Survey of Nordic Cancer Registries

Danish Cancer Society
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http://ncu.cancer.dk/ancr
Survey of Nordic Cancer Registries

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Preface

This survey of Nordic cancer Registries describes details of how cancer registration has taken place in the Nordic countries. It was agreed by the board of the ANCR to keep an updated account of registration and coding practices, to facilitate comparative and collaborative studies on cancer in the Nordic countries. Hopefully it will be widely distributed or made known to the staff of the registry and research organizations or collaborators. We thank all the cancer registries in the Nordic countries for their willingness and patience when replying to the extensive questionnaire and the personal interviews. We plan to make yearly revisions of the document, and wish to thank the registries for their excellent collaboration in this effort.

The survey is carried out by Ellii Michelsen Lund, Inge Haustrup Clemmensen, Hans H. Storm and edited by Gerda Engholm.

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Hans H. Storm
Danish Cancer Society
December 2000

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SURVEY OF NORDIC CANCER REGISTRIES

Introduction

The cancer registries in the Nordic countries, Sweden, Norway, Finland, Iceland and Denmark are operating in populations that are rather alike. They are all based on total populations, each having its unique personal identification system. Furthermore a very close contact and co-operation between the registries has ensured many similarities.

The paradigm has therefore been that the data material is alike and comparable without too many artefacts or confounders. The registries have thus often been used in comparative and multicentre studies including all or some of the Nordic countries.

One such study was comparing the relative survival of cancer patients in the Nordic countries. The results showed however some unexpected differences, for which possible explanations are still being explored. These results supported the plan for investigating and describing the differences and similarities between the registries.

The work has now been carried out and this report describes some of the more important differences. During the investigation some important differences showed up of which a few should be mentioned here: The sources for the registries are different (appendix 3 table 2). Different classification systems are used and there have been changes of systems at different points in time as well as different exceptions (even for the ICD-7 classification system) (table 3A, table 3 in appendix 3, appendix 5). Tumours included in the incidence data also vary between the countries (table 4), as do the way multiple tumours are registered and counted (table 5), furthermore there is variation in the choice of tumours for which screening is carried out (table 6). This all calls for attention when comparing data between the Nordic countries.

A description of each of the Nordic cancer registries is the starting point for this report. It has therefore been necessary to visit all the registries and describe the methods of each. This we expect will form a base for future research projects involving the Nordic cancer registries, and thus provide information for future comparability studies. The report will furthermore be expected to be of some use for ongoing activities evaluating and comparing survival in the Nordic Countries.

Material

The material used from each registry is:
- Coding - guidelines.
- Incidence publication as well as other registry material with description of the registry.
- Notes from personal interviews carried out from March 1997 to July 1997.

Method

Each registry was visited and interviews held, with persons responsible for the registry or delegated to respond. For this a structured questionnaire (appendix 1) was used as guideline for the information
collected. Based on the questionnaire responses and the information obtained by interview, the resulting tables describing registry operations were constructed. The questionnaire responses do not compare with the final tabular results. The actual coding procedures were also observed during the visits.

The information collected was related to (see questionnaire in Appendix 1):

- specification of registry
- demographic items (population covered/area and number)
- history, (including changes in coding / coding systems / reporting practices over time / multiple cancers)
- staff and organisation
- reporting (how and by whom is the reporting done)
- sources (General Practitioner/Hospital/Laboratories inc. pathology and haematology/Death certificate/Administrative)
- information recorded (how and by whom)
- identification of person (CPR: personal identification number/name/address/marital stage)
- incidence date (definition)
- basis for diagnosis (e.g. histology/clinical/death certificate only)
- classification (actual system and former systems - e.g. ICD 7; ICD O1; SNOMED)
  - topography (definition and source e.g. clinician)
  - morphology (definition and source e.g. pathology report)
  - behaviour (rules for change and creation of multiple tumours)
- reportable tumours
- transformation to other classification systems
- tumours included in incidence tables (apart from malignant, e.g. papilloma of bladder)
- extent of tumour/stage (definition and differences)
- multiple primaries (definition and rules see also appendix 3)
- treatment (detail and dates)
- death (date and cause of death)
- trace back / follow up
- screening programmes
- confidentiality
- quality control
- weak points
- check of registry
- output from registry

Results:

A description of each registry has been completed and is attached in appendix 2, organised alphabetically. The information from the descriptions has been compiled and is shown in tabulated form in appendix 3. In appendix 3 the information of interest is furthermore noted briefly with the number of reference in
appendix 2, so that it is possible to study the comments in more details. - The more important points are mentioned below.

Table 1: Population

<table>
<thead>
<tr>
<th>Question no</th>
<th>Denmark</th>
<th>Finland</th>
<th>Iceland</th>
<th>Norway</th>
<th>Sweden</th>
</tr>
</thead>
<tbody>
<tr>
<td>First year of incidence data</td>
<td>28</td>
<td>1943</td>
<td>1953</td>
<td>1954</td>
<td>1953</td>
</tr>
<tr>
<td>Updating of date of death</td>
<td>103</td>
<td>Annually</td>
<td>Monthly</td>
<td>Monthly</td>
<td>Monthly</td>
</tr>
<tr>
<td>Updating of emigration</td>
<td>103</td>
<td>Only in projects</td>
<td>Annually</td>
<td>Monthly</td>
<td>Monthly</td>
</tr>
</tbody>
</table>

Though the registries are population based the size of the population covered naturally is different, as is the year of start. There are differences in the frequencies of updating the registries for death and emigration. It should also be noted that in Denmark there are no rules for updating the registry with regard to emigration. However in Denmark the information is accessible from the Central Population Registry if needed, though permission has to be applied for.

Table 1 in appendix 3 throws more light on the demographic information available and its actuality. Furthermore it illuminates the age of the registry, legal status and the staff and the activities run in the registry.

Table 2 shows who reports to the registries by sending notifications and which other sources of information are available. All except Denmark receive notifications from pathology departments. Only Iceland receives copies regularly from all departments. However both the Swedish and Norwegian registries receive copies of reports from the pathologists regularly. Finally Sweden is the only country not receiving a copy of the death certificate.

---

1 NB The numbers in the descriptions are not the same as in the structured questionnaire. The numbers given to the tables below are the same as the numbers in appendix 2 + 3
Table 2: Sources used alone or in combination

<table>
<thead>
<tr>
<th>Source</th>
<th>Denmark</th>
<th>Finland</th>
<th>Iceland</th>
<th>Norway</th>
<th>Sweden</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pathology-notification</td>
<td>66</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>Pathology autopsy notification</td>
<td>68</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>Haematological laboratory</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>Poor</td>
<td>✔️</td>
</tr>
<tr>
<td>Notification form:</td>
<td>61-73</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>- General practitioner</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>- Specialist practitioner</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>- Hospital departments</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>Copy of hospital notes</td>
<td>77</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>Copy of pathology report</td>
<td>78</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>Copy of autopsy report</td>
<td>79</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>Copy of death certificate</td>
<td>57 + 81</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
</tbody>
</table>

Table 2 in appendix 3 furthermore highlights the information available through the Central Population Registry and in the personal identification number (CPR).

Table 3 in appendix 3 is giving an overview of table 3A-C as well as giving some more information about "incidence date", "basis of diagnosis" and definitions of "topography" and "morphology", none of which differ significantly amongst the countries. With regard to the topography of the tumour all countries are relying on the clinician, except Iceland, where the pathologist may correct the topography. For the morphology all the countries are receiving the notification directly from the pathologist, except Denmark where the registry is receiving the histological information on a transcript of the pathological report carried out by the clinician.
Table 3 A: Classification systems used (131)

<table>
<thead>
<tr>
<th></th>
<th>Denmark</th>
<th>Finland</th>
<th>Iceland</th>
<th>Norway</th>
<th>Sweden</th>
</tr>
</thead>
<tbody>
<tr>
<td>ICD-7</td>
<td>1943 → present</td>
<td>1952 → present</td>
<td>1954 → present</td>
<td>1952 → present</td>
<td>1958 → present</td>
</tr>
<tr>
<td>ICD-9</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1987 → present</td>
</tr>
<tr>
<td>ICD-10</td>
<td>1995 → present</td>
<td></td>
<td></td>
<td>1993 except for leukaemia and lymphoma</td>
<td></td>
</tr>
<tr>
<td>MOTNAC 51</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MOTNAC 68</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SNOP</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C24</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>M: 1958 → present</td>
</tr>
<tr>
<td>SNOMED</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>M: 1993 → present</td>
</tr>
<tr>
<td>ICD-O1 T+M</td>
<td>1978 → present</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ICD-O2</td>
<td>Some for M</td>
<td></td>
<td></td>
<td>1993 → present</td>
<td></td>
</tr>
</tbody>
</table>

Table 3 A shows the systems which have been and are used for classifying the site and histology of tumours. Different classification systems are used in the countries, and different systems have been used over time; except for Finland. Change in classification systems and thereby creation of new transformation tables may lead to problems in grouping tumours into the same classes as formerly. Unexpected changes in trends of incidence rates should therefore be checked against change in classification systems.

Table 3 B: ICD-7 (132)

<table>
<thead>
<tr>
<th></th>
<th>Denmark</th>
<th>Finland</th>
<th>Iceland</th>
<th>Norway</th>
<th>Sweden</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exceptions (see also appendix 5)</td>
<td>Special use of 1st digit and of 4th</td>
<td>Several differences</td>
<td>Skin, lymphoma and leukaemia</td>
<td>Lymphoma and leukaemia</td>
<td>Skin tumours, lymphoma and leukaemia</td>
</tr>
</tbody>
</table>

The only common system used over time and in all countries is the ICD-7 classification system. However even this has not been used in exactly the same way in the countries. In Denmark the first digit has been used to distinguish e.g. different morphologies (appendix 5), while some of the codes xxx7 have not been used. In Finland there are several differences and there have been changes over the years (appendix 5). In Iceland no exemptions were described to the ICD-7 coding system though skintumours/lymphoma and leukaemia are coded according to a special system.
In Norway lymphoma and leukaemia are coded according to Kiel's classification. Sweden is also using a special system for coding lymphoma and leukaemia as shown in the incidence publication (appendix 5 + 6).

Table 3 C: Behaviour (138-139)

<table>
<thead>
<tr>
<th></th>
<th>Denmark</th>
<th>Finland</th>
<th>Iceland</th>
<th>Norway</th>
<th>Sweden</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change of behaviour</td>
<td>≤ 4 months change to highest malignancy</td>
<td>Individual assessment - special rules for cervix and papilloma of the bladder</td>
<td>≤ 2 months change to highest malignancy</td>
<td>≤ 4 months change to highest malignancy</td>
<td>Cervix ≤ 1 year change to highest malignancy, otherwise no rules</td>
</tr>
</tbody>
</table>

Concerning change of behaviour of the tumour, there are some differences. In Denmark and Norway the behaviour will only be changed to the more malignant if this change is within 4 months of date of diagnosis. In Iceland this time limit is 2 months. If the time limit is passed a new invasive tumour is registered with a new date of diagnosis in those three countries. In Finland and Sweden there is no such time limit, and each case will be evaluated individually. This may mean that a tumour developing from in situ to invasive will have the invasive behaviour diagnosed at the earliest date in Finland and Sweden, while a new invasive tumour is registered in Denmark, Norway and Iceland (if it is diagnosed more than 4 months - 2 months after the in situ tumour).

The list of reportable tumours is very similar in the Nordic countries (appendix 2 no 140 for each country). However in Sweden and Finland also the hormonal active tumours of the endocrine glands are reportable, while in the other countries only those endocrine tumours situated intracranial are reportable.

Table 4 shows a list of special tumours which are regarded differently in the countries. They are the tumours mentioned being included in incidence data in some registries and not in others. It should thus be observed that of these the most frequent tumours in 1993 amounted to the number of cases mentioned below in Denmark:

- Cancer in situ of the breast - including the intraductal - 165 tumours (morphology xxxx.2)
- Borderline ovary tumours - 104 tumours (morphology xxxx.1)
- Urinary tract tumours - 843 tumours (morphology = 8120.0 + 8120.1 + 8121.0 + 8121.1).

The differences ought therefore to be observed in comparative studies.

Finland thus includes the carcinoma in situ and the intraductal breastcancer in the incidence publication, while Denmark includes the intraductal breastcancers. For borderline ovary tumours only Norway includes none of them, while the others include some or all. With regard to benign bladder tumours Finland does not include them, while the other countries do.
Table 4: Tumours included in incidence data (141 – 164)

<table>
<thead>
<tr>
<th>Tumour</th>
<th>Denmark</th>
<th>Finland</th>
<th>Iceland</th>
<th>Norway</th>
<th>Sweden</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benign brain tumours</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Pituitary gland</td>
<td>some</td>
<td>+</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Carotid body tumour</td>
<td>some</td>
<td>+</td>
<td>✓</td>
<td>+</td>
<td>✓</td>
</tr>
<tr>
<td>Benign bladder tumour (papilloma)</td>
<td>✓</td>
<td>+</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Intraductal carcinoma in the breast</td>
<td>✓</td>
<td>✓</td>
<td>+</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Carcinoma in situ in the breast – other</td>
<td>+</td>
<td>✓</td>
<td>+</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Borderline tumour in the ovary</td>
<td>some</td>
<td>✓</td>
<td>✓</td>
<td>+</td>
<td>some</td>
</tr>
<tr>
<td>Chromaffinoma of the adrenal gland</td>
<td>+</td>
<td>?</td>
<td>+</td>
<td>+</td>
<td>✓</td>
</tr>
<tr>
<td>Argentaffinoma</td>
<td>✓</td>
<td>?</td>
<td>✓ except for appendix</td>
<td>+</td>
<td>✓</td>
</tr>
<tr>
<td>Invasive mola</td>
<td>+</td>
<td>+</td>
<td>✓</td>
<td>+</td>
<td>✓</td>
</tr>
<tr>
<td>Adenoma of endocrine glands</td>
<td>+</td>
<td>✓</td>
<td>+</td>
<td>intracranial</td>
<td>✓</td>
</tr>
</tbody>
</table>

As shown in table 5 the rules are different for multiple tumours in organs where there often is more than one tumour. This is especially the case for paired organs, skin, colon, and urinary tract system. Furthermore, some of the rules have changed over the years; it is therefore too complicated to describe all the differences in this report, so only the most obvious have been mentioned in the table above.

Table 5 in appendix 3 gives some of the more basic information concerning registration of multiple tumours. All countries are registering multiple if there is no doubt of the patient having more than one tumour, except for the tumours mentioned above. There may be others which have not been mentioned during the survey and which were not revealed during the visits.
Table 5: Multiple tumours (166)

<table>
<thead>
<tr>
<th></th>
<th>Denmark</th>
<th>Finland</th>
<th>Iceland</th>
<th>Norway</th>
<th>Sweden</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skin tumours</td>
<td>1 for each M. If multiple* and same M: T = 173.8 (incl. B)</td>
<td>1 for each M. If multiple* and same M: T = 190.8 (B separately)</td>
<td>1 for each M. If multiple* and same M: T = xxx,8 (B separately)</td>
<td>Depends on time period between first and second tumour (±B till 1993)</td>
<td>1 for each M (±B) If multiple* at same time: T = xxx,8; but at different time counted as separate multiple* tumours</td>
</tr>
<tr>
<td>Colon</td>
<td>each tumour is counted</td>
<td>1 per year or 153.7</td>
<td>depends on the pathologist</td>
<td>all registered but counted as 1</td>
<td>All registered But counting varies</td>
</tr>
<tr>
<td>Urinary tract</td>
<td>1 at each site individually evaluated</td>
<td>1 at each site</td>
<td>1 at each site</td>
<td>1 at each site</td>
<td>1 at each site; more after 1 year</td>
</tr>
<tr>
<td>Brain (Astrocytoma glioma)</td>
<td>2 tumours</td>
<td>1 tumour</td>
<td>1 tumour</td>
<td>1 tumour</td>
<td>1 tumour</td>
</tr>
<tr>
<td>Paired organs (167 – 169)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>same M = 1 different M = 2</td>
<td>same M = 1 different M = 2</td>
<td>Depends on pathologist</td>
<td>same M = 1 different M = 2</td>
<td>Varies for same M different M = 2</td>
</tr>
<tr>
<td>Kidney</td>
<td>same M = 1 different M = 2</td>
<td>same M = 1 different M = 2</td>
<td>Depends on pathologist</td>
<td>1 bilateral tumour</td>
<td>Varies for same M different M = 2</td>
</tr>
<tr>
<td>Lungs</td>
<td>same M = 1 different M = 2</td>
<td>same M = 1 different M = 2</td>
<td>Depends on pathologist</td>
<td>1 bilateral tumour</td>
<td>Varies for same M different M = 2</td>
</tr>
</tbody>
</table>

B = Basal cell carcinoma; T = Topography; M = morphology; multiple* = more than one tumour

Table 6: Screening (190 – 194)

<table>
<thead>
<tr>
<th></th>
<th>Denmark</th>
<th>Finland</th>
<th>Iceland</th>
<th>Norway</th>
<th>Sweden</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cervix</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Breast</td>
<td>2 counties and 2-3 on the verge of starting</td>
<td>✔</td>
<td>✔</td>
<td>4 counties</td>
<td>✔</td>
</tr>
<tr>
<td>Colon</td>
<td>Pilot</td>
<td>Pilot</td>
<td>✗</td>
<td>Considered</td>
<td>2 study-programs</td>
</tr>
<tr>
<td>Melanoma</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
<td>2 programs</td>
</tr>
<tr>
<td>Prostate</td>
<td>✗</td>
<td>Pilot</td>
<td>✗</td>
<td>Pilot</td>
<td>2 studies</td>
</tr>
</tbody>
</table>

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The screening done in the Nordic countries varies a great deal, both with regard to type, year of start and the screened age-groups. As is shown in the table only cervix screening is universal, but if the details are checked it will be found that the frequency and the age-groups vary as does the year of start. With regard to breast screening, it is carried out in Finland, Iceland and Sweden, while it is still being worked on in Norway and Denmark.

Table 6 in appendix 3 illuminates the screening differences in more details, though for information on the age-groups covered, year of start and frequency the description for each registry has to be consulted (appendix 2). Furthermore the basic rules for confidentiality are shown.

Table 7: Quality

<table>
<thead>
<tr>
<th></th>
<th>Denmark</th>
<th>Finland</th>
<th>Iceland</th>
<th>Norway</th>
<th>Sweden</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completeness</td>
<td>213 special projects</td>
<td>special projects + follow-up routines</td>
<td>3%</td>
<td>4%</td>
<td>3.6%</td>
</tr>
<tr>
<td>Unknown primary site</td>
<td>225 2.4%</td>
<td>3%</td>
<td>3.4%</td>
<td>4%</td>
<td></td>
</tr>
<tr>
<td>Histology Percentage</td>
<td>229 92%</td>
<td>94%</td>
<td>95.5%</td>
<td>92.8%</td>
<td>98%</td>
</tr>
<tr>
<td>Death Certificate Only percentage</td>
<td>242 1.9%</td>
<td>1.8%</td>
<td>0.2%</td>
<td>2.6%</td>
<td>±(*)</td>
</tr>
<tr>
<td>Mortality / Incidence ratio</td>
<td>243 ±</td>
<td>±</td>
<td>±</td>
<td>✓</td>
<td>±(*)</td>
</tr>
<tr>
<td>Under-reported tumours</td>
<td>246 skin + brain + other benign tumours + none-solid tumours</td>
<td>chr. leukaemia + intra-cranial benign tumours</td>
<td>None-solid + intra-cranial tumours</td>
<td>none-solid + intra-cranial tumours</td>
<td>none-solid tumours</td>
</tr>
</tbody>
</table>

*Number of cancer cases on Death Certificate Notes is shown in the incidence publication as being 4%. They are however not checked, but an investigation carried out earlier showed that about 55% of these did not have cancer (Incidence publication 1993)

* has been calculated in "Cancer i siffror".

Table 7 shows the completeness of the registries. Only in Sweden completeness of the registry is subject to regular checking, while the other countries do it in special projects. However all are calculating different measures for completeness of detail. The percentage for "unknown primary site" varies between 2.4% and 4%, while the histological confirmation percentage varies a little more between 92% and 98%. The inclusion of "Death Certificate Only" cases varies between Sweden not including any and 2.6% included in Norway.

The tumours, which are expected to be under-reported, are to a very high degree the same, being the intra-cranial tumours and the none-solid tumours (e.g. leukaemia) causing problems.

Table 7, 8 and 9 in appendix 3 are giving information about the quality of the registries with regard to completeness of registry, completeness of detail, maintenance of quality, weak points and output from registry.
Discussion

Visiting the registries in the Nordic countries and studying the ways of working reveals different methods in cancer registration and how results are reached.

The first striking point is the variation in the responsibilities and working conditions for the coding assistants. In some places they are only coding straightforward tumours and the problematic ones are sent either on-line or on paper to a medical supervisor, who will do the coding of these cases. In other places the coding assistants will do the coding but after discussing it with the supervising medical doctor. In some places most coding is done mainly relying on the pathologist, while others receive no such information.

The material used for the report varies as some have large and detailed coding guidelines, while others have very minor written instructions, so that it may be difficult for people outside the registry to get the relevant information as well as getting documentation for it. This may give rise for caution as changes may have happened but are documented to different degrees.

The method used for investigating the registration was carried out using a structured questionnaire as basis for the interviews held. But the quality of the interviews, though carried out by one person, may vary as the responders in the different registries were holding different positions, having different education and different experience in registration as well as having been in the registries for very different time periods. This means that some remember all changes, others have only read about the more important ones. This urges to caution when studying results.

The above means that the base of the registries are resting on routines which are so different that it is not possible by short visits to ensure that the registries are reaching the same results. It should nevertheless be pointed out that all the registries are of a very high standard and their qualities are controlled regularly.

Disregarding the above reservations this report describes the most important differences between the registries. This makes it possible to carry out studies comparing the Nordic countries as well as multicentre studies without too many or serious differences between the countries, which may be explained by variations in registration methods, and not by real differences in incidence or survival. It must however always be born in mind that apparent differences might be explained by registration routines. The results mentioned in this report are however evident and should therefore be observed when studies are carried out.

As seen in table 1, the populations the registries are working in are of different sizes, but only for Iceland this is important since the incidence figures will be small even for the frequent cancers. The updating of date of death might be expected to cause differences in calculating survival. This is of cause the case if the cancer registries are the only source for survival analysis. In Denmark survival analysis would typically be carried out with access to CPR, and therefore would not be a problem as the date of death is updated continuously in the CPR. The same counts for emigration where the updating is carried out in the actual project. All registries are however updated regularly and at least annually.
In table 2 the differences mentioned are the sources and notifications received. The fact that Denmark does not receive pathology reports may cause concern, on the other hand as may be seen in table 7 the differences in histological confirmation and tumours from “Death Certificates Only” are not very large, which may be read as a very high coverage. The other point of cause for concern is that in Sweden the tumours mentioned on “Death Certificates Only” are not included, however a special project showed that the number of cases missed in this way amounts to maximum 2 percent of the total number. It should however be borne in mind especially when comparing survival analysis more so that the tumour types on death certificates may vary in frequencies, so that some types are mentioned more frequently than others and thereby causing a skewed picture.

In tables 3a and 3b, the various classification systems used are mentioned. This calls for attention as it is rather difficult to get hold of which cancers are included in which group more so as the transformation systems from one classification system to another may vary between the countries even though they may all use a recognised transformation system investigating the details may reveal differences as mentioned in appendix 5.

As mentioned in table 3c the way, tumours which first was registered as in situ and then later become invasive are handled, varies. This means that in Denmark, Iceland and Norway there is a time limit for when the second report calls for registration of a new invasive tumour with a new date of diagnosis. However in Finland and Sweden each case is evaluated individually so that sometimes the first date of diagnosis is used and only the character of the tumour is changed from in situ to invasive. This difference in registration might theoretically cause differences in survival. However the number of patients being registered first with an in situ and then later with an invasive tumour is not very high. There might nevertheless be a problem with tumours of the cervix and it may therefore be worthwhile when comparing those to ensure that differences in survival are not due to registration methods.

Tumours included in the incidence data are showed in table 4. Any difference is of course of interest as it may influence a specific research project. However it should be noted that the tumours mentioned in the table are those found in this project and it is probably complete. But especially registration of e.g. some of the haematologic tumours has changed over the years and vary greatly between the countries. The importance of ensuring that the same tumours are included when carrying out comparative studies, therefore need to be stressed.

Of the differences revealed in this study the most frequent are mentioned below the table. They are having the topographies of the breast, ovary and urinary tract, while the others are very rare tumours. Also registration of multiple tumours as seen in table 5 calls for attention. Skintumours are thus registered differently in Norway and Sweden compared with the others, while only Denmark includes the Basal cell carcinoma. For the colon tumours Norway and Finland only count one tumour a year, while the others do it each in their own way. Brain tumours also vary as most will only count 1 tumour if an astrocytoma after some years develops into a glioma, however in Denmark each tumour is counted based on the difference in ICD-O code. In the paired organs differences are also observed, and it may therefore be wise in comparative studies to count only one tumour for each site.

Screening is done in all the countries, but the tumours screened for, the time of starting screening, the agegroups and frequency of screening vary. This means that studies of tumours where screening is carried
out, call for special attention in comparative studies, as the frequency typically will rise when the screening of a new tumour starts and then later get to a more normal level.

The quality of the registries is very high as seen in table 7, 8 and 9. The quality may be judged by the percentage of "unknown primary site", "histology percentage" as well as the number of new tumours found by “Death Certificates Only”, and here the frequency is around 2% in all countries, though they are not included in the Swedish incidence data.

Conclusion

The project has shown that even if the Nordic countries are very similar in many ways, the methods used for cancer-registration, the classification systems and inclusion of some tumours vary somewhat. It is however registries of very high quality with coding principles well known to those carrying out the work. We expect that this report may facilitate research so that whenever Nordic cancer studies are carried out, it will be relatively easy to pinpoint possible problem areas and correct or circumvent them early in the process before too much work is carried out. It is from this survey obvious that the differences between the Nordic Cancer Registries are minor and that data can be compared safely in descriptive cancer studies. However for some sites / subsites the researcher should be cautious. Ideally the registries should create a cancer common outline for the data to the extent possible by e.g. eliminating multiple primaries not recorded in all registries, and by adopting similar standards for coding cancer by using the ICD-O classification.

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We want to thank all the registries for assistance in responding to questionnaires and in proof-reading the tables and documents.
Appendix 1: Original Questionnaire

BASIC CHARACTERISTICS OF THE REGISTRY

date:

1. Registry (official name)
2. Postal address
3. Postal code
4. Country
5. Telephone
6. Fax
7. e-mail

Persons interviewed:

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Training/Degree</th>
<th>Abbreviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Head of department:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

I THE REGISTRY

IS YOUR REGISTRY:

13. Population-based (records all new cases in a defined population)?
14. Hospital-based (records all cases in a given hospital or group of hospitals)?
15. Please define your population
16. Do your population figures include all the people in your area (e.g. "lapper", "færinger", minorities, refugees, other non-residents etc.) (variations)
17. Does your registry restrict data collection to certain types of cancer?
   (e.g. digestive tract, childhood)
18. If yes, please specify
19. Do you have special registries in your countries

II DEMOGRAPHICAL INFORMATION

WHAT DOES THE REGISTRY COVER:

20. The whole nation?
21. One or more regions? (länder, district "svenske udtryk")
22. Do you make your own incidence-publication

Changes

23. Coverage of another (larger/smaller) part of the population?
   Year(s) of change(s)
24. Coverage of another area?
   Year(s) of change(s)
25. Other differences?
   Whatever the change, please specify and indicate year for any change.
Appendix 1 Original questionnaire

WHAT IS THE RESIDENT POPULATION IN THE AREA COVERED BY THE REGISTRY?
(Please state the number)
26 a Males ? __________
27 b Females ? __________
28 c Total ? __________
29 TO WHAT YEAR DO THE POPULATION DATA (IN Q 26,27,28) REFER?

DO YOU HAVE EXACT POPULATION FIGURES FOR THE AREA WHICH THE REGISTRY COVERS?
- Where do you get the information from? (source e.g. census data and how frequent census are / Central Personal Registry)
30 Do you have exact annual population figures?
31 - since when?

PLEASE STATE METHOD USED BY THE REGISTRY FOR CALCULATION OF POPULATION BETWEEN CENSUS YEARS (e.g. linear interpolation, midyear average, etc.)
32 Describe your hospital setup and healthsystem

Are the following population data available to your registry?
If yes, please indicate if used by your registry.
Sex and age available used
37 a One-year age group................................................................. ● ●
38 b Five-year ................................................................. ● ●
39 c Other: please specify.................................................. ● ●
40 d Occupation: List (or enclose) categories, or state classifications, e.g. ILO .... ● ●
41 e Religion: list (or enclose) categories................................. ● ●
42 f Ethnic groups (grønlænder/lapper/indvandrere) and / or place of birth list (or enclose) categories ........................................................... ● ●
43 g Urban versus rural: How are these defined (or enclose list) ?......................... ● ●
44 h Geographically ............................................................... ● ●
45 i County ............................................................................... ● ●
46 j Region ............................................................................... ● ●
47 k Cities ................................................................................. ● ●
48 l Other: please specify ........................................................... ● ●

III HISTORY

WHAT YEAR DID YOUR REGISTRY START OPERATION?
50 FROM WHICH DATE CAN THE REGISTRY PRESENT POPULATION BASED DATA?

Availability of comparable data over long periods of time.
Has the registry changed any of the following characteristics since the year from which your registry can present population based data:

51 CROSS-MATCHING WITH OTHER REGISTRIES TYPE AND YEAR (e.g. Hospital Discharge Registry, Pathology Registry , Death Index, etc.)
52 How have cancers from these registries been included/excluded
53 *OTHER CHANGES? type and year.
54 HAVE YOU ANY DESCRIPTION / KNOWLEDGE OF CHANGES IN HOSPITAL PROCEDURES (e.g. examination, former inpatients becoming outpatients, treatment, autopsy-rates etc.) which may influence your registry? - preferable with date on year and/or investigations enlightening this problem.
If you have please describe or send reprints of the studies.

HAS REPORTING OF CANCER CASES TO THE REGISTRY CHANGED:
55 Compulsory ? time-period
Appendix 1 Original questionnaire

56 Voluntary ? time-period
57 Some sources compulsory, others voluntary ? time-period
58 Other: please specify
59 How is it at present?

HAS OPERATION OF THE REGISTRY BEEN DISCONTINUED AT ANY TIME DUE TO :
60 War ?
61 Political problems ?
62 Financial problems ?
63 Confidentiality problems ?
64 Other ?

IS YOUR REGISTRY
65 public?
66 private?
67 who owns the data?

IV STAFF & ORGANIZATION

68 PLEASE PRODUCE A LIST OF EMPLOYEE'S TITLES AND associations to different departments

WHICH OF THE FOLLOWING DEPARTMENTS DO YOU HAVE, AND WHAT ARE THEIR ACTIVITIES?
69 Registration
70 Research departments (statistical, EDB, etc.)
71 Evaluation
72 Health Care planning

PLEASE OUTLINE BRIEFLY THE ORGANIZATION OF THE REGISTRY
73 ( Do you operate from more than one office ? )
74 Who do you co-operate with (e.g. clinical departments, research departments)?
75 Who are you located -physically- with?

WHAT ARE THE SOURCES OF FINANCE FOR
76 Registration of cancer
77 Research projects
78 Other activity
79 WHERE IS THE CODING OF SITE AND MORPHOLOGY CARRIED OUT:
80 At the registry
81 data source (e.g. hospital)
82 both places
83 elsewhere ?

84 WHO PERFORMS THE CODING / CLASSIFICATION OF NEOPLASMS TO SITE AND MORPHOLOGY CODES (more than one category may apply, but do not include doctors who act only as consultants for unusual cases) (Coding clerks / Medical doctors / nurses / other medical health personnel / Data automatically transferred (by computer)

* WHO USUALLY SUPERVISES CODING AND RESOLVES CODING PROBLEMS ?

85 * Registry : Pathologist / Other MD / Other academic staff / Other staff ?
86 * External consultants : Pathologist / Other MD / Other academic staff / Other staff

* Letters / Telephone
87 - is reporting department asked for clarification, how and how often?
88 - are other departments/hospitals asked for clarification, how and how often?
V REPORTING

89 Describe the way of information about a cancer from the cancer patient till it has been entered into the registry:
Please try to tell the story of the way a "normal" patient is entered into the registry - mention all the doctors/registries etc. he will pass
(cancer case -> doctor -> hospital -> etc.)

90 Is a fee paid to the reporting physician or institution?

*Who reports cancer cases actively:
91 * Public institutions?
92 * Private institutions?
93 * Private specialists (e.g. dermatologists)?
94 * General practitioners?
95 * Other?

Who reports cancer cases passively (e.g. linkages):
96 Public institutions?
97 Private institutions?
98 Other?

99 * Do you record name and/or address of the reporting hospital / clinical department / practitioner / or other source so that it is POSSIBLE TO FOLLOW BACK TO THE REPORTING PERSON AND GET ADDITIONAL INFORMATION? (electronic or/and microfilm etc.)

100 * Does the registry have information which would enable you to GO BACK TO THE ORIGINAL RECORDS? (medical/pathology)

V1 SOURCES

*From which sources does your registry systematically obtain information:

Hospitals
104 Clinical departments?
105 Medical records departments?
106 Outpatient clinics?
107 Hospices?
108 Long stay hospitals and homes for the elderly?

Laboratories (in or outside hospitals)
109 Pathology, general?
110 Pathology, specialised?
111 Haematology?
112 Autopsy reports?
113 Institute of forensic medicine?
114 Other?

115 Death certificates?
Appendix 1 Original questionnaire

Other
116 General practitioners?
117 Specialist practitioners?
118 Health Insurance?
119 Screening programs?

Administrative sources
120 Central population registers?
121 Central medical registers (e.g. hospital information systems, pathology registry)?
122 Other?

123 If the registry has more than one primary source, please rank the main primary data sources for the registry by percentage (if possible) of total notifications received.

124 Does your registry record information about cancer from notification or reporting forms?
125 If yes, who completes (signs) the forms (Physicians / nurses or other medical health personnel / Administrative hospital staff / General practitioners / Specialists / Other persons)?

*Does your registry routinely receive (or otherwise have regular access to) copies of the following for cancer patients and on what media:

126 Medical records?
127 Pathology reports?
128 Autopsy reports?
129 Radiotherapy notes or summaries?
130 Discharge letters or case summaries?
131 Death certificates?
132 Data from hospital information systems?
133 Other documents?

134 * Do the staff at your registry regularly visit institutions to gather or code necessary information?
* If yes, please specify which:
135 Hospital depts. (incl. medical records)?
136 Pathology or other laboratories?
137 Other?

138 Do you store the original notifications:
All / Some / none (only coded data are stored)?

If you store all or some of the notifications received on paper, do you keep them:

139 In paper files?
140 As micro film or microfiche?
141 As scanned images?
142 Other?

143 Please state your definition of place of "residence":

* Does the definition of residence pose major problems (i.e. is it difficult to assess if a patient belongs to the population covered)?
* If yes, which categories give problems?
* How are immigrants and/or non-residents classified?
* How have immigrants been classified - (CPR no, other ID)?
Year(s) of change(s)
* Are there any special subgroups/minorities in the population (e.g. færinger/lapper/border-population, etc.)
* How are they classified?
* How have they been classified?
Year(s) of change(s)
Appendix 1 Original questionnaire

151 DO YOU SUBMIT YOUR DATA TO A LARGER REGISTRY?
152 What percentage of your registrations received in your registry refer to other registries (i.e. the place of residence is the catchment area of another registry)?
153 What percentage is reported to other registries?
154 DOES YOUR REGISTRY RECORD TUMOURS IN PATIENTS WHO ARE NOT PERMANENT RESIDENTS OF THE REGISTRY TERRITORY (e.g. tourists, non-resident patients admitted to a hospital in your area)?
155 If yes, is the data passed to another registry?
156 Are these data included in the incidence?
157 How can they be excluded?
158 DOES YOUR REGISTRY ATTEMPT TO RECORD TUMOURS IN RESIDENTS OF ITS AREA DIAGNOSED/TREATED OUTSIDE THE AREA?
159 If yes, briefly describe the methods used:

VII INFORMATION RECORDED

160 HOW IS THE CODING OF DATA CARRIED OUT:
Manually / directly by computer dictionaries (which variables) / by other procedures?

PROCESSING OF DATA
161 * Do you process each form individually, as they are received?
162 * Without consulting other forms for the same patient?
163 * With consulting all forms ever received for the same patient?
164 * Do you collect all notification forms for a given patient (e.g. for 1 year) and process them together only after this period has elapsed?

HOW DO YOU DETERMINE IF TWO OR MORE NOTIFICATIONS RELATE TO THE SAME PERSON (LINKAGE):
165 Manually?
166 Electronically?
167 Other?

168 DO YOU OPERATE ANY SPECIAL PROCEDURE FOR RAPID REPORTING?
If yes, is this:
169 To get rapid estimates of incidence?
170 To improve efficiency of collection of missing data items?
171 To enable research projects (e.g. case-control studies) to be done?

172 WHAT VARIABLES DO YOU USE IN LINKAGE: Unique identifier (specify)/ Family name / First (given) name / Sex / Residence / Date of birth / Place of birth / Other?

173 DO YOU CARRY OUT COMPUTERIZED CASE-RESOLUTION?
(Case-resolution is the process of resolving potentially conflicting data received on two or more notifications for the same person.)

174 If yes, briefly describe the approach embodied in the case-resolution program

VIII THE PERSON

175 DOES THE REGISTRY ASSIGN A UNIQUE INDEX NUMBER TO EACH PATIENT
176 If yes, please specify how this index number is constructed.
177 PERSONAL IDENTIFICATION (METHODS USED AND CHANGES)

* DOES THE REGISTRY RECORD THE FOLLOWING ITEMS:
* - What are the sources for the information (CPR / Hospital records / death certificates / administrative source / pathology reports):

* Identification number of patient
178 - Personal or national identity number (if any)?
Appendix 1 Original questionnaire

179 - How is this number constructed?
180 - What information is available in the personal identity number (e.g. date of birth/sex/place of birth/ethnicity etc.)?
181 - Does the number change if an immigrant is granted citizenship?
182 Social security number (=CPR?)
183 How is this constructed and what information does it contain?
184 Health (or national) insurance number (=CPR?)
185 How is this constructed and what information does it contain?
186 Other comparable number?
187 How is this constructed and what information does it contain?

*Names of patient
188 Full name?
189 Maiden name?
190 Father's name?
191 Mother's name?
192 Other?

193 *Date of birth? (e.g. from CPR/report/med. record etc.)?

*Place of birth
194 Location in your country?
195 Country of birth

*Residence/address at the time of registration
196 Full address?
197 Postal code?
198 Community?
199 Country?
200 Change of address?

*Sex?

202 *Age at incidence date: Where is this information from (Calculated from CPR/reported)?

203 *Nationality? Categories (e.g. French, Danish, or national/foreign)
204 *Year of immigration? (if relevant)
205 *Nationality of father and/or mother? Categories
206 *Marital/civil status at diagnosis?

*Do you use any of the following categories:
207 Married?
208 Separated?
209 Divorced?
210 Widow/widower?
211 Cohabitation?
212 Single?
213 Other?

214 *Number of live births? Categories (actual number)
215 *Religion? Categories (e.g. catholic, Protestant, Muslim etc.)
216 Ethnic groups? Categories (e.g. Turk, Arab, Grønlænder, Lapper, etc.)
217 Race? Categories (e.g. Asian, African etc.)
218 *Information on patient's education? Categories (e.g. primary/secondary/university/years of schooling etc.)
219 *Occupation and industry? Categories (ILO?)
220 *Social class or socio-economic status? Categories:
221 *Information about patient’s exposure to carcinogens? Categories: (e.g. tobacco / radiation / drugs etc.).

**IX INCIDENCE DATE**

**DATE OF DIAGNOSIS (LEVEL OF DETAIL):**

222 Day?
223 Month?
224 Year?

225 *HOW DO YOU DEFINE THE DATE OF DIAGNOSIS?

Please rank the following dates in order of preference for the cancer incidence date. (If not used, please state "NU").

226 Date of first symptom?
227 Date of first health care system attendance (consultation)?
228 Date of first diagnosis of the cancer by a physician?
229 Date of death?
230 Date of pathology (histology) report?
231 Date of hospital admission?
232 Date of discharge?
233 Date of report (notification)?
234 Date of clinical investigations (e.g. x-ray)?
235 Date of first treatment?
236 "Diagnose date" (as written on the form)
237 Other?

*Concerning a tumour first notified on a death certificate, does the registry:

238 Attempt to trace earlier information about the tumour?
239 Register the case without further efforts as a death certificate only (DCO)?
240 Refuse to register cases from death certificate notes (DCN) in any circumstances?

*For a patient known as a DCO case is the incidence date:

241 Date of death?
242 Date of reported diagnosis on DCN?
243 Other?

*For a patient known from autopsy only, is the incidence date:

244 Date of death?
245 Date of reported diagnosis on autopsy?
246 Other?

**X BASIS OF DIAGNOSIS**

METHODS

247 * Do you collect data on all methods used to make the diagnosis?
248 * Do you code each method separately?
249 * Do you code "most valid basis"? (e.g. "histology" rather than surgery, etc.)

*If you do code "most valid basis", please indicate ranking order for the following:

*Microscopic, rank (1-6)

250 No histology, cytology, marrow or bloodtests.
251 Cytology (expectorate, aspirate etc.).
252 Haematology / Specific biochemical / immunological tests.
253 Histology of primary / bone marrow / metastases
254 Unknown.
Appendix 1 Original questionnaire

255 Death certificate only.
256 If no histology - cytology please rank the *macroscopic* investigations:
   Clinical only (bloodiest, palpation, laboratory, etc.) /
   Clinical investigation (incl. x-ray, ERCP, CT-scan etc.).
   Surgery (incl. biopsy) / autopsy.
   Ultrasound, needlebiopsy, scintigraphy, MR-scan.
   Endoscopy (bronchoscopy, gastroscopy, rectoscopy, cystoscopy, etc.).
   Unknown.
   Death certificate only.

XI CLASSIFICATIONS

257 WHICH CLASSIFICATION(S) do you currently use for diagnosis (SNOP / MOTNAC 1955 / MOTNAC 1965 /
   SNOMED / ICD-O 1976 / ICD-O 1990 / Other) ?
   * List classification systems, (SNOP, MOTNAC 1955, MOTNAC 1965, ICD-7, ICD-O 1976, ICD-O-
   1990) and period of use
258 Are there any exceptions to the classification rules ?
   * HOW DO YOU DEFINE ”TOPOGRAPHY” (PRIMARY TUMOUR) ?
259 How do you choose the code ?
260 Can the Topography be changed? Describe rules.
261 *HOW DO YOU DEFINE ”MORPHOLOGY” ?
262 Describe how you choose the code (e.g. Do you have a ranking system, if there is more than one
   histology given by the pathologist ?)
263 Can the morphology be changed ? -describe rules.
264 *HOW DO YOU DEFINE ”BEHAVIOUR OF TUMOUR” ?
265 Describe how you choose the code
266 Do you have any ranking system of behavioural code (e.g. there is more than one behaviour given
   from the pathologist) ?
267 Can the behavioural code be changed ? Describe rules.

270 LIST REPORTABLE TUMOURS
271 * List reportable tumours and time-period
272 * List tumours included in incidence publications and time-period (spec. carcinoma in situ of cervix,
   testis, breast etc., borderline tumours in ovaries)
273 which of the reportable tumours are not included in the incidence publication?
274 which of those not included, can be tabulated?
275 Does the registry perform any conversions of ICD classifications ?

IF YOU PERFORM ANY CONVERSION OF ICD :
276 Please specify nature of conversion (e.g. ICD-7 to 9; ICD-0 to ICD-9)
277 Specify time-period for conversion tables.
278 How do you create conversion tables ?
279 How do you maintain conversion tables ?
280 How do you control conversion tables (e.g. visual check, electronic check - e.g. IARC's program,
   pathologist check etc.) ? (lists).

GIVE THE PURPOSE OF THE CONVERSION OF ICD CLASSIFICATIONS :
281 Comparability with old data ?
282 To make your data comparable with data from other registries ?
283 Other purposes ?

WHICH DIAGNOSIS, IF ANY, IS RECORDED IN ADDITION TO THE CANCER DIAGNOSIS CODED BY THE
   REGISTRY:
284 Admission diagnosis ?
285 Discharge diagnosis ?
286 Death certificate diagnosis ?
Autopsy diagnosis?
None?
Other (e.g. AIDS / Hepatitis ICD-10: B21)?

Are any malignant diseases (e.g. non-melanoma skin cancer) routinely excluded when reporting data from the registry?
If yes please specify (ICD-ranges or numbers)

*Do you record the tumours below?
If yes, are they included in the incidence?

<table>
<thead>
<tr>
<th>Tumour type</th>
<th>Record yes</th>
<th>Record no</th>
<th>Included yes</th>
<th>Included no</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benign Brain tumours</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benign bladder tumours (papilloma)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intraductal carcinoma (8500/2) in the breast</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carcinoma in situ in the breast, other than above</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Borderline tumour in the ovary</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carcinoma in situ in testis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Precancerous lesions in the cervix</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Are any other benign or precancerous lesions coded to or included with categories of malignant tumours?
*If yes, please specify

*Do you record clinical stage / extent of tumour?
*How do you define stage / extent?
*How do you choose the code?
*Do you have any ranking system of stage / extent of tumour (incl. e.g. Figo / Duke before extent)? Describe

*Do you use TNM staging schemes:
Clinical?
Pathological?

*If clinical stage is recorded, which system is being used:
Cervix uteri?
Bladder? (Bergquist grading)
Gynaecological tumours?
Colon and rectum?
Malignant melanoma?
Hodgkin's disease?
Testis?
Lymphoma, leukaemia, myelomatosis?
Other sites?

* e.g. TNM, FIGO for gynaecological, Clarke's for melanoma, etc.

*Do you record the date for clinical staging / extent of tumour?
If yes, please specify the rules you follow

*Do you ever update the clinical stage / extent of tumour?
(e.g. for Hodgkin's / bladder - "benign" tumour)
If yes, please specify for which cancers and your rules.

Can you tabulate:

Carcinoma in situ / precancer
Please specify organs?
Appendix 1 Original questionnaire

XII MULTIPLE PRIMARIES

*PLEASE DESCRIBE CHANGES IF ANY OF MULTIPLE CANCERS, AND YEAR.
*PLEASE STATE THE RULES USED TO CODE MULTIPLE CANCERS IN YOUR REGISTRY (or provide a copy of your instructions if this is more convenient):

ICD-O 1976 rules ?
ICD-O 1990 rules ?
SEER ?
Berg ?
Other ? please specify
please comment on the rules on attached sheet (table 1+2 from "Comparability and quality in cancer registration)

*RULES FOR CODING CANCERS IN PAIRED ORGANS:

How are tumours with the same morphology in each side coded / counted ?
How are tumours with different morphology in each side coded / counted ?
How are tumours with different behaviour (e.g. intraductal carcinoma in left breast and duct carcinoma in right breast) coded / counted ?
*HAS THERE BEEN ANY CHANGES IN YOUR RULES FOR CODING OF TUMOURS IN PAIRED ORGANS? Please describe the changes and the year.

XIII TREATMENT

*PLEASE DEFINE "INITIAL TREATMENT" (e.g. treatment given within two months of diagnosis)

*DO YOU DISTINGUISH THE FOLLOWING TREATMENT CATEGORIES:

Curative ?
Palliative ?
Other ?

*DO YOU RECORD AND CODE THE INITIAL TREATMENTS MENTIONED:

Surgery ?
Type of surgery ?
Only explorative surgery ?
Radical surgery ?
Radiotherapy ?
Cytotoxic treatment, which type ?
Hormonal treatment, which type (e.g. "medical": tamoxiphen/honvan etc., "hormonal operation": castration for prostate / oophorectomy for breast cancer)
No treatment ?
Other ?

*DO YOU RECORD AND CODE SUBSEQUENT TREATMENT:

Surgery ?
Type of surgery ?
Only explorative surgery ?
Radical surgery ?
Radiotherapy ?
Cytotoxic treatment, which type ?
Hormonal treatment, which type ?
Other ?

IF YOU RECORD AND CODE SUBSEQUENT TREATMENT, PLEASE DEFINE
Appendix 1 Original questionnaire

*IF SUBSEQUENT OR INITIAL TREATMENT IS NOT RECORDED, COULD IT BE OBTAINED FROM MEDICAL RECORDS FOR SPECIAL STUDIES (E.G. FROM LPR) ?

357  Easily ?
358  With some difficulties ?
359  With major difficulties ?
360  Not obtainable ?

*WHICH DATES FOR PRIMARY TREATMENT DO YOU RECORD AND CODE ?

361  Date of start ?
362  Date of end ?
363  Other ?

*WHICH DATES FOR SUBSEQUENT TREATMENT DO YOU RECORD AND CODE ?

364  Date of start ?
365  Date of end ?
366  Other ?

367  *DO YOU RECORD PLACE OF TREATMENT ?

XV DEATH

368  * DO YOU RECORD DATE OF DEATH ?
If yes, give detail:
369  Day ?
370  Month ?
371  Year ?

*If yes please rank source in order of preference (1-4) in the event of any discrepancy :
372  Reporting hospital/doctor
373  Death certificate
374  Pathology laboratories
375  Other

376  * DO YOU RECORD CAUSE OF DEATH ?
*If yes, please rank source in order of preference (1-4) in the event of any discrepancy:
377  Reporting hospital/doctor
378  Death certificate
379  Administrative autopsy (pathology lab.)
380  Other

381  *If yes, please describe how the causes are recorded and received
382  *HOW ARE DISCREPANCIES BETWEEN "CAUSE OF DEATH" AS STATED ON THE DEATHCERTIFICATE AND THE CANCER KNOWN IN THE REGISTRY (e.g. stomachcancer on death-certificate / eosophagus-cancer in registry) solved ? Describe.
383  *DO YOU CORRECT CAUSE OF DEATH ( in the death index and/or cancer registry) by use of cancer registry data ?

XVII FOLLOW-UP and TRACE-BACK

A  By follow-up we mean that the registry follows up registered cases to obtain information about e.g. recurrence, treatment, or death.

B  By trace-back we mean, that the registry actively attempts to obtain further information about a tumour, (e.g. first notified on a death certificate, or if the information on a patient is not satisfactory for other reasons) in order to complete the coding of the tumour recorded.
**Appendix 1 Original questionnaire**

*DO YOU ACTIVELY (A) OBTAIN OR ROUTINELY (R) (PASIVELY) RECEIVE DATA FROM ANY OF THE FOLLOWING SOURCES FOR FOLLOW-UP AND/OR TRACE-BACK?*

<table>
<thead>
<tr>
<th><strong>Hospitals</strong></th>
<th>trace-back</th>
<th>follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>384 Clinical departments ?</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>385 Medical records ?</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>386 Outpatient clinics ?</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>387 Hospices ?</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>388 Long stay hospitals and homes for the elderly ?</td>
<td>*</td>
<td>*</td>
</tr>
</tbody>
</table>

**Laboratories** (in or outside hospitals)

| 389 Pathology, general ? | * | * |
| 390 Pathology, specialised ? | * | * |
| 391 Haematology ? | * | * |
| 392 Autopsy reports ? | * | * |
| 393 Institute of forensic medicine ? | * | * |
| 394 Other ? | * | * |

**Death certificates ?**

| 395 | * | * |

**General practitioners ?**

| 396 | * | * |

**Specialist practitioners ?**

| 397 | * | * |

**Health insurance ?**

| 398 | * | * |

**Screening programmes ?**

| 399 | * | * |

**Administrative sources**

| 400 Central population registers ? | * | * |
| 401 Central medical registers (e.g. hospital information systems) ? | * | * |
| 402 Other ? | * | * |

*IF YOU CARRY OUT FOLLOW-UP:

| 403 | For how many years do you follow-up a patient ? |
| 404 | If this varies, please specify |

*IS THE STATUS OF THE PATIENT DETERMINED AT A GIVEN DATE of cancer diagnosis or registration?*

*If yes what do you enquire about - and do you only enquire in case of doubt:*

| 406 Recurrence or extension of primary tumour ? |
| 407 Metastases ? |
| 408 Further treatment ? |
| 409 Date of death ? |
| 410 Cause of death ? |
| 411 Other ? |

*IS THE STATUS OF THE PATIENT DETERMINED AT SUCCESSIVE ANNIVERSARIES OF CANCER DIAGNOSIS OR REGISTRATION?*

*If yes what do you enquire about - or do you only ask in cases of doubt:*

| 413 Recurrence or extension of primary tumour ? |
| 414 Metastases ? |
| 415 Further treatment ? |
| 416 Date of death ? |
| 417 Cause of death ? |
| 418 Other ? |

DESCRIBE HOW AND HOW OFTEN THE REGISTRY IS UPDATED FOR DEATH AND IMMIGRANTS/EMMIGRANTS?

*IF NO DEATH NOTIFICATION IS RECEIVED, IS THE PATIENT CONSIDERED TO BE STILL ALIVE ? (For the purpose of survival analysis and prevalence estimation) ?
Appendix 1 Original questionnaire

**XIX SCREENING PROGRAMMES**

**ARE THERE ANY SCREENING PROGRAMMES IN THE AREA YOU COVER?**

If yes please specify cancer-type

- cervix
- breast
- colon
- melanoma
- prostate
- other

- 421 year of start
- 422 age-group
- 423 how often

**DO YOU COOPERATE WITH (e.g. provide information about interval cases to) OR RECEIVE INFORMATION (e.g. list of cases) FROM ANY SCREENING PROGRAMMES?**

If yes, please specify for each cancer-type how you co-operate and/or if you receive lists:

- Cervix
- Breast
- Colon
- Melanoma
- Prostate
- other

- 424 year of start
- 425 age-group
- 426 how often

**XX USE OF COMPUTER**

**WHAT SOFTWARE IS THE REGISTRY USING?**

**WHAT STATISTICAL PACKAGE IS THE REGISTRY USING:**

- On mainframe
- On minicomputer
- On PC or PC network
- System developed especially for the registry (very brief description)

**XXI CONFIDENTIALITY**

- 433 DOES YOUR REGISTRY OBSERVE A SET OF RULES ON CONFIDENTIALITY?
- Please give a copy of your rules and the law for confidentiality

- 434 ARE YOU LEGALLY PERMITTED TO LINK THE REGISTRY WITH OTHER FILES?
- If yes, are such data linkages regulated:
- 435 By law or administrative order?
- 436 By the registry's own code of conduct?
- 437 In other ways?

**DO YOU HAVE RULES ON DELETING IDENTIFIABLE INFORMATION IN THE REGISTRY?**

- 438 after a specific period of time?
- 439 At a given date (e.g. death of a patient)?
- 440 Other?

- 441 CAN AN INDIVIDUAL LEGALLY OBTAIN ACCESS TO DATA ABOUT HIMSELF/HERSELF IN YOUR REGISTRY?

- 442 CAN AN INDIVIDUAL DECIDE NOT TO BE INCLUDED IN THE CANCER REGISTRY?

- 443 IS AN INDIVIDUAL REQUIRED TO GIVE ORAL OR WRITTEN CONSENT BEFORE HIS/HER DATA CAN BE INCLUDED IN THE CANCER REGISTRY?

