6

6 – Communication

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Study Advisory Group question: *How well are care plans communicated to patients and their families?*

Why is this important? *Good communication underpins all clinical practice and is encouraged by the:*

- *General Medical Council's 2015 Duties of a Doctor guidance "You must listen to patients, take account of their views and respond honestly to their questions"*[23]
- *UK National Health Service's constitution: "Staff should aim to be open with patients, their families, carers or representatives, including if anything goes wrong; welcoming and listening to feedback and addressing concerns promptly and in a spirit of co-operation"*[24]
- *Good doctor-patient communication correlates positively with increased patient satisfaction.*[25]

Communication about diagnosis

Communication between families and professionals at the start of the clinical journey sets the scene and is remembered. NICE Guideline NG62[19] makes recommendations about the information and support that professionals should share with families on an ongoing basis. SCOPE (previously known as the Spastics Society) produced guidance on 'sharing the news' of a child's disability, known as 'Right from the Start'.[3] Data from the paediatric inpatient and community care questionnaires reported that 'Right from the Start' or equivalent guidance was embedded in general paediatric practice in only 27/80 organisations and in community paediatric practice in only 46/75 organisations. Specific training in 'Right from the Start' or equivalent guidance for those communicating disability diagnoses had been delivered for general paediatric teams in only 25/82 organisations and for disability or community paediatric teams in only 19/75 organisations. Parents were reported to be given written information about the diagnosis by general paediatric teams in only 51/81 organisations in only 57/73 organisations completing the community paediatric care questionnaire.

Data from the community paediatric care organisational questionnaire indicated that parents were provided with sources of support and information locally in 66/74 organisations and nationally in 60/74 organisations.

Leads for the disability care for individual patients reported that the patient and family had been given written information about their cerebral palsy and associated health conditions in 115/154 cases, but not in 39/154. This was unknown for 67/221. Of GPs who responded, 7/9 reported their patients had been given adequate written information about their cerebral palsy and associated conditions and 15/23 patients this was unknown.

Communication with the patient and family

In their opinion, case reviewers reported that sufficient effort had been made to communicate directly with 156/245 (63.7%) patients. The patient's preferred communication method had been ascertained for 159/275 (57.8%) patients, which varied with age as shown in Table 6.1.

Reviewers reported evidence that the patient was, where possible, included in all discussions and decision-making about them, including where appropriate in the consent process for 91/180 admitted patients and 48/97 day case patients. Documentation of inclusion of the patient in discussions and decision-making in the opinion of the case reviewers is shown in Table 6.2. 11

Table 6.1 Preferred communication method ascertained, by age - reviewers' opinion

	1-4 years	5-9 years	10-14 years	15-19 years	20-25 years	Total
	n=	n=	n=	n=	n=	n=
Yes	25	50	33	26	25	**159**
No	17	31	26	26	16	**116**
Subtotal	**42**	**81**	**59**	**52**	**41**	**275**
Unable to answer	0	6	5	9	4	**24**
Not applicable	21	10	7	9	4	**51**
Total	**63**	**97**	**71**	**70**	**49**	**350**

Table 6.2 Documentation of inclusion of patient in discussions and decision-making - reviewers' opinion

	Admitted patients		Day case patients	
	n=	%	n=	%
Yes	120	40.0	59	39.9
No	180	60.0	89	60.1
Subtotal	**300**		**148**	
Unable to answer	52		34	
Total	**352**		**182**	

There was room for improvement in the documentation of inclusion of the parent carers in discussions and decision-making in the opinion of the case reviewers for only 50/206 (24.3%) patients.

Documentation of decision-making for the patient could have been better, in the opinion of case reviewers, for 106/236 (44.9%) patients. Reviewers were unable to answer in 116/352 cases reviewed. Table 6.3 shows whether documentation of decision-making for the patient could have been better by age group.

CASE STUDY 4

A young adult patient with a cerebral palsy was admitted as a day case for an investigation. The patient signed their own consent form. The procedure was without complication and they went home the same day.

The case reviewer found documentation showing the patient had sent the questions they wanted to ask the surgeon in advance via their alphabet board. This made the discussion about consent meaningful and appropriate to their needs, as the patient did not use speech to communicate.

