

# Publication Report



## **Cancers in Teenagers and Young Adults in Scotland (1979-2008)**

**Publication date – 29 March 2011**

## Contents

|   |    |
|---|----|
| About ISD .....   | 2  |
| Official Statistics .....                                     | 2  |
| Introduction.....   | 3  |
| Key points.....   | 4  |
| Results and Commentary .....                                  | 5  |
| Incidence.....  | 5  |
| Survival .....  | 8  |
| Glossary .....  | 10 |
| List of Tables and Figures .....                              | 11 |
| Contact.....  | 12 |
| Further Information .....                                     | 12 |
| Appendix.....   | 13 |
| A1 – Background Information.....                              | 13 |
| A2 – Publication Metadata (including revisions details) ..... | 14 |
| A3 – Early Access details (including Pre-Release Access)..... | 16 |

## About ISD

Scotland has some of the best health service data in the world combining high quality, consistency, national coverage and the ability to link data to allow patient based analysis and follow up.

Information Services Division (ISD) is a business operating unit of NHS National Services Scotland and has been in existence for over 40 years. We are an essential support service to NHSScotland and the Scottish Government and others, responsive to the needs of NHSScotland as the delivery of health and social care evolves.

**Purpose:** To deliver effective national and specialist intelligence services to improve the health and wellbeing of people in Scotland.

**Mission:** Better Information, Better Decisions, Better Health

**Vision:** To be a valued partner in improving health and wellbeing in Scotland by providing a world class intelligence service.

## Official Statistics

Information Services Division (ISD) is the principal and authoritative source of statistics on health and care services in Scotland. ISD is designated by legislation as a producer of 'Official Statistics'. Our official statistics publications are produced to a high professional standard and comply with the Code of Practice for Official Statistics. The Code of Practice is produced and monitored by the UK Statistics Authority which is independent of Government. Under the Code of Practice, the format, content and timing of statistics publications are the responsibility of professional staff working within ISD.

ISD's statistical publications are currently classified as one of the following:

- National Statistics (ie assessed by the UK Statistics Authority as complying with the Code of Practice)
- National Statistics (ie legacy, still to be assessed by the UK Statistics Authority)
- Official Statistics (ie still to be assessed by the UK Statistics Authority)
- other (not Official Statistics)

Further information on ISD's statistics, including compliance with the Code of Practice for Official Statistics, and on the UK Statistics Authority, is available on the [ISD website](#).

## Introduction

The distribution of cancers in teenagers and young adults is different from that in adults and in children; in order to describe this distribution and to address the provision of services for diagnosis and treatment of this group, a separate classification system was developed in 2002 by Birch *et al.* and updated by Barr *et al.* (2006). The updated classification used in this analysis is presented in [Table 1](#).

## Key points

- In the 30 year period 1979-2008 there were 5,267 cancers diagnosed in persons aged between 15 and 24 years, an average of 176 per year and representing less than 1% of malignant neoplasms diagnosed in a given year.
- Incidence has risen over the period 1979-2008, but has been largely stable over the last two 5 year periods with the exception of some specific types of cancer.
- The observed survival rate has increased over the same time period: for all cancers combined, survival at one year after diagnosis has increased by 11 percentage points, to approximately 94% of diagnoses, while five year survival has increased by 16 percentage points to 83%.

