POLICY and PRACTICE

A New Model Population-based Cancer Registration System in Aichi Prefecture, Japan

Manami Inoue,[1] Kazuo Tajima,[2] Suketami Tominaga,[3] Kunio Aoki,[4] and Masahiro Kato[5]

Abstract

A dramatic overhaul of the population-based cancer registration system in Aichi Prefecture, Japan - Aichi Cancer Registry (ACR) - was undertaken in 1998, with a view to rationalization and strengthening of its effectiveness, supported by a grant from the Ministry of Health and Welfare. A more comprehensive organization encompassing the prefectural cancer center and prefectural public health centers (PPHCs), promoting PPHC-based primary and secondary cancer prevention has now been in operation since January 1999. Application of its basic components is also feasible for other population-based cancer registries in Japan, which share similar operation characteristics. This paper introduces the new cancer registration system in Aichi Prefecture, Japan.

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Background

Aichi Prefecture is located in the approximate center of Japan, with the Pacific Ocean on its southern edge. The prefecture spans an area of 5,146 square kilometers and has a population of 7 million. The prefectural capital is Nagoya, and the prefecture includes 87 municipalities as well as the 16 wards of Nagoya-city itself.

The Aichi Cancer Registry (ACR) was established in 1962 as a population-based cancer registry, with the purpose of providing an accurate picture of cancer in Aichi Prefecture, Japan, as a basis for effective control (Department of Health, Aichi Prefectural Government). It was the fourth registry initiated in Japan after those in Hiroshima-city, Nagasaki-city, and Miyagi Prefecture and one of the first-organized as part of a prefectural cancer control program (Oshima et al., 1998). Initially under the direction of the Department of Health, Aichi Prefectural Government, all medical institutions in Aichi Prefecture were requested to report incident cancer cases on the basis of cancer registry guidelines.

However, several issues have prevented the ACR from accomplishing its aim satisfactorily. First, as with other cancer registries in Japan, data provision has been carried out entirely on a voluntary basis, because of a lack of legal structure to support for population-based cancer registration in Japan. Especially for registries with such a large population as ACR, thorough capture of the new cases within the covered area is therefore a great challenge. Second, the limited number of ACR personnel for such a large population has caused work overload and inevitably restrained the registry staff from active data collection or making extensive improvements to the system. Internationally, it has been recommended from a practical point of view that there be one registry staff member for each 1,000 new cases occurring annually in the population covered (Jensen and Whelan, 1991). Applying this to Aichi Prefecture, the ACR would need as many as 20 registry staff, far more than the current ACR reality, as with most

[1] Senior Researcher, Division of Epidemiology, Aichi Cancer Center Research Institute, Nagoya 464-8681, Japan and Aichi Cancer Registry, Health Promotion Division, Department of Health, Aichi Prefectural Government, Nagoya 460-8051, Japan, [2] Chief, Division of Epidemiology, Aichi Cancer Center Research Institute, Nagoya 464-8681, Japan, [3] Director, Aichi Cancer Center Research Institute, Nagoya 464-8681, Japan, [4] President Emeritus, Aichi Cancer Center, Nagoya, 464-8681, Japan. [5] Director, Health Promotion Division, Department of Health, Aichi Prefectural Government, Nagoya 460-8051, Japan.
Corresponding Author: Manami Inoue, M.D., Division of Epidemiology, Aichi Cancer Center Research Institute,1-1 Kanokoden Chikusa-ku Nagoya 464-8681 Japan, TEL: +81 52 762 6111 FAX: +81 52 763 5233, E-mail: minoue@aichi-cc.pref.aichi.jp

other population-based cancer registries in Japan. Each registry in Japan has no choice but to adjust its own system to optimize achievement of its aims. To increase the number of reports, ACR notification forms have substantially been simplified twice, but this caused the insufficiencies in the registry data. Under the circumstances, a dramatic overhaul of the registration system has been deemed necessary, with a view to rationalizing the ACR and strengthening its effectiveness.

In 1998, an ACR remodeling project was undertaken, supported by a grant from the Ministry of Health and Welfare, Japan. The major purpose of this project was to make improvements commensurate with providing information necessary for cancer control measures among the community, by reconstructing the operation scheme. Another aim was to establish a new population-based cancer registry model applicable to most communities in Japan. The results are introduced in the present report.

