# Chapter 3. Classification and coding 

S.L. Whelan

## Classification used to present date on incidence

The Cancer Incidence in Five Continents series has followed the evolution of the International Classification of Diseases (ICD) through four revisions and the creation of a coding scheme for oncology, the International Classification of Diseases for Oncology (ICD-O), now in its third edition. Volumes I and II (Doll et al., 1966; 1970) presented data on cancer incidence coded to the 7 th Revision (ICD-7; WHO, 1957). Volume III (Waterhouse et al., 1976) published data using both the 7th and the 8th (ICD-8; WHO, 1967) revisions. ICD-8, which came into effect in 1968, was used in Volume IV (Waterhouse et al., 1982), presenting data for the years 1973-77. The 9th revision of the ICD (ICD-9; WHO, 1977) was used for Volumes V (Muir et al., 1987), VI (Parkin et al., 1992) and VII (Parkin et al., 1997). The data in the present volume are presented according to ICD-10 (WHO, 1992).

The data are published at the level of the three-character ICD10 codes in the individual registry tables and, as in previous volumes, some grouping of ICD codes has been used. Malignant neoplasms of gum, floor of mouth and other and unspecified parts of mouth have been put together (ICD-10 C03-C06). Follicular (nodular) non-Hodgkin lymphoma, diffuse non-Hodgkin lymphoma, peripheral and cutaneous T-cell lymphomas and other and unspecified types of non-Hodgkin lymphoma have been combined as non-Hodgkin lymphoma. Other categories have been combined to correspond to a single three-digit rubric in ICD-9, for example base of tongue + other and unspecified parts of tongue (ICD-10 C01-C02), rectosigmoid junction and rectum (C19-C20). Table 3.1 presents the ICD-10 individual site codes, the full ICD-10 titles, the Volume VIII groupings and the short titles used in the tables of incidence. Note that two sets of data, Algiers (Algeria) and Hong Kong, are presented according to ICD-9 in this volume because the original data were coded to the ICD-9 three-digit level, and it was not possible to convert them to ICD-10. For the ICD-9 classification and groupings, see Volume VII of this series.

## Classifications used in the cancer registry

Since the publication, in 1976, of the first edition of the ICD-O (WHO, 1976) with clearly defined axes of anatomical location, histology and behaviour, international conformity to standard classification systems and coding rules has increased steadily. For data published in Volume IV (1973-77), $90 \%$ of registries recorded histological diagnosis; for coding just over one-third of the registries used MOTNAC (ACS, 1951, 1968), one-third had started to use ICD-O and $12 \%$ used SNOP (CAP, 1965). $75 \%$ of contributors to Volume V used ICD-O to code histology, and this figure rose to over $90 \%$ for Volumes VI and VII. Only six of the 186 contributors to the present volume did not code their histological data to ICD-O.

Data submitted for the first four volumes of Cancer Incidence in Five Continents were sent in tabular format, by sex, site and fiveyear age-group, on tape, diskette or, most frequently, the forms designed for the purpose. The only verification possible was to tally the columns and rows. For the fifth volume, registries were given the opportunity of sending data in the form of a case-listing coded
to ICD-9 topography only, or to ICD-9 or ICD-O topography plus ICD-O morphology. A very small minority of registries sent data coded to ICD-O. Contributors to Volume VI were encouraged to send data as a listing of cases, but $24 \%$ sent tabulated data. For Volumes VII and VIII, data had to be sent as a case listing. This made it easier to judge what was being included within the different codes, as well as to decide whether or not to include certain benign, uncertain or in situ diagnoses in the tables. In practice, it was still necessary to ask registries some questions, notably in relation to non-melanoma skin, breast, ovary and bladder cancer (see Table 3.3).

While the majority of the data submitted for this volume had been coded or converted to ICD-O (see Chapter 6), registries were asked what classification systems were used for coding data in the registry during the period. Of the 186 registries contributing data to this volume, 117 (63\%) coded to ICD-O topography and morphology, 26 (16.6\%) to ICD-9 or ICD-10 topography and ICD-O morphology, and $3(1.6 \%)$ did not register histology and coded topography to ICD-9. Of the 'Other' category, 20 registries changed the classification used during the period, and 9 used ICD-O-1 topography with ICD-O-2 morphology. One registry coded morphology to SNOMED, one to SNOP, two to MOTNAC and two used a local system.

