

# Reducing deaths of people with a learning disability in NHS acute (hospital) trusts in England: an improvement tool

User manual

November 2019



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# Introduction

People with a learning disability die earlier than the general population<sup>1</sup> and this is understandably a significant concern for policy-makers, families and self-advocates alike.<sup>2</sup>

In many instances premature deaths are not the inevitable result of health differences that are inherently associated with the cause of a person's learning disability but rather a consequence of differential exposure to known and identifiable determinants of health.<sup>3</sup> A death is considered to be preventable if, in the light of understanding of the determinants of health at the time of death, all or most deaths from that cause could be avoided through public health interventions in the broadest sense.

Similarly a death is described as amenable (treatable) if, in the light of medical knowledge and technology available at the time of death, all or most deaths from that cause could be avoided through good quality healthcare. There is compelling evidence that significant numbers of deaths of people with a learning disability in NHS acute (hospital) trust services are amenable to better healthcare.<sup>4</sup>

In combination avoidable deaths are considered to be all those defined as preventable, amenable or both.

We have developed this improvement tool to help NHS acute (hospital) trusts evaluate and understand the capability of their systems and structures to reduce premature mortality of people with a learning disability in their care, and to make improvements where needed.

The tool is for use:

- on a voluntarily basis by acute NHS (hospital) trusts providing inpatient and outpatient hospital services

<sup>1</sup> Heslop P, Blair PS, Fleming P, Hoghton M, Marriott A, Russ L (2013) *The Confidential Inquiry into premature deaths of people with learning disabilities*. University of Bristol: Bristol.

<sup>2</sup> Department of Health and Social Care (2018) *The government response to the Learning Disabilities Mortality Review (LeDeR) Programme second annual report*. London: DHSC

<sup>3</sup> Emerson E, Baines S, Allerton L, Welch V (2012). *Health inequalities and people with learning disabilities in the UK: 2012*. Improving Health and Lives: Learning Disabilities Observatory.

<sup>4</sup> Hosking FJ, Carey IM, Shah SM, et al (2016) Mortality among adults with intellectual disability in England: comparisons with the general population. *Am J Public Health* 106(8): 1483-90.

- by NHS England and NHS Improvement when providing targeted or mandated support to trusts, in accordance with the Single Oversight Framework.

## National improvement standards and improvement measures

In June 2018 NHS Improvement published the learning disability improvement standards for all NHS trusts.

These are supplemented by a framework of improvement measures or actions that trusts are expected to take to make sure they can meet the standards and deliver the outcomes that people with a learning disability and their families expect. A mapping exercise with the Care Quality Commission (CQC) suggests that trusts that deliver these improvement measures are likely to be more concordant with CQC's key lines of enquiry (KLOE).

For acute hospitals in particular:

- delivering rights-focused improvement measures is associated with CQC's effective and responsive KLOEs
- inclusion and engagement of people and families is linked with CQC's caring and responsive KLOEs
- taking action to implement the workforce improvement measures supports CQC's safe, effective and well-led KLOEs.

## Improvement metrics

When developing the NHS learning disability improvement standards and improvement measures, people with a learning disability and their families and carers described the key outcomes that mattered to them when accessing universal healthcare services (see [Appendix 1](#)).

We then worked with system partners and professionals to identify measurable attributes of service performance, or metrics, that align with these outcomes. Metrics for managers focus on how services are structured – that is, the provision of appropriate resources, policies, etc. Metrics for staff examine the processes by which care and support is actually provided to people with a learning disability who use trusts' services.

Following publication of the Learning Disabilities Mortality Review (LeDeR) programme's second annual report,<sup>5</sup> we worked with partners from the LeDeR programme to identify a critical subset of metrics which reflect the consistent findings from mortality reviews. These were used to develop this improvement tool and are particularly concerned with:

- systems issues
- interagency and interdepartmental communication and working
- adherence to legislation and guidance, particularly the Mental Capacity Act (2005)
- direct provision of care
- the need for training
- communication with non-professionals, ie families, carers and people with a learning disability.

## How the tool was developed

The tool has been rigorously developed and piloted.

- Our action orientated learning process involved four plan–do–study–act (PDSA) cycles.
- Four pilot sites were identified, one in each of the NHS England and NHS Improvement regions at the time.<sup>6</sup> These varied in size, local geography and the provision of hospital liaison services.
- Pilot work was locally supported by the trusts' executive leads for learning disability.
- A preliminary spreadsheet was developed to cross-reference manager and staff metrics against the NHS learning disability standards and improvement measures.
- Levels of analysis and how findings are presented were modelled and agreed.
- Each pilot site hosted a day of externally facilitated workshops for managers and frontline staff to:

<sup>5</sup> The Learning Disabilities Mortality Review (LeDeR) Programme (2018) *Annual report*. Bristol: Norah Fry Centre for Disability Studies.