**WHO CAN GET ACCESS TO THE CANCER REGISTRY DATA:**

- On case by case basis - anonymous
- On case by case basis - with identifying information
- Neither

- 444 The patient?
- 445 Physician for research purposes?
- 446 International release?
Appendix 1 Original questionnaire

XXII QUALITY CONTROL

Completeness of coverage:

WHAT METHOD DO YOU USE TO ESTIMATE COMPLETENESS OF REGISTRATION:

Primary source review:
447 Disease index comparison? (e.g. hosp. statistics)
448 Outpatient logs?
449 Pathology department logs?
450 Comparison with patients enrolled in trial protocols?
451 Random sampling of patients admitted to hospital and scrutiny of records for missed cases (capture-recapture)?
452 Surveillance of numbers of registrations from each source?
453 Other?

Completeness of detail:

454 Do you calculate the average number of sources/notifications per case?
455 Has the number changed over the years?
456 - What are/were the numbers?

Please give figures for a recent year for the following:
457 Percent of "unknown primary site"?
458 Percent of "age unknown"?
459 Percent of "treatment unknown"?
460 Percent of "stage unknown"?
461 Percent of "no histology"?
462 Percent of "basis of diagnosis unknown"?
463 Percent of "date of birth unknown"?
464 Percent of "residence unknown"?
465 Percent of "place of birth unknown"?
466 year/period to which these figures apply?

WHAT IS THE MOST RECENT YEAR YOU CAN PUBLISH?
(How many years/months delay?)

WHICH OF THE FOLLOWING METHODS OR MEASURES DO YOU USE TO MAINTAIN QUALITY CONTROL OF THE REGISTRY'S DATA:

468 Independent re-abstraction of a sample of cases?
469 Independent re-coding of a sample of cases?
470 Independent duplicate data entry of a sample of cases?
471 Input logical checks?
472 Use of test cases?
473 Proof-reading of coded notification forms?
474 Summary tabular frequency checks?
(e.g. site by morph)
475 Histological verification (percent)?
476 Incidental autopsy finding (percent)?
477 Death certificate (percent)?
478 Mortality/incidence ratio - highest/lowest site?
479 Stability of rates over time?
480 Comparison with neighbouring registries?
481 Other?

XXIII WEAK POINTS

482 LIST MALIGNANCIES YOU BELIEVE MAY BE UNDER-REPORTED:
(with comments if possible)
483 LIST MALIGNANCIES YOU BELIEVE MAY BE OVER-REPORTED IN ERROR:
(with comments if possible)
XXIV CHECKS

If possible, you may wish to attach a list of the checks carried out by your system

484 ARE YOU USING THE IACR CHECKPROGRAMME or some other computer-based check program
Please describe and provide a list - EDB (special questionnaire)

485 DO YOU PERFORM MANUAL/VISUAL CHECKS?
If yes, please specify at least the essential variables checked

XXV OUTPUT FROM REGISTRY

IN YOUR REGULAR/ANNUAL ROUTINE PUBLICATIONS OF INCIDENCE RATES, DO YOU GIVE TABLES OF RATES BY :

486 year ?
487 Sex ?
488 Age ?
489 Site ?
490 Occupation ?
491 Social group ?
492 Residence ?
493 Geographical subdivision of your territory ?
494 Do you show trends ?
495 Other variable ?

IN YOUR REGULAR/ANNUAL PUBLICATIONS, DO YOU USE :

496 World Standard and year ?
497 European Standard and year ?
498 Own Standard ?
499 Other ?

IN YOUR REGULAR/ANNUAL ROUTINE PUBLICATIONS OF MORTALITY RATES, DO YOU GIVE TABLES OF RATES BY :

500 year ?
501 Sex ?
502 Age ?
503 Site ?
504 Occupation ?
505 Social group ?
506 Residence ?
507 Other variable ?
508 Do you carry out evaluation of incidence trends
BASIC CHARACTERISTICS OF THE REGISTRY

DENMARK

date: October 3rd 1997

1) Danish Cancer Registry
2) Amaliegade 13
3) Dk Copenhagen K
4) Denmark
5) Tel: +45 33 91 16 01
6) Fax: +45 33 91 22 48
7) e-mail:

websites: www.sst.dk and www.cancer.dk

Persons interviewed:

Name: Jesper Pihl Birgitte Brandt Elli Michelsen Lund Hans H. Storm
Position: EDB co-ordinator /data-processing Registry MD Former registry MD Former Director of the Cancer registry
Training/Degree JP BB EML HHS

abbreviation: JP BB EML HHS

I THE REGISTRY

8) The registry is population-based and covers: Denmark and Greenland.

9) The population includes all the people in the area who are entered into the official population statistics that have been given a personal identification number. Greenland is included, while the population of the Faro-islands is not included. Home-address at time of diagnosis is registered.

10) Special registries - management-programmes: There are no special registries in the Danish cancer-registry. There are however registries run separately from the cancer registry e.g. by the Danish Breast Cancer Group (DBCG).

II DEMOGRAPHICAL INFORMATION

11) An incidence publication is made every year on country and county level - Greenland is not included in this nor in the information below.

12) There has been no changes in population covered by the registry.

The resident population in the area (excl. Greenland) covered by the registry was in 1993

13) a Males: .............................................................................................................. 2 559 019
14) b Females: .............................................................................................................. 2 629 604
15) c Total: ................................................................................................................... 5 188 623

16) The population figures are exact from 1968, before that they were interpolated from Census.

17) Population figures used for incidence calculation are the midyear average figures.

18) The Health system: There are General Practitioners, with a "house-doctor" organisation. They refer the patient to hospital for surgery, or they send the patient for investigations by private specialists or in the hospitals. In each county there are several hospitals and 1 "district"-hospital. Associated to the medical faculties at the universities there are furthermore University-hospitals.

19) The hospitals are governed by the local authorities for counties / municipalities.
REGARDING POPULATION DATA THE FOLLOWING ARE AVAILABLE IN THE REGISTRY

<table>
<thead>
<tr>
<th></th>
<th>available</th>
<th>used</th>
</tr>
</thead>
<tbody>
<tr>
<td>20)</td>
<td>Sex in one-year age groups</td>
<td>x</td>
</tr>
<tr>
<td>21)</td>
<td>Sex in five-year age groups</td>
<td>x</td>
</tr>
<tr>
<td>22)</td>
<td>Information on occupation, education and social groups</td>
<td>-</td>
</tr>
<tr>
<td>23)</td>
<td>Information on religion</td>
<td>-</td>
</tr>
<tr>
<td>24)</td>
<td>Information in the registry for &quot;ethnic groups&quot; and &quot;country of origin&quot;</td>
<td>-</td>
</tr>
<tr>
<td>25)</td>
<td>The urbanity-degree is available</td>
<td>x</td>
</tr>
<tr>
<td>26)</td>
<td>The information about the geographic distribution</td>
<td>x</td>
</tr>
<tr>
<td>27)</td>
<td>The address as a land registry-number (koordinatsystem)</td>
<td>-</td>
</tr>
</tbody>
</table>

III HISTORY

28) The registry started operating in the 1942 under the Cancer Society, from 1997 under the National Board of Health

29) The registry can present population based data from 1943

CHANGES

30) Since 1987 the registry has been linked to the hospital discharge registry annually, but the tumours found this way are only included if they are verified - tumours not included in the incidence calculation are not investigated (e.g. in situ; border-line; not known if benign/malignant) - this may have influenced the trends

31) There have been no changes in inclusion / exclusion of tumours.

32) Changes in hospital procedures:
   a) e.g. needle-biopsy and later PSA for prostate cancer, which may have caused an increase in the frequency of clinical diagnosis.
   b) At the same time the autopsy-rates have decreased during the 80'ies, but may not have influenced the incidence, as better investigation methods have been developed during the same time.
   c) Regarding brain tumours the development of MR-scanners may result in more tumours being detected in old people.

33) Reporting of cancer cases has been compulsory since 1987. From 1942 to 1987 it was voluntary, but this change has not influenced the trend in cancer incidence.

34) At present reporting of tumours is compulsory for:
   a) Any medical Doctor employed privately or in a hospital department, who has diagnosed the tumour disease clinically or microscopically.
   b) Any medical Doctor writing a tumour disease on the death-certificate even if diagnosed after death.
   c) The pathological and haematological laboratories and doctors do not have to report cancer cases...
except in case of autopsy.

35) Operation of the registry has not been discontinued at any time.

36) The registry is run technically by the National Board of Health from 1. January 1997. Before that: from 1942 till 31. December 1996 it was run by the Cancer Society but supported financially by the Danish Government.

37) The data are reported annually as Cancer Incidence of Denmark until the 1993 "Incidence book" by the Cancer Registry under the Cancer Society; from the publication of the 1994 "incidence book" by the National Board of Health. The data was until 1. January 1997 owned by the Cancer Society, but are now owned by the Danish government.

IV STAFF & ORGANIZATION

38) EMPLOYEES: 1 EDB co-ordinator and data processor
1 Medical Doctor
8 coders for the registry (locally trained)

39) The cancer registry has always been working very closely with research scientists both locally in the Cancer Society and internationally as well as with clinicians from the whole country.

40) The registry is at present working closely with the following departments: For the data material the registry is working with all the health departments and also locally with the other registries in the National Board of Health. Furthermore there is an agreement with the Cancer Society that the registry continues - for a period - to deliver updated data regularly to the Cancer Society, in order that the cancer epidemiology may continue.

41) The registry is administratively under the National Board of Health.

42) The registry is not involved in e.g. mass screening or other cancer control programmes.

43) The cancer-registry is located in the National Board of Health, while the archives with all the old microfilms still are kept at the Cancer Society.

SOURCES OF FINANCE:

44) Registration of cancer is financed by the government.

45) Research projects are not carried out in the cancer registry any more since 1. January 1997. Though data are still delivered to the Cancer Society for research projects.

CODING

46) Coding of site and morphology is carried out at the registry, and plaintext must appear on the notification forms.

47) The coding / classification of neoplasms to site and morphology is carried out by the coding assistants, who have received special training at the registry.

48) Supervision of coding and solving of coding problems is done by a Medical Doctor (MD).

49) In difficult cases - external consultation with the reporting medical doctor and at times with a pathologist is done.

50) Coding problems are either solved by the Registry doctor, or a pathologist may be contacted.
Appendix 2  Denmark

51) Coding problems are not brought up at special meetings - as in Sweden.

**LETTERS / TELEPHONE**

52) The registry has to request for clarification in many of the cases either written or by telephone.

53) Sometimes notifications are not received - and very often it is the same data providers who fail. This may be revealed by the annual linkage to the Discharge registry and the Cause of Death registry.

**V REPORTING**

*TUMOUR REGISTRATION FROM DIAGNOSIS TO REGISTRY:*

54) The general practitioners may refer the patient to hospital for surgery or other treatment, or they send the patient for investigations by private specialists or in the hospitals.

55) No fee is paid to the reporting physician or institution, but until the 1987 a fee was paid.

56) Most often it is the medical secretary who writes the report, and the doctor signs it.

57) Linkages is carried out with the Cause of Death Registry in order to include those cases not reported in other ways. Linkage with the Hospital Discharge registry is also carried out annually, but from this only the cases are included, which are confirmed by a notification form. Linkage with the Central Population Registry is carried out to check the persons name and CPR-number before the coding starts.

58) Information on name and address of the reporting hospital / clinic / practitioner / or other source is kept in the microfilm, but not coded into the registry.

59) Information which makes it possible to go back to the original hospital or private practitioner records is thus available.

60) Patients have their "own" GP. - But the registry does not have access to that information

**VI SOURCES**

*THE REGISTRY REGULARLY RECEIVES NOTIFICATIONS FROM:*

61) Hospitals
62) Medical records departments - no
63) Outpatient clinics
64) Hospices
65) Long stay hospitals and homes for the elderly

**Laboratories** (in or outside hospitals)
66) Pathology - no
67) Haematology - no
68) Autopsy notifications - yes
69) Institute of forensic medicine

70) **Death certificates** are used as source for tumour registration.
Appendix 2  Denmark

Other
71) General practitioners
72) Specialist practitioners
73) Screening programmes - no.

FORMS RECEIVED
74) The registry receives most forms from the clinical departments.
75) It has not been calculated how many are diagnosed clinically only, as most notifications come from clinical departments and very few from autopsy only.
76) The information about cancer is recorded from the notification forms, which must be filled in plain-text, that is coding number only - even from pathologist - are not accepted.

THE REGISTRY RECEIVES (OR HAS REGULAR ACCESS TO) COPIES OF THE FOLLOWING FOR CANCER PATIENTS:
77) Medical records.............................................................. no
78) Pathology reports.......................................................... no
79) Autopsy reports............................................................. no
80) Discharge letter............................................................. no
81) Death certificates............................................................ yes
82) Radiotherapy reports....................................................... no
83) Hospital information system (via Hospital Discharge Registry)................................................ yes
84) The staff at the registry does not visit the oncologic clinics.
85) The original notification forms are stored on microfilms.
86) DEFINITION OF PLACE OF "RESIDENCE":
The address of the place where the patient is living on the date of diagnosis.
87) Immigrants and/or non-residents are not included.
88) Refugees are not include in the registry.
89) Special subgroups/minorities in the population may not be isolated.
90) Tumours in patients who are not permanent residents of the registry territory are not registered.
91) Residents working abroad and belonging to the country are not included unless the diagnosis is made in Denmark - or made available to the registry.
92) The data are not submitted to a larger registry

VII INFORMATION RECORDED
93) THE CODING OF DATA: On receipt a coding assistant makes a "rapid primary coding" according to ICD 10 on opening the mail and enters the person's identification number as well as the primary coding into a special "notification database".
Appendix 2  Denmark

94) **THE PROCESSING OF DATA** on registration all forms on the person are consulted and found (e.g. in case of multiple tumours). After 1-2 years the primarily coded tumours are coded by trained coders.

95) Two or more notifications are linked electronically using the unique personal identification number.

96) After receiving and coding all the available information, a second form may be requested from the relevant source if the first was incomplete or e.g. the patient referred from / to another department which may have more information. The tumours are entered into the cancer registry continuously.

97) **COMPUTERIZED CASE RESOLUTION** is not carried out.

VIII THE PERSON

98) **THE SOURCE FOR INFORMATION ON THE PERSON** is the Central Personal Registry (CPR), which assigns a unique number to each resident in Denmark.

99) The patient is not given another number in the registry.

100) The unique personal registry number is constructed of: 2 digits for day, 2 for month, 2 for year of birth and 4 serial numbers where the first digit designates the century in which the person was born, and the last digit designates the sex, uneven for male and even for female; and at the same time the last number is a figure which is used as control.

101) Immigrants are assigned a CPR number when they become residents.

102) The number does not indicate where the person was born nor if he/she belongs to any minority and it does not indicate ethnicity - but it is possible through the CPR to trace former addresses.

103) The registry receives an update on individuals for date and cause of death from the Death certificate registry annually on tape and it is transferred directly, accepting the official cause of death. However vital status is available for research projects continuously as the registry is on-line with CPR. It is therefore possible to update individual information if needed including year of emigration.

Names of patient

104) The patient's full name is registered from the 1st of January 1994; before that only the first letters in the names were registered.

105) The maiden name is not registered unless the patient got married after the tumour was registered. None of the following are registered: Father's name / Mother's name

106) The CPR number of the next of kin is not registered.

Residence/address at the time of registration

107) The code for the patient's address is received automatically once the patient is checked against CPR.

108) This code gives the municipality.
109) Change of address is accessible if necessary from the CPR, but the address at the time of diagnosis is the one kept in the registry.

110) The age at the incidence date is calculated from the CPR- number.

111) The persons nationality (e.g. French, Danish) is not registered.

112) No further information is used from the CPR.

113) The nationality of father and/or mother are not available.

114) Marital/civil status at diagnosis is available by the following categories through linkage to CPR:

   a) Married - yes
   b) Separated - yes
   c) Divorced - yes
   d) Widow/widower - yes
   e) Cohabitation - yes
   f) Single - yes

115) Death - yes

116) Number of live births and categories (actual number) are not used as it is not very reliable, but is available through linkage to CPR and the Birth registry.

117) Religion - no

118) Ethnic groups - no

119) Race - no

120) Patient's education no

121) Occupation - is available from CPR, but this is not a very reliable source- see "24"

122) Special enquet studies for occupation - yes

123) Social class or socio-economic status - no

124) Patient's exposure to carcinogens - no

IX  INCIDENCE DATE

Date of diagnosis (level of detail):

125) The date is recorded as the year and month of diagnosis.

126) The date of diagnosis is defined as the earliest date written on the received notification forms.

127) A tumour first notified on a death certificate is traced to get earlier information about the tumour.

128) 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.

129) For a patient known from autopsy only, the incidence date is the date of death if the cancer
was not known before death. If the cancer was known, but no other notification form is available the date is still the date of death.

X BASIS OF DIAGNOSIS

Methods
130) The "most valid basis" is coded in the following ranking order:
   a) Histology / bone marrow
   b) Cytology (expectorate, aspirate etc.).
   c) Blood smear in leukaemia
   d) Surgery (including endoscopy), autopsy without histology, X-ray and some specified laboratory examinations.
   e) Clinical examination only.

XI CLASSIFICATIONS

131) Classification(s):
   a) From 1942: Tumours were coded according to a Nordic Classification system. They have however all been transferred into the actual ICD-7 systems and the old classification is no longer existing.
   b) From 1955: topography was coded according to ICD 7 with some local special coding numbers.
      morphology was included in the ICD 7 codes by giving the first digit special meaning - (see 158d)
   c) From 1978: topography was coded according to ICDO-1 and with transformation tables to ICD 7
      morphology was coded according to ICDO-1 code equal to SNOMED
   d) From 1995: topography was coded according to ICD 10, ICDO-1 with transformation to ICD 7.
      morphology was coded according to ICDO-2 (SNOMED).

132) Exceptions to the ICD 7 of WHO classification rules or special rules:
   a) Usually the coding figures are the same on 3 digit level, while there are several differences on the more specific 4th digit.
   b) usually xxx,7 is not used
   c) often there are different figures for the fourth digit indicating the morphology, e.g.
      adenocarcinoma of the lungs or oat cell carcinoma.
   d) the first digit is used to differentiate between carcinoma - sarcoma (8) - reticulasarcoma (7) 
      - metastasis (6) - uncertain whether benign/malign (9) - precancrose (5) or indicate 
      special cases [as mesothelioma of the pleura (462.2)]
   e) 190,5 and 191,5 ): anus cancer included in trunk skin cancer has been given a separate number: 091.0 - but is included in the total of skin under either 190 or 191.
   f) 165 is not used
   g) sarcoma - see "d" are given special first digit numbers according to the organ of origin, so
      200,0-200,2 are only used for sarcoma etc in the lymph-nodes
   h) Brain tumours have been much more differentiated than in the WHO version, but all are
      included under 193.

133) Topography (primary tumour) is defined according to all the available information and the code is chosen according to specificity -the more detailed location of the primary tumour is given preference.

134) Topography codes may be changed if new information is more specific.
135) **MORPHOLOGY** is defined according to histologic description reported by the clinician.

136) Morphology may be changed if a histological description with a "more specific" number is received, this is often indicating a more specific diagnosis from a better specimen - if there are different morphologies, the most likely is chosen or the case is validated to decide whether there are 2 tumours.

137) **BEHAVIOUR OF TUMOUR** is given by the description and within the first 4 month of date of diagnosis. The code chosen is the most malignant (behaviour 3 > 2 > 1 according to ICD-O1).

138) If the behavioural code changes a new tumour has to be registered, with a new date of diagnosis. That means if the new notification is referring to a tumour at the same site and the same morphology but malignant and not "just" in situ and the date of diagnosis is 4 months after the first tumour. For different topo and morpho see "multiple".

139) Papilloma of the urinary tract which becomes invasive is counted as from the date of diagnosis of the papilloma and the behavioural code is not changed.

140) **List of reportable tumours in ICD-10:**
   a) All malignant tumours - C00-C97
   b) Tumours not known if benign or malignant (D37-D48) and O01
   c) All urinary tract tumours (D09.0-D09.1 + D30)
   d) Benign tumours in the brain, meninges and other parts of the central nervous system; and benign tumours in intracranial endocrine tumours.
   e) Cervix: dysplasia and Carcinoma in situ (N87 + D06).
   f) Testis: other tumours (D07.6)
   g) Carcinoid syndrome (E34.0)

141) **List of tumours included in cancer incidence:**
   a) Diseases mentioned under 140 a, c, d and g.
   b) The reportable tumours mentioned under 140 b, e and f are not included in the cancer incidence, but some are tabulated separately in the incidence publication.

**Conversion of ICD :**

142) Conversion tables from one coding system to another is updated continuously as new tumour-diagnosis are included from the histological description, and found in topographies not earlier described in the registry. This updating is done by the medical doctor and used to be checked by the director of the Cancer-registry to ensure that topo-morpho combinations which are not possible are not entered into the system.

**The purpose of the conversion of ICD classification is:**

143) To ensure comparability with old data.

144) To make data comparable with data from other registries (e.g. Eurocare).

**Diagnosis recorded in addition to the cancer diagnosis coded by the registry:**

145) Admission diagnosis - not coded.

146) Discharge diagnosis - not coded.

147) Cause of death - is registered.

148) Autopsy diagnosis - is not coded.

149) Of other diagnosis AIDS (ICD-10: B21) are coded in the precoding.
Malignant diseases routinely included / excluded when reporting data from the registry:

150) Basal cell carcinoma of the skin are included in skin tumours, but can be separated from 1978, using the morphology.

THE TUMOURS BELOW are recorded and included in incidence data as shown:

<table>
<thead>
<tr>
<th>Tumour type</th>
<th>Record yes</th>
<th>Record no</th>
<th>Included yes</th>
<th>Included no</th>
</tr>
</thead>
<tbody>
<tr>
<td>151) Benign Brain tumours</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>152) Benign tumours of the Pituitary gland</td>
<td>x</td>
<td>x if M*=93501 or M*=95300</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>153) Carotid body tumour</td>
<td>x</td>
<td>x if M=87110</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>154) Benign bladder tumours (papilloma)</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>155) Intraductal carcinoma (8500/2) in the breast</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>156) Carcinoma in situ in the breast, other than above (lobular)</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>157) Borderline tumour in the ovary</td>
<td>x</td>
<td>x if M*=82401; 86301; 86321; 86501; 90911</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>158) Carcinoma in situ in testis</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>159) Chromaffinoma (8700/0) of the adrenal glands</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>160) Argentaffinoma (8241/1)</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>161) Chordoma (9370/3)</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>162) Invasive mole (9100/1)</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>163) Precancerous lesions in the cervix</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

a) M: morphology

164) Other benign or precancerous lesions coded to or included with categories of malignant tumours: Testis teratoma (M*=90801)

165) Clinical stage / extent of tumour is recorded.

a) The stage / extent can be devided into:
   - Localised
   - Regional spread
   - Metastasis of distant organ
   - Unknown

b) The code is chosen as the stage at the time of diagnosis (including the first 4 months)

c) The ranking of the systems is that usually Duke and Figo have preference if noted; the TNM system is sometimes used.

d) All information on staging within the first four months of diagnosis is entered into the system.

e) The date (including the first 4 months) of the staging is the date of diagnosis.

f) The stage may be updated if better information is received.

g) It is therefore possible to tabulate cancers according to the staging as described above - (though the staging as coded in the registry should be evaluated before use).
Appendix 2 Denmark

XII MULTIPLE PRIMARIES

166) The rules used to code multiple cancers in the registry:

a) Tumours with DIFFERENT TOPOGRAPHY on the 4 digit level and where it is clear that none of them are metastasis from the other are coded as multiple. - while in case of adjoining tumours involving more parts of the same organ, but with independent T-codes, the tumours are coded as one tumour with xxx.8. (according to the ICD-O rules)

b) Tumours with DIFFERENT MORPHOLOGY on the 4 digit level even with the same Topography code are coded as multiple. Exceptions are skin and connective tissue tumours, which are only coded as multiple if there is a difference in the first 3 digits of the M-code. Skin tumours with the same morphology are thus given the "multiple" skin-topography code: 173.8 SKIN TUMOURS with difference in morphology, which normally would give rise to multiple cancers are however not coded double, if the first tumour was diagnosed before 1. January 1978, in stead the first tumour is given the morphology of the first tumour and the topography = 173.8 (exempted are melanomas)

c) For tumours within the SAME ORGAN -: the first 3 digits of the Topo are the same-, and with the same Morphology it has to be very clear on the notification that the tumours are independent of each other if multiple tumours are to be accepted.

d) In case of CHANGE IN BEHAVIOUR and if 5 months or more have passed since the first date of diagnosis a new tumour has to be registered, except for urinary tract tumours within the same topography.

e) Change of GRADE in urinary tract tumours does not cause multiple tumour registration.

f) The registry counts tumours and not patients except for skin tumours - see "b"

g) URINARY TRACT TUMOURS - if more than one tumour (incl. in situ) are diagnosed at the same topography - see "c" they are counted as one tumour. At different topographies they are counted separately.

h) Astrocytoma grade 1 which after some years develop into multiform glioblastoma are counted and registered as 2 tumours.

Rules for coding cancers in paired organs:

167) Tumours with the same morphology on each side are coded as one tumour but bilateral and counted as one.

168) Tumours with different morphology - four digit level - on each side are coded as two tumours, and counted as such.

169) Tumours with different behaviour (e.g. intraductal carcinoma in left breast and duct carcinoma in right breast) are coded as 2 tumours since 1. November 1995.

XIII TREATMENT

170) TREATMENT is registered and defined as

a) Treatment given within 4 month of the diagnosis, and divided into: surgical / radiotherapy / cytostatic / hormonal

b) Place of treatment is not registered.
XVII FOLLOW-UP and TRACE-BACK

A By follow-up we mean that the registry follows up fully registered cases to obtain information about e.g. recurrence, treatment, or death.

B By trace-back we mean, that the registry actively attempts to obtain further information about a tumour, (e.g. first notified on a death certificate, or if the information on a patient is not satisfactory for other reasons) in order to complete the coding of the tumour recorded.

| Active (a) or passively (p) receipt of data from the following sources for follow-up and/or trace-back |
|-------------------------------------------------|-------------------------------------------------|
| Hospitals                                      | trace-back | follow-up |
| 171) Clinical departments                      | a          | p         |
| 172) Medical records                           |           |           |
| 173) Outpatient clinics                        | a          | p         |
| 174) Hospices                                  | a          | p         |
| 175) Long stay hospitals and homes for the elderly | a          | p         |

Laboratories (in or outside hospitals)

| Pathology, general                            | -         |           |
| Pathology, specialised                        | -         |           |
| Haematology                                   | -         |           |
| Autopsy reports                               | a          | p         |
| Institute of forensic medicine                | a          | p         |
| Other                                         | -         |           |

| Death certificates                            | a          | p         |

| General practitioners                         | a          | -         |
| Specialist practitioners                      | a          | -         |

| Health insurance                              | -         |           |

| Screening programmes                          | -         |           |

Administrative sources

| Central population registers                  | -         | p         |
| Central medical registers (e.g. hospital information systems) | a          | -         |
| Other                                         | -         |           |
XIX SCREENING PROGRAMMES

<table>
<thead>
<tr>
<th>Type and year of start</th>
<th>age-group</th>
<th>how often</th>
</tr>
</thead>
<tbody>
<tr>
<td>190) cervix: started in a few counties in the sixties. Recommended 1986, since then steady increase of coverage and finally 1995 organised screening in all counties.</td>
<td>23 - 59 years</td>
<td>every 3 years</td>
</tr>
<tr>
<td>191) breast: two counties and 2-3 starting soon</td>
<td>23 - 59 (74) years</td>
<td></td>
</tr>
<tr>
<td>192) colon: pilot</td>
<td></td>
<td></td>
</tr>
<tr>
<td>193) melanoma none</td>
<td></td>
<td></td>
</tr>
<tr>
<td>194) prostate: none</td>
<td></td>
<td></td>
</tr>
<tr>
<td>195) There is no co-operation with the cervix screening programmes - though tumours diagnosed in this way are notified through the normal channels (see also 47).</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

XX USE OF COMPUTER

196) The software used in the registry is "SAS".

XXI CONFIDENTIALITY

The registry observes the following set of rules on confidentiality:
The registry is regulated by the law for public authority registries no. 294 of 1978 with changes of 1991. (see appendix)

197) The information in the registry is confidential

a) The material may only be used in the project specified in the application.
b) Personal information must be kept so that unauthorised persons cannot gain access to the information
c) Direct contact to the person in question, relatives etc. may not be done by you without permission from the medical Doctor in charge of the ward or the chief Consultant at the current department
d) At the end of research-projects all material containing personal data drawn from the cancer registry must be destroyed by the scientist.
e) Publication of material must be done in such a way that no individual can be identified.

198) Current guidelines given by the Data-inspection for use of data-material from the cancer registry must be followed

199) When ordering personal identifiable extract on a data-medium (floppy-disc) the permission from the data-inspection must be enclosed. As the database of the cancer registry continuously is changed continuously these data-extractions cannot be kept updated.

200) In case of questions concerning annulment or quality of the delivered material the cancer registry is to be contacted first.
201) The Cancer registry presupposes that the registry is mentioned as source in all prospective publications.

202) The signing of the order in the application is at the same time a confirmation that you have participated in and accepted the conditions, listed above, for handling the material and the reservations given for publication of the given information.

203) The registry is legally permitted to link with other files.

This is regulated by:

204) The Data-inspection / Dataombudsmand

205) In certain cases also by the scientific ethical committee system.

206) There are no rules that identifiable information should be deleted in the registry.

207) An individual can legally obtain access to data about himself/herself in the registry, but only after having identified himself in an appropriate way.

208) An individual cannot refuse to be included in the cancer registry.

209) An individual does not have to be asked or informed before being included in the cancer registry.

The following can get access to the cancer registry data:

210) On case by case basis - anonymously there are no special restrictions.

211) On case by case basis - with identifying information:

a) The scientist according to the rules described above.

b) The patient can as described.

212) International release may only be done after the data have been made anonymous.

XXII QUALITY CONTROL

Completeness of coverage:

213) There is no routine for estimating the completeness of registration - it has however been done in special projects.

214) Forms from pathological departments and haematologists are not received except in case of autopsy as they have no obligation to notify the cancer registry except for autopsies.

215) Forms from the clinical departments - as mentioned earlier often have to be requested.

216) Target directed registries: are not available.

217) Hospital discharge registry is used, but only those cases are included in the registry, which after trace-back are confirmed by a notification.

218) Outpatient logs - not used.

219) Pathology department logs - not used.

220) Comparison with patients enrolled in trial protocols may be done; and information received from scientists is used and included in the registry, and in this way research is contributing to
the completeness of the registry.

221) Random sampling of patients admitted to hospital and scrutiny of records for missed cases (capture - recapture) is not done.

222) Surveillance of numbers of registrations from each source is not done.

Completeness of detail:

223) The average number of notifications per tumour is not used.

224) The number of sources are not known over the years

Figures for a recent year for the following:

225) Figures for "unknown primary site (199 in ICD7)" were in 1993 = 565 out of 27,836 new cases which equals 2.0%.

226) Percent of "age unknown" - irrelevant.

227) Percent of "treatment unknown" - is not calculated - but may be done

228) Percent of "stage unknown" - is not calculated - but may be done

229) Percent of "histology + cytology" was in 1993: 92%

230) Percent of "basis of diagnosis unknown" - is not calculated - but may be done

231) Percent of "place of birth unknown" - is not recorded.

232) Year/period to which these figures apply: 1993.

233) The most recent year published for the country is 1994.

Methods used to maintain quality control of the registry's data:

234) Independent re-abstraction is not done.

235) Independent re-coding of a sample of cases is not done.

236) Independent duplicate data entry is not done.

237) Input logical checks is used - see below

238) Use of test cases is not done

239) Proof-reading of coded notification is done.

240) Summary tabular frequency checks is used when preparing the incidence publication.

241) Incidental autopsy finding is not calculated

242) Cancer cases from Death Certificates Only (DCO) were 1.9%.

243) Mortality/incidence ratio - highest/lowest site is not used as quality control.

244) Stability of rates over time is followed.

245) Comparison with neighbouring registries is not done.
XXIII  WEAK POINTS

246)  Malignancies which may be under-reported :
   a)  Skin tumours, brain and bladder tumours (all "benign tumours"), leukaemia and
       lymphoma

XXIV  CHECKS

Automatic computer-based checks

247)  Data entered for essential variables is checked   yes

248)  "Invalid" code for almost any variable   yes
   a)  hospital code is valid
   b)  clinic code is valid
   c)  pathology laboratory is very rare
   d)  home-address is valid
   e)  ICD7 code is valid
   f)  Basis of diagnosis is valid
   g)  slide number is not used
   h)  Cancer death comes from the Cause of Death registry.
   i)  Autopsy result is not checked

Other examples of checks

Date of diagnosis

249)  Before or equal to date death   yes

250)  Before or equal to date of post-mortem   yes

251)  Before or equal to date of report   no

252)  Date of death before or equal to date of post-mortem   yes

253)  In case of only autopsy finding: date = date of death

Tumour type

254)  Sex compatible with site   yes

255)  Age compatible with tumour type   no

256)  Site of tumour compatible with histological type   yes

257)  Site of tumour compatible with code for laterality (paired organ)   yes

258)  Site of tumour compatible with method of diagnosis   no

259)  Histology compatible with method of diagnosis   no

260)  The IACR check-programme is not used.

261)  Manual/visual checks: see above
XXV OUTPUT FROM REGISTRY

In the regular routine publications of incidence rates, tables of rates are given by:

262) Year yes
263) Sex yes
264) Age yes
265) Site yes
266) Occupation no
267) Social group no
268) Residence no
269) Geographical subdivision of your territory yes at county level
270) Trends yes
271) Other variable no
   a) Cases found incidentally at autopsy (site, sex) no
   b) Number of second and multiple primaries (site, sex, med.region) no
   c) Percentage cytologically and histologically verified yes

In the regular publications, the following standards are used:

272) World Standard yes
273) European Standard and year no
274) Own Standard no
275) Other no

There are no regular/annual routine publications of mortality rates but they are available

276) Evaluation of incidence trends is carried out
Appendix 2  Finland

BASIC CHARACTERISTICS OF THE REGISTRY
FINLAND
date: March 24-26th 1997

1) Finnish Cancer Registry
2) Liisankatu 21 B
3) FIN-00170 Helsinki
4) Finland
5) Tel: +358 9/ 135331
6) Fax: +358 9/ 1355378
7) e-mail: registry@cancer.fi  website: www.cancerregistry.fi

Persons interviewed:
Name: Position: Training/Degree Abbreviation:
Lyly Teppo  Head of department  Medical Doctor  LT
Marja Lehtonen  Actuary  M.S.Sc.  ML
Eero Pukkala  Chief of data-processing  Ph.D  EP
Bengt Söderman  ADP Analyst  BS

I THE REGISTRY

8) The registry is population-based and covers: Finland.

9) The population includes all the people in the area who are entered into the official population statistics, that is have been given a personal identification number. The population includes the people of Åland, and always has included them (around 25,000 people).

10) Special registries - management-programmes: There are no special registries in the Finnish Cancer Registry though several attempts have been made.

II DEMOGRAPHICAL INFORMATION

11) An incidence publication is made every year on country level; on health care district level annually for 5-year periods.

12) There has been no changes in the population covered by the registry.

The resident population in the area covered by the registry was in 1994

13) a Males: .......................................................... 2,481,700
14) b Females: .......................................................... 2,616,700
15) c Total: .......................................................... 5,098,400

16) The population figures are exact since 1953

17) Population figures used for incidence calculation are the midyear average figures.

18) The Health system: There are municipality based Health Centres with general practitioners. They refer the patient to hospital for surgery, or they send the patient for investigations to places where they are cheapest: e.g. mammography, laboratory tests etc. There are 22 "Central hospitals" in 22 districts. There are 5 University hospitals better equipped than the others. There are 9 with radiotherapy units with medical oncology.

19) The hospitals are governed by municipalities.
Regarding population data the following are available in the registry

<table>
<thead>
<tr>
<th></th>
<th>available</th>
<th>used</th>
</tr>
</thead>
<tbody>
<tr>
<td>20)</td>
<td>Sex in one-year age groups</td>
<td>x</td>
</tr>
<tr>
<td>21)</td>
<td>Sex in five-year age groups</td>
<td>x</td>
</tr>
</tbody>
</table>
| 22) | Information on occupation, education and social groups referring to 1970 and  
| a) | every 5 years thereafter | x | x |
| 23) | No information on religion |   |   |
| 24) | There is some information in the registry for "ethnic groups" and "country of origin" - as there has been a separate code number for country of origin and minorities. |   |   |
| 25) | The urbanity-degree is available | x | x |
| 26) | The information about the geography is by municipality of residence and by coordinates of 10 m accuracy; ad hoc areas can thus be created for research purposes | x | x |
| 27) | The address as a land registry-number (koordinatsystem -see above) | x | - |

### III HISTORY

28) The registry started operating in the summer 1952

29) The registry can present population based data from 1953

30) Once the registry was linked to the Hospital Discharge Registry - and thousands of not registered tumours came out. They were all thoroughly surveyed. But most of them could be excluded - though a deficit regarding chronic leukaemia and myeloma was found - is was not repeated. Another linkage for haematological tumours is being planned.

31) **Changes in inclusion / exclusion** (see Incidence publication 1994 p 5: Explanatory notes).

a) "Papilloma of the urinary organs" were from 1964 until 1992 mentioned separately at the bottom of the incidence publication, though not included in the total incidence number.

b) "Borderline ovary tumours" are included from 1969 and onwards.

b) "Polycythemia vera" cases are included from 1969 onwards, and mentioned separately at the bottom of the tables.(they are not included in the total incidence numbers).

d) "Braintumours" have from 1979 onwards also included "acoustic neurinomas", "intradural schwannomas" and "spinal meningiomas". (benign tumours of the pituitary gland are not included).

e) "Waldenström" has been included in "lymphomas" since 1965.

f) "Stomach" and "cardiac" were separated in 1971 - the "cardiac tumours" (except for epidermoid carcinomas) are included in the incidence figures for "stomach cancer", but can now also be separated.

g) Since 1978 it has become possible to separate "anus tumours" from the "rectum tumours".

h) The "leukaemia" histology was changed in 1964 from 4 different types into 10 different categories.

32) Changes in hospital procedures:

a) Needle-biopsy and later PSA for prostate cancer, which may have caused an increase in the incidence.
b) The autopsy-rates have decreased during the 80’s, but may not have materially influenced the incidence, as better investigation methods have been developed during the same time.

c) Regarding brain tumours the development of CT and MR-scanners may have resulted in more tumours being detected in old people.

d) Bladder papilloma is more often now mentioned as carcinoma grade 1, so this may influence the figures slightly as the papillomas at present only amount to 10% of the numbers in the 1950’s.

e) Staging of tumours may have changed so that “localized” have decreased as the diagnostic techniques have improved.

33) REPORTING OF CANCER CASES has been compulsory since 1963. From 1952 to 1962 it was voluntary, but this change did not influence the trend in cancer incidence. Furthermore there is no penalty for people who do not report new cancer cases.

34) At present reporting of tumours is compulsory for:

a) Any medical Doctor employed privately or in a hospital, who has diagnosed or treated a tumour disease.

b) Any medical Doctor writing a tumour disease on the death-certificate even if diagnosed after death.

c) Pathological / cytological / haematological laboratories, Forensic departments.

d) Dentists who have diagnosed and treated cancer.

35) Operation of the registry has not been discontinued at any time.

36) The registry is run technically by the Cancer Society of Finland, but supervised by the National Research and Development Centre for Welfare and Health (STAKES).

37) The data are reported annually as Cancer Incidence of Finland as the Cancer Statistics of the National Research and Development Centre for Welfare and Health. Original (patient) data are owned by this Centre.

IV STAFF & ORGANIZATION

38) EMPLOYEES: Permanent:

1 Medical director of the cancer registry
1 Chief for data processing
1 EDB analyst
1 Chief statistician
1 Actuar
2 coding assistants
2 other clerical staff

39) The cancer registry is working closely with different scientists, who also may become included as part of the professional staff. The Director of the registry is 20% Professor in Cancer Epidemiology at The University of Tampere. The Chief Statistician is an Associate Professor at the University of Helsinki. Furthermore the registry staff is actively participating in or carrying out research projects of local or European origin.

40) The registry is working closely with the different departments as seen above.

41) The registry is administratively independent.

42) The registry is also involved in other things such as mass-screening programs in Finland. The PAP-smear screening is run by the Cancer Society in cooperation with the municipalities. Letters of invitation are sent out from the Cancer Registry and results returned to the Registry.
43) The Cancer-Registry is located in the same premises as the Cancer Society of Finland; Cancer Society of Southern Finland; National Society of Cancer Patients; Cancer Foundation; Foundation for Cancer Research.

Sources of finance:

44) Registration of cancer is financed by the Cancer society of Finland and The Slot Machine Association.

45) Research projects are also partly financed from external funds, after application and acceptance of the project.

Coding

46) ALL CODING IS CARRIED OUT at the registry, and plain-text must appear on the notification forms.

47) THE CODING is primarily carried out by the coding assistants.

48) Supervision of coding and solving of coding problems is done by LT, the Director of the registry, who is a Medical Doctor (MD).

49) In difficult cases - external consultation is seldom done - see below.

50) Coding problems are usually solved by the Registry director.

51) Coding problems brought up at special meetings - as in Sweden is not done.

Letters / Telephone

52) The registry has to request for clarification in 500-600 of the cases per year. ML writes and phones with many places. The registry used to send out many questions for clarification to the reports, but this is now mainly carried out by telephone, up to ½ hour per day.

53) Sometimes they forget to send the notifications - and very often they are the same places. The haematologists are sending from 5-10 places and covering around 85%, while the pathology labs are sending 100%. They are called if the number of cases are going down. A separate bookkeeping is carried out for that purpose.

V REPORTING

Tumour registration from patient to registry:

54) There are Municipality based Health Centres with general practitioners. They may refer the patient to a hospital for further diagnostic evaluation and treatment but they may also, as may the hospitals, buy investigations where they are cheapest: e.g. mammography, laboratory tests etc.

Treatment is given:
   a) leukaemia in the medical departments in the University Hospitals
   b) paediatric tumours in special paediatric clinics
   c) gynaecological cancers are treated at the gynaecological clinics.
   d) ORL, Eye and Brain tumours in their respective clinics

55) No fee is paid to the reporting physician or institution, but until the mid 70's a fee was paid.
56) Most often it is the medical secretary who writes the report, and the doctor signs it.

57) Linkages is carried out with the Cause of Death Registry in order to include those cases not reported on other ways. Linkage with the Central Population Registry is also carried out to check the names, ID-numbers and municipality of residence.

58) Information on name and address of the reporting hospital / clinic / practitioner / or other source is kept as all information is put into computer, and coded later.

59) It is thus possible to go back to the original records.

60) Patients do not have their "own" GP.

VI SOURCES

The registry regularly receives notifications from:

61) Hospitals
62) (wards and Medical records departments)
63) Outpatient clinics
64) Hospices
65) Long stay hospitals and homes for the elderly

Laboratories (in or outside hospitals)
66) Pathology / cytology
67) Haematology
68) Autopsy reports
69) Institute of forensic medicine

70) Death certificates are used as source for tumour registration.

Other
71) General practitioners and dentists
72) Specialist practitioners
73) Screening programs.

Forms received

74) The registry receives most forms from the haematologist for the pathological and clinical notifications the data source varies with the site.

75) 1% are clinical data only. - and there is a 99% completeness for solid tumours and 95% for haematological

76) THE INFORMATION ABOUT CANCER IS recorded from the notification forms, which must be filled in plain-text, that is code numbers only - even from pathologist - are not accepted.
The registry receives / receives not (or has regular access to) copies of the following for cancer patients:

77) Medical records............................................................................................................ no
78) Pathology reports. ........................................................................................................... no
79) Autopsy reports. ............................................................................................................ no
80) Discharge letter............................................................................................................. no
81) Death certificates ......................................................................................................... yes
82) Radiotherapy reports. .................................................................................................... no
83) Hospital information system........................................................................................ no
84) The staff at the registry does not visit clinics.
85) The original notification forms are stored on microfilms, but from 1981 onwards, they are stored in the computer.
86) definition of place of "residence":
The address of the place where the patient is living on the 1st of January of the year the cancer was diagnosed (as in population registry).
87) There are very few Immigrants and/or non-residents so there are no specific rules.
88) The registry has no experience with refugees, none were noted - this is also the case for those with a "protected address".
89) Special subgroups/minorities in the population may be defined, though this will probably end soon.
90) Tumours in patients who are not permanent residents of the registry territory are not registered.
91) Residents working abroad and belonging to the population of the country are as far as possible kept separate if they are living permanently in the other country as are 300.000 Finns living in Sweden.
92) The data are not submitted to a larger registry

VII INFORMATION RECORDED

93) THE CODING OF DATA: On receipt an assistant writes the text into the system where an automatic precoding is being carried out - or it is filled in by a disk, which has been checked.
94) THE PROCESSING OF DATA: on registration all previous forms on the person are consulted (e.g. in case of multiple tumours). After 1-2 years the precoded tumours are checked and coded by trained coders.
95) Two or more notifications are linked electronically using the unique personal identification number.
96) After receiving and typing the text, those with only one notification form from pathological lab. or Death Certificates are separated and a second form is requested from the relevant
source, usually the clinical department. The tumours are entered into the cancer registry when adequate information is available, thus 1 informative form is accepted.

97) computerised case resolution is not carried out.

VIII THE PERSON

98) **THE SOURCE FOR INFORMATION ON THE PERSON** is the Central Population Registry (CPR), which assigns a number to each resident in Finland

99) The patient is not given another number in the registry. Except when data are submitted abroad for research purpose.

100) The unique person number is constructed of 2 digits for day, 2 digits for month and 2 digits for year of birth; and 4 digits of which one may be a letter, furthermore the century of birth 18- or 19- may be seen from the number as "+" or "-" respectively; the last digit but one designate the sex, uneven for male and even for female; while the last number may be a figure or a letter, which is used as control.

101) Immigrants are assigned a personal number when they have been promised permission to stay, after 1-2 weeks.

102) The number does not indicate where the person was born nor if he/she belongs to any minority and it does not indicate ethnicity. The place of birth is not registered, but has until now been available in the Central Population Registry.

103) The cancer registry receives updated information every month from Statistical Central Bureau for address and eventually date of death. The registry is updated once a year for emigration from CPR. It is linked with the Death registry once a year for date and cause of death. Furthermore every 5 years all ’living’ patients are actively checked for death or emigration.

a) Date of death is given as day/month/year
b) Cause of death is coded as: 1 = died of cancer; 2 = died with cancer; 3 = died without cancer.

c) The official cause of death is ranked highest of the sources for the cause of death, but the evaluation of the cause of death as given by the registry is more reliable.

**NAMES OF PATIENT**

104) The patient's full name is registered.

105) Sometimes the maiden name is registered, but none of the following are registered: Father's name / Mother's name

106) The ID number of the next of kin is not registered.

**RESIDENCE/ADDRESS AT THE TIME OF REGISTRATION**

107) The number for the patients postal code is registered.

108) This information includes the municipality - and at present the GIS-code is available

109) Change of address is given from the CPR monthly, but the address at the time of diagnosis is kept in the registry as address at date of diagnosis.

110) The age at incidence date is calculated from CPR

111) The person's nationality (e.g. French, Danish) is not registered.

112) No further information is used from the CPR.
113) The nationality of father and/or mother may possibly be available.

114) Marital/civil status at diagnosis is unreliable, but is available by the following categories:
   a) Married - available for special purposes from Population Registry or Census data.
   b) Separated - as for a
   c) Divorced - as for a
   d) Widow/widower - as for a
   e) Cohabitation - no
   f) Single - as for a

115) Death - yes, as for 114

116) Number of live births and categories (actual number) not used any more - was unreliable, but is available as for 114

117) Religion - as for 114

118) Ethnic groups - as for 114

119) Race - no

120) Patient's education - through linkage with e.g. years of schooling - see as for "114".

121) Occupation - from special studies - as for "114"

122) Special enquet studies for occupation - yes and as for "114"

123) Social class or socio-economic status - based on occupation.

124) Patient's exposure to carcinogens - no

IX INCIDENCE DATE

DATE OF DIAGNOSIS (LEVEL OF DETAIL):

125) The date is recorded as the month and year of diagnosis.

126) The DATE OF DIAGNOSIS is usually defined as the earliest date written on the received notification forms (all available information is used for evaluation). It is however not the date when the suspicion of cancer arose, but the date of the diagnosis - when the diagnosis will be accepted in the registry without further information.

127) A tumour first notified on a death certificate is traced to get earlier information about the tumour.

128) 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 unless the DC indicates something else (duration of disease, date of operation etc.) - or unless there is uncertainty expressed in some way.

129) For a patient known from autopsy only, the incidence date is the date of death if the cancer was not known before death. If the cancer was known, but no other notification form is available the date is registered as "year" and for month "99".
X BASIS OF DIAGNOSIS

METHODS

130) The "most valid basis" is coded in the following ranking order:

a) Histology / bone marrow / blood smear in leukaemia

b) Cytology (expectorate, aspirate etc.).

c) Surgery (including endoscopy), autopsy without histology, X-ray and some specified laboratory examinations.

d) Clinical examination only.

XI CLASSIFICATIONS

131) CLASSIFICATION(S):

a) From 1952: topography was coded according to a special topography nomenclature with transformation to WHO ICD 7 though the Finnish ICD-7 is slightly different. Morphology was coded according to an American Cancer Society 2 digit nomenclature from 1951 (Motnac 51).

b) For changes see above

132) Exceptions to the ICD 7 of WHO classification rules or special rules:

a) 155.8 multiple sites of biliary passage and liver: not used as each tumour is coded as a separate primary tumour

b) 163 malignant neoplasm of lung, unspecified as to whether primary or secondary: goes to 162

c) 181,7 other urinary organs: includes ureter, which in WHO is included in 180 kidneys.

d) 193,3 peripheral nerves: has not been used since 1976

e) 193,8 multiple sites: not used as separate primaries are registered as separate tumours.

f) 195,8 multiple glands: not used

g) 196,9 multiple bone sites and unspecified: used only for "bone NOS".

h) 200 + 202 exclude extra-nodal lymphomas.

i) Bilateral tumours are counted once if synchronous. Metachronous tumours are individually evaluated.

j) Other and special rules:

i) See malignancy code to exclude non malignant lesions

ii) See primary site + histology code to identify extra-nodal lymphomas

iii) See histology code to classify non-Hodgkins lymphomas

iv) Extra-nodal lymphomas are included with the tumours of the primary site.

v) See histology code to classify leukaemia

vi) Renal pelvic tumours are included with renal tumours.

vii) Rectum includes recto-sigmoidum.

133) Topography (primary tumour) is defined according to all the available information, though the clinician's assessment weighs most. The code is chosen according to specificity.

134) Topography codes may be changed according to what is most specific.

135) Morphology is defined according to pathology description. The morphology is given from the pathologist and coded according to the special American nomenclature (Motnac 51).
136) Morphology may be changed if a histological description from a better specimen is received after a cytological description - if there are different morphologies, the most likely is chosen or the case is validated.

137) The code is chosen so that the most malignant is coded
   a) Behaviour of Tumour is given as shown below:
   b) 0 = malignant tumour
   c) 1 = in situ
   d) 2 = polycythaemia vera, bronchial adenoma
   e) 4 = brain tumour with uncertain behaviour
   f) 5 = benign intracranial tumour
   g) 7 = CIN III
   h) 8 = basal cell carcinoma and papilloma of urinary organs
   i) 9 = dysplasia gravis of the cervix uteri

138) The behavioural code changes: A new tumour has to be registered if it is a cancer.

139) This however has to be evaluated as no specific time limits were mentioned and each case is assessed individually, otherwise the behaviour of the tumour is changed. While cervical dysplasia and CIN which becomes invasive is counted as malignant from the date of diagnosis of the diagnosis; this also counts for papilloma of the urinary tract.

140) List of Reportable Tumours:
   a) All malignant tumours - and in addition:
   b) plasmacytoma
   c) mycosis fungoides
   d) polycythaemia vera
   e) carcinoma in situ (except in the skin)
   f) papillomas of the urinary tract
   g) all brain tumours (incl. benign tumours)
   h) dysplasia gravis of cervix uteri and CIN III
   i) teratoma of testis

141) List of tumours included in incidence publications:
   a) Diseases mentioned under 140 a - c and g and i.
   b) The reportable tumours mentioned under 140 d - f and h are not included in the cancer incidence, but some are tabulated separately.

Conversion of ICD:
142) Conversion tables from one coding system to another was updated in 1990.

The purpose of the conversion of ICD classification is:
143) To ensure comparability with old data - not relevant as the same system has been used all the time.
144) To make data comparable with data from other registries (e.g. Eurocare)

Diagnosis Recorded in Addition to the Cancer Diagnosis Coded by the Registry:
145) Admission diagnosis - not coded.
146) Discharge diagnosis - not coded.
147) Cause of death - is registered.
148) Autopsy diagnosis - is not coded.
149) Other diagnosis (e.g. AIDS / Hepatitis ICD-10: B21) are not coded.

MALIG NANT DISEASES ROUTINELY EXCLUDED WHEN REPORTING DATA FROM THE REGISTRY:
150) Basal cell carcinoma of the skin are reported separately.

THE TUMOURS BELOW are recorded and included in incidence data as shown:

<table>
<thead>
<tr>
<th>Tumour type</th>
<th>Record yes</th>
<th>Record no</th>
<th>Included yes</th>
<th>Included no</th>
</tr>
</thead>
<tbody>
<tr>
<td>151) Benign Brain tumours</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>152) Benign tumours of the Pituitary gland</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>153) Carotid body tumour</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>154) Benign bladder tumours (papilloma)</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>155) Intraductal carcinoma (8500/2) in the breast</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>156) Carcinoma in situ in the breast, other than above (lobular)</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>157) Borderline tumour in the ovary</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>158) Carcinoma in situ in testis</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>159) Chromaffinoma (8700/0) of the adrenal glands</td>
<td>no information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>160) Argentaffinoma (8241/1)</td>
<td>no information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>161) Chordoma (9370/3)</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>162) Invasive mole (9100/1)</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>163) Precancerous lesions in the cervix</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

164) OTHER BENIGN OR PRECANCEROUS LESIONS CODED TO OR INCLUDED WITH CATEGORIES OF MALIG NANT TUMOURS AND OTHER SPECIFIC INFORMATION: Thymoma, phaeocromocytoma, teratoma

165) CL INICAL STAGE / EXTENT OF TUMOUR IS RECORDED:
   a) The stage / extent is defined as:
      0 = unknown
      1 = localised
      2 = metastasis of regional lymph node
      3 = metastasis of distant organ / local infiltration in neighbouring organ
      4 = non localised but unknown whether 2 or 3
   b) The code is chosen as the stage at the time of diagnosis
   c) There is no ranking system of which staging method is used, though usually the TNM description will be used if it is noted and the information satisfactory (rarely)
   d) All available information on staging is entered into the system
   e) The date of the staging is the date of diagnosis
   f) The stage may be updated if better information is received.
   g) It is therefore possible to tabulate cancers according to the staging as described above.

XII MULTIPLE PRIMARIES

166) THE RULES USED TO CODE MULTIPLE CANCERS IN THE REGISTRY:
   a) The main rule is that if you think there are two independent tumours you count them as two.
   b) 2 with different morphology in the stomach are counted as 2;
c) The registry counts tumours not patients except for:

d) **SKIN TUMOURS** - if "malignant melanomas" are diagnosed in the same subarea within 20 years they are registered and coded as one. If melanomas are diagnosed in different skin regions within one year, they are coded with the topography multiple 190,8. If melanomas are diagnosed at same site separated by 20 years or more, or at different sites separated by 1 year or more, they are coded as separate tumours. These rules of melanoma apply also for non-melanoma skin cancer.

e) colon are counted as 2 if the second comes at a different time, e.g. after 1 year; if it is at the same time e.g. within 1 month they are registered with a "multiple" code: 153,7.

f) For Astrocytoma grade 1 which after some years develop into multiform glioblastoma no change is made as the histology code is the same.

