Public Health England

Synthesis of published data on brain/CNS tumour statistics

National Cancer Intelligence Network (NCIN)
Central Nervous System SSCRG Workshop
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Overview

- Data collection for brain tumours in England

- Incidence

- Mortality

- Survival

- Routes to Diagnosis

- Routes from Diagnosis

- Prevalence

- Service Profiles

- Data sources

- Closing summary

Brain tumour data collection

- England data collected by National Cancer Registration Service (NCRS) at Public Health England through one system: ENCORE:

  Using the WHO International Classification of Diseases, version 10 (**ICD-10**)
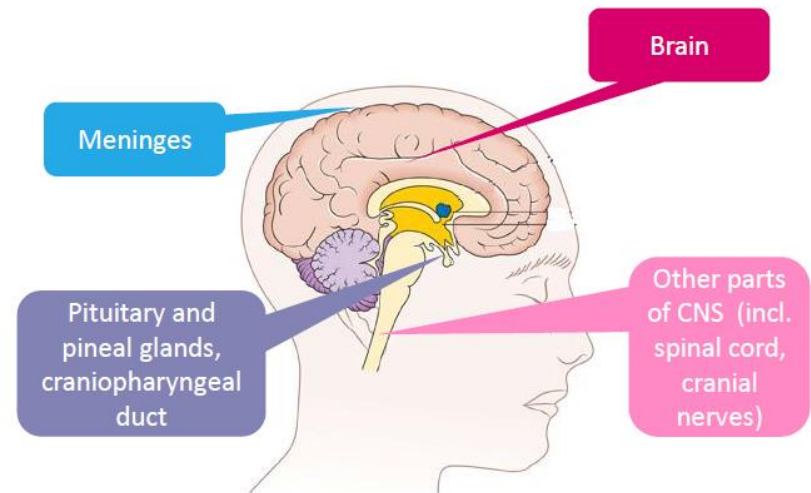
- ICD-10 codes grouped:
  (i) **malignant** (or invasive, or C-codes)
  (ii) **benign** and uncertain or unknown behaviour types (or non-invasive, or D-codes).

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

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

Brain
Meninges
Pituitary and pineal glands, craniopharyngeal duct
Other parts of CNS (incl. spinal cord, cranial nerves)

- **New system**:

  WHO International Classification of Diseases for Oncology, 3rd Edition (**ICD-O-3**) → grade information

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

Incidence – CNS tumours

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
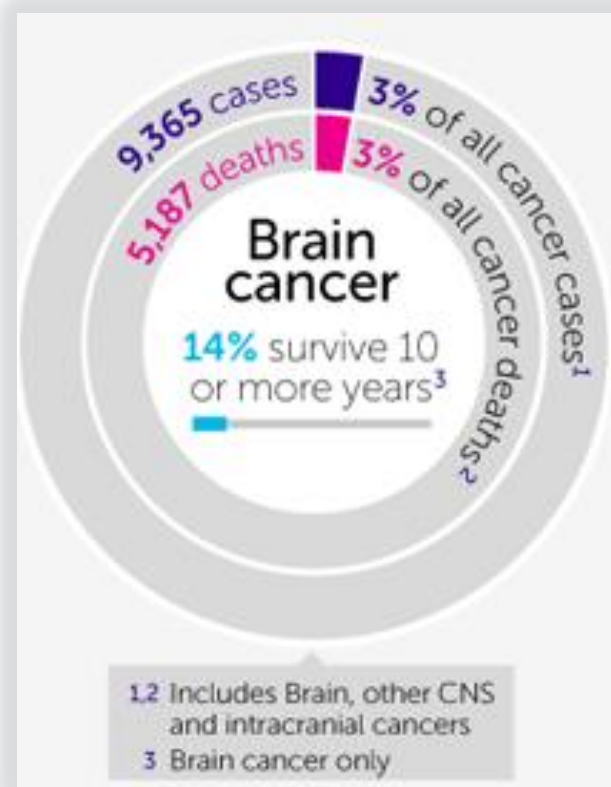
9,365 diagnoses in the UK in 2011

