

## 8 – Description of needs and ongoing symptom management

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**Study Advisory Group question:** *Do children and young people with a cerebral palsy have their comorbidities and associated conditions proactively managed, or does the absence of this lead to more hospital admissions and attendances than other children?*

**Study Advisory Group question:** *Are service pathways designed to enhance user experience, and to enable access to specialised services where appropriate.*

**Why is this important?** *If the many needs of children and young people with cerebral palsies are to be appropriately met and reasonable adjustments made to allow participation in everyday activities and access to services, needs must first be accurately identified and described.*

### Gross Motor Function

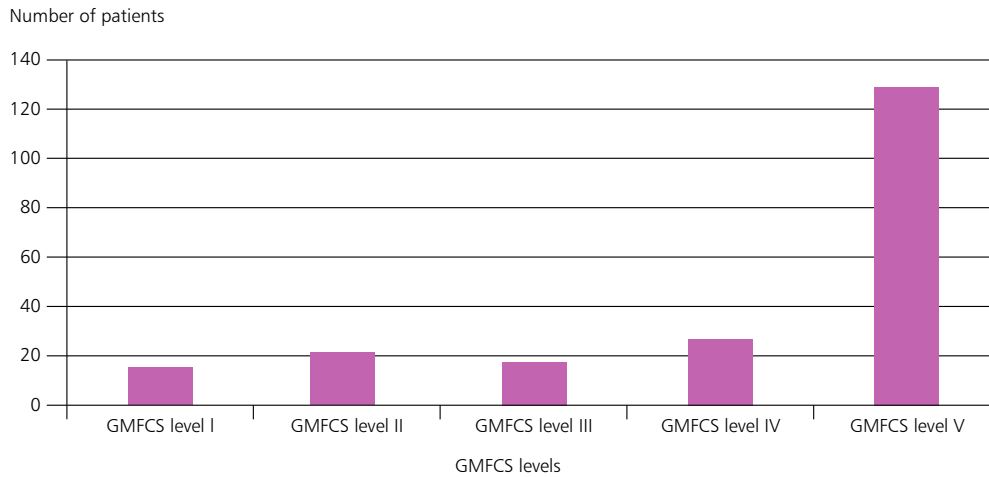
The cerebral palsies are, by definition, primarily conditions with effects on posture and movement, albeit with a wide range of possible associated impairments across domains of functioning as well as associated medical conditions, each with their own implications for management.

The Gross Motor Function Classification System (GMFCS) is a well-established, simple, straight-forward five-level classification that differentiates children and young people with cerebral palsies based on their current gross motor function and need (or not) for assistive technology and wheeled mobility. Description of GMFCS levels informs realistic goal setting, appropriate surveillance and intervention planning.<sup>30</sup>

Case note reviewers reported great variation in documentation of GMFCS level in case notes. The GMFCS level was documented somewhere in the case notes in 155/547 (28.3%) of cases reviewed, was not documented anywhere in the case notes in 392/547 (71.7%), reviewers were unable to answer in 7/554 (1.3%) cases (Table 8.1).

**Table 8.1 Documentation anywhere in the case notes of a GMFCS level - reviewers' opinion**

	0-4 years	5-9 years	10-14 years	15-19 years	20-25 years	Total
Yes	24	56	47	23	5	155
No	72	80	56	84	100	392
<b>Subtotal</b>	<b>96</b>	<b>136</b>	<b>103</b>	<b>107</b>	<b>105</b>	<b>547</b>
Unable to answer	2	1	4	0	0	7
<b>Total</b>	<b>98</b>	<b>137</b>	<b>107</b>	<b>107</b>	<b>105</b>	<b>554</b>



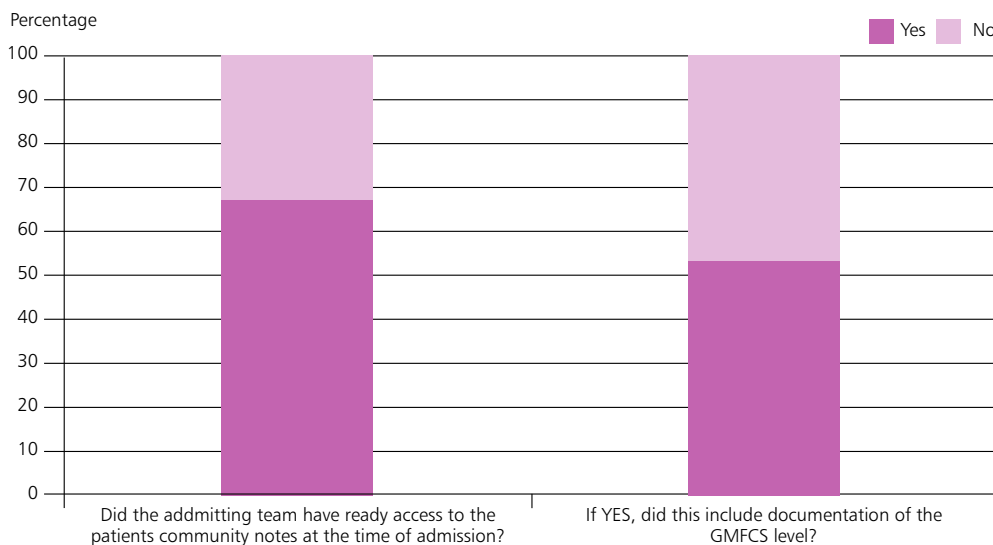
**Figure 8.1 GMFCS level reported by the lead clinician**

Figure 8.1 shows the GMFCS levels for each patient as reported by their lead clinician. This was marked as not recorded in 10/221 (4.5%) patients.

