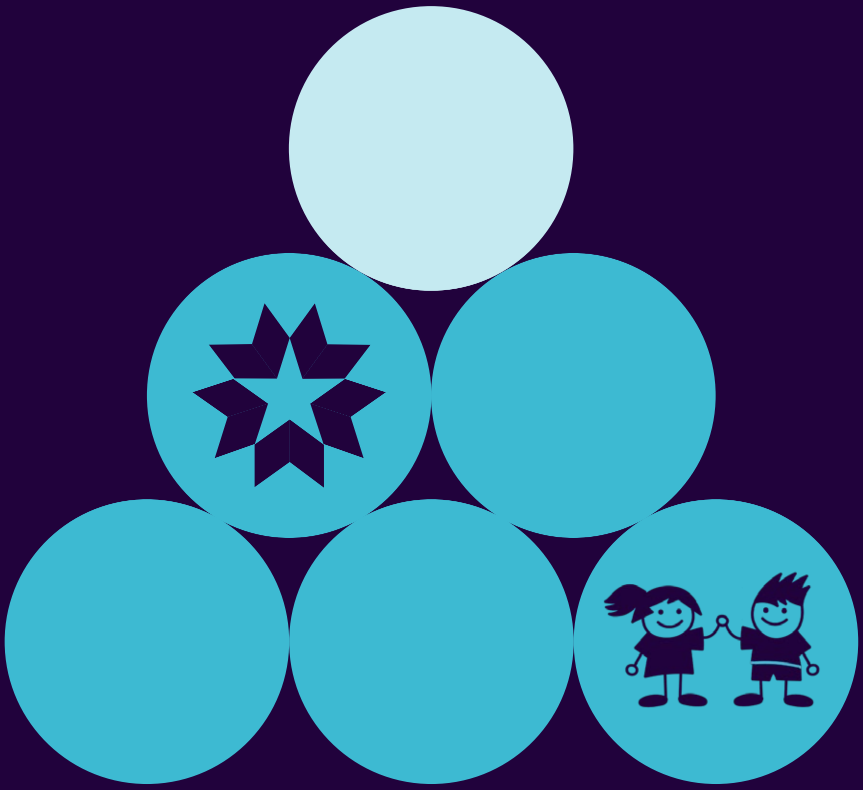
Tessa Jowell
BRAIN CANCER MISSION

Towards excellence

Building a better future for children with a brain tumour



Key findings and recommendations from the Tessa Jowell Centre of Excellence for Children Designation Programme

December 2025
Beccy Weir / Andrew Wright
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The Designation Committee members were instrumental in defining the Standards of Excellence and integral to the rigorous review process. Their expertise was essential in validating the data and contextualising the findings that underpin this report. This work would not have been possible without their dedication.

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The Mission Partners

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Forewords

Dr Stephen Lowis

Dr. Stephen Lowis

TJBCM Paediatric Programme Lead
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To care for a child with a brain tumour is difficult. Treatment is complex, changes often, and is fraught with complications. At times, the best course of action is not clear, and that uncertainty causes immense anxiety for families. There are so many professionals needed to diagnose and treat the tumour, to protect and stabilize the child and to bring him or her back to health, that often, the process is not smooth. Gaps in service become obvious, and small things can end up causing major disruption to a child and their family.

The best teams have managed to anticipate these gaps, have engaged with managers to ensure appropriate investment in the service, and make full use of the exceptional people who are in those teams. In the past three years we have found excellence in every paediatric oncology team, but some have struggled to achieve the smooth operation which matters to the patient. In time, I am confident we can help all centres to reach this goal.

For three years, I have been proud to be associated with the Tessa Jowell Brain Cancer Mission, a beacon for everyone involved in brain tumour care, a guiding light showing us all how to improve. With the many true experts in managing children with brain tumours, we have brought improvements across the country. The dedication and immense goodwill we have found in every centre reassures me that this will continue in coming years.

Louise Fox

My name is Louise Fox, and I am the proud mum of George Fox, who was just 13 years old when we tragically lost him to a Glioblastoma in April 2022. George was a bright, kind and caring boy who dreamed of becoming an architect and loved Lego, Arsenal and golden retrievers. George had a devastating 11.5 months from the first headache to losing his life, one he so desperately wanted to live to its fullest. During his illness, we encountered moments of exceptional care, but we also faced stark disparities in access—geographically and in support services. It became heartbreakingly clear: whether a child lives in London, Newcastle, or a small town or village can determine the treatment journey they receive. This is not fair. Every child deserves the best care, wherever they live.

In our grief, I found others like me—mothers who had walked the same unimaginable path. In October 2023, eight of us came together to form the Angel Mums—a group of mothers who had all lost a child to a brain tumour. Our shared motto is simple yet powerful: "From pain comes hope." We want George's life—and the lives of all our children—to mean something more. We want future families to receive timely diagnoses, world-class care, access to holistic support, and opportunities to join pioneering clinical trials.

This report, the UK's first comprehensive review of paediatric neuro-oncology services, validates our experiences. It shines a light on centres of excellence, and on unequal access that still persists. Even as it celebrates remarkable achievements, it challenges every stakeholder—government, NHS, charities, and healthcare providers—to turn these insights into action.

As Angel Mums and as supporters of the Tessa Jowell Brain Cancer Mission, we stand united in our mission: to ensure that no family endures what we endured. That no child's survival, or standard of care, depends on their postcode. Let's honour George—and all our angels—by making this roadmap to equitable, world-class care a reality.

This work gives me hope — that with enough courage, collaboration and commitment, we can transform the future for children diagnosed with brain tumours.

We owe it to George.
We owe it to every child and every family walking this path.

Lou, Matt, Jamie and Issy
Family of George Fox #Forever13

Co founder of The Angel Mums
Supporters of Tessa Jowell Brain Cancer Mission
& Tessa Jowell Foundation

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Executive summary

Why have we produced this report?

Brain tumours are the most common and lethal solid tumours affecting children, with over 400 new diagnoses every year in the UK, making up around 25% of paediatric cancers (1). Brain tumours have the lowest survival rate of all childhood cancers, surpassing leukaemia (2).

With complex treatment and lifelong impact, it is vital that every child diagnosed with a brain tumour gets access to the best care available on the NHS as close to home as possible. Yet, patient testimony suggests that treatment, care and research opportunities are not equitably available. To examine this, the Tessa Jowell Brain Cancer Mission (TJBCM) has completed the UK's first comprehensive review of paediatric neuro-oncology services, reviewing 15/17 UK centres, covering 94% of the UK population, with the aims of identifying key barriers and designing solutions to improve care standards.

This report highlights both excellence and disparities in care, and identifies key recommendations for improvement to ensure every child with a brain tumour receives world-class treatment, care, and access to research, no matter where they live.

15 centres underwent a comprehensive review of their brain tumour services and are now part of the Tessa Jowell Network, which aims to deliver excellence for all patients with a brain tumour.
This landmark review, carried out through the Tessa Jowell Centre of Excellence for Children programme (3), examined 168 distinct areas of the patient pathway through extensive data collection, interviews with each centre, and feedback from 211 patients and their families. The assessment was guided by Standards of Excellence (3) developed by 26 experts and focused on four critical aspects of the patient pathway: clinical treatment, quality-of-life care, ongoing care, and research.

The review of centres identified:

- **Six 'Tessa Jowell Centres of Excellence for Children':** these centres met or exceeded the Standards in all areas along the patient pathway and showed no major points of concern.

- **Nine 'Tessa Jowell Network Centres':** these centres met or exceeded the Standards in most areas, with a few aspects of their service facing small challenges that meant they did not yet fully meet the Standards. They deliver safe and high-quality treatment in adherence to speciality protocols and, as with all members of the Tessa Jowell Network, are committed to the programme's vision and are actively working to further develop their services.

Following extensive service developments supported by the TJBCM, in 2025 four centres (Bristol, Cambridge, Glasgow & Aberdeen, and the South London Network) reapplied and were awarded Tessa Jowell Centre of Excellence for Children status. To ensure consistent comparison across centres, the analysis in this report only includes data collected during the 2023 application round and does not capture the changes these services have subsequently made.

A data-driven roadmap, based on real patient experiences and NHS best practice, to drive equity in treatment, care and research for children and young people with a brain tumour

The review identified clear challenges in the delivery of treatment, care and research for children and young people with a brain tumour. To address these, we have set out 13 actionable recommendations to deliver more equitable services which have important implications for key stakeholders:

For UK Political and NHS Leadership

Prioritise addressing geographical inequities, ensuring:

a. no patient waits for either a formal pathological/radiological diagnosis or to start surgical/oncological treatment due to a shortage of NHS staff or equipment;
b. no geographical disparities in access to holistic, wraparound care (such as rehabilitation, palliative care and psychological support);
c. where available, every patient can be offered access to a late phase clinical trial.

A child's postcode should never determine their access to treatment, care or research. By supporting the recommendations in this report, NHS and policy leaders across the UK's nations and regions can act to ensure every patient, no matter where they live, has access to the highest standard of care the NHS has to offer.

For NHS neuro-oncology centres

Collaborate on national challenges while using data and national best practice to address individual roadblocks. Certain challenges facing neuro-oncology services require national-level solutions; UK neuro-oncology centres are well established in their networks and should use these connections to work together on developing improvements to treatments and services. Individual centres also have a powerful opportunity to drive meaningful improvement locally, and we strongly encourage all centres to use the benchmarking data collected by the TJBCM to identify and target specific areas for development.

For the charity sector

Ensure investments balance sustainability and equitable impact. Charities play an essential and vital role in supporting neuro-oncology services and research. Building on excellent models of best practice already in the field, work should be done with hospitals and charities to ensure investments balance sustainability with the need to provide funding where it will make the most difference. This should ensure equity of access to charity support, be it locally among patient groups or nationally across parts of the UK. It is also important to continue to collect evidence on the impact of charity-funded roles to support cases for key services to be funded by the NHS.

For the TJBCM

Work with partners to improve research treatment and care by sharing data, best practise and training, and offer a platform for national collaboration.
To support the efforts of the entire community to drive equity, TJBCM will work with charity partners, the UK Government and the NHS to facilitate the sharing of best practice, work with centres on individual areas for improvement and offer training and networking – building on the principle of "bringing the best to the rest". These activities will be delivered through the Tessa Jowell Academy for Paediatrics, a new national platform established to facilitate service improvement and deliver projects contributing to excellence and equity in treatment and care.

Recommendations

The review looked to answer five key questions about paediatric brain tumour services, from which we have identified key recommendations to improve services.

Can patients access appropriate, evidence-based and high-quality clinical treatment, quickly and as close to home as possible?

The community has gone to great lengths to standardise treatment for paediatric brain tumours, reflected in data showing that patients across the Tessa Jowell Network can access the same core treatments, regardless of location. However, a minority of centres face delays in diagnostic testing (including whole genome sequencing (WGS)), initiation of surgery and systemic therapy. There is significant variation in both the structure of shared care* networks and the range of services offered by individual Paediatric Oncology Shared Care Units (POSCUs) within these. This variability can sometimes limit the ability to provide the best possible care closer to home, as not all units are equipped to deliver the full spectrum of necessary services—meaning some children must travel further to access optimal treatment.

Recommendation 1
Prioritise equitable access to key diagnostic and treatment services.

Recommendation 2
Ensure timely access to molecular and genetic testing for patients across the whole of the UK.

Recommendation 3
Disseminate best practice in shared care, from the primary treatment centre to care in shared care units and the community, to help eliminate “unwarranted” variation.

Is comprehensive quality-of-life care accessible? Is it holistic, specialist and meeting the child’s needs?

Providing essential care to manage symptoms, address emotional and cognitive challenges, and facilitate rehabilitation after treatment is a priority for all clinical teams. However, resourcing is a challenge. While many centres have developed highly specialised, wraparound services in areas such as rehabilitation and psychological care, there is considerable variation in resources and staffing capacity across centres.

Recommendation 4
Establish additional national guidelines and frameworks for quality-of-life care and research, taking into consideration local service structure and geography.

Recommendation 5
Support centres in developing enhanced care for families before, during and after bereavement.

Recommendation 6
Ensure protected time and funding for neuro-oncology-specific training of nurses and allied health professionals (AHPs).

**See section 1 for further explanation of shared care.*

Is support available beyond the core boundaries of treatment, both in terms of time (late effects) and place (education)?

Ongoing support is usually available, but it is not always easily accessible. Patients face numerous challenges beyond hospital-based care, and long-term support and reintegration into education remain inconsistently accessible despite significant effort to standardise services.

Recommendation 7
Strengthen clinical and educational support for schools to ensure appropriate provisions for pupil reintegration, with adjustments in education provisions if and when long-term symptoms (“late effects”) arise to ensure continued support.

Recommendation 8
Ensure proactive, comprehensive and accessible late effects care, closing any gaps between the end of treatment and the involvement of late effects specialists.

Are there opportunities to participate in research and clinical trials?

For most, but not all, patients. While the UK is a hub of research and trials activity in paediatric brain tumours, equitable access to trial opportunities, both geographically and across all tumour types, remains a challenge. To ensure, where possible, every patient can be offered participation in a late phase trial at their nearest primary treatment centre (PTC), we recommend:

Recommendation 9
Increase the breadth of research and trials, ensuring inclusion of all tumour types, and support translation of research findings into clinical practice.

Recommendation 10
Develop the NHS workforce supporting clinical trials, with dedicated staff (including clinical academics, trial nurses, administrators and other support staff) and protected time for neuro-oncology. Ensure necessary trial assessments (e.g. neuropsychological, ophthalmology, endocrinology etc.) are appropriately funded and resourced.

Recommendation 11
Where feasible, ensure patients can access clinical trials as close to home as possible by tackling barriers that delay trials from opening across more centres.

What is the role of the charity sector?

The 111+ charities supporting children and young people with a brain tumour make a vital contribution to services and research not currently funded by the public sector. However, there are variations and challenges in accessing charitable support across the UK. Some collaborations also lack long-term sustainability, at times relying on time-limited posts to temporarily address problems rather than establishing permanent solutions.

Recommendation 12
Ensure charitable investments balance equitable impact with long-term sustainability, working closely with the NHS to safeguard key services should funding be reduced or withdrawn.

Recommendation 13
To improve equitable access to charitable support and grants, both regionally and nationally, a central directory of neuro-oncology charity services should be established.

Introduction

Every year, 420 children in the UK are diagnosed with a brain tumour. While many survive, the risk of death is higher than for other types of cancer, and for some types of brain tumour a cure is not possible. For those who are cured, many will experience severe long-term effects from both the tumour and treatment (4). Therefore, it is more important than ever to ensure that children and young people with a brain tumour are able to access the highest standard of NHS treatment and care, and that any barriers to innovative practice or research are overcome.

Children with a brain tumour in the UK are treated within the NHS systems of the four devolved nations. Despite different organisational structures and service specifications, patients should receive the same high-quality treatment, wraparound care and access to potentially outcome-changing trials no matter where they live. Anecdotal evidence and patient feedback suggest that treatment, care and research are not consistently delivered across the UK's 17 paediatric neuro-oncology centres. Understanding geographical barriers to patient care and research across the UK is key to improving national cancer outcomes. This is an increasing area of focus for health policymakers and researchers (5–7), with a particular emphasis in paediatric cancer to ensure that patients can access treatment as close to home as possible (8–10).

The TJBCM therefore set out to review activity across UK paediatric neuro-oncology centres. Building on the work done through the Centre of Excellence for Adults since 2020 **(Box 1)** and following an extensive engagement phase with the paediatric brain tumour community, in 2023 the TJBCM launched the Centre of Excellence for Children Initiative. The programme was designed to identify, recognise and support excellence in brain tumour treatment, care and research while working locally and nationally to address emerging challenges. Applications were open to all shared care networks in the UK, who together provide the entire pathway of care for children and young people with a brain tumour. 17 centres across all UK regions were eligible and 15 centres applied in the first round.

Box 1: The Tessa Jowell Brain Cancer Mission and Centre of Excellence for Adults Programme

Following Dame Tessa Jowell's moving call for action to the House of Lords in 2018 to improve brain tumour outcomes, the Tessa Jowell Brain Cancer Mission (TJBCM) was formed to design and deliver a new national strategy for brain tumours. Today, the TJBCM delivers eight transformational programmes in the areas of research, trials, training, and patients. The Mission is supported by government, charities, academics, health care professionals, patients and representatives, and receives funding from 13 key organisations: Act for Cancer, brainstrust, The Brain Tumour Charity, Brain Tumour Research, Brain Tumour Support, Brainwaves Northern Ireland, Cancer Research UK, Cancer Research Wales, Children with Cancer, Great Ormond Street Hospital Charity, Minderoo Foundation, The National Institute for Health and Care Research (NIHR), and The Tessa Jowell Foundation.

In 2020, the TJBCM launched the Tessa Jowell Centre of Excellence for Adults initiative, with the aim of recognising excellent adult neuro-oncology centres and providing targeted support to centres to improve their care and research. To date, 18 adult centres in the UK have been awarded "Tessa Jowell Centre of Excellence" status for their excellence in clinical practice, patient care and research. Furthermore, 30 centres with almost 1500 members are active on the Tessa Jowell Academy, where workshops, networks and peer-to-peer connections are offered to improve services and research.

Following the success of the adult programme, in 2023 the TJBCM launched the Centre of Excellence for Children, with the first six centres obtaining 'Excellence' status. The Academy for Paediatrics is also set to launch in 2025.

The Centre of Excellence for Children is a peer-led initiative, directed by a committee of 28 brain tumour professionals with expertise spanning surgery, oncology, nursing, allied health practice, education and play therapy, as well as patient and charity representatives. This expert committee together designed the "Standards of Excellence"(11), key requirements against which centres are assessed; these standard go beyond NHS guidelines, with a strong emphasis on research and quality-of-life. The areas of assessment can be divided into five areas **(Figure 1)**.

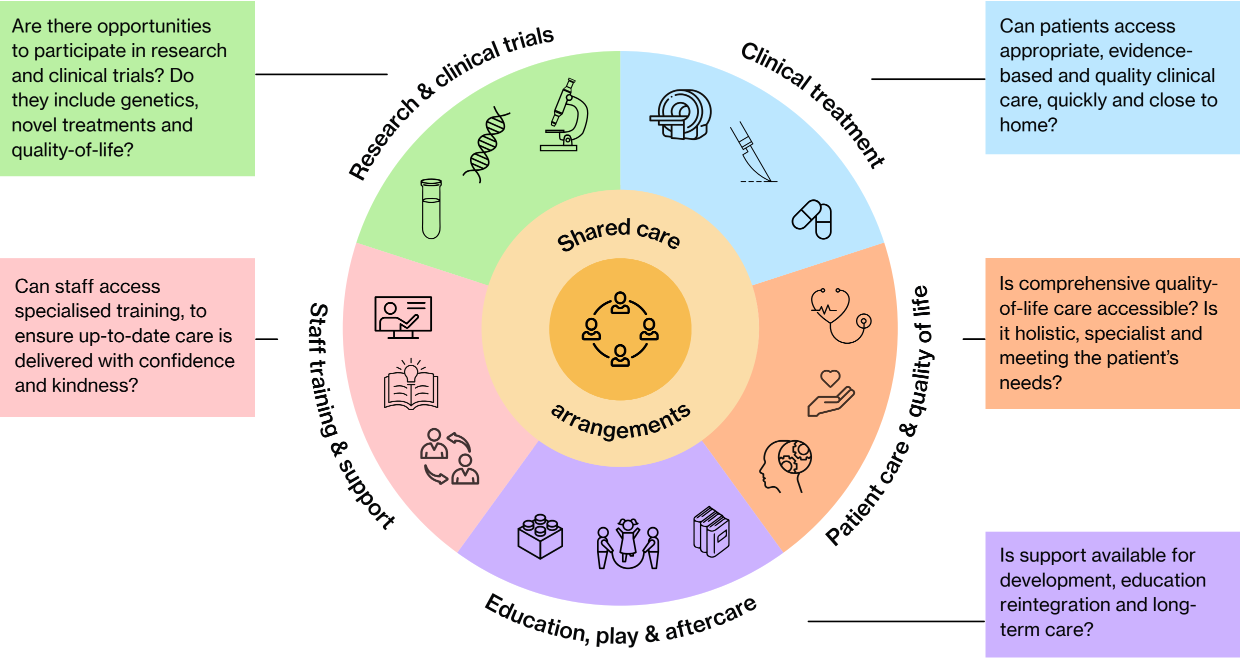
The application form for each centre comprised of three components:

1. An extensive application form covering 168 aspects of the patient pathway;
2. Patient feedback collected from 211 children and young people (and/or their family members/carers) who had been treated within a set 2-year period;
3. A 2-hour virtual site visit with each centre to discuss their strengths and areas for improvement with representatives from the committee.