<sup>6</sup> There are now seven NHS England and NHS Improvement regions.

- enter consensus answers to sets of questions into the tool
- consider the summary performance reports generated by the tool and its potential utility in informing local improvement planning processes
- most importantly, gather feedback about the tool and its use.
- Successive revisions of the tool were tested by the pilot sites.

# Running improvement workshops to complete the tool

We have designed the tool to be completed in two separate workshops, one for trust managers and one for frontline staff. An independent facilitator helps participants explore questions concerning each of the metrics. Consensus performance ratings from pre-set menus are entered into the improvement tool, in real time. This information serves as a starting point for reflection on performance and improvement action planning.

Workshops inevitably draw frontline staff and managers away from day-to-day service delivery but their investment of time should yield positive returns in reducing risk of avoidable deaths among patients with a learning disability.

It is not our intention to be prescriptive about precisely how workshops should be organised. We recognise that local requirements and context may determine precisely how a trust elects to use the tool. But we do strongly recommend that trusts follow a process similar to that developed and refined during pilot work.

## Workshop agenda

Manager and staff workshops need to be entirely separate.

The two workshops should be held on a single day to maintain a clear focus. Also people tend to find it easier to block off sufficient time on one day rather than over a series of days. Feedback and initial action planning sessions should ideally be held on the same day, with participants in the manager and staff workshops coming together.

Two hours is typically enough time for an introductory discussion and full consideration of all questions.

Our recommended agenda is:

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10am–12pm	Manager workshop
1–3pm	Staff workshop
3.30–4pm	Feedback and reflection on improvement summary to smaller representative group of staff and managers
4–5pm	Staff and manager initial discussions of improvement action plans

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## Workshop scope

The wards/departments you include will depend on your trust's size and the range of services it provides.

- Smaller trusts that operate out of one or two relatively small hospital sites should be able to use the tool in workshops to profile their entire trust-wide services. Participants report this allows sharing of information and practice, and planning of improvement actions on the basis of trust-wide and inter-departmental collaboration.
- For larger hospital trusts, run over multiple sites, workshops focusing on discrete hospital sites or clusters of wards and departments will have greater sensitivity.
- The tool can also be used on a ward-by-ward or department-by-department basis. This can be a useful approach where internal outcome monitoring suggests that some wards or departments have particular difficulties, or alternatively are delivering exemplary outcomes for people with a learning disability.

## Participants

Workshops should typically involve 12 to 15 participants.

The full range of hospital wards and clinical departments should be able to participate and contribute, and derive benefits.

But the vast array of different roles and job titles in hospitals means you need to be pragmatic in how you allocate participants to either the 'manager' or 'staff' workshops.



'Staff' are those workers who spend most of their working hours directly providing care, support and treatment; and have considerable face-to-face contact with patients and their families. Their role means they are well placed to comment on the day-to-day processes that support people on wards and in hospital departments. Staff participants should typically include a mix of healthcare support workers, nurses up to and including matrons, doctors, allied health professionals (AHPs) and possibly discharge team staff.

'Managers' are those workers who spend minimal, if any, time directly delivering care, support and treatment to patients. They are likely to be responsible for the strategic, financial and day-to-day management of hospital services and are therefore well placed to comment on issues such as policy, audit, training compliance, complaints investigations, performance, etc. Manager participants typically include directors, deputy directors, assistant directors, general managers, clinical leads (medical, nursing and AHPs), safeguarding leads, governance leads and in some instances ward and departmental managers.

An acute learning disability liaison nurse (where employed) attending both staff and manager workshops can support workshop facilitators and participants in exploring questions about both the local service context and the wider learning disability improvement agenda.

## Facilitation

Workshops should, wherever possible, be independently facilitated by someone outside the trust. Trusts could look to set up a reciprocal arrangement with their neighbours for external facilitators. Learning disability liaison nurses or governance leads in particular are well suited to facilitate workshops; or alternatively local learning disability strategic health facilitators (where such posts exist).

In the event the tool is used to evaluate a single ward or department, it may be appropriate to use a facilitator, such as an experienced acute liaison nurse, who is based elsewhere in the trust.

Facilitators must fully familiarise themselves with the use of the tool before running workshops. Its functionality may appear complex but with a little practice and experimentation facilitators will find it very intuitive to use.

Facilitators should start sessions by giving some background: the NHS learning disability improvement standards, the reasons for their development and the aims of the tool.