## Results and Commentary

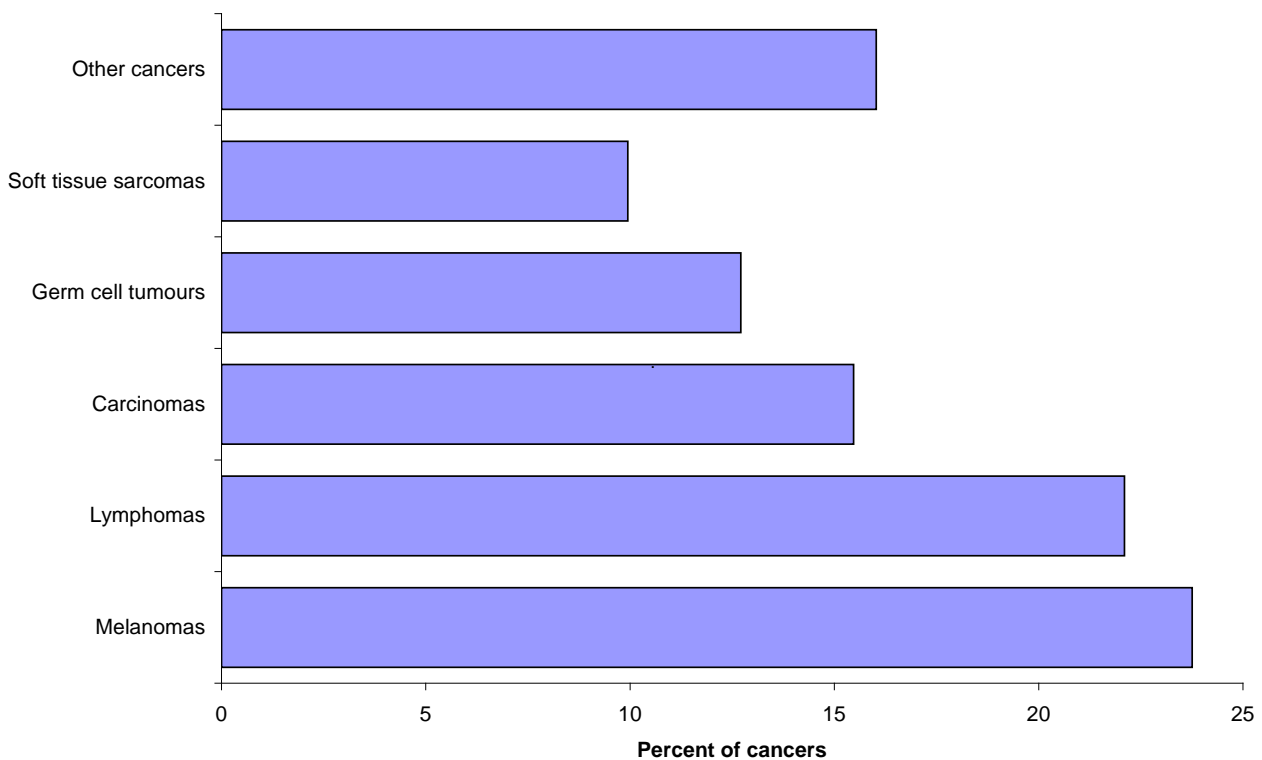
### Incidence

In the 30 year period 1979-2008, there were 5,267 cancers diagnosed in persons aged between 15 and 24 years, corresponding to an average of 176 cancers every year ([Table 2](#)). Cancers in 15-24 year olds represent less than 1% of all malignant neoplasms, excluding non-melanoma skin cancers.

During the whole 30 year period, lymphomas accounted for the highest proportion of cancers in this age group, at 22% of all diagnoses. The combination of leukaemias, lymphomas, carcinomas, melanoma and germ cell tumours accounted for 80% of all cancer diagnoses in this age group. Between the two age groups, the majority (65%) of cancers were diagnosed in the 20-24 year olds.

Of the cancers diagnosed in teenagers and young adults in 2008, melanomas make up a higher proportion than lymphomas ([Figure 1](#)), in contrast to the 30 year pooled figures. This corresponds with the increasing incidence of malignant melanoma in 20-24 year olds seen in the [main incidence publication](#). Soft tissue sarcomas in 2008 are also a higher proportion of the total diagnoses, at 10% in contrast with approximately 5% in the 30 year pooled figures.

