4 DELIVERY OF CARE

CASE STUDY: GOOD CARE

A 30-year-old patient with a severe learning disability, complex needs and epilepsy was admitted to hospital with pneumonia. The patient was unable to provide a history, but a full set of observations was taken when they arrived at the emergency department. Their NEWS2 was nine and they were quickly identified as rapidly deteriorating. Care was escalated appropriately and a diagnosis of sepsis secondary to pneumonia was made.

Reviewers considered that NEWS2 had enabled a rapid response and without this the seriousness of the patient's condition could have taken longer to recognise.

CASE STUDY: ROOM FOR IMPROVEMENT

A 36-year-old patient with a learning disability was admitted to hospital following a fall. The patient was discharged home despite concerns from their carers regarding the patient's overall mobility and safety. No information was given on discharge around progression or safe mobility. The patient was seen by a community physiotherapist but at the time they were alone, so it was unclear whether they were able to understand and retain the information. The patient was then readmitted following another fall in the community.

Reviewers thought learning disability team involvement could have ensured that information was provided in an accessible format and there was better communication with the patient's carers.

Observations and investigations

Reviewers found that 50/342 (14.6%) patients did not have a full set of observations recorded on arrival at hospital, and the frequency of re-recording was inadequate for 23/310 (7.4%) patients. The most missed elements were consciousness level and respiratory rate. Pain was not recorded for 43/50 (86.0%) patients where observations had been assessed as incomplete (T4.1).

T4.1 Omitted observations on arrival at hospital	Number of patients
Pain score	43
Consciousness level	20
Respiratory rate	13
Blood pressure	12
Oxygen saturation	11
Pulse rate	10
Temperature	9
Total	**50**

Reviewer assessment form data

The Learning from Lives and Deaths – People with a Learning Disability and Autistic People (LeDeR) 2023 report identified a delay in care or treatment in 37.2% of deaths, highlighting the importance of timely assessment and initiation of treatment.[6] Reviewers reported that 27/343 (7.9%) patients did not have all appropriate blood tests and/or investigations undertaken. There were clinically significant delays in the undertaking of these investigations for 26/332 (7.8%) patients, resulting in delayed treatment for ten patients (T4.2).

T4.2 Delays in investigations being undertaken	Clinician questionnaire		Reviewer assessment form	
	Number of patients	%	Number of patients	%
Yes	26	4.3	26	7.8
No	578	95.7	306	92.2
Subtotal	**604**		**332**	
Unknown	62		34	
Total	**666**		**366**	

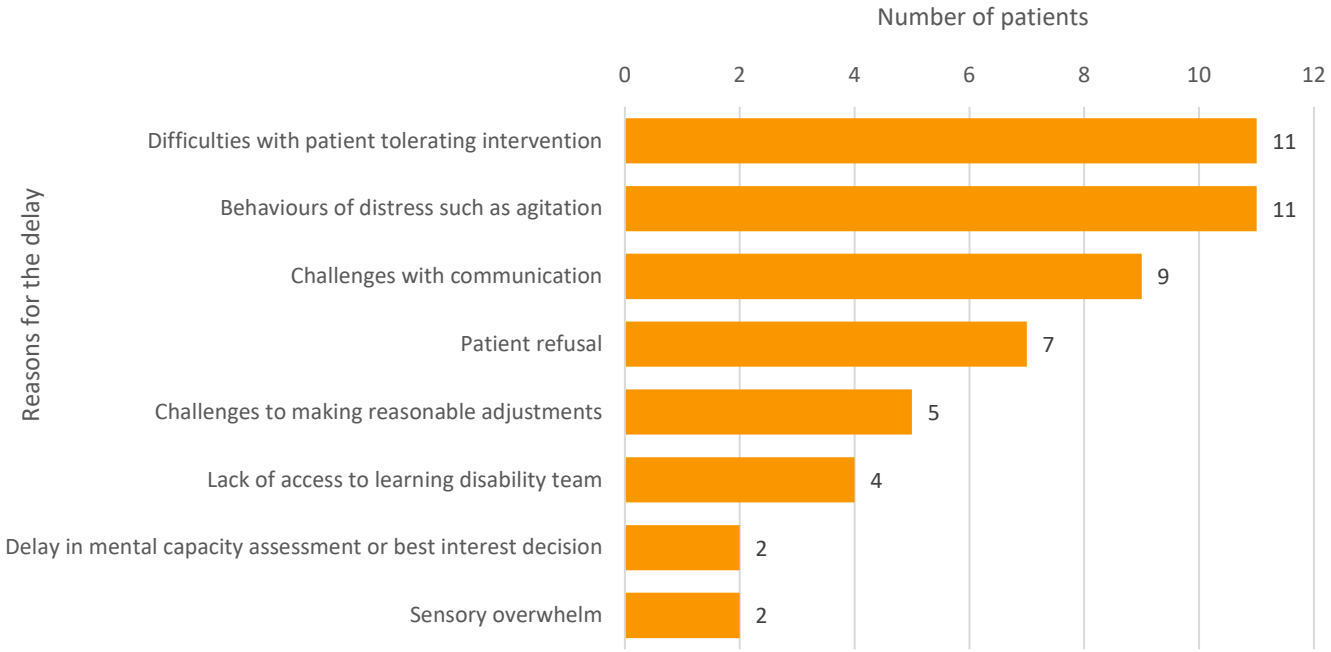
Clinician questionnaire and reviewer assessment form data

