

**PRESENTING BRAIN TUMOUR  
STATISTICS TO THE PUBLIC:  
UNRAVELLING COMPLEXITY**

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NCIN CANCER OUTCOMES CONFERENCE, 14<sup>TH</sup> JUNE 2013

### From the CRUK Facebook page...

Where do you get your statistics? Brain tumour research charities estimate 16,000 people are diagnosed in the UK every year, and that is thought to be an underestimate.

My wife is dying from a brain tumour but CRUK only included her in their figures 2 years after diagnosis as this was when it progressed from a grade 2 tumour to a grade 3, despite us being told by her consultant it was terminal on day 1. CRUK also do not include under-16s in their figures or secondary tumours.

## Sources of advice

### NATIONAL CANCER REGISTRATION SERVICE (EASTERN)

- Sally Vernon
- David Greenberg

### NCIN CENTRAL NERVOUS SYSTEM SITE-SPECIFIC CLINICAL REFERENCE GROUP (SSCRG)

- Peter Collins and others

### NCRI BRAIN CLINICAL STUDIES GROUP (CSG)

- Colin Watts and others

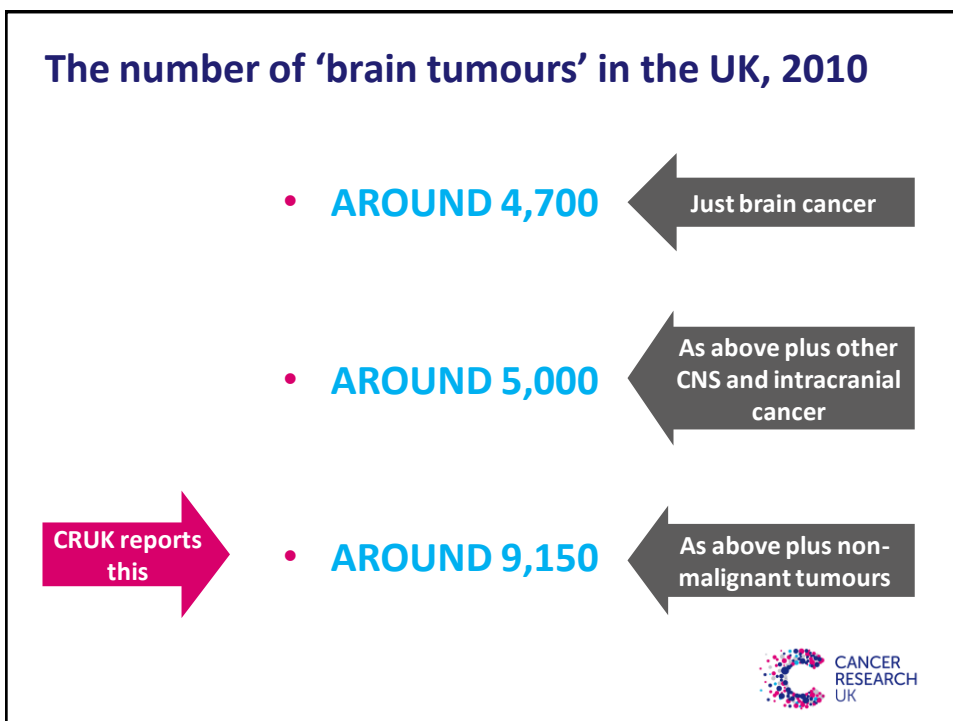
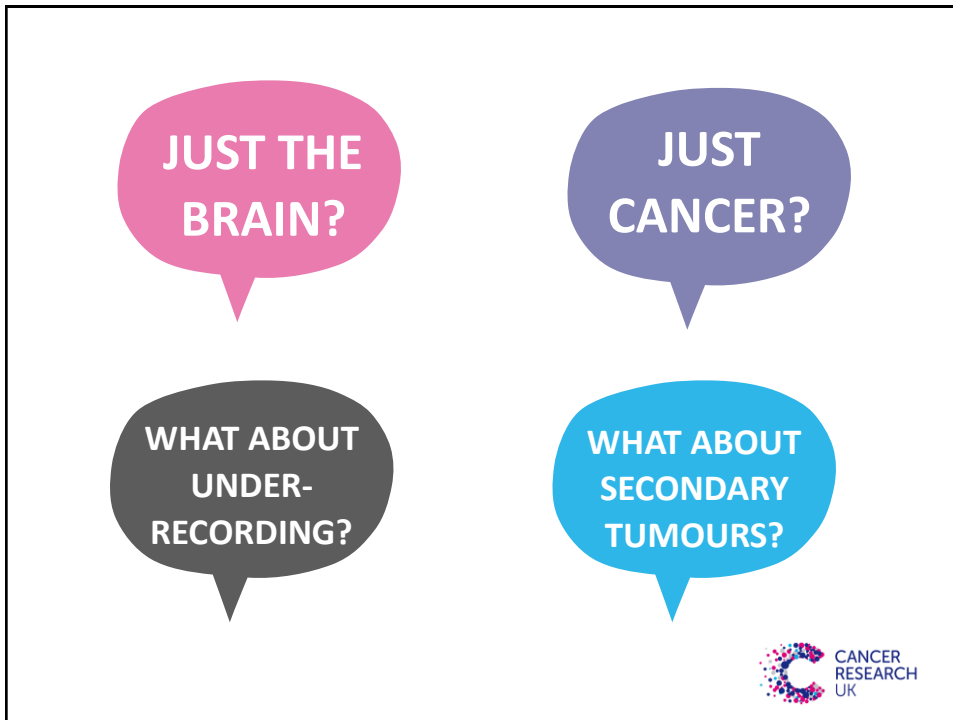
### CHILDHOOD AND TYA CANCER CLASSIFICATIONS