26 people are diagnosed each day

9th most common cancer in the UK

- _Type_: 55% malignant; 45% benign
- _Location_: 58% brain; 23% meninges
- _Morphology_: astrocytomas (34%); meningiomas (21%)
- Around 50/50 split between ♂ and ♀
- Three-quarters of cases in under 75s
- Around 400 cases p.a. in 15 and under –
 **2nd most common type in children in Britain**

9,365 cases
5,187 deaths
3% of all cancer cases[1]
3% of all cancer deaths[2]

Brain cancer

14% survive 10 or more years[3]

1,2 Includes Brain, other CNS and intracranial cancers
3 Brain cancer only

Mortality – CNS tumours

Public Health England

5,187 deaths from brain tumours in 2012

14 people die each day

8th most common cause of cancer death in the UK
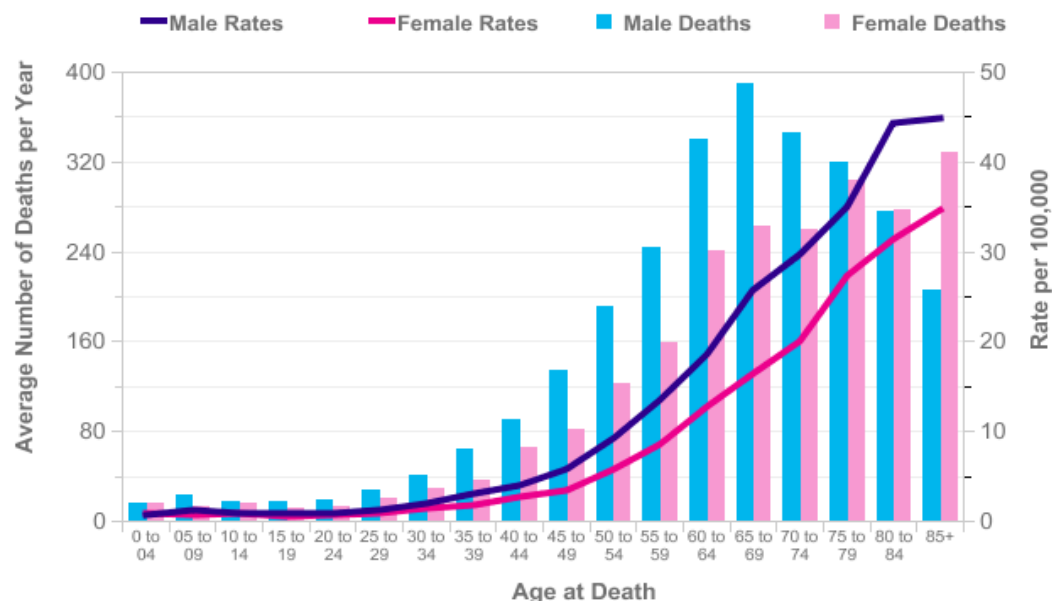
- Male:female ratio of 3:1
- Two-thirds of deaths are in the under 75s
- Most common cause of cancer death in children, teenagers and young adults
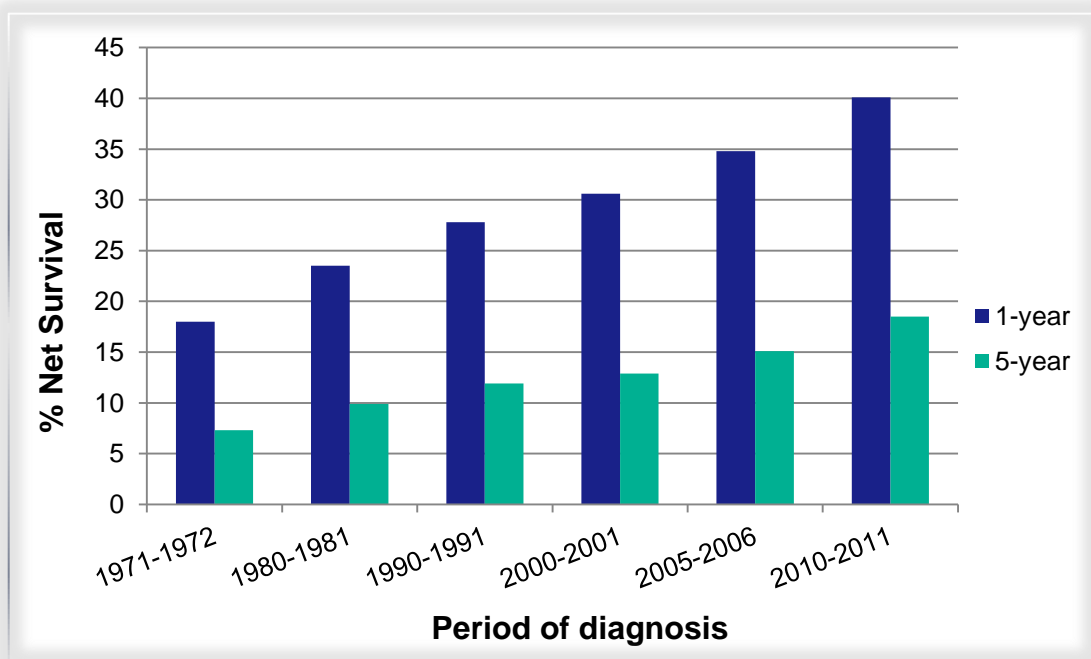
Survival – malignant brain cancer