Escalation and delays

The National Early Warning Score (NEWS2) is an essential tool for identifying the early signs of deterioration and ensuring that further assessment and treatment is commenced in a timely manner. NEWS2 offers an objective way to measure illness severity in patients with learning disabilities who may be unable to provide a clinical history. Clinicians reported the calculation of NEWS2 scores at first assessment for 559/597 (93.6%) patients. NEWS2 scores of ≥5 were reported in 112/493 (22.7%) patients.

A total of 81/629 (12.9%) patients were reviewed by the critical care outreach team during their hospital admission, with 55 patients subsequently being admitted to critical care.

Reviewers found there were delays in the delivery of care for 43/341 (12.6%) patients (unknown in 25), with 24 of these delays being attributed to the patient having a learning disability. The most common reasons for delays were difficulty tolerating interventions (11), behaviours of distress or agitation (11) and challenges with communication (9) (F4.1). Of the 24 patients who experienced a delay in the delivery of care, ten did not have any reasonable adjustments made during their admission; reviewers thought that appropriate reasonable adjustments may have prevented these delays.



F4.1 Reason(s) for delay in the delivery of care

Reviewer assessment form data. Answers may be multiple; n=24

Community learning disability teams

Community learning disability teams provide care when needed in the patient's home/community setting and do not have a long-term involvement during acute admissions. In this study, 322/631 (51.0%) patients reviewed were known to the community learning disability team prior to their admission.

Acute hospital learning disability services

A learning disability service was reported to be present in 186/199 (93.5%) hospitals, with most services being employed directly (140/186; 75.3%) and based onsite (177/185; 95.7%). Only 35/186 (18.8%) learning disability services were multidisciplinary, with 69/186 (37.1%) uni-professional and 82/186 (44.1%) comprising a single individual, both of which were predominantly nurses (T4.3).

T4.3 Composition of a learning disability service	Number of hospitals	%
An individual	82	44.1
Uni-professional	69	37.1
Multidisciplinary	35	18.8
Subtotal	**186**	
No learning disability service	13	
Total	**199**	