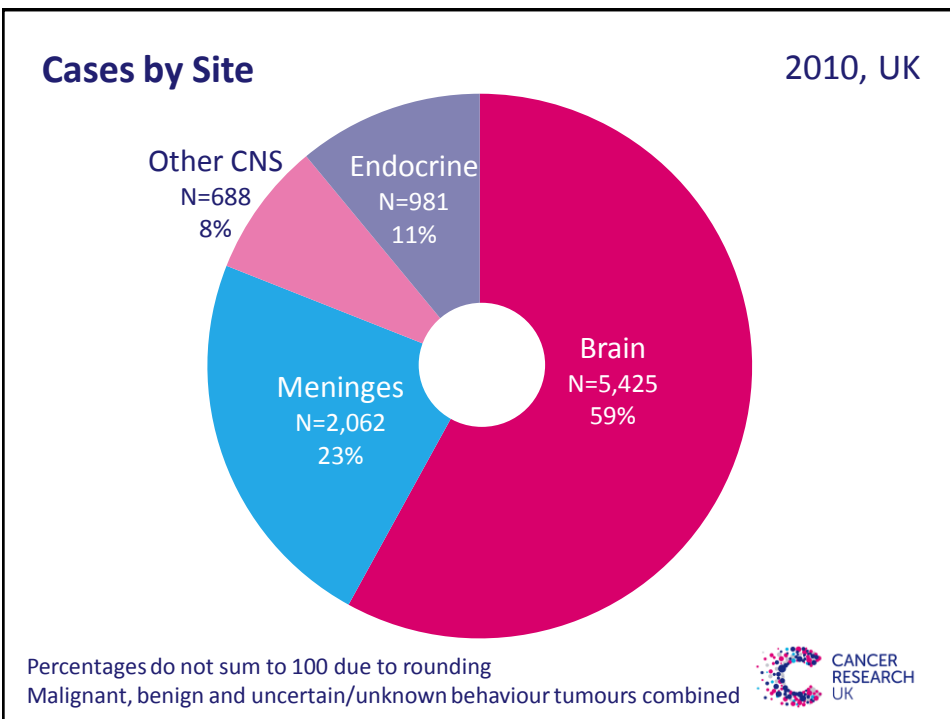
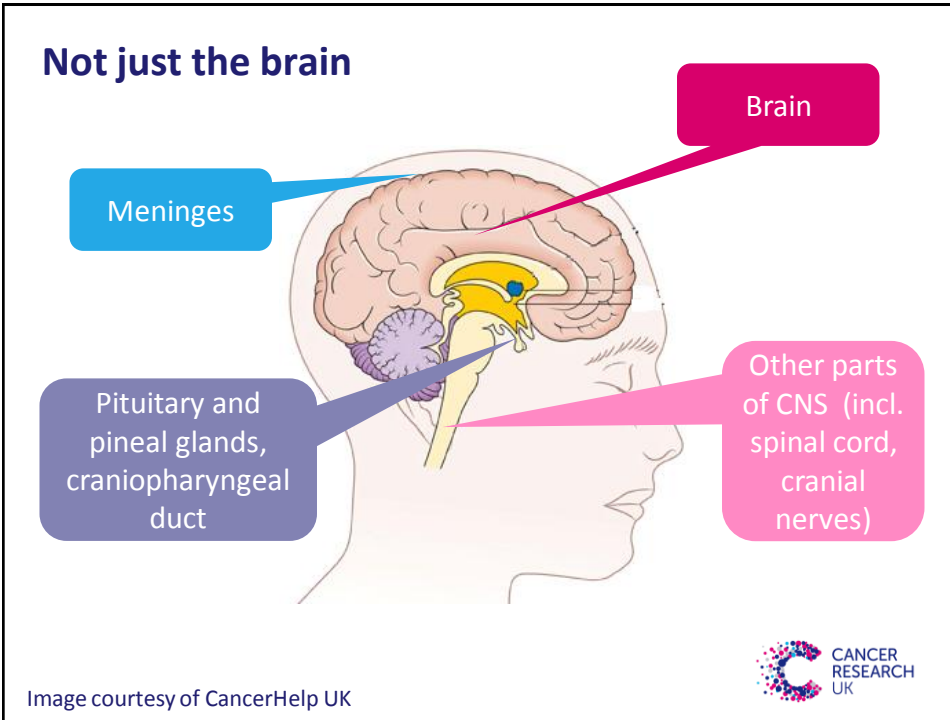