Ground rules should be discussed informally at the beginning of workshops and typically include:

- the evidence nationally is incontrovertible that people with a learning disability experience worse outcomes as a result of the structure and processes by which services are delivered
- the purpose of the workshop is to deliver improvements to a vulnerable and marginalised population
- job titles are left at the door – everyone’s views and experiences (managers and staff alike) are of equal value
- managers have specialist knowledge and insight concerning trust structures; and frontline staff, regardless of seniority, profession or grade, have specialist knowledge concerning the day-to-day support of people with a learning disability who use trust services
- everyone should share their experiences and perceptions
- differences should be respected; nobody should discount the ideas of others or dismiss their concerns
- everyone should be open to new concepts or ideas
- participants should ask a question when they have one
- the role of facilitators is to cut to the chase
- everyone should keep confidences and assume that others will do so – no attributable notes to be maintained.

Facilitators should, work sequentially through either questions for managers or those for staff, depending on the workshop participants. Each question needs to be explored in some depth and people given the chance to discuss their experiences and views, to arrive at a consensus answer which is then entered into the software by the facilitator.

## Resources

Workshops need to be held in comfortable and private meeting rooms that are large enough to accommodate up to 15 participants. Suitable refreshments can encourage the full engagement of participants!

The tool is a sophisticated Microsoft Excel spreadsheet designed to be either projected or displayed on a large screen in front of groups of participants. The question being asked at any time can be highlighted to focus participants' attention on it.

During the course of workshops, while questions are being discussed, staff and managers often make ad-hoc commitments, such as to share information and resources, to raise issues with colleagues not in attendance, or to review aspects of service delivery. It can be useful to ask for a volunteer among the participants to note these.

## Links with the Learning Disability Review (LeDeR) programme

The aim of the LeDeR programme<sup>7</sup> is to address the premature mortality of people with a learning disability. LeDeR is a service improvement programme which draws its evidence for change from the completion of reviews of the death of everyone with a learning disability aged four and over in England.

The deaths of children and young people aged 4-18 are reviewed through the Child Death Review process with the findings shared with the LeDeR programme. The deaths of adults aged 18 and over are reviewed using the LeDeR methodology – reviewing case notes and interviewing people who knew the deceased well to build a holistic view of the care and support they experienced over their life.

Learning from Deaths<sup>8</sup> clearly set out the expectation of trusts to notify deaths of people with a learning disability to the LeDeR programme. In addition to a LeDeR review, trusts should also be conducting a learning from deaths review. The

<sup>7</sup> [www.england.nhs.uk/learning-disabilities/improving-health/mortality-review/](http://www.england.nhs.uk/learning-disabilities/improving-health/mortality-review/)

<sup>8</sup> <https://improvement.nhs.uk/resources/learning-deaths-nhs/>

outcomes of learning from deaths reviews should be made available to the LeDeR reviewer<sup>9</sup>.

Your trust should be a member of a local LeDeR steering group – steering groups are made up of Clinical Commissioning Groups, NHS trusts, local authorities, independent sector organisations, people with a learning disability and family carers then develop action plans to address the learning arising from completed reviews to reduce the health inequalities and premature mortality experienced by people with a learning disability. The outcomes of the self-assessment shouldn't be viewed in isolation but in conjunction with the steering group action plan.

<sup>9</sup> [www.bristol.ac.uk/media-library/sites/sps/leder/2118\\_Comparison\\_PDF.pdf](http://www.bristol.ac.uk/media-library/sites/sps/leder/2118_Comparison_PDF.pdf)

# Using the tool

The improvement tool profiles and analyses the differing perspectives of service managers and frontline staff regarding the care and support of people with a learning disability who use acute (hospital) NHS trust services. This informs the development of improvement action plans to reduce potentially avoidable deaths among these people.

The tool has been developed to be completed by groups of staff and service managers during facilitated workshops.

## Data security

Users of the tool are advised to ensure that they are aware of and compliant with their organisational information governance, data security, data protection and other relevant policies. In particular, users should be aware that emailing completed copies of the tool is not advisable without due consideration for the security of the data it contains.

## Opening the tool

The improvement tool is a Microsoft Excel-based workbook that has been designed to be portable and to run on most Windows-based systems. It is not compatible with Mac operating systems. Users should save a blank working copy to a secure file location.

The tool is opened like any other file (usually with a double click). Users **may** get a message requiring them to 'enable editing'; in which case, it is safe to do so.

Next users need to 'enable macros'. The prompt for this action may vary according to their version of Excel and security settings. In any event the macros in the tool can be safely enabled.

The tool home page will then open.

## Home page

The home page provides a brief introduction and instructions on use.

