

Cohort profile: treatable but not curable cancer in England, an estimation of the population using the cancer registry and linked datasets.

## Appendix 1 - Protocol Text

An Excel Workbook of the results is available at: <http://www.ncin.org.uk/view?rid=4153>

The Macmillan-NCRAS Treatable but Not Curable (TbnC) Workbook contains the results of this protocol and is designed to allow for further data exploration. It also contains background and methodological information.

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## Initial inclusion and exclusion criteria of the cohort

For this work we identified cases of TbnC cancer from a cohort of people with a cancer diagnosis in the National Cancer Registration Dataset.

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**Inclusions** Confirmed cancer diagnosis – ICD C00-99

Diagnosed 2001- 2015

English resident

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**Exclusions** Tumours staged as 0

Specific cancer types:

Exclude Hodgkin lymphoma, T/NK cell lymphomas, non-melanoma of skin, testis - ICD C81, C84, C62, C44

Exclude lymphoid leukaemia and myeloid leukaemia except for CLL and CML - ICD C910, C913-920, C922-929

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## The twelve selection criteria

These are additionally summarised in (Appendix 2 - Protocol Table 1) and the TbnC Workbook.

### 1. Diagnosed with a particular cancer and stage combination in the National Cancer Registration Dataset

People diagnosed with at least one of the cancer type and stage combinations, marked as 'TbnC' for the main cohort with cancer defined as Treatable but not Curable or 'Group B' for those who the project's clinical working group believe are not TbnC but still at increased risk of recurrence or having their life shortened by cancer in Table 1. This inclusion table is based on clinical consultation and survival rates.

<b>'TbnC' includes:</b>	All stage 4 cancers apart from thyroid and testicular cancer (excluded due to their high survival rates)  Haematological cancers classified through review by haematologists, based on chance of cure  In addition, mesothelioma as there is general consensus that with current standard/approved treatment eradicating disease is very unlikely.
<b>'Group B' includes:</b>	Cancers at stage 1 to 3 or with an unknown stage that generally have a 5-year net survival of 50% or less, as per clinical recommendation  It also includes haematological cancers that are sometimes curable

If people meet the criteria for both 'TbnC' and 'Group B', they are only included in the 'TbnC' group.

### 2. Had a diagnosis of secondary malignant neoplasm (metastatic disease) in HES APC

People who had at least one admission to hospital, where the reason for admission indicated metastatic cancer in HES.

<b>'TbnC' includes:</b>	ICD C78 - Secondary malignant neoplasm of respiratory and digestive organs – all cancers  ICD C79 - Secondary malignant neoplasm of other and unspecified sites – all cancers
<b>'Group B' includes:</b>	ICD C77 - Secondary and unspecified malignant neoplasm of lymph nodes - only cancers designated to 'Group B' when diagnosed at stage 3: (C15, C16, C22, C23, C24, C33, C34, C67, C51, C54, C55, C56)

If people meet the criteria for both 'TbnC' and 'Group B', they are only included in the 'TbnC' group.

Inclusion was based on clinical insight. In HES APC, under the diagnosis section, there are many fields to record the multiple diagnoses a patient may have presented with. This analysis was based on a review of the

20 diagnostic codes recorded for each admission record. It excludes admissions more than 3 months before the patient's first cancer diagnosis (since 2001).

**NOTE:** all other criteria (3-12) designates exclusively to 'TbnC', and never to 'group B'

### 3. Received treatment for metastatic disease or progression of primary cancer in CWT

People who received at least one treatment, where the reason for treatment event indicated metastatic disease in CWT.

Where metastatic cancer is defined by:

- Distant recurrence of cancer
- First treatment for metastatic disease following an unknown primary cancer
- Second or subsequent treatment for metastatic disease following an unknown primary cancer
- Treatment for progression of primary cancer

### 4. Received treatment for metastases in RTDS

People who received at least one radiotherapy treatment, where the reason for treatment recorded was for radiation of metastases in RTDS.

### 5. Received selected chemotherapy in SACT

People who received at least one particular chemotherapy regimen, for a particular cancer type in SACT. Cancer and chemotherapy combinations included were based on surveys completed by clinical advisors. Combinations were included where the majority of clinicians noted that the combination 'always' indicated TbnC. Additional cancer and chemotherapy combinations selected from the Cancer Drugs Fund list were also included. (Appendix 2 - Protocol Table 4).

### 6. Received selected radiotherapy in RTDS

People who received at least one radiotherapy treatment at specific anatomical site, for a particular cancer type, in RTDS, i.e. cancer type and radiotherapy anatomical target site combination. These combinations were based on clinical insight. (Appendix 2 - Protocol Table 5).

### 7. Received chemotherapy more than one-year post diagnosis in SACT

People who received at least one chemotherapy regimen, that commenced more than one year post initial cancer diagnosis, in SACT. This excludes breast cancer patients on trastuzumab, or trastuzumab in combination with pertuzumab; and excludes those with multiple cancers.

#### 8. Received radiotherapy more than six months post initial treatment in RTDS

People who received at least one radiotherapy treatment that occurred more than six months post initial round of radiotherapy, excluding those with multiple cancers, in RTDS.

#### 9. Received chemotherapy recorded as having palliative intent in SACT

People who received at least one chemotherapy regimen labelled with either palliative intent or as disease modifying in SACT.

#### 10. Received radiotherapy treatment recorded as having palliative intent in RTDS

People who received at least one radiotherapy treatment labelled with palliative intent in RTDS.

#### 11. Received treatment from a palliative consultant in CWT

People who received at least one treatment given by a 'specialist palliative care' or 'non-specialist palliative care (excluding Active Monitoring)' consultant in CWT.

#### 12. Received treatment from a palliative consultant in HES OP

People who received at least one treatment labelled as given by a consultant working in a palliative care specialty during the period of care in HES OP, within one month of a hospital inpatient admission in HES APC, where the diagnosis given in HES APC indicated cancer. Cancer is indicated as per the ICD10 codes in the inclusions and exclusions laid out in the initial inclusion and exclusion criteria of the cohort section.

## The final populations quantified

From this population the search criteria were applied to identify three populations.

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Prevalence	<p>Estimated number of people living with TbnC cancer at the end of 2015.</p> <p>This includes those alive at end of 2015 and having met criteria between 2012 and 2015.</p> <p>This is a persons level count so people are counted once under the first of the 12 criteria that they met in the analysis period.</p>
Occurrence	<p>Estimated number of times a TbnC criteria was met.</p> <p>This includes those alive at end of 2015 and having met criteria between 2012 and 2015.</p> <p>This is an event level count so people are counted up to 12 times, once per each new criteria met. Those who meet the same criteria more than once are only counted once.</p>
Incidence	<p>Estimated number of people who became TbnC during 2015.</p> <p>For those meeting criteria anytime in 2015, and not anytime previously (2012-2014).</p> <p>This is a persons level count so people are counted once under the first of the 12 criteria that they met in the analysis period. Vital status is not considered.</p>

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All three cohorts are additionally split by whether the algorithms indicated the analytical groups 'TbnC' and 'Group B'. Prevalence and Occurrence are also split by the EoL status of the patient (EoL positive indicates they died within a year of the end of 2015 i.e. at the end of 215 they were in their last year of life rather than TbnC).