## Comparability

The use of a standard, well designed coding system such as the ICD should make analysis and tabulation of comparable results a simple matter. In practice, it has been a never-ending exercise in detection for the editors of Cancer Incidence in Five Continents to establish exactly how registries code different cancers. A survey of coding practices was carried out among contributors to Volumes IV, V and VI in an attempt to ascertain how registries coded selected diagnostic terms, and to assess the effect this might have on comparability. 50 -odd terms believed to present problems of inconsistency were selected, and the results were analysed and presented in the books as well as serving as the basis for the flags denoting variations in coding practices and the corresponding notes. For the present volume, registries were asked whether any malignant diagnoses were excluded from their data and how they coded intraduct carcinoma NOS, ductal and lobular carcinoma in situ of breast, ovarian cystadenoma of borderline malignancy and borderline tumour of ovary, and invasive, non-invasive and unspecified malignant carcinoma of bladder.

Non-melanoma skin cancer
The incidence of non-melanoma skin cancer (NMSC) is difficult to assess. These cancers are very common but rarely fatal, and completeness of registration varies widely depending on access to outpatient records and general practitioners. Most NMSCs are basal-cell (BCC) or squamous-cell (SCC) carcinomas; other skin cancers are rare. While some registries record the first occurrence of all NMSC, others register SCC only, several registries collect information for lip and/or genital sites only, and many do not collect
data on either SCC or BCC. Table 3.3 shows which NMSC diagnoses are included within C 44 for the individual registries.

## Breast cancer

Intraductal carcinoma and ductal carcinoma in situ (DCIS) of breast are classified in the ICD as in situ cancers. Mammographic screening has led to a dramatic increase in their detection. The majority of registries collect these diagnoses, and a very few code one or other of these diagnoses with a malignant behaviour code (3) (Table 3.3). Lobular carcinoma in situ has consistently been coded as an in situ diagnosis.

## Ovarian cancer

Over half the registries in Volume IV of Cancer Incidence in Five Continents coded borderline ovarian malignancies as a malignant neoplasm (classified as an unspecified tumour in ICD-8). In ICD-9 these borderline tumours were classified to 236.2 (neoplasm of uncertain behaviour), but nearly a quarter of the registries in Volume V included them in the malignant category. In Volume VI, only $5 \%$ of registries counted the borderline ovarian cancers as malignant. ICD10 and the ICD-O Field Trial and second editions categorize the borderline tumours as invasive, and registries using these classifications for part of or the whole of their submission to Volumes VII and VIII included such diagnoses in ICD183/C56. As registries were not asked about their coding of borderline ovarian cancer for Volume VII, it is not possible to know what proportion of registries using ICD-O-1 or ICD-9 continued to include them in the malignant category, with behaviour code $/ 3$. Registries contributing to this volume were asked how they coded ovarian cystadenoma of borderline malignancy and borderline tumour of ovary, and the behaviour codes used are tabulated in Table 3.3. Clearly for these diagnoses, registration practice varies considerably. The issue has been further complicated by the advent of ICD-O-3 (Fritz et al., 2000), in which many of these borderline ovarian diagnoses have been changed back to the /1 borderline category, although they fall within the malignant section of ICD-10. Borderline ovarian tumours accounted for $13 \%$ of all ovarian cancers in the area served by the Fred Hutchinson Cancer Surveillance System in the USA (Harlow \& Weiss, 1989).

## Bladder cancer

The problem of the coding of non-invasive tumours, taking into account recorded level of invasion and grade, and which to include in the tables as 'cancer of the bladder' has long been a subject of debate. In Volume VI it was decided, for the sake of geographical comparability, to exclude tumours of benign, in situ and unspecified behaviour. Bladder was marked in the tables if such diagnoses were not excluded, and a note drew attention to the fact that ICD-9 188 included non-invasive tumours.