All reasonable adjustments should be proactively in place to ensure that disabled people are treated no less favourably because of their disability, in line with the Equality Act 2010.

Table 6.3 Clarity of documentation of decision-making by patient's age - reviewers' opinion

	1-4 years	5-9 years	10-14 years	15-19 years	20-25 years	Total
	n=	n=	n=	n=	n=	n=
Yes	5	20	17	22	42	**106**
No	31	30	27	19	23	**130**
Subtotal	**36**	**50**	**44**	**41**	**65**	**236**
Not answered	21	35	21	28	11	**116**
Total	**57**	**85**	**65**	**69**	**76**	**352**

Communication in an emergency – Emergency Health Care Plans/Emergency Care Summary (Scotland)

There is evidence that parents and families have a strong preference not to keep having to tell their child or young person's story endlessly to new people and this is most frustrating of all in an emergency.

Paediatricians worked with the Council for Disabled Children to produce training materials about Emergency Health Care Planning, including video exemplars of the communication required to underpin such plans.[26] Training resources to underpin advance care planning can also be found in the 'Disability Matters' resources.[27]

Variations were reported in whether (or not) systems were in place for the preparation of such emergency plans for patients with the most complex medical/surgical needs (Table 6.4).

Table 6.4 An agreed system in place for preparing written Emergency Health Care Plans

	Paediatric outpatient care	Community paediatric care	Paediatric inpatient care	Adult outpatient care	Adult inpatient care	Emergency department care
Yes	58	66	67	24	35	69
No	23	11	20	21	13	20
Subtotal	**81**	**77**	**87**	**45**	**48**	**89**
Not answered	3	4	3	8	18	3
Total	**84**	**81**	**90**	**53**	**66**	**92**

Table 6.5 Emergency Health Care Plans were available in different formats

	Paediatric outpatient care	Community paediatric care	Adult outpatient care	Adult inpatient care
Yes	34	26	17	26
No	45	50	24	18
Subtotal	**79**	**76**	**41**	**44**
Not answered	5	5	12	22
Total	**84**	**81**	**53**	**66**

Table 6.5 shows whether Emergency Health Care Plans and other communications were available in other languages or formats. For both the existence of, and the availability of format, it can be seen that they were not as frequent in the adult services as paediatric services.

Systems in place for recording Emergency Health Care Plans were not well embedded. In 5/69 organisations written advice about care on presentation to the emergency department was not present. Senior emergency department clinicians were not involved in setting up systems for emergency health care planning in 27/69 organisations and Emergency Health Care Plans were reported to be fully accessible for disabled people and their families in only 47/87 organisations.

Table 6.6 shows where there was evidence in the notes and/or admission questionnaire that the team treating the patient on admission had access to an Emergency Health Care Plan or similar document that recorded what had been previously discussed about appropriate levels of intervention, variation from advanced life support guidance, treatment limitations.

Table 6.6 Access to an Emergency Health Care Plan or similar - reviewers' opinion

	n=	%
Yes – Emergency Health Care Plan present in the clinical case notes for the recent admission	24	7.9
Yes – Emergency Health Care Plan recorded as available in the admission questionnaire	20	6.6
No evidence of the existence of an Emergency Health Care Plan or similar	202	66.2
NA – Emergency Health Care Plan not appropriate in this patient	59	19.3
Subtotal	**305**	
Not answered	47	
Total	**352**	

Case note reviewers found evidence of an Emergency Health Care Plan or similar document in just 7.9% of records and data from the clinical questionnaire that this would have been available in 12.7% based on information provided by admitting responsible clinicians. Whilst Emergency Health Care Plans are not appropriate in all admission scenarios, the majority of patients in this study, where GMFCS level was documented, were felt to have motor function at GMFCS level V i.e. those most likely to have the most complex needs, where such a plan may be particularly important and useful.

CASE STUDY 5

A young teenager with bilateral cerebral palsy, with motor functioning at GMFCS level V, profound learning disabilities, gastrostomy tube fed and dislocated hip was admitted via the emergency department to paediatric intensive care. The patient had a stormy course, prolonged stay and, on discharge, was even more frail than before.

