

Population-Based Cancer Registries in Korea: A New Model

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INTRODUCTION

A population-based cancer registry (PBCR) records all new cases in a defined population (most frequently a geographical area), it must collect information on every case identified within a specified population over a given period of time. This implies that the registry will operate within a defined geographical area, be able to distinguish between residents of the area and those who have come from outside, and register cases of cancer among residents diagnosed/treated outside, as well as within the area. To avoid registering the same case twice or more, it must have sufficient information on each one, and have access to an adequate number of sources within the area¹⁾.

It is obviously important that the registration of cancer cases should be as complete as possible; the value of a registry depends on the quality of its data and the extent to which they are used in research and the planning of health services. The completeness of registration usually depends on the availability of data sources,

and on methods of data collection. Records of cases diagnosed and treated in medical facilities are the main source of information; data are thus usually obtained from

- Medical records (department)
- Autopsy services
- Hematology and other laboratories
- Death certificates
- Health insurance documents
- Screening programs
- Hospices and other sources.

Methods of data collection have traditionally been classified as active or passive. Active collection at source involves registry personnel who actually visit sources of data and transfer the required information to special forms, or obtain copies of the necessary documents. Passive reporting relies upon other health care workers to complete notification forms and forward them to the registry, or to send copies of discharge abstracts, for example, from which the necessary data can be obtained. In practice, however, a mixture of these methods may be used, with, for example, active hospital visits being supplemented by passive receipt of copies of pathology re-

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porting forms and death certificates¹⁾.

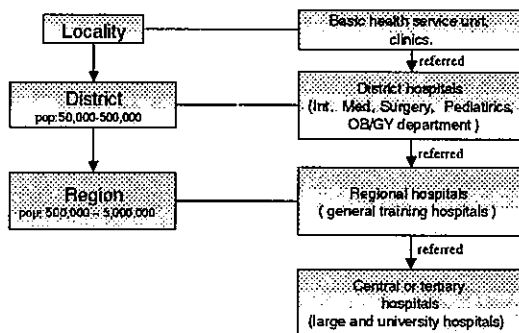
To operate the PBCR, there must be a system for reporting clinical and pathological data, and reliable population data should be available. However, the way in which a registry operates depends, inevitably, on local conditions and on the material resources available. There is generally a medical care system, i.e. cancer patients have access to medical facilities at some point in their illness. In some locations, the operation of a number of registries has been seriously curtailed by laws or regulations, designed to ensure secrecy of information; these prevent cross-linkage of different data files, including access to the personal identity of deceased persons in death records.

KOREA AND ITS MEDICAL CARE SYSTEM

The total area of South Korea is about 99,394 km², with seven metropolitan cities and nine provinces as administrative unit. In 1995, the total population was 44,551,183 (22,365,520 males and 22,185,663 females)²⁾. Medical insurance, either public or private, covers almost all Koreans. The national health care delivery system is characterized by a three-step

Figure 1. Medical care system, Korea

- Coverage of medical insurance: nearly 100 %
- Service areas are classified as ;



referral and zoning system³⁾. Service areas are classified as “Locality”, “District”, and “Region” according to referral level. An individual who wants medical care usually first visits a clinic or health center in his/her locality, and is then referred, if necessary, to the first referral level unit, a district hospital (Figure 1). He/she may then be referred to the second referral level, a regional hospital. Each region usually provides for a population of 500,000-5,000,000. Several large general hospitals are nominated as the third referral level unit, and it is at these that patients referred from a regional hospital are cared for.

There are at present eight Regions of service area in Korea. When a patient is seeking medical care at a hospital located in a Region other than his/her own, he/she needs the approval of the medical insurance company.

HISTORY OF CANCER REGISTRATION IN KOREA

It was not until 1980 that cancer registration was started in Korea; official registration began under the financial support of World Health Organization on July 1st of that year (Table 1). Forty-five training and two non-training hospitals throughout the country initiated voluntary registration of patients in whom neoplasms had been found. All completed data sheets, containing 15 items of patient information, were to be sent from each hospital to the Korean Central Cancer Registry Center (KCCR) at the National Medical Center⁴⁾. A few years later, the Ministry of Health and Welfare compelled all the university and training hospi-

tals to join the program.