LeDeR Focused Improvement Toolkit for Acute Trusts 3.3 - Excel

Questions for managers Questions for staff Improvement summary Action plan Save Save as Print Page

# Improvement Tool

NHS

## Reducing deaths of people with a learning disability in NHS acute (hospital) trusts in England

**Contents**  
*Instructions*  
*Questions for managers*  
*Questions for staff*  
*Improvement summary*  
*Action plan*

Name of trust	
hospitals, wards and departments included	
Name of trust LD lead	
Date of completion	
Facilitator	
Contributors	

**Introduction:**  
In June 2018 NHS Improvement published the learning disability improvement standards for NHS trusts. These comprised four standards. Three apply to all NHS trust services whilst the fourth applies solely to services that have been commissioned for people with a learning disability.

The standards aim to reduce unacceptable variations in the quality and outcomes that people experience, by driving improvements in the planning and coordination of support to people with a learning disability; and ensuring that their rights are fully respected and protected.

In developing the standards, NHS Improvement engaged widely with people who have lived experience of using services in order to understand the outcomes that people expect to see, if the standards are being met. We also engaged with academic and practice partners to understand and describe the systems and structures that are necessary to deliver these outcomes.

This tool focuses on the actions that are needed by acute NHS (hospital) trusts to address concerns about the premature deaths of people with a learning disability.

Questions for managers focus on critical service structures, whilst questions for staff explore the processes by which people are supported.

This is also the screen where users should record basic trust details; which hospitals, wards, departments, etc are being considered; date of workshops at which the tool was completed; name of the workshop facilitator; and details of staff and managers who contributed.

Users can print a hard copy of the home page, as they can all other pages in the tool.

Users can save any changes by clicking the 'save' button on any page in the tool. The home page has a 'save as' option so users can change the filename to avoid overwriting the original.

By clicking on the buttons at the top of the home page users can navigate to:

- Questions for managers This is where workshop facilitators enter consensus answers to the questions senior managers are asked about current service structures and the potential for improvement over the next 12 months.
- Questions for staff This is where workshop facilitators enter consensus answers to the questions frontline staff are asked about the processes to support people with a learning disability when using the trust's wards and departments.
- Improvement summary Once all staff and manager answers have been entered, this page presents an analysis of current performance, along with the top five recommended areas for further attention.
- Action plan Once managers and staff have reflected on the improvement summary, provisional details of the proposed improvement action plan are recorded on this page against specific improvement measures. Also, where there is good metric evidence that improvement measures are already being achieved, a sustainability action plan should be recorded (to indicate how current levels of performance will be maintained).

## Questions for managers

Clicking on the ‘questions for managers’ button from any page navigates you to this screen.

Improvement measures	Questions for managers	Manager rating
Trusts must have measures in place to promote anti discriminatory practice in relation to people with learning disabilities.	Question 1 Does your trust have systems in place to ensure that senior managers hear about the experiences of patients with learning disabilities and their families, who use your services; and if so, can these be disaggregated, so that the views of patients with learning disabilities can be considered separately, and compared to other patients.	Not fully achieved, but will in the next 12 months.
	Question 2 Does your trust monitor the 'clinical outcomes' of services delivered to patients with learning disabilities in a way that allows data about service use to be disaggregated for patients with learning disabilities, so that any inequalities in service use can be identified and addressed?	Currently achieving.
	Question 3 Does your trust monitor numbers of patients with lengths of their waits, so that comparisons can be made, and if there are concerns, do you proactively report these to service users and the public?	Currently achieving.
	Question 4 Does your trust have a robust Mental Capacity Act policy to support patients to make their own decisions, and if a patient has been assessed as lacking capacity to make their own decisions, outline how the decision is to be made in accordance with the Act?	Not achieving and unlikely to do so in next 12 months.
	Question 5 Does your trust undertake at least annual audits of compliance with its Mental Capacity Act Policy so that you can understand how effectively it is being followed; and make improvements where needed?	
	Question 6 Does your trust have a clear policy (based on the principles of the Mental Capacity Act), which guides and supports staff when making decisions about withdrawing life sustaining treatments, or not to attempt cardio-pulmonary resuscitation?	
	Question 7 Does your trust audit clinical records and communications to ensure that information about a patient's learning disability and the reasonable adjustments they need is shared both within the trust and with other services?	

This sheet contains 34 questions that ask managers how well the trust is doing:

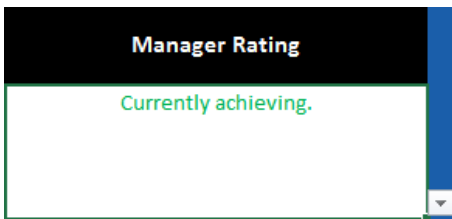
- 21 are about how people’s rights are respected and protected
- five are about inclusion and engagement
- eight are about workforce issues.

The relevant NHS improvement standards are shown above each group of questions and the relevant improvement measures to the left of the questions.

The facilitator can focus participants’ attention on the question being asked by clicking on it to highlight it in yellow. This will also bring up a ‘What this means...’ box giving information and prompts about the questions and the underlying metrics.

