Special Issue

Data quality at the Cancer Registry of Norway

Table of contents

1 Data Sources And Registration Routines At The Cancer Registry Of Norway 6
1.1 Notifications and sources of information 6
1.1.1 Clinical and pathological notifications 6
1.1.2 Death certificates 6
1.1.3 The Patient Administrative Database (PAD) 7
1.1.4 Data items registered in the Cancer Registry of Norway 7
1.2 Dispatching of reminders 8
1.3 Data sources and methods used in this Special Issue 8

2 Comparability 9
2.1 Definition 9
2.2 International standards for cancer registration 9
2.2.1 International Statistical Classification of Diseases, Injuries, and Causes of Death (ICD) 9
2.2.2 Manual of Tumor Nomenclature and Coding (MOTNAC) 10
2.2.3 International Classification of Diseases for Oncology (ICD-O) 10
2.3 International standard for definition of incidence 10
2.3.1 Incidence date 10
2.3.2 Multiple primaries 11
2.3.3 Incidental diagnosis 11
2.4 Results: comparability at the Registry 12
2.4.1 Cancer registration from 1952 to present 12
2.4.2 Staging information 12
2.4.3 Defining incidence 13
2.5 Comment: impact of changing classification and coding on comparability 15

3 Completeness 17
3.1 Definition 17
3.2 Methodological issues in estimating completeness 17
3.2.1 Qualitative methods 17
3.2.2 Quantitative methods 18
3.3 Methods used in this report 22
3.4 Previous studies of completeness 22
3.5 Results 23
3.5.1 Semi-quantitative analyses of completeness 23
3.5.2 Quantitative analyses of completeness 27

4 Validity (Accuracy) 38
4.1 Definition 38
4.2 Methodological issues in assessing validity 38
4.2.1 Reabstracting and recoding 38
4.2.2 Diagnostic criteria methods 39
4.2.3 Missing Information 39
4.2.4 Internal consistency 39

4.2.5 Previous studies of validity 39
4.3 Results: accuracy of data at the Registry 40
4.3.1 Accuracy based on specific indicators 40
4.3.2 Internal consistency 41
5 Timeliness 45
5.1 Definition 45
5.2 Methodological issues in assessing timeliness 45
5.2.1 Delay-adjusted rate 45
5.3 Results: timeliness at the Registry 45
5.3.1 Timeliness of receiving data 45
5.3.2 Timeliness of reporting at CRN 46
References 49
Appendix 1-7 51
Appendix 8 76
Appendix 9 77

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 clinicians - 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.

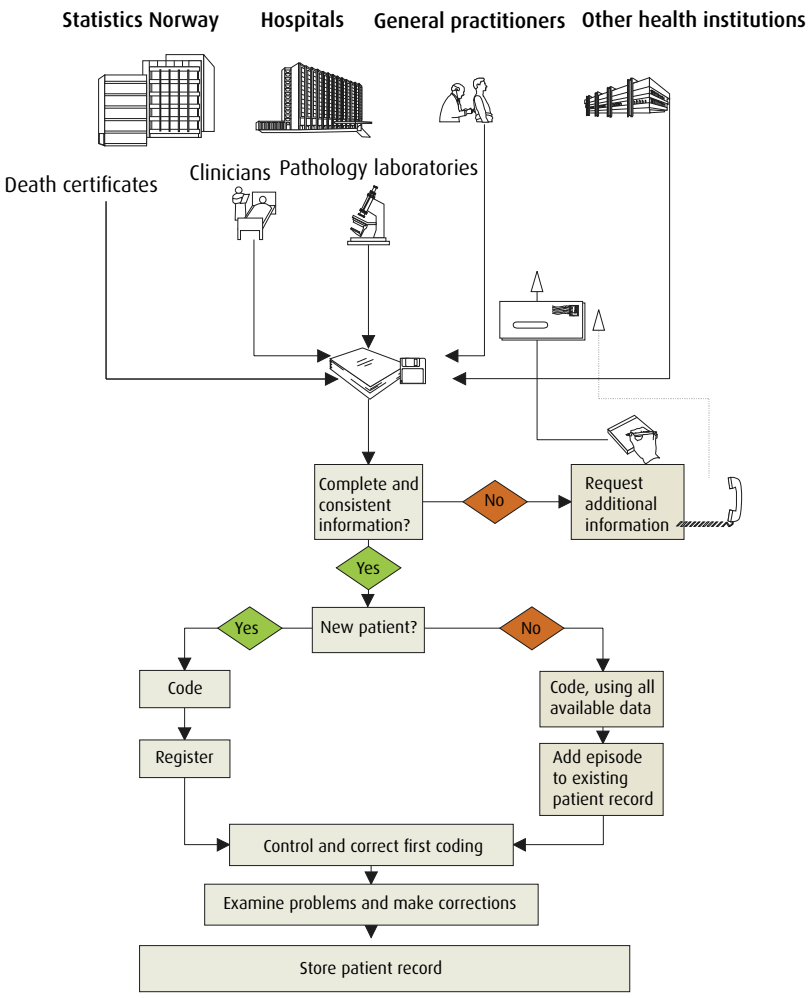
1.1.1 Clinical and pathological notifications

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:

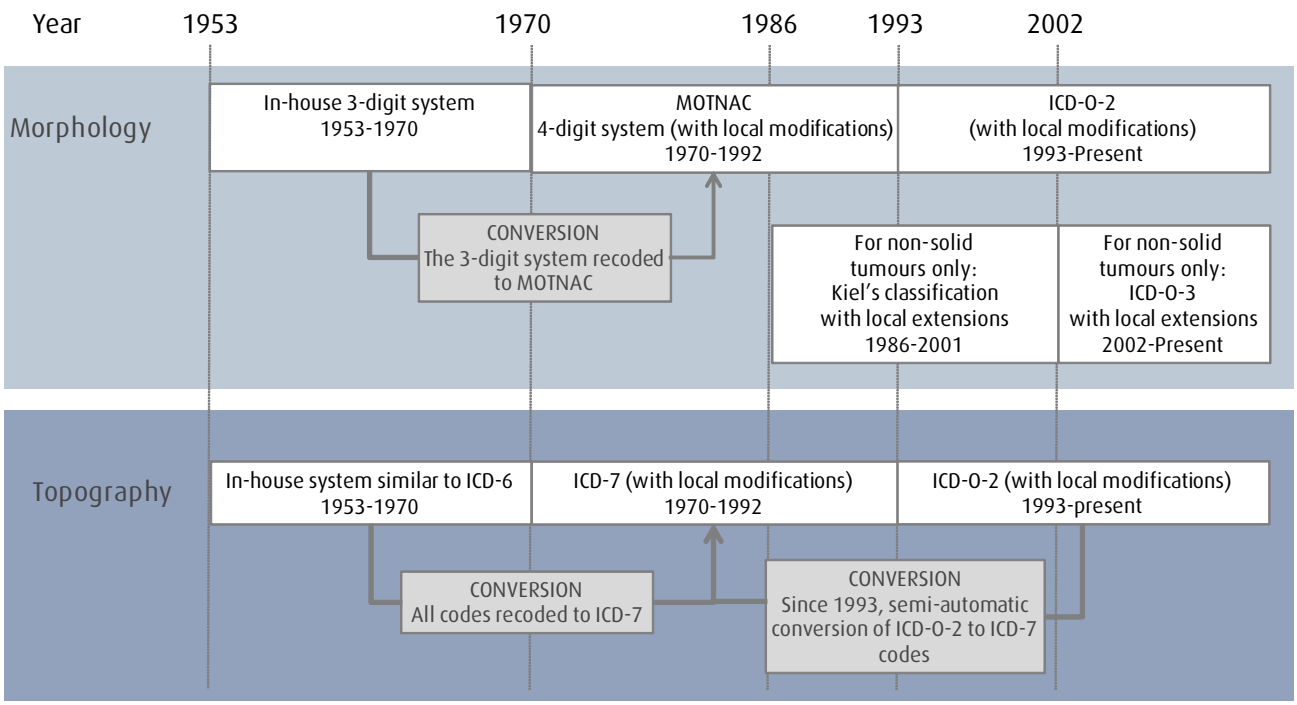
- Topography - location of the tumour in the body (synonyms are anatomical location or site).
- Morphology – cell type and its biological activity and behaviour.

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, leukaemias, 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

http://www.iacr.com.fr

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.encr.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.encr.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

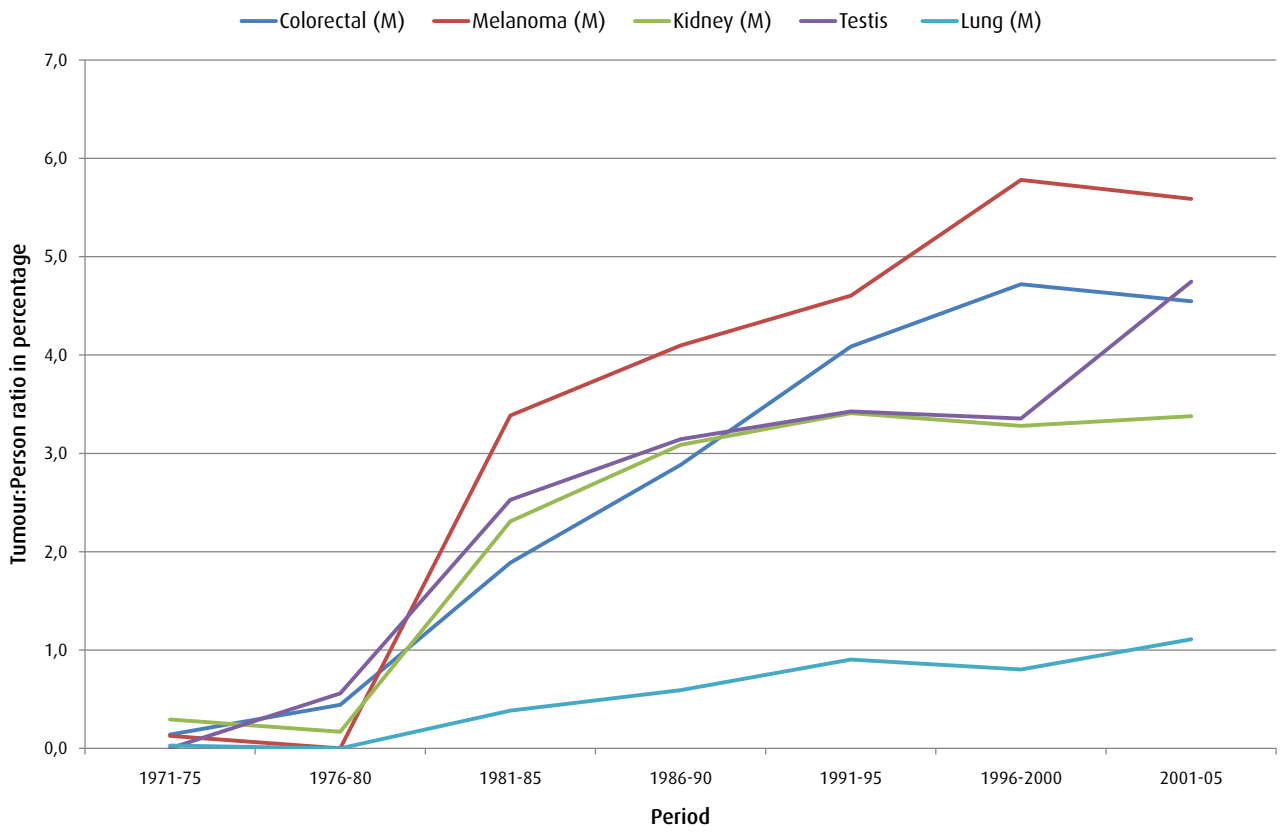
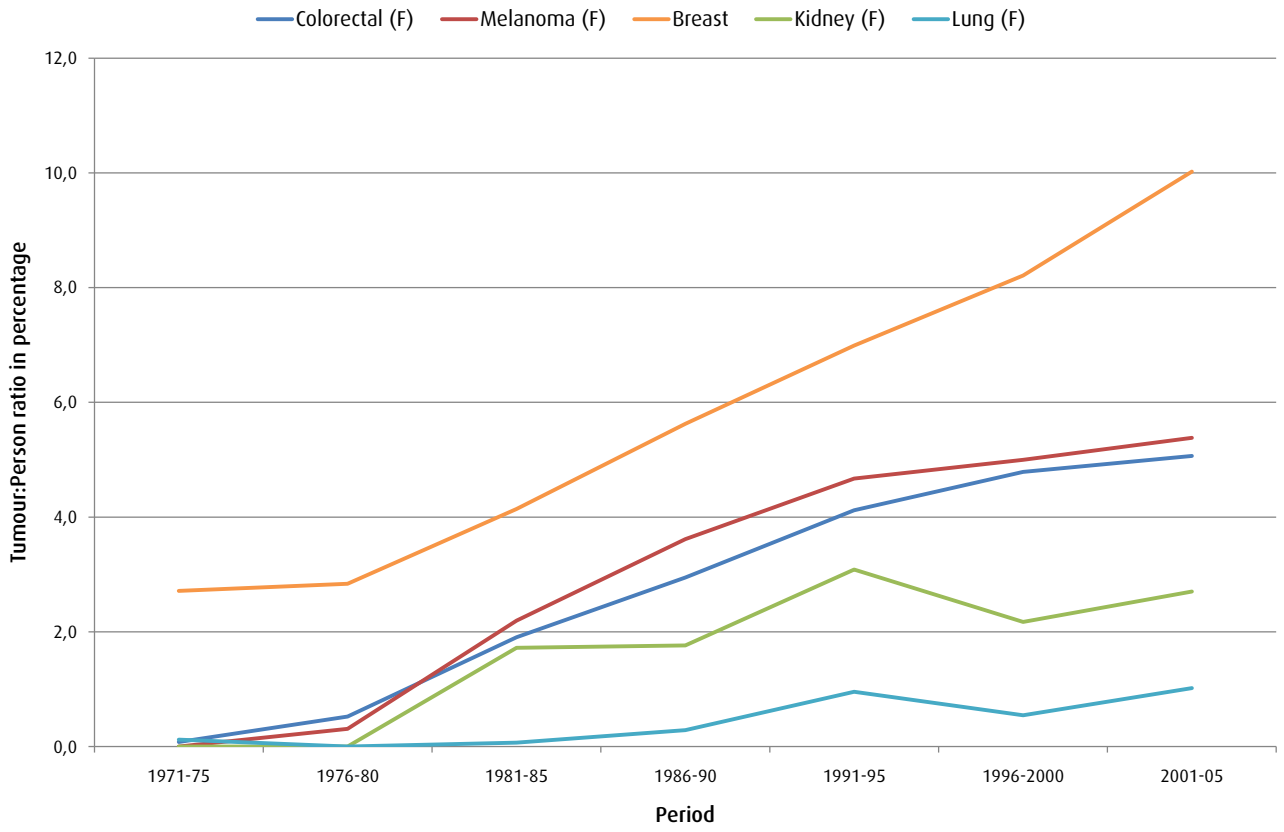