The reviewer noted 28 admissions in the previous year, including five to high dependency or intensive care, but there was no evidence in the medical record of the existence of an Emergency Health Care Plan, nor of a documented discussion with the family about their wishes for their child's care or discussion about resuscitation.

Resuscitation status

Admitting clinicians were asked whether, where appropriate, the resuscitation status of the patient was recorded at the point of admission. In 169/232 (72.8%) patients this was recorded but in a further 96 patients it was unknown (Table 6.7).

Table 6.7 Resuscitation status (where appropriate) was recorded on admission

	n=	%
Yes	169	72.8
No	63	27.2
Subtotal	**232**	
Unknown	96	
Not applicable	177	
Not answered	31	
Total	**536**	

Table 6.8 Resuscitation status at the point of admission was clear, by urgency of admission

	Yes	No	Subtotal	Unknown	Not applicable	Not answered	Total
Emergency (including urgent)	124	52	**176**	53	94	14	**337**
Elective (including planned)	38	8	**46**	39	74	13	**172**
Subtotal	**162**	**60**	**222**	**92**	**168**	**27**	**509**
Not answered	7	3	**10**	4	9	4	**27**
Total	**169**	**63**	**232**	**96**	**177**	**31**	**536**

Documentation of resuscitation status was reported to be less well done in patients with a cerebral palsy admitted as an emergency. This was clear on emergency admission in 124/176 (70%) patients, compared to 38/46 patients admitted electively (Table 6.8).

The number of elective admissions was relatively small but this finding might be explained by there being more time for consideration of resuscitation status when an admission is planned, and possibly the risk of deterioration being more routinely considered when a patient is admitted for particularly major surgery. Lack of clarity on the part of the admitting team about escalation of care in the face of an acute and severe deterioration in health may cause real problems in an emergency setting for patients with ongoing major complex needs. The admitting clinicians will usually be less familiar with the patient's underlying condition.

A 'Do Not Attempt Cardiopulmonary Resuscitation' or similar Personal Resuscitation Plan was reported to be in place by 41/271 (15.1%) case reviewers, with evidence that this was validated with the patient and their family at the time of admission for only 21/36 patients.

CASE STUDY 6

An older teenager with bilateral spastic cerebral palsy, with motor functioning at GMFCS level V, profound learning disability, relentlessly challenging epilepsy, gastrostomy tube fed due to unsafe swallow, scoliosis, and recurrent chest infections was admitted from the local hospice for a routine change of gastrostomy button without anaesthetic. The procedure was uneventful. The patient was discharged the same day back to the hospice, where they died peacefully four days later.

The reviewer noted strong leadership of multidisciplinary care and a clear Emergency Health Care Plan in place, which had been discussed and agreed with the family, the GP and multidisciplinary care team. This documented a decision, taken in the patient's best interests, that in the event of their sudden collapse, they would be allowed a natural death, with all their symptoms promptly addressed, care for their dignity and support for the patient's family. Possible clinical scenarios that could be predicted were included in the plan, with step by step action plans. A completed Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) was also available, as per local agreed procedures. The reviewer noted that the care plan had been carefully followed and there was evidence of excellent clinical care and support for the family.

Lead clinicians for disability care reported documented discussions with the patient and their family or primary carers about appropriate levels of intervention for only 85/183 patients, and this was unknown for 38/221. The outcome of this discussion was no limitation to interventions, with full resuscitation and intensive care as required for 56/84 patients, limitation to treatment, with no intubation or intensive care for 17/84 and 'other' for 11/84.

Emergency Health Care Plans should be proactively drawn up with the family and in discussion with the MDT who knows the person best. This should include a statement as to what had been discussed and agreed about levels of intervention, including a resuscitation decision, either within the plan itself or on a separate template, as per local policy. This can facilitate communication with changing junior doctors and saves families from telling their stories again on each occasion. This also encourages families to share their views on appropriate levels of intervention in the circumstances.

Capacity assessment for young people aged 16 years and over

The Mental Capacity Act 2005 in England and Wales states that when there are concerns that a young person aged 16 years or older who may have an impairment of their brain or mind, which may affect decision-making at a particular time and in a particular context, then an assessment should be made of their capacity in relation to that decision. Similar legislation exists in Scotland and Northern Ireland. The extent to which mental capacity was routinely assessed according to this legislation was variable (Table 6.9).

