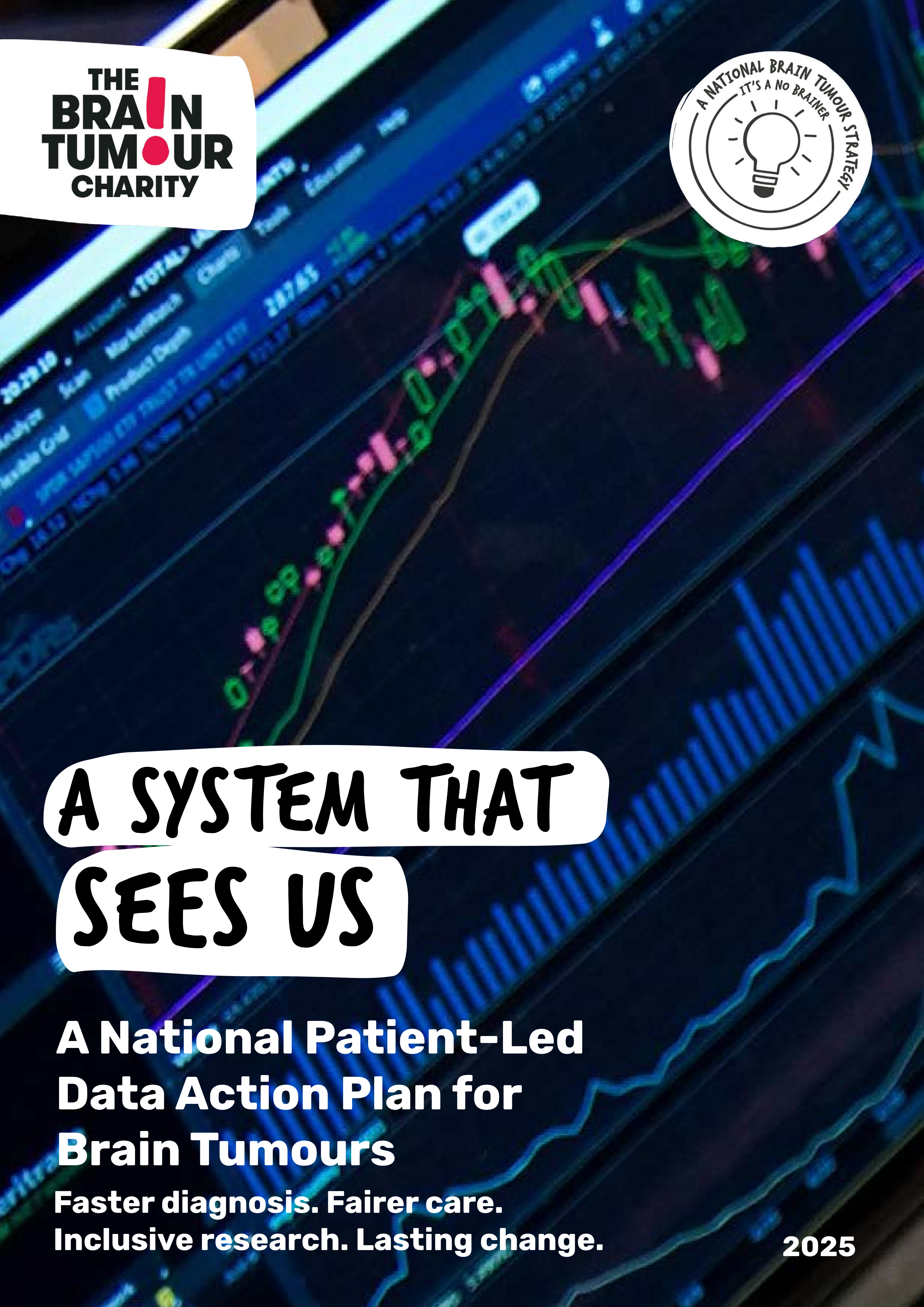


THE BRAIN TUMOUR CHARITY

A NATIONAL BRAIN TUMOUR STRATEGY
IT'S A NO BRAINER

A SYSTEM THAT SEES US

A National Patient-Led Data Action Plan for Brain Tumours

Faster diagnosis. Fairer care.
Inclusive research. Lasting change.

2025


INVESTIGATING DNA REPAIR ON A
IN GLIOBLASTOMA
Mr Ola Romi
Sheffield Teaching Hospitals
NHS
REATING GLIOBLASTOMA
Luxembourg Institute of Health
RESULTS
A CURE CAN'T WAIT!
RACHEL
Kiran

CONTENTS

EXECUTIVE SUMMARY

People affected by brain tumours are too often unseen, unheard and unsupported. This is a systemic failure that must change. Every delay, gap and missed opportunity costs lives and limits innovation.

This action plan, commissioned by The Brain Tumour Charity, is built on evidence and engagement. It draws on desk research, targeted stakeholder interviews, national workshops with people affected by brain tumours, and a survey spanning age, tumour type, and geography. At its core is data – the common currency that connects lived experience, care and research, and the lever through which change becomes measurable and accountable.

The challenges are structural and they are data failures as much as service failures. Patients and carers describe repeating their stories, navigating fragmented records and facing disconnection at every stage. Clinicians and researchers can't access complete, consistent datasets to deliver care or design inclusive trials. Policymakers lack joined-up evidence to act with urgency. Reform is overdue.

The moment to act is now. This plan builds on the Darzi investigation, the Sudlow review, the NHS Secure Data Environment strategy and the establishment of the new Health Data Research Service. It also aligns with forthcoming commitments in the National Cancer Plan, the 10-Year Health Plan, and the Data Use and Access Act, translating national intent into concrete delivery for the brain tumour community.

We must enact on five levers for change

1. **Link and standardise records.** We must define and adopt a national core dataset, so that every record connects, delays are reduced and care is safer and more continuous.
2. **Build public trust and participation.** We must earn trust through co-governance, transparent reporting and dynamic consent, so that people can share data confidently and see clear benefits.
3. **Listen and learn from patient voices.** We must embed patient-reported outcomes, experiences and carer insights into routine datasets, so that services reflect the realities of daily life.
4. **Accelerate research access.** We must integrate trial visibility into care, so that every eligible patient is proactively offered opportunities and research becomes inclusive and efficient.
5. **Grow skills and sustain change.** We must equip the workforce with data literacy, fund long-term infrastructure and embed reforms, so that progress is durable and improvements last.

Each lever follows a golden thread: lived experience reveals the system gap; the lever defines the response; recommendations set out the action; and metrics will hold the system to account (see Golden Thread map, Part 1.4).

Together these levers will deliver faster diagnosis, fairer care, more inclusive research, visible equity and sustained change.

Equity, trust and accountability

Equity runs through every recommendation. Today, people in more deprived areas face longer diagnostic delays, minority groups remain under-represented in trials and equity variables are too often missing from datasets.

Progress will be measured by age, ethnicity, geography, gender and deprivation so inequalities are visible and cannot be ignored.

Trust will be earned through transparency, oversight and plain-language communication.

Accountability will be delivered through a Knowledge-to-Action (KTA) dashboard that tracks survival, quality of life, equity and learning speed, including the time it takes for new evidence to reach practice.

Quick wins and long build
Change must be both urgent and enduring. Early actions include piloting patient-reported outcome measures (PROMs) and carer check-ins, linking datasets across priority sites, embedding trial prompts in clinical pathways, and publishing plain-English data-use statements.

Longer-term reforms include scaling the core dataset within secure data environments, embedding mandatory GP and multi-disciplinary team training, rolling out dynamic consent tools, and securing multi-year funding for infrastructure and trial coordination.

The Brain Tumour Charity's role
The Brain Tumour Charity will act as convenor, translator and accountability driver. We'll convene patients, carers, clinicians, researchers, policymakers and system leaders. We'll translate lived experience into policy-ready evidence and equity metrics timed to decision windows. We'll track and publish progress across each lever, embedding co-governance to ensure the plan is built with the community, not just for it.