NCEPOD identified a sample population for this study from hospital admissions. The least independently mobile patients, especially those with motor function at GMFCS level V, are known to be more likely to be admitted to hospital.<sup>31</sup>

**Descriptors of functioning**

Lead clinicians for acute inpatient care reported having access to community case notes at the point of admission in only 292/414 (70.5%) cases and this was reported to include documentation of GMFCS level in only 105/197 (53.3%) cases and to be unknown in 95/292 (32.5%) cases. Lead clinicians for inpatient care reported that GMFCS level was clearly assessed and documented on admission for 51/405 (12.6%) patients and not known in 131/536 (24.4%) patients (Figure 8.2). Where GMFCS



**Figure 8.2 Access to community notes and was GMFCS level documented in them**

level was not assessed or recorded on admission, it was documented during the admission in only 21/333 (6.3%) cases reviewed (Figure 8.3).

their mobility in 232/333 (69.7%) admitted patients and 92/173 (53.2%) day case patients. The case reviewers were unable to answer for 19/352 (5.4%) admitted patients and 9/173 (5.2%) day case patients (Figure 8.4).

Case note reviewers reported that it was clear from the admission notes how the patient’s cerebral palsy affected

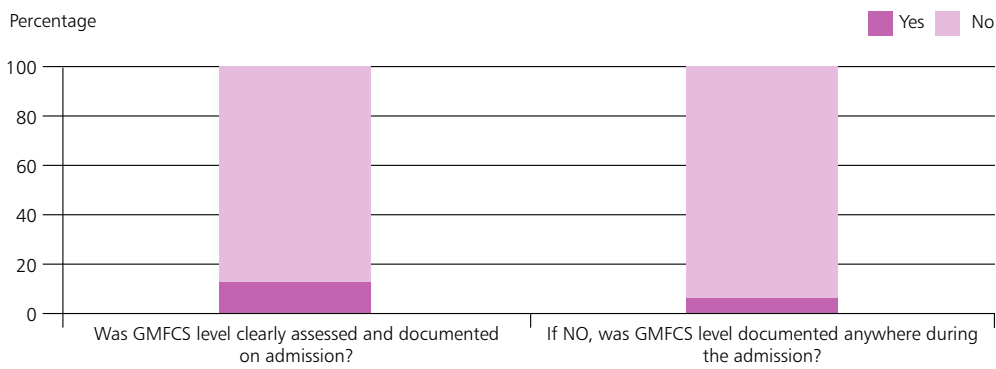


Figure 8.3 GMFCS level was documented on or during the admission

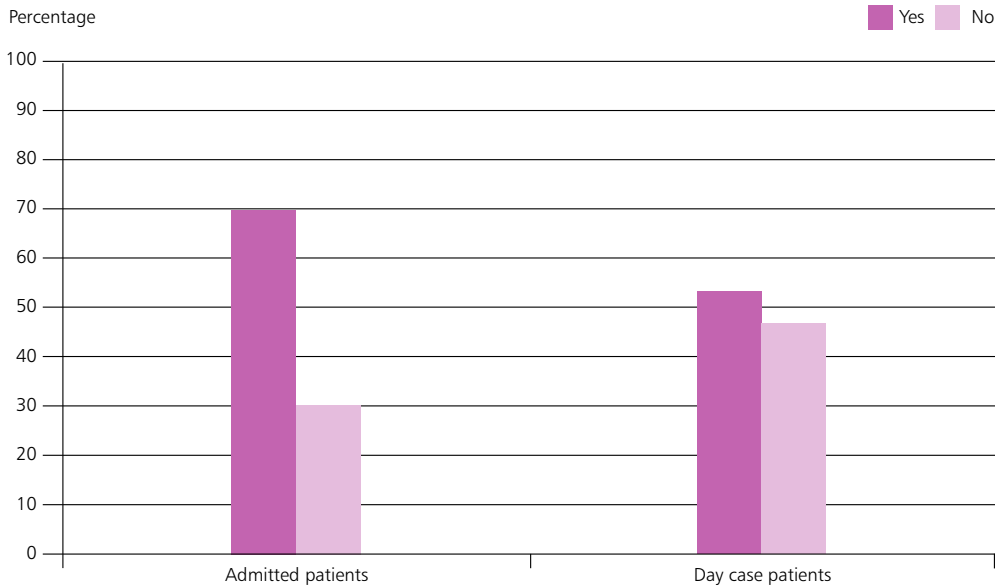


Figure 8.4 Documentation of how patient’s cerebral palsy affected their mobility- reviewers’ opinion

A proactive approach to symptom and postural management was reported not to have been taken by 18/207 (8.7%) lead clinicians for disability care and 1/18 GP, reportedly because of lack of available specialist clinical expertise according to 8/18 lead clinicians and 1/1 GP; because of lack of engagement with the family (3/18 lead clinicians) and lack of engagement with the patient (1/18

lead clinicians). Adequate symptom control on admission to hospital was reported by case reviewers to be absent for 23/285 (8.1%) patients. Adequate attention to posture, mobility and safe transfers, with timely access to appropriate equipment as required on the ward was reported by reviewers to be lacking in 67/245 (27.3%) cases.

The range of symptoms reported by lead clinicians for disability care at the time of the most recent assessment is shown in Table 8.2.

