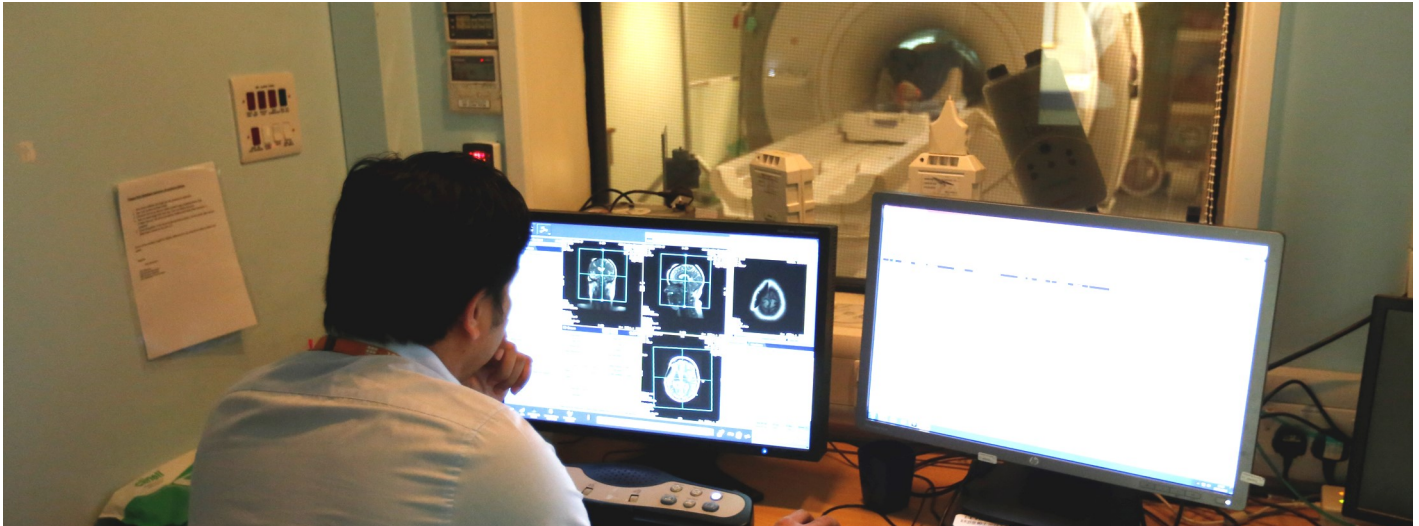


The Cancer Registry

Making a difference



“Data in the cancer registry is important because it gives us an unbiased and accurate view of what’s happening with brain tumour care on a national level. We know that there are variations in care across the country, but without this data it’s difficult to understand and improve this.”

Dr Matthew Williams, Clinical Oncologist at Imperial College London, is currently using patient data to investigate glioblastoma.

Cancer registry data can be used to drive improvements in the prevention of cancer, standards of cancer care and clinical outcomes and experience for patients. We have gathered together several examples of how data has made a difference for people affected by brain tumours.

Glioblastomas (GBM) in England: 2007-2011

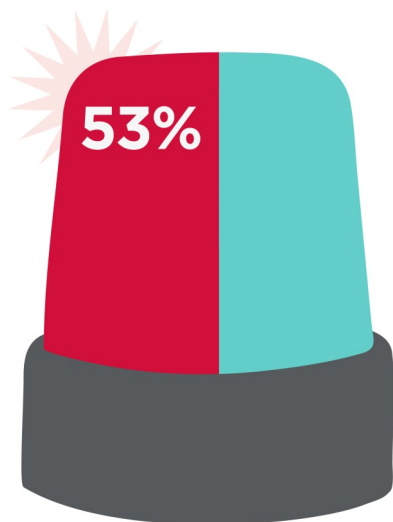
Cancer registry data were used to report on the incidence and survival of people affected by a glioblastoma and examine the relationship between age, sex, geographical region and treatment outcome.

Analysis of the data showed that median survival with the maximal combination treatment (debulking surgery, chemotherapy and probably radiotherapy) is longer for all age groups.

However, currently just 15% of patients over the age of 70 received the maximal combination treatment for a GBM because it is an aggressive treatment and increasing age is a poor prognostic factor (predicts a worse outcome).

More research may be needed to establish how the maximal combination treatment for elderly people with a GBM affects quality of life and if this mitigates any improvement in survival. However, this evidence suggests the potential to offer the maximal combination treatment as the standard treatment of care of the elderly affected by a GBM.