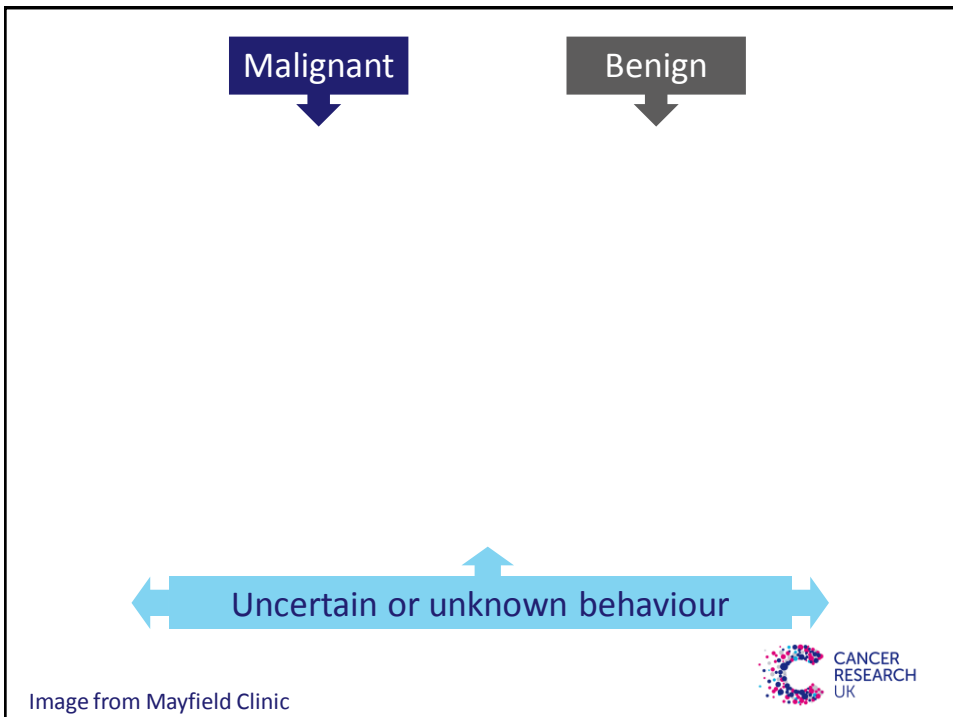
**HOW MANY  
PRIMARY  
'BRAIN TUMOURS'  
ARE THERE IN THE UK  