**Table 8.2 Range of symptoms present**

	Symptom present			If present, current status			
	Yes	No	Subtotal	Not documented	Active/Symptomatic	Quiet on treatment	Not answered
	n=	n=	n=	n=	n=	n=	n=
<b>Constipation</b>	92	94	<b>186</b>	35	16	74	2
<b>Feeding/swallowing issues</b>	140	66	<b>206</b>	15	42	91	7
<b>Gastro-oesophageal reflux</b>	100	94	<b>194</b>	27	21	77	2
<b>Droling</b>	101	91	<b>192</b>	29	34	63	4
<b>Sleep issues</b>	78	98	<b>176</b>	45	39	36	3
<b>Airway issues</b>	57	139	<b>196</b>	25	30	24	3
<b>Respiratory issues</b>	84	118	<b>202</b>	19	40	42	2
<b>Medication administration issues</b>	33	168	<b>201</b>	20	13	18	2
<b>Nutritional issues</b>	91	115	<b>206</b>	15	39	45	7
<b>Behavioural emotional issues</b>	50	143	<b>193</b>	28	36	12	2
<b>Continence issues</b>	120	66	<b>186</b>	35	43	73	4
<b>Postural/transfer issues</b>	135	62	<b>197</b>	24	62	65	8

### National Routine Data

Within the routinely collected NHS datasets most cases were recorded as G80.9 (non-specific cerebral palsy) and thus the specific type of cerebral palsy was rarely recorded. There are no clinical codes for functional severity of the condition. Other than data reported to the Northern Ireland Cerebral Palsy Survey, the only routinely collected population data about GMFCS levels at this time in the UK is that collected by paediatric physiotherapists and reported to the Cerebral Palsy Integrated Programme Scotland (CPIPS).

At the start of this study the aim was to identify cohorts of children and young people with one of the cerebral palsies from two regional cerebral palsy registers and the Support Needs System (SNS) in Scotland and link these to routinely collected datasets. However, during the study the North of England Collaborative Cerebral Palsy Survey (NECCPS) was no longer supported as a standalone dataset and the data linkage was not possible. Problems identifying NHS numbers for those within the Northern Ireland Cerebral Palsy Register (NICPR) could not be resolved for data linkage within the timescale of the project. The SNS is not routinely

or consistently used across the twelve NHS Health Boards and data were not considered representative of the population. Therefore, analysis of data within the NECCPS and NICPR, as standalone datasets, was undertaken to give a description of the potential healthcare needs of two representative populations of children and young people with a cerebral palsy according to levels of functional impairment and related morbidity.

The NICPR is a confidential record of every child with one of the cerebral palsies born in Northern Ireland since 1977 or living in the area since 1992. The dataset received from the NICPR included those born between 1981 and 2011. There were 1,802 children with cerebral palsies aged up to 33 years by 2014 (but within the age range 0-24 within the study time period).

The dataset received from NECCPS included 429 children born between 2004 and 2014 with one of the cerebral palsies living in the North of England. The patients within the cohort were aged 0-12 years old by the end of the study period (2014) and data were collected prospectively. These data are summarised in Table 8.3.

**Table 8.3 Data recorded within NECCPS and NICPR about the demographics, cerebral palsy type, GMFCS level and mortality of children and young people with one of the cerebral palsies.**

Variable		NECCPS (n=429) Date of birth 2004-2014		NICPR (n=1,802) Date of birth 1981-2011	
		Frequency	Proportion (95% CI)	Frequency	Proportion (95% CI)
<b>Gender</b>	Male	260	60.6 (55.9-65.1)	1,037	57.5 (55.3-59.8)
	Female	168	39.2 (34.7-43.9)	763	42.3 (40.1-44.6)
	Missing	1	0.2 (0.0-1.3)	2	0.1 (0.0-0.4)
<b>Deprivation</b>	1 (least)	NA	NA	105	5.8 (4.8-7.0)
	2	NA	NA	93	5.2 (4.2-6.3)
	3	NA	NA	148	8.2 (7.0-9.6)
	4	NA	NA	306	17.0 (15.3-18.8)
	5 (most)	NA	NA	861	47.8 (45.5-50.1)
	Missing	NA	NA	289	16.0 (14.4-17.8)

**Table 8.3 Data recorded within NECCPS and NICPR about the demographics, cerebral palsy type, GMFCS level and mortality of children and young people with one of the cerebral palsies (Continued).**

Variable		NECCPS (n=429) Date of birth 2004-2014		NICPR (n=1,802) Date of birth 1981-2011	
		Frequency	Proportion (95% CI)	Frequency	Proportion (95% CI)
<b>Cerebral palsy type</b>	Spastic bilateral	218	50.8 (46.1-55.5)	913	50.7 (48.4-53.0)
	Spastic unilateral	177	41.3 (36.7-46.0)	717	39.8 (37.6-42.1)
	Dyskinetic	9	2.1 (1.1-3.9)	88	5 (4.0-6.0)
	Dyskinetic choreoathetoid	3	0.7 (0.0-1.3)	NA	NA
	Dyskinetic dystonic	10	2.3 (1.3-4.2)	NA	NA
	Ataxic	NA	NA	48	3 (2.0-3.5)
	Unclassifiable	NA	NA	9	0 (0.3-0.9)
	Missing	12	2.8 (1.6-4.8)	27	1 (1.0-2.2)
<b>GMFCS level</b>	I	65	32.3 (26.3-39.1)*	300	16.6 (15.0-18.4)
	II	54	26.9 (21.2-33.4)*	683	37.9 (35.7-40.2)
	III	20	9.9(6.5-14.9)*	283	15.7 (14.1-17.5)
	IV	26	12.9 (9.0-18.9)*	114	6.3 (5.3-7.5)
	V	36	17.9(13.2-23.8)*	393	21.8 (20.0-23.8)
	Unknown	1		NA	NA
	Missing	227		29	1.6 (1.1-2.3)
<b>DIED</b>	Yes	17	4.0 (2.5-6.3)	83	4.6 (3.7-5.7)
	No	412	96.0 (93.7-97.5)	1,719	95.4 (94.3-96.3)

\* Proportion calculated for the population where GMFCS level was recorded in NECCPS (as these data were only recorded in less than half of the cases they should be interpreted with caution)

There was a greater proportion of males amongst children and young people with one of the cerebral palsies and NICPR confirmed a strong relationship between social deprivation and the cerebral palsies.

