

Routes to Diagnosis: Cancer of Unknown Primary

NCIN Data Briefing

Background

The Routes to Diagnosis (RtD) study has been updated to include all patients diagnosed in 2006-2010, covering 1.3 million newly diagnosed tumours. The methodology has remained the same as the previous RtD publication.ⁱ An improvement in the completeness of Hospital Episode Statistics (HES) data linked to cancer registrations has led to HES data being available for more tumours than in the previous iteration of RtD.

This five year cohort enables overall Routes to be calculated for less common cancer sites, which previously had too few cases to produce meaningful results. This data briefing looks at the results for "Cancer of Unknown Primary", included for the first time, with breakdowns available by sex, age and deprivation.

KEY MESSAGES:

- 57% of patients diagnosed with Cancer of Unknown Primary presented as an emergency, which reflects the non-specific symptoms experienced by these patients.
- One-year survival for Cancer of Unknown Primary for managed Routes is above 24%, whereas for those who present as emergencies it is 5%.

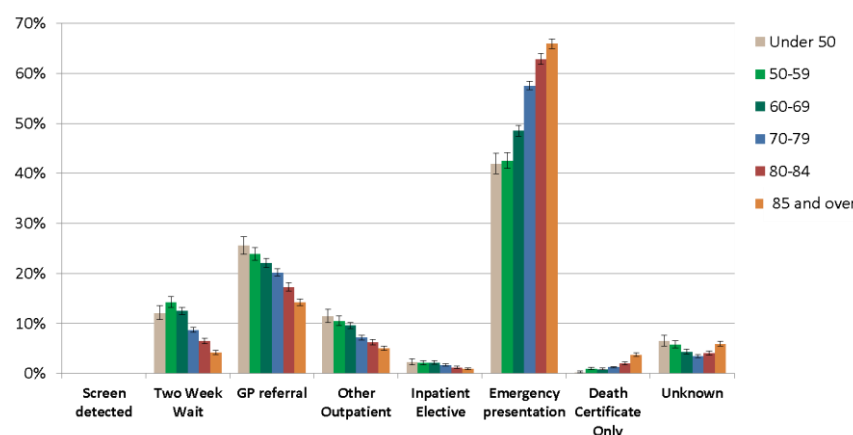
Cancer of Unknown Primaryⁱⁱ

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. In the period under study, CUP was a term applied to a spectrum of conditions ranging from "malignancy of undefined origin (MUO)", where metastatic disease has been identified without an obvious primary site, but prior to full investigation, and "confirmed CUP (cCUP)" when metastatic malignancy has been confirmed (usually) histologically and all relevant investigations have failed to determine the origin. It is believed that cases conventionally recorded as CUP fall predominantly into the latter category. CUP accounted for 3% of all tumours in this cohort. There were 44,100 cases of CUP diagnosed in 2006-2010, with a ratio of 1 male to 1.2 females; 5% of patients were aged under 50 and nearly 40% were aged 80 and over. There was a statistically significant difference in the proportion of CUP patients by socio-economic gradient, with 17% in the least deprived compared to 21% in the most deprived group.

A higher percentage of patients diagnosed with CUP presented as an emergency compared to all cancers, with 57% of CUP patients (25,000 cases) compared to 23% for all cancers; 45% were aged 80 and over, and 4% were aged under 50. CUP accounted for 9% of all Emergency Presentations in the cohort (compared to 21% for lung and 13% for colorectal cancers). A lower percentage of CUP patients are diagnosed through GP referral, 19% compared to 27% for all cancers. The most deprived

CUP patients are more likely to present as an emergency, 62% compared to 50% for the least deprived. Figure 1 shows the variation for CUP in routes to diagnosis by age, with the percentage of patients presenting as emergencies increasing, and GP referrals decreasing with age.