Data is not abstract. It's the foundation through which dignity, equity and accountability are delivered. Behind every metric is a person – a mother awaiting diagnosis, a carer navigating exhaustion, a researcher working to make trials fair and representative. The following action plan turns lived experience into system change and holds all of us to account for delivering it.

This is why we act - for faster diagnosis, fairer care, inclusive research, and lasting change.

PART 1 – WHY THIS MATTERS NOW

Every year, around 12,700 people are diagnosed with a brain tumour in the UK – a number that continues to rise[1]. Brain tumours now rank as the ninth most common cancer in the UK. Yet survival remains stark: fewer than 12% of people survive five years after being diagnosed with a high grade tumour[1]. While other cancers have seen significant gains, progress in brain tumour care and research has not kept up.

Not all brain tumours are aggressive. Some grow slowly or are benign, but even these can cause life-altering symptoms, long-term disability and emotional trauma.

The system isn't delivering the care, research or accountability that people affected by brain tumours deserve. This section sets out the case for urgent reform, combining hard evidence with lived experience to show where the system is falling short and where data can make the biggest difference.

It begins with the voices of those affected: patients, carers clinicians, and researchers who've shared their frustrations, delays and determination. It then maps those experiences to the structural barriers that hold the system back: fragmented records, inconsistent standards and invisible inequalities.

Finally, it identifies five priority areas where action is most needed and most likely to deliver impact. Each area grounded in what people have told us matters most and in what the system must do to respond.

1.1 Why now?

1.1.1 This isn't just timely, it's overdue

This plan responds to a growing recognition – across the brain tumour community, the NHS and national policy - that the current system cannot deliver the outcomes people affected by brain tumours deserve. It's a call to act on what we already know: that data, when used ethically and inclusively, can transform lives.

Brain tumours are the leading cause of cancer death in children and adults under 40, yet they receive just 1% of the national cancer research budget[2]. In 2018, the Government announced a £45 million funding commitment for research into brain tumours — which, if evenly distributed over five years, would equate to around £789 per diagnosed patient annually — but much of this funding has yet to be allocated or spent. If this commitment were fully met, it would still fall far short of parity with other cancers like breast, lung and prostate, which receive 5-10 times more funding per patient[3]. Brain tumours also account for a disproportionately high number of life-years lost compared with other cancers.

Reports such as *Harnessing the Power of Data for Cancer*[4] highlight how patients feel excluded due to data gaps, limited involvement in strategy, fragmented care and inequitable access to trials and services. Reform is needed to address digital exclusion, disconnected records and the absence of patient-centred data governance.

International examples show what's possible. The case study in Saving the National Cancer Plan demonstrates how Denmark reversed poor cancer outcomes through coordinated, evidence-led reform. Denmark's success underscores the power of coordinated action and the dangers of valuing opinion over evidence[5].

As Professor Mark Lawler put it, "Denmark lagged behind on cancer, as we are now, but an ambitious cancer strategy turned it around. We need to do a Denmark".

This action plan is built on what people have told us matters most. It is grounded in stakeholder interviews, patient workshops, and national policy reviews. The time to act is now.

1.1.2 The case for change is clear

People affected by brain tumours are consistently excluded from decisions about their care, research priorities and system reform. Their stories reveal delays in diagnosis, disjointed care and missed opportunities for research. Clinicians and researchers describe the frustration of working with partial records and disconnected systems.

Policymakers have signalled reform. Initiatives such as the NHS Long Term Plan[6], the Darzi Report[7], the Sudlow Review[8], the NHS Secure Data Environment Strategy[9] and the Health Data Research Service[10] all point to a growing ambition to use data more effectively.

Yet the brain tumour community still lacks the joined-up evidence and infrastructure needed to fully engage policymakers and drive change.

1.1.3 We need to act urgently

Momentum is building. Stakeholders across the system – from the NHS to Health Data Research UK (HDR UK), the National Institute for Health and Care Research (NIHR), Cancer Research UK (CRUK) and the International Brain Tumour Alliance – are already playing vital roles in shaping the future of data-driven cancer care. The Brain Tumour Charity calls upon them to go further: to align behind this action plan and help drive its delivery. But funding and resources remain critical barriers.

Without action now, the system will continue to fail those it is meant to serve. The evidence is compelling, the voices are urgent and the opportunity for change is real. This action plan offers a way forward – one that is inclusive, intelligent and achievable. It is not just a technical solution. It is a moral imperative.

1.2 System barriers to change

1.2.1 The healthcare system cannot fix what it cannot see. And right now, it sees too little, too late.

To ground this action plan in evidence, we identified and reviewed 43 data sources across the UK relevant to research into brain tumours. These span routine care, specialist diagnostics, registries, tissue banks and longitudinal studies. They were mapped through desk research, stakeholder interviews and expert workshops. This provided not only a picture of what data exists, but also where the gaps, barriers and opportunities lie.

The findings reveal three interlocking barriers that prevent the healthcare system from delivering the care, research and accountability that people affected by brain tumours deserve. Unless these barriers are addressed, the system will continue to miss diagnoses, delay treatments, slow innovation and overlook lives.

1. **Gaps in data quality**
   Data is meant to illuminate, but in the brain tumour landscape it often falls short. Records are incomplete, fragmented or missing, leaving critical gaps in understanding patient experiences, outcomes and needs. Without common standards or a shared language, datasets are difficult to compare or connect. Unstructured data cannot support joined-up care, robust research or system-wide accountability. It cannot show who is being missed, what is working or where to act.

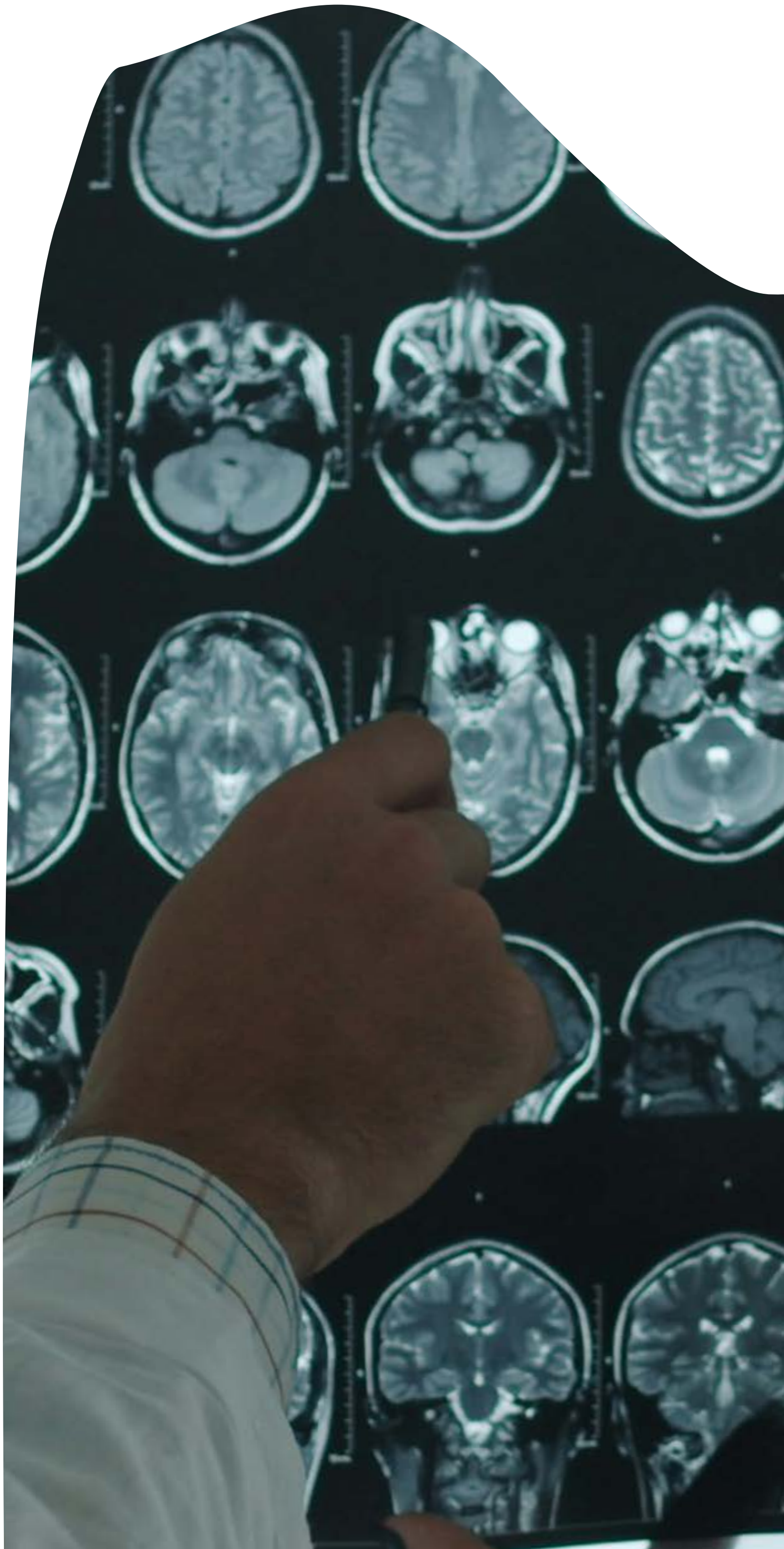
2. **Limited discoverability and accessibility**
   Even when data exists, it is too often inaccessible – including to those who need it most: researchers, clinicians and people living with brain tumours. Accessibility is not only technical. It requires governance, plain-language clarity, transparency of use and relevance to lived experience. If patients and professionals cannot understand or use the data, it cannot drive change.

