

# Appendix G

## Data – background information

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### Availability of data

At the time the work on this atlas began, cancer incidence and mortality data were available for the following periods:

### Table G1

#### Time periods covered by incidence and mortality data

	Incidence	Mortality
England	1991-1999	1991-2000
Wales	1991-1999	1991-2000
Scotland	1991-1999	1991-1999
Northern Ireland	1993-1999	1991-2000
Ireland	1994-1999	1994-2000

As there may have been varying trends in the incidence of, and mortality from, some cancers in the five countries since 1991, the slightly different time periods covered should be borne in mind when interpreting any apparent differences in cancer rates between countries.

### International Classification of Diseases (ICD)

Over the period 1991 to 2000, the ninth and tenth revisions of the International Classification of Diseases (ICD) were in use at various times.<sup>1,2</sup> The constituent countries of the UK and Ireland were asked to supply their data coded to whichever ICD revision they were using at the time of diagnosis or death. Table G2 gives the site codes in both the ICD9 and ICD10 classifications used for each of the main cancer types included in this atlas. All results have been presented in terms of ICD10.

ONS has been advised by both expert epidemiologists and by members of the former Steering Committee on Cancer Registration that non-melanoma skin cancer (ICD10 C44) is greatly under-registered. Registration varies widely depending on a cancer registry's degree of access to outpatient records and general practitioners. It also frequently happens that a person has more than one tumour of this type, and registries had adopted different practices in recording these multiple tumours. Figures in this publication for 'all cancers' therefore exclude non-melanoma skin cancer (nmisc).

### Table G2

#### Cancer site codes in ICD9 and ICD10

Cancer site	ICD9	ICD10
All cancers	140-208 x173	C00-C97 xC44
Lip, mouth and pharynx	140-149	C00-C14
Oesophagus	150	C15
Stomach	151	C16
Colorectal	153-154.1	C18-C20
Pancreas	157	C25
Larynx	161	C32
Lung	162.2-162.9	C34
Melanoma of skin	172	C43
Breast (female)	174	C50
Cervix	180	C53
Uterus	182 (+179*)	C54 (+C55*)
Ovary	183.0	C56
Prostate	185	C61
Testis	186	C62
Kidney	189.0	C64
Bladder	188	C67
Brain	191	C71
Hodgkin's disease	201	C81
Non-Hodgkin's lymphoma	200, 202.0-202.2, 202.8	C82-C85
Multiple myeloma	203.0-203.1	C90
All leukaemias	202.4, 204-208	C91-C95

\* Deaths only.

### Cancer registrations

More is known about the incidence of, and survival from, cancer than for most other diseases. This is because in the UK and Ireland there are population-based cancer registration systems with 100 per cent geographical coverage and mechanisms in place to follow up cases. However, cancer registration is not statutory and the implications of this are discussed below.

#### England

Cancer registration in England is conducted by nine regional registries which submit notifications to the National Cancer Intelligence Centre (NCIC) at the Office for National Statistics (ONS, [www.statistics.gov.uk](http://www.statistics.gov.uk), formerly the Office of Population Censuses and Surveys). Most registries get their principal information from hospitals' patient administrations systems (PAS) – usually electronically – and pathology laboratories. Some registries also use hospital records staff to collect data, while others employ peripatetic clerks who visit hospitals, but information is also obtained from coroners, GPs and private nursing homes. In addition, the registries regularly receive from ONS notifications of deaths where cancer is mentioned on the

death certificate. Registries match these against their records to indicate possible cases not already known to them, or to update details of existing records. Cancer registrations are recorded in the National Health Service Central Register (NHSCR, part of ONS), as are deaths supplied by the statutory civil registration process (see below). The subsequent linkage of incidence and death records enables calculation of survival (that is, time from diagnosis to death).

## Wales

In Wales, cancer registration is carried out by the Welsh Cancer Intelligence and Surveillance Unit (WCISU, a division within the Velindre NHS Trust, [www.velindre-tr.wales.nhs.uk/wcisu](http://www.velindre-tr.wales.nhs.uk/wcisu)). They receive their cancer notifications from hospital trusts and the NHS Clearing Service via the computerised Patient Episode Database Wales, as well as from pathology records and other registries. Welsh cancer notifications are – like those for England – submitted to the NCIC at ONS, and recorded in the NHSCR and linked with death records.

Although cancer registration began in 1962, the Welsh Cancer Registry did not cover the whole of Wales until 1974 when an electronic registry was established based on the hospital activity database. It remained essentially unchanged until 1997, when all matters relating to health were devolved to the National Assembly of Wales (NAW), and WCISU took over responsibility for the service, publishing all cancer incidence data for Wales from 1995 onwards.

