Chapter 2. History of cancer registration

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The early years

The registration of persons suffering from cancer has developed as a slow process with many detours and blind alleys. This chapter briefly summarizes the history of cancer registration; for a full review the reader is referred to Clemmesen (1965) and Wagner (1985).

A first, unsuccessful, cancer census took place in London in 1728 and, up to the beginning of this century, attempts at establishing reliable and comparable mortality or morbidity statistics were abortive and little factual knowledge was gained (Kennaway, 1950). Around the year 1900, critical voices in England and, above all, in Germany demanded improved statistical investigations on the spread of cancer in the population as an indispensable basis for etiological research. Katz (1899) requested a general survey on cancer in Hamburg, and in 1900 an attempt was made to register all cancer patients in Germany who were under medical treatment. Questionnaires were sent to every physician in the country, via the Prussian Ministry of Culture, to record the prevalence on 15 October 1900 (Komitee für Krebsforschung, 1901).

This approach was repeated between 1902 and 1908 in the Netherlands, Spain, Portugal, Hungary, Sweden, Denmark and Iceland. In the report on the survey in Germany, it was noted that "little more than half of the physicians addressed" had filled in and returned the questionnaires (von Leyden *et al.*, 1902). The survey was regarded a failure, as were similar attempts to obtain country-wide cancer morbidity statistics in Heidelberg (in 1904) and Baden (in 1906) (Hecht, 1933). In the 1905 report of the Imperial Cancer Research Fund in London, Bashford and Murray (1905) advised against a cancer census, finding that the effort in Germany had left cancer problems much where they were. Because of the unsatisfactory participation in most of these surveys, Wood (1930) suggested that cancer should be made a notifiable disease in the USA and that compulsory registration of all cancer cases should be introduced. However, cancer registration had started on a pilot basis in the state of Massachusetts in 1927 and was considered a failure, as only about one third of the cancer cases were reported (Hoffman, 1930).

The continuous recording of individuals with cancer began in Mecklenburg in 1937 with the aim of producing cancer morbidity statistics (Lasch, 1940). This represented a methodological progress, since reporting by name made it possible for the first time to eliminate multiple registrations and to determine individual outcomes. All medical practitioners, hospitals and pathological institutes received registration cards or forms, which had to be filled in for cancer patients and sent to the statistical office of Rostock every two weeks. There the reports were checked and entered into a card index. Missing reports were requested by daily reminders over the telephone. This registration scheme seems to have worked fairly well, as indicated by the rate of coverage, which in 1937–38 was about 200 new patients per 100 000 inhabitants (Wagner, 1985). Following this favourable experience, similar investigations were instituted in Saxony-Anhalt, in Saarland and in Vienna in 1939. They soon had to be discontinued, however, because of the political developments.

At about the same time, attempts were made to collect cancer incidence data in *ad hoc* morbidity surveys in the United States of America. All cases of cancer were recorded during one calendar year in 10 metropolitan areas in 1937–38; this national cancer survey was repeated in 1947–48 and 1969–71. The sole purpose of these early cancer surveys in the USA and Europe was the acquisition of data about morbidity, mortality, and prevalence of the different forms of cancer. The fate of the cancer patients covered by these investigations was unknown. It was, therefore, decided in advance that the third national cancer survey in the USA would be the last of its kind, since a continuous registration was considered superior for studies of end results (Haenszel, 1975).

Modern developments

The oldest example of a modern cancer registry is that of Hamburg, which was started with the idea that cancer control involves not only medical and scientific, but also public health and economic aspects. In 1926, an after-care organization for cancer patients was founded on a private basis. From 1929, it obtained official status as the follow-up patient care service of the Hamburg Public Health Department (Bierich, 1931; Sieveking, 1930, 1933, 1935, 1940). Three nurses visited hospitals and medical practitioners in Hamburg at regular intervals. They recorded the names of new cancer patients and transferred data to a central index in the health department. The card index was in turn compared once a week with official death certificates, and formed the basis of the Hamburg Cancer Registry (Keding, 1973).