3. **Infrastructure and resource constraints**
   The healthcare system is not built to deliver what the brain tumour community needs. Platforms are outdated, workforce capacity is stretched and governance is complex. Even for cancers that are more common or better understood, these limitations slow progress, fragment efforts and block development of a secure, interoperable and sustainable data ecosystem. As the Sudlow Review highlighted, UK health data systems are often too complex and disconnected, delaying research and letting patients down. Health data must be treated as critical national infrastructure if care and outcomes are to improve.

1.2.2 These are not minor obstacles. They are foundational failures.

They prevent the system from seeing clearly, responding quickly and improving equitably. They leave clinicians, researchers and policymakers working in the dark.

Addressing these barriers is not optional. It's the starting point for change. The next section shows where better data can make the greatest difference – the priority areas where acting on these failures will have the most impact. Part two then sets out the levers that turn those opportunities into system reform.



1.3 Where data makes the biggest difference

1.3.1 Data is not just a tool; it's a force for change

The Brain Tumour Charity's research has identified five priority areas where better data – complete, standardised, linkable, inclusive and patient-centred – can deliver faster diagnosis, fairer care and more inclusive research. These are the places where lives are lost, care is poorly managed, where hope is delayed and where change is most urgently needed.

1.3.2 Five priority areas for improvement

1. **Faster, fairer detection and diagnosis**
Too many people face delays because their symptoms are missed, misattributed or dismissed. Linking data across primary care, referral, imaging, diagnostic and molecular pathways can reveal where delays happen, expose inequities and enable earlier intervention. AI tools can also help spot red-flag patterns and improve diagnostic accuracy.

2. **More personalised and optimised care**
Clinical metrics alone do not capture the realities of life after a brain tumour. A core dataset that includes patient-reported outcomes – fatigue, cognition, emotional well-being and recovery goals – can help tailor care to what matters most. Patients define progress not just in survival, but in regaining mobility, managing fatigue, caring for family or returning to work or education. Recording these goals also helps signal treatment response or progression earlier.

   Compassionate care depends on understanding the whole person, not only the disease.

3. **Wider access to research**
Research should be available for every eligible patient, not a hunt for the few with awareness, determination or online access. Today, many patients only hear about trials through chance conversations or social media, leaving participation skewed towards the most connected. By linking core clinical data, automated pre-screening can make opportunities visible at the point of care, so clinicians can raise them proactively. Patients told us they would take part "if only someone had asked." Routine reporting on equity in referrals will ensure that access is fair, inclusive and representative of the whole brain tumour community.

4. **Stronger planning and accountability**
We can't improve what we don't measure. Publishing survival, recurrence and inequality data openly is a moral as well as a technical imperative. Doing so makes progress visible, exposes gaps and drives targeted improvement. Patients told us they want results reported back in plain language, not hidden in technical reports.

   Accountability is not a threat but a promise: to do better, to be better and to serve better.

5. **Accelerated innovation**
Innovation depends on data. Making tissue, genomic and imaging data more discoverable and linkable while ensuring appropriate governance opens the door to new therapies and breakthroughs. This aligns with UK-wide investment in platforms such as BRAIN UK and PRIME, which are accelerating trials and patient-centred innovation. It supports faster development, smarter targeting and more effective treatments. The future of brain tumour care depends on the data we unlock today[14].

1.3.3 From evidence to action

These five areas highlight *where* better data can make the greatest difference. They aren't standalone solutions but the evidence base for the levers in part two: faster diagnosis through linked records; personalised care through patient voices; wider access through research pathways; accountability through transparency and trust; and lasting progress through skills and infrastructure. Together, they bridge the barriers in 1.2 with the reforms that follow.

1.4 The challenges we face and how we can respond

This action plan is grounded in the lived experiences of people affected by brain tumours – patients, carers, clinicians and researchers – who shared their frustrations, insights and hopes.

The table below captures the key steps on our journey to this plan, drawing on workshops, survey responses and desk research. It reflects the voices we heard, the evidence we gathered and the collaborative process that shaped our understanding.

These insights form the golden thread that runs through this action plan: from lived experience to system gap, to lever for change, to measurable impact. This is where personal stories translate into strategic action, connecting what people face, what the system lacks and what must be done to deliver meaningful impact.

Voice from the community	System gap	Lever for change	Action to take	Impact if we act
"I have to repeat my story to every clinician – the system doesn't talk to itself."	Records are fragmented, inconsistent, and not linked across providers.	**2.1 Link and standardise records**	Define a national brain tumour core dataset; adopt consistent coding; enable secure cross-provider linkage within SDEs.	Fewer delays, safer and more continuous care, better evidence for research and policy.
"No one tells me what's happening with my data – or what's in it."	Low transparency and outdated consent processes.	**2.2 Build public trust and participation**	Publish a plain-language Data Charter; create feedback loops on data use; establish a patient data oversight panel; introduce dynamic consent tools.	Greater willingness to share data, stronger public mandate, more representative datasets.
"I keep my own notes because no one else does."	Patient and carer insights are not routinely captured or linked to clinical data.	**2.3 Listen and learn from patient voices**	Deploy short PROMs/PREMs at key points; add a carer check-in; link results to clinical records and registries/SDEs; publish plain-English dashboards and require service response.	Earlier signalling of issues; more responsive, person-centred care; equity in experience made visible.
"I'd take part in research if I knew about it and it was easier to join."	Research discovery and referral are fragmented; participation depends on self-navigation.	**2.4 Accelerate research access**	Embed trial visibility in MDTs and records; standardise a single national referral; appoint research navigator roles; monitor and publish equity of offers and uptake.	Faster, fairer, and more inclusive recruitment; stronger, more generalisable evidence.
"GPs missed my symptoms – I lost months." / "We've been here before – changes don't last."	Gaps in workforce training and data literacy; short-term projects without sustained funding or governance	**2.5 Grow skills and sustain change**	Make primary and secondary care clinician training on warning signs routine; add data literacy to curricula and refreshers; secure multi-year funding for data infrastructure and trial coordination; publish annual progress and adoption reports.	Earlier diagnosis; confident data use across the workforce; pilots converted to permanent improvements with visible accountability.

