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The Comprehensive Cancer Monitoring Programme in Europe

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Background: There continue to be major public health challenges arising from the increasing cancer burden in Europe. Drawing upon expertise from other European centres and networks, the Comprehensive Cancer Monitoring Programme in Europe project (CaMon) provides a central information resource of the cancer profile in European populations. Methods: The cancer indicators fundamental to disease monitoring in Europe are illustrated in terms of definitions and availability. Where necessary data are supplemented by estimates, in order to make available cancer data to individuals and institutions in all Member and Applicant countries of the European Union (EU). The relevant methodologies are discussed. Finally, a major ongoing project examining time trends of cancer incidence and mortality in 38 European countries is described. Results: In the European Union, there were approximately 1.6 million new cases of cancer according to the latest year available, and approximately, one million cancer deaths. About 2.6 million new cases of cancer, and 1.6 million deaths were estimated in Europe. Lung cancer is the most common cancer in Europe and together with cancers of the colon and rectum and female breast represent approximately 40% of new cases in Europe. Conclusion: The statistics generated by the project on cancer incidence, mortality, survival and prevalence, together with time trends and projections will be regularly updated and made available to a European Commission, and to a Community-wide audience via the CaMon website and via other means of dissemination, such as peer-reviewed journals.

Keywords: epidemiology, incidence, mortality, neoplasms, public health

Over one-quarter of the global burden of cancer incidence occurs in Europe,[1] despite the fact that persons living in Europe comprise only approximately one-eighth of the world's population. There continue to be major public health challenges arising from the increasing cancer burden in Europe. The Comprehensive Cancer Monitoring Programme in Europe project (CaMon) provides a central information resource of the cancer profile in European populations. Drawing upon expertise from other European centres and networks, the cancer indicators fundamental to disease monitoring are made available to individuals and institutions in all Member and Applicant countries of European Union (EU). The project is supported by the Health Monitoring Programme (Health and Consumer Protection Directorate-General) of the European Commission as part of the EU action in public health.

The main aim of the CaMon project is to develop a cancer surveillance system for cancer occurrence and outcome (incidence, mortality, prevalence and survival), permitting situation analysis and monitoring of cancer burden in the Member States of the European Union and Applicant States. Further, to disseminate this information within the European Union, in greater-Europe and worldwide, as well as to incorporate the information into the multi-disease databases being constructed by the European Union Public Health Programme. The tasks include:

- the compilation and maintenance of an updateable database of indicators of cancer burden and outcome for the EU and Europe;
- the study of time trends and the provision of projections of cancer incidence and mortality in the EU and Europe;
- the organisation of international workshops reviewing i) available methods for producing time trends and predictions of future cancer burden; ii) definitions and methodological aspects of prevalence in public health monitoring.

Some of the required indicators are collected through existing programmes, or are available at the national level. Information on cancer incidence, mortality and prevalence are generated through the European Network of Cancer Registries (ENCR) project supported by the 'Europe Against Cancer' Programme. The overall aim of the ENCR since its inception in 1989 has been to support and encourage the use of cancer registries in cancer control, health-care planning and cancer research in Europe. A major component involves improving the quality, comparability and availability of incidence data from European cancer registries. The CaMon project extends the role of the ENCR beyond its broad aim of promoting cancer registration, contributing a major statistical resource for cancer surveillance in Europe.

This paper describes the main activities of the CaMon project, with an emphasis on illustrative examples

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describing the current profile of cancer in the European Union and in Europe, using the most recent datasets available.

METHODS

Database of indicators of cancer burden

The provision of high-quality and comparable cancer statistics in representative populations is a crucial part of a cancer-monitoring programme. There are a number of measures that are essential for this task, three of which quantify cancer frequency: incidence, mortality and prevalence. A fourth, more complex statistic, survival, describes one impact of disease on cancer patients.

Definition of measures and data sources

– Incidence is the number of new cases occurring in a defined population and time period. It can be expressed, for example, as the absolute number of cases per year (the volume of new patients presenting for treatment) or as a rate per 100,000 persons per year. The latter provides an approximation to the average risk of developing a cancer, and is necessary in order to compare the risk of disease between populations, or in one population over time. For summary comparisons, age standardized rates are usually calculated which take into consideration the differing age structure of the underlying populations.

– Incidence data are produced by population-based cancer registries which collect information on all new cases of cancer in a defined population. Incidence rates derived from cancer registries are considerably more restricted in availability than mortality. European cancer registries may cover national populations or, more often, certain regions within countries.

