

Identifying and counting people living with treatable but not curable cancer in the England cancer registry

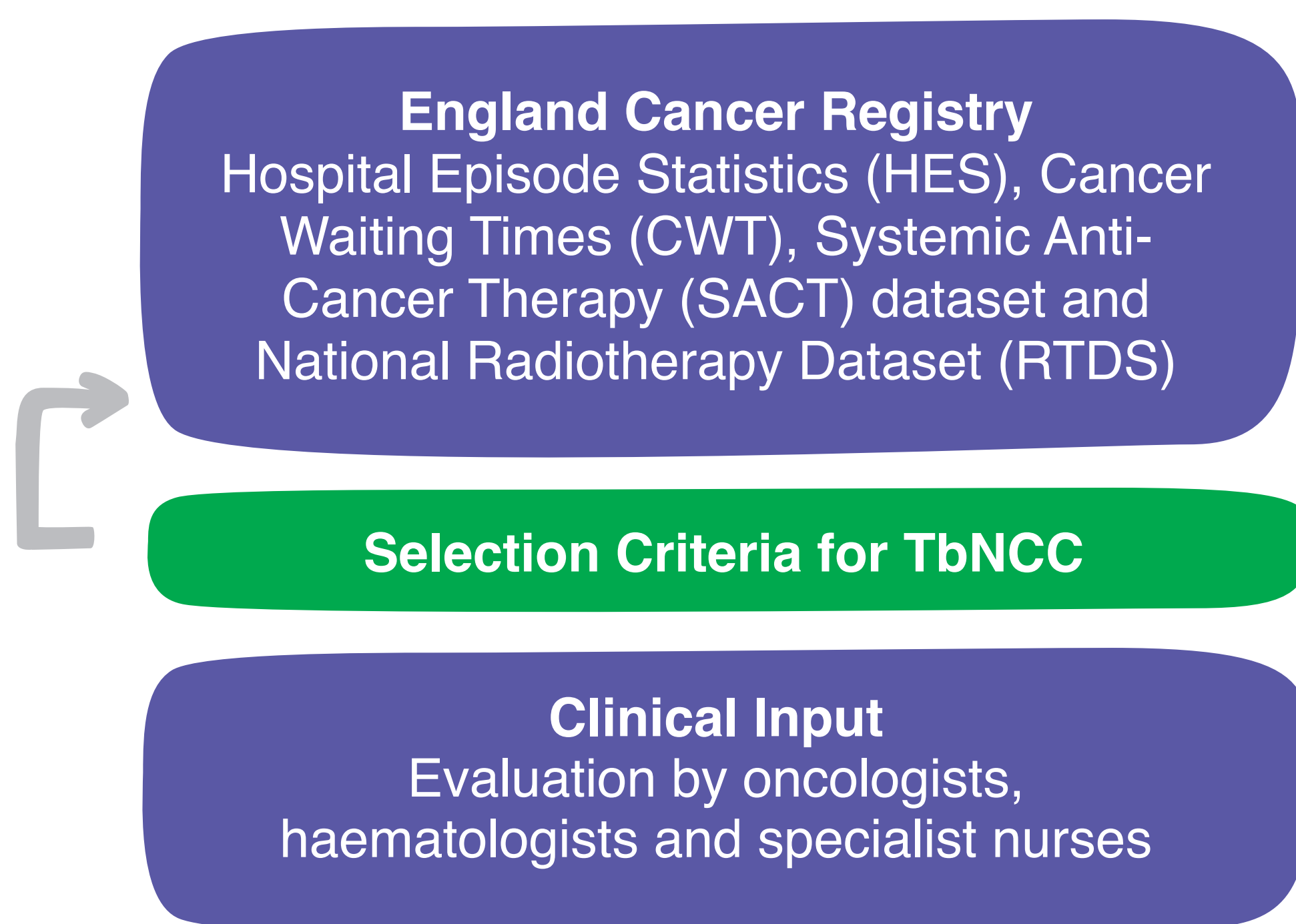
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Background

Our project aims to define, categorise and quantify, in the England cancer registry, the population living with treatable but not curable cancer (TbNCC). This cohort is comprised of people who, although they cannot be cured of their cancer, are on treatments that can delay its progression, reduce its burden, alleviate symptoms and prolong life. This is a heterogeneous group with different prognoses and treatments, who are living with cancer as a long term condition which is not well understood by the public and by some healthcare professionals. The lack of understanding of the experience of this group means that services are not necessarily designed to meet their particular needs.

Method



Results

The summary, below, provides the findings from our initial analysis of the population with TbNCC, in England.

Diagnosed in 2015

- **76,000 people**
Stage IV at diagnosis or multiple myeloma, chronic lymphocytic leukemia (CLL) or chronic myeloid leukaemia (CML).
- **57,000 people**
Diagnosed with an intermediate survival cancer, based on the Three Cancer Groups Framework¹.
- **78,000 people**
Diagnosed with a shorter-term survival cancer, based on the Three Cancer Groups Framework¹.

