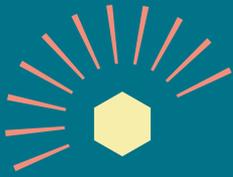

Reimagining Rehabilitation for Adults with Brain Tumours

A Roadmap

MARCH 2024





Executive Summary

Rehabilitation is a multidisciplinary approach that helps people with brain tumours physically and psychologically cope with life-changing symptoms or recover from intensive treatment.^{1,2} Rehabilitation is provided by allied health professionals (AHPs), including physiotherapists, occupational therapists, speech and language therapists, and dietitians who support patients' holistic needs.

Several policy reports and publications have called for reform and re-evaluation of rehabilitation, including in brain cancer.³⁻⁵ Despite clear evidence that rehabilitation improves patients' quality of life, the availability and quality of rehabilitation services for people with brain tumours are inconsistent across the United Kingdom (UK).^{4,5}

“Life will not wait for a cure – this is why we need to reimagine rehabilitation [for people with brain tumours]”

– AHP

On the 15th November 2023, Costello Medical, in collaboration with Tessa Jowell Brain Cancer Mission, hosted a roundtable meeting to discuss the current challenges associated with rehabilitation for adults with brain tumours, and identify potential solutions and recommendations for action. Ten participants, including specialist AHPs, consultant oncologists and key charity stakeholders/patient representatives, shared their insights and experiences of rehabilitation services across the UK.

The roundtable discussions identified the following, interlinked key challenges: insufficient evidence base; inadequate coverage of rehabilitation in brain tumour guidelines; lack of awareness of the benefits of rehabilitation for people with brain tumours; suboptimal patient referrals; and limited continuity of care. Participants proposed a number of solutions to reimagine rehabilitation for patients and their families, grouped into **3 overarching themes**:

→ **1** **Build the evidence base** that quantifies the patient need for rehabilitation by providing funding/infrastructure for AHP-led research

→ **2** Develop **clinical consensus recommendations** on rehabilitation to inform guidelines for adults with brain tumours

→ **3** **Raise awareness** of the benefits of rehabilitation for adults with brain tumours among all stakeholder groups

Meeting Participants

Attendees

Dr Nicky Huskens Meeting Chair	CEO, Tessa Jowell Brain Cancer Mission
Dr Helen Bulbeck	Founder and Director of Services and Policy, Brainstrust
Nicola Day	Chartered Physiotherapist, Senior Physiotherapist and Cancer Exercise Specialist, Cambridge University Hospitals NHS Foundation Trust
Catherine Fraher	Director of Services and Digital Health, The Brain Tumour Charity
Dr Pinelopi Gkogkou	Consultant Clinical Oncologist, Norfolk and Norwich University Hospitals NHS Foundation Trust
Dr Fiona Harris	Consultant Clinical Oncologist and Neuro-Oncology MDT Lead, Cambridge University Hospitals NHS Foundation Trust
Sara Melhuish	Highly Specialist Speech and Language Therapist (Oncology), Barts Health NHS Trust
Ellie Stephenson	Clinical Lead Physiotherapist in Neuro-Oncology, Leeds Teaching Hospitals NHS Trust
Lindsay Sudell	Physiotherapist, Specialist AHP Brain and Spinal Tumour Rehabilitation, Christie NHS Foundation Trust
Helen Urwin	Neuro-Oncology and ROWTATE Occupational Therapist, Leeds Teaching Hospitals NHS Trust

Meeting Organisers

Dr Arianna Psichas Strategic oversight and facilitation	Consultant, Health Policy, Costello Medical
Kerris Chappell Organisation	Senior Analyst, Costello Medical
Eve Sullivan Report writing	Analyst, Costello Medical

Introduction

In the UK, more than 12,000 people are diagnosed with a primary brain tumour each year.⁶ Brain tumours can affect people of any age, including children.

