WORLD HEALTH ORGANIZATION

EUROPEAN NETWORK OF CANCER REGISTRIES (ENCR)

EUROPEAN COMMISSION

STANDARDS AND GUIDELINES FOR CANCER REGISTRATION IN EUROPE

THE ENCR RECOMMENDATIONS

Vol. I

Edited by: Jerzy E. Tyczynski, Eva Démaret, D. Maxwell Parkin

IARC Technical Publication No.40

Standards and Guidelines for Cancer Registration in Europe

INTERNATIONAL AGENCY FOR RESEARCH ON CANCER

The International Agency for Research on Cancer (IARC) was established in 1965 by the World Health Assembly, as an independently financed organization within the framework of the World Health Organization. The headquarters of the Agency are at Lyon, France.

The Agency conducts a programme of research concentrating particularly on the epidemiology of cancer and the study of potential carcinogens in the human environment. Its field studies are supplemented by biological and chemical research carried out in the Agency's laboratories in Lyon, and, through collaborative research agreements, in national research institutions in many countries. The Agency also conducts a programme for the education and training of personnel for cancer research.

The publications of the Agency are intended to contribute to the dissemination of authoritative information on different aspects of cancer research. Information about IARC publications and how to order them is available via the Internet at: **http://www.iarc.fr/**

EUROPEAN NETWORK OF CANCER REGISTRIES (ENCR)

The European Network of Cancer Registries (ENCR) project, established within the framework of the Europe Against Cancer Programme of the European Commission in 1989, has been in operation since 1990.

The main goal of the Network is to improve the quality, comparability and availability of information on occurrence and outcome of cancer in Europe.
The specific objectives of the Network are:

- to improve the quality, comparability and availability of cancer incidence data,
- to create a basis for monitoring cancer incidence and mortality in the European Union,
- to provide regular information on the burden of cancer in Europe,
- to promote the use of cancer registries in cancer control, health-care planning and research.

The Network promotes collaboration between cancer registries, defines data-collection standards, provides training for cancer registry personnel and regularly disseminates information on incidence and mortality from cancer in the European Union and elsewhere in Europe.

The main fields of ENCR activity are:

1) Standardization of registry procedures on:
   (a) data definitions
   (b) data collection procedures
   (c) analysis and reporting methods
2) Central collection and validation of data
3) Dissemination of information
4) Training

Specific activities of the ENCR include surveys of the registries, Working Groups on definitions and coding, fellowships for registry personnel, consultancies, courses (on cancer registration, statistical methods, and coding), workshops, development and maintenance of cancer databases and software (i.e. EUROCIM, EUCAN, ACCISpass), and publications on cancer occurrence in Europe.

All activities of the ENCR are available to its 185 member registries and are announced at its Internet site: www.encr.com.fr.

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Foreword

When the European Commission established the “Europe against Cancer” programme more than a decade ago, one of the priorities was to promote high quality cancer registration within Europe. The aim was to achieve comparable information on cancer burden, which could be used for setting up and evaluating cancer control activities at the European level. To achieve this aim, the European Network of Cancer Registries (ENCR) was established, and has now been active for 13 years with the financial support of the Cancer Programme of the European Union.

Since cancer registries play an important role in planning and managing cancer control activities, one of the major tasks of the ENCR has been to provide support for the creation and development of cancer registries in Europe. Planning and monitoring of such activities as prevention, early detection, treatment, rehabilitation and palliative care require knowledge about national and local cancer patterns and trends. Priority setting for cancer care implies knowledge of how many patients develop cancer, and what are the most frequent sites. Assessment of the efficacy of programmes of prevention, early detection (screening) and the effectiveness of treatment procedures can all be achieved through the use of cancer registry data (e.g., by analysing trends in incidence, stage of disease, and survival).

All these activities depend on the quality of the data in the registry – that they are comparable, complete and of good quality. To achieve this, the ENCR has established Working Groups aimed at developing standards and recommendations in relation to different aspects of cancer registry practice. Some of these guidelines and recommendations deal with technical aspects of data collection, others with problems of confidentiality and privacy protection within the process of cancer registration. All the topics considered by ENCR Working Groups, and published in this monograph, are of fundamental importance to cancer registration, and, hence, to cancer control activities within the European Union and in Europe as a whole.

This monograph provides a set of the most up-to-date guidelines and recommendations prepared by ENCR Working Groups and approved by the ENCR Steering Committee and will be a useful tool for people involved in collection and registration of cancer data in Europe.

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Commissioner
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Introduction

The European Network of Cancer Registries (ENCR) project was established in 1989 and is supported by the Cancer Programme of the European Commission (Health and Consumer Protection Directorate-General, DG SANCO).

The original objectives of the ENCR were:

- to improve the quality, comparability and availability of cancer incidence data,
- to create a basis for monitoring cancer incidence and mortality in the European Union,
- to provide regular information on the burden of cancer in Europe,
- to promote the use of cancer registries in cancer control, health-care planning and research.

The Network:

- promotes continuous collaboration between cancer registries,
- defines data collection standards,
- provides training for cancer registry personnel,
- disseminates information on incidence and mortality from cancer in the European Union and elsewhere in Europe.

Recently, the Health Monitoring Programme of the Public Health Directorate has established projects (i.e. CaMon and EUROCHIP) which are aimed at monitoring the cancer burden in the European Union. The ENCR member registries are key data providers for such activities.

Comparability of the data between registries is therefore an important issue, and harmonizing the registries' procedures is one of the main goals of the Network. The number of cancer registries in Europe is continuously growing and creates new challenges to maintain and improve data quality among European registries allowing their use in comparative studies within Europe, and with the rest of the world.

ENCR has established several Working Groups, which recommended standard procedures to be implemented by the registries.

The year 2002 was the last year for which a programme specifically devoted to the control of cancer was part of the Public Health Programme. This publication summarizes the ENCR achievements in harmonization of registry activities.

It brings together all recommendations and guidelines that have been prepared so far by the ENCR Working Groups, as well as recommendations prepared by the International Association of Cancer Registries (IACR) and adapted by the Network.

Several other topics, not included in this volume, are currently being studied by Working Groups, or are planned for the future. New guidelines and recommendations will be included in updates to these ENCR Recommendations.

The editors have noted that information on on-going ENCR projects could be useful for the registries. Several appendices have been added to the volume containing information about the EUROCIM software and databases, the ACCIS project on childhood cancers, automated registration, and structured registry reviews (audits). The complete address list of the member registries and a list of selected ENCR publications are also included.

We hope that this publication will be a useful tool for all the ENCR member registries. The ENCR Secretariat will welcome comments, which could help in preparing subsequent volumes.

The Editors

Chapter I

Recommendations on registry practices

Section I.1. Minimum data-set

No recommendations on the minimum data-set have been made by ENCR.

However, in the recommendations with respect to Confidentiality in Population-Based Cancer Registration in the European Union (Chapter II), the Working Group made the following observation:

Data items

Cancer registries should observe the principles related to data quality (Directive 95/46/EC Article 6) and collect data that are adequate, relevant and not excessive in relation to the purpose, as well as being accurate, complete and up to date. The number of data items should thus be limited for two reasons – quality (the fewer data items the greater the likelihood that these will be recorded correctly) and confidentiality (the more data items the more chance of an unintended breach of confidentiality when releasing data).

The data items in the recommended minimum data-set for cancer registries are listed in Table 1.

Standardized definitions for recording and coding of several of these data items have been prepared.

Reference

Jensen, O.M., Parkin, D.M., MacLennan, R., Muir, C.S. & Skeet, R.G., eds, *Cancer Registration – Principles and Methods* (IARC Scientific Publications No. 95), Lyon, International Agency for Research on Cancer

Table 1. Items of information collected by registries (from Jensen *et al*., 1991)

Essential variables	
Personal identification	Names (in full) AND/OR unique personal identification number
Sex	Male or female
Date of birth	Day, month, year
Address	Usual residence (coded)
Incidence date	At least month and year
Most valid basis of diagnosis	
Topography (site) of primary	ICD-O
Morphology (histology)	ICD-O
Behaviour	ICD-O
Source of information	
Recommended variables	
Date of last contact	At least month and year
Status at last contact	(At least dead or alive)
Stage or extent of disease	
Initial treatment	

Section I.2. Incidence date

The date of the first event (of the six listed below) to occur chronologically should be chosen as incidence date. If an event of higher priority occurs within three months of the date initially chosen, the date of the higher-priority event should take precedence.

Order of declining priority:

1. Date of first histological or cytological confirmation of this malignancy (with the exception of histology or cytology at autopsy). This date should be, in the following order:

   a) date when the specimen was taken (biopsy)

   b) date of receipt by the pathologist

   c) date of the pathology report.

2. Date of admission to the hospital because of this malignancy.

3. When evaluated at an outpatient clinic only: date of first consultation at the out-patient clinic because of this malignancy.

4. Date of diagnosis, other than 1, 2 or 3

5. Date of death, if no information is available other than the fact that the patient has died because of a malignancy.

6. Date of death, if the malignancy is discovered at autopsy.

Whichever date is selected, the date of incidence should not be later than the date of the start of the treatment, or decision not to treat, or date of death.

The choice of the date of incidence does not determine the coding of the item "basis of diagnosis".

Section I.3. Basis of diagnosis

Registries may choose to record all of the notifications which they receive for a given cancer case (including date, source, and basis of diagnosis). This permits calculations of the number of notifications per case, number of sources per case, and the number of death certificate notifications (DCN).

However, for comparison between registries, and as a measure of validity, only the "most valid basis of diagnosis" is required.

The suggested codes are hierarchical, so that the higher number represents the more valid basis, and should thus be used for this purpose.

If there is no information on how the diagnosis had been made (information obtained from an automated source, for example) the code 9 (Unknown) should be used. Such cases are excluded from calculations of the percentage of cases diagnosed clinically, microscopically, by death certificate alone, etc.

Table 1. Basis of diagnosis codes

Code	Description	Criteria
0	**Death certificate only**	The only information to the registry is from a death certificate.
Non-microscopic		
1	**Clinical**	Diagnosis made before death, but without the benefit of any of the following (2–7)
2	**Clinical investigation**	To include all diagnostic techniques, including X-ray, endoscopy, imaging, ultrasound, exploratory surgery (e.g., laparotomy) and autopsy, without a tissue diagnosis.
4	**Specific tumour markers**	To include biochemical and/or immunological markers which are specific for a tumour site (Table 2).
Microscopic		
5	**Cytology**	Examination of cells whether from a primary or secondary site, including fluids aspirated using endoscopes or needles. Also to include the microscopic examination of peripheral blood films and trephine bone marrow aspirates.
6	**Histology of a metastasis**	Histological examination of tissue from a metastasis, including autopsy specimens.
7	**Histology of a primary tumour**	Histological examination of tissue from the primary tumour, however obtained, including all cutting techniques and bone marrow biopsies. Also to include autopsy specimens of a primary tumour.
9	**Unknown**	

Table 2. Specific tumour markers

Human chorionic gonadotrophin (HCG)	In diagnosis of choriocarcinoma (usually >100,000 iu in urine)
Prostate-specific antigen (PSA)	In diagnosis of prostate carcinoma (usually >10 µg/l serum)
Alphafetoprotein (AFP)	In diagnosis of hepatocellular carcinoma (usually >200 ng/ml serum)
Catecholamine degradation products (HVA, VMA)	In diagnosis of neuroblastoma
Elevated serum immunoglobulins	Myeloma (IgG >35 g/l or IgA > 20 g/l), Waldenström's macroglobulinaemia (IgM > 10 g/l)
Urinary immunoglobulins	Myeloma (light chain excretion >1 g/24 h)

"Specific" histology codes in absence of microscopic verification

The ICD-O M code is not allocated for the purpose of specifying the basis of diagnosis. However, it would be extremely unlikely (or impossible) for some specific morphological diagnoses to have been made without a histological (or cytological) examination.

Registries may therefore wish to establish some internal consistency checks, so that the combination of morphology codes 8001–9989 and basis of diagnosis code 0–4, or 9 are flagged for verification. However, certain combinations are exceptions to this general rule, as shown in Table 3.

Table 3. Combinations of specific morphology codes, and non-microscopic basis of diagnosis codes, which are considered acceptable

MORPHOLOGY		Most valid basis	Other criteria
Code	Description		
8800	(Sarcoma NOS)	2	
9590	Lymphoma NOS	1 or 2	
9800	Leukaemia NOS	1 or 2	
8720	Melanoma	1 or 2	
9140	Kaposi sarcoma	1 or 2	HIV-positive (excl. Africa)
8960	Nephroblastoma	2	Age 0–8
9100	Choriocarcinoma	4	Female, and age 15–49
9500	Neuroblastoma	2 or 4	Age 0–9
9510	Retinoblastoma	2	Age 0–5
9732	Myeloma	4	Age 40+
9761	Waldenström's macroglobulinaemia	4	Age 50+
8170	Hepatocellular carcinoma	4	
8150–8154	Islet cell tumours, gastrinomas	4	
9380	Glioma	2	C71.7 (brain stem)
9384/1	Subependymal giant cell astrocytoma	2	Tuberous sclerosis patient
9530–9539	Meningioma	2	C70
9350	Craniopharyngioma	2	
8270–8281	Pituitary tumours	4	C75.1

Section I.4. Topography, morphology, behaviour

The International Classification of Diseases for Oncology is the standard for recording site (topography), morphology (including grade of malignancy) and behaviour. The current edition (*International Classification of Diseases, Oncology*, 3rd Edition, Eds. Fritz A., Percy C., Jack A., Shanmugaratnam K., Sobin L., Parkin D.M., Whelan S.) was published by WHO, Geneva in 2000.

This edition takes into account the recommendations made by a Working Group of the ENCR with respect to the coding of leukaemias and lymphomas (the members of the Working Group were R. Otter, A. Astudillo, P.-M. Carli, A. Jack and H. van Krieken)

Section I.5. Recording multiple primary tumours

The recommendations follow those in the Third Edition of the International Classification of Diseases for Oncology (ICD-O-3). They are reproduced below. A small error in Table 24 of ICD-O-3, and in the corresponding Table 1 of the ENCR Recommendations has been corrected.

The IARC/IACR rules state the following:

1. Recognition of the existence of two or more primary cancers does not depend on time.

2. A primary cancer is one that originates in a primary site or tissue and is neither an extension, nor a recurrence, nor a metastasis.

3. Only one tumour shall be recognized as arising in an organ or pair of organs or tissue. For a tumour where site is coded by the first edition of ICD-O (or by ICD-9), an organ or tissue is defined by the three-character category of the topography code.

   ICD-O second and third editions and ICD-10 have a more detailed set of topography code. Some groups of codes are considered to be a single organ for the purpose of defining multiple tumours. These topography code groups are shown in Table 1.

   Multifocal tumour – that is, discrete masses apparently not in continuity with other primary cancer originating in the *same* primary site or tissue, for example bladder – are counted as a single cancer.

   Skin cancer presents a special problem as the same individual may have many such neoplasms over a lifetime. The IARC/IACR rules imply that only the first tumour of a defined histological type, *anywhere on the skin*, is counted as an incident cancer unless, for example, one primary was a malignant melanoma and the other a basal cell carcinoma.

4. Rule 3 does not apply in two circumstances:

   4.1 For systemic or multicentric cancers potentially involving many discrete organs, four histological groups – lymphoma, leukaemias, Kaposi sarcoma, and mesothelioma (groups 7, 8, 9 and 10 in Table 2) – are included. They are counted only once in any individual.

   4.2 Other specific histologies – groups 1, 2, 3, 4, 6, and 11 in Table 2 – are considered to be different for the purpose of defining multiple tumours. Thus, a tumour in the same organ with a ‘different’ histology is counted as a new tumour. Groups 5 and 12 include tumours that have not been satisfactorily typed histologically and cannot therefore be distinguished from the other groups.

Table 1. Groups of topography codes from ICD-O-2 and ICD-O-3 considered a single site in the definition of multiple cancers

ICD-O-2/3		ICD-O-1
C01	Base of tongue	
C02	Other and unspecified parts of tongue	141
C05	Palate	
C06	Other and unspecified parts of mouth	145
C07	Parotid gland	
C08	Other and unspecified major salivary glands	142
C09	Tonsil	
C10	Oropharynx	146
C12	Pyriform sinus	
C13	Hypopharynx	148
C19	Rectosigmoid junction	
C20	Rectum	154
C23	Gallbladder	
C24	Other and unspecified parts of biliary tract	156
C30	Nasal cavity and middle ear	
C31	Accessory sinus	160
C33	Trachea	
C34	Bronchus and lung	162
C37	Thymus	164
C38.0–3	Heart and mediastinum	164
C38.8	Overlapping lesion of heart, mediastinum and pleura	165.8
C40	Bones, joints and articular cartilage of limbs	
C41	Bones, joints and articular cartilage of other and unspec. sites	170
C51	Vulva	
C52	Vagina	184
C56	Ovary	
C57	Other specified female genital organs	183
C60	Penis	
C63	Other and unspecified male genital organs	187
C64	Kidney	
C65	Renal pelvis	
C66	Ureter	
C68	Other and unspecified urinary organs	189
C74	Adrenal gland	
C75	Other endocrine glands and related structures	194

Table 2. Groups of malignant neoplasms considered to be histologically "different" for the purpose of defining multiple tumours (adapted from Berg, 1994)

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

Section I.6. Recording bladder tumours*

All bladder tumours should be registered, whatever the histological type and level of invasion.

Principles

The coding of tumour behaviour (/1, /2, /3) takes into account both the anatomo-pathological definition and the extent of invasion. It is, therefore, essential to have access to reports of any pathological examinations.

Rules

Tumour behaviour code: /1

Normal or slightly abnormal histology: low grade papillary urothelial tumours, not invasive. In the various anatomopathological classifications these tumours are called:

- benign or simple papillomas,
- papillary urothelial tumours,
- stage I carcinoma (Broders' classification),
- well differentiated papillary carcinoma (Jewett's classification),
- grade I carcinoma (in the WHO classification), or
- classes I and IIs (Chome's classification).

Extent of invasion – none.

Tumour behaviour code: /2

Presence of mitoses and more markedly atypical cells than in the previous categories. It includes both high-grade papillary urothelial tumours and flat tumours.

Extent of invasion – none.

Tumour behaviour code: /3

Invasion present, whatever the anatomo-pathological definition.

Particular cases:

– Carcinoma *in situ*: /2

The particular entity which consists of carcinoma *in situ* displaying clear anaplasia of the superficial epithelium without the formation of a papillary structure and without invasion is coded to 8010/2.

– Anatomopathological examination indicates the existence of a tumour, but it is

* Currently being revised by the 2nd Working Group.

not possible to determine the degree of malignancy on the specimen examined:

Code: /1 tumour benign or of uncertain malignancy

– Anatomopathological proof unavailable, but the clinical appearance is confirmed by the clinician:

8000/0: No microscopical confirmation: tumour clinically benign.

8000/1: No microscopical confirmation: tumour clinically of uncertain behaviour.

8000/3: No microscopical confirmation: tumour clinically malignant.

Section I.7. Recording central nervous system tumours

Tumours to be registered

It is recommended that cancer registries include in their database *all intracranial and intraspinal neoplasms* irrespective of their behaviour (benign/uncertain/malignant).

The principal reasons are:

- It is difficult to distinguish benign from malignant tumours by symptoms alone
- All brain and spinal tumours are capable of producing severe clinical effects, irrespective of malignancy
- Etiological and clinical syndromes associated with certain benign tumours may be of especial interest (meningiomas, pituitary tumours...)
- Certain tumours – notably astrocytomas – progress from low grade (benign) to high grade (malignant) during their clinical course

Certain 'tumours' such as benign vascular lesions of meninges (haemangiomas) and cysts may, however, be excluded.

Reporting of brain and spinal lesions may or may not include benign/uncertain neoplasms, according to the comparisons being made.

WHO grade (malignancy scale)

1. The recording of grade is an important, although not indispensable element in typing of central nervous system (CNS) tumours. It is essential to the interpretation of data on clinical outcomes. Use of the new WHO classification of brain tumours resolves a great many of the problems of determining tumour grade, since in most cases tumour grade is implicit in the diagnostic category.

GRADE I
(e.g. pilocytic astrocytoma). Tumours with a low proliferative potential, a frequently discrete nature, and a possibility of cure following surgical resection alone.

GRADE II
Generally infiltrating tumours low in mitotic activity, but with a potential to recur. Some tumour types tend to progress to lesions with higher grades of malignancy (e.g. well differentiated astrocytomas, oligodendrogliomas and ependymomas).

GRADE III Histological evidence of malignancy, generally in the form of mitotic activity, clearly expressed infiltrative capabilities, and anaplasia.

GRADE IV
Mitotically active, necrosis-prone neoplasms, generally associated with a rapid pre- and post-operative evolution of the disease.

2. These definitions are not the same as those proposed for the general grading of tumours via the 6th digit of the morphology code of ICD-O (page xxviii of ICD-O, Second Edition), which relates primarily to degree of differentiation.