In principle, the availability of data on histological type and behaviour has made it possible to publish only data on malignant cancer by excluding diagnoses with any behaviour code other than $/ 3$. When registries were questioned about the behaviour codes used for the non-invasive and unspecified diagnoses of malignant bladder cancer in Volume VII and in the present volume (see Table 3.3), it transpired that many of them assign the behaviour code $/ 3$ to both non-invasive and unspecified diagnoses, so making it impossible to distinguish such cases. The editors decided to accept that non-invasive diagnoses of bladder cancer are considered malignant by pathologists in general, and for Volumes VII and VIII the bladder cancer category includes the in situ and unspecified categories, unless otherwise indicated by a dagger sign against C67 in the tables and a note on the data. A few registries preferred not to include such cases in their data-set, even when available in the registry, for the sake of continuity over time.

Several registries have made the comment that tumours with unspecified behaviour (/1) are uncommon in their area, as pathologists are asked for more precision.

Brain and central nervous system
Many registries choose to include benign and unspecified tumours of the brain and central nervous system in their data because of the potentially serious clinical consequences of these tumours. Before Volume VII, such tumours may therefore have been included in the tables, along with cancers of the brain and nervous system. However, the proportion of such cases varies widely between registries, so for Volume VII and the present volume they are no longer included, and for registries which did include such diagnoses previously, there would be an artefactual decline in incidence from the time-period covered in Volume VII. Studies of trends in incidence should take into account the practice in previous volumes.

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## Table 3.1. Classification used in incidence tables

| Site | Full title | Groupings used in tables | Short title used in tables |
| :---: | :---: | :---: | :---: |
| C00 | Malignant neoplasm of lip | - | Lip |
| C01 | Malignant neoplasm of base of tongue | C01-C02 are grouped | Tongue |
| C02 | Malignant neoplasm of other and unspecified parts of tongue |  |  |
| C03 | Malignant neoplasm of gum | C03-C06 are grouped | Mouth |
| C04 | Malignant neoplasm of floor of mouth |  |  |
| C05 | Malignant neoplasm of palate |  |  |
| C06 | Malignant neoplasm of other and unspecified parts of mouth |  |  |
| C07 | Malignant neoplasm of parotid gland | C07-C08 are grouped | Salivary gland |
| C08 | Malignant neoplasm of other and unspecified major salivary glands |  |  |
| C09 | Malignant neoplasm of tonsil | - | Tonsil |
| C10 | Malignant neoplasm of oropharynx | - | Other oropharynx |
| C11 | Malignant neoplasm of nasopharynx | - | Nasopharynx |
| C12 | Malignant neoplasm of pyriform sinus | C12-C13 are grouped | Hypopharynx |
| C13 | Malignant neoplasm of hypopharynx |  |  |
| C14 | Malignant neoplasm of other and ill-defined sites in the lip, oral cavity and pharynx | - | Pharynx unspecified |
| C15 | Malignant neoplasm of oesphagus | - | Oesophagus |
| C16 | Malignant neoplasm of stomach | - | Stomach |
| C17 | Malignant neoplasm of small intestine | - | Small intestine |
| C18 | Malignant neoplasm of colon | - | Colon |
| C19 | Malignant neoplasm of rectosigmoid junction | C19-C20 are grouped | Rectum |
| C20 | Malignant neoplasm of rectum |  |  |
| C21 | Malignant neoplasm of anus and anal canal | - | Anus |
| C22 | Malignant neoplasm of liver and intrahepatic bile ducts | - | Liver |
| C23 | Malignant neoplasm of gallbladder | C23-C24 are grouped | Gallbladder etc. |
| C24 | Malignant neoplasm of other and unspecified parts of biliary tract |  |  |
| C25 | Malignant neoplasm of pancreas | - | Pancreas |
| C26 | Malignant neoplasm of other and ill defined digestive organs | C26 is included in other and unspecified |  |
| C30 | Malignant neoplasm of nasal cavity and middle ear | C30-C31 are grouped | Nose, sinuses, etc. |
| C31 | Malignant neoplasm of accessory sinuses |  |  |
| C32 | Malignant neoplasm of larynx | - | Larynx |
| C33 | Malignant neoplasm of trachea | C33-C34 are grouped | Trachea, bronchus and lung |
| C34 | Malignant neoplasm of bronchus and lung |  |  |
| C37 | Malignant neoplasm of thymus | C37-C38 are grouped | Other thoracic organs |
| C38 | Malignant neoplasm of heart, mediastinum and pleura |  |  |
| C39 | Malignant neoplasm of other and ill-defined sites in the respiratory system and introthoracic organs | C39 is included in other and unspecified |  |
| C40 | Malignant neoplasm of bone and articular cartilage of limbs | C40-C41 are grouped | Bone |
| C41 | Malignant neoplasm of bone and articular cartilage of other and unspecified sites |  |  |
| C43 | Malignant melanoma of skin | - | Melanoma of skin |
| C44 | Other malignant neoplasms of skin | - | Other skin |
| C45 | Mesothelioma | - | Mesothelioma |
| C46 | Kaposi sarcoma |  | Kaposi sarcoma |
| C47 | Malignant neoplasm of peripheral nerves and autonomic nervous system | C47+C49 are grouped | Connective and soft tissue |
| C48 | Malignant neoplasm of retroperitoneum and peritoneum | C48 is included in other and unspecified |  |
| C49 | Malignant neoplasm of other connective and soft tissue | C49 is grouped with C47 |  |
| C50 | Malignant neoplasm of breast | - | Breast |
| C51 | Malignant neoplasm of vulva | - | Vulva |
| C52 | Malignant neoplasm of vagina | - | Vagina |
| C53 | Malignant neoplasm of cervix uteri | - | Cervix uteri |
| C54 | Malignant neoplasm of corpus uteri | - | Corpus uteri |
| C55 | Malignant neoplasm of uterus, part unspecified | - | Uterus unspecified |
| C56 | Malignant neoplasm of ovary | - | Ovary |
| C57 | Malignant neoplasm of other and unspecified female genital organs | - | Other female genital organs |