The proportion of cerebral palsy types was similar in both populations with an estimated 50% of the population having bilateral spastic cerebral palsy and 40% unilateral spastic cerebral palsy.

The distribution of GMFCS levels differed between the NICPR and the NECCPS populations. In both populations an estimated 1 in five children and young people had a GMFCS level V score. The proportion of GMFCS level V in these population samples was lower than in the case note review that identified children and young people from hospital admission case notes and is likely to represent the more seriously affected group.

## Pain management

Pain is known to be a significant determinant of levels of participation and quality of life for children and young people with cerebral palsies and has been prioritised by parent carers as well as health professionals as an area requiring optimisation in routine management. <sup>32-36,19</sup>



A policy of always asking about the presence of pain at each consultation with a patient with cerebral palsy was reported to be in place in the paediatric outpatient care questionnaire in 29/80 organisations and in the community or disability paediatric care questionnaire in only 33/80 organisations.

Respondents from 60% of organisations reported that they did not have a policy in place to promote routine enquiries about the presence of pain at each consultation where the patient had a cerebral palsy.

Chronic pain was reported by lead clinicians for disability care to be adequately assessed for 159/184 (86.4%) patients, but not for 25/184 (13.6%) patients (Table 8.4). There was evidence of a management plan for pain in just 98/126 (77.8%) patients and frequently this was not known (Table 8.5).

**Table 8.4 Adequacy of enquiries made about the presence of pain**

	Lead clinician for disability care		Case note reviewer	
	n=	%	n=	%
Adequate	159	86.4	173	61.6
Inadequate	25	13.6	108	38.4
<b>Subtotal</b>	<b>184</b>		<b>281</b>	
Unknown	37		69	
<b>Total</b>	<b>221</b>		<b>350</b>	

**Table 8.5 Presence and adequacy of a pain management plan - reviewers' opinion**

	If pain was present:			
	Was a clear management plan made to address this?		Is there evidence in the notes that pain was adequately controlled?	
	n=	%	n=	%
Yes	98	77.8	78	64.5
No	28	22.2	43	35.5
<b>Subtotal</b>	<b>126</b>		<b>121</b>	
Unable to answer	59		61	
Not applicable	71		60	
Not answered	94		108	
<b>Total</b>	<b>350</b>		<b>350</b>	

Reviewers were of the opinion that pain management could have been improved for 102/203 (50.2%) patients. They were unable to answer for 50/350 (16.9%) patients, found the question not applicable for 43/350 (12.3%) patients and did not answer for 54/350 (15.4%) patients. Reviewers reported that pain management could have been improved as in Table 8.6.

**Table 8.6 Improvement that could have been made to the pain management plan - reviewers' opinion**

	n=
Documentation of pain enquiry	85
Use of an appropriate scoring system	65
Evidence of a pain management plan	51
Referral to a specialist pain team	11
<b>Total</b>	<b>102</b>

\*Answers may be multiple

### Hand function

A clear description of the patient's level of hand function is important, to know what they may be able to manage independently by way of self-care and everyday activities and where support may be needed across settings. Lead clinicians reported information about patients' level of hand function for 212/221 (96%) patients.

### Learning ability or learning disability

A clear understanding of the patient's level of learning or intellectual ability is important as this determines what

support the patient will need to be involved in decision-making about their care and the level of language and communication style required to receive and convey information. People with learning disabilities are known to have worse outcomes overall than people without learning disabilities; men and women with learning disabilities are likely to die 13 and 20 years younger than men and women without learning disabilities respectively.<sup>37</sup> Contributing to premature mortality amongst people with learning disabilities is **diagnostic overshadowing**, when the condition or disability is blamed for a symptom or sign and is a barrier to the thorough, systematic evaluation of symptoms and signs that anyone without disabilities would expect. These oversights can lead to poor nutrition, postural deformities, pain, and premature death, as illustrated by the 'six lives' described in Mencap's report 'Death by indifference'.<sup>38</sup>

Case note reviewers reported documentation in the case notes of the patient's learning **ability** for the admission and in clinic letters/summaries (Table 8.7).

A learning disability was specifically documented in the case notes, as reported by the case reviewers, in 306/532 (57.5%) patients.

The patient's level of learning ability was clearly assessed and documented on admission to hospital, as reported by the lead paediatrician for acute care, in only 188/433 (43.4%) patients. This item was documented as 'unknown' in 58/536 (10.8%) patients and was not answered in 45.

