

7 COMMUNICATION AROUND CARE PROVIDED

CASE STUDY: GOOD CARE

A 42-year-old patient with a profound learning disability and unable to speak was admitted with a urine infection. The patient's sibling carers were involved throughout and were able to share that when the patient was happy, they smiled and made specific sounds such as 'woo', but when experiencing pain would frown and shout out.

Reviewers thought that sharing these 'soft signs' made it easier for the clinical team to understand how the patient was feeling, enabling the delivery of more personalised care.

CASE STUDY: ROOM FOR IMPROVEMENT

A 28-year-old patient with a moderate learning disability was admitted after being hit by a car. It was advised that the patient should wear a neck support until a full assessment of their cervical spine had been completed, but the patient refused. There was no evidence that the risks of not wearing the neck support were explained.

Reviewers felt that if the risks and benefits had been shared in a way the person could understand more easily this could have helped the discussion on why a neck support was being recommended, and the patient may have made a different decision to protect their cervical spine.

Effective communication with patients is key to the delivery of excellent healthcare. Whenever possible, a person with a learning disability should be at the centre of and involved in all decisions about their care, recognising that this may not always be feasible depending on the severity of the learning disability.

While family members and carers cannot make a consent decision on behalf of anyone else, NICE guidance on the 'care and support of people growing older with learning disabilities' recommends that the support network of a person with a learning disability should be actively involved in the planning and delivery of their care.^[18]

Clinicians found evidence of attempts to involve the patient and/or their carer/next of kin in decisions around their care for 553/593 (93.3%) patients (unknown in 73).

Reviewers found that although 200/366 (54.6%) patients were involved in decisions regarding their care in the acute setting, this was often inconsistent (85/366; 23.2%). There was also inconsistent evidence of the involvement of the patients' carers/next of kin in care decisions (T7.1).

T7.1 Evidence of patient and carer involvement in care decisions	Patient involvement		Carer involvement	
	Number of patients	%	Number of patients	%
Yes - all the time	115	31.4	168	45.9
Yes - inconsistently	85	23.2	107	29.2
No	166	45.4	75	20.5
Not applicable - no carer/next of kin	-	-	16	4.4
Total	366		366	

