RESEARCH ACTIVITIES OF EPIDEMIOLOGY IN JAPAN
Cancer
Present Status and Research Activities of Cancer Registries in Japan

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Population-based cancer registries in Japan were first established in the cities of Hiroshima and Nagasaki in 1957-1958 for assessing radiation effects and in Miyagi in 1959 for promoting epidemiological researches, while most other prefectures in Japan set up cancer registries as a part of their own cancer programs. This resulted in the broader use of registry data in Japan.

In 1975, the Research Group for Population-based Cancer Registration in Japan was first organized with a research grant under the National Cancer Research Promotion Program. Since then, continuous efforts have been made by the Group to improve the quantity and quality of registry data and to develop methodologies to utilize it.

Studies being conducted using registry data cover (1) descriptive epidemiology, (2) analytical epidemiology, (3) evaluation of screening programs, and (4) evaluation of regional cancer medical care.

In 1992, 32 regional cancer registries which were operating in Japan set up the Japanese Association of Cancer Registries. However, there are still many difficulties to overcome in order to achieve completeness of reporting in registries. Further improvement of reporting rate, together with standardization of registry data are left for future efforts. J Epidemiol, 1996; 6: S37-S41.

cancer registry in Japan, history of cancer registration, system of cancer registration, registry data usage

HISTORY OF POPULATION-BASED CANCER REGISTRATION IN JAPAN

During several years from 1958, the 1st-3rd National Cancer Surveys were conducted by the Japanese Ministry of Health and Welfare. From the results, National Cancer Programs were first implemented in 1966, although a cancer registration program was not included in the National Program.

Population-based cancer registries in Japan were first established in the cities of Hiroshima in 1957 and of Nagasaki in 1958 by the Atomic Bomb Causality Commission (ABCC), presently known as the Radiation Effects Research Foundation (RERF), for studying the long term effects of atomic bomb radiation on human health.

After conducting a 3-year morbidity survey from 1952, the Miyagi Tumor Registry was started in 1959 by the Department of Public Health, Tohoku University Medical School with the support of a research grant from the National Cancer Institute in US to assess cancer risk in the prefecture.

Cancer registration schemes, as a part of the prefectural cancer programs, were first provided in 1962 by the Health Departments of the Prefectural Governments of Aichi and of Osaka independently, for which they requested the cooperation of their Prefectural Medical Associations. Subsequently, this type of cancer registry has gradually spread throughout Japan, resulting in utilization of the data in broader fields in Japan.

In 1975, the Research Group for Population-based Cancer Registration in Japan was first organized with a research grant under the National Cancer Research Promotion Program. Since then, continuous efforts have been made by the Group to improve quantity and quality of registry data as well as to develop methods for utilizing it.

The 4th National Cancer Survey was conducted in 1979 to collect data on cancer incident cases in 1975, their medical care received, and the three-year survival rates. All cancer registries participating in the Research Group were requested to cooperate with the survey and to submit their collected cancer data to the Ministry. The Osaka Cancer Registry, the secretari-
at of the Research Group, analysed these data and reported the results to the Ministry. Through the Survey, the importance of the population-based cancer registry was identified. Ten years later, the 5th National Cancer Survey was conducted again with the cooperation of all registries belonging to the Research Group in the same way as in the 4th Survey.

The Rojin Hoken Hoo (Health Promotion Act for the Aged) was enacted in Japan in 1983 to promote health and welfare for the aged. As a part of the act, the director of the Bureau of Health, Ministry of Health and Welfare issued a Notice in which he recommended that cancer registration be set up by prefectural governments for planning and evaluating cancer control programs in each prefecture. Thus, prefectural cancer registries have developed in a more systematic administrative basis since then, a number of prefectures have opened prefectural cancer registries, even though a national scheme for cancer registration had not yet been established.

In 1992, the Japanese Association of Regional Cancer Registries was established with 32 members comprised of existing prefectural and city cancer registries. The Association holds a scientific meeting once a year and encourages younger registries to improve data reliability, while the Research Group has promoted standardization and utilization of registry data with participation of 13 qualified registries in Japan with the capability of conducting epidemiological studies using their own registry data.

**PREFECTURAL CANCER REGISTRATION SYSTEMS IN JAPAN**

*Registration System in Osaka*

Cancer registration systems vary according to prefecture. The system in Osaka is described below as an example. The Osaka Prefectural Department of Health prepares a budget and the Osaka Prefectural Medical Association collects cancer reports from all medical institutions located in the prefecture. The Association requests physicians and hospitals to mail cancer reports to the Association. Cancer reports are prepared in hospitals by medical doctors or by medical record librarians, and sent to the Association. Those are transported once a month from the Association to the central registry. The registry is located in the Department of Cancer Control and Statistics, Osaka Medical Center for Cancer and Cardiovascular Diseases. The Osaka Prefectural Department of Health periodically sends copies of cancer death certificates of Osaka residents to the central registry with the permission of the Ministry of Health and Welfare. Cancer patients are registered from these two sources. After five years from the first diagnosis of cancer, the prognosis of all aliveing cases are surveyed by health center staff. They match these files with the citizen's register in the city office and confirm whether they are alive or dead. Some patients are found to have moved outside the prefecture. These cases are further surveyed and accurate survival rates are calculated. Proportion of lost cases was less than 5%.

