

Capturing Cancer of Unknown Primary (CUP) Data: Known Unknowns or Unknown Unknowns?

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Aim of the study

To understand how CUP data are recorded presently by Cancer registries with a view to establishing:

- (1) completeness and accuracy of the data
- (2) whether there is consistency of practice between registries
- (3) the extent of analysis and data presentation
- (4) how the quality of data collection might be improved in the future.

Methodology

A questionnaire was devised with the help of one of the cancer registries and sent to all registries in the United Kingdom.

ICD 10 codes usually ascribed to Cancer of Unknown Primary

C76 Malignant neoplasm of other and ill-defined sites
C77 Secondary and unspecified malignant neoplasm of lymph nodes
C78 Secondary malignant neoplasm of respiratory and digestive organs
C79 Secondary malignant neoplasm of other and unspecified sites
C80 Malignant neoplasm without specification of site

Source: <http://www.icd10data.com/ICD10CM/Codes/C00-D49/C76-C80>

Box 1

Results

Replies were received from eight out of the eleven registries in the UK. They showed that all registries use the UKACR definitions and training manual. Scotland produces its own guidelines, along similar lines. Six of the eight registries stated they use ICD 10 classification although three mentioned using ICD 02 or 03. Two registries mentioned both. Five stated that if the site of metastasis was unknown they would classify to C80. If the site was known they would use C77-C79. In one case C76 was also mentioned. C80 appeared to be the most commonly used code. Definitions are shown in Box 1.

Registries were asked the total numbers and proportion of cancers of unknown primary they registered during 2008. Unfortunately not all provided the total numbers, so it is not possible to provide a total, but all provided the proportion. This varied between registries from 0.7% to 4.0%. The supporting evidence used to come to an unknown primary coding included death certificate, pathology, MDT records and clinical notes. Two registries mentioned talking to clinicians, both within secondary care and primary care. One registry mentioned that it would discuss the classification with the coding department in the reporting hospital.

Distinguishing between unknown primaries and tumours that may be a metastasis from an existing tumour registration, showed that the greatest emphasis was placed on the morphology. If there was an existing primary with the same morphology then it was assumed that it was a metastasis from the primary tumour. Basal cell carcinomas were excluded from this rule. If there was no morphology or there was doubt, then one registry stated that they would register a second tumour. Other registries also talked about discussion with pathologists or clinicians involved with the case before coming to a decision.

If new information becomes available in relation to the registration, all registries reported that they would amend the registration. One registry qualified this saying that they would only use good quality information; another commented that they would only update within 12 months of the original registration.

In terms of data presentation, the information is usually presented within the ‘other’ category. In a small minority the numbers for cases within the classification C77-C80 or C76-C80 is available. One registry lists the number of cases on its website but does not separate them in its reports.

No registries were able to provide any specific reports. Only one registry, NYCRI, reported having done a specific analysis for registrations of C77-C80 made between 2002 - 2006 looking at incidence, morphology, treatment and survival.

