

Creating the magic of the ordinary - engaging patients and the public

The Cochrane approach

Dr Helen Bulbeck | brainstrust – the brain cancer people

Director of Services & Policy | Co-founder

Why patient engagement matters

Andrew is 42 years old, recently divorced, with three teenage children. Diagnosed with glioblastoma - the most aggressive of brain tumours. With treatment, a prognosis of 9 to 15 months. He has lost his driving licence and his job as a carpenter. He is angry, isolated and fearful.

And yet every conversation with his clinical team focuses on treatment and symptoms; he doesn't know how to begin to talk about what really matters to him.

To improve outcomes for people like Andrew — people like Andrew need to drive the research agenda.

About brainstrust

Our vision

Everyone with a brain tumour feels less afraid, less alone, and more in control.

What we do

A coaching-led support model, PPIE infrastructure through PRIME, policy advocacy and research partnership across the full brain tumour pathway.

brainstrust has been in the DNA of neuro-oncology PPIE since 2013 — the mortar connecting all stakeholder groups.

The James Lind Alliance Priority Setting Partnership

What is the JLA?

Brings patients, caregivers and clinicians together to identify and prioritise uncertainties for clinical research. Established 2004; hosted by NIHR NETSCC since 2013.

The Neuro-oncology PSP

Launched in 2015, narrowing down over 400 community responses to determine the top 10 clinical research priorities for brain tumours in the UK.

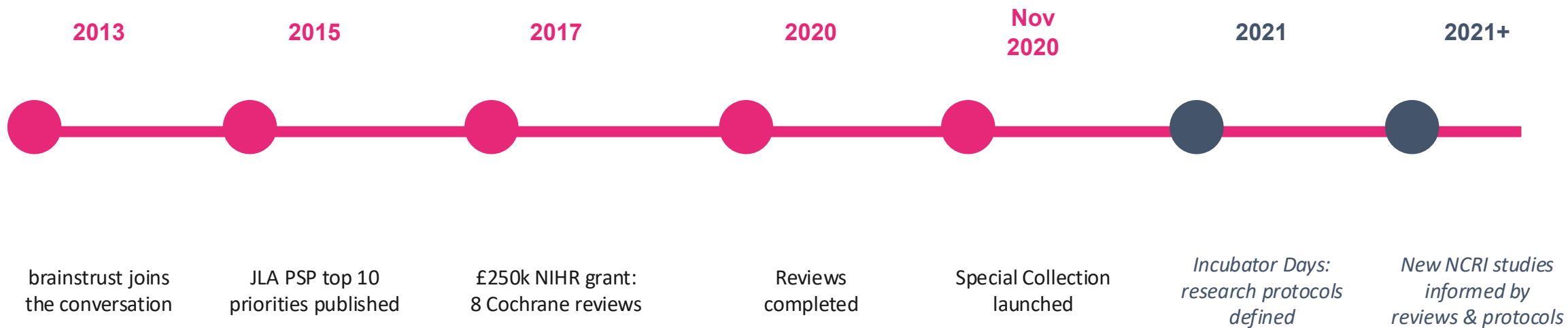
brainstrust was present from the very first conversation in 2013.

600+

community responses gathered

Transparency in the research selection process is vital — to ensure no conflict of interest, or bias towards cell-based research that detracts from the clinically relevant research the brain tumour community needs.

From priorities to lasting impact: A 10-year journey



At every stage, people with lived experience were in the DNA — identifying topics, applying for funding, shaping lay summaries, defining protocols, and influencing the ongoing research agenda.

The eight Cochrane reviews

PG41 1p19q co-deletion as a diagnostic marker in glioma

PG42 Prognostic role of MGMT methylation

PG43 Long-term neurocognitive effects of radiotherapy in glioma

PG44 Interval imaging of cerebral glioma

PG45 Time to diagnosis of brain tumours

PG46 Treatment options at recurrence in glioblastoma

PG47 GBM management in older people

PG48 Intraoperative technology for extent of resection

+ Additional reviews on fatigue interventions & caregiver support (2019)

Three themes rooted in patient priorities

1

Prompt, safe & accurate diagnosis

Diagnosing a brain tumour is complex — there are real benefits and harms to early detection. The reviews shift the conversation from 'early' to 'prompt' diagnosis.

2

Shared decision making & risk sharing

Patients focus on quality of life, function and symptom relief. Shared decision making makes everyone a co-pilot in their care.

3

Understanding best treatment when decisions are difficult

At recurrence, there is no clear protocol. The evidence review opens a transformative conversation when first-line treatment fails.