The data collected as part of the Centre of Excellence for Adults programme (since 2020) and Children (since 2023) have provided insight into brain cancer treatment, care and research across the UK and have informed health service planning and policy for brain tumours, as well as the wider debate about geographical variations in care for other cancers and diseases.

This report presents an overview of the Centre of Excellence review process alongside key national insights and recommendations. In detailing our key findings, we focus on five areas that are central for the community. The report outlines the excellence and best practice present in each of these areas, as well as highlighting key challenges reported by centres.

Figure 1 : Overview of areas assessed through the Tessa Jowell Centre of Excellence for Children process, and key questions asked about the services.



Are there opportunities to participate in research and clinical trials? Do they include genetics, novel treatments and quality-of-life?

Can patients access appropriate, evidence-based and quality clinical care, quickly and close to home?

Can staff access specialised training, to ensure up-to-date care is delivered with confidence and kindness?

Is comprehensive quality-of-life care accessible? Is it holistic, specialist and meeting the patient's needs?

Is support available for development, education reintegration and long-term care?

Review process and designation outcomes

Data collection

Applications to be reviewed for Centre of Excellence for Children designation were open to all UK paediatric NHS neuro-oncology centres, defined as a hospital, or a network of hospitals, providing a complete patient pathway from diagnosis to end-of-life care for patients with brain cancer. A "centre" in the context of this report can therefore be defined as a single NHS Trust, or a group of two or more NHS Trusts that together constitute a patient pathway. For example, one Trust might provide surgical services with another Trust providing oncology care.

Data were submitted by 15 centres out of the 17 eligible to apply in July 2023, covering 94% of the UK population. Each applicant centre was sent a self-reported application form designed to review performance over 168 areas of their service, split into six sections:

1. Shared care arrangements
2. Clinical treatment
3. Patient care and quality-of-life
4. Education, therapeutic play and aftercare
5. Staff training and support
6. Brain cancer research and clinical trials

Questions were developed iteratively in close collaboration with subject specialists.

Responses from centres were reviewed by a committee of 28 experts, all NHS clinical specialists and often also leading academics in their speciality **(Figure 2)**. Committee members assumed responsibility for the section of every application relevant to their speciality (as expert reviewer), as well as individual committee members being assigned one centre to review in its entirety (as lead reviewer). Patient feedback collected through The Brain Tumour Charity's questionnaire "Improving Brain Tumour Care"(12) also fed into the overview of each centre's review. Each application was then subject to peer review by the full committee. Following the committee's peer review, feedback was sent to each centre before a virtual site visit was conducted to clarify issues raised at peer review and gain further insight into service provisions. Finally, all data were reviewed against the Standards of Excellence and calibrated (where centre scores were agreed and compared) by the committee.

Figure 2 : The review process for centres applying to the Tessa Jowell Centre of Excellence for Children programme.

Input Stage

1 Centres are invited to complete the Tessa Jowell Centre Application form

2 Patients provide feedback through the Brain Tumour Charity's BRIAN app

Analysis & Peer Review Stage

3 Centre application forms are systematically reviewed by 26 expert reviewers & TJBCM and patient feedback is also taken into account

4 Data are extracted from the forms and a large benchmarking file is generated to allow for peer comparison

5 Peer review meeting held to discuss the applications and define follow up questions

Follow-up Stage

6 Centres receive written feedback report with follow up questions for site visit

7 Virtual site visit: Applicants and reviewers discuss strengths and areas to improve

Outcome Stage

8 Final calibration meeting

9a Centres will receive written feedback report, are offered ongoing support and become of the TJ Network

9b Centres designated as "Excellent" at award ceremony invited to share their excellence with peers in the TJ Network

10 Feedback provided to national leadership on gaps in funding and areas to improve (NHS, DHSC)

Data analysis

The application form consisted of questions designed to collect both quantitative and qualitative data. Questions could be metricised, yes/no, open-ended, open-ended with request for examples, and mixed format questions which combine two or more question types.

Data were extracted from the submitted application forms and analysed in two ways:

1. **Quantitative data:** Numerical data were collected, extracted, and recorded in Microsoft Excel to allow comparisons between centres. Where centres provided a range of data rather than an exact value, or provided data from its network sites, care was taken to define a representative score e.g. weighted average. It is also noted when centres reported estimates of numerical data, rather than data collected through audits or medical management software.
2. **Qualitative data:** Descriptive data were collected and analysed thematically to identify common themes (13). For example, narratives were summarised by picking out representative examples of common themes, or strategies within an area of service provisions were modelled to display how a service is delivered.

Data presentation

The results presented in this report rely on data extracted from application forms, in cross-reference with responses from the virtual site visits. The patient feedback collected, while invaluable for the Centre of Excellence Designation Programme, is proprietary to The Brain Tumour Charity and is not discussed in detail. The data presented focuses on consistencies, areas of variation, challenges, and examples of excellence among centres and within each section of the services. Centres are anonymised throughout and are generally represented from 1-15 (or A-O) in descending or ascending value, meaning that centre 1 on one graph does not necessarily align with centre 1 on the next graph. Quantitative data are represented as n (%) except where otherwise stated, with percentages rounded to the nearest integer. Where relevant, data have been normalised. This is most often based on the patient population size each centre represents in order to more clearly and accurately compare certain elements of the services between centres. In this case, data were normalised by dividing the data point by the number of patients seen by each centre in the 12-month period of 2022 and multiplying it by the average number of patients (n=50) across all centres.

Box 2: Limitations of data collected

- **Self-reported data:** Centres may have provided overly positive responses to questions or omitted critical information. Several steps were taken to ensure accuracy of data. Virtual site visits enabled the gathering of further evidence and direct, detailed questioning, further confirming if a centre was meeting the set-out criteria. Patient feedback also ascertained whether patient experiences aligned with the services reported by centres. In general, centres were transparent and willing to discuss challenges, potential weaknesses, and areas for improvement during virtual site visits. Nevertheless, it is important to acknowledge that self-reporting with a finite number of questions may result in incomplete data and inconsistencies in results among centres. The review process did not request whistle-blower statements or incident reports.

- **Free text elements in application:** Free text elements provide an opportunity to acquire data in an unrestricted manner. However, variations may occur in the detail and content provided by centres. This may have led to perceived rather than actual differences in service delivery.

- **Many members completing the questionnaire:** Due to the diverse nature of the questionnaire, certain questions may have been completed by individuals not expert in the relevant content. These issues were addressed in the virtual site visits, where centres were provided with an opportunity to clarify areas where limited information was provided.

- **Quantitative data drawn from audits and staff estimates:** The quantitative data presented in this report were drawn from audits (either from formal audits or automatically collected by medical management software) as well as staff estimates. The latter are likely to be less accurate but were included to permit comparisons across Centres. Estimates are clearly highlighted.

- **Broad funding, reported by hospitals:** Grants reported were described by hospital staff rather than by the associated research institutions, therefore some may have been missed. There will also be research institutions who are not affiliated to a hospital that are conducted research relevant to brain tumours whose funding will not have been included in our numbers. Some grants benefiting brain cancer patients are given for non-brain cancer specific projects, and others are given across multiple institutions. This making reporting more complex.

Outcomes

Following the assessment of the 15 centres that applied to the Tessa Jowell Centre of Excellence for Children programme, six centres were awarded 'Centre of Excellence' status. The remaining nine centres were provided with recommendations on how they could develop their services to meet the Standards of Excellence in future review rounds. All 15 centres are now part of the Tessa Jowell Network **(Figure 3)**.

Network Centres: A Tessa Jowell Network Centre is a centre that is recognised for safe and good quality treatments in adherence with the speciality protocols. A Network Centre has signed up to the programme's vision of striving to provide the highest quality and equitable care and is actively working to further push up its standards of care.

Each Network Centre also demonstrates impressive pockets of excellence and offers several opportunities to participate in a clinical trial.

Centres of Excellence: The 'Excellence' status allows patients to feel confident that they are receiving the very best care in the NHS, recognising that their staff are going beyond what is normally expected. The six accredited Centres of Excellence met the high Standards of Excellence in each of the 168 assessed areas, providing high-quality care across every single service.

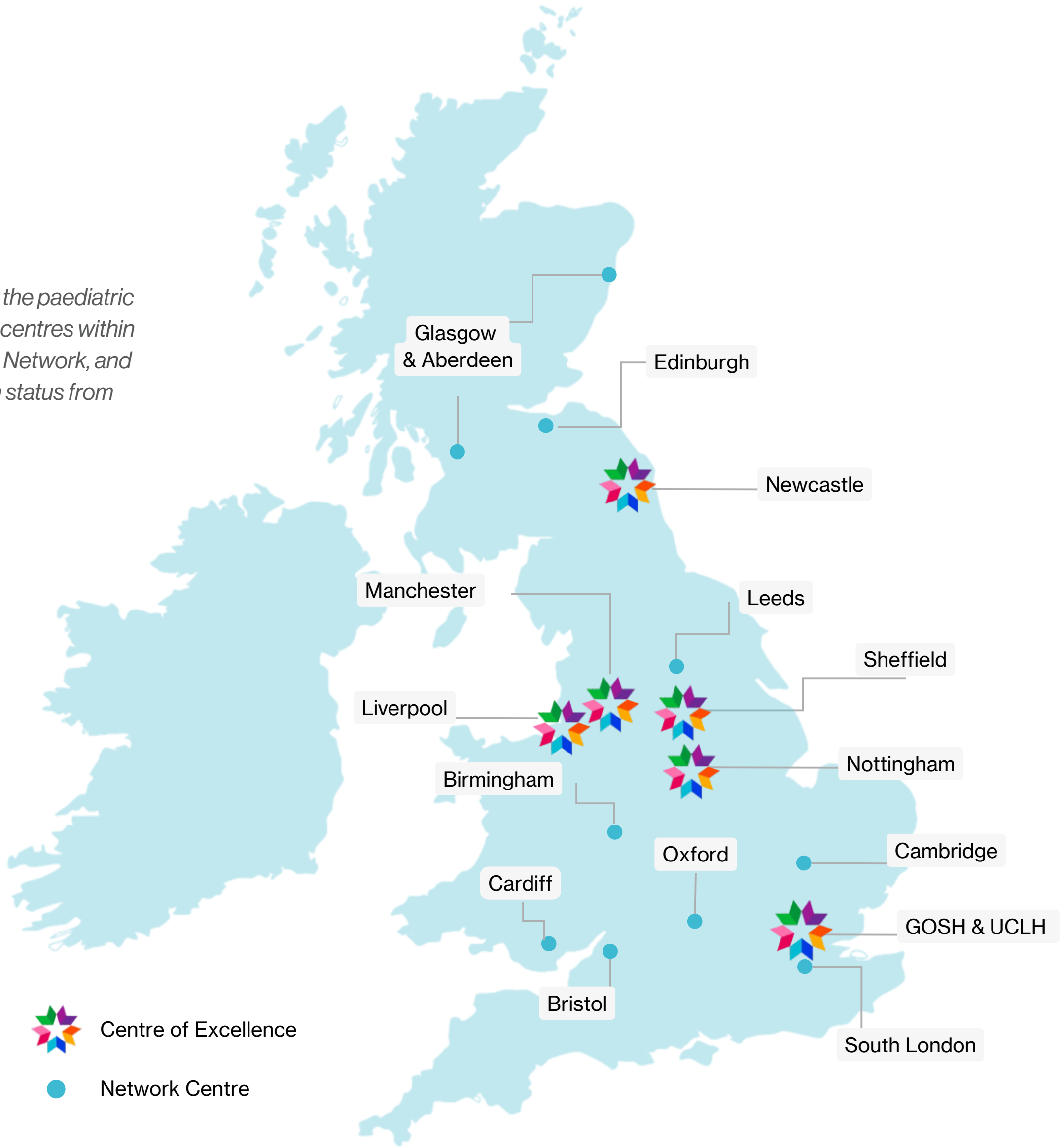


Figure 3 : Map of the paediatric neuro-oncology centres within the Tessa Jowell Network, and their designation status from the 2023 review.

Heat map

During the assessment, centres were graded in all areas of the treatment, care and research pathway as follows:

- 🟨 Yellow indicates 'meeting the Standard of Excellence"
- 🟩 Light green indicates 'exceeding the Standard'
- 🟩 Dark green indicates 'exceeding the Standard in more than one way'
- 🟥 Red indicates that the 'Standard is not met'

Figure 4 provides an overview of how the centres scored in each step of the treatment and research pathway. Both excellence and issues to address were found across the pathway.

Figure 4 : Heatmap representing review of 15 paediatric neuro-oncology centres against expert-set Standards of Excellence. Each cell represents how a specific centre (labelled A-O) performed in each area of the patient pathway.

Total scores		A	B	C	D	E	F	G	H	I	J	K	L	M	N	O
	Flags	0	0	0	0	0	0	-2	-3	-4	-8	-8	-9	-9	-9	-12
	Passes	11	10	14	18	19	24	17	17	19	9	15	10	16	17	14
	Exceeds	37	35	23	18	15	7	19	16	12	19	9	13	7	5	2

Library of Excellence

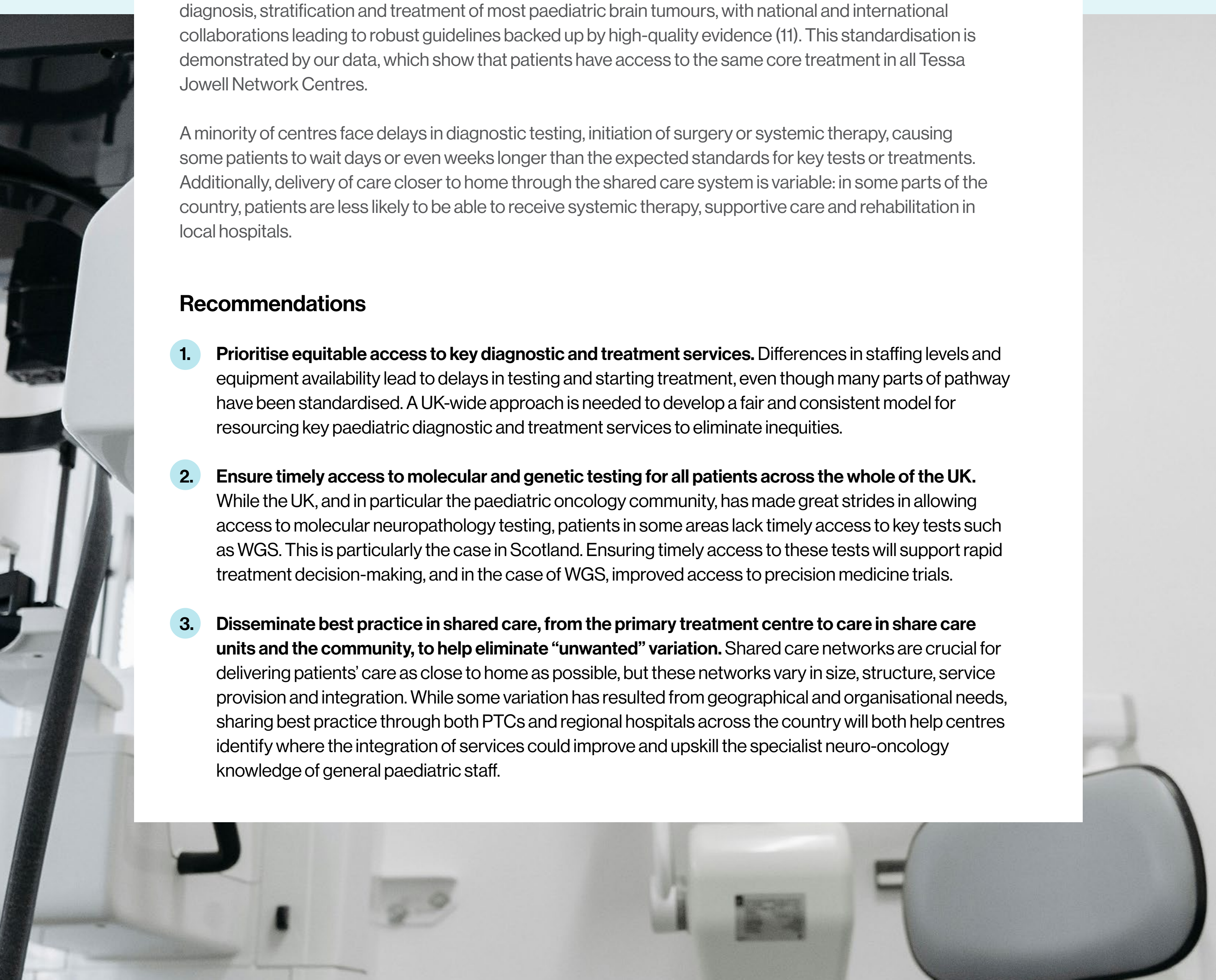
Figure 5: Library of Excellence, examples of best practice identified by expert committee through the patient pathway.