EACH YEAR?**

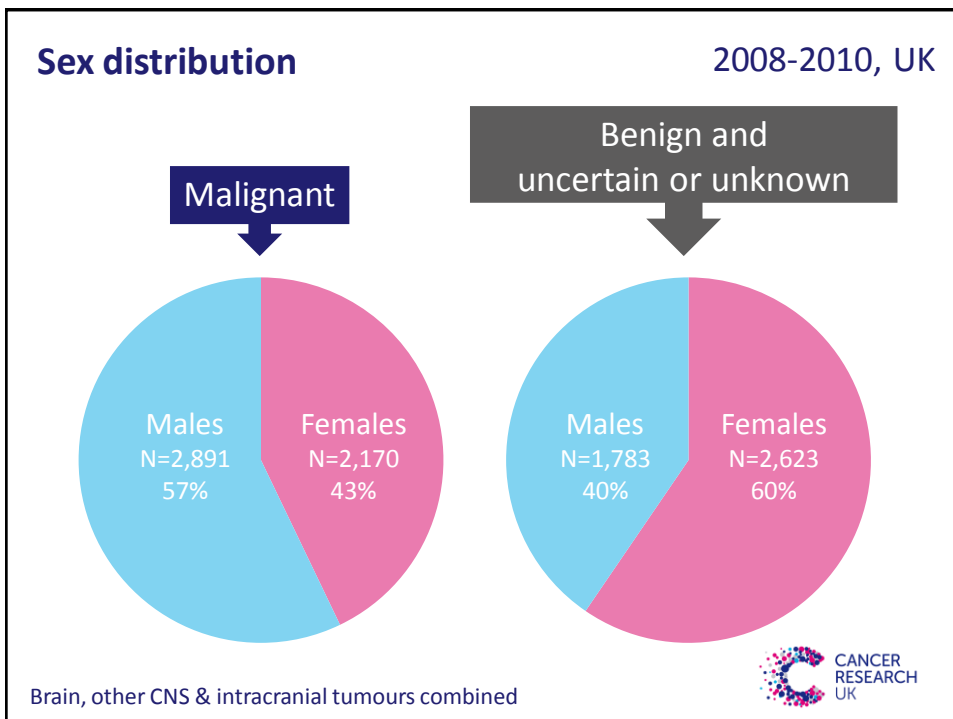
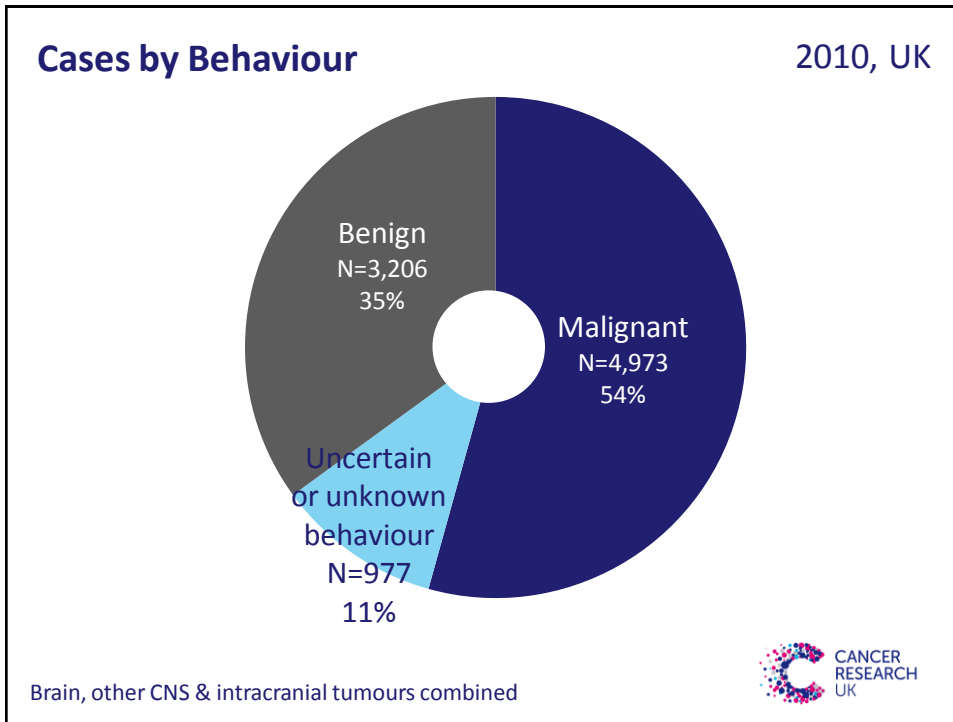
**AROUND  
9,150**

