



# Paediatric neuro-oncology rehabilitation in the UK: carer and provider perspectives

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## ABSTRACT

**Objective** The provision of rehabilitation services after childhood brain tumour has not been established, despite a recent parliamentary call for urgent action. This service evaluation aimed to determine what specialist paediatric neuro-oncology rehabilitation services were available across the UK at the time of the surveys and whether the needs of patients and their families were being met.

**Design** Cross-sectional on-line surveys.

**Participants** Survey 1: neuro-oncologist and nurse specialist members of the Children's Cancer and Leukaemia Group (CCLG) at Children's Principle Treatment Centres (PTCs) in the UK; Survey 2: parents of paediatric neuro-oncology patients belonging to The Brain Tumour Charity (TBTC) Research Involvement Network (RIN).

**Results** 17 of the 20 (85%) PTCs in the UK and two teenagers and young adult cancer units responded to Survey 1, and 17 members of TBTC's RIN responded to Survey 2. Access to inpatient and outpatient neuro-oncology rehabilitation services after treatment for a central nervous system (CNS) tumour varied across regions in the UK. Service users in the RIN identified a need for an established neuro-oncology rehabilitation service for young people, a need for better communication across services and with families, and a need to fill gaps in multidisciplinary teams.

**Conclusion** The urgent need for specialist paediatric, teenage and young adult neuro-oncology rehabilitation services in the UK is often unmet, particularly for outpatients. Where services are not provided for those children and young people disadvantaged by the diagnosis of a CNS tumour, in clear breach of current guidelines, remedial action needs to be taken to ensure appropriate and equal access.

## BACKGROUND

Central nervous system (CNS) tumours are the most common type of solid tumour to develop in children and young people, and every year around 400 newly diagnosed cases receive care at Children's Principle Treatment Centres (PTCs) in the UK, all of which belong to the UK Children's Cancer and Leukaemia Group (CCLG). The cumulative risk for a young person developing a brain tumour from birth until age 25 is

## What is known about the subject?

- Survivors of childhood central nervous system tumour are at significant risk of adverse 'late effects'; rehabilitation is therefore a key part of the journey to recovery.
- The provision of rehabilitation services after childhood brain tumour has not been specified by health-care purchasers, despite a recent parliamentary call for urgent action.
- The services currently provided and their perceived ability to meet the needs of affected families have not been assessed.

## What this study adds?

- Highlights an urgent need to establish equal access across the UK to a comprehensive neuro-oncology rehabilitation service for children, young people and their families.
- The first insight into the core needs of young people and their families from neuro-oncology rehabilitation services, barriers to accessing services and gaps in services.
- Recommendations for how to implement such service provisions.

1/980 (information from Public Health England), with brain tumours accounting for 20%–25% of all cancers in the first 25 years of life. This is undoubtedly a significant health risk for young people.

Across Europe, 5-year survival for all CNS tumours has been reported to be 65.4%.<sup>1</sup> Survivors of childhood CNS tumour are at significant risk of unwanted health-related effects including neurocognitive dysfunction, seizures, sensory and motor deficits, endocrinopathies and psychosocial difficulties.<sup>2–5</sup> Many of these effects arise or continue after completion of antitumour treatment and are then conventionally referred to as 'late effects'.<sup>6–8</sup> However, this does not acknowledge that 'brain effects'



are not necessarily 'late'. Rehabilitation is therefore an important part of the journey to recovery from immediately after the diagnosis of a CNS tumour.

Services for children and young people with cancer and CNS tumours are commissioned by NHS England and the devolved administrations in Wales, Scotland and Northern Ireland. There are 17 Children's PTCs in England and similar centres in Cardiff and Belfast. Scotland has a managed clinical network of four centres.<sup>9</sup> NHS England also commissions PTCs for Teenagers and Young Adults (TYAs) up to the age of 25.<sup>10</sup> The need for services to meet the specific needs of children with CNS tumours, including neuro-rehabilitation, was recognised in a 1997 report<sup>11</sup> and reinforced by The National Institute for Health and Care Excellence (NICE) 2005 guidelines on the commissioning of oncology services for young people in England and Wales. This recognised that, among cancer survivors, those diagnosed with CNS tumours experience the greatest needs due to the effects of the tumour and multimodal therapies.<sup>12</sup>

The 2005 NICE guidance has been reinforced in subsequent published guidelines recommending neuro-oncology rehabilitation for young people<sup>13 14</sup> and also in the November 2018 report of the All Party Parliamentary Group on Brain Tumours (<https://www.braintumourresearch.org/campaigning/inquiry>) 2018.<sup>15</sup> This report detailed the severe long-term consequences of brain tumours for children and young people and recommended that the Recovery Package, which is currently being rolled out across England, (be implemented) by 2020 and made available to all children and young people living with and beyond a brain tumour diagnosis ensuring inclusion of specific services, for example, neuro-rehabilitation.' (ibid.).

