

QUALITY OF LIFE 2025 RESEARCH SANDPIT

Living longer, living better: Supporting recovery for adults with low grade brain tumours

Purpose and scope

The impact of a brain tumour and its treatment can have a uniquely devastating impact on somebody's quality of life. Enabling people to live well for as long as possible with a brain tumour requires appropriate support before, during and after treatment.

While a range of rehabilitation and prehabilitation approaches exist, access to these services varies significantly across the UK. Often, little is known about how effective these interventions are. To ensure that everyone affected by a brain tumour receives the best possible care, we must move beyond isolated examples of innovation to develop evidence-based, system-wide improvements that can be adopted nationally.

The **Quality of Life 2025 Sandpit and Award** will foster new multidisciplinary collaborations focused on rehabilitation and prehabilitation for adults with low grade brain tumours. This initiative will bring together experts from diverse fields alongside people with lived experience to develop innovative solutions that reduce or manage the side effects of low grade brain tumours and their treatment. These collaborative teams will have the opportunity to develop and design research projects. This may include assessing the effectiveness of repurposed, optimised or newly developed prehabilitation and rehabilitation interventions with a view to supporting the recovery of physical or cognitive function.

Funding will be available to support the most promising projects. To apply for this funding, you must attend the creative and collaborative sandpit workshop. This will be an interactive two-day event, with additional meetings via Zoom, where you will:

- network and meet new collaborators from a variety of research areas and organisations
- generate new and innovative research ideas as part of a multidisciplinary team
- develop and pitch projects for research funding.

What is a sandpit?

The Brain Tumour Charity's Quality of Life Sandpit is an interactive and innovative workshop that takes place over two days. The sandpit will bring together people from a range of disciplines and individuals with lived experience of low grade brain tumours to explore novel ways to improve the quality of life for adults living with or recovering from treatment. We'll start by scoping the problem, before generating ideas and novel solutions which can then be refined into research projects.

The sandpit will be a two-day residential event in Birmingham, supported by three half-day online events before and after the sandpit. The first online event will help us get to know each other and understand the challenges before the sandpit. The other two online events will take place after the sandpit and will give project teams more time to develop their ideas into research proposals.

Don't worry – you're not expected to come with well-developed research ideas! The goal will be to develop ideas and solutions through discussions with experts from a variety of areas. The sharing of ideas and different perspectives will be key to successful outcomes. Everyone will be encouraged to share freely during the event, with confidentiality respected outside of the sandpit.

The event will be led by our sandpit director, Professor Sara Faithfull, who'll be helping to define the problem and facilitate the discussions. Professor Faithfull brings a wealth of experience in cancer survivorship and developing complex interventions which are particularly relevant for this event. She will be supported by several members of our Scientific Advisory Board (SAB) and people with lived experience of a low grade brain tumour.

Feedback from SAB members and people with lived experience will be shared throughout the process, enabling 'real-time peer review' of ideas as they develop. The SAB members and researchers from relevant disciplines will also act as provocateurs, sharing their ideas and stimulating discussion.

During the sandpit, the ideas will coalesce into genuinely innovative research proposals and project teams will form. Following the residential event, there will be an online feedback session where the outline of projects are presented and participants can share ideas to strengthen the research and highlight any concerns. A final online session will be held 3-4 weeks after the residential event, where the developed proposals will be presented, and the funding panel will then decide which projects will be awarded.

Award

Awards will be made to UK institutions. Both primary (qualitative/quantitative) and secondary (evidence synthesis) research is eligible for funding. Projects should generate evidence to inform the delivery of interventions or services and promote the sharing of best practice to improve the quality of life of adults living with low grade brain tumours and/or their family carers.

Maximum award: £100,000

Maximum duration: 18 months

Project teams can apply for up to £100,000. Funding will be awarded on a case-by-case basis and seed funding is available for pilot projects and projects exploring novel ideas and concepts. Projects must be directed to improving outcomes for patients.

We won't be asking for project ideas during the application process.

Key Dates

Call for applications opens: 21 May

Deadline for applications: 16 July

Applicants notified of outcome: September

We'll work with our SAB and experienced workshop facilitators to identify up to 30-40 applicants to take part in the sandpit event. Please see the assessment criteria below.

If your application is successful, attendance at the residential sandpit event and the online sessions is mandatory.