Organisational questionnaire data

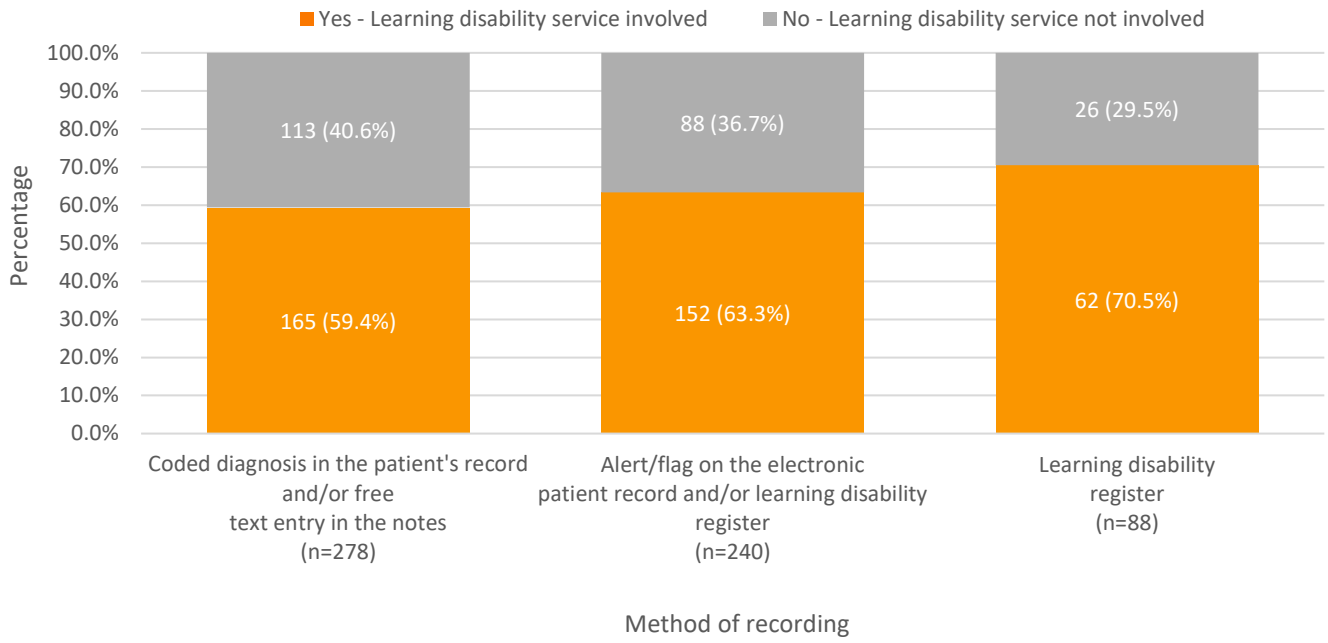
A total of 127/186 (68.3%) of acute hospital learning disability services were only available during normal working hours (Monday to Friday, 0800-1800), and only 184/418 (44.0%) of health and social care professionals surveyed stated there was sufficient access to acute hospital learning disability services in the acute setting. In total, 96/536 (17.9%) patients who were admitted via the emergency department were reviewed by the acute hospital learning disability service. Where the acute hospital learning disability service was not involved in the emergency department, reviewers stated that they should have been for a further 116 patients. Community learning disability teams provided in-reach services to support admissions in 95/188 (50.5%) acute hospitals.

Clinicians reported that acute hospital learning disability service involvement occurred at the correct time for most patients (254/275, 92.4%). However, reviewers disagreed, reporting that input was provided at an appropriate time for 125/181 (69.1.%) patients and that patients received an appropriate level of input for only 141/336 (42.0%) patients. Early and consistent involvement of learning disability liaison nurses or teams is essential to support the identification of needs, reduce clinical risk, and support effective communication and planning.[15]

Alerting the learning disability service

The Care Quality Commission (CQC) is clear that people with a learning disability have a right to access the care that they need and that this should start from the first point of contact with a hospital.[16] If the person is known to have a learning disability this should trigger a notification to the acute hospital learning disability service on their arrival in hospital. The Health Services Safety Investigations Body (HSSIB) has highlighted that people with a learning disability who are admitted to an acute hospital are often cared for by staff without specialist training, skills and experience in working with people with a learning disability.[17]

There were 169/199 (84.9%) hospitals in which a policy stated which specific clinicians should be contacted when a person with a learning disability is admitted. Responses showed that in most cases the hospital's learning disability liaison nurse was alerted (118/169; 69.8%). When a patient was on a learning disability register or had an alert in place, the learning disability service was most likely to be involved throughout the admission (165/278; 59.4% vs 62/88; 70.5%) (F4.2).



