

Chapter 3. Purposes and uses of cancer registration

O. M. Jensen and H. H. Storm

*Danish Cancer Registry, Danish Cancer Society,
Rosenvaengets Hovedvej 35, PO Box 839, Copenhagen, Denmark*

The cancer registry is an essential part of any rational programme of cancer control (Muir *et al.*, 1985). Its data can be used in a wide variety of areas of cancer control ranging from etiological research, through primary and secondary prevention to health-care planning and patient care, so benefiting both the individual and society. Although most cancer registries are not obliged to do more than provide the basis for such uses of the data, cancer registries possess the potential for developing and supporting important research programmes using the information which they collect.

The main objective of the cancer registry is to collect and classify information on all cancer cases in order to produce statistics on the occurrence of cancer in a defined population and to provide a framework for assessing and controlling the impact of cancer on the community. This purpose is as valid today as it was 50 years ago, when the first functioning registries were established (Chapter 2) and when the registry “was obliged to do nothing more than to establish a basis for research” (Clemmesen, 1965).

The collection of information on cancer cases and the production of cancer statistics are only justified, however, if use is made of the data collected. Cancer registry information may be used in a multitude of areas, and the value of the data increases if comparability over time is maintained. In this chapter, examples are given of the uses of cancer registry data in epidemiological research, in health care planning and monitoring, and in certain other areas.

The emphasis will differ from registry to registry according to local circumstances and interests. In general terms, the data become useful for more and more purposes as they are accumulated over longer periods of time.

Epidemiological research

Cancer epidemiologists use their knowledge of the distribution of cancer in human populations to search for determinants of the disease. Evidently, the cancer registry provides a crucial basis for epidemiology since it holds information on the distribution of cancer, including non-fatal cases. However, in addition to the production of incidence figures, the collection of records of cancer patients from a defined population facilitates the in-depth study of cancer in individuals whilst minimizing the selection bias found in clinical series. In the following, a distinction is

made between the use of the cancer register for descriptive studies and for analytical studies. It must be emphasized, however, that these two aspects of epidemiology are complementary and often overlap.

Descriptive studies

The cancer registry's enumeration of cancer cases in a defined population permits assessment of the scale of the cancer problem in terms of the number of new cases and the computation of incidence rates. The type of statistics emerging from the cancer registry should be adapted to local needs and interests, bearing in mind the importance of international comparability (for examples and computations see Chapters 10–12). Ability to calculate rates depends on the availability of population denominators. Indeed, the information on cancer cases should be collected and classified so that it accords with the population statistics produced by the statistical office (Chapter 6). Basic, descriptive statistics should be produced and presented for diagnostic entities (Chapter 7) mainly according to topography of the tumour. Cancers of most sites are rare, and it may therefore be necessary to aggregate cases over several years in order to minimize random fluctuations in the numbers (Chapters 10 and 11).

In addition to incidence figures, statistics on the prevalence of cancer complete the basic information of cancer occurrence in the community. Such statistics may be estimated from knowledge of incidence and survival (MacMahon & Pugh, 1972; Hakama *et al.*, 1975). However, when a registry has been in operation for many years, so that all patients diagnosed with cancer before the establishment of the registry have died, the prevalent cases may simply be enumerated from the registry file, provided, of course, that the registry receives information on deaths and emigrations of cases registered (Danish Cancer Registry, 1985). Table 1 gives examples of basic cancer registry statistics. A more detailed description of the reporting of cancer registry results is given in Chapter 10.

Comparison of cancer occurrence in various populations may provide clues to etiology, and the demonstration of variation in incidence (and mortality) has made an important contribution to the recognition of the environmental origin of many cancers, thus pointing to the possibilities for prevention (Higginson & Muir, 1979; Doll & Peto, 1981). Statistics by age and sex show widely different patterns and variations between sites (Figure 1). Such basic features of cancer incidence may not always be easily understood and explained, but they should provoke the epidemiologist's curiosity and are useful in the generation of etiological hypotheses.

The contribution of cancer registries to our knowledge of international variation in cancer incidence (Table 2) is an important but often overlooked purpose of registering cancer cases. Systematic comparisons are published in the monographs *Cancer Incidence in Five Continents* (Doll *et al.*, 1966; Muir *et al.*, 1987; Waterhouse *et al.*, 1970, 1976, 1982). The stimulation of etiological ideas from such geographical comparisons of cancer incidence may be enhanced by correlation with statistics on potential risk factors (e.g., Armstrong & Doll, 1975). The international pattern of cancer can also point to regions of the world where a research effort may be particularly rewarding, e.g. comparisons of human papilloma virus infection in

Table 1. Cancer statistics for Denmark 1982, for selected sites. Data from Danish Cancer Registry (1985)

Tumour site	Males					Females				
	No. of new cases	Incidence per 100 000		No. of prevalent cases	Prevalence per 100 000	No. of new cases	Incidence per 100 000		No. of prevalent cases	Prevalence per 100 000
		Crude	Age-stand. ^a				Crude	Age-stand. ^a		
All sites	11 533	457.4	297.6	49 471	1962.0	11 723	451.9	270.2	80 744	3112.5
Buccal cavity and pharynx	334	13.2	9.2	3128	124.1	144	5.6	3.1	1218	47.0
Stomach	547	21.7	13.1	1037	41.1	353	13.6	6.2	725	27.9
Lung	2209	87.6	56.5	2401	95.2	779	30.0	18.5	901	34.7
Breast	27	1.1	0.7	125	5.0	2469	95.2	63.8	21 318	821.8
Cervix uteri	—	—	—	—	—	638	24.6	18.9	12 014	463.1
Testis	230	9.1	8.2	2895	114.8	—	—	—	—	—
Melanoma of skin	204	8.1	6.3	1406	55.8	273	10.5	7.8	2973	114.6
Hodgkin's disease	74	2.9	2.4	732	29.0	52	2.0	1.7	521	20.1