**RULES FOR CODING CANCERS IN PAIRED ORGANS:**

167) Tumours with the same morphology on each side are coded as "tumours of both sides", and counted as one when calculating incidence rates.

168) Tumours with different morphology on each side are coded as two tumours, and counted as such.

169) Tumours with different behaviour (e.g. intraductal carcinoma in left breast and duct carcinoma in right breast) are coded as 2 tumours, and counted as two tumours if separated by a couple of years.

**XIII TREATMENT**

170) **TREATMENT** is registered and defined as:

a) Treatment given within 4 month of the diagnosis, and divided into: surgical / radiotherapy / cytostatic / hormonal / other (5 one-digit codes).

b) All treatment and the date for start of treatment is registered.

c) If the start of any of the treatment modalities is > 4 months it is registered as "late treatment".

d) Place of treatment is put in the system, but not coded.

**XVII FOLLOW-UP and TRACE-BACK**

A **By follow-up** we mean that the registry follows up fully registered cases to obtain information about e.g. recurrence, treatment, or death.

B **By trace-back** we mean, that the registry actively attempts to obtain further information about a tumour, (e.g. first notified on a death certificate, or if the information on a patient is not satisfactory for other reasons) in order to complete the coding of the tumour recorded.
Appendix 2 Finland

**ACTIVE (A) OR PASSIVELY (P) RECEIPT OF DATA FROM THE FOLLOWING SOURCES FOR FOLLOW-UP AND/OR TRACE-BACK**

<table>
<thead>
<tr>
<th>Hospitals</th>
<th>trace-back</th>
<th>follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>171) Clinical departments</td>
<td>a</td>
<td>p</td>
</tr>
<tr>
<td>172) Medical records</td>
<td>a</td>
<td>p</td>
</tr>
<tr>
<td>173) Outpatient clinics</td>
<td>a</td>
<td>p</td>
</tr>
<tr>
<td>174) Hospices</td>
<td>a</td>
<td>p</td>
</tr>
<tr>
<td>175) Long stay hospitals and homes for the elderly</td>
<td>a</td>
<td>p</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Laboratories (in or outside hospitals)</th>
<th>trace-back</th>
<th>follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>176) Pathology, general</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>177) Pathology, specialised</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>178) Haematology</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>179) Autopsy reports</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>180) Institute of forensic medicine</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>181) Other</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>182) Death certificates</td>
<td>a</td>
<td>p</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Administrative sources</th>
<th>trace-back</th>
<th>follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>187) Central population registers</td>
<td>-</td>
<td>p</td>
</tr>
<tr>
<td>188) Central medical registers (e.g. hospital information systems)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>189) Other</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

**IX SCREENING PROGRAMMES**

<table>
<thead>
<tr>
<th>Type</th>
<th>age-group</th>
<th>how often</th>
</tr>
</thead>
<tbody>
<tr>
<td>cervix</td>
<td>30 - 50 years must be done (25-60 years may be done)</td>
<td>every 5 years</td>
</tr>
<tr>
<td>breast</td>
<td>50 - 59 years (from 1990) must be done (50-64 years can be done)</td>
<td>every second year</td>
</tr>
<tr>
<td>colon</td>
<td>pilot</td>
<td></td>
</tr>
<tr>
<td>melanoma</td>
<td>none</td>
<td></td>
</tr>
<tr>
<td>prostate</td>
<td>pilot</td>
<td></td>
</tr>
</tbody>
</table>

195) There is co-operation with the cervix and breast screening programmes (see also 47).

**XX USE OF COMPUTER**

196) THE SOFTWARE USED IN THE REGISTRY is called "MUMPS", which is a hospital system. The statistic package is VAX - a VMS-system (not a unix system)
XXI CONFIDENTIALITY

The registry observes the following set of rules on confidentiality: (see appendix)

“Law 471 (personregisterlag = law about person-registry) and 476 (personregisterförordning = order for person-registry)

197) The information in the registry is confidential
   a) The material on the level of individuals may only be used after permission of authorities
   b) Personal information must be kept so that unauthorised persons cannot gain access to the information
   c) Direct contact to the person in question, relatives etc. may not be done without permission from Ministry of Social Welfare; contacts must be effected through the medical Doctor in charge of the ward or the chief Consultant at the current department
   d) At the end of the project all material containing personal data must be destroyed.
   e) Publication of material must be done in such a way that no individual can be identified.


199) When ordering personal identifiable extract on a data-medium (floppy-disc) the permission from STAKES must be enclosed.

200) In case of questions concerning annulment or quality of the delivered material the cancer registry is to be contacted only.

201) The Cancer registry presupposes that the registry is mentioned as source in all prospective publications.

202) The signing of the given application is at the same time a confirmation that you accepted the conditions, for handling the material and the reservations given for publication of the given information

203) The registry is legally permitted to link with other files

This is regulated by:

204) By the Data-inspection / Dataombudsmand

205) In certain cases also by the ethical committee

206) There are no rules that identifiable information should be deleted in the registry, though they may have to be archived (law 476 §1 + §14).

207) An individual can legally obtain access to data about himself/herself in the registry but only through STAKES(41) (law 476 §9).

208) An individual cannot refuse to be included in the cancer registry

209) An individual does not have to be asked / informed before being included in the cancer registry

The following can get access to the cancer registry data:

210) - On case by case basis - anonymously there are no special restrictions

211) - On case by case basis - with identifying information:
   a) The scientist according to the rules described above (after permission)
   b) The patient cannot as described
International release may only be done to countries with laws equal to the Finnish concerning data-confidentiality (§ 22 in law no 471 from 1987 law about registration of persons)

XXII QUALITY CONTROL

Completeness of Coverage:

213) There are few routines for estimating the completeness of registration, such as follow-up of input of information and follow-up of regional rates - it has also been done in special projects

214) The number of forms from the pathological departments and haematologists arrive at regular intervals, and a constant number is expected - if that is not reached then an inquiry is started (86).

215) Forms from the clinical departments - as mentioned earlier often have to be requested.

216) Target directed registries: are not available.

217) Disease index / Hospital discharge registry is not used.

218) Outpatient logs - not used

219) Pathology department logs - not used.

220) Comparison with patients enrolled in trial protocols may be done; and information received from scientists is used and included in the registry, and in this way research is contributing to the completeness of the registry. In clinical and clinic pathological studies patient documents and specimens are perused, and cancer registry information checked, corrected or cases deleted.

221) Random sampling of patients admitted to hospital and scrutiny of records for missed cases (capture - recapture) is not done.

222) Surveillance of numbers of registrations from each source is done.

Completeness of Detail:

223) The average number of notifications per case is 5 per tumour, while in most instances the sources are at least 2: the pathological laboratory and a clinical notification

224) The number of sources are known over the years

Figures for a recent year for the following:

225) Figures for "unknown primary site (199 in ICD7)" were in 1994 = 606 out of 19,914 new cases which equals 3%.

226) Percent of "age unknown" - irrelevant.

227) Percent of "treatment unknown" - not calculated

228) Percent of "stage unknown" - is not calculated

229) Percent of "histology + cytology" was in 1994: 94%

230) Percent of "basis of diagnosis unknown" - 1-2%

231) Percent of "place of birth unknown" - is not recorded.

232) Year/period to which these figures apply: 1994.
233) THE MOST RECENT YEAR PUBLISHED for the country is 1995 (September 1997).

METHODS USED TO MAINTAIN QUALITY CONTROL OF THE REGISTRY'S DATA:
234) Independent re-abstraction is not done.
235) Independent re-coding of a sample of cases is not done.
236) Independent duplicate data entry is not done.
237) Input logical checks is used - see below
238) Use of test cases is not done
239) Proof-reading of coded notification is not done.
240) Summary tabular frequency checks is not used, but an electronic check is done.
241) Incidental autopsy finding is not calculated
242) Cancer cases from Death Certificates Only (DCO) were 1,8%.
243) Mortality/incidence ratio - highest/lowest site is not used as quality control.
244) Stability of rates over time is followed.
245) Comparison with neighbouring registries is not done.

XXIII WEAK POINTS

246) MALIGNANCIES WHICH MAY BE UNDER-REPORTED:
Chronic leukaemia, Myelomas and Benign intracranial tumours.

XXIV CHECKS

AUTOMATIC COMPUTER-BASED CHECKS

247) Data entered for essential variables is checked
248) "Invalid" code for almost any variable
   a) hospital code is valid
   b) clinic code is valid
   c) pathology laboratory is valid
   d) home-address is valid
   e) ICD7 code is valid
   f) Basis of diagnosis is valid
   g) slide number is valid
   h) Cancer death is valid
   i) Autopsy result is valid

OTHER EXAMPLES OF CHECKS

DATE OF DIAGNOSIS
249) Before or equal to date death
250) Before or equal to date of post-mortem
251) Before or equal to date of report

Survey of Nordic Cancer Registries, 2000
Appendix 2  Finland

252) Date of death before or equal to date of post-mortem yes
253) In case of only autopsy finding: date = date of death

TUMOUR TYPE
254) Sex compatible with site yes
255) Age compatible with tumour type no
256) Site of tumour compatible with histological type yes
257) Site of tumour compatible with code for laterality (paired organ) yes
258) Site of tumour compatible with method of diagnosis yes
259) Histology compatible with method of diagnosis yes

260) THE IACR CHECK-PROGRAMME is not used.

261) MANUAL/VISUAL CHECKS: see above

XXV OUTPUT FROM REGISTRY

IN THE REGULAR ROUTINE PUBLICATIONS OF INCIDENCE RATES, TABLES OF RATES ARE GIVEN BY :
262) Year yes
263) Sex yes
264) Age yes
265) Site yes
266) Occupation no
267) Social group no
268) Residence no
269) Geographical subdivision of your territory yes at health care district level
270) Trends yes
271) Other variable
   a) Cases found incidentally at autopsy (site, sex) no
   b) Number of second and multiple primaries (site, sex, med.region) no
   c) Percentage cytologically and histologically verified yes

IN THE REGULAR PUBLICATIONS, THE FOLLOWING POPULATION STANDARDS ARE USED :
272) World Standard yes
273) European Standard and year no
274) Own Standard no
275) Other no

There are no regular/annual routine publications of mortality rates but they are available

276) Evaluation of incidence trends is carried out
Appendix 2  Finland
BASIC CHARACTERISTICS OF THE REGISTRY

ICELAND

date: May 26-27th 1997

1) Icelandic Cancer Registry
2) P.O. Box 5420, 15 - 125
3) Reykjavik
4) Iceland
5) Tel: +354 562 1414
6) Fax: +354 562 1417
7) e-mail: first-name@krabb.is (e.g. kristin@krabb.is)  web-site: www.krabb.is

Persons interviewed:

Name: Hrafn Tullinius  Position: Head of registry  Training/Degree: Professor, dr.Med.  Abbreviation: HT
Name: Kristin Bjarnadottir  Position: Registrar  Training/Degree: historian / lab. technician (local training since 1988)  Abbreviation: KB

I THE REGISTRY

8) The registry is population-based and covers: Iceland

9) The population includes all the people in the area who are entered into the official population statistics that is have been given a personal identification number. Guest-workers usually get a personal identification number very quickly after entering the country. Students studying abroad are included in the population as well as members of the diplomatic service, while others working and taking ill abroad are registered, but not included in the population and incidence.

10) Special registries:
   a) Breast-cancer registry for research in relationship with relatives
   b) Relative-family research registries

II DEMOGRAPHICAL INFORMATION


12) There has been no changes in the population covered by the registry.

THE RESIDENT POPULATION IN THE AREA COVERED BY THE REGISTRY was in 1995

13) a) Males: .................................................................................................................. 134 038
14) b) Females: ................................................................................................................ 133 342
15) c) Total: .................................................................................................................... 267 380

16) The population figures are exact as the mean-population of 1995.

17) Population figures used for incidence calculation are the midyear average figures.

18) The Health system: the patient can choose a private practitioner - or a health-station who may refer the patient to a local hospital, from where the patient can be referred to a special hospital.

19) The local hospitals are governed by the local authorities.
REGARDING POPULATION DATA THE FOLLOWING ARE AVAILABLE IN THE REGISTRY

<table>
<thead>
<tr>
<th></th>
<th>available</th>
<th>used</th>
</tr>
</thead>
<tbody>
<tr>
<td>20</td>
<td>Sex in one-year age groups</td>
<td>-</td>
</tr>
<tr>
<td>21</td>
<td>Sex in five-year age groups</td>
<td>x</td>
</tr>
<tr>
<td>22</td>
<td>Information on occupation is partly available (from the trade unions)</td>
<td>x</td>
</tr>
<tr>
<td>23</td>
<td>Information on religion</td>
<td>-</td>
</tr>
<tr>
<td>24</td>
<td>Information in the registry for &quot;ethnic groups&quot; and &quot;country of origin&quot; may be available in the Statistical Bureau</td>
<td>-</td>
</tr>
<tr>
<td>25</td>
<td>The urbanity-degree is found in Reykjavik / the rest of the country - or in the 8 election - municipalities</td>
<td>x</td>
</tr>
<tr>
<td>26</td>
<td>Information about geography is by municipality and is one of the figures in the code</td>
<td>-</td>
</tr>
<tr>
<td>27</td>
<td>The address as a land registry-number (co-ordinate-system)</td>
<td>-</td>
</tr>
</tbody>
</table>

III HISTORY and TUMOURS INCLUDED

28) The registry started operating in 1954

29) The registry can present population based data from 1955

CHANGES:

30) The registry has not been linked to the hospital discharge registry.

31) No changes in inclusion / exclusion of tumours were described.

32) CHANGES IN HOSPITAL PROCEDURES:

a) e.g. mammography can have led to an increase in esp. intraductal carcinoma (8500/2).

b) the autopsy-rate has decreased from 500 to 200 per year over a 2-3 years period.

c) e.g. PSA for prostate cancer as well as better treatment may have increased the number of prostate cancer.

33) Reporting of cancer cases has always been voluntary, which means that a decrease in the general hospital budget results in fewer notifications.

34) At present reporting of tumours is not compulsory for any, but the registry receives as mentioned a disk from one of the pathology departments and notification on paper from the other two pathology departments. However there is a problem with not operated tumours partly connected to declining autopsy rates.

35) Operation of the registry has not been discontinued at any time.

36) The registry is under the Cancer Society.

37) The data are reported regularly as Cancer Incidence of Iceland.
Appendix 2 Iceland

IV STAFF & ORGANIZATION

38) **EMPLOYEES**
- 1 Head of registry, professor, Dr. med.
- 2 Medical doctors (urologist + pathologist)
- 1 Epidemiologist
- 1 Computer-specialist
  For the cancer registry 1 registrar and 1 coding assistant
  For the family registry 1 registrar.

39) The registry is working with hospice, associations, and the patient-registry.

40) The registry is also working closely with: For the data material the registry is working with all the health departments. Apart from this there is co-operation with different departments on research projects.

41) The registry is administratively under the Cancer society.

42) There is good co-operation between the registry and the screening for cervix cancer and breast cancer.

43) The cancer-registry is located separately within the Cancer-Society building.

SOURCES OF FINANCE:

44) Registration of cancer is financed by the Cancer Society but receiving support from the government for 2 person-years.

45) Research projects are also carried out in co-operation with others and are financed from funds, after application and acceptance of the project.

CODING

46) **CODING OF SITE AND MORPHOLOGY IS CARRIED OUT** at the registry.

47) **THE CODING / CLASSIFICATION OF NEOPLASMS TO SITE AND MORPHOLOGY** is carried out by the coding assistants - though the morphology is often coded by the pathologist, and the code checked at the registry.

48) Supervision of coding and solving of coding problems is done by a Head of the registry or by the medical doctor who is also a pathologist.

49) In difficult cases the signing pathologist may be contacted if necessary.

50) Coding problems are usually solved at the registry by one of the medical doctors.

51) Coding problems are not brought up at special meetings - as in Sweden.

LETTERS / TELEPHONE

52) The registry has to request for clarification in around 3-5% of the cases mainly with respect to date of diagnosis.

53) Cases first noted from Death Certificates amount to 2,5% - 3,5%. Almost all of them get verified from clinical department or medical centres.
V REPORTING

TUMOUR REGISTRATION FROM DIAGNOSIS TO REGISTRY:

54) A patient will usually go to the general practitioner - either the private or at the health station, who may refer him/her to a hospital or a specialist who in its/his turn refers the patient to the specialised hospital. In case of a breast-tumour the patient will often be referred directly to the screening station for mammography. All these entities may send a notification form. But the most reliable source is the pathologist.

55) A small fee was paid until 1989.

56) Most often it is the medical secretary who writes the report, and the doctor signs it.

57) Linkages is carried out with the Cause of Death Registry in order to ensure that official date of death and cause of death is available in the Cancer registry and to include those cases not reported on in other ways. Linkage with the population registry (SCB- Statistical Central Bureau) is also carried out to check the persons name and ID-number.

58) Information on name and address of the reporting hospital / clinic / or other source is kept. For each tumour information on all those giving the information are kept - not just those giving the most valuable information.

59) The registry thus has information, which makes it possible to GO BACK TO THE ORIGINAL RECORDS.

60) Patients "own" General Practitioner is not registered.

VI SOURCES

THE REGISTRY REGULARLY RECEIVES NOTIFICATIONS FROM:

61) Hospitals - though from many places only on request
62) Medical records departments - no
63) Outpatient clinics - as for hospitals
64) Hospices - the administrative part is at the registry, so the coders will check the files regularly.
65) Long stay hospitals and homes for the elderly

Laboratories (in or outside hospitals)
66) Pathology - from one on disk and the other two on forms.
67) Haematology are using the data, so they are reporting actively.
68) Autopsy notifications- the coders are checking it themselves.
69) Institute of forensic medicine - the coders are checking it themselves.

70) Death certificates are used as source for tumour registration

Other
71) General practitioners
72) Specialist practitioners
73) Screening programmes - once a year.

FORMS RECEIVED
74) The registry receives most forms from the pathological and clinical notifications.

75) Those diagnosed clinically only are few as there are 96% with histologic diagnosis. Morphology for brain-tumours may however be accepted with radiologic description only.

76) THE INFORMATION ABOUT CANCER IS recorded from the notification forms or the disks from the pathologists, as well as information on paper from pathologists.
THE REGISTRY RECEIVES / RECEIVES NOT (OR HAS REGULAR ACCESS TO) COPIES OF THE FOLLOWING FOR CANCER PATIENTS:

77) Medical records. - if requested............................................................................................................yes
78) Pathology reports of the histological and cytological descriptions. ............................................yes
79) Autopsy reports - are fetched and copied.......................................................................................yes
80) Discharge letter - if requested............................................................................................................yes
81) Death certificates - yes for cancer-deaths others have to be requested ......................................yes
82) Radiotherapy reports .........................................................................................................................no
83) Hospital information system..............................................................................................................no
84) No information on the staff at the registry visiting clinics was given.
85) The original notification forms are stored in paper-files.
86) definition of place of "residence":
   The address of the place (on "syssel" level) where the patient is living on the date for the diagnosis, except for students who are given the address of their home-municipality, not that of the study-place. Diplomats are given the address of the Embassies.
87) Immigrants and/or non-residents are not entered into the registry, if they do not have a personal identification number.
88) Refugees are not existing.
89) Special subgroups/minorities in the population are not found.
90) TUMOURS IN PATIENTS WHO ARE NOT PERMANENT RESIDENTS OF THE REGISTRY TERRITORY are not registered.
91) Residents working abroad and belonging to the country are registered but not included in the incidence publication.
92) The data are not submitted to a larger registry

VII INFORMATION RECORDED

93) THE CODING OF DATA: The coding is done manually by the pathologists, and this information is transferred to the disk received at the registry. The information is then checked against the existing cancer registry.
94) THE PROCESSING OF DATA: on registration all forms on the person are consulted if in doubt of it being the same tumour (e.g. in case of multiple tumours).
95) Two or more notifications are linked electronically using the unique personal identification number.
Appendix 2  Iceland

96) After receipt those with only one notification form (usually the pathology) are isolated and if needed a second form is requested from the relevant source, usually the clinical department.

97) COMPUTERISED CASE RESOLUTION is not carried out but "legal/permitted" combinations are used and if the combination is not permitted, the computer warns and the case is discussed. (XXIV Checks)

VIII THE PERSON

98) **THE SOURCE FOR INFORMATION ON THE PERSON** is the Central Personal Registry (CPR), which assigns a number to each resident in Iceland.

99) The patient is not given another number in the registry.

100) **THE UNIQUE PERSONAL REGISTRY NUMBER** is constructed of: 10 digits, which are composed of: 2 digits for day, 2 digits for month and 2 digits for year of birth; The next 4 digits are the serial numbers, with the 3rd digit being a control-number and the 4th digit giving the century

101) Immigrants are assigned a CPR number when they become residents.

102) The number does not indicate where the person was born nor if he/she belongs to any minority and it does not indicate ethnicity. The place of birth is available from the CPR.

103) The cancer registry receives updated information monthly from the Central Statistical Unit for **date of death and change of address**. Date of death is given with day/month/year. However the registry is also **linked annually** to the Death Index registry for the date and the cause of death. Cancers found in this way are included. This linkage has always taken place, but since 1994 it has been done electronic.

**The cause of death** is received yearly for all persons in the registry who died that year, from the Cause of death registry. Regarding **date of emigration** - as people are often working abroad, and while being there may choose to emigrate - the registry is not always updated for that date.

**NAMES OF PATIENT**

104) The patients full name is registered in order of the first name (=Christian name) being the "chief name" and only then the surname.

105) The following are all registered: Maiden name / Father's name but not Mother's name (as the maiden name is usually kept, and it is the fathers name).

106) The ID number of the next of kin is not registered.

**RESIDENCE/ADDRESS AT THE TIME OF REGISTRATION**

107) The code for the patients address is registered as "kommune" with 2 digits.

108) This information includes election municipality and a part of it.

109) Change of address is given from the CPR monthly, but the address at the time of diagnosis is kept in the registry as the address code at date of diagnosis.

110) The age at incidence date is calculated as year of diagnosis minus the year of birth.

111) The persons nationality (e.g. French, Danish) is not registered but is available.

112) No further information is used from the CPR.
113) The nationality of father and/or mother is not available.

114) Marital/civil status at diagnosis is coded in the registry from the CPR as it is on the date of diagnosis. It is available in the following categories from CPR:
   a) Married - yes
   b) Separated - yes
   c) Divorced - yes
   d) Widow/widower - yes
   e) Cohabitation - no
   f) Single - yes

115) Death - yes

116) Number of live births and categories (actual number) - no

117) Religion - no

118) Ethnic groups - no

119) Race - no

120) Patient's education - no

121) Occupation - may be available sporadic on titles.

122) Special enquet studies for occupation - no

123) Social class or socio-economic status - no

124) Patient's exposure to carcinogens - no

IX INCIDENCE DATE

DATE OF DIAGNOSIS (LEVEL OF DETAIL):

125) The date is recorded as the day, month and year of diagnosis.

126) The DATE OF DIAGNOSIS is defined as the earliest date written on the received records with confirmed diagnosis. This is however not the date when the suspicion of cancer arose, but rather the date of the diagnosis and very often the date of biopsy - unless the clinical notification form gives an earlier date.

127) A tumour notified only on a death certificate is traced, in order to get earlier information about the tumour.

128) Cases from the death certificate notes are registered as "Death certificate only" (DCO) and the date is the date of death. Those for which no report is received are included as DCO unless there is uncertainty expressed on the death certificate or in the histology.

129) For a patient known from autopsy only, the incidence date is the date of death.
X BASIS OF DIAGNOSIS

METHODS

130) All the methods used for diagnosing is coded in the "ur-register" (the basic registry). While only 2 methods are registered in the final cancer registry and they are coded as the most valid basis. The "most valid basis", is having the following ranking order (they are ranked automatically in the system)

a) Histology of primary / metastases (from autopsy/operation/biopsy)
b) Cytology (expectorate, aspirate etc.) / Bone marrow / Haematology or bloodtest
c) No histology, cytology, or bone marrow
d) No histology, cytology or haematology (e.g. clinical investigation / X-Ray / operation-autopsy without histology).

Basis of diagnosis used by the Icelandic Cancer Registry
1 = Death certificate only
2 = Clinical observation / exploratory surgery without histology
3 = Biochemical tests
4 = CT, X-ray, ultrasound etc.
6 = Cytology from bone-marrow or organs (aspiratio)
7 = Histology of biopsy (might be metastasis)
8 = Histology of organs
9 = Autopsy

If available, two digits are used in the dataset, the higher number first
e.g. 94 = autopsy plus x-ray
72 = histology plus clinical obs.
9 = autopsy only

We are planning to change this.
As we no longer use the digit 5, we would like to convert the digit 6 (cytology) to 5 and use the digit 6 for histologically diagnosed metastases. But we have to check very carefully first if we can convert the whole registry backwards before we go on with this.

XI CLASSIFICATIONS

131) classification(s):

a) From 1955: topography was coded according to ICD 7
morphology has been recoded according to SNOP at the registry from 1955-65

b) From 1965: topography was coded according to ICD 7
morphology was coded according to SNOP.

c) From 1981: topography was coded according to ICDO-1 / ICD 9 and to ICD 7
morphology was coded according to SNOMED / ICDO-1 code.

d) From 1991: topography was coded according to ICD 10, ICD 9 and ICD 7 and the SNOMED Topography.
morphology was coded according to ICD O2.

132) Exceptions to the classification rules: None were described – however skin, leukaemia and lymphoma are coded according to ICD-9 + morphology and according to ICD-7.
Appendix 2 Iceland

133) **Topography** (primary tumour) is defined by the clinician possibly corrected by the pathologist. The code is chosen according to specificity. - except for breast tumours, which are always localized to C50.9 or 174.9.

134) Topography codes may be changed according to what is most specific.

135) **Morphology** is defined by the best pathology description. The description of the material is given from the pathologist and coded according to SNOMED.

136) Morphology may be changed if e.g. a histological description is received after a cytological description, or the material from an operation or autopsy is better than from a biopsy, and material from the primary tumour is better than from a metastasis - the code is therefore changed accordingly.

137) **Behaviour of Tumour** is given by the pathology - description. The code is chosen so that the most malignant is coded (behaviour 3 > 2 > 1 according to ICD-O2).

138) The behavioural code may be changed if the pathologist changes the diagnosis from the same date. otherwise in case of change from CIS (carcinoma in situ) to cancer between 4 weeks and 2 months, the behaviour is changed and the first date kept. But if it is more than 2 months the cancer is given the new date as date of diagnosis): the new behaviour means a new tumour is registered.

139) There are no special rules for e.g. cervix tumours.

140) **List of reportable tumours:**
   
a) All definitely malignant neoplasms (e.g. carcinoma, sarcoma, malignant lymphoma, leukaemia and malignant teratoma) and tumours within the cranium and the vertebrae column.

b) All precancer cases.

c) All tumours with a morphology in the SNOMED with a code equal to or more then 8xxx or 9xxx.

141) **List of tumours included** in incidence publications:
   
a) Diseases mentioned under 140 A are included in the incidence publication. So are benign papillomas of the transitional cell-lined urinary tract together with the invasive cancers of these sites. Furthermore all neoplasms of the central nervous system, benign and malignant are tabulated together, and borderline tumours of the ovary are included as well. Carcinoma in situ of the cervix and of the breasts can be tabulated separately and are not included in the total number of tumours.

b) The reportable tumours mentioned under 140 B are not included in the cancer incidence except for those mentioned above.

**Conversion of ICD:**

142) Conversion table from ICD-10 to ICD-9 to ICD-7 is linked to the registry when necessary

The purpose of the conversion of ICD classification is:

143) To ensure comparability with others.

144) To make data comparable with data from other registries (e.g. Eurocare)
**Appendix 2  Iceland**

**DIAGNOSIS RECORDED IN ADDITION TO THE CANCER DIAGNOSIS CODED BY THE REGISTRY:**

145) Admission diagnosis - in case of cancer

146) Discharge diagnosis - in case of cancer

147) Cause of death - the information is only received if the patient died of cancer - or was treated for cancer and died with the cancer.

148) Autopsy diagnosis - the information is only received if the patient died of cancer - or was treated for cancer and died with the cancer.

149) Other diagnosis (e.g. AIDS / Hepatitis ICD-10: B21) are not coded.

**MALIGNANT DISEASES ROUTINELY EXCLUDED WHEN REPORTING DATA FROM THE REGISTRY:**

150) Basocell-carcinoma are not included.

### The Tumours Below are recorded and included in incidence data as shown

<table>
<thead>
<tr>
<th>Tumour type</th>
<th>Record yes</th>
<th>Record no</th>
<th>Included yes</th>
<th>Included no</th>
</tr>
</thead>
<tbody>
<tr>
<td>151) Benign Brain tumours</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>152) Pituitary gland</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>153) Carotid body tumour</td>
<td>none recorded yet</td>
<td></td>
<td>would be included</td>
<td></td>
</tr>
<tr>
<td>154) Benign bladder tumours (papilloma)</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>155) Intraductal carcinoma (8500/2) in the breast</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>156) Carcinoma in situ in the breast, other than above</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>157) Borderline tumour in the ovary</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>158) Carcinoma in situ in testis</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>159) Chromaffinoma (8700/0) of the adrenal glands</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>160) Argentaffinoma (8241/1) as carcinoid</td>
<td>x as carcinoid</td>
<td></td>
<td>x</td>
<td>x (appendix not included)</td>
</tr>
<tr>
<td>161) Chordoma (9370/3)</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>162) Invasive mole (9100/1)</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>163) Precancerous lesions in the cervix</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
</tbody>
</table>

164) **Other benign or precancerous lesions coded to or included with categories of malignant tumours and other specific information:**

Haematologic precancerous or benign diseases are registered but not included.

165) **Clinical stage / extent of tumour is not recorded but it is coming.**
XII MULTIPLE PRIMARIES

166) **THE RULES USED TO CODE MULTIPLE CANCERS IN THE REGISTRY:**

a) The counting of multiple tumours is dependent on the pathologist. Usually more are counted multiple than according to the IARC-rules.

b) The registry counts tumours not patients except for:

c) **SKIN TUMOURS** - melanomas are coded xxx.8 if there are more than one tumour.

d) **URINARY TRACT TUMOURS** - only one tumour may be counted in each location.

e) Colon tumours - number is dependent on pathologist

f) For Astrocytoma grade 1 which after some years develop into multiform glioblastoma is regarded as the same.

**RULES FOR CODING CANCERS IN PAIRED ORGANS:**

167) Tumours with the same morphology on each side are coded and counted according to the pathologist.

168) Tumours with different morphology on each side are coded and counted according to the advice from the pathologist.

169) Tumours with different behaviour (e.g. intraductal carcinoma in left breast and duct carcinoma in right breast) are coded as 2 tumours, but counted as one tumour. (the intraductal is not counted)

XIII TREATMENT

170) **TREATMENT** is registered, but the information in the basic registry ("urregistret") are incomplete, so they cannot be trusted.

Treatment given is divided into: surgical / radiotherapy / cytostatic / hormonal.

XVII FOLLOW-UP and TRACE-BACK

**A** By follow-up we mean that the registry follows up fully registered cases to obtain information about e.g. recurrence, treatment, or death.

**B** By trace-back we mean, that the registry actively attempts to obtain further information about a tumour, (e.g. first notified on a death certificate, or if the information on a patient is not satisfactory for other reasons) in order to complete the coding of the tumour recorded.
ACTIVE (A) OR PASSIVELY (P) RECEIPT OF DATA FROM THE FOLLOWING SOURCES FOR FOLLOW-UP AND/OR TRACE-BACK

**Hospitals**

<table>
<thead>
<tr>
<th>Source</th>
<th>Trace-back</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>171) Clinical departments</td>
<td>a</td>
<td>p</td>
</tr>
<tr>
<td>172) Medical records</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>173) Outpatient clinics</td>
<td>a</td>
<td>p</td>
</tr>
<tr>
<td>174) Hospices</td>
<td>a</td>
<td>p</td>
</tr>
<tr>
<td>175) Long stay hospitals and homes for the elderly</td>
<td>a</td>
<td>p</td>
</tr>
</tbody>
</table>

**Laboratories (in or outside hospitals)**

<table>
<thead>
<tr>
<th>Source</th>
<th>Trace-back</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>176) Pathology, general</td>
<td>a</td>
<td>p</td>
</tr>
<tr>
<td>177) Pathology, specialised</td>
<td>a</td>
<td>p</td>
</tr>
<tr>
<td>178) Haematology (are looked up)</td>
<td>a</td>
<td>p</td>
</tr>
<tr>
<td>179) Autopsy reports (are looked up)</td>
<td>a</td>
<td>p</td>
</tr>
<tr>
<td>180) Institute of forensic medicine (are looked up)</td>
<td>a</td>
<td>p</td>
</tr>
<tr>
<td>181) Other</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Source</th>
<th>Trace-back</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>182) Death certificates</td>
<td>a</td>
<td>p</td>
</tr>
<tr>
<td>183) General practitioners</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>184) Specialist practitioners</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>185) Health insurance</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>186) Screening programmes (co-operation)</td>
<td>a</td>
<td>-</td>
</tr>
</tbody>
</table>

**Administrative sources**

<table>
<thead>
<tr>
<th>Source</th>
<th>Trace-back</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>187) Central population registers</td>
<td>a</td>
<td>p</td>
</tr>
<tr>
<td>188) Central medical registers (e.g. hospital information systems)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>189) Other</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

**XIX SCREENING PROGRAMMES**

<table>
<thead>
<tr>
<th>Programme</th>
<th>Type</th>
<th>Age-group</th>
<th>How often</th>
</tr>
</thead>
<tbody>
<tr>
<td>190) cervix</td>
<td>1964-87</td>
<td>25-69 years</td>
<td>every 2 years</td>
</tr>
<tr>
<td>191) breast</td>
<td>1987</td>
<td>40-69 years</td>
<td>every 2 years</td>
</tr>
<tr>
<td>192) colon</td>
<td>none</td>
<td>20-69 years</td>
<td>every 2 years</td>
</tr>
<tr>
<td>193) melanoma</td>
<td>none</td>
<td></td>
<td></td>
</tr>
<tr>
<td>194) prostate</td>
<td>none</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

195) There is co-operation with the cervix and breast screening programmes, as the registry receives lists once a year from the programme and more information is easily accessible. Cases from the breast and cervix screening registries are thus included.

**XX USE OF COMPUTER**

196) The software used in the registry is tailor-made for the registry, while information from the pathologists is partly received on disks.
XXI CONFIDENTIALITY

THE REGISTRY OBSERVES THE FOLLOWING SET OF RULES ON CONFIDENTIALITY:

197) The information in the registry is confidential so all employees have professional secrecy.

198) Current regulations in the law concerning data must be followed.

199) All research projects using identifiable data must have permission from the data-inspection and the Ethic committee.

200) In case of questions concerning annulment or quality of the delivered material no rules that the cancer registry is to be contacted first.

201) The Cancer registry presupposes that the registry is mentioned as source in all prospective publications.

202) The signing of the order in the application form - this is not relevant as the permission from the data-inspection and the ethical committee must go together with the application form.

203) THE REGISTRY IS PERMITTED TO LINK WITH OTHER FILES after permission from the data-inspection.

This is regulated by:

204) By the Data-inspection

205) In certain cases also by the ethical committee

206) There are no rules that identifiable information should be deleted in the registry.

207) An individual can legally obtain access to data about himself/herself in the registry but only through a Medical Doctor. The patient may thus write a letter to the registry, and the information is sent to the General Practitioner, who can explain the answer to the patient.

208) AN INDIVIDUAL CANNOT REFUSE TO BE INCLUDED IN THE CANCER REGISTRY

209) An individual does not have to be asked / informed before being included in the cancer registry

THE FOLLOWING CAN GET ACCESS TO THE CANCER REGISTRY DATA:

210) - On case by case basis - anonymously: There are no special restrictions

211) - On case by case basis - with identifying information:
   a) The scientist according to the rules described above
   b) The patient as described
   c) The hospital may receive information about its "own" patients until "date of death", but not about "cause of death".

212) International release may only be done after making the persons anonymous, e.g. by giving serial numbers to the persons in international studies, and having the key only in the country of origin.
XXII QUALITY CONTROL

**Completeness of Coverage:**

213) There is no routine for estimating the completeness of registration.

214) The number of forms from the pathological departments and haematologists is not estimated, but as mentioned above, the coverage of forms is very high for pathological departments.

215) The forms from the clinical departments - as mentioned earlier often have to be requested.

216) Target directed registries / registries from trial protocols: are not used.

217) Disease index / Hospital discharge registry is not used.

218) Outpatient logs - not used.

219) Pathology department logs - are used.

220) Comparison with patients enrolled in screening programmes are done, and information received from scientists is used and included in the registry, and in this way research is contributing to the completeness of the registry.

221) Random sampling of patients admitted to hospital and scrutiny of records for missed cases (capture - recapture) is not done.

222) Surveillance of numbers of registrations from each source is not done.

**Completeness of Detail:**

223) The average number of notifications per case is not calculated.

224) The number of sources over the years is not known.

**Figures for a Recent Year for the Following:**

225) Figures for "unknown primary site (199 in ICD7)" were in 1995 = 35 out of 1024 new cases which equals 3,4%.

226) Percent of "age unknown" - irrelevant.

227) Percent of "treatment unknown" - not calculated.

228) Percent of "stage unknown" - irrelevant.

229) Percent of "histology" was in 1995: 95,8% for men and 95,2% for women.

230) Percent of "basis of diagnosis unknown" - was zero.

231) Percent of "place of birth unknown" - is not recorded.

232) Year/period to which these figures apply: 1995.

233) The most recent year published for the country is 1995.

**Methods Used to Maintain Quality Control of the Registry’s Data:**

234) Independent re-abstraction is done for one tumour type at the time.
235) Independent re-coding of a sample of cases is not done.

236) Independent duplicate data entry is not done.

237) Input logical checks is used - see below

238) Use of test cases is not done

239) Proof-reading of coded notification is done.

240) Summary tabular frequency checks are not used, but an electronic check is done.

241) Incidental autopsy finding is calculated.

242) Cancer cases from Death Certificates Only (DCO) were 0,2% in 1991 - 1995.

243) Mortality/incidence ratio is not calculated.

244) Stability of rates over time is estimated.

245) Comparison with neighbouring registries is done in Nordic projects.

XXIII WEAK POINTS

246) MALIGNANCIES WHICH MAY BE UNDER-REPORTED:
Non-solid tumours, intracranial tumours in older people who are not investigated and all tumours which are not operated.

XXIV CHECKS

AUTOMATIC COMPUTER-BASED CHECKS

247) Data entered for essential variables is checked yes

248) "Invalid" code for almost any variable yes

a) hospital code is valid
b) clinic code is valid
c) pathology laboratory is valid
d) home-address is valid
e) ICD7 code is valid
f) Basis of diagnosis is valid
g) slide number is valid
h) Cancer death is valid
i) Autopsy result is valid
j) Permitted codes for every area - the three different topography figures must agree

OTHER EXAMPLES OF CHECKS

DATE OF DIAGNOSIS

249) Before or equal to date death yes

250) Before or equal to date of post-mortem yes

251) Before or equal to date of report

252) Date of death before or equal to date of post-mortem yes

253) In case of only autopsy finding: date = date of death
Appendix 2 Iceland

**TUMOUR TYPE**

254) Sex compatible with site yes
255) Age compatible with tumour type - through the IARC check programme yes
256) Site of tumour compatible with histological type yes
257) Site of tumour compatible with code for laterality (paired organ) yes
258) Site of tumour compatible with method of diagnosis yes
259) Histology compatible with method of diagnosis yes

260) THE IACR CHECK-PROGRAMME is used.

261) MANUAL/VISUAL CHECKS: are done.

**XXV OUTPUT FROM REGISTRY**

**IN THE REGULAR ROUTINE PUBLICATIONS OF INCIDENCE RATES, TABLES OF RATES ARE GIVEN BY:**

262) Year yes
263) Sex yes
264) Age yes
265) Site yes
266) Occupation no
267) Social group no
268) Residence no
269) Geographical subdivision of your territory no
270) Trends yes in 10 years trends
271) Other variable yes
   a) Cases found incidentally at autopsy no
   b) Number of second and multiple primaries (site, sex, med. Region) no
   c) Percentage cytologically and histologically verified yes

**IN THE REGULAR PUBLICATIONS, THE FOLLOWING STANDARDS ARE USED:**

272) World Standard yes
273) European Standard and year (was used formerly, and is available in the computer-programme) no
274) Own Standard for Iceland yes
275) Other no

**THERE ARE NO REGULAR/ANNUAL ROUTINE PUBLICATIONS OF MORTALITY RATES BUT THEY ARE AVAILABLE**

276) Evaluation of incidence trends is carried out
Appendix 2  Norway

BASIC CHARACTERISTICS OF THE REGISTRY
NORWAY  

1) The Cancer Registry of Norway  
   Institute for Epidemiologic Cancer Research  
   Fridtjof Nansens vei 17, 0369 Oslo (visiting address)  
   Montebello, (postal address)  
   N 0310 Oslo  
   Norway  
   Tel: +47/ 22451300  
   Fax: +47/ 22451370  
   e-mail: first-name.last-name@kreftregisteret.no  
   web-site: www.kreftregisteret.no

Persons interviewed:  
Name: Position Training/Degree Abbreviation:  
Aage Johansen Chief of data-processing AaJ  
Svein Hansen Medical adviser to coding personnel Medical Doctor SH  
Grethe Kjølberg Coding assistant (Medisinsk koder) GK  
Tove Dahl Leader of coding personnel TD

I THE REGISTRY

8) The registry is population-based and covers: Norway.

9) The population includes all the people in the area who are entered into the official population statistics that is have been given a personal identification number. Guest-workers usually get a personal identification number very quickly after entering the country.

10) Special registries:  
    a) Colo-rectal treatment project registry,  
    b) Paediatric cancer registry,  
    c) Polyposis registry,  
    d) Special registries for screening of cervix and breast  
    e) Special registry for prostate cancer is at the planning stage.

II DEMOGRAPHICAL INFORMATION

11) An incidence publication is made every year on country and county (fylke) level; on district health care level annually for 5-year periods.

12) Changes: Some municipalities have been split up and others united.

THE RESIDENT POPULATION IN THE AREA COVERED BY THE REGISTRY was in 1993

13) a Males: ................................................................................................................. 2 138 079  
14) b Females: ................................................................................................................ 2 185 463  
15) c Total:.................................................................................................................... 4 323 542  

16) The population figures are exact for 1 year age groups since 1967 on municipality level. Before 1967 population figures are available for the years 1955, 1960 and 1965 for 5 years age groups at municipality level.

17) Population figures used for incidence calculation are the end of the year figures.
18) The Health system: the patient can choose a general practitioner - there is no "house-doctor system" - who may refer the patient to a local hospital, from where the patient can be referred to a special hospital (see 61, 69).

19) The local hospitals are governed by the county (fylke), while the University hospitals and the specialised hospitals are governed by the Department of Health and Social Affairs.

**REGARDING POPULATION DATA THE FOLLOWING ARE AVAILABLE IN THE Registry**

<table>
<thead>
<tr>
<th></th>
<th>available</th>
<th>used</th>
</tr>
</thead>
<tbody>
<tr>
<td>20</td>
<td>Sex in one-year age groups</td>
<td>x</td>
</tr>
<tr>
<td>21</td>
<td>Sex in five-year age groups</td>
<td>x</td>
</tr>
<tr>
<td>22</td>
<td>Information on occupation are available from other registries around every 10 years from census calculations</td>
<td>x</td>
</tr>
<tr>
<td>23</td>
<td>Information on religion</td>
<td>-</td>
</tr>
<tr>
<td>24</td>
<td>Information in the registry for &quot;ethnic groups&quot; and &quot;country of origin&quot;</td>
<td>-</td>
</tr>
<tr>
<td>25</td>
<td>The urbanity-degree is found in the municipality codes</td>
<td>x</td>
</tr>
</tbody>
</table>

The municipalities are administratively divided into urban/not urban areas.

26) Information about geography is by municipality and is one of the figures in the code

27) The address as a land registry-number (co-ordinate-system) - -

**III HISTORY and TUMOURS INCLUDED**

28) The registry started operating in 1952

29) The registry can present population based data from 1953

**CHANGES:**

30) The registry has not been linked to the hospital discharge registry as that registry is very poor. Cases from other special registries are included: From screening programmes: The registry receives disks from all laboratories on the screenings every month with all the results which makes it possible to follow up on those with invasive cancers.

31) No changes for inclusion / exclusion of tumours were described. From 1971 the inquiry of notification of cases became electronic based.

32) There may have been changes in hospital procedures:
   a) e.g. PSA for prostate cancer
   b) the autopsy-rate has probably changed
   c) e.g. X-ray investigation (MR-scan)
   d) laboratory tests have changed in type and quality

33) Reporting of cancer cases has been compulsory since 1953 for pathological laboratories and hospitals as well as for any doctor diagnosing and / or treating cancer.

34) At present reporting of tumours is compulsory for:
   a) Any medical Doctor employed privately or in a hospital department, who has diagnosed the tumour disease clinically or microscopically.
   b) Any medical Doctor writing a tumour disease on the death-certificate even if diagnosed after death.
c) The doctor responsible for: pathological / cytological laboratories, the Forensic department, the Haematological lab., and other service departments.

35) Operation of the registry has not been discontinued at any time.

36) The registry is under the National Social- and Health-department. But from 1952 to 1979 it was owned and run by the Norwegian Cancer Society.

37) The data are reported annually as Cancer Incidence of Norway by the "Institute for epidemiological cancer research".

IV STAFF & ORGANIZATION

38) EMPLOYEES: 1 Chief of department "B" 1 Medical Doctor giving medical coding advice 1 Medical specialist 10 coders, of whom one is coding leader extra hands in variable numbers

39) The Norwegian Cancer registry is divided into 5 departments, each having different tasks. They are all participating in or supporting research. Apart from that the responsibilities are:
   a) Administration + research
   b) Coding of cancers + research - this is the department in which the above mentioned persons are employed, and where the 'construction' of the cancer registry is taking place as this is where the notification forms are received and coded.
   c) Screening and research
   d) Biological cancer research
   e) E: Occupation / cancer research.

40) The registry is working closely with the following departments: For the data material the registry is working with all the health departments. Apart from this there is co-operation with different clinical departments on research projects

41) The registry is part of the Norwegian Cancer registry, which is administratively under the Department of Health and Social Affairs

42) The registry is also running the PAP-smear screening for cervix cancer and starting the trial of breast cancer screening in four counties.

43) The cancer-registry is located separately, but used to be located with the Norwegian Radiumhospital (the oncologic treatment centre).

SOURCES OF FINANCE:

44) Registration of cancer is financed by the government and so are some of the research and screening projects.

45) Research projects are also carried out in co-operation with others and are financed from funds, after application and acceptance of the project. Other special activities are projects run in co-operation with e.g. the Nordic countries.

CODING

46) ALL CODING IS CARRIED OUT at the registry, but plain-text must appear on the notification forms.

47) THE CODING is carried out by the coding assistants.

48) Supervision of coding and solving of coding problems is done by a Medical Doctor (MD).
49) In difficult cases a pathologist may be contacted.

50) Coding problems are usually solved by the Registry medical adviser - however the pathology reports are usually clear.

51) Coding problems are not brought to special meetings - as in Sweden.

LETTERS / TELEPHONE

52) The registry has to request for clarification in some of the cases, how many is not known. The coders usually send requests for clarification to the "mother-hospital".

53) Sometimes they forget to send the notifications - especially from the clinical departments.

V REPORTING

TUMOUR REGISTRATION FROM DIAGNOSIS TO REGISTRY:

54) A patient will usually go to the general practitioner, who may refer him/her to the local hospital. There the patient may be referred to the specialised hospital. - Any of these may send a notification form. However the pathologist is the most reliable source. The notification forms from the clinic are coded after the year has ended, while the pathological forms are sorted according to laboratory, year of diagnose and year of birth. These forms are used as basis for requesting the clinical forms if they are not received. The notification forms for gynaecological, breast and colorectal tumours are coded and registered immediately as they are part of special registries.

55) A fee is paid to the laboratories for the copy of the pathology-description.

56) Most often it is the medical doctor who writes the report and signs it.

57) Linkages is carried out with the Death Registry in order to ensure that official date of death and cause of death is available in the Cancer registry and to include those cases not reported on in other ways. Linkage with the CPR (Central Population Registry) is also carried out to check the persons name and ID-number

58) Information on name and address of the reporting hospital / clinic / or other source is kept. While the GP is only registered as "9999". For each tumour information on those giving the most valuable information are kept.

59) The registry has information, which makes it possible to GO BACK TO THE ORIGINAL RECORDS.

60) Patients do not have a "House-Doctor"

VI SOURCES

THE REGISTRY REGULARLY RECEIVES NOTIFICATIONS FROM:

61) Hospitals
62) (Medical records departments – no)
63) Outpatient clinics
64) Hospices
65) Long stay hospitals and homes for the elderly
Laboratories (in or outside hospitals)
66) Pathology
67) Haematology including hospital laboratories - very poor in reporting
68) Autopsy reports
69) Institute of forensic medicine

70) Death certificates are used as source for tumour registration and are received on a quarterly basis, from 1999 on a monthly basis (see 32 + 200).

Other
71) General practitioners
72) Specialist practitioners
73) Screening programmes - for cervix screening the tumours are coded from the pathology-descriptions. The registry receives disks from all laboratories on the screenings every month with the results which makes it possible to follow up on those with invasive cancers.

FORMS RECEIVED

74) The registry receives most forms from the pathological departments. For clinical notifications the number of source varies with the site.

75) It is not known how many are diagnosed clinically only. There is 99% coverage for solid tumours and 95% for haematological.

76) THE INFORMATION ABOUT CANCER is recorded from the notification forms, which must be filled in plain-text, that is coding number only - even from pathologist - are not accepted.

THE REGISTRY RECEIVES / RECEIVES NOT (OR HAS REGULAR ACCESS TO) COPIES OF THE FOLLOWING FOR CANCER PATIENTS:

77) Medical records. .......................................................... .......................................................... no
78) Pathology reports of the histological and cytological descriptions. ......................................yes
79) Autopsy reports .......................................................... .......................................................... yes
80) Discharge letter .......................................................... .......................................................... yes
81) Death certificates .......................................................... .......................................................... yes
82) Radiotherapy reports .......................................................... .......................................................... no
83) Hospital information system .......................................................... .......................................................... no
84) The staff at the registry does not visit the oncologic clinics.
85) The original notification forms are stored as microfilms, but from the autumn 1997 scanning of notifications has been used.

86) Definition of place of "residence":
The address of the municipality where the patient is living on the date for the diagnosis, except for students who are given the address of their home-municipality, not that of the study-place.

87) Immigrants and/or non-residents - who do not have a personal identification number are not entered into the registry. However notifications on persons without a personal identification number must be checked as newborn Norwegians may not have received a personal identification number at the time of notification.

88) Refugees with no id-number - and those with a "protected address"- or new id-number, are not entered into the registry, - they are probably very few.

89) Special subgroups/minorities in the population may not be isolated.
TUMOURS IN PATIENTS WHO ARE NOT PERMANENT RESIDENTS OF THE REGISTRY TERRITORY are registered as they get a personal id-number quickly.

Norwegian citizens working abroad are entered if they receive treatment in Norway. They are entered, with the date of re-entering the country.

The data are not submitted to a larger registry.

VII INFORMATION RECORDED

THE CODING OF DATA: On receipt the forms are sorted according to year of diagnosis for the pathology forms and for the clinical forms according to the year they arrived.

THE PROCESSING OF DATA: On registration all forms on the person are consulted. (e.g. in case of multiple tumours). They are collected for 1 year before they are coded.

Two or more notifications are linked electronically using the unique personal identification number.

After receipt those with only one notification form (usually the pathology) are isolated and a second form is requested from the relevant source, usually the clinical department.

COMPUTERISED CASE RESOLUTION is not carried out but "legal/permitted" combinations are used. (XXIV checks).

VIII THE PERSON

THE SOURCE FOR INFORMATION ON THE PERSON is the Central Personal Registry (CPR), which assigns a number to each resident in Norway and also register the name, place of residence and date of death.

The patient is not given another identification code-number in the registry.

THE UNIQUE PERSONAL REGISTRY NUMBER is constructed of: 11 digits, which are composed of: 2 digits for day, 2 digits for month and 2 digits for year of birth; The next 3 digits are serial numbers, with 000-499 for 19xx (century) and 500-749 for 18xx (century). The uneven number designating male and the even number female. The last 2 numbers are control numbers (K1 and K2).

Immigrants are assigned a CPR number when they become residents or get a working permit.

The number does not indicate where the person was born, nor if he/she belongs to any minority and it does not indicate ethnicity.

The cancer registry has since 1999 received updated information every month from Statistics Norway for date of death and for emigration. Formerly this information was received 4 times a year for date of death and for emigration every 2-3 years. The registry has been linked electronically to the Death Index Registry since 1970. Before that the linkage was done manually. Cause of death has in this way been updated 4 times a year. From 1999 the registry receives information about cause of death from Statistic Norway where it is registered.

a) date of death is given with day/month/year
b) patients are followed to date of death / emigration
c) The official cause of death is regarded as the cause of death. The registry however sends information about cancer to Statistics Norway, so that the official cause of death may be corrected if necessary.
d) the vital status is not always known after emigration
Appendix 2  Norway

**Names of Patient**

104) The patients full name is registered.

105) None of the following are registered: Maiden name / Father's name / Mother's name

106) The ID number of the next of kin is not registered.

**Residence/Address at the Time of Registration**

107) The patients address is registered as the code for the municipality at the time of diagnosis.

108) This information includes county, municipality and status for urbanity (township/rural area).

109) Change of address is given from the CPR annually, but the address at the time of diagnosis is kept in the registry as address at date of diagnosis.

110) The age at incidence date is calculated on the basis of date of birth and date of diagnosis.

111) The persons nationality (e.g. French, Danish) is not registered.

112) The information used from the CPR is thus the personal ID-number, the name, place of residence and date of death.

113) The nationality of father and/or mother is not available in the cancer registry.

114) Marital/civil status at diagnosis may be found in the CPR and is available in the following categories
   a) Married – yes
   b) Separated – yes
   c) Divorced – yes
   d) Widow/widower – yes
   e) Cohabitation – no
   f) Single - yes

115) Death - yes

116) Number of live births - no

117) Religion - no

118) Ethnic groups - no

119) Race - no

120) Patient's education – no (is available but not in CPR)

121) Occupation - may be available from the census every 10 years.

122) Special enquet studies for occupation - no

123) Social class or socio-economic status – (available in other registries) - no

124) Patient's exposure to carcinogens - no
IX INCIDENCE DATE

DATE OF DIAGNOSIS (LEVEL OF DETAIL):

125) The date is recorded as the month and year of diagnosis. From 1999 it will also be possible to register the day the month.

126) The date of diagnosis is defined as the date coded in the cancer registry. This date is however not the date when the suspicion of cancer arose, but the date the cancer was diagnosed (as written on the form). The ranking of the dates of diagnosis is that the earliest given date is recorded.

127) A tumour found only on a death certificate is traced, in order to get earlier information about the tumour.

128) 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.

129) For a patient known from autopsy only, the incidence date is the date of death.