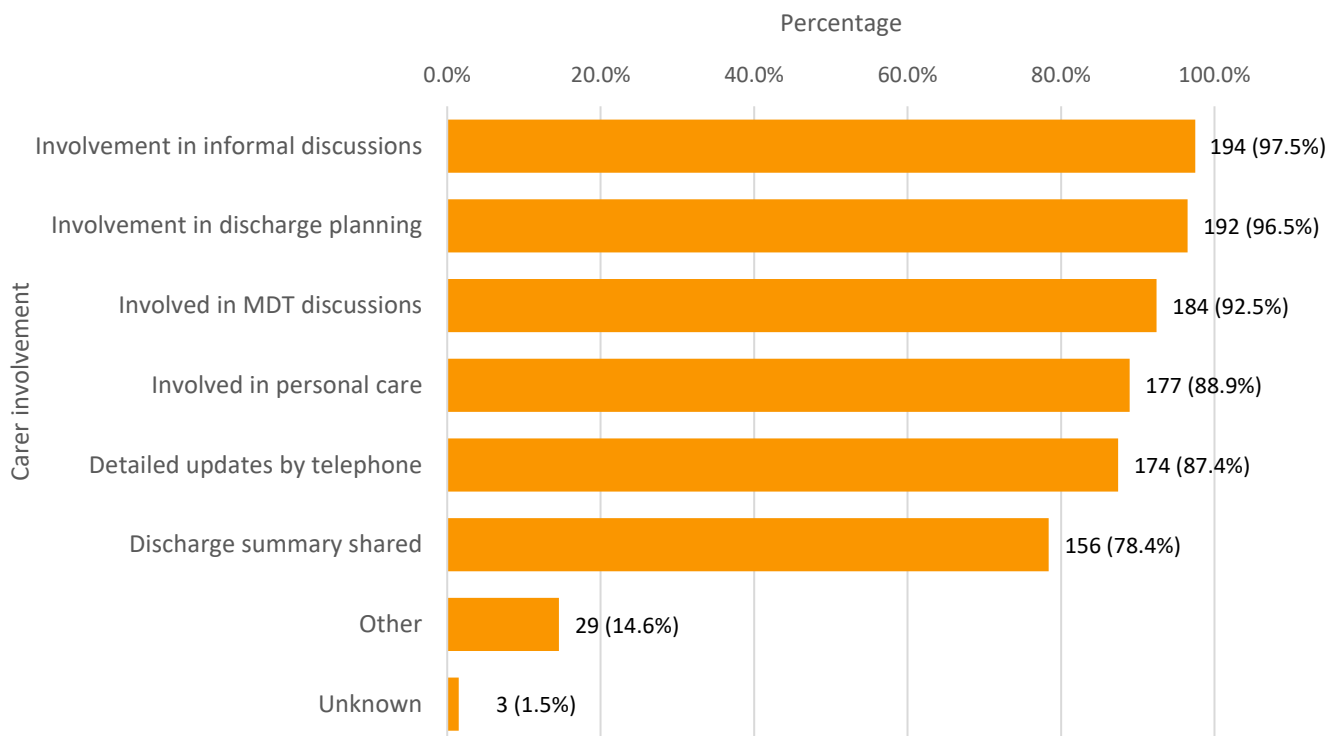
Reviewer assessment form data

Carer involvement in discussions

NICE guidance on 'supporting adult carers' recommends that carers should be acknowledged as expert partners in care and their skills and knowledge about the person they care for should be valued. The

needs of the accompanying carer must also be assessed and supported, for example there may be a family history of learning disability that may need to be considered.^[26]

Carer involvement was reported to take many different forms, but this often depended on the needs of the individual and sometimes included involvement in decisions regarding mental capacity and best interest decisions (F7.1).



F7.1 Carer involvement in aspects of treatment and care of the person they work with
Organisational questionnaire data. Answers may be multiple; n=199

Carer survey respondents felt that their role was to help the people they work with ‘understand what was happening’ while in hospital (36/39) and to be a familiar presence in what can often be a daunting environment. Carers can also help the navigation of care by helping with decision-making, in addition to providing practical help such as helping the person they work with to wash and dress (33/39) or eat and drink (32/39).

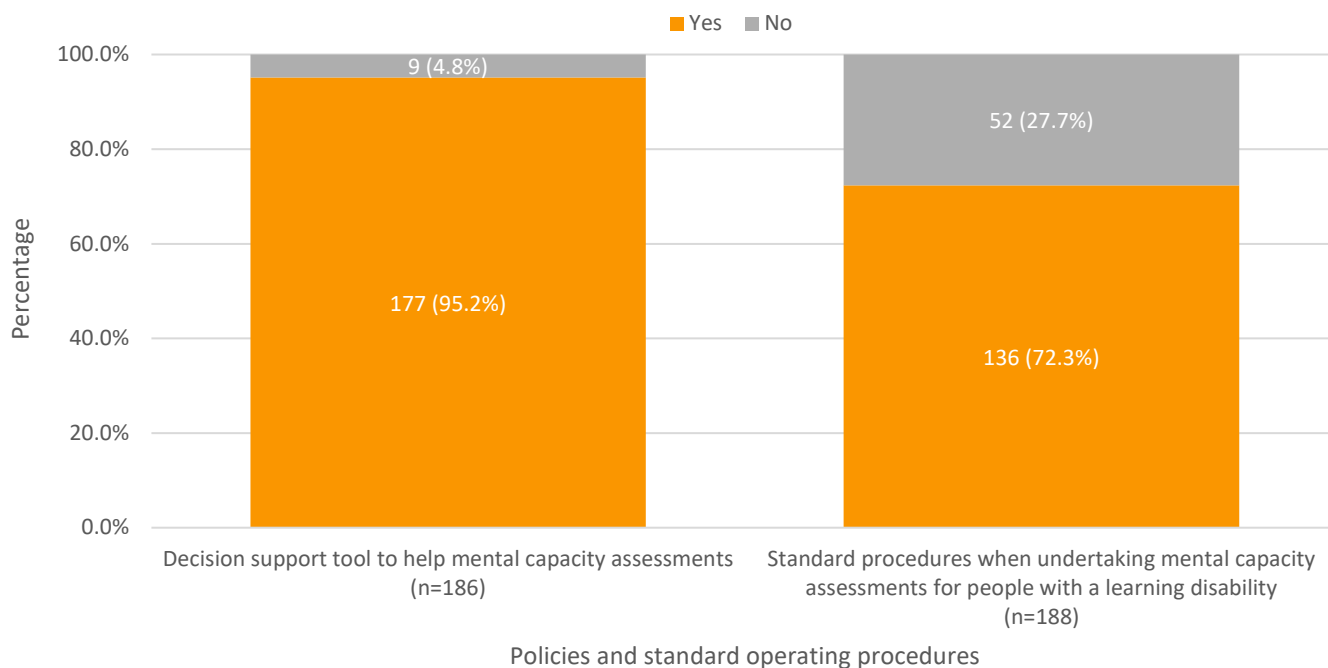
Carers possess valuable information about the individual and their health and may spot changes in behaviour, helping clinicians to identify and treat the acute illness.^[20]