^a World Standard population

Table 2. Worldwide variation in incidence of cancer at various sites.Rates based on less than 10 cases are excluded. Data from Muir *et al.* (1987)

Site	ICD-9	Males			Females		
		Highest	Lowest	Ratio of highest to lowest	Highest	Lowest	Ratio of highest to lowest
Lip	(140)	Canada, Newfoundland 15.1	Japan, Osaka 0.1	151.0	Australia, South 1.6	U.K. England & Wales 0.1	16.0
Oral cavity	(143-14)	France, Bas-Rhin 13.5	Japan, Miyagi 0.5	27.0	India, Bangalore 15.7	Japan, Miyagi 0.2	78.5
Nasopharynx	(147)	Hong Kong 30.0	UK, South Wales 0.3	100.0	Hong Kong 12.9	USA, Iowa 0.1	129.0
Oesophagus	(150)	France, Calvados 29.9	Romania, County Cluj 1.2	24.9	India, Poona 12.4	Czechoslovakia, Slovakia 0.3	41.3
Stomach	(151)	Japan, Nagasaki 82.0	Kuwait, Kuwaitis 3.7	22.2	Japan, Nagasaki 36.1	USA, Iowa 3.0	12.0
Colon	(153)	USA, Connecticut, whites 34.1	India, Madras 1.8	18.9	USA, Detroit, blacks 29.0	India, Nagpur 1.8	16.1
Rectum	(154)	FR Germany, Saarland 21.5	Kuwait, Kuwaitis 3.0	7.2	FR Germany, Saarland 13.2	India, Madras 1.3	10.2
Liver	(155)	China, Shanghai 34.4	Canada, Nova Scotia 0.7	49.1	China, Shanghai 11.6	Australia, N.S. Wales 0.4	29.0
Pancreas	(157)	USA, Los Angeles, Koreans 16.4	India, Madras 0.9	18.2	USA, Alameda, blacks 9.4	India, Bombay 1.3	7.2
Larynx	(161)	Brazil, São Paulo 17.8	Japan, Miyagi 2.2	8.1	USA, Connecticut: Black 2.7	Japan, Miyagi 0.2	13.5
Lung	(162)	USA, New Orleans, blacks 111.0	India, Madras 5.8	19.0	New Zealand, Maoris 68.1	India, Madras 1.2	56.8
Melanoma	(172)	Australia, Queensland 30.9	Japan, Osaka 0.2	154.5	Australia, Queensland 28.5	India, Bombay 0.2	142.5
Other skin	(173)	Australia, Tasmania 167.2	India, Madras 0.9	185.8	Australia, Tasmania 89.3	Switzerland, Zurich 0.6	148.8

Breast	(175/174)	Brazil, Recife 3.4	Finland 0.2	17.0	Hawaii, Hawaiian 93.9	Israel, non-Jews 14.0	6.7
Cervix uteri	(180)	—	—	—	Brazil, Recife 83.2	Israel: non-Jews 3.0	27.7
Corpus uteri	(182)	—	—	—	USA, San Francisco Bay Area, whites 25.7	India, Nagpur 1.2	21.4
Ovary, etc.	(183)	—	—	—	NZ, Pacific Polyn. Isl. 25.8	Kuwait, Kuwaitis 3.3	7.8
Prostate	(185)	USA, Atlanta: blacks 91.2	China, Tianjin 1.3	70.2	—	—	—
Testis	(186)	Switzerland, Basle 8.3	China, Tianjin 0.6	13.8	—	—	—
Penis, etc.	(187)	Brazil, Recife 8.3	Israel: All Jews 0.2	41.5	—	—	—
Bladder	(188)	Switzerland, Basle 27.8	India, Nagpur 1.7	16.4	Kuwait, non-Kuwaitis 8.5	India, Poona 0.8	10.6
Kidney, etc.	(189)	Canada, NWT and Yukon 15.0	India, Poona 0.7	21.4	Iceland 7.6	India, Poona 0.6	12.7
Brain	(191/192)	NZ, Pacific Polyn. Isl. 9.7	India, Nagpur 1.1	8.8	Israel, born Israel 10.8	India, Madras 0.8	13.5
Thyroid	(193)	Hawaii, Chinese 8.8	Poland, Warsaw City 0.4	22.0	Hawaii, Filipinos 18.2	India, Nagpur 1.0	18.2
Lympho- sarcoma	(200)	Switzerland, Basel 9.2	France, Calvados 0.9	10.2	Australia, Cap. Territ. 7.2	Japan, Miyagi 0.4	18.0
Hodgkin's disease	(201)	Canada, Quebec 4.8	Japan, Miyagi 0.5	9.6	Switzerland, Neuchatel 3.9	Japan, Osaka 0.3	13.0
Multiple myeloma	(203)	USA, Alameda, blacks 8.8	Philippines, Rizal 0.4	22.0	USA, Connecticut, blacks 7.4	China, Shanghai 0.4	18.5
Leukaemia	(204-8)	Canada, Ontario 11.6	India, Nagpur 2.2	5.3	Pacific Polyn. Isl. 10.3	India, Madras 1.1	9.4