– Mortality is the number of deaths occurring in a defined population and time period, and the mortality rate is the number of deaths per 100,000 persons per year. The number of deaths provides one measure of the outcome, or impact of cancer. Mortality rates measure the average risk to the population of dying from a specific cancer.

– Mortality data are derived from vital registration systems, where the occurrence and cause of death are certified, usually by a medical practitioner. The International Classification of Diseases (ICD) provides a uniform system of nomenclature and coding, and a recommended format for the death certificate. The great advantage of mortality statistics is their comprehensive coverage; the vast majority of European countries being covered by vital registration systems produce mortality statistics on cancer. Not all of these are, however, of the same quality. Time trends of mortality obviously reflect changes in treatment, as well as risk of disease, as estimated by incidence.

– The survival of a cancer patient is defined as the time that elapsed between diagnosis and death. The most basic measure of patient survival is the observed survival, with the 5-year observed survival being the percentage of patients alive after five years after the date of diagnosis. Not all deaths among cancer patients will, however, be due to the primary cancer in question. Deaths from other causes lower the observed survival rate and preclude comparison between groups for which probabilities of death in the general population vary. Relative survival rates avoid this problem of comparability. Relative survival is the observed survival in a patient group divided by the expected survival of a comparable group in the general population with respect to age, sex and calendar period of investigation. As with statistics on incidence, survival estimates are produced by cancer registries. They require follow-up of registered cancer cases, either actively or by matching death certificates against cancer notifications and assuming that unmatched cases are still alive.

While incidence, mortality and survival are established indicators in the cancer domain, the appropriate measures of prevalence are less well defined in cancer monitoring. Indeed, one of the tasks of the CaMon project is to convene a meeting of methodologists and users to establish the most appropriate measure of prevalence in public health monitoring.

– Total prevalence is the number of persons in a defined population alive at a given time who have had cancer diagnosed at some time in the past. However, the resource requirements for treating newly diagnosed patients are very different from those for supporting long-term survivors. Thus, overall prevalence is not particularly useful for health care planning purposes, especially as a large proportion of long-term survivors can be considered cured, and estimating this latter proportion would be an important qualifier.

– Partial prevalence, which limits the number of patients to those diagnosed during a fixed time in the past, is therefore a more useful measure of cancer burden. Prevalence for cases diagnosed within one, three and five years are likely to be of relevance to the different stages of cancer therapy, namely, initial treatment (one year), clinical follow-up (three years) and cure (five years). Patients who are still alive five years after diagnosis are usually considered cured since the death rates of such patients are similar to those in the general population. There are some exceptions, primarily that of female breast cancer, for which the risk of death remains higher than the general population for many more years. The quantification of residual disability weightings are important in this respect.

Making comparable estimates of cancer burden and outcome in Europe

Using data on incidence, mortality, and survival, it is possible to prepare estimates of the numbers of new and prevalent cancer cases and deaths by site, sex and age group, which are more or less accurate, for different European countries, depending on the extent and accuracy of locally available data. The method used is to estimate incidence, mortality, and prevalence for 11 age groups (0–14, 15–34, 35–44, 45–49, 50–54, …, 70–74 and 75 and over) and both sexes for the Member States of the European Union,[2] and for the 38 United-Nations defined countries in Europe, for 23 different types of cancer.[1]

Incidence, mortality, prevalence and survival in the EU

The EUCAN database[2] holds information on cancer incidence, mortality, prevalence and survival in the EU and its 15 Member States. The most recent national mortality data from the WHO mortality databank (and available for each country) are used to obtain information on cancer deaths. National incidence data are available for several countries with nation-wide cancer registration. For countries where national data are not available, a technique is required to supplement the recorded incidence with a set of estimates. Good quality population-based cancer registry data are available at the regional level for the majority of Member States, thus the national estimate for the number of new cases was calculated as a product of national mortality (the number of deaths) and the incidence/mortality ratio, based on regression models of appropriate aggregated cancer registry data. The improvement in the quality of cancer registry data, coupled with an increased number of registries from which data were available, enabled the use of several country-specific models to estimate annual national incidence figures. See: http://www-dep.iarc.fr/eucan/database.pdf for details of the estimations.

Observed and relative survival rates, based on data from a number of European cancer registries, are obtained via collaborations with the EUROCARE group.[3] The most recent results are based on submitted data on patients diagnosed between 1985 and 1989 from 35 cancer registries in 10 of the 15 Member States of the European Union. One, three, and five year cumulative relative survival rates have been made available to the CaMon project. Updates (including ten year survival) will follow when results of the EUROCARE-3 study are published.