Read more about this work [here](#)



53% of adult high grade brain tumours were diagnosed as an emergency in 2013



Brain tumours reduce life expectancy by, on average, 20 years - the highest of any cancer.

Routes to diagnosis

The National Cancer Registration and Analysis Service (NCRAS) analyse the routes to diagnosis for all patients diagnosed with cancer and look at the variation by cancer type, age, sex and deprivation. They also provide relative survival estimates by presentation route and cancer type across a number of selected survival times.

This evidence has contributed to recommendations made in the *Achieving world-class cancer outcomes: a strategy for England 2015-2020* which look to prioritise and improve early diagnosis for people affected by cancer to increase survival (1).

Analysis of the data also showed that just 1% of people with a brain tumour are diagnosed through the Two Week Wait. This shows the failure of the Two Week Wait intervention to diagnose brain tumours early.

The authors of *Achieving world-class cancer outcomes: a strategy for England 2015-2020* acknowledge that the threshold of suspicion of cancer for the Two Week Wait is higher than other countries and made several recommendations such as direct access to diagnostic tests for GP to address this (1).

Analysis showed that 53% of adult high grade brain tumours were diagnosed as an emergency in 2013. Of those diagnosed through emergency presentation just 28% survive one year following diagnosis – the poorest survival across all routes to diagnosis for adults with a high grade brain tumour.

Read more about this work [here](#)

Years of Life Lost

Mortality is frequently used as a measure of the burden of cancer. Mortality for all cancers combined has decreased over time and there have been significant improvements in survival for common cancers (3). There is a correlation between spend on research into cancer type and improved survival and this suggests that more resource and investment in research into brain tumours is needed. Mortality for men affected by a high grade brain tumour has risen over time yet research spend on brain tumours remains at just 3.3% (4,5).

Years of life lost (YLL) as a measure of cancer burden is helpful to understand the impact of a brain tumour and underscore why more resource is needed for funding for brain tumour research. YLL takes into account the age of individual and gives greater weight to deaths at a younger age. Brain tumours are the 8th most common cause of cancer death in the UK however they are the biggest cancer killer of children and people under 40 (3,6,7).

Analysis of data from the East Anglian Cancer Registry compared average YLL to research spend and concluded that brain tumours have high individual cancer burden but low research spend.

Read more about this work [here](#)

Rare and less common cancers

Until recently data on many rare and less common cancers had not been published routinely. The NCRAS and Cancer52 (an umbrella group of rarer cancer organisations) collaborated to bring together incidence and mortality figures from 2010-2013 for 280 rare and less common cancers in one document.

Data for brain tumours includes number of incident cases and mortality cases and incidence and mortality rate per 100,000 population.

This data allows us to evaluate how incidence and mortality compares with other rare cancers. Over the three year period the crude mortality rate for brain tumours is higher than most other rare or less common cancers and the difference between crude incidence and crude mortality is relatively small (19,216 and 15,245 respectively).

You can read more about this work [here](#).

Proton Beam Therapy (PBT)

Since 2008, some people have accessed PBT in the USA through the NHS England's Proton Overseas Programme. Two new centres that specialise in PBT will open in University College London Hospitals (UCLH) and The Christie NHS Foundation Trust in Manchester in 2018.

The new centres aim to treat approximately 1500 patients per year (including 250 children). To help inform how many PBT centres to build in the UK data from the Children's Cancer and Leukaemia Group (CCLG) database has been cross-checked with cancer registry data.

