CANCER OF UNKNOWN PRIMARY

- Commonly a term for cancers that have spread from the primary site (i.e. metastases) for which site of origin cannot be determined with confidence; involving a single or multiple metastases.
- CUP can also cover a primary cancer of an ill-defined, possibly limited to an anatomical area, with or without the mention of metastases.
- In Australia and the UK, latest figures show CUP as the 7th/9th most common cancer diagnosis and 6th/5th most common cancer cause of death, respectively.[12][13]
- Prognosis for these cases is generally poor, although there are a small proportion of subtypes that have better outcomes.

**Textbox 1: Why might CUP registration be problematic?**

CUP is clinically heterogeneous, comprising a range of morphologies and often complex presentations.

This clinical uncertainty leads to ambiguous notifications with varying terminologies, which result in coding differences at registration.

CUP codes used for reporting CUP vary substantially:

- England tends to use ICD10 codes C77-C80;
- Some countries use just C80;
- Others again use C26, C39 and C76 in addition to either of the above.

This obscures accurate assessment of the CUP burden, both nationally and internationally.

**FUTURE DEVELOPMENTS?**

How cancers of unknown or ill-defined primary and metastatic presentations are counted and reported has the potential to have a significant impact on the profile of CUP, research investment, research findings, and ultimately patient treatment, experience and outcomes.

- The ultimate goal is to ascertain accurate and comparable CUP incidence and mortality.
- This requires national and international standardisation of coding practices for cancer of unknown primary (including the recording of metastases) and ill-defined primary cancers.
- It is hoped that the data provided in response to this survey can help start and support such a standardisation process.

**Textbox 2: Core issues towards standardisation?**

More specific guidance might be helpful with regards to:

- Coding of ill-defined or unknown primaries and metastatic presentations: record and report ill-defined primaries similar to CUP notifications? assess differences in coding rules for metastases, especially multiple metastases?
- Emphasis on seeking clarification about ambiguous CUP notifications: cases to reflect genuine clinical uncertainty, rather than bad documentation.
- Follow-up process of CUP notifications: reviewing CUP or ill-defined primary cases after a set period with regards to further information becoming available.
- Consistent process for death certificate notifications: in particular for CUP cause of death relating to a site-specific registration, or site-specific cause of death relating to a prior CUP registration.

Differences resulting from the use of differing coding systems (ICD10[14] and ICD03[15]) may also benefit from agreed ‘translation table’ of codes from one system to another to avoid reporting differences between countries.

**REFERENCES AND NOTES**


**ACKNOWLEDGEMENTS**

We would like to acknowledge the essential work of the cancer registries, without whom there would be no data. Their expertise is critical to much of today’s data and intelligence-based policy and decision-making process, from survival analyses to local service provision.

Thanks go to all staff in the Australian, UK and Irish registries for their participation in this project.

Thanks also go to other members of the National Cancer Intelligence Network, University of New South Wales and Cancer Research UK involved in this project, for their support and advice, in particular Catherine Thomson, Sean Gallagher and Lisa Chalmers and for their help in creating and circulating the survey.

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