Brain tumours and their treatment can cause a range of long-term symptoms. These might include challenges with vision, fatigue, cognition/memory or mobility, and longstanding emotional or psychosocial effects.¹ To help people with brain tumours **maintain function and quality of life**, support is needed from a range of healthcare professionals (HCPs), including physiotherapists, speech and language therapists, occupational therapists and dietitians (collectively referred to as AHPs). This is called **rehabilitation**.

It is vital that people living with brain tumours are considered for referral for rehabilitation at diagnosis and every stage of follow-up.⁸ Unfortunately, there are stark geographical variations in the quality and extent of rehabilitation services for people with brain tumours in the UK.⁵ Rehabilitation is recognised as an unmet need of adults with brain tumours and adult survivors of childhood brain tumours.^{9, 10}

As such, there is a clear need to strengthen the case for financial and organisational support for integration of rehabilitation services into brain tumour care pathways in the UK. This report summarises discussions from a multistakeholder roundtable meeting on the topic of improving rehabilitation for adults with brain tumours and highlights key recommendations for action.

Percentage of adults with a brain tumour accessing rehabilitation services



Source: The Brain Tumour Charity Improving Brain Tumour Care Surveys, adults diagnosed with a brain tumour or in treatment Sept 2021–Sept 2023 (n=822).⁷

What does rehabilitation involve for adults with brain tumours?

INTERVENTIONS

- ◆ **Physiotherapy:** optimisation of mobility, balance and function
- ◆ **Occupational therapy:** activities of daily living and functional assessments
- ◆ **Dietetics:** nutrition and weight management
- ◆ **Speech therapy:** management of communication and swallowing

OUTCOMES

- ◆ Cope with and recover from treatment
- ◆ Help with independence
- ◆ Re-establish or maintain physical function
- ◆ Improve quality of life
- ◆ Help to stay in employment
- ◆ Understand diagnosis and treatment
- ◆ Support with participation in meaningful activities

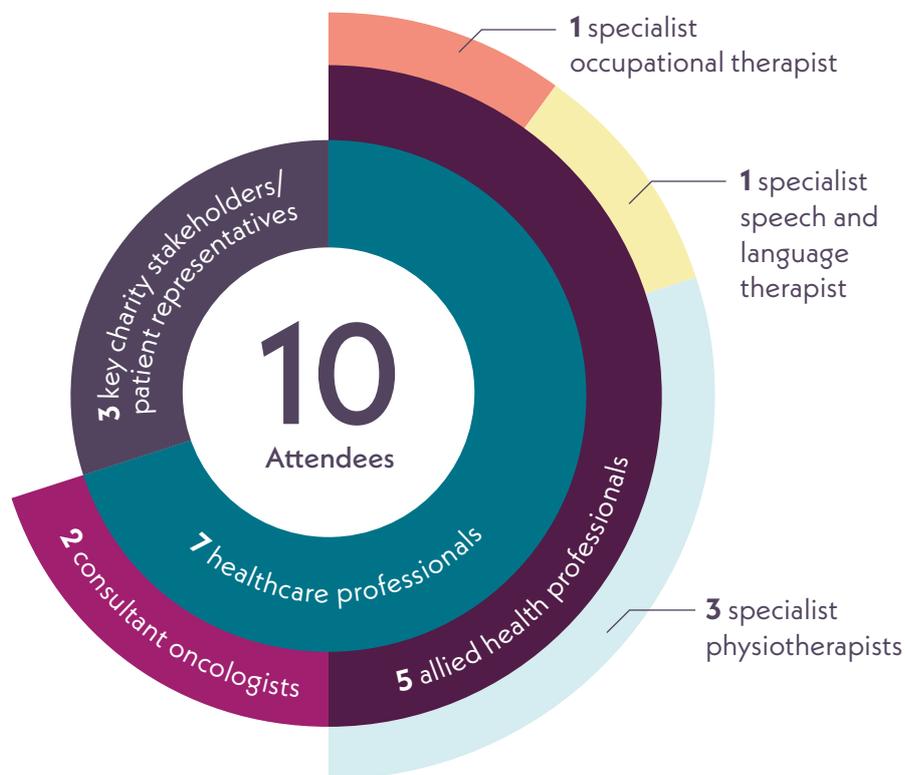


Background

Wednesday 15th November 2023

Costello Medical, in collaboration with Tessa Jowell Brain Cancer Mission, hosted the **Reimagining Rehabilitation for Adults with Brain Tumours** roundtable to discuss current challenges associated with the provision of brain tumour rehabilitation in the UK, and identify potential solutions and recommendations for action.