HOWEVER
For malignant tumours of the central nervous system (site codes C70–C72, C75.1–C75.3), the grade should be recorded as the sixth digit of the ICD-O M code, according to the definition in Section 1.

3. Table 1 details the available grades.

Table 1. WHO grading system (malignancy scale) for CNS tumours and ICD-O behaviour code

Tumour type	Grade				ICD-O behaviour code
	I	II	III	IV	
Astrocytic tumours					
Subependymal giant cell	*				1
Pilocytic	*				3
Low grade		*			3
Pleomorphic xanthoastrocytoma		*	*		3
Anaplastic			*		3
Glioblastoma				*	3
Oligodendrogliomas					
Low grade		*			3
Anaplastic			*		3
Oligo-astrocytomas					
Low grade		*			3
Anaplastic			*		3
Ependymal tumours					
Subependymoma	*				1
Myxopapillary	*				1
Low grade		*			3
Anaplastic			*		3
Choroid plexus tumours					
Papilloma	*				0
Carcinoma			*	*	3
Neuronal/glial tumours					
Gangliocytoma	*				0
Ganglioglioma	*	*			1
Anaplastic ganglioglioma			*		3
Desmoplastic infantile ganglioglioma	*				0
Dysembryoplastic neuroepithelial tumour	*				-
Central neurocytoma	*				0
Pineal tumours					
Pineocytoma		*			1
Pineocytoma/pineoblastoma			*	*	-
Pineoblastoma				*	3
Embryonal tumours					
Medulloblastoma				*	3
Other PNETs				*	3
Medulloepithelioma				*	3
Neuroblastoma				*	3
Ependymoblastoma				*	3
Cranial and spinal nerve tumours					
Schwannoma	*				0
Malignant peripheral nerve sheath tumour			*	*	3
Meningeal tumours					
Meningioma	*				0
Atypical meningioma		*			1
Papillary meningioma		*	*		1
Haemangiopericytoma		*	*		3
Anaplastic meningioma			*		3

Footnote: " - " = no specific histology or malignancy code

Unused ICD-O codes

The European Network of Cancer Registries working group recommends that cancer registries no longer use certain morphology codes, which correspond to diagnostic terms considered to be obsolete. When these terms are encountered, the appropriate code (and diagnostic synonym) is as follows:

References

Kleihues, P., Burger, P.C. & Scheithanen, B.W., eds (1993) *Histological Typing of Tumours of the Central Nervous System*, 2nd edition (WHO Histological Classification of Tumours), Berlin, Heidelberg, Springer-Verlag

Kleihues, P. & Cavenee, W.K., eds (2000) *Pathology, Genetics and Tumours of the Nervous System* (World Health Organization Classification of Tumours), Lyon, IARCPress

Table 2. Neurological tumours: proposed ICD-O-2 codes for obsolete categories

Current code	Description	Proposed code	ICD-O-2 rubric
9393/1	Papillary ependymoma	9391/3	Ependymoma, NOS
9422/3	Spongioblastoma, NOS	9443/3	Primitive polar spongioblastoma
9423/3	Spongioblastoma polare	9443/3	
9460/3	Oligodendroblastoma	9473/3	Primitive neuroectodermal tumour
9480/3	Cerebellar sarcoma, NOS	9473/3	
9481/3	Monstrocellular sarcoma	9440/3	Glioblastoma, NOS
9502/3	Teratoid medulloepithelioma	9501/3	Medulloepithelioma, NOS
9503/3	Neuroepithelioma, NOS	9500/3	Neuroblastoma, NOS
9504/3	Spongioneuroblastoma	9500/3	
9511/3	Retinoblastoma, differentiated	9510/3	Retinoblastoma, NOS
9512/3	Retinoblastoma, undifferentiated	9510/3	
9520/3	Olfactory neurogenic tumour	9522/3	Aesthesioneuroblastoma
9521/3	Aesthesioneurocytoma	9522/3	
9532/0	Fibrous meningioma – Fibroblastic meningioma	9530/0	Meningioma, NOS
9536/0	Haemangiopericytic meningioma	9150/3	Haemangiopericytoma, malignant
9541/0	Melanotic neurofibroma	9560/0	Neurilemmoma, NOS
9560/1	Neurinomatosis	9560/0	
9560/3	Neurilemmoma, malignant – Malignant schwannoma – Neurilemmosarcoma	9540/3	Neurofibrosarcoma
9570/0	Neuroma, NOS	9540/0	Neurofibroma, NOS

Table 3. Supplementary index: terms not appearing in the ICD-O-2 alphabetical index

9505/0	Dysembryoplastic neuroepithelial tumour (DNET)
9505/0	Desmoplastic infantile ganglioglioma
9505/3	Anaplastic (malignant) ganglioglioma
9361/1	Mixed/transitional pineal tumour
8726/1	Melanocytoma
9390/3	Choroid plexus carcinoma
9506/0	Central neurocytoma
9530/1	Atypical meningioma
9540/3	Malignant peripheral nerve sheath tumour
9470/3	Melanotic medulloblastoma (Kleihues *et al*., 1993)
9470/3	Lipomatous medulloblastoma (Kleihues & Cavanee, 2000)
8963/3	Atypical teratoid/rhabdoid tumour (Kleihues & Cavanee, 2000)

Some codes are ‘matrix codes’ – i.e., already exist but without the behaviour code specified

Section I.8. Recording non-melanoma skin cancers

1. Non-melanoma skin cancers to be recorded

Non-melanoma skin cancers are extremely common in some European populations. Each registry must decide whether it has the necessary resources to record all such cancers, and whether the costs involved are reasonable, with respect to the utility of the resulting statistics. The main uses of such data are

- to quantify the workload imposed by treatment of these tumours
- to indicate exposure to carcinogens (including sunlight, occupation)
- for studies of associations with other cancers
- to document trends in occurrence

There are three options:

(a) Record all skin cancers
(b) Record all skin cancers, excluding basal cell carcinomas (M809-811)
(c) Record all skin cancers, excluding basal and squamous cell carcinomas (M805–811)

2. Topography

The subsites of skin which may be coded using ICD-O (C44.0–C44.7) are rather limited for clinical or epidemiological purposes.

For registries which do decide to collect data on skin cancers, a more detailed coding scheme, requiring a fourth digit, may be used. A suggested coding scheme is presented in Table 1.

3. Multiple tumours

The revised IARC/IACR rules (Table 2), which appear in the third edition of ICD-O, imply that only a first tumour of a defined histological type, *anywhere on the skin*, is counted as an incident cancer.

The defined histological types now separate squamous cell carcinomas (group 1) and basal cell carcinomas (group 2). The rare tumours of glandular origin are included with the adenocarcinoma group (group 3).

Notification of second (or subsequent) basal cell carcinomas in the same individual may be recognized by updating the recorded morphological code to 8091 (multifocal superficial basal cell carcinoma).

4. Multifocal tumours

For cancer registries which wish to record the occurrence of every skin cancer (not just the first), a special field must be reserved to denote the existence of multifocal cancer(s), in addition to the link between individuals and cancers, in the registry database.

Table 1. ICD-O extended subsite topography of the skin for research purposes

ICD-O	ENCR recommendation
C44.0 Skin of lip, NOS Skin of lower lip Skin of upper lip	**C44.09 Skin of lip, NOS** Skin of lower lip Skin of upper lip
C44.1 Eyelid Lid, NOS Palpebra Canthus, NOS Inner canthus Lower lid Meibomian gland Outer canthus Upper lid	**C44.19 Eyelid**
C44.2 External ear Auricle, NOS Pinna Ceruminal gland Concha Ear, NOS Ear lobule Earlobe External auditory canal Auditory canal, NOS Auricular canal, NOS External auricular canal Ear canal External auditory meatus Helix Skin of auricle Skin of ear, NOS Tragus	**C44.29 External ear**
C44.3 Skin of other and unspecified parts of face Skin of: • cheek • chin • face • forehead • jaw • nose • temple Ala nasi Chin, NOS Columnella Eyebrow Brow External cheek External nose Forehead, NOS Temple, NOS	**C44.30 Cheek** **C44.31 Forehead** Temple Eyebrow Brow **C44.32 Nose** Columnella **C44.33 Chin** Jaw **C44.39 Face, NOS**
C44.4 Skin of scalp and neck Skin of head, NOS Skin of neck Skin of scalp Scalp, NOS Skin of cervical region Skin of supraclavicular region	**C44.40 Skin of neck** Skin of cervical region Skin of supraclavicular region **C44.41 Skin of scalp** Scalp, NOS **C44.49 Skin of head, NOS**

C44.5 Skin of trunk

Skin of:
- abdomen
- abdominal wall
- anus
- axilla
- back
- breast
- buttock
- chest
- chest wall
- flank
- groin
- perineum
- thoracic wall
- thorax
- trunk
- umbilicus
- gluteal region
- infraclavicular region
- inguinal region
- sacrococcygeal region
- scapular region

Perianal skin
Umbilicus, NOS

C44.6 Skin of upper limb and shoulder

Skin of:
- antecubital space
- arm
- elbow
- finger
- forearm
- hand
- palm
- shoulder
- thumb
- upper limb
- wrist

Finger nail
Palmar skin

C44.7 Skin of lower limb and hip

Skin of:
- ankle
- calf
- foot
- heel
- hip
- knee
- leg
- lower limb
- popliteal space
- thigh
- toe

C44.50 Trunk, anterior, upper
Axilla
Breast
Chest
Infraclavicular region

C44.51 Trunk, anterior, lower
Abdomen
Abdominal wall
Flank
Groin
Inguinal region
Pubis
Umbilicus

C44.52 Trunk anterior, NOS
Thorax

C44.53 Trunk, posterior, upper
Back
Scapular region

C44.54 Trunk, posterior, lower
Buttock
Gluteal region
Sacrococcygeal region

C44.55 Trunk, posterior, NOS

C44.56 Perineum
Anus
Perianal skin

C44.59 Trunk, NOS

C44.60 Skin of upper arm
Elbow
Shoulder
Antecubital space

C44.61 Skin of lower arm
Forearm
Wrist

C44.62 Skin of hand, dorsal

C44.63 Skin of hand, palmar

C44.64 Skin of hand, NOS

C44.65 Skin of finger, dorsal

C44.66 Skin of finger, palmar

C44.67 Skin of finger, subungual
Nail

C44.68 Skin of finger, NOS

C44.69 Skin of arm, NOS

C44.70 Skin of leg
Hip
Knee
Popliteal space
Thigh

C44.71 Skin of lower leg
Ankle
Calf
Heel
Shin

C44.72 Skin of foot, dorsal

C44.73 Skin of foot, plantar
Sole

C44.74 Skin of foot, NOS

C44.75 Skin of toe, dorsal

Plantar skin Sole of foot Toe nail	**C44.76 Skin of toe, plantar** **C44.77 Skin of toe, subungual** Nail **C44.78 Skin of toe, NOS** **C44.79 Skin of leg, NOS**
C44.8 Overlapping lesion of skin	**C44.83 Overlapping lesion of skin of face or face and head/neck** **C44.84 Overlapping lesion of skin of head or head and neck** **C44.85 Overlapping lesion of skin of trunk or trunk and neck** **C44.86 Overlapping lesion of skin of upper limb or upper limb and shoulder/trunk** **C44.87 Overlapping lesion of skin of lower limb or lower limb and hip/trunk** **C44.89 Overlapping lesion of skin, NOS**
C44.9 Skin, NOS	**C44.99 Skin, NOS**
C51.0 Labium majus Skin of labia majora	**C51.0 Skin of labia majora**
C51.9 Vulva, NOS Skin of vulva	**C51.9 Skin of vulva**
C60.9 Penis, NOS Skin of penis	**C60.9 Skin of penis**
C63.2 Scrotum, NOS Skin of scrotum	**C63.2 Skin of scrotum**

Table 2. IARC/IACR rules for multiple primaries

Groups of malignant neoplasms considered to be histologically "different" for the purpose of defining multiple tumours (revised in ICD-O-3, 2000)	
Carcinomas	
1. Squamous carcinomas	M805–808, M812–813
2. Basal cell carcinomas	M809–811
3. Adenocarcinomas	M814, M816, M819–822, M826–833, M835–855, M857, M894
4. Other specific carcinomas	M803–804, M815, M817–818, M823–825, M834, M856, M858–867
(5.) Unspecified carcinomas (NOS)	M801–802
6. **Sarcomas** and other soft tissue tumours	M868–871, M880–892, M899, M904, M912–913, M915–925, M937, M954–958
7. **Lymphomas**	M959–972
8. **Leukaemia**	M980–996, M998
9. **Kaposi sarcoma**	M914
10. **Mesothelioma**	M905
11. **Other specified** types of cancer	M872–879, M893, M895–898, M900–903, M906–911, M926–936, M938–953, M973–976
(12.) **Unspecified** types of cancer	M800, M997

Section I.9. Method of detection (in relation to screening)

The old codes for 'method of first detection' in *Cancer Registration: Principles and Methods* (p. 56) are no longer considered relevant due to the difficulty in differentiating between a true 'incidental finding' and 'clinical presentation (with symptoms)', and to the currently low proportion of deaths with autopsy ('incidental finding at autopsy').

With respect to screening, the evaluation and monitoring of a programme ideally require that the records of the screening programme be linkable to the records of the cancer registries. This allows, e.g. separation of cancers in non-respondents or non-invited individuals.

1. Where feasible, cancer registries should collect a data item called '**Method of detection in relation to screening**'.

- The item has utility only in the evaluation and monitoring of organized cancer screening programmes. It is not useful to record cancer cases detected by unorganized screening programmes, or by opportunistic screening.
- Each registry should define the sites, the screening tests and the populations concerned.
- An 'organized screening programme' is defined as 'men and/or women in an *identified population*, *invited* to participate in a screening programme'.
- Each registry should define 'screening', i.e., early detection of disease by a screening test (e.g. for breast it would be mammography, for cervix pap smear, etc.).
- 'Early detection of disease by a screening test' should be defined as the initiation of the diagnostic process by a positive result in the screening test.

2. Where possible, registries should code the **Method of detection in relation to screening** using the following codes:

   1) Screen detected
   2) Interval cancer (according to local definition)*
   8) Other
   9) Unknown or not applicable

Whatever codes are used, they should be exclusive (no overlap).

Reference

Jensen, O.M., Parkin, D.M., MacLennan, R., Muir, C.S., & Skeet, .RG., eds, *Cancer Registration – Principles and Methods* (IARC Scientific Publications No. 95), Lyon, International Agency for Research on Cancer

* The time interval between a negative screen and diagnosis should be recorded.

Section I.10. Recording and coding extent of disease

Condensed TNM for coding the extent of disease in cancer registration

1. UICC/AJCC TNM classification system

1.1 The extent of disease should be recorded in terms of the three digit code of the TNM system. The rules for coding the stage of disease according to the TNM system are described in *TNM Classification of Malignant Tumours*, 6th Edition, 2002 (L.H. Sobin and Ch. Wittekind).

1.2 The TNM system is not used for coding of the extent of lymphomas, leukaemias, brain tumours and childhood cancers (defined as < 15 years of age at diagnosis).

2. pTNM vs. cTNM

When the stage/extent of the cancer is recorded in the clinical/pathological records according to the TNM system, these codes should be registered. The registry should record the best available data - that is pT (rather than cT) and pN (rather than cN), if they are available. Normally, if there is any evidence (clinical or pathological) of metastatic disease, M will be recorded as 1.

3. Time of diagnosis

Extent of disease at diagnosis is based upon all examinations carried out to plan treatment, plus surgery and pathological examination of resected specimen(s) (including the radicalization of primary surgery). Examinations carried out post-surgery, but during the same hospital stay, are included.

In the absence of surgery, staging is based upon examinations carried out prior to medical treatment, or radiotherapy, or during the hospital stay when these treatments were started, or a decision made to withhold them.

For non-hospitalized patients, staging is based upon examinations, clinical and instrumental, carried out to establish the primary treatment, or decision not to treat.

The detection of metastatic disease after the first course of treatment (including during adjuvant treatment or hormonal therapy) does not change coding of extent of disease at diagnosis.

4. Condensed TNM

4.1 When T, and/or N, and/or M have not been explicitly recorded in the clinical/ pathological records, **the cancer registry should attempt to score extent of disease according to the Condensed TNM scheme:**

T :	**L** (**L**ocalized)	**A** (**A**dvanced)	**X** (cannot be assessed)
N :	**0**	**+**	**X** (cannot be assessed)
M :	**0**	**+**	**X** (cannot be assessed)

where T and N are extracted, if possible, from the pathology report, or, in its absence, from the clinical record (endoscopy, X-ray etc.). M is based on the best available information, whether clinical, instrumental or pathological. For M, clinical signs and findings are enough to justify M+ in the absence of pathological confirmation of metastatic deposits.

4.2 The Condensed TNM should be based on all available clinical and pathological information, or on sound reasoning based on the understanding of clinical practices.

4.3 The conventional values of T, which correspond to T (**L**ocalized) and T (**A**dvanced) are given in Table 1, and a summary of the corresponding definitions from the TNM Manual in Annex 1.

N**+** refers to spread to regional lymph nodes. The definition of 'regional nodes' for each site is provided in the TNM manual and in summary form in Annex 2.

4.4 For some primary sites, correct allocation of T and N requires detailed specification of site, otherwise the extent of spread (T), or the regional nodes cannot be defined. This is the case for the cancers of head & neck, oesophagus and skin.

4.5 If the primary site is unknown (ICD-O code C80.9), T and N cannot be correctly assigned (although the fact that the tumour is M+ may be obvious).

5. Unknown or unavailable TNM or other extent of disease information

5.1 If the only recorded T, N or M is **X**, then this value should be registered. However, **X** should only be coded if it appears to be the best value based on *all available information*.

5.2 If T, N or M are recorded as X (cannot be assessed) based on pathology (pTNM), then use the best available information from *clinical* examination to code TNM, rather than coding **X**.

5.3 N and M should be coded to **X** (cannot be assessed), only if there is no reasonable evidence of zero (**0**). For example, code N**0**/M**0** instead of N**X**/M**X**, when a resection is performed for an abdominal tumour but no nodes were found in the resected specimen by the pathologist. Similarly, code N**0**/M**0** for a digestive system tumour completely resected by endoscopy (e.g. polypectomy, transanal excision).

5.4 Cancers* which are *non-resectable*, but without evidence of metastases, should be classified with M+ cases. Non-resectable cancers, and those with metastases, are advanced malignancies with a similar prognosis. Classifying such cases as M+ allows them to be distinguished from cases which have been resected, and for which no pathology report is available (NX and/or MX).

6. Tabulation of results

Extent of disease should be tabulated as:

Tumour localized	(T**L**/N**0**/M**0**)
Tumour with local spread	(T**A**/N**0**/M**0**)
Tumour with regional spread	(anyT/N**+**/M**0**)
Advanced cancer	
• Metastatic	(any T/any N/M**+**)
• Non-resectable tumours*	(MX)
Unknown extent	(TX/NX/MX)

7. Optional data

7.1 *Size of tumour*

This is relevant to the allocation of the T code. For some purposes, the exact size of the tumour is important, for example, in the evaluation of a screening programme. Registries should decide for which sites it is important to record tumour size, and provide a separate field for this purpose.

Size is recorded as maximum diameter (in mm), and is registered from the pathology report; in the absence of pathology, it is recorded from imaging or clinical examination. If size is given for both the fresh and the fixed tissue and the two measurements are discrepant, then record that obtained from the histological (fixed) specimen(s). In the case of multiple simultaneous tumours that are not independent primaries, the tumour with the greatest diameter should be used for classification.

7.2 *Number of nodes*

The presence or absence of positive nodes may depend on the number of nodes that have been examined pathologically.

