

## FOCUS-GROUP FEEDBACK

I would like to thank you again for providing feedback on the 'Ways Ahead' study. It has allowed me to make improvements to the study design, interview guides and participant information sheets. Before I go on maternity leave, I thought I would provide you with an update on how your feedback has contributed to the project.

I have taken onboard your comments about medical terms such as 'gliomas', 'astrocytoma' and 'oligodendroglioma' and am now using the term 'brain tumour' instead. I am avoiding terms such as 'self-management' or 'self-care' as you suggested that it could be misconstrued as 'do-it-yourself' healthcare. I have also removed the word 'communication' and have tried to avoid long words and sentences in the patient information sheet and interview questions. I have proposed that we make a video version of the patient information sheet, in case people find reading difficult.

Your recommendations about the questions in the interview guide have led me to make several changes. I have been making some of the questions more specific, as you told me that some were too broad. I have changed the wording of some of the questions to make sure that I am more sensitive about potentially upsetting topics. I have also provided some example questions in the participant information sheets so that potential participants know that they may be asked personal questions about their lives. I will recommend that the interviewees are clear that research participants do not have to answer any questions that they do not feel comfortable answering.

You told me that the type or grade of tumour makes less of a difference to people's experience of living with a brain tumour than other factors in their lives, but that people with all types and grades of tumour have shared experiences. I have conveyed these comments to the research lead, Linda Sharp. Unfortunately, the funding of the current project means that we need to focus on low- and intermediate grade gliomas in the short-term, however we will take your comments into account as we look to the future of service development in this area.

I have noted your dislike of the term 'carers' and will avoid it in this research. I have also noted your comments on the need for a separate service for the partners/family-members/close friends who support people with brain tumours. I have discussed this with Linda. At the moment we have to focus our resources on developing a service for people with brain tumours, although I think it will be useful to find out whether research participants would like us to incorporate some elements that include partners/family-members. However, we hope that your comments, and those of interviewees in the research itself, will allow us to undertake future work to develop a service that addresses the needs of the partners/family-members/close friends who support individuals with brain tumours.

Our plan was to provide a post-treatment support service. However, you told me about the challenges of coping at earlier stages and the need for support between the "*gaps in the care-pathway*". As a result, I have suggested that we try to find out whether people with brain-tumours would prefer the service to start post-diagnosis, during treatment, immediately post-treatment (where treatment is given), or later. I have also noted your recommendation

to provide sign-posting to pre-existing services. I like the idea that this gives people flexibility to pick-and-choose when they access services, as and when they feel the need for support.

Your positive comments about the need for services to support people with brain tumours will help us to get our research approved by ethics. The fact that you have established your own charity, to provide some similar services, shows that there is a need for further support for people with brain tumours. You mentioned that, although Newcastle and the surrounding areas are well served by the Maggie's group and The Three Tumours, there could be more support, and that other regions may not be so lucky to have these services. These comments will help us to demonstrate the importance of this research.

These are just some of the things that I have learnt from the focus-groups. Your input has helped me to get a better understanding of the experiences of people with brain tumours. I have made detailed notes so that the person that replaces me during my maternity leave can learn from your experiences and use your comments to guide the research going forward.