F4.2 Method of identifying patients with a learning disability and learning disability service involvement
Clinician questionnaire data - patients could be identified via individual records, by flags on the system or at an organisational level in a learning disability register. Answers may be multiple

Identifying carers

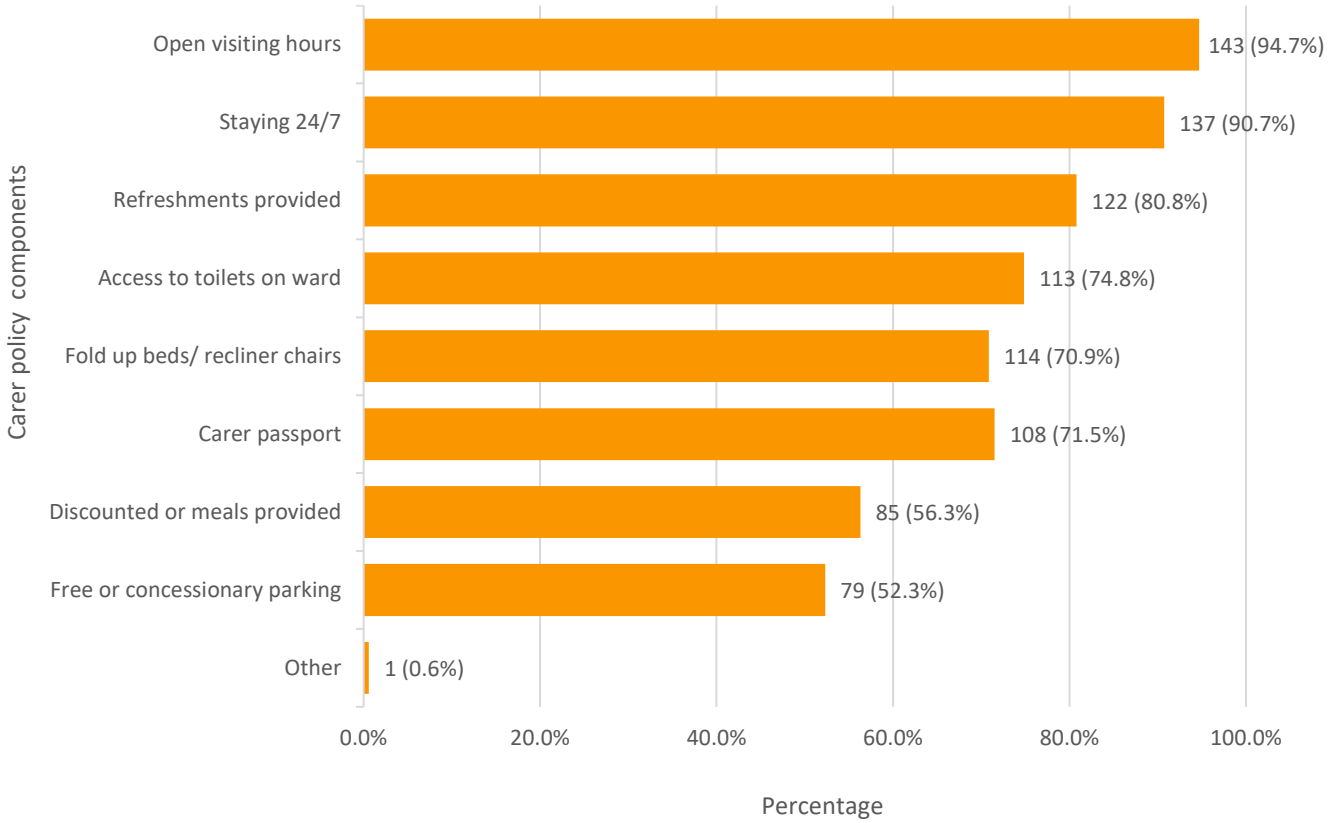
To involve carers, it must be possible for staff to be able to identify them easily. In 123/199 (61.8%) hospitals there was mostly an informal approach to identifying patients' carers. Where present, more formal examples included alerts and documentation in the patient's electronic patient record or mention in the patient's hospital passport.