Figure S2.2b The tumour:person ratio (%) for selected cancers and sex, females, Norway 1971-2005



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.

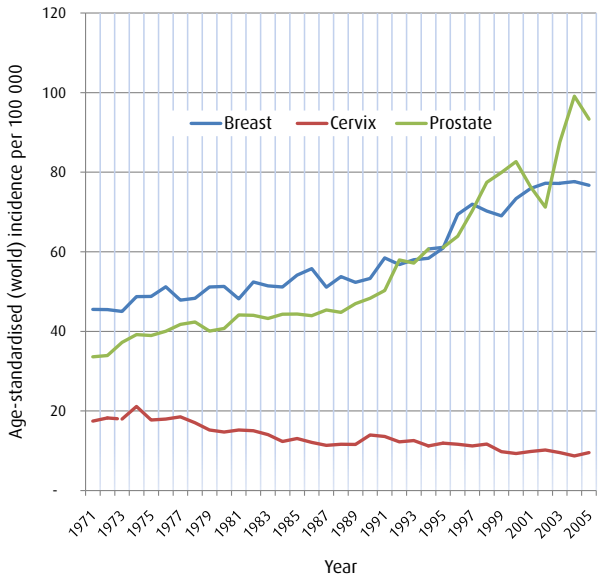
The Norwegian Breast Cancer Screening Programme (NBCSP) started in 1995-96 as a four-year pilot study in four of Norway's 19 counties, and became nationwide in 2005. The NBCSP has its own screening database within the Registry, and is thus able to calculate statistics on screen-detected cancers.

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))



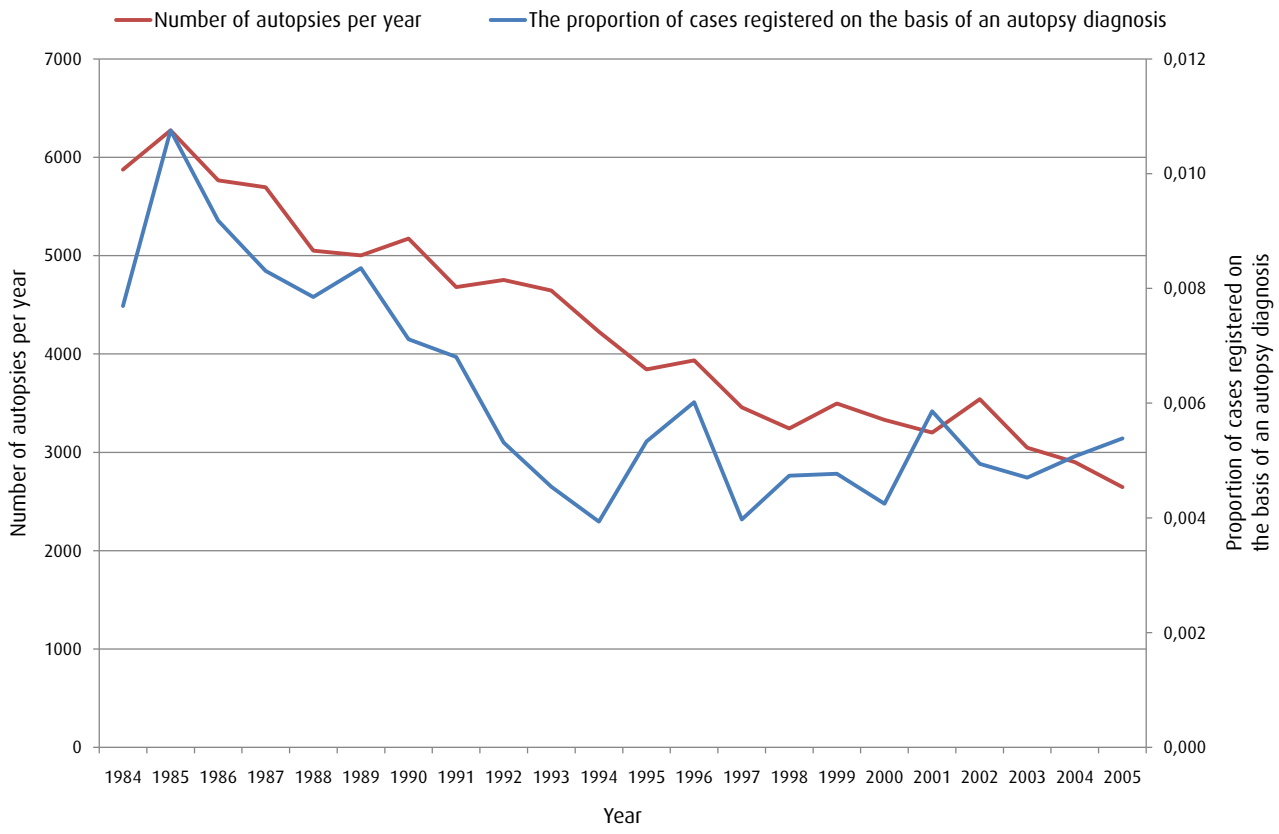
Cervical cancer: National screening program initiated in 1995
Prostate cancer: PSA-test commercially available in 1989
Breast cancer: A pilot study initiated in 4 counties in 1995, all counties included in 2005

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))

	Boys (reference)		Boys in Norway[1]	Girls (reference)		Girls in Norway[1]
Age	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.ancr.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 dependence 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

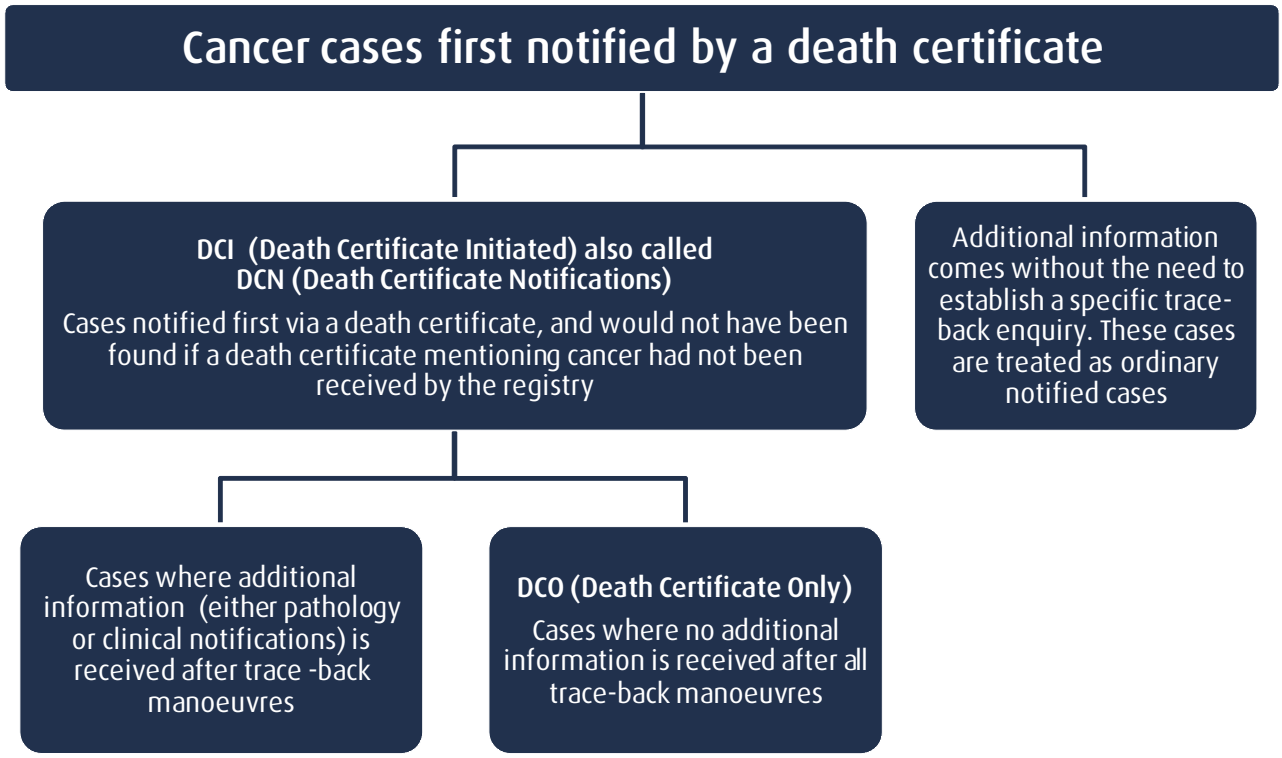
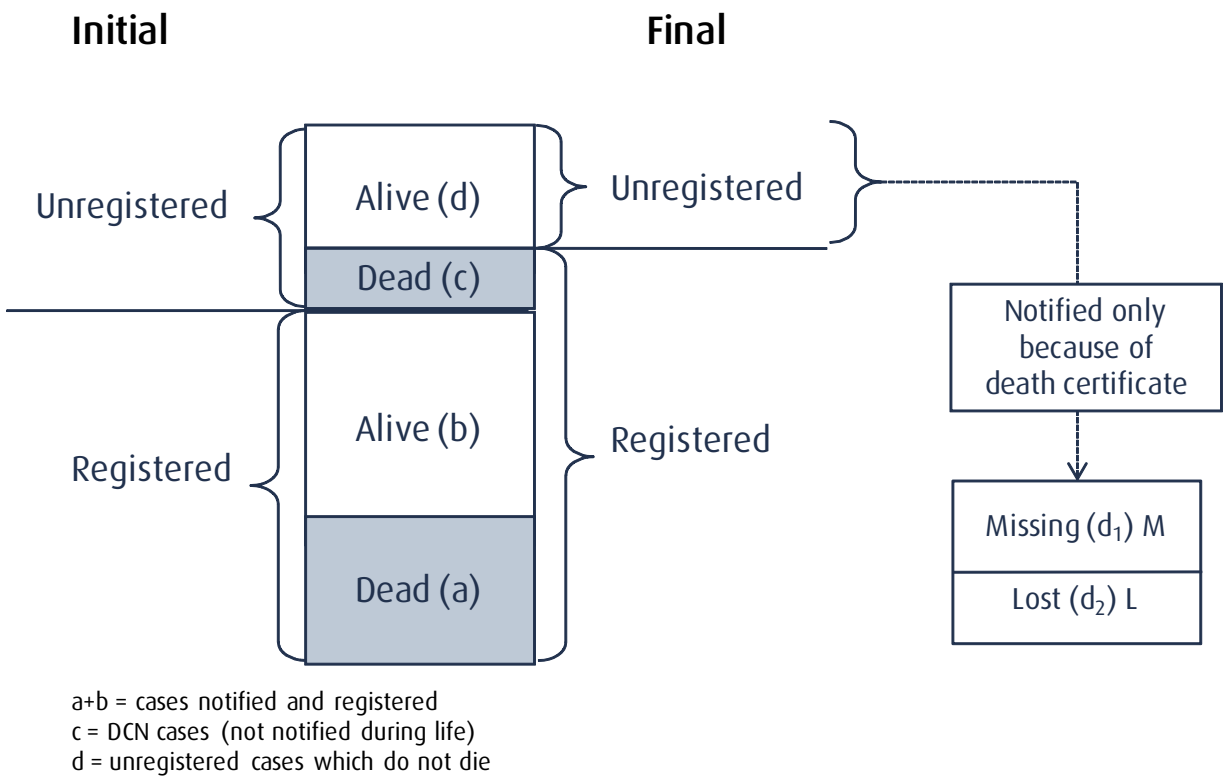