Table 3.1 (contd). Classification used in incidence tables

| Site | Full title | Groupings used in tables | Short title used in tables |
| :---: | :---: | :---: | :---: |
| C58 | Malignant neoplasm of placenta | - | Placenta |
| C60 | Malignant neoplasm of penis | - | Penis |
| C61 | Malignant neoplasm of prostate | - | Prostate |
| C62 | Malignant neoplasm of testis | - | Testis |
| C63 | Malignant neoplasm of other and unspecified male genital organs | - | Other male genital organs |
| C64 | Malignant neoplasm of kidney, except renal pelvis | - | Kidney |
| C65 | Malignant neoplasm of renal pelvis | - | Renal pelvis |
| C66 | Malignant neoplasm of ureter | - | Ureter |
| C67 | Malignant neoplasm of bladder | - | Bladder |
| C68 | Malignant neoplasm of other and unspecified urinary organs | - | Other urinary organs |
| C69 | Malignant neoplasm of eye and adnexa | - | Eye |
| C70 | Malignant neoplasm of meninges | C70-72 are grouped | Brain, nervous system |
| C71 | Malignant neoplasm of brain | together |  |
| C72 | Malignant neoplasm of spinal cord, cranial nerves and other parts of central nervous system | - |  |
| C73 | Malignant neoplasm of thyroid gland | - | Thyroid |
| C74 | Malignant neoplasm of adrenal gland | - |  |
| C75 | Malignant neoplasm of other endocrine glands and related structures |  | Adrenal gland Other endocrine |
| C76 | Malignant neoplasm of other and ill-defined sites | C76 is included in other and unspecified |  |
| C81 | Hodgkin disease | - | Hodgkin disease |
| C82 | Follicular (nodular) non-Hodgkin lymphoma | C82-C85, C96 are | Non-Hodgkin lymphoma |
| C83 | Diffuse non-Hodgkin lymphoma | grouped |  |
| C84 | Peripheral and cutaneous T-cell lymphomas |  |  |
| C85 | Other and unspecified types of non-Hodgkin lymphoma |  |  |
| C88 | Malignant immunoproliferative diseases | - | Immunoproliferative diseases |
| C90 | Multiple myeloma and malignant plasma cell neoplasms | - | Multiple myeloma |
| C91 | Lymphoid leukaemia | - | Lymphoid leukaemia |
| C92 | Myeloid leukaemia | C92-C94 are grouped | Myeloid leukaemia |
| C93 | Monocytic leukaemia | (following ICD-O-3) |  |
| C94 | Other leukaemias of specified cell type |  |  |
| C95 | Leukaemia of unspecified cell type | - | Leukaemia unspecified |
| C96 | Other and unspecified malignant neoplasms of lymphoid, haematopoietic and related tissue | C96 is grouped with C82-C85 |  |
| O\&U |  | Includes C26, 39, 48, 75, C76 | Other and unspecified |
| ALL |  |  | All sites |
| ALLbC44 |  |  | All sites but C44 |

