

10 – Acute Hospital Care

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Study Advisory Group question: *On admission to hospital, are children and young people with a cerebral palsy being seen in a timely manner and by the correct specialties. Where there are complex needs are opportunities used to enquire about all aspects of the multidisciplinary care pathway?*

Why is this important? *In an acute admission it is important that all the needs of the patient with a cerebral palsy are met.*

This chapter briefly reviews the pathway of care for patients with a cerebral palsy admitted to acute general hospitals and the opportunities for joint working with neurodisability teams. Patients with a cerebral palsy are relatively frequent attendees of acute general hospitals and this is supported by the routine national data findings presented in this chapter and by other

published work.^{31,43} Children, young people and young adults with a cerebral palsy were identified in this study based on an admission some of which were on a day stay basis.

Approximately two thirds of admissions were emergencies (including urgent) and 23.4% were seriously ill (75/321) which was replicated in the routine national data. The remainder of the sample were planned and usually (135/164) underwent a procedure or surgery and this patient group is discussed in chapter **11**

Whilst it is known that patients with a higher level of motor disability (based on GMFCS level) are more likely to require hospital care⁴⁴ GMFCS level was very poorly recorded in the study population as shown in chapter **8**

Routine national data

The proportion of hospital admissions for children and young people with a cerebral palsy followed the same pattern across

the age groups for each of the four countries (Figure 10.1). Within each age group the proportion of these admissions was greatest for Northern Ireland (with the exception of 20-24 year olds) and lowest for Wales. When assessing

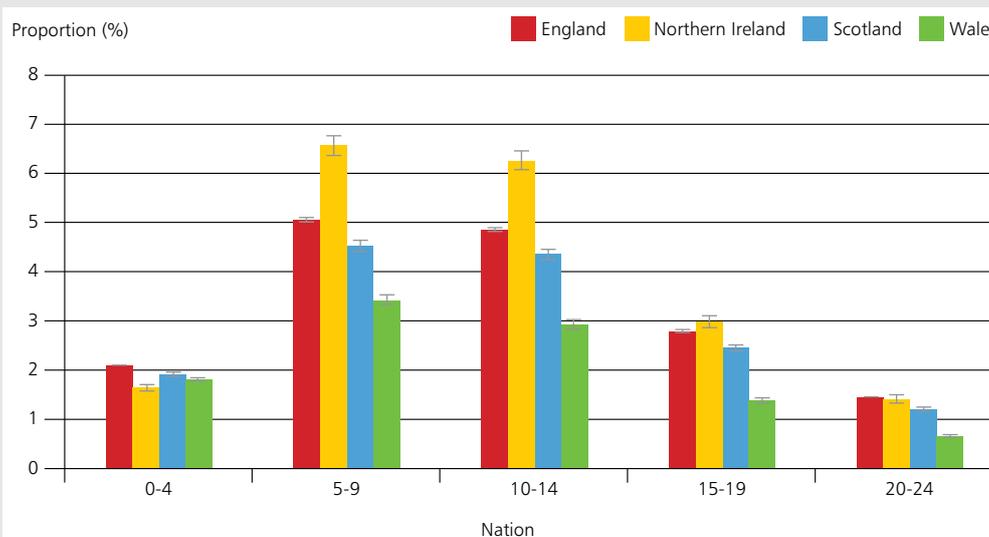


Figure 10.1 Proportion of total hospital admissions for children and young people with a recorded diagnosis of a cerebral palsy for England, Wales, Northern Ireland and Scotland by age group between 2004-2014. (HES, PAS, SMR01, PEDW)

these results the reader should bear in mind the previous finding of a lower prevalence of cerebral palsy in linked datasets from Wales (2.8/1000) than in England (3.5/1000) and the fact that it was not possible to estimate population prevalence figures for Scotland or Northern Ireland.

For children and young people in England, the rate of hospital admissions for children and young people with one of the cerebral palsies (Figure 10.2) was significantly greater than for children and young people without one of the cerebral palsies (Figure 10.3) for all age groups.

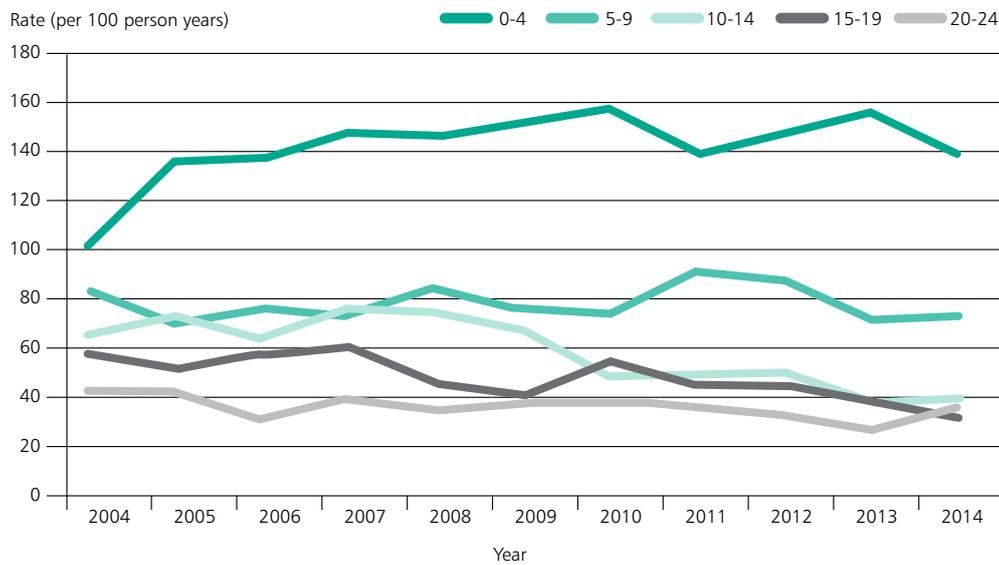


Figure 10.2 Rate of hospital admissions for children and young people with a cerebral palsy by age group and year (CPRD: England HES Linked)

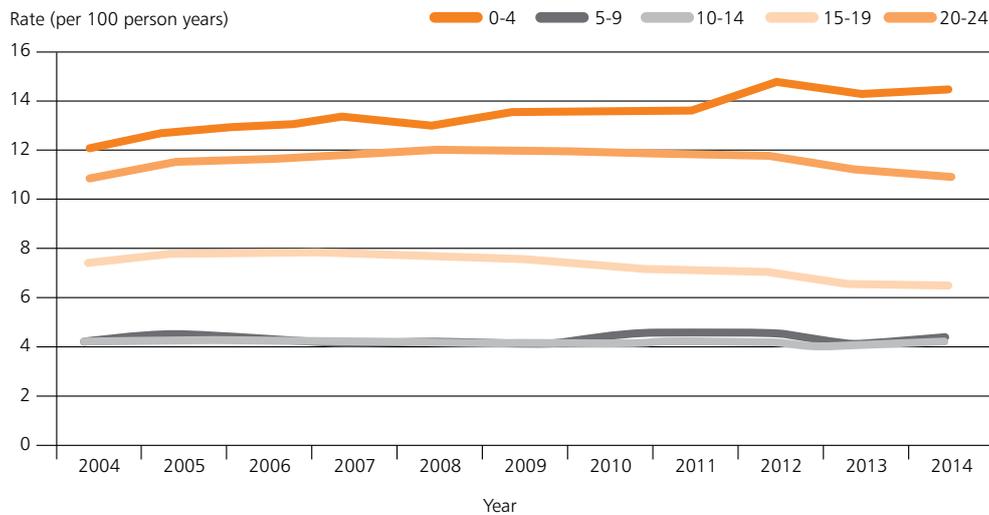


Figure 10.3 Rate (per 100 person years at risk) of hospital admissions for children and young people without a cerebral palsy (with at least one admission) by age and year (CPRD: England HES Linked)

The rate was greatest for those aged 0-4 years and decreased across the age groups. By contrast the rate of hospital admissions was greatest for age groups 0-4 years and 20-24 years for those without a cerebral palsy. Overall the rate of hospital admissions were more than ten times greater for 0-4 year olds and more than three times greater for 20-24 year olds with a cerebral palsy than for those without.

In Wales (PEDW) the hospital admission rate remained constant between 2004 -2014 at an estimated 55 per 100 person years at risk for children and young people with one of the cerebral palsies and at 10 per 100 person years at risk for those without.

The median number and IQR of annual admissions for the two populations across all age groups was less than one admission per year as the majority of children in both groups were not admitted to hospital on an annual basis, with the exception of 0-4 year olds where 50% of children with a cerebral palsy had one or more admissions per year.

Whilst the rate of hospital admissions for children without a cerebral palsy increased with social deprivation, there was no clear relationship between social deprivation and hospital admissions for children and young people with a cerebral palsy (Figure 10.4).

Children and young people with a cerebral palsy had longer hospital stays than those without a cerebral palsy across all age groups. Whilst the rate of hospital admissions decreased across the older age groups for young people with a cerebral palsy, the length of stay increased in the older age groups (Figure 10.5).

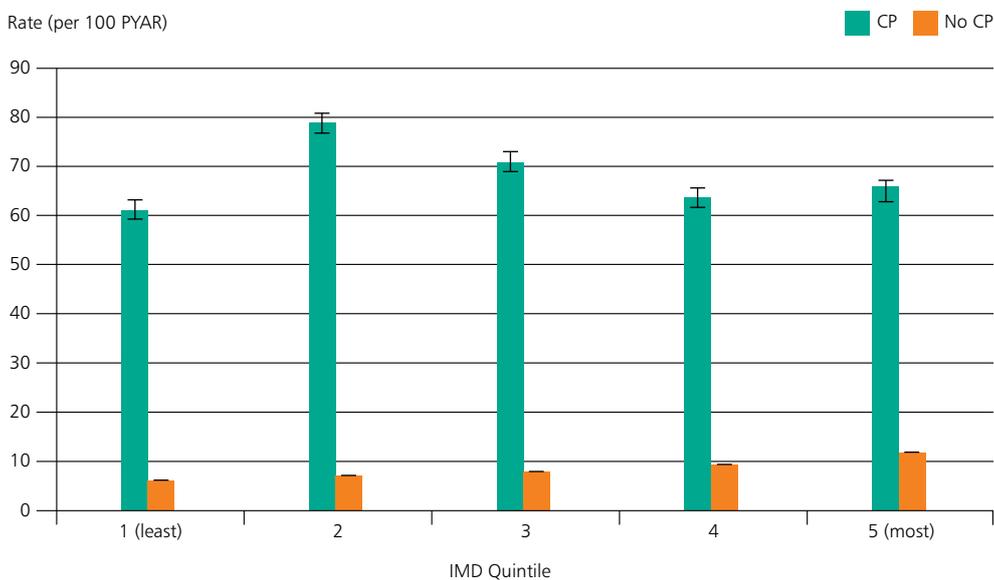


Figure 10.4 Rate of hospital admissions per 100 child years for children and young people with and without a cerebral palsy by IMD quintile (CPRD: England HES Linked)