Figure S3.2 DCN as a measure of completeness (adapted from (5))



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 $s(t_i)$ x $u(t_i)$

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

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

N years after diagnosis, the lost cases would be

$$\Sigma ni=0 \quad [s(ti) - s(ti+1)] \times [1 - m(ti)] \times [u(ti)]$$

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 quantitative 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%).

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
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 histopatologic 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. Histolological 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.

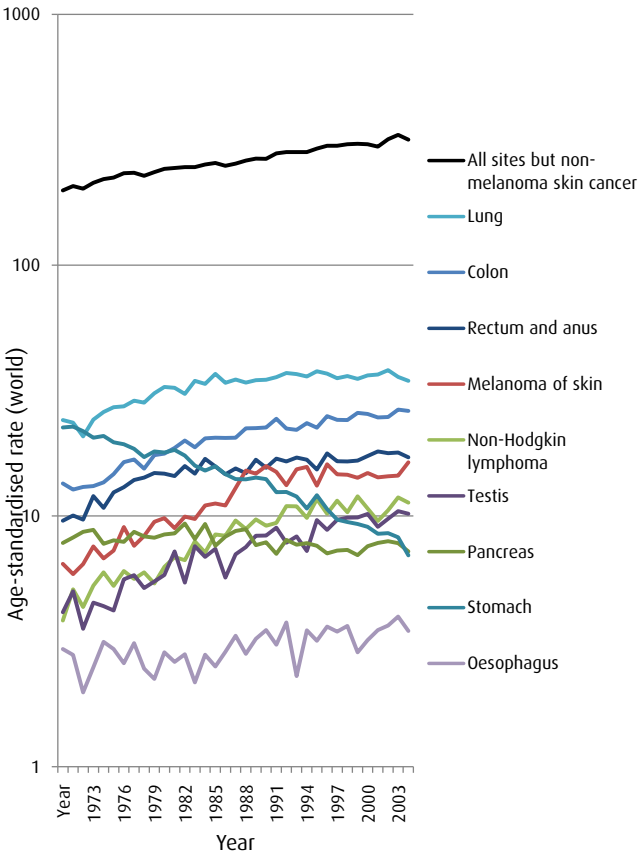
Mortality Incidence ratios

If the reporting of cause of death is completely accurate, and the incidence and survival rates are stable then the *M:I ratio = 1 - 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

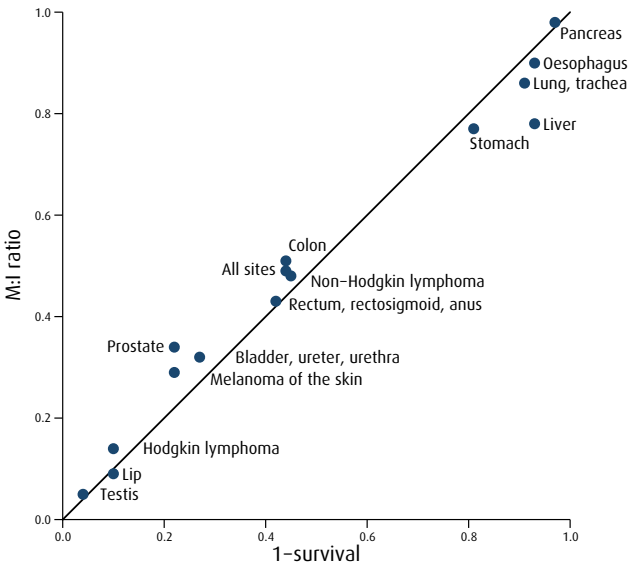
a) MALES



b) FEMALES

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

a) MALES



b) FEMALES

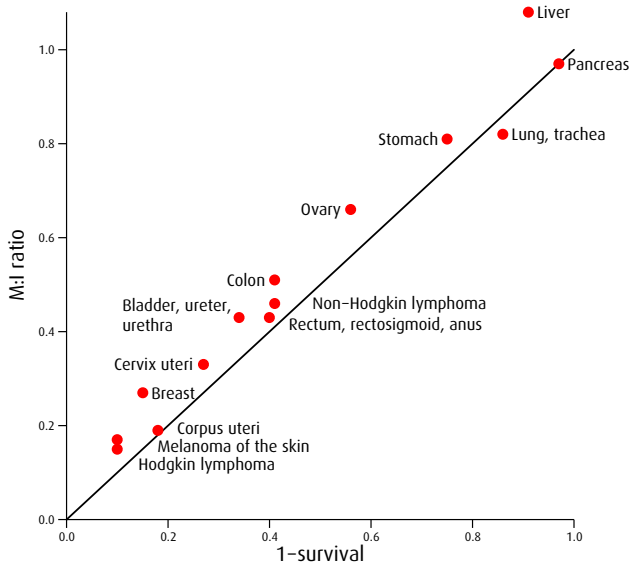


Table S3.3: Percentage morphologically verified (MV%), percentage obtained from death certificate only (%DCO), Norway 2001-2005, and the ratio of number of deaths to number of new cases (M:I ratio) 2000-2004

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).

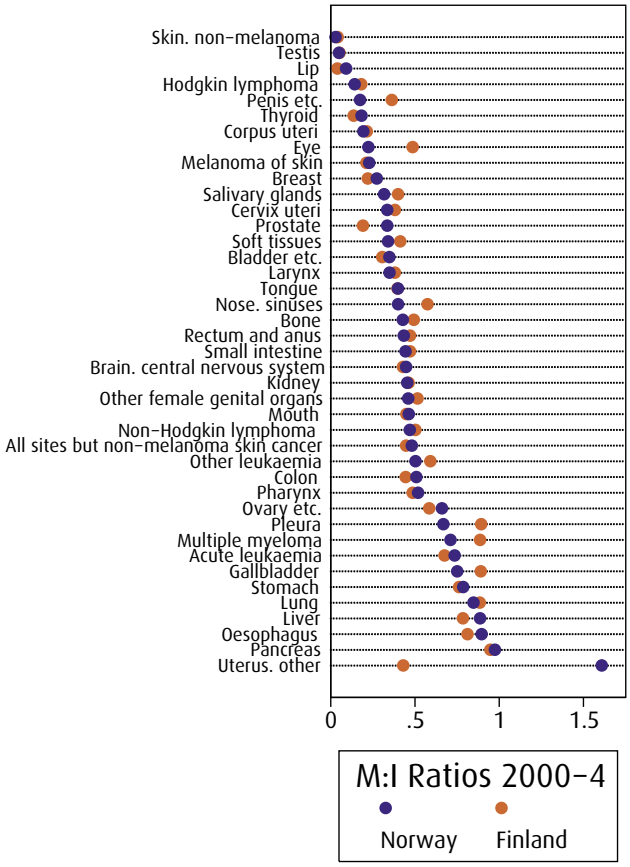
Figure S3.5 show the M:I ratios for all sites, 2000-2004 in Norway and Finland based on NORDCAN data (8). In general there is good concordance with the M:I ratios in Norway with those in Finland. Using the tests outlined in Appendix 9, 11 of the 34 sites showed some significant differences. Those cancers 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



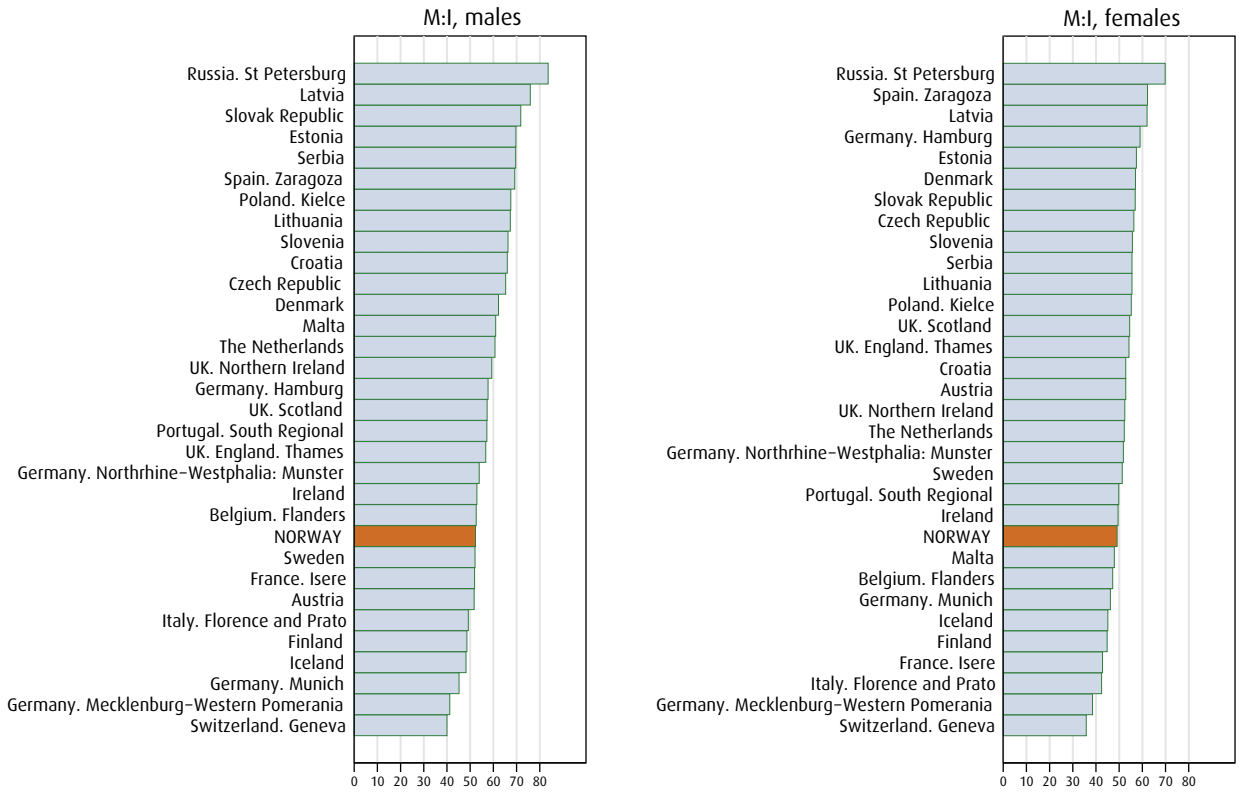
3.5.2 Quantitative analyses of completeness