The KCCR has continued without interruption and has published an annual report. The number of member hospitals and registered cancer cases has been increasing steadily year by year. In 1996, around 80,000 cases from 119 hospitals were registered throughout the country⁵⁾. Although the KCCR is a national cancer control program and covers almost all the large training hospitals in Korea, it cannot provide incidence data. It is, however, the only registry of its kind in the world, being neither population- nor hospital-based.

In 1983, a population based cancer registry was launched in a small county, Kangwha, by Yonsei University Medical College. Kangwha County is a small island area connected by a bridge to the mainland, and is 50 Km from Seoul. It has around 80,000 inhabitants. All data were collected by active methods, and incidence statistics for 1986-1992 appeared in Vol. VII of the Cancer Incidence in Five Continents⁶⁾. However, the population covered is too small to be representative of the whole of Korea.

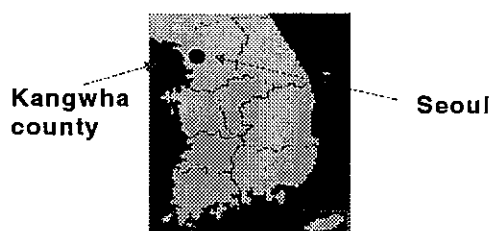
In 1990, the initial study for a population-based cancer registry in Seoul was carried out by several researchers in-

Table 1. History of Cancer Registration in Korea

1. Central Cancer Reporting Program
(Korea Central Cancer Registry, KCCR)

- Started in 1980. 7. 1.
- 47 hospitals initiated at the beginning.
- All the data sheets of 15 items completed are to be sent to Central Cancer Reporting Program, National Medical Center, from each hospital.
- Published annual report since 1983.
- In 1996, around 80,000 cases were registered from 119 hospitals throughout the country.

2. Kangwha population-based cancer registry



- Started in 1983
- Population size: less than 80,000
- Incidence statistics, 1986-1992, was published in Vol. VII, Cancer Incidence of Five Continents, IARC (1997).

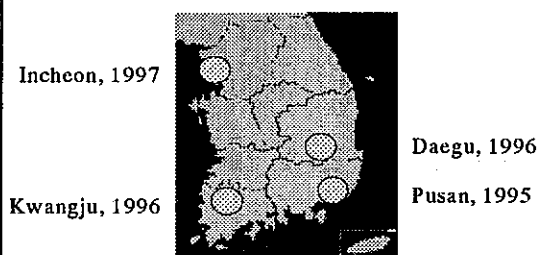
3. Seoul Cancer Registry

• The Implementation Study of Population-Based Cancer Registry in Seoul (1990-1992)

- Supported by Korean Foundation for Cancer Research
- Study objectives;
 - 1) to test the feasibility of operating PBCR in Seoul with dual source of case registration.
 - 2) to provide the cancer incidence statistics.

• Seoul Cancer Registry has started in 1991.

4. Feasibility studies for PBCR in Pusan, Daegu, Kwangju and Incheon.



• One year after the feasibility study, PBCR in each city had launched.

cluding this author. It was supported by a civilian foundation, the Korean Foundation for Cancer Research. The study had two objectives: 1) to test the feasibility of operating a population-based cancer registry in the Seoul area, with dual sources of case

registration, i.e., from the KCCR and also including cases diagnosed in small hospitals, and 2) to provide the cancer incidence for all sites in the Seoul area with completeness and validity assessment. In 1993 the major findings were reported, and it was suggested that the methods of data collection used in the study could be used as a model for a future population-based cancer registry in other areas of Korea⁷⁾. The Seoul cancer registry (SCR) started in 1991 and since then has operated continuously⁸⁾.

The program and methodology used by the SCR was extended to other large cities: Pusan in 1995, Daegu and Kwangju in 1996, and Incheon in 1997. In each area a study of patterns of utilization of existing medical facilities by cancer patients was first carried out, and after this the registry was launched. As of 1998, five population-based cancer registries are running in Korea. The Kangwha area, the earliest registry area, merged with Incheon.

