

# New evidence for workforce planning

R White, J Goodchild Macmillan Cancer Support

#### Background

For some people the primary site of malignancy cannot be established; this is known as 'cancer of unknown primary' (CUP). This can happen when extensive investigations fail to determine the primary site, when patients are too ill to undergo invasive tests or have cancer at such an advanced stage that further investigations would no longer aid their treatment.

CUP can be "a devastating and bewildering diagnosis for the patient and family". Patients:

- are often (57%) diagnosed following an emergency presentation<sup>2</sup>
- require additional support due to the uncertainty surrounding their diagnosis
- face increased risk of poor care coordination, investigation and treatment delays<sup>1</sup>

The role of specialist nursing is therefore critical in supporting these patients and so Macmillan commissioned the Specialist Adult Cancer Nurse Census (2014) that collected information on the CUP workforce for the first time.

#### Method

The methodology was largely based on previous National Cancer Action Team (NCAT) censuses undertaken in England<sup>3</sup>. Data was primarily collected through bespoke spreadsheets. These were sent to senior or lead cancer nurses / managers between April and June 2014. Respondents were asked to describe all hospital-based specialist adult cancer nurse posts on the 24 April 2014.

#### Inclusion criteria:

- Nurses who treat, support and manage adult cancer patients and promote health and wellbeing
- Agenda for Change band 5 to 9
- Vacant and filled posts

#### **Excluded nurses:**

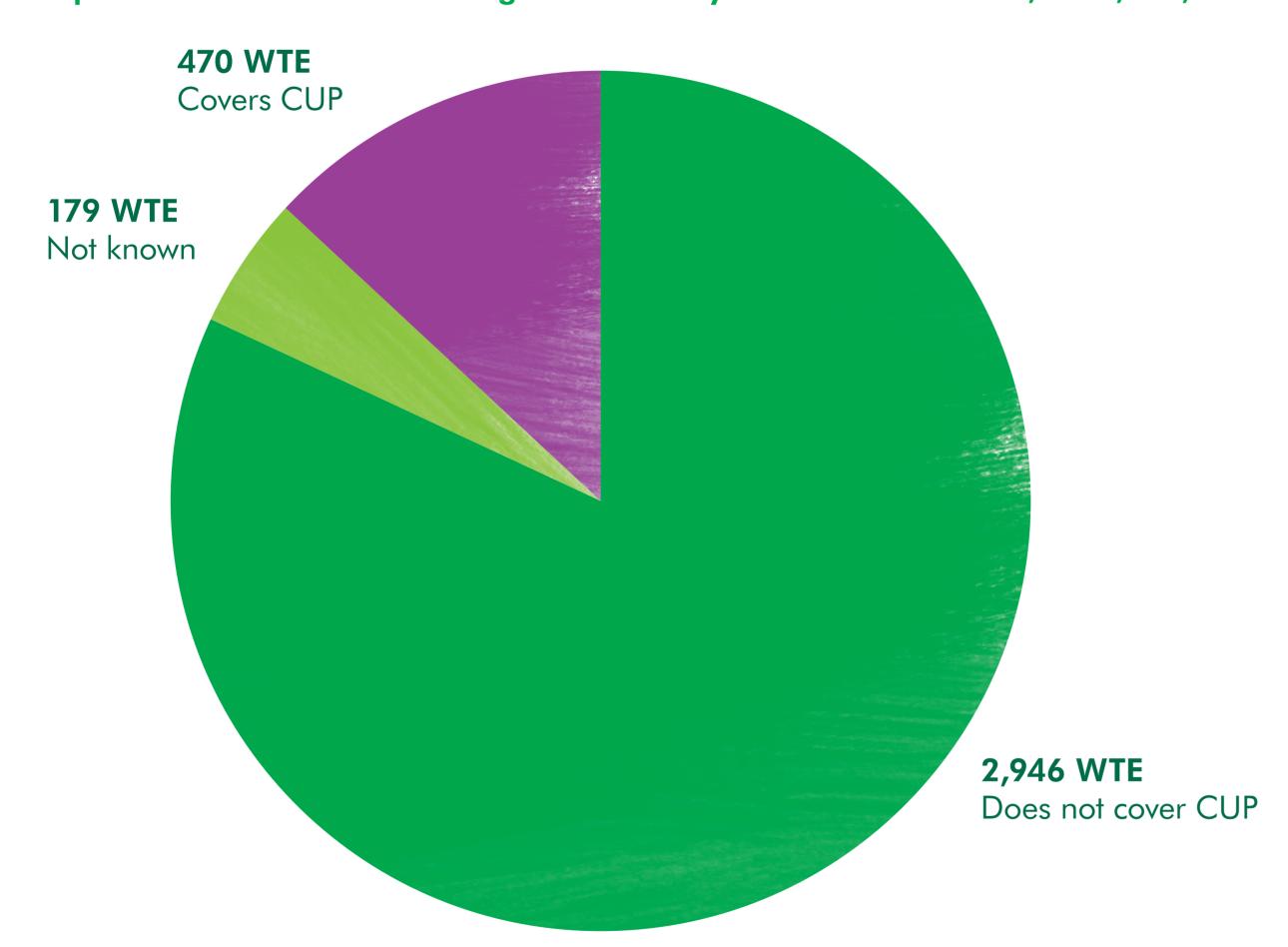
- Specialists in chemotherapy, radiotherapy, palliative care or pain management
- Roles focusing on paediatrics or teenagers and young adults
- Community care
- Non-patient facing roles
- 'As and when required' bank and agency staff

