

# 1 METHODS

## Study advisory group

A multidisciplinary group of clinicians was convened to steer the study from design to completion, define the objectives of the study and advise on the key questions. The group comprised a person with lived experience of a learning disability, healthcare professionals in emergency, intensive care and acute medicine, general practice and surgery, as well as allied health professionals and experts in the field, and healthcare professionals.

## Study aims and objectives

The objectives of the study were to identify avoidable and modifiable factors associated with poor quality of care in patients with a learning disability admitted to hospital when acutely unwell, including:

- Guidelines/protocols in use for the management of acute illness in patients with a learning disability
- Organisational structures in place to deliver care and reasonable adjustments to patients with a learning disability
- Areas for improvement in the investigation and treatment of patients with a learning disability.

## Hospital participation

Data were included from NHS hospitals in England, Wales, Northern Ireland and Jersey.

## Study population and case ascertainment

### Inclusion criteria

All patients with a learning disability aged 18 years and over, who were admitted to hospital as an emergency between 1st July and 30th September 2024 inclusive. Patients were identified retrospectively using F70-F79 ICD10 codes in any position at discharge and/or learning disability registers within the acute trust/health board.

### Exclusion criteria

Patients admitted as a day case, including same day emergency care (SDEC) admissions, as there would not be enough data to review.

### Identification of a sample population

A pre-set spreadsheet was provided to every local reporter to identify all patients meeting the study criteria during the defined time period. From this initial cohort, up to six patients were randomly selected from each hospital for inclusion in the study.

## Data collection

### Clinician questionnaire

A clinician questionnaire was sent to the named consultant caring for each patient. This collected data on the care provided throughout the admission, focusing on investigation, treatment, reasonable adjustments and mental capacity.

### **Primary care questionnaire**

A primary care questionnaire was sent to the named general practitioner for patients in the sample. This short questionnaire collected data on the organisational structures in place in the GP practice that promote quality care for patients with a learning disability who have recently been admitted to hospital.

### **Organisational questionnaire**

An organisational questionnaire was sent to every hospital with an emergency department to collect data around the organisational structures, staffing provision and policies to care for this group of patients.

### **Case notes**

Copies of the case notes were requested for the included admission of each patient for peer review. A list detailing the elements of the case notes that were required was provided to the NCEPOD local reporters, who collated the notes from each participating trust/health board.

### **Peer review of the case notes and questionnaire data**

A multidisciplinary group of case reviewers comprising consultants, resident doctors and clinical nurse specialists from the following specialties: emergency, intensive care, acute medicine, general practice and surgery, and allied health professionals were recruited to peer review the case notes and associated clinician questionnaires.

Using a semi-structured electronic questionnaire, each set of case notes was reviewed by at least one reviewer within a multidisciplinary meeting. A discussion, chaired by an NCEPOD clinical co-ordinator, took place at regular intervals, allowing each reviewer to summarise their cases and ask for opinions from other specialties or raise aspects of the case for further discussion.

### **Surveys**

An online anonymous clinician survey collected information on the training, experience and opinions of clinicians who treat people with a learning disability.

Online anonymous carer and patient surveys, aimed at people with a learning disability and those who work with them, collected data on their individual experiences of being admitted to hospital as an emergency.

Surveys were distributed via the NCEPOD website, relevant charities, the SAG, case reviewers and local reporter network. Surveys were also provided in an easy read format and could be completed via the telephone.

### **Data analysis**

Following cleaning of the quantitative data, descriptive data summaries were produced. Qualitative data collected from the case reviewers' opinions and free-text answers in the clinician questionnaires were coded, where applicable, according to content to allow quantitative analysis. As the methodology provides a snapshot of care over a set point in time, with data collected from several sources to build a national picture, denominators will change depending on the data source, but each source is referenced throughout the document. This deep dive uses a qualitative method of peer review, and anonymised case studies have been used throughout this report to illustrate themes. The sampling method of this

enquiry, unlike an audit, means that data cannot be displayed at a hospital/trust/health board/regional level.

#### **Data analysis rules**

- Small numbers have been suppressed if they risk identifying an individual.
- Any percentage under 1% has been presented in the report as <1%.
- Percentages were not calculated if the denominator was less than 100 so as not to inflate the findings, unless to compare groups within the same analysis.
- There is variation in the denominator for different data sources and for each individual question as it is based on the number of answers given.

#### **Information governance**

All data received and handled by NCEPOD complied with all relevant national requirements, including the General Data Protection Regulation 2016 (Z5442652), Section 251 of the NHS Act 2006 14 (PIAG 4-08(b)/2003, App No 007), and the Code of Practice on Confidential Information. Each patient was given a unique NCEPOD number.