Health and social care professionals identified key themes that they thought would have improved the delivery of care for patients with a learning disability when they became acutely unwell. These included improving communication, listening to relatives and carers, and enabling family members and carers who know the individual well to be present if at all possible.

In 105/151 (69.5%) hospitals a carer's passport was used to support identification of carers. These hospitals had carer policies that incorporated a carer passport scheme. However, only 2/36 carer survey respondents were aware of carer passports, while 38/40 thought that a carer passport would be helpful. A carer's charter was available in 91/137 (66.4%) hospitals; carers were made aware of this through the trust/health board websites (73/91) and information posters (59/91). However, one hospital mentioned a carer's liaison officer, and three hospitals had a carer's hub.

A total of 151/179 (84.4%) hospitals had a carer policy. The most common components in the policy reported by the clinicians were open visiting hours (143/151; 94.7%). However, the practical help offered to carers was limited. Free parking was only offered by 69/151 (45.7%) hospitals, although a few offered

concessionary parking (10/151; 6.6%), and recliner chairs (7/151; 4.6%) rather than fold-up beds (107/151; 70.9%) were offered in a small number of hospitals (F4.3).



F4.3 Carer policy components

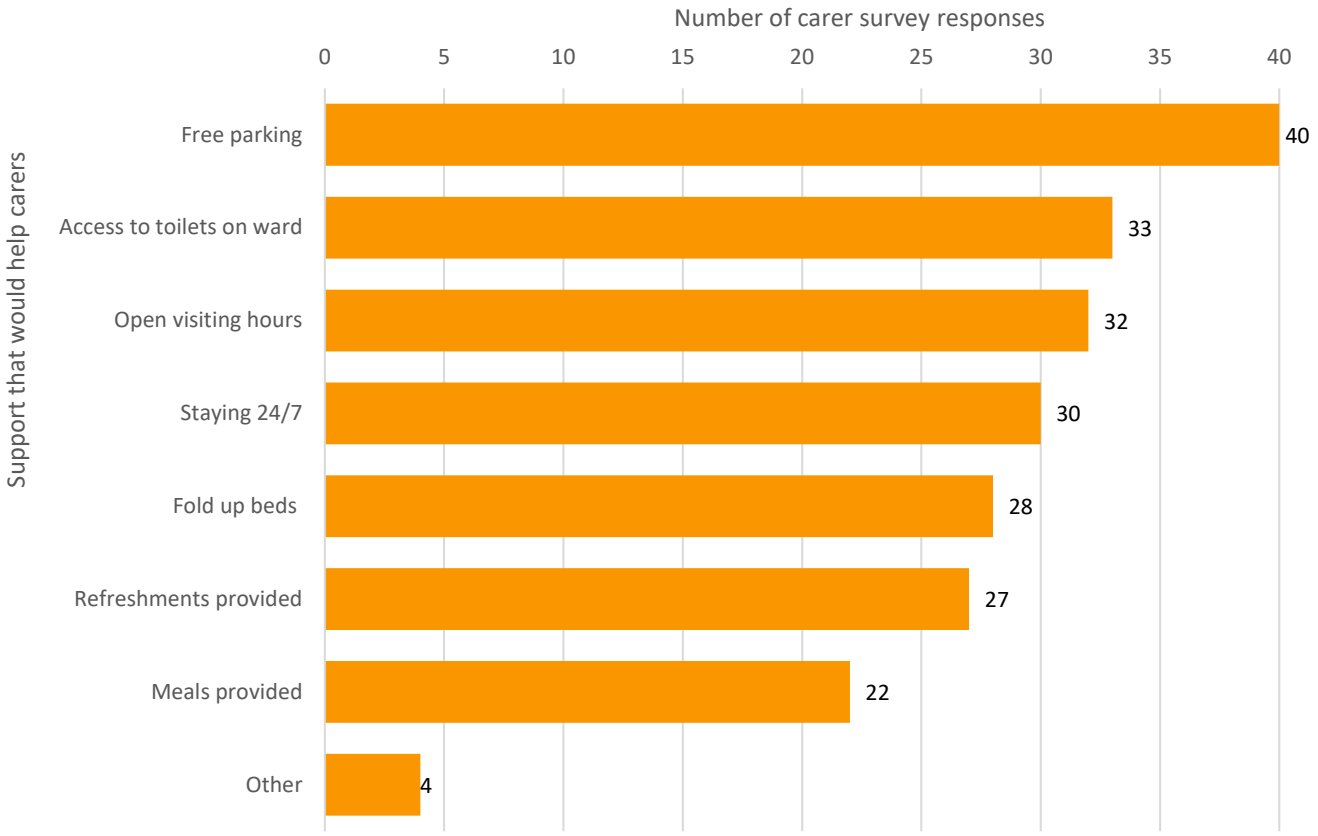
Organisational questionnaire data. Answers may be multiple; n=151

