

Exploring how National Cancer Registry data can be used for the benefit of the brain tumour community

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Background

Until recently, population level data on less common cancers such as brain tumours has been limited. *brainstrust* and Public Health England's National Cancer Registration and Analysis Service (NCRAS) have been working to solve this problem. The *Get Data Out* project sees the regular release of new brain tumour data. This data will help us all to understand the impact of brain tumours at a population level.

There is a widening gap between the 'traditional' approach to epidemiology of cancer and questions that the clinical and patient communities have. The All Party Parliamentary Group (APPG) on Cancer, too, asks for increased data transparency, making more of it available to the public. This must include rare and less common cancers.³

brainstrust, the brain cancer people, has worked with NCRAS in partnership to scope out how to meet this call, and increase data available to meet the needs of cancer patients and cancer charities. To do this the publications of the National Cancer Registration and Analysis service must go beyond traditional indicators to fully utilise the data collected on the patient pathway.

The aims were to:

- look at Registry data for a less common cancer (brain) in new ways to address important questions for the brain tumour community
- broaden the discourse around epidemiology of care so that some of the wider questions that patients, carers and clinicians have around care can be addressed⁴
- establish a process that can be used by other cancer sites
- develop partnership working to make data more meaningful.

Method

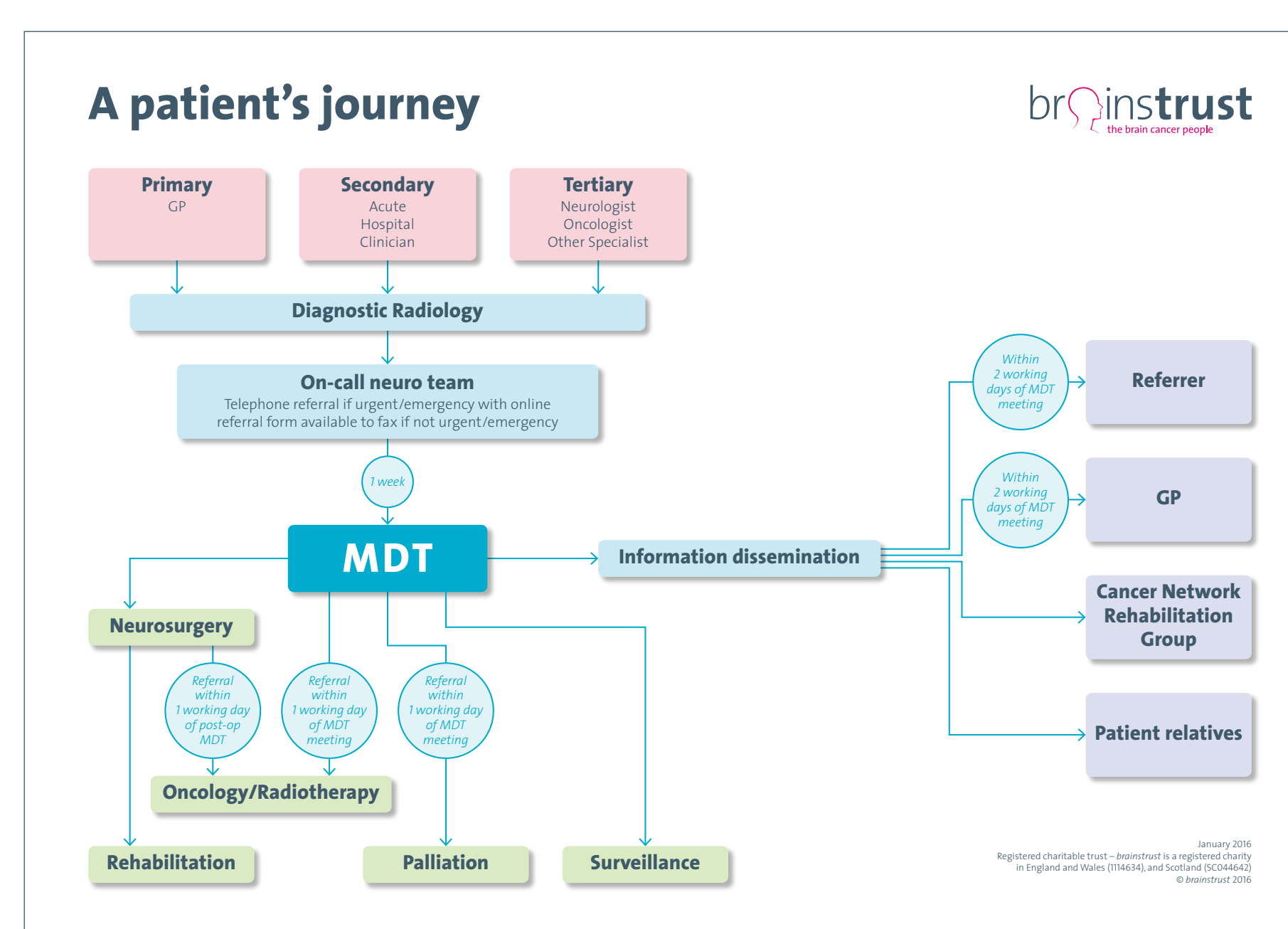
Stakeholder representatives (patients, carers, clinicians, allied health professionals and PHE analysts) from the UK brain cancer community attended an initial workshop to:

