Public Health
England

What do the latest national data releases tell us about patients with, and services for, brain and CNS tumours?

Sarah Miller
Senior Cancer Intelligence Analyst, National Cancer Registration and Analysis Service, Cambridge

Overview

- Data collection for brain tumours in England

- Incidence

- Mortality

- Survival

- Prevalence

- Routes to Diagnosis

- Routes from Diagnosis

- Clinical Headline Indicators

- Summary of data sources

- Partnership analytical opportunities with NCRAS

Brain tumour data collection

- England national data collected by National Cancer Registration and Analysis Service (NCRAS) at Public Health England.

  Uses the WHO International Classification of Diseases, version 10 (**ICD-10**).

- ICD-10 codes grouped
  (i) **malignant** (or invasive, or C-codes)
  (ii) **benign** and uncertain or unknown behaviour types
  (or non-invasive, or D-codes).

- **Inconsistent historical collection** of benign tumour data, improved from early 2000s

  Consideration for Analysts - improvement in collection/quality and diagnostic techniques that affect time trend analysis

- **New system**:

  WHO International Classification of Diseases for Oncology, 3rd Edition (**ICD-O-3**) → moving to 4th Edition (ICD-04) in 2016

Brain

Meninges

Pituitary and pineal glands, craniopharyngeal duct

Other parts of CNS (incl. spinal cord, cranial nerves)

Source: NCRAS and Cancer Research UK http://www.cancerresearchuk.org/cancer-info/cancerstats/types/brain
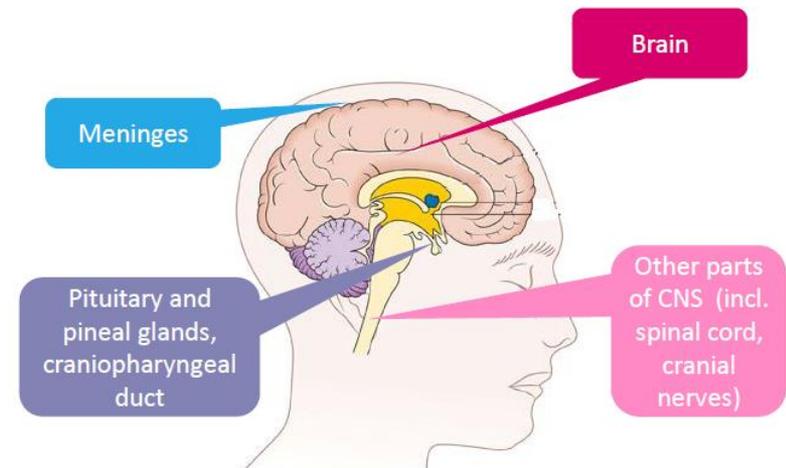
Brain and CNS tumours incidence

There are over 130 different types of tumour that can occur in the brain, other parts of the Central Nervous System (CNS) or intracranial region

10,624 diagnoses in the UK in 2013

200+ people are diagnosed each week

8th most common cancer in the UK

- Account for 3% of all new cases in the UK
- Age-standardised rate: 17.7 per 100,000 persons
- Around 50/50 sex split
- Around 6 in 10 of cases occur in 60+
- 2nd most common cancer type in children in GB

Proportion of all cases

3%

Percentage brain tumour is of total cancer cases, 2013, UK
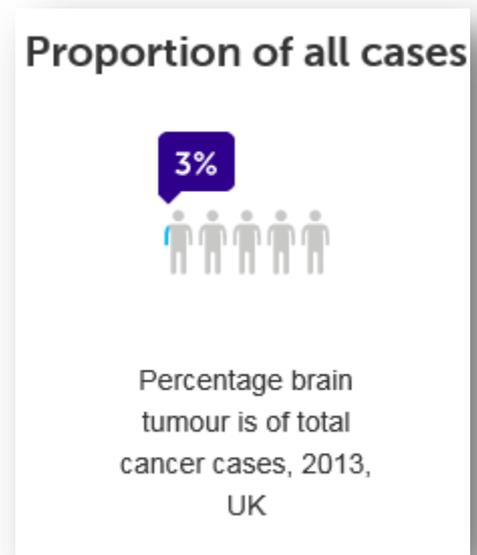
Brain and CNS tumours incidence

- *Type*: 53% malignant; 47% benign

- *Location*: 58% brain; 24% meninges

  o Most **malignant** tumours occur in the brain.

  o Most **benign** tumours occur in the meninges.