Figure 1: Percentage of patients by Route and age group for Cancer of Unknown Primary, 2006-2010, England



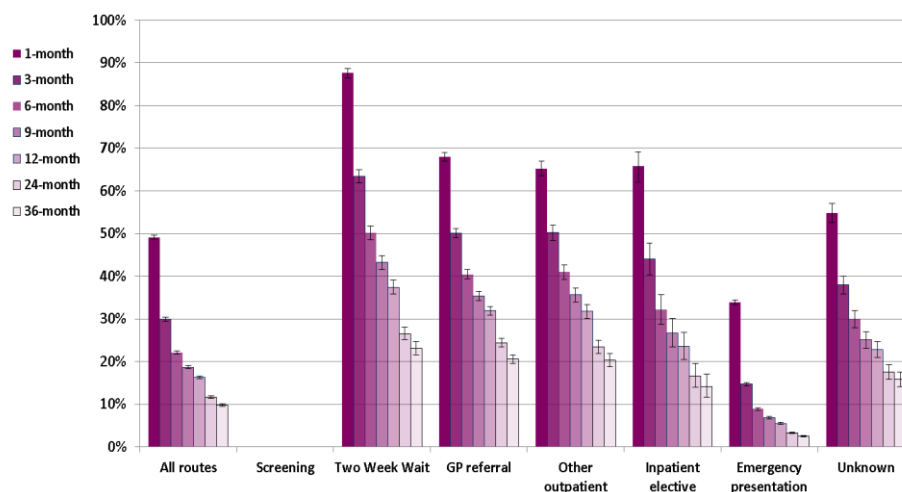
Emergency subgroup

Several pathways are grouped together into the Emergency Presentation Route based on the source of referral or admission method.ⁱⁱⁱ The breakdown of emergency pathways shows that 62% of emergency CUP patients were admitted from the A&E department; this is a similar proportion as for all cancers. Emergency referral from a GP accounted for 32% of the CUP patient emergency presentations; this can be compared to 28% for all cancers.

Survival

One-year relative survival for CUP is 16% for patients diagnosed during 2006-2010, however the very low survival estimates for Emergency Presentations is a major factor in this estimate. Figure 2 shows survival by presentation route and survival time. Tumours diagnosed as Emergency

Figure 2: Relative survival estimates by presentation route and survival time, Cancer of Unknown Primary, 2006-2010



Presentations have the lowest survival of all Routes, whereas CUPs that present through more managed Routes have significantly better survival. Whilst relative survival estimates of managed Routes are between 65% and 88% at one month, this falls to between 24% and 37% at 12 months. For Emergency presentations, relative survival estimates fall below 10% at 6-months post diagnosis.

Conclusions

These results show that nationally more than half (57%) of newly diagnosed cases of Cancer of Unknown Primary came through as emergency presentations, and this represents 9% of all cancer cases that present as emergencies. The high proportion of emergency presentations for CUP patients is in part a reflection of the non-specific symptoms experienced by these patients. Site-specific referral is thus difficult, and currently referral systems for generic investigation are poorly developed. NICE guidance on suspected cancer is currently being reviewed to reduce the importance of specific symptoms, broadening the range of symptoms and enabling more patients to be referred with non-specific symptoms. CUP multi-disciplinary teams (MDTs) are being established to ensure patients diagnosed with CUP are given guided treatment that is steered and supported. Many patients diagnosed with CUP have widespread malignancies, and as a consequence this limits what is achievable in improving their outcomes. Further work needs to examine both the reasons for the large proportion of CUP patients that present as emergencies, and the clinical basis of a diagnosis of CUP.

ⁱ Elliss-Brookes L, McPhail S, Ives A, Greenslade M, Shelton J, Hiom S, Richards M (2012) Routes to diagnosis for cancer - determining the patient journey using multiple routine data sets. *Br J Cancer* 107: 1220-1226.

ⁱⁱ CUP is open to different definitions. 2010 NICE Guideline (<http://www.nice.org.uk/CG104>) proposed that the majority of CUP can be covered by the International Classification of Disease, tenth revision (ICD-10) codes C77-C80. In this analysis, 50% of all CUP cases were coded to C80.

ⁱⁱⁱ [Routes to Diagnosis: Exploring Emergency Presentations](#)

FIND OUT MORE:

NCIN Routes to Diagnosis project: http://ncin.org.uk/publications/routes_to_diagnosis.aspx

NCIN Cancer of Unknown Primary: http://ncin.org.uk/publications/data_briefings/cancer_of_unknown_primary

The National Cancer Intelligence Network (NCIN) is a UK-wide partnership operated by Public Health England. The NCIN coordinates and develops analysis and intelligence to drive improvements in prevention, standards of cancer care and clinical outcomes for cancer patients.