An innovative information system for clinical oncologists has been in use in the Velindre Trust since 1990 for clinical care of patients. Under the Cancer Information Framework, it has been extended to the whole of Wales to support multi-disciplinary teams across hospital sites. It will form the basis of a new way of capturing clinically rich cancer data items in real time, including better quality for clinical audit and population-based cancer registration data.

## Scotland

In Scotland, up to 1997, cancer registration was carried out by five regional cancer registries; they relied mainly on hospital in-patient sources, pathology records and death records. The role of the Scottish Cancer Registry (part of the NHS National Services Scotland Information Services (ISD Scotland: [www.isdscotland.org/cancer\\_information](http://www.isdscotland.org/cancer_information))) was limited to co-ordination, data collection from the regional registries, analysis and publication. From 1997, the national registry has been responsible for all aspects of cancer registration (with the core registration function funded by the Scottish Executive Health

Department) and has established a network of out-posted peripatetic cancer registration officers based in the main hospitals.

Registrations are identified from four main computerised sources: hospital discharge records; oncology records; pathology records; and death records. Information from these and non-computerised sources is linked to create provisional registrations made available to the cancer registration officers. They in turn refer to medical records to validate the provisional registration and abstract additional information not currently collected electronically. Follow-up is achieved by linkage to computerised death records supplied by the Registrar General for Scotland (via the General Register Office for Scotland (GROS)).

The Scottish Cancer Registry has an active programme of quality assurance and the results of many of its studies in this field have been published.

## Northern Ireland

The Northern Ireland Cancer Registry (NICR, [www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr)) was established in 1994 and replaced an existing Department of Health and Social Services registry – this had relied on clinicians to complete registration cards and, consequently, ascertainment of cases was incomplete. Complete data are available from 1993.

The registry uses an automated electronic system with the main source being the patient administration system (PAS) used by all hospital trusts. From the PAS, the registry obtains basic tumour information on cancer site and behaviour and this is supplemented by electronic downloads from pathology laboratories which give additional information on the morphology of the tumour. Death certificates are supplied by the Registrar General of Northern Ireland (via the General Register Office for Northern Ireland (GRONI)) and matched against the registry database. Cases notified only from PAS or a death certificate have case records checked to validate the diagnosis.

In addition, there are three disease-specific registries in Northern Ireland, with which the registry data are compared. These were set up independently from the cancer registry and contain information on specific sites – malignant melanomas (incorporated into the NICR), colorectal cancers (historical only) and leukaemia and lymphomas (active).

NICR is part of the Centre for Clinical and Population Sciences at the Queen's University of Belfast, and is involved in a programme of cancer-related research. It also provides a cancer information service for the region and has close connections with the breast and cervical screening services.

## Ireland

The National Cancer Registry of Ireland (NCRI, [www.ncri.ie/ncri](http://www.ncri.ie/ncri)) was founded in 1991, taking over the functions of the Southern Tumour Registry, which had provided population-based registration for about one sixth of the country since 1975. Collection of cancer data for the entire country began in 1994 and is fully funded by the Department of Health and Children.

Most notifications come from pathology departments, with a small number from other hospital sources, death certificates and general practitioners. Death certificates received from the Central Statistics Office are followed up with the hospital of death or the certifying doctor, if the cancer is not already registered. At the time of preparing this atlas, the registry did not accept an unconfirmed death certificate (DCO) as a basis for registration. This position subsequently changed and the implications for the data and their interpretation are discussed below.

## Quality of cancer registration data

### Level of ascertainment

As noted above, cancer registries differ considerably in their methods of data collection. They probably also differ in terms of the level of ascertainment of their data, that is, the proportion of cancer incidence in the population that is actually recorded by registries. General indications of the level of ascertainment can be obtained by comparing the numbers of registrations by cancer site with deaths from the same cancer in a given period and within the same geographical area. Such mortality-to-incidence ratios (see Appendix H) by sex and site are presented in Appendix B. These ratios have several limitations, but it would be difficult to explain any major differences between countries and regions unless there were similar differences in ascertainment. The ratios also provide a crude indication of survival: cancers with poorer survival rates usually have higher mortality-to-incidence ratios.

A high proportion of cancer registrations made solely on the basis of information from a death certificate (DCO) also implies under-ascertainment. This is because the registry is failing to register some patients who die from cancer while they were alive. Also, some cancer patients will not die of their disease and so the cancer will not be mentioned on their death certificate. Therefore, some of these patients would not be registered either when they were alive, or at death. As noted above, the National Cancer Registry of Ireland initially did not accept DCOs as a basis for registration, but have recently 'added back' DCOs to incidence cases from 1994. Although it was not feasible to re-compute numbers and rates for this

