

THE STORY BEHIND THE DATA: developing the conversation about brain cancer data beyond traditional indicators

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Background

brainstrust and the National Cancer Registration Services (NCRAS) of Public Health England (PHE) recognised that there is need, and scope, for an evolving registration service to develop the conversation about cancer beyond traditional indicators of age, incidence, prevalence, mortality and morbidity. As a result, the *Get Data Out* project has seen the regular release of new brain tumour data. This data helps us to understand the impact of brain tumours at a population level, through regular publication of anonymised data on:

- brain Tumour Incidence
- survival
- brain tumour treatment
- routes to diagnosis.

Method

NCRAS fulfils its duty as a public health agency responsible for cancer prevention and control in England, by a range of outputs, including official statistics and reports, and support for public health research on cancer. Currently the Standard Output Tables are produced for four statistical areas (incidence, routes to diagnosis, treatment and survival) and for brain tumours only. Further statistical areas will be added.



Results

Three themes have emerged from this first statistical release:

1. 10% (over 500) of people with a non-malignant brain tumour (NMBT) do not survive one year.

2. 5–9-year-olds receiving RT dropped from 43% in 2013 to 27% in 2014.
3. Groups of people (30–49-year-olds and 50–69-year-olds) have similar treatment but have a big gap in outcomes.

What this means for the brain cancer community

The first report will explore the recent finding that 10% (572 in 2014) of people diagnosed with a NMBT will die within the first year after being diagnosed.

1. NMBTs are a diverse group of tumours, including meningiomas, schwannomas, pituitary adenomas and other tumours.
2. About 9,000 primary brain tumours are diagnosed every year. 50% are non-malignant.
3. Over 1 in 10 people with a NMBT will not survive the first year (over 500 deaths annually).
4. When crude³ and net⁴ survival data is considered, there is no difference in the >49 age cohorts, and the difference is smaller than 0.6% in the >69 age cohorts.
5. 30% of people with a NMBT are diagnosed through A&E.



Conclusion

Key recommendations:

1. The word *benign* should not be used to describe NMBTs. A significant number of people diagnosed with a NMBT die within the first year, and those that survive carry a high symptom burden for many years.

2. There is a need for better public understanding, resources and information. People living with a NMBT need more information about:
 - growth and recurrence
 - types of NMBTs
 - surgery
 - causes
 - symptoms and side effects
 - life expectancy.
3. Support for people with a NMBT should be stratified more effectively according to a clear set of determinants (tumour type, treatment, the person).
4. Relevant and timely models of support should be developed, including high quality information and involvement of palliative support:
 - supported self-care for everyone living with a NMBT
 - shared care for those who need a little more support
 - complex management involving external agencies for the few who need intensive support.
5. There must be parity of voice between non-malignant and malignant brain tumour communities.

This is the vanguard to a wider piece of work to establish ways of producing anonymised data on rarer cancers. With the systems now established, and patient anonymity guaranteed, the stage is set for unprecedented access to data on rarer cancers.

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³ Probability of death in the real world where you may die of other causes before the cancer kills you
⁴ Probability of death in a hypothetical world where the cancer under study is the only possible cause of death