Progress

Essential features of the ACR remodeling

Establishing the ACR remodeling project puts stress on the reinforcement of overall cancer control measures within the prefecture. Concretely, main aims were: 1) to establish a more comprehensive organization, encompassing the prefectural cancer center as the core institution for cancer research and treatment, and prefectural public health centers (PPHCs) as core facilities for community health service; and 2) to promote primary and secondary prevention of cancer based on PPHCs.

Major points of revision

1) To establish a more comprehensive organization:
The former ACR was a directly managed undertaking of the Department of Health, and the prefectural cancer center participated in the ACR by offering technical assistance in terms of advanced statistical analyses of the registry data (Figure 1). In Japan, many prefectures operate their own cancer centers, most of which put most emphasis on the treatment as a local core hospital for cancer and few have a department in charge of epidemiology and biostatistics as a whole, and thus are less well equipped to contribute to the population-based cancer registry. In Aichi Prefecture, the cancer center houses professional expertise on epidemiology and cancer prevention measures as well as technical skills of cancer treatment. Therefore, it is in a good position to coordinate registration. The new ACR system thus has been located in a central registry office in prefectural cancer center for improved registry data management (Figure 2).

At the same time, stress has been placed on PPHCs as core facilities for community-based local health services, which were not included in the former ACR system. There are seventeen PPHCs and six branches, as well as three large cities that administer their own public health centers (Nagoya-city, Toyota-city and Toyohashi-city). The present public health center system was started in 1947 with the enactment of the Public Health Center Act for the whole Japan. According to the amendment of Community Health Act in 1994 and the change of disease predominance from infectious diseases such as tuberculosis to lifestyle-related diseases such as cancer, however, PPHCs have been re-examining for their roles within community health services. For many decades, PPHCs in Japan have administered various public health activities in jurisdictional municipalities, and accordingly have a close links with local medical institutions. Therefore, it is effective and timely for population-based cancer registries in Japan to welcome the assistance of PPHCs as local core centers for the ACR, especially for the terminal data exchange such as submission of notification forms and feedback of cancer information to residents and medical institutions. In the new ACR operating scheme, notification forms, which were submitted directly from each medical institution to the Department of Health in the previous system, are first assembled at PPHCs, where primary notification files are constructed using the ACR data input software. For this purpose, a personal computer system was distributed to each PPHC. PPHCs also encourage each medical institution to report cancer cases continuously, and in turn feedback information derived from the ACR to promote cancer control activities.

2) To revise the ACR notification form:
To streamline collection of incidence and mortality information, several items, which are related to cancer screening and lifestyle such as smoking and alcohol intake, were deleted in previous revisions of the notification form. However, information on these items is essential for evaluation of cancer control measures in the community, and therefore, included again in the new ACR notification form.

3) To effect installation of a hospital cancer registration system:
When improving both quantity and quality of reports, it is rational in terms of efficiency that a hospital-based cancer registration system be installed in medical institutions. The ACR has therefore developed common cancer registration software, modified that generated by Osaka Cancer Registry, Japan (Koyama and Ajiki, 1998), and the CANREG developed by the International Agency for Research on Cancer (IARC) (Coleman and Bieber, 1991) into an ACR specific version. This system functions under the Japanese common application software, which is widely used by Japanese medical staff (Filemaker Pro 4.1J, 1998). Two types of systems have been prepared, one for the ACR input, and the other for hospital cancer

