Supplemental file 2: Method for calculating the TYA Cancer Specialism Scale (TYA CSS) to assign level of care

The TYA CSS is derived from admitted patient care data using linked Hospital Episode Statistic (HES) data. HES data from 2011/12 to 2016/17 were obtained from NHS Digital and linked to patients from the BRIGHTLIGHT cohort using the following identifiers: NHS Number, sex and postcode. The method for calculating the TYA CSS is adapted from an approach first proposed by Birch in 2013[1].

Hospital activity within HES is recorded in three ways (Figure 1):
1. Finished consultant episodes (FCEs)
2. Spells (sequential hospital encounters with different consultants)
3. Continuous inpatient spells (CIPS: hospital admissions for the same patient receiving care from different consultants and different providers/trust within two days after discharge)

FCE is the standard measurement unit for hospital activity and considered to provide more accurate estimates of consultant workload and hospital resources[2]. FCE was used for the basis of analysis and derivation of the TYA CSS to ensure we used all available data on consultant care at the deepest level of granularity available.

Figure 1: Different classifications of hospital admission for an example patient based on HES
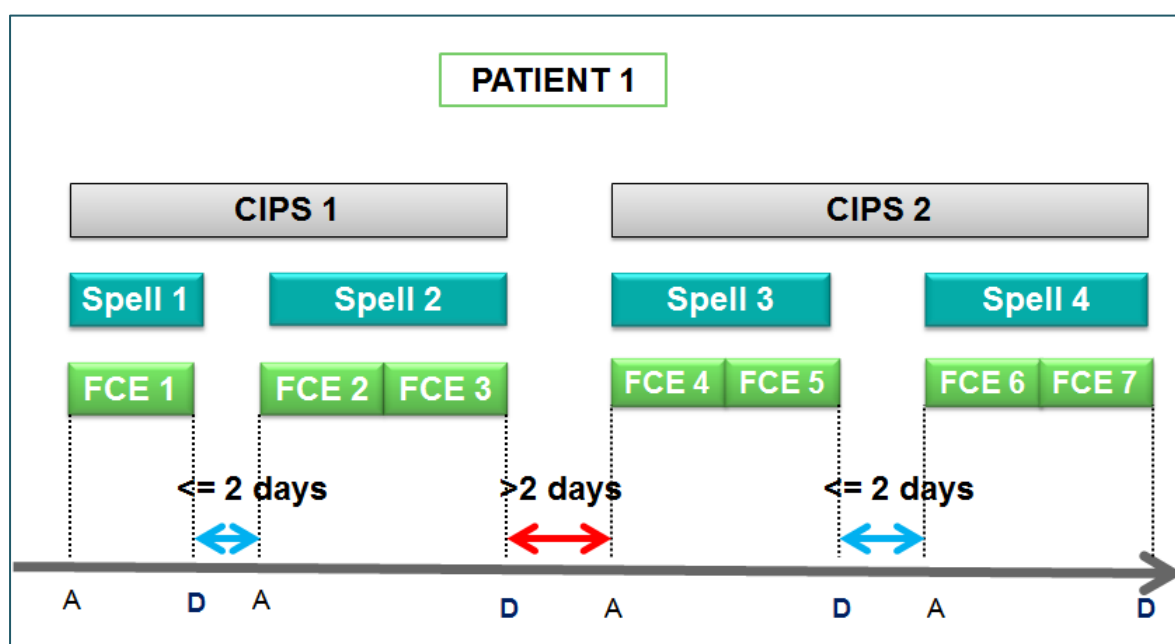

Abbreviation: FCEs -finished consultant episodes, CIPs -continuous inpatient spells, A-admission, D- discharge.
Source: Analysing Patient-Level Data Using Hospital Episode Statistics (HES), University of York.

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[1] Birch RJ. Teenage and young adult cancer in England – the patient journey and experience. The University of Leeds, PhD Thesis 2013
[2] Hargreaves DS, Viner RM. Adolescent inpatient activity 1999–2010: analysis of English Hospital Episode Statistics data. Archives of disease in childhood 2014; 99: 830-833

The development of the TYA CSS is summarised in Figure 2.