The next section sets out how these voices translate into five levers for change – the framework through which this plan delivers system reform.

PART 2 – THE FIVE LEVERS FOR CHANGE

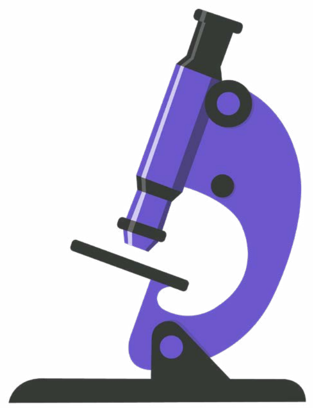
The cost of inaction is measured in lives and the opportunity for change is real.

This part of the report sets out five interdependent levers for brain tumour data reform. Each lever is grounded in lived experience, supported by evidence and aligned with both national and international policy. Together, they form an actionable framework for building a system that sees, hears and supports every person affected by brain tumours.

The five levers are:
i) Link and standardise records,
ii) Build public trust and participation,
iii) Listen and learn from patient voices,
iv) Accelerate research access and
v) Grow skills and sustain change.
They respond directly to what people told us matters most and to what the system must do to act.

These levers are reinforced by a wave of recent policy commitments. The NHS Secure Data Environment Strategy[9] and new Health Data Research Service (2025)[10] frame health data as critical national infrastructure, while the Data (Use and Access) Act 2025 mandates common formats and interoperability. The 10-Year Health Plan[6] and forthcoming National Cancer Plan commit to earlier diagnosis, digital-first care and equity. Lord Darzi's review[7] and the Sudlow Review[8] call for integrated records, data science capacity and trial coordination. At European level, the European Health Data Space (EHDS)[15] sets a framework for secure, interoperable data use and the latest Spending Review and NHS App reforms extend patient access and embed security by default.

This part answers the question: ***Why now? And why this plan?***



2.1 Link and standardise records

2.1.1 Every life must be visible. Every record must connect

The stakeholder engagement conducted by IQVIA for The Brain Tumour Charity revealed that:

1. There are 43 data sources across the UK relevant to research into brain tumours, but few are brain tumour-specific and many lack standardisation.
2. Coding discrepancies, inconsistent terminology and absent protocols block data integration.
3. Stakeholders – including clinicians, researchers and data managers – called for a core dataset including diagnostic milestones, treatment, recurrence, survival and socio-demographic fields (age, sex, ethnicity, geography and deprivation).
4. The absence of prospective, validated patient-reported outcomes (PROs) and incomplete follow-up data limits the system's ability to track long-term outcomes and equity.

People affected by brain tumours told us they must repeat their story at every turn. Their care is fragmented, their records scattered and their experience lost in systems that don't connect.

Researchers described the impact: incomplete datasets, inconsistent coding and poor documentation of tumour heterogeneity make it difficult to compare studies, track disease progression or evaluate treatment efficacy. Clinical teams stressed how the lack of standardised protocols and interoperable systems undermines collaboration and slows innovation.

Together, this creates a data landscape that obscures patterns, delays discovery and hides the realities of brain tumour care. Linking and standardising records is therefore the first and most foundational step in building a system that sees, hears and responds to every person affected. Without it, there is no continuity of care, no accountability in policy and no equity in research.

2.1.2 What we heard

> *"I saw my GP five times before anyone mentioned a scan."*
>
> *"They gave me a leaflet, but it didn't say what it meant for me."*
>
> *"I keep my own notes because no one else does."*

Our survey findings confirm this picture:
- very few participants had been given a tool by a clinician to track their symptoms or care journey.
- participants actively searched for a tool but couldn't find one.
- many said they would be interested in using a tool if one were available.

2.1.3 What must change

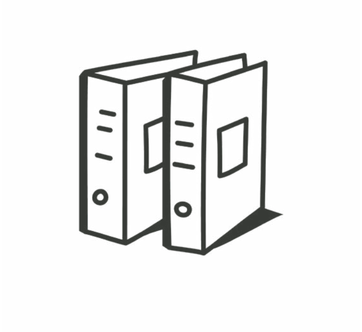
We must move from fragmented records to a unified, equitable data ecosystem.
That requires:

1. Define and publish a national brain tumour core dataset by 2026, covering diagnostic milestones, treatment, recurrence, survival and equity fields (age, sex, ethnicity, geography and deprivation).

2. Co-design and validate the dataset standards with patients, carers, clinicians and researchers, convened by The Brain Tumour Charity to ensure relevance and trust.

3. Track and publish adoption annually across NHS trusts and regions, aiming for [≥90%] coverage within three years, with data openly disaggregated to expose inequalities.

These actions are not only technical fixes. They ensure dignity, equity and discovery are built into every patient journey.



2.1.4 What to expect

A linked and standardised dataset will:

1. illuminate diagnostic pathways and provide insights towards the creation of an optimal care and treatment pathway, including the often-overlooked pre-diagnosis journey.

2. enable real-time equity monitoring and longitudinal analysis.

3. reduce duplication, support earlier clinical action and clarify treatment pathways.

4. support more inclusive research and faster, fairer trial recruitment.

2.1.5 Progress meassures

This lever supports the Health Data Research Service's (HDRS)[10] emphasis on treating health data as critical national infrastructure, enabling secure, ethical and interoperable data use to drive research, improve outcomes and reduce inequalities. It also aligns with the Darzi Report's call for patient-centred outcomes and transparency in data use, and the Sudlow Review's recommendation for clearer governance and public-facing data tools[8].

It further reinforces the recommendations made in The Brain Tumour Charity's Fighting for Faster Diagnosis report, which calls for a best practice timed pathway to reduce delays and improve diagnostic equity[11]. Without this, we remain reliant on fragmented datasets that obscure the true diagnostic journey for brain tumour patients.

We can track:

1. **Annual change in dataset completeness,** with trends reported by region and equity group.

2. **Median time from first GP presentation to diagnostic milestones** (including referral, imaging (e.g. MRI) and confirmed diagnosis) using existing cancer pathway metrics where available.

3. **Variation in trial eligibility and recruitment turnaround times,** stratified by age, geography, ethnicity and deprivation.

This lever is the foundation for continuity of care, visible equity and research that reflects real lives.

2.2 Build public trust and participation

2.2.1 Trust isn't built by systems, it's earned through transparency, respect and shared purpose

People affected by brain tumours told us they're asked to share their data but rarely given clarity, control or feedback. They feel excluded from decisions, uncertain about where their information goes and unsupported when they want to exercise choice.

Building trust is not a compliance or communication exercise but about respecting people's rights: knowing how data is used, shaping its purpose and seeing evidence of benefit.

2.2.2 What we heard

People affected by brain tumours told us they're asked to share their data but rarely given clarity, control or feedback. They feel excluded from decisions, uncertain about where their information goes and unsupported when they want to exercise choice.

Building trust is not a compliance or communication exercise but about respecting people's rights: knowing how data is used, shaping its purpose and seeing evidence of benefit.

> *"No one tells me what's happening with my data – or what's in it."*
>
> *"I'd like to be asked, not have a blanket 'you can use it for anything'"*
>
> *"You don't want people talking to you in the language of a textbook."*

These frustrations are not isolated.
Our survey confirmed the same picture:

- few respondents had clear information about how their data would be used.
- concerns about privacy, misuse, and lack of control were common.
- trust was described as fragile. though many said they would support linking health information if systems were transparent, inclusive and respectful.

2.2.3 What must change

We need to move from fragile, one-off consent to a transparent, ongoing model of trust. To achieve this ambition, we must:

1. **Publish a Brain Tumour Data Charter in 2026.** The Brain Tumour Charity Working with patients and carers, The Brain Tumour Charity should setting out in plain language people's rights and what happens when they share their data.

2. **Provide feedback loops.** The Brain Tumour Charity and the research teams they fund should commit to showing participants how their data contributed to care or research (e.g. plain-language updates, dashboards).