For each post, respondents were asked to select the area of practice where the post holder most frequently delivers care and answer 'does this post cover cancer of unknown primary?'.

## Results

The census identified the whole time equivalent (WTE) of 3,595 nurse posts, across the UK, of which 3,416 had a known CUP status, of these 14% (470 WTE) were identified as covering CUP – Figure 1.

Figure 1 - Specialist adult cancer nursing workforce by involvement in CUP, WTE, UK, 2014



## Conclusion

MAC15447\_NCIN\_posters\_2015\_CUP\_AW.indd

Data suggests that about 3% of new cancer cases and 7% of cancer deaths<sup>4</sup> are CUP and that in the last decade age-standardised incidence rates for CUP have fallen by almost 40%<sup>5</sup>. The numbers are influenced by registration practice, as patients initially diagnosed with CUP, may subsequently have their primary site determined (either during the diagnostic or treatment process or at post-mortem) and are then no longer counted as CUP. There are also a few cases that are misclassified as CUP when the information transmitted to the Cancer Registry is insufficient. This means the numbers of CUP cases are partly determined by diagnostics and registration practices.

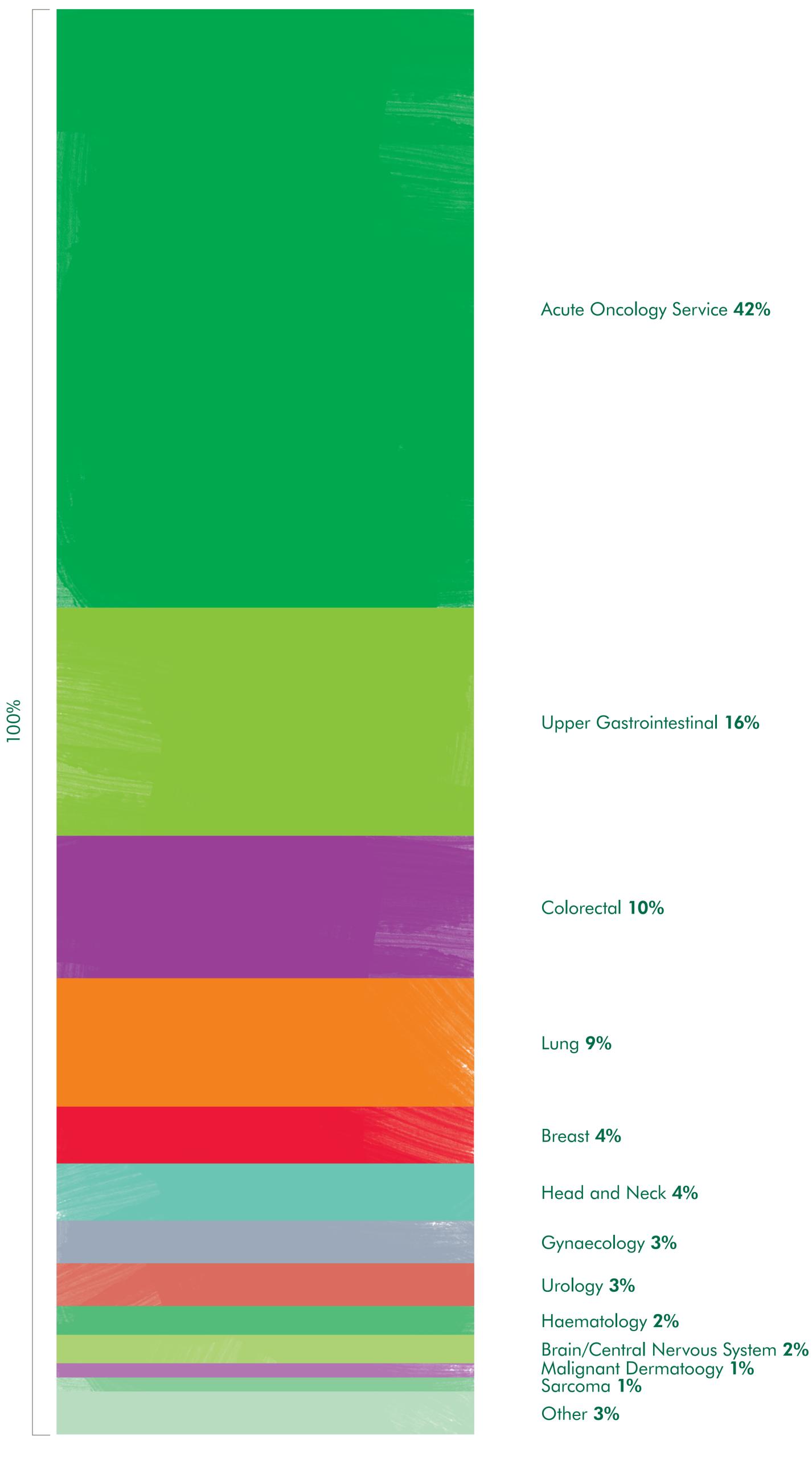
The NICE clinical guideline<sup>6</sup> state that every hospital with a cancer centre should establish a CUP team and ensure that patients have access to the team. The team should include a CUP specialist nurse or key worker as a minimum. The CUP team should be involved in the patient's care until the patient is referred to a site-specialist consultant, referred for palliative care alone or diagnosed with a nonmalignant condition. If CUP is confirmed, the CUP team should continue managing the patient's care.

