Management of Acute Illness in people with a Learning Disability

Study Protocol

Study Advisory Group Members

Charly Annesley	Consultant Learning Disability Physician
Helen Beaumont-Waters	Head of Clinical Development – College of Paramedics
Jonathan Beebee	Royal College of Nursing
Lesley Brown	Consultant Speech and Language Therapist
Carol Boys	Down’s Syndrome Association
Andrew Bright	Thera Trust
Sam Browning	GP Learning Disability Physician and Clinical Lead
Umesh Chauhan	LeDeR
Sara Danby	Thera Trust
Rizwana Dudhia	Lead pharmacist for learning disabilities and autism
Stacey Endacott	Professional Lead for Mental Capacity
Jane Greaves	NCEPOD Trustee
Liz Herrieven	Royal College of Emergency Medicine
Helen Justice	Occupational Therapy Professional Lead
Kirsten Lamb	Royal College of General Practitioners
Jessica Lister	UK Learning Disability Consultant Nurse Network
Mildred Mhlanga	Silva Care
Anna Petsas	Consultant Intensivist
Anne Pullyblank	Association of Surgeons of Great Britain & Ireland
Andrew Rochford	Royal College of Physicians
Jacqui Rogers	Transition Lead Nurse
Rohit Shankar	Consultant in Adult Developmental Neuropsychiatry
Paula Shrubsole	Lead Nurse
David Standley	Clinical Specialist Physiotherapist
Andre Strydom	LeDeR
Chris Subbe	Consultant in Acute, Respiratory & Critical Care Medicine
Katy Welsh	RCN Learning Disability Nursing Forum

NCEPOD Clinical Co-ordinators

David McWilliams	Clinical Co-ordinator - Physiotherapy
Alison Tavaré	Clinical Co-ordinator - Primary care

Non-Clinical Staff

Neil Smith	Senior Clinical Researcher
Dee Koomson	Clinical Researcher
Holly Hamilton	Research Assistant
Marisa Mason	Chief Executive

Introduction

Public Health England (PHE) and the Office for National statistics (ONS) estimate that 2.16% of the adult population in the United Kingdom (UK) have a learning disability. This equates to 1.5million people.[1] The Learning from Lives and Deaths of People with a Learning Disability and Autistic People (LeDeR) 2022 annual report showed adults with a learning disability die up to 30 years earlier than the general population and experience much higher rates of co-morbidities.[2] The report identified people with learning disability have multiple health needs, that they die around 30 years earlier, and experience barriers in accessing healthcare, such as problems in communication and in applying the mental capacity act. NHS England (NHSE), driven by the Equalities Act 2010, recognise that further understanding is essential in tackling specific inequalities people with learning disability face, making learning disability healthcare inequalities centre stage within the NHS Long Term Plan (NHSLTP)[3]. Approximately half of deaths were deemed avoidable, doubling the incidence in the general population. However, to date there are no large-scale UK studies that have focused upon the variation in healthcare delivery in the acute sector to patients with a learning disability irrespective of survival outcome.

LeDeR focus on avoidable deaths and highlights where the care of people with a learning disability can be improved to address premature deaths. However, the cases reviewed are those of people who have died, regardless of setting, and which have been reported to the LeDeR team. The Learning Disability Improvement standards provide a benchmark against which all trusts can measure their performance in delivering services to people with learning disabilities, autism to driving quality improvement [4]. However, these standards outline strategic objectives and priorities, presenting an opportunity for a more comprehensive analysis of how organisations provide care to people with learning disabilities.

References

1. Public Health England - Learning Disabilities Observatory People with learning disabilities in England 2015: Main report https://assets.publishing.service.gov.uk/media/5a81e329ed915d74e3400976/PWLDIE_2015_main_report_NB090517.pdf
2. LeDeR Annual Report Learning from Lives and Deaths: People with a Learning Disability and Autistic People 2022https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-2022-v2.0.pdf
3. NHS Long term Plan https://www.longtermplan.nhs.uk/
4. NHS Improvement - The learning disability improvement standards for NHS trusts https://www.england.nhs.uk/wp-content/uploads/2020/08/v1.17_Improvement_Standards_added_note.pdf

Guidelines and standards

HS England Learning Disability Improvement Standards Project (3)
https://www.nhsbenchmarking.nhs.uk/nhsi-ld-project-documentation-outputs

Acute Care Toolkit 16: Acute Medical Care for People with a Learning Disability, RCP, 2022
https://www.gov.uk/government/publications/health-equity-assessment-tool-heat

NICE Care and Support of People Growing Older with a Learning Disability
https://www.nice.org.uk/guidance/ng96/chapter/Context

Northern Ireland Regulation and Improvement Authority Guidelines on caring for people with a Learning Disability in acute hospital settings
https://www.rqia.org.uk/RQIA/files/41/41a812c6-fee8-45ba-81b8-9ed4106cf49a.pdf

Definitions

The Department of Health and Social Care defines a learning disability as “a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood.” Throughout the protocol this definition has been used.