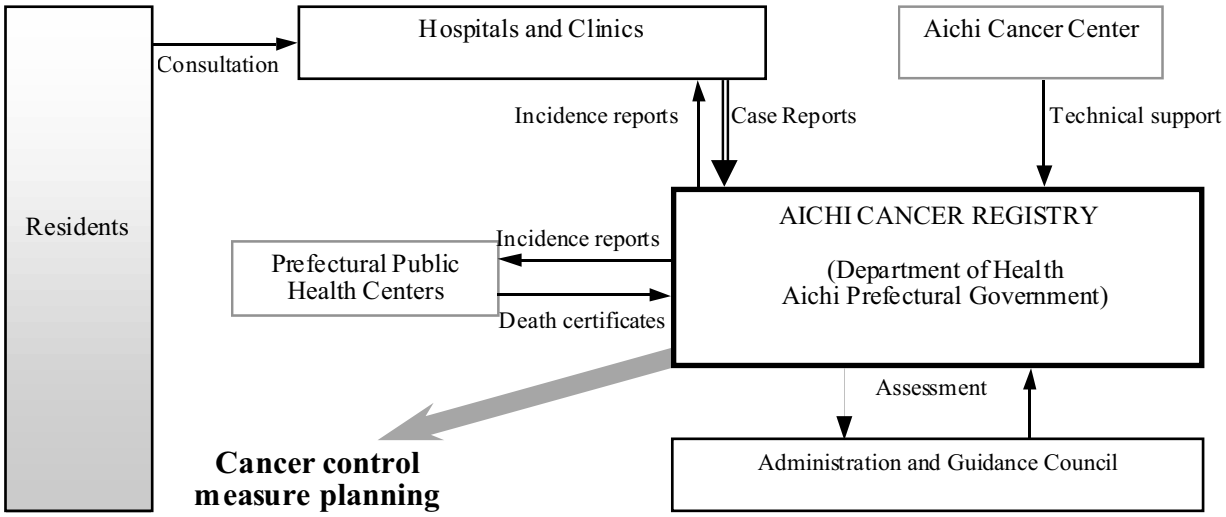

Figure 1. Former Cancer Registration System in Aichi Prefecture

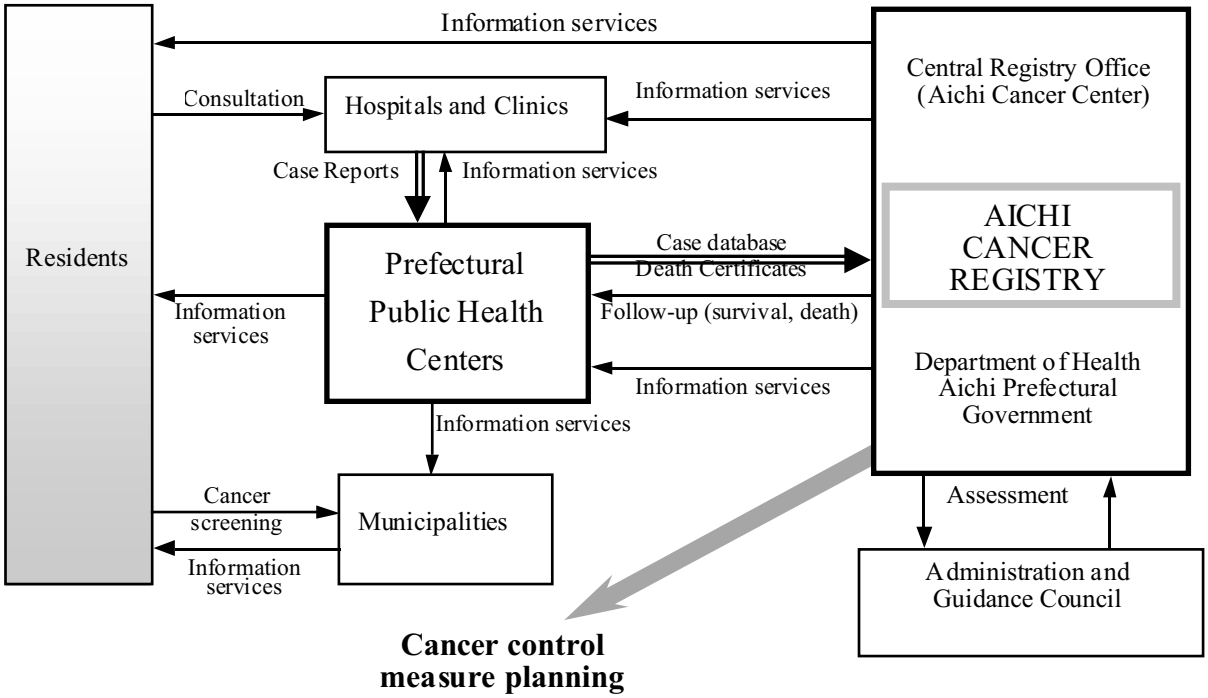

Figure 1. New Cancer Registration System in Aichi Prefecture

registry. The former has items for the ACR only, limiting input to Aichi Prefecture residents. The latter system has detailed items for hospital cancer patient management, including all items for ACR, and helps the medical institutions administer their patients' information by themselves.