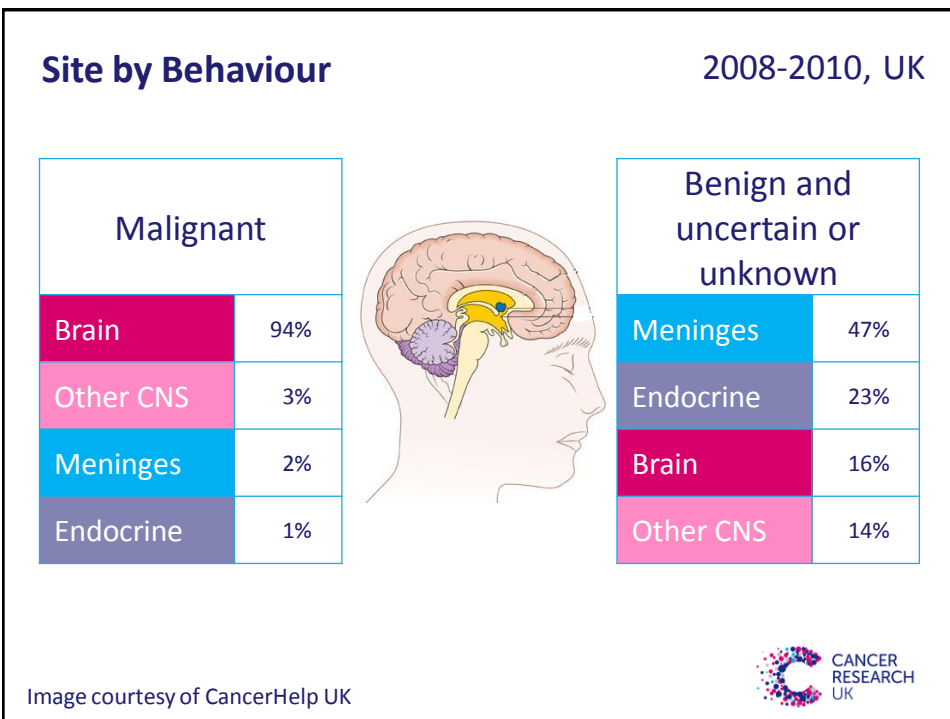
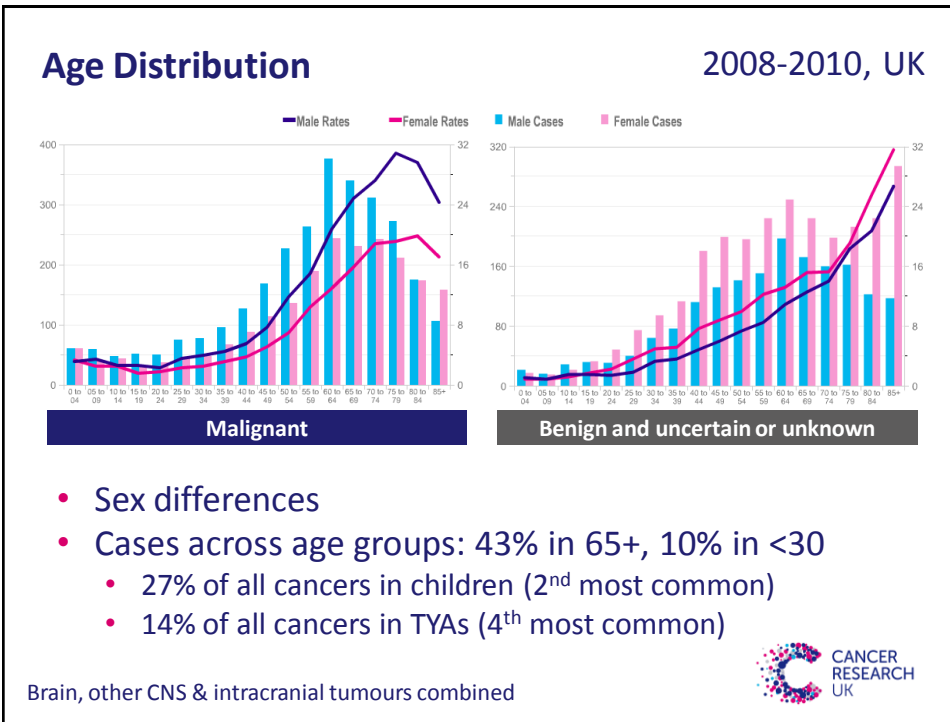