A learning disability is different for everyone. The degree of disability can vary greatly, and historically has been classified as mild, moderate, severe or profound but it is now common practice to use the generic code of ‘learning disability’. In all cases, a learning disability is a lifelong condition and cannot be resolved.

A learning disability is different to a learning difficulty, which is a reduced intellectual ability for a specific form of learning and includes conditions such as dyslexia, dyspraxia and attention deficit hyperactivity disorder (ADHD). A person with a learning disability may also have one or more learning difficulties.

A learning disability is not a physical disability.

Aims and objectives

Overall aim:

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

Objectives:

Organisational

To review the structures and systems in place to deliver a high-quality service to patients with a learning disability:

- Acute hospital care pathways (emergency medical or surgical admissions)
- Guidelines and protocols in place for the care of patients with a learning disability
- The use of local policies and protocols
- Learning disability registers and system flags
- Multidisciplinary team working
- Staffing and training
- Clinician confidence and understanding of lives of people with a learning disability
- Discharge and follow-up arrangements
- Serious adverse events
- Audit, Quality Improvement (QI) and coding
    - Participation in national audits
    - Active local audits and QI
- Examples of good practice

Clinical

To explore remediable factors in the process of care of patients with a learning disability throughout the pathway, with a focus on the following areas:

- Access to and involvement of specialist teams, including learning disability teams
- Presentation of acute illness
- Delays diagnosis, referrals to specialists
- Appropriate clinical setting
- Reasonable adjustments
- Mental capacity assessments
- Treatment
- Investigations and Imaging
- Sharing of any treatment escalation plans
- Communication with patient, carer and other involved parties
- Medication management, including review of current medications
- Discharge and follow up
- Readmissions
- Serious adverse events to highlight areas of care for improvement
- Examples of good practice
- Remediable factors in the quality of care received and produce recommendations for improvement

Method

Study advisory group (SAG)

A multidisciplinary group of relevant stakeholders (listed on the first page) comprising of consultants, associate specialists, trainees and clinical nurse specialists, from the following specialties: emergency, intensive care and acute medicine, general practice and surgery, as well as allied health professionals, experts in the field, healthcare professionals, a person with lived experience were convened to finalise the areas of care that should be reviewed, the method to be undertaken and the inclusion criteria. This group will also provide oversight of the report recommendations at the end of the study.

Early patient involvement

A member of the SAG is an expert with lived experience of a learning disability. He is able to contribute his lived experience of both personally receiving healthcare as a person with a learning disability and as a carer of someone with a learning disability who has been acutely unwell and needed hospital review. Their input into the NCEPOD study has been crucial in steering the study from an early stage.

The NCEPOD team have been guided by the expert with lived experience and their co-leader to ensure that he has been actively involved. This has included documents being shared in a more accessible format, online meetings before study advisory groups, and modifying the delivery of face-to-face meetings.

Participating hospitals

Data will be collected from all hospitals in England, Wales and Northern Ireland and the States of Jersey, which admit and treat acutely unwell patients.

Population

All patients aged 18 years and over who were admitted to hospital as an emergency between **1st July – 30th September 2024** inclusive with a learning disability.

Inclusions

Patients will be identified retrospectively using ICD10 codes (in any position at discharge) and/ or Learning Disability registers within the acute trust.

ICD10 Code	
F70	Mild disorder of intellectual development
F71	Moderate disorder of intellectual development
F72	Severe disorder of intellectual development
F73	Profound disorder of intellectual development
F78	Other disorder of intellectual development
F79	Unspecified disorder of intellectual development
F80	Specific developmental disorders of speech and language
F81	Specific developmental disorders of scholastic skills
F82	Specific developmental disorder of motor function
F83	Mixed specific developmental disorders
F84	Pervasive developmental disorders

F88	Other disorders of psychological development
F89	Unspecified disorder of psychological development

Up to 6 cases per hospital will be included for questionnaire completion and peer review

Exclusions

Patients admitted as a day case, including Same day emergency care (SDEC) admissions as not enough data would be available for a review.

