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# FOREWORDS

# WELCOME FROM THE STRATEGY STEERING GROUP

It's a great opportunity, and my legacy, to be a part of this co-creation for the sake of all those touched by this terrible disease.

Andy Tudor, diagnosed with a meningioma

A warm welcome from the Strategy Steering Group to this bold leap forward for people affected by brain tumours. We're excited to introduce The Brain Tumour Charity's seven-year strategy for change, created by us and for us: the brain tumour community.

We're a diverse group of 45 people from across the community who were invited by The Charity to come together and share what matters most to us. These discussions formed the three core commitments of this brave blueprint for a better future: the need to accelerate cures for all brain tumours, to drive the best lifelong care and to raise our global voices for change.

We began this co-creation process by sharing our reality of a brain tumour diagnosis and what problems we urgently need to solve. We heard from over 1,200 voices in the community, identified the key issues and looked for radical solutions. And now it's up to all of us, and The Brain Tumour Charity, to take these solutions forward together.

Why this strategy, and why now? Because people affected by this disease urgently need cures, as well as longer and better lives today. Brain tumours still kill more children and young adults than any other cancer. And they reduce life expectancy by far more than any other cancer or significant disease. Until recently, survival rates and treatments had barely improved for a generation, but that's now changing, with research funding tripling in the last decade! It's crucial that, together, we not only sustain but accelerate this progress.

This strategy sets out a vision, goals and commitments that we must drive forward as a collaborative ecosystem, not just in the UK but globally. It's a transformative step change in taking on brain tumours, laser-focused to create the most impact. And above all, it stands as a community mandate for striding forward towards our shared vision of accelerating cures for all brain tumours and living longer and better.

Thank you, **The Strategy Steering Committee** 



# THE COMMUNITY'S MANDATE FOR CHANGE

Over 1,200 voices weighed in on what really matters when you're diagnosed with a brain tumour. This is the community's mandate for change, which forms the lynchpin of our strategy.



## "Brain tumours feel like the forgotten cancer."

Stephen Lee, member of the Strategy Steering Group

The stark fact is that brain tumour treatments have barely changed for decades, and most come with a heavy cost to quality of life. We urgently need new and improved treatments for all types of brain tumours, with early access to those treatments where appropriate.

# FEEL MORE HOPE AND LESS FEAR

"No one is saying that having a brain tumour diagnosis is easy, but it certainly feels easier with positivity around you."

Rebecca Taylor, member of the Strategy Steering Group

A brain tumour diagnosis is a step into the unknown, a truly frightening and unsettling time. Finding ways to manage this transition with more hope and less fear is central to being able to cope. We must shift perspective, develop positive mindsets as best we can, improve our resilience and embrace hope.

# COLLABORATE TO ACCELERATE CHANGE

"By speaking with a unified voice, greater progress could be made."

We're stronger together. Charities and organisations driving change must build on existing collaborations and be globally connected. We must ensure we seize opportunities to unite within and beyond the brain tumour sector to maximise impact for everyone affected.

# BE DIAGNOSED PROMPTLY, WITH THE BEST CARE FOR LIFE

"Lengthy and slow diagnosis doesn't just limit time to treatment – it has a huge impact on mental health."

Diagnosis varies hugely, particularly how long it takes and how it's done. Once diagnosed, there's wide variation in care between centres and countries. We need prompt diagnosis and fast access to the best holistic treatment and support for life, based on a best standard.



# MAKE CHOICES ABOUT WHAT MATTERS TO US

"I had a thousand questions
I wanted answered after my
diagnosis and before my surgery."
Kate Dooley, member of the Strategy
Working Group

We're all different and everyone's experience of a brain tumour is unique. We want to be able to explore options and make choices about what matters to us. That means we need collated, trusted information and signposting so we feel more in control of our situation and can make informed decisions.

# FEEL CONNECTED AND POWERFUL

"Greater awareness of the impact of brain tumours in the community as a whole would be highly desirable." Neil Munn, member of the Strategy Working Group

Having a brain tumour or being a carer is a very isolating experience. Most of the public aren't well informed about this often 'invisible' disease. We need to feel connected and heard, to belong to a wider, powerful community standing together, supporting each other and speaking out to make a difference.

# BE PEOPLE NOT JUST PATIENTS

"There's more work to be done looking at the whole patient and how a brain tumour impacts them physically and mentally."

Anya Jones, member of the Strategy Working Group

We're perceived as patients from the moment of diagnosis. The focus is on treating the tumour, but this sometimes overlooks the person, their life and their needs across many different areas. We need to be listened to and heard as the people we are, not just seen as patients with little voice - or choice.



### OUR STRATEGY

### **WELCOME FROM** THE BRAIN TUMOUR CHARITY

This past year has been rewarding, challenging and hugely enriching as we've come together with the brain tumour community to co-create this strategy.

Living Longer and Better is a bold step forward in ambition and collaboration, and that boldness comes from the strength and power in the community. It's their experiences that underpin this strategy and their voices that are steering our future.