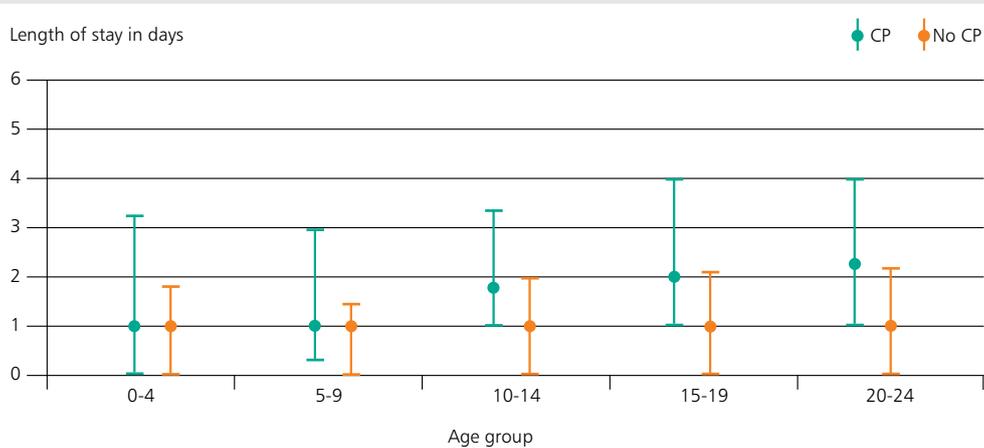


Figure 10.5 Median (IQR) length of stay (in days) of hospital admissions between 2004-2014 for children and young people with and without a cerebral palsy by age group (HES England; NHS Digital)

The rates of day case admissions were significantly greater for children and young people with a cerebral palsy (Figure 10.6) than for those without (Figure 10.7). The rate decreased with age. The rate ratio between those with

cerebral palsy and those without decreased as the age groups increased (Overall rate ratio for hospital admissions for those aged 0-4 years old was 15 vs. 4 for those 20-24 years old).

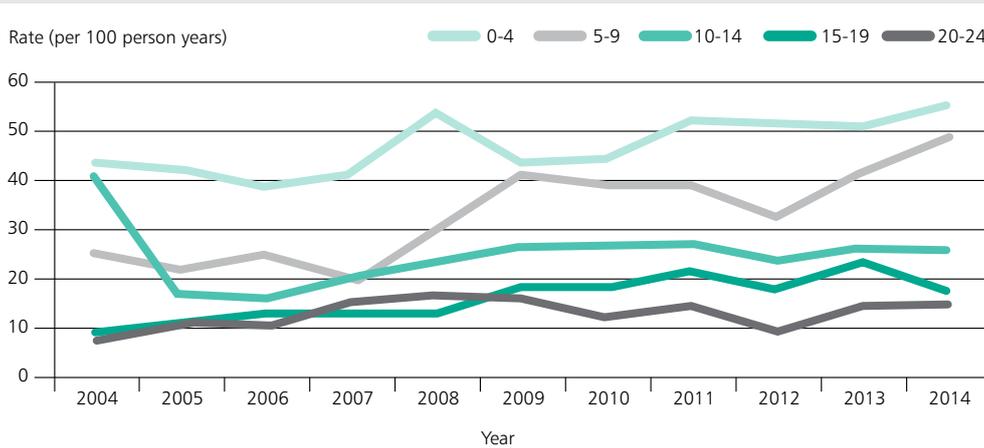


Figure 10.6 Rate of day case admissions per 100 person years at risk by age for children and young people with one of the cerebral palsies between 2004 – 2014 by year and age group (CPRD: England HES Linked)

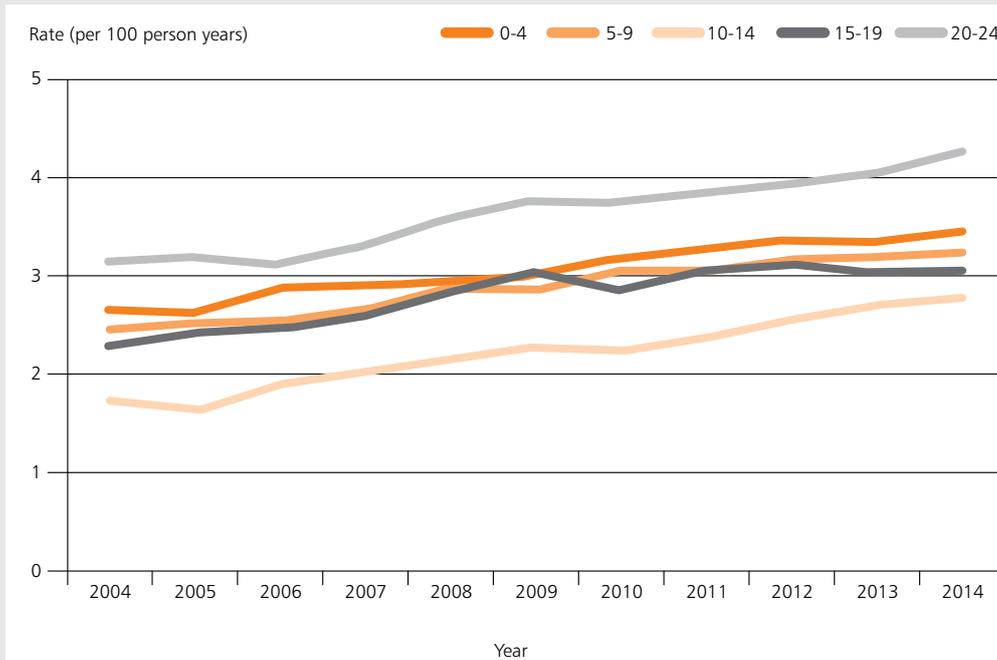


Figure 10.7 Rate of day case admissions per 100 person years at risk by age for children and young people without one of the cerebral palsies between 2004 – 2014 by year and age group (CPRD: England HES Linked)

The specialities that were mostly involved in day case admissions were neurological, trauma and orthopaedics and paediatrics. By contrast for children and young people without cerebral palsies, dental, ENT, genitourinary and surgery prevailed (Figure 10.8). The pattern of specialities most commonly involved for children and young people with the cerebral palsies may well reflect day case admissions for clinical interventions such as botulinum toxin etc. As seen in the outpatient data there was an under representation of dental specialities for those with a cerebral palsy.

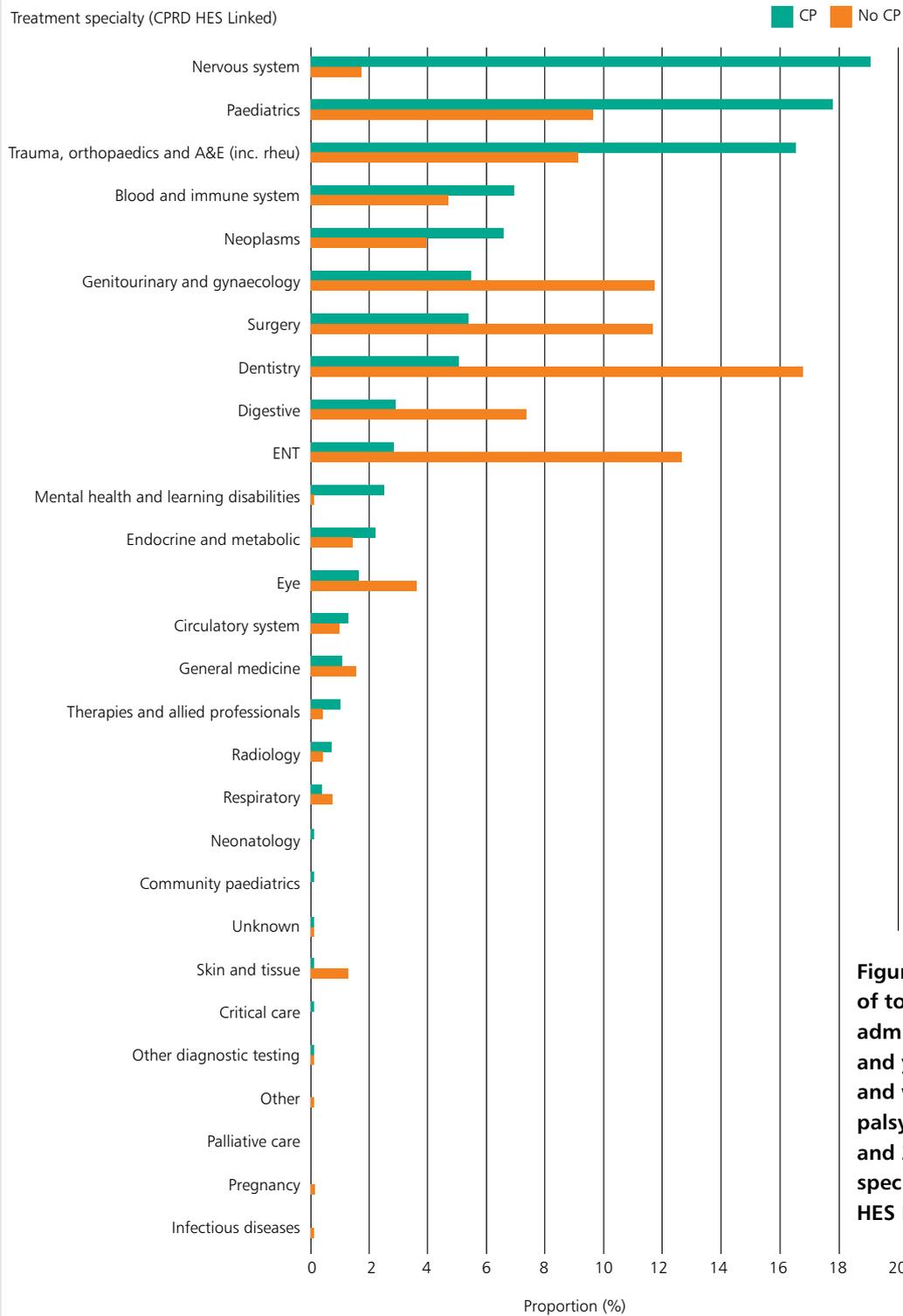


Figure 10.8 Proportion of total day case admissions for children and young people with and without a cerebral palsy between 2010 and 2014 by treatment specialty (CPRD: England HES Linked)

Overall, the proportion of elective admissions within NHS Digital HES APC data recorded (42.9% (95% CI: 42.7-43.1%)) was significantly greater for children and young people with a cerebral palsy than for those without (16.8% (95% CI; 16.7-16.8)), and decreased between 2004 and 2010 for both groups (Figure 10.9).

