

CANCER

Registry of Norway

INSTITUTE OF POPULATION-
BASED CANCER RESEARCH



Cancer in Norway 2006

Cancer incidence, mortality,
survival and prevalence in Norway

Special issue:
*Data Quality at the
Cancer Registry of Norway*



Cancer in Norway 2006

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Request for cancer information, data or possible research collaboration are welcome, and should be sent to datautlevering@kreftregisteret.no in the first instance.



Cancer in Norway 2006



Cancer incidence, mortality,
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Special issue:
*Data Quality at the
Cancer Registry of Norway*

Foreword

As with the last year's report, *Cancer in Norway 2006* maintains the commitment of the Cancer Registry of Norway to two key attributes of the annual incidence report: The first concerns the timely delivery of high quality cancer statistics to the community at large, the second, the inclusion of a *special issue* – a supplementary report on a theme of national importance.

The report contains cancer incidence data for the year 2006, compiled and published in 2007, within one year of the close of registration. The legal framework for cancer registration makes the reporting of cancer obligatory in Norway and ensures a well-functioning registry, but it is the proficiency of the hospitals and the clinical community in providing reports on each patient in a timely manner, and the dedication of our staff to the task of interpreting, coding and registering new cases of cancer that ensures the swiftness of the operation, from registration to reporting. Assuming a degree of underreporting analogous to that which we observed while publishing *Cancer in Norway 2005* (in late 2006), we can estimate the deficit in cases diagnosed in 2006 at this time to be around 2.5% or around 600 cases. We consider this level of underreporting to be sufficiently minor to enable us to publish the incidence data in this report.

The special issue concerns a subject of fundamental concern to a functioning registry, that of *data quality*. In this edition of *Cancer in Norway*, we provide an overview and assessment of the quality of the data within The Cancer Registry of Norway, focusing on those data items primarily used for the study of incidence (within the *incidence registry*). The ongoing expansion and integration of the *clinical registries* should ensure a further improvement in the quality of the registry data overall, and the first reports that document the reliability of the clinical data will be published as of when these registries sufficiently mature.

The Registry has established a wide-ranging research portfolio that includes the elucidation of the causes of cancer, the management and surveillance of the national breast and cervix screening programmes, and the clinical follow-up of cancer patients in Norway. The Registry collaborates widely with the clinical and research community at the national and international level to ensure high-quality population-based cancer research. Its value to carry out such comprehensive activities relies heavily on the quality of the registry data itself, and the quality control procedures in place, hence the motivation for a thorough report on the topic.

As ever, we look forward to continuing our close collaboration with the regional cancer and the clinical community in Norway, and with our research colleagues, both in Norway and abroad.



Oslo, December 2007
Frøydis Langmark
Director

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Special issue:

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Data Sources and Methods

The population of Norway

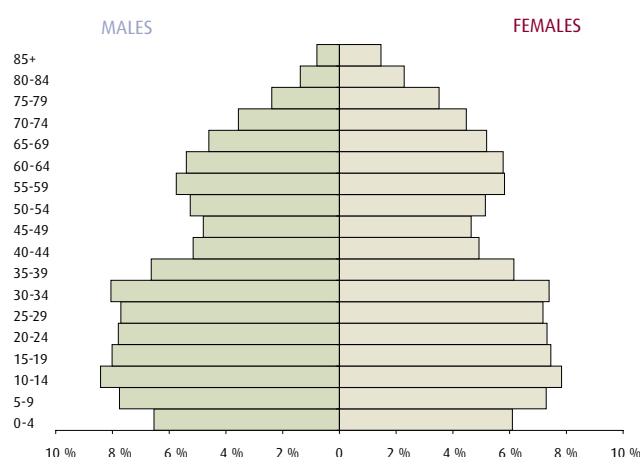
The Norwegian population is principally white Caucasian, with an immigrant population (from over 200 countries) comprising around 9% of the total population of 4.7 million in 2006 (Table 1). Figure 1 illustrates the changing population size and age structure of Norway, comparing population estimates in 1980 and 2006 with projections for 2030 (Statistics Norway, 2006). The population of Norway has been increasing since records began, and this growth is expected to continue in the next decades. The total number of inhabitants in Norway has increased by 12% during the last 25 years, largely as a result of rising life expectancy and more recently, increases in net immigration. By 2030, the size of the population is expected to increase a further 17% to about 5.4 million (Statistics Norway, 2004). The elderly will represent an increasingly large proportion of the population of Norway in the next quarter of a century, predominantly as a result of lengthening life expectancy. It is projected that by 2030 over one million inhabitants, or one-fifth of the population will be aged 65 or over.

Table 1: Number of inhabitants in Norway 31.12.2006

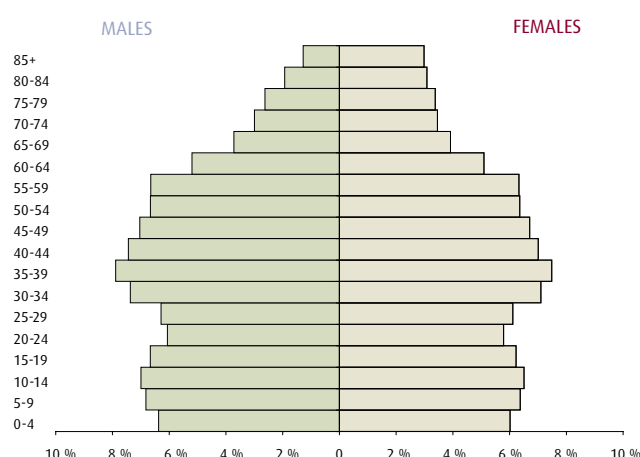
Age	Males	Females
0-4	147 973	141 812
5-9	154 758	147 436
10-14	161 448	152 504
15-19	157 915	150 355
20-24	142 064	136 433
25-29	145 390	143 448
30-34	165 907	162 101
35-39	182 349	176 455
40-44	175 641	167 158
45-49	163 161	156 908
50-54	155 972	152 057
55-59	149 713	144 519
60-64	131 703	130 357
65-69	87 570	93 263
70-74	68 877	79 949
75-79	59 963	77 813
80-84	44 618	70 574
85+	15 383	72 204
Total	2 325 788	2 355 346

Figure 1

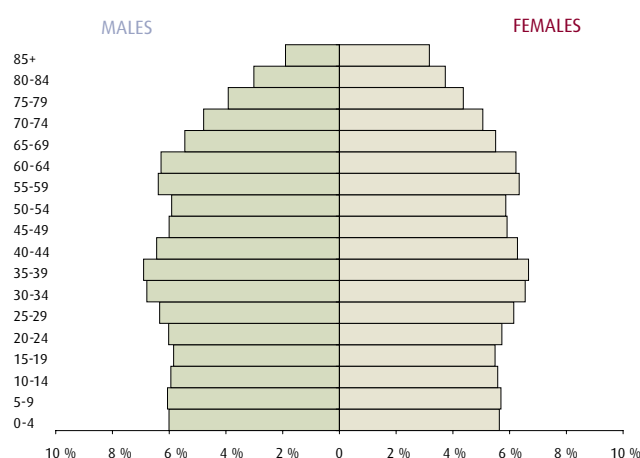
Age structure of the Norwegian population, 1980



Age structure of the Norwegian population, 2006



Age structure of the Norwegian population, 2030*



*Forecasted, Statistics Norway

Special issue on data quality

This special issue *Data Quality at the Cancer Registry of Norway* supplements this report, and in the first chapter introduces the information sources, data items collected, and the in-house routines - the notification and reminder systems - maintained by the Registry (Chapter S1). The primary objective of the special issue is to provide an overview of the data quality at the Registry. The chapters that follow describe in detail the key aspects of data quality: comparability, completeness, validity and timeliness, and these are very briefly summarised below. Each chapter begins with a general discussion of that topic, followed by a comprehensive examination of the data held at the Cancer Registry of Norway.

Comparability (Chapter 2)

There must be comparability of the statistics generated by registries to allow appropriate geographical and temporal comparisons. The fundamental prerequisite for comparable data is a standardisation of registry practices with regards the systems used for the classification and coding of incident cases, as well as consistent and appropriate definition of what constitutes a cancer case (e.g. the date of cancer incidence and the recording and reporting of multiple primary cancers).

In general, the Registry's in-house coding and classification systems adhere with certain international standards. Up to and including 1992, the Registry has coded cancer topography according to ICD-7, and from 1993, according to ICD-O-2, with the topography axis standardised with ICD-10. This and the previous annual report has reported results using the ICD-10 nomenclature, following a conversion of the registry data from ICD-7. Morphology was coded according to MOTNAC from 1970 to 1992, and using ICD-O morphology system from 1993; separate systems have been employed for non-solid tumours since 1986. A complete transformation to coding and registration according to ICD-O-3 is now entering its initial phase.

The incidence date - recorded as the day, month and year of diagnosis - adheres to the ENCR recommendations, with the exception that the Registry always registers the earliest incidence date irrespective of the notification source, rather than based upon a hierarchy of possible sources. Since 1981, recognition of the existence of two or more primary cancers was enabled for all neoplasms at the Registry. In general, there is coherence with the IACR (ICD-O-2) rules, although there are some discrepancies.

Completeness (Chapter 3)

Completeness can be defined as the extent to which all new cases of cancer occurring in Norway are included in the incidence registry. Cancer incidence and survival statistics will only be close to their true value if the case-finding procedures at the cancer registry are optimal. There are several established statistical methodologies available for its estimation, and several methods are applied to provide semi-quantitative as well as quantitative estimates of the completeness of the Registry data. The latter includes capture-recapture methods, which on the basis of several (unverifiable) assumptions indicate completeness for the registration period 2001-5 to be greater than 95% for most cancer sites but lower for a number of cancers associated with poorer survival. Collapsing on sources that were considered dependant yielded still higher estimates of completeness for most cancer sites, and gave an overall completeness at the Registry of 99.7%.

A second method was used to examine how completeness of the registration of cancer patients in a given year increases with time since diagnosis. Completeness at the Registry for the year 1999 (for patients followed up until 31.12.2004) was over 95% three years after diagnosis. As the median number of days between diagnosis and registration of cancer patients was considerably reduced for registrations in 2005 and onwards, we should anticipate completeness to be at a similar level one year from the end of registration for years 2005 and 2006; this can be formally estimated once sufficient follow-up time of these patients has accrued.

Validity (Chapter 4)

Validity or accuracy refers to the proportion of registered cases with a given characteristic that truly have that attribute, and depends on the precision of source documents and the level of expertise in abstracting, coding, and recording. There are several key indicators of the accuracy of the data. For most cases, the accuracy of the stated diagnosis is likely to be higher if it is based on histological examination by a pathologist. The percentage of cases morphologically verified was estimated to be 88% at the Registry for the period 2001-5, although the proportion was higher for colon, breast and cervix cancer, but much lower for cancers of the pancreas and liver. The proportion of cancers for which no information other than a death certificate mentioning cancer can be obtained - death certificate only registration is another measure of validity, since death certificate information is known to have less accuracy or precision than records from clinical or pathology sources. The proportion of such cases for

the period 2000-4 was about 0.7% at the Registry, but again there were variations according to cancer site. The proportion is somewhat higher for 2005, although this will likely fall once a batch of death certificates - having arrived late at the Registry - are duly processed.

Finally, a high proportion of cases assigned to the category 'primary site unspecified' generally implies poor diagnostic precision or failure to specify the site of the primary cancer in cases diagnosed on the basis of tissue obtained from a metastasis. At the Registry, the proportion of cases registered within this group was around 3% yearly between 2001 and 2005, but achieved less specificity as age of diagnosis increased. The level accords with those observed in other high-quality registries in Europe.

Timeliness (Chapter 5)

The timeliness of the reporting of registry results is a further aspect of quality, and clearly influences the extent to which data are complete and accurate. Access to recent data is a priority for most registries, although they are constantly updating as reports are received, some notifications, especially those from death certificates, arrive long after the cases were diagnosed. The result is that incidence for the recent period of registration can be considered somewhat incomplete.

The Registry's obligation to provide timely information on cancer in Norway that is also accurate and complete provides a good example of this phenomenon. As there has been a major reduction in the delay between registration and publication since 2005, the last two reports have been published within 12 months of the registration period. We can estimate the level of underascertainment for the registration year 2006 by comparing the observed number of cancer cases diagnosed in 2005 (as extracted in November 2006) with the figures retrieved from the incidence registry in November 2007. Assuming the registration processes in 2005 and 2006 are reasonably analogous, and therefore that the shortfall between publication and accrual given the passage of one year would be similar, we estimate the shortfall in 2006 to be approximately 2.5% or around 600 cases. The percentage varies substantially by cancer site, and it would be anticipated that larger deficits (10-20%) are observed for cancers of the lip, central nervous system and leukaemia.

The incidence registry

The incidence registry contains the basic data items collected from clinicians and pathologists, as well as from administrative patient discharge and mortality sources. As of mid-November 2007, the Incidence re-

gistry contained information from 1953 on 1 333 220 cancer cases and premalignant conditions in 1 086 042 persons. A total of 3 102 732 notifications have been received since 1969. For all cases registered since 1953, 86.5% are histologically verified and 1.3% of the diagnoses are based on death certificates alone. The incidence registry is updated continuously with information on both new cases, as well as cases diagnosed in previous years.

Statistical methods used in this report

Four measures are used in this report to describe the burden and risk of disease: incidence, mortality, survival and prevalence.

Incidence and mortality refer to the number of new cases and deaths occurring, respectively. The latter is the product of incidence and the fatality of a given cancer, the proportion of cancer patients that die. Both measures can be expressed as the absolute number of cases (or deaths), or as the incidence (or mortality) rate, taking into account the size of the population at risk. Rates are essential in the comparisons between groups, and within groups over time. The denominator is the underlying person-time at risk in which the cases or deaths in the numerator arose. Prevalence and survival (see below) are proportions rather than rates as there is no time dimension, although the term is frequently attached to both measures.

Cancer incidence and mortality in Norway are presented in this report as both numbers and rates. Several types of rate are used in this report.

Age-specific rates

There are compelling grounds for adjusting for the effects of age when comparing cancer risk in populations. Age is a very strong determinant of cancer risk, with rates of epithelial cancers increasing approximately as a fifth power of age (Armitage and Doll, 1954). The *crude rate*, a rate based on the frequency of cancer in the entire population, is calculated ignoring possible stratifications by age. Although the measure can be useful as an indicator of the extent of burden, its utility in comparing cancer risk is severely limited where there are differing age structures across groups, or where demographic changes have impacted on the size and age structure of a population over time.

To obtain a more accurate picture of the true risk of cancer, rates are calculated for each age strata, usually grouped in five-year intervals. The age-specific rate for age class i , denoted as r_i is obtained by dividing the number of events in each age class d_i by the corresponding person-years of observation Y_i and multiplying by 100 000:

$$r_i = d_i / Y_i \times 100\,000$$

Rates are given separately for males and females, because of the often very different cancer patterns by sex. Age and sex-specific incidence and mortality rates are the foundation of epidemiological analysis of cancer frequency data.

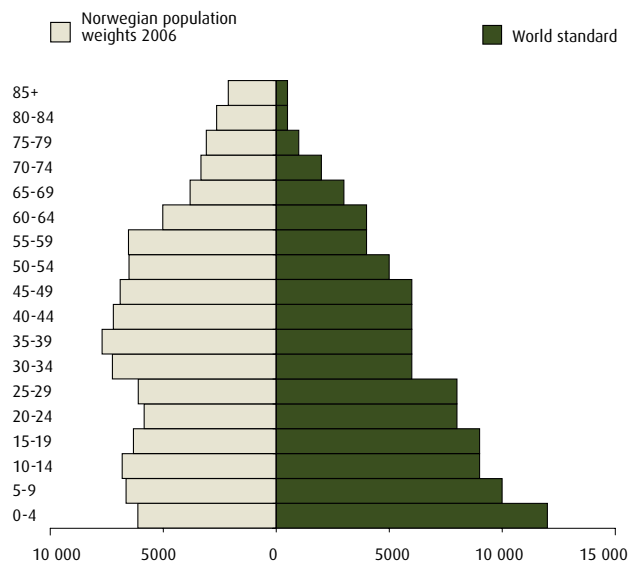
Age-standardised rates

To facilitate comparisons however, a summary rate is required that absorbs the schedule of age-specific rates in each comparison group. The summary measure that appears in this report is the age-standardised rate (ASR), a statistic that is independent of the effects of age, thus allowing comparisons of cancer risk between different groups. The calculation of the ASR is an example of direct standardisation, whereby the observed age-specific rates are applied to a standard population. The populations in each age class of the Standard Population are known as the *weights* to be used in the standardisation process. Many possible sets of weights, w_i , can be used. The *world* standard population, a commonly-used reference, is utilised in this report (Segi, 1960; Doll *et al*, 1966). Although the weights of the world standard fail to resemble those of the Norwegian population in 2006 (Figure 2), this observation is of relatively little importance, since it is the *ratio* of ASRs, an estimate of the age-adjusted relative risk between populations or within a population over time, that is the focus of interest. This characteristic has been shown to be rather insensitive to the choice of standard (Bray *et al*, 2002).

For weights w_i in the i th age class of the world standard and for A age classes with $i = 1, 2, \dots, A$, r_i , as before, is the age-specific rate in the i th age class. The ASR is calculated as:

$$ASR = \frac{\sum_i r_i w_i}{\sum_i w_i} \times 100\,000$$

Figure 2: Comparison of population weights



Survival

The study of cancer survival using registry data allows a population-based perspective, important for monitoring and evaluating the effectiveness of cancer care in Norway. The survival time of a cancer patient is defined as the time that elapsed between diagnosis and death. Computation of survival depends upon follow-up of diagnosed cancer patients, and the calculation of the numbers surviving after different intervals of time. In order to estimate *cause-specific* (or *corrected*) survival, we require accurate data on cause of death. Such information is generally based on the coding of death certificates, a source that is generally not considered to be sufficiently reliable.

A common alternative to corrected survival – and as used in this report – is to compute *relative survival* and compare the observed mortality (or *hazard*) rate in patients with the expected rate in the population from which they arise (Ederer *et al*, 1961). Relative survival is defined as the observed survival among cancer patients divided by the expected survival for a comparable group from the general population with respect to the main factors affecting survival, commonly sex, age, and calendar year.

To calculate observed survival the *actuarial* method was used, the period of observation was thus partitioned into a series of time intervals and the conditional (interval-specific) survival proportions for five consecutive 1-year intervals estimated. Cumulative survival $S(t)$ up to time t was estimated as the product of the interval-specific survival proportions for all intervals up to and including the specified interval. The cor-

responding expected survival probabilities were calculated using the *Ederer II* method (Estève *et al*, 1994), from the published annual probabilities of death in Norway. The appropriate probability was obtained on stratification by sex, the age of the patient, and the year of registration, obtained from population life tables.

The cohort-based approach to survival analysis was used here, whereby patients diagnosed from the beginning of 1997 to the end of 2001 were followed up with regards their vital status for at least five years. Trends in cancer survival for cancer patients diagnosed in five-year periods from 1957 through to 2001 are also provided in this report. DCO registrations were excluded from the analyses.

Prevalence

Prevalence is the proportion of a population that has the disease at a given point in time. It is a rather complex measure of cancer incidence, fatality, and other influences operating in affected individuals prior to death or *cure*. Although prevalence usefully describes the number of individuals requiring care for disease like hypertension and diabetes, many persons diagnosed with cancer in the past may now be considered cured, in that they no longer have an excess risk of death. Some residual disability may be present however, subsequent to a specific treatment intervention, for example.

Lifetime cancer prevalence can be defined as all persons living and ever diagnosed with cancer, and such a measure can easily be derived at the Cancer Registry of Norway given the very long-term registration of cases, and complete follow up of vital status over many years. Although such statistics are provided in this report, *partial* prevalence estimates are perhaps of more utility in quantifying resource requirements: the numbers of persons alive as of 31 December 2006, whom were diagnosed with cancer within one year, one to four years, five to nine years, and 10 or more years, are therefore also incorporated into this report.

Definitions*

Incidence

The number of new cases of cancer in a defined population within a specific period of time.

Incidence rate

The number of new cases that arise in a population (incidence) divided by the number of people who are at risk of getting cancer in the same period. The rate is expressed per 100 000 person-years**.

Crude rate

As above, with rates estimated for the entire population ignoring possible stratifications, such as by age group.

Age-specific rate

A rate calculated on stratifying by age, often based on a five-year interval.

Age-standardised incidence rate

Age-standardised (or age-adjusted) incidence rates are summary rates which would have been observed, given the schedule of age-specific rates, in a population with the age composition of a given standard population. The World standard population (Doll *et al*, 1966) is used in this report.

Relative survival

The ratio of the observed survival to the expected survival for a group of patients. The expected survival is based on the mortality in a comparable group of people in the total population. This group has the same age and sex distribution as the patient group in the same time period.

Prevalence

Prevalence is the proportion of a population that has the disease at a given point in time.

* Last's "A Dictionary of Epidemiology 4th Ed" was consulted.

** *Person-years* is a measurement that combines persons and time (in years) as the denominator in rates.

Table 2 Number of new cases by primary site and sex - 2006

ICD10	Site	Males	Females	Total
C00-96	All sites	12903	11585	24488
C00-14	Mouth, pharynx	269	198	467
C00	Lip	63	41	104
C01-02	Tongue	47	37	84
C03-06	Mouth, other	53	56	109
C07-08	Salivary glands	16	21	37
C09-14	Pharynx	90	43	133
C15-26	Digestive organs	2613	2520	5133
C15	Oesophagus	142	45	187
C16	Stomach	298	202	500
C17	Small intestine	62	41	103
C18	Colon	1046	1232	2278
C19-21	Rectum, rectosigmoid, anus	640	535	1175
C22	Liver	79	35	114
C23-24	Gallbladder, bile ducts	52	67	119
C25	Pancreas	262	320	582
C26	Other digestive organs	32	43	75
C30-34, C38	Respiratory organs	1512	992	2504
C30-31	Nose, sinuses	18	20	38
C32	Larynx, epiglottis	114	11	125
C33-34	Lung, trachea	1369	953	2322
C38	Mediastinum, pleura	11	8	19
C40-41	Bone	23	16	39
C43	Melanoma of the skin	544	634	1178
C44	Skin, non-melanoma	706	633	1339
C45	Mesothelioma	43	20	63
C46	Kaposi's sarcoma	7	4	11
C47	Autonomic nervous system	5	8	13
C48-49	Soft tissues	62	78	140
C50	Breast	14	2673	2687
C51-58	Female genital organs		1522	1522
C53	Cervix uteri		294	294
C54	Corpus uteri		639	639
C55	Uterus, other		14	14
C56	Ovary		447	447
C51-52, C57	Other female genital		125	125
C58	Placenta		3	3
C60-63	Male genital organs	4110		4110
C61	Prostate	3815		3815
C62	Testis	255		255
C60, C63	Other male genital	40		40
C64-68	Urinary organs	1287	565	1852
C64	Kidney excl. renal pelvis	335	194	529
C65	Renal pelvis	47	25	72
C66-68	Bladder, ureter, urethra	905	346	1251
C69	Eye	34	23	57
C70-72	Central nervous system	339	450	789
C73	Thyroid gland	73	142	215
C37, C74-75	Other endocrine glands	11	14	25
C39, C76, C80	Other or unspecified	227	285	512
C81-96	Lymphoid and haematopoietic tissue	1024	808	1832
C81	Hodgkin lymphoma	69	47	116
C82-85, C96	Non-Hodgkin lymphoma	473	379	852
C88	Malignant immunoproliferative diseases	21	17	38
C90	Multiple myeloma	171	134	305
C91-95	Leukaemia	290	231	521

Incidence

In 2006, there were 24 488 incident cases of cancer in Norway, of which 12 903 occurred among men and 11 585 among women (Table 4). The four most common forms continue to be cancers of the prostate, female breast, colon and lung, and they are responsible for half of the total cancer burden (12 277 new cases). Prostate cancer is the most frequent cancer in men (3815), followed by colorectal (1686) and lung cancer (1369). With 2673 new cases in 2006, breast cancer is the most frequently-occurring neoplasm in women, colorectal and lung cancer rank second and third, with 1767 and 953 incident cases, respectively.

Cancer rates increase rapidly with age, and the vast majority in Norway – about 85% in men and 75% in women occur in persons aged over 55 (Figure 3). The highest proportion of cancers occur in the 55-74 age group, with close to half of all cancers diagnosed in men, and approximately 40% of those diagnosed in women, occurring within this age range. A further one-third of the burden cancer affects elderly men and women (aged 75 or over). It is of note that close to one in five cancers diagnosed in women occur within the ages 30 to 54, a higher proportion than seen in men (about one in ten men).

The relative impact of different forms of cancer varies considerably with age. Figure 4 identifies those cancer sites that contribute substantially to the disease burden

in children (aged 0-14), adolescents and young adults (15-29), the middle-aged and the elderly (30-54, 55-74 and age 75 or over).

Table 3 compares the age-standardised rates and sex ratios for selected cancer types in 1978-1982 and 2002-2006. Men tend to have an excess of incidence for most cancer forms in both time periods, with the exceptions of melanoma of the skin, and, most notably, thyroid cancer. The highest male:female (M:F) ratios are seen for several head and neck cancers, although a number of the most frequent cancer forms - lung, bladder, stomach and rectum - are consistently more common among men. The declines in M:F ratios for several neoplasms over the 25 year period may be explained by decreasing trends among men, increasing trends among women, or indeed a combination of both. For lung cancer, the halving of the M:F ratios during the last quarter century points to a more rapid increase in trends in female rates relative to those in men.

The time trends of selected cancers in Figure 5 provide more detail regarding the changing evolution of cancer risk among Norwegian men and women. Of note are: 1) the unparalleled rise in prostate cancer incidence since 1990, largely as a result of the rapidly increasing use of the Prostate Specific Antigen (PSA) test since it became commercially available in 1989; 2) the continued increases in both breast cancer and lung cancer among women, and colon cancer in both sexes; 3) the continuing declines in stomach cancer in both sexes; and 4) the rapid increases in a number

Figure 3: Percentage distribution of cancer incidence by age, 2002-2006

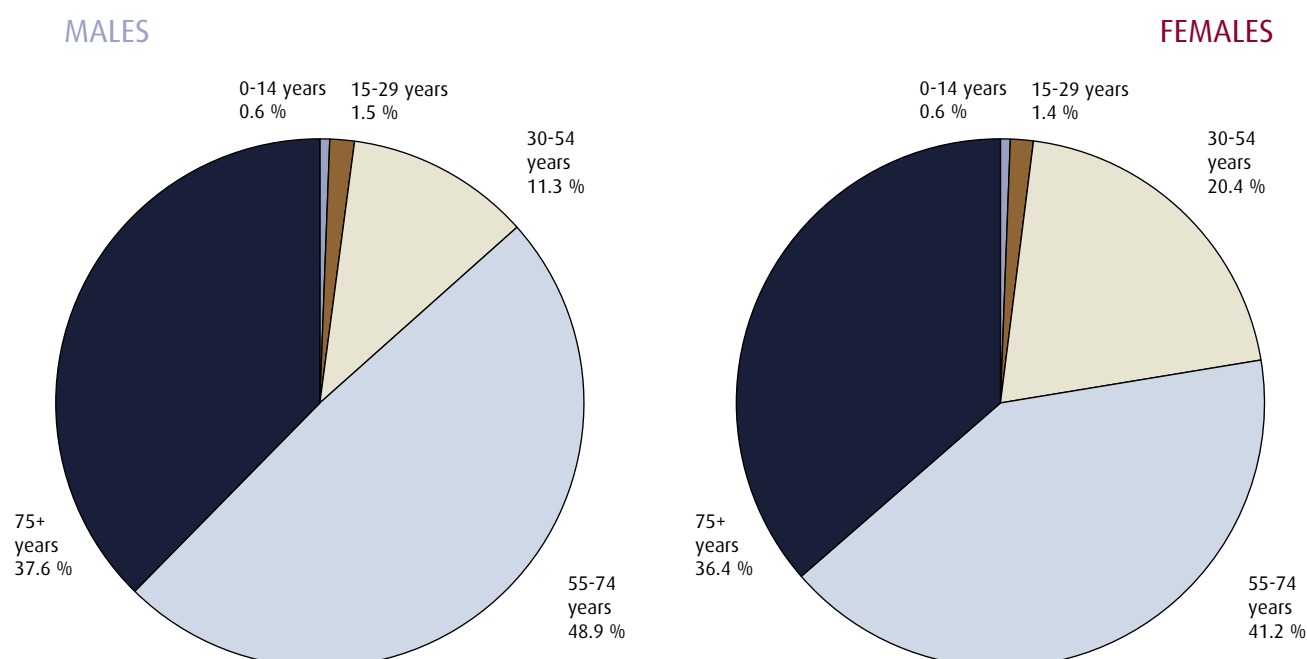
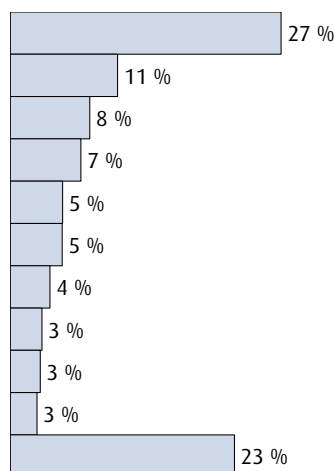
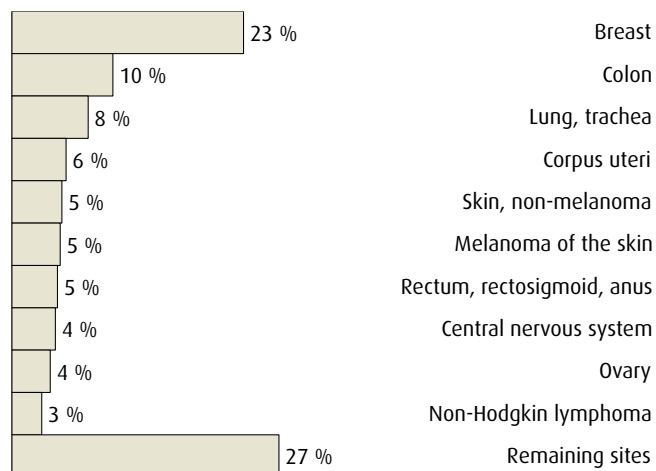


Figure 4: The most frequent incident cancers by age and sex, 2002–2006

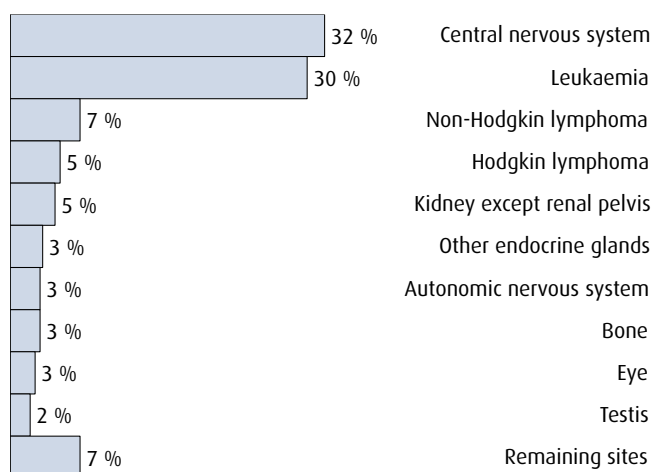
MALES all ages (63 601 cases)



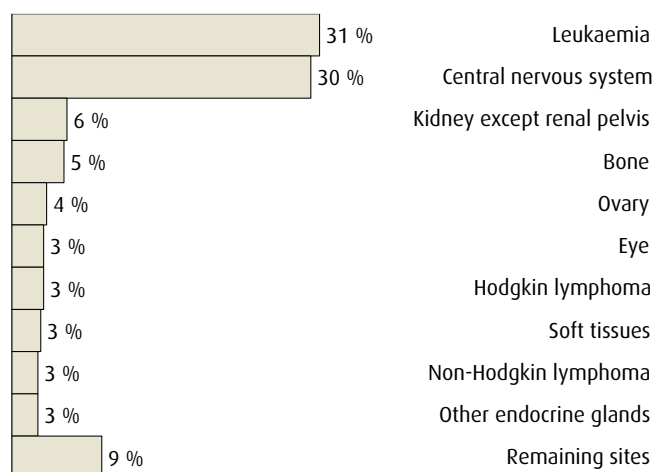
FEMALES all ages (58 249 cases)



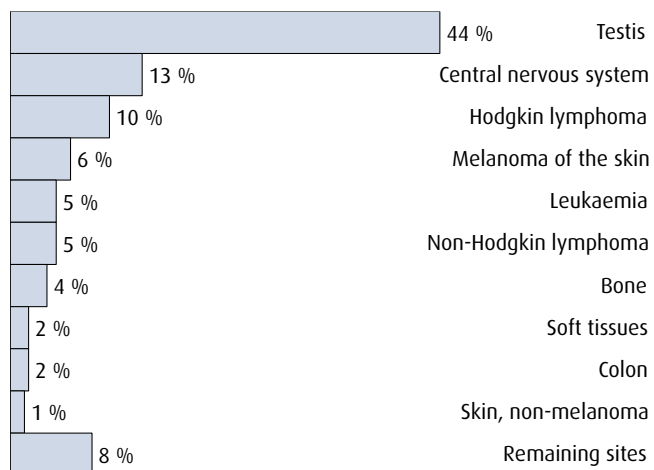
MALES 0–14 years (394 cases)



FEMALES 0–14 years (339 cases)



MALES 15–29 years (961 cases)



FEMALES 15–29 years (821 cases)

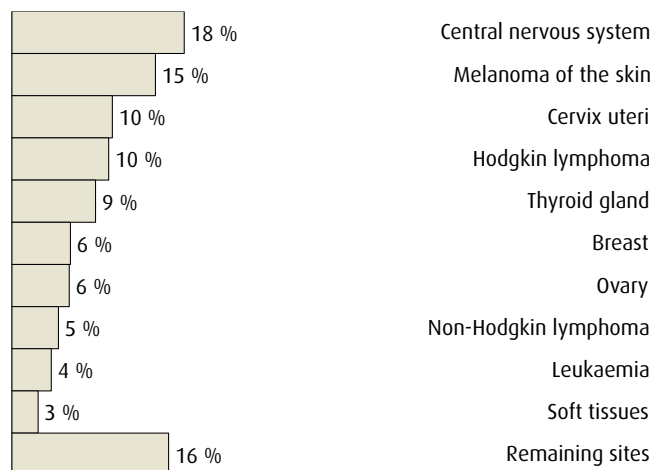
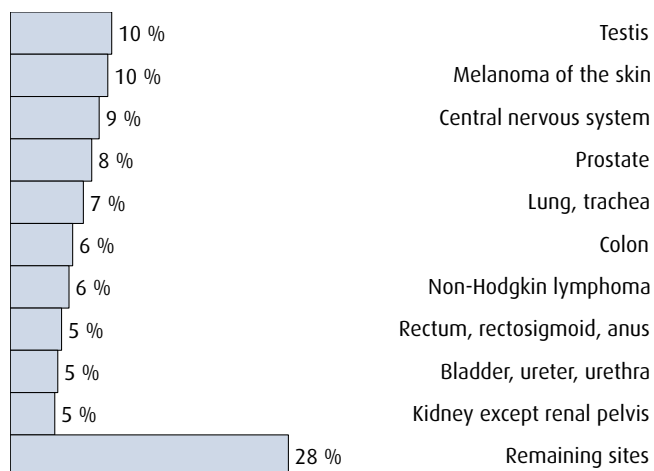
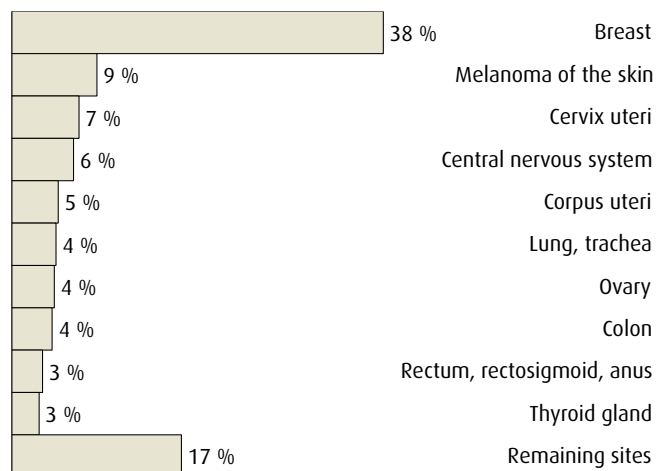


Figure 4 cont.

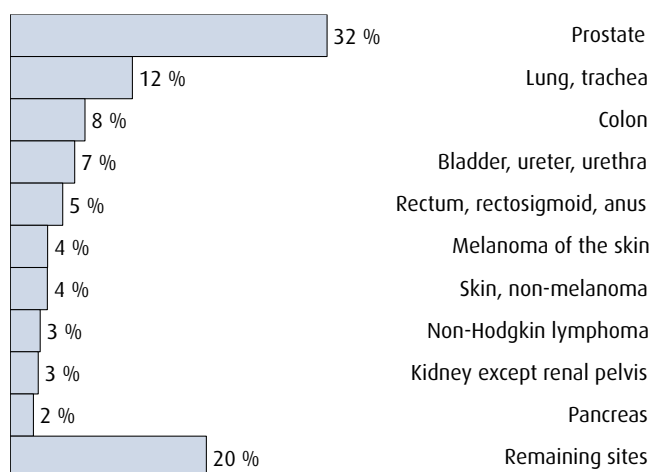
MALES 30–54 years (7214 cases)



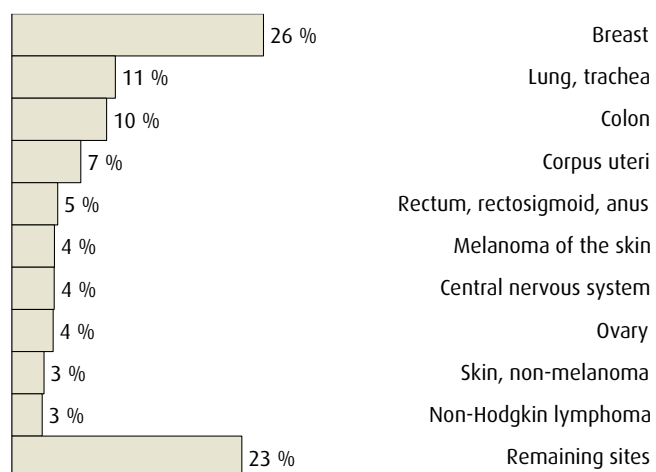
FEMALES 30–54 years (11 876 cases)



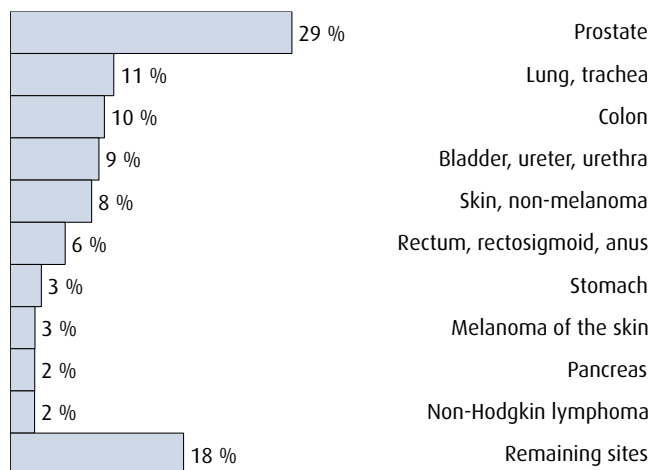
MALES 55–74 years (31 126 cases)



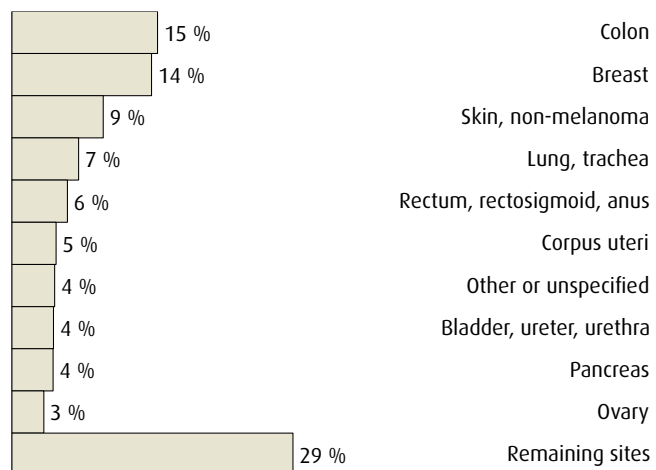
FEMALES 55–74 years (24 018 cases)



MALES 75+ years (23 906 cases)



FEMALES 75+ years (21 195 cases)



of cancers for which the underlying causes (and prospects for primary prevention) remain enigmatic: testicular cancer in men and non-Hodgkin lymphoma in both sexes.

The total burden of cancer in Norway - expressed as the number of new cases - has been increasing in the last decade (Table 4 and 5), as it has been since the Registry began reporting. This observation reflects real increases in the risk of several common cancers including female breast, colorectal and lung cancer, but it also relates to an increasing ability to diagnose the disease with time, particularly for prostate cancer in the 1990s. The increases in these common cancers are partially compensated by decreasing incidence trends of several cancer types, notably stomach cancer (in both sexes) and cervix cancer in women. Melanoma of the skin is stabilising in both sexes, while rates of lung cancer in men are beginning to decline (Figure 5).

As was described in Figure 1, a larger proportion of the increasing burden can be attributed to the demographic effects of population growth and ageing (see

the special issue of CiN 2005, for predictions of cancer in Norway up to 2020, by Health Region.)

Tables 6-19 provide further information on the distribution of cancer incidence in Norway. The number of incident cases and rates are tabulated according to year of diagnosis, age group and county of residence.

Further information

In keeping with previous Cancer in Norway reports, further graphical descriptions for 23 cancer sites are available on our website. Graphical descriptions of age-specific incidence rates for the year 2006, time trends of age-adjusted incidence rates 1957-2006, and maps depicting the geographical variation by region 2002-2006 can be downloaded from our website by following the link:

www.cancerregistry.no/cin

Table 3: Sex ratios (male:female) of age-adjusted rates (world) in 1978-82 and 2002-2006 for selected primary sites, sorted in descending order in the latest period

ICD10	Site	1978-82			2002-06		
		M	F	M/F ratio	M	F	M/F ratio
C32	Larynx, epiglottis	3.1	0.3	10.3	2.9	0.4	7.5
C15	Oesophagus	2.7	0.7	3.8	3.7	1.1	3.5
C66-68	Bladder, ureter, urethra	18.2	5.5	3.3	22.0	6.4	3.4
C09-14	Pharynx	1.7	0.5	3.3	2.6	1.0	2.8
C22	Liver	1.8	1.0	1.8	2.1	1.0	2.2
C01-02	Tongue	1.0	0.4	2.6	1.5	0.7	2.1
C00	Lip	3.4	0.4	7.9	1.3	0.6	2.0
C64	Kidney excl. renal pelvis	7.5	4.0	1.9	9.7	4.9	2.0
C65	Renal pelvis	1.0	0.4	2.3	1.0	0.5	1.9
C16	Stomach	18.0	9.2	2.0	7.8	4.3	1.8
C33-34	Lung, trachea	30.9	7.3	4.2	35.9	21.8	1.6
C91-95	Leukaemia	8.1	5.4	1.5	9.2	6.1	1.5
C90	Multiple myeloma	4.6	3.0	1.5	4.5	3.0	1.5
C19-21	Rectum, rectosigmoid, anus	14.7	10.1	1.5	17.3	11.5	1.5
C81	Hodgkin lymphoma	2.6	1.6	1.6	2.8	1.9	1.5
C82-85, C96	Non-Hodgkin lymphoma	6.2	4.5	1.4	11.6	8.4	1.4
C25	Pancreas	8.4	5.3	1.6	7.6	6.1	1.2
C23-24	Gallbladder, bile ducts	1.1	1.6	0.7	1.5	1.4	1.1
C18	Colon	17.1	17.4	1.0	25.3	23.0	1.1
C43	Melanoma of the skin	8.9	10.4	0.9	14.9	16.3	0.9
C73	Thyroid gland	1.6	5.1	0.3	1.8	4.7	0.4

Figure 5: Time trends in age-standardised incidence rates (world) in Norway for selected cancers (semi-log scale)

MALES

FEMALES

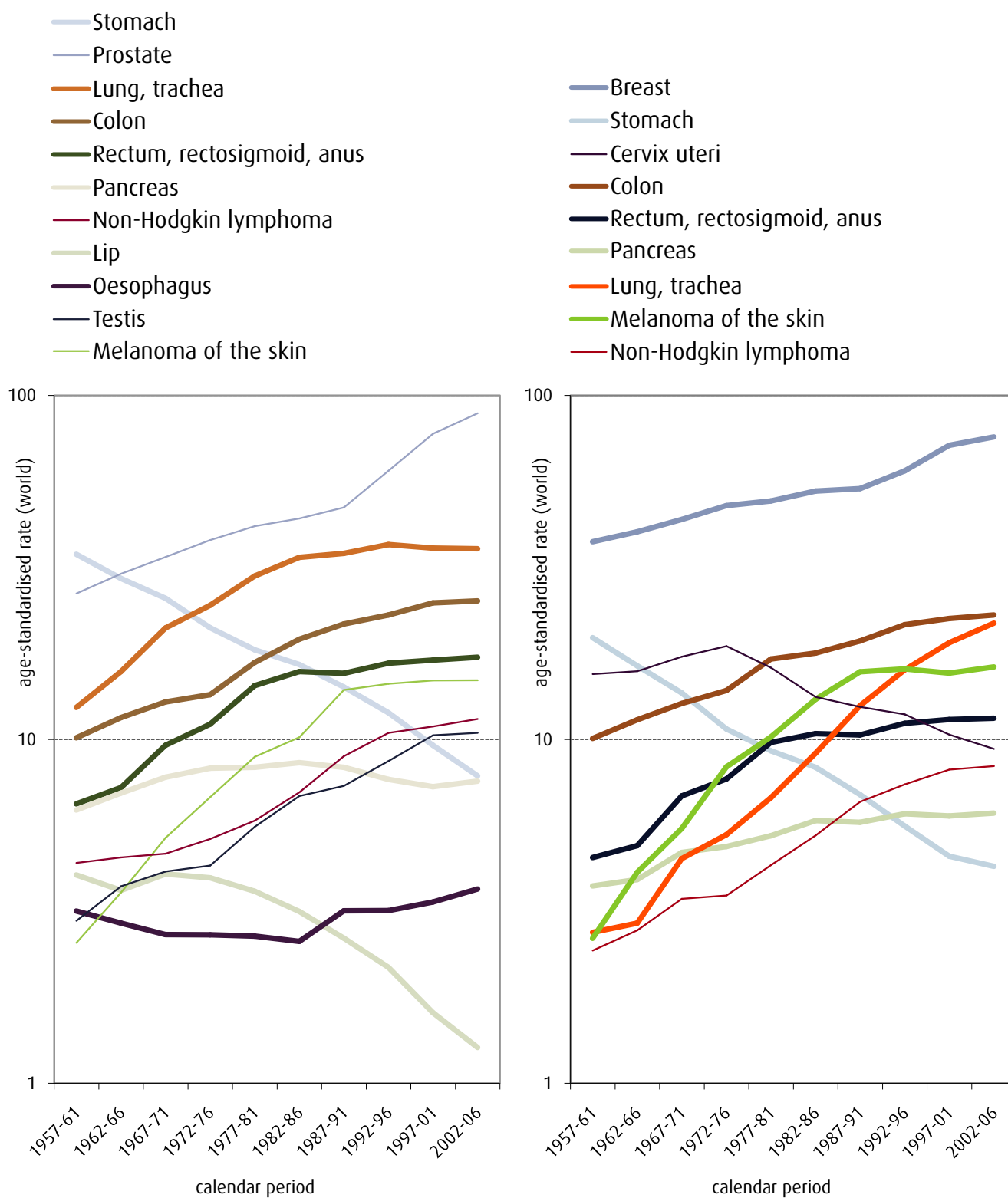


Table 4 Number of new cases by primary site and year - 1997-2006

MALES

ICD10	Site	Year									
		1997	98	99	00	01	02	03	04	05	2006
C00-96	All sites	11091	11317	11341	11535	11651	11588	12503	13144	12942	12903
C00-14	Mouth, pharynx	268	256	252	276	240	255	249	256	239	269
C00	Lip	72	52	58	62	51	60	40	35	44	63
C01-02	Tongue	53	49	51	41	51	50	52	54	45	47
C03-06	Mouth, other	44	42	50	57	36	46	52	52	38	53
C07-08	Salivary glands	22	22	22	28	21	22	17	17	25	16
C09-14	Pharynx	77	91	71	88	81	77	88	98	87	90
C15-26	Digestive organs	2559	2540	2506	2554	2666	2632	2689	2790	2716	2613
C15	Oesophagus	121	126	134	102	121	123	136	149	133	142
C16	Stomach	404	387	370	366	369	332	346	348	298	298
C17	Small intestine	42	45	39	45	66	46	57	44	49	62
C18	Colon	914	940	901	987	1000	969	992	1070	1059	1046
C19-21	Rectum, rectosigmoid, anus	640	604	595	621	634	687	679	692	688	640
C22	Liver	46	69	86	71	79	83	74	82	74	79
C23-24	Gallbladder, bile ducts	62	59	61	54	70	53	56	69	72	52
C25	Pancreas	274	272	275	271	288	306	311	297	308	262
C26	Other digestive organs	56	38	45	37	39	33	38	39	35	32
C30-34, C38	Respiratory organs	1427	1368	1429	1450	1493	1503	1565	1520	1523	1512
C30-31	Nose, sinuses	21	25	24	27	23	28	17	25	24	18
C32	Larynx, epiglottis	99	88	113	111	120	115	93	98	96	114
C33-34	Lung, trachea	1286	1241	1274	1298	1334	1348	1437	1386	1392	1369
C38	Mediastinum, pleura	21	14	18	14	16	12	18	11	11	11
C40-41	Bone	23	18	21	20	22	28	21	28	26	23
C43	Melanoma of the skin	481	450	466	467	486	472	479	486	582	544
C44	Skin, non-melanoma	581	548	532	579	582	654	641	688	665	706
C45	Mesothelioma	37	52	56	51	61	51	64	72	71	43
C46	Kaposi's sarcoma	9	6	3	3	6	6	6	9	9	7
C47	Autonomic nervous system	3	7	7	7	4	5	7	2	6	5
C48-49	Soft tissues	48	51	45	51	50	56	48	52	48	62
C50	Breast	11	21	14	17	13	14	20	14	18	14
C60-63	Male genital organs	2977	3256	3317	3352	3201	3043	3712	4140	3970	4110
C61	Prostate	2714	2988	3041	3076	2902	2766	3404	3829	3665	3815
C62	Testis	221	234	249	248	268	237	255	265	255	255
C60, C63	Other male genital	42	34	27	28	31	40	53	46	50	40
C64-68	Urinary organs	1137	1185	1134	1132	1184	1245	1256	1418	1294	1287
C64	Kidney excl. renal pelvis	286	304	284	271	322	327	333	389	348	335
C65	Renal pelvis	42	34	37	41	36	39	32	57	33	47
C66-68	Bladder, ureter, urethra	809	847	813	820	826	879	891	972	913	905
C69	Eye	25	26	27	35	23	31	40	31	27	34
C70-72	Central nervous system	302	324	346	340	378	371	417	384	431	339
C73	Thyroid gland	50	45	45	52	52	53	52	50	67	73
C37, C74-75	Other endocrine glands	11	8	15	19	9	12	18	11	7	11
C39, C76, C80	Other or unspecified	300	285	276	261	237	233	250	208	220	227
C81-96	Lymphoid and haematopoietic tissue	842	871	850	869	944	924	969	985	1023	1024
C81	Hodgkin lymphoma	59	52	61	63	54	54	87	75	65	69
C82-85, C96	Non-Hodgkin lymphoma	331	370	330	389	357	345	385	413	433	473
C88	Malignant immunoproliferative diseases	28	17	20	14	27	29	33	26	19	21
C90	Multiple myeloma	176	168	155	149	182	166	164	173	211	171
C91-95	Leukaemia	248	264	284	254	324	330	300	298	295	290

Table 5 Number of new cases by primary site and year - 1997-2006

FEMALES

ICD10	Site	Year									
		1997	98	99	00	01	02	03	04	05	2006
C00-96	All sites	10293	10236	10273	10846	10918	11313	11375	11749	11788	11585
C00-14	Mouth, pharynx	112	136	133	128	140	134	127	133	181	198
C00	Lip	29	28	19	23	31	27	21	23	41	41
C01-02	Tongue	19	24	34	29	27	27	25	27	31	37
C03-06	Mouth, other	41	35	25	29	35	34	29	41	43	56
C07-08	Salivary glands	11	20	22	23	24	18	19	11	26	21
C09-14	Pharynx	12	29	33	24	23	28	33	31	40	43
C15-26	Digestive organs	2434	2486	2410	2564	2467	2547	2544	2555	2599	2520
C15	Oesophagus	48	50	45	56	51	48	56	54	64	45
C16	Stomach	260	262	233	240	209	257	223	219	233	202
C17	Small intestine	29	51	40	48	47	61	48	50	42	41
C18	Colon	1089	1109	1080	1155	1135	1137	1225	1180	1190	1232
C19-21	Rectum, rectosigmoid, anus	504	506	507	534	515	521	506	573	563	535
C22	Liver	33	41	62	52	48	44	41	40	62	35
C23-24	Gallbladder, bile ducts	82	82	83	89	62	80	83	63	74	67
C25	Pancreas	323	330	294	334	345	352	318	330	309	320
C26	Other digestive organs	66	55	66	56	55	47	44	46	62	43
C30-34, C38	Respiratory organs	701	672	790	828	840	854	929	969	961	992
C30-31	Nose, sinuses	13	19	17	13	15	15	10	29	16	20
C32	Larynx, epiglottis	19	21	19	19	22	18	18	13	17	11
C33-34	Lung, trachea	663	627	743	788	795	817	899	916	921	953
C38	Mediastinum, pleura	6	5	11	8	8	4	2	11	7	8
C40-41	Bone	17	9	28	22	21	20	19	15	16	16
C43	Melanoma of the skin	564	443	482	532	528	554	545	553	569	634
C44	Skin, non-melanoma	457	458	452	506	481	517	569	572	670	633
C45	Mesothelioma	4	10	10	10	5	8	11	11	8	20
C46	Kaposi's sarcoma	7	2	3	8	0	3	2	3	2	4
C47	Autonomic nervous system	10	8	2	4	5	4	3	7	4	8
C48-49	Soft tissues	44	50	63	75	68	64	70	87	82	78
C50	Breast	2401	2416	2408	2528	2621	2694	2723	2787	2799	2673
C51-58	Female genital organs	1400	1487	1372	1426	1497	1532	1488	1564	1553	1522
C53	Cervix uteri	331	345	284	285	300	308	296	268	297	294
C54	Corpus uteri	465	520	490	564	593	588	626	684	669	639
C55	Uterus, other	8	11	8	15	6	11	13	9	7	14
C56	Ovary	464	476	458	455	450	517	423	461	424	447
C51-52, C57	Other female genital	128	132	126	105	145	105	126	138	150	125
C58	Placenta	4	3	6	2	3	3	4	4	6	3
C64-68	Urinary organs	551	501	507	522	522	590	568	578	583	565
C64	Kidney excl. renal pelvis	206	187	184	180	186	214	203	210	233	194
C65	Renal pelvis	24	22	29	20	30	31	36	28	18	25
C66-68	Bladder, ureter, urethra	321	292	294	322	306	345	329	340	332	346
C69	Eye	29	30	29	20	28	34	34	37	23	23
C70-72	Central nervous system	374	386	413	414	471	516	515	570	522	450
C73	Thyroid gland	102	113	120	146	129	139	130	168	160	142
C37, C74-75	Other endocrine glands	9	16	12	15	9	14	11	12	16	14
C39, C76, C80	Other or unspecified	314	298	296	326	285	311	309	287	276	285
C81-96	Lymphoid and haematopoietic tissue	763	715	743	772	801	778	778	841	764	808
C81	Hodgkin lymphoma	31	43	40	64	33	43	54	46	50	47
C82-85, C96	Non-Hodgkin lymphoma	331	304	333	329	337	345	335	372	342	379
C88	Malignant immunoproliferative diseases	12	14	8	10	16	20	14	21	16	17
C90	Multiple myeloma	155	139	157	123	172	162	152	150	149	134
C91-95	Leukaemia	234	215	205	246	243	208	223	252	207	231

Table 6 Age-adjusted (world) incidence rates per 100 000 person-years by primary site and year - 1997-2006