Identified between 2012-2015

- **264,000 people**
Identified as TbNCC from diagnosis, still alive in 2015 (Figure 1).
- **204,000 people**
Identified as TbNCC from diagnosis, still alive in 2016 (Figure 2).
- **139,000 people**
with at least one hospital admission for metastatic cancer in HES, still alive in 2015.
- **25,000 people**
receiving treatment for metastatic disease in the CWT dataset, still alive in 2015.

There is a considerable number of people included in more than one of the above criteria. The analysis of this overlap will enable the criteria to be ultimately unified into one overarching method for classifying the TbNCC population.

Figure 1. People diagnosed as TbNCC between 2012 to 2015 and still alive on the 31 Dec 2015 by stage at diagnosis in England

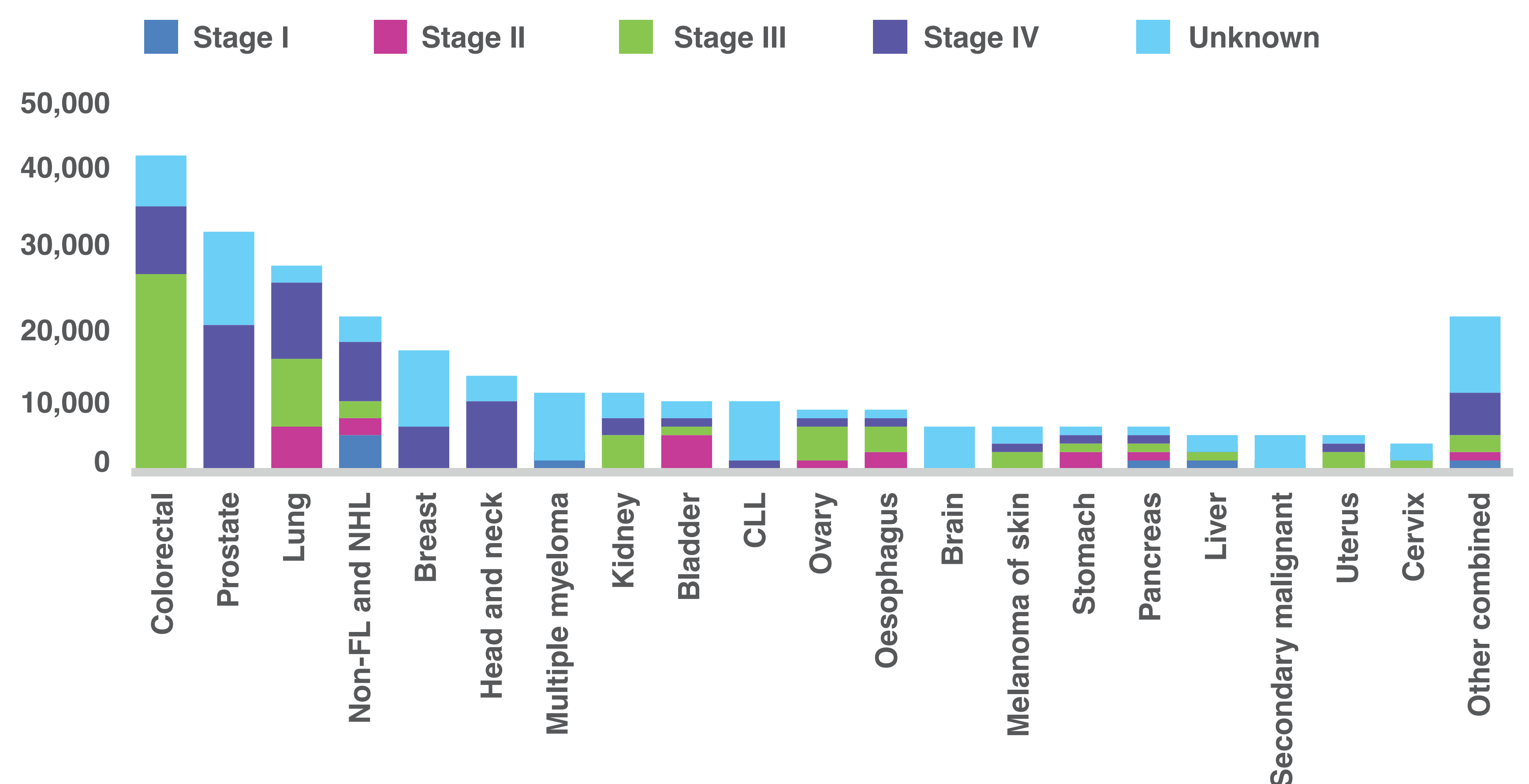
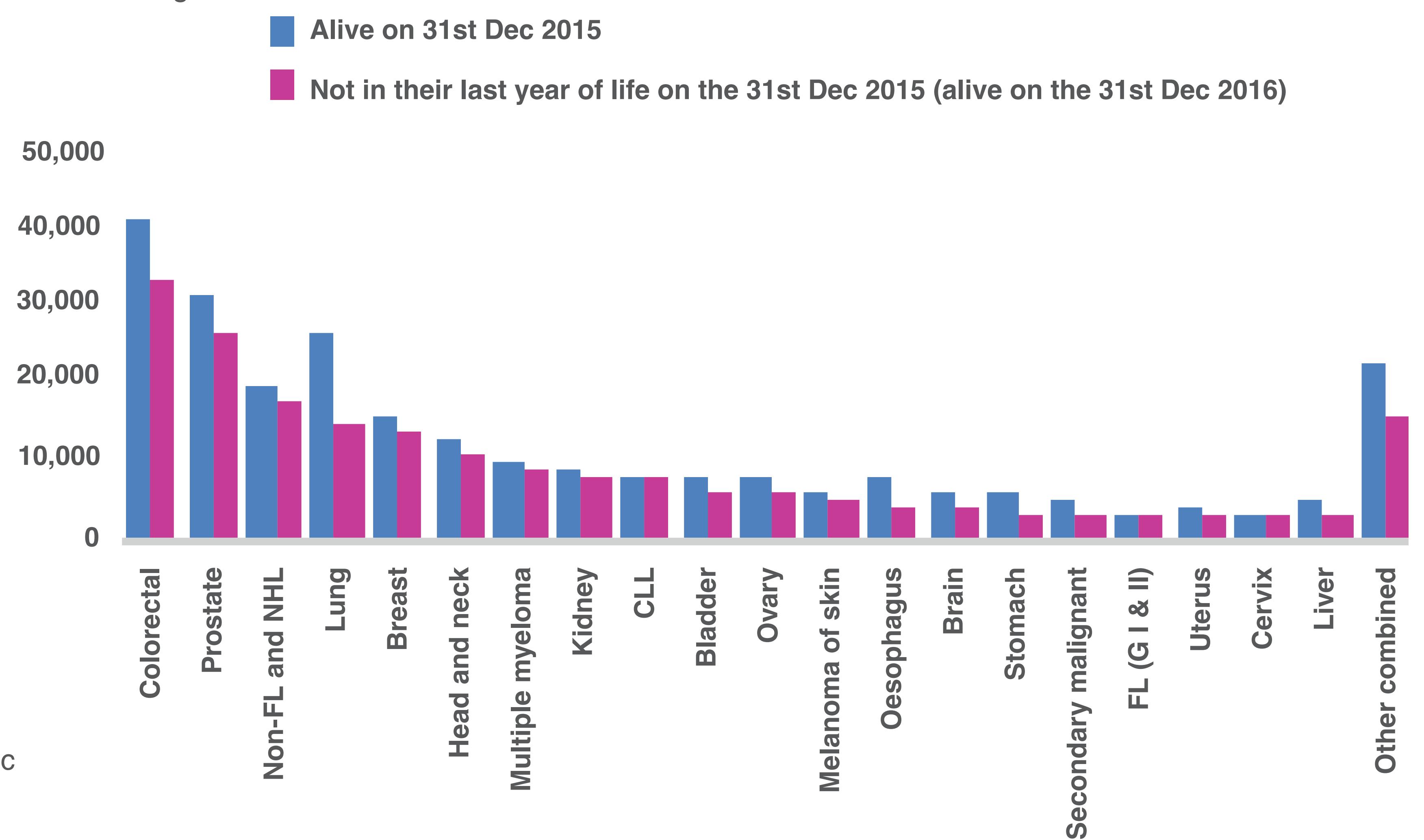


