

Identifying the Top 10 priorities for clinical research in primary brain and spinal cord tumours: James Lind Alliance Neuro-Oncology Priority Setting Partnership

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Introduction

The James Lind Alliance (JLA) is a non profit-making initiative, which brings patients, carers and clinicians together to identify and prioritise the top 10 uncertainties, or ‘unanswered questions’, about the effects of treatments that they agree are most important. The information helps to ensure that those who fund health research are aware of what matters most to people with brain and spinal cord tumours and those who care for them.

Objectives

The primary objective of the UK-based JLA Neuro-Oncology Priority Setting Partnership (PSP) was to identify the brain and spinal cord tumour community’s top 10 uncertainties in diagnosis, treatment, recovery and prognosis in primary brain and spinal cord tumours.

A secondary objective was to highlight the necessity of a collaborative approach to priority setting in clinical research.

A third objective is to encourage other countries to use the PSP methodology to draw international comparisons.

Methods

The Neuro-Oncology PSP followed a protocol based on the JLA guidance, which consisted of six main stages:

- Initiation** – a steering group involving healthcare professionals, patients, charity representatives, JLA and Cochrane Collaboration group members determined the scope of the research.
Scope: clinical uncertainties of interventions for primary brain or spinal cord tumours, any age, from diagnosis to terminal stages.
- Consultation** – a survey was developed, accessible on a JLA Neuro-Oncology website, and publicised internally and externally through charity, clinical and research organisations.
- Collation** – responses were gathered and, where possible, uncertainties were placed into PICO format (population, intervention, comparison, outcome) and categorised.
- Consultation** – all questions were scored by the stakeholders and prioritised. The 44 prioritised questions were then sent out in a second survey to patients, carers and healthcare professionals.

- Prioritisation** – a workshop was held to prioritise the last 25 questions, using a modified Delphi and nominal group technique. The final top 10 was agreed.
- Dissemination** – results are being disseminated widely to the brain tumour community, including the government and potential funders.

Further information

- Successful identification of stakeholder representatives from a cross section of the UK brain and spinal cord tumour community (28 members)
- Funding from three brain tumour charities, a children’s cancer charity, Cochrane Neuro-Oncology Group and Edinburgh and Lothians Health Foundation
- Development of a specific website (www.neuro-oncology.org.uk)
- Systematic Cochrane style literature searches to ensure genuine uncertainties
- Questions also sourced from an in-person patient forum and the UK Database of Uncertainties about the Effects of Treatments (UK DUETs)
- Formatting of questions double checked by pairs of stakeholders
- Regular teleconferences.