For detailed staging studies of specific designated tumours, record:

Number of nodes positive (two-digit code)
Number of nodes examined (two-digit code)

7.3 *Certainty of information*

The TNM manual allows for the coding of the C-factor, to define the certainty of the information on which the TNM staging was based (Appendix 3). As the condensed TNM does not distinguish between c (clinical) and p (pathology-based) codes, registries might wish to consider the use of a simplified C code:

C1 Evidence from standard diagnostic means (e.g. inspection, palpation, standard radiography, intraluminal endoscopy)

C2 Evidence from special diagnostic means
- imaging: special radiographic projections, CT scan, ultrasound, lymphography, angiography, scintigraphy, MRI
- endoscopic biopsy or cytology

Cp Evidence based upon post-surgical (or autopsy) histopathology

Annexes

1. T**L**/T**A** precise definitions for each site

2. N list of regional nodes for each site

3. C C-factor

* This proposal does not apply to prostate cancers

Condensed TNM scheme

Table 1. Conventional values of T corresponding to T Localized and T Advanced

Site	**L**ocalized	**A**dvanced
Lip and oral cavity	T1–T2	T3–T4
Pharynx	T1–T2	T3–T4
Larynx	T1–T2	T3–T4
Paranasal sinuses	T1–T2	T3–T4
Salivary glands	T1–T2	T3–T4
Thyroid	T1–T3	T4
Oesophagus	T1–T2	T3–T4
Stomach	T1–T2	T3–T4
Small intestine	T1–T2	T3–T4
Colon and rectum	T1–T2	T3–T4
Anal canal	T1–T2	T3–T4
Liver	T1–T2	T3–T4
Gallbladder	T1–T2	T3–T4
Extrahepatic bile ducts and ampulla	T1–T2	T3
Pancreas	T1–T2	T3–T4
Lung	T1–T2	T3–T4
Pleura	T1–T2	T3–T4
Bone	T1	T2
Soft tissue	T1	T2
Skin	T1–T3	T4
Melanoma	T1–T3	T4
Breast	T1–T3	T4
Vulva	T1–T2	T3–T4
Vagina	T1–T2	T3–T4
Cervix	T1–T2	T3–T4
Corpus	T1–T2	T3–T4
Ovary	T1	T2–T3
Fallopian tube	T1	T2–T3
Trophoblastic	T1	T2
Penis	T1–T2	T3–T4
Prostate	T1–T2	T3–T4
Testis	T1–T2	T3–T4
Kidney	T1–T2	T3–T4
Pelvis and ureter	T1–T2	T3–T4
Bladder	T1–T2	T3–T4
Urethra	T1–T2	T3–T4
Eye	T1–T3	T4
Except for sarcoma of orbit	*T1–T2*	*T3–T4*

Annex 1. ENCR Condensed TNM scheme

T: L(ocalized) or **A**(dvanced)

(see Table 1 of ENCR recommendations)

Definition of **A**(dvanced)
(usually minimum criteria for T3, else specified in text)

Based on: Sobin, L.H. and Wittekind, Ch., eds, UICC International Union Against Cancer, *TNM Classification of Malignant Tumors*, Sixth Edition, New York, Wiley-Liss, 2002

Lip and oral cavity
T3, Tumour more than 4 cm in greatest dimension

Pharynx (including base of tongue, soft palate, and uvula)
Oropharynx: T3, Tumour more than 4 cm in greatest dimension
Nasopharynx: T3, Tumour invades bony structures or paranasal sinuses
Hypopharynx: T3, Tumour more than 4 cm in greatest dimension or with fixation of hemilarynx

Larynx
Supraglottis: T3, Tumour limited to larynx with vocal cord fixation and/or invades any of the following: post-cricoid area, pre-epiglottic tissues, paraglottic space, thyroid cartilage
Glottis: T3, Tumour limited to larynx with vocal cord fixation, involvement of paraglottic space, thyroid cartilage
Subglottis: T3, Tumour limited to larynx with vocal cord fixation

Paranasal sinuses
Maxillary sinus: T3, See TNM manual
Ethmoid sinus: T3, See TNM manual

Salivary glands - parotid, submandibular, and sublingual
T3, Tumour more than 4 cm in greatest dimension or having extraparenchymal extension

Thyroid gland
T4, Tumour of any size extending beyond the thyroid capsule
(Anaplastic carcinomas are all T4, irrespective of extent)

Oesophagus
T3, Tumour extends beyond the muscle coat of the oesophagus

Stomach
T3, Tumour penetrates serosa (visceral peritoneum)

Small intestine
Colon and rectum
T3, Tumour invades extends beyond the muscle coat of the intestine

Anal canal
T3, Tumour more than 5 cm in greatest dimension

Liver (including intrahepatic bile ducts)
T3, Multiple tumours >5 cm in diameter or involving major branch of portal or hepatic veins

Gallbladder
T3, Tumour penetrates serosa (visceral peritoneum) or invades adjacent structures

Extrahepatic bile duct
T3, Tumour invades adjacent structures: liver, pancreas, duodenum, gallbladder, colon, stomach

Ampulla of Vater
T3, Tumour invades pancreas or other adjacent structures (note: duodenal wall is T2)

Pancreas
T3, Tumour not limited to pancreas

Lung
Pleural mesothelioma
T3, See TNM manual

Bone
T2, Tumour more than 8 cm in greatest dimension

Soft tissues
T2, Tumour more than 5 cm in greatest dimension

Carcinoma of the skin (excluding eyelid, vulva, and penis)
T4, Tumour invades deep extradermal structures (cartilage, skeletal muscle, bone)

Malignant melanoma of the skin (excluding eyelid)
pT4, Tumour more than 4 mm in thickness.

Breast
T4, Tumour of any size with direct extension to chest wall or skin

Vulva
T3, Tumour invades beyond vulva or perineum (urethra, vagina, anus/rectum, bladder)

Vagina
T3, Tumour extends to pelvic wall or further

Cervix uteri
T3, Tumour extends beyond uterus to pelvic wall or lower third of vagina, or further, or causes hydronephrosis or non-functioning kidney

Corpus uteri
T3, Tumour involves serosa or extends beyond uterus

Ovary
Fallopian tube
T2, Tumour with pelvic extension

Gestational trophoblastic tumours
T2, Tumour extends beyond uterus

Penis
T3, Tumour invades urethra or prostate

Prostate
T3, Tumour extends through the prostatic capsule

Testis
pT3, Tumour invades spermatic cord

Kidney
T3, Tumour extends beyond kidney

Renal pelvis and ureter
T3, Tumour invades beyond muscularis

Urinary bladder
T3, Tumour invades perivesical tissue

Urethra
T3, Tumour invades beyond corpus spongiosum, prostate, or periurethral muscle

Eye
T4 (T3 for sarcoma of the orbita), See TNM manual

Annex 2. ENCR Condensed TNM scheme

Definitions of regional lymph nodes (N+)

Based on: Sobin, L.H. & Wittekind, Ch., eds, UICC International Union Against Cancer, *TNM Classification of Malignant Tumors*, Sixth Edition, New York, Wiley-Liss, 2002

Lip and oral cavity
Pharynx (including base of tongue, soft palate, and uvula)
Larynx
Paranasal sinuses
Salivary glands — parotid, submandibular, and sublingual
Cervical nodes

Thyroid gland
Cervical and upper/superior mediastinal nodes

Oesophagus

Cervical oesophagus:	Scalene, internal jugular, upper and lower cervical, perioesophageal, supraclavicular
Intrathoracic oesophagus:	Upper perioesophageal (above the azygous vein), subcarinal, lower perioesophageal (below the azygous vein), mediastinal and perigastric nodes, excluding coeliac nodes

Stomach
Perigastric nodes along the lesser and greater curvatures
Nodes along the left gastric, common hepatic, splenic, and celiac arteries
Hepatoduodenal nodes
Gastro-oesophageal junction: paracardial, left gastric, coeliac, diaphragmatic, and the lower mediastinal paraoesophageal

Small intestine

Duodenum:	Pancreaticoduodenal, pyloric, hepatic (pericholedochal, cystic, hilar), and superior mesenteric nodes
Ileum and jejunum:	Mesenteric, including superior mesenteric nodes
Terminal ileum only:	Ileocolic, including posterior caecal nodes

Colon and rectum
The regional lymph nodes are the pericolic and perirectal nodes and those located along the ileocolic, right colic, middle colic, left colic, inferior mesenteric, superior rectal (haemorrhoidal), internal iliac arteries, mesorectal, lateral sacral, presacral, and sacral promontory (Gerota).

Anal canal
Perirectal, internal iliac, and inguinal nodes

Liver (including intrahepatic bile ducts)
The regional lymph nodes are the hilar nodes (i.e., those in the hepatoduodenal ligament), hepatic (along the proper hepatic artery), periportal (along the portal vein), and those along the abdominal inferior vena cava above the renal veins (exept the inferior phrenic nodes).

Gallbladder
Extrahepatic bile duct
Cystic duct, pericholedochal, hilar, peripancreatic (head only), periduodenal, periportal, coeliac, and superior mesenteric nodes

Ampulla of Vater

Superior: Lymph nodes superior to the head and body of the pancreas
Inferior: Lymph nodes inferior to the head and body of the pancreas
Anterior: Anterior pancreaticoduodenal, pyloric, and proximal mesenteric nodes
Posterior: Posterior pancreaticoduodenal, common bile duct, and proximal mesenteric nodes

Pancreas

The regional lymph nodes are the peripancreatic nodes, which may be subdivided as follows:
Superior: Lymph nodes superior to the head and body of the pancreas
Inferior: Lymph nodes inferior to the head and body of the pancreas
Anterior: Anterior pancreaticoduodenal, pyloric (for head only), and proximal mesenteric lymph nodes
Posterior: Posterior pancreaticoduodenal, common bile duct, and proximal mesenteric nodes
Splenic: Hilum of the spleen and tail of the pancreas (for tumours in the body and tail only)
Celiac: (for tumours of head only)

Lung
Pleural mesothelioma

All regional nodes are above the diaphragm. They include the intrathoracic, scalene, internal mammary (for pleural mesothelioma only) and supraclavicular nodes.

Bone

The regional lymph nodes are those appropriate to the site of the primary tumour.

Soft tissues

The regional lymph nodes are those appropriate to the site of the primary tumour.

Carcinoma of the skin (excluding eyelid, vulva, and penis)
Malignant melanoma of the skin (excluding eyelid)

The regional lymph nodes are those appropriate to the location of the primary tumour.
Unilateral tumours

Head, neck	Ipsilateral preauricular, submandibular, cervical, and supraclavicular lymph nodes
Thorax	Ipsilateral axillary lymph nodes
Arm	Ipsilateral epitrochlear and axillary lymph nodes
Abdomen, loins and buttocks	Ipsilateral inguinal lymph nodes
Leg	Ipsilateral popliteal and inguinal lymph nodes
Anal margin and perianal skin	Ipsilateral inguinal lymph nodes

With tumours in the boundary zones between the above, the lymph nodes pertaining to the regions on both sides of the boundary zone are considered to be regional lymph nodes. The following 4 cm-wide bands are considered boundary zones:

Between	*Along*
Right/left	Midline
Head and neck/ thorax	Clavicula–acromion–upper shoulder blade edge
Thorax/arm	Shoulder–axilla–shoulder
Thorax/abdomen, loins, buttocks	Front: Middle between navel and costal arch Back: Lower border of thoracic vertebrae (midtransverse-axis)
Abdomen, loins, and buttock/leg	Groin-trochanter-gluteal sulcus

Breast
The regional lymph nodes are:
1. Axillary (ipsilateral): interpectoral (Rotter's) nodes and lymph nodes along the axillary vein and its tributaries, which may be divided into the following levels:
   (i) Level I (low-axilla): lymph nodes lateral to the lateral border of the pectoralis minor muscle
   (ii) Level II (mid-axilla): lymph nodes between the medial and lateral borders of the pectoralis minor muscle and the interpectoral (Rotter's) lymph nodes
   (iii) Level III (apical axilla): lymph nodes medial to the medial margin of the pectoralis minor muscle, excluding those designated as subclavicular, infraclavicular.

Note: Intramammary lymph nodes are coded as axillary lymph nodes.

2. Infraclavicular (subclavicular) (ipsilateral).
3. Internal mammary (ipsilateral): lymph nodes in the intercostal spaces along the edge of the sternum in the endothoracic fascia.
4. Supraclavicular (ipsilateral).

Any other lymph node metastasis is coded as a distant metastasis (M1), including cervical, or contralateral internal mammary lymph nodes.

Vulva
The femoral and inguinal nodes

Vagina
Upper two-thirds of vagina: pelvic nodes, including obturator, internal iliac (hypogastric), external iliac and pelvic nodes, NOS
Lower third of vagina: inguinal and femoral nodes

Cervix uteri
Paracervical, parametrial, hypogastric (internal iliac, obturator), common and external iliac, presacral and lateral sacral nodes

Corpus uteri
Pelvic (hypogastric [obturator, internal iliac], common and external iliac, parametrial and sacral) and para-aortic nodes

Ovary
Fallopian tube
Hypogastric (obturator), common and external iliac, lateral sacral, para-aortic and inguinal nodes

Gestational trophoblastic tumours
Regional lymph nodes: Not applicable

Penis
Superficial and deep inguinal nodes and pelvic nodes

Prostate
The regional lymph nodes are the nodes of the true pelvis, which essentially are the pelvic nodes below the bifurcation of the common iliac arteries.

Testis
Abdominal para-aortic (periaortic), preaortic, interaortocaval, precaval, paracaval, retrocaval and retroaortic nodes, and nodes along the spermatic vein
Intrapelvic and inguinal nodes are considered regional after scrotal or inguinal surgery.

Kidney
Renal hilar, abdominal para-aortic and paracaval nodes

Renal pelvis and ureter
Renal hilar, abdominal para-aortic and paracaval nodes
Intrapelvic nodes (for ureter only)

Urinary bladder
The regional lymph nodes are the nodes of the true pelvis, which essentially are the pelvic nodes below the bifurcation of the common iliac arteries.

Urethra
Inguinal and pelvic nodes

Carcinoma of the eyelid
Carcinoma of the conjunctiva
Malignant melanoma of the conjunctiva
Malignant melanoma of the uvea
Retinoblastoma
Sarcoma of the orbit
Carcinoma of the lacrimal gland
Preauricular, submandibular, and cervical lymph nodes

Brain
Hodgkin disease and
Non-Hodgkin lymphoma
Not TNM classifiable

Annex 3. C-Factor

From: Sobin, L.H. & Wittekind, Ch., eds, UICC International Union Against Cancer, *TNM Classification of Malignant Tumors*, Sixth Edition, New York, Wiley-Liss, 2002

The C-factor, or certainty factor, reflects the validity of classification according to the diagnostic methods employed. Its use is optional.

The C-factor definitions are:

C1 Evidence from standard diagnostic means (e.g., inspection, palpation, and standard radiography, intraluminal endoscopy for tumours of certain organs)

C2 Evidence obtained by special diagnostic means (e.g., radiographic imaging in special projections, tomography, computerized tomography [CT], ultrasonography, lymphography, angiography; scintigraphy; magnetic resonance imaging [MRI]; endoscopy, biopsy, and cytology)

C3 Evidence from surgical exploration, including biopsy and cytology

C4 Evidence of the extent of disease following definitive surgery and pathological examination of the resected specimen

C5 Evidence from autopsy

Example: Degrees of C may be applied to the T, N, and M categories.
A case might be described as T3C2, N2C1, M0C2.

The TNM clinical classification is therefore equivalent to C1, C2, and C3 in varying degrees of certainty, while the pTNM pathological classification generally is equivalent to C4.

Chapter II

Guidelines on confidentiality in population-based cancer registration in the European Union

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Summary of conclusions and recommendations

A. Principles of confidentiality and the role of the cancer registry

A.1 The purposes for which data collected by the cancer registry are to be used should be clearly defined (section 3.5).

A.2 The legal basis of cancer registration should be clarified and it should be ensured that all reporting bodies have legal authority to report cancer, whether registration is compulsory or voluntary (section 3.2).

A.3 The cancer registry must maintain the same standards of confidentiality as customarily apply to the doctor–patient relationship; this obligation extends indefinitely, even after the death of the patient (sections 4.1 and 4.6).

A.4 Identifiable data may be provided to a clinician for use in the treatment of cancer patients (section 6.3) observing that only the data necessary for the stated purpose are released (section 6.2).

A.5 Identifiable data may be transferred to a collaborating or central registry for the purposes of complete and accurate cancer registration (section 3.5.2).

A.6 The scope of confidentiality extends not only to identifiable data about data subjects and data suppliers, but also to other directly or indirectly identifiable data stored in or provided to the registry (sections 2.5 and 4.7).

A.7 Data on deceased persons should be subject to the same procedures for confidentiality as data on living persons (section.4.6).

A.8 Guidelines for confidentiality apply to all data regardless of storage or transmission media (sections 4.8, 5.6 and 5.8).

B. Measures for data confidentiality, protection and security

B.1 The Director of the registry is responsible for data security (section 5.1).

B.2 The staff of the registry should sign, as part of their contract of employment, a declaration that they will not release confidential information to unauthorized persons. This declaration should remain in force after cessation of employment (section 5.2).

B.3 Suitable control of access to the registry, both physical and electronic, and a list of persons authorized to enter the registry, should be maintained by the Director (section 5.4).

B.4 The Director should maintain a list of staff members indicating the nature and extent of their access to registry data (section 5.1).

B.5 Notices reminding staff of the need to maintain confidentiality should be prominently displayed (section 5.3).

B.6 Cancer registries should consider providing proof of identity to staff engaged in active registration (section 5.5).

B.7 Identifiable data should not be transmitted by any means (post, telephone, electronic) without explicit authority from the Director or a staff member to whom such authority has been delegated (section 5.6). Transmission by telephone should in general be avoided (section 5.7).

B.8 Cancer registries should consider the use of registered post or courier services for confidential data, as well as separating names from other data for transmission (section 5.6.1).

B.9 Precautions should be taken for both physical and electronic security of confidential data sent on magnetic or electronic media (section 5.6.2). This could be by separating identifying (ID)

information and tumour-related data, or via encryption of the ID (section 5.8.1).

B.10 Use of the computer for confidential data should be controlled by electronic and, if possible, physical measures to enhance the security of the data, including use of a separate room, use of passwords, different levels of access to data, automatic logging of all attempts to enter the system, and automatic closure of sessions after a period of inactivity (section 5.8.1).

B.11 Demonstrations of the computer system should be performed with separate and fictitious or anonymized data-sets (section 5.8.2).

B.12 Special precautions should be taken for the physical security of electronic back-up media (section 5.8.3).

B.13 Expert advice on security against unauthorized remote electronic access should be sought if necessary (section 5.9).

B.14 Measures should be taken to ensure the physical security of confidential records held on paper, microfilm, microfiche, and other electronic media (section 5.10), and to protect such data from corruption (section 2.8).

B.15 A policy should be developed for the safe disposal of confidential waste (section 5.11).

B.16 Security procedures should be reviewed at suitable intervals, and consideration should be given to obtaining specialist advice (section 5.12).

C. Release of registry data

C.1 Release of cancer registry data for research and for health care planning is central to the utility of the registry. The registry should develop procedures for data release that ensure the maintenance of confidentiality (sections 3.5 and 6.4).

C.2 The Director of the registry, a scientific committee or an authority should be made responsible for deciding if a request for identifiable data meets the requirements of the law and the registry's guidelines on confidentiality. Also the scientific soundness of the project should be judged (section 6.1).

C.3 In the absence of written consent from data subjects and data suppliers, a cancer registry should not release identifiable data on data subjects or data suppliers for purposes other than research and statistics (section 6.2). National legislation with respect to confidential data should be observed.

C.4 Physicians should be given access to data needed for the management of their patients, if identified as such and if in accordance with national law (section 6.3).

C.5 Data on a subject must be provided to the subject upon request, unless a national law exempts such a release. It is recommended that data subjects be advised to make the request via their own physician (section 6.5).

C.6 Enquiries from the press should be referred to the Director of the registry or to a staff member nominated for this purpose (section 6.7).

C.7 Requests for identifiable data to be used for research should include a detailed justification with a commitment to adhere to the registry's guidelines on confidentiality (section 6.4).

C.8 Registries should provide a document describing their procedures and criteria for the release of data (especially identifiable data) to researchers who request access to the data (section 6.4).

C.9 If allowed by national law, cross-border transfer of identifiable individual data should only be carried out if required for the conduct of a research project and if the level of protection is satisfactory (section 6.6).

C.10 It is recommended that advance plans should be made for the possible cessation of registry activity, including a description of procedures, variables, coding manuals, programs, etc., in order to maintain the subsequent utility of the database while safeguarding the confidentiality of its data (section 6.8).

1. Purpose of guidelines on confidentiality in the cancer registry

1.1 Background

The present guidelines for confidentiality in population-based European cancer registries build upon the guidelines published by the International Association of Cancer Registries in 1992. The background for these guidelines is presented in a paper by Coleman *et al.* (1992). In brief, the code of confidentiality in cancer registration defines what information should be regarded as confidential, and describes measures of security, periodic review and surveillance of security procedures, conditions for the release of confidential data and protection of the individual's rights, including both the patient, the doctor and the hospital.

These guidelines represent a review consistent with the European Directive 'on protection of individuals with regard to the processing of personal data and on the free movement of such data' (Directive 95/46/EC), which provides the basis for national legislation for the protection of individuals with regard to the processing of personal data. The review was carried out with a view to the modernization of cancer registration procedures, from primarily a paper-based system to one based on computerized data capture and storage. New information technology promises to make accurate information more readily available at a lower cost, but also raises concerns from the point of view of confidentiality, because of the easy storage and dissemination of huge volumes of data. These concerns and recommendations related to the protection of electronic health information have been dealt with by various committees worldwide (National Academy Press, 1997).