	1-year	5-year	10-year
Men	41%	18%	13%
Women	39%	20%	14%
All adults	40%	19%	14%

E&W, ages 15-99, age-standardised net survival: predicted five and 10-year survival based on excess hazard statistical model

One- and five-year net survival 1971-2011 ⟶
Survival is improving over time

Brain cancer survival by age:
Five-year net survival 2007-2011
<u>60%</u> in 15-39; **1%** in 80-99 years

- More than 7 in 10 children survive for at least 5 years
- More than 8 in 10 teenagers and young adults survive for at least 5 years

Source: Statistical Information Team, Cancer Research UK http://www.cancerresearchuk.org/cancer-info/cancerstats/types/brain
Accessed February 2015

Routes to Diagnosis
Where were CNS patients diagnosed?

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

2006-2010 registrations	Two Week Wait	GP referral	Other Outpatient	Inpatient Elective	Emergency presentation	Death Certificate Only	Unknown	Number of cases
Benign Cerebral Meningioma	0%	28%	19%	4%	45%	1%	3%	6,345
Benign Cranial Nerves	0%	50%	29%	4%	12%	0%	5%	1,869
Benign Pituitary	0%	42%	32%	4%	19%	0%	3%	3,161
Benign/Uncertain/Unknown behaviour Brain	0%	20%	15%	3%	58%	1%	3%	2,915
Malignant Brain	1%	15%	12%	5%	63%	0%	3%	19,284
Other central nervous system - malignant	1%	26%	22%	5%	41%	1%	4%	1,257
Other central nervous system - non-invasive	0%	34%	22%	6%	35%	0%	3%	2,171