Orientation session: 23 October 10am-12:15pm (online)

Sandpit event: 3-4 November 2025 at The Writer's Suite, Edgbaston Park Hotel and Conference Centre, Birmingham

Feedback session: 18 November 10am-12:30pm (online)

Presentation session: 5 December (online) – project teams will be given a 15-minute slot between 10am-4pm

Theme

The 2025/26 Quality of Life funding call focuses on improving rehabilitation and prehabilitation for adults living with low grade brain tumours. Rehabilitation plays a crucial role in managing the long-term health-related quality of life (HRQoL) impairments experienced by this group, yet access to services remains highly inconsistent across the UK.¹

Low grade brain tumours present a unique and often overlooked challenge when it comes to rehabilitation. Adults living with these brain tumours can experience a wide range of HRQoL impairments, such as fatigue and cognitive difficulties. Importantly, these individuals may live with the chronic side effects of their tumour and treatment for many years.² Unlike other conditions such as stroke, where rehabilitation services and guidelines are more structured, those with low grade brain tumours are often

¹ <https://www.tessajowellbraincancermission.org/wp-content/uploads/2023/02/TJBCM-Does-It-Matter-Where-You-are-Treated-Designation-Report.pdf>

² Rimmer, B., Balla, M., Dutton, L., Williams, S., Lewis, J., Gallagher, P., Finch, T., Burns, R., Araújo-Soares, V., Menger, F. and Sharp, L., 2024. "It changes everything": Understanding how people experience the impact of living with a lower-grade glioma. *Neuro-Oncology Practice*, 11(3), pp.255-265.

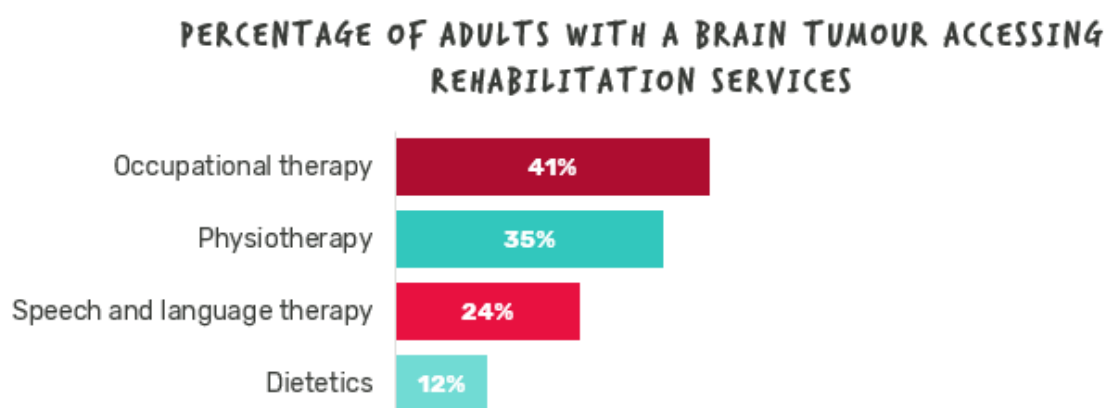
discharged without a comprehensive care plan.^{3,4} Many struggle to access the rehabilitation services needed to manage their recovery, return to work or maintain independence.

“Aftercare has been non-existent - we feel abandoned.” - IBTC survey

National Institute for Health and Care Excellence (NICE) guidelines recommend that all adults with a brain tumour should have access to a neurological rehabilitation assessment including physical, cognitive and emotional function, at diagnosis and at every stage of follow-up.⁵ However, data from the Tessa Jowell Centres of Excellence reports and The Charity’s Improving Brain Tumour Care surveys show significant gaps in rehabilitation services across treatment centres.^{6,7}

According to the surveys, approximately 74% of patients report at least one unmet need, such as psychological support or symptom and side-effect management. Furthermore, one in five patients are unsure what to expect during recovery.

“I can’t fault the doctor, CNS, and the team but there has been nothing since in terms of recovery or support including from my own GP. Any rehabilitation has been of my own doing without any advice or guidance.” - IBTC survey



SOURCE: The Brain Tumour Charity Improving Brain Tumour Care Surveys

³ <https://www.nice.org.uk/guidance/ng236/chapter/Recommendations#intensity-of-stroke-rehabilitation>

⁴ Sage, W., Fernández-Méndez, R., Crofton, A., Gifford, M.J., Bannykh, A., Chrysaphinis, C., Tingley, E., Bulbeck, H., Brahmabhatt, M., Pickard, J.D. and Walter, F.M., 2019. Defining unmet clinical need across the pathway of brain tumor care: a patient and carer perspective. *Cancer Management and Research*, pp.2189-2202.