The main objective of guidelines for confidentiality was outlined by Muir (in Jensen *et al.*, 1991): (a) to ensure the protection of the confidentiality of data about individuals whose cancer is reported to the registry, so the information cannot reach unauthorized third parties; (b) to ensure that the cancer registry data are of the best possible quality; and (c) to ensure that the best possible use is made of the registry data to the benefit of cancer patients, the population and for medical research. A code of confidentiality helps in defining the proper balance between the right to privacy for the individual and the right of fellow citizens to benefit from the knowledge on cancer causation, prevention, treatment and survival, as derived from cancer registration. Guidelines may make clear to the public how cancer registries handle the data entrusted to them in confidence, as well as guiding registries in the creation of appropriate safeguards for all aspects of their operation, from data collection to analysis, and the release of data for research purposes.

1.2 Aims of the document

The aims of this document are to give updated guidance in relation to the European data protection Directive, on:

(a) The definition of terms of relevance for cancer registration and the Directive text.

(b) The articles and exemptions in the Directive of relevance to cancer registration.

(c) The need for a code of conduct in the maintenance of confidentiality in cancer registration, and the definition of what should be considered confidential.

(d) The objectives of confidentiality measures in cancer registration, and their legal basis.

(e) The principles of confidentiality, including the measures to maintain and survey security procedures.

(f) Guidelines for the preservation of confidentiality; and for the use and release of registry data in accordance with these principles.

1.3 European Directive 95/46/EC on data protection

1.3.1 Privacy

The right to privacy with respect to the processing of personal data (e.g. cancer registration) is listed as one of the fundamental rights and freedoms of a person, and the protection of this right is the main objective of the European Directive 95/46/EC. Recommendations on ethical issues in research have been published; however these do not have the same status as a law (Directive).

1.3.2 Informed consent

Many of the uses of registry data, both in health care planning and in research, involve the use and release of identifiable data on

individuals registered with cancer. The Directive 95/46/EC Article 7 indicates that 'informed consent' is needed unless this use is based on contractual, legal, vital and public interest. Furthermore, the Directive prohibits the processing of data 'concerning health' (Directive 95/46/EC, Article 8).

The informed consent principle makes it virtually impossible to use data from a cancer registry, for various reasons:

(a) The practical workload of seeking consent each time data are processed is a disproportionate and very heavy burden for population-based cancer registries.

(b) The repeated burden to the patients and/or their relatives being asked to consent is of concern.

(c) Seeking general consent for any scientific and statistical use of the cancer registration process poses a further load on medical personnel and may lead to unacceptably low coverage of registration (as seen in Hamburg).

(d) From a legal point of view, consent can only be given for a limited period of time.

(e) The proportion of non-coverage (resulting from differences in patterns of asking for or giving consent) may vary by population, and true differences in cancer incidence may become confounded by differences in the accuracy of registration.

1.3.3 Derogation to the requirement of informed consent

The derogations to the European Directive 95/46/EC (Articles 8.3 and 8.4 and further explained in recital 34 of the Directive; Cordier, 1995) legalize the processing of data by a health professional subject to professional secrecy, without informed consent, for preventative medicine, medical diagnosis, the provision of care or treatment or the management of health care services, including scientific research. This includes all elements enshrined in cancer registration. National legislation may add further exemptions in the public interest by law or legal order. This does not override the requirement for data processing to be 'fair and lawful' (see para. 3.2).

1.3.4 Derogation to the obligation to inform subjects about data processing

The Directive 95/46/EC Article 11.1 also specifies the need to inform the data subject about the disclosure of data to a third party at the time when data are disclosed. The registries, however, fall under the derogation in Article 11.2 when processing is for statistical, historical or scientific research, and the subjects cannot be informed (deceased persons), or provision of information involves a disproportionate effort, or disclosure of information is allowed by national law. In conclusion cancer registries can operate without informing data subjects about processing and disclosure. Member states shall in these cases provide appropriate safeguards that must be observed by registries.

1.3.5 Clinical use of data

Data release for clinical purposes may be included in the function of some cancer registries. These data will be used for the benefit of the individual cancer patient, and should be subject to the legislation concerning the transfer and release of clinical data in the country.

1.4 Use of guidelines

In order for cancer registry data to be of value for clinical, statistical and research purposes, the data recorded must be as complete, accurate and reliable as prevailing circumstances permit. Irrespective of any legislative measures, these standards of quality can be achieved only if both the public and the physicians and institutions treating cancer patients are confident that the data required are necessary for the objectives of cancer registration and medical research, and that confidential data will be adequately safeguarded.

These guidelines are not intended to be adopted *en bloc* as a fixed set of procedures for the maintenance of rconfidentiality in any particular cancer registry or without modification needed as a consequence of national legislation. Rather, they are intended to present the basic principles of confidentiality with a view to the European Directive 95/46/EC, and to provide a set of measures from which a registry may select and reformulate, as appropriate, those measures considered to be most useful in the preparation or revision of a local code of practice on confidentiality.

The applicability of these guidelines will be kept under review by the ENCR, and amendments will be made as necessary.

2. Definitions

2.1 Cancer

The term 'cancer' is used in this document to imply all neoplasms and conditions suspected as such, as defined in the International Classification of Diseases for Oncology, third edition (Fritz *et al*., 2000).

2.2 Cancer registry

A cancer registry may be defined as an organization for the collection, storage, analysis and interpretation of data on persons with cancer.

2.2.1 Hospital-based

Cancer registries that limit their aims to recording the particulars of cancer cases seen in a given hospital or group of hospitals irrespective of boundaries of geographical areas are said to be hospital-based.

2.2.2 Population-based

Cancer registries that aim to register details of every cancer that occurs in a defined population, usually those persons resident within the boundaries of a defined territory or geographical region, are said to be population-based.

2.2.3 General cancer registry

Each of the two mentioned registry types (2.2.1 and 2.2.2) can be general if all cancers are recorded in the defined catchment area (hospital or population).

2.2.4 Specialized cancer registry

Each of the two mentioned registry types (2.2.1 and 2.2.2) can be specialized if registration is restricted to cancers of a given site group or age group in the defined catchment area (hospital or population).

2.2.5 Record linkage data register

A cancer registry which uses record linkage of already computerized and coded data; it may be any of the subtypes in 2.2.

2.3 Cancer registration

Cancer registration is the process of the continuing, systematic collection of data on the characteristics of all cancers and of the persons diagnosed with cancer, and is the basic activity of a cancer registry.

2.4 Data subject

An identified or identifiable natural person, on whom information is processed.

2.5 Confidential data (personal data)

For the purposes of this document, any data collected and stored by a cancer registry, which could permit the identification of an individual patient (data subject) or, in relation to a particular data subject, of an individual physician or institution (data supplier) are considered to be confidential. An identifiable person is one who can be identified directly or indirectly by reference to a reference number or other identifying (ID) information such as names, date of birth, etc., or to factors specific to his or her physical, physiological, mental, economic, cultural or social identity.

The collection of unambiguous ID information on the data subject is necessary to secure quality and use of the registry. Furthermore, the dates of birth and death are needed for many research purposes, but may in many instances be sufficiently detailed by month and year. The data which, in association with a cancer diagnosis, are considered confidential alone, and in combination with other data items (x) are listed below:

(a) Names

(b) Unique reference numbers (e.g. national identity numbers)

(c) Address

(d) Full date of birth (x), combined with sex and small area code for place of residence or death

(e) Date of death (x), combined with sex and small area code or full date of birth

(f) Small area code (x), combined with sex and 2.5.4 or 2.5.5.

In rare instances the combination of age, sex, year of diagnosis and small area code may be regarded confidential because a person might be identified if the

population in the area is sufficiently small. In the UK, cancer registries work on the principle that patients may be identified if the population denominator is less than 1000. Release of such data is strictly controlled.

2.6 Treating physician

The treating physician may be defined as the patient's general practitioner (GP), the doctor primarily responsible for the patient's cancer treatment, or a doctor to whom the patient has been referred for additional investigation or treatment. The medical director of the institution where the treating physician is or was employed when treating the patient in question may also act on behalf of the physician.

2.7 Security

Security denotes the measures taken to prevent unauthorized access to the registry data, whether stored on paper, microfilm, microfiche or magnetic media, or transmitted by any of these means.

2.8 Data protection

Includes both the prevention of physical access to the data (security), and the protection of the data to avoid corruption during many years of storage. The term should in this context not be confused with confidentiality (privacy), the aim of which is to protect the individual from unauthorized disclosures.

2.9 Processing of personal data (Directive 95/46/EC definition)

Denotes any operation or set of operations that is performed upon personal data, whether or not by automatic means, such as collection, recording, organization, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, blocking, and erasure.

2.10 Filing system

Denotes any means to achieve a structured set of personal data that are accessible according to specific criteria, whether centralized, decentralized or dispersed on a functional or geographical basis.

2.11 Controller

Denotes the natural or legal person (Registry Director), public authority, agency or any other body that alone determines the purposes and means of processing personal data. When the purposes and means of processing are determined by laws or regulations, the controller or the specific criteria for his or her nomination may be designated by law.

2.12 Processor

Means a natural or legal person, public authority, agency or any other body that processes the personal data on behalf of the controller.

2.13 Third party

Means any natural or legal person, public authority, agency or any other body than the data subject, the controller, the processor and the person who, under the direct authority of the controller or the processor, is authorized to process the data.

2.14 Recipient

Means a natural or a legal person, public authority, agency or any other body to whom data are disclosed, whether a third party or not.

2.15 Informed consent

Means any freely given specific and informed indication of the wishes of the data subject by which the data subject signifies his or her agreement to personal data relating to him or her being processed.

3. Role of the cancer registry

3.1 Function of the cancer registry

The cancer registry plays a central role in all aspects of cancer control (Muir *et al*., 1985), not only for the population covered but also for other populations with which results can be compared. The systematic collection, recording and analysis of data relating to the lifetime of identified individuals with cancer enables analysis and interpretation of clinical and pathological characteristics of cancer, cancer incidence, mortality, prevalence, recurrence and

survival for various population subgroups. It also opens the way for epidemiological research on cancer determinants, exposure to carcinogens and effects of interventions in prevention and early diagnosis, provided that patients can be identified and linked individually to other files. The cancer registry has in many countries also proved to be an important tool for evaluating and planning health services, in addition to research; again preferably if data can be linked to other files, for example, from the hospital and the clinicians involved with the case.

3.2 Legal basis of registration

Cancer registration may be based on compulsory or voluntary notification of cancer patients to the registry. The basis for compulsory registration may be legislation passed by a parliament or elected legislative body (primary legislation), or an administrative order issued under the aegis of a statutory agency such as the Ministry of Health or a provincial health authority.

In some countries, the storage and use of personal data on cancer patients require informed consent of the data subject. However, the European Directive 95/46/EC on the protection of individual's rights makes exemption for processing done to comply with a legal obligation (Article 7), or when data are required for preventive medicine (Article 8.3). In the same Directive it is explicitly stated (Article 6) that personal data must be processed fairly and lawfully, collected for specified purposes, be adequate and relevant for the purpose, be accurate, complete and kept up to date, and not kept identifiable longer than necessary for those purposes. Data for historical, statistical and scientific purposes may be processed further (e.g. data linkages), and stored for longer periods, provided the Member State provides appropriate safeguards. Such safeguards need not be of a technical nature, including complicated organizational and computerized procedures, but may be of a legal nature, with supervisory bodies controlling data use and registry procedures as seen in the Nordic countries with data inspection agencies.

Some cancer registries may obtain both voluntary and compulsory notifications, depending on the source of information. In some areas, for example, pathologists report voluntarily, whereas the patient's physician in hospital or general practice is legally required to do so; in others, pathologists are legally required to report cancers to the registry, whereas treating physicians report voluntarily. Vital Statistics Offices may be legally required to report the vital status, and if deceased, the cause of death on cancer patients.

Fulfilling the legal requirement to 'report' can mean simply allowing access for registry staff to abstract specified information (so-called active cancer registration). It may require, on the other hand, provision of copies of various documents from the patient records, on special notification forms, or electronic notification either by a dedicated electronic form or by extracting already computerized information.

If the registration is based on data linkage of one or more patient-related registries, vital statistics registries, and population registries, legal provision must be in place for the use of such registries for this purpose, and for the data items that may be transferred to the cancer registry. Usually this should be stated in the by-laws of the registries in question, as well as in the cancer registry by-laws.

3.3 Sources of information

Registries should restrict themselves to the collection of the most important data, of a high quality and completeness (Jensen *et al*., 1991), and ensure they can link to other databases for various other data items when necessary.

Notifications of cancer may be derived from many sources, such as the treating physician, surgeon, radiologist or radiotherapist; hospital admissions and records departments, the hospital discharge report, or laboratories of pathology, cytology, haematology or biochemistry; medical records of social security systems, private or government health insurance systems, hospital patient registries or central patient registries and coroners and vital statistics offices (death certificates). Notifications may be submitted on paper records or, increasingly, on magnetic media, or may be derived from computerized data linkage between e.g. hospital-based patient registries, pathology registries and cause of death registries (vital statistics). In some areas, registry employees may visit the source of information to obtain notifications (active registration), whereas in others the

sources of information may submit these directly to the registry (passive registration). Many registries use both active and passive methods of registration.

An important part of the information about the data subject comes from population registers, which confirm the identity of the data subject, date of birth, address and maybe occupation, and whether the subject belongs to the population to be covered by the registry (residence). Follow-up information on deaths or emigrations may also come from this source.

3.4 Data items

Cancer registries should observe the principles related to data quality (Directive 95/46/EC Article 6) and collect data that are adequate, relevant and not excessive in relation to the purpose, as well as being accurate, complete and up to date. The number of data items should thus be limited for two reasons – quality (the fewer data items the greater the likelihood that these will be recorded correctly) and confidentiality (the more data items the more chance of an unintended breach of confidentiality when releasing data).

The data items in the recommended minimum data-set for cancer registries are listed in Table 1.

3.5 Use of cancer registry data

The purposes for which data collected by the cancer registry are used should be clearly defined. Cancer registries are important sources of data, both for clinical purposes and for research intended to advance the understanding of the causes, occurrence and outcome of cancer. However, there is a distinction between clinical use and research in the Directive. Clinical use requires that the data subject be informed about processing, and the subject has the right to obtain information about him or herself from the controller. This is not the case if the cancer registry is using the collected data solely for scientific research or statistical purposes (Articles 11, 12 and 13.2).

Data may be either identifiable or aggregate (anonymous), depending on the nature of the research. Some examples of the use of cancer registry data in relation to confidentiality are outlined below. The list is not intended to be exhaustive, but to identify major categories of use.

3.5.1 Quality of diagnosis, treatment and health care

The clinical use of identifiable data relating to patients registered with cancer arises in context of their diagnosis, treatment and follow-up by the treating physician(s). The availability of identifiable data to the treating physician is essential to avoid the duplication of diagnostic procedures, to permit the exchange of information between treating physicians, and to allow the physician to evaluate the outcome of treatment in individual patients or in groups of patients. Identifiable data required for such clinical purposes may therefore be provided to the treating physician on request, and in accordance with the procedures outlined in section 6, in order to assist the physician in the management of his or her patients with cancer, provided this purpose is included in the registry by-laws. Identification of the person is indispensable for these tasks. It is pertinent that the registry and the physician observe the

Table 1. Items of information collected by registries (from Jensen *et al*., 1991)

Essential variables	
Personal identification	Names (in full) AND/OR unique personal identification number
Sex	Male or female
Date of birth	Day, month, year
Address	Usual residence (coded)
Incidence date	At least month and year
Most valid basis of diagnosis	
Topography (site) of primary	ICD-O
Morphology (histology)	ICD-O
Behaviour	ICD-O
Source of information	
Recommended variables	
Date of last contact	At least month and year
Status at last contact	(At least dead or alive)
Stage or extent of disease	
Initial treatment	

confidentiality of the personal information on the data subject during the transmission of data (see below).

3.5.2 Transfer of identifiable data for registration purposes

In two circumstances, registries may need to transfer identifiable data to other cancer registries for the purposes of complete registration, quality control and the avoidance of duplication. The first case involves a tumour diagnosed in a person who proves to be resident in the territory of another, usually adjacent, registry. The second case involves regional registries that contribute data to a larger or national registry, or specialized registries that also contribute data to a general population-based registry. In each case, data may be transferred for the purposes of complete and accurate registration, provided that the recipient registry adheres to comparable standards of confidentiality.

3.5.3 Use of identifiable data for research

(*a*) *Studies of causes of cancer*

Case–control and cohort studies help in identifying the causes of cancer. Both types of study require information about individuals with cancer. In a cohort study, for example, linking the cohort members against the cancer registry files (or against a file of death certificates) enables cancers and deaths arising in the cohort to be detected. This has proved a highly efficient, economical and confidential method of detecting risk. Such linkages may be manual, computerized or both, and whereas linkage always requires knowledge of the identity of individuals with cancer, irrespective of whether the ID information appears in encrypted form or not (see 5.8.1), the resulting publications always present anonymous or aggregated data. It is, however, pertinent for the quality control in such studies that the researcher has the possibility to check the quality of the linkage procedures manually and sort out spurious findings, and for these purposes identifiable data must be available. The credibility of studies in which such quality control cannot be performed is low, and results in the worst-case scenario can be misleading.

Registries are frequently used as a source of cases (and sometimes also of controls) for case–control studies. The value of these studies for identifying risk factors is enhanced by the availability of a representative sample of tumours diagnosed in the population. It must be observed, however, that contact with the data subjects should be undertaken through the treating physician or hospital, and with the approval of ethical committees in place in the country.

(*b*) *Evaluation of screening*

Cancer registries play a major role in the evaluation of screening programmes, by providing information to enable the assessment of whether, in comparison with an unscreened population, invasive cancer, e.g. of uterine cervix or breast, develops less frequently and mortality decreases in a screened population or subgroup. This requires the comparison of lists of individuals with cancer detected by the screening programme with cancer registry files. The cancer registry may thus be essential for adequate evaluation of a population-based cancer screening programme, providing the information is not available in any other way.

(*c*) *Evaluation of survival from cancer*

By matching death certificates to cancer notifications received by the registry, it is possible to assess the survival of all persons with cancer in a defined population. Survival from cancer in the population as a whole is frequently quite different from that reported for selected series of patients (e.g. in clinical trials). Such data may be used to evaluate the extent and speed with which new or improved cancer treatments are incorporated into routine clinical practice. It is also possible to assess population survival for a given cancer by the extent of spread at diagnosis, or by the type of treatment. This type of research is possible only if the registry can link identifiable cancer registrations with death certificates; such evaluation of cancer survival is now routine practice in many registries.

3.5.4 Genetic counselling

The use of data in cancer registries on families for genetic counselling of individuals concerned about a possible heritable cancer disease is tempting, because of the completeness of cancer registries and the fact that all the necessary data are available in the registry (cancer type, sex, age of family member at cancer

and/or death). Such use is, however, not compatible with Article 7 of the Directive, because the counselling cannot be considered of 'public interest' [although inaccurate counselling may lead to overestimation of risks and unwarranted consequences, e.g. prophylactic mastectomy], nor are such activities included in Article 8 under medical diagnosis and preventive medicine. Therefore the use of registries for genetic counselling can only be on the basis of the informed consent principle. The policy below was developed by the United Kingdom Association of Cancer Registries:

"(i) Request for cancer registry information from registered medical practitioners working in genetic counselling clinics concerning living family members, related to a proband undergoing counselling should be accompanied by a signed consent form obtained from each family member (or legal guardian) about whom information is requested. The consent form should permit the release to the named registered medical practitioner of information relating to cancer from medical and hospital records. The consultant and, when possible, the GP responsible for the family member, should be informed about the data release. Information regarding living cancer patients should not be released without their signed consent.
(ii) Information regarding patients known to have died can be released to a registered medical practitioner for counselling purposes, upon request, without seeking consent.
(iii) Registered medical practitioners receiving cancer registry information must undertake to maintain the confidentiality of the data, keep it securely and release it only for counselling purposes. The duty of confidentiality relating to medical information extends beyond death, and the above requirements must be adhered to for information relating to both living and deceased patients.
(iv) The information released for counselling purposes should consist of the minimum necessary to achieve the objectives required. In normal circumstances this would comprise: name, address, date of birth, date of diagnosis, cancer site and histology, name of hospital of managing consultants and (for living patients) name and address of GP."

The medical practitioner, or other recipient of the data responsible for the request, should sign a declaration to the effect that he or she has understood and agrees to act in accordance with the policy statement.

3.5.5 Use of aggregate data

(*a*) *Research*

One of the most important contributions of the cancer registry is to provide current data on the incidence of various types of cancer, and on variations in incidence by age, sex, place of birth, occupation, ethnic group, etc. These data can also be used to study differences in histological types and between urban and rural areas, and to examine trends in incidence over time. Only aggregate, anonymous data are used in such studies after the compilation of the data-set during which data are identifiable.