Evidence that an assessment of mental capacity was made was reported by reviewers for only 42/135 patients. Variation in whether documentation of decision-making could have been better varied with the age of the patient, as shown in Table 6.10.

Table 6.9 Mental capacity was routinely assessed

	Emergency department care	Paediatric inpatient care	Adult inpatient care	Adult outpatient care
Yes	69	50	39	30
No	17	38	4	12
Subtotal	**86**	**88**	**43**	**42**
Other	NA	NA	4	NA
Not answered	6	2	19	11
Total	**92**	**90**	**66**	**53**

Table 6.10 Assessment of whether documentation of decision-making could have been better, by age - reviewers' opinion

	1-4 years	5-9 years	10-14 years	15-19 years	20-25 years	Total
	n=	n=	n=	n=	n=	n=
Yes	5	20	17	22	42	**106**
No	31	30	27	19	23	**130**
Subtotal	**36**	**50**	**44**	**41**	**65**	**236**
Not answered	21	35	21	28	11	**116**
Total	**57**	**85**	**65**	**69**	**76**	**352**

Best-interests decision-making

Leads for different aspects of service reported variation in whether (or not) a best interests decision-making process was embedded in practice for those patients assessed as not having capacity to make a specific decision at a specific time and in a specific circumstance, as shown in Table 6.11. 12

Children, young people and competent young adults were reported to be routinely included in the decision-making and consent process. They were assisted to complete written consent where possible, as appropriate to their level of understanding prior to surgery or invasive procedures in 75/84 organisations providing paediatric inpatient care and in 43 organisations providing adult inpatient care.

Table 6.11 A best interests decision-making process was embedded for young people aged 16 years or older

	Paediatric outpatient care	Community paediatric care	Paediatric inpatient care	Adult outpatient care	Adult inpatient care	Emergency department care
Yes	47	44	57	34	40	68
No	30	33	27	9	8	16
Subtotal	**77**	**77**	**84**	**43**	**48**	**84**
Not answered	7	4	6	10	18	8
Total	**84**	**81**	**90**	**53**	**66**	**92**

Communication between professionals

Leads for the patient's inpatient care reported that the admitting team did not have ready access to the patient's community records and clinic letters regarding their cerebral palsy at the time of admission for 122/414 (29.5%) patients and this was unknown for 122/536 patients Access to these community/disability notes varied with age, as shown in Table 6.12.

Data from the emergency department (ED) organisational questionnaire indicated that ED summaries were routinely copied to the GP in 88/89 organisations, to the usual lead clinician in only 12/89 organisations, to the usual therapists in even fewer: 7/89 organisations and to the family or disabled person in just 15/89 organisations.

Table 6.12 Access to community records by age

	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	65	87	73	34	31	290	2	**292**
No	17	20	13	28	42	120	2	**122**
Subtotal	**82**	**107**	**86**	**62**	**73**	**410**	**4**	**414**
Unknown	18	18	13	26	32	107	4	**111**
Not answered	0	3	1	3	2	9	2	**11**
Total	**100**	**128**	**100**	**91**	**107**	**526**	**10**	**536**

Communication with the patient's wider multidisciplinary team about aspects of their health and wellbeing whilst they were inpatients was reported by case reviewers to be inadequate for 137/285 (48.1%) patients. This also varied by age, as shown in Table 6.13.

Organisational data from the paediatric and adult inpatient care questionnaires indicated that discharge planning meetings were held that included the patient's usual healthcare team as shown in Table 6.14.

There was evidence of multidisciplinary discharge planning as reported by case reviewers for only 50/144 (34.7%) patients. Reviewers could not answer for 25/169 patients. It is important to note that multidisciplinary discharge planning will only be needed for complex patients. ⑩

Variation in the reported adequacy of communication on discharge by case reviewers is shown in Tables 6.15 and 6.16. The data highlighted that communication was relatively good with patients and their GP, but lacking for the wider multidisciplinary team. This is particularly important for day case patients as they will need timely intervention with physiotherapy, but if the physiotherapists, for example, are not alerted to the patient's needs, they will not know to make contact.

Where discharge was to a community setting, Table 6.17 shows where written communication was directed.