- *Morphology*: astrocytomas (34%); meningiomas (21%)

- Since late-1970s, incidence rates **increased** by 34% in GB

  o Mainly accounted for by improvements in diagnostics and data collection

- **1 in 74** people will be diagnosed with a brain, other CNS or intracranial tumour during their lifetime.

- Malignant and benign brain tumours produce the same **symptoms**, including: headaches, sickness, vomiting, confusion, personality changes and seizures.

Source: Statistical Information Team, Cancer Research UK http://www.cancerresearchuk.org/cancer-info/cancerstats/types/brain
Macmillan Cancer Support http://www.macmillan.org.uk/information-and-support/brain-tumours/diagnosing
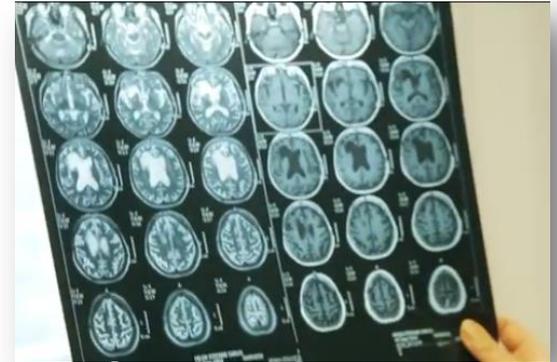
Brain and CNS tumours - mortality

5,187 deaths in 2012

100 people die each week

8th most common cause of cancer death in the UK
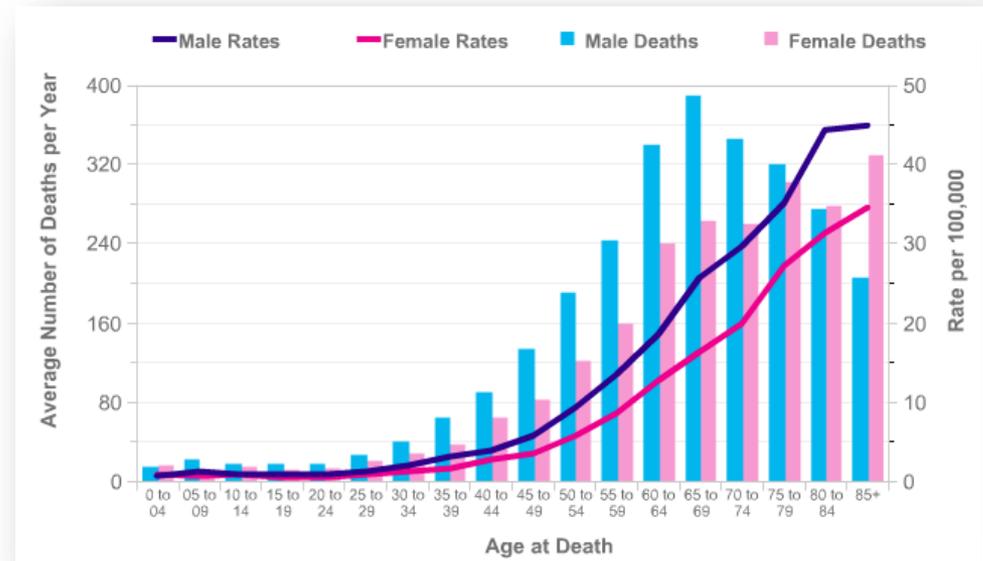
- Account for 3% of all cancer deaths