MALES

ICD10	Site	Year									
		1997	98	99	00	01	02	03	04	05	2006
C00-96	All sites	316.8	316.9	318.8	321.2	320.1	315.3	336.0	346.5	336.0	331.6
C00-14	Mouth, pharynx	8.2	8.0	7.8	8.3	7.2	7.7	7.5	7.6	6.7	7.3
C00	Lip	1.9	1.5	1.6	1.7	1.4	1.7	1.1	0.9	1.1	1.5
C01-02	Tongue	1.7	1.6	1.6	1.2	1.6	1.6	1.7	1.6	1.3	1.3
C03-06	Mouth, other	1.4	1.3	1.6	1.7	1.1	1.3	1.5	1.5	1.0	1.5
C07-08	Salivary glands	0.7	0.7	0.7	0.8	0.6	0.6	0.5	0.5	0.7	0.4
C09-14	Pharynx	2.5	2.9	2.4	2.9	2.5	2.4	2.7	2.9	2.5	2.6
C15-26	Digestive organs	69.9	67.0	67.4	67.1	69.6	68.4	68.8	70.0	67.1	63.5
C15	Oesophagus	3.6	3.5	3.7	2.8	3.2	3.5	3.7	4.0	3.4	3.8
C16	Stomach	10.7	9.6	9.4	9.3	9.0	8.5	8.5	8.2	7.0	7.0
C17	Small intestine	1.2	1.3	1.1	1.3	1.9	1.3	1.7	1.2	1.3	1.7
C18	Colon	25.1	24.2	24.1	25.8	25.5	24.7	24.7	26.4	26.0	24.6
C19-21	Rectum, rectosigmoid, anus	17.7	16.6	16.6	16.6	17.4	18.1	17.9	17.8	17.2	15.7
C22	Liver	1.5	1.9	2.4	1.9	2.0	2.3	2.1	1.9	2.1	2.1
C23-24	Gallbladder, bile ducts	1.6	1.5	1.5	1.4	1.9	1.4	1.4	1.7	1.9	1.2
C25	Pancreas	7.1	7.4	7.3	7.0	7.6	7.9	8.0	7.8	7.5	6.7
C26	Other digestive organs	1.3	0.9	1.2	1.0	0.9	0.8	0.9	1.0	0.8	0.8
C30-34, C38	Respiratory organs	41.6	39.2	40.7	39.7	40.4	40.8	41.6	39.2	38.4	38.5
C30-31	Nose, sinuses	0.6	0.8	0.8	0.8	0.6	0.9	0.5	0.7	0.7	0.4
C32	Larynx, epiglottis	3.2	2.5	3.2	3.3	3.1	3.3	2.8	2.7	2.6	3.1
C33-34	Lung, trachea	37.0	35.5	36.1	35.3	36.2	36.3	37.9	35.5	34.8	34.7
C38	Mediastinum, pleura	0.7	0.4	0.5	0.4	0.5	0.3	0.4	0.3	0.3	0.2
C40-41	Bone	1.2	0.9	0.8	0.9	0.9	1.2	0.8	1.1	1.0	1.0
C43	Melanoma of the skin	16.1	14.6	14.5	14.2	14.8	14.2	14.4	14.4	16.4	15.0
C44	Skin, non-melanoma	14.5	13.5	13.1	14.3	13.9	15.3	14.5	14.9	14.5	14.9
C45	Mesothelioma	1.2	1.3	1.7	1.3	1.6	1.4	1.7	1.8	1.7	1.1
C46	Kaposi's sarcoma	0.3	0.1	0.1	0.1	0.2	0.1	0.2	0.3	0.2	0.1
C47	Autonomic nervous system	0.2	0.3	0.4	0.3	0.2	0.3	0.4	0.1	0.4	0.2
C48-49	Soft tissues	1.4	1.7	1.5	1.7	1.6	1.8	1.4	1.6	1.5	2.0
C50	Breast	0.4	0.5	0.3	0.5	0.4	0.3	0.5	0.3	0.5	0.3
C60-63	Male genital organs	81.3	88.6	91.0	93.8	88.1	82.1	98.8	110.2	104.6	106.7
C61	Prostate	70.6	77.6	80.0	82.5	76.2	71.1	87.0	98.3	92.5	95.3
C62	Testis	9.5	10.1	10.3	10.5	11.0	9.9	10.3	10.9	10.7	10.4
C60, C63	Other male genital	1.2	0.9	0.7	0.8	0.9	1.2	1.5	1.0	1.4	1.0
C64-68	Urinary organs	31.6	32.4	30.3	30.0	31.0	32.5	32.5	35.3	31.9	31.2
C64	Kidney excl. renal pelvis	8.7	9.0	8.2	8.0	9.4	9.6	9.4	10.8	9.4	9.3
C65	Renal pelvis	1.2	1.1	1.0	1.0	0.9	1.0	0.7	1.4	0.9	1.2
C66-68	Bladder, ureter, urethra	21.7	22.3	21.2	20.9	20.8	22.0	22.3	23.1	21.7	20.8
C69	Eye	0.8	1.0	1.1	1.0	0.7	1.0	1.1	1.1	0.8	1.0
C70-72	Central nervous system	11.3	11.6	12.4	11.7	12.9	13.3	14.8	12.6	14.2	11.0
C73	Thyroid gland	1.8	1.6	1.5	1.8	1.8	1.7	1.6	1.5	2.1	2.2
C37, C74-75	Other endocrine glands	0.5	0.3	0.5	0.8	0.3	0.4	0.7	0.5	0.2	0.5
C39, C76, C80	Other or unspecified	7.8	7.2	6.7	6.6	5.5	5.7	5.7	4.7	4.9	5.5
C81-96	Lymphoid and haematopoietic tissue	26.7	27.2	26.9	27.3	28.9	27.2	29.0	29.3	28.9	29.4
C81	Hodgkin lymphoma	2.5	2.2	2.6	2.6	2.2	2.2	3.5	3.1	2.7	2.6
C82-85, C96	Non-Hodgkin lymphoma	10.2	11.5	10.3	12.1	10.8	10.0	11.3	12.0	11.8	12.9
C88	Malignant immunoproliferative diseases	0.7	0.4	0.5	0.4	0.8	0.8	0.7	0.6	0.4	0.5
C90	Multiple myeloma	4.8	4.4	4.0	3.9	5.0	4.3	4.3	4.3	5.2	4.4
C91-95	Leukaemia	8.5	8.7	9.4	8.3	10.1	9.9	9.2	9.3	8.7	9.0

Table 7 Age-adjusted (world) incidence rates per 100 000 person-years by primary site and year - 1997-2006

FEMALES

ICD10	Site	Year									
		1997	98	99	00	01	02	03	04	05	2006
C00-96	All sites	268.8	259.0	261.4	270.6	273.8	280.2	277.2	285.1	281.2	276.6
C00-14	Mouth, pharynx	2.7	3.6	3.6	3.1	3.1	3.4	3.2	3.2	4.1	4.8
C00	Lip	0.5	0.7	0.5	0.5	0.6	0.6	0.4	0.5	0.7	0.9
C01-02	Tongue	0.5	0.7	0.9	0.7	0.5	0.7	0.6	0.7	0.7	0.9
C03-06	Mouth, other	1.0	0.9	0.6	0.7	0.6	0.9	0.7	0.9	0.9	1.2
C07-08	Salivary glands	0.3	0.5	0.7	0.6	0.7	0.5	0.5	0.2	0.7	0.5
C09-14	Pharynx	0.4	0.9	1.0	0.7	0.6	0.8	0.9	0.8	1.1	1.2
C15-26	Digestive organs	49.8	50.1	49.3	50.7	50.0	50.6	49.8	51.2	50.2	49.4
C15	Oesophagus	0.9	1.2	0.9	1.0	1.1	0.9	1.1	1.1	1.2	0.9
C16	Stomach	5.0	4.7	4.6	4.7	3.9	4.8	4.0	4.5	4.4	3.8
C17	Small intestine	0.7	1.2	1.1	1.3	1.1	1.5	1.0	1.2	1.0	1.0
C18	Colon	22.1	22.4	22.3	22.8	22.8	22.5	23.7	23.2	22.5	23.2
C19-21	Rectum, rectosigmoid, anus	11.8	11.4	11.1	11.5	11.3	11.5	10.9	12.0	11.8	11.5
C22	Liver	0.8	1.0	1.3	1.1	1.1	0.9	0.9	0.9	1.4	0.7
C23-24	Gallbladder, bile ducts	1.7	1.4	1.7	1.7	1.4	1.4	1.4	1.2	1.4	1.4
C25	Pancreas	6.0	6.2	5.5	5.9	6.4	6.4	6.3	6.3	5.5	6.1
C26	Other digestive organs	0.8	0.8	1.0	0.7	0.8	0.7	0.6	0.8	1.0	0.7
C30-34, C38	Respiratory organs	19.0	17.5	21.0	21.7	21.5	21.4	22.9	23.3	22.5	23.4
C30-31	Nose, sinuses	0.3	0.5	0.4	0.3	0.4	0.5	0.2	0.5	0.4	0.5
C32	Larynx, epiglottis	0.6	0.5	0.5	0.4	0.6	0.5	0.5	0.3	0.5	0.3
C33-34	Lung, trachea	18.0	16.4	19.8	20.8	20.4	20.4	22.2	22.3	21.6	22.5
C38	Mediastinum, pleura	0.1	0.1	0.2	0.2	0.2	0.0	0.0	0.2	0.1	0.2
C40-41	Bone	0.6	0.4	1.1	0.9	0.9	0.9	0.8	0.6	0.6	0.6
C43	Melanoma of the skin	18.6	13.3	14.8	15.6	15.5	16.2	15.7	15.6	15.8	17.9
C44	Skin, non-melanoma	8.3	7.8	7.8	8.3	8.6	8.4	9.2	9.5	10.2	9.9
C45	Mesothelioma	0.1	0.3	0.2	0.2	0.1	0.2	0.2	0.2	0.2	0.4
C46	Kaposi's sarcoma	0.1	0.0	0.0	0.2	0.0	0.0	0.0	0.0	0.0	0.1
C47	Autonomic nervous system	0.4	0.3	0.1	0.3	0.2	0.3	0.1	0.3	0.2	0.3
C48-49	Soft tissues	1.3	1.3	1.6	2.0	2.1	1.6	2.0	2.5	2.5	2.2
C50	Breast	71.6	69.9	68.6	72.9	75.4	76.7	76.7	77.0	76.3	72.4
C51-58	Female genital organs	40.9	42.2	39.1	39.1	40.7	41.4	39.6	41.0	40.3	38.7
C53	Cervix uteri	11.3	11.7	9.7	9.3	9.8	10.2	9.5	8.6	9.5	9.1
C54	Corpus uteri	13.8	13.5	13.4	14.8	14.9	15.0	16.1	17.0	16.3	15.2
C55	Uterus, other	0.2	0.2	0.1	0.3	0.1	0.2	0.2	0.2	0.2	0.3
C56	Ovary	12.8	13.7	12.9	12.3	12.6	13.7	11.0	12.2	10.8	11.1
C51-52, C57	Other female genital	2.8	3.0	2.8	2.3	3.2	2.3	2.8	2.8	3.2	2.8
C58	Placenta	0.2	0.1	0.3	0.1	0.1	0.1	0.1	0.2	0.3	0.2
C64-68	Urinary organs	12.0	10.6	11.7	11.1	11.3	12.4	11.6	11.3	12.3	11.9
C64	Kidney excl. renal pelvis	5.1	4.3	4.7	4.2	4.2	4.7	4.8	4.8	5.4	4.8
C65	Renal pelvis	0.5	0.3	0.6	0.4	0.7	0.6	0.8	0.5	0.3	0.5
C66-68	Bladder, ureter, urethra	6.4	5.9	6.3	6.4	6.5	7.0	6.0	6.0	6.6	6.6
C69	Eye	0.8	0.9	0.8	0.4	0.7	1.0	0.8	1.0	0.8	0.7
C70-72	Central nervous system	12.4	12.1	13.1	12.9	14.4	16.8	15.7	16.9	16.4	13.2
C73	Thyroid gland	3.3	3.7	3.8	5.0	4.3	4.5	4.2	5.3	5.0	4.5
C37, C74-75	Other endocrine glands	0.3	0.7	0.4	0.5	0.4	0.4	0.3	0.4	0.7	0.5
C39, C76, C80	Other or unspecified	6.4	5.4	5.3	5.6	4.5	5.1	4.7	4.9	4.6	5.1
C81-96	Lymphoid and haematopoietic tissue	20.1	18.7	19.2	20.0	20.0	18.9	19.5	21.1	18.5	20.9
C81	Hodgkin lymphoma	1.3	2.0	1.6	2.7	1.4	1.6	2.1	1.7	2.1	2.1
C82-85, C96	Non-Hodgkin lymphoma	8.8	7.6	8.4	8.2	8.4	8.2	7.9	9.0	8.0	9.0
C88	Malignant immunoproliferative diseases	0.2	0.2	0.2	0.2	0.3	0.4	0.3	0.5	0.3	0.4
C90	Multiple myeloma	3.3	2.8	3.2	2.5	3.5	3.3	2.8	3.1	3.1	2.5
C91-95	Leukaemia	6.5	6.2	5.8	6.5	6.4	5.4	6.4	6.8	5.0	6.9

Table 8 Number of new cases by primary site and five-year age group - 2006

ICD10	Site	0-4	5-9	10-14	15-19	20-24	25-29
C00-96	All sites	43	18	21	33	49	81
C00-14	Mouth, pharynx	0	0	0	0	1	1
C00	Lip	0	0	0	0	0	0
C01-02	Tongue	0	0	0	0	0	0
C03-06	Mouth, other	0	0	0	0	0	0
C07-08	Salivary glands	0	0	0	0	0	1
C09-14	Pharynx	0	0	0	0	1	0
C15-26	Digestive organs	1	0	0	3	0	3
C15	Oesophagus	0	0	0	0	0	0
C16	Stomach	0	0	0	0	0	0
C17	Small intestine	0	0	0	0	0	1
C18	Colon	0	0	0	1	0	0
C19-21	Rectum, rectosigmoid, anus	0	0	0	0	0	1
C22	Liver	1	0	0	1	0	1
C23-24	Gallbladder, bile ducts	0	0	0	0	0	0
C25	Pancreas	0	0	0	1	0	0
C26	Other digestive organs	0	0	0	0	0	0
C30-34, C38	Respiratory organs	0	0	0	0	0	0
C30-31	Nose, sinuses	0	0	0	0	0	0
C32	Larynx, epiglottis	0	0	0	0	0	0
C33-34	Lung, trachea	0	0	0	0	0	0
C38	Mediastinum, pleura	0	0	0	0	0	0
C40-41	Bone	0	2	1	3	1	3
C43	Melanoma of the skin	1	0	0	0	0	6
C44	Skin, non-melanoma	0	0	0	0	1	0
C45	Mesothelioma	0	0	0	0	0	0
C46	Kaposi's sarcoma	0	0	0	0	0	0
C47	Autonomic nervous system	1	0	1	0	0	0
C48-49	Soft tissues	2	0	1	1	2	2
C50	Breast	0	0	0	0	0	0
C60-63	Male genital organs	0	0	2	6	30	45
C61	Prostate	0	0	0	0	0	0
C62	Testis	0	0	2	6	30	45
C60, C63	Other male genital	0	0	0	0	0	0
C64-68	Urinary organs	4	2	0	0	2	1
C64	Kidney excl. renal pelvis	4	2	0	0	1	0
C65	Renal pelvis	0	0	0	0	0	0
C66-68	Bladder, ureter, urethra	0	0	0	0	1	1
C69	Eye	3	0	0	0	0	0
C70-72	Central nervous system	7	5	6	4	6	4
C73	Thyroid gland	0	0	0	0	1	0
C37, C74-75	Other endocrine glands	3	1	1	0	0	0
C39, C76, C80	Other or unspecified	0	0	0	0	0	1
C81-96	Lymphoid and haematopoietic tissue	21	8	9	16	5	15
C81	Hodgkin lymphoma	0	1	3	5	2	8
C82-85, C96	Non-Hodgkin lymphoma	4	0	0	6	2	2
C88	Malignant immunoproliferative diseases	0	0	0	0	0	0
C90	Multiple myeloma	0	0	0	0	0	2
C91-95	Leukaemia	17	7	6	5	1	3

Age												
30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70-74	75-79	80-84	85+	
123	140	216	334	615	1193	1703	1769	1901	2020	1553	1091	
2	2	3	17	25	34	50	40	25	27	29	13	
0	0	1	3	3	5	11	9	5	11	8	7	
0	0	1	2	5	6	10	8	4	1	8	2	
0	0	0	3	4	7	11	8	9	6	5	0	
2	1	0	0	1	2	0	2	0	1	3	3	
0	1	1	9	12	14	18	13	7	8	5	1	
11	15	35	64	138	226	334	295	419	428	350	291	
0	0	3	5	7	14	29	20	25	16	11	12	
1	3	5	4	15	22	39	25	45	50	39	50	
0	0	0	3	2	8	13	9	11	9	4	2	
5	4	17	24	51	66	105	108	188	197	162	118	
5	5	7	14	35	66	97	74	86	99	93	58	
0	1	2	4	7	7	6	7	15	12	5	10	
0	1	0	0	4	5	7	5	7	11	5	7	
0	1	0	9	15	36	37	43	35	33	28	24	
0	0	1	1	2	2	1	4	7	1	3	10	
1	4	11	35	76	163	234	236	250	254	167	81	
0	0	1	0	0	1	3	1	3	4	2	3	
0	0	1	4	12	18	14	24	15	13	8	5	
1	4	9	31	64	143	214	210	231	236	154	72	
0	0	0	0	0	1	3	1	1	1	3	1	
2	0	2	3	1	0	1	2	1	1	0	0	
13	22	34	29	44	65	69	57	66	59	50	29	
1	4	4	8	17	34	46	70	104	114	159	144	
0	0	0	1	1	3	7	8	7	7	4	5	
1	0	0	0	0	0	0	0	0	3	1	2	
0	0	0	0	0	1	1	0	0	0	0	1	
3	1	3	4	5	8	4	3	9	7	4	3	
0	0	0	0	0	0	2	3	3	2	3	1	
42	43	37	46	124	364	628	696	659	624	473	291	
0	0	1	27	110	354	617	682	654	614	468	288	
41	42	34	15	14	9	7	7	3	0	0	0	
1	1	2	4	0	1	4	7	2	10	5	3	
3	4	15	42	60	108	133	172	179	280	171	111	
0	2	6	18	26	44	49	52	46	46	28	11	
0	0	1	2	3	6	3	4	10	10	4	4	
3	2	8	22	31	58	81	116	123	224	139	96	
1	0	0	1	4	3	4	1	7	4	4	2	
20	26	26	25	31	38	36	33	22	23	12	15	
4	2	8	7	8	9	10	6	6	6	3	3	
0	1	0	0	0	0	2	0	1	2	0	0	
0	0	5	7	12	24	20	28	36	36	31	27	
19	16	33	45	69	113	122	119	107	143	92	72	
7	3	6	7	5	6	5	3	2	4	1	1	
5	8	12	22	35	65	67	54	53	72	36	30	
0	0	1	1	3	2	3	1	2	3	2	3	
0	0	3	5	13	16	20	30	20	28	21	13	
7	5	11	10	13	24	27	31	30	36	32	25	

Table 9 - Number of new cases by primary site and five-year age group - 2006

ICD10	Site	0-4	5-9	10-14	15-19	20-24	25-29
C00-96	All sites	30	16	19	49	50	79
C00-14	Mouth, pharynx	0	1	0	0	1	1
C00	Lip	0	0	0	0	0	0
C01-02	Tongue	0	0	0	0	1	0
C03-06	Mouth, other	0	0	0	0	0	0
C07-08	Salivary glands	0	0	0	0	0	1
C09-14	Pharynx	0	1	0	0	0	0
C15-26	Digestive organs	1	0	2	3	3	3
C15	Oesophagus	0	0	0	0	0	0
C16	Stomach	0	0	0	0	1	1
C17	Small intestine	0	0	0	1	0	1
C18	Colon	0	0	1	1	2	1
C19-21	Rectum, rectosigmoid, anus	0	0	0	0	0	0
C22	Liver	1	0	0	1	0	0
C23-24	Gallbladder, bile ducts	0	0	0	0	0	0
C25	Pancreas	0	0	0	0	0	0
C26	Other digestive organs	0	0	1	0	0	0
C30-34, C38	Respiratory organs	0	0	0	0	0	2
C30-31	Nose, sinuses	0	0	0	0	0	0
C32	Larynx, epiglottis	0	0	0	0	0	0
C33-34	Lung, trachea	0	0	0	0	0	2
C38	Mediastinum, pleura	0	0	0	0	0	0
C40-41	Bone	0	1	1	2	0	1
C43	Melanoma of the skin	0	0	0	6	7	19
C44	Skin, non-melanoma	0	1	1	2	0	1
C45	Mesothelioma	0	0	0	0	0	0
C46	Kaposi's sarcoma	0	0	0	0	0	1
C47	Autonomic nervous system	0	1	0	1	0	0
C48-49	Soft tissues	1	1	1	1	3	0
C50	Breast	0	0	0	0	4	3
C51-58	Female genital organs	1	1	0	4	8	18
C53	Cervix uteri	0	0	0	0	4	13
C54	Corpus uteri	0	0	0	0	0	0
C55	Uterus, other	0	0	0	0	0	0
C56	Ovary	1	1	0	4	3	3
C51-52, C57	Other female genital	0	0	0	0	0	1
C58	Placenta	0	0	0	0	1	1
C64-68	Urinary organs	2	0	0	0	1	3
C64	Kidney excl. renal pelvis	2	0	0	0	0	2
C65	Renal pelvis	0	0	0	0	0	0
C66-68	Bladder, ureter, urethra	0	0	0	0	1	1
C69	Eye	2	0	0	0	0	0
C70-72	Central nervous system	1	6	6	6	6	10
C73	Thyroid gland	0	0	0	3	2	7
C37, C74-75	Other endocrine glands	2	0	0	0	0	0
C39, C76, C80	Other or unspecified	0	0	0	0	0	0
C81-96	Lymphoid and haematopoietic tissue	20	4	8	21	15	10
C81	Hodgkin lymphoma	1	1	0	9	8	5
C82-85, C96	Non-Hodgkin lymphoma	0	1	1	7	3	4
C88	Malignant immunoproliferative diseases	0	0	0	0	0	0
C90	Multiple myeloma	0	0	0	0	0	0
C91-95	Leukaemia	19	2	7	5	4	1

FEMALES

Age												
30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70-74	75-79	80-84	85+	
166	280	405	637	886	1148	1344	1193	1210	1325	1358	1390	
3	3	3	6	20	25	25	23	27	20	16	24	
0	1	0	1	4	6	3	7	4	6	3	6	
0	0	1	0	4	3	7	3	6	3	2	7	
0	1	1	0	5	4	7	6	12	7	9	4	
1	1	0	1	3	0	1	3	3	3	1	3	
2	0	1	4	4	12	7	4	2	1	1	4	
10	23	31	66	104	155	283	267	318	368	463	420	
0	0	1	2	3	2	5	5	5	8	5	9	
1	3	3	6	11	6	16	15	30	35	34	40	
0	0	0	1	2	4	10	6	4	4	5	3	
4	9	17	23	36	80	124	134	155	181	255	209	
4	6	8	23	37	27	75	63	67	76	85	64	
0	0	0	1	2	1	4	1	4	6	7	7	
1	2	0	4	3	9	4	7	9	6	13	9	
0	3	1	6	9	23	43	32	41	43	49	70	
0	0	1	0	1	3	2	4	3	9	10	9	
3	8	11	25	57	122	153	138	165	146	95	67	
1	0	0	1	1	2	2	5	2	2	0	4	
0	1	1	0	2	1	1	0	1	1	2	1	
2	7	10	24	54	118	149	132	160	143	92	60	
0	0	0	0	0	1	1	1	2	0	1	2	
1	0	0	0	1	5	3	1	0	0	0	0	
26	42	52	52	67	59	63	48	50	47	46	50	
2	3	4	8	21	34	25	42	69	90	131	199	
0	0	2	0	0	1	0	5	1	2	7	2	
0	0	0	0	0	0	0	0	0	0	1	2	
0	0	1	2	0	2	0	0	0	0	1	0	
0	4	2	2	6	8	11	10	7	9	7	5	
36	75	167	295	345	351	369	290	163	175	195	205	
43	62	61	71	138	193	167	163	156	169	145	122	
35	41	31	19	32	31	17	13	14	19	14	11	
2	9	13	21	59	92	78	88	78	82	66	51	
0	0	0	1	0	2	3	2	0	2	0	4	
3	9	14	24	35	56	59	46	51	49	48	41	
2	3	3	6	12	12	10	14	13	17	17	15	
1	0	0	0	0	0	0	0	0	0	0	0	
4	5	11	16	21	32	71	70	72	98	70	89	
0	1	7	11	11	15	31	23	28	31	19	13	
1	2	0	0	1	1	2	3	3	6	3	3	
3	2	4	5	9	16	38	44	41	61	48	73	
1	0	1	2	1	3	4	0	4	1	2	2	
14	24	25	34	41	53	51	34	46	40	30	23	
13	14	10	17	8	21	10	6	11	8	8	4	
0	1	0	1	1	2	2	3	0	0	2	0	
0	2	5	6	13	18	20	32	27	41	48	73	
10	14	19	34	42	64	87	61	94	111	91	103	
3	2	1	2	3	3	2	0	2	3	0	2	
2	5	11	21	21	33	50	32	43	60	45	40	
0	0	1	0	2	3	4	1	1	4	0	1	
0	1	1	2	6	10	14	9	21	27	23	20	
5	6	5	9	10	15	17	19	27	17	23	40	

Table 10 - Age-specific incidence rates per 100 000 person-years by primary site and five-year age group - 2006

ICD10	Site	0-4	5-9	10-14	15-19	20-24	25-29
C00-96	All sites	29.1	11.6	13.0	20.9	34.5	55.7
C00-14	Mouth, pharynx	0.0	0.0	0.0	0.0	0.7	0.7
C00	Lip	0.0	0.0	0.0	0.0	0.0	0.0
C01-02	Tongue	0.0	0.0	0.0	0.0	0.0	0.0
C03-06	Mouth, other	0.0	0.0	0.0	0.0	0.0	0.0
C07-08	Salivary glands	0.0	0.0	0.0	0.0	0.0	0.7
C09-14	Pharynx	0.0	0.0	0.0	0.0	0.7	0.0
C15-26	Digestive organs	0.7	0.0	0.0	1.9	0.0	2.1
C15	Oesophagus	0.0	0.0	0.0	0.0	0.0	0.0
C16	Stomach	0.0	0.0	0.0	0.0	0.0	0.0
C17	Small intestine	0.0	0.0	0.0	0.0	0.0	0.7
C18	Colon	0.0	0.0	0.0	0.6	0.0	0.0
C19-21	Rectum, rectosigmoid, anus	0.0	0.0	0.0	0.0	0.0	0.7
C22	Liver	0.7	0.0	0.0	0.6	0.0	0.7
C23-24	Gallbladder, bile ducts	0.0	0.0	0.0	0.0	0.0	0.0
C25	Pancreas	0.0	0.0	0.0	0.6	0.0	0.0
C26	Other digestive organs	0.0	0.0	0.0	0.0	0.0	0.0
C30-34, C38	Respiratory organs	0.0	0.0	0.0	0.0	0.0	0.0
C30-31	Nose, sinuses	0.0	0.0	0.0	0.0	0.0	0.0
C32	Larynx, epiglottis	0.0	0.0	0.0	0.0	0.0	0.0
C33-34	Lung, trachea	0.0	0.0	0.0	0.0	0.0	0.0
C38	Mediastinum, pleura	0.0	0.0	0.0	0.0	0.0	0.0
C40-41	Bone	0.0	1.3	0.6	1.9	0.7	2.1
C43	Melanoma of the skin	0.7	0.0	0.0	0.0	0.0	4.1
C44	Skin, non-melanoma	0.0	0.0	0.0	0.0	0.7	0.0
C45	Mesothelioma	0.0	0.0	0.0	0.0	0.0	0.0
C46	Kaposi's sarcoma	0.0	0.0	0.0	0.0	0.0	0.0
C47	Autonomic nervous system	0.7	0.0	0.6	0.0	0.0	0.0
C48-49	Soft tissues	1.4	0.0	0.6	0.6	1.4	1.4
C50	Breast	0.0	0.0	0.0	0.0	0.0	0.0
C60-63	Male genital organs	0.0	0.0	1.2	3.8	21.1	31.0
C61	Prostate	0.0	0.0	0.0	0.0	0.0	0.0
C62	Testis	0.0	0.0	1.2	3.8	21.1	31.0
C60, C63	Other male genital	0.0	0.0	0.0	0.0	0.0	0.0
C64-68	Urinary organs	2.7	1.3	0.0	0.0	1.4	0.7
C64	Kidney excl. renal pelvis	2.7	1.3	0.0	0.0	0.7	0.0
C65	Renal pelvis	0.0	0.0	0.0	0.0	0.0	0.0
C66-68	Bladder, ureter, urethra	0.0	0.0	0.0	0.0	0.7	0.7
C69	Eye	2.0	0.0	0.0	0.0	0.0	0.0
C70-72	Central nervous system	4.7	3.2	3.7	2.5	4.2	2.8
C73	Thyroid gland	0.0	0.0	0.0	0.0	0.7	0.0
C37, C74-75	Other endocrine glands	2.0	0.6	0.6	0.0	0.0	0.0
C39, C76, C80	Other or unspecified	0.0	0.0	0.0	0.0	0.0	0.7
C81-96	Lymphoid and haematopoietic tissue	14.2	5.2	5.6	10.1	3.5	10.3
C81	Hodgkin lymphoma	0.0	0.6	1.9	3.2	1.4	5.5
C82-85, C96	Non-Hodgkin lymphoma	2.7	0.0	0.0	3.8	1.4	1.4
C88	Malignant immunoproliferative diseases	0.0	0.0	0.0	0.0	0.0	0.0
C90	Multiple myeloma	0.0	0.0	0.0	0.0	0.0	1.4
C91-95	Leukaemia	11.5	4.5	3.7	3.2	0.7	2.1

Age												
30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70-74	75-79	80-84	85+	
74.1	76.8	123.0	204.7	394.3	796.9	1293.1	2020.1	2760.0	3368.7	3480.7	3546.1	
1.2	1.1	1.7	10.4	16.0	22.7	38.0	45.7	36.3	45.0	65.0	42.3	
0.0	0.0	0.6	1.8	1.9	3.3	8.4	10.3	7.3	18.3	17.9	22.8	
0.0	0.0	0.6	1.2	3.2	4.0	7.6	9.1	5.8	1.7	17.9	6.5	
0.0	0.0	0.0	1.8	2.6	4.7	8.4	9.1	13.1	10.0	11.2	0.0	
1.2	0.5	0.0	0.0	0.6	1.3	0.0	2.3	0.0	1.7	6.7	9.8	
0.0	0.5	0.6	5.5	7.7	9.4	13.7	14.8	10.2	13.3	11.2	3.3	
6.6	8.2	19.9	39.2	88.5	151.0	253.6	336.9	608.3	713.8	784.4	945.8	
0.0	0.0	1.7	3.1	4.5	9.4	22.0	22.8	36.3	26.7	24.7	39.0	
0.6	1.6	2.8	2.5	9.6	14.7	29.6	28.5	65.3	83.4	87.4	162.5	
0.0	0.0	0.0	1.8	1.3	5.3	9.9	10.3	16.0	15.0	9.0	6.5	
3.0	2.2	9.7	14.7	32.7	44.1	79.7	123.3	273.0	328.5	363.1	383.5	
3.0	2.7	4.0	8.6	22.4	44.1	73.7	84.5	124.9	165.1	208.4	188.5	
0.0	0.5	1.1	2.5	4.5	4.7	4.6	8.0	21.8	20.0	11.2	32.5	
0.0	0.5	0.0	0.0	2.6	3.3	5.3	5.7	10.2	18.3	11.2	22.8	
0.0	0.5	0.0	5.5	9.6	24.0	28.1	49.1	50.8	55.0	62.8	78.0	
0.0	0.0	0.6	0.6	1.3	1.3	0.8	4.6	10.2	1.7	6.7	32.5	
0.6	2.2	6.3	21.5	48.7	108.9	177.7	269.5	363.0	423.6	374.3	263.3	
0.0	0.0	0.6	0.0	0.0	0.7	2.3	1.1	4.4	6.7	4.5	9.8	
0.0	0.0	0.6	2.5	7.7	12.0	10.6	27.4	21.8	21.7	17.9	16.3	
0.6	2.2	5.1	19.0	41.0	95.5	162.5	239.8	335.4	393.6	345.2	234.0	
0.0	0.0	0.0	0.0	0.0	0.7	2.3	1.1	1.5	1.7	6.7	3.3	
1.2	0.0	1.1	1.8	0.6	0.0	0.8	2.3	1.5	1.7	0.0	0.0	
7.8	12.1	19.4	17.8	28.2	43.4	52.4	65.1	95.8	98.4	112.1	94.3	
0.6	2.2	2.3	4.9	10.9	22.7	34.9	79.9	151.0	190.1	356.4	468.0	
0.0	0.0	0.0	0.6	0.6	2.0	5.3	9.1	10.2	11.7	9.0	16.3	
0.6	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	5.0	2.2	6.5	
0.0	0.0	0.0	0.0	0.0	0.7	0.8	0.0	0.0	0.0	0.0	3.3	
1.8	0.5	1.7	2.5	3.2	5.3	3.0	3.4	13.1	11.7	9.0	9.8	
0.0	0.0	0.0	0.0	0.0	0.0	1.5	3.4	4.4	3.3	6.7	3.3	
25.3	23.6	21.1	28.2	79.5	243.1	476.8	794.8	956.8	1040.6	1060.1	945.8	
0.0	0.0	0.6	16.5	70.5	236.5	468.5	778.8	949.5	1024.0	1048.9	936.1	
24.7	23.0	19.4	9.2	9.0	6.0	5.3	8.0	4.4	0.0	0.0	0.0	
0.6	0.5	1.1	2.5	0.0	0.7	3.0	8.0	2.9	16.7	11.2	9.8	
1.8	2.2	8.5	25.7	38.5	72.1	101.0	196.4	259.9	467.0	383.3	360.8	
0.0	1.1	3.4	11.0	16.7	29.4	37.2	59.4	66.8	76.7	62.8	35.8	
0.0	0.0	0.6	1.2	1.9	4.0	2.3	4.6	14.5	16.7	9.0	13.0	
1.8	1.1	4.6	13.5	19.9	38.7	61.5	132.5	178.6	373.6	311.5	312.0	
0.6	0.0	0.0	0.6	2.6	2.0	3.0	1.1	10.2	6.7	9.0	6.5	
12.1	14.3	14.8	15.3	19.9	25.4	27.3	37.7	31.9	38.4	26.9	48.8	
2.4	1.1	4.6	4.3	5.1	6.0	7.6	6.9	8.7	10.0	6.7	9.8	
0.0	0.5	0.0	0.0	0.0	0.0	1.5	0.0	1.5	3.3	0.0	0.0	
0.0	0.0	2.8	4.3	7.7	16.0	15.2	32.0	52.3	60.0	69.5	87.8	
11.5	8.8	18.8	27.6	44.2	75.5	92.6	135.9	155.3	238.5	206.2	234.0	
4.2	1.6	3.4	4.3	3.2	4.0	3.8	3.4	2.9	6.7	2.2	3.3	
3.0	4.4	6.8	13.5	22.4	43.4	50.9	61.7	76.9	120.1	80.7	97.5	
0.0	0.0	0.6	0.6	1.9	1.3	2.3	1.1	2.9	5.0	4.5	9.8	
0.0	0.0	1.7	3.1	8.3	10.7	15.2	34.3	29.0	46.7	47.1	42.3	
4.2	2.7	6.3	6.1	8.3	16.0	20.5	35.4	43.6	60.0	71.7	81.3	

Table 11 Age-specific incidence rates per 100 000 person-years by primary site and five-year age group - 2006

ICD10	Site	0-4	5-9	10-14	15-19	20-24	25-29
C00-96	All sites	21.2	10.9	12.5	32.6	36.6	55.1
C00-14	Mouth, pharynx	0.0	0.7	0.0	0.0	0.7	0.7
C00	Lip	0.0	0.0	0.0	0.0	0.0	0.0
C01-02	Tongue	0.0	0.0	0.0	0.0	0.7	0.0
C03-06	Mouth, other	0.0	0.0	0.0	0.0	0.0	0.0
C07-08	Salivary glands	0.0	0.0	0.0	0.0	0.0	0.7
C09-14	Pharynx	0.0	0.7	0.0	0.0	0.0	0.0
C15-26	Digestive organs	0.7	0.0	1.3	2.0	2.2	2.1
C15	Oesophagus	0.0	0.0	0.0	0.0	0.0	0.0
C16	Stomach	0.0	0.0	0.0	0.0	0.7	0.7
C17	Small intestine	0.0	0.0	0.0	0.7	0.0	0.7
C18	Colon	0.0	0.0	0.7	0.7	1.5	0.7
C19-21	Rectum, rectosigmoid, anus	0.0	0.0	0.0	0.0	0.0	0.0
C22	Liver	0.7	0.0	0.0	0.7	0.0	0.0
C23-24	Gallbladder, bile ducts	0.0	0.0	0.0	0.0	0.0	0.0
C25	Pancreas	0.0	0.0	0.0	0.0	0.0	0.0
C26	Other digestive organs	0.0	0.0	0.7	0.0	0.0	0.0
C30-34, C38	Respiratory organs	0.0	0.0	0.0	0.0	0.0	1.4
C30-31	Nose, sinuses	0.0	0.0	0.0	0.0	0.0	0.0
C32	Larynx, epiglottis	0.0	0.0	0.0	0.0	0.0	0.0
C33-34	Lung, trachea	0.0	0.0	0.0	0.0	0.0	1.4
C38	Mediastinum, pleura	0.0	0.0	0.0	0.0	0.0	0.0
C40-41	Bone	0.0	0.7	0.7	1.3	0.0	0.7
C43	Melanoma of the skin	0.0	0.0	0.0	4.0	5.1	13.2
C44	Skin, non-melanoma	0.0	0.7	0.7	1.3	0.0	0.7
C45	Mesothelioma	0.0	0.0	0.0	0.0	0.0	0.0
C46	Kaposi's sarcoma	0.0	0.0	0.0	0.0	0.0	0.7
C47	Autonomic nervous system	0.0	0.7	0.0	0.7	0.0	0.0
C48-49	Soft tissues	0.7	0.7	0.7	0.7	2.2	0.0
C50	Breast	0.0	0.0	0.0	0.0	2.9	2.1
C51-58	Female genital organs	0.7	0.7	0.0	2.7	5.9	12.5
C53	Cervix uteri	0.0	0.0	0.0	0.0	2.9	9.1
C54	Corpus uteri	0.0	0.0	0.0	0.0	0.0	0.0
C55	Uterus, other	0.0	0.0	0.0	0.0	0.0	0.0
C56	Ovary	0.7	0.7	0.0	2.7	2.2	2.1
C51-52, C57	Other female genital	0.0	0.0	0.0	0.0	0.0	0.7
C58	Placenta	0.0	0.0	0.0	0.0	0.7	0.7
C64-68	Urinary organs	1.4	0.0	0.0	0.0	0.7	2.1
C64	Kidney excl. renal pelvis	1.4	0.0	0.0	0.0	0.0	1.4
C65	Renal pelvis	0.0	0.0	0.0	0.0	0.0	0.0
C66-68	Bladder, ureter, urethra	0.0	0.0	0.0	0.0	0.7	0.7
C69	Eye	1.4	0.0	0.0	0.0	0.0	0.0
C70-72	Central nervous system	0.7	4.1	3.9	4.0	4.4	7.0
C73	Thyroid gland	0.0	0.0	0.0	2.0	1.5	4.9
C37, C74-75	Other endocrine glands	1.4	0.0	0.0	0.0	0.0	0.0
C39, C76, C80	Other or unspecified	0.0	0.0	0.0	0.0	0.0	0.0
C81-96	Lymphoid and haematopoietic tissue	14.1	2.7	5.2	14.0	11.0	7.0
C81	Hodgkin lymphoma	0.7	0.7	0.0	6.0	5.9	3.5
C82-85, C96	Non-Hodgkin lymphoma	0.0	0.7	0.7	4.7	2.2	2.8
C88	Malignant immunoproliferative diseases	0.0	0.0	0.0	0.0	0.0	0.0
C90	Multiple myeloma	0.0	0.0	0.0	0.0	0.0	0.0
C91-95	Leukaemia	13.4	1.4	4.6	3.3	2.9	0.7

FEMALES

Age												
30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70-74	75-79	80-84	85+	
102.4	158.7	242.3	406.0	582.7	794.4	1031.0	1279.2	1513.5	1702.8	1924.2	1925.1	
1.9	1.7	1.8	3.8	13.2	17.3	19.2	24.7	33.8	25.7	22.7	33.2	
0.0	0.6	0.0	0.6	2.6	4.2	2.3	7.5	5.0	7.7	4.3	8.3	
0.0	0.0	0.6	0.0	2.6	2.1	5.4	3.2	7.5	3.9	2.8	9.7	
0.0	0.6	0.6	0.0	3.3	2.8	5.4	6.4	15.0	9.0	12.8	5.5	
0.6	0.6	0.0	0.6	2.0	0.0	0.8	3.2	3.8	3.9	1.4	4.2	
1.2	0.0	0.6	2.5	2.6	8.3	5.4	4.3	2.5	1.3	1.4	5.5	
6.2	13.0	18.5	42.1	68.4	107.3	217.1	286.3	397.8	472.9	656.0	581.7	
0.0	0.0	0.6	1.3	2.0	1.4	3.8	5.4	6.3	10.3	7.1	12.5	
0.6	1.7	1.8	3.8	7.2	4.2	12.3	16.1	37.5	45.0	48.2	55.4	
0.0	0.0	0.0	0.6	1.3	2.8	7.7	6.4	5.0	5.1	7.1	4.2	
2.5	5.1	10.2	14.7	23.7	55.4	95.1	143.7	193.9	232.6	361.3	289.5	
2.5	3.4	4.8	14.7	24.3	18.7	57.5	67.6	83.8	97.7	120.4	88.6	
0.0	0.0	0.0	0.6	1.3	0.7	3.1	1.1	5.0	7.7	9.9	9.7	
0.6	1.1	0.0	2.5	2.0	6.2	3.1	7.5	11.3	7.7	18.4	12.5	
0.0	1.7	0.6	3.8	5.9	15.9	33.0	34.3	51.3	55.3	69.4	96.9	
0.0	0.0	0.6	0.0	0.7	2.1	1.5	4.3	3.8	11.6	14.2	12.5	
1.9	4.5	6.6	15.9	37.5	84.4	117.4	148.0	206.4	187.6	134.6	92.8	
0.6	0.0	0.0	0.6	0.7	1.4	1.5	5.4	2.5	2.6	0.0	5.5	
0.0	0.6	0.6	0.0	1.3	0.7	0.8	0.0	1.3	1.3	2.8	1.4	
1.2	4.0	6.0	15.3	35.5	81.7	114.3	141.5	200.1	183.8	130.4	83.1	
0.0	0.0	0.0	0.0	0.0	0.7	0.8	1.1	2.5	0.0	1.4	2.8	
0.6	0.0	0.0	0.0	0.7	3.5	2.3	1.1	0.0	0.0	0.0	0.0	
16.0	23.8	31.1	33.1	44.1	40.8	48.3	51.5	62.5	60.4	65.2	69.2	
1.2	1.7	2.4	5.1	13.8	23.5	19.2	45.0	86.3	115.7	185.6	275.6	
0.0	0.0	1.2	0.0	0.0	0.7	0.0	5.4	1.3	2.6	9.9	2.8	
0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	1.4	2.8	
0.0	0.0	0.6	1.3	0.0	1.4	0.0	0.0	0.0	0.0	1.4	0.0	
0.0	2.3	1.2	1.3	3.9	5.5	8.4	10.7	8.8	11.6	9.9	6.9	
22.2	42.5	99.9	188.0	226.9	242.9	283.1	310.9	203.9	224.9	276.3	283.9	
26.5	35.1	36.5	45.2	90.8	133.5	128.1	174.8	195.1	217.2	205.5	169.0	
21.6	23.2	18.5	12.1	21.0	21.5	13.0	13.9	17.5	24.4	19.8	15.2	
1.2	5.1	7.8	13.4	38.8	63.7	59.8	94.4	97.6	105.4	93.5	70.6	
0.0	0.0	0.0	0.6	0.0	1.4	2.3	2.1	0.0	2.6	0.0	5.5	
1.9	5.1	8.4	15.3	23.0	38.7	45.3	49.3	63.8	63.0	68.0	56.8	
1.2	1.7	1.8	3.8	7.9	8.3	7.7	15.0	16.3	21.8	24.1	20.8	
0.6	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	
2.5	2.8	6.6	10.2	13.8	22.1	54.5	75.1	90.1	125.9	99.2	123.3	
0.0	0.6	4.2	7.0	7.2	10.4	23.8	24.7	35.0	39.8	26.9	18.0	
0.6	1.1	0.0	0.0	0.7	0.7	1.5	3.2	3.8	7.7	4.3	4.2	
1.9	1.1	2.4	3.2	5.9	11.1	29.2	47.2	51.3	78.4	68.0	101.1	
0.6	0.0	0.6	1.3	0.7	2.1	3.1	0.0	5.0	1.3	2.8	2.8	
8.6	13.6	15.0	21.7	27.0	36.7	39.1	36.5	57.5	51.4	42.5	31.9	
8.0	7.9	6.0	10.8	5.3	14.5	7.7	6.4	13.8	10.3	11.3	5.5	
0.0	0.6	0.0	0.6	0.7	1.4	1.5	3.2	0.0	0.0	2.8	0.0	
0.0	1.1	3.0	3.8	8.5	12.5	15.3	34.3	33.8	52.7	68.0	101.1	
6.2	7.9	11.4	21.7	27.6	44.3	66.7	65.4	117.6	142.6	128.9	142.7	
1.9	1.1	0.6	1.3	2.0	2.1	1.5	0.0	2.5	3.9	0.0	2.8	
1.2	2.8	6.6	13.4	13.8	22.8	38.4	34.3	53.8	77.1	63.8	55.4	
0.0	0.0	0.6	0.0	1.3	2.1	3.1	1.1	1.3	5.1	0.0	1.4	
0.0	0.6	0.6	1.3	3.9	6.9	10.7	9.7	26.3	34.7	32.6	27.7	
3.1	3.4	3.0	5.7	6.6	10.4	13.0	20.4	33.8	21.8	32.6	55.4	

Table 12 Average annual number of new cases by primary site and 5-year period 1957-2006

ICD10	Site	1957-61	1962-66	1967-71
C00-96	All sites	4091	4718	5587
C00-14	Mouth, pharynx	187	189	215
C00	Lip	97	94	113
C01-02	Tongue	20	22	21
C03-06	Mouth, other	23	22	31
C07-08	Salivary glands	12	13	15
C09-14	Pharynx	34	38	35
C15-26	Digestive organs	1659	1741	1892
C15	Oesophagus	77	78	80
C16	Stomach	843	786	745
C17	Small intestine	10	13	18
C18	Colon	246	306	369
C19-21	Rectum, rectosigmoid, anus	157	193	277
C22	Liver	22	23	41
C23-24	Gallbladder, bile ducts	21	22	27
C25	Pancreas	148	185	226
C26	Other digestive organs	134	135	109
C30-34, C38	Respiratory organs	350	477	676
C30-31	Nose, sinuses	19	21	21
C32	Larynx, epiglottis	34	50	68
C33-34	Lung, trachea	284	396	575
C38	Mediastinum, pleura	13	10	13
C40-41	Bone	12	17	18
C43	Melanoma of the skin	56	80	117
C44	Skin, non-melanoma	83	68	106
C45	Mesothelioma	1	2	4
C46	Kaposi's sarcoma	3	4	4
C47	Autonomic nervous system	19	15	14
C48-49	Soft tissues	21	25	34
C50	Breast	7	8	9
C60-63	Male genital organs	764	962	1158
C61	Prostate	689	871	1057
C62	Testis	55	68	78
C60, C63	Other male genital	20	23	23
C64-68	Urinary organs	321	433	519
C64	Kidney excl. renal pelvis	106	128	159
C65	Renal pelvis	10	11	21
C66-68	Bladder, ureter, urethra	205	293	339
C69	Eye	20	17	24
C70-72	Central nervous system	125	136	150
C73	Thyroid gland	20	26	35
C37, C74-75	Other endocrine glands	6	7	5
C39, C76, C80	Other or unspecified	63	88	127
C81-96	Lymphoid and haematopoietic tissue	374	424	479
C81	Hodgkin lymphoma	47	53	61
C82-85, C96	Non-Hodgkin lymphoma	99	115	133
C88	Malignant immunoproliferative diseases	0	0	2
C90	Multiple myeloma	73	83	95
C91-95	Leukaemia	156	172	188

Period						
1972-76	1977-81	1982-86	1987-91	1992-96	1997-01	2002-06
6510	7626	8656	9333	10467	11387	12616
245	237	257	254	259	258	254
118	112	101	91	73	59	48
28	27	36	36	43	49	50
30	38	46	47	57	46	48
14	14	15	18	18	23	19
55	46	58	62	68	82	88
1977	2195	2380	2392	2460	2565	2688
82	89	84	104	107	121	137
650	601	580	520	448	379	324
17	19	30	27	32	47	52
417	541	675	761	847	948	1027
336	459	529	540	584	619	677
54	50	69	61	59	70	78
29	38	47	49	54	61	60
252	271	297	295	280	276	297
142	127	68	36	51	43	35
828	1055	1226	1286	1394	1433	1525
23	25	21	24	21	24	22
74	93	107	105	104	106	103
711	918	1087	1148	1249	1287	1386
20	19	12	8	20	17	13
23	21	24	20	21	21	25
161	220	264	380	426	470	513
183	223	294	379	477	564	671
9	21	27	38	38	51	60
7	6	8	13	13	5	7
12	8	8	8	7	6	5
47	52	44	43	47	49	53
10	11	12	13	13	15	16
1390	1670	1898	2117	2679	3221	3795
1282	1526	1717	1923	2437	2944	3496
85	115	151	169	206	244	253
23	28	30	25	36	32	46
681	825	1008	1059	1154	1154	1300
177	211	252	257	269	293	346
26	33	39	35	44	38	42
478	582	717	767	840	823	912
18	27	25	23	29	27	33
169	194	221	243	280	338	388
36	44	46	52	42	49	59
9	9	13	14	13	12	12
160	186	230	280	297	272	228
545	621	672	719	819	875	985
62	68	53	51	51	58	70
145	172	225	283	326	355	410
7	8	10	8	17	21	26
126	151	152	155	167	166	177
205	222	232	223	258	275	303

Table 13 Average annual number of new cases by primary site and 5-year period 1957-2006

ICD10	Site	1957-61	1962-66	1967-71
C00-96	All sites	4230	4667	5451
C00-14	Mouth, pharynx	60	69	73
C00	Lip	8	8	11
C01-02	Tongue	11	14	17
C03-06	Mouth, other	11	13	17
C07-08	Salivary glands	8	14	13
C09-14	Pharynx	22	20	16
C15-26	Digestive organs	1392	1467	1610
C15	Oesophagus	23	32	28
C16	Stomach	581	532	492
C17	Small intestine	8	11	15
C18	Colon	286	359	438
C19-21	Rectum, rectosigmoid, anus	127	149	229
C22	Liver	12	13	23
C23-24	Gallbladder, bile ducts	49	52	59
C25	Pancreas	105	124	167
C26	Other digestive organs	202	195	159
C30-34, C38	Respiratory organs	93	111	167
C30-31	Nose, sinuses	13	12	14
C32	Larynx, epiglottis	2	5	6
C33-34	Lung, trachea	73	86	143
C38	Mediastinum, pleura	4	7	5
C40-41	Bone	10	9	14
C43	Melanoma of the skin	60	93	128
C44	Skin, non-melanoma	53	40	59
C45	Mesothelioma	0	1	2
C46	Kaposi's sarcoma	0	1	2
C47	Autonomic nervous system	16	9	16
C48-49	Soft tissues	18	26	27
C50	Breast	937	1066	1224
C51-58	Female genital organs	894	967	1130
C53	Cervix uteri	348	362	404
C54	Corpus uteri	181	222	268
C55	Uterus, other	24	17	15
C56	Ovary	269	297	358
C51-52, C57	Other female genital	69	66	80
C58	Placenta	3	3	4
C64-68	Urinary organs	200	226	274
C64	Kidney excl. renal pelvis	78	90	117
C65	Renal pelvis	6	6	12
C66-68	Bladder, ureter, urethra	117	130	145
C69	Eye	15	16	18
C70-72	Central nervous system	111	119	131
C73	Thyroid gland	53	61	91
C37, C74-75	Other endocrine glands	5	5	5
C39, C76, C80	Other or unspecified	54	70	100
C81-96	Lymphoid and haematopoietic tissue	259	312	381
C81	Hodgkin lymphoma	33	37	47
C82-85, C96	Non-Hodgkin lymphoma	64	83	116
C88	Malignant immunoproliferative diseases	0	0	1
C90	Multiple myeloma	40	64	79
C91-95	Leukaemia	122	128	137

FEMALES

Period						
1972-76	1977-81	1982-86	1987-91	1992-96	1997-01	2002-06
6210	7093	7935	8580	9539	10513	11562
80	90	105	109	131	130	155
11	16	22	27	29	26	31
17	17	25	22	24	27	29
16	23	25	29	36	33	41
12	15	12	12	20	20	19
24	19	21	18	21	24	35
1730	2039	2169	2208	2359	2472	2553
31	32	34	40	40	50	53
419	407	387	340	295	241	227
18	21	27	31	29	43	48
514	693	786	886	1015	1114	1193
275	382	431	451	491	513	540
30	36	44	42	42	47	44
56	72	82	75	73	80	73
189	224	274	282	311	325	326
199	172	104	61	63	60	48
203	257	353	483	622	766	941
13	13	15	14	17	15	18
7	11	11	11	20	20	15
173	227	323	453	579	723	901
9	6	4	5	7	8	6
13	14	14	14	19	19	17
200	264	361	442	489	510	571
114	153	222	297	400	471	592
2	2	5	7	9	8	12
5	2	6	6	5	4	3
9	5	6	9	8	6	5
38	41	46	46	46	60	76
1410	1538	1734	1844	2082	2475	2735
1246	1289	1296	1320	1401	1436	1532
441	400	354	346	342	309	293
326	371	390	412	468	526	641
7	8	5	6	8	10	11
340	379	433	448	460	461	454
128	128	110	103	118	127	129
2	3	3	6	4	4	4
327	380	431	464	498	521	577
118	138	157	182	191	189	211
16	18	19	24	26	25	28
194	225	256	259	281	307	338
20	21	22	25	29	27	30
151	185	225	259	305	412	515
110	132	143	136	137	122	148
4	9	13	16	11	12	13
112	177	225	286	317	304	294
436	493	561	608	671	759	794
43	40	38	34	34	42	48
117	151	204	253	279	327	355
4	4	6	7	11	12	18
108	128	133	133	141	149	149
163	170	180	181	205	229	224

Table 14 Age-adjusted (world) incidence rates per 100 000 person-years by primary site and five-year period 1957-2006

ICD10	Site	1957-61	1962-66	1967-71
C00-96	All sites	172.9	183.0	201.2
C00-14	Mouth, pharynx	7.8	7.4	7.8
C00	Lip	4.0	3.6	4.1
C01-02	Tongue	0.8	0.8	0.8
C03-06	Mouth, other	1.0	0.9	1.1
C07-08	Salivary glands	0.5	0.5	0.5
C09-14	Pharynx	1.5	1.5	1.3
C15-26	Digestive organs	68.3	65.4	65.6
C15	Oesophagus	3.2	2.9	2.7
C16	Stomach	34.5	29.4	25.7
C17	Small intestine	0.5	0.5	0.7
C18	Colon	10.1	11.6	12.9
C19-21	Rectum, rectosigmoid, anus	6.5	7.2	9.6
C22	Liver	1.0	0.9	1.5
C23-24	Gallbladder, bile ducts	0.9	0.8	0.9
C25	Pancreas	6.2	7.0	7.8
C26	Other digestive organs	5.5	5.0	3.8
C30-34, C38	Respiratory organs	15.3	18.9	24.9
C30-31	Nose, sinuses	0.8	0.8	0.8
C32	Larynx, epiglottis	1.5	1.9	2.6
C33-34	Lung, trachea	12.4	15.7	21.1
C38	Mediastinum, pleura	0.6	0.4	0.5
C40-41	Bone	0.7	0.9	0.8
C43	Melanoma of the skin	2.6	3.6	5.2
C44	Skin, non-melanoma	3.3	2.5	3.6
C45	Mesothelioma	0.0	0.1	0.2
C46	Kaposi's sarcoma	0.1	0.1	0.1
C47	Autonomic nervous system	0.9	0.7	0.6
C48-49	Soft tissues	0.9	1.1	1.4
C50	Breast	0.3	0.3	0.3
C60-63	Male genital organs	30.3	35.0	38.8
C61	Prostate	26.6	30.3	33.9
C62	Testis	3.0	3.7	4.1
C60, C63	Other male genital	0.8	0.9	0.8
C64-68	Urinary organs	13.7	16.7	18.5
C64	Kidney excl. renal pelvis	4.7	5.1	5.9
C65	Renal pelvis	0.4	0.5	0.8
C66-68	Bladder, ureter, urethra	8.6	11.1	11.8
C69	Eye	0.9	0.8	1.1
C70-72	Central nervous system	6.3	6.5	7.0
C73	Thyroid gland	0.9	1.1	1.4
C37, C74-75	Other endocrine glands	0.3	0.3	0.3
C39, C76, C80	Other or unspecified	2.7	3.5	4.5
C81-96	Lymphoid and haematopoietic tissue	17.4	18.2	19.1
C81	Hodgkin lymphoma	2.4	2.6	2.7
C82-85, C96	Non-Hodgkin lymphoma	4.6	4.9	5.3
C88	Malignant immunoproliferative diseases	0.0	0.0	0.1
C90	Multiple myeloma	3.0	3.2	3.3
C91-95	Leukaemia	7.4	7.6	7.7

Period						
1972-76	1977-81	1982-86	1987-91	1992-96	1997-01	2002-06
220.0	243.2	262.6	274.1	299.3	318.7	333.1
8.5	7.9	8.5	8.2	8.4	7.9	7.4
4.0	3.6	3.2	2.6	2.2	1.6	1.3
1.0	0.9	1.2	1.3	1.4	1.5	1.5
1.0	1.3	1.6	1.5	1.9	1.4	1.4
0.5	0.5	0.5	0.6	0.6	0.7	0.6
1.9	1.6	2.0	2.2	2.4	2.6	2.6
64.4	67.3	69.2	67.8	67.9	68.2	67.6
2.7	2.7	2.6	3.2	3.2	3.4	3.7
21.1	18.2	16.5	14.2	12.0	9.6	7.8
0.6	0.6	0.9	0.8	0.9	1.4	1.4
13.5	16.7	19.6	21.7	23.0	25.0	25.3
11.1	14.3	15.7	15.6	16.7	17.0	17.3
1.8	1.6	2.2	1.8	1.7	2.0	2.1
0.9	1.1	1.4	1.4	1.5	1.6	1.5
8.3	8.3	8.6	8.3	7.6	7.3	7.6
4.5	3.7	1.7	0.9	1.3	1.1	0.8
28.7	34.5	38.4	39.1	41.4	40.3	39.7
0.8	0.8	0.7	0.7	0.6	0.7	0.6
2.6	3.2	3.5	3.4	3.3	3.1	2.9
24.5	29.8	33.8	34.8	36.8	36.0	35.9
0.8	0.7	0.4	0.2	0.6	0.5	0.3
1.0	0.9	1.1	0.9	0.9	0.9	1.0
6.8	8.9	10.1	13.9	14.5	14.8	14.9
5.6	6.5	8.1	10.0	12.0	13.8	14.8
0.3	0.7	0.8	1.2	1.1	1.4	1.5
0.2	0.2	0.2	0.4	0.4	0.1	0.2
0.6	0.4	0.4	0.5	0.3	0.3	0.3
1.9	2.0	1.6	1.6	1.6	1.6	1.6
0.3	0.3	0.4	0.4	0.4	0.4	0.4
43.0	48.2	51.7	55.3	70.1	88.6	100.5
38.0	41.7	43.9	47.2	60.5	77.4	88.8
4.3	5.6	6.8	7.3	8.7	10.3	10.4
0.8	0.9	0.9	0.8	1.0	0.9	1.2
23.1	26.2	30.6	30.5	32.4	31.1	32.7
6.3	7.2	8.4	7.9	8.1	8.7	9.7
0.9	1.1	1.2	1.0	1.2	1.0	1.0
15.9	17.9	21.1	21.5	23.0	21.4	22.0
0.7	1.1	1.0	0.9	1.0	0.9	1.0
7.4	8.3	9.0	9.5	10.5	12.0	13.2
1.4	1.6	1.6	1.9	1.4	1.7	1.8
0.4	0.5	0.6	0.6	0.6	0.5	0.5
5.4	5.8	6.7	7.8	7.9	6.8	5.3
20.2	21.9	22.6	23.7	26.3	27.4	28.8
2.7	2.8	2.1	2.1	2.2	2.4	2.8
5.3	6.0	7.6	9.4	10.6	11.0	11.6
0.2	0.2	0.3	0.2	0.5	0.6	0.6
4.1	4.7	4.5	4.4	4.6	4.4	4.5
7.9	8.2	8.1	7.6	8.5	9.0	9.2