3. **Establish a Patient Data Oversight Panel.** Led by the NDRS, with diverse patient and carer voices, the panel should meeting regularly and publishing an annual report on data use and lessons learned.

4. **Introduce dynamic consent tools by 2027.** Owned by NHS, these should enableing patients to see how their data is used and change preferences over time, with The Brain Tumour Charity ensuring brain tumour patients are included in design and rollout.

These reforms turn data use from a hidden process into a visible, co-owned system where patients have clarity, control and confidence.

2.2.4 What to expect

This lever reflects the ambitions of the Tessa Jowell Brain Cancer Mission, which urges patient-centred data collection and integration of real-world evidence. It also supports the NHS Long Term Plan's commitment to personalised care and expanded use of patient-reported outcomes6 and the European Health Data Space's encouragement of reuse of health data for research and policy, including patient-generated data[15].

When trust is built through clear rights, feedback, oversight and choice:

- **participation** will increase as more patients and carers agree to share data.
- **datasets** will become more representative, including younger patients, minority groups and rural communities.
- **transparency** will improve as people see how their data is used and are able to change their mind if they wish.
- **confidence** will rise as patients feel safe, informed and respected as partners in care and research.

Progress can be tracked through the proportion of patients who report understanding how their data is used, the diversity of patients represented in feedback loops and oversight panels, and the uptake of dynamic consent tools once rolled out, with The Brain Tumour Charity monitoring inclusion of brain tumour patients.

2.3 Listen and learn from patient voices

2.3.1 If we don't ask, we don't know. If we don't measure, we don't act.

People affected by brain tumours aren't passive recipients of care. They're experts in their own experience: navigating fatigue, fear, cognitive changes and the ongoing impact on daily life. Yet too often, these voices are missing from the data that drives decisions. Symptoms go unrecorded, emotional distress goes unacknowledged and the strain on carers is invisible. This silence distorts what the system values and holds back improvements in care and research.

2.3.2 What we heard

People affected by brain tumours told us they're asked to share their data but rarely given clarity, control or feedback. They feel excluded from decisions, uncertain about where their information goes and unsupported when they want to exercise choice.

Building trust is not a compliance or communication exercise but about respecting people's rights: knowing how data is used, shaping its purpose and seeing evidence of benefit.

> *"The fatigue is like walking through treacle every day."*
>
> *"I was always tired… I'd come home from work and be asleep on the sofa by quarter past four."*
>
> *"Looking back, they're classic, classic signs of brain tumours. But at the time, I didn't think about brain tumours, so I guess the GP didn't either."*
>
> *"It stole his life. It stole my life, my husband's life, and his brother's life, because our lives have evolved around fighting for him, fighting the NHS, getting the treatment he needed, or trying to find the treatment."*

Survey findings confirm this picture:

- fatigue and cognitive changes are widespread yet rarely tracked in care settings.
- emotional distress is under-recognised, with many reporting anxiety or low mood but little access to psychological support.
- carer burden is significant, with the highest strain reported by women aged 35 to 54.
- patient priorities such as quality of life, functional recovery and day-to-day stability are largely absent from treatment planning, where survival metrics dominate.

2.3.3 What must change

We need to treat patient and carer voices as evidence, systematically collected, routinely reviewed and visibly acted upon. That means we must:

1. **Make patient voices routine within research** by collecting short patient-reported outcome and experience measures (PROMs/PREMs) at key points in care and research, focusing on fatigue, cognition and emotional wellbeing.
2. **Recognise carer burden** by embedding a short check-in for carers during each treatment cycle, with clear routes to support when high strain is flagged.
3. **Connect lived experience** to national data by ensuring patient and carer-reported measures are included in the National Cancer Registry and NHS Secure Data Environments by 2027[9].
4. **Show and act on results** by publishing plain-language dashboards twice yearly and requiring NHS Trusts to demonstrate how they are responding.

These reforms turn data use from a hidden process into a visible, co-owned system where patients have clarity, control and confidence.

2.3.4 What to expect

This lever supports the NHS Long Term Plan's ambition to diagnose 75% of cancers at stage one or two by 2028 and expand personalised care[7]. It also answers the Sudlow Review's call for patient-centred data and the European Health Data Space's goal of making health data available for research and innovation[9].

When patient and carer voices are captured and used:

- **care becomes more responsive** as clinicians act on fatigue, cognition and emotional wellbeing, not just clinical markers.
- **research becomes more inclusive** by drawing on outcomes that reflect real lives and widening participation in studies.
- **equity becomes visible** through routine reporting of quality of life and carer strain, disaggregated by age, ethnicity, geography and deprivation.

Progress will be tracked by the proportion of patients and carers completing check-ins, the timeliness of clinical responses to red-flag symptoms and the publication of dashboards showing how feedback is shaping services.

This is not just about collecting new metrics. It is about shifting what counts as evidence, ensuring that survival is measured alongside the quality of life and daily realities of those living with brain tumours.

2.4 Accelerate research access

2.4.1 Every trial should be visible. Every patient should be asked.

People affected by brain tumours are willing to take part in research. They're motivated, generous and hopeful that their contribution will help others. Yet the system makes participation hard. Trial information is scattered, signposting is weak and many patients only hear about opportunities through chance or social media.

This is more than a frustration. It is a failure of equity. Access depends on where people live, how confident they are online or whether they already have support networks. Those with fewer resources are left out and the research base becomes skewed towards the most connected. That leaves care and innovation shaped by partial evidence.

To change this, research opportunities must be part of the care journey. Every eligible patient should be proactively offered a chance to participate, every clinician should know the pathway and support should be available to help patients make informed choices.

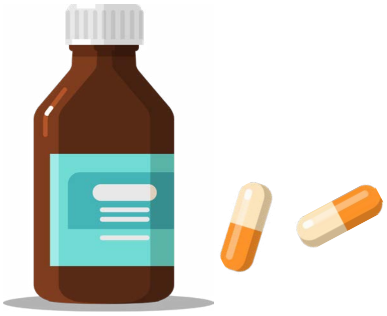
This lever sets out how to move from a system where people must hunt for trials to one where research is visible, accessible and embedded in care.

2.4.2 What we heard

People affected by brain tumours told us they're asked to share their data but rarely given clarity, control or feedback. They feel excluded from decisions, uncertain about where their information goes and unsupported when they want to exercise choice.

Building trust is not a compliance or communication exercise but about respecting people's rights: knowing how data is used, shaping its purpose and seeing evidence of benefit.

> *"I had to Google everything and still didn't know if I qualified."*
>
> *"No one mentioned trials; I found out in a Facebook group."*



These are not rare frustrations. Our survey confirmed that:

- many patients had never been offered trial details or written guidance.
- more than half said they only heard about opportunities through their own searching or peer networks, echoing the workshop stories.
- respondents called strongly for clearer signposting and a central platform, stressing that barriers were both practical and emotional: people needed simple guides, clinical support and peer reassurance to feel able to take part.

These findings align with The Brain Tumour Charity's published recommendations in "Six ways to remove the barriers to research participation"[12], which highlight the urgent need to:

- improve awareness and accessibility of trials.
- provide tailored information and emotional support.
- build trust through peer-led engagement and clinician endorsement.

Trial access is therefore not a matter of individual determination but a systemic failure. Information is scattered, referral routes are inconsistent, consent processes are unclear and no one is monitoring whether opportunities are reaching all communities fairly.

2.4.3 What we heard

We must replace fragmented discovery with a clear research access pathway that builds on national tools, is proactive in care and fair across communities.

1. Integrate research into clinical care by embedding trial visibility from NIHR's Be Part of Research into multidisciplinary team (MDT) agendas and electronic records, aiming for ≥80% of eligible patients to have a trial discussion recorded in their notes by 2027.
2. Standardise referral processes through a single national referral form linked to the cancer registry, with ≥90% of referrals logged and tracked within three years.
3. Provide dedicated navigator roles in every neuro-oncology centre by 2026, with each navigator supporting patients through eligibility, consent and logistics.
4. Monitor equity in access and leadership with an annual public dashboard, showing trial offers and uptake by age, ethnicity, geography and deprivation – aiming to narrow equity gaps year-on-year. It should alsoreport where trials are led and run. .