Theme 1: prompt, safe and accurate diagnosis

Reframing provocatively:

"Early diagnosis isn't all that it seems." Currently, there is no evidence from good quality studies to inform patients, health professionals or service planners on how to reduce the time to diagnosis — nor on the cost of such initiatives.

What the review found

Detecting a brain tumour is complex. Earlier is not always better — imaging, surgical and biopsy pathways carry their own risks. The key is a prompt and safe diagnostic journey, not simply a faster one.

What it means for people

Patients and families deserve honest conversations about the diagnostic pathway — including what is, and isn't, yet evidenced. This also reveals a clear gap that the community can act on through future research.

Theme 2: Shared Decision Making & Risk Sharing

The tension

Researchers & clinicians focus on:

- Overall survival
- Progression-free survival
- Tumour response

Patients focus on:

- **Quality of life**
- **Function**
- **Symptom relief**

Shared decision making reconciles both, making everyone a co-pilot in their care. This opens a new model: maintenance of wellness as well as treatment of illness.

The principle

"Clinicians are the expert on the options available to you — and you are the expert on you: your context, appetite for risk, and your values."

brainstrust, to every person we support

MGMT and 1p19q reviews provide the molecular information patients need to participate meaningfully in these conversations.

Theme 3: when decisions are difficult

There comes a point in the brain tumour pathway where a malignant tumour will return. New decisions must be made when emotions are high and hope needs to be nurtured when the future looks bleak.

The challenge at recurrence

There is currently no clear protocol for what to do when first-line treatment fails. The PG46 review provides the evidence base for a transformative conversation.

GBM in older people

Treatment decisions for older patients are often more complex. PG47 provides a clearer evidence base for conversations that balance benefit, burden and quality of life.

Intraoperative technology (PG48)

The extent of surgical resection matters — but choosing between technologies is complex. The review helps patients and teams understand the trade-offs.

The incubator days: from evidence to action

Each of the eight systematic reviews was followed by a dedicated Incubator Day - a structured, facilitated workshop that translated findings into research protocols.

~25

invitees per event

A carefully curated mix:

- Patients & caregivers
- Leading clinicians
- Researchers
- Methodologists

01

Review the evidence

Teams presented the key findings from each systematic review in accessible, patient-friendly language.

02

Identify the gap

Participants asked: what does this review tell us is missing? What should be studied next, and why does it matter to people?

03

Co-design the protocol

Working groups defined research questions, outcomes that matter to patients, and study design principles for each new protocol.

04

A lasting footprint

These protocols fed directly into NCRI working groups and influenced subsequent NIHR funding calls — including FUTURE-GB and SPRING.

What genuine involvement looks like

Setting the agenda	600+ community responses → JLA PSP top 10. No academic gatekeeping. Patients and caregivers defined what needed to be asked.
Securing the funding	brainstrust co-applied for the £250k NIHR grant alongside Cochrane CGNOC and NCRI. Patient advocacy at the table from day one.
Shaping the reviews	Lay summaries and patient-facing outputs reviewed throughout the process for accessibility, accuracy and relevance.
Co-designing protocols	Eight Incubator Days: patients, caregivers, clinicians and researchers defined what should be studied next.
Influencing the agenda	Reviews and protocols fed into NCRI studies. NIHR funding now requires alignment with PSP priorities — a structural, lasting change.

What's next?

01

Remaining 15 uncertainties

The JLA PSP top 10 was published in 2015. Priorities 11–25 remain. We need to understand what is outstanding and whether the PSP itself needs renewing for today's landscape.

02

Position statements

Working with NCRI and clinical partners to develop position statements based on the systematic reviews — translating evidence into practice and policy.

03

Renewing the PSP

The JLA PSP is like the Forth Road Bridge. A decade on, we need to ask again: what matters most to people with a brain tumour today? Vorasidenib. PRIME. New trial landscape.

"None of us is as smart as all of us."

brainstrust.org.uk | hello@brainstrust.org.uk | 01983 292 405

Back to Andrew

What hasn't changed

Andrew is still 42. Still facing a glioblastoma. Still looking at a prognosis of 9–15 months. Still angry, isolated, and fearful. Still desperate for a conversation that goes beyond treatment and symptoms.

What has changed

The research that will shape Andrew's care was shaped by people like Andrew.

The questions that were asked — about prompt diagnosis, about shared decision making, about what happens when first-line treatment fails — were the questions his community said mattered most.

The protocols that will drive the next generation of trials were written in rooms where patients sat alongside clinicians as equals, not as afterthoughts.

That's not nothing. That's everything.