Population-based cancer registration with an epidemiological and ecological objective started in the USA in 1935, when a division of cancer research was formed in the Connecticut State Department of Health "to make investigations concerning cancer, the prevention and treatment thereof and the mortality therefrom, and to take such action as it may deem will assist in bringing about a reduction in the mortality due thereto". The Connecticut Tumor Registry began operation on a statewide basis in 1941, registering cases retrospectively back to 1935 (Griswold *et al.*, 1955; Connelly *et al.*, 1968). Further cancer registries were established in the USA and Canada in the early 1940s (Stocks, 1959; Barclay, 1976).

The Danish Cancer Registry was founded in 1942 under the auspices of the Danish Cancer Society and is the oldest functioning registry covering a national population. Cases were reported by physicians on a voluntary basis with the support of the Danish Medical Association, while the National Board of Health assisted by

Table 1. Population-based cancer registries established before 1955

Country (region)	Year of establishment	Notification
FR Germany (Hamburg)	1929	Voluntary
USA (New York State)	1940	Compulsory
USA (Connecticut)	1941	Compulsory (since 1971)
Denmark	1942	Compulsory (since 1987)
Canada (Saskatchewan)	1944	Compulsory
England and Wales (S.W. Region)	1945	Voluntary
England and Wales (Liverpool)	1948	Voluntary
New Zealand	1948	Compulsory
Canada (Manitoba)	1950	Voluntary
Yugoslavia (Slovenia)	1950	Compulsory
Canada (Alberta)	1951	Compulsory
USA (El Paso)	1951	Voluntary
Hungary (Szabolcs, Miskolc, Vas)	1952	Compulsory
Norway	1952	Compulsory
USSR	1953	Compulsory
German Democratic Republic	1953	Compulsory
Finland	1953	Compulsory (since 1961)
Iceland	1954	Voluntary

giving full access to death certificates and all mortality data. The task of the registry was outlined as the collection of data serving as a basis: (*a*) for an individual follow-up of patients; (*b*) for reliable morbidity statistics with a view to an accurate estimate of therapeutic results; and (*c*) for an accurate evaluation of variations in incidence of malignant neoplasms, secular as well as geographical, occupational etc. (Clemmesen, 1965). From the mid-1940s, cancer registries were started up in a number of countries, as listed in Table 1.

Probably the most important impetus for the worldwide establishment of cancer registries came from a conference that took place in Copenhagen in 1946 upon the initiative of Dr Clemmesen, Director of the Danish Cancer Registry (Schinz, 1946). A group of 12 internationally leading experts in the field of cancer control recommended the worldwide establishment of cancer registries to the Interim Commission for the World Health Organization (Clemmesen, 1974). They suggested that:

(*a*) great benefit would follow the collection of data about cancer patients from as many different countries as possible;

(*b*) such data should be recorded on an agreed plan so as to be comparable;

(*c*) each nation should have a central registry to arrange for the recording and collection of such data;

(*d*) there should be an international body whose duty it should be to correlate the data and statistics obtained in each country.

Four years later, the World Health Organization established a subcommittee on the registration of cases of cancer and their statistical presentations which worked out recommendations for the establishment of cancer registries (Stocks, 1959). At the

International Symposium on Geographical Pathology and Demography of Cancer, arranged by the International Union Against Cancer (UICC) in 1950, which represented another milestone, the need for the enumeration of all new cases of cancers in a defined area was emphasized (Clemmesen, 1951). On the basis of the recommendations of the Symposium, UICC established a Committee on Geographical Pathology. In 1965, the International Agency for Research on Cancer (IARC) was established as a specialized cancer research centre of the World Health Organization.

As a natural consequence of this development, the International Association of Cancer Registries (IACR) was formed in 1966 in Tokyo. The IACR serves as a membership organization for cancer registries "concerned with the collection and analysis of data on cancer incidence and with the end results of cancer treatment in defined population groups". The association collaborates closely with the IARC.

The historical development of cancer registration can thus be clearly traced. About 200 population-based cancer registries exist in various parts of the world (Coleman & Wahrendorf, 1989). In addition, there are approximately 34 registries that cover only the registration of specific age groups or cancer sites (e.g., childhood tumours in Mainz, Germany, Oxford, UK, and Australia; gastrointestinal cancers in Dijon, France). In addition, a large number of hospitals have developed hospital-based cancer registration (see Chapter 13).