

## COBRA: PATIENT REPORTED OUTCOMES IN BRAIN TUMOUR TRIALS

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**Summary:** Brain cancer studies traditionally focus on tumour responses and overall survival. But there is growing recognition that studies need to better consider high quality information about outcomes such as quality of life (QoL) and function, important to those living with a brain tumour. This is particularly relevant where survival benefits are modest e.g. high-grade glioma. Results can then be related to patients' own lived experience, allowing informed choices about care.

Patient Reported Outcomes (PROs) record patients' experience of their disease and its treatment e.g. QoL information. Use of PROs allows assessment of trade-offs between tumour responses and effects on patients.

We know that:

- many brain tumour trials gather PRO information but the vast majority either *never* report it, or don't assess its importance alongside tumour response.
- there is no consensus on types of patient outcomes assessed, negating opportunities to compare results between studies, or combine powerful information across studies.

To remedy this, we will seek consensus amongst patients, families and researchers about essential domains of patient/family experience to be collected across every glioma (grades II-IV) trial. The consensus will produce a patient oriented Core Outcome Set (COS) applied across UK studies. COS development in other conditions has improved the quality and consistency of information captured, facilitating data sharing to produce practice changing results.

### Aims:

The aims of the study are to:

- reach UK consensus on a core set of patient centred outcomes that will represent the minimum which should be measured across high grade glioma studies.
- collaborate with funders, trialists and clinical trials units on implementation of the COS and the consistent application of international standards for collection, analysis and reporting of PROs within the outcome set across all studies.

### Progress:

Study research associate appointed in January 2021.

### Funder:

The Brain Tumour Charity

### Sponsor:

Cardiff University

### Ethics Approval:

Awaited

### Research networks:

NCRI Brain Palliative and Supportive Care subgroup

The MATRIX Trial Platform

Birmingham Centre for Patient Reported Outcomes