**Table G3**

### Mortality-to-incidence ratios for Ireland: effect of DCO registrations

Cancer site	ICD10	DCOs included <sup>1</sup>		DCOs excluded <sup>2</sup>	
		Male	Female	Male	Female
All cancers	C00-C97 xC44	0.63	0.53	0.64	0.54
Lip, mouth and pharynx	C00-C14	0.48	0.49	0.47	0.50
Oesophagus	C15	1.02	0.94	1.05	0.95
Stomach	C16	0.76	0.80	0.77	0.83
Colon	C18	0.62	0.55	0.63	0.57
Rectum	C19-C20	0.36	0.33	0.35	0.34
Pancreas	C25	1.08	1.00	1.13	1.03
Larynx	C32	0.49	0.52	0.50	0.53
Lung	C34	0.95	0.93	0.98	0.99
Melanoma of skin	C43	0.21	0.13	0.21	0.13
Breast	C50	-	0.36	-	0.37
Cervix	C53	-	0.42	-	0.42
Uterus	C54	-	0.23	-	0.23
Ovary	C56	-	0.65	-	0.67
Prostate	C61	0.42	-	0.43	-
Testis	C62	0.09	-	0.09	-
Kidney	C64	0.51	0.48	0.54	0.49
Bladder	C67	0.34	0.35	0.33	0.36
Brain	C71	0.82	0.85	0.85	0.88
Hodgkin's disease	C81	0.39	0.24	0.37	0.25
Non-Hodgkin's lymphoma	C82-C85	0.53	0.48	0.55	0.51
Multiple myeloma	C90	0.77	0.81	0.80	0.82
All leukaemias	C91-C95	0.62	0.58	0.65	0.60

1 Calculated using 1994-99 mortality and incidence age-standardised rates.

2 Calculated using 1994-99 incidence and 1994-2000 mortality age-standardised rates.

publication, Table G3 shows the differences in the mortality-to-incidence ratios for Ireland when DCOs are included and excluded.

### Completeness

Completeness is the extent to which all appropriate data items have been recorded in a registry database. If high proportions of essential data items are missing, this is an indicator of poor quality. For cases that have been registered solely from the information on a death certificate (DCO), the incidence date is unknown and has to be taken as the date of death. Other quality indicators include the proportion of cases where the primary site is unknown, or where important information, such as the age of the patient or their postcode, is missing. The proportions of such cases are extremely low.

## Accuracy

As with completeness, the accuracy of the data (that is, the proportion of cases that truly have the recorded characteristic) is only occasionally known directly, usually from special studies. Various indirect measures, however, suggest that there is considerable variation between areas. A report of a project to audit the quality and comparability of cancer registration data in the UK, carried out under the aegis of the United Kingdom Association of Cancer Registries (see Appendix J), was published in 1995.<sup>3</sup> Variations among the registries were found in data quality for diagnostic factors, incidence date, stage of disease, treatment information, and use of death information. The review concluded, however, that cancer registry records were largely complete, accurate and reliable. The review also found that the quality of cancer registry data depended heavily on the competence and experience of staff in the registry, on maintaining good relationships with clinicians, staff in health authorities, and scientists, and on the registry's active involvement in research.

## Timeliness

Registration of newly diagnosed cases of cancer is a dynamic process in the sense that the data files are always open. Cancer records may be amended – for example, the site code may be modified should more accurate information become available at a later date. The date of death is added for cases registered when the person was alive. Also, complete new 'late' registrations may be made after publication of what was thought at the time to be virtually complete results for a particular year. These are often prompted by information from a death certificate.

## Duplicate registrations

While late registrations result in previously published figures being too low, duplicate registrations can artificially inflate them. Such duplication may arise if a patient is resident in one region but treated in another; this is particularly so for those resident in areas bordering another country for example, patients resident in North Wales and treated in Liverpool. Registrations are therefore carefully examined to distinguish duplicate records from true multiple primary cancers.

## Other quality issues

Inaccuracies and incompleteness may arise from diagnostic practice, and changes in it, although such errors and changes come from outside the cancer registration system and are not under its control. Misclassification of cancers is more likely to occur when there is no opportunity to obtain histological confirmation of disease, or if the tumour has a pre-malignant

stage which can be confused with invasive carcinoma.

Misclassification may also result from mistakes in the collection, abstraction or coding of information, both before and after it reaches a registry. Also, clinical and pathological (and registry) definitions of cancer may change over time and between places, particularly for borderline malignant conditions.

## Mortality

For the constituent countries of the UK, there is a statutory requirement to register a death within five days. In Ireland, deaths have to be registered within one year of occurrence.

Most deaths are certified by a medical practitioner. The death certificate is then (normally) taken to a registrar of births and deaths by a person known as an informant – usually a near relative of the deceased. In certain cases, deaths are referred to (and sometimes then investigated by) a coroner who sends information to the registrar of births and deaths which is used instead of that from the medical practitioner.

