

## **Appendix 3 (a) The Danish Cancer Registry, a self-reporting national cancer registration system with elements of active data collection**

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### *Introduction*

#### **Denmark and its health service**

The kingdom of Denmark (excluding Greenland and the Faeroe isles) covers 43 080 square kilometres between 55 and 58 degrees north and 8 and 12.5 degrees east. The population on 1 January 1986 was 5.1 million. The medical care system is organized into a private sector of general practitioners and specialists under contract with the National Health Insurance, and a public sector operating hospitals under the authority of the counties, communities or the Danish State. Health care is provided free to all inhabitants.

In 1980, there were 5.6 hospital beds and 2.2 physicians per 1000 inhabitants. Surgical treatment of cancer is carried out both at general and at oncological centres. The hospital departments are serviced by 28 institutes of pathology. Non-surgical cancer treatment is partially centralized at five regional radiotherapy and oncological centres. Almost everyone in the population is able to reach one of the regional cancer centres within a few hours.

#### **The Danish Cancer Registry mission**

The Danish Cancer Registry was founded in May 1942 as a nationwide programme to register all cancer cases in the Danish population. It is operated by the Danish Cancer Society on behalf of the National Board of Health and is supported by the Danish Medical Association. Incidence figures are available from 1 January 1943.

The original mission of the Cancer Registry (Clemmesen, 1965) was to collect material that could serve as the basis for:

- (a) reliable morbidity statistics with the aim of obtaining accurate estimates of therapeutic results in cancer;
- (b) an accurate estimate of differences in incidence of malignant diseases at various times and between various areas, occupations etc;

(c) statistics on individual patients for the use of physicians as well as for the study of multiple cancer, coincidence of cancers etc.

The Registry produces morbidity statistics with a view to monitoring the variation in the incidence of cancer over time, geographical location, occupation and other factors. It also conducts epidemiological research within the field of cancer causation and prevention.

### **Basis of incidence**

The Registry is tumour-based, and tumours (with some exceptions, i.e. multiple cancers of skin and paired organs with similar morphological characteristics), are the unit registered. For the first 25 years of operation, the key identifiers linking tumour records for a person were date of birth and name. Since 1968, registration has been facilitated by the introduction of a unique personal identifying number (PNR) which is now used as the key-identifier. This identification number facilitates internal linkages to avoid duplicate registrations.

### *Reporting*

#### **Legal aspects**

Until March 1987, reporting was voluntary and a small token fee was paid for each notification form received. On 1 March 1987, reporting became mandatory (Sundhedsstyrelsen, 1987), without otherwise changing the reporting system in operation since 1943. Legally, the responsibility for reporting to the Registry lies with the heads of clinical hospital departments, the heads of pathology departments performing post-mortem or practising physicians undertaking treatment or follow-up, without referring patients to hospital.

#### **Reportable diseases and reporting**

All malignant neoplasms, including carcinomas, sarcomas, leukaemias, lymphomas and all brain and central nervous system tumours, all bladder tumours irrespective of behaviour, and all precancerous lesions on the cervix uteri must be reported to the Cancer Registry. Other precancerous lesions are not reportable. The reportable diseases correspond to the following categories of the ICD-8 classification (the classification currently in use by the Danish National Health Authorities): ICD-8 140–207, 223, 225, 230–239.

The rules for notification state that all newly diagnosed cases of reportable diseases must be notified, and that a separate report must be submitted to the Registry for each primary tumour if a patient has multiple primaries. The following must also be notified:

- all revisions of diagnosis for a previously reported case;
- progression of dysplasia;

**Table 1. Data sources of the Danish Cancer Registry**


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<b>Medical:</b>	
Notification forms:	General practitioners Practising specialists Hospital departments Institutes of pathology Institutes of forensic medicine
Death certificates:	Computerized and microfilm
<b>Non-medical:</b>	
Central Population Registry	(Computerized)
Local population registers	(Not computerized)

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- progression of precancerous lesion or carcinoma *in situ*;
- autopsy results on newly or previously diagnosed cancer cases.

### Data sources

The Danish Cancer Registry receives notifications from clinical hospital departments, pathology departments and practising physicians as well as death certificates as outlined in Table 1 and explained in detail below. This information is supplemented with personal data from the central population register.

#### *Medical data sources*

Hospital departments are asked to notify the Registry of any cancer case the first time the patient is admitted for treatment or diagnosis. Typically a patient enters the hospital care system at local level and is then referred to more specialized departments for further diagnosis or treatment. Many cancer patients are referred to one of the five major oncological centres in Denmark for radiotherapy or other highly specialized treatments. The Cancer Registry thus receives multiple notifications on each cancer case. If one or two hospital departments fail to report a case, there is a fair chance that it will be known to the Registry from other notifications. The high level of completeness of the Danish Cancer Registry is thus a consequence of the operation of the health care system (Østerlind & Jensen, 1985; Storm, 1988). Only clinical hospital departments are asked to fill in and submit the clinical notification form, stating results from specialized service departments, such as diagnostic X-ray and histopathology. Receipt of information from those responsible for treatment and follow-up facilitates coding and avoids misinterpretation of data from other sources, such as departments of pathology or diagnostic X-ray. Physicians in general practice are asked to report cancer cases that are not referred for further treatment and diagnosis within the hospital system.