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 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

			Year of diagnosis				
ICD-10	**Site**	**Type**	**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

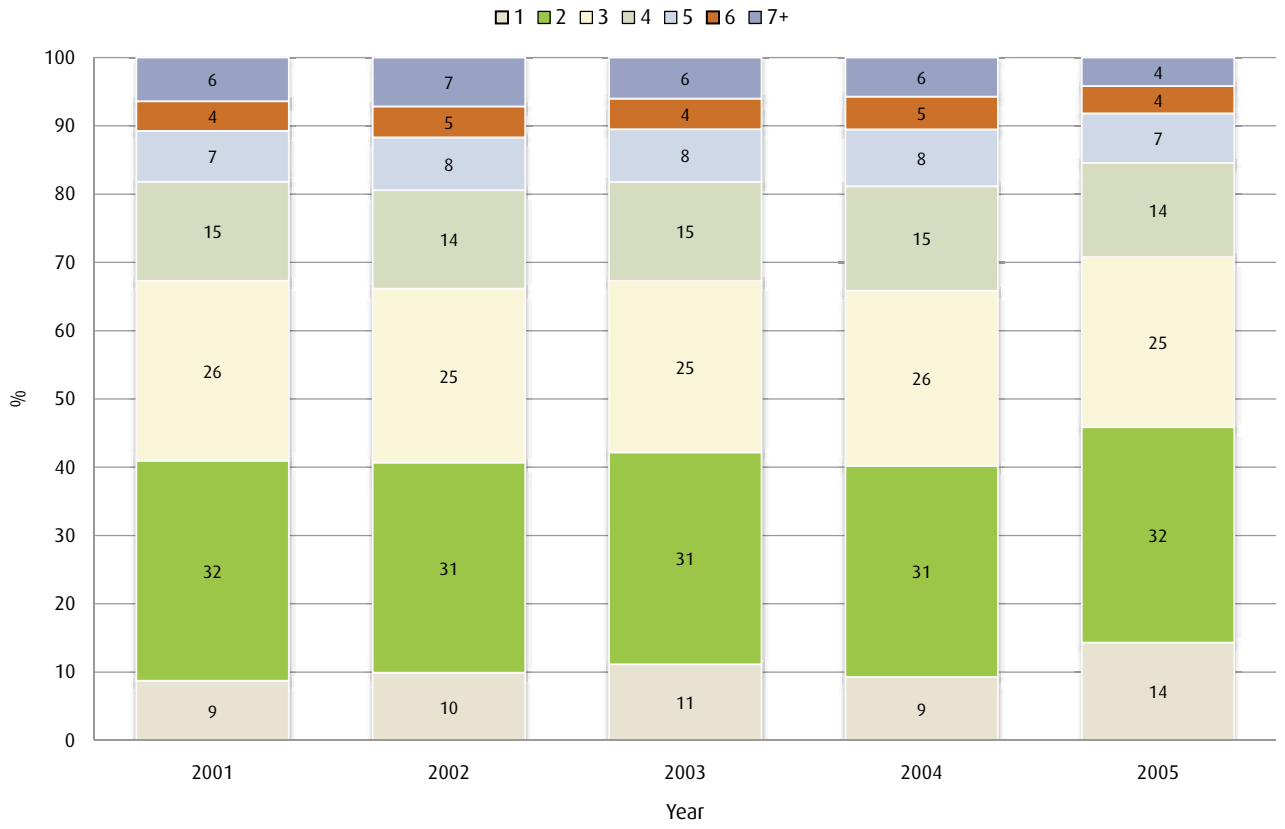
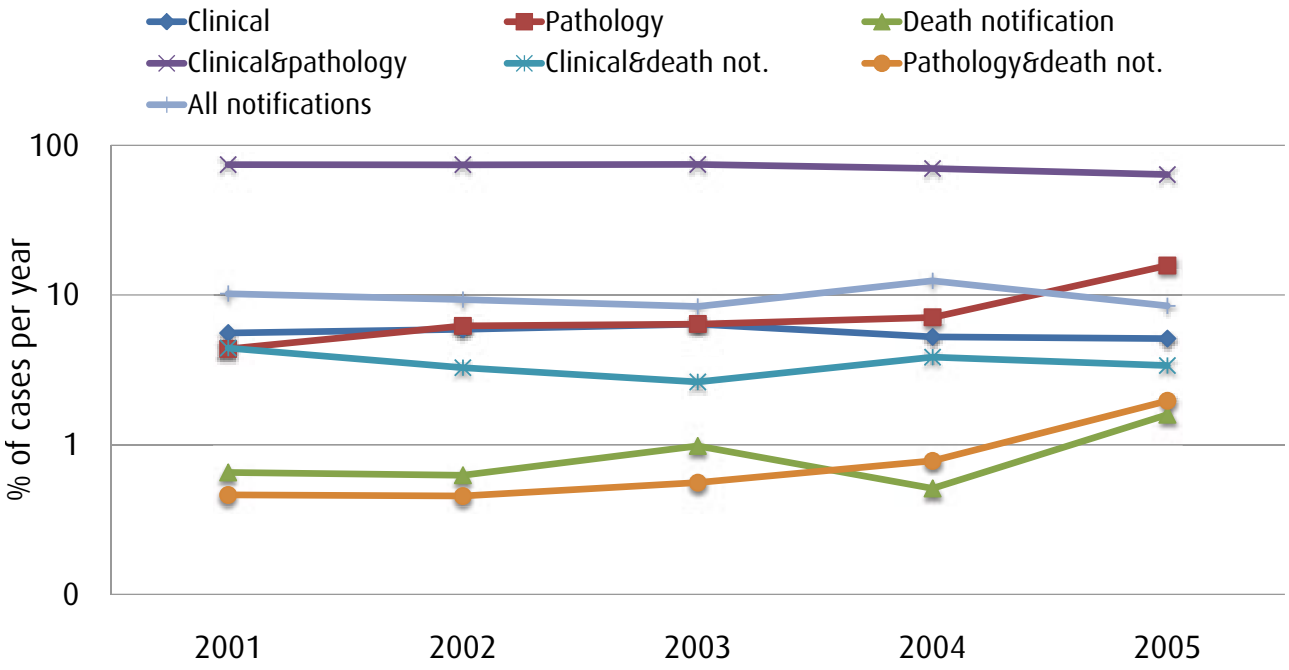


Figure S3.8: Percentage of annual cases registered with information from one, two, or three sources, Norway 2001-2005



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.

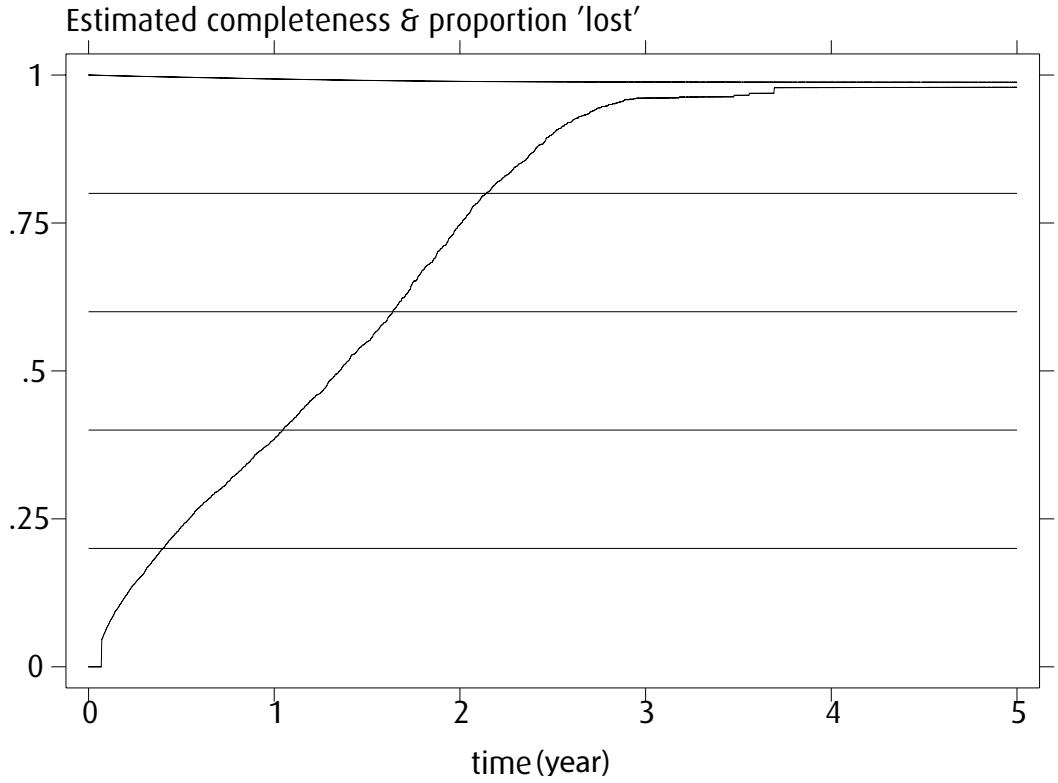
On this basis, and with the exception of lung cancer, completeness estimates for 2001-5 were extremely high for the most common cancers, and ranged from 99.8% to 100% for cancer of the bladder, colon and rectum, lung, breast and prostate and melanoma of the skin. The completeness was lower for cancers 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 registrations 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

	Clinical records: death certificate vs. pathology				Pathology records: clinical vs. death certificate				Death certificate records: clinical vs. pathology			
Site	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:

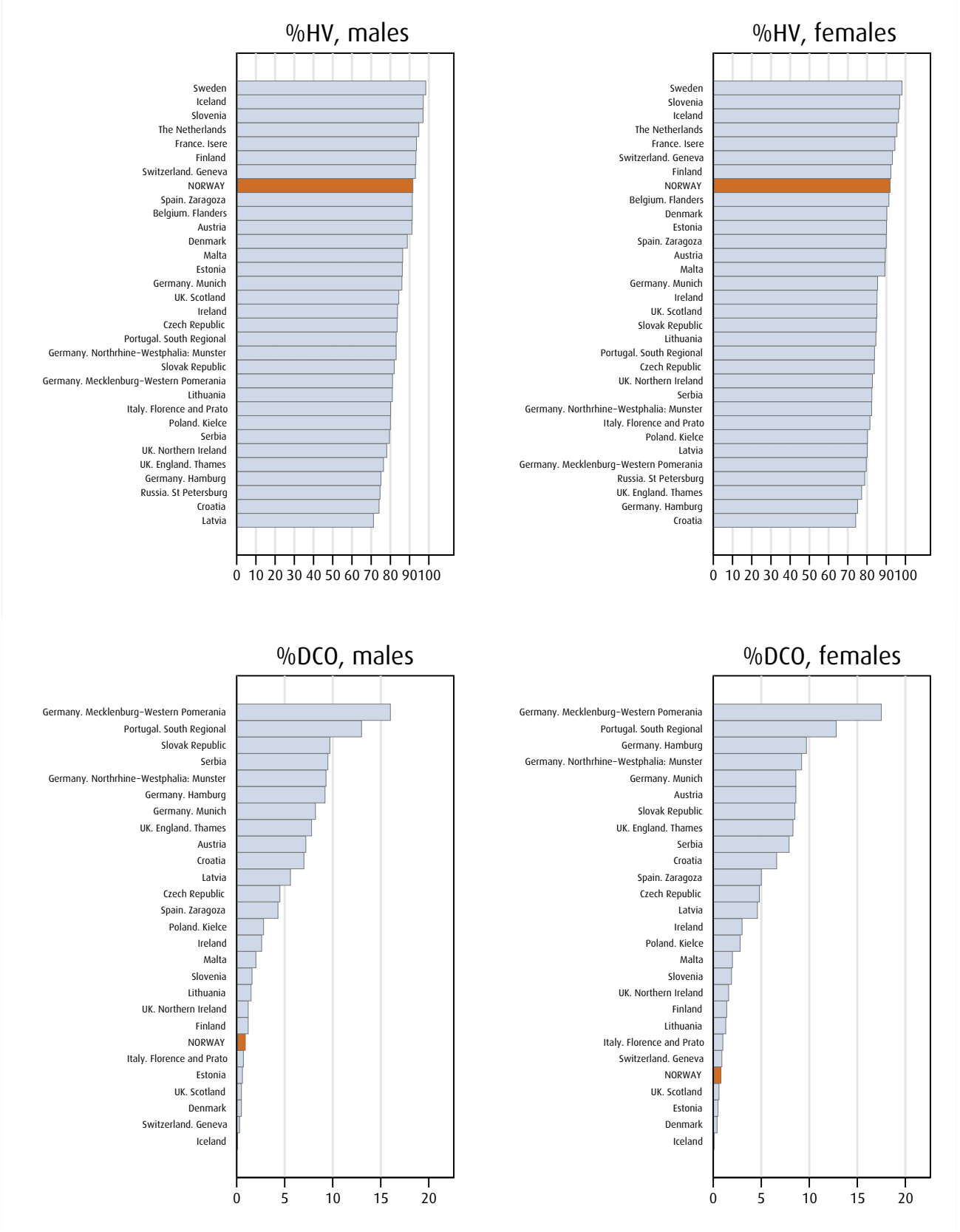
C26	Other digestive organs
C48-49	Soft tissues
C51-52,C57	Other female genital
C60-63	Other male genital
C 37,C74-75	Other endocrine glands

