Exploring parent and school collaboration and communication when supporting children living with the effects of a brain tumour

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Abstract

Children diagnosed with brain tumours are a vulnerable group of children who are likely to need Special Educational Needs (SEN) support upon return to school and throughout their educational trajectory. There is lack of research focusing on communication and collaboration between *school and home* when supporting the needs of a child with a brain tumour, yet the present study has found that this relationship is integral to school staff being able to identify and understand the range of changing support needs of CBTS.

A qualitative case study approach was used along with thematic analysis to draw together and analyse the views of parents of childhood brain tumour survivors (CBTS), CBTS themselves and key school staff. Two case studies were carried out, one at a primary school and one at a secondary school. All participants took part in semi-structured interviews, sharing their experiences of supporting CBTS at school and the practicalities involved in home-school collaborative practice.

The present study demonstrated the importance of the home -school relationship when supporting CBTS, reporting on the need for *early and ongoing* communication between parents and key school staff and for school staff to access CBTS support training, for understanding the narrative of the brain tumour journey and the long-term impact of a brain tumour on child and parents. In addition, the voice of CBTS highlighted the need for school and home to work closely to ensure CBTS were supported appropriately in order to develop skills and independence and experience a longed for ‘normality’. Findings will inform the development of a CBTS school support pathway, CBTS support policy and a CBTS educational liaison service.

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Glossary

ABI	Acquired Brain Injury
APPG	All Party Parliamentary Group
BESA	British Educational Suppliers Association
CBTS	Childhood Brain Tumour Survivor
CRT	Cranial Radiation Therapy
CYP	Children/Young Person
DfE	Department for Education
DIPG	Diffuse Intrinsic Pontine Glioma
DISS	Deployment and Impact of Support Staff in Schools
DFID	Government's Department for International Development
EDTA	Effective Deployment of Teaching Assistants
EHCP	Education Health and Care Plan
GP	General Practitioner
HCP	Health Care Practitioner
IBTA	International Brain Tumour Alliance
IEP	Individual Education Plan
IPBIS	International Paediatric Brain Injury Society
ISCED	International Standard Classification of Education
LAs	Local Authorities
LSCBTC	Levi's Star Children's Brain Tumour Charity
MRI	Magnetic Resonance Imaging
NASEN	National Association for Special Educational Needs
NHS	National Health Service
NQTs	Newly Qualified Teachers
OFSTED	Office for Standards in Education, Children's Services and Skills
RQ	Research Questions
RtE	Return to Education
SATs	Standard Assessment Tests
SEN	Special Educational Needs
SENCO	Special Educational Needs Coordinator
SENCoP	Special Educational Needs and Disability Code of Practice
SLT	Senior Leadership Team
SSRS	Social Skills Rating System questionnaire
SRS	Social Responsiveness questionnaire

TA	Teaching Assistant
UK	United Kingdom
USA	United States of America
UNCRC	United Nations Convention on the Rights of the Children
WASI	Wechsler Abbreviated Scale Intelligence
WHO	World Health Organisation

Background to Study

The study has been influenced by my personal experience of losing my son to a brain tumour. In 2006 my son was unexpectedly diagnosed with a brain tumour aged 6. He underwent an emergency 12-hour operation to debulk a tumour on his brain stem and cerebellum. Watching Levi fight for his life without being able to do anything to help him was an extremely traumatic experience. After spending six weeks on life support, the intensive care consultant team delivered the exceptionally distressing news that Levi was no longer "compatible with life". My son later died in my arms surrounding by devastated, broken family members.

Experiencing such a life changing and beyond devastating loss, compelled us to ensure something positive resulted out of the trauma and intense sadness we were experiencing. Finding ourselves in the centre of the brain tumour community allowed us to identify areas of practical and financial support often needed by families of CBTS and so, after the loss of Levi, we established a charity in his memory to help support other children with brain tumours and their families going through a similar nightmare journey. In addition to supporting CBTS families on a practical level, my professional background of being a SEN teacher, deputy SENCO and a dyslexia assessor, enabled me to understand how my skills could be used to support CBTS upon their return to school after (and sometimes during) brain tumour treatment. This led to the charity expanding and being funded by Macmillan to deliver an educational outreach service for CBTS. Funding for this service unfortunately ceased after 3 years, due to Macmillan making a national decision to stop funding projects relating to supporting *children* with cancer. However, CBTS educational support needs have not ceased and so the educational outreach service continues….without funding.

Working with families of CBTS in my professional role, allowed me to develop an understanding of the range of school support CBTS often require, and the level of communication parents needed with school, but did not always access. My understanding of school reintegration for CBTS does not mean I have complete knowledge of good practice or barriers to practice in this area. I do, however, have an awareness that the level of home-school communication and support accessed by CBTS can vary from school to school, with some schools being unaware of the severity and long-term impact of a childhood brain tumour diagnosis. In addition, attending the hospital brain tumour oncology clinic in my professional role at Levi's Star, allowed me to provide help and advocacy for parents of CBTS regarding communicating their concerns to school, to ensure their child accessed appropriate support upon return to school. I have also spoken to parents whose children were several years post treatment and they were still finding it challenging to communicate with school regarding support for their child.

My research has therefore been influenced not only by my personal journey of losing a child to a brain tumour, but by my professional experience of working closely with parents of CBTS and individual schools and seeing how the level of communication between parents and school can be variable. This is turn can impact the level of support in place for CBTS and the level of stress parents experience when trying to ensure their child is fully supported at school. The study used two qualitative case studies to gather a detailed view of home-school communication and collaboration when supporting CBTS at school, to help identify good practice and areas for development.

Chapter 1 focuses on existing literature that helps our understanding of 1) key concepts, definitions and prevalence of childhood brain tumours and 2) previous research on i) the long-term effects of a childhood brain tumour ii) current guidance for schools when supporting CBTS at school, and iii) perspectives and lived experiences of families of CBTS and school staff, regarding and informing school support for CBTS.

In the interest of transparency, Levi's Star Children's Brain Tumour Charity funded the study, which in combination with my role within the charity could be considered a conflict of interest. However, my professional judgement in the study was not compromised by any personal interest and potential bias was carefully and continually addressed in the study using a reflexive approach (see pg 49).

Chapter 1: Literature Review

1.1 Defining childhood brain tumours, prevalence and diagnosis

To explore and understand the need for close home-school communication and collaboration when a child is diagnosed with a brain tumour, it is necessary to understand what a brain tumour is and the prevalence of childhood brain tumours in the UK.

A brain tumour is a solid tumour in the brain that can be benign and slow growing or malignant and potentially aggressive (https://www.childrenwithcancer.org.uk). It is reported around 420 children are diagnosed with brain tumour every year in the UK (https://www.cancerresearchuk.org). Delays in diagnosing childhood brain tumours in the UK were reported by Walker et al. (2015) in the HeadSmart:Be Brain Tumour Aware campaign. This was successfully set up to develop a strategy to reduce delays in diagnosis on a national and international level, and to create support tools and clinical guidance for healthcare professionals to refer to, when a child presents with potential brain tumour symptoms. Experiencing delay in diagnosis is something I experienced as a parent of a child with a brain tumour and something I have repeatedly heard from parents I work with as part of Levi's Star Children's Brain Tumour Charity (LSCBTC). Several of these parents recall GPs saying they are only likely to ever see one patient with a brain tumour in their career. However, this is of little consolation to the parent whose child has been given a devastating and life altering diagnosis. In addition, national brain tumour charities such as 'The Brain Tumour Charity' (http://www.thebraintumourcharity.org) and Brain Tumour Research (http://www.braintumourresearch.org) report brain tumours are, in fact, the leading cancer cause of death for children and young adults under the age of 40 in the UK (at the time of writing this statistic has been extrapolated by Brain Tumour Research, from a dataset in the Office for National Statistics, 2015 Death Registration Summary Tables). The children's Cancer and Leukaemia Group (http://www.cclg.org.uk) tell us "brain tumours are the most common tumours that develop in children" and slightly more boys than girls are affected. The Great Ormond Street based charity 'Children with Cancer UK' (http://www.childrenwithcancer.org.uk) highlight brain tumours have the highest death rate within childhood cancer. Despite these worrying statistics, Brain Tumour Research (http://www.braintumourresearch.org) report brain tumours receive only 1% of national cancer research spend funding. This disparity makes for alarming reading especially considering there are over 100 different types of childhood brain tumour (www.childrenwithcancer.org.uk) and, as reported by Action Medical Research (https://action.org.uk) "brain tumours are the most deadly of all childhood cancers". The average 5-year survival rate for childhood brain tumours is 74%, but this is not the case for all brain tumours, with survival rates varying depending on tumour type; the saddest statistic being for incurable DIPG tumours (brain stem) where less than 10% of children survive beyond 2 years (www.childrenwithcancer.or.uk).

Although there is a lack of government funding into research and cures for brain tumours (www.braintumourresearch.org) and treatment for a childhood brain tumour has lacked progress in the last two decades, new treatments are being developed (www.thebraintumourcharity.org). Brain Tumour Research have also lobbied parliament calling for NHS England to work towards increasing survival rates for childhood brain tumours. Set against this backdrop, there is increased focus on quality of life for CBTS, (Hocking et al., 2015; Barrera et al., 2017), including the need to better understand educational support needs and outcomes. If school staff are to provide appropriate and targeted support for CBTS and recognise the need to work closely with parents, they require an understanding not only of the prevalence and survival rate backdrop, but of long-term effects of a childhood brain tumour and implications for support practice.

1.2 Research informing our understanding of the range of long-term effects of a childhood brain tumour and the impact on academic outcomes and social adjustment at school

Recognising and supporting individual needs of CBTS requires school staff to be aware of the range of long-term needs CBTS may experience after treatment. Although children with cancer other than brain tumours can also experience difficulties upon return to school (Saatci et al.2019), CBTS are a unique group of children among childhood cancer survivors, whose treatment may include radiotherapy, chemotherapy, proton therapy *and* brain surgery to debulk or remove the tumour. CBTS therefore can be left with a range of long-term difficulties classed as an acquired brain injury (ABI) (discussed on page 20). This section reviews the literature and research which informs current understanding of the potential long-term impacts of a childhood brain tumour, and how this can impact on school performance and outcomes. Research in this field is typically quantitative in design with the upper age of participants being 18 years.

Depending on the size and position of the tumour, children diagnosed with a brain tumour may undergo treatment including neurosurgery to debulk the tumour, chemotherapy, radiotherapy and proton therapy (Cancer Research UK www.cancerresearchuk.org 2019). Having a child diagnosed with a brain tumour is an understandably extremely traumatic, stressful and frightening experience for parents. Afterall, in addition to some brain tumours threatening the child's life (for example, only 10% of children with DIPG tumours survive for more than two years after diagnosis, compared to 90% of children with grade 1 and 2 astrocytoma's surviving for 5 years plus after surgery www.thebraintumourcharity.org), having treatment for a brain tumour can result in negative changes for the child and family, impacting on the present and future. De Ruiter et al. (2012:2) suggest neurosurgery, radiotherapy and chemotherapy treatments for brain tumours cause "structural brain damage". This can lead to neurocognitive sequelae for the child, (Mulhern et al., 2004; De Ruiter et al., 2012; Ullrich, Embry., 2012; Krull et al.,2018; Phillips et al., 2021).

It is unsurprising, after treatment for a brain tumour, a child may be identified as having additional needs (that they did not have prior to diagnosis). Because of damage to the brain, and as reported by the Royal Marsden Guide for Teachers (2019) for children with brain tumours, CBTS can be left with physical, cognitive and social and emotional difficulties that school need to be aware of. Physical impairments can include vision difficulties (Nuijts et al. 2019), hearing difficulties (Williams et al., 2005), motor skills and mobility issues (Varedi et al., 2021), cognitive processing fatigue (Irestorm et al., 2021) ,speech, language and communication needs (The Brain Tumour Charity www.thebraintumourcharity.org) and executive functioning, working memory and processing speed difficulties (Mulhern et al., 2004; Olsson et al. 2014; Van't Hooft et al., 2016). Such a range of difficulties can impact the school performance and experience of CBTS (Mabbott et al., 2005; Barrera et al., 2005; Upton and Eiser, 2006; Kieffer et al., 2012). This is further highlighted in Lonnerblad et al.'s (2017) retrospective longitudinal study and Saatci et al.'s (2019) meta-analysis research study, reported on below.

Lonnerblad et al. (2017) reported CBTS can experience weakness in core academic skills. This retrospective study was carried out in Stockholm with 45 CBTS between the ages 7-18 years, using medical records and standardised academic tests to assess and report on CBTS' literacy and numeracy skills. Tests were carried out with CBTS a year after treatment ended, at the start of a school year, or the year before a key stage transition. Despite having a relatively small sample size, using standardised results was a strength of the study in showing reliability and validity. Results reported CBTS experienced weakness in reading speed, spelling ability and basic arithmetic, with skills in arithmetic and spelling ability deteriorating over time. No information was provided in the study regarding literacy and numeracy skills of CBTS prior to diagnosis and treatment, although such information would have been useful in understanding the level of decline in skills upon the child's school return. In the same way, standardised data gathered upon return to school could help track decline in attainment levels for CBTS that may occur over time. Declining literacy skills are also reflective of a study by Barrera et al., 2005 (see page 6), where parents of CBTS reported their child experienced difficulties in maths and literacy post brain tumour treatment (but again, no information was provided regarding these skills prior to the child's treatment, or the *rate of decline* in these skills over time).

Using individual literacy standardised assessment scores, as opposed to a blanket score for SEN was another strength of the Lonnerblad et al. (2017) study. This meant authors could specifically identify the above reported skills were more negatively impacted than reading comprehension, word comprehension and number sense, indicating CBTS' understanding of concepts appeared to be stronger than their performance in tasks requiring processing speed skills. However, cognitive processing and working memory factors were not measured in this study and could have provided more information regarding reasons for the discrepancy in core skill scores. Other areas of literacy such reading efficiency and writing speed, as well as general ability were not assessed, but could be helpful in further understanding areas of academic weakness for CBTS to inform classroom support and intervention. Despite only focusing on certain areas of literacy and numeracy, Lonnerblad et al.(2017) recommended academic progress of CBTS should be monitored through ongoing assessments, recognising CBTS are not only impacted upon initial return to school, but may need ongoing support, due to experiencing late effects and a decline in neurocognition over time. The study is therefore important in highlighting the need for long- term plans and SEN assessments when supporting CBTS at school. The authors do not, however, advise who is best placed to carry out such assessments, (e.g., school, hospital, school liaison), what specific areas of a child's learning should be included in SEN assessments, or *how* such weaknesses can be supported in the classroom.

1.2.1 Educational Outcomes for CBTS

The stark reality is, as Saatci et al.'s (2019) meta-analysis review of the educational attainment of childhood cancer survivors points out (and concurring with previous studies by Anderson et al., 2009; Lonnerblad et al., 2017), it is children with central nervous system tumours (including brain tumours) who have the poorest educational outcomes out of all childhood cancers and are more likely to have SEN needs. Measuring educational outcomes of children with cancer using the International Standard Classification of Education framework across 11 high income countries, contributed to the reliability and validity of the study. Strengths (particularly relevant to CBTS) include highlighting it is not only cancer related factors and treatment that impact a child's academic performance at school, but the preparedness of school in supporting the child's needs upon reintegration. A school reintegration pathway was therefore recommended by the authors to ensure teachers understand the learning profiles of children with cancer. Recommendations did not, however, suggest which professionals would be responsible for creating such a pathway. In addition, although the study is important in highlighting the need for clinicians, teachers and policy makers to be aware of educational difficulties experienced by children with cancer, it does not focus on what specific educational support or policy should include in practice. It may also be useful for schools to understand more about differences in difficulties according to cancer and brain tumour type, and the combination of treatment; the authors recognised having a wide review question was a limitation of the study.

1.2.2 CBTS can experience psychosocial skills difficulties

If schools are to fully support CBTS, they need to be aware that difficulties experienced by children with brain tumours not only impact academic attainment but psychosocial skills too. For example, the Royal Marsden's (2019: 28) guide to supporting children with cancer at school, (which is an OT guide aimed at primary school staff), reports psychosocial impact on children who have had cancer treatment (including CBTS) can include "lack of confidence, body image, self-esteem, motivation, anxiety, avoidance behaviours, withdrawal, depressions and developmental regressions". Particular concern over social skills development as part of the range of psychosocial difficulties experienced by CBTS has been the focus of several studies (Fuemmeller et al., 2002; Bonner et al., 2008; Schulte and Barrera, 2010; Schulte et al., 2015; Hocking et al.,2015; Salley et al.,2015; Edmond et al.,2016). Focusing on the more recent UK research mentioned above, Edmond et al. (2016) carried out a study measuring social competence skills of CBTS (age

8-16 years in mainstream education) in comparison to a control group of same aged children. Children, parents and teachers completed the Social Skills Rating System questionnaire (SSRS) and the Social Responsiveness System questionnaire (SRS). Scale results according to teachers and parents indicated, compared to healthy peers, CBTS experienced difficulties in social adjustment, including processing information, social interactions, and understanding social cues. However, CBTS did not self- recognise these areas as difficulties in this study, consistent with findings from other studies (Salley et al. 2015). Although Edmond et al.'s (2016) findings also suggest teachers and especially parents may overstate social difficulties of CBTS, as they are used to focusing on the child's relative weaknesses (as part of monitoring their progress), using the SSRS and SRS, were valid and reliable measures. In addition, two subtests of standardised underlying ability assessments using the Wechsler Abbreviated Scale Intelligence (WASI), Wechsler (1999) were used to measure word knowledge and abstract reasoning ability of CBTS. However, cognitive processing skills and verbal reasoning skills were not measured, which may also have an impact on social interactions. The authors noted observations of CBTS social interactions could have provided more detail. Limitations of the study also included small teacher response rates for CBTS.

Even though the authors advised caution regarding generalisability, due to variability in scores and context, the study was important in highlighting CBTS are at risk of experiencing social isolation and difficulty with peer relationships. The study also highlighted a need for HCPs to carry out assessments of CBTS' social competence skills and emotional and behavioural difficulties, to inform school support. No information was provided on translating this to the practice of supporting CBTS at school.

In addition, a quantitative, retrospective large-scale Canadian study by Barrera et al. (2005) was the first international study to compare late effect educational *and* social outcomes of 800 children with cancer up to the age 17 (including brain tumours), as perceived by parents, with a control group of 923 children who had never been diagnosed with cancer. Parents completed a mailed survey focusing on their child's health related quality of life after treatment for a brain tumour. A positive of the study included results highlighting, out of the group of children with cancer, it was brain tumour survivors who, as a group, experienced the highest level of reported difficulties in health and education, with the poorest outcome in social skills (i.e, having close friendships and friends they could confide in). Within this group of

CBTS, children treated with cranial radiation (CRT) had the weakest educational and social outcomes.

Only including parent perceptions of social and academic difficulties of CBTS could be considered a limitation of the study. In addition, the questionnaire required parents to report a ‘grade’ for their child’s academic attainment in each subject area. It is unclear exactly where parents sourced this information and, as teacher input was not included, parent reports of academic attainment and social adjustment could be considered subjective. Also, the study does not provide a standardised measure of core skills and no information is provided regarding general underlying ability of children. Conclusions therefore cannot be made as to whether children are reaching their full potential in comparison to their underlying ability or whether they have experienced a decline in underlying ability post brain tumour treatment. A longitudinal study was also recommended by the authors to further identify and understand areas of weakness experienced by CBTS. Despite limitations, the study was important in recommending at risk groups such as CBTS should access rehabilitation support to help support and develop academic *and* social skills. It did not, however, translate this to practice or suggest which professionals would be best placed to lead this.

To summarise, existing research consistently demonstrates CBTS are a group of vulnerable learners who, as a result of the brain tumour and treatment can experience a range of long-term difficulties negatively impacting academic skills, social functioning and school experience, upon return to school, and over time (Lonnerblad et al., 2017; Barrera et al’s.,2005; Saatci et al.,2019; De Ruiter et al., 2012; Salley et al., 2015; Edmond et al., 2016). Unsurprisingly, returning to school after brain tumour treatment can result in CBTS needing ongoing SEN support, (that they did not need prior to their brain tumour treatment). Understanding the range of needs CBTS may experience is therefore a vital part of identifying school support, yet there are limited research studies focusing on practicalities of school support for CBTS and how this is underpinned by the relationship between school and parents. Of the school reintegration CBTS studies that do exist, the focus is mainly on communication between HCPs, school and parents and not specifically communication between parents and school. The next section therefore identifies existing research informing our understanding of what key stakeholders report works well and any gaps in communication and provision when supporting CBTS. Research in these areas is typically qualitative in design.

1.3 Research focusing on the perspectives and experiences of families of CBTS, CBTS and school staff when supporting CBTS at school

This section focuses on research exploring perspectives and experiences of parents of CBTS and school staff, regarding supporting CBTS upon return to school after hospital treatment has ended. Although research in this area is limited, existing qualitative studies typically aim to better understand how CBTS are supported upon school reintegration, through semi-structured interviews. Participants of these studies include parents, teachers and HCPs, and in some cases views of CBTS, to evaluate current CBTS support provision and practice and how this is underpinned by communication between stakeholders.

One of the earliest studies that aimed to better understand the school experiences of CBTS in the UK was carried out by Upton and Eiser (2006) in the North of England and Wales. A CBTS strengths and difficulties questionnaire (SDQ) (Goodman 1997) was completed by school staff including the class teacher (n=11) and schools SENCOs (n=10). Some were also completed by the headteacher, one head of year and 4 TAs. Questionnaires were also used with 40 mothers of CBTS, along with semi-structured interviews. CBTS were aged between 6-16 years and had completed treatment at least 2 years previously. The majority of children attended mainstream school (33/40), with a minority attending either a special school (5/40) or a private school (1/40). The study focused on parent and teacher perspectives of SEN needs of CBTS. It was based on their observed profiles of the child's strengths and difficulties using the SDQ, regarding school experiences and attendance on return to school, including the child's physical, social, emotional, behavioural and learning difficulties, and the impact having a brain tumour has on school attendance.

Findings of the study were important in demonstrating CBTS are at a disadvantage upon return to school, due to experiencing long-term physical, cognitive and social and emotional difficulties. The majority of children were identified as having SEN (78%). Difficulties in literacy and numeracy (reflective of research by Lonnerblad et al. 2017, as noted earlier) were reported by teachers and parents as being areas often affected for CBTS. Although school absence during treatment was reported as a potential reason for these difficulties, there was no mention of weakness in neurocognition being a contributor. Parents and teachers also reported CBTS experienced difficulties in memory and concentration, speech, vision, behaviour and emotions, and peer relationships (e.g., social skills and bullying or isolation). In addition, attendance levels of CBTS were negatively impacted not only during treatment, but upon return to school, due to illness and attending hospital appointments. For some children (n=2), attending school part time further exacerbated challenges in academic progress. Highlighting CBTS are clearly at risk of experiencing difficulties after treatment has ended is an important contribution of the study and most of this group were reported as having an Individual Education Plan (IEP) in place. This is a plan for teachers to follow, made up of learning targets for children with SEN. IEP's are determined by school and are part of the stages involved in identifying SEN needs of children, adhering to the UK 2015 Special Educational Needs Code of Practice (SENCoP). Targets of IEP's in the study included social, emotional and behavioural, academic, physical and attendance. Despite reporting on the range of difficulties CBTS experienced, the study only suggested CBTS may need support at school "sometime after diagnosis, even when they are considered medically cured" (Upton and Eiser 2006:16); the study failed to highlight the risk of a decline in abilities over time and the need for support *throughout* their school career (although it is noted the absence of longitudinal data may have resulted in the authors being cautious of such conclusions).

Limitations of the study include small participant numbers and methodological limitations such as not including the child's voice, and only interviewing mothers and not teachers. There was also a lack of practice-based information regarding classroom support needs and no mention of specific home-school communication, despite a conclusion recommending the need for an improved level of communication between *HCPs and school* upon school reintegration, and better sharing of information to support CBTS after returning to school. The study did not discuss the dynamics of the home-school relationship underpinning and facilitating school support for CBTS throughout the child's trajectory. This may partly be due to there being less emphasis on the importance and practice of parent-school partnerships in the UK at the time of the study. Although teachers and parents were able to identify the range of difficulties displayed by CBTS compared with community norms, they viewed the level of difficulty with varying degrees of concern. The study, to a certain extent, tried to justify some of the lower levels of teacher concern regarding the child's abilities, by suggesting it was unreasonable to expect teachers to have a knowledge of the effects of a brain tumour (Eiser et al.2004). This implies there was a lack of school CBTS training and guidance available at that time, but it is acknowledged that in context, the study was carried out prior to Education Health and Care Plans (EHCP) being introduced, where multidisciplinary work between education and healthcare is required. An EHCP is a plan in the UK for children who need additional support in education, health or social needs and provides funding for needs to be met up to the age of 25 years.

In 2016, Tresman et al. carried out qualitative research exploring school reintegration for children who had survived a medulloblastoma brain tumour in North England. Medulloblastoma is reported to be the most common high grade children's brain tumour (www.thebrain tumourcharity.org). The data collection methods included using questionnaires with parents of 9 CBTS, semi-structured interviews with teachers and healthcare professionals (HCPs), a focus group with HCPs, and thematic analysis. The combination of multiple data collection methods and thematic analysis was a strength of the study. Key findings included the need to share information upon school reintegration regarding the needs of CBTS, between HCPs and parents. A formalised draft reintegration protocol was used to help ensure support needs of CBTS were documented and all relevant information was transferred between HCPs and school, in a timely manner. To my knowledge, the protocol was the first of its kind in the UK aiming to provide early guidance for schools when supporting CBTS upon school reintegration. The objective of the protocol was to ensure there was a consistent level of school support for CBTS across and within schools. The study also introduced the idea of parents and school taking responsibility for ensuring CBTS accessed appropriate support, as opposed to HCPs (although HCP guidance was still important).

While the protocol aimed to help ensure support needs of CBTS were recorded, shared and monitored as part of multi-disciplinary communication, it did not focus or report on availability or the need for CBTS school training. Although the protocol suggested time frames regarding initial and longer-term communication between HCPs and school (for example, a progress meeting after 18 months of child's return), it overlooked the need for close, ongoing communication between school and home *throughout* the academic year. There was a lack of specific practical guidance in the protocol regarding supporting CBTS at school and developing a strong home- school collaborative relationship.

The study drew attention to the need to define roles and responsibilities of stakeholders involved in supporting CBTS, but the protocol does not report on which key members of staff this should involve. Furthermore, the study recommends a named nurse would be best placed to coordinate school communication initially, but does not suggest who could potentially take over this role in the long- term (especially considering HCPs will not have contact with CBTS after they have been medically discharged from hospital, and may not have knowledge of school SEN support systems). It is also unclear if the draft protocol was developed and used in schools; follow up research reporting on its effectiveness would have been useful. Similarly, Vanclooster et al. (2019) carried out a qualitative study based in Belgium, focusing on school reintegration for CBTS. A multi-case study used semi-structured interviews and thematic analysis, to explore the experiences and perspectives of 5 CBTS, parents and teachers (class teachers and specialised teachers) and HCPs, after CBTS had returned to school. This was one of the first studies to include perspectives and experiences of CBTS regarding school reintegration. CBTS, teachers and parents were interviewed 3 times over a 2-year period.

Five CBTS took part in the study, 3 were aged 10 (2 males, one female), one aged 8 (female) and one aged 7 (male). The gathering of child data was aided at times using toys, to help children who were struggling to provide detailed responses. Despite this, authors reported a limitation of the study was the level of information CBTS provided (due to the young ages of children). Nevertheless, analysing child data allowed authors to report CBTS were happy to return to school because school represented normalcy, freeness from illness and the opportunity to see peers, but whose reality (according to parents and teachers) presented social skills and friendship challenges.

Consistent with studies by Upton and Eiser (2006) and Tresman et al. (2016), a key finding of this study was recognition of the importance of communication between HCPs, school and parents when supporting CBTS upon school reintegration (but it did not focus on the need for communication prior to reintegration). Seeking the voice of parents and teachers, but not TAs or the SENCO, could be considered a limitation of this study in understanding the home-school relationship dynamic, especially as teachers are not the only (or even the main) staff members who support CBTS (this could, however, be due to a different SEN support structure in mainstream schools in Belgium).

Although the study reported a need for shared expectations between school and home regarding the child’s academic attainment and psychosocial wellbeing, as well as close monitoring of the child’s progress, it highlighted parents were not convinced teachers had adequate knowledge regarding supporting CBTS.

Teachers admitted they felt more confident after attending relevant conferences, but no information was provided in the study regarding the training needs of teachers working with CBTS. A lack of training regarding the home-school partnership was perhaps indicated by teachers seeking colleague advice when supporting CBTS, instead of parental guidance.

There was a lack of information in this study regarding home-school collaborative practice, but the study was important in suggesting schools should have a CBTS policy in place (although no information was provided regarding who would be responsible for creating, implementing and evaluating a policy). Highlighting a need for a school liaison role to coordinate meetings between home, school and HCPs was another positive outcome of the study, along with suggesting this should ideally be someone with SEN work experience and a comprehensive understanding of the child's needs. This partly echoes Soanes et al. (2009) longitudinal, explorative case study with 9 mothers and 9 fathers lived experiences of supporting CBTS, during hospital-based treatment in the UK. The study reports parents felt a key HCP at the hospital (someone who knew their child well), would be best placed to guide them through treatment, answer questions and liaise with doctors. Vanclooster et al. (2019:1444) also suggest CBTS should access academic and psychosocial assessments upon return to school, carried out by an independent service with "a combined expertise in education and healthcare". It is, however, unclear if this would or could be the same role as the liaison link.

The need for a school liaison role was reported in research by Bruce et al. (2012) in their evaluation of a Canadian school liaison pilot programme, set up to support teachers when designing individualised support, to meet the needs of 9 CBTS attending schools in the region. Nine families of CBTS, their teachers, the school liaison link and clinic nurse were interviewed to examine stakeholder experiences and the benefits of individualised programmes, to address each child's support needs. Thematic analysis was used to identify themes regrading successes and challenges of the liaison programme. Results suggested the liaison link played an integral role in key factors involved in successful outcomes for CBTS including: (i) establishing realistic expectations of levels of progress for CBTS and facilitating open channels of communication between school, home and health care when supporting CBTS (ii) informing and monitoring individual school support plans for CBTS, based on the child's specific range of individual needs (including academic, social, emotional, behavioural and medical needs) (iii) helping school staff understand the range of *long- term* difficulties associated with CBTS , offering advocacy, and improving collaborative practice between school, parents, HCPs and CBTS, needed to help children reach their potential.

Reported successful outcomes of the programme (by teachers and parents) included less absenteeism and improved academic attainments and social integration for CBTS. Furthermore, the study emphasised the importance of the ‘school liaison’ being an educator, rather than a clinician due to their understanding of school SEN support systems and challenges involved in providing support and intervention for CBTS, along with knowledge of how to match school resources with individual needs of CBTS. Stakeholders felt it was important for a liaison link to be able to assess the initial needs of CBTS after treatment, track and monitor progress and then re-assess. However, the study did not provide further information on what areas assessments should focus on. Authors concluded the liaison programme helped support CBTS surpass early academic and psychosocial targets, but it is not known if this programme was further developed or used by schools and HCPs.

One school reintegration programme that does exist can be found in the Children’s Hospital of Philadelphia, USA where the funding of a school liaison role is part of a school reintegration service for children with cancer. This is a good example of how CBTS research can be used to directly inform practice. For example, funding of the school liaison role was an outcome of Hocking et al’s. (2018) study which on the education needs of children with cancer, using a modified HOPE needs assessment tool (Peterson et al.2005). This descriptive study reported on positive and negative school experiences of children with cancer (including CBTS) through exploring parent perspectives and concerns. The study was part of a larger study focusing on an improvement project to enhance school reintegration services for children with cancer (including brain tumours). Research involved 102 families of children being treated for cancer, over a period of 6 months, of which 23.4% were children with brain tumours. Using the HOPE needs assessment was a strength of the study in ensuring reliability of data. It was used to identify areas of difficulty experienced upon the child’s return to school after the end of treatment, as reported by parents. Authors reported educational concerns of CBTS parents in particular, needed further attention. The study also highlighted the negative impact absenteeism has on academic attainment of children with cancer. It recommended increased availability of neuropsychological assessments for children and more IEP’s, to help school identify and monitor the child's needs, along with a school reintegration team to support and advocate for child and family.

Even though not including school or children's perspectives could be considered a limitation of the study, data provided enough evidence of need for a hospital- based education liaison coordinator role to be funded. The liaison worker provides school with information regarding a child's diagnosis and support needs, along with coordinating communication between hospital, school and parents of children in hospital. Although this service is not specific to children with brain tumours and can be accessed by children who access hospital services, it would be interesting to explore to what extent the liaison coordinator is able to identify, assess and inform schools on the individual needs of CBTS, or if the role provides more of general advocacy, administrative support for children returning to school after illness.

Despite CBTS being a very vulnerable group of learners, there continues to be a lack of specific CBTS school support research, and of the research that does exist, minimal links are made to school support practice or the importance of home-school communication. Lack of CBTS school support research is also evident in a systematic review of qualitative research investigating families' experiences of CBTS by Young et al. (2022). Thirty studies published since 2000 were included, yet only two focused specifically on school support for CBTS (Bruce et al., 2012; Vanclooster et al., 2019). The review unsurprisingly reports on the need for close, ongoing communication between parents, HCPs and school when supporting school reintegration for CBTS. It also reports the need to develop a social, emotional and learning approach to tackling bullying that CBTS may experience. In line with Bruce et al. (2012) and Hocking et al. (2015), the review highlights the need for a liaison link to lead stakeholder communication when supporting the return to school for CBTS and when accessing appropriate community services. However, reflective of previous CBTS school support studies, there is no discussion in this review regarding the importance and practicalities of the home-school relationship, the need for school staff to access CBTS training and the link between research and practice of supporting CBTS at school.

To summarise, there is a scarcity of CBTS school support studies that seek detailed understanding of support needs of CBTS and that include the voice of parents of CBTS, CBTS and key school staff. Although existing CBTS school reintegration support studies highlight a need for early communication between parents of CBTS, school and HCPs, along with the need for a consistent approach to informing school support about the range of needs of CBTS, studies do not focus on the importance of communication between school and parents, as an essential foundation of early and ongoing support for CBTS throughout the child's education trajectory. There is also a lack of CBTS school support research exploring how schools identify and support the needs of CBTS and a lack of research focusing on the need for, availability of, or impact of CBTS school training. In addition, although studies of a qualitative nature provide a detailed understanding of stakeholder experience regarding supporting CBTS at school, findings have not been translated into school CBTS support policy and practice.

1.4 Reflections from my professional practice regarding approaches to supporting CBTS at school

In addition to the above areas of research focusing on supporting CBTS at school, my professional experience of working with CBTS and parents, coupled with my understanding of UK SEN support structures, allowed me to identify three additional areas of importance when supporting CBTS at school: i) the need to include the voice of TAs and SENCOs regarding CBTS school support ii) the importance of school staff understanding the complexities of a childhood brain tumour journey, in other words the narrative, in order to develop relationships with child and parents, and iii) the need to explore if collaborative home-school practice with parents of CBTS is underpinned by policy. The following section focuses on what the literature says regarding these areas.

1.4.1 Importance of the TAs role in supporting CBTS and working in collaboration with parents

Understanding the role TAs play in supporting CBTS and communicating with parents is an important part of developing home-school communication in the UK, especially as TAs are likely to spend the most time supporting CBTS daily at school (particularly if the child has an EHCP in place). While there is a lack of research focusing specifically on the role of TAs supporting CBTS at school, the pedagogical role of TAs in inclusive classrooms and the effectiveness of and training and deployment of TAs in mainstream schools, in general, are well debated in literature; Sharma and Salend (2016) conducted a systematic review of UK and USA empirical studies addressing TAs working in inclusive classrooms. The review reported on 61 studies between published between 2005 and 2015 that focused on the role, impact and influences of TA practice. In addition, in the UK the Department for Education's

(DfE) DISS Project by Blatchford et al. (2006) carried out over 5 years, explored the roles and responsibilities of support staff within schools. It reported TAs had a negative impact on SEN and low attaining student progress outcomes. Blatchford et al. (2012) carried out a follow- on project, the Effective Deployment of Teaching Assistants (EDTA project), to address concerns highlighted in the DISS project regarding the effectiveness of TAs. The EDTA project focused further on the use and deployment of TAs, working with 40 teachers and TAs across 10 schools and two Local Education Authorities. Authors maintained it was unfair to judge the effectiveness of TA practice, using criteria connected to decisions made by the Senior Leadership Team (SLT), such as TA deployment and how much opportunity was given to TAs to plan and liaise with teachers. The study called for a change in national policy regarding TA deployment and more clarity on roles and responsibilities of TAs, but no mention was made regarding the practice or potential of TA communication with parents.

More recently Webster et al. (2021:295) drew attention to how TA research generally only reports on a “recurring set of limited themes” such as TA deployment and the impact of TAs on pupils with SEN. They called for international research to focus on additional areas of importance regarding TAs. This is reflective of Giangreco (2021) who also draws attention to the need for TA research to report on areas other than, for example, training and the role of TAs, and claims existing studies in these areas “repeatedly confirms what we have long known and rarely tells us much new or compelling” Giangreco (2021:289). Sharma and Salend’s (2016) study also identified a need for a wider focus of TA studies. To fill this gap, some of the identified areas for future research pertinent to my study, include focusing on parent and SEN student perspective of TAs, how to create partnerships with parents and TAs, and how to involve students in decisions about their education (Webster et al., 2021, Sharma and Salend., 2016. Giangreco., 2021). In addition, Moore (2016: 77) draws attention to how TAs could help facilitate important communication between school and home, suggesting:

> *“More proactive use of Teaching Assistants in connecting schools and parents would enable Teaching Assistants to contribute hugely to the life of a school as well as to increase a sense of their ‘being valued’, yet there is a lack of research considering how this relates to practice*”.