- Age-standardised mortality rate: 6.2 per 100,000

- 56% of brain and CNS tumour deaths occur in males

- 7 in 10 deaths in the over 60s

- Most common cause of cancer death in children, teenagers and young adults

Source: Statistical Information Team, Cancer Research UK http://www.cancerresearchuk.org/cancer-info/cancerstats/types/brain

Survival – brain cancer

- **1 in 7** survive 10 years or more (1 in 20 in the 1970s)

- **1 in 5** survive 5 years or more

- **2 in 5** survive for 1 year or more

- More than **7 in 10 children** survive for at least 5 years

- More than **4 in 5 teenagers and young adults** survive for at least 5 years

- **Unknown aetiology** – generally not hereditary; ionising radiation increases risk; no strong evidence for non-ionising radiation e.g. mobile phones, power lines; nor for viruses

   o Less than 1% linked to lifestyle risk factors

Prevention

Less than 1%

Preventable cases of brain tumours, UK

Brain tumours - Routes to Diagnosis

➤ Routes to Diagnosis study - methodology to categorise **the route the patient follows to the point of diagnosis** (Elliss-Brookes et al., 2012)

• Brain tumour patients are more likely to be diagnosed through the emergency presentation route than any other cancer site included in RtD 2006-2013

• Over three-fifths (61%) of brain tumours have been diagnosed as an emergency

• However, the proportion has decreased significantly over time, from 64% in 2006 to 53% in 2013

• Emergency presentation increased with age: more than three-quarters (78%) of 85+ year olds diagnosed through EP route vs 50% of the under 50s
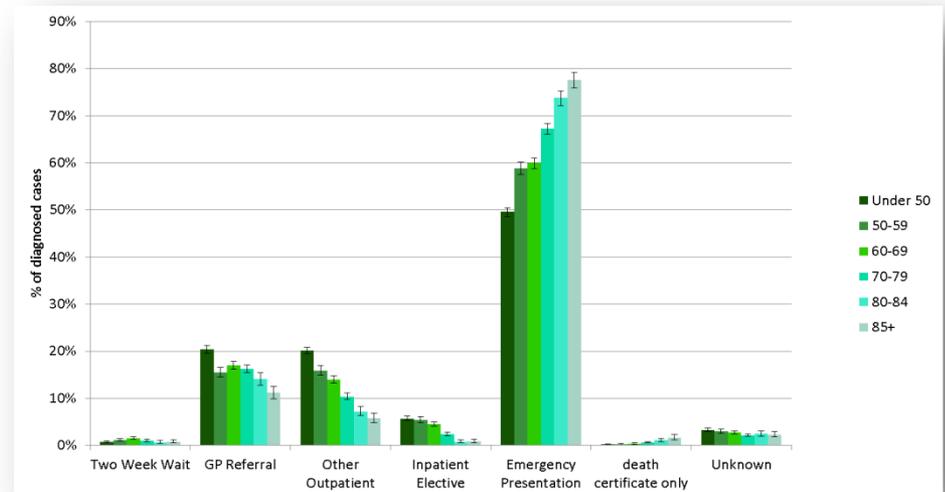
Routes from Diagnosis
Survivorship pathway

- Survivorship – what are the pathways after diagnosis?

