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Cancer Incidence in The Netherlands in 1989 and 1990: First Results of the Nationwide Netherlands Cancer Registry

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The first results are presented of the newly established Netherlands Cancer Registry, which covers the whole Dutch population (approximately 15 million people). The registry receives data on incident cancer cases from nine autonomous regional cancer registries. Notification occurs primarily through the national registry of all pathology and haematology departments, with additional reporting by medical records' departments of all hospitals. Data on cancer patients are abstracted directly from the medical records by trained registration clerks. In the years 1989–1990, the most common cancer sites among males were cancers of the lung, prostate and colon. For females, breast cancer ranked first, followed by cancer of the colon and lung. A comparison with age-adjusted (world standard population) incidence rates reported by other western cancer registries showed a relatively high incidence of lung cancer among males (72.9 per 100 000) and breast cancer among females (76.2 per 100 000). Through its near completeness and the high quality of the registered data, the Netherlands Cancer Registry offers excellent opportunities for epidemiological and clinical research.

Key words: neoplasms, registries, incidence, The Netherlands
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INTRODUCTION

THE FIRST attempts to establish a national cancer registry in The Netherlands were initiated in the early 1950s by the Dutch government and the Dutch Cancer Society. Unfortunately, funding was withdrawn in the 1970s because of suspected incompleteness and infrequent use of the registry data for research. Only the Eindhoven Cancer Registry managed to survive without financial support from outside sources [1, 2]. In the mid-1980s, this registry was included in a new system for a nationwide population-based cancer registry. A decentralised structure with nine autonomous regional registries and one national registry was established. The regional cancer registries are housed in Comprehensive Cancer Centres, which were established in The Netherlands during the late 1970s and early 1980s, with the primary task of improving care for cancer patients. They are funded through health insurance. Figure 1 shows the regions covered by the nine Comprehensive Cancer Centres. The Association of Comprehensive Cancer Centres, formerly the Coordinating Council of Comprehensive Cancer Centres, has final responsibility for the national cancer registry.

The Netherlands Cancer Registry now has incidence data for the years 1989 and 1990, which have been published in two reports [3, 4]. In this paper, average age-standardised incidence rates are presented for several major cancer sites and compared to those in other Northwestern European and North American countries.

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Figure 1. Regions of the nine Comprehensive Cancer Centres in The Netherlands. 1. Middle Netherlands (IKMN); 2. Amsterdam (IKA); 3. Stedendriehoek Twente (IKST); 4. Northern Netherlands (IKN); 5. East (IKO); 6. Limburg (IKL); 7. South (IKZ); 8. Rotterdam (IKR); 9. West (IKW).

PATIENTS AND METHODS

Methods of cancer registration

The nine regional cancer registries receive, on a regular basis, lists of newly diagnosed cancer patients from the pathology and haematology departments in their region. Notification of incident cancer cases by the pathology departments is relatively easy since all pathological diagnoses are entered into a nationwide computer system (Dutch Network and National Database for Pathology). In addition, lists of hospitalised cancer patients are obtained from the medical records' departments of all hospitals, based on data from the National Medical Registry. Often, regional cancer registries use additional notification sources (e.g., from radiotherapy departments). Due to privacy regulations and the absence of a personal identification number, death certificates cannot be used as an additional source of notification of cancer cases in The Netherlands.

Following notification, the medical records of newly diagnosed patients (and tumours) are traced and relevant information for the cancer registry is abstracted and coded by trained registration clerks. All regional cancer registries collect a minimum data set, which includes personal identification and tumour information (e.g., topography, morphology, stage, date of diagnosis), and information on primary treatment. Date of death is also registered, but this is done systematically for all patients only by the Eindhoven Cancer Registry (through a periodic check of vital status with the municipal registries). All invasive and most *in situ* malignancies (including non-infiltrating bladder cancer), which have been diagnosed from 1989 onwards, are registered nationwide. Because information on basal cell carcinomas of the skin is collected in only a few regional cancer registries [5], national incidence data for these tumours are not available. Tumour data are coded according to ICD-O, first edition. An extensive computer control programme is applied to all data submitted to the national database.

