



NHS England – Learning Disability Improvement Standards (LDIS) project

Guidance Notes

January 2026

Should you have any queries about completing any element of the NHS England – LD Improvement Standards project data collection, please contact the NHS Benchmarking Network email nhsbn.nhsildsupport@nhs.net



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NHS ENGLAND – LEARNING DISABILITY IMPROVEMENT STANDARDS PROJECT

GUIDANCE NOTES FOR ALL PARTICIPATING ORGANISATIONS

1. Introduction

This document is intended to provide guidance on each aspect of the NHS England – Learning Disability Improvement Standards (LDIS) project data collection for all participating organisations.

Overview

The NHS England - LDIS project is open to all NHS Trusts in England. In **November 2025**, two elements opened for data collection, described below.

1. Organisational Survey

- The survey questions relate to policies and protocols in place within your organisation, as well as activity, workforce and quality and outcomes.
- To be completed by a nominated Executive Learning Disability lead or named board member.
- Data collection is open from **3rd November 2025** to **31st March 2026**
- This is an **online** data collection with data to be submitted via the NHSBN [Members' Area](#).
- Further information available on [page 5](#)

2. Staff Survey

- The survey questions relate to delivery of care, workforce capacity and training.
- To be completed by staff members occupying any role, chosen by the Trust/organisation, who have experience of working with patients with a learning disability.
- Data collection is open from **3rd November 2025** to **31st March 2026**
- This is an **online** survey, for which each project lead will receive a unique URL for their organisation. The URL link can be distributed to multiple staff members (maximum of 150) to complete the Staff Survey. All responses are anonymised.
- Further information available on [page 5](#)

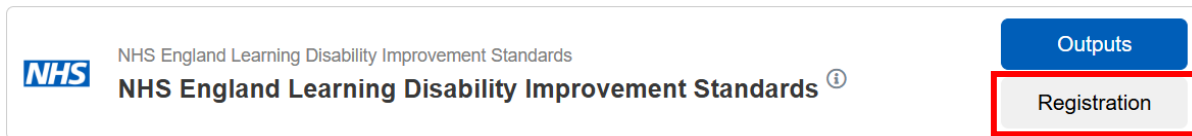
Following collaboration and scoping with NHS England and LD England, a further four components launched in **January 2026**:

1. Seven regional patient focus groups – facilitated by LD England
2. An online Patient Survey
 - Accessed via a URL/QR code.
3. An online Family/Carer Survey
 - Accessed via a URL/QR code.
4. A pilot clinical case note review. Participating Trusts are asked to review 5-10 clinical case notes of patients with a learning disability who have been seen by the Trust during the last year.



2. Registration

All participating Trusts will need to register for the project via the NHS Benchmarking Network Members' Area prior to data collection opening.



Previous participants

Participants that took part in previous rounds of the project can re-register directly via the NHSBN Members' Area. If you require a log in or cannot remember your log in details, please contact nhsbn.nhsildsupport@nhs.net

New participants

New participating organisations are asked to email nhsbn.nhsildsupport@nhs.net with the nominated Project Lead's details. Log in details will then be emailed to the Project Lead.

Once log in details are received, please log in to the [NHSBN Members' Area](#) and click the blue "register" button to the right of the words NHS England Learning Disability Improvement Standards, circled in red above.

Registration details

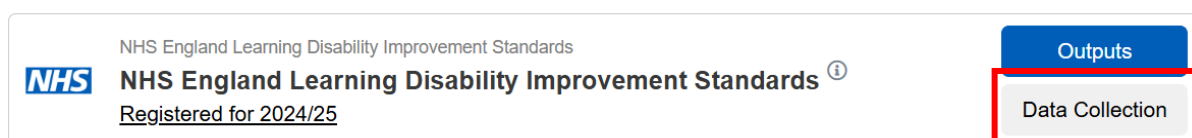
During registration each organisation is asked to provide the following details:

1. **Project Lead:** This is the overall lead for the project in your Trust/organisation and the main contact throughout. The Project Lead has full access to all the elements of the audit and can assign Deputy Project Leads at any stage of data collection. The Project Lead is responsible for the overall coordination of the data collection within each Trust.
2. **Deputy Project Lead(s):** These will have the same access to the data collection pages as the Project Lead. However, Deputy Project Lead will not be the project's main point of contact.

