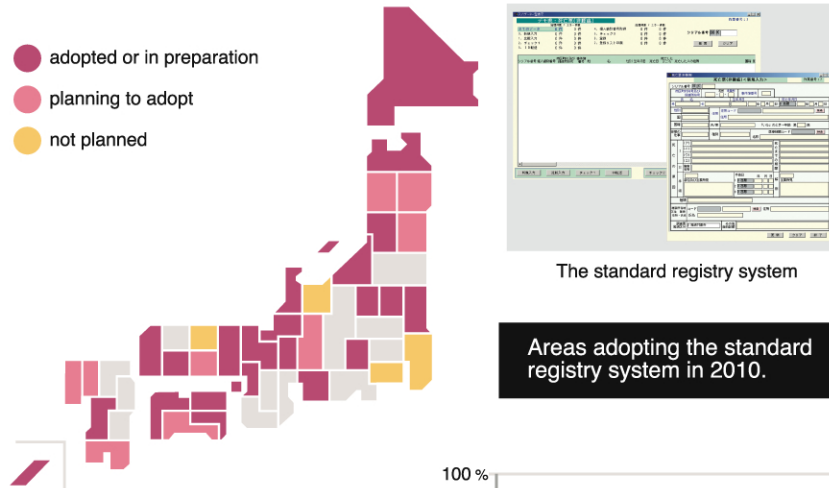
Standard registry form containing the 25 standard items

Standard registry system

The standard database system for the regional cancer registries (standard registry system) was developed by the Radiation Effects Research Foundation (RERF) in Hiroshima. The system is implemented to standardize procedures of cancer registries in Japan and has undergone repeated testing in the model area (Yamagata Prefectural Cancer Registry).

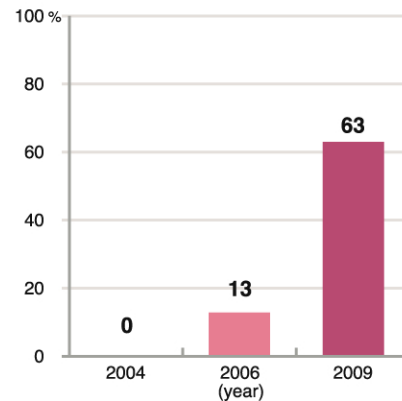
The standard registry system was updated following the determination of the standard procedures by the JCSRG.

As of October 2010, 21 of 38 population-based cancer registries in Japan have adopted the standard registry system. Initial training is provided to adopting registries by the JCSRG for three days at the cancer registry central office. As a result of the adoption of the standard registry system, improvements in standardization have been observed and its use is expected to increase rapidly in the future.



The standard registry system

Areas adopting the standard registry system in 2010.



Proportion of registries adopting the standard database system in 2004, 2006, and 2009.

Training and education for registration staff

All 3 Japanese cancer registry organizations (the JCSRG, the CIS in the National Cancer Center, and the JACR) provide training for cancer registry staff members. In particular, the CIS holds various training courses throughout the year:

1. One 2-day population-based cancer registry training course;
2. Ten or more 1-day hospital-based cancer registry training courses to disseminate the standardization of cancer registries;
3. Three 1-week hospital-based cancer registry training courses to disseminate the standardization of cancer registries.



Training course

The future of population-based cancer registries

Although there have been dramatic improvements regarding the standardization of population-based cancer registries, some challenges remain.

Legal background

In light of the supplementary resolution to the Basic Law on Cancer Control Measures, the JACR issued a statement in Sept. 2006 requesting a legal basis for reporting through the enactment of the Cancer Registry Operations Law (tentative title). When this legislation will come into effect is unclear, but action is expected regarding the enactment of Cancer Registry Laws.

Development of completeness and quality of registry data

Recently, hospital-based cancer registries have been dramatically enhanced through the implementation of a network of designated cancer care hospitals* by the national government. The key strategy for developing complete cancer incidence data in the population-based cancer registries is to increase the development of hospital-based cancer registries.

*A cancer care hospital, designated by the national government, should have a hospital-based cancer registry and should cooperate with the population-based cancer registries. In 2010, 377 hospitals were designated as cancer care hospitals in Japan.

Tumor registrar education and certification

While we do not have a certification system for a tumor registrar yet, we recognize that tumor registrars are essential for improving the population-based cancer registry. JACR have plans to establish a complete tumor registrar training course and certification system in the future.

Use of registry data for cancer control and epidemiological research

The incidence data of the population-based cancer registry should be used effectively and often for cancer control planning in prefectures and epidemiological research.

Reference

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