

[Click here to go to the Contents Page](#)

# Cancer statistics registrations

**Registrations of cancer diagnosed in 2008, England**

Edition No.: **MB1 39**

**Office for National Statistics**

**MB1 39**

ISSN 0143-4829

## A National Statistics publication

National Statistics are produced to high professional standards set out in the Code of Practice for Official Statistics. They are produced free from political influence.

## About us

### The Office for National Statistics

The Office for National Statistics (ONS) is the executive office of the UK Statistics Authority, a non-ministerial department which reports directly to Parliament. ONS is the UK government's single largest statistical producer. It compiles information about the UK's society and economy, and provides the evidence-base for policy and decision-making, the allocation of resources, and public accountability. The Director-General of ONS reports directly to the National Statistician who is the Authority's Chief Executive and the Head of the Government Statistical Service.

### The Government Statistical Service

The Government Statistical Service (GSS) is a network of professional statisticians and their staff operating both within the Office for National Statistics and across more than 30 other government departments and agencies.

## Contacts

### This publication

For information about the content of this publication, contact Vital Statistics Outputs Branch  
Tel: 01329 444110  
Email: [vsob@ons.gsi.gov.uk](mailto:vsob@ons.gsi.gov.uk)

### Other customer enquiries

ONS Customer Contact Centre  
Tel: 0845 601 3034  
International: +44 (0)845 601 3034  
Minicom: 01633 815044  
Email: [info@statistics.gsi.gov.uk](mailto:info@statistics.gsi.gov.uk)

Fax: 01633 652747  
Post: Room 1.101, Government Buildings,  
Cardiff Road, Newport, South Wales NP10 8XG  
[www.ons.gov.uk](http://www.ons.gov.uk)

### Media enquiries

Tel: 0845 604 1858  
Email: [press.office@ons.gsi.gov.uk](mailto:press.office@ons.gsi.gov.uk)

## Copyright and reproduction

© Crown copyright 2010

You may re-use this information (not including logos) free of charge in any format or medium, under the terms of the Open Government Licence.

To view this licence, go to:

<http://www.nationalarchives.gov.uk/doc/open-government-licence/>

or write to the Information Policy Team, The National Archives, Kew, London TW9 4DU

email: [psi@nationalarchives.gsi.gov.uk](mailto:psi@nationalarchives.gsi.gov.uk)

# Contents

Navigate through this document by using Bookmarks, or Links from the Contents listed below. There are more sub-categories in the Bookmarks than there are in the Contents listing. Prevent the printing of these instructions by unchecking 'Annotations' in the Print dialogue box

Select the HAND tool. Position it over the Contents list below and when an ARROW appears on the hand click the mouse button once to enlarge the text. Continue clicking the arrowed hand tool to advance down the page. When the HAND tool changes to a POINTED FINGER click the mouse button once to link to the listed item

1. Introduction .....	5
2. The role of ONS in cancer registration.....	7
3. Cancer registrations, 2008 .....	9
4. Guidance notes and definitions.....	15
5. Maps and contact addresses .....	26
References.....	31
Glossary.....	34

## List of Figures

Figure A	The cancer registration system in England.....	9
Figure B	All malignant neoplasms (excl. nmsc): incidence rates by age group, 2008 .....	12
Figure C	All malignant neoplasms (excl. nmsc): frequency distribution by age group, 2008 .	13
Figure D	All malignant neoplasms (excl. nmsc): standardised registration ratios by Government Office Region, 2008 .....	13
Figure E	Registrations by major sites, 2008.....	15
Figure F	Number of registrations published in ARVs and currently on the National Cancer Registry database 1971–2008.....	20
Figure G	Advantages and disadvantages of incidence and mortality data.....	22
Figure H	Areas covered by the regional cancer registries, England 2010 .....	26
Figure I	Areas covered by the Government Office Regions, England, 2010 .....	27

## List of Tables in the Text

Table A	Data items submitted to ONS .....	8
Table B	The three most common cancers, 2008 .....	14
Table C	Number of newly diagnosed cancers by quality status 1971–2008 England.....	19
Table D	Distribution of the European Standard Population.....	24

# List of Tables

Table 1	Registrations of newly diagnosed cases of cancer (3rd digit): site, sex and age, 2008.	England
Table 2	Estimated resident population: sex and age, as at 30 June 2008.	England, Government Office Regions
Table 3	Directly age-standardised and age-specific rates per 100,000 population of newly diagnosed cases of cancer (3rd digit): site, sex and age, 2008.	England
Table 4	Registrations of newly diagnosed cases of cancer (3rd digit): site, sex and Government Office Region of residence, 2008.	England, Government Office Regions
Table 5	Directly age-standardised rates per 100,000 population of newly diagnosed cases of cancer (3rd digit): site, sex and Government Office Region of residence, 2008.	England, Government Office Regions
Table 6	Standardised registration ratios: site, sex and Government Office Region of residence, 2008.	Government Office Regions
Table 7	Registrations of newly diagnosed cases of cancer (4th digit): site, sex and age, 2008.	England
Table 8	Age-specific rates per 100,000 population of newly diagnosed cases of cancer (4th digit): site, sex and age, 2008.	England
Table 9	Cancer mortality to incidence ratios: site, sex and Government Office Region of residence, 2008.	England, Government Office Regions
Table 10	Directly age-standardised registration rates per 100,000 population: site and sex, 1999 – 2008.	England

## 1. Introduction

### 1.1 Background

This publication presents data for England on those patients who were diagnosed with cancer during 2008 and whose registrations were received at the Office for National Statistics (ONS) by August 2010.

Cancer registration is the process of maintaining a systematic collection of data on the occurrence and characteristics of malignant neoplasms and certain non-malignant tumours. The procedure is widely established throughout the world and generally follows guidelines established by bodies such as the International Union Against Cancer (UICC), the International Association of Cancer Registries (IACR),<sup>1,2</sup> and the International Agency for Research on Cancer (IARC) of the World Health Organisation (WHO).

In England, cancer registration is carried out by eight regional registries that collect information on cancers registered to residents of their areas on a voluntary basis. These cancer registrations are subsequently submitted to ONS as a standard dataset. Figure H in Section 5 presents a map of the areas covered by the eight English cancer registries. There are similar systems of cancer registration in Scotland, Wales and Northern Ireland, co-ordinated by the Information and Statistics Division (ISD) of the NHS in National Services Scotland, the Welsh Cancer Intelligence and Surveillance Unit, and the Northern Ireland Cancer Registry respectively.

All cancer registries in the UK are members of the UK Association of Cancer Registries (UKACR), with the Childhood Cancer Research Group in Oxford and ONS. The full addresses, telephone and fax numbers of the registries in England, and the registries in Wales, Scotland and Northern Ireland, are given in section 5. Further information about the work of UKACR is available at: [www.ukacr.org/](http://www.ukacr.org/)

The National Cancer Intelligence Network (NCIN) was launched in June 2008, funded by the Department of Health for England, to bring together patient-level datasets with the expertise needed to provide quality assurance and high quality cancer intelligence on a national scale, to coordinate information definition, compilation and usage. NCIN oversees and co-ordinates the provision of national information needed to improve cancer services, and is tasked with ensuring optimal use is made of all bodies of data currently collected, and to identify and eliminate duplication of effort. Further information about the work of NCIN is available on the NCIN website at: [www.ncin.org.uk/](http://www.ncin.org.uk/)

For the purposes of the national cancer registration scheme the term 'cancer' includes all malignant neoplasms and the reticulosos, that is conditions listed under site code numbers C00 to C97 of the Tenth Revision of the International Statistical Classification of Diseases and Related Health Problems.<sup>3</sup> In addition, all in situ neoplasms (D00–D09), certain benign neoplasms (D32–D33, D35.2–D35.4) and neoplasms of uncertain or unknown behaviour (D37–D48) are registered.

Early volumes in this series (numbers 1 to 27; 1971 to 1994 respectively),<sup>4</sup> presented figures for England and Wales. From number 28 onwards, figures have presented for England only,<sup>5</sup> since all matters relating to health in Wales have been devolved to the Welsh Assembly Government. For

years prior to 1971, statistics were published in the Registrar General's Statistical Review of England and Wales, Supplements on Cancer.

In 2001 ONS published the book *Cancer Trends in England and Wales 1950–1999*.<sup>6</sup> This brought together for the first time the long-term trends in cancer incidence, mortality, prevalence and survival for all the major cancers (which together make up almost 90 per cent of the total cases in both males and females) accompanied by brief notes on aetiology (causes) and risk factors. Analyses, based on data for the whole population, highlight the wide variations in cancer incidence and mortality with socio-economic deprivation. The book paints the broad picture of the cancer burden and illustrates the baselines against which progress in cancer control is measured.

## 1.2 Acknowledgements

ONS is very grateful for the work of the regional cancer registries over the years that the national scheme has been in operation, and their close co-operation with the national registry. The current directors of the registries in England are:

Northern & Yorkshire	Professor J Wilkinson (co-director) Professor B Ferguson (co-director)
Trent	Mr D Meechan
Eastern	Dr J Rashbass
Thames	Professor H Møller
Oxford	Dr M Roche
South West	Dr J Verne
West Midlands	Dr G Lawrence
North West	Dr T Moran

## 1.3 Outline of contents

Section 2 begins with a brief history of the cancer registration scheme and then outlines the role of ONS in cancer registration. Overall results for all cancer sites in 2008 are provided in section 3. Section 4 provides guidance notes and definitions and a discussion of some factors relevant to the interpretation of cancer registration data. Section 5 provides maps and contact information on the cancer registries.