In spite of the existence of these guidelines, implementation of their recommendations nationally has not been assessed and there are no specific guidelines dedicated exclusively to rehabilitation of brain tumour survivors. More generally, the provision of a rehabilitation service after childhood brain tumour, including interdisciplinary working between paediatric oncology, paediatric neurology, nursing, therapy, psychology, dietetic, educational and social care providers, has not been specified by healthcare purchasers. This is in contrast to the national commissioning of neuro-rehabilitation services for children and young people surviving other types of brain injury. Links between those providing neuro-rehabilitation to these two groups of children and young people are often weak and sometimes absent.

This service evaluation therefore used surveys of service providers and service users to determine what specialist paediatric neuro-oncology rehabilitation services were available at the time of the surveys and what future research and changes in provision are required by service users and their families.

## METHODS

### Participants

Neuro-oncologist members of the CCLG and nurse specialists from all 20 PTCs and some TYA PTCs within the UK were sent invitations to participate in Survey 1 (see online supplementary appendix 1). Members of TBTC's Research Involvement Network (RIN), which consists of current and previous CNS tumour patients and their families, were involved in Survey 2 (see online supplementary appendix 2).

### DESIGN AND MEASURE

Both on-line surveys were designed for the purpose of this study with support from members of the CCLG's Neuro-oncology Special Interest Group and a paediatric neuro-rehabilitation nurse specialist at University Hospital Southampton NHS Foundation Trust. The surveys were administered by SurveyMonkey. Survey 1 'Neuro-oncology rehabilitation services survey - children and young people' included 20 items with a mixture of open-ended and closed questions asking for details about what neuro-oncology rehabilitation services their centre currently provided. All items were accompanied by an optional open response text box for elaboration of the response given. Survey 2 'Patients' and Families' Experiences Following Treatment for a CNS tumour in Childhood' consisted of 10 open-ended items and aimed to gather information about the RIN's views of current services and what research into the needs of survivors and changes in provision are required within the UK.

### PROCEDURE

In March 2017, an invitation to participate in Survey 1 was emailed from the CCLG co-ordinating office to members of the CCLG with a special interest in neuro-oncology at all 20 PTCs and some TYA PTCs in the UK. Respondents were asked to complete the survey themselves or pass it to another appropriate neuro-oncologist or specialist nurse in their centre, or complete it jointly, one survey per centre. Fortnightly reminders to complete the survey were sent to centres who had not yet participated. The survey was active for 12 weeks. In July 2017, TBTC's patient involvement and project officer emailed an invitation to TBTC's RIN to complete Survey 2. Fortnightly reminders to complete the survey were sent to members. The survey was active for 8 weeks.

### Analysis of surveys' items

The two surveys were analysed separately. Descriptive statistics were used to report the quantitative data, and the narrative content of the open-ended responses was summarised.

**Table 1** Occupation of respondent by the number of centres, which responded to the service evaluation survey

Occupation of centre respondent	Number (n=19)
Paediatric or adult neuro-oncologist	11
Lead or specialist nurses in neuro-oncology	5
Physiotherapist	3 (1 co-completed with a neuro-oncologist)
Occupational therapist	1
Paediatric psychologist	1 (co-completed with a neuro-oncologist)

## PATIENT AND PUBLIC INVOLVEMENT

Patients and the public were not involved in the design of or recruitment to this study. Health professionals helped to design both surveys, informed by their clinical work with survivors. They also helped with the planning for recruitment. Members of TBTC's RIN completed Survey 2, which gathered their views of current neuro-oncology rehabilitation services.

## RESULTS

### Survey 1: neuro-oncology rehabilitation services offered by Children's PTCs and TYA PTCs treated for CNS tumours

Seventeen of 20 (85%) PTCs and two TYA PTCs participated. Three PTCs and an unknown number of TYA PTCs did not respond to the invitation to participate. A response was also received from Dublin but was not included in this report as it is outwith the UK health

system. A range of healthcare professionals completed the survey (table 1).