Educational activities

Continuous education to enlighten medical staff of the importance of their efforts for ACR and maintain their cooperation is necessary to improve the quality of registration, as well as to make the new ACR function effectively. Concretely, two types of lecture courses has been held by the authors as the first step at each of seventeen prefectural public health centers and their branches; 1) lectures to clarify the roles of the population-based cancer registry (by K. Aoki, S. Tominaga and K. Tajima) and 2) instruction about data input software for the ACR (by M. Inoue). Each PPHC managed their own courses, and the prefectural cancer center supported them by providing lecturers. These courses also gave important opportunities to exchange opinions on cancer registry from various points of view, among ACR staff, PPHC staff and various other medical personnel in Aichi Prefecture.

Central registry office

Other than the progress mentioned above, a new data processing flow was introduced into the central registry office at the prefectural cancer center. The former system applied batch-based data processing using the mainframe in the prefectural government building shared with many other prefectural businesses, which made lack of flexibility for data processing in ACR. The new central registry office aims at downsizing of computers as well as labor- and waste- saving by avoiding, for example, paper printouts. Workstations with personal computers are applied in the new system, this becoming possible for large population registries such as the ACR in memory-consuming languages like Japanese, due to rapid progress in computer technology. The data processing system was developed with the consideration of CANREG (Coleman and Bieber, 1998) and the Osaka Cancer Registry data check program (Ajiki., 1997), and has the ability to store and process vast amounts of data.

Future Perspectives

Collaboration structure

The new ACR system has been in operation since January 1999, and the collection of notification forms through PPHCs is proceeding satisfactorily at present. Cooperation of medical institutions and their understanding of the ACR should now be built up further by continuing educational activities and diffusion of knowledge.

Installation of cancer registration software has been viewed by medical institutions with great interest, and there is a general consensus for the need for constructing a patient database. Particularly in large hospitals without computerized patients' data management, difficulty in identifying cancer cases has prevented them from comprehensive reporting to the ACR. Installation of appropriate software into these hospitals not only has promoted registration but also has helped them introduce computerized patient data management systems.

Application to primary prevention

The population-based cancer registration system is a basis for cancer control measures in the community. Feedback of information to the community is essential to this effort. To make this latter more effective, a new project has been started to develop education software for cancer control activities. The information incorporated in this education tool is derived from the epidemiological database constructed at the prefectural cancer center reflecting the lifestyle of the same population, helping self-interest in prevention efforts. By making use of the software, residents are able to assess the risk of their own lifestyle for cancer, as well as obtaining information on general knowledge and treatment of cancer. The software will be utilized mainly at PPHCs for the primary prevention activities.

Another noticeable movement in consequence of this project was the inauguration of a volunteer society to promote community-based cancer prevention in Aichi Prefecture (Chairman: K. Aoki). By including various health professionals and others who wish to contribute to the cancer prevention activities in Aichi Prefecture, the society is active in various aspects of support non-profit making cancer prevention activities.

General applicability to other cancer registries in Japan

The new ACR model is affordable for most population-based cancer registries in Japan in terms of cost, work force, and operation efficiency. Collaboration with prefectural public health centers is crucial for the general introduction of this new type of cancer registry model to other registries in Japan. With continuous monitoring to evaluate its operation, the new ACR system should provide a lead in assessment and control of the cancer problem.

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Personal Profile: **Manami Inoue**

Manami Inoue was born Yokohama, Japan in 1965. She graduated from the School of Medicine, University of Tsukuba and obtained her M.D. in 1990. She started epidemiological research at the Division of Epidemiology, Aichi Cancer Center Research Institute, Nagoya, Japan from 1992, and at the same time commenced her career in population-based cancer registration. After being awarded a Ph.D. at Nagoya University School of Medicine in 1995 for research on epidemiology of digestive tract cancers, she studied at the Harvard School of Public Health and obtained S.M. specialized in cancer epidemiology in 1996. Now she is a senior researcher at the Division of Epidemiology, Aichi Cancer Center Research Institute and concurrently in charge of the Aichi Cancer Registry at the Department of Health, Aichi Prefectural Government. Her study interests are the analytic epidemiology of digestive tract cancers, and the descriptive epidemiology of cancer as well as cancer registration methodology.