X BASIS OF DIAGNOSIS

METHODS

130) Different basis of diagnosis may be coded from the different notifications, but the most valid is given priority. They are having the following ranking order (but are ranked automatically in the system)
   a) Histology of primary / metastases (from biopsy/operation/autopsy).
   b) Cytology (expectorate, aspirate etc.) / Bone marrow.
   c) Haematology or blood test, but no histology, cytology, marrow.
   d) No histology, cytology or haematology (e.g. clinical investigation / X-Ray / operation-autopsy without histology) is not ranked.

XI CLASSIFICATIONS

131) classification(s):
   a) From 1952: topography was coded according to ICD 7, morphology was coded according to own 3-digit system
   b) From 1970: topography was coded according to ICD 7, morphology was coded according to Motnac - 4 digit and locally modified
   c) From 1993: Topography was coded according to ICDO-2/10 (with exceptions for lymphomas and leukaemias), and to ICD 7, morphology is coded according for the SNOMED/ICDO-2 code.

132) Exceptions to the classification rules:
   Lymphomas (C77) are coded according to Kiel classification from 1983 and this was extended in 1993.

133) TOPOGRAPHY (PRIMARY TUMOUR) is defined by the clinician's assessment. The code is chosen according to specificity.

134) Topography codes may be changed according to what is most specific.

135) MORPHOLOGY is defined by the best pathology description. The description of the material is given from the pathologist and coded according to SNOMED / ICDO2.
136) Morphology may be changed if e.g. a histological description is received after a cytological description, or the material from an operation is better than from a biopsy, and material from the primary tumour is better than from a metastasis - the code is therefore changed accordingly.

137) 

BEHAVIOUR OF TUMOUR is given by the pathology – description. The code is chosen so that the most correct is coded, not necessarily the most malignant.

138) The behavioural code may be changed within 4 month, after that a new tumour has to be registered if it is a cancer.

139) There are no special rules for e.g. cervix tumour.

140) List of reportable tumours:

a) All definitely malignant neoplasms (e.g. carcinoma, sarcoma, malignant lymphoma, leukaemia and malignant teratoma).

b) All precancer cases

c) Histologically benign tumours of the central nervous system and meninges, transitional cell papillomas of the urinary tract, all tumours of the endocrine glands within the central nervous system.

141) LIST OF TUMOURS INCLUDED in incidence publications:

a) Diseases mentioned under 140 a are included in the incidence publication, - so are atypical epithelial lesions and benign papillomas of the transitional cell-lined urinary tract together with the invasive cancers of these sites, - furthermore all neoplasms of the central nervous system, benign and malignant are tabulated together. - Carcinoma in situ of the cervix and borderline tumours of the ovary are tabulated separately and not included in the total number of tumours

b) The reportable tumours mentioned under 140 b are not included in the cancer incidence, except those mentioned above.

CONVERSION OF ICD:

142) All ICD-O topography codes are routinely converted to ICD-7 electronically and manually.

THE PURPOSE of the conversion of ICD classification is:

143) To ensure comparability with old data.

144) To a certain degree to make data comparable with data from other registries (e.g. Eurocare)

DIAGNOSIS RECORDED IN ADDITION TO THE CANCER DIAGNOSIS CODED BY THE REGISTRY:

145) Admission diagnosis - not coded

146) Discharge diagnosis - not coded, but discharge letters are sometimes received.

147) Cause of death - is received 4 times a year.

148) Autopsy diagnosis - is coded and evaluated with other information.

149) Other diagnosis (e.g. AIDS / Hepatitis ICD-10: B21) are not coded.

MALIGNANT DISEASES ROUTINELY EXCLUDED WHEN REPORTING DATA FROM THE REGISTRY:

150) Formerly Basocell-carcinoma was not included, but from 1993 they will be.
THE TUMOURS BELOW are recorded and included in incidence data as shown

<table>
<thead>
<tr>
<th>Tumour type</th>
<th>Record yes</th>
<th>Record no</th>
<th>Included yes</th>
<th>Included no</th>
</tr>
</thead>
<tbody>
<tr>
<td>151) Benign Brain tumours</td>
<td>X</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>152) Pituitary gland</td>
<td>X</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>153) Carotid body tumour</td>
<td>X</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>154) Benign bladder tumours papilloma</td>
<td>X</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>155) Intraductal carcinoma (8500/2) in the breast</td>
<td>X</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>156) Carcinoma in situ in the breast, other than above</td>
<td>X</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>157) Borderline tumour in the ovary</td>
<td>X</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>158) Carcinoma in situ in testis</td>
<td>X</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>159) Chromaffinoma (8700/0) of the adrenal glands</td>
<td>X (not systematically)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>160) Argentaffinoma (8241/1)</td>
<td>X</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>161) Chordoma (9370/3)</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>162) Invasive mole (9100/1)</td>
<td>X</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>163) Precancerous lesions in the cervix</td>
<td>X</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>164) Other benign or precancerous lesions coded to or included with categories of malignant tumours and other specific information: Endocrine tumours are only included if they are malignant or intra-cranial.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>165) CLINICAL STAGE / EXTENT OF TUMOUR IS RECORDED.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) The stage / extent is coded according to a 10 level system. On the basis of these codes the tumours are grouped in localised, regional and disseminated tumour.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) The code is chosen as the stage at the month of diagnosis and up to 4 months after the date of diagnosis.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) There is no ranking system of which staging method is used, though the PTNM codes are used for breast tumours, FIGO for cervix tumours and Ann Arbor stage for malignant lymphoma, while the rest are coded according to the above definitions.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) All available information on staging is entered into the system. This also counts for information on stage more than 4 months after diagnosis. This however is only entered so that it may be seen but it is clearly shown that it is more than 4 months after diagnosis. The definition of clinical stage is however mentioned.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e) The date of the staging is the date of diagnosis.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f) The stage may be updated if better information is received and the staging is within 4 months of date of diagnosis.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g) It is therefore possible to tabulate cancers according to the staging as described above</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

XII MULTIPLE PRIMARIES

166) The rules used to code multiple cancers in the registry:
| a) All primary malignant tumours are coded separately regardless of time of diagnosis, topography or morphology. |
| b) The registry counts tumours not patients except for: |
| i)SKIN TUMOURS - if "malignant melanomas" are diagnosed in the same area and on the same occasion they are registered and coded as one - but if it is different occasions each is registered. If more melanomas are diagnosed in different regions on the same occasion, they are coded separately, but the tumours are only counted as one. |
i) Other skin-cancers are given a code for multiple tumours if more than one.
c) URINARY TRACT TUMOURS - only one tumour may be counted in each location
d) For Astrocytoma grade 1 which after some years develop into multiform glioblastoma no second tumour is registered.

RULES FOR CODING CANCERS IN PAIRED ORGANS:
167) Tumours with the same morphology on each side are coded as bilateral tumours and counted as one when calculating incidence rates.

168) Tumours with different morphology on each side are
   a) coded as two tumours, and counted as such if it is breast tumours after 1994;
   b) tumours in the kidneys, testis and ovaries are usually counted as 1 and registered bilateral;

169) Tumours with different behaviour (e.g. intraductal carcinoma in left breast and duct carcinoma in right breast) are coded as 2 tumours, but counted as one tumour. (the intraductal is not counted)

XIII TREATMENT

170) PRIMARY TREATMENT is registered and defined as
   a) Treatment given within 4 month of the diagnosis, and divided into: surgical / radiotherapy / cytostatic / hormonal
   b) All treatment and the date for start of treatment is registered.
   c) If the start of the treatment is > 4 months after date of diagnosis it is registered as "late treatment".
   d) Place of treatment is registered

XVII FOLLOW-UP and TRACE-BACK

A By follow-up we mean that the registry follows up fully registered cases to obtain information about e.g. recurrence, treatment, or death.

B By trace-back we mean, that the registry actively attempts to obtain further information about a tumour, (e.g. first notified on a death certificate, or if the information on a patient is not satisfactory for other reasons) in order to complete the coding of the tumour recorded.
Appendix 2  Norway

**ACTIVE (A) OR PASSIVELY (P) RECEIPT OF DATA FROM THE FOLLOWING SOURCES FOR FOLLOW-UP AND/OR TRACE-BACK**

**Hospitals**
171) Clinical departments ................................................................. a  p
172) Medical records ................................................................. -  p
173) Outpatient clinics ................................................................. a  p
174) Hospices ................................................................. a  p
175) Long stay hospitals and homes for the elderly ......................................... a  p

**Laboratories (in or outside hospitals)**
176) Pathology, general ................................................................. a  p
177) Pathology, specialised ................................................................. a  p
178) Haematology ................................................................. -  p
179) Autopsy reports ................................................................. a  -
180) Institute of forensic medicine ................................................................. a  p
181) Other ................................................................. -  -

182) **Death certificates** ................................................................. a  p
183) **General practitioners** ................................................................. a  p
184) **Specialist practitioners** ................................................................. a  p
185) **Health insurance** ................................................................. -  -
186) **Screening programmes** ................................................................. -  -

**Administrative sources**
187) Central population registers ................................................................. -  p
188) Central medical registers (e.g. hospital information systems) ................................................................. -  -
189) Other ................................................................. -  -

**XIX SCREENING PROGRAMMES**

<table>
<thead>
<tr>
<th>Type and year of start</th>
<th>age-group</th>
<th>How often</th>
</tr>
</thead>
<tbody>
<tr>
<td>cervix:1970 - 91 opportunistic from 1995 country-wide</td>
<td>25 - 69 years</td>
<td>Every 3 years</td>
</tr>
<tr>
<td>breast:1995 as a project in 4 counties</td>
<td>50 - 59 years</td>
<td>Every second year</td>
</tr>
<tr>
<td>colon: is under consideration</td>
<td></td>
<td></td>
</tr>
<tr>
<td>melanoma: none:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>prostate: trial</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

195) A co-operation with the cervix screening programmes and the breast screening programme is discussed. However the registry already receives floppy-disks from all laboratories monthly with the results of all the screened material. (35 + 47 + 83).
**XX USE OF COMPUTER**

196) The software used in the registry is an interactive database with terminals

**XXI CONFIDENTIALITY**

The registry observes the following set of rules on confidentiality:

197) The information in the registry is confidential so all employees have professional secrecy

198) Current regulations in the law concerning data must be followed.

199) All research projects using identifiable data do have permission in the concession of the registry. There are therefore no special rules for how to handle floppy-disks concerning identifiable data

200) In case of questions concerning annulment or quality of the delivered material the cancer registry is to be contacted.

201) The Cancer-registry presupposes that the registry is participating as co-author in all projects, where data from the Cancer-registry is used

202) The registry is legally permitted to link with other files according to the intention of the registry.

203) In cases of linkage with registries outside the cancer-registry a special permission is required from the data-inspection

This is regulated by:

204) By the data-inspection

205) In certain cases also by the ethical committee

206) There are no rules that identifiable information should be deleted in the registry.

207) An individual can legally obtain access to data about himself/herself in the registry but only through a Medical Doctor. The patient may thus write a letter to the registry, and the information is sent to the General Practitioner, who can explain the answer to the patient.

208) An individual cannot refuse to be included in the cancer registry

209) An individual does not have to be asked / informed before being included in the cancer registry

The following can get access to the cancer registry data:

210) On case by case basis - anonymously: There are no special restrictions

211) On case by case basis - with identifying information:
   a) The scientist according to the rules described above
   b) The patient as described
   c) The hospital receives information about its "own" patients, even after death, but not about "cause of death".

212) International release may only be done after making the persons anonymous, e.g. by giving serial numbers to the persons in international studies, and having the key only in the country of origin.
XXII QUALITY CONTROL

Completeness of coverage:

213) There is no routine for estimating the completeness of registration - it has however been done in special projects.

214) The number of forms from the pathological departments is not estimated, but as mentioned above, the coverage of forms is very high for pathological departments.

215) Forms from the clinical departments - as mentioned earlier often have to be requested.

216) Target directed registries are not available.

217) Disease index / Hospital discharge registry is sometimes used in projects: by comparison with hospital statistics.

218) Outpatient logs - not used

219) Pathology department logs - not used.

220) Comparison with patients enrolled in screening programmes and trial protocols may be done. Information received from scientists is used and included in the registry, and in this way research is contributing to the completeness of the registry.

221) Random sampling of patients admitted to hospital and scrutiny of records for missed cases (capture - recapture) is not done.

222) Surveillance of numbers of registrations from each source is not done regularly, the numbers are however followed.

Completeness of detail:

223) The average number of notifications per case is not calculated - though it was estimated in 1992.

224) The number of sources over the years are not known.

Figures for a recent year for the following:

225) Figures for "unknown primary site (199 in ICD7)" were in 1993 = 794 out of 18950 new cases which equals 4%.

226) Percent of "age unknown" - irrelevant.

227) Percent of "treatment unknown" - not calculated

228) Percent of "stage unknown" - is calculated for some tumours and shown as diagrams in the incidence publication.

229) Percent of "histology + cytology" was in 1993: 92.8%

230) Percent of "basis of diagnosis unknown" - not estimated

231) Percent of "place of birth unknown" - is not recorded.

232) Year/period to which these figures apply: 1993.

233) The most recent year published for the country is 1995.
METHODS USED TO MAINTAIN QUALITY CONTROL OF THE REGISTRY'S DATA:

234) Independent re-abstraction is not done.

235) Independent re-coding of a sample of cases is not done at present. One person is doing the coding and the computer-programme only permits certain combinations. Formerly one person would do the coding, another enter the codes, and a third person control.

236) Independent duplicate data entry is not done.

237) Input logical checks is used - see below

238) Use of test cases is not done

239) Proof-reading of coded notification is not done any-more.

240) Summary tabular frequency checks is used before publication of data.

241) Incidental autopsy finding is calculated.

242) Cancer cases from Death Certificates Only (DCO) were 2.6% in 1993.

243) Mortality/incidence ratio was calculated in 1992 and published for each site in the incidence-book.

244) Stability of rates over time has once been estimated as the ratio maximum / minimum incidence.

245) Comparison with neighbouring registries is done in Nordic projects.

XXIII WEAK POINTS

246) OVER- UNDERREPORTING:

a) Malignancies which may be under-reported. Non-solid tumours, intracranial tumours in older people who are not investigated. Before 1990 there was a steady increase in the incidence and mortality of prostate cancer. The percentage of localised prostate cancer was constant, but after the introduction of PSA the localised percentage has increased. Furthermore there used to be a high frequency of autopsy, but from 1970 the incidence has been decreasing in probably due to the decrease in autopsy frequency.

b) MALIGNANCIES WHICH MAY BE OVER-REPORTED: None can be pointed out as being over-reported, though there may be a tendency to over-diagnose pancreas tumours in the 1980’s.

XXIV CHECKS

AUTOMATIC COMPUTER-BASED CHECKS

247) Data entered for essential variables is checked

yes
Appendix 2 Norway

248) "Invalid" code for almost any variable  yes
    a) Hospital code is valid
    b) Clinic code is valid
    c) Pathology laboratory is valid
    d) Home-address is valid
    e) ICD7 code is valid
    f) Basis of diagnosis is valid
    g) Slide number is valid
    h) Cancer death is valid
    i) Autopsy result is valid
    j) Permitted codes for every area

OTHER EXAMPLES OF CHECKS

DATE OF DIAGNOSIS

249) Before or equal to date death ................................................................. yes
250) Before or equal to date of post-mortem .................................................... yes
251) Before or equal to date of report ............................................................. no
252) Date of death before or equal to date of post-mortem ................................. yes
253) In case of only autopsy finding: date = date of death

TUMOUR TYPE

254) Sex compatible with site ................................................................. yes
255) Age compatible with tumour type ........................................................ no
256) Site of tumour compatible with histological type ................................. yes
257) Site of tumour compatible with code for laterality (paired organ) ........ yes
258) Site of tumour compatible with method of diagnosis ......................... yes
259) Histology compatible with method of diagnosis ................................... yes

260) THE IACR CHECK-PROGRAMME is not used.

261) MANUAL/VISUAL CHECKS: are not done.

XXV OUTPUT FROM REGISTRY

IN THE REGULAR ROUTINE PUBLICATIONS OF INCIDENCE RATES, TABLES OF RATES ARE GIVEN BY :

262) Year ................................................................. yes
263) Sex ................................................................. yes
264) Age ................................................................. yes
265) Site ................................................................. yes
266) Occupation ............................................................. no
267) Social group ............................................................. no
268) Residence – on municipality level with several years interval .............. no
269) Geographical subdivision of your territory ........................................ yes at regional and county level
270) Trends .............................................................................. yes
271) Other variable .................................................................:
    a) Number of second and multiple primaries (site, sex, med.region) .......... no
    b) Percentage cytologically and histologically verified ......................... yes
    c) Cases found incidentally at autopsy (site, sex) ................................ no
Appendix 2  Norway

_IN THE REGULAR PUBLICATIONS, THE FOLLOWING STANDARDS ARE USED:_

272) World Standard .......................................................................................................................... yes
273) European Standard and year (was used formerly, and is available) ........................................... no
274) Own Standard (rarely) .............................................................................................................. no
275) Other ........................................................................................................................................ no

_THERE ARE NO REGULAR/ANNUAL ROUTINE PUBLICATIONS OF MORTALITY RATES BUT THEY ARE AVAILABLE_

276) Evaluation of incidence trends is carried out.
Appendix 2 Sweden

BASIC CHARACTERISTICS OF THE REGISTRY
SWEDEN date: April 18th 1997

1) Centre for Epidemiology
2) National Board of Health and Welfare
3) SE-106 30 Stockholm
4) Sweden
5) Tel: +46-8-5555 30 00/+46-8 5555 34 43
6) Fax: +46-8-5555 33 27
7) e-mail: cancerregistret@sos.se /lotti.barlow@sos.se web-site: www.sos.se/epc

Persons interviewed:
Name: Lotti Barlow Position: Assistant Director, Sociologist Abbreviation: LB
Gunn-Marie Tranberg Co-ordinator for coding-questions and Cancer archive GMT

I THE REGISTRY

8) The registry is population-based and covers: All of Sweden

9) The population includes all the people in the area who are entered in the official population statistics and have been given a personal identification number.
   a) Immigrants do get this ID even before they have received resident permit.
   b) Refugees who are living in camps are excluded.

10) Special registries: Management (vård)-program registries etc. are not part of the Central Cancer registry.

II DEMOGRAPHICAL INFORMATION

11) An incidence publication is made every year on national and regional level.

   Changes
12) There has been no changes in the population covered.

The resident mean population in the area covered by the registry was in 1998
13) a Males: ................................................................................................................. 4 373 766
14) b Females: ............................................................................................................... 4 477 208
15) c Total: ................................................................................................................. 8 850 974

16) The population figures are exact and the numbers are given in one-year age groups - once a year - at the turn of the year, from Statistics Sweden (SCB) - in Stockholm, handling demographic data also on individual level.

17) Population figures used for incidence calculation are the midyear average figures.

18) The Health system:
   a) Primary ward, run by general practitioners in "healthcenters" (vårdcentraler)
   b) "Länselssjukehus" - minor hospital
   c) "Länssjukehus" - "County"-hospital
   d) "Regional hospital"

19) The hospitals are governed by the local authority - for the county ("Landstinget"), which is also responsible for collecting taxes for that purpose.
Regarding population data the following are available in the registry

<table>
<thead>
<tr>
<th></th>
<th>available</th>
<th>used</th>
</tr>
</thead>
<tbody>
<tr>
<td>20</td>
<td>Sex in one-year age groups on parish register level</td>
<td>x</td>
</tr>
<tr>
<td>21</td>
<td>Sex in five-year age groups</td>
<td>x</td>
</tr>
<tr>
<td>22</td>
<td>There is no information on occupation in the cancer registry (CR), but the information is available in the census data. The &quot;Cancer-environmental registry&quot; is a linked registry between the cancer registry and the census in 1960 and 1970.</td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>Information on religion</td>
<td>-</td>
</tr>
<tr>
<td>24</td>
<td>For &quot;ethnic group&quot; and &quot;place of birth&quot;: From Statistics Sweden there is information available on &quot;country of birth&quot; – or if born in Sweden on &quot;county of birth&quot; as well as on &quot;parents country of birth&quot;</td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>The urbanity-degree was given from the Central registry on municipality level and was the only information given</td>
<td>x</td>
</tr>
<tr>
<td>26</td>
<td>Information about the geographic distribution is given in a number with 6-digits: two first derived from county, two middle from municipality, two last from the parish registry (the smallest administrative unit (&quot;församlingen&quot;)</td>
<td>x</td>
</tr>
<tr>
<td>27</td>
<td>Each address has a land registry-number (koordinatsystem – GIS)</td>
<td>-</td>
</tr>
</tbody>
</table>

However the information is available in Statistics Sweden.

### III HISTORY

28) The registry started operating in 1958 in Stockholm, and data for cancer registration were collected centrally. Between 1974 and 1980 the data from 1958 and onward together with the data collection were gradually transferred to the Regional Tumour registries. The Regional Tumour Registries have since the transfer sent the collected and coded data to the central registry on an annual basis.

29) The registry can present population based data from 1958 on a national level and from 1968 on a regional level.

30) Direct access to the population registry secures updating of the status including death and immigration / emigration can be obtained.

31) It is not relevant to be able to include/exclude cancers from other registries, for the time being.

32) There have been CHANGES IN HOSPITAL PROCEDURES: e.g. needle-biopsy for prostate cancer, which may have caused an increase in the frequency of clinical diagnosis, however at the same time the autopsy-rates have decreased and caused the post-mortem frequency of prostate cancer diagnosis to decrease, consequently the influence of either cannot be detected. Cervix and breast screening have on the other hand influenced the incidence rates at the time when they started to be implemented.

33) REPORTING OF CANCER CASES has always been compulsory for pathology- and hospital departments. Since 1985 it has also been compulsory for haematological laboratories and private practitioners. This led to no change in incidence, though the diagnosis of haematological diseases became based on microscopical investigation in more cases.
34) At present reporting of tumours is compulsory for:
   a) Any medical Doctor employed privately or in a hospital department, who has diagnosed the tumour disease clinically or microscopically.
   b) Any medical Doctor writing a tumour disease on the death-certificate even if diagnosed after death.
   c) The doctor responsible for: pathological / cytological laboratories, the Forensic department, the Haematological lab., and other service departments.

35) Operation of the registry has not been discontinued at any time.

36) The registry is public so the government is responsible for the data.

37) The data belong to the National Board of Health and Welfare.

IV STAFF & ORGANIZATION

38) **EMPLOYEES:**
   - Director for the Central cancer registry
   - Coding co-ordinator
   - EDB expert for the cancer registry
   - Lay-out assistant
   - Distribution assistant
   - Pathology consultant
   - Medical consultant

39) The cancer registry is co-ordinating the data from the six regions, doing statistics and development of registration methods and material (e.g. updating guidelines, classification, changes of coding-numbers)

The following departments/institutions are working closely with the registry:

40) The Centre for Epidemiology (EPC) is a department of The National Board of Health and Welfare in Sweden. Within EPC there are different registries:
   a) the Cancer Registry
   b) the Cancer Environment Registry
   c) the Medical Birth and Malformation Registry
   d) Abortion and sterilisation statistics
   e) the Hospital Discharge Registry
   f) the Cause of Death Registry (Production at Statistics Sweden)
   g) The research and development unit also situated in the Centre for Epidemiology (EpC) are handling evaluation and health care planning

41) The Department of Medical Epidemiology is placed at Karolinska Institute, Stockholm

42) There is close co-operation with the regional registries which are all delivering data to the central registry

43) The registry is physically located with the National Board of Health and Welfare

**SOURCES OF FINANCE:**

44) Registration of cancer is financed by the government.

45) Research projects are financed from funds, after application and acceptance of the project.
CODING

46) Coding of site and morphology is carried out at the regional registries.

47) Other special activities are organisation of coding meetings (see also below).

48) The coding / classification of neoplasms to site and morphology is carried out by the regional coding assistants. They are medical secretaries, who have received an additional training in the registry as well as at The National Board of Health and Welfare.

49) Information about changes in coding procedures are sent to all regional registries in the coding instructions from the Central registry.

50) The final supervision of coding and solving of coding problems is done by a Pathologist (Jan Ericsson). Furthermore Torgil Möller from the registry in Lund and Per Leuner from Umeå is acting as consultants, some coding problems are discussed at the annual registry meeting, led by Jan Ericsson.

51) Coding problems may be brought to meetings for the coding group (1 coding assistant from each region, the co-ordinator and the 2 doctors), which are held 2 times a year and organised by the Central registry. Once a year a course for all coding personnel (30 persons) is organised.

LETTERS / TELEPHONE

52) The Central registry has no contact with the reporting department, as coding is not done there.

53) The registry receives no pathological description as no coding is taking place centrally.

V REPORTING

TUMOUR REGISTRATION FROM PATIENT TO REGISTRY:

54) The patient contacts the GP, who makes some investigations and/or refer the patient to the hospital. In the hospital further investigations are carried out, and in most cases biological material is sent to the pathologist, finally the patient is referred to the relevant treatment centre.

55) The reporting is compulsory, so no fee is paid to the reporting physician or institution.

56) It is not relevant to the EpC who signs and writes the forms.

57) Linkages is carried out with the Cause of Death Registry in order to ensure that official date of death and cause of death is available in the Central registry and this information is sent to the Regional registries as well. From this linkage it is also possible to follow the number of cancer cases mentioned on the death certificate but not included in the registry.

58) Information on name and address of the reporting hospital / clinic / practitioner / or other source is also kept centrally. For each tumour only one clinic and the pathologist incl. pathology number of biopsy is recorded.

59) The registry has information which makes it possible to go back to the original records.

60) Patients do not have their "own" GP, and are free to go, wherever they want, but the cheapest is to go to the local clinic (vårdcentral).
VI SOURCES

The registry regularly receives reports only from the Regional tumour registries, and therefore all the places mentioned below are not relevant.

61) Hospitals - Not relevant
62) Medical records department - Not relevant
63) Outpatient clinics - Not relevant
64) Hospices - Not relevant
65) Long stay hospitals for the elderly - Not relevant

Laboratories (in or outside hospitals)
66) Pathology - Not relevant
67) Haematology - Not relevant
68) Autopsy reports - Not relevant
69) Institute of forensic medicine - Not relevant

70) Death certificates are not used as source for tumour registration, but tumours reported on death certificates and not recorded in the registry are reported separately in the incidence publication.

Other
71) General practitioner - Not relevant
72) Specialist practitioner - Not relevant
73) Screening programmes - Not relevant

FORMS RECEIVED
74) Notification forms from pathologists are not received
75) 2% (1998) of the cancer cases are only diagnosed clinically. Notification form from clinicians are not received

76) The information about cancer is received from the Regional registries

THE REGISTRY RECEIVES (OR HAS REGULAR ACCESS TO) COPIES OF THE FOLLOWING FOR CANCER PATIENTS:
77) Medical records ................................................................. no
78) Pathology reports ................................................................. no
79) Autopsy reports ................................................................. no
80) Discharge letter ................................................................. no
81) Death certificates are not received but are available from SCB. .............................. yes
82) Radiotherapy reports ............................................................. no
83) Hospital information system .................................................... no
84) The staff at the registry does not visit any clinics or hospitals.
85) The copies of notifications have been received from the Regional registries and stored at the National registry until 1986, except Uppsala which continued to send the notification forms until 1995.

86) DEFINITION OF PLACE OF "RESIDENCE":
The address as it is written in the parish register - (which is the permanent address -bopæl).
Before 1969 this information was only detailed down to municipality-level.

87) Immigrants and/or non-residents are given a personal registration number after one year. At that time the date of immigration is available, and the country of origin can be found by matching with SCB.

88) Refugees have a temporary personal identification number, and are not registered, but are kept separately at the regional registries.

89) Special subgroups/minorities in the population cannot be recovered (e.g. færinger/lapper/border population, etc), however in 1973 the medical Birth registry was established, and from that it is possible to get information about the place of birth.

90) Tumours in patients who are not permanent residents of the registry territory are not registered.

91) Swedes working abroad are only included if resident in Sweden.

92) Information on tumours in patients registered in another region than the region they belonged to at the date of diagnosis is transferred from the registering region to the relevant region. THE DATA ARE RECEIVED IN THE CENTRAL REGISTRY ONCE A YEAR when the coding is completed and checked.

VII INFORMATION RECORDED

93) The coding of data - not relevant, as coding is done at the regional registries.

94) The processing of data - not relevant, as above.

95) Two or more notifications - not relevant, as above

96) The notification forms - not relevant, as above

97) COMPUTERIZED CASE RESOLUTION - is not carried out, but "legal/permitted" combinations are used in checking (see below).

VIII THE PERSON

98) THE SOURCE FOR INFORMATION ON THE PERSON is the Central Personal Registry (CPR), which assigns a Personal registration number to each resident in Sweden

99) The person is not assigned another number in the registry

100) THE UNIQUE PERSONAL REGISTRATION NUMBER is constructed of: 2 digits for the century + 10 digits, which are composed of: 2 digits for year, 2 digits for month and 2 digits for day of birth; The next 2 digits formerly gave the place of birth, 1 digit gives the sex: the odd for male and the even for female and the last digit is the control number for the index number.
Appendix 2  Sweden

101) Immigrants are assigned a CPR number when they become residents.

102) The number does not any longer indicate where the person was born nor if he/she belongs to any minority and it does not indicate ethnicity.

103) The Regional cancer registries receive updated information on electronic media from the CPR once a year and can in this way follow the civil information on every person: e.g. address, death, etc. The information at the time of diagnosis is however kept, so the civil history of the patient may be followed. The registry has had access to these data from the start of the registry, though in the period up to 1969 only on county-level and for census-years. The cancer registry is linked to the Cause of Death registry, but the cancers found by this method are not included in the incidence calculation. Date of death is given with century/year/month/day (2 digits for each) from the Cause of Death Registry. The cause of death is ranked as the 1. underlying cause of death and 2. the contributory cause of death.

NAMES OF PATIENT

104) The patients full name is given electronically from the ID number.

105) None of the following are registered: Maiden name / Father's name / Mother's name

106) The ID number of the next of kin: The partners or the mothers - is available from the "Second generation registry" at Statistics Sweden.

RESIDENCE/ADDRESS AT THE TIME OF REGISTRATION

107) The code for the patients address is registered. It is constructed of 2 digits for county, 2 digits for municipality and 2 digits for parish (församling).

108) This information includes: County, municipality, parish register.

109) Change of address is given from the CPR annual updating, but the address at the time of diagnosis is kept in the regional registries.

110) The age at incidence date is calculated from CPR

111) The persons nationality (e.g. French, Danish) is not registered.

112) The year of immigration is given from the CPR - and will be linked into the registry. From the CPR-number it is possible to see if the patient is registered in the correct Regional registry, as well as in the cause of death registry or has immigrated.

113) The nationality of father and/or mother are available.

114) Marital/civil status at diagnosis is not registered but will become available. This gives the following result for availability of the categories:
   a) Married - no
   b) Separated - no
   c) Divorced - no
   d) Widow/widower - no
   e) Cohabitation - no
   f) Single - no

115) Death - yes

116) Number of live births and categories (actual number) is available from the fertility registry or the medical birth registry

117) Religion - no

118) Ethnic groups - no

119) Race - no
Information on patient's education may to a certain degree be available from the cancer-environmental registry from the censuses and also from the “Education registry” at SCB.

Occupation may be known from the cancer-environmental registry and from the censuses, but it is not very specific as the same titles are used in different occupations (e.g. foreman).

Special enquêt studies are giving better information when occupation is to be included in a study.

Social class or socio-economic status is available from the cancer-environmental registry.

Information about patient's exposure to carcinogens is only available from the cancer-environmental registry and special studies.

IX  INCIDENCE DATE

DATE OF DIAGNOSIS (LEVEL OF DETAIL):

The date is recorded as the century (2 digits), year, month and day of diagnosis.

The DATE OF DIAGNOSIS is defined as the earliest date for establishing the tumour diagnosis. The date of diagnosis is thus not the date when the suspicion arose.

A tumour first notified on a death certificate is not traced to get earlier information. The Doctor signing the death certificate is not asked to report the case.

Cases from the death certificate notes are not registered as "Death certificate only" (DCO), but the data are available e.g. in the incidence publication table A1 and A2.

For a patient known from autopsy only, the incidence date is the date of death.

X  BASIS OF DIAGNOSIS

METHODS

The "most valid basis" ("histology") is coded and is having the following ranking order:

a) Histology of primary / bone marrow / metastases (from biopsy/operation/autopsy)

b) Cytology (expectorate, aspirate etc.) / Haematology.

c) No histology, cytology, marrow or bloodtest.

d) No histology or cytology (e.g. clinical investigation / X-Ray / operation-autopsy without histology) is not ranked, but if possible the patient case story is checked.

XI  CLASSIFICATIONS

classification(s)

a) From 1958: topography was coded according to ICD 7

b) morphology was coded according to C24

c) From 1987: topography was coded according to ICD 9 and translated into ICD 7

d) morphology was coded according to C24

e) From 1993: Topography was coded according to ICDO-2/10 with a few exceptions, and translated into ICD 9 and ICD 7

f) morphology is coded according for the SNOMED / ICDO-2 code and translated into C24
132) **Exceptions to the classification rules:**

Topography according to **ICDO-2** where the following are coded according to **ICD 10:**
- Malignant melanoma in the skin: C43
- Hodgkin’s lymphoma: C81
- Follicular non-Hodgkin Lymphoma: C82
- Diffuse non-Hodgkin Lymphoma: C83
- Peripheral and cutaneous T-cell lymphomas: C84
- Malignant lymphoma, NOS, or diffuse: C85 (see special list in the incidence publication as ICD 10 also differs slightly from the classification)
- Immunoproliferative diseases: C88
- Plasma cell tumours: C90
- Lymphatic leukaemia: C91
- Myeloid leukaemia: C92
- Myelodysplastic syndrome: D46
- Monocytic leukaemia: C93
- Other specified leukaemia: C94
- Leukaemia, NOS: C95
- Neoplasma malignum telae lymphatica et haematopoeticae/ other and unspecified tumours in lymphoid and haematopoietic tissue: C96 / D45 / D47 / D76

These are all transformed to the ordinary ICD 7 code: 200x - 209x, where each group contains the types of lymphoma / leukaemia as defined in Sweden (see table W2 in the Incidence publication)

133) **TOPOGRAPHY (PRIMARY TUMOUR)** is defined according to the clinician’s assessment. The code is chosen according to specificity

134) Topography codes may be changed according to what is most relevant

135) **MORPHOLOGY** is defined according to pathology description. The code is given from the pathologist and coded according to SNOMED (ICD-O2) / C24

136) Morphology may be changed if a histological description is received after a cytological description, and it is more specific.

137) **BEHAVIOUR OF TUMOUR** is given by the PAD. The code is chosen so that the most malignant is coded (behaviour 3 > 2 > 1 according to ICD-O2)

In C24: 1 = benign; 3 = uncertain whether benign or malignant; 4 = in situ; 5 = localised tumour; 6 = malignant

138) The behavioural code: Change from a precancerous change (cancer in situ) to invasive cancer will in most cases mean a change where the invasive tumour has to be counted as a new primary tumour - however no time limit for registering a new tumour was mentioned (see also comments from regional registries).

139) Squamous cell carcinoma on the cervix causes a new tumour to be registered when it changes from in situ to invasive tumour (in the regions if more than 1 year has passed) - an important exception is transitional cancers in the urinary tract system, where no new tumour is registered. (rule 1 in principles for registration of primary tumours etc.).

140) List of reportable tumours:
   a) All definitely malignant neoplasms (e.g. carcinoma, sarcoma, malignant lymphoma, leukaemia and malignant teratoma).
   b) Carcinoid tumours of digestive organs, granulosa tumours of the ovary, thymomas, adamantinomas and chordomas.
   c) Histologically benign tumours of the central nervous system and meninges, transitional
appendix 2 sweden

cell papillomas of the urinary tract, all hormonal active tumours of the endocrine glands (except the thyroid) and the entero-chromaffin and neuroendocrine systems.

d) Precancerous lesions of lip, mouth, larynx, bronchus, trachea, cervix uteri, skin, vulva and vagina, gastro-intestinal polyps with suspected malignancy, bronchial adenomas, atypical epithelial proliferations of the breast (carcinoma in situ type) and adenoma phylloides, precancerous endometrial lesions, hydatidiform moles of placental tissue, and ovarian cystadenomas of borderline type.

141) List of tumours included in incidence publications:

a) Diseases mentioned under 140 A-C are included in the incidence publication, although a number of the tumours listed under C are considered not to be "infiltrating and metastasising" and are therefore also listed separately (papilloma, urinary tract; histologically benign tumours of the central nervous system; histologically benign tumours of endocrine glands; low grade fibrosarcoma (incl. dermatofibro-sarcoma protuberans).

b) The reportable tumours mentioned under 140 D are not included in the cancer incidence, but are tabulated separately. Basaliomas have not been registered.

conversion of icd:

142) Conversion tables from one coding system to another are created centrally in stockholm (centre for epidemiology) continuously by a pathologist, but in cooperation with the coding-group. From the centre the set-up and changes are distributed to all the regional registries; furthermore the conversion tables are given in the annual "incidence book".

the purpose of the conversion of icd classification is:

143) To ensure comparability with old data.

144) To a certain degree to make data comparable with data from other registries (e.g. eurocare)

diagnosis recorded in addition to the cancer diagnosis coded by the registry:

145) Admission diagnosis - not relevant.

146) Discharge diagnosis - not relevant.

147) Cause of death registry is available on the electronic net in the centre for epidemiology (which from 1st january 1996) is responsible for that registry, though the coding takes place at the statistic sweden (scb)

148) Autopsy diagnosis is available from the cause of death registry

149) Other diagnosis (e.g. aids / hepatitis icd-10: b21) not relevant.

malignant diseases routinely excluded when reporting data from the registry:

150) Formerly basal cell carcinoma of the skin were excluded except for mixed basal cell carcinoma (8094/3). A trial to collect basal cell carcinoma has been in operation since 1998 for one region in sweden. the notification is only taken from the pathology lab. from year 2002 this will be the case for the whole of sweden.
THE TUMOURS BELOW are recorded and included in incidence data as shown

<table>
<thead>
<tr>
<th>Tumour type</th>
<th>Record yes</th>
<th>Record no</th>
<th>Included yes</th>
<th>Included no</th>
</tr>
</thead>
<tbody>
<tr>
<td>151) Benign brain tumours</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>152) Pituitary gland</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>153) Carotid body tumour</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>154) Benign bladder tumours (papilloma)</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>155) Intraductal carcinoma (8500/2) in the breast</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>156) Carcinoma in situ in the breast, other than above</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>157) Borderline tumour in the ovary</td>
<td>x</td>
<td>x (only granulosa cell tumours)</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>158) Carcinoma in situ in testis</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>159) Chromaffinoma (8700/0) of the adrenal glands</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>160) Argentaffinoma (8241/1)</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>161) Chordoma (9370/3)</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>162) Invasive mole (9100/1)</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>163) Precancerous lesions in the cervix</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
</tbody>
</table>

164) Other benign or precancerous lesions coded to or included with categories of malignant tumours are mentioned above.

165) Clinical stage / extent of tumour will be recorded from year 2002. Until then several benign and precancerous lesions can be tabulated: lip and mouth: larynx, trachea and bronchus; epithelial lesions of skin; malignant melanoma in situ of skin; vulva and vagina; gastro-intestinal polyp with precancerous change; breast and adenoma phyllodes; CIS ("stage 0") of uterine cervix; Hydatidiform mole; precancerous endometrial change; ovarian cystadenoma with borderline malignancy; preleukemia.

XII MULTIPLE PRIMARIES

166) The rules used to code multiple cancers in the registry

Rules are given from the Central Cancer registry (National Board of Health and Welfare). Until 1993 the regional registries followed different practice in registration of multiple cancers. The tumours affected by this are: breast cancers; skin cancers; colon cancers; urinary bladder tumours; (see appendix for details).

a) Rules for astrocytoma developing into glioblastoma were not discussed
b) The registry counts tumours, not patients.

167) Tumours with the same morphology on each side are coded as two tumours, and counted as two when calculating incidence rates, provided they are not metastases one from the other.

168) Tumours with different morphology on each side are coded as two tumours, and counted as such.
169) Tumours with different behaviour (e.g. intraductal carcinoma in left breast and invasive duct carcinoma in right breast) are coded as two tumours, but counted as one tumour.

XIII TREATMENT

170) TREATMENT is not recorded.

XIV FOLLOW-UP and TRACE-BACK

A By follow-up we mean that the registry follows up registered cases to obtain information about e.g. recurrence, treatment, or death.

B By trace-back we mean, that the registry actively attempts to obtain further information about a tumour, (e.g. first notified on a death certificate, or if the information on a patient is not satisfactory for other reasons) in order to complete the coding of the tumour recorded.

Active (a) or passively (r) receipt of data from the following sources for follow-up and/or trace-back - this information is not relevant as EpC is receiving the end results from the clinics

<table>
<thead>
<tr>
<th>Hospitals</th>
<th>trace-back</th>
<th>follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>171) Clinical departments</td>
<td></td>
<td>p</td>
</tr>
<tr>
<td>172) Medical records</td>
<td></td>
<td></td>
</tr>
<tr>
<td>173) Outpatient clinics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>174) Hospices</td>
<td></td>
<td></td>
</tr>
<tr>
<td>175) Long stay hospitals and homes for the elderly</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Laboratories (in or outside hospitals)

<table>
<thead>
<tr>
<th>Laboratories</th>
<th>trace-back</th>
<th>follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>176) Pathology, general</td>
<td></td>
<td></td>
</tr>
<tr>
<td>177) Pathology, specialized</td>
<td></td>
<td></td>
</tr>
<tr>
<td>178) Haematology</td>
<td></td>
<td></td>
</tr>
<tr>
<td>179) Autopsy reports</td>
<td></td>
<td></td>
</tr>
<tr>
<td>180) Institute of forensic medicine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>181) Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Death certificates                         |            | p         |
| General practitioners                      |            |           |
| Specialist practitioners                   |            |           |
| Health insurance                          |            |           |
| Screening programmes                       |            |           |

Administrative sources

| Central population registers               |            | p         |
| Central medical registers (e.g. hospital information systems) |            |           |
| Other                                      |            |           |
XIX SCREENING PROGRAMMES

<table>
<thead>
<tr>
<th>Type and year of start</th>
<th>age-group</th>
<th>how often</th>
</tr>
</thead>
<tbody>
<tr>
<td>190) cervix:</td>
<td>determined in the regions</td>
<td></td>
</tr>
<tr>
<td>191) breast:</td>
<td>determined in the regions</td>
<td></td>
</tr>
<tr>
<td>192) colon:</td>
<td>none</td>
<td></td>
</tr>
<tr>
<td>193) melanoma:</td>
<td>determined in the regions</td>
<td></td>
</tr>
<tr>
<td>194) prostate:</td>
<td>determined in the regions</td>
<td>-</td>
</tr>
</tbody>
</table>

195) Dependent on the regional registries how co-operation with the screening programmes is carried out.

XX USE OF COMPUTER

196) The software used in the registry has been developed locally using the SAS programme. It used to be on mainframe, but is now on PC - PC network.

XXI CONFIDENTIALITY

The registry observes the following set of rules on confidentiality:

197) The information is given on the condition that the regulations in the law on confidentiality 1980:100 14 chapt 9§ are followed
   a) The material may only be used the project specified in the application.
   b) Personal information must be kept so that unauthorised persons cannot gain access to the information
   c) Direct contact to the person in question, relatives etc. may not be done by you without permission from the medical Doctor in charge of the ward or the chief Consultant at the current department
   d) At the end of the project all material containing personal data must be destroyed. Concerning data-media see also the regulations from the Data-inspection
   e) Publication of material must be done in such a way that no individual can be identified.

198) Current regulations in the law concerning data 1982-07-01 must be followed. See also in the instructions on adaptation of the law on data.

199) When ordering personal identifiable extract on a data-medium (diskette) the permission from the data-inspection must be enclosed. As the database of the cancer registry continuously is changed continuously we cannot keep these data-extractions updated.

200) In case of questions concerning annulment or quality of the delivered material the cancer registry is to be contacted first.

201) The Centre for Epidemiology presupposes also that the registry is mentioned as source in all prospective publications. We therefore ask you to send us a copy of the publication (or equivalent) when the work is ended.

202) The signing of the order in the application is at the same time a confirmation that you have participated in and accepted the conditions, listed above, for handling the material and the reservations given for publication of the given information

203) The registry is legally permitted to link with other files.
This is regulated by:

204) By the “Lag om hälsoedataregister” (1998: 543) (law of health-data-registry)
205) In certain cases also by the ethical committee
206) In principle identifiable information cannot be deleted in the registry
207) AN INDIVIDUAL CAN LEGALLY OBTAIN ACCESS TO DATA ABOUT HIMSELF/HERSELF IN THE REGISTRY. Patient requests are handled by EpC which is sending the print out to the person concerned.
208) An individual cannot refuse to be included in the cancer registry
209) An individual does not have to be asked / informed before being included in the cancer registry

THE FOLLOWING CAN GET ACCESS TO THE CANCER REGISTRY DATA:

210) - On case by case basis - anonymously there are no special restrictions
211) - On case by case basis - with identifying information:
   a) The scientist according to the rules described above
   b) The patient as described
212) International release may only be done after making the person anonymous; e.g. by giving serial numbers to the persons in international studies, and having the key only in the country of origin.

XXII QUALITY CONTROL

COMPLETENESS OF COVERAGE:

213) The registry is matched against the Cause of Death Registry.
214) The number of forms from the pathological departments cannot be followed as the registry only receives the data-material from the regional registries and no forms.
215) The number of forms from the clinical departments - as above.
216) Target directed registries: quality registries and study-registries are used if they are covering the whole country and started from the Central registry.
217) Disease index / Hospital discharge registry is used for quality studies.
218) Outpatient logs - not used
219) Pathology department logs - not used.
220) Comparison with patients enrolled in trial protocols is done.
221) Random sampling of patients admitted to hospital and scrutiny of records for missed cases (capture - recapture) is not done at the moment, but will be done for quality studies.
222) Surveillance of numbers of registrations from each source is not done.
Completeness of Detail:

223) The average number of sources/notifications per case is not calculated

224) The number of sources are not known over the years

Figures for a Recent Year for the Following:

225) Figures for "unknown primary site (199 in ICD7)" were in 1998 = 1671 for the whole country which equals 3.8%.

226) Percent of "age unknown" - irrelevant

227) Percent of "treatment unknown" - treatment is not recorded

228) Percent of "stage unknown" - stage is not recorded, but will be from year 2002.

229) Histological verification (98% in 1998) is calculated.

230) Percent of "basis of diagnosis unknown" - irrelevant

231) Percent of "place of birth unknown" - not studied.

232) Year/period to which these figures apply: 1998.

233) The most recent year published for the country is 1998. Since year 2000 the publications are only published on the internet www.sos.se.

Methods Used to Maintain Quality Control of the Registry’s Data:

234) Independent re-abstraction is dependent on the regions and is not done centrally.

235) Independent re-coding of a sample of cases is dependent on the regions, not done centrally

236) Independent duplicate data entry of a sample of cases is dependent on the regions, is not done centrally.

237) Input logical checks is used - see below

238) Use of test cases is not done

239) Proof-reading of coded notification is not done centrally but the following is done: checks:
   a) That the regions have used the same layout and filled in the same squares: Some minor important variables show differences.
   b) The tumours are given numbers and the persons with unusual many tumours registered totally during the years of diagnosis are checked
   c) Interregional duplicates and other suspected duplicates are picked up and checked.
   d) The likelihood in the coding is checked: ICD7 against C24 and for the new coding: ICDO/10 against new SNOMED, furthermore that the BEN (marking of benign) is put in the correct relation against these. Relationship control of sex against ICD-code.
   e) Lists containing wrong or suspicious posts are sent to the regions to be checked and eventually changed - as all changes are done at regional level. Centrally only openly absurdities are excluded in expectation of the corrections from the regions received together with the data from the next year. (app from Pauli Vaittinen 1997-04-17)
Summary tabular frequency checks is not used, but the Medical Director (TM) checks topography against morphology for rare combinations and from this checklists for the regions are produced.

Incidental autopsy finding (2 - 3% in 1998) is calculated.

Cancer cases from Death Certificates Only (DCO) are not included in the incidence rates, but the number of cases found as DCO are calculated, but not checked, and was in 1997: 2337 cases = 5,5% of the total number of new cases. As they are not checked the number of missed cases is lower, as shown by Brittta Mattsson in 1984 (Brittta Mattsson, Cancer Registration in Sweden, academic thesis, Karolinska Institute 1984) (See also "Cancer incidence in Sweden 1998" p.10-11)

Mortality/incidence ratio - highest/lowest site is not used as quality control, but is calculated for teaching purposes and shown in "Cancer i siffror".

Stability of rates over time is followed.

Comparison with neighbouring registries is done through the Nordic projects.

**XXIII WEAK POINTS**

Malignancies which may be under-reported:

i) Leukemias, Polycythemia and Myelofibrosis may all be under-reported

ii) Prostate cancer may be under-reported as the autopsy rate is decreasing, however at the same time the use of specific immunological tests as well as needle biopsy is increasing and thus the rate is influenced in the opposite direction.

Malignancies which may be over-reported:

iii) In 1990 there was a malignant melanoma campaign - in 1995 a sun campaign

iv) Furthermore there are different screening activities, which may influence the figures and even cause over-reporting.

**XXIV CHECKS**

**AUTOMATIC COMPUTER-BASED CHECKS** (see app for details)

Data entered for essential variables is checked

"Invalid" code for almost any variable, e.g.:

a) Personal ID - number and name is checked against "SPAR"

b) The coded topography according to ICD7/ICD9 is checked against the pathology/cytology code according to C24.

c) ICD on 3-digit level is checked against permitted combinations of C24, first on 2-digit level, then on 3-digit level.

i) The regions are using slightly different methods, as Stockholm checks according to the new coding ICDO/10 and the new SNOMED, which has been adjusted from 1993.

d) BEN, code for benign, is coded or filled in automatically from the topography and the C24-code.

e) Further logical checks are carried out using the variables basis of diagnosis and sex.

**DATE OF DIAGNOSIS**

After or equal to start of cancer registry
Appendix 2 Sweden

250) After or equal to date of birth yes
251) Before or equal to date death yes
252) Before or equal to date of post-mortem yes
253) Date of death before or equal to date of post-mortem yes

Tumour type

254) Sex compatible with site yes
255) Age compatible with tumour type no
256) Site of tumour compatible with histological type yes
257) Site of tumour compatible with code for laterality (paired organ) not mentioned
258) Site of tumour compatible with method of diagnosis yes
259) Histology compatible with method of diagnosis yes
260) The IACR check-programme is not used.

261) Manual/visual checks: see above

XXV OUTPUT FROM REGISTRY

In the regular routine publications of incidence rates, tables of rates are given by :

262) Year yes
263) Sex yes
264) Age yes
265) Site yes
266) Occupation no
267) Social group no
268) Residence no
269) Geographical subdivision of your territory yes at regional and county level
270) Trends yes
271) Other variable
   a) Basis for diagnosis yes
   b) Age specific rates yes
   c) Cases found incidentally at autopsy (site, sex, med.region) yes
   d) Number of second and multiple primaries (site, sex, med.region) yes
   e) Percentage cytologically and histologically verified yes

IN THE REGULAR PUBLICATIONS, THE FOLLOWING STANDARDS ARE USED :

272) World Standard yes
273) European Standard and year no
274) Own Standard Sweden 1970
275) Other no

There are no regular/annual routine publications of mortality rates but they are available

276) Evaluation of incidence trends is carried out
Appendix 2  Sweden
BASIC CHARACTERISTICS OF THE REGISTRY

Gothenburg  date: May 20th 1997

1) Oncological Centre for the Western Health Care Region
2) Sahlgrenska University Hospital
3) S-413 45 Gothenburg
4) Sweden
5) Tel: +46-31/ 200550
6) Fax: +46-31/ 209250
7) e-mail: mail@oc.gu.se

Persons interviewed:
Name: Position:  Training/Degree  Abbreviation:
Erik Holmberg  Systems Analyst      EH
Gunnel Persson  Systems Analyst     GP

I THE REGISTRY

8) The registry is population-based and covers: The Western Health Care Region.

9) The population includes all the people in the area who are entered in the official population statistics that is have been given a personal identification number.

10) Special registries - management-programmes:

    a)  Breast cancer (1)
    b)  Breast cancer in situ
    c)  Bladder cancer (1)
    d)  Corpus Uterus cancer (1)
    e)  Vulva/vagina cancer (1)
    f)  Hodgkin lymphoma (2)
    g)  Brain tumours (glioma)(1)
    h)  Lungcancer (2)
    i)  Malignant melanoma (1,2)
    j)  Multiple myeloma (3)
    k)  Non-Hodgkin lymphoma (1)
    l)  Ovary cancer (1)
    m)  Prostate cancer (1)
    n)  Midgut carcinoid (3)
    o)  Tumour diseases in children (2,3)
    p)  Rectum cancer (1)
    q)  Oesophagus cancer (1)
    r)  Ear-Nose-Throat cancer registry (2)
        • (1): regional programme
        • (2): national programme
        • (3): international programme

The data from these management-programmes are owned by special groups, who decide who may gain access to the data - it is therefore necessary to approach the management-programme-group if the more detailed data from the programmes are wanted.
II DEMOGRAPHICAL INFORMATION

11) An incidence publication is made every 5 years on county and on regional level.

12) A few parishes have been put together and other changes may come if some of the municipalities are dropped.

The resident population in the area covered by the registry was in 1994 (from Cancer Incidence in Sweden 1994)

13) Males: .................................................................................................................... 811508
14) Females: ............................................................................................................. 825776
15) Total: ............................................................................................................. 1637284

16) The population figures are exact for the years 1960, 1965 and for every year since 1968.

17) Population figures used for incidence calculation are the average population figures on 31st of December in two successive years.

18) The Health system:
   a) Primary ward, run by general practitioners in "healthcenters" (vårdcentraler)
   b) "Lånsdelssjukhus" - minor hospital
   c) "Länssjukhus" - "County"-hospital
   d) "Regional hospital"

19) The hospitals are governed by the authority for the county ("Landstinget"), which is also responsible for collecting taxes for that purpose.

Regarding population data the following are available in the registry

<table>
<thead>
<tr>
<th>Available</th>
<th>used</th>
</tr>
</thead>
<tbody>
<tr>
<td>20) Sex in one-year age groups</td>
<td>-</td>
</tr>
<tr>
<td>21) Sex in five-year age groups</td>
<td>x</td>
</tr>
<tr>
<td>22) Information on occupation in the cancer registry (CR) was very poor, so it is not collected</td>
<td>-</td>
</tr>
<tr>
<td>23) Information on religion</td>
<td>-</td>
</tr>
<tr>
<td>24) &quot;Ethnic group&quot; and &quot;place of birth&quot;,</td>
<td>-</td>
</tr>
<tr>
<td>25) The urbanity-degree</td>
<td>x</td>
</tr>
<tr>
<td>26) Information about the geographic distribution is given in a number with 6-digits: two first derived from county, two middle from municipality, two last from the parish registry (the smallest administrative unit &quot;församlingen&quot;).-at time of diagnose</td>
<td>x</td>
</tr>
<tr>
<td>27) The address as a land registry-number (koordinatsystem - GIS)</td>
<td>-</td>
</tr>
</tbody>
</table>

III HISTORY

28) The Swedish Cancer Registry was established in 1958 in Stockholm. During the 1970’s the registration was decentralised into six Regional registries. The registry for the Western Health Region started operation in 1982. The Regional Tumour Registries have since the transfer sent the collected and coded data to the central registry on an annual basis.
29) The registry can present population based data from 1958

Changes

30) The Cancer Register is linked to SPAR (population register) once a month given information on actual address, change of name, date of death etc. While the cause of death is given via the Central Cancer registry.