Autopsy rates are high (35%) in Denmark and 43% of all cancer deaths are autopsied (Storm & Andersen, 1986). The results from autopsies on cancer patients are reported by the institutes of pathology directly to the Registry, irrespective of the

presence of tumour tissue. Cases unsuspected prior to death and diagnosed only at autopsy are also reported and included in the register. Since 1943, the Danish Cancer Registry has received information on cases on the death certificate either as the underlying or the contributing cause of death. The identification of such cases was achieved by a manual linkage with the national death certificate system. Since 1971, the linkage has been computerized. The fraction of cancer cases verified by means of death certificate only has diminished from approximately 19% in 1943-47, to 1-2% in 1977-82 (Jensen *et al.*, 1985), as shown in Table 2. The Registry performs a follow-back procedure for such death certificate cases, requesting notification forms from either the physicians or hospital departments indicated on the death certificate which have failed to notify the Registry.

#### *Non-medical data sources*

Any cancer patient accepted by the Registry must be a Danish resident at the date of diagnosis. In the Central Population Register (CPR) a continuously updated file on all Danish inhabitants is kept, with information on name, addresses, marital status, dates of emigration and immigration, occupation and date of death. Details are available on dates of changes, and historical data are available regarding changes in marital status, addresses etc. Every reported case of cancer is linked to the CPR using the unique personal identification number (PNR) allocated at birth or when taking up permanent residence in Denmark. This linkage serves two purposes: to check the identity of a notified person, and to transfer information on the above-mentioned items, i.e., names etc., with due reference to the date of diagnosis.

#### *Future data sources*

Computerization is now widespread within the health care system. A National Hospital Discharge Register (HDR) has been in operation since the late 1970s. The HDR may be used for identification of non-reported cancer patients in the future (Østerlind & Jensen, 1985). A computerized system of pathology diagnoses, using the SNOMED classification is now effective in 50% of Danish departments of pathology. This registration system may also be used for identification of cancer patients, and possibly provide information on morphologies of poorly reported cancers. Neither of these systems was created for cancer registration and they may only supplement the regular registration scheme. The major drawback of the systems is the decentralized interpretation and coding of diagnoses (including all non-cancer diagnoses), often performed by less experienced medical staff or non-medical staff, which may result in imprecision of diagnostic information.

#### **Notification forms**

The notification forms used are simple, requesting only a limited amount of information for each case. The forms are largely self-explanatory and include boxes for ticking specific questions, as well as dedicated space for entering names, occupation, previous treating hospitals, tumour and treatment details and dates of various events. The forms are made on self-copying paper, the copy to be retained in

**Table 2. Percentage distribution of method of confirmation for all cancers combined by year of diagnosis for males and females. Denmark, 1943–80**

	Year of diagnosis								All years
	1943–47	1948–52	1953–57	1958–62	1963–67	1968–72	1973–77	1978–80	
Cases registered	49 144	55 439	64 238	74 043	86 902	103 282	118 118	79 921	631 087
Type of confirmation (%)									
Microscopically confirmed									
Without autopsy	37.1	43.3	43.8	46.6	48.9	50.5	54.6	65.6	50.2
With autopsy	15.6	19.6	24.3	29.0	32.0	35.2	31.8	24.8	28.0
Not microscopically confirmed									
Clinical report only	23.5	20.8	18.0	14.4	11.0	7.9	6.9	7.6	12.2
Autopsy report only	4.6	2.6	2.3	2.0	2.0	1.9	1.8	0.7	2.1
Death certificate only	19.3	13.7	11.7	8.0	6.1	4.5	5.0	1.3	7.5

From Jensen *et al.* (1985)

the hospital record. Brief guidelines on completing the form are given on the reverse side of the copy. These are supported by a booklet with detailed guidelines mailed to all reporting institutions. Two different forms are in use, one for practising physicians and hospital departments (Figure 1) and one for institutes of pathology (Figure 2).

#### *Clinical notification form (Figure 1)*

The tumour diagnosis, given as topography and morphology, is requested in clear text. Date of diagnosis is taken as month and year of first admission or first outpatient visit for the malignant disease. The extent of disease is ticked off in predetermined boxes categorized as precancerous lesion, localized, regional metastatic, distant metastatic or unknown. For certain cancers more detailed staging, such as FIGO for gynaecological tumours, may be indicated in clear text. The basis of the diagnosis is indicated by ticking boxes for histology, bone marrow examination, cytology, surgery without histology, other specified, clinical alone and incidental autopsy finding.