Table 6.13 Communication with the patients' wider multidisciplinary team, by age - reviewers' opinion

	0-4 years	5-9 years	10-14 years	15-19 years	20-25 years	Total
	n=	n=	n=	n=	n=	n=
Yes	33	37	33	28	17	**148**
No	18	32	21	20	46	**137**
Subtotal	**51**	**69**	**54**	**48**	**63**	**285**
Unable to answer	6	16	11	21	13	**67**
Total	**57**	**85**	**65**	**69**	**76**	**352**

Table 6.14 Discharge planning included the patient's usual healthcare team

	Paediatric inpatient care	Adult inpatient care
For all paediatric/surgical inpatient episodes lasting a specified number of weeks	8	10
For all inpatient episodes where the young adult's needs have changed significantly since admission	23	25
On an ad hoc basis	57	24
Rarely	1	2
Never	1	0
Subtotal	**88**	**50**
Not answered	2	16
Total	**90**	**66**

**Answers may be multiple*

Table 6.15 Adequate communication on discharge to the community from inpatient care for admitted patients - reviewers' opinion

Admitted patients	Patient and their family		General practitioner to the community		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**	

Table 6.16 Adequate communication on discharge to the community for day case patients - reviewers' opinion

Day case patients	Patient and their family		General practitioner to the community		The lead clinician for cerebral palsy management		The patient's usual MDT	Community physiotherapy services
	n=	%	n=	%	n=	%	n=	n=
Yes	130	92.9	127	84.1	45	41.7	27	30
No	10	7.1	24	15.9	63	58.3	66	62
Subtotal	**140**		**151**		**108**		**93**	**92**
Unable to answer	40		24		49		53	46
Not applicable	0		2		14		23	30
Not answered	2		5		11		13	14
Total	**182**		**182**		**182**		**182**	**182**

Table 6.17 Groups provided with written discharge information

	n=	%
General practitioner	422	94.2
Lead clinician for cerebral palsy care	87	19.4
Community allied health professionals	69	15.4
Community care medical and nursing staff	56	12.5
No discharge summary in the notes	22	4.9
Social care	12	2.7
Palliative care team	7	1.6
Subtotal	**448**	
Not answered	34	
Total	**482**	

The written communication was reported by lead clinicians for inpatient care to include a clear discharge plan for 448/478 (93.7%) patients. This was not answered for 58/536. The patient and family were copied in to the discharge plan for 327/384 (96.2%) patients. This was unknown for 64/448. The written communication included input from all relevant members of the multidisciplinary team providing care during admission for only 210/391 (53.7%) patients, and was unknown for 145/536. The written communication included information to all relevant members of the multidisciplinary team providing care to follow admission for just 190/368 (51.6%) patients, and was not known for 168/536. ⑩

Lead clinicians for disability care reported that they were made aware of the acute admission for just 108/197 (54.8%) patients, this was unknown for 24/221.

Lead clinicians for disability care reported being made aware of or copied in to discharge summaries and further planning for only 112/200 (56%) patients. This was unknown for 21/221.

Lead clinicians for disability care reported there to have been ongoing communication between different healthcare providers e.g. acute, community, specialist, including in regional or national centres, therapies etc. for 186/207 (89.9%) patients, but not for 21/207. This was unknown for 14/221.

Data from the inpatient allied health professional paediatric inpatient care questionnaire indicated that communication between allied health professionals providing inpatient care for disabled children and young people and allied health professionals who provide usual outpatient or community care routinely occurred by telephone or email in 45/62 organisations, by a written report on discharge in 11/62 and on an ad hoc basis in 12/62. Data from the adult allied health professional inpatient care questionnaire indicated such communication to occur routinely by telephone or email in 27/51 organisations, with a written report on discharge for 23/51 organisations and on an ad hoc basis for 5/51.

Data from the adult outpatient care questionnaire indicated that organisations had clear policies in place to ensure continuity of patient care, including close handover between professionals and familiarisation with case histories, at all interfaces and points of transition of care in only 17/43 organisations.

Case note reviewers assessed the overall adequacy of communication regarding the patient's healthcare during the admission as shown in Figure 6.1.