# WHAT PATIENTS HEAR



GRADE



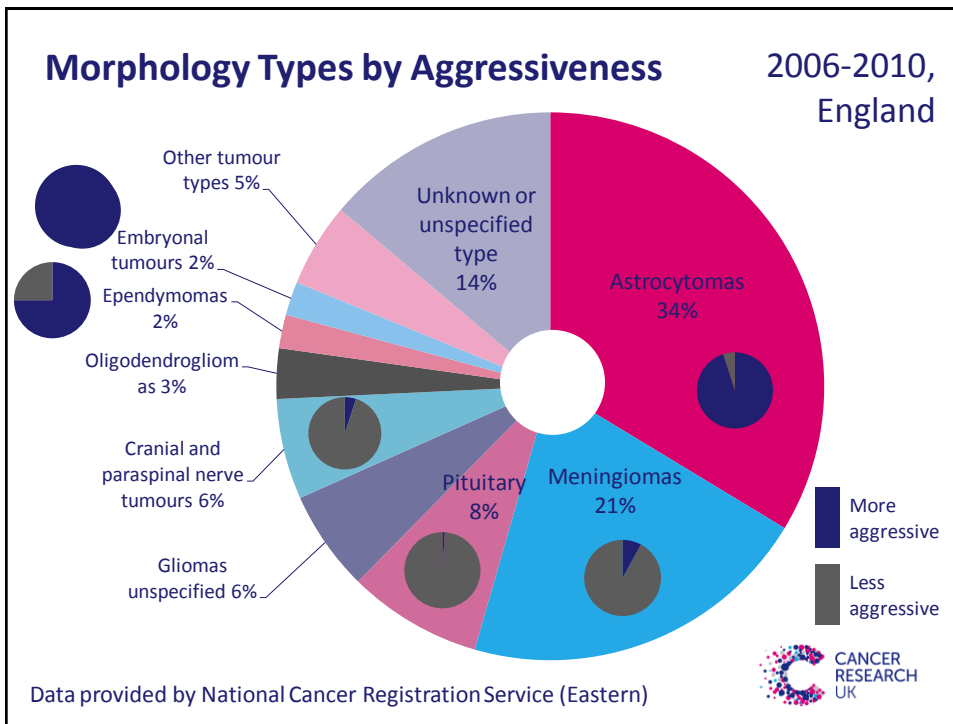
HOW  
AGGRESSIVE

Grade I	Almost all benign & uncertain/unknown Few malignant
Grade II	Most malignant Few benign & uncertain/unknown
Grade III-IV	Almost all malignant Few benign & uncertain/unknown

Link between ICD-10 groups and tumour grade provided by  
National Cancer Registration Service (Eastern)







### You may see other estimates of the number of 'brain tumours' per year...

- CRUK: 50% is too high** → **AT LEAST 18,300** ← UK 2010 cases, plus estimated 50% of cases not recorded
- CRUK: can't include secondaries in total** → **AT LEAST 24,000** ← UK 2010 cases, plus 3 secondary 'brain' cancers for every primary malignant tumour
- AT LEAST 52,500** ← UK 2010 cases, plus secondary 'brain' cancer in 6% of prevalent cancer patients

UK 2010 cases: brain, other CNS & intracranial tumours; malignant, benign and uncertain or unknown behaviour; 2010, UK  
 Estimated 50% under-recording: [Pobereskin 2001](#), [Counsell 1997](#)  
 Estimated 6% of cancer patients experience brain metastasis: [Davis 2012](#)  
 5-yr prevalence, UK, 31.12.2006, all cancers excl NMSC, NCIN 2010: 722,001

CANCER RESEARCH UK

# UNDER-RECORDING



## Evidence for under-recording?

### TWO STUDIES FOUND 50% OF CASES WERE UNRECORDED BY CANCER REGISTRIES (SO MISSED FROM OFFICIAL STATISTICS)

- 1990s data, relatively few cases
- Shortfall mainly in benign tumours
  - But registries weren't aiming to collect these at that time
  - Comprehensive UK registration only from ~2000 onwards

	Ascertainment rate (%)		
	Malignant	Benign	Overall
Counsell (Lothian 1989-90)	78	22-29	54
Pobereskin (Devon & Cornwall 1992-96)	72	42	52

- Tayside 1992 (Brewster): 97% ascertainment for malignant tumours

Pobereskin L. 2001. [The Completeness Of Brain Tumour Registration In Devon And Cornwall](#). Counsell C et al. 1997. [Limitations of using a cancer registry to identify incident primary intracranial tumours](#).  
Brewster DH et al. 1997. [Completeness of case ascertainment in a Scottish regional cancer registry for the year 1992](#).