**Table 8.7 Documentation in the case notes of learning ability - reviewers' opinion**

	In a clinic letter					Total
		Yes	No	Subtotal	Not answered	
In the case notes	Yes	144	38	182	45	227
	No	83	166	249	63	312
	<b>Subtotal</b>	<b>227</b>	<b>204</b>	<b>431</b>	<b>108</b>	<b>539</b>
	Not answered	6	4	10	5	15
	<b>Total</b>	<b>233</b>	<b>208</b>	<b>441</b>	<b>113</b>	<b>554</b>



Intellectual impairment was recorded in 791/1760, 44.9% (95% CI (42.6 - 47.3)) of the NICPR population. Data on intellectual ability with respect to GMFCS levels were available for 1,708 children and young people (Table 8.8).

Of 1,629 children where place of education was recorded, 46% attended special schools, 40% attended main stream, the remainder were home tutored, had left education or had alternative provision.

Similar data were available for 196 children and young people on the NECCPS where an estimated 40%+ were recorded to have IQ < 80. The trends in intellectual impairment across GMFCS levels were similar to that found in the NICPR data (Table 8.9).

This figure was slightly higher than the overall figure within the NICPR and NECCPS but consistent with the fact that hospital admissions represent children and young people with more serious levels of impairment.

**Table 8.8 Intellectual ability as recorded for 1,708 children and young people on the NICPR according to GMFCS level (frequency and %)**

	GMFCS level					Total
	I	II	III	IV	V	
No impairment IQ > 70	238 (79.3)	467 (68.4)	166 (58.7)	31 (27.2)	26 (6.6)	<b>928</b>
Moderate IQ 50-69	28 (52.8)	94 (50.8)	57 (52.8)	27 (36.0)	32 (8.9)	<b>238 (30.5)</b>
Severe IQ < 50	16 (30.2)	84 (45.5)	45 (41.7)	43 (57.3)	312 (86.9)	<b>500 (64.1)</b>
Unknown	9 (17.0)	7 (13.2)	6 (5.6)	5 (6.7)	15 (4.2)	<b>42 (5.4)</b>
<b>Total</b>	<b>291</b>	<b>652</b>	<b>274</b>	<b>106</b>	<b>385</b>	<b>1708</b>

**Table 8.9 Intellectual ability as recorded for 196 children and young people in the NECCPS, according to GMFCS level (frequency and %)**

IQ	GMFCS level					Total
	I	II	III	IV	V	
> 80	51 (79.7)	39 (75.0)	13 (68.4)	6 (25.0)	* (< 1%)	<b>109+</b>
50-80	10 (15.6)	11 (21.2)	6 (31.6)	12 (50.0)	8 (22.2)	<b>47</b>
< 50	* (< 5%)	2 (3.8)	0 (0)	5 (20.8)	26 (72.2)	<b>33+</b>
<b>Total</b>	<b>61+</b>	<b>52</b>	<b>19</b>	<b>23</b>	<b>34</b>	<b>189</b>

\*Figures were < 5 and report small numbers cannot be reported (total figures are therefore more than recorded in the total columns)

## Communication

Communication is more than just talking and can also involve facial expressions, gestures, eye gaze, behaviours, signs, symbols and/or low or high level technological aids.<sup>27</sup> Establishing how a patient communicates is vital to be able to glean information from them, share information with

them and involve them in decision-making about their care. Table 8.10 shows the variation reported in documentation of the patient's preferred communication method. The lead clinicians for inpatient care indicated that 143/287 (49.8%) patients had special communication needs.

**Table 8.10 Documentation in the case notes of preferred communication method - reviewers' opinion**

	In a clinic letter					Total
		Yes	No	Subtotal	Not answered	
In the case notes	Yes	99	47	146	41	187
	No	58	211	269	74	343
	<b>Subtotal</b>	<b>157</b>	<b>258</b>	<b>415</b>	<b>115</b>	<b>530</b>
	Not answered	6	7	13	11	24
	<b>Total</b>	<b>163</b>	<b>265</b>	<b>428</b>	<b>126</b>	<b>554</b>

Of the 1,756 children and young people in the NICPR, where communication skills were recorded, 795 (45.27% (42.93-47.63%)) had a communication difficulty. The figure

for children and young people in the NECCPS cohort was similar at 96/208 (46.15% (39.27-53.17%)) (Table 8.11).

**Table 8.11 Means of communication as recorded for 1,756 children and young people in the NICPR and for 208 children and young people from the NECCPS dataset**

Communication method	NICPR		NECCPS	
	Freq.	Percent	Freq.	Percent
Age appropriate communication skills	961	54.72 (52.39-57.04)	111	53.37 (46.59-60.02)
Speech	286	16.29 (14.63-18.09)	53	25.48 (20.04-31.81)
Formal methods <i>Speech and formal method</i>	130	7.40 (6.27-8.72)	22	10.58 (7.09-15.49)
<i>Formal methods only</i>	88	5.11 (4.09-6.13)		
	42	2.39 (1.77-3.22)		
No verbal communication or formal method used	332	18.91 (17.14-20.81)	21	10.10 (6.7-14.94)
Missing	47	2.68 (2.02-3.54)		
<b>Total</b>	<b>1756</b>	<b>100</b>	<b>208</b>	

**Table 8.12 Communication impairment as recorded for 1,742 children and young people with one of the cerebral palsies according to GMFCS level in the NICPR (frequency and %)**

	GMFCS level					Total
	I	II	III	IV	V	
Impaired level of communication	47 (15.8)	185 (27.4)	107 (38.5)	75 (66.4)	374 (95.9)	<b>788 (44.9)</b>
<b>Total</b>	<b>296</b>	<b>669</b>	<b>278</b>	<b>113</b>	<b>386</b>	<b>1,742</b>

### Vision

The case reviewers reported that an enquiry had been made on admission about the patient's level of vision/vision impairment in 139/252 (55.2%) cases reviewed, but were unable to answer in 60 cases. The question was marked as not applicable in 17 and was not answered in 23 cases. The lead clinicians for acute care reported 110/214 (51.4%) patients to have vision impairment.