Although Upton and Eiser’s (2006) study includes TA’s views on supporting CBTS at school and the role of the TA is mentioned in Royal Marsden’s (2019) teacher guide to supporting CBTS, communication between TAs and parents of CBTS is not focused on. Yet TAs may have a detailed understanding of CBTS support needs and progress at school, due to working with them daily. This potentially places TAs in a prime position to communicate with parents of CBTS and is reflective of Moore (2016) who draws attention to "the importance of positioning Teaching Assistants as the cutting edge of initiatives to advance the agenda for inclusion through focus on the indispensable role they can play in family contact" Moore (2016:85). To my knowledge, focusing on the importance and potential of TAs when working closely with parents of CBTS, is an area that hasn't been reported on within CBTS school support research, but is an area that deserves attention.

1.4.2 Importance of school staff knowing the narrative of the childhood brain tumour journey

The relevance of school staff knowing the narrative of CBTS when supporting them, was highlighted at the International Brain Tumour Alliance conference in 2019 at the Word Health Organisation (WHO) in Maryland USA, (which I attended and presented at, on behalf of LSCBTC). I observed a presentation 'An Introduction to Narrative Medicine' by Scharle (2019), regarding the power of storytelling and creating meaning through shared experience within the medical training setting. The importance of medical professionals knowing the narrative through close listening to the story of individual patients, as a way of developing empathic support and for advocacy and action has been noted by several researchers in the field (Scharle, 2019; Charon, 2021).

Part of key school staff building a positive relationship with CBTS and parents, also requires them to consider the narrative; how the experience of, and journey through a child's brain tumour diagnosis and treatment can be a frightening and physically and emotionally exhausting time for parents and child. Indeed, school should appreciate how the brain tumour journey can be highly distressing for parents and child, as reported by Muscara et al. (2015). Knowing how to access and use the CBTS narrative to empathise with parents and child, to understand the journey at a deeper level, is therefore an area worthy of exploration. Yet there is a lack of understanding, research and practice around using the narrative as part of CBTS school support. Due to the lack of training for school staff in using the narrative as an educational tool, parallels could, instead, be made with the world of physicians and medics, where knowing and using the narrative to help understand a patient's journey and support them through illness, is a growing practice. Further support for narrative medicine comes from a systematic review by Milota et al. (2019), recommending it as a medical educational tool, even though the review also concluded there was a need for more evidence to understand possible impacts in practice from these communicative interactions.

Through better understanding of knowing how to use and share the narrative of CBTS, exists potential to strengthen the home-school partnership. Knowing the narrative is an area that could be used within CBTS school training to help key school staff listen closely to, empathise with and understand the complexities involved in the individual brain tumour journey of child and parents. The importance of understanding the unique challenges of a childhood brain tumour journey and the impact on parents was also partly highlighted by Norberg & Steneby (2009) in their qualitative study, exploring the experiences of 11 parents of CBTS in Sweden, through semi-structured interviews. The authors make a compelling argument through analysing the views of parents, that support for the family of CBTS must include an understanding of how parents “may be in a process of rehabilitation from psychological exhaustion and fully assimilating the experience, as well as adapting to the general alterations of life” Norberg & Steneby (2009:379).

Knowing the narrative also encompasses staff being aware that in addition to parents and child having to cope with the physical challenges of brain tumour treatment, the long-term effects and adjusting to negative changes in their lives, parents may be trying to maintain hope for their child’s future. Russell et al. (2016) carried out a qualitative study using grounded theory methods and semi-structured interviews with 12 parents of CBTS and 12 CBTS, to explore how parents and children managed to maintain a sense of ‘normality’ and positivity amid an uncertain future. They reported parents were able to do this through supporting each other as a family unit, accepting support from others and adjusting to the life changes of having a child diagnosed with a brain tumour. When communicating with home, through understanding the narrative, school staff should be aware parents of CBTS can be faced with “the complexity of living with a childhood brain tumour, including relationships with grief, uncertainty, optimism, and the creation of a “new normal” Russell et al. (2016: 389).

Experiences of parents of ABI children maintaining a sense of hope was also explored by Bray (2015). This study adopted a Heideggerian phenomenological approach, where parents of ABI children were interviewed individually. Bray (2015:25) recognised how a childhood brain injury, changes:

> *“The present as well as future dreams and aspirations. The child and family need to come to terms with the child’s acquired disabilities and loss of function, and accept the new challenges they face on a daily basis, however, it is still important to be able to maintain hope that things will get better in the future*”.

Knowing the narrative has the potential to help school staff understand tension can exist for parents of CBTS between feeling relief that their child has survived a brain tumour, yet fearful of reoccurrence (Norberg & Steneby;2009). In addition, parents of CBTS may be not only be living with the uncertainty of the future but may be concerned about the quality of survivorship and future opportunities for their child (Vance et al., 2004; Deatrick et al., 2009; Forinder & Norberg, 2010).

1.4.3 Home-school partnership policy

In addition to understanding the relationship between key school staff and parents of CBTS in the study, my professional experience helped me identify the necessity of exploring if collaborative practice is guided and underpinned by home-school partnership policy. The importance of schools working in partnership with parents of children with SEN is not a new concept. The Warnock Report (DES 1978:150) highlights the “successful education of children with SEN is dependent upon the full involvement of their parents”. The Lamb Inquiry (2009) explored parental confidence in the school SEN system; one of the areas reported on was the need for parents to be listened to and have a stronger voice. The Lamb Inquiry (2009:4) recognised “Face-to-face communication with parents, treating them as equal partners with expertise in their children’s needs is crucial to establishing and sustaining confidence”. However, my study recognises school partnerships with parents of CBTS may be more complex than just recognising parents as experts in their child, as although they may be ‘experts’ in their child, they are not necessarily experts in all areas of their child’s difficulties that occur *post brain tumour treatment,* or in knowing how this translates into classroom support needed for their child.

The positive impact home- school collaboration has on a child’s learning in general is also a well-researched area (Hoover-Dempsey & Sandler,1995,1997; Epstein, 1996, 2019; Christenson & Sheridan, 2001; Christenson, 2004; The Lamb Inquiry, 2009). Green and Edwards (2021: 145) report in NASEN’s ‘Leading on Inclusion’ book for SENCOs, how close collaboration between parents and ‘professionals’ particularly helps SEN children make academic and social progress. However, research focusing on the need for and impact of home-school collaboration *for*

CBTS is lacking.

If schools are to understand the complexities involved in supporting CBTS and working with parents to help children reach their full potential, specialist training should be available. The availability of UK school CBTS training and guidance is the focus of the next section.

1.5 The need for school CBTS and ABI support training

The following section focuses on current UK CBTS and ABI school support guidance, training availability and the need for school staff to access training when supporting CBTS and working closely with parents. The need for school to access CBTS support training is extremely important, not only because of the range of potentially complex long-term difficulties CBTS can be left with, but because it is statistically probable that schools will lack experience of supporting a student with a brain tumour. For example, there are around 420 children diagnosed with a brain tumour in the UK each year (Cancer Research UK, 2019), yet in comparison, figures provided by the British Educational Suppliers Association (BESA*,* 2021) tell us there are currently 32,163 schools in the UK.

1.5.1 Importance of understanding brain tumours are classed as ABIs

In 2021, The National Acquired Brain Injury in Learning and Education Syndicate (N-ABLES) created a guide to help staff support children with an ABI upon their return to school. The guide (2021:3) reports that an ABI is “any injury to the brain which has occurred following birth, following a period of typical development” and this includes medical conditions such as brain tumours. This definition is echoed by the International Paediatric Brain Injury Society (IPBIS) and The Children’s Trust (www.thechildrenstrust.org.uk). However, the link between brain tumours and ABIs, is not necessarily referred to within brain tumour support information aimed at parents and school, except for the Royal Marsden Teachers guide for pupils with brain tumours (2019), which makes this link. In addition, my experience of working with parents of CBTS and as a parent of a child with a brain tumour, led me to understand parents do not always have direct conversations with hospital professionals regarding their child’s difficulties being classed as an ABI. Although Bray (2015:26) when researching the importance of parents of ABI children maintaining a sense of hope for their child’s future, reported health care professionals (HCPs) should be prepared to relay information to parents regarding the child’s long-term difficulties, Ruble et al. (2018), reported confusion existed over who was responsible (within healthcare) for explaining childhood cancer survivor's potential long-term difficulties to parents. Vanclooster et al. (2019) highlighted HCP's felt it was their responsibility to have a discussion with parents about realistic levels of progress for their chid, but it was unclear whether this included them using the term ABI. A consequence of school and parents being unaware of brain tumours being classed as ABIs was witnessed in my professional role. I observed a CBTS school support meeting where parents and school were not aware the child's difficulties were classed as an ABI. For parents, hearing (for the first time) their child had an ABI was an upsetting experience and one that should not have been shared in the middle of a school meeting. School training within CBTS and ABI support would help prevent such difficult situations. Training would help staff understand the long-term impact of childhood brain tumours, equipping staff with the knowledge and skills needed to support parents and child.

1.5.2 Availability of CBTS and ABI training

Despite a need for school CBTS and ABI support training, there is a lack of available UK CBTS training for schools and limited ABI training. At the time of writing, the only specific piece of CPD school ABI training was a workshop (virtual and in person) and an Early Years course, provided by The Child Brain Injury Trust (https://www.childbraininjurytrust.org.uk). Lack of access to available school *ABI* training was noted by Linden, Braiden and Miller (2013). They carried out a cross-sectional postal survey in Northern Ireland looking at knowledge, experience and training of educational professionals working in schools with ABI children (age range of pupils 4-18). A total of 388 responses were provided mainly by school principals and some pastoral care staff and SENCOs. Results highlighted a lack of knowledge and training availability regarding supporting children with an ABI; as a result, some school staff carried out their own research in order to understand the needs of ABI students. In March 2020, the Department for Education (DfE), funded a series of videos aimed at raising the awareness of school staff supporting children with a range of SEN needs. As part of this series, they worked collaboratively with UKABIF and N-ABLES, creating an ABI training video aimed at newly qualified teachers (NQTs), teaching staff, TAs and SENCOs (https://player.vimeo.com/video/394442257). This video features a student with a brain tumour, as an example of how to support a student with an ABI. However, this video is not included in all CBTS support websites (who may not automatically be aware of its existence). In addition, CBTS and ABI school support training are not part of UK National SENCO training (National Award for SEN Coordination), TA training qualifications, or initial UK teacher training (ITT core content framework DfE, 2019). In 2021, N-ABLES (UKABIF - Acquired brain injury: A guide for schools Whole School SEND) also noted how the SENCoP (2015) and initial teacher training do not mention ABIs. The All-Party Parliamentary Group on Acquired Brain Injury's 'Time for Change Report' (2019:7) recommends*:*

> "*All education professionals should have a minimum level of awareness and understanding about Acquired Brain Injury and the educational requirements of children and young people with this condition (i.e. completion of a short online course for all school-based staff). Additional training should be provided for the named lead professional who supports the individual with Acquired Brain Injury, and for Special Educational Needs Coordinators".*

Reflective of the above, although all teachers are teachers of SEN (SENCoP: 2015) and therefore should access CBTS training, additional training for TAs and SENCOs may be warranted. They are arguably the members of staff who have the highest level of involvement in supporting CBTS and working closely with parents. For example, TAs are members of the SEN department employed to support the daily needs of children with SEN and EHCPs, within an inclusive whole school setting. SENCOs also have an integral role to play in supporting CBTS, as they have "day to day responsibility for the operation of the SEN policy and co-ordination of specific provision made to support individual pupils with SEN" SENCoP (2015:6.89*).* The remit of the SENCO's role in the UK is diverse and includes leading the SEN team, identifying support needs of children with SEN, ensuring all staff are appropriately guided and trained to meet those needs, and communicating with parents and other professionals involved in the child's support. CBTS or ABI training for SENCOs is essential in ensuring the SENCO (in their leadership role) understands the unique range of support needs CBTS present with. After all, SENCOs cannot realistically be expected to have detailed knowledge of all areas of SEN without having accessed specialist training in the area concerned.

This is reflective of Howe and Ball (2017) who carried out an exploratory study within a UK local authority, focusing on SENCO's knowledge and understanding of students with an ABI. One hundred and eight SENCO's (primarily primary school SENCO's) were invited to take part in an online fixed choice questionnaire. The study highlighted the need for SENCOs to access specialist training to develop knowledge and understanding of the long-term needs of ABI children. The study reported a lack of training and knowledge, resulted in SENCO's experiencing barriers to supporting ABI students upon school return and in their subsequent learning. Authors identified SENCOs therefore relied on developing their skills through real life experience of supporting ABI students, which, “given the complexities involved in meeting the needs of many pupils with an ABI, is not an ideal situation for either the SENCO or the pupil” Howe and Ball (2017:97).

Lack of specialist CBTS and ABI training is perhaps reflective of a wider UK concern regarding school staff finding it difficult to access CPD SEN training. A survey carried out in 2017 by the National Association of Schoolmasters Union of Women Teachers (NASUWT) gathered views of 1,615 UK primary, secondary and specialist provision school staff, focusing on highlighting challenges within SEN due to austerity measures. Respondents included mainly class teachers, but also SEN teachers, SENCOs, head of inclusion and head or assistant headteachers. An area of concern reported by staff was difficulty accessing CPD SEN training, due to a lack of time, a heavy workload, lack of school funding for CPD training and lack of availability of high calibre training.

1.5.3 CBTS and ABI training as part of inclusive practice

There is also a lack of research exploring the need for, or effectiveness of CBTS or ABI school training, as an important part of inclusive school practice. As there is no single definition of inclusive school practice in the UK, inclusive practice may look different across schools. Schuelka (2018) was commissioned by the UK’s Department for International Development (DFID) to report on the implementation of inclusive education in the UK. He maintained inclusive education “means all children are together in mainstream classrooms for the majority of their day. This has demonstrated positive effects on student achievement and social wellbeing for *all* children” Scheuelka (2018:2). He also reported a need for trainee teachers to access training on inclusive practice and qualified teachers to access ongoing CDP training in this area. Ofsted’s framework of school inspection (2022) was concerned with how schools support students with SEN within an inclusive classroom and whole school setting in accordance with the SENCoP (2015). Whereas, although the SENCoP (2015) provides general guidance for inclusive school policy and practice regarding removing barriers to learning for children with SEN, it does not offer practical classroom or intervention strategies. Inclusive practice therefore may vary in each school. CBTS training could help ensure teachers, TAs and SENCOs are trained and equipped in practical terms to meet the specific and ongoing needs of CBTS within an inclusive environment, in order for CBTS to make progress and experience a successful transition to adulthood. After all, Hornby (2021: 1) maintains the ultimate goal of inclusive education for children with SEN is to enable "their maximum inclusion in the community as adults".

Although there is a lack of availability of CBTS and ABI school training and gaps in research exploring the need for such school support training, 3rd sector information in the UK can be found to help guide parents and school upon the child's return to school.

1.5.4 Availability of 3rd sector literature guiding schools and parents when supporting CBTS

In addition to the need for CBTS or ABI school support training, 3rd sector organisations have an important role to play in developing and providing literature guiding parents and school when supporting CBTS. The availability of such 3rd sector literature has steadily increased. For example, in 2019, The Brain Tumour Charity (www.thebraintumourcharity.org) updated its education information and guidance by creating a bank of downloadable educational resources for schools supporting CBTS, prior to and upon school return. This includes educational support strategies, 'quick glance' strategies and an educational charter providing guidance and information for schools and colleges. Updated CBTS literature also includes the Royal Marsden Hospital's (2019) 'Teacher's guide for pupils with brain tumours during and after treatment' which was written in partnership with 3rd sector brain tumour charity Cerebra and is based on experiences of CBTS treated at the hospital, parents and school staff. I found this comprehensive 3rd edition to contain helpful information for schools when supporting CBTS' return to education. Yet in my professional experience there is a danger of CBTS returning to school without staff having accessed or being aware of such information.

There is also a growing bank of ABI literature provided by 3rd sector organisations aimed at guiding school support for ABI students; this information is very relevant to supporting CBTS. For example, in 2021 N-ABLES (part of The UK Acquired Brain Injury Forum and set up as a result of recommendations from the ABI All Party Parliamentary Group report 'Time for Change' 2019), published a much needed and comprehensive guide 'ABI Return-Children and Young People with Acquired Brain Injury-guiding their return to education' aimed at schools, parents and the child or young person. The guide recognised how "The return to education (RtE) has a significant role in the child's/young person's (CYP) recovery process, and schools play a crucial role in rehabilitation and helping them to achieve positive outcomes."

(N-ABLES 2021: 2). The Children's Trust (https://www.thechildrenstrust.org.uk) also provide schools with ABI support guidance in the form of informative, downloadable resources. In addition, online ABI guidance for schools was provided by NASEN (2018). Although this guidance is very relevant to CBTS support, it does not specifically mention CBTS (apart from including them in UK annual incidence statistics of children with ABI's).

On a positive note, in the UK, links are gradually being strengthened between children's ABI and brain tumour 3rd sector support organisations, as shown in part of the N-ABLES guide focusing on the return to education for ABI students (2021). This provides links to other organisations offering information regarding supporting ABI students at school, one of these being The Brain Tumour Charity (www.thebraintumourcharity.org). However, there is still a need for national and local brain tumour charities to work more collaboratively with national ABI charities and organisations moving forward. Working together could help inform, develop and disseminate good practice around supporting the needs of CBTS at school, working closely with parents of CBTS and ensuring information is visible and easily accessible by parents of CBTS and key school staff, nationwide.

1.5.5 No school support CBTS pathway

In addition to a lack of specific CBTS training for schools and a risk of school staff not accessing CBTS or ABI 3rd sector literature, there is no UK CBTS school pathway of support to guide school staff upon a child's brain tumour diagnosis. In 2006, Upton and Eiser's study (discussed on page 8) drew attention to the lack of a national CBTS guidance pathway for schools in the UK; 17 years later this is still the case. Although The Sam White pathway (2017) provides a wealth of helpful strategies and advice for schools in the Nottinghamshire area of the UK, regarding the return to education for ABI students (and is based on a child with a brain tumour), this is not a national pathway in itself. In my professional experience, I have seen how lack of CBTS school support training and no CBTS school guidance pathway, can result in variable levels of school support for CBTS and fluctuating levels of school communication with parents of CBTS. In addition, it is worth noting in the UK, although the SENCoP (2015) offers statutory guidance to schools and local authorities (LAs) regarding supporting students with SEN in England, the level of SEN support and funding for EHCPs can vary geographically across LAs and schools. To explain further, LAs in England have statutory responsibility for children and young people with SEN and are required to publish a SEND 'Local Offer' which informs and guides schools and parents about educational provision, services and support for children and young people with SEND in the area. However, the level of guidance, available SEN support services and funding for EHCPs, can differ across LAs. For example, LAs award EHCPs for children who qualify, but the banding of funding for EHCPs can vary across LAs. LAs also signpost schools and parents to relevant support agencies regarding SEN, but this can also vary due to availability of support services across regional and local areas. The interpretation of SENCoP (2015) guidance and LA guidance for SEN support school may also differ in practice across and within schools, as there is no set standardised framework in place to guide support for SEN students. Set against this fluctuating backdrop of the level of support in place for SEN students in England, it may prove difficult to initiate national guidance pathways of support for SEN needs such as children with ABIs and brain tumours (see page x for further information).

To summarise, not only is there a lack of CBTS school training and no CBTS school support pathway in the UK, there is a lack of academic research specifically reporting on the need for, availability of and impact of CBTS school training. Although the increase in ABI and CBTS 3rd sector school support information is an area of welcome progress, guidance does not typically provide detail regarding the level of home-school communication required when working with parents of CBTS. How therefore can schools prepare their staff to appropriately support CBTS and work collaboratively with parents? My study considers this.

1.6 Home-school partnerships frameworks

When designing the research, two existing home-school partnership conceptual frameworks were chosen as a lens to help me understand home-school communication and collaborative practice in each case study, and to explore if the frameworks could be used to guide CBTS school support policy and practice. Deciding which conceptual frameworks to use was influenced by Yamauchi et al. (2017:1) who carried out a systematic review of family-school partnership study articles published between 2007-2011. The two conceptual frameworks that were reportedly used the most were Hoover-Dempsey and Sandler's (1995, 1997, 2005) model of the parent involvement and Epstein's (1987, 1995, 2011) types of family involvement. I used the most recent versions of both conceptual frameworks as described below:

1.6.1 Revised model of parental involvement

Hoover-Dempsey and Sandler's (2010) revised model of parental involvement suggests parental involvement in a child's education has an impact on the child's attainment. The model has 5 levels focusing on, i) what motivates parents to be involved in their child's schooling, ii) how parent involvement is administered by school, iii) how parents support their child's learning skills, iv) what students think about parental support methods, and v) student self-belief and motivation to learn and student achievement. I focused on the first level of the model, due to the large scale of the framework and because I felt this level was particularly relevant to understanding the context and unique reasons for CBTS parental involvement with school. Indeed, level 1 focuses on why parents do or don't become involved in their child's schooling, how the life-context of parents can influence their level of involvement and the role schools play in inviting and welcoming parental involvement, Hoover-Dempsey and Sandler (2010).

1.6.2 Overlapping spheres of influence model

Epstein's (1987, 1992, 1996, 2011) 'Overlapping Spheres of Influence model', has evolved over time and takes a holistic approach to encouraging support of children, through communication and collaboration between school, parents and the community. Epstein's revised model (2018) suggests six types of involvement are an essential part of school, home and community working in alliance. These areas include "parenting, communicating, volunteering, learning at home, decision making and collaborating with the community" Epstein et al. (2019 :155). This model was also used as a lens in my study, to further understand collaborative practice between school and parents of CBTS.

How the above conceptual frameworks linked to the study and if they could be used to help guide future home-school collaborative policy and practice when supporting CBTS, are discussed as part of interpreting the findings from my research in the Discussion chapter on pages 97-100.

1.7 Rationale and aims of study

My study has been influenced by my personal and professional experience of childhood brain tumours, existing research and literature focusing on school support for CBTS, and gaps in research and provision regarding the home-school collaborative relationship that underpins support for CBTS.

CBTS are clearly a group of vulnerable children whose lives and futures have been negatively impacted. If schools are to help CBTS rehabilitate and build skills to reach their full potential, they need to work collaboratively not only with HCPs but with parents. The value and potential of the collaborative school relationship with parents of CBTS needs to be better understood and further developed. The relationship is especially important considering CBTS are at a disadvantage, not only upon their return to school, but as they progress through their education. Research repeatedly highlights the importance of school working closely with parents and HCPs, to identify and fully understand the individual's range of long-term support needs that may include physical, neurocognitive and psychosocial needs. Although I recognise the importance of school and parents working closely with HCP's involved in the treatment of CBTS, my study focuses specifically on the relationship between school and parents. While HCP's provide invaluable guidance and medical advice to school upon the child's reintegration, day to day communication takes place at school between parents and school, and not external professionals (who may attend review or transition meetings and offer guidance, but are not, realistically, in a position to speak to school every day). My study recognises as CBTS progress through school, the relationship between home and school is more likely to be *underpinned* with expert knowledge and guidance from HCP's, but it is not completely dependent upon it; understandably, HCPs tend to become less involved with the child, parents and school, the greater the length of time from the end of the child's treatment. This contrasts with the relationship between home and school, which may become more involved in helping meet the child's evolving needs throughout their school life. It makes sense, as suggested by Tresman et al. (2016) that school and parents should take responsibility for the implementation of school support for CBTS, and not HCPs.

There is limited research regarding supporting school reintegration of CBTS and, of the studies that do exist, the focus is not specifically on the relationship between home and school when supporting CBTS to make progress. Yet in my professional experience, it is exactly this relationship that parents are keen to establish and develop in preparation for their child's return to school; knowing who to communicate with at school to secure support for CBTS (especially at high school), is an area parents have expressed concern over, along with knowing how to ensure their child's needs will be understood and supported at school. In a similar way, in my professional experience, schools have reported needing relevant information and guidance around supporting CBTS and, in some cases, schools had little or no communication with HCPs or parents before the child returned to school. My study therefore recognises a gap in research focusing on the level of and practicalities involved in communication and collaboration *between school and home* when supporting CBTS upon school reintegration, and as the child progresses through education.

To my knowledge my study is unique in exploring the role of TAs in relation to supporting CBTS and working in collaboration with parents; it considers if this happens, how it happens and why this is an area of value worthy of focus. The study also explores whether staff are aware of the narrative of the brain tumour journey for child and parents who have found themselves unexpectedly immersed in the frightening world of childhood brain tumours.

Understanding the complexities involved in supporting CBTS at school requires staff to access appropriate training. However, there are gaps in the provision of school CBTS training and ABI training and a lack of research exploring training provision and impact. My study explores if school staff accessed CPD CBTS or ABI training, if this was helpful and what training staff felt would be beneficial moving forward. In addition, as highlighted in Young's (2022) review of research drawing on experiences of parents and schools when supporting CBTS, there is no national programme to guide school staff in supporting the rehabilitation of CBTS upon school return. Tresman et al. (2016) recommended the launch of a formalised school reintegration protocol for medulloblastoma survivors to help guide schools when supporting the child and when working with parents, noting the observed variation in school provision from their research. To aid home-school communication and to help transfer information regarding the needs of CBTS between stakeholders, a liaison role was also suggested by Vanclooster et al., 2019; Hocking et al., 2018 and Bruce et al., 2012. My study focuses on the potential of these areas in helping parents and school understand and meet the support needs of CBTS.

The overall aim of the study was to develop a detailed understanding of the level of home-school collaboration and communication in place at school to support the long-term needs of CBTS, to understand how or if policy underpins and guides home-school collaborative practice, and if this, in turn, impacts progress of CBTS. Views and perspectives of key stakeholders were gathered to help identify challenges and barriers to home-school collaboration when supporting CBTS and to help inform future practice and policy regarding CBTS school support.

Reflective of the importance of staff being aware of the narrative of the child's brain tumour journey as part of supporting CBTS at school, using a case study design helped me understand the brain tumour narrative of child and parents in the study. A case study design and semi-structured interviews aimed to capture the detailed layers of the journey of CBTS and family through diagnosis, treatment and back to school. To my knowledge, my study is unique in including parents, CBTS and key school staff *as identified by parents* (the SENCO, assistant SENCo (at high school), class teacher (at primary school) and TAs). After all, establishing an effective approach to supporting CBTS at school should be informed not only by the voice of key school staff, but by parents and children, who are ultimately at the heart of experiencing life-changing consequences of having a brain tumour.

Research questions

1. What are the experiences and views of parents of CBTS in relation to home-school collaboration and communication?
2. What are the experiences and views of key school staff in relation to school-home collaboration and communication with parents of CBTS?
3. How can the child's view and experiences of school be used to help inform the level of home-school collaboration and communication?
4. To what extent does home-school collaboration and communication help support the child's academic and psychosocial development?

Research impact objectives:

1. Identify existing models of home-school collaboration and communication that inform and can help develop two-way home-school policy and practice when working with parents of children with brain tumours.
2. Identify strategies that work well and challenges and barriers to home-school collaboration and communication, when supporting a childhood brain tumour survivor at school.
3. Seek to inform a two-way model of home-school collaboration and communication that can be used as part of a school CBTS pathway of support.

Chapter 2 Methodology

2.1 Introduction

The first section of this chapter provides an overview of and rationale for the qualitative case study design, before describing the participant sampling approache~~s~~, data collection methods and procedures, and finally an outline of the thematic data analysis method. The chapter ends with a short section on reflexivity and other specific design features of the research.

2.2 Design of Study

The aim of the research was to gain a detailed understanding of the relationship between school and parents of childhood brain tumour survivors, upon the child's diagnosis (or in the lead up to diagnosis), upon their return to school and as they progress through their school career. A qualitative approach and case study design using two holistic, exploratory case studies Yin (2018), allowed me to seek a detailed understanding of this relationship. This approach reflects my constructivist worldview in recognising the importance of investigating individual perspectives to understand phenomena. Indeed, Cohen and Manion (1994: 8) describe constructivism as being concerned "with an understanding of the way in which the individual creates, modifies and interprets the world in which he or she finds himself or herself". Using two individual case studies focusing on home-school communication and collaboration allowed me to explore the wide range of views, experiences, perceptions and future hopes for CBTS, of all key stakeholders.

I was aware using a case study approach "is not a method in itself" Thomas (2021:9). Rather, "it is a focus and the focus is on one thing, looked at in depth and from many angles", Thomas (2021:9). My study explored views of stakeholders, to develop an understanding of multi-layers involved in home-school collaboration when supporting CBTS at school. The qualitative case study approach allowed me to consider "the details of what is happening" (Thomas 2021:46) regarding the realities of ensuring support is in place for CBTS at school and if or how, the progress of CBTS was helped by home and school, working together. This also reflects Thomas (2021: 6) who cited Flyvbjerg (2001:132) in saying case studies are about "getting close to reality". The case studies were based on a reality that I already had an understanding of, in my personal experience and professional practice. Despite this and maybe because of this, I still had questions as a practitioner around how school and parents of CBTS worked together or could work together; my questions regarding what happens between school and home when a child is diagnosed with a brain tumour and how does or could the home-school relationship support CBTS and parents of CBTS, were at the very centre of the case studies.

Although my study recognised the need for school to understand the long-term medical, physical and emotional impacts of having a childhood brain tumour, the study is also reflective of the social model of disability (Oliver 1983). This model views disability as a result of barriers created by society, preventing disabled individuals from being fully included in society in the same way non-disabled people are included. In this sense, the study explored how or if home-school communication helped ensure CBTS accessed full inclusion at school. A qualitative case study approach worked well in providing space to explore if or how home - school communication helped ensure school understood not only the range of long-term impairments CBTS had been left with, but *how* CBTS were fully included and supported at school, educationally, physically, socially and emotionally.

2.3 Generalisations

O'Reilly et al. (2013:161) reports "Qualitative research focuses on words and meanings and does not seek to find a single or objective truth" and this was true of my study. My study did not seek direct replication. Yin (2018) acknowledges case studies only represent themselves and my study cannot be used to generalise to the wider CBTS population. However, Braun & Clarke (2022:143) suggest "transferability refers to research in qualitative research that is richly contextualised in a way that allows the reader to make a judgement about whether, and to what extent, they can safely transfer the analysis to their own context or setting". In this sense, findings of my study may be something other families of CBTS and schools who are supporting CBTS can relate to, and could be used to help inform or influence practice and policy, not only at the two schools involved in the study, but at other schools who find themselves in a position of supporting CBTS.

2.4 Sample and recruitment

Thomas (2021: 67) says a sample in a case study is where the researcher looks at a "selection of subject" "without any expectation that it represents the wider population". This was true of my study where selective sampling was used; I used my own judgement in selecting and inviting two sets of parents of CBTS and two children to take part in the research. To be included as a case study in this research, the following criteria had to be met:

- The child had been diagnosed with and completed treatment for a brain tumour within the previous 3 years.
- The child had returned to school following treatment.
- The child and their parents were able to identify key school staff to invite to participate in the study.
- The child's school and parents were willing to share EHCP documents with me.

Due to the limited field of individuals who met the inclusion criteria, a pilot case study was not carried out. However, peer debriefing was used to guide semi-structured interview questions (see page 48). Ten participants were invited to take part in the research, 5 people in each case study, including the child. Case study 1 focused on 'Luke' who was of primary school age at the time of the study, and when he was diagnosed and returned to school after treatment. Case study 2 focused on 'Lucy' who was at high school (but had been diagnosed with a brain tumour and returned to school when she was at junior school). Parents of Luke and Lucy were invited to take part. Although the invitation was open to fathers too, it was Luke's mother 'Mrs X' and Lucy's mother 'Mrs Y' who agreed to take part. Pseudonyms were used for parents and children. Key school staff, as identified by parents and children, were invited and agreed to take part in the study. In case study 1, only one key member of school staff initially identified by Luke and Mrs X, (Luke's previous class teacher when Luke first returned to school after brain tumour treatment), refused to take part in the study; this decision was respected. Luke's current teacher was instead identified by Mrs X and Luke, and agreed to take part. Lucy's numerous subject teachers at high school were not included in the study because they were not identified by Mrs Y or Lucy as key members of staff involved in communicating with home. It was important for parents and children to identify key staff to help avoid potential bias on my part. Table 1 shows an overview of study participants.

Table 1 Overview of participants included in each case study

Case Study 1	**Case Study 2**
Primary age CBTS (Luke)	Secondary age CBTS (Lucy)
Mother of Luke (Mrs X)	Mother of Lucy (Mrs Y)
SENCO	SENCO
Class Teacher	Assistant SENCO
Teaching Assistant (TA)	Teaching Assistant (TA)

2.5 Ethical considerations

Yin (2018:80) says “desirable research skills include the ability to ask good questions, to “listen”, to be adaptive, to have a firm grasp of the issues being studied, and to know how to bring high ethical standards to the research”. Ethical approval for this study was granted by Leeds University (AREA 19-071). Following approval, information about the study was emailed to all invited participants and informed consent was sought. Participants were given two weeks to consider if they wanted to take part. Participants were encouraged to ask questions if they needed clarification on any aspect of the research process. The ethics panel highlighted the importance of making sure no participant felt under obligation to take part in the research; it was made clear that participant involvement was entirely voluntary, and it was acceptable to choose not to take part.

2.5.1 Ethical considerations when working with children

Mrs X and Mrs Y as gatekeepers of Luke and Lucy were approached regarding Luke and Lucy taking part in the study. They were happy for their child to take part, providing the child wanted to. Child - friendly information about the study was sent to Mrs X and Mrs Y, who shared it with Luke and Lucy, along with informed consent forms. After participants provided consent to take part in the study, I negotiated access to each child with parents and school. I worked with Luke at school, adhering to school safeguarding procedures. Lucy and her mother wanted Lucy to be interviewed at home during the school holidays, to avoid Lucy missing lessons.

Although I initially wanted to explore the range of psychosocial difficulties CBTS may experience, parents did not want me to discuss their child’s brain tumour journey with the child and were, understandably, keen for me to avoid causing their child unnecessary upset. As an ethical researcher I had to ensure I did not leave CBTS feeling upset by asking questions about sensitive psychosocial difficulties they were experiencing post brain tumour treatment. For example, I did not focus on how CBTS felt about the change in their appearance or any anxieties they may be experiencing as a result of having a brain tumour. I therefore narrowed the focus of psychosocial experiences of CBTS to exploring if there was a need for social skills support at school (for example did CBTS need help to socially readjust upon school reintegration or help developing friendship making skills). This was also an area within my professional experience parents of CBTS repeatedly expressed concern over.

Luke and Lucy were therefore not asked questions about their brain tumour journey as part of the interview process, but the ethics panel questioned how they would be supported if they did talk about their journey and became upset as a result. It was made clear to Luke and Lucy that it was okay for them not to answer questions they found upsetting (this was stated in the information letter and repeated verbally when working with them). Having the TA present in Luke's interview and Lucy's mother present in Lucy's interview, helped ensure each child felt safe and secure in the interview space.

2.6 Potential risks of taking part in the study

Participants were made aware of potential risks of taking part in the study. For example, I was advised by the ethics panel to ensure parents were aware taking part in the study would involve discussing their child's brain tumour journey and relative difficulties their child may have been left with; this had the potential to trigger feelings of upset for parents. An interview schedule therefore allowed parents time to prepare themselves mentally and emotionally for the interview. They were also given an option to opt out of questions they didn't want to answer. No questions were opted out of.

An interview schedule was also sent to all key school staff in advance of the interview, allowing them time to read, process and carefully consider interview questions and answers. I recognised staff may not wish to answer interview questions about school processes when supporting CBTS (especially if they were reporting negative experiences) and so they had the option of opting out of questions they didn't want to answer. No questions were opted out.

2.7 Confidentiality and anonymity

Participants were informed about the limits of confidentiality and anonymity when taking part in the study. Full confidentiality was not promised but participants were reassured a realistic level of confidentiality would be offered. Pseudonyms were used with parents and children as part of anonymisation. Participants were given the option to withdraw from the study at any point (up until research findings had been written up), but no participant withdrew. Participants were made aware of how data would be stored and for how long.

2.8 Positionality

The positionality of a researcher in a qualitative study is a necessary consideration, because the researcher has a central role in interpreting data (Thomas 2021). Reflexive practice throughout the study required me to “recognise that you (researcher) have an undeniable position, and this position affects the nature of the observations and interpretations you make” Thomas (2021: 73). My positionality in this study was that of an ‘insider and outsider’. I was an ‘insider’ as I already knew the mothers and children invited to take part in the research through my professional role at LSCBTC. I acknowledge my ‘insider’ position may have influenced parents’ decision to take part in the study. However, it also helped them trust me as a professional who had already worked sensitively with their child. Having already built a positive relationship with Luke and Lucy helped each child trust me and feel comfortable enough to agree to take part in the study. I was aware “by building up a relationship in advance of the research, there is a greater risk that you will influence their responses” O’Reilly (2013:120), but having only worked with Lucy and Luke for a short period of time previously, I did not have a close relationship that a TA or teacher may have with a student. Hence, there was less risk of Luke and Lucy trying to answer questions in ways they thought I wanted. I could also be considered an ‘insider’ in the study as a mother who had lost a son to a brain tumour. My positionality was also that of an ‘outsider’ as although both schools had accessed previous short-term support from LSCBTC through its CBTS educational outreach service, I was not employed by either school; I had no official influence over existing school practice or policy in connection to supporting CBTS.

