

Impact report 2023



In the evolving landscape of brain tumour healthcare and research, PRIME (Patient Research Involvement Movement) continues to bring patients closer to research and research closer to patients. As we reflect on the year, this impact report encapsulates the journey of PRIME in 2023. This highlights our efforts to raise the value patient involvement and engagement (PPIE) – ensuring it is seen as an essential step in the design of new studies, trials and treatments.

Join us in exploring the achievements, challenges, and the collective efforts that have propelled PRIME into a force driving positive change in brain tumour research.

‘As a neurosurgeon-scientist, my work is first and foremost to benefit my patients. brainstrust facilitated a patient centered approach to designing my research questions and how best to translate the research into patient benefit.’

Ali Bakhsh
Department of Neurosurgery,
The Walton Centre NHS
Foundation Trust

PRIME Brought People Closer to Research

Patients and caregivers are experts in their own care, and PRIME offers a way for the community to put their knowledge to use for the betterment of the standards of future treatments.

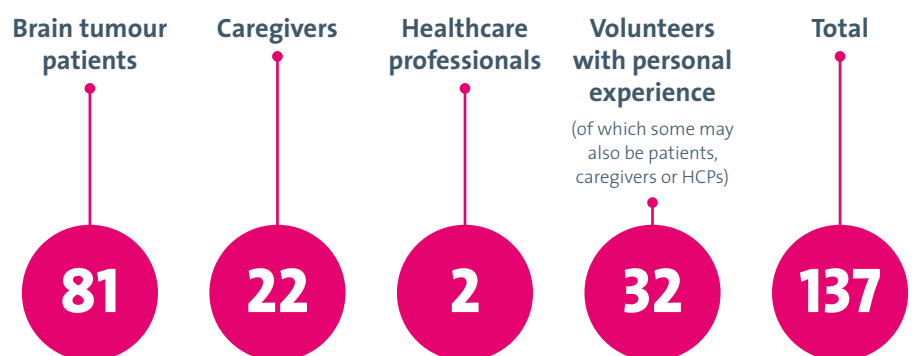
PRIME offers two roles to our community so that they can be

involved in supporting current research. The first is the PRIME advocate role. Advocates are contacted personally with relevant opportunities to provide insight and contribute to discussions. The second role is the research partner, which offers a 6-month training programme covering everything you would need to know to deliver top-level PPI support.

‘A bonus for me would be if I could inspire somebody along the way to pursue life’s adventures as best they can despite their or their loved one’s diagnosis.’

Patient

We have a total of 137 people signed up to PRIME, this is comprised of:



Of these 137 people, 19 are research partners and attend training meetings every 8 weeks.

A closer look at our service

Here is an example of how we supported Dr Gerben Borst in his PORTRAIT study, engaging him with patients who would go on to influence and improve the direction of the trial design.

1. Initial contact:

We first met Dr Gerben Borst after Helen Bulbeck attended an NCRI Proposal Guidance meeting. Once Helen provided some feedback on his study idea, we reached out to offer further PPIE support.

2. Strategy meeting: We met with Gerben soon after where he shared his study proposal in greater detail – the PORTRAIT study aimed to explore how using Optune prior to and following surgery might improve surgical outcomes. We made a plan for the PPIE strategy, leading to setting up focus groups.

3. Focus groups: We organised, recruited for and facilitated a couple of focus groups for Gerben. Here, he went on to share the study design with the community and they fed back their thoughts and feelings.

4. Research partner: Following review of the study design, the next part of the strategy was to produce patient-facing



materials. One of our research partners, Grant Stobart, was then recruited to provide ongoing insight and guidance on these materials.

5. Producing materials: The PRIME team, Grant and the PORTRAIT team met regularly to work on informational videos for those recruited to the study. This also served to determine language, accessibility and preferences for those enrolled.

6. Ongoing input: Throughout the design process of the study, Gerben would refer to Grant and me for input and discussion.