Information and tables on cancer incidence and mortality in the United Kingdom, for the most common cancers can be found on the ONS website at:

[www.statistics.gov.uk/statbase/Product.asp?vlnk=14209](http://www.statistics.gov.uk/statbase/Product.asp?vlnk=14209).

The cancer site codes and descriptions reflect the adoption by the NHS in 1995 of the Tenth Revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10).<sup>3</sup> Table 10 presents data for the ten most recent years available, which have been updated using the live database of cancer registrations.

Tables can be accessed by clicking on the links contained within the List of Tables on page 4 or clicking on the links within the text.

Special extracts and tabulations of cancer registration data for England are available to order (subject to legal frameworks, confidentiality thresholds and agreement of costs, where appropriate). Such requests enquiries should be made to:

Cancer Analysis Team, Centre for Health Analysis & Life Events  
Office for National Statistics  
Government Buildings  
Cardiff Road  
Newport  
Gwent NP10 8XG  
Tel: 01633 456801  
E-mail: [cancer.newport@ons.gsi.gov.uk](mailto:cancer.newport@ons.gsi.gov.uk)

## 2. The role of ONS in cancer registration

This chapter presents a brief history of the cancer registration system in England and an outline of the role of ONS in the system. The section of text on 'background and early history' published in earlier volumes has now been removed from this publication. This information can be found in earlier volumes (up to and including number 38), available to download from the ONS website at:

[www.statistics.gov.uk/statbase/Product.asp?vlnk=8843](http://www.statistics.gov.uk/statbase/Product.asp?vlnk=8843)

Since January 1993 it has been mandatory for the NHS, including trusts, to provide the core items listed in the cancer registration minimum dataset to the regional cancer registries, and for the registries to send these data to ONS (see Table A). ONS is responsible for the primary data processing of registry data (for England and Wales), and all reporting of National Statistics on cancer incidence, mortality and survival (for England). The NHS Information Centre for Health and Social Care (NHS-IC) is responsible for flagging cancer registrations with information collected at death registration (for England and Wales). Much of the secondary analysis and research on cancer survival is carried out by the cancer survival group at the London School of Hygiene and Tropical Medicine (LSHTM), on behalf of ONS.

Most registries collect a large amount of information about the patient, the tumour and the treatment. The registries carefully collate all the data for any one patient to avoid duplication of records. This is not a quick process, as information is often not made available to the registry until the main course of treatment is finished. A subset of the data, as defined in the cancer registration minimum dataset,<sup>7</sup> is sent to the national registry at ONS. A diagram illustrating the cancer registration system in England is presented in Figure A. The data items included in the minimum dataset are shown in Table A.

These data are loaded onto a database and validated. The extensive checks include the compatibility of the cancer site and the associated histology, and are closely based on those promulgated by IARC.<sup>1</sup> Once all the expected records for any one incidence year have been received and validated at ONS, detailed tables are published on the numbers and rates of all types of cancer by age and sex, and by region of residence, as presented in this volume.

**Table A Data items submitted to ONS**

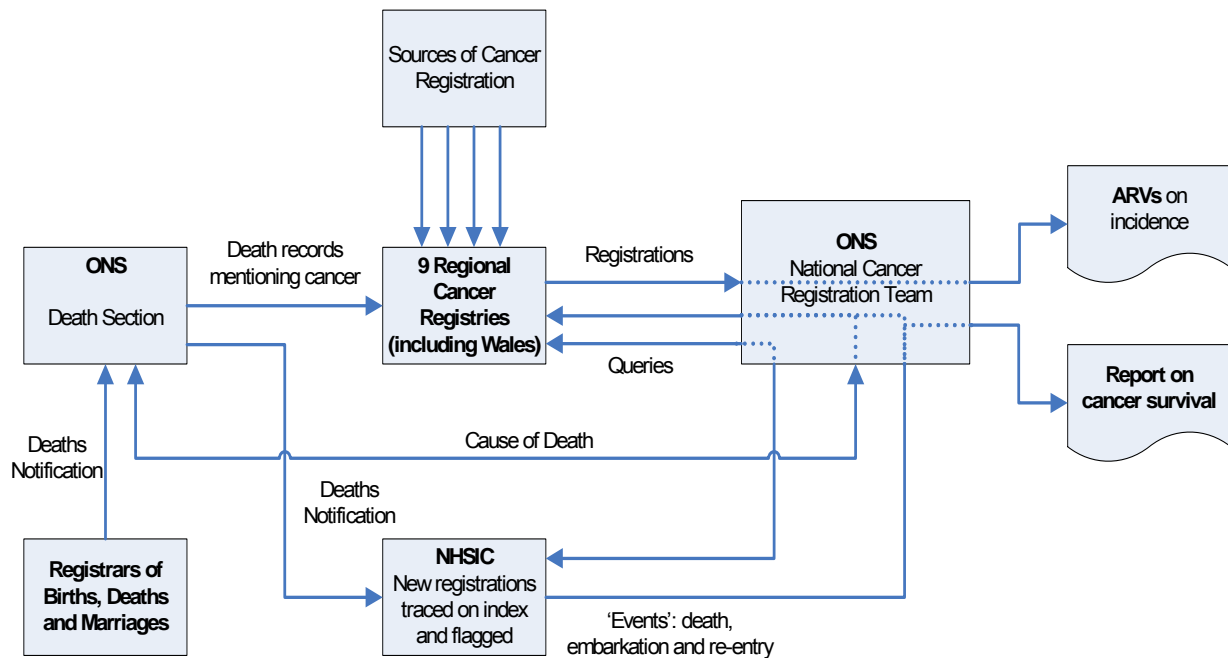
<b>Core</b>	<b>Optional</b>
Record type (new registration, amendment, deletion)	Country of birth
Identity number (unique)	Ethnic origin*
Patient's name	Patient's occupation
Patient's previous surname	Patient's employment status
Patient's address	Patient's industry
Postcode	Head of household's occupation
Employment	Head of household's employment status
Sex	Head of household's industry
NHS number	Diagnosis from screening*
Marital status	
Date of birth	
Date of death (if dead)	
Incidence date	
Site of primary growth	
Type of growth	
Behaviour of growth	
Multiple tumour indicator	
Previous registration details	
Basis of diagnosis*	
Death certificate only indicator*	
Side (laterality)*	
Treatment(s) (indicators)*	
Stage†	
Grade†	

\* From incidence year 1993

† From incidence year 1993; phased introduction – initially only for breast and cervix.

Source: Department for Health



**Figure A The cancer registration system in England**

Source: ONS

### 3. Cancer registrations, 2008

#### 3.1 Interpretation

Care is needed when interpreting cancer registration statistics, particularly when addressing either trends over time or differences between regions.

Registration of cases of cancer is a dynamic process in the sense that the data files both in the cancer registries and at ONS are always open. Cancer records may be amended, for example, the site code may be modified should later and more accurate information become available. The date of death is added to the record for those cases registered when the person was alive. Records may be cancelled, although this is relatively unusual. Also, complete new 'late' registrations may be made after either the cancer registry or ONS, or both, have published what were thought at the time to be virtually complete results for a particular year.

Consequently, the figures for registrations published by a cancer registry in its reference volume may differ from those in the corresponding annual reference volume (ARV) published by ONS (series MB1), which will generally have been produced at a different time. In addition, both sets of published figures will differ again from the numbers of registrations currently on the databases. Further differences between cancer registry and ONS figures may arise if records that have been rejected by the validation process at ONS have not been corrected by the registry concerned before the corresponding ARV tables are produced.

In section 4.1, it is noted that the cancer registries probably differ in their levels of completeness of registration. It may be difficult to interpret any apparent trends in cancer registrations because the registries are continually striving to increase their levels of ascertainment of cases. Any particularly large increases from year to year in the numbers of registrations for an individual registry are most likely to have arisen because of this.