→ More detail: you can drill down, e.g. for meningioma by deprivation and route

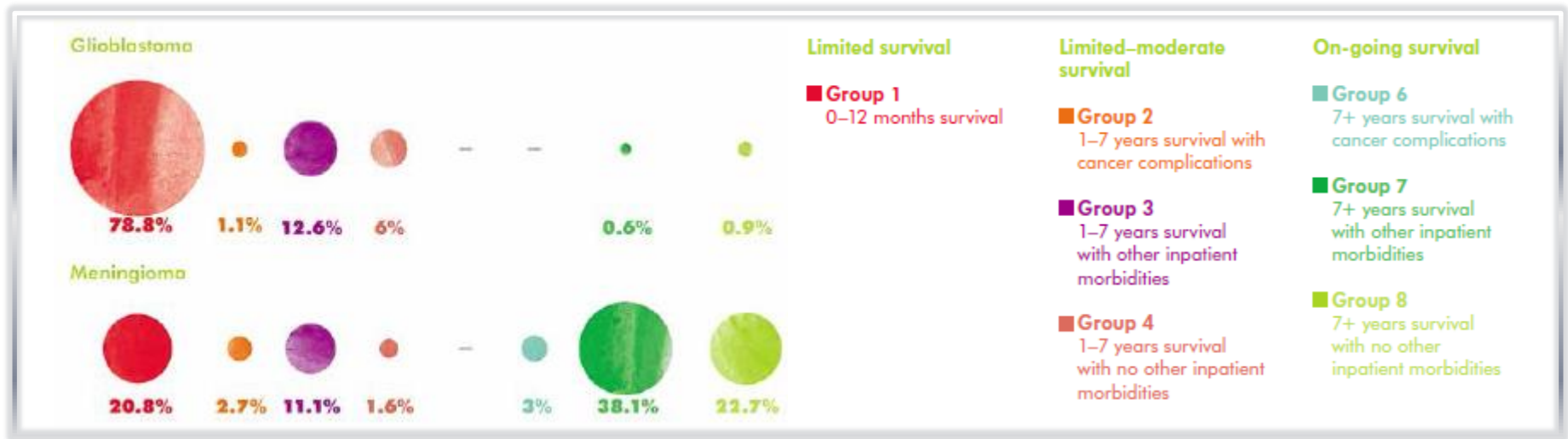| Benign Cerebral Meningioma	Two Week Wait	GP referral	Other Outpatient	Inpatient Elective	Emergency presentation	Death Certificate Only	Unknown	Number of cases
1 (least deprived)	0%	28%	22%	6%	38%	1%	5%	1,321
2	0%	29%	18%	5%	45%	1%	2%	1,353
3	1%	29%	17%	3%	47%	1%	2%	1,365
4	0%	27%	19%	3%	47%	1%	3%	1,270
5 (most deprived)	0%	28%	18%	3%	47%	1%	3%	1,036

Routes from Diagnosis
what is the CNS survivorship pathway?

FINDINGS FOR BRAIN AND CENTRAL NERVOUS SYSTEM TUMOURS

- Survivorship – what are the pathways **after** diagnosis?

- Report focused on: glioblastoma, meningioma and nerve sheath tumours

Glioblastoma
78.8%   1.1%   12.6%   6%   0.6%   0.9%

Meningioma
20.8%   2.7%   11.1%   1.6%   3%   38.1%   22.7%

Limited survival
■ **Group 1**
0–12 months survival

Limited–moderate survival
■ **Group 2**
1–7 years survival with cancer complications