The same trend of admissions was seen in Wales (PEDW), Scotland and Northern Ireland. Elective admissions accounted for 56.9% of admissions for children and young people with cerebral palsy vs. 15.3% for those without in Northern Ireland, 25.9% vs. 11.6% for Wales and for the period 2008-2014 the proportion with elective admissions was 43.7% for those with a cerebral palsy vs. 20.6% for those without, in Scotland.

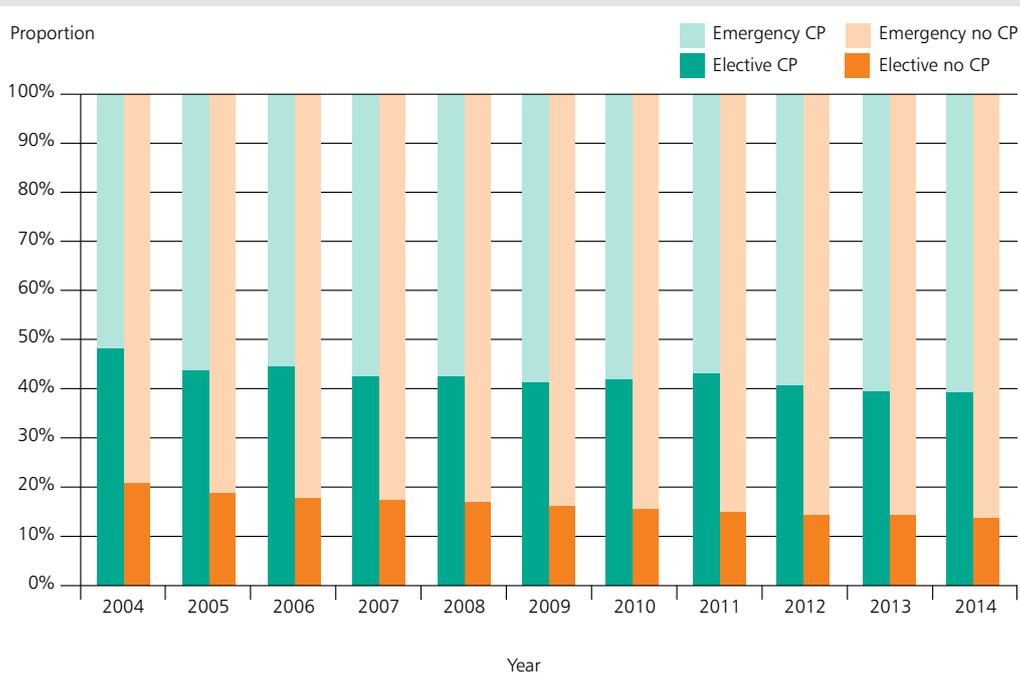


Figure 10.9 Proportion of emergency and elective hospital admissions for children and young people with and without cerebral palsies 2004-2014 (HES England: NHS digital, 4N person spell) (maternity admissions excluded)

The three most common primary diagnostic categories for elective admissions were neurological, mental health and behavioural and musculoskeletal concerns for children and young people with one of the cerebral palsies (Figure 10.10). For emergency admissions these were respiratory, neurological, external causes and injury and poisoning (Figure 10.11).

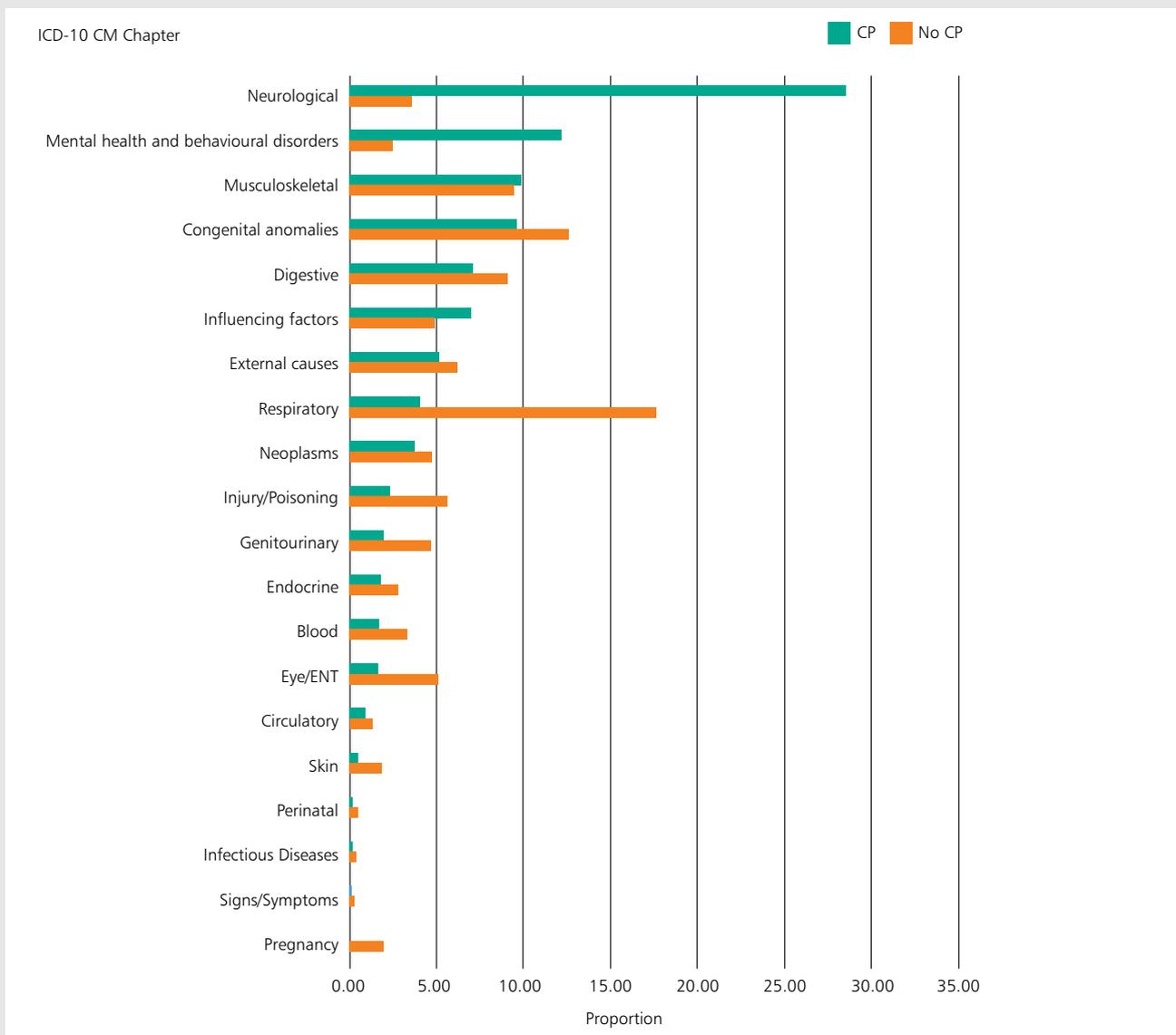


Figure 10.10 Proportion of elective hospital admissions according to primary diagnosis for children and young people with and without a cerebral palsy by ICD-10 Chapter (cerebral palsy n=102,682; No cerebral palsy n=2,092,957) (HES England: NHS Digital, 4N person spell)

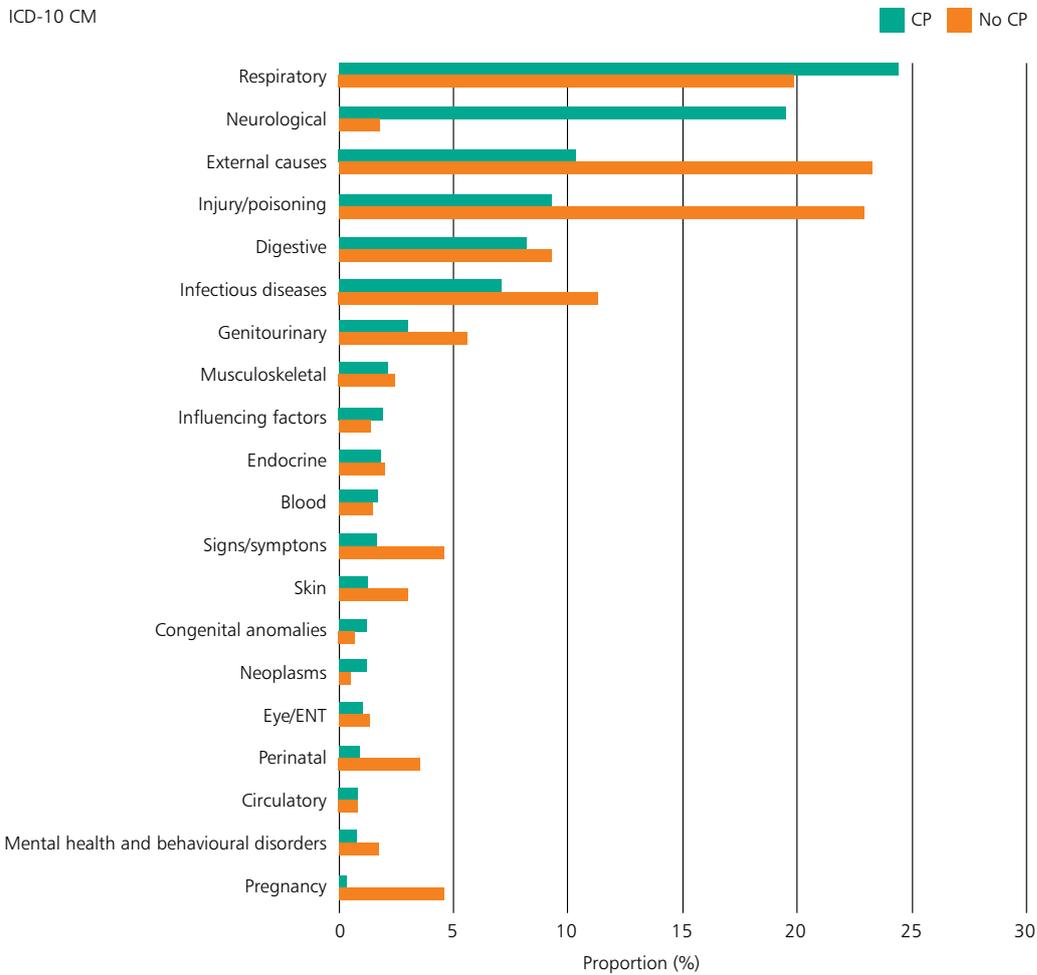


Figure 10.11 Proportion of emergency hospital admissions according to diagnosis for children and young people with and without a cerebral palsy by ICD-10 CM Chapter (cerebral palsy n=175,438; no cerebral palsy n=9,579,888) (HES England: NHS Digital, 4N person spell)

The data in Figure 10.12 includes all procedures performed at any time during the study period regardless of procedure position and regardless of the type of hospital admission (ordinary, day case etc.). The rate of procedures within the total study period for children and young people with a cerebral palsy was 231 per 100 person years at risk and the rate for those without a cerebral palsy was 23 per 100 person years at risk.