- understand the range of cancer registry data available
- understand how it is currently used

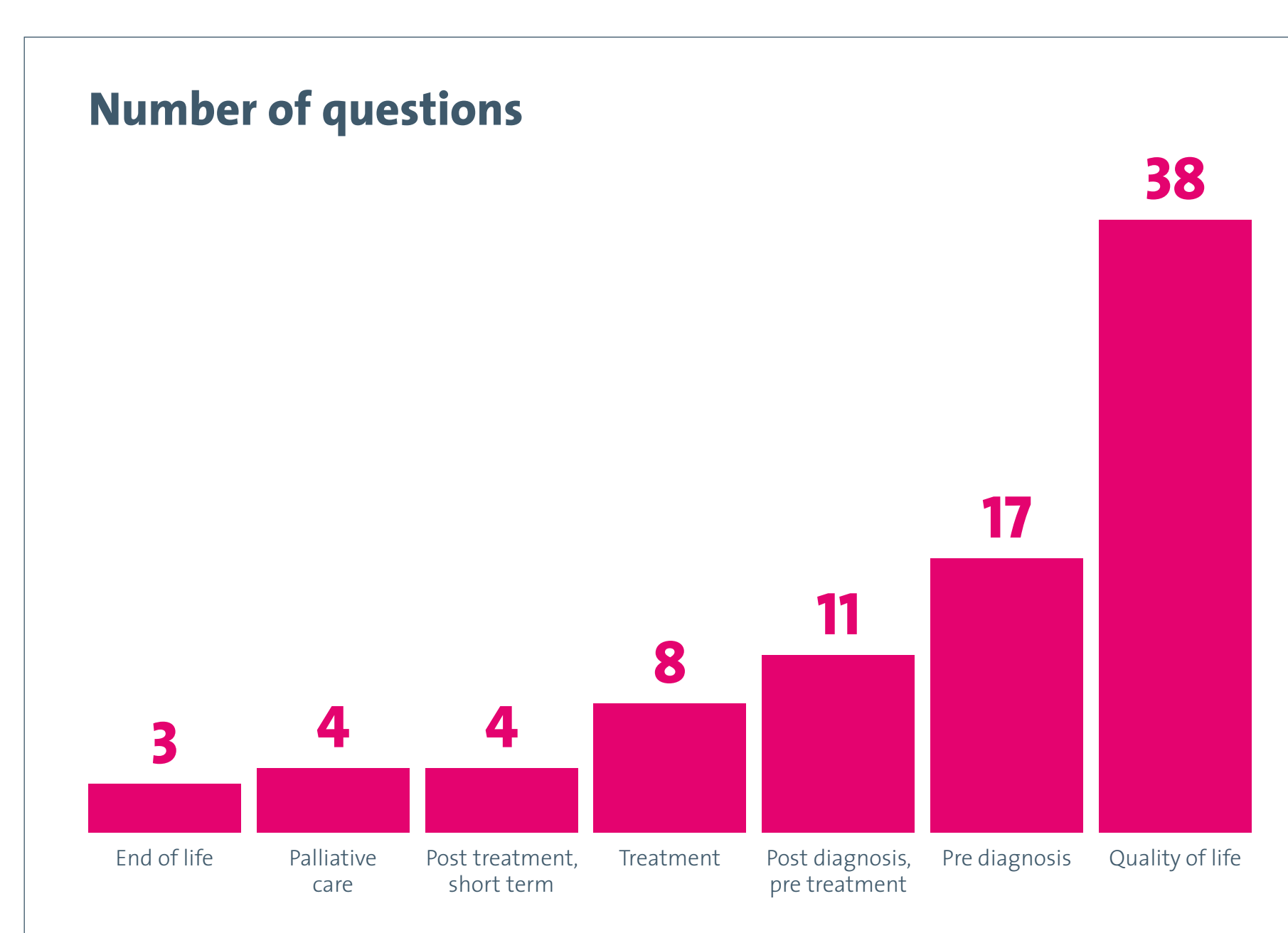


- define what more it could be doing
- identify what questions can be asked of the data.

85 questions were identified, representative of the patient journey:



There was a significant emphasis on quality of life (45% of questions):



Working with PHE, we triaged which of these questions could be answered with cancer registration data that was currently collected. We then developed a methodology so that more granular data could be published whilst protecting patient data.

You can see the data, as published by Public Health England, here: www.cancerdata.nhs.uk/standardoutput

This data sits behind and drives the brain tumour data dashboard, which you can access here: www.brainstrust.org.uk/brain-tumour-data

Results

Data on its own does not tell a story. Early analysis of this data brings meaningful narrative and bears some significant headlines for our community:

1. Until now we have had oceans of data but only a few puddles with any meaning. What this has done is brought nuance and story to the headline figures. For example, incidence data. We have known that there are just over 9,000 primary brain tumours diagnosed every year.

What we now know is that there is a J curve (incidence in under 5s and the elderly is higher) and that this is unusual in most other cancers.