31) A few cases are included from the management-programme-registries, but usually the information goes the other way.

32) There have been changes in hospital procedures: e.g. Blood-PSA for prostate cancer, which may have caused an increase in the frequency of clinical diagnosis
   a) Breast screening may have influenced the incidence rates, but it seems to have reached the apex at present.
   b) Finally there was in 1990 a special "out-patient"-project, where people would be invited to get their "dots" checked (melanoma).

33) Reporting of cancer cases has always been compulsory for pathology- and hospital departments. Since 1985 it has also been compulsory for haematological laboratories and private practitioners.

34) At present reporting of tumours is compulsory for:
   a) Any medical Doctor employed privately or in a hospital department, who has diagnosed the tumour disease clinically or microscopically.
   b) Any medical Doctor writing a tumour disease on the death-certificate even if diagnosed after death.
   c) The doctor responsible for: pathological / cytological laboratories, the Forensic department, the Haematological lab., and other service departments.

35) Operation of the registry has not been discontinued at any time.

36) The registry is public so the local authorities (counties) are responsible for the data.

37) The data are reported annually to the National Board of health and Welfare but are owned by the local authorities.

IV STAFF & ORGANIZATION

38) Employees: 1 Medical director of the cancer registry
   2 Systems Analysts for the cancer registry
   3 Coding assistants for the registry
   1 Assistant for the management-programmes
   1 Office assistant

39) Research is carried out as co-operation projects where the initiative comes from outside. Furthermore several of the management-programmes are run in close co-operation with the registry and the incidence-publication is the basis for health planning and finally the registry is answering questions also for municipalities.

40) The registry is working closely with all departments within the oncologic departments - especially with those running the management-programmes, and the registry has a contact-person in each department, who takes management of missing information.
41) The registry has a board of directors with representatives from the health authorities of the five counties in the health management region. Furthermore here is a Regional Oncological Council with representatives from the different medical specialities who are concerned with the treatment of the cancer patients in the region.

42) The registry is also one of the sources for information on need of resources - in e.g. health planning see above.

43) The cancer-registry (Oncological Centre) is located in Göteborg. (Close to Sahlgrenske University Hospital).

Sources of finance:

44) Registration of cancer is financed by the counties in the region, on a proportional basis, according to population.

45) Research projects are carried out in co-operation with others and are financed from funds, after application and acceptance of the project. Other special activities are the management-programmes, though they are run independently with special assistants.

Coding

46) Coding of site and morphology is carried out at the registry, but plaintext must appear on the notification forms.

47) The coding / classification of neoplasms to site and morphology is carried out by the regional coding assistants. They are medical secretaries / nurses, who have received an additional training in the registry as well as at The National Board of Health and Welfare.

48) Supervision of coding and solving of coding problems is done by the Medical director of the registry, who is a Haematologist and Oncologist.

49) In difficult cases a pathologist or other oncologists will be contacted.

50) Some coding problems are discussed at the annual registry meeting, led by Jan Eriksson, who is a pathologist.

51) Coding problems may be brought to the coding group meetings, which are held 3 times a year and organised by the Central registry. Changes are sent to all in the coding instructions from the Central registry. (36 + 157)

Letters / Telephone

52) The registry has to request for about 1/4 of the "A" notification forms from the hospital departments, while the "B" forms from the pathological departments are usually received.

53) How many questions to the notifications need to be answered and clarified, was not discussed.

V REPORTING

Tumour registration from diagnosis to registry:

54) The patient contacts the GP, who makes some investigations and/or refer the patient to the hospital. There are oncologic clinics in 2 places while lung-tumours are managed at a third place.

55) No fee is paid to the reporting physician or institution.
56) Most often it is the medical secretary who writes the report, and the doctor signs it.

57) There in no linkages carried out.

58) Information on name and address of one reporting hospital / clinic / practitioner / or other source is kept and is only changed if a notification containing very important information is received. Also the reporting pathology department is registered. For each tumour all notifications are kept.

59) The registry thus has information which makes it possible to goes back to the original records.

60) Patients do not have their "own" GP, and are free to go, wherever they want, but the cheapest is to go to the local clinic (vårdcentral).

VI SOURCES

The registry regularly receives reports from:

61) Hospitals
62) Medical records departments - no
63) Outpatient clinics
64) Hospices
65) Long stay hospitals and homes for the elderly

Laboratories (in or outside hospitals)
66) Pathology
67) Clinical chemistry
68) Autopsy notifications
69) Institute of forensic medicine

70) Death certificates are not used as source for tumour registration.

Other
71) General practitioners
72) Specialist practitioners
73) Information is received from screening programmes if they diagnose a cancer.

Forms received
74) The registry receives forms from the pathologist on almost all cases - from the pathological department in Gothenburg a diskette is received monthly with SNOMED codes - regardless of whether it is a primary tumour or a metastasis. Forms are also received from the clinic (surgical, gynaecological, medical ward) as mentioned above, but usually the pathological forms are received first.

75) For year 1995 0,4% of the cases were "Clinical diagnosed only", 2,1% were either "clinical diagnosed only" or "X-ray diagnosed".

76) The information about cancer is recorded from the notification forms, which must be filled in plaintext

The registry receives routinely (or has regular access to) copies of the following for cancer patients:

77) Medical records - happens that a copy is received -but usually just on the last few which were not notified ............................................................... rarely
78) Pathology reports - the whole pathology description is received from 2 places but from the other places only in some cases. ................................................................. yes

79) Autopsy reports - as for the above. ................................................................. yes

80) Discharge letter ............................................................................................... no

81) Death certificates ............................................................................................. no

82) Radiotherapy reports .................................................................................... no

83) Hospital information system .......................................................................... no

84) The staff at the registry visits the oncologic clinic in connection with the management-programmes. Furthermore there is regularly held information meetings for persons sending notification of new tumours. They are told the reason for collecting the cases and what sort of statistics is produced etc. The staff are also members of the working group which produce the "Clinical guidelines for cancer management".

85) The original notification forms are stored in paper files.

86) definition of place of "residence":
    The address as it is written in the parish register - (which is the permanent address -bopæl). on the date of diagnosis.

87) Very little change of address is experienced in the region, so the registry has no special rules for Immigrants and/or non-residents except that those who are non-residents are kept in a special file

88) The registry has no experience with refugees, but would follow the same procedure as above.

89) Special subgroups/minorities in the population are not known.

90) TUMOURS IN PATIENTS WHO ARE NOT PERMANENT RESIDENTS OF THE REGISTRY TERRITORY are not registered but the forms are sent to the relevant registry - and forms are received from the other registries.

91) Concerning residents working abroad and belonging to the region –see the report for the Epi Centre.

92) The data are submitted to the Central registry in Stockholm once a year when the coding is completed.

VII INFORMATION RECORDED

93) The coding of data is done manually - notifications received on diskette are linked electronically to the regional cancer register, and afterwards checked manually.

94) The processing of data: on registration all forms on the person are consulted (e.g. in case of multiple tumours).

95) Two or more notifications are linked electronically using the unique personal identification number.

96) The tumours are not registered in the cancer registry until both notification forms (if there has to be two) are received, but the person that id-number and name (incl. address) and the type
of the notification form is registered on receipt and then checked against SPAR. No special rapid coding procedure is done as notification forms are coded within 1 month of receipt.

97) Computerised case resolution is not carried out.

**VIII THE PERSON**

98) **THE SOURCE FOR INFORMATION ON THE PERSON** is the Central Personal Registry (CPR), which assigns a number to each resident in Sweden.

99) The patient is not given another number in the registry.

100) **THE UNIQUE PERSONAL REGISTRY NUMBER** is constructed of: 1 digit for the century + 10 digits, which are composed of: 2 digits for year, 2 digits for month and 2 digits for day of birth; The next 2 digits formerly gave the place of birth, 1 digit gives the sex: the odd for male and the even for female and the last digit is the control number for the index number.

101) Immigrants are assigned a CPR number when they become residents.

102) The number does not any longer indicate where the person was born, nor if he/she belongs to any minority and it does not indicate ethnicity.

103) The cancer registry receives updated information once a month from "SPAR". Including the year of immigration. The date of death is also received with year/month/day once a month, but this information is kept separately from the information given on the notification form, so that it is possible to see both (18 + 115 + 223). **THE CAUSE OF DEATH** is recorded. The autopsy diagnosis as cause of death is registered as one of the sources for the cause of death, but the official cause of death is ranked highest.

**NAMES OF PATIENT**

104) The patients full name is registered.

105) None of the following are registered: Maiden name / Father's name / Mother's name.

106) The ID number of the next of kin is not registered.

**RESIDENCE/ADDRESS AT THE TIME OF REGISTRATION**

107) The code for the patients address at the time of diagnosis is registered.

108) The code is constructed of 2 digits for county, 2 digits for municipality and 2 digits for parish register (församling).

109) Change of address is given from the SPAR, but the address at the time of diagnosis is kept in the registry.

110) The age at incidence date is given from CPR.

111) The persons nationality (e.g. French, Danish) is not registered.

112) No further information is used from the CPR.

113) The nationality of father and/or mother is not available.
114) Marital/civil status at diagnosis is not registered, but the actual status is available from SPAR.
   a) Married - yes
   b) Separated – yes
   c) Divorced - no
   d) Widow/widower – no
   e) Cohabitation – yes
   f) Single - no

115) Death - yes

116) Number of live births and categories (actual number) no

117) Religion - no

118) Ethnic groups - no

119) Race - no

120) Patient's education - no

121) Occupation - no

122) Special enquet studies for occupation - no

123) Social class or socio-economic status – no

124) Patient's exposure to carcinogens - is available from the cancer-environmental registry

IX  INCIDENCE DATE

DATE OF DIAGNOSIS (LEVEL OF DETAIL):

125) The date is recorded as the year, month and day of diagnosis.

126) The Date of Diagnosis is defined as the earliest date written on the received records. The date of diagnosis is however not the date when the suspicion of cancer arose, but rather the date of the diagnosis (as written on the form).

127) Tumours notified only on death certificates are not traced to get earlier information.

128) Cases from the death certificate notes are not registered as "Death certificate only" (DCO) or at all, unless a notification form is received (e.g. from the doctor signing the death certificate).

129) For a patient known from autopsy only, the incidence date is the date of death.

X  BASIS OF DIAGNOSIS

METHODS

130) The "most valid basis" ("histology") is coded in the following ranking order (from the SOS-guidelines):

   a) Histology of primary / bone marrow / metastases (from biopsy/operation/autopsy)
   b) Cytology (expectorate, aspirate etc.) / Haematology. "cytology" is however not changed to "histology" unless the "histology" has changed the diagnosis.
   c) No histology, cytology, marrow or bloodtest.
d) No histology or cytology (e.g. clinical investigation / x-ray / operation-autopsy without histology) is not ranked.

XI CLASSIFICATIONS

131) classification(s) as from SOS:
   a) From 1958: topography was coded according to ICD 7
   b) morphology was coded according to C24
   c) From 1987: topography was coded according to ICD 9 and ICD 7
   d) morphology was coded according to C24
   e) From 1993: Topography was coded according to ICD-O2/10 with a few exceptions, and to ICD 9 and ICD 7
   f) morphology is coded according for the SNOMED / ICD-O2 code and C24.

132) Exceptions to the classification rules:
   Topography according to ICDO-2 where the following are coded according to ICD 10:
   • Malignant melanoma in the skin: C43
   • Hodgkin’s lymphoma: C81
   • Follicular non-Hodgkin Lymphoma: C82
   • Diffuse non-Hodgkin Lymphoma: C83
   • Peripheral and cutaneous T-cell lymphomas: C84
   • Malignant lymphoma, NOS, or diffuse: C85 (see special list in the incidence publication as ICD 10 also differs slightly from the classification)
   • Immunoproliferative diseases: C88
   • Plasma cell tumours: C90
   • Lymphatic leukaemia’s: C91
   • Myeloid leukaemia’s: C92
   • Myelodysplastic syndrome: D46
   • Monocytic leukaemia’s: C93
   • Other specified leukaemia’s: C94
   • Leukaemia’s, NOS: C95
   • Neoplasm malignum telae lymphatica et haematopoeticae / other and unspecified tumours in lymphoid and haematopoietic tissue: C96/D45/D47/D76

These are all transformed to the ordinary ICD 7 code: 200x - 209x, where each group contains the types of lymphomas / leukaemia’s as defined in Sweden (see table W2 in the Incidence publication for the whole country)

133) TOPOGRAPHY (PRIMARY TUMOUR) is defined according to the clinician’s assessment. The code is chosen according to specificity.

134) Topography codes may be changed according to what is most specific

135) MORPHOLOGY is defined according to pathology description. The code is given from the pathologist and coded according to SNOMED (ICD-O2) / C24

136) Morphology may be changed if a histological description is received after a cytological description, and it is more specific - if there are different morphologies, the pathologist is asked or each case is validated.

\[^{1}\text{C24} = \text{WHO/HS/CANC/24.1}\]
137) **BEHAVIOUR OF TUMOUR** is given by the PAD - the pathologist decide the evaluation/criteria for the quality of the information. The code is chosen so that the most malignant is coded (behaviour 3 > 2 > 1 according to ICD-O2).

138) The behavioural code changes: A new tumour has to be registered if it is a cancer.

139) This (138) however has to be evaluated if the behaviour changes within e.g. a year, as no specific time limits were mentioned otherwise the behaviour of the tumour is changed - especially if it is within the period of investigation. However Cervix CIS, which becomes invasive within a year is counted as malignant from the date of diagnosis of the CIS but after 1 year a new tumour is registered.

140) **List of reportable tumours:**

   a) All definitely malignant neoplasms (e.g. carcinoma, sarcoma, malignant lymphoma, leukaemia and malignant teratoma).
   
   b) Carcinoid tumours of digestive organs, granulosa tumours of the ovary, thymomas, adamantinomas and chordomas.
   
   c) Histologically benign tumours of the central nervous system and meninges, transitional cell papillomas of the urinary tract, all hormonal active tumours of the endocrine glands (except the thyroid) and the entero-chromaffin and neuroendocrine systems.
   
   d) Precancerous lesions of lip, mouth, larynx, bronchus, trachea, cervix uteri, skin, vulva and vagina, gastro-intestinal polyps with suspected malignancy, bronchial adenomas, atypical epithelial proliferations of the breast (carcinoma in situ type) and adenoma phylloides, precancerous endometrial lesions, hydatidiform moles of placental tissue, and ovarian cystadenomas of borderline type.

141) **LIST OF TUMOURS INCLUDED in incidence publications:**

   a) Diseases mentioned under 140 A-C are included in the incidence publication.
   
   b) The reportable tumours mentioned under 140 D are not included in the cancer incidence. Basaliomas have not been registered.

**CONVERSION OF ICD:**

142) Tables for converting codes from one system to another are created continuously in Stockholm (Epidemiologic centre) by a pathologist, but in co-operation with the coding-group. From the centre the set-up and changes are distributed to all the regional registries; furthermore the conversion tables are given in the annual "Incidence book".

**THE PURPOSE of the conversion of ICD classification is:**

143) To ensure comparability with old data.

144) To a certain degree to make data comparable with data from other registries (e.g. Eurocare)

**DIAGNOSIS RECORDED IN ADDITION TO THE CANCER DIAGNOSIS CODED BY THE REGISTRY:**

145) Admission diagnosis - not coded

146) Discharge diagnosis - not coded

147) Cause of death - is not coded

148) Autopsy diagnosis - is not coded

149) Other diagnosis (e.g. AIDS / Hepatitis ICD-10: B21) are not coded.
MALIGNANT DISEASES ROUTINELY EXCLUDED WHEN REPORTING DATA FROM THE REGISTRY:

150) Formerly Basalcell carcinomas of the skin were excluded except for Mixed Basalcell carcinoma (8094/3). Now all are going to be included only on reports from the pathologists.

The tumours below are recorded and included in incidence data as shown:

<table>
<thead>
<tr>
<th>Tumour type</th>
<th>Record yes</th>
<th>Record no</th>
<th>Included yes</th>
<th>Included no</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benign Brain tumours</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pituitary gland</td>
<td>no information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carotid body tumour</td>
<td>no information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benign bladder tumours (papilloma)</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intraductal carcinoma (8500/2) in the breast</td>
<td>X</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Carcinoma in situ in the breast, other than above</td>
<td>X</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Borderline tumour in the ovary</td>
<td>X</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Carcinoma in situ in testis</td>
<td>X</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Chromaffinoma (8700/0) of the adrenal glands</td>
<td>no information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Argentaffinoma (8241/1)</td>
<td>no information</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Chordoma (9370/3)</td>
<td>no information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Invasive mole (9100/1)</td>
<td>no information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Precancerous lesions in the cervix</td>
<td>X</td>
<td></td>
<td></td>
<td>x</td>
</tr>
</tbody>
</table>

164) OTHER BENIGN OR PRECANCEROUS LESIONS CODED TO OR INCLUDED WITH CATEGORIES OF MALIGNANT TUMOURS AND OTHER SPECIFIC INFORMATION: From 1993 Myeloproliferative disease is included as are adenoma of endocrine glands.

165) Clinical stage / extent of tumour is recorded only in specific management-programmes and the information will only be available in co-operation with the respective boards.

XII MULTIPLE PRIMARIES

166) The rules used to code multiple cancers in the registry are given from the Central Cancer registry (National board of Health and Welfare). -

a) From 1993 breastcancer has been coded double in the same breast.

b) Tumours in the intestines are registered separately even if they are having the same topography and morphology.

c) Astrocytom grade 1, which after some years develops into multiform glioblastoma is counted as 1 tumour, but it is written on the case, that this change has happened.

d) The registry counts tumours not patients except for:
   • SKIN TUMOURS - if they are diagnosed: “in the same area and at the same occasion” they are registered and coded as one tumour with multiple location xxx.8 - but if it is different occasions they are counted separately.
• URINARY TRACT TUMOURS - if more than one tumour (incl. in situ) are diagnosed at the same topography it will depend on the investigation time whether they are counted as one tumour (C68.8) or separately.

RULES FOR CODING CANCERS IN PAIRED ORGANS:

167) Tumours with the same morphology on each side are coded as two tumours, and counted as two when calculating incidence rates. Though it does depend on where it is and whether they are reported as 2 tumours.

168) Tumours with different morphology on each side are coded as two tumours, and counted as such.

169) Tumours with different behaviour (e.g. intraductal carcinoma in left breast and duct carcinoma in right breast) are coded as two tumours, but counted as one tumour.

XIII TREATMENT

170) TREATMENT is not recorded.

XIV FOLLOW-UP and TRACE-BACK

A  By follow-up we mean that the registry follows up registered cases to obtain information about e.g. recurrence, treatment, or death.

B  By trace-back we mean, that the registry actively attempts to obtain further information about a tumour, (e.g. first notified on a death certificate, or if the information on a patient is not satisfactory for other reasons) in order to complete the coding of the tumour recorded.
ACTIVE (A) OR PASSIVELY (P) RECEIPT OF DATA FROM THE FOLLOWING SOURCES FOR FOLLOW-UP AND/OR TRACE-BACK

**Hospitals**

<table>
<thead>
<tr>
<th>Number</th>
<th>Source</th>
<th>Trace-Back</th>
<th>Follow-Up</th>
</tr>
</thead>
<tbody>
<tr>
<td>171</td>
<td>Clinical departments</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>172</td>
<td>Medical records</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>173</td>
<td>Outpatient clinics</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>174</td>
<td>Hospices</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>175</td>
<td>Long stay hospitals and homes for the elderly</td>
<td>a</td>
<td>-</td>
</tr>
</tbody>
</table>

**Laboratories (in or outside hospitals)**

<table>
<thead>
<tr>
<th>Number</th>
<th>Source</th>
<th>Trace-Back</th>
<th>Follow-Up</th>
</tr>
</thead>
<tbody>
<tr>
<td>176</td>
<td>Pathology, general</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>177</td>
<td>Pathology, specialised</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>178</td>
<td>Haematology</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>179</td>
<td>Autopsy reports</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>180</td>
<td>Institute of forensic medicine</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>181</td>
<td>Other</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number</th>
<th>Source</th>
<th>Trace-Back</th>
<th>Follow-Up</th>
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<tbody>
<tr>
<td>182</td>
<td>Death certificates</td>
<td>-</td>
<td>p</td>
</tr>
<tr>
<td>183</td>
<td>General practitioners</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>184</td>
<td>Specialist practitioners</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>185</td>
<td>Health insurance</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>186</td>
<td>Screening programs</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

**Administrative sources**

<table>
<thead>
<tr>
<th>Number</th>
<th>Source</th>
<th>Trace-Back</th>
<th>Follow-Up</th>
</tr>
</thead>
<tbody>
<tr>
<td>187</td>
<td>Central population registers (SPAR)</td>
<td>-</td>
<td>p</td>
</tr>
<tr>
<td>188</td>
<td>Central medical registers (e.g. hospital information systems)</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>189</td>
<td>Other</td>
<td>-</td>
<td></td>
</tr>
</tbody>
</table>

**XIX SCREENING PROGRAMMES**

<table>
<thead>
<tr>
<th>Type and year of start</th>
<th>Age-group</th>
<th>How often</th>
</tr>
</thead>
<tbody>
<tr>
<td>190) cervix: varies from the end</td>
<td>23 - 60 years</td>
<td>for 23-50 years every 3 years</td>
</tr>
<tr>
<td>191) of 60'ies-70'ies</td>
<td></td>
<td>for 51-60 years every 5 years</td>
</tr>
<tr>
<td>192) breast: varies</td>
<td>50 - 69 (74) years</td>
<td>every second year</td>
</tr>
<tr>
<td>193) colon: none</td>
<td></td>
<td></td>
</tr>
<tr>
<td>194) melanoma: none</td>
<td></td>
<td></td>
</tr>
<tr>
<td>195) prostate: none but a study on 10.000 was carried out from 1995</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

196) The Oncological Centre is involved in the follow-up of the screening program for breast-cancer.
XX USE OF COMPUTER

197) **THE SOFTWARE USED IN THE REGISTRY is MUMPS**

XXI CONFIDENTIALITY

THE REGISTRY OBSERVES THE FOLLOWING SET OF RULES ON CONFIDENTIALITY:

(copied from the report from Lund, as it contains the same requirements with slightly different wording)

The conditions for delivering of information from the registry are as follows:

198) The information is given on the condition that the regulations in the law on confidentiality 1980:100 14. chapter 9§ are followed
   a) The material may only be used for the project specified in the application.
   b) Personal information must be kept so that unauthorised persons cannot gain access to the information
   c) Direct contact to the person in question, relatives etc. may not be done by you without permission from the medical Doctor in charge of the care or the chief Consultant at the current department
   d) At the end of the project all material containing personal data must be destroyed. Concerning data-media see also the regulations from the Data-inspection
   e) Publication of material must be done in such a way that no individual can be identified.

199) Current regulations in the law concerning data 1982-07-01 must be followed. See also in the instructions on adaptation of the law on data.

200) When ordering personal identifiable extract on a data-medium (floppy-disc) the permission from the data-inspection must be enclosed. As the database of the cancer registry continuously is changed continuously we cannot keep these data-extractions updated.

201) In case of questions concerning annulment or quality of the delivered material the cancer registry is to be contacted first.

202) The Epidemiological Centre presupposes also that the registry is mentioned as source in all prospective publications. We therefore ask you to send us a copy of the publication (or equivalent) when the work is ended.

203) The signing of the order in the application is at the same time a confirmation that you have participated in and accepted the conditions, listed above, for handling the material and the reservations given for publication of the given information.

THE REGISTRY IS LEGALLY PERMITTED TO LINK WITH OTHER FILES

This is regulated by:

204) By the Data-inspection
205) In certain cases also by the ethical committee

206) **THERE ARE NO RULES THAT IDENTIFIABLE INFORMATION SHOULD BE DELETED IN THE REGISTRY**

207) **AN INDIVIDUAL CAN LEGALLY OBTAIN ACCESS TO DATA ABOUT HIMSELF/HERSELF IN THE REGISTRY, but this is usually done at regional level. Patient requests are handled by the local government forwarding requests to the relevant regional registries.**

208) **AN INDIVIDUAL CANNOT REFUSE TO BE INCLUDED IN THE CANCER REGISTRY**
209) An individual does not have to be asked / informed before being included in the cancer registry.

THE FOLLOWING CAN GET ACCESS TO THE CANCER REGISTRY DATA:

210) - On case by case basis - anonymously there are no special restrictions

211) - On case by case basis - with identifying information:
   a) The scientist according to the rules described above
   b) The patient as described

212) International release may only be done after making the person anonymous; e.g. by giving serial numbers to the persons in international studies, and having the key only in the country of origin.

XXII QUALITY CONTROL

COMPETENESS OF COVERAGE:

213) There is no routine for estimating the completeness of registration

214) The forms from the pathological departments arrive at regular intervals - no calculation or routine check on numbers received is done.

215) Regarding the number of forms from the clinical departments - no routine check of numbers is done.

216) Target directed registries: are not used.

217) Disease index / Hospital discharge registry is not used.

218) Outpatient logs - not used

219) Pathology department logs - not used.

220) Comparison with patients enrolled in trial protocols is not done, but information received from scientists is used and included in the registry, and in this way research is contributing to the completeness of the registry.

221) Random sampling of patients admitted to hospital and scrutiny of records for missed cases (capture - recapture) is not done.

222) Surveillance of numbers of registrations from each source is not done.

COMPETENESS OF DETAIL:

223) The average number of sources/notifications per case is not calculated

224) The number of sources are not known over the years

FIGURES FOR A RECENT YEAR FOR THE FOLLOWING:

225) Figures for "unknown primary site (199 in ICD7)" was in 1994: 3,5% in the region compared to 4,2% in the whole country.

226) Percent of "age unknown" - irrelevant.

227) Percent of "treatment unknown" - treatment is not recorded.
Appendix 2 Sweden – Göteborg

228) Percent of "stage unknown" - stage is not recorded.
229) Histological verification was in 1994 = 96%.
230) Percent of "basis of diagnosis unknown" - irrelevant.
231) Percent of "place of birth unknown" - is not recorded.
232) Year/period to which these figures apply: 1994
233) THE MOST RECENT YEAR PUBLISHED for the region is 1981-1990. While the latest regional data was published together with the other regions in "Cancer Incidence in Sweden 1994"

METHODS USED TO MAINTAIN QUALITY CONTROL OF THE REGISTRY'S DATA:

234) Independent re-abstraction is not done.
235) Independent re-coding of a sample of cases is not done.
236) Independent duplicate data entry is not done.
237) Input logical checks is used - see below
238) Use of test cases is not done
239) Proof-reading of coded notification is done: as one person is coding and another is proof-reading and vice versa.
240) Summary tabular frequency checks is not used, but an electronic check is done after which lists of strange combinations are produced and checked manually; they amount to 100 out of around 6000 cases.
241) Incidental autopsy finding is not calculated.
242) Cancer cases from Death Certificates Only (DCO) are not included in the incidence rates.
243) Mortality/incidence ratio - highest/lowest site is not used as quality control.
244) Stability of rates over time is followed.
245) Comparison with neighbouring registries is not done.

XXIII WEAK POINTS

246) Malignancies which may be under-reported: Haematologic tumours and possibly kidney tumours.
Malignancies which may be over-reported: At the start of a screening, and chronic leukaemia /lymphoma

XIX CHECKS

AUTOMATIC COMPUTER-BASED CHECKS (the same system is used as in Lund)

247) Data entered for essential variables is checked

Survey of Nordic Cancer Registries, 2000

138
248) "Invalid" code for almost any variable yes
   a) hospital code is valid
   b) clinic code is valid
   c) pathology laboratory is valid
   d) home-address is valid
   e) ICDO code is valid
   f) ICD9 code is valid
   g) ICD7 code is valid
   h) SNOMED code is valid
   i) C24 code is valid
   j) Metastasis code is valid
   k) Basis of diagnosis is valid
   l) slide number is valid
   m) Cancer death is valid
   n) Autopsy result is valid

OTHER EXAMPLES OF CHECKS

DATE OF DIAGNOSIS
249) Before or equal to date death yes
250) Before or equal to date of post-mortem yes
251) Before or equal to date of report
252) Date of death before or equal to date of post-mortem yes
253) In case of only autopsy finding: date = date of death

TUMOUR TYPE
254) Sex compatible with site yes
255) Age compatible with tumour type no
256) Site of tumour compatible with histological type yes
257) Site of tumour compatible with code for laterality (paired organ) yes
258) Site of tumour compatible with method of diagnosis yes
259) Histology compatible with method of diagnosis yes
260) THE IACR CHECK-PROGRAMME is not used.

261) MANUAL/ VISUAL CHECKS: see above

XXV OUTPUT FROM REGISTRY

IN THE REGULAR ROUTINE PUBLICATIONS OF INCIDENCE RATES, TABLES OF RATES ARE GIVEN BY :

262) Year yes
263) Sex yes
264) Age yes
265) Site yes
266) Occupation no
267) Social group no
268) Residence no
269) Geographical subdivision of your territory yes at regional and county level
270) Trends no
271) Other variable yes
   a) Cases found incidentally at autopsy (site, sex) yes
   b) Number of second and multiple primaries (site, sex, med.region) no
   c) Percentage cytologically and histologically verified no
   d) IN THE REGULAR PUBLICATIONS, THE FOLLOWING STANDARDS ARE USED :
Appendix 2  Sweden – Göteborg

272) World Standard no
273) European Standard and year no
274) Own Standard Sweden 1970
275) Other no

There are no regular/annual routine publications of mortality rates but they are available.

276) Evaluation of incidence trends is carried out
BASIC CHARACTERISTICS OF THE REGISTRY
LINKÖPING

1) Oncologic centre for the South East Region
2) The University Hospital
3) S-581 85 Linköping
4) Sweden
5) Tel: +46-013/ 223459
6) Fax: +46-013/ 222846
7) e-mail: Kerstin.nordenskjold @ oce.us.lio.se

Persons interviewed:

Name: Position: Training/Degree Abbreviation:
Bo Nordenskjöld Head of department Professor, Oncology BN
Kerstin Nordenskjöld Medical Doctor KN
Britt Pettersson Assistant nurse BP
Margaretha Sundén Assistant secretary + local training MS

I THE REGISTRY

8) The registry is population-based and it covers: Easter Götland, Jönköping and Kalmar - The Southeast region.

9) The population includes all the people in the area who are entered in the official population statistic that is have been given a personal identification number.

10) Special registries - management-programmes:

a) Acute leukaemia (2)
b) Hodgkin lymphoma (2)
c) Chronic myeloid leukaemia (2)
d) Non-Hodgkin lymphoma (2)
e) Malignant myeloma (2)
f) Promyelocytic leukaemia (2)
g) Breast cancer (1)
h) Corpus uterus cancer (1)
i) Gynaecological cancer (1,2,3) (other than corpus uteri cancer and ovarian cancer)
j) Ovarian cancer (1)
k) Bladder cancer (1)
l) Prostate cancer (1)
m) Testis tumours (2)
n) Small intestine carcinoid (3)
o) Colorectal cancer (1)
p) Hypophysis tumours (prolactinom) (2)
q) Brain tumour (1)
r) Lungcancer (1+2)
s) Malignant melanoma (1)
t) Sarcoma - soft tissue (2)
u) Osteosarcoma (2)
v) Tumour diseases in children (2,3)
- (1): regional programme
- (2): national programme
- (3): international programme

The data in these management-programmes are collected by special groups. To gain access to the data it is necessary to approach the regional registry, which can assist in contact to the members in question. The material is used for quality control of cancer treatment and studies of morbidity and mortality.

II DEMOGRAPHICAL INFORMATION

11) An incidence publication is made every year on county and regional level.

12) There has been no changes in the population.

THE RESIDENT POPULATION IN THE AREA COVERED BY THE REGISTRY was in 1995

13) Males: ........................................................................................................................................... 483 201
14) Females: ....................................................................................................................................... 489 076
15) Total: .......................................................................................................................................... 972 277

16) The population figures are exact.

17) Population figures used for incidence calculation are the midyear average figures.

18) The Health system:
   a) Primary ward, run by general practitioners in "healthcentres" (vårdcentraler)
   b) "Länsdelssjukehus" - minor hospital
   c) "Länssjukehus" - "County"-hospital
   d) "Regional hospital"
   e) "University hospital"

19) The hospitals are governed by the authority for the county ("Landstinget"), which is also responsible for collecting taxes for that purpose.

REGARDING POPULATION DATA THE FOLLOWING ARE AVAILABLE IN THE REGISTRY

available used
20) Sex in on-year age groups on parish register level ................................................................. - -
21) Sex in five-year age groups ....................................................................................................... x x
22) Information on occupation in the cancer registry (CR). .......................................................... - -
23) Information on religion ........................................................................................................... - -
24) "Ethnic group" and "place of birth", ..................................................................................... - -
25) The urbanity-degree ................................................................................................................. x -
26) Information about the geographic distribution is given in a number with 6-digits): *two first derived from county, two middle from municipality, two last from the parish registry (the smallest administrative unit ("församlingen")*. ................................................................. - -
27) The address as a land registry-number (koordinatsystem - GIS) ............................................. - -
III HISTORY

28) The Swedish Cancer Registry was established in 1958. During the 1970’s registration was decentralized into six regional registries. From 1982 the data have been collected at the regional registry. The Regional Tumour Registries have since the transfer sent the collected and coded data to the central registry on an annual basis.

29) The registry can present population based data from 1958.

CHANGES

30) Some changes happened in 1995 as the data were always delayed because of continuous tracing-back, this has now changed as well as most of the staff - the data for 1996 are almost complete especially for the management-programmes. The cancer registry has not been linked to the hospital discharge registry and no change of that kind has been made.

31) A few cases are included from the management-programme- and quality-control-registries, but usually the information goes the other way: For prostate-cancer 98% of the number are included in the prostate-cancer programme and for breast cancer it is 95%.

32) There have been Changes in hospital procedures: e.g. needle-biopsy for prostate cancer, which may have caused an increase in the frequency of clinical diagnosis, however at the same time the autopsy-rates have decreased and caused the post-mortem frequency of prostate cancer diagnosis to decrease, consequently the influence of either cannot be detected. Breast screening has on the other hand influenced the incidence rates, but it seems to have reached the plateau at present.

33) Reporting of cancer cases has always been compulsory for pathology- and hospital departments. Since 1985 it has also been compulsory for haematological laboratories and private practitioners.

34) At present reporting of tumours is compulsory for:

   a) Any medical doctor employed privately or in a hospital department, who has diagnosed the tumour disease clinically or microscopically.

   b) Any medical doctor writing a tumour disease on the death-certificate even if diagnosed after death.

   c) The doctor responsible for: pathological / cytological laboratories, the Forensic department, the Haematological lab., and other service departments.

35) Operation of the registry has not been discontinued at any time.

36) The registry is public so the local authorities (counties) are responsible for the data.

37) The data are reported annually to the National Board of health and Welfare but are owned by the local authorities.
IV STAFF & ORGANIZATION

38) EMPLOYEES:
Head of the cancer registry
1 Assistant medical Director
1 EDB expert for the cancer registry
1 Statistician
2 coding assistants for the registry
2 assistants for the management-programmes

39) The task of the registry is to collect the data which form the foundation for research. The management-programmes contain valuable basis for clinical and epidemiological studies.

40) The registry is working closely with the following departments: Oncological, surgical, neurosurgical, haematological, pathological, the department for clinical chemistry and the dermatological unit.

41) The oncological clinic is administratively tied to the department for gynaecological oncology, lung diseases, urology and haematology.

42) The registry is also one of the sources for information on need of resources - and will therefore in the future concentrate more on writing about "prevalence" than about "incidence" and "mortality".

43) The cancer-registry is located in the University hospital. The Oncologic Centre (OC) is administering the total resources for oncology in the region. The consultative assembly for OC is responsible for the co-ordination of activities in cancer management of the region.

SOURCES OF FINANCE:
44) Registration of cancer is financed by the counties in the region, on a proportional basis, according to population.

45) Research projects are carried out in co-operation with others and are financed from funds, after application and acceptance of the project. Other special activities are the management-programmes, though they are run independently with special assistants.

Coding

46) CODING OF SITE AND MORPHOLOGY IS CARRIED OUT at the registry, but plaintext must appear on the notification forms.

47) THE CODING / CLASSIFICATION OF NEOPLASMS TO SITE AND MORPHOLOGY is carried out by the regional coding assistants. They are medical secretaries / nurses, who have received an additional training in the registry as well as at The National Board of Health and Welfare.

48) Supervision of coding and solving of coding problems is done by KN, (physician at the registry)

49) In difficult cases a pathologist in the particular field will be consulted.

50) Some coding problems are discussed at the annual registry meeting, led by Jan Eriksson, who is a pathologist.

51) Coding problems may be brought to the coding group meetings, which are held 3 times a year and organised by the Central registry. Changes are sent to all in the coding instructions from the Central registry.
Appendix 2  Sweden – Linkoping

Letters / Telephone
52) The registry has to make special request for about 30% of the reporting forms from the hospital departments, while the forms from the pathological departments are usually received (at most 50-100 cases are traced back to the pathological departments).

53) The registry used to have to send out many questions for clarification of the reports, but this has decreased considerably and is now around 5% of the cases. The inquiry is often carried out by returning the form, while a copy is kept.

V REPORTING

TUMOUR REGISTRATION from patient to registry:
54) The patient contacts the GP, who makes some investigations and/or refer the patient to the hospital. Often the patients are sent to Linköping for special investigations and treatment as radiation and chemotherapy is only carried out here and in Jönköping. The surgical treatment however is carried out at 10 different hospitals. Usually the form from the pathologist is received every two weeks or once a month with information about the cytology/histology. After that it takes some time before the form from the clinician is received, but if more than 8-10 weeks have passed the form will be demanded.

55) No fee is paid to the reporting physician or institution.

56) Most often it is the medical secretary who writes the report, and the doctor signs it.

57) Linkage with the population registry (SCB-Statistical Central Bureau) is also carried out to check the persons name and ID-number

58) Information on name and address of the reporting hospital / clinic / practitioner / or other source is kept, however only information on those giving the most valuable information is kept.

59) The registry thus has information which makes it possible to GO BACK TO THE ORIGINAL RECORDS.

60) Patients do not have their “own” GP, and are free to go, wherever they want, but the cheapest is to go to the local clinic (vårdcentral).

VI SOURCES

THE REGISTRY REGULARLY RECEIVES REPORTS FROM:

61) Hospitals
62) Medical records departments - rarely
63) Outpatient clinics
64) Hospices
65) Long stay hospitals and homes for the elderly

Laboratories (in or outside hospitals)
66) Pathology
67) Haematology
68) Autopsy reports
69) Institute of forensic medicine

70) Death certificates are not used as source for tumour registration.
Other

71) General practitioners
72) Specialist practitioners
73) No special information is received from screening programmes.

FORMS RECEIVED

74) The registry receives forms from the pathologist on almost all cases - at most 50-100 cases are traced back to the pathological departments.

75) It was not mentioned how many are only diagnosed clinically, but as only 50-100 cases have to be traced to pathological departments it is very few.

76) THE INFORMATION ABOUT CANCER IS recorded from the reporting forms, which must be filled in plaintext, that is coding number only - even from pathologist - are not accepted.

THE REGISTRY DOES NOT USUALLY RECEIVE (OR HAS REGULAR ACCESS TO) COPIES OF THE FOLLOWING FOR CANCER PATIENTS, THOUGH:

77) Medical records - happens that a copy is received .........................................................rarely

78) Pathology reports - a summary is received on the B-form - the complete description is available on request. ..............................................................yes

79) Autopsy reports - as for the above. ............................................................................yes

80) Discharge letter.............................................................................................................no

81) Death certificates ........................................................................................................no.

82) Radiotherapy reports .................................................................................................no.

83) Hospital information system .........................................................................................no.

84) The staff at the registry visits the oncologic clinic in Linköping by the end of the year if some information is missing.

85) The original notification forms are stored in paper files.

86) DEFINITION OF PLACE OF "RESIDENCE":
The address as it is written in the parish register - (which is the permanent address -bopæl).

87) Very little change of address is experienced in the region, so the registry has no special rules for Immigrants and/or non-residents except that those who are non-residents are kept in a special file (less than 10 a year incl. "100" below).

88) The registry has no experience with refugees, but would follow the same procedure as above - this is also the case for those with a "protected address".

89) Special subgroups/minorities in the population are not known.

90) TUMOURS IN PATIENTS WHO ARE NOT PERMANENT RESIDENTS OF THE REGISTRY TERRITORY are not registered but the forms are sent to the relevant registry - and forms are received from the other registries.

91) Concerning residents working abroad and belonging to the region – see the report from the Epidemiologic Centre.
The data are submitted to the Central Registry in Stockholm once a year when the coding is completed.

**VII INFORMATION RECORDED**

93) **THE CODING OF DATA** is done manually.

94) **THE PROCESSING OF DATA**: on registration all forms on the person are consulted (e.g. in case of multiple tumours).

95) Two or more notifications are linked electronically using the unique personal identification number.

96) The tumours are not registered in the cancer registry until both notification forms (if there has to be two) are received, but the person (incl. address) and the type of the notification form is registered on receipt. For research purposes a rapid registration may be carried out.

97) **COMPUTERIZED CASE RESOLUTION** is not carried out.

**VIII THE PERSON**

98) **THE SOURCE FOR INFORMATION ON THE PERSON** is the Central Personal Registry (CPR), which assigns a number to each resident in Sweden.

99) The patient is not given another number in the registry.

100) **THE UNIQUE PERSONAL REGISTRY NUMBER** is constructed of: 1 digit for the century + 10 digits, which are composed of: 2 digits for year, 2 digits for month and 2 digits for day of birth; The next 2 digits formerly gave the place of birth, 1 digit gives the sex: the odd for male and the even for female and the last digit is the control number for the index number.

101) Immigrants are assigned a CPR number when they become residents.

102) The number does not any longer indicate where the person was born nor if he/she belongs to any minority and it does not indicate ethnicity.

103) The cancer registry receives updated information every 2 weeks from Statistical Central Bureau for date of death, emigration and immigration. The linking to the cause of death is done centrally and the information transferred to the regional registry annually. **THE CAUSE OF DEATH** is recorded. The autopsy diagnosis as cause of death is ranked highest of the sources for the cause of death, but the official cause of death is also registered. The registry is also regularly updated for immigrants/emigrants.

**NAMES OF PATIENT**

104) The patients full name is registered.

105) None of the following are registered: Maiden name / Father's name / Mother's name

106) The ID number of the next of kin is not registered.

**RESIDENCE/ADDRESS AT THE TIME OF REGISTRATION**

107) The code for the patients address is registered,
108) This information includes: County, municipality, parish register (församling).

109) Change of address is given from the CPR annually, but the address at the time of diagnosis is kept in the registry as address at date of diagnosis.

110) The age at incidence date is calculated from CPR.

111) The nationality of the person (e.g. French, Danish) is not registered.

112) No further information is used from the CPR.

113) The nationality of father and/or mother is not available.

114) Marital/civil status at diagnosis is not registered.

**Availability of the following categories:**

115) Death – yes

116) Number of live births and categories (actual number) - no

117) Religion - no

118) Ethnic groups - no

119) Race - no

120) Patient's education - no

121) Occupation - no

122) Special enquet studies for occupation - no

123) Social class or socio-economic status - no

124) Patient's exposure to carcinogens - no

**IX  INCIDENCE DATE**

**DATE OF DIAGNOSIS (LEVEL OF DETAIL):**

125) The date is recorded as the year, month and day of diagnosis.

126) The DATE OF DIAGNOSIS is defined as the earliest date written on the received records.

127) Tumours first notified on a death certificate is not traced to get earlier information about the tumour.

128) Cases from the death certificate notes are not registered as "Death certificate only" (DCO) or at all, unless a notification form is received (e.g. from the doctor signing the death certificate).

129) For a patient known from autopsy only, the incidence date is the date of death.
Appendix 2 Sweden – Linkoping

X BASIS OF DIAGNOSIS

METHODS
130) The "most valid basis", is having the following ranking order (from the SOS-guidelines):
   a) Histology of primary / bone marrow / metastases (from biopsy/operation/autopsy)
   b) Cytology (expectorate, aspirate etc.) / Haematology. ("cytology is not changed to “histology”
      unless the “histology” has changed the diagnosis)
   c) No histology, cytology, marrow or bloodtest.
   d) No histology or cytology (e.g. clinical investigation / X-Ray / operation-autopsy without
      histology) is not ranked.

XI CLASSIFICATIONS

131) classification(s) as from SOS:
   a) From 1958: topography was coded according to ICD 7
      morphology was coded according to C24
   b) From 1987: topography was coded according to ICD 9 and ICD 7
      morphology was coded according to C24
   c) From 1993: topography was coded according to ICDO-2/10 with a few exceptions, and to ICD 9
      and ICD 7
      morphology is coded according for the SNOMED / ICDO-2 code and C24.

132) Exceptions to the classification rules:

   Topography according to ICDO-2 where the following are coded according to ICD 10:
   - Malignant melanoma in the skin: C43
   - Hodgkins lymphoma: C81
   - Follicular non-Hodgkin Lymphoma: C82
   - Diffuse non-Hodgkin Lymphoma: C83
   - Peripheral and cutaneous T-cell lymphomas: C84
   - Malignant lymphoma, NOS, or diffuse: C85 (see special list in the incidence publication as ICD 10 also differs slightly
     from the classification)
   - Immunoproliferative diseases: C88
   - Plasma cell tumours: C90
   - Lymphatic leukaemia’s: C91
   - Myeloid leukaemia’s: C92
   - Myelodysplastic syndrome: D46
   - Monocytic leukaemia’s: C93
   - Other specified leukaemia’s: C94
   - Leukaemia’s, NOS: C95
   - Neoplasm malignum telae lymphatica et haematopoeticae/ other and unspecified tumours in lymphoid and haematopoietic
     tissue: C96 / D45 / D47 / D76

   These are all transformed to the ordinary ICD 7 code: 200x - 209x, where each group contains the
   types of lymphomas / leukaemia’s as defined in Sweden (see table W2 in the Incidence publication for
   the whole country)

133) Topography (primary tumour) is defined according to the clinician's assessment. The code is
     chosen according to specificity.

134) Topography codes may be changed according to what is most specific.

135) Morphology is defined according to pathology description. The code is given from the
     pathologist and coded according to SNOMED (ICD-O2) / C24
Morphology may be changed if a histological description is received after a cytological description, and it is more specific - if there are different morphologies, the pathologist is asked or each case is validated. Chronic leukaemia changing into acute leukaemia is not changed.

**Behaviour of tumour** is given by the PAD - the pathologist decide the evaluation/criteria for the quality of the information. The code is chosen so that the most malignant is coded (behaviour 3 > 2 > 1 according to ICD-O2).

The behavioural code changes: A new tumour has to be registered if it is a cancer.

This (above) however has to be evaluated if the behaviour changes within a year, as no specific time limits were mentioned (except the 1 year limit) otherwise the behaviour of the tumour is changed. However Myelodysplastic syndrome (9989/1) developing into a malignant disease more than 2 months after being diagnosed is registered as a new malignant tumour. While Cervix CIS which turns malignant within a year is counted as malignant from the date of diagnosis of the CIS.

**List of reportable tumours:**

a) All definitely malignant neoplasms (e.g. carcinoma, sarcoma, malignant lymphoma, leukaemia and malignant teratoma).

b) Carcinoid tumours of digestive organs, granulosa tumours of the ovary, thymomas, adamantinomas and chordomas.

c) Histologically benign tumours of the central nervous system and meninges, transitional cell papillomas of the urinary tract, all hormonal active tumours of the endocrine glands (except the thyroid) and the entero-chromaffin and neuroendocrine systems.

d) Precancerous lesions of lip, mouth, larynx, bronchus, trachea, cervix uteri, skin, vulva and vagina, gastro-intestinal polyps with suspected malignancy, bronchial adenomas, atypical epithelial proliferation of the breast (carcinoma in situ type) and adenoma phylloides, precancerous endometrial lesions, hydatidiform moles of placental tissue, and ovarian cystadenomas of borderline type.

**List of tumours included in incidence publications:**

a) Diseases mentioned under 140 A-C are included in the incidence publication, although a number of the tumours listed under C are considered not to be "infiltrating and metastasising" and are therefore also listed separately (papilloma, urinary tract; histologically benign tumours of the central nervous system; histologically benign tumours of endocrine glands; low grade fibrosarcoma (incl. dermatofibrosarcoma protuberans).

b) The reportable tumours mentioned under 140 D are not included in the cancer incidence, but are tabulated separately. Basaliomas have not been registered.

**Conversion of ICD:**

Conversion tables from one coding system to another are created centrally in Stockholm (Epidemiologic centre) by a pathologist continuously, but in co-operation with the coding-group. From the centre the set-up and changes are distributed to all the regional registries; furthermore the conversion tables are given in the annual "Incidence book".

**The purpose** of the conversion of ICD classification is:

b) To ensure comparability with old data.

d) To a certain degree to make data comparable with data from other registries (e.g. Eurocare)
### DIAGNOSIS RECORDED IN ADDITION TO THE CANCER DIAGNOSIS CODED BY THE REGISTRY:

145) Admission diagnosis - not coded
146) Discharge diagnosis - not coded
147) Cause of death - is not coded
148) Autopsy diagnosis - is not coded
149) Other diagnosis (e.g. AIDS / Hepatitis ICD-10: B21) are not coded.

### MALIGNANT DISEASES ROUTINELY EXCLUDED WHEN REPORTING DATA FROM THE REGISTRY:

150) Formerly Basalcell carcinoma of the skin were excluded except for Mixed Basalcell carcinoma (8094/3). Now all are going to be included only on reports from the pathologists.

### THE TUMOURS BELOW are recorded and included in incidence data as shown

<table>
<thead>
<tr>
<th>Tumour type</th>
<th>Record yes</th>
<th>Record no</th>
<th>Included yes</th>
<th>Included no</th>
</tr>
</thead>
<tbody>
<tr>
<td>151) Benign Brain tumours</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>152) Pituitary gland</td>
<td>X</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>153) Carotid body tumour</td>
<td>X</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>154) Benign bladder tumours (papilloma)</td>
<td>X</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>155) Intraductal carcinoma (8500/2) in the breast</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>156) Carcinoma in situ in the breast, other than above</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>157) Borderline tumour in the ovary</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>158) Carcinoma in situ in testis</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>159) Chromaffinoma (8700/0) of the adrenal glands</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>160) Argentaffinoma (8241/1)</td>
<td>no information</td>
<td>no information</td>
<td>no information</td>
<td>no information</td>
</tr>
<tr>
<td>161) Chordoma (9370/3)</td>
<td>no information</td>
<td>no information</td>
<td>no information</td>
<td>no information</td>
</tr>
<tr>
<td>162) Invasive mole (9100/1)</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>163) Precancerous lesions in the cervix</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

164) **OTHER BENIGN OR PRECANCEROUS LESIONS CODED TO OR INCLUDED WITH CATEGORIES OF MALIGNANT TUMOURS AND OTHER SPECIFIC INFORMATION:** Urothelial tumours even without invasion are given the malignant code: 81203.

165) Clinical stage / extent of tumour is recorded only in specific management-programmes and the information will only be available in co-operation with the respective boards. However some precancerous lesions be tabulated as CIS ("stage 0") of uterine cervix.

### XII MULTIPLE PRIMARIES

166) The rules used to code multiple cancers in the registry are given from the Central Cancer registry (National board of Health and Welfare).
a) For Astrocytoma grade 1 which after some years develop into multiform glioblastoma no change is made and a second tumour is not registered.

b) The registry counts tumours not patients except for:
   SKIN TUMOURS - if “malignant melanomas” are diagnosed in the same area and on the same occasion they are registered and coded as one - but if it is different occasions they are counted separately. If more melanomas are diagnosed in different regions on the same occasion, they are coded with the topography C43.8.
   URINARY TRACT TUMOURS - if more than one tumour (incl. in situ) are diagnosed at the same topography and within one year, they are counted as one tumour, after one year they will be counted separately. At different topographies they are counted separately.

RULES FOR CODING CANCERS IN PAIRED ORGANS:

167) Tumours with the same morphology on each side are coded as two tumours, and counted as two when calculating incidence rates.

168) Tumours with different morphology on each side are coded as two tumours, and counted as such.

169) Tumours with different behaviour (e.g. intraductal carcinoma in left breast and duct carcinoma in right breast) are coded as two tumours, but counted as one tumour.

XIII TREATMENT

170) TREATMENT is not recorded.

XVII FOLLOW-UP and TRACE-BACK

A By follow-up we mean that the registry follows up registered cases to obtain information about e.g. recurrence, treatment, or death.

B By trace-back we mean, that the registry actively attempts to obtain further information about a tumour, (e.g. first notified on a death certificate, or if the information on a patient is not satisfactory for other reasons) in order to complete the coding of the tumour recorded.
ACTIVE (A) OR PASSIVELY (P) RECEIPT OF DATA FROM THE FOLLOWING SOURCES FOR FOLLOW-UP AND/OR TRACE-BACK

**Hospitals**

171) Clinical departments ................................................................. a -
172) Medical records .......................................................... a -
173) Outpatient clinics ............................................................... a -
174) Hospices ................................................................. a -
175) Long stay hospitals and homes for the elderly ..................... a -

**Laboratories (in or outside hospitals)**

176) Pathology, general ................................................................. a -
177) Pathology, specialised ......................................................... a -
178) Haematology ................................................................. a -
179) Autopsy reports ................................................................. a -
180) Institute of forensic medicine ........................................... a -
181) Other ................................................................. - -
182) Death certificates .............................................................. - p
183) General practitioners .......................................................... a -
184) Specialist practitioners ....................................................... a -
185) Health insurance ............................................................... - -
186) Screening programmes ....................................................... - -

**Administrative sources**

187) Central population registers ................................................ - p
188) Central medical registers (e.g. hospital information systems) ....................................................... - -
189) Other ................................................................. - -

**XIX SCREENING PROGRAMMES**

<table>
<thead>
<tr>
<th>Type and year of start</th>
<th>Age-group</th>
<th>how often</th>
</tr>
</thead>
<tbody>
<tr>
<td>190) cervix: as in the rest of Sweden</td>
<td></td>
<td></td>
</tr>
<tr>
<td>191) breast: mammography 78 in Öster-Götland</td>
<td>5 years</td>
<td>40 every second year</td>
</tr>
<tr>
<td>77 in Kopparberg</td>
<td></td>
<td></td>
</tr>
<tr>
<td>86 in Jönköping</td>
<td></td>
<td></td>
</tr>
<tr>
<td>86 in Kalmar</td>
<td></td>
<td></td>
</tr>
<tr>
<td>192) colon: none</td>
<td></td>
<td></td>
</tr>
<tr>
<td>193) melanoma none</td>
<td></td>
<td></td>
</tr>
<tr>
<td>194) prostate: none</td>
<td></td>
<td></td>
</tr>
<tr>
<td>195) There is no special co-operation with the screening programmes.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
XX USE OF COMPUTER

196) The software used in the registry is the same as in Lund. (DSM)

XXI CONFIDENTIALITY

The registry observes the following set of rules on confidentiality:
(copied from the report from Lund, as it contains the same requirements with slightly different wording)

The conditions for delivering of information from the registry are as follows:

197) The information is given on the condition that the regulations in the law on confidentiality 1980:100 14 chap. 98 are followed
   a) The material may only be used for the project specified in the application.
   b) Personal information must be kept so that unauthorised persons cannot gain access to the information
   c) Direct contact to the person in question, relatives etc. may not be done by you without permission from the medical Doctor in charge of the ward or the chief Consultant at the current department
   d) At the end of the project all material containing personal data must be destroyed. Concerning data-media see also the regulations from the Data-inspection
   e) Publication of material must be done in such a way that no individual can be identified.

