

## Experiences of Cancer of Unknown Primary (CUP)

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### Background

Cancer of Unknown Primary (CUP) is a neglected and poorly understood disease. In 2010, the incidence of CUP (ICD-10, C77- 80) in the UK was **9,585** (EASR: 10.2\*) and there were **10,472** CUP deaths (EASR: 10.7\*),<sup>1, 2</sup> making it the **fifth most common cause of cancer death**.

Coping with CUP can be particularly challenging because of the uncertain diagnosis and difficulties in understanding both the condition and the tests used during investigations.<sup>3</sup> There is little existing research evidence about the experiences of patients, families and health professionals who encounter CUP.

\* European age-standardised rate per 100 000 population

### Aims

To explore the key issues and experiences associated with a diagnosis of CUP, from the perspective of CUP patients, their families and friends (informal carers) and their health professionals.

### Methods

A case study approach was taken. Each case study centred on one CUP patient and was constructed by exploring the experiences of the patient, their friends and family members (informal carers) and their health professionals. Data were collected via in-depth interviews and NHS patients' medical records.

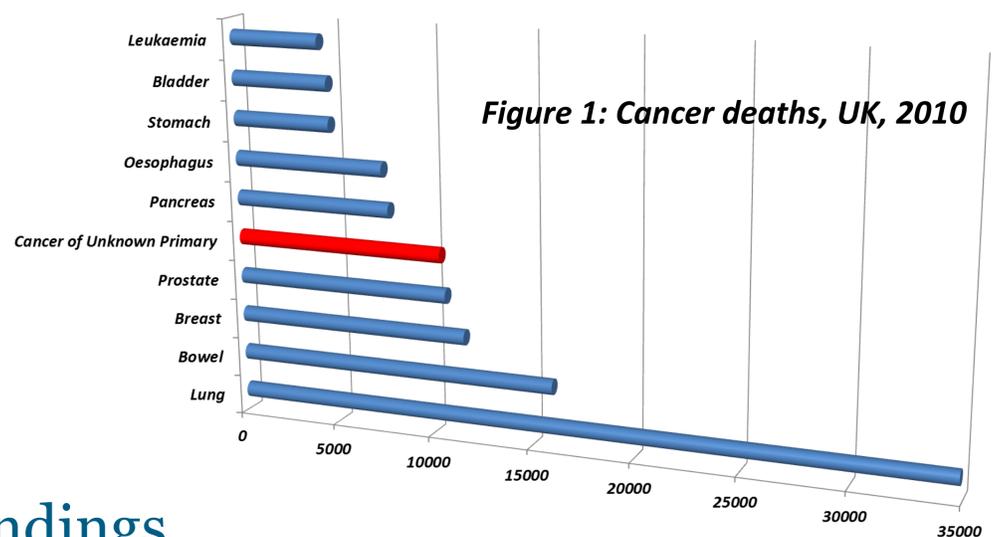
Eligible CUP patients were identified either by clinicians in three NHS Trusts, or through self-referral in response to a notice posted on the CUP Foundation website. Informal carer and health professional interviewees were nominated by patients.

### Findings

There were **17** cases, involving **44** interviewees. 14 patients were recruited from NHS Trusts and 3 from the CUP Foundation website. Patients' ages ranged from 41 to 78. Nine had been diagnosed within the last six months and all had undergone surgery, chemotherapy or radiotherapy.

**Figure 2: Interviewee characteristics**

17 patients	14 family members and friends	13 health professionals
<ul style="list-style-type: none"> <li>• 10 female, 7 male</li> <li>• Mean age = 61</li> </ul>	<ul style="list-style-type: none"> <li>• 10 female, 4 male</li> <li>• Mean age = 55</li> </ul>	<ul style="list-style-type: none"> <li>• 5 oncologists, 2 CNSs, 2 GPs, 2 surgeons, 1 dietician, 1 radiographer</li> </ul>



### Findings

**Uncertainty** was a feature of most patients' and informal carers' experiences, often leading to anxiety regarding diagnosis, prognosis, treatment and possible recurrence.

Some CUP patients experienced **disruptions in continuity of care**. Negative experiences related to care accountability, care co-ordination and timeliness of care. They were often associated with 'transitions', when patients were referred from health professional to health professional, or team to team. **'MDT tennis'**, where patients 'bounced' between teams, was evident in six cases.

Health professionals reported concerns about the impact of uncertainty on CUP patients and some described experiencing a **'test or treat dilemma'**: whether to test further for the primary, or start treatment with limited data.

### Conclusions

Uncertainty in CUP has negative consequences for patients, informal carers and health professionals and contributes to the poor outcomes of this group.

CUP patients are also susceptible to disruptions in continuity of care, often as a result of uncertainty.

Reducing uncertainty by minimising disruptions in continuity of care and providing appropriate information could lead to better support and improved experiences for patients and those involved in their care.

#### References:

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2. Cancer Research UK, UK Cancer Incidence (2010) by Country Summary, April 2013. [http://publications.cancerresearchuk.org/downloads/Product/CS\\_DT\\_INCMORTRATES.pdf](http://publications.cancerresearchuk.org/downloads/Product/CS_DT_INCMORTRATES.pdf) (Accessed 24th May 2013)
3. Macmillan Cancer Support. Coping with cancer of unknown primary (reviewed 2011). [www.macmillan.org.uk/Cancerinformation/Cancertypes/Unknownprimary/LivingwithCUP/CopingwithCUP.aspx](http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Unknownprimary/LivingwithCUP/CopingwithCUP.aspx) (Accessed 21st May 2013)

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