- Focus: glioblastoma, meningioma and nerve sheath tumours
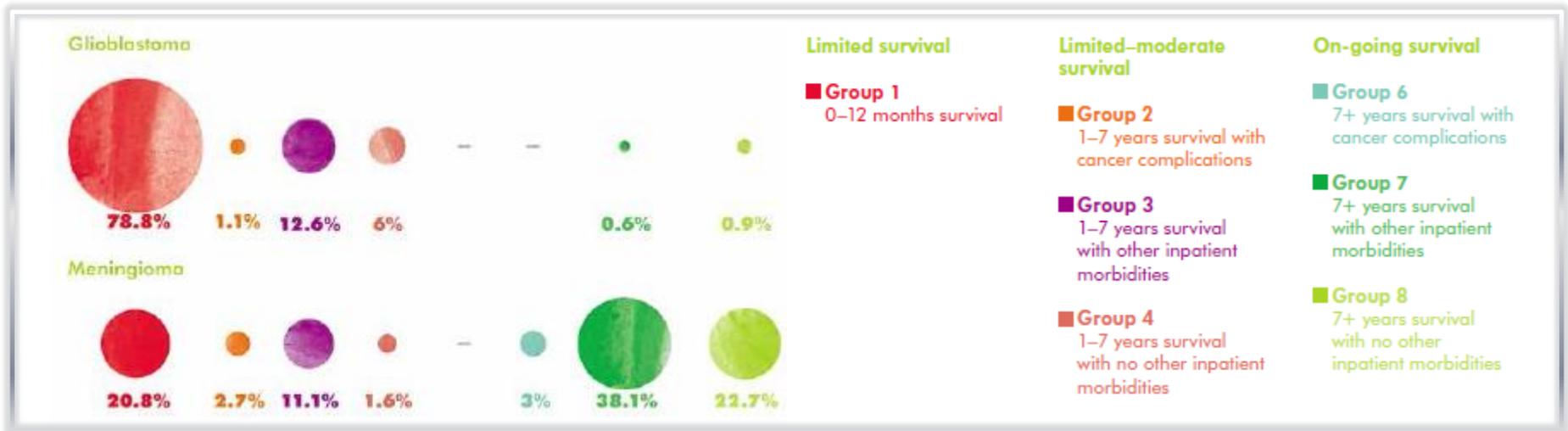

- Patients with **meningioma** and **nerve sheath** tumours = notably better outcomes:
    Majority survive 7+ years (63.8% and 87.2% respectively)
    Group 7: major long-term health service demands

- Over half (55%) of cancer patients with **glioblastoma** tumours did not survive past 6 months
    Show similar short-term survival outcomes to lung cancer patients

Source: Macmillan Cancer Support

Routes from Diagnosis Costs

FINDINGS FOR BRAIN AND CENTRAL NERVOUS SYSTEM TUMOURS
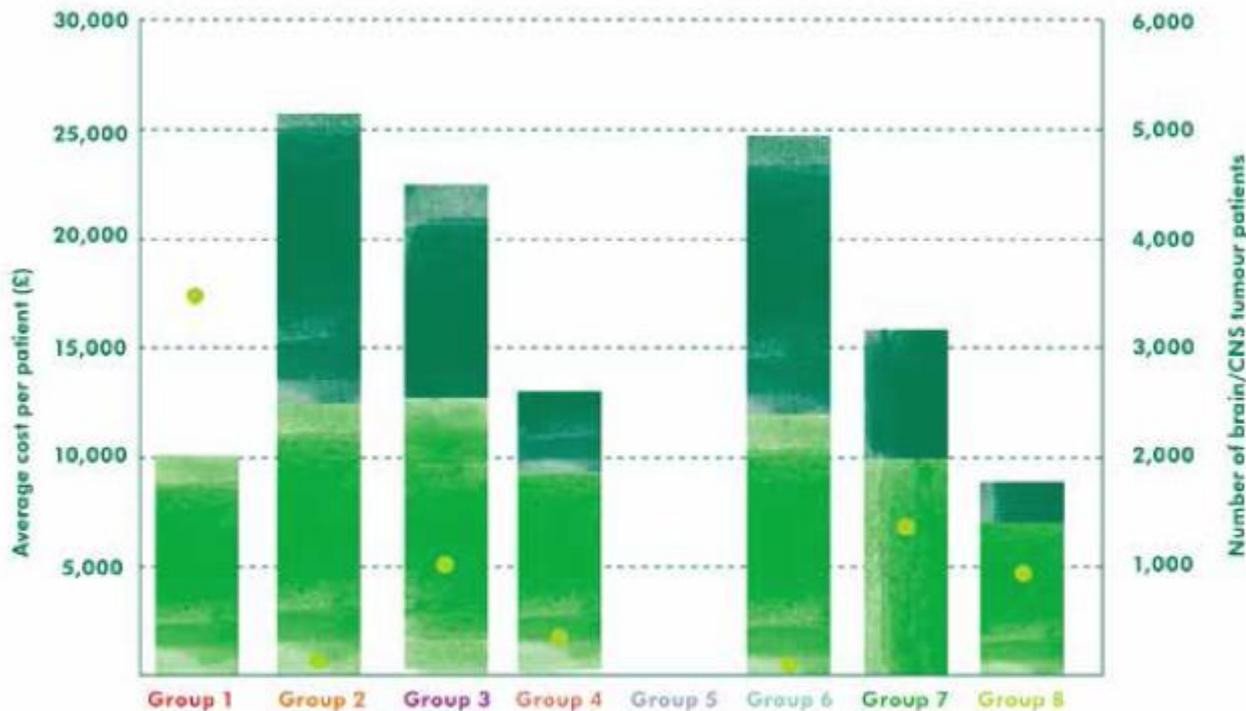
Cost after first year post-diagnosis
**Cost in first year post-diagnosis**
● **Number of patients**