In 2008 particular anomalies to note are:

- A large increase in the number of non-melanoma skin cancer (nmisc) registrations from the Eastern Cancer Registry and Information Centre (ECRIC): This is largely explained by improved methods of obtaining data, since ECRIC are now getting electronic data feeds that can in some cases be registered automatically. ECRIC have also taken over registration from the Thames Cancer Registry (TCR), for the populations of Hertfordshire and Essex. TCR does not record nmisc in their areas, whereas ECRIC always have. ONS does not report specifically on the number of nmisc registrations (see section 3.2). However, this increase is reflected in the total number of registrations reported to ONS by this registry and the total number of cancer registrations held on the National Cancer Registry database.
- Impact of the introduction of ICD-O3 morphology coding on 2008 cancer registrations sent to ONS by the Northern and Yorkshire Cancer Registry and Information Service (NYCRIS): Consistent with discussions at the UKACR Executive, NYCRIS introduced ICD-O3 morphology coding for 2008 diagnoses onwards and data were routinely submitted to ONS using the combination of ICD-10 site codes and ICD-O3 morphology codes. In implementing ICD-O3 morphology coding, the behaviour of some conditions changed. These were mainly associated with haematological conditions. For example, polycythaemia vera (ICD-10 codes D45, D47.1) and myelodysplastic syndromes/refractory anaemia (ICD-10 codes D46, D47.3) changed from borderline to malignant behaviour. As an ICD-10 'D' code is invalid with a malignant behaviour, the most appropriate site code that could be associated with these morphologies was 'C96 – Other and unspecified malignant neoplasms of lymphoid, haematopoietic and related tissue'. This resulted in an observable increase in the reported incidence of C96 cancers. If ONS reported on the full range of non-malignant ICD-10 'D' codes, equivalent decreases in these sites would also be observed. During 2009 the Executive revised their decision and advised that Registries should back-convert ICD-O3 morphology codes prior to submission to ONS. NYCRIS have implemented a mapping table to achieve this so that data for 2009 diagnoses will not be similarly affected. Also, the 2008 C96 registrations affected by this coding rule change will be resubmitted by NYCRIS before the next annual edition of the MB1 publication, to ensure these registrations are coded consistently over time in the National Cancer Registry database.

Other aspects of the cancer registration system that are relevant to the interpretation of the data are discussed in detail in section 4.1.

### 3.2 Exclusions

ONS has been advised by expert epidemiologists and members of the former Steering Committee on Cancer Registration, that non-melanoma skin cancer (ICD-10 C44) is greatly under-registered. Registration varies widely depending on a registry's degree of access to out-patient records and general practitioners. This under-registration of non-melanoma skin cancer is not just a problem for the cancer registries in England. Cancer Incidence in Five Continents Volume VI8 reported that

cancer registries in the United States, Australia, and parts of Europe, also collected very limited information on these skin cancers. In the commentary that follows, the figures for 'all malignancies' (ICD-10 C00–C97) exclude non-melanoma skin cancer (nm-sc). Also, it is not mandatory to register hydatidiform mole (ICD-10 O010). Therefore, these registrations are excluded from the figures, since they are not collected by all the registries.

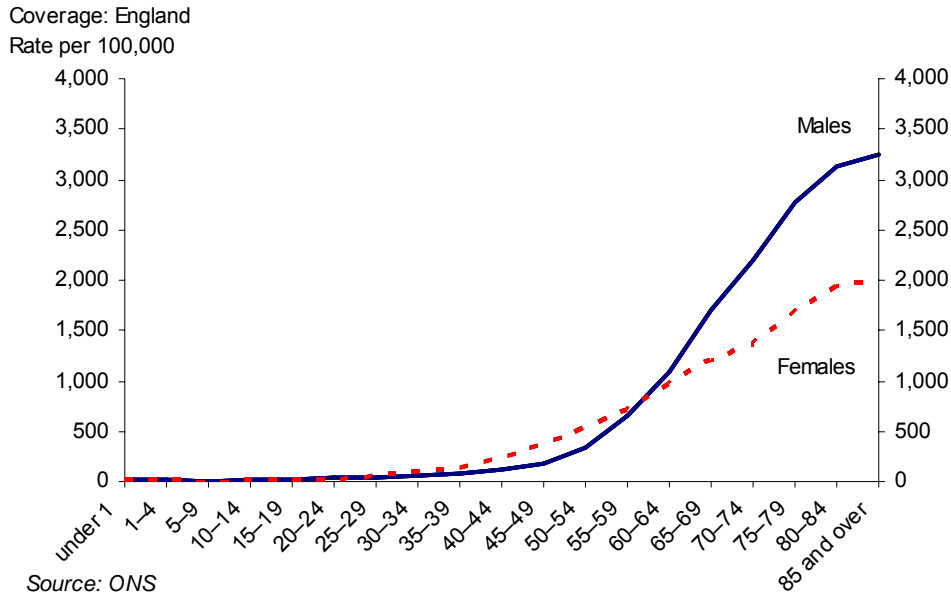
### 3.3 Cancer registrations in England, 2008

In total, there were around 198,000 new cases of cancer registered (malignant and non-malignant) for males and 212,500 for females, for 2008. These figures include the non-mandatory non-malignant neoplasms (D10–D31, D34, D35.0, D35.1, D35.5–D35.9 and D36), which comprise around 3,000 registrations for males and 2,500 for females. These are not shown in this publication as some registries do not send them to ONS.

In the ICD-10,<sup>3</sup> malignant neoplasms are coded C00–C97 and benign, in situ, uncertain and unknown neoplasms are coded D00–D48. Just under half of the non-malignant neoplasms for females were carcinoma in situ of the cervix (ICD-10 D06).

Cancer is predominantly a disease of the elderly. The overall crude rates of cancer registrations (excluding nm-sc) – 506 per 100,000 population for males and 485 per 100,000 population for females – conceal wide differences between the sexes and across the age groups, as illustrated in Figure B. The numbers on which this is based are given in Table 3. Following the small decrease in rates after early childhood, rates increased continuously across the age range for both males and females. From the 25–29 age group up to the 55–59 age group, rates of cancer were higher in females than in males. In the 40–44 age group, the rate in females was more than double that for males. Rates of cancer were higher in males than females from the 60–64 age group onwards, with an increasing difference in rates between the sexes with age up to 85 years and over. Rates of cancer were just over 40 per cent higher for males than for females in the 65–69 age group, but were over 60 per cent higher in those aged 80–84.

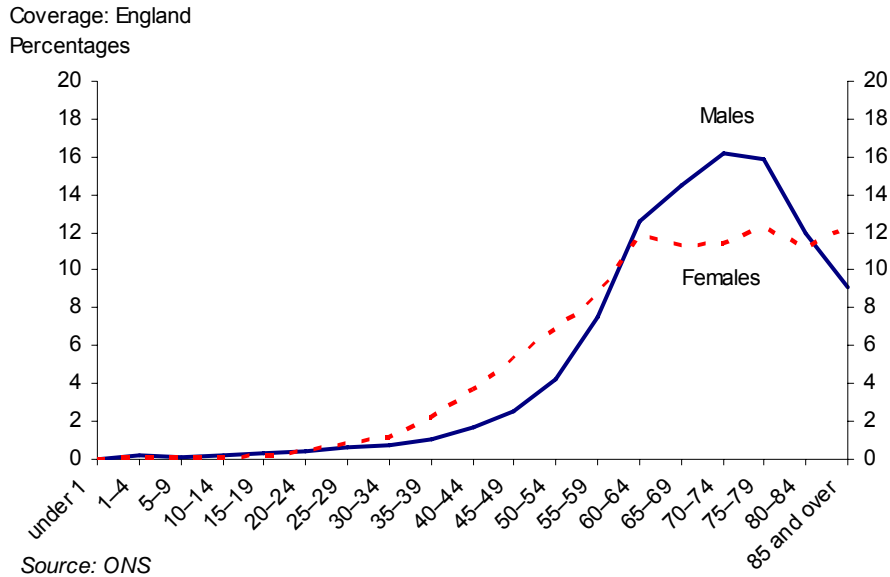
**Figure B All malignant neoplasms (excl. nmsc): incidence rates by age group, 2008**



The age distribution of malignant neoplasms is shown in Figure C. The numbers on which this figure is based are given in Table 1. Of the total of 254,809 malignancies, only 1,169 (0.5 per cent) occurred in children aged under 15; of these, 359 (31 per cent) were leukaemias (ICD-10 C91–C95). From ages 25–29 to 55–59, the per cent of cancers within each five-year age group was higher in females than in males, mainly because of the influence of the incidence of cancers of the breast (ICD-10 C50) and of the cervix (ICD-10 C53). Cancers in those aged under 45 amounted to 5.4 per cent of the total for males and 8.9 per cent for females. There was a clear peak in the age group frequency distribution for males, at 70–74 years. For females, there was no such clear peak, with similar frequencies being reported across the age groups from 60–64 up to 85 years and over.

The standardised registration ratios (SRRs) by Government Office Region (GOR) are illustrated in Figure D. The numbers on which this figure is based are given in Table 6. These SRRs should be interpreted with caution because it is difficult to separate the effect of variation in levels of ascertainment from genuine differences in incidence. See section 4.1.

**Figure C All malignant neoplasms (excl. nmsc): frequency distribution by age group, 2008**



**Figure D All malignant neoplasms (excl. nmsc): standardised registration ratios by Government Office Region, 2008**



### 3.4 Major cancer sites

In the ICD-10, there are 88 three-digit site codes relating to malignant neoplasms; of these, four relate to males only and eight to females only. For both males and females just three of the sites (different ones for each sex) constituted just over half of the total registrations in 2008, as shown in Table B.