From NICPR data, it was possible to analyse means of communication by GMFCS level for 788 children and young people where both factors were recorded (Table 8.12).

The proportion of children and young people with visual impairment were similar in the two populations at 29.7% (95% CI: 27.7-31.9) in the NICPR and 36% (95%CI: 29.7-43.1) in the NECCPS (Table 8.13).

**Table 8.13 Visual impairment recorded according to GMFCS in the NICPR and NECCPS cohorts where both factors were recorded (frequency % and 95% CI)**

Visual impairment	GMFCS level					Total
	I	II	III	IV	V	
NICPR	39/300 (13.0 (9.7-17.3))	185 (27.4) (21.5 (18.6-24.8))	91 /283 (32.2 (27.0-37.8))	46 /114 (40.4 (31.8-49.5))	207 /393 (52.7 (47.7-57.6))	536 /1802 (29.7 (27.7-31.9))
NECCPS	11/64 (17.2 (9.9-28.2))	15/51 (28.8 (18.7-43.0))	6 /18 (31.6 (16.3-56.3))	11/55 (42.3 (11.6-32.4))	27/35 (77.1 (61.0-87.9))	70/194 (36.1 (29.7-43.1))

### Hearing

Case note reviewers reported that an enquiry had been made about the presence of hearing impairment in just 53/119 (44.5%) cases reviewed. They were unable to answer from the information available in 36 cases and the question was not applicable in 14/169 (48.3%) cases. The lead clinician for inpatient care reported documentation of hearing impairment in 39/287 (13.6%) patients.

**Table 8.14 Hearing impairment recorded according to GMFCS level in the NICPR cohort where both factors were recorded (frequency % and 95% CI)**

NICPR		GMFCS level						Missing	Total
		I	II	III	IV	V			
NICPR	Hearing impairment	10/287 (3.5 (1.9-6.3))	48/670 (7.2 (4.4-8.0))	9/277 (3.3 (1.7-6.1))	8/108 (7.4 (3.8-13.9))	57/386 (14.8 (11.6-18.7))	3/13 (23.1 (8.2-50.3))	<b>135/1746</b> <b>(7.7 (6.6-9.1))</b>	
	Uncertain		8 (1.2 (0.6-2.3))			51 (13.2 (10.2-17.0))		<b>74</b> <b>(4.2 (3.4-5.3))</b>	

Table 8.14 shows that there was no significant difference between the overall proportion of children and young people recorded with hearing impairment within the NICPR (7.7%: 95% CI: 6.6-9.1) (Table 8.14) and the NECCPS dataset (5.05%: (95% CI: 2.77-9.05) (10/198) (The numbers in the NECCPS were too small within each GMFCS level to report).

### Eating and drinking ability and nutritional status

Inadequate food intake leads to poor nutrition and growth, which is common among children with cerebral palsies.<sup>39,40,41</sup> Multiple challenges can occur from difficulties in how the mouth handles food and drink to swallowing and digestion.

Lead clinicians for disability care reported 33/217 (15.2%) patients to have feeding difficulties but could eat orally with some adjustment. A further 22/217 (10.1%) required a feeding tube to augment oral feeding and 98/217 (45.2%) required a feeding tube for total nutrition as unable to eat or drink safely.

Case note reviewers reported that the patient's weight had been recorded in the medical record during the admission for only 254/333 (76.3%) admitted patients and 104/177 (58.8%) day case patients.

Lead clinicians reported their patient's nutritional status had been considered and recorded in the last year for 189/208 (90.9%) patients and was unknown for 13 patients.

Lead clinicians for acute admissions reported that weight was documented during the admission in only 359/536 (67%) patients, of which 285 were based on actual weights,

59 estimated weights and for 13 this was unknown. The reasons given for not weighing inpatients were lack of availability of suitable equipment in seven patients, the patient was too sick to be moved in 22 patients and no reason was given in 25 patients.

Accurate fluid and drug calculations depend on accurate weight measurement. Wider availability of weighing equipment in inpatient settings suitable for people of all ages with a range of disabilities is essential if disabled people are to receive high quality healthcare. **9**

Lead clinicians for acute admissions reported that height was documented during the admission in only 63/536 (11.8%) patients, of which 55 were based on actual height measurement the remaining were estimated heights.

There were reported to be clinical concerns about the weight, growth or nutritional status of the patient in 62/213 (29.1%) patients, yet lead clinicians for disability care were able to report the most recent weight of only 195/221 (88.2%) patients and height or length of 79/142 (55.6%) patients. Where the weight or height/length was not available, this was reported to be because of lack of suitable equipment to assess weight in five patients and to assess height/length in 34 patients, lack of an available hoist in four for weight and seven for height/length. Postural deformities were reported to prevent accurate measurement of height/length of 56/133 (42.1%) patients, and the patient was in pain and could not be moved was the reason given in 2/113 (1.8%) patients. Only 21/221 (9.5%) leads for disability care reported using other anthropometric measures (triceps skin fold thickness, mid arm circumference). Where clinical leads reported there

to be suboptimal nutritional status, input was not sought from a dietician in 13/114 (11.4%) patients nor from a gastroenterologist in 50/84 patients.