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

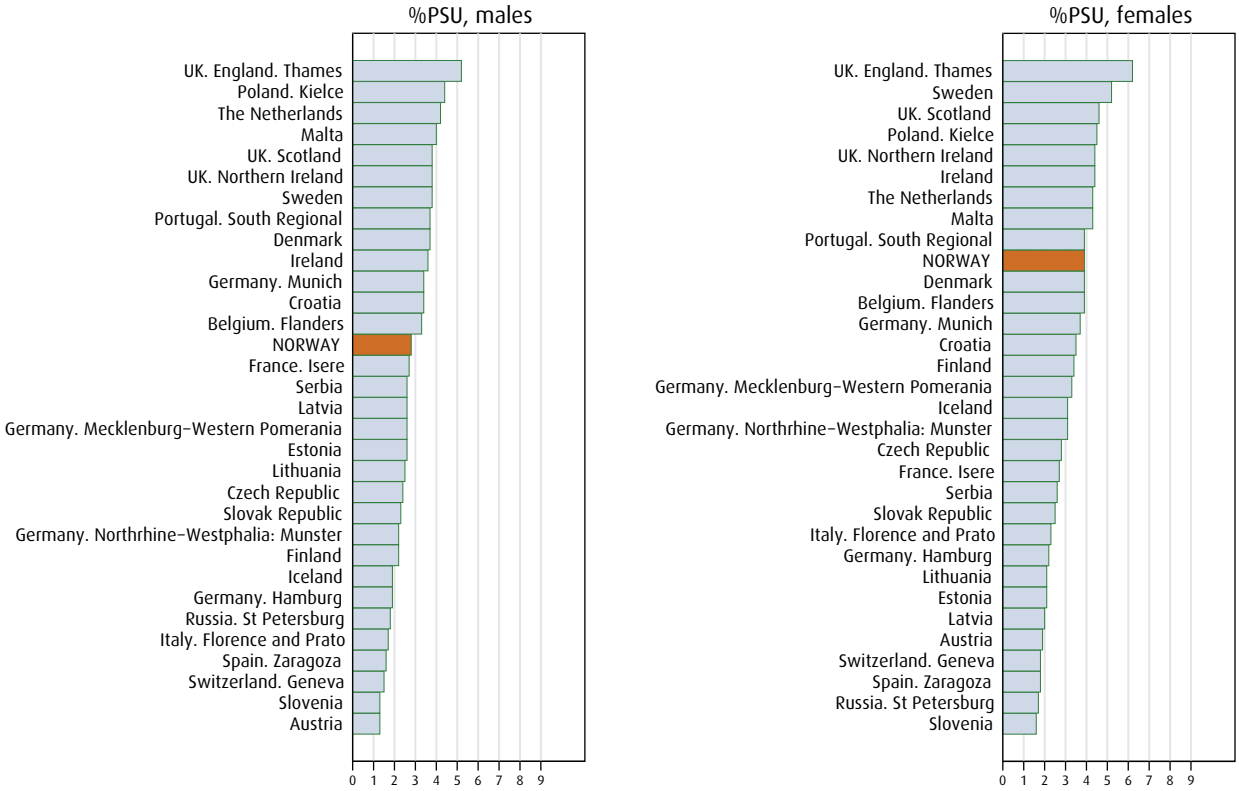


unspecified, with 4% of diagnoses registered with unknown stage for cervix and 0.5% for breast cancer.

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

	Age			
Year	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

	Cases per reported stadium							
Site	**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

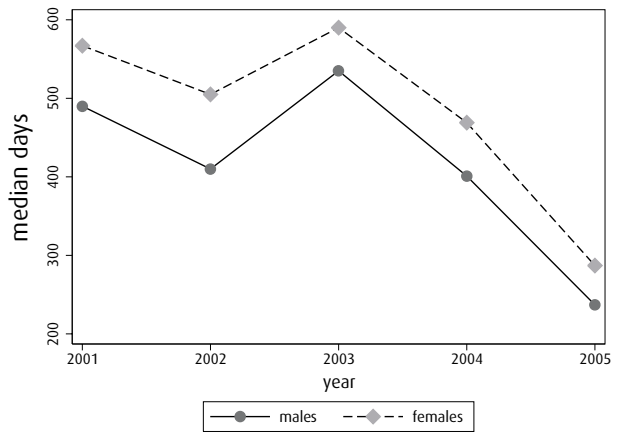
Registries are constantly updating their database as reports are received, and some, especially death certificate notifications, arrive long after the case was diagnosed. Thus, incidence figures for recent years will need future updates. If interest is in the profile of cancer, in terms of incidence 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 that 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 %

References

1. Brewster D. Improving the quality of cancer registration data. J.R.Soc. Med. 1995;88:268-71.

2. Storm HH. Cancer registries in epidemiologic research. Cancer Causes Control 1996;7:299-301.

3. Storm HH, Michelsen EV, Clemmensen IH, Pihl J. The Danish Cancer Registry--history, content, quality and use. Dan.Med.Bull. 1997;44:535-9.

4. Skeet RG. Quality and quality control. In: Jensen OM, Parkin DM, macl, MacLennan R, Muir CS, Skeet RG. Cancer Registration. Principles and Methods., N 95 ed. Lyon: IARC Scientific Publications, 1991:101-7.

5. Parkin, D. M., Chen, V. W., Ferlay, J., Galceran, J., Storm H.H., and Whelan S.L. Comparability and Quality Control in Cancer Registration. IARC Technical Report No. 19. 1994. Lyon, International Agency for Research on Cancer World Health Organization and International Association of Cancer Registries.

6. Lund, E. In: The Cancer Registry of Norway. Incidence of Cancer in Norway 1978.. Cancer Registry of Norway, 1981:11-14.

7. Helseth A, Langmark F, Mork SJ. Neoplasms of the central nervous system in Norway. I. Quality control of the registration in the Norwegian Cancer Registry. APMIS 1988;96:1002-8.

8. Engholm G, Storm H, Ferlay J, Christensen N, Bray F, Ólafsdóttir E et al. NORDCAN: Cancer Incidence and Mortality in the Nordic Countries, Version 3.0. Association of Nordic Countries. Danish Cancer Society, 2007.

9. Ferlay J, Bray F, Pisani P, Parkin DM. GLOBOCAN 2002: Cancer Incidence, Mortality and Prevalence Worldwide. IARC CancerBase No. 5. version 2.0. Lyon: IARCPress, 2004.

10. Parkin DM, Whelan S.L., Ferlay J, Teppo L, Thomas DB, (Eds.). Cancer incidence in five continents, Volume VIII, no 155 ed. Lyon: International Agency for Research on Cancer, 2002:LVII, 781.

11. Curado MP, Edwards B, Shin HR, Storm H, Ferlay J, Heanue M et al. Cancer Incidence in Five Continents, vol. IX. Lyon: IARC, 2007.

12. Fritz A. International classification of diseases for oncology: ICD-O. Geneva: World Health Organization, 2000:VII, 240.

13. World Health Organization. Manual of the international statistical classification of diseases, injuries and causes of death: based on the Recommendations of the Seventh Revision Conference, 1955, and adopted by the Ninth World Health Assembly under the WHO Nomenclature Regulations. Geneva: WHO, 1957:2.

14. American Cancer Society. Task Force to Revise the Manual of Tumor Nomenclature and Coding for the American Cancer Society IEd. Manual of Tumor Nomenclature and Coding. New York: American Cancer Society, Inc, 1951:74.

15. College of American Pathologists. Systematized nomenclature of pathology. Chicago, IL.: 1965:XXI, 439.

16. American Cancer Society. Task Force to Revise the Manual of Tumor Nomenclature and Coding for the American Cancer Society IE. Manual of Tumor Nomenclature and Coding: 1968 ed. New York: American Cancer Society, Inc, 1968:74.

17. World Health Organization. International classification of diseases for oncology. Geneva: WHO, 1976:xxiii, 131.

18. Systematized nomenclature of medicine, vol. Vols I and II. Skokie, IL.: College of American Pathologists, 1977:2.

19. Percy C, Van Holten V, Muir C. International classification of diseases for oncology: ICD-O, Second ed. Geneva: World Health Organization, 1990:xlv, 144.

20. Parkin DM, Plummer M. Comparability and quality of data. In: Parkin DM, Whelan S.L., Ferlay J, Teppo L, Thomas DB. Cancer incidence in five continents, Volume VIII, no 155 ed. Lyon: IARC Scientific Publications, 2002:57-74.

21. International Association of Cancer Registries. Multiple primaries. IARC Internal Report 2000/03. International Agency for Research on Cancer (IARC), 2000.

22. International Association of Cancer Registries. International rules for multiple primary cancers (ICD-O Third Edition). IARC Technical Report 2004/02. International Agency for Research on Cancer (IARC), 2004.

23. Harbitz TB, Haugen OA. Histology of the prostate in elderly men. A study in an autopsy series. Acta Pathol.Microbiol.Scand.[A] 1972;80:756-68.

24. Schouten L, Botha H, Paci E. Method of detection in relation to screening. In: Tyczynski JE, Démaret E, Parkin DM. Standards and guidelines for cancer registration in Europe: the ENCR recommendations, volume 1. Lyon: International Agency for Research on Cancer, 2003:14.

25. Saxen E. Trends: Facts or fallacy. In: Magnus K. Trends in cancer incidence: causes and practical implications. Washington, D.C.: Hemisphere Pub., 1982:xvi,446.

26. Manual of the international statistical classification of diseases, injuries, and causes of death. Geneva: World Health Organization, 1948:2.

27. International statistical classification of diseases and related health problems. Geneva: WHO, 1992:3.

28. Pedersen E. Cancer registration in Norway: the incidence of cancer in Norway 1953-1954, no. 1 ed. Oslo: Landsforeningen mot kreft, 1959:183.

29. Cancer in Norway 2005. Oslo: Cancer Registry of Norway. Institute of Population-based cancer research, 2006.

30. Wittekind C, Greene FL, Hutter RVP, Klimpfinger M, Sobin LHE. TNM atlas: illustrated guide to the TNM/pTNM classification of malignant tumours, 5th ed. Berlin: Springer, 2004:XV, 383.

31. Pecorelli S, Benedet JL, Creasman WT, Shepherd JH. FIGO staging of gynecologic cancer. 1994-1997 FIGO Committee on Gynecologic Oncology. International Federation of Gynecology and Obstetrics. Int. J.Gynaecol.Obstet. 1999;64:5-10.

32. Carbone PP, Kaplan HS, Musshoff K, Smithers DW, Tubiana M. Report of the Committee on Hodgkin's Disease Staging Classification. Cancer Res. 1971;31:1860-1.

33. Musshoff K. [Clinical staging classification of non-Hodgkin's lymphomas (author's transl)]. Strahlentherapie. 1977;153:218-21.

34. Nygård, Jan F. Effectiveness of cervical cancer screening: an epidemiological study based on register data from a population-based, co-ordinated cervical cancer screening programme. 1. 2005. Faculty of Medicine, University of Oslo.

35. Perry N. European guidelines for quality assurance in mammography screening. Luxembourg: Office for Official Publications of the European Communities, 2001:366.