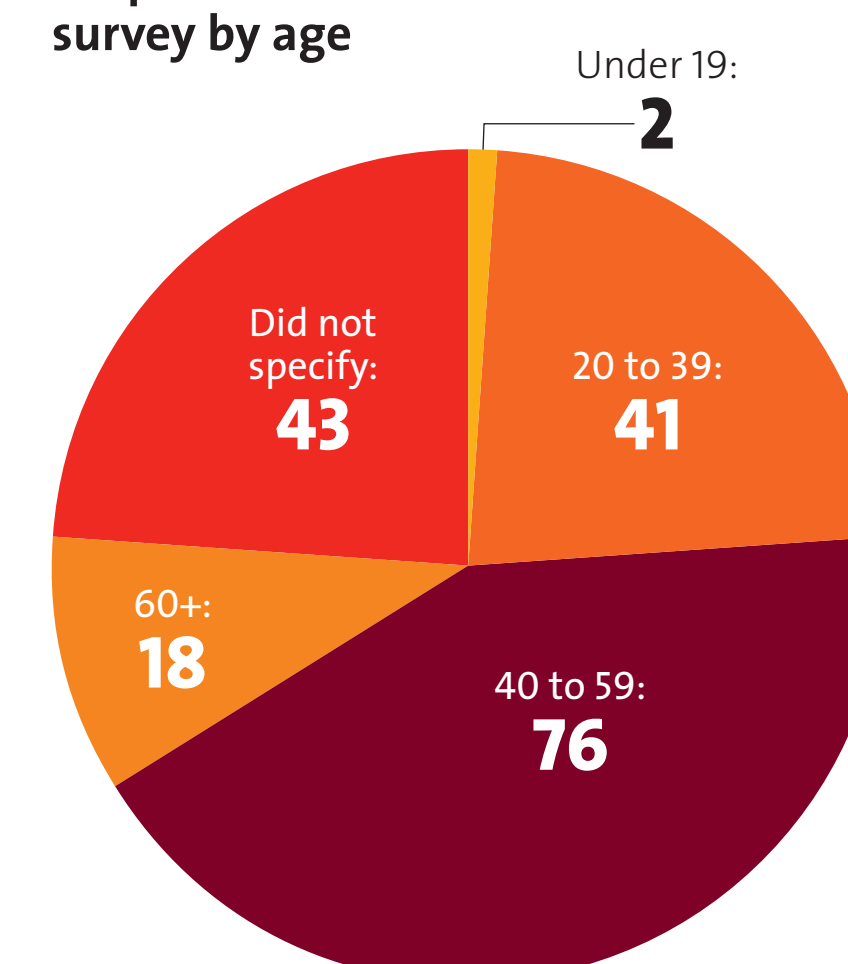
Results

Over 600 individual uncertainties were generated in the first round. After duplicates were removed or combined, and answered or out of scope uncertainties were removed, stakeholders selected from the remaining uncertainties to put forward 44 for a second survey. After voting by over 200 people, the number of uncertainties was reduced to 25. These 25 were discussed and ordered at the prioritisation workshop and the final top 10 agreed.

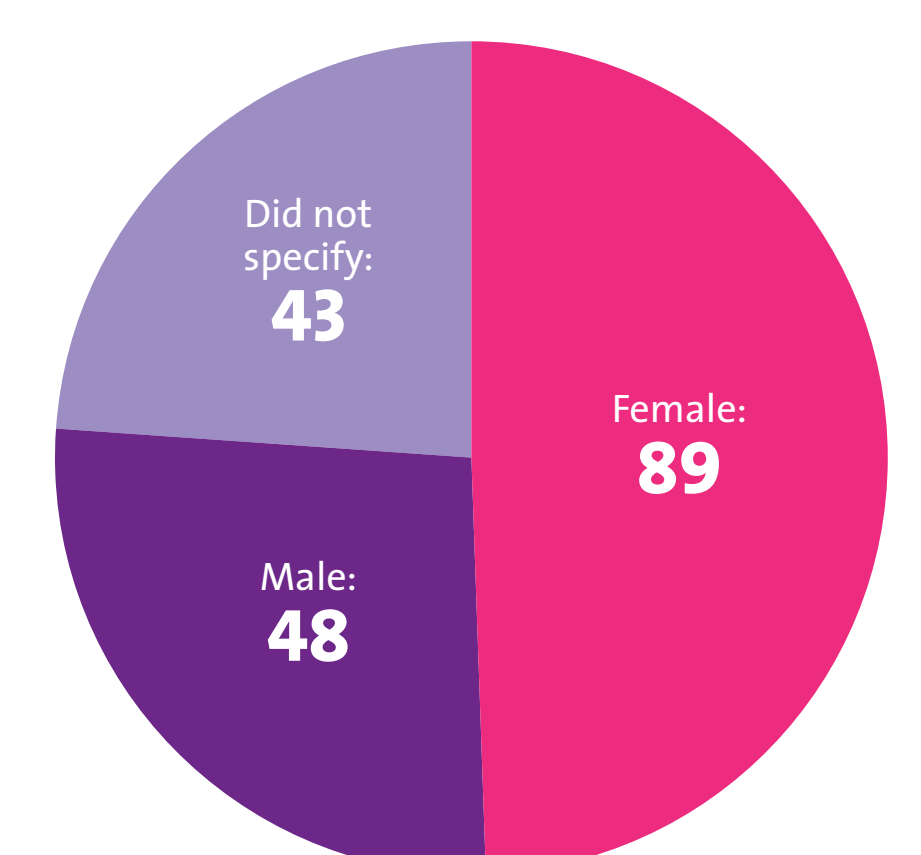
Conclusion

This has been a very successful and productive collaboration between CNS patients and carers, major brain and spinal cord tumour charities and multidisciplinary professional organisations. The top 10 UK clinical research uncertainties are identified and these will be promoted to governmental, neuroscience and charity funders throughout 2015/16. It is also the intention to encourage other countries to conduct similar neuro-oncology priority setting partnerships. This will enable international comparisons to be made regarding what the various stakeholders in the wider brain tumour community view as their top 10 clinical research uncertainties.