(*b*) *Health care planning*

Information provided by the cancer registry on the numbers of cancer patients can help health authorities in various ways, including long-term planning for the provision of medical facilities and the training of health care professionals; the establishment of priorities and programmes for cancer control; evaluation of the effects of intervention; and estimation of the numbers of cancer patients in the future (projections). For most these purposes, the identity of individual cancer patients is neither needed nor provided; only aggregate data are used.

4. Principles of confidentiality

4.1 Underlying concept of medical confidentiality

The set of principles outlined below relates to the preservation of confidentiality in connection with or during the process of collection, storage, use, and transmission of identifiable data by the cancer registry. A cancer registry must maintain the same standards of confidentiality in handling identifiable data as customarily apply to the doctor–patient relationship; this obligation

extends indefinitely, even after the death of the patient.

These guidelines are intended to help ensure the confidentiality of data about individuals whose cancer is reported to the registry, so that information on registered persons cannot reach unauthorized third parties.

4.2 Sharing of confidential clinical information

For serious diseases such as cancer, 'in modern medical practice, the doctor can seldom be the sole confidant, since effective care involves others, both medical and non-medical, technical and clerical, who provide services and manage the health care institutions' (Medical Research Council, 1985). Despite this essential dispersion of confidential information within the clinical team, the ultimate responsibility for the maintenance of confidentiality remains with the treating physician. The treating physician who provides information to a cancer registry about a patient with cancer therefore has the right to expect that the registry observes strict rules of confidentiality (see section 5.1).

4.3 Legal protection of data suppliers

Unless cancer is a disease that must be notified to a cancer registry by virtue of a law or administrative order, the data recorded by the cancer registry are supplied on a voluntary basis by the physician or institution. In some countries, therefore, it may be necessary for the registry to ensure that there is at least legal authority for physicians to report cancer, in order to protect data suppliers from legal action for breach of confidentiality in submitting identifiable data to the cancer registry.

4.4 Confidentiality and utility

Effective operation of the cancer registry depends on the continuous supply of confidential information from several sources, notably clinicians, pathologists, hospital patient registration systems and vital statistics offices. These data suppliers can only be expected to continue to provide such information if the cancer registry can be trusted to maintain confidentiality and to make good use of the data. Data suppliers will therefore need to be satisfied that the registry adheres to an adequate set of guidelines on confidentiality, and that data of high quality are being collected and used for the benefit of cancer patients and cancer research. It is important to observe that confidentiality rules follow the intention laid down in the Directive 95/46/EC, and are not so strict that the rules will hinder usage of the data, which again is described in the aims of the registry.

4.5 Scope of confidentiality measures

Maintenance of the confidentiality of identifiable data held by the cancer registry should extend beyond information on cancer patients and those notifying them (data subjects and data suppliers), to include identifiable data from medical records, census data, interview records, death certificates and lists of members of industrial cohorts or other study populations that may be stored in or provided to the cancer registry as part of its routine operations or for research projects.

4.6 Confidentiality of data on deceased persons

Data on deceased persons held in the cancer registry should be subject to the same procedures regarding confidentiality as data on living persons, even though death certificates or related information may be available from other sources. For deceased persons, as for live, information on data disclosure is exempt based on article 11.2. A supervisory regulatory body may provide sufficient safeguards against breaches of confidentiality for deceased persons.

4.7 Indirectly identifiable data

Individual records from which names and address have been removed, but from which it might still be possible to identify an individual indirectly by the use of the remaining data, e.g. an identity number, should also be subject to measures for the preservation of confidentiality in the cancer registry.

4.8 Methods of data storage and transmission

Guidelines for the maintenance of confidentiality are applicable not only to the storage of identifiable data on computers,

but also to the storage of such data in the form of paper records, microfilm, image scanned records and magnetic media, and their transport or transmission by registry personnel in any of these formats. The procedures involved may differ, but the underlying principle is the same.

Precautions should be taken when maintaining electronic files, and the transmission of confidential data by means of the Internet or via e-mail must be carried out in accordance with the recommendations in sections 5.6 and 5.8 below.

4.9 Ethics

Ethics in medical research are enshrined in the Helsinki Declaration and in the Nuremberg Codes of Conduct. One basic principle is, as in the European Directive, informed consent. This principle cannot be followed for successful cancer registration and the European Directive exempts cancer registration from informed consent (1.3.2).

5. Measures for data confidentiality

5.1 Responsibility

The Director of the cancer registry is usually in legal terms the 'controller' or the 'processor' (Directive 95/46/EC, Articles 2(d) and 2(e)) responsible for maintaining the confidentiality of identifiable data. The Director must ensure that the registry staff and 'third parties' are aware at all times of their individual responsibilities with respect to confidentiality, and that the security measures adopted by the registry are known and adhered to. It is recommended that an up-to-date list of staff members and 'third parties' be maintained, indicating the type of data to which each of them has access, and there should be an adequate system of computerized security measures (see section 5.8.1). Further fulfilment of the conditions for released data should be followed by the Director (see section 6). The specific criteria for the Director's nomination (responsibility for data privacy and security) may be designated by law. If not, the criteria should be detailed in the Director's job description, and failure to comply will be considered a breach of the oath of secrecy (see section 5.2).

5.2 Oath of secrecy

Duly trained and specialized staff should be appointed to run the cancer registry in accordance with its aims and rules of operation. It is recommended that, as part of their contract of employment or conditions of service, each member of the registry staff be required to sign a special declaration to the effect that they will not disclose confidential information held by the cancer registry, or brought to their attention in the line of work (e.g. active registration) to an unauthorized person at any time, or to any other person except as permitted within the context of the registry's guidelines on confidentiality. The terms of the contract of employment should make it clear that a breach of this undertaking will result in disciplinary action, which may involve dismissal. Furthermore, it should be made clear that a dismissal on these grounds will be disclosed to employers within the health sector if so requested, thereby making the oath of secrecy comparable to the professional medical oath of secrecy. This declaration of secrecy shall remain in effect even after the staff member ceases to be employed in the cancer registry.

For staff involved in active cancer registration (see section 5.5), it is recommended that they are made aware of, and sign, the confidentiality rules of each data provider, and that these rules and declarations are attached to the general oath of secrecy kept in the registry.

5.3 Display of reminders

It is recommended that notices reminding staff of the need to maintain confidentiality be prominently displayed within the registry.

5.4 Physical access to the registry

Unauthorized access should be prevented. Physical access to the registry premises has to be restricted by adequate technical safeguards. Suitable locks and alarm systems should be installed to control physical access to the registry. Consideration should be given to the use of special locks with entry codes, or

electronic methods of controlling access, and to the maintenance of a record of persons other than staff members who enter the registry. The Director of the registry should maintain an up-to-date list of all persons authorized to enter the registry.

5.5 Active registration

Registry staff assigned to collect information at source (active registration) are responsible for maintaining the confidentiality not only of identifiable data they may collect on persons with cancer for the registry, but also of other information of a confidential nature that they may read or hear at the source (see section 5.2).

Cancer registries using active methods of registration should give consideration to the safe transport of confidential information (see section 5.6), measures to avoid the accidental loss of such material, e.g. by keeping a back-up at the source, and to providing staff with suitable means of identification as an employee of the cancer registry.

The identity of such staff should be made known to the relevant person(s) at each of the sources that they visit to collect information for the registry, and where possible, changes in personnel should be notified to these sources in advance.

5.6 Transmission of information

Authority to transmit identifiable data from the registry, irrespective of the method, must be given by the Director (controller) or other nominated staff member to whom specific responsibility for such transmission has been delegated (processor) (Directive 95/46/EC, Articles 2(d) and 2(e)).

5.6.1 Postal and courier services

If postal or courier services are needed for transfer of confidential information, be it on paper or electronic media, consideration should be given to the use of registered post or other forms of recorded acceptance and delivery by the service. The ID information should be mailed separately from the health information, to be combined using an internal code number by authorized staff upon receipt of both mailings.

For data on electronic media, the encryption of ID information with a special key is an alternative to the procedure of two separate mailings (see also section 5.8.1).

The use of double envelopes, the external envelope giving a general address, and the internal envelope being marked for opening only by a named individual is a precaution against accidental access to the information by unauthorized personnel.

If a courier service is officially authorized to handle confidential data and is used, the registry may consider if derogation from the separate mailing and encryption is acceptable.

5.6.2 Magnetic or electronic data transmission

When identifiable data are sent electronically by magnetic or other machine-readable form, suitable precautions should be taken to ensure the physical security and the confidentiality of the material in transit. In addition to the steps taken to ensure that the data cannot easily be read by an unauthorized person, measures to check for incorrect or corrupt files must also be taken (Directive 95/46/EC Article 17). Among the precautions that might be taken are:

(a) Encrypting of names and other ID information at various levels of complexity, with a special key available only to authorized users (see also section 5.8.1).

(b) Sending the file, tape, diskette (etc.) containing names, address and other identifiable data separately from the media containing tumour-related or other data, using a link number to enable the reconstitution of the record by the intended recipient, and giving maximum security to the media containing identifiable data.

(c) Including tabulations and counts by which the content of the transferred data can be checked, and the program written to produce the tabulations and counts.

5.6.3 Processing and matching of data by external agencies

The registry files may need to be processed or matched against other computer files, either to provide missing data items or for the purposes of research. If it is necessary for such processing to be undertaken outside the registry, e.g. in a vital statistics office or on an external computer, or in another country (see also

section 6.6), the registry must ensure that the confidentiality of its records will be preserved by the agency receiving the registry data and that the measure complies with the national law (Directive 95/46/EC Article 4). Transmission should be in accordance with the above procedures.

Any unnecessary transfer of identifiable data outside the registry should be avoided. Alternatively, data may be provided with a key for identifying individuals and the key kept at the cancer registry.

5.7 Use of telephone

It must be clearly recognized that use of the telephone, although convenient, may easily give rise to a breach of confidentiality. It is under normal circumstances virtually impossible to document the content of a telephone conversation; hence it is difficult to handle in legal terms.

As a general rule, no identifiable data or confidential information of any kind should be given to telephone callers by registry staff, nor should the registry staff seek information in this way.

The need for the registry to pass identifiable information to external callers by telephone should be infrequent. In rare instances in which the telephone method can be justified by the Director, the identity of the caller (name, position, title and address) must be checked and a call-back procedure followed, using only officially published telephone numbers.

5.8 Use of computer

Physical and electronic measures should be used to prevent unauthorized access to information held on the computer. Electronic measures are subject to rapid evolution, and better solutions may emerge than those discussed in general terms here.

5.8.1 Access to data

(a) Workstations used for data access should be placed in a separate room(s), access to which is restricted.

(b) User names and passwords should be used that do not appear on the screen when typed.

(c) Passwords should be changed at intervals, and minimum requirements for changes (interval and password) stated in the registry code for confidentiality.

(d) An automatic log should be kept by the computer of all successful and unsuccessful attempts to enter the system, with regular checks of this log against written records of sessions spent at the terminal by authorized users.

(e) Different levels of access to the database, supported by password protection and user recognition, should be defined, such that only users authorized to gain access to identifiable data can do so. The Director should keep an updated list of persons allowed each access level.

(f) Sessions which have been inactive for more than 10 minutes should be automatically closed, and instructions given to staff to close sessions immediately after use.

Encryption of data has been proposed for preserving confidentiality in storage and communication of confidential data (Anderson, 1995).

The matching and linking of encrypted individuals however need great care, as also errors may be encrypted. Only limited experience exists with these methods in cancer registries. So far fully functioning systems have not been developed.

One other method to increase the difficulty of unauthorized use is the separation of the identity information and the cancer data. The computer of the cancer registry may be kept in complete isolation from the rest of the computer world. One-way traffic of data may be controlled with a specific security program, the so-called firewall.

All testing of new hardware and software should be carried out with special test data. Hard disks, floppy disks and tapes must be efficiently erased or destroyed when taken out of use.

Technical measures administered for the sake of data protection should not lead to a compromise in the quality of the basic data or make the use of the data unacceptably difficult or expensive.

5.8.2 Demonstrations

When the database and the computer system are demonstrated, fictitious or anonymized data should be utilized. Screen displays should be labelled appropriately to make visitors aware of this. A special data-set for demonstrations is recommended.

5.8.3 Back-up

Back-up copies of the database and its changes should be made frequently and regularly as a protection to avoid the loss of the database, and should be stored in a physically separate, safe location.

5.9 Unauthorized access to computer system

It must be recognized that some persons may attempt to gain remote electronic access to computer systems, often to show that this is possible rather than to examine the data. It is unlikely that registries using computer systems to which remote electronic access is possible can provide absolute protection against any such attempt at a reasonable cost. The level of security built into such systems should at least be capable of foiling casual attempts to gain unauthorized access. Consideration should also be given to obtaining expert advice on enhancing the electronic security of such computer systems; this aspect of security should be regularly reviewed (see section 5.12). Although it may not always be possible, it is preferable that the cancer registry has an isolated data processing system.

5.10 Storage of original data

Electronic methods of storage of identifiable, validated and coded data in cancer registries are now almost universal, but most registries also store original data received on paper, either in paper form, copied on to microfilm, or image scanned to electronic media. Such material may include cancer registry notification forms, medical records, copies of pathology reports, copies of death certificates, etc. It is recommended that the original data be preserved for quality control and research purposes, in line with the code of good conduct of the International Epidemiological Association for other research data. The storage of records on paper should be reduced to a minimum for both confidentiality and practical reasons. Paper records or copies thereof (irrespective of media) are accessible to casual inspection, and require no special expertise to gain access. Image scanned files which may be password protected are thus an exception. Specific measures for 'paper records' that may be considered include:

(a) Defining who has access to the registry premises.

(b) Defining which members of staff have access to the room where these materials are kept.

(c) Providing lockable storage cabinets in which all confidential materials should be stored at the end of a working session.

(d) Ensuring that persons not authorized to do so (e.g. cleaning personnel) are not able to scrutinize paper or other physical records containing confidential data.

5.11 Disposal of physical records

A suitable policy should be developed for the safe disposal of waste paper and other physical records containing identifiable data, be it computer output or original data copied to either film or electronic media. The destruction of paper would normally involve shredding. This should preferably be performed within the premises of the registry. When the volume of confidential records to be destroyed is large, it may be necessary to employ specialized and officially authorized services for the safe disposal of confidential waste.

5.12 Review of confidentiality and security procedures

It is recommended that cancer registries undertake formal review of their security procedures annually, and at the same occasion revise access files and logs. It may be helpful at five-year intervals to recruit the services of specialist advisers to ensure that the registry's procedures for the maintenance of confidentiality are up to date, and cover all aspects of the registry's operations.

6. Release of data

The release of aggregate data, in tabular or equivalent formats, and anonymized data does not breach confidentiality. However, care should be taken that an individual may not potentially be identified from such data, e.g. by date of birth (age), sex, and residence in a small geographical area. As a general rule, only

data specifically needed for the question raised should be released.

Many of the uses of registry data, both in health care planning and in research, involve the release of identifiable data on individuals registered with cancer. The derogations to the European Directive 95/46/EC (Articles 8.3 and 8.4, and further explained in recital 34 of the Directive) can be applied in order to legalize the use and the release of data for preventive medicine, including 'public health purposes and scientific research'. National legislation may in the public interest add further exemptions by law or legal order.

Furthermore, the Directive 95/46/EC (Article 11.1) specifies the need to inform the data subject about the disclosure of data to a third party at the time when data are disclosed. The registries have, however, derogation in Article 11.2 when the processing is for statistical, historical or scientific research, and the provision of information is impossible (deceased persons) or involves a disproportionate effort or national law allows the disclosure. Member states shall in these cases provide appropriate safeguards that must be observed by registries.

Procedures must be developed to deal with requests for the release of confidential data. Examples of such procedures are given below.

6.1 Responsibility for data release

The Director (controller) ensures that the law and national guidelines are followed and confidentiality is preserved when data are released. The research projects for which the data are to be released should be scientifically sound. A mechanism to decide about what can be regarded as sound should be established. The director, a scientific committee or an authority could be made responsible for that decision.

6.2 Limitations on data release

(a) National legislation with respect to data confidentiality, patients' rights etc. should be observed.

(b) In the absence of written consent from all the parties concerned, a cancer registry should not release identifiable data either about a registered person (data subject) or, in relation to such a person, about a treating physician or institution (data supplier), for any purpose other than those outlined for clinical and research purposes (section 3.5).

c) The data released should be limited to the variables needed for the stated purpose.

(d) Requests for information, even from physicians, may be received for identifiable data concerning individuals (who may or may not have a cancer recorded at the registry), from agencies such as pension schemes, health care cost reimbursement schemes or industrial disease compensation panels, or in the context of medical examination for life insurance or employment. Such requests should be refused, and the enquirer should be asked to obtain information directly from the subject or the subject's treating physician.

6.3 Release of identifiable data for clinical purposes

Access to identifiable data in the context of treating a patient registered with cancer should be given to the treating physician, subject to the legislation concerning the transfer and release of medical (clinical) data in the country.

6.4 Release of identifiable data for scientific and health care planning purposes

The registry should prepare a public, written document that sets out the criteria and procedures applicable to the release of its data, particularly the release of identifiable data for research. This document could be provided to researchers requesting identifiable data, and reference made to any national legal and ethical requirements.

A request for the release of confidential data should be made in writing to the supervising authority (an example form is attached, see Appendix 1). The release should fall within the accepted uses of registry data and the requirements for safeguarding the confidentiality of the data.

6.4.1 The request should include*:*

(a) The purpose for which the data are needed.

(b) The information required, and a justification of the need for confidential data.

(c) The name and position of the person in charge of the data after their release.

(d) The name and position of other persons who will have access to the data after their release.

(e) The period of time for which the data would be used, the way the data would be handled and the way in which the data (with all its copies) would be disposed of, returned or destroyed after this period has elapsed.

6.4.2 The requesting party should also give an assurance to the cancer registry director or the body in charge of data release, by verified signature, that the intended recipient of the identifiable data will:

(a) Observe the same principles and obey the same laws as are observed and obeyed by the staff of the cancer registry.

(b) Comply with all restrictions on the use of the data imposed by the registry, in particular that the data will not be used for purposes other than those agreed upon at the time of the provision of the data, and that they will not be communicated to other parties.

(c) Not contact registered persons (or their relatives) whose identities have been provided in confidence by the cancer registry (e.g. for research based on interviews) unless a written authorization to do so has first been obtained from the treating physician. When appropriate, approval by ethical committees should also be sought.

(d) Ensure that no publication of the results will enable any individual to be identified.

(e) If the period of time exceeds 12 months, provide the registry director with an annual status report on the data.

(f) Report in writing to the cancer registry director when the data are disposed of, returned or destroyed as agreed.

(g) Give due acknowledgement to the registry for provision of the data.

(h) Provide the registry with a copy of all published and pertinent results when accepted for publication or, if not published, at the time of disposal of the data.

6.5 Provision of data to individuals

The code of confidentiality for cancer registries (IARC/IACR Guidelines on Confidentiality in the Cancer Registry, 1992) advises that registries should not generally inform individuals whether or not there are data about them held in the registry, but divulge such information only through the treating physician. The reason for this is to avoid causing unwarranted anxiety to the patient and to ensure that they obtain medical advice and support when interpreting the information.

Unless a national law explicitly exempts the controller from releasing information to the data subject, or the data are being processed solely for scientific research (Directive 95/46/EC Article 13), registries are obliged, upon request at reasonable intervals, without excessive delay and expense, to inform a data subject whether or not data relating to him or her are in the cancer registry. The information should contain the purpose, the categories of data (variables) and categories of the recipients of the data (Directive 95/46/EC Article 12).

It is recommended that such data are released by registered mail to the data subject using double envelopes, a sealed one containing the print-out of the registry data and in the main envelope an accompanying letter advising the data subject to consult a physician when breaking the seal, in order to obtain proper guidance and advice in interpreting the cancer registry information.

6.6 Transfer of data across borders

One of the reasons for the European Directive 95/46/EC is the expected increase in scientific and technical cooperation (recital 6). The Directive 95/46/EC on the protection of individuals with regard to the processing of personal data and on the free movement of such data regulates the cross-border flow of data in a consistent manner, and safeguards the fundamental rights of individuals. Furthermore, the Directive should lead to an approximation of national laws, and secure a similar and higher level of protection for the rights and freedoms of individuals, and in particular the right to privacy. Within the European Union the processing of personal data is governed by the laws of the member state in which the data is processed (machines, software). In

principle personal data can be transferred, but this should be done only when necessary. When the study design requires that identifiable data be transmitted across registry or national borders, and if national legislation permits and the level of protection satisfies Article 25 of the Directive, then such data can be transferred. The data should at least remain subject to the same rules of confidentiality as in the registry of origin. Cancer registries participating in such studies should satisfy themselves that their data will be treated accordingly, and seek approval for the transfer with national authorities.

The transfer of personal data to third countries (Article 25) is also allowed if the country complies with the national provisions for confidentiality and the European Directive, and if the country in question can afford an adequate level of protection, which has been assessed by a member state of the European Union. A derogation (Article 26.1(d)) from these requirements can be made if the transfer is necessary on important public interest grounds.