Ninety five per cent of the surveyed centres reported that they had access to an inpatient and outpatient rehabilitation service for young people diagnosed with a CNS tumour (table 2). All types of rehabilitation services were reported by each centre as more available and accessible for inpatients than for outpatients. Physiotherapy and occupational therapy were the most available rehabilitation services for inpatients, and both of these services were reported as being easily accessible to inpatients in most centres. The least available rehabilitation services for inpatients were neuropsychology for cognitive testing and educational support (variable depending on geographical location but most likely provided by hospital education services and outreach by paediatric neuro-oncology nurse specialists). Nevertheless, access to these services was still reported by most centres as being moderately or easily accessible, respectively. Physiotherapy and psychology for emotional and behavioural support were reported to be the most available services for outpatients, although ease of access to these services was reported to be moderate and difficult, respectively. Speech and language therapy was reported as the least available rehabilitation service for outpatients.

Seventeen centres (89%) identified a variety of gaps and barriers in their access to neuro-oncology rehabilitation services. The comments provided as free text are grouped together below into five principal domains or themes: neuro-oncology rehabilitation services not being established at their centres, lack of communication about such services, lack of specific types of rehabilitation, barriers specifically to outpatients and absence of

**Table 2** Numbers of treatment centres (%) that confirmed each rehabilitation service to be accessible at their centre for children and young people diagnosed with a CNS tumour, with main level of accessibility to those services for inpatients and for outpatients in 2016

Rehabilitation	Inpatient services		Outpatient services	
	Number of centres able to access, n=19 (%)	Ease of access if available	Number of centres able to access, n=19 (%)	Ease of access if available
Physiotherapy	19 (100)	Easy	18 (95)	Moderate
Occupational therapy	19 (100)	Easy	16 (84)	Moderate
Speech and language therapy	18 (95)	Easy	13 (68)	Difficult
Neuropsychology for cognitive testing	16 (84)	Moderate	17 (89)	Difficult
Psychology for emotional and behavioural support	18 (95)	Moderate	18 (95)	Difficult
Endocrinology	18 (95)	Easy	16 (84)	Moderate
Ophthalmology	17 (89)	Easy	17 (89)	Moderate
Audiology	17 (89)	Easy	17 (89)	Easy
Educational support	16 (84)	Easy	14 (74)	Moderate
Other	5 (26)		3 (16)	
None	1 (5)		1 (5)	

CNS, central nervous system.

barriers (as two centres did not report any barriers to neuro-rehabilitation) (table 3).

### Survey 2: potential needs of patients and families for neuro-oncology rehabilitation services

Eighteen members of TBTC's RIN responded to Survey 2. Every respondent was a parent or carer of a young person who had been treated for a CNS tumour and their responses related to the care their child had experienced in 14 different PTCs in the UK. There were no responses to the survey from children or young people who had themselves been treated for a CNS tumour.

It is clear from the free text responses of parents that there were strongly held views that the neuro-rehabilitation of their children with brain tumours had not been met as reported in full in table 4. Seven survey respondents (39%) stated that a good level of communication between health professionals and families post-treatment for a CNS tumour was fundamental. Survey respondents reported a need for clear guidance about how the patients and their families can manage at home once discharged from hospital; a need for more detailed information about the different CNS tumour treatments and their consequences; and a need for an established point of contact at which families could obtain advice once discharged from hospital. Fourteen (78%) survey respondents reported four disciplines within the multi-disciplinary team to be the core rehabilitative resources needed after treatment for a CNS tumour: physiotherapy, occupational therapy, speech and language therapy, and clinical psychology for emotional and behavioural support. The first three of these were needs of the patient themselves, whereas the last of these was a need of both the patient and their families.

Five (29%) survey respondents also recommended changes to the way rehabilitation services are managed and operated. Respondents expressed their need for neuro-oncology rehabilitation services to be more locally available to patients' homes and that the different rehabilitation services need to collaborate better across young peoples' rehabilitative journey following treatment for a CNS tumour. Respondents recognised that more financial investment was needed in neuro-oncology rehabilitation services to improve patients' experiences of them.

## DISCUSSION

This study has provided the first insight into the available paediatric neuro-oncology rehabilitation services in the UK. It identified the core needs that patients and their families have with respect to these services, a range of barriers to accessing services and gaps in services. The lack of an established system for rehabilitation of children and young people in the UK after treatment for a CNS tumour was the barrier most often cited by clinicians (Survey 1) and was also prominent in the responses by service users (Survey 2). Services also appeared to be generally

more available for inpatients than for outpatients, while access to types of support service (eg, psychosocial, cognitive) varied across treatment centres, thus creating inequality of access to rehabilitation services. For outpatient services, speech and language therapy was the most difficult to access.