When you bring such a powerful community together, incredible things can happen. And our co-creation has resulted in a blueprint for radical change - one we simply could not have generated alone! Built around three core commitments - accelerating cures for all brain tumours, driving the best lifelong care and raising our global voices - we know this blueprint gives us the best chance of reaching our shared vision.

The overarching themes of this strategy are collaboration and going global. We recognise and embrace that we're part of a global ecosystem of people and organisations united by a common purpose. We haven't created this strategy alone and we're not going to deliver it alone - we must work together, even across borders, and go further, faster to achieve our goals.

As experts in funding world-class research, driving the best lifelong care and raising awareness of brain tumours, we, The Charity, commit and look forward to working alongside all of you, together striding forward towards cures for all brain tumours and a world where people diagnosed can live longer and better.

We've learnt so much from, and are deeply grateful to, the Strategy Steering Committee for this gift you have given, and particularly the Working Group: you've given so much of your time and expertise to create the work this strategy depends on.

Now that we've experienced the power of co-creation, and how dynamic and courageous it makes us, we're resolved to collaborate in everything we do. And we invite you to please join us in any way that suits you - become a voice for change, apply for a research grant, volunteer, raise funds, download our BRIAN app... There are lots more ways to get involved.

Visit thebraintumourcharity.org/getinvolved to find out more, and contact involvement@thebraintumourcharity.org to give feedback on our plans.

Thank you, **Graham Norton** Interim CEO The Brain Tumour Charity

1 MILLION people globally and 88,000 PEOPLE in the UK are living

of people survive brain

- Global burden of Disease, accessed 2023: https://vizhub.healthdata.org/gbd-results/ (global data for those with slow growing tumours is not available but will be multiples higher) The Brain Tumour Charity prevalence estimate (2020) based on published survival rates and incidence from cancer registry data for England, Northern Ireland, Wales and Scotland. Details of
- Global burden of Disease, accessed 2023: https://vizhub.healthdata.org/gbd-results/ (global data for those with slow growing tumours is not available but will be multiples higher). Cancer Research UK Statistics, accessed 2023; https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/brain-other-cns-and-intracranial-tumour



# OUR INTERNATION

Our vision is for people diagnosed with a brain tumour to live longer and better lives.

We'll achieve this by accelerating cures for all brain tumours, driving the best lifelong care and raising our global voices.





### **LIVE LONGER**

Our goal is to double survival by 2030.

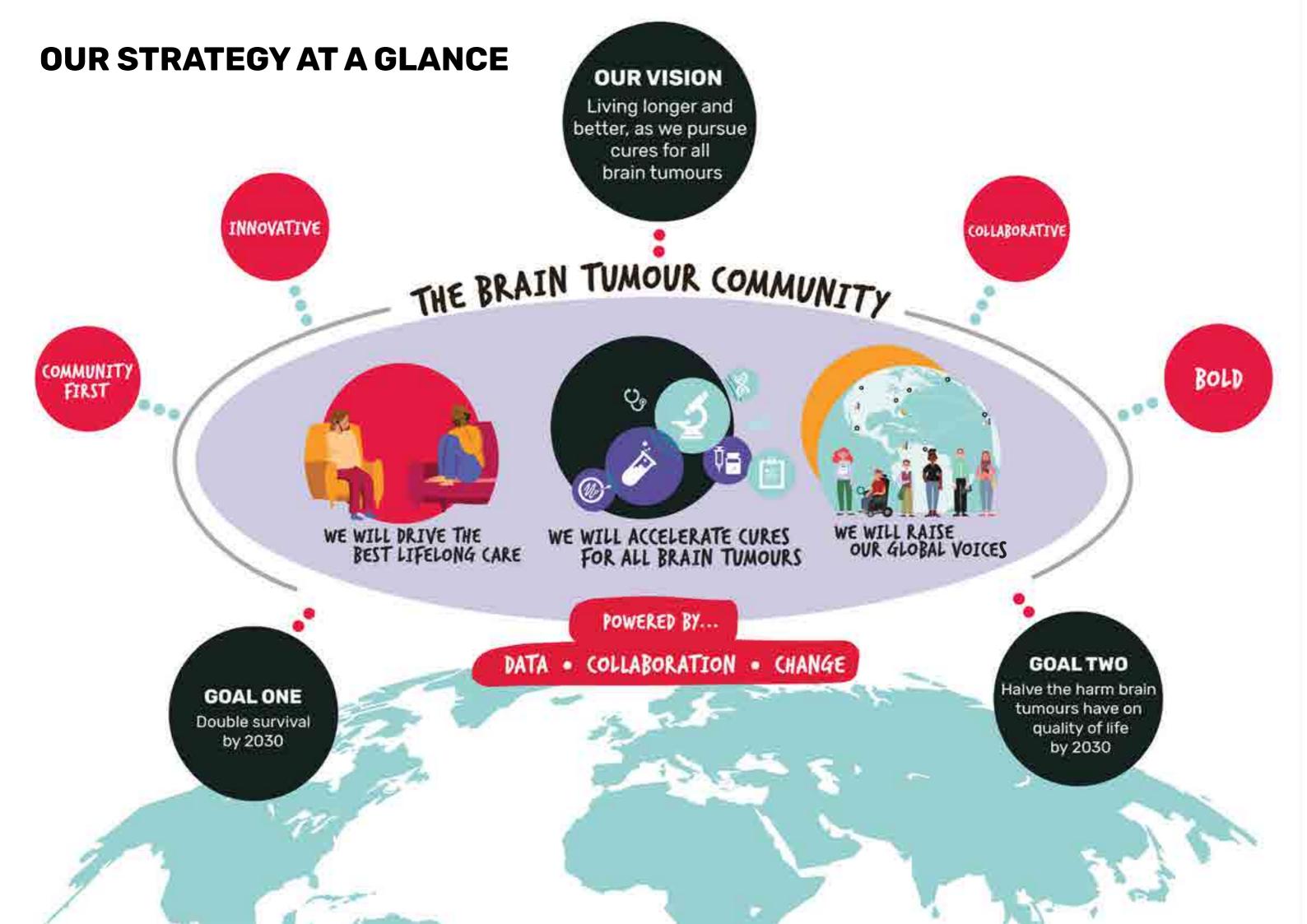
For people with fast-growing tumours, our aim is to halve the average years of life lost to a brain tumour from 27.3 years (2015) to 13.6 years by 2030. We'll use one-year survival rates as an early indicator of our progress. For people with slow-growing tumours, we aim to determine a benchmark and baseline it, then double survival by 2030.