Collection of data about cancer patients is done with the agreement of and collaboration with medical specialists and hospitals. For legal reasons, cancer patients are informed about the existence of the registry through a leaflet, but they do not have to give their explicit permission; less than 0.01% refuse to be included.

Mortality data for 1990 and 1991 in The Netherlands were obtained from the mortality register of the Central Bureau of Statistics. These data are based on notification by the doctor who certified death.

Population data

Annual population data, which are kept by each municipality, were provided by the Central Bureau of Statistics. In 1989 and 1990, The Netherlands had an average population of 14 900 000, of whom 7 363 000 were men and 7 537 000 were women. With 439 inhabitants per square kilometre of land area (as of 1 January 1990), the population density is the highest of all European countries. The majority of the population lives in the western part of the country, while particularly the northern and south-western parts of the country are less densely populated. Approximately 11% of the population lives in rural, 38% in suburban and 51% in urban municipalities. The Dutch population is still relatively young compared to other European countries (48% are between 15 and 44 years of age). However, the birth rates fell after 1970 and the number of people over 65 years of age is now growing rapidly. On 1 January 1990, 4.5% of the population of The Netherlands possessed Dutch nationality, but were born outside The Netherlands. They comprise ethnic minorities originating from the former Dutch colonies of Indonesia, Surinam and The Netherlands Antilles. The population not possessing Dutch nationality, mainly Turks and Moroccans, constituted another 4.3% of the total population in 1990.

RESULTS

In 1989 and 1990, on average, 56 434 invasive malignancies were registered per year by the Netherlands Cancer Registry; 29 882 among males and 26 552 among females. Besides skin melanoma, approximately 2400 other skin tumours, excluding basal cell carcinoma, were included in the total annual number. The number of tumours registered in females increased by 900 from 1989 to 1990, due mainly to a higher breast cancer incidence in 1990. Of all registered invasive malignancies, 88.5% had been histologically verified, for 7.2% there was cytological but no histological confirmation, and for 4.3% the diagnosis was based on clinical criteria only.

In Figure 2, annual age-adjusted incidence rates per 100 000 inhabitants (standardised according to the world standard population) are presented for the 20 most frequent tumours in The Netherlands. The age-adjusted incidence rates for all cancers combined (excluding non-melanoma skin cancers) are 285.0 and 220.4 for males and females, respectively (male/female ratio of 1.3). Most cancers occurred more frequently in males than in females, with the exception of skin melanoma, cancer of the gall bladder, and of the thyroid (male/female ratios of 0.7, 0.4 and 0.4, respectively). High male/female ratios were found especially for cancer of the pleura (8.0), larynx (7.1), lung (6.0) and urinary bladder (5.1). For males, the five most frequent invasive tumours