Issues identified in both surveys include disparate resources allocated to neuro-oncology rehabilitation services compared with the resources allocated to anti-tumour treatments; a lack of outpatient rehabilitation services to support the developing child throughout his/her growing years; and the need for access to a comprehensive paediatric neuro-rehabilitation service. The fact that these issues emerge from both surveys suggests that the identified barriers and gaps result in a failure to meet the rehabilitation needs of these children and young people and their families. It is also particularly notable that parents wanted services to be provided more locally as outpatients. One interesting discrepancy between the surveys was the identification of limited or absent access to neuro-psychology as a problem by care providers in several centres but not by the parents of brain tumour survivors, whereas the need for clinical psychology support was apparent in responses from both these groups. This may simply reflect lack of awareness among service users of the distinction between these two types of psychological services.

The main strengths of this study were its high response rate, with 17 of 20 PTCs providing information and its inclusion of the perspectives of both care providers and service users. The findings are therefore likely to be reliable and generalisable to paediatric neuro-oncology services across the UK. A limitation of the study was that the responders in the RIN were all parents of brain tumour survivors. The perspective of the survivors themselves was therefore not represented, and the sample of parents who responded to the survey was a group who were motivated to join TBTC's RIN and who were able to receive and respond to an on-line questionnaire. Although the individual responses remain valid, as a group they may not be representative of all children and their parents affected by brain tumours. It is unknown whether there were survivors themselves as members of the RIN at the time of the survey, who could have taken part. As well as this, only two TYA PTCs provided responses to the survey. Additionally, the cross-sectional survey design of the study limits the conclusions that can be drawn from the results. It was not possible to validate the responses from the individual centres, and therefore, the availability of services may have been under-reported or over-reported in some cases. However, the survey was anonymous so there was no incentive to do either. A prospective investigation of provision of services, obtaining feedback from both parents and patients, would validate the results we obtained. A way of achieving this might be to include time to provision of services as an outcome measure at peer review.

**Table 3** Views of providers of neuro-oncology services (responses to Survey 1) in 19 UK Children's Cancer Treatment Centres on neuro-rehabilitation services for children with brain tumours

Type of barrier or gap	Number of centres identifying barrier/lack n=19 (%)	Quotations
Lack of establishment of neuro-oncology rehabilitation services and dedicated space and resources	11 (58)	<p>'Lack of dedicated beds for Neuro-rehabilitation' (Centre 3)</p> <p>'Availability of beds' (Centre 4)</p> <p>'There are not any designated neuro rehabilitation beds within the centre and no neuro rehabilitation tariff for these patients.' (Centre 5)</p> <p>'accessibility of beds/slots for rehab' (Centre 12)</p> <p>'Lack of dedicated beds for Neuro-rehabilitation' (Centre 3)</p> <p>'No dedicated neuro-rehab team in paediatric neuro-oncology and at present neuro-oncology rehab is separate from non-oncological neuro-rehab.' (Centre 13)</p> <p>'service only developed early 2016' (Centre 15)</p> <p>'Staffing and timing; prioritizing acute patient care and discharge above rehabilitation. No dedicated Neuro-oncology rehabilitation team' (Centre 16)</p> <p>'There is not a clearly defined single point of contact for a neuro rehabilitation MDT/service' (Centre 17)</p> <p>'Capacity of therapies facilities, although this will be improved following relocation to a new site next year. Can be barriers for patients from areas elsewhere (neuro-oncology in (PTC name) covers the whole of (region of PTC)).' (Centre 9)</p> <p>'bed numbers on rehabilitation ward.' (Centre 14)</p> <p>'Expertise, specialist equipment. availability of beds. Commissioning' (Centre 4)</p> <p>'Resources and funding' (Centre 8)</p> <p>'specialised equipment, inpatient beds and time, limited staff, community very limited resources. Time delay between inpatient and outpatient services impacts on children's rehab. Inequality across region.' (Centre 8)</p>
Lack of communication with other departments and services	5 (26)	<p>'referral pathways and commissioning unclear' (Centre 4)</p> <p>'local services refusing to support patients with complex needs.' (Centre 4)</p> <p>'time constraints related to clinical deterioration' (Centre 12)</p> <p>'Follow -up during and after treatment' (Centre 16)</p> <p>'communication between centres' (Centre 12)</p> <p>'Poor co-ordination of services in the community.' (Centre 13)</p>
Lack of individual components of the multidisciplinary team	8 (42)	<p>'Limited therapy time dedicated to neuro onc' (Centre 10)</p> <p>'Lack of local SALT and educational rehab.' (Centre 1)</p> <p>'Provision of SALT' (Centre 7)</p> <p>'No dedicated SALT' (Centre 10)</p> <p>'Lack of speech and language support.' (Centre 13)</p> <p>'speech therapy in particular.' (Centre 14)</p> <p>'educational support, SALT' (Centre 1).</p> <p>'SALT - fulltime equivalent required' (Centre 7)</p> <p>'Lack of speech and language support.' (Centre 13)</p> <p>'No on site neuro-psychology but we have a business case in progress for one.' (Centre 1)</p> <p>'Service demands - particularly neuropsych assessment and supportive psychology.' (Centre 6)</p> <p>'Lack CAMHS/tertiary psychiatry' (Centre 10)</p> <p>'Neuropsychology' (Centre 1)</p> <p>'Neuro-psych assessment Psychology support.' (Centre 6)</p> <p>'Neuro-psychology' (Centre 8).</p> <p>'Neuro-psychology/psychology - stretched services' (Centre 18)</p> <p>'reduced staffing for occupational therapy' (Centre 14)</p> <p>'Difficulty in accessing on site dietitians due to low numbers of staff.' (Centre 1)</p> <p>'Dietetics' (Centre 1)</p>