Figure 2. People diagnosed as TbNCC between 2012 to 2015 and still alive on the 31 Dec 2015 or 2016 in England



The next phase of the analysis will quantify TbNCC, based on treatments received.



Chemotherapy

- Selected regimens, through expert consultation.
- Subsequent regimens starting > a year from initial cancer diagnosis (excl. breast, prostate and multiple cancers).
- Chemotherapy regimens with palliative intent.



Radiotherapy

- Regimens likely to be palliative, based on an algorithm.
- Receiving a second round of radiotherapy, more than six months from the first.

Conclusions

Although requiring refinement, through the input of clinicians and further analyses, our initial estimate of the TbNCC population in England highlights the considerable size of this cohort. Once finalised, this will enable better understanding of the needs of this group of people and support decision makers and service designers to recognise its importance and provide tailored services.

References

1. McConnell H, White R, Maher J. Categorising cancers to enable tailored care planning through a secondary analysis of cancer registration data in the UK. *BMJ Open* 2017;7:e016797. doi:10.1136/bmjopen-2017-016797

Data for this study is based on patient-level information collected by the NHS, as part of the care and support of cancer patients. The data is collated, maintained and quality assured by the National Cancer Registration and Analysis Service, which is part of Public Health England (PHE).

Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (804). Also operating in Northern Ireland. MAC17399_Treatable_not_curable