Average post-diagnostic inpatient cost for brain and CNS tumour patients = **£13,200**
→ higher than for other RfD cancer cohorts (breast, lung, prostate).

Some of the highest inpatient costs are associated with **moderate survival**, rather than longest periods of survival.

- Survivors of 1-7 years = **£26,147**
- 7+ years = **£24,800**

Source: Macmillan Cancer Support

Prevalence

- There are around 40,000 brain and CNS tumour survivors in England
- 51% female
- 61% have survived for five years or more
- Largest proportion aged 45-64 (37%)
- Most diagnosed aged 25-44 (29%) and 45-64 (37%)

2010 | 2020 | 2030
2 million | 3 million | 4 million

2010	2030
220,000	370,000
570,000	990,000
1,290,000	2,680,000

Years since diagnosis
<1 year
1–5 years
≥5 years

Sources: Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. Br J Cancer 2012; 107: 1195-1202
Macmillan Cancer Support and NCRAS partnership project on UK Cancer Prevalence
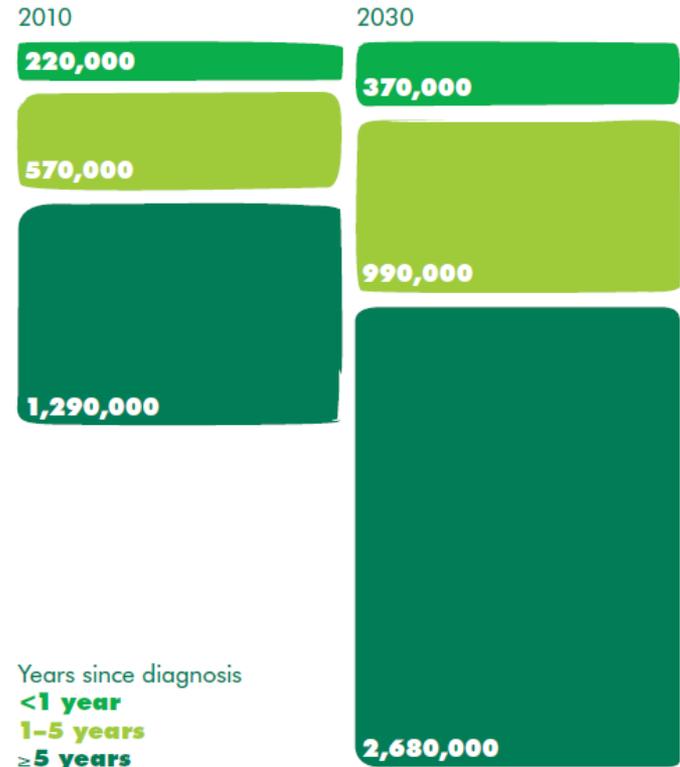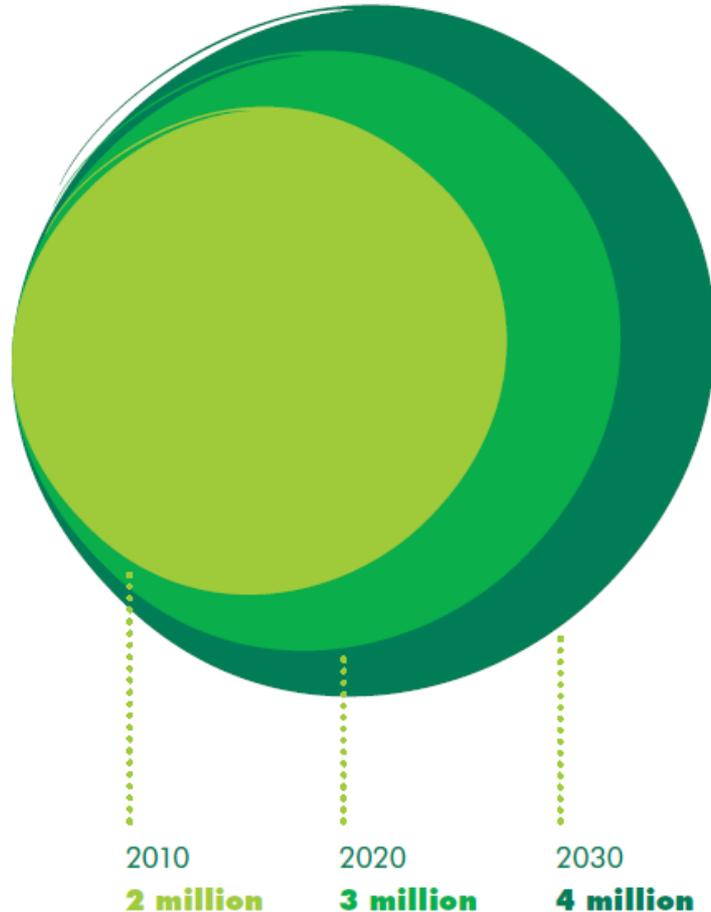
Clinical Headline Indicators

- A number of cancer metrics per Trust for England

- Currently being worked on at Public Health England

- The indicators will be made available in the CancerStats portal

- 'Generic' indicators, applicable to all or most cancer sites

- **Example:**

