

Learning Disability - Organisational Questionnaire

A. Introduction

Please complete this organisational questionnaire for each hospital in your Trust/Health Board that treats patients with a learning disability who present to hospital acutely unwell.

Study aim

To identify avoidable and modifiable factors in the care of patients with a learning disability who were admitted to hospital acutely unwell.

Who should complete this questionnaire

This questionnaire has been designed to collect data on the organisational structures surrounding the care provided to patients with a learning disability.

It should be completed by or with input from, clinician(s) that provide care to this group of patients. This is likely to include, but not limited to emergency medicine, acute and general medicine and the learning disability team.

Questions or help

Further information regarding the study can be found here: <https://www.ncepod.org.uk/Learning.html>

If you have any queries about the study or this questionnaire, please contact: learning@ncepod.org.uk or telephone 0207 251 9060

About NCEPOD

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) reviews healthcare practice by undertaking confidential studies, and makes recommendations to improve the quality of the delivery of care, for healthcare professionals and policymakers to implement. Data to inform the studies are collected from NHS hospitals and Independent sector hospitals across England, Wales, Northern Ireland and Jersey. NCEPOD are supported by a wide range of bodies and the Steering Group consists of members from the Medical Royal Colleges and Specialist Associations, as well as observers from The Coroners Society of England and Wales, and the Healthcare Quality Improvement Partnership (HQIP).

Impact of NCEPOD

Recommendations from NCEPOD reports have had an impact on many areas of healthcare including: Development of NICE Clinical Guidelines for Acute Kidney Injury (CG169), published 2013 - 'Adding Insult to Injury' (2009).

Development of ICS Standards for the care of adult patients with a temporary Tracheostomy, published 2014 - 'On the right Trach?' (2014).

Development of guidelines from the British Society of Gastroenterology: diagnosis and management of acute lower gastrointestinal bleeding, published 2019 - 'Time to Get Control' (2015).

Development of the British Thoracic Society's Quality Standards for NIV, published 2018 - 'Inspiring Change' (2017).

Development of NHSE Children and young people's cancer service specification - 'On the Right Course?' (2018)

Development of the Centre for Perioperative Care Guideline for Perioperative Care for People with Diabetes Mellitus Undergoing Elective and Emergency Surgery, published 2021 - 'Highs and Lows' (2018)

Update to NICE 'Transition from children's to adults' services' Quality Standard (QS140), updated 2023 - 'The Inbetweeners' (2023)

Update to NICE 'Endometriosis: diagnosis and management' guideline (CG73), updated 2024 - 'A long and painful road' (2024)

Development of the GIRFT Children and Young People: Testicular torsion pathway, published 2024 - 'Twist and Shout' (2024)

This study was commissioned by The Healthcare Quality Improvement Partnership (HQIP) as part of the Clinical Outcome Review Programme into Medical & Surgical care.

B. Learning disability identification

1. Which staff members were involved in the completion of this questionnaire?

Please tick all that apply

- | | | |
|-------------------------------------|--|--|
| <input type="checkbox"/> Consultant | <input type="checkbox"/> Clinical nurse specialist | <input type="checkbox"/> Learning disability nurse |
| <input type="checkbox"/> Key worker | <input type="checkbox"/> Unknown | |

Please specify any additional options here...

2a. Can patients with a learning disability be identified on your patient record system?

This could include Electronic Patient Records (EPR) or Patient Administration System (PAS)

- ☐ Yes ☐ No ☐ Unknown

2b. If answered "Yes" to [2a] then:

How are patients with a learning disability identified on the hospital system or patient record?

Please tick all that apply

- | | |
|---|---|
| <input type="checkbox"/> Coded diagnosis in patient record | <input type="checkbox"/> Free text entry in notes |
| <input type="checkbox"/> Alert/ flag on Electronic Patient Record (EPR) | <input type="checkbox"/> Learning disability register |
| <input type="checkbox"/> Unknown | |

Please specify any additional options here...

2c. If answered "Learning disability register" to [2b] then:

Approximately, how many people are on the learning disability register?

☐ Unknown

3a. Is it hospital policy for specific clinicians to be contacted/ alerted when a patient with a learning disability has been admitted to hospital?

- ☐ Yes ☐ No ☐ Unknown

3b. If answered "Yes" to [3a] then:

Which of the following would happen?