**Table B The three most common cancers,<sup>1</sup> 2008**

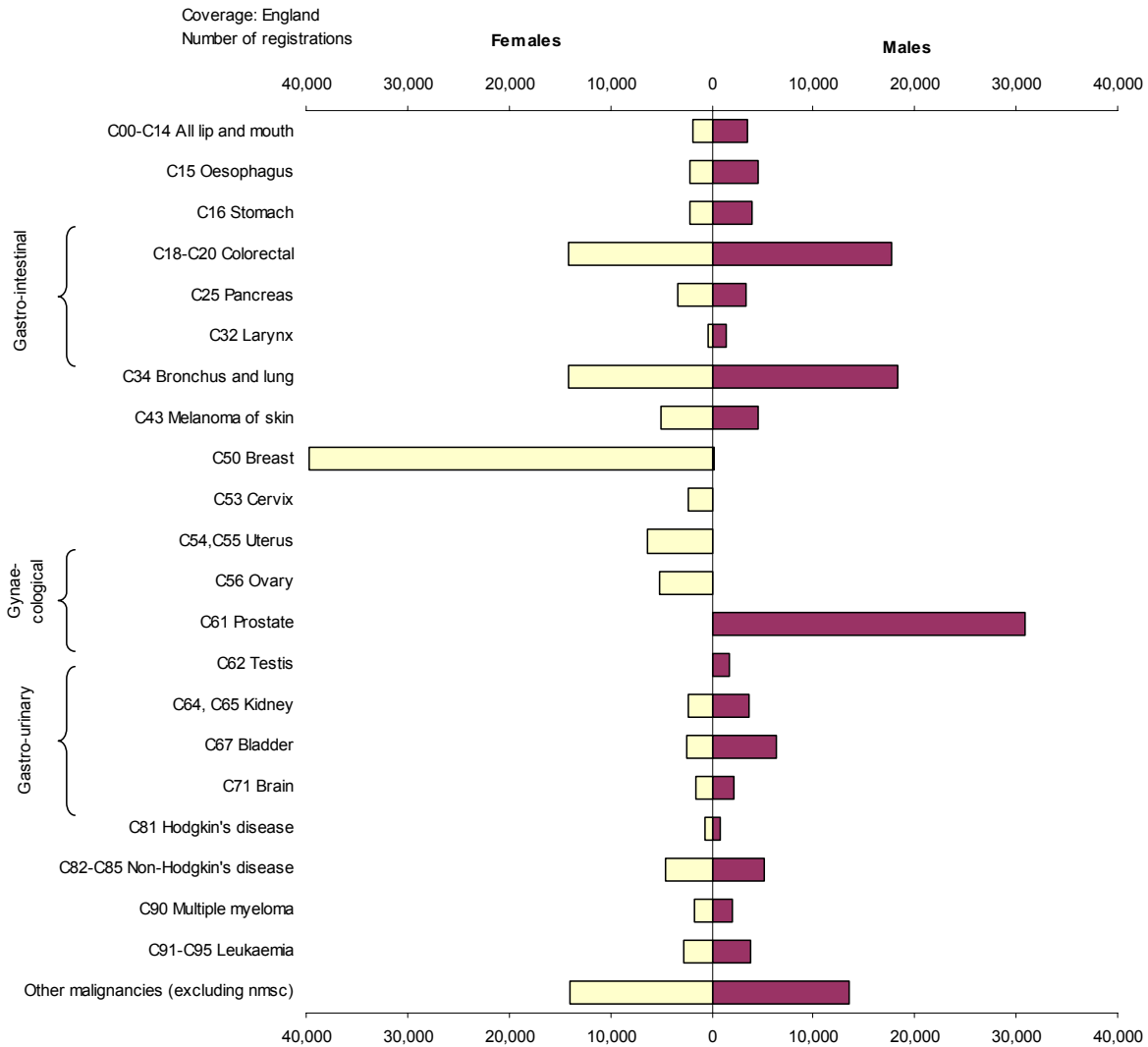
	ICD-10	Site description	Number of registrations	% of total malignancies
(a)	Males			
1	C61	Prostate	30,893	24.1
2	C34	Lung	18,382	14.3
3	C18-20	Colorectal	17,732	13.8
		Total	67,007	52.3
		All malignancies <sup>1</sup>	128,103	100.0
(b)	Females			
1	C50	Breast	39,681	31.3
2	C34	Lung	14,131	11.2
3	C18-20	Colorectal	14,114	11.1
		Total	67,926	53.6
		All malignancies <sup>1</sup>	126,706	100.0

<sup>1</sup> Excluding nmsc (ICD-10 C44) – See section 3.2.

Source: ONS

The numbers of registrations for the major sites are illustrated in Figure E (and given in Table 1). The numbers of registrations for these 21 major sites represent 89 per cent of the total for both males and females in 2008.

**Figure E Registrations by major sites, 2008**



Source: ONS

## 4. Guidance notes and definitions

### 4.1 Quality of cancer registration data

The essential features of the current cancer registration system have remained largely unchanged for 40 years. Some aspects of the system that are relevant to the interpretation of the data have been discussed in considerable detail by Swerdlow.<sup>9</sup> These aspects are discussed below, along with others including geographic coverage; methods of data collection; ascertainment (or completeness of registration); completeness of recording of data items; validity; accuracy; timeliness; late registrations, deletions and amendments; duplicate and multiple registrations; registrations from information on death certificates; clinical and pathological definitions and diagnoses; changes in coding systems; completeness of flagging for death registrations; and error.

Over the years, changes have occurred to the number of registries and to their geographic coverage. Full coverage of England (but not 100 per cent ascertainment of cases – see below) was achieved in 1962. Individual registries are likely to differ in the level of ascertainment of their data (that is the degree to which reportable incident cases of cancer in the population are actually recorded in the registry), but the best are known to have very high levels. Direct measures are only available from occasional special studies.<sup>10,11</sup> That by Hawkins and Swerdlow<sup>10</sup> estimated that the under-ascertainment of registration of childhood cancers by the regional registries was just under 5 per cent, although this figure may be greater for adults. General indications of ascertainment levels can be obtained from comparisons of the numbers of registrations and deaths in a period. The figures for deaths are those coded to a particular type of cancer as the underlying cause of death in residents of the same geographical area. Such mortality to incidence ratios by sex and site for 2008 are presented in Table 9. These ratios have several limitations, but there are variations between regions (and over time) that would be difficult to explain unless there were similar variations in ascertainment.

It should be noted that some cancer registries are not always able to collect complete information about benign, uncertain and unknown neoplasms and therefore these registration rates are almost certainly underestimates of the true incidence. In particular, this should be noted when interpreting regional differences.

It may be difficult to interpret any apparent trends in cancer registrations because the registries are continually striving to increase their levels of ascertainment of cases. Any particularly large increases from year to year in the numbers of registrations for an individual registry are most likely to have arisen because of this. For example, the recorded incidence for residents in some parts of the Thames regional health authorities was unusually high in 1992, and unusually low in 1993, as a result of a one-off exercise by the Thames Cancer Registry in 1993 to find further information for people with cancer mentioned on their death certificate.<sup>12</sup>

Completeness is the extent to which all appropriate data items have been recorded in the registry database. Some data items are essential, and if high proportions of such items are missing this is an indicator of poor quality. For example, 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. Therefore, the case may well be recorded against the wrong calendar year. A high DCO rate also implies under-ascertainment<sup>1</sup> because patients are being missed by the registry while they are alive and not all cancer patients die of their disease (in which case, cancer is not mentioned on the death certificate). Other quality indicators are the proportion of cases where the primary site is unknown, and the proportions where important information, such as the age of the patient or their postcode, is missing. Tables giving the proportions of registrations by region that have zero survival (which include both DCO cases and patients who were known to have died on the day of diagnosis – true zero survival) are given in Appendix E1 of the Cancer Trends volume;<sup>6</sup> tables giving the proportions of registrations by region with site unspecified are given in Appendix E2.

The agreed procedures to be followed by the cancer registries and ONS when submitting and processing data are set out in the 'Registry/ONS Interface Document'.<sup>13</sup> When a registry's submission is loaded onto the database at ONS, a large number of validity checks are carried out. There are over 40 checks on individual data items. These include that dates are valid, or that an



'indicator' is either 0 or 1 (or '&' if not known). There are around 30 cross checks between data items. These include the consistency of dates, for example that the incidence date is not after the date of death, and that the cancer site and histology are compatible, and are based closely on those promulgated by the International Agency for Research on Cancer (IARC)<sup>1</sup> when verifying data for inclusion in *Cancer Incidence in Five Continents*.<sup>14</sup> Combinations of site and histology are checked against three lists:

- (i) histology codes that will be accepted in combination with any site code
- (ii) histology codes that will only be accepted if the site code is in the appropriate group
- (iii) histology codes that will not be accepted in combination with any of the sites in a group

If a record passes all validation checks, it is given a quality status of 1. If a record fails any one of a small number of vital validation checks – for example if the date of birth is invalid, making it not possible either to include the record in an output table in the ONS annual reference volume or to flag the person concerned at the NHS-IC – it is given a quality status of 3. If a record passes all the vital checks but fails one or more other checks, it is given a quality status of 2, and along with records that have a quality status of 1, can be used in outputs and sent to the NHS-IC for flagging. Information about all records that fail any of the validation checks is sent to the registries for them to investigate and submit corrections.

The national standards for cancer registries<sup>15,16,17</sup> require that when a registry's data for a particular year are complete, no more than 0.5 per cent of records should have a quality status of 3. The quality status of all the records on the ONS cancer registration database from 1971 up to 2008 is shown in Table C. Over the past nine years, the proportion of records with serious errors has consistently been 0.1 per cent or less.