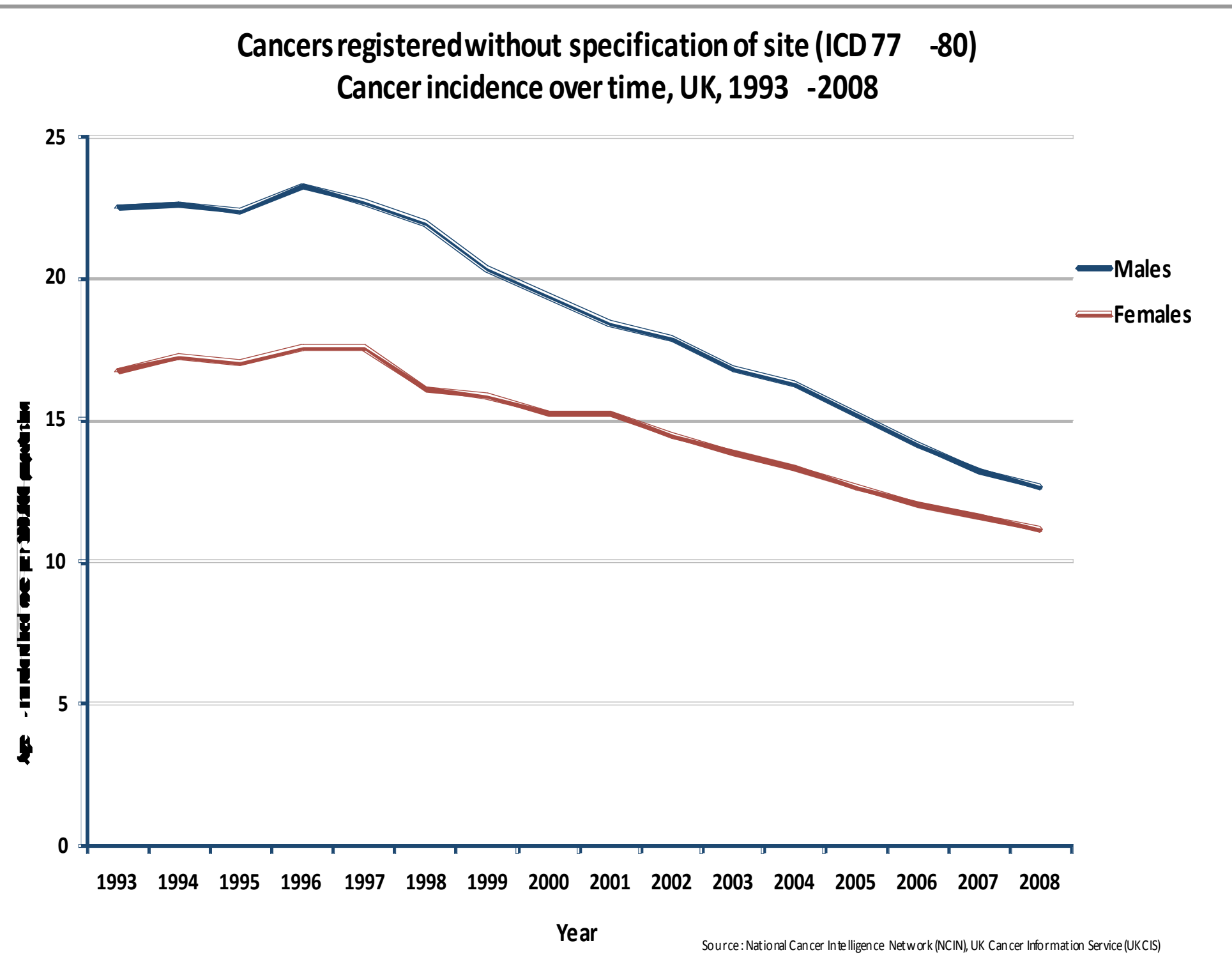


Figure 1

Poster presentation for "Liberating Information, Improving Outcomes". The NCIN and UKACR Conference. 15-17 June 2011, London.

Definitions of Cancer of Unknown Primary described by NICE 2010

<http://www.nice.org.uk/CG104>

Malignancy of undetermined primary origin (MUO)

Metastatic malignancy identified on the basis of a limited number of tests, prior to comprehensive investigation

Provisional Carcinoma of Unknown Primary (pCUP)

Metastatic epithelial or neuro-endocrine malignancy identified on the basis of histology / cytology, with no primary detected despite an initial screen of investigations, prior to specialist review and possible further specialised investigations

Confirmed Carcinoma of Unknown Primary (cCUP)

Metastatic epithelial or neuro-endocrine malignancy identified on the basis of definitive histology, with no primary detected despite a selected screen of investigations, specialist review, and completion of further appropriate specialised tests

Box 3

Discussion

Cancer of unknown primary accounted for 10,752 new cases in 2008 (Source: NCIN) . The results from this survey showed that whilst there are similarities in the processes for registering a cancer of unknown primary there are also potentially significant differences.

Six of the eight registries said they were using ICD 10 for coding using codes between C76 and C80. For definitions see Box 1. However two only mentioned ICD 02 or 3 coding. Six said they were using ICD C77-80. Of those two said they were also using C76, which does not necessarily need to be a secondary tumour.

The NICE Guidance highlighted that there are a great many unknowns for patients with unknown primary. As noted by NICE Guidance there is little evidence as to the diagnostic tests that would provide the greatest benefit. There is little evidence as to the best management and there is no evidence as to the cost effectiveness of treatments, or indeed if active management is always in the patient’s best interest.