Please tick all that apply

- ☐ Hospital's learning disability liaison nurse is alerted
- ☐ Hospital's learning disability team would be alerted
- ☐ Hospital's learning disability team will be contacted by email
- ☐ Hospital's learning disability team will be contacted by phone
- ☐ Community learning disability team will be contacted by email
- ☐ Community learning disability team will be contacted by phone

Please specify any additional options here...

1a. Does this hospital have a learning disability service?

- ☐ Yes ☐ No

1b. If answered "Yes" to [1a] then:**Is the learning disability service on-site at this hospital?**

- ☐ Yes ☐ No ☐ Unknown

1c. If answered "Yes" to [1a] and "Yes" to [1b] then:**What hours are they available?**

- ☐ 24/7
☐ Normal working hours - 7 days/ week (e.g 8am - 6pm)
☐ Normal working hours - Monday - Friday (e.g 8am - 6pm)
☐ Extended hours - 7 days/ week
☐ Extended hours - Monday - Friday

If not listed above, please specify here...

1d. If answered "Yes" to [1a] then:**Is the learning disability service:**

- ☐ An individual ☐ Uniprofessional ☐ Multi-disciplinary team

1e. If answered "An individual" or "Uniprofessional" to [1d] then:**What discipline?**

- ☐ Nurse(s) ☐ Doctor(s)

If not listed above, please specify here...

1f. If answered "Multi-disciplinary team" to [1d] then:**Which professional groups are included in the learning disability service?***Please tick all that apply*

- | | |
|---|---|
| <input type="checkbox"/> Nurses | <input type="checkbox"/> Doctors |
| <input type="checkbox"/> Psychologists | <input type="checkbox"/> Psychiatrists |
| <input type="checkbox"/> Occupational therapists | <input type="checkbox"/> Physiotherapists |
| <input type="checkbox"/> Speech and language therapists | <input type="checkbox"/> Pharmacists |
| <input type="checkbox"/> Dietitians | <input type="checkbox"/> Inclusion health consultants |
| <input type="checkbox"/> Arts therapists | |

Please specify any additional options here...

1g. If answered "Yes" to [1a] then:**What is included within the usual role of the learning disability service?***Please tick all that apply*

- | | |
|--|---|
| <input type="checkbox"/> Supporting admissions | <input type="checkbox"/> Supporting Mental Capacity Assessments |
| <input type="checkbox"/> Supporting reasonable adjustments | <input type="checkbox"/> Discharge planning |
| <input type="checkbox"/> Supporting clinical care | |

Please specify any additional options here...

1h. If answered "Yes" to [1a] then:**Is the learning disability service employed by this hospital?**

- ☐ Yes ☐ No ☐ Unknown

2a. How many whole time equivalent learning disability nurses are employed at this hospital?

WTE

☐ Not Applicable ☐ Unknown

2b. Is this a dedicated role?

☐ Yes ☐ No ☐ Not applicable ☐ Unknown

3a. Does the community learning disability team provide in-reach to this hospital to support admission and discharges?

☐ Yes ☐ No ☐ Not applicable ☐ Unknown

**3b. If answered "Yes" to [3a] then:
What hours are they available?**

- ☐ 24/7
☐ Normal working hours - 7 days/ week (e.g 8am - 6pm)
☐ Normal working hours - Monday to Friday (e.g 8am - 6pm)
☐ Extended hours - 7 days/ week
☐ Extended hours - Monday - Friday

If not listed above, please specify here...

Leadership

4a. Do you have an executive at board level with learning disabilities within their remit?

☐ Yes ☐ No ☐ Unknown

4b. Does this hospital have a senior clinician* with learning disabilities within their remit?

**Chief Medical Officer or Chief Nursing Officer*

☐ Yes ☐ No ☐ Unknown

5a. Does this hospital have a learning disability champion?

☐ Yes ☐ No ☐ Unknown

5b. If answered "Yes" to [5a] then:

At which level does the learning disability champion operate?

Please tick all that apply

- ☐ Ward ☐ Hospital wide ☐ Specialty ☐ Divisional
☐ Trust wide

Please specify any additional options here...

6. Please state any additional comments concerning staffing in relation to the delivery of services for individuals with learning disabilities when in hospital:

1. Does this hospital have a policy on the use of reasonable adjustments?

- ☐ Yes ☐ No ☐ Unknown

2a. Does this hospital flag reasonable adjustments for learning disability?