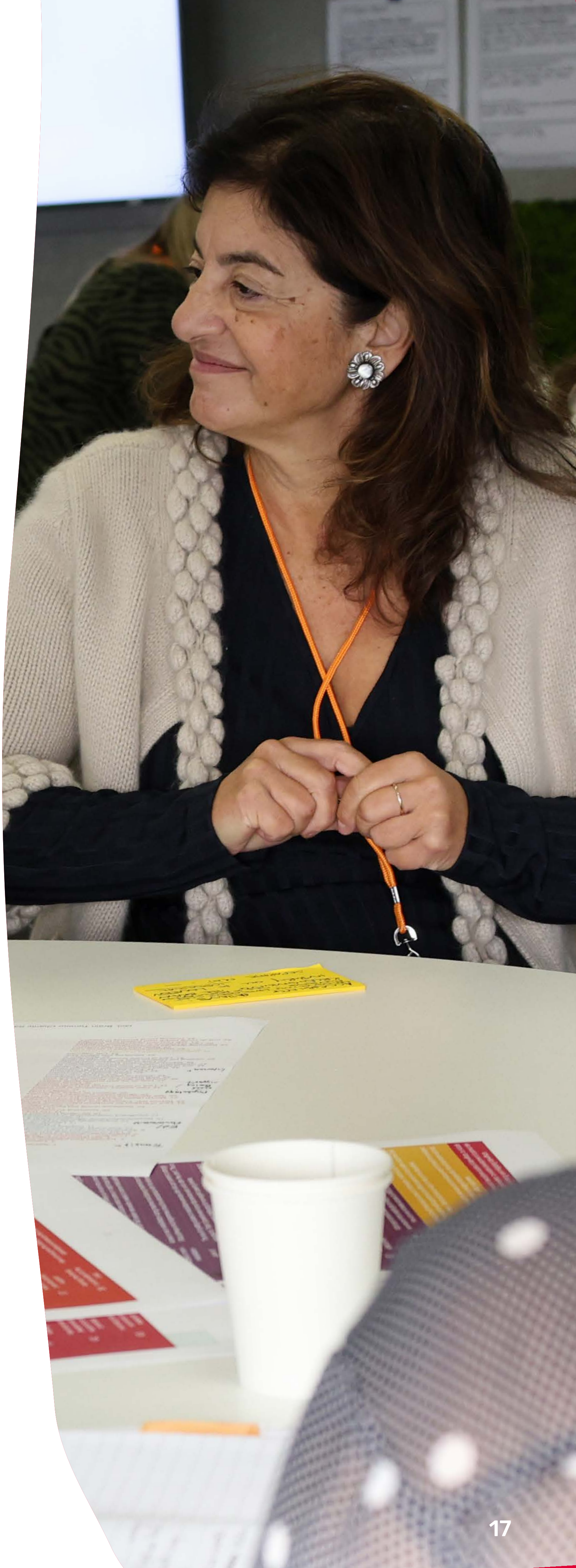
2.4.4 What to expect

This lever builds on national policy priorities: the Darzi Report's call for digital transformation[7], the NHS Long Term Plan's investment in digital infrastructure and workforce[6] and the Sudlow Review's focus on trial coordination and data science capacity[8]. It addresses two linked goals: ensuring every patient has fair access to research and ensuring researchers have the infrastructure and skills to deliver it. This includes both clinical trials and real-world evidence studies, which rely on linked, representative datasets to show how treatments work in everyday settings.

When research access is embedded in care:

- patients will be proactively informed and supported, with trial opportunities routinely offered as part of the care journey.
- clinicians will have systematic prompts through MDT discussions and electronic records, so eligibility is consistently considered.
- recruitment will become faster and more inclusive, with participation reflecting the full diversity of the brain tumour community.
- equity will be visible and actionable through routine reporting of who is offered trials, who takes part and which communities are represented in the evidence base.

This is not only operational improvement but a shift in mindset: research offered as a right, not a privilege; evidence shaped by all communities, not just the most connected.



2.5 Grow skills and sustain change

2.5.1 Change must be built to last and led by people who are equipped to deliver it.

People affected by brain tumours told us their symptoms were dismissed, diagnoses delayed and improvements in care often faded as quickly as they appeared. These experiences reflect systemic weaknesses: frontline staff are not consistently trained to recognise warning signs, data is collected but too rarely understood or used and promising initiatives stall when short-term funding runs out.

But the issue runs deeper than training alone. As highlighted in our Barriers to Research Participation report, healthcare professionals are stretched to capacity12. Many know they should be having longer conversations with patients about trials and care options, but time pressures force them to move on. Departments often lack dedicated staff for research recruitment, leaving clinicians to juggle complex eligibility checks, consent processes and emotional support without the infrastructure to do so effectively. We know that even the smallest improvements in workflow efficiency could free up time for clinicians to have vital conversations about research and data.

This lever sets out how to strengthen workforce competence and embed reforms in long-term infrastructure, so that progress in brain tumour care is sustained and accountable.

2.5.2 What we heard

> *"They said it was stress, not a tumour."*
>
> *"Change doesn't last – things start, then fizzle out."*

Survey responses confirmed these experiences:

- many people faced delays at the GP stage, with symptoms often misattributed to stress, migraines, or other benign conditions.
- awareness of warning signs varied widely between clinicians, leaving patients unsure they could trust their GP to recognise serious symptoms.
- respondents felt improvements in awareness campaigns or local services were short-lived, with progress lost once projects ended or funding stopped.

2.5.3 What must change

We must build competence and continuity so that progress in brain tumour care does not fade.

1. Introduce mandatory training on brain tumour warning signs within national cancer education programmes, audited annually, for general practitioners, nurses, physician associates, pharmacists, emergency staff, advanced nurse practitioners and junior doctors. Embed this training from undergraduate study through continuing professional development. **Make workforce learning continuous** by rolling out refresher modules and MDT-based teaching, as well asby adding data literacy to oncology and primary care curricula so staff can act on insights, not just record them.

2. **Commit multi-year funding** for secure neuro-oncology data infrastructure and trial coordination posts across major centres, reviewed every three years.

3. **Publish annual progress reports** that track training coverage, funding continuity and adoption rates at Trust and regional level, making performance visible and accountable.

2.5.4 What to expect

This lever builds on clear national priorities. The NHS Long Term Plan commits to diagnosing cancers earlier, expanding digital infrastructure and supporting personalised care[6]. Lord Darzi's investigation highlights that the NHS remains in the "foothills of digital transformation" and calls for sustained investment in workforce readiness to use data effectively[7]. The Sudlow Review identifies persistent gaps in data science and trial coordination, urging that health data be treated as critical national infrastructure[8].

The Brain Tumour Charity's proposals translate these broad commitments into targeted, disease-specific action. By focusing on workforce training, data literacy and long-term infrastructure, this lever sustains momentum while ensuring brain tumour patients and researchers are not left behind.

When skills are grown and change is sustained:

- more symptoms are recognised at the first presentation, reducing avoidable diagnostic delay.
- workforce learning becomes routine, regularly refreshed and updated, ensuring it's embedded across the workforce, with staff confident to use data as well as collect it. Pilot projects are converted into permanent improvements, backed by secure, multi-year funding.
- progress is made visible through annual reports,giving patients confidence that reforms will last.

This is not only about training, but also about trust: trust that the workforce is equipped, that improvements will endure and that the system will keep its promises to people affected by brain tumours.

PART 3 – Call to action: from vision to delivery: a shared agenda for change

The time to act

Brain tumours have been left behind in research and care. Patients have waited too long, researchers have faced fragmented data, and clinicians have lacked the tools to personalise treatment. This plan sets out what must change, and how to deliver it.