– Partial prevalence for cases diagnosed within one, three and five years are derived based on by combining the annual number of new cases and the corresponding probability of observed survival by time. Details of the statistical methodology can be found elsewhere.[4]

Cancer incidence and mortality estimates in 38 European countries

This analysis extends the methodology used to estimate cancer burden in the Member States to estimate cancer incidence of, and mortality from 25 cancer sites in the 38 UN-defined countries (incorporating the high quality incidence and mortality data available from the expanding number of population-based cancer registries in all European areas. The recorded sources and methods of estimation can be found on the CaMon website – for incidence at: http://www-dep.iarc.fr/europe95/incidence.pdf and mortality at: http://www-dep.iarc.fr/europe95/mortality.pdf.

Estimation of cancer trends in European populations over time

The study of time trends in cancer incidence and mortality is an essential tool for monitoring changes in lifestyle and environmental risk factors at the population level and evaluating the effectiveness of health systems in cancer prevention and treatment. Accordingly, a major focus of this CaMon project is a comprehensive and systematic analysis of time trends and short-term predictions of incidence and mortality of 23 cancers in Europe. Analyses will be lead and coordinated by a series of site-specific experts in liaison with cancer registry personnel and staff working on the CaMon project. Each of trends analyses by cancer will be written and disseminated in peer-reviewed journals. The joint analysis of trends by age, period and birth cohort will be preformed, together with the provision of short-term predictions of cancer incidence and mortality for 2010 and 2020.

The first phase is to identify the optimum strategy for a systematic analysis of time trends in cancer. This component commenced with a workshop of experts who reviewed the methodological aspects of systematic time trend analyses, discussing issues related to the availability, quality and comparability of cancer incidence and mortality data, the rationale of time trends and predictions of cancer, graphical displays, and the use of statistical models for age–period-cohort analyses and the short-term prediction of future cancer burden.

Analysis of time trends of incidence and mortality

While graphical displays of age-specific trend data are invaluable, they can be greatly enhanced by the use of statistical modelling which provide quantitative and comparable estimates of trends based on objective criteria for choosing the best description of the data. The age–period-cohort model[5–7] provides such a summary, allowing a formal statistical examination of whether temporal trends are due to secular changes in risk (*period* effects) or changes in risk from generation to generation (birth *cohort* effects) in different populations. Unfortunately, the model suffers from the well-known problem of identifiability. There are an infinite number of possible solutions to the model containing age, period and cohort effects because the separation of the linear components of each is impossible. There has been a considerable body of work on how one might proceed in view of this unsolvable mathematical problem.

Short-term prediction of cancer of incidence and mortality

It is evident from a review of time trends for the major cancer sites, that it is not easy to predict what effect the use of the rates of disease from a previous period will have on the accuracy of the 'burden' estimate for a subsequent one. Time trend data are necessarily based on historical patterns, which do not always provide a sound basis for future projections. Nevertheless predictions of cancer incidence and mortality can play a valuable role in planning health care strategies. Two main areas of their use have been identified.[8,9] In administrative settings, accurate predictions of future burden are necessary to determine the required allocation of resources for diagnosis, treatment and rehabilitation. In scientific settings, their uses include the monitoring of intervention and early detection programmes.[8] In this context, predictions which do not come true can still be important. Assuming that past trends will continue into the future (e.g. in the absence of an intervention), a deviation from the

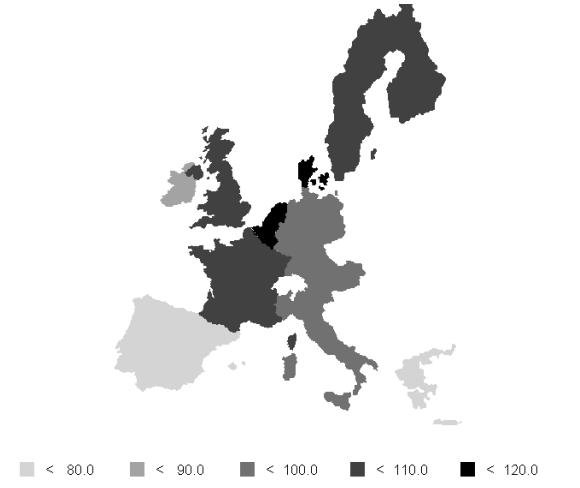

Figure 1A Incidence of female breast cancer 1997: ASR (European) (all ages)