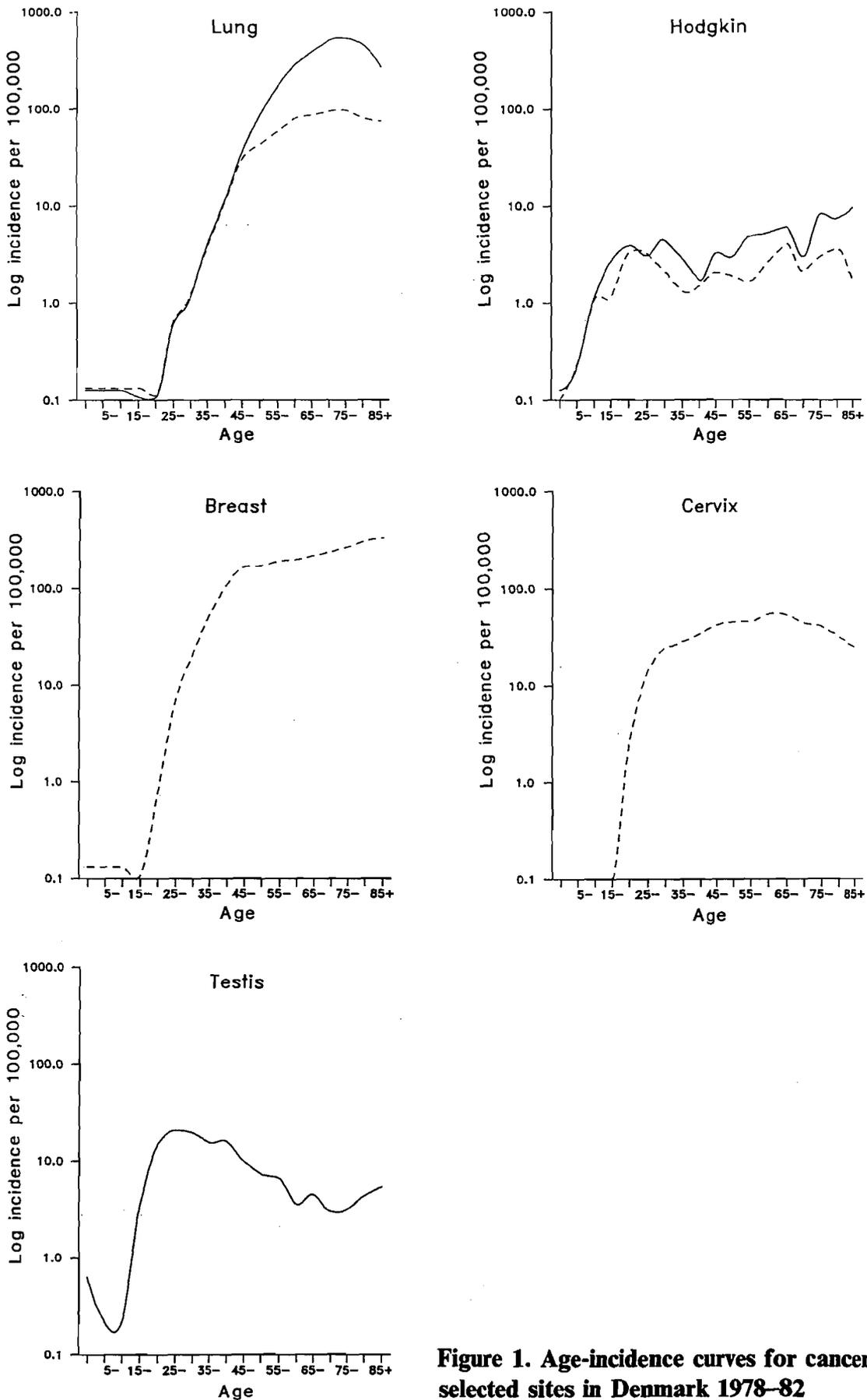


Figure 1. Age-incidence curves for cancers of selected sites in Denmark 1978-82

Table 3. Urban-rural rate-ratios in cancer incidence in males (M) and females (F) for selected sites and areas around 1980.Data from Muir *et al.* (1987)

Tumour site	France, Doubs		Norway		Japan, Miyagi Prefecture	
	M	F	M	F	M	F
Oesophagus	0.8	0.6	1.7	1.3	1.0	1.0
Stomach	1.2	1.1	1.0	1.0	1.0	1.0
Colon	1.0	1.2	1.2	1.1	1.3	1.4
Rectum	1.2	0.9	1.2	1.2	1.1	1.1
Larynx	1.3	0.8	1.6	2.0	1.1	0.7
Lung	1.4	1.7	1.6	1.8	1.1	1.1
Melanoma of skin	1.1	0.9	1.3	1.3	1.4	2.0
Breast	—	1.1	—	1.2	—	1.3
Cervix uteri	—	1.0	—	1.3	—	1.5
Testis	0.9	—	1.2	—	1.1	—
Bladder	1.1	1.2	1.3	1.6	1.1	1.8
Hodgkin's disease	0.7	0.7	1.0	1.1	0.4	1.0

Table 4. Age-standardized^a incidence rates per 100 000 for selected sites in Miyagi, Japan, and in Japanese and whites in the USA (San Francisco Bay Area) around 1980.Data from Muir *et al.* (1987)