Continued

Table 3 Continued

Type of barrier or gap	Number of centres identifying barrier/lack n=19 (%)	Quotations
Outpatient-specific barriers	8 (42)	<p>'Need to be in-patient for formal neuro-rehab - haven't got a developed out-patient neuro-rehab service.' (Centre 6)</p> <p>'Availability of outpatient rehabilitation is limited.' (Centre 13)</p> <p>'Patients access community based services during follow up however there are variable issues with waiting time and intensity of treatment that patients need' (Centre 10)</p> <p>'Out-patient therapy' (Centre 10)</p> <p>'When patients are discharged - some difficulties with patients accessing local services' (Centre 2)</p> <p>'Deficit of outpatient rehab service.' (Centre 13)</p> <p>'patients have to remain admitted for longer since no local services could offer supportive therapies frequently enough' (Centre 15)</p> <p>'Longer term/ongoing or newly arising rehab problems - sometimes difficult to re-access support/rehab services.' (Centre 17)</p> <p>'Medium to long term rehabilitation' (Centre 18)</p> <p>'gaps between inpatient and outpatients, that is, access is good while inpatient but once an outpatient access is slow and not a proactive service, the OP service is reactive.' (Centre 12)</p>
Absence of barriers	3 (16)	<p>'None' (Centre 2)</p> <p>'Nil' (Centre 19)</p> <p>'No major gaps' (Centre 9)</p> <p>'We don't have any gaps in the rehab services' (Centre 19)</p>

. CAMHS, child and adolescent mental health services; PTC, Principle Treatment Centres; SALT, speech and language therapy.

### Implications for service provision

The provision of a paediatric neuro-oncology rehabilitation service has been the standard of care expected since the publication of the 2005 NICE guidelines on the commissioning of oncology services for young people.<sup>12</sup> These guidelines contain the following recommendations:

- ▶ Clear and agreed routes of referral for rehabilitation services across children's cancer networks including the community setting.
- ▶ All children with CNS malignancy should have access to a neuro-rehabilitation service during treatment and for years following treatment.
- ▶ Cancer networks should liaise with other National Health Service Trusts, local health boards and agencies to establish rehabilitation strategies for psychosocial support and communication with educational services.
- ▶ All children with cancer and their families are offered psychological support with clear routes of referral in PTCs and other treatment settings, including during long-term follow-up.
- ▶ An appropriate keyworker is assigned to all patients on long-term follow-up.

Similarly, the All Party Parliamentary Group on Brain Tumours 2018 report recommended that 'all children and young people living with and beyond a brain tumour diagnosis' be offered 'specific services, for example neuro-rehabilitation', by 2020.<sup>10</sup>

The deficiencies apparent from these surveys highlight an urgent need to establish equal access across the UK to a comprehensive neuro-oncology rehabilitation service for children and young people who are survivors of CNS tumours, whether inpatients or outpatients. Services that are currently lacking should be put in place to provide access and equality of access to the children and young people who require them.