Facilitators should assist participants to consider each of the 34 questions in turn and then enter the consensus responses to them.





Each manager rating response box has a dropdown menu of answers, revealed by clicking the arrow in the bottom right-hand corner.

Managers should select from these response options:

Once all questions have been answered, the manager workshop should be drawn to a close.

Manager ratings:
Currently achieving.
Confident we will achieve within 6 months.
Not fully achieved, but will in the next 12 months.
Not achieving and unlikely to do so in next 12 months.
N/A

## Questions for staff

Clicking on the 'questions for staff' button from any page navigates users to this screen:

**Staff responses:**

**Respecting and protecting peoples' rights**  
All NHS trusts must ensure that they meet their Equality Act Duties to people with learning disabilities; and ensure that their wider human rights are respected and protected, as required by the Human Rights Act.

Improvement Measures	Questions for Staff	Staff Rating
Trusts must have measures in place to promote anti discriminatory practice in relation to people with learning disabilities.	Question 1: As far as you know, does your Trust use systems and measures to check whether the experiences of patients with learning disabilities who use your services, are the same as anyone else's?	Yes, definitely
	Question 2: Within your team, do you ever get to see and reflect on data that shows how clinically effective your Trust/service is at supporting patients with learning disabilities?	Yes, routinely
	Question 3: When offering learning disabled patients choices, do you think a patient might lack the ability to make a decision, do staff: routinely consult the person, consult, do they know how to arrange a referral?	Sometimes / partially
	Question 4: If a learning disabled patient has been found to lack capacity, do staff: routinely consult the person, consult, do they know how to arrange a referral?	Yes, routinely
	Question 5: Have staff been trained to understand their duty to respect and protect learning disabled patients' right to life; and importantly, to follow processes that are consistent with the Mental Capacity Act, if contributing to decisions about withholding life sustaining treatments?	Yes, in detail
	Question 6: If staff make referrals to other departments within the Trust, or other external agencies, are they always explicit if a patient has a learning disability, and about any reasonable adjustments they are known to require?	Yes, routinely
Trusts must demonstrate that reasonable adjustments are made to care pathways, to allow people with learning disabilities to access highly personalised care, and to achieve equality of outcomes.	Question 7: Do Trust staff always ask about, read and pay attention to the contents of 'Health/ Hospital Passports' (or equivalent) in the way they provide services and make reasonable adjustments; and, if learning disabled patients do not have already have one, do staff either support them to develop one, or know how to direct them to someone who can?	Sometimes / partially
	Question 8: Do Trust staff routinely check and record learning disabled patients' 'communication and information' needs; and then modify their communication including verbal and written materials, in ways that make it easier for patients to understand what is going on and make	Sometimes / partially

This sheet contains 33 questions that ask staff to rate how well the trust is doing. These are made up of:

- 20 are about how people’s rights are respected and protected
- six are about inclusion and engagement
- seven are about workforce issues.

Again the relevant NHS improvement standards are shown above groups of questions and improvement measures to the left. Clicking on a question highlights it in yellow and brings up supplementary information relating to it in a ‘What this means...’ box.

As in the managers’ workshop, facilitators should assist participants to consider each of the 33 questions in turn and then enter the consensus responses to them.

In contrast to managers, staff are asked to focus on current systems of care, support and treatment and are not asked to comment on the likelihood of improvements being achieved over the forthcoming 12 months.

Response sets for staff reflect the language used in pilot workshops. This encourages fuller use of rating scales and therefore increases the sensitivity of responses. Response sets for staff therefore depend on the nature of each question and include those shown opposite.

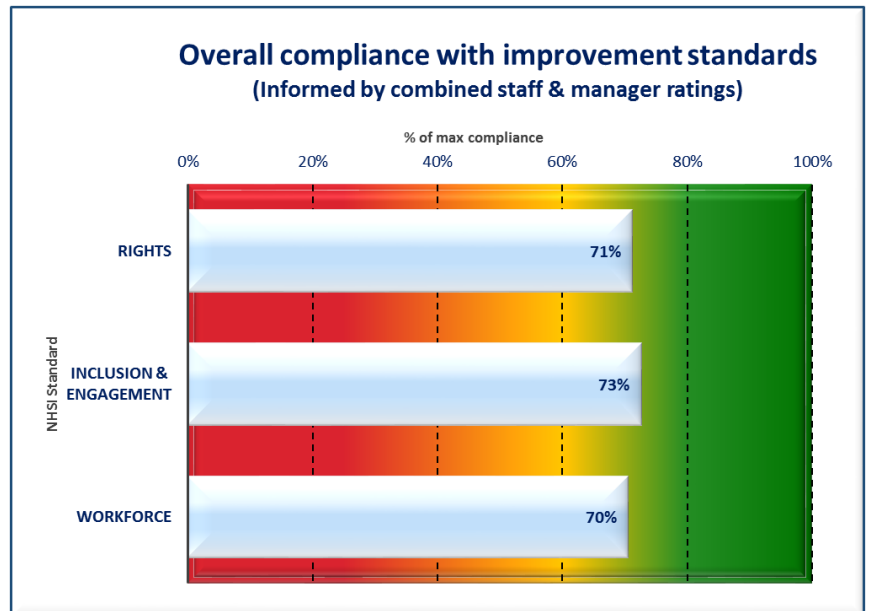
Once all questions have been answered, the staff workshop should be drawn to a close.