2.9 Data collection methods

The following section describes data collection methods used to capture and triangulate the views and real-life experiences of stakeholders in the study. Yin (2018:26) draws attention to how qualitative research methods are used to “access personal accounts and capture how individuals talk about their life experiences”. Semi-structured interviews were used with parents and school staff to explore school support for CBTS and the existing relationship between school and home. Semi-structured interviews were also used with CBTS. Additional research tools helped facilitate the process. Three research tools previously used with children in other research were selected (see pages 40, 41 and 43). Document inspection allowed me to view school policy and provision in connection with parent-school communication and collaboration.

2.9.1 Interview questions rationale

Semi-structured interview questions for adults and children were influenced by my professional knowledge and experience of supporting CBTS at school, by previous research and gaps in research and literature in the field (as reviewed in Chapter 1), and by the research questions and impact objectives. Appendices 1-10 shows all stakeholder questions. Questions were also guided by the peer debrief. For example, preliminary interview questions were carried out with colleagues to help refine questions and check for bias. My colleague who had a good understanding of school support of children with SEN, drew attention to some questions needing further clarification; my understanding of the school SEN support system meant, at times, I had overlooked asking specific details about CBTS support at school. My colleague who had a good understanding of the world of CBTS, stressed the need to ask school about the importance of knowing the emotional impact on a family when a child diagnosed with a brain tumour. Allowing parents' opportunity to discuss how they thought the narrative should be shared with school, as opposed to me just providing them with options, was also highlighted.

2.9.2 Semi-structured interviews with parents and key school staff

Yin (2018:121) considers interviews to be "an essential source of case study evidence because most case studies are about human affairs or actions". Semi-structured interviews were carried out with all adult participants, using a mixture of open and closed questions, to explore the level of communication between parents of CBTS and school. Interviews "assumed a conversational manner" Yin (2018:119), reflective of my relationship with participants. This helped parents feel relaxed within the interview process.

Interviews with parents aimed to gain a deeper understanding of their experiences, perceptions, concerns, and expectations of home-school communication and collaboration, upon their child's brain tumour diagnosis and throughout treatment and transition back to school. Interviews with key school staff focused on gathering views, experiences, thoughts and feelings about working collaboratively with parents of CBTS. An interview schedule of questions was sent to parents and key school staff. This allowed stakeholders time to read the questions, prepare answers, and consider if there were any questions they would rather not answer. Participants were happy to answer all questions. Stakeholders were told interviews would be audio recorded and transcribed verbatim. Table 2 summarises the venue, order of and type of interviews carried out with participants.

Table 2: Venue, order and type of stakeholder interviews

Stakeholder	Venue of Interview
Mrs X case study 1	Face to face at LSCBTC office
Mrs Y case study 2	Face to face at parent's house
Lucy case study 2	Face to face at parent's house
SENCO case study 1	Face to face at school
SENCO case study 2	Face to face at school
Luke case study 1	Face to face at school (with Luke's TA present)
TA case study 1	Face to face at school
Assistant SENCO case study 2	Telephone Interview
TA case study 2	Telephone Interview
Teacher case study 1	Telephone Interview

Due to the sensitive nature of the content of parent interviews, there was a need for privacy when carrying out in person interviews; it was important for parents to feel comfortable in their choice of venue. Mrs X chose to be interviewed at private office space at LSCBTC and Mrs Y chose her home. Luke and Lucy were not present during Mrs X and Mrs Y's interviews, allowing parents freedom to speak openly about their experiences, thoughts, feelings, expectations, hopes and fears.

Interviews with the SENCO in both case studies and with Luke's TA (case study 1) were carried out face-face in the school environment. Although my initial intention was to work this way with all key school staff, part way through my data collection, COVID 19 restrictions were put in place across the UK. I therefore had to be flexible arranging interviews with key staff and adhered to COVID 19 and school rules regarding social distancing. As shown in Table 2, interviews with the primary class teacher (case study 1) and the TA and deputy SENCO in secondary school (case study 2), were therefore carried out over the phone. Telephone interviews provided an equal level of detail as face-face interviews.

2.9.3 Reflections on the interview process with parents and key school staff

Yin (2018:83) suggests case study researchers should have "an inquiring mind during data collection, not just before or after the activity". This was my experience during semi-structured interviews, where participants had the freedom to take the conversation in any direction. Interview questions therefore did not always follow the order of the interview schedule. I was able to respond to the flow of the interview, make sense of responses and understand how responses linked to context. Using semi-structured interviews allowed me the flexibility of asking unplanned questions, allowing interviewees the freedom to tell their own truth. For example, it was important for me to take time to listen carefully to the parent narrative, showing respect for the difficult journey they had encountered during their child's diagnosis and treatment. The narrative and parental emotions attached to having a child diagnosed with a brain tumour were respected and honoured throughout the interview.

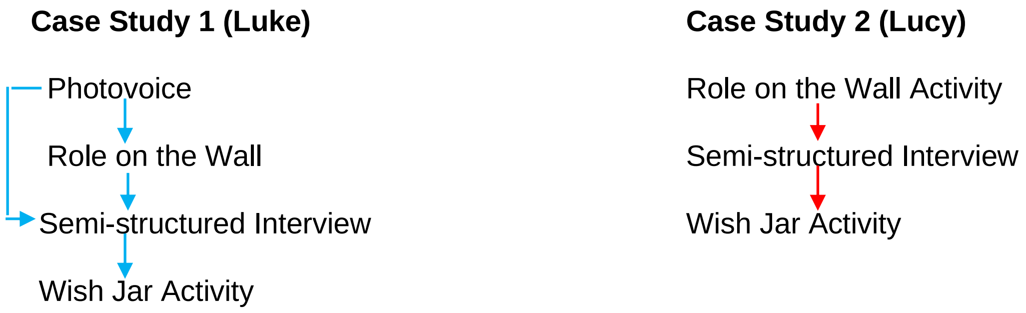
2.9.4 Capturing the child's voice

As reported in the United Nations Convention on the Rights of the Child (1989) Article 12, children have a right to be part of decision-making processes regarding their lives. Seeking the voice CBTS is my study recognised this. Indeed, long-term needs of CBTS can result in them needing SEN support at school and the SENCoP (2015) requires children with SEN needs to be consulted and included as part of discussions regarding their support. In addition, the Ofsted inspection framework (2022) aligns with the SENCoP (2015) in requiring inspectors to listen to views of children with SEN regarding their education. As such, the voice of CBTS was sought in the study where their views and experiences of school following brain tumour treatment were listened to and valued. There is a lack of research focusing on exploring the views of CBTS regarding school support, as highlighted by Vanclooster et al. (2019). My study sought to not only listen to the views of CBTS regarding their school experience, but to understand if, or how, their voices were or could be used as part of home-school collaboration.

O'Reilly (2013:165) reminds us "Due to the flexibility of qualitative methods, they are well situated to understanding the meanings and experiences of children". A gentle, qualitative approach was taken when working with each child to engage and encourage them to explain their views and feelings about school. Being aware it is the researcher's "responsibility to fit into the child's world rather than expecting the child to understand yours" O'Reilly (2013:117), I used a range of data collection methods for the semi-structured interview, to try and do so. Creative, participatory data collection methods (see figure1) were used. These methods included the use of photovoice (see page 40), 'role on the wall' (see page 42) and wish jar activities (see page 43). The latter two activities were similar in nature to activities used in the Mosaic approach (Clark, 2017), where researchers collect data through creative means when working with children, combining "traditional qualitative research methods of observing and interviewing with participatory methods in which children play a direct role in constructing and discussing research material". (Clark; 2017:17).

In case study 1, stages 1 and 2 of photovoice were carried out first, with stage 3 being used as part of the interview process. In both case studies, role on the wall was used at the start of the interview process and the wish jar activity was used at the end of the interview process.

Figure 1 below shows the breakdown of data collection methods used with each child and the order of administration.



2.9.4.1 Use of photovoice in case study 1

Photovoice was used when working with Luke, as a child friendly participatory method. Photovoice methodology was first developed by health promotion researchers Wang and Burris (1997). The process includes asking participants to take photographs of aspects of their lives and then select and interpret images taken. Latz (2017:43) says photovoice is used by researchers to "encourage participants to document elements of their lives within their own terms". I did not use photovoice in its entirety as a data collection method; aspects were used to provide Luke with visual prompts for his subsequent interview. Using his chosen photographs as a visual aid in the semi-structured interview allowed Luke time to process and respond to questions when expressing his thoughts and feelings about school. Using images to support language (Latz 2017) was helpful when working with Luke, as it compensated for weakness in short- term memory and helped prompt his thoughts and ideas. It was, however, important to be aware, as reported by Latz (2017: 74) "photographs taken during photovoice are not data in and of themselves. Rather, they serve as data antecedents, eliciting responses from the participants". The following stages of photovoice process were used with Luke:

Stage 1: Briefing participant and TA on photovoice and taking the photographs

Stage 2: Participant taking the photographs during a week at school
Stage 3: Narration (this took place as part of the semi-structured interview session)

Stage 1

The documentation stage of photovoice Latz (2017) required me to explain to Luke why he was being asked to take photographs of a week at school and to demonstrate how to use the child friendly digital camera I supplied. The photographs could include what Luke enjoyed doing at school, anything he found more difficult, plus anything else he wanted to tell me about regarding his week at school. Visual prompts, Latz (2017) were used within the initial discussion to help Luke consider what photographs he may want to take during his week at school (see appendix 2). Luke’s TA was present in this session to support Luke.

Stage 2

Luke’s TA supported him taking photographs of a week at school. It was stressed that each photograph must be Luke’s choice, as all photographs had to be ‘child directed’ Christensen (2017). Luke was given a week to take photographs. I then collected the camera from school and printed 25 photographs Luke had taken. Mrs X was made aware any photographs taken of Luke or by Luke may be referred to in my thesis but would not be shared or used in publications. Photographs would only be used as a visual prompt for talking points in the semi-structured interview.

Stage 3

The following week I met Luke and his TA and commenced the ‘narration’ section of photovoice. This involved Luke discussing and explaining his photographs. Latz (2017:74) quoted Wang (1999;186) in describing the narration section as being where participants discuss “the images that they have produced, and by doing so, they give meaning to, or interpret their images”. Some of the photographs Luke took of his week at school were very similar. Where this was the case (for example Luke took 3 similar photographs of having lunch), he chose and gave a caption to only one. Being aware “it is not the researcher’s role to interpret these photographs” Latz (2017: 74), I was careful to allow Luke processing time to explain why he took each photograph and what it showed.

Photovoice was not used when working with Lucy. This decision was made because (as pointed out by the ethics panel), Lucy attended a large secondary school, and it would have proved difficult to gain informed consent for every child (or even identify every child) who could potentially appear in the background of Lucy's photographs. In addition, upon reflection, I knew from previously working with Lucy that she was an articulate girl with a strong command of spoken language. Lucy was clearly able to relay her thoughts verbally in an interview. Although she may need processing time, Lucy did not need visual prompts in the form of photographs.

2.9.4.2 Role on the Wall

As a gentle way into the semi-structured interview and as a way of allowing each child adequate processing time, they were asked to complete a 'role on the wall' activity. In research by Oulton et al. (2017:4) "a toolkit of creative activities was devised to use with children and young people during interviews to facilitate them sharing their views and experiences of being in hospital". They used a similar craft activity (but in 3rd person), to the 'role on the wall' task used in my study. The task in my study required Luke and Lucy to use an outline figure representing themselves, recording information about them at school on the outside of the figure, and any thoughts or feelings about school on the inside. This is also a strategy used within school drama lessons to help students explore thoughts and feelings of characters, and was chosen as another creative, participatory way of preparing Luke and Lucy to answer interview questions about school. Although Luke chose not to complete this task, Lucy was happy to record her thoughts and feelings about school in writing (one of her strengths) and engaged well with this task. Lucy's completed role on the wall sheet (see appendix 11) was visible throughout her interview, as a visual prompt if needed.

2.9.4.3 Semi-structured interviews with children

Semi-structured interviews were used with CBTS to explore what they felt was working well for them at school and what could be improved. Interviews were audio recorded and transcribed. This was something children were made aware of (in child friendly terms) before the interview took place. Semi-structured interviews were conversational in style and open and closed questions were used. Interview questions allowed Luke and Lucy the freedom to answer exactly as they wanted to. This helped guard against me influencing their responses; there was no 'right or wrong' way to answer the interview questions, only an honest way. I was careful not to ask Luke or Lucy about their journey through brain tumour treatment or how they felt about the range of difficulties they had been left with. This was something parents were keen for me to avoid and their request was respected. Lucy was interviewed at her home on the same day as her mother. Lucy's mother was present during Lucy’s interview (sitting some distance away from Lucy but in the same room). Luke’s TA was present during Luke’s interview. This did not appear to inhibit Luke or Lucy in their responses and was reflective of O’Reilly et al.’s (2013:120) view where “as long as you feel you are getting honest answers to your questions, you should not worry about having someone else in the room”. Lucy’s mother and Luke’s TA occasionally helped Luke and Lucy clarify answers (when asked for help by the child) but were careful not to change the meaning of Luke and Lucy’s original responses.

2.9.4.4 Wish jar activity

Greig et al. (2013) highlight engaging children in research may require innovative techniques. This, coupled with not wanting to leave Luke or Lucy with any implication of failure Greig (2013), influenced my choice of including a wish jar activity at the end of the interview process; this was a practical and creative way of leaving each child with positive thoughts. Luke and Lucy created a ‘wish jar’ (that they could keep), by decorating a glass jar in a way they chose at the end of the interview. They were asked to write on small strips of paper what they felt could be made better for them at school and any ambitions for the future. These strips were placed in their jar. Both children engaged with and enjoyed this task.

2.9.5 Policy collection

Triangulation of data collection methods included examining school data in the form of relevant school policies relating to SEN policy, and home and school partnership, when supporting CBTS. I also accessed school websites to understand, a) policies relating to home-school partnership in place at each school and b) if school SEN information or policies included specifically supporting CBTS or working with parents of CBTS. Accessing school policies online meant I avoided placing further time demands on busy school SENCOs. I was also given permission by the school SENCO and parents to access Luke and Lucy’s most recent ECHP, which recorded the child’s support needs, provision in place to meet those needs and outcomes to measure the child’s progress in accordance with the SENCoP (2015).

2.10 Data analysis method

This section reports how themes were identified and analysed once all data had been collected. Braun & Clarke’s (2019) method of thematic analysis was used to identify themes. Thematic analysis of the data set was a suitable choice for my study in exploring and giving voice to CBTS, parents and key school staff, not only due to its flexible nature, but because it allowed me to capture inductive and latent meanings of data, Braun and Clarke (2022). I worked in an inductive way taking "the dataset as the starting point for engaging with meaning" Braun and Clarke (2022:56) where the experiences of participants formed the basis of analysis.

Thematic analysis allows the researcher to view subjectivity as a strength and "as something valuable, rather than problematic" Braun and Clarke (2022:12). This was appealing for me as a researcher, as it encouraged me to recognise the validity and relevance of my experiences as a parent and a professional in the world of CBTS; I acknowledge to a certain extent my coding and analysis were shaped by my experience and knowledge of CBTS. This aligns with Braun and Clarke (2022:56) who view "coding as a subjective process shaped by what we bring to it. Coding is a process of interpretation" "and researcher subjectivity fuels that process."

2.10.1 Stages of thematic analysis

The following thematic analysis steps to coding and theme identification were followed:

1.Audio data was transcribed verbatim.
2.Familiarisation of data required me to carefully read all interview data several times to digest content, immerse myself in responses and critically engage with data.
3.Complete coding across the entire dataset helped me identify important individual pieces of data regarding answering research questions. First cycle coding across the entire data set generated 449 individual codes, highlighting areas of specific interest.
4.Second cycle coding then occurred where first cycle codes were collated according to shared meaning. Creating an initial visual theme map helped me explore codes and make links between collated codes and potential themes. Figure 2 below shows an initial theme map.

Figure 2 Initial Theme Map

5. Second cycle collated codes were used to develop and identify initial themes and themes were then reviewed, defined and named. Themes were also amended over time, as I constantly reflected and considered if collated codes and potential themes answered the research questions and if any themes could be merged, kept as they were, split or discarded, Braun and Clarke (2022). It was also important for me to consider how "themes are constructed by the researcher based around the data, the research questions, and the researcher's knowledge and insights." Braun and Clarke (2022: 35). Table 3 shows an example of collated codes used in second cycle coding. Appendix 12 shows another example of identified themes and collated codes.

Table 3: Example of collated codes used in the identified theme 'Need for CBTS training for school staff'

Merged codes	Data extract examples
No previous experience of CBTS and no CBTS, ABI or parent partnership training.	Asst SENCO case study 1 *"Lucy is the first person I've supported with a brain tumour and I've not heard about any others that have been supported. So, there's limited experience.* *"I think some difficulties with SEN is that people just presume as a SENCO or as a support assistant that you have that knowledge, but if you've not come across that area of need, then you haven't."* SENCO case study 2
Children with cancer hospital training accessed by teacher, but not TA.	*"It was useful for the class teacher to have that whole awareness of the child, not just particularly in school but also the needs of the*

	child at home as well. It was hopefully supporting the teachers when they had that communication with the parent" SENCO case study 1 "*In hindsight* (it*) would have been nice if I did it just because I was working with him on a daily basis*" TA case study 1 *"I remember telling school If I could give you one piece of advice, get your school in on one of these meetings"* Mrs X
Lack of CBTS training resulted in staff being nervous and cautious when supporting CBTS.	*"I think last year I was very, oh I've got to look after him and he's very delicate.*" TA case study 1 TA case study 2 *"It would just have given you that bit more like a comfort blanket. Oh yeah I do know kind of what to do in x. y, z situations. Just so you're not shaking*."
Need to recognise CBTS=ABI	Asst SENCO case study 2 *"it's only because of Lucy that I know a little bit more about acquired brain injury. I know that they put a brain tumour under that umbrella."* Mrs Y case study 1 **"***Well, that's what we've got now it's an acquired brain injury that we're dealing with now because the brain tumour, we're in remission."* *"The current is an acquired brain injury and the impacts from that, that we're living with for long-term.*
Staff felt ongoing CBTS training is needed	SENCO case study 1 *"It will be a good thing to support the teacher that's working with that child. Just to basically say 'This is quite normal' and thinking of different strategies that we could put in place to support that child."* SENCO case study 2 *"I think with training it's about something that's accessible … strategies that you can use that can be shared".* SENCO case study 2 *"I think we would certainly benefit from more training. Definitely."*
Staff sourced their own training	SENCO case study 2 *"We try and signpost in terms of CPD that they can do. But obviously the onus sometimes is on staff finding time to be able to do that"* Deputy SENCO case study 2 *"I constantly do research."*

	"But not research in the way that going into real depth about it and having a real understanding kind of thing."

6.Final themes were then identified (reported in Chapter 3).

2.11 Trustworthiness of Study

Reliability and validity of a study help to prove credibility of findings and "this is particularly vital in qualitative work, where the researchers' subjectivity can so readily cloud the interpretation of the data" (Brink 1993:35). However, validity of my research could not be measured statistically, because, as a qualitative researcher I was "not interested in causal laws but in people's belief, experience and meaning systems from the perspective of the people" Brink (1993: 35). Thomas (2021: 68) also holds the view that different from the use of reliability in quantitative research, where the "consistency of findings" are important, in a qualitative study, "expectations about reliability drop away". The aim of my research was not, after all, to prove findings "consistent from one time to another or one researcher to another" Thomas (2021: 68), but to gain a deep understanding of each case in its own context. The subjective, qualitative nature of the study design also meant an inevitable risk of bias had to be acknowledged. Galdas (2017:2) maintains although qualitative researchers "are an integral part of the process and final product, and separation from this is neither possible nor desirable ", there is still a need for qualitative researchers to be "transparent and reflexive about the processes by which data have been collected, analysed, and presented". Galdas (2017:2) Adopting an honest, reflexive approach throughout the research process helped establish trustworthiness in the study and guard against bias. I was also aware there are no set guidelines or frameworks for avoiding bias within qualitative research. Because of this, and due to my unique positionality proposing a potential risk to bias and the need to be objective when gathering and interpreting the layers of subjective data, Lincoln and Guba's (1985) alternative set of criteria for establishing the credibility or 'trustworthiness' were applied throughout my study, as part of my reflexive approach. The following sections report on how I used this alternative set of criteria to guard against bias throughout the process, including triangulation, thick description, peer debriefing, member check and underpinning reflexivity:

2.11.1 Triangulation

Triangulation was used in my study as a way of “improving the possibility that findings and interpretations will be found credible”. Lincoln and Guba (1985: 305). Yin (2018:17) explains how “features of a case study” include relying on “multiple sources of evidence, with data needing to converge in a triangulating fashion”. I used different methods of data collection as part of triangulation, and I also triangulated perspectives of different participants including parents, children and key school staff. The views and perspectives of different key school staff were triangulated in themselves, by including school staff who held different positions and varying levels of responsibility at school.

2.11.2 Thick description

Thick description is used within qualitative research as a way of achieving external validity Lincoln and Guba (1985). In Ponterotto’s (2006:541) quest to further define “thick description” in qualitative research, he draws attention to commonalities in Schwandt’s (2001) and Holloway’s (1997) definitions where “thick description” “speaks to context and meaning as well as interpreting participant intentions in their behaviours and actions”. I used thick description within my study to describe and analyse in detail the journey of CBTS upon return to school and the context, actions, thoughts, experiences and feelings of all participants, regarding how school and home work together to support CBTS. This level of rich detail helped ensure the case studies “present adequate “voice” of participants” Ponterotto (2006:547).

2.11.3 Peer debriefing

Peer debriefing is used within qualitative research to “provide an external check on the inquiry process” Lincoln and Guba (1985:301). I debriefed with two colleagues throughout the process; one colleague had a good understanding of school support for children with additional needs, and one had a good understanding of CBTS. Peer debriefing was used throughout the study in areas such as designing interview questions (see page 36) where listening to alternative perspectives helped me consider any areas that needed further exploration. Discussing data as part of peer debrief also helped me separate my brain tumour narrative from the narrative of participants, thus protecting me from becoming too emotionally impacted by data findings and protecting findings from bias.

2.11.4 Member checks

Member checking in qualitative research includes sharing data and findings with stakeholders involved in the study, Lincoln and Guba (2005). Member checking was used in my study to help verify my findings were accurate and honest. This was done informally, where, at the end of each interview, I reflected main points to participants, and they had the opportunity to provide feedback or clarify anything they felt I had misunderstood. For example, after interviewing Luke's teacher in case study 1, I reflected the main points of the interview back to her. She further verified the challenges of balancing being a class teacher required to support students with a range of SEN needs, with maintaining a healthy home-work balance. None of the participants disagreed with what I reflected to them, they only verified, repeated or provided more examples of the points they were making.

2.11.5 Reflexivity

Olmos-Vega et al (2023), highlight several definitions of reflexivity, such as that of Dowling (2006:13 (3) 7-21), as "a continuous self-critique and self-appraisal where the researcher explains how his or her own experience has or has not influenced the stages of the research process". Braun and Clarke (2022) also advise a reflexive approach is an essential part of analysis and is an ongoing process. A reflexive approach underpinned my study and helped me maintain an ongoing critical account of processes involved, increasing trustworthiness and reducing the risk of bias. For example, Lincoln and Guba (1985) hold the view that researcher, reactivity and respondent bias can threaten the validity of qualitative research. These areas were carefully considered as part of my reflexive approach and helped guard against bias. For example, researcher bias refers to the danger of a study being negatively influenced by the researcher's assumptions or prior knowledge. I was highly aware as a parent of a child who had been diagnosed with a brain tumour, coupled with my professional experience of supporting CBTS at school, that I was in a unique position to carry out this research. My position provided me with knowledge of and insights into the world of CBTS and school SEN support that helped inform my participant selection, guide my research aims and influence my methodology. Given my strong personal and professional connection to the world of CBTS, I acknowledge it was therefore impossible to avoid a degree of subjectivity in my study, but took the stance of "not being unashamed or afraid of subjectivity" in my case study approach, Thomas (2021; 73). However, because of my strong personal and professional connection with CBTS, I also carefully guarded against researcher bias through adopting strategies as part of a reflexive approach, such as peer debrief and keeping a reflexive journal, Lincoln and Guba (1985). These strategies allowed me to discuss and record ideas, questions, decisions and feelings about the process, data and interpretations, critically reflecting on findings and making sense of choices (see appendix 13) throughout the process.

Being open to positive and negative findings of the study also helped reduce researcher bias and required me to include a balance of evidence in my data, avoiding only focusing on aspects that may have supported my preconceived ideas and avoiding including only data that I felt was relevant. For example, in being honest and open about any preconceived views, it was necessary to acknowledge how, in my role at LSCBTC, I had heard parents of CBTS report many more negative than positive experiences regarding communicating with school. I guarded against this potential bias by welcoming the views of all participants (whose range of positive responses actually outweighed negative responses and were very different to any preconceived notion about home-school communication that I potentially had). I also adopted a transparent, non-judgmental approach when interviewing stakeholders, avoiding making assumptions about what parents, school or children would report in the study.

In addition, using a reflexive journal and peer debrief strategies helped reduce the risk of reactivity bias, Lincoln and Guba (1985) where the researcher's own reactions to the study could negatively influence data. This was especially relevant to me, given my personal narrative of having a child diagnosed with and losing a child to a brain tumour. Peer debrief helped me reflect upon any emotional reactions I had when listening to parental narratives. In my reflexive journal, I was also careful to separate out in note form, my emotional reactions to data, based on my personal experience of having had a child with a brain tumour, from my objective interpretations of data. This was an ongoing process, as I could not predict in advance which areas of data collection and analysis would have an emotional impact on me. It is also important to note, as an educational practitioner I am used to separating my personal emotive responses to working with CBTS from my professional practice. For example, when providing guidance for educational support and feedback about a child's literacy and cognitive processing profile, this feedback remains professional and objective. I adopted the same professional stance in the study and although I could empathise with stakeholders, I was mentally and emotionally well prepared to view data through the lens of a qualitative researcher.

In a similar way, respondent bias, Lincoln and Guba (1985) was guarded against in the study. This refers to the threat to bias when stakeholders provide answers to research questions based on what they think the researcher wants to hear, or where stakeholders do not provide honest answers because they perceive a threat in doing so. Using a case study approach and semi-structured interviews delivered in a sensitive way, allowed me to work gently with stakeholders, ensuring none felt threatened by the content or delivery of interview questions. Stakeholders were sent research questions in advance of the interview and could opt out of any questions they felt uncomfortable with. CBTS also felt secure enough to provide open and honest answers to research questions due to the relaxed, non-judgemental and gentle nature of the interview process. In addition, asking open ended interview questions provided space for all participants to share the fullness and truth of their own views, which also helped overcome respondent bias.

In addition to using Lincoln and Guba’s (1985) aforementioned strategies to help guard against bias, I carefully recorded all research data and processes such as transcripts, audio recordings, raw data, journals, policies, coding’s, data analysis and peer debrief discussions. Having such a transparent approach to the study helped minimize validity threats.

Chapter 3 Data Results Analysis and Discussion

3.1 Introduction

This chapter reports, analyses and discusses data collected from stakeholders and from policy collection in both case studies. It also discusses how conceptual frameworks of parent partnership can be used to help understand and guide home-school collaborative practice when supporting CBTS at school.

The following data findings report on experiences, perceptions and views of stakeholders regarding collaboration and communication between home and school when supporting CBTS. Although research questions were influenced by existing and gaps in CBTs school support research, an inductive approach to thematic analysis was used in identifying the main themes below:

Theme 1: Importance of early communication between parents and school when a child is diagnosed with a brain tumour, throughout the child’s absence from school and upon initial return to school
Theme 2: Need for CBTS training for school staff
Theme 3: Importance of knowing the narrative of the child and parents brain tumour journey
Theme 4: What works well and what are the barriers within home-school collaboration when supporting CBTS at school
Theme 5: Sharing future hopes for CBTS and stakeholder advice with other CBTS parents and schools
Theme 6: School and Parent Partnership Policy when supporting CBTS

3.2 Context: Background history of Luke and Lucy’s brain tumour journey

To help understand the journey of Luke and Lucy through diagnosis, treatment and back to school, the following background history was collected in the data gathering process:

Luke was diagnosed with a large cell anaplastic medulloblastoma brain tumour when he was 6 years old and at primary school. He underwent neurosurgery, chemotherapy and radiotherapy and was absent from school for 5 months. In case study 2, Lucy was diagnosed with an ependymoma brain tumour when she was in year 6 at primary school and her treatment included neurosurgery, chemotherapy and proton therapy. Lucy returned to primary school after being absent for most of the academic year. She transitioned to high school shortly after her return to primary school. Although return to school represented a return to ‘normality’ for Luke and Lucy, life had changed considerably for both children who had been left with long-term physical, neurocognitive and psychosocial challenges, that they did not have prior to treatment. Both required ongoing SEN support upon return to school and had an Education, Health and Care Plan (EHCP) in place. Luke and Lucy’s range of EHCP support needs were identified across all four areas of need, according to the SENCoP (2015):

- communication and interaction.
- cognition and learning.
- social, emotional and mental health difficulties.
- sensory and/or physical needs.

3.3 Theme 1: Importance of early communication between parents and school when a child is diagnosed with a brain tumour and throughout the child’s school absence

The need for early communication between school and parents, or carers of CBTS, is important as the child’s brain tumour journey does not start with their return to school. The study highlights it begins much earlier, upon diagnosis, or even in the build up towards diagnosis. This is an area not reported on in existing CBTS literature.

3.3.1 Communicating with school upon or in the lead up to a child’s brain tumour diagnosis

In case study 1, Mrs X said close communication with her son’s school started before his diagnosis, as he became progressively unwell. Staff notified her when Luke was unwell at school:

> “*His teacher, she rang me and said he’s been sick”.*
> *“That’s when the biggest issue started”.* (Mrs X)

The doctor diagnosed Luke with an ear infection but:

> *“Then the sickness started”*
> *“I was backwards and forwards to the hospital, I went to the hospital about four times.”* (Mrs X)

She was told:

> *"It was probably migraines and the reason he was being sick was probably because he got tummy migraines. So, as you can imagine it was getting quite frustrating."* (Mrs X)

Mrs X was referred to a paediatrician and told to just keep a headache diary*:*

> *"So then I had to communicate with school and I had to have a medical diary in place for them to administer Calpol."*
> *"School kept saying to me 'Are you sure it's just this?' and I said 'Listen this is the medical advice that I've been given, this is what I've been told to do,'*
> *"It was getting worse with him to the point that school was having to continuously contact me to ask for authorisation to give medication. I was getting to the point where I was getting worried, when I was thinking to myself, he's going to go to bed one night and he's not going to wake up. But I just wasn't been listened to."*
> *"So this was all prior to the diagnosis really, they (*school*) were just on it and they were just keeping an eye on him".* (Mrs X)

In case study 2, parents did not need close contact with school prior to Lucy's diagnosis as:

> "*The only thing we noticed was she occasionally had some headaches and occasionally felt sick on a morning*." (Mrs Y)

They did, however communicate with school upon Lucy's diagnosis.

3.3.2 Who did parents communicate with at school upon their child's brain tumour diagnosis?

The diagnosis of a childhood brain tumour is an understandably extremely frightening and stressful experience for parents and child. In case study 1, Mrs X communicated with the headteacher upon Luke's eventual diagnosis, drawing attention to the life- threatening nature of his condition. The headteacher informed the SENCO, who later took strategic lead in communicating with Mrs X. The headteacher continued to take an interest in Luke's well-being but did not lead the communication:

> "*What she's always been great at is she always talks to Luke, she always acknowledges. She's very aware of what's going on. But I don't need her to be involved if that makes sense. Because there's no need for her to be. She's aware, she knows what the situation is. She always checks in, she always asks me, how is he and how we're doing as a family?* (Mrs X)

In case study 2, Mrs Y communicated with the headteacher upon Lucy's diagnosis.

> *"We messaged the headteacher and I popped in to see her. Initially all my contacts were with the headteacher. But it was kind of a couple of face to face but obviously it was quite upsetting at the time. We also had to let them know because of Lucy's younger brother. And then they were very*

> *good, we had personal email communication with the headteacher."* (Mrs Y)

The study is novel in highlighting how, although the headteacher needs to be informed of a child's brain tumour diagnosis, the school SENCO (in the UK) should also be immediately alerted, in order to lead the communication with parents of CBTS. This is due to the range of difficulties and support needs CBTS may be left with and the level of support they may require upon return to school. The importance of the SENCO's role in relation to supporting CBTS and working closely with parents is not reported on in CBTS school support literature. Yet in the UK the SENCO has an integral and central role to play; SENCOs are responsible for the daily operation of a school's SEN policy, along with coordinating support and provision for students with SEND and liaising with parents. It is the SENCOs responsibility "to ensure that the statutory duties to children with SEND, as outlined by the Children and Families Act, are fulfilled" Bennett et al (2022:3). The SENCO in both case studies played a key role in working closely with parents and external professionals, to ensure Luke and Lucy's needs were recognised, understood, prepared for and met upon return to school. The SENCO also ensured communication occurred *throughout* the child's absence from school.

3.3.3 Importance of regular two-way communication between school and home *throughout* the child's brain tumour hospital treatment

The SENCO in case study 1 spoke about the importance of communicating with Mrs X throughout Luke's treatment:

> "*On diagnosis the parent did keep us very much up to date and well informed of his progress and what treatment he was going to be receiving*."(SENCO)

Parents in both case studies found it equally helpful when key school staff maintained regular contact throughout their child's hospital-based brain tumour treatment, because it showed them how much school cared**.** In case study 1, Mrs X appreciated school:

> "*Were with us consistently throughout, before diagnosis and then when he collapsed at school*."
> "*We did regular emails with school just to update them of what the plans were. We'd share and celebrate when he'd gone through his surgeries and how well he'd come out of it. And they were just really, really good. I couldn't have asked for more.*" (Mrs X)

In case study 2 knowing primary school was concerned about Lucy was *"massively"* helpful for Mrs Y:

> *"It was the fact that they were concerned and they wanted to know how she was doing."* (Mrs Y)

Mrs Y communicated with primary school through:

> *"Mostly emails because we weren't going into school because we were in hospital with Lucy, so all that period we were in hospital, I did a couple of popping in to see the headteacher because they just said 'Do you want to pop in for a chat?'*
> *"I basically had the email of the headteacher so if I was worried about anything or I wanted to inform her of anything I just sent her a note".*
> (Mrs Y)

Mrs Y also communicated with Lucy's primary teacher and Lucy's younger brother's teacher (who attended the same school) throughout Lucy's treatment, highlighting the importance of school emotionally supporting siblings of CBTS.

Mrs X and Mrs Y valued Luke and Lucy's classmates communicating with them throughout treatment (as organised by school); this helped ensure Luke and Lucy felt they were still part of their class and had a sense of belonging. In case study 1 the class teacher made sure Luke's classmates:

> "*Regularly sent cards or pictures or photographs of something that they'd been doing in class. So hopefully he still felt part of the class and he knew he was going back into that same class and would see his friends*." (SENCO)

In case study 2, school communicated with Lucy and her brother during Lucy's trip to America for proton therapy:

> "*The two school teachers organised the kids in the class to write to Lucy and her brother and we organised for Lucy and her brother, well Lucy wrote some stuff back. So that was very nice. Because Lucy at one point got a little email from everybody in her class."* (Mrs Y)

School staff did not visit Luke or Lucy in hospital during treatment and parents did not want them to.

> *"I wouldn't have expected them to. It was quite a busy time and I wouldn't have appreciated that."* (Mrs Y)

Mrs Y does not think the frequency or type of communication between home and school could have been improved when Lucy was absent from school:

> *"I think it was fine for us because once we'd got the email contact setup, if school needed to ask us something they did. But I think they*

> *were very conscious that they didn't want to butt in which was appreciated." (*Mrs Y)
>
> "*It was just the fact that they genuinely cared. They sent gifts for him. They did home visits, his class teacher, his TA came to see him."* (Mrs X)

Although CBTS school support research does not typically focus on home-school communication, findings of my study build on Tresman et al.'s (2016) CBTS school reintegration guidance protocol. The protocol suggests an official letter from HCPs should initially be sent to school informing them of a child's brain tumour diagnosis. My findings add to this showing how *personal* communication between school and home *upon* a child's brain tumour diagnosis and *throughout treatment* was valued. This is an important foundation of building a positive relationship between home and school (although CBTS school guidance by the Royal Marsden (2019) advocates the need for school communication throughout treatment). Study data draws attention to how early and ongoing communication helped parents feel supported and know their child was cared about by school, CBTS felt less isolated and still part of school, and key staff were better prepared for the child's return to school. Although schools were mindful of allowing family and child privacy during the child's difficult hospital-based treatment, two-way communication where parents and key school staff took joint responsibility for communication was evident in both case studies *well before the child returned to school*; this was a foundation of positive communication.