Details of the system of registration of deaths for the constituent countries of the UK and Ireland have been published elsewhere.<sup>4-7</sup>

## Advantages and disadvantages of incidence and mortality data

Cancer incidence data are coded to both cancer site (using ICD) and histological type (using ICD-O) in the countries of Great Britain. Incidence is coded only to ICD in Northern Ireland, and in Ireland to ICD-O with translation to ICD. Mortality data are coded only to ICD in the UK, and in Ireland to ICD with translation to ICD-O.

Around 10 per cent of deaths in England and Wales are coded to 'site unspecified'<sup>4</sup> whereas the corresponding proportion for incidence data is only 3 per cent.<sup>8</sup> Consequently, diagnostic accuracy is less certain for mortality than for incidence.

Mortality data are generally more timely than incidence data because of the statutory requirement to register a death within five days (UK only), and for the large majority of deaths there is only one source document. The data are also virtually 100 per cent complete. Cancer registration is not statutory and collating information from the variety of data sources is time consuming. Final results are only published once it is believed data have been received from all the relevant sources, but this can be difficult to quantify and data may still be incomplete due to late registrations.

In the UK, there is a long time series for deaths data, although this has been affected by coding and classification changes over the years. Details of the effects of these changes during

## Table G4

### Summary of advantages and disadvantages of incidence and mortality data

Incidence	Mortality
<p><b>Advantages</b></p> <ul style="list-style-type: none"> <li>- high quality coding</li> <li>- both cancer site and histology</li> <li>- very low proportion of 'site unspecified'</li> <li>- date of diagnosis known</li> </ul> <p><b>Disadvantages</b></p> <ul style="list-style-type: none"> <li>- may not be complete</li> <li>- may not be sufficiently timely</li> <li>- data for England and Wales available only from 1971, with evidence of under-ascertainment in the 1970s; data for Scotland, Northern Ireland and Ireland available from 1959, 1993 and 1994, respectively</li> </ul>	<p><b>Disadvantages</b></p> <ul style="list-style-type: none"> <li>- diagnostic accuracy less certain than for incidence</li> <li>- cancer site only, no histology</li> <li>- around 10 per cent 'site unspecified'</li> <li>- deaths in any one year result from cancers diagnosed over a long time period</li> </ul> <p><b>Advantages</b></p> <ul style="list-style-type: none"> <li>- virtually 100 per cent complete</li> <li>- timely</li> <li>- long time series (UK only), but affected by ICD changes, and in England and Wales by coding and other changes in 1984 and 1993</li> </ul>

the 1990s for England and Wales have been published,<sup>9,10</sup> giving an indication of the likely effect on cancer registrations.

Even if survival rates remain unchanged, trends in mortality give only a delayed indication of trends in new cases because for cancers with moderate or good survival, those dying in any one year may have been diagnosed and treated many years earlier. Cancer mortality trends are therefore a 'fuzzy' indicator of trends in the efficacy of treatment – they reflect earlier trends in incidence and survival, and cannot be interpreted sensibly without them.<sup>11</sup> This has made incidence data increasingly more important for early monitoring of trends, and for assessment of major public health interventions such as breast and cervical screening.

### Geography

The United Kingdom (UK) comprises England, Wales, Scotland and Northern Ireland, but does not include the Isle of Man or the Channel Isles.

In this publication, incidence and mortality are presented by country, health regional office (England), health authority (England and Wales), health board (Scotland and Ireland), and health and social services board (Northern Ireland). For simplicity, the term 'health authority' has been used throughout this atlas to refer to the 127 administrative health areas within Scotland, Northern Ireland and Ireland as well as those in England and Wales (see Table G5). For consistency over the period 1991-2000, the health authorities are based on boundaries as at April 2001.

The ordering of the health regional offices and countries in the tables and charts in this atlas is the standard for National

## Table G5

### Health authorities in the UK and Ireland

Country	Number of health authorities
England	95
Wales	5
Scotland	15
Northern Ireland	4
Ireland	8
<b>Total</b>	<b>127</b>

Statistics. However, for ease of reference, the health authorities appear alphabetically within each country or region of England in the tables in Appendix B.

### Population

Population figures have been used in this atlas as denominators to calculate incidence and mortality rates. For the countries of the UK, mid-year population estimates (revised in light of the 2001 UK Census) were used. For Ireland, the population figures used for 1996 are official national census figures, and for 1994-95 and 1997-2000 are official intercensal estimates published by the Central Statistics Office.

Although the UK census population figures for 2001 were overall some one million lower than the previously published population estimates, the differences were concentrated largely in the younger age groups, particularly for males. Cancer is a disease predominantly of the elderly, and checks on data for England and Wales have shown that in general, the effects on previously published cancer incidence rates of using

populations for the 1990s that have been revised in the light of the results of the 2001 census, and subsequently, are very small.

Appendix C contains population estimates for 1996 by sex and country, health regional office in England, and health authority.

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