Staff ratings:
Yes, definitely Yes, routinely Yes, in detail Yes, in depth.
Now and again More often than not Mostly To a fair extent.
Not certain but I expect so Not often Sometimes / partially Not sure but I think so
I doubt it Not really I don’t think so
N/A

## The improvement summary

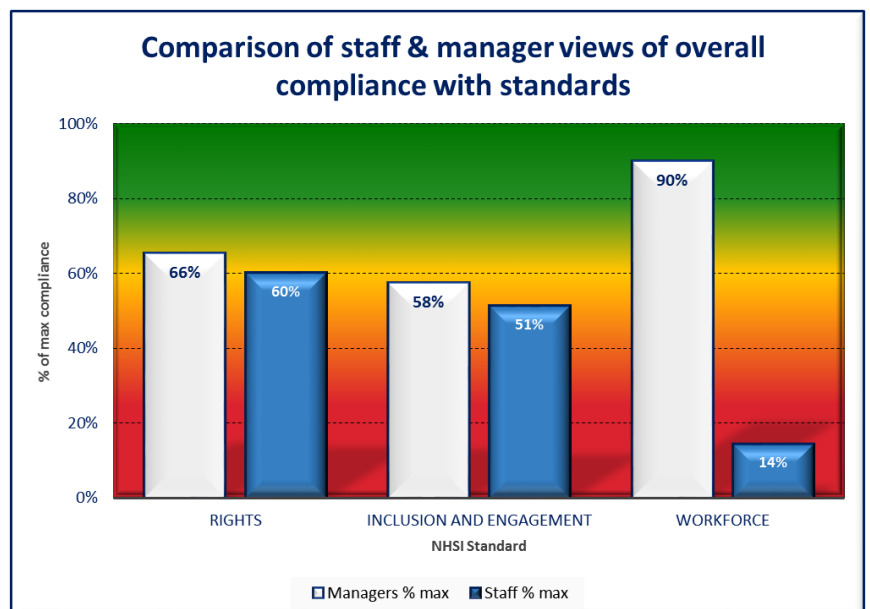
Clicking on the 'improvement summary' reveals an analysis of the answers to questions for staff and managers, as recorded in their respective workshops.

The first chart gives an overall measure of the trust's compliance with the NHS improvement standards. Responses to questions from both managers and staff about the metrics are combined and also moderated by algorithms which take into account cross-linked metrics. For example, while some questions ask about the workforce standard, compliance with this standard also supports delivery of the inclusion standard.



The next chart examines the same data but this time compares the views of staff and managers.

Wide discrepancies between the two viewpoints should raise particular concern.



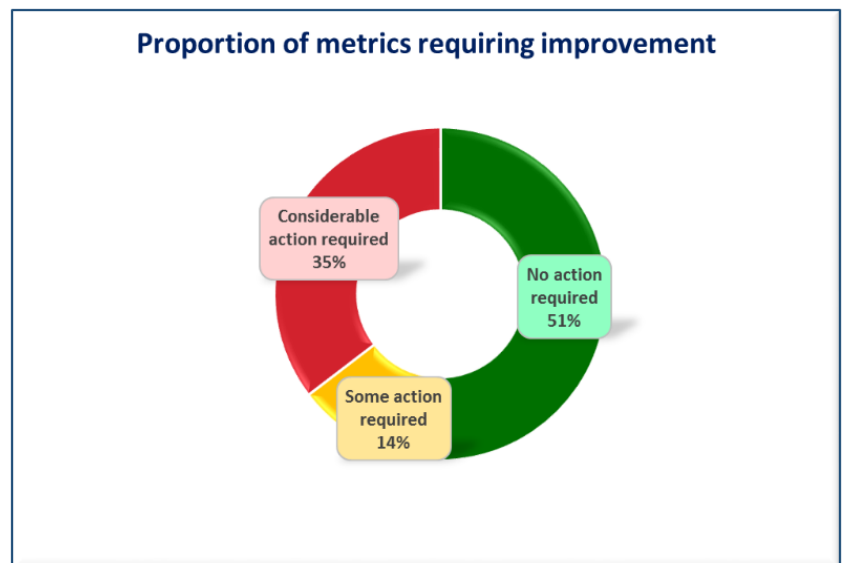
The next chart is a dashboard to help trusts understand the need for action on particular improvement measures. This summarises the extent to which the trust has successfully implemented each of nine improvement measures. Where responses to questions about metrics suggest an improvement measure has not been fully implemented, staff and manager responses are used to determine the likelihood of achieving this within the next 12 months.