A shared agenda

Progress depends on acting across all five levers - linking records, building trust, embedding lived experience, accelerating research and growing skills. These are interdependent. They must be adopted together, not as isolated initiatives.

What this will deliver

- Faster diagnosis through better data linkage and GP training.
- Fairer care by embedding equity metrics and acting on lived experience.
- More inclusive research with visible, navigable trials.
- Stronger accountability by tracking outcomes and publishing progress.

Why this matters

This is not only about improving datasets. It is about improving care, experience and outcomes. A system that listens and learns is one that treats people with dignity and fairness.

A collective commitment

The Brain Tumour Charity will convene, translate evidence and drive accountability. But delivery requires a collective effort:

- Researchers and clinicians need to adopt shared standards and co-create solutions.
- Funders and policymakerneed to invest in infrastructure that lasts.
- Patients and carersneed to continue shaping priorities through lived experience.

This agenda is aligned with national reforms already underway. What's needed now is commitment to act on it - together.

With shared accountability, we can ensure every person affected by a brain tumour is visible in data, reflected in research and respected in care.

Appendices

Method summary and stakeholder input plan

This report is grounded in the voices of the brain tumour community and shaped by a rigorous, inclusive evidence-gathering process.

It draws on three complementary sources:

- **Workshops** with people affected by brain tumours - including patients and carers – captured lived experience in their own words. These sessions surfaced the emotional, practical and systemic realities of navigating diagnosis, care and research.
- **An online survey** tested and extended emerging themes, ensuring breadth across age, tumour type, geography and background. The survey provided a wider lens on shared challenges and priorities, amplifying the reach of the workshop insights.
- **Stakeholder interviews** with clinicians, researchers, commissioners and system leaders explored feasibility, alignment with existing initiatives and opportunities for system-wide reform. These conversations helped bridge lived experience with operational reality.

Insights from these sources were coded thematically and mapped against the system assessment developed through stakeholder review. This created a clear and traceable "golden thread", going from lived experience to system gap, to lever for change, and then to actionable recommendation.

This approach ensures that every proposal in the report is not only evidence-based, but also community-led, system-aware and ready to deliver impact.

Outputs by source

To ensure this strategy is not only visionary but deliverable, The Brain Tumour Charity commissioned IQVIA to conduct targeted interviews with clinical, research and system leaders. These conversations tested feasibility, surfaced operational barriers and helped align recommendations with existing initiatives.

Interviewees included neuro-oncologists, neurosurgeons, specialist nurses, data managers, researchers and NHS commissioners. Their insights reflected deep expertise and a shared commitment to improving outcomes for people affected by brain tumours.

Across disciplines, stakeholders identified consistent system-level challenges:

- Fragmented datasets, with variable quality and incomplete linkage across services and systems.
- No agreed core dataset for brain tumours, limiting consistency in care, research and reporting.
- Equity data – such as ethnicity, deprivation, and region – is rarely captured, making it difficult to monitor disparities or design targeted interventions.
- Trial referral processes are unstandardised, slowing recruitment and reducing visibility of opportunities for patients.
- Skills and capacity gaps persist across the NHS workforce, particularly in data science, digital infrastructure and clinical trial coordination.

These findings reinforce the need for a joined-up, equity-led plan, that links records, builds trust and grows the skills needed to sustain change.

Outputs by source

To ensure this action plan reflects the real needs of the brain tumour community, The Brain Tumour Charity convened a dedicated workshop with patients, carers and advocates. Their stories were powerful, personal and consistent – revealing urgent areas for national attention.

The session was designed to be trauma-informed, inclusive and supportive. Participants were invited to share only what felt safe and comfortable, with options to pause, step away or follow up later. In total, seven people – either diagnosed with a brain tumour or caring for someone who has been diagnosed with a brain tumour – took part.

A structured discussion guide explored four key themes:

- Patient care and personalised medicine: experiences of diagnosis, treatment and the impact on daily life.
- Healthcare operations: interactions with healthcare professionals and satisfaction with services.
- Research and innovation: awareness of clinical trials, willingness to share data and preferences for information formats.
- Support and unmet needs: sources of support, gaps in care and ideas for improvement.

Participants represented a mix of low and high grade diagnoses, different age groups, carers and regions. Their contributions revealed consistent challenges:

- Delays to diagnosis, with symptoms often misattributed to stress, migraines or mental health conditions.
- Inconsistent or insensitive communication, especially around scan results and prognosis.
- Fragmented care, with patients repeatedly retelling their history across services.
- Barriers to research participation, with access dependent on self-search and informal peer networks.
- A strong call for equity monitoring and co-governance, to ensure that data and decisions reflect the full diversity of the brain tumour community.

Direct quotes by theme

Diagnosis and care journey

> "I didn't have any symptoms at all… one morning, I tripped over at home and had a seizure. By 4 o'clock that afternoon, someone told me I had a lesion."
>
> "She was going back and forth to her GP, who kept treating her for sinusitis… she died. That's what brought me to my son."
>
> "I had 10 to 20 years of daily headaches… since my surgery, I've not had another migraine."

Equity and representation

> "I had to fight for everything for my mum. I had to fight for the steroids so she could fulfil her pantomimes and parties."
>
> "Nobody should fight when someone's on palliative care. Everybody should be running to help you."

Emotional and psychological impact

> "It stole his life. It stole my life, my husband's life, and his brother's life."
>
> "I've been living with the sword of Damocles above my head."
>
> "We were the Lucky Pennys. Now I feel like I took that name away from us."

Information and support needs

> "There didn't seem to be any source of layman's terms. I had to text my wife what they said, and she'd Google it."
>
> "I'd like someone to ask me about my lifestyle. Try to find out what might have caused this tumour."
>
> "I don't want the propaganda the government wants you to watch. I want real news."

Data sharing and consent

> "I promised my mum I would share her story. If I can save one life just through telling somebody, I've done something."
>
> "If the charity had looked at it and said, 'that information's appropriate,' I'd trust it."
>
> "I'd be happy for my tumour to be used in research – leave a little bit in the freezer in London, just in case."

System impact and levers for change

> "The NHS is world-class in an emergency. But the minute it is not an emergency, it is a chaotic mess."
>
> "I had to bring it to their attention for them to eventually look… and then I got a letter of apology."
>
> "You don't want to be spending your time and energy fighting the system."

Survey:

To ensure this plan reflects the breadth and diversity of the brain tumour community, The Brain Tumour Charity invited its network to take part in an online survey. The survey tested and extended themes raised in stakeholder interviews and workshops, offering a wider lens on shared challenges, preferences and priorities.

In total, 256 people – either living with a brain tumour or caring for someone who is – responded. Their insights were clear, consistent and deeply valuable, reflecting a strong appetite for meaningful data use, inclusive research and emotionally attuned care. They also highlight systemic gaps that must be addressed to build a more equitable and responsive data ecosystem.

Key findings by theme:

Diagnosis and care journey

- Many respondents actively sought ways to track symptoms, quality of life, and treatment impact, demonstrating a clear desire to contribute meaningful data to improve care.
- There was strong support for digital tools such as wearables and apps, driven by motivations including improved care, greater personal control, and a commitment to helping others through research.
- While comfort with data sharing was high, it was not unconditional. Respondents consistently raised concerns around privacy, transparency, and control.

Research access and participation

- Respondents endorsed the use of data to identify and prioritise research gaps but called for greater clarity on how decisions would be made and communicated.
- Key concerns included lack of transparency, potential bias in research agendas, and the risk of excluding under-represented groups.

Equity and representation

- Demographic data revealed a wide spread of age, gender, and ethnic backgrounds, but also exposed gaps in how equity data is captured and used.
- Respondents urged for better visibility of inequalities and more inclusive approaches to data governance.

Emotional and psychological impact

- Fatigue, anxiety, and cognitive changes were frequently reported, yet rarely addressed in care settings.
- Respondents advocated for tools and systems that recognise emotional wellbeing as integral to clinical care, not an optional extra.