The Osaka Cancer Registry started a cancer information service program since 1975 in which prognostic information concerning each reported patient as well as the hospital's cancer statistics were provided free at the request of participating hospitals or hospital doctors. The registry has held conference annually on cancer registration in Osaka, inviting all large and middle sized hospitals and clinical departments of medical university to report cancer registration activities. Through these activities, the cancer registry has greatly contributed to the progress and assessment of cancer medical care in hospitals.

*Registries in Japan*

Prefecture-wide cancer registries have generally been organized by prefectural governments. Exceptions are the Hiroshima and Nagasaki city registries, which are organized by the City Medical Association and the Radiation Effect Research Foundation.

Type of institution in which central registries are located varies according to prefecture. They are usually established in a prefectural cancer center or in a prefectural general hospital. If there are no such institutions in the prefecture, it is often set up within a prefectural medical association, cancer society, cancer detection center, research institute on health and environment, or medical university, etc.

Cancer registration in Japan has been operating on a voluntary basis. Data on patients are collected actively in three registries (Hiroshima, Nagasaki and Miyagi) and passively in all other registries because of budgetary limitations and a lack of registry personnel. Medical record librarian is not posted in most hospitals, therefore it is extremely difficult for central registries to achieve a complete reporting. In many registries the staff visit hospitals to help with completing cancer reports when necessary.

A one-week training program for cancer registry personnel has been held twice a year at the National Cancer Center in Tokyo under the sponsorship of the Ministry of Health and Welfare since 1987 with technical support from the Research Group.

One fourth of existing registries have conducted periodical matching with all death certificates of residents in the prefecture to obtain patient prognostic information. Only a few registries have had further active follow-up surveys. These registries have reported 5-year survival rates every year.

Half of the existing registries in Japan have published annual registry reports and distributed them to the authorities concerned. Additionally, cancer incidence rates are published yearly by the Research Group for the 13 member registries.

*UTILIZATION OF REGISTRY DATA*

**Descriptive Epidemiology**

Cancer statistics should be prepared for each level of nation,
prefecture, city, town and village. The group has estimated
cancer incidence in Japan on a yearly basis using data from
selected registries whose reporting rates match a certain stan-
standard[19]. Based on these trends, the magnitude and trends of
cancer occurrence in Japan in the future have also been periodic-
cally estimated[20].

In the field of descriptive epidemiology, besides studies on
cancer incidence and the trends[17-19], studies on multiple can-
cers have been conducted according to site. Incidence rates of
multiple cancers in cancer patients were calculated and com-
pared with their expected incidence rates to clarify risk factors
for occurrence of multiple cancers[20-30]. Cancer registries have
been collecting data on the histological diagnosis of tumors.
Incidence rates by histological group were calculated for
selected sites. The magnitude of risk and the time trends of
specific histological groups were studied in relation to changes
in etiological factors[25-28].

The figures for cancer prevalence are important indices in
planning cancer medical services and in evaluating the effec-
tiveness of the services. A method estimating the numbers of
long-term and short-term survivors was developed using reg-
istry data. Short-term cancer survivors with shorter survival
period than 5 years were regarded as an approximation of can-
cer prevalence[29,30].

Analytical Epidemiology

In the field of analytical epidemiology, accurate and effective
cohort follow-up studies have become feasible by using a
method of record linkage between two files; the one is com-
posed of data on each person with well-defined epidemiologi-
cal features and the other is a registry’s cancer patients’
file[31,32]. Many studies have been conducted using this method
to identify causal factors, and to assess risks[33,34,35] or to
observe natural history of cancers[36,37].

Evaluating Cancer Screening Programs

Historically, population-based cancer registration has been
conducted mainly to estimate cancer incidence in many
countries. Since it was started, the Research Group has strived
not only to use cancer registry data for cancer statistics and for
epidemiological studies but also to actively utilize this data for
planning and evaluating cancer programs in a region, and has
long promoted the development of methodologies for these
objectives.

In the field of assessment of validity of cancer screening pro-
grams, an accurate identification of cancer cases newly diag-
nosed after screening (interval cases or false negative cases)
had been regarded as nearly impossible until the method of
record linkage was developed for matching between screeners
and cancer patients. Since then, validity has been easily esti-
mated for specific screening procedures[38,39]. Clinical diagnos-
tic methods introduced in hospitals have also been assessed quan-
titatively, using the same method[40,41].

Evaluation of Regional Cancer Medical Care

Trends of cancer statistics obtained from population-based
registries, such as cancer incidence, mortality, stage dis-
tribution, medical examination rates, treatment rates and sur-
vival rates of cancer patients, were analysed to assess cancer
prevention and the medical care programs conducted[42-45].

CONCLUSION

Population-based cancer registries were operating in two
cities and 33 prefectures out of 49 prefectures in Japan as of
1995 which cover 70% of the entire population in Japan, while
fewer than 10 registries have achieved roughly satisfied com-
pleteness of reporting[45]. When the registries adopt a method
of passive collection of data, it is essential that hospitals have a
central medical record library. This is, however, not always
realized under the present service system in hospitals.

The Research Group for population-based cancer registries
has carried out various activities to promote utilization of reg-
istry data for more than 20 years. The results reported from the
Group are now being highly evaluated in every fields of cancer
related medical sciences. It has been four years since the
Japanese Association of Cancer Registries was established.
The Association will help registries to improve reliability of
their own data.

Achievement of sufficient completeness of reporting and
standardization of the methods will be the focus of future
efforts. It is expected that the methodology developed thus to
utilize registry data will be broadly practiced to bring new and
positive results in cancer epidemiology.

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