Ultimately, as a research-led charity, we aim to find cures for all brain tumours so that no one's life expectancy is dictated by their tumour.

### **LIVE BETTER**

Our goal is to halve the harm that brain tumours have on quality of life by 2030.

For people with both fast and slow-growing tumours, their families and carers, we aim to select and baseline a quality of life measure with user groups and clinicians in 2023.



### OUR CORE COMMITMENT:

# WE WILL ACCELERATE CURES FOR ALL BRAIN TUMOURS

Research is our highest priority, because it's research that will propel the most powerful change for everyone diagnosed with a brain tumour – now and in the future. We'll continue to focus our funding on areas that will have the biggest impact for the brain tumour community, collaborating across borders and disciplines.

### We will create new knowledge

We'll further knowledge and understanding of how brain tumours develop, grow and behave, empowering us to discover better ways of detecting and treating them.

### We'll do this by continuing to invest in the best research that helps us understand:

- the developmental origins of brain tumours
- where treatments are weak or fail
- the role of the tumour microenvironment
- the reasons behind resistance to treatments.

Target: Publish at least 400 new publications, research tools and databases by 2030.



### We will accelerate new treatments

We'll accelerate new treatments by ensuring promising scientific breakthroughs are translated into benefits for people with brain tumours.

### We'll do this by establishing:

- a new Translational Award
- a Translational Advisory Board
- an innovative Virtual Biotech to fast-track the development of new treatments.

### We will also continue to:

- support interventional clinical trials
- accelerate trials with complex and innovative designs.

Target: Develop at least two new treatments from the Virtual Biotech for evaluation in clinical trials by 2030.

### We will enhance quality of life

We'll ensure evidence-based interventions that enhance quality of life are implemented into standard of care.

### We'll do this by:

- assessing and championing the most effective ways to sustain quality of life
- working with others, including the Tessa Jowell Brain Cancer Mission, to identify areas
  of best practice in care and emerging interventions, and fund the research needed to
  validate them across the network of neuro-oncology centres.

Target: By 2030, provide the research evidence to validate a lifelong quality of life standard, so every person diagnosed can live well for as long as possible.

There's not nearly enough funding into research for this deadly disease – too many people are losing their lives. Many children receive chemotherapy drugs developed over 50 years ago, which have devastating side effects.

Hayley Conroy, Trustee of The Brain Tumour Charity

### OUR CORE COMMITMENT: WE WILL ACCELERATE CURES FOR ALL BRAIN TUMOURS

### We will build a solid base for our research

We'll reach our objectives faster by improving underlying research capability and efficiency.

### We'll do this by;

- investing in people continuing to fund exceptional researchers across the globe, including supporting the careers of early-career researchers, attracting and retaining the most talented people to the field of neuro-oncology
- collaborating for a cure continuing to encourage collaborations across borders and disciplines to optimise the research environment
- harnessing the power of data ensuring that data from people with brain tumours is used responsibly to generate insights for improving survival and quality of life, including developing BRIAN, our pioneering databank and app.



Our studies will help to accelerate a future where treatments can eradicate cancer cells in every part of the tumour and provide the long-term survival patients desperately need.

Dr Ola Rominiyi, one of our research Future Leaders (2023)

# MEASURES OF SUCCESS BY 2030

- **UK:** Attract £200 million of funding for research (£50 million directly invested by The Brain Tumour Charity and an additional £150 million attracted from others).
- **Global:** The key global funders of brain tumours are connected, sharing information and starting to collaborate over the levels and types of research funding.