At discharge, reviewers found evidence of attempts to involve the patient in decisions regarding their care in 86/353 (24.4%) sets of notes, while there were attempts to involve the patient’s carer/next of kin in decisions for 174/353 (49.3%) patients. However, in 148/353 (41.9%) cases there were no attempts to involve the patient or the patient’s carer/next of kin at discharge.

Mental capacity assessments

The Mental Capacity Act (MCA) provides the legal framework for making decisions on behalf of people who lack the capacity to make those decisions by themselves. All individuals aged 16 years and over must be treated as having decision-making capacity unless it is proven otherwise.^[27,28]

A decision support tool to support mental capacity assessments was available in 177/186 (95.2%) hospitals, but only 136/188 (72.3%) had a standard operating procedure (SOP) to follow when assessing mental capacity in people with a learning disability (F7.2).^[29]



F7.2 Organisational policies and tools supporting mental capacity assessments

Organisational questionnaire data

Mental capacity decisions were reported as being recorded in most hospitals (196/199; 98.5%) (T7.2). The methods used to record these decisions varied, with 138/196 (70.4%) using electronic forms and 95/196 (48.5%) using paper forms, making accessing information difficult. Other hospitals had defined electronic templates which also included decisions on DNACPR and consent for surgery, making sharing of mental capacity decisions much easier.

T7.2 How mental capacity decisions are recorded	Number of hospitals	%
Electronic form	138	70.4
Paper form	95	48.5
Variable	36	18.4
Other	27	13.8
Total	196	

Organisational questionnaire data. Answers may be multiple

Assessing mental capacity can be challenging because while some decisions may be relatively simple, such as someone choosing between a cup of tea or coffee, for more complex decisions patients must be able to understand what they are being asked to consent to, be able to retain the information and use that information to make a decision on the proposed treatment. Mental capacity assessments are therefore decision, time and situation specific.

When patients are admitted to hospital this can involve decisions throughout the stay and mental capacity should be assessed whenever there is reason to doubt an individual's ability to make a specific decision at a specific time.^[27] Clinicians reported that formal assessments of mental capacity were made in 177/538 (32.9%) patients, but this was also unknown for 128 patients.

Reviewers reported that formal mental capacity assessments were made consistently during the admission for 104/366 (28.4%) patients, inconsistently for 33/366 (9.0%) patients and not made at all for 229/366 (62.6%) patients.

Reviewers were of the opinion that 121/229 (52.8%) patients who did not have a formal assessment of mental capacity should have received one. These findings support previous work on the variation in staff understanding and application of the Mental Capacity Act.^[18]

Best interest decisions

If a person is found to lack the capacity to make a specific decision in a specific timeframe, any decision made on their behalf must be in their best interests in line with the Mental Capacity Act and should be the least restrictive option to achieve the desired outcome. Clinicians reported that 161/552 (29.2%) patients had a best interest decision made during the admission. The best interest decision was recorded in paper form for 64 patients.