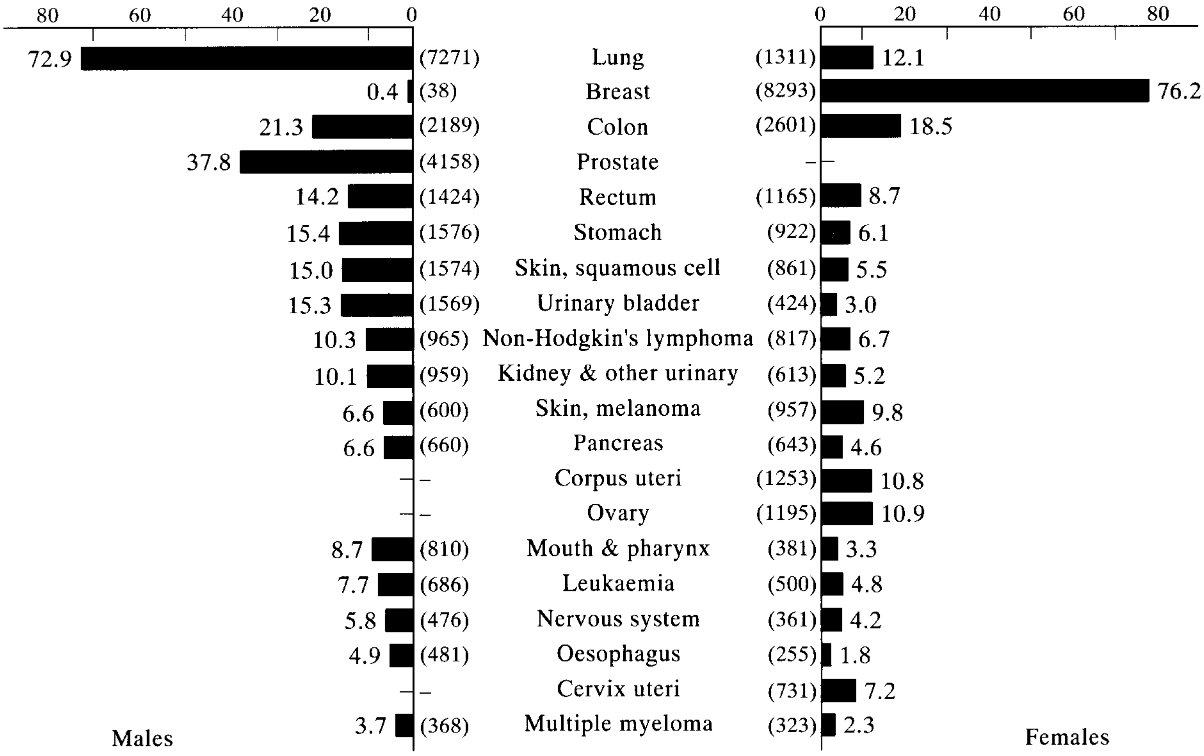


Figure 2. Age-standardised (world standard population) annual incidence rates per 100 000 for the 20 most frequent invasive tumours according to the absolute number in males and females combined. The Netherlands Cancer Registry, 1989–1990 (average number of registered cases per year given in parentheses). For carcinomas, three digit topographical codes of ICD-O are used; non-infiltrating urinary bladder cancer is excluded among ICD-O 188. For haematolymphopoietic malignancies and skin tumours (melanoma and other skin tumours, excluding basal cell carcinoma) morphological codes of ICD-O are also used, which have been grouped according to the corresponding ICD-9 codes.

were lung cancer, with an age-adjusted incidence rate of 72.9 per 100 000 (world standard population), cancer of the prostate (37.8), colon (21.3), stomach (15.4) and urinary bladder (15.3). For females, breast cancer ranked first, with an incidence rate of 76.2 per 100 000, followed by cancer of the colon (18.5), lung (12.1), ovary (10.9) and corpus uteri (10.8).

A comparison of the absolute number of incident cancer cases (1989/1990) with the absolute number of patients who died of cancer approximately 1 year later (1990/1991), showed that the mortality/incidence ratio for all cancers (non-melanoma skin cancers excluded) was 0.70 for males and 0.60 for females. In Figure 3, mortality/incidence ratios are presented for selected cancer sites. Ratios of more than one are reported for liver cancer (1.3 among males and 1.8 among females), pancreatic cancer (1.3 among males and females) and oesophageal cancer among males (1.1).

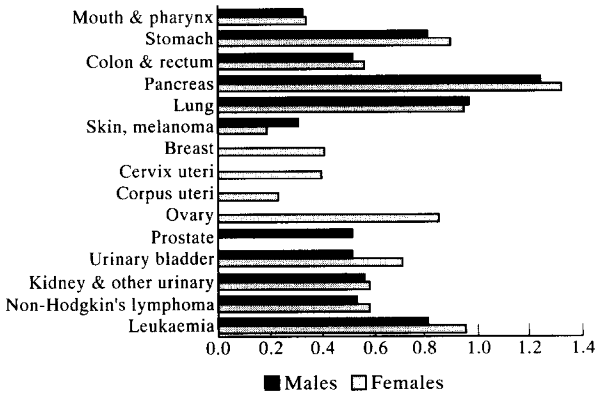


Figure 3. Ratios of mortality in 1990 and 1991 divided by incidence in 1989 and 1990 (absolute numbers) for selected cancer sites. Incidence: The Netherlands Cancer Registry, 1989–1990; Mortality: Central Bureau of Statistics, 1990–1991.

DISCUSSION

Although some underregistration of incidence cases in a population-based registry is inevitable, particularly at the start of registration, there are indications that the Netherlands Cancer Registry is already quite complete. First, despite unavailability of death certificates to the cancer registry, comparison of national mortality data with incidence data showed that the mortality/incidence (M/I) ratio exceeded 1 only for pancreatic cancer, liver cancer and oesophageal cancer (males). This might suggest some underreporting of the incidence of these highly lethal tumours, although differences in methods of registration and coding practices between the Netherlands Cancer Registry and the mortality register of the Central Bureau of Statistics might also partly explain the higher mortality for these sites. Slightly higher mortality than incidence rates for lethal cancers may also be explained by yearly variations in the number of new cancers; it should be kept in mind that M/I ratios are essentially different from survival rates in that the numerator and the denominator do not necessarily relate to the same patient population. Another indication for completeness of the cancer registry is that the number of registered cases varied little between 1989 and 1990, except for the higher breast cancer incidence in 1990 among

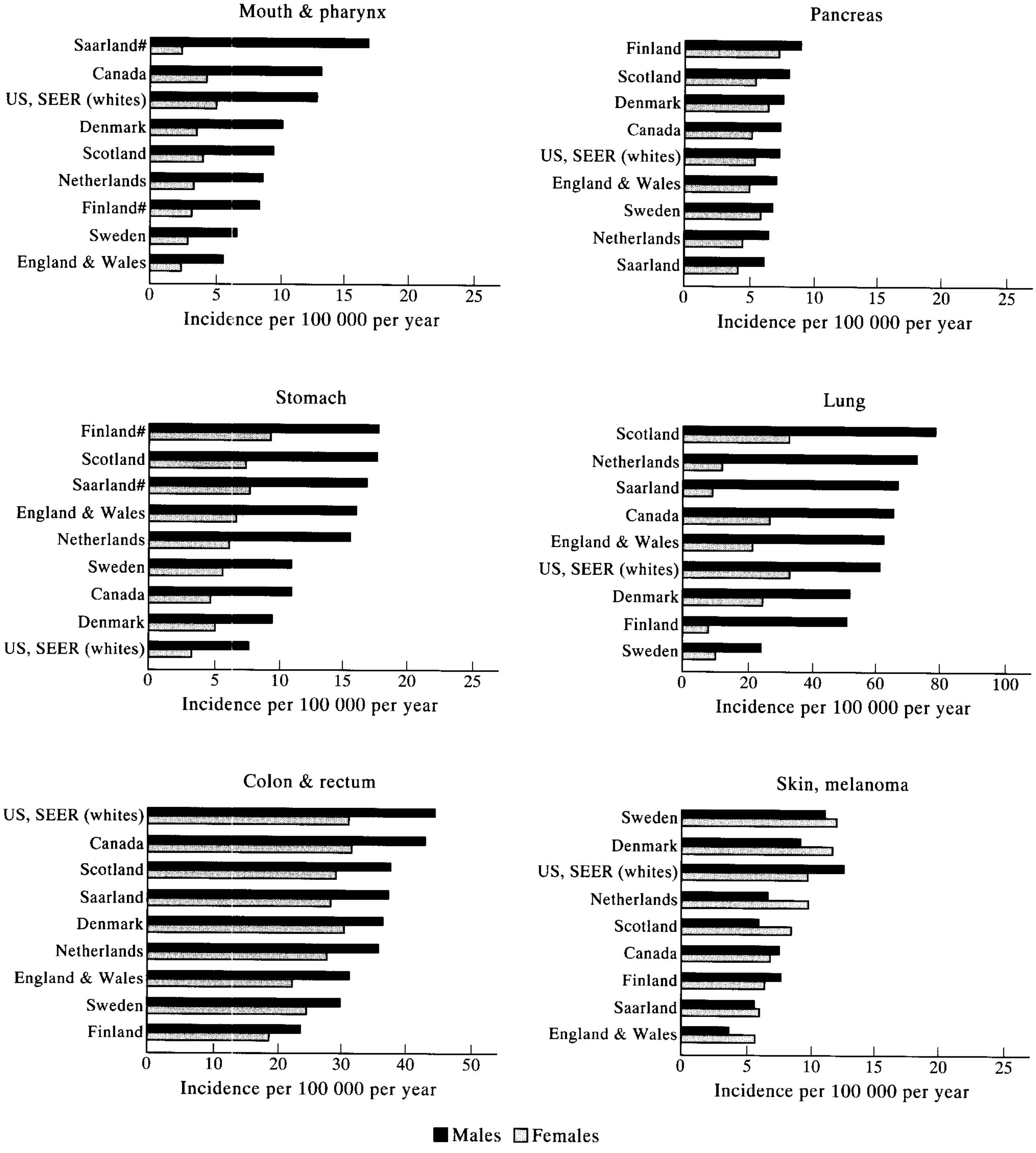
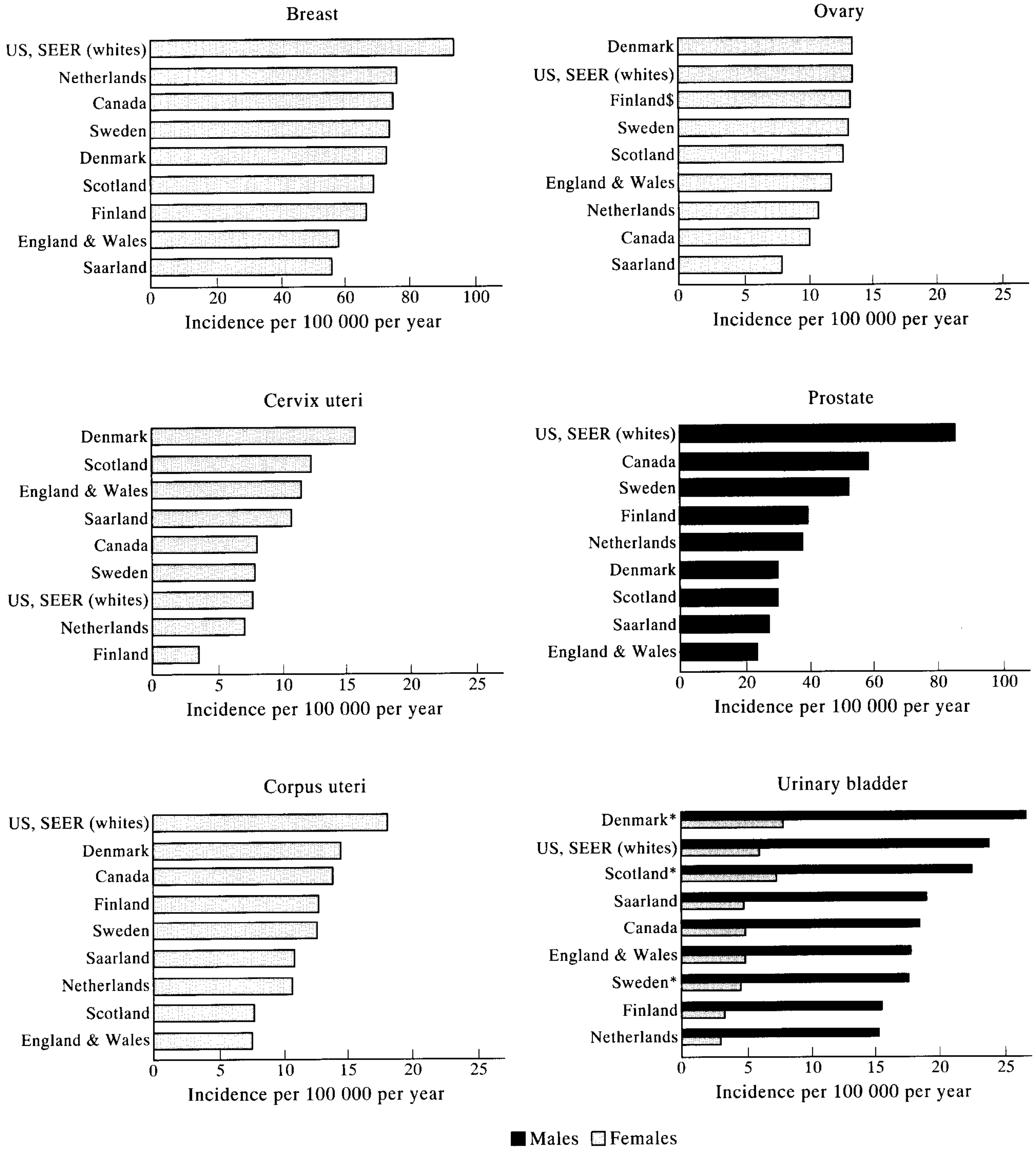


Figure 4. Continued overleaf.

females, which was probably due mainly to the expansion of the breast cancer screening programme in The Netherlands. Finally, in two regions, a comparison has been made between data of the cancer registry and data of general practitioners. In the registries of the Comprehensive Cancer Centre, Middle Netherlands and the Comprehensive Cancer Centre, Limburg (IKL), systematic underregistration was estimated at 1.3% and 1.6%, respectively [6, 7]. Tumours systematically not recorded in the cancer registries occurred in patients treated by their general practitioner only, in ambulatory patients without a histological diagnosis, and among patients diagnosed and treated abroad. In the IKL cancer registry, another 2.2% of all malignancies that should have been registered, were not recorded due to occasional errors in the notification procedures, the total incompleteness being 3.8% [7]. Recently, the capture–recapture method was used to estimate the level of underregistration as a consequence of shortcomings in the notification procedures in the regional cancer registries of the Comprehensive Cancer Centres, Limburg, Middle Netherlands and East [8]. The estimate was very similar to that reported by the IKL cancer registry (i.e., 1.7% versus 2.2%). Cancer registries outside of The Netherlands, which have a longer history, have reported comparable estimates of incompleteness [9–11].

Another important aspect of the reliability of a cancer registry



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is the accuracy of the data. In the Netherlands Cancer Registry, data about cancer patients are abstracted directly from the medical records by trained registration clerks. A comparison of data coded by registration clerks with those coded by clinicians in the IKL region showed that registration personnel are able to collect data with a high degree of accuracy [12]. A national coding committee and a 2 year national evaluation of case histories coded by all registration clerks assure that data are coded in a uniform manner. In addition to consistency checks at the regional level, an extensive control programme is applied to the national database.

As illustrated in Figure 4, high incidence rates in The Netherlands (in both absolute and relative terms) are reported for lung and stomach cancer among males, breast cancer among females and colorectal cancer among both males and females compared with other countries in Northwestern Europe and North America [13–24]. The incidence of prostate cancer appears to be average compared to other Western countries. Some of the international variation in the incidence of breast and prostate cancer can probably be explained by the influence of trends towards earlier diagnosis. In The Netherlands, a nationwide screening programme for breast cancer for women aged 50–70 years was introduced in a phased manner in 1990. However, according to older incidence rates in the Southeast of The