Treatment information is sparse and only primary treatment, i.e., given within the first four months, is recorded. Surgery is indicated by ticking yes or no, giving date of surgery and in clear text the surgical procedure, e.g., colectomy. The physician is asked to indicate whether the surgical treatment was only diagnostic, palliative or attempted radical. Other treatments are given as radiotherapy, cytotoxic treatment, or hormone treatment without further details. Date of start of treatment is requested. Furthermore, it is possible to tick no treatment given or other treatment, and to specify this in clear text. The ticking of boxes is cross-checked against the information otherwise stated on the form, such as histological diagnosis, surgical procedures and autopsy result. For deceased patients, date of death should be given. If an autopsy was performed, the hospital and department where it was performed, as well as the overall conclusion on cancer should be stated. Furthermore, the pathologist who performed the autopsy is asked to report the findings on the special form for institutes of pathology.

#### *Pathology (autopsy) notification form (Figure 2)*

The notification form on autopsy findings from a department of pathology holds the same information as the form from a clinical department, except for treatment. The pathologist is asked to give the name of the department which treated the patient. This enables the registry to request notification forms from the clinical department if the case has not been previously notified. Since several cancers may be found at autopsy, the form provides space for notification of three different cancers per person.

### *Registration procedures*

#### **Receipt of notifications**

Notification forms are received daily by mail and processed in weekly batches (approximately 1000 forms) in accordance with the flow diagram shown in Figure 3. The initial phase includes, as a first step, the creation of a data-base named after the



## REVERSE SIDE OF NOTIFICATION FORM CONCERNING MALIGNANT OR PREMALIGNANT TUMOURS

Notification to the Cancer Registry is compulsory for all physicians as written in instruction no. 50 from the Danish Board of Health of 15 January 1987: "Instruction for physicians concerning notification to the Cancer Registry of cases of cancer".

## INSTRUCTIONS

### WHICH DISEASES ARE TO BE REPORTED ?

All cases of malignant tumours, such as carcinomas, leukaemias, malignant lymphomas and all brain tumours (including benign), all bladder tumours and uterine precancerous lesions are to be reported to the Cancer Registry.

Previously diagnosed tumours that are not refound at autopsy should be indicated under the heading "remarks"; e.g. Neoplasma malignum pulmonum dextri (adenocarc.) tractum. 1978—not found at autopsy.

All cases of doubt should be reported.

### NOTIFICATION SHOULD TAKE PLACE FOR :

1. All cases of newly diagnosed tumours.
2. Cases of multiple tumours in the same person, with separate reports for each tumour that is considered a new primary tumour.
3. Revision of previous diagnosis.
4. The ascertainment that a previously reported tumour did not exist after all.
5. The progression of precancerous lesions or carcinoma in situ, including a change to an invasive tumour.

The report should be submitted, at the latest, when the patient is discharged from the hospital.

### OCCUPATION

The patient's trade or profession should be specified. Please avoid imprecise statements; e.g. "bank manager" should be stated instead of just "manager", "journeyman carpenter" instead of just "carpenter", and "farm owner", instead of just "farmer". For retired people please state their former occupation also, e.g. "former bricklayer".

### HOSPITAL AND DEPARTMENT OR GENERAL PRACTITIONER

The name of the department and hospital reporting should be stated. For reports from a general practitioner or specialist, the name and address of the physician should be stated.

### DIAGNOSIS

State the discharge diagnosis, and describe the exact position of the primary tumour, as regards both organ and localization of the tumour in the organ.

### THE HISTOLOGICAL DIAGNOSIS OF THE TUMOUR should be stated.

If a histological examination has only been carried out for metastases, please state. For cancer in the bladder and papillomas, state a grade from I to IV.

Stages for cancer of the cervix uteri should be stated. The spreading of the tumour should be ticked.

### TREATMENT

Treatment directed at the primary tumour or metastases during the present admission should be stated.

### DEATH

If the patient is deceased please give the information required.

### AUTOPSY

Autopsy number, hospital where autopsied, and tumour diagnosis should be stated (please see detailed instruction).

### INCIDENTAL AUTOPSY FINDING

For every tumour, tick whether the tumour was an incidental autopsy finding, i.e. a disease (tumour) which gave no symptom or objective sign when the patient was alive.