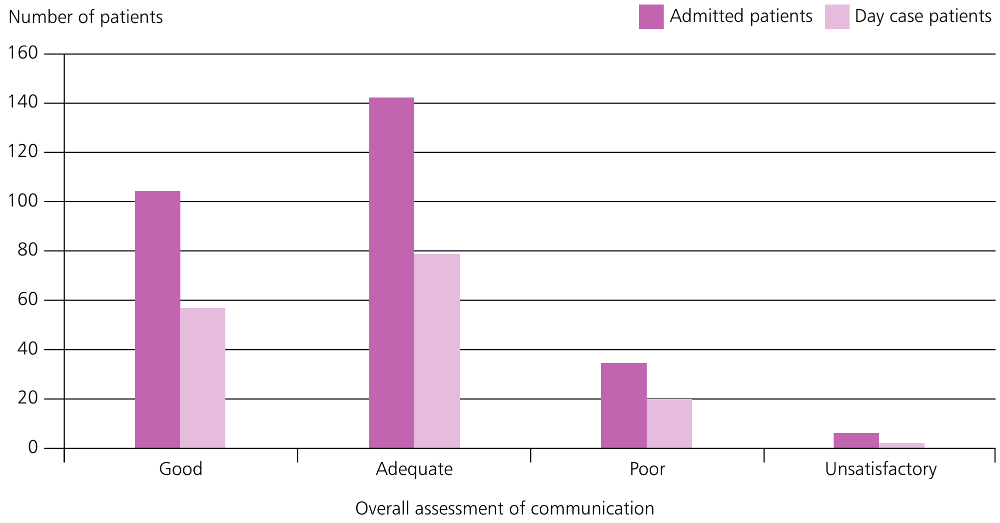

Figure 6.1 Overall quality of communication about patient healthcare during the inpatient admission - reviewers' opinion

Key Findings – questionnaire, case note review and organisational data

- Reviewers reported insufficient efforts to communicate with the family in 89/245 (36.3%) cases
- The preferred communication method of the patient was only ascertained for 159/275 (57.8%) patients
- Reviewers reported the patient was, wherever possible, fully included in all discussions and decision-making about them in 139/277 (50.2%) patients. Reviewers did not answer this question or were unable to answer for 72/534 (13.5%) cases reviewed
- There was room for improvement in the documentation of inclusion of the patient in the decision-making process in 179/448 (40%) cases reviewed
- There were agreed systems in place for preparing written Emergency Health Care Plans/Emergency Care Summaries in:
  58/81 organisations providing paediatric outpatient care;
  66/77 organisations providing paediatric community care;
  67/87 organisations providing paediatric inpatient care;
  24/45 organisations providing adult outpatient care;
  35/48 organisations providing adult inpatient care; and
  69/89 organisations providing emergency department care. Where they were in place, in a majority of organisations these were only partially implemented
- Reviewers found no evidence of the existence of an Emergency Health Care Plan or similar (either in the case notes or documented in the admission questionnaire) in 202/305 (66.2%) cases
- A 'Do Not Attempt Cardiopulmonary Resuscitation', or similar personal resuscitation plan, was reported to be in place by 41/271 (15.1%) reviewers. There was evidence this was validated with the patient and their family at the time of admission in 21/36 cases reviewed
- Around one third of organisational leads for paediatric inpatient (27/84), outpatient (30/77) and community services (33/77) reported that a best interests decision-making process was not embedded for young people aged 16 years or over who had been assessed as not having capacity to make a specific decision at a specific time and in a specific circumstance
- Around a quarter of organisational leads of emergency departments (16/84), one fifth of organisational leads for adult inpatient care (8/48) and four in ten leads for adult outpatient care (9/43) reported having no such best interests process embedded
- Communication with the child, young person or young adult with cerebral palsy's wider multidisciplinary team about aspects of their health and wellbeing whilst they were inpatients was reported by case reviewers to be inadequate in 137/285 (48.1%) cases
- Reviewers reported that discharge summaries about episodes of inpatient care were not copied to lead clinicians for cerebral palsy care in almost half of cases (103/223 admissions; 63/108 day cases) and were only copied to the community physiotherapist in 32% (30/92) for day case patients and 38% (70/184) for admitted patients.

SEE RECOMMENDATIONS
11•19•20•22•25•26•28•29•30•31 32•33