Basic and translational research	Collaboration between research and clinical institutions to support transition of cutting edge research into clinical care. Research activities across specialties beyond clinical treatment, including imaging and psychology. Trial planned and funded to include dedicated clinical research staff and clinical support services.
Clinical trials	International trials open at UK centres bringing opportunities for a wider range of tumour types. Early involvement of research teams in treatment planning supports access to trials. Innovative CAR T-cell and immunotherapy trials open in UK. Some aspects of trials delivered at POSCUs reduce patient travel.
Staff training	Training programme for POSCU staff to develop specialist neuro-oncology knowledge. Investment into CNS development with extensive training opportunities across oncology, neurosurgery and supporting families. AHP and nursing staff are provided with financial support and protected time to attend conferences and external training days. Team members share learnings with the group after attending external training days.
Imaging	24/7 access to MRI scanning with anaesthetic support. Play specialists support patients through scans to reduce the use of anaesthesia. Regional communication system to allow open access to scans between local hospitals and the PTC.
Surgery	Dedicated retrieval pathways to transfer patients to the PTC in emergency cases. Same-day emergency admission pathways, some of which are aided by electronic referral services. Use of intraoperative-MRI scans for safer, more precise tumour removal - reducing risk, recovery time and reliance on post operative imaging. Extensive involvement in national and international neuro-oncology organisations as well as neurosurgical groups.
Pathology	Dedicated theatre-to-lab porter to ensure timely, accurate sample transfer. Rapid molecular testing to integrate a tumour's genomic profile into diagnosis and guide clinical decision-making.
Chemotherapy	Pro-active bed management to enable timely chemotherapy access, supported by POSCU step-downs, early discharge, home treatment, outpatient follow-up, and virtual wards to ease pressure. PTCs provide POSCU teams with open access to e-prescribing systems, supporting seamless communication and up-to-date treatment delivery. Home-based chemotherapy delivery facilitated by POONs.
Radiotherapy	Peer review of contour and beam plans used as an educational tool for trainees. Patients are reviewed by radiographer and nurse weekly or more for toxic and adverse effects. Remote rehabilitation support is offered to ensure continuity of care while patients travel for PBT.
Nurse-led care	Cross-department ward nurse training, with opportunities for rotations and joint learning. Nurse-led outreach clinic for off-treatment support guided by a framework to monitor evolving patient needs. Neuro-oncology and aftercare CNSs provide dedicated, holistic support, guiding end-of-treatment plans, follow-up imaging, rehabilitation referrals, and coordination with community and adult care teams.
Psychological care	Neuropsychology assessments at regular intervals for all patients. Psychologists are involved in education and rehabilitation decisions. Sibling's toolkit developed with Tom's Trust. Support on offer for siblings and family as well as patients.
Play	Play involvement throughout the care pathway to support imaging, radiotherapy, rehabilitation and easing medication fears. Art-based support to help patients explore and express emotions following surgery, supporting emotional recovery. Access to an outreach or community health play specialist.
Rehabilitation	Comprehensive early assessments by physiotherapy, occupational therapy, and speech and language specialists for early identification of needs. Specialised neuro-rehabilitation pathway for neuro-oncology patients with multidisciplinary input. Holistic, long-term, multi-disciplinary support provided by PTC rehabilitation team, ensuring continued access to specialist support. "Passports" to share patient progress and goals between hospital and community teams.
Palliative & end-of-life care	Supportive care team are involved from diagnosis. Community and hospice teams integrated into the care pathway to ensure seamless post-discharge support. 24/7 palliative nurse-led end-of-life care at home. Dedicated bereavement teams.
Education	Hospital school curriculum links to the four areas of a child's need: communication & interaction, cognition & learning, social & emotional health, sensory & physical needs. Discharge reports outline progress, gaps, and support strategies for child's school, with next steps to guide reintegration. Child's school invited to meetings with the nursing and/or education team.
Late effects and aftercare	Multi-disciplinary aftercare clinic as a 'one-stop shop' check-in for all long-term needs. Aftercare wellbeing practitioner supports holistic care post-treatment. Clinical psychologist attends medical follow-up appointments to provide integrated psychological support. Access to gynaecology and urology specialising in young people.
TYA	Robust transition pathway following 'Ready, Steady, Go' framework. TYA end-of-treatment day. Dedicated TYA neuro-oncology CNS. TYA-specific neuro-psychology support group. Independent consultations to offer autonomy to older patients.
Charity collaborations	Active charitable network with a wide range of organisations offering a variety of support. Quarterly departmental meetings to ratify new charity collaborations. Local charities funding roles and resources for services, including charity-funded family support workers on wards and in outreach posts.

01

Diagnosis & Treatment

What do we mean by diagnosis and treatment? In this section, we look at the diagnosis and treatment services provided by centres to children and young people with a brain tumour. Within the constraints of our data, diagnosis includes the imaging, pathology and genomic tests conducted once the patient has reached the PTC, excluding the pathway to the diagnosis of a brain tumour at the patient's general practitioner (GP) or local hospital. Treatment includes the services provided in neurosurgery and systemic therapy (chemo- and radiotherapy), whether delivered at the PTC or local hospitals.



The paediatric neuro-oncology field has made significant progress in recent years, standardising the diagnosis, stratification and treatment of most paediatric brain tumours, with national and international collaborations leading to robust guidelines backed up by high-quality evidence (11). This standardisation is demonstrated by our data, which show that patients have access to the same core treatment in all Tessa Jowell Network Centres.

A minority of centres face delays in diagnostic testing, initiation of surgery or systemic therapy, causing some patients to wait days or even weeks longer than the expected standards for key tests or treatments. Additionally, delivery of care closer to home through the shared care system is variable: in some parts of the country, patients are less likely to be able to receive systemic therapy, supportive care and rehabilitation in local hospitals.

Recommendations

1. **Prioritise equitable access to key diagnostic and treatment services.** Differences in staffing levels and equipment availability lead to delays in testing and starting treatment, even though many parts of pathway have been standardised. A UK-wide approach is needed to develop a fair and consistent model for resourcing key paediatric diagnostic and treatment services to eliminate inequities.

2. **Ensure timely access to molecular and genetic testing for all patients across the whole of the UK.** While the UK, and in particular the paediatric oncology community, has made great strides in allowing access to molecular neuropathology testing, patients in some areas lack timely access to key tests such as WGS. This is particularly the case in Scotland. Ensuring timely access to these tests will support rapid treatment decision-making, and in the case of WGS, improved access to precision medicine trials.

3. **Disseminate best practice in shared care, from the primary treatment centre to care in share care units and the community, to help eliminate "unwanted" variation.** Shared care networks are crucial for delivering patients' care as close to home as possible, but these networks vary in size, structure, service provision and integration. While some variation has resulted from geographical and organisational needs, sharing best practice through both PTCs and regional hospitals across the country will both help centres identify where the integration of services could improve and upskill the specialist neuro-oncology knowledge of general paediatric staff.

Shared care

A key focus of paediatric oncology is to ensure that patients receive treatment and care as close to home as possible, minimising the cost and time of travelling long distances and reducing the disruption to the education of the patient and the work of family members and carers. To achieve this, many UK centres have established formal shared care networks. Highly-specialised surgery, clinical trials and certain systemic therapies are delivered in the PTC, while other aspects of treatment and care are devolved to local hospitals, called POSCUs (9,10). While the principle of centralising certain specialised aspects of care to large tertiary treatment centres and devolving others to local hospitals is common in the NHS, the formality and level of cooperation across the shared care networks is almost unique to paediatric oncology and is a significant strength of the sector.

Each of the 15 paediatric neuro-oncology centres applying for Tessa Jowell Centre of Excellence status serves a region with unique geography. As a result, shared care networks have developed organically and vary significantly in size, structure, and the relationships between hospitals **(Box 3)**.

These variations include:

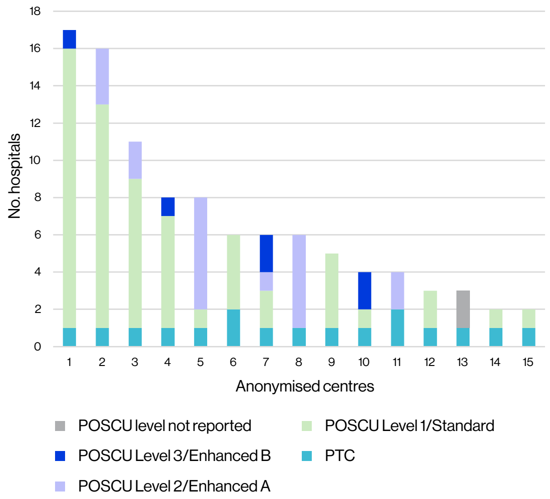
- **Network size and structure:** POSCUs are classified as either 'Standard', which provide supportive care but not systemic anti-cancer therapy (SACT) services, or 'Enhanced', providing supportive care and SACT services. The number of each type of POSCU varies substantially between centres – for example, four networks do not have any enhanced POSCUs within their network, while other centres have many standard POSCUs with one or two enhanced POSCUs **(Figure 6)**. This means that not only where in the country a patient lives, but also where in a network they live, can determine whether they are able to receive certain aspects of their care close to home.

- **Services provided:** In part due to the variation in size and structure, centres vary in the proportion of POSCUs that can offer key services. Most centres have a POSCU that can offer imaging, symptom management and palliative care, saving patients long journeys to the PTC for routine care. In contrast, half of the POSCU centres are unable to offer chemotherapy, and a third are unable to offer rehabilitation anywhere other than their PTC **(Figure 7)**.

- **Methods of communication and collaboration:** Given the different size and reach of shared care networks, it is not surprising that the level and form of integration between centres varies. While almost all centres (14/15) have POSCU team members joining multidisciplinary team (MDT) meetings regularly, centres differ on the extent to which key MDT members have responsibility for regularly updating POSCUs, such as a named point of contact at the PTC (5/15 centres). Mechanisms for referring patients from POSCUs to the PTC in an emergency also vary. While all PTCs have formal escalation pathways in place, only 8/15 reported 24/7 PTC expertise available for POSCUs.

> "[There were] so many effects that the hospital say they expected but hadn't prepared us for. Communication between departments, doctors and NHS trusts needs to improve as does continued support in the community"
>
> Patient feedback through the Brain Tumour Charity's "Improving Care" surveys.

Figure 6: Number of POSCUs and their levels within each of the 15 shared care networks.



Box 3: Why does shared care vary across the UK?

Our data show that shared care delivery varies substantially across the UK. For national and local policymakers, patients, their families and clinicians, it is important to understand this variation, its key drivers and whether it needs to be addressed. We identified three key sources of variation in shared care:

Geographical need: each centre serves a unique geographical area, differing in size, population, transportation links and number of population centres. In some regions, where one or two well-connected cities serve most of the population, it makes sense to centralise care in these hubs. In contrast, some areas—particularly in the North and West of the UK—may require patients to travel long distances to reach a PTC. In these cases, it is more practical to provide some aspects of care closer to home, at smaller local hospitals.

Existing infrastructure and expertise: Some POSCUs cannot offer certain types of care due to limited resources. As a result, PTC teams may choose to retain more of the patient's care at the main centre to ensure timely treatment by staff with the appropriate expertise. Shared care networks are therefore more robust where there are already established paediatric teams with oncology specialists, as well as resources such as beds and imaging equipment.

Complex coordination across borders: a more negative driver may be complications with PTC catchments covering multiple counties' health authorities, making it more complicated to establish robust shared care pathways between multiple councils or districts. This may result in centralisation of services at the potential cost of patients living far from the PTC.

Table 1: Aspects of care available at POSCUs within the 15 shared care networks. 'Other services' include psychology, late effects care, endocrinology, ophthalmology, dietetics, play therapy surgery and supportive care. Each cell represents the percentage of POSCUs within the relevant network providing a given service. Where no centres provide this, 0% was imputed. Where no data were provided, a ^ was imputed.

Anonymised centres	No. POSCUs	Imaging	Chemotherapy	Symptom management	Rehabilitation	Palliative care	Other services
1	5	100%	100%	100%	100%	100%	100%
2	7	100%	86%	100%	100%	100%	100%
3	15	100%	100%	100%	100%	100%	13%
4	2	100%	100%	100%	100%	100%	0%
5	1	100%	0%	100%	100%	100%	100%
6	5	100%	80%	80%	80%	80%	51%
7	10	100%	20%	100%	100%	100%	^
8	4	100%	0%	100%	100%	100%	^
9	2	100%	0%	100%	100%	33%	33%
10	3	100%	67%	100%	0%	67%	33%
11	16	100%	93%	100%	21%	20%	22%
12	7	100%	14%	100%	14%	100%	14%
13	2	100%	0%	100%	0%	100%	^
14	4	25%	0%	100%	0%	75%	100%
15	1	0%	0%	100%	0%	0%	^

Imaging

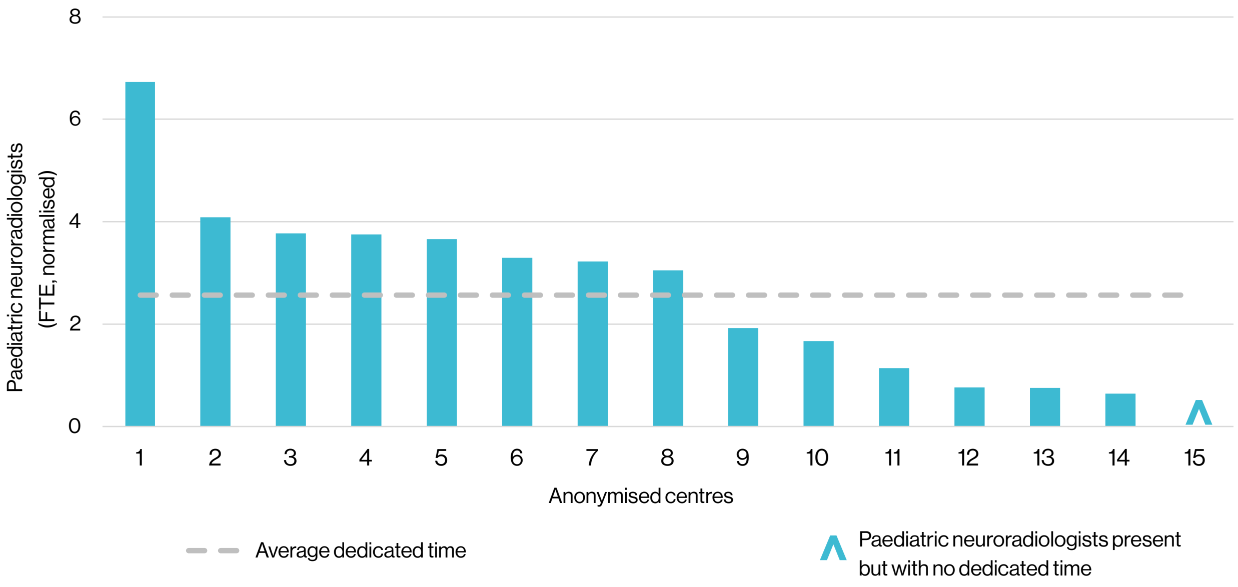
Neuroimaging, principally using Magnetic Resonance Imaging (MRI), is an essential part of diagnosis, staging, treatment planning and monitoring of brain tumours. The unique challenges associated with brain and central nervous system tumour imaging, particularly for children and young people, demand highly specialised interpretation beyond general paediatric or neuro-radiology training.

This has led to the emergence of paediatric neuro-radiology as a discrete field. Significant efforts have been made to standardise protocols and approaches, including the use of guidelines from the European Society for Paediatric Oncology (SIOPE) and the Response Assessment in Paediatric Neuro-oncology (RAPNO) (16,17).

Overall, neuroimaging was an area where the majority of centres exhibit an excellent and standardised service, with a minority of centres facing challenges related to staffing or equipment access. Key areas that some centres excelled in but others face challenges include:

- **Use of guidelines:** All but one centre (14/15) reported using RAPNO/SIOPE guidelines for scanning at presentation/diagnosis and follow-up. While in most centres >90% scans at the PTC adhere to these protocols, adherence is much more variable at POSCUs, which may be why 6/15 centres only conduct scans at the PTC.
- **Emergency scan access:** All centres are able to offer emergency scans; however, the need for a general anaesthetic (GA) for some patients poses as a barrier to same-day scan access. Only 4/15 centres can offer same-day emergency scans under GA to all patients.
- **Routine scan turnaround times:** Most centres (11/15) are able to perform a routine scan within 2 weeks, with 8/15 able to report these scans within 3 days. However, patients in some centres had to wait significantly longer than this. Two centres reported a wait of >3 weeks for routine scans, taking an average of 7 days to then complete the report.
- **MRI capacity:** The availability of MRI scanning time for all paediatric imaging ranged from 25 to over 300 hours per week between centres (normalised by patient numbers). Intraoperative MRI (IoMRI) to support surgery is available in 10/15 centres.
- **Staffing:** There is variation in the amount of specialist time dedicated to paediatric cases **(Figure 8)** and team composition (i.e. whether they include general paediatric radiologists or adult neuroradiologists). While all centres have specialist paediatric neuroradiologists within their team, many are limited in the number of individuals with this level of expertise (2/15 centres have one expert, 4/15 centres have 2 experts). Therefore, there are some concerns about service resilience.

Figure 8: Paediatric neuroradiologist time dedicated to all paediatric cases (including neuro-oncology) in full-time equivalent (FTE). Data are normalised by patient numbers to an average centre size of 50 patients per year.



Neurosurgery

Neurosurgery plays a central role in the modern management of paediatric brain tumours. As well as the therapeutic goal of "maximum safe resection" – the removal of as much tumour tissue as possible without compromising neurological function – surgery provides tissue for diagnostic and prognostic analyses (18).

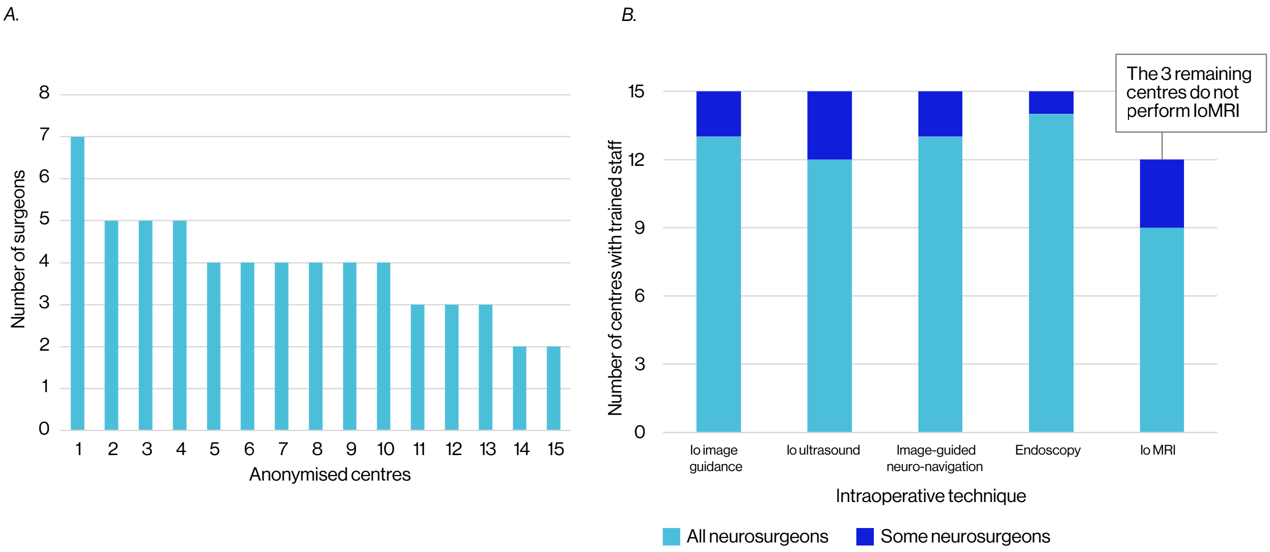
Paediatric neurosurgery is highly specialised and all centres met the NHS guidelines requiring subspecialised surgeons. Given that subspecialisation in paediatric neurosurgery is associated with improved outcomes and lower mortality rates (19,20), it is encouraging that all centres have at least two surgeons who regularly operated on children and young people with a brain tumour **(Figure 9)**. All centres also reported at least two surgeons trained in key intraoperative techniques such as image guidance, ultrasound, neuro-navigation and endoscopy.

Paediatric neurosurgery is an exemplar speciality for collecting and sharing data. All centres audit morbidity and mortality (M+M) through regular M+M meetings, allowing treatment delivery to be accurately tracked, and many centres collect additional data specific to the surgery, to the tumour, and/or to a patient's use of healthcare (such as readmission rates or certain interventions). Almost all centres (14/15) reported sharing these data with the British Paediatric Neurosurgery Group (BPNG) to track national outcomes.

National and international collaboration is key in paediatric neurosurgery, and every centre is engaged with at least one key (inter)national professional organisation. The most common organisations being BPNG (14/15 centres), the International Society of Paediatric Neuro-Oncology (ISPNO, 12/15 centres), the Children and Young People's Cancer Association (CCLG, 10/15 centres) and SIOPE (8/15 centres). Most centres also reported having surgeons who had undertaken an international fellowship.

While many aspects of paediatric neurosurgical care are consistent across centres, wait times for surgery vary, with some centres reporting delays. Nine centres reported experiencing delays to paediatric brain tumour surgery, with bed delays (6/15 centres), theatre capacity and staff capacity (3/15 each) being the most commonly reported challenges.

Figure 9: A. Number of specialised surgeons operating on brain tumours in each neuro-oncology centre. B. Neurosurgical expertise in intraoperative techniques across all centres.



Neuropathology and genomics

Molecular neuropathology is vital to the neuro-oncology MDT, with specialist input essential for tumour classification and treatment planning. Since the 2021 World Health Organisation (WHO) classification (21), genetic testing has become standard for many brain tumours, complementing histology and immunohistochemistry **(Figure 10)**. In paediatric neuro-oncology, this improves understanding of tumour biology, guides targeted therapy, and helps match patients to clinical trials.