198) Current regulations in the law concerning data 1982-07-01 must be followed. See also in the instructions on adaptation of the law on data.

199) When ordering personal identifiable extract on a data-medium (floppy-disc) the permission from the data-inspection must be enclosed. As the database of the cancer registry continuously is changed continuously we cannot keep the data-extraction updated.

200) In case of questions concerning annulment or quality of the delivered material the cancer registry is to be contacted first.

201) The Epidemiological Centre presupposes also that the registry is mentioned as source in all prospective publications. We therefore ask you to send us a copy of the publication (or equivalent) when the work is ended.

202) The signing of the order in the application is at the same time a confirmation that you have participated in and accepted the conditions, listed above, for handling the material and the reservations given for publication of the given information

203) The registry is legally permitted to link with other files

This is regulated by:

204) By the Data-inspection

205) In certain cases also by the ethical committee

206) There are no rules that identifiable information should be deleted in the registry

207) An individual can legally obtain access to data about himself/herself in the registry, but this is usually done at regional level. Patient requests are handled by the local government forwarding requests to the relevant regional registries.

208) An individual cannot refuse to be included in the cancer registry

209) An individual does not have to be asked / informed before being included in the cancer registry
THE FOLLOWING CAN GET ACCESS TO THE CANCER REGISTRY DATA:

210) - On case by case basis - anonymously there are no special restrictions

211) - On case by case basis - with identifying information:
    a) The scientist according to the rules described above
    b) The patient as described

212) International release may only be done after making the person anonymous; e.g. by giving serial numbers to the persons in international studies, and having the key only in the country of origin.

XXII QUALITY CONTROL

COMPLETENESS OF COVERAGE:

213) THERE IS NO ROUTINE FOR ESTIMATING THE COMPLETENESS OF REGISTRATION

214) The number of forms from the pathological departments arrive at regular intervals, and a constant number is expected - if that is not reached then an inquiry is started.

215) The number of forms from the clinical departments - as mentioned earlier often have to be requested. The haematologists are interested in the data so they are notifying the registry of all cases.

216) Target directed registries: are not used.

217) Disease index / Hospital discharge registry is not used.

218) Outpatient logs - not used

219) Pathology department logs - not used.

220) Comparison with patients enrolled in trial protocols is not done, but information received from scientists is used and included in the registry, and in this way research is contributing to the completeness of the registry.

221) Random sampling of patients admitted to hospital and scrutiny of records for missed cases (capture - recapture) is not done.

222) Surveillance of numbers of registrations from each source is not done.

COMPLETENESS OF DETAIL:

223) The average number of sources/notifications per case is not calculated

224) The number of sources are not known over the years

FIGURES FOR A RECENT YEAR FOR THE FOLLOWING:

225) Figures for "unknown primary site (199 in ICD7)" were in 1995 = 178 out of 4918 new cases which equals 3.6%.

226) Percent of "age unknown" - irrelevant.

227) Percent of "treatment unknown" - treatment is not recorded.
228) Percent of "stage unknown" - stage is not recorded.
229) Histological verification was in 1995 > 95%.
230) Percent of "basis of diagnosis unknown" - irrelevant.
231) Percent of "place of birth unknown" - is not recorded.
232) Year/period to which these figures apply: 1995.
233) THE MOST RECENT YEAR PUBLISHED for the country is 1995.

METHODS USED TO MAINTAIN QUALITY CONTROL OF THE REGISTRY'S DATA:

234) Independent re-abstraction is not done.
235) Independent re-coding of a sample of cases is not done.
236) Independent duplicate data entry is not done.
237) Input logical checks is used - see below
238) Use of test cases is not done
239) Proof-reading of coded notification is done: as one person is coding and another is entering the data into the system - and vice versa.
240) Summary tabular frequency checks is not used, but an electronic check is done after which lists of strange combinations are produced and checked manually; they amount to 100 out of around 6000 cases.
241) Incidental autopsy finding (3% for men and 1,6% for women in 1995) is calculated.
242) Cancer cases from Death Certificates Only (DCO) are not included in the incidence rates.
243) Mortality/incidence ratio - highest/lowest site is not used as quality control.
244) Stability of rates over time is followed.
245) Comparison with neighbouring registries is not done.

XXIII WEAK POINTS

246) Malignancies which may be under-reported :None are known
    Over-reported: At the start of a screening there may be some overreporting

XXIV CHECKS

AUTOMATIC COMPUTER-BASED CHECKS (the same system is used as in Lund)

247) Data entered for essential variables is checked yes
Appendix 2  Sweden – Linkoping

248) "Invalid" code for almost any variable  yes

  a) hospital code is valid
  b) clinic code is valid
  c) pathology laboratory is valid
  d) home-address is valid
  e) ICDO code is valid
  f) ICD9 code is valid
  g) ICD7 code is valid
  h) SNOMED code is valid
  i) C24 code is valid
  j) Metastasis code is valid
  k) Basis of diagnosis is valid
  l) slide number is valid
  m) Cancer death is valid
  n) Autopsy result is valid

OTHER EXAMPLES OF CHECKS

DATE OF DIAGNOSIS

249) Before or equal to date death  yes
250) Before or equal to date of post-mortem  yes
251) Before or equal to date of report
252) Date of death before or equal to date of post-mortem  yes
253) In case of only autopsy finding: date = date of death

TUMOUR TYPE

254) Sex compatible with site  yes
255) Age compatible with tumour type  no
256) Site of tumour compatible with histologic type  yes
257) Site of tumour compatible with code for laterality (paired organ)  yes
258) Site of tumour compatible with method of diagnosis  yes
259) Histology compatible with method of diagnosis  yes
260) THE IACR CHECK-PROGRAMME is not used.

261) MANUAL/VISUAL CHECKS: see above

XXV OUTPUT FROM REGISTRY

IN THE REGULAR ROUTINE PUBLICATIONS OF INCIDENCE RATES, TABLES OF RATES ARE GIVEN BY:

262) Year  yes
263) Sex  yes
264) Age  yes
265) Site  yes
266) Occupation  no
267) Social group  no
268) Residence  no
269) Geographical subdivision of your territory  yes at regional and county level
270) Trends  no
271) Other variable  yes
  a) Cases found incidentally at autopsy (site, sex)  yes
  b) Number of second and multiple primaries (site, sex, med.region)  no
  c) Percentage cytologically and histologically verified  no
IN THE REGULAR PUBLICATIONS, THE FOLLOWING STANDARDS ARE USED:

272) World Standard no
273) European Standard and year no
274) Own Standard Sweden 1970
275) Other no

THERE ARE NO REGULAR/ANNUAL ROUTINE PUBLICATIONS OF MORTALITY RATES BUT THEY ARE AVAILABLE

276) Evaluation of incidence trends is carried out
Appendix 2  Sweden – Lund

BASIC CHARACTERISTICS OF THE REGISTRY

LUND  

1) Southern Swedish Regional Tumour Registry
2) Lund University Hospital
3) S-221-85 Lund
4) Sweden
5) Tel: +46-46-177550 /177560
6) Fax: +46-46-188143
7) e-mail: torgil.moller@onk.lu.se

Persons interviewed:
Name:   Position:   Training/Degree Abbreviation:
Torgil R. Möller Director, Associate Professor of Oncology M.D.Ph.D TM
Gjertrud Andersson Coding assistant GA
Bo Midberg Computer specialist BM

I THE REGISTRY

8) The registry is population-based and covers Södra Sjukvårdsregionen
9) The population includes all the people in the area who are entered in the official population statistics. This excludes refugees who are living in camps.
10) Special registries:
   a) -Care-programme registries for:
   b) -Thyroid cancer
      (1) -Breast cancer
      (2) -Malignant sarcoma
      (3) -Children tumours
      (4) -Gynaecological cancers
   c) -Quality programme registries:
   d) -Malignant melanoma
      (1) -Prostate cancer
      (2) -Rectal cancer
   e) -Study programme registry for:
   f) -Kidney cancer
      (1) -Malignant lymphoma

These registries are more detailed than the ordinary cancer registry. For more information, contact the local registry.

II DEMOGRAPHICAL INFORMATION

11) An incidence publication is made for the region every five years on municipality level.
12) There has been no changes in the population covered

The resident population in the area covered by the registry was in 1992
13) Males: .............................................................................................................................. 827.376
14) Females: ................................................................................................................ ......... 855.712
15) Total: .................................................................................................................. .......... 1.683.088
16) The population figures are exact, and the numbers are given in one-year age groups once a year at the turn of the year, from DAFA, which is the central authority in Stockholm, handling
Appendix 2 Sweden – Lund

demographic data also on individual level.

17) Population figures used for incidence calculation are available for any time of the year, but usually the figures at the time of the new year are used - though sometimes figures for midyear are used.

18) The Health system:
a) Primary ward, run by general practitioners in "healthcenters" (vårdcentraler)
b) "Länsdelssjukehus" - minor hospital
c) "Länsjukehus" - "County"-hospital
d) "Regional hospital" : one in Malmö and one in Lund, both are University hospitals

19) The hospitals are governed by the authority - for the county ("Landstinget"), which is also responsible for collecting taxes for that purpose. Malmö municipality however forms its own "hospital unity".

Regarding population data the following are available in the registry

<table>
<thead>
<tr>
<th>available</th>
<th>used</th>
</tr>
</thead>
<tbody>
<tr>
<td>20) Sex in one-year age groups</td>
<td>x</td>
</tr>
<tr>
<td>21) Sex in five-year age groups</td>
<td>x</td>
</tr>
<tr>
<td>22) There is no information on occupation in the cancer registry (CR), but the information is available in another registry (Cancer-environmental registry), so the information is easily accessible.</td>
<td></td>
</tr>
<tr>
<td>23) Information on religion</td>
<td>-</td>
</tr>
<tr>
<td>24) For &quot;ethnic group&quot; and &quot;place of birth&quot;, there is information centrally, about whether a person was born in Sweden, Scandinavia, Europe, outside Europe. Up to sometime in the 80's it was possible to get information about a persons birthplace from the personal registration number, but since then this information is only available in a central registry</td>
<td>x</td>
</tr>
<tr>
<td>25) The urbanity-degree for each municipality is given from the Central registry (formerly this was the only information given).</td>
<td>x</td>
</tr>
<tr>
<td>26) Information about the geographic distribution is given in a number with 6-digits): two first derived from county, two middle from municipality, two last from the smallest administrative unit: the parish (&quot;församlingen&quot;).</td>
<td>x</td>
</tr>
<tr>
<td>27) Each address has a land registry-number (koordinatsystem - GIS)</td>
<td>x</td>
</tr>
</tbody>
</table>

III HISTORY

28) The Swedish cancer registry started operating in 1958 in Stockholm, and in 1978 the data were transferred to the regional registry. Since 1978 the data for Southern Swedish Regional Tumour registry have been collected in Lund.

29) The registry can present population based data from 1958

CHANGES

30) There is no Linkage with other registries and has never been any in the region.

31) Cancers from other registries as care- and quality program registries are included.
32) There may have been changes in hospital procedures (e.g. examination, former inpatients becoming outpatients, treatment, autopsy-rates etc), but none of these have influenced the incidence.

33) Reporting of cancer cases to the registry has always been compulsory for pathology- and hospital departments. Since 1985 it has also been compulsory for haematological laboratories and for private practitioners; this did not lead to any change in incidence.

34) At present reporting of tumours is compulsory for:
   a) Any medical doctor employed privately or in a hospital department, who has diagnosed the tumour disease clinically and/or microscopically.
   b) Any medical doctor writing a tumour disease diagnosed after death, on the death certificate.
   c) The doctor responsible for: pathological / cytological laboratories, the Forensic department, the Haematological lab., and other service departments.

35) Operation of the registry has not been discontinued at any time.

36) The registry is public so the county / local government is responsible for data.

37) The data belong to the National Board of health and Welfare.

IV STAFF & ORGANIZATION

38) Employees:
   (a) Director
   (b) Assistant director also working at the department of Onkology
   (c) Chief epidemiologist handling research and statistics
   (d) 6 Coding assistants
   (e) Computer - specialist for the cancer registry
   (f) Computer - specialist for the special programmes
   (g) 2 assistants for special programme and for lay-out

39) The registry is one department, but several external people are associated and come to work at the registry.

The following departments/institutions are working closely with the registry:

40) The University
41) The Oncological clinic, where the director used to work for 25% of his time (up to 1993)
42) The Environmental - Public - Occupational Health departments
43) The registry is physically located with the Oncological clinic's inpatient department.

SOURCES OF FINANCE:

44) Registration of cancer is financed by the counties in the region, on a proportional basis, according to population

45) Research projects are financed from funds, after application and acceptance of the project. These money pays for research time. Other activities are: care-programmes, clinical studies, epidemiological studies, education, prevention

CODING:

46) Coding of site and morphology is carried out at the registry.
47) **THE CODING / CLASSIFICATION OF NEOPLASMS TO SITE AND MORPHOLOGY** is carried out by the coding assistants. They are medical secretaries, who have received an additional training in the registry as well as at The National Board of Health and Welfare and continuously receive training at special meetings for coding assistants from the whole country.

48) Supervision of coding and solving of coding problems is done by TM, the director of the registry, who also is a Medical Doctor (MD).

49) In difficult cases a pathologist will be contacted.

50) Some coding problems are discussed at the annual registry meeting, led by Jan Eriksson, who is a pathologist.

51) Coding problems may be brought to the coding group meetings, which are held 3 times a year. Changes are sent to all in the coding instructions from the Central registry. (see 36 + 157)

**LETTERS / TELEPHONE**

52) The departments reporting cases may be asked for clarification, formerly in up to 25% of the cases, but now only in 10% of the cases.

53) Since 1996 the registry receives the pathological description, and thus very few cases need clarification.

**V REPORTING**

**TUMOUR REGISTRATION FROM PATIENT TO REGISTRY:**

54) The patient usually contacts the GP, who makes some investigations and/or refers the patient to the hospital. In the hospital further investigations are carried out, and in most cases biological material is sent to the pathologist, finally the patient is referred to the relevant treatment centre. The GP is to report as soon as the tumour has been diagnosed. If he does not report he has to make a note on the referral letter, that he did not report the tumour to the registry. Very often the hospital doctor reports it anyway. The pathologist must always report his findings of tumours to the registry.

55) The reporting is compulsory, so no fee is paid to the reporting physician or institution.

56) Most often it is the medical secretary who writes the report, and the doctor signs it.

57) **PASSIVE REPORTING THROUGH e.g. linkages is not carried out, and no linkages are done for this purpose. However once a month the registry receives an update on individuals from the whole country. The registry has had access to these data since 1982.**

58) Information on name and address of the reporting hospital / clinic / practitioner / or other source is recorded, so that it is POSSIBLE TO TRACE BACK TO THE REPORTING PERSON AND GET ADDITIONAL INFORMATION. For each tumour however only one clinic and the pathologist incl. pathology number of biopsy is recorded.

59) The registry has information which makes it possible to GO BACK TO THE ORIGINAL RECORDS. Very often the pathology description is included in the report from the pathological department.

60) Patients do not have their "own" GP, and are free to go, wherever they want, but the cheapest is to go to the local primary health care centre (vårcentral).
VI SOURCES

The registry regularly receives reports from:

61) Hospitals
62) Medical records departments
63) Outpatient clinics and Primary Health Care Centres
64) Hospices
65) Long stay hospitals and homes for the elderly, though they are not very active.

Laboratories (in or outside hospitals)
66) Pathology, - there are 10 pathology registries in the region, each reporting to the tumour registry
67) Haematology
68) Autopsy reports
69) Institute of forensic medicine
70) Death certificates are not used as source for tumour registration.

Other
71) General practitioners
72) Specialist practitioners
73) Screening programmes - Information about Cervix dysplasia is only received from the pathological dep., as soon as it is Carcinoma in situ it has to be reported from the clinician as well.

Forms received
74) The registry receives forms from the pathologist on almost all cases - 6-8% are only autopsy reports. Forms are received from the clinic (oncological as well as all other departments and GP’s but must sometimes be traced) - very often the pathological report has been received before the clinical report and is the most reliable.
75) 2% (1988-92) are only diagnosed clinically
76) The information about cancer is recorded from the reporting forms and they must be written in plaintext, that is coding numbers only - even from the pathologist - are not accepted.

The registry receives routinely (or has regular access to) copies of the following for cancer patients:
77) Medical records - especially in Lund ................................................................. yes
78) Pathology reports - almost always ................................................................. yes
79) Autopsy reports - frequently ........................................................................ yes
80) Discharge letter ............................................................................................. no
81) Death certificates ........................................................................................... no
82) Radiotherapy reports ...................................................................................... no
83) Hospital information system ........................................................................... no
84) The staff at the registry do sometimes visit the oncologic clinic in Lund to gather necessary information.
85) The original notifications are stored for 5 years in paper files; and then they are stored as microfilm.

**DEFINITION OF PLACE OF "RESIDENCE":**

86) The address as it is written in the parish register - which is the permanent address (bopæl)

87) Immigrants and/or non-residents are given a personal registration number after one year. At that time only the date of immigration is available, not the country of origin.

88) Refugees have a temporary personal id. number, formerly they were kept separately, but they are very rare in any case.

89) Special subgroups/minorities in the population cannot be recovered.

90) TUMOURS IN PATIENTS WHO ARE NOT PERMANENT RESIDENTS OF THE REGISTRY TERRITORY are registered as described, while e.g. tourists, non-resident patients admitted to a hospital in the area are not registered.

91) Swedes working abroad have a special parish number and may thus be recovered - they are included in the incidence figures.

92) Information about patients who are not residents in the region is sent centrally as well as information about patients from the region, treated elsewhere - is received from Stockholm. THE DATA ARE SUBMITTED TO THE CENTRAL REGISTRY IN STOCKHOLM ONCE A YEAR when the coding is completed and checked.

**VII INFORMATION RECORDED**

93) The coding of data is done manually.

94) THE PROCESSING OF DATA is done after consulting all forms ever received for the same patient.

95) Two or more notifications are linked electronically using the unique personal identification number.

96) The notification forms are being coded continuously, and they are to be coded within one week after receipt.

97) computerised case resolution is not carried out.

**VIII THE PERSON**

98) **THE SOURCE FOR INFORMATION ON THE PERSON** is the Central Personal Registry (CPR), which assigns a number to each resident in Sweden.

99) In the Cancer Registry the person is furthermore assigned a serial number which is used only for communication with the central registry in Stockholm. While the patient otherwise is followed by the CPR-number.

100) **THE UNIQUE PERSONAL REGISTRY NUMBER** is constructed of: 1 digit for the century + 10 digits, which are composed of: 2 digits for year; 2 digits for month and 2 digits for day of birth; The next 3 digits are the serial number where the last(3rd digit) indicates the sex: the odd for male and the even for female - The last digit is a check digit obtained by the modulus-10 method.
101) Immigrants are assigned a CPR number when they become residents.

102) The number does not indicate where the person was born, not if he/she belongs to any minority and it does not indicate ethnicity.

103) The cancer registry receives updated information on electronic media from the CPR every month and thus can follow the civil information on every person: e.g. address, death, etc. The information at the time of diagnosis is however kept, so the civil history of the patient may be followed. DATE OF DEATH is given with year/month/day from the population registry. The official date of death, is given the highest rank. But direct access to a house population registry was given in 1982, and thus the status including death and immigration / emigration is updated. Centrally a separate check of the cause of death registry is carried out, but cancer on death certificate notes are not and never were included in the cancer registry unless a report is received.

NAMES OF PATIENT

104) The patients full name is given electronically from the ID number. It is checked against the name on the notification. If the name on the notification does not tally with the name tied up with the ID number it is checked, and eventually the county administration or / and the reporting department is contacted for verification / correction

105) None of the following are registered: Maiden name / Father's name / Mother's name

106) The ID number of the next of kin: The partners or the mothers - is registered

RESIDENCE/ADDRESS AT THE TIME OF REGISTRATION

107) The code for the address of the patient is registered.

108) The code is constructed of 2 digits for county, 2 digits for municipality and 2 digits for parish (församling). The information also includes postal code

109) Change of address is given through the monthly updating from CPR, but the address at the time of diagnosis is kept in the registry.

110) The age at incidence date is calculated from CPR.

111) The persons nationality (e.g. French, Danish, or national/foreign) is not registered

112) The year of emigration is given from the CPR. From the CPR-number it is also possible to see if the patient is registered in any of the other registries in the department: Care program register - special registries - occupational registry - cause of death registry.

113) The nationality of father and/or mother is not registered, but there are plans to do it in the CR, so that in the future it may become available.

114) Marital/civil status at diagnosis is registered and the following categories are used:
   a) Married – yes
   b) Separated – yes.
   c) Divorced – yes
   d) Widow/widower – yes
   e) Cohabitation is not used, and may only be found out by using the land register number
   f) Single – yes

115) Death - yes
116) Number of live births and categories (actual number) can be made available from the National Board of Health and Welfare where there is a fertility registry.

117) Religion - not available

118) Ethnic groups - not available

119) Race - not available

120) Information on patient's education is available, but permission to get the information is required.

121) Occupation may be known from the environmental-cancer registry, but it is not very specific as the same titles are used in different occupations (e.g. foreman).

122) Special enquet studies are giving better information when occupation is to be included in a study.

123) Social class or socio-economic status is available.

124) Information about patient's exposure to carcinogens is only available from special studies.

IX INCIDENCE DATE

DATE OF DIAGNOSIS (LEVEL OF DETAIL):

125) Up to 1975 the date of diagnosis was recorded as year and month of diagnosis. Since 1975-76 the date has been recorded as the year, month and day of diagnosis.

126) The DATE OF DIAGNOSIS is defined by the earliest date written on the received records. It differs between the clinics which date is written on the form, it may therefore be: date of first symptom / Date of first health care system attendance (consultation) / Date of first diagnosis of the cancer by a physician / Date of pathology (histology) report / Date of hospital admission / Date of clinical investigations (e.g. x-ray) / Date of first treatment / "Diagnose date" (as written on the form).

127) Tumours notified only on death certificates are not traced in order to get earlier information.

128) Cases from the death certificate notes are not registered as "Death certificate only" (DCO) or at all, unless a notification form is received from the doctor signing the death certificate. The cause of death registry is not matched with the cancer registry.

   a) A special study for checking death certificates revealed that by not including cases from death certificates the registry were short of around 500 cases or 1-2% of the total cases, which probably ought to be in the registry.

129) For a patient known from autopsy only, the incidence date is the date of death.

X BASIS OF DIAGNOSIS

METHODS

130) The "most valid basis" (e.g. "histology" rather than surgery, etc.) is coded in the following ranking order:

   a) Histology of primary / bone marrow / metastases
   b) Cytology (expectorate, aspirate etc.) / Haematology.
   c) No histology, cytology, marrow or bloodtest.
   d) No histology - cytology (macroscopic only) is not ranked, but if possible the patient case story is checked.
XI CLASSIFICATIONS

131) classification(s)
   a) From 1958: topography was coded according to ICD 7
   b) morphology was coded according to C24
   c) From 1987: topography was coded according to ICD 9 but with conversion tables to ICD7
   d) morphology was coded according to C24
   e) From 1993: Topography was coded according to ICDO-2 with a few exceptions, but with conversion tables to ICD 7
   f) morphology is coded according for the SNOMED / ICDO-2 code

132) **Exceptions** to the classification rules:
   Topography according to ICDO-2 where the following are coded according to ICD 10:
   - Malignant melanoma in the skin: C43
   - Hodgkins lymphoma: C81
   - Follicular non-Hodgkin Lymphoma: C82
   - Diffuse non-Hodgkin Lymphoma: C83
   - Peripheral and cutaneous T-cell lymphomas: C84
   - Malignant lymphoma, NOS, or diffuse: C85 (Malignant lymphoma of the stomach is thus not coded to the organ but to malignant lymphoma)
   - Immune-proliferative diseases: C88
   - Plasma cell tumours: C90
   - Lymphatic leukemias: C91
   - Myeloid leukemias: C92
   - Myelodysplastic syndrome: D46
   - Monocytic leukemias: C93
   - Other specified leukemias: C94
   - Leukemias, NOS: C95
   - Neoplasma malignum telae lymphatica et haematopoeticae/ other and unspecified tumours in lymphoid and haematopoietic tissue: C96 / D45 / D47 / D76

   These are all transformed to the ordinary ICD 7 code: 200x - 209x

133) **TOPOGRAPHY (PRIMARY TUMOUR)** is defined according to the clinician's assessment. The code is chosen according to specificity

134) Topography codes may be changed according to what is most relevant.

135) **MORPHOLOGY** is defined according to pathology description. The code is given from the pathologist and coded according to SNOMED (ICD-O2) / C24

136) Morphology may be changed if a histological description is received after a cytological description.

137) **BEHAVIOUR OF TUMOUR** is given by the PAD. The code is chosen so that the most malignant is coded (behaviour 3 > 2 > 1 according to ICD-O2)
   a) In C24: 1 = benign; 3 = uncertain whether benign or malignant; 4 = in situ; 5 = localised tumour;
   b) 6 = malignant

138) The behavioural code may be changed. There are no specific rules for this as each case is evaluated individually

139) Except for dysplasia and carcinoma in situ of the cervix, which are not changed if they become malignant after 1 year. In these cases a new malignant cancer is registered.

140) List of reportable tumours:
   a) All definitely malignant neoplasms (e.g. carcinoma, sarcoma, malignant lymphoma, leukaemia and malignant teratoma).
b) Carcinoid tumours of digestive organs, granulosa tumours of the ovary, thymomas, adamantinomas and chordomas.

c) Histologically benign tumours of the central nervous system and meninges, transitional cell papillomas of the urinary tract, all hormonal active tumours of the endocrine glands (except the thyroid) and the entero-chromaffin and neuroendocrine systems.

d) Precancerous lesions of lip, mouth, larynx, bronchus, trachea, cervix uteri, skin, vulva and vagina, gastro-intestinal polyps with suspected malignancy, bronchial adenomas, atypical epithelial proliferations of the breast (carcinoma in situ type) and adenoma phylloides, precancerous endometrial lesions, hydatidiform moles of placental tissue, and ovarian cystadenomas with suspected malignancy.

141) LIST OF TUMOURS INCLUDED in incidence publications:

a) Diseases mentioned under 140 A-C are included in the incidence publication.

b) The reportable tumours mentioned under 140 D are not included in the cancer incidence, but are tabulated separately.

c) Conversion of ICD:

142) Tables for converting codes from one system to another are created centrally - Stockholm - by a pathologist. From the centre the set-up is distributed to all the regional registries.

THE PURPOSE of the conversion of ICD classification is:

143) To ensure comparability with old data.

144) To a certain degree to make data comparable with data from other registries (e.g. Eurocare)

Diagnosis recorded in addition to the cancer diagnosis coded by the registry:

145) Admission diagnosis - not coded

146) Discharge diagnosis - not coded

147) Death certificate diagnosis may be added from the cause of death registry. (up to 15 underlying causes may be given)

148) Autopsy diagnosis is available from the cause of death registry

149) Other diagnosis (e.g. AIDS / Hepatitis ICD-10: B21) are not recorded.

Malignant diseases routinely excluded when reporting data from the registry:

150) Formerly Basalcell carcinoma of the skin were excluded except for Mixed Basalcell carcinoma (8094/3)

Now all are included - starting 1998.
THE TUMOURS BELOW are recorded and included in incidence data as shown

<table>
<thead>
<tr>
<th>Tumour type</th>
<th>Record yes</th>
<th>Record no</th>
<th>Included yes</th>
<th>Included no</th>
</tr>
</thead>
<tbody>
<tr>
<td>151) Benign Brain tumours</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>152) Pituitary gland</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>153) Carotid body tumour</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>154) Benign bladder tumours (papilloma)</td>
<td>x papilloma</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>155) Intraductal carcinoma (8500/2) in the breast</td>
<td>x</td>
<td>some, but</td>
<td></td>
<td></td>
</tr>
<tr>
<td>156) Carcinoma in situ in the breast, other than</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>157) Borderline tumour in the ovary</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>158) Carcinoma in situ in testis</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>159) Chromaffinoma (8700/0) for the adrenal glands</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>160) Argentaffinoma (8241/1)</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>161) Chordoma (9370/3)</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>162) Invasive mole (9100/1)</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>163) Precancerous lesions in the cervix</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>164) Other benign or precancerous lesions coded to or included with categories of malignant tumours are mentioned above.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>165) Clinical stage / extent of tumour is recorded only in the special care-programmes.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

XII MULTIPLE PRIMARIES

166) The rules used to code multiple cancers in the registry are given from the Central Cancer registry (National board of Health and Welfare)

   a) For Astrocytoma grade 1, which after some years have developed to multiform glioblastoma no change is made and no second tumour is registered. -(this is still being discussed)

   b) The registry counts tumours not patients.

RULES FOR CODING CANCERS IN PAIRED ORGANS:

167) Tumours with the same morphology on each side are coded as two tumours, but not counted as two when calculating incidence rates

168) Tumours with different morphology on each side are coded as two tumours

169) Tumours with different behaviour (e.g. intraductal carcinoma in left breast and duct carcinoma in right breast) are coded as two tumours
XIII TREATMENT

170) TREATMENT is only recorded in the CARE-PROGRAMMES not in the general cancer registry

XVII FOLLOW-UP and TRACE-BACK

A By follow-up we mean that the registry follows up registered cases to obtain information about e.g. recurrence, treatment, or death.

B By trace-back we mean, that the registry actively attempts to obtain further information about a tumour, (e.g. first notified on a death certificate, or if the information on a patient is not satisfactory for other reasons) in order to complete the coding of the tumour recorded.

Active (a) or passively (r) receipt of data from the following sources for follow-up and/or trace-back

<table>
<thead>
<tr>
<th>Hospitals</th>
<th>trace-back</th>
<th>follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>171) Clinical departments</td>
<td>a</td>
<td>p</td>
</tr>
<tr>
<td>172) Medical records</td>
<td>a</td>
<td>p</td>
</tr>
<tr>
<td>173) Outpatient clinics</td>
<td>a</td>
<td>p</td>
</tr>
<tr>
<td>174) Hospices</td>
<td>a</td>
<td>p</td>
</tr>
<tr>
<td>175) Long stay hospitals and homes for the elderly</td>
<td>a</td>
<td>p</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Laboratories (in or outside hospitals)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>176) Pathology, general</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>177) Pathology, specialised</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>178) Haematology</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>179) Autopsy reports</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>180) Institute of forensic medicine</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>181) Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Death certificates                                                       | -          | a         |

| General practitioners                                                    | a          | -         |

| Specialist practitioners                                                 | a          | -         |

| Health insurance                                                         | -          |           |

| Screening programmes                                                     | -          |           |

<table>
<thead>
<tr>
<th>Administrative sources</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>187) Central population registers</td>
<td>-</td>
<td>p</td>
</tr>
<tr>
<td>188) Central medical registers (e.g. hospital information systems)</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>189) Other</td>
<td>-</td>
<td></td>
</tr>
</tbody>
</table>
XIX SCREENING PROGRAMMES

190) Type and year of start cervix: started in the 60's and was complete in the 70's, there is also a lot of spontaneous screening

191) age group how often

192) breast: started in 1977 in Malmö with 45-69 years. 1988-89 screening was done at most places varies: starting at: 40 years; 45 years; 50 years ending at: 45 years; 65 years; 70 years; 74 years every 18th - 24th month

193) colon: A study on sigmoidoscopy is going on 55 years old

194) melanoma: random screening is offered by Cancer society at e.g. beaches during the summer

195) prostate: unstructured screening of PSA

196) There is NO COOPERATION WITH or reception of information from any screening programmes.

XX USE OF COMPUTER

197) THE SOFTWARE USED IN THE REGISTRY has been developed locally using DSM

XXI CONFIDENTIALITY

The registry observes the following set of rules on confidentiality:

198) The conditions for delivering of information from the registry are as follows:

a) The information is given on the condition that the regulations in the law on confidentiality 1980:100 14 chapter 9§ are followed

b) Personal information must be kept so that unauthorised persons cannot gain access to the information

c) Direct contact to the person in question, relatives etc. may not be done by you without permission from the medical Doctor in charge of the ward or the chief Consultant at the current department

d) At the end of the project all material containing personal data must be destroyed.

Concerning data-media see also the regulations from the Data-inspection

e) Publication of material must be done in such a way that no individual can be identified.

199) Current regulations in the law concerning data 1982-07-01 must be followed. See also in the instructions on adaptation of the law on data.

200) When ordering personal identifiable extract on a data-medium (diskette) the permission from the data-inspection must be enclosed. As the database of the cancer registry is changed continuously we cannot keep these data-extractions updated.

201) In case of questions concerning annulment or quality of the delivered material the cancer registry is to be contacted first.

202) The regional cancer registry presupposes also that the registry is mentioned as source in all prospective publications. We therefore ask you to send us a copy of the publication (or
equivalent) when the work is ended.

203) The signing of the order in the application is at the same time a confirmation that you have participated in and accepted the conditions, listed above, for handling the material and the reservations given for publication of the given information.

204) The registry is legally permitted to link with other files.

This is regulated by:

205) By the Data-inspection
206) In certain cases also by the ethical committee

207) In principle identifiable information cannot be deleted in the registry.

208) An individual can legally obtain access to data about himself/herself in the registry. This is regulated according to § 10 about registries. In a hospital case sheet certain information may be removed, but not in the cancer registry, there it is ordered that the individual has a right to get all the information. Patient requests are handled by the local government forwarding requests to the relevant registries.

209) An individual cannot refuse to be included in the cancer registry.

210) An individual does not have to be asked/informed before being included in the cancer registry.

The following can get access to the cancer registry data:

211) - Tabulated data - anonymously there are no special restrictions
212) - On case by case basis - with identifying information:
   a) The scientist according to the rules described above
   b) The patient as described
213) International release may only be done after making the person anonymous; e.g. by giving serial numbers to the persons in international studies, and having the key only in the country of origin.

XXII QUALITY CONTROL

Completeness of coverage:

214) There is no routine for estimating the completeness of registration.

215) The number of forms from the pathological departments are followed annually, and it is found that within 1 month more than 80% of the reports are received and after ½ year the number is almost complete (app ).

216) The number of forms from the clinical departments are followed annually, and within 12 months the number is almost complete (app ).

217) Target directed registries: care-programme registries, quality registries and study-registries are good measures of quality and a quality control as the co-operation is very close. Tumours found in these special registries and not in the cancer registries are evaluated and vice-versa.

218) Disease index comparison is only used in special investigations (e.g. hospital statistics)
   a) In one investigation regarding breast cancer four cases were missing.

219) Outpatient logs - not used.
Pathology department logs in a special investigation

a) For Malmö a comparison was made with the pathology-registry, and it turned out that the pathologists sometimes reclassify without informing the cancer registry furthermore they did not report correctly, so now the cancer registry receive the full pathological description (since 1996)

Comparison with patients enrolled in trial protocols is done

Random sampling of patients admitted to hospital and scrutiny of records for missed cases (capture - recapture) is not done

Surveillance of numbers of registrations from each source is not done, but the number of forms are followed annually

Completeness of detail:

The average number of sources/notifications per case is not calculated

The numbers are not known over the years - but may be calculated

Figures for a recent year for the following:

Figures for "unknown primary site" (199 in ICD7) were in 1994: 300 in Lund (3%)

Percent of "age unknown" - irrelevant

Percent of "treatment unknown" - treatment is not recorded

Percent of "stage unknown" - stage is only recorded in special programmes, not in the cancer registry

Percent of "no histology" was: 2.1%

Percent of "basis of diagnosis unknown" - irrelevant

Percent of "place of birth unknown" - is not recorded

Year/period to which these figures apply: 1988-92

The most recent year published for the region is 1988-92, as they are only published every 5 years locally. But data are every year, with 1 years delay sent to the central registry and data for Sweden are published from there earlier than the regional data.

Methods used to maintain quality control of the registry's data:

Independent re-abstraction of a sample of cases is not done

Independent re-coding of a sample of cases is not done

Independent duplicate data entry of a sample of cases is not done

Input logical checks is used - see below

Use of test cases is not done
Proof-reading of coded notification forms is done by the coding assistant, after which she hands over the forms and a list of the tumours to a colleague, who checks the forms against the list.

Summary tabular frequency checks is not used, but the Medical Director (TM) checks topography against morphology for rare combinations.

Incidental autopsy finding (percent) is calculated.

Cancer cases from Death certificates are not included.

Mortality/incidence ratio - highest/lowest site is not used.

Stability of rates over time is followed.

Comparison with neighbouring registries is not done locally.

**XXIII WEAK POINTS**

Malignancies which may be under-reported:
- Multiple squamous skin cancers, as the rules are not quite clear
- Leukemias, Polycythemia and Myelofibrosis may all be under-reported
- Overreported: Breastcancers

**XXIV CHECKS**

**AUTOMATIC COMPUTER-BASED CHECKS (SEE APPENDIX FOR DETAILS)**

Data entered for essential variables.................................................................yes

"Invalid" code for almost any variable..........................................................yes

**Other examples of checks**

**DATE OF DIAGNOSIS**

After or equal to start of cancer registry.........................................................yes

After or equal to date of birth........................................................................yes

Before or equal to date death.........................................................................yes

Before or equal to date of post-mortem........................................................yes

Date of death before or equal to date of post-mortem.................................yes

**TUMOUR TYPE**

Sex compatible with site.............................................................................yes

Age compatible with tumour type...............................................................no

Site of tumour compatible with histological type.......................................yes

Site of tumour compatible with code for laterality (paired organ).............yes

Site of tumour compatible with method of diagnosis...............................yes
Appendix 2  Sweden – Lund

260) Histology compatible with method of diagnosis ............................................yes

261) The IACR check-programme is only used for special tasks in connection with different studies

262) Manual/visual checks: see above

XXV OUTPUT FROM REGISTRY

In the regular routine publications of incidence rates, tables of rates are given by:

263) Year .................................................................................................................. calculated over a 5 year period
264) Sex ....................................................................................................................yes
265) Age .......................................................................................................................yes - graphically
266) Site .......................................................................................................................yes
267) Occupation .........................................................................................................no
268) Social group ......................................................................................................no
269) Residence .........................................................................................................yes
270) Geographical subdivision of your territory ......................................................yes at county level
271) Trends ................................................................................................................no
272) Other variable
   a) Basis for diagnosis .............................................................................................yes
   b) Relative rate to Swedish mean incidence (for municipality) .........................yes
   c) In the regular publications, the following standards are used:

273) World Standard .................................................................................................yes
274) European Standard and year ........................................................................Available but not published
275) Own Standard ...................................................................................................Sweden 1970
276) Other ................................................................................................................no

There are no regular/annual routine publications of mortality rates but they are available

277) Evaluation of incidence trends is carried out.
BASIC CHARACTERISTICS OF THE REGISTRY

STOCKHOLM

date: April 17th 1997

1) Oncologic centre for Stockholm and Gotland
2) Karolinska Hospital, M8
3) Box 100, S-171 76 Stockholm
4) Sweden
5) Tel: +46-8 51770000 (operator) - 51772980 (direct)
6) Fax: +46-8/ 348640
7) e-mail:

Persons interviewed:
Name: Position: Training/Degree Abbreviation:
Thomas Hatschek Oncologist TH
Ingvar Rosendahl Statistician IR

I THE REGISTRY

8) The registry is population-based and covers 1 region consisting of two counties: Stockholm and Gotland

9) The population includes all the people in the area who are entered in the official population statistics that is have been given a personal identification number. The HIV positive patients are not always entered, but the information about them is available in a special file.

10) Special registries - management (vård)-programmes:

   a) Breast cancer
   b) Bladder cancer
   c) Gynaecological cancer
   d) Lungcancer
   e) Non-Hodgkin lymphoma
   f) Prostate cancer
   g) Pancreas cancer
   h) Colorectal cancer
   i) Malignant melanoma
   j) Ventricle cancer
   k) Ear-nose-throat cancer
   l) Central nervous system tumours
   m) Metastasis to the skeleton
   n) Care taking of mouth-problems in cancer treatment

The data from these management (vård)-programmes are owned by special groups. They decide who may gain access to the data - it is therefore necessary to approach the management (vård)-programme-group if the more detailed data from the programmes are wanted.

II DEMOGRAPHICAL INFORMATION

11) An incidence publication was made annually till 1990, now one for the period 1991-93 will be coming soon - on county, health-ward area and on regional level.

12) There have been no changes in the population covered since the registry became regional in 1976. (see 28)
Appendix 2 Sweden – Stockholm

THE RESIDENT POPULATION IN THE AREA COVERED BY THE REGISTRY WAS IN 1994

13) a Males: ................................................................................................................ .......... 854 236
14) b Females: ............................................................................................................... .......  901 125
15) c Total: .......................................................................................................................... 1 755 361

16) The population figures are exact as the registry is linked directly to DAFA

17) Population figures used for incidence calculation are the midyear average figures, which are received annually from Umeå in 5 years age groups.

18) The Health system: (see 61 + 69)
   a) Primary ward, run by general practitioners in "healthcenters" (vårdcentraler)
   b) "Länsdelssjukehus" - minor hospital
   c) "Länssjukehus" - "County"-hospital
   d) "Regional hospital"

19) The hospitals are governed by the authority for the county ("Landstinget"), which is also responsible for collecting taxes for that purpose.

Regarding population data the following are available in the registry

20) Sex in one-year age groups on parish register level .................................................. -          -
21) Sex in five-year age groups ........................................................................................... x          x
22) Information on occupation in the cancer registry (CR). ............................................ -           -
23) Information on religion...................................................................................................-           -
24) "Ethnic group" and "place of birth" ..............................................................................-           -
25) The urbanity-degree ...................................................................................................... x            -
26) Information about the geographic distribution is given in a number with 6-digits: two first derived from county, two middle from municipality, two last from the parish registry (the smallest administrative unit "församlingen"). ........................................................... x          x
27) The address as a land registry-number (koordinatsystem - GIS)- on street-level . x          x

III HISTORY

28) The Swedish Cancer Registry was established in 1958. During the 1970’s registration was decentralized into six regional registries. The registry for the Stockholm-Gotland region started in 1976. The Regional Tumour Registry has since the transfer sent the collected and coded data to the central registry on an annual basis

29) The registry can present population based data from 1958

CHANGES

30) The Cancer registry has not been linked to the hospital discharge registry and no change of that kind has been made.

31) A few cases are however included from the management (vård)-programme - but usually the information goes the other way (47 + 83 + 230)
32) There have been CHANGES IN HOSPITAL PROCEDURES: Breast screening has in the beginning - 1976 when it started till it became general in 1987-88- made the incidence rates increase, but it seems to have reached the apex at present.

33) REPORTING OF CANCER CASES has always been compulsory for pathology- and hospital departments. Since 1985 it has also been compulsory for haematological laboratories and private practitioners.

34) At present reporting of tumours is compulsory for:
   a) Any medical Doctor employed privately or in a hospital department, who has diagnosed the tumour disease clinically or microscopically.
   b) Any medical Doctor writing a tumour disease on the death-certificate even if diagnosed after death.
   c) The doctor responsible for: pathological / cytological laboratories, the Forensic department, the Haematological lab., and other service departments.

35) Operation of the registry has not been discontinued at any time.

36) The registry is public so the local authorities (counties) are responsible for the data.

37) The data are reported annually to the National Board of health and Welfare but are owned by the local authorities.

IV STAFF & ORGANIZATION

38) EMPLOYEES: Medical Doctor - one day per week
   1 Statistician
   ½ Computer expert
   1 full time coding assistants for the registry
   4 assistants for the management (vård)-programmes and the registry

39) The cancer registry used to have a cancer-epidemiologist associated to / employed, and the plan is that another one will come to the registry soon - there is however also epidemiologists at the Karolinska Hospital and there is co-operation with the registry for heart diseases.

40) The registry is at present working closely with the following departments: Oncological department, and all with cancer wards (e.g. surgical, neurosurgical, haematologist and the skin clinic). Furthermore there is a close cooperation with the National Board of Health and Welfare- EPI-centre.

41) The registry has since 1998 been part of the Division for Public Health.

42) The registry is also one of the sources for information on need of resources.

43) The cancer-registry is located at the Karolinska Hospital

SOURCES OF FINANCE:

44) Registration of cancer is financed by the counties in the region, on a proportional basis, according to population.

45) Research projects are carried out in cooperation with others and are financed from funds, after application and acceptance of the project. Other special activities are the management (vård)- programs, though they are run with special assistants.
CODING

46) CODING OF SITE AND MORPHOLOGY IS CARRIED OUT at the registry, but plaintext must appear on the notification forms.

47) THE CODING / CLASSIFICATION OF NEOPLASMS TO SITE AND MORPHOLOGY is carried out by the regional coding assistants. They have received special training at the registry and at the national registry. They were originally trained as medical secretary / nurse etc.

48) Supervision of coding and solving of coding problems is done by the Medical Doctor (MD)-(TH).

49) In difficult cases a pathologist or other MD's will be contacted if necessary.

50) Some coding problems are discussed at the annual registry meeting, led by Jan Eriksson, who is a pathologist.

51) Coding problems may be brought to the coding group meetings, which are held 3 times a year and organised by the Central registry. Changes are sent to all in the coding instructions from the Central registry.

LETTERS / TELEPHONE

52) The registry is writing 2-3 times a week for clarification or to request notification forms. In this way the request for missing forms is first requested by letter and later by phone - sometimes the MD will call the pathologist on phone for clarification.

53) The registry has direct access to the admission-registry for Stockholm, which contains diagnosis, date and treatment.

V REPORTING

Tumour registration from diagnosis to registry:

54) The patient contacts the GP, who makes some investigations and/or refer the patient to the hospital - from there the patient may be sent on to a Department of Oncology

55) No fee is paid to the reporting physician or institution.

56) Most often it is the medical secretary who writes the report, and the doctor signs it.

57) Linkages may be carried out with the admission registry in Stockholm. Linkage with the population registry (SCB- Statistics Sweden) is carried out to check the persons name and ID-number. The registry receives an update on individuals continuously - as it is on line with DAFA.

58) Information on name and address of the reporting hospital / clinic / practitioner / or other source is kept. For each tumour however only the name of first/most important reporting (eventually the second) health facility is kept.

59) The registry thus has information which makes it possible to GO BACK TO THE ORIGINAL RECORDS.

60) Patients do have their "own" GP, but are free to go wherever they want. However, the fee is differentiated between the local clinic (vårdcentral) and a specialised department at a hospital.
VI SOURCES

THE REGISTRY REGULARLY RECEIVES NOTIFICATIONS FROM:

61) Hospitals
62) Medical records departments - rarely
63) Outpatient clinics
64) Hospices
65) Long stay hospitals and homes for the elderly

Laboratories (in or outside hospitals)
66) Pathology
67) Clinical chemistry
68) Autopsy notifications
69) Institute of forensic medicine

70) Death certificates are not used as source for tumour registration.

Other
71) General practitioners
72) Specialist practitioners
73) No special information is received from screening programmes.

FORMS RECEIVED

74) The registry receives B-forms from the pathologist on 80-90% of the cases - and 50-60% of the A-forms from the clinical departments without a reminder. Usually the big clinics are responsible for lack of notification forms -if a form is missing it is marked in the registry. Usually the pathological forms are received first. (Computer-controlled)

75) In 1994 114 cases out of 9709: 1,2% were diagnosed clinically only

76) The information about cancer is recorded from the notification forms.

THE REGISTRY RECEIVES ROUTINELY (OR HAS REGULAR ACCESS TO) COPIES OF THE FOLLOWING FOR CANCER PATIENTS:

77) Medical records ........................................................................................................... no
78) Pathology reports - from 4 out of the 6 departments - but for the two largest ordinary B-forms are received. ...........................................................................................................yes
79) Autopsy reports - as for the above. .....................................................................................yes
80) Discharge letter .......................................................................................................... no
81) Death certificates ........................................................................................................ no
82) Radiotherapy reports ................................................................................................. no
83) Hospital information system is not used but management (vård)-programme forms are accepted if they contain necessary information......................................................... no
84) The staff at the registry does not visit the oncologic clinic.
85) The original notification forms are stored in paper files and are also scanned into the computer.
86) **DEFINITION OF PLACE OF "RESIDENCE":**
The address as it is written in the parish register - (which is the permanent address -bopæl).

87) There are no special rules for Immigrants and/or non-residents except that those who are non-residents are kept in a special file.

88) The registry follows the same rules for refugees. - This is also the case for those with a "protected address".

89) Special subgroups/minorities in the population are not known.

90) TUMOURS IN PATIENTS WHO ARE NOT PERMANENT RESIDENTS OF THE REGISTRY TERRITORY are not registered but the forms are sent to the relevant registry (around 50 per month esp. to Uppsala) - and forms are received from the other registries.

91) Tumours in residents working abroad and belonging to the region are not registered.

92) The data are submitted to the Central registry in Stockholm once a year when the coding is completed.

**VII INFORMATION RECORDED**

93) THE CODING OF DATA is done manually.

94) THE PROCESSING OF DATA: on registration the forms are coded as they arrive and information on the person is checked in the registry (e.g. in case of multiple tumours).

95) Two or more notifications are linked electronically using the unique personal identification number.

96) The tumours are registered in the cancer registry immediately on arrival. But those tumours, which are not in the coding manual are not registered.

97) Computerized case resolution is not carried out.

**VIII THE PERSON**

98) **THE SOURCE FOR INFORMATION ON THE PERSON** is the Central Personal Registry (CPR), which assigns a number to each resident in Sweden

99) The patient is not given another number in the registry.

100) **THE UNIQUE PERSONAL REGISTRY NUMBER** is constructed of: 1 digit for the century + 10 digits, which are composed of: 2 digits for year, 2 digits for month and 2 digits for day of birth; The next 2 digits formerly gave the place of birth, 1 digit gives the sex: the odd for male and the even for female and the last digit is the control number for the index number.

101) Immigrants are assigned a CPR number when they become residents.

102) The number does not any longer indicate where the person was born, not if he/she belongs to any minority and it does not indicate ethnicity, but this may be available from the cancer-environmental registry.

103) The cancer registry is on line with DAFA and therefore receives updated information continuously. The year of emigration is also given from DAFA continuously. DATE OF DEATH is
given with year/month/day from the Statistics Sweden (SCB) until 1994. Now the linking to the cause of death registry is done centrally, and the information transferred to the regional registry - but the date of death is received directly, though with delay of 1 month. (18 + 115 + 223) The official cause of death ranks highest of the sources for the cause of death, but the autopsy cause of death is also registered.

**NAMES OF PATIENT**

104) The full name of the patient is registered. Maiden name may be kept in case of a multiple cancer coming after change of name

105) None of the following are registered: Maiden name (see also above) / Father's name / Mother's name

106) The ID number of the next of kin is not registered.

**RESIDENCE/ADDRESS AT THE TIME OF REGISTRATION**

107) The code for the address of the patient is registered.

108) The code is constructed of 2 digits for county, 2 digits for municipality and 2 digits for parish register (församling).

109) Change of address is given continuously, but the address at the time of diagnosis is kept in the registry - and from 1993 the whole history of the patient's address is kept - furthermore the tumour-number may be linked to the address-number.

110) The age at incidence date is calculated from CPR.

111) The nationality of the person (e.g. French, Danish) is not registered.

112) No further information is used from the CPR.

113) The nationality of father and/or mother is not available.

114) Marital/civil status at diagnosis is not registered.

115) Death - yes

116) Number of live births and categories (actual number) - no

117) Religion - no

118) Ethnic groups - no

119) Race - no

120) Patient's education - no

121) Occupation - no

122) Special enquet studies for occupation - no

123) Social class or socio-economic status - no

124) Patient's exposure to carcinogens - no
IX INCIDENCE DATE

DATE OF DIAGNOSIS (LEVEL OF DETAIL):

125) The date is recorded as the year, month and day of diagnosis.

126) The DATE OF DIAGNOSIS is defined as the earliest date written on the received notification forms.

127) Tumours notified only on death certificates are not traced in order to get earlier information.

128) Cases from the death certificate notes are not registered as "Death certificate only" (DCO) or at all, unless a notification form is received (e.g. from the doctor signing the death certificate). (see 103)

129) For a patient known from autopsy only, the incidence date is the date of death.

X BASIS OF DIAGNOSIS

METHODS

130) The "most valid basis", is having the following ranking order (from the SOS-guidelines):
   a) Histology of primary / bone marrow / metastases (from biopsy/operation/autopsy)
   b) Cytology (expectorate, aspirate etc.) / Haematology. ("cytology" is not changed to "histology" unless the "histology" has changed the diagnosis).
   c) No histology, cytology, marrow or bloodtest.
   d) No histology or cytology (e.g. clinical investigation / X-Ray / operation-autopsy without histology) is not ranked.

XI CLASSIFICATIONS

131) classification(s) as from SOS:
   a) From 1958: topography was coded according to ICD 7
   b) morphology was coded according to C24
   c) From 1987: topography was coded according to ICD 9 and ICD 7
   d) morphology was coded according to C24
   e) From 1993: Topography was coded according to ICD-2/10 with a few exceptions, and to ICD 9 and ICD 7
   f) morphology is coded according for the SNOMED / ICDO-2 code and C24.
132) **Exceptions** to the classification rules:
Topography according to ICDO-2 where the following are coded according to ICD 10:
- Malignant melanoma in the skin: C43
- Hodgkins lymphoma: C81
- Follicular non-Hodgkin Lymphoma: C82
- Diffuse non-Hodgkin Lymphoma: C83
- Peripheral and cutaneous T-cell lymphomas: C84
- Malignant lymphoma, NOS, or diffuse: C85 (see special list in the incidence publication as ICD 10 also differs slightly from the classification)
- Immunoproliferative diseases: C88
- Plasma cell tumours: C90
- Lymphatic leukemias: C91
- Myeloid leukemias: C92
- Myelodysplastic syndrome: D46
- Monocytic leukemias: C93
- Other specified leukemias: C94
- Leukemias, NOS: C95
- Neoplasm malignum telae lymphatica et haematopoeticae/ other and unspecified tumours in lymphoid and haematopoietic tissue: C96 / D45 / D47 / D76
These are all transformed to the ordinary ICD 7 code: 200x - 209x, where each group contains the types of lymphoma / leukaemia as defined in Sweden (see table W2 in the Incidence publication for the whole country)

133) **TOPOGRAPHY (PRIMARY TUMOUR)** is defined according to the clinician's assessment - and the Clinician weighs heavier than the pathologist. The code is chosen according to specificity.

134) Topography codes may be changed if new information is more specific.

135) **MORPHOLOGY** is defined according to pathology description and the Pathologist weighs heavier than the clinician. The code is given from the pathologist and coded according to SNOMED (ICD-O2) / C24

136) Morphology may be changed if a histological description is received after a cytological description, and it is more specific - if there are different morphologies, the pathologist is asked or each case is validated.

137) **BEHAVIOUR OF TUMOUR** is given by the PAD - the pathologist decide the evaluation/criteria for the quality of the information. The code chosen is the most malignant.

138) If the behavioural code changes, a new tumour has to be registered - with a new diagnose-date - if e.g. an in situ tumour becomes invasive.

139) This (above) however has to be evaluated in each case, as no specific time limits were mentioned otherwise the behaviour of the tumour is changed. However Myelodysplastic syndrome (9989/1) developing into a malignant disease more than 2 months after being diagnosed is registered as a new malignant tumour. And Cervix CIS which becomes invasive within a year is counted as malignant from the date of diagnosis of the CIS.