### HOW WE'RE MAKING A DIFFERENCE TOGETHER...

The Everest Centre is a groundbreaking international research collaboration to propel our understanding and improve treatment of childhood brain tumours. Just one of the exciting achievements so far has been collaborating to provide a clinical trial drug.

Find out more here.

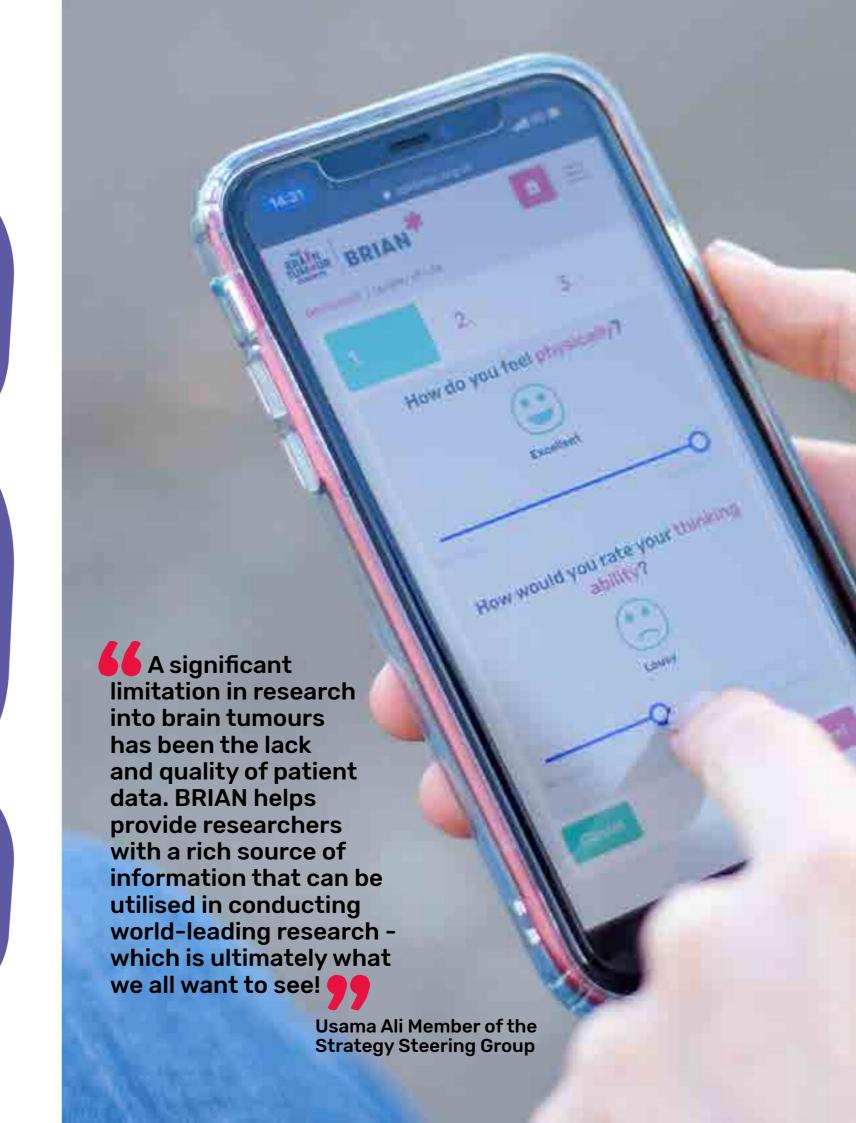
### WHAT IS BRIAN?

BRIAN is our app that helps people cope with a brain tumour, while also collecting and sharing data responsibly with researchers to accelerate a cure and clinicians to deliver better lifelong care. In the next few years, we'll evolve BRIAN to collect fully-connected data for research, supercharge its ability to generate insights through AI partnerships, and attract and fund a wider range of researchers in academia and industry to use BRIAN to propel progress towards a cure.

Find out more here.

### WHAT IS VIRTUAL BIOTECH?

This model relies on partnerships with other organisations who provide research capabilities and additional funding to speed up the translation of the most promising discoveries into new treatments. It means we can leverage already existing infrastructure rather than establishing a large team of scientists and expensive labs for this effort.



### OUR CORE COMMITMENT:

# WE WILL DRIVE THE BEST LIFELONG CARE

We will ensure equal access to lifelong, world-class, holistic treatment and support according to the individual needs and choices of people affected by brain tumours.

### We will wrap support around everyone

From the moment people are diagnosed with a brain tumour, they'll join a supportive community that wraps around them with information and support at the right time and in the right way, based on what matters most to them.

### We'll do this by:

- reaching everyone affected by a brain tumour with a network of support. This will include making services accessible for everyone, connecting people to global digital support by leveraging a network of partners and digital solutions, and scoping an open source community knowledge base
- growing and improving support in a collaborative, scalable and sustainable way, expanding and enriching peer support, digital support including developing BRIAN, one on-one and specialised support including counselling, palliative and end of life support
- reaching people earlier in their journey by being there for them from before diagnosis, helping them get diagnosed earlier and embedding ourselves into treatment pathways, centres and neuroscience teams.