Paediatric neuro-oncology centres have made strong progress in embedding molecular genomic testing into routine care, supported by regular audits that reflect a national commitment to diagnostic equity and improved clinical outcomes. **Nonetheless, significant challenges remain:**

- **Tissue freezing:** All centres freeze tissue for genetic sequencing, but some freeze relatively few samples (range = 9 to 147 per centre, normalised by caseload) and obtaining the recommended volume of 1cm^3 is not always possible (on average 33% samples per centre met this criteria). Disparities in tissue freezing practice highlight the need for standardised protocols and removal of any local barriers preventing storage.

- **Molecular testing:** All centres submit samples for key molecular and genomic testing to improve diagnostic accuracy, prognostic information, and therapeutic decision-making. However, the number of samples submitted for routine molecular tests varies (ranging from 6 to 299 samples per centre, normalised by caseload), and over a third of centres' testing turnaround times exceed the recommended Standard, contributing to delays in the final integrated diagnoses.

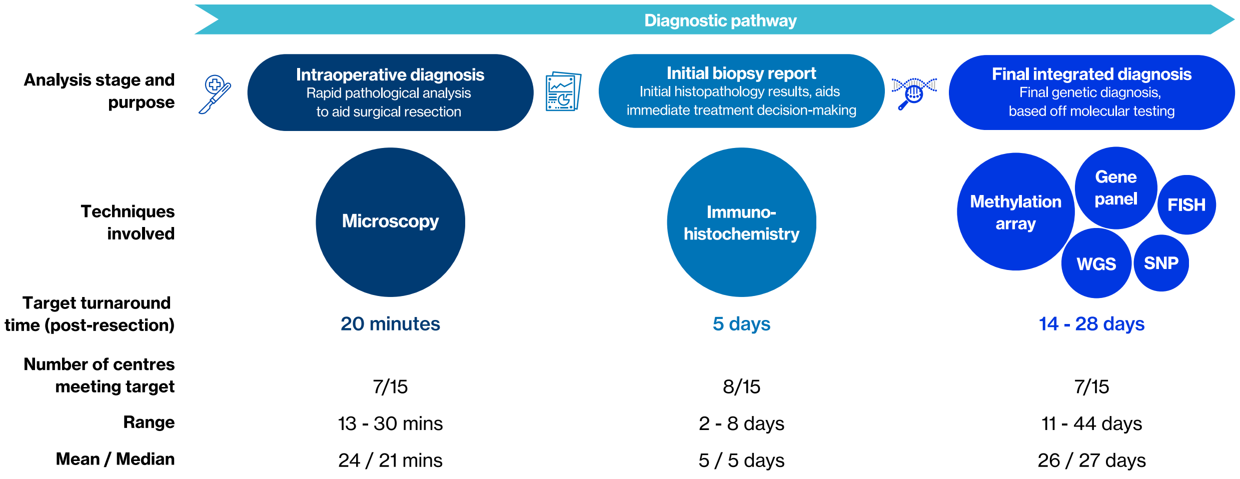
  Patients in Scotland, Wales, and Northern Ireland face additional delays in routine molecular testing, as samples must be sent through England, creating logistical hurdles.

- **Report turnaround times:** Centres face significant challenges in delivering all three stages of pathological analysis within the timeframes stated in the Tessa Jowell Standards of Excellence **(Figure 10)**. The reason for delays in key turnaround times varied across centres, including limitations in the volume of tissue retrieved during surgery (7/15 centres), delays and logistical issues with delivering samples (6/15 centres), access to testing out-of-hours (5/15 centres), and resourcing shortages (4/15 centres).

Access to WGS is complex and a particular challenge in Scotland. All centres in England and Wales submit samples for WGS, a marked improvement over rates reported in the TJBCM Centre of Excellence for Adults Programme and the 2024 "Closing the Gap" report (22). However, some centres submit few samples, and turnaround times often exceed the 42-day target by months. Due to devolved genomic services Scottish patients currently access WGS only via London, but the Scottish Government have included improved access to WGS in their most recent 5-year Genomic Medicine Strategy (23).

Pathology samples are submitted for future research via biobanking. 13/15 centres regularly contribute to the CCLG VIVO biobank, though sample volumes vary. Nine centres offer this to all patients, and two to select eligible patients. Tumour and blood samples are the most commonly submitted tissue types.

Figure 10: Paediatric molecular neuropathology diagnostic pathway, with key standards and national benchmark data (number of centres meeting target, range and mean/median).



Analysis stage and purpose	**Intraoperative diagnosis** Rapid pathological analysis to aid surgical resection	**Initial biopsy report** Initial histopathology results, aids immediate treatment decision-making	**Final integrated diagnosis** Final genetic diagnosis, based off molecular testing
Techniques involved	Microscopy	Immuno-histochemistry	Methylation array Gene panel FISH WGS SNP
Target turnaround time (post-resection)	20 minutes	5 days	14 - 28 days
Number of centres meeting target	7/15	8/15	7/15
Range	13 - 30 mins	2 - 8 days	11 - 44 days
Mean / Median	24 / 21 mins	5 / 5 days	26 / 27 days

Chemotherapy

Chemotherapy is used more commonly in paediatric than adult tumours, often with the intention of delaying or avoiding radiotherapy. Consistent delivery of chemotherapy according to agreed strategies is important to reduce variability in outcomes. Oncologists have worked hard at national and international levels to agree consistent and safe approaches for the delivery of chemotherapy. Each UK nation has guidelines for the delivery of chemotherapy, with service specifications dictating delivery across PTC and POSCUs (11,15,24).

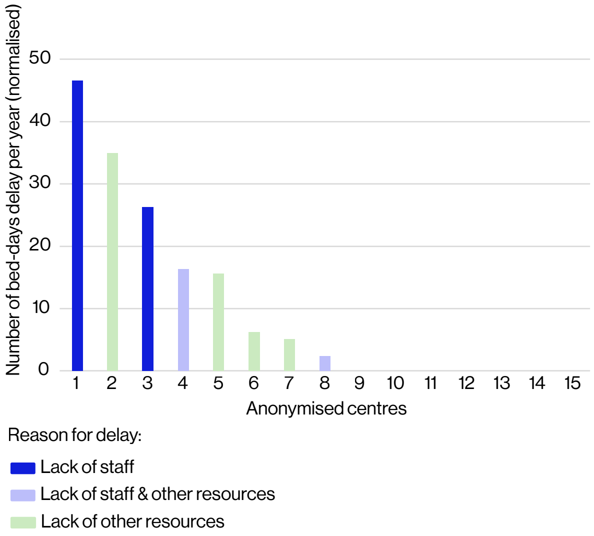
Insights collected from centres demonstrate the effort invested in standardising chemotherapy provision for children and young people with a brain tumour. Examples of this standardisation include:

- **Protocols for chemotherapy delivery:** All centres use nationally or internationally agreed guidelines and clinical trial protocols for paediatric neuro-oncology chemotherapy.
- **Chemotherapy prescribing:** 14/15 centres now use entirely e-prescribing for their PTC, a transition likely to improve auditing and reduce prescribing errors. The remaining centre is transitioning from a currently mixed paper/electronic system.
- **Shared care prescribing:** While POSCUs also often use e-prescribing, more variation is seen in shared care networks. Almost every network has a slightly different set-up, with POSCUs varying in prescribing duties and the extent to which systems were shared with the PTC, impacting the consistency of chemotherapy delivery.
- **Monitoring of service resilience and errors:** Monitoring prescribing practices and identifying errors is a crucial part of providing a safe and effective service. All centres have systems in place to monitor and rapidly report prescribing errors, alongside policies for system interruptions.

There are two key areas in which centres face challenges:

- **Bed and staffing capacity:** Bed capacity varies across the UK. 6/15 centres reported chemotherapy delays in the previous year due to bed availability **(Figure 11)**, and 4/15 centres reported delays to starting chemotherapy due to staff shortages. However, all centres have systems in place to monitor bed and staff capacity, and to mitigate the effects of shortages where found. The fact that these data were available in all centres demonstrates their efforts to remove barriers to delivering treatment in a timely manner.
- **Access to novel therapies:** All centres are able to provide innovative therapeutics to patients if standard therapies have not been effective. Waiting times to receive novel treatment vary from one to seven weeks. Extended wait times, potentially causing distress to a patient as well as delaying any therapeutic benefit, are mostly due to administrative delays outside the control of the treatment team.

Figure 11: Total number of bed delays reported across the 15 centres. Coloured by reason for delay. Data are normalised by patient numbers to an average centre size of 50 patients per year.



Radiotherapy

Radiotherapy is often used alongside chemotherapy to treat paediatric brain tumours. Current options include proton beam therapy (PBT), photon therapy, stereotactic radiosurgery and molecular radiotherapy, with specific options highly tailored to the many subtypes of paediatric brain tumours. Radiation therapy can have significant adverse and long-term effects on the neurodevelopment and endocrine function of children and young people. Hence, there is a strong drive to optimise radiation usage, ensuring that it is delivered consistently by highly specialised teams according to nationally-agreed guidelines.

PBT, which is delivered centrally in the UK (see **Box 4**), is considered for most children and young people with a brain tumour. Due to the centralised nature of PBT delivery, it is essential that patients are provided with support during the treatment process.

Box 4: Delivery of Proton Beam Therapy in the UK

PBT for children and young people with a brain tumour is delivered in two sites - in Manchester by The Christie NHS Foundation Trust and in London by University College London Hospital NHS Foundation Trust.

Eligibility criteria require patients to have a curable tumour, a “reasonable disease-specific five-year survival expectation”, be fit to travel and be treated on an outpatient basis. Referrals are processed by the PBT centres who treat according to the eligibility criteria. This means that PBT is unlike other parts of the patient pathway – being a centrally funded and delivered pathway – and challenges related to this service often require action on a national level.

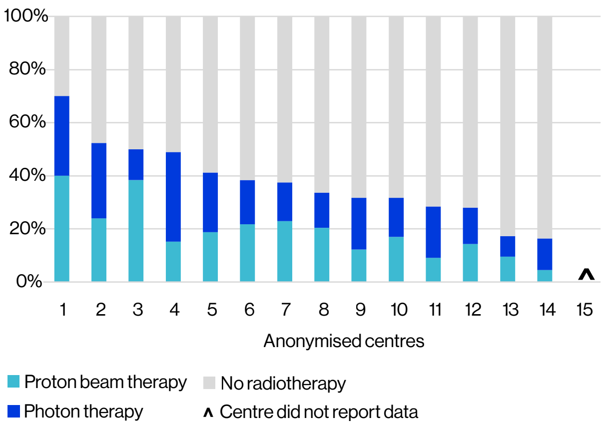
Centres reported a consistent approach to supporting patients during PBT:

- **Access:** The majority of patients referred for PBT are accepted for treatment and are able to receive it in a timely manner. Where there are delays to starting treatment, these are mainly caused by medical complications, with teams often offering a holding treatment until the patient is able to undergo PBT.
- **Rehabilitation:** before, during (as an outpatient), and after PBT is available to patients. However, this may not meet the needs of those requiring intensive inpatient rehabilitation. All patients can also access neuropsychology input if they are undergoing PBT.
- **Support during a patient’s stay**: Both PBT centres provide free accommodation (accessible if needed) to patients and up to two carers. Of the 14 centres reporting data, 13 provide additional support for accommodation, often through the charity Young Lives Vs Cancer, and 13 provide additional clinical support through ongoing contact with a clinical nurse specialist (CNS), support worker or paediatric oncology outreach nurse (POON). Ten centres also provide support for transportation to the PBT site and three offer other support such as food vouchers or financial grants.

For those patients not accepted or referred for PBT, photon therapy is available. Centres have access to the latest techniques and modern equipment to deliver photon therapy, and have a broadly consistent approach to much of the delivery of photon therapy, including peer review, monitoring of toxicity, and following national guidelines.

Despite access to the latest treatment options through both PBT and photon therapy, there is an unexplained variation in the percentage of brain tumour patients receiving radiotherapy between centres (Figure 12). While our data shows little variation in the number of patients with medulloblastoma and ependymoma receiving radiotherapy, other tumour types see much greater variation, most likely due to the need for individual treatment decision-making. Given the wide variety in different tumour types, and therefore the fluctuation in the number of patients receiving radiotherapy, there is a need for in-built “flex” in the system to ensure all patients who need this treatment can receive it in a timely manner. In addition, some variation may be due to geographical barriers, e.g. some patients prefer to avoid travelling long distances to a specialist treatment centre, and others prefer to travel for a single round of radiotherapy treatment compared to ongoing travel for chemotherapy. These factors more commonly influence decisions for families in rural communities or those from lower socio-economic backgrounds.

Figure 12: Proportion of brain tumour patients receiving proton beam and photon therapy across a 2 year period across 15 centres.



02

Quality-of-Life Care

What do we mean by quality-of-life care? In this section, we look at the quality-of-life care provided to patients with a brain tumour; this includes nursing, rehabilitation, therapeutic play, psychological and supportive/palliative care that wraps around the patient's treatment and recovery journey. It is holistic, encompassing all aspects of being a cancer patient. It supports the physical, emotional, developmental and practical needs of the patient and their family/carers.

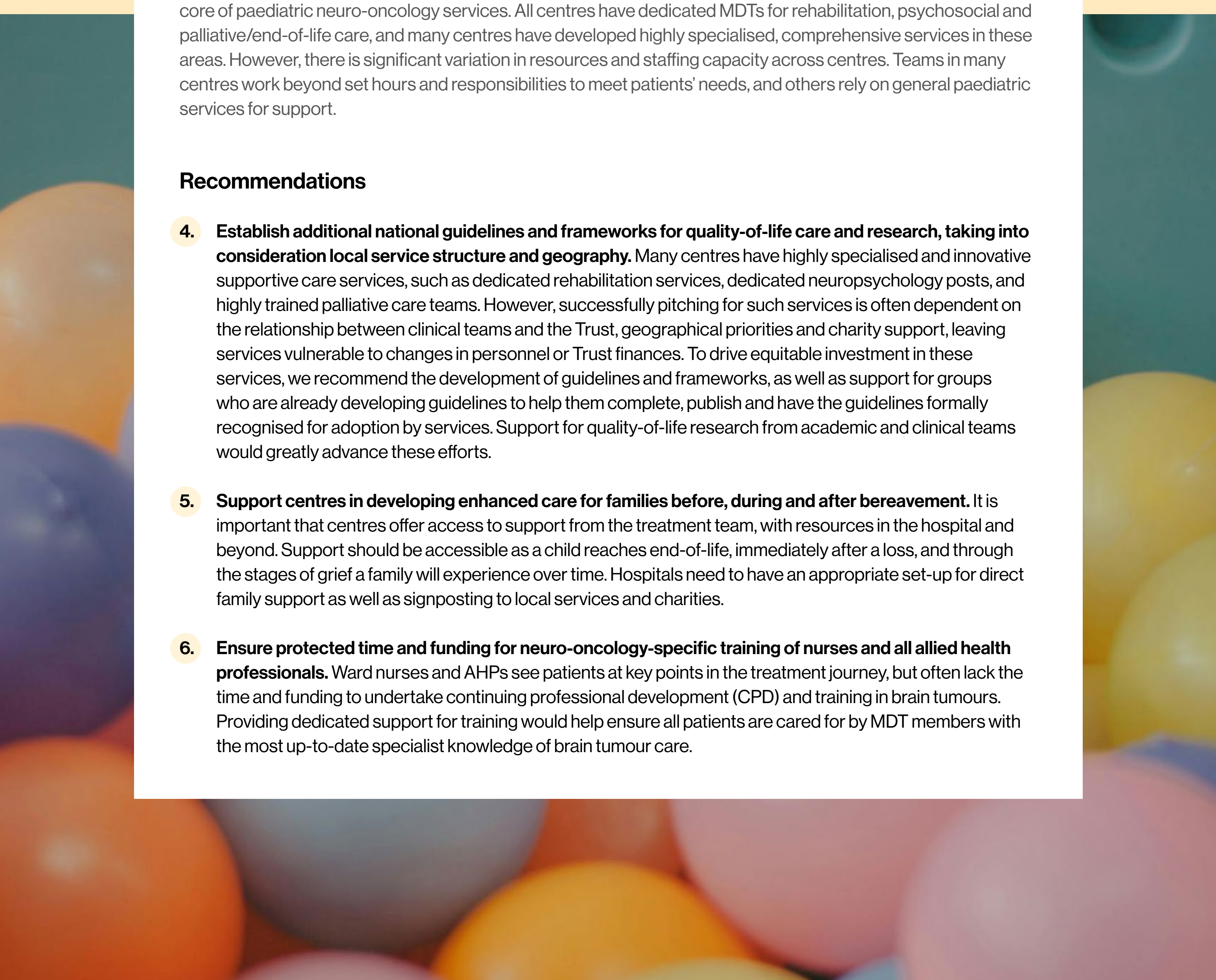
A service that ensures patients' needs are met from diagnosis through to end-of-life care or survivorship is at the core of paediatric neuro-oncology services. All centres have dedicated MDTs for rehabilitation, psychosocial and palliative/end-of-life care, and many centres have developed highly specialised, comprehensive services in these areas. However, there is significant variation in resources and staffing capacity across centres. Teams in many centres work beyond set hours and responsibilities to meet patients' needs, and others rely on general paediatric services for support.

Recommendations

4. **Establish additional national guidelines and frameworks for quality-of-life care and research, taking into consideration local service structure and geography.** Many centres have highly specialised and innovative supportive care services, such as dedicated rehabilitation services, dedicated neuropsychology posts, and highly trained palliative care teams. However, successfully pitching for such services is often dependent on the relationship between clinical teams and the Trust, geographical priorities and charity support, leaving services vulnerable to changes in personnel or Trust finances. To drive equitable investment in these services, we recommend the development of guidelines and frameworks, as well as support for groups who are already developing guidelines to help them complete, publish and have the guidelines formally recognised for adoption by services. Support for quality-of-life research from academic and clinical teams would greatly advance these efforts.

5. **Support centres in developing enhanced care for families before, during and after bereavement.** It is important that centres offer access to support from the treatment team, with resources in the hospital and beyond. Support should be accessible as a child reaches end-of-life, immediately after a loss, and through the stages of grief a family will experience over time. Hospitals need to have an appropriate set-up for direct family support as well as signposting to local services and charities.

6. **Ensure protected time and funding for neuro-oncology-specific training of nurses and all allied health professionals.** Ward nurses and AHPs see patients at key points in the treatment journey, but often lack the time and funding to undertake continuing professional development (CPD) and training in brain tumours. Providing dedicated support for training would help ensure all patients are cared for by MDT members with the most up-to-date specialist knowledge of brain tumour care.



Nurse-led care

Three types of nurses support neuro-oncology patients: 1) ward nurses from both the neurosurgical and oncology wards deliver daily care while the child is in hospital; 2) POONs deliver care in the community when children have returned home; 3) clinical nurse specialists (CNS) are involved throughout the entire care pathway and are key in identifying unmet needs, signposting and referring patients to relevant services (25,26), supporting their wraparound care and reintegration into education. In line with NHS England's POSCU service specification (27), PTCs are expected to have one full-time CNS for the whole service, with larger centres having multiple.

As experts in neuro-oncology, with detailed knowledge of the impact of brain tumours and their treatment, CNSs play a crucial role in the care of children and young people with a brain tumour. They often act as the interface between patients, the wider MDT, and general nursing staff such as ward nurses and POONs. The CNS team are often key in providing brain tumour education for hospital and community staff. Our data reinforced **the central role played by CNSs in paediatric neuro-oncology:**

- **CNSs have expertise that is essential across all specialities involved in caring for children with a brain tumour.** As a result, they are frequently required to attend multiple MDTs and other meetings **(Table 2)**;

- **In all centres, the CNS is the key link between the PTC and shared care services, although the exact model varies.** Centres demonstrate many excellent examples of how to ensure patients' care is coordinated between the PTC, POSCU and community services, with the CNS often playing a central role. In 8/15 centres, CNS have oversight of and provide specialist input to the POONS who deliver outreach care. In the remaining centres, 5/15 centres have PTC CNSs directly doing outreach, and two centres hand care over to the community but with ongoing CNS contact.