Tumour site	Males			Females		
	Miyagi	Japanese (Bay Area)	White (Bay Area)	Miyagi	Japanese (Bay Area)	White (Bay Area)
Stomach	79.6	24.3	10.4	36.0	10.8	4.8
Colon	9.8	29.8	30.6	9.4	20.8	23.7
Rectum	9.9	13.6	15.4	7.4	12.4	11.0
Lung	29.6	33.0	65.8	8.7	12.1	33.3
Breast	—	—	—	22.0	48.9	87.0
Cervix uteri	—	—	—	10.0	5.9 ^b	8.9
Corpus uteri	—	—	—	2.8	19.6	25.7
Ovary	—	—	—	4.2	8.8	12.9
Prostate	6.3	16.5	50.0	—	—	—

^a World standard population.^b Number based on less than ten cases

Greenland and Denmark with a five- to six-fold difference in cervical cancer incidence (Kjaer *et al.*, 1988).

Cases of cancer may be classified according to place of residence at the time of diagnosis, and may thus serve to describe geographical differences within the registration area. The incidence rates can be tabulated, for example, by county or municipality and the rates can be displayed in cancer atlases, as shown in Figure 2 (Glattre *et al.*, 1985; Kemp *et al.*, 1985; Carstensen & Jensen, 1986; Jensen *et al.*,

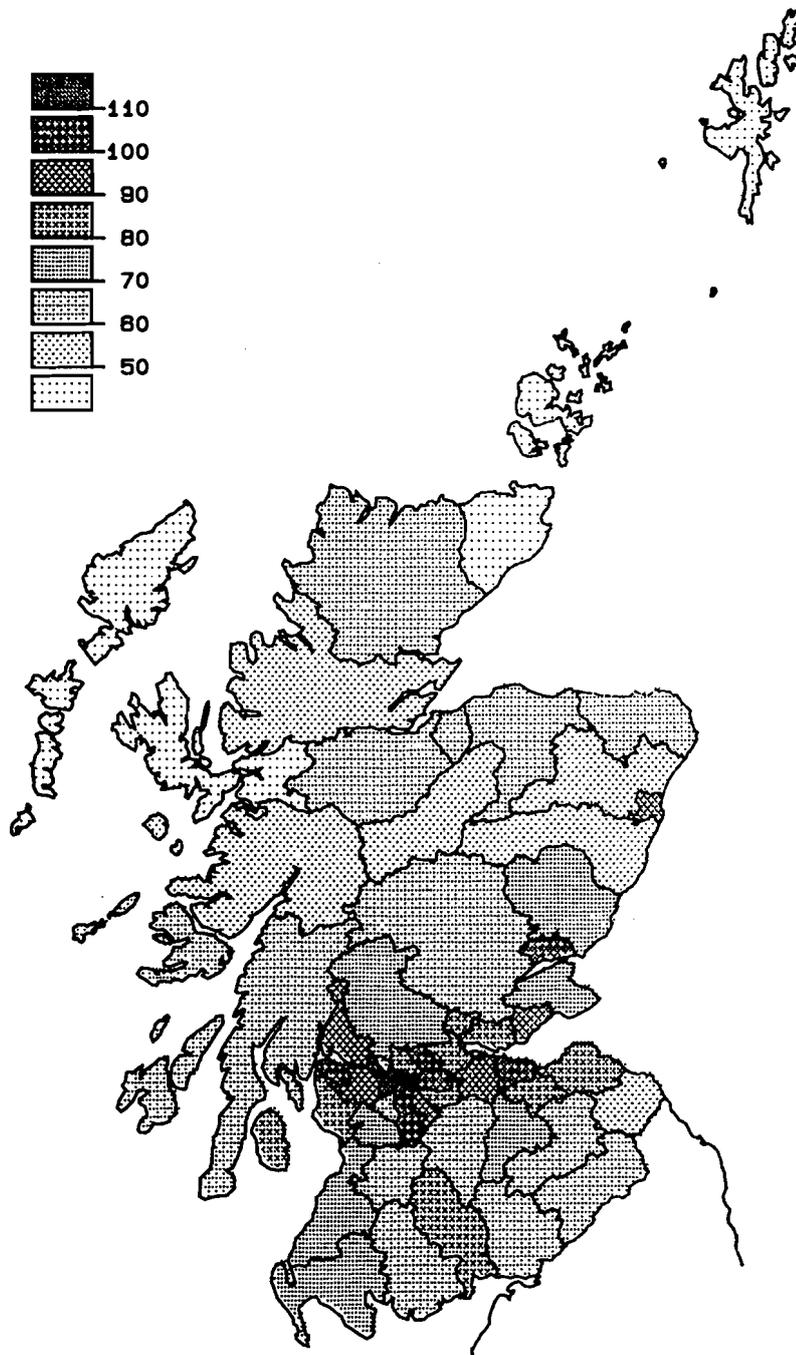


Figure 2. Map of lung cancer incidence in males in Scotland 1975–80

From Kemp *et al.* (1985). The figures in the key are the age-standardized incidence rates (world standard) per 100 000

1988). Regions of a country may also be aggregated according to population density. Incidence rates can then be tabulated, for example, for urban and rural areas (Table 3) or for areas with other common characteristics such as way of life (Teppo *et al.*, 1980).