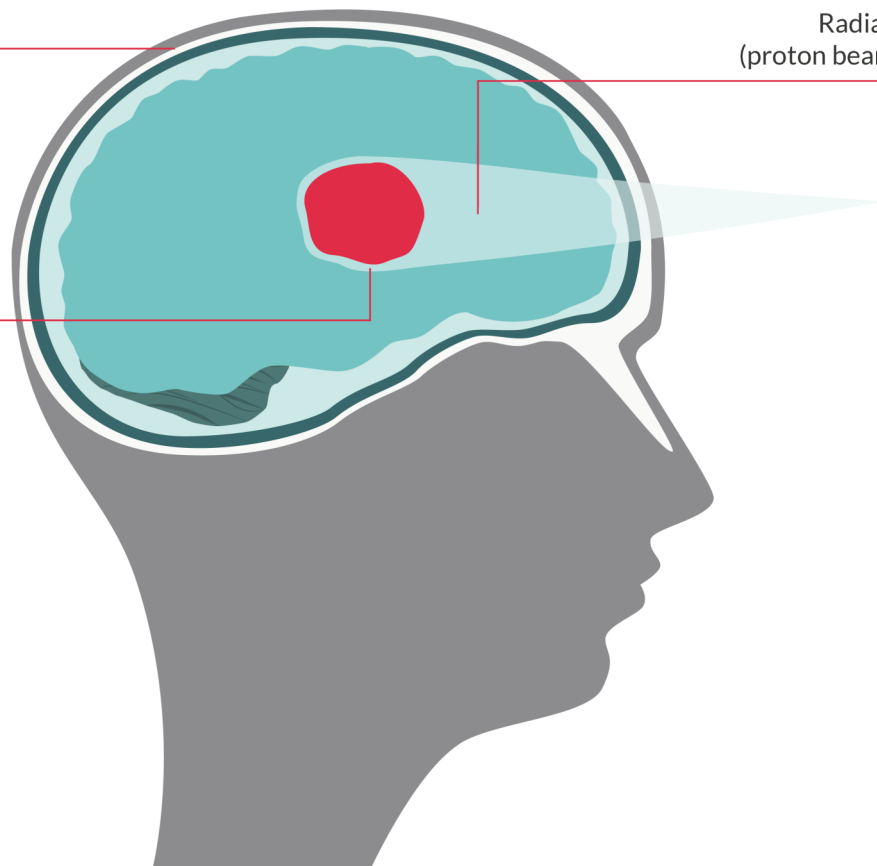
You can read more about this work [here](#).

PBT is a form of radiotherapy that uses high energy proton beams to destroy cancerous cells and prevent their continued growth. There's emerging evidence that PBT might reduce the exposure to radiation and reduce side effects for children with some types of tumour (8).

Skull bone

Radiation beam
(proton beam therapy)

Tumour



GBMs are high grade and just

55%

survive 6 months after diagnosis.

Routes from diagnosis

Macmillan Cancer Support, the NRCAS and Monitor Deloitte collaborated to produce a map of cancer survivorship for 2013/14 to better understand what happens to someone with cancer after diagnosis and the longer-term health needs of a tumour type. The data includes three common brain tumour types (Glioblastoma, Meningioma and Nerve Sheath) split by survivorship (limited survival 0-12 months, limited-moderate survival of 1-7 years and on-going survival of 7 years and over).

Analysis showed that Meningioma and Nerve Sheath tumours have marginally better outcomes than Glioblastomas and that a majority of people affected survive seven years or more. Glioblastomas are high grade and just 55% survive 6 months after diagnosis.

Variation in inpatient costs was analysed by survivorship group. Average inpatient costs post diagnosis for someone with a brain tumour are higher than other cancers in the study.

Data showed that a substantial percentage of people affected by either a Meningioma or Nerve Sheath tumour survive seven years or more with other inpatient morbidities (co-occurring diseases). This means long term demands on the health service.

You can read more about this work *here*.

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1. Independent Cancer Taskforce. Achieving world-class cancer outcomes: A strategy for England 2015-2020 [Internet]. 2015. Available from: http://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf
 2. Elliss-Brookes L, McPhail S, Ives A, Greenslade M, Shelton J, Hiom S, et al. Routes to diagnosis for cancer - determining the patient journey using multiple routine data sets. *Br J Cancer*. 2012 Oct 9;107(8):1220–6.
 3. Cancer Research UK. Cancer mortality for all cancers combined | Cancer Research UK [Internet]. [cited 2016 Apr 13]. Available from: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/mortality/all-cancers-combined#heading-One>
 4. Cancer Research UK. Brain, other CNS and intracranial tumours mortality statistics [Internet]. 2014 [cited 2015 May 19]. Available from: <http://www.cancerresearchuk.org/health-professional/brain-other-cns-and-intracranial-tumours-mortality-statistics>
 5. NCRI. Cancer Research Spend Data Package 2014 Final [Internet]. 2014. Available from: <http://www.ncri.org.uk/what-we-do/research-database/>
 6. CRUK. Children's cancers mortality statistics [Internet]. 2014. Available from: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/childrens-cancers/mortality>
 7. Deaths Registered in England and Wales (Series DR), 2012 Table 5. See table 5.2. [Internet]. Office for National Statistics; 2015. Available from: <http://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredinenglandandwalesseriesdrreferencetables>
 8. Yock TI, Yeap BY, Ebb DH, Weyman E, Eaton BR, Sherry NA, et al. Long-term toxic effects of proton radiotherapy for paediatric medulloblastoma: a phase 2 single-arm study. *Lancet Oncol* [Internet]. 2016 Jan [cited 2016 Feb 10]; Available from: <http://linkinghub.elsevier.com/retrieve/pii/S1470204515001679>
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