3.3.4 Academic support for CBTS during school absence

CBTS may be absent from school for a considerable period while undergoing brain tumour treatment, as noted by Upton and Eiser (2006) and Lonnerblad (2017). In addition to experiencing long-term difficulties as a result of the brain tumour and treatment (Maddrey et al., 2005; Bruce et al., 2008; Ellenberg et al., 2009; De-Ruiter et al., 2012; Lovely et al., 2013; Castellino et al., 2014; Lonnerblad et al., 2017; Vanclooster et al., 2019), lengthy school absence can exacerbate a potential attainment gap between CBTS and peers, within core skills areas such as literacy and numeracy (Lonnerblad et al. 2017). Luke was absent from school for 5 months and Lucy missed most of the academic year, before both children accessed a phased return to primary school. The data drew attention to how, when CBTS are in hospital (and if they are well enough to access schoolwork) school should be prepared to communicate with hospital teachers to ensure appropriate schoolwork is provided. In both case studies school also provided academic work for CBTS when they were at home rehabilitating during and after treatment. This helped ease the child's feelings of isolation, along with providing an educational stimulus for them.

In case study 1, Mrs X asked the school SENCO to organise schoolwork for Luke:

> "*Because even though he was getting school lessons in hospital school, I was still conscious that he still wanted to feel a little bit involved*." (Mrs X)

Luke subsequently accessed home-schooling with a tutor (arranged by school) throughout his school absence. Mrs X spoke positively about the experience and found it especially helpful that the tutor informed school about Luke's progress:

> "*She has been through the whole process with us from home schooling into getting him back into school" (*Mrs X*)*

In case study 2, Mrs Y acknowledged the benefit of primary school providing work for Lucy at home:

> *"It was really helpful because it did give her a focus to do some bits of work actually when she was stuck at home and she was too poorly to go into school."* (Mrs Y)

Parents spoke positively of work being provided by school during their child's recovery period at home; they were mindful of how a lengthy absence from school can contribute to the potentially widening attainment gap between CBTS and their peers.

3.3.5 Importance of increased frequency of meetings between school and home in preparation of CBTS return to school

Both children experienced long-term difficulties after brain tumour treatment, resulting in them requiring SEN support at school including physical support, cognitive classroom-based support and intervention and social skills support. Tresman et al. (2016) draws attention to the importance of school staff having early and detailed information of the unique needs of CBTS, to inform school support and a transition plan. In case study 1, this was done through close communication with parents and HCPs. The frequency of communication between the SENCO and Mrs X increased as it drew closer to Luke's school reintegration:

> *"I was in and out of school, I can't even tell you how many meetings I had."* (Mrs X)
>
> "*It was very much about just going in, having the meetings, telling them where I thought he was. Having assessments around his reading, his*

> *writing, his mathematical knowledge. And his general wellbeing. Because for me his wellbeing was just as important as his education. But I didn't want him to be treated any different. I didn't want him to be isolated".* (Mrs X)
>
> *"We had regular meetings before he actually returned to get some kind of transition plan in place so that he could obviously come back to school. But to make sure that school were well equipped and ready for his return". (*SENCO)

Regular communication before Luke returned to school ensured the SENCO was:

> "*Very, very aware. So right from quite early on we talked quite openly about what that (*school*) would look like for Luke because I said 'My biggest concern is that Luke has already lost a batch of school, what do we do now?' So he (*SENCO*) started putting lots of things in place to get things moving with the Support Plan because obviously the Support Plan then went to EHCP. Which again he was just all over it." (*Mrs X*)*

Close and ongoing communication between the SENCO, Mrs X and external professionals, resulted in a timely and successful ECHP application, ensuring Luke received funding for full time TA support. Mrs X told the SENCO:

> *"I will do absolutely everything I can to help and support you to get that funding that you need, but you need to work with me as well. And in fairness they have*." (Mrs X)

In case study 2, Mrs Y was impressed with how the headteacher at primary school anticipated Lucy's return and ensured support was in place, even before they knew the outcome of Lucy's EHCP application:

> *"The headteacher knew that Lucy would need some support so she just got on and employed somebody before the EHCP."*
>
> *"So they reassigned a TA to look after Lucy when she was going back."*
>
> *"They had set things in motion to get somebody, so Lucy had full-time support. And in the end the EHCP did say she needed it and they got the funding. But they didn't wait for that*." (Mrs Y)

3.3.6 Working with external professionals helped school prepare to support the needs of CBTS upon school reintegration

Due to the potential range of support needs CBTS may have, schools should ensure the correct level of academic, social, emotional and physical support is in place for CBTS when they return to school, from day 1. This must be planned *in advance*. Yet, in the UK, there is currently no pathway of guidance for schools to refer to when a child has been diagnosed with a brain tumour. Key staff in both case studies therefore relied on working closely not only with parents, but sought, accepted and valued guidance from external professionals involved in the child's medical support and rehabilitation. In case study 1, when preparing for Luke's return to school, the SENCO recognised:

> "*Each agency had a really important role in making sure that transition was smooth but also that he was making progress back in school. The OT and the hospital were also involved. His medical needs had to be checked. And making sure that we had the healthcare plan as well in place. And again, that was shared with staff so everybody had that awareness*." (SENCO)

He said of working with all outside agencies:

> "*Anything they put in as recommendations or anything additional, we've put in place*." (SENCO)

Mrs X and the SENCO were keen to involve all relevant external agencies in Luke's reviews:

> *"His mother has been very keen to have as many external organisations in place to support the child at home and within school. We'd like to think that school have worked very closely with the parents to make sure that we have all those agencies linked in really because of his varying needs."* (SENCO)

Working closely with external professionals and parents was beneficial because it:

> *"Helped school. Just to make sure that the child is well integrated back into school and also feels very much a part of his class and with his peers as well so that he isn't missing out in any way in the curriculum."* (SENCO)

Mrs X noted school have:

> "*Done remarkably well to adapt and to be open to change."*
> *"They were absolutely willing to adapt whatever they needed to adapt so that he could go to school and have an effective days' learning*." (Mrs X)

In both case studies school also welcomed external support from the 3rd sector CBTS education outreach liaison service offered by LSCBTC. Luke and Lucy accessed standardised literacy and cognitive processing assessments to inform school about the level of classroom support and intervention needed. Although CBTS may be assessed by a neuropsychologist post brain tumour treatment, these assessments did not take place until well after Luke and Lucy had returned to school. However, school still needed advice and guidance regarding the child's support needs *upon* their return to school. In addition, although neuropsychology assessments inform a child's neurocognitive profile (Cheung et al, 2014) and make practical recommendations for school, these reports do not typically cover the same areas of assessment as those carried out by a specialist teacher. Specialist teacher assessments (as accessed by Luke and Lucy) specifically inform classroom support, literacy intervention and exam concessions recommendations. The latter is important as even though when a child has an EHCP in place in the UK this includes exam concession recommendations, when CBTS first return to school EHCP applications may not have been processed. Therefore, in the meantime, specific exam access arrangement recommendations guide school regarding concessions for the child. It is also important to recognise CBTS who don't require an EHCP may still require exam concessions. Reporting on the importance of CBTS accessing exam concession guidance upon school return is a novel finding of the study. In case study 2, Mrs Y felt this guidance was extremely useful as it enabled Lucy to access appropriate support in Standard Assessment Tests (SATs) examinations, which she sat when she returned to primary school.

> *"I don't think she would have got anything like the results that reflected what she was like in her intelligence if we hadn't had that extra time, it was really important".* (Mrs Y)

Early communication and meetings with parents and external professionals allowed key school staff in both case studies adequate time to identify and understand the range of support needs of CBTS, *well before* the child's school reintegration. Findings are consistent with and build on research by Bruce et al.,(2012); Tresman et al.,(2016); and Vanclooster et al.(2019), regarding the need for early intervention meetings between school, parents and HCPs, to help prepare for CBTS' return. However, my study findings add to research by highlighting the importance of standardised literacy and cognitive processing assessments to help inform the level of differentiation needed within Quality First teaching, TA support and small group intervention programmes for CBTS, upon school reintegration. Quality First teaching in the UK is where teachers are required to teach mainstream classes in an inclusive way.

Early and ongoing meetings and appropriate assessments helped school gather relevant evidence of the child's individual needs and submit timely and successful EHCP applications, which, in turn, provided school with extra funding to meet the needs of CBTS at school. However, whether an EHCP is applied for or not, understanding the range of needs of *all CBTS,* well in advance of their return to school, allows school adequate time to carry out risk assessments and develop appropriate support plans *before* the child returns to school.

Reflective of Tresman et al.’s (2016) school reintegration guidance protocol, the data also showed school and parents were happy to take the lead in implementing CBTS school support (as opposed to HCPs). This does not mean the input of HCPs is not valued or needed (especially upon initial return to school), however, the support needs of CBTS can cut across areas of school that HCPs may have no expertise in. HCPs are, after all, not involved in meeting the daily support needs of CBTS at school in the way school staff and parents are.

3.3.7 Preparing for Luke and Lucy’s school reintegration

Supporting the child in preparation for and upon return to school was important in the study, especially considering “the profound experience of dealing with the diagnosis, treatment and life after cancer can be isolating. Good social reintegration is essential if the pupil is to get any sense of belonging”, Royal Marsden Guidance for Teachers (2019:99). Carefully planned initial visits to school are the first step in welcoming CBTS back to school, ensuring they feel safe and supported and the experience is a positive one for child and parents. In case study 1, early school visits not only allowed CBTS to see peers, but helped prepare peers for changes in their classmate. Mrs X worked closely with school to prepare Luke for his return:

> “*when we were integrating him back into school we went into school and we did a let’s go see your friends, you’ve not seen them for quite a few months. So we went into the library and we had story time with his class and the kids got to say hi to him.”*
> *“Also it got them used to seeing him in a wheelchair as well.”* (Mrs X)

Mrs X recognised how Luke returning to school:

> “*Was the next natural stage for him. I knew that he wanted to get back out and all he kept saying was ‘I just want to be normal, I just want to see my friends’. That’s all he’s done, all through the whole process, ‘I just want to be normal’.* (Mrs X)

Despite working closely with school and being happy with the level of support in place for Luke, Mrs X felt nervous about his school return:

> “*Because it’s almost like you have to trust someone else again. And the day that I had to trust a surgeon to bring my son back out alive, you know there’s nothing can compare to how you feel as a parent. But I’d had to do that quite a lot*.” (Mrs X)
>
> *“So I was nervous but I was also confident because we’d had that many planning meetings and I’d also got all the support of all the professionals.*” (Mrs X)

In case study 2, Mrs Y spoke about how she felt regarding Lucy's return to primary school:

> *"We were fine with it because we see the importance of school and it's where she sees her friends and she'd been away from them for a while, we didn't want her to be separate from people. But it's very hard because she's obviously different. But you've got to do it and it's the best thing, it's just different."* (Mrs Y)

Parents could see regaining a sense of 'normality' was an important part of their child's school reintegration. This echoes research by Vanclooster et al (2019), where CBTS looked forward to seeing their peers and returning to 'normality'.

Careful consideration of what to tell the child's peers as part of preparing them for CBTS' return to school was important to parents and schools in the study; this is an area highlighted in The Sam White Pathway (2017), Guidance from Royal Marsden (2019) and by The Brain Tumour Charity (www.thebraintumourcharity.org). In both case studies school had to consider how, or if, to communicate sensitive information about CBTS to other parents and students. Mrs X and Mrs Y held differing views. In case study 1, school asked Mrs X's permission to tell staff and other parents about Luke's diagnosis in the form of an assembly and a newsletter.

> "*I just said, I want you to be honest with these people."*
> *"I basically wrote a statement, told them what they could discuss. "They made it their mission to make sure that Luke was still involved in school. That he was still part of their community."* (Mrs X)

The SENCO said of the assembly:

> "*We made it more of a whole school approach, that awareness and that understanding to respect and understand that some children may have different needs*." (SENCO)

School communicated more specifically with Luke's peers, making sure:

> "*The children within the class were well prepared for his return because the child hadn't been in class for a long time and he had different needs that maybe the children may not be used to and we didn't want the children to be alarmed in any way."* (SENCO)
>
> *"We talked through in quite simple terms that the child hadn't been very well and had to have some major operations as well to try and make sure he's better. But that might well have affected some of the things that we take for granted. And just making sure that he was going to be welcomed back and felt very much a part of the class*." (SENCO)

Mrs X believed being honest with Luke's peers helped them and him upon his return:

> “*I do believe it’s because we’ve been honest with them. I do believe it’s because we’ve not tried to shield it and make it some big secret*.”(Mrs X)

She felt by sharing information with Luke’s peers, they have “*seen his journey”* and said they say:

> “*Luke is amazing, he’s such a super-hero.”* (Mrs X)

In case study 2, Mrs Y did not want primary school to communicate to other parents what had happened to Lucy, but she was concerned over the emotional wellbeing of Lucy’s classmates. School spoke to Lucy’s peers about her brain tumour, helping them understand and cope with any fears they had. Lucy’s Macmillan nurse visited Lucy’s class as:

> “*Lucy’s friends were a bit upset at the time”*.
> *“Lucy’s support nurse did say you get the obvious things of them asking in class, ‘Is Lucy going to die?’ So they get that out of their systems don’t they? Then the nurses can say things to the other children which is ‘No not necessarily, people can get treatment nowadays’ ”. (*Mrs Y)

Information about Lucy’s brain tumour was not subsequently shared with her secondary school peers when she later transitioned to high school. Lucy’s choice not to tell her peers at high school was respected:

> “*We just wanted her to be as normal as possible. They did ask us if we wanted people to know or not in her year and Lucy didn’t really want that.” (*Mrs Y)

However, as a result of this:

> “*Not many people knew her. They just know that she’s in a special needs group and she’s got some physical problems and her TA walks around with her. I’m not sure whether she’s told any of her friends.”*
>
> *“Nobody really knows her story I don’t think.*” (Mrs Y)

Upon reflection, the assistant SENCO at high school felt telling Lucy’s peers may have been helpful:

> “*I felt this should be done. I didn’t know exactly how it should be done but I felt like it should be done.”*
> *“I would have liked to have been able to explain or even getting her to be involved as well and explain a bit of the back story.”*
> *“I think knowing a bit of the back story makes you understand a lot of the behaviours much easier.”* (Assistant SENCO)

3.3.8 Accessing intervention as part of inclusion for Luke upon school reintegration

In case study 1 upon Luke’s return to school, although Mrs X was keen for him to access appropriate school support, she was concerned about the amount of time he may have to spend out of the classroom, in ‘intervention’. She shared this concern with school, making it:

> *“Very clear throughout that I do not want him spending the whole of his class sessions in that room (*intervention room*) and missing more of whole classwork”.* (Mrs X)
>
> *“And that was a big concern for me. I said ‘How are you going to manage that? Because I don’t want Luke to feel that he’s in a room and he’s been isolated, he’s just spent nearly a year in isolation in hospital. He needs to feel like he’s part of a classroom’. And I’ve got be honest, they really did make it work.”* (Mrs X)

Listening carefully to Mrs X’s concerns was an important part of school tailoring support to meet Luke’s needs; Luke’s TA said his routine worked well for him *because* it provided a positive balance between specialised intervention that he needed to access to meet his specific needs, and classroom learning:

> *“He’s sat at the front where he can see everything. He’s not taken out very much but if he is taken out, he’s taken out with a group. So, he’s not singled out in any way*.” (TA)

Mrs X also recalled having concerns around Luke’s social reintegration upon his return to school, which she shared with the class teacher and SENCO:

> “*His teacher had a very strict way of how he set up his classroom. He had children in the class that he classed as being the disruptors and the children that he felt were going to be beneficial to Luke”.*
>
> *“I was like ‘But you can’t tell Luke who to be friends with.*
> *I struggle that you’re telling him who he can have as friends.”* (Mrs X)

In addition, Mrs X said Luke told her he “*couldn’t keep up with the teacher*” when he first returned to school:

> *“It was quite difficult to begin with because it was his teaching style. And I felt quite frustrated with him (*the teacher*) because he didn’t attend the first few (*support) *meetings and I felt quite cross about that. And I actually said to the SENCO ‘I just think it’s really poor’.* (Mrs X)
>
> *“From my point of view, he needed to be there. Especially when it was getting close to Luke coming back to school”.* (Mrs X)

The SENCO responded positively to Mrs X’s concerns and Luke’s teacher subsequently attended Luke’s My Support Plan and EHCP meetings. Mrs X felt comfortable and confident voicing her concerns at Luke’s support meetings. For example, she communicated to Luke's teacher how the pace of the lesson was too fast for Luke:

> "*And I was quite strong to be honest in saying to them 'Look you need to slow it down, you need to take it back a little bit. You need to make sure that we've got resources available to him such as maybe a word processor or even down to the type of pens that he uses."*
>
> *"You actually need to go back over it with him as well and check his understanding because he's not retaining it. But also, what I was conscious of is I didn't want Luke to feel he's not achieving".*
>
> *"I don't want him to feel like he's daft. Because he's not daft."*
> *"I just said to him* (Luke's teacher*) I don't agree with him, I just don't agree. And that is purely because I felt so strongly about Luke's mental wellbeing as well as his educational wellbeing."*
>
> *"People underestimate just what they're (*CBTS*) going through,"* (Mrs X)

3.3.9 The importance of TAs when supporting CBTS and communicating with home

The importance of the role of TAs when communicating with parents of CBTS and supporting CBTS was evident in the study. Mrs X spoke about the significant role TA's play in communicating with home and in supporting Luke:

> "*The key people in his classroom environment are his TAs if I'm being honest."*
> *"Simply because they are on a level with me because on a daily basis, they are the people that communicate and they are the people that work with Luke. So, they are the ones that have a vested interest the same as I do".* (Mrs X)

Mrs X recognised TAs have:

> "A *tough job, they're in the middle of a teacher and a SENCO and a parent. Because they've got to provide support all around to make sure that everyone is getting what they need*." (Mrs X)

She also felt schools should acknowledge the importance of TAs:

> "*They're so undervalued it's unbelievable, so undervalued*." (Mrs X)

For example, Mrs X felt Luke's TA should be invited to *all* meetings about his support due to the important role she played within his support. Mrs X had a conversation with Luke's TA when preparing for Luke's school return:

> "*I just said 'How are you feeling about everything?' and she just said 'I'm really nervous.' And I said 'What are you nervous about?' So, she said 'I need to make sure the teacher gives me information.' And I said 'I'll tell you what I need, I need you to be in that (*meeting*) room'. And she just looked at me and went 'I totally agree'.* (Mrs X)

> "*And that's when I started pulling her in and I just said to the SENCO 'We need to involve a TA. The TAs play a massive, massive role. It's no disrespect to the teacher, but that TA is going to be with him 24/7. And after that both of them were in every meeting. Because they need the information and information gets diluted when it goes down the chain if they're not part of something. So, I just said 'Look I'd rather that she gets it first- hand.'* (Mrs X)

The TA also recognised the importance of her being involved in all of Luke's support meetings:

> "*I said I want to be in there because I'm with him every day. It's not fair on me and I also felt for mum she needs to see the person who is looking after him."* (TA)

Luke's TA explained she is the one who supports Luke's needs daily and sees his progress:

> *"I'm the one who sees it. Yeah, they see the finished piece of work but they've not seen what I have to do to get to that*." (TA)

The SENCO listened carefully to Mrs X's concerns and subsequently included all key staff in Luke's support meetings; this was a necessary part of ensuring school staff had a full understanding of Luke's specific needs and his areas of progress. Listening carefully to Mrs X's concerns helped school adapt Luke's support as necessary and facilitated a positive home-school relationship.

Daily communication between Luke's TA and home was reported to work well. He accessed staggered start and finish times (allowing for the level of fatigue Luke initially experienced) and was met at school by his TA every morning. This was part of school:

> "*Making sure that the communication is there before he actually comes into school so that the teaching assistant has that opportunity to speak to the parent when Luke comes in."* (SENCO)

Meeting daily with Luke's TA allowed important information to be directly communicated between school and home.The use a home-school communication book was helpful initially:

> "*They fill in his diary to tell me how much he's eaten, how much he's drank."*
> *"They'll also tell me if he's not had a great time when he's been in class. Or if he's become quite tired*." (Mrs X)
>
> *"Last year we had a home school book so I used to write things in that and put it in his bag because mum works, she doesn't always pick him up."* (TA)

> *"And if she has any worries she can write in that book*." (TA)

Luke's TA reported Mrs X's level of proactive communication ensured school were updated with his medical progress:

> "*We know exactly what appointments he's got, when he's going, why he's having them. She lets us know the results."*
>
> *"If she feels there's something to let us know that could affect him in school, she'll let us know*." (TA)
>
> "*It helps me support him a lot better because I know if he's got little things going on at home, I know about that, and then I can adjust*." (TA)

Working closely with Mrs X also helped his TA set behaviour boundaries for Luke. Mrs X recognised school were initially struggling with this and recalled telling them:

> "*If you don't keep boundaries with him then you're going to allow him to get away with it and it's going to get harder.' They said 'Yeah but he's just been through so much' and I said 'I know but do you think I let him get away with everything at home?' And they just sort of looked and went 'No'. 'We just need to know that you're comfortable with us saying 'Right Luke, this is what we've got to do today and this is how we're going to do it and if we don't do it, these are the consequences.' I went 'Absolutely fine'*. (Mrs X)

The TA's confidence increased through taking the lead from Mrs X:

> *"If we do something she's* (Mrs X*) very much onside with us, she wants him to be treated the same. And if he's told off or something then tell him off. If he's done something wrong then he's dealt with like anybody else*." (TA)
>
> "*I'd like to think I'm doing what mum would do or I'd like to think I'm on the same wavelength. I would think, would mum want that? But there's a fine line between being the mum or being in school where he's got rules."* (TA)

Although Webster et al. (2021) and Moore (2016) draw attention to the importance of TAs in relation to home-school communication in general, there is a lack of CBTS research focusing specifically on TAs being in a prime position to develop the home-school relationship. My study was novel in exploring this. Mrs X regarded the TA as being the most important point of contact for her at school, due to the TA being the staff member who worked most closely with Luke. In both case studies TAs worked very closely with CBTS and communicated with parents (or family) in person, daily, at school drop off and pick up points. School should be aware of the potentially powerful position TAs are in regarding building strong links with parents. However, in allowing TAs greater responsibility in building and championing partnerships with parents of CBTS, appropriate training must be provided. Careful consideration by school senior leadership must also be given to the parameters of the TAs role. For example, in the study, TAs were happy to work closely with parents of CBTS as the member of staff who had a very detailed understanding of the child's daily performance, but they were equally aware of professional boundaries and relied on guidance from the SENCO when relaying information to parents. The TA in case study 2 valued daily face to face communication with parents, but was conscious of not relaying messages or communicating specific information to parents without the SENCO's permission:

> *"We're careful because we have to run a lot of stuff past the SENCO, but anything in general we can chat or pass messages on."* (TA)

This also partly aligns with Moore (2016:78) who drew attention to how "capitalising on the willingness of TAs to strengthen engagement with parents and caregivers" "is not necessarily easy to operationalise".

3.4 Theme 2: The need for CBTS school training

CBTS training is essential for school staff not only in working closely and sensitively with parents, but in understanding the impact of childhood brain tumours, knowing how to identify and support the potentially complex individual needs of CBTS, and ensuring ongoing support is tailored to meet those needs in an inclusive school setting. However, none of the staff in the study accessed specialist CBTS or ABI training. This is reflective of a lack of UK based CBTS school training availability. There is also a lack of research focusing on the availability and impact of specific CBTS school training.

3.4.1 Lack of school experience and training when supporting CBTS

None of the staff in the study had experienced supporting a child with a brain tumour prior to working with Luke and Lucy and none had accessed CBTS or ABI training. Guidance for school regarding supporting CBTS therefore came from parents and external professionals.

In case study 1, although Luke's TA was required to support him daily, she relied on understanding his needs through:

> **"***His EHCP, it was done through mum, the physio, they came in and told me what he needed, how he needed to sit, the equipment that he needed and things like that". (*TA)

Although Luke's teacher attended a day of *generic* hospital training focused on supporting children with cancer, this was not specific to CBTS:

> "*The course was based around the needs of the child within class but also having that awareness of how parents may be coping with the treatment that the child has had and their own mental well-being. So, it was useful for the class teacher to have that whole awareness of the child, not just particularly in school but also the needs of the child at home as well. It was hopefully supporting the teachers when they had that communication with the parent*." (SENCO)

The class teacher displayed a greater understanding of Luke's needs after attending the generic hospital training, but there was still a need to work sensitively with Luke:

> *"He'd come back from this seminar and I think Luke had gone to school and he (*the teacher*) just said 'I've been on that course, it says about cancer.' And Luke just looked at me and went 'I had cancer?' So I was like great, amazing. But in fairness we'd never said to Luke 'This is what you'd had.' So again, we just had to have an open frank conversation with him and it was fine"*. (Mrs X)

Due to school budget restrictions, only the class teacher attended the generic hospital training, but Luke's TA felt:

> "*It would have been nice if I did it just because I was working with him on a daily basis*." (TA)

Luke's TA also felt accessing specific CBTS school training would have been helpful and the SENCO agreed regular CBTS staff training was necessary:

> *"to support the teacher that's working with that child. Just to basically say 'This is quite normal' and thinking of different strategies that we could put in place to support that child."* (SENCO)

The SENCO in case study 2 felt specific CBTS training was needed as even though staff members may work within SEN, this does not mean they are specialists in every area of SEN:

> *"I think some difficulties with SEN is that people just presume as a SENCO or as a support assistant that you have that knowledge, but if you've not come across that area of need, then you haven't. So, I think making sure that we've got a really secure knowledge, that would be really helpful."* (SENCO case study 2)

It was recognised although SEN staff are used to working with students with a wide range of additional needs, supporting CBTS is:

> "*A really specialist area, it's an area that we don't come into contact with very often. So, it's certainly an area of expertise within school and certainly for me I think I would have benefitted from strategies and advice. Just giving you confidence really that you're supporting the child in the appropriate way*." (SENCO case study 2)

In case study 2, the high school transition process helped staff understand Lucy's ongoing needs. Parents met with the high school assistant SENCO (who led the transition process), at Lucy's final EHCP review meeting at primary school:

> *"Our policy and practice is when a child is in primary school, we would attend sometimes in year 5, but definitely in year 6, the meeting for the EHCP. I did attend the meeting and it was a long meeting where parents went through a lot of different things and we were able to say, and I was able to say, what would work." (*Assistant SENCO*)*

She felt the meeting was successful:

> *"I can't imagine not having it."* (Assistant SENCO)

The assistant SENCO communicated with parents, primary school and external professionals to develop an understanding of Lucy's support needs prior to transition. This was done:

> "*With a lot of support from other people to start off with".*
> *"It was really beneficial just listening to all the experts and the parents are included in that, in what we needed to do.*
> *"It was just really helpful to talk to somebody, well to people who knew better than me."* (Assistant SENCO)

High school key staff relied on developing an understanding of Lucy's needs through her existing EHCP targets and the assistant SENCO recalled being 'massively' open to guidance and support in preparing to support Lucy's transition to key stage 3. However, the transition process alone, although extremely important, did not replace the need for CBTS school training. School staff felt accessing training would have been helpful in preparing them to support Lucy:

> *"Absolutely. Massively. Because somebody with a brain tumour is something out of the ordinary for our school."* (Assistant SENCO)
>
> *"It would just have given you that bit more like a comfort blanket. Oh yeah, I do know kind of what to do in x, y, z situations. Just so you're not shaking*." (TA)

The SENCO felt CBTS school training should include *"things that can make a real difference"* to CBTS and said training should be:

> *"accessible …strategies that you can use that can be shared. So staff aren't having to spend lots and lots of time because time is so precious to them."* (SENCO)

The data highlighted how a lack of time in the school day can prevent busy school staff from attending CPD training:

> “*We try and signpost in terms of CPD that they can do. But obviously the onus sometimes is on staff finding time to be able to do that.” (*SENCO)

The assistant SENCO relied on carrying out her own research to help understand Lucy’s needs, but recognised the limitations of this, saying it was:

> *“not research in the way that going into real depth about it and having a real understanding.”* (Assistant SENCO)

Lack of access to school CPD CBTS training aligns with an NASUWT survey carried out in 2018. This reported school staff experienced challenges accessing SEN CPD training due to difficulty balancing a heavy workload, school not being in a financial position to fund CPD training and lack of availability of effective training.

The SENCO summarised specific CBTS staff training would help staff:

> *“feeling that preparedness really on arrival, that confidence. Because I think with confidence comes the ability to make some wise choices and to sometimes take risks and if you feel you’ve got that knowledge that helps.”* (SENCO)

Moving forward, she would also like to include the voice of the child within staff training:

> *“that’s a route that I’d really like to go because actually the voice of the child and listening to their experience is far more powerful than somebody like me stood at the front reading off a sheet”* (SENCO)

3.4.2 Importance of school recognising CBTS can experience long-term difficulties classed as an Acquired Brain Injury (ABI)

CBTS training for schools would help staff understand having a childhood brain tumour is unlike being diagnosed with other forms of cancer. Brain tumours (including low grade tumours) can not only be life threatening due to the location in the brain and treatment, but can leave children with long-term difficulties impacting on school performance (Vanclooster et al., 2019; Bruce et al., 2008; Maddrey et al.,2005; Ellenberg et al.,2009; Castellino et al., 2014). Long-term effects of a brain tumour are classed as an ABI (IPBIS, The Children’s Trust www.thechildrenstrust.org.uk). Yet knowing the link between CBTS and ABI is not necessarily a connection that educational professionals automatically make (especially if they have limited knowledge about brain tumours and ABI’s in the first instance). In the study, parents were aware Luke and Lucy had been left with an ABI affecting their physical, cognitive and social skills, but staff displayed a variable level of knowledge of this link.

Luke had been left with an ABI resulting in short-term memory and processing speed difficulties along with:

> "*Long-term high frequency hearing loss. He has been left with a tremor. He has poor muscle control in the centre of his body, in his hips and his left side, because he was completely paralysed so he had the PFS which is Posterior Fossa Syndrome. And because of all the swelling that was going on around there, he didn't have the ability to talk. He didn't have the ability to move. I think it took him probably about a month to start talking to us."* (Mrs X)

Mrs X felt it was important school staff recognised that a brain tumour is classed as an ABI:

> *"The more information they have, the more informed they are to be able to deal with a child with a brain injury because at the end of the day that's what it's classed as now. Somebody has had their brain opened and messed about with and all the mechanisms have been knocked about. And he's gone through all what he's gone through and done so well but there are days where he has really bad days. And they need to be aware of what that looks like*." (Mrs X)

In case study 2, Mrs Y was aware Lucy had an ABI, long-term in nature:

> **"***Well, that's what we've got now it's an acquired brain injury that we're dealing with now because the brain tumour, we're in remission."* (Mrs Y)
>
> *"The current is an acquired brain injury and the impacts from that, that we're living with for long-term."* (Mrs Y)

Mrs Y was aware of Lucy's difficulties before she returned to school, but learnt more about long-term impacts around a year post treatment, after Lucy had been assessed by a hospital neuropsychologist:

> *"I think we were all aware of when she was going back to school of the obvious things we could see. She'd not been able to speak but she'd learnt to speak again so that was obviously still quite difficult for her. Her physical problems were still quite hard for her because she was still struggling to move around and she had a wheelchair. She got quite tired. She was going through chemo. So I think we were aware of all those kinds of challenges really without anybody having to spell anything out to us. I think it was later on when she was getting a lot better that we went into the fine detail of things."* (Mrs Y)

In case study 1, the TA, SENCO and class teacher all regarded a brain tumour to be an ABI (but none of them had accessed training in this area). A range of responses were provided by staff in case study 2 when asked if they considered a brain tumour to be an ABI:

> *"I'm not sure actually, yes". SENCO*
>
> "*I see the child as important, not the condition.*" (TA)

The assistant SENCO previously thought if someone had a brain tumour and survived and recovered:

> "*Then everything was fine again. That is again my ignorance in that probably. But I think if it' terms under acquired brain injury, I think it makes you realise that it's a lasting condition".*
> *"I think when it's considered an ABI, I just think the terminology in it makes it sound that it's kind of more of a long-term thing."* (Assistant SENCO)

For parents of CBTS, recognising their child has an ABI can add yet another stressful and upsetting layer to the difficult journey they are already on. School staff should be aware of this when communicating with home. In order for school staff to understand the range of long-term difficulties CBTS can be left with, training is needed to draw attention to how effects of a brain tumour are classed as an ABI. Lack of available school ABI training was noted by Linden et al. (2013). Eight years later my study has found this still to be the case, with key staff recognising they had limited knowledge and experience of childhood brain tumours as an ABI. Although pockets of available training regarding school supporting children with *ABI's* are offered, such as those provided by the Child Brain Injury Trust (https://www.childbraininjurytrust.org.uk), staff in the study did not access specific CBTS *or* ABI training in preparation of supporting CBTS. If school staff are not actually aware of the relevance of ABI training when supporting CBTS at school, they may not know to source this training in the first place.

3.4.3 Lack of training resulted in school staff feeling cautious when supporting CBTS

Inductive data analysis highlighted lack of training and experience around supporting CBTS had a negative impact on staff confidence, leaving them feeling anxious and nervous when required to support the range of needs of Luke and Lucy. The high school SENCO in case study 2 noted staff were initially:

> *"very, very nervous, very over cautious doing lots and lots." (*SENCO)

The TA spoke about initial fears when supporting Lucy:

> *"I think we were really worried that something was going to happen, that she's going to fall over or just something was going to happen and that she'd get injured or something like that."*
> *"It's really scary."* (TA)

Staff sought external advice and were reassured by Lucy's physiotherapist:

> *"We kind of felt a little bit like we were mollycoddling her. Because we were frightened for her. And the physiotherapist tried to explain to us that we've got to let her go a bit for her to learn." (*Assistant SENCO*)*

Through listening to external professionals, seeking parental guidance, along with being supported by the SENCO and assistant SENCO, and developing a relationship with Lucy, TA level of confidence grew when supporting her:

> "*It's great to see their journey in that they've developed a relationship where they can read each other a little bit, they actually listen to the voice of the child because that's really important."* (SENCO)

Despite not accessing CBTS or ABI training, schools in both case studies provided effective, caring, adaptive and reflective support for CBTS. However, they relied on developing their knowledge and skills of supporting CBTS through their own professionalism, conscientiousness, pride in their work, care for the child and their ability to build strong collaborative links with parents and external professionals.

3.5 Theme 3: Importance of school knowing the narrative of the child and family's brain tumour journey

My study was novel in considering if knowing the narrative of the child and family's brain tumour journey, helped school develop a deeper understanding of the impact of a brain tumour on child and parents. The importance of school understanding the narrative is not reported in CBTS school support research, but I identified this as an area of importance after listening to Scharle (2019) speak about narrative medicine and brain tumours, at the International Brain Tumour Alliance conference. I also attended a brain tumour symposium in the UK (Yorkshire's Brain Tumour Symposium 2022), where Mr Ryan Mathew, Associate Professor and Honorary Consultant Neurosurgeon, spoke about the importance of personal narrative approaches when working with brain tumour patients. His human centred approach to surgery meant treating a brain tumour patient included understanding the impact a tumour has on a person's life. In this sense, knowing the narrative could also help school staff understand the impact of the brain tumour journey on the lives of child and parents in the following areas:

3.5.1 Parents of CBTS 'battle' for their child's diagnosis

Knowing the narrative could help school be aware that the lead up to a child's brain tumour diagnosis can be an extremely stressful time for parents and child. Some parents of CBTS I have worked with felt they had to 'battle' for their child's diagnosis; this resonated with me on a personal level. In case study 1 Luke was becoming progressively more unwell and was eventually diagnosed with a large cell anaplastic medulloblastoma brain tumour after collapsing at school. Mrs X said Luke needed an immediate:

> "*a lifesaving operation, otherwise he wouldn't be with us*". (Mrs X)

She spoke about the frustration she experienced when repeatedly communicating her concerns to medical staff prior to Luke's diagnosis:

> *"It was a battle getting his diagnosis."*
> *"And then when I did get blue lighted to the hospital on that day, the doctor turned around and said 'I can't believe you've been sending him to school,' and I just looked at him and went 'Just don't. Just don't.' Because you trust the professionals." (*Mrs X)

In case study 2, Mrs Y experienced a considerable wait before Lucy was diagnosed:

> "*Lucy had been to the opticians and we were waiting on the optician appointment for about six months because they'd seen something in her eyes."*
> "*They were short staffed and I think they put her into the low- risk bucket for some reason."* (Mrs Y)

Lucy's father then took Lucy to a hospital appointment where:

> "*They did some tests and went 'Oh we better look a bit further' and then they decided they wanted an MRI. So she went through to an MRI the following week. As soon as they did the MRI it was straight to hospital*." (Mrs Y)

Although parents in the study reported a positive experience of working closely with school to ensure Luke and Lucy's needs were understood post brain tumour treatment, they were also ready and prepared to "fight" to secure support for their child if necessary. Such a highly proactive approach may be partly due to parents of CBTS remaining in 'fight mode' after supporting their child through a fight for life and having had to 'fight' for their child's initial brain tumour diagnosis. Knowing the narrative would help school understand and be sensitive to the context of such parental determination.