## Under-recording today?

- Registration improvements since 1990s
- Diagnostic improvements since 1990s
- As in past, most unrecorded cases today probably non-malignant
  - Non-fatal or conservatively-treated = fewer events for registries to pick up

50% under-recording  
for all brain tumours combined  
is unlikely today

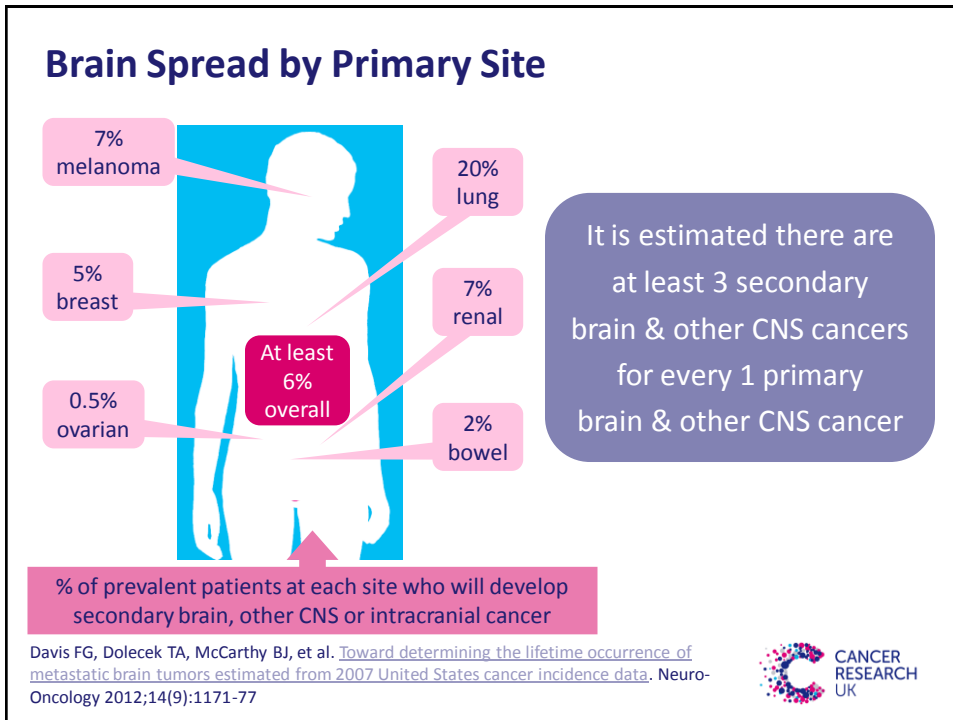


**SECONDARY  
CANCERS**

WE DON'T  
INCLUDE THEM  
IN 'BRAIN  
TUMOURS'  
TOTAL...

**...BUT WE  
RECOGNISE  
THEIR  
IMPACT**





## Conclusions

- **NEED TO INCLUDE MORE THAN JUST BRAIN IN THESE STATS**
  - We report brain, other CNS, and intracranial tumours
- **NEED TO INCLUDE MORE THAN JUST CANCERS IN THESE STATS**
  - We report malignant, benign & uncertain/unknown behaviour
- **UNDER-RECORDING UNLIKELY TO STAND AT 50% TODAY**
  - Work needed to quantify problem and identify solutions
- **CANNOT INCLUDE SECONDARY CANCERS IN THESE STATS**
  - Would mean double-counting, we don't do it for any other site
  - But patients face similar issues whether primary or secondary tumours – substantial part of workload for clinical teams

## For more information

- **EMAIL:**
  - [katrina.brown@cancer.org.uk](mailto:katrina.brown@cancer.org.uk)
- **VISIT CANCER RESEARCH UK CANCER STATISTICS WEBSITE:**
  - [cruk.org/cancerstats](http://cruk.org/cancerstats)
- **VISIT CANCER RESEARCH UK SCIENCE BLOG**
  - Brain tumours blog out later this month
  - [cruk.org/blog](http://cruk.org/blog)