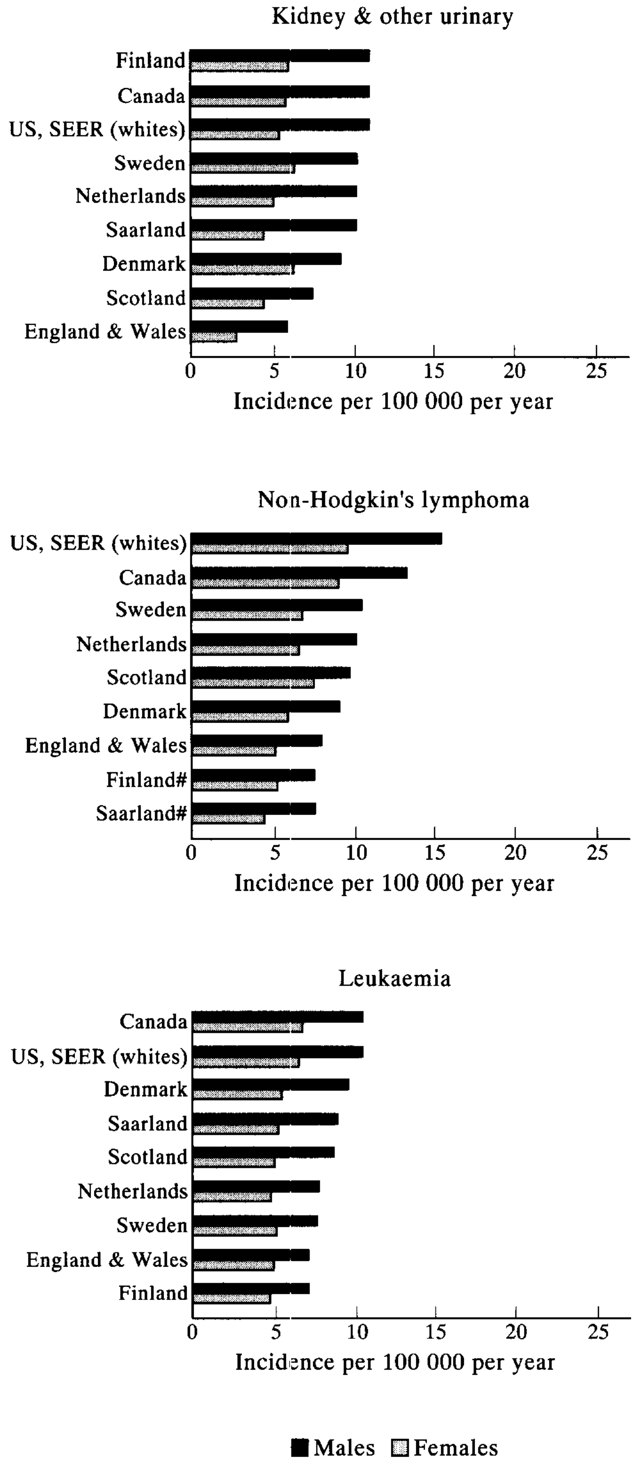

Figure 4. Age-adjusted incidence rates (world standard population) of selected cancer sites, as reported by different cancer registries in Northwestern Europe and North America in 1989/1990, except for Saarland (1988–1990) and England & Wales (1987). Sources: The Netherlands Cancer Registry, Danish Cancer Registry [21, 22], Finnish Cancer Registry [13], The Swedish Cancer Registry [23, 24], Cancer Registry of Saarland, Germany [17], England & Wales National Cancer Registry [15], Scottish Cancer Registration [18], National Cancer Incidence Reporting System (Canada) [19, 20], SEER, United States [14]. Because incidence rates in Ontario, Canada [16] correspond very well to national incidence rates of Canada, the figures from the Ontario Cancer Registry are excluded in this figure. Incidence of urinary bladder cancer includes non-invasive tumours; for Scotland only in the West-region; # Extranodal non-Hodgkin's lymphomas are included in the incidence figures of the primary site; $ Incidence of ovary cancer includes semimalignant or borderline tumours.

Netherlands [1, 2], the incidence of breast cancer in The Netherlands was already one of the highest in Europe long before the Dutch screening programme was introduced. In the period 1989/1990, there were no screening programmes for prostate cancer in The Netherlands.

Less frequently occurring sites for which incidence rates are relatively high in The Netherlands include cancers of the larynx and pleura in males (age-adjusted incidence rates of 6.4 and 2.4, respectively). Compared with Northwestern European countries, non-Hodgkin's lymphomas also are reported relatively frequently in The Netherlands among both males and females. It should be noted, however, that the incidence of non-Hodgkin's lymphomas in some other cancer registries is underreported because extranodal lymphomas are included in the incidence figures of the primary site [13, 17].

In comparison, relatively low rates are reported for lung cancer among females, leukaemia among both males and females, as well as for cancer of the urinary bladder, pancreas, uterus (mainly cervix) and nervous system. However, special problems arise when comparing the incidence rates of urinary bladder cancer and tumours of the nervous system, because some (mainly Scandinavian) cancer registries include non-invasive tumours in the incidence figures. *In situ* carcinomas of the cervix, which are more often diagnosed in areas with active screening programmes, have been excluded in all incidence rates of Figure 4. In The Netherlands, screening activities for cervical cancer among 35–55-year-olds decreased after 1983, but in 1989 a new screening programme for this tumour was introduced.

Overall, the incidence rate of all cancers combined (excluding non-melanoma skin cancers) in males in The Netherlands is high compared to other Northwestern European countries; for females, the incidence of all sites combined is approximately average. For both white males and females, the highest total incidence rates are reported by the SEER cancer registry, especially for cancers of the breast, prostate and large bowel. However, the incidence of stomach cancer in the United States is half of that reported in The Netherlands for both males and females.