Whilst the proportion of operative, diagnostic, neurological and upper digestive tract procedures for children and young people with a cerebral palsy greatly exceeded that for those without the condition, the proportion of dental (mouth), dermatological, ear nose and throat procedures were amongst those that were lower for the cerebral palsy population. **11**

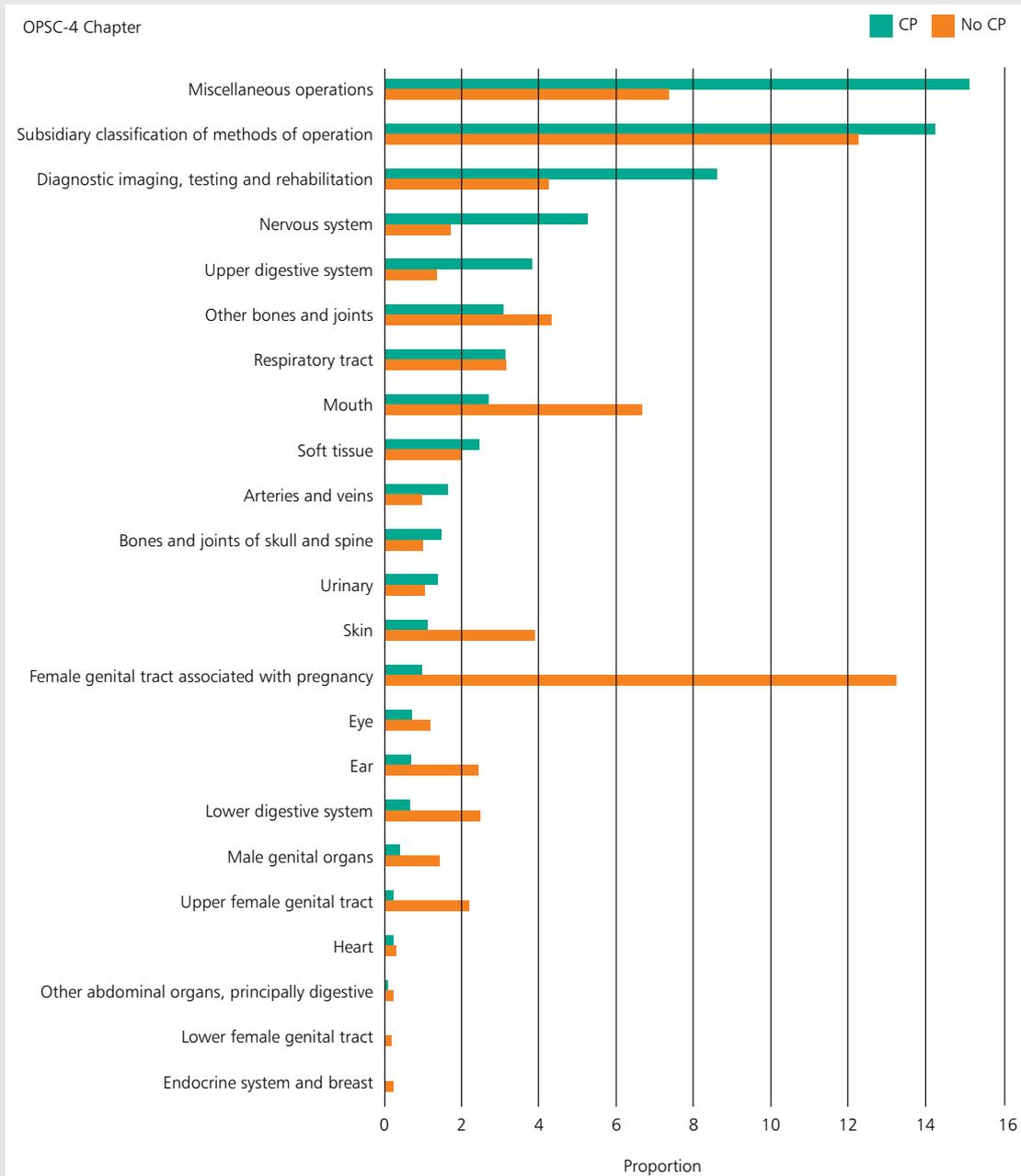


Figure 10.12 Proportion of hospital admissions according to procedures undertaken for children and young people with and without a cerebral palsy by OPSC- 4 Chapter codes (cerebral palsy n=175,438; no cerebral palsy n=9,579,888) (CPRD: England HES Linked)

Many children, young people and young adults with a cerebral palsy have their overall healthcare needs managed in the community, some under the supervision of a multidisciplinary neurodisability team. If admitted to acute general hospitals for whatever reason this offers an opportunity for interface between appropriate specialist teams and the (wider) MDT and therefore potential for improvement in overall patient care.

When admitted to hospital one in three patients with a cerebral palsy in this study did not have a recorded neurodisability lead and this was least likely to be the case in young adults. This important detail was found in only 240/380 (63.2%) records reviewed for children and young people and in 31/133 (23.3%) of young adults with cerebral palsies. **12**

It was also unclear in case notes how the cerebral palsy affected mobility in 101/333 (30.3%) patients who were

admitted as inpatients. An important descriptor of motor ability (GMFCS level) was assessed and documented on admission to acute general hospitals in only 51/405 (12.6%) cases, and in just 6.3% of cases thereafter. If information from lead clinicians for neurodisability had been available at this point there would potentially have been better knowledge of GMFCS level since this was recorded by them in almost all cases (211/221). See also Figure 8.3. These data provide an example of where improved routine recording and communication of a key descriptor of function which is assessed by neurodisability teams could facilitate inpatient care if it were made available. Patient held records might also offer a partial solution to the problem, and may be particularly beneficial for patients with the most complex needs and would encourage patient autonomy. **8** (See Appendix 1)

The range of associated medical conditions identified by reviewers is shown in Table 10.1.

Table 10.1 Documented associated medical conditions

	Present	Documented in the case notes	Documented in a clinic letter
Epilepsy	330	275	221
Constipation	179	103	125
Gastro-oesophageal reflux disease	214	138	148
Feeding and swallowing issues	304	231	204
Drooling	130	65	65
Airway issues	158	131	103
Respiratory issues	237	205	144
Scoliosis	148	79	101
Sleep issues	141	58	97
Nutritional issues	258	186	166
Behavioural/Emotional issues	123	73	84
Presence or not of pain	202	159	106

Answers may be multiple

Overall symptom management on admission was assessed by reviewers to be adequate for 299/333 (89.8%) admitted and 136/158 (86.1%) day case patients, but inadequate for 34/333 (10.2%) admitted and 22/158 (13.9%) day case patients. However, other unmet needs were reported by reviewers in 52/237 (21.9%) admitted and 13/110 (11.8%) day case patients, which were evidenced as addressed for 25/50 admitted and 7/12 day case patients, but not addressed for 22/50 admitted and 4/12 day case patients.

Admission also offers an opportunity to review wider aspects of care such as nutrition. However some inpatient wards did not have the appropriate equipment such as slings and hoists available to weigh patients accurately, and in many this was not even estimated. **9**

CASE STUDY 12

A young adult patient was admitted for insertion of a feeding tube under the care of a gastroenterologist and as requested by the patient's GP. As well as poor weight gain and unsafe swallow their notes clearly indicated a hip dislocation and consequent difficulty in weighing the patient due to pain.

Reviewers agreed that this case demonstrated substandard care in several areas and of some duration. Attempts were being made to rectify the situation and the patient required careful follow-up and support from speech and language therapy, dietetics, and orthopaedics when their nutritional state allowed.

Whilst several other teams were frequently involved with care whilst the patient was in hospital there were very few multidisciplinary team (MDT) discussions. Even though some patients were admitted for very short periods of time offering little opportunity for face to face discussion, the overall mean duration of admission was 7.7 days with a Median of 4 days. However multidisciplinary team meetings occurred for fewer than one in five patients. This may constitute missed opportunities for better joined up care. **7**

There were very few examples in cases that were reviewed of this occurring.

CASE STUDY 13

A young child with 'spastic quadriplegia', GMFCS level V had a 2 week admission for aspiration pneumonia during which time they saw many other teams for 'catch-up'. This included a change of their feeding tube, review of their epilepsy management and a wheelchair assessment.

Reviewers commented that this was an example of excellent care. However more often than not there was a sense that when children and young people with a cerebral palsy were admitted with an acute medical problem, their neurodisability was "peripheral" to their care needs and it is often about treating the system failure and not the whole patient.

Whilst this case illustrates a longer admission there were also patients where it was clear that more opportunities to review and maximise care should have been used.

CASE STUDY 14

A young child weighing just 12kg with a GMFCS level V cerebral palsy secondary to a severe hypoxic event at birth had had multiple admissions in the last 2 years with chest infections and seizures. There was no record of swallow having been assessed. However the notes from a lead in neurodisability, based in the community, mentioned that the parents were "just managing with feeding and that the child is otherwise well cared for".

Reviewers reflected upon the difficulties encountered by families in accepting the need to consider supplementary or gastrostomy feeds. There had been multiple opportunities for this patient's overall care to be reviewed by the wider multidisciplinary team which had not been maximised, with consequent deterioration in patient wellbeing.

Clinicians responsible for inpatient admission felt that delays in first assessment for patients with a cerebral palsy were generally minimal (Table 10.2).

Table 10.2 Delays in first assessment

	n=	%
Yes	13	2.9
No	428	97.1
Subtotal	441	
Unknown	98	
Total	539	

Where data was returned the majority of patients (elective and emergency) were seen by a member of medical staff within six hours of admission (256/273; 93,8%). However, data was missing in 263/536 (49.1%) cases.

Grade and specialty of first assessment

Two-thirds of patients 263/447 (58.8%) had their first medical assessment performed by a consultant or senior

specialist trainee. In most they were seen by a specialist in paediatrics (55.1%), however 14% were seen by a general or other medical specialty and 10.2% by orthopaedics. In 135/536 (25.2%) patients this question was not answered by the senior admitting clinicians. This may be because of poor/incomplete recording of the episode in the patient notes.