As with completeness, the accuracy of the data (that is the proportion of cases recorded with a given characteristic that truly have the attribute) is only occasionally known directly from special studies. Historically, various indirect studies have suggested there is considerable variation between regions. In 1995 a report was published on a project to audit the quality and comparability of cancer registration data in the United Kingdom.<sup>18</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. A study at the Merseyside and Cheshire Registry<sup>19</sup> also found that data quality within a registry varied by the age of the patient, the cancer site, and area of residence. However, a substantial audit of Scottish cancer registry data,<sup>20</sup> in which information was re-abstracted from the available records, found that severe discrepancies occurred in under 3 per cent of cases.

The timeliness of national data, based on the full set of individual records, depends on the speed of the slowest registry in completing its submissions to ONS. Cancer registration is not statutory, and ONS has no organisational, managerial or financial control over regional registries. Local requirements for up-to-date information have resulted in considerable improvements in timeliness in some areas. Also, several registries have recently redeveloped their computer systems, which has led to dramatic improvements in timeliness.

The point in time at which ONS, in consultation with the cancer registries, decides to produce the tables for the annual reference volume (ARV) is necessarily a compromise between two principal considerations: the need to minimise the delay between the relevant data year and the publication of the detailed results, and the requirement to obtain a very high level of completeness of the data and hence minimise the number of late registrations. The gap between the data year and production of tables has varied considerably over time. As a result there are currently varying proportions of additional cancer registrations held on the ONS database in comparison with the numbers published in the corresponding ARV, as shown in Figure F. Over the 38-year period reported, differences have averaged around 5 per cent.

The cancer registration database is 'dynamic' in the sense that records may be modified or deleted if new information is obtained. The information from 'trace back' of a death certificate may result in a case being registered many years after the true incidence date. Late deletions and amendments to data are in general a much smaller problem than late new registrations.

While late registrations result in the figures published in the ARV being too low, duplicate registrations can artificially inflate them. Such duplication may arise if a patient is resident in one area but treated in another; this is particularly so for those patients resident in North Wales and treated in Liverpool, and for those patients resident around London who are treated in central London. Duplications are prevented firstly by cancer registries checking whether a cancer is already registered, and secondly as a result of the NHS-IC flagging records. If on flagging, a previous registration is found for an individual, the registrations are examined to see if they are duplicates or true multiple primary cancers. The rules for decisions on duplicates/multiples have changed over time. ONS attempts to resolve all cases with any queries returned to cancer registries for resolution. All decisions are taken according to an agreed set of rules.

Copies of information from all death certificates in England and Wales mentioning cancer are sent by ONS to the registry covering the area in which the death occurred. Any cancers registered solely from the information on a death certificate were not included in the published information prior to 1974, at which point an abrupt increase occurred. Registries use the death certificate information in different ways. For example, some check the data by reference to clinical notes or other local data sources; others simply enter the death as a registration (with the year of death as the incidence year).

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 that 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 the registry. Also, clinical and pathological (and registry) definitions of cancer may change over time and between places, particularly for borderline malignant conditions.

**Table C**      **Number of newly diagnosed cancers<sup>1</sup> by quality status<sup>2</sup>  
1971–2008<sup>3</sup> England**

Year	Total	Status 1	Status 2	Status 3	Percentage of Status 3 records
1971	143,501	140,888	2,063	550	0.4
1972	145,997	143,477	1,666	854	0.6
1973	151,806	148,533	1,454	1,819	1.2
1974	156,667	154,559	376	1,732	1.1
1975	157,150	155,045	187	1,918	1.2
1976	158,153	154,984	171	2,998	1.9
1977	161,009	158,406	164	2,439	1.5
1978	160,942	158,996	155	1,791	1.1
1979	164,506	163,523	254	729	0.4
1980	169,941	168,635	292	1,014	0.6
1981	174,840	172,568	1,353	919	0.5
1982	175,893	173,160	1,421	1,312	0.7
1983	179,977	176,470	1,857	1,650	0.9
1984	179,635	175,389	2,661	1,585	0.9
1985	190,125	187,976	1,154	995	0.5
1986	187,386	184,780	1,424	1,182	0.6
1987	192,068	188,879	1,873	1,316	0.7
1988	197,743	194,345	2,183	1,215	0.6
1989	198,257	194,415	2,561	1,281	0.6
1990	199,442	180,644	18,216	582	0.3
1991	202,883	198,836	3,362	685	0.3
1992	211,243	206,511	3,634	1,098	0.5
1993	207,923	203,347	4,033	543	0.3
1994	213,311	212,160	328	823	0.4
1995	215,326	214,639	29	658	0.3
1996	216,036	215,404	24	608	0.3
1997	222,925	222,505	23	397	0.2
1998	223,133	222,571	26	536	0.2
1999	230,490	229,509	371	610	0.3
2000	230,212	230,058	13	141	0.1
2001	233,777	233,640	7	130	0.1
2002	231,800	231,548	6	246	0.1
2003	236,290	236,108	6	176	0.1
2004	241,601	241,436	33	132	0.1
2005	246,078	245,916	56	106	0.0
2006	252,233	252,083	65	85	0.0
2007	252,782	252,634	31	117	0.0
2008	256,848	256,682	33	133	0.1

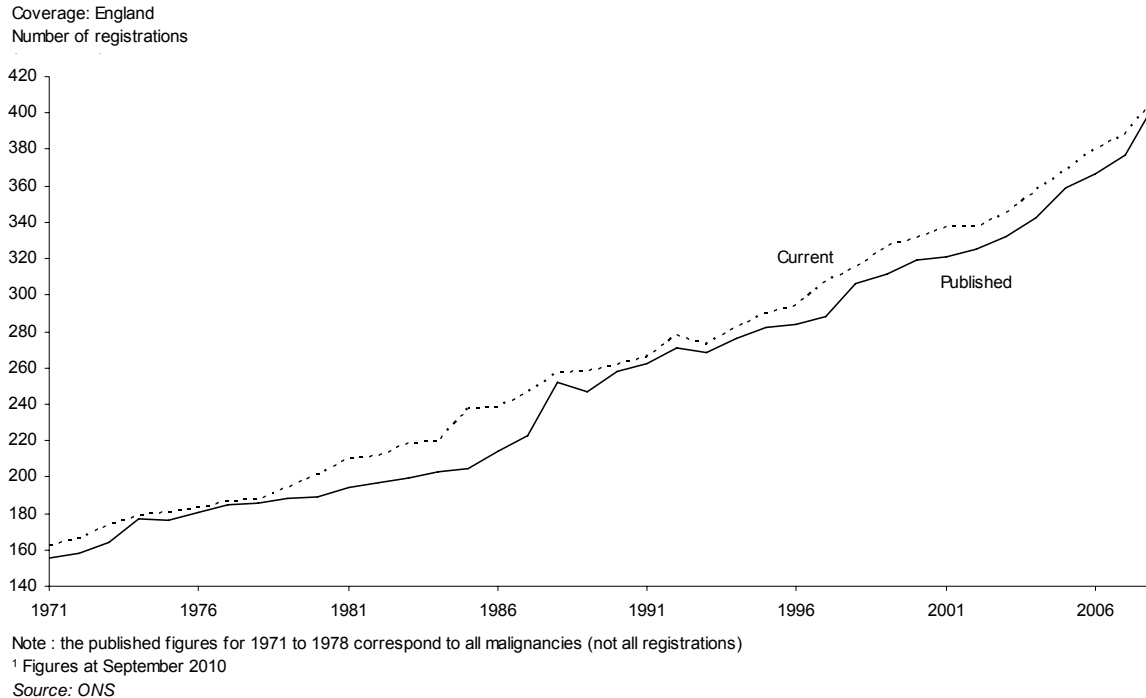
<sup>1</sup>All malignant neoplasms excluding nmsc (ICD-10 C44) - see section 3.2.

<sup>2</sup> See section 4.1 on 'validity'.

<sup>3</sup> Figures at September 2010.

Source: ONS

**Figure F** Number of registrations published in ARVs and currently on the National Cancer Registry database<sup>1</sup> 1971–2008



Changes in coding systems may also cause discontinuities in published data. For the national data held by ONS for incidence years 1971 to 1978, sites are coded to ICD-8 and histology by the Manual of Tumor Nomenclature and Coding (MOTNAC) 1968 edition.<sup>21</sup> For incidence years 1979 to 1994, sites are coded to ICD-9 and histology to ICD-O,<sup>22</sup> and from incidence year 1995 onwards, sites are coded to ICD-10 and histology to ICD-O<sup>23</sup>. In addition, there have been some minor changes in ONS coding and classification rules.<sup>8</sup> Over time, data submission by registries to ONS on abstract cards was superseded by electronic submissions. Abstract cards were coded at ONS whereas magnetic tapes and diskettes were coded by the registry before being sent to ONS. Therefore, a change to electronic submission (the last registry to do so was Oxford in 1985) may have been accompanied by changes in interpretation of coding.

