



Building better brain tumour resources



Information and Consent: Brain Tumour Patient or Carer Focus Group

THE UNIVERSITY
OF QUEENSLAND
AUSTRALIA

Research Team

Principal Investigator

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Ms Tricia Berman, Ms Janet Micallef & Mr Philip Steel, Brain Tumour Alliance Australia

Ms Judith Meiklejohn, Independent researcher

Invitation to participate

As a person who has been diagnosed with a brain tumour, or a family member or friend who has cared for or supported someone with a brain tumour, we invite you to participate in a study aiming to improve access to information for Australians diagnosed with a brain tumour and their families. You must be aged 18 years or over to participate.

This study has been funded by Brain Tumour Alliance Australia (BTAA) and Cancer Australia through the 'Supporting People with Cancer' grant initiative, funded by the Australian Government.

Who is Brain Tumour Alliance Australia?

Brain Tumour Alliance Australia is a volunteer organisation that supports people with brain tumours, their families, and caregivers. It is primarily led by a group of brain tumour patients and current or former carers and seeks to represent the brain tumour community from this viewpoint. BTAA has partnered with researchers from the University of Queensland and other organisations to conduct this project.

What is this project about?

The journey of being diagnosed with a brain tumour, making treatment decisions and navigating the healthcare system is a complicated and involved process, and clear information is essential. Few up-to-date resources are available for brain tumour patients and their families. Accessing information is also often more difficult for patients and families in rural or remote areas, or those from culturally and linguistically diverse backgrounds. This project aims to develop a core set of information suitable for people affected by brain tumours. The resources will be adapted/translated into a number of languages including Arabic, Greek, Italian, simplified Chinese, Vietnamese, and easy English.

Two patient resources have been identified as needing adapting and updating initially. We are asking brain tumour patients and their family members or carers to participate in group discussions about how to make them better. The materials will then be updated and reviewed for accuracy, translated and distributed to the wider brain tumour patient community.

What will I have to do?

If you agree to take part in this study, you will be asked to attend one group discussion with approximately 8 other people, facilitated by a member of the project team. The main topic of discussion will be what information the patient resources need to include, and how to make these resources available. An example of the kinds of questions that will be asked is: *What is the most important thing you think people need to know to understand their medical care when they or a family member have a brain tumour?*

Group discussions will be held in Brisbane, Sydney and Melbourne. The discussion will last for 1-1.5 hours. Separate groups will be held for people who have been diagnosed with a brain tumour, and family or friends. All discussions will be audio-recorded, and it is not possible to participate in this study without being audio-recorded.

You will also be asked to complete a short demographic survey while attending the group discussion to allow us to describe the characteristics of those who participate in this study.

What are the possible risks and benefits?

Participation in this study should involve no physical or mental discomfort, and no risks beyond those of everyday living. If, however, you should find any point of discussion uncomfortable, you are free to not participate in that element of the discussion, or to not continue participating in the group discussion.

We don't expect this study to benefit you personally, but we expect the results of the study to help people affected by brain tumours in the future to more easily access better quality information.

Participation is voluntary

You will be asked to sign the consent page of this document prior to participation. You are free to ask any questions about the study or about this consent form before agreeing to participate. Please feel free to discuss your participation with your family or doctor if you would like.

Participation is completely voluntary. You may decline to participate in the study, or if you agree to take part in the study and later change your mind, you are free to withdraw from the study at any time by contacting the study coordinator by phone or e-mail. If you withdraw from the study, we will not be able to exclude any data you have already provided as data collection will be anonymous.

Taking part or not taking part in the study will not in any way affect your relationship with BTAA, The University of Queensland or other organisations, or the research team, and will not affect your or your family member's brain tumour treatment or care.

Confidentiality

All information collected will be treated as strictly confidential. Group discussions will be audio-recorded, but recordings will only be accessible to the research team. The data you provide will only be used for the specific research purposes of this study.

The findings from the study may be used in preparing research publications and conference presentations. All data will be reported in such a way that responses will not be able to be linked to any individual, and you will remain anonymous.

Further Information

If you have any questions regarding this study, please do not hesitate to contact the research team. Their contact details are:

Tricia Berman, Brain Tumour Alliance Australia

Telephone: 1800 857 221

Email: secretary@btaa.org.au

Ethics Approval

The ethical aspects of this research project have been approved by the Human Research Ethics Committees at the University of Queensland in accordance with the National Health and Medical Research Council's guidelines. If you would like to speak to an officer of The University of Queensland, not involved in the study, you may contact the Ethics Coordinator on 07 3443 1656.

Thank you for considering participating in this study



Patient & Carer Focus Group Consent Form



Project Title

Building better brain tumour resources

Investigators

Dr Danette Langbecker, Ms Dianne Legge, Ms Tricia Berman, Ms Janet Micallef, Mr Philip Steel, Ms Judith Meiklejohn

I acknowledge that by signing this form:

- I have read or had read to me the contents of the Information and Consent Form and I understand the purposes, procedures and risks of this research project as described within it.
- I agree that the information collected from my group discussion be audio-recorded and used for research and educational purposes with support organisations and healthcare professionals through conferences and publications.
- I understand that while the information gained from the project may be published, I will not be identified and all personal information will remain confidential.
- I am aware that I can choose to receive information about the outcomes of this study by providing my email address below. I am aware that I can also access information about the project outcomes which will be available on the BTAA website (www.btaa.org.au).
- I recognise that my participation in this study is completely voluntary and that I can choose to withdraw consent from participating in this project at any time, for any reason, without affecting my relationship with BTAA, The University of Queensland or other organisations involved, the research team, or my or my family member's treatment or care.
- I understand that if I withdraw from the study, any data I have already provided will not be able to be excluded from the study as data collection will be anonymous.

Consent of Participant

Name:

Signature: Date:

I am a person who has been diagnosed with a brain tumour

family member or carer of a person who has a brain tumour

If you would like to be sent information about the outcomes of this study, please provide your email address here:

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