## Seceret tilfælde af malign lidelse - Indberetning fra et Patologisk Institut



Indsendes til: Kræftens Bekæmpelse, Cancerregisteret, Rosenvængets Hovedvej 35, Box 839, 2100 Kbh. Ø. Tlf. 01 26 88 66

(Beretnes venligst uddybt på skrive-maskinen)

<b>CPR. nr.</b>	Personal identification number (10-digits) provided to all Danish citizens 1 April 1968. Composed of date, month, year of birth, and a 4-digit check-number including sex, and century of birth.	Forbeholdt Cancerregisteret For registry use
<b>Efternavn<sup>a</sup></b>	Family name (and maiden name)	Stilling <input type="text"/> Occupation Diag dato <input type="text"/> Month/year of diagnosis Topo <input type="text"/> ICD-0 topography Morfo <input type="text"/> ICD-0 morphology Opt/grad <input type="text"/> ICD-0 Behaviour and Bergkvist grading urothelial tumours Lateral/udbred <input type="text"/> Laterality of paired organs and stage of disease Grundig 1 <input type="text"/> 2 <input type="text"/> Methods of confirmation Behand <input type="text"/> Treatment within first 4 months
<b>Fornavn<sup>a</sup></b>	First name(s)	
<b>Adresse<sup>a</sup></b>	Address (municipality and county)	
<b>Stilling (a)</b>	Occupation	
<b>Dødsdato</b>	Date of death = date of diagnosis if no other information than this form is available	
<b>Sidste indl.</b> Last hospital admission	Indl. dato Date of admission Sygehus afdeling Hospital and department	
<b>Sektions nr.</b> Reference number of autopsy	Ald. nr. iflg. Sundhedsstyrelsen Reference number for department according to the Danish Board of Health	
<b>Sektionssygehus</b>	Hospital where autopsy was performed	
<b>FOR TUMORER, DER INDBERETTES TIL CANCERREGISTERET</b> (se vejledning på bagsiden) (instructions, see reverse)		

**Primær Tumor 1** - First primary tumour

**Endelig sektionsdiagnose:** - Final autopsy diagnosis (only tumour diagnosis)  
(kun tumordiagnosen)

**Histologisk diagnose:** - Morphology (text)

Histologisk verifikation:  ja  nej  
 Histologically verified  
 Udbredelse:  lokal  regional  fjernmetast.  ukendt  uoplyst  
 Stage of disease  
 Uventet (tilfældigt) sektionsfund:  ja  nej  
 Incidental autopsy finding

hvis nej anfor behandlende hospitalsald. - if no, please indicate the treating hospital department Diagnoseår Year of diagnosis

**Primær Tumor 2<sup>b</sup>**

**Endelig sektionsdiagnose:**  
(kun tumordiagnosen)

**Histologisk diagnose:**

Histologisk verifikation:  ja  nej  
 Udbredelse:  lokal  regional  fjernmetast.  uoplyst  
 Uventet (tilfældigt) sektionsfund:  ja  nej

hvis nej anfor behandlende hospitalsald.

Diagnoseår

**Primær Tumor 3**

**Endelig sektionsdiagnose:**  
(kun tumordiagnosen)

**Histologisk diagnose:**

Histologisk verifikation:  ja  nej  
 Udbredelse:  lokal  regional  fjernmetast.  uoplyst  
 Uventet (tilfældigt) sektionsfund:  ja  nej

hvis nej anfor behandlende hospitalsald.

Diagnoseår

**Bemærkninger**  
Special remarks

Dato - date

Underskrift - signature (must be MD)

**Figure 2. Danish Cancer Registry: registration form for use by an institute of pathology**

REVERSE SIDE OF NOTIFICATION FORM CONCERNING AUTOPSIED CASE OF MALIGNANT DISEASE—  
REPORT FROM A PATHOLOGICAL INSTITUTE**INSTRUCTIONS****WHICH DISEASES ARE TO BE REPORTED?**

All cases of malignant tumours, such as carcinomas, leukaemias, malignant lymphomas and all brain tumours (including benign), all bladder tumours and uterine precancerous lesions are to be reported to the Cancer Registry.

Previously diagnosed tumours that are not refound at autopsy should be indicated under the heading "remarks"; e.g. Neoplasma malignum pulmonis dextri (adenocarc.) tractatum. 1978—not found at autopsy.

**INSTRUCTIONS FOR FILLING IN THE NOTIFICATION FORM FOR THE CANCER REGISTRY REGARDING AUTOPSIED CASES OF MALIGNANT DISEASE:****1. OCCUPATION**

The patient's trade or profession should be specified. Please avoid imprecise statements; e.g. "bank manager" should be stated instead of just "manager", "journeyman carpenter" instead of just "carpenter", and "farm owner", instead of just "farmer". For retired people please state their former occupation also, e.g. "former bricklayer".

**2. ADMISSION**

State the date of admission and name of the hospital and department. Date of death should be stated for a person who has not been in hospital.

**3. AUTOPSY**

Autopsy number and hospital should be stated. Reference number for departments according to the Danish Board of Health's Classification of Hospitals should be stated (valid as per 1 January 1982).

**4. AUTOPSY DIAGNOSIS AND MORPHOLOGICAL DIAGNOSIS**

For every single tumour, even unverified, the final autopsy diagnosis should be stated, including information on the anatomical localization and morphology.