- **Almost all centres involve CNSs beyond the end of treatment.** 11/15 centres reported that the CNS is involved in continued care beyond the end of treatment, with 4/15 offering regular face-to-face appointments and a further seven offering contact via phone. 13/15 centres involve CNSs in preparing Special Educational Needs (SEN) assessments/Educational Health Care Plans (or devolved nations equivalents) for a patient's return to school.

CNSs are therefore central to the delivery of care for patients with a brain tumour; yet CNS resourcing, level of practice, and specific responsibilities vary substantially, reflecting a general lack of standardisation in this area.

Key variations identified are:

- **Team size and composition:** Determining the exact number of CNSs involved in the care of patients with a brain tumour is challenging, with some centres providing care through a wider team of paediatric or oncology CNSs, and others through a smaller number of specialised neuro-oncology nurses. However, it is clear that team capacity and level of practice varies. In the most robust models nursing teams have a range of levels of practice, including band 8 positions, with time dedicated to leadership and forward-planning, and band 6/7 nurses, for succession planning and resilience.

- **Neuro-oncology specialisation:** The number of senior nurses dedicated to neuro-oncology patients shows a fourfold variation (when normalised) between centres **(Figure 13).** Having only one part-time CNS specialised in neuro-oncology presents a challenge for service sustainability and staff wellbeing **(Figure 13).** The size of the oncology and neurosurgical CNS teams supporting these patients also varied.

- **Number of additional responsibilities:** In 5/15 centres, CNSs attend more than 10 regular (weekly and monthly) team meetings to provide expertise **(Table 2)**; a timetable filled with meetings may limit CNS capacity for direct patient contact, training of ward nurses, and service development, particularly in small or single-handed teams. While it is important that they are abreast of each aspect of the patient's care, ensuring that there are enough nursing staff to spread the load, or providing support workers to take on administrative tasks, would ensure CNS time and expertise is used effectively.

> "The neuro nurse was incredible, answering any questions we had and always there for support."
>
> "If I have any questions my child has an amazing key worker, so I can ring or text when I have any questions."
>
> Patient feedback through the Brain Tumour Charity's "Improving Care" surveys.

We also collected data on ward nursing, which revealed key challenges for this important group of nursing staff:

1. **Centres vary in the number of ward nurses available and the level of practice, which in some centres could lead to delays in treatment.** 8/15 centres reported delays in delivering chemotherapy, often attributed to lack of staff or other resources.
2. **Training opportunities for ward nurses vary, with insufficient protected time and funding.** 5/15 centres had protected training time, and only 3/15 had dedicated funding from their Trust for training. Neuro-oncology specific training opportunities for ward nurses are particularly lacking in shared care units, with only 4/15 centres providing this.

Figure 13: Bars showing number of full-time equivalent (FTE) neuro-oncology dedicated senior nursing staff (Clinical Nurse Specialists, Neuro-Oncology Outreach Nurses and Advanced Nurse Practitioners), by level of practice. Also displayed is the number of other senior nurses across oncology and neuroscience reported by the centre as involved in care (Y=yes other nurses are involved but no number provided). Data are normalised by patient number to an average centre size of 50 patients per year.

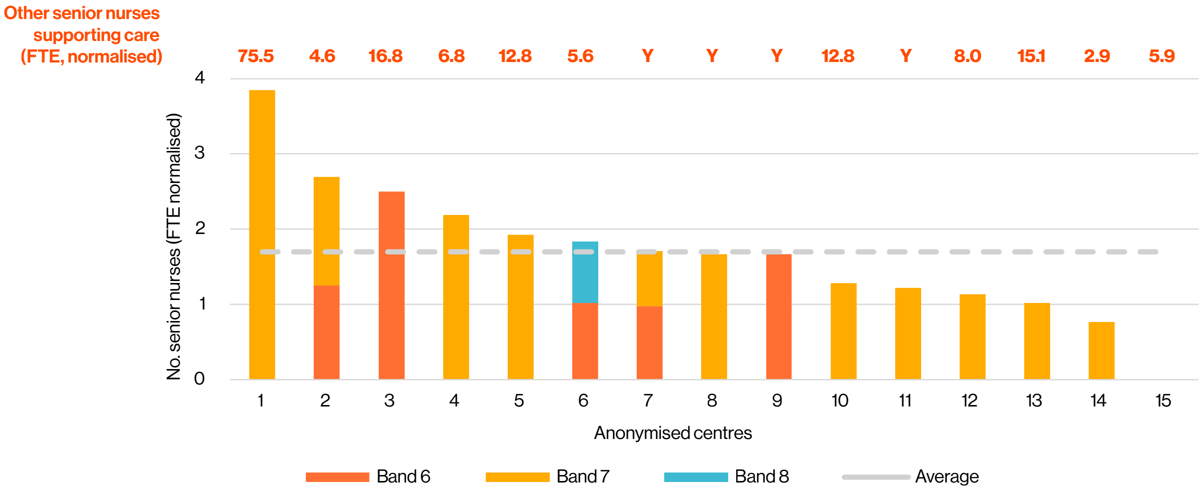


Table 2: MDTs and other meetings attended by Clinical Nurse Specialists, by number of centres reporting attendance at each meeting.

MDT meetings that neuro-oncology CNSs can attend		**Number of centres where CNSs attend MDT (n=15)**
Core	Diagnostic/therapeutic	14
	Psycho-social	14
	Palliative	11
	Rehabilitation	10
Others	Treatment planning *(Endocrinology, Proton therapy, Complex cases, Integrated care, Ward management, Pharmacist & Consultant liaisons, Stem cell transplant)*	13
	Continued provisions *(Team around family/child, Discharge, Long-term follow up, POSCU, Teenage and Young Adult transition)*	12
	Rounds & Handovers *(Daily or weekly handovers, (Grand)ward rounds)*	4
	Patient wellbeing *(Neuropsychology, Holistic)*	3
	Non-clinical *(Departmental business, Governance)*	1

Rehabilitation

Many children are faced with considerable impairments as a result of their brain tumour. Immediate quality-of-life is affected, but more importantly, there are often long-term implications for their cognitive, physical and social development (28–31). Rehabilitation is important to maintain or improve function and long-term quality-of-life, reducing the impact of tumour symptoms or treatment side effects (32). Evidence suggests that early access to rehabilitation is key (31).

Rehabilitation requires multidisciplinary working and may include physiotherapy (PT), occupational therapy (OT), speech and language therapy (SALT), psychology, dietetics, education and social care. It can be delivered in a number of different settings (33):

- acute rehabilitation alongside treatment;
- tertiary specialist neurorehabilitation;
- long-term rehabilitation, provided either through a centre's outpatient or community services (11).

We found a number of integrated neuro-rehabilitation services providing effective rehabilitation for in-patients, and **our data identified many areas of best practice across the UK:**

- **Several centres have highly specialised paediatric neuro-rehabilitation services**, including AHPs with specialist training and time dedicated to brain tumours.

- **All PTCs offer inpatient rehabilitation** which includes PT, OT and SALT. 13/15 centres have a dedicated rehabilitation MDT meeting, where therapists, nurses, consultants and other specialists meet to discuss the ongoing rehabilitation needs of patients.

- **Several centres have developed standardised assessment protocols** that feed into a clear and comprehensive care plan. Two centres have developed patient passports to document needs and support communication with shared care services.

The significant long-term impact of brain tumours and their treatment is well-recognized, and it is essential that all patients are offered access to dedicated rehabilitation services (34,35). **Many centres reported challenges in achieving this goal:**

- **Understaffed inpatient services, with 13/15 centres reporting AHP resourcing challenges.** While all centres are able to provide physiotherapy sessions to inpatients, 3/15 are unable to provide occupational therapy or speech and language therapy beyond assessment or emergency input. Staffing levels also affect waiting times for patients to receive therapeutic intervention, which varies greatly across centres **(Figure 14).**

- **Reliance on overstretched community services for ongoing outpatient rehabilitation.** 4/15 centres lack outpatient PT, OT, and SALT services at their PTCs. Fewer than half (7/15) offer these services at POSCUs or through community outreach. As a result, many centres depend on local community services, which are often overstretched and may lack the expertise to meet the complex needs of children and young people with brain tumours. 11/15 centres identified this as a barrier to meeting patients' rehabilitation needs.

> Only 46% of responses from the patient feedback surveys indicated that they had access to a speech and language therapist.

- **Assessment and care planning are not standardised across centres.** Assessments differ in timeframe, personnel undertaking assessments and the tools used. Assessments do not always feed into a detailed care plan, with only 5/15 centres conducting formal rehabilitation plans for all patients (7/15 centres did this for some patients, and 3/15 were unable to provide a formal plan due to staffing pressures). This variation in practice, while partly impacted by a lack of staff, also reflects a lack of high-quality evidence and guidance in this area, and impacts the ability of centres to generate care plans and to effectively coordinate care in collaboration with community services.

- **Many centres provide specialist training to AHPs working in neuro-oncology, but the types of opportunities, level of protected time and funding available vary significantly.** 4/15 centres offer no neuro-oncology specific training. Only 3/15 centres are able to fully fund training for AHPs working in neuro-oncology, with a further 10/15 centres relying on charities for some or all funding. 2/15 are unable to fund any specific training at all.

Figure 14: Variation in wait times for inpatient rehabilitation services (for physiotherapy [PT], occupational therapy [OT] and speech and language therapy [SALT]) across centres, ranked by total average wait time across all three specialties. No waiting time/immediate access was imputed as "0".

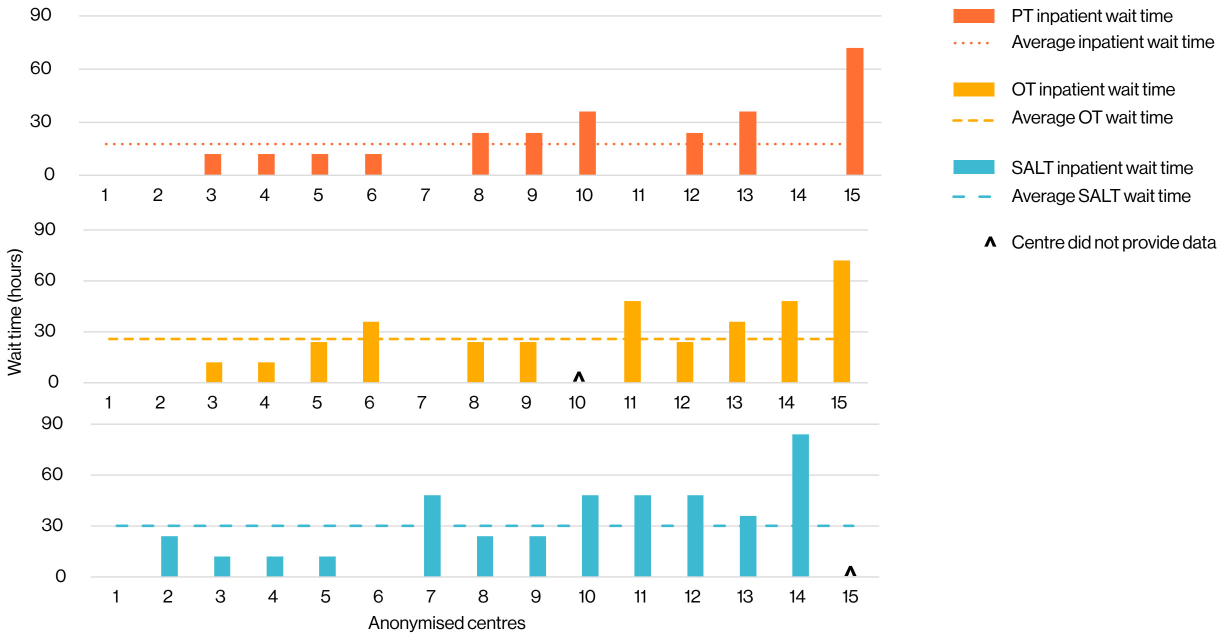
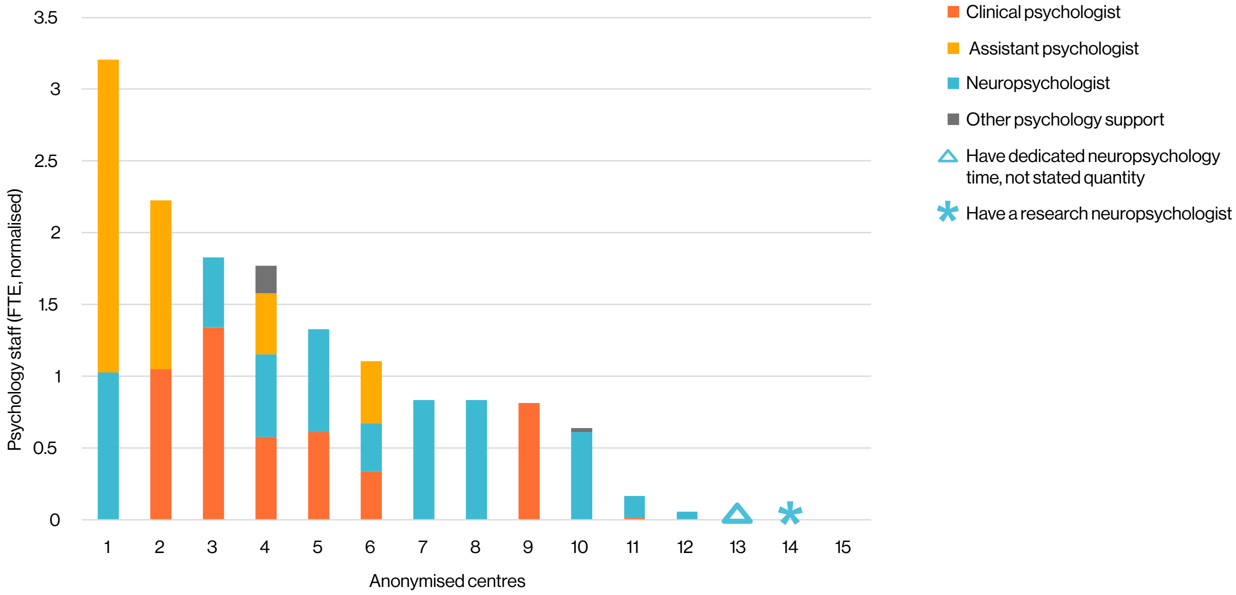


Figure 15: Psychology time dedicated to neuro-oncology in full time equivalent (FTE), across clinical psychologists, neuropsychologists, assistant psychologists and other psychology support. Data are normalised by patient numbers to an average centre size of 50 patients per year.



Psychological care

Brain tumours and their treatment can cause profound cognitive, behavioural and mood-related challenges, potentially affecting a child's quality-of-life, emotional wellbeing and long-term development (36). Neuropsychologists and clinical psychologists play a key role in identifying, assessing and monitoring these deficits through structured neuropsychological assessments. They have a central role in supporting the quality-of-life of children, providing appropriate interventions and advice to support development and mental health (37,38). Inclusion of neuropsychological outcomes has become a primary research aim for clinical trials in paediatric neuro-oncology, with collaboration through the neuropsychology community and SIOPE recommending standardised testing for children (39–41). However, the reliance on the standard testing pathway means that, in centres that are unable to provide neuropsychology follow-up, trial assessments are often delayed or incomplete.

The importance of accessing both clinical psychology and neuropsychology is recognised by all centres, with every centre demonstrating some involvement in psychology research. This is an important achievement, given the relative lack of research into many other aspects of the supportive care of brain tumours, such as rehabilitation. Further work should focus on psychological interventions to improve quality-of-life in those living with the long-term effects of a brain tumour.

In the most extensive pathways, centres are able to offer:

- Structured follow-up and ongoing care well beyond treatment end;
- A flexible and accessible service, available for urgent care;
- Excellent sibling and family support;
- Extensive collaboration with the wider neuro-oncology MDT, including training other specialists in the psychological needs of children and young people with brain tumours;
- Research activity beyond involvement in clinical trials.

Some, but not all, centres have highly specialised neuro-oncology psychology teams. 10/15 centres reported dedicated neuropsychology support for patients with brain tumours, and 7/15 centres have dedicated clinical psychology support **(Figure 15)**. Two out of 15 centres lack any dedicated clinical time from a psychologist for neuro-oncology patients. While this does not mean that patients are unable to access psychological support, brain tumour-specific symptoms and sequela may be missed by a generalist without training in the specific needs of patients with a brain tumour.

Challenges to delivering timely and comprehensive neuropsychology and clinical psychology care for all patients include:

- **Long waiting times in neuropsychology, with an inability to fast-track patients in some centres.** A risk for centres without dedicated support is that patients with a brain tumour cannot be prioritised; outpatient neuropsychology waiting times range from 5 to 52 weeks (mean 19 weeks), and a third of centres are unable to fast-track high-risk patients to neuropsychology. This impacts the assessment and understanding of often substantial neurocognitive and rehabilitation needs.

- **While all centres can fast-track patients for urgent clinical psychological intervention, some face challenges in meeting all patients' needs.** When asked about the proportion of patients receiving clinical psychology support following assessment of needs, 4/15 centres reported 100% of patients, a further 8/15 reported most (range 78-90%), and 3/15 centres reported limited-to-no capacity to fulfil patient needs, instead relying on nursing teams, charity services and community support.

- **Structured follow-up in both neuropsychology and clinical psychology is not always available to patients.** Patients treated with PBT are typically able to access structured, long-term neuropsychological assessments, but in 6/15 centres other patients are not provided with any structured follow-up, including those with high-risk needs such as treatment with photon radiation. In clinical psychology, 6/15 centres provide no regular follow-up of patients, relying on other MDT members to identify emergent symptoms, while three other centres only follow-up patients with previously identified challenges.

> "There is a large gap in psychologist support […] you get assigned one but they are stretched so thinly you virtually never see them so they can't build up relationships with kids."

> "Support after surgery has been more difficult, particularly regarding psychological support and understanding the long-term implications on behaviour and learning. We have to fight all the way to get access."

Patient feedback through the Brain Tumour Charity's "Improving Care" surveys.

Therapeutic and holistic play

Therapeutic and holistic play is a branch of allied health practice that provides support to children throughout the treatment pathway. Play helps children to make sense of healthcare-related experiences and learn to process, communicate and regulate their emotions. Health play specialists (HPS) are often crucial members of the neuro-oncology MDT, working closely with other clinical members to prepare children for treatment and scans by providing a distraction to reduce their anxiety, as well as helping with post-surgical recovery and rehabilitation (24,33,42). As well as supporting the emotional needs of patients and their families, the involvement of an HPS in a neuro-oncology team can help optimise resources, reducing the need for anaesthesia or repeated scanning (11).

Box 5: Example of best practice in therapeutic and holistic play

One centre ran a trial using an HPS to prepare patients for, and support them during, MRI scans without general anaesthesia. Over 7 months, 93% of the 180 patients who would have needed anaesthesia to undertake a scan had good quality images without it due to the HPS's input.

All centres are able to provide therapeutic play to patients to prepare them for, distract during, and process emotions after healthcare experiences. Centres provide play until at least age 16 (with no lower age limit), with some centres able to offer support beyond 16, mostly during radiotherapy or if patients had developmental delays. Centres have a wide variety of therapeutic and holistic play options available to patients, with teams showing a great deal of creativity to provide normal play alongside support during healthcare procedures.

HPSs are an integral part of the child's support system at the hospital, but are not always part of regular updates on patient care. In most centres, HPSs are integrated into the wider MDT (attending MDT meetings in 9/15 centres, and engaging with teams across the shared care network in 12/15 centres). However, only 3/15 centres reported that their play teams are involved in daily handovers with the nursing staff to be updated on a child's needs.