Timing of senior review

The RCPCH and RCP have stated that emergency admissions should receive senior review by a consultant or a senior doctor with equivalent competences/level of responsibility within 14 hours of admission (Figure 10.3). In total and where timings were recorded 180/247 of all patients admitted (72.9%) were seen by a consultant within 14 hours. Just 116/170 patients (68.2%) admitted urgently or as an emergency were seen within 14 hours by a consultant. The purpose of early senior review is generally to provide timely decision making and these data suggest that this was more likely to occur in elective than urgent or emergency cases.

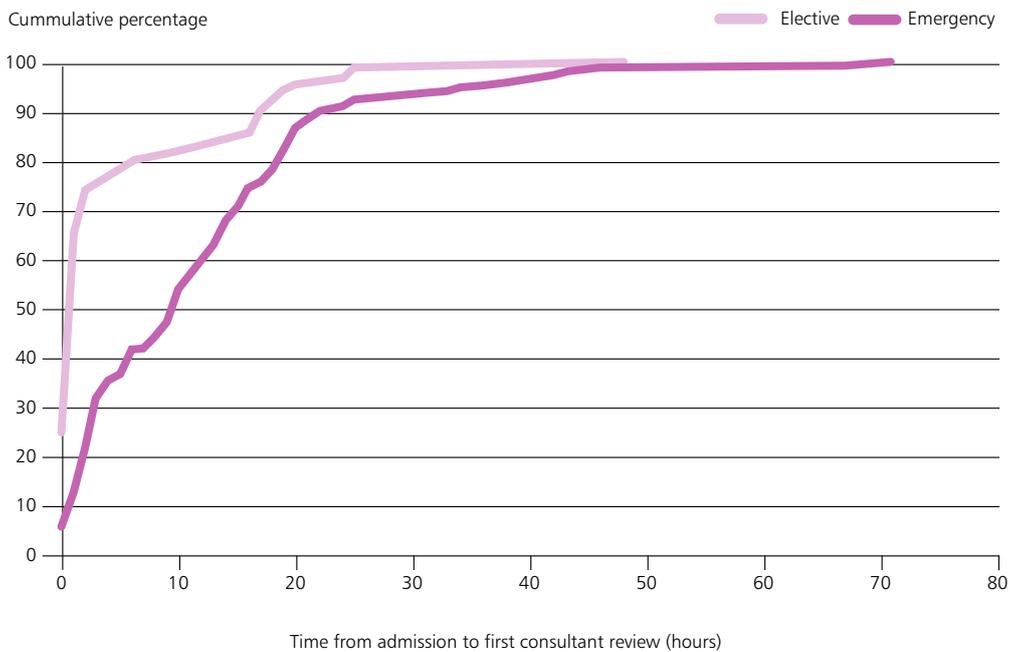


Figure 10.13 Time from admission to first consultant review

The seriously ill patient

About a quarter of patients with a cerebral palsy and admitted to hospital were seriously ill (75/321; 23.4%) Table 10.3. This was defined as a patient who required or potentially required critical care at Level 3 whether their condition was medical or surgical. A recent seven year study from Australia has also shown that patients with the cerebral palsies have a higher rate of presentation with illness with higher levels of acuity than the general population of the same age.⁴⁴

Table 10.3 The patient was seriously ill on admission

	n=	%
Yes	75	23.4
No	246	76.6
Subtotal	321	
Unknown	6	
Not answered	10	
Total	337	

Virtually all seriously ill patients (70) had long-term/chronic comorbidities, often more than one. The most common was epilepsy (57/70) and/or lung disease (24/70) (Table 10.4).

Table 10.4 Comorbidities of the seriously ill patient

	n=
Epilepsy	57
Lung disease	24
Scoliosis	22
Endocrine disease	5
Congenital heart disease	1
Other	27
Total	70

**Answers may be multiple*

Many patients also had "associated conditions" (65/73). For about half this included gastro-oesophageal reflux (32) and/or nutritional problems (34). A substantial number had airway (25) and/or respiratory issues (33).

Many of those patients who were seriously ill on admission were reliant on additional technologies, with most requiring artificial feeding and a quarter receiving ventilation or continuous positive airway pressure (CPAP) prior to this hospital admission (Table 10.5).

Table 10.5 Additional technologies required by the seriously ill patient

	n=
Gastrostomy or other feeding tube	55
Ventilation/CPAP	15
Hearing aid(s)	3
Hoist for transfer	25
Other	4
Subtotal	58
Not answered	17
Total	75

**Answers may be multiple*

The 2015 RCPCCH revised acute care standards state that all children admitted to a paediatric department with an acute medical problem should be seen by a healthcare professional with the appropriate competences to work on the tier two (middle grade) paediatric rota within four hours of admission.⁴⁵

Table 10.6 shows that most seriously ill patients with a cerebral palsy, where data was available, underwent a medical assessment within the first 4 hours following admission. However, in 19/75 patients the data on timings were incomplete and could not be provided by responsible admitting clinicians.

Table 10.6 Timing of medical assessment - seriously ill patient

	n=
On admission	16
4 hours or under	16
5 - 10 hours	4
More than 10 hours	3
Assessment prior to admission	17
At least one date or time missing	19
Total	75

In sick patients it is particularly important to have a baseline set of observations and other essential patient parameters (e.g. weight) on which to base management decisions and monitor change. In all patient groups early warning scoring on admission can assist with triage and allocation of the patient as to the most appropriate level of care/nurse dependency. An early warning score (EWS) was recorded in 79% 298/377 of all patients on admission but was recorded slightly more often (in 84%) in the seriously ill. Whilst there is no universal agreement as to the most important elements within a paediatric physiological scoring system to identify serious illness, the use of a Paediatric Early Warning Scores (PEWS) is recommended by the RCPCH and others in the triage of all hospitalised patients.⁴⁶ Patients with chronic neurodisability that are admitted to hospital are more likely to have multiple associated co-morbidities and even when well their acuity may differ markedly from other children and young people when admitted e.g. in the context of elective surgery. Certain parameters of the score may be more difficult in the presence of high levels of neurodisability e.g. recording blood pressure if the patient has a movement disorder or severe contractures. At least one evaluation of PEWS has specifically included patients with a cerebral palsy in the patient cohort and noted no deterioration in score performance.⁴⁷

Despite the fact that not all patients with serious illness were seen within 4 hours of admission by a member of the medical team and in others this was not recorded, admitting clinicians felt that delays in identifying serious illness and providing resuscitation in all emergency admissions were minimal and reported that in just eight patients presenting as an emergency (3.1% of total admissions) there were delays in providing specific treatment.

Where delay occurred in those patients who were admitted as an emergency there were four cases where there was diagnostic uncertainty, in three delays was attributed to technical difficulty and in just two uncertainties about how aggressive treatment should be. Whilst these are common reasons for delay in a paediatric population, their significance may be greater given the possibility of severe associated co-morbidity.

CASE STUDY 15

A baby with a severe cerebral palsy who had undergone several operations for ventriculoperitoneal shunt insertion and had a feeding gastrostomy was admitted with fever, uncontrolled seizures, low oxygen saturation and poor peripheral perfusion. Intravenous access was very difficult and the baby initially needed an intraosseous placement which was secured approximately 15 minutes after arrival. This was used to administer more anticonvulsant medication and a fluid bolus. The baby subsequently developed respiratory depression and was intubated by an on-site anaesthetic registrar with the assistance of a consultant paediatrician and critical care registrar. The baby was further resuscitated and stabilised with input from consultants in anaesthesia and critical care and was transferred approximately 100 miles to the nearest paediatric intensive care unit.

Reviewers commented that babies and children with neurodisability are frequent users of emergency services. Care may be complicated by difficulties with venous access e.g. due to previous extreme prematurity, intravenous feeding and surgery as in this case. Delays in resuscitation are not uncommon and required a skilled and timely team approach to provide best outcomes.

Generally the largest proportion of seriously ill patients who present to hospital in the paediatric age range are under the age of five years and this age group of patients more frequently require paediatric critical care admission.⁴⁸ Whilst numbers in the sample were small and some data were missing, the patients with a cerebral palsy and serious illness in this study broadly reflected this age group. However, there were also a number of young people and young adults admitted with serious illness (28/84 in the

Table 10.7 Age of the patients who were seriously ill on admission

	0-4 years	5-9 years	10-14 years	15-19 years	20-25 years	Subtotal	Not answered	Total
	n=	n=	n=	n=	n=	n=	n=	n=
Yes	19	17	11	13	15	75	0	75
No	56	63	42	33	51	245	1	246
Subtotal	75	80	53	46	66	320	1	321
Unknown	3	3	2	2	6	16	0	16
Total	78	83	55	48	72	336	1	337

15-25 age range) (Table 10.7). This may reflect the longer term significance of severe chronic illness in those patients with greater levels of neurodisability. This also makes it more likely that acute respiratory and/or neurological events will lead to decompensation to a level requiring intensive care admission. This was reflected in cases reviewed and has been reported in similar patient populations.^{31,49}

It is reflected in the routine national data findings within this study stated on page 121.

CASE STUDY 16

A young adult with a long term tracheostomy was admitted for seizures under the care of a respiratory clinician with support from a neurologist in a different centre. The patient had had a similar admission three weeks earlier with no clear ongoing management plan. During this admission they were seen daily by the critical care outreach team with excellent documentation of the tracheostomy care and respiratory status. However there was no overall leadership of the patients neurodisability needs.

The case reviewers commented that had clear leadership been in place in the community admission might have been avoided.

Critical care admission

Children, young people and young adults with a cerebral palsy may require all or part of their hospital care delivered within a critical care environment as a result of acute severe illness and/or particular technology dependencies. Admissions may be planned (e.g. peri-operative) or unplanned. In this study 5% (25/471) of patients were admitted directly to critical care. This included elective as well as emergency admissions.

Of all patients who were admitted 1 in 10 required ventilation or CPAP (Table 10.8). In some hospitals use of non-invasive ventilation, CPAP and/or a tracheostomy will dictate some level of critical care provision, particularly if the patient is very young and/or has other complex co-morbidity.

Table 10.8 Technologies/equipment required by the patient to facilitate day to day care

	n=	%
Gastrostomy or other feeding tube	231	81.9
Ventilation/CPAP	32	11.3
Hearing aid(s)	13	4.6
Hoist for transfer	122	43.3
Other	24	8.5
Subtotal	282	
Not answered	254	
Total	536	

CASE STUDY 17

A young person with complex needs receiving ventilation at night was admitted to a paediatric critical care unit for surgical change of a feeding tube. There was a delay to the procedure being undertaken due to lack of elective theatre time and ultimately the patient remained in the paediatric critical care unit for 3 days as their surgery was not deemed 'urgent'.

The reviewers agreed that patients dependent on complex technology were now more often cared for at home. However admission to ward areas other than critical care may then be impossible as staffing numbers, competence and confidence may be insufficient to permit this to safely take place.