INCORPORATION OF KCCR INTO POPULATION BASED REGISTRIES IN KOREA

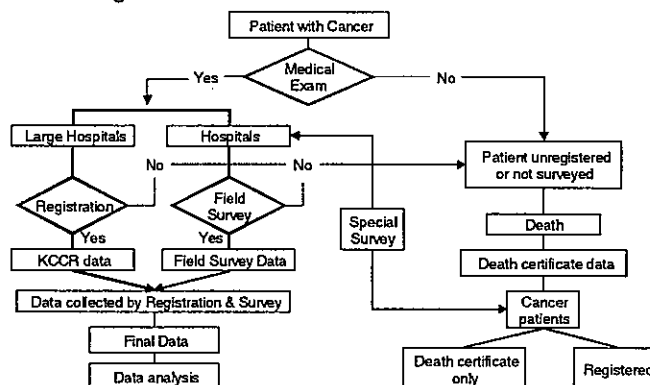
The basic idea of the model for a population based cancer registry in Korea is the incorporation of KCCR data into PBCR data. Cancer patients who seek medical care at large hospitals, in other words 'KCCR-affiliated' hospitals are usually and automatically registered with the KCCR. Those who visit smaller medical facilities are actively surveyed by registry collecting staff prior to registration.

There are two main sources of in-

Table 2. Development of a New Model for PBCR in Korea

1. Implementation Study of Seoul Cancer Registry (1990-1992)
2. Feasibility and Implementation Study of Pusan Cancer Registry (1995-1996)
3. Feasibility Study of Daegu Cancer Registry (1996)
4. Feasibility Study of Kwangju Cancer Registry (1996)
5. Feasibility Study of Incheon Cancer Registry (1997-1998)
6. Evaluation Study of the Completeness of KCCR (1995-)

Figure 2. Flow chart of PBCR in Korea



completeness of case registration in the Korean PBCR model (Table 2, Figure 2); one is the degree of completeness of the KCCR and the other is the coverage of case registration by active surveillance of smaller medical facilities. In the latter case, the facilities to be surveyed are determined in advance, and a feasibility study, or one which determines the pattern of medical utilization, provide a valid basis for decision-making. For this purpose, several such studies have been conducted; these include an implementation study (Seoul Cancer Registry, 1990-1992), feasibility and implementation study of Pusan Cancer Registry (1995-1996), and three feasibility studies: Daegu Cancer Registry (1996-1997), Kwangju Cancer Registry (1996-1997), and Incheon Cancer Registry (1997-1998). And for the former, studies aimed at evaluation and improvement of the completeness of KCCR has been conducted since 1995.

CANCER REGISTRATION FLOW IN THE SEOUL CANCER REGISTRY

The primary source of the SCR data is the registry files of the KCCR. From these files, the records of patients residing in Seoul are extracted. Patients diagnosed in KCCR-non-affiliated hospitals are actively surveyed by SCR data collection team, who visit each hospital at regular intervals.

Prior to the implementation study, it was hoped that cancer patients in Seoul would not need to go elsewhere to seek better diagnosis/treatment, and that many such patients who first visit small hospitals would be referred to larger (KCCR) hospitals. If this had happened, it might have been unnecessary to survey non-KCCR hospitals. In the implementation study⁷¹, it was estimated that less than 1% of cancer patients visit hospitals out of Seoul, and around 10% first visit non-KCCR hospitals. Among those utilizing these latter, however, only 6.2% of patients were subsequently referred to, or visited, larger hospitals. According to duplicate record data, transfer rates from non-KCCR to KCCR hospitals were lower among older age groups than among others, and were lower in elderly females than elderly males. This implies that visit-and-abstract surveillance of the non-KCCR hospitals would improve the registration rate of new patients especially those who are older. Registry data from the implementation study were evaluated in terms of completeness and validity; several indices were used, including the mortality/incidence