If you need any help with registration, please contact nhsbn.nhsildsupport@nhs.net

3. Data collection

Data collection can be accessed through the [Members' Area](#) by clicking the 'Data Collection' button next to the NHS England Learning Disability Improvement Standards title (Please note, the Members' Area is different to the Data and Improvement Tool where you view your Trust's results). The button will be available once data collection opens on 3rd November 2025, as shown below on the right-hand side of the Members' Area home page:





The Organisational-level and Staff Surveys include questions that are specific to specialist learning disability trusts. If your trust has recently become a specialist trust or has previously been a specialist trust but this is no longer the case, please get in touch with the team and we will update our records to reflect this.

Organisational Survey

The Organisational Survey reviews the policies and protocols in place within your organisation, as well as activity, workforce, quality and outcomes.

The Organisational Survey for NHS England – LDIS project is completed through the NHS Benchmarking Network [Members' Area](#). On the [LDIS Data Collection page](#), select the 'Project Questions' button to access the Organisational Survey pages as shown below. This data collection will cover your Trust/organisation and will only need to be completed once.

Project Questions

Access the project questions for NHS England Learning Disability Improvement Standards. These questions are asked once per submission.

[Project Questions](#)

The deadline for submission for the Organisational Survey is **31st March 2026**.

On the above date, all data collection pages **will be locked**, and the data saved within these pages will be automatically submitted for analysis. At this point you will not be able to access the data collection pages to add, edit or delete the data submitted. If you need to make any changes at this point, please contact the NHSBN team at nhsbn.nhsildsupport@nhs.net.

Staff Survey

This survey is to be completed by staff members occupying any role, who have experience of working with patients with a learning disability. The questions relate to delivery of care, workforce capacity and training.

The Staff Survey can be accessed via a URL link which will be open for use from **3rd November 2025** until **31st March 2026**.

The Staff Survey URL for your Trust can be found on the LDIS Data Collection page, below the Organisational Survey. A QR code that links to the survey is also available, which can be downloaded and printed, for display in staff rooms, included in news bulletins, etc.



Staff Survey

Please send the following link to 150 staff members who have seen patients with Learning Disabilities or Autism.

<https://surveys-nhsbn.co.uk>

Click on the link above to select it, then copy it (CTRL+C). You can then paste it into an email or company communication to share it with your staff. Alternatively, download the QR code to share the link on notice boards or posters.

So far, **0** staff surveys have been completed for your submission.



Project Leads are requested to distribute the URL/QR code to staff members who will then access this URL link and complete the staff survey online, with a maximum of 150 submissions permitted per organisation. The link will automatically close once 150 submissions have been received.

The deadline for completion of the Staff Survey is **31st March 2026** however, we encourage you to distribute the link as soon as possible.

Online Patient and Family/Carer Survey

The online Patient and Family/Carer Surveys have been designed to capture perceptions of the quality of care and overall experience of NHS services for people with a learning disability, as reported by individuals themselves and by their family members or carers, within NHS trusts.

The **Patient Survey** is to be completed by service users with a learning disability over the age of 18 years old who accessed care in the last year. The Patient Survey can be completed with the help of a family member or carer.

