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**The challenges of coding cancer of unknown primary (CUP) - a survey of current registration and reporting practices in the UK, Republic of Ireland and Australia**

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**Background**

Cancer of unknown primary (CUP) is a malignancy without an identified primary site. Previous research indicated that the definitions of CUP used in existing publications, as well as the underlying data, are inconsistent. This impedes a precise assessment of the burden of CUP, both nationally and internationally. The aim of the study was to compare the current CUP registration and reporting practices in Australia, the Republic of Ireland and the countries of the UK, with a view to making recommendations for improving national and international standardisation.

**Method**

Directors of population-based cancer registries were asked to complete a survey concerning the guidelines and coding rules followed in the registration of CUP, and the reporting of CUP statistics. A total of 20 regional registries in Australia (n=8), the UK (n=11) and Ireland (n=1) were approached and agreed to participate. The survey data were analysed using descriptive statistics.

**Results**

The findings show no evidence of consistent national or international coding guidance for registering and reporting CUP, resulting in varied cancer registration practices. The variation in practice includes differing interpretations of ICDO3 and ICD10 codes, the investigation of death certificate only notifications, electronic notifications, consideration of prior registrations of site-specific cancers, and the types of notifiers approached for additional information. In addition, there is variation in coding practices for tumours with non-epithelial morphologies such as melanoma and sarcoma, and the use of ill-defined primary site codes such as 'gastrointestinal' cancer. Reporting practices also vary, with some registries using ICDO3 codes and others using different ICD10 codes to represent CUP.

**Conclusions**

Inconsistencies in the registration practices for CUP impact on CUP incidence reporting and hinder comparisons between jurisdictions. This obscures an accurate understanding of the burden of the disease which is important for its management. The survey results will be used to develop a better understanding of historic data issues whilst informing future national and international registration guidance.