140) **List of reportable tumours:**
- All definitely malignant neoplasms (e.g. carcinoma, sarcoma, malignant lymphoma, leukaemia and malignant teratoma).
- Carcinoid tumours of digestive organs, granulosa tumours of the ovary, thymomas, adamantinomas and chordomas.
- Histologically benign tumours of the central nervous system and meninges, transitional cell papillomas of the urinary tract, all hormonal active tumours of the endocrine glands (except the thyroid) and the entero-chromaffin and neuroendocrine systems.
Appendix 2 Sweden – Stockholm

d) Precancerous lesions of lip, mouth, larynx, bronchus, trachea, cervix uteri, skin, vulva and vagina, gastro-intestinal polyps with suspected malignancy, bronchial adenomas, atypical epithelial proliferations of the breast (carcinoma in situ type) and adenoma phylloides, precancerous endometrial lesions, hydatidiform moles of placental tissue, and ovarian cystadenomas of borderline type.

141) **List of tumours included** in incidence publications:
   a) Diseases mentioned under A-C are included in the incidence publication, although a number of the tumours listed under C are considered not to be "infiltrating and metastasising" and are therefore also listed separately (papilloma, urinary tract; histologically benign tumours of the central nervous system; histologically benign tumours of endocrine glands; low grade fibrosarcoma (incl. dermatofibro-sarcoma protuberans).
   b) The reportable tumours mentioned under D are not included in the cancer incidence, but are tabulated separately.
      i) Basaliomas have not been registered.

**Conversion of ICD:**

142) Tables for converting codes from one system to another are created centrally in Stockholm (Epidemiologic centre) by a pathologist continuously, but in co-operation with the coding-group. From the centre the set-up and changes are distributed to all the regional registries; furthermore the conversion tables are given in the annual "Incidence book". E.g. ICD-O -> ICD-9 was created in this registry and then discussed with the central registry - who are now maintaining it.

**The purpose** of the conversion of ICD classification is:

143) To ensure comparability with old data.
144) To a certain degree to make data comparable with data from other registries (e.g. Eurocare)

**Diagnosis recorded in addition to the cancer diagnosis coded by the registry:**

145) Admission diagnosis - not coded
146) Discharge diagnosis - not coded
147) Cause of death - is not coded
148) Autopsy diagnosis - is not coded
149) Other diagnosis (e.g. AIDS / Hepatitis ICD-10: B21) are not coded.

**Malignant diseases routinely excluded when reporting data from the registry:**

150) Formerly Basalcell carcinomas of the skin were excluded. Now it is discussed to include them as well. Furthermore the tumours, which in the guidelines are marked 1b are not included in the incidence publication - see appendix for details.
Appendix 2  Sweden – Stockholm

THE TUMOURS BELOW are recorded and included in incidence data as shown:

<table>
<thead>
<tr>
<th>Tumour type</th>
<th>Record yes</th>
<th>Record no</th>
<th>Included yes</th>
<th>Included no</th>
</tr>
</thead>
<tbody>
<tr>
<td>151 Benign brain tumour</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>152 Pituitary gland</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>153 Carotid body</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>154 Benign bladder tumour (papilloma)</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>155 Intraductal carcinoma (8500/2) in the breast</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>156 Carcinoma in situ in the breast, other than above</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>157 Borderline tumour in the ovary</td>
<td>X</td>
<td></td>
<td>Morpho= 86301/85901/86211/86321/86700</td>
<td>X</td>
</tr>
<tr>
<td>158 Carcinoma in situ in testis</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>159 Chromaffinoma (8700/0) of the adrenal gland</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>160 Argentaffinoma (8241/1)</td>
<td>No information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>161 Chordoma (9370/3)</td>
<td>No information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>162 Invasive mole (9100/2 – in the ICD-O: 9100/1)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>163 Pre-cancerous lesion in the cervix</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

164) Other benign or precancerous lesions coded to or included with categories of malignant tumours and other specific information: Parathyroid adenoma

165) Clinical stage / extent of tumour is recorded only in specific management (vård)-programmes and the information will only be available in co-operation with the respective boards. However some pre-cancerous lesions will be tabulated as CIS ("stage 0") of uterine cervix.

XII MULTIPLE PRIMARIES

166) The rules used to code multiple cancers in the registry are given from the Central Cancer registry (National board of Health and Welfare)

a) Colon tumours - formerly only one tumour was registered if there were e.g. more than one tumour in the transverse colon. Now each is registered if it can be proved that they are separate tumours. Adenomas are registered separately.

b) For Astrocytoma grade 1 which after some years develop into multiform glioblastoma no information was obtained.

c) The registry counts tumours not patients except for:

d) Skin tumours - if "skin tumours" are diagnosed in the same area and on the same occasion they are registered and coded as one (e.g. if more cancers on the same arm: only registered as one) - but if it is different occasions they are counted separately. If more melanomas are diagnosed in different regions on the same occasion, they are coded with the topography C43.8.

e) Urinary tract tumours - if more than one tumour (incl. in situ) are diagnosed at the same topography and within one year - this problem was not discussed. At different topographies they are counted separately.

RULES FOR CODING CANCERS IN PAIRED ORGANS:
Appendix 2  Sweden – Stockholm

167) Tumours with the same morphology on each side - for breasts - are coded as two tumours, and counted as two when calculating incidence rates.

168) Tumours with different morphology on each side are coded as two tumours, and counted as such.

169) Tumours with different behaviour (e.g. intraductal carcinoma in left breast and duct carcinoma in right breast) are coded as two tumours, but counted as one tumour.

XIII TREATMENT

170) TREATMENT is not recorded in the Cancer Registry, but is available through the Cancer management (vård) Programmes.

XVII FOLLOW-UP and TRACE-BACK

A By follow-up we mean that the registry follows up fully registered cases to obtain information about e.g. recurrence, treatment, or death.

B By trace-back we mean, that the registry actively attempts to obtain information about a tumour, (e.g. first notified on a death certificate, or if the information on a patient is not satisfactory for other reasons) in order to complete the coding of the tumour recorded.

<table>
<thead>
<tr>
<th>Active (a) or passively (p) receipt of data from the following sources for follow-up and/or trace-back</th>
<th>trace-back</th>
<th>follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospitals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>171) Clinical departments</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>172) Medical records</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>173) Outpatient clinics</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>174) Hospices</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>175) Long stay hospitals and homes for the elderly</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>Laboratories (in or outside hospitals)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>176) Pathology, general</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>177) Pathology, specialised</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>178) Haematology</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>179) Autopsy reports</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>180) Institute of forensic medicine</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>181) Other</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>182) Death certificates</td>
<td>-</td>
<td>p</td>
</tr>
<tr>
<td>183) General practitioners</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>184) Specialist practitioners</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>185) Health insurance</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>186) Screening programmes</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>Administrative sources</td>
<td></td>
<td></td>
</tr>
<tr>
<td>187) Central population registers (DAFA-SPAR)</td>
<td>-</td>
<td>p</td>
</tr>
<tr>
<td>188) Central medical registers (e.g. hospital information systems)</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>189) Other</td>
<td>-</td>
<td></td>
</tr>
</tbody>
</table>

Survey of Nordic Cancer Registries, 2000 188
XIX SCREENING PROGRAMMES

<table>
<thead>
<tr>
<th>Type and year of start</th>
<th>age-group</th>
<th>how often</th>
</tr>
</thead>
<tbody>
<tr>
<td>190) cervix: 1968</td>
<td>years</td>
<td>25 every third year</td>
</tr>
<tr>
<td>191) breast: 1989</td>
<td>years</td>
<td>50 every second year</td>
</tr>
<tr>
<td>192) colon: none</td>
<td></td>
<td></td>
</tr>
<tr>
<td>193) melanoma none</td>
<td></td>
<td></td>
</tr>
<tr>
<td>194) prostate: none</td>
<td></td>
<td></td>
</tr>
<tr>
<td>195) There is no special co-operation with the screening programmes.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

XX USE OF COMPUTER

196) The software used in the registry is developed by a Consulting firm.

XXI CONFIDENTIALITY

The registry observes the following set of rules on confidentiality:
(copied from the report from Lund, as it contains the same requirements with slightly different wording)

THE CONDITIONS FOR DELIVERING OF INFORMATION FROM THE REGISTRY ARE AS FOLLOWS:

197) The information is given on the condition that the regulations in the law on confidentiality 1980:100 14 chapt 9§ are followed
   a) The material may only be used in the project specified in the application.
   b) Personal information must be kept so that unauthorised persons cannot gain access to the information
   c) Direct contact to the person in question, relatives etc. may not be done by you without permission from the medical Doctor in charge of the ward or the chief Consultant at the current department
   d) At the end of the project all material containing personal data must be destroyed.
   Concerning data-media see also the regulations from the Data-inspection
   e) Publication of material must be done in such a way that no individual can be identified.

198) Current regulations in the law concerning data 1982-07-01 must be followed. See also in the instructions on adaptation of the law on data.

199) According to a new law, only permission from the Ethics committees is required to use data in research projects. As the database of the cancer registry continuously is changed continuously we cannot keep these data-extractions updated.

200) In case of questions concerning annulment or quality of the delivered material the cancer registry is to be contacted first.

201) The Epidemiological Centre presupposes also that the registry is mentioned as source in all prospective publications. We therefore ask you to send us a copy of the publication (or equivalent) when the work is ended.

202) The signing of the order in the application is at the same time a confirmation that you have participated in and accepted the conditions, listed above, for handling the material and the reservations given for publication of the given information.
Appendix 2  Sweden – Stockholm

203) The registry is legally permitted to link with other files

This is regulated by:
204) By the Data-inspection

205) In certain cases also by the ethical committee

206) There are no rules that identifiable information should be deleted in the registry

207) AN INDIVIDUAL CAN LEGALLY OBTAIN ACCESS TO DATA ABOUT HIMSELF/HERSELF IN THE REGISTRY, but this is usually done at regional level. Patient requests - has not been actual.

208) An individual cannot refuse to be included in the cancer registry

209) An individual does not have to be asked / informed before being included in the cancer registry

THE FOLLOWING CAN GET ACCESS TO THE CANCER REGISTRY DATA:

210) On case by case basis - anonymously there are no special restrictions

211) On case by case basis - with identifying information:
   a) The scientist according to the rules described above
   b) The patient as described - no actual problem.

212) International release - has not as yet been relevant -(may only be done after making the person anonymous; e.g. by giving serial numbers to the persons in international studies, and having the key only in the country of origin).

XXII QUALITY CONTROL

Completeness of coverage:

213) There is no routine for estimating the completeness of registration

214) The number of forms from the pathological departments - not mentioned as source for following the completeness of the registry.

215) The number of forms from the clinical departments - was not mentioned as a source to be followed

216) Management (vård) programme registries: are used.

217) Disease index / Hospital discharge registry is not used.

218) Outpatient logs - not used

219) Pathology department logs - not used.

220) Comparison with patients enrolled in trial protocols is not done, but information received from scientists is used and included in the registry, and in this way research is contributing to the completeness of the registry.

221) Random sampling of patients admitted to hospital and scrutiny of records for missed cases (capture - recapture) is not done.
Appendix 2  Sweden – Stockholm

222) Surveillance of numbers of registrations from each source is not done.

**COMPLETENESS OF DETAIL:**

223) The average number of sources/notifications per case is not calculated

224) The number of sources are not known over the years

**FIGURES FOR A RECENT YEAR FOR THE FOLLOWING:**

225) Figures for "unknown primary site (199 in ICD7)" is not known.

226) Percent of "age unknown" - irrelevant.

227) Percent of "treatment unknown" - treatment is not recorded.

228) Percent of "stage unknown" - stage is not recorded.

229) Percent of "no histology" was not calculated.

230) Percent of "basis of diagnosis unknown" - irrelevant.

231) Percent of "date of birth unknown" - irrelevant, is always known.

232) Year/period to which these figures apply: not relevant

233) THE MOST RECENT YEAR PUBLISHED for the region is 1990, and 1991-93 is on the way.

**METHODS USED TO MAINTAIN QUALITY CONTROL OF THE REGISTRY'S DATA:**

234) Independent re-abstraction is not done.

235) Independent re-coding of a sample of cases is not done. Formerly however one person would do the coding on the notification form and another would type the figures into the system.

236) Independent duplicate data entry is not done.

237) Input logical checks is used - see below

238) Use of test cases is not done

239) Proof-reading of coded notification is not done.

240) Summary tabular frequency checks are not used, but an electronic check is done after which lists of strange combinations are produced and checked manually for histology versus topography.

241) Incidental autopsy finding - not calculated

242) Cancer cases from Death Certificates Only (DCO) are not included in the incidence rates. (103)

243) Mortality/incidence ratio - highest/lowest site is not used as quality control.

244) Stability of rates over time is followed.

245) Comparison with neighbouring registries is not done.
XXIII WEAK POINTS

246) Malignancies which may be under-reported:
AIDS-related tumours may have been under-reported in a period. Leukaemia have caused
problems as the coding has changed over time.

XXIV CHECKS

AUTOMATIC COMPUTER-BASED CHECKS (the same system is used as in Lund)

247) Data entered for essential variables is checked yes

248) "Invalid" code for almost any variable yes
   a) hospital code is valid
   b) clinic code is valid
   c) pathology laboratory is valid
   d) home address is valid
   e) ICDO code is valid
   f) ICD9 code is valid
   g) ICD7 code is valid
   h) SNOMED code is valid
   i) C24 code is valid
   j) Metastasis code is valid
   k) Basis of diagnosis is valid
   l) slide number is valid
   m) Cancer death is valid
   n) Autopsy result is valid

OTHER EXAMPLES OF CHECKS

DATE OF DIAGNOSIS

249) Before or equal to date death yes
250) Before or equal to date of post-mortem yes
251) Before or equal to date of report
252) Date of death before or equal to date of post-mortem yes
253) In case of only autopsy finding: date = date of death

TUMOUR TYPE

254) Sex compatible with site yes
255) Age compatible with tumour type no
256) Site of tumour compatible with histological type yes
257) Site of tumour compatible with code for laterality (paired organ) yes
258) Site of tumour compatible with method of diagnosis yes
259) Histology compatible with method of diagnosis yes

260) The IACR check-programme is not used.

261) Manual/visual checks: see above

XXV OUTPUT FROM REGISTRY

In the regular routine publications of incidence rates, tables of rates are given by:

262) 5-Years periods yes
263) Sex yes
264) Age yes
265) Site yes
266) Occupation no
Appendix 2  Sweden – Stockholm

267) Social group
268) Residence
269) Geographical subdivision of your territory yes at regional and county level
270) Trends
271) Other variable

IN THE REGULAR PUBLICATIONS, THE FOLLOWING STANDARDS ARE USED:

272) World Standard
273) European Standard and year
274) Own Standard Sweden 1970
275) Other

There are no regular/annual routine publications of mortality rates but they are available

276) Evaluation of incidence trends is not carried out.
Appendix 2  Sweden – Umeå

BASIC CHARACTERISTICS OF THE REGISTRY
UMEÅ date: April 29th 1997

1) Oncologic centre for the Northern Region
2) University Hospital
3) S-901 85 Umeå
4) Sweden
5) Tel: +46-90/ 7851990
6) Fax: +46-90/ 127464

Persons interviewed:
Name: Position: Training/Degree Abbreviation:
Lena Damber  Head of department Statistician/epidemiologist LD
Håkan Jonsson    Statistician/epidemiologist HJ

I THE REGISTRY

8) The registry is population-based and covers: Västernorrland, Jämtland, Västerbotten and Norrbotten - The Northern region.

9) The population includes all the people in the area who are entered in the official population statistics that is have been given a personal identification number.

10) Special registries - management-programmes:
   a) Breast cancer (1)
   b) Urothelial cancer (1)
   c) Lungcancer (1)
   d) Malignant melanoma (1)
   e) Sarcoma - soft tissue (3s)
   f) Non-Hodgkin lymphoma (1)
   g) Osteosarcoma (3s)
   h) Ewingsarcoma (3s)
   i) Prostate cancer (1)
   j) Testis tumours (non-seminomas) (2+3s)
   k) Rectum cancer (1+2)
   l) Gynaecological cancer (1)
   m) Acute leukaemia (1)
      i)(1): regional programme
      ii) (2): national programme
      iii) (3): international programme (3s): Scandinavian

II DEMOGRAPHICAL INFORMATION

11) An incidence publication is made every year on county and on regional level. In the publication is the aggregate incidence for the last five years.

Changes

12) Furthermore in 1984 the county of Jämtland was included in this region, which took over all the data for Jämtland.
The resident population in the area covered by the registry was in 1994

13) a Males: .............................................................................................................. 463,365
14) b Females: .............................................................................................................. 460,654
15) c Total: .............................................................................................................. 924,019

16) The population figures are exact.

17) Population figures used for incidence calculation are the figures for the end of the year, and are updated annually from the Statistic Central Bureau.

18) The Health system: (see 61 + 69)
   a) Primary ward, run by general practitioners in "healthcentres" (vårdsentraler)
   b) "Länssjukhus" - minor hospital
   c) "Länsjukhus" - "County"-hospital
   d) "Regional hospital"

19) The hospitals are governed by the authority - for the county ("Landstinget"), which is also responsible for collecting taxes for that purpose.

Regarding population data the following are available in the registry

<table>
<thead>
<tr>
<th>Available</th>
<th>Used</th>
</tr>
</thead>
<tbody>
<tr>
<td>20) Sex in one-year age groups on parish register level.</td>
<td>x</td>
</tr>
<tr>
<td>21) Sex in five-year age groups</td>
<td>x</td>
</tr>
<tr>
<td>22) Information on occupation in the cancer registry (CR).</td>
<td>-</td>
</tr>
<tr>
<td>23) Information on religion</td>
<td>-</td>
</tr>
<tr>
<td>24) For &quot;ethnic group&quot; and &quot;place of birth&quot;, there is no information in the registry.</td>
<td>-</td>
</tr>
<tr>
<td>25) The urbanity-degree is available</td>
<td>x</td>
</tr>
<tr>
<td>26) Information about the geographic position is given in a number with 6-digits): two first derived from county, two middle from municipality, and the two last from the parish registry (the smallest administrative unit) (&quot;församlingen&quot;).</td>
<td>x</td>
</tr>
<tr>
<td>27) The address as a land registry-number (koordinatsystem - GIS)</td>
<td>-</td>
</tr>
</tbody>
</table>

III History

28) The registry started operating in 1958 in Stockholm, and from 1978 the data have been collected at the regional registry. The Regional Tumour Registries have since the transfer sent the collected and coded data to the central registry on an annual basis.

29) The registry can present population based data from 1958.

Changes

30) The registry is linked with other registries: management-programme registries, since 1959 to the clinic registry and receives electronic notifications through this - for some cancers up to 90% are received this way. Furthermore the registry is linked with research-registries including clinical studies and receives updates and corrections through this channel.

31) A few cases are included from the management-programme- and quality-control-registries, but usually the information goes the other way.
Appendix 2 Sweden – Umeå

32) There have been changes in hospital procedures: e.g. needle-biopsy for prostate cancer as well as the PSA, which may have caused an increase in the frequency of clinical diagnosis, however at the same time the autopsy-rates have decreased and caused the post-mortem frequency of prostate cancer diagnosis to decrease, consequently the influence of either cannot be detected.
   a) Breast screening has on the other hand influenced the incidence rates. In the 1960’s people seemed to be less disposed for notifying cancer-cases.

33) Reporting of cancer cases has always been compulsory for pathology- and hospital departments. Since 1985 it has also been compulsory for haematological laboratories and private practitioners.

34) At present reporting of tumours is compulsory for:
   a) Any medical Doctor employed privately or in a hospital department, who has diagnosed the tumour disease clinically or microscopically.
   b) Any medical Doctor writing a tumour disease on the death-certificate even if diagnosed after death.
   c) The doctor responsible for: pathological / cytological laboratories, the Forensic department, the Haematological lab., and other service departments.

35) Operation of the registry has not been discontinued at any time.

36) The registry is public so the local government (counties) are responsible for the data and owns them.

37) The data are reported annually to the National Board of health and Welfare.

V STAFF & ORGANIZATION

38) Employees:
   a) Local government (landsting)
   b) 1 Oncologist
   c) 1 Head of department of the cancer registry, data system and research-projects.
   d) 1 Statistician
   e) 4 assistants for cancer-management-programme registries + cancerregistry Research funds (forskningsanslag)
   f) 2 Statistician connected to research -projects
   g) 3 Secretary (management-programmes; clinical studies, research-projects)

39) There is close co-operation with different groups always depending on which research-project is being worked on, e.g. groups of clinician working on the management-programmes, scientists on other research projects.

THE FOLLOWING DEPARTMENTS/INSTITUTIONS ARE working closely with the registry:
40) Research groups - see above.
41) Groups of clinicians - see above.
42) Other projects - see above.
43) The cancer-registry is located with the oncological centre (OC) of which it is part. The OC is located at the "Norrlands" University Hospital in Umeå.

SOURCES OF FINANCE:

44) Registration of cancer is financed by the local government, which gets the funds from the counties in the region, on a proportional basis, according to population.
45) Research projects are carried out in co-operation with others and are financed from funds, after application and acceptance of the project.

Codings:

46) **Coding of Site and Morphology is carried out** at the registry.

47) **The coding / classification of neoplasms to site and morphology** is carried out by the 3 regional coding assistants.

48) Supervision of coding and solving of coding problems is done by a medical doctor, who is specialised in oncology. He is having an office at the registry, but is also spending some of his time at the clinic.

49) In difficult cases other MD’s (often oncologist) or a pathologist will be contacted, if necessary.

50) Some coding problems are discussed at the annual registry meeting, led by Jan Ericsson, who is a pathologist.

51) Coding problems may be brought to the coding group meetings, which are held 3 times a year and organised by the Central registry. Changes are sent to all in the coding instructions from the Central registry.

Letters / Telephone:

52) The registry has to request for clarification for about 30% mainly concerning "Topography". There are only few cases not reported from the pathologist.

53) The coders are writing to the relevant departments for this.

V Reporting:

Tumour registration from patient to registry: (see 20)

54) The patient contacts the GP at the Health-station (vårdcentral), who makes some investigations and/or refer the patient to the hospital in Umeå.

55) No fee is paid to the reporting physician or institution.

56) Most often it is the medical secretary who writes the report, and the doctor signs it.

57) Linkages is carried out with the Population Registry in order to ensure that official date of death every week. Linkage with the population registry (SCB- Statistics Sweden) is also carried out to check the persons name and address every week.

58) Information on name and address of the reporting hospital / clinic / practitioner / or other source is kept. For each tumour only information on the first reporting clinical department is kept.

59) The registry thus has information which makes it possible to go back to the original records as far back as to 1974.

60) Patients do not have their "own" GP, and are free to go, wherever they want, but the cheapest is to go to the local clinic/health-station (vårdcentral).
Appendix 2 Sweden – Umeå

VI SOURCES

THE REGISTRY REGULARLY RECEIVES REPORTS FROM:

61) Hospitals.
62) Medical records departments - no reports.
63) Outpatient clinics.
64) Hospices.
65) Long stay hospitals and homes for the elderly.

Laboratories (in or outside hospitals)
66) Pathology.
67) Haematology.
68) Autopsy reports.
69) Institute of forensic medicine.

70) Death certificates are not used as source for tumour registration but for a few years the information is available. They are not included in the incidence computation, but would increase the figures with a few percent, though varying with the diagnosis.

Other
71) General practitioners.
72) Specialist practitioners.
73) The screening programmes are linked to the cancer registry continuously as they are all managed from the cancer registry.

FORMS RECEIVED

74) The registry receives forms from the pathologist on almost all cases.
75) It was not mentioned how many are only diagnosed clinically. Forms are received from the clinic as mentioned above, but usually the pathological forms are received first.
76) THE INFORMATION ABOUT CANCER IS recorded from the reporting forms.

THE REGISTRY DOES RECEIVE (OR HAS REGULAR ACCESS TO) COPIES OF THE FOLLOWING FOR CANCER PATIENTS, THOUGH:

77) Medical records - only if necessary.............................................................. rarely
78) Pathology reports - (complete description).................................................yes
79) Autopsy reports - as for 78........................................................................yes
80) Discharge letter ............................................................................................... no
81) Death certificates are not received, though the certificates were received for some years...... no
82) Radiotherapy reports ...................................................................................... no
83) Hospital information system in the way of the very close co-operation with the management-programmes.................................................................yes
84) The staff at the registry visits the oncologic clinic in Umeå if some information is missing and collect patient-paper.
85) The original notification forms are stored in paper files.
DEFINITION OF PLACE OF "RESIDENCE":

86) The address as it is written in the parish register - (which is the permanent address -bopæl).

87) Very few immigrants and/or non-residents, but they are not included in the registry.

88) The registry has no experience with refugees, but would follow the same procedure as above - this is also the case for those with a "protected address".

89) Special subgroups/minorities in the population are not known.

90) Tumours in patients who are not permanent residents of the registry territory are not registered but the forms are sent to the relevant registry - and forms are received from the other registries.

91) Residents working abroad and belonging to the region are included if they belong to the population ; they must be written in the population registry.

92) The data are submitted to the central registry in Stockholm once a year when the coding is completed.

VII INFORMATION Recorded

93) The coding of data is done manually and immediately.

94) The processing of data: on registration all forms on the person are consulted if necessary (e.g. in case of multiple tumours). In case of obscurity the coder will either write to the department or wait for more notification forms to arrive.

95) Two or more notifications are linked electronically using the unique personal identification number.

96) The tumours are registered in the cancer registry immediately within the week of arrival.

97) Computerised case resolution is not carried out.

VIII THE PERSON

98) The source for information on the person is the Central Personal Registry (CPR), which assigns a number to each resident in Sweden

99) The patient is not given another number in the registry.

100) The unique personal registry number is constructed of: 1 digit for the century + 10 digits, which are composed of: 2 digits for year, 2 digits for month and 2 digits for day of birth; The next 2 digits formerly gave the place of birth, 1 digit gives the sex: the odd for male and the even for female and the last digit is the control number for the index number.

101) Immigrants are assigned a CPR number when they become residents.

102) The number does not any longer indicate where the person was born nor if he/she belongs to any minority and it does not indicate ethnicity.

103) The cancer registry receives updated information concerning date of death / emigration / immigration every week from the local government (SCB). The cancer registry was linked to
the Cause of Death registry for the cause of death, but this information is now received from SOS. The cause of death given on the cancer / autopsy report is also recorded.

**Names of Patient**

104) The full name of the patient is registered.

105) None of the following are registered: Maiden name / Father's name / Mother's name

106) The ID number of the next of kin is not registered.

**Residence/Address at the Time of Registration**

107) The code for the patient's address is registered.

108) The code is constructed of 2 digits for county, 2 digits for municipality and 2 digits for parish register (församling).

109) Change of address is given from the SCB weekly, but the address at the time of diagnosis is kept in the registry as address at date of diagnosis.

110) The age at incidence date is calculated from CPR

111) The person's nationality (e.g. French, Danish) is not registered.

112) No further information is used from the CPR.

113) The nationality of father and/or mother is not available.

114) Marital/civil status at diagnosis is not registered, but the following categories are available:
   a) Married – no
   b) Separated – no
   c) Divorced – no
   d) Widow/widower – no
   e) Cohabitation – no
   f) Single – no

115) Death - yes

116) Number of live births and categories (actual number) no

117) Religion - no

118) Ethnic groups - no

119) Race - no

120) Patient's education - no

121) Occupation - no

122) Special enquet studies for occupation - no

123) Social class or socio-economic status - no

124) Patient's exposure to carcinogens - no

**IX Incidence Date**

**Date of Diagnosis (Level of Detail):**

125) The date is recorded as the year, month and day of diagnosis.

126) The date of diagnosis is defined as the earliest date written on the received notification reports, but will very often be the date of the pathology/histology report, but if the clinicians date of diagnosis is earlier, that date is chosen. The date of diagnosis is however not the date when the
suspicion of cancer arose, but rather the date of the diagnosis (as written on the form).

127) Tumours notified only on death certificates are not traced to get earlier information about the tumour.

128) Cases from the death certificate notes are not registered as "Death certificate only" (DCO) or at all, unless a notification form is received (e.g. from the doctor signing the death certificate).

129) For a patient known from autopsy only, the incidence date is the date of death.

X BASIS OF DIAGNOSIS

METHODS

130) The "most valid basis", is having the following ranking order (from the SOS-guidelines) "cytology" is not changed to "histology" unless the "histology" has changed the diagnosis.

a) Histology of primary / bone marrow / metastases (from biopsy / operation / autopsy)

b) Cytology (expectorate, aspirate etc.) / Haematology.

c) No histology, cytology, marrow or blood-test.

d) No histology or cytology (e.g. clinical investigation / X-Ray / operation-autopsy without histology) is not ranked.

XI CLASSIFICATIONS

131) classification(s) as (in the rest of Sweden) from SOS:

a) From 1958: topography was coded according to ICD 7
   morphology was coded according to C24
b) From 1987: topography was coded according to ICD 9 and ICD 7
   morphology was coded according to C24
c) From 1993: Topography was coded according to ICD-2/10 with a few exceptions, and to ICD 9
   and ICD 7
   morphology is coded according for the SNOMED / ICDO-2 code and C24.

132) Exceptions to the classification rules:

Topography according to ICDO-2 where the following are coded according to ICD 10:

- Malignant melanoma in the skin: C43
- Hodgkin's lymphoma: C81
- Follicular non-Hodgkin Lymphoma: C82
- Diffuse non-Hodgkin Lymphoma: C83
- Peripheral and cutaneous T-cell lymphomas: C84
- Malignant lymphoma, NOS, or diffuse: C85 (see special list in the incidence publication as ICD 10 also differs slightly from the classification)
- Immunoproliferative diseases: C88
- Plasma cell tumours: C90
- Lymphatic leukemias: C91
- Myeloid leukaemia: C92
- Myelodysplastic syndrome: D46
- Monocytic leukaemia: C93
- Other specified leukaemia: C94
- Leukaemia, NOS: C95
- Neoplasm malignum tela lymphatica et haematopoeticae/other and unspecified tumours in lymphoid and haematopoietic tissue: C96/D45/D47/D76
These are all transformed to the ordinary ICD 7 code: 200x - 209x, where each group contains the types of lymphomas / leukaemia as defined in Sweden (see table W2 in the Incidence publication for the whole country)

133) Topography (primary tumour) is defined according to the clinician's assessment. The code is chosen according to specificity.

134) Topography codes may be changed according to what is most specific

135) Morphology is defined according to pathology description. The code is given from the pathologist and coded according to SNOMED (ICD-O2) / C24

136) Morphology may be changed if a histological description is received after a cytological description, and it is more specific.

137) Behaviour of tumour is given by the PAD - the pathologist decide the evaluation/criteria for the quality of the information. The code is chosen so that the most malignant is coded (behaviour 3 > 2 > 1 according to ICD-O2).

138) If behaviour is changed the tumour is changed to a new one and so is the diagnose date.
   a) Exceptions are bladder tumours, where the date is not changed
   b) Carcinoma in situ of the cervix, where > 1 year has to pass before a new tumour is registered - that is the change in "behaviour" will for this tumour mean that the tumour registered as in-situ will be changed to invasive if that change happens within one year.
   c) Brain-tumours are not changed, but a remark is added, that it has become malignant.

139) This however has to be evaluated if the behaviour changes within a year, as no specific time limits were mentioned (except the 1 year limit) otherwise the behaviour of the tumour is changed. While Cervix CIS which turns malignant within a year is counted as malignant from the date of diagnosis of the CIS.

140) List of reportable tumours:
   a) All definitely malignant neoplasms (e.g. carcinoma, sarcoma, malignant lymphoma, leukaemia and malignant teratoma).
   b) Carcinoïd tumours of digestive organs, granulosa tumours of the ovary, thymomas, adamantinomas and chordomas.
   c) Histologically benign tumours of the central nervous system and meninges, transitional cell papillomas of the urinary tract, all hormonal active tumours of the endocrine glands (except the thyroid) and the entero-chromaffin and neuroendocrine systems.
   d) Precancerous lesions of lip, mouth, larynx, bronchus, trachea, cervix uteri, skin, vulva and vagina, gastro-intestinal polyps with suspected malignancy, bronchial adenomas, atypical epithelial proliferation of the breast (carcinoma in situ type) and adenoma phylloides, precancerous endometrial lesions, hydatidiform moles of placental tissue, and ovarian cystadenomas of borderline type.

141) List of tumours included in incidence publications:
   a) Diseases mentioned under A-C above are included in the incidence publication, although a number of the tumours listed under C are considered not to be “infiltrating and metastasising” and are therefore also listed separately (papilloma, urinary tract; histologically benign tumours of the central nervous system; histologically benign tumours of endocrine glands; low grade fibrosarcoma (incl. dermatofibro-sarcoma protuberans).

   b) The reportable tumours mentioned under D are not included in the cancer incidence, but are tabulated separately.
c) Basaliomas have not been registered.

**CONVERSION OF ICD:**

142) Tables for converting codes from one system to another are created centrally in Stockholm (Epidemiologic centre) by a pathologist continuously, but in co-operation with the coding-group. From the centre the set-up and changes are distributed to all the regional registries; furthermore the conversion tables are given in the annual "Incidence book".

**THE PURPOSE of the conversion of ICD classification is:**

143) To ensure comparability with old data.

144) To a certain degree to make data comparable with data from other registries (e.g. Eurocare)

**DIAGNOSIS RECORDED IN ADDITION TO THE CANCER DIAGNOSIS CODED BY THE REGISTRY:**

145) Admission diagnosis - not coded

146) Discharge diagnosis - not coded

147) Cause of death - is coded - as given from the death certificate.

148) Autopsy diagnosis - is not coded

149) Other diagnosis (e.g. AIDS / Hepatitis ICD-10: B21) are not coded.

**MALIGNANT DISEASES ROUTINELY EXCLUDED WHEN REPORTING DATA FROM THE REGISTRY:**

150) Formerly Basalcell carcinoma of the skin were excluded except for Mixed Basalcell carcinoma (8094/3). Now all are going to be included only on reports from the pathologists

**THE TUMOURS BELOW are recorded and included in incidence data as shown**

<table>
<thead>
<tr>
<th>Tumour type</th>
<th>Record yes</th>
<th>Record no</th>
<th>Included yes</th>
<th>Included no</th>
</tr>
</thead>
<tbody>
<tr>
<td>151) Benign Brain tumours</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>152) Pituitary gland</td>
<td>no information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>153) Carotid body tumour</td>
<td>no information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>154) Benign bladder tumours (papilloma)</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>155) Intraductal carcinoma (8500/2) in the breast</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>156) Carcinoma in situ in the breast, other than above</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>157) Borderline tumour in the ovary</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>158) Carcinoma in situ in testis</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>159) Chromaffinoma (8700/0) of the adrenal glands</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>160) Argentaaffinoma (8241/1)</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>161) Chordoma (9370/3)</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>162) Invasive mole (9100/1)</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>163) Precancerous lesions in the cervix</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

164) Other benign or precancerous lesions coded to or included with categories of malignant tumours and other specific information: None were mentioned.
Appendix 2  Sweden – Umeå

165) **Clinical stage / extent of tumour is not recorded**
   a) However some precancerous lesions be tabulated as CIS ("stage 0") of uterine cervix.
   b) As well as may lesions with distant spread.

XII  MULTIPLE PRIMARIES

166) **The rules used to code multiple cancers in the registry are given from the Central Cancer registry (National board of Health and Welfare).**
   a) Astrocytom grade 1, which after some years develops into multiform glioblastoma is counted as 1 tumour, but it is written on the case, that this change has happened.
   b) The registry counts tumours not patients except for:
      - **SKIN TUMOURS** - if more than one “malignant melanoma” are diagnosed in the same area and on the same occasion, at hey are registered and coded as one – but if it is different occasions they are counted separately. If more are diagnosed in different sub-locations / regions on the same occasion, they are coded with the topography C43.8.
      - **URINARY TRACT TUMOURS** - if more than one tumour (incl. in situ) are diagnosed at the same topography they are counted as two tumours, regardless of any time-interval. At different topographies they are counted separately.

**RULES FOR CODING CANCERS IN PAIRED ORGANS:**

167) Tumours with the same morphology on each side are coded as two tumours, and counted as two when calculating incidence rates for breast cancer, while other paired organs are registered “double-sided” and counted as one.

168) Tumours with different morphology on each side are coded as two tumours, and counted as such – if it is stated on the pathology report – ovaries are usually counted as one.

169) Tumours with different behaviour (e.g. intraductal carcinoma in left breast and duct carcinoma in right breast) are coded as two tumours, but counted as one tumour.

XIII  TREATMENT

170) **TREATMENT is not recorded.**

XVII  FOLLOW-UP and TRACE-BACK

A  **By follow-up** we mean that the registry follows up registered cases to obtain information about e.g. recurrence, treatment, or death.

B  **By trace-back** we mean, that the registry actively attempts to obtain further information about a tumour, (e.g. first notified on a death certificate, or if the information on a patient is not satisfactory for other reasons) in order to complete the coding of the tumour recorded.
### ACTIVE (A) OR PASSIVELY (P) RECEIPT OF DATA FROM THE FOLLOWING SOURCES FOR FOLLOW-UP AND/OR TRACE-BACK

<table>
<thead>
<tr>
<th>Hospital Source</th>
<th>Trace-Back</th>
<th>Follow-Up</th>
</tr>
</thead>
<tbody>
<tr>
<td>171) Clinical departments</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>172) Medical records</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>173) Outpatient clinics</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>174) Hospices</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>175) Long stay hospitals and homes for the elderly</td>
<td>a</td>
<td>-</td>
</tr>
</tbody>
</table>

### Laboratories (in or outside hospitals)

<table>
<thead>
<tr>
<th>Laboratory Source</th>
<th>Trace-Back</th>
<th>Follow-Up</th>
</tr>
</thead>
<tbody>
<tr>
<td>176) Pathology, general</td>
<td>a</td>
<td>p</td>
</tr>
<tr>
<td>177) Pathology, specialised</td>
<td>a</td>
<td>p</td>
</tr>
<tr>
<td>178) Haematology</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>179) Autopsy reports</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>180) Institute of forensic medicine</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>181) Other</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>182) Death certificates</td>
<td>-</td>
<td>p</td>
</tr>
</tbody>
</table>

### General practitioners

<table>
<thead>
<tr>
<th>Source</th>
<th>Trace-Back</th>
<th>Follow-Up</th>
</tr>
</thead>
<tbody>
<tr>
<td>183) General practitioners</td>
<td>a</td>
<td>-</td>
</tr>
</tbody>
</table>

### Specialist practitioners

<table>
<thead>
<tr>
<th>Source</th>
<th>Trace-Back</th>
<th>Follow-Up</th>
</tr>
</thead>
<tbody>
<tr>
<td>184) Specialist practitioners</td>
<td>a</td>
<td>-</td>
</tr>
</tbody>
</table>

### Health insurance

<table>
<thead>
<tr>
<th>Source</th>
<th>Trace-Back</th>
<th>Follow-Up</th>
</tr>
</thead>
<tbody>
<tr>
<td>185) Health insurance</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

### Screening programmes

<table>
<thead>
<tr>
<th>Programme</th>
<th>Trace-Back</th>
<th>Follow-Up</th>
</tr>
</thead>
<tbody>
<tr>
<td>186) Screening programmes</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

### Administrative sources

<table>
<thead>
<tr>
<th>Source</th>
<th>Trace-Back</th>
<th>Follow-Up</th>
</tr>
</thead>
<tbody>
<tr>
<td>187) Central population registers</td>
<td>-</td>
<td>p</td>
</tr>
<tr>
<td>188) Central medical registers (e.g. hospital information systems)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>189) Other</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

### XIX SCREENING PROGRAMMES

<table>
<thead>
<tr>
<th>Programme</th>
<th>Type and year of start</th>
<th>Age-group</th>
<th>How often</th>
</tr>
</thead>
<tbody>
<tr>
<td>190) cervix</td>
<td>varies from the end of 60'ies-70'ies</td>
<td>30 – 50 years</td>
<td>Every 5 years</td>
</tr>
<tr>
<td>191) breast</td>
<td>mammography 89 Norrbotten 90 Västernorrland 95 Västerbotten 96 Jämtland</td>
<td>40 – 74 years</td>
<td>every 20 – 22 months</td>
</tr>
<tr>
<td>192) colon</td>
<td>none</td>
<td></td>
<td></td>
</tr>
<tr>
<td>193) melanoma</td>
<td>none</td>
<td></td>
<td></td>
</tr>
<tr>
<td>194) prostate</td>
<td>none</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Information on patients found during screening is received from the screening programmes.

### XX USE OF COMPUTER

196) The software used in the registry is developed in co-operation with the University. For statistics the SPSS on PC or S-plus is used.
XXI CONFIDENTIALITY

THE REGISTRY OBSERVES THE FOLLOWING SET OF RULES ON CONFIDENTIALITY:
(copied from the report from Lund, as it contains the same requirements with slightly different wording)

The conditions for delivering of information from the registry are as follows:

197) The information is given on the condition that the regulations in the law on confidentiality 1980:100 14. chapter 9§ are followed
   a) The material may only be used for the project specified in the application.
   b) Personal information must be kept so that unauthorised persons cannot gain access to the information
   c) Direct contact to the person in question, relatives etc. may not be done by you without permission from the medical Doctor in charge of the care or the chief Consultant at the current department
   d) At the end of the project all material containing personal data must be destroyed. Concerning data-media see also the regulations from the Data-inspection
   e) Publication of material must be done in such a way that no individual can be identified.

198) Current regulations in the law concerning data 1982-07-01 must be followed. See also in the instructions on adaptation of the law on data.

199) When ordering personal identifiable extract on a data-medium (floppy-disc) the permission from the data-inspection must be enclosed. As the database of the cancer registry continuously is changed continuously we cannot keep these data-extractions updated.

200) In case of questions concerning annulment or quality of the delivered material the cancer registry is to be contacted first.

201) The Epidemiological Centre presupposes also that the registry is mentioned as source in all prospective publications. We therefore ask you to send us a copy of the publication (or equivalent) when the work is ended.

202) The signing of the order in the application is at the same time a confirmation that you have participated in and accepted the conditions, listed above, for handling the material and the reservations given for publication of the given information

203) THE REGISTRY IS LEGALLY PERMITTED TO LINK WITH OTHER FILES

   This is regulated by:
   204) By the Data-inspection
   205) In certain cases also by the ethical committee
   206) There are NO RULES THAT IDENTIFIABLE INFORMATION SHOULD BE DELETED IN THE REGISTRY, but a few have a protected address - the report on these are in the registry though their address is not available in the registry.
   207) AN INDIVIDUAL CAN LEGALLY OBTAIN ACCESS TO DATA ABOUT HIMSELF/HERSELF IN THE REGISTRY, but this is usually done at regional level. Patient requests are handled by the local government forwarding requests to the relevant regional registries.
   208) AN INDIVIDUAL CANNOT REFUSE TO BE INCLUDED IN THE CANCER REGISTRY
   209) An individual does not have to be asked / informed before being included in the cancer registry
THE FOLLOWING CAN GET ACCESS TO THE CANCER REGISTRY DATA:

210) On case by case basis - anonymously there are no special restrictions

211) On case by case basis - with identifying information:
   a) The scientist according to the rules described above
   b) The patient as described

212) International release may only be done after making the person anonymous; e.g. by giving serial numbers to the persons in international studies, and having the key only in the country of origin.

XXII QUALITY CONTROL

COMPLETENESS OF COVERAGE:

213) There is no routine for estimating the completeness of registration

214) The forms from the pathological departments arrive at regular intervals, and a constant number is expected – if that is not reached then an inquiry is started.

215) The forms from the clinical departments – as mentioned earlier often have to be requested.

216) Target directed registries: are not used.

217) Disease index is not used., but Hospital registry is used as is management-program registries.

218) Outpatient logs - not used.

219) Pathology department logs - not used.

220) Comparison with patients enrolled in trial protocols is not done.

221) Random sampling of patients admitted to hospital and scrutiny of records for missed cases (capture - recapture) is not done.

222) Surveillance of numbers of registrations from each source is not done.

COMPLETENESS OF DETAIL:

223) The average number of sources/notifications per case is not calculated

224) The number of sources are not known over the years

FIGURES FOR A RECENT YEAR FOR THE FOLLOWING:

225) Figures for "unknown primary site (199 in ICD7)" are few, but not checked.

226) Percent of "age unknown" - irrelevant.

227) Percent of "treatment unknown" - treatment is not recorded.

228) Percent of "stage unknown" - stage is not recorded.

229) Histological verification was not known.
Appendix 2 Sweden – Umeå

230) Percent of "basis of diagnosis unknown" – not calculated.
231) Percent of "place of birth unknown" - is not recorded.
232) Year/period to which these figures apply irrelevant.
233) THE MOST RECENT YEAR PUBLISHED for the region is 1995.

METHODS USED TO MAINTAIN QUALITY CONTROL OF THE REGISTRY’S DATA:

234) Independent re-abstraction is not done.
235) Independent re-coding of a sample of cases is not done.
236) Independent duplicate data entry is not done.
237) Input logical checks is used - see below
238) Use of test cases is not done
239) Proof-reading of coded notification is not done.
240) Summary tabular frequency checks is not used, but an electronic check is done after which lists of strange combinations are produced and checked manually.
241) Incidental autopsy finding is not calculated.
242) Cancer cases from Death Certificates Only (DCO) are not included in the incidence rates.
243) Mortality/incidence ratio - highest/lowest site is not used as quality control.
244) Stability of rates over time is followed and the registry is used for research all the time.
245) Comparison with neighbouring registries is not done.

XXIII WEAK POINTS

246) MALIGNANCIES WHICH MAY BE UNDER-REPORTED:
Possibly haematological tumours, as no PAD-reports are received on them.

XXIV CHECKS

AUTOMATIC COMPUTER-BASED CHECKS (the same system is used as in Lund)

247) Data entered for essential variables is checked  yes
248) "Invalid" code for almost any variable  yes
   a) hospital code is valid
   b) clinic code is valid
   c) pathology laboratory is valid
   d) home-address is valid
   e) ICDO code is valid
   f) ICD9 code is valid
   g) ICD7 code is valid
   h) SNOMED code is valid
Survey of Nordic Cancer Registries, 2000

Appendix 2  Sweden – Umeå

i) C24 code is valid
j) Metastasis code is valid
k) Basis of diagnosis is valid
l) slide number is valid
m) Cancer death is valid
n) Autopsy result is valid

OTHER EXAMPLES OF CHECKS

DATE OF DIAGNOSIS
249) Before or equal to date of death yes
250) Before or equal to date of post-mortem yes
251) Before or equal to date of report yes
252) Date of death before or equal to date of post-mortem yes
253) In case of only autopsy finding: date = date of death

TUMOUR TYPE
254) Sex compatible with site yes
255) Age compatible with tumour type no
256) Site of tumour compatible with histological type yes
257) Site of tumour compatible with code for laterality (paired organ) yes
258) Site of tumour compatible with method of diagnosis yes
259) Histology compatible with method of diagnosis yes
260) THE IACR CHECK-PROGRAMME is not used.

261) MANUAL/VISUAL CHECKS: see above – strange topo-morpho combinations are checked.

XXV OUTPUT FROM REGISTRY

IN THE REGULAR ROUTINE PUBLICATIONS OF INCIDENCE RATES, TABLES OF RATES ARE GIVEN BY :

262) Year yes
263) Sex yes
264) Age – 10 years groups yes
265) Site yes
266) Occupation no
267) Social group no
268) Residence no
269) Geographical subdivision of your territory yes at county level
270) Trends yes
271) Other variable yes
   a) Cases found incidentally at autopsy (site, sex) no
   b) Number of second and multiple primaries (site, sex, med.region) no
   c) Percentage cytological and histological verified no

IN THE REGULAR PUBLICATIONS, THE FOLLOWING STANDARDS ARE USED :

272) World Standard no
273) European Standard and year no
274) Own Standard Sweden 1970
275) Other no

There are no regular/annual routine publications of mortality rates but they are available

276) Evaluation of incidence trends is carried out
BASIC CHARACTERISTICS OF THE REGISTRY

UPPSALA

date: April 28th 1997

1) Regional Oncologic Centre for Uppsala/Örebro Region
2) University Hospital
3) S-751 85 Uppsala
4) Sweden
5) Tel: +46-(0)18/ 151910
6) Fax: +46-(0)18/ 711445
7) e-mail:

Persons interviewed:

<table>
<thead>
<tr>
<th>Name:</th>
<th>Position:</th>
<th>Training/Degree</th>
<th>Abbreviation:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hans-Olov Isaksson</td>
<td>Registry</td>
<td>Statistician</td>
<td>HOI</td>
</tr>
<tr>
<td>Ingegerd Kyllerstedt</td>
<td>Assistant</td>
<td>Coding staff</td>
<td>IK</td>
</tr>
</tbody>
</table>

I THE REGISTRY

8) The registry is population-based and covers: Uppsala - Örebro regions.

9) The population includes all the people in the area who are entered in the official population statistics that is have been given a personal identification number.

10) Special registries - management-programmes:
    a) Lung cancer
    b) Rectum cancer
    c) Malignant melanoma
    d) Breast cancer
    e) Prostate cancer (is starting)
    f) Brain tumours (is coming)
    g) Bladder tumours (is coming)

The data from these management-programmes are owned by special groups and they decide who may gain access to the data - it is therefore necessary to approach the management-programme-group if more detailed data from the programmes are wanted.

II DEMOGRAPHICAL INFORMATION

11) An incidence publication is made every 5 years for the region on county level.

Changes

12) In 1982 Örebro region was included - while Jämtland was transferred to the registry in Umeå - but all relevant data were transferred to the respective registries.

THE RESIDENT POPULATION IN THE AREA COVERED BY THE REGISTRY was in 1994 (from cancer incidence in Sweden 1994 p 14)

13) a Males: ...................................................................................................................965,947
14) b Females: ...............................................................................................................981,747
15) c Total: ..................................................................................................................1,947,694
16) The population figures are exact.

17) Population figures used for incidence calculation are the midyear average figures.
Appendix 2  Sverige – Uppsala

18) The Health system:
   a) Primary ward, run by general practitioners in "healthcenters" (vårdcentraler)
   b) "Länsdelssjukhus" - minor hospital
   c) "Länssjukhus" - "County"-hospital
   d) "Regional hospital"

19) The hospitals are governed by the local authority - for the county ("Landstinget"), which is also responsible for collecting taxes for that purpose.

REGARDING POPULATION DATA THE FOLLOWING ARE AVAILABLE IN THE REGISTRY

<table>
<thead>
<tr>
<th>Available</th>
<th>Used</th>
</tr>
</thead>
<tbody>
<tr>
<td>20) Sex in one-year age groups on parish register level</td>
<td>-</td>
</tr>
<tr>
<td>21) Sex in five-year age groups</td>
<td>x</td>
</tr>
<tr>
<td>22) Information on occupation in the cancer registry (CR)</td>
<td>-</td>
</tr>
<tr>
<td>23) Information on religion</td>
<td>-</td>
</tr>
<tr>
<td>24) &quot;Ethnic group&quot; and &quot;place of birth&quot;</td>
<td>-</td>
</tr>
<tr>
<td>25) The urbanity-degree is available</td>
<td>-</td>
</tr>
<tr>
<td>26) This information is given in a number with 6-digits: two first derived from county, two middle from municipality, two last from the parish registry (the smallest administrative unit (&quot;församlingen&quot;).</td>
<td>x</td>
</tr>
<tr>
<td>27) The address as a land registry-number (koordinatsystem - GIS)</td>
<td>-</td>
</tr>
</tbody>
</table>

III  HISTORY

28) The registry started operating in 1958 in Stockholm. But in 1980 the data from the central registry were transferred to this region and since then the data for the region have been collected regionally. The Regional Tumour Registries have since the transfer sent the collected and coded data to the central registry on an annual basis.

29) The registry can present population based data from 1958

CHANGES

30) The cancer registry has not been linked to the hospital discharge registry and no change of that kind has been made.

31) A few cases are included from the management-programme- and quality-control-registries, but usually the information goes the other way.

32) There have been changes in hospital procedures: e.g. the autopsy-rates have decreased and may have caused the post-mortem frequency of cancer diagnosis to decrease.

33) Reporting of cancer cases has always been compulsory for pathology- and hospital departments.

34) At present reporting of tumours is compulsory for:
   a) Any medical Doctor employed privately or in a hospital department, who has diagnosed the tumour disease clinically or microscopically.
   b) Any medical Doctor writing a tumour disease on the death-certificate even if diagnosed after death.
Appendix 2  Sverige – Uppsala

c) The doctor responsible for: pathological / cytological laboratories, the Forensic department, the Haematological lab., and other service departments.

35) Operation of the registry has not been discontinued at any time.
36) The registry is public so the local authorities (counties) are responsible for the data.
37) The data are reported annually to the National Board of health and Welfare but are owned by the local authorities.

IV  STAFF & ORGANIZATION

38) Employees:
   - Medical director of Oncological centre
   - Organisation secretary
   - EDB expert for the cancer registry
   - Statistician
   - 2 coding assistants for the registry
   - 2 assistants for the management-programmes/clinical studies/diagnose registries

39) The regional cancer registry is responsible for the registration and classification of new cancer-cases, - at the same time it is part of the Regional Oncologic Centre.

THE FOLLOWING DEPARTMENTS/INSTITUTIONS ARE working closely with the registry:

40) The teams taking care of the management-programmes, clinical studies, diagnose registry, quality control, - and thus with the University hospital
41) The public health department, statistical evaluation, information, training, screening and development of systems. -
42) The registry is independent administratively having its own budget.
43) The cancer-registry is located separated from the cancer-treating clinics in the city, but as mentioned having close contact with many different departments.

SOURCES OF FINANCE:

44) Registration of cancer is financed by the counties in the region, on a proportional basis, according to population.
45) Research projects are carried out in co-operation with others and are financed from funds, after application and acceptance of the project. Other special activities are the management-programmes / studies etc., though they are run independently with special assistants.

CODING:

46) Coding of site and morphology is carried out at the registry.
47) The coding / classification of neoplasms to site and morphology is carried out by the regional coding assistants. They are medical secretaries / nurses, who have received an additional training in the registry as well as at The National Board of Health and Welfare.
48) Supervision of coding and solving of coding problems is done by a pathologist visiting the registry every 2 weeks.
49) In difficult cases an external pathologist or other MD’s will be contacted by telephone as necessary.

50) Some coding problems are discussed at the annual registry meeting, led by Jan Eriksson, who is a pathologist.

51) Coding problems may be brought to the coding group meetings, which are held 3 times a year and organised by the Central registry. Changes are sent to all in the coding instructions from the Central registry.

LETTERS / TELEPHONE

52) The registry has to request for reporting forms in average every 3-4 weeks.

53) It is not quite clear how often the registry has to send out questions for clarification to the reports.

V REPORTING

TUMOUR REGISTRATION FROM PATIENT TO REGISTRY:

54) The patient contacts the GP, who makes some investigations and/or refer the patient to the hospital. Very few reports come from the GP’s.

55) No fee is paid to the reporting physician or institution.

56) Most often it is the medical secretary who writes the report, and the doctor signs it.

57) Linkages is carried out with the Cause of Death Registry in order to ensure that official date of death and cause of death is available in the Central registry. This information is received in the Regional registry. Linkage with the population registry (SCB- Statistics Sweden) is also carried out to check the persons name and ID-number.

58) Information on name and address of the reporting hospital / clinic / practitioner / or other source is kept. For each tumour the largest hospital / clinic is registered.

59) Reports are kept until the incidence-book is published, then the reports are sent to the National Board of Health and Social Welfare. The registry thus has information which makes it possible to go back to the original records.