Although we have restricted the geographical comparison to relatively few industrialised countries, incidence rates show considerable variation, particularly for tumours associated with lifestyle risk factors. Tobacco-related sites also show considerable geographical variation with regard to the male/female ratios of incidence rates. The male/female ratios of urinary bladder cancer (5.1), larynx cancer (7.1) and particularly lung cancer (6.0) in The Netherlands are among the highest in Northwestern Europe and North America. These high male/female ratios reflect both the historically high prevalence of cigarette smoking among Dutch males, and the delayed popularity of smoking among Dutch females. However, paralleling changes in smoking habits of the Dutch population over the past decades [25], the incidence of lung cancer in The Netherlands is now increasing for females and declining for males [26, 27].

The very low incidence of urinary bladder cancer among males in The Netherlands as compared to other Western countries, suggests that smoking is not the only factor influencing bladder cancer risk; perhaps Dutch men are less exposed to other (occupational) risk factors, or more exposed to some (unknown) protective factors. To elaborate on these hypotheses, it would be necessary to obtain more information about (1) the number of tumours recorded per patient in the different cancer registries (see Appendix); and (2) the biological behaviour of the tumours included in the incidence figures. Incidence rates of tumours of the upper digestive tract (mouth, pharynx and oesophagus) in

The Netherlands are approximately average for both males and females, and, as for most Western countries, the incidence among males is two to three times higher than among females (except for Saarland, Germany which reports a male/female ratio of about 7). Furthermore, it is interesting to note that, within the selected cancer registries, both the geographical variation and the differences between males and females are relatively small for pancreatic and kidney cancer; tumours which are also assumed to be related to life-style factors. However, there is a clear variation in the global incidence of these tumours, especially of kidney cancer [2].

The relatively high incidence of cancer of the pleura among Dutch males, in contrast to females, probably reflects the exposure to asbestos, which was used widely as insulation in the Dutch heavy industry and shipyards before 1977 [28].

A higher incidence of melanoma among females is reported by most European cancer registries [2], including the Netherlands Cancer Registry (male/female ratio of 0.7). Typically, in North America and in Finland a higher incidence is seen among males, just as in some (high risk) areas in Australia [2]. Further studies are needed to explain these differences. In The Netherlands, the incidence of squamous cell skin carcinoma was 2.7 times higher among males than among females, which suggests that the aetiological pathway of this tumour is different from that of melanoma.

It should be noted that part of the variation in incidence rates reported by different cancer registries may be explained by differences in methods of registration, or differences in coding of tumours. For example, cancer registries employ different criteria for the coding of multiple primary tumours, which could substantially affect the incidence rates of urinary bladder cancer, breast cancer, colorectal tumours and non-melanoma skin cancer (see Appendix); of all new primary cancers of these sites, the Netherlands Cancer Registry already recorded 0.2, 2.0, 2.1 and 4.1%, respectively, as second or subsequent primaries in 1989/1990. Furthermore, incidence rates averaged over 2 years might still be subject to random variation, especially with regard to rare tumours.

In conclusion, the Netherlands Cancer Registry has developed a system of data collection and an extensive quality control programme which ensures a high level of reliability and completeness. The registry is currently being used for detailed descriptive studies, and as a sampling frame for case–control and cohort studies [29, 30]. As the registry matures, new opportunities will emerge for a wide range of epidemiological investigations.

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APPENDIX

In the Netherlands Cancer Registry, the rules for coding multiple primary tumours are different from those proposed by the IARC/IACR. The Netherlands Cancer Registry recognises two or more primary cancers when the interval is 3 months or more, even when tumours are of the same histology, except for urinary bladder cancer. When the interval is less than 3 months, tumours must be of different histology to count each of them as a primary tumour. More specifically, tumours must be different with regard to the three digit morphological code of ICD-O, whereas the IARC/IACR guidelines use broad groups to define "different" histology. Multiple tumours are also recognised in paired organs and in subsites of the colon, rectum, skin, soft tissue and bone (as defined by the four-digit rubric of the ICD), whereas according to the IARC/IACR rules, only one tumour would be recognised.