Case note reviewers were of the opinion that 59.5% (198/333) of patients were nutritionally vulnerable, affecting all age groups. There was evidence of adequate, regular assessment of the patient's nutritional status in 160/185 (86.5%) cases reviewed, but not in 25/185 (13.5%). Reviewers reported 170/315 (54%) patients to be tube fed and that there were specific problems with tube feeding for 69 patients. Reviewers reported evidence to suggest issues with the safety of the patient's eating and drinking (i.e. aspiration risk) for 144/311 (46.3%) patients and that there was evidence that this had been formally assessed in the last three years for 107/125 (85.6%) patients, but not for 18/125 (14.4%) patients. Table 8.15 shows data from the routine data where this was recorded.

### CASE STUDY 9

A young child with bilateral cerebral palsy and multiple associated health conditions was admitted with a chest infection. The patient was prescribed antibiotics and after a short period of observation was discharged home again.

A teenager with bilateral cerebral palsy, GMFCS level IV was admitted as a day case for botulinum toxin injections. The procedure was completed and the patient discharged home.

*The case reviewers of both cases found no documentation of the patient's weight anywhere in the records. These were patients with complex disabilities at high risk of nutritional compromise. The reviewers were of the opinion that this was concerning, because accurate dose calculation depends on weight, especially in a disabled patient whose weight might not be as expected for age. Good practice would have been for the patients to have been weighed on admission using appropriate equipment for their disabilities and for this to have been clearly recorded in the medical records.*

**Table 8.15 Frequency table showing feeding problems recorded among those in the NICPR (n=1,802)**

Feeding problems	Freq.	Percent
No problem	1,248	69.26
Feeds via nasogastric tube	34	1.89
Gastrostomy in situ	85	4.72
Unknown method	134	7.44
Feeding orally with difficulty	134	7.44
Gastroesophageal reflux	26	1.44
Missing	141	7.82
<b>Total</b>	<b>1,802</b>	<b>100</b>

### Spasticity

The NICE Clinical Guideline 145: 'Spasticity in under 19's':<sup>29</sup> management' recommendations 1.1.1 and 1.1.2 state that "children and young people with spasticity should have access to a network of care that uses agreed care pathways supported by effective communication and integrated team working and that this network should include a team of healthcare professionals experienced in the care of children and young people with spasticity."

It was seen in chapter 5 that reviewers noted the diagnostic term used to describe the patient's cerebral palsy did not include information about the specific tone variation (i.e. spasticity, dyskinesia, dystonia, choreoathetosis, ataxia) in 297/521 (57%) cases reviewed. Spasticity was reported to be present by 186/218 (85.3%) lead clinicians for disability care, who reported routine access to a network of care that uses agreed care pathways supported by effective communication and integrated team working for 162/179 (90.5%) patients. The patients views about the effectiveness of treatments and interventions were reported to be recorded, as appropriate for age and cognitive ability, by 58/85 lead clinicians, but not for 27/85 patients. Lead clinicians reported 78/173 (45.1%) of their patients to have fixed contractures. **5**

There was sufficient information to assess the quality of spasticity management for patients with spastic cerebral palsy over the last three years for 207/271 (76.4%) patients. In the reviewers opinions, spasticity management was supervised by a team with specialist expertise in spasticity for 176/196 (89.8%) patients, but not for 20/196 (10.2%) patients.

### Associated conditions

A wide range of conditions are known to be regularly associated with the cerebral palsies and need to be addressed in the overall care plan if the patient is to experience the least possible symptoms and enjoy maximum participation and the best quality of life.

Lead clinicians for inpatient care reported 396/491 (80.7%) patients to have associated conditions. This was unknown for 45/491 (9.2%) patients. As an example, Table 8.16 shows the prevalence of seizures in this group of patients.

**Table 8.16 Prevalence of seizures in children and young people with one of the cerebral palsies**

Condition	Frequency	Proportion
Seizures	NECCPS 60/201	NICPR 450/1802
	28.6 (22.7-35.3)	25.0 (23.0-27.0)

**Table 8.17 Room for improvement in the admission documentation about how the patients cerebral palsy affected the patient's health, mobility and social functioning – reviewers' opinion**

	Health		Mobility		Social functioning	
	n=	%	n=	%	n=	%
Yes	116	38.2	144	47.8	166	<b>57.0</b>
No	188	61.8	157	52.2	125	<b>43.0</b>
<b>Subtotal</b>	<b>304</b>		<b>301</b>		<b>291</b>	
Unable to answer	20		23		32	
Not answered	28		28		29	
<b>Total</b>	<b>352</b>		<b>352</b>		<b>352</b>	

### CASE STUDY 10

A young child with dystonic cerebral palsy was admitted for a procedure as a day case. The procedure was completed and the patient was discharged home

*The case reviewer found the admission case notes to be scanty, with no description of how the child's condition affected the patient, nor their level of functioning in any domain. Review of the community case notes also found no description of levels of functioning, other than a need for hoisting, suggesting the patient was non-mobile. The community notes documented that the patient's weight was falling, but there was no documented action plan to address this or evidence of dietician input or referral.*

Seizures were recorded in the case notes of one in four children and young people with a cerebral palsy.

Reviewers reported that the patient's health needs were not adequately described in 58/350 (24.3%).

Reviewers were asked if there was room for improvement in the admission documentation about how the patient's cerebral palsy affected their health, mobility and social functioning. The findings are shown in Table 8.17.

**CASE STUDY 11**

A teenager with bilateral cerebral palsy, with motor function at GMFCS level V, was admitted with a lower respiratory tract infection which was treated. The patient improved and was discharged next day.