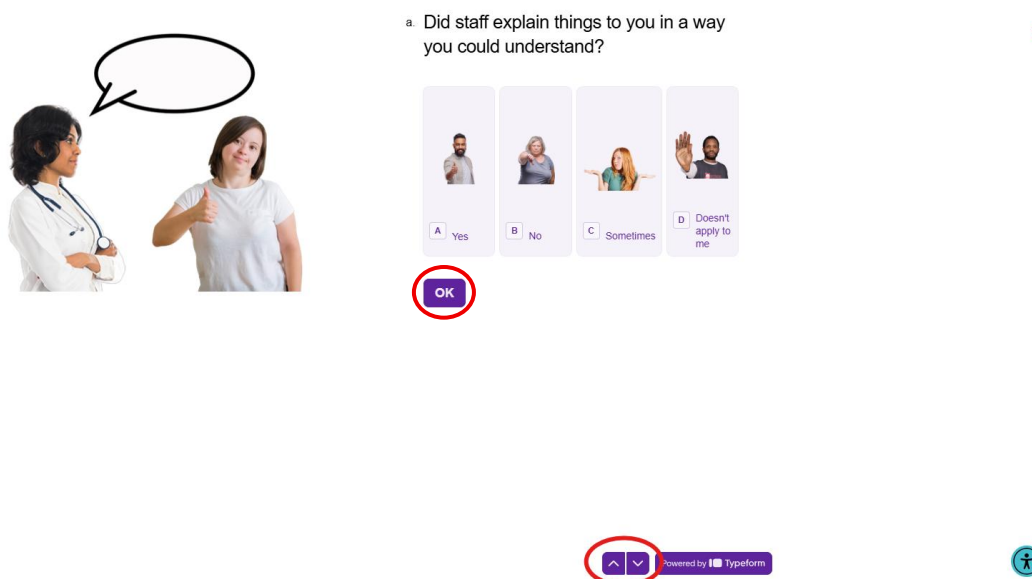
Meanwhile the **Family/Carer Survey** is to be completed by families/carers of individuals with a learning disability who accessed care in the last year.

The survey can be accessed via your organisations unique URL - which will have been shared with you and will be open for use until the **31st March 2026**.

The Patient Survey should take roughly 6 minutes to complete while the Family/Carer Survey should take roughly 7 minutes. Users don't have to answer all questions, only the questions that mean something to them.



Using the Patient Survey as an example, questions will look like the image below with answer options and pictures provided:



Once users have selected their answer the next question will appear. If they don't want to answer they can press "OK". Alternatively, they can move to the next question or previous question using the arrows in the bottom right corner (circled in red above). When users have reached the end of the survey, all they need to do is press the "submit" button.

We have also produced some template promotional material which you can edit for your own purposes along with instructions on how to create a QR code for the unique URLs:

[Online Patient and Family/Carer Poster template](#)

As the Patient Survey and Family/Carer Survey are also being disseminated nationally by LD England, there is also a generic URL for the surveys. This link has some additional initial steps which include asking who is completing the survey, where they live and where they (or the person they care for) received care. This is so we can identify which NHS Trust their responses are relating to. Guidance for users accessing the links via this method will be available on the webpage.

Pilot Case Note Review

The pilot Case Note Review (CNR) element collects patient-level data on the care received by people with a learning disability over the past year. It is designed to complement the Organisational-level and Staff Surveys by providing an objective view of how care is delivered in practice, as recorded in case notes. The CNR supports triangulation of data across multiple sources, helping to identify variation in practice, gaps in reasonable adjustments, and examples of good care. Findings will be used to inform learning and quality improvement, strengthening understanding of how care is experienced in practice and where services can better meet the needs of people with a learning disability.

Guidance on how to complete data collection for this element can be found here:

[Pilot Case Note Review Guidance](#)

To support organisations with the pilot CNR launch, drop-in sessions will be held. Visit www.improvementstandards.nhs.uk/events for further information.



4. Key project dates

Please see below a summary of the project milestones.

Date	Milestone
3 rd November 2025	Organisational Survey opens on Members' Area Data Collection page
	Staff Survey is accessible via each Trust/organisation's unique URL link/QR code
19 th January 2026	Additional elements launch: <ul style="list-style-type: none">• focus groups (facilitated by LD England)• patient survey, family and friends survey<ul style="list-style-type: none">• case note review
27 th January 2026	Pilot Case Note Review Drop-In Session
17 th February 2026	Pilot Case Note Review Drop-In Session
31 st March 2026	Organisational Survey closes for validation period
	Staff Survey closes – URLs/QR codes are no longer accessible
	Online patient and family/carer survey closes
	Pilot case note review closes
April 2026	Data validation

A period of data validation will take place during April 2026, during which time you may be contacted by the project team regarding any data queries. You will receive a draft toolkit to analyse your positions in Spring 2026 and can use this to identify any changes you wish to make to your data. If needed, you can contact the NHSBN team throughout the validation period to amend your submitted data.

Should you have any queries about completing any element of NHS England Learning Disability Improvement Standards data collection, please contact the team via nhsbn.nhsildsupport@nhs.net