Incidence and prevalence

Public Health England (PHE) and the Office for National statistics (ONS) estimate that 2.16% of our adult population in the UK have a learning disability. This equates to 1.5million people. [PHE 2016_ Learning Disabilities Observatory People with learning disabilities in England 2015: Main report https://assets.publishing.service.gov.uk/media/5a81e329ed915d74e3400976/PWLDIE_2015_main_report_NB090517.pdf]

Below are the number of admissions (and emergency admissions) for where the primary ICD10 code relates to learning disability (using the inclusion codes above).

Hospital Episodes Statistics (HES) for England data 2023/24

	Any position diagnosis: 3-character code and description			
	All diagnoses	**Main diagnosis**	**Emergency admissions**	
F70 - F79	70,431	423	6,249	
F80 - F89	327,862	3,002	42,353	
Total	**398,293**	**3,425**	**48,602**	
			4,050	**Monthly**
			12,150	**Over 3m period**

The corresponding all diagnoses ICD10 codes data was not available for Wales.

Case identification

Within each Trust/Health Board NCEPOD has a Local Reporter (usually employed in clinical audit) who is responsible for providing the details of cases for inclusion to NCEPOD. At the start of the study the Local Reporter will be contacted and advised to set-up a study contact who can interrogate, where available, learning disability registers so patients with a learning disability can be identified retrospectively.

ICD10 code data as detailed above and/or learning disability registers will be used to identify a cohort of patients with a learning disability, that were admitted to hospital as an emergency (for any condition) during the study period. Selected data from central hospital records will be collected for this cohort via completion of a spreadsheet. This will include patient details (NHS number, hospital number, date of birth), admission/discharge dates, source of admission, critical care admission, procedure details (where applicable), and discharge location.

Methods of data collection

Data collection

There will be four main ways of collecting data for the study:

1. Clinician questionnaires

In-hospital clinician questionnaire

A questionnaire will be sent to the named consultant responsible for the patient's care when they were treated in hospital during their acute illness. Within this there will be instruction to pass the questionnaire on to most appropriate clinician should it not be the named person.

Data collected will include information on the hospital admission including discharge and follow up, the involvement of the specialist teams, reasonable adjustments made, treatments and investigations the patient received in hospital, specialist reviews and readmissions, use of protocols and clinical pathways.

The questionnaires will be disseminated via the NCEPOD online questionnaire system which is accessed by NCEPOD local reporters. The local reporters will then be able email the relevant clinician, granting them access to the online questionnaire. Reminder emails will be sent at six and ten weeks where the data are outstanding. The Local Reporter will be asked to return copied extracts of the patient's case notes to NCEPOD alongside the completed questionnaires.

GP and community clinical questionnaire

A questionnaire will be disseminated to the patient's GP. In addition to specific questions regarding the care the individual patient received within the community, questions with respect to the organisation of services for patients with a learning disability in the community will be included.

2. Organisational questionnaire

Hospital organisational questionnaire

An organisational questionnaire will be sent to all hospitals that admit acutely unwell patients as an emergency. An organisational questionnaire will be sent to all community trusts that treat patients with a learning disability. Data collected will include information around the organisation of services in the process of identifying, screening, assessing, treating patients with a learning disability, networks of care, multidisciplinary team working, the use of guidelines/protocols and training. The questionnaires will be disseminated via the online questionnaire system. Local reporters will be able to invite multiple clinicians to complete the questionnaire.

3. Anonymous surveys

Anonymous online healthcare professional survey

An anonymous online survey for healthcare professionals who treat patients with a learning disability. This questionnaire will be targeted at, but not limited to, clinicians and allied health professionals working in hospitals and the community. The survey will collect data on the views of healthcare professionals regarding their own confidence and training level in providing care to this cohort of patients. The data will not be linked to any other aspects of data collection.

Anonymous online patient/ carer survey

An anonymous online survey will gather data on the patient and carer views on the care received following an emergency admission to hospital. These surveys will be codeveloped with people with learning disabilities to ensure appropriate language is used and that the surveys are simple to complete. NCEPOD will ensure that the surveys will be available in easy read format, and there will be a telephone number for surveys to be orally completed. The data will not be linked to any other aspects of data collection.

4. ***Case note review***

Case note review will be undertaken for a sample of patients who presented to hospital as an emergency with a learning disability.

Case notes

Photocopies of the case notes of each included patient will be requested at the time of questionnaire dissemination.