All centres have dedicated HPSs for neuro-oncology (Figure 16) but their capacity is limited. The need for play to be involved in multiple aspects of the patients' care (treatments, rehabilitation, education and psychological care) means that the small number of dedicated staff are at times stretched, with 4/15 often relying on team members from the wider hospital play team to assist.

Only 49% of respondents to the patient feedback surveys reported access to a play specialist.

14/15 centres also employ play leaders or facilitators, alongside a range of other specialists such as support workers (8/15 centres), play managers (7/15 centres) and external services such as music, sport, art, stories, clown doctors and pets. While 4/15 centres have funded dedicated radiology HPSs available to support all hospital patients during this particularly challenging aspect of treatment, only 8/15 centres reported capacity from the neuro-oncology play team to support patients through imaging and radiotherapy.

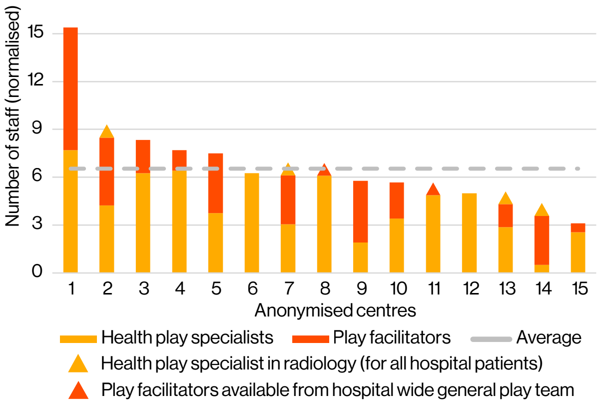
While almost all centres reported access to sensory equipment, a playroom and toys, some centres are limited in access to creative and exercise resources. Centres are highly dependent on charity funding for play resources; 11/15 centres rely entirely on charities to provide play equipment, while only 1/15 has entirely Trust-funded play resources.

> "I like the hospital as the play therapist plays with me and lets me do arts and crafts ... My favourite [specialist] is the play therapist."

> "There wasn't anything in place for special need children, the children play specialist hardly came to see my child."

Patient feedback through the Brain Tumour Charity's "Improving Care" surveys.

Figure 16: Number of play staff available across centres. Data are normalised by patient numbers to an average centre size of 50 patients per year.



Supportive, palliative and end-of-life care

Supportive and palliative care aims to improve quality-of-life by treating the symptoms and side-effects of brain tumours and treatment. It also includes end-of-life care focused on the last 6 months of a terminally ill patient's life (11,43). A crucial aspect of this care is ensuring appropriate planning and coordination as part of an ongoing discussion with patients and their families (44), decreasing uncertainty, improving hope, and reducing decision regret (45). Palliative care can include many different specialities, with the overarching aim that patients and their families are able to lead as close to a normal life as possible (44).

Ensuring supportive care for all children and young people with a brain tumour was a key focus for all centres. Despite the challenging environment, clinical teams are striving to go above and beyond to ensure, where possible, that patients could receive end-of-life care in the place chosen by them and their families. Remarkable dedication and compassion were seen from team members who deliver this care, often on top of other clinical duties (11).

Centres generally reported two models of delivering palliative care:

- In 9/15 centres, palliative care is led by a specialist and a separate palliative care team.
- In 6/15 centres, palliative care delivery is led by the neuro-oncology MDT, with support from palliative care teams

This variation may be because paediatric palliative care is a relatively new speciality (46), with centres developing services at different rates. Each model has its own advantages and challenges, balancing the need for experience of palliative care with specialist knowledge of brain tumours.

Regardless of the model chosen, centres reported regularly planning for palliative care needs, with almost all (13/15) planning for palliative care in parallel to active treatment. 14/15 report the use of advance care plans, where a patient and their family are involved in planning future care, using standardised tools such as the Child and Young Person's Advance Care Plan (CYPACP) (47).

Centres also reported specific challenges in delivering palliative care. Capacity, particularly for out-of-hours care, is a common problem **(Figure 17)**, with only a minority of centres (6/15) able to provide 24/7 care for all of their patients. Generally, palliative care provision across the entire region is difficult in centres with large, rural geographies. The availability of services is often dependent on the local set-up of hospices, the distance to the PTC, and the ability of individual MDT members to drive to see patients.

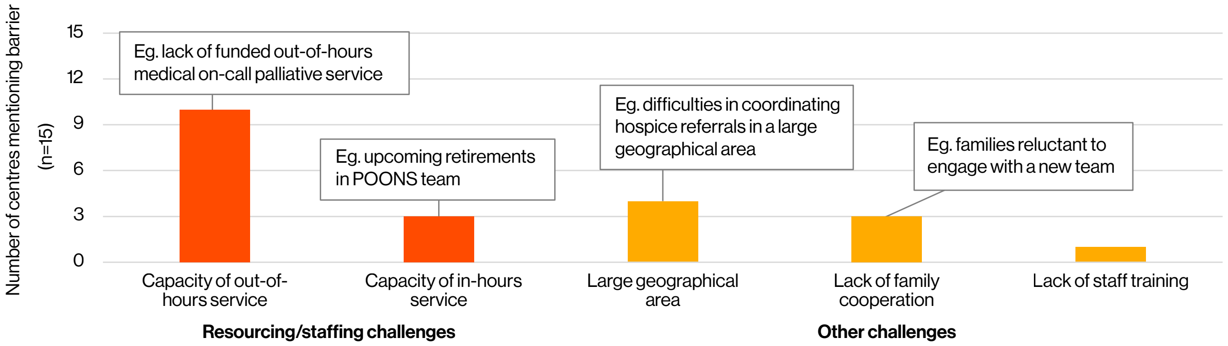
Although working with community teams was often reported as a challenge, many centres have developed innovative solutions, ensuring GPs, local hospitals, community teams and hospices are informed of patients' needs. These include:

- Community services being able to attend hospital meetings (7/14 centres), e.g. community/hospice teams participating in weekly palliative care MDT or GPs being invited to discharge meetings. One centre integrates PTC services with a local hospice, with joint appointments and a shared computer system.

- The POONS/nursing team providing outreach care (6/14 centres), e.g. joint home visits with POONs, a hospice nurse and/or the GP.

Bereavement support is always available, but what is on offer varies. At its best, there is comprehensive support from the nursing, oncology, palliative care, psychology and play therapy teams, with assistance from charities and hospices. For some, this is limited to signposting to local charity options.

Figure 17: Perceived barriers to providing wraparound palliative/end-of-life care for children and young people, as reported by the 15 neuro-oncology centres. Resourcing/staffing capacity (red) was the largest single challenge, particularly out-of-hours, although centres reported other challenges (orange).



03

Beyond Treatment

What do we mean by “beyond treatment”? In this section, we look at the services provided to patients beyond the traditional bounds of treatment, a unique aspect of treating children and young people with a brain tumour. This includes the support needed to move back into education and continue to be monitored for late effects, as well as transitioning into adult services.

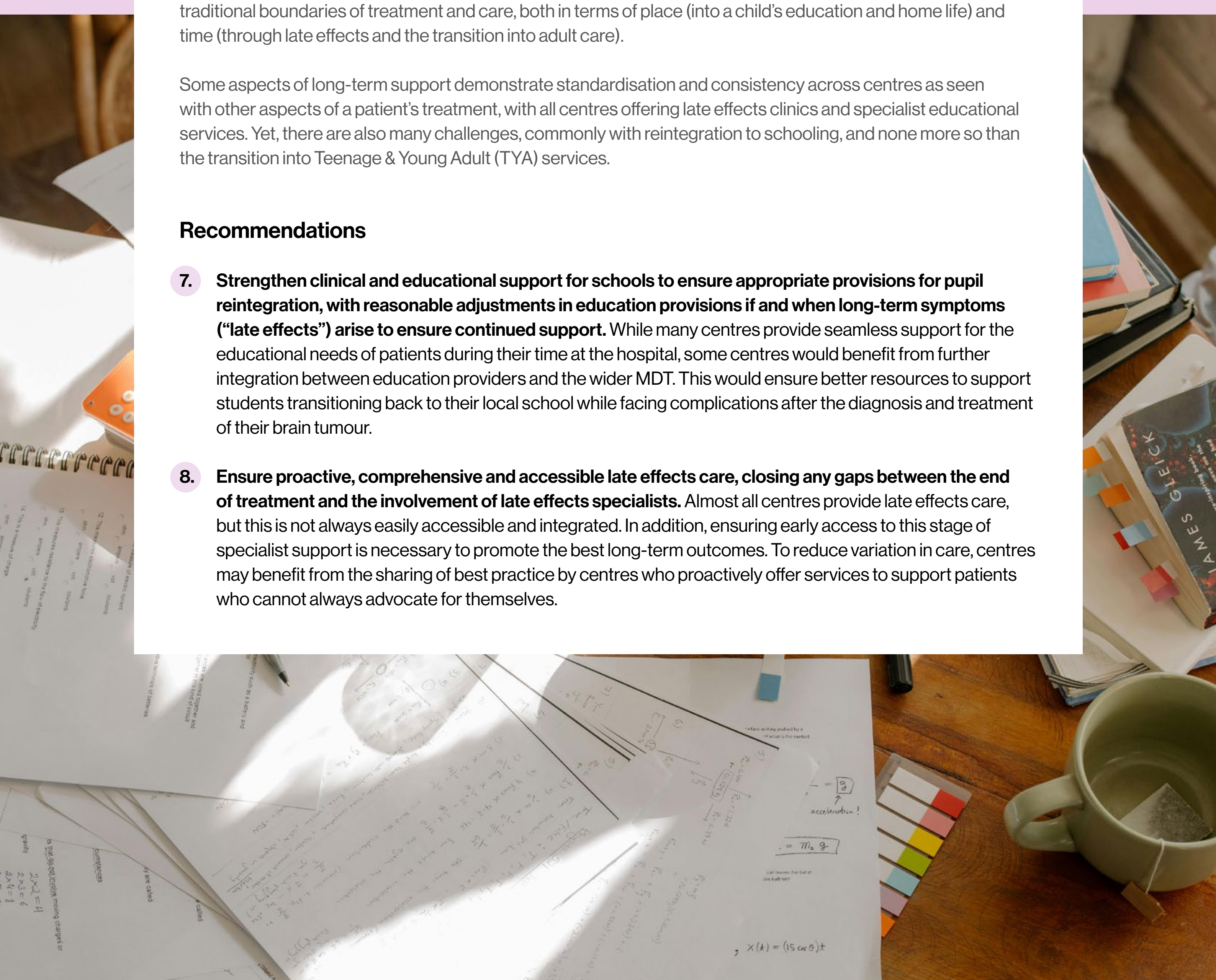
The impact of a brain tumour on a child or young person is complex and wide-ranging, extending far beyond the traditional boundaries of treatment and care, both in terms of place (into a child’s education and home life) and time (through late effects and the transition into adult care).

Some aspects of long-term support demonstrate standardisation and consistency across centres as seen with other aspects of a patient’s treatment, with all centres offering late effects clinics and specialist educational services. Yet, there are also many challenges, commonly with reintegration to schooling, and none more so than the transition into Teenage & Young Adult (TYA) services.

Recommendations

7. **Strengthen clinical and educational support for schools to ensure appropriate provisions for pupil reintegration, with reasonable adjustments in education provisions if and when long-term symptoms (“late effects”) arise to ensure continued support.** While many centres provide seamless support for the educational needs of patients during their time at the hospital, some centres would benefit from further integration between education providers and the wider MDT. This would ensure better resources to support students transitioning back to their local school while facing complications after the diagnosis and treatment of their brain tumour.

8. **Ensure proactive, comprehensive and accessible late effects care, closing any gaps between the end of treatment and the involvement of late effects specialists.** Almost all centres provide late effects care, but this is not always easily accessible and integrated. In addition, ensuring early access to this stage of specialist support is necessary to promote the best long-term outcomes. To reduce variation in care, centres may benefit from the sharing of best practice by centres who proactively offer services to support patients who cannot always advocate for themselves.



Education

A unique challenge in the treatment of children and young people with cancer is dealing with the inevitable impact on their education; frequent hospital trips can lead to time out of school, while the impact of a tumour and its treatment can cause profound cognitive, physical and psychological impairments that negatively impact learning (48). With everything else in a child's life set to change following diagnosis, school can play an important role in helping a child and their family maintain a sense of normalcy, maintain contact with friends, and enhance wellbeing.

Education provisions initially involve hospital-based education for children receiving treatment and care as inpatients, before moving on to school- (or home-)based education during and following treatment. Local authorities are legally responsible for arranging education for a child whose illness prevents them from attending school, and hospitals are expected to work with schools to provide alternative provision (49–51). When returning to their school or education provider, health advice and suggested learning support provisions are often provided by the hospital team to the child's local school, but there is no standardised way to provide this information.

There are several areas of consistency across education, reflecting areas where guidelines are present, with all centres working hard to ensure access to appropriate education while a child was in hospital:

- **Nearly all centres (12/14*) are able to provide educational support by the legally required sixth day** of missing school, if the child is well enough to access it, with 5/14* centres consulting the parents and medical staff to determine when it is best for the child to begin.

- **11/14* centres acquire attainment information from the child's school** to feed into their pupil profile, with all centres conducting their own internal assessments. However, what is assessed and how these results are used varies, with more evidence needed to understand how beneficial and impactful these assessments are.

- **All centres collate evidence through a combination of the educational and nursing staff to support the EHCP** application if a patient's needs meet the requirements of the local authority.

Centres also reported **challenges and barriers** to delivering optimal education to patients with a brain tumour:

- **Specialist training:** While all 14* centres have specialist teaching staff trained in the impact of a brain tumour, and have support from a special educational needs coordinator (SENDCo), only 6/14* centres reported that the educational teams are trained to support patients with physical disabilities or profound and multiple learning difficulties (PMLD).

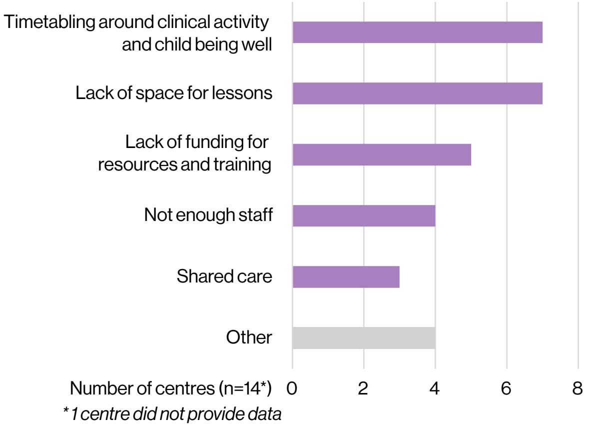
- **Integration between the clinical and educational teams:** While 8/14* centres refer patients upon admission (2/14* automatically), 6/14* centres require the hospital school to find patients in need of educational support, and teachers do not attend any MDTs in 2/14* centres.

- **Funding and resources:** The child's health is an understandable barrier to delivering educational support, but hospital staff reported others, including lack of space and lack of funding for both resources and training **(Figure 18)**.

> "The medical expertise is amazing but the day-to-day support [after leaving hospital] is just not available … [the patient] has struggled significantly at school and there have been very few resources to help with that."
>
> Patient feedback through the Brain Tumour Charity's "Improving Care" surveys.

Challenges also emerge at the point of discharge. Although all centres contact the child's local school and provide a plan for reintegration, there are no guidelines on the depth of provisions to support local school teachers to understand the child's needs and adapt their teaching accordingly. Nor is there any clarity on whether the education teams are involved in regular check-ups with the child and their school at key transition points or when a child's needs have changed.

Figure 18: Barriers to providing educational support to patients while at a hospital, as reported by centres.



Late effects and aftercare

"Late effects" describes the long-term impacts of a brain tumour, which are experienced by a significant proportion of survivors of childhood brain tumours, as a result of their treatment or secondary to their tumour (30,52). These symptoms can vary significantly - including challenges with mobility, puberty and fertility, seizures, impaired cognitive functioning, and psychological wellbeing - and can emerge many years after treatment has finished (52).

There is an increasing recognition of the importance of long-term follow-up of children and young people who have received treatment for a brain tumour, particularly with the emergence of new chemotherapeutic agents and the improving survival rate of many types of brain tumour. Initiatives such as the National Cancer Survivorship Initiative are looking at long-term side effects of cancer treatment from a national perspective (53), but it is also essential that centres proactively put in place infrastructure to plan care and support patients in the long-term.

> "We are missing people understanding that a brain tumour isn't something that can just be taken out. It lasts for the rest of your life."
>
> Survivor of a childhood brain tumour

Generally, centres are consistent across their model of delivering late effects care, including:

- **Teams involved:** Most centres deliver late effects care through the neuro-oncology MDT for the first 5 years post-treatment, before passing on to a dedicated late effects team; 12/15 centres followed this model **(Figure 19)**.

- **The type of care delivered:** 14/15 centres provide late effects and aftercare clinics, 14/15 have dedicated CNS support, and most (11/15) have wellbeing checks with psychology. All centres also offer multiple contact points to follow-up with patients' aftercare needs. These are dependent on the needs of each patient, be it endocrinology support, surveillance imaging or general clinic appointments.

Other areas of the late effects services show variation in provisions for patients:

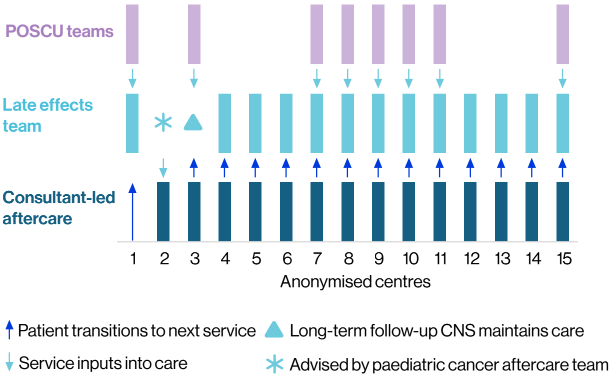
- **Specialities involved:** Most centres involve a consultant in late effects (10/15 centres) alongside other medical consultants, nurses (late effects CNS in 12/15 centres, and/or paediatric CNSs in 10/15 centres) and a variety of other support staff (10/15 centres). It is common to continue to provide access to psychological care (12/15 centres), although long-term rehabilitation is only available in 6/15 centres.

- **Use of end-of-treatment summaries:** All centres provide end-of-treatment summaries as a key component of aftercare, ensuring all clinical teams remain informed of the treatment status and needs of patients. These are also provided to patients and their families to ensure they are aware of these issues and to support their input into long-term follow-up. However, the time at which these are produced and how comprehensive they are vary greatly. Summaries are provided within 3 months of care to all patients in 10/15 centres, but only to some patients in 3/15 centres, while the remaining two centres provide this at a later point in the patient journey. The details provided in the end of treatment summaries are not consistent, with only 5/15 centres including a follow-up plan. More data are needed to determine how these summaries are used and how well they support patients' long-term aftercare.

What is not yet clear is the consistency and depth of long-term support on offer. Some centres indicated that patients were required to advocate for themselves, which may be beyond a person's ability. Access to support from key specialists, such as endocrinologists, psychologists or rehabilitation specialists, may require multiple appointments and referrals, rather than a patient being provided with a proactive and coordinated approach. Further investigation in future review rounds will seek to uncover more details to determine where practices can improve.

> Only 46% of responses from the patient feedback surveys indicated that they were told about support for late effects.

Figure 19: Schema of how late effects care is delivered across different the 15 centres, representing patient transition and service input into care.



Teenagers and young adults

Children and adults require very different care and commonly have very different tumours. The transition from paediatric to adult services, particularly those in the 16-24 age category, poses a challenge to patients needing continuity of care through changing needs. Ensuring proper transition for these teenagers and young adults is essential due to the complex needs of this patient group, who often react differently to treatments, can have lower survival rates, face barriers to entering clinical trials, and experience unique psycho-social and developmental challenges (54–56).