Ethnic groups that live in the same area may exhibit differences in incidence, for example, in Singapore (Lee *et al.*, 1988), as shown in Figure 3. Immigrants to Israel from various parts of the world show large differences in cancer incidence (Steinitz *et al.*, 1989). The contrasting cancer patterns of Japanese in Japan and Japanese

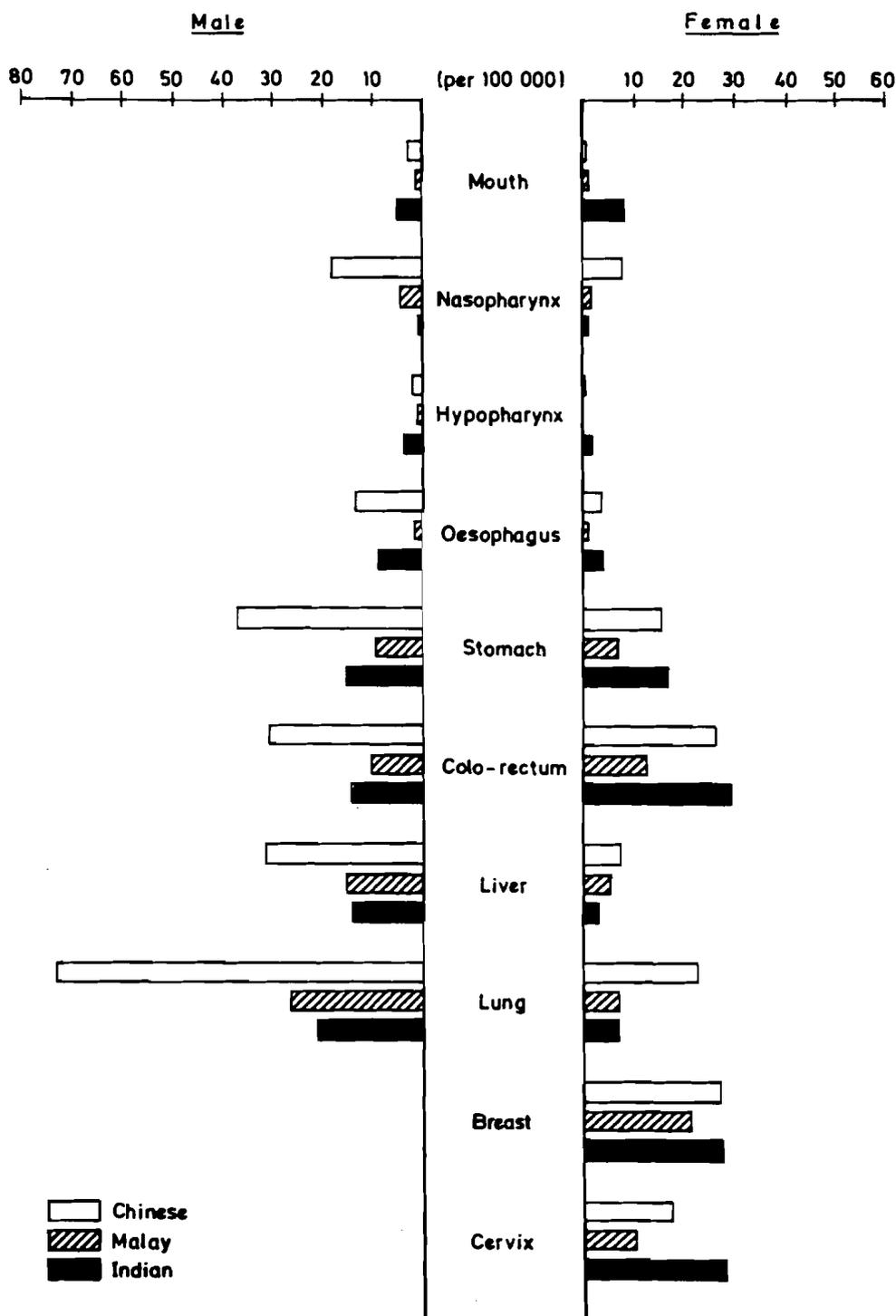


Figure 3. Age-standardized incidence rates for selected sites by sex and ethnic group, Singapore 1978-82

From Lee *et al.* (1988).

immigrants in the USA are now directly available from routine statistics on cancer occurrence (Muir *et al.*, 1987), as shown in Table 4. Furthermore, opportunities may exist for a registry to compare cancer incidence rates for different occupational groups, socioeconomic classes, or religious groups either alone or in combination.