Research projects involving the provision of data about individuals from many cancer registries, sometimes in different countries, have provided valuable information about cancer risk. Although it may be necessary for individuals to be identifiable within the context of such studies, identifiable data should not normally be transmitted to other registries or countries. Each subject may be allocated a suitable number by which his or her record can be traced in the cancer registry of origin by registry staff, for data verification within the study. This number can then be used instead of the subject's identity in data files contributed to the study coordinating centre. It should, however, be observed that the data in legal terms are still personal and identifiable.

6.7 News media

Cancer registries are frequently approached by the press for information on cancer. It is recommended that all such enquiries be referred to the Director or other nominated staff member, to whom specific responsibility for dealing with the press has been delegated.

Great care should be taken not to disclose any personal data, or data that by linkage to other data may disclose the identity of individuals (such as sex, age, small area) to the media.

6.8 Cessation of cancer registration

Each cancer registry should develop a policy for the actions to be taken in the event that the registry ceases operation. Consideration should be given to methods of storage of the registry database in an archive, so as to preserve its utility for the purposes outlined above (section 3.5), while ensuring the maintenance of confidentiality. It is recommended that, where possible, a suitable agency such as the national or regional archives regulated by law be identified, in advance, to store the registry archive, a registry description including data capture and handling, description of variables, quality control measures, code manuals, definitions and computer programs used, and a description of the structure of the archived file for a minimum of 50 years. The archive should undertake to make the database available for the purposes defined by the registry and under the same rules of confidentiality as applied by the registry. Consideration should also be given to the data selected for storage and the method of archiving. Selected paper records might be microfilmed or image scanned, and selected computer files archived on electronic media. The safe disposal of confidential records not included in an archive deposit should also be planned in advance.

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Annex 1. Example of application/release form

APPLICATION/RELEASE FORM

1. NAME OF PROJECT
2. ORGANIZATION RESPONSIBLE FOR THE PROJECT
3. PERSON IN CHARGE (NAME, POSITION, ADDRESS)
4. OTHER PERSONS WITH ACCESS TO THE DATA (SAME DETAILS AS IN POINT 3)
5. VENUE FOR THE PROJECT
6. CONTACT PERSON (NAME, ADDRESS, PHONE, FAX, E-MAIL)
7. TYPE OF PROJECT
   - DURATION (BEGINNING, END)
   - DEFINITION OF THE DATA ITEMS REQUESTED FROM THE CANCER REGISTRY
   - OTHER DATA MATERIALS TO BE USED, THEIR WAY OF USE AND PERMISSION RECEIVED OR (TO BE) APPLIED FOR
8. GOAL OF THE USE OF THE DATA (ATTACH PROJECT PLAN, APPENDIX B)
9. DATA SECURITY MEASURES TO BE USED
10. FATE OF THE CANCER REGISTRY MATERIAL RECEIVED
    - TO BE DESTROYED: WHEN, HOW
    - TO BE ARCHIVED: WHEN, HOW
11. ASSURANCE

I agree to handle the data according to the terms included in Appendix A.

Date, signature

Person in charge of the project

Date, signature

Other persons with access to the data to be released

Date, signature

Documents to be appended to application/release form:
Appendix A. Terms for use of the data (see below)
Appendix B. Project plan
Appendix C. Other permissions received
Appendix D. Ethical committee's statement
Appendix E. A short CV of the person in charge

Appendix A. Terms for use of the data (sample):

1. The data may only be used for the purpose specified in the project plan.

2. The data may not be released further to a third party.

3. The privacy of the individual persons included in the data file must be respected. Only authorized contacts with patients through a treating unit are allowed.

4. The data protection measures described must be adhered to.

5. The data must be destroyed or archived according to the project plan. A notification must be made when this takes place.

6. Any changes in the project plan, particularly with respect to the items reported on the application form, must be notified immediately, and a new application including the changes must be submitted.

7. A report focusing on confidentiality must be given within a year of finishing the project. No individual may be identified in this or in any other report based on the project.

8. Resulting publications should be presented to the cancer registry.

9. Acknowledgement of the data source should be included in the publications.

Annex 2 Sample oath of secrecy

Confidentiality agreement

Declaration of confidentiality
Permanent staff

Name: _____

All the data collected and held by the Thames Cancer Registry are confidential data relating to identified individuals. The manual and computer files are registered under the Data Protection Act 1998. Data are not to be accessed, disclosed, published or communicated in any way other than as provided for in the Registry's standing instructions on security of information, computer systems and premises.

All Registry staff also have a duty to preserve the confidentiality of anything of a confidential nature seen or heard in the course of their work during and after their employment at the Registry. **This includes not discussing cases that you have seen during your work. For example if you have seen a case for a famous person, those details are confidentional and should not be discussed with family, friends, neighbours etc.**

All Registry staff have a duty to know the standing instructions on security and comply with them. In case of doubt staff are required to consult their department manager.

To be signed by the member of staff:

I have read the above declaration and understand that any breach of confidentiality may result in disciplinary action, which may extend to dismissal.

Signed: _____

Dated: _____

Appendix 1

EUROCIM software and databases

Guidelines for use of EUROCIM data

The EUROCIM package comprises:

(i) the databases of cancer incidence and mortality data;

(ii) the data analysis software.

The package is available only to registries which contribute data to the EUROCIM project.

The following guidelines for the use of EUROCIM should be adopted:

For contributing cancer registries

Registries wishing to compare their own data with those of other registries for annual reports etc., at the level of the main site categories (i.e. those in the main tables of *Cancer Incidence in Five Continents*), should be able to do so as long as they acknowledge the original data providers and provide them with copies of the resulting publications. For more detailed analyses (e.g. using the epidemiological entities) which might lead to a scientific publication, collaborative effort and shared authorship of publications are strongly encouraged. At the very least, the contributing cancer registries must be consulted before any submission for publication, to allow local experts to comment and advise on the data, analysis and interpretation, and to discuss authorship and/or acknowledgement issues.

For other users of cancer registry data

Researchers who are not part of a cancer registry organization which is participating in the EUROCIM project are advised to approach a local cancer registry. Registries should be free to use the EUROCIM data in collaboration with external researchers as long as they can ensure that the guidelines above are respected.

General information about EUROCIM

EUROCIM is a facility developed by the European Network of Cancer Registries. The current version (4.0) comprises a comprehensive database of cancer incidence and mortality, together with analytical software. Information about participating registries, and contact details, are available via the ENCR website (www.encr.com.fr).

The flexible facilities enable the user to construct Working Datasets comprising populations covered by selected cancer registries, years, age/sex groups, and cancers of interest. These can be investigated using a suite of statistical tools within EUROCIM. There is also a comprehensive, context-related Help system.

Output from EUROCIM sessions can be produced in the form of reports or graphs, and a comprehensive range of statistical functions is provided for analysis. In addition, export facilities are provided to allow EUROCIM data and outputs to be used by other applications.

The EUROCIM databases

Incidence data are obtained from European population-based cancer registries. The data are classified according to either ICD-10 codes, or combinations of ICD-O topography and morphology codes. Cancer registries in Europe use a variety of classifications to record cancer incidence, so the data in EUROCIM have been converted to ensure consistency. The original coding systems used by the registries are listed in the Help section of the corresponding database.

Mortality data are also available in respect of the participating registries. These are based on official national statistics and the WHO Mortality Databank, and are classified to ICD codes.

The cancer registries included in the EUROCIM database and the years for which their data are available are listed separately for incidence and mortality.

Creating a new population and/or entities

EUROCIM permits users to group populations and cancers of interest from the selected database and to save them as user-defined populations and user-defined cancer groups respectively (Figures 1 and 2).

Standard populations

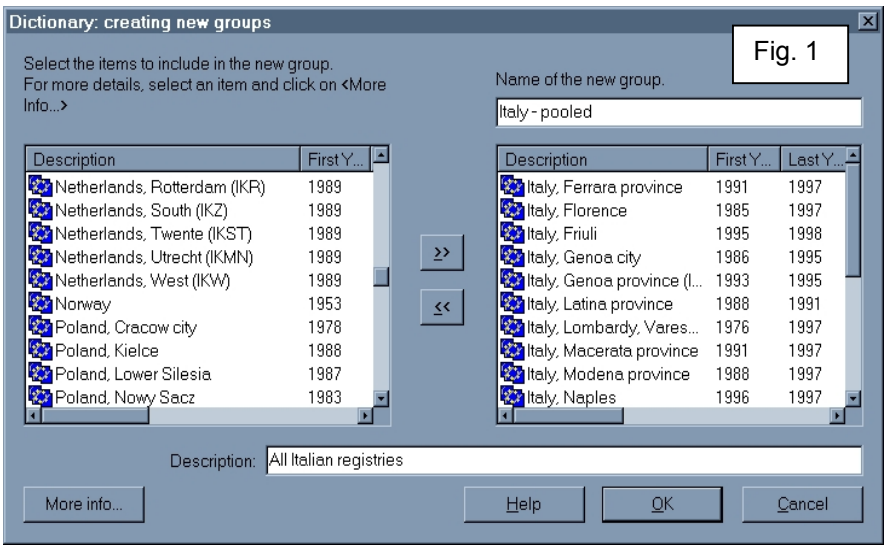
EUROCIM provides the World and European standard populations for age-standardization purposes, and also allows users to define their own standard populations.

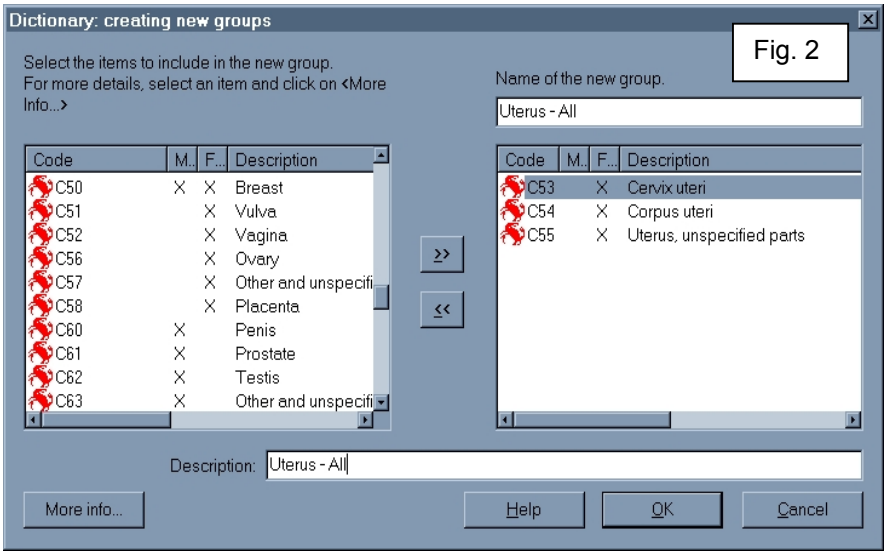
Working Dataset

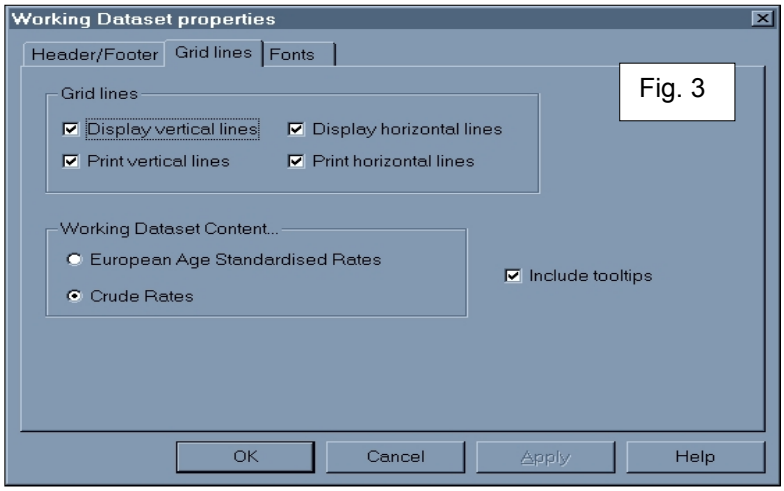
A Working Dataset is a user-defined subset of the database. It comprises selected populations served by specified cancer registries, for specified years, age/sex groups and cancers of interest. The user can create a new Working Dataset, or open an existing Working Dataset defined and saved in a previous session. It is also possible to modify a Working Dataset.

The Working Dataset, once defined, can be used for generating models for statistical analysis, and output can be generated in the form of reports and graphs.

Data in a Working Dataset is displayed in a grid in which the columns represent cancers by sex, and the rows represent populations/ periods for the age-range selected. The grid appearance can be configured by the user using the *Edit* menu. The grid displays either Crude or European Standardized Rates, depending on the user's specification (Fig. 3).





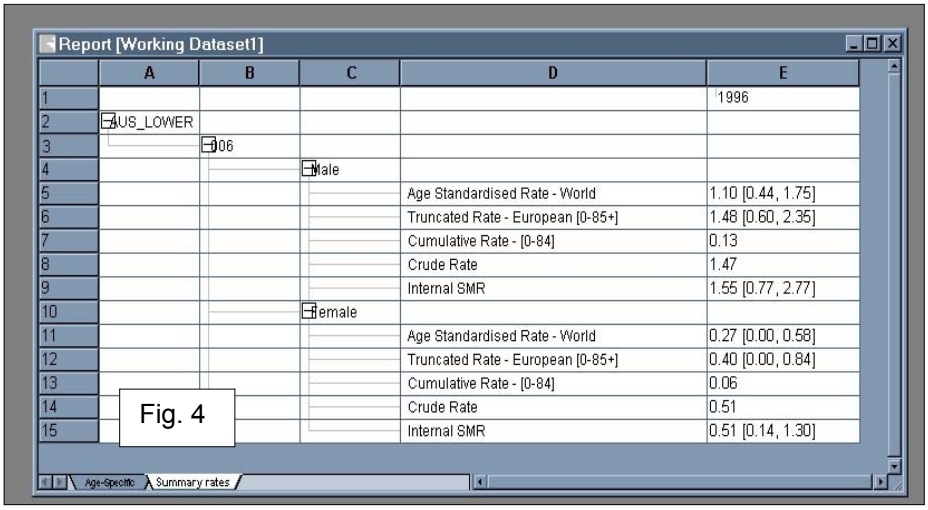


Report facilities

EUROCIM includes facilities for generating reports from data in the current Working Data-set. A Report Wizard is provided to facilitate this. Generated reports may include age-specific and summary rates, or information on a statistical model.

The following statistics can be included in reports:

- *Observed numerators*
- *Expected numerators*
- *Residual numerators*
- *Observed rates*
- *Expected rates*
- *Residual rates*
- *Denominators*
- *Age-specific parameters*
- *Age-standardized rates*
- *Age-truncated rates*
- *Cumulative rates*
- *Internal SMRs*
- *Maximum likelihood estimates*


Report [Working Dataset1]

	A	B	C	D	E
1					1996
2	AUS_LOWER				
3		006			
4			Male		
5				Age Standardised Rate - World	1.10 [0.44, 1.75]
6				Truncated Rate - European [0-85+]	1.48 [0.60, 2.35]
7				Cumulative Rate - [0-84]	0.13
8				Crude Rate	1.47
9				Internal SMR	1.55 [0.77, 2.77]
10			Female		
11				Age Standardised Rate - World	0.27 [0.00, 0.58]
12				Truncated Rate - European [0-85+]	0.40 [0.00, 0.84]
13				Cumulative Rate - [0-84]	0.06
14				Crude Rate	0.51
15				Internal SMR	0.51 [0.14, 1.30]

Age-Specific | Summary rates

Fig. 4

It should be noted that the following statistical functions require the creation of a log-linear model:

- *Expected numerators*
- *Residual numerators*
- *Expected rates*
- *Residual rates*
- *Age-specific parameters*
- *Maximum likelihood*

Figure 4 shows an example of output from a report.

Graph facilities

EUROCIM includes facilities for creating graphs from data in the current Working Dataset. It is possible to create graphs based on either age-specific or summary rates, as well as to display fitted values from the current model if generated. A *Graph Wizard* is provided to facilitate this. The statistics that can be displayed on the graphs are:

- *Observed numerators*
- *Expected numerators*
- *Observed rates*
- *Expected rates*

By default all curves defined in the Working Dataset are included in the graph. One can override this and select only the curves desired.

Age–period–cohort (time trends) module

It is possible to formally examine age, period and cohort trends in cancer rates over time using the command *APCView*, which fits age-period-cohort models to the selected population's incidence or mortality rates. A *Time Trends* working dataset by definition must include at least 15 years of incidence or mortality data from one population (with no years missing). In addition, only one cancer site and sex can be analysed at one time.

The active Working Dataset displays the selected data. To examine age, period and cohort effects click on 'APC View' from the 'Working Dataset' menu. There are now three windows which display information on the fit of each of the models; the parameters obtained; and to help with interpretation, a graphical display of the parameters.

Methodological aspects of the APC modelling

The analysis of the temporal variation of cancer incidence and mortality rates is one of the main concerns of descriptive epidemiology. While graphical displays of age-specific trend data are invaluable, they can be greatly enhanced by the use of statistical modelling by providing quantitative and comparable estimates of trend. These are based on objective criteria for choosing the best description of the data, and statistical tests to decide whether trends are real or random (Estève *et al*., 1994) and consequently subjective graphical interpretations are avoided. The age–period–cohort model (APC) (Clayton & Schifflers, 1987a, b; Holford, 1983; Mason & Fienberg, 1985) provides such a summary of trend data, allowing a formal statistical examination of whether temporal trends are due to secular changes in risk (period effects) or changes in risk from generation to generation (birth cohort effects) in different populations. EUROCIM Version 4 provides a means to describe such trends in Europe, using the APCView option.

Modelling age, period and cohort simultaneously is not a simple task. The fitting of such effects mean that the resulting models suffer from the problem of identifiability. For A age groups, if we denote a_i as the age effect in age group i, p_j the effect of jth period and c_k the birth cohort effect, then age, period and cohort effects are all linearly dependent on one another as $k=A–i–j$. Thus there are an infinite number of possible solutions to the

"full" APC model (the model containing age, period and cohort effects) because the separation of the linear effects of the three parameters is impossible.

There are several subsets of the full model for which the parameters are estimable. The adequate fit to the data of an age-period model suggests that secular trends may be of importance. An exposure to a sudden intervention which affects the risk of each age group equally would result in such a model – changes in disease coding over time (which affect all age groups) is one such example. In contrast, the age-cohort model will provide a good fit to the observed data if some intervention affects the age groups in different ways; such an effect is a special form of the age-period interaction. The multistage theory of carcinogenesis (Day & Brown, 1980) suggests that for some cancers (given their long latency period), changes in exposures related to the underlying risk should show up more clearly in birth cohorts (Cuzick, 1990).

Clayton and Schifflers (1987a) introduced the term "drift" to describe a model for which age-period and age-cohort parameters fit the data equally well. The model implies the same linear change in the logarithm of the rates over time in each age group and thus such a model serves as an estimate of the rate of change of the regular trend. It can be shown that period-drift and cohort-drift models lead to identical fitted rates. In assessing the best-fitting model, Clayton and Schifflers (1987a) recommend that the age-drift model should be fitted after the model of no temporal trend (the age model) in the hierarchical fitting process. This convention is used in APCView. The model-fitting process continues with the fitting of age–period and age–cohort models (which include drift). Such time trend analyses are however not so absolute as to allow one to attribute incidence or mortality to purely secular or generation effects. Any gradual linear effect can be attributed to either factor, given that only changes of a non-linear nature are identifiable—thus their interpretation should always be on the cautious side.

When neither age-drift, age-period or age-cohort terms give an adequate explanation of the data, the full APC model in which age, period and cohort effects are included, needs to be considered. As mentioned above however, the algebraic relationship between the effects is such that it is impossible to obtain a unique solution of their linear effects (there are an infinite number of them) without resorting to some (often arbitrary) constraint (Clayton & Schifflers, 1987b). The drift component defined above cannot be attributed to period or cohorts effects and thus the APC model is a mixture of age, drift, non-linear period and non-linear cohort effects. There has been a considerable body of work on how one can then proceed in view of this identifiability problem in the APC model.

The main differences in the methodologies are in the way they differentiate between linear and non-linear effects (Holford, 1992). In choosing a method for which to describe secular trends it seems appropriate to avoid imposing constraints without a biological basis for doing so. The "second differences" method of Clayton and Schifflers (1987b) has been shown to produce estimates on the conservative side, and is not particularly easy to interpret. Nevertheless, it is preferable to other methods, as it does not make further assumptions (McNally *et al*., 1997) or require an additional arbitrary mathematical constraint to overcome identifiability. In addition, the risk of over-interpretation of the resulting parameters (perhaps more serious than under-interpretation) is more likely to be avoided using this method. It is therefore this method which has been used in EUROCIM's *APCView* to provide a unique set of parameters representing the full APC model.