Table 3.2 Coding practices

| Registry | $\begin{aligned} & \text { ICD-O-1 } \\ & (T+M) \end{aligned}$ | $\begin{aligned} & \text { ICD-O-2 } \\ & \text { (T + M) } \end{aligned}$ | $\begin{aligned} & \text { ICD-10(T) + } \\ & \text { ICD- O-2 (M) } \end{aligned}$ | $\begin{aligned} & \text { ICD-9(T) + } \\ & \text { ICD-0-1 (M) } \end{aligned}$ | $\begin{gathered} \text { ICD-9(T) + } \\ \text { ICD-O-2 (M) } \end{gathered}$ | $\begin{gathered} \text { ICD-10 (T) } \\ \text { No M } \end{gathered}$ | Other |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Africa (6) | 0 | 4 | 0 | 1 | 0 | 0 | 1 |
| Central and South <br> America (11) | 1 | 5 | 1 | 0 | 0 | 0 | 4 |
| North America (26) | 0 | 25 | 0 | 0 | 1 | 0 | 0 |
| Asia (43) | 9 | 17 | 5 | 5 | 1 | 3 | 3 |
| Europe (90) | 15 | 39 | 6 | 5 | 1 | 0 | 24 |
| Oceania (10) | 1 | 1 | 1 | 2 | 2 | 0 | 3 |
| Total (186) | 26 | 91 | 13 | 13 | 5 | 3 | 35 |




 Africa
Algeria, Algiers
France, La Réunion
The Gambia
Mali, Bamako
Uganda, Kyadondo County
Zimbabwe, Harare
South America
Argentina, Bahia Blanca
Argentina, Concordia
Brazil, Campinas
Brazil, Goiania
Colombia, Cali
Costa Rica
Cuba, Villa Clara
Ecuador, Quito
France, La Martinique
US, Puerto Rico
Uruguay, Montevideo
North America
Canada
Canada, Alberta
Canada, British Columbia
Canada, Manitoba
Canada, New Brunswick
Canada, Newfoundland
Canada, Northwest Territories
Canada, Nova Scotia
Canada, Ontario
Canada, Prince Edward Island
Canada, Quebec
Canada, Saskatchewan
Canada, Yukon
USA, California, Los Angeles
USA, California, San Francisco
USA, Connecticut
USA, Georgia, Atlanta
USA, Iowa