Table 19 Age-adjusted (world) incidence rates per 100 000 person-years by primary site and five-year period 1957-2006

ICD10	Site	1957-61	1962-66	1967-71
C00-96	All sites	164.7	168.5	184.3
C00-14	Mouth, pharynx	2.2	2.3	2.2
C00	Lip	0.3	0.3	0.3
C01-02	Tongue	0.4	0.5	0.4
C03-06	Mouth, other	0.4	0.4	0.5
C07-08	Salivary glands	0.3	0.5	0.5
C09-14	Pharynx	0.8	0.7	0.5
C15-26	Digestive organs	48.2	45.9	45.7
C15	Oesophagus	0.8	0.9	0.8
C16	Stomach	19.8	16.4	13.6
C17	Small intestine	0.3	0.4	0.5
C18	Colon	10.1	11.4	12.7
C19-21	Rectum, rectosigmoid, anus	4.5	4.9	6.8
C22	Liver	0.5	0.5	0.7
C23-24	Gallbladder, bile ducts	1.7	1.6	1.6
C25	Pancreas	3.7	3.9	4.7
C26	Other digestive organs	6.8	5.9	4.2
C30-34, C38	Respiratory organs	3.5	3.8	5.3
C30-31	Nose, sinuses	0.5	0.4	0.4
C32	Larynx, epiglottis	0.1	0.2	0.2
C33-34	Lung, trachea	2.7	2.9	4.5
C38	Mediastinum, pleura	0.2	0.3	0.2
C40-41	Bone	0.6	0.4	0.6
C43	Melanoma of the skin	2.6	4.1	5.5
C44	Skin, non-melanoma	1.9	1.2	1.6
C45	Mesothelioma	0.0	0.0	0.1
C46	Kaposi's sarcoma	0.0	0.1	0.0
C47	Autonomic nervous system	0.7	0.4	0.8
C48-49	Soft tissues	0.8	1.0	1.1
C50	Breast	37.6	40.2	43.6
C51-58	Female genital organs	37.8	38.4	43.1
C53	Cervix uteri	15.5	15.8	17.4
C54	Corpus uteri	7.3	8.3	9.4
C55	Uterus, other	0.8	0.5	0.4
C56	Ovary	11.4	11.4	13.3
C51-52, C57	Other female genital	2.6	2.2	2.4
C58	Placenta	0.2	0.2	0.2
C64-68	Urinary organs	7.5	7.5	8.2
C64	Kidney excl. renal pelvis	3.1	3.2	3.7
C65	Renal pelvis	0.2	0.2	0.3
C66-68	Bladder, ureter, urethra	4.2	4.1	4.1
C69	Eye	0.7	0.7	0.7
C70-72	Central nervous system	5.3	5.2	5.7
C73	Thyroid gland	2.1	2.5	3.6
C37, C74-75	Other endocrine glands	0.3	0.2	0.2
C39, C76, C80	Other or unspecified	2.0	2.4	3.0
C81-96	Lymphoid and haematopoietic tissue	11.0	12.1	13.2
C81	Hodgkin lymphoma	1.6	1.7	2.0
C82-85, C96	Non-Hodgkin lymphoma	2.6	3.1	4.0
C88	Malignant immunoproliferative diseases	0.0	0.0	0.0
C90	Multiple myeloma	1.5	2.1	2.2
C91-95	Leukaemia	5.4	5.2	5.0

FEMALES

Period						
1972-76	1977-81	1982-86	1987-91	1992-96	1997-01	2002-06
198.5	211.4	222.5	231.4	250.0	266.7	280.1
2.3	2.4	2.8	2.8	3.4	3.2	3.7
0.3	0.4	0.5	0.6	0.7	0.6	0.6
0.4	0.4	0.7	0.6	0.6	0.7	0.7
0.4	0.6	0.6	0.7	0.9	0.8	0.9
0.4	0.4	0.4	0.4	0.6	0.6	0.5
0.7	0.5	0.6	0.6	0.6	0.7	1.0
45.4	48.9	48.3	47.4	49.3	50.0	50.2
0.7	0.7	0.7	0.9	0.8	1.0	1.1
10.7	9.3	8.3	6.9	5.6	4.6	4.3
0.6	0.6	0.7	0.8	0.7	1.1	1.1
13.9	17.1	17.8	19.3	21.5	22.5	23.0
7.7	9.8	10.4	10.3	11.1	11.4	11.5
0.8	0.9	1.1	0.9	1.0	1.1	1.0
1.3	1.6	1.7	1.5	1.5	1.6	1.4
4.9	5.2	5.8	5.7	6.1	6.0	6.1
4.8	3.7	1.7	1.0	1.0	0.8	0.8
6.2	7.6	9.9	13.3	17.1	20.1	22.7
0.4	0.3	0.4	0.3	0.4	0.4	0.4
0.2	0.3	0.3	0.3	0.6	0.5	0.4
5.3	6.8	9.1	12.5	15.9	19.1	21.8
0.3	0.1	0.1	0.1	0.2	0.2	0.1
0.6	0.6	0.6	0.6	0.8	0.8	0.7
8.3	10.2	13.1	15.7	16.0	15.6	16.3
2.9	3.4	4.5	5.6	7.3	8.2	9.4
0.1	0.1	0.1	0.2	0.2	0.2	0.2
0.1	0.0	0.1	0.1	0.1	0.1	0.0
0.4	0.3	0.3	0.4	0.4	0.2	0.3
1.4	1.4	1.5	1.4	1.4	1.7	2.1
47.8	49.4	52.7	53.6	60.4	71.7	75.8
45.7	45.1	42.5	41.3	42.0	40.4	40.2
18.7	16.2	13.3	12.4	11.8	10.3	9.4
11.0	12.1	12.3	12.5	13.6	14.1	15.9
0.2	0.2	0.1	0.1	0.2	0.2	0.2
12.2	13.2	13.9	13.6	13.6	12.8	11.8
3.5	3.3	2.7	2.5	2.7	2.8	2.8
0.1	0.2	0.2	0.3	0.2	0.2	0.2
9.0	9.9	10.1	10.9	11.1	11.3	11.9
3.6	4.0	4.0	4.7	4.7	4.5	4.9
0.4	0.4	0.4	0.5	0.6	0.5	0.5
5.0	5.4	5.6	5.7	5.9	6.3	6.4
0.8	0.7	0.9	0.9	1.0	0.7	0.9
6.3	7.3	8.5	9.3	10.4	13.0	15.8
4.3	5.0	5.2	4.8	4.7	4.0	4.7
0.2	0.4	0.6	0.7	0.5	0.5	0.5
3.0	4.3	4.9	5.9	6.2	5.4	4.9
13.8	14.6	15.9	16.5	17.7	19.6	19.8
1.7	1.6	1.4	1.3	1.4	1.8	1.9
3.7	4.5	5.8	6.9	7.4	8.3	8.4
0.1	0.1	0.1	0.2	0.3	0.2	0.4
3.0	3.1	3.0	2.9	2.8	3.0	3.0
5.4	5.3	5.6	5.3	5.8	6.3	6.1

Table 16 Average annual number of new cases by primary site and county - 2002-2006

ICD10	Site	Norway	Østfold	Akershus	Oslo	Hedmark	Oppland	Buskerud
C00-96	All sites	12616	737	1164	1232	635	568	693
C00-14	Mouth, pharynx	254	19	26	31	11	8	14
C00	Lip	48	5	4	3	3	1	3
C01-02	Tongue	50	3	5	6	3	2	3
C03-06	Mouth, other	48	4	4	5	2	2	3
C07-08	Salivary glands	19	1	2	1	1	0	0
C09-14	Pharynx	88	6	10	15	2	3	6
C15-26	Digestive organs	2688	166	243	248	134	118	143
C15	Oesophagus	137	7	13	14	6	9	8
C16	Stomach	324	23	22	25	15	14	15
C17	Small intestine	52	3	5	4	3	2	2
C18	Colon	1027	64	98	90	55	41	57
C19-21	Rectum, rectosigmoid, anus	677	41	62	59	31	29	37
C22	Liver	78	5	6	15	3	3	4
C23-24	Gallbladder, bile ducts	60	4	5	6	2	2	3
C25	Pancreas	297	17	28	32	16	15	14
C26	Other digestive organs	35	2	3	3	3	2	2
C30-34, C38	Respiratory organs	1525	98	137	139	68	59	75
C30-31	Nose, sinuses	22	1	1	2	1	1	1
C32	Larynx, epiglottis	103	8	9	10	4	5	6
C33-34	Lung, trachea	1386	88	125	126	63	51	68
C38	Mediastinum, pleura	13	1	2	1	0	1	0
C40-41	Bone	25	1	3	2	2	1	2
C43	Melanoma of the skin	513	34	61	56	25	19	29
C44	Skin, non-melanoma	671	43	59	67	38	26	56
C45	Mesothelioma	60	4	7	6	3	3	5
C46	Kaposi's sarcoma	7	0	0	2	0	0	0
C47	Autonomic nervous system	5	0	1	1	0	0	0
C48-49	Soft tissues	53	3	5	5	3	3	3
C50	Breast	16	1	1	2	1	0	1
C60-63	Male genital organs	3795	191	327	367	198	202	205
C61	Prostate	3496	173	298	333	186	187	193
C62	Testis	253	14	25	28	9	13	10
C60, C63	Other male genital	46	4	5	6	3	2	2
C64-68	Urinary organs	1300	85	114	130	68	57	61
C64	Kidney excl. renal pelvis	346	26	35	34	18	16	16
C65	Renal pelvis	42	3	3	4	3	2	2
C66-68	Bladder, ureter, urethra	912	56	77	92	47	39	43
C69	Eye	33	2	2	4	1	3	2
C70-72	Central nervous system	388	21	42	39	17	14	20
C73	Thyroid gland	59	3	6	5	4	3	3
C37, C74-75	Other endocrine glands	12	1	2	1	1	1	0
C39, C76, C80	Other or unspecified	228	14	21	24	11	9	15
C81-96	Lymphoid and haematopoietic tissue	985	51	106	104	51	43	58
C81	Hodgkin lymphoma	70	6	7	8	4	4	4
C82-85, C96	Non-Hodgkin lymphoma	410	19	44	46	23	17	20
C88	Malignant immunoproliferative diseases	26	1	4	2	0	2	1
C90	Multiple myeloma	177	8	19	16	8	8	11
C91-95	Leukaemia	303	17	31	32	15	12	23

Finmark	Troms	Nordland	Nord-Trøndelag	Sør-Trøndelag	Møre og Romsdal	Sogn og Fjordane	Hordaland	Rogaland	Vest-Agder	Aust-Agder	Telemark	Vestfold
172	400	684	371	714	728	341	1175	1039	451	320	499	694
4	9	15	6	13	11	8	20	20	8	7	10	14
1	1	2	1	4	2	2	3	5	2	2	1	3
1	2	4	1	1	1	2	5	3	1	2	2	2
1	2	3	1	2	2	3	4	4	1	1	2	3
0	1	1	1	1	1	0	1	2	1	0	1	1
1	3	6	3	4	4	1	6	6	2	2	4	4
42	94	160	79	168	163	74	268	213	87	57	94	137
3	5	7	3	7	5	4	13	10	5	3	7	8
9	15	22	10	23	21	11	33	26	9	6	10	16
0	1	4	2	6	3	1	5	4	1	1	2	1
13	34	65	33	62	66	28	102	79	35	19	33	53
10	20	38	18	44	40	20	72	60	22	13	24	34
1	4	4	2	4	4	1	6	5	3	3	2	3
1	2	4	1	4	2	2	7	4	3	2	3	5
4	12	16	8	17	18	6	29	22	8	7	11	16
1	1	1	1	1	5	1	2	3	1	2	2	0
33	59	89	45	89	86	35	140	119	61	46	59	88
1	1	1	0	2	1	1	2	2	1	0	1	1
2	6	6	3	4	6	2	9	7	4	4	4	5
30	51	81	41	82	78	32	128	109	57	41	53	81
0	0	1	1	1	0	0	1	1	0	0	1	0
1	0	1	1	2	1	1	3	2	1	0	1	2
3	11	11	15	35	23	9	44	53	19	12	22	34
4	11	22	15	33	28	12	62	59	37	22	35	42
0	1	1	1	2	3	1	6	3	3	1	3	6
0	0	1	0	1	0	0	2	0	0	0	0	0
0	0	0	0	0	0	0	1	0	0	0	0	0
1	2	4	1	3	2	2	5	4	3	1	2	3
0	1	1	1	2	1	0	1	1	1	1	0	1
44	114	208	117	194	236	120	346	332	136	103	155	199
39	106	197	107	175	215	115	313	305	126	98	143	187
4	7	8	9	17	18	5	28	24	8	4	10	10
1	1	3	1	2	3	0	4	3	2	1	2	2
17	42	81	36	79	76	32	124	105	42	28	51	72
6	10	22	11	21	18	7	28	31	11	6	12	20
0	2	2	1	3	2	1	4	3	1	1	2	4
11	31	57	24	55	56	25	91	71	30	21	37	48
1	1	2	1	2	1	2	3	2	1	1	0	2
4	15	17	12	25	24	11	43	29	11	9	16	20
2	1	3	2	3	4	3	5	5	1	1	2	2
0	0	2	1	1	1	1	1	1	1	0	0	1
3	8	16	7	10	9	7	24	15	5	6	11	13
12	29	50	33	55	59	24	78	77	33	25	40	58
1	2	3	2	3	6	2	5	6	2	1	2	4
5	14	22	13	23	22	10	31	35	16	11	16	24
0	1	1	2	1	1	1	3	1	0	1	1	1
3	4	11	7	11	11	4	17	11	4	5	10	8
3	9	14	9	17	18	7	22	24	11	7	12	22

Table 17 Average annual number of new cases by primary site and county - 2002-2006

ICD10	Site	Norway	Østfold	Akershus	Oslo	Hedmark	Oppland	Buskerud
C00-96	All sites	11562	689	1145	1345	540	490	673
C00-14	Mouth, pharynx	155	10	14	21	7	6	10
C00	Lip	31	2	3	2	1	1	2
C01-02	Tongue	29	1	3	4	2	1	2
C03-06	Mouth, other	41	2	4	6	2	2	3
C07-08	Salivary glands	19	1	2	2	1	1	2
C09-14	Pharynx	35	3	2	8	1	1	2
C15-26	Digestive organs	2553	159	221	284	113	113	135
C15	Oesophagus	53	2	6	9	2	3	4
C16	Stomach	227	11	15	24	10	10	11
C17	Small intestine	48	3	4	6	4	1	3
C18	Colon	1193	74	99	126	51	50	63
C19-21	Rectum, rectosigmoid, anus	540	37	53	60	24	26	32
C22	Liver	44	2	4	5	3	2	2
C23-24	Gallbladder, bile ducts	73	5	5	7	4	5	3
C25	Pancreas	326	22	28	41	14	15	14
C26	Other digestive organs	48	3	5	6	2	1	2
C30-34, C38	Respiratory organs	941	56	93	120	41	35	51
C30-31	Nose, sinuses	18	2	2	3	0	1	0
C32	Larynx, epiglottis	15	1	2	1	1	1	1
C33-34	Lung, trachea	901	53	90	114	40	33	50
C38	Mediastinum, pleura	6	1	0	1	0	0	0
C40-41	Bone	17	1	1	1	1	0	2
C43	Melanoma of the skin	571	43	64	65	22	20	38
C44	Skin, non-melanoma	592	46	50	62	28	18	48
C45	Mesothelioma	12	1	2	2	0	0	1
C46	Kaposi's sarcoma	3	0	0	0	0	0	0
C47	Autonomic nervous system	5	1	1	0	0	0	0
C48-49	Soft tissues	76	3	10	8	3	2	4
C50	Breast	2735	156	301	341	127	116	175
C51-58	Female genital organs	1532	82	150	167	84	82	82
C53	Cervix uteri	293	15	33	35	15	12	17
C54	Corpus uteri	641	32	63	72	37	38	35
C55	Uterus, other	11	1	0	1	1	1	0
C56	Ovary	454	27	44	43	25	26	23
C51-52, C57	Other female genital	129	6	10	15	7	5	7
C58	Placenta	4	0	0	0	0	0	0
C64-68	Urinary organs	577	34	55	67	29	22	33
C64	Kidney excl. renal pelvis	211	12	20	20	11	9	11
C65	Renal pelvis	28	1	1	5	1	1	2
C66-68	Bladder, ureter, urethra	338	21	33	42	16	12	19
C69	Eye	30	1	4	2	1	1	3
C70-72	Central nervous system	515	29	49	49	23	24	24
C73	Thyroid gland	148	6	16	18	9	3	7
C37, C74-75	Other endocrine glands	13	1	2	2	1	0	1
C39, C76, C80	Other or unspecified	294	16	27	39	17	15	16
C81-96	Lymphoid and haematopoietic tissue	794	45	86	96	34	34	44
C81	Hodgkin lymphoma	48	2	6	8	2	2	3
C82-85, C96	Non-Hodgkin lymphoma	355	19	37	41	14	15	18
C88	Malignant immunoproliferative diseases	18	1	3	2	1	1	1
C90	Multiple myeloma	149	9	14	18	6	6	7
C91-95	Leukaemia	224	15	26	27	10	10	15

FEMALES

Finmark	Troms	Nordland	Nord-Trøndelag	Sør-Trøndelag	Møre og Romsdal	Sogn og Fjordane	Hordaland	Rogaland	Vest-Agder	Aust-Agder	Telemark	Vestfold
144	334	629	312	676	606	253	1058	894	426	269	462	617
1	5	11	3	10	8	4	12	9	7	3	5	8
1	1	1	0	2	2	1	2	3	3	1	1	1
1	1	2	0	2	2	1	3	2	0	0	1	2
0	2	3	1	2	2	1	3	2	1	0	1	2
0	0	1	1	1	1	1	1	1	1	1	1	1
0	1	3	1	3	1	0	3	2	2	1	1	2
33	78	141	73	154	155	64	273	196	84	59	89	128
1	2	3	1	2	2	1	4	4	2	1	3	3
5	11	14	7	13	14	8	25	20	5	4	10	9
1	1	2	1	4	4	1	4	2	2	1	2	2
14	34	66	38	68	80	30	137	91	44	27	40	62
5	16	29	13	33	26	13	58	45	13	13	16	27
1	2	3	1	4	2	1	3	3	2	1	1	2
2	2	3	2	5	4	2	7	5	4	3	4	2
5	9	18	8	23	20	8	32	22	10	7	12	18
0	1	3	1	3	4	1	3	4	2	1	2	2
15	29	57	27	57	43	16	70	65	43	25	40	57
0	0	1	0	1	1	1	2	1	1	1	1	1
0	1	1	0	1	1	0	1	1	1	0	1	1
15	28	54	26	55	41	15	67	63	42	24	38	55
0	0	0	0	1	0	0	0	0	0	0	0	0
1	1	1	1	2	0	1	1	1	1	1	1	1
3	11	16	16	33	27	9	50	61	20	11	24	40
3	9	17	16	32	22	10	46	61	34	18	37	35
0	0	0	0	0	1	0	1	1	0	1	1	1
0	0	1	0	0	1	0	0	0	0	0	0	0
0	0	1	0	0	1	0	1	0	0	0	0	0
1	2	5	4	7	5	2	4	6	3	2	3	3
30	78	139	73	152	145	56	246	202	94	53	105	145
21	46	91	35	84	69	32	149	123	57	37	65	76
4	11	21	7	13	11	5	27	23	12	6	12	14
9	17	37	17	34	31	14	63	50	24	14	26	29
0	1	0	0	0	0	1	2	1	0	0	1	1
6	13	26	9	26	20	9	47	37	16	12	20	25
2	4	6	3	10	6	4	10	11	5	4	6	7
0	1	0	0	0	0	0	0	1	0	0	0	0
9	18	42	15	35	34	14	46	40	21	14	19	31
5	7	16	6	14	13	5	16	15	10	3	8	11
0	1	2	1	3	1	1	2	1	0	1	0	2
4	10	24	8	19	19	8	28	24	11	10	11	18
0	0	2	1	2	3	1	2	2	1	2	1	1
7	16	31	12	38	28	13	46	39	20	15	22	32
3	7	12	3	8	10	4	16	7	4	2	7	6
0	0	1	0	1	0	0	2	1	0	0	0	1
4	10	18	8	17	11	8	24	22	9	7	12	12
12	24	43	24	44	44	19	71	57	28	20	30	40
1	1	3	1	3	2	1	4	4	1	1	1	2
7	10	19	12	22	20	7	32	27	14	9	14	17
0	0	1	1	0	1	0	1	1	0	0	0	1
1	5	10	3	6	12	5	14	10	6	4	6	8
3	7	11	7	13	9	5	19	15	7	6	9	12

Table 18 Age-adjusted (world) incidence rates per 100 000 person-years by county and primary site - 2002-2006

ICD10	Site	Norway	Østfold	Akershus	Oslo	Hedmark	Oppland	Buskerud
C00-96	All sites	333.1	329.0	311.4	332.8	336.6	322.8	327.3
C00-14	Mouth, pharynx	7.4	9.2	7.2	8.8	7.1	4.6	7.5
C00	Lip	1.3	2.0	1.1	0.7	1.9	0.7	1.6
C01-02	Tongue	1.5	1.6	1.5	1.9	2.1	1.4	1.4
C03-06	Mouth, other	1.4	2.2	1.2	1.4	1.0	0.8	1.3
C07-08	Salivary glands	0.6	0.6	0.6	0.3	0.9	0.2	0.2
C09-14	Pharynx	2.6	2.7	2.8	4.6	1.2	1.6	3.1
C15-26	Digestive organs	67.6	71.9	61.5	64.6	67.4	64.0	64.9
C15	Oesophagus	3.7	3.2	3.6	3.9	3.2	5.0	3.9
C16	Stomach	7.8	9.3	5.5	6.4	6.9	7.1	7.1
C17	Small intestine	1.4	1.5	1.5	1.2	2.1	1.2	1.2
C18	Colon	25.3	27.3	24.4	23.3	26.3	21.7	25.5
C19-21	Rectum, rectosigmoid, anus	17.3	17.9	15.9	15.4	16.4	17.1	16.6
C22	Liver	2.1	2.4	1.5	4.2	1.7	1.9	2.2
C23-24	Gallbladder, bile ducts	1.5	1.7	1.3	1.6	1.3	1.2	1.0
C25	Pancreas	7.6	7.9	7.3	7.9	8.6	8.0	6.6
C26	Other digestive organs	0.8	0.8	0.8	0.6	1.0	0.9	0.8
C30-34, C38	Respiratory organs	39.7	42.3	35.2	37.6	35.7	32.6	35.6
C30-31	Nose, sinuses	0.6	0.6	0.3	0.5	0.5	0.7	0.5
C32	Larynx, epiglottis	2.9	3.6	2.3	3.1	2.3	2.9	2.8
C33-34	Lung, trachea	35.9	37.6	32.1	33.6	32.7	28.5	32.2
C38	Mediastinum, pleura	0.3	0.4	0.5	0.3	0.1	0.5	0.2
C40-41	Bone	1.0	0.3	1.0	1.1	1.3	1.3	1.5
C43	Melanoma of the skin	14.9	17.0	16.9	15.0	15.4	12.5	15.2
C44	Skin, non-melanoma	14.8	16.1	13.9	14.1	16.6	11.6	21.9
C45	Mesothelioma	1.5	1.7	1.8	1.4	1.6	1.4	2.4
C46	Kaposi's sarcoma	0.2	0.2	0.1	0.5	0.2	0.2	0.2
C47	Autonomic nervous system	0.3	0.0	0.4	0.3	0.2	0.0	0.4
C48-49	Soft tissues	1.6	2.0	1.5	1.5	1.8	2.2	2.0
C50	Breast	0.4	0.6	0.4	0.6	0.3	0.1	0.4
C60-63	Male genital organs	100.5	82.8	90.1	101.7	101.6	114.5	96.4
C61	Prostate	88.8	70.5	78.7	91.5	89.1	98.3	87.1
C62	Testis	10.4	10.7	10.2	8.5	10.6	14.9	8.3
C60, C63	Other male genital	1.2	1.7	1.2	1.7	1.9	1.2	1.0
C64-68	Urinary organs	32.7	37.0	28.8	33.6	34.2	31.0	27.1
C64	Kidney excl. renal pelvis	9.7	12.2	9.5	9.3	10.0	9.7	7.9
C65	Renal pelvis	1.0	1.5	0.7	1.2	1.5	0.9	0.8
C66-68	Bladder, ureter, urethra	22.0	23.3	18.6	23.0	22.7	20.5	18.3
C69	Eye	1.0	1.0	0.6	1.3	0.6	2.3	1.1
C70-72	Central nervous system	13.2	12.0	13.8	12.9	12.0	10.8	11.4
C73	Thyroid gland	1.8	1.5	1.6	1.5	2.5	1.6	2.0
C37, C74-75	Other endocrine glands	0.5	0.6	0.5	0.2	0.7	0.4	0.0
C39, C76, C80	Other or unspecified	5.3	6.0	5.2	5.9	5.9	4.0	6.2
C81-96	Lymphoid and haematopoietic tissue	28.8	26.9	30.6	30.3	31.6	27.6	31.1
C81	Hodgkin lymphoma	2.8	3.8	2.8	2.5	4.5	3.8	3.2
C82-85, C96	Non-Hodgkin lymphoma	11.6	9.7	12.6	13.1	13.2	10.5	10.3
C88	Malignant immunoproliferative diseases	0.6	0.3	1.0	0.6	0.1	0.9	0.4
C90	Multiple myeloma	4.5	3.6	5.1	4.6	4.5	4.2	4.3
C91-95	Leukaemia	9.2	9.5	9.2	9.6	9.2	8.2	12.9

Vestfold	Telemark	Aust-Agder	Vest-Agder	Rogaland	Hordaland	Sogn og Fjordane	Møre og Romsdal	Sør-Trøndelag	Nord-Trøndelag	Nordland	Troms	Finmark
368.4	326.5	368.4	362.3	365.0	326.4	352.9	337.1	325.0	313.4	322.1	325.4	297.6
8.3	7.4	8.5	7.0	7.6	6.4	8.9	5.7	6.3	5.5	8.0	8.3	7.2
1.4	0.8	2.5	1.8	1.6	1.0	1.8	0.6	1.7	0.8	1.0	1.1	1.4
1.4	1.6	2.8	1.3	1.2	1.5	1.7	0.7	0.7	0.6	1.9	1.8	2.5
1.9	1.6	0.9	1.1	1.3	1.4	4.1	1.2	1.0	0.9	1.4	1.4	1.0
0.7	0.4	0.2	0.9	0.9	0.4	0.2	0.8	0.6	0.6	0.6	0.9	0.5
2.7	3.1	2.2	1.9	2.6	2.1	1.2	2.5	2.3	2.7	3.1	3.1	1.9
68.5	57.7	61.4	66.4	73.1	70.9	70.6	69.8	70.0	62.7	72.4	74.4	73.0
4.4	4.8	4.1	4.1	3.6	3.8	3.7	2.4	3.0	2.0	3.7	3.9	4.8
7.3	5.6	6.0	6.6	8.6	8.0	9.9	8.5	9.2	7.7	9.5	11.7	15.4
0.8	1.5	1.3	1.1	1.5	1.2	0.5	1.5	2.8	1.6	1.9	1.1	0.6
25.8	19.3	19.9	26.1	26.7	26.5	26.0	27.9	25.3	26.0	28.7	26.2	22.3
17.9	14.5	14.1	16.9	21.2	19.5	19.9	17.1	19.0	15.6	17.7	16.2	18.5
1.1	1.8	4.0	2.2	1.7	1.9	1.1	1.4	1.9	1.9	1.6	3.4	1.3
2.4	1.9	1.8	2.3	1.4	1.8	1.9	0.8	1.4	0.9	1.5	1.5	1.6
8.3	7.2	8.2	6.3	7.5	7.7	6.6	7.7	7.0	6.4	7.4	9.4	6.6
0.3	1.2	1.8	0.7	0.9	0.4	1.0	2.6	0.6	0.4	0.4	0.8	1.9
46.4	38.6	52.6	49.8	42.0	39.5	36.6	38.5	38.4	36.9	40.6	45.6	55.8
0.7	0.7	0.4	0.8	0.7	0.6	0.7	0.7	0.8	0.2	0.7	0.8	1.5
3.1	2.8	4.6	3.6	2.6	2.7	2.1	3.2	1.6	2.5	2.9	5.4	3.2
42.4	34.8	47.1	45.4	38.5	35.9	33.7	34.5	35.7	33.7	36.6	39.2	50.4
0.2	0.3	0.4	0.0	0.2	0.3	0.0	0.2	0.3	0.5	0.5	0.2	0.7
1.4	0.8	0.6	0.9	0.8	1.2	0.5	1.0	1.0	0.5	1.1	0.7	2.9
20.1	15.5	15.0	17.0	19.5	13.2	9.7	13.1	18.0	14.9	6.3	10.0	6.3
20.2	18.3	21.4	26.2	18.2	14.4	10.3	9.6	12.4	10.2	8.6	8.0	6.3
3.0	1.7	1.2	2.2	1.2	2.0	0.7	1.2	1.1	0.7	0.6	1.2	0.6
0.0	0.0	0.3	0.0	0.0	0.4	0.1	0.1	0.2	0.0	0.3	0.1	0.0
0.2	0.0	0.0	0.0	0.1	0.5	0.7	0.1	0.3	0.0	0.1	0.5	1.2
2.2	1.8	0.9	2.1	1.5	1.4	1.6	1.0	1.5	0.5	2.0	2.4	1.9
0.4	0.1	0.9	0.6	0.2	0.2	0.2	0.7	0.8	0.4	0.2	0.6	0.3
104.8	100.2	119.9	111.0	115.6	97.0	122.6	110.2	91.8	99.8	97.1	92.0	75.1
94.5	87.3	111.6	100.3	103.5	84.0	113.3	94.8	79.0	84.3	88.7	82.9	62.6
8.9	11.8	7.8	9.8	11.0	11.7	8.8	14.3	11.7	14.7	7.1	8.6	11.3
1.3	1.0	0.6	0.9	1.1	1.3	0.5	1.1	1.2	0.8	1.3	0.5	1.2
36.0	33.6	29.8	32.1	35.0	32.4	32.7	34.6	34.4	28.5	35.9	32.5	28.0
11.4	9.3	7.8	9.6	11.3	8.1	7.4	9.7	10.3	9.7	11.1	8.1	9.8
1.8	1.0	0.7	1.0	1.0	1.1	0.6	0.9	1.4	0.7	0.8	1.2	0.0
22.8	23.3	21.3	21.5	22.7	23.2	24.7	24.0	22.7	18.1	24.1	23.2	18.2
1.3	0.3	1.3	0.7	0.6	0.9	2.3	0.5	0.8	1.0	2.0	1.4	0.8
13.6	14.3	15.9	10.8	12.9	14.8	15.8	14.8	14.7	13.8	10.8	14.8	8.9
1.2	1.3	2.0	1.3	1.8	1.8	4.3	2.6	1.8	2.1	1.6	1.2	2.9
0.5	0.0	0.5	0.8	0.4	0.2	0.5	0.8	0.4	0.8	1.2	0.3	0.0
6.1	6.0	5.5	3.5	4.7	6.0	6.2	3.3	3.4	5.0	6.2	6.3	4.8
34.4	28.8	30.8	30.1	29.6	23.0	28.7	29.3	27.5	30.1	27.2	25.1	21.6
3.3	2.4	1.9	2.0	2.8	1.9	3.5	4.3	2.0	3.1	2.8	2.1	2.0
13.2	11.5	14.5	13.7	13.2	8.7	10.8	10.6	11.0	11.6	11.4	11.5	10.2
0.6	0.5	0.7	0.4	0.5	0.8	1.3	0.6	0.4	1.5	0.4	0.4	0.3
4.2	6.1	5.5	3.7	3.7	4.5	4.4	4.8	4.6	5.9	4.6	3.5	4.0
13.2	8.3	8.1	10.3	9.4	7.1	8.7	9.0	9.5	8.1	8.1	7.6	5.1

Table 19 Age-adjusted (world) incidence rates per 100 000 person-years by county and primary site - 2002-2006

ICD10	Site	Norway	Østfold	Akershus	Oslo	Hedmark	Oppland	Buskerud
C00-96	All sites	280.1	282.5	279.0	288.7	286.3	272.8	294.4
C00-14	Mouth, pharynx	3.7	4.2	3.5	5.1	2.9	2.7	4.2
C00	Lip	0.6	0.6	0.8	0.4	0.4	0.4	0.6
C01-02	Tongue	0.7	0.8	0.8	0.9	0.8	0.5	0.5
C03-06	Mouth, other	0.9	1.0	0.8	1.1	1.0	1.0	1.2
C07-08	Salivary glands	0.5	0.4	0.5	0.6	0.2	0.2	1.1
C09-14	Pharynx	1.0	1.5	0.7	2.0	0.5	0.6	0.8
C15-26	Digestive organs	50.2	52.1	46.2	49.2	47.2	50.3	49.4
C15	Oesophagus	1.1	0.7	1.4	1.6	0.9	1.0	1.5
C16	Stomach	4.3	3.6	3.2	4.3	3.8	3.7	3.5
C17	Small intestine	1.1	1.3	1.1	1.0	2.0	0.8	1.3
C18	Colon	23.0	24.1	20.1	21.6	19.8	21.8	23.4
C19-21	Rectum, rectosigmoid, anus	11.5	13.0	11.8	11.1	11.0	12.5	12.4
C22	Liver	1.0	0.5	1.0	0.9	1.9	1.1	0.6
C23-24	Gallbladder, bile ducts	1.4	1.8	1.1	1.3	1.3	2.4	0.8
C25	Pancreas	6.1	6.5	5.7	6.6	6.0	6.5	5.3
C26	Other digestive organs	0.8	0.8	1.0	0.9	0.5	0.5	0.6
C30-34, C38	Respiratory organs	22.7	22.8	22.2	24.9	20.8	18.9	21.5
C30-31	Nose, sinuses	0.4	0.6	0.5	0.6	0.0	0.6	0.3
C32	Larynx, epiglottis	0.4	0.4	0.4	0.3	0.4	0.4	0.3
C33-34	Lung, trachea	21.8	21.6	21.2	23.9	20.4	17.7	20.8
C38	Mediastinum, pleura	0.1	0.2	0.1	0.2	0.0	0.1	0.1
C40-41	Bone	0.7	0.7	0.4	0.5	0.6	0.0	1.3
C43	Melanoma of the skin	16.3	20.3	17.2	15.4	12.9	12.8	19.4
C44	Skin, non-melanoma	9.4	13.2	8.9	8.6	8.6	5.6	13.3
C45	Mesothelioma	0.2	0.2	0.5	0.3	0.0	0.0	0.3
C46	Kaposi's sarcoma	0.0	0.0	0.0	0.0	0.0	0.0	0.0
C47	Autonomic nervous system	0.3	0.4	0.3	0.0	0.0	0.0	0.2
C48-49	Soft tissues	2.1	1.8	2.4	2.2	1.6	1.5	2.2
C50	Breast	75.8	73.8	80.0	84.7	78.1	76.3	86.3
C51-58	Female genital organs	40.2	36.5	38.2	39.0	49.8	47.9	38.7
C53	Cervix uteri	9.4	9.2	9.4	9.4	11.9	10.1	9.9
C54	Corpus uteri	15.9	13.5	15.4	16.7	19.5	20.9	15.7
C55	Uterus, other	0.2	0.1	0.1	0.1	0.4	0.2	0.0
C56	Ovary	11.8	11.5	11.1	9.9	14.2	14.1	10.3
C51-52, C57	Other female genital	2.8	1.9	2.1	2.8	3.9	2.6	2.6
C58	Placenta	0.2	0.2	0.1	0.1	0.0	0.0	0.1
C64-68	Urinary organs	11.9	13.4	11.5	12.3	13.6	10.0	12.6
C64	Kidney excl. renal pelvis	4.9	5.6	5.1	4.1	6.1	3.9	4.8
C65	Renal pelvis	0.5	0.5	0.2	1.0	0.6	0.4	0.9
C66-68	Bladder, ureter, urethra	6.4	7.3	6.2	7.2	6.8	5.7	7.0
C69	Eye	0.9	0.9	1.2	0.7	1.1	0.3	1.3
C70-72	Central nervous system	15.8	14.8	13.9	13.9	16.9	17.5	13.9
C73	Thyroid gland	4.7	2.5	4.8	5.2	6.2	3.0	4.1
C37, C74-75	Other endocrine glands	0.5	0.3	0.6	0.6	0.5	0.1	0.5
C39, C76, C80	Other or unspecified	4.9	4.9	5.0	5.8	6.6	5.2	5.2
C81-96	Lymphoid and haematopoietic tissue	19.8	19.7	22.1	20.4	19.0	20.4	19.9
C81	Hodgkin lymphoma	1.9	1.6	2.4	2.6	2.0	2.0	1.9
C82-85, C96	Non-Hodgkin lymphoma	8.4	7.7	8.9	8.5	7.1	8.5	7.8
C88	Malignant immunoproliferative diseases	0.4	0.3	0.8	0.4	0.7	0.5	0.4
C90	Multiple myeloma	3.0	2.9	2.9	3.5	2.7	2.9	2.9
C91-95	Leukaemia	6.1	7.2	7.0	5.4	6.5	6.4	7.0

FEMALES

Vestfold	Telemark	Aust-Agder	Vest-Agder	Rogaland	Hordaland	Sogn og Fjordane	Møre og Romsdal	Sør-Trøndelag	Nord-Trøndelag	Nordland	Troms	Finmark
297.8	288.9	277.7	298.4	284.4	269.9	253.8	265.2	284.4	253.9	289.9	261.9	246.7
3.7	3.1	2.8	5.4	2.8	3.1	4.0	3.4	4.3	2.4	4.9	3.8	2.5
0.2	0.5	0.9	1.7	0.9	0.6	1.3	0.7	0.7	0.0	0.3	0.9	0.8
0.8	0.6	0.1	0.2	0.6	0.7	0.8	0.8	0.8	0.1	1.1	0.9	1.2
1.2	0.7	0.1	0.7	0.4	0.9	0.9	1.1	1.0	1.0	1.6	1.0	0.0
0.5	0.3	1.0	0.8	0.3	0.2	1.0	0.6	0.5	0.5	0.6	0.2	0.0
1.0	1.1	0.6	2.0	0.6	0.6	0.0	0.3	1.3	0.8	1.4	0.8	0.4
50.0	45.0	50.8	50.1	50.4	55.6	52.2	52.8	52.5	47.0	52.2	49.4	47.2
1.2	1.3	1.0	1.3	1.0	0.6	0.7	0.5	0.7	0.7	0.8	1.3	1.8
3.1	5.2	2.9	2.8	5.1	5.1	6.7	4.2	3.9	3.9	4.7	7.9	7.7
1.0	1.3	0.9	1.6	0.7	1.1	1.1	1.3	1.5	1.2	0.9	1.0	1.1
22.9	20.8	24.0	24.7	23.3	27.3	22.4	26.2	23.3	23.9	24.3	20.8	18.5
12.2	7.8	12.2	9.3	12.3	12.9	11.5	11.0	11.6	9.7	12.1	10.1	8.5
0.6	0.7	1.4	1.1	0.8	0.8	1.6	0.6	1.4	0.3	1.3	1.3	0.8
1.0	1.9	2.0	2.1	1.3	1.3	1.8	1.0	1.5	1.2	1.2	1.0	1.7
7.3	5.5	5.8	5.8	5.3	6.1	6.1	6.2	7.6	5.3	6.0	5.3	6.3
0.7	0.5	0.6	1.3	0.6	0.3	0.3	1.9	1.0	0.8	1.0	0.5	0.8
25.8	23.7	27.9	29.6	22.5	19.3	16.9	18.7	24.3	22.4	25.9	21.6	27.1
0.3	0.4	0.6	0.4	0.3	0.5	0.5	0.5	0.2	0.4	0.5	0.2	0.1
0.5	0.3	0.4	0.6	0.3	0.5	0.0	0.4	0.5	0.1	0.5	0.6	0.2
25.0	23.0	26.9	28.6	21.7	18.3	16.3	17.8	23.4	21.7	24.9	20.8	26.8
0.0	0.0	0.0	0.0	0.2	0.1	0.1	0.0	0.2	0.3	0.1	0.0	0.0
1.4	1.0	2.1	0.5	0.7	0.6	1.3	0.1	1.2	0.7	0.7	0.8	1.0
22.9	19.8	13.0	17.2	22.5	14.9	9.3	14.5	17.8	17.1	9.3	9.1	5.8
10.6	13.3	10.5	16.0	13.4	7.6	6.0	6.5	9.3	10.0	5.3	5.4	5.0
0.4	0.5	0.9	0.0	0.3	0.1	0.0	0.2	0.0	0.0	0.2	0.2	0.4
0.0	0.0	0.0	0.0	0.0	0.0	0.1	0.1	0.0	0.0	0.3	0.1	0.1
0.0	0.4	0.0	0.2	0.3	0.6	0.1	1.1	0.0	0.1	0.4	0.0	0.0
2.0	2.9	1.8	2.7	2.1	1.2	1.8	2.3	3.1	3.6	2.6	2.3	1.1
80.9	73.8	59.5	74.3	72.6	73.1	67.0	74.0	75.0	69.0	73.7	68.3	56.2
38.7	44.7	43.7	42.2	41.8	42.3	37.2	33.3	37.1	30.5	46.3	40.2	38.3
8.7	11.1	9.2	11.7	9.4	9.2	6.8	7.0	6.6	6.8	13.9	11.0	8.5
14.3	15.5	14.6	16.4	15.6	17.5	13.9	13.4	14.4	12.6	18.0	14.4	17.0
0.2	0.3	0.1	0.2	0.3	0.3	0.9	0.2	0.2	0.0	0.3	0.5	0.0
11.8	14.8	16.0	10.9	13.2	12.8	10.8	10.1	12.3	8.9	11.6	10.5	9.8
3.3	3.0	3.9	3.0	2.9	2.6	4.2	2.6	3.6	2.3	2.2	2.7	2.9
0.4	0.0	0.0	0.0	0.4	0.0	0.6	0.0	0.0	0.0	0.4	1.2	0.0
11.3	10.1	10.6	12.3	11.3	9.9	10.6	12.0	12.3	10.5	16.4	12.0	13.7
4.9	4.4	3.1	6.1	4.6	4.3	3.4	4.9	5.5	4.6	6.9	4.8	7.4
0.4	0.1	0.8	0.0	0.3	0.3	1.3	0.5	0.9	0.5	0.9	0.8	0.1
5.9	5.6	6.7	6.2	6.4	5.4	5.9	6.6	5.9	5.4	8.7	6.4	6.1
0.6	0.4	1.8	1.2	0.6	0.6	0.6	1.4	1.0	1.0	0.7	0.4	0.6
20.4	19.3	20.6	17.5	15.8	13.5	18.5	15.9	19.0	11.5	17.6	17.0	14.7
4.2	6.3	2.4	4.4	2.5	5.2	5.8	6.9	3.9	3.9	7.1	6.1	4.6
0.7	0.7	0.3	0.0	0.4	0.6	0.7	0.1	0.3	0.2	0.9	0.3	0.5
4.3	4.0	4.8	3.5	5.1	4.1	5.8	3.0	4.7	4.6	5.7	4.9	5.2
19.9	19.9	24.1	21.3	19.4	17.5	16.0	18.7	18.4	19.4	19.7	20.2	22.8
1.8	0.8	3.0	1.7	1.8	1.6	1.0	1.5	1.3	1.9	2.3	1.6	3.2
7.7	9.6	8.8	9.4	8.8	8.1	7.5	7.9	9.0	9.1	8.0	7.9	13.6
0.3	0.0	0.3	0.2	0.2	0.2	0.2	0.5	0.2	0.4	0.2	0.3	0.4
3.0	2.6	3.7	3.6	2.9	2.6	3.9	3.9	2.0	1.6	3.5	3.3	1.6
7.1	7.0	8.2	6.3	5.6	5.0	3.3	5.0	5.9	6.3	5.7	7.1	3.8

Table 20 Number of cancer deaths in Norway by primary site and sex - 2004 (Source: Statistics Norway)

ICD10	Site	Males	Females	Total
C00-96	All sites	5589	4900	10489
C00-14	Mouth, pharynx	88	50	138
C00	Lip	1	1	2
C01-02	Tongue	21	11	32
C03-06	Mouth, other	21	19	40
C07-08	Salivary glands	7	3	10
C09-14	Pharynx	38	16	54
C15-26	Digestive organs	1606	1467	3073
C15	Oesophagus	137	59	196
C16	Stomach	244	164	408
C17	Small intestine	20	24	44
C18	Colon	562	608	1170
C19-21	Rectum, rectosigmoid, anus	244	172	416
C22	Liver	65	70	135
C23-24	Gallbladder, bile ducts	23	31	54
C25	Pancreas	297	325	622
C26	Other digestive organs	14	14	28
C30-34, C38	Respiratory organs	1227	758	1985
C30-31	Nose, sinuses	11	4	15
C32	Larynx, epiglottis	37	9	46
C33-34	Lung, trachea	1174	740	1914
C38	Mediastinum, pleura	5	5	10
C40-41	Bone	13	12	25
C43	Melanoma of the skin	143	123	266
C44	Skin, non-melanoma	12	15	27
C45	Mesothelioma	40	10	50
C46	Kaposi's sarcoma	0	0	0
C47	Autonomic nervous system	1	0	1
C48-49	Soft tissues	24	39	63
C50	Breast	3	694	697
C51-58	Female genital organs		599	599
C53	Cervix uteri		81	81
C54	Corpus uteri		81	81
C55	Uterus, other		50	50
C56	Ovary		330	330
C51-52, C57	Other female genital		57	57
C58	Placenta		0	0
C60-63	Male genital organs	1091		1091
C61	Prostate	1074		1074
C62	Testis	13		13
C60, C63	Other male genital	4		4
C64-68	Urinary organs	434	235	669
C64-65	Kidney	153	107	260
C66-68	Bladder, ureter, urethra	281	128	409
C69	Eye	2	3	5
C70-72	Central nervous system	177	134	311
C73	Thyroid gland	11	18	29
C37, C74-75	Other endocrine glands	6	10	16
C39, C76, C80	Other or unspecified	220	309	529
C81-96	Lymphoid and haematopoietic tissue	491	424	915
C81	Hodgkin lymphoma	9	8	17
C82-85, C96	Non-Hodgkin lymphoma	170	141	311
C88	Malignant immunoproliferative diseases	9	8	17
C90	Multiple myeloma	129	123	252
C91-95	Leukaemia	174	144	318

Mortality

In 2004, the latest year for which detailed cancer-specific mortality was available, there were almost 10 500 cancer deaths in Norway, 5589 in men and 4900 in women (Table 20). Lung, colorectal, prostate and female breast cancer were responsible for about half of the total cancer mortality burden. In terms of numbers of deaths, lung cancer ranks first in men, responsible for 1174 deaths, followed by prostate cancer (1074 deaths) and colorectal cancer (806 deaths). In women, cancers of the large bowel (780 deaths), lung (740 deaths) and breast (694 deaths) are the most frequent causes of cancer death. Figure 6 shows the distribution of age-standardised mortality rates by cancer site. Lung cancer is the leading cause of cancer death in both men and women, although breast cancer mortality rates in women are almost equal to those of lung in women.

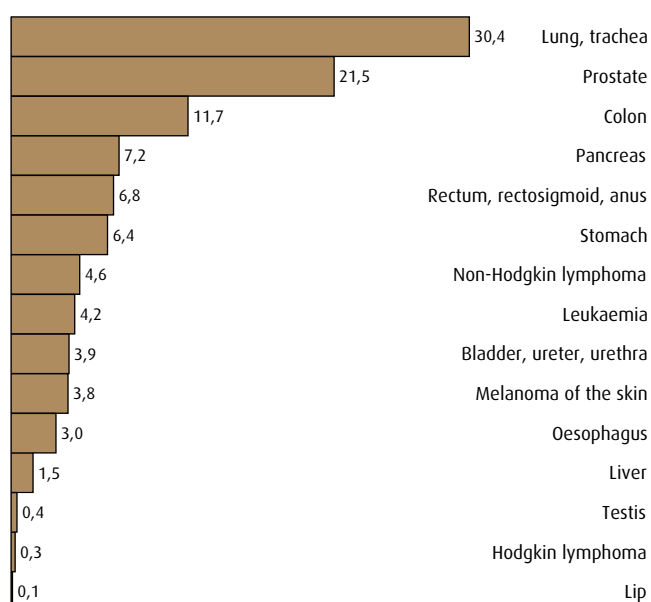
Figure 7 shows the sex-specific time trends of mortality rates for selected cancer forms. In men, there have been steady increases in the mortality rates of the three most frequent causes of cancer death in Norway

- lung, prostate and colorectal cancer - since the 1970s. There is some evidence however that recent mortality trends are more favorable for these cancer forms, with trends plateauing or beginning to decline. In women, lung cancer mortality has been rising rapidly in the last decades relative to other cancers. In the last decade however, both breast and rectal cancer mortality rates in females have been decreasing. As observed for incidence, there is a steady long-term decline in stomach cancer mortality in Norway for both sexes.

There are declines in mortality among younger populations of several common cancers, including testicular cancer in men and leukaemia in both sexes. Advances in cancer care, including the development of new treatment regimens and a multidisciplinary approach to cancer care are contributors to this favourable trend.

Figure 6: Age-standardised (world) mortality rates in Norway 2004 for selected cancers
(Source: Statistics Norway)

MALES



FEMALES

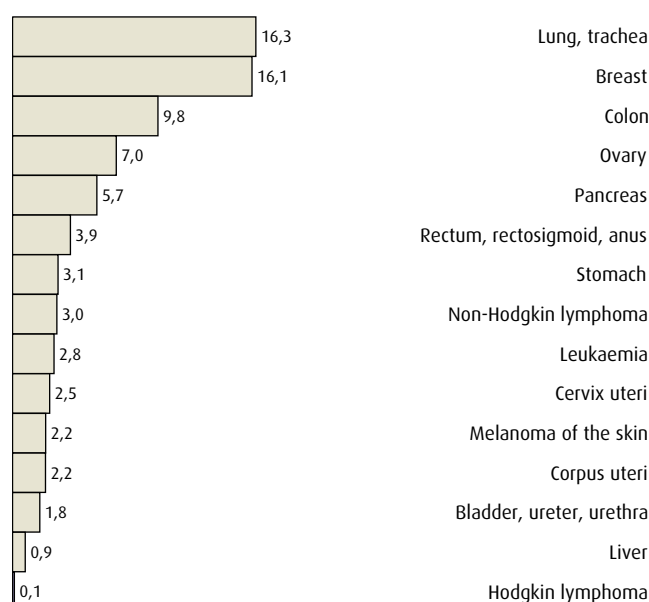
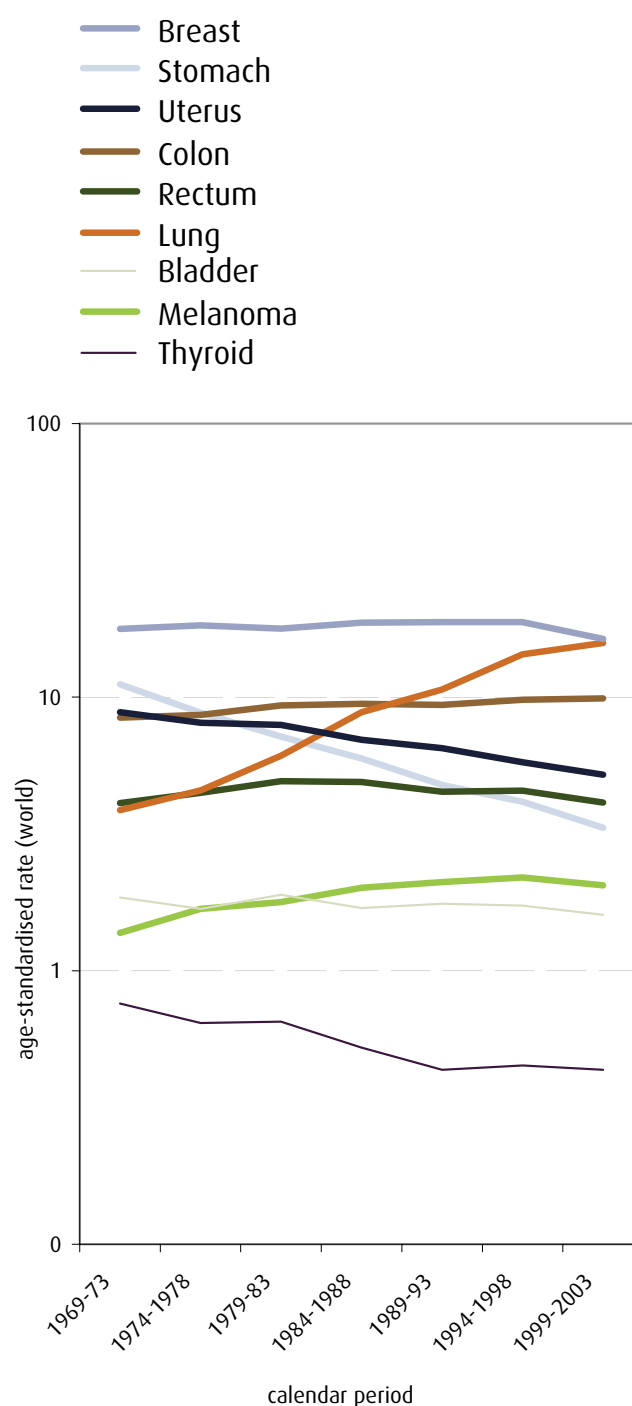
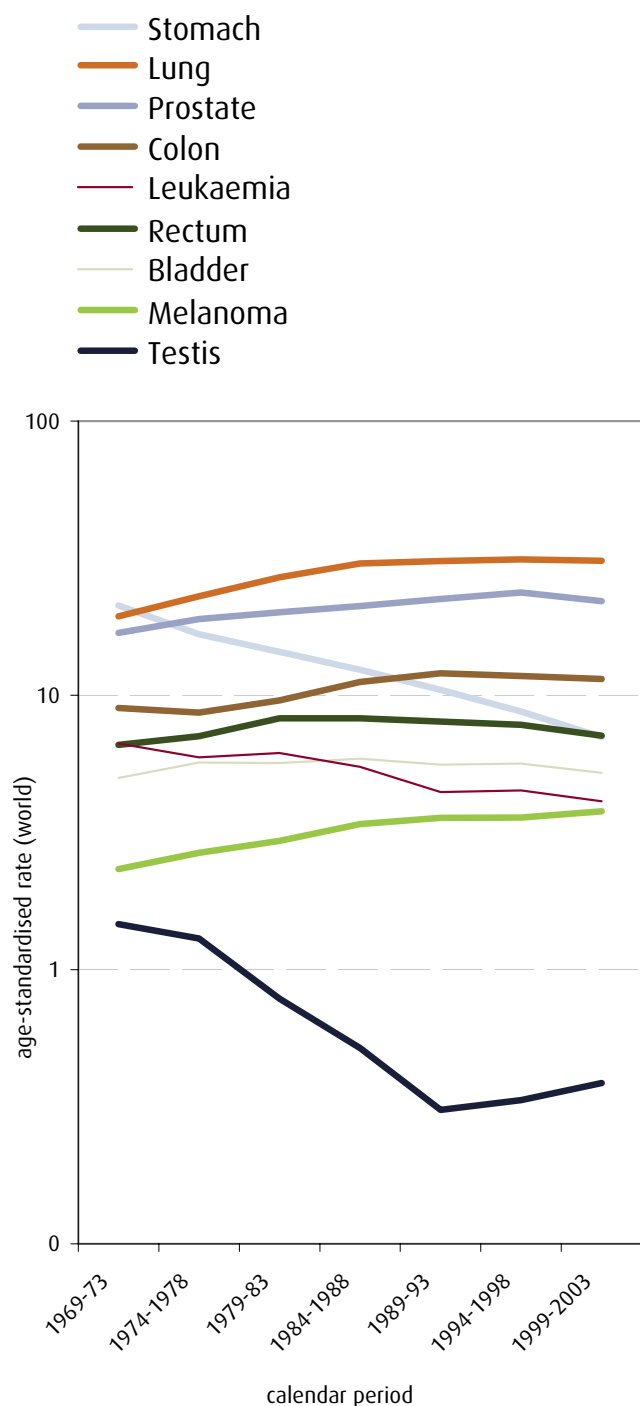


Figure 7: Time trends in age-standardised (world) mortality rates in Norway for selected cancers (semi-log scale)
(Source: WHO)

MALES

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Survival

As can be seen in Figure 8, there is considerable variability in prognosis following the diagnosis of different cancer types. Testicular cancer, for example, the most frequent cancer among young men in Norway, has a very good prognosis, with five-year survival estimated at 96% for all patients diagnosed 1997-2001. Five-year survival is generally higher for cancers where early diagnosis and treatment can materially influence survival prospects, as is the case for certain frequently-occurring neoplasms including breast and colorectal cancer.

Table 21-22 shows five-year relative survival probabilities according to five-year period of diagnosis by primary site, sex and stage. Survival five years after a cancer diagnosis was estimated at 57% and 63% for men and women respectively, a differential partly reflecting the more frequent occurrence of tumours associated with better prognosis among women, relative to men. Survival probabilities in men have doubled from the late 1950s in men, and by 50% in women.

Caution should be applied to the interpretation of stage-specific survival, particularly where the proportions of patient with stage unknown is high. Survival estimates based on fewer than 50 patients in the latest period are not shown.