Clinicians were asked whether patients were admitted to critical care at a later date during their admission. Thirty patients were subsequently referred to critical care with the majority of referrals occurring during the normal working day, and nine overnight (18.00 to 08.00). The majority of the critical care admissions (32/49) where data was provided were unplanned.

Not all hospitals have paediatric critical care facilities on-site but almost all will have a general critical care facility. Initial referrals to critical care were most commonly to on-site intensive care teams be they paediatric or primarily adult.

Table 10.9 Group of clinicians to which the referral made

	n=
On-site paediatric critical care team	13
On-site adult critical care team	14
Off-site paediatric critical care or transfer team	3
Off-site adult critical care team	0
Total	30

10/13 referrals to on-site paediatric critical care were for patients aged 15 years or under. However, there were three referrals to off-site paediatric critical care and all were of patients aged 18 years (Table 10.9). When paediatric critical care is not available on-site, initial resuscitation and stabilisation and/or short term care is often initiated on a general (adult) unit with subsequent transfer as required or requested due to local unit competences. In total there were around 600 admissions of children and young people under 16 years in 2015 to adult general critical care and according to recent national PICANet data. Most of these patients were in the 11-15 age range.⁴⁸

CASE STUDY 18

A young person with a cerebral palsy (GMFCS level V) was initially admitted to an adult critical care unit after a severe seizure and possible aspiration. The patient was intubated and ventilated on-site and then required paediatric critical care transfer to a unit where they were known to the service and had had several previous admissions. Community notes when available gave clear evidence of a very detailed management plan including maximum levels of care/hospice care which had been agreed. However there appeared to have been no knowledge of this Emergency Health Care Plan by the local acute team in the district general hospital or discussion with the patient's family about long term plans. Similarly after admission to the paediatric critical care unit there was no evidence that discharge notes were copied to the community team, though the GP was sent a copy.

Case reviewers felt that this was not an uncommon scenario in the highly complex patient who may be better known to specialist services than the local DGH. Therefore more comprehensive information sharing between healthcare providers, particularly for patients with complex needs is essential. A regularly updated hand held summary and Emergency Health Care Plan or patient passport is a possible solution which works for some patients and is used in some networks with success.

Overall there were 11 admissions of patients of 18 years and older to critical care. Whilst numbers are very small this tended to mirror the data already presented suggesting that there were slightly more older patients with a cerebral palsy that are admitted with serious illness and this may result in critical care admission. Many of these patients have very complex needs and some had pre-existing Emergency Health Care Plans and “Do not attempt cardiopulmonary resuscitation” (DNACPR) plans in place. However case reviewers found that in only 241/305 (7.9%) of cases was there an Emergency Health Care Plan recorded in the patient notes. DNACPR status was recorded in just 124/176 (70.4%) of emergency admissions. Ideally clinicians who know the patient and family well and been involved with care for some time are involved in such important decision making well in advance of a serious illness or event such as emergency admission to hospital. This requires a “team approach” and the involvement of senior clinicians is extremely important as is the documentation and ready availability of a well worked Emergency Health Care Plan which the patient and family own and recognise. The lack of robust systems for good communication in this circumstance is highlighted in chapter 6. It is particularly important that this advance planning takes place well before transition to adult services. 

CASE STUDY 19

A young adult with a GMFCS level V cerebral palsy was admitted with a lower respiratory tract infection and poor blood gases despite already receiving ventilation at night at home. There was otherwise an excellent care plan for the patient’s ongoing needs but there was limited information within it about escalation plans and DNACPR. The patient’s last admission had been to paediatric critical care two years previously at which point a decision had been made with his family not to perform tracheostomy. The patient’s mother now regretted this decision and demanded that all should be done.

Reviewers commented that whilst decisions about ongoing long term care for patients with very severe disability are always difficult and need to be regularly reviewed, it is very important that information is transferred between teams and that families are fully aware of the content of any long term health care plans.

The care of children, young people and young adults in paediatric critical care was also reflected in the national datasets.

National routine data

PICANet is a clinical audit that collects critical care data across all 34 paediatric intensive care units (PICU) in the UK and Ireland and 6 specialist transport organisations. PICANet data were analysed for all admissions (2008-2014). Whilst it is standard practice for PICUs to provide healthcare for children (0-16 years) the dataset received from PICANet included data for children and young people aged 0-24 years 2008-2014.

During this time period 3,314 (2.65%) admissions were for children and young people with a cerebral palsy (3,314) from a total of 121,646 PICU admissions (Table 10.10). This is approximately 10 times greater than would be expected given that the estimated population prevalence of a cerebral palsy is 0.2-0.3%. There was little variation in the proportion of admissions for cerebral palsy between 2008 and 2014.

Table 10.10 Demographic details of PICU admissions for children and young people with and without a cerebral palsy by age and gender at admission (n=3,301) (2008-2014) (PICANet data)

	Cerebral palsy (n=3,314)	No cerebral palsy (n=121,646)	All admissions (n=124,960)
Male	1,867 (56.3%)	68,768 (51.0%)	70,635 (56.5%)
Female	1,447 (43.7%)	52,842 (48.5%)	54,289 (43.4%)
Ambiguous	0 (0%)	30 (0.4%)	30 (0%)
Unknown	0 (0%)	6 (0.1)	6 (0%)
Age Group			
<1	102 (3.1%)	55,972 (46.0%)	56,074 (44.9%)
1-4	919 (27.7%)	31,414 (25.8%)	32,333 (25.9%)
5-9	901 (27.2%)	13,861 (11.4%)	14,762 (11.8%)
10-14	926 (27.9%)	14,121 (11.6%)	15,047 (12.0%)
15-19	453 (3.7)	6,223 (5.1%)	6,676 (5.3%)
20-24	13 (0.4%)	55 (0.1%)	68 (0.1%)

Primary diagnosis group

All CP

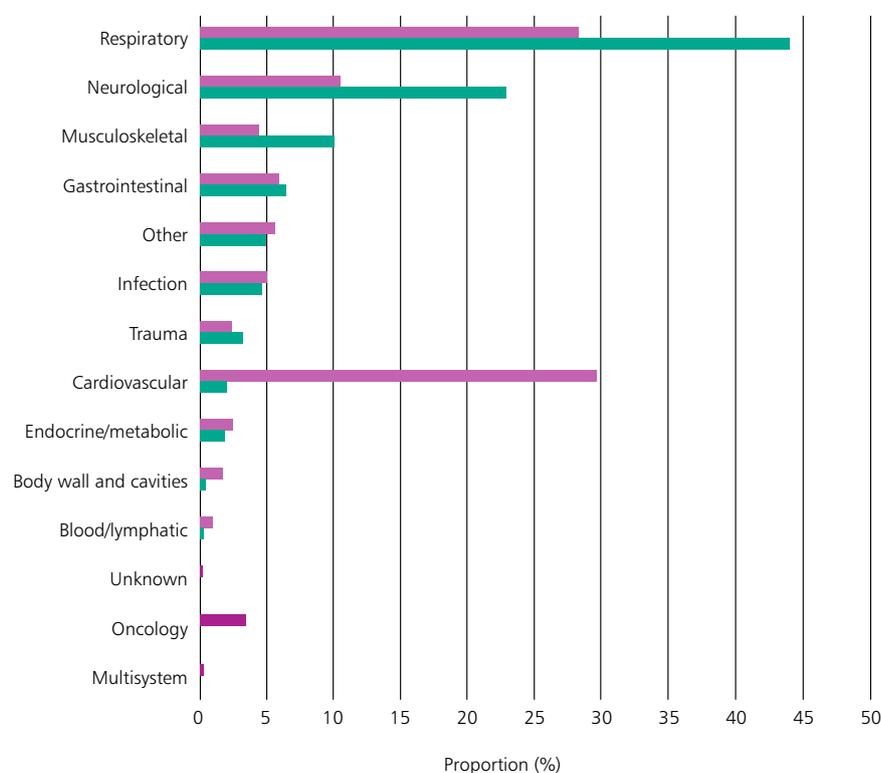


Figure 10.14 Proportion of PICU admissions for children and young people with a cerebral palsy compared with all admissions by primary diagnosis group. (Data presented for 2012-2014 where comparative data were available from the Paediatric Intensive Care Audit Network: 2015 Annual Report (published November 2015): Universities of Leeds and Leicester)

The most common reason for admission to PICU for children and young people with a cerebral palsy was for respiratory conditions (43.8%). Children and young people with a cerebral palsy had significantly greater proportions of admissions for musculoskeletal, respiratory and neurological conditions than for all children and young people admitted

to a paediatric intensive care unit (Figure 10.15). Of the 1,322 admissions with a primary diagnosis of a respiratory condition (2008-2014), 339 (26%) were described as lower respiratory tract admissions, 286 (22%) for pneumonia and 202 (15%) for respiratory failure.

Where data were returned, the majority of referrals to critical care were made by a consultant or senior specialist trainee (24/26) and the majority of patients were reviewed by a member of the critical care team on-site (23/28). Most referrals were accepted with just four patients where this was not the case, because severity of illness did not meet the need for critical care.

Overall this data demonstrates that children, young people and young adults with a cerebral palsy are not infrequent users of critical care services, which relates to both acute severe illness and the requirement for additional physiological monitoring and support in association with surgery. Both situations are likely to be less well tolerated when there are longstanding medical co-morbidities and more often seen in association with severe degrees of motor disability. There was no evidence that critical care admission was delayed or refused in this population. The duration of stay on critical care varied markedly and was between one day and just under four weeks.

The majority of patients (46/49) survived to critical care discharge but there was one death (Table 10.11).

In the routine national data the mortality rate was greatest in the 20-24 year olds with a cerebral palsy. There were only a few admissions to PICU in this age group however the high mortality rate reflects that these young adults were likely to have had complex morbidities (Figure 10.18).

Table 10.11 Outcome of the critical care admission

	n=
Patient survived to critical care discharge	46
Patient died on critical care	1
Subtotal	47
Not answered	4
Total	51

Length of stay and patient outcome for patients with cerebral palsy receiving paediatric critical care was also consistent with the national routine data.

National routine data

Length of PICU stays for a cerebral palsy compared to all admissions (2008-2014)

Children and young people with a cerebral palsy in all age groups except infants (under one year) had longer stays in PICUs than those without a cerebral palsy (Table 10.12); 2.5% (83) children and young people with a cerebral palsy

were admitted to PICUs for longer than 25 days and the longest admission was recorded as 133 days (Figure 10.15).

Discharge destination

The majority of children and young people with a cerebral palsy were transferred to a ward within the same hospital and a greater proportion were transferred to HDU compared to non cerebral palsy group across all age groups (Figure 10.16).