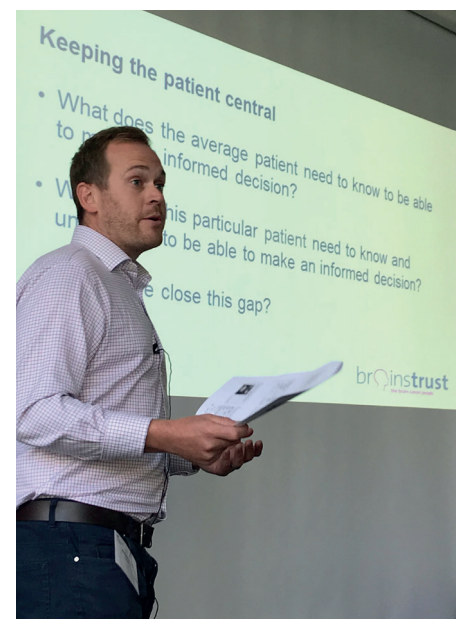
7. Funding: Gerben was able to use our ongoing PPI input to support his funding application, increasing the strength of the study proposal.

We are proud to have supported Dr Borst, his team, and the PORTRAIT study with our PPIE service.

Our impact on the research landscape

Since PRIME's launch, it has **helped to attract over £28 million in funding** to brain tumour trials aiming to deliver a new and improved standard of care for patients diagnosed with a brain tumour.


In 2023, PRIME supported more than **30 unique research projects** which range from multi-national drug and technology trials to quality-of-life focused wellbeing intervention tools, the development of core-outcome sets for patients and their families, as well as forward thinking research into liquid biopsies for improved care.



Over **£28 million** attracted to research



Over **30 unique** research projects supported in 2023



137 research advocates supporting research projects





Over 20 publications
published in our research library



1,202 people reading our research news in our monthly newsletter




Raising the profile of research into brain tumours

Between our Monthly Brew newsletter, social media updates and blogs and articles on our website, our community has prompt access to any news or stories surrounding research for brain tumours – ensuring accessibility, transparency and robustness.

Current readership of the PRIME Monthly Brew, our research-focused newsletter is now at **1,202**.

Additionally, our online Research Library was re-launched this year. Currently, the library has **over 20 unique publications** which *brainstrust* has supported in/ contributed to producing and is continuously growing. The library spans a wide array of topics crucial to understanding and addressing the complexities of living with a brain tumour.

We also had **2,345** page views on our research and PRIME focused pages of the website.

In 2023, PRIME has been visible at multiple national and international conferences, meetings and patient events. These include the British Neuro-Oncology Society conference, the Society of British Neurological Surgeons meeting, The European Association of Neuro-oncology

conference and **the first ever BTR-NTA** (Brain Tumour Research Novel Therapeutics Accelerator) meeting where we aided in giving feedback for newly designed brain tumour trials.

Reflection and next steps

Reflecting on 2023, there are achievements that we can celebrate. Highlights include being chosen to be the voice of the patient community at the BTR-NTA, seeing multiple large-scale studies being funded following our support, and watching our PRIME community continue to grow. Some things we wanted to achieve in 2023 however didn't come to pass, and so we look forward to ensuring we meet those goals in 2024.

Some of these goals include:

- Updating our research library with published videos and academic posters.
- Doubling our number of patient and caregiver advocates signed up to PRIME to 150 (we were just shy at 137).
- Every one of our research partners involved in an appropriate project.

Moving forward, we look to ensure these goals are met while we strive for even greater successes alongside the patient, caregiver and clinical community – working

to achieve our shared goal of improved outcomes and quality of life for anyone impacted by a brain tumour.

'PRIME is now entering its fourth year, and as it matures so does its goals; We aim to continue and improve on our work to establish PPIE as an essential and powerful tool in designing the best research projects possible and therefore giving the clinical community the best chance to make the changes we need for the brain cancer community.'

Adam Thomson,
patient involvement officer,
brainstrust

PRIME is proudly in partnership with Brain Tumour Research, whose collaboration and support amplified our voice and deepened our impact in 2023. Together, we now plan for an even more ambitious and empowering 2024.

We would also like to thank the Rank Foundation, The Garfield Weston Foundation and The Naseem Manx Brain Tumour Charity for their support of PRIME.

Registered charitable trust – *brainstrust* is a registered charity in England and Wales (1114634), and Scotland (SC044642).
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