- ☐ Yes ☐ No ☐ Unknown

2b. Is there a standardised approach to identify reasonable adjustments for patients with a learning disability?

- ☐ Yes ☐ No ☐ Unknown

2c. How are the reasonable adjustment flags shared?

- | | |
|---|--|
| <input type="checkbox"/> Digitally on patient administration system | <input type="checkbox"/> Digitally on patient record |
| <input type="checkbox"/> National digital flag | <input type="checkbox"/> Pop up alert |
| <input type="checkbox"/> Paper record | |

Please specify any additional options here...

3. What reasonable adjustments are routinely available?

Please tick all that apply

- ☐ Time - Increased appointment length
- ☐ Time - Early/late appointments
- ☐ Environment - Quiet private rooms
- ☐ Environment - Equipment to support sensory needs (noise cancelling headphones etc)
- ☐ Attitude - Involving patients in decision making
- ☐ Attitude - MCAs
- ☐ Communication - Accessible information - easy read formats
- ☐ Communication - Accessible information - audio-visual versions
- ☐ Communication - Learning disability team involvement
- ☐ Communication - Support from someone who knows the person and can support communication
- ☐ Communication - Strategies to support understanding and expression (Key word signing)
- ☐ Help - From someone the patient knows
- ☐ Help - Involving advocates
- ☐ Help - Referring to hospital passport
- ☐ None of the above

Please specify any additional options here...

4a. Does this hospital comply with the Accessible Information Standard?

https://www.ncepod.org.uk/pdf/current/Learning/Learning_Definitions.pdf

- ☐ Yes ☐ No ☐ Unknown

4b. Does this hospital offer clinical information and letters in accessible formats?

This can include easy read formats and audio-visual versions.

- ☐ Yes - Always ☐ Yes - Sometimes ☐ No ☐ Unknown

Mental Capacity Assessments (MCAs)

1. Does this hospital have a Standard Operating Procedure(s) to specifically follow when making MCAs for people with a learning disability?

☐ Yes ☐ No ☐ Unknown

2a. Does this hospital have a decision support tool to help in making mental capacity assessments?

☐ Yes ☐ No ☐ Unknown

**2b. If answered "Yes" to [2a] then:
Does this include best interest decisions?**

☐ Yes ☐ No ☐ Unknown

2c. Does this hospital record mental capacity decisions?

☐ Yes ☐ No ☐ Unknown

**2d. If answered "Yes" to [2c] then:
How are decisions recorded?**

☐ Paper form ☐ Electronic form ☐ Variable ☐ Unknown

Please specify any additional options...

3a. Does this hospital have access to Independent Mental Capacity Advocates (IMCAs)?

☐ Yes ☐ No ☐ Unknown

**3b. If answered "Yes" to [3a] then:
What hours are the IMCAs available?**

☐ 24/7
☐ Normal working hours - 7 days/ week (e.g. 8am - 6pm)
☐ Normal working hours - Monday - Friday (e.g. 8am - 6pm)
☐ Extended hours - 7 days/ week
☐ Extended hours - Monday - Friday
☐ Unknown

If not listed above, please specify here...

1. Does this hospital have a specific adults not brought/ Did Not Attend policy that includes people with a learning disability?

☐ Yes ☐ No ☐ Unknown

Carer involvement

2a. Does this hospital have a carer policy?

☐ Yes ☐ No ☐ Unknown

2b. If answered "Yes" to [2a] then:

What is the included in the carer policy?

Please tick all that apply

- | | | |
|---|--|--|
| <input type="checkbox"/> Carer passport | <input type="checkbox"/> Free parking | <input type="checkbox"/> Refreshments provided |
| <input type="checkbox"/> Meals provided | <input type="checkbox"/> Open visiting hours | <input type="checkbox"/> Staying 24/7 |
| <input type="checkbox"/> Fold up beds | <input type="checkbox"/> Access to toilets on ward | |

Please specify any additional options here...

3a. Does this hospital have a carer's charter?

☐ Yes ☐ No ☐ Unknown

3b. If answered "Yes" to [3a] then:

How are carers made aware of the charter?

