

## Participant Information Sheet

### What is the aim of the project?

The Priority Setting Partnership (PSP) has been set up to give people living with a tumour of the brain or spinal cord and those who care for them the opportunity to influence the research agenda. We want you to tell us what questions you think need to be researched about tumours of the brain and spinal cord in the areas of prevention, diagnosis, treatment and support. After gathering questions from as wide a range of patients, relatives and healthcare professionals as possible, the PSP will establish a 'Top 10' of research questions. Our hope is that this will ensure the time and money available for research is directed to the issues that matter most to you.

### Why have I been invited?

We would like to hear from people who have a tumour of the brain or spinal cord, or those close to them, and from people who have suffered the loss of someone they love due to a tumour of the brain or spinal cord. We also want to hear from health professionals whose work involves treating or supporting those with a tumour of the brain or spinal cord. We want to focus on patients, their carers and clinicians so we are not looking for questions from non-clinical researchers or organisations that represent them. Representatives of organisations deemed by JLA or the Steering Group to have conflicts of interest will also be excluded.

### What will I have to do?

You can help by filling in our survey with any questions you have about tumours of the brain or spinal cord. We are looking for questions that research hasn't found the answer to yet. You don't have to worry about this as we'll check to see if your question has already been answered or not. You can ask as many questions as you like. Consent for your participation will be implied through voluntary completion of the survey. You can fill in the survey online ([www.neuro-oncology.org.uk](http://www.neuro-oncology.org.uk)) or by contacting Laura or Julia (tel: 0131 537 2875 or email: [jlagroup@exseed.ed.ac.uk](mailto:jlagroup@exseed.ed.ac.uk)) for a paper copy with a FREEPOST envelope.

### Do I have to take part?

No, your participation is completely voluntary and will not affect the level of care you or your relatives receive.

### What are the possibly disadvantages and risks of taking part?

Recalling personal experiences associated with tumours of the brain and spinal cord may potentially lead to upsetting thoughts or emotions. If you would like to receive further support with any issues raised by completing this survey, this can be found through:

The Brain Tumour Charity <a href="http://www.thebraintumourcharity.org">www.thebraintumourcharity.org</a> 0808 800 0004 (Mon-Fri 9am-5pm) <a href="mailto:support@thebraintumourcharity.org">support@thebraintumourcharity.org</a>	<i>brainstrust</i> <a href="http://www.brainstrust.org.uk">www.brainstrust.org.uk</a> 0198 329 2405 (24/7) <a href="mailto:hello@brainstrust.org.uk">hello@brainstrust.org.uk</a>	Brain Tumour Action <a href="http://www.braintumouraction.org.uk">www.braintumouraction.org.uk</a> 0131 466 3116 (24/7) <a href="mailto:lorraine@lmtherapies.co.uk">lorraine@lmtherapies.co.uk</a>
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### Will my taking part in the study be kept confidential?

The demographic information we ask for is to help us ensure that different interest groups are represented in the findings. If you would prefer not to share this information, that is fine. Any personal information you do supply will be used only in conjunction with the PSP and held until it ends in December 2014. If you have supplied an email address and we think you could help us beyond that date, we will contact you for permission to keep your details in a database.

### Who do I contact for help or more information?

For more information on who is leading the project, our partners and funders, or the research process, please visit our website at [www.neuro-oncology.org.uk](http://www.neuro-oncology.org.uk). For more information about the James Lind Alliance (JLA), which has run many PSPs, please visit their website at [www.lindalliance.org](http://www.lindalliance.org). For any further information, please contact the Neuro-Oncology Group management team (Laura and Julia) by email ([jlagroup@exseed.ed.ac.uk](mailto:jlagroup@exseed.ed.ac.uk)), telephone (0131 537 2875) or post (Neuro-Oncology Group (JLA), Edinburgh Centre for Neuro-Oncology, Division of Clinical Neurosciences, Western General Hospital, Crewe Road South, Edinburgh, EH4 2XU).

For independent advice about participation, contact Mr Imran Liaquat: [Imran.Liaquat@nhslothian.scot.nhs.uk](mailto:Imran.Liaquat@nhslothian.scot.nhs.uk).

If you wish to make a complaint about the study please contact *NHS Lothian Complaints Team*:  
2<sup>nd</sup> Floor, Waverly Gate, 2-4 Waterloo Place, Edinburgh, EH1 3EG  
Tel: 0131 465 5708