Reviewers identified 76/366 (20.8%) patients who refused or declined investigations or treatment. Concerns were expressed by reviewers that if patients refused treatment, the treatment or intervention was often stopped without consideration of mental capacity or best interests.

Restriction and restraint

Sometimes is it necessary to restrict someone's liberty to keep them safe. In such instances, the Mental Capacity Act includes Deprivation of Liberty Safeguards (DoLS) to protect people and ensure that restrictions are only used when necessary.^[27] Examples include restricting a patient to keep them safe for continuous supervision and monitoring, or use of physical restraints such as cot sides on a bed.

Reviewers found evidence of restrictive practice during the admission for 67/366 (18.3%) patients. The restrictive practice was not underpinned by a DoLS form in 39/67 patients.

Overall, clinicians reported there was a DoLS application for 77/666 (11.6%) of patients.

Reviewers noted that restraint was required during the admission for 30/366 (8.2%) patients. In 12/30 instances the restraint was physical and in 16/30 medication was used. Reassuringly, the reviewers deemed the use of medication to be appropriate for all of the patients who were given it. However, physical restraint was considered to be inappropriate for two patients, although reviewers acknowledged that there may have been limited options available out of hours.

Independent Mental Capacity Advocate (IMCA)

Under the Mental Capacity Act, if a person who lacks capacity has no family or friends to represent them, an Independent Mental Capacity Advocate (IMCA) must be involved in decisions about serious medical treatment. Their role is to support and represent the person, ensuring that views, wishes and feelings are considered in decisions about them.^[27]

Patients had access to IMCAs in 193/197 (98.0%) hospitals, and this was mostly within normal working hours (142/193; 73.6%) (T7.3).

T7.3 Independent Mental Capacity Advocate working hours	Number of hospitals	%
24/7	1	<1
Normal working hours - 7 days/week (e.g. 0800-1800)	11	5.7
Normal working hours - Monday-Friday (e.g. 0800-1800)	130	67.4
Extended hours - 7 days/week	5	2.6
Extended hours - Monday-Friday	3	1.6
Other	21	10.9
Unknown	22	11.4
Total	193	

Organisational questionnaire data

Reviewers found that IMCAs were involved for six patients (T7.4) but also identified additional patients where IMCAs should have been involved (28/254; 11.0%) (unknown in 35).

T7.4 Documented that an Independent Mental Capacity Advocate was involved	Number of patients	%
Yes	6	2.0
No	289	98.0
Subtotal	295	
Unknown	9	
Not applicable	62	
Total	366	

Reviewer assessment form data

CASE STUDY: GOOD CARE

A 69-year-old individual with a severe learning disability was admitted to hospital with a fractured neck of femur after a fall. Surgery was recommended but the surgeon considered that the patient did not have the capacity to consent to an operation. The learning disability liaison nurse was involved, an Independent Mental Capacity Advocate was appointed and, after discussions with the carers, it was agreed that surgery was in the person's best interests. All discussions were well-documented.

Reviewers thought that the surgeon had made an excellent assessment of the patient's mental capacity and ensured that the best care was delivered without undue delay.

Consent for surgery

In total 244/648 (37.7%) patients were reviewed by a surgical team during the admission and 101/654 (15.4%) underwent surgery (T7.5). While this study did not explicitly ask if an assessment of mental capacity was made at the time the patient gave consent for surgery, it was noted that a record of a formal assessment of mental capacity was carried out at any point during the admission for 36/76 patients who underwent surgery (unknown in 25). For patients who are unable to give consent, a Consent Form 4 is used which requires a statement of a best interests discussion as well as a documented mental