While we asked centres to describe their TYA services, this was not an area on which they were assessed given that these services are generally separate and/or delivered in collaboration with adult neuro-oncology MDTs. We recognise the unique challenges that TYA services face and in order to assess the provision of their service in the future, this area requires a more in-depth review.

Centres differed significantly in how they delivered TYA services, reflecting a lack of consistency in how these services were set up and funded. Key areas of variation included:

- **Transition age and period:** The majority of patients leave the paediatric service after the end of treatment at 16 years old, to be supported by TYA teams, and reach adult services at 19 years old, but there is variation. Patients can enter TYA services from 13 to 18 years old, and can enter adult services between 18 and 25 years old.

- **Service staffing:** While many centres have well-staffed and dedicated TYA services, 4/15 centres do not have a dedicated TYA unit and 5/15 centres do not have either a dedicated TYA CNS or support worker. Most centres also do not have dedicated TYA psychosocial and rehabilitation teams or support for relevant concerns like fertility.

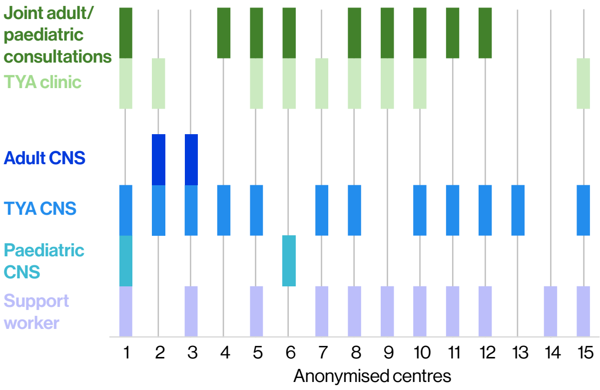
- **Service funding:** TYA services are often funded by charities; indeed, four centres lack any NHS-funded TYA posts. Across the UK, charities fund five TYA units, four TYA CNS posts and nine TYA support worker posts, with the Teenage Cancer Trust being the main funder. While charity funding allows patients to access additional services, it can create inequality across the UK and is a less sustainable funding source compared to NHS-funded services.

- **Support for transition from the paediatric team:** The paediatric MDT usually coordinates patients moving to TYA services, and 12/15 centres continue to provide input even after patients have transitioned to TYA services. However, across teams, the exact input from the paediatric and adult teams during the TYA transition varies, with no centre having exactly the same set-up **(Figure 20).**

Given the national variation in TYA services, it is unsurprising that many centres reported challenges with the transition of patients to TYA care. These challenges include:

- Some services not being available to adults (e.g. specialised psychological support or rehabilitation, 7 centres);
- Poor communication of transition plan/no clear pathway (5 centres);
- Delays to transferring care to certain adult services (4 centres);
- Barriers to continued trial access after transitioning to adult care (4 centres).

Figure 20: Schema of different staff members/clinics supporting patients transitioning from paediatric to TYA services across the 15 centres.



04

Research and Clinical Trials

What do we mean by research and trials? In this section, we look at the pre-clinical research activity in paediatric neuro-oncology, which includes basic and translational research being carried out by scientific research groups (normally at an associated university, but at times also in collaboration with clinical staff). We then look at clinical trials, including trials open or about to open to patients at the time of data collection.

The UK is a hub of research and trials activity in paediatric brain tumours, demonstrating significant strength in the breadth of activity and collaboration. Key challenges remain in ensuring equitable access to trial opportunities, both geographically and across all tumour types.

Recommendations

9. **Increase the breadth of research into new treatment and care options, ensuring the inclusion of all tumour types.** This will ensure all children and young people with a brain tumour can benefit from the UK's strong research infrastructure, no matter how rare their tumour. Research funding should cover both patient quality-of-life and the development of new treatment options, with a strong focus on translating this work into clinical practice.

10. **Build out the NHS workforce supporting clinical trials with allocated staff and protected time, including clinical academics, trials nurses, administrators and other support staff.** Ensure necessary trial assessments (e.g. neuropsychological, ophthalmology, endocrinology etc.) are appropriately funded and resourced. Increasing the ability of the NHS workforce to support clinical trials, which may require additional dedicated staff such as research nurses, or other clinical staff such as psychologists or radiologists, and dedicated time from academic clinicians, will ensure that all nations and regions of the UK have the capacity to open new trials.

11. **Where feasible, ensure patients can access clinical trials as close to home as possible, by tackling barriers that delay trials from opening across more centres.** Centres should work to ensure patients can access clinical trials, and novel therapies, as close to home as possible. Where this is not feasible, funding should be available for family travel and accommodation to ensure equitable access.

Pre-clinical research

Pre-clinical research is essential in deepening the understanding of brain tumour aetiology, driving the discovery of new treatments and improving diagnostic methods. An active and broad community engaging in basic and translational research is essential, because it is common for many potential therapies to falter in early phases of clinical trials.

Our data highlighted a number of key strengths in preclinical research for paediatric brain tumours in the UK. **Areas of excellence included:**

- **A broad range of organisations fund pre-clinical paediatric brain tumour research, suggesting a healthy and competitive funding ecosystem.** Centres held over £55 million in grants for preclinical paediatric brain tumour research between 2016 - 2023 from 60 different organisations. Charities play a central role in driving forward developments from laboratory testing to clinical practice, funding almost 90% of basic and translational research **(Figure 21).** Conversely, the government provides over half of all infrastructure spending in paediatric brain tumour research; this input to support research capacity is a marked contrast to the situation in adult brain tumours (57).

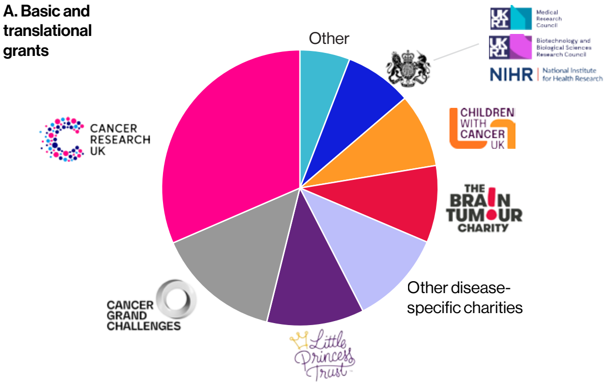
- **The UK research community is well-networked, with all centres engaging in national and international networks.** The UK paediatric brain tumour community demonstrated excellent networking and integration, with most centres reporting work with key national and international organisations: individual special interest groups alongside CCLG (14/15 centres), SIOPE (13/15 centres) and the Experimental Cancer Medicine Centres Network (ECMC) (12/15 centres). Many centres also reported strategies to encourage collaboration across research and clinical groups: supporting staff to take on research positions, having the clinical team engage with students, and holding conferences to share findings and collaborate on new ideas.

However, we also identified **key variations and potential challenges:**

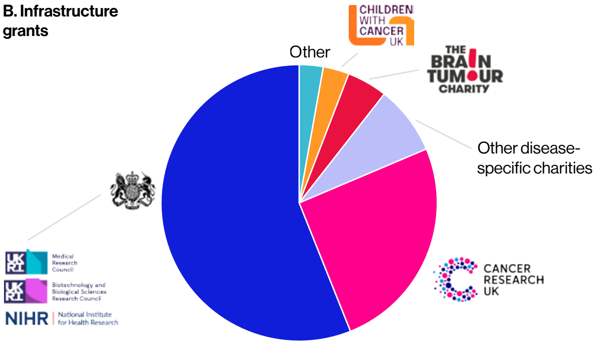
- **Despite the large and varied funding landscape for basic and translational research, four centres received 98% of all grant funds.** Centres also reported corresponding differences in the number of staff supporting research and a variation in the number of papers published in the previous 5 years (as a proxy of research output), varying from 0 to 363. While a concentration of research activity in a small number of academic centres will not inherently impact patients, variations between centres in research infrastructure may impact clinical research activity.

- **Most pre-clinical research activities focus on astrocytomas and medulloblastomas**. The vast majority of reported grants focus on either astrocytomas or medulloblastomas (35 for the former and 19 for the latter, out of a total of 73 grants) with non-tumour specific research being the next most common. Fewer research projects are focusing on ependymomas, pituitary tumours and atypical teratoid rhabdoid tumours **(Figure 22).**

Figure 21: Proportion of funding reported for paediatric neuro-oncology research reported by the 15 centres in 2016 – 2023, by funder, for A. Basic and translational research and B. Infrastructure.

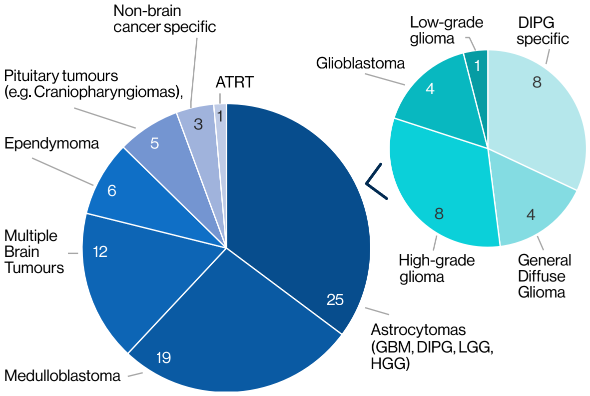


A. Basic and translational grants



B. Infrastructure grants

Figure 22: Number of paediatric neuro-oncology grants reported by the 15 centres in 2016 – 2023, by cancer type.



Clinical trials

Clinical trials serve as platforms to test novel therapies that may improve survival, enhance stratification, or optimise existing treatments. Due to the rarity of paediatric brain tumours, it is essential that research is coordinated nationally or even internationally; clinical trials are often organised at a European level. At a UK level, the coordination of the funding for, and opening of, clinical trials is often led by the Cancer Research UK Clinical Trials Unit (CTU) in Birmingham. Given the poor prognosis of many types of paediatric brain tumours, it is the ambition that every child who is eligible for a trial is offered the opportunity to participate, no matter where they live in the UK.

Our data outline an active clinical trials landscape in UK neuro-oncology centres, with every centre reporting at least one open interventional clinical trial:

- **All centres are participating in trials offering patients access to new treatment methods or supporting research for future treatments (Figure 23),** with every centre running between 3-8 phase III trials. New treatment and early phase trials (I-II) are more commonly open in the largest centres.

- **Of the 30 trials/studies open* in UK paediatric neuro-oncology centres in the summer of 2023, 22 were interventional trials, and 16 of those focused on new treatments (Figure 24).** Of the 16 new treatment trials, three were testing new compounds, while the other 13 were repurposing compounds. The majority of these trials were non-brain cancer-specific, although several focused on glioma. In contrast to the amount of pre-clinical research activity, very few trials focus on medulloblastoma and germ cell tumours. Other rare tumour types are also lacking clinical trials.

- **Industry plays an important role in trial funding.** While overall funding for all trials is split 50:50 between commercial and non-commercial funders, the majority of new treatment trials receive commercial funding (63%).

While phase I and II trials require complex set-up and specific resources to deliver, phase III trials should be able to be run in any PTC. Only 3/9 phase III trials are open in all 15 PTCs, hindering access to these novel therapies for many patients across the UK (highlighted in **Figure 24**). **Centres reported key barriers to widening access to trials for children and young people with a brain tumour:**

- **The largest reported barrier to running trials is the lack of support services and clinical staff, principally research nurses.** Despite significant enthusiasm and commitment to research, clinicians, nurses and AHPs struggle to gain time for research and often there is no additional research funding provided by the Trust to support staff. Additionally, alongside insufficient admin capacity, limited capacity of services that support trials, such as psychology, ophthalmology and radiotherapy, were cited as barriers. Wider funding to allow the inclusion of these services within trial grants, as well as ensuring protected time for the staff involved, may be necessary to remove the barriers preventing centres from opening more trials.

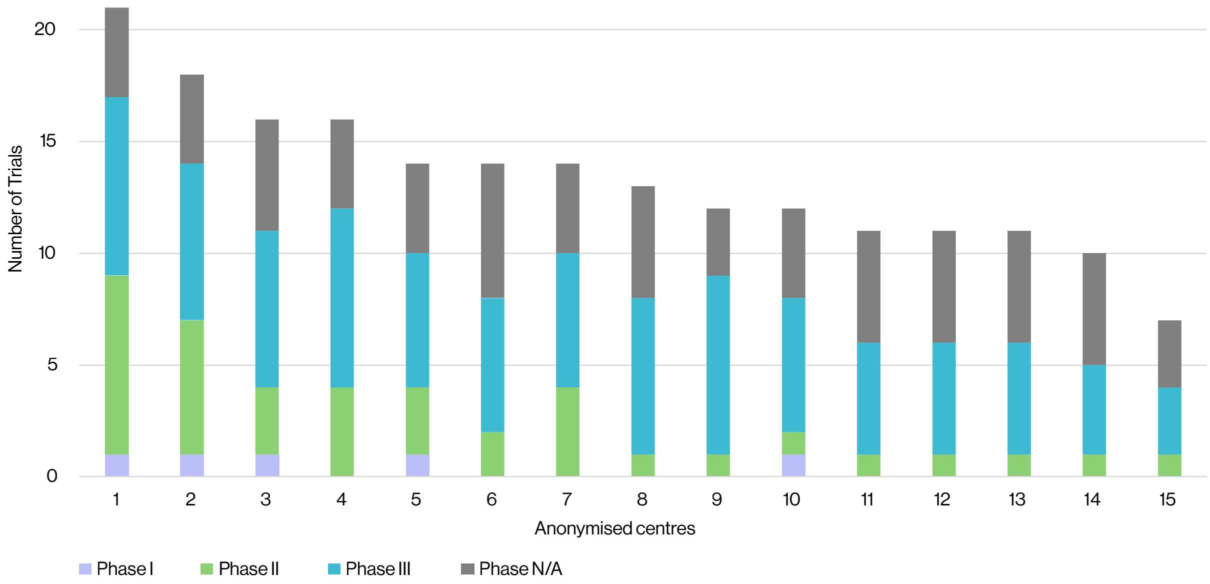
- **Most trials require significant travel for patients, especially those living rurally and/or far from the PTC.** Most centres (12/15) reported that they can refer patients to clinical trials at other centres, but this could be anywhere in the UK. Even when a trial is available at a patient's local PTC, trial treatments are rarely delivered close to home, making access more difficult for patients living in rural areas; only 3 out of 15 centres said that elements of trials can be offered at local POSCUs. As a result, many families must travel long distances to participate in trials, adding significant strain and creating a major barrier to accessing these novel treatments.

While the research and healthcare communities are working hard to find and deliver new treatments, support is needed to translate innovative research into therapeutic candidates. It is well documented that there is a "translational gap" between bench-side research and clinical testing. One recent advancement that has made it through the translational gap is T-cell therapy, now being offered in phase I trials to patients. Programmes such as the Brain Tumour Research Novel Therapeutics Accelerator (58), the Brain Tumour Charity's Translational Award (59), the Great Ormand Street Hospital Charity's Accelerating Novel Therapies Award (60), Cancer Research UK's Childhood Cancer Therapeutic Catalyst (61), and Children With Cancer UK's Research Grants (62), aim to strengthen the flow of novel therapeutics to improve patient outcomes.

** Open trials include any trial in a UK centre that is in set-up or actively recruiting in summer 2023, allowing neuro-oncology patients at the time the possibility of accessing it.*

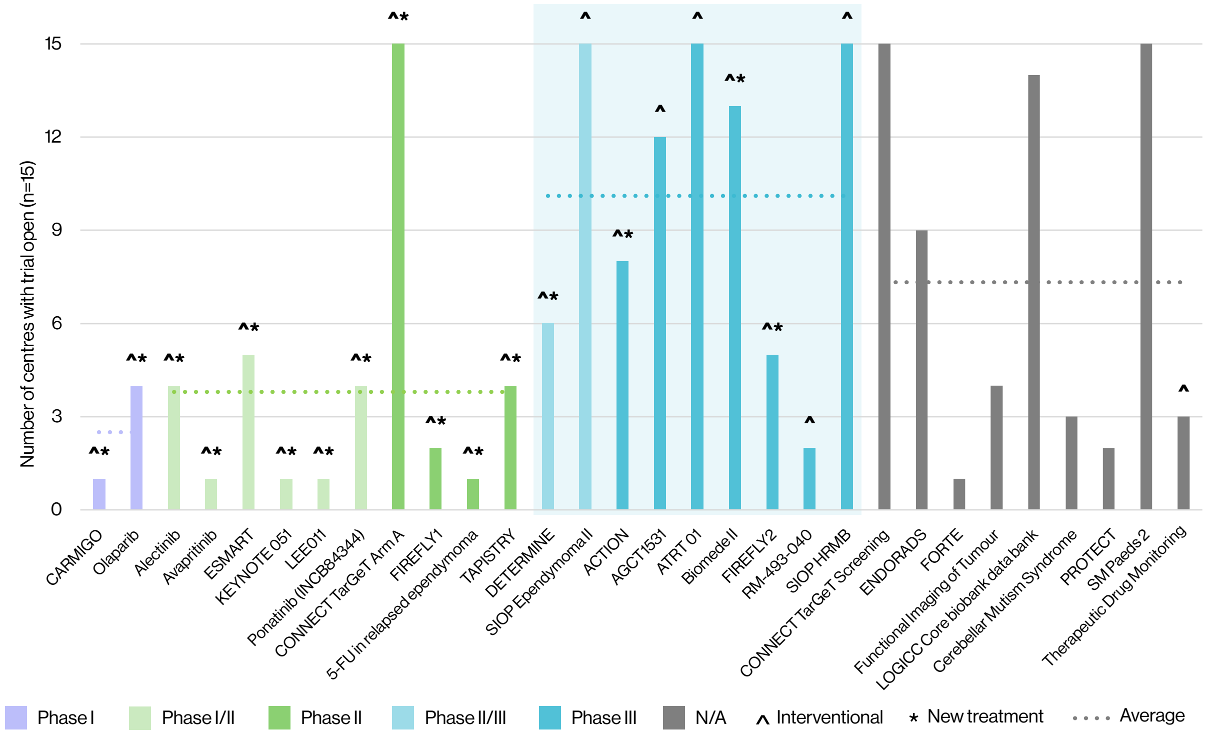
Clinical trials cont.

Figure 23: Trial types open† in 2023 to children and young people with a brain tumour across centres, by phase; N/A imputed where trial phase not given or is not relevant (e.g. observational studies).



† Self reporting means some trials may be open in more centres but location information was not available

Figure 24: Trials open† in 2023 to children and young people with a brain tumour and the number of centres they were open in, by phase and treatment type. Phase N/A imputed where trial phase not given or is not relevant (e.g. observational studies). Phase III trials highlighted as explained in text.



† Self reporting means some trials may be open in more centres but location information was not available

05

Charity Collaborations

Charities support almost every part of the paediatric neuro-oncology pathway. As well as providing support direct to patients, they fund diagnostic and treatment equipment, sponsor key supportive and administrative staff, and provide the majority of research grants. There are at least 111 charities supporting children and young people with a brain tumour, making vital contributions to services and research not currently funded by the public sector. However, there are variations and challenges in accessing charitable support from across the UK, partly related to the breadth of support on offer. Some collaborations also lack long-term sustainability, at times relying on time-limited posts to temporarily address problems rather than establishing permanent solutions

Recommendations

12. **Ensure charitable investment balances equitable impact with long-term sustainability, working closely with the NHS to safeguard key services should charitable funding be reduced or withdrawn.** Centres should ensure they continue to build evidence of the impact of charity-funded roles, arguing for sustainable NHS funding of key services. This can be supported by the sharing of best practice models where services have been successful, backed up by national benchmarking data.

13. **Establish a central directory of neuro-oncology charity services to improve equitable access to support and grants, both regionally and nationally.** Display what is available across regions and the accessibility of grants, helping centres to explore types of available support, and highlighting nationally how charity support is reaching different geographical areas and socioeconomic groups.