Neuro-rehabilitation services for children with other types of acquired brain injury have also been historically patchy in the UK but are now commissioned as regional specialised inpatient and outpatient services for acquired neurological injury. A comprehensive paediatric neuro-rehabilitation service is necessarily interdisciplinary and its elements are specified in the NHS Standard Contract for Paediatric Neurorehabilitation.<sup>16</sup> Brain tumours are included in the case of need made within that standard contract (ibid. p.2). Its component parts include physio-, occupational, speech and language, and play therapies, clinical and neuro-psychology, dietetics, neurology/neurorehabilitation, the hospital education service, access to neuropsychiatry and child and adolescent mental health services (CAMHS), and close liaison with local paediatric neuro-disability services. Although likely to be a cost-effective solution where available, the benefits of linking paediatric neuro-rehabilitation following childhood tumours of the CNS with other paediatric neuro-rehabilitation services will depend on the ways in which the various regional and local specialist services

**Table 4** Parents' views (responses to survey 2) of the neuro-rehabilitation health needs of children and young people diagnosed with a brain tumour

Needs	Number of respondents expressing need, n=18 (%)	Quotations
Good communication between healthcare professionals and families	7 (39)	<p>'The lack of communication, it feels very isolating.' (Respondent 12)</p> <p>'...day/care) access with knowledge and skills.' (Respondent 16)</p> <p>'More help on understanding on what to do after all treatments are finished.' (Respondent 6)</p> <p>'further info when leaving hospital. I was just told to check nhs website.' (Respondent 10)</p> <p>'Communication about what is happening and why it is happening.' (Respondent 2)</p> <p>'More information on posterior fossa syndrome' (Respondent 18)</p> <p>'More information about side effects of chemo- we are given a sheet detailing all possible side effects but that was as alarming as it was informative.' (Respondent 2)</p> <p>'People should not be sent to home from hospital with a 10 year old after emergency brain surgery and not even have a contact phone number.' (Respondent 5)</p>
Specific rehabilitation services	14 (78)	<p>'Support for children and parents' (Respondent 5)</p> <p>'rehabilitation programme and psychological/social help' (Respondent 16)</p> <p>'Besides treatment for the tumour itself, psychological help has been the most important for us' (Respondent 15)</p> <p>'better support for parents and carers in dealing with changes and more psychological help' (Respondent 14)</p> <p>'For us all aspects. Desperately needed learning support, physiotherapy, psychological support, OT input for physical support' (Respondent 7)</p> <p>'Psychological help on accepting what you have been through, how to move forward and having help to understand the changes brain damage has caused.' (Respondent 6)</p> <p>'Ot and physio, speech, counselling if need be' (Respondent 10)</p> <p>'That professionals are experienced with the condition. Understanding, empathy and consistent interventions to meet their needs. Prompt referrals for mental wellbeing. Support for the child and the family.' (Respondent 1)</p> <p>'more support after care in dealing with what's just happened and support adjust to try to go back to normality' (Respondent 14)</p> <p>'How can we stop CNS tumours affecting our children's behaviour and mood.' (Respondent 11)</p> <p>'mood swings...' (Respondent 10)</p> <p>'What support is available for social inclusion?' (Respondent 7)</p> <p>'Counselling should be offered to parents as well as children. I suffer from ptsd now as a result of watching helplessly as my daughter fought for her life. It has a debilitating effect on all of the family' (Respondent 17)</p> <p>'Physio, OT... straight away' (Respondent 18)</p> <p>'Physiotherapist' (Respondent 13)</p> <p>'Help groups, social worker, practical support.' (Respondent 7)</p> <p>'Access to physio as an outpatient needs improving.' (Respondent 2)</p>
Better organisation and management of rehabilitation services	5 (29)	<p>'more specialist rehab locally for acquired brain injury from surgery...' (Respondent 16)</p> <p>'nhs services away from (name of PTC) have been a struggle for us in our area' (Respondent 4)</p> <p>'services need to be better joined up and look at the future needs of these kids, not just at getting them to survive. What's the point of surviving a CNS tumour if the child/young person has no life.' (Respondent 11)</p> <p>'More investment in rehab could dramatically alter the long term disability of a child. If more resources at this stage more recovery equals better standard of life and less long term support from NHS for rest of their lives. Cheaper in long term...' (Respondent 9)</p> <p>'Plus all the recent budget cuts to services has meant very little intervention.' (Respondent 1)</p>

CNS, central nervous system; PTC, Principle Treatment Centres.



are deployed in each region. The need to consider this possibility applies to all PTCs in the UK.

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