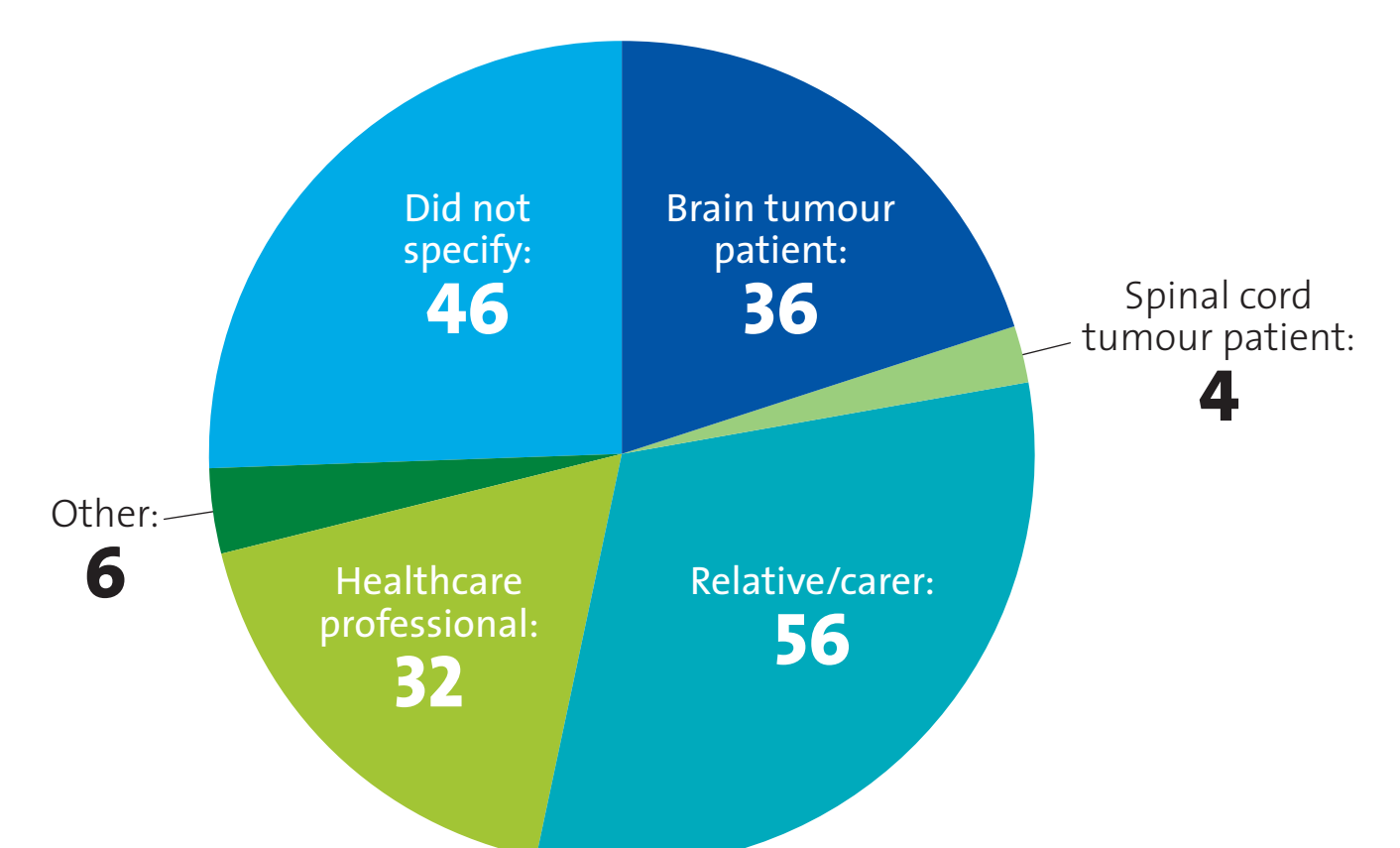
Respondents to initial survey by age



Respondents to initial survey by gender



Respondents to initial survey by type



Top 10 uncertainties*

- Do **lifestyle factors** (e.g. sleep, stress, diet) influence tumour growth in people with a brain or spinal cord tumour?
- What is the effect on prognosis of **interval scanning** to detect tumour recurrence, compared with scanning on symptomatic recurrence, in people with a brain tumour?
- Does **earlier diagnosis** improve outcomes, compared to standard diagnosis times, in people with a brain or spinal cord tumour?
- In **second recurrence glioblastoma**, what is the effect of further treatment on survival and quality of life, compared with best supportive care?
- Does **earlier referral to specialist palliative care services** at diagnosis improve quality of life and survival in people with a brain or spinal cord tumour?
- Do **molecular subtyping** techniques improve treatment selection, prediction and prognostication in people with a brain or spinal cord tumour?
- What are the **long-term physical and cognitive effects of surgery and/or radiotherapy** when treating people with a brain or spinal cord tumour?
- What is the effect of interventions to help **carers** cope with changes that occur in people with a brain or spinal cord tumour, compared with standard care?
- What is the effect of additional strategies for managing **fatigue**, compared with standard care, in people with a brain or spinal cord tumour?
- What is the effect of **extent of resection** on survival in people with a suspected glioma of the brain or spinal cord?

*Uncertainties relate to any age.



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