**Figure 1. Most common cancers\* in adolescents and young adults, aged 15-24, in Scotland, 2008**

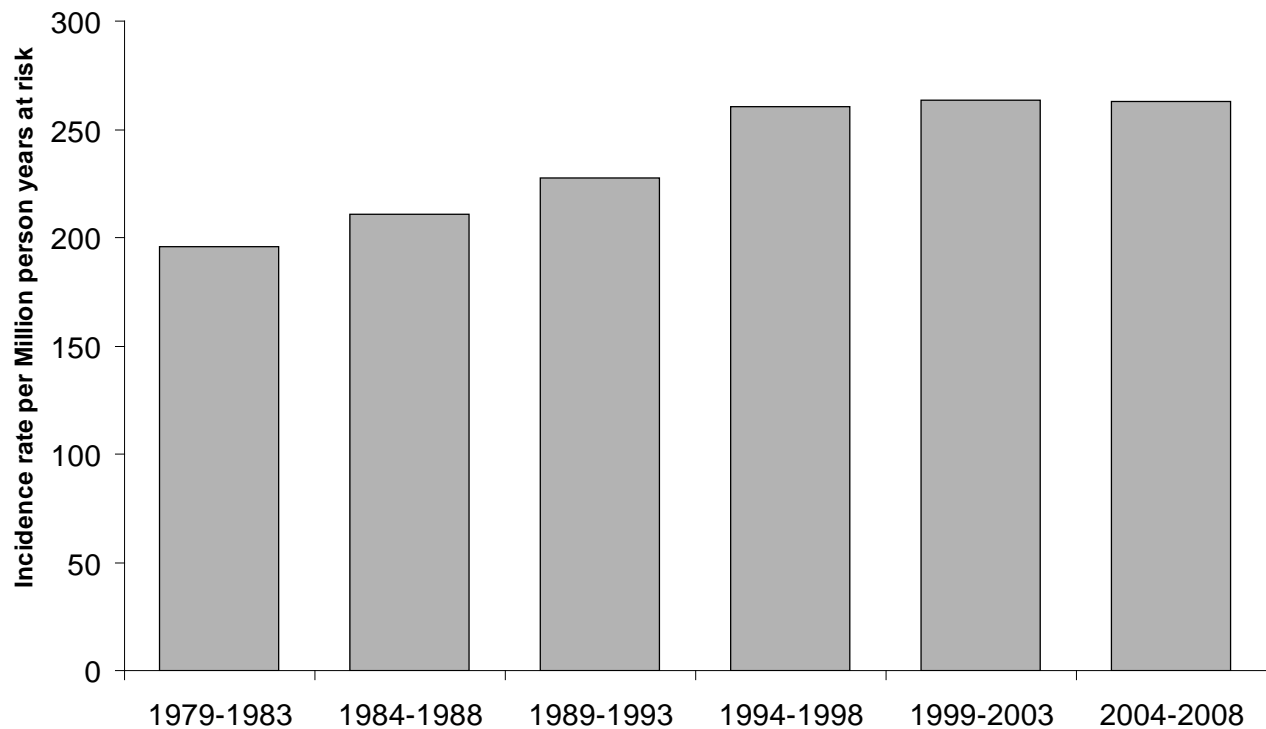


Source: Scottish Cancer Registry, ISD Scotland

Age-specific incidence rates allow more direct comparison of the two age groups, as they take into account the different population sizes between the younger (15-19 years) and older (20-24 years) groups. The age specific incidence rates ([Table 3](#)) for all cancers combined show similar trends to the observed numbers, with higher incidence in the older age group and in males compared to females. Looking at cancers individually, for both sexes combined, leukaemias (particularly in females) and bone tumours have a higher incidence in the younger age group, the incidence of CNS and brain tumours is roughly equivalent between the two, and the remainder of the tumours have higher incidence in the older age group. Incidence is higher in males for the majority of cancers except melanomas, carcinomas (particularly cancer of the thyroid and of the genitourinary tract), and miscellaneous specified tumours.

Incidence rates of all cancers combined in teenagers and young adults have increased over time ([Table 4](#)) up to the period 1999-2003, and have remained stable in the subsequent 5 year period 2004-2008 ([Figure 2](#)).