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Appendix 2

Structured reviews of cancer registries

This is a service of ENCR to cancer registries which wish to have their performance evaluated. A standard structured review process is applied. Positive and negative aspects of a registry's procedures and outputs are identified, taking account of available resources.

It is a fundamental principle that the review should be a constructive, non-threatening experience aimed at helping registries to improve their performance, in some cases by providing independent, objective evidence of a need for additional resources. In some instances, the review may be able to assist in removing legal or organizational obstacles to registration.

A request for a structured review will normally be made by the funding body or host institution, but could also come from the cancer registry itself. Requests should be made to the ENCR Secretariat. A review team (normally consisting of two external experts, plus one person from the ENCR Secretariat) is selected by the Steering Committee and the Secretariat. The questionnaire presented on the following pages is completed by the registry and is reviewed by the team, which subsequently spends about two days in the registry. A review report is prepared.

There is no charge for the review itself. However, the inviting body is expected to meet the travel and other expenses of the review team.

ENCR REGISTRY REVIEW QUESTIONNAIRE

Please try to answer each question comprehensively, if appropriate, making use of your responses to previous questionnaires (e.g. for Cancer Incidence in Five Continents). When asked to provide additional information which cannot be incorporated in this electronic questionnaire (e.g., a data flow diagram, charts of age-standardized incidence rates, etc.), it would be helpful if an electronic copy of the information could be provided.

SECTION 1 - GENERAL ISSUES

1.1 Describe the area covered by your registry, in terms of the population (administrative unit, size, proportion of national population covered and distribution by age, socio-economic status, ethnicity and urban-rural residence), and main industries/occupations. Please provide a map of your country, indicating the area covered by your registry.

1.2 Provide a brief description of your country's health care system, particularly as it relates to cancer services (including prevention and screening).

1.3 What year was your registry established? Describe any major changes in the operation of the registry since its establishment (give dates of any significant milestones, e.g., death records becoming routinely available).

1.4 What legislation applies to cancer registration in your country (e.g., is it a statutory function, data protection, etc.)?

1.5 How do you define the purpose of your registry?

1.6 What are the arrangements for funding your registry?

1.7 Please provide a breakdown of your registry staff in terms of numbers of individuals, numbers of whole-time equivalents and job titles/functions (if possible, in the format of an organisation chart). Please distinguish between permanent staff and staff on short-term contracts. *(Please attach separate sheet)*

1.8 Please summarize your registry's arrangements for training of new staff and continuous professional development of existing staff.

1.9 Please provide a copy of any internal data confidentiality, data protection, and data security guidelines which apply to your registry. *(Please attach)* If the registry uses e-mail and internet, please indicate how you deal with data protection in this context.

1.10 Please provide copies of your registry's guidelines and form(s) relating to release of data and/or linkage to other databases. *(Please attach)*

1.11 Please describe the arrangements in place for obtaining permission to carry out research projects, both for in-house projects and for external researchers (including arrangements for review by research ethics committees).

1.12 Please indicate what you feel to be the strengths and weaknesses of your registry (if any). If you have identified any weaknesses, how do you feel they could be addressed?

SECTION 2 - DATA COLLECTION, DATA PROCESSING AND DATA QUALITY

2.1 What method of data collection is used in your registry?

☐ Active ☐ Passive ☐ Automated **What is the frequency?** _____

2.2 Please indicate the data sources which you use routinely to *identify* registrations or potential registrations, e.g.:

hospital discharge records	☐	hospital medical records	☐
histopathology records	☐	hospice records	☐
cytopathology records	☐	private hospital records	☐
haematology records	☐	radiology records	☐
radiation oncology records	☐	primary care records	☐
medical oncology records	☐	other cancer registries	☐
death records	☐	other _____	☐
autopsy records	☐		

2.2 Please indicate which of these records are theoretically available routinely for every case in your catchment area, and which are only available sporadically or only provide partial coverage of your catchment area.

	Routinely	*Sporadically*		*Routinely*	*Sporadically*
hospital discharge records	☐	☐	hospital medical records	☐	☐
histopathology records	☐	☐	hospice records	☐	☐
cytopathology records	☐	☐	private hospital records	☐	☐
haematology records	☐	☐	radiology records	☐	☐
radiation oncology records	☐	☐	primary care records	☐	☐
medical oncology records	☐	☐	other cancer registries	☐	☐
death records	☐	☐	other _____	☐	☐
autopsy records	☐	☐			

2.3 Please indicate which of your available data sources are in electronic form and which are paper-based.

	Electronic	*Paper*		*Electronic*	*Paper*
hospital discharge records	☐	☐			
histopathology records	☐	☐	hospital medical records	☐	☐
cytopathology records	☐	☐	hospice records	☐	☐
haematology records	☐	☐	private hospital records	☐	☐
radiation oncology records	☐	☐	radiology records	☐	☐
medical oncology records	☐	☐	primary care records	☐	☐
death records	☐	☐	other cancer registries	☐	☐
autopsy records	☐	☐	other _____	☐	☐

2.4 Are there any major data sources which are not available to you for practical reasons or because of restrictive legislation?

2.5 Please describe the way you collaborate with the different centres identifying the cancer patients. Do you monitor the notification routine (by region/district/hospital/pathology laboratory)?

2.6 Please describe your registration method (eg, entirely automated, entirely manual, mixed) and provide a data flow diagram which incorporates your available data sources, and summarises the registry processes. *(Please attach data flow diagram)*

2.7 Do you ever make registrations based on one source only (excluding DCOs)?

2.8 Please list any records which you use to *verify* potential registrations identified by other sources. Approximately what proportion of registrations are verified using these records?

2.9 Do you routinely monitor indicators of data quality (e.g., %MV, %DCO) in your registry and by region/district?

2.10 Describe briefly the validation checks in place in your registry (e.g., the IARC Check program)

2.11 How are records relating to a single individual linked to each other?

2.12 How do you record multiple tumours and how do you link them?

2.13 How is conflicting information from one or more sources reconciled?

2.14 What procedures are in place to minimize the risk of duplicate registration? How often is the registry database checked for duplicate registrations and how is this achieved?

2.15 Which classification(s) do you use for coding diagnosis (eg, ICD-O, ICD-10, etc.)? If classification has changed during the existence of the registry, please indicate which classification was used for which period.

2.16 Who is/are responsible for coding of the diagnosis of registered cases?

2.17 Do you follow up registered patients for vital status?

2.18 How does your registry define the incidence date?

2.19 When is a patient considered alive, dead or lost to follow-up?

2.20 Describe the data sources and procedures used to follow up patients for vital status. How often is this being done?

2.21 What is the most recent 'closing date' (i.e. the last date on which the vital status was confirmed for all patients)?

2.22 Can your registry identify patients who have subsequently emigrated, and their dates of emigration?

2.23 If you receive information about a person who is resident in the catchment area of another cancer registry, do you regularly pass this on? If so, how often and when was the last time you did so?

2.24 Do you receive information on patients resident in your registration area but diagnosed or treated elsewhere? Please give details on how you deal with this.

2.25 Please provide a brief description of your registry computer system indicating the operating system, database, network and application software.

2.26 Who supplied the computer application?

2.27 Is the computer application documented?

2.28 Who maintains the computer hardware and software?

2.29 How often are the contents of the registries' databases backed-up to external media?

2.30 Is the back-up medium stored/archived off-site and if so, how often?

2.31 If applicable, what does your registry use e-mail and the internet for. If you have a webpage please provide the address.

2.32 Please supply a copy of your registry's data definitions and any additional registration guidelines for staff. ***(Please attach documents)***

2.33 Does your registry collect staging information for any tumours? ☐ yes ☐ no

If so, please indicate:

Tumours for which you collect staging information	Year you started collecting this information	Staging classification used	% recorded as unknown stage in most recent available year of data

2.34 Please provide the following information for the following selected cancers:

Oesophagus (ICD9 150; ICD10 C15)
Stomach (ICD9 151; ICD10 C16)
Colon and rectum (ICD9 153 + 154; ICD10 C18 – C21)
Liver (ICD9 155; ICD10 C22)
Pancreas (ICD9 157; ICD10 C25)
Trachea, bronchus and lung (ICD9 162; ICD10 C33 + C34)
Bone (ICD9 170; ICD10 C40 + C41)
Malignant melanoma of skin (ICD9 172; ICD10 C43)
Female breast (ICD9 174; ICD10 C50 + sex = female)
Brain (ICD9 191; ICD10 C71)

(a) Percentage of death certificate only (DCO) records (as defined in *Comparability and Quality Control in Cancer Registration* (Parkin *et al.*, 1994)). By age group and crude total. *(Please attach table)*

(b) Percentage of microscopically verified (MV) records (as defined in *Comparability and Quality Control in Cancer Registration* (Parkin *et al.*, 1994)). By age group and crude total. *(Please attach table)*

(c) Mortality/incidence (M/I) ratios (as defined in *Comparability and Quality Control in Cancer Registration* (Parkin *et al.*, 1994)).

Oesophagus	_____
Stomach	_____
Colon and rectum	_____
Liver	_____
Pancreas	_____
Trachea, bronchus and lung	_____
Bone	_____
Malignant melanoma of skin	_____
Female breast	_____
Brain	_____

(d) Charts showing annual age-standardized incidence and mortality rates separately for males and females for the longest time period available (including the most recent year for which incidence data are believed to be essentially complete). Please specify the standard population used (World or European). *(Please attach charts)*

(e) Tables showing relative survival (%) at five years, by sex for consecutive five-year periods of diagnosis covering the longest time period available. *(Please attach tables)*

2.35 Has your registry (or anyone else) undertaken any recent detailed assessments of completeness of case ascertainment (e.g., using the independent comparison method, capture-recapture, etc.)? If so, please provide details of the methods used and a summary of the results. ***(Please attach summary of results)***

2.36 Has your registry (or anyone else) undertaken any recent detailed assessments of data validity either by using the reabstraction method or through validation of registry data in the course of a research or clinical review project? If so, please provide details and a summary of the results. ***(Please attach summary of results)***

SECTION 3 - USE OF DATA AND OUTPUT

3.1 Is any effort made to inform patients and the public of the existence of the cancer registry and the uses of the data? If so, how is this achieved?

3.2 What arrangements do you have for feeding back information to clinicians (both regionally and nationally)?

3.3 Please provide a list of groups you regard as having regular contact with your registry (eg, state and local health authorities, clinicians, researchers, charities and the voluntary sector, politicians, the media, patient organizations, the lay public, etc.). Approximately how often do you have contact with each of these?

3.4 Please provide a list of all peer-reviewed publications by your registry or involving members of its staff in the last two years. ***(Please attach)***

3.5 Please provide a list of all registry publications (e.g. annual reports) in the last two years, including electronic publications. Please indicate the intended audience for each type of publication. ***(Please attach)***

3.6 Do you have any evidence that your registry publications are used (e.g., from unsolicited feedback, questionnaire surveys, citation in other publications, etc)? If so, please give details.

3.7 How many *ad hoc* requests for information did your registry receive in the most recent complete calendar year?

3.8 Do you have a systematic research programme or plan for registry output and, if so, how far into the future does it extend?

3.9 Please provide a summary of your registry's current research portfolio. For each project, please indicate the sources of funding and the collaborators, if any (name and institute). *(Please attach)*

3.10 Does your registry undertake survival analysis?

3.11 In which international studies/databases have you participated? If you decided not to participate in a project, please give the reasons for this.

Name	Period(s)
CI5	
IICC	
EPIC	
EUROCIM	
EUROCARE	
EUROCLUS	
ACCIS	
Other	

Appendix 3

ACCIS – Automated Childhood Cancer Information System

Rationale

In the European Union about 1% of all cancers occur in children under 15 years of age, corresponding to an estimated 11,000 new cases per year. This number may seem insignificant in comparison with the total of 1.6 million new cancer cases of all ages (Ferlay *et al*., 1999). However, cancer is the second cause of death (after injuries) in children between 1 and 14 years of age, despite the considerable success achieved in its treatment over the last 30 years (Draper *et al*., 1982; Capocaccia *et al*., 2001). Even though almost 75% of childhood cancer patients survive five years after diagnosis, many of these survivors bear consequences in terms of physical, mental or reproductive impairment throughout their life.

Preventive measures are non-existent, largely because of uncertainty about the causes of cancer in childhood. The short exposure period suggests that genetic factors play a role, although the proportion of childhood tumours due to known genetic abnormalities is estimated to be less than 5% Narod *et al*., 1991).

An important obstacle to study of the etiology of tumours in children is their rarity and the diverse spectrum of morphological tumour types. While over 80% of malignancies in adults are carcinomas, in childhood these represent less than 10%. Common childhood tumour types are sarcomas (45%), leukaemias (30%) and lymphomas (15%) (Miller & Myers, 1983; Parkin *et al*., 1997). Presumably, the different morphology is a reflection of different histogenesis and probably also its etiology and cause. To address the importance of a separate study of clearly defined tumour groups, a specific International Classification of Childhood Cancer (ICCC) is used (Kramárová & Stiller, 1996).

Large geographical areas or long time periods are needed to permit the collection of enough cases for a study to have sufficient power to give answers to specific hypotheses of causality. Sources of standardized data on childhood cancer incidence are the two volumes of *International Incidence of Childhood Cancer* (IICC) produced by IARC (Parkin *et al*., 1988, 1998). Survival of children with cancer was uniformly analysed within the EUROCARE study and published as a special issue of the *European Journal of Cancer* (Capocaccia *et al*., 2001) for a large number of tumour groups.

The aim of the ACCIS project is to collect, standardize, interpret and disseminate data on indicators of cancer burden in the childhood population of Europe. These objectives are being achieved by:

1. Construction of the ACCIS database containing information on incidence and survival of childhood cancer patients in Europe.

2. Development of the ACCISpass software designed for storage, analysis, presentation, interpretation and dissemination of the collected data.

3. Setting up an Internet site for wide distribution of information on the ACCIS project and the collected data.

4. Evaluation and interpretation of results of data analyses.

With some 160,000 cancer cases registered in Europe over the last 30 years and the population at risk of around 2.6 billion person-years, the ACCIS database is the largest database of young cancer patients in the world. ACCISpass accommodates the ACCIS database and permits analysis of groups of patients selected with great flexibility. Continuous updating and exploration of the database will ensure that ACCIS becomes the reference source of data and expertise on childhood cancer, not only in Europe, but worldwide.

The ACCIS database

Eighty population-based cancer registries in 30 countries of Europe have provided data for the construction of the ACCIS database, which includes all cases of cancer incident before the age of 20 years. Traditionally, the specialized paediatric cancer registries

provided cancer data only for patients younger than 15 years of age at diagnosis.

Every registry provided a list of individual records of cancer cases with a standard set of variables. The data were validated to limit coding errors, to allow standard interpretation of the results obtained and to evaluate the overall comparability of the data-sets (Parkin *et al*., 1994). Questions concerning the data were resolved in collaboration with the participating registries. At IARC, all records were classified into ICCC (Kramárová & Stiller, 1996) categories using the Child-Check program (Kramárová *et al*., 1996). Length of survival time was calculated for each case where the follow-up information was available: date of death for the deceased patients or date of last contact for patients who were still alive.

The population data file ideally contained the number of residents in the registration area in each calendar year of the reported period, by sex and single year of age. For registries that were not able to provide population data in the required detail, the missing data were estimated at IARC.

All participants also completed a questionnaire, which provided the coordinating centre with information on the registry and its registration and coding practices.

The ACCIS Scientific Committee examined and commented on each dataset. Any issues possibly influencing the interpretation of the results are documented within the ACCIS database. With the exception of a few submitted data-sets (missing mandatory variables or clearly incomplete coverage), virtually all were included in the ACCIS database. The latter is destined for dissemination to the contributing registries within ACCISpass. The majority of the data-sets were also considered sufficiently comparable for display to the general public on the Internet site. Regional registries with a relatively small number of cases are not presented on the Internet in detail, although they contribute to the national estimates. This cautious approach was adopted in order to avoid misinterpretation by a lay user of naturally large variations of statistics based on small numbers.

ACCISpass

ACCISpass is the software designed to accommodate the ACCIS database and present the collected data. ACCISpass was developed jointly by IARC and Lambda^{+}, the company involved in the development of the EUROCIM software (European Network of Cancer Registries, 2001). It was therefore possible to adapt the modules developed within EUROCIM for incorporation into ACCISpass.

The most important asset of ACCISpass is the usage of the database of individual records for data analysis and presentation. This novelty in comparison with EUROCIM allows maximum flexibility in the creation of groups of cases. This potential is fully exploitable (within the confidentiality restrictions) starting with ACCISpass version 2.00.

Another important feature is a distinction between two types of data-set, according to the age-range of the cases. Paediatric data-sets cover the age-range 0–14, while the general cancer registries include all cancer cases aged 0–19.

A further useful function of ACCISpass is the availability of observed survival proportions for the datasets with complete follow-up.

ACCISpass provides fast access to a comprehensive overview of the childhood cancer indicators for data-sets defined by the combination of a registry and a period, using the options “standard incidence tables” and “standard survival tables”.

Finally, the results of the review of the datasets have become part of the software as “commentaries”. The aim of these comments is to provide guidance to the user in interpretation of the results, especially because virtually no quality-based selection was made among the submitted data-sets for their inclusion in the ACCIS database.

ACCISpass is destined for free distribution to all the contributors to the ACCIS database.

Internet site

An Internet site was developed to present the ACCIS project, display the conditions for contribution, give information about participants in the study, link to resources of data on (childhood) cancer and, most importantly, disseminate data on childhood cancer incidence and survival, together with help in the interpretation of the results. The user is able to consult incidence rates and survival proportions of childhood cancer cases in those registries whose data-sets were chosen for display on the Internet, by the ICCC diagnostic group and five-year age group. The tables are displayed in PDF format. The web

page can be explored at the address http://www-dep.iarc.fr/accis.htm.

Data protection

Since the ACCIS database contains individual cancer records, precautions have been taken against possible misuse of the data. The level of detail for data dissemination is defined by the ACCIS Scientific Committee, which in turn respected the wishes of the individual contributors.

On the Internet, only aggregated data are displayed.

The ACCIS database, disseminated with ACCISpass, is encoded and readable only within the software. The coded database contains no names and the dates of birth, diagnosis and death are in general trimmed to the format MMYYYY, unless more strict conditions apply for a particular data-set.

In addition, the ACCIS software that allows detailed exploration of the ACCIS database is being distributed only to the registries whose data-sets form part of this database.

The future of the ACCIS project

The ACCIS database was established with a view to continuous updating. In parallel with the database, all other aspects of the project evolve to make full use of this precious data source. Envisaged directions of growth include:

1. Analysis, interpretation and dissemination of the accumulated information through scientific publications.

2. Further development of the ACCISpass software, notably the inclusion of a period-survival method and calculation of the years of life lost.

3. Further development of the Internet site.

4. Implementation of automatic procedures for data validation, to speed up the process of updating of the ACCIS database.

5. Enlargement of the ACCIS database by incorporating more recent data-sets from the current participants and inviting new participants possibly also from outside Europe to strengthen the power of future studies.

Provision of up-to-date information on childhood cancer incidence and survival will have an impact on public health policy, both directly and indirectly. The explanation of the registration techniques permits the data users to become familiar with the significance and limitations of the observed results. This will clearly demonstrate the value of data collection and hopefully relieve anxiety about data abuse and breaching of confidentiality laws.

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ACCIS participants

The existence of this project depends upon the collaboration of the European population-based cancer registries, the members of European Network of Cancer Registries (Table 1).

All aspects of the development of the ACCIS project are directed by the ACCIS Scientific Committee, an international group of scientists with relevant experience. They advise on methodology of analysis, and on data protection and dissemination, and evaluate the submitted data-sets.

The members of the ACCIS Scientific Committee are:

Franco Berrino	Director, Epidemiology Unit, National Cancer Institute, Milan, Italy
Jan Willem Coebergh	Research Director of Eindhoven Cancer Registry, Consulting Epidemiologist to the Dutch Childhood Leukaemia Study Group, Eindhven, The Netherlands
Peter Kaatsch	Director, German Childhood Cancer Registry, University of Johannes Gutenberg, Mainz, Germany (since 2002)
Brigitte Lacour	Coordinator of the French National Registry of Childhood Solid Tumours, Children's Hospital, Vandoeuvre, France (since 2002)
Joerg Michaelis	Director, Institute of Medical Statistics and Documentation, German Childhood Cancer Registry, University of Johannes Gutenberg, Mainz, Germany (until 2001)
Max Parkin	Chief, Unit of Descriptive Epidemiology, International Agency for Research on Cancer, Lyon, France
Charles Stiller	Research Officer, Childhood Cancer Research Group, Department of Paediatrics, University of Oxford, Oxford, United Kingdom

The ACCIS project is coordinated within the Unit of Descriptive Epidemiology at the International Agency for Research on Cancer:

Eva Šteliarová-Foucher	Scientific coordinator of the ACCIS project
Sue Dunderdale	Secretary
Nicolas Mitton	Database manager
Trinidad Valdivieso	Webmaster

ACCISpass is developed by the Lambda^{+} company, Gembloux, Belgium.

