

Position paper: Access to clinical trials

This document provides an overview of access to clinical trials, The Brain Tumour Charity's position, and what we are doing to address the issues raised.

What do we mean by access to clinical trials?

Access to clinical trials refers to the enrolment of people with a brain tumour in clinical research. Clinical trials are important because there are currently limited treatment options available for high grade brain tumours. Just one in five people survive 5 years or more (1) and over 62% of children are left with a life altering, long-term disability after treatment (2). Clinical trials can have a significant impact on survival and quality of life for future populations of people affected by a brain tumour. For example, a trial into the effect of the oral chemotherapy drug Temozolomide on high grade brain tumours showed extended survival and as a result its use is standard practice of care on the NHS (3). Access to clinical trials can also have immediate benefits for an individual with a brain tumour. These include faster access to potential treatments, improved treatment outcomes (4,5) and the opportunity to contribute to defeating the disease.

In spite of the clear benefits of research on outcomes and patient experience only 3% of people with a brain tumour take part in a clinical trial (6) compared to an average of 7% across all cancers (7). Access problems that contribute to the low participation include a failure to discuss participation, the absence of a strong research culture across the NHS and a lack of suitable trials for rare tumour types across the UK.

The Brain Tumour Charity's View

We believe that every patient should have the opportunity to take part in relevant clinical research. Evidence shows that people have an interest in being asked about research and there is a willingness to be involved if the opportunity arises. A 2014 poll of 1000 members of the public commissioned by The Brain Tumour Charity revealed that 81% thought that everyone diagnosed with cancer should be offered the opportunity to take part in a clinical trial (8). A public poll undertaken by the Health Research Authority in 2014 showed that 65% of people are interested in opportunities to participate in health research (9) and National Cancer Patient Experience Surveys (NCPES) have shown that of people with a high grade brain tumour who knew about opportunities, 75% went on to take part in England and 64% in Wales (10,11).

To improve access to clinical research there needs to be greater awareness among people affected by a brain tumour and clinicians. A survey of clinicians revealed that 52% of their patients had not asked or asked less frequently than once a year about opportunities to be involved in research (12) and the NCPES showed that taking part in research has been discussed with 37% of people with a brain tumour in England and just 29% in Wales (11,10).

The development of a culture of research within the NHS is essential. Interviews with clinicians have revealed that research is underrepresented in career development and should play a more integral part in professional training and development (13). Part of this learning needs to emphasise the relationship between research activity and quality of care (14).

We agree with the National Cancer Research Institute (NCRI) that suitability for trial participation should be a core responsibility of a patient's multi-disciplinary team (MDT) (13). Relevant opportunities to participate in clinical research should be addressed at the first appropriate opportunity. We support the call from the NCRI Brain Tumour Clinical Studies Group that a discussion and assessment of clinical research opportunities should be accommodated shortly after diagnosis and prior to surgery (15).

A report on clinical trial activity for brain tumours showed that a common barrier to patient participation in research was the lack of suitable trials (15). The low numbers of people with a brain tumour at any particular hospital site results in logistical difficulties and additional costs to set up brain tumour studies and recruit suitable participants. Hospitals without the internal infrastructure for research into rarer diseases will often lack resources in radiology such as the ability to recruit a radiologist or to conduct additional scans for trial participants (15,16).

The inability to participate in clinical research at a local hospital is a barrier to access for people on a physically demanding treatment plan (13,16). People affected by a brain tumour should not miss out on research because of where they live. More needs to be done to involve more and smaller centres in clinical trials to improve access and opportunities for people with a brain tumour to be involved in research (13, 17).

What is currently available?

The NHS Constitution commits the NHS to informing people of research studies in which they may be eligible to participate (18). The National Institute for Health and Care Excellence (NICE)'s guidance on *Improving outcomes for people with brain and other CNS tumours* recommends that information be provided to patients on opportunities to participate in research studies (19).

For a list of available clinical trials see our online resource:

<http://www.thebraintumourcharity.org/about-brain-tumours/clinical-trials>.

What is The Brain Tumour Charity doing?

We are working to ensure equal access to the best treatment and care, including access to clinical trials. We promoted the National Institute for Health Research (NIHR)'s '[OK to Ask](#)' campaign through social media and our support networks to encourage people with a brain tumour and their loved ones to ask about relevant opportunities to be involved in clinical trials.

To increase the number of clinical trials available we are committed to increasing our investment into translational and early-phase clinical trials and will continue to co-fund feasibility studies as part of our five year research strategy.

The Brain Tumour Charity is developing a research network to raise awareness among people affected by a brain tumour of the benefits of their participation in clinical trials to improve outcomes. Our information and support team also support people affected by a brain tumour who want more information on opportunities to take part in a clinical trial.

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