Target: Work collaboratively to ensure every UK household affected by a diagnosis each year is offered specific and significant support for brain tumours. Grow our own support by 10% a year (nearly doubled by 2030), with 85%+ helped significantly.





### We will set the standard for wraparound care

We'll set a standard of excellence for the whole journey, not just active treatment - including rehabilitation, palliative care and ongoing support. We won't just focus on the health outcomes of the person diagnosed but their wider quality of life and that of everyone affected, including families and carers.

### We'll do this by:

- developing a Wraparound Care Standard that's used across UK centres and services to ensure the best lifelong quality of life, sharing it with everyone in the community to help them make informed choices and access the best care
- partnering with others in the UK, principally Tessa Jowell Centres of Excellence, and internationally to identify and share best practice in a Global Best Care Network
- measuring UK performance against the Wraparound Care Standard on a national and local centre level and for all the different groups of people affected
- capturing quality of life and using it to improve pathways.

Target: Ensure the Wraparound Care Standard - delivering lifelong quality of life - is in place for the UK by 2030, with input from global leaders in brain tumour care.

### We will fill the gaps in wraparound care

We'll collaborate across the UK and globally to continuously improve the best standard of care, collecting and sharing evidence and expertise to close gaps and make care for brain tumours the gold standard for all cancers and life-limiting conditions.

### We'll do this by:

- developing and delivering solutions that directly address gaps and release expert resource to focus on specialist care - such as BRIAN, the HNA (Holistic Needs Assessment) tool, clinic volunteers and a CNS (Clinical Nurse Specialist) hotline
- sharing and funding best practice so it spreads more easily from centre to centre and is recognised and supported by Trusts and commissioners
- campaigning to drive change in policy and practice, uniting with those affected, experts and partners to address key gaps, as well as improve brain tumour diagnosis, treatment and care in the NHS.

Target: Work together to eliminate unwarranted differences in care between UK treatment centres using the Improving Brain Tumour Care surveys and reduce UK-wide care gaps by at least half by 2030.

Impacts on daily life are huge but it feels like unless it's a life or death situation, you're not important.

### OUR CORE COMMITMENT: WE WILL DRIVE THE BEST LIFELONG CARE

Knowing that my responses can help others make positive, informed decisions about their treatment and care is absolutely fantastic.

Emma, a young adult diagnosed with a brain tumour, on our Improving Brain Tumour Care Surveys

I love that the counselling service is specific to people affected by brain tumours. The experiences of this illness can be very unique and having a counsellor that understood this was incredibly helpful.

Feedback from our pilot counselling service

# MEASURES OF SUCCESS BY 2030

- **UK:** Every person newly diagnosed with a brain tumour in the UK is signposted to support and they all access the best Wraparound Care from all UK treatment centres.
- Global: Connect a Global Best Care Network community sharing an understanding of what best care looks like in major countries (US, Canada, Australia) and where the largest gaps exist.



### WHAT'S AN HNA?

An HNA is a holistic needs assessment – an assessment of all a person's needs and how they might be met. Only 21% of people get a good HNA and a resulting personalised care plan – this must improve. So we're developing an HNA tool in BRIAN to help address this gap.

### ACCELERATING CHANGE IN CARE

Our Improving Brain Tumour Care Surveys are the biggest survey of brain tumour care in the UK. It's showing us where the gaps are against our National Brain Tumour Standard of Care and enabling us to feed into the assessment of Tessa Jowell Centres of Excellence. We plan to renew the survey to reflect the more ambitious Wraparound Care Standard.

Find out more here

### GROWING OUR COUNSELLING SERVICE

91% of people say their brain tumour has affected their emotional or mental health. We launched our free counselling service to help fill the big gap in emotional support for people affected by a brain tumour – and we plan to grow the service to help over 1,000 people by 2024/5.

Find out more here



### OUR CORE COMMITMENT:

### WE WILL RAISE OUR GLOBAL VOICES

We'll raise our global voices, connecting and collaborating in the UK and abroad to amplify awareness of brain tumours, be activists for progress and generate the resources and income we need to power change!

### We will build the community

We'll grow and strengthen the community, uniting with each other, welcoming and including everyone, raising awareness of the cause and empowering people with the resources, evidence and insight to drive change.

### We'll do this by:

- turning up the volume raising our voices to spread awareness of brain tumours, bringing together all those who share our aims and reaching out to everyone in need or who can accelerate progress, so we can stand together to build powerful momentum
- diversifying our voices proactively seeking out and listening to all voices, including those underrepresented or unheard, experts by experience and those in other sectors who can accelerate change
- strengthening our voices developing, agreeing and sharing accessible data insights with the community and other charities around funding, diagnosis, survival, experience and quality of life.

Target: Grow our active community by 50% globally by 2030.

### We will grow our resources

Our resources are a vital springboard for everything we do. To grow them, we'll build on existing momentum, raise awareness and attract new and diverse resource and funding opportunities. We'll use our entire network and reach wider audiences.