■ **Group 3**
1–7 years survival with other inpatient morbidities

■ **Group 4**
1–7 years survival with no other inpatient morbidities

On-going survival
■ **Group 6**
7+ years survival with cancer complications

■ **Group 7**
7+ years survival with other inpatient morbidities

■ **Group 8**
7+ years survival with no other inpatient morbidities

- 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

Routes from Diagnosis Costs

FINDINGS FOR BRAIN AND CENTRAL NERVOUS SYSTEM TUMOURS
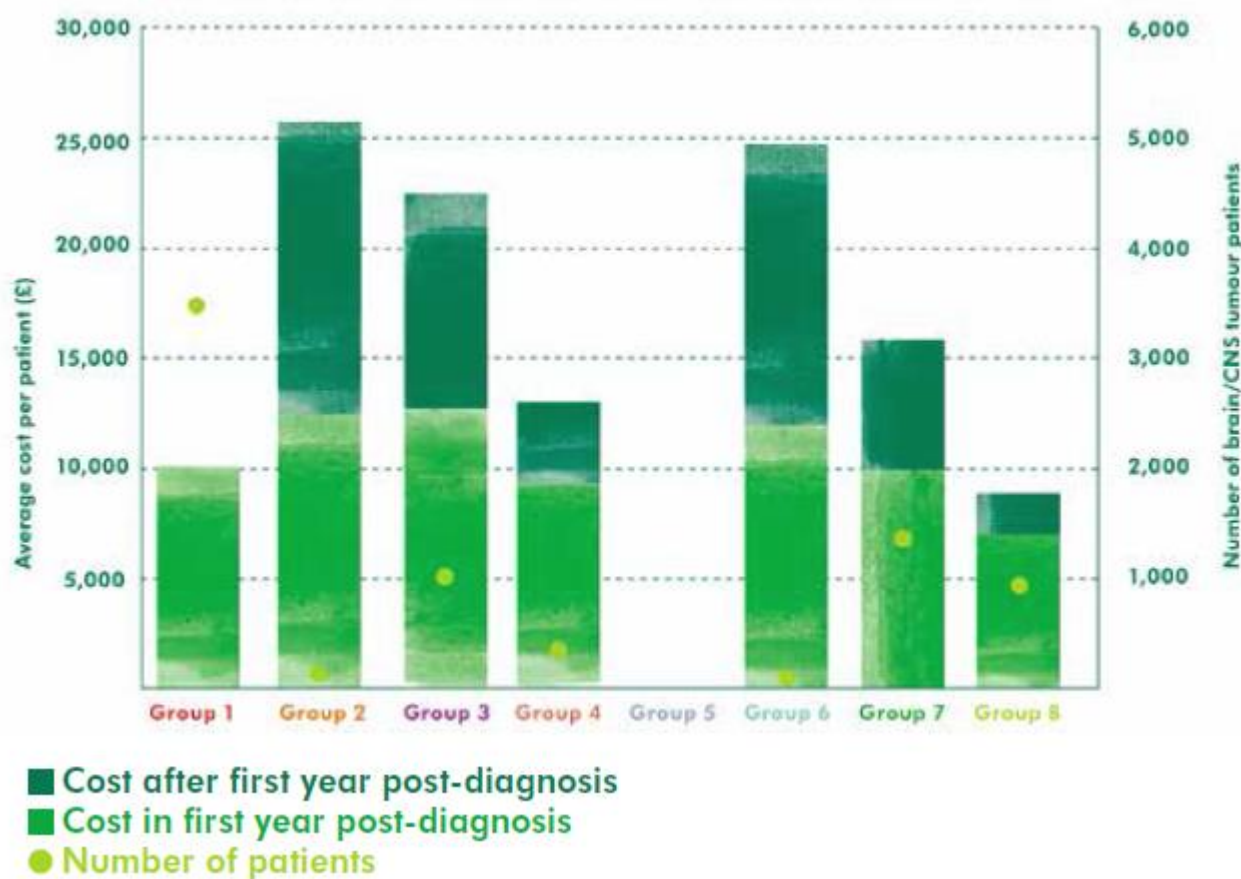
Average post-diagnostic inpatient cost for brain/CNS tumour patients = **£13,200**
→ **higher** than for other RfD cancer cohorts (breast, lung, prostate).
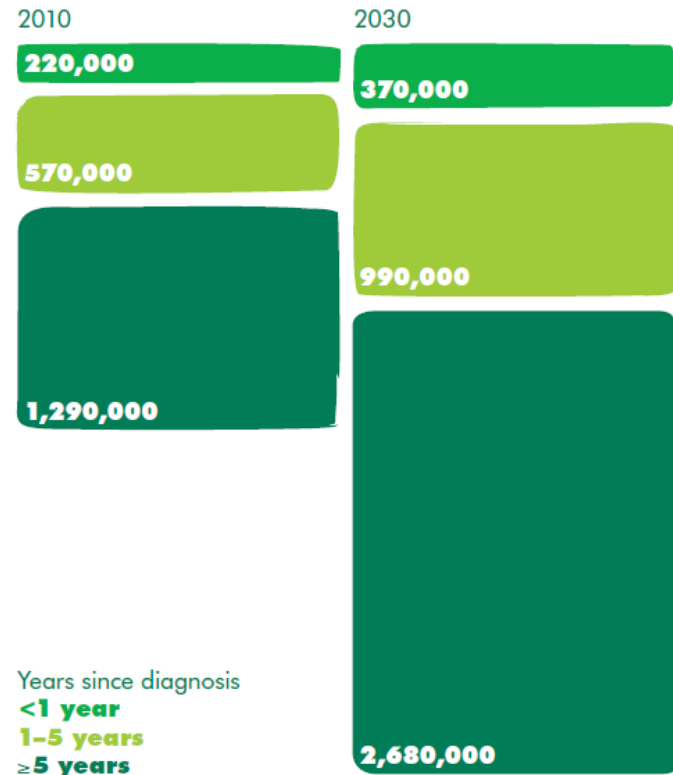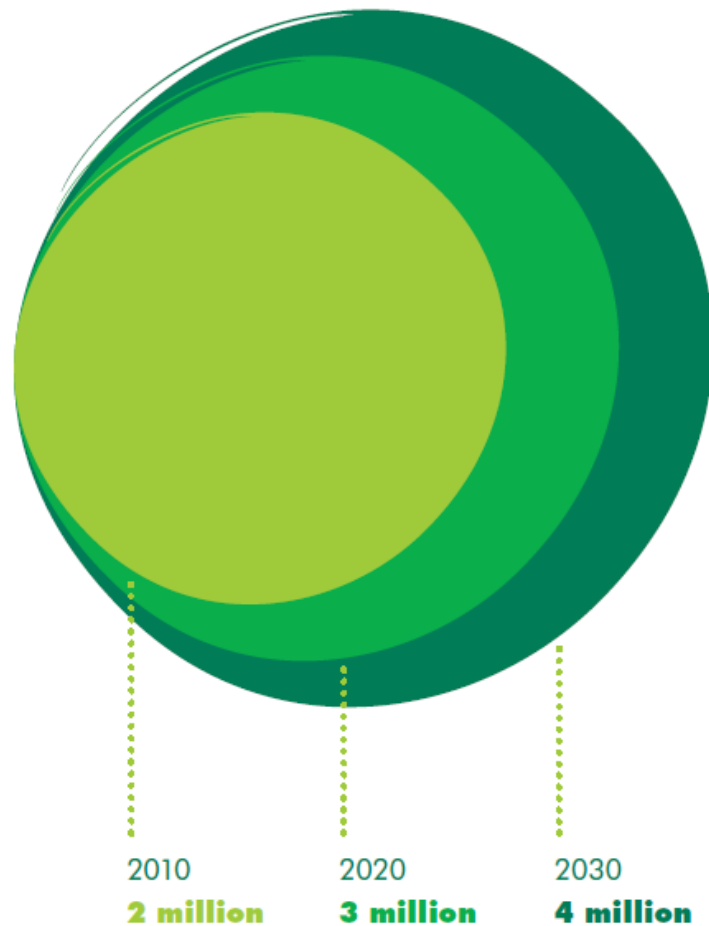
Some of the highest inpatient costs are associated with **moderate survival**, rather than longest periods of survival.