The ACCIS project is sponsored by the Europe Against Cancer Programme of the European Commission.

Table 1. List of the population-based cancer registries contributing data to the ACCIS database

Country	Registry	Country	Registry
AUSTRIA	National Cancer Registry	ITALY	Veneto Cancer Registry
BELARUS	National Childhood Cancer Subregistry	LATVIA	National Cancer Registry
BELGIUM	National Cancer Registry	LITHUANIA	National Cancer Registry
BULGARIA	National Cancer Registry	MALTA	National Cancer Registry
CROATIA	National Cancer Registry	NETHERLANDS	National Cancer registry
CZECH REPUBLIC	National Cancer Registry	NETHERLANDS	Eindhoven Cancer Registry of CCC South (IKZ)
DENMARK	National Cancer Registry	NETHERLANDS	Dutch Childhood Leukaemia Study Group (DCLSG)
ESTONIA	National Cancer Registry	NORWAY	National Cancer Registry
FINLAND	National Cancer Registry	POLAND	Cracow City and District Cancer Registry
FRANCE	Childhood Cancer Registry of Brittany	POLAND	Regional Cancer Registry of Kielce
FRANCE	Childhood Cancer Registry of Lorraine	PORTUGAL	Coimbra Oncology Centre (Central Zone)
FRANCE	Cancer Registry of Provence, Alps, Côte d'Azur and Corsica	PORTUGAL	Cancer Registry of Northern Region (Porto)
FRANCE	Children's Cancer Registries of the Rhône Alps Region	PORTUGAL	Cancer Registry of Southern Region (Lisbon)
FRANCE	Cancer Registry of Calvados	ROMANIA	Cancer Registry of Bihor County
FRANCE	Doubs Cancer Registry	SLOVAKIA	National Cancer Registry
FRANCE	Hérault Cancer Registry	SLOVENIA	National Cancer Registry
FRANCE	Isère Cancer Registry	SPAIN	National Childhood Cancer Registry (RNTI-SEOP)
FRANCE	Cancer Registry of La Manche	SPAIN	Albacete Cancer Registry
FRANCE	Bas-Rhin Cancer registry	SPAIN	Asturias Cancer registry
FRANCE	Haut-Rhin Cancer Registry	SPAIN	Cancer Registry of the Basque Country
FRANCE	Somme Cancer Registry	SPAIN	Cancer Registry of the Canary Islands
FRANCE	Tarn Cancer Registry	SPAIN	Girona Cancer Registry
GERMANY	National Registry of Childhood Malignancies	SPAIN	Granada Cancer Registry
GERMANY	National Cancer Registry of the former GDR	SPAIN	Mallorca Cancer Registry
HUNGARY	National Paediatric Cancer Registry	SPAIN	Navarra Cancer Registry
ICELAND	National Cancer Registry	SPAIN	Tarragona Cancer Registry
IRELAND	National Cancer Registry	SPAIN	Cancer Registry of Zaragoza
ITALY	Childhood Cancer Registry of Piedmont	SWEDEN	National Cancer Registry
ITALY	Childhood Cancer Registry of the Marche Region	SWITZERLAND	Basel Cancer Registry
ITALY	Ferrara Cancer Registry	SWITZERLAND	Geneva Cancer Registry
ITALY	Cancer Registry of the Latina Province	SWITZERLAND	Cancer Registry of Graubünden and Glarus
ITALY	Ligurian Cancer Registry	SWITZERLAND	Cancer Registry of St. Gallen-Appenzell
ITALY	Lombardy Cancer Registry	SWITZERLAND	Cancer Registry of Valais
ITALY	Parma Province Cancer Registry	TURKEY	Izmir Cancer Registry
ITALY	Piedmont General Cancer Registry	UNITED KINGDOM	Childhood Cancer Registry of England and Wales
ITALY	Ragusa Cancer Registry	UNITED KINGDOM	Cancer Registry of Northern Ireland
ITALY	Sassari Cancer Registry	UNITED KINGDOM	Cancer Registry of Scotland
ITALY	Tuscany Cancer Registry	YUGOSLAVIA	Cancer Registry of Central Serbia
ITALY	Cancer Registry of Umbria	YUGOSLAVIA	Cancer Registry of Vojvodina

Appendix 4

Automation in cancer registration

Background

Algorithms aimed at replacing the manual decision-making process, usually carried out by registry personnel on *ad hoc* registry forms, were first introduced in the early 1970s by the Ontario Cancer Registry (OCR). The forms containing the information on cancer patients were coded and computerized at the OCR and subsequently treated by software developed by the OCR for this purpose. All the diagnoses of cancer were assigned by the program using the data available electronically (Clarke *et al*., 1991).

In the early 1990s, the project of the Venetian Tumour Registry (RTV) explored for the first time the possibility of using, as primary sources of data for the registration process, electronic routine data from the hospitals, pathology departments, and other health institutions in the north-east region of Italy.

The data were coded according to ICD-9 (hospital discharges and death certificates) or SNOMED (pathology records). By applying a rather simple algorithm (Table 1) to the electronic data, it was possible to assign a diagnosis to the majority of the incident cases (Simonato *et al*., 1996).

The methodology was subsequently adopted by the Northern Ireland Cancer Registry (NICR), and partially by the Thames Cancer Registry, with similar results. More recently, a network of registries in the north-east of Italy, the North-East of Italy Cancer Surveillance Network (NEICSN) adopted and further developed the registration system.

Basically the method consists of a binary decisional system of concordance/ discordance, through which a potential incident case is accepted with a consolidated diagnosis of cancer, or rejected. Cases rejected by the program are resolved manually by the registry personnel. Figure 1 illustrates the standard data flow, while an example of its application by NEICSN is shown in Figure 2.

The example reported in Figure 2 shows how incidence was obtained by NEICSN for the period 1999–2000. All the electronic data available from the three sources, consisting of 4,401,914 hospital discharges, 197,859 death certificates and 2,516,832 pathology records are used in the process, in which the first phase consists of record linkage with the various sources, in order to eliminate cancer cases with diagnosis before 1 January 1999.

Of these, 1,103,147 (15.4%) records with a diagnosis of neoplasia are selected and *summarized* into 305,369 subjects with at least one record of cancer (average number of records per subject 3.6). Out of these, 246,655 (80.8%) were prevalent cases, and 8,869 (2.9%) turned out to be non-residents at the moment of diagnosis. This leaves 49,845 subjects potentially affected by at least one incident cancer.

In the following step, the cases are *consolidated* by the program, and 39,148 cases are entered in the registry database. These constitute 78.5% of all cancer cases. The remaining 10,697 cases are revised and 21.5% of the total are entered by the registry personnel.

A large and increasing number of cases accepted belong to the categories of benign tumours, *in situ* tumours, and tumours of uncertain nature. This would allow follow-up studies of non-malignant tumours.

Table 1. NEICSN criteria for case consolidation

No.	*The criteria according to which the SITE program operates*
1.	Cancer cases with full concordance between two or more sources
2.	Histologically confirmed cases with at least one concordant or compatible (e.g. metastases or ill-defined) hospital discharge or death certificate
3.	Histologically confirmed skin cancer (ICD 173) unless in combination with skin melanoma (ICD 172)
4.	Histologically confirmed benign, *in situ*, and uncertain behaviour tumours

Applicability of automated cancer registration (ACR) techniques

The ACR methodology can be used only if the three traditional sources of information for a registry (hospital discharges, death certificates, pathology records) are available in an electronic form and are coded according to the ICD classification. Pathology records, often coded according to SNOMED, are transformed into ICD through a conversion table.

If a registry is just starting operation, it is recommended to wait for a number of years before starting to calculate incidence, in order to avoid the inclusion of prevalent cases in the incidence figure. This problem does not apply to existing registries, which will identify prevalent cases by record-linkage with their historical database.

The completeness and the quality of the original electronic data are crucial in determining the efficiency of the automated process. This needs to be carefully checked before embarking on ACR processing of the data. Low quality of the information sources will increase the proportion of discordant diagnoses, resulting in a lower efficiency of the system, while it is less likely to produce false positives as independent sources have a very low probability of making concordant ICD errors.

Summarization

This is the process by which the electronic records containing health information are linked to the individuals in the population file by using an ID code. Once the quality of the original data is ascertained, electronic and coded records undergo a process of record linkage with the population file resulting in a number of individuals for whom one or more cancer diagnoses have been *summarized* by computer.

These cancer histories are then ordered chronologically, which allows the computer-based exclusion of prevalent cases. The remaining individuals are the patients potentially affected by an incident neoplastic disease, who have one or more records with a coded diagnosis of cancer.

Consolidation

This is the process by which software based on the algorithm adopted evaluates the consistency of the coded diagnosis of cancer within the same subject, according to a number of established criteria.

There is no standard at present, and one of the goals of the ENCR Working Group on Automated Cancer Registration is to agree on the number and nature of these criteria. Those currently used in the algorithm by the NEICSN are presented in Table 1. Further development is in progress, but the results do not differ greatly between the few existing automated registries.

The proportion of accepted cases ranges from 50% to 75%, the variability being attributable more to the characteristics of the information sources than to the performance of the algorithm.

Certain groups of cases are systematically rejected by the present algorithm and are therefore manually checked by the registry personnel. These represent the largest proportion of rejected cases and comprise multiple tumours (non-melanotic skin cancer excluded), cases based on hospital records only, and cases based on death certificate only.

The system also systematically registers non-malignant tumours (benign, *in situ*, uncertain) which could be of interest for prospective studies of individuals at higher risk.

Developments

Management of large databases requires a sophisticated and efficient record linkage system, which implies a variable degree of computer-assisted decision making.

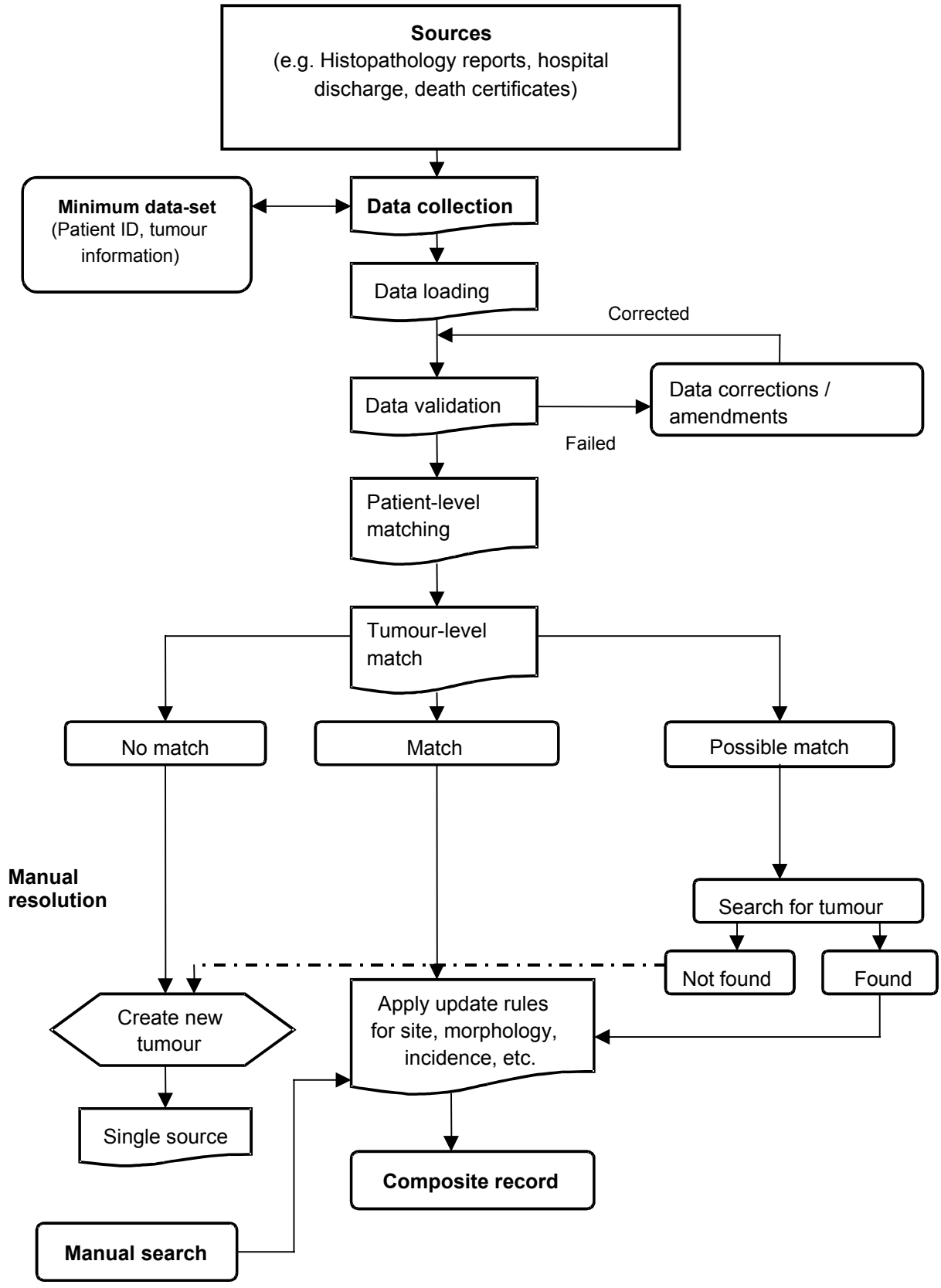
The increasing availability of coded pathology, hospital and death certificate records offers the possibility, not previously available, of directly using coded information for case resolution.

This development is promising, but may introduce additional problems regarding certain aspects of cancer registration which have already been under scrutiny, such as quality of diagnosis, and, even more important, comparability of cancer incidence data across cancer registries. The results so far available do not indicate major new problems of quality from registries which use the ACR methodology. The evidence is, however, at present based on the experience of very few registries and needs further evaluation. Very important is the issue of comparability, both between registries and within the same registration system, when moving from a manual system to ACR.

The availability of computerized data of different quality might lead to considerable differences between cancer registries, particu-

larly when different algorithms for case consolidation are used. This will be a crucial issue in the development of ACR, and highlights the need for standardization of the data source definitions, and of the computer-assisted case consolidation processes, an additional task for international organizations such as ENCR and IACR.

Figure 1. Process of automated cancer registration



The field of automated processes applied to medical data is evolving, mainly due to the increasing computerization of information in the hospital. Of particular importance is the extension to laboratory and imaging departments, and the increasing availability of electronic data on drug consumption.

This implies that in the very near future, an increasing amounts of different types of computerized information will be available for entry into the automated process, with the target of building up population-based surveillance systems which can be extended also to diseases other than cancer.

In view of such developments in registration of cancer, as well as of other diseases, cancer registries need to plan extension of their activities beyond the production of cancer incidence statistics: to establishing tools, within public health systems, for cancer surveillance, planning intervention studies and their evaluation, and carrying out etiological investigations taking advantage of the easy access to population-based information.

ACR techniques can make a valuable contribution to the development of this new situation by improving the timeliness and completeness, and by reducing the costs, provided that, in parallel, strict and efficient quality control is systematically performed.

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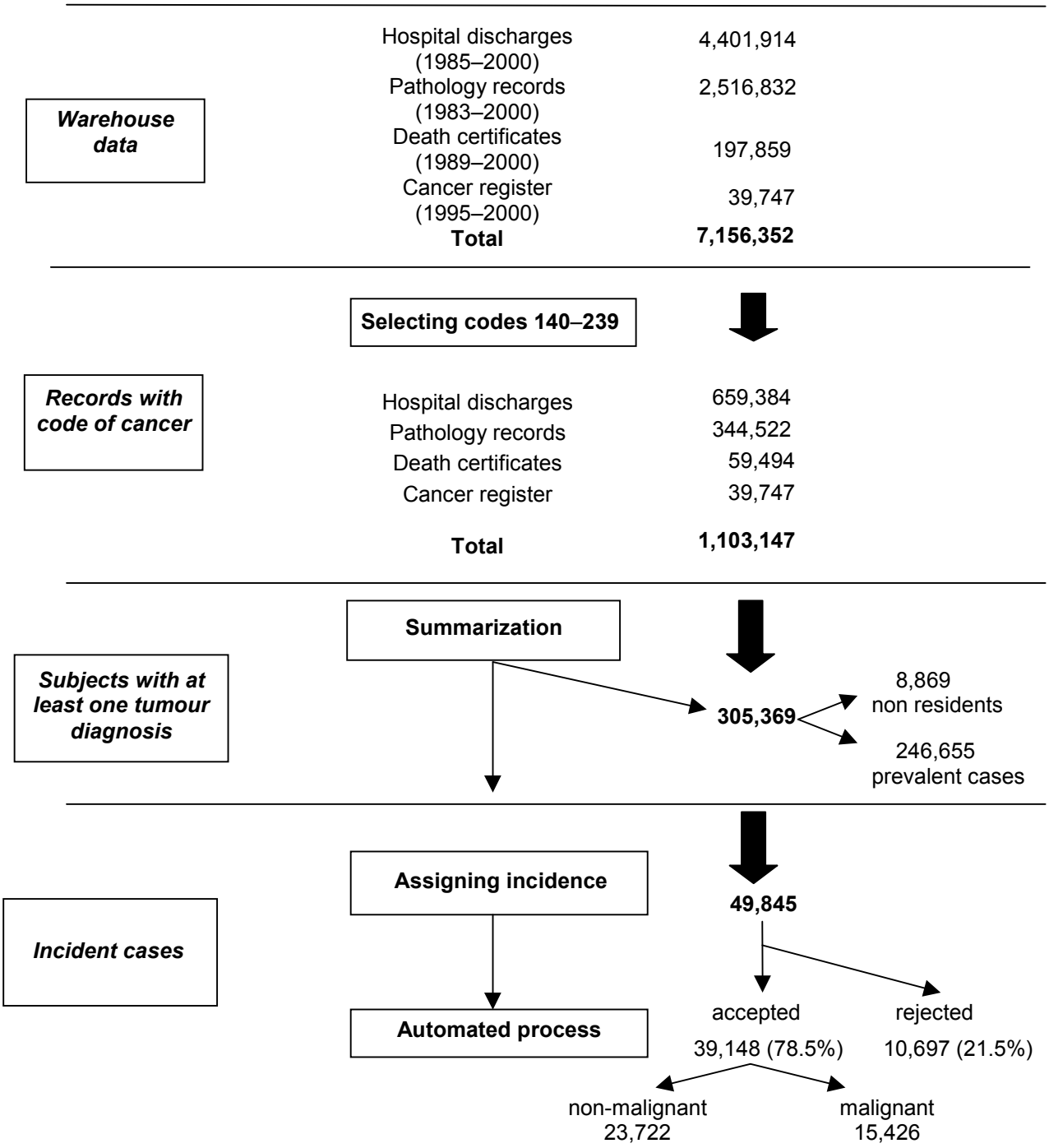
Figure 2. Generation of incidence data by the North-East of Italy Cancer Surveillance Network (NEICSN) 1999–2000



Appendix 5

List of selected ENCR publications

Lung cancer in Europe in 2000: epidemiology, prevention, and early detection
By J.E. Tyczynski, F. Bray and D.M. Parkin, *Lancet Oncology*, 2003, **4**, 45–55

Standards and Guidelines for Cancer Registration in Europe
Editors: J.E. Tyczynski, E. Démaret and D.M. Parkin (IARC Technical Publication No. 40) (2003), Lyon, IARCPress

Cancer in Portugal
By P.S. Pinheiro, J.E. Tyczyński, F. Bray, J. Amado, E. Limbert, E. Matos and A.C. Miranda (IARC Technical Publication No. 38) (2003), Lyon, IARCPress

Evaluation of Clinical Care by Cancer Registries
Editors: R. Sankila, R. Black, J.W. Coebergh, E. Démaret, D. Forman, G. Gatta and D.M. Parkin (IARC Technical Publication No. 37) (2003), Lyon, IARCPress

Estimates of cancer incidence and mortality in Europe in 1995
By F. Bray, R. Sankila, J. Ferlay and D.M. Parkin, *European Journal of Cancer,* 2002, **38**, 99–166

Evaluation and monitoring of screening programmes
Editors: R. Sankila, E. Démaret, M. Hakama, E. Lynge, L.J. Schouten and D.M. Parkin.
Authors: A. Anttila, J.W. Coebergh, J. van Dijck, J. Faivre, M. Hakama, T. Hakulinen, E. Läärä, E. Lynge, S. Moss, D.M. Parkin, R. Sankila, L.J. Schouten, J. Smith, R.A. Stephenson, D. Stockton, L. Tryggvadóttir, S. Wait, M. Zappa (2001), Brussels-Luxembourg, European Commission

EUROCIM version 4.0
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