### We'll do this by:

- relentlessly raising resources and funds to power change giving people and organisations opportunities to support us that suit them, inspiring and motivating them, and always innovating, testing and learning
- uniting the community collaborating with people, charities and organisations in the UK and globally, standing as one voice in order to achieve more
- thinking differently being continuously creative, taking on the best ideas and innovations, and constantly adapting, improving, working smartly and doing more with less.

Target: Raise at least £25 million a year by 2030.

It's important to me that, by sharing my own knowledge and experiences, I can help accelerate positive change in how people affected by brain tumours are diagnosed, supported and cured.

Nicola Clark, one of our Involvement Champions

Brain tumours need to be more widely known about. People with these tumours disappear into the background because they cannot be seen.

Baljit Ahluwalia, member of the Strategy Steering Group

### OUR CORE COMMITMENT: WE WILL RAISE OUR GLOBAL VOICES

### We will drive earlier, faster diagnosis

We'll raise awareness of the signs and symptoms of brain tumours to push forward earlier and faster diagnosis, helping to reduce the impact of a brain tumour. We'll do more research into the evidence behind earlier diagnosis.

### We'll do this by:

- spreading awareness of the signs and symptoms of brain tumours far and wide through long-term, sustained awareness campaigns, going global once success is proven
- developing our campaigns to target difficult-to-reach and adversely affected groups
- exploring the impact of earlier, faster diagnosis through research and evidence-gathering.

Target: Increase the number of people who can name at least one symptom of a brain tumour from 28% to 75% and expand our Better Safe Than Tumour Campaign internationally by 2030.

### We will advocate for change

We'll campaign and influence to improve care together, developing evidence-led policy solutions to the issues that matter the most to us and which will have the most impact.

### We'll do this by:

- working with experts and voices from across the community, using the best evidence,
   expertise and data to develop robust policy solutions and recommendations for change
- ensuring people affected are at the heart of our campaigning, supporting them and empowering their voices for change, developing easily usable and shareable campaign materials and using innovative tactics to ensure we're heard by decision makers in all four devolved nations
- uniting with other charities and organisations where we can be heard better by standing as one voice
- building our profile in the media, driving our cause up the agenda and work with people affected, including passionate high-profile supporters, to raise awareness of brain tumours and our work.

Target: Lead and collaborate on policy changes to improve research and care for those affected by brain tumours and drive actions by campaigners in 85% of parliamentary constituencies in the UK by 2030.

# MEASURE OF SUCCESS BY 2030

Build an active and engaged international community to increase our income and resources and develop a worldwide network of collaborators to spread awareness of brain tumours



### OUR CORE COMMITMENT: WE WILL RAISE OUR GLOBAL VOICES

I wanted to become a Young Ambassador to help ensure that all young people affected by brain tumours can go on to achieve their personal best, and to feel fully supported while doing so.

Rebecca, one of our Young Ambassadors

### GIVING THEIR TIME TO CHANGE LIVES

Our incredible Involvement Network is a group of volunteers who use their experiences of brain tumours to drive our work – we have over 1,000 people in the Network who have enriched dozens of projects.

Find out more here.

### WHO ARE OUR YOUNG AMBASSADORS?

Our 23 Young Ambassadors are passionate about changing the future for those affected by brain tumours. They get involved in everything from speaking at Parliament and championing our early diagnosis campaigns to hosting podcasts and supporting people at events or in our online support groups!

Find out more here.

### BETTER SAFE THAN TUMOUR

We launched our huge new signs and symptoms campaign, Better Safe Than Tumour, in 2022. So far, the campaign's reached over 13.5 million people on social media, with 90,000 clicks. An amazing 3,600 people have used the symptom checker, 5 million watched our video and 2 million listened in on Heart Radio!

Find out more here.

### STRIDING TOWARDS A CURE!

The Twilight Walk, our inspiring flagship event, sees the community come together to walk 10km, raise funds and awareness, and stride in solidarity with loved ones and others affected. In the last nine years, it's raised an extraordinary £2.8 million and united over 10,000 people in pursuit of a better future.



### ENABLING COMMITMENTS:

### **OUR SUCCESS WILL BE...**

### POWERED BY COLLABORATION

We'll use the power of collaboration as a springboard for change, seeking to become part of a globally connected network.

We'll do this by:

- collaborating in all we do, joining together with other charities, organisations and individuals to maximise impact and reach our goals, at all times being led by the community
- leaving no voice unheard, being inclusive, and welcoming diverse voices, including having a representative championing diversity and inclusivity in each of our collaborative networks.

Target: Ensure sustainable networks are in place, supporting each of the three commitments, with successful delivery of UK and international collaboration projects by 2030.

### THE POWER OF CO-CREATION...

The strategy you're now reading shows the power of collaboration to drive progress – it was formed by and for the brain tumour community, and we hope some of the early benefits and pilots springing from the discussions we've had are demonstrating the power of collaboration to others, too!