3.5.2 Importance of school being aware of the child's journey through brain tumour treatment

Being aware of the narrative could provide school staff with an insight into the physically and emotionally exhausting treatment pathway CBTS may have experienced, helping school empathise with the difficult journey child and parents have endured. In case study 1 Mrs X spoke about Luke's treatment journey:

> "*To be honest the prognosis was not good long-term. And we didn't even know whether the treatment was actually going to do what we needed it to do. So it was a bit scary."* (Mrs X)

Luke underwent lengthy brain surgeries to remove the tumour and spent 40 days on a specialist Paediatric Neurosciences hospital ward for children. He also had radiotherapy and intensive chemotherapy. His treatment lasted around 7 months. Luke was extremely poorly during his chemotherapy:

> "*The end of round three and the whole of round four was horrific, absolutely horrific. It was just his body was starting to feel the intensity of the chemotherapy. His kidneys were starting to fail and on the last round we very nearly ended up in intensive care".*
>
> *"it absolutely annihilated him."* (Mrs X)

In case study 2, Lucy's ependymoma brain tumour:

> *"Was around the back. That was one of the problems with the operation because it was right next to the brainstem, so that's why it was quite dangerous when they were trying to remove it because they had to be careful because obviously it's quite an important area, and if damaged that there could be problems. And I think that's part of the reason why she had all these kinds of problems afterwards as well."* (Mrs Y)

Lucy underwent two lengthy operations:

> "*The first one was within 24 hours of her MRI. I think it was actually about 14 hours long."*
> *"And they'd not managed to get rid of everything".*
> *"And then they went in for a second operation".* (Mrs Y)
>
> "*She was quite poorly after her brain operations because she had quite a lot of bad reactions from the brain surgery so she stopped being able to talk. She couldn't walk. On one of her sides, she couldn't move any of it, so she was very, very poorly."* (Mrs Y)

Being aware of the intense challenges CBTS and family have faced through treatment is an important part of key staff being able to support child and family with compassion, sensitivity and understanding.

3.5.3 The impact of a childhood brain tumour being a new and frightening world for parents

Knowing the narrative could also include drawing key school staff's attention to how parents may find themselves unexpectedly immersed in the frightening world of paediatric brain tumours, as was the case for Mrs X and Mrs Y. In addition to the traumatic diagnosis and challenging brain tumour treatment, Luke and Lucy were left needing SEN support upon school reintegration; this was a new experience for both children and one set of parents. In case study 1 although Mrs X had prior knowledge and experience of the SEN system and EHCP process (which helped her navigate the system for Luke), she did not have experience of needing this support for Luke. Neither child needed additional support at school prior to diagnosis. Mrs X said she had a ‘normal’ relationship with Luke’s school before he became ill and Mrs Y said Lucy:

> *“Was absolutely normal” and “in the top part of the class in everything”* (Mrs Y)

When communicating with parents of CBTS, school should be aware that navigating the complex word of SEN support can be yet another new, challenging, emotive, distressing and exhausting experience for parents, and parents may need guidance, advocacy and support. Therefore, knowing the individual stories of CBTS and understanding the narrative of the brain tumour journey for child and family can help school support the needs of CBTS and work sensitively with parents; parents who may be trying to process their child’s ‘new normal’. Being aware of the challenges of the brain tumour journey can help school hear the parental voice, empathise with the brain tumour journey, avoid any further ‘battle’ and build a relationship based on support, understanding, collaboration and trust.

School staff in case study 1 reported knowing the narrative helped school empathise with Luke and his family:

> *“I felt like I knew what he’d been through. I felt a bit closer to the family.”* (TA)

Luke’s class teacher felt it was essential to understand the narrative as

> “*it’s their journey and we want to be part of that”*
> *“We need to make sure that the relationship is a positive one*.” (Teacher)

Understanding Luke before his brain tumour diagnosis was also important to the teacher:

> *“I wanted to know Luke as a person. And understand that it’s not just about what he’s been through.”*
> *“Having that understanding of him as a little boy is important as well.”* (Teacher)

In case study 2, understanding the details of the narrative was regarded by Lucy’s high school SENCO as:

> *“Very, very important. I think for any family with any child who has a barrier to their learning, I think parents have had very different experiences and their experience in another setting might have been*

> *quite negative in terms of those relationships. So, I think it's very, very important that we are aware of that."* (SENCO)

She acknowledged knowing the family's brain tumour journey has a:

> *"Huge impact on how we interact with the parents and how we interact with a child as well, so I think it's absolutely vital to the work that we do.*" (SENCO)

3.5.4 How should the narrative of CBTS be shared with school staff?

Parents of CBTS may have differing views on how, or if, to share their child's personal brain tumour narrative with school. Mrs X felt sharing Luke's narrative should be an ongoing process throughout his school trajectory, ensuring all staff who work with Luke have knowledge of his brain tumour journey and support needs. She would be happy to present to groups of school staff, as well as to individual staff and felt it was important to be open with school staff when sharing details of Luke's brain tumour journey:

> *"Absolutely knowledge is power".* (Mrs X)
>
> *"I think the only way that they can be equipped is if you go and talk to them and you tell them*." (Mrs X)

In case study 2, Mrs Y did not share the narrative of Lucy's journey with all primary school staff in person because it was:

> "*Written in the EHCP. It talks about diagnosis and the hospital and then America and then chemo".* (Mrs Y)

When Lucy transitioned to high school, part of her narrative was shared through the transfer of key support information from Lucy's EHCP, to a pupil profile. This was available for all teaching staff to read. Mrs Y was impressed with this system:

> *"Each child has their own kind of page of information who have got special needs. So, each teacher that gets them should read these. So it's almost like they've got a little file."*
> *"So, Lucy's information about what's happened to her and what her particular issues are, are on a document."*
> *"That should be available for all teachers. So as long as they follow their protocol and I have to trust that they do, when new teachers come in, they know that when they get their new class, they should look for the children with a special folder, read what their problems are and then know what they need to do to cater for them".* (Mrs Y)
>
> *"And that's what we rely on, we rely on that system for them to know her story".* (Mrs Y)

However, partial narratives recorded in a child's EHCP may not be as detailed or have as much impact on staff as being aware of the full narrative. Mrs Y therefore also shared the reality of Lucy's story with high school by signposting the SENCO to a TV documentary telling the story of another child's similar brain tumour journey:

> *"It's a visual thing isn't it? Because somebody can read something but it's not the same as watching it happen, do you see what I mean?" (*Mrs Y)
>
> *"One of the really powerful bits of sharing of information that Mrs Y did that had a real impact on lots of staff, there was a TV programme about a child that had gone through exactly that same in terms of the operation and recovery and they flagged that up to us and we were able to share. And I think that was really powerful for staff to appreciate what the young person had gone through and is still going through and the impact it had."* (SENCO)

A tension also existed for Mrs Y between needing both schools to know about Lucy's journey, but wanting them to be aware of and sensitive to Lucy's desire for 'normality':

> *"We've never been a showy-off family. We want people to understand but you almost don't want to tell people, you don't want to be seen as a, how can I describe it? Charity. Somebody for pity or sympathy, oh gosh no, we want people to understand and we want people to just have that knowledge in their back pocket when they're thinking about it but what Lucy will say is she just wants to be treated normally. So, she doesn't want to stand out, she wants to be treated normally. Yeah there are certain things that are making her stand out and making her not normal so she'd rather that they just went away. But from our point of view, we want people to understand what they are and help her achieve normally despite them. But it's really hard to explain to people what happens unless you've been through it."* (Mrs Y)

In considering how to share the narrative, staff felt having a child diagnosed with a brain tumour was a very personal journey and the confidential nature of the narrative should be respected when sharing Lucy's story.

> *"I think a lot of it is private, isn't it really? The key things that they want to share, that they need to share with us, they will. But some of it is intensely private."* (TA)

This is reflective of Tresman et al. (2016) where it was reported some staff worried about sharing information due to confidentiality. Working closely with parents can guide school regarding the level of detail it is appropriate to share with staff. Avoiding asking parents to repeat Lucy's narrative was also an area high school were sensitive to:

> *"For any parent having to say a story over and over again is quite traumatic. Sometimes they might have told that story and given that context so many times to so many people. And I think it's very, very important that we know and our staff know, so parents don't feel like they're having to repeat all the time. Because that can be emotionally draining". (*SENCO*)*

This partly echoes findings of Tresman et al (2016:1638) which highlighted concern regarding parents being asked to “make repeated explanations of the same information surrounding the child’s needs each academic year”. However, as Lucy progresses through high school, she may encounter staff who are not aware of her brain tumour journey. The SENCO therefore felt it was important to regularly share Lucy’s brain tumour history with all school staff, being mindful of the personal nature of Lucy’s narrative, but providing them with the essential context of Lucy’s support needs. She felt this could be done through staff training, raising the awareness of any staff who do not already know Lucy’s story and refreshing the memory of staff who do:

> *“I think it needs to be done on a very regular basis. It’s very easy to see sometimes when lots of progress has been made to forget what’s gone on before. And also, that underneath all that there’s lots and lots going on, so I think it’s really important that we share that regularly and we do flag that on training days. (*SENCO)

Perhaps it is a case of school allowing parents the option to continue sharing the narrative with school, without being caused emotional distress or having to repeat their story *unnecessarily*. Alternatively, parents could give permission for school to share the narrative with staff on whole school training days. Part of Tresman et al.’s (2016) school reintegration protocol could be used to help record and transfer CBTS information. In this sense, written templates could be helpful in sharing the narrative, alongside the power of parent personal or visual sharing of the CBTS journey. Discussions between parents, school and child are a necessary part of deciding which way of sharing the narrative is most appropriate for CBTS.

3.6 Theme 4: What worked well and what were the barriers to home-school communication and collaboration when supporting CBTS at school

Parents and school staff in both case studies spoke about what worked well within home-school collaborative practice and what areas were more difficult to navigate.

3.6.1 Single point of contact at school helped home-school communication

Having a single point of contact for parents of CBTS was reported to be an area of good practice within home-school communication. In case study 2, the high school operated a case and key worker system for children with EHCP’s. Case workers oversaw a group of EHCP students and were a point of contact for parents, and key workers (TAs) were a point of contact for the child. The assistant SENCO was Lucy’s case worker and key point of contact for Mrs Y. A single point of contact was reported to be particularly helpful at high school because the SEN team and number of teaching staff working with a child is much larger than at primary school. For example, in case study 1, Luke had one teacher and 2 TAs (as a job share), whereas in case study 2 Lucy was supported by a larger group of TAs (there were 11 TAs in the team but Lucy was typically supported by a key team of 3 or 4). Lucy could also be taught by up to 5 subject teachers per day. The SENCO in case study 2 spoke about the potential difficulties involved in communicating regularly with parents at high school, compared to primary school:

> "*The dynamics of high school are different to primary school"*
> *"It's much easier in primary school where you might have one or two teachers and a TA in a classroom. Whereas in secondary school our setting is so different. You could be coming into contact with five or six different teachers every single day. And that's quite daunting for a parent because you're thinking, oh my word they're going to see so many teachers and I need them to have a picture of my child.*" (SENCO)

Having a nominated key point of contact builds on guidance from The Sam White Pathway (2017) and the Royal Marsden Teacher Guide (2019). It helped parents in the study communicate questions or concerns directly to the nominated member of staff who had a strong understanding of the child's needs. Mrs Y felt knowing there was someone at school who knew her child and was "on your side" was helpful. She felt communicating regularly with her key point of contact was:

> *"Really important to have that concept to do that because otherwise you feel very lost. So long as you've got the email and then you can ask, that's all you want as a parent. You want to know, what do I need to do? What happens? And if somebody could just tell you what it is then that's great and your worries go away*." (Mrs Y)

Having a key point of contact allowed information or parental concerns to be dealt with or passed onto the appropriate member of staff in a timely manner. This helped prevent a barrier to communication, reported by Tresman et al. (2016:1638), where CBTS information was "not getting to correct personnel in schools". A key point of contact helped parents feel secure in the knowledge that their child was cared about and safe at school; this is reflective of my professional work where parents of CBTS often speak about the essential nature of school "knowing their child well".

In addition to having a key point of contact, the high school SENCO explained the benefits of having a flexible 'team around the child' approach to supporting Lucy:

> *"We tried to build up a bit of a team around so we could share knowledge and we could share expertise*." (SENCO)

Indeed, Lucy's high school operated a whole school approach to supporting children with additional needs. The SENCO was keen to highlight students with an EHCP or additional needs are not the sole responsibility of the SEN department; *all* teachers are teachers of SEN (SENCop 2015):

> "*It's the ethos of our school and we've worked really hard on that"* (SENCO)

3.6.2 Importance of and challenges in daily home-school communication

In both case studies, daily home-school communication worked well when supporting CBTS and occurred through email, by telephone and in person. Face to face communication between TA's and parents occurred at school drop off and pick up times.

The SENCO in case study 1 said of daily communication:

> "*I've always made it open and if there's anything that she (*Mrs X*) feels school needs to be aware of, she will email the school or myself at any time*." (SENCO)

The assistant SENCO in case study 2 spoke about the importance of:

> *"Being able to let parents know that we are here to support and that we have this open-door policy that she can contact me any time and she does."*
> *"We communicate via email that can sometimes be a daily basis, it could be many times a day".*
> *"It's just not confined to nine until three for queries."* (Assistant SENCO)

Mrs Y felt having 'open door' communication helped maintain a consistent and ongoing level of communication:

> "*I'm afraid I treat everything as an open- door policy. I think that's probably me as a mum. I've always been an organiser. I'm an initiator anyway as well. So, I've not been a parent who waited for school to organise what's going to happen.* (Mrs Y)

She valued ongoing two -way communication with staff *who were receptive*:

> "*You've got to have somebody who wants to help on the other side. So, any school that is stressed and is overworked and they don't have the time, I guess you're going to have problems in communication.*" (Mrs Y)

However, both schools were aware of challenges involved in balancing time constraints of the school day, with regular communication with parents:

> *"I think the difficulty and this is just a very practical thing, is time. At school everybody is always run off their feet"*.
> *"you're trying to juggle all these."*
> *"it's quite easy maybe to lose sight of the individual."* (Assistant SENCO case study 2)

> *"You've got to have the open-door policy. Even though it's quite difficult to keep up with the communication."* (Teacher case study 1)
>
> "*And there's other children with other needs. There's other children whose parents' I need to communicate with. And it's difficult because obviously I want to have that relationship and want to have that open door policy but the time constraints are the biggest barrier for me as a professional."* (Teacher case study 1)

The importance of daily communication is an area to emerge out of the study that spans positive and negative practice. Due to the ongoing and changing needs of CBTS, open door communication was considered a necessary part of building positive communication links between school and parents of CBTS. Although not specific to communicating with parents of CBTS (who were respectful of and had realistic expectations of timeframes when working with school professionals), teaching professionals were aware of the general need to maintain a healthy work-home life balance; they were conscious of 'open door communication' practice threatening that balance. Inductive data analysis indicated the home-work life balance can be challenging for dedicated school staff who are committed to supporting CBTS as particularly vulnerable students, and who understand the value of and want to develop a close level of home-school communication, but who recognise the time constraints of a school day.

3.6.3 Listening to the voice of CBTS

The SENCoP (2015) requires children with SEN to be consulted and included in discussions around their support needs. The study demonstrated key school staff and parents actively sought and listened to the child's voice throughout the academic year, to monitor progress and adjust support as needed. The study explored the voice of Luke and Lucy to further understand what areas of school they felt were working well for them, what areas, if any, could be improved and how they felt about support from school and home.

3.6.3.1 Luke's voice

As described on page 40, use of photovoice helped Luke communicate his thoughts about school in the semi-structured interview. Luke took pictures of a week at school and chose 9 photographs he felt best represented his thoughts and feelings about school (see table 4). Luke named each photograph, summing up the meaning in one or two words. These photographs acted as visual prompts during his semi-structured interview.

Table 4 Luke's chosen photographs

Name of Chosen Photograph	**The Photograph Showed Luke:**
Lunchtime	Enjoyed lunchtime
PE	Found PE difficult
Schoolwork	Enjoyed creative tasks and was making progress
Maths	Enjoyed maths
iPad and computers	Enjoyed working on iPad and is good at it Liked working on a computer and used it at home for homework
1-1	Liked being on a morning met by his TA
Playtime	Enjoyed playtime
Mr Bean	Enjoyed watching Mr Bean at lunchtime if it was raining (this helped detract from the noise of rain which he didn't like)
Corridor	Used his walker initially along the corridor but was making progress

Role on the wall was also used to help Luke process his thoughts at the start of the semi-structured interview. Although he was not asked to write anything on the 'role on the wall' sheet himself (I acted a scribe for him, recording his words in writing), Luke did not fully engage with this task and only wanted to record the words "I feel tired coming to school". Luke chose not to complete this task and so, to maintain his focus and interest, we moved onto the semi-structured interview questions. Luke was asked open and closed questions about school and used his chosen photographs to help recall and process verbal responses. Luke engaged well with interview questions, providing open and honest responses:

Luke said:
Playtime and lunchtime made him happy at school. His TA helped explain his lunch time picture showed him eating with peers and this represented progress. When Luke first returned to school, he had lunch in his classroom and not the school canteen, to avoid him being caught in a crush of children in the canteen. The aim of this was to keep him physically safe, but in doing so he felt isolated from peers.

Luke enjoyed being met by his '1-1' (TA) when he came into school. He explained he used a walker at school and said of his photograph:

> "*It's showing me and my walker going through the corridors."*
> *"I use it to go to the disabled toilet and I use it to go to playtime*." (Luke)

Luke and his TA felt he had made progress using his walker, but Luke did not always want to use it and strived for independence. Luke also said he liked being creative and was aware of his improving skills. Luke's photograph of cutting and sticking in class showed he was aware of his progress:

> *"It's just improvement after hospital I weren't able to cut and stick*." (Luke)

Luke said he "*loves iPads*" and computers and enjoyed using them at school and home. His parents helped him with homework which he did on a computer:

> "*I used to bring my book home because (instructions) were stuck in there but now they send me it on class Dojo* (an online communication platform used by Luke's school)." (Luke)

Luke also enjoyed taking part in extra reading intervention in the SEN room with his TA. In addition, Luke said he enjoyed nature, maths, phonics, computing and history. Luke felt he didn't need help with everything:

> "*I can do them on my own but I have a teacher saying alphabet letters 'n' that*."

The following lessons were his least favourite:

> "*English, science, PE*." (Luke)

Luke further explained running was hard for him in PE and he linked this to his time in hospital:

> "*You see, I can't run because in the hospital I was paralysed, I couldn't move, talk, I couldn't do anything*." (Luke)

He spoke about how his friend (who also had a brain tumour) at hospital got him '*out of being paralysed'*

> "*So he was walking me over to his bed, so I can watch a film with him*." (Luke)

Luke said his '1-1's' and his teacher help him most at school. He also liked working with the behaviour support member of staff, "the anti-bullying teacher" in case he was ever bullied. Luke said he would tell his teachers and his 1-1 if he was ever bullied. When asked if there was anything that made him feel unhappy at school he said:

> "*Just when I can't read it…*"(Luke)

Luke didn't know what might help him more at school.

In the wish jar activity that followed the interview, Luke was happy to decorate the jar but did not want to complete any written hopes regarding school. Throughout the interview, Luke displayed an awareness of his progress, a consistent desire for independence, spoke positively about TA support and enjoyed doing the activities that he felt he was good at and didn't need as much support with. Although Luke did not report difficulties with friendships, he was aware of the 'anti- bullying teacher'.

3.6.3.2 Lucy's voice

Using the role on the wall activity helped Lucy process her thoughts and feelings about school and acted as a visual prompt during the interview. Lucy reflected on her thoughts and feelings with honesty, eloquence and maturity. She demonstrated astute awareness of the difference between providing answers adults may want to hear and her own answers:

Interviewer: *Is school important to you*?

> Lucy: *As a teenager I'd say no. School is not important. I can do things myself. If I'm saying this to an adult as a child who goes to school, who has to by law, school is good*.

Upon transition to high school, Lucy recalled feeling positive:

> *"I felt good about it because my best friend was going as well."* (Lucy)

Having extra transition visits to high school was helpful for Lucy, giving her the chance to walk around her new school. Lucy didn't remember meeting her TAs upon transition. Once at high school, Lucy had an awareness of what she found helpful in lessons:

> "*Teachers are nice and they try to help".*
> *"They usually sit with me and remind me what I'm doing."* (Lucy)

Lucy spoke about enjoying lessons where she has to write, as this is her strength. She also enjoyed drama because the teacher allowed her more independence, which was important to Lucy. Lucy recorded on role on the wall that her drama teacher 'doesn't overly help her' which she viewed as a positive.

Mrs Y clarified:

> "*Does she treat you like everybody else and not different*?" (Mrs Y)

> "*Yeah, she doesn't really hover over me. And makes sure I'm ok with everything. And there isn't stuff to read or anything, she just tells us, what's what. And puts us into groups and then we're off."* (Lucy)

Lucy reported the drama lesson worked well for her because:

> "*You can talk to people. In classes you've got to put your hand up to talk and it's a room full of quite often 20 or 30 children. In drama you're in groups of five or six so it's easier to talk to."* (Lucy)

Lucy said of the lessons she didn't enjoy as much:

> *"It's kind of the pace of the lesson and there's a lot of information. Even if it was slowed down. And even if I had notes it's just lots of information."* (Lucy)

She was helped to make notes by her TA but found doubling up on notes confusing:

> "*Sometimes in science I try to make notes but my teaching assistant also makes notes. So it kind of gets confusing*." (Lucy)

Although Lucy accesses TA support in every lesson, she felt she did not always need support. She preferred it when her TA allowed her independence so that:

> "*They're not always focussing on me then*." (Lucy)

In addition, there was a need for Lucy's pupil profile information to be updated for teaching staff:

> "*I don't want to sound rude and my German teacher probably has the best intentions but there's normal sized writing which he gives to everyone in the class but then there's these giant sheets he just gives me every time. And I know he wants to be helpful, like I might not be able to read it properly, but I can read it fine."* (Lucy)
>
> "*I think that's from her old EHCP when she was first poorly, bigger writing was easier for her. But I think it's changed now so that's something I need to contact school about because your plan needs to be updated for that teacher so that they don't do that."* (Mrs Y)

Despite feeling she did not need all the support school and home put in place for her at school, Lucy was mainly happy at school**:**

> "*I'd like to say yes. I mostly am, usually."*(Lucy)

However, Lucy recorded on role on the wall that she felt lonely at school. She gave an example of how, having to arrive and leave lessons early meant:

> "*I don't really talk to anyone and I have to go five minutes early and I get there before everyone else. So while everybody is still getting to the class I'm already there and I'm just sat waiting and whenever everyone does come in the lesson starts and then when everybody is talking I'm usually finishing up to go."* (Lucy)

Lucy was "*not sure*" what school could do differently about this but would like more independence and time away from her TAs and teachers:

> "*I think when adults are around, I can't really be the real me."*
> *"I'm always with teachers so teachers are adults and teachers are teachers, you can't really be a teenager with a teacher around*."
> "*Because people are watching me, I can't talk to people as much*." (Lucy)

Lucy was very aware of her difficulties and Mrs Y highlighted:

> "*The thing that's come up quite a lot with Lucy feeding back over the last couple of years, she doesn't like being patronised. She doesn't like being singled ou*t". (Mrs Y)

Lucy did not like:

> "*The look in people's eyes when they talk to me. And the tone of voice that they have*." (Lucy)

Lucy said her peers did not know her history and Mrs Y felt:

> "*But that's a problem sometimes you've had a few comments from unknown children as you go past with your teaching assistant*." (Mrs Y)

Having more freedom at school and being independent were important to Lucy. She felt school could help her more by:

> "*To forget I exist*."
> "*That would be above all the most helpful thing. Because I could just concentrate on, I don't know it would just be easier to concentrate on myself learning and being individual and not having a person hover over me and it would be easier. But I know that won't happen*." (Lucy)

Lucy wrote in the wish jar activity she would like to be allowed independence inside and outside of school.

The main reported concerns of CBTS regarding school included a desire for independence (and time away from adult support) and (for Lucy) opportunities to develop her social circle. Salley et al. (2015) report CBTS may not recognise social skills as being an area they find difficult, but my study indicated Lucy was very aware of "feeling lonely" at school due to lack of peer interaction opportunities.

3.6.4 Collaborating with parents and listening to the voice of CBTS helped school strike a balance between encouraging independence of CBTS and providing ongoing support

Data analysis showed school staff and parents recognised Luke and Lucy's desire for more independence, but this presented school with challenges within health and safety. In case study 1, Luke's teacher spoke about the difficulty in balancing Luke's support needs with allowing him an increased level of independence:

> "*It can be difficult because we are obviously aware of his physical needs and we wouldn't want him to topple over or injure himself."*
> *But as he's growing older, he doesn't want to appear different from the others."* (Teacher)

Taking the lead from Mrs X helped increase the TAs confidence in allowing Luke a growing level of independence:

> "*I've not mollycoddled him so I can carry on the amazing work she's doing at home."* (TA)

In case study 2, SEN staff were very aware of Lucy's desire for independence, as communicated to them throughout the academic year by Lucy and her parents. Mrs Y and key staff were sensitive to Lucy's desire to fit in with peers:

> *"You reach an age where that independence and not having somebody at the side of you is so, so important because you want to be like your peers."* (SENCO)

All changes in the level of Lucy's school support were carefully considered and discussed with parents:

> "*Obviously we wouldn't want to do anything that they weren't happy with". "Everybody has the same aim of her being independent as much as possible walking independently around school*." (SENCO)

The assistant SENCO described striking a balance between providing opportunities for Lucy to develop independence and ensuring her safety, as:

> "*Massively hard*". (Assistant SENCO)
>
> "*It's very challenging because your natural instinct and certainly our team, our natural instinct is to nurture and you want to protect. And a lot of that independence has really come from the work that parents have done with this, in annual reviews and their voice. Just them giving us that confidence, that's alright, we need to try that and it's OK".* (SENCO)
>
> "*They've said many times 'Please don't feel you have to wrap her up in cotton wool'. That's been more recently, that wasn't necessarily the case in Year 7, but over time that's been the message."* (SENCO)

A similar tension existed in the classroom between supporting Lucy to help her reach her academic potential, while simultaneously reducing the level of TA support:

> *"This is a tricky one in the classroom, because she's so bright and because she's feeling like she doesn't want an adult constantly around her, which I can understand completely, it's tricky to get the balance right*". (Assistant SENCO)

Mrs Y was very conscious of Lucy's desire for 'normality' and independence, but was equally aware of the need for a balanced approach to support, ensuring Lucy was physically safe at school:

> *"Well, we're different now to when she first went back to school because it was very much about she was in a wheelchair, fire safety, what happens with the wheelchair".*
> *"Whereas now she's now walking around and she doesn't need a wheelchair but she's unstable so she needs to be able to be supported so that she doesn't fall downstairs."*
> *"She wants more independence so we've got to a stage now where if the classroom is very close, they've stopped doing close transition. They've said she can leave at the same time with everyone else but somebody would just be following her. So, it's making her feel a bit more normal."* (Mrs Y)

Mrs Y noted:

> *"You have to base it in risks".*
>
> *"It must be an organisational nightmare"*
> *"I think if you can manage that then I think it's quite an achievement."* (Mrs Y)

Mrs Y was supportive of school increasing Lucy's level of independence:

> *"Well that's got to be the focus for the future as well because that's where we want to go."*
> *"But it's about doing it safely."*
> "*She wants to be more independent and we want that. When she's 16/17, what do we do then? She can't have somebody helping her around college, we've got to get to a place where she can safely start to move around on her own." (*Mrs Y)
>
> "*it's one of those things. It's all or nothing. You either have somebody there or you don't. There isn't a middle way."* (Mrs Y)

The assistant SENCO felt:

> *"It's really baby steps but at the end of the day all those little steps then get a little bit bigger don't they? And a little bit more, a little bit more."* (Assistant SENCO)

3.6.5 Social skills support for CBTS at school

As explained on page 34, within the range of psychosocial difficulties CBTS may experience, my study focused specifically on whether CBTS needed or accessed social skills support at school. The importance of supporting CBTS' social skills development is reflective of the SENCoP (2015) which highlights school should support children with SEN to make 'progress within wider development or social needs in order to make a successful transition to adult life' SENCoP (2015: 6.18).

In case study 1, although Luke did not voice concern over friendships, close communication with school helped Mrs X monitor his changing friendship group after he returned to school:

> "*What we found is there was a lot of the children that he wasn't necessarily friends with and playing with in school before, but they kind of had taken that protective shield, looking after him".* (Mrs X)

The TA felt Luke was:

> "*Struggling a little bit with friendships. He's got a few key friends but sometimes, like today he didn't want to play with them*."
> "*It's up and down"*. (TA)

Having a wider friendship circle was something the TA highlighted:

> "*I think having some more friends he can go to at playtime. Because he's got his walker so he is different when he's outside".* (TA)

Luke had not so far attended social skills intervention at school, but this was an area school would consider if needed.

Social skills support for Lucy was an area school and home collaborated closely over in case study 2. The SENCO said although Lucy has made:

> *"A huge amount of progress" (*and is*) "fiercely independent which is fantastic to see. We're still doing lots of work around friendships and establishing and maintaining that social circle".* (SENCO)

Mrs Y and school recognised complexities involved in supporting Lucy at school to help widen her friendship circle and develop her social skills. Having adult support hindered opportunities for Lucy to develop peer friendships:

> *"She's very separate from people, she gets brought in at a different time and then she sits down in class in the seat allocated to her. They can't really talk in class. And then she leaves early. She doesn't talk to anybody other than the people in the special needs' rooms."*
> "*I don't think she gets that group where she walks and talks with somebody. Or before school starts, she's picked up by her TA and goes somewhere else*"
> "And so Lucy doesn't "*get that chitchat with people*". (Mrs Y)
>
> "*Socially is another tricky one because it's a bit like a vicious circle because she has had a lot of adult support with her a lot of the time." "And in that sense, it kind of, probably puts other students off."* (Assistant SENCO)

Mrs Y was supportive of school providing Lucy with social opportunities and encouraged her to attend school clubs to widen her friendship circle. However, this did not necessarily mean Lucy enjoyed all the groups. Lucy also said of being taken out of a lesson to take part in a social skills intervention group:

> "*I haven't really gained anything from it. But I haven't lost anything from being in the group*."(Lucy)

There is a need for more research focusing on existing and the impact of social skills programmes for or relevant to CBTS.

3.6.6 Close collaboration between home and school helped CBTS feel supported and safe at school

Despite longing for more independence, CBTS were helped to make progress and feel safe at school through a consistent home-school approach to support. This is an area not reported on in CBTS school support research. In case study 1, Luke's teacher said:

> "*He knows that we've got that open communication and we try to be consistent as well. So if we can have a consistent approach and mum has got the same approach then that helps him to feel safe and know what to expect when he comes into school*." (Teacher)

In case study 2 having a consistent approach from school and home ensured Lucy felt:

> *"Comfortable to know that her needs are going to be met and that the family know that her needs are going to be met. So they've got the confidence in us to do what is needed for their child*." (Assistant SENCO)

Lucy was aware of the close relationship between school and home and this was considered a positive:

> "*I think when the children know that, I think that's an added bonus. Because I think she understands that her parents are doing their best*." (Assistant SENCO)

Lucy's TA felt:

> *"Lucy realises that we've got her best interest at heart and she's comfortable and confident that we're working towards what's best for her."*
> "*I get the impression that Lucy appreciates how much mum and dad are involved with school for her."*
> *"If she wants something to change, the impression I get is that she has a chat with her mum and dad and they let school know."*
> *"It works really well."* (TA)

3.6.7 Tracking the progress of CBTS through close home-school communication

Listening to the voice of CBTS helped school and parents ensure support was adapted according to changing academic, physical, social or emotional support needs of CBTS *throughout* the year. Monitoring progress was done formally through EHCP reviews, which included the child's voice. EHCP reviews provide a formal opportunity for school staff, parents, child and external professionals to meet in person and review the child's progress, discuss concerns, update and record targets and share good practice. In case study 1, the SENCO reported Luke's EHCP.

> *"Review is normally every year, we've looked to have regular review meetings because obviously he's a very special case, where we have to review his needs because they're ever changing really*."(SENCO)

In preparation of Luke's EHCP review, it worked well when Mrs X sent the SENCO:

> "*Lots of evidence as well to support, I'm a bit of a stickler for stuff like that. So at least then he knows I know what I'm talking about, I'm not just talking waffle"*. (Mrs X)

After the review the SENCO:

> "*Will always ring me and we'll have a conversation about it as well just before he finalises it, he'll ask me to review it and then make sure that I'm happy with everything*." (Mrs X)

Mrs X viewed Luke's EHCP review as more of:

> "*A constant review, it's a constant document that's a working documen*t."(Mrs X)

In case study 2, the assistant SENCO said:

> *"We have meetings with parents three times a year through the EHCP but we speak much more than that."* (Assistant SENCO)

School valued Mrs Y's voice as part of the review process, recognising parents had:

> *"Massive knowledge about Lucy and to be able to share that, like we often do in meetings and to be open about it all. I think for us to know that, to want their input massively, I think that's really important*." (Assistant SENCO)
>
> *"Everything is done with the voice of the child and the voice of the parents in mind. We wouldn't change anything in terms of the support without having those conversations first".* (Assistant SENCO)

Mrs Y felt her views were listened to and respected during Lucy's EHCP reviews:

> *"Yes definitely. And they sometimes get Lucy involved as well.*

> *Because she's getting older, she needs to be part of it as well. Though she sits back quite often and leaves it to us."* (Mrs Y)

In addition to EHCP communication, sharing information between home and school throughout the academic year helped key staff monitor the changing needs of CBTS, ensuring the right level of *ongoing* school support was in place to facilitate progress. In case study 2, Lucy's progress was positively impacted when parents shared expectations and communicated concerns regarding her academic progress:

> *"I don't have responsibility for Lucy's progress and there were times last year when mum was emailing me because she was concerned about Lucy being in a group that she felt that it was too easy and I put her in touch with the year head and they started talking about sets. And another time she was thinking the work was too hard. So yeah, I think it helps massively for everybody to be on the same page."* (Assistant SENCO)

The SENCO felt close communication with home had a positive impact on Lucy's progress, as:

> *"There will be things that we possibly missed in the classroom that parents have picked up on at home, so I think that's had a huge impact on progress actually."* (SENCO)

In addition, Mrs Y felt it was important to remind school about Lucy's 'invisible needs' in the classroom.

> "*These are the things we just need to keep on top of. These are things because it's three years now since she was poorly, she looks much more normal now. I don't always feel 100% they've remembered".*
> *"Which is good but perhaps she's having a memory problem. So, it's those odd reminders. And her homework takes twice as long because we have to sit and help her through it and keep her concentration, things like that."* (Mrs Y)
>
> *"And I'm still striving for better in the sense that we're three years past treatment now. She's starting to move around more she looks more normal."* (Mrs Y)

The high school SENCO was also aware of the need to continue to support Lucy, helping her make and maintain progress:

> *"You can look at a child and they've made a huge amount of progress and the child that arrived to you in year 7 looks very different outwardly but actually lots of the same things are going on. And actually, the progress that's been made had been down to the strategies that had been put in place. And if you take those strategies away that can have a massive impact."* (SENCO)

This is reflective of Vanclooster et al. (2019), whose study drew attention to the need for close communication throughout the child's schooling, to track and monitor progress and adjust support as necessary. Collaborating closely with school helped parents in my study ensure teaching staff were kept up to date with the child's progress or changing needs *over time*. As also highlighted by Tresman et al. (2016), this is especially important considering some of the needs of CBTS may become less visible as the child makes physical progress.

Mrs Y continued to work closely with school to ensure an appropriate level support was in place for Lucy and concluded her level of involvement with school was at:

> "*The right level, we just need to keep on top of making sure the attention is still there in the right places. But we're also moving forward, things don't stay the same so it is right to reassess things. Now I think we're at the right level.*"(Mrs Y)
>
> *"Nothing is going to be perfect but I think it's probably the best we can get it."* (Mrs Y)

3.6.8 The importance of honesty, trust and pride as part of home-school collaboration

Staff and parents in both case studies felt honesty and trust underpinned their relationship:

> *"When things don't work so well, we always ask about it, because occasionally in any organisation some things don't always work as well. But yeah, it's based on trust. We give them information, we say what we want for our child and we hope and we trust that they'll do the best for us".* (Mrs Y)
>
> *"We need to trust each other that the needs of the child are put first. And I think we do that. And we take pride in that we are doing that."* (TA case study 2)
>
> "*I've got quite a good relationship I think with Lucy's parents and it feels like they tell you exactly, it's a very honest relationship."*
> *"We're all working for the benefit of that child and we're not going to get upset if they say something."* (Assistant SENCO)

The SENCO in case study 2 felt it was important when working closely with Lucy's parents to':

> *"Acknowledge we can get things wrong. Sometimes we might try something, it doesn't work but that's ok. If you're open and honest about that then you can move forward. If you're not then that makes that relationship really difficult. I think parents will have worked with lots and lots of different people, had lots of different experiences, sometimes positive and sometimes negative and without trust you can't move*

> *forward. As parents you want to be able to trust that your child is coming to school, they feel safe, they're supported, they're getting everything that they need. And if something flags up and you feel that that's not the case that actually you can contact, somebody will communicate with you and somebody listens, it's essential*." (SENCO)

Inductive data analysis also highlighted school staff took great pride in their work and in the progress of CBTS:

> *"I'm just really proud of her and what she's achieved already*," (TA case study 2)

> "*I pride myself on being caring and doing a lot of work with individuals and really supporting. And it's kind of making me reflect that I know that I'm caring but I probably don't know enough about Lucy's condition as what I probably should."* (Assistant SENCO)

In case study 1, Luke's TA took pride in being able to recognise small steps of progress, to "*really see*" what a brain tumour survivor can achieve:

> "*It's those things that make a big difference. Just think that you were a part of changing that child's life for the better."* (TA)

Mrs X recognised school were:

> "*Dedicated to getting him where they need to get him*" (Mrs X)

School's dedication to supporting Luke resulted in parents being able:

> "*To have that confidence that they know school is doing as much as they possibly can to support him. Because we're here to do that. That's our duty to do that*." (SENCO)

3.6.9 School and home celebrated the progress of CBTS

Staff in both case studies displayed a high level of care and commitment towards supporting CBTS and wanted to celebrate and share the child's progress and successes with parents. A culture of praise was reported to work well by staff in both case studies. In case study 1:

> "*We felt that we've really praised the child on his return and that's ongoing. And we recognise even just those really small steps in his achievement to make sure that he's being praised*." (SENCO)

> "*I always pass on positive messages if he's making really good progress within school*." (Teacher)

Mrs X sent Luke's teacher photographs of his achievements out of school and his TA fed positive comments back to Mrs X. Praise was given to Luke:

> "*With merits, with stickers, we've got role models. If somebody is shown as a really good role model their names will go up. Again, we don't always single Luke out, but he's included in that*." (TA)

The SENCO was mindful of the power of providing regular positive feedback to Luke's parents and felt it was important for parents to:

> "*See some of the steps forward that child is making. Even if it's just the little things, that can be a positive approach."*
> *"If we can see that because they're not in school and they're not seeing it, if we can feed that back, again that's a positive thing for parents."*
> (SENCO)

In case study 2, the SEN team celebrated Lucy's success through phone calls home and certificates for Lucy. All of Lucy's teachers were encouraged to share Lucy's achievements with parents as part of the school's inclusive ethos:

> *"So, we try and broaden it than just being sat with SEN because it's all too easy and quite often falls into 'that's a child with SEN and therefore we want you' - actually it should be bigger than that, it should be everybody playing a role and celebrating that*." (SENCO)

The SENCO was aware of the value of sharing Lucy's school successes with her parents:

> *"Being able to celebrate success, that's very, very important. I know as a parent myself you sometimes just get totally lost in the day to day and actually when you get a phone call from school or a message from school, that can make a huge difference".* (SENCO)

Sharing such feedback could be considered especially valuable for parents of CBTS who, after supporting their child through exhausting, life-threatening treatment may really appreciate such positive school feedback.