N.B. If the primary tumour is unknown, this must be evident from the diagnosis. The expression "cancer metastaticus" can be used, e.g. c. metast. pulm. dext. or c. metast. hepatis. For every gynaecological tumour the stage should be indicated. For cancer of the bladder (including papilloma), grade I to IV should be stated.

It should be indicated whether there has been histological verification and whether there is spreading of the tumour.

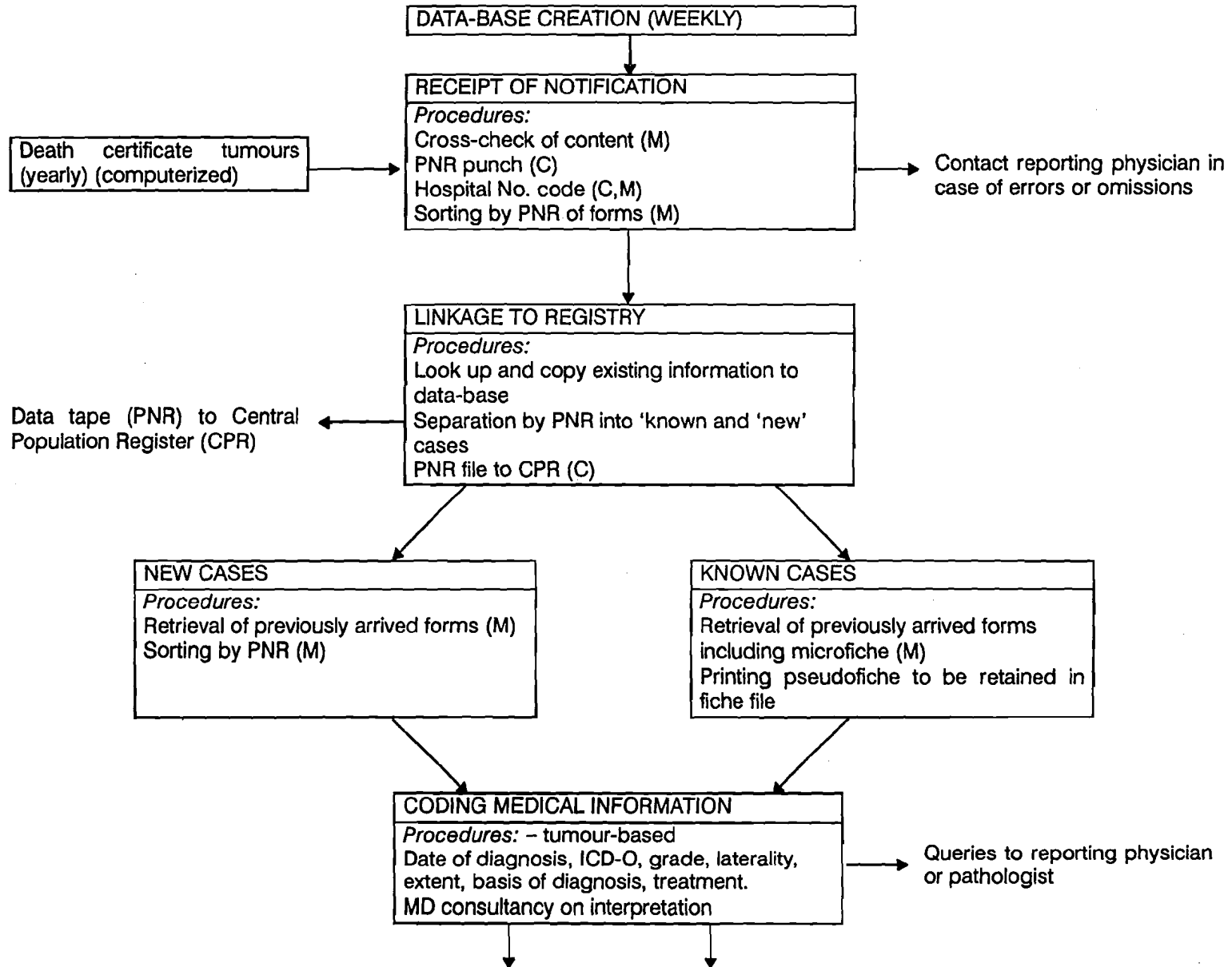
**5. INCIDENTAL AUTOPSY FINDING**

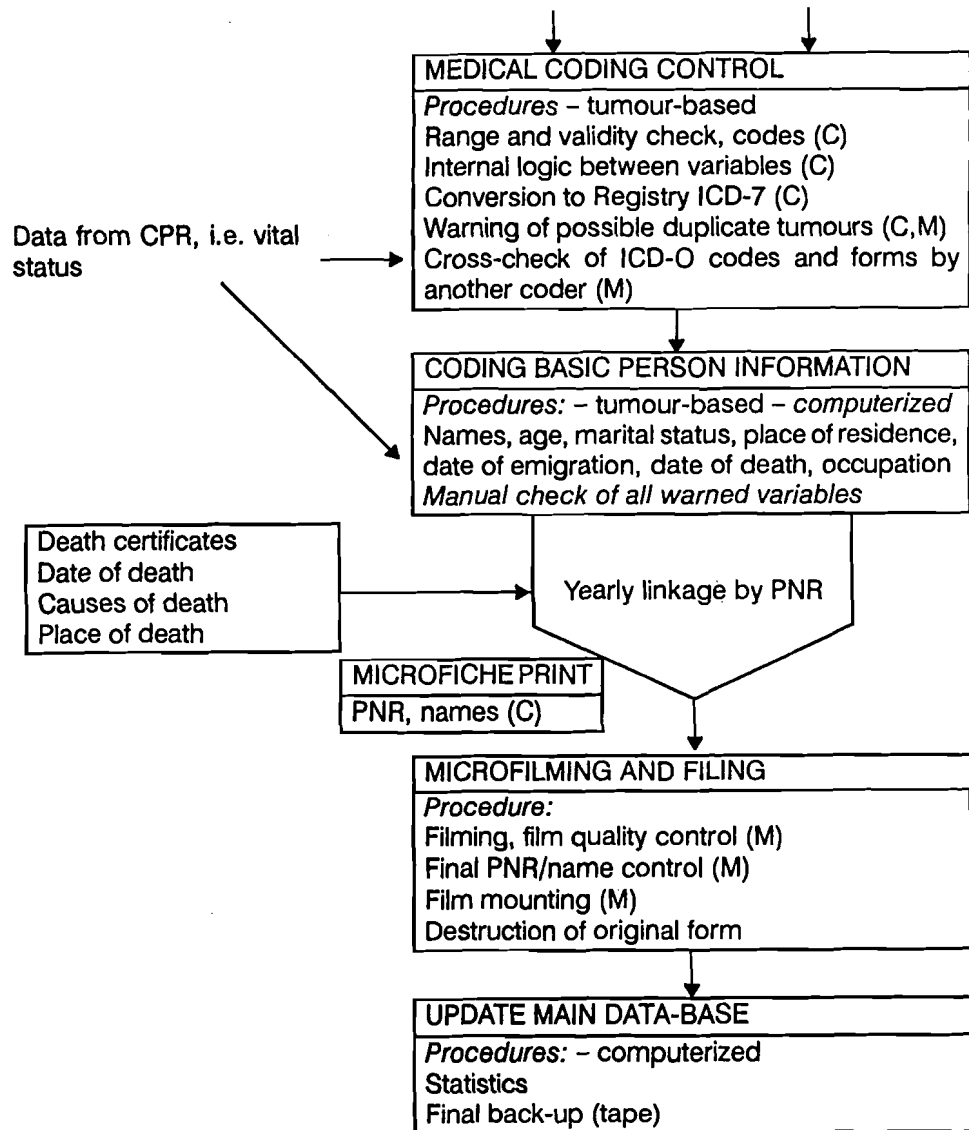
For every tumour, tick whether the tumour was an incidental (unexpected) autopsy finding, i.e. a disease (tumour) which gave no symptom or objective sign when the patient was alive.

**6. THE TREATING HOSPITAL DEPARTMENT**

If the tumour was known before autopsy, state the treating hospital department and year of diagnosis.

N.B. If you have any question on how to fill in the form, please contact The Danish Cancer Society, The Cancer Registry, telephone: 01 26 88 66.





**Figure 3. Flow diagram of the Danish cancer registration system**

(M) Manual/visual checking procedure

(C) Computerized checking procedure

CPR Central Population Register

PNR Personal identification number

MD Medical doctor

ICD-O International Classification of Diseases for Oncology (WHO, 1976b)

calendar-week. When the notification form arrives, the personal identification number, the identification number of the reporting hospital and the week of arrival are entered into the data-base. A computer check of the validity of the personal and hospital number is performed. A visual check of content of the notification form is made, and the reporting physician is contacted if major omissions are observed. For each weekly batch of notifications, a computer search is made in the Registry for previous reports on the same persons, and the weekly batch can thereafter be separated into persons previously known by the Cancer Registry and new cancer patients. These two parts of the batch are processed somewhat differently, since data on known cases already exist on microfilm. All existing information on a person is retrieved (microfilm, forms under process and computerized information) and moved to the current weekly batch. Following sorting procedures by PNR, the coders meticulously check correspondence between the content of the data-base and the compiled notification forms. A data tape with PNRs for linkage with the CPR is created at this step. The same person (coder) is responsible for the processing of one weekly batch of notifications (receipt, coding, data entry, checking and correcting).