Improvement Measures: current position (Informed by combined staff & manager ratings)		
Currently achieving	Achievable within 6 months	Unlikely to be achieved in next 12 months
Respecting & Protecting People's Rights	Inclusion & Engagement	Workforce
Anti-discriminatory practice	Partnerships with people and families	Enough of the right staff
Reasonable adjustments	Learning from investigations	The right training
Monitoring & reducing restrictions of liberty		Effective workforce planning
Learning when people die in services		

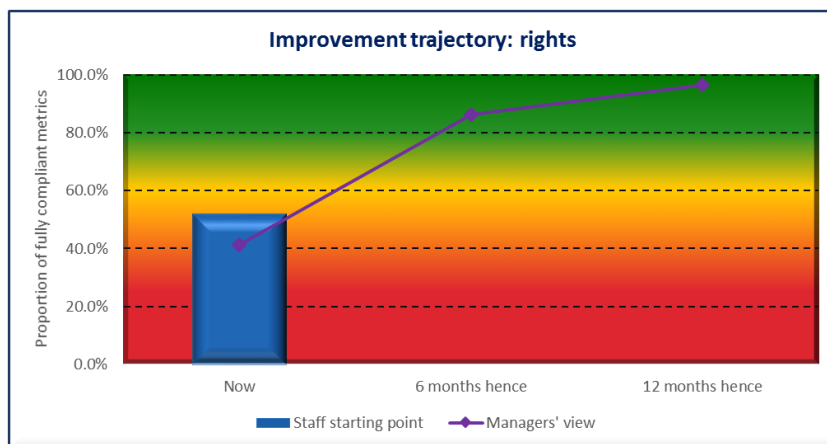
Improvement action plans should include sustainability plans for any improvement measures that are already being fully implemented, to ensure that this performance is maintained. The action plan template in the tool will automatically show where these are required.

The next chart drills down to the level of individual metrics and, based on staff and manager responses, indicates the proportions of metrics requiring 'no', 'some' or 'considerable' improvement.

This should help the trust understand the scale of the likely commitment it will need to give to ensure compliance with the NHS improvement standards.



The next four charts build on this by showing for each standard the percentage of metrics which managers and staff feel the trust is currently fully compliant with. Again this will highlight any discrepant views between staff and managers. The charts also plot a projected improvement trajectory, based on manager responses; this indicates the percentage of metrics that managers feel the trust will become fully compliant with over the next 12 months.



Finally, as a starting point in informing improvement action planning, the tool suggests the top five areas that should be considered.

These are considered the most potent actions because as well as targeting areas of clear concern, they also contribute to improved performance against other improvement measures and metrics.

Top five areas to meet NHSI standards:
1. Making reasonable adjustments to all complaints handling processes.
2. Making sure due regard is paid to the content of hospital passports, across all wards / departments.
3. Making sure that reasonable adjustments are made with regard to the Trust's duty of candour responsibilities.
4. Ensuring that all clinical staff are aware of their responsibilities to support the national LD mortality review.
5. Developing plans to mitigate the impact of short and longer term shortages of key groups of staff.

## Action plan

Improvement action plans should aim to maximise overall compliance against all standards.

Clicking on the 'action plan' button on any page navigates users to this screen:

The screenshot shows a web application window titled "LeDeR Focused Improvement Toolkit for Acute Trusts 3.3 - Excel". The interface includes a navigation bar with buttons for "Home", "Questions for managers", "Questions for staff", and "Improvement summary". There are also "Spell check" and "Print page" buttons, and a "Save" button. The main content area is titled "NHSI learning disability improvement standards: action plan" and contains a table with the following structure:

NHSI learning disability improvement standards: action plan						
Complete the columns below by inserting relevant information concerning your action plan.						
	Improvement Measure	Type of plan needed	Think about things like	What needs to be done to achieve the standard / sustain adherence?	Who will be responsible for making sure it happens?	When does it need to be done by?
R1	Trusts must have measures in place to promote anti discriminatory practice in relation to people with learning disabilities.	Sustainability plan	How the Mental Capacity Act is applied; outcomes monitoring; waiting list management; reasonable adjustments; and access to learning disabilities specialists.			
R2	Trusts must demonstrate that reasonable adjustments are made to care pathways, to allow people with learning disabilities to access highly personalised care, and to achieve equality of outcomes.	Improvement plan	The use of health passports; meeting information and communication needs; adapted assessments; care coordination; environmental modifications; outcomes monitoring; access to specialists; training.			
R3	Trusts must demonstrate that they vigilantly monitor any restrictions or deprivations of liberty associated with the delivery of care and treatment.	Improvement plan	Policies; training; user involvement; governance; and data driven practice.			
R5	Trusts must have processes to investigate and learn lessons if people with learning	Improvement	Engagement with LeDeR programme; governance structures; data analysis; and			

Users should use this template to record initial reflections on the improvement summary and actions as a result. (In view of the amount of text that may need to be entered, a 'spell check' button is included on this page).