It is unclear how recorded patient numbers relate to the number of patients needing specialist CUP care. This makes workforce planning difficult. Therefore it is important to improve CUP recording so that only 'true' cases of CUP are included. Also we need to find the number who initially need the support of the CUP team but go on to be managed by site-specialist teams or diagnosed with a non-malignant condition. To use these numbers future work must establish how best to meet the needs of people with CUP and investigate how to support the CUP workforce.

Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). MAC15447\_CUP

Nurses that cover CUP work in all areas of practice. 42% of CUP nurses specialise in Acute Oncology Services, 16% specialise in upper gastrointestinal cancer and 10% specialise in colorectal cancer – Figure 2.

Figure 2 - CUP workforce by majority area of practice, WTE, UK, 2014



## **Acknowledgements**

Mouchel Management Consulting Ltd (with support from the Centre for Workforce Intelligence)

Full research reports available here - http://www.macmillan.org.uk/Aboutus/Ouresearchandevaluation/Researchandevaluation/ Researchandevaluationreports.aspx#DynamicJumpMenuManager 2 Anchor 2

For more information please contact Rachel White, rwhite@macmillan.org.uk

## June 2015

## References

- 1. Richardson, A., Wagland, R., Foster, R., Symons, J., Davis, C., Boyland, L., Foster, C. and Addington-Hall, J. (2013) Uncertainty and anxiety in the cancer of unknown primary patient journey: a multiperspective qualitative study. BMJ Supportive & Palliative Care (http://www.cupfoundjo.org/wp-content/uploads/2013/12/BMJ Support Palliat Care-2013.pdf)
- 2. National Cancer Intelligence Network. Routes to Diagnosis: Cancer of Unknown Primary. 2014. http://www.ncin.org.uk/view?rid=2597 3. NCAT Quality in Nursing. Clinical nurse specialists in cancer care: Provision, proportion and performance. A census of the cancer
- specialist nurse workforce in England 2011
- 4. Cancer Research UK. Cancer of unknown primary statistics http://www.cancerresearchuk.org/cancer-info/cancerstats/types/cancer-ofunknown-primary/
- 5. National Cancer Intelligence Network. Cancer of Unknown Primary. 2012. http://www.ncin.org.uk/view?rid=1257 6. National Institute for Health and Care Excellence. Metastatic malignant disease of unknown primary origin. July 2010. http://www.
- nice.org.uk/guidance/cg104