⁵ <https://www.nice.org.uk/guidance/ng99/chapter/Recommendations#neurorehabilitation-needs-of-people-with-brain-tumours>

⁶ <https://www.tessajowellbraincancermission.org/wp-content/uploads/2024/04/reimagining-rehabilitation-for-adults-with-brain-tumours.pdf>

⁷ The Brain Tumour Charity. Improving brain tumour care surveys. The Brain Tumour Charity. <http://bit.ly/IBTCsurvey> (2022).

A recent survey of healthcare professionals working in neuro-oncology has identified major barriers to referring brain tumour patients for rehabilitation.⁸ These include a shortage of specialised services tailored to the complex needs of this group and limited availability of key rehabilitation staff, such as nurses and allied health professionals.

There are examples of excellent practice around the UK but there isn't a robust evidence base to support referrals for rehabilitation. This means many people miss out on the support they need and reinforces the need for targeted research to develop and improve access to evidence-based rehabilitation and supportive care pathways.

This funding call supports research into novel care solutions and interventions in rehabilitation for adults with low grade brain tumours, focusing on recovering physical and cognitive function. Psychological support can also be included to encourage engagement with interventions. Interventions that take place before treatment are also eligible for funding under this award.

The research ideas developed at the sandpit event could include:

- evaluation studies with the potential to lead to changes in national practice, fill an evidence gap, create new knowledge or build the evidence base and would have a significant impact on quality of life for people affected by a brain tumour
- research to establish feasibility and to pilot novel interventions that aim to address an unmet need related to rehabilitation
- research that focuses on adapting an existing intervention to a new context or amalgamation of separate, defined interventions so that they complement each other.

All research proposals developed at the event must have a clear route to patient benefit.

Who can apply?

We're welcoming applications from a diverse range of disciplines with an interest in improving rehabilitation and quality of life for adults affected by brain tumours. To make a real difference in this area we need experts from a broad range of fields and at all stages of their career. The aim of the sandpit event is to bring people together who wouldn't normally interact to come up with exciting new ways to support people affected by brain tumours.

Applicants may come from any discipline including, but not limited to: neuro-oncology, nursing, neuroscience, psychology, occupational therapy, physiotherapy, speech and language therapy, dietetics, radiation oncology, data science, service design, service transformation, statistics, health economics, behavioural science, implementation

⁸ Boele, F., Rosenlund, L., Nordentoft, S., Melhuish, S., Nicklin, E., Rydén, I., Williamson, A., Donders-Kamphuis, M., Preusser, M., Le Rhun, E. and Kiesel, B., 2024. Inequalities in access to neuro-oncology supportive care and rehabilitation: a survey of healthcare professionals' perspectives. *Neuro-Oncology Practice*, 11(4), pp.484-493.

science – indeed anyone who's interested in this area of research and improving the quality of life for people affected by brain tumours.

Eligibility criteria

Researchers and professionals working from a wide range of disciplines with a passion to improve the quality of life for adults with low grade brain tumours are encouraged to apply. Applicants must be:

- collaborative and able to work effectively as part of a team
- creative and driven to find new ways to solve the challenges facing people affected by brain tumours
- willing to engage with key stakeholders, including patients and carers, from a variety of backgrounds
- able to attend all days of the workshop (3 and 4 November 2025) and can commit to attending online events before and after the workshop
- affiliated with a UK academic or medical institution

We particularly welcome applications from those working as nurses, Healthcare Practitioners and Allied Health Professionals with an interest in the quality of life of brain tumour patients.

We'd also love to see applications from those working outside the field to bring new thinking and expertise to the area. Diversity is also important to The Brain Tumour Charity and consideration will be given to discipline, experience, gender and location.

Assessment criteria

Applicants are invited to apply to participate in the sandpit event on 3 and 4 November 2025. Applications will be assessed based on the following criteria:

- **Expertise**

The applicant's expertise must add value to this event and any potential award.

- **Collaboration**

The applicant must demonstrate an ability to work in teams and collaborate with those from different backgrounds.

- **Patient focused**

All awards must offer the potential for patient benefit and applicants must clearly demonstrate a willingness to work with people affected by brain tumours throughout their research.

- **Innovation**

Applicants must be prepared to think creatively about problems and share radical ideas to solve the biggest problems facing people affected by brain tumours.

Our panel of experts will make recommendations for funding based on the presentation at the end of the sandpit exercise. Successful teams will then be given the opportunity to develop a full proposal before funding will be awarded. The assessment criteria for proposals will be shared with attendees to the sandpit event.