Collaborations between centres and patient organisations

Charities play a significant role in paediatric neuro-oncology internationally and the UK is no exception, from funding essential research to providing valuable guidance and support throughout treatment and during key transition points (e.g. transition from paediatric to adult services) to end of treatment and beyond. Moreover, charity support can be vital in supporting children and their families to connect with other patients and families undergoing a similar experience, providing peer support and reducing feelings of isolation and loneliness (11).

At least 111 charities provide dedicated support to children and young people with a brain tumour, reflecting a broad and active charity landscape in the UK. Alongside funding research, national and local charities work to support patients, either by providing advice, support and grants directly to patients, or through funding key services and equipment at centres **(Table 3)**. The most commonly mentioned charities providing direct support or information to patients were Young Lives Vs Cancer (YLVC), The Brain Tumour Charity and Child Brain Injury Trust. However, more centres mentioned working with local charities than any one national charity, except YLVC, reflecting the vital importance of local fundraisers in improving the supportive care services available for patients.

82% of responses from the patient feedback surveys said that they were told about support from charities.

Charities funded over £40 million in research and services in the last 7 years, funding almost all paediatric brain tumour pre-clinical research (see Section 4), and making a significant contribution to care, particularly supportive services like rehabilitation, play therapy, psychological care and TYA support.

While over 80% of charitable funding was for research, centres also reported around £6 million in grants for clinical services **(Table 3)**.

Table 3: Types of support provided to patients by charities, with examples.

	Type of support	Details
Direct to patient support	**Information, resources and advice**	A wide range of national charities, including those specific to paediatric cancers (e.g. YLVC, CCLG, Teenage Cancer Trust), specific to brain tumours (e.g. the Brain Tumour Charity, brainstrust) and specific to the impact of acquired brain injury in children (Childhood Brain Injury Trust)
	Financial grants/ assistance	As well as many national charities who provide advice on eligibility for welfare support, a number of national and local charities provide direct grants to patients and their families, including Family Fund.
	Gifts and experiences	A wide variety of charities, many local, provide experiences and gifts for patients, such as: • Gifts to help adapt to changed life (e.g. wigs from Little Princess Trust) • Holidays/trips away (e.g. sailing holidays from Ellen McCarthur Trust) • Granting patient-specific “wishes” (e.g. Make-a-Wish and Rays of Sunshine) • Memory-making and creative therapy (e.g. Josie’s Dragonfly)
	Bereavement and family support	Many charities focus specifically on providing support to families and siblings: Support around bereavement (e.g. Childhood Bereavement UK and Siblings United) • Family support centres or services (e.g. Candlelighters’ support centre in Leeds, or Grace Kelly Childhood Cancer Trust, whose support workers work across three English counties) • Accommodation for during treatment and as a break (e.g. Calum’s Cabin, a holiday home in West of Scotland for the families)
Support via neuro-oncology centre	**Play therapy resources**	14/15 centres reported funding of play therapy resources by (mostly local) charities
	Clinical staff	10/15 centres reported funding for specific clinical positions, often from local charities, but also nationwide charities such as Tom’s Trust (see case study below).
	Clinical equipment	5/15 centres, including funding for pathology, surgery and imaging equipment.
	Staff training	4/15 centres, highlighting funding provided by Macmillan.
	Building/ refurbishment	3/15 centres, including clinic refurbishment.

This demonstrates the extent to which supportive care services depend on charity input; while this input clearly improves patient care, it presents a challenge in ensuring equitable and sustainable services across the UK – particularly given that charitable funding is vulnerable to the volatile fiscal environment in the UK since 2016.

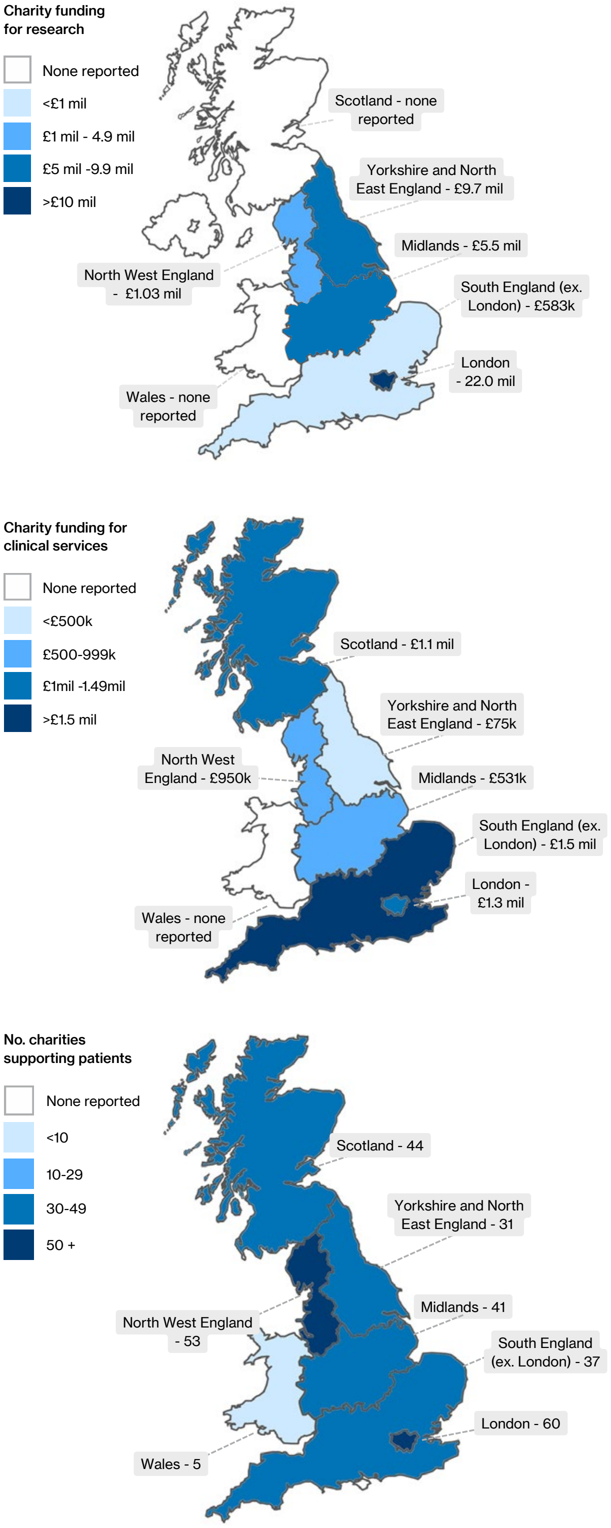
Box 6: Example of a charity supporting development of equitable services

Tom's Trust is a UK charity committed to driving up standards of psychological care for children with a brain or central nervous system tumour through targeted, needs-based funding of clinical and neuropsychology posts. Periodically, formal invitations for applications are welcomed from across the UK, with funding decisions based on gaps in current provision, equity across services, and potential to strengthen the broader network, including collaboration with existing Tom's Trust sites. In parallel, Tom's Trust supports the wider professional community with funding for training, events, and resources, and is launching an online "Resources Hub" to give all psychologists access to high-quality, trusted materials.

This three-tiered approach targets the greatest needs, builds professional capacity, and advances psychological research and care.

Charity funding and support are not equally distributed across the UK, with centres reporting challenges with complex applications, opacity of who offers what, and a lack of options for some patient groups (Figure 25). Centres ranged from holding no charitable grants to holding multiple grants, totalling over £18 million, while the number of charities to which centres signpost ranged from 4 to 49. 7/15 centres reported barriers to working more closely with charities, including lack of time to complete funding applications (3/15), a large number of charities offering overlapping services (2/15), and limited funding for specific regions/patient groups (2/15). Conversely, some centres have developed innovative models of working with charity partners, such as a dedicated committee to assess charity support, charity workers sitting on the MDT, and honorary NHS contracts for charity support workers. While the offer of charity support is extensive, the wide range of different charities and varying restrictions on where funds can be allocated suggest a landscape that could be challenging for some centres to navigate. Therefore, there may be scope for a resource to make it easier for clinicians to have an overview of what support is available to their patients, and to help navigate the complexity of a landscape where at least 111 charities are offering support to patients.

Figure 25: Charity support received by regions of the country – from top to bottom: total research funding; total services funding; total number of charities supporting patients/services.



Conclusions: Strengths and challenges

Brain tumours are the most common cause of cancer death in children; the tumour and its treatment have a profound impact on the physical, cognitive, emotional, social and educational development of children, shaping the rest of a child's life.

It is essential that children and young people diagnosed with a brain tumour have access to the highest quality of treatment, care and research the NHS can provide. Through a comprehensive review of the treatment, care and research provided in 15 UK paediatric neuro-oncology centres, this review has helped highlight the strengths of the NHS as well as common challenges. This has helped us generate an actionable set of recommendations to drive more equitable care across the UK.

What are the key strengths of the paediatric neuro-oncology community?

A key strength in the field that should not be overlooked is the high level of collaboration between UK paediatric neuro-oncology centres. They work closely together as a network via CCLG, national advisory panels and regular meetings between clinical specialities. Clinicians often reach out for informal advice from colleagues in other centres to ensure every patient receives the best possible diagnosis, treatment and support.

This approach has led to a high level of standardisation in treatment and care across the many different tumour types, backed up by high-quality research with most aspects of treatment and radiological and pathological diagnosis underpinned by publications from international organisations such as SIOPE. Additionally, the focus on ensuring patients can receive care as close to home as possible has led to the introduction of robust shared care infrastructure in many parts of the UK, which, despite challenges, remains a significant strength of the field.

As well as in the treatment of paediatric brain tumours, this review revealed striking examples of best practice in quality-of-life care. This is despite the relative lack of standardisation, with several centres having set up comprehensive and specialised rehabilitation, psychological care, play therapy and palliative care services based on a strong desire to improve the wellbeing of patients, rather than because this is required by guidelines. This also ties into an increasing recognition of the importance of long-term support and follow-up, with frameworks in place to guide the educational needs of patients as well as support through late effects. Many of these services are supported by a broad range of charities (with 111 identified in this review) who often fund supportive services that the public sector will not, or cannot.

Finally, it is undeniable that paediatric neuro-oncology benefits from a strong and dynamic research environment, supported by robust collaborations both nationally and internationally. While improvements are not only possible but crucial to ensuring equitable access and encouraging faster progress, the progress made to date would not have been possible without the tireless commitment of researchers, clinicians and charities, working across borders and disciplines.

What are common challenges in paediatric neuro-oncology?

Despite strengths in the field, this review has identified several key challenges impacting the delivery of timely and appropriate care. One of the most significant issues is the delays to some molecular testing and the variation in access to WGS that can impact treatment decisions and trial access. While there is no evidence of variation in outcomes across centres, delays can still have a serious impact on a patient's wellbeing and quality-of-life, adding emotional strain for families at an already difficult time.

Another critical challenge identified in the review is the lack of standardisation in quality-of-life care; without consistent guidelines and frameworks, teams can struggle to argue for spending on certain important services, such as psychological care, rehabilitation, or play therapy. This may result in a substantial variation in resources and staffing capacity across centres identified in this review, with a reliance on general paediatric services in some centres, and teams in many centres work beyond set hours and responsibilities to meet patients' needs. This key challenge is apparent in patient feedback, which demonstrates uneven experiences and outcomes for children and their families, depending on where they receive treatment.

Paediatric oncology involves input into a patient's life far beyond the traditional boundaries of clinical care, whether in terms of place (e.g. education) or time (late effects and transition to adult care). While there has been a lot of effort to develop frameworks in this area, this review highlights limited integration of certain essential services, particularly in the area of education. Children undergoing treatment for brain tumours often face disruptions to their schooling, yet education support is not uniformly embedded into care pathways. The implications for long-term outcomes, development and reintegration post-treatment are profound, with consequences for the child's capacity to lead an independent life in the future.

Finally, there are notable disparities in access to clinical trial opportunities. Participation in clinical trials and other research initiatives is often determined by tumour type or geographical location, limiting access to potentially outcome-changing innovations. A particular challenge is ensuring patients who live far from large academic centres can still participate in new research.

Next steps: A roadmap to delivering more equitable brain tumour care

Throughout this review, we have highlighted recommendations by area of focus. Below, we reflect on what our recommendations mean for key stakeholders in paediatric neuro-oncology as a roadmap to delivering more equitable brain tumour treatment, care and research. The tools and networks already exist to close the gap, and with collaborative action the field can deliver lasting change.

For UK political and NHS leadership: Prioritising access to key diagnostic, treatment and care services to eliminate geographical inequities

The dial on brain tumour outcomes will only move if attention is paid to whether services are equitably funded and delivered. The NHS and government should therefore work to ensure:

a) no patient waits for a formal diagnosis or to start treatment due to NHS resource challenges;

b) there are no geographical disparities in access to holistic, wraparound and long-term care;

c) every patient can be offered access to a late phase clinical trial where available.

This can be achieved through our recommendations, to ensure equitable diagnostic and treatment services, facilitate standardisation of key quality-of-life care services, bolster specialty-specific training for nurses and AHPs, increase the breadth of research and trials, and build capacity in the NHS workforce supporting trials. By implementing these recommendations, national and local leaders can ensure that no child or young person with a brain tumour has their access to treatment, care or research impacted by where they live.

For NHS centres: Collaborating on national challenges while leveraging data and national best practice to address individual road blocks

Some challenges require nationwide action, and the UK paediatric neuro-oncology community should continue its collaborative work through organisations such as CCLG and SIOPE to drive further improvements and standardisation in treatment and care. Other difficulties faced by patients arise from challenges in integration or communication between parts of the patient pathway. Many centres excel in the parts of the pathway for which the MDT are directly responsible – such as clinical treatment and research – but face challenges in more "distant" parts of the pathway – shared care, late effects, education – which are not always well-integrated with the central team. Some centres are able to seamlessly integrate these – and this is the "value added" to ensure patients get a truly excellent service.

Specifically, centres should use the benchmarking data and best practice collected by this review to look at all aspects of their treatment pathway, including those further from the PTC, to ensure a joined up, holistic service.

For the charity sector: Ensuring resilient, long-term investment and prioritise support in areas where centres are not well equipped

The 111+ charities supporting children and young people with a brain tumour make a significant contribution to services or research that the public sector does not currently fund. However, charity support is not always provided in the way that maximises impact and minimises inequity; our data revealed variations and challenges with accessing charitable support in some parts of the UK, as well as concerns about the sustainability of some charity funding within the difficult economic landscape. The charity sector and hospitals should, alongside the NHS, collaboratively consider new approaches to ensure the sustainability and safeguarding of key charity posts.

Another recommendation that emerged during the review was the need for improvement of support available for siblings and families around the time of bereavement. Charities nationally should consider building on local best practice in these areas to ensure families are supported as a patient reaches the end of their life and afterwards.

For the TJBCM: Addressing national challenges and sharing best practice through the Tessa Jowell Academy

TJBCM have a full and ambitious timeline planned to build on their early progress and will continue to work collaboratively with mission partners to address many of the recommendations outlined in this report through its two core paediatric programmes: Centres of Excellence for Children and the upcoming Tessa Jowell Academy for Paediatrics.

Tessa Jowell Academy for Paediatrics

In 2025, TJBCM will launch the TJ Academy for Paediatrics, delivered in partnership with CCLG: The Children & Young People's Cancer Association, the national professional organisation for those working in paediatric cancer, including brain tumours. The Academy will be a free, national platform connecting NHS paediatric brain tumour centres to share best practices and tackle challenges in treatment, care, and research. CCLG runs active brain tumour related groups that foster education, mentorship, and collaboration, complementing the Academy's goals.

Led by an expert Founding Committee, the Academy's content will be developed by and for the community, supporting all brain tumour centres and their staff. It will give professionals greater access to brain tumour-specific training and support, upskilling members in different aspects of neuro-oncology from fundamental courses to advanced training. The Academy will:

- Provide clarity to around existing support and resources already provided by charities and Trusts, improving the accessibility of existing resources for professionals.
- Develop new training resources and courses, including educational workshops, show-and-tell seminars, to address identified areas of unmet need.
- Establish national networks and working groups to collaboratively address key challenge areas.
- Provide opportunities for professionals to connect with other UK specialists to share best practice more broadly across the UK, share experiences, and offer peer support.

Centres of Excellence for Children Programme

Centres who submitted their data to the Centres of Excellence initiative will continue to be supported to deliver services improvements through the provision of bespoke data packages, building on their feedback reports, to help implement recommendations. This support will inform service transformation, empowering centres to advocate for elevated service, and drive ongoing progress.

With each future Centres of Excellence designation round, the Standards of Excellence will be reviewed and refined to reflect evolving best practices and support continuous improvement, raising the bar on what is expected from an excellent neuro-oncology service. Over time, these updates will lead to measurable service improvements as centres work to meet and exceed established standards, as has been evidenced in the adult Centres of Excellence programme, moving TJBCM closer to its 10-year goal of ensuring that every child has access to high-quality, equitable treatment and care.

Abbreviations and glossary

AHP	Allied health professional
BPNG	British Paediatric Neurosurgery Group
CCLG	Children and Young People's Cancer Association
CNS	Clinical nurse specialist
CPD	Continuing professional development
CTU	Clinical trials unit
CYPAPC	Child and young person's advance care plan
DHSC	Department of Health and Social Care
ECMC	Experimental Cancer Medicine Centre
FTE	Full time equivalent
GA	General anaesthetic
GP	General practitioner
HPS	Health play specialist
ISPNO	International Society of Paediatric Neuro-Oncology
MDT	Multidisciplinary team
M+M	Morbidity and mortality
MRI	Magnetic resonance imaging
NHS	National Health Service
OT	Occupational therapy/therapist
PBT	Proton beam therapy
POON	Paediatric oncology outreach nurse
POSCU	Paediatric oncology shared care unit
PT	Physiotherapy/therapist
PTC	Primary treatment centre
RAPNO	Response assessment in paediatric neuro-oncology
SACT	Systemic anti-cancer therapy
SALT	Speech and language therapy/therapist
SEN	Special educational needs
SENDCo	Special educational needs coordinator
SIOPE	European Society for Paediatric Oncology
TJBCM	Tessa Jowell Brain Cancer Mission
TYA	Teenage & Young Adult
WGS	Whole genome sequencing
WHO	World Health Organization
YLVC	Young Lives Vs Cancer

Aetiology – the cause(s) of a specific disease

Biobanking - a storage place for biological samples (such as human tissue, blood, or DNA) that may be used especially for future medical research

Histology – the examination of biopsy or excision material taken from a patient. This can be used to detect and diagnose disease, disease progression or response to treatment

Immunohistochemistry – a laboratory technique used to assist with tumour classification and diagnosis

Early phase trial – a clinical study testing a new treatment on a small group of people to determine whether a drug is safe or the side effects it causes

Late phase trial – a clinical study on a larger group of patients which aims to test whether a new treatment is better than existing treatments

Shared care - the joint delivery of care, not necessarily in the same place or at the same time, both by cancer specialists based at a PTC (such as a consultant oncologist and specialist nursing team) and local care teams (such as POSCU staff, district general hospital staff, GPs and hospice staff). This is often to provide treatment and care for a child closer to their home.

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Tessa Jowell
BRAIN CANCER MISSION

About the Tessa Jowell Brain Cancer Mission

The Tessa Jowell Brain Cancer Mission (TJBCM) is a convening body which delivers transformative national programmes to improve brain tumour treatment, care and research in the UK. It designs and delivers a national portfolio of eight innovative programmes focused on accelerating research, advancing clinical trial infrastructure, improving care for today's patients, and connecting and training NHS staff.

The Mission's work is funded and supported by the government through the National Institute of Health Research, as well as eleven influential cancer charities. Over 100 NHS doctors, nurses, allied health professionals and scientists from across the UK work daily with the Mission to design and deliver its programmes, which are jointly delivered with its partner organisations. TJBCM is a registered Community Interest Company.

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