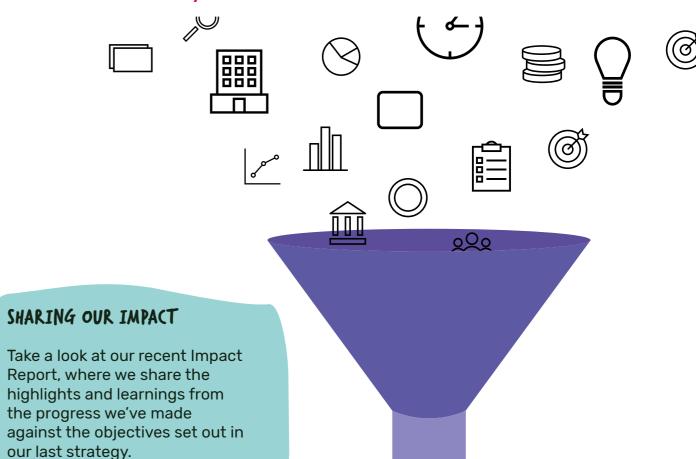
### POWERED BY DATA

We'll use and share data responsibly to accelerate discoveries and create insights that inform, empower choice, tackle inequality and drive change.

We'll do this by:

- developing BRIAN, our app and databank, promoting it as an invaluable support tool
  from the point of diagnosis as well as supercharging its capabilities and benefits for
  people affected, researchers, policy makers, clinicians and healthcare professionals
- being evidence- and data-driven in all we do, focusing primarily on the needs and wishes of people affected, to drive research discoveries, tackle inequalities and take action to meet needs and close gaps in care
- developing our knowledge base by gathering and sharing knowledge from reputable sources such as BRIAN, our Improving Brain Tumour Care Surveys, experts by experience, research publications and health service and government sources
- celebrating our progress together, using data to measure and celebrate the progress we've made against the commitments in this strategy.

Target: Grow use of trusted collective data to help individuals to make their own personal decisions and to enable and accelerate initiatives in each of the three commitments by 2030.



### POWERED FOR CHANGE

We'll organise ourselves to be powered for change, with the people, skills, technology and operations necessary to deliver our commitments and maximise impact.

We'll do this by being...

- powered by people recruiting, developing and retaining the best people who reflect the community, share our values, are inspired by our vision and can be agile in the pursuit of our goals
- skilled for the future bringing people with a growth and global mindset into the team, supporting our team to continually develop the skills needed to accelerate towards our goals and responding nimbly as new skills and training are needed
- technology-enabled investing in future-proofed, scalable and efficient technology, enabling us to connect and collaborate more effectively, be more productive, reduce costs and solve problems
- networks of teams working in an agile and collaborative way, delivering projects as empowered networks of teams, blending voices for change into all that we do and linking to global networks where appropriate
- a future-ready organisation building an organisation that's adaptable, responsive (and responsible), and future-ready.

Target: Nurture an adaptive, efficient, effective and socially responsible organisation delivering this strategy, with a minimum of 80% of its expenditure on the Charitable Objectives over the period of the strategy.



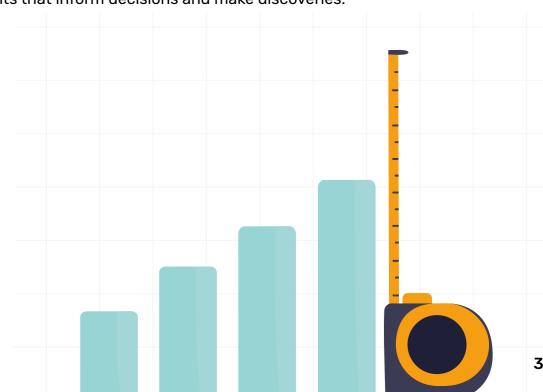
### OUR CHARITY CHAMPIONS

We established four champion groups to help us build connections, gain new skills and create a better eco-system at The Charity – these are our Equality, Diversity and Inclusion (EDI) Champions, Sustainability Champions, Culture Champions and Everymind At Work Champions.

# HOW WILL WE MEASURE OUR PROGRESS?

The commitments you've just read will drive the following outcomes, and it's these outcomes we'll use to measure the progress we're making towards our goals.

- Sufficient, sustained resources Research into brain tumour treatment and care gets
  the sustainable funding and resources it deserves, given the burden on society, adults
  and children.
- New treatments and services New treatments, products and services that improve survival and/or quality of life for all brain tumours.
- Best lifelong treatment and support Those affected get the best holistic treatment and support for us as people, not just patients, to support survival and quality of life for their lifetimes.
- High awareness of brain tumours Raised awareness of the impact of brain tumours across the community, including signs and symptoms to drive early and fast diagnosis.
- **Positive mindset and control** Positive mindset and control to cope with the impact of a brain tumour diagnosis, helped by the support and information received.
- Supportive, connected community Everyone diagnosed or in treatment, who wishes
  to, feels connected, supported by others in the community and empowered to make
  a difference.
- Collaborative, global networks for change Globally connected networks that drive change through collaborations of mutual interest, saving resources and making more impact by acting as one.
- Shared data to drive impact A real-time brain tumour knowledge base for sharing data and insights that inform decisions and make discoveries.