In addition, the completeness of flagging of registrations by NHS-IC is important for cohort studies. The proportion of cancer registrations received by ONS that were successfully linked to an NHS-IC record was on average about 96 per cent from 1971 up to 1989. With the computerisation and improvements in cancer registry data quality, this has risen to over 99 per cent for data for 1993 and subsequent years. The importance for any particular study of the records not traced will depend upon any bias by area, cancer site or other main factors of interest.<sup>23</sup>

Finally, in published data on the scale of the national cancer registration system, it is almost inevitable that straightforward errors will occur, for example in the transcription and printing of tables. Corrections to known errors have been published.

## 4.2 Mortality data

Most deaths are certified by a medical practitioner. The death certificate is then usually 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 deaths, which is used in place of information from the medical practitioner. In some cases, additional information from the coroner's certificate is forwarded to ONS by the registrar.

A full set of notes and definitions for mortality data has been published by ONS.<sup>24</sup> This includes base populations; registrations; geographic coverage; death rates and standardisation; certification of cause of death; coding the underlying cause of death; analysis of conditions mentioned on the death certificate; amended cause of death; accelerated registrations; and legislation on registration of deaths and the processing, reporting and analysis of mortality data

## 4.3 Advantages and disadvantages of incidence and mortality data

Mortality data are generally more timely than incidence data. This is largely because there is a statutory requirement to register a death within five days. Cancer registration is not statutory, and information is collated from a wide variety of sources by registries. ONS cannot produce final results for England until data have been received from all registries. 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. Since the 1970s, five-year survival from many of the major cancers, for example breast (in females), cervix, larynx, melanoma of skin, testis and uterus, was in the range 50–70 per cent and since then there have been notable improvements in survival for almost all except the highly fatal cancers (lung, oesophagus, pancreas).<sup>25,26</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.<sup>27–30</sup>

Deaths are not always correctly certified, nor the underlying cause correctly coded. Although mortality data are considered to be 100 per cent complete, around 7 per cent of deaths in England and Wales that have an underlying cause of 'malignant neoplasm' (C00–C97) are coded to 'Malignant neoplasm without specification of site',<sup>31</sup> whereas the corresponding proportion for incidence data is only 2 per cent. These and other advantages and disadvantages of incidence and mortality data are summarised in Figure G.

Cancer mortality trends are, therefore, an imperfect and fuzzy indicator of trends in the efficacy of treatment. They reflect earlier trends in both incidence and survival and cannot be interpreted sensibly without them. Incidence and survival trends published by ONS, in collaboration with the Cancer Survival Group at the London School of Hygiene & Tropical Medicine, provide additional insights into the complex problems of cancer control. None of these indicators are perfect, and none are adequate on their own.<sup>32</sup>

## Figure G 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 site unspecified</li> <li>• incidence date known (except for small proportion registered solely from a death certificate)</li> </ul>	<p><b>Disadvantages</b></p> <ul style="list-style-type: none"> <li>• diagnostic accuracy less certain than for incidence</li> <li>• site only, no histology</li> <li>• around 7 per cent site unspecified</li> <li>• deaths in any one year result from cases diagnosed over a long previous period</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>• national coverage not achieved until 1962; evidence of under-ascertainment in the early 1970s</li> <li>• regional variation</li> </ul>	<p><b>Advantages</b></p> <ul style="list-style-type: none"> <li>• virtually 100 per cent complete</li> <li>• timely (within months of the end of a data year)</li> <li>• very long time series</li> </ul>

### 4.4 Populations

The population figures in Table 2 used to calculate incidence rates are mid-2008 estimates of the resident population of England based on the 2001 Census of Population. These allow for births, deaths, net migration and ageing of the population. Revised mid-2002 to mid-2008 population estimates for England and Wales were published on 13 May 2010. Revised estimates for 2001 were published on 9 September 2004 and revised estimates for 1992 to 2000 were published on 7 October 2004. Further information on population estimates and their methodology can be found at [www.statistics.gov.uk/popest](http://www.statistics.gov.uk/popest).

### 4.5 Government Office Regions (GORs)

Regional incidence data in this ARV are presented by the patient's GOR of usual residence. Some cancer registry publications present statistics based on the number of patients treated in the cancer registry area. Statistics in some cancer registry reports may therefore differ from the analyses by region of residence given in this volume.

### 4.6 Methods

#### Age-specific rates

The age-specific rates shown in Tables 3 and 8 are derived from the registrations of newly diagnosed cases of cancer in England in 2008 and the corresponding mid-year resident population from Table 2. The 'All ages' rate is referred to as the crude rate.

Crude rate is defined as total registrations per 100,000 population, or:

$$(\text{Total registrations} / \text{Total population}) \times 100,000$$

Age-specific rates may be calculated for each age group and these are defined as the number of registrations in the age group per 100,000 population in the same age group:

$$\text{ASR}_k = (r_k/p_k) \times 100,000$$

where  $\text{ASR}_k$  = age-specific rate for age group k

$r_k$  = registrations in age group k

$p_k$  = population in age group k

k = 0, 1–4, 5–9, ... , 80–84, and 85 and over

Age-specific rates may be calculated separately for males and females, or for both sexes combined.

### Age-standardised rates

The incidence of cancer varies greatly with age. Differences in the age structure of populations between geographical areas or over time therefore need to be controlled to give unbiased comparisons of incidence. This can be achieved through either direct or indirect standardisation.<sup>33</sup>

(i) Direct standardisation: age- and sex-specific rates in each group in the populations to be compared are multiplied by the corresponding number of people in a 'standard' population, World or (here) European Standard Population (Table D), and then summed to give an overall rate per 100,000 population.

Thus, the directly standardised incidence rate using the European Standard Population is given by:

$$I (\text{ASR}/E) = \{ \sum_k \text{ASR}_k P_k \} / \sum_k P_k$$

where  $\text{ASR}_k$  = observed incidence rate in age group k

k = 0, 1–4, 5–9, ... , 80–84, and 85 and over

$P_k$  = European standard population in age group k

Such directly standardised rates are presented in Tables 3, 5 and 10, which gives time-series for 1999 to 2008.

**Table D**      **Distribution of the European Standard Population**

Age	Population	Age	Population
0	1,600	45–49	7,000
1–4	6,400	50–54	7,000
5–9	7,000	55–59	6,000
10–14	7,000	60–64	5,000
15–19	7,000	65–69	4,000
20–24	7,000	70–74	3,000
25–29	7,000	75–79	2,000
30–34	7,000	80–84	1,000
35–39	7,000	85 and over	1,000
40–44	7,000		
		<b>Total</b>	<b>100,000</b>

Source: L Sharp et al, *Cancer registration statistics Scotland, 1981-1990*, (Edinburgh, Information and Statistics Division of NHS Scotland, 1993).

(ii) Indirect standardisation: one set of age- and sex-specific rates (here those for England as a whole) is taken as the standard. These rates are then applied to each of several index populations of known age structure to show how many registrations would have been expected in these index populations had they, at each age, experienced the cancer incidence of the standard population. The 'expected' incidence is then compared with the observed, their ratio being multiplied by 100 to give an index, called the standardised registration ratio (SRR), in which 100 is the value for the standard population. Calculations are based on 19 age groups (those used in Table 1).

The use of the SRR enables data for a particular site and sex to be presented as a single index figure relative to a defined standard or baseline. However if the incidence patterns in the various age groups are different in the two populations or time periods, SRRs are an unreliable guide to comparison, and age-specific rates should be examined.

Table 6 shows the SRRs in GORs of residence for 2008. For each cancer, the registration rates in England are taken as standards (with the sexes considered separately). For example, the SRR for cancer of the stomach in the East Midlands GOR was calculated as:

$$\text{SSR} = \frac{\text{observed incidence}}{\text{expected incidence}} \times 100 \quad \text{OR} \quad \frac{100 \times \text{No. of registrations of cancer of the stomach in East Midlands GOR}}{\sum [\text{Population in each age group, East Midlands GOR} \times \text{registration rate for cancer of the stomach for that age group, England}]}$$

### Cancer mortality to incidence ratios

The mortality to incidence ratios shown in Table 9 are derived from the deaths due to cancer in England in 2008 and the registrations of newly diagnosed cases of cancer in England in 2008.



The ratio is calculated as:

$$\text{Mortality to incidence ratio} = \frac{\text{Count of death registrations}}{\text{Count of incidence}}$$

The calculations for the cancer mortality to incidence ratios in table 9 are now based upon death registrations, this is a change from previous years when death occurrences were used. This change brings this publication in line with the majority of other mortality outputs and ensures consistency across the main publications. The move from occurrences to registrations is documented in the Mortality Statistics: Deaths Registered in 2009 annual reference volume found here [www.statistics.gov.uk/StatBase/Product.asp?vlnk=15096](http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=15096). Cancer mortality incidence ratios for 2008 are therefore not fully comparable with those for previous years.

## Survival

The latest national and sub-national cancer survival releases are all available to download from the Office for National Statistics website.<sup>34-36</sup>

## 4.7 Symbols and conventions used

0.0 less than 0.05

- nil

.. not available

: not appropriate

nos not otherwise specified

nec not elsewhere classified

Rates in Tables 3, 5, 8 and 10 and ratios in Table 6 that are calculated from less than 20 events are distinguished by italic type as a warning to the user that their reliability as a measure might be affected by the small number of events.