36. Den Norske Patologiforening. Obduksjoner i Norge 1984-2005. http://www.legeforeningen.no/asset/33118/1/3318_1. 2007. 24-8-

2007.

37. Havener L. Standards for Cancer Registries Volume III: Standards for Completeness, Quality, Analysis and Management of Data. Springfield (IL): North American Association of Central Cancer Registries, 2004.

38. Ajiki W, Tsukuma H, Oshima A. [Index for evaluating completeness of registration in population-based cancer registries and estimation of registration rate at the Osaka Cancer Registry between 1966 and 1992 using this index]. Nippon Koshu Eisei Zasshi 1998;45:1011-7.

39. Bullard J, Coleman MP, Robinson D, Lutz JM, Bell J, Peto J. Completeness of cancer registration: a new method for routine use. Br.J.Cancer 2000;82:1111-6.

40. Storm HH. Completeness of cancer registration in Denmark 1943-1966 and efficacy of record linkage procedures. Int.J.Epidemiol. 1988;17:44-9.

41. Swerdlow AJ, Douglas AJ, Vaughan HG, Vaughan HB. Completeness of cancer registration in England and Wales: an assessment based on 2,145 patients with Hodgkin's disease independently registered by the British National Lymphoma Investigation. Br.J.Cancer 1993;67:326-9.

42. Schouten LJ, Hoppener P, van den Brandt PA, Knottnerus JA, Jager JJ. Completeness of cancer registration in Limburg, The Netherlands. Int. J.Epidemiol. 1993;22:369-76.

43. Villard-Mackintosh L, Coleman MP, Vessey MP. The completeness of cancer registration in England: an assessment from the Oxford-FPA contraceptive study. Br.J.Cancer 1988;58:507-11.

44. Parkin DM, Wabinga H, Nambooze S. Completeness in an African cancer registry. Cancer Causes Control 2001;12:147-52.

45. Hook EB, Regal RR. Capture-recapture methods in epidemiology: methods and limitations. Epidemiol.Rev. 1995;17:243-64.

46. Schouten LJ, Straatman H, Kiemeney LA, Gimbrere CH, Verbeek AL. The capture-recapture method for estimation of cancer registry completeness: a useful tool? Int.J.Epidemiol. 1994;23:1111-6.

47. Brenner H, Stegmaier C, Ziegler H. Estimating completeness of cancer registration in Saarland/Germany with capture-recapture methods. Eur.J.Cancer 1994;30A:1659-63.

48. Crocetti E, Miccinesi G, Paci E, Zappa M. An application of the two-source capture-recapture method to estimate the completeness of the Tuscany Cancer Registry, Italy. Eur.J.Cancer Prev. 2001;10:417-23.

49. Seddon DJ, Williams EM. Data quality in population-based cancer registration: an assessment of the Merseyside and Cheshire Cancer Registry. Br.J.Cancer 1997;76:667-74.

50. Tilling K. Capture-recapture methods--useful or misleading? Int. J.Epidemiol. 2001;30:12-4.

51. Brenner H. Limitations of the death certificate only index as a measure of incompleteness of cancer registration. Br.J.Cancer 1995;72:506-10.

52. Brenner H. Use and limitations of the capture-recapture method in disease monitoring with two dependent sources. Epidemiology 1995;6:42-8.

53. Regal RR, Hook EB. The effects of model selection on confidence intervals for the size of a closed population. Stat.Med. 1991;10:717-21.

54. Robles SC, Marrett LD, Clarke EA, Risch HA. An application of capture-recapture methods to the estimation of completeness of cancer registration. J.Clin.Epidemiol. 1988;41:495-501.

55. Tilling K, Sterne JA. Capture-recapture models including covariate effects. Am.J.Epidemiol. 1999;149:392-400.

56. Parkin DM, Muir CS. Comparability and quality of data. In: Parkin DM, Muir CS, Whelan S.L., Gao Y-T, Ferlay J, Powell J. Cancer incidence in five continents, Volume VI (IARC Scientific Publications No.120), no 120 ed. Lyon: International Agency for Research on Cancer, 1992:45-173.

57. Silcocks PB, Robinson D. Completeness of ascertainment by cancer registries: putting bounds on the number of missing cases. J.Public Health (Oxf) 2004;26:161-7.

58. Mork J, Thoresen S, Faye-Lund H, Langmark F, Glattre E. Head and neck cancer in Norway. A study of the quality of the Cancer Registry of Norway's data on head and neck cancer for the period 1953-1991. APMIS 1995;103:375-82.

59. Harvei S, Tretli S, Langmark F. Quality of prostate cancer data in the cancer registry of Norway. Eur.J.Cancer 1996;32A:104-10.

60. Tingulstad S, Halvorsen T, Norstein J, Hagen B, Skjeldestad FE. Completeness and accuracy of registration of ovarian cancer in the cancer registry of Norway. Int.J.Cancer 2002;98:907-11.

61. Percy C, Stanek E, III, Gloeckler L. Accuracy of cancer death certificates and its effect on cancer mortality statistics. Am.J.Public Health 1981;71:242-50.

62. Brewster D, Crichton J, Muir C. How accurate are Scottish cancer registration data? Br.J.Cancer 1994;70:954-9.

63. Parkin DM. Comparability and quality of data. In: Parkin DM, Whelan SL, Ferlay J, Raymond L, Young J. Cancer Incidence in Five Continents, vol. Vol VII IARC Scientific Publications No. 143. Lyon: International Agency for Research on Cancer, 1997:45-57.

64. Ferlay, J, Burkhard, C., Whelan, S., and Parkin, D. M. Check and conversion programs for cancer registries (IARC/IACR Tools for Cancer Registries). IARC Technical Report. 42. 2005. Lyon.

65. Smith-Gagen J, Cress RD, Drake CM, Felter MC, Beaumont JJ. Factors associated with time to availability for cases reported to population-based cancer registries. Cancer Causes Control 2005;16:449-54.

66. Midthune D, Fay M, Clegg L, Feuer E. Modeling reporting delay and reporting corrections in cancer registry data. J Am Stat Assoc 2005;100:61-70.

MELDING TIL KREFTREGISTERET

SOLIDE SVULSTER

Skjema i kraft fra 01.01.2003 — MONTEBELLO, 0310 OSLO — Non-solide svulster meldes på eget skjema

PASIENT

Fødselsnr. — Postnr. — Poststed

Etternavn — Fornavn

BEHANDLINGSINSTITUSJON — **DIAGNOSETIDSPUNKT**

Institusjon — Avdeling — Dag Mnd År

Innlagt — Poliklinisk — Dag Mnd År — Utskrevet — I live — Død

Dato

PRIMÆRTUMORS UTGANGSPUNKT: Organ og område innen organet (f. eks. «høyre lunge, overlapp»)

Side: H — V — Begge — Ikke relevant — Sideuligent

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 — Funnet ved screening — Hvilke symptomer eller sykdomstegn

Dag Mnd År

Når oppsto første symptomer — Når søkt lege

Arvelig disposisjon for kreft Nei — Påvist — Mistenkt — Hva slags?

SYKDOMMENS UTBREDELSE PÅ DIAGNOSETIDSPUNKTET (bestemt på grunnlag av informasjon tilgjengelig før behandling)

Klinisk TNM: T — N — M — eller Stadium — Ifg stadie-klassifikasjon

Beskrivelse av sykdomsutbredelsen på diagnosetidspunktet basert på all tilgjengelig viten etter utredning og undersøkelse av evt. operasjonspreparat

Gjennomvekst av naturlig organbegrensning — Ja — Nei — Primærtumors største diameter ____ - ____ cm

Innvekst i naboorgan/-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

Bildediagnostikk (røntgen, UL, CT, MR) — Ja — Nei

Evt. andre undersøkelser (f.eks. bidkjemisk u.s., skopi, stemal-marg, kirurgisk eksplorasjon) — Ja — Nei

Hvilke

	År	Preparatnummer	Laboratorium
Cytologisk prep.			
Histologisk prep.			
Histologisk prep.			
Obduksjonsprep.			

PRIMÆRBEHANDLING

Dag Mnd År

Startet når — Ingen primærbehandling — Primærbehandlingens siktemål — Helbredelse — Palliasjon

Kirurgisk behandling — Ja — Nei — Hvilken? — Op. metode (op. beskrivelse må vedlegges)

Strålebehandling — Ja — Nei

Hormonbehandling — Ja — Nei

Cytostatisk behandling — Ja — Nei

Annen behandling — Ja — Nei — Hvilken

Er ytterligere behandling planlagt? Ja — Nei — Hvilken behandling — Hvilken institusjon?

Restumor etter primærbehandling — Ja, makroskopisk — Ja, mikroskopisk — Nei — Vet ikke

OPPLYSNINGER SOM REGISTRERES HVIS IKKE PASIENTEN MOTSETTER SEG DET

Røyker Ja — Nei — Tidligere røyker — Motsetter seg reg. — Yrke — Motsetter seg reg.

TILLEGGSOPPLYSNINGER

Dag Mnd År

Meldt:

Pasientansvarlig lege (Etternavn, fornavn - trykte bokstaver) — Legens underskrift

Id. nummer — Id. nummer

Utfylling av meldeskjemaet for

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 tilsvarer 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 remissenummer, 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

SOLIDE SVULSTER

HAUKELAND SYKEHUS KIRURGISK 030502

010502

COLON ASCENDENS

ADENOCARCINOM

BLODIG AVFØRING

101201 280202

3 / /

PERITONEUM, LEVER

02 1234 GADES

030502

HØ. HEMICOLECTOMI

010602 OVERLEGE GUNNAR MO 0368 357

GUNN ALVG 0859 251

Eksempelet er fiktivt

MELDING TIL KREFTREGISTERET

NON-SOLIDE SVULSTER

Skjema i kraft fra 01.01.2003

MONTEBELLO, 0310 OSLO

Solide svulster meldes på eget skjema

PASIENT

Fødselsnr. Postnr. Poststed

Etternavn Fornavn

BEHANDLINGSINSTITUSJON

Institusjon Avdeling

Innlagt Poliklinisk Dag Mnd År Utskrevet Lever Død

Dato

DIAGNOSETIDSPUNKT

Dag Mnd År

SYKDOMSKATEGORI (velg én av de ni hovedgruppene - morfologisk undergruppe spesifiseres nedenfor) (Se også veiledning på baksiden)

- Lymfom
- Mb. Waldenstrøm
- Atypisk lymfoid hyperplasi
- Myeloproliferativt syndrom (polycythemia vera, essensiell trombocytemi, primær myelofibrose)
- Leukemi
- Myelomatose eller lign. plasmacelletumor
- Malign histiocytose eller lign.
- Myelodysplastisk syndrom (MDS 1-5)
- Non-solid tumor av annen eller ukjent type

MORFOLOGISK UNDERGRUPPE (etter mikroskopisk undersøkelse av lymfeknutebiopsi, benmargsutstryk, blodutstryk, etc.)

Eks: lymfogranulomatose blandet celletype, kronisk myelomonocyttleukemi (MDS-4), prolymfocyttleukemi av B-celletype, etc.)

Ved manglende eller inkonklusiv morfologisk u.s: Anses sykdommen som en klinisk sikker cancer? Ja Nei

SYKDOMSTEGN, LEGEKONTAKT

Hadde pasienten symptomer Ja Nei Funnet ved screening Hvilke symptomer eller sykdomstegn

Når oppsto første symptomer Dag Mnd År Når søkt lege Dag Mnd År

Arvelig disposisjon for kreft Nei Påvist Mistenkt Hva slags?

SYKDOMMENS UTBREDELSE PÅ DIAGNOSETIDSPUNKTET (bestemt på grunnlag av informasjon tilgjengelig for behandling)

For lymfomer: Stadium (f.eks. IB, IIA, IIIB, etc.) For myelomatose: Durie-Salmon stadium (f.eks. III, 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 lymfeknuteregion?
2) Benmarg
3) Annet organ - hvilket organ?
4) Det er ikke mulig å ta stilling til utgangspunktet p.g.a. utbredt sykdom på diagnosetidspunktet (sett evt. kryss)

BASIS FOR KREFTDIAGNOSEN

- Benmargsutstryk
- Perifert blodutstryk
- Benmargsbiopsi
- Immunofenotyping/immunhistokjemi
- Cytogenetisk undersøkelse
- Spinalvæskeundersøkelse
- DNA-/RNA-/kromosom-diagnostikk
- Serum- og/eller urinelektroforese
- Bildediagnostikk (røntgen, UL, CT, MR)

	År	Preparatnummer	Laboratorium
Cytologisk prep.			
Histologisk prep.			
Histologisk prep.			
Obduksjons prep.			