# THE WAY THE CHARITY WORKS OUR CHARITY VALUES ARE...

### COMMUNITY FIRST

We put the community's needs first, ensuring our work is informed by those with experience and that they are the driving force behind our decisions. We include everyone, amplifying their voices and uniting in our shared purpose to create change.

### COLLABORATIVE

We know that we're stronger together, so we choose to lean on each other, share openly and utilise expertise and knowledge wherever it exists. We seek out and support diverse perspectives, operate without ego and are part of a connected eco-system that everyone can join.

### BOLD

We are unapologetically ambitious and true to ourselves. We'll be brave and think bigger – as there's just no time to waste. We'll be confident and relentless in challenging the status quo, even when that means making difficult decisions. We're determined, focused and unstoppable.

### INNOVATIVE

We are creative and adopt a growth mindset, always using our experience and imaginations to find smarter and more effective ways to propel progress. We're not afraid to think differently, find new ways to solve problems and be agile in 'testing and learning', so we can move at pace in pursuit of our vision.

# WHO ARE THE STRATEGY STEERING GROUP?

We're incredibly grateful to the Steering Group who joined us to co-create this strategy. Those highlighted are also in the Working Group.

# OTHER BRAIN TUMOUR CHARITY/NON-PROFIT

David Aarons
Ashley Bailey
Courtney Davies
Ralph Devito
Sue Farrington-Smith
Will Jones
Tina Mitchell-Skinner
Gordon Oliver
Kathy Oliver

### PERSONALLY AFFECTED

Baljit Ahluwalia Usama Ali

Phil Askham

Katie Bushby

Nicola Clark Laura Colantoni Heather Dearie

Kate Dooley

Donald Innes
Alex Johnasen

Anya Jones

Sacha Langton-Gilks Linda Lawton Stephen Lee

Neil Munn

Victoria Neill Ben Pullen

Sarah Pullen

Rebecca Taylor

Katie Tillson Andy Tudor

### RESEARCHER, CLINICIAN, SURGEON OR OTHER HEALTH CARE PROFESSIONAL

Keyoumars Ashkan Sigourney Bonner Paul Brennan Anthony Byrne Susan Chang Richard Gilbertson Denise Sheer Colin Watts

# THE BRAIN TUMOUR CHARITY TEAM

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# THANK YOU

# TO THE CHARITIES WHO SUPPORTED THE DEVELOPMENT OF THIS STRATEGY

A number of charities have generously supported our strategy work by participating in the Steering Group. We'd like to say thank you and acknowledge their vital roles in the collaborative ecosystem working to build a better future for people affected by brain tumours.

### The American Brain Tumor Association ABTA abta.org

The ABTA, a US-based charity, aims to advance the understanding and treatment of brain tumors with the goals of improving, extending and, ultimately, saving the lives of those impacted by a brain tumor diagnosis. They do this through interactions and engagements with brain tumor patients and their families, collaborations with allied groups and organizations, and the funding of brain tumor research.

### **brainstrust** brainstrust.org.uk

brainstrust provides personalised brain tumour support to help people live the best life possible with a brain tumour. They work with people to eliminate isolation, improve knowledge and understanding, and overcome fear to engage with challenges and care. Key aspects of their work include coaching and support, building communities, information and education, delivering regional insight and relevance, clinical engagement, and involving people in research.

### Brain Tumour Research braintumourresearch.org

Brain Tumour Research aim to increase the UK investment in brain tumour research. They're the only national charity in the UK focused on finding a cure for all types of brain tumours through campaigning to increase the national investment in brain tumour research to £35 million per year, while fundraising to create a network of seven sustainable Brain Tumour Research Centres of Excellence across the UK.

### **Brain Tumour Support** braintumoursupport.co.uk

Brain Tumour Support offers emotional and practical support for anyone affected by any type or grade of brain tumour. The free service is personally tailored to needs, with a deep understanding of the complex impact on life that a brain tumour has. Integral in-house services include specialist counselling and expert finance and welfare benefits guidance. The service provides a consistent point of contact for patients and their loved ones, with help at any stage and for as long as support is needed.

### The International Brain Tumour Alliance IBTA theibta.org

As a unique global network, the IBTA advocates for the best treatments, information, support and quality of life for brain tumour patients offering them, their families and caregivers hope – wherever they live in the world. By facilitating collaboration within the global neuro-oncology community and building bridges with all stakeholder groups, the IBTA provides a strong, collective voice across the world, encouraging the establishment of brain tumour organisations in countries where they don't yet exist, championing patients' rights and focusing on healthcare policy and inequalities.

### National Brain Tumor Society braintumor.org

The National Brain Tumor Society (NBTS), a US-based charity, unrelentingly invests in, mobilizes, and unites the brain tumor community to discover a cure, deliver effective treatments, and advocate for patients and caregivers. They drive and influence best-in-class medical research to develop and deliver new innovative treatments and potential cures to brain tumor patients as quickly as possible. They convene, educate, and unite the brain tumor community. They fuel the voice and power of the brain tumor community to advocate and influence public policy.