*The case reviewer found excellent documentation of the patient's wider needs across domains of functioning and the associated medical conditions. The opportunity of admission was taken to review the patient's needs and further unmet needs were identified. The care plan on the ward and on discharge comprehensively addressed all identified needs and communicated clearly to the multidisciplinary team. The reviewer also found evidence in the outpatient notes of excellent, proactive healthcare.*

Identification of all needs is the first step to them being addressed as part of the comprehensive care plan. The opportunity of a hospital visit can be used to achieve this.

**Safeguarding**

Issues were reported in the last three years by lead clinicians for disability care for 35/208 (16.8%) patients and in one case the clinician reported a delay in the identification of safeguarding issues, although this was not reported to be due to lack of available specialist clinical expertise.

**Documentation of adjustments required**

Documentation in the case notes of adjustments that patients may require during hospital admissions was reported by 135/263 (51.3%) reviewers, with no such documentation reported by 128/263 (48.7%).

**Assessment of needs on discharge from hospital**

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 in 153/234 (65.4%) cases, but this was reported as inadequate in 81/234 (34.6%) cases. Reviewers were unable to answer in 82 cases and did not answer this question in 36 cases.

**Key Findings – routine national data**

- Prospective and focused data collection utilising specific data fields that relate to the cerebral palsies provides rich data to categorise disease severity and to identify healthcare needs on a population basis. Incorporating these fields into Community Services Routine data collection has the potential to improve this knowledge base on a national population scale
- The analysis showed a very similar pattern of disease severity, functional impairment and associated morbidity across two populations of children and young people from different regions of the UK, collected over different time periods
- The data from NECCPS and NICPR showed a greater populations of males for the children and young people with cerebral palsies. There was a strong relationship between cerebral palsies and social deprivation and an overall mortality rate of 4-4.6%
- These datasets gave a picture of the type and severity of cerebral palsies within the general population and showed that 50% were spastic bilateral and 40% spastic unilateral. Data recorded regarding GMFCS level varied across the datasets but showed that approximately one in five had a GMFCS level of V
- The NICPR identified intellectual impairment in 45%; 46% of the children and young people with one of the cerebral palsies attended special schools, 40% attended mainstream and the remainder were home tutored
- Both cerebral palsy registers confirmed communication difficulties in around 45%, visual impairment in 30-36% and hearing impairment in 5-7.7% of children and young people with one of the cerebral palsies.

### Key Findings – questionnaire, case note review and organisational data

- Reviewers could find evidence of GMFCS level documentation in the case notes in only 155/547 (28.3%) cases
- Data from the admission questionnaire indicated GMFCS level was clearly assessed and documented on admission in only 51/405 (12.6%) patients. Furthermore, where not documented on admission, GMFCS level was documented during the admission in only 21/333 (6.3%) patients
- Room for improvement in documentation in inpatient case notes about how a person's cerebral palsy affected their mobility was reported in 47.8% (144/301) of cases reviewed
- A learning disability was specifically documented in the case notes in 306/532 (57.5%) cases
- The level of learning ability was reported as assessed and documented on admission in 188/433 (43.4%) of admission questionnaires. This was unknown or not answered in 103/536 (19.2%) cases reviewed
- Reviewers identified documentation of the preferred communication method recorded in the case notes of 187/530 (35.3%), and in a clinic letter for 163/428 (38.1%) patients
- Reviewers reported that the patient's weight was recorded in the case notes of 254/333 (76.3%) admitted patients, and 104/177 (58.8%) day case patients
- Weight was reported as documented during the admission in 359/536 (67%) admission questionnaires, and in a majority of cases (285/344; 82.8%) this was the actual weight rather than an estimate
- Data from the ongoing care questionnaire indicated the patient's nutritional status had been considered and recorded in the last year in 189/208 (90.9%) of cases included
- Reviewers reported that the patient's health needs were adequately described in 278/350 (79.4%) of cases
- Data from the ongoing care questionnaire indicated adequate enquiries were made about the presence of pain in 159/184 (86.4%) patients, however reviewers found evidence in the notes in only 173/281 (61.6%) cases
- A policy of always asking about the presence of pain at each consultation with a patient with cerebral palsy was reported to be in place in only 40% of organisations.
- Reviewers reported evidence to suggest issues with the patient's eating and drinking in 144/311 (46.3%) of cases reviewed
- Case note reviewers reported that six out of ten patients with cerebral palsies whose case notes were reviewed were nutritionally vulnerable (198/333; 59.5%), more than ten percent (25/185; 13.5%) had evidence of inadequate nutritional surveillance
- Reviewers reported evidence of risk of aspiration (unsafe swallow) in 46% (144/311) patients with cerebral palsies, but no evidence that this had been assessed in the last three years in 14.4% (18/125) of these cases
- Reviewers reported that the range of health needs of more than one in ten children (58/350; 16.6%), young people and young adults with cerebral palsies were inadequately described in their case notes
- Overall symptom management was assessed by reviewers as inadequate for more than one in ten children, young people and young adults with cerebral palsies whose case notes were reviewed (34/333; 10.2% admitted patients; 22/158; 13.9% day case patients)
- Case note reviewers reported no documentation about adjustments required to meet the needs of half of the children, young people and young adults with cerebral palsies whose case notes were reviewed (128/263; 48.7% admitted patients)
- Inadequate 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 in one third of cases reviewed (81/234; 34.6% admitted patients).

### SEE RECOMMENDATIONS

**4•5•8•9•10•11•12•15•17•18•19•20  
22•25•26•27•28•29•30•31•32•33**