Figure 2: Summary of the process for calculating the TYA CSS
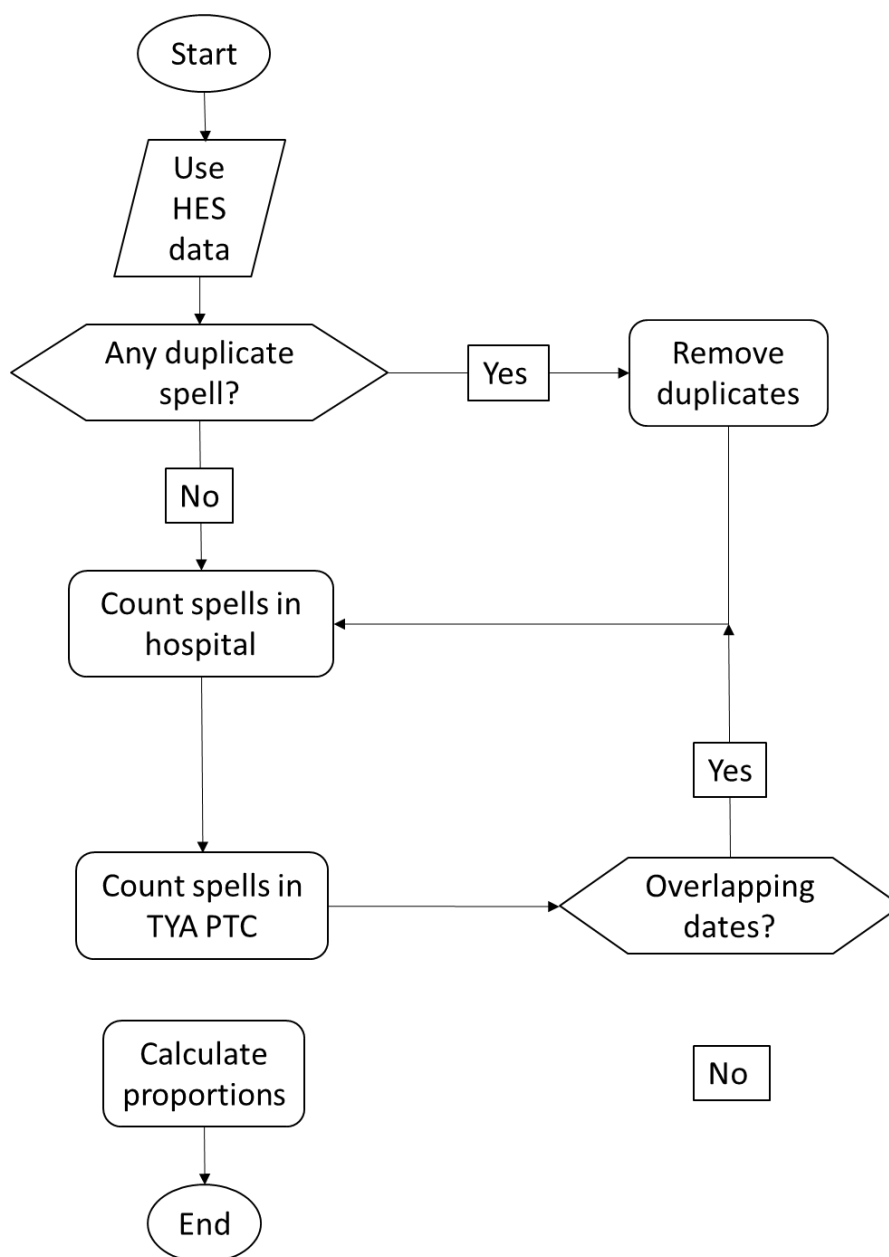
Data cleaning
HES data were cleaned to remove duplicates and to clarify some of the diagnostic coding. Reference was made to the HES admitted patient care data dictionary[3] to guide the data cleaning process in order to ensure accuracy and consistency in the recording and analysis of the HES records.

Duplicates were removed to ensure there were not several copies of the same admission being recorded for the same patient. These were identified by ascertaining whether more

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[3] HSCIC. HES data dictionary. HEALTH AND SOCIAL CARE INFORMATION CENTRE 2016, 20 January 2016; Available from: http://www.hscic.gov.uk/hesdatadictionary

than one admission began on the same date for a single patient and then cross checking this against admission reasons, procedure codes and treating physician code. Examples of fields which would be indicative of duplicate admission records include multiple HES_IDs, episode start date, episode end date, admission date and discharge date.

Location of specialist care centres

The aim of the study is to evaluate the value of specialist cancer services. 'Specialist' was originally defined in the *Improving Outcomes Guidance (IOG)[4]* as 13 principal treatment centres (PTCs) across England. To account for the age range of the BRIGHTLIGHT cohort starting at 13 years, PTCs also included children's PTCs where the age of admission for the TYA PTC did not include younger adolescents (Table 1). The hospital codes for the look up tables were taken from NHS Digital[5].

Calculation of the scale

The level of specialist care received was calculated from the time of diagnosis (taken from the date recorded in the National Cancer Registration and Analysis Service dataset)
1. Six months after diagnosis: Spells in TYA PTC from diagnosis at 6 months/Total spells from diagnosis at 6 months
2. 12 months after diagnosis: Spells in TYA PTC from diagnosis at 12 months/Total spells from diagnosis at 12 months

For every individual, HES data were used to calculate the number of inpatient and day case bed days spent in a specialist centre (A), as well as the number of total bed days across all secondary care services (B) within the first 6 and 12 months after diagnosis. The proportion of time spent in a specialist centre was then derived as (A)/(B).

Defining the levels of care

Inpatient HES data were successfully linked to 1,074 out of 1,114 young people recruited to BRIGHTLIGHT. The distribution of the proportion of care by 6 months and 12 months after diagnosis suggested there were three natural groups occurring within the data (Figure 3).