The description and monitoring of time trends in the incidence of cancer is an

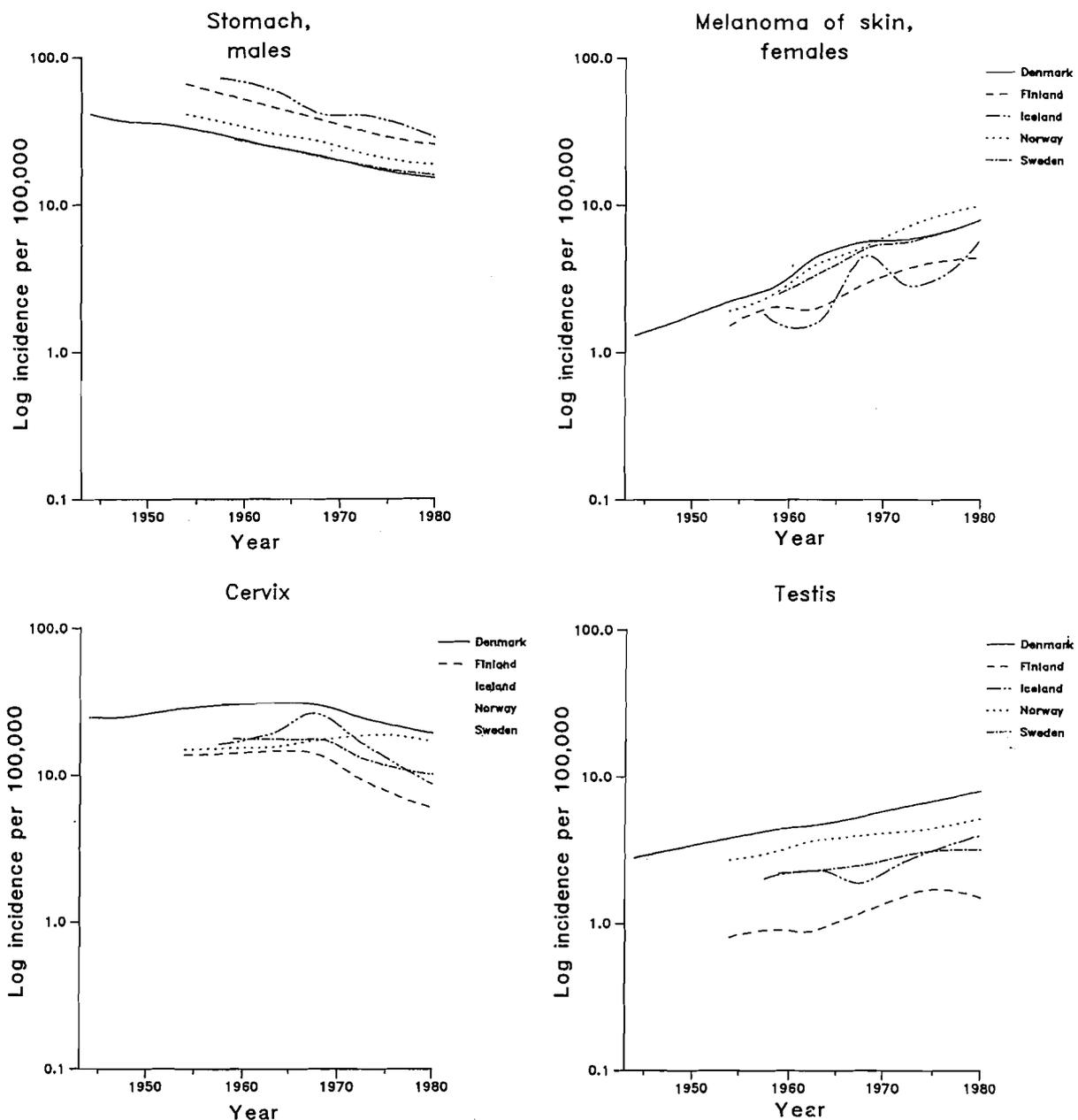


Figure 4. Trends in incidence of stomach cancer, malignant melanoma of the skin, testis cancer and cervical cancer in the Nordic countries
From Hakulinen *et al.* (1986)

important objective of the cancer registry (Hakulinen *et al.*, 1986), since mortality is influenced by patient survival and may not reflect trends in cancer risk, e.g., childhood leukaemia, testis cancer, Hodgkin's disease. Trends over time may point to an altered influence of risk factors in the population like the increase in malignant melanoma of the skin in many populations (Jensen & Bolander, 1981) or the decreasing incidence of stomach cancer (Jensen, 1982). Examples of time trends in the Nordic countries are given in Figure 4. Monitoring of cancer trends is equally important for the evaluation of primary and secondary preventive measures as well as for planning purposes in the health care system (see below). The effects of primary prevention (reduced exposure to risk factors, such as tobacco smoking) are best

interpreted by observing trends in incidence while the best measure for estimating the effects of secondary prevention (e.g., breast cancer screening) is mortality statistics.

The production of statistics on cancer occurrence in population groups is much enhanced in registries where possibilities exist for the linkage of cancer registry records within the registry itself or with records from other sources, often collected for different purposes. Cancer registries record tumours, and registries thus contain information on the development of multiple primary cancers in a person. By the linkage of tumour records for a given individual, registries have played a substantial role in describing the association of different cancers in individuals (Curtis *et al.*, 1985; Storm *et al.*, 1985; Teppo *et al.*, 1985). The linkage of cancer registry records with external data sources such as census data has been undertaken in particular in the Nordic countries (Denmark, Finland, Iceland, Norway and Sweden), but also in North America. The primary purpose has been the investigation of occupational cancer (Lyng & Thygesen, 1988). Such linked data files provide clear advantages over occupational statistics where the numerator and the denominator are derived from different sources.

Analytical studies

Associations of a statistical nature from descriptive studies rarely imply causality, and hypotheses emerging from such observations must be subjected to in-depth studies in humans, and may be supplemented by studies in animals. Cancer registries form a valuable data base for such analytical studies owing to the availability of information on identified individuals.

The ability to link cancer registry records with other data files is essential for the registry's role in analytical studies. This of course requires uniform identifying information in both the registry and the external data source (Acheson, 1967). Cancer registry information has served as an endpoint in numerous cohort studies to evaluate risks associated with occupational exposures, drug-taking, smoking, diet etc. The longer the registry has been in operation and the larger the area it covers (preferably a whole country), the more useful will its data be for cohort studies.