## Coding

### *Medical information*

The specially trained coder codes the forms according to the rules and guidelines set forth in coding manuals. From 1943 to 1978, recorded tumours were classified according to a modified and expanded version of the seventh revision of the International Classification of Diseases (ICD-7) (WHO, 1957). Since 1978 the Registry has used the ICD-O classification system (WHO, 1976b). This code has been expanded by a code for Bergkvist grade of bladder tumours (Bergkvist *et al.*, 1965), a code for laterality of paired organs, as well as codes for basis of diagnosis, thus not relying on the rules inherent in the ICD-O coding system. ICD-O codes are converted to the modified ICD-7 code by a computer program. Finally, extent of disease and treatment in the first four months after diagnosis are recorded.

A number of checks are performed online while others are performed in batch after one week's forms have been coded. Repeat runs are made until no further coding errors are identifiable.

At this point all notification forms, as well as listings of computerized information, are handed over to another coder for proof-reading key variables such as topography and morphology. Throughout the coding process the coders have support from a medical doctor who interprets questionable cases and takes responsibility for queries to reporting physicians and pathologists. It is our experience that communication at professional level increases the rate and quality of response. Mail responses are preferred since documentation of the response is easily stored; if the telephone is used, the response is written down in order to ensure proper documentation.

### *Basic personal information*

After termination of the medical coding, the coders perform computer-assisted coding of basic personal information. The official names, marital status, occupation,

place of residence and date of emigration or death of the patient are retrieved from the CPR. The information stored is that recorded at the date of diagnosis of the tumour. It is thus possible to apply strict criteria on, for instance, whether the patient was in fact a Danish resident at the time of diagnosis, and to transfer a correct address of the patient, i.e. municipality and county, as well as calculating age at the time of diagnosis. Names are used to check whether the name and CPR number on the notification form correspond to the information retrieved from the Central Population Register. This enables the coders to pick up discrepancies on numbers of persons and names, since a valid number may be attributed to a wrong name by the reporting institution, or punching errors may by chance fulfil the logical checks of the PNR. Names may also change, e.g., by marriage, and the coders have to inspect and use historical records given in the CPR for full verification. Occupation is not considered to be an important variable by the Central Population Register and may often be coded on the basis of the notification form alone. Parts of the automated coding must be verified by the coders, if uncertainty applies to the transferred data. After verification, a check programme is run to ensure that there are no non-verified discrepancies between CPR and registry data.

## Quality control

### *Visual*

Instant and continuous quality control is an important part of the registration process. Visual inspection of notification forms for content is performed at an early stage and acted upon if omissions are obvious. If information necessary for medical coding is missing, this information is requested. So is information to clarify non-logical entries on the form. The visual check of correspondence between computerized information on the tumour topography and morphology and the actual notification form is regarded as very important, since no duplicate coding or punching is performed. A final visual inspection on the identity of the patient and the reported tumour is performed in conjunction with mounting and filing microfilm copies.

### *Computerized*

The visual quality control is supported by a number of computerized checks and warnings. *Errors* in logic must be corrected in order to complete the coding process; *warnings* may pass without altering coded information. Only the head of the Registry may enter non-logical information, if this is required (e.g., a male with sex-change operation to female and testis cancer). Value-ranges are checked at punching. A check program ensures that allocated codes are valid, and the following logical checks are performed:

- date of diagnosis must be equal to or prior to current date or date of death;
- sex-specific tumours may only occur in the relevant sex;
- paired organs must have laterality specified (including unknown);
- histology must be present if basis of diagnosis is histology or cytology;
- autopsy as basis of diagnosis is only accepted if the patient has died;

—if curative surgery has been performed, surgery should appear as basis of diagnosis;

—curative surgery is only accepted for localized or regional extent of disease;

—spurious combinations of topography and morphology are only accepted after inspection.

The final check is a programme of warnings—i.e., possible but not plausible events. If more than one tumour is coded to the same ICD-7 code (3-digit specificity), a warning is given that duplication is a possibility. Similar warnings will be applied to multiple cancers in adjacent sites and to rare combinations of topography and morphology in the ICD-O. The check program on personal information searches for inconsistencies between the CPR and coded information. However, no further warnings are raised if the information is accepted by the coders by keying 'accepted at visual inspection'.

### **Filing and updating**

After a batch of notification forms have passed through the above-mentioned procedures, the Registry's main data-base is updated with the new information. Summary statistics on the result of updating are printed routinely, as are listings of rejected/deleted PNRs and variables.

Microfiche sheets are printed with key identification, PNR and names of all new patients. All notification forms are microfilmed, and the photographic copy stored in microfiche with space available for 15 microfilmed forms per person. During this process, the film, original form and microfiche PNR and name are cross-checked. If these do not correspond, the case is flagged manually. If errors are identified, the notification form and changes are 'mailed' to the registration system for renewed processing. If no errors are detected and film quality is accepted, the original paper notification is destroyed.