Table 10.12 Median length of stay in PICU with IQR

Age group	Cerebral palsy	All admissions
<1	3.0 (1.8-6.3)	3.08 (1.2-6.3)
1-4	2.3 (0.9-5.7)	1.67 (0.9-4.0)
5-9	2.1 (0.9-5.9)	1.36 (0.8-3.2)
10-14	2.7 (1.0-6.0)	1.22 (0.8-3.2)
15-19	1.9 (1.0-5.6)	1.10 (0.8-2.8)
20-24	2.7 (1.3-4.9)	2.39 (0.9-5.3)

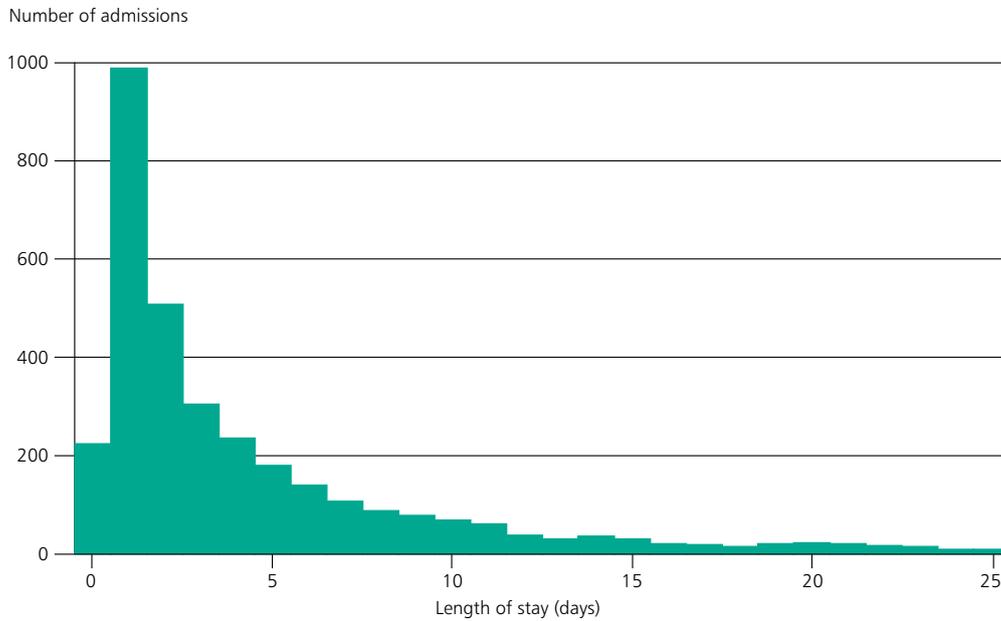


Figure 10.15 Frequency distribution of length of PICU stay for children and young people with a cerebral palsy between 2008 and 2014
n=3,231 (where data were recorded)

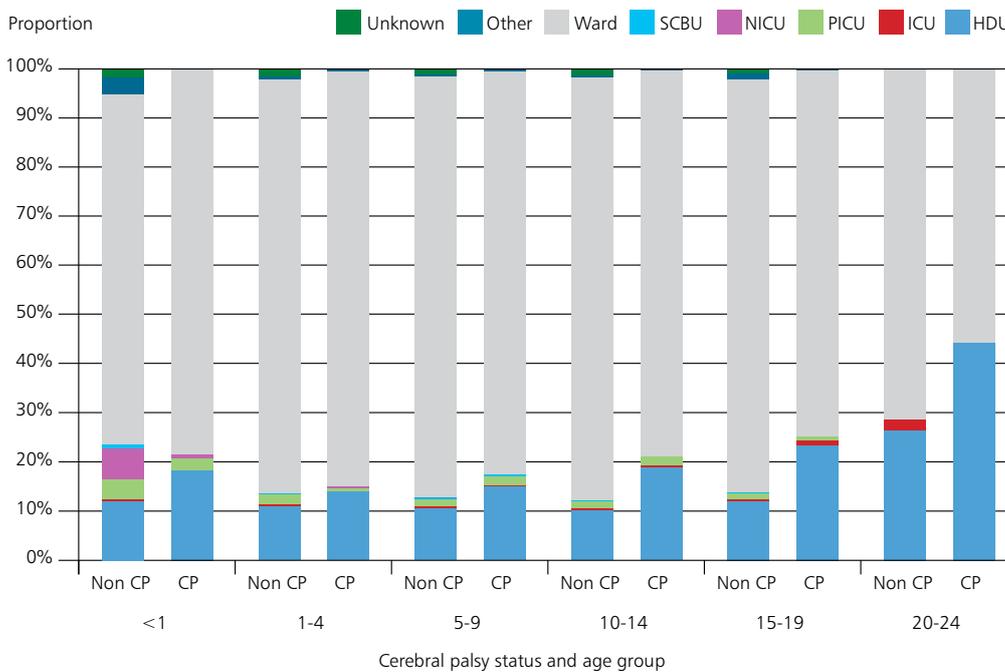


Figure 10.16 Proportion of children and young people with and without a cerebral palsy discharged to another hospital unit by age group (PICANet)

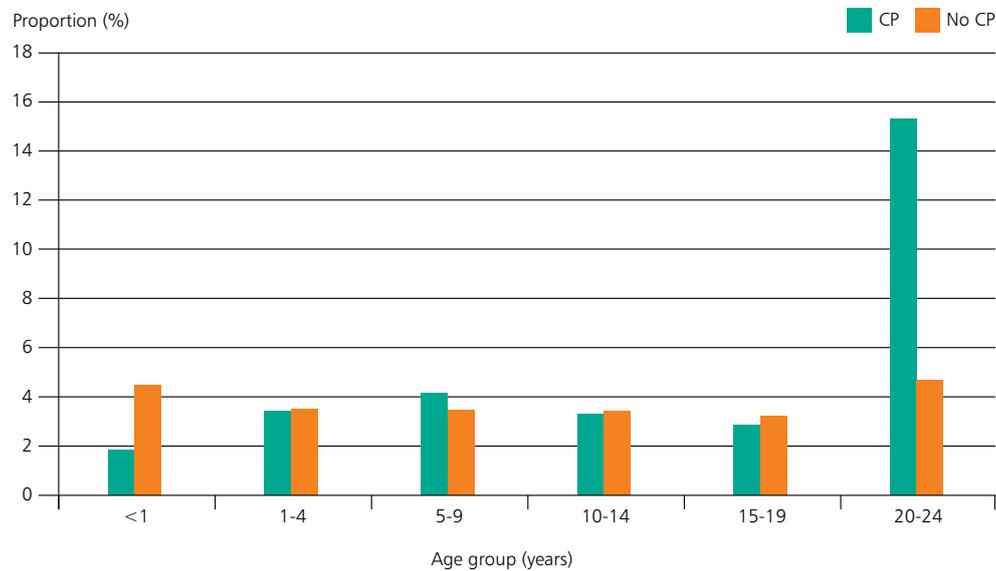


Figure 10.18 Proportion of admissions that resulted in a death in PICUs for children and young people with and without a cerebral palsy by age group

Palliative care

Overall there were three deaths recorded in this study. Where children and young people required palliative care, there was considerable variation in the information provided from various organisations as to who provided it, as shown in Table 10.13. The data collected here suggested that it was most likely to be provided by paediatricians (either general or with specialty training) and/or community paediatric nurses but with significant input from general practitioners. There was considerably less representation from palliative care specialists in organisations responding on behalf of paediatric or adult inpatient care.

NICE standards for paediatric palliative care recently published stress the need for both specialist care leadership and multidisciplinary team involvement to supporting the family.⁵⁰

CASE STUDY 20

A young child with GMFCS level V bilateral spastic cerebral palsy was admitted from a hospice for change of their gastrostomy tube due to technical issues. The child was receiving full care to control seizures, treat painful spasms, and medication and regular suction for excessive oral secretions due to a very poor swallow. The patient's family, in conjunction with the neurodisability team and a consultant paediatric neurologist, had recently agreed a plan of care which was based on her comfort and palliation of symptoms.

Reviewers commented upon a very good proforma which was completed by admitting paediatricians and which clearly outlined the patient's particular needs as well as who is to be informed and how decisions will be made in the event of sudden deterioration, and with a clear outline of what interventions should be provided along with DNACPR status in this case.

Table 10.13 Providers of palliative care

	Paediatric outpatient care	Paediatric community care	Paediatric inpatient care	Adult inpatient care
General practitioner	40	42	NA	18
General paediatrician	54	47	60	NA
Community paediatrician	43	51	45	NA
Paediatrician with specific expertise in disability (disability, community or general with specific expertise) and palliative care	39	46	44	NA
Paediatric palliative care consultant	45	58	36	NA
Palliative care physician	NA	NA	NA	37
Adult physician	5	1	NA	24
Adult palliative care consultant	8	8	8	NA
Community children's nurse	53	55	53	NA
Specialist palliative care nurse	41	31	29	NA
Specialist nurse	NA	NA	NA	31
Other (please specify)	2	3	6	23
Subtotal	82	78	84	43
Not answered	2	3	6	23
Total	84	81	90	66

Duration of overall admission, discharge planning and outcomes

Admission duration

The duration of admission varied considerably (Figure 10.18). Of those cases reviewed, and where data was recorded, 93.8% of patients were admitted for fewer than 21 days and 68.4% fewer than seven days. The mean duration of admission was 7.6 days with a median of four days.

Discharge planning and communication

Given the multiple co-morbidities and additional needs which patients with a cerebral palsy may have, communication at discharge is a particularly important opportunity to update and inform members of the wider multidisciplinary team. Admitting clinicians responsible for inpatient care were asked about the content and inclusion of information from relevant MDT members involved in the inpatient admission in provision of communication at discharge.