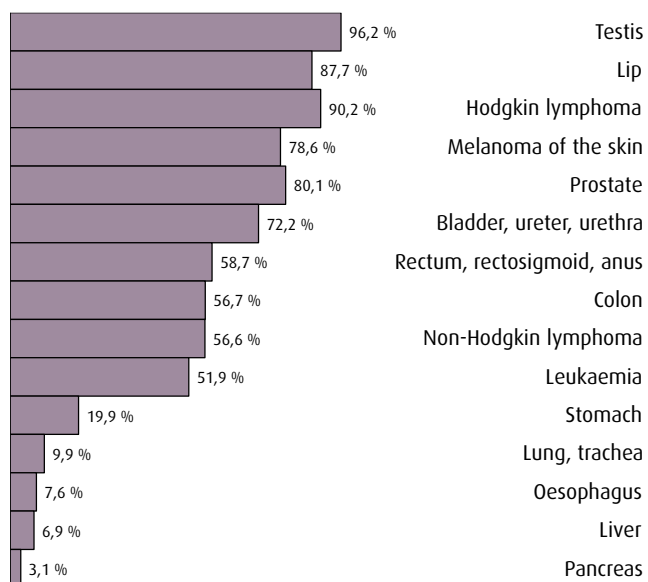
Survival of cancer patients in Norway has increased steadily from the 1950s for a number of specific primary sites, predominantly as a result of advances in cancer therapy and management during this time (Figure 9).

Special Issue on cancer survival

In keeping with this and the previous Cancer in Norway reports, a special issue will appear with the 2007 report with the topic *Cancer Survival in Norway*. This will provide detailed results of the follow-up of recently-diagnosed patients for 24 cancer types and the systematic analyses of changes in the prognosis of these cancers over time. Period survival approaches will be used to enable more up-to-date estimates of survival (Brenner et al, 2004); a systematic analysis of age-adjusted time trends of cancer survival 1958-2002 will also be included.

Figure 8: Five-year relative survival probabilities in Norway for selected cancers, diagnoses 1997-2001

MALES



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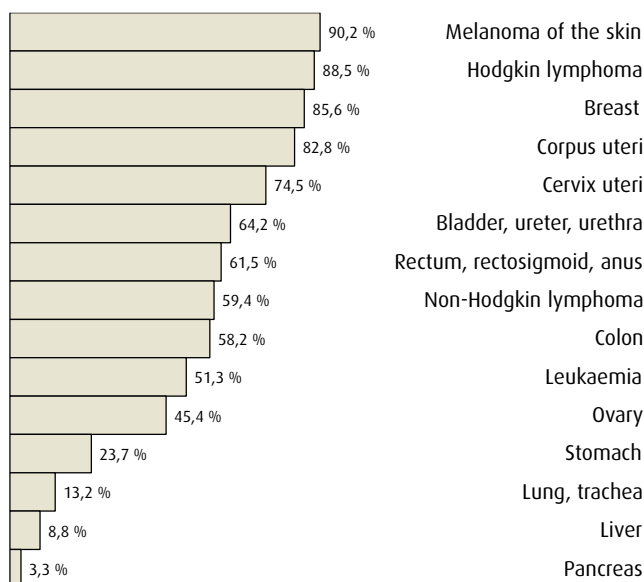


Table 21 Five-year relative survival in percent by selected primary sites, stage and period of diagnosis - 1957-2001

MALES

ICD10	Site	Stage	n 1997-2001	Relative survival (%)								
				1957-1961	1962-1966	1967-1971	1972-1976	1977-1981	1982-1986	1987-1991	1992-1996	1997-2001
C00-96	All sites	Total	55655	28.7	28.3	31.8	36.6	40.6	43.1	45.9	50.9	56.8
C00	Lip	Total	295	92.1	87.6	94.4	95.1	90.7	87.8	92.8	91.8	87.7
		Localized	208	94.3	89.3	97.0	97.5	93.4	90.0	97.1	95.3	93.9
		Regional	17	55.1	65.1	50.6	45.7	43.2	41.1	27.3	41.1	71.1
		Distant	4	0.0	0.0	0.0	0.0	0.0	0.0	94.0	28.7	0.0
		Unknown	66	87.1	65.0	87.7	114.9	96.8	0.0	58.2	94.3	79.2
C15	Oesophagus	Total	592	2.6	2.5	3.9	3.3	2.5	5.1	5.1	5.7	7.6
		Localized	125	3.6	3.8	5.7	4.4	2.6	6.7	8.8	10.2	18.3
		Regional	120	2.6	0.0	2.0	1.5	3.9	8.1	5.1	5.7	6.9
		Distant	172	0.0	1.4	0.0	0.0	1.2	0.0	0.7	0.0	0.7
		Unknown	175	0.0	0.0	9.0	22.4	0.0	0.0	10.3	0.0	8.0
C16	Stomach	Total	1870	12.2	11.9	12.5	14.6	18.8	17.9	20.0	18.5	19.9
		Localized	324	30.0	31.0	34.9	41.7	43.9	38.6	40.5	41.5	55.9
		Regional	547	13.0	11.6	13.9	13.6	21.5	20.2	21.3	17.3	22.3
		Distant	656	1.8	1.7	1.6	1.9	1.4	1.2	0.6	0.8	2.2
		Unknown	343	3.3	3.5	6.2	8.4	3.1	4.1	6.4	5.0	17.0
C18	Colon	Total	4656	34.0	33.1	36.2	41.1	45.4	49.2	48.5	51.8	56.7
		Localized	847	54.9	56.4	65.1	71.1	73.0	79.5	78.3	83.4	91.2
		Regional	2273	35.7	34.8	39.9	45.2	55.2	57.2	57.7	63.3	71.0
		Distant	1211	4.3	4.7	4.9	6.4	6.7	4.7	4.4	4.6	7.4
		Unknown	325	9.7	7.1	17.1	18.1	15.4	14.1	15.8	20.4	53.2
C19-21	Rectum, rectosigmoid, anus	Total	3077	27.6	29.6	30.5	36.3	43.7	45.1	48.3	52.5	58.7
		Localized	928	48.6	50.2	51.2	60.2	64.1	66.8	69.8	75.3	84.0
		Regional	1199	12.1	17.5	21.1	24.4	39.4	41.3	46.5	53.4	66.7
		Distant	610	1.9	2.5	3.0	3.5	4.5	2.8	3.8	3.8	10.4
		Unknown	340	8.8	0.0	18.5	14.4	28.1	20.8	49.0	16.5	51.1
C22	Liver	Total	317	0.0	0.0	0.0	4.7	4.1	2.5	3.9	7.2	6.9
		Localized	107	0.0	0.0	0.0	9.2	5.8	3.9	6.5	10.7	17.6
		Regional	22	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
		Distant	75	0.0	0.0	0.0	1.3	3.4	0.0	0.0	2.6	0.0
		Unknown	113	0.0	0.0	0.0	0.0	0.0	4.5	0.0	2.7	2.4
C25	Pancreas	Total	1314	3.0	2.1	1.7	1.9	1.5	1.5	1.8	2.6	3.1
		Localized	91	4.0	4.0	4.2	5.3	2.7	3.1	2.4	5.7	7.6
		Regional	188	1.7	1.2	3.7	1.6	3.0	2.0	5.8	6.0	6.0
		Distant	657	0.9	1.3	0.4	0.9	0.5	0.3	1.2	1.0	1.7
		Unknown	378	14.2	3.6	0.0	1.5	4.3	3.8	0.8	1.8	2.8
C33-34	Lung, trachea	Total	6234	7.4	7.8	8.8	7.6	8.3	8.9	8.2	9.0	9.9
		Localized	1069	17.9	15.5	19.8	17.0	18.2	19.6	16.3	20.1	34.0
		Regional	1598	7.1	10.2	9.8	8.6	9.5	9.9	11.6	9.9	10.6
		Distant	2776	0.0	0.5	0.7	1.1	1.0	0.8	0.9	0.6	0.8
		Unknown	791	3.4	3.6	2.6	2.4	4.1	2.3	3.9	7.2	8.8
C43	Melanoma of the skin	Total	2342	47.6	48.7	52.3	65.9	69.5	72.5	76.7	79.6	78.6
		Localized	1481	60.0	65.1	63.3	77.4	78.3	82.2	84.5	86.7	88.3
		Regional	80	36.1	17.9	36.5	24.3	33.9	27.5	40.2	32.6	40.9
		Distant	147	9.7	15.6	12.9	7.7	7.8	2.7	9.3	12.6	8.1
		Unknown	634	54.3	27.2	56.5	83.1	50.1	61.8	42.7	58.1	76.2
C61	Prostate	Total	14385	43.8	44.9	49.2	53.3	56.6	57.2	59.6	68.0	80.1
		Localized	5010	55.6	55.6	61.4	66.5	71.7	72.8	73.2	78.6	95.9
		Regional	545	31.1	32.7	38.2	37.8	40.1	41.8	58.8	73.6	77.8
		Distant	1957	20.6	18.4	18.4	19.3	19.3	21.4	25.4	24.1	25.7
		Unknown	6873	40.3	44.1	50.1	38.1	38.4	46.0	52.5	64.6	82.6
C62	Testis	Total	1216	60.7	64.7	67.0	69.2	84.7	93.5	95.2	95.6	96.2
		Localized	671	75.1	84.3	84.6	87.6	96.1	98.3	98.3	98.9	99.1
		Regional	183	73.9	62.5	76.2	73.6	90.0	95.7	96.3	97.0	97.7
		Distant	165	11.9	20.6	13.8	26.6	49.8	75.5	78.6	77.0	80.1
		Unknown	197	76.6	56.3	69.2	30.9	77.1	47.9	96.9	83.1	98.1
C66-68	Bladder, ureter, urethra	Total	4090	52.8	51.9	54.4	62.0	66.0	69.4	70.6	73.6	72.2
		Localized	2219	61.6	59.2	62.8	72.4	74.7	77.1	76.8	78.8	83.8
		Regional	210	12.0	11.3	11.2	20.8	27.8	23.2	29.2	25.0	24.4
		Distant	168	7.1	1.6	3.6	5.8	0.0	3.2	8.8	7.1	4.0
		Unknown	1493	31.2	38.4	47.3	33.0	28.3	35.6	56.5	64.5	69.0
C81	Hodgkin lymphoma	Total	286	21.6	26.3	45.3	57.1	58.1	66.9	77.8	85.4	90.2
		Unknown	286	21.6	26.3	45.3	57.1	58.1	66.9	77.8	85.4	90.2
C82-85, C96	Non-Hodgkin lymphoma	Total	1745	26.6	25.6	29.0	34.9	43.3	44.8	48.2	52.0	56.6
		Unknown	1745	26.6	25.6	29.0	34.9	43.3	44.8	48.2	52.0	56.6
C91-95	Leukaemia	Total	1309	8.8	10.3	14.2	21.1	25.8	30.3	37.1	45.1	51.9
		Unknown	1309	8.8	10.3	14.2	21.1	25.8	30.3	37.1	45.1	51.9

Table 22 Five-year relative survival in percent by selected primary sites, stage and period of diagnosis - 1957-2001

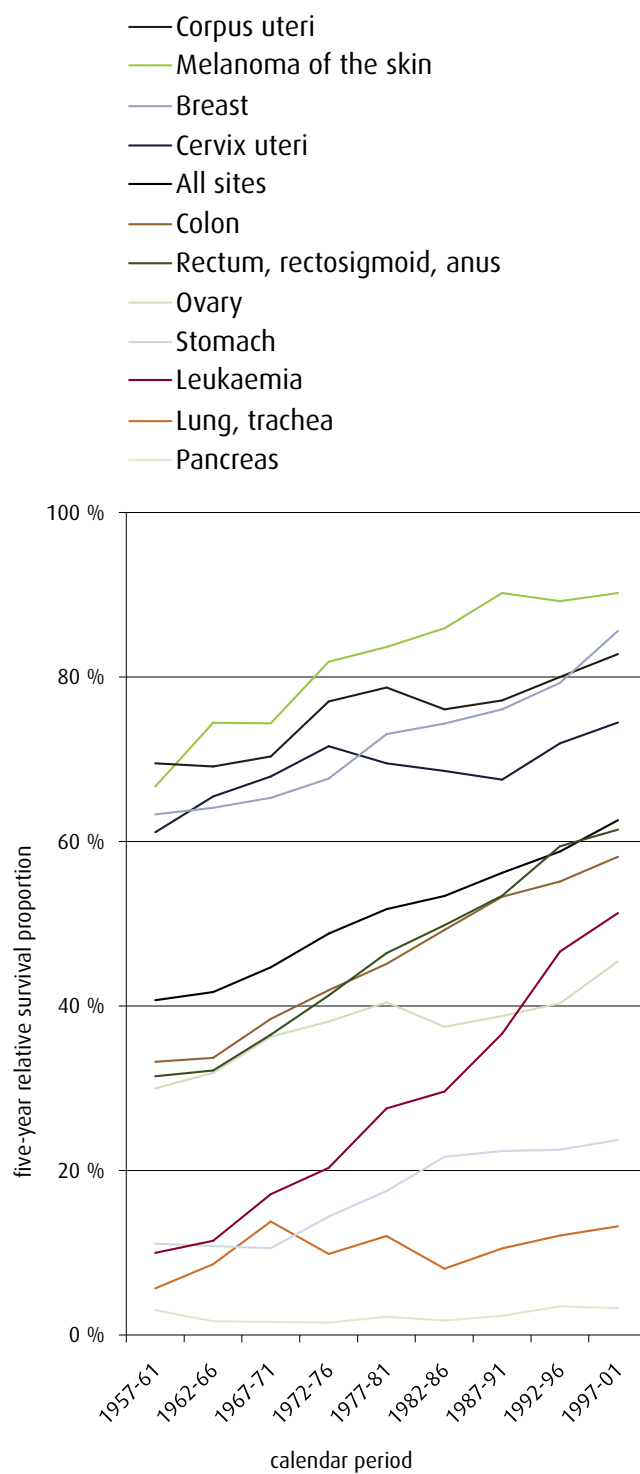
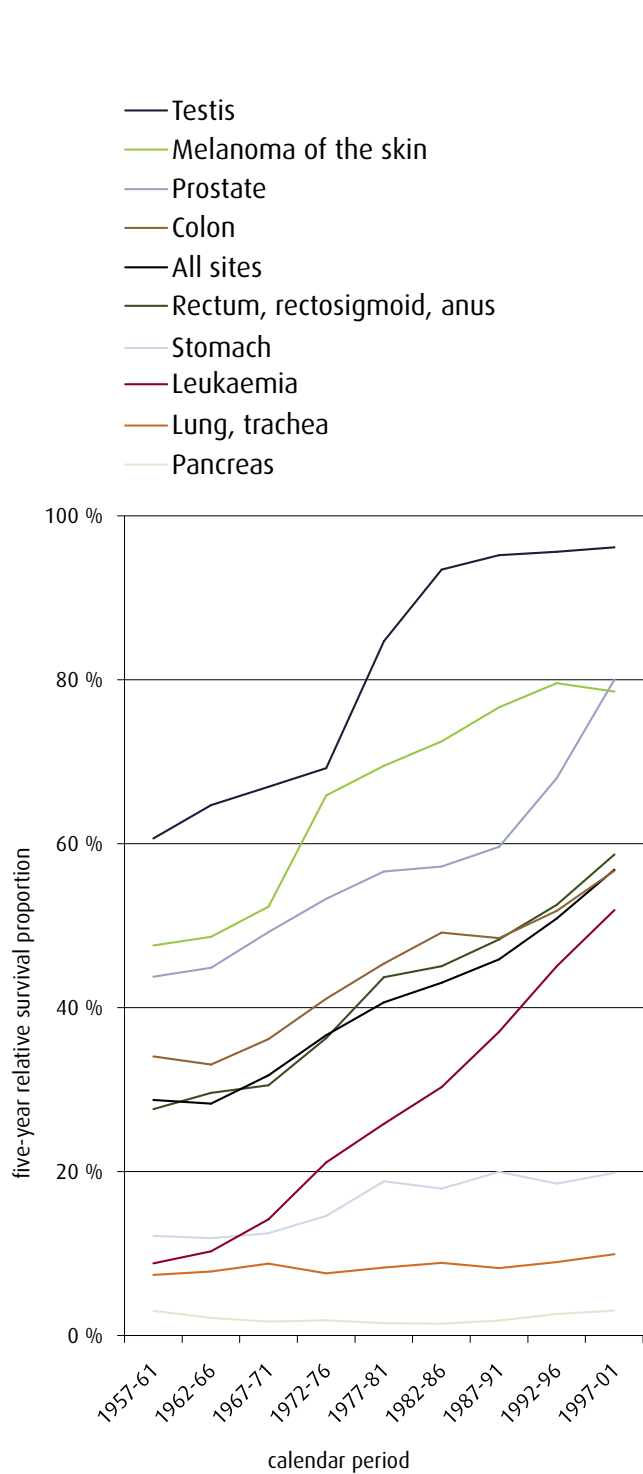
FEMALES

ICD10	Site	Stage	n 1997 -2001	Relative survival (%)								
				1957- 61	1962- 66	1967- 71	1972- 76	1977- 81	1982- 86	1987- 91	1992- 96	1997- 01
C00-96	All sites	Total	51572	40.7	41.7	44.7	48.8	51.8	53.4	56.2	58.8	62.6
C16	Stomach	Total	1178	11.1	10.8	10.6	14.4	17.5	21.7	22.4	22.5	23.7
		Localized	227	25.6	26.8	32.8	37.6	42.1	45.6	42.9	43.0	66.0
		Regional	306	14.2	11.1	12.7	18.7	17.6	22.1	22.3	27.3	28.7
		Distant	385	1.8	1.6	1.4	2.7	1.0	1.2	0.9	1.6	3.2
		Unknown	260	7.1	3.1	5.0	2.5	8.8	7.7	20.3	7.3	12.8
C18	Colon	Total	5488	33.2	33.7	38.4	41.9	45.1	49.2	53.3	55.1	58.2
		Localized	1038	54.9	56.8	63.8	73.8	72.1	80.1	83.1	85.5	89.0
		Regional	2712	37.9	35.2	43.3	44.3	56.5	56.7	62.2	64.2	71.1
		Distant	1268	1.8	4.7	5.1	5.0	4.4	4.2	4.9	6.8	8.6
		Unknown	470	7.3	13.3	23.5	26.7	20.9	13.7	23.1	26.1	49.7
C19-21	Rectum, rectosigmoid, anus	Total	2545	31.5	32.2	36.5	41.3	46.4	49.8	53.4	59.4	61.5
		Localized	803	48.8	52.9	61.5	67.6	69.0	72.6	73.2	79.5	89.2
		Regional	952	24.8	19.7	23.6	27.7	39.8	45.3	51.5	61.0	65.4
		Distant	454	2.1	1.6	4.7	3.9	7.5	6.4	3.0	5.6	7.8
		Unknown	336	20.6	14.3	30.9	31.0	12.0	21.0	42.7	34.1	55.1
C22	Liver	Total	211	0.0	3.7	6.0	6.0	1.5	6.9	7.8	10.3	8.8
		Localized	54	0.0	4.2	11.6	11.1	3.2	11.2	11.4	13.7	22.0
		Regional	25	0.0	0.0	0.0	0.0	0.0	7.3	11.4	10.8	4.9
		Distant	48	0.0	0.0	2.6	0.0	0.0	1.7	2.5	3.1	0.0
		Unknown	84	0.0	40.2	0.0	0.0	0.0	5.6	0.0	9.8	6.2
C25	Pancreas	Total	1539	3.1	1.7	1.6	1.5	2.2	1.8	2.3	3.5	3.3
		Localized	124	5.1	2.6	4.5	5.3	2.5	3.7	5.2	8.8	14.6
		Regional	199	5.7	4.1	1.3	1.0	8.3	3.6	4.2	7.0	3.1
		Distant	690	1.8	0.8	0.6	0.5	1.0	0.7	0.4	1.2	0.9
		Unknown	526	0.0	0.0	0.0	0.0	0.0	0.8	2.5	2.2	4.3
C33-34	Lung, trachea	Total	3478	5.7	8.6	13.8	9.9	12.0	8.1	10.5	12.1	13.2
		Localized	503	20.3	22.3	30.4	25.9	28.5	21.5	24.4	28.6	48.6
		Regional	815	7.2	4.7	14.9	10.1	16.7	7.9	11.7	13.0	13.3
		Distant	1634	0.0	1.1	2.2	1.1	1.1	0.6	1.3	1.2	1.8
		Unknown	526	0.0	5.3	14.5	6.2	9.0	8.3	6.3	6.2	15.1
C43	Melanoma of the skin	Total	2545	66.7	74.4	74.4	81.9	83.6	85.9	90.2	89.2	90.2
		Localized	1683	74.6	82.6	84.8	88.2	89.0	91.3	93.7	93.2	96.0
		Regional	55	41.2	38.1	41.7	32.7	40.6	44.1	43.7	57.0	59.8
		Distant	113	10.9	29.0	16.8	25.5	12.7	5.5	17.1	19.6	19.7
		Unknown	694	94.1	56.4	73.9	41.3	70.5	67.0	70.3	76.9	89.3
C50	Breast	Total	12320	63.3	64.1	65.3	67.7	73.1	74.3	76.1	79.3	85.6
		I	6580	83.8	84.4	85.5	84.8	87.4	87.4	89.6	90.7	94.5
		II	4648	55.1	55.7	54.9	57.5	64.5	68.3	74.0	76.6	83.9
		III	407	34.2	37.2	39.5	49.3	50.9	53.0	53.2	64.2	62.4
		IV	619	12.0	13.9	12.1	12.2	15.7	15.2	18.9	18.4	16.3
C53	Cervix uteri	Unknown	66	68.4	56.4	75.3	77.5	77.8	88.5	59.6	62.6	99.1
		Total	1540	61.1	65.5	67.9	71.6	69.5	68.6	67.5	71.9	74.5
		I	898	77.6	86.1	86.5	89.4	87.8	86.6	85.1	86.8	92.5
		II	320	59.9	62.3	60.2	66.5	61.6	59.1	58.5	59.2	62.7
		III	173	35.1	30.5	29.2	30.6	33.4	31.7	24.3	34.5	39.8
C54	Corpus uteri	IV	120	11.1	10.2	7.1	9.7	7.8	7.5	20.9	19.8	9.7
		Unknown	29	51.5	61.7	31.8	8.9	25.5	50.5	77.8	65.8	59.3
		Total	2620	69.5	69.1	70.4	77.0	78.7	76.1	77.2	80.0	82.8
		Localized	1703	79.1	77.1	81.7	84.5	88.4	86.4	87.1	89.1	93.3
		Regional	291	25.1	32.3	26.2	54.4	62.2	58.2	66.9	72.5	75.9
C56	Ovary	Distant	342	17.2	24.0	19.8	24.4	19.8	25.3	26.7	38.1	34.5
		Unknown	284	52.1	38.7	65.3	42.1	45.0	33.2	30.4	39.9	83.1
		Total	2272	30.0	31.9	36.3	38.1	40.4	37.5	38.8	40.3	45.4
		Localized	452	62.7	66.3	74.4	69.3	82.6	81.5	82.8	85.9	92.9
		Regional	60	26.9	38.4	41.2	39.5	46.7	48.2	50.0	49.8	59.4
C66-68	Bladder, ureter, urethra	Distant	1504	10.1	11.9	13.8	14.7	21.0	16.7	18.7	21.8	27.7
		Unknown	256	26.0	31.4	23.5	16.9	58.9	33.9	17.6	31.0	60.4
		Total	1515	31.8	38.8	46.2	49.1	53.7	60.3	63.8	62.5	64.2
		Localized	727	46.5	54.8	60.6	64.6	68.1	71.0	72.3	71.2	83.6
		Regional	89	2.2	12.7	12.5	13.9	13.4	16.4	18.2	21.7	28.8
C81	Hodgkin lymphoma	Distant	116	4.3	4.2	9.5	6.8	2.6	5.4	3.3	8.4	2.1
		Unknown	583	3.5	20.1	49.4	20.8	23.3	22.7	44.5	42.9	57.2
		Total	208	29.7	47.2	47.9	50.6	65.4	65.7	76.9	83.7	88.5
C82-85, C96	Non-Hodgkin lymphoma	Unknown	208	29.7	47.2	47.9	50.6	65.4	65.7	76.9	83.7	88.5
		Total	1603	29.1	32.6	31.5	39.7	45.6	49.1	57.7	53.8	59.4
C91-95	Leukaemia	Unknown	1603	29.1	32.6	31.5	39.7	45.6	49.1	57.7	53.8	59.4
		Total	1093	10.0	11.5	17.1	20.3	27.6	29.6	36.6	46.6	51.3
		Unknown	1093	10.0	11.5	17.1	20.3	27.6	29.6	36.6	46.6	51.3

Figure 9: Time trends in five-year relative survival in Norway for selected cancers, diagnoses 1957-2001

MALES

FEMALES



Prevalence

At the end of 2006, over 174 000 persons were alive having been previously diagnosed with cancer in Norway. The cancer prevalence measures in Table 23 are those that approximate the number of patients in Norway (of both sexes) requiring some form of cancer care, that is, persons alive and diagnosed with cancer a given number of years after diagnosis (<1, 4-9, 5-9 and ≥10 years).

A comparison of prevalence with incidence is a good pointer to the long-term prognosis of specific cancers or the “survivability” of different cancer forms, given the measure depends on the occurrence of cancer and

the subsequent survival.

Ten-year prevalence is an indicator of the number of patients that might be considered “cured” of cancer. Breast, colorectal and prostate cancer, frequently-diagnosed cancers associated with reasonable prognosis, have the highest 10-year prevalence counts in Norway. The 7883 persons alive and diagnosed with melanoma of the skin 10 or more years after diagnosis ranks second only to breast cancer (12217 persons), while the prevalence of melanoma is seven times that of lung cancer (709 persons). Differences in prognosis rather than incidence explains much of the prevalence differential; while lung cancer incidence is twice that of melanoma in Norway, lung cancer survival is poor in absolute and relative terms.

Table 23 Prevalence of cancer 31.12.1996 and 31.12.2006, both sexes

ICD10	Site	Total no. of persons alive		Years after diagnosis			
		31.12.96	31.12.06	<1	1-4	5-9	10+
C00-96	All sites	115956	174241	19007	53130	40615	61489
C00-14	Mouth, pharynx	2969	3384	401	956	713	1314
C00	Lip	1386	1178	102	225	214	637
C01-02	Tongue	365	549	70	185	143	151
C03-06	Mouth, other	531	614	97	191	117	209
C07-08	Salivary glands	361	443	30	110	98	205
C09-14	Pharynx	380	639	111	252	149	127
C15-26	Digestive organs	20388	27569	3745	8895	6435	8494
C15	Oesophagus	178	281	111	94	42	34
C16	Stomach	2375	1974	327	509	370	768
C17	Small intestine	316	578	85	221	140	132
C18	Colon	10937	15212	1883	4912	3696	4721
C19-21	Rectum, rectosigmoid, anus	6607	9105	1032	2981	2203	2889
C22	Liver	108	198	53	63	26	56
C23-24	Gallbladder, bile ducts	207	280	58	95	57	70
C25	Pancreas	331	494	231	155	53	55
C26	Other digestive organs	78	127	28	58	15	26
C30-34, C38	Respiratory organs	4061	5523	1483	1827	1040	1173
C30-31	Nose, sinuses	223	275	36	86	68	85
C32	Larynx, epiglottis	987	1058	111	304	281	362
C33-34	Lung, trachea	2819	4172	1335	1439	689	709
C38	Mediastinum, pleura	57	43	8	8	6	21
C40-41	Bone	423	586	36	124	103	323
C43	Melanoma of the skin	10990	15725	1125	3436	3281	7883
C44	Skin, non-melanoma	6664	10355	1287	3765	2600	2703
C45	Mesothelioma	62	83	38	33	4	8
C46	Kaposi's sarcoma	104	87	8	22	20	37
C47	Autonomic nervous system	222	239	11	26	28	174
C48-49	Soft tissues	831	1116	120	266	209	521
C50	Breast	22444	32603	2597	9451	8338	12217
C51-58	Female genital organs	16867	19607	1336	4168	3669	10434
C53	Cervix uteri	6653	6720	274	923	993	4530
C54	Corpus uteri	6081	7938	593	2035	1700	3610
C55	Uterus, other	40	49	9	13	9	18
C56	Ovary	3467	4020	360	939	762	1959
C51-52, C57	Other female genital	831	1062	114	307	256	385
C58	Placenta	116	142	3	14	16	109
C60-63	Male genital organs	15669	28945	3870	11439	7915	5721
C61	Prostate	12117	23389	3584	10346	6716	2743
C62	Testis	3370	5253	249	963	1129	2912
C60, C63	Other male genital	286	380	40	136	83	121
C64-68	Urinary organs	10966	14017	1520	4464	3274	4759
C64	Kidney excl. renal pelvis	2712	3791	434	1285	839	1233
C65	Renal pelvis	438	523	59	145	124	195
C66-68	Bladder, ureter, urethra	8071	9970	1050	3126	2373	3421
C69	Eye	701	865	53	215	155	442
C70-72	Central nervous system	4310	7937	668	2423	1832	3014
C73	Thyroid gland	3118	3898	202	676	616	2404
C37, C74-75	Other endocrine glands	197	250	19	50	47	134
C39, C76, C80	Other or unspecified	467	574	178	177	84	135
C81-96	Lymphoid and haematopoietic tissue	8197	12514	1460	4033	2907	4114
C81	Hodgkin lymphoma	1335	1929	108	402	400	1019
C82-85, C96	Non-Hodgkin lymphoma	3614	5697	702	1849	1361	1785
C88	Malignant immunoproliferative diseases	187	275	35	116	69	55
C90	Multiple myeloma	1014	1269	235	610	276	148
C91-95	Leukaemia	2097	3420	394	1076	820	1130

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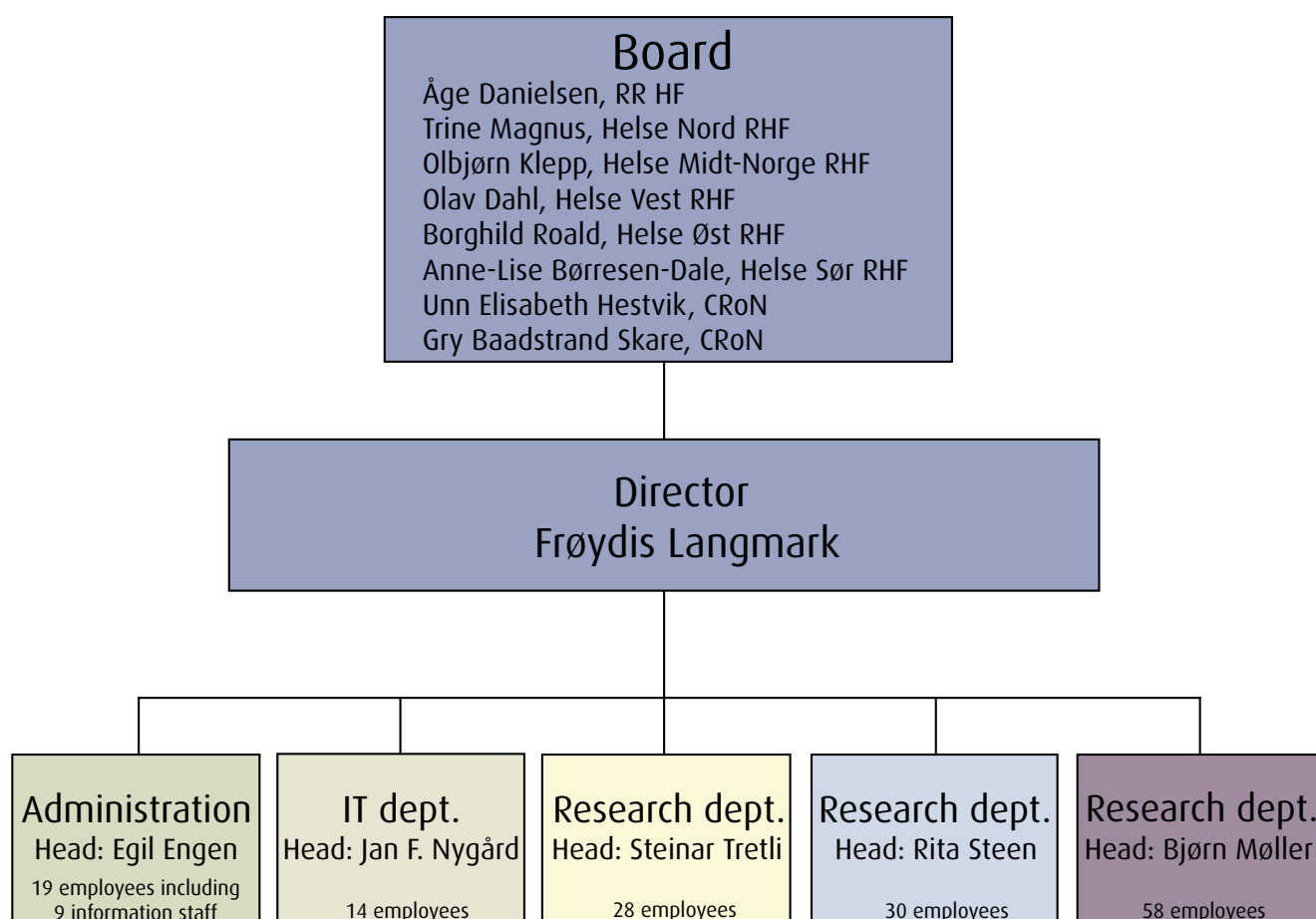
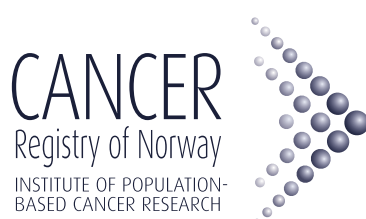
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Research activities at the Registry

Organisation and founding principles

The Cancer Registry of Norway is a national, population-based cancer research institute, which was founded and financed by the Cancer Society 1951-1979. Since then the institution has been governmental, with a board (except for the period 1994-2002) and a chapter in the National Budget plan. Since 2002 it has been allied to the Norwegian Radium Hospital and from 2005 to the merged Rikshospitalet-Radiumhospitalet Health Trust (RR HF). This organisational platform signals the importance attached to close links with cancer research milieus and cancer clinics. It also increases the possibilities for Norway as a nation to move towards the Comprehensive Cancer Centre organisational model. As early as 1951, reporting of cancer and some precancers has been mandatory from all milieus that diagnose and treat cancer. From 2002 however, new regulations have strongly enforced the legal premises, substantially improving the Registry's capacity to perform clinical population-based research and evaluate the quality control of health care. Comparative advantages are compulsory reporting without patients' consent and the uniquely identifying personal number. As a result of these advantages, organ-specific treatment quality registries are increasingly part of the Registry's duties, in close collaboration with the clinical milieus.

Structure of the Cancer Registry of Norway 2007



Department of Etiological Research

Head: Prof Steinar Tretli PhD

Department objectives

The principal goal of the Department of Etiological Research is to provide new insights into the causes of cancer. The focal points for research in recent years have been cancer risk and its relation to occupational and environmental factors, and to hormonal status and diet. In future studies, an increased emphasis will be put on testable biologically-founded hypotheses, using biological markers of exposures, and collaboration with researchers in the relevant fields. Specifically this will include utilisation of the JANUS serum bank. The tradition of collaboration with the different research milieus in the other Nordic countries, as well as international collaboration will be continued and expanded. The high quality population-based registries in the Nordic countries make such partnerships especially valuable.

Current research priorities

Lifecourse research

A focus on the total lifecourse implies research on long-term effects of lifestyle factors and other exposures during early life *in utero*, childhood, youth and adult life. The department will give priority to research that increases the understanding of what early-life conditions means in relation to exposure and later risk of cancer. Several studies have focused on the importance of early life on adult cancer risk, specifically for hormone-related cancers such as breast, prostate, and testicular cancer.

Occupational and environmental cancer studies

Research on cancers associated with occupational and environmental exposures has a long tradition in the Department, and the identification and quantification of such risks will still be in focus. Studies on working populations may often be the only method to obtain knowledge of possible population effects of low-dose exposures. Occupation is also an important classification variable concerning the knowledge on differences in cancer risk by social class.

Modelling and simulation studies

The understanding of the carcinogenic process has traditionally been based on three sources of information: experimental, clinical, and epidemiological research. Through modelling and simulation we will assess the importance of different mechanisms in the disease process. Ongoing projects are studying the growth rates of tumours and the variation of these rates in

breast cancer patients. This research is rooted in the mammography screening database.

Recent important results

In 2006, the research activity at the department led to about 40 scientific publications in national and international journals. The publications focused on risk factors including organochlorine, nickel, cancer treatment, nightwork, diet, alcohol, physical activity, pregnancy, inheritance, and life conditions after cancer. Some of the results are from international collaboration studies. In addition, two doctoral dissertations were published in 2006.

Theses published in 2006

Klæboe L. Intercranial tumours and electromagnetic fields. University of Oslo 2006.

Department of Screening-based Research

Head: Rita Steen MD PhD

Department objectives

The Screening Department administers two programmes for early detection of cancer and premalignant disease, the Breast Cancer Screening Programme and the Cervical Cancer Screening Programme. Since 1995, the Cervical Cancer Screening Programme has recommended women aged 25-69 years to undergo a PAP smear every third year, whereas all women aged 50-69 years are offered mammography screening every two years. The Cervical Cancer Screening Programme mails a personal letter to women whom have not had a PAP test in the last three years, with a recommendation to take a test. Invitation to mammography screening is mailed to eligible women, together with a pre-specified date of examination.

The Screening Department monitors the programmes' effectiveness and efficacy by examining early quality indicators (e.g. coverage/attendance, detection rate, tumour stage for breast cancer, and stage of premalignant lesions of the cervix), as well as changes in rates of incidence and mortality of the cancers. The main objective of the Norwegian Breast Cancer Screening Programme is to reduce mortality by 30% among women invited to mammography screening. For the Cervical Cancer Screening Programme, the main objective is to achieve a reduction of 50% in the incidence and mortality rates of cervical cancer compared to the rates prior to the programme launch. The most impor-

tant factor determining the success of these screening programmes is high coverage. In 2005, coverage was 79% in the Cervical Cancer Screening Programme, and the attendance rate was 76% in the Breast Cancer Screening Programme, raising expectations that the programmes will accomplish these objectives.

Current Research Priorities

The current research priorities of the Cervical Cancer Screening Programme are:

- 1) Evaluation of the CIN (cervical intraepithelial neoplasia) register, a follow-up register with data on treatment, established in 1997.
- 2) Study of the impact of HPV-testing in triage after PAP smear screening on CIN 2+.
- 3) Study of the impact of changing the screening interval and screening age range.
- 4) Studies of the efficacy and effectiveness of screening in women aged 25-69 years.
- 5) Study of the screening history of women diagnosed with cervical cancer before reaching the age of 25, including a re-examination of their PAP tests, pathological tissue and samples.
- 6) Study of the screening history of women aged over 70 years diagnosed with cervical cancer.
- 7) Investigate the need for a more individual-orientated approach to Cervical Cancer Screening Programme, dependent on vaccination status.
- 8) Investigate non-attendance in the cervical cancer screening program
- 9) Long-term follow-up after HPV vaccination of women participating in the vaccine trials. Study of HPV prevalence among women 18-45 years, both in the general population and in those with premalignant disease and cervical cancer.

The current research priorities of the Breast Cancer Screening Programme are:

- 1) Further investigations of early (process) indicators and tumor characteristics in screening.
- 2) Study of the effectiveness of the programme in relation to breast cancer survival and mortality.
- 3) Study of overdiagnosis associated with the Breast Cancer Screening Programme.
- 4) Study of attendance by socio-economic factors and of attendance pattern.
- 5) Study of moments in connection to an expansion of the programme to cover age groups outside of 50-69 years.
- 6) Study of breast cancer screening in Norway and the U.S. (Vermont).
- 7) Study of hormone therapy and risk of breast cancer

For the Breast Cancer Screening Programme, one PhD student is currently studying socio-demograp-

hic differences in attendance and mortality between attendees and non-attendees in the programme and investigating effects of mammography screening on breast cancer survival. Another PhD student is evaluating the Norwegian Breast Cancer Screening Program with regards DCIS, overdiagnosis and implementation of new technology . Within the Cervical Cancer Screening Programme, one PhD student is undertaking a population-based follow-up study on women diagnosed with severe cervical dysplasia in Norway.

Theses published in 2006

Gondal GG. Colorectal Cancer Screening By Flexible Sigmoidoscopy – Baseline findings in the NORCCAP (NORwegian Colorectal CANcer Prevention) trial. University of Oslo 2006.

Department of Clinical- and Registry-based Research

Head: Dr Bjørn Møller PhD

Department objectives

The Clinical Research department has a broad remit. One of its fundamental responsibilities is the continued collection, storage and quality control of data on all cases of cancer in Norway, as defined by the Statutory Regulations. This information is collected from clinicians, pathologists, administrative patient discharge files, and the Cause of Death Registry.

The Department provides relevant information on cancer patterns and changes in cancer over time in Norway, via various dissemination routes including scientific publications and reports such as the Cancer in Norway series. The Department has put an emphasis on activating and collaborating in good research projects at the national and international level, initiated in-house, or via external requests or invitations.

The Department is organised into three Sections, according to three key areas of ongoing activity:

- 1) Section for Registration. Management of the incidence register, with an emphasis on the documentation of quality control and the revision of in-house coding procedures;
- 2) Section for Research. Research using the incidence register, focusing on areas of particular public health importance alongside the application of appropriate methodologies;
- 3) Section for Innovation. Focusing on building strong ties with the clinical community in Norway, the continued technical development of the Registry infrastruc-

ture, and launch of several clinical registries. These Registries offer novel opportunities for population-based research into cancer care (see below).

Clinical registries

The Statutory Regulations for the Cancer Registry of Norway include the registration of treatment and follow-up of Norwegian cancer patients. Clinical registries – comprehensive registration schemes dedicated to specific cancers – have been established to include detailed information on diagnostic measures, therapy, and follow-up. By fostering strong collaborative links with the clinical community, the aims are to provide an empirical base for scientific studies concerning prognostic factors and treatment outcomes as well as evaluation of quality of cancer care.

The ongoing and expanding activities of these clinical registries is a major focus for the Registry, and several clinical registries are now established. Each clinical register is underpinned by a Reference Group, a panel of multi-disciplinary experts drawn from the clinical and research milieu in Norway, whose remit is to advise on the operations of the registry, and its strategic direction. These newly-established clinical registries will be integrated into the Registry's coding and registration

activities. The table below indicates the status of these subregistries as of December 2007.

Status of the special registries, December 2007.

Registry	Name	Date of launch or anticipated date
Integrated Clinical Registries	Norwegian Prostate Cancer Registry	01.01.2004
	Colorectal Cancer Registry	01.01.2007
	Norwegian Breast Cancer Registry	01.01.2008
	Norwegian Malignant Melanoma Registry	01.01.2008
	Norwegian Lymphoma Registry	01.01.2009
"Standalone" Clinical Registries	Lung Cancer Registry	1993-2002
	Ovarian Cancer Registry	01.01.2002
	Rectal Cancer Registry*	01.01.1993-31.12.2006
Other	Nordic Solid Tumours in children (NOPHO)	01.01.1982
	Polyposis Families Registry	1974 / 1994**
Screening Registries***	Mammography Screening Registry	01.01.1996
	Cervical Screening Registry	01.01.1992
	Colorectal Screening Registry (NORCCAP)	1999-2001

* From 01.01.2007 Registry expanded to include colon cancer, and integrated with the incidence registry.

** Housed in the Clinical Research Department since 1994.

*** Housed in the Screening Department.

List of publications 2006

Registry staff and affiliated researchers collaborated on 83 research papers in 2006.

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Special Issue

Data quality at the Cancer Registry of Norway

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The main concepts in assessing data quality

There are four main aspects that help to characterise the quality of the information in the cancer registry (Parkin et al, 1994; see ref (5)).

Comparability

There must be comparability of the statistics generated for different population groups (registries, geographical areas etc.), and within these groups over time. A basic requirement to ensure comparability is the standardisation of practices concerning the classification and coding of new cases, and consistency in basic definitions of incidence, such as rules for the coding of multiple primaries, whereby one must decide whether two or more cancers in the same individual represent a new case of cancer, or an extension, recurrence, or metastasis of the first tumour. Comparability also necessitates that the data are accurate in terms of their completeness and validity.

Completeness

Completeness is the extent to which all of the incident cancers diagnosed in the Norwegian population are included in the registry. Incidence rates and survival proportions will be close to their true value if maximum completeness in case-finding procedures can be achieved.

Validity

Validity refers to the proportion of cases in the registry with a given characteristic that truly have that attribute, and depends on the precision of source documents and the level of expertise in abstracting, coding, and recording.

Timeliness

Timeliness of reporting of cancer registry results is a further aspect of registry quality that can be considered as a separate issue, although this clearly influences the extent to which data are complete and accurate. Access to recent data is perceived as a priority by users, but, since registries are constantly updating their database as reports are received, and some notifications, especially those from death certificates, may arrive long after the case was diagnosed, incidence figures for recent periods will be incomplete, and will need future updates. There is, therefore, some conflict between the requirement for timely data, and other aspects of data quality, particularly completeness.

The first part of this report aimed to meet one of the central aims of a cancer registry, namely the provision of timely and relevant information on cancer incidence, survival and prevalence. These are the basic functions of registries worldwide, but their activities have developed far beyond this, to include studies of cancer cause and prevention, and to provide the information needed for planning and evaluation of cancer control programmes. The Cancer Registry of Norway, as a population-based cancer research institute, embraces this more active and expanded role in cancer prevention and cancer control. The three research departments within the Registry are dedicated to i) elucidating the causes of cancer; ii) managing and monitoring the national breast and cervix screening programmes, and iii) describing the cancer profile and follow-up of cancer patients in Norway, and the role of prognostic and treatment outcomes on the quality of cancer care. The Registry seeks to collaborate with the clinical and research community at the national and international level to ensure high-quality cancer research. A further key objective of the Registry is to promote use of the cancer registry data for research and information purposes, liaising with clinicians, researchers, politicians and journalists and other interest groups to provide both datasets and results.

The value of a cancer registry and its ability to carry out such activities relies heavily on the quality of the data, and the quality control procedures in place (1;2); when a research programme is an integral component of the registry, this can help improve the quality of the routine statistics, by activating interest among clinicians and researchers in the daily registration procedures (3). Nevertheless, as Skeet writes in the standard text on registry methodology, “all registries should be able to quote some objective measure of [ascertainment] rather than relying on received wisdom and pious hope”(4). This advice is not always heeded by registries in general, however, and in Norway, while a number of studies have investigated and reported specific aspects of data quality for specific cancer sites, there remains a pressing need for a comprehensive evaluation of the Registry’s data.

In this edition of Cancer in Norway, we have taken the opportunity to provide such an assessment, partly to verify whether previous reports of high standards are met in general and in recent periods of registration, and partly to justify the extensive use of the registry data. The main focus here is on examining the quality of the *incidence registry*; those data items contained at the Registry for the purposes of studying incidence. The ongoing expansion and integration of the *clinical registries* - with the active engagement of clini-

cians - should further enhance the completeness and reliability of the Registry data overall. Quality control procedures are in place to monitor the quality of the diagnostic and treatment information collected as part of this activity, and results will be reported, as the clinical registries mature.

Orientation in reading this report

This part of the annual report aims to document and evaluate the quality of the data collected, stored and analysed at the Cancer Registry of Norway. In Chapter 1, data sources and the registration routines at the Registry are documented. The chapter includes a description of the sources of information, the notification and reminder systems in place, as well as the data items recorded. The remaining four chapters take up the specific aspects of data quality at a cancer registry, summarised on page S2. Chapter 2 discusses the comparability of cancer registry data, and the extent to which the Registry’s in-house coding and classification systems adhere with international standards. In Chapter 3, established statistical methodologies are documented and applied to estimate the completeness of the Registry data. The validity or accuracy of the variables that the Registry collects is evaluated in Chapter 4. Each of these Chapters includes results and some comments on the key findings. Finally, Chapter 5 discusses the timeliness of the registry data, and the Registry’s obligation to provide timely information on cancer in Norway that is also accurate and close to 100% complete.

1 Data sources and registration routines at the Cancer Registry of Norway

The Cancer Registry of Norway has, since 1952, systematically collected notifications on cancer for the Norwegian population, and the total number of registrations of cancer collected for a given year has, from the following year, 1953, been considered to be very close to complete. The reporting of neoplasms (and certain precancerous lesions) has been compulsory following a directive from the Ministry of Health and Social Affairs in 1951. A Health Registry Act came into force in 2002 that included statutory regulations for the Registry (*Regulations on the collection and processing of personal health data in the Cancer Registry of Norway*), strengthening the legal obligation to report new cases to the Registry and defining its main objectives as:

- To collect and, within the scope of the Regulations, process data relating to cases of cancer and carry out studies in Norway in order to document the distribution of cancer in the country and describe changes over time;
- To conduct, promote and provide a basis for research to develop knowledge of the causes of cancer, their diagnosis and natural course, and the effects of treatment via the follow-up of patients, with a view to improving the quality of preventive measures and medical assistance to combat cancer;
- To provide advice and information to public administrative bodies, special interest groups, and the general population, including measures that may help prevent the development of cancer.

THE 11-DIGIT PERSONAL NUMBER

A unique 11-digit personal identification number is assigned to all newborns, and to people residing in Norway. This number provides a reliable means of tracking patients and keeping the potential duplication of registered cases down to a minimum.

1.1 Notifications and sources of information

INFORMATION ABOUT VITAL STATUS - MATCHING WITH THE NATIONAL POPULATION REGISTRY

The Registry is matched monthly to the National Population Registry. This regular processing of matching ensures active follow-up of each and every patient with regards any changes in their vital status: death or emigration is flagged alongside the date of the event.

The sources of information and the notification process are illustrated in Figure S1.1. Hospitals, laboratories, general practitioners and *Statistics Norway* provide the key information that enables the Registry to collect, code and store data on cancer patients in Norway. Information from clinical notifications, pathological notifications and death certificates are the main reporting sources, and these are processed and registered in the incidence registry. Since 1998, information from the Patient Administrative Data (PAD) system in the hospitals has proven an important additional source for identifying patients that were unregistered.

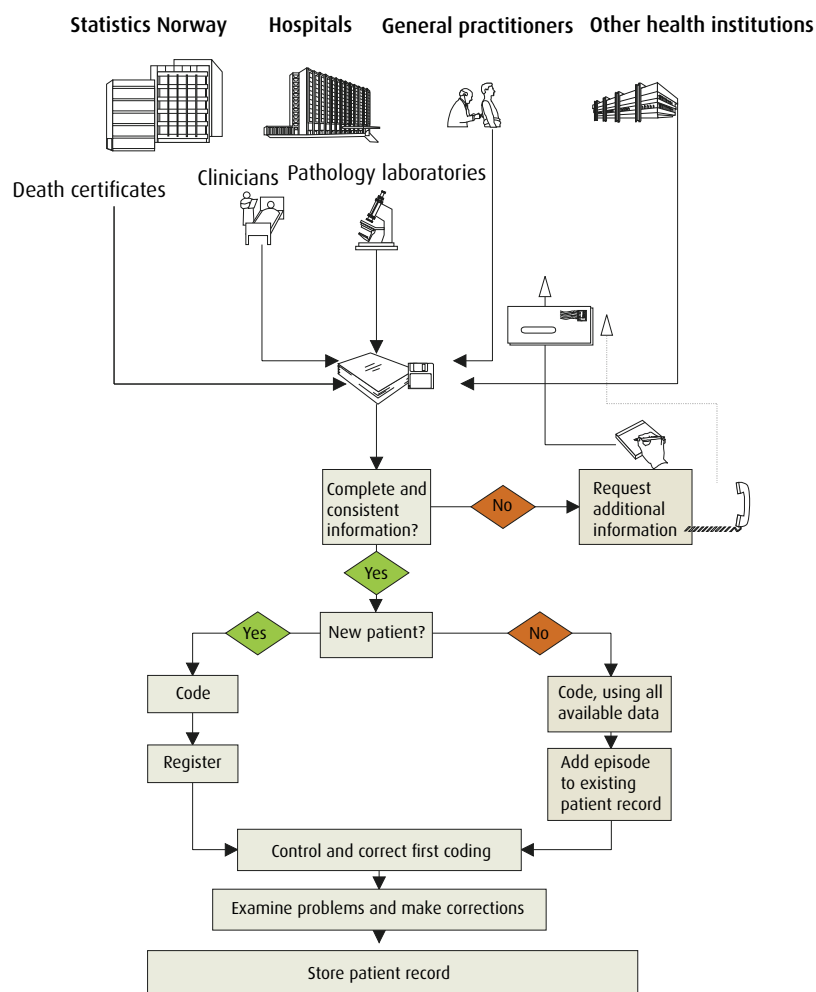
1.1.1 Clinical and pathological notifications

The Cancer Registry Regulations, as issued by the Ministry of Health and Social Affairs, require all hospitals, laboratories and general practitioners in Norway to report all new cases of cancer, irrespective of whether the patient is treated, admitted, or seen only as an outpatient. The Registry also receives mandatory reports from individual physicians, and from pathology and cytology laboratories. There are two generic paper-based forms for the reporting of solid or non-solid tumours (Appendices 1 and 2), respectively. Some specific sites (colorectum, breast, ovary, prostate, malignant lymphoma and chronic lymphatic leukaemia) are reported on separate forms with extended information on case history and treatment (Appendices 3-7). Notifications of pathological information are received from hospitals and individual laboratories. These notifications may provide either histological, cytological or autopsy information.

1.1.2 Death certificates

Records held in the Registry are supplemented with relevant information on vital status from the National Population Registry, and are regularly matched with the Cause of Death Register run by the National Statistics Bureau, *Statistics Norway*. The Registry receives and registers the death certificates in one or several batches in a given year. The automated procedure that matches registered patients to death certificates is an important aspect in maintaining quality control, faci-

Figure S1.1: Sources of information and the processes of cancer registration at the Registry



litating a high level of completeness and ensuring validity of the Registry data items.

Death certificates are also a complementary source of information on new cancer cases; those inconsistently specified or unmatched to registry files are subject to further scrutiny. Cancer cases first identified from death certificates are traced back to the certifying hospital or physician. The Registry needs to ascertain from the registrar completing the certificate whether the patient had been investigated and diagnosed when alive, or whether the diagnosis was made following death. A reminder is sent to the physician or institution responsible for the treatment of the patient before death, as indicated on the death certificate. In many cases, a nursing home is the point of contact, and they refer the Registry to the treating physician or hospital where the cancer was diagnosed.

1.1.3 The Patient Administrative Database (PAD)

Since 2002 the Registry has received data files from the PAD system running in all Norwegian hospitals.

These files contain information on all patients treated for malignant and premalignant conditions from 1998, and PAD has been a key source to the Registry in ascertaining information on unreported cases since that date.

1.1.4 Data items registered in the Cancer Registry of Norway

There is obligatory reporting and registration at the Registry of the following:

- All definitely malignant neoplasms (e.g. carcinoma, sarcoma, malignant lymphoma, leukaemia and malignant teratoma).
- All precancerous cases.
- All histologically benign tumours of the central nervous system and meninges.
- All histologically benign transitional cell papillomas of the urinary tract.
- All tumours of the endocrine glands within the central nervous system.

1.2 Dispatching of reminders

It is mandatory to report clinical information on new cases of cancer within two months of the diagnosis. Reminders are therefore sent to all hospitals and physicians failing to initially report new cases, or in cases where the received forms do not yield relevant information. About 40 000 reminders are sent annually, including, in some instances, repeat requests for information. There are two main sources of information used to send out reminders to the reporting institutions and physicians:

1 Reminders sent out on the basis of pathological information or death certificates

Pathology and cytology laboratories regularly send copies of pathology reports and autopsies to the Registry. Death certificates are received from the Deaths Registry at Statistics Norway. In those cases where the clinical form for the cancer case notified from these sources is missing, information on the hospital/ward/physician responsible for the diagnosis and treatment of the patient is used to send out the reminder.

2 Reminders sent out on the basis of PAD

Previous studies have shown that there is a degree of underreporting of non-solid cancers and brain neoplasms in Norway (6;7). These tumours are less frequently histologically-verified, and for this reason, fewer reminders are sent out based on pathological information, and thus fewer retrievals of the clinical form. The Registry augments existing sources of information with electronic patient forms received directly from each Norwegian Hospital. The PAD system database captures all C- and some D-diagnoses (D00.0- D48.9) (ICD-10) and these can be matched with the current information in the Registry database. Reminders are sent for those cases where no information about the specific diagnosis exists in the Registry.

An example of the usage of PAD in ascertaining unregistered cases in 2005 is given in Appendix 9. The Registry sent out reminders for 8989 PAD-diagnoses that were not already registered, and consequently, notifications were received for 5448 of these cases. Of the 3541 PAD-diagnoses still missing, 2155 PAD-diagnoses of these resulted where hospitals have reported to the Registry that erroneous diagnoses have been used. The most common erroneous diagnoses were typing errors (e.g. ICD10: G50 → C50, L02 → C02), phonetical errors (e.g. S18 → C18), tentative diagnoses (e.g.

registration of C61, but examinations revealed an N40, hyperplasia of the prostate) or incorrect use of codes (e.g. C34 to register a metastasis to the lung, correct code C78.0).

For 1386 PAD-diagnoses, the Registry still lacks any information about the specific diagnosis. Information regarding another cancer diagnosis exists for 841 of the missing PAD-diagnoses, but for the remaining 545 PAD-diagnoses, we still lack information. Many hospitals have made great efforts to improve their reporting system, in some instances in collaboration with the Registry. With the planned introduction of an electronic system for clinical notifications, we envisage that reporting to the Registry will further improve. Regarding the PAD-diagnoses currently missing in Registry, we will follow up these actively, continuing our close collaboration with the Norwegian hospitals.

1.3 Data sources and methods used in this Special Issue

The data extracted, analysed and presented in the tables and figures pertain mainly to the five-year period 2001-5 on the basis of an extraction of the data from the incidence registry as of 29.10.2007. The precancerous cases included are i) atypical epithelial lesions and benign papillomas of the transitional cell-lined urinary tract, together with invasive cancers at these sites, and ii) all neoplasms of the central nervous system (benign or malignant). The precancerous conditions, cervical carcinoma *in situ*, ovarian borderline tumours, and basal cell carcinoma of the skin are excluded. Codes are translated from ICD-7 to ICD-10 using a combination of topography and morphology. Population data, stratified by year, sex and age, are provided by *Statistics Norway*. For comparative purposes, data from other European countries has been extracted from NORDCAN (8), GLOBOCAN (9) and Cancer Incidence in Five continents Volumes VIII and IX (10;11) The incidence reported includes all definitely malignant neoplasms

Chapters 2, 4 and 5 examine the surrounding issues and comments on aspects of completeness, validity and timeliness at the Registry, respectively. Chapter 3 provides, as well as definition of completeness, a general description of the methodological issues and the specific methods used in this report, with a justification provided for their use.

2 Comparability

2.1 Definition

The *comparability* of cancer data is identified via a thorough review of the registration routines in place, including a specification of the standards and definitions that have been followed. Precise knowledge of current and historical registration practices and definitions are of great importance in the analyses and interpretation of geographical and temporal variations in cancer incidence. The adherence of registries to agreed international standards with precise definitions should ensure that conclusions resulting from comparisons of registry data are appropriate. In the evaluation of comparability, three topics demand particular attention:

- The system used for classification and coding of neoplasms.
- The definition of incidence, i.e. what is defined as a cancer case, and what is the definition of the incidence date.
- The distinction between primary and multiple cases.