2. This work adds colour to other data sets, e.g. early diagnosis. We know that the routes to diagnosis for a brain tumour mean that, nationally, 58% of patients will present through A&E. What we now understand is that this tends to be the case in the very old and the very young. GP referral is also common. This will bring weight to early diagnosis work that is looking at identifying the best pathway for earlier diagnosis of brain tumour presenting with headache, through direct access to cerebral scanning.
3. Routinely publishing these statistics means that we can compare changes between years. For example, the proportion of 5–9-year-olds receiving RT has dropped from 43% in 2013 to 27% in 2014. As there are only around 100 5–9-year-olds diagnosed with a malignant brain tumour each year, it is not yet clear if this change is statistically significant, but as more data is released routinely it will enable us to monitor the change.
4. 10% of people with a non-malignant brain tumour do not survive one year. Over 500 people are dying within the year, and most of the people who don't survive the year die within three months of diagnosis.
5. Rates of chemotherapy and radiotherapy in 30–49-year-olds and 50–69-year-olds with malignant brain tumours were similar, but 1 year net-survival was very different in these groups.

Conclusion

It is possible to provide anonymised population-level brain tumour data for public use in the form of standard output tables (www.cancerdata.nhs.uk/standardoutput), in a way that is meaningful for the brain tumour community. This has been a successful, rewarding collaboration between PHE, patients, caregivers, clinicians and *brainstrust*.

Acknowledgements/References/Funding

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³ APPG on Cancer Inquiry December 2017

⁴ www.neuro-oncology.org.uk/priorities/index.php