Clinicians documented that support was provided to the carer in 89/284 (31.3%) cases but for 227 patients it was not known, which could indicate that there was an unmet need (T4.4). NICE guidelines on supporting adult carers state that families and carers should be offered support that meets their needs based on assessment.[18]

T4.4 Documented that support was provided to the carer	Number of patients	%
Yes	89	31.3
No	195	68.7
Subtotal	**284**	
Unknown	227	
Not applicable	155	
Total	**666**	

Clinician questionnaire data

Although open visiting hours were the most common measure of support offered by hospitals, 10/49 respondents to the carer survey felt that they were unable to spend as much time as they needed or wanted with the person they look after. All (39/39) carer survey respondents who were able to stay in hospital with the person they looked after found it helpful. Carers said that free parking (40/46), access to toilets on ward (33/46) and open visiting hours (32/46) would be the most helpful forms of support (F4.4).



F4.4 Things carers would find helpful while supporting hospital admissions

Carer survey data. Answers may be multiple; n=46

Discharge

Patients spent a median of six days in hospital, and most were discharged back to the location they were admitted from (T4.5). Where length of stay was considered inappropriate, this tended to be related to issues with restarting or changing social care packages, or safeguarding concerns. Reviewers considered that the length of stay was appropriate for most patients (298/366; 81.4%), and that care was provided in the appropriate setting (326/366; 89.1%). Where length of stay was considered inappropriate, this tended to be related to issues with restarting or changing social care packages, or safeguarding concerns.

T4.5 Discharge destination	Number of patients	%
Own home	276	42.7
Supported living	129	20.0
Nursing home	89	13.8
Residential home	81	12.5
Patient died during admission	32	5.0
Transferred to another hospital	13	2.0
Hospice	2	<1
Other	24	3.7
Subtotal	**646**	
Unknown	20	
Total	**666**	