Notes requested relating to the index emergency admission:

- All inpatient annotations/medical notes for the index admission
- Nursing notes
- Safeguarding forms
- Critical care notes
- Operation/procedure notes
- Hospital passport
- DNACPR, MCA, DOLS forms
- Anaesthetic charts
- Observation charts
- Haematology/biochemistry results
- Fluid balance charts
- Blood transfusion records
- Drug charts
- Nutrition/dietitian notes
- Consent forms
- Discharge letter/summary for index admission
- Discharge letters relating to up to 6m of readmissions
- Correspondence relating to up to 6m of readmissions
- DATIX
- Autopsy report, if applicable

Upon receipt at NCEPOD the case notes will be anonymised removing patient identifiable information.

Reviewer assessment form

A multidisciplinary group of reviewers (details below) will be recruited to assess the case notes and questionnaires and give their opinions on the quality of care via the reviewer assessment form.

Below are the anticipated sample sizes of each type of data collected:

Data Source Target	**Number**
Hospital organisational questionnaire	~200
Clinician questionnaire	~500
Case note review	~500
Clinician survey	~100
Patient/ Carer survey	~50

Study method test

The data collection methods and data collection tools will be tested to ensure they are robust.

Confidentiality and data protection

All electronic data are held in password protected files and all paper documents in locked filing cabinets. As soon as possible after receipt of data NCEPOD will encrypt electronic identifiers and anonymise paper documents. Section 251 approval has been obtained to perform this study without the use of patient consent in England and Wales.

Study promotion

Prior to data collection, NCEPOD will contact all hospitals that admit and treat acutely unwell patients with patients with a learning disability. The study will also be promoted to via patient groups, NCEPOD Local Reporters (sending the study poster on to the relevant departments), via study contacts recruited as part of the case identification strategy, and via the relevant Colleges and Associations. NCEPOD will also create audio files, videos and easy read leaflets explaining the study for the website.

Review of case notes

A multidisciplinary group of reviewers will be recruited to assess the case notes and questionnaires and provide their opinion on the care the patients received. The group of case reviewers will comprise consultants, associate specialists, trainees and clinical nurse specialists, from the following specialties: emergency, intensive care and acute medicine, general practice and surgery, as well as allied health professionals.

An advert will be sent to Local Reporters to disseminate throughout the relevant departments. It will also be placed on the NCEPOD website. Successful applicants will be asked to attend a training day where they will assess the same two anonymised case notes to ensure consistent assessment using the reviewer assessment form. A series meeting dates will be arranged, and each reviewer will then be asked to attend a minimum of a further 4 meetings. NCEPOD staff will ensure there is a mix of specialties at each meeting from across the UK. Each meeting will be chaired by an NCEPOD clinical coordinator who will lead discussion around the cases under review. The meetings will be held in person at the NCEPOD office. They may also be held virtually via Microsoft Teams.

Towards the end of the study the reviewers will be invited to attend a meeting where the data will be presented to and discussed with them. The reviewers will also be sent two copies of the draft report for their comment as this is developed.

Dissemination

On completion of the study a report will be published and widely disseminated all stakeholders to encourage local quality improvement (QI) (further details available in the communication plan). In addition to the report, supporting tools will be made available including:

- A summary report
- Infographics
- The recommendation checklist
- An audit tool
- A slide set
- A guide for commissioners
- Fishbone diagrams
- Useful links for patients and carers
- A question sheet for patients with a learning disability to use when they are admitted to hospital as an emergency
- Audio files and a video explaining the study's findings

Examples of good practice will be shared, and additional QI tools will be developed where appropriate. Key messages from the report will be shared via social media.

Following publication, the report findings will be shared at national and local conferences, study days and other events; and papers submitted to journal for consideration for publication.

Data sharing

Post-publication of the study there is the potential to share anonymised data sets with interested parties working in the same field. This will be undertaken following a strict process and will ensure the data does not become identifiable in their nature due to small numbers.

Timeline

	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25	Apr-25	May-25	Jun-25	Jul-25	Aug-25	Sep-25	Oct-25	Nov-25	Dec-25	Jan-26	Feb-26	Mar-26
Advertise the study through primary contacts (LRs) and all stakeholders	■	■	■																
Advertise for reviewers through all contacts and social media				■															
Create the database				■															
Start patient identification					■														
Clinician questionnaires						■	■	■	■	■									
Organisational questionnaires						■	■	■	■	■									
Online patient/clinician surveys/interviews						■	■	■	■	■									
Appoint and train case reviewers						■													
Reviewer meetings							■	■	■	■									
Data cleaning							■	■	■	■									
Data analysis								■	■	■									
Write the report								■	■	■	■								
Report production 1st review											■	■							
Report production 2nd review												■	■						
Report production 3rd review													■	■					
To HQIP - SRP															■				
Develop QI tools																■	■		
PUBLISH																		■	
Follow-up work and stakeholder meeting 1 year on																			■