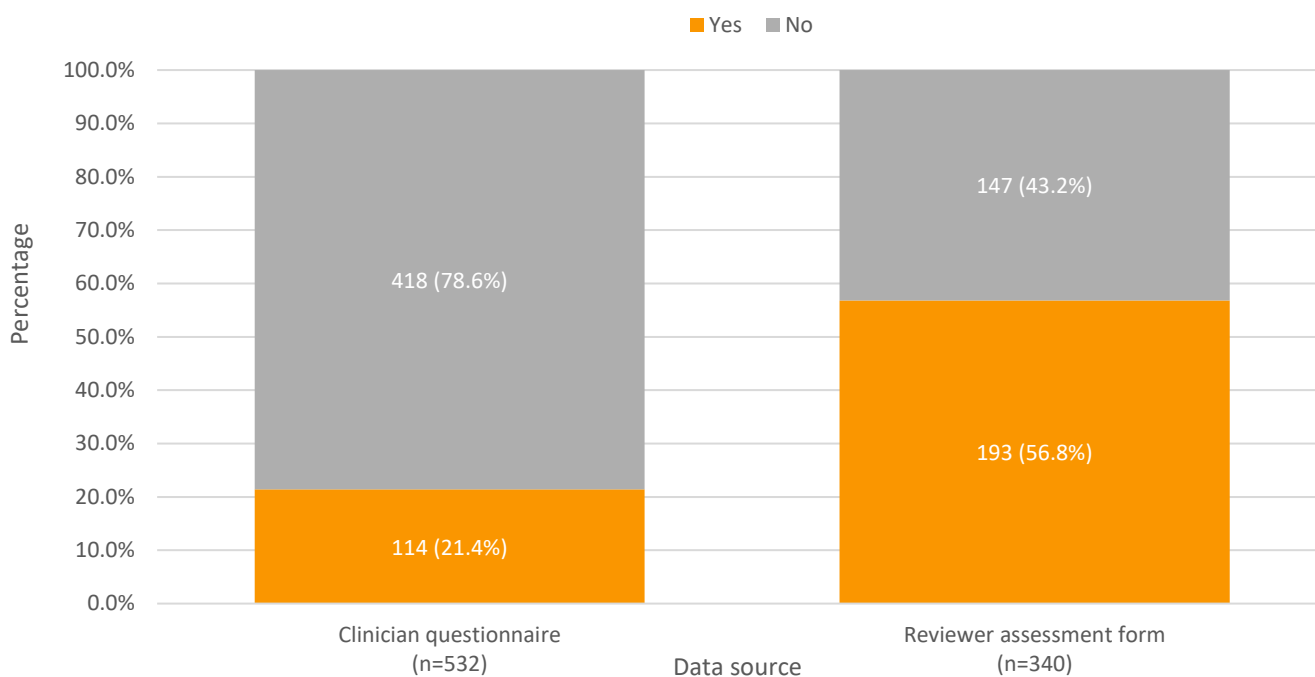
capacity assessment. A Consent Form 1 is for patients who have capacity and will include some patients with a mild learning disability. It was not documented which form was used. However, reviewers highlighted that best practice would be to record a mental capacity assessment separately.

T7.5 Surgical input during the admission	Underwent surgical team review		Underwent surgery	
	Number of patients	%	Number of patients	%
Yes	244	37.7	101	15.4
No	404	62.3	553	84.6
Subtotal	648		654	
Unknown	18		12	
Total	666		666	

Clinician questionnaire data

Improving mental capacity assessments

Both the clinicians and reviewers considered that there could be improvements in the assessment of mental capacity (F7.3). Suggestions included involving learning disability services and making reasonable adjustments so patients could understand what they were being asked. Carers highlighted the value they could add when decisions had to be made if the person they look after did not have mental capacity.



