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BE SPeCiaL

Brain tumours: Enhancing Supportive and Palliative Care in patients and Loved ones

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Background

Primary Malignant Brain Tumour (PMBT) patients, and those who care for them, not only face a poor prognosis but also face:

- patients' cognitive impairment[1, 2];
- psychological distress[3-5];
- symptom burden[6, 7];
- and unmet needs[8, 9].

Such effects limit patients' quality of life (QoL) and independence[2, 10, 12], but also impact carers' well-being[8, 11].

Evidence-based interventions that can improve outcomes for PMBT patients and carers exist, but are **not routinely implemented** in current UK care pathways – including at Leeds Teaching Hospitals NHS Trust (LTHT).

Aim

To maximise accessibility for PMBT patients and their carers by tailoring evidence-based interventions and undertake a service improvement project.

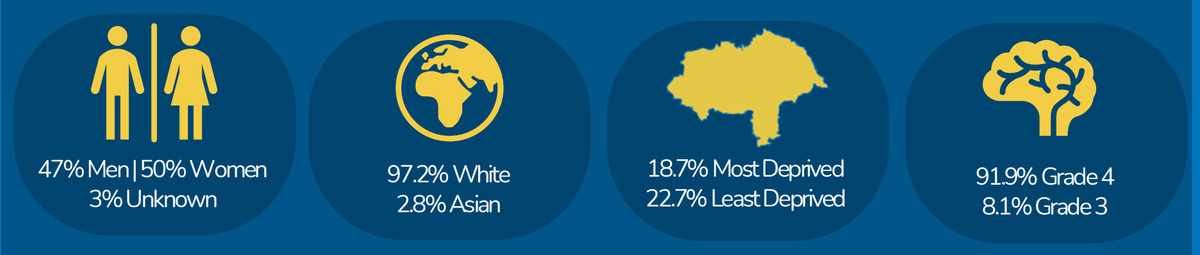
Methods

A multi-phase, mixed-methods, non-randomised implementation project which evaluates current care and introduces three evidence-based supportive interventions for PMBT and their carers.

Participants

Participants are recruited via LTHT and include individuals aged ≥18 years with a confirmed PMBT tissue diagnosis within 8 months, a life expectancy of ≥3 months, and caregivers providing support.

So far, for Phase 1a, we have recruited 76 participants (37 patients, 39 caregivers).



Data Collection

Quantitative: Data on patients' and carers' instrumental activities of daily living[a], QoL[b], unmet needs[c] mood[d], mastery[e], healthcare costs, and survival.
Qualitative: Semi-structured interviews and focus groups.

Project Phases

Phase 1a + b

(a) Current Service Evaluation

Collecting quantitative data (see methods section) shortly after diagnosis, at three, and six months from 75 patients and 68 carers.

(b) Intervention Tailoring

We are tailoring three existing evidence-based interventions with patients, carers, and healthcare professionals to enhance accessibility and fit.

1) Activity Enhancement & Rehabilitation

Deliver activity-enabling rehabilitation to maximise functional independence via a multidisciplinary team (physiotherapy, occupational therapy, speech & language therapy).

Tailoring: The approach and specialist skills will be based on each patient's specific problems and impairments.

2) Early Access to Advanced Care Planning

Using the STEP (Supporting Timely Engagement with Palliative Care) tool to guide timely advanced care planning conversations via a ~45 minute consultation and provide patients with accessible information about palliative care.

Tailoring: Originally developed for advanced cancer, we are adapting based on PMBT needs.

3) Carer Online Guided Support

Online resource offering problem-solving techniques across 32 care guides (information, advice, tips, quotes, signposting to support).

Tailoring: Updating with new evidence and information and adapting the resources to be UK specific.

Phase 2

Tailored Intervention Rollout

- Participants choose which interventions they want to take part in.
- A target of ~125 patients and ~114 carers for the intervention group.
- We will interview select participants to explore experiences, barriers, and acceptability to inform further tailoring.

Phase 3

We will **compare** outcomes, service use, and associated costs between PMBT patients with (Phase 2) and without (Phase 1a) enhanced care.

Outcomes

We hope that this project will improve services by:

- Ensuring LTHT oncology services are more responsive to the **real-world needs** of patients, carers, and clinicians through co-design;
- Providing earlier, **coordinated rehabilitation** to help PMBT patients maintain independence and QoL for longer;
- Enabling **timely, structured palliative care** conversations;
- Offering carers **more accessible, practical support** to reduce burden and improve confidence;
- Creating clearer, more **consistent pathways** across LTHT;
- Supporting **wider implementation of evidence-based practices** across the UK.

Footnotes

[a] EORTC IADL-BN32; [b] EORTC QLQ-C30 and BN20; CQOLC, EQ-5D-5L; [c] SCNS-ST9 and DaCNS; [d] PHQ-9 and GAD-7; [e] Mastery Scale

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