**Figure 2. Trends in age-standardised incidence of cancers in persons aged 15-24 years, in Scotland**



Source: Scottish Cancer Registry, ISD

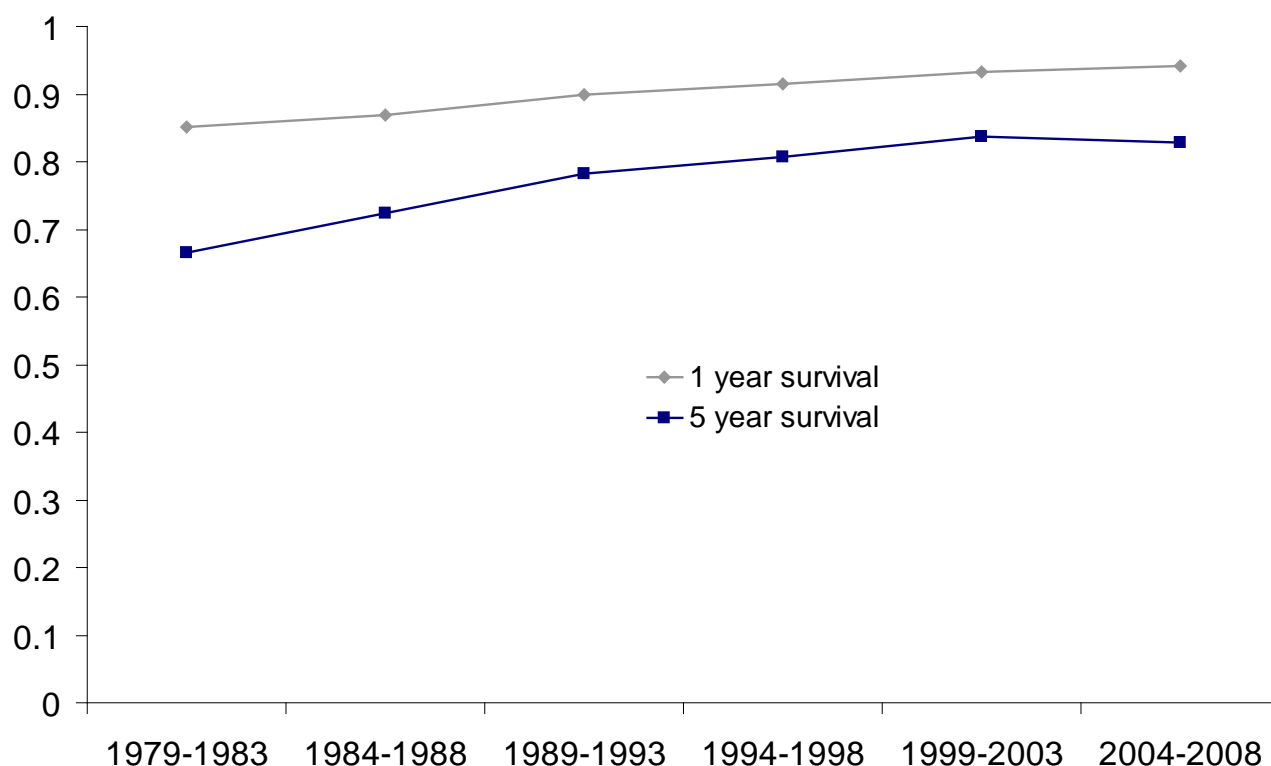
This approximate trend is followed by many of the individual cancers, when looking at both sexes combined, with the exceptions of a decrease in the incidences of miscellaneous specified and unspecified tumours, a gradual increase in lymphomas and sarcomas and a striking increase in melanomas over the 30 year period, from 19 to almost 60 cases per million person years at risk. (For an explanation of person years at risk, please see our [FAQs](#).)



## Survival

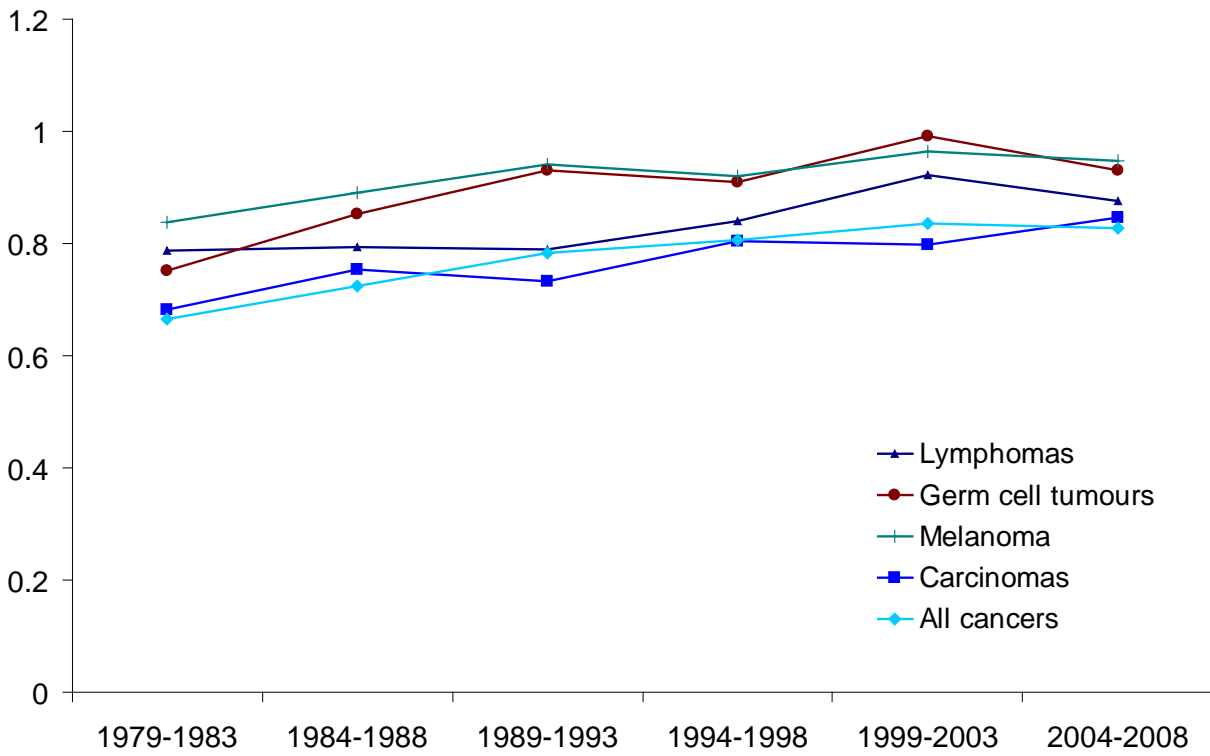
One year observed survival from all cancers combined in teenagers and young adults has increased by 11 percentage points, from 85% for those diagnosed in 1979-1983 to 94% for those diagnosed in the period 2004-2008 (Table 5, Figure 3). This increase is also apparent when cancers are examined individually, except for lymphomas where one year survival has fluctuated between 90% and 95% since the period 1979-1983. Five year survival has increased 16 percentage points (from 67% to 83%)(Figure 3 and Figure 4), and this is generally the case for the individual cancers with the exception of CNS tumours in the 2004-2008 period, which included an unusually high proportion of patients with 'Glioblastoma and anaplastic astrocytoma', known to have a generally very poor prognosis. Note that unspecified malignant neoplasms (not otherwise specified) (group 10) are not shown in Table 5 due to small numbers of cases.

**Figure 3. Trends in observed survival 1 and 5 years after diagnosis of cancer for persons aged 15-24 years, in Scotland**



Source: Registrations: Scottish Cancer Registry, ISD  
Deaths: General Register Office for Scotland

**Figure 4.** Observed 5 year survival for persons aged 15-24, following diagnosis of specific types of cancer



Source: Registrations: Scottish Cancer Registry, ISD  
Deaths: General Register Office for Scotland

## Glossary

neoplasm

cancer

## List of Tables and Figures

| No.      | Name  | Time period | File & size  |
|----------|---|-------------|--------------|
| Table 1  | <a href="#">Classification of adolescent cancers</a>                                    |             | Excel [31kb] |
| Table 2  | <a href="#">Number of cases of adolescent cancers in Scotland</a>                       | 1979-2008   | Excel [25kb] |
| Table 3  | <a href="#">Adolescent cancer incidence rates in Scotland</a>                           | 1979-2008   | Excel [25kb] |
| Table 4  | <a href="#">Age standardised adolescent cancer incidence rates in Scotland</a>          | 1979-2008   | Excel [25kb] |
| Table 5  | <a href="#">Observed survival from adolescent cancers in Scotland</a>                   | 1979-2008   | Excel [23kb] |
| Figure 1 | <a href="#">Most common adolescent cancers in Scotland</a>                              | 2008        | Excel [25kb] |
| Figure 2 | <a href="#">Trends in adolescent cancer incidence in Scotland</a>                       | 1979-2008   | Excel [23kb] |
| Figure 3 | <a href="#">Trends in adolescent cancer survival in Scotland (all cancers combined)</a> | 1979-2008   | Excel [19kb] |
| Figure 4 | <a href="#">Trends in adolescent cancer survival in Scotland (selected cancers)</a>     | 1979-2008   | Excel [21kb] |

## Contact

### **Susan Jensen**

Principal Information Analyst

[Susan.Jensen@nhs.net](mailto:Susan.Jensen@nhs.net)

0131 275 6125

### **Paula McClements**

Senior Statistician

[Paula.McClements@nhs.net](mailto:Paula.McClements@nhs.net)

0131 275 7666

## Further Information

Further information on cancer statistics can be found on the [Cancer Information Programme website](#).

For information on other health topics, please see the [ISD website](#).

## Appendix

### A1 – Background Information

#### A1.1 Notes on analysis

1. Results are presented for cases diagnosed in the period 1979-2008 for the 10 main categories of cancers in teenagers and young adults. The period was chosen to provide an analysis covering a 30 year period up to the most recent data available. Note that the follow-up period for survival analyses was to 31 December 2009.
2. The MS Access database containing the classification algorithm was obtained from the CRUK Paediatric and Familial Cancer Research Group, part of the Paediatric and Adolescent Oncology research programme at the University of Manchester, in November 2009.
3. Mid-year population estimates used for calculating the rate per million population were supplied by GROS and are published on [their website](#) (last accessed 14 December 2010).
4. Because of the small number of registrations and deaths many of the trends and differences amongst groups must be interpreted with caution, as even small absolute changes can introduce large percentage differences.

#### A1.2 References

2002

Birch JM, Alston RD, Kelsey A, Quinn MJ, Babb P, McNally RJQ. (2002). Classification and incidence of cancers in adolescents and young adults in England 1979-1997. *Br J Cancer*, 87, 1267-74. [Full text DOI:10.1038/sj.bjc.6600647](https://doi.org/10.1038/sj.bjc.6600647)  
(<http://www.nature.com/bjc/journal/v87/n11/full/6600647a.html>)

2006

Barr RD, Holowaty EJ, Birch JM. (2006). Classification schemes for tumors diagnosed in adolescents and young adults. *Cancer*, 107 (7), 1425-1430.  
Full text DOI:10.1002/cncr.21773  
(<http://onlinelibrary.wiley.com/doi/10.1002/cncr.21773/full>)

## A2 – Publication Metadata (including revisions details)

| Metadata Indicator                       | Description   |
|--|---|
| Publication title                        | Cancers Teenagers and Young Adults in Scotland  |
| Description                              | Enumerating incidence, mortality and survival of cancers in persons aged between 15 and 24 years in Scotland in the years 1979-2008, using the Classification of Cancers in Adolescents and Young Adults (CCAYA).   |
| Theme                                    | Health and Social Care  |
| Topic                                    | Conditions and Diseases   |
| Format                                   | PDF report  |
| Data source(s)                           | Scottish Cancer Registry (SMR06), General Register Office for Scotland  |
| Date that data was acquired              | November 2010   |
| Release date                             | 29 March 2011   |
| Frequency                                | Occasional  |
| Timeframe of data and timeliness         | A 30 year period was desirable for the analysis and extracted to give most recent data available at the time of extraction. Completion of the analysis was delayed as a result of analyst availability.   |
| Continuity of data                       | The previous report on cancers in Teenagers and young adults used the first edition of the CCAYA; this uses the second edition. There may be some artefactual differences in trends as a result.  |
| Revisions statement                      | As with other population-based cancer registries, the Scottish Cancer Registry is dynamic, with ongoing updating of records. Each year's release includes a refresh of the previous years, and as new registrations from previous years come to light, or changes in the coding are taken into account, the numbers may change. The timing of the release is intended to balance the likelihood of significant revision with timeousness of data.   |
| Concepts and definitions                 | <a href="#">Cancer Information FAQs</a>   |
| Relevance and key uses of the statistics | Incident cases and survival rates allow the Scottish Government to plan for provision of cancer diagnosis and treatment services, and palliative care for the under 15 year olds.   |
| Accuracy                                 | Registry data are subject to validation at data entry and quality assurance procedures. See the <a href="#">Cancer Information FAQs</a><br><br>For coding of deaths: <a href="http://www.gro-scotland.gov.uk/statistics/deaths/death-certificates-and-coding-the-causes-of-death/index.html">http://www.gro-scotland.gov.uk/statistics/deaths/death-certificates-and-coding-the-causes-of-death/index.html</a><br><br>Reported data are compared to previous years' figures and to expected trends. |
| Completeness                             | At time of extraction, data for the most recent year are estimated to be at least 98% complete. See   |

|                                    |   |
|------------------------------------|---|
|                                    | above note on Revisions. Routine indicators of data quality are compared to the rest of the UK and to other countries, and are available at <a href="http://www.ukacr.org">www.ukacr.org</a> . There have been adhoc studies of data completeness in the past. See the <a href="#">Cancer Information FAQs</a>  |
| Comparability                      | Cancer incidence data are regularly compared with the UK and other countries, for example in the publication <a href="#">Cancer Incidence in Five Continents</a> . Cancer mortality data are regularly compared with other UK countries and the UK as a whole (eg NCIS) and international reports (eg EUROCIM). In such comparisons, data are provided only at national (Scotland) level. |
| Accessibility                      | It is the policy of ISD Scotland to make its web sites and products accessible according to published guidelines.<br>For further details <a href="#">go to our accessibility page</a> .   |
| Coherence and clarity              | The report is available as a .pdf file with tables and charts either contained therein or clearly linked for ease of use.   |
| Value type and unit of measure     | Numbers of cases, rates of cases as crude and age and sex standardised rates. Survival expressed as percentages.  |
| Disclosure                         | The <a href="#">ISD protocol on Statistical Disclosure Protocol</a> is followed.<br>For this publication, at the levels of aggregation presented, the risk of disclosure was assessed as being low risk and so no further statistical disclosure control methods were employed.   |
| Official Statistics designation    | Official Statistics   |
| UK Statistics Authority Assessment | Not applicable  |
| Help email                         | <a href="mailto:nss.isdcancerstats@nhs.net">mailto:nss.isdcancerstats@nhs.net</a>   |
| Date form completed                | 11 April 2011   |



## **A3 – Early Access details (including Pre-Release Access)**

### **Pre-Release Access**

Under terms of the "Pre-Release Access to Official Statistics (Scotland) Order 2008", ISD are obliged to publish information on those receiving Pre-Release Access ("Pre-Release Access" refers to statistics in their final form prior to publication). The standard maximum Pre-Release Access is five working days. Shown below are details of those receiving standard Pre-Release Access and, separately, those receiving extended Pre-Release Access.

Standard Pre-Release Access:  
Scottish Government Health Department  
NHS Board Chief Executives  
NHS Board Communication leads

### **Extended Pre-Release Access**

This extended Pre-Release Access is given to a small number of named individuals in the Scottish Government Health Department (Analytical Services Division). This Pre-Release Access is for the sole purpose of enabling that department to gain an understanding of the statistics prior to briefing others in Scottish Government (during the period of standard Pre-Release Access).

Scottish Government Health Department (Analytical Services Division)