Clear definitions and good data collection underpin the ability to undertake high quality research and audit. Without this it will be impossible to improve the management of, and outcome for, these patients.

The introduction of a single national data collection system for cancer registries provides an opportunity for better quality data. This, together with strengthened definitions, along the lines suggested by NICE, and routinely available data gives the potential to gain a better understanding of this condition and improved outcomes for patients.

There was considerable variation in the proportion of registrations registered to unknown primary, ranging from 0.7% to 4.0% of all registrations. This could have been due to a difference in the incidence of the disease but could also have been differences in coding practice. It is also reflected in the incidence rates shown by cancer network in Box 2. Figure 1 also shows that the incidence of cancer of unknown primary appears to be falling. This might be due to real changes in the incidence but could also reflect improvements in identifying the primary site, such as better access to diagnostics; the effectiveness of MDT working or changes in coding practice. Anecdotal evidence suggests that CUP patients reviewed at MDTs are often classified as having a probable primary tumour which corresponds to the site-specialty of the MDT. While this is understandable, and indeed may be correct in some cases, this approach involves unreasonable assumptions, as well as being non-uniform (different MDTs will have different “thresholds” for attributing a probable site-specific diagnosis).

NICE developed new definitions for cancer of unknown primary (Box 3). Cancer of unknown primary is a spectrum of conditions ranging from newly diagnosed patients with metastatic malignancy of undefined origin before extensive testing, through to “confirmed” Unknown Primary Cancer, when exhaustive investigations have truly failed to find a source. In the absence of rules for when such patients are considered in MDT meetings, and when a final diagnosis is attached, it is anticipated that there will be variability between MDTs in terms of the precision of the diagnosis recorded, and a lack of uniformity when total number of cases is reported. Greater clarity in definitions will improve the consistency of diagnosis and data recording.

It was pleasing to see that records were updated as new information became available. Currently this will mean that any previous classification will be lost. In order to understand the pathways for these patients it is necessary to be able to capture the different stages that a patient passes through on the path to a final diagnosis.

One of the best ways of improving data quality is to use it. Finding published information about cancer of unknown primary within routinely collected data is difficult. Until the NICE guidance was published, the data was not routinely published in a form that made it readily accessible. Usually it was hidden within a ‘catch all’ category. It was also disappointing to see that whilst some registries did make this data available as identifiable to codes C77-80, frequently as raw data, none had produced any publications on this relatively common cancer with a poor prognosis. In this study, only one registry reported undertaking any specific analysis of the epidemiology of this group of patients.

Cancers registered without specification of site (ICD 77-80) by country and cancer network

Incidence, Persons, United Kingdom, 2008.

Country/Cancer Network	Rate per 100,000*
England	11.8
N01 Lancashire and South Cumbria	15.3
N02 Greater Manchester & Cheshire	14.7
N03 Merseyside and Cheshire	16.7
N06 Yorkshire	11.4
N07 Humber and Yorkshire Coast	13.4
N08 North Trent	12.3
N11 Pan Birmingham	10.0
N12 Arden	11.6
N20 Mount Vernon	10.9
N21 North West London	8.9
N22 North London	11.8
N23 North East London	11.9
N24 South East London	11.0
N25 South West London	10.1
N26 Peninsula	9.2
N27 Dorset	9.6
N28 Avon, Somerset and Wiltshire	9.0
N29 3 Counties	9.5
N30 Thames Valley	11.7
N31 Central South Coast	9.9
N32 Surrey, W. Sussex and Hants	8.9
N33 Sussex	11.2
N34 Kent and Medway	12.4
N35 Greater Midlands	12.5
N36 North of England	13.8
N37 Anglia	12.3
N38 Essex	14.1
N39 East Midlands	11.5
Scotland	12.3
NOSCAN North of Scotland	11.7
SCAN South East Scotland	9.7
WOSCAN West of Scotland	14.2
Wales	10.7
Northern Ireland	15.4
United Kingdom	11.9

Source: National Cancer Intelligence Network (NCIN), UK Cancer Information Service (UKCIS)

Box 2

Conclusion

- There is a lack of clarity in defining and coding CUP
- There are differences in practice between registries
- The move to a single IT system within registries presents an opportunity to agree definitions and bring about greater consistency in recording
- NICE definitions should be adopted
- Analysis and presentation of data need to be improved