### *Staff*

The registration is headed by a section chief (a medical doctor) who supervises the staff running the system, and is also responsible for initiatives taken to improve the existing registry system, for collaboration with the computer section, and with clinicians and pathologists throughout the country.

Approximately 1000 notification forms are received per week. These are processed by a staff of five coders, four other clerical staff, and one programmer. The clerical staff who conduct the basic coding are specially trained for this purpose. Coding and classification of all reported cases is supervised by two medical doctors. Other professional staff members act as consultants for personal information received from the CPR.

### *Computer system*

The registration system is programmed using data-base system SIR (1985) with additional programs in other languages. An SAS (1985) version of the register is

maintained for tabulation purposes. A batch of 1000 notification forms per week was chosen as the size of the data-base, these being the cases undergoing changes. The major advantage of working with small data-bases, rather than online with the main registry data-base is the security and smaller impact of errors in the hardware or data-base software. Back-up procedures are also less time-consuming with smaller amounts of data. The main registry data-base is updated monthly with the processed weekly batches. The computerized registration system run on a PRIME computer 9955. The main SIR register occupies 200 megabyte disk storage. The entire registration system, including programs, documentation and transactions occupies up to 700-800 megabytes.

## *Manuals and documentation*

### **Coding manuals**

To ensure that coding between coders and over time is comparable, detailed coding manuals have been developed. The ICD-O manual is the basis for coding of topography and morphology. Supplementing this manual is an itemized manual on all variables, giving general and specific rules for coding. The manual holds all accepted codes in the registration system. No changes are accepted unless stated in the manual, with clear documentation for date of change and action taken towards previous coded information (if any). This manual is supported by machine-readable documentation concerning specific codes.

### **Data processing manuals**

Manuals for the various steps in the computerized system are in existence. The manual follows closely the flow outlined in the flow-diagram (see Figure 3) and specifies how to call and run programmes for data entry and checking. The manual is available in machine-readable form.

### **Documentation of registration system**

Detailed documentation and strict rules have not always been in operation. However, a meticulous documentation of all procedures and changes in the registration system is now available. The documentation gives an in-depth description of programs, codes and conversion between codes. A fairly accurate documentation of procedures in operation in the earlier days has been created retrospectively. Any errors found have been rectified or documented. In order to avoid errors in the current registration system, the values and labels of all variables (i.e. the definitions) are kept in a single data-base, documentary data-base (DOK-DB), which is used by all programs of the entire registration system. Whenever changes or corrections in code values and labels have to be made, the corrections are made to this data-base. A computer print-out of the changes made, as well as the dates of change and the initials of the person changing the variable is checked visually at each update. The version number of the DOK-DB used is stated in the tumour records



in the main register. Of particular interest is that the conversion between the ICD-O coding system and the Danish ICD-7 system is created by a table within the DOK-DB. Easy access for changes in conversions, and for adding new conversions of ICD-O topography/morphology combinations never before encountered is thus possible.

### *Data protection/confidentiality*

Because of legislation and the use of PNR numbers, the Registry follows very strict rules set forth by the Minister of Health. All operations on an individual are logged and retained for inspection. Data on an individual is only released if the requesting party fulfils criteria which are stated in the rules of registry operations. No individual can get information on registered information unless requested and interpreted by a physician. Research on the data is permitted, however no contact with individuals must be made without the consent of the notifying physician.

### *Output from the registry*

Direct look-up facilities with display of all coded information on a person, using PNR as key, or day, month, year of birth and as second selection names, is possible. Easy access for tabulation of any coded variable and cross-tabulation with others is possible utilizing the SAS computer package. Age-adjusted and age-specific incidence rates by site are available in computerized form. Routine data, i.e., number of cases per year, sex, site, age and county is published (e.g., Danish Cancer Society, 1987) along with age-adjusted standardized rates (World Standard Population). Furthermore the Registry tabulates the validity of coded information and prevalent cases at the end of each calendar year.

### *Concluding remarks*

The Registry requests limited information on each cancer case and all information must be given in clear text. The Registry thus does not rely on coding performed outside the Registry. All coding and processing takes place centrally under supervision and following strictly documented rules. This is believed necessary to achieve high comparability of data over time. The centralized coding has the advantage of gathering information from many sources, and classification and coding of cases can be resolved taking all information into account. By performing coding and classification centrally, the Registry itself is in charge of the level of expertise and the effort put into the cancer registration process. The Registry thus may direct the effort towards items important for cancer registration with a view to studies of epidemiology and cancer statistics and diminish the effort within areas which from a clinical point of view, may be important in dealing with single patients.

Most important for the success and quality of a registry is the use made of the data compiled. In this regard, the Danish Cancer Registry seeks to facilitate output of data and to encourage and inspire physicians and researchers to make use of the data by pointing towards areas where incidence data may form a solid basis for in-depth investigations.