Clinician questionnaire data

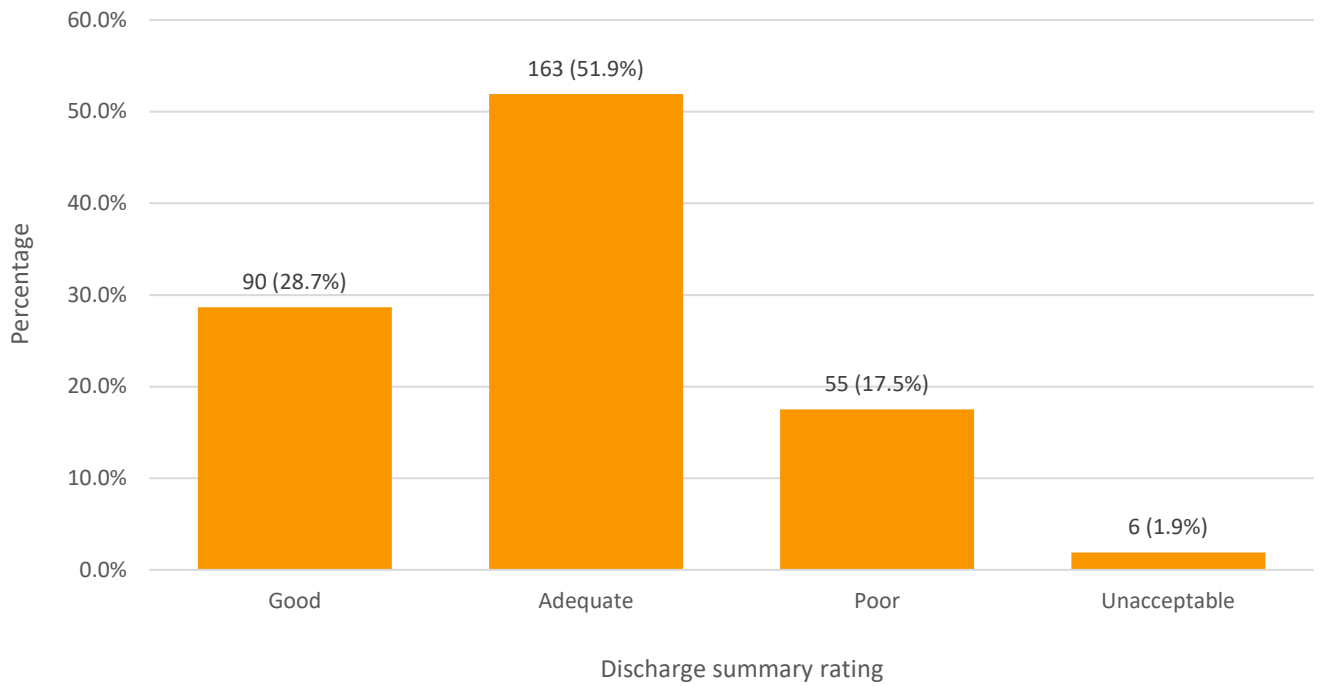
Discharge summary

Discharge summaries were sent to the general practitioner for 552/628 (87.9%) patients (unknown in 38). Discharge summaries were provided to 118/276 (42.8%) patients who were discharged to their own home. However, discharge summaries were accessible for only 51/118 (43.2%) patients.

Most discharge summaries included information regarding the reason for admission (306/314; 97.5%) and management/treatment (284/314; 90.4%). However, reviewers found key information was often missing from discharge summaries, specifically a lack of coding related to the learning disability (T4.6). As a result, discharge summaries were rated as poor or unacceptable in 61/314 (19.4%) cases reviewed (F4.5).

T4.6 Components of the discharge summary	Number of patients	%
Reason for admission	306	97.5
Management/treatment	284	90.4
Medications	277	88.2
Follow-up arrangements	210	66.9
Coding of the learning disability	128	40.8
Mental capacity assessments	7	2.2
Reasonable adjustments made during admission	6	1.9
Other	5	1.6
Total	**314**	

Reviewer assessment form data. Answers may be multiple



F4.5 Discharge summary rating

Reviewer assessment form data (n=314)

Reviewers identified inadequate follow-up for 69/293 (23.5%) patients. The main reasons for this were a lack of acute hospital learning disability or community team involvement, and social care breakdowns often leading to hospital readmission.

Readmissions

In total, 115/519 (22.2%) patients were readmitted within 30 days of discharge, which was more than three times higher than readmission figures for people without a learning disability.[19] For 67/115 (58.3%) patients the readmission was related to the original admission under review. This was confirmed by reviewers, who reported that of the 29/211 (13.7%) patients readmitted to hospital, 21/29 readmissions were related to the index condition, and 14/21 patients were identified as having room for improvement regarding their original discharge planning.