PRIMÆRBEHANDLING

Startet når Dag Mnd År Ingen primærbehandling Primærbehandlingens sikte mål Helbredelse Palliasjon

Kirurgisk behandling Ja Nei Hvilken? Op. metode (op. beskrivelse må vedlegges)

Strålebehandling Ja Nei Annen behandling Ja Nei Hvilken

Cytostatikabehandling Er ytterligere behandling planlagt? Ja Nei Hvilken behandling Hvilken institusjon?

Anses pasienten sykdomsfri etter primærbehandling? Ja Nei Vet ikke Ikke relevant

OPPLYSNINGER SOM REGISTRERES HVIS IKKE PASIENTEN MOTSETTER SEG DET

Røyker Ja Nei Tidligere røyker Motsetter seg reg. Yrke Motsetter seg reg.

TILLEGGSOPPLYSNINGER

Meldt: Dag Mnd År

Pasientansvarlig lege (Etternavn, fornavn - trykte bokstaver)

Id. nummer

Legens underskrift

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.

MELDING TIL KREFTREGISTERET

NON - SOLIDE SVULSTER

PASIENT

[redacted]

BEHANDLINGSINSTITUSJON

VEST-AGDER SYKEHUS

MEDISINSK

080302

DIAGNOSETIDSPUNKT

080302

SYKDOMSKATEGORI

X

MORFOLOGISK UNDERGRUPPE

B-CELLE LYMFOM

SYKDOMSTEGN. LEGEKONTAKT

NATTESVETTE

301101

130102

SYKDOMMENS UTBREDELSE PÅ DIAGNOSETIDSPUNKTET

IVB

SYKDOMMENS LOKALISASJON DEBUTORGAN

HALS OG AXILLE

BASIS FOR KREFTDIAGNOSEN

02 1234

VAS

PRIMÆRBEHANDLING

080302

X

TILLEGGSOPPLYSNINGER

070502

OVERLEGE ELIN SVENSK

0203 381

ELDAR HAUGEN

0663 489

Eksempelet er fiktivt

Basis for kreftdiagnosen

De diagnostiske prosedyrer som danner grunnlaget for diagnosen, avkrysses. For undersøkelser utført i patologilaboratorium 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.

KREFT registeret
INSTITUTT FOR POPULASJONS-BASERT KREFTFORSKNING

MELDING TIL COLORECTALCANCERREGISTERET
KREFTREGISTERET, 0310 OSLO

Svulster i colon/rectum – skjema i kraft fra 01.01.2007

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 ☐ Søkum ☐ Ascendens ☐ Høyre fleksur

☐ Transversum ☐ Venstre fleksur ☐ Descendens ☐ Sigmoideum (≥ 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:					**CEA:**	
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 lymfeknuter** ○ 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	☐ Fremre reseksjon	☐ Hartmann
☐ Hemicol. sin	☐ Utvidet hemicol. sin	☐ Amputatio recti	☐ Polypektomi
☐ Transv. reseksjon	☐ Transv. + fleksurreseksjon	☐ Lokal reseksjon	☐ Transanal endoskopisk mikrokirurgi
☐ Sigmoidreseksjon	☐ Subtotal kolektomi	☐ Annen	
☐ Annen			
○ Medialt/sentralt først	○ Lateralt først	**Anastomosenivå** |__|__| cm over analåpning	
Lymfeknutedisseksjon			
○ D3 Kar avsatt inntil a. mes. sup./aorta		**Anastomoseteknikk:**	
○ D2 Intermediær avsetting av kar		○ ende-ende	○ side-ende ○ J-Pouch/Reservoir
○ 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:				**KONSEKVENS:**	
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
Innvekst 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

Innhold

1. Introduksjon 3

2. Lovhjemmel 3

3. Opprettelse av Norsk Colorectalcancer Gruppe 3

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

4.1 Utfylling av skjema for primærtumor 4
4.2 Utfylling av skjema for lokalt residiv 7
4.3 Utfylling av skjema for metastaser 7
4.4 Utfylling av skjema ved obduksjon 7

5. Kontaktpersoner på Kreftregisteret 8

1 Introduksjon

Fra 1. januar 2007 innfører Kreftregisteret i samarbeid med Norsk Colorectalcancer Gruppe nytt meldeskjemaet for svulster i colon og rectum. Skjemaet er utviklet av gastrokirurger og referansegruppemedlemmer 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 colorectalcancer 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 Colorectalcancer Gruppe

Norsk Colorectalcancer 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 Krfetregisteret og Norsk Colorectalcancer 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 før 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 cancere 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 comatøs pasient med intracraniell blødning.

Nyfødt < 3 mndr Røker > 5 sigaretter daglig **Eksempel:** Lett organisk hjertesykdom Ukomplisert diabetses (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 organkomplikasjoner Invalidiserende hjertesykdom Moderat til alvorlig lungesykdom Angina pectoris Gjennomgått hjeteinfarkt (> 6 mndr)	**D. Donor.** Hjernedød pasient som preserveres 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 anastomosenivå 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 anastemoselekkasje 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.

Skjema i kraft fra 01.01.2003

Meldeskjema for brystkreft

Kreftregisteret

Sendes Kreftregisteret, Montebello - 0310 Oslo

Ved bilateral sykdom skal to skjemaer fylles ut

Sykehus (stempel)

Avdeling

Navn

Adresse

Postnummer | Poststed

Fødselsnr.

1. Henvisningsgrunnlag

Mammografifunn: Mammografprogrammet (off. screening) ☐
Privat screening ☐

Palpabel tumor ☐

Andre brystsymptomer ☐

Høyrisikokontroll (arv) ☐

Når oppsto første symptomer (Dag Mnd År)

Henvisning mottatt dato (Dag Mnd År)

Poliklinisk behandlet (Dag Mnd År)

Innlagt (Dag Mnd År)

Arvelig disposisjon for kreft? Nei ☐ Påvist ☐ Mistenkt ☐ Hva slags?

2. Klassifisering av tilfellet

(Høyrisikomålgruppe)
(Ved bilateral sykdom skal to skjemaer fylles ut)

Infiltrerende kreft ☐

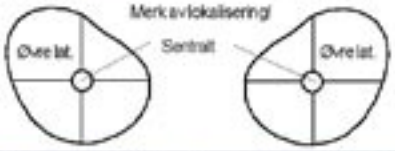
DCIS (ductal carcinoma in situ) ☐

Andre premaligne tilstander ☐

3. Topografi

☐ Høyre ☐ Venstre

Merk av lokalisering!



Multiple primære (Meld største svulst) ☐

Palpabel:

	Ja	Nei
Bryst	☐	☐
Armhule	☐	☐

4. Diagnostiske metoder

(Kryss av for de metodene som er benyttet)

Klinisk undersøkelse ☐

Bildediagnostikk ☐

Finnålsaspirasjon (FNAC) ☐

Preoperativ biopsi

Sylinderbiopsi ☐

Diagnostisk merkebiopsi ☐

Andre metoder

Endelig diagnosedato (Dag Mnd År)

5. Diagnostisk konklusjon

	Ja	Nei	Ukjent
Metastase i armhulens lymfeknuter	☐	☐	☐
Metastase til lymfeknuter bak brystbenet	☐	☐	☐
Metastaser i andre organer	☐	☐	☐

NB! Angitt spredning skal være på sykdommens diagnosetidspunkt

Morfologisk diagnose

Ved manglende eller inkonklusiv morfologisk undersøkelse. Anses sykdommen som klinisk sikker kreft? Ja ☐ Nei ☐

	År	Preparatnummer	Laboratorium
Cytologisk prep.			
Histologisk prep.			
Histologisk prep.			
Obduksjons prep.			

pTNM pT pN pM

6. Behandling

Behandlingens sikdemål: Helbredelse ☐ Palliasjon ☐

Pasienten skal reserveres fra Mammografprogrammet i 10 år. Ja ☐

7. Kirurgi

Endelig kirurgi

Bryst: Ingen ☐
Brystbevarende ☐
Ablatio ☐

Armhule: Ingen ☐
Toilette ☐
Sentinel node ☐

Start kirurgisk primærbehandling (Dag Mnd År)

Fullført kirurgisk primærbehandling (Dag Mnd År)

Antall kirurgiske inngrep

Kirurgikoder
(op. beskrivelse må vedlegges)

8. Stråleterapi

Ingen ☐
Postop. mot brystet som ledd i brystbevarende kirurgi ☐
Postop. mot regionale lymfeknuter ☐
Annen stråleterapi ☐

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. ☐ | Yrke: Motsetter seg reg. ☐

Tilleggsopplysninger

Meldt (Dag Mnd År)

Pasientansvarlig lege (Etternavn, fornavn - trykte bokstaver)
Id. nummer

Legens underskrift
Id. nummer

Skjemaet skal sendes til: Kreftregisteret, Montebello, 0310 Oslo

Hva skal meldes på dette skjemaet?
Alle tilfeller av infiltredende brystkreft og Duktalt Carsinom in Situ (DCIS).
For pasienter diagnostisert i Mammografiprogrammet: Også andre forstadier.
Andre kreftformer skal meldes som før 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 kirugiske 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	
HAC 25	Radikal mastektomi	Med aksillære lymfeknuter Inklusive: Eksisjon av brystmuskler, utvidet mastektomi med reseksjon av ribbein og sternum
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 OVARII
primærdiagnose
inkl. borderline

PASIENT — LEGG VED OPERASJONSBESKRIVELSE

Fødselsnr. Postnr. Poststed

Etternavn Fornavn

Navnelapp

LEGE/SYKEHUSKONTAKT

Første legekontakt Dato Dag Mnd År — Funnet ved screening

Innlagt — Poliklinisk — Innleggelsesdato Dag Mnd År

Lokal/ sentralsykehus — Avdeling

Henvist regionsykehus Ja Nei — Hvilket

DIAGNOSETIDSPUNKT*
Dag Mnd År

PRIMÆRTUMORS UTGANGSPUNKT

Ovarie(r) — Tube(r) — Peritoneum — Side H — V — Bilat. — Ikke relevant — Ukjent

MORFOLOGISK DIAGNOSE: Hovedgruppe og type (f. eks. «adenokarsinom, serøst papillært»)*

Ploidi-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 Dag Mnd År — Menopause Ja — Nei — Årstall

Antall fødsler — Antall aborter — P-piller Ja — Nei — Antall år

Tidligere sykdom/ årstall

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 før behandling:

MR bekken/abdomen — Pipelleprøve endometriet
Abdominal ultralyd — Colonoskopi — Urografi
CT bekken/abdomen — Rtg. colon — Rtg. thorax
Fraksjonert abrasio — Vaginal ultralyd — Andre

		Årstall	Preparatnummer	Laboratorium
Cytologisk prep.				
Histologisk prep.				
Histologisk prep.				
Obduksjons prep.				