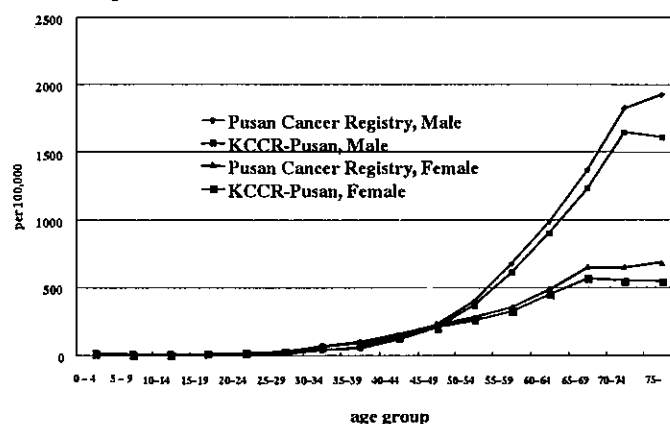
(M/I) ratio and age-specific incidence curve for the completeness, and histological verification (HV%), primary site unknown (PSU%), and age unknown (Age UNK %) for validity⁹¹.

FEASIBILITY STUDIES IN LARGE CITY AREAS

The medical utilization pattern of cancer patients in Korea varies somewhat according to area, including between large cities. In order to estimate the rate of non-registration, feasibility or medical utilization studies were carried out in Pusan, Daegu, Kwangju, and Incheon.

Pusan, in the southeast of Korea, is its second largest city, according to a feasibility study¹⁰, 91.4% of cancer cases there were registered with the KCCR, and the remainder through active surveillance. Among patients who first visited a non-KCCR hospital, 8.5% visited one located outside Pusan. More than one quarter of cancer patients attending a small hospital, however, later visit or are referred to a KCCR hospital. When using two data sources for cancer patient registration, i.e. KCCR files and active surveillance of non-KCCR hospitals in Pusan, the degree of case loss was estimated

Figure 3. Cancer Incidence in Pusan



at 1.2%. Active surveillance increased the rate of registration, especially of patients who were older (Figure 3).

The medical utilization pattern of cancer patients in Daegu was nearly same as in Pusan. The use of two sources of registration data indicated that 1.5% of patients were not registered.

Kwangju City is located in the southwestern part of Korea, about 82% and 18% of cancer patients there are registered through KCCR files and active surveillance, respectively^{11, 12)}, and only 6% of cancer patients visiting non-KCCR facilities use medical services at facilities/hospitals located outside the city. Dual data sources indicated that 2.2% of patients were not registered.

In Incheon, 40 km from Seoul, a feasibility study is still going on, and will be completed very soon. The medical utilization pattern of cancer patients is somewhat different from those in Pusan or Kwangju, with a relatively larger proportion using medical services outside the city. About half those registered in KCCR files visit hospitals in Seoul, and about 17% of those under active surveillance use medical facilities elsewhere¹³⁾. It is thus not easy to select medical facilities for active surveillance, though the

final results of the feasibility study should make the decision much easier.

DEGREE OF COMPLETENESS OF CASE REGISTRATION IN THE KCCR

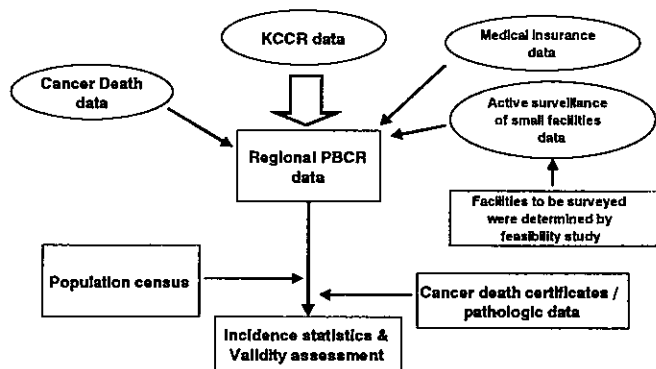
Studies aimed at evaluating and improving the completeness of the KCCR have been under way since 1995¹⁴⁾. Each year, several KCCR hospitals are selected and surveyed; whether any cancer cases have not been reported to the KCCR, the reasons for any such omission, and ways of improving the completeness of reporting can thus be determined. During 1995 and 1996, seventeen hospitals were surveyed and evaluated, but the outcome was disappointing. More than half these hospitals failed to register 5% or more of their patients, and were due for re-survey one or two years later.