As in the use of cancer registry data in prospective follow-up studies, the cancer registry facilitates the assessment of outcome of intervention trials. For example, the incidence of cancer of the lung and other sites has been monitored following administration of beta-carotene and tocopherol supplementation in Finnish men who are heavy smokers.

The case-control study, where exposures are compared between cancer patients and disease-free controls, has become a widely used method for the investigation of risk factors. In general, cancer registries are not regarded as well suited for the conduct of such studies; delays in reporting and processing of cases limit the usefulness of the cancer registry for case-control studies with continuous case recruitment. The main value of the registry in such investigations is to evaluate the completeness and representativeness of the case series. The cancer registry has, however, proved to be a valuable point of departure for case-control studies. Data recorded routinely by the cancer registry can thus be analysed by case-control methodology. This is particularly useful when denominators are not available, e.g.,

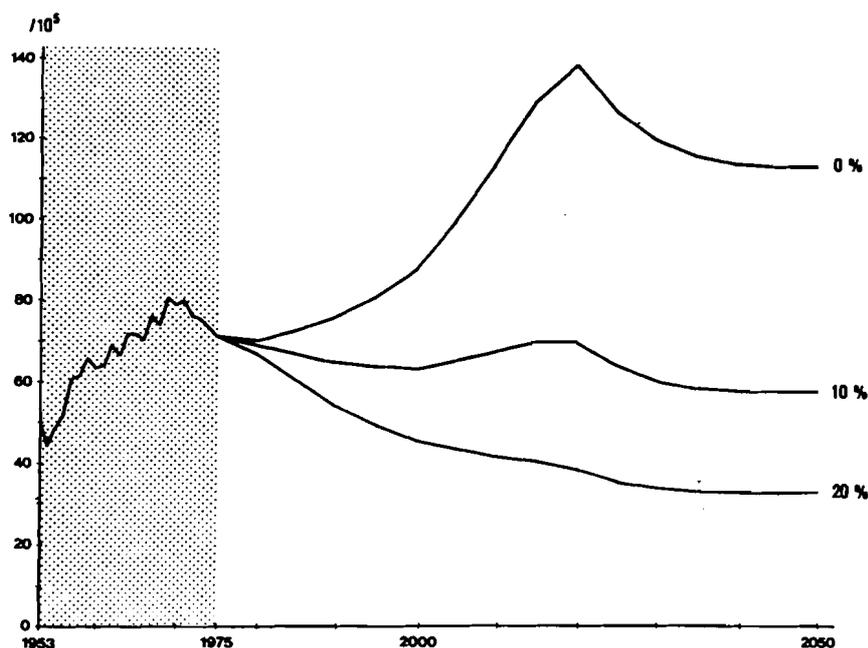


Figure 5. Age-adjusted incidence rates (per 100 000 person-years) for lung cancer in males in Finland 1953–75 and three forecasts for the rates in 1980–2050

The forecasts have been derived by a simulation model with the following assumptions: in each consecutive five-year period in 1976–2050, 30% of non-smokers aged 10–14, 15% of those aged 15–19, and 5% of those aged 20–24 years will start smoking; 0%, 10% or 20%, respectively, of the smokers in each category will stop smoking in each consecutive five-year period. The distribution of amount of adopted smoking by age is the same as for smokers in 1975 who were five years older.

using information on place of birth (Kaldor *et al.*, 1990) or occupation (Jensen, 1985). The Registry can also draw exposure information from existing records, in particular hospital records, since it often records hospital chart numbers. Cancer registries have thus contributed substantially to studies of cancer risks associated with radiotherapy and other cancer treatments (Day & Boice, 1983; Kaldor *et al.*, 1987). By nesting case-control studies within a cohort of women with cervical cancer and using patient information in cancer registries to gain access to medical records, it has been possible to determine radiation dose-response relationships for leukaemia (Storm & Boice, 1985; Boice *et al.*, 1987), and for a large number of solid tumours (Boice *et al.*, 1988). The cancer registry can also be used as a source of cases (and controls) for studies seeking exposure information from other records, from the patients, or from their relatives. In the Danish Cancer Registry, occupational histories have thus been compared for nasal cancer cases and controls with other cancers to investigate the possible risk associated with formaldehyde exposure (Olsen & Asnaes, 1986).

Health-care planning and monitoring

The cancer registry provides statistical information on the number of cases in the population. This may be used for the planning and establishment of cancer treatment and care facilities directed towards various types of cancer. Geographical differences in cancer occurrence may be taken into account, and so may time trends in the incidence of cancer. Knowledge of trends may then be used for the projection of future incidence rates, case loads, and needs for treatment facilities (Hakulinen &

Pukkala, 1981), as shown in Figure 5. Cancer incidence information has been used for the planning of radiotherapy services in the United Kingdom (Wrighton, 1985) and the Netherlands (Crommelin *et al.*, 1987). Knowledge of the incidence and distribution of childhood tumours in England and Wales has proved valuable for the planning of specialized paediatric oncological services (Wrighton, 1985). The evaluation of patient demands on treatment facilities may be deduced from registry data and projections, while statistics of a more administrative nature (e.g., bed occupancy) normally fall outside the scope of the population-based cancer registry. For a detailed review, see Parkin *et al.* (1985b).