3.7 Using two conceptual frameworks of parent partnership to help understand and guide home-school collaborative practice when supporting CBTS at school

I wanted to explore existing home-school partnership policy and collaborative home-school collaborative practice in both case studies when supporting CBTS. I also wanted to understand if this could be further guided by two existing conceptual frameworks (Hoover-Dempsey and Sandler's (2010) revised model of parental involvement and Epstein's (2018) model of six types of home, school and community partnership were used in the study). Neither of the conceptual frameworks were fully reflected in or applicable to home-school communication and collaborative CBTS practice in the study (and no policy was in existence as reported on page 106). However, *elements* of both conceptual frameworks were identified within home-school collaborative practice, as summarised below. These elements clarify the uniqueness of home school partnership with CBTS parents and could be used to further guide CBTS practice and policy.

3.7.1 Hoover-Dempsey and Sandler's (2010) revised model of parental involvement

This a framework made up of 5 levels. Level 1 was focused on in the study and is comprised of three main areas focusing on why parents (in general) become involved in their child's education, how they are invited to do so by school and how life context influences parental involvement. Applying Level 1 of the framework to the relationship between school and parents of CBTS in the study, illuminated the unique reasons why parents of CBTS become involved in their child's schooling, and this is something key school staff need to be aware of within seeking the narrative. Hoover, Dempsey and Sandler (2005) argued that personal motivators of parental involvement with school are reflective of the social status of parents, including their own experience of school. However, for parents of CBTS, reasons for being involved in their child's education appear to go beyond being influenced by their own experiences of school and level of education. The impetus for parental involvement was to ensure the child's range of needs were understood, that they accessed appropriate support after neurosurgery and brain tumour treatment and were safe and cared for at school and supported to reach their full potential. Hoover - Dempsey and Sandler (2010) also maintain parents respond to general, specific and child invitations to be involved in their child's schooling. However, due to the serious nature of their child's brain tumour diagnosis, parents in the study did not wait for invitations from staff to be involved with school; they were compelled to be involved, highly proactive and often initiated and followed up communication. Parents played a vital role in initiating two- way home-school collaboration. They continued their high level of involvement with school as their child progressed through education, and this increased whenever their child was experiencing areas of difficulty at school. This model could be used to help ensure *all CBTS parents* are invited and involved in their child's education, especially considering not all parents will have the same high level of proactiveness as Mrs X and Mrs Y.

'Life context variables' in level 1 of the model was also applicable to my study as it refers to parental skills and knowledge that potentially influence the level of school engagement. Hoover-Dempsey and Sandler (2010) maintain this can depend on the school activity parents are being asked to take part in, if time constraints prevent parental involvement and how family or culture influence involvement. Applying this to school working collaboratively with CBTS, the context of the brain tumour journey should be recognised as the strongest driver of parental engagement. In the study**,** the life context of supporting a child through brain tumour treatment resulted in parents having a strong understanding of the child's immediate and long-term needs. They had first-hand experience of how the tumour impacted their child's life physically, academically, socially and emotionally, and shared this knowledge with school. Parents' lives had also been drastically changed upon their child's diagnosis and although they had demands placed upon them to juggle work and family life with their child's support needs, making sure their child was safe and supported at school took priority. In the study, the context of having a child with a brain tumour meant parents engaged fully and continuously with school. This conceptual framework could be used to ensure staff recognise the need to respect and understand the context and complexities of the brain tumour journey when preparing to work closely with CBTS and parents.

3.7.2 Epstein's (2018) model of six types of home, school and community partnership involvement

In addition to understanding the unique reasons for close parental involvement when working with parents of CBTS**,** Epstein's (2018) model of six types of home, school and community partnership involvement, was used to further understand collaborative practice in the study. This model suggests successful home, school and community partnership is made up of 'six types of involvement', including "parenting, communicating, volunteering, learning at home, decision making and collaborating with the community" Epstein et al. (2019 :155). Although not all the 'six types of involvement' were evident in the case studies regarding home-school collaboration, the following elements were identified and could also help guide CBTS school support policy and practice:

Type 1: Parenting refers to school supporting parents in establishing home environments conducive to the child's learning. In the case of CBTS, this included home visits, arranging home tuition for CBTS and listening to, respecting and valuing parent knowledge about the child's strengths and weaknesses. School could also signpost parents to CBTS support organisations if needed (although parents in the study did not feel they needed this).

Type 2: Communicating is classed as establishing two -way communication between school and home regarding the child's progress. In the study, school and home communicated regularly to meet the changing support needs of CBTS and to monitor their progress at school. Communication occurred through various channels, including EHCP reviews, in person, communication platforms, through a home-school book (case study 1), emails and phone calls. Interactions between home and key school staff were positive and, especially at high school, having a single point of contact was helpful for parents in navigating the SEN system and communicating with school.

Type 4: Learning at home involves school supporting parents to support children with homework and school choices. In the study, parents understood the importance of helping their child complete homework but they also wanted school to offer more support recording and communicating homework instructions. Shared home-school expectations of CBTS helped encourage and support Luke and Lucy to engage with school tasks (at home and school), and to engage with support and intervention, to reach their full potential.

Type 5: Decision making refers to parents being included in the decision- making process regarding their child's education. In the study, school and parents of CBTS made joint decisions regarding the child's support and all views were valued and respected. CBTS were included in decision making as part of their EHCP review and through sharing their views with school and home throughout the academic year. School and parents responded to problems or challenges CBTS were experiencing through ongoing discussions, resulting in support being appropriately adapted. This facilitated small steps of progress for CBTS, which were celebrated by parents and school.

The above reported elements of frameworks could potentially be used (along with other reported data that doesn't apply to these two frameworks) to help guide future development of CBTS school support policy, practice and training.

3.8 Theme 5: School and parents share future hopes for CBTS and offer advice to other CBTS parents and schools

3.8.1 Importance of sharing hopes for CBTS

Parents felt sharing future hopes for CBTS with school is part of building a close level of communication and collaboration. This is reflective of studies concerned with the quality of survivorship for CBTS and the importance of parents maintaining hope for the future (Vance et al., 2004; Deatrick et al., 2009; Forinder & Norberg., 2010). School staff also need to be sensitive to how parents of CBTS may be living with the uncertainty of their child's future.

In case study 1, Mrs X explained:

> "*Even though his scans are stable and clear, they never tell you you're cancer free. We're now on what they call a five- year programme. So for every year that we get is a year of celebration. And it's a case of if we get past five years then that's real success. Because with the type of tumour Luke had, it's quite an aggressive tumour and it can come back as a secondary at any point*, *anywhere in his body. And what that would look like going forward, we don't know*." (Mrs X)

She remained positive and keen for school to understand that having a brain tumour:

> "*doesn't have to be a death sentence. If there's one big thing we learn, you live every day. And it's day by day."* (Mrs X)

Mrs X was very aware that young people with additional needs can certainly have:

> "*Good outcomes, go to university and get good jobs"*
> "*You tell me a parent that doesn't want that for their child*?" (Mrs X)

Mrs X spoke about her hopes and aspirations for Luke as he progresses through school:

> "*Just to do the best that he can. To feel confident. And to enjoy it, I want him to enjoy it.*
> *"That boy has been through so much."*
> *"He deserves to have a decent education*." (Mrs Y)

Staff also reflected on their future hopes for Luke. The SENCO's hopes for Luke through his school life were:

> "*For him to make progress.*
> *"It's not just about his attainment …but as a whole child. Making sure that he's integrated well. That he's adapting and able to socially form friendships to make sure he feels part of that year group.* (SENCO)
>
> *"Having that independence in a safe way. In an environment where he feels like he can just be himself. I know he does need to have that adult support but it would be lovely to see him just being him really. And progressing educationally.* (Teacher)

Luke's TA responded:

> "*I want him to be able to just be in class and not singled out and just enjoy life."*
> *"I want him to be able to go and have a game of football. I want him to run around and play tig."*
> *"I just want to see him be eight and nine and ten and just be in that class with everybody else*."(TA)

And through life:

Staff in case study 1 said:

> "*That he can progress in life and just becomes a teenager, adult and get a job."*
> *"I want him to be able to hopefully put that trauma behind him*." (TA)
>
> "*Hopefully he can move on and be in line with his peers as much as possible. That he can achieve*." (SENCO)
>
> "*Become a confident member of society. And embrace who he is. Because I guess things have changed for him so much".*
> *"And for him to become a happy individual who can contribute to society as well. And I'm sure he will.*" (Teacher)

Mrs X reflected:

> "*I just want Luke to enjoy his life, whatever that may well be. And I used to worry. I used to worry that if the next scan shows it's come back. And I don't worry like I did before and I know that probably sounds really strange. But it would consume so much of our life and your energy focussing on the negatives and you would just lose sight of all them positives and I think you've just got to keep going. Luke has done it, and he's done it with a smile."* (Mrs X)

In case study 2 Mrs Y and school voiced their hopes and aspirations for Lucy as she progresses through education:

> **"***To be happy at school. To have some friends. To do well in her exams as far as she can do, have as normal a life as she can."* (Mrs Y)
>
> *"To increase her independence where we can. We do a lot of work around social skills and really developing a confidence in making friends, maintaining friendships"*
> *"Because that will really prepare her for moving onto next setting, college, she'll be at the forefront, there's no reason at all, a really good quality post 16 course and just thriving and being happy. I'd like Lucy to be able to self-reflect and think, wow, how far have I come?"* (SENCO)
>
> *"Do whatever she wants to do."* (TA)
>
> *"To help her transitioning around school and walking around school independently would be massive. I think getting a group of friends or helping her to socialise".* (Assistant SENCO)
>
> *"I just want her to do the best that she can."* (Assistant SENCO)

Hopes for Lucy’s future included:

> **“***Go and do what she wants to do.”* (Mrs Y)
>
> “*To be independent, to be happy, to be fulfilled. To be able to have aspirations really. Knowing that the world is their oyster really and having the confidence to believe that’s the case. And understanding that if there are limitations what impact will it have. But actually, there’s so many possibilities. But just having a really through understanding of themselves because there will come a point where parents won’t advocate eventually.”* (SENCO)
>
> *“Be happy, does what she wants, achieves what she wants.”* (TA)
>
> *“Just to be true to herself, be happy. Just do what she can do, live a life, be happy, have friends. A great job would be great but only if you’re happy.”* (Assistant SENCO)

3.8.2 Stakeholder advice to other parents of CBTS

There is a lack of CBTS school support research providing practical stakeholder advice for schools and parents when working in collaboration. In my study, due to their lived experience of supporting CBTS, school and parents were keen to offer valuable practical advice to other school and parents, as reported below:

3.8.2.1 Parents had a proactive approach

Being proactive was an important part of parents communicating with school:

> *“I’m literally in their face and I am being direct in what I want. And I’m very respectful that they are teachers and I’ve said to them that I respect that they are his teachers, they’re all trained in their own specifics however he’s my son and I know my son. And that for me is massively important”.* (Mrs X)
>
> “*Don’t wait for other people to contact you, you contact them.*
> *“I always contacted first. And then once you get contact keep on asking questions. If you’re not sure about something ask a question. And I do it by email.*
> *“it’s about equal engagement.”* (Mrs Y)

Mrs X believed making sure CBTS access ongoing and effective support to help them succeed in the future is:

> *“Down to who you are as a parent with your kids. Just because a child has got a disability it doesn’t mean to say that you need to treat them as a disabled child. They are entitled to as much of an opportunity as any other child without a disability. And I’m a big believer in that, it’s how you are as a parent and if you advocate for them, then absolutely they will succeed.”* (Mrs X)

She advised other parents to:

> **“***Challenge. Challenge it back when they tell you they can’t do it. Be honest with them and be open. Nothing is impossible. There’s always a way around something. And it might feel like it’s really overwhelming and really daunting at the time but it gets easier, it does get easier. And what you’ve got to think about is at the end of the day your focus is around your child. And the school is there to support that child through their education and that child is entitled to an education. So why should they be treated any different just because they have a brain injury?*” (Mrs X)

3.8.2.2 School advice for parents of CBTS case study 1 included:

> “*I think to come in and speak to the school. And have that occasion where they’re able to talk through their concerns, anxieties that they may have with their child returning back to school. And talk through the processes within school*.” (SENCO case study 1)
>
> “*To communicate well. To keep them (*school*) updated with any changes at home is really important for us. Because then we can try and work out if there’s changes at school. To let us keep updated about medical appointments and what the outcome of the medical appointments are as well is really helpful. Keep us up to date with how the needs of the child are changing, whether that’s a physical need or an emotional or social need. Or developmental need.”* (Teacher case study 1)
>
> *“At the same time having the understanding about the time constraints that we sometimes have. And understanding that there’s a balance for everybody*.” (Teacher)
>
> “*Trust the school and trust the TA’s. If as a parent you feel your child is ready to go back to school then trust the school and trust the other agencies that work with that child*.” (TA)

3.8.2.3 Case study 2, advice to other parents of CBTS included:

> “*Don’t make the assumption that staff have the wealth of knowledge because it might be the first time that they’ve come across a child and that’s with any need”.*
>
> *“Be open, talk to us if there’s something that you’re concerned about.”*
> *“I would always make sure that you’ve maybe got one or two people as a point of contact that has a real overview, I think that’s incredibly important.”* (SENCO)
>
> “*School are often doing their best but there’s lots of children”.*
> *Sometimes things might get forgotten or might not take place”.*
> *I would want the parent maybe to remind me, or if the parent emailed and me and said ‘We talked about doing that, two weeks in, so have you started it?’ I wouldn’t take offence at that, I want parents to do that because I think that’s kind of holding me to account”.* (Assistant SENCO)
>
> *“The more information you can give (*staff*) in an easy manner, I don’t mean bombarding them with a 100- page leaflet.”* (Assistant SENCO)

> *“Speak to school, talk to the SENCO, find out what their policies are, their procedures, visit schools, have a look round and see if what they’ve got suits the needs for their child.”* (TA)
>
> *“Know that there is somebody that’s rooting for your child and putting things in place and being on the same page I suppose, wanting the same goals, agreeing with those goals*.” (Assistant SENCO)

3.8.2.4 School would like to feel that they are making a difference

Receiving positive feedback from parents regarding the child’s progress, helps build staff morale. The high school SENCO in case study 2 highlighted the importance of parents telling school staff**:**

> *“When they get it right as well, that’s really, really important. Because we’re used to finding out when we get things wrong and schools do get things wrong or when something hasn’t worked. But as a school you do get a lot of things right. Communicate that with us and tell us. Because we can then share that expertise and we can share that good practice”.*
> *“you want to feel like the things that you put in place are making a difference for the family and the child. So it’s really important we know that*.” (SENCO)
>
> “*When we sit and have meetings as a team, the fact that we’re just seeing a young person become more independent and actually sharing that as a team. That has a huge impact on staff morale.* (SENCO)

3.8.2.5 Have realistic expectations of school

In case study 2, Mrs Y felt parents of CBTS need to have a realistic view of school support:

> *“I mean you can’t have everything because you can’t go in and ask for perfection.”*
> “*as a parent you feel a bit guilty about making a fuss about some of these things when they’ve got a lot on their plates already trying to manage lots of children”.*’
> “*Am I asking for too much, I don’t know*?” (Mrs Y)

3.8.3 Key stakeholder advice to other schools

In case study 1, Mrs X advised other schools to:

> “*Listen to the parents. Get yourself on the seminars and understand what you’re working with. And be open to change because one rule doesn’t fit all kids*.” (Mrs X)

Mrs X felt the following were important elements of effective home-school collaboration and communication:

> “*Being open. Being honest. Being clear on what you want and what that child needs. And just work together*.” (Mrs X)

> *“You’ve got to have the open-door policy. Even though it’s quite difficult to keep up with the communication, I think that’s important. The difficult situation that the family have been through, they need to know that their child is going to a place of safety. A place where adults care about them.* (Teacher)

Advice to other TAs from the TA includes:

> “*Just encourage parents to give as much information as they can. Just so you’ve got as much information as you need to be able to deal with their child in the school setting. Be open and honest really and to go to meetings and to say to the head, the SENCO, the teacher, that you want to be in that meeting.”*
> *“say ‘please let me come into the meeting as I’m dealing with that child day in and day out’*.” (TA case study 1)

The SENCO in case study 2 advised listening, supporting, being flexible, continuing to raise staff’s awareness of CBTS needs, monitoring progress and being adaptable to change, were important elements of working in partnership with parents of CBTS. In case study 2, Mrs Y advised other schools:

> “*Learn about it and take advantage of all the information available. I think you better serve people when you understand what their problems are. So, it’s not just oh she’s got balance issues and she’s got memory problems. Having a bit of background that says what’s happened, why it causes problems and all the ideas and solutions being offered to them as well.”* (Mrs Y)

The assistant SENCO advised other SEN departments:

> *“Even though it might have been a few years ago it’s still helpful to know that back story because it just sits in your mind when other things are happening, it sometimes helps moving forward”*
> *“Be open to suggestions, don’t think you know everything even if you’ve read up”.*
> *“Try and have an open, honest relationship with parents. Try not to promise things that you can’t act upon. Have high expectations probably. Have high aims and goals just like I’m sure the parents would.”* (Assistant SENCO)

The SENCO also advised school staff:

> *“Talk about transition, have a very open conversation with primary school. Go out and observe if you can go out and observe in setting, that’s really important. Don’t just rely on a piece of paper and information because while it might give you lots of information, actually at the centre it is a human being that has their own voice. And what it says on a piece of paper is sometimes a total opposite of what you see in setting. So go out and observe, speak to the young person, speak to the parents and make sure that they’re part of that package that you’re putting together, that’s incredibly important because if not, you’re losing before you even start.”* (SENCO)

She also spoke about the need for schools to be adaptable, not afraid to make mistakes and for the SENCO to communicate carefully with staff:

> *"Communication in your team is really important as well because quite often you might not be working directly with that young person."*
> *"You won't pick up on* (the child's needs*) if you're just overseeing what's going on. Parents might not pick up on that at home and if a child can't advocate for themselves or don't even realise, that's where those voices of the people or the team that's working around that child are really important.* (SENCO)

> *"But always that communication with parents and the child be at the centre of everything that they do."* (SENCO)

3.9 Theme 6: School and parent partnership policy when supporting CBTS

The study explored if or how home-school partnership policy was used to guide CBTS school support practice. Surprisingly, there was no home-school partnership policy in place in either case study. In case study 1, a home-school agreement was in place but no specific home-school partnership policy.

> "*We have a home-school agreement that all parents get a copy of when their child starts at school and that's something that works through the year groups. And that covers a whole range of areas and information and SEN information within school*." (SENCO)

There was also confusion around the difference between a home-school partnership policy and a general home-school agreement. Luke's teacher felt the home-school partnership agreement *was* a policy. When asked if she felt it needed amending, as prompted by working with parents of a CBTS, she responded:

> "*Possibly, yeah if we feel like there's a need for specific children, I suppose that could be on the policy. But I guess it needs to be more dynamic really doesn't it? So, depending on the needs of the children, you sort of work with what's needed at the time."* (Teacher)

A welcome booklet was available on the school website for all parents and included a wealth of useful information including *generic* home-school expectations, as part of the home-school agreement. The SENCO was asked if school may benefit from having a specific home school partnership policy in addition to a home-school agreement:

> "*It kind of overlaps into other policies really."* (SENCO)

Luke's teacher felt the same strategies were employed when communicating with Mrs X, as when communicating with all parents and this was reflective of the school's SEN policy which stated:

> ‘*The school aims to promote positive, collaborative partnerships with parents. We recognise the value of the active participation of parents in the education of their children and encourage this wherever possible.”* (Teacher)

In a similar way, in case study 2, there was no home-school partnership policy in place, but there was a ‘Parent Advice Zone’ on the school website with links to support and advice regarding children’s well-being *in general*, and a ‘Parent Well-Being’ section with links to local support; none of the links were specific to parents of CBTS.

In both case studies, school websites had a SEN section providing comprehensive general information for parents regarding supporting SEN students at school. This did not include information regarding home-school partnership practice when working with CBTS or ABI students. Although Vanclooster et al. (2019) recommend school should have a specific CBTS policy in place, this was not the case in either case study. Instead, school general SEN policy was used to guide key school staff when supporting CBTS and working with parents. School SEN policies in the UK are based upon legislation. Schools are required to comply with national guidance set out in the SENCoP (2015), when supporting children with SEN. While SEN policy therefore should be used to help guide home-school collaboration and support for CBTS, due to the unique range of needs of CBTS, a CBTS school policy or pathway of support would help ensure school staff fully understand the complexities of supporting this vulnerable, unique group of children. Arguably, SEN policy alone is not specific enough to fully guide school and parents regarding the complexities involved in CBTS school support.

Chapter 4 Answering the research questions and conclusion

4.1 Introduction

This final chapter draws on results of the study to summarise answers to the research questions (RQ). It also explains how findings address the study's impact objectives and how findings are consistent with, build on and fill gaps in existing CBTS school support literature, research and services.

4.2 Answering research questions 1 and 2:

RQ1 What are the experiences and views of parents in relation to school-home collaboration and communication with parents of CBTS?
RQ2 What are the experiences and views of key school staff in relation to school-home collaboration and communication with parents of CBTS?

Answers to RQ 1 and RQ 2 were evident across all themes. Parents of CBTS and key school staff provided mainly positive, but some negative experiences regarding working in collaboration to identify and meet the needs of CBTS at school. The study contributes to existing CBTS school support research, by focusing on the importance of understanding practicalities involved in ongoing home-school collaboration, when supporting CBTS to make progress. Exploring the views and perceptions of parents, key school staff and CBTS, through using a qualitative case study approach, allowed me to gain a rich understanding of the complexities involved in home-school collaboration when supporting CBTS at school. Although existing CBTS school support research draws attention to the importance of supporting CBTS upon return to school (Upton & Eiser., 2006; Mulhern et al.,2004; Bruce et al., 2012; Van't Hooft et al., 2016; Tresman et al., 2016; Vanclooster et al.,2019), it does not go into detail about the relationship between key school staff and home, or the practicalities involved in communication and collaboration that underpin inclusive CBTS school support. In addition, some qualitative CBTS school support studies explore the teacher's perspective (Vanclooster et al., 2019; Upton and Eiser 2006; Bruce et al., 2012), but views of the SEN team are not typically included. My study added to CBTS school support research by focusing on the importance of home-school communication not only with teachers, but with the team of key school SEN staff who worked most closely with CBTS and parents.
Key findings of the study include:

4.2.1 Importance of *early* communication between school and parents of CBTS

The study is consistent with existing CBTS school support research and literature in drawing attention to CBTS as a vulnerable group of students, who are at a disadvantage upon return to school and through school. In addition to having what could be a life threatening and life changing brain tumour (as in both case studies), CBTS may have endured challenging treatment including neurosurgery, chemotherapy, radiotherapy and proton therapy. As a result of the tumour, treatment and having an ABI, CBTS can experience long- term physical, neurocognitive and psychosocial difficulties, negatively impacting on academic performance, social skills and friendships, and school experience (Maddrey et al.,2005; Bruce et al., 2008; Ellenberg et al.,2009; De-Ruiter et al., 2012; Lovely et al., 2013; Castellino et al., 2014; Lonnerblad et al., 2017; Vanclooster et al., 2017). Upton and Eiser (2006:10) suggest "After the end of treatment, children are expected to be 'back to normal' and achieve as well as others. In reality they are at a considerable disadvantage". The study is novel in reporting the need for *early and personal* communication between parents of CBTS and school.

An early level of communication between school and home upon the child's brain tumour diagnosis (or before if the child was becoming increasingly unwell at school) was reported as good practice in the study. Early communication between parents of CBTS, the school headteacher *and* the school SENCO upon the child's diagnosis and throughout treatment was valued by parents in the study. The role of the SENCO was highlighted as a key figure in leading communication and identifying the child's support needs. This was logical, considering the responsibilities of the SENCO in the UK include coordinating and leading SEND provision and liaising with external professionals. In addition, as directed by the SENCoP (2015), school have a legal duty to work in partnership with parents when a child has been identified as having SEN, and liaison with parents *should* be led by the SENCO. Despite this, the importance of the SENCO when supporting CBTS is not focused on in CBTS school support research. If parents of CBTS are not aware of the need to contact the SENCO along with the headteacher, or do not have time to contact both upon their child's diagnosis, it should be the headteacher's responsibility to ensure a child's brain tumour diagnosis is immediately shared with the school SENCO.

Existing CBTS school support studies highlight the importance of communication between school, parents and HCPs *upon return to school* for CBTS (Upton & Eiser., 2006; Mulhern et al.,2004; Bruce et al., 2012; Van't Hooft et al., 2015; Vanclooster et al. 2019). Although Vanclootser et al. (2017) noted the need for communication *just before* CBTS return to school and The Brain Tumour Charity (www.thebraintumourcharity.org) in their educational charter for CBTS suggest school support should be in place *within 2 weeks* of the child's return to school, there is a lack of research reporting on the level of personal communication between home and school needed *throughout a child's brain tumour treatment*, *starting from diagnosis*. My study draws attention to the need for CBTS support to be in place *from the very first day* of the child's return to school. This is made possible by school communicating closely with parents throughout the child's brain tumour journey. Tresman et al. (2016) created a CBTS school reintegration guidance protocol suggesting an official letter from HCPs should initially be sent to school informing them of a child's brain tumour diagnosis. My findings add to this, showing how direct *personal* communication between school and parents *upon* a child's brain tumour diagnosis and *throughout the child's treatment and absence from school* is an important foundation of building a positive home-school relationship. Ongoing communication throughout the child's brain tumour treatment ensured CBTS felt less isolated and were still part of school, an appropriate level of schoolwork was provided for CBTS, parents could see their child was cared about by school, and school were kept up to date regarding the child's progress through treatment.

An increased level of communication with parents, HCPs and external professionals as it grew closer to CBTS' return to school, helped school identify support needs of CBTS, to prepare transition and support plans for reintegration. Early identification of the needs of CBTS aligns with the SENCoP (2015:6.9) which guides school stating thought should "be given in advance to what disabled children and young people might require and what adjustments might need to be made to prevent disadvantage".

Novel to the study, part of school and parent preparation in supporting CBTS school reintegration, included working with a 3rd sector CBTS educational liaison service. CBTS accessed literacy and cognitive processing assessments as part of this service. Knowing the child's literacy and cognitive processing profile guided school regarding the level of differentiation needed within mainstream classroom teaching, exam access arrangement concessions and specific intervention Luke and Lucy needed to access upon return to school. In addition, outcomes of these assessments provided school with additional evidence of the child's needs when applying for an EHCP for Luke and Lucy. However, whether an EHCP is applied for or not, understanding the range of needs of *all CBTS,* well in advance of their return to school, allows school adequate time to develop support plans *before* the child returns to school. The study showed early communication between school, parents, child, HCPs and external professionals is a vital part of ensuring a package of appropriate support is in place for CBTS from day 1 of their return. This level of preparedness helps parents feel re-assured and confident that their child will be safe at school, supported appropriately, understood and cared for.

4.2.2 The need for school CBTS support training

The study highlighted communication and collaboration with parents should happen *in addition* to school accessing CBTS support training, to ensure staff understand and are equipped to meet the range of needs of CBTS. Yet there is a lack of available UK CBTS school training, limited ABI school training, and no UK CBTS school support pathway in place to guide schools when a child is diagnosed with a brain tumour. It is unsurprising teachers and TAs in the study did not access CBTS or ABI school support training. In addition, SENCOs in their position of leading and coordinating support for children with SEN, did not access CBTS or ABI training. This is also unsurprising considering National SENCO training itself does not include CBTS or ABI training. Lack of ABI training for SENCOs is consistent with studies by Howe and Ball (2017) and more recent findings from Bennett et al. (2022) whose cross- sectional survey- based study with SENCOs in Nottinghamshire (UK) concluded a need still exists for school SENCOs to access ABI training. The Government's recent 'Schools White Paper, Opportunity for All: Strong schools with great teachers for your child', (2022:20) reports the forthcoming SEND review will include a consultation:

> *"On introducing a leadership level SENCO National Professional Qualification to replace the National Award in SEN Coordination as the mandatory qualification for new SENCOs. This will align SENCO qualifications with our reformed teacher development system and ensure that these professionals are fully supported to meet the needs of children and young people with SEND".*

No detail is provided on what areas of SEN will be covered in the proposed new SENCO training, but, arguably, training should include supporting the potentially complex needs of CBTS, (even if part of larger scale ABI training). Teacher and TA training in the UK also does not focus on working with CBTS or students with ABIs, as an especially vulnerable group of learners. Although the DfE paper (2022: 8) pledges to provide “500,000 teacher training and development opportunities by 2024, giving all teachers and school leaders access to world-class, evidence-based training and professional development at every stage of their career”, no mention has been made in relation to TA training, or if areas of teacher training will include focusing on supporting students with ABI (including brain tumours). Whereas even though Vanclooster et al. (2019) draw attention to the need for teachers to access CBTS training, they do not focus on the need for *all staff* to be trained.

Adhering to inclusive practice in accordance with the SENCoP (2015), SENCOs in both case studies were keen to highlight supporting CBTS is a *whole school* responsibility. In this sense, *all staff* should have access to relevant CBTS or ABI training. This is consistent with the ‘Time for Change’ ABI report (2019) which advocates all school staff should access a basic level of ABI training.
SENCOs in the study felt accessible CBTS school training that *makes a difference* to practice would provide school staff with tools, skills, knowledge and confidence to meet the ongoing needs of CBTS, in the classroom and wider school setting.

The study also contributes to CBTS school support literature by demonstrating a lack of CBTS training can result in key staff feeling vulnerable, afraid and cautious when required to support CBTS at school (this particularly impacted TAs in the study, due to them working so closely with CBTS). Staff were, in essence, ‘learning on the job’ Howe and Ball (2017:97), when supporting the unique and complex needs of CBTS. Lack of training also resulted in key staff finding it difficult to maintain a balance between supporting CBTS and keeping them physically safe, with providing opportunities for CBTS to develop independence and autonomy. This concurs with the Royal Marsden teachers’ guide (2019) which reports school staff can be over cautious when supporting CBTS. This tension was carefully managed in the study by schools working closely with parents to adjust support levels in a safe way, while still managing the expectations of the child. Small steps of progress were made by CBTS, and progress was captured and celebrated through a close level of communication between school and home.

4.2.3 Importance of school understanding brain tumours are ABIs

Understanding the link between brain tumours and ABIs is another area not focused on in existing CBTS school support research, yet study findings indicate being aware of this link could help staff source and access a wider range of training and literature relevant to supporting CBTS. For example, although training regarding supporting children with ABI's exists and can be applied to supporting CBTS, such as training provided by the Child Brain Injury Trust (https;//childbrain injurytrust.org.uk), and school CBTS guidance such as The Royal Marsden (2019), The Brain Tumour Charity (2019) and the Sam White Pathway (2017), staff in the study were not aware of and did not access these guides. Despite this, on a positive note, 3rd sector ABI organisations are beginning to work more closely with CBTS support organisations when offering guidance and advice to parents and school. Bennet and Costello (2022:2) in their recent paper 'Back to School After Brain Injury (https://nasen.org.uk/resources/nasen-connect-magazine-january-2022) acknowledge the importance of collaboration not only between parents and school but on a wider, strategic level to develop support for ABI students: "It is hoped that together, charities and organisations such as N-ABLES can work alongside teachers and SENCOs, as well as politicians and the Department for Education, to improve the understanding of childhood ABI in schools". After all, the DfE White Paper (2022:41) recognises:

> *"A world-class school system must deliver brilliant outcomes for all children and, if we are to deliver our mission by 2030, we must ensure that vulnerable children and children with SEND are provided a better quality of education, underpinned by more effective, joined-up support".*

Although it is positive parents in the study understood the link between brain tumours and ABIs, school staff had a more variable level of awareness. A package of accessible CBTS and ABI training and information should be available to *all schools* when working closely with parents to support the individual and long-term needs of CBTS.

4.2.4 Importance of school staff knowing the narrative of the childhood brain tumour journey for child and parents

Medical practitioners use the narrative of brain tumour patients as a tool to better understand the holistic journey when supporting them through treatment (Charon et al., 2017; Milota et al., 2019). There is, however, a lack of CBTS research focusing on the value of school staff using the narrative of the journey of CBTS and parents, to inform home-school collaborative practice. My study was novel in exploring this.

Knowing the narrative of the CBTS journey helped school staff in the study recognise the enormity of a childhood brain tumour diagnosis for child and parents. Staff acknowledged the importance of understanding how the brain tumour journey through diagnosis and treatment may be highly distressing for child and parents and this is reflective of Muscara et al. (2015). Parents of CBTS may not only be processing their child's potentially life-threatening diagnosis and life-altering difficulties the child has been left with, but also must navigate the complex school SEN system, to ensure an appropriate level of school support is provided. Knowing the narrative can act as a reminder to school to work sensitively with parents and child. Understanding the narrative can also help school identify which parents need help communicating with school, advocacy or signposting to relevant CBTS external support agencies. Finally, listening closely to the narrative can help ensure staff empathise with parents who have not only supported their child through exhausting brain tumour treatment, but who are left trying to re-build their child's life, help their child regain a sense 'of 'normality' and maintain hope for their child's future. This is partly consistent with research reporting on the importance of ABI parents being able to 'maintain hope' (Bray 2015). The study also showed a harsh reality of understanding the narrative and working with parents of CBTS requires school to recognise the future may be uncertain CBTS, as profoundly reported by Mrs X who said the hospital "never tell you you're cancer free".

Ensuring key school staff are aware the narrative of CBTS could help strengthen home and school communication, yet this is not an area focused on in CBTS school support research. The importance of school knowing the narrative and the lived experience of CBTS and parents does, however, build on the DfE's School White Paper 'Opportunity for All: Strong schools with great teachers for your child' (2022), which raised awareness of the importance of parental engagement with school. NASEN responded positively to this recognising how "Understanding, respecting and listening to the lived experiences of parents, families and young people themselves is critical" (NASEN https://nasen.org.uk/news/schoolswhitepaper nasen responds to release of Schools White Paper | Nasen).In addition, understanding the narrative of the brain tumour journey for child and parents could potentially help schools incorporate elements of medical *and* social models of disability in order to identify support needs and guide effective inclusive support and provision at school for CBTS.

4.2.5 Value of TAs in supporting CBTS and communicating with parents

The TA was highlighted by Mrs X as a key member of school staff involved in supporting the needs of CBTS *and* communicating with parents. The value of TAs communicating with parents is not an area focused on within CBTS school support research, but is reflective of Moore (2016), who drew attention to the central role TAs play within home-school partnership. Arguably, there is a need for schools to recognise, value and invest in the development of TAs as members of staff in a prime position to champion home-school communication, considering they work closely with SEN students and are already involved in daily communication with families.

In the study, Mrs X felt TAs were “undervalued” by school. She drew attention to the need for TAs to be included (along with all key school staff) in CBTS school support meetings, allowing everyone involved in supporting Luke the opportunity to discuss, share and understand his progress and support needs. Not including the TA in support meetings meant the TAs detailed knowledge of Luke’s progress was not shared. It also meant the TA did not access first- hand information about Luke’s changing needs discussed at the meeting. This was reported by Mrs X as a barrier to communication. Coupled with a lack of CBTS training, not accessing support meetings resulted in Luke’s TA feeling vulnerable and nervous about supporting him initially.