SUMMARY

The Korean or 'pillar' model for a population based cancer registry is a new one. The KCCR is the only one of its kind in the world, being neither hospital- nor population-based. It has been running continuously for nearly 20 years (Figure 4).

According to feasibility studies undertaken in five large city areas, the KCCR data file is a reliable basis, as a pillar, for a population-based cancer registry in each area. The main framework of the model for such a registry is the incorporation of data from additionally surveyed cases; the data related to cancer deaths, medical insurance claims, and visit-and-

Figure 4. Schematic Presentation of the Korean Model for PBCR



abstract surveillance of non-KCCR hospitals with a KCCR data file. Continuous efforts to improve the completeness of registration with the KCCR and of active surveillance are still needed, however.

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韓国における地域がん登録—新しいモデル アン・ユンオク

一定の集団(通常は地理的に限定された地域)において発生したすべてのがん症例を登録するのが「地域がん登録」である。すなわち、ある特定集団内で一定期間に同定されたすべてのがん患者についての情報を収集しなければならない。登録の完全性は通常、情報源の利用可能性とデータ収集方法にかかっているが、それでも主要な情報源は医療機関におけるがん患者の診断・治療記録である。データの収集方法は、伝統的に、「能動的、積極的」方法と「受動的、消極的」方法に分類されてきたが、実際に登録室がどちらの方法で運営していくかは、必然的に、その地域の現状—がんに罹患した患者がある時点で医療機関にかかることができるかどうかというような医療体制—、あるいはどのような情報源が利用できるのかに依存してしまう。韓国の医療提供体制は、地区(Locality)、管区(District)、広域(Region)の3段階医療圏紹介制によって特徴づけることができ、例えば、居住している管区や広域以外にある病院で医療を受けたい場合は、医療保険会社の許可が必要となる。

韓国では、1980年7月1日に、公式のがん登録である「中央がん登録プログラム(KCCR)」が発足することにより、ようやくがん登録が開始され、当初、国内全域の47病院の参加があった。15項目に及ぶ患者情報の記入された届出票が、各医療機関より国立医療センター内に設置されたKCCRに送付されるというもので、KCCRでは、これまで途切れることなく継続的に年報を刊行している。開

始後は参加医療機関が年々安定して増加しており、1996年には国内119の大規模病院から約80,000件の症例が登録されている。しかしながら、KCCRが国家主導のがん制圧プログラムの一つであり、国内のほぼすべての大規模教育病院を網羅しているにも関わらず、実際にはがん罹患統計を提供できていない。

1990年に、ソウルの地域がん登録を実施するための調査が開始され、1)KCCRの登録症例と小規模医療施設からの追加登録という二元的な情報源を用いた場合の、ソウル地域における地域がん登録運営の実行可能性、2)登録の完全性や妥当性の評価を含めたソウル地域の全部位がんの罹患データの提供、の2点についての評価が行われた。この結果、韓国内のいくつかの地域に普及可能な地域がん登録のモデルを提示することができた。そして、ソウルの地域がん登録で用いられたプログラムと方法論を、1995年にはプサンに、1996年にはテグ及びクワンジュに、1997年にはさらにインチョンに拡大することとなった。この際、どの地域においてもまず、がん患者の医療利用状況の点からがん登録の実行可能性に関する調査を行い、その結果を受けて、実際に登録を開始するようにした。韓国では、1998年現在、5つの地域がん登録が運営されている。韓国における地域がん登録では、KCCRからの情報の貢献度が大きく、支柱(pillar)のような存在となっているため、このような韓国型の地域がん登録は、「支柱型登録」と呼ぶことができる。この登録方式は現在さらに、完成度を高めつつある。

(地域がん登録全国協議会第7回総会研究会抄録集より引用)