2.2 International standards for cancer registration

The standards of classification and coding of neoplasms have since the late 1940s been published by the

World Health Organization (WHO). Recommended guidelines for the definitions of incidence have been published by the European Network of Cancer Registries (ENCR), and the International Association of Cancer Registries (IACR) has developed a set of rules for the reporting of multiple cancers. These are reviewed below, and details and comparisons with the in-house rules and procedures at the Registry are set out in 2.4.

There are two important items of information regarding the classification of neoplasms:

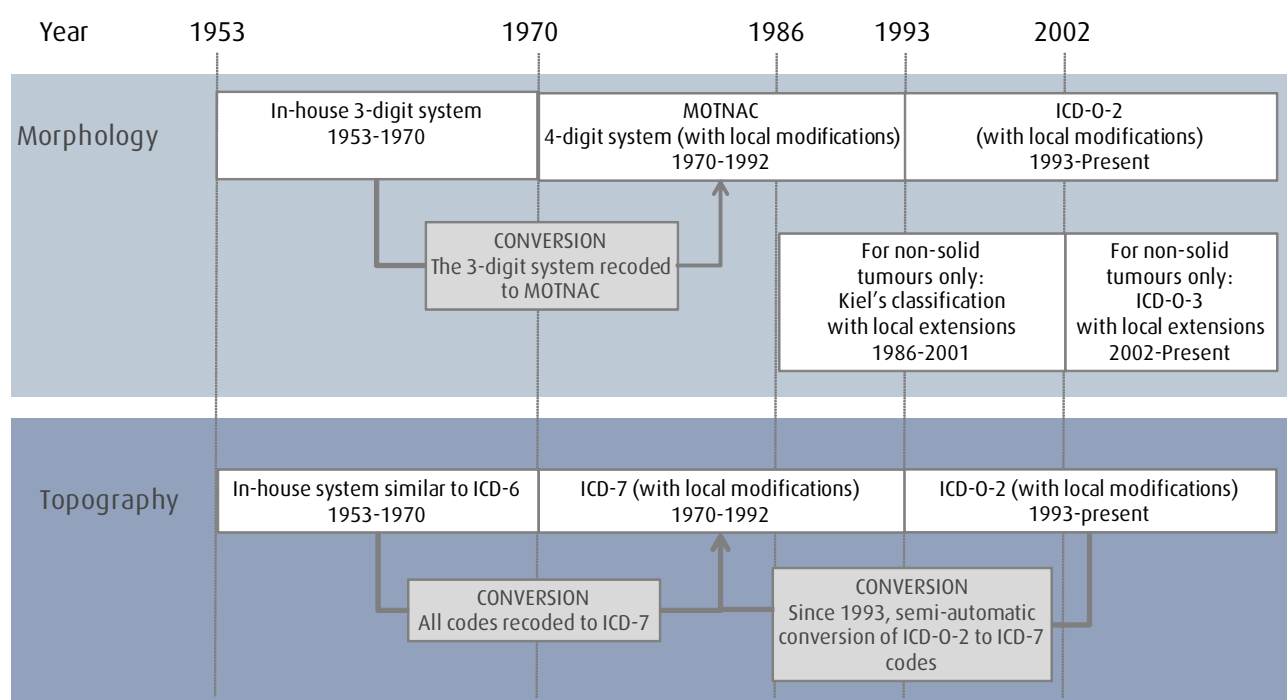
- Topography - location of the tumour in the body (synonyms are anatomical location or site).
- Morphology - cell type and its biological activity and behaviour.

A historical overview of the coding system used is given in the Third Edition of the ICD-O (12). The history of classification and coding of neoplasms in the Cancer Registry of Norway is presented in Figure S2.1. The registration of cancers in Norway has followed three international standards in the last 50 years, each of which are discussed below.

2.2.1 International Statistical Classification of Diseases, Injuries, and Causes of Death (ICD)

The consecutive editions of the ICD classification system have been the principal reference for the coding of topography in cancer registries. In the Cancer Registry of Norway, all cancer cases registered conti-

Figure S2.1 Topography/morphology codes at the Cancer Registry of Norway over time



nue to be assigned a specific ICD-7 code (13) for the cancer site. The topographic classification of ICD-7, is primarily arranged according to the anatomical site of the tumour (except for a few histological types such as melanomas, lymphomas and leukaemias), and the site of the neoplasms is specified using a three-digit code. The subsite, or further anatomical details, is given in a fourth digit after a decimal point.

2.2.2 Manual of Tumor Nomenclature and Coding (MOTNAC)

The first coding manual providing an index of morphology for neoplasms was published by the American Cancer Society (ACS) in 1951 as the *Manual of Tumor Nomenclature and Coding* (MOTNAC) and consisted of a two-digit code for morphology with a third digit denoting the behaviour of the neoplasm (14). In the 1960s the College of American Pathologists (CAP) developed a code for all pathologic entities, and, with the aid of the ACS, published the *Systematized Nomenclature of Pathology* (SNOP)(15). SNOP provided a morphology code including two sections on neoplasms (Sections 8 and 9), together with a new, more-detailed topography classification to cover the whole body. The agreement with ACS stipulated that the ACS could use the SNOP neoplasm morphology sections 8 and 9 and publish these with their own topography codes. Since cancer registries had always used the *Malignant Neoplasms* section of ICD for topography, ACS based topography on ICD-8. Hence a new *Manual of Tumor Nomenclature and Coding* (MOTNAC) (16), was published by the ACS in 1968 and was used extensively by cancer registries, including the Cancer Registry of Norway (see section 2.4.1).

In 1976, WHO published the first edition of the *International Classification of Diseases for Oncology* (ICD-O) (17) which had a topography section based on the malignant neoplasm rubrics of ICD-9 and a morphology section that was a one-digit expansion of the MOTNAC morphology. The College of American Pathologists adopted the morphology of ICD-O for their revised edition of SNOP entitled the *Systematized Nomenclature of Medicine* (SNOMED) (18). SNOMED's topography was, however, entirely different from that of ICD-O.

2.2.3 International Classification of Diseases for Oncology (ICD-O)

ICD-O is a dual classification with coding systems for both topography and morphology. In ICD-O the topography code describes the site of origin of the neoplasm, and the morphology code describes the cell type of the tumour and its biological activity.

The second edition of the *International Classification of Diseases for Oncology* (ICD-O-2) was published in 1990 by WHO for use in cancer registries, pathology and other departments specialising in cancer (19). The architecture of ICD-O-2 is similar to ICD-O-1 with a dual classification and coding system for both topography and morphology. The topography code uses the same four-character categories used in ICD-10 for malignant neoplasms (C00.0 - C80.9), with a decimal point separating subdivisions of the three-character categories.

Structure of a Topography Code

C___.
site subsite

ICD-O morphology terms have five-digit codes ranging from M-8000/0 to M-9989/3. The first four digits indicate the specific histological term, while the fifth digit after the slash (/), is a behaviour code, which indicates whether a tumour is malignant, benign, in situ or uncertain (whether malignant or benign). There is also a sixth digit providing supplementary information regarding histological grading or differentiation. For lymphoma or leukaemia, this element of the code is used to identify T-, B-, Null-, and NK-cell origin. Only malignant tumours are graded.

Structure of a Morphology Code

_____/_____
Histology behaviour grade

In the third edition of ICD-O (12) the morphology code for neoplasms was revised, particularly in relation to lymphomas and leukaemias, including the incorporation of the revised WHO classification of lymphomas, and the French-American-British (FAB) classification for leukaemias.

2.3 International standard for definition of incidence

Incidence is defined as the number of new cases of the disease that develops in a population at risk during a specific period. There are several aspects which may be at variance with this standard definition however, and further specification is needed regarding:

2.3.1 Incidence date

Cancers develops through an accumulation of mutations in genes. As the natural history of cancer often take decades from initiation to clinical detection, there

is a need for a specific definition for what point in time the disease should be stated to have become incident, the *incidence date*. The standard definitions of incidence as recommended by the ENCR are given in Table S2.1.

Table S2.1 ENCR recommendations for defining the incidence date of a cancer registration

Rules for registration of incidence date, in decreasing order of priority:	
1	Date of first histological or cytological confirmation of this malignancy (with the exception of histology or cytology at autopsy). This date should be, in the following order: a) Date when the specimen was taken (biopsy) b) Date of receipt by the pathologist c) Date of the pathology report
2	Date of admission to the hospital because of this malignancy.
3	When evaluated at an outpatient clinic only: date of first consultation at the outpatient clinic because of this malignancy
4	Date of diagnosis, other than 1, 2 or 3
5	Date of death, if no information is available other than the fact that the patient has died because of a malignancy
6	Date of death, if the malignancy is discovered at autopsy
NOTE: Whichever date is selected, the date of incidence should not be later than the date of the start of the treatment, or decision not to treat, or date of death. The choice of incidence does not determine the coding of the item "basis of diagnosis"	

<http://www.encr.com.fr>

2.3.2 Multiple primaries

There are some variations in the definition of multiple tumours across cancer registries. In general, multiple primaries occur where two or more primary cancers develop within the same organ (or pair of organs), as opposed to a recurrence or extension of an existing cancer. The cancers might occur at the same time (synchronous) or in sequence (metachronous). The cancer sites likely to be most affected by varying definitions of multiple primaries are cancers of the breast, colon, kidney, testis, lung, and melanoma of the skin (20). The IACR developed a set of rules for the reporting of multiple cancers (see Table S2.2). The version for use with data coded by ICD-O-2 was published in 2000 (21)(Table S2.2). A revised version for use with ICD-O-3, was published in 2004 (22).

2.3.3 Incidental diagnosis

Incidental diagnosis is the detection of cancer incidentally, in asymptomatic individuals. Such cancers may be detected either during autopsy, or during microscopic examination of tissues that have been removed for a non-cancerous condition. The commonest cir-

Table S2.2 IACR recommendations for the coding of multiple primaries

The IARC/IACR rules state the following:

- 1 Recognition of the existence of two or more primary cancers does not depend on time.
- 2 A primary cancer is one that originates in a primary site or tissue and is neither an extension, nor a recurrence, nor a metastasis.
- 3 Only one tumour shall be recognized as arising in an organ or pair of organs or tissue. For a tumour where site is coded by the first edition of ICD-O (or by ICD-9), an organ or tissue is defined by the three-character category of the topography code. ICD-O second and third editions and ICD-10 have a more detailed set of topography code. Some groups of codes are considered to be a single organ for the purpose of defining multiple tumours.
Multifocal tumours – that is, discrete masses apparently not in continuity with other primary cancers originating in the *same* primary site or tissue, for example bladder – are counted as a single cancer.
Skin cancer presents a special problem as the same individual may have many such neoplasms over a lifetime. The IARC/IACR rules imply that only the first tumour of a defined histological type, *anywhere on the skin*, is counted as an incident cancer unless, for example, one primary was a malignant melanoma and the other a basal cell carcinoma.
- 4 Rules 3 does not apply in two circumstances:
 - 4.1 For systemic or multicentric cancers potentially involving many discrete organs, four histological groups – lymphoma, leukemias, Kaposi sarcoma and mesothelioma- are included. They are counted only once in any individual.
 - 4.2 Other specific histologies – group 1-4; 6 and 11 in list below – are considered to be different for the purpose of defining multiple tumours. Thus, a tumour in the same organ with a 'different' histology is counted as a new tumour. Group 5 and 12 include tumours that have not been satisfactorily typed histologically and cannot therefore be distinguished from the other groups.

Groups of malignant neoplasms considered to be histologically "different" for the purpose of defining multiple tumours

Carcinomas		
1.	Squamous carcinomas	M805-808, M812-813
2.	Basal cell carcinomas	M809-811
3.	Adenocarcinomas	M814, M816, M819-822, M826-833, M835-855, M857, M894
4.	Other specific carcinomas	M803-804, M815, M817-818, M823-825, M834, M856, M858-867
(5.)	Unspecified carcinomas (NOS)	M801-802
6.	Sarcomas and other soft tissues	M868-871, M880-892, M899, M904, M912-913, M915-925, M937, M954-958
7.	Lymphomas	M959-972
8.	Leukaemia	M980-996, M998
9.	Kaposi sarcoma	M914
10.	Mesothelioma	M905
11.	Other specified types of cancer	M872-879, M893, M895-898, M900-903, M906-911, M926-936, M938-953, M973-976
(12.)	Unspecified types of cancer	M800, M997

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cumstance, however, is where cancers are detected as a result of a screening examination.

Screen-detected cancers

Screening aims to detect cancers that are asymptomatic, at an earlier stage than those presenting clinically, hence permitting a greater probability of cure. When a screening programme is introduced into a population, incidence rates increase. This is because: (a) the test identifies “prevalent” cancers that are detectable, but have not yet progressed to the stage where they cause symptoms; (b) the cancers are diagnosed at an earlier age, so that, for cancers for which incidence rates rise with age, there is an increase in age-specific rates, and (c) some cancers are detected that would otherwise never have been diagnosed during the subjects lifetime, either because he/she would have died from some other cause in the meantime, or the cancer so found would never have become invasive (“pseudodisease”). This phenomenon is called “overdiagnosis”.

After the initial rounds of screening, the “prevalent” cases will all be detected, and incidence falls, but not to its pre-screening level, because the effects of (b) and (c) will still be operating. Overdiagnosis is a particular problem of screening for prostate cancer. The PSA test identifies many small malignant tumours – not surprising since the prevalence of malignant change in the prostates of elderly men is very high, 40% at the age of 70 in a Norwegian autopsy study (23). Most of these cancers will not progress to invasive cancer, and it is not possible – at present – to distinguish which of those detected by a PSA test will do so. Incidence rates in the presence of screening can therefore be very high.

A working group of the ENCR recommended that cancer registries should collect a data item called *Method of Detection in Relation to Screening* (24). The authors note that the item has utility only in the evaluation and monitoring of organised cancer screening programmes. It is not possible to define screen-detected cancer cases in unorganised or opportunistic screening settings.

Autopsy diagnosis

Autopsy diagnosis occurs when cancer is diagnosed through autopsy, without any suspicion of malignancy before death. Where autopsies have been frequently performed, the incidence of certain cancers can be dramatically altered. Saxén drew attention to this on comparing the incidence of prostate cancer in Malmo, Sweden (25). In 1972, 46% of cases had been diagnosed at autopsy only, and the incidence was almost twice that of the country as a whole, with only 7% of cases diagnosed at autopsy, nationally.

2.4 Results: comparability at the Registry

The following section considers the degree to which the Registry data is comparable over time, and with other registries by relating in-house practices to the international standards and guidelines, stated above.

2.4.1 Cancer registration from 1952 to present

Figure S2.1 describes the classification systems used at the Registry from its inception through to the present day.

Topography

The Registry initially coded topography according to an in-house system akin to ICD-6 (26). From the early 1970s and up to and including 1992, the topographical codes of the cancer site were coded according to ICD-7 (13). Then, since 1993, the basis for coding has been ICD-O-2 (19), with the topography axis standardised with the C section of ICD-10 (International Classification of Diseases, 10th edition (27)).

The Registry has, since its first report in the late 1950s (28), utilised ICD-7 as a means of providing a description of the cancer-specific burden in Norway. *Cancer in Norway 2005* (29) marked a departure, being the first annual report reporting results using the ICD-10 nomenclature, following a tentative conversion of the registry data from ICD-7. Solid tumours are tabulated according to organ of origin, stated or presumed to be primary, of specified sites (C00-C75). Non-solid tumours - stated or presumed to be primary of the lymphoid, haematopoietic and related tissue (C81-C96) - are presented according to disease category irrespective of the organ of origin. The use of ICD-10 to report incidence data now corresponds with the system used by *Statistics Norway* to code deaths from cancer.

Morphology

Up to the 1970s the Registry used an in-house 3-digit system for the coding of tumour morphology. Then, from 1970-92, tumour morphology was coded within the Registry according to MOTNAC (16), and all in-house morphology codes were, during the same period, converted to MOTNAC codes. In 1993 the Registry adopted the ICD-O morphology codes. Since 1986, non-solid tumours have been coded according to separate coding systems, specified in Figure S2.1.

2.4.2 Staging information

For most sites, with the exceptions of breast; cervical cancer and malignant lymphoma, the extent of the disease is classified at the Registry into ten different categories, which is thereafter grouped as localized, regional, distant or of unknown spread (Table S2.3).

Table S2.3 Defining extent of disease at the Registry

Extent of the disease	Stage
Micro invasive growth, carcinoma with an incipient infiltration	Localized
No infiltration to neighbouring tissue/organs, lymph node metastasis or organ metastasis. Metastasis within the same organ as the primary tumour	Localized
Lymph node metastasis to ¹	Regional
Microscopically infiltration in neighbouring structure	Regional
Macroscopically infiltration in neighbouring structure (any examination method)	Regional
Lymph node metastasis to other places than ¹	Distant
Organ metastasis to ¹	Distant
Organ metastasis to other places than ¹	Distant
Metastasis stated, but tissue/organ unknown	Unknown
Unknown extent of the disease at the date of diagnosis	Unknown

¹ Organ/tissue is specific for each topography
<http://www.enccr.com.fr>

There are specific definitions for classification of regional and distant spread for each topography, however.

TNM classification

The TNM classification (30) provides an international standard in cancer staging, providing information on the extent or stage of the cancer for primary tumour site (T), regional lymph node involvement (N) and presence or otherwise of distant metastatic spread (M).

At present, breast cancer is the only topography that is systematically coded in the Registry according to the TNM classification. For the other topographies, information about TNM has been poorly reported or not stated at all, and these data are of insufficient quality for publication. Analyses of the year 2005 indicate that clinical TNM status was reported at the Registry in about 50% of all clinical notifications. The information on pathology TNM was generally of poorer quality, with 12% to 25% of the different clinical notifications stating a TNM-code. Thus, the TNM classification is registered when reported, but for most solid tumours the extent of disease codes as described above, are used. The accuracy of staging information at the Registry is discussed in Chapter 4.

2.4.3 Defining incidence

Incidence date

Since 1999, the incidence date has been recorded as the day, month and year of diagnosis. The rules for the registration of incidence date in the Registry are given in Table S2.4. An obvious departure from the ENCR recommendations (Table S2.1) is that the Registry

always registers the earliest incidence dates reported on the sources of notification, whereas the ENCR rules are based upon a hierarchy of the possible sources.

Table S2.4 Defining incidence date at the Registry

Rules for registration of incidence date in CRN

- 1 The date of diagnosis is defined as the date when the cancer was diagnosed, and not the date when the suspicion of malignancy arose.
- 2 The incidence date is defined as the earliest date written on one of the following notification reports received:
 - Incidence stated by a clinician on the clinical form
 - Date for histologically verified diagnosis
 - Date of death
- 3 Cases from the death certificate notes are registered as "Death certificate only (DCO)", and the date for these are given as the date of death if no other information can be collected. (It is important to differentiate between tumours coded from only one source and the final coding of the patients disease at the time of diagnosis).
- 4 For a patient known from autopsy only, the incidence date is the date of death.

<http://www.enccr.com.fr>

Multiple primaries

Recording

In the early 1970s the registration system was modified to allow multiple breast cancers to be recorded. Since 1981, the existence of two or more primary cancers was recognised for all neoplasms at the Registry, and since then, each primary tumour has been reported separately regardless of whether they are located in the same organ. Primary tumours diagnosed within a four month period from the date of diagnosis of the first tumour are however not recorded as multiple primaries. There are the following exceptions:

- **Malignant melanoma**

Multiple melanomas are recorded as separate tumours if they are diagnosed in different locations on the body irrespective of time of diagnosis.

- **Skin tumours other than malignant melanoma**

Multiple tumours are not recorded separately but as a single cancer, the fourth digit of the ICD-7 code is used to specify that there are multiple diagnoses of skin tumour (e.g. 191.8, with the digit 8 specifying that the patient has had multiple tumours).

- **Astrocytoma grade 1**

These may develop into multiform glioblastoma, and no second tumour is registered.

Paired organs

Tumours with the same morphology in paired organs are coded as bilateral tumours. Tumours with different morphology on each side are recorded separately, including tumours of the kidneys, testis and ovaries.

Reporting

Incidence reporting in the last decade including publication of *Cancer in Norway* only allows reporting

of the first tumour registered for each patient within a specific ICD-10 category. This includes bilateral tumours. Figures S2.2 a and b show the ratio of pati-

Figure S2.2a The tumour:person ratio (%) for selected cancers and sex, males, Norway 1971-2005

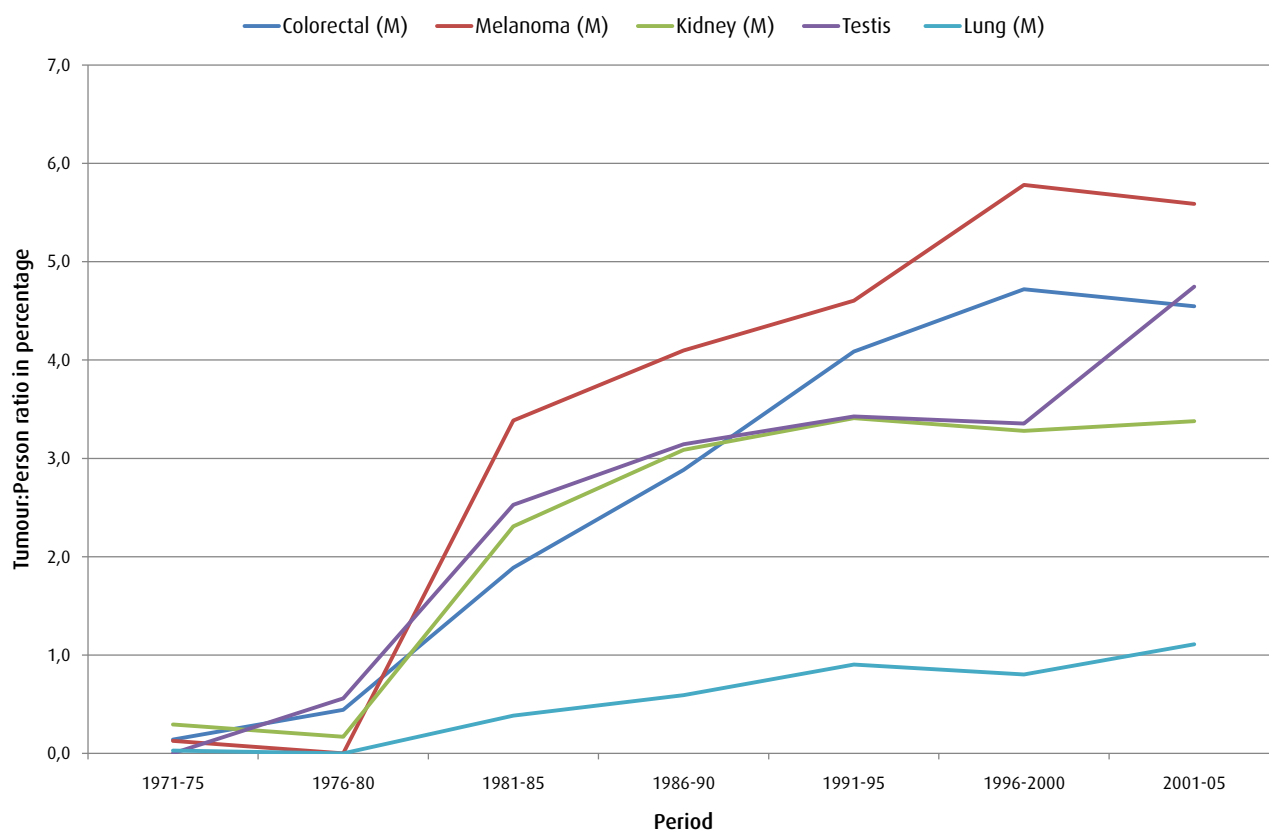
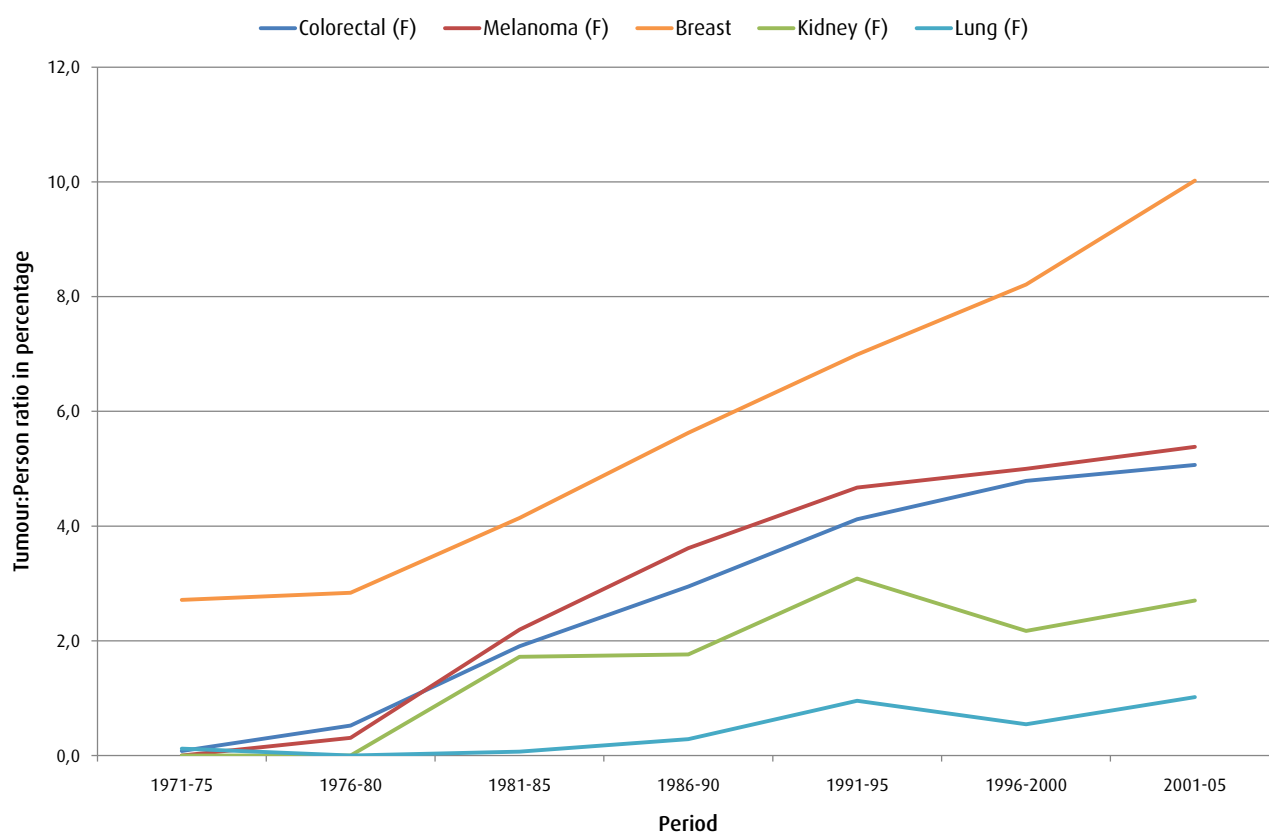


Figure S2.2b The tumour:person ratio (%) for selected cancers and sex, females, Norway 1971-2005



ents to tumours (by sex) in the incidence registry for cancers of the colorectum, kidney, lung, testis, breast and melanoma of the skin for the period 1971-2005. The elevated percentages for melanoma and cancers of the breast, testis and colorectal cancers illustrate the importance of clearly-defined reporting rules for multiple cancers; the reporting of *tumours* rather than *patients* would have increased the aggregated incidence of these neoplasms by around 5%.

Incidental diagnoses

Screen-detected cancers

The cervical screening programme was introduced in 1995, following several decades of opportunistic screening (starting in the 1970s). There is no registration of screen-detected cervical cancers, but by linking to the cytology register, it may be estimated (34). The screening programme defines *screen-detected* cancers as cases detected among women registered with a Pap smear test in the interval from four years to 6 months before diagnosis. *Clinically-detected* cancers are defined as cancers detected among women without any Pap-smear tests registered between four years and six months before diagnosis. Some cases defined as screen-detected will be the result of symptoms leading to a test, and thus are strictly clinically-detected cases.

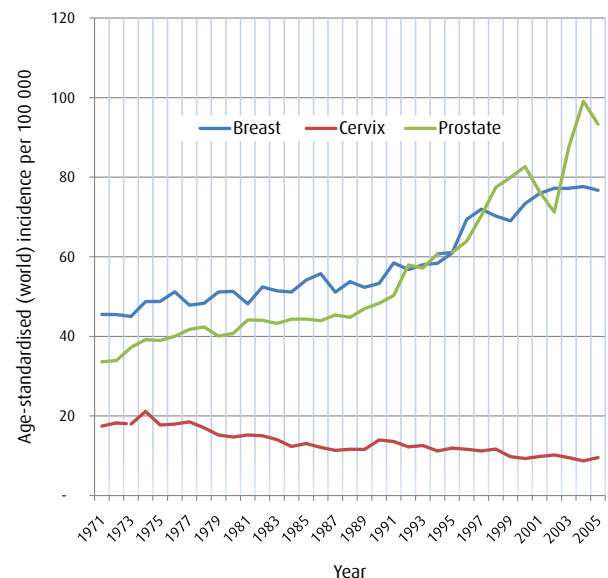
The Norwegian Breast Cancer Screening Programme (NBCSP) started in 1995-96 as a four-year pilot study in four of Norway's 19 counties, and became nationwide in 2005. The NBCSP has its own screening database within the Registry, and is thus able to calculate statistics on screen-detected cancers.

Wild screening for prostate cancer has increased considerably in Norway since the Prostate Specific Antigen (PSA) test became commercially available in 1989. Figure S2.3 illustrates the incidence rates for breast, cervix and prostate cancers in relation to the introduction of the national screening programmes for breast and cervix cancer and the rapid increases in prostate cancer incidence during the 1990s following the increased use of PSA-testing in diagnosis.

Autopsy diagnosis

According to national statistics from The Norwegian Society of Pathology the numbers of autopsies at hospitals performed during the period between 1984-2005 decreased from more than 6000 yearly in 1984, to less than 3000 in 2004-05 (36). The decline in autopsy rates was not reflected in the trends in the number of cases registered with autopsy which has remained rather stable. Due to increasing cancer incidence however, the proportion of cases registered on the basis of an autopsy diagnosis has slightly declined over the period (see Figure S2.4).

Figure S2.3 Time trends in age-standardised (world) incidence rates of breast, cervix and prostate cancer in Norway, 1971-2005 (Source: (8))



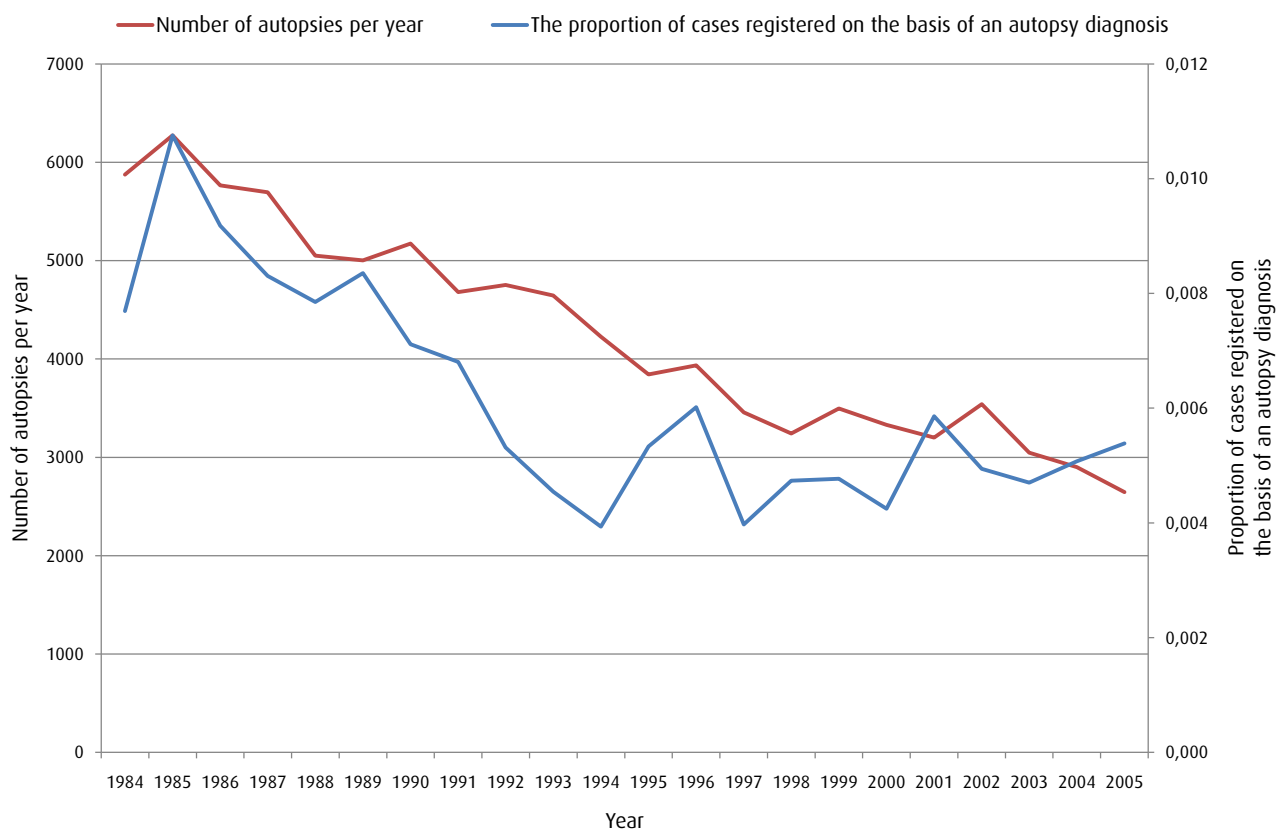
Cervical cancer: National screening program initiated in 1995
 Prostate cancer: PSA-test commercially available in 1989
 Breast cancer: A pilot study initiated in 4 counties in 1995, all counties included in 2005

2.5 Comment: impact of changing classification and coding on comparability

The Registry is in the process of a complete conversion of all incidence records to ICD-O-3. There is a sound justification for this given that some of the terminology is no longer clinically relevant, and a number of codes having been removed or modified through consecutive editions of the ICD manuals. A true conversion to ICD-O-3 will certainly facilitate national and international collaborations with other registries and external research groups. The process will be initiated in 2008, with coding and registration thereafter administered solely according to ICD-O-3.

The conversion of the codes from the present classification systems containing as it does, both redundant and newly-defined codes will obviously not provide a perfect translation to ICD-O-3. There will be a number of mis-specified codes, for which a direct conversion is not possible. Such a conversion will however provide a dataset that is comparable at a level of detail that is generally considered acceptable; where a detailed review of problematic groups is warranted, the old coding system will still be available for checking.

Figure S2.4 Numbers of autopsies in hospitals in Norway (source: (36)) and the proportion of cases registered on the basis on an autopsy.



3 Completeness

3.1 Definition

Completeness is the extent to which all incident cancers in the Norwegian population are included in the incidence registry. Incidence rates and survival proportions will be close to their true value if maximum completeness in case-finding procedures can be achieved.

3.2 Methodological issues in estimating completeness

It is useful to separate the methods for estimating completeness into qualitative (or semi-quantitative) methods, which give an indication of completeness *relative to other registries, or over time*, and quantitative methods, which provide a numerical evaluation of the extent to which all eligible cases have been registered.

3.2.1 Qualitative methods

Among the qualitative methods we might include:

1. Historic data methods:
 - a. Comparison of incidence rates in different populations.
 - b. Stability of incidence rates over time.
 - c. Shape of age-specific curves.
 - d. Incidence rates of childhood cancers.
2. Mortality:Incidence ratios.
3. Number of sources/notifications per case.

Historic data methods

Historic data methods have been widely used in the evaluation of datasets for *Cancer Incidence in Five Continents* (CI5) (10). For selected indicators, region-specific standards were defined for the expected incidence rates of the major cancers (by sex), and the observed values compared with these standards.

With respect to childhood cancer, the incidence rates (for all types combined) in the childhood age groups tend to show much less variability than in adults, although there are well documented differences by geography or ethnicity for specific types of childhood

cancer. The possibility of under-enumeration (or duplicate registrations) in this age range can be investigated by comparing the observed age-specific rates in the childhood age range with an “expected” range of values. The limiting values for the lowest and highest deciles, as they were published in CI5 Volume VIII (10) are shown in Table S3.1.

Mortality:Incidence ratio

The mortality:incidence (M:I) ratio is an important indicator of completeness, an example of the *independent case ascertainment method* (5), since it is a comparison of the number of deaths, which must come from an independent source, and the number of new cases from a specific cancer registered in a specific period. When the quality of the mortality data is good, and with a steady state of constant incidence and survival, the ratio will equal *1 - the survival probability*. When cancer survival is not changing, the ratio should be reasonably stable. In general, M:I ratios should be less than one except when incidence is declining rapidly relative to mortality (1).

Since both survival and the quality of the mortality and incidence data are somewhat related to geographical region, the regional location of the registry is important in the evaluation of the M:I ratio. In compiling datasets for inclusion in CI5, observed M:I ratios can be compared with standard values from the same region, testing for significant differences, as described by Parkin and Plummer (20) (see Appendix 9).

The method has been used within the U.S. to provide a *quantitative* estimate of completeness of the different state registries (37). In this instance, the assumption is made that the standard set of M:I ratios (site- and sex-specific, age adjusted) from the SEER registries are applicable everywhere, and that death registration is complete, so that, based on local mortality rates, *expected* rates are estimated for state registries. Completeness is evaluated as the observed/expected age-adjusted rates, allowing for the possibility that 20% of the difference (Expected – Observed) is due to differences in the M:I ratio between the locality tested, and the standard (SEER).

Table S3.1: Reference incidence rates (per 100 000) for upper and lower deciles of childhood cancer (source: (10))

Age	Boys (reference)		Boys in Norway ¹	Girls (reference)		Girls in Norway ¹
	Lowest	Highest		Lowest	Highest	
0–4	<12.3	>24.7	22.0	<9.7	>21.4	18.2
5–9	<8.5	>15.6	11.4	<6.9	>12.0	13.5
10–14	<8.5	>15.0	14.7	<6.8	>13.6	10.4

¹ Age-specific incidence rates per 100 000 in the period 2001–2005 (Source: www.anccr.nu)

Number of sources/notifications per case

Chapter 1 described the sources used to collect information on Norwegian cancer cases. The Registry uses a number of sources for this purpose, the main sources being information from clinical and pathological notifications and death certificates. In addition, the Registry has within the last decade received information from the PAD system from all hospitals in Norway. The rationale for using as many sources as possible is that it reduces the possibility of cancer diagnoses going unreported, thus increasing the completeness of the Registry data. There are therefore two indices that measures this aspect of data quality indirectly, the average number of sources per case, and the average number of notifications per case.

The Registry obtains the following information: 1) clinically-notified cases are those usually reported by hospitals, general practitioners, or other health institutions, 2) pathologically-notified cases are usually reported by a pathological department, and 3) deaths are reported via death certificates obtained from the *Deaths Registry* at *Statistics Norway*. Information from the PAD system is not included in our calculations of source per case as this information is not registered in the incidence registry, rather it is used as an additional source for the detection of non-reported cases, via the regular matching of the PAD-reported cases, as described in Appendix 8.

There may be multiple notifications in the reporting of one tumour, for example where a pathology department may provide updated information on a specific patient following further examinations of a tumour. Thus, while the number of sources per cancer does not extend beyond three, the number of notifications per tumour can be considerably greater, and can range from one to more than 10 notifications per case.

3.2.2 Quantitative methods

There are three methods that provide a more quantitative evaluation of the degree of completeness of registration:

1. Independent case ascertainment methods;
2. Capture-recapture methods;
3. Death certificate methods:
 - a. DCN/M:I method (38);
 - b. The "Flow" method (39).

Independent case ascertainment

Broadly speaking, the method falls into two categories:

- Re-screening the sources that had been used by the registry, to detect any case missed during the registration process;

- The use of one or more independent sources of cancer cases, and comparison of the incidence registry with them.

Case-finding audits are widely used in North America (see *Standards for Cancer Registries Volume III* (37)). These involve an independent reascertainment of records, usually in a sample of facilities and, within each facility, a sample of time periods. Records of cancer cases identified during the audit are enumerated and matched against the registry's files. Unmatched cases are followed back to verify their reportability, and the percentage of cases actually missed that should have been reported is calculated. Most of these studies focus on hospital reporting and thus provide an estimate of the completeness of reporting for hospitals only, not a true estimate of completeness from a multi-source population-based registry. More realistically, this method has been used to evaluate completeness of case ascertainment by individual reporting facilities.

Comparison of the incidence registry with sets of cancer cases which have been compiled *independently* of the cancer registry case-finding procedures is a particularly useful and objective method that has been frequently used. It requires record linkage between the cancer registry and the independent case series, to estimate the numbers of cases in the latter "missed" by the registry. The proportion of eligible patients who are already registered is a direct and quantitative estimate of completeness. The method has been widely used, sometimes to investigate completeness of registration of all cancers, sometimes of a single type of cancer. Independent sources used for the purpose have included:

- Cases recruited into an international clinical follow-up study (40);
- Patients enrolled into a multicentre clinical trial (41);
- The database of a Registration Network of Family Practices (42);
- Cases identified in a cohort study (43);
- Cases recruited into a multi-hospital case-control study (44).

Capture-recapture

Capture-recapture methods have been advocated for use in estimating completeness of a register (45). These methods were originally developed to estimate the size of a closed animal population. The procedure involves capturing, tagging and releasing a number of animals in an area at one time - the *capture* stage, and

then at a later time repeating the exercise - the *recapture* stage. The number of animals in each sample, and the number common to both, are used to estimate the number in the total population (assuming that capture and recapture are independent). The method has been applied several times to estimate the completeness of cancer registry data (46-49) .

Practically, capture-recapture analysis of completeness requires that record linkage is successfully carried out (so that cases identified by each and every source is correctly classified), and, if death certificates are used as a source, that the relevant cancer is correctly identified on them. In addition, two assumptions are made when using the simple capture-recapture method. The first is that when there are two sources, they are assumed to be independent, and more generally, that there is no dependency between all sources in a multi-source model. The second is that all individuals have the same probability of being captured. Neither can be directly tested, and violation of either could lead to over- or under-estimation of the true population size.

It is likely that these assumptions will not hold true in cancer registration. For example, in a cancer registry the sources commonly used are hospital discharge records, pathology reports, and death certificates. Cases captured by one source may be more, or less, likely to be also captured by the others, leading to dependence (positive or negative) between the sources and violating the first assumption. For example, terminally ill cases may be less likely to be admitted to hospital (and so not appear on a discharge record) and to die (and to have cause of death recorded as cancer), so that there would be a negative dependence between these two sources. It is also possible that some subject characteristics would be associated with probability of capture (for example, subjects living near the border of the registration area may go to hospitals outside of it, and be missed by the hospital-based sources). These problems have led to distrust of capture-recapture as a method for estimating the completeness of registry data (50). However, Brenner (51) using the Saarland cancer registry database, tested the interdependence of pairs of sources (clinical records, pathology, death certificates), by evaluating the estimate of completeness for each pair, with respect to their known completeness in the third. Although the two-source capture-recapture estimates of completeness differed from the known values, the deviation was generally quite small, and the deviation was less severe than the bias made by assuming 100% completeness (no missed cases).

The problem of dependency between sources can be dealt with in several ways. Crocetti et al (48) used Brenner's method (52) to identify the degree of de-

pendence between pairs of sources, then grouped those sources with the most dependence, before estimating the missing cases in a two-way method with a third source. When the sources are all dependent, this approach cannot work, and log-linear modeling is needed. There are many possible models depending on the interactions included (e.g. eight possible models with three sources), but the best approach is may be to use the model with all possible interactions (53).

Robles et al (54), who were one of the first to apply capture-recapture using three sources (clinical records, pathology records, death certificates) to estimating completeness of the cancer registry of Ontario. The method was applied in two fashions; first, using three data sources in a modelling approach: and second, using two data sources and standard, simple capture-recapture methods. The modelling approach was more flexible, since several variables that influence cancer registration can be considered and can be used to identify reporting patterns of different data sources, although the estimates of completeness of the registry as a whole were remarkably similar using either two or three data sources.

The log-linear modeling approach does not deal with the problem of the characteristics associated with capture, and an alternative is the inclusion of capture-related covariates in a logit model, which should improve accuracy of the estimate of the population size compared to estimates from a simple model (55). In addition, this method can identify patient characteristics related to probability of capture by the different sources. Such information could be useful for improvement of an ongoing register by identifying patient subgroups with a high probability of being missed by the register. The parameters from the model can also be used to estimate the number of cases in different population subgroups. For example, adjusted age- and sex-specific incidence rates could be derived.

Death Certificate Methods

Death certificates provide an important source of information for cancer registries. As far as incidence statistics are concerned, they function as a means of capturing information on cases that escaped the registration process during life. The means of using statistics on 'death certificate cases' to evaluate quality of cancer registry data still apparently causes confusion, although this has been clearly defined (5;56). Completeness of registration may be evaluated on the basis of the proportion of incident cancers that come to the registry's attention via a death certificate mentioning cancer. A death certificate initiated (DCI) or death certificate notified (DCN) case is one for which

the first information comes via a death certificate, *and*, without the death certificate, the case would not have been found. That is – any information from other sources (clinical, pathology, for example) was found as *a result* of trace-back procedures, *initiated* because of the death certificate.

Death certificate only (DCO) cases represent the residuum of cases – *after all trace-back manoeuvres have been completed on DCN cases* – for which no other information than a death certificate mentioning cancer could be obtained. By itself, therefore, the %DCO is *not* an indicator of completeness of registration; a low %DCO *may* indicate efficient case-finding, but it could equally well result from the efficient trace-back of DCN cases. Nevertheless, the %DCN will always be equal to, or greater than, the %DCO, so an elevated %DCO is suggestive of incompleteness. Even this must be interpreted in the light of local circumstances; in some developing countries, the quality of death certificates may be very poor, with a fair number of erroneous cancer deaths, which the registry may have difficulty tracing back to a hospital capable of confirming (or not) the death certificate statement. Figure S3.1 illustrates the death certificate procedures.

Barring the relatively few instances where cancer was erroneously mentioned on the death certificate, DCN cases represent a failure to identify cases during life,

and it can therefore be used to provide a quantitative estimate of completeness.

Two death certificate-based methods of evaluating completeness are available, and can be used for all cases, or subsets defined by cancer site or age group.

The DCN/M:I method (Ajiki et al, 1998)

The background to this method was described by Parkin (5). It requires that DCN cases can be explicitly identified by the registry, and makes use of the M:I ratio to estimate the proportion of the initially unregistered cancer cases that do not die. The principle is illustrated in Figure S3.2.

After inclusion of the DCN cases (*c*) in the registry database, *d* represents the undetected cases still alive, and the final degree of under-registration is given by $d/(a+b+c+d)$. In order to obtain a numerical estimate of *d*, it has to be assumed that the proportion of unregistered cancers which die ($c/(c+d)$) is the same as the proportion of registered cases which die ($a/(a+b)$).

Thus, if $c/(c+d)=a/(a+b)$ then $d=bc/a$ or $(b/a) \times c$, where *d* represents the undetected cases still alive, so the degree of completeness may be estimated as:

$$\frac{\text{Final registrations}}{\text{Final registrations} + d} \quad \text{or} \quad \frac{a + b + c}{a + b + c + d}$$

Figure S3.1: Illustration of concepts of death certificate notification (DCN) and Death certificate only (DCO) cases

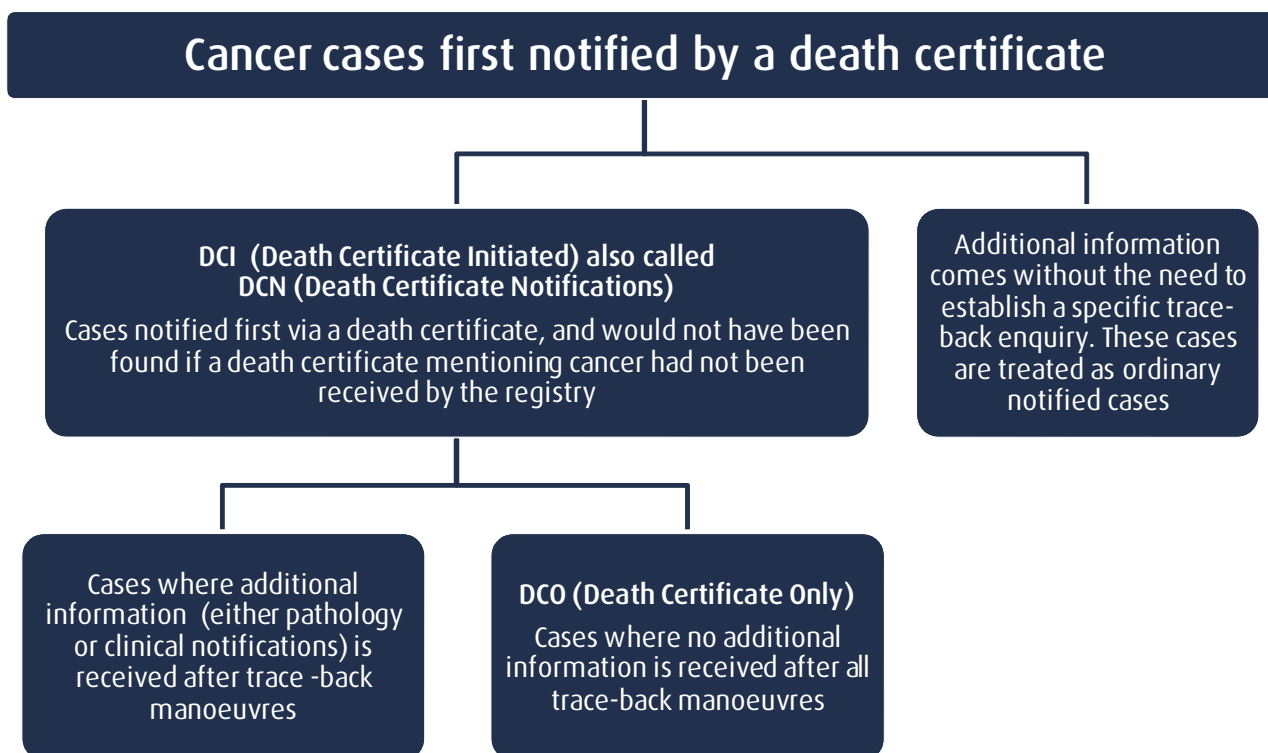
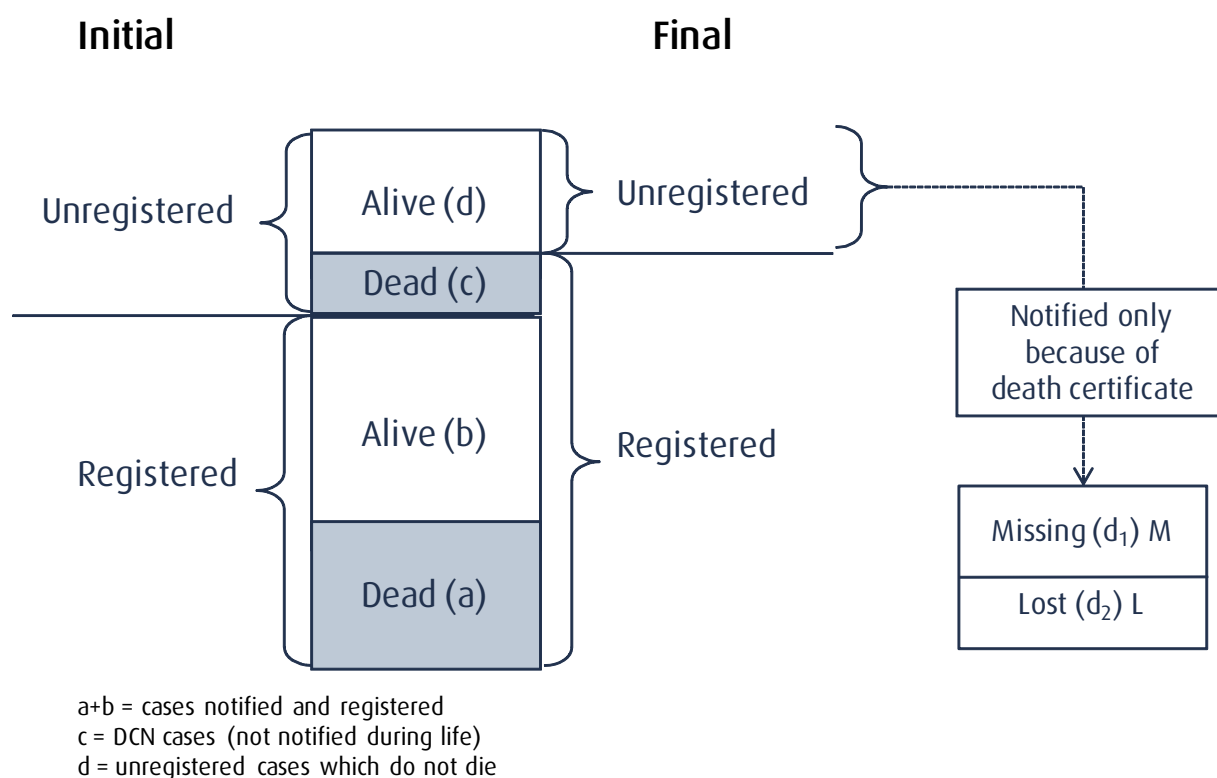


Figure S3.2 DCN as a measure of completeness (adapted from (5))



The variables required are the DCN cases (c) and, for the cases registered during life, the ratio between those that are alive and those that are dead (b/a).

This method requires that the cases registered independently of a death certificate are followed up to determine the number of them which die. An approximation to this case fatality is the mortality/incidence ratio (M:I) which is usually obtainable from death registration, independently of individual follow-up of registered cases. Although the M:I ratio includes DCN cases (in the nomenclature of Figure S3.2, it is $(a+b)/(a+b+c)$), in practice this is not very different from the case fatality of non-death certificate cases ($a/(a+b)$), provided that the proportion of DCN cases is relatively small (say <10%).

Ajiki et al (1998) provide a formula for estimating completeness from DCN and the M:I ratio (both expressed as proportions):

$$\frac{1 - (DCN \times (1/M:I))}{1 - DCN}$$

Note that the assumption behind these various estimates is that the case fatality is the same for registered and unregistered cases. This is probably untrue, since other studies suggest that such cases are likely to be older, less investigated and less intensively treated - and hence with higher fatality - than the cases detected by the usual case-finding procedures of the registry.

The Flow method (Bullard et al, 2000)

This method estimates the cases not traced via death certificates using information on survival of registered cases, and, based on cancer patients that have died, the probability of registration at different intervals post-diagnosis (39). It does not, therefore, require that DCN cases are explicitly enumerated, and is not sensitive to the proportion of DCNs, nor to the assumption of equal M:I ratios in cases that are, or are not, traced.

Referring to Figure S3.2, we first note that d , the cases remaining unregistered even after inclusion of DCN cases, includes two components:

d_1 - Missing cases – those that did not die, and were not registered (M)

d_2 - Lost cases – those who died, and were not already registered, and in whom cancer was NOT mentioned on the death certificate (L).

To estimate these two fractions, three parameters must be derived:

i) *The probability of surviving different intervals after diagnosis $s(t_i)$* This is derived by a conventional survival analysis (actuarial method), but the DCO cases should not be excluded, since, if they are numerous, the survival probability will be too great. But, DCO cases are conventionally assigned date of diagnosis equals the date of death (i.e. zero survival). To avoid this, DCO cases are taken as incident cases in the year they occur (the conventional assumption), but, their survival is imputed from that of the DCN cases registered in the same year.

ii) *The probability that cancer is not mentioned on the death certificate, at different intervals post-diagnosis $1 - m(t)$* , where $m(t)$ is obtained for the cancer patients who died in the survival analysis.

iii) *The probability that a patient that died had not been registered at different intervals post diagnosis $u(t_i)$* . This is calculated based on the cancer patients who died, as $1 -$ (probability of registration at time t_i post-diagnosis). Bullard et al suggest omitting the year before death, when calculating $u(t_i)$.

Missing cases, (M) are given by $s(t_i) \times u(t_i)$

Note that, here, $u(t_i)$ should be the probability that a patient *that had not died* had not been registered at different intervals post diagnosis. Clearly, Bullard et al assume that this would be well approximated by the statistic calculated in (iii), based on dead patients only.

Lost cases (L) are given by

$$[s(t_i) - s(t_i+1)] \times [1 - m(t_i)] \times [u(t_i)]$$

N years after diagnosis, the lost cases would be

$$\sum_{ni=0} [s(t_i) - s(t_i+1)] \times [1 - m(t_i)] \times [u(t_i)]$$

Completeness at time T ($C(T)$) is given by

$$1 - M(T) - L(T)$$

A computer program is available for carrying out the necessary computations (57).

3.3 Methods used in this report

In keeping with the methods described above, the results are separated into semi-quantitative and quan-

titative methods. The former approaches used here include *internal* assessments of the stability of overall Registry incidence figures over time, and a comparison of M:I ratios with the inverse of 5-year survival, and *external* comparisons, whereby childhood cancer incidence rates and M:I ratios obtained from Registry data are evaluated alongside those from high-quality cancer registries. One may have also included a comparison of cancer-specific incidence between countries in this analysis, hypothesising that systematic deviations could imply possible underascertainment. This approach is not adopted here, as a comparison of Norwegian incidence rates with those from an appropriate reference group (such as Finland or Sweden) would likely yield considerable variability for certain cancers related more to differences in the prevalence and distribution of known or putative risk factors (e.g. cancers of the lung, colorectum, testis), and/or practices concerning screening and early diagnosis (e.g. cancers of the female breast, cervix and prostate).

Two quantitative methods are also explored, namely the capture-recapture and death certificate-based “flow” methods (39;52). The DCN/M:I method (38) is not examined in this report as DCN proportions cannot be accurately determined at present. The Registry relies on the receipt of death certificates (where cancer is mentioned as the underlying, or contributing cause of death) to initiate registrations which (at that time) had not been reported from either the clinical or histopathological sources. There are difficulties at present, however, in determining whether, for a given patient, registration of clinical and/or pathological information was initiated exclusively as a result of the receipt of the death certificate, or whether such information was received independently; the Registry is in need of a flagging system which records the source and date of newly-received information, irrespective of the source from which the information came.

3.4 Previous studies of completeness

While there has been no comprehensive evaluation of the completeness of the Registry, there has been a pilot study by Lund involving 12% of the total Norwegian population published in 1981, as part of the 1978 annual report (6). The study indicated that overall completeness in the registry in two counties in 1976 (accounting for 12% of the total Norwegian population) was 97.6% for solid tumours, but was less complete for leukaemia and multiple myeloma, possibly as a result of failure to diagnose some cases at the pathological laboratories.