60) Patients do not have their "own" GP, and are free to go, wherever they want, but the cheapest is to go to the local clinic (vårdcentral). Information about the GP used by the patient may be available on the report.

VI SOURCES

THE REGISTRY REGULARLY RECEIVES REPORTS FROM:

61) Hospitals
62) Medical records departments - no
63) Outpatient clinics
64) Hospices
65) Long stay hospitals and homes for the elderly


**Laboratories** (in or outside hospitals)

66) Pathology general and specialised
67) Haematology
68) Autopsy reports
69) Institute of forensic medicine

70) **Death certificates** are not used as source for tumour registration.

**Other**

71) General practitioners
72) Specialist practitioners
73) Screening programmes.

**FORMS RECEIVED**

74) The registry is sending out most inquiries to the clinics as more reports are received from the pathologist.
75) Only few are only diagnosed clinically.
76) **The information about cancer** is recorded from the reporting forms, but plaintext must appear on the notification forms.

**THE REGISTRY RECEIVES ROUTINELY (OR HAS REGULAR ACCESS TO) COPIES OF THE FOLLOWING FOR CANCER PATIENTS:**

77) Medical records - happens that a copy is received ............................................................... rarely
78) Pathology reports - on request.................................................................................................yes
79) Autopsy reports - as above though more often.................................................................yes
80) Discharge letter ...................................................................................................................... rarely.
81) Death certificates .................................................................................................................... no
82) Radiotherapy reports are not received normally, but sometimes the cancer-diagnose is only an x-ray diagnose and these cases are not registered, but kept separately as long as the patient is alive. When he dies and if it is a brain-tumour the tumour is registered, otherwise not........................yes
83) Hospital information system ................................................................................................. no
84) The staff at the registry does not visit the oncologic clinics.
85) The original notification forms are stored in paper files -until the publication of the incidence data, then they are sent to the EPI-centre.
86) **Definition of place of "Residence"**:
    The address as it is written in the **parish register** - (which is the permanent address -bopæl) - and is given as county-municipality-parish (with 2 digits for each)
87) **Immigrants** and/or non-residents are kept in a special file for 3 years.
88) The registry has no experience with refugees, but would follow the same procedure as above - this is also the case for those with a "protected address".
89) Special **subgroups/minorities** in the population are not known.
Appendix 2  Sverige – Uppsala

90) TUMOURS IN PATIENTS WHO ARE NOT PERMANENT RESIDENTS OF THE REGISTRY TERRITORY are not registered but the forms are sent to the relevant registry - and forms are received from the other registries.

91) Residents working abroad and belonging to the region are registered, but later they are sent on to the EPI-centre - it is very few cases.

92) THE DATA ARE SUBMITTED TO THE CENTRAL REGISTRY IN STOCKHOLM ONCE A YEAR when the coding is completed (January-February).

VII INFORMATION RECORDED

93) THE CODING OF DATA is done manually: the code-number is written on the notification form and then punched into the system.

94) THE PROCESSING OF DATA: on registration the information on the new form is compared with what is already registered, and if necessary all forms on the person are consulted. (e.g. in case of multiple tumours).

95) Two or more notifications are linked electronically using the unique personal identification number.

96) The tumours are usually not registered in the cancer registry until both notification forms (if there has to be two) are received, so normally the clinical notification form will be requested if it has not arrived within 3 months.

97) COMPUTERIZED CASE RESOLUTION is not carried out.

VIII THE PERSON

98) THE SOURCE FOR INFORMATION ON THE PERSON is the Central Personal Registry (CPR), which assigns a number to each resident in Sweden.

99) The patient is not given another number in the registry.

100) THE UNIQUE PERSONAL REGISTRY NUMBER is constructed of: 1 digit for the century + 10 digits, which are composed of: 2 digits for year, 2 digits for month and 2 digits for day of birth; The next 2 digits formerly gave the place of birth, 1 digit gives the sex: the odd for male and the even for female and the last digit is the control number for the index number.

101) Immigrants are assigned a CPR number when they become residents.

102) The number does not any longer indicate where the person was born nor if he/she belongs to any minority and it does not indicate ethnicity.

103) The cancer registry receives updated information regularly for date of death and immigration/emigration and an update on individuals annually from the Statististical Central Bureau (SCB). THE CANCER REGISTRY is linked to the Cause of Death registry for the date of death and the cause of death, but the cancers found by this method are not included in the incidence calculation. THE CAUSE OF DEATH is recorded and given from the Central Cancer registry. The autopsy diagnosis as cause of death is ranked highest of the sources for the cause of death, but the official cause of death is also registered. Furthermore it is registered whether the person died of or with the cancer.
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Names of patient
104) The patients full name is registered.
105) None of the following are registered: Maiden name / Father's name / Mother's name
106) The ID number of the next of kin is not registered.

Residence/address at the time of registration
107) The number for the patients address is registered, and constructed as 2 digits for county, 2 for municipality and 2 for parish register (församling).
108) This information includes: County, municipality, parish register.
109) Change of address is given from the SCB annually, but the address at the time of diagnosis is kept in the registry as address at date of diagnosis. The address of the patient has been easier to follow after the pathology-registry has got on-line with the CPR - formerly it was often necessary to make inquires about the address
110) The age at incidence date is calculated from CPR
111) The persons nationality (e.g. French, Danish) is not registered.
112) No further information is used from the SCB/CPR.
113) The nationality of father and/or mother is not available.
114) Marital/civil status at diagnosis is not registered, but the following categories are available:
   a) Married - no
   b) Separated - no
   c) Divorced - no
   d) Widow/widower - no
   e) Cohabitation - no
   f) Single - no
115) Death - yes
116) Number of live births and categories (actual number) no
117) Religion - no
118) Ethnic groups - no
119) Race - no
120) Patient's education - no
121) Occupation - no
122) Special enquet studies for occupation - no
123) Social class or socio-economic status - no
124) Patient's exposure to carcinogens - no

IX  INCIDENCE DATE

Date of diagnosis (level of detail):
125) The date is recorded as the year, month and day of diagnosis.
126) The DATE OF DIAGNOSIS is defined as the date of biopsy, as received from the pathologist. If there is no biopsy and only clinical notification the date for admission is used as date of diagnosis. If none of the above mentioned dates are available, the date for the notification form is used. The ranking of the dates of diagnosis is that the date given by the pathologist is recorded if available.
127) Tumours first notified on death certificate are not traced to get earlier information about the tumour. Cases from the death certificate notes are not registered as "Death certificate only" (DCO) or at all, unless a notification form is received (e.g. from the doctor signing the death certificate).

128) The cause of death registry is matched with the cancer registry but the Doctor signing the death certificate is not asked to report the case.

129) For a patient known from autopsy only, the incidence date is the date of death.

X BASIS OF DIAGNOSIS

METHODS

130) The "most valid basis" ("histology") is coded though "cytology" is not changed to "histology" unless the "histology" has changed the diagnosis. The following ranking order is used (from the SOS-guidelines):
   a) Histology of primary / bone marrow / metastases (from biopsy/operation/autopsy)
   b) Cytology (expectorate, aspirate etc.) / Haematology.
   c) No histology, cytology, marrow or bloodtest.
   d) No histology or cytology (e.g. clinical investigation / X-Ray / operation-autopsy without histology) is not ranked.

XI CLASSIFICATIONS

131) classification(s) as from SOS:
   a) From 1958: topography was coded according to ICD 7
      morphology was coded according to C24
   b) From 1987: topography was coded according to ICD 9 and ICD 7
      morphology was coded according to SNOMED (from 1980) and C24
   c) From 1993: Topography was coded according to ICDO-2/10 with a few exceptions, and to ICD 9 and ICD 7
      morphology is coded according for the SNOMED / ICDO-2 code and C24.

132) Exceptions to the classification rules:
   Topography according to ICDO-2 where the following are coded according to ICD 10:
   - Malignant melanoma in the skin: C43
   - Hodgkins lymphoma: C81
   - Follicular non-Hodgkin Lymphoma: C82
   - Diffuse non-Hodgkin Lymphoma: C83
   - Peripheral and cutaneous T-cell lymphomas: C84
   - Malignant lymphoma, NOS, or diffuse: C85 (see special list in the incidence publication as ICD 10 also differs slightly from the classification)
   - Immunoproliferative diseases: C88
   - Plasma cell tumours: C90
   - Lymphatic leukemias: C91
   - Myeloid leukemias: C92
   - Myelodysplastic syndrome: D46
   - Monocytic leukemias: C93
   - Other specified leukemias: C94
   - Leukemias, NOS: C95
   - Neoplasm malignum tela lymphatica et haematopoeticae/ other and unspecified tumours in lymphoid and haematopoietic tissue: C96 / D45 / D47 / D76
These are all transformed to the ordinary ICD 7 code: 200x - 209x, where each group contains the types of lymphomas / leukemias as defined in Sweden (see table W2 in the Incidence publication for the whole country)

133) **TOPOGRAPHY (PRIMARY TUMOUR)** is defined according to the clinician's assessment. The code is chosen according to specificity.

134) Topography codes may be changed according to what is most specific.

135) **MORPHOLOGY** is defined according to pathology description. The code is given from the pathologist and coded according to SNOMED (ICD-O2) / C24

136) Morphology may be changed if a histological description is received after a cytological description, and it is more specific - if there are different morphologies, the pathologist is asked or each case is validated.

137) **BEHAVIOUR OF TUMOUR** is given by the PAD - the pathologist decides the evaluation/criteria for the quality of the information. The code is chosen so that the most malignant is coded (behaviour 3 > 2 > 1 according to ICD-O2).

138) The behavioural code changes: If a tumour changes from precancer to invasive cancer a new tumour is registered after a couple of years.

139) This however has to be evaluated if the behaviour changes within a year, as no specific time limits were mentioned, otherwise the behaviour of the tumour is changed from in situ to invasive. Cervix CIS which turns malignant within a year is however counted as malignant from the date of diagnosis of the CIS.

140) **List of reportable tumours:**
   a) All definitely malignant neoplasms (e.g. carcinoma, sarcoma, malignant lymphoma, leukaemia and malignant teratoma).
   b) Carcinoid tumours of digestive organs, granulosa tumours of the ovary, thymomas, adamantinomas and chordomas.
   c) Histologically benign tumours of the central nervous system and meninges, transitional cell papillomas of the urinary tract, all hormonal active tumours of the endocrine glands (except the thyroid) and the entero-chromaffin and neuroendocrine systems.
   d) Precancerous lesions of lip, mouth, larynx, bronchus, trachea, cervix uteri, skin, vulva and vagina, gastro-intestinal polyps with suspected malignancy, bronchial adenomas, atypical epithelial proliferations of the breast (carcinoma in situ type) and adenoma phylloides, precancerous endometrial lesions, hydatidiform moles of placental tissue, and ovarian cystadenomas of borderline type.

141) **List of tumours included in incidence publications:**
   a) Diseases mentioned under A-C above are included in the incidence publication, although a number of the tumours listed under C are considered not to be "infiltrating and metastasising" and are therefore also listed separately (papilloma, urinary tract; histologically benign tumours of the central nervous system; histologically benign tumours of endocrine glands; low grade fibrosarcoma (incl. dermatofibro-sarcoma protuberans).
   b) The reportable tumours mentioned under D are not included in the cancer incidence, but are tabulated separately.
   c) Basaliomas have not been registered.
Conversion of ICD:

142) Conversion tables from one coding system to another are created centrally in Stockholm (Epidemiologic centre) by a pathologist continuously, but in co-operation with the coding-group. From the centre the set-up and changes are distributed to all the regional registries; furthermore the conversion tables are given in the annual "Incidence book".

THE PURPOSE of the conversion of ICD classification is:

143) To ensure comparability with old data.
144) To a certain degree to make data comparable with data from other registries (e.g. Eurocare)

Diagnosis recorded in addition to the cancer diagnosis coded by the registry:

145) Admission diagnosis - not coded
146) Discharge diagnosis - not coded
147) Cause of death - is not coded
148) Autopsy diagnosis - is not coded
149) Other diagnosis (e.g. AIDS / Hepatitis ICD-10: B21) are not coded.

Malignant diseases routinely excluded when reporting data from the registry:

150) Formerly Basalcell carcinoma of the skin were excluded except for Mixed Basalcell carcinoma (8094/3). Now all are going to be included only on reports from the pathologists

THE TUMOURS BELOW are recorded and included in incidence data as shown:

<table>
<thead>
<tr>
<th>Tumour type</th>
<th>Record yes</th>
<th>Record no</th>
<th>Included yes</th>
<th>Included no</th>
</tr>
</thead>
<tbody>
<tr>
<td>151) Benign Brain tumours</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>152) Pituitary gland</td>
<td>no information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>153) Carotid body tumour</td>
<td>no information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>154) Benign bladder tumours (papilloma)</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>155) Intraductal carcinoma (8500/2) in the breast</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>156) Carcinoma in situ in the breast, other than above</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>157) Borderline tumour in the ovary</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>158) Carcinoma in situ in testis</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>159) Chromaffinoma (8700/0) of the adrenal glands</td>
<td>no information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>160) Argentaffinoma (8241/1)</td>
<td>no information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>161) Chordoma (9370/3)</td>
<td>no information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>162) Invasive mole (9100/1)</td>
<td>no information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>163) Precancerous lesions in the cervix</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>164) Other benign or precancerous lesions coded to or included with categories of malignant tumours and other specific information: none</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Survey of Nordic Cancer Registries 220
165) Clinical stage / extent of tumour is recorded only in specific management-programmes and the information will only be available in cooperation with the respective boards. However some precancerous lesions may be tabulated as CIS ("stage 0") of uterine cervix.

XII MULTIPLE PRIMARIES

166) The rules used to code multiple cancers in the registry are given from the Central Cancer registry (National board of Health and Welfare).
   a) Since the 80'ies each part of the intestines are registered, formerly only one tumour was registered. And it is rare to use the code for "multiple tumour" (e.g. xxx.8).
   b) Concerning Astrocytoma grade 1 which after some years develops into multiform glioblastoma no information was received.
   c) The registry counts tumours not patients except in a few cases:
      i) skin tumours - if "malignant melanomas" are diagnosed in the same area and on the same occasion they are registered and coded as one. If two melanomas are diagnosed with the same morphology in different regions on the same occasion, they were coded as one till 1993, while if there were more than 2 tumours they would be coded separately.
      ii) URINARY TRACT TUMOURS - if more than one tumour (incl. in situ) are diagnosed at the same topography and within one year, they are counted as one tumour, after one year they will be counted separately. At different topographies they are counted separately.
      iii) COLON TUMOURS - diagnosed on the same occasion: counted as 2 (or more) if they have the same morphology, but different sub-localisation or if they have different morphology and the same sub-localisation.

Rules for coding cancers in paired organs:

167) Tumours with the same morphology on each side are coded as two tumours, and counted as two when calculating incidence rates. This counts for e.g. kidneys, lungs, while ovaries are only counted as one and the urinary tract tumours are evaluated by the pathologist.

168) Tumours with different morphology on each side are coded as two tumours, and counted as such - as above.

169) Tumours with different behaviour (e.g. intraductal carcinoma in left breast and duct carcinoma in right breast) are coded as two tumours, but counted as one tumour.

XIII TREATMENT

170) Treatment is not recorded.

XVII FOLLOW-UP and TRACE-BACK

A By follow-up we mean that the registry follows up registered cases to obtain information about e.g. recurrence, treatment, or death.

B By trace-back we mean, that the registry actively attempts to obtain further information about a tumour, (e.g. first notified on a death certificate, or if the information on a patient is not satisfactory for other reasons) in order to complete the coding of the tumour recorded.
Active (a) or passively (p) receipt of data from the following sources for follow-up and/or traceback

<table>
<thead>
<tr>
<th>Hospitals</th>
<th>trace-back</th>
<th>follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>171) Clinical departments</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>172) Medical records</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>173) Outpatient clinics</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>174) Hospices</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>175) Long stay hospitals and homes for the elderly</td>
<td>a</td>
<td>-</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Laboratories (in or outside hospitals)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>176) Pathology, general</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>177) Pathology, specialised</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>178) Haematology</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>179) Autopsy reports</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>180) Institute of forensic medicine</td>
<td>a</td>
<td>-</td>
</tr>
<tr>
<td>181) Other</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

| 182) Death certificates                       | -          | p         |
| 183) General practitioners                   | -          | -         |
| 184) Specialist practitioners                | -          | -         |
| 185) Health insurance                         | -          | -         |

| 186) Screening programmes                     | -          | -         |

<table>
<thead>
<tr>
<th>Administrative sources</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>187) Central population registers</td>
<td>-</td>
<td>p</td>
</tr>
<tr>
<td>188) Central medical registers (e.g. hospital information systems)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>189) Other</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

**XIX SCREENING PROGRAMMES**

<table>
<thead>
<tr>
<th>Type and year of start</th>
<th>age-group</th>
<th>how often</th>
</tr>
</thead>
<tbody>
<tr>
<td>cervix: 1978</td>
<td>25-60 years</td>
<td>every 3 years</td>
</tr>
<tr>
<td>breast: mammography 1986</td>
<td>?</td>
<td>every 3 years</td>
</tr>
<tr>
<td>colon: study-programme</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Melanoma: management-programme</td>
<td></td>
<td></td>
</tr>
<tr>
<td>prostate: management-programme</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| 195) The screening programme for cervix is organised from RTR and the same was the case for the breast-screening until 1991. | |

**XX USE OF COMPUTER**

| 196) The software used in the registry is PC-based, and the programmes used are SAS and Excel. | |
XXI CONFIDENTIALITY

The registry observes the following set of rules on confidentiality:
(copied from the report from Lund, as it contains the same requirements with slightly different wording)

The conditions for delivering of information from the registry are as follows:

197) The information is given on the condition that the regulations in the law on confidentiality 1980:100 14 chapter 9\$ are followed
   a) The material may only be used the project specified in the application.
   b) Personal information must be kept so that unauthorised persons cannot gain access to the information
   c) Direct contact to the person in question, relatives etc. may not be done by you without permission from the medical Doctor in charge of the ward or the chief Consultant at the current department
   d) At the end of the project all material containing personal data must be destroyed. Concerning data-media see also the regulations from the Data-inspection
   e) Publication of material must be done in such a way that no individual can be identified.

198) Current regulations in the law concerning data 1982-07-01 must be followed. See also in the instructions on adaptation of the law on data.

199) When ordering personal identifiable extract on a data-medium (floppy-disc) the permission from the data-inspection must be enclosed. As the database of the cancer registry continuously is changed continuously we cannot keep these data-extractions updated.

200) In case of questions concerning annulment or quality of the delivered material the cancer registry is to be contacted first.

201) The Epidemiological Centre presupposes also that the registry is mentioned as source in all prospective publications. We therefore ask you to send us a copy of the publication (or equivalent) when the work is ended.

202) The signing of the order in the application is at the same time a confirmation that you have participated in and accepted the conditions, listed above, for handling the material and the reservations given for publication of the given information

203) The registry is legally permitted to link with other files

This is regulated by:

204) By the Data-inspection

205) In certain cases also by the ethical committee

206) There are no rules that identifiable information should be deleted in the registry

207) AN INDIVIDUAL CAN LEGALLY OBTAIN ACCESS TO DATA ABOUT HIMSELF/HERSELF IN THE REGISTRY, but this is usually done at regional level. Patient requests are handled by the local government forwarding requests to the relevant regional registries.

208) An individual cannot refuse to be included in the cancer registry

209) An individual does not have to be asked / informed before being included in the cancer registry

The following can get access to the cancer registry data:
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210) - On case by case basis - anonymously there are no special restrictions

211) - On case by case basis - with identifying information:
   a) The scientist according to the rules described above
   b) The patient as described

212) International release may only be done after making the person anonymous; e.g. by giving serial numbers to the persons in international studies, and having the key only in the country of origin.

XXII  QUALITY CONTROL

Completeness of coverage :

213) There is no routine for estimating the completeness of registration

214) The number of forms from the pathological departments are not calculated

215) The number of forms from the clinical departments - as mentioned earlier often have to be requested.

216) Target directed registries: are not used.

217) Disease index / Hospital discharge registry is not used.

218) Outpatient logs - not used

219) Pathology department logs - not used.

220) Comparison with patients enrolled in trial protocols is not done. But information received from scientists is used and included in the registry, and in this way research is contributing to the completeness of the registry.

221) Random sampling of patients admitted to hospital and scrutiny of records for missed cases (capture - recapture) is not done.

222) Surveillance of numbers of registrations from each source is not done - but the number of new cases per year is continuously followed.

Completeness of detail :

223) The average number of sources/notifications per case is not calculated

224) The number of sources are not known over the years

Figures for a recent year for the following :

225) Figures for "unknown primary site (199 in ICD7)" is not followed.

226) Percent of "age unknown" - irrelevant.

227) Percent of "treatment unknown" - treatment is not recorded.

228) Percent of "stage unknown" - stage is not recorded.

229) Percent of "no histology" was not calculated.

230) Percent of "basis of diagnosis unknown" - irrelevant.
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231) Percent of "place of birth unknown" - is not recorded.
232) Year/period to which these figures apply: irrelevant
233) The most recent year published for the region is 1993.

Methods used to maintain quality control of the registry's data:

234) Independent re-abstraction is not done.
235) Independent re-coding of a sample of cases is not done, but a list received from the Central Cancer registry over strange combinations (topo-morph) is checked.
236) Independent duplicate data entry is not done.
237) Input logical checks is used - see below
238) Use of test cases is not done
239) Proof-reading of coded notification is done.
240) Summary tabular frequency checks is not used, but an electronic check is done after which lists of strange combinations are produced and checked manually; - according to a programme from the central registry
241) Incidental autopsy finding is not calculated.
242) Cancer cases from Death Certificates Only (DCO) are not included in the incidence rates.
243) Mortality/incidence ratio - highest/lowest site is not used as quality control.
244) Stability of rates over time is followed.
245) Comparison with neighbouring registries is not done.

XXIII  WEAK POINTS

246) Malignancies which may be under-reported:
   a) Kaposi Sarcoma, suspicion of lymphoma, those diagnosed only by X-ray and who are still alive are not registered.
   b) Malignancies which may be over-reported:
   c) Probably at the beginning of new screenings as for breast-tumours in 1989
   d) Lymphomas -> leukaemia are registered twice as are leukaemia -> lymphomas.

XXIV CHECKS

  AUTOMATIC COMPUTER-BASED CHECKS (the same system is used as in Lund)

247) Data entered for essential variables is checked

   yes
"Invalid" code for almost any variable

a) hospital code is valid
b) clinic code is valid
c) pathology laboratory is valid
d) home-address is valid
e) ICDO code is valid
f) ICD9 code is valid
g) ICD7 code is valid
h) SNOMED code is valid
i) C24 code is valid
j) Metastasis code is valid
k) Basis of diagnosis is valid
l) slide number is valid
m) Cancer death is valid
n) Autopsy result is valid

OTHER EXAMPLES OF CHECKS

Date of diagnosis

249) Before or equal to date death yes
250) Before or equal to date of post-mortem yes
251) Before or equal to date of report
252) Date of death before or equal to date of post-mortem yes
253) In case of only autopsy finding: date = date of death

TUMOUR TYPE

254) Sex compatible with site yes
255) Age compatible with tumour type no
256) Site of tumour compatible with histological type yes
257) Site of tumour compatible with code for laterality (paired organ) yes
258) Site of tumour compatible with method of diagnosis yes
259) Histology compatible with method of diagnosis yes

The IACR check-programme is not used.

Manual/visual checks: see above

XXV OUTPUT FROM REGISTRY

In the regular routine publications of incidence rates, tables of rates are given by:

262) Year for selected tumours and 5 years periods yes
263) Sex yes
264) Age in selected age-groups yes
265) Site yes
266) Occupation no
267) Social group no
268) Residence no
269) Geographical subdivision of your territory yes at regional and county level
270) Trends yes
271) Other variable yes
   a) mortality
   b) risk calculation and possible causes of selected cancers.
In the regular publications, the following standards are used:

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>272)</td>
<td>World Standard</td>
<td>no</td>
</tr>
<tr>
<td>273)</td>
<td>European Standard and year</td>
<td>no</td>
</tr>
<tr>
<td>274)</td>
<td>Own Standard</td>
<td>Sweden 1970</td>
</tr>
<tr>
<td>275)</td>
<td>Other</td>
<td>no</td>
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There are regular publications of mortality rates - see above.

276) Evaluation of incidence trends is carried out
### TABLE 1

<table>
<thead>
<tr>
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<th>Iceland</th>
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<th>Sweden</th>
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<tr>
<td><strong>Demographic information</strong></td>
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<tr>
<td>Population covered</td>
<td>8</td>
<td>Denmark + Greenland</td>
<td>Finland incl. Åland</td>
<td>Iceland</td>
<td>Norway</td>
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<tr>
<td>Updating of date of death</td>
<td>103</td>
<td>Annually</td>
<td>Monthly</td>
<td>Monthly</td>
<td>Every month from 1999</td>
</tr>
<tr>
<td>Updating for emi- / immigration</td>
<td>103</td>
<td>Only in projects</td>
<td>Annually</td>
<td>Monthly</td>
<td>Every month from 1999</td>
</tr>
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<td>Population figures (average)</td>
<td>13-15</td>
<td>5.188.623 (excl. Greenland)</td>
<td>5.098.400</td>
<td>267.380</td>
<td>4.323.542</td>
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<td>1-year age groups</td>
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<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<td>5-years age groups</td>
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<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<td>Urbanity</td>
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<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<td>Address - detail</td>
<td>26</td>
<td>Municipality code</td>
<td>ad hoc area 10m coordinate</td>
<td>Municipality code</td>
<td>Municipality code</td>
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<td><strong>Registry</strong></td>
<td>1.st year of incidence data</td>
<td>28</td>
<td>1943</td>
<td>1953</td>
<td>1954</td>
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<td><strong>Staff</strong></td>
<td>38</td>
<td></td>
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<td>Coding assistants (locally trained)</td>
<td>8</td>
<td>2 + 2</td>
<td>1 coding assistant 2 registrars (1 in the cancer- and 1 in the family registry)</td>
<td>10</td>
<td>1 Central + Regional</td>
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<td>Medical Doctors</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td>2 consultants Central + Regional</td>
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<tr>
<td>Epidemiologist / statistician</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>-</td>
<td>1 Central + Regional</td>
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<tr>
<td>EDB - computer staff</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>-</td>
<td>1 Central + Regional</td>
</tr>
<tr>
<td>Research</td>
<td>39</td>
<td>In co-operation with scientists</td>
<td>Independent + in co-operation with scientists</td>
<td>Independent + in co-operation with scientists</td>
<td>Independent + in co-operation with other departments in Cancer Registry</td>
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<tr>
<td>Letter / telephone enquiries for clarification of notification</td>
<td>52</td>
<td>10% of notifications</td>
<td>500-600 notifications /year</td>
<td>3-5% of notifications</td>
<td>2% of notifications</td>
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Question no = question number in Appendix 2
### Table 2: Sources and CPR

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<tr>
<td><strong>Sources:</strong></td>
<td>61-73</td>
<td></td>
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<tr>
<td>Notification form - GP and Private specialists</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
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<tr>
<td>Notification form - clinical department</td>
<td>74</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
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<tr>
<td>Notification form - pathological department</td>
<td>66</td>
<td>+</td>
<td>√</td>
<td>√</td>
<td>√</td>
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<tr>
<td>Copy of hospital notes</td>
<td>77</td>
<td>+</td>
<td>-</td>
<td>√</td>
<td>+</td>
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<tr>
<td>Copy of pathology report</td>
<td>78</td>
<td>+</td>
<td>+</td>
<td>√</td>
<td>+</td>
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<tr>
<td>Copy of autopsy report</td>
<td>79</td>
<td>+</td>
<td>+</td>
<td>√</td>
<td>√</td>
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<td>Copy of discharge summary</td>
<td>80</td>
<td>+</td>
<td>+</td>
<td>√ (on request)</td>
<td>√</td>
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<tr>
<td>Copy of X-ray description</td>
<td>82</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>rare</td>
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<td>Hospital information system -link</td>
<td>83</td>
<td>√</td>
<td>+</td>
<td>+</td>
<td>+</td>
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<td>Copy of death certificates</td>
<td>57, 81</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>+</td>
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<td>Immigrants and refugees - (if no CPR number)</td>
<td>87</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
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<td></td>
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<tr>
<td>CPR-construction</td>
<td>100</td>
<td>ddmmyy - sssx: s = serial number; x = sex and control number</td>
<td>ddmmyy ± ssxz: + = 1800 / ∓ = 1900; s= serial no; x = sex; z = control</td>
<td>ddmmyy sszzq: s = serial no; z = control no; Q = century</td>
<td>ddmmyy sszzx: sss = century + serial no + sex x + z = check numbers</td>
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<tr>
<td>Name - full name registered</td>
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<td>√</td>
<td>√</td>
<td>√</td>
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<td>Relatives</td>
<td>105,106</td>
<td>+</td>
<td>+</td>
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<td>+</td>
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<td>Sex</td>
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<td>from CPR</td>
<td>from CPR</td>
<td>From CPR</td>
<td>from CPR</td>
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<td>from CPR</td>
<td>from CPR</td>
<td>From CPR</td>
<td>from CPR</td>
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<td>Emigration update</td>
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<td>not regularly</td>
<td>Annually</td>
<td>Monthly - not always</td>
<td>every 2-3 years</td>
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<td>Marital status</td>
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<td>Unreliable</td>
<td>From CPR</td>
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### TABLE 3  DATE - BASIS - CLASSIFICATION

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<tr>
<td><strong>Incidence date</strong></td>
<td>125</td>
<td>yy mm</td>
<td>mm yy</td>
<td>dd mm yy</td>
<td>dd mm yy</td>
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<tr>
<td><strong>Definition of date</strong></td>
<td>126</td>
<td>Earliest date</td>
<td>Earliest date</td>
<td>Earliest date</td>
<td>Earliest date - often biopsy date</td>
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<tr>
<td><strong>Death Certificate only (DCO)</strong></td>
<td>128</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<tr>
<td><strong>Basis of diagnosis:</strong> Histology / cytology</td>
<td>130</td>
<td>a) histo / marrow b) cyto c) blood</td>
<td>a) histo / marrow / blood b) cytology</td>
<td>a) histo b) cytology/marrow / blood</td>
<td>a) histo b) cytology/marrow c) blood</td>
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<tr>
<td><strong>Other none microscopical a &gt; b≥</strong></td>
<td>131</td>
<td>a) surgery / X-ray b) clinical</td>
<td>a) surgery / X-ray b) clinical</td>
<td>Surgery / X-ray / clinical</td>
<td>Surgery - X-ray</td>
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<tr>
<td><strong>Exceptions</strong></td>
<td>134</td>
<td>Special use of 1.digit 4.digit - NB -different sometimes</td>
<td>Several differences (see appendix 5)</td>
<td>Skin/Lymphoma/ Leukaemia</td>
<td>Lymphoma + leukaemia</td>
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<td><strong>Topography definition</strong></td>
<td>135</td>
<td>All available information</td>
<td>Clinician</td>
<td>Clinician / pathologist</td>
<td>Clinician</td>
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<td><strong>Morphology definition</strong></td>
<td>136</td>
<td>Clinicians histologic description</td>
<td>Pathologist</td>
<td>Pathologist</td>
<td>Pathologist</td>
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<td><strong>Behaviour definition</strong></td>
<td>137</td>
<td>Most malignant according to ICD-O definition</td>
<td>Most malignant local grading</td>
<td>Most malignant according to ICD-O2 definition</td>
<td>The most correct not always the most malignant</td>
</tr>
<tr>
<td><strong>Behaviour changes</strong></td>
<td>138-139</td>
<td>+ ≤ 4 months</td>
<td>Individual assessment cervix + papilloma special rules</td>
<td>≤ 2 months unless pathologist changes first diagnosis</td>
<td>≤ 4 months</td>
</tr>
</tbody>
</table>

1In case of more than one basis of diagnosis, the diagnosis associated with a) will usually be chosen. If it is already registered with another basis but the same diagnosis, the basis is not changed consequently e.g. from cytology to histology
### TABLE 4

<table>
<thead>
<tr>
<th>Question no</th>
<th>Denmark</th>
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<tr>
<td><strong>Reportable tumours - range and exceptions</strong></td>
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<td>140</td>
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<tr>
<td><strong>Tumours included in incidence apart from malignant:</strong></td>
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<td></td>
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<td>141</td>
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<tr>
<td>Benign brain tumours</td>
<td>151</td>
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<td>✓</td>
<td>✓</td>
<td>✓</td>
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<td>Pituitary gland</td>
<td>152</td>
<td>Some</td>
<td>+</td>
<td>✓</td>
<td>✓</td>
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<tr>
<td>Carotid body tumour</td>
<td>153</td>
<td>Some</td>
<td>+</td>
<td>✓</td>
<td>+</td>
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<tr>
<td>Benign bladder tumour (papilloma)</td>
<td>154</td>
<td>✓</td>
<td>+</td>
<td>✓</td>
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<td>Intraductal carcinoma in the breast (8500/2)</td>
<td>155</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<tr>
<td>Carcinoma in situ in the breast - other</td>
<td>156</td>
<td>+</td>
<td>✓</td>
<td>+</td>
<td>+</td>
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<td>Borderline tumour in the ovary</td>
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<td>Some</td>
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<td>✓</td>
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<td>Carcinoma in situ in testis</td>
<td>158</td>
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<td>✓</td>
<td>+</td>
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<tr>
<td>Chromaffinoma (8700/0) of the adrenal glands</td>
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<td>no information</td>
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<td>✓</td>
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<td>Argentaffinoma (8241/1)</td>
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<td>✓ (except appendix)</td>
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<td>Chordoma (9370/3)</td>
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<td>✓</td>
<td>✓</td>
<td>✓</td>
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<td>Invasive mola (9100/1)</td>
<td>162</td>
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<td>✓</td>
<td>✓</td>
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<td>Precancerous lesion of the cervix</td>
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<td>+</td>
<td>+</td>
<td>+</td>
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<tr>
<td>Adenoma of endocrine glands</td>
<td>165</td>
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<td>✓</td>
<td>+</td>
<td>Intracranial</td>
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<td><strong>Stage / extent of tumour recorded</strong></td>
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<td>✓</td>
<td>✓</td>
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### TABLE 5

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<th>Sweden</th>
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<tbody>
<tr>
<td><strong>Multiple tumours</strong></td>
<td>166</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skin count</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td></td>
<td>1 for each Morphology If multiple and same Morphology: ( T = 173.8 ) (incl. Basal cell carcinoma)</td>
<td>1 for each Morphology. If multiple, same Morphology, &lt; 1 year and separate sites: ( T = 190.8 ). Each tumour if &gt; 1 year and separate sites</td>
<td>1 for each Morphology. If multiple and same Morphology: ( T = xxx.8 ) (Basal cell carcinoma)</td>
<td>Depends on time-period</td>
<td>1 for each Morphology. If multiple at same time: ( T = xx.8 ); but at different time counted as separate multiple tumours (± Basal cell).</td>
</tr>
<tr>
<td>Colon</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Each tumour counted adjoining topo xxx.8</td>
<td>1 if &lt; 1 year or 153.7 if separate sites. Each tumour if &gt; 1 year and separate sites</td>
<td>Depends on pathologist</td>
<td>All registered but counted as = 1</td>
<td>All are registered, but counting practice varies</td>
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</tr>
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<td></td>
<td>1 at each site</td>
<td>No specific rules</td>
<td>1 at each site</td>
<td>1 at each site</td>
<td>1 at each site ≤ 1 year &gt; 1 year → more</td>
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<td>Brain (Astrocytoma -&gt; glioma?)</td>
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<td></td>
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<td></td>
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<td></td>
<td>2 tumours</td>
<td>1 tumour</td>
<td>1 tumour</td>
<td>1 tumour</td>
<td>1 tumour</td>
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<tr>
<td>Paired organs</td>
<td>Breast 167-169</td>
<td>same Morphology = 1 diff. Morphology = 2</td>
<td>same Morphology = 1 diff. Morphology = 2</td>
<td>Depends on pathologist</td>
<td>Varies for same Morphology diff. Morphology = 2</td>
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<td></td>
<td>Kidneys</td>
<td>- &quot; -</td>
<td>- &quot; -</td>
<td>- &quot; -</td>
<td>1 bilateral tumour</td>
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<td></td>
<td>Lungs</td>
<td>- &quot; -</td>
<td>- &quot; -</td>
<td>- &quot; -</td>
<td>1 tumour</td>
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### TABLE 6  OTHER - SCREENING - CONFIDENTIALITY

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<th>Norway</th>
<th>Sweden</th>
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<td><strong>Treatment - registered</strong></td>
<td>170</td>
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<td>✓</td>
<td>+</td>
<td>✓</td>
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<td>Date of death</td>
<td>103,125 128</td>
<td>dd mm yy</td>
<td>dd mm yy</td>
<td>dd mm yy</td>
<td>dd mm yy</td>
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<td>Cause of death - official</td>
<td>57,81,103</td>
<td>Cause of death registry</td>
<td>Cause of death registry</td>
<td>Cause of death registry</td>
<td>Death certificates</td>
</tr>
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<td><strong>Screening programmes</strong></td>
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<td>Cervix</td>
<td>190</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<tr>
<td>Breast</td>
<td>191</td>
<td>2 counties, and 2 - 3 more starting soon</td>
<td>✓</td>
<td>✓</td>
<td>4 counties</td>
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<tr>
<td>Colon</td>
<td>192</td>
<td>1 pilot</td>
<td>pilot</td>
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<td>Considered</td>
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<td>Melanoma</td>
<td>193</td>
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<td>+</td>
<td>+</td>
<td>+</td>
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<tr>
<td>Prostate</td>
<td>194</td>
<td>+</td>
<td>pilot</td>
<td>+</td>
<td>Trial</td>
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<tr>
<td>Law</td>
<td>197</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<td>Data-inspection / Ethical committees</td>
<td>204-205</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<td>Linking / permission needed</td>
<td>203</td>
<td>✓ / sometimes</td>
<td>✓ - the registry is permitted to link with other registries</td>
<td>✓ / + permission</td>
<td>✓ / + permission</td>
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<tr>
<td>Individual rights and handling</td>
<td>207</td>
<td>Access to personal data</td>
<td>Through STAKES</td>
<td>Through Medical Doctor</td>
<td>Through Medical Doctor</td>
</tr>
<tr>
<td>Access - scientist</td>
<td>211</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>International release</td>
<td>212</td>
<td>codified</td>
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dd = day; mm = month; yy = year; qq = century
### TABLE 7

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<th>Finland</th>
<th>Iceland</th>
<th>Norway</th>
<th>Sweden</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completeness of registry</td>
<td>213 Special projects</td>
<td>Few routines and special projects</td>
<td>+</td>
<td>Special projects</td>
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<td>Number of forms from pathological department</td>
<td>214 + Followed</td>
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<td>+ but high coverage</td>
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<td>Number of forms from clinical department</td>
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<td>+ - often have to be requested</td>
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<td>Disease index / Hospital discharge registry</td>
<td>216-217 + + +</td>
<td>+</td>
<td>+</td>
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<td>Outpatient logs</td>
<td>218 + + + +</td>
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<td>+</td>
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<td>Pathology logs</td>
<td>219 + + +</td>
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<td>220 Sometimes</td>
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<td>Sometimes</td>
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<td>Capture-recapture</td>
<td>221 + + + +</td>
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<td>229 92% 94% 95.5% 92.8% 98%</td>
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<td>94%</td>
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<td>Re-abstraction</td>
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<td>Chr.leukaemia + myeloma + intra-cranial benign tumours</td>
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<td>None-solid Intra cranial (prostate?)</td>
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<td>Year</td>
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<td>Age</td>
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<td>Evaluation of incidence trends</td>
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Table 1: POPULATION AND REGISTRY

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<th>Stockholm</th>
<th>Umeå</th>
<th>Uppsala</th>
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<tbody>
<tr>
<td>Population covered</td>
<td>8</td>
<td>Sweden</td>
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<td>On line → annually</td>
<td>Individual monthly incl. emigrants + death</td>
<td>Every 2 weeks + annually on death</td>
<td>Monthly</td>
<td>On line individually</td>
<td>Weekly</td>
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<td>Population figures (average),</td>
<td>13-15</td>
<td>8,780,755</td>
<td>1,637,284</td>
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<td>Autopsy, PSA, breast</td>
<td>PSA / Breast screen</td>
<td>PSA / Breast</td>
<td>Breast screen</td>
<td>PSA - autopsy Breast</td>
<td>Autopsy</td>
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<td>Staff</td>
<td>38</td>
<td>Coding assistants</td>
<td>1 central + regional</td>
<td>3</td>
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<td>Medical Doctors</td>
<td>2 consultants central + regional</td>
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<td>1</td>
<td>1</td>
<td>1 every week</td>
<td>1</td>
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<td>1 central + regional</td>
<td>2 system analysers</td>
<td>1 statistician</td>
<td>1 epidemiologist, 1 statistician</td>
<td>1 statistician</td>
<td>2 (1 of whom is also in charge)</td>
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<td>EDB-staff</td>
<td>1 central + regional</td>
<td>+</td>
<td>1 EDB - expert</td>
<td>2 EDB experts</td>
<td>1 EDB expert</td>
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<td>Research</td>
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<td>Not independently - but in cooperation</td>
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<td>Associated to external research</td>
<td>External research groups</td>
<td>Part of ROC where research is done</td>
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<td>2-3 times a week</td>
<td>30% for clarification of Topography</td>
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Question no. = Question number in Appendix 2
### TABLE 2

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<th>Lund</th>
<th>Stockholm</th>
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<th>Uppsala</th>
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<tr>
<td>Sources</td>
<td>61-73</td>
<td>Hospital + GP; Lab incl. Path + Haem.; + DCN</td>
<td>Hospital lab.; + screen; + GP; + DCN</td>
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<td>= Göteborg +screen</td>
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<td>Clinical / pathological notifications</td>
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<td>Receipt of copy of hospital notes</td>
<td>77-82</td>
<td>See regions</td>
<td>Hospital rare / pathology + / X-ray no</td>
<td>Hospital rare / pathology + / X-ray no</td>
<td>Hospital rare / pathology + / X-ray no</td>
<td>Hospital rare / pathology 4 out of 6 / X-ray no</td>
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<td>Hospital information system -link</td>
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<td>Staff visits to clinic/hospital</td>
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<td>+</td>
<td>+</td>
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<td>Immigrants and refugees</td>
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<td>Special file for non residents</td>
<td>Special file for non residents</td>
<td>Special file for non residents</td>
<td>When given CPR - included</td>
<td>Special file for non residents</td>
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<td>qqyymmdd-ssxz = q: century; y: year; m: month; d: day; s: serial number; : sex (odd for men) (even for women); z: serial and check</td>
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<td>Weekly</td>
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<th>Uppsala</th>
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<td><strong>Incidence date</strong></td>
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<td>YY MM DD (year/month/day)</td>
<td>YY MM DD</td>
<td>YY MM DD</td>
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<td>Earliest date of diagnosis</td>
<td>Earliest diagnosis</td>
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<td>Earliest diagnosis</td>
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<td><strong>Classification</strong></td>
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<td><strong>Exceptions</strong></td>
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<td><strong>Behaviour changes</strong></td>
<td>138-139</td>
<td>Registration of new invasive - except cervix &lt; 1 year</td>
<td>New if invasive Cervix &gt; 1 year</td>
<td>New invasive Except cervix myelodysplastic syndrome.</td>
<td>Individual Cervix ≥ 1 year</td>
<td>New except: cervix &lt; 1 year; myelo-dysplasia ≤ 2 month</td>
<td>New except: Brain benign → malign; breast + cervix &lt; 1 year</td>
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### TABLE 4

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<th>Question no</th>
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<td>each tumour</td>
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| **Paired organs** | 167-169 | | | | | | |
| Breast | 2 | 2 | 2 | 1 same; 2 diff M | 2 | 2 | 2 |
| Kidneys | 2 | 2 | 2 | 1 same; 2 diff M | 2 | 1 | 2 |
| Lungs | 2 | 2 | 2 | 1 same; 2 diff M | 2 | 1 | 2 |
### TABLE 6

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</table>
Appendix 5  Classifications used and Exceptions – country wise

Appendix 5  Classifications used and Exceptions

Denmark:
CLASSIFICATION(S):
From 1942: Tumours were coded according to a Nordic Classification system. This has however all been transferred into the actual ICD-7 systems and is no longer existing.
From 1955: topography was coded according to ICD 7 with some local special coding numbers to distinguish some morphology e.g. carcinoma / reticulosarcoma / sarcoma.
From 1978: topography was coded according to ICDO-1 and with transformation tables to ICD 7
morphology was coded according to ICDO-1 code equal to SNOMED
From 1995: topography was coded according to ICD 10, ICDO-1 with transformation to ICD 7. morphology was coded according to ICDO-2 (SNOMED).

Finland:
CLASSIFICATION(S):
From 1952: topography was coded according to a special topography nomenclature with transformation to WHO ICD 7 though the Finnish ICD-7 is slightly different
morphology was coded according to MOTNAC 1951 (an American 2 digit nomenclature). No changes except as described under "36".

Iceland:
CLASSIFICATION(S):
From 1955: topography was coded according to ICD 7
morphology has been recoded according to SNOP at the registry from 1955-65
From 1965: topography was coded according to ICD 7
morphology was coded according to SNOP.
From 1981: topography was coded according to ICDO-1 / ICD 9 and to ICD 7
morphology was coded according to SNOMED / ICDO-1 code.
From 1991: topography was coded according to ICD 10 and ICD 7 and the SNOMED Topography. morphology was coded according to SNOMED.

Norway:
CLASSIFICATION(S):
From 1952: topography was coded according to ICD 7
morphology was coded according to own 3- digit system
From 1970: topography was coded according to ICD 7
morphology was coded according to Motnac 1968 - 4 digit and locally modified
From 1993: Topography was coded according to ICDO-2/10 (with exceptions for lymphomas and leukaemia), and to ICD 7 morphology is coded according for the SNOMED / ICDO-2 code.

Sweden:
CLASSIFICATION(S)
From 1958: topography was coded according to ICD 7
morphology was coded according to C24
From 1987: topography was coded according to ICD 9 and translated into ICD 7
morphology was coded according to C24
From 1993: Topography was coded according to ICDO-2/10 with a few exceptions, and translated into ICD 9 and ICD 7. Morphology is coded according for the SNOMED / ICDO-2 code and C24.

Denmark

Exceptions to the ICD 7 of WHO classification rules or special rules:
Usually the coding figures are the same on 3 digit level, while there are several differences on the more specific 4th digit.
190,5 and 191,5: anus cancer included in trunk skin cancer has been given a separate number: 091.0 - but is included in the total of skin under either 190 or 191.
165 is not used.
162,0-162,2 are only used for sarcoma etc in the lymph-nodes.
Brain tumours have been much more differentiated than in the WHO version, but all are included under 193.

Finland

Exceptions to the ICD 7 of WHO classification rules or special rules:
155.8 multiple sites of biliary passage and liver: not used as each tumour is coded as a separate primary tumour.
163 malignant neoplasm of lung, unspecified as to whether primary or secondary: goes to 162.
181,7 other urinary organs: includes ureter, which in WHO is included in 180 kidneys.
193,3 peripheral nerves: has not been used since 1976.
193,8 multiple sites: not used as separate primaries are registered as separate tumours.
195,8 multiple bone sites and unspecified: used only for "bone NOS".
200 + 202 exclude extra-nodal lymphomas.
Bilateral tumours are counted once.
Other:
See malignancy code to exclude none malignant lesions.
See histology code to identify extra-nodal lymphomas.
See histology code to classify none-Hodgkin’s lymphomas.
See histology code to classify leukaemia.

Iceland

Exceptions to the classification rules:
None were described - according to the tables however leukaemia and lymphomas are coded according to ICD-9 + morphology and according to ICD-7.

Norway

Exceptions to the classification rules:
Lymphomas (C77) and Leukaemia (C42) are coded according to Kiel classification from 1983 and was extended in 1993.
Sweden

Exceptions to the classification rules:
Topography according to ICDO-2 where the following are coded according to ICD 10:
- Malignant melanoma in the skin: C43
- Hodgkin’s lymphoma: C81
- Follicular none-Hodgkin Lymphoma: C82
- Diffuse none-Hodgkin Lymphoma: C83
- Peripheral and cutaneous T-cell lymphomas: C84
- Malignant lymphoma, NOS, or diffuse: C85 (see special list in the incidence publication as ICD 10 also differs slightly from the classification)
- Immunoproliferative diseases: C88
- Plasma cell tumours: C90
- Lymphatic leukemias: C91
- Myeloid leukemias: C92
- Myelodysplastic syndrome: D46
- Monocytic leukemias: C93
- Other specified leukemias: C94
- Leukemias, NOS: C95
- Neoplasma malignum telae lymphatica et haematopoeticae/other and unspecified tumours in lymphoid and haematopoietic tissue: C96 / D45 / D47 / D76
These are all transformed to the ordinary ICD 7 code: 200x - 209x, where each group contains the types of lymphoma / leukaemia as defined in Sweden (see appendix 5 = table W2 in the Incidence publication)

Finland:

Changes in inclusion / exclusion (see Incidence publication 1994 p 5: Explanatory notes) (13).
- "Papilloma of the urinary organs" were from 1964 until 1992 mentioned separately at the bottom of the incidence-publication, though not included in the incidence number.
- "Borderline ovary tumours" were included from 1969.
- "Polycythemia vera" were calculated from 1969, and mentioned separately at the bottom of the tables.
- "Brain-tumours" have from 1979 also included "acoustic neurinoma", "intradural schwannoma" and "spinal meningioma". (benign tumours of the pituitary gland are not included).
- "Waldenström" has been included in "lymphomas" since 1965.
- "Stomach" and "cardia tumours" were separated in 1971 - the "cardia tumours" (except for epidermoid carcinomas) are still included in the incidence figures for "stomach tumours", but can now be separated.
- Since 1978 it has become possible to separate "anus tumours" from the "rectum tumours".
- The "leukaemia" histology was changed in 1964 from 4 different types into 10 different types.
Appendix 6  Translation of site codes

Appendix 6  
Translation of site codes from IDC-O-2 / ICD-10 to ICD-7 and ICD-9, including relevant morphology codes. Developed by the Swedish Cancer Registry.

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<td>D463</td>
<td>Refractory anemia with excess of blasts with transformation</td>
<td>223</td>
<td>2059</td>
<td>2059</td>
</tr>
<tr>
<td>D467</td>
<td>Myelodysplastic syndrome, NOS</td>
<td>223</td>
<td>2059</td>
<td>2059</td>
</tr>
<tr>
<td>D469</td>
<td>Dysmyelopoietic syndrome, NOS, preleukemia</td>
<td>223</td>
<td>2059</td>
<td>2059</td>
</tr>
<tr>
<td>D470</td>
<td>Mastocytoma, NOS</td>
<td>381</td>
<td>2021</td>
<td>2029</td>
</tr>
<tr>
<td>D471</td>
<td>Chronic myeloproliferative disease, NOS</td>
<td>216</td>
<td>209</td>
<td>2090</td>
</tr>
<tr>
<td>D471</td>
<td>Myelofibrosis or myelosclerosis</td>
<td>216</td>
<td>209</td>
<td>2090</td>
</tr>
<tr>
<td>D473</td>
<td>Idiopathic thrombocythemia</td>
<td>293</td>
<td>2079</td>
<td>2089</td>
</tr>
<tr>
<td>D760</td>
<td>Eosinophilic granuloma (Langerhans´ cell histiocytosis)</td>
<td>386</td>
<td>2021</td>
<td>2029</td>
</tr>
<tr>
<td>D760</td>
<td>Histiocytosis X</td>
<td>386</td>
<td>2021</td>
<td>2029</td>
</tr>
<tr>
<td>D760</td>
<td>Hand-Schüller-Christian disease</td>
<td>386</td>
<td>2021</td>
<td>2029</td>
</tr>
</tbody>
</table>
Appendix 6  Translation of site codes
Update procedures for Survey of Nordic Cancer registries

The Survey of the Nordic Cancer Registries published by the ANCR year 2000, is planned updated regularly with changes in cancer registry procedures, including access to data, confidentiality etc. The updates will be carried out in the central documents based on the Danish Cancer Society Web site with annual update sheets to the report. Whenever an update occurs in a registry to one of the items in the report, an asterisk will be placed in the report referring the reader to the update sheets.

In order to secure that registries do give updating of the document priority, a questionnaire will be mailed each year to each of the cancer registries in the Nordic countries to be filled in and submitted to the ANCR Board at its annual meeting. The update of the publication is going to be a permanent agenda item at the ANCR Board Meeting.

The questionnaire is composed with open questions, allowing the Cancer Registry to include what is found useful to users of the registry data.

Questionnaires should be circulated to the ANCR Board, and a copy sent to the secretariat at Danish Cancer Society Department of Cancer Prevention and Documentation att. Hans H. Storm fax +45 3525 7731 E-mail hans@cancer.dk
Update procedures
Questionnaire for yearly update of Survey of Nordic Cancer Registries.

**Question 1: Population and registry:**
Are there any changes in the population – areas covered by the registry, such as new administrative unit, recording of special population’s etc?

Answer 1: No  
Answer 2: Yes, please specify

**Question 2: Data sources and population registry files:**
Has there been any change in the data sources, used by the cancer registry, or changes in the population or other support registries used by the cancer registry in its activities?

Answer 1: No  
Answer 2: Yes, please specify

**Question 3: Has there been any changes in the definition or recording of tumour characteristics, such as date of diagnosis, basis for the cancer registry record, change in classification of the site of cancer, morphology, staging etc.?**

Answer 1: No  
Answer 2: Yes, please specify

**Question 4: Reportable and tumours included in the incidence publications by the registry.**
Has the range of reportable tumours been changed during the last year, and have you changed attitude towards inclusions/exclusion of specific tumours of i.e. benign/carcinoma in situ type?

Answer 1: No  
Answer 2: Yes, please specify
Questionnaire for yearly update

Question 5: Multiple tumours.

Multiple tumours. Have you introduced any change during the last year in definition and coding of multiple primary cancer, and have you made any changes related to these in your incidence publications?

Answer 1: No
Answer 2: Yes, please specify

Question 6: Screening.

Have you had any change in screening programmes in the registration area during the last year, introduced new screening, changed the age range of those offered screening, stopped screening programmes etc.?

Question 7: Other.

Have you had any other activities during the past year that may influence the incidence recording of the cancer registry?

Answer 1: No
Answer 2: Yes, please specify

Question 8: Confidentiality.

Have you had any change in confidentiality rules of the registry, new laws in your country on data protection and access to data, data delivery etc.?

Answer 1: No
Answer 2: Yes, please specify

Question 9: Quality control

Have you adopted new quality control procedures of the registry data in the past year (like new computer edits, stratified sampling with recording, linkage to other clinical databases, hospital record surveys etc.)?

Answer 1: No
Answer 2: Yes, please specify
Questionnaire for yearly update

**Question 10: Outputs and standards.**

Have you had any changes in your regular data output/publications by the registry, and have you made data accessible in any way or in a new way on the Internet/International databases etc.?

Answer 1: No
Answer 2: Yes, please specify

**Question 11: Any other changes.**

Have you made any other major changes in your data base such as a site specific clean up, influencing data back in time, studies of the quality of treatment variables etc., that may be of use to the users?

Answer 1: No
Answer 2: Yes, please specify

This questionnaire can be mailed electronically to hans@cancer.dk. By fax to the Danish Cancer Society, Department of Cancer Prevention and Documentation, fax: +45 3525 7706, and should be mailed to the Registry responsible for the ANCR meeting of the year, at least 3 weeks in advance of the annual symposium.
Questionnaire for yearly update