F7.3 Improvements in mental capacity assessments by data source

Clinician questionnaire and reviewer assessment form data

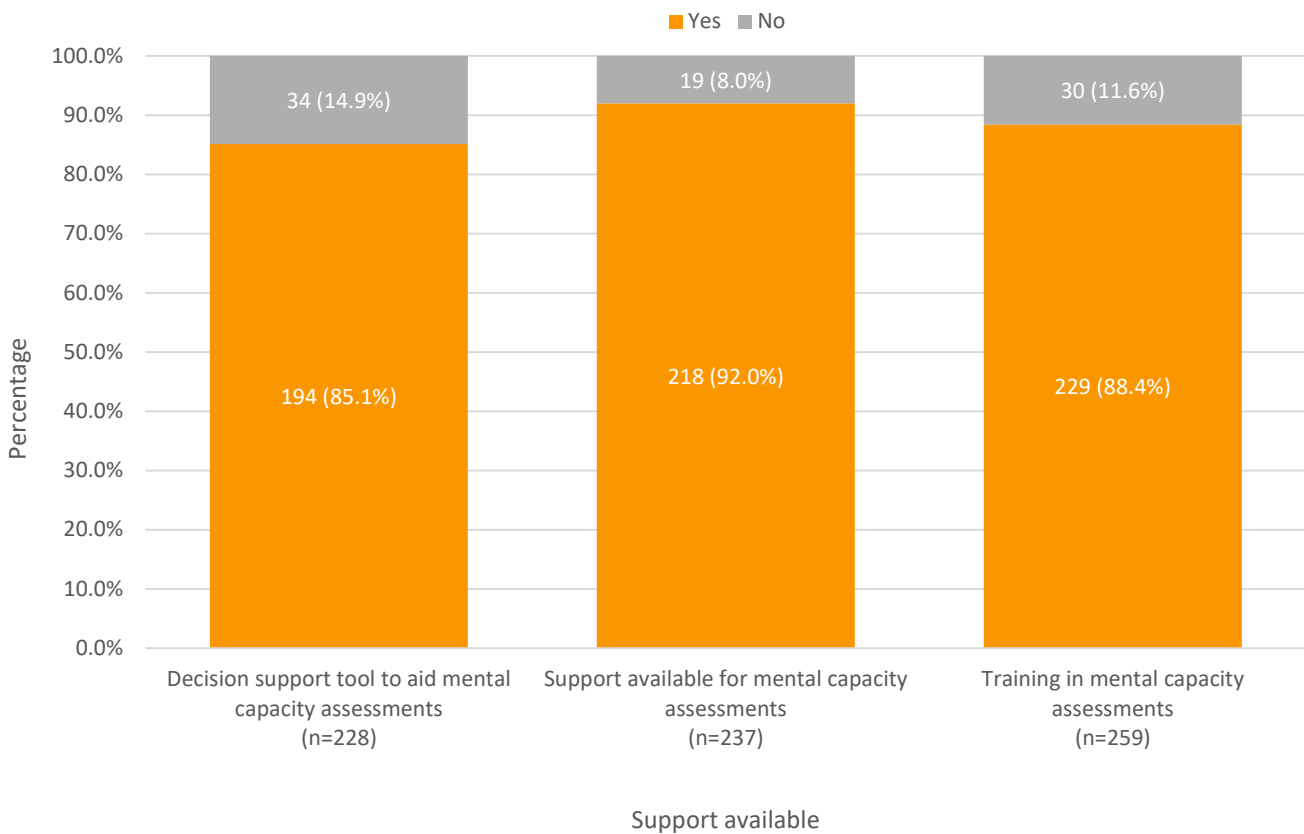
Improving confidence to make mental capacity assessments

A lack of understanding of the Mental Capacity Act and the lack of specialist advice and support for complex situations have been identified as barriers to the effective implementation of mental capacity assessments.^[20] Although 277/475 (58.3%) health and social care survey respondents assessed mental capacity as part of their role within the acute setting (T7.6), only 169/277 (61.0%) felt confident to do so.

T7.6 Acute setting only - mental capacity assessments are made as part of your role	Number of responses	%
Yes	277	58.3
No	142	29.9
Not applicable - not part of my job role	56	11.8
Subtotal	475	
Not answered	9	
Total	484	

Health and social care professional survey data

Health and social care survey respondents reported wide use of decision support tools and training in mental capacity assessments (F7.4), and those who had received mental capacity assessment training within the previous two years, reported an improvement in confidence in carrying out the assessments (78/97; 80.4%).



F7.4 Support and training for mental capacity assessments

Health and social care professional survey data