Ways Ahead
Improving support for people with brain tumours

Summary of co-design findings

What we did… We conducted interviews and discussion groups with people living with a brain tumour, family-members, and healthcare professionals, and received responses from people with a brain tumour and family on a survey.

People told us about the support they desired, and their design preferences for a potential "supported self-management programme", including what needs to be considered to make sure it is acceptable, accessible, and feasible.

WHAT topics do people want support with?

- *Psychological:* knowing what to expect, managing future uncertainty, acceptance and adjustment, managing mood and emotions.
- *Symptoms:* fatigue, seizures, memory impairment, physical impairment.
- *Social:* maintaining independence, work and hobbies, driving licence, seeking financial benefits, speaking with children.
- Include information and support for family-members so that they know what to expect and how to help provide support.

WHAT support do people want?

- An information 'toolkit', including up-to-date advice on what to expect, signposting to available support, contact details for the care team, possible self-management strategies, and a space to share experiences with others.
- Keep the level of detail concise, use audio, images and short videos, where possible.
- Offer a physical resource for people not comfortable with technology.

WHO do people want to deliver the support?

- Desire to hear about the self-management strategies used by other people with a brain tumour.
- Most important that the person is knowledgeable and sensitive to the condition.
- Healthcare professional input is valuable for signposting to available support.

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HOW do people want support to be delivered?

- Provide opportunities to engage with others to share advice and experiences.
- Groups can be valuable for education and support, but do not appeal to everyone.
- A combination of an information 'toolkit' and support group could be beneficial.

WHERE do people want to receive the support?

- Face-to-face might ease interactions with other people with a brain tumour.
- Local, community settings are preferred for face-to-face support.
- Due to transport challenges, online support may be more accessible.

WHEN do people want support to be delivered?

- Brief introduction following diagnosis, then more following treatment, once people have had time to adjust and identify their challenges.
- Needs can change over time so support needs to be readily accessible.
- Frequent initial contact, with long-term follow-up to identify support needs.

Ways to TAILOR the support to the individual.

- Everyone is individual, use clearly labelled topics to avoid information overload.
- Identify individual support needs to develop personalised goals and strategies.
- Enable access to support in different ways (face-to-face, online, group, individual).

Next steps… These activities have given us a better understanding of how to design a programme that can be integrated alongside current care for people with brain tumours.

From this we have designed a prototype "supported self-management programme". We will apply for more research funding to further develop our programme and test whether it does help people living with a brain tumour. All updates and research outputs are available on the project website (*https://research.ncl.ac.uk/waysahead*), as and when they go live.

For more information or if you have any questions:
Call: 07704 300 509 or **Email:** ben.rimmer@newcastle.ac.uk
Website: research.ncl.ac.uk/waysahead