Patient care

Care provided to the individual patient is an integral part of the health care system. Cancer registries contribute only indirectly to patient care, for example, by describing pathways of referral or by assisting treating physicians with follow-up of their patients by reminding them of the anniversary date of diagnosis. A more direct contribution is the management of cancer patient care programmes, established in some areas (e.g., Sweden) to ensure that all patients with a given cancer are given state-of-the-art diagnosis and treatment (Möller, 1985). Such activities consist of agreed means of referral, diagnosis, classification and staging, treatment, and follow-up of patients with specific neoplastic disease. The monitoring of patient survival is an integral part of a care programme.

Survival

Most cancer registries follow up each patient for death, and collect information on date and cause of death. An important indirect contribution to patient care and to health-care planning is the monitoring of population-based survival rates (Cancer Registry of Norway, 1980; Hakulinen *et al.*, 1981; Young *et al.*, 1984). This supplements the more detailed information often available from specialized hospitals. Registry information may be used for the monitoring of survival in subsections of the population (e.g., by geographical areas, age groups, sex, socioeconomic groups), as well as over time, as shown in Figure 6. If true differences are found, diagnostic and treatment facilities may be directed to parts of the population that experience less favourable survival.

The influence of various treatment modalities on cancer cure and survival is best evaluated by randomized clinical trials. These require *ad hoc* design, and the cancer registry's role is often limited to providing background information on the number of new cases, stage distribution and population-based survival. The cancer registry may play a more active part in such trials by assisting with data management and follow-up of patients, which are reported to the registry as part of its normal operations.

Screening

Examination of asymptomatic persons to detect cancer at an early stage is becoming increasingly important in the control of certain malignant diseases. Registries have played a crucial role in demonstrating the effect which cervical cancer screening programmes have in lowering the incidence of cervical cancer (Hakama, 1982;

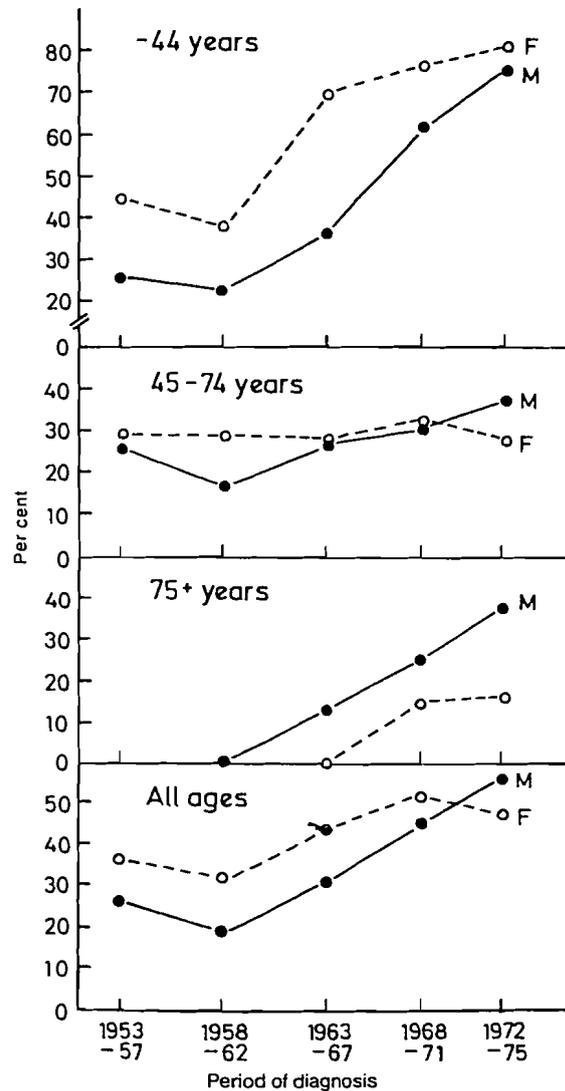


Figure 6. Five-year relative survival rates for Hodgkin's disease in Norway
From Cancer Registry of Norway (1980)

Lynge, 1983; Parkin *et al.*, 1985a) by comparing trends in cervical cancer between areas where such screening has been practised with different intensity, e.g., Finland versus Norway (see Figure 4). While the effect of cervical cancer screening can be monitored with invasive cancer incidence trends, the effect of early detection and treatment of cancerous lesions in other organs must be evaluated by monitoring trends in mortality, e.g., screening for breast cancer. In the early phases of such programmes, cancer registries may serve to monitor changes in stage distribution.

Other aspects of cancer registration

Many of the uses of data collected by the cancer registry are an integral part of its own operations. In addition to registering cases and using its data, the registry becomes an important data resource for hospital departments and research institutions to whom the cancer registry may provide lists of cancer patients for *ad hoc* statistics. Such uses of the registry's data by external researchers should be encouraged, since the registry is normally unable to exploit all aspects of the data, and the dissemination of data

increases knowledge about cancer registration and its usefulness. Intensive and extensive use of the registry's data also tends to maintain and improve their quality.

By virtue of their duties, the cancer registry's staff often have considerable expertise in disease registration, epidemiology and public health questions. The cancer registry may thus serve in the teaching not just of cancer epidemiology, but also of epidemiological methods. For teaching purposes, the registry has the advantage of possessing material for graduate as well as postgraduate training.

The registry's staff may also be called upon to provide advice both to authorities in the health field and to the public on questions of disease registration, cancer causation, cancer prevention and planning of cancer care.