Please tick all that apply

- | | | | |
|----------------------------------|--|-------------------------------|-----------------------------------|
| <input type="checkbox"/> Posters | <input type="checkbox"/> Trust website | <input type="checkbox"/> PALS | <input type="checkbox"/> Informal |
|----------------------------------|--|-------------------------------|-----------------------------------|

Please specify any additional options here...

4. How do staff know that someone is a carer?

- | | | | |
|---|-----------------------------------|--|----------------------------------|
| <input type="checkbox"/> Card | <input type="checkbox"/> Badge | <input type="checkbox"/> Card on lanyard | <input type="checkbox"/> Booklet |
| <input type="checkbox"/> Sticker in notes | <input type="checkbox"/> Informal | <input type="checkbox"/> Unknown | |

Please specify any additional options here...

5. How can carers be involved in aspects of treatment and care of the person they care for?

Please tick all that apply

- | | |
|--|--|
| <input type="checkbox"/> Involvement in informal discussions | <input type="checkbox"/> Involved in MDT discussions |
| <input type="checkbox"/> Involved in personal care | <input type="checkbox"/> Involvement in discharge planning |
| <input type="checkbox"/> Detailed updates by telephone | <input type="checkbox"/> Discharge summary shared |
| <input type="checkbox"/> Unknown | |

Please specify any additional options here...

6a. Are people with a learning disability involved in the development of hospital pathways?

☐ Yes ☐ No ☐ Unknown

**6b. If answered "Yes" to [6a] then:
Please expand on your answer:**

7. Does this hospital have a standardised admission checklist for people with a known learning disability?

This may be a series of questions relating to learning disability in the standard admission checklist

☐ Yes ☐ No ☐ Unknown

8. Does this hospital comply with the NHS learning disability improvement standards?

https://www.england.nhs.uk/wp-content/uploads/2020/08/v1.17_Improvement_Standards_added_note.pdf

☐ Yes ☐ No ☐ Unknown

9a. Does this hospital have a Call for Concern or Martha's rule service?

☐ Yes ☐ No ☐ Unknown

9b. If answered "Yes" to [9a] then:

Has there been any adaptations to ensure the service is accessible to people with a learning disability?

☐ Yes ☐ No ☐ Unknown

**9c. If answered "Yes" to [9b] then:
Please give examples:**

Training

10a. Does this hospital offer training on the care of people with a learning disability?

☐ Yes ☐ No ☐ Unknown

10b. If answered "Yes" to [10a] then:

Which training:

☐ Oliver McGowan Mandatory Training ☐ Modified local training

Please specify any additional options here...

10c. If answered "Yes" to [10a] then:

Is an expert with lived experience involved in delivering training?

☐ Yes ☐ No ☐ Unknown

**10d.If answered "Yes" to [10a] then:
How is the training delivered?**

☐ In-person ☐ Virtually ☐ Unknown

Please specify any additional options here...

Evaluation and audit data collection

11a.Has this hospital audited the care provided to people with a learning disability in the past 3 years?

☐ Yes ☐ No ☐ Unknown

**11b.If answered "Yes" to [11a] then:
How are findings shared?**

Please tick all that apply

☐ A written report ☐ Reported to staff
☐ Reported at a board level
☐ Committee/steering group for learning disability

Please specify any additional options here...

**11c.If answered "Yes" to [11a] then:
Did the audit result in any improvement actions?**

☐ Yes ☐ No ☐ Unknown

**11d.If answered "Yes" to [11c] then:
Please give further details (improvement)**

12. Is there a specific audit/ reporting process for complaints relating to people with a learning disability?

☐ Yes ☐ No ☐ Unknown

13a.Does this hospital refer the deaths of patients with a learning disability to LeDeR (learning from deaths and mortality review)?

<https://www.kcl.ac.uk/research/leder>

☐ Yes ☐ No ☐ Not applicable ☐ Unknown

**13b.If answered "Yes" to [13a] then:
How is learning shared with the clinical team who cared for the patient after the LeDer review?**

☐ In-person ☐ Virtually

Please specify any additional options here...

14a.Are you aware of any gaps in the service you provide to people with a learning disability?

☐ Yes

☐ No

☐ Unknown

14b.If answered "Yes" to [14a] then:

Please give further details:

15a.Is there any quality improvement work or examples of good practice relating to the learning disability service at this hospital that you would like to share?

☐ Yes

☐ No

☐ Unknown

15b.If answered "Yes" to [15a] then:

Please provide details: