

# Cancer of Unknown Primary

## NCIN and CR-UK Data Briefing

### What is Cancer of Unknown Primary?

This briefing looks at individuals whose tumour is recorded to one of the secondary or unspecified ICD-codes. Patients are recorded as having Cancer of Unknown Primary (CUP) if the primary site of the malignancy cannot be established or the tumour has been registered without specification of site. Most patients have relatively poor outcomes. The uncertainty of the primary site of the tumour at time of treatment often severely impedes the management and treatment of patients. The statistics presented here are our best current understanding of the incidence of CUP.

CUP is open to different definitions. Although there is not a specific classification in the International Classification of Disease (ICD) nomenclature, the 2010 NICE Guideline (<http://www.nice.org.uk/CG104>) proposed that the majority of CUP can be covered by the ICD tenth revision (ICD-10) codes C77-C80. Descriptions and the number of newly diagnosed cases (incidence) for CUP by ICD-10 code in the UK in 2009 are shown below.

#### KEY MESSAGE:

*CUP accounts for 3.3% of all newly diagnosed cancers in the UK, and 7.1% in those aged 85+. Incidence rates have fallen by around 40% since the mid 1990s due to improved registration practice and advances in diagnostic methods. Further analyses are needed to improve diagnosis and treatment for these patients.*

### How many?

CUP accounted for more than 3% of all cancers in the UK in 2009. There were 10,470 newly diagnosed cases of CUP, with a European age-standardised rate of 11.5 per 100,000 population. These rates were significantly higher in males than females (12.2 vs. 10.9 per 100,000, respectively).

In the UK in 2009, nearly half (49%) of newly diagnosed cases of CUP were coded to ICD-10 C80, whilst only 9% were coded to ICD-10 C77.

There were 10,472 deaths from CUP in the UK in 2010, accounting for around 7% of all deaths from cancer. Of these, 9,780 (93%) were coded to ICD-10 C80, with 4 to C77 (0.04%), 444 to C78 (4%) and 244 to C79 (2.3%).

### Incidence has fallen, but why?

Since the mid 1990s, age-standardised incidence for CUP in the UK has fallen by around 40%, from 19.2 per 100,000. This is possibly the consequence of improvements in diagnostic methods, more information sources, and better registration practices by cancer registries, leading to more unknown primaries being coded to a specific cancer site during the investigatory process. For ICD-10 codes C78, C79 and C80, incidence rates are now lower than they were in the mid 1990s, but for ICD-10

| ICD-10 Code            | Description  | UK Incidence 2009 | Percentage of total incidence of CUP (C77-C80) |
|------------------------|--|-------------------|--|
| C77                    | Secondary and Unspecified Malignant Neoplasm of Lymph Nodes<br><i>(exc. malignant neoplasm of lymph nodes specified as primary) Lymph nodes of head, face &amp; neck (inc. supraclavicular); intrathoracic, intra-abdominal, axillary &amp; upper limb (inc. pectoral), inguinal &amp; lower limb, and intrapelvic lymph nodes; lymph nodes of multiple regions, lymph node unspecified</i>  | 972               | 9%   |
| C78                    | Secondary Malignant Neoplasm of Respiratory and Digestive Organs<br><i>Secondary malignant neoplasm of lung, mediastinum, pleura (inc. malignant pleural effusion NOS), other &amp; unspecified respiratory organs, small intestine, large intestine &amp; rectum, retroperitoneum &amp; peritoneum (inc. malignant ascites NOS), liver &amp; intrahepatic bile duct, other &amp; unspecified digestive organs</i>   | 3,163             | 30%  |
| C79                    | Secondary Malignant Neoplasm of Other and Unspecified Sites<br><i>Secondary malignant neoplasm of kidney &amp; renal pelvis, bladder &amp; other &amp; unspecified urinary organs, skin, brain &amp; cerebral meninges, other &amp; unspecified parts of nervous system, bone &amp; bone marrow, ovary, adrenal gland, secondary malignant neoplasm of other specified site, secondary malignant neoplasm unspecified site (inc. disseminated, generalized, multiple secondary cancer NOS, sarcomatosis (secondary))</i> | 1,230             | 12%  |
| C80                    | Malignant Neoplasm Without Specification of Site<br><i>Malignant neoplasm, primary site unknown so stated, malignant neoplasm unspecified (inc. cancer NOS, carcinoma NOS, malignancy NOS, malignant cachexia NOS and multiple cancer NOS)</i>   | 5,105             | 49%  |
| <b>TOTAL (C77-C80)</b> | <b>Cancer of Unknown Primary</b>   | <b>10,470</b>     | <b>100%</b>                                    |

code C77 the rates are slightly higher (**Figure 1**). The proportion of all cancers diagnosed as CUP has also fallen since the mid 1990s from around 5.8% of all cancer diagnoses in 1997 to 3.3% in 2009.

### More reported in older age groups

The distribution of CUP is more skewed to older ages. Over half (55%) of CUP cases occur in those aged 75 and over. For all cancers excluding CUP, just over a third (35%) of cases occur in the over 75s.

Incidence rates increased with age for all ICD-10 codes within the CUP grouping (**Figure 2**). There are around 1,550 cases of CUP diagnosed in those aged under 60 each year. The proportion of all cancers diagnosed as CUP increases sharply from the 70-74 age group, where the proportion was 3.2%, to 3.9% in 75-79 year olds, 5.1% in 80-84 year olds and 7.1% in those aged 85 and over.

### Variation across the UK

The proportion of all cancers diagnosed as CUP ranged from 4.5% in Northern Ireland to 2.9% in Scotland (3.3% in England and 3.1% in Wales). The age-standardised incidence for CUP ranged from 17.6 per 100,000 in Northern Ireland (significantly higher than the other countries) to 10.8 per 100,000 in Scotland (11.4 per 100,000 in England and 11.0 per 100,000 in Wales).

However, the composition of CUP and incidence rates by ICD-10 code varied by country (**Figure 3**). Whilst in England and Scotland, the majority of cases of CUP are coded to ICD-10 C80 (51%, 5.8 per 100,000 and 45%, 5.1 per 100,000 respectively); in Wales and Northern Ireland, the majority are coded to ICD-10 C78 (47%, 5.2 per 100,000 and 39%, 6.1 per 100,000 respectively). The lower incidence rates of malignant neoplasms without specification of site (ICD-10 C80) in Wales and Northern Ireland may reflect better registration practice.

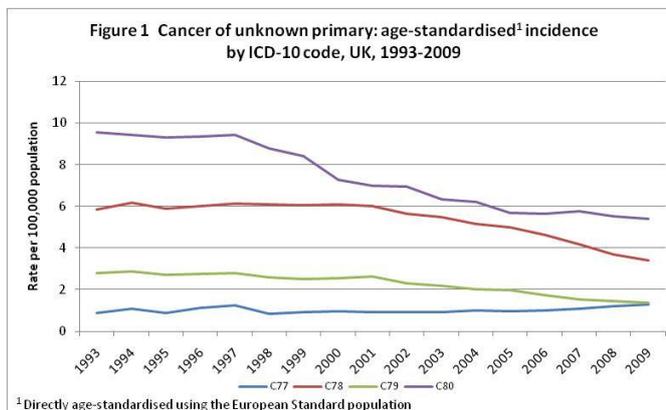
#### FIND OUT MORE:

National Cancer Intelligence Network  
<http://www.ncin.org.uk>

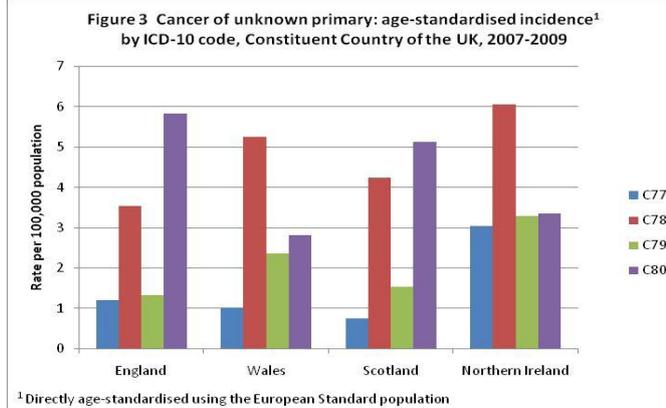
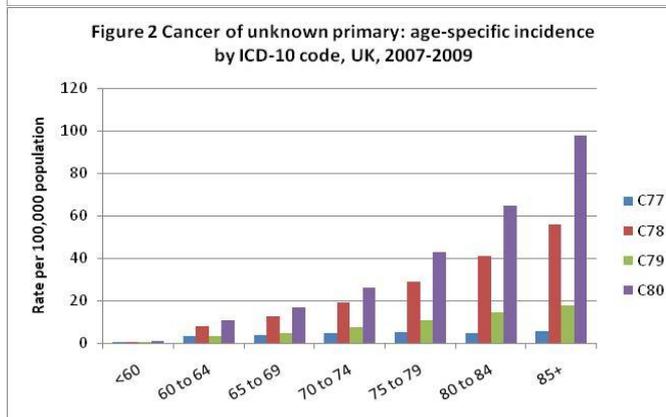
Cancer Research UK

CancerStats – Key facts and detailed statistics for health professionals  
<http://info.cancerresearchuk.org/cancerstats/>

The National Cancer Intelligence Network is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research. Sitting within the National Cancer Research Institute (NCRI), the NCIN works closely with cancer services in England, Scotland, Wales and Northern Ireland. In England, the NCIN is part of the National Cancer Programme.



<sup>1</sup> Directly age-standardised using the European Standard population



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