Beskrivelse av funn

PRIMÆRBEHANDLING

Navnelappeller 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 (Dag Mnd År) ☐☐ ☐☐ ☐☐ Asdites Ja ☐ Nei ☐ Mengde _____ ml

Ruptur av ovariatumor under operasjonen Ja ☐ Nei ☐

Resttumor* Ingen (R0) ☐ Mikroskopisk (R1) ☐ Makroskopisk (R2) ☐ Ukjent (RX) ☐

Lokalisasjon _____ Største diameter _____ X _____ cm

Komplikasjon(er) til operasjonen(e) Ja ☐ Nei ☐ Hvilke(n) _____

Behandling av komplikasjon(er) _____

Blødningsmengde under operasjonen ☐☐☐☐ ml Transfusjon Ja ☐ Nei ☐ Antall enheter ☐☐

CYTOSTATIKA

Planlagt Ja ☐ Nei ☐ Hvis nei, oppgi grunn _____

Hvis ja, hvilken _____

Påbegynt cytostatikabehandling Dato (Dag Mnd År) ☐☐ ☐☐ ☐☐ Avsluttet cytostatikabehandling Dato (Dag Mnd År) ☐☐ ☐☐ ☐☐

Type cytostatika _____ Antall kurer ☐☐

Forandring av kur Ja ☐ Nei ☐ Hvis ja, oppgi grunn _____

Nykur _____ Antall nye kurer ☐☐

Cytostatikabehandling inngår i Standard regime ☐

Protokoll ☐ Hvilken? _____

Individuell ☐

CA-125 før første kur ☐☐☐☐

Bivirkninger _____ **CA-125 tre uker etter siste kur** ☐☐☐☐

Klinisk respons etter avsluttet behandling* CR PR 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 (Dag Mnd År) ☐☐ ☐☐ ☐☐

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

Meldt (Dag Mnd År) ☐☐ ☐☐ ☐☐

Pasientansvarlig lege (Etternavn, fornavn - trykte bokstaver) _____

ID-nummer _____

Legens underskrift _____

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 selvhjulpen
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

*** Stadieinndeling 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, ument, 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 før 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*** x ***M*** x ***U:***

CA-125 Absolutt tallverdi
M Menopausal status
Premenopausal = 1
Postmenopausal = 3

U U = 0 for ultralydscore 0
= 1 for ultralydscore 1
= 3 for ultralydscore 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) Komplett 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 nytilkommet tumor/metastase eller økning av største tvermål 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.

Appendix 6

Veiledning på baksiden

Skjema i kraft fra 01.01.2004

MELDING TIL KREFTREGISTERET

MONTEBELLO, 0310 OSLO

CANCER PROSTATAE

Tilleggsmelding til ordinært meldeskjema

PASIENT

Fødselsnr. ☐☐☐☐☐☐☐☐☐☐☐ Postnr. ☐☐☐☐ Poststed

Etternavn Fornavn

Evt. klistremerke

INSTITUSJON (sykehus/avdeling/legepraksis)

ÅRSAK TIL UTREDNING

1. PSA initiert av: lege ☐ pasient ☐ ukjent ☐
2. Palpasjonsfunn (rektal eksplorasjon) ☐
3. Urinveissymptomer ☐
4. Metastasemistanke ☐
5. Tilfeldig funn v/ TUR-P ☐
6. Andre årsaker ☐ spesifiser .....

DATO FOR HENVISNING TIL SPESIALISTHELSETJENESTEN ☐☐☐☐☐☐ Ikke henvist ☐

Gleason score ..... + ... = ☐

Morfologisk basis: biopsi ☐ TUR-P ☐ metastase ☐ andre ☐ spesifiser .....

DIAGNOSEGRUNNLAG

PSA ved diagnosetidspunktet ☐☐☐☐,☐ µg/l

Skjelettscintigrafi: positivt funn ☐ negativt funn ☐ ikke utført ☐

Annen bildediagnostikk: utført ☐ ikke utført ☐ hvilken .....

Ultralyd prostata: utført ☐ ikke utført ☐

Lymfadenektomi pN ☐☐ Operasjonsbeskrivelse må vedlegges

FUNKSJONSTILSTAND

☐ 0: Normal aktivitet, uten begrensning

☐ 1: Lett redusert arbeidskapasitet

☐ 2: > 50% av dagen oppegående. Ikke i arbeid, helt selvhjulpen

☐ 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)

STUDIEINKLUSJON

Er pasienten inkludert i studie Ja ☐ Nei ☐ hvilken .....

TILLEGGSOPPLYSNINGER

Meldt: Dag Mnd År ☐☐☐☐☐☐

Pasientansvarlig lege (Etternavn, fornavn - trykte bokstaver) Id. nummer

Legens underskrift 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. *NB: Tumor som er påvist i én eller begge lapper ved nålebiopsi, men som ikke er palpabel eller påvisbar ved bildediagnostikk klassifiseres som T1c.*
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. *NB: Innvekst i apex prostatae eller inn i (men ikke gjennom) prostatakapselen klassifiseres som T2.*
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 lyskebåndet). 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

MALIGNT LYMFOM og KLL

PASIENT

Fødselsnr. | Postnr. | Poststed

Etternavn | Fornavn

BEHANDLINGSINSTITUSJON | **DIAGNOSETIDSPUNKT** (positiv biopsi/cytologi/utstryk)

Sykehus | Avdeling | dd mm åå

☐ Innlagt ☐ Poliklinisk Dato (ddmmåå) | Utskrevet ☐ I live ☐ Død

MORFOLOGISK DIAGNOSE

Hovedgruppe ☐ Hodgkin lymfom ☐ Nodalt NHL ☐ Primært ekstra-nodalt NHL ☐ KLL ☐ Annet

Klinisk sikker diagnose ved manglende/inkonklusiv morfologisk u.s.? ☐ Ja ☐ Nei

Morfologisk diagnose (i.h.t. WHO)

Ved to samtidige lymfomer: Andre morfologiske diagnose (i.h.t. WHO)

SYKDOMSTEGN, LEGEKONTAKT

Hadde pasienten symptomer? ☐ Ja ☐ Nei Hvilke symptomer eller sykdomstegn

Første symptomer (ddmmåå) Lege søkt første gang (ddmmåå)

Arvelig disposisjon for kreft ☐ Nei ☐ Påvist ☐ Mistenkt Hva slags?

STADIUM på diagnosetidspunktet

HODGKIN LYMFOM, NODALT NON-HODGKIN LYMFOM: Ann Arbor stadium

☐ I ☐ II ☐ IIE* ☐ II_1 ☐ III ☐ IIIE* ☐ IV

E*: invekst i ekstranodalt organ/vev

Er fullstendig stadieutredning utført ☐ Ja ☐ Nei

Stadium I og II: ☐ Over diaphragma ☐ Under diaphragma

Waldeyers svelgring affisert ☐ Ja ☐ Nei

PRIMÆRT EKSTRANODALT NON-HODGKIN LYMFOM: Musshoff stadium

☐ PeI ☐ PeIE ☐ PeII ☐ $PeII_1$ ☐ $PeII_1E$ ☐ $PeII_2$ ☐ $PeII_2E$ ☐ Uklart Primært ekstranodalt organ:

EKSTRANODAL LYMFOMAFFEKSJON (angis for nodale og ekstranodale lymfomer)

☐ Benmarg	☐ CNS	☐ Lunge	☐ Nyre	☐ Pancreas	☐ Skjelett	☐ Testikkel	☐ Tynntarm	☐ Uterus	☐ Øye
☐ Bihule	☐ Hud	☐ Munnhule	☐ Orbita	☐ Peritoneum(sidet)	☐ Spyttkjertel	☐ Thyreoidea	☐ Tårekjertel	☐ Vagina	☐ Annet
☐ Bryst	☐ Lever	☐ Muskulatur	☐ Ovarium	☐ Pleura	☐ Subcutis	☐ Tykktarm	☐ Urinblære/ureter	☐ Ventrikkel	

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

	År	Preparatnummer	Laboratorium
Histologisk prep.			
Histologisk prep.			
Cytologisk prep.			
Obduksjon			

☐ Kirurgisk biopsi
☐ Grovnålsbiopsi
☐ Finnålspunksjon
☐ Cytologi (annen)
☐ Benmargsbiopsi
☐ Benmargsutstryk
☐ Blodutstryk
☐ Flowcytometri
☐ Spinalvæskeundersøkelse
☐ Serum- og/eller urinelektroforese
☐ Cytogenetisk undersøkelse
☐ DNA-/RNA-/kromosom-diagnostikk
☐ Serologisk undersøkelse
☐ Bildediagnostikk (røntgen, UL, CT, MR)
☐ Annet:

Immunfenotyping / immunhistokjemi ☐ B-celle ☐ T-celle ☐ 0-celle ☐ Ukjent

PRIMÆRBEHANDLING

Behandlingstrengende 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	Hvilken behandling

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 HVIS IKKE PASIENTEN MOTSETTER SEG DET

Røyker ☐ Ja ☐ Nei ☐ Tidligere røyker ☐ Motsetter seg reg. Yrker (nåværende og tidligere) ☐ Motsetter seg reg.

TILLEGGSOPPLYSNINGER

Meldt: dd mm åå

Pasientansvarlig lege (Etternavn, fornavn - trykte bokstaver) | Legens underskrift

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 Haematopoetic and Lymfoid 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
IIE	Lymfom i én eller flere lymfeknuteregioner på samme side av diafragma med innvekst i ekstranodalt organ/vev†
II_1	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 svelgring regnes som *nodal* affeksjon.

Primært ekstranodalt lymfom: Stadium etter **Musshoff** (Musshoff K. Klinische Stadieeinteilung 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 II_1	Lymfom primært i ekstranodalt organ/vev med spredning til regionale lymfeknuter
Pe II_1E	Lymfom primært i ekstranodalt organ/vev med spredning til regionale lymfeknuter og overvekst på annet organ/vev
Pe II_2	Lymfom primært i ekstranodalt organ/vev med spredning til lymfeknuter utenfor de regionale, men på samme side av diafragma
Pe II_2E	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.

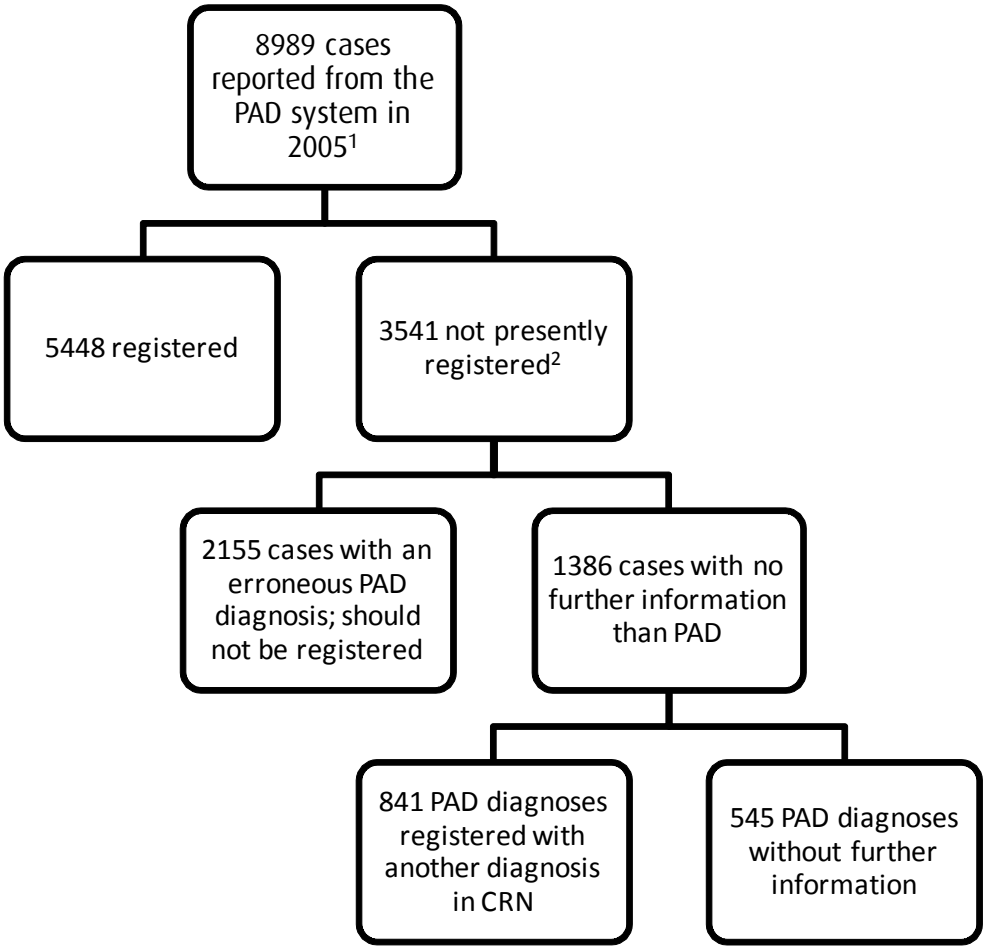
Røyking/yrke: Opplysninger om røykevaner og yrke anføres om ikke pasienten motsetter seg det.

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 $i = 1,\ldots, n$.
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

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

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

$$Z^2 = \frac{\left(m_j - \hat{\theta} d_j\right)^2}{\hat{\phi} n_j \hat{\theta}} \sim \chi_1^2$$

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