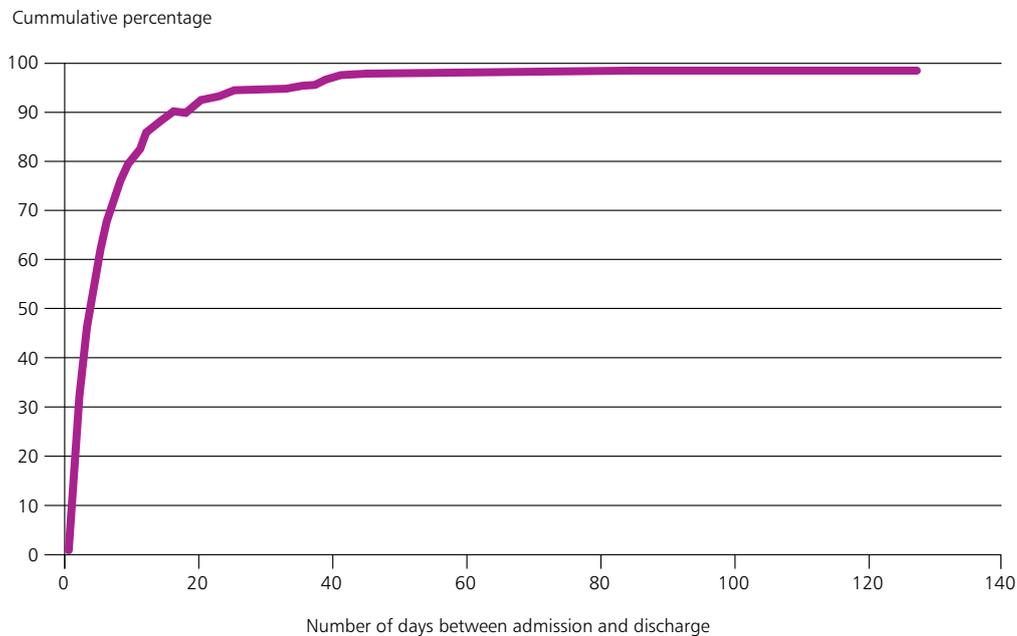


Figure 10.18 Duration of admission

Chapter 6 on ‘communication’ highlighted that there was evidence of multidisciplinary discharge planning as reported by case reviewers for 105/287 (36.6%) patients, but not for 182/287 (63.4%). **6**

The quality of this communication varied and was stated by reviewers to be better with patients and families (adequate in 93.1% and 86.7% respectively) than with lead clinicians and the patients usual MDT.

Variation in the reported adequacy of communication on discharge by case reviewers is shown in Table 10.14.

Table 10.14 Adequate communication - reviewers’ opinion

Admitted patients	Patient and their family		General practitioner		The lead clinician for cerebral palsy management?		The patient’s usual MDT		Community physiotherapy services	
	n=	%	n=	%	n=	%	n=	%	n=	%
Yes	244	93.1	242	86.7	120	53.8	84	42.9	70	38.0
No	18	6.9	37	13.3	103	46.2	112	57.1	114	62.0
Subtotal	262		279		223		196		184	
Unable to answer	43		34		57		75		84	
Not applicable	44		36		21		27		30	
Not answered	3		3		51		54		54	
Total	352		352		352		352		352	

Clinicians in charge of general hospital care stated that in only 210/391 (53.7%) patients did discharge communication contain input from relevant members of the inpatient team. Communication did not necessarily contain information relevant to all members of the multidisciplinary team involved in providing care after admission (Table 10.15) which occurred in 190/368 (51.6%) cases. In a total for 168 cases this information was unknown or was not provided.

Table 10.15 Communication included information to all relevant members of the MDT providing care after admission?

	n=	%
Yes	190	51.6
No	178	48.4
Subtotal	368	
Unknown	101	
Not answered	67	
Total	536	

Adequate review of personal care and activities of daily living prior to discharge from hospital, including access to equipment and appropriate support in the community was reported by reviewers to have occurred in 153/234 (65.4%) cases reviewed, but was felt to be inadequate in 81/234 (34.6%) cases. Reviewers were unable to answer in 82 cases and did not answer this question in 36 cases. This is covered in more detail in chapter 

Outcome of the admission and overall assessment of inpatient care

Admitting clinicians stated that the majority of patients were discharged with either an improved level of function (25.7%) or the same level as before admission (70.7%).

Table 10.16 Outcome of the admission

	n=	%
Discharged with and IMPROVED level of function/mobility	138	26.9
Discharged with the SAME level of function/mobility	360	70.2
Discharged with a WORSE level of function/mobility	8	1.6
Discharged for a higher level of support including critical care	4	0.8
Death	3	0.6
Subtotal	513	
Not answered	23	
Total	536	

When the study sample was divided into those patients admitted for any medical reasons vs. those admitted for planned procedures or surgery there were a larger number of patients with planned admissions who left hospital with improved function, which occurred in half of the planned admissions as opposed to about a third of all others. Whilst numbers are small this might be foreseen given that a planned procedure or surgery generally has the explicit aim of improving or rectifying function. In most instances these episodes of care will be undertaken when the patient is relatively well. Patients who underwent emergency medical admission made up the largest number in this study and in these it was least likely that an improvement in function and/or mobility was seen and occurred in only 17.3% (48/277) patients.

Only 12 (2.9%) patients either had a worse level of function or had to be transferred for a higher level of critical care. Three of these patients had initially been admitted for a planned procedure or surgery (Table 10.17). The decision to operate on patients with complex co-morbidity is often a difficult one, the risk of failure is greater and a multidisciplinary team approach is required. This is discussed further in chapter  and chapter 

Table 10.17 Level of function/mobility by admission type

	Elective surgical	Emergency surgical	Elective medical	Emergency medical	Other
Discharged with and IMPROVED level of function/mobility	59	12	8	48	11
Discharged with the SAME level of function/mobility	69	20	20	222	29
Discharged with a WORSE level of function/mobility	3	0	1	2	1
Discharged for a higher level of support including critical care	0	1	0	2	2
Death	0	0	0	3	0
Subtotal	131	33	29	277	43
Not answered	4	0	0	5	14
Total	135	33	29	282	57

Overall quality of general hospital care

Admitting clinicians were asked to comment upon the overall quality of care and whether in their opinion there were aspects of care that could have been improved. In only nine patients there were felt to be preventable or remediable factors in the process of care and these related to delay in

recognition or diagnosis in one case and delayed treatment in 1 other. However, In the opinion of the case reviewers and in comparison with community based neurodisability care; overall general hospital care was felt to be less good both for inpatients and day case patients, with room for improvement in both clinical and organisational aspects of care (Figure 10.19).

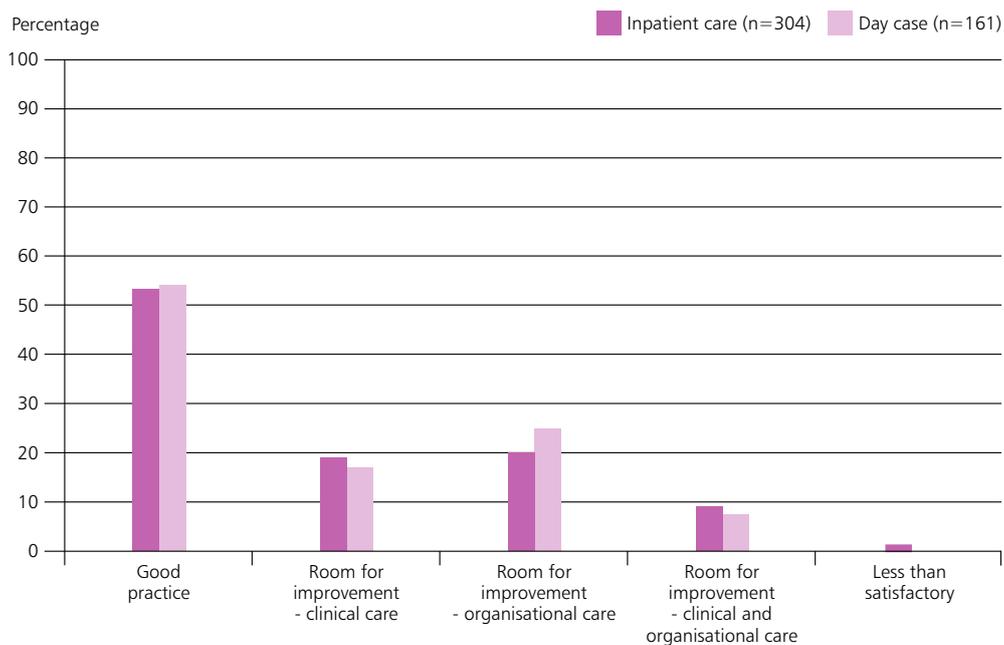


Figure 10.19 Overall quality of care - reviewers' opinion

Overall **inpatient** care was rated as good in 161/304 (53%) cases reviewed. The reviewers stated that there was room for improvement in clinical and/or organisational care in 142/304 (46.7%). There was one patient where the overall care was felt to be less than satisfactory.

Key Findings – questionnaire, case note review and organisational data

- 180/247 (72.9%) of patients with a cerebral palsy were seen within 14 hours of admission by a senior clinician. This was only the case in 116/170 (68.2%) patients admitted urgently or as an emergency and these data were poorly recorded in case notes
- 75/321 (23.4%) of patients with a cerebral palsy were seriously ill on admission. However, only 7.9% of patients reviewed had an Emergency Health Care Plan/ Emergency Care Summary present in case notes
- Discharge communication included input from the relevant members of the inpatient team in 210/391 (53.7%) patients with a cerebral palsy after admission to acute general hospitals
- Reviewers reported there was adequate review of personal care and activities of daily living prior to discharge in 153/234 (65.4%) patients with a cerebral palsy; reviewers indicated this was inadequate in 81/234 (34.6%) cases reviewed. This was unknown or unanswered in 118 cases
- 138/513 (26.9%) patients with a cerebral palsy were estimated by admitting clinicians to have been discharged with an improved level of function
- Overall inpatient care was rated as good in 161/304 (53%) patients with cerebral palsy. There was room for improvement in clinical or organisational care or both in 142/304 (46.7%) patients.

SEE RECOMMENDATIONS

**11•14•15•19•20•22•23•26•27•28
29•30•31•32•33**

Overall **day case patient** care was rated as good in 87/161 (54%) cases reviewed. The reviewers stated that there was room for improvement in clinical and/or organisational care in 74/161 (46%).

Key Findings – routine national data

- The rate of hospital admissions for children and young people with one of the cerebral palsies was significantly greater than for those without cerebral palsies across all age groups. The difference decreased across the older age groups; the rate of admissions were on average 10 times greater for 0-4 year olds falling to 3 times greater for 20-24 year olds
- There was a higher proportion of elective admissions in patients with a cerebral palsy compared with those without
- Neurological conditions accounted for the greatest proportion of elective admissions, followed by mental health and behavioural and musculoskeletal concerns for children and young people with one of the cerebral palsies
- For emergency admissions among cerebral palsy patients the three most common reasons were respiratory, neurological and injury and poisoning. The most common admissions to PICU replicated this trend as they were for neurological, respiratory and musculoskeletal reasons
- There were significantly more day case admissions for children and young people with one of the cerebral palsies than for those without, (0-4 year olds had 15 times more and 20-24 year olds 4 times more admissions) the rate of day case admissions increased between 2004 and 2014, which may indicate an increase in proactive treatment
- The mean length of hospital admissions and admissions to PICU for children and young people with one of the cerebral palsies were greater than for those without a cerebral palsy
- Respiratory conditions accounted for the greatest proportion of primary care attendances, emergency hospital admissions, admissions to PICU and deaths for children and young people with a cerebral palsy.