The roundtable agenda was shaped by a targeted literature review and insight from an expert focus group. The meeting was chaired by Nicky Huskens, CEO, Tessa Jowell Brain Cancer Mission, and attended by 9 additional experts from across the brain tumour community:



The roundtable began with a short talk on the current rehabilitation landscape for adults with brain tumours, including the patient voice (via audio clips), before moving on to dedicated discussion sessions covering the following topics:

- ◆ **PART 1: Key challenges** in providing appropriate rehabilitation for adults with brain tumours
- ◆ **PART 2: Potential solutions** to address the identified barriers
- ◆ **PART 3: Roadmap with key actions** to improve rehabilitation services for adults with brain tumours in the UK

The outcomes from the roundtable discussions are captured in this report.

PART 1

Key Challenges

Lack of an evidence base

Robust evidence on symptom prevalence and rehabilitation needs along the brain tumour pathway is lacking. The evidence gap is due in part to **limited infrastructure and funding to support AHP research**, and the challenges associated with conducting research in a patient group with terminal diagnoses, short prognoses and/or rapidly changing symptom profiles. Where evidence is available and would be relevant for people with brain tumours, it is underused in healthcare settings. One example is the Dietz classification, which could help to **reframe rehabilitation** for those with a terminal cancer diagnosis by highlighting the importance of maintaining (rather than improving) function.¹¹

Inadequate guidelines

The limited evidence base impacts guidelines. In the 2018 National Institute for Health and Care Excellence (NICE) guideline for adults with brain tumours, the rehabilitation section summarising current evidence begins with “**No evidence was identified**”.¹² No additional evidence was included in the 2021 quality standard.¹³ This is in stark contrast to the recently updated NICE stroke rehabilitation guideline, which recommends rehabilitation to people following a stroke for at least 3 hours a day, 5 days a week.¹⁴ The participants also felt that there should be a greater focus in the brain tumour guidelines on managing patient mood and fatigue in particular, as well as encouraging a patient-centred approach.

Lack of awareness

Another key challenge described was the general lack of awareness, among HCPs and patients/carers, of how different types of rehabilitation can benefit people with brain tumours. Attendees noted that HCPs tend to work in silos, with limited communication between different teams resulting in challenges with coordinating care, and delayed or absent referrals to rehabilitation. A lack of awareness, coupled with inadequate guidelines, may contribute to the variation in provision of rehabilitation services across the UK.⁵



Suboptimal referrals

Many people with brain tumours would benefit from rehabilitation but are not identified for referral. The reasons for this are manifold:

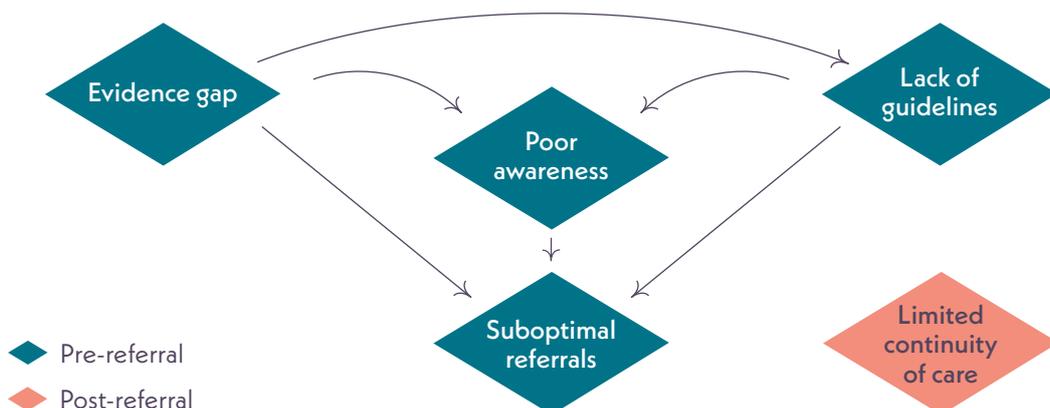
1. Patients often have symptoms that are periodic/intermittent or less apparent (e.g. mild cognitive impairment, fatigue, etc.). The 'hidden' nature of these symptoms requires the input of specialist AHPs for identification. Without the presence of these AHPs in secondary care, patient needs may be missed.
2. There is a perception that people with brain tumours who have a poor prognosis cannot benefit from rehabilitation, with poor prognosis identified as a main barrier for an appropriate assessment.¹²
3. There is no clear evidence on symptom prevalence across the pathway to guide HCPs.
4. Clinical teams, carers and patients themselves are often unaware of how rehabilitation can help improve symptoms or maintain function.¹⁵

These factors impede identification of patients for referral, which in turn creates a **false perception that rehabilitation needs among people with brain tumours are low**. Furthermore, when patients are referred for rehabilitation, integration throughout the patient journey, from diagnosis to recovery or end of life, is limited.¹⁶

"The reality for a patient like me is having a ticking time bomb in your head. On bad days, it feels like waiting on medical death row. That's why for me, rehabilitation has been integral to my recovery and return to a normal, functional life. [...] It's given me the tools I need to figure out how to evolve into this new life living with a brain tumour."
 – Patient

Limited continuity of care

Finally, attendees discussed the challenge with providing continued rehabilitation in the context of current funding for outpatient appointments. As of March 2023, each NHS provider was tasked with reducing outpatient follow-up appointments by a minimum of 25% compared with 2019/20 baseline activity, to address the disruption to elective care caused by the COVID-19 pandemic.¹⁷ Payments for follow-up appointments are fixed at 85%, regardless of the number of follow-ups delivered.¹⁷ In some NHS trusts, this has resulted in an increased drive to reduce follow-up appointments and/or provide them virtually, negatively impacting provision of rehabilitation and continuity of care for people with brain tumours.



PART 2

Solutions



As AHPs, we are taught to fix, fix, fix, but we can't do that [for patients with brain tumours]. We need to unlearn that and focus on what the patient needs. Our presence will enable the patient to reframe and reimagine their life living with brain cancer." –AHP

Building the evidence base

The first solution discussed was providing more funding and support for AHP-led research. Robust evidence is urgently needed to better understand symptom prevalence and define rehabilitation needs along the brain tumour pathway. As an interim solution, attendees proposed conducting **audits** or **service evaluations** to begin to assess the rehabilitation needs of patients, and optimise rehabilitation services and pathways for adults with brain tumours.

Digital apps/tools already available (e.g. BRIAN [the **B**rain tumou**R** Information and **A**nalysis **N**etwork]) could be used to collect data on rehabilitation usage and needs for people with brain tumours, being mindful of symptoms that could prevent this patient population from engaging with these, as well as the inherent biases of self-reported data more generally.¹⁸

Data are needed to demonstrate the **cost benefit of providing rehabilitation**, which, for example, could help people with brain tumours and/or their carers return to work.

A Delphi panel was discussed as a potential method to gather consensus on rehabilitation from experts in the field.

Delphi panels are recognised by NICE and could be used to generate a set of rehabilitation guidelines or recommendations. Moreover, **Priority Setting Partnerships**, which enable HCPs, patients and their carers to work together to prioritise evidence uncertainties that could be answered by research, were also discussed as a potential solution to begin building the brain tumour rehabilitation evidence base.

