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 unspecified site
C77 Secondary and unspecified malignant neoplasm of lymph nodes
C78 Secondary malignant neoplasm of respiratory and digestive organs
C79 Malignant neoplasm of unspecified site

Definitions are shown in Box 1.


Table 1: Results
Registries 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.

No registries were able to provide any specific reports. Only one registry, Dorset, reported undertaking any specific analysis of the epidemiology of this group of patients.

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Definitions of Cancer of Unknown Primary described by NICE 2010
• 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.

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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.

There was considerable variation in the proportion of registrations recorded to unknown primary, ranging from 0.7% to 4.0% of all registrations. This could be due to differences in the incidence of the disease but could also have been differences in coding practice.

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.

To understand the pathways for these patients it is necessary to be able to capture the 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 is expected but that 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.

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