The study was novel in reporting how, when key staff are not invited to, or do not attend CBTS support meetings, this can negatively impact the level of sensitivity displayed towards the child and their choice of language used around the child, regarding the child’s diagnosis. This proved problematic for parents in case study 1 and potentially damaging for the child, when a key staff member made reference to Luke about Luke’s “cancer”. Luke had not previously been aware of this, and the careful approach parents had taken in shielding their 6-year-old child from such a frightening diagnosis was therefore undermined. This in part also reflects findings of Vanclooster et al. (2019:1442) where parents of CBTS identified barriers to home-school communication included “negative experiences characterised by misunderstanding, incomprehension and absence of commitment”.

4.2.6 Importance of collaborative practice between parents and school when supporting CBTS

While Green and Edwards (2021:140) report some parents can feel “side lined, powerless, isolated, angry and exhausted” when trying to work collaboratively with school, this was not reported in my study. In addition, Vanclooster et al. (2019) report barriers to open communication between parents of CBTS and school include a lack of detail regarding the child’s needs being transferred to school, and conflict of opinion over the child’s level of school support. This was also not found to be the case in my study. Indeed, parents were very proactive, and regularly provided school with updated information regarding their child. They had realistic expectations of school support and were open to discussing concerns with staff.

The study showed the parental voice was welcomed and valued by school and helped staff identify, support and adapt to the changing needs of CBTS; parents spoke positively of this. This is consistent with Vanclooster et al. (2019:7) who reported positive collaborative practice resulted in parents feeling “involved and appreciated. They were reassured by the school’s staff willingness to make plans and adjustments and to communicate frequently”. Staff in my study also recognised parents ‘knew their child best’, and, partly due to lack of CBTS training and lack of experience working with CBTS, valued following the lead of parents in areas such as setting behaviour boundaries and allowing CBTS a greater level of independence. This, in part, also reflects Vanclooster et al.’s research (2019:9) where teachers valued “parental input and help with practical or curriculum-related matters”. In addition, close collaboration with parents helped staff strike a balance between having empathy with CBTS and ensuring school rules applied to them as to any other child; this was after all part of the child accessing the ‘normality’ of school life, a ‘normality’ that CBTS strived for.

My study also reflects findings of previous CBTS school support research (Upton and Eiser 2006; Bruce et al., 2012; Hocking et al., 2015; Vanclooster et al., 2019) highlighting how *ongoing*, home-school communication is needed to support the changing needs of CBTS over time. Collaborative practice ensures school staff are aware and *reminded* of visible *and* invisible support needs of CBTS (such as working memory and speed of processing difficulties) especially as the child develops skills and progresses through their education. The SENCO in case study 2 recognised the importance of supporting ongoing needs of CBTS, through working closely with home, at all stages of the child’s education and noted although Lucy was making good progress:

> “*things can change and could change in a heartbeat”.*

The SENCO felt staff should not forget how, for CBTS:

> *" every day is a challenge and every day is difficult and there's still so much that we need to do." (*SENCO)

4.2.7 Inclusive practice when supporting CBTS at school

The child's desire for 'normality' in the study was listened to and validated by home and school staff and addressed through ensuring CBTS had access to and were included at school in all areas. Despite not accessing CBTS or ABI training, aligning with Schuelka's (2018) definition of school inclusion and adhering to SENCoP (2015) guidance, staff in both studies, led by the SENCO, were keen to ensure CBTS were included in the mainstream classroom and wider school setting. The study added to CBTS school support research by demonstrating how close communication between home and school ensured CBTS accessed the full curriculum and were placed in classes or sets according to their underlying ability. Literacy and cognitive processing skills were supported and CBTS experienced appropriate differentiation within the classroom environment as part of Quality First teaching. In addition, a close level of home - school communication ensured CBTS accessed appropriate small group intervention, without CBTS feeling they were being excluded from whole class activities. SENCOs in the study were also keen to ensure inclusive practice meant class teachers did not view support of CBTS as the sole responsibility of the SEN department. This adheres to the SENCoP (2015) which requires all teachers to be teachers of SEN. However, providing support and intervention for CBTS as part of inclusive school practice, had to be carefully managed. For example, Mrs Y in the study reported Lucy felt excluded from social opportunities because of the level of adult support in place to make sure she was safe at school and accessed full participation at school. Parents were proactive in discussing such concerns with school. Staff were receptive and adaptive and worked collaboratively with parents to address the challenges involved in balancing safety measures in place when supporting for CBTS, with increasing levels of independence for CBTS. It is important to note not all parents will be as proactive, confident or articulate as Mrs X and Mrs Y when communicating and negotiating levels of support with school. In addition, it is recognised that parents who took part in the study were highly articulate and engaged in the interview process. School staff were equally engaged in the study, and this was also reflective of the strong level of ongoing communication between school and parents of CBTS and the level of support and provision in place for Luke and Lucy. Such a high level of stakeholder engagement helped generate rich layers of data in the study. However, I am aware if there had been socioeconomic disparity between parents involved in the study, their ability to articulate views or their commitment to the study may have been negatively impacted, potentially resulting in less detailed data. Conversely, I also feel interviewing less engaged stakeholders may have resulted in more areas of weakness being highlighted regarding the level of support and communication between school and home; this could have been very useful data in itself when guiding CBTs support practice. In addition, being mindful of disparities in the socioeconomic status of parents of CBTS and the potential impact this may have on the level of home-school communication, provides another strong reason for the need for school- parent partnership advocates (such as provided by CBTS outreach services), to help support *all parents* of CBTS to engage positively and successfully communicate with school, regarding their child’s changing support needs.

4.2.8 Honesty and trust as part of home and school collaboration

Contributing to CBTS school support research, the study draws attention to the importance of school adopting a transparent and honest approach to working with parents of CBTS, in order to build trust. For example, staff openly acknowledged to parents that they “don’t always get it right” when supporting CBTS, due to lack of experience and training in this area. Lack of CBTS support knowledge was not used as an excuse by staff, but as a reason for needing and valuing ongoing guidance from parents and external professionals. Positive school communication was also underpinned by mutual respect and valuing the views, knowledge, expertise and input of all stakeholders involved in the child’s support, with parents and child being central to support decisions being made (SENCoP 2015).

A novel finding of the study included schools desire for parents of CBTS to communicate *positive* feedback regarding their child’s school support. This helped boost the morale of staff who were working hard to meet the needs of CBTS. The high level of care key school staff displayed when supporting CBTS was evident in the study, as was the level of pride they took in their work and in the child’s progress. It was very clear staff cared about the welfare and progress of CBTS. They cared equally about creating an honest, trusting and positive relationship with parents of CBTS, after all **“**the way schools care about children is reflected in the way schools care about children’s families” Epstein (2019:11). This could be considered particularly relevant to school working collaboratively with parents of CBTS; parents who experience unique and ongoing worries, concerns and challenges as part of supporting a child with a brain tumour.

4.2.9 Lack of home-school partnership and CBTS school support policies

The relevance of home-school partnership policy in guiding collaborative practice to help ensure CBTS are supported, fully included and make progress at school, is not reported on in existing CBTS school support research. Both schools in the study had a general home-school agreement in place, but there was no home-school partnership policy. A lack of parent partnership policy is consistent with Hornby and Blackwell (2011) who report schools tend to include parental involvement as part of other policies, but don't necessarily focus on parent partnership as a policy in its own right. However, arguably, a working policy *in its own right* could guide collaborative practice between school and home. This would help support parents (not only parents of CBTS) when working with school to enhance the child's development and school experience.

Vanclooster et al. (2019) recommend school should have a specific CBTS policy in place, but again, this was not the case in either case study. School SEN policy was, however, used in both case studies to help inform and guide support and intervention for CBTS. While it is necessary and appropriate to use school SEN policy information to help guide support for CBTS, this guidance alone is arguably not specific enough to meet the unique needs of CBTS. There was no mention of CBTS or children with ABI's within school SEN policy in either case study and no mention in either LAs 'Local Offer'; this, in addition to a lack of CBTS school training meant key school staff were completely reliant on seeking detailed information about the unique support needs of CBTS from parents, HCPs and external professionals (and is another reason why early communication was so vital). Building on recommendations by Vanclooster et al. (2019) there is a case to be made for the implementation of CBTS school policy and school - parent partnership policy, to help guide the complexities of practice when supporting CBTS and working collaboratively with parents.

4.3 Answering research questions 3 and 4:

Vanclooster et al. (2019) explored the views of CBTS upon school reintegration and The Sam White Pathway (2017) *used* the voice of a CBTS to help inform school guidance for ABI students, but there is a lack of research directly seeking the voice of CBTS regarding school support, and their view of school and home working closely to support them. My study explored these areas through RQ3 and RQ4 :

RQ3 How can the child’s view and experiences of school be used to help inform the level of home-school collaboration and communication?

RQ4 To what extent does home-school collaboration and communication help support the child’s academic and psychosocial development?

4.3.1 The importance of listening to the voice of CBTS as part of home-school collaborative practice

In answering RQ3, close, ongoing and positive relationships between school and home resulted in CBTS feeling secure enough to share thoughts and feelings about school, mainly with parents and their TA’s. It was reported CBTS liked the fact school and home worked as a team, felt safe and reassured by this and were generally happy at school. However, in considering whether the child’s voice can be used to further inform home-school collaboration in the study, CBTS were not particularly aware of the high level of collaboration and communication that occurred regularly between school and home, in order to support their visible and invisible needs. Mrs Y felt it was important to:

> *“just making everything smooth sailing so that when she goes she doesn’t notice anything different. It’s like that isn’t it? You prepare everything, everything is in place and she just turns up and thinks that’s how it was going to be anyway.”* (Mrs Y)

4.3.2 Listening to the child’s voice helps inform the level of school support needed for CBTS to make progress

Relevant to RQ3 *and* RQ4, it was evident school and parents listened carefully to the voice of CBTS regarding their support needs throughout the academic year. This was done not only as part of the EHCP review process, but through parents and staff knowing the child well, observing the progress of CBTS, actively listening to CBTS and caring about the child’s well-being on a daily basis. In this way, parents and school were able to identify the child’s ‘intrinsic and explicit’ views (Hoover- Dempsey and Sandler: 2018) about school, to inform support. Parents were especially skilled at picking up intrinsic views due to knowing their child so well; these views were then translated into spoken concerns and shared with school. For example, in case study 1, upon return to school, Luke’s mother noticed he was unhappy because the pace of the lesson was too fast, and he could not “keep up” with his class. This resulted in Mrs X raising and resolving the issue with his teacher, subsequently helping Luke access and cope with the demands of the classroom without feeling overwhelmed or demoralised. Knowing their voice was very much valued by school and home and was used to inform school support could empower CBTS, encouraging them to continue sharing their thoughts and feelings with school and home over time.

The study builds on Vanclooster et al. (2019), by drawing attention to how listening to the views of CBTS was an integral part of staff and parents being able to recognise and celebrate the child's small steps of progress, address problems as they arose and safely adjust support as needed. For example, CBTS in the study typically wanted more independence at school and 'normality'. School and parents listened to and cared about the child's desire for independence, but there was a tension between school managing 'risk' and keeping CBTS physically safe while under their care, with allowing them a greater level of independence. Parents and school worked closely to facilitate small steps of independence for CBTS in the classroom and in the wider school setting, recognising this was important to and for CBTS in the present and the future.

4.3.2.1 The voice of CBTS informs social skills support at school

In the study, school and home recognised the importance of supporting social skills development of CBTS. This is consistent with findings of Bruce et al. (2008:339) whose study drew attention to how "Equipping the children with the skills to manage social situations and build positive relationships could strengthen their ability to overcome the challenges they face". Aligning with Vanclooster et al. (2019), CBTS in the study looked forward to returning to school to see peers. However, consistent with previous research findings (Fuemmeller et al., 2002; Bonner et al., 2008; Schulte and Barrera.,2010., Schulte et., 2015; Hocking et al.,2015; Salley et al.,2015 and Edmond et al.,2016), CBTS can also struggle socially, finding it difficult to fit in with peers after they have returned to school. Although Luke did not report on friendship difficulties, he was aware of the "anti-bullying teacher". Parents and school were also carefully monitoring Luke's changing friendship group upon school return, with the TA observing he found it difficult to take part in some peer playground games at break time (due to needing a walker for his balance). Lucy reported feeling "lonely at school", wanted more social opportunities with peers and communicated frustration at always having adult support with her. Lucy's higher level of awareness of social struggles at school may also be reflective of her age and stage of education; being an adolescent at high school, she appeared to have a stronger self-concept when relating to peers than Luke, who was much younger and as such, accessed a very nurturing primary school environment.

School and home listened to Lucy's voice and worked closely to facilitate appropriate social opportunities for her. They also included her in a general social skills intervention group. There is, however, a lack of research focusing on the existence and effectiveness of social skills programmes specifically relevant to the needs of CBTS. Lucy questioned the effectiveness of the social skills programme she accessed and did not feel she had "gained anything" from the intervention.
The study also added to research by highlighting a balance needs to be maintained between providing social skills support and intervention for CBTS and facilitating social opportunities, with the level of adult support CBTS access at school; having full-time TA support was viewed as preventing social opportunities for Lucy. This concurs with Royal Marsden teacher guidance (2019:60) which reports "Reliance on an LSA has implications for the social isolation, welfare, independence and confidence of any pupil and therefore needs to be carefully managed". School and parents were aware of this tension and worked closely to resolve it. This is an example of how inclusion for CBTS at school can become exclusion if support is not monitored and adapted according to the changing needs of the child, through listening to the voice of the child and through close home-school collaboration.

4.4 Meeting the research impact objectives

The impact objectives of the study were:

1. Identify existing models of home-school collaboration and communication that inform and can help develop two-way home-school policy and practice when working with parents of children with brain tumours.
2. Identify strategies that work well and challenges and barriers to home-school collaboration and communication, when supporting a childhood brain tumour survivor at school.
3. Seek to inform a two-way model of home-school collaboration and communication that can be used as part of a school CBTS pathway of support.

4.4.1 Meeting impact objectives 1 and 2

Impact objective 1 refers to identifying models of home- school collaboration in existence in the case studies, that could be used to further inform policy and practice. It also refers to identifying existing conceptual models of parent partnership outside of the study that could also be used to guide home-school collaborative policy and practice. Hoover-Dempsey and Sandler's (2010) revised model of parental involvement and Epstein's (2018) model of six types of home, school and community partnership were used in the study. Elements of these two conceptual models were identified in the study (discussed on pages 96-99), drawing attention to how school staff should be aware of the unique nature of home-school collaboration with parents of CBTS. These elements could be used to further guide CBTS school support policy and practice. Although there was no specific ‘model’ of collaborative practice in place in each case study, areas of good practice and barriers to CBTS home-school collaborative practice were reported in detail throughout the study. The wealth of practical strategies and stakeholder advice reported throughout the study, meet impact objective 2. This information could be used to help guide the development of a model of home-school collaborative practice, as part of a CBTS school support pathway of guidance, which is also relevant to impact objective 3.

4.4.2 Meeting impact objective 3

The lack of home-school partnership policy was novel to CBTS school support research and there was also no CBTS school support policy or home-school partnership policy in place in either case study. Although Upton and Eiser (2006) suggested a need for the creation of a CBTS school pathway of support, there is still no existing UK school support pathway of guidance for CBTS. The need for a CBTS school support pathway of guidance and benefits of a CBTS educational liaison service, build on existing research (Upton and Eiser (2006); Bruce et al., (2012); Vanclooster et al., (2019); and Hocking et al., (2018). My research adds to this by advocating a CBTS school support pathway should include practical strategies *and* relevant CBTS and home -school partnership policies. Such a pathway would help ensure schools are guided when supporting CBTS *as soon as they are aware of a child’s brain tumour diagnosis*. Recognising the need for a pathway builds on Tresman et al. (2016), who created a protocol to guide school reintegration of medulloblastoma brain tumour survivors (but it did not include detail or guidance on the practicalities involved specifically in communication between school and home when supporting CBTS). In addition, comprehensive literature aimed at guiding school support of CBTS upon return to school provided by the Royal Marsden (2019) and The Brain Tumour Charity (www.thebraintumourcharity.org), contain helpful information for schools, but are not national pathways in themselves. In a similar way information for schools when supporting ABI students by Bennett et al. (2017), as part of the Sam White Pathway and the UK ABIF (2021) guide for schools in supporting children with an ABI, are not national CBTS pathways, even though comprehensive guidance is very relevant to supporting CBTS.

In meeting impact objective 3, my study draws attention to the need for the creation of a *visual and easily accessible* CBTS pathway of guidance for schools to refer to *as soon as they are informed of a child's diagnosis.* The creation of a visual pathway should include signposting information for schools regarding access to CBTS support training. CBTS training, in turn, should include the importance of knowing the narrative of CBTS, ensuring key staff understand the potential long-term impact of a brain tumour diagnosis on child and parents. Being aware of the narrative could also provide an important bridge for school in recognising not only the long-term disabilities of CBTS, but understanding *how* to support the ongoing social, emotional, educational and physical needs of CBTS in an inclusive setting and how to build a collaborative, positive and trusting relationship with parents of CBTS. Training would also help prepare staff in undertaking important roles supporting the rehabilitation of CBTS and developing positive collaborative relationships with parents. Indeed, the creation of a visible and accessible CBTS school pathway of guidance would help key school staff understand CBTS are a very vulnerable group of children whose families "have made it clear that the ramifications of childhood brain tumour are unique and last a lifetime, and that there is much to be done to address these" Young et al. (2021:18).

Also relevant to meeting impact objective 3, the study draws attention to gaps in CBTS school support services, such as the absence of a national UK CBTS home-school liaison service. However, individual 3rd sector brain tumour charities operate across different regional areas of the UK offering varying packages of support for CBTS and families. For example, The Brain Tumour Charity (www.thebraintumourcharity.org) offers individual online and telephone support, as well as educational resources such as an educational charter for CBTS, providing statutory guidance on education and support at school. The Child Brain Injury Trust (https://www.childbraininjurytrust.org.uk) offers a family support service, including advocacy for the family and child upon return to school and Levi's Star Children's Brain Tumour Charity (https://www.levisstar.com) offers a CBTS educational outreach support service. Despite the existence of the above services, school staff in the study did not access them all, perhaps due to lack of experience when first supporting CBTS and limited time in the school day in which to research and access appropriate training and guidance. This in part concurs with an NASUWT (2018) survey where school staff reported barriers to accessing CPD SEN training in general, included time constraints, heavy workload and a lack of school funding. Although staff in the study wanted to access training and relevant information, they did not know where to find this or have time in the busy school day to research it effectively.

In meeting impact objective 3, and in addition to having a visual, accessible CBTS school pathway of guidance, my research suggests a CBTS educational liaison service would provide an important link between parents, school, and hospital, helping support school reintegration of CBTS. This builds on Bruce et al. (2012) who demonstrated how an educational liaison link, as part of a home-school liaison programme, worked well in providing advocacy for CBTS and help for teachers and parents in identifying the child's support needs. Upton and Eiser, (2006), Vanclooster et al., (2017) and Hocking et al., (2018), also advocate the need for an educational liaison service upon the child's school reintegration. My study draws particular attention to the value of a 3rd sector educational liaison service in assessing literacy and cognitive processing skills of CBTS, in order to inform support, intervention and exam concessions upon school reintegration. This again builds on Vanclooster et al. (2019) whose study draws attention to the need for CBTS to access academic and psychosocial needs assessments upon return to school, and The Sam White Pathway (2017) in making recommendations for CBTS to access neuropsychology assessments. In the UK neuropsychology assessments do not always happen before the child has returned to school (as in the study). Specialist teacher assessments can therefore help bridge this gap in services and provision, ensuring CBTS, parents and school do not find themselves in the position of having to wait until a neuropsychology assessment has been administered, before an appropriate level of intervention is informed. Specialist teacher assessments are needed to identify additional needs of CBTS to inform school planning for early support (although it is important to note specialist teacher assessments of CBTS are not offered *instead* of a neuropsychology assessment, but in *addition* to and probably in advance of). A CBTS educational liaison service should also be accessible upon the point of a child's brain tumour diagnosis and throughout their educational trajectory.

To summarise, testament to the schools involved in the study, despite a lack of CBTS school training, the absence of a national CBTS school guidance pathway, no LA CBTS guidance and no CBTS support or home-school partnership policies in place at either school, this did not prevent staff from working closely and positively with parents in order to support CBTS effectively; practice organically evolved due to the proactiveness of parents and the professionalism, conscientiousness and care of school staff. Mrs X and Mrs Y felt they had a positive relationship with school underpinning their child's support and progress, but recognised this level of support is not automatically the case for all CBTS and parents.

> "*I think I've been really lucky. Because there are families out there that have been through this process and they haven't got half as much support as I've had. But I've only got that support because I've gone out and I've found it and I've made sure that it happened. Because you're not always aware and I think that if you're not fully aware of what the process is and what the system is, there are things that can be left. But for me he's my child and I want the best for him. He didn't ask to have a brain tumour. He didn't ask to go through all of this, and it's my job as a parent to make sure that he gets the education that he deserves."* (Mrs X)
>
> *"I'd hope this is what everybody gets. Possible they don't because of all the situations but this is what you should get."* (Mrs Y)

This observation is reflective of Tresman et al. (2016:16410) who reported a "lack of a standardised protocol" led to "vast differences in a school experience" for CBTS. Seven years later, there still remains a need for a standardised level of CBTS school support or at the very least, access to school CBTS support guidance and training. This would help ensure support is not dependent on many variables such as knowledge of staff and LAs regarding CBTS, the proactiveness of parents in ensuring support is in place, and the strength of school links with external professionals. However, when considering the need for and how to implement a national school pathway of guidance and support for CBTS, it is also important to acknowledge (as explained on pages 25-26) national challenges exist within the SEND system itself, resulting in variable levels of SEN support and funding being in place across LAs and schools in England. Set against this inconsistent backdrop of SEN support, implementing national guidance pathways for specific areas of SEN may therefore prove challenging, especially considering there is no standardised model of SEN support practice in place for schools to implement to begin with. Yet as the need for the creation of a school guidance pathway of support for CBTS continues to exist, it is necessary to understand developing and promoting a CBTS school guidance support pathway is not about accessing LA funding, but about ensuring, firstly, that such a pathway exists and secondly that it is visible and easily accessible by school and parents. Afterall, not all CBTS will require an EHCP that needs LA funding, but *all* will require school staff to understand their support needs and brain tumour narrative, and this is something a pathway could provide guidance on. A solution could therefore be, to ensure a national CBTS school guidance support pathway is promoted across all LAs as part of the 'Local Offer'. The SENCoP (2015) could also signpost school professionals and parents to a CBTS school support guidance pathway, even if it is as part of signposting to ABI support. Afterall, the SENCoP (2015) signposts school professionals to organisations offering guidance and advice regarding supporting other areas of SEN, such as dyslexia, ASD and speech and language. Although the SENCoP (2015) notes these organisations have worked with the DfE to improve SEN support, arguably, the voice of ABI and CBTS support organisations should also be part of working with the DfE in this way. A school CBTS school support guidance pathway could also be published in the Government Education Hub (https://educationhub.blog.uk) and be made available on websites of all CBTS 3rd sector (and ABI) support organisations. This high level of visibility would mean when schools are required to support CBTS, they are able to easily access guidance in the form of a CBTS school support guidance pathway *as soon as the child is diagnosed*. Hospital paediatric neuro oncology and hospital social work teams could also signpost parents and schools to a CBTS school guidance support pathway. Indeed, 3rd sector childhood brain tumour support organisations should work collaboratively with hospitals *and* LAs in providing relevant pathway information and signposting links for schools and parents of CBTS. Creating, reviewing and updating guidance of a CBTS school support pathway should ideally be done through collaboration between CBTS and ABI 3rd sector support organisations and appropriate CBTS stakeholders.

4.5 Limitations and strengths of the study

A limitation of the study included participants not being involved as co-designers of the research (due to time limitations). I was also aware the study did not include parents and schools who had a more negative experience of supporting CBTS and working in collaboration. However, case study methodology was not intended to be generalisable or representative of the wider childhood brain tumour population.

Strengths of the study included gaining a detailed understanding of the experiences of stakeholders and complexities involved in supporting CBTS, through using a case study design and thematic analysis. As thematic analysis is not focused on quantifying content, it enabled me to identify the value and relevance of all reported data in my study. It also provided flexibility when summarising coded data into relevant themes, allowing me to present a comprehensive picture of the complexities involved in school and home communicating and collaborating when supporting CBTS. However, the volume of data generated by this design proved difficult to edit without losing the essence and power of the child and parent narrative. Editing and analysing data was also a very time- consuming process.

4.6 How the study will be used in the future

Information generated by the study will be used by LSCBTC to help guide the creation of a visual, easily accessible pathway of CBTS school guidance. LSCBT will continue to develop its educational outreach liaison service with the point of access for parents and school being upon diagnosis, or at any point in the child's brain tumour journey. The service can be accessed by all CBTS and not only the ones who need an EHCP. The funding of such a service potentially being rolled out nationally needs careful consideration and may be something 3rd sector organisations can collaborate over to facilitate. CBTS school policy could also potentially be created and guided by study findings (including elements of the two conceptual frameworks). In addition, CBTS training materials for school will be developed.

4.7 Dissemination

Presenting research findings as a stakeholder analysis could help inform dissemination. Key findings of the study will also be shared with:
Participants and brain tumour 3rd sector organisations and national organisations such as Brain Tumour Support, the APPG, The Tessa Jowell Brain Cancer Mission and international organisations such as International Brain Tumour Alliance (ABTA). We will also share findings with ABI 3rd sector charities and organisations. In addition, key findings will be shared with the oncology team, social work team and oncology outreach nurse team at the LGI hospital. Findings will be submitted to peer reviewed journals such as NASEN, SEN Journal, the International Journal of Inclusive Education and the European Journal of Cancer Care. Presenting findings at children's brain tumour and ABI conferences will be helpful for parents and schools in understanding how building a strong partnership provides an important foundation of good practice when supporting CBTS at school.

4.8 Areas for future research

The study indicates further research would be prudent in the following areas:

1.Exploring the lived experiences of CBTS, parents and school throughout the child's school trajectory, using a qualitative approach, longitudinal case study design and observational data, would help develop an understanding of the support needs of CBTS throughout their school journey, to becoming independent young adults.

2.A systematic review of the effectiveness of existing CBTS social skills programmes or alternative programmes relevant to CBTS social skills support would be useful in guiding schools intending to use such interventions.

3.Developing school usage of the narrative when supporting CBTS and working collaboratively with parents needs further attention. Using existing medical narrative training models as frameworks, along with semi-structured interviews with school SENCOs, 3rd sector CBTS or ABI trainers, and a focus group could help develop the use of the narrative in a school setting.

4.Critical policy analysis research focusing on the existence and development of home-school partnership policies being used as a working document to guide schools working collaboratively with *all* parents (not just parents of children with SEN), would be useful.

4.9 Conclusion

Exploring the views and perceptions of parents, key school staff and CBTS, through using a qualitative case study approach, allowed me to gain a rich understanding of the complexities involved in home-school collaboration when supporting CBTS at school. CBTS are clearly a vulnerable group of children whose lives and futures may be negatively impacted by a brain tumour. They are likely to experience a range of physical, cognitive and psychosocial support needs (classed as an ABI) that they did not have prior to brain tumour treatment. The study showed for school to recognise the enormity of a childhood brain tumour diagnosis, the impact on the lives of child and parents and to understand how to support the child’s initial and ongoing needs, a close level of home-school communication and collaboration is essential. Personal communication between school and home should start upon the child’s diagnosis (or before if the child is unwell at school), continue throughout the child’s treatment and be led (in the UK) by the school SENCO.

Alongside ensuring positive home-school collaborative practice is in place when a child is diagnosed with a brain tumour, it is also essential for schools to access CBTS support training, ideally before the child returns to school. Yet the need for CBTS and ABI school training is not reported in CBTS school support research, This would equip all staff*, including the TA*, with an understanding of the child and families brain tumour narrative and with the tools and confidence to support the potentially complex and long-term needs of CBTS. Accessing training *and* working closely with parents (and HCPs initially) would therefore ensure an appropriate level of support is in place from day 1 of the child's return to school and continues throughout the child's trajectory.

Ongoing home-school collaborative practice includes listening to and valuing the child's voice in order to identify, track, monitor and adapt changing support needs of CBTS. Collaborative practice is an integral part of supporting CBTS to make academic, social and physical progress, access and experience the fullness of school life and reach their potential as young adults. A positive home-school relationship could be considered a foundation of ensuring CBTS are not only safe at school, understood and cared for, but are supported to develop a level of independence needed for quality of survivorship. Understanding the range of practicalities involved in developing effective home-school communication and collaboration when supporting CBTS, should be part of CBTS school support training and part of a school CBTS support guidance pathway.

In addition, signposting school staff to CBTS training and 3rd sector CBTS support organisations, including CBTS educational liaison services, should also be part of a school CBTS support guidance pathway. Such guidance would help prevent a fluctuating level of support for CBTS across schools. Finally, developing CBTS support policy and home-school partnership policy would mean schools do not have to rely on *generic* school SEN policy guidance, which does not provide staff with specific information needed to support *the ongoing and wide range of individual needs* of CBTS.

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Appendices

Appendix 1 Primary parent interview questions

Part 1: Background history questions:

1. Did your child access extra support at school prior to his brain tumour diagnosis? This could for example include TA support in the classroom, differentiated activities in the classroom, small group support, social skills or behaviour support, or support at break and lunchtime. If so, please describe.
2. How would you describe your relationship with school prior to your child's brain tumour diagnosis? This could include for example your relationship with class teachers, teaching assistants, the SENCO and school management.
3. When was your child diagnosed with a brain tumour and how old was he?
4. What type of tumour was it?
5. How much communication did you have with school prior to your child's diagnosis? Who did you communicate with and how?
6. How much communication did you have with school upon diagnosis and who did you communicate with?

Part 2: Please tell me about the period of time when your child underwent treatment for a brain tumour:

1. What type of treatment did your child have?
2. How long did it last and when did treatment end?
3. How much physical time out of school did your child have?
4. Did school communicate with you throughout your child's absence?

4a. If so, who contacted you, how, and how often eg daily, weekly, monthly termly?

4b. Was this communication helpful for you?

5.Did any member of school staff visit you and your child in hospital or at home?

5a. If so, was this helpful?

5b. If not, would you have liked this to happen?

6. Did your child access home schooling during his time away from school?

6a. If so, who made the referral?

6b. How were you and school involved in communicating with his tutor?

7. Could the frequency or type of communication between you and school have been improved during your son's absence? If so, please explain how.
8. Were you made aware by hospital professionals of any potential difficulties your child may experience as a result of his brain tumour/treatment and what kind of support he may need at school?

8a. If so, was this relayed to school prior to his return and by who?

Part 3: When your child returned to school questions:

1. When did your child return to school?

2. Had he completed treatment?

3. Did you meet with or communicate with school in preparation for your child's return to school?

4. If so, who did you meet with or speak to and what was discussed?

4a. Did you have an opportunity to meet with your child's TA prior to him returning to school?

5. How did you feel about your child returning to school?

5a. Did you get an opportunity to convey your thoughts and feelings about your child's return to members of school staff?

5b. If yes, how did you do this and was it helpful?

5c. If no, why not and would you have liked to?

6. What were your expectations of school upon your child's return to school?

7. How did your child feel about returning to school?

Part 4: The level of support your child has needed since returning to school and the level of involvement you have in deciding what support is needed:

1. Does your son experience any difficulties learning in the classroom, any physical social or behavioural difficulties that he that he did not have before treatment for a brain tumour? If so, please describe.

2. Your child has an EHCP. What level of communication and collaboration did/do you have with school to identify and meet the initial and any ongoing needs of your child?

3. Do you feel your contribution is welcome and valued in EHCP meetings?

4. Does your child access TA support? If yes, please describe how many hours of support, how many TA's he has and what support they provide?

5. Does your son access social skills support at school? If so, please describe.

5a. If not, how is he coping socially at school?

6. Does your son access support for any behaviour related need, for example anger management support or self-esteem support?

6a. Do you and school work together to help support any social skills or behavioural needs of your son?

6b. If so, how?

7. How do school communicate any changes in your child's needs or any progress he has made?

8. What do you think is working well for your child at school?

8a. Is there anything that isn't working well for him at school?

8b. How is this information shared between school and you?

9. To what extent do school help you make links with outside agencies to support you and your child?

Part 5: Your relationship with school questions:

1. Who are the key staff in supporting your child at school?

2. Who are the key school staff in communicating with you?

3. Do school have an open-door policy when communicating with you? For example, are you encouraged to go into school outside of formal meetings, to discuss your son's needs and progress?

3a. If not, would this be helpful?

4. How often are you in contact with school?

4a. Who do you mostly speak to?

4b. Is the frequency of contact enough? Please explain.

4c. Has the frequency of contact changed since he went back to school?

5. Is there any member of school staff you would like to be in contact with if you are not already?

6. To what extent do you feel communicating with school staff impacts your son's progress at school?

7. What do you think makes an effective school and home partnership?

8. Is there anything that hasn't or doesn't work well with regards school/home communication and partnership in your experience? If yes, please explain.

9. To what extent do you feel your engagement with school is going to influence your child's success at school: academically/ socially /emotionally

10.Would you like to be further involved with school to help support your son's progress at school?

10a. If so, how?

Part 6: Looking to the future questions:

1. What are your hopes for your child as he progresses through school?

1a. Would you like this to be included in the narrative you share with school?

2. What are your hopes for your son in the future?

2a. Would you like this to be included in the narrative you share with school?

3. What are your child's hopes for the future?

3a. Would you like this to be included in the narrative you share with school?

4. Do you, your son and school share in celebrating your child's successes?

4a. If so, how?

4b. if not, would you like this to happen?

5. If you could offer other parents of children with brain tumours advice about working in partnership with school, what would you say?
6. If you could offer school advice about working in partnership with parents of children with brain tumours what would it be?
7. Is there anything else you would like to add? Thank you so much for your time and valuable contribution

Appendix 2 Visual stimulus of question/prompts for primary age CBTS (using photovoice)

1. What lessons do you enjoy most at school?
2. What lessons do you enjoy least?
3. How do you learn best in lessons?
4. What is more difficult for you in lessons?
5. Do you have extra support at school?
6. What makes you feel happy at school?
7. What do you do at playtime and lunchtime?
8. Do you enjoy seeing your friends at school?
9. Is there anything that makes you feel unhappy at school?
10. Who meets you when you come into school each morning?
11. Which members of staff do you feel help you the most at school?
12. Do you get homework?
13. If you could tell your teachers and teaching assistants what you think would help you more at school, what would you say?

Appendix 3 Questions for primary school SENDCO

Part 1: Background

1. What is your professional role?
2. How long have you been a SENDCO?
3. Do you do this role full time?
4. Do you have a specialism within SEN? Please explain.

Part 2: Brain tumour awareness

1. Is X the first child you have supported with a brain tumour?
2. Have you or your staff accessed any level of CPD training focusing on working with a childhood brain tumour survivor and his/her parents?

2a. If so, was this before working with X or during?
2b. Was the training helpful?
2c. If so, in what way?

1. If you didn't access training, do you think this would have been useful?

2. Do you regard a brain tumour to be an acquired brain injury (ABI)?

3. Have you or your staff accessed any training focusing on supporting students with an ABI, and working with their parents?

Part 3: School and parent partnership, policy and practice

1. Does your school have a home/school partnership policy?

1a. If so, how long has this policy been in place?

1b. Do you know if this policy is based on any academic home-schoolpartnership frameworks?

1c. How often is the policy reviewed?

2. Do you offer staff training focusing on working in partnership with parents?

3. Do you consider your school has a positive attitude towards collaborating with parents?

4. What does your school do to encourage parental engagement with your school?

5. How does your school and parent partnership policy relate to working with parents of a child with a brain tumour?

6. Has working with parents of a child with a brain tumour prompted a need to amend or review the policy?

Part 4: Communication during X's diagnosis and treatment

1. Can you describe the level of communication you had with X's parents upon X's initial diagnosis?

2. Were you in contact with X's parents during his treatment?

2a. If so, how, how often and was this useful?

2b. Did you encourage contact from his teacher and classmates?

3. Did you inform all staff about X's diagnosis?

3a. If so, how and at what point?

4. Did you inform other students about X's brain tumour?

4a. If so, how was this done?

5. Did you inform other parents about X's diagnosis? Please explain

6. Was informing staff, parents and students, done in collaboration with X's parents?

Part 5: Supporting X and collaborating with his parents

1. How prepared did you feel about supporting X upon his return to school?

2. Did you deliver any training to staff about working with X and his family prior to his return? Please explain.

3. Do you think knowing the narrative of the family's journey has been helpful to you and your staff in supporting X and his parents? Please explain.

3a. How often do you think this narrative should be shared with school staff?

4. How did you identify X's support needs upon initial return to school? Was this done in collaboration with his parents?

5. To what extent did communicating with X's parents help you support X on his return?

6. How closely do you work with X's parents when making decisions about X's support and intervention?

6a. To what extent do you value and welcome X's parent's contributions?

7. Have X's teacher and TA's been included in all review meetings about X?

7a. What level of support did/do X's teacher and TA's need in order to support X and to work with his parents?

8. Do you include X in review meetings?

9. Do you think it helps X, knowing that you work closely with his parents?

10. Did any other agency support you as a school in preparing to support X and work with his family?

10a. Have you referred X or his family to other community agencies or peer support groups?