## 5. Maps and contact addresses

**Figure H** Areas covered by the regional cancer registries, England 2010



Map reproduced by permission of Ordnance Survey on behalf of HMSO. © Crown copyright and database right 2010. All rights reserved. Ordnance Survey Licence number ONS GD272183.

**Figure I** Areas covered by the Government Office Regions, England, 2010



Map reproduced by permission of Ordnance Survey on behalf of HMSO. © Crown copyright and database right 2010. All rights reserved. Ordnance Survey Licence number ONS GD272183.

**Cancer registries in the United Kingdom:**

Current directors, addresses, telephone and fax numbers

United Kingdom Association of Cancer Registries website: [www.ukacr.org](http://www.ukacr.org)

**(a) England**

Northern and Yorkshire

Professor J Wilkinson (co-director)  
Professor B Ferguson (co-director)

Tel: 0113 206 8830

Fax: 0113 206 8766

[John.Wilkinson@nycris.leedsth.nhs.uk](mailto:John.Wilkinson@nycris.leedsth.nhs.uk)\*

[Brian.Ferguson@nycris.leedsth.nhs.uk](mailto:Brian.Ferguson@nycris.leedsth.nhs.uk)

\* For information / enquiries, please contact Prof J Wilkinson  
Northern and Yorkshire Cancer Registry and Information Service  
St James's Institute of Oncology  
Level 6, Bexley Wing  
St James University Hospital  
Beckett Street  
LEEDS, LS9 7TF

Tel: 0113 206 8830

Fax: 0113 206 8766

Trent

Mr D Meechan

Trent Cancer Registry  
5 Old Fulwood Road  
SHEFFIELD, S10 3TG

Tel: 0114 226 3560

Fax: 0114 226 3561

Eastern

Dr J Rashbass, Director  
Dr C Brown, Medical Director

Eastern Cancer Registration and Information Centre  
Unit C, Magog Court  
Shelford Bottom  
Hinton Way  
CAMBRIDGE, CB22 3AD

Tel: 01223 213499

Fax: 01223 213571

[jem@ecric.nhs.uk](mailto:jem@ecric.nhs.uk)

Thames

Professor H Møller, Director and Professor of Cancer Epidemiology

Thames Cancer Registry  
1st Floor, Capital House  
42 Weston Street

LONDON, SE1 3QD

Tel: 020 7378 7688  
Fax: 020 7378 9510  
[henrik.moller@kcl.ac.uk](mailto:henrik.moller@kcl.ac.uk)

Oxford

Dr M Roche, Medical Director

Oxford Cancer Intelligence Unit  
4150 Chancellor Court  
Oxford Business Park South  
OXFORD, OX4 2GX

Tel: 01865 334770  
Fax: 01865 334794  
[monica.roche@sph.nhs.uk](mailto:monica.roche@sph.nhs.uk)

South West

Dr J Verne, Director

South West Public Health Observatory  
Grosvenor House  
149 Whiteladies Road  
BRISTOL, BS8 2RA

Tel: 0117 970 6474  
Fax: 0117 970 6481  
[julia.verne@swpho.nhs.uk](mailto:julia.verne@swpho.nhs.uk)

Mr T Malik, Deputy Director

South West Cancer Intelligence Service  
South West Public Health Observatory  
The Meadows  
Dean Hill Park  
WILTSHIRE, SP5 1EZ

Tel: 01794 344690  
Fax: 01794 344699  
[tariq.malik@swpho.nhs.uk](mailto:tariq.malik@swpho.nhs.uk)

West Midlands

Dr G Lawrence, Director

West Midlands Cancer Intelligence Unit  
Public Health Building  
The University of Birmingham  
Edgbaston  
BIRMINGHAM, B15 2TT

Tel: 0121 415 8129  
Fax: 0121 414 7714  
[gill.lawrence@wmciu.nhs.uk](mailto:gill.lawrence@wmciu.nhs.uk)

North West

Dr T Moran, Director of Intelligence and Research  
Mr S Raynor, General Manager

North West Cancer Intelligence Service  
2nd Floor, Muspratt Building  
The University of Liverpool  
LIVERPOOL, L69 3GB

Tel: 0151 794 5691  
Fax: 0151 794 5700  
[info@nwcis.nhs.uk](mailto:info@nwcis.nhs.uk)

North West Cancer Intelligence Service  
The Christie NHS Foundation Trust  
The Palatine Centre  
63-65 Palatine Road  
MANCHESTER, M20 3LJ

Tel: 0161 446 8080  
Fax: 0161 446 3590  
[NWCIS.info@nhs.net](mailto:NWCIS.info@nhs.net)

**(b) Wales**

Dr J Steward, Director

Welsh Cancer Intelligence & Surveillance Unit  
Floor 13, Brunel House  
2 Fitzalan Road  
CARDIFF, CF24 0HA

Tel: 029 20 373500  
[john.steward@velindre-tr.wales.nhs.uk](mailto:john.steward@velindre-tr.wales.nhs.uk)

**(c) Scotland**

Dr D Brewster, Director of Cancer Registration in Scotland

Scottish Cancer Registry  
Information Services Division of NHS National Services Scotland  
(ISD Scotland)  
Area 155  
Gyle Square  
1 South Gyle Crescent  
EDINBURGH, EH12 9EB

Tel: 0131 275 6092  
Fax: 0131 275 7511  
[Nss.isdCancerStats@nhs.net](mailto:Nss.isdCancerStats@nhs.net)

**(d) N Ireland**

Dr A Gavin, Director

Northern Ireland Cancer Registry  
Queens University of Belfast  
School of Medicine, Dentistry & Biomedical Sciences  
Mulhouse Building  
Grosvenor Road  
BELFAST, BT12 6BJ

Tel: 028 9063 2573  
Fax: 028 9024 8017  
[nicr@qub.ac.uk](mailto:nicr@qub.ac.uk)

## References

1. Parkin DM, Chen VW, Ferlay J, Galceran J, Storm HH and Whelan SL (1994). Comparability and Quality Control in Cancer Registration. IARC Technical Report No. 19. Lyons: International Agency for Research on Cancer.
2. Jensen OM, Parkin DM, Maclennan R, Muir CS and Skeet RG (eds) (1991). Cancer Registration: Principles and Methods. IARC Scientific Publications No.95. Lyons: International Agency for Research on Cancer.
3. World Health Organisation (1992–94). International Statistical Classification of Diseases and Related Health Problems, volumes 1, 2 and 3 (Tenth Revision). Geneva: WHO.
4. Office for National Statistics (2000). Cancer statistics – registrations, England and Wales, 1994. Series MB1 no.27. London: The Stationery Office.
5. Office for National Statistics (2010). Cancer statistics – registrations, England, 2007. Series MB1 no. 37. London: Office for National Statistics. Available on the Office for National Statistics website at: [www.statistics.gov.uk/StatBase/Product.asp?vlnk=8843](http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=8843)
6. Quinn MJ, Babb P, Brock A, Kirby L and Jones J (2001). Cancer Trends in England and Wales 1950–1999. Studies on Medical and Population Subjects No.66. London: The Stationery Office.
7. NHS Management Executive (1992). Minimum dataset for the National Cancer Registration System. EL(92)95. London: Department of Health.
8. Parkin DM, Muir CS, Whelan SL, Gao Y-T, Ferlay J and Powell J (1993). Cancer Incidence in Five Continents, Volume VI. IARC Scientific Publications No. 120. Lyons: International Agency for Research on Cancer.
9. Swerdlow AJ (1986). 'Cancer registration in England and Wales: Some aspects relevant to interpretation of the data'. Journal of the Royal Statistical Society Series A 1986; 149: pp 146–160.
10. Hawkins MM and Swerdlow AJ (1988). 'Completeness of cancer and death follow-up obtained through the National Health Service Central Register for England and Wales'. British Journal of Cancer 1992; 66: pp 408–413.
11. Villard-Mackintosh L, Coleman MP and Vessey MP (1988). 'The completeness of cancer registration in England: an assessment from Oxford FPA study'. British Journal of Cancer 1988; 58: pp 507–511.
12. Office for National Statistics (1999). Cancer statistics registrations, England and Wales, 1993. Series MB1 no.26. London: The Stationery Office.