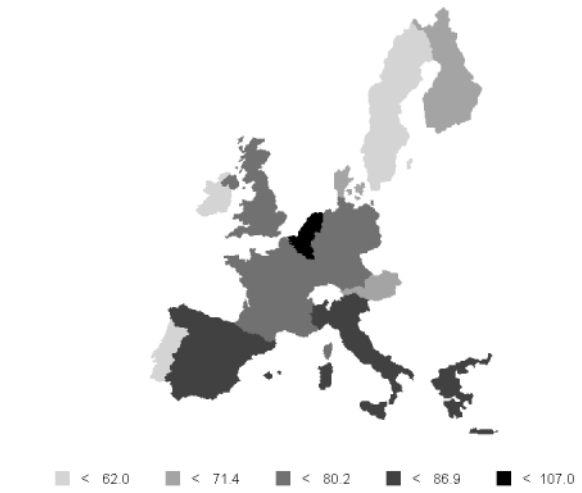

Figure 1B Incidence of lung cancer 1997: ASR (European) (males, all ages)

predicted cancer burden may point to the success (or failure) of public health policies.

RESULTS

Cancer incidence, mortality, and prevalence in the European Union

According to the latest estimates available from EUCAN[2], it is estimated that there were over 1.6 million new cases of cancer (excluding non-melanoma skin cancer) in the European Union in 1997, of which, slightly more than half (53%) occurred in men (*table 1*). Approximately, one million persons died from cancer in the same year, of which 56% were males. Age-adjusted rates indicate that overall risk of disease tends to be higher in Northern and Western countries of the EU relative to those in the South, in part reflecting the distribution of the most common cancers, particularly lung cancer incidence in men and breast cancer in women (*figures 1A and 1B*).

Table 2 shows the distribution of the number of new cases, deaths and five-year prevalent cancer cases in the Member States in 1997 and *figure 2*, age-standardised incidence and mortality rates sorted by descending order of occurence for males and females. The three most common cancers that develop in men (lung, colorectal and prostate) and in women (breast, colorectal, and lung) comprise almost half of the total cancer incidence experienced in the EU. Lung cancer continues to be the principal

Table 1 Estimated incidence of, and recorded mortality from all cancers (excluding non-melanoma skin cancer) in European Union countries in 1997, by sex (numbers of cases / deaths rounded to 100s)

	Incidence, 1997					Mortality, 1997				
	Males		Females		Both sexes	Males		Females		Both sexes
	Number	ASR (E)[a]	Number	ASR (E)[a]	Number	Number	ASR (E)[a]	Number	ASR (E)[a]	Number
Austria	18400	460.3	18500	327.4	36900	10200	255.0	10100	159.9	20300
Belgium	26000	473.1	21500	318.8	47500	15700	280.2	11600	151.4	27300
Denmark	11600	407.6	13400	396.5	25000	8400	286.7	8600	227.6	17000
Finland	10600	425.0	11100	326.7	21700	5600	224.5	5600	145.9	11200
France	141700	460.7	106000	284.7	247700	98500	310.8	64600	144.2	163100
Germany	177500	413.6	179100	300.1	356600	116900	273.2	115900	171.0	232800
Greece	21000	338.1	15800	231.4	36800	15300	241.1	10200	135.7	25500
Ireland	7000	367.0	6800	273.9	13800	4400	206.6	4000	132.0	8400
Italy	145000	433.0	120400	291.4	265400	95800	280.7	71400	150.9	167200
Luxembourg	900	450.2	800	307.6	1700	500	255.4	500	175.1	1000
Netherlands	35200	465.6	33200	359.5	68400	22700	298.7	19000	183.6	41700
Portugal	19500	385.7	16600	265.1	36100	13100	255.0	9500	137.6	22600
Spain	89100	426.7	61200	242.1	150300	60600	281.3	38000	131.3	98600
Sweden	19500	356.9	19400	326.0	38900	11200	192.3	10100	139.3	21300
UK	139900	433.3	145000	366.8	284900	89700	272.6	85100	192.8	174800
EU	863100	426.1	768800	302.5	1631900	568700	275.9	464200	159.7	1032900

a: ASR (E): age-standardised rate (European population) per 100,000.

cause of death in men (one-quarter of all male cancer deaths), followed by colorectal and prostate cancers (10% each). In women, the three major causes of death are breast cancer (16% of all female deaths), colorectal (12%) and lung cancer (9%). Stomach cancer is the fourth most common cause of cancer death in both sexes, comprising more than 5% of total cancer deaths in both men and women.