A detailed description of each of the previous cancer-specific studies reported in peer-reviewed journals is

given in Table S3.2. In summary, a report of the quality of head and neck cancer registrations 1953-91 indicated that virtually all new cases were reported when compared against hospital-based registries (58); for prostate cancer, the deficiency in reporting was reported to be less than 1% (59). A report on the quality of histologically-verified ovarian cancers diagnosed 1987-96 in one region in Mid-Norway (14% of the total Norwegian population) estimated organ-specific completeness at 95.3% (60).

3.5 Results

3.5.1 Semi-quantitative analyses of completeness

Stability of incidence rates over time

The time trends for a number of frequent cancers in the period between 1971 and 2005 are shown in Figure S3.3a and S3.3b for males and females, respectively. While the gradient is variable, the annual trends can be seen to be rather free of major fluctuation e.g. there are no instances of rapid increases or decreases in the

Table S3.2: Peer-reviewed reports describing the quality of data at the Cancer Registry of Norway

Reference	Site	Quality aspects	Study period	Methods	Main results and conclusions
Lund, 1981 (6)	All cancer sites	Completeness	1976	Completeness was estimated by matching of cases registered in Cancer registry of Norway against those registered within the Economic and Medical Information system. The study included cancer cases diagnosed in 1976 in the hospitals of either Rogaland or Oppland county.	The overall completeness, three years after diagnosis, was estimated to be 97.6%. In total, 34 cases out of 1417 cancer cases registered in EMI were not registered in the Cancer Registry of Norway. The study revealed local differences in reporting routines between the hospital departments. For cancer of lymphatic and hemopoietic tissues reporting was markedly poorer than for other sites; especially for multiple myeloma or leukaemia, where completeness was estimated to be 78.6% and 91.8%, respectively.
Helseth et al, 1988 (7)	Neoplasms of central nerve system	Validity/Quality of data	1955-1984	All cases registered with primary central nervous system neoplasms diagnosed in the period between 1955 and 1984 were included (n=8933). Validity The data set was checked for errors, and seven categories of neoplasms records likely to be faulty were defined and identified for extensive study (n=109). Quality of data The second approach was to evaluate the quality of the corrected data. This was done by a random draw of 300 cases.	Validity In total, 86 cases were found to be registered with minor or major errors that were corrected. The main source of error was misinterpretation of data by cancer registry staff (67 out of 109 cases). Quality of data Errors concerning total incidence rates and rates for main groups of gliomas, meningiomas and neurilemmomas represented 0.3% of the total, and altogether 9.3% of errors of varying severity were revealed. The study concluded that the data in the Norwegian Cancer Registry was of sufficient validity.
Harvei et al, 1996 (59)	Prostate cancer	Completeness Internal validity	Completeness 1960, 1975 and 1981 Internal validity 1957-1986	Completeness Data were matched and evaluated against diagnostic indices at eight selected hospitals in Norway and against death certificates from Statistics Norway. Internal validity The validity control was based on detailed reanalysis of an approximately 1% sample of the registered data during the period 57-86.	Completeness The deficiency in reporting of prostate cancer was less than 1%. The completeness was found to improve with number of years following registration: 99% and close to 100% after 5 and 10 years, respectively. The completeness following 1 year of registration was 95%. Internal validity The validity control revealed errors in 0.5% of the data elements. One false positive case was found among 298 cases controlled (0.3%).

Reference	Site	Quality aspects	Study period	Methods	Main results and conclusions
Mork et al, 1995 (58)	Head and neck cancer	Consistency of classification and coding and basis of diagnosis Completeness	1953-1991	Consistency and basis of diagnosis All histological codes for (16 104) cases of head and neck malignancies were reviewed. A set of criteria for acceptable histological diagnosis were defined, and cases that did not meet the acceptance criteria were subjected to a re-evaluation of the pathologists' reports (369 cases). The percentage of cases not histologically verified or solely registered on the basis of death certificate was calculated for consecutive decades throughout the study period. Completeness Completeness was checked against hospital-based registries in two university clinics in Oslo.	Consistency and basis of diagnosis Of 16 104 cases, 369 (2.3%) fulfilled criteria for further scrutiny. No changes were made in 98.4% of the cases in the crude series. The level of erroneous coding was highest in the late sixties and the early seventies, and dropped to an all time low after 1980. Only 46 cases were registered solely on the basis of death certificates. The percentage of cases lacking microscopic confirmation dropped from 5.7% in 1953-1962 to 2.1% in 1983-1991. Completeness All patients in the hospital-based patient registry were also registered in the Cancer Registry. In addition, 44 patients treated in the hospitals, were found in the cancer registry and not in the hospital registry.
Tingulstad et al, 2002 (60)	Ovarian	Completeness Reproducibility of the histopathologic diagnosis	1987-1996	Completeness Re-ascertainment. Persons identified with ovarian cancer in the Cancer Registry or in the hospital's discharge registers were included in the study. Histological re-evaluation of 729 cases	Completeness The overall completeness for ovarian cancer was found to be 99.6%. The organ specific completeness of registration of histologic verified ovarian cancer within the Cancer Registry was 95.3%; 0.9% was erroneously coded and 3.5% had their diagnosis changed to ovarian cancer at re-evaluation. Histological re-evaluation In total 91% of the cases had a primary histologic diagnosis. The accuracy of the diagnosis for 591 cases identified with a histologic diagnosis was estimated at 92%. Coding errors were found in 2% of these cases, while in 6% of the cases it was not possible to reproduce the original diagnosis of ovarian cancer at re-evaluation.

overall incidence at specific points in time that would raise suspicion of a change in completeness of registration.

Incidence rates of childhood cancers

Table S3.1 shows the upper and lower deciles of age and sex specific incidence for childhood cancers for cancer registries worldwide (10) as compared to rates in Norway 2001-2005. In general, the Norwegian rates fall between the limits, with the exception of the incidence rate of 13.5 for Norwegian girls aged 5-9 years, given the upper decile in the reference group is 12.

Mortality Incidence ratios

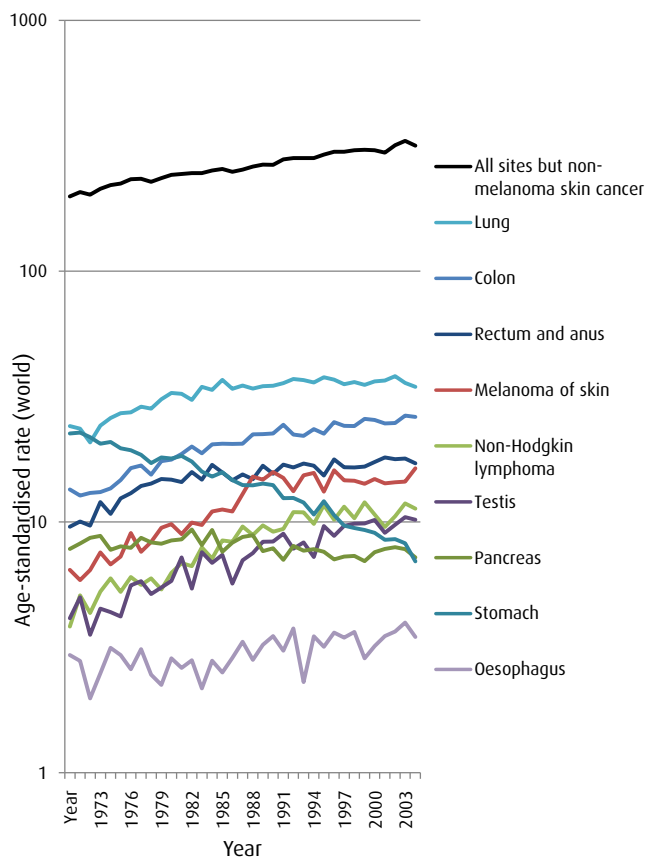
If the reporting of cause of death is completely accurate, and the incidence and survival rates are stable then

the $M:I \text{ ratio} = 1 - \text{overall survival}$. Table S3.3 shows the M:I ratio by site, for both sexes combined 2000-4. Cancers with poor survival rates are expected to have a M:I ratio close to 1, and the highest M:I ratios are seen for cancers of the pancreas (0.97), liver (0.89), oesophagus (0.89) and lung (0.85). The ICD-codes 'Uterus, other (C55)' has M:I ratios above 1, probably in part the result of inaccuracies in the reporting of ill-defined causes of death on the death certificates.

Figures S3.4 a and b shows the Norwegian M:I ratios vs. the 1-survival rates for the most common sites in males and females, respectively. Discrepancies between the two variables, were mostly in the direction of M:I ratios being higher than would be predicted. A possible reason for this may be inaccuracies in

Figure S3.3: Annual trends in age-standardised (world) incidence rates for all cancers combined, and for selected common cancers 1971-2005

a) MALES



b) FEMALES

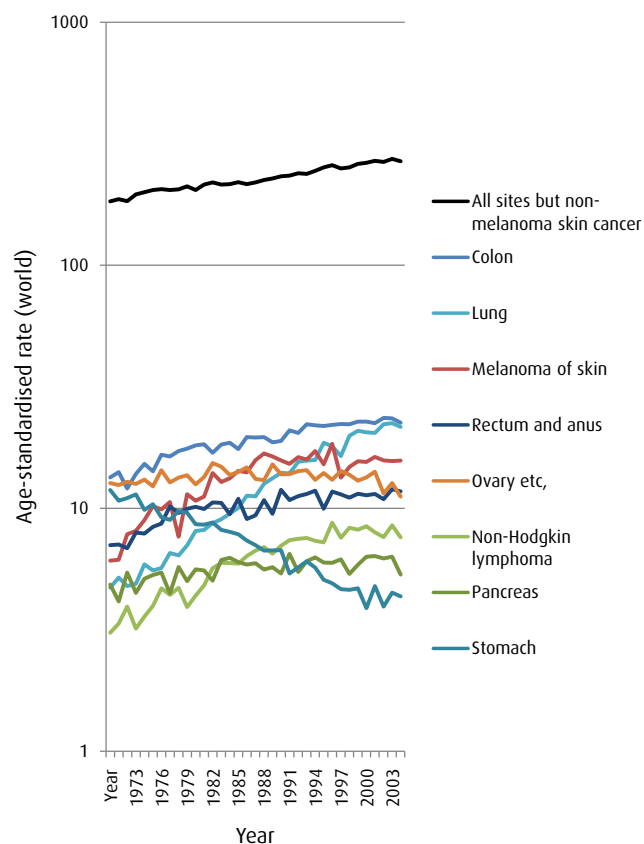
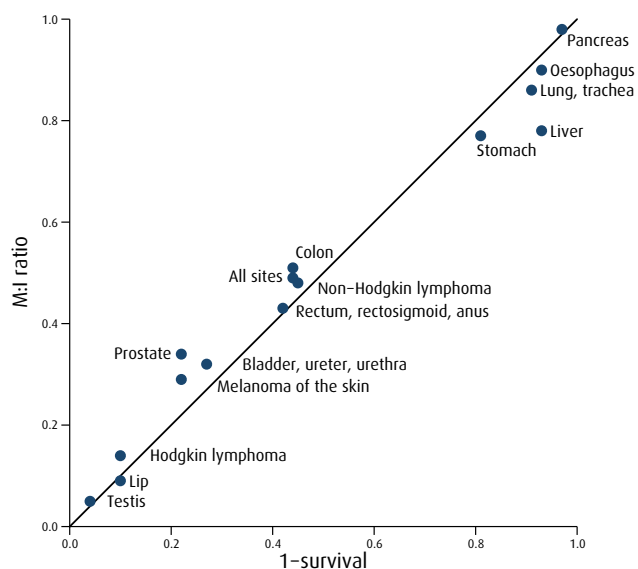


Figure S3.4: Mortality:Incidence ratio (2000-2004) vs. 1-survival (diagnoses 1996-2000), Norway

a) MALES



b) FEMALES

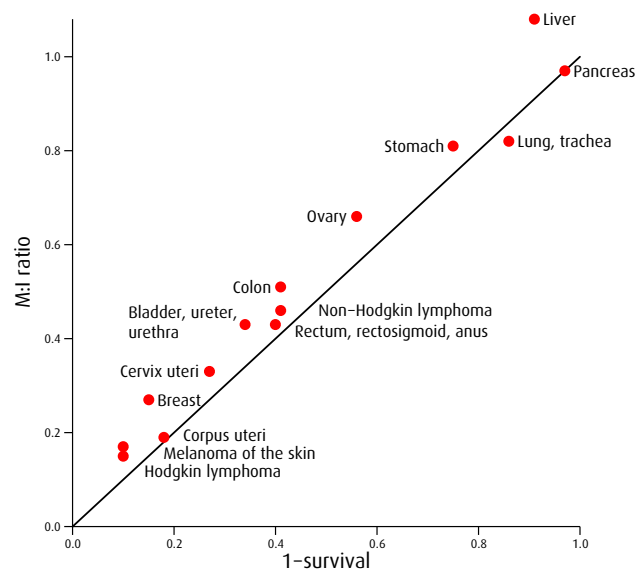


Table S3.3: Percentage morphologically verified (MV%), percentage obtained from death certificate only (%DCO), Norway 2001-2005, and the ratio of number of deaths to number of new cases (M:I ratio) 2000-2004

ICD10	Site	Cases	MV%	%DCO	M:I ratio
C00-96	All sites	118960	88.0	0.9	0.45
C00-14	Mouth, pharynx	1954	97.2	0.1	0.38
C00	Lip	373	99.7	0.0	0.08
C01-02	Tongue	389	97.9	0.0	0.40
C03-06	Mouth, other	404	99.8	0.0	0.50
C07-08	Salivary glands	199	88.4	0.0	0.32
C09-14	Pharynx	589	96.4	0.2	0.50
C15-26	Digestive organs	26204	88.3	1.2	0.60
C15	Oesophagus	935	93.7	1.4	0.89
C16	Stomach	2835	95.0	0.6	0.78
C17	Small intestine	510	95.1	0.0	0.44
C18	Colon	10956	94.8	0.7	0.51
C19-21	Rectum, rectosigmoid, anus	6057	97.1	0.4	0.43
C22	Liver	627	73.5	3.3	0.89
C23-24	Gallbladder, bile ducts	682	67.7	1.5	0.73
C25	Pancreas	3164	53.7	3.6	0.97
C26	Other digestive organs	438	47.3	11.4	0.46
C30-34, C38	Respiratory organs	12156	78.1	1.4	0.81
C30-31	Nose, sinuses	201	99.0	0.0	0.39
C32	Larynx, epiglottis	609	97.5	0.2	0.35
C33-34	Lung, trachea	11245	76.9	1.5	0.85
C38	Mediastinum, pleura	101	61.4	4.0	0.89
C40-41	Bone	216	96.8	0.5	0.49
C43	Melanoma of the skin	5256	99.1	0.2	0.23
C44	Skin, non-melanoma	6040	99.1	0.0	0.03
C45	Mesothelioma	360	89.7	0.0	0.69
C46	Kaposi's sarcoma	46	91.3	0.0	0.02
C47	Autonomic nervous system	47	95.7	0.0	0.23
C48-49	Soft tissues	625	94.9	0.0	0.56
C50	Breast	13701	97.2	0.2	0.27
C51-58	Female genital organs	7637	95.8	0.5	0.40
C53	Cervix uteri	1469	99.5	0.1	0.34
C54	Corpus uteri	3161	98.8	0.2	0.19
C55	Uterus, other	46	78.3	4.3	2.04
C56	Ovary	2276	90.4	0.8	0.67
C51-52, C57	Other female genital	665	94.9	2.0	0.45
C58	Placenta	20	45.0	0.0	0.06
C60-63	Male genital organs	18063	93.2	0.9	0.31
C61	Prostate	16563	92.7	0.9	0.33
C62	Testis	1280	99.1	0.2	0.05
C60, C63	Other male genital	220	97.7	0.9	0.17
C64-68	Urinary organs	9234	91.3	0.7	0.36
C64	Kidney excl. renal pelvis	2763	80.6	1.0	0.45
C65	Renal pelvis	340	94.4	0.0	0.33
C66-68	Bladder, ureter, urethra	6131	95.9	0.6	0.32
C69	Eye	308	49.7	0.3	0.22
C70-72	Central nervous system	4572	62.0	0.9	0.33
C73	Thyroid gland	1000	93.2	0.2	0.18
C37, C74-75	Other endocrine glands	120	80.0	2.5	0.64
C39, C76, C80	Other or unspecified	2616	52.3	5.9	1.07
C81-96	Lymphoid and haematopoietic tissue	8805	72.6	1.1	0.51
C81	Hodgkin lymphoma	561	98.6	0.2	0.14
C82-85, C96	Non-Hodgkin lymphoma	3665	96.6	0.3	0.46
C88	Malignant immunoproliferative diseases	221	54.3	2.3	0.37
C90	Multiple myeloma	1680	44.6	1.8	0.71
C91-95	Leukaemia	2678	53.5	2.0	0.57

the specified cause of death (5). For example, a study on cancer registration in US showed that deaths from cancers of the large bowel are over-reported as colon cancer, and under-reported as cancer of the rectum (61). The M:I ratio for liver cancer among females is above one (Figure S3.4a), and could relate to the increasing deaths from liver cancer among women (from 36 deaths in 2002 and 2003, up to 70 in 2004).

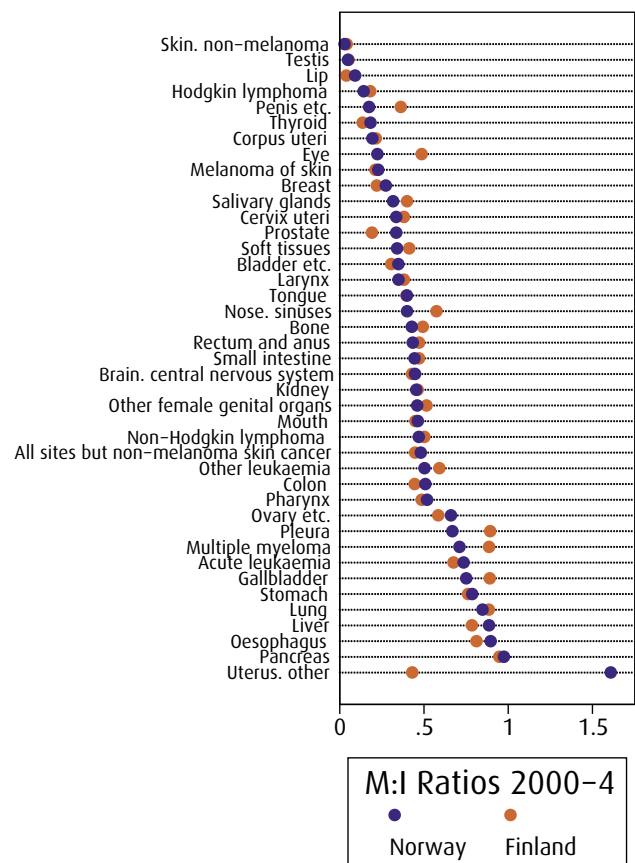
Figure S3.5 show the M:I ratios for all sites, 2000-2004 in Norway and Finland based on NORDCAN data (8). In general there is good concordance with the M:I ratios in Norway with those in Finland. Using the tests outlined in Appendix 9, 11 of the 34 sites showed some significant differences. Those cancers flagged as unusual were gallbladder, other leukaemia, multiple myeloma, pleura, melanoma of skin, penis etc., bladder etc., eye, lip, colon and prostate. As Figure S3.4 implied, reasons for the significant variations may include true differences in case fatality between the two countries; it is also worth nothing that the list also includes a number of “difficult” cancer sites, several associated with few deaths (lip, penis), and at least two which are heavily influenced by variations in diagnostic intensity or registration practices (prostate and bladder, respectively).

Figure S3.6 shows the M:I ratios for all cancers combined, on comparison with selected European registries for registrations diagnosed 1998-2002, as part of the compilation of CI5 Volume IX (11); the M:I ratios of 52.3% and 49.1% for males and females respectively are not representative of extreme observations in the European context, being close to a number of registries known to have high levels of completeness.

Number of sources/notifications per case

Table S3.4 shows the average number of notifications and sources per case, by site and year (2001-2005). The average numbers of notifications and sources per case are lowest in 2005. For the period between 2001 and 2005, 32% (Figure S3.7) of the cases was registered with two notifications per case. The most common combination of sources was one clinical and one pathological notification. Figure S3.8 shows that about 70% of the cases diagnosed in this period were registered on the basis of information from these two sources. The decline in the delay time between registration and reporting (see Chapter 5) is a likely explanation for the increase of cases registered and reported on the basis of pathological notifications only; the clinical notifications usually have, in relative terms, the longest reporting time lag of the three sources.

Figure S3.5 Comparisons of M:I ratios by cancer site, Norway vs. Finland, 2000-2004



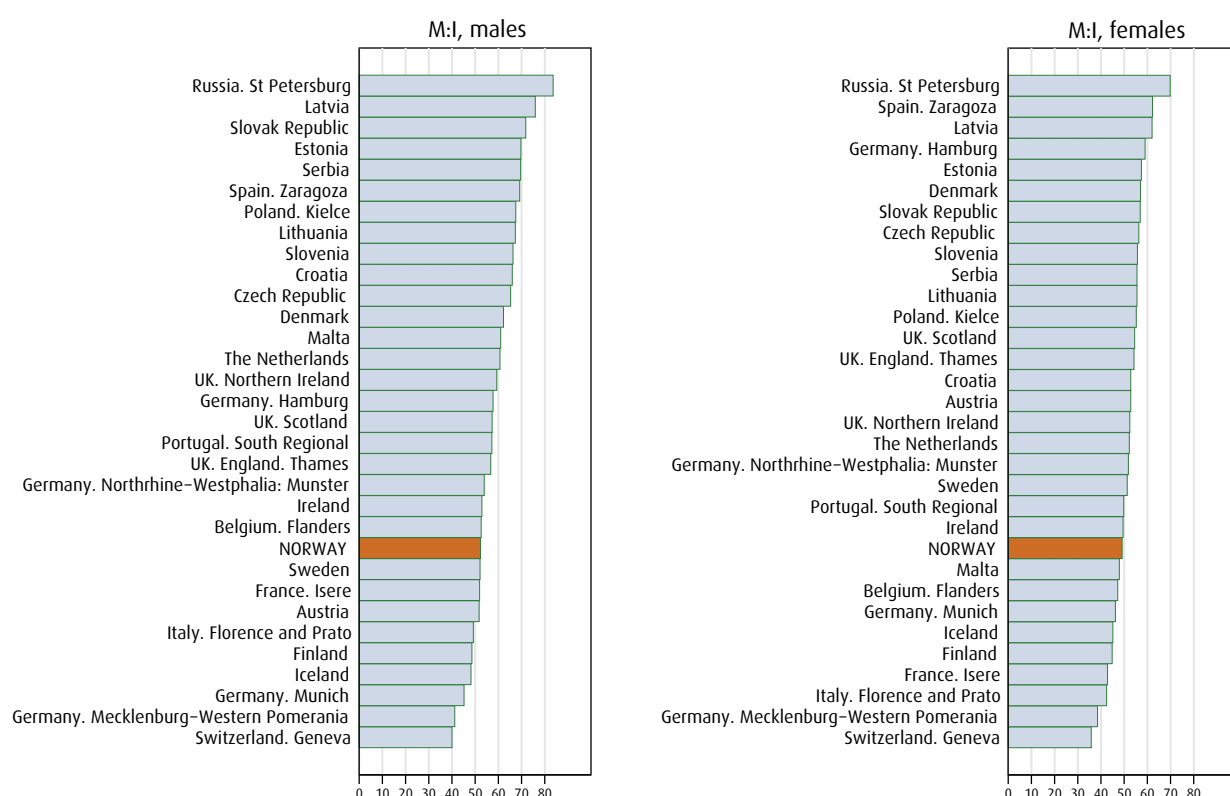
3.5.2 Quantitative analyses of completeness

Capture-Recapture using three primary sources, registrations 2001-5

Degree of ascertainment is estimated here by examining the numbers obtained from two complementary sources for patients notified by clinicians, pathologist and death certificates during the registration period 2001-5. Table S3.7 illustrates for each cancer site, the number of cases, the estimated completeness, the percentage of maximum dependency between reports from two sources, and whether that dependency is positive or negative. The completeness estimates are in essence therefore two-source estimates that one derives on ignoring information from one of the sources.

The percentage of maximum dependency indicates the degree to which being registered by one source is associated with the likelihood of being registered with the other, with lower values implying a lack of dependence and increasingly higher values a greater degree of dependency between sources. Predicting the likely direction of any dependency of two sources in the entire population helps determine if the two-source capture-recapture estimate is likely to be plausible or an under- or overestimate of the true total number of

Figure S3.6 Mortality:Incidence (M:I) ratio: comparison with selected European registries for diagnoses 1998-2002 (source: (11))



cases (45). *Positive* dependence between two sources indicates that the probability of being registered by one source tends to increase the likelihood of being registered with the other, leading to an underestimate of the true number of cases and an overestimate of completeness; conversely, *negative* dependence overestimates the true number of cases, leading to underestimation of completeness.

The vast majority of patients diagnosed 2001-5 in Norway were registered by clinicians and/or pathology. The overall estimate of completeness for notifications from pathology and death sources for cases notified by clinicians was 93.2%. For most cancers, completeness was estimated at greater than 95% but for lung cancer it was slightly lower (93.2%), and lower still for a number of cancers associated with poorer survival including cancers of the liver (86.5%), pancreas (79.9%), and multiple myeloma (56.7%). The relatively high negative dependencies between pathology and death sources may reflect that pathology reports are less frequently available for cancers with a generally poor prognosis, and the completeness of notifications by these sources may be underestimated.

For cases notified by pathology, completeness of notifications from the other two sources was estimated

as 91.4%. The dependencies were mainly (weakly) positive between notifications by clinicians and death certificates, probably as a result of an increased likelihood that patients who eventually die from their cancer would be more likely to have contact with clinicians than other patients. Finally, completeness for cases notified by the death certificate was 93.1%. For most cancers, the dependence between notifications from clinicians and pathologists was positive possible due to the fact that patient who are treated are more likely to be reported by both pathologists and clinicians. An exception was breast cancer where the dependency was negative between these sources; this might be due to the fact that those records that included a request for additional information from the clinicians who completed the death certificates would not have had notifications previously via pathologists.

Finally, estimates of overall completeness are provided in Table S3.8 by correcting for the known dependencies between the sources (Table S3.7). The method involves combining two sources where dependence is suspected to a single group, and comparing this aggregated source with the third source. After correction for the greatest dependence among the three sources of information, the estimates of completeness at the Re-

Table S3.4: Mean number of notifications and sources per case by cancer and year of registration, Norway 2001-05

ICD-10	Site	Type	Year of diagnosis				
			2001	2002	2003	2004	2005
C00-96	All sites	Tumours	22577	22920	23887	24914	24751
		Notifications	74441	76883	77679	81979	74895
		Notifications per case	3.2	3.3	3.2	3.2	3.0
		Sources per case	1.9	1.9	1.9	1.9	1.8
C00-14	Mouth. pharynx	Tumours	380	389	376	389	419
		Notifications	1586	1819	1737	1744	1670
		Notifications per case	4.1	4.6	4.6	4.4	3.9
		Sources per case	2.0	2.0	2.0	2.0	1.8
C00	Lip	Tumours	82	87	61	58	85
		Notifications	253	331	223	216	294
		Notifications per case	3.0	3.8	3.6	3.7	3.4
		Sources per case	1.9	1.9	1.9	1.8	1.7
C01-02	Tongue	Tumours	78	77	77	81	76
		Notifications	374	436	359	374	316
		Notifications per case	4.7	5.6	4.6	4.6	4.1
		Sources per case	2.1	2.0	2.0	2.0	1.7
C03-06	Mouth. other	Tumours	71	80	81	92	80
		Notifications	344	399	417	389	347
		Notifications per case	4.8	4.9	5.1	4.2	4.3
		Sources per case	2.1	2.0	2.0	2.0	1.8
C07-08	Salivary glands	Tumours	45	40	36	28	50
		Notifications	174	173	156	130	175
		Notifications per case	3.8	4.3	4.3	4.6	3.5
		Sources per case	2.0	1.9	2.0	2.0	1.7
C09-14	Pharynx	Tumours	104	105	121	130	128
		Notifications	441	480	582	635	538
		Notifications per case	4.2	4.5	4.8	4.8	4.2
		Sources per case	2.1	2.1	2.0	2.1	1.8
C15-26	Digestive organs	Tumours	5131	5174	5230	5341	5313
		Notifications	15465	15662	15621	16304	14424
		Notifications per case	3.0	3.0	2.9	3.0	2.7
		Sources per case	2.0	2.0	2.0	2.1	1.9
C15	Oesophagus	Tumours	172	170	192	203	197
		Notifications	592	588	656	733	582
		Notifications per case	3.4	3.4	3.4	3.6	2.9
		Sources per case	2.2	2.1	2.1	2.3	2.0
C16	Stomach	Tumours	578	589	568	567	531
		Notifications	1900	1957	1864	1896	1605
		Notifications per case	3.2	3.3	3.2	3.3	3.0
		Sources per case	2.2	2.1	2.1	2.2	2.0
C17	Small intestine	Tumours	113	107	105	94	91
		Notifications	330	344	338	289	229
		Notifications per case	2.9	3.2	3.2	3.0	2.5
		Sources per case	2.0	2.0	1.9	2.0	1.8
C18	Colon	Tumours	2134	2106	2216	2249	2249
		Notifications	6198	6094	6392	6576	5974
		Notifications per case	2.9	2.8	2.8	2.9	2.6
		Sources per case	2.0	2.0	2.0	2.0	1.9

ICD-10	Site	Type	2001	2002	2003	2004	2005
C19-21	Rectum, rectosigmoid, anus	Tumours	1148	1206	1185	1262	1250
		Notifications	4076	4276	4137	4276	3706
		Notifications per case	3.5	3.5	3.4	3.3	2.9
		Sources per case	2.0	2.0	2.0	2.0	1.8
C22	Liver	Tumours	127	127	115	122	136
		Notifications	330	338	293	311	335
		Notifications per case	2.5	2.6	2.5	2.5	2.4
		Sources per case	2.1	2.0	1.9	2.1	1.9
C23-24	Gallbladder, bile ducts	Tumours	132	132	139	132	146
		Notifications	373	352	391	396	347
		Notifications per case	2.8	2.6	2.8	3.0	2.3
		Sources per case	2.0	1.9	2.0	2.0	1.8
C25	Pancreas	Tumours	633	657	628	627	616
		Notifications	1467	1505	1359	1620	1405
		Notifications per case	2.3	2.2	2.1	2.5	2.2
		Sources per case	1.9	1.8	1.8	2.1	1.9
C26	Other digestive organs	Tumours	94	80	82	85	97
		Notifications	199	208	191	207	241
		Notifications per case	2.1	2.6	2.3	2.4	2.4
		Sources per case	1.9	1.8	1.7	1.6	1.9
C30-34, C38	Respiratory organs	Tumours	2332	2355	2491	2486	2481
		Notifications	7823	7926	8221	8855	8034
		Notifications per case	3.3	3.3	3.3	3.5	3.2
		Sources per case	2.0	2.0	2.0	2.2	2.1
C30-31	Nose, sinuses	Tumours	38	43	27	54	39
		Notifications	185	224	125	261	157
		Notifications per case	4.8	5.2	4.6	4.8	4.0
		Sources per case	2.0	2.0	2.0	2.1	1.9
C32	Larynx, epiglottis	Tumours	142	133	111	111	112
		Notifications	595	580	521	484	389
		Notifications per case	4.1	4.3	4.6	4.3	3.4
		Sources per case	2.0	2.0	2.0	2.0	1.8
C33-34	Lung, trachea	Tumours	2128	2163	2333	2299	2312
		Notifications	6968	7080	7501	8026	7434
		Notifications per case	3.2	3.2	3.2	3.4	3.2
		Sources per case	2.0	2.0	2.0	2.2	2.1
C38	Mediastinum, pleura	Tumours	24	16	20	22	18
		Notifications	75	42	74	84	54
		Notifications per case	3.1	2.6	3.7	3.8	3.0
		Sources per case	1.9	1.6	2.1	2.5	1.9
C40-41	Bone	Tumours	43	48	40	43	42
		Notifications	205	253	194	231	167
		Notifications per case	4.7	5.2	4.8	5.3	3.9
		Sources per case	2.0	1.9	2.1	2.1	1.8
C43	Melanoma of the skin	Tumours	1014	1026	1025	1039	1151
		Notifications	3347	3374	3196	3113	2986
		Notifications per case	3.3	3.2	3.1	2.9	2.5
		Sources per case	1.9	1.9	1.8	1.8	1.6
C44	Skin, non-melanoma	Tumours	1063	1171	1210	1260	1336
		Notifications	2557	2672	2807	2970	2826
		Notifications per case	2.4	2.2	2.3	2.3	2.1
		Sources per case	1.7	1.5	1.6	1.6	1.5

ICD-10	Site	Type	2001	2002	2003	2004	2005
C45	Mesothelioma	Tumours	66	59	75	82	78
		Notifications	207	241	309	353	264
		Notifications per case	3.1	4.0	4.1	4.3	3.3
		Sources per case	2.1	2.3	2.4	2.4	2.1
C46	Kaposi's sarkoma	Tumours	6	9	8	12	11
		Notifications	14	31	14	26	26
		Notifications per case	2.3	3.4	1.7	2.1	2.3
		Sources per case	1.8	2.1	1.5	1.7	1.5
C47	Autonomic nervous system	Tumours	9	9	10	9	10
		Notifications	40	50	52	41	34
		Notifications per case	4.4	5.5	5.2	4.5	3.4
		Sources per case	2.3	2.0	2.1	2.0	2.0
C48-49	Soft tissues	Tumours	118	120	118	139	130
		Notifications	584	616	554	627	524
		Notifications per case	4.9	5.1	4.6	4.5	4.0
		Sources per case	2.1	2.0	2.0	2.0	1.9
C50	Breast	Tumours	2634	2708	2743	2800	2816
		Notifications	11175	12082	11875	12539	12156
		Notifications per case	4.2	4.4	4.3	4.4	4.3
		Sources per case	1.9	1.9	1.9	1.9	1.8
C51-58	Female genital organs	Tumours	1495	1530	1488	1562	1552
		Notifications	7655	7920	7531	7735	7272
		Notifications per case	5.1	5.1	5.0	4.9	4.6
		Sources per case	2.0	2.0	2.0	2.0	1.9
C53	Cervix uteri	Tumours	300	308	296	268	297
		Notifications	1800	1761	1906	1623	1682
		Notifications per case	6.0	5.7	6.4	6.0	5.6
		Sources per case	2.0	1.9	2.0	1.9	1.9
C54	Corpus uteri	Tumours	593	588	626	684	669
		Notifications	2811	2711	2916	3313	3113
		Notifications per case	4.7	4.6	4.6	4.8	4.6
		Sources per case	2.0	2.0	2.0	1.9	1.9
C55	Uterus, other	Tumours	6	11	13	9	7
		Notifications	14	33	52	23	21
		Notifications per case	2.3	3.0	4.0	2.5	3.0
		Sources per case	2.0	1.9	1.8	2.2	1.7
C56	Ovary	Tumours	450	515	423	459	423
		Notifications	2228	2845	1932	2137	1842
		Notifications per case	4.9	5.5	4.5	4.6	4.3
		Sources per case	2.1	2.0	2.1	2.1	2.0
C51-52, C57	Other female genital	Tumours	143	105	126	138	150
		Notifications	794	564	707	625	602
		Notifications per case	5.5	5.3	5.6	4.5	4.0
		Sources per case	2.0	2.0	2.0	1.9	1.8
C58	Placenta	Tumours	3	3	4	4	6
		Notifications	8	6	18	14	12
		Notifications per case	2.6	2.0	4.5	3.5	2.0
		Sources per case	1.6	1.3	1.7	1.5	1.3
C60-63	Male genital organs	Tumours	3198	3042	3711	4139	3969
		Notifications	8463	7993	9551	10892	10136
		Notifications per case	2.6	2.6	2.5	2.6	2.5
		Sources per case	1.9	1.9	1.9	1.9	1.9

ICD-10	Site	Type	2001	2002	2003	2004	2005
C61	Prostate	Tumours	2899	2765	3403	3828	3664
		Notifications	7466	7108	8544	9878	9207
		Notifications per case	2.5	2.5	2.5	2.5	2.5
		Sources per case	1.9	1.9	1.9	1.9	1.9
C62	Testis	Tumours	268	237	255	265	255
		Notifications	871	698	780	829	719
		Notifications per case	3.2	2.9	3.0	3.1	2.8
		Sources per case	1.9	1.9	1.9	1.9	1.8
C60, C63	Other male genital	Tumours	31	40	53	46	50
		Notifications	126	187	227	185	210
		Notifications per case	4.0	4.6	4.2	4.0	4.2
		Sources per case	1.9	2.0	1.9	1.9	1.7
C64-68	Urinary organs	Tumours	1723	1865	1841	2029	1913
		Notifications	5482	5981	5703	6082	4908
		Notifications per case	3.1	3.2	3.0	2.9	2.5
		Sources per case	1.9	1.9	1.9	1.9	1.8
C64	Kidney	Tumours	507	540	536	598	580
		Notifications	1205	1313	1316	1423	1198
		Notifications per case	2.3	2.4	2.4	2.3	2.0
		Sources per case	1.9	1.9	1.9	1.9	1.7
C65	Renal pelvis	Tumours	66	70	68	85	51
		Notifications	183	189	193	277	142
		Notifications per case	2.7	2.7	2.8	3.2	2.7
		Sources per case	2.0	2.0	2.0	2.0	1.8
C66-68	Bladder, ureter, urethra	Tumours	1150	1255	1237	1346	1282
		Notifications	4094	4479	4194	4382	3568
		Notifications per case	3.5	3.5	3.3	3.2	2.7
		Sources per case	2.0	1.9	1.9	1.9	1.8
C69	Eye	Tumours	51	65	74	68	50
		Notifications	137	162	198	146	111
		Notifications per case	2.6	2.4	2.6	2.1	2.2
		Sources per case	1.8	1.7	1.7	1.7	1.4
C70-72	Central nervous system	Tumours	849	887	932	954	950
		Notifications	1914	2014	2010	2049	1939
		Notifications per case	2.2	2.2	2.1	2.1	2.0
		Sources per case	1.7	1.6	1.6	1.6	1.6
C73	Thyroid gland	Tumours	181	192	182	218	227
		Notifications	655	685	713	782	774
		Notifications per case	3.6	3.5	3.9	3.5	3.4
		Sources per case	1.9	1.9	1.9	1.8	1.7
C37, C74-75	Other endocrine glands	Tumours	18	25	29	23	23
		Notifications	82	77	78	92	99
		Notifications per case	4.5	3.0	2.6	4.0	4.3
		Sources per case	2.0	1.8	1.8	1.9	1.9
C39, C76, C80	Other or unspecified	Tumours	521	544	558	495	496
		Notifications	1313	1312	1269	1274	1239
		Notifications per case	2.5	2.4	2.2	2.5	2.4
		Sources per case	2.0	1.8	1.7	1.9	1.9
C81-96	Lymphoid and haematopoietic tissue	Tumours	1745	1702	1746	1826	1784
		Notifications	5737	6013	6046	6124	5306
		Notifications per case	3.2	3.5	3.4	3.3	2.9

ICD-10	Site	Type	2001	2002	2003	2004	2005
		Sources per case	1.8	1.9	1.8	1.8	1.7
C81	Hodgkin lymphoma	Tumours	87	97	141	121	115
		Notifications	321	380	577	441	416
		Notifications per case	3.6	3.9	4.0	3.6	3.6
		Sources per case	2.0	2.0	2.0	1.9	1.8
C82-85, C96	Non-Hodgkin lymphoma	Tumours	694	690	719	785	775
		Notifications	3085	3288	3275	3410	2929
		Notifications per case	4.4	4.7	4.5	4.3	3.7
		Sources per case	2.1	2.1	2.0	2.0	1.8
C88	Malignant immunoproliferative diseases	Tumours	43	49	47	47	35
		Notifications	98	114	102	92	74
		Notifications per case	2.2	2.3	2.1	1.9	2.1
		Sources per case	1.5	1.7	1.6	1.5	1.7
C90	Multiple myeloma	Tumours	354	328	316	323	359
		Notifications	783	748	679	698	705
		Notifications per case	2.2	2.2	2.1	2.1	1.9
		Sources per case	1.6	1.6	1.6	1.6	1.5
C91-95	Leukemia	Tumours	567	538	523	550	500
		Notifications	1450	1483	1413	1483	1182
		Notifications per case	2.5	2.7	2.7	2.6	2.3
		Sources per case	1.7	1.8	1.7	1.8	1.6

Figure S3.7: Percentage of cases registered according to number of notifications received at the Registry, Norway 2001-2005

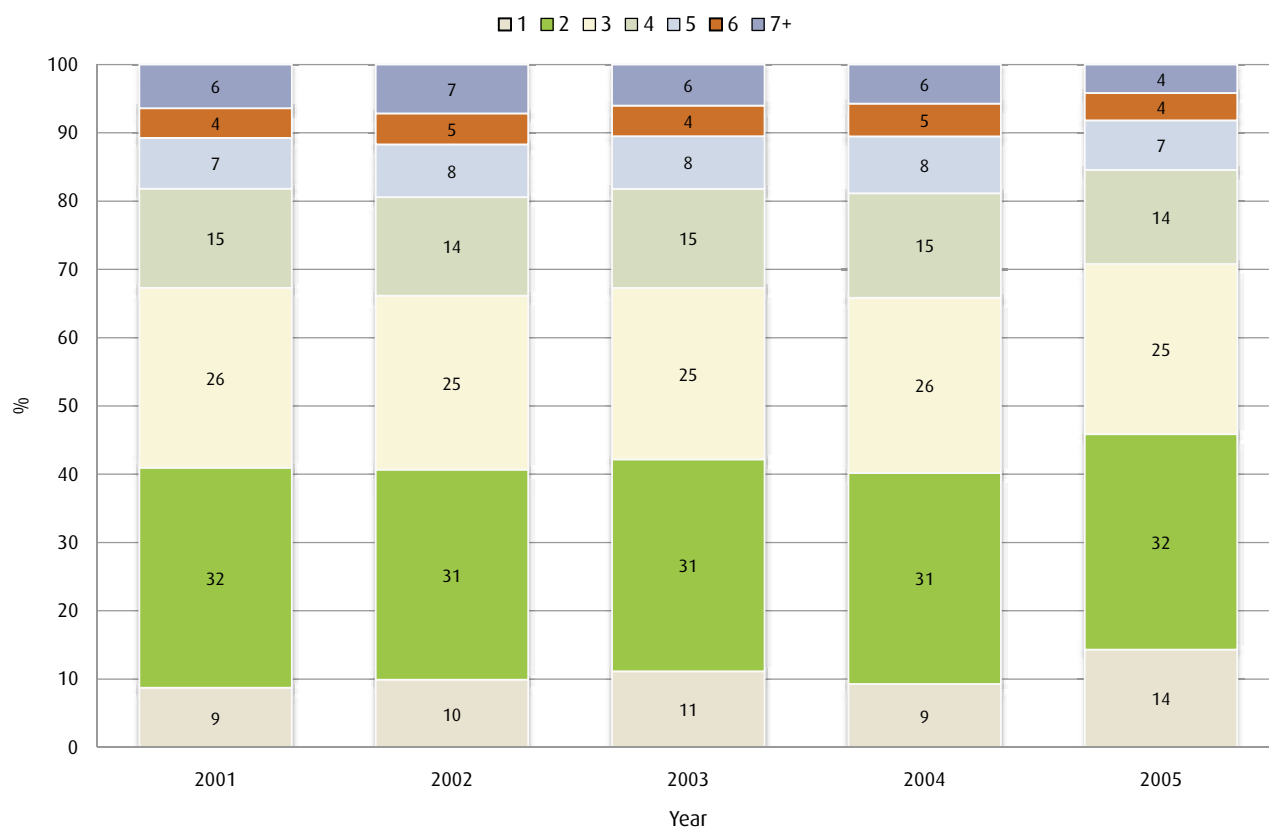
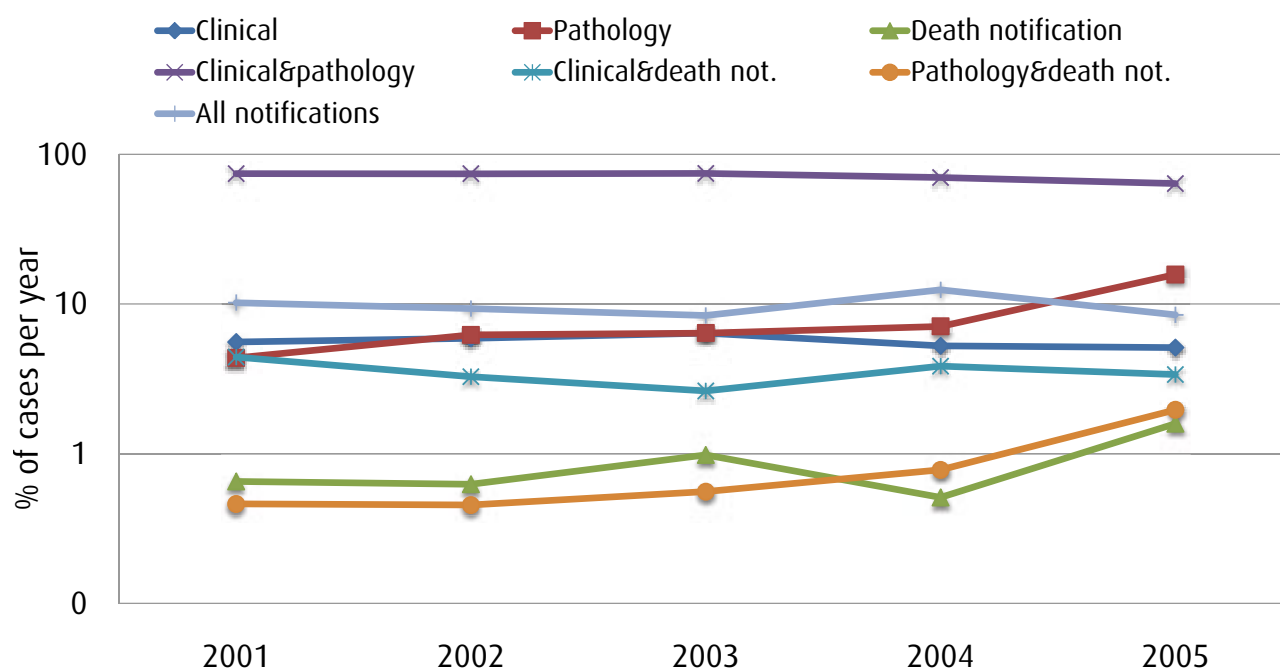


Figure S3.8: Percentage of annual cases registered with information from one, two, or three sources, Norway 2001-2005



gistry for the period 2001-5 was 99.7% for all cancers combined. These estimates on merging sources were mainly permissible as a result of the reasonably negative dependencies of the clinical records on comparing the other two sources and equivalent positive dependencies for two source dependencies for all death certificates and pathology records, respectively. They must however be interpreted with some caution; the method, for example, accounts neither for three-source dependencies nor variable catchability between sources.

On this basis, and with the exception of lung cancer, completeness estimates for 2001-5 were extremely high for the most common cancers, and ranged from 99.8% to 100% for cancer of the bladder, colon and rectum, lung, breast and prostate and melanoma of the skin. The completeness was lower for cancers with the poorest prognosis, and those for which the Registry was particularly reliant on death certificates as a sources of information. This included cancers of the lung (97.7%), multiple myeloma (97.2%) and pancreas (97.3%). The lowest estimate of completeness was observed for cancers of the central nervous system, for which ascertainment was estimated at 93.0% for the period 2001-5. The completeness of leukaemia regis-

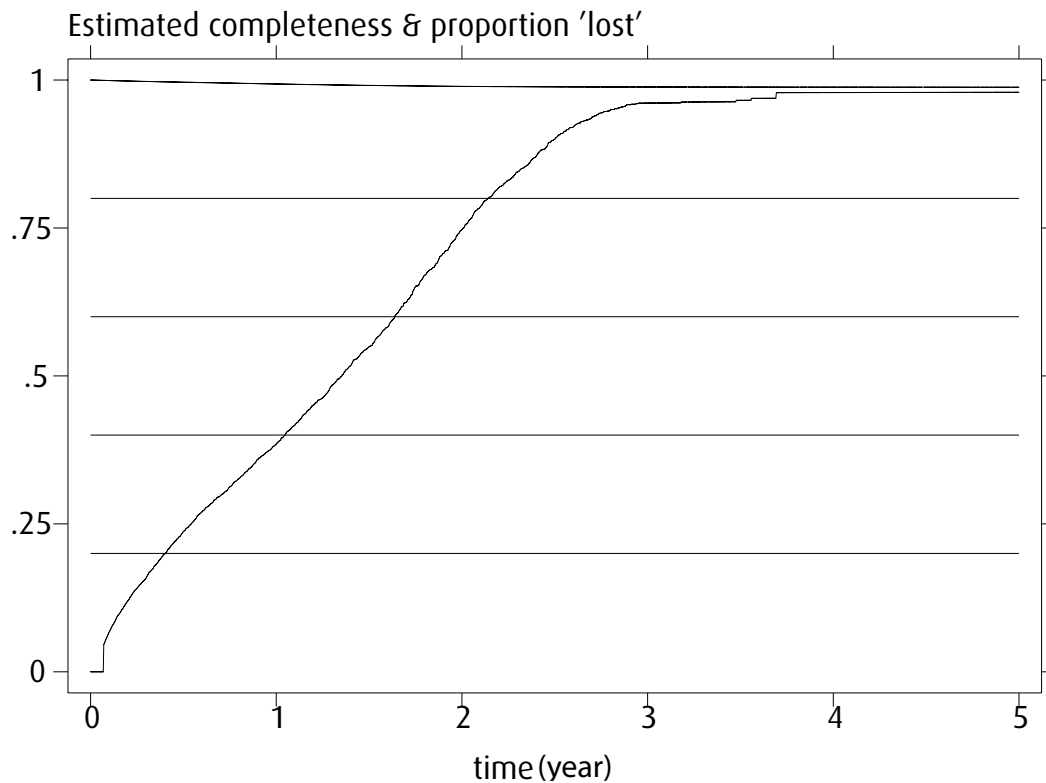
trations was also considered to be somewhat lower (97.1%).

"Flow" Method: completeness registered 1999

This method estimates completeness by deriving the proportion of unregistered patients from the time distribution of three probabilities (the probability of survival, of registration of the cancer during a patient's life, and of the mention of cancer on the death certificate of a cancer patient who dies), each of which can be directly estimated from the Registry's data. The advantage of this method is that it shows how the completeness of registration of cancer patients diagnosed in a given year increases with time since diagnosis. A limitation is necessity to focus on completeness in earlier years; one can only estimate completeness where there is follow-up of vital status. Here completeness is examined in Table S3.8 for cases diagnosed in the year 1999 and whom were followed up until 31.12.2004.

Overall, completeness was low for the first and second year for cancers diagnosed at the Registry in 1999 but the figure increased to well over 95% during the third year (Figure S3.9). Four years after the year of diagnosis, the Registry can be considered almost complete, with an estimate of completeness of all sites combined of 98.0% for 1997 (data not shown) and 99.2% for 1999. The increase in completeness is likely

Figure S3.9: Completeness of ascertainment and proportion of "lost" according to time since diagnosis, all cancer sites combined, Norway 1999



to be related to the information on new cases received from the PAD-system. The delay in achieving close-to-complete ascertainment is expected to radically change for diagnoses 2005 and onwards (see Chapter 5); the median number of days between the diagnosis and registration of males fell from 401 days in 2004 to 237

days in 2005, and for females, from 469 days in 2004 to 287 days by 2005 (see Chapter 5). We eagerly await cause of death data up to and including 2006 to apply this method and estimate completeness of cancers diagnosed at the Registry in 2005.

Table S3.7: Capture/recapture estimation of missing cases according to three data sources, Norway 2001-5

Site	Clinical records: death certificate vs. pathology				Pathology records: clinical vs. death certificate				Death certificate records: clinical vs. pathology			
	No.of cases	%	% max. dep.	Dep.	No.of cases	%	% max. dep.	Dep.	No.of cases	%	% max. dep.	Dep.
All sites	103644	93.0	27.5	-	99552	93.1	0.4	+	17786	93.1	11.2	+
Lip	331	99.4	>0.1	+	371	88.7	0.4	+	10	100.0	*	*
Tongue	348	98.6	0.3	+	384	90.1	1.0	+	55	100.0	*	*
Mouth, other	360	100.0	100.0	-	401	90.0	0.4	+	51	100.0	100.0	-
Salivary glands	172	99.4	45.2	-	197	87.8	0.4	-	18	100.0	100.0	-
Pharynx	539	99.1	34.2	-	577	93.6	0.6	-	95	98.9	9.5	+
Oesophagus	841	97.4	35.5	-	867	94.3	0.7	-	308	95.5	23.1	+
Stomach	2601	97.7	38.9	-	2668	94.4	0.0	+	837	98.0	9.7	+
Small intestine	452	95.1	10.7	-	472	91.1	0.0	+	77	97.4	11.9	+
Colon	10188	97.0	41.4	-	10238	94.2	0.1	+	1653	95.5	12.0	+
Rectum	5570	98.5	40.1	-	5850	93.0	0.3	+	759	96.4	19.1	+
Liver	540	86.5	21.4	-	431	93.5	0.0	+	250	88.8	11.6	+
Gallbladder, bile duct	615	82.6	17.7	-	463	91.4	1.2	+	248	94.8	1.9	+
Pancreas	2877	79.9	17.4	-	1762	95.3	0.7	-	1462	91.5	3.1	+
Other digestive organs	318	89.0	41.8	-	258	76.0	11.5	+	229	79.0	11.2	+
Nose, sinuses	187	97.9	0.4	+	197	93.4	0.6	+	28	100.0	*	+
Larynx, epiglottis	559	97.9	11.3	-	592	92.9	0.3	-	62	98.4	15.5	+
Lung, trachea	10505	93.2	30.6	-	9498	96.9	0.6	-	3501	94.7	10.7	+
Mediastinum, pleura	92	83.7	8.5	-	66	95.5	3.1	+	44	90.9	14.4	+
Melanoma of the skin	4294	98.7	14.5	-	5174	82.1	0.6	+	296	97.6	16.7	+
Mesothelioma	334	97.0	43.5	-	325	96.0	0.0	+	147	98.6	24.7	+
Kaposi's sarcoma	31	90.3	1.6	-	42	69.0	2.7	+	6	83.3	2.5	+
Autonomic nervous system	47	93.6	1.0	+	44	100.0	0.0	+	6	100.0	*	*
Soft tissues	561	97.5	25.1	-	602	90.4	>0.1	+	111	100.0	100.0	-
Breast	12514	99.4	45.3	-	13526	91.8	1.1	+	687	96.7	15.9	+
Cervix uteri	1361	99.6	8.7	-	1459	93.0	0.0	+	87	98.9	47.6	+
Corpus uteri	2994	99.4	56.8	-	3109	95.1	0.2	+	200	97.0	15.1	+
Uterus	35	91.4	40.3	-	35	80.0	5.3	+	17	82.4	18.3	+
Ovary	2220	97.2	40.8	-	2122	98.9	0.1	+	384	94.5	20.0	+
Other female genitals	578	98.4	45.6	-	630	88.9	1.3	+	89	85.4	48.4	+
Placenta	20	50.0	0.0	-	10	100.0	>0.1	+	0	*	*	*
Prostate	15613	95.6	26.5	-	15279	95.9	>0.1	+	1281	86.3	23.4	+
Testis	1234	97.7	2.7	-	1247	96.6	>0.1	+	14	71.4	72.0	+
other male genitals	189	98.4	0.1	+	213	87.8	0.5	+	16	87.5	100.0	+
Kidney	2756	90.3	31.3	-	2504	92.0	0.4	+	510	89.4	9.6	+
Bladder, ureter, urethra	5578	96.9	28.2	-	5957	89.8	0.3	+	624	93.8	19.4	+
Eye	300	67.3	1.9	+	208	97.6	0.8	-	16	100.0	100.0	-
Central nervous system	4433	62.6	2.6	-	2571	98.4	>0.1	-	545	89.2	8.4	+
Thyroid gland	864	98.0	15.1	-	945	89.6	>0.1	+	52	84.6	56.7	+
Other endocrine glands	101	90.1	35.2	-	94	88.3	0.6	+	25	80.0	15.4	+
Other or unspecified	2181	83.5	24.6	-	1552	88.0	2.2	+	1253	87.3	5.1	+
Hodgkin lymphoma	528	98.9	29.6	-	550	94.7	0.1	+	31	96.8	17.0	+
Non-Hodgkin lymphoma	3286	97.9	31.7	-	3512	91.1	0.6	-	602	97.2	16.8	+
Malignant immunopr. diseases	215	61.9	3.8	-	122	99.2	0.1	+	25	80.0	11.8	+
Multiple myeloma	1569	56.7	3.9	-	730	90.1	1.3	+	398	92.5	2.0	+
Leukaemia	2519	68.1	8.1	-	1488	94.2	0.0	-	647	92.3	2.7	+
Bone	194	99.0	53.5	-	210	91.0	0.4	-	30	96.7	16.7	+

*No estimation as little or no data

Table S3.8: Completeness of ascertainment according to time since diagnosis, by cancer site, Norway 1999

	True number of cases	1	2	3	% completeness ⁴
All sites	111249	-	+	+	99.7
Lip	346	+	+	.	*
Tongue	397	+	+	.	*
Mouth, other	407	-	+	-	99.9
Salivary glands	198	-	-	-	*
Pharynx	582	-	-	+	100.0
Oesophagus	892	-	-	+	99.7
Stomach	2811	-	+	+	99.9
Small intestine	423	-	+	+	99.7
Colon	10578	-	+	+	99.9
Rectum	5855	-	+	+	99.9
Liver	602	-	+	+	98.8
Gallbladder, bile duct	677	-	+	+	98.8
Pancreas	3107	-	-	+	97.3
Other digestive organs	412	-	+	+	98.1
Nose, sinuses	190	+	+	+	*
Larynx, epiglottis	601	-	-	+	100.0
Lung, trachea	10880	-	-	+	97.7
Mediastinum, pleura	97	-	+	+	99.7
Melanoma of the skin	5176	-	+	+	99.8
Mesothelioma	329	-	+	+	99.9
Kaposi's sarcoma	48	-	+	+	98.6
Autonomic nervous system	51	+	+	*	*
Soft tissues	617	-	+	-	100.0
Breast	14594	-	+	+	100.0
Cervix uteri	1655	-	+	+	100.0
Corpus uteri	3089	-	+	+	100.0
Uterus	42	-	+	+	98.2
Ovary	2321	-	+	+	100.0
Other female genitals	582	-	+	+	99.8
Placenta	22	-	+	*	*
Prostate	16509	-	+	+	99.8
Testis	1494	-	+	+	100.0
other male genitals	193	+	+	+	*
Kidney	2782	-	+	+	99.4
Bladder, ureter, urethra	5282	-	+	+	99.8
Eye	298	+	-	-	99.7
Central nervous system	4510	-	-	+	93.0
Thyroid gland	1036	-	+	+	99.8
Other endocrine glands	128	-	+	+	99.3
Other or unspecified	2524	-	+	+	98.6
Hodgkin lymphoma	641	-	+	+	100.0
Non-Hodgkin lymphoma	3605	-	-	+	98.5
Malignant immunopr. diseases	198	-	+	+	99.1
Multiple myeloma	1624	-	+	+	97.2
Leukaemia	2619	-	-	+	97.1
Bone	225	-	-	+	96.4

1 Direction of dependency between pathology and death certificate sources for all clinical records.

2 Direction of dependency between clinical and death certificates sources for all pathology records.

3 Direction of dependency between clinical and pathology sources for all death certificates.

4 Shading indicates which of the two sources were merged; those with the same-direction dependencies were collapsed to a single group and were then compared with the third source to obtain estimates of completeness based on a two-source capture-recapture analysis (Brenner et al, 1995)

* Lip, tongue, autonomic nervous system and placenta: no estimate of dependency for all death certificates as little or no data. For cancers of the salivary glands, nasal cavity and other male genitals, dependencies were positive for all three two-source estimates

4 Validity

4.1 Definition

Validity or *accuracy*, as defined as the proportion of cases in a dataset with a given characteristic (e.g., cancer site, age at diagnosis) which truly have the attribute.