"A physiotherapist routinely came to my bed whilst I was an inpatient and I received speech and language therapy to help me adjust my food. I did not receive any [rehabilitation] input during my chemotherapy for nine months, as there was no availability. [...] Stopping my rehabilitation for so long was detrimental to my recovery."

– Patient

Raising awareness among all stakeholders

Sharing **positive patient stories** was noted by participants as a potential method to raise awareness of the benefits of rehabilitation for adults with brain tumours.

Patients and caregivers

There are a considerable number of resources available to people with brain tumours. However, patients and caregivers need to be encouraged to access them and they have to be easy to find. To improve accessibility, the attendees proposed developing a **centralised resource bank** that brings together all existing resources developed by the various organisations. It was also discussed that to ensure patients and their family members are able to find the resources relevant to them, resources on rehabilitation should be grouped by patient need rather than by specific AHP roles. The participants recommended that materials should be aphasia-friendly to ensure they are understandable by everyone.

HCPs

Attendees noted that developing more digital resources and videos could be a useful way to raise awareness of rehabilitation services amongst HCPs. For oncologists specifically, it was discussed that **on-demand learning** may be helpful, as well as the development of a single-page **information sheet** to support with the clinical conversation at the time of diagnosis. The AHPs mentioned that they often develop their own resources for clinical use, so having resources in one place that is accessible to all HCPs would reduce this burden and ultimately improve consistency and access to brain tumour rehabilitation.

Improving engagement with rehabilitation

To improve engagement, one attendee suggested there should be a greater emphasis on patient coaching in rehabilitation. Coaching is a **patient-centred approach** that teaches people personalised strategies and tools to improve their quality of life.¹⁹ Coaching helps empower patients through behavioural change to take control early on in their patient journey, and reimagine their life living with a brain tumour.¹⁹



PART 3

Roadmap

Based on the solutions proposed by the roundtable attendees, 3 key recommendations were prioritised. It is hoped that these recommendations, broken down into key actions, provide a **roadmap** that will improve quality of life for people with brain tumours across the UK.

RECOMMENDATION 1

Establish an evidence base to understand the patient need for rehabilitation, and inform guidelines, through research into:

- ◆ Prevalence and evolving nature of symptoms along the disease course
- ◆ Optimal timing and duration of interventions
- ◆ Impact of specialist AHP support on relevant patient outcomes and quality of life

These research priorities can only be achieved through:

- ◆ Protected research time for AHPs and investment in dedicated AHP research fellowships
- ◆ Training for AHPs on how to conduct research, e.g. through professional networks
- ◆ Financial support for AHP research, e.g. funding calls from charities or the National Institute for Health and Care Research (NIHR) for quality of life research
- ◆ Patient involvement, e.g. through co-production of work with patient groups or Patient and Public Involvement experts

RECOMMENDATION 2

Develop clinical consensus recommendations on rehabilitation to inform guidelines for adults with brain tumours

- ◆ Recruit a multidisciplinary group of experts to develop a set of consensus recommendations on best practice in rehabilitation for adults with brain tumours, e.g. via a Delphi panel

RECOMMENDATION 3

Raise awareness of the benefits of rehabilitation for adults with brain tumours across all stakeholder groups

Healthcare professionals

- ◆ Develop information sheets to empower HCPs and guide discussions with patients
- ◆ Set up protocols for assessing patients' needs and delivering care
- ◆ Develop positive 'patient stories' and best practice case studies for dissemination
- ◆ Increase awareness of the roles of AHPs in supporting people with brain tumours:
 - ◆ Showcase current AHP pathways within the NHS through professional networks
 - ◆ Establish a career framework for AHP roles in neuro-oncology in the NHS

Funders

- ◆ Raise awareness of the type of research needed to support AHP guideline development
- ◆ Raise awareness of AHP training needs

Patients and caregivers

- ◆ Develop a centralised resource bank with materials grouped by patient need
- ◆ Encourage coaching to empower patients to engage with rehabilitation and drive the agenda based on their individual goals

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