|  |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |

Table 3.3 (Contc). Coding practices

|  |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |


|  |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |

Table 3.3 (Contid). Coding practices

|  | Non-melanoma skin cancers excluded | Behavio |  |  |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  | Intraduct ca NOS breast | Ductal ca in situ breast | Lobular ca in situ breast | Ovarian cytadeno borderline | Ovary borderline tumour | Bladder malig. invasive | Bladder malig. non-invasive | Bladder malig. NOS |
| Sweden | BCC | 2 | 2 | 2 | 3 | 3 | 3 | 3 | 3 |
| Switzerland, Basel | None | 2 | 2 | 2 | NA | 1 | 3 | 4 | 2/3 |
| Switzerland, Geneva | None | 2 | 2 | 2 | 1/3 | 1/3 | 3 | 2 | 2/3 |
| Switzerland, Graubünden and Glarus | None | 2 | 2 | 2 | 3 | 3 | 3 | 3 | 3 |
| Switzerland, Neuchâtel | None | 2 | 2 | 2 | 1 | 1 | 3 | 1 | 1 |
| Switzerland, St Gall-Appenzell | None | 2 | 2 | 2 | 3 | 3 | 3 | 2 | 3 |
| Switzerland, Ticino | BCC | 2 | 2 | 2 | 3 | 3 | 3 | 2 | 2/3 |
| Switzerland, Valais | None | 2 | 2 | 2 | 1;3 | 1 | 3 | 2 | 2/3 |
| Switzerland, Vaud | None | 2 | 2 | 2 | 1 | 1 | 3 | 1 | 1 |
| Switzerland, Zurich | BCC, SCC | 2 | 2 | 2 | 1 | 1 | 3 | 3 | 3 |
| UK, England | See individual registrie |  |  |  |  |  |  |  |  |
| UK, England, East Anglia | None | 2 | 2 | 2 | 1/3 | Depends* | 3 | 1 | 3 |
| UK, England, Mersey | None | 2 | 2 | 2 | 1 | 1 | 3 | 3 | 3 |
| UK, England, North Western | NA | 2 | 2 | 2 | 1 | 1 | 3 | 2 | 3 |
| UK, England, Oxford | None | 2 | 2 | 2 | 3 | 1/3 | 3 | 3 | 3 |
| UK, England, South Thames | BCC | 2 | 2 | 2 | 1 | 1 | 3 | 2 | 3 |
| UK, England, South Western | C44 excl. for half pop. | 2 | 2 | 2 | 3 | 3 | 3 | 2 | 1 |
| UK, England, Trent | None | 2 | 2 | 2 | 3 | 3 | 3 | 3 | 3 |
| UK, England, West Midlands | None | 2 | 2 | 2 | 3 | 1 | 3 | 3 | 3 |
| UK, England, Yorkshire | None | 2 | 2 | 2 | 3 | 3 | 3 | 2 | 3 |
| UK, Northern Ireland | None | 2 | 2 | 2 | 3 | 3 | 3 | 1 | 3 |
| UK, Scotland | None | 2 | 2 | 2 | 1/3 | 1 | 3 | 1/2 | 3 |
| Yugoslavia, Vojvodina | None | 2 | 2 | 2 | 3 | 3 | 3 | 2 | 3 |
| Oceania |  |  |  |  |  |  |  |  |  |
| Australian Capital Territory | NMSC | 2 | 2 | 2 | 1 | 1 | 3 | 2 | 3 |
| Australia, New South Wales | NMSC | 2 | 2 | 2 | 1 | 1 | 3 | 2 | 3 |
| Australia, Northern Territory | NMSC | 2 | 3 | 2 | 0 | 1 | 3 | 3 | 3 |
| Australia, Queensland | BCC, SCC | 2 | 2 | 2 | 3 | 1 | 3 | 3 | 3 |
| South Australia | BCC, SCC excl. lip and genital sites | 2 | 2 | 2 | NR | NR | 3 | 2 | 3;/2 |
| Australia, Tasmania | NMSC | 2 | 2 | 2 | 1 | 3 | 3 | 3 | 3 |
| Australia, Victoria | BCC, SCC excl. lip and genital sites | 2 | 2 | 2 | 1/3 | 1 | 3 | 3 | 3 |
| Western Australia | BCC, SCC | 2 | 2 | 2 | 1 | 1;2;3 | 3 | 2 | 3 |
| New Zealand | BCC, SCC | NA | NA | NA | NA | NA | NA | NA | NA |
| USA, Hawaii | BCC, SCC excl. genital | sites 2 | 2 | 2 | 3 | 1 | 3 | 2 | 3 |
| Notes: <br> NA, information no NAP, not applicabl NR, not registered * Grade taken into | vailable (not provided by th <br> count when assigning beh | registry) <br> viour code |  |  |  |  |  |  |  |