- To be followed by site-specific metrics

Cancer data sources and links

- **CancerStats and CancerData**

- **Cancer Commissioning Toolkit: Decommissioned**

- **Fingertips Public Health Profiles tool**

- **Health Profiles**

- **Local Cancer Intelligence: statistics by Clinical Commissioning Group**

- **Cancer prevalence statistics**

- **Routes to diagnosis of cancer**

Partustanship opportunities

- NCRAS can provide opportunities for charities, NHS and other cancer organisations to fund partnership Analysts based within Public Health England

  - ➢ **Direct access** to cancer data including linked datasets (after IG training)

  - ➢ Undertake **projects** in line with your organisation's objectives, co-branded with NCRAS

  - ➢ Regular team meetings and **communication** with PHE and NCRAS staff

  - ➢ Internal **support** for partnership Analysts

  - ➢ **Multi-region** offices around England

  - ➢ *Current partnership Analysts*: Macmillan Cancer Support, Cancer Research UK, Transforming Cancer Services Team (London)

The CRUK-NCIN partnership: improving outcomes through cancer intelligence

Macmillan-NCIN Work Plan: Understanding the cancer survivorship population

Public Health England

Thank you!

Please contact:

sarah.miller@phe.gov.uk

Or for general enquiries

ncinenquiries@phe.gov.uk