According to the prevalence figures, there are over 4.5 million people living with cancer in the European Union, who were diagnosed with cancer during the previous five years. Prevalence reflects both incidence and fatality of the disease, and hence breast cancer (one in five prevalent cases), colo-

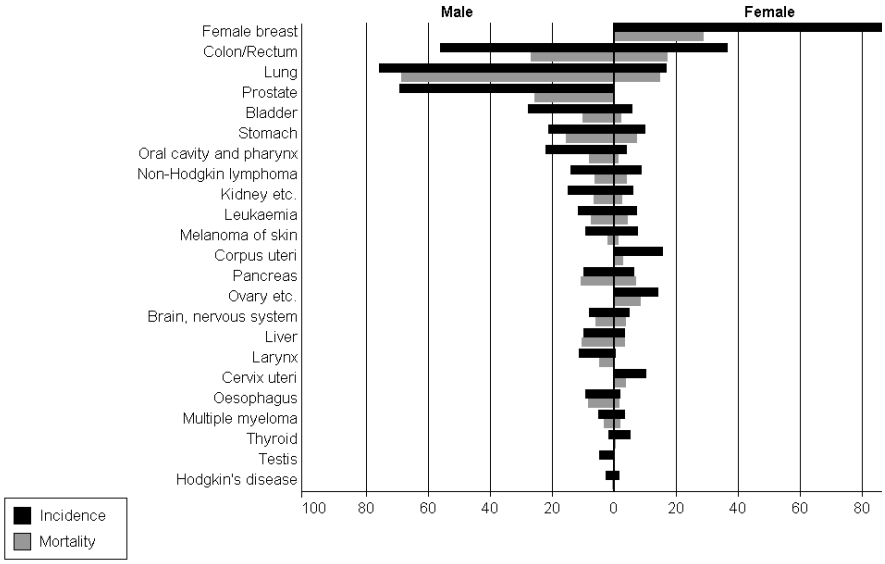

Figure 2 Incidence and mortality age-standardized rates (Europe) of 23 cancers in the European Union, 1997

Table 2 Estimated new cancer cases, deaths and five-year prevalence in the European Union 1997, by cancer site and sex (numbers of incident cases / deaths / prevalent cases rounded to 100s)

	Incidence				Mortality				Prevalence	
	No. cases			% of total	No. deaths			% of total	Five-year	%
	Male	Female	Both sexes		Male	Female	Both sexes		Both sexes	
Oral cavity and pharynx	42100	10600	52700	3.2	15600	4100	19700	1.9	172100	3.8
Oesophagus	18400	6300	24700	1.5	16700	6000	22700	2.2	32200	0.7
Stomach	43600	31000	74600	4.6	32400	24200	56600	5.5	127300	2.8
Colon/Rectum	114100	106900	221000	13.5	55800	55100	110900	10.7	656900	14.6
Liver	20400	10500	30900	1.9	21900	11700	33600	3.3	23400	0.5
Pancreas	20300	20300	40600	2.5	22200	22700	44900	4.3	27700	0.6
Larynx	21900	2100	24000	1.5	9700	1000	10700	1	94800	2.1
Lung	152300	44600	196900	12.1	139600	41000	180600	17.5	252200	5.6
Melanoma of skin	18100	18100	36200	2.2	4500	4100	8600	0.8	151800	3.4
Female breast	0	220800	220800	13.5	0	74800	74800	7.2	934500	20.7
Cervix uteri	0	22800	22800	1.4	0	10400	10400	1	85600	1.9
Corpus uteri	0	38300	38300	2.3	0	9000	9000	0.9	153200	3.4
Ovary etc.	0	34300	34300	2.1	0	23300	23300	2.3	86800	1.9
Prostate	145000	0	145000	8.9	55500	0	55500	5.4	492400	10.9
Testis	9700	0	9700	0.6	700	0	700	0.1	40400	0.9
Bladder	56800	18200	75000	4.6	22100	8500	30600	3	267000	5.9
Kidney etc.	29500	17100	46600	2.9	13600	8600	22200	2.2	136100	3
Brain, nervous system	15300	11900	27200	1.7	11600	9400	21000	2	33900	0.8
Thyroid	3900	11600	15500	0.9	1100	2100	3200	0.3	57300	1.3
Non-Hodgkin lymphoma	27700	23800	51500	3.2	13200	12200	25400	2.5	150000	3.3
Hodgkin's disease	5200	4000	9200	0.6	1400	1100	2500	0.2	31300	0.7
Multiple myeloma	10500	10300	20800	1.3	7000	7200	14200	1.4	55600	1.2
Leukaemia	23300	19100	42400	2.6	15500	13500	29000	2.8	96500	2.1
All sites but skin	863100	768800	1631900	100	568700	464200	1032900	100	4512900	100