Part 6: Effective home/school partnership with X's parents

1. What do you think makes an effective home/school partnership when supporting a child with a brain tumour?

2. Do you feel you work in partnership with X's parents in order to support X? Please explain.

3. Has your partnership with X's parents changed since his return to school? Please explain.

4. How important is trust when working with the family of a pupil with a brain tumour?

5. To what extent do you think working in partnership with X's parents impacts his learning?

6. Do you and X's parents take part in joint celebrations about X's progress?

7. What works well when working in collaboration with X's parents?

8. What could be improved?

9. Do you have an open-door policy when working with X's parents?

9a. If so, how does this work?

9b. Do you have an open-door policy with all parents of children with SEN

10. What do you think is working well for X at school?

11. What do you think could be improved for X at school

12. How do you communicate the above to X's parents?

Part 7: Advice to others

1. If you could offer advice to other schools about working with parents of a brain tumour survivor what would it be?
2. If you could offer advice to other families of a child diagnosed with a brain tumour, about working with school, what would it be?
3. What are your aspirations for X as he progresses through school?
4. What are your aspirations for X as he progresses through life?
5. What is the most important thing you have learnt about working in partnership with X's parents since his return to school?
6. Is there anything you feel would help you develop your practice in relation to supporting a child with a brain tumour and working in partnership with his/her parents?
7. Is there anything else you would like to add?

Thank you for your time and valuable contribution.

Appendix 4 Interview questions for TA (primary)

Part 1: Background

1. What is your professional role?
2. How long have you been a qualified TA?
3. How long have you supported X?
4. Were you employed to specifically support X or did you already work as a TA at school?

4a. Do you only support X?

4b. Will you support him in each year group throughout primary school?

Part 2: Brain tumour awareness and training

1. Is X the first child you have supported with a brain tumour?
2. Did you know X before you became his TA?

2a. If so, was this helpful in building a relationship with X when you became his TA?

3. Have you accessed any level of CPD training focusing on working with a childhood brain tumour survivor and his/her parents?

3a. If so, was this before working with X or during?

3b. Was the training helpful?

3c. If so, in what way?

4. If you didn't access training, do you think this would have been useful?
5. If you have accessed training, would updated training be helpful?
6. Do you regard a brain tumour to be an acquired brain injury (ABI)?

7. Have you accessed any training focusing on supporting students with an ABI, and working with their parents?

8. Have you accessed any staff training focusing on working in partnership with parents

Part 3: Supporting X and collaborating with his parents

1. At what point in X's journey did you first have any communication with X's parents? (Prompt if necessary eg upon initial diagnosis, after treatment, when he came back to school?)

2. Did you communicate with the class teacher and SENDCO in order to make contact with X and his parents initially?

3. Were you aware of X and his family's brain tumour journey before you began working with him?

4. Do you think knowing the narrative of the family's journey has been helpful to you in supporting X and his parents? Please explain.

4a. How often do you think this narrative should be shared with school staff?

5. How prepared and confident did you feel about supporting X upon his return to school after treatment ended?

6. Were you involved in identifying X's support needs upon initial return to school? If so, how?

6a. Was this done in collaboration with his parents?

7. Were/are you included in all review meetings about X?

8. How important is it to you to be involved in all school meetings about X?

9. Is X involved in his review meetings?

9a. How often does X get the opportunity to tell you what's working well for him or not?

10. What support does X need in the classroom and around school?

11. Have his needs changed since his initial return to school (after treatment ended). Please explain.

11a. Do you discuss any changing needs with X's parents?

12. How and how often do you communicate with X's parents? (Prompt if needed, eg face-face. Email, home-school diary?)

12a. Do you feedback this communication to the teacher and SENDCO?

13. To what extent does communicating with X's parents help you to support X at school?

14. To what extent do you value and welcome X's parent's contributions?

15. How closely and how often do you work with X's teacher and SENDCO in planning the support of X at school?

16. Do you work with any outside agency in supporting X at school? (Prompt if needed, eg OT, SALT etc)

16a. If so, is this done in collaboration with the teacher, SENDCO and X's parents?

17. Do you think it helps X make progress, by working closely with his parents? Please explain (prompt if needed eg academic progress, behaviour, social skills, emotional)

18. Is it important to have a consistent approach from you and home, when supporting X at school?

19. How important is it to maintain a balance between supporting X and encouraging independence?

19a. Does working with X's parents help you do this?

20. How often do you feedback to the teacher and SENDCO about X's progress or any concerns you may have?

20a. Do you feedback directly to X's parents about X's progress or any concerns you have?

20b. What is working well for X at school?

20c. What do you think could be improved?

21. Do you feel you need any further support or training in order to support X at school or to work with his parents?

Part 4: Effective home/school partnership

1. Do you feel you work in partnership with X's parents in order to support X? Please explain.
2. Has the level of your communication with X's parents changed since his return to school? Please explain.
3. How important is trust when working with the family of a pupil with a brain tumour?
4. To what extent has the school home-school agreement that's in place at your school, guided your communication with the parents of X?
5. Do you and X's parents take part in joint celebrations about X's progress?
6. What works well when working in collaboration with X's parents?
7. What could be improved?

Part 5: Advice to others

1. If you could offer advice to other TA's and schools about working with parents of a brain tumour survivor what would it be?
2. If you could offer advice to other families of a child diagnosed with a brain tumour, about working with TA's and school, what would it be?
3. What are your aspirations for X as he progresses through school?

4. What are your aspirations for X as he progresses through life?
5. Is there anything else you would like to add?

Thank you for your time and valuable contribution.

Appendix 5 Interview questions for primary teacher

Part 1: Background

What is your professional role?

1. How long have you been in this role?
2. Do you do this role full time?
3. Have you accessed any training within SEN? Please explain
4. Are you a member of SLT

Part 2: Brain tumour awareness

1. Is X the first child you have supported with a brain tumour?
2. Have you accessed any level of CPD training focusing on working with a childhood brain tumour survivor and his/her parents?

2a. If so, was this before working with X or during?

2b. Was the training helpful?

2c. If so, in what way?

3. If you didn't access training, do you think this would have been useful?
4. Do you regard a brain tumour to be an acquired brain injury (ABI)?

4a. If so, why is this important?

5. Have you accessed any training focusing on supporting students with an ABI, and working with their parents?

Part 3: School and parent partnership, policy and practice

1. Does your school have a home/school partnership policy?

1a. If so, how long has this policy been in place?

1b. Do you know if this policy is based on any academic home-school partnership frameworks?

1c. As a member of SLT, are you involved in reviewing the policy?

2. Have you accessed staff training focusing on working in partnership with parents?
3. Do you consider your school has a positive attitude towards collaborating with parents?
4. What do you do as a teacher to encourage parental engagement with X's parents?
5. How does your school and parent partnership policy relate to working with parents of a child with a brain tumour?

6. Has working with parents of a child with a brain tumour prompted a need to amend or review the policy?

Part 4: Preparing to support X?

1. Did you communicate with X's parents before you began teaching him?

1a. If so, when and how did you communicate with them and was this helpful?

2. Did you speak to the SENDCO, X's previous teacher and his TA in order to understand his support needs?

3. What support does X need in the classroom?

Part 5: Supporting X and collaborating with his parents

1. How prepared did you feel about supporting X in your class?

2**. Do you know the narrative of the family's journey? If so, has this been helpful to you and in supporting X and communicating with his parents?**

3. How important is it to be aware of the emotional impact on parents of having a child diagnosed with a brain tumour?

4. How important is it to be aware of the emotional impact on a child of being diagnosed with a brain tumour?

5. How closely do you work with X's parents when making decisions about X's support and intervention?

6. To what extent do you value and welcome X's parent's contributions?

7. How often do you communicate with X's parents?

8. Are you included in review meetings about X?

9. How closely do you work with X's TA's in order to support X?

10. Does X access intervention?

11. Does X need support academically, socially or emotionally?

12. Do you think it helps X make progress knowing that you work closely with his parents?

13. How important is it maintaining a balance between supporting X and encouraging independence?

14. Do you have a consistent approach to supporting X from home and school?

Part 6: Effective home/school partnership with X's parents

1. What do you think makes an effective home/school partnership when supporting a child with a brain tumour?

2. Do you feel you work in partnership with X's parents in order to support X? Please explain.

3. How important is trust when working with the family of a pupil with a brain tumour?

4. To what extent do you think working in partnership with X's parents impacts his learning?
5. Do you and X's parents take part in joint celebrations about X's progress?
6. What works well when working in collaboration with X's parents?
7. What could be improved?
8. Do you have an open-door policy when working with X's parents?
8a. If so, how does this work?
9. What do you think is working well for X at school?
9a. How do you celebrate X's success?
10. What do you think could be improved for X at school?
11. How do you communicate the above to X's parents
12. How important is it to you to keep improving your knowledge about brain tumours and how they can affect young people?

Part 7: Advice to others

1. If you could offer advice to other schools and teachers about working with parents of a brain tumour survivor what would it be?
2. If you could offer advice to other families of a child diagnosed with a brain tumour, about working with school and teachers, what would it be?
3. What are your aspirations for X as he progresses through school?
4. What are your aspirations for X as he progresses through life?
5. What is the most important thing you have learnt about working in partnership with X's parents since his return to school?
6. Is there anything you feel would help you develop your practice in relation to supporting a child with a brain tumour and working in partnership with his/her parents?
7. Is there anything else you would like to add?

Thank you for your time and valuable contribution.

Appendix 6 Interview questions for secondary parent

Part 1: Background history

Questions:

1. Did your child access extra support at school prior to her brain tumour diagnosis? This could for example include TA support in the classroom, differentiated activities in the classroom, small group support, social skills or behaviour support, or support at break and lunchtime. If so, please describe.
2. How would you describe your relationship and communication with school prior to your child's brain tumour diagnosis? This could include for example your

relationship with class teachers, teaching assistants, the SENCO and school management.

3. When was your child diagnosed with a brain tumour and how old was she?
4. What type of tumour was it?
5. How much communication did you have with school upon diagnosis? Who did you communicate with?

Part 2: Please tell me about the period of time when your child underwent treatment for a brain tumour

Questions:

1. What type of treatment did your child have?
2. How long did it last and when did treatment end?
3. How much physical time out of school did your child have?
4. Did school communicate with you throughout your child's absence?

4a. If so, who contacted you, how and how often eg daily, weekly, monthly termly?

4b. Was this communication helpful for you?

5. Did any member of school staff visit you and your child in hospital or at home?

5a. If so, was this helpful?

5b. If not, would you have liked this to happen?

6. Did your child access home schooling during her time away from school?

6a. If so, who made this referral?

6b. How were you and school involved in communicating with her tutor?

7. Could the frequency or type of communication between you and school have been improved during your daughter's absence? If so, please explain how.
8. Were you made aware by hospital professionals of potential difficulties your child may experience as a result of his brain tumour/treatment and what kind of support she may need at school?

8a. If so, was this relayed to school prior to her return and by who?

Part 3: When your child returned to school

Questions:

1. When did your child return to school?
2. Had she completed treatment?
3. Did you meet with or communicate with school in preparation for your child's return to school?
4. If so, who did you meet with or speak to and what was discussed?

4a. Did you have an opportunity to meet with your child's TA prior to her returning to school?

5. How did you feel about your child returning to school?

5a. Did you get an opportunity to convey your thoughts and feelings about your child's return to school to members of school staff?

5b. If yes, how and was this helpful?

5c. If no, why not and would you have liked to?

6. What were your expectations of school upon your child's return to school?

7. How did your child feel about returning to school?

8. Were school staff aware of her thoughts and feelings about returning to school?

9. Did school staff meet with your daughter before she returned?

9a. If yes, please give details of this contact, what was discussed and if or how it helped her upon her return to school.

10. What did school do to support you and your child when she first returned to school?

11. Did school communicate with your daughter's classmates and their parents about why your child had been absent from school?

11a. If yes, was this helpful?

11b. If no, would you have liked this to happen?

12. What level of communication and collaboration did you have with school in order to identify and meet the initial needs of your child?

13. Did school undergo any training in connection with supporting a pupil with a brain tumour?

13a. If not, do you think this would have been helpful?

14.Do you think your daughter's initial transition back to school was successful?

14a.Please explain what areas worked well or could have been improved.

15. Did you get an opportunity to tell primary school staff about the journey you and your child have been on?

15a. If so, please explain how this was done.

15b. If no, would you have liked the opportunity?

Part 4: Transition to high school

1. How long had your daughter been back at school before she transitioned to high school?

2. Who did you communicate with at secondary school in order to prepare for your daughter's transition? How was this done? Eg email, face to face etc

3. Did you get an opportunity to communicate with all the members of school staff you wanted to?

4. Did you get an opportunity to share your journey with secondary school staff?

4a. If so at what point and how?

4b. If not, would this have been helpful?

5. How do you think sharing your narrative with school does or would work best?
6. Would you consider using any of the following in order to help tell your narrative to school staff?

- Video
- In person
- Advocacy
- Written account
- Use of photographs/pictures

7. How often would you like your story to be shared with school staff, as your child progresses through school?
8. How did you feel about your daughter transitioning to high school? Please explain.
9. Did you get an opportunity to share any thoughts/feeling/concerns with high school? Please explain.

Part 5: The level of support your child has needed since returning to school

1. Does your daughter experience any difficulties learning in the classroom, or any physical or social/behavioural difficulties that she did not have before treatment for a brain tumour? If so, please describe.
2. Does your child access TA support? If yes, please describe how many hours of support, how many TA's she has and what kind of support they provide in the classroom and around school.
3. Are there any differences in the range of support your daughter accessed at primary school and what she accesses at secondary school?
4. Have her needs changed over time? Please explain.
5. Do you and school work together to monitor her needs and progress? If so, how.
6. Does your daughter access social skills support at school? If so, please describe.

6a. If not, how is she coping socially at school?

7. Does your daughter access support for any behaviour related need, for example anger management support or self-esteem support?

7a. Do you and school work together to help support any social skills or behavioural needs of your daughter? If so, how?

8. Who do you communicate with to ensure she receives the right level of ongoing support at school?
9. Do you feel your contribution is welcome and valued in EHCP meetings?
10. How often do you have EHCP review meetings?

11. How do school communicate any changes in your child's needs or any progress she has made?
12. What do you think is working well for your child at school?
12a. Is there anything you think that isn't working well for her at school?
12b. How is this information shared between school and you?
13. To what extent do school help you make links with outside agencies to support you and your daughter?

Part 6: Your relationship with high school

Questions:

1. Who are the key staff in supporting your child at school?
2. Who are the key school staff in communicating with you?
3. Do school have an open-door policy when communicating with you? For example, are you encouraged to go into school or contact school outside of formal meetings, to discuss your daughter's needs and progress?
3a. If not, would this be helpful?
4. How often are you in contact with school?
4a. Is the frequency of contact enough? Please explain.
4b. Has the frequency of contact changed since your daughter started high school?
5. Is there any member of school staff you would like to be in contact with if you are not already?
6. To what extent do you feel communicating and engaging with school impacts your daughter's progress at school? Eg, academically, socially and emotionally?
7. What do you think makes an effective school and home partnership?
8. To what extent does trust pay a part in your relationship with school?
9. Is there anything that hasn't or doesn't work well with regards school/home communication and partnership in your experience? If yes, please explain.
10. Would you like to be further involved with school in order to help support your daughter's progress at school? If so, how?
11. How do you think your child feels about you working closely with school?
12. Do you think school should consider a brain tumour to be an acquired brain injury? Please explain.
13. Have secondary school staff accessed any training for supporting a student with a brain tumour?
14. If not, do you think they should**?**

Part 7: Looking to the future

Questions:

1. What are your hopes for your child as she progresses through school?

2. What are your hopes for your daughter in the future?

2a. Would you like these hopes to be included in the narrative you share with school?

3. What are your child’s hopes for the future?

3a. Should this be included in the narrative you share with school?

4. Do you, your daughter and school share in celebrating her successes?

4a. If so, how?

4b. If not, would you like this to happen?

5. If you could offer other parents of children with brain tumours advice about working in partnership with school, what would you say?

6. If you could offer school advice about working in partnership with parents of children with brain tumours what would it be?

7. Is there anything else you would like to add?

Thank you so much for your time and valuable contribution

Appendix 7 Questions as prompts for the semi-structured interview with secondary age child

1. What year are you in at school?

2. Can you remember how you felt when you first started high school? Eg nervous, excited, happy, etc.

3. Did you get to visit high school to help prepare for year 7?

4. Was this helpful?

5. Did you get to meet your TA at high school before you started year 7?

6. Do you have the same TA all the time at school?

7. What subjects/lessons do you enjoy most at school? Please say why?

8. What subjects/lessons do you enjoy least at school? Please say why?

9. What lessons do you think you are good at in school?

10 How do you think you learn best in lessons?

10a Prompt if needed for example, do you have TA support, do you prefer practical lessons, do you use any equipment such as a laptop, do you prefer it when the pace is slower and you have information repeated?

11 Is there anything you find more difficult in any lesson? Can you explain?

12. Do you get the chance to tell your parents and school what you find difficult?

13. If not, would you like the opportunity?

14. Do you have a key worker?

15. Who do you talk to at school if you have a problem?

16. Are you taken out of lessons for extra support in anything?

17. What makes you feel happy at school? Please explain.
18. What do you do at breaktime and lunchtime?
19. Do you take part in any lunchtime or after school clubs? If not, would like to?
20. Do you take part in any out of school clubs, or activities? Please explain
21. Which members of staff do you feel support you the most at school?
22. Is there anything that makes you feel unhappy at school?
23. You have an EHCP plan. Do you attend EHCP review meetings at school with your parents? If not, would you like to?
24. Does anyone help you at home with homework?
25. If you could tell school what you think would help you more, what would you say?
26. Do you get a chance to tell school and parents your thoughts and feelings about what is working or not working well for you at school?
27. Do school and home work together to support you at school?
28. Is it helpful for you when school and home work together?
29. Do you think they could work together more to help and support you? If so how? (prompt eg send work in advance)
30. Would you like to be included more when school and home work together? If so, how do you think they should include you more?
31. Is school important to you? Please explain your answer.
32. What would you like to do for a job when you leave school?
33. Do you know what your predicted levels are?
34. Do you have exam concessions?
35. Is there anything else you want to say about school and how they support you?

Appendix 8 Interview questions for secondary school SENDCO

Part 1: Background

1. What is your professional role?
2. How long have you been a SENDCO?
3. Do you do this role full time?
4. Do you have a specialism within SEN? Please explain
5. How much contact do you have with Y at school

Part 2: Brain Tumour Awareness

1. Is Y the first child you have supported with a brain tumour?
2. Have you or your staff accessed any level of CPD training focusing on working with a childhood brain tumour survivor and his/her parents?

2a. If so, was this before working with Y or during?

2b. Was the training helpful?

2c. If so, in what way?

3. If you didn't access training, do you think this would have been useful?

4. If you didn't access training, did you do your own research on childhood brain tumours and their effects?

5. Do you regard a brain tumour to be an acquired brain injury (ABI)?

5a. If so, why is this important?

6. Have you or your staff accessed any training focusing on supporting with students with an ABI, and working with their parents?

Part 3: School and parent partnership, policy and practice

1. Does your school have a home/school partnership policy?

1a. If so, how long has this policy been in place?

1b. Do you know if this policy is based on any academic home-school partnership frameworks?

1c. How often is the policy reviewed?

2. Do you offer staff training focusing on working in partnership with parents?

3. Do you consider your school has a positive attitude towards collaborating with parents?

4. What does your school do to encourage parental engagement with your school?

5. How does your school and parent partnership policy relate to working with parents of a child with a brain tumour?

6. Has working with parents of a child with a brain tumour prompted a need to amend or review the policy?

Part 4: Y's Transition from primary school

1. What level of communication did you have with primary school in preparation for Y's transition to high school?

2. Were you in contact with Y's parents before or during her transition? Please explain

3. When did you first meet Y?

4. Did Y have extra transition visits?

5. How did you identify Y's needs in order to inform the support she needed upon transition? Was this done in collaboration with Y and her parents?

6. Did you attend any of her previous EHC reviews at primary?

7. Did Y and her parents meet her TA's before transition?

8. Did you inform all staff about Y's needs?

8a. If so, how and at what point?

8b. Was this done in collaboration with Y's parents?

9. Did you tell Y’s peers anything about her brain tumour diagnosis?

10. How prepared did you feel about supporting Y upon her transition to your school?

11. Did you deliver any training to staff about working with Y and her family? Please explain.

12. Do you think knowing the narrative of the family’s journey has been helpful to you and your staff in supporting Y and her parents? Please explain.

12a How often do you think this narrative should be shared with school staff?

Part 5: Supporting Y and collaborating with parents

1. What support does Y need at school? (prompt if needed eg, support in the classroom, around school, social support?)

1a. Have her support needs changed over time?

1b. Do you communicate changes in need to home and staff?

2. What level of support did/do Y’s teachers and TA’s need in order to support X and to work with her parents?

3. How often do you communicate with Y’s parents?

4. How often do teachers communicate with Y’s parents?

5. How often do TA’s communicate with Y’s parents

6. Who has the most contact with Y and her parents?

7. Does Y have a key worker?

8. What members of staff are included in review meetings about Y?

8a. How often do you have review meetings?

9. To what extent do you value Y’s input and her parents input in review meetings?

10. Do you include Y in all review meetings?

11. How important is it maintaining a balance between supporting Y and encouraging independence?

12. Do you work collaboratively with any other agency in order to support Y at school and work with her family?

13. Have you referred Y or her family to other community agencies or peer support groups?

14. Do you have a consistent approach to supporting Y from home and school?

Part 6: Effective home/school partnership with Y’s parents

1. What do you think makes an effective home/school partnership when supporting a child with a brain tumour?

2. Do you feel you work in partnership with Y’s parents in order to support Y? Please explain.

3. Has your partnership with Y's parents changed since she started high school? Please explain?
4. How important is it to have an awareness of the emotional impact on parents of having a child diagnosed with a brain tumour?
5. Does this influence how you support Y and communicate with her parents?
6. How important is trust when working with the family of a student with a brain tumour?
7. To what extent do you think working in partnership with Y's parents impacts her learning?
8. Do you and Y's parents take part in joint celebrations about Y's progress?
9. What works well when working in collaboration with Y's parents?
10.What could be improved?
11. Do you have an open-door policy when working with Y's parents?
11a. If so, how does this work?
11b. Do you have an open-door policy with all parents of children with SEN?
12. What do you think is working well for Y at school?
13. What do you think could be improved for Y at school?
14. How do you communicate the above to Y's parents?
15. To what extent have you have improved your knowledge and understanding about working a childhood brain tumour survivor through supporting Y?
16. How important is it to you to keep improving your knowledge about brain tumours and how they can affect young people?

Part 7: Advice to others

1. If you could offer advice to other schools about working with parents of a brain tumour survivor, what would it be?
2. If you could offer advice to other families of a child diagnosed with a brain tumour, about working with school, what would it be?
3. What are your aspirations for Y as she progresses through school?
4. What are your aspirations for Y as she progresses through life?
5. What is the most important thing you have learnt about working in partnership with Y's parents?
6. Is there anything you feel would help you develop your practice in relation to supporting a child with a brain tumour and working in partnership with his/her parents?
7. Is there anything else you would like to add?

Thank you for your time and valuable contribution.

Appendix 9 Interview questions for assistant SENDCO (Secondary)

Part 1: Background

1. What is your professional role?

2. How long have you been in this role?

3. Do you do this role full time?

4. Do you have a specialism within SEN? Please explain

Part 2: Brain Tumour Awareness

1. Is Y the first child you have supported with a brain tumour?

2. Have you, TAs or teaching staff accessed any level of CPD training focusing on working with a childhood brain tumour survivor and his/her parents?

2a. If so, was this before working with Y or during?

2b. Was the training helpful?

2c. If so, in what way?

3. If you didn’t access training, do you think this would have been useful?

4. If you didn’t access training, did you do your own research on childhood brain tumours and their effects?

5. Do you regard a brain tumour to be an acquired brain injury (ABI)?

5a. If so, why is this important?

6. Have you, TAs or teaching staff accessed any training focusing on supporting with students with an ABI, and working with their parents?

Part 3: School and parent partnership, policy and practice

1. Does your school have a home/school partnership policy?

1a. If so, how long has this policy been in place?

1b. Do you know if this policy is based on any academic home-school partnership frameworks?

1c. How often is the policy reviewed?

2. Have you accessed staff training focusing on working in partnership with parents?

3. Do you consider your school has a positive attitude towards collaborating with parents?

4. What does your school do to encourage parental engagement with your school? (prompt if needed, eg, CPD training, meeting agendas, member of staff to champion parent partnerships, parent drop-in sessions, welcome environment?

5. How does your school and parent partnership policy relate to working with parents of a child with a brain tumour?

6. Has working with parents of a child with a brain tumour prompted a need to amend or review the policy?

Part 4: Y's transition from primary school

1. What level of communication did you have with primary school in preparation for Y's transition to high school?

2. Were you in contact with Y's parents before or during her transition? Please explain

3. When did you first meet Y?

4. Did X have extra transition visits?

4a. If yes, how did this help Y and her parents?

5. How did you identify Y's needs in order to inform the support she needed upon transition? Was this done in collaboration with Y and her parents?

5a. Was this done in collaboration with outside agencies or your school EP?

6. Did you attend any of her previous EHC reviews at primary?

7. Did X and her parents meet her TA's before transition?

8. Did you inform all staff about Y's needs?

8a. If so, how and at what point?

8b. Was this done in collaboration with Y's parents?

9. Did you tell Y's peers anything about her brain tumour diagnosis?

10. How prepared did you feel about supporting Y upon her transition to your school?

11. Did you deliver any training to staff about working with Y and her family? Please explain.

12. Do you think knowing the narrative of the family's journey has been helpful to you and your staff in supporting Y and his parents? Please explain.

12a. How often do you think this narrative should be shared with school staff?

13. How important is it to recognise the emotional impact on parents of having a child diagnosed with a brain tumour?

13a How important is it to recognise the emotional impact on a child of being diagnosed with a brain tumour?

14. Does this influence how you support Y and communicate with her parents?

Part 5: Supporting Y and collaborating with parents

1. Are you Y's key worker?

2. What does this involve?

3. How much contact do you have with Y at school?

4. How many TAs support Y?

5. What support does Y need at school? (prompt if needed eg, support in the classroom, around school, social support?)

5a. Have her support needs changed over time?

5b. Do you communicate changes in need to home and staff?

6. What level of support did/do Y's teachers and TA's need in order to support Y and to work with her parents?

7. How often do you communicate with Y's parents?

8. How often do teachers communicate with Y's parents?

9. How often do TA's communicate with Y's parents?

9a. Do TA's feedback to parents through you?

10. Who has the most contact with Y and her parents?

11. What members of staff are included in review meetings about Y?

11a. How often do you have review meetings?

12. To what extent do you value Y's input and her parents input in review meetings?

13. Do you include Y in all review meetings?

14. Do you provide updated information or reminders about Y to teachers? If so, how often?

15. How important is it maintaining a balance between supporting Y and encouraging independence?

16. Do you work collaboratively with any other agency in order to support Y at school and work with her family? (Prompt if needed) For example the EP, OT, SALT, hospital specialists?

17. Have you referred Y or her family to other community agencies or peer support groups?

18. Do you have a consistent approach to supporting Y from home and school?

Part 6: Effective home/school partnership with Y's parents

1. What do you think makes an effective home/school partnership when supporting a child with a brain tumour?

2. Do you feel you work in partnership with Y's parents in order to support Y? Please explain.

3. Has your partnership with Y's parents changed since she started high school? Please explain?

4. How important is trust when working with the family of a student with a brain tumour?

5. To what extent do you think working in partnership with Y's parents impacts her learning?

7. What works well when working in collaboration with Y's parents?

8. What could be improved?

9. Do you have an open-door policy when working with Y's parents?

9a. If so, how does this work?

9b. Do you have an open-door policy with all parents of children with SEN?

10. What do you think is working well for Y at school?

11. What do you think could be improved for Y at school?

12. How do you communicate the above to Y's parents?

13. To what extent have you have improved your knowledge and understanding about working a childhood brain tumour survivor through supporting Y?

14. How important is it to you to keep improving your knowledge about brain tumours and how they can affect young people?

Part 7: Advice to others

1. If you could offer advice to other schools about working with parents of a brain tumour survivor what would it be?
2. If you could offer advice to other families of a child diagnosed with a brain tumour, about working with school, what would it be?
3. What are your aspirations for Y as she progresses through school?
4. What are your aspirations for Y as she progresses through life?
5. What is the most important thing you have learnt about working in partnership with Y's parents?
6. Is there anything you feel would help you develop your practice in relation to supporting a child with a brain tumour and working in partnership with his/her parents?
7. Is there anything else you would like to add?

Thank you for your time and valuable contribution.

Appendix 10 Interview questions for TA (secondary)

Part 1: Background

1. What is your professional role?
2. How long have you been in this role?
3. How long have you supported Y?

3a. Did you support Y during her transition to year 7?

3b. If so, when did you first meet her parents?

4. Were you employed to specifically support Y or did you already work in your role at school?

4a. Do you support Y in any particular lesson or subject area?

4b. Will you support Y in each year group throughout secondary school?

Part 2: Brain tumour awareness and training

1. Is Y the first child you have supported with a brain tumour?

2. Have you accessed any level of CPD training focusing on working with a childhood brain tumour survivor and his/her parents?

2a. If so, was this before working with Y or during?

2b. Was the training helpful?

2c. If so, in what way?

3. If you didn't access training, do you think this would have been useful?

4. If you have accessed training, would updated training be helpful?

5. Do you regard a brain tumour to be an acquired brain injury (ABI)?

6. Have you accessed any training focusing on supporting students with an ABI, and working with their parents?

7. Have you accessed any staff training focusing on working in partnership with parents?

Part 3: Supporting Y and collaborating with her parents

1. Were you aware of Y and her family's brain tumour journey when you began working with her?

2. Do you think knowing the narrative of the family's journey has been helpful to you in supporting Y and working with her parents? Please explain.

2a. How often do you think this narrative should be shared with TA's and other school staff?

3. How prepared and confident did you feel about supporting Y when you first began working with her?

3a. Did you communicate with Y's parents to help you to understand Y's needs at school?

4. How do you support Y:

4a. In the classroom?

4b. Moving around school?

4c. Socially?

4d. Emotionally?

5. Does Y access any intervention?

6. Were/are you included in review meetings about Y?

7. How important is it to you to be involved in review school meetings about Y?

8. Has your level of confidence increased in connection with supporting Y, since you have been working with her? Please explain

8a. If so, what has helped your confidence grow? (prompt if needed, eg school support or communication with home?)

8b. Have your done any of your own research on supporting students with a brain tumour?

9. Does Y tell you what's working well for her at school or what's not working well?

9a. If so, who do you feed this back to? (prompt if needed, eg, school or home?)

10. Have Y's needs changed since you have been supporting her?

10a. Do you discuss any changing needs (including progress) with Y's parents?

10b. The deputy SENDCO or SENDCO?

10c. Other TA's who support Y?

10d. Y herself?

11. How and how often do you communicate with Y's parents?

12. How do you celebrate Y's progress?

12a. Do you share Y's progress with other staff and parents?

13. To what extent does communicating with Y's parents help you support Y at school?

14. To what extent do you value and welcome Y's parent's contributions?

15. Do you work with Y's teachers in planning the support of Y at school?

15a. If not, do you communicate with Y's teachers about the level of support she needs?

16. Do you work with any outside agency in supporting Y at school? (Prompt if needed, eg. OT, SALT etc.)

16a .If so, is this done in collaboration with the deputy SENDCO/SENDCO and Y's parents?

17. Do you think it helps Y make progress, by working closely with her parents? Please explain (prompt if needed eg academic progress, behaviour, social skills, emotional)

18. Is it important to have a consistent approach from you and home, when supporting Y at school? Please explain.

19. How important is it to maintain a balance between supporting Y and encouraging independence?

19a. Does working with Y's parents help you maintain a balance?

20. What is working well for Y at school?

21. What do you think could be improved for Y at school?

22. Do you feel you need any further support or training in order to support Y at school or to work with her parents?

22a If so, in what area/s?

Part 4: Effective home/school partnership

1. Do you feel you work in partnership with Y's parents in order to support Y? Please explain.

2. Has the level of your communication with Y’s parents changed since she started high school? Please explain.
3. How important is trust when working with the family of a pupil with a brain tumour?
4. To what extent has the school home-school agreement that’s in place at your school, guided your communication with the parents of Y?
5. What do you think works well when working in collaboration with Y’s parents?
6. What could be improved?
7. How important is it to understand the emotional impact on parents of having a child diagnosed with a brain tumour?

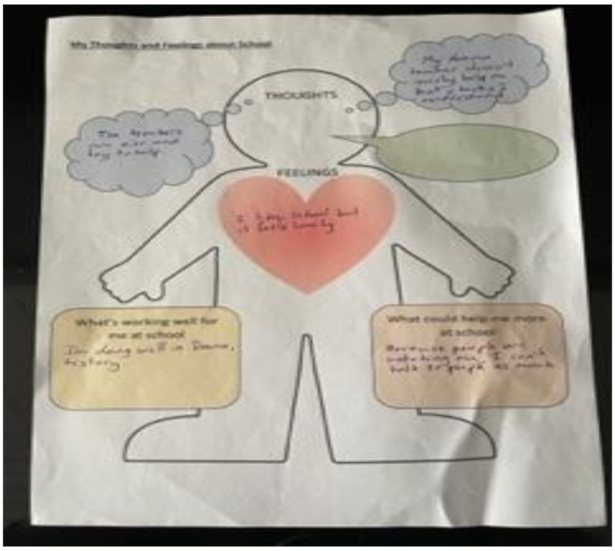
7a. Does this influence your relationship with Y and her parents?

Part 5: Advice to others

1. If you could offer advice to other TA’s and schools about working with parents of a brain tumour survivor, what would it be?
2. If you could offer advice to other families of a child diagnosed with a brain tumour, about working with TA’s and school, what would it be?
3. What are your aspirations for Y as she progresses through school?
4. What are your aspirations for Y as she progresses through life?
5. Is there anything else you would like to add?

Thank you for your time and valuable contribution.

Appendix 11: Role on the wall (Lucy)



Appendix 12: Example of second cycle codes and quotes:

1. Importance of early communication between parents and school when a child is diagnosed with a brain tumour and throughout the child's absence from school

Collated Second Cycle Codes	Quote Examples
Communication with headteacher upon diagnosis and importance of SENCO's involvement	*Mrs Y "We messaged the headteacher and I popped in to see her. Initially all my contacts were with the headteacher"*
Importance and value of communication between school and parents and child throughout child's treatment	*Mrs X "It was lovely because I knew they genuinely cared.*" *Mrs Y* "*The two school teachers organised the kids in the class to write to Lucy and her brother and we organised for Lucy and her brother, well Lucy wrote some stuff back. So that was very nice. Because Lucy at one point got a little email from everybody in her class."* *SENCO cs 1 said teacher "Regularly sent cards or pictures or photographs of something that they'd been doing in class. So hopefully he still felt part of the class and he knew he was going back into that same class and would see his friends*." *"We did regular emails with school just to update them of what the plans were. We'd share and celebrate when he'd gone through his surgeries and how well he'd come out of it Mrs X* SENCO cs 1 *"We had regular meetings before he actually returned to get some kind of transition plan in place so that he could obviously come back to school. But to make sure that school were well equipped and ready for his return."*
Importance of multi-agency meetings to help identify needs of CBTS	*Mrs Y (extra time assess) I don't think she would have got anything like the results that reflected what she was like in her intelligence if we hadn't had that extra time, it was really important* *SENCO cs 1 "Each agency had a really important role in making sure that transition was smooth but also that he was making progress back in school"* *SENCO cs2 "we know certainly from the work you've done at Levi's Star that's had a huge impact for us in terms of how the student learns and we've been able to share resources with*

	staff which has really helped them. And it has allowed the student to increase their independence in lessons."
CBTS were provided with school work during their absence from school	Mrs X *"even though he was getting school lessons in hospital school, I was still conscious that he still wanted to feel a little bit involved"* *"It was really helpful because it did give her a focus to do some bits of work actually when she was stuck at home and she was too poorly to go into school."* Mrs Y
Meetings increased in volume closer to return of CBTS	*"I was in and out of school, I can't even tell you how many meetings I had." Mrs X* *"We had regular meetings before he actually returned to get some kind of transition plan in place so that he could obviously come back to school. But to make sure that school were well equipped and ready for his return".* SENCO cs 1
Early MDT meetings identify child's needs and can contribute to EHCP application	*"His mother has been very keen to have as many external organisations in place to support the child at home and within school".* SENCO cs 1 Mrs X told the SENCO: "*I will do absolutely everything I can to help and support you to get that funding that you need, but you need to work with me as well. And in fairness they have*." Mrs Y *"The headteacher knew that Lucy would need some support so she just got on and employed somebody before the EHCP."* Mrs Y

Appendix 13: Reflexive diary content example

At the international brain tumour conference in the USA, Dr Scharle (2019) spoke about the importance of knowing the narrative when working with a brain tumour patient. It made me think about how using the narrative as part of school working with CBTS and parents. Attending a brain tumour symposium in the UK, Mr Ryan Mathew, Associate Professor and Honorary Consultant Neurosurgeon, spoke about using the narrative as part of a personal approach to working with brain tumour patients. These two presentations helped validate the importance of 'knowing the narrative' in my study. I wanted to include it not because it was just something I was personally interested in, but because it was an area recognised by international medical professionals working with children and adults with brain tumours.