4.2 Methodological issues in assessing validity

4.2.1 Reabstracting and recoding

Reabstracting and recoding audits are used to evaluate accuracy (agreement with source medical records), and reproducibility (agreement among data collectors) of registry data. Audits involve samples of cases, and in accordance with a study protocol that states the study objectives, describes the sampling scheme, and outlines plans for the analysis. These methods provide the most objective way of assessing the validity of cancer registration (62).

Reabstracting describes the process of independently reabstracting records from a given source, coding the data, and comparing the abstracted and coded data to the data already in the registry (5). The objective is to characterize the level of agreement between data in the registry and data reabstracted and recoded from source records (usually hospital medical records) by expert auditors. For each reabstracted data item, the auditor's codes are compared to the original codes to identify discrepancies. If the codes do not match, the discrepancy is classified as to severity. A variety of grading schemes for severity have been used. These studies require an arbitration or reconciliation mechanism to determine which of the discrepant answers is correct for the purpose of the study.

Recoding involves independently reassigning codes to abstracted text information (without reviewing the source documents), and evaluating the level of agreement with records already in the registry database. As in a reabstracting study, for each recoded case, codes for each data item are compared for discrepancies with those assigned by the expert. This type of study is useful in training new coders; it is easier and less expensive to perform than reabstracting, but the method cannot itself detect problems with abstracting.

Reliability studies are designed to test participants' understanding and adherence to coding rules and practices. This type of study evaluates the overall performance of coders and abstractors. The participants

code from identical source documents under controlled conditions. When the coding phase of the study is complete, the coders and abstractors can work with experts to reconcile answers. The final results can be statistically represented by comparing the results to accuracy goals for each data item.

4.2.2 Diagnostic criteria methods

Morphological verification

For most cases, the validity of the stated diagnosis is likely to be higher if it is based on histological examination by a pathologist. Previous surveys have shown that many cancer registries code diagnoses based on exfoliative cytology or on haematological examination of peripheral blood in the same category as histological examinations, so that it is impossible to distinguish between them. Partly for this reason, the index of validity generally is the percentage of cases morphologically verified (MV%).

The main value of the MV% is as an indicator of the validity of the diagnostic information (5). However, a very high proportion of cases diagnosed by histology or cytology/haematology – higher than might reasonably be expected – would imply an over-reliance on the pathology laboratory as a source of information, and failure to find cases diagnosed by other means.

The absolute value of the MV% can have little meaning, without comparing it with an “expected” value that is reasonable given the circumstances (state of medical technology, local clinical practice) in which the registry operates. Therefore, the MV% values (usually calculated by site and sex) should be compared with a set of standards, and values that are significantly different can be flagged. Standards may be derived based on the average from registries in the corresponding region (by sex and site) (as in *Cancer Incidence in Five Continents*, Volume VIII), or in the same country, if the MV% values are being examined for sub national areas.

Death certificate only

The proportion of cancers for which no information other than a death certificate mentioning cancer can be obtained - death certificate only registration or DCOs – is another measure of validity, since the information on death certificates is well known to suffer from lack of accuracy, or lack of precision, compared with that obtained from clinical or pathology records. It is often (mistakenly) cited as an indicator of completeness e.g. (48;51). DCO cases represent the residuum of cases – *after all trace-back manoeuvres have been completed* – for which no other information than a death certificate mentioning cancer could be obtained. Thus, while

a high percentage of DCOs is indicative of inadequate case-finding procedures (and thus low ascertainment levels), a low %DCO cannot guarantee the converse. Since most registries attempt to trace back cases notified to them via death certificates - the DCN cases - a low DCO may simply reflect success in tracing the cases missed by the normal case-finding procedures (63).

Given the many considerations involved in interpretation, and the sensitivity of the %DCO to local circumstances (availability of death certificates, quality of cause-of-death statements, facility to trace back cases), no objective criteria of acceptability of %DCO have been proposed. However, as for other indices (such as M:I and MV%), local values can be compared with a standard, based on other registries in the same country, or within a region where similar practices with respect to death registration and the use of death certificates within the registry apply.

4.2.3 Missing Information

The proportion of registered cases with unknown values for various data items can be an indicator of data quality. Unknown values can result from problems with:

- The data collection system, or access to necessary source documents.
- Item and code values that are defined.
- Misapplication of coding rules.

Unknown values may, however, have nothing to do with the registration process, but reflect inadequate case histories or investigation, or ambiguity in the medical record. The definitions used will influence the proportion of unknown codes, for instance, when evaluating cases with "Primary Site Uncertain". The proportion of unknown values usually varies by primary site (see below).

Primary site uncertain

A high proportion of cases assigned to this category generally implies poor diagnostic precision (as evidenced by the low percentage of histologically-verified cases observed for this rubric), or failure to specify the site of the primary cancer in cases diagnosed on the basis of tissue obtained from a metastasis. The ICD-O includes a rubric for "Unknown Primary Site" (C 80.9 in ICD-O-3), but the category may contain other rubrics. In CI5, Volume VIII, for example, a table is provided showing the percentage of cancers in the "Other and Unspecified" category, which includes malignant neoplasms of ill defined organs of the digestive

system (ICD 10 C26), respiratory system (C39) endocrine system (C75), and peritoneal and retroperitoneal neoplasms (C48) as well as those of "other and ill defined sites" (C76).

4.2.4 Internal consistency

Data edits are logical rules, typically embodied in a computer algorithm, that evaluate to "true," "false," or "maybe," for any value(s) of (a) data item(s). Central registry edits are applied to all records to check for item validity, internal consistency, and inter-record consistency. Data edits may involve a single field, multiple fields in a single record, multiple fields in different records within one database, or multiple fields in multiple databases. Data editing may be performed interactively, or as a batch process, or both, and can be carried out at several points in the registration process, for example:

- To newly submitted tumour records before they are linked with the central registry database.
- To the registry database, after the addition of new records
- To the registry database, after any changes have been made.

The check/edit procedure should allow for "override flags", for those records which the edit identifies a rare condition that needs review, but which has been verified to be correct. The override flag prevents the condition from continuing to be identified as an error in subsequent runs of the edit/check procedure.

The CHECK program written by IARC (64) carries out a variety of edits for data coded to ICD-O 3. This includes verification of the validity of codes for sex, incidence and birth dates, and ICD-O-3 topography and morphology codes. It also carries out a series of checks for the validity and for the consistency between variables:

- Age/Incidence and birth dates
- Age/Site/Histology
- Site/Histology
- Sex/Site
- Sex/Histology
- Behaviour/Site
- Behaviour/Histology
- Grade/Histology
- Basis of diagnosis/Histology

4.2.5 Previous studies of validity

As with the evaluation of completeness, the accuracy of registry data in Norway has been reviewed for certain

sites (See Table S3.2). Helseth *et al* examined almost 9000 cancers of the central nervous system diagnosed 1955-84, drawing a random sample of 300 cases to examine potential errors in the coding (7). Over 9% of cases were reported to be erroneous, although only 0.3% of the series contained errors on restricting the analysis to the main histological groupings.

A re-evaluation of a sample of 369 cases from a corrected series of head and neck cancers diagnosed 1953-1991 indicated discrepancies between the pathologists' classification and the registry's coding in 1.6% of all cases, and further, that the proportion without histological verification fell from 5.7% in the first decade to 2.1% during the last nine-year period (58).

A study examining a 1% sample of prostate cancer cases diagnosed 1957-86 indicated 6% of the patient files had an error in one of the fields in the record, irrespective of their perceived importance (59). Tingulstad *et al* evaluated the accuracy of ovarian cancers diagnosed in a single region 1987-96 reporting that, of 591 cases identified with a histological diagnosis at the registry, accuracy was in the region of 92%. Coding errors were found in 2% of these cases, while in a further 6% it was not possible to reproduce the original diagnosis of ovarian cancer at re-evaluation (60).

Continuous internal validation of data has been performed, often initiated by data enquiries via external research projects, or by the merging of the clinical registries and the incidence registry.

4.3 Results: accuracy of data at the Registry

4.3.1 Accuracy based on specific indicators

Morphological verification (MV%)

In total, 88% of the cases registered in the period 2001-2005 were histologically verified. However, there are some quite substantial differences between sites (Table S3.3). The MV% was above 92% for over half of the cancer sites listed including colon, breast and cervix cancer. The MV% was however quite low and below 75% for a number of sites, among them leukaemia, multiple myeloma, other and unspecified cancers, and cancers of the pancreas, liver and central nervous system. Figure S4.1 shows a comparison of MV% for selected European cancer registries using Volume IX of CI5; in terms of ranking with the other European registries, the MV% in Norway is relatively high for both sexes.

Death certificate only (%DCO)

Table S3.3 shows the percentage of DCO cases by cancer site. The proportion of DCO cases 2001-5 was about 0.9%, but there were some variations according to cancer site. Three-quarters of the cancer sites listed

had DCO percentages under 1%; the highest proportions were for several other/unspecified categories, and several poor-prognosis cancers including pancreas (3.6%) and liver (3.3%). Figure S4.1 shows a comparison of %DCO of all cancers combined with selected European cancer registries for the period 1998-2002; the DCO proportions in Norway rank amongst the lowest in Europe, irrespective of sex. Figure S4.3 shows the evolution of DCOs from 1986 though to 2005; the %DCO was highest in 1993 in Norway, but since then the percentage per annum has generally been lower than 1%. In 2005, the %DCO has again increased (to around 1.6%). This is a result of the late arrival of some 10-15% of death certificates for 2005, and it is anticipated that the %DCO will be reduced once the notification processes for these cases is completed.

Primary site uncertain (%PSU)

In Cancer in Norway, the codes C76 and C80 (and C39 – although only one person has been registered with this code since 2001) are defined as *other or unspecified cancers*. Neoplasms, for which the site of origin is not precisely recorded, are assigned to the following sites, which are tabulated separately:

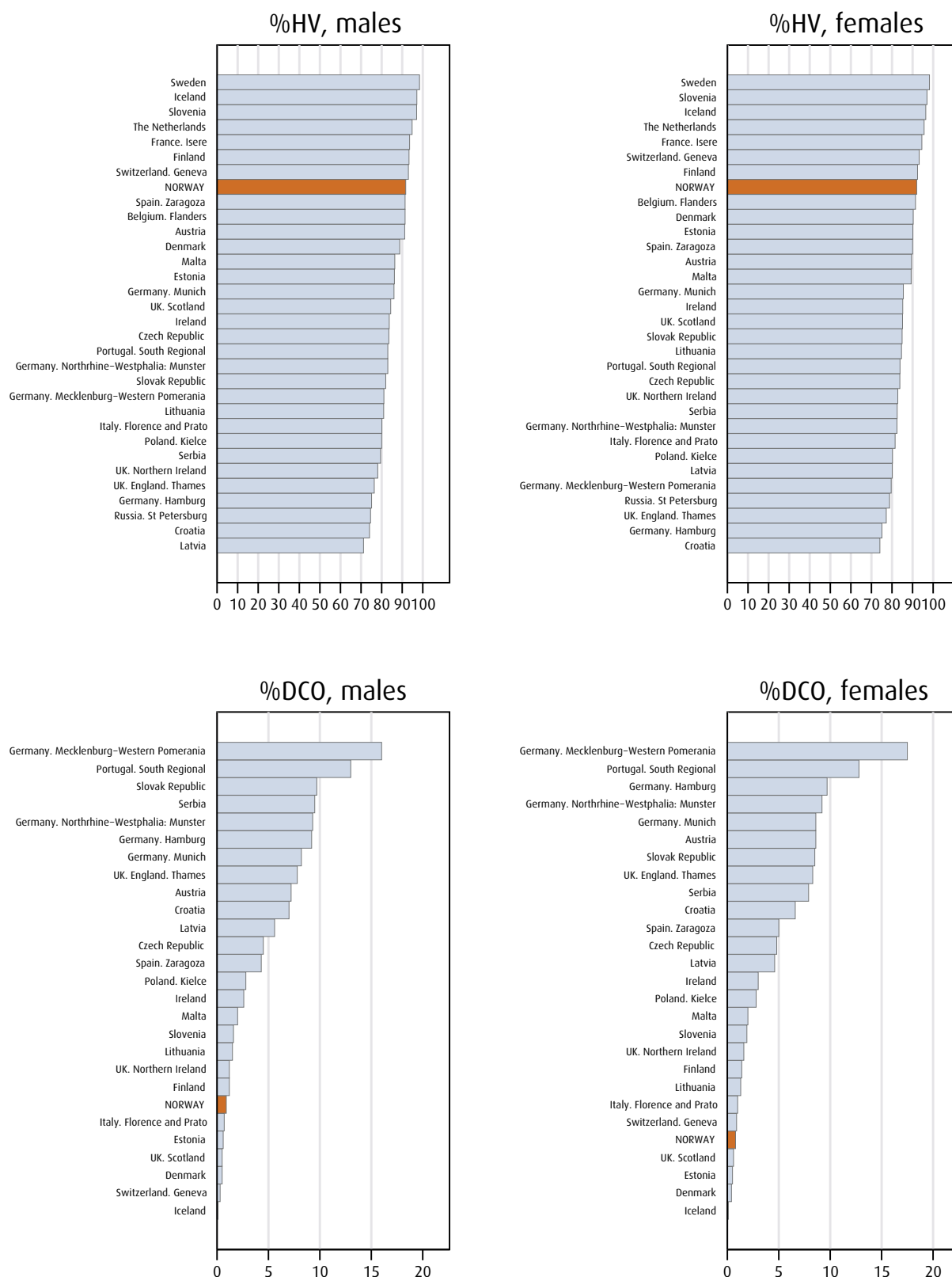
C26	Other digestive organs
C48-49	Soft tissues
C51-52,C57	Other female genital
C60-63	Other male genital
C 37,C74-75	Other endocrine glands

Table S4.1 shows the proportion of cases registered with primary site unknown (%PSU) over the period between 1971-2005. As a total, the proportion of cases registered within this group did not vary much over time, the proportion being consistently around 3%. Table S4.2 gives %PSU by age group 2001-2005, the percentages are fairly constant in each of the five years, but are, as would be expected, higher as age of diagnosis increases. Figure S4.2 shows a comparison of %PSU with selected European cancer registries for the Volume IX of CI5, and indicates that the indicator is in line with the values obtained from other high-quality registries in Europe.

Stage unknown

The stage distribution of cases diagnosed 2001-2005 by cancer sites is shown in Table S4.3. The proportion with stage unknown varies considerably by cancer site, and ranges from 44% missing stage information for prostate cancer to 13% for lung cancer to 9% for colon cancer. The staging system for breast and cervix cancer have however very minor proportions with staging

Figure S4.1: Percentage histologically verified (%HV) and % death certificate only: (%DCO) comparison of Norway with selected European registries, 1998-2002



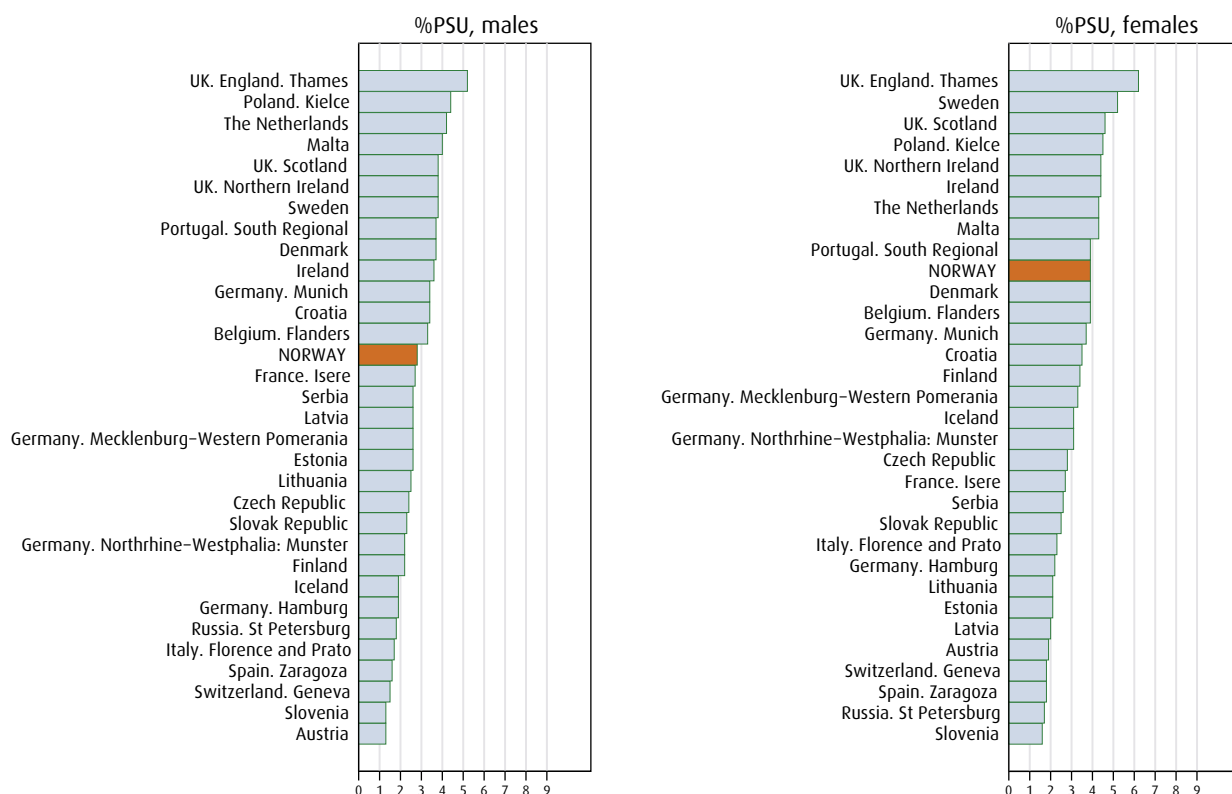
unspecified, with 4% of diagnoses registered with unknown stage for cervix and 0.5% for breast cancer.

4.3.2 Internal consistency

The completed conversion of MOTNAC and ICD-7 codes to ICD-O-3 codes has been initiated. In total,

there are 865,546 notifications registered with a MOTNAC code, and a total of 1142 different MOTNAC codes has been used. After a review of about two-thirds of all the MOTNAC codes (in October, 2007), 6% were considered as irregular codes and records with these codes will be flagged and recoded, where necessary

Figure S4.2: Percentage primary site unspecified (%PSU) comparison with selected European registries for diagnoses 1998-2002



and possible. A negligible proportion of ICD-7 codes have been found to be irregular.

Since 2000, more than 200 new rules have been installed (in addition to already existing ones) as automatic computer-based checks within the incidence registry. The rules prevent illogical registrations, and should a rule be broken, an error message is displayed. In 2007, many of the checks IARC-CHECK program has been implemented to provide warnings where the criteria are violated.

Figure S4.3: Annual trends in percentage of registrations obtained from DCO (death certificate only) cases, Norway 1986-2005



Table S4.1: Percentage of registrations with primary site unknown (%PSU) in consecutive 5-year periods, Norway 1971-2005

Time period	Numbers of unknown	Total number of registered cases	% of cases with unknown primary site (C39, C76, C80)
1971-1975	1245	61538	2,02 %
1976-1980	1723	72060	2,39 %
1981-1985	2211	80952	2,73 %
1986-1990	2696	88123	3,06 %
1991-1995	3006	97966	3,07 %
1996-2000	3004	107912	2,78 %
2001-2005	2613	119049	2,19 %

Table S4.2: Proportion of registrations with primary site unknown (%PSU) in four age groups, Norway 2001-5

Year	Age			
	0-44	45-64	65-74	75+
2001	0,2 %	1,1 %	1,9 %	3,9 %
2002	0,4 %	1,4 %	2,2 %	3,7 %
2003	0,4 %	1,2 %	2,0 %	3,9 %
2004	0,4 %	1,2 %	1,7 %	3,1 %
2005	0,5 %	1,4 %	1,4 %	3,2 %

Table S4.3: Availability of cancer-specific stage information, Norway 2001-2005

Site	Cases per reported stadium							
	Localized	%	Regional	%	Distant	%	Unknown	%
C00 Lip	231	62%	32	9%	5	1%	105	28%
C01 Base of tongue	10	10%	71	70%	10	10%	10	10%
C02 Other and unspecified parts of tongue	123	43%	100	35%	8	3%	57	20%
C03 Gum	45	28%	59	36%	11	7%	47	29%
C04 Floor of mouth	55	41%	55	41%	3	2%	20	15%
C05 Palate	38	40%	21	22%	5	5%	32	33%
C06, Other and unspecified parts of mouth	3	23%	6	46%	1	8%	3	23%
C07, Parotid gland	62	39%	46	29%	13	8%	37	23%
C08 Other and unspecified major salivary gland	14	34%	12	29%	2	5%	13	32%
C09 Tonsil	32	10%	236	74%	11	3%	41	13%
C11 Nasopharynx	4	5%	57	76%	7	9%	7	9%
C12 Pyriform sinus	21	14%	96	65%	9	6%	21	14%
C14 Other and ill-defined sites in the lip, oral cavity and pharynx	2	7%	13	43%	3	10%	12	40%
C15 Oesophagus	186	20%	226	24%	272	29%	251	27%
C16 Stomach	505	18%	839	30%	975	34%	516	18%
C17 Small intestine	69	14%	146	29%	213	42%	82	16%
C18 Colon	1956	18%	5430	50%	2690	25%	880	8%
C19 Rectosigmoid junction	114	22%	233	44%	131	25%	52	10%
C20 Rectum	1382	26%	2167	42%	956	18%	714	14%
C21 Anus and anal canal	107	35%	90	29%	33	11%	78	25%
C22 Liver	185	30%	60	10%	130	21%	252	40%
C23 Gallbladder	13	8%	41	24%	85	50%	30	18%
C24 Other and unspecified parts of biliary tract	99	19%	140	27%	130	25%	144	28%
C25 Pancreas	240	8%	616	19%	1573	50%	735	23%
C26 Other digestive organs	7	2%	21	5%	222	51%	188	43%
C30 Nasal cavity and middle ear	54	48%	22	20%	3	3%	33	29%
C31 Accessory sinuses	10	11%	58	65%	3	3%	18	20%
C32 Larynx, epiglottis	319	52%	134	22%	18	3%	138	23%
C33 Trachea	6	25%	5	21%	6	25%	7	29%
C34, Bronchus and lung	1492	13%	2972	26%	5355	48%	1402	12%
C37 Thymus	4	17%	7	29%	2	8%	11	46%
C38 Mediastinum, pleura	15	15%	25	25%	23	23%	38	38%
C40 Bone and articular cartilage of limbs	22	21%	23	22%	15	14%	44	42%
C41 Bone and articular cartilage of other and unspecified sites	21	19%	32	29%	22	20%	37	33%
C43, Melanoma of the skin	3053	58%	182	3%	284	5%	1737	33%
C44, Skin, non-melanoma	3415	57%	97	2%	38	1%	2490	41%
C45, Mesothelioma	92	26%	102	28%	53	15%	113	31%
C46, Kaposi's sarcoma	16	35%	0	0%	3	7%	27	59%
C47, Autonomic nervous system	14	30%	13	28%	10	21%	10	21%
C48 Retroperitoneum and peritoneum	26	10%	37	15%	141	56%	47	19%
C49 Malignant neoplasm of other connective and soft tissue	152	41%	34	9%	73	20%	115	31%
C51 Vulva	244	58%	96	23%	27	6%	54	13%
C52 Vagina	42	44%	18	19%	14	15%	21	22%
C54 Corpus uteri	1956	62%	369	12%	407	13%	429	14%
C55 Uterus, other	12	26%	5	11%	8	17%	21	46%
C56 Ovary	425	19%	64	3%	1530	67%	257	11%
C57 Other and unspecified female genital organs	20	13%	5	3%	89	60%	35	23%

C58, Placenta	5	25%	0	0%	13	65%	2	10%
C60, Penis	94	54%	42	24%	8	5%	29	17%
C61, Prostate	6794	41%	899	5%	1995	12%	6875	42%
C62, Testis	704	55%	229	18%	138	11%	209	16%
C63, Other and unspecified male genital organs	29	62%	7	15%	2	4%	9	19%
C64, Kidney except renal pelvis	1192	43%	326	12%	591	21%	654	24%
C65, Renal pelvis	139	41%	67	20%	46	14%	88	26%
C66, Ureter	109	41%	36	13%	16	6%	107	40%
C67, Bladder	3067	53%	418	7%	229	4%	2027	35%
C68, Other and unspecified urinary organs	21	17%	16	13%	24	20%	61	50%
C69, Eye	225	73%	19	6%	9	3%	55	18%
C73, Thyroid gland	417	42%	338	34%	82	8%	163	16%
C74, Adrenal gland	12	16%	9	12%	38	49%	18	23%
C75, Other endocrine glands and related structures	8	42%	2	11%	1	5%	8	42%
C76, Other and ill-defined sites	0	0%	6	0%	665	25%	1944	74%

Site	Benign	%	Malignant	%
C70, Meninges	1677	98%	30	2%
C71, Brain	543	24%	1724	76%
C72, Spinal cord, cranial nerves and other parts of central nervous system	519	87%	79	13%

Site	I	%	II	%	III	%	IV	%	U	%
C50, Breast	6947	51%	5602	41%	445	3%	643	5%	64	0%
C53, Cervix uteri	849	58%	274	19%	162	11%	131	9%	53	4%

Sites with no stage information in period:

C10, Oropharynx
C39, Other and ill-defined sites in the respiratory system and intrathoracic organs
C81, Hodgkin lymphoma
C82, Follicular [nodular] non-Hodgkin's lymphoma
C83, Diffuse non-Hodgkin's lymphoma
C84, Peripheral and cutaneous T-cell lymphomas
C85, Other and unspecified types of non-Hodgkin's lymphoma
C88, Malignant immunoproliferative diseases
C90, Multiple myeloma
C91, Lymphoid leukaemia
C92, Myeloid leukaemia
C93, Monocytic leukaemia
C94, Other leukaemias of specified cell type
C95, Leukaemia of unspecified cell type
C96, Other and unspecified malignant neoplasms of lymphoid, haematopoietic and related tissue

5 Timeliness

5.1 Definition

There is no standard definition of *timeliness* in relation to cancer registration. Smith-Gagen et al (65) define *time to availability* as the interval between date of diagnosis (or *date of incidence*, however defined) and the date the case was available in the registry for research. For many registries, the latter will equate to the date at which the database is “frozen” in order to calculate annual statistics for an official report. This period comprises two intervals: the time until received (date of diagnosis to date the report was received by the registry), and the process time (date from receipt until availability).

Timely reporting of tumour information is an important goal for a registry: all users benefit from speedy access to the most current information. However, completeness and validity of data also are essential goals. The speed with which registry data can be collected, processed, analyzed, and reported depends on many factors, some of which are within the registry’s control and others that are not. Efficient data collection methods, computer and software training, telecommunications, and well-trained staff all can influence the timeliness of reporting of tumour records. Many facilities are capable of concurrent reporting and can complete abstracts in “real time.” Electronic data capture has expedited case identification and the abstracting process for some registries.

Transmission of cases from a reporting facility to the central cancer registry also impacts the timeliness of reporting, and registries often have sets of time intervals (monthly, twice yearly etc) at which they expect to receive case notifications.

Once tumour records have been received by the central registry, a wide variety of registration procedures need to be implemented, and all these processing steps take time. Receipt of death certificate data, matching with the registry database, and initiating traceback for unmatched cases is generally a time consuming procedure.

5.2 Methodological issues in assessing timeliness

There are no international standards with respect to timeliness of cancer registry data. In North America, several agencies (notably those that provide funding via contract) have set timeliness standards:

- American College of Surgeons: Cases must be abstracted within 6 months of date of first contact.
- Surveillance, Epidemiology, and End Results Program: The registry is under contract to provide complete counts of new cases for a calendar year within 22 months after the calendar year ends.
- Centers for Disease Control and Prevention/ National Program of Cancer Registries: Within 12 months of the close of the diagnosis year, 90 percent of expected, unduplicated cases are available to be counted as incident cases at the central cancer registry; and, within 24 months of the close of the diagnosis year, 95 percent of expected, unduplicated cases are available to be counted as incident cases at the central cancer registry.
- North American Association of Central Cancer Registries: Within 23 months of the close of a diagnosis year, the registry should contain at least 95 percent of the expected cases of reportable cancer occurring in residents during that year.

5.2.1 Delay-adjusted rate

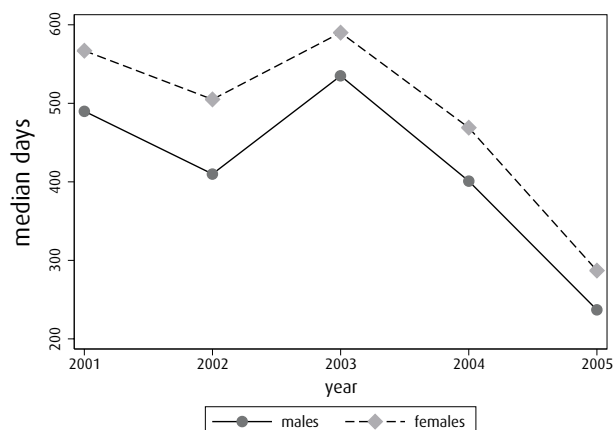
Registries are constantly updating their database as reports are received, and some, especially death certificate notifications, arrive long after the case was diagnosed. Thus, incidence figures for recent years will need future updates. If interest is in the profile of cancer, in terms of incidence at different sites, or comparisons between different places, or subgroups, a few years delay is usually of little importance, although receiving data that are “out of date” generally causes distress among non-professionals. More relevant are the distortions to time trends that can result if the level of undercounting becomes greater with each year up to the latest reported. Several approaches have been proposed to produce more timely statistics, while minimising under-reporting. In the USA, for example, the SEER program uses a delay model (66), to estimate the undercount at the time of reporting (22 months after the close of the relevant year), and to adjust the reported rates.

5.3 Results: timeliness at the Registry

5.3.1 Timeliness of receiving data

Figure S5.1 shows the median time between diagnosis and registration, by site and sex, for the period 2001–2005. The Registry has become more timely in recent years, with the median time from date of diagnosis to registration of a new case shortened from over 500 days in 2001 to about half that in 2005. The average

Figure S5.1: Median time between diagnosis and registration, by site and sex, Norway 2001-2005.



number of days in 2005 between diagnosis and registration varies between cancer sites (Table S5.1). This may, in part, be due to differences in diagnostic and treatment methods. Another probable explanation is the fact that, certain sites are, at different times, given registration priority due to ongoing studies or projects. For example all gynaecological sites have been given priority status since the cervical cancer screening program began in 1995 and the median time between diagnosis and registration was 105 days in 2005.

As a result of delays in notification, the number of cases registered for a given year will generally increase over time. Table S5.2 shows the number of cases reported in the annual reports for a given year, and the number available in reports for subsequent years. Thus 24434 cases appear in *Cancer in Norway 2004*, while 24822 (an increase of 1.6%) were available for the same year at the time of publishing the 2005 report.

5.3.2 Timeliness of reporting at the Registry

For the registry, rapid dissemination of accurate and close-to-complete data outweigh concerns regarding the accrual of additional cases over several years, given they represent a minor proportion of the total annual incidence. During the last 2-3 years there has been a major shift in time from diagnosis to publication. CiN 2002, for instance was published some two and a half years (July 2005) after the pertaining year of registration (2002), whereas CiN 2005 was published within 12 months (December 2006) of the registration period (2005).

Table S5.3 shows the number of cancer cases diagnosed in the year 2005 as enumerated on 29 November 2006, and 15 November 2007. The number of cancer

Table S5.1: Median number of days between diagnosis and registration by cancer site and sex, Norway 2005

ICD-10	Site	Males	Females
C00-96	All sites	237	287
C00-14	Mouth, pharynx	280	270
C00	Lip	307	278
C01-02	Tongue	256	220
C03-06	Mouth, other	301	279
C07-08	Salivary glands	288	236
C09-14	Pharynx	276	279
C15-26	Digestive organs	280	294
C15	Oesophagus	261	323
C16	Stomach	274	294
C17	Small intestine	270	327
C18	Colon	272	285
C19-21	Rectum, rectosigmoid, anus	270	266
C22	Liver	313	317
C23-24	Gallbladder, bile ducts	301	326
C25	Pancreas	336	359
C26	Other digestive organs	311	369
C30-34, C38	Respiratory organs	303	288
C30-31	Nose, sinuses	288	243
C32	Larynx, epiglottis	238	267
C33-34	Lung, trachea	305	288
C38	Mediastinum, pleura	352	294
C40-41	Bone	233	253
C43	Melanoma of the skin	283	287
C44	Skin, non-melanoma	274	269
C45	Mesothelioma	303	419
C46	Kaposi's sarkoma	362	275
C47	Autonomic nervous system	335	229
C48-49	Soft tissues	302	275
C50	Breast	288	301
C51-58	Female genital organs		186
C53	Cervix uteri		105
C54	Corpus uteri		226
C55	Uterus, other		125
C56	Ovary		176
C51-52, C57	Other female genital		265
C58	Placenta		450
C60-63	Male genital organs	90	
C61	Prostate	85	
C62	Testis	265	
C60, C63	Other male genital	235	
C64-68	Urinary organs	278	289
C64	Kidney	277	312
C65	Renal pelvis	275	231
C66-68	Bladder, ureter, urethra	278	277
C69	Eye	348	372
C70-72	Central nervous system	349	364
C73	Thyroid gland	281	281
C37, C74-75	Other endocrine glands	297	315
C39, C76, C80	Other or unspecified	325	346
C81-96	Lymphoid and haematopoietic tissue	341	349
C81	Hodgkin lymphoma	396	386
C82-85, C96	Non-Hodgkin lymphoma	326	331
C88	Malignant immunoproliferative diseases	349	393
C90	Multiple myeloma	350	383
C91-95	Leukemia	346	368

Table S5.2: Stability of incidence data over time, Norway 1992-2006

	Incidence year														
Publ.year	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
1992	19059														
1993	19158	18950													
1994	19169	19341	19284												
1995	19219	19459	19568	19863											
1996	19299	19560	19777	20185	20780										
1997	19199	19432	19642	19986	20655	20981									
1998	19257	19445	19673	20034	20539	21280	21199								
1999	19312	19516	19750	20136	20671	21427	21449	21200							
2000	19330	19535	19770	20187	20716	21438	21466	21414	22185						
2001	19353	19561	19781	20230	20749	21425	21530	21533	22402	22468					
2002	19375	19591	19815	20231	20738	21374	21502	21544	22304	22481	22694				
2003	19384	19595	19823	20236	20739	21376	21504	21541	22307	22495	22779	23307			
2004	19389	19598	19827	20246	20760	21391	21528	21582	22337	22520	22815	23613	24434		
2005	19439	19643	19866	20287	20829	21433	21577	21639	22400	22585	22900	23873	24822	24229	
2006	19452	19661	19840	20286	20805	21384	21553	21614	22381	22569	23103	24058	25066	24926	24697
Max	19452	19661	19866	20287	20829	21438	21577	21639	22402	22585	23103	24058	25066	24926	
Min	19059	18950	19284	19863	20539	20981	21199	21200	22185	22468	22694	23307	24434	24229	
Average	19293	19492	19724	20159	20726	21351	21479	21508	22331	22520	22858	23713	24774	24578	
Max - min	393	711	582	424	290	457	378	439	217	117	409	751	632	697	
Max variation, %	2,1%	3,8%	3,0%	2,1%	1,4%	2,2%	1,8%	2,1%	1,0%	0,5%	1,8%	3,2%	2,6%	2,9%	

cases reported for Norway appearing in CiN2005 will be about 2.2% fewer than those available a year later, with the differences varying by site (+0.7% for breast cancers, +18.2% for cancers of the CNS, for example). By comparing the shortfall in incidence in 2005 when CiN was published, with the accumulation of late registrations one year later (at the time of extracting the incidence data for this report), we can estimate the expected number of cases missing for 2006 (see Part 1). It can be observed that the net effect of the accrual of registrations 12-24 months beyond the year of diagnosis (2005) further increased the number of new registrations for that year by 2.2%, or approximately 530 cases.

Table S5.3: Registered cancer cases in Norway, 2005 as obtained from the incidence registry extracted 29th November 2006 and 19th November 2007

Cases		Cases diagnosed 2005 in			
ICD10	Site	2006	2007	Difference	%
C00-96	All sites	24199	24730	531	2,2 %
C00-14	Mouth, pharynx	415	420	5	1,2 %
C00	Lip	77	85	8	10,4 %
C01-02	Tongue	77	76	-1	-1,3 %
C03-06	Mouth, other	81	81	0	0,0 %
C07-08	Salivary glands	48	51	3	6,3 %
C09-14	Pharynx	132	127	-5	-3,8 %
C15-26	Digestive organs	5202	5315	113	2,2 %
C15	Oesophagus	198	197	-1	-0,5 %
C16	Stomach	515	531	16	3,1 %
C17	Small intestine	89	91	2	2,2 %
C18	Colon	2219	2249	30	1,4 %
C19-21	Rectum, rectosigmoid, anus	1228	1251	23	1,9 %
C22	Liver	131	136	5	3,8 %
C23-24	Gallbladder, bile ducts	140	146	6	4,3 %
C25	Pancreas	575	617	42	7,3 %
C26	Other digestive organs	107	97	-10	-9,3 %
C30-34, C38	Respiratory organs	2421	2484	63	2,6 %
C30-31	Nose, sinuses	38	40	2	5,3 %
C32	Larynx, epiglottis	109	113	4	3,7 %
C33-34	Lung, trachea	2252	2313	61	2,7 %
C38	Mediastinum, pleura	22	18	-4	-18,2 %
C40-41	Bone	43	42	-1	-2,3 %
C43	Melanoma of the skin	1136	1151	15	1,3 %
C44	Skin, non-melanoma	1342	1335	-7	-0,5 %
C45	Mesothelioma	73	79	6	8,2 %
C46	Kaposi's sarcoma	9	11	2	22,2 %
C47	Autonomic nervous system	9	10	1	11,1 %
C48-49	Soft tissues	124	130	6	4,8 %
C50	Breast	2798	2817	19	0,7 %
C51-58	Female genital organs	1550	1553	3	0,2 %
C53	Cervix uteri	292	297	5	1,7 %
C54	Corpus uteri	666	669	3	0,5 %
C55	Uterus, other	11	7	-4	-36,4 %
C56	Ovary	422	424	2	0,5 %
C51-52, C57	Other female genital	153	150	-3	-2,0 %
C58	Placenta	6	6	0	0,0 %
C60-63	Male genital organs	3928	3970	42	1,1 %
C61	Prostate	3631	3665	34	0,9 %
C62	Testis	249	255	6	2,4 %
C60, C63	Other male genital	48	50	2	4,2 %
C64-68	Urinary organs	1843	1877	34	1,8 %
C64	Kidney excl. renal pelvis	565	581	16	2,8 %
C65	Renal pelvis	51	51	0	0,0 %
C66-68	Bladder, ureter, urethra	1227	1245	18	1,5 %
C69	Eye	47	50	3	6,4 %
C70-72	Central nervous system	806	953	147	18,2 %
C73	Thyroid gland	226	227	1	0,4 %
C37, C74-75	Other endocrine glands	19	23	4	21,1 %
C39, C76, C80	Other or unspecified	504	496	-8	-1,6 %
C81-96	Lymphoid and haematopoietic tissue	1704	1787	83	4,9 %
C81	Hodgkin lymphoma	113	115	2	1,8 %
C82-85, C96	Non-Hodgkin lymphoma	780	775	-5	-0,6 %
C88	Malignant immunoproliferative diseases	32	35	3	9,4 %
C90	Multiple myeloma	330	360	30	9,1 %
C91-95	Leukaemia	449	502	53	11,8 %

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MELDING TIL KREFTREGISTERET										SOLIDE SVULSTER	
Skjema i kraft fra 01.01.2003				MONTEBELLO, 0310 OSLO				Non-solid svulster meldes på eget skjema			
PASIENT											
Fødselsnr.				Postnr.		Poststed					
Etternavn				Fornavn							
BEHANDLINGSINSTITUSJON										DIAGNOSETIDSPUNKT	
Institusjon										Avdeling	
Innlagt ☐		Poliklinisk ☐		Dag		Mnd		År		Dag	
				Dato		Utdrevet ☐		I live ☐		Død ☐	
PRIMÆRTUMORS UTGANGSPUNKT: Organ og område innen organet (f.eks. «høyre lunge, overlapp»)											
Side: H ☐ V ☐ Bist ☐ Mennlevant ☐ Sideulgent ☐											
MORFOLOGISK DIAGNOSE: Hovedgruppe og type (f.eks. «adenokarsinom, endometroid type»)											
Anses sykdommen som en klinisk sikker cancer? Ja ☐ Nei ☐											
SYKDOMSTEGN, LEGEKONTAKT											
Hadde pasienten symptomer Ja ☐ Nei ☐ Funn ved screening ☐ Hvilke symptomer eller sykdomstegn											
Når oppsto første symptomer				Når søkt lege							
Dag				Dag				Mnd			
								År			
Anvendt disposisjon for kreft: Nei ☐ Påvist ☐ Mistenkt ☐ Hva slags?											
SYKDOMMENS UTBREDELSE PÅ DIAGNOSETIDSPUNKTET (bestemt på grunnlag av informasjon tilgjengelig for behandling)											
Klinisk TNM: T N M eller Stadium Iflg. stadie-klassifisering											
Beskrivelse av sykdomsutbredelsen på diagnosetidspunktet basert på all tilgjengelig vten eller utredning og undersøkelse av evt. operasjonspreparat											
Gjennomvasket av naturlig organbegrensning Ja ☐ Nei ☐ Primærtumors største diameter cm Invasksi i nabooorgan/-struktur Ja ☐ Nei ☐ = Hvor Regionale lymfeknutemetastaser Ja ☐ Nei ☐ = Hvor Fjerne lymfeknutemetastaser Ja ☐ Nei ☐ = Hvor Organmetastaser Ja ☐ Nei ☐ = Hvor											
NB! ANGITT SPREDNING SKAL VÆRE PÅ SYKDOMMENS DIAGNOSE TIDSPUNKT											
BASIS FOR KREFTDIAGNOSEN											
Klinisk undersøkelse alene Ja ☐ Nei ☐				År		Preparatnummer		Laboratorium			
Bilddiagnostikk (røntgen, UL, CT, MR) Ja ☐ Nei ☐				Cytologisk prep.							
Evt. andre undersøkelser (f.eks. biopsi, skopi, sternalmarg, kirurgisk eksplorasjon) Ja ☐ Nei ☐				Histologisk prep.							
				Histologisk prep.							
				Obduksjons prep.							
Hvilke											
PRIMÆRBEHANDLING											
Startet når				Ingen primærbehandling ☐		Primærbehandlingens siktemål		Helbredelse ☐		Palliasjon ☐	
Dag											
Mnd											
År											
Kirurgisk behandling Ja ☐ Nei ☐				Hvilken?		Op. metode (op. beskrivelse må vedlegges)					
Strålebehandling Ja ☐ Nei ☐				Annen behandling Ja ☐ Nei ☐		Hvilken					
Hormonbehandling				Erytterogene behandling planlagt? Ja ☐ Nei ☐		Hvilken behandling		Hvilken institusjon?			
Cytostatiskbehandling											
Resttumor etter primærbehandling Ja, makroskopisk ☐				Ja, mikroskopisk ☐		Nei ☐		Vet ikke ☐			
OPPLYSNINGER SOM REGISTRERES HVIS IKKE PASIENTEN MOTSETTER SEG DET											
Rayler Ja ☐ Nei ☐				Tidligere rayler ☐		Motsetter seg reg. ☐		Yrke		Motsetter seg reg. ☐	
TILLEGGSOPPLYSNINGER											
Dag				Pasientens svarlig lege (Etternavn, fornavn - trykke bokstaver)				Legens underskrift			
Mnd											
År											
Meldt				Id. nummer				Id. nummer			

Solide svulster

Diagnosetidspunkt

Tidspunktet diagnosen forelå - ikke tidspunktet for symptomdebut eller første konsultasjon hos lege.

Primærtumors utgangspunkt

Organlokalisasjonen hvor sykdommen først oppsto. Bruk nøyaktige angivelser av organ og anatomisk avsnitt, f.eks. "magesekk, cardia" eller "venstre bryst, øvre mediale kvadrant".

Morfologisk diagnose

Når det foreligger mikroskopisk undersøkelse av cytologi, biopsi, operasjonspreparat eller obduksjonspreparat, ønskes detaljert angivelse av den morfologiske diagnosen, f.eks. "adenokarsinom, endometroid type" (ikke bare "adenokarsinom") eller "malignt melanom, superfisiell spredning" (ikke bare "malignt melanom"). Når sykdommen er erkjent på grunnlag av andre diagnostiske metoder, f.eks. røntgen-, CT- eller MR-undersøkelse, ønskes diagnosen angitt med den grad av sikkerhet som undersøkelsen tillater.

Sykdommens utbredelse

Klinisk TNM (cTNM)

Angir kreftsykdommens utbredelse på diagnosetidspunktet slik den var oppfattet basert på utredning (klinisk undersøkelse, bildediagnostikk, endoskopi, biopsi, kirurgisk eksplorasjon og evt. andre undersøkelsesmetoder), men før kirurgisk behandling og undersøkelse av operasjonspreparat. Siste versjon av TNM-klassifikasjonen skal benyttes (TNM Classification of Malignant Tumours, Sixth Edition, 2002).

Sykdommens utbredelse

Stadium

For de svulstene som ikke TNM-klassifiseres (f.eks. sarkomer), og i de tilfellene hvor tumor ikke har blitt TNM-bestemt, kan i stedet stadium og den stadieklassifikasjonen som er benyttet, oppgis. Det understrekes at det er sykdomsutbredelse på diagnosetidspunktet som skal meldes.

Sykdomsutbredelse basert på all tilgjengelig viten

Tumors lokale vekst, regionale spredning og fjernspredning rapporteres basert på all tilgjengelig viten om sykdommen - inkludert histologisk undersøkelse av operasjonspreparat. Dette tilsvarende retningslinjene for patologisk TNM (pTNM). Det understrekes at det er sykdomsutbredelse på diagnosetidspunktet som skal meldes.

Basis for kreftdiagnosen

De diagnostiske prosedyrer som danner grunnlaget for diagnosen, avkrysses. For undersøkelser utført i patologilaboratorium anføres remisenummer, diagnoseår og laboratorium.

Tilleggsopplysninger

Dersom uttømmende informasjon om sykdommen ikke kan gis, ønskes oppgitt hvor denne kan innhentes, f.eks. dersom pasienten er henvist til annen avdeling for utredning og/eller behandling.

MELDING TIL KREFTREGISTERET
MONITORISERT, NYE OLSO

SOLIDE SVULSTER
Når svulste svulster inngår på eget skjema

PASIENT
Fødselsnr. [REDACTED] Fødselsdato [REDACTED]
Etternavn [REDACTED] Fornavn [REDACTED]
E-post [REDACTED] Telefon [REDACTED]

BEHANDLINGSPUNKT
Institusjon: **HAUKELAND SYKEHUS** Avdeling: **KIRURGISK**
Klinikk: [REDACTED] Dato: **01.03.02** Tidspunkt: **03.05.02**

PRIMÆRTUMORS UTGANGSPUNKT Organ og anatomi (se organet i: vkt. -f.eks. lunge, overlegg-)
COLON DESCENDENS Site: [REDACTED] Tidspunkt: [REDACTED]

MORFOLOGISK DIAGNOSE Hovedgruppe og type (f.eks. -adenokarsinom, endometroid type-)
ADENOCARCINOM Graden av sikkerhet: [REDACTED]

SYKDOMSUTBREDELSE
Hvor pasienten symptomer: [REDACTED] Fører til sykdom: [REDACTED] Hvilke symptomer eller tegn: **BLODIG AVFØRING**
Når oppsto første symptomer: **10.12.01** Når oppsto tegn: **28.02.02**
Anvendt diagnostikk for å fastslå: [REDACTED] Hvilket stadium? [REDACTED]

SYKDOMSUTBREDELSE PÅ DIAGNOSTIDPUNKTET (basert på informasjon tilgjengelig før behandling)
Klinisk TNM: **T3 N1 M0** Stadium: [REDACTED] Hvilket stadium? [REDACTED]

BEHANDLING
Operasjon: [REDACTED] Preoperativt: [REDACTED] Postoperativt: [REDACTED]
Operasjon: [REDACTED] Preoperativt: [REDACTED] Postoperativt: [REDACTED]
Operasjon: [REDACTED] Preoperativt: [REDACTED] Postoperativt: [REDACTED]

PRIMÆRBEHANDLING
Start dato: **03.05.02** Hvilket stadium? [REDACTED] Hvilket stadium? [REDACTED]
Hvilket stadium? [REDACTED] Hvilket stadium? [REDACTED] Hvilket stadium? [REDACTED]

OPPLYSNINGER SOM REGISTRERES HOS PASIENTEN MOTSETTER SEG DET
Hvor: [REDACTED] Hvilket stadium? [REDACTED] Hvilket stadium? [REDACTED]

TILLEGGSOPPLYSNINGER
Hvor: [REDACTED] Hvilket stadium? [REDACTED] Hvilket stadium? [REDACTED]

OVERLEVERE **GUNN RING** **Gunn Ring**
Mottatt: **01.06.02** Mottatt: **01.06.02** Mottatt: **01.06.02**

Eksempelet er fiktivt

MELDING TIL KREFTREGISTERET				MONTEBELLO, 0310 OSLO				NON-SOLIDE SVULSTER							
Skjema i kraft fra 01.01.2003												Solide svulster meldes på eget skjema			
PASIENT															
Fødselsnr.								Postnr.				Poststed			
Etternavn								Fornavn							
BEHANDLINGSINSTITUSJON												DIAGNOSETIDSPUNKT			
Institusjon												Avdeling			
Innlagt ☐ Poliklinisk ☐ Dag Mnd År Utskrevet ☐ I live ☐ Død ☐												Dag Mnd År			
SYKDOMSKATEGORI (velg én av de ni hovedgruppene - morfologisk undergruppe spesifiseres nedenfor) (Se også veiledning på baksiden)															
☐ Lymfom ☐ Mb. Waldenström ☐ Atypisk lymfoid hyperplasi ☐ Myeloproliferativt syndrom (polycytemia vera, essensiell trombocytemi, primær myelofibrose)															
☐ Leukemi ☐ Myelomatose eller lign. plasmacell tumor ☐ Malign histiocytose eller lign. ☐ Myelodysplastisk syndrom (MDS 1-5)															
Ved manglende eller inkonklusiv morfologisk u.s.: Anses sykdommen som en klinisk sikker cancer? Ja ☐ Nei ☐															
SYKDOMSTEGN, LEGEKONTAKT															
Hadde pasienten symptomer Ja ☐ Nei ☐ Funn ved screening ☐ Hvilke symptomer eller sykdomstegn															
Når oppsto første symptomer Dag Mnd År Når søkt lege Dag Mnd År															
Anslått disposisjon for kreft Nei ☐ Råvst ☐ Mistanke ☐ Hveslags? ☐															
SYKDOMMENS UTBREDELSE PÅ DIAGNOSETIDSPUNKTET (bestemt på grunnlag av informasjon tilgjengelig for behandling)															
For lymfomer: Stadium (f.eks. IB, IIA, IIB, etc.) For myelomatose: Durie-Salmon stadium (f.eks. IB, IIA, etc.)															
For KLL: Binet stadium (sett kryss) A ☐ B ☐ C ☐ DET UNDERSTREKES AT ANGITT STADIUM SKAL VÆRE PÅ DIAGNOSETIDSPUNKTET															
SYKDOMMENS LOKALISASJON/DEBUTORGAN (velg én av de fire mulighetene)															
1) ☐ Lymfeknute - hvilken lymfeknute-region? 2) ☐ Benmarg 3) ☐ Annet organ - hvilket organ? 4) ☐ Det er ikke mulig å ta stilling til utgangspunktet p.g.a. utbredt sykdom på diagnose tidspunktet (sett evt. kryss)															
BASIS FOR KREFTDIAGNOSEN															
Benmargsubstryk ☐ Cytologisk prep. År Preperatnummer Laboratorium															
Perifer blodstryk ☐ Histologisk prep.															
Benmargsbiopti ☐ Histologisk prep.															
Immunofenotyping/immunhistokjemi ☐ Obduksjons prep.															
Cytogenetisk undersøkelse ☐															
Spinalvevskundersøkelse ☐															
DNA/RNA/teknisk diagnose ☐															
Serum- og/eller urinspektralanalyse ☐															
Billediagnostikk (røntgen, UL, CT, MR) ☐															
PRIMÆRBEHANDLING															
Startet når Dag Mnd År Ingen primærbehandling ☐ Primærbehandlingens skjemall ☐ Helbredelse ☐ Palliasjon ☐															
Kirurgisk behandling Ja ☐ Nei ☐ Hvilken? Op. metode (op. beskrivelse må vedlegges)															
Strålebehandling Ja ☐ Nei ☐ Annen behandling Ja ☐ Nei ☐ Hvilken															
Cytostatiskbehandling Ja ☐ Nei ☐ Er ytterligere behandling planlagt? Ja ☐ Nei ☐ Hvilken behandling Hvilken institusjon?															
Anses pasienten sykdomsfri etter primærbehandling? Ja ☐ Nei ☐ Vel ikke ☐ Ikke relevant ☐															
OPPLYSNINGER SOM REGISTRERES HVIS IKKE PASIENTEN MOTSETTER SEG DET															
Rayler Ja ☐ Nei ☐ Tidligere rayler ☐ Motsetter seg reg. ☐ Yrke Motsetter seg reg. ☐															
TILLEGGSOPPLYSNINGER															
Meldt Dag Mnd År Pasientens varige lege (Etternavn, fornavn - trykte bokstaver) Legens underskrift															
Id. nummer Id. nummer															

Utfylling av meldeskjemaet for

Non-solide svulster

Diagnosetidspunkt

Tidspunktet diagnosen forelå - ikke tidspunktet for symptomdebut eller første konsultasjon hos lege.

Sykdomskategori og morfologisk undergruppe

Hovedkategori av non-solide svulster som sykdomstilfellet tilhører angis ved avkrysning (lymfom, leukemi, myelomatose, etc.). I tillegg angis morfologisk undergruppe med den grad av nøyaktighet som de tilgjengelige diagnostiske hjelpemidler har gitt anledning til. Eksempelvis vil én og samme sykdom f.eks. kunne rapporteres enten som "akutt myelogen leukemi type M2" eller bare som "akutt myelogen leukemi".

Sykdommens utbredelse

For lymfom, myelomatose og kronisk lymfatisk leukemi angis stadium på diagnosetidspunktet i henhold til sykdommenes respektive klassifikasjonssystemer: Ann Arbor for lymfom, Durie-Salmon for myelomatose og Binet for kronisk lymfatisk leukemi. Det understrekes at det er sykdomsutbredelse på diagnosetidspunktet som skal meldes.

Sykdommens lokalisasjon/debutorgan

For non-solide tumorer som har begrenset utbredelse på diagnosetidspunktet, kan det være mulig å angi i hvilket organ eller region sykdommen hadde sitt utspring, f.eks. non-Hodgkins lymfom i magesekk eller lymfogranulomatose med affeksjon av lymfeknuter bare på halsen.

Basis for kreftdiagnosen

De diagnostiske prosedyrer som danner grunnlaget for diagnosen, avkrysses. For undersøkelser utført i patologi-laboratorium anføres remissenummer, år og laboratorium.

Tilleggsopplysninger

Dersom uttømmende informasjon om sykdommen ikke kan gis, ønskes oppgitt hvor denne kan innhentes, f.eks. dersom pasienten er henvist annen avdeling for utredning og/eller behandling.