The template automatically prompts users to enter an 'improvement plan' for any improvement measures that have not yet been achieved. For those that are currently being achieved, users are prompted to enter a 'sustainability plan' – this should be a record of what will be done to ensure that current performance is maintained.

The 'Think about...' column indicates the sorts of wider considerations relevant to each improvement measure; it is not bespoke.

Those completing the action plan should carefully consider their actions in response to the 'top five recommendations' identified on the improvement summary page. We

also recommend careful attention to those standards about which staff and managers expressed widely discrepant views on current performance.

We recognise that NHS trusts routinely use their own action planning and implementation processes and systems, and this template is not intended to replace them. Trusts may well decide to transfer the improvement action plan to the templates they use locally.

# Appendix 1: User-defined outcomes

## Standard 1: Respecting and protecting people's rights



People expect these outcomes:

1. If people are waiting to be seen, someone gets in touch to check how they are doing; and to let them know how much longer they will be waiting.
2. Appointments are at convenient times of day and in places that people can easily access.
3. Staff look at people's hospital passports.
4. Staff make the reasonable adjustments that are written in people's hospital passports.
5. Staff check whether people have had an annual health check and help them get one if needed.
6. Staff check if people need any other health screening and if they do, tell them how to get it.
7. Staff ask people how it is best to communicate with them.
8. Staff document how a person shows they are in pain and use this information when supporting a person.
9. People have a key contact for their health issues and know how to get hold of them.
10. Staff give people advice about how to stay healthy.
11. If people have used a service before, next time they present staff will already know they have a learning disability.
12. If people have used services before, next time they present staff will already know what reasonable adjustments are helpful to them.
13. If people have not used services before, unless presenting as an emergency, staff already know they have a learning disability and what reasonable adjustments are helpful.
14. If staff learn new ways of helping people, they share these with other health staff such as GPs.
15. If people are unable to make their own choices, their family are involved in deciding what is in their best interests.
16. If people are stopped from doing things they want to do or made to do things they don't want to do, staff tell them why and what to do if they are not happy about it.
17. If staff stop people leaving a place or tell them that they can't leave, they tell them why and what their rights are.



## Standard 2: Inclusion and engagement



People said they expected these outcomes:

1. Trusts deliver on their promises.
2. Trust actions match their words.
3. Staff treat people with dignity/respect.
4. Staff tell people what they can expect from services and help them to understand their rights.
5. Staff explain to people that they have a right to make their own choices about their care and treatment.
6. Staff spend time asking and listening to people's views and worries about their health.
7. People are asked what outcomes they hope their treatment will lead to.
8. People are included in all meetings about their health (unless they choose not to be).
9. Staff help people prepare for meetings and make sure they are fully involved.
10. People are given information about meetings that have happened, in a way that makes it easier for them to understand.
11. People know who the senior managers are and how to contact them.
12. People are encouraged to say what is good or bad about their services.
13. If there is a problem or mistakes are made, staff tell people and say that they are sorry.
14. People are given information about how to complain.
15. People don't worry that they will be treated badly because they make a complaint.
16. People feel they can tell any member of staff they have a concern.
17. People are told that there is independent help for them if they want to make a complaint.
18. If people complain they are listened to by staff and their complaint is taken seriously.
19. If people complain, they are told how it will be investigated and kept informed all the way through.
20. If people complain they are told what will be done differently in future.
21. If staff think a person is at risk of abuse they are helped to understand safeguarding processes.

## Standard 3: Workforce



People said they expected these outcomes:

1. People are seen by staff who have the right knowledge and skills to help them.
2. People feel that they are respected and not treated any worse than other people, simply because they have a learning disability.
3. Staff understand what a learning disability is and how it affects people.
4. Staff know about reasonable adjustments and talk to people about the extra help and support they need.
5. Staff use assessment tools and approaches that are suitable for people with a learning disability, so that they can be fully involved.
6. Staff know how to communicate and support people to make their own choices.
7. Staff help families and carers understand how to spot if a person's health is getting worse and to know what to do about it.
8. If people are seen by health staff from more than one team or trust, they work well together and share important information.

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