Information and support needs

- Many respondents had never seen clear explanations of how their data is used.
- There was strong support for plain-language data use statements and dynamic consent models that allow ongoing control and engagement.

Stakeholder engagement plan

The Brain Tumour Charity will implement a structured and transparent stakeholder engagement model to support the delivery of its data strategy. This plan outlines how The Brain Tumour Charity will ensure that stakeholder voices are embedded in governance, implementation and evaluation.

1. Engagement objectives

- Ensure the strategy reflects the lived experience of patients and carers.
- Enable researchers, clinicians and data custodians to shape implementation.
- Build trust, transparency and shared ownership across the ecosystem.

2. Engagement structures

- Advisory Panels: Establish panels for patients, clinicians and researchers to provide ongoing input.
- Working Groups: create time-bound groups to co-design specific initiatives (e.g. core datasets, PRO tools).
- Strategic Partners Forum: convene quarterly meetings with national bodies (e.g. NHS
- England, HDR UK, NCRAS) to align on priorities and progress.

3. Engagement methods

- Regular workshops and roundtables.
- Surveys and feedback loops.
- Co-authorship of guidance and tools.
- Transparent reporting on how input is used.

4. Governance and accountability

- The Brain Tumour Charity will publish an annual stakeholder impact report.
- Stakeholder representatives will be included in the strategy's steering group.
- A named lead at The Brain Tumour Charity will be responsible for stakeholder engagement delivery.

5. Timeline

Engagement structures will be launched within three months of strategy publication, with the first full review cycle completed within 12 months.

Glossary

Term	Definition in this report
Brain tumour core dataset	The agreed minimum set of data collected for every person diagnosed with a brain tumour. It forms the foundation for visibility, comparability, and equitable access to research.
Co-governance	A shared decision-making model where stakeholders – including patients, clinicians, researchers, and policymakers – actively participate in the design, implementation, and evaluation of strategic initiatives.
Cohort discovery	The process of identifying groups of patients who meet specific criteria for research or clinical trials, enabling targeted recruitment and inclusive participation.
Core dataset	A standardised set of data fields collected across systems to support joined-up care, robust research and informed policymaking.
Data landscape assessment	The Brain Tumour Charity's first national study of brain tumour data gaps and system barriers. It provides the baseline for this strategy and highlights where change is most needed.
Dynamic consent	A flexible, ongoing model of consent that empowers patients to update their preferences over time, supporting autonomy and trust.
Equity metrics	Measures that track whether outcomes differ between groups (e.g. by postcode, ethnicity or income). These metrics help identify and address inequalities in diagnosis, care and research access.
Federated data access	A model that enables researchers to access and analyse data across multiple sources without centralising it, preserving privacy while allowing collaboration.
Knowledge-to-Action latency	The time between new evidence being generated and that evidence being put into practice. The Brain Tumour Charity will track this as a measure of system responsiveness and accountability.
Lived experience data	Information shared by patients and carers about daily life, symptoms and care experiences. It complements clinical data and brings human insight into system design.
MDT (Multidisciplinary Team)	A group of healthcare professionals from different specialties who collaborate to provide holistic, person-centred care.
Patient finder	A tool that uses structured data to identify patients who may be eligible for clinical trials, supporting faster, fairer access to research.
PGD (Patient-Generated Data)	Data recorded directly by patients (e.g. symptoms, side effects, quality of life), which can be linked with NHS records to enrich understanding and personalise care.
PREMs (Patient-Reported Experience Measures)	Tools that capture patients' experiences of care delivery, highlighting what works, what doesn't and where improvement is needed.
PROMs (Patient-Reported Outcome Measures)	Tools that capture patients' views on their health, symptoms and quality of life, ensuring that care reflects what matters most to them.
Referral pathway	The route by which a patient moves from first contact to specialist care or trial participation. Currently highlighted as inconsistent and fragmented, it is a key area for reform.
SDE (Secure Data Environment)	A controlled NHS platform that enables secure access to de-identified data for research, ensuring safety, privacy and public trust.
System lever	A point in the health or research system where change can unlock wider improvement. Each patient challenge is linked to a lever for strategic action.
Trusted Research Environment (TRE)	Often used interchangeably with SDE, TREs are secure platforms for accessing sensitive health data for research, ensuring compliance with ethical and legal standards.

References and evidence sources

1. **Brain, Other CNS and Intracranial Tumours Statistics – Cancer Research UK:** Confirms brain tumours as the UK's ninth most common cancer.

2. **CBTRUS Statistical Report (2023) – Society for Neuro-Oncology:** Provides comprehensive data on primary brain and other CNS tumours diagnosed in the United States, confirming brain tumours as the leading cause of cancer death in children and young adults.

3. **Brain Cancer Research to Receive £45 Million Funding (2018) – Department of Health and Social Care:** Announces a joint £45 million commitment from DHSC and Cancer Research UK to accelerate research into brain tumours, including new centres of excellence and a formal NIHR funding call.

4. **Harnessing the Power of Data to Transform Cancer Research, Care and Innovation Across the Island of Ireland (2025) – The eHealth Hub for Cancer:** Sets out Ireland's vision for secure, connected digital health systems, empowering patients and enabling data-driven care and innovation.

5. **Saving the National Cancer Plan: The Triumph of Evidence Over Opinion (2025):** Makes the case for reinstating a UK-wide cancer strategy – showing that countries with consistent national plans achieve better outcomes and equity in care.

6. **The NHS Long Term Plan (2019):** Sets out a 10-year vision to transform health outcomes through prevention, personalised care, and digital innovation.

7. **Independent Investigation of the NHS in England (2024):** Led by Lord Darzi, this review calls for bold reform to improve NHS performance, transparency, and patient-centred care.

8. **Uniting the UK's Health Data: A Huge Opportunity for Society (2023):** Authored by Professor Cathie Sudlow, this review identifies barriers to health data use and proposes a national service to unlock its full potential.

9. **Secure Data Environments – Data Saves Lives (The NHS Secure Data Environment Strategy):** Outlines NHS England's shift from data sharing to secure, transparent access, enabling faster, safer research and innovation.

10. **Health Data Research Service (2025):** A landmark initiative to unify and accelerate health data research across the UK, driving discovery and improving outcomes.

11. **Fighting for Faster Diagnosis (2023) - The Brain Tumour Charity**: outlines eight policy recommendations to reduce diagnostic delays for brain tumours and calls for a best practice timed pathway and improved data collection to ensure faster, fairer diagnosis and better patient outcomes.

12. **Barriers to Research Participation (2025) - The Brain Tumour Charity**: outlines six actions to improve trial access, including better signposting, dedicated staffing, and cultural change to embed research in routine care.

13. **Research Funded Initiatives – Brain Tumour Research:** Highlights UK-wide investment in platforms like BRAIN UK and PRIME, accelerating trials and patient-centred innovation.

14. **Accelerating the Search for New Glioblastoma Treatments (2025) – Cancer Research UK:** Spotlights a pioneering platform trial tackling stalled drug development, bringing new hope to glioblastoma patients.

15. **European Health Data Space (EHDS) – European Commission (2024):** Sets out a harmonised legislative framework for secure, interoperable health data sharing across the EU, enabling both primary and secondary use of electronic health data for care, research, and innovation.

Acknowledgement

This action plan was developed with the contribution of people affected by brain tumours and expert stakeholders who shared their experiences and insight. The report was co-written with support from IQVIA's James Buckley (Strategy Lead and overall plan design), Julia Levy (Data Landscape and Real-World Evidence) and Jez Simms (Lived Experience Research and Analysis).

IQVIA's Patient Advocacy Centre of Excellence works alongside patient organisations to design data strategies, capture lived experience, and link evidence to system change. By combining strategic insight with analytical expertise, the team helps charities and communities turn patient voices into actionable evidence for research, policy, and care improvement.
Learn more at patientadvocacy@iqvia.com.

THE BRAIN TUMOUR CHARITY