Eksempellet er fiktivt

1. PASIENT/BEHANDLINGSINSTITUSJON

Fødselsnr		Institusjon	
Fornavn		Avdeling	
Etternavn		☐ Innlagt ☐ Poliklinisk	Dato
Postnr		Poststed	
		Utskrevet	☐ I live ☐ Død

2. MELDINGSTYPE (bare ett kryss)

☐ Primær tumor	☐ Residiv*	Dato	☐ Metastase*	Dato
☐ Obduksjon**	Dato			

* Gå til punkt 5 **Fyll kun ut punkt 4

3. SYKDOMSTEGN OG DIAGNOSTIKK

Hadde pasienten symptomer?	☐ Ja ☐ Nei	Symptomdebut (måned/år)	
Arvelig predisposisjon	☐ Ja ☐ Nei		
Colo/rectoskopi	☐ Ja, tumor sett ☐ Utført, tumor ikke sett ☐ Ikke utført		
Rtg colon	☐ Ja, tumor sett ☐ Utført, tumor ikke sett ☐ Ikke utført		
CT-abdomen	☐ Ja, tumor sett ☐ Utført, tumor ikke sett ☐ Ikke utført		
Colografi (CT)	☐ Ja, tumor sett ☐ Utført, tumor ikke sett ☐ Ikke utført		
Klinisk undersøkelse alene	☐ Ja, sikker tumor		
Biopsi av tumor	☐ Ja ☐ Nei	Pat. lab	
		Diagnosetidspunkt	

4. TUMORS LOKALISASJON

Tumors lokalisasjon (Hvis flere, kryss av for de aktuelle)			
☐ Appendix	☐ Cökum	☐ Ascendens	☐ Høyre fleksur
☐ Transversum	☐ Venstre fleksur	☐ Descendens	☐ Sigmoidum (≥ 20 cm)
☐ Rectosigmoid (16–< 20 cm)	☐ Rectum (< 16 cm fra analåpning på stivt skop)	cm	
Målt ved MR: øvre kant av m. puborektalis til nedre kant av tumor cm			

5. SYKDOMSUTBREDELSE VED DIAGNOSE

			Utførte undersøkelser (basis for diagnostikk)			
Levermetastaser	☐ Nei ☐ Ja ☐ Mistenkt	→	☐ Ultralyd	☐ CT	☐ MR	☐ Ingen
Lungemetastaser	☐ Nei ☐ Ja ☐ Mistenkt	→	☐ Rtg thorax	☐ CT	☐ MR	☐ Ingen
Andre fjernmetastaser (inkl. perit. carcinomatose)	☐ Nei ☐ Ja ☐ Mistenkt	→	☐ Ultralyd	☐ CT	☐ MR	☐ Ingen
Hvis ja, hvor:						
Dybdevekst av tumor i rectum og rectosigmoid	☐ I tarmvegg (T1-T2) ☐ Gjennom tarmvegg (T3) ☐ Innvekst naboorgan (T4)	→	☐ Ultralyd	☐ CT	☐ MR	☐ Ingen
Antatt CRM	mm	Antatt positive lymfeknuder	☐ Ja ☐ Nei ☐ Ikke utført			

6. FORBEHANDLING

☐ Ingen	☐ Strålebehandling	☐ Kjemoterapi	☐ Radiokjemoterapi	☐ Avlastende stomi	☐ Stenting
--------------------------------	---	--------------------------------------	---	---	-----------------------------------

7. BEHANDLING

Operert	☐ Ja	Dato		☐ Nei	Årsak:
Hastegrad	☐ Elektiv ☐ Akutt pga obstruksjon ☐ Akutt pga perforasjon ☐ Akutt pga annet				
Kirurgens preop. intensjon	☐ Kurativt	☐ Palliativt	☐ Usikker	ASA-score:	
GJENNOMFØRT OPERASJON	Opr. type	☐ Åpen	☐ Laparoskopi	☐ Laparoskopi, konvertert åpen	
a) Reseksjon av tumor	☐ Ja	☐ Nei (gå til b)	Pat. lab		
Colon	Rectum				
☐ Hemicol. dxt ☐ Utvidet hemicol. dxt ☐ Hemicol. sin ☐ Utvidet hemicol. sin ☐ Transv. reseksjon ☐ Transv. + fleksurreseksjon ☐ Sigmoidreseksjon ☐ Subtotal kolektomi ☐ Annen ☐ Medialt/sentralt først ☐ Lateralt først			☐ Fremre reseksjon ☐ Hartmann ☐ Amputatio recti ☐ Polypektomi ☐ Lokal reseksjon ☐ Transanal endoskopisk mikrokirurgi ☐ Annen Anastomosenivå cm over analåpning Anastomoseteknikk: ☐ ende-ende ☐ side-ende ☐ J-Pouch/Reservoir		
Lymfeknutedisseksjon	☐ D3 Kar avsatt inntil a. mes. sup./aorta ☐ D2 Intermediær avsetting av kar ☐ D1 Tarmnær avsetting av kar				
Anastomose etter reseksjon	☐ Ja	☐ Nei	Avlastende stomi etter res./anast. ☐ Ja ☐ Nei		
Endestomi	☐ Ja	☐ Nei			
b) Operasjon uten reseksjon av tumorbærende tarmsegment:					
☐ Bypass ☐ Avlast. stomi ☐ Kun ekspl. lap. ☐ Stenting					
INTRAOPERATIVT FUNN/DIAGNOSE:			KONSEKVENNS:		
Levermetastaser	☐ Nei	☐ Ja, klinisk sikker	☐ Ja, mistenkt	☐ Biopsi tatt	☐ Reseksjon utført
Peritoneal met./carcinomat.	☐ Nei	☐ Ja, klinisk sikker	☐ Ja, mistenkt	☐ Biopsi tatt	☐ Reseksjon utført
Lymfeknutemet. utenfor res. område	☐ Nei	☐ Ja, klinisk sikker	☐ Ja, mistenkt	☐ Biopsi tatt	☐ Reseksjon utført
Innvekt i naboorgan	☐ Nei	☐ Ja, klinisk sikker	☐ Ja, mistenkt	☐ Biopsi tatt	☐ Reseksjon utført
Hvilke(t) organ:					
Perforasjon under operasjonen	☐ Nei	☐ Tarm	☐ Tumor		
Resttumor lokalt (kirurgens vurdering)	☐ Nei	☐ Ja, sikker	☐ Mulig		

8. KOMPLIKASJONER TIL OPERASJON

Komplikasjoner	☐ Nei	☐ Anastomoselekkasje	☐ Annen	Spesifiser:
Reoperasjon	☐ Nei	☐ Ja	Dato	
Spesifiser:				

9. ETTERBEHANDLING

Planlagt etterbehandling	☐ Nei	☐ Ikke avklart	☐ Ja	Hvis ja: ☐ Strålebehandling ☐ Kjemoterapi ☐ Radiokjemoterapi ☐ Kirurgi for metastaser
Institusjon:				

Meldingsdato	Meldt av (navn (blokkbokstaver) + ID-nr.)	Signatur

Manual

Melding til Colorectalcancerregisteret Kreftregisteret for svulster i colon og rectum

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1 Introduksjon

Fra 1. januar 2007 innfører Kreftregisteret i samarbeid med Norsk Colorectalancer Gruppe nytt meldeskjemaet for svulster i colon og rectum. Skjemaet er utviklet av gastrokirurger og referansegruppedlemmer i Norsk Rectum Cancer Gruppe og bearbeidet av Kreftregisteret for tilpasning til den tidligere databasen. Skjemaet erstatter både det tidligere kliniske Registreringsskjema for rectumcancer og skjemaet Melding til Kreftregisteret for solide svulster.

Formålet er å få et spesialregister for colorectalancer som både er et insidens-, utrednings-, diagnostikk-, og behandlingsregister. Målet er å skaffe kunnskap som kontinuerlig vil bidra til å optimalisere behandlingsforløpet for denne pasientgruppen.

2 Lovhjemmel

Kreftregisteret har fra 1953 hatt et omfattende landsdekkende kvalitetssikret register med alle nødvendige konsesjoner fra Datatilsynet. I desember 2001 fikk Kreftregisteret en forskrift som ytterligere sikrer innsamling av personidentifiserbare kliniske data om diagnostikk og behandling av kreftpasienter for hvert organ/hver kreftform.

3 Opprettelsen av Norsk Colorectalancer Gruppe

Norsk Colorectalancer Gruppe ble opprettet i februar 2006. Det er en utvidelse av Norsk Rectum Cancer Gruppe til å også omfatte registrering av coloncancer. Det innebærer et utvidet samarbeid med Kreftregisteret. Samarbeidet mellom Kreftregisteret og Norsk Colorectalancer Gruppe er regulert i egne statutter.

4 Om Melding til Colorectalcancerregisteret Kreftregisteret for svulster i colon og rectum

Skjemaet Melding til Colorectalcancerregisteret og Kreftregisteret for svulster i colon og rectum skal fylles ut ved følgende hendelser:

- Primærtumor i colon og rectum
- Lokalt residiv av cancer i colon og rectum
- Metastaser fra tumor i colon og rectum

4.1 Utfylling av skjema for primærtumor

I den påfølgende oversikten vil hvert punkt i skjemaet bli presentert. Det er i hovedsak fokusert på opplysninger av spesiell viktighet og informasjon om punkter som kan misforstås.

1. Pasient/Behandlingsinstitusjon

Pasientrelatert informasjon skal fylles ut i kolonnen til venstre. Institusjonsdata er plassert til høyre slik at stempel kan anvendes.

2. Meldingstype

Her skal det fylles inn hva som meldes, er det en primærtumor, et residiv, metastase eller er tumor funnet ved obduksjon? Merk følgende:

- Dersom pasienten har både residiv og metastase skal det fylles ut et skjema for hver av tilstandene for å kartlegge behandlingsforløpet.
- Dersom pasienten har en annen cancer i et annet organ som blir oppdaget samtidig med coloncancer eller rectumcancer, skal denne meldes på et eget skjema *Melding til Kreftregisteret for solide svulster*.
- Dersom den preoperative utredningen av en pasient med rectumcancer viser at det også foreligger en coloncancer, skal bare ett skjema fylles ut.
- Dersom colon-eller rectumcancerdiagnosen stilles og behandlingen startes ved et sykehus for så å fullføres på annet sykehus, skal melding sendes fra begge sykehus. *Eksempel: Et sykehus legger ut en avlastende stomi for strålebehandling av cancer recti og pasienten strålebehandles og opereres ved et annet sykehus.* I slike tilfeller vil meldinger fra begge sykehusene bli samordnet i databasen til Colorectalcancerregisteret.

3. Sykdomstegn og diagnostikk

Dette punktet skal bare fylles ut ved primærtumor. Kommentarer:

- Diagnosetidspunktet er den dato diagnosen klinisk sikker cancer ble stilt. Dersom det klinisk ikke kunne stilles en sikker diagnose, benyttes dato for biopsi.
- Det er ikke lenger nødvendig å fylle ut patologiremissenummer. Det er tilstrekkelig å fylle ut navnet på patologilaboratoriet som ble benyttet.
- Punktet klinisk undersøkelse alene benyttes for pasienter som ikke skal undergå videre utredning eller behandling. *Eksempel: Sykehjems-pasienter som ved rektaleksplorasjon/palpasjon av abdomen får oppdaget en tumor, men der alder/allmenntilstand ikke tilsier videre utredning*

4. Tumorlokalisasjon

Her skal tumoren(e)s lokalisasjon merkes. Ved rectumcancer skal radiologene angi avstand fra øvre kant av m.puborectalis til nedre kant av tumor. Målet er at MR i framtiden skal kunne måle avstand fra analåpning til nedre kant av tumor og gi et mer nøyaktig mål enn det rectoskopi med stivt skop angir.

5. Sykdomsutbredelse ved diagnose

- Feltene om metastaser preoperativt skal fylles ut for **alle** colorectalcancere.
- CEA verdi tatt preoperativt (ved diagnosetidspunkt) angis i mikrogram per liter.
- Det fargede feltet **gjelder kun cancer i rectum og rectosigmoid**. Disse opplysningene kan hentes ut fra en preoperativ MR-undersøkelse.
 - Dybdevekst av tumor.
 - CRM står for Circumferentiell Resection Margin. CRM er den korteste distanse fra den ytre del av tumor til reseksjonskanten, eller ytre kant av malign lymfeknute til reseksjonskanten. Radiologene skal ut fra MR angi antatt CRM.
 - Antatt positive lymfeknuter kan radiologene angi ut fra MR.

6. Forbehandling

Har pasienten fått **preoperativ** onkologisk eller kirurgisk behandling krysser melder av her. Merk at det er et skille på om pasienten har fått strålebehandling alene, eller radiokjemoperati (kombinasjonsbehandling). Postoperativ behandling skal det ikke krysses for her.

7. Behandling

Dersom pasienten har blitt operert skal opplysningene om operasjonstype og funn registreres her.

- Kirurgens preoperative intensjon er ment å reflektere hva kirurgen vurderer som mulig ut fra den preoperative utredning. Det er **ikke** identisk med kirurgens vurdering av resttumor som er det siste spørsmålet under punkt 7.
- ASA-klassifisering har vist seg å være en prognostisk faktor for pasienter som opereres for coloncancer. Tabell 1 viser grunnlaget for klassifiseringen.

Tabell 1: ASA-klassifisering: Pasientene vurderes preoperativt og plasseres i en av fem grupper uavhengig av planlagt operativt inngrep. (men pasientenes aktuelle lidelse vurderes med)

1. "Frisk pasient" Ingen organisk, fysiologisk, biokjemisk eller psykiatrisk forstyrrelse. Aktuell lidelse er lokalisert og gir generelle symptomforstyrrelser. Røker < 5 sigaretter daglig Alder < 80 år.	4. Livstruende organisk sykdom som ikke behøver å være relatert til den aktuelle kirurgiske lidelse eller som ikke alltid bedres ved det kirurgiske inngrepet. Eksempel: Malign hypertensjon Nylig (< 6 mndr) gjennomgått hjerteinfarkt Sterkt fremskreden lever, nyre, lunge eller endokrin dysfunksjon. Manifest hjertesvikt. Ustabil angina pectoris. Subarachnoidal blødning, våken – somnolent pasient.
2. Moderat organisk lidelse eller forstyrrelse som ikke forårsaker funksjonelle begrensinger, men som kan medføre spesielle forholdsregler eller anestesitekniske tiltak. Lidelsen(e) kan enten være forårsaket av den aktuelle sykdom pasienten skal opereres for, eller av annen patologisk prosess. Alder > 80 år	5. Moribund pasient som ikke forventes å overleve 24 timer med eller uten kirurgi. Eksempel. Pasient med aortaaneurisme i sjokk. Dypt comatos pasient med intracraniell blødning.

Nyfødt < 3 mndr Røker > 5 sigaretter daglig Eksempel: Lett organisk hjertesykdom Ukomplisert diabetes (type 1 og 2) Benign ukomplisert hypertensjon Frisk 20-åring med kjeveleddsperre.	
3. Alvorlig organisk sykdom eller forstyrrelse som gir definert funksjonelle begrensinger. Eksempel: Diabetes med organskomplikasjoner Invalidiserende hjertesykdom Moderat til alvorlig lungesykdom Angina pectoris Gjennomgått hjerteinfarkt (> 6 mndr)	D. Donor. Hjernedød pasient som preserves for organdonasjon.

- Det er nødvendig å oppgi patologilaboratorium for operasjonspreparatet da det kan være forskjellig fra laboratoriet biopsien ble sendt til.
- Operasjonstypene og metodene er delt mellom colon (til venstre) og rectum (til høyre).
- **Colon:** Det skal krysses av hvorvidt lymfeknutedisseksjon var utført med
 - D3 reseksjon: Karene settes av sentralt og inntil arteria mesenterica superior eller aorta
 - D2-reseksjon: Karene settes av et sted mellom arteria mesenterica superior/aorta og tarmnært
 - D1-reseksjon: Karene settes av tarmnært
- **Rectum:** Ved fremre reseksjon skal anastomosnivå og anastomoseteknikk registreres.

Spørsmålene fra og med **Anastomose etter reseksjon** og **Avlastende stomi etter reseksjon** gjelder for både colon-og rectumcancer.

8. Komplikasjoner

Her registreres komplikasjoner i løpet av de 30 første dager etter kirurgi. Det gjelder både anastomoselekkasje og alle typer reoperasjon. Ved reoperasjon spesifiser hva årsaken til reoperasjon er. Det er bare plass til å registrere første reoperasjon. Alle komplikasjoner som er viktige nok til å igangsette behandling (kurve, journal, epikrise) og få en egen DRG-kode tas med.

9. Etterbehandling

- Her krysses av dersom pasienten skal til kirurgisk eller onkologisk behandling postoperativt, eller når det er planlagt onkologisk behandling som eneste behandling.
- Det er lagt vekt på at meldeskjemaet skal kunne fylles ut når pasienten skrives ut fra sykehuset. Noen ganger vil ikke svaret på den histologiske undersøkelsen foreligge før pasienten utskrives. Kryss da av for ikke avklart.

4.2 Utfylling av skjema for lokalt residiv

Når en pasient som er diagnostisert og operert for primærtumor får lokalt residiv, skal skjemaet fylles ut. Det skal da krysses av for **Residiv** under **2. Meldingstype**, og melder skal ikke fylle inn punkt 3 og 4. Det er viktig at melder noterer dato for residivet under punkt 2. Fra **5. Sykdomsutbredelse ved diagnose** skal skjemaet fylles ut som for primærtumor.

4.3 Utfylling av skjema for metastaser

Når en pasient som er diagnostisert og operert for primærtumor får metastaser, skal skjemaet fylles ut. Følgende opplysninger skal registreres ved metastaser:

2. Meldingstype

Det skal krysses av for **Metastase** og datoen for metastasen skal noteres.

3. og 4. skal ikke fylles ut

5. Sykdomsutbredelse ved diagnose

Her kan lokalisasjonen på metastasene registreres i tillegg til hvilke undersøkelser som har blitt gjort for å detektere dem.

6. Forbehandling

Fylles inn hvis pasienten preoperativt har fått onkologisk behandling for sine metastaser.

7. Behandling

Her skal bare noen få opplysninger fylles ut:

- Operert og eventuelt operasjonsdato
- Kirurgens preoperative intensjon
- Resttumor lokalt (kirurgens vurdering)

8. Komplikasjoner til operasjon

Her skal det krysses av om pasienten har komplikasjoner etter metastaseoperasjonen og hvis pasienten blir reoperert.

9. Etterbehandling

Her krysses det ut hvis pasienten skal til onkologisk behandling postoperativt.

4.4 Utfylling av skjema ved obduksjon

Hvis det ved obduksjon blir funnet en cancer i rectum eller colon skal **Obduksjon** krysses av under **2. Meldingstype**. For denne pasientgruppen skal bare **4. Lokalisasjon** registreres.

5 Kontaktpersoner på Kreftregisteret

Forskningsassistent:

Liv Marit R. Dørum

Tlf: 23333971

E-post: lmrd@kreftregisteret.no

Prosjektleder:

Dr.med. Maria Gaard

Tlf: 23333972

E-post: mg@kreftregisteret.no

Manualen vil fra 1.1.2007 ligge elektronisk på Kreftregisterets hjemmeside:
www.kreftregisteret.no.

Meldeskjema for brystkreft Krefregisteret Nasjonal register for kreftsykdommer Sendes Krefregisteret, Montebello - 0310 Oslo Ved bilateral sykdom skal to skjemaer fylles ut		Sykehus (stempel) Avdeling	Navn Adresse Postnummer Poststed Fødselsnr.
1. Henvisningsgrunnlag Mammografi: Mammografiprogrammet (off screening) ☐ Revis screening ☐ Papabelfumor ☐ Når oppsto første symptomer Andre brystsymptomer ☐ Høyriskokontroll (arv) ☐ Arvelig disposisjon for kreft? Nei ☐ Påvis ☐ Mistenkt ☐ Hvilslags?		Henvisning mottatt dato Poliklinisk behandlet Innlagt 	
2. Klassifisering av tilfellet Høygrad av pålitelighet Incidental sykdom skal to skjemaer fylles ut Infiltrerende kreft ☐ DCIS (ductal carcinoma in situ) ☐ Andre premaligne tilstander ☐		3. Topografi ☐ Høyre ☐ Venstre Multiple primære (Meld største svulst) ☐ Papabelf ☐ Ja Nei Bryst ☐ Ja Nei Amhule ☐ Ja Nei	
4. Diagnostiske metoder (Krys av for de metodene som er benyttet) Klinisk undersøkelse ☐ Bildediagnostikk ☐ Finneraspisjon (FNAC) ☐ Preoperativ biopsi ☐ Syndebiopsi ☐ Diagnostisk merkebiopsi ☐ Andre metoder Endelig diagnose dato 		5. Diagnostisk konklusjon Metastase i armhulens lymfeknuder ☐ Ja Nei Ukjent Metastase til lymfeknuder bak brystbenet ☐ Ja Nei Ukjent Metastaser i andre organer ☐ Ja Nei Ukjent Morfologisk diagnose Ved tillegg eller inkonklusiv morfologisk undersøkelse, Angi sykdommen som klinisk sikker kreft? Ja ☐ Nei ☐ Cytoplogisk prep. Preperatnummer Histologisk prep. Histologisk prep. Obduksjons prep. Laboratorium pTNM pT pN pM 	
6. Behandling Behandlingsformål Helbredelse ☐ Palliasjon ☐ Pasienten skal reserveres fra Mammografiprogrammet i 10 år. Ja ☐		8. Stråleterapi Ingen ☐ Postop. mot brystet som ledet i brystbevarende kirurgi ☐ Postop. mot regionale lymfeknuder ☐ Annen stråleterapi ☐	
7. Kirurgi Endelig kirurgi Bryst: Ingen ☐ Brystbevarende ☐ Ablato ☐ Amhule: Ingen ☐ Totale ☐ Sentinel node ☐ Start kirurgisk primærbehandling Fullført kirurgisk primærbehandling Antall kirurgiske inngrep Kirurgikoder (op. beskrivelse må vedlegges) 		9. Medikamentell behandling Ingen ☐ Preop. cytostatika ☐ Postop. cytostatika ☐ Postop. endokrin behandling ☐	
10. Opplysninger som registreres hvis ikke pasienten motsetter seg det Røyker Ja ☐ Nei ☐ Tidligere røyker ☐ Motsetter seg reg. ☐ Ytter: Motsetter seg reg. ☐			
Tilleggsopplysninger 			
Meld 		Pasientens varlig lege (Etternavn, fornavn - trykke bokstaver) Id. nummer 	
Legens underskrift 		Id. nummer 	

Skjemaet skal sendes til: Kreftregisteret, Montebello, 0310 Oslo

Hva skal meldes på dette skjemaet?

Alle tilfeller av infiltrerende brystkreft og Duktalt Carsinom in Situ (DCIS).
For pasienter diagnostisert i Mammografiprogrammet: Også andre forstadier.
Andre kreftformer skal meldes som for på gammelt skjema "Melding til Kreftregisteret".

Hvem skal melde? Klinikere skal melde alle nye diagnostiserte tilfeller av de ovenfor nevnte sykdomstilstander. I tillegg skal alle tilfeller hvor det foreligger begrunnet mistanke om kreft meldes. Ved tvil om meldeplikt bør melding sendes.

Ad punkt 4:

Endelig diagnosedato: Datoen endelig diagnose forelå etter utredning (oftest svar fra patologisk laboratorium) – ikke tidspunktet for symptomdebut eller første konsultasjon hos lege.

Ad punkt 5:

Diagnostisk konklusjon: Opplysningene skal være om sykdommens art og utbredelse på diagnosetidspunktet.

Morfologisk diagnose: Når det foreligger histologisk undersøkelse ønskes detaljert engivelse av den morfologiske diagnosen, f.eks. "infiltrerende duktalt karsinom" ikke bare "adenokarsinom".

pTNM: Det er kun patologisk TNM (pTNM) som skal fylles inn (ikke cTNM).

Ad punkt 6:

Reservasjon fra Mammografiprogrammet: Dersom pasienten ikke skal inviteres til Mammografiprogrammet, må dette feltet krysses ut.

Ad punkt 7:

Kirugi koder: Kodene er hentet fra "Klassifikasjon av kirurgiske inngrep 1999" utgitt av Statens helsetilsyn og Kompetansesenter for IT i Helsevesenet.

Kode	Tekst	Forklaring
HAB 00	Ekstirpasjon av lesjon i mamma	Inklusive: Av fistel
HAB 40	Kilereseksjon av mamma	
HAB 99	Annen reseksjon av mamma	
HAC 10/15	Subcutan mastektomi	Bevart brystvorte/Eksisjon av brystvorte
HAC 20	Total mastektomi	Med aksillære lymfeknuter Inklusive: Eksisjon av brystmuskler, utvidet mastektomi med reseksjon av ribbein og sternum
HAC 25	Radikal mastektomi	
HAC 99	Annen mastektomi	

Tilleggsopplysninger: Dersom uttømmende informasjon om sykdommen ikke kan gis, ønskes oppgitt hvor denne kan innhentes, f.eks. dersom pasienten er henvist til annen avdeling for utredning og/eller behandling.

Veiledning (se vedlegg*) I kraft fra 01.05.2003		MELDING TIL KREFTREGISTERET MONTEBELLO, 0310 OSLO		CANCER OVARI primærdiagnose inkl. borderline	
PASIENT			LEGG VED OPERASJONS BESKRIVELSE		
Fødselsnr.		Postnr.		Poststed	
Etternavn		Fornavn		Navnelapp	
LEGE/SYKEHUSKONTAKT					
Første legekontakt Dato		Funnet ved screening ☐			
Innlagt ☐ Poliklinisk ☐		Innleggesdato			
Lokal/ sentralsykehus		Avdeling		DIAGNOSETIDSPUNKT*	
Henvist regionsykehus Ja ☐ Nei ☐		Hvilket		Dag Mnd År	
PRIMERTUMORSUTGANGSPUNKT					
Ovariet(r) ☐	Tube(r) ☐	Peritoneum ☐	Side H ☐ V ☐	Ekst. ☐	Ikke relevant ☐ Ukjent ☐
MORFOLOGISK DIAGNOSE: Hovedgruppe og type (f. eks. «adenokarsinom, serøst papillært»)*					
Ploid-status ☐			Diploid ☐	Aneuploid ☐	Ukjent ☐ Annen ☐
Ved manglende eller ikke-konklusiv undersøkelse, anses sykdommen som en klinisk sikker cancer? Ja ☐ Nei ☐					
ANAMNESE					
Symptomer ved diagnose* Ja ☐ Nei ☐ Hvilke					
Funksjonstilstand ved diagnosetidspunkt* 0 1 2 3 4 Ukjent ☐					
Første symptom		Menopause Ja ☐ Nei ☐ Årstill			
Antall fødsler		Antall aborter		P-piller Ja ☐ Nei ☐ Antall år	
Tidligere sykdom/ årstill					
Arvelig disposisjon for kreft Nei ☐ Påvist ☐ Mistenkt ☐ Type kreft/ familierelasjon					
SYKDOMMENS UTBREDELSE PÅ DIAGNOSETIDSPUNKTET					
Primærtumors største diameter X cm		NB! ANGITT SPREDNING SKAL VÆRE PÅ SYKDOMMENS DIAGNOSETIDSPUNKT			
FIGO-stadium* I II III IV		Ukjent ☐		Substadium A B C Ukjent ☐	
Hvis stadium IV, spredning til hvilken lokalisasjon				Verifisert m/histologi/cytologi Ja ☐ Nei ☐	
Regionale lymfeknutemetastaser* Ja ☐ Nei ☐		Hvor			
Fjerne lymfeknutemetastaser* Ja ☐ Nei ☐		Hvor			
Organmetastaser Ja ☐ Nei ☐		Hvor			
BASIS FOR KREFTDIAGNOSEN					
Klinisk undersøkelse alene Ja ☐ Nei ☐		CA-125 før behandling		U/I Ikke tatt ☐	
Brukes RMI (Risk of Malignancy Index)?* Ja ☐ Nei ☐		RMI			
Undersøkelse utført for behandling:		År		Preparatnummer	
MR bekken/abdomen ☐	Pipelleprøve endometriet ☐	Cytologisk prep.			
Abdominal ultralyd ☐	Colonoskopi ☐	Histologisk prep.			
CT bekken/abdomen ☐	Rtg. colon ☐	Histologisk prep.			
Fraksjonert abrasio ☐	Vaginal ultralyd ☐	Andre			
Beskrivelse av funn					

PRIMÆRBEHANDLING				Navnelapp eller fødselsnummer			
Primærbehandlingens siktemål* Helbredelse ☐ Livsforlengelse ☐ Palliasjon ☐							
Ingen primærbehandling ☐							
KIRURGI				NB legg ved operasjonsbeskrivelse!			
Er pasienten operert? Ja ☐ Nei ☐ Hvis nei, oppgi grunn _____							
Dato for operasjon Asotes Ja ☐ Nei ☐ Mengde _____ ml							
Ruptur av ovarialtumor under operasjonen Ja ☐ Nei ☐							
Resttumor* Ingen (R0) ☐ Mikroskopisk (R1) ☐ Makroskopisk (R2) ☐ Ukjent (R3) ☐							
Lokalisasjon _____ Største diameter _____ X _____ cm							
Komplikasjon(er) til operasjonen(e) Ja ☐ Nei ☐ Hvilke(n) _____							
Behandling av komplikasjon(er) _____							
Blodningsmengde under operasjonen ml Transfusjon Ja ☐ Nei ☐ Antall enheter							
CYTOSTATIKA							
Planlagt Ja ☐ Nei ☐ Hvis nei, oppgi grunn _____							
Hvis ja, hvilken _____							
Påbegynt cytostatikabehandling Dato Avsluttet cytostatikabehandling Dato							
Type cytostatika _____ Antall kurser							
Forandring av kur Ja ☐ Nei ☐ Hvis ja, oppgi grunn _____							
Nykur _____ Antall nye kurser							
Cytostatikabehandling inngår i Standard regime ☐ Protokoll ☐ Individuell ☐ Hvilken? _____							
Bivirkninger _____ CA-125 før første kur							
CA-125 tre uker etter siste kur							
Klinisk respons etter avsluttet behandling* CR ☐ RR ☐ SD ☐ PD ☐ Ikke evaluerbar ☐							
Funksjonstilstand ved avsluttet behandling* 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ Ukjent ☐							
ANNEN BEHANDLING							
Strålebehandling Ja ☐ Nei ☐ Spesifiser _____							
Hormonbehandling Ja ☐ Nei ☐ Hvilken _____							
Annen behandling _____							
Siste konsultasjon Dato							
Ingen tegn til sykdom ☐ Pasienten syk med kreft ☐ Pasienten død av kreft ☐ Pasienten død av annen sykdom ☐							
OPPLYSNINGER SOM REGISTRERES HVIS IKKE PASIENTEN MOTSETTER SEG DET*							
Røyker Ja ☐ Nei ☐ Tidligere røyker ☐ Motsetter seg reg. * ☐							
Yrker (nåværende og tidligere) _____ Motsetter seg reg. * ☐							
TILLEGGSOPPLYSNINGER							
Dag Mnd År Pasientansvarlig lege (Etternavn, fornavn - trykte bokstaver) _____ Legens underskrift _____							
Meldt ID-nummer _____ ID-nummer _____							

*** Diagnosetidspunkt:**

Dato for histologisk/cytologisk verifisering. Hvis diagnosen stilles kun på klinisk grunnlag brukes dato for avsluttet utredning.

*** Morfologisk diagnose:**

Hvis det er forskjellig morfologi (histologi) på høyre og venstre side, sendes ett skjema for hver cancer.

*** Anamnese (symptomer ved diagnose):**

Under symptomer oppgir man de viktigste symptomene til pasienten.

Eksempler: Tretthet, svimmelhet, tungpust, smerter i øvre eller nedre del av abdomen, utspilt abdomen, kul i magen, blod fra skjeden, uregelmessige blødninger, utflod, forandring i avføringsmønster: hyppigere avføring, sjeldnere avføring, tykkelsen mindre, blod i avføring. Kvalme, oppkast, vekttap.

*** Funksjonstilstand WHO:**

- 0 Normal aktivitet
- 1 Symptomer, men oppegående og selvhjulpne
- 2 Må delvis holde sengen, men mindre enn 50% av dagen
- 3 Sengeliggende mer enn 50% av dagen
- 4 Helt sengeliggende, helt avhengig av andres pleie

*** Stadielinndeling etter FIGO:**

Stadium I Karsinom bare i ovariene

Stadium IA

Karsinom i ett ovarium, ingen ascites eller bukskyllevæske som inneholder maligne celler. Intet karsinom på overflaten av ovariet, kapselen intakt.

Stadium IB

Karsinom i begge ovarier, ingen ascites eller bukskyllevæske som inneholder maligne celler. Intet karsinom på overflaten av ovariene, kapselen intakt.

Stadium IC

Stadium IA eller IB med ett eller flere av følgende kriterier: rumpert kapsel (under operasjonen eller gjennomvekst), karsinom på overflaten av ett eller begge ovarier, maligne celler i ascites eller bukskyllevæske.

Stadium II Karsinom involverer ett eller begge ovarier med spredning til bekkenet.

Stadium IIA

Spredning og/eller metastaser til uterus og/eller tube(r).

Stadium IIB

Spredning eller metastaser til andre bekkenorgan (blære, colon sigmoideum og rectum), ingen maligne celler i ascites eller bukskyllevæske.

Stadium IIC

Stadium IIA eller IIB med ett eller flere av følgende kriterier: rumpert kapsel (under operasjonen eller gjennomvekst), karsinom på overflaten av ett eller begge ovarier, maligne celler i ascites eller bukskyllevæske.

Stadium III Karsinom i ett eller begge ovarier med mikroskopisk verifisert peritoneal spredning utenfor bekkenet og/eller positive regionale lymfeknutemetastaser, se veiledning*. Karsinom med utbredelse i det lille bekken, men med bekreftet histologisk infiltrasjon i andre organer (f.eks. tynntarm, oment, colon ascendens og transversum).

Stadium IIIA

Mikroskopiske peritoneale metastaser utenfor bekkenet.

Stadium IIIB

Makroskopiske peritoneale metastaser utenfor bekkenet, 2 cm eller mindre som største diameter.

Stadium IIIC

Peritoneale metastaser utenfor bekkenet over 2 cm som største diameter og/eller regionale lymfeknutemetastaser, se veiledning*.

Stadium IV Karsinom i ovariet med fjernmetastaser (peritoneale metastaser hører ikke med). Se veiledning*.

NB! Lever/ miltkapselmetastase(r) er stadium III, lever/ miltparenkymmetastase(r) er stadium IV. Pleuravæske må verifiseres med cytologisk prøve for stadiet defineres som IV.

*** Regionale lymfeknutemetastaser:**

Langs nervus obturatorius, arteria iliaca communis, arteria iliaca externa, lateralt for sacrum, paraaortalt og lyske.

*** Fjerne lymfeknutemetastaser:** Mediastinum, axille, parasternalt, supraklavikulært og hals

*** RMI (Risk of Malignancy Index) $CA-125 \times M \times U$:**

CA-125	Absolutt tallverdi
M	Menopausal status Premenopausal = 1 Postmenopausal = 3
U	U = 0 for ultralydsscore 0 = 1 for ultralydsscore 1 = 3 for ultralydsscore 2 - 5
	Ja Nei
Multilokulær	1 0
Solide områder	1 0
Bilateral	1 0
Ascites	1 0
Peritoneale metastaser	1 0

*** Primærbehandlingens siktemål:**

Helbredelse: Målsettingen for behandlingen er helbredende, å gjøre pasienten fri for kreftsykdom slik at pasienten oppnår forventet levealder.

Livsforlengelse: Målsettingen for behandlingen er å forlenge pasientens liv.

Palliasjon: Målsettingen for behandlingen er å gi symptomlindring, symptomforebygging og livskvalitetsbedring.

*** Resttumor:**

R0 Ingen påviselig makroskopisk eller mikroskopisk tumor ved operasjonens avslutning.

R1 Det blir påvist mikroskopisk tumor i biopsier eller i reseksjonsflaten.

R2 Det er synlig tumor igjen ved operasjonens avslutning.

RX Det er ikke mulig med sikkerhet å fastslå om det foreligger resttumor.

Største diameter: Hvis det foreligger flere tumorer skal den største angis.

*** Klinisk respons etter avsluttet behandling (responskriterier):**

CR (Complete Remission) Komplet remisjon: Alle målbare/påviselige sykdomstegn blir helt borte i minst 4 uker.

PR (Partial Remission) Partiell remisjon: Minst 50% reduksjon av samlet tumor/metastasevolum, ingen tumorer eller metastaser må være tilkommet eller vist vekst.

SD (Stationary Disease) Uforandret sykdom: Ingen signifikant remisjon eller progresjon.

PD (Progressive Disease) Progresjon: Enhver nyttilkommet tumor/metastase eller økning av største tverrmål med 20% eller mer.

*** Opplysninger som registreres hvis ikke pasienten motsetter seg det:**

Opplysninger om røykevaner/yrke kan registreres hvis ikke pasienten motsetter seg det.

*** Tilleggsopplysninger:**

Dersom uttømmende informasjon om sykdommen ikke kan gis, ønskes oppgitt hvor denne kan innhentes, for eksempel dersom pasienten er henvist til annen avdeling for utredning og/eller behandling.

Veiledningen er à jour pr. 28.09.2004. Se eventuelle oppdateringer på Kreftregisterets hjemmeside: www.kreftregisteret.no. Kreftmeldingen er hjemlet i Kreftregisterforskriften, i kraft fra 01.01.2002.

Veiledning på baksiden		MELDING TIL KREFTREGISTERET		CANCER PROSTATAE
Skjema i kraft fra 01.01.2004		MONTEBELLO, 0310 OSLO		Tilleggsmelding til ordinært meldeskjema
PASIENT				
Fødselsnr.		Postnr.	Poststed	Evt. klistremerke
Etternavn		Fornavn		
INSTITUSJON (sykehus/avdeling/legepraksis)				
ARSAK TIL UTREDNING				
1. PSA initiert av	lege ☐ pasient ☐ ukjent ☐	2. Palpasjonsfunn (rektal eksplorasjon) ☐	4. Metastasemistanke ☐	5. Andre årsaker ☐ spesifiser
		3. Urinveisssymptomer ☐	5. Tilfeldig funn v/ TUR-P ☐	
DATO FOR HENVISNING TIL SPESIALISTHELSETJENESTEN Ikke henvist ☐				
Gleason score + ... =		Morfologisk basis ☐ biopsi ☐ TUR-P ☐ metastase ☐ andre ☐ spesifiser		
DIAGNOSEGRUNNLAG				
PSA ved diagnose tidspunktet µg/l		Skjelettscintigrafi ☐ positivt funn ☐ negativt funn ☐ ikke utført ☐		
Ultralyd prostata ☐ utført ☐ ikke utført ☐		Annen billediagnostikk ☐ utført ☐ ikke utført ☐ hvilken		
		Lymfadenektomi pN Operasjonsbeskrivelse må vedlegges		
FUNKSJONSTILSTAND				
☐ 0: Normal aktivitet, uten begrensning		☐ 2: > 50% av dagen oppegående, ikke i arbeid, helt selvhjulpent		
☐ 1: Lett redusert arbeidskapasitet		☐ 3: > 50% av dagen i seng/stillesittende. Behov for endel hjelp til personlig stell		
		☐ 4: Helt avhengig av andre. Totalt stillesittende eller i seng hele dagen		
PLANLAGTE TILTAK				
Pasienten observeres ☐ årsak ☐ alder ☐ dårlig almenntilstand ☐ pasienten ønsker ikke behandling ☐ ikke medisinsk indikasjon ☐ andre ☐ spesifiser		Pasienten får behandling/ behandling planlagt (meldes på ordinært meldeskjema) ☐		
STUDIENKLUSJON				
Er pasienten inkludert i studie ☐ Ja ☐ Nei ☐ hvilken				
TILLEGGSOPPLYSNINGER				
Meldt: Dag Mnd År		Pasientansvarlig lege (Etternavn, fornavn - trykte bokstaver)		Legens underskrift
Id. nummer		Id. nummer		

VEILEDNING TIL UTFYLLING AV SKJEMAET
MERK AT DETTE ER ET TILLEGGSSKJEMA TIL ORDINÆRT MELDESKJEMA TIL KREFTREGISTERET.
BEGGE SKJEMAER MÅ FYLLES UT.

Årsak til utredning: Under dette punktet oppgir man de viktigste årsakene til at pasienten ble utredet med hensyn på prostatacancer. Det kan krysses av på flere punkter hvis dette er nødvendig.

Gleason score: Primær Gleason grad (1-5) + sekundær Gleason grad (1-5) = Gleason score (2-10) anføres. Eks. Gleason grad 3 + grad 4 = Gleason score 7. Er det kun angitt en Gleason grad blir primær og sekundær grad identiske. Eks. Gleason grad 3 + grad 3 = Gleason score 6.

Diagnosegrunnlag: De diagnostiske prosedyrer som danner grunnlaget for diagnosen prostatacancer. Usikkert funn etter skjelettscintigrafi skal oppgis som negativt funn og eventuelt kommenteres i feltet "tilleggsopplysninger" nederst på meldeskjemaet.

Planlagte tiltak: Utført og planlagt primærbehandling rapporteres også på ordinært meldeskjema.

Definisjon av klinisk TNM for primærtumor i prostata (2002-versjonen). Skal registreres på ordinært meldeskjema. Klassifikasjonen gjelder bare adenokarsinom.

Sykdomsutbredelse bestemmes på grunnlag av følgende diagnostiske/eksplorative prosedyrer:

T	Klinisk undersøkelse, bildediagnostikk, endoskopi, biopsi og biokjemiske undersøkelser.
N	Klinisk undersøkelse og bildediagnostikk.
M	Klinisk undersøkelse, bildediagnostikk, skjelettundersøkelser og biokjemiske undersøkelser.

Definisjon av T-, N- og M-kategoriene

T Primær tumor	
TX	Primærtumor kan ikke vurderes.
T0	Primærtumor ikke påvist.
T1	Klinisk ikke erkjennbar tumor, ikke palpabel eller påvisbar ved bildediagnostikk.
T1a	Tumor, tilfeldig funn i 5% eller mindre av resesert vev.
T1b	Tumor, tilfeldig funn i mer enn 5% av resesert vev.
T1c	Tumor påvist ved nålebiopsi (f.eks. på grunn av forhøyet PSA).
T2	Tumor begrenset til prostata. <i>NB: Tumor som er påvist i én eller begge lapper ved nålebiopsi, men som ikke er palpabel eller påvisbar ved bildediagnostikk klassifiseres som T1c.</i>
T2a	Tumor omfatter en halv lapp eller mindre.
T2b	Tumor omfatter mer enn halvparten av en lapp, men ikke begge lapper.
T2c	Tumor omfatter begge lapper.
T3	Tumor vokser gjennom prostatakapselen. <i>NB: Innvekst i apex prostatae eller inn i (men ikke gjennom) prostatakapselen klassifiseres som T2.</i>
T3a	Ekstrakapsulær vekst (unilateral eller bilateral).
T3b	Tumor vokser inn i sædblære(r).
T4	Tumor er fiksert eller vokser inn i nabostruktur(er) annet enn sædblære(r): blærehals, musculus sphincter externus, rectum, levator-muskulatur og/eller er fiksert til bekkenveggen.
N Regionale lymfeknuter: Lymfeknuter i det lille bekken (mellom bifurkaturen av arteria iliaca communis og lyskebandet). Lateralitet påvirker ikke N-klassifikasjonen	
NX	Spredning til regionale lymfeknuter kan ikke vurderes.
N0	Ingen regionale lymfeknutemetastaser.
N1	Regional(e) lymfeknutemetastase(r).
M Fjernmetastaser (fjerne lymfeknutemetastaser og organmetastaser)	
MX	Fjernmetastasering kan ikke vurderes.
M0	Ingen fjernmetastaser
M1	Fjernmetastase(r).
M1a	Metastase(r) til fjern(e) lymfeknute(r).
M1b	Metastase(r) til skjelett.
M1c	Annen/andre fjernmetastase(r), med eller uten skjelettmetastaser.

Veiledningen er à jour pr. 01.01.2004. Se eventuelle oppdateringer på Kreftregisterets hjemmeside: www.kreftregisteret.no. Kreftmeldingen er hjemlet i Kreftregisterforskriften, i kraft fra 01.01.2002.

Veiledning på baksiden I kraft fra 01.01.2003		MELDING TIL KREFTREGISTERET MONTEBELLO, 0310 OSLO		MALIGN LYMFOM og KLL	
PASIENT					
Fødselsnr.		Postnr.		Poststed	
Etternavn		Fornavn			
BEHANDLINGSINSTITUSJON				DIAGNOSETIDSPUNKT	
Sykehus		Afdeling		(positiv biopsi/cytologi/utstryk)	
☐ Innlagt ☐ Poliklinisk Dato (ddmmåå)		Utskrevet ☐ I live ☐			
MORFOLOGISK DIAGNOSE					
Hovedgruppe ☐ Hodgkin lymfom ☐ Nodalt NHL ☐ Primært ekstra-nodalt NHL ☐ KLL ☐ Annet ☐				Klinisk sikker diagnose ved manglende/inkonklusiv morfologisk u.s.?	
Morfologisk diagnose (i.h.t. WHO)					
Ved to samtidige lymfomer: Andre morfologiske diagnose (i.h.t. WHO)				☐ Ja ☐ Nei	
SYKDOMSTEGN, LEGEKONTAKT					
Hadde pasienten symptomer? ☐ Ja ☐ Nei Hvilke symptomer eller sykdomstegn					
Første symptomer (ddmmåå) Lege søkt første gang (ddmmåå)					
Annelig disposisjon for kreft: ☐ Nei ☐ Påvist ☐ Mistenkt Hva slags?					
STADIUM på diagnosetidspunktet					
HODGKIN LYMFOM, NODALT NON-HODGKIN LYMFOM: Ann Arbor stadium					
☐ I ☐ II ☐ IE* ☐ II ₁ ☐ III ☐ IIE* ☐ IV		Er fullstendig stadiutredning utført ☐ Ja ☐ Nei			
E*: innvekst i ekstranodalt organ/vev		Stadium I og II: ☐ Over diaphragma ☐ Under diaphragma			
		Waldeyers sveigring affisert ☐ Ja ☐ Nei			
PRIMÆRT EKSTRANODALT NON-HODGKIN LYMFOM: Musshoff stadium					
☐ Pe I ☐ Pe IE ☐ Pe II ₁ ☐ Pe II ₂ ☐ Pe II ₃ ☐ Pe II ₄ ☐ Uklart		Primært ekstranodalt organ:			
EKSTRANODAL LYMFOMAFFEKSJON (angis for nodale og ekstranodale lymfomer)					
☐ Benmarg ☐ CNS ☐ Lunge ☐ Nyre ☐ Pankreas ☐ Skjelett ☐ Testikkel ☐ Tynntarm ☐ Uterus ☐ Øye ☐ Bhule ☐ Hud ☐ Munnhule ☐ Orbita ☐ Peritoneum(sider) ☐ Spyttkjertel ☐ Thyroides ☐ Tårekjertel ☐ Vagina ☐ Annet ☐ Bryst ☐ Lever ☐ Muskulatur ☐ Ovarium ☐ Pleura ☐ Subcutis ☐ Tykktarm ☐ Urinblæreslureter ☐ Ventrikel					
B-symptomer ☐ Ja ☐ Nei Hvis ja: ☐ Vekttap ☐ Feber > 38 grader ☐ Gjentatt nattsvette					
«Bulky» sykdom: isolert lymfeknute eller konglomerat av lymfeknuter > 10 cm eller lymfom i mediastinum > 1/3 av thoraxdiameteren i nivå Th5-Th6 ☐ Ja ☐ Nei					
KRONISK LYMFATISK LEUKEMI: Binet stadium ☐ A ☐ B ☐ C					
PROGNOSTISKE FAKTORER					
Funksjonsstatus (WHO) ☐ 0 Full daglig aktivitet ☐ 1 Oppegående ☐ 2 Sengeliggende < 50% ☐ 3 Sengeliggende > 50% ☐ 4 Helt sengeliggende					
S-LD U/I Normalverdi ☐ Forhøyet verdi ☐ Ikke utført ☐					
DIAGNOSTIKK					
☐ Ja ☐ Nei Preparatnummer Laboratorium		☐ Kirurgisk biopsi ☐ Spinalvæskeundersøkelse ☐ Grovnålsbiopsi ☐ Serum- og/eller urinelektroforese ☐ Finnerålpunksjon ☐ Cytogenetisk undersøkelse ☐ Cytologi (annen) ☐ DNA-RNA-kromosom-diagnostikk ☐ Benmargsbibliopsi ☐ Serologisk undersøkelse ☐ Benmargsutstryk ☐ Billedagnostikk (røntgen, UL, CT, MR) ☐ Blodutstryk ☐ Annet: ☐ Flowcytometri			
Obduksjon ☐		Immunfenotyping / immunhistokjemi ☐ B-celle ☐ T-celle ☐ D-celle ☐ Ukjent ☐			
PRIMERBEHANDLING					
Behandlingsregende sykdom ☐ Ja ☐ Nei		Behandling startet (ddmmåå)		Siktemål ☐ Helbredelse ☐ Palliasjon ☐	
Kirurgisk behandling ☐ Ja ☐ Nei		Sykehus		Operasjonsmetode (op. beskrivelse må vedlegges)	
Strålebehandling ☐ Ja ☐ Nei		Sykehus			
Kjemoterapi ☐ Ja ☐ Nei		Sykehus			
Annen behandling ☐ Ja ☐ Nei		Sykehus		Hvilebehandling ☐	
Studieprotokoll:					
Er ytterligere behandling planlagt? ☐ Ja ☐ Nei Sykehus Hvilken behandling					
Anses pasienten sykdomsfri etter primærbehandling? ☐ Ja ☐ Nei Pasienten fortsatt under behandling ☐ Ingen primærbehandling ☐					
OPPLYSNINGER SOM REGISTRERES HVS IKKE PASIENTEN MOTSETTER SEG DET					
Røyker ☐ Ja ☐ Nei		Tidligere røyker ☐ Motsetter seg reg. ☐		Yrker (nåværende og tidligere) Motsetter seg reg. ☐	
TILLEGGSOPPLYSNINGER					
dd mm åå		Pasientens ansvarlig lege (Etternavn, fornavn - trykte bokstaver)		Legens underskrift	
Meldt:		ID-nummer		ID-nummer	

VEILEDNING

Valg av skjema: Det finnes forskjellige skjemaer for ulike kreftsykdommer. I tillegg til dette skjemaet for malignt lymfom/kronisk lymfatisk leukemi finnes et skjema for øvrige non-solide svulster, et skjema for solid svulst og spesialskjemaer for brystkreft og eggstokkreft. Riktig skjema må benyttes. Operasjonsbeskrivelse må vedlegges hvis kirurgisk behandling er utført.

Veiledning til utfylling av enkelte sykdomsopplysninger:

Det vises til *Norsk handlingsprogram for utredning og diagnostikk av maligne lymfomer (Norsk lymfomgruppe, 2003)*. Opplysningene skal være om sykdommens art og utbredelse **på diagnosetidspunktet**.

Diagnosetidspunkt er dato for verifikasjon av diagnosen ved biopsi/cytologi/blod- eller benmargsutstryk, eventuelt annen verifikasjon.

Morfologisk diagnose angis i henhold til WHO: *Pathology and Genetics of Tumours of Haematopoietic and Lymphoid Tissues* (IARC Press, 2001) og Den norske SNOMED (www.kith.no). Ved samtidige ulike lymfomer eller diskordans anføres alle morfologiske typer.

Stadium på diagnosetidspunktet: Ulike stadieklassifikasjoner benyttes for nodale og primært ekstranodale lymfomer og kronisk lymfatisk leukemi. Klassifikasjonene er angitt nedenfor. For primært ekstranodalt lymfom må debutorgan angis.

Nodalt lymfom: Stadium i henhold til *Ann Arbor* (Carbone PP, Kaplan HS, Musshoff K, Smithers DW, Tubiana M. Report of the Committee on Hodgkin's Disease Staging Classification. *Cancer Res* 3: 1860-1861, 1971)

- I Lymfom i én lymfeknuteregion over eller under diafragma
 - II Lymfom i to eller flere lymfeknuteregioner på samme side av diafragma
 - IIIE Lymfom i én eller flere lymfeknuteregioner på samme side av diafragma med innvekst i ekstranodalt organ/vev[†]
 - II₁ Affeksjon av to naboregioner som naturlig inngår i ett strålefelt
 - III Lymfom i én eller flere lymfeknuteregioner på begge sider av diafragma
 - IIIE Lymfom i lymfeknuteregioner på begge sider av diafragma med innvekst i ekstranodalt organ/vev[†]
 - IV Diffust utbredt eller disseminert lymfom i ett eller flere ekstranodale organ/vev[†] med eller uten lymfeknuteaffeksjon
- [†]Affeksjon av milt, thymus og Waldeyers svelgving regnes som *nodal* affeksjon.

Primært ekstranodalt lymfom: Stadium etter **Musshoff** (Musshoff K. Klinische Stadieteilung der Nicht-Hodgkin Lymphome. *Strahlentherapie* 153: 218-221, 1977) modifisert av Nordisk lymfomgruppe 1997 for lymfomer som med stor grad av sikkerhet oppsto primært i et ekstranodalt organ (f.eks. magesekk)

- Pe I Lymfom primært i ekstranodalt organ/vev
- Pe IIE Lymfom primært i ekstranodalt organ/vev med overvekst på annet organ/vev
- Pe II₁ Lymfom primært i ekstranodalt organ/vev med spredning til regionale lymfeknuter
- Pe II₁E Lymfom primært i ekstranodalt organ/vev med spredning til regionale lymfeknuter og overvekst på annet organ/vev
- Pe II₂ Lymfom primært i ekstranodalt organ/vev med spredning til lymfeknuter utenfor de regionale, men på samme side av diafragma
- Pe II₂E Lymfom primært i ekstranodalt organ/vev med spredning til lymfeknuter utenfor de regionale, men på samme side av diafragma, samt overvekst på annet organ/vev

Ekstranodal lymfomaffeksjon: Alle affiserte organer/vev avkrysses.

B-symptomer foreligger (for nodalt og ekstranodalt lymfom) når ett eller flere av følgende finnes:

- Vekttap på mer enn 10% seneste 6 måneder
- Persisterende eller residiverende feber > 38°C seneste måned
- Gjentatt kraftig nattesvette seneste måned

Kronisk lymfatisk leukemi: Stadium i henhold til **Binet** (Binet JL, Auquier A, Dighiero G, Chastang C, Piguet H, Goasguen J *et al.* A New Prognostic Classification of Chronic Lymphocytic Leukemia Derived from a Multivariate Survival Analysis. *Cancer* 48: 198-206, 1981)

- A Hb≥10 og trombocytter ≥100.000 og < 3 forstørrede områder[‡]
- B Hb≥10 og trombocytter ≥100.000 og ≥ 3 forstørrede områder[‡]
- C Hb<10 og/eller trombocytter <100.000 (uansett antall forstørrede områder)

[‡]Fem omr
milt.

Diagnostikk: De diagnostiske prosedyrer som danner grunnlaget for diagnosen, avkrysses. For undersøkelser utført i patologi-laboratorium anføres remissenummer og år samt laboratorium ansvarlig for undersøkelsen.

Studieprotokoll: Angi hvilken studie, norsk eller internasjonal, fase I, II eller III.

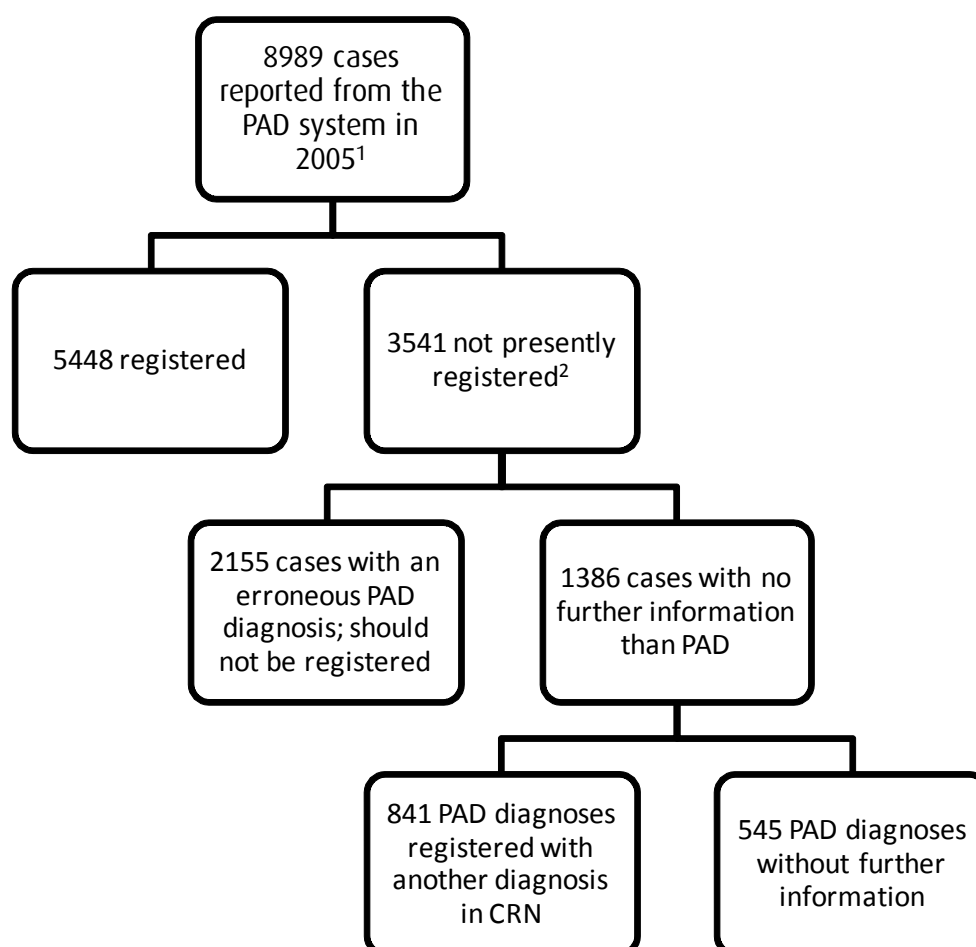
Røyking/yrke: Opplysninger om røykevaner og yrke anføres om ikke pasienten motsetter seg det.

Tilleggsopplysninger: Dersom uttømmende informasjon om sykdommen ikke kan gis, ønskes oppgitt hvor denne kan innhentes, f.eks dersom pasienten er henvist annen avdeling for utredning og/eller behandling.

Veiledningen er à jour pr. 01.04.2003. Se eventuelle oppdateringer på Kreftregisteret hjemmeside: www.kreftregisteret.no.
Kreftmeldingen er hjemlet i Kreftregisterforskriften (www.lovdata.no).

Appendix 8

An example of the PAD enquiry system – reminders sent, notifications received and missing cases for registrations in 2005 at the Registry



¹ As of 1st of November 2007

² The total for the two subgroups of missing cases do not add up to 3541. This occurs due to reminders being sent to two or more wards/hospitals for cases where we have received different information from the wards/hospitals involved.

Appendix 9

Comparison of the Registry M:I ratio, by site, with standard values.

The comparison populations are registries in the same country, or region indexed by

$i = 1, \dots, n$.

d_i = number of cases in Registry i

m_i = number of deaths in Registry i

We start with a *Poisson* model for m_i, d_i in which the ratio of expected values is θ . This model can be converted to a binomial model by conditioning on the total number of cases and deaths

$n_i = m_i + d_i$.

Then

$$\hat{\theta} = \frac{\sum_{i=1}^n m_i}{\sum_{i=1}^n d_i}$$

Define

$$\hat{\phi} = \frac{1}{n-1} \sum_{i=1}^n \frac{(m_i - \hat{\theta}d_i)^2}{n_i \hat{\theta}}$$

For the Registry under test, with cases d_j and deaths m_j , the test statistic is

$$Z^2 = \frac{(m_j - \hat{\theta}d_j)^2}{\hat{\phi}n_j\hat{\theta}} \sim \chi^2_1$$

So the Registry is flagged as unusual if $Z^2 \geq 3.84$.