Figure 3: Distribution of the proportion of care receive in a TYA PTC
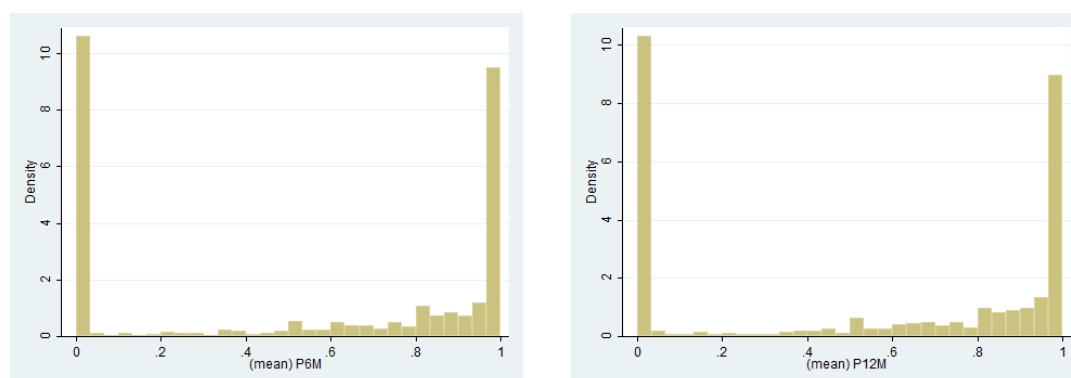
[4] National Institute for Health and Care Excellence. Guidance on cancer services: improving outcomes in children and young people with cancer. NICE, London 2005https://www.nice.org.uk/guidance/csg7/resources/improving-outcomes-in-children-and-young-people-with-cancer-update-773378893 [Accessed 30/08/18]
[5] https://digital.nhs.uk/services/organisation-data-service

Table 1: List of principal treatment centres in England (2012-2014) for young people aged 13-24 years

Principal Treatment Centre	Hospital
Cambridge University Hospitals NHS Foundation Trust	Addenbrookes Hospital (aged 14-24)
The Christie NHS Trust	Christie Hospital (aged 16-24)
Manchester University Hospitals NHS Foundation Trust	Royal Manchester Children's Hospital (aged 13-15)
Clatterbridge Centre for Oncology NHS Foundation Trust	Clatterbridge Centre (aged 16-24)
Alder Hey Children's NHS Foundation Trust	Alder Hey Children's Hospital (aged 13-19)
Royal Liverpool and Broadgreen University Hospital NHS Foundation Trust	Royal Liverpool Hospital
Royal Liverpool and Broadgreen University Hospital NHS Foundation Trust	Broadgreen Hospital
Leeds Teaching Hospitals NHS Trust	Leeds General Infirmary (aged 13-16)
Leeds Teaching Hospitals NHS Trust	St James's University Hospital (aged 17-24)
Nottingham University Hospitals NHS Trust	City Campus (aged 18-24)
Nottingham University Hospitals NHS Trust	Queens Medical centre (aged 13-18)
Sheffield Teaching Hospitals NHS Foundation Trust	Weston Park Hospital (aged 16-24)
Sheffield Teaching Hospitals NHS Foundation Trust	Royal Hallamshire Hospital (aged 16-24)
Sheffield Teaching Hospitals NHS Foundation Trust	Sheffield Children's Hospital (aged 13-16)
Southampton University Hospitals NHS Trust	Southampton General Hospital (aged 16-24)
Southampton University Hospitals NHS Trust	Southampton Children's Hospital (aged 13-15)
The Newcastle-upon-Tyne Hospitals NHS Foundation Trust	Northern Centre for Cancer Care (aged 19-24)
The Newcastle-upon-Tyne Hospitals NHS Foundation Trust	Royal Victoria Infirmary (aged 13-18)
The Royal Marsden NHS Foundation Trust	The Royal Marsden Sutton (aged 13-24)
The Royal Marsden NHS Foundation Trust	The Royal Marsden Fulham (aged 17-24)
University College London Hospitals NHS Foundation Trust	University College Hospital (aged 13-24)
University College London Hospitals NHS Foundation Trust	Cancer Centre (aged 13-24)
University Hospital Birmingham NHS Foundation Trust	Queen Elizabeth Hospital (aged 16-24)
Birmingham Children's Hospital NHS Trust	Birmingham Children's Hospital (aged 13-18)
University Hospital Bristol NHS Foundation Trust	Bristol Haematology & Oncology Centre (aged 17-24)
University Hospital Bristol NHS Foundation Trust	Royal Hospital for Children (aged 11-16)
University Hospital Bristol NHS Foundation Trust	Bristol Royal Infirmary
University Hospital Bristol NHS Foundation Trust	St Michael's Hospital
University Hospitals of Leicester NHS Trust	Leicester Royal Infirmary (aged 13-24)
Oxford University Hospital NHS Trust	Churchill Hospital (aged 18-24)
Oxford University Hospital NHS Trust	John Radcliffe Children's Hospital (aged 13-18)