13. Office of Population Censuses and Surveys (1994). Registry/ONS Interface Document. National Cancer Registration System, England and Wales. London: OPCS 1994 (subsequently revised).
14. Parkin DM, Whelan SL, Ferlay J, Teppo L and Thomas DB, (eds) (2003). Cancer Incidence in Five Continents, Vol. VIII. IARC Scientific Publications No.155. Lyons: International Agency for Research on Cancer.
15. NHS Executive (1996). Core contract for purchasing Cancer Registration. EL(96)7. London: NHS Executive.
16. Winyard G (1998). EL(96)7: Core contract for purchasing cancer registration (letter). Leeds: NHS Executive.
17. Department of Health (2001). Cancer Registry Standards for England, v2.1. London: Department of Health.
18. Huggett C (1995). Review of the Quality and Comparability of Data held by Regional Cancer Registries. Bristol: Bristol Cancer Epidemiology Unit incorporating the South West Cancer Registry.
19. Seddon DJ, Williams EMI (1997). 'Data quality in population based cancer registration: an assessment of the Merseyside and Cheshire Cancer Registry'. British Journal of Cancer 1997; 76: pp 667–674.
20. Brewster D, Crichton J and Muir C (1994). 'How accurate are Scottish cancer registration data?' British Journal of Cancer 1994; 70: pp 954–959.
21. American Cancer Society (1951). Manual of tumor nomenclature and coding (MOTNAC). Washington DC: American Cancer Society.
22. World Health Organisation (1977). International Classification of Diseases – (Ninth Revision). Geneva: WHO.
23. Quinn MJ (2000). 'Progress on flagging cancers at NHSCR'. The Researcher 2000; 14: pp 4–5.
24. Office for National Statistics (2010). Mortality statistics: Deaths registered in 2009, England and Wales. Series DR, DR\_09.
25. Coleman MP, Babb P, Damiecki P, Grosclaude P, Honjo S, Jones J, Knerer G, Pitard A, Quinn MJ, Sloggett A, and De Stavola B (1999). Cancer Survival Trends in England and Wales, 1971–1995: deprivation and NHS Region. Studies in Medical and Population Subjects No. 61. London: The Stationery Office.
26. Coleman MP, Babb PJ, Harris S, Quinn MJ, Sloggett A, and De Stavola BL (2000). Report: 'Cancer survival in England and Wales, 1991–98'. Health Statistics Quarterly 2000; 6: pp 71–80.



27. Quinn MJ and Allen EJ, on behalf of the United Kingdom Association of Cancer Registries (1995). 'Changes in incidence of and mortality from breast cancer in England and Wales since introduction of screening'. *British Medical Journal* 1995; 311: pp 1391–1395.
28. Blanks RG, Moss SM, McGahan CE, Quinn MJ and Babb PJ (2000). 'Effect of NHS breast screening programme on mortality from breast cancer in England and Wales, 1990–8: comparison of observed with predicted mortality'. *British Medical Journal* 2000; 321: pp 665–669.
29. Quinn MJ, Babb PJ, Jones J and Allen E, on behalf of the United Kingdom Association of Cancer Registries (1999). 'The effect of screening on the incidence of and mortality from cancer of the cervix in England: evaluation based on routinely collected statistics'. *British Medical Journal* 1999; 318: pp 904–908.
30. Sasieni P and Adams J (1999). 'Effect of screening on cervical cancer mortality in England and Wales: analysis of trends with an age-cohort model'. *British Medical Journal* 1999; 318: pp 1244–1245.
31. Office for National Statistics (2009). *Mortality statistics: Deaths registered in 2008, England and Wales*. Series DR, DR\_08.
32. Coleman MP, Babb PJ, Stockton D, Forman D and Møller H (2000). Trends in breast cancer incidence, survival and mortality in England and Wales. *Lancet* 2000; 356: pp 590–591 (letter).
33. dos Santos Silva I (1999). *Cancer Epidemiology: Principles and Methods*. Lyons: International Agency for Research on Cancer.
34. Office for National Statistics (2010) 'Statistical Bulletin – Cancer survival in England: one-year and five-year survival for 21 common cancers, by sex and age'. Available on the Office for National Statistics website at:  
[www.statistics.gov.uk/StatBase/Product.asp?vlnk=14007&Pos=3&ColRank=1&Rank=422](http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=14007&Pos=3&ColRank=1&Rank=422)
35. Office for National Statistics (2010) 'Statistical Bulletin – Cancer survival in the Spearhead Primary Care Trusts of England, 2001–08'. Available on the Office for National Statistics website at:  
[www.statistics.gov.uk/StatBase/Product.asp?vlnk=14821&Pos=1&ColRank=1&Rank=272](http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=14821&Pos=1&ColRank=1&Rank=272)
36. Office for National Statistics (2010) 'Statistical Bulletin – Relative survival from cancer in English Regions, 2001–03'. Available on the Office for National Statistics website at:  
[www.statistics.gov.uk/StatBase/Product.asp?vlnk=15379](http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=15379)

## Glossary

**Aetiology** The cause(s) of a disease.

**Age-specific rate** The number of cancer registrations or deaths for a particular sex and age group divided by the corresponding sex- and age-specific mid-year population; usually expressed per 100,000 population (see section 4.6 for fuller explanation).

**Age standardisation** A way of controlling for differences in the age structure of populations between geographical areas or over time, to allow unbiased comparison of incidence or mortality rates (see section 4.6 for fuller explanation).

**Age-standardised rate** An incidence or mortality rate which has been weighted using a standard population (in this book the European Standard Population) to control for differences in populations between geographical areas or over time, to allow unbiased comparison; usually expressed per 100,000 population (see section 4.6 for full explanation).

**Benign** Tumours which are usually slow growing, in which the cells resemble those of their tissue of origin, which do not invade surrounding tissue or metastasise to distant sites, and which are not usually fatal.

**Carcinoma** A malignant tumour derived from epithelial tissue (tissue covering the internal organs and other internal surfaces of the body; also forms glands).

**Cohort** A defined group of people. A birth cohort is a group of people, selected by their year of birth, whose characteristics can be followed as they enter successive age and time periods.

**Cohort study** An epidemiological study in which rates of disease are compared in groups with different exposures. For example, a group of smokers (exposed) and a group of non-smokers (not exposed) are followed up over time to see which ones develop lung cancer. The rates of lung cancer in the two groups are then compared to determine whether smoking (the exposure) increases the risk of developing lung cancer (in other words, is a risk factor for lung cancer).

**Death certificate only** Cases of cancer registered solely from information provided on the death certificate. These patients necessarily appear to have zero survival time (as the date of diagnosis has to be taken to be the date of death).

**Deprivation** Usually refers to socio-economic deprivation indicated by poor housing conditions and low income.

**DH** Department of Health.

**GOR** Government Office Region.

**Grade** An estimate of the degree of malignancy of a tumour, based on the proportion of its cells which resemble the cells of origin. Grade I has the least degree of malignancy and grade IV has the greatest.

Great Britain England including the Scilly Isles, Wales and Scotland including Orkney and Shetland (excludes the Isle of Man and the Channel Islands, which are Crown Dependencies).

Histology The study of cells and tissues at the microscopic level; in terms of cancer, the type of cell from which the tumour arises.

Incidence The number or rate (per head of population) of new cases of a disease diagnosed in a given population during a specified time period (usually a calendar year). The crude rate is the total number of cases divided by the mid-year population, usually expressed per 100,000 population (see also age-standardised rate).

ICD-10 Tenth Revision of the World Health Organisation's International Statistical Classification of Diseases and Related Health Problems.

In situ Localised tumour which has not invaded surrounding tissues or spread to other parts of the body.

Invasive Tumour which has spread to surrounding tissues.

Lead-time bias If an individual participates in a screening programme which detects a disease earlier than it would have been detected in the absence of screening, the amount of time by which diagnosis is advanced as a result of screening is called the lead time. Since the point of diagnosis is brought forward in time, survival as measured from diagnosis is lengthened, even if total length of life is not increased.

Leukaemia A group of cancers of the white blood cells in the bone marrow and/or the lymph nodes, classified according to whether they arise from lymphocytes (lymphocytic and lymphoblastic leukaemias) or from granulocytes (myeloid leukaemias), and according to whether they progress rapidly (acute) or slowly and intermittently (chronic).

Life tables Tables giving statistics on life expectancy of a population, based on mortality rates. Used to calculate lifetime risk and relative survival.

Malignant Tumours which grow by invasion into surrounding tissues and have the ability to metastasise to distant sites.

Misclassification An error in the process of cancer registration whereby a primary tumour could be classified as a secondary or vice versa, or a primary tumour could be classified to the wrong ICD site code.

Mortality The number or rate (per head of population) of deaths in a given population during a specified time period (usually a calendar year). The crude rate is the total number of deaths divided by the mid-year population, usually expressed per 100,000 population (see also age-standardised rate).

NCIC National Cancer Intelligence Centre.

NCIN National Cancer Intelligence Network.

**Neoplasm** A growth of abnormal tissue (also known as a tumour).

**NHS-IC** NHS Information Centre for Health and Social Care.

**ONS** Office for National Statistics.

**OPCS** Office of Population, Censuses and Surveys.

**Secondary tumours** Tumours formed at sites distant from the site of the original tumour (also known as metastases).

**Site** The anatomical location of a tumour, as specified by the ICD code.

**Standardised Registration Ratio (SRR)** A method of indirect standardisation applied to allow cancer incidence in an area to be compared to a standard population. The age and sex specific rates of the standard population are applied to a particular area and this 'expected' incidence can then be compared to that actually observed in the standard population. SRRs are generally expressed as an index with the standard population having a value of 100.

**Tumour** A mass of abnormal tissue, the growth of which exceeds and is uncoordinated with the normal tissue from which it originates, and which persists in the same excessive manner after the stimuli which evoked the change have ceased (also known as a neoplasm).

**United Kingdom (UK)** England including the Scilly Isles, Wales, Scotland including Orkney and Shetland, and Northern Ireland (excludes the Isle of Man and the Channel Islands, which are Crown Dependencies).

**UKACR** United Kingdom Association of Cancer Registries.

**VSOB** Vital Statistics Output Branch (part of ONS based in Titchfield).