rectal cancer (one in seven prevalent cases) and prostate cancer (one in ten prevalent cases) comprise 46% of the cancers in men and women in the EU. Lung cancer, although the second most common tumour overall, is associated with a very poor prognosis, thus the number of prevalent cases is relatively small, with about one in 20 persons alive with this neoplasm in the EU.

Further tables of incidence, mortality and prevalence in the EU can be found via the Internet version of EUCAN on the CaMon website at:
http://www-dep.iarc.fr/HMP/CAMON.htm.

Cancer incidence and mortality in Europe

According to estimates of cancer incidence and mortality calculated for 1995[1] in the four UN-defined areas of Europe, there were about 2.6 million new cases of cancer in Europe. The corresponding number of deaths from cancer was estimated at approximately 1.6 million. After adjusting for differing population age structures, overall incidence rates in men were highest in the Western European countries and lowest in the Northern European countries, although very high rates were observed in certain Eastern European countries, notably Hungary and the Czech Republic. In contrast to men, the highest rates in women were observed in Northern Europe and lowest in Eastern Europe, although again rates were high in Hungary and in the Czech Republic.

There was greater disparity in the mortality rates within Europe – generally rates were highest in Eastern European countries, notably in Hungary, reflecting a combination of poorer cancer survival rates and a higher incidence of the more lethal neoplasms, notably cancer of the lung.

Lung cancer, with an estimated 377,000 cases, was the most common cancer in Europe in 1995. Rates were notably high in many Eastern European countries, a reflection of current and past tobacco smoking habits of many of its inhabitants. Together with cancers of the colon and rectum (334,000) and female breast (321,000), the three cancers represented approximately 40% of new cases in Europe. In men, the most common primary sites were lung (22% of all cancer cases), colon and rectum (12%), and prostate (11%). In women, cancer of the breast (26%), colon and rectum (14%) and stomach (7%) dominate. By far the most common cause of death was lung cancer (330,000 deaths), accounting for about one-fifth of the total number of cancer deaths in Europe in 1995. Deaths from cancers of the colon and rectum and stomach cancer ranked second and third, respectively, the latter of which, due predominantly to a poorer prognosis, ranked higher than breast cancer. Lung cancer was the most common cause of death from cancer in men (29%). Breast cancer was the leading cause of death in females (17%).

Detailed tabular and graphical information describing the geographical variations in incidence and mortality in Europe can be found via the CaMon website at: http://www-dep.iarc.fr/HMP/CAMON.htm.

Knowledge of the patterns of incidence and mortality are an essential basis for establishing policies for cancer control in Europe. Rates of lung cancer in men have begun to decline in some European countries, particularly in Northern and Western areas where the prevalence of smoking was among the first to decline. However, rates are still rising in Eastern Europe. Incidence and mortality rates in women, who acquired the smoking habit somewhat later than men, are now on the increase in many European countries. The lessons for primary prevention – the importance of decreasing and preventing tobacco smoking – are evident. Such measures will have an impact upon other tobacco-related neoplasms such as those of the oral cavity and pharynx, oesophagus, pancreas, larynx and bladder.

CONCLUSIONS

The CaMon project extends the activities of the ENCR to provide a central information resource of the fundamental cancer indicators, and actively disseminates this information to individuals and institutions in all Member and Applicant countries. Moreover, the statistics generated by the project: cancer incidence, mortality, survival and prevalence, together with time trends and projections will be regularly updated and made available to a Community-wide audience via the CaMon website at: http://www-dep.iarc.fr/HMP/CAMON.htm. Other means of dissemination include peer-reviewed scientific literature, specially-written software on CD-ROM, as well as scientific meetings, conferences and workshops.

Close contact with representatives of the national health statistics departments, as well as technical experts (cancer registries and individuals in the scientific community) will enable an assessment of the project and the utility of the output. The project will establish a basis for annual estimates of the core cancer indicators at the national and sub-national level, and provide regularly updated databases for the EUPHIN website of the Health and Consumer Protection DG.

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