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

Legend:
- ■ Cost after first year post-diagnosis
- ■ Cost in first year post-diagnosis
- ● Number of patients

Prevalence

THE CHANGING STORY OF CANCER

Cancer prevalence is the number or % of people who have been diagnosed with cancer and are still alive on a given date

2010
- 220,000
- 570,000
- 1,290,000

2030
- 370,000
- 990,000
- 2,680,000

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

2010	2020	2030
2 million	3 million	4 million

Source: Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. Br J Cancer 2012; 107: 1195-1202
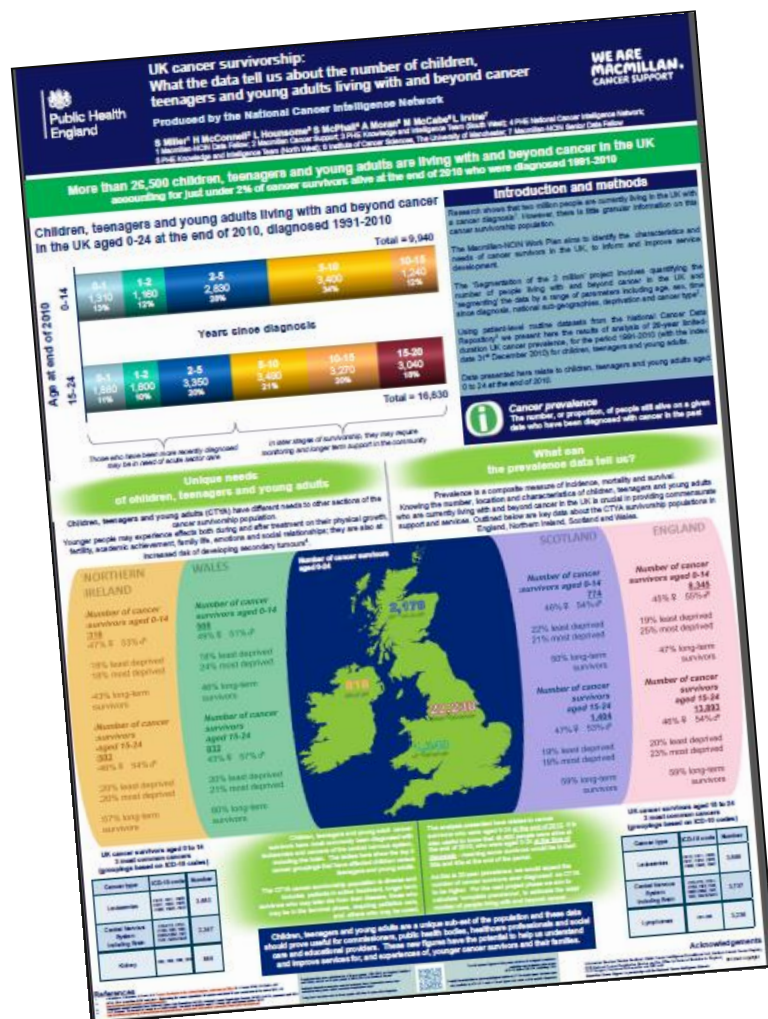Image: Macmillan Cancer Support http://www.macmillan.org.uk/Aboutus/Ouresearchandevaluation/Programmesofwork/CPEP.aspx

Prevalence
Macmillan and NCIN

New **20-year cancer prevalence** figures (1991-2010) due in summer 2015: by range of parameters.

Figures will be available for Central Nervous System tumours for:
- England
- Northern Ireland
- Scotland
- Wales
- UK combined
- A range of national sub-geographies

One of the most common diagnoses for 0-24 year old cancer survivors in the UK are CNS tumours:
- ☐ c.**2,340** children are living with and beyond a brain/CNS tumour diagnosis
- ☐ c.**3,700** teenagers and young adult are brain/CNS tumour survivors
  diagnosed between 1991 and 2010 and still alive at the end of 2010

Service Profiles – CNS metrics

- A number of cancer metrics presented by Trust for England

- The next release will include **5 new indicators** for brain and CNS tumours

Number of trials for brain tumour open at each trust
Number of brain tumour patients recruited to clinical trials
Survival data at a network level 1 year for Glioblastoma (brain)
Survival data at a network level 1 year for Meningioma (WHO Grade I cranial)
Survival data at a network level 5 year for Meningioma (WHO Grade I cranial)

- These will be released in the coming months by the NCIN

- Alongside 22 general cancer indicators and other site-specific cancer metrics

Data sources

- **Cancer Analysis System** – CAS (restricted use, by PHE employees)

- **CASCADE** – for NHS/PHE users (cancer incidence, mortality, survival)

- **Cancer Commissioning Toolkit**, NCIN https://www.cancertoolkit.co.uk/

- **Fingertips**, PHE http://fingertips.phe.org.uk/

- **NCIN projects**: Cancer by deprivation, Routes to Diagnosis, Macmillan-NCIN Partnership www.ncin.org.uk

- **Macmillan Cancer Support**, Routes from Diagnosis http://www.macmillan.org.uk/Aboutus/Ouresearchandevaluation/Programmesofwork/Routesfromdiagnosis.aspx

- **Cancer Research UK**: wide range of key statistics http://www.cancerresearchuk.org/cancer-info/cancerstats/types/brain/

In closing…

- Many **valuable national and routine sources** for brain and CNS tumour data

- A **worthwhile exercise** for understanding site-specific tumour trends and statistics

- By bringing the stats together, clinicians, registration staff and Analysts can provide important messaging, caveats and considerations when interpreting the results

- Re-affirms why **data quality** is so important, these top-level figures are often accessed by: *charities*, for lobbying and campaigns, and the *public*, including patients and their families

Acknowledgements

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Public Health England

Thank you

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