

Learning from lives and deaths - People with a learning disability and autistic people (LeDeR):

Action from learning report 2021/22



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An easy read version of this document is available.

A supporting LeDeR 2022 additional resources document is also available. The NHS cannot be held responsible for the content of external websites.

Foreword



Tom Cahill,
National Director
for Learning
Disability and
Autism, NHS
England

As the National Director for Learning Disability and Autism, I am committed to ensuring that local health systems implement actions from learning; these will improve health, prevent premature mortality and create equality of opportunity for people with a learning disability and autistic people.

We continue to learn from every LeDeR review what needs to change to ensure people with a learning disability and autistic people – in all communities – live longer, happier, healthier lives.

We do so in the sad knowledge that we may be learning from the death of someone who died prematurely. People with a learning disability and autistic people are still dying too young and their health outcomes have deteriorated during the COVID-19 pandemic. We are determined to address these challenges.

Integrated care systems¹ will help us do this. A new LeDeR ‘champion’ – a named responsible officer at executive level – will sit on every integrated care board to ensure the needs of people with a learning disability and autistic people are met. They will drive individualised care, highlight good practice, and develop and implement policy to improve the health and wellbeing of people with a learning disability and autistic people.

The examples in this report demonstrate how, working together, NHS staff, our partners, self-advocates, families, carers and people working in health and social care can substantially improve the lives and health of individuals with a learning disability and autistic people.

¹ More [information about integrated care systems](#) can be found on our website



Dr Roger Banks,
National Clinical
Director, Learning
Disability and
Autism, NHS
England

An essential element of LeDeR is to inform and empower people with a learning disability and autistic people to have a greater say in and control over their care. We work with all areas of the NHS to make this happen.

The insights gathered on the health inequalities experienced by people with a learning disability and autistic people during the COVID-19 pandemic reinforce the commitment across the NHS to improve services for people who experience health inequalities. LeDeR captures this determination, accelerates strategic programmes and increases engagement across all NHS England directorates to ensure that the voices of people with a learning disability and autistic people are heard and their health inequalities are understood at a strategic and practical level.

We continue to address specific as well as systemic inequalities, with people who are not 'just' patients at the heart of our work. For example, by staff trained in intersectionality undertaking focused LeDeR reviews of the lives and deaths of people from minority ethnic groups; and working to ensure reasonable adjustments are provided for every person who needs them. It is heartening to see so many examples in this report of services working to deliver improvements.



Carl Shaw,
Learning Disability
and Autism
Adviser, NHS
England

In my role as a learning disability and autism lived experience adviser for NHS England I often hear parents, carers, autistic people and people who have a learning disability say that they have had to ask a GP or a doctor in a hospital for basic reasonable adjustments. I believe it is really important that we now have autism reviews so we can understand what the issues are.

I also think it's very important that we have focused LeDeR reviews for people from a minority ethnic group.

In my own experience, and because many of my friends are autistic, I believe it is really important that all clinicians read this report. I would also encourage them to learn as much as they can about the needs of people with a learning disability as well as the needs of autistic people because they are often thought of as having the same needs and people can have very different ones. It is good that LeDeR is addressing lots of these issues.

What is LeDeR?

LeDeR is a service improvement programme to help make services better for people with a learning disability and autistic people. It was established in 2017 and is funded by NHS England. Until this year (2022), LeDeR looked at the lives and deaths of people with a learning disability, but from January 2022, it also does so for people who are autistic.

People with a learning disability and autistic people die earlier on average than, and do not always receive the same quality of care as, people without a learning disability or who are not autistic.

The NHS works to change this – through implementing what we learn from LeDeR reviews in our local systems, by improving our treatment pathways and by listening to people with a learning disability and autistic people and their families and carers, and ensuring they are at the heart of our work.

When a person dies, a LeDeR review looks at the health and social care they received throughout their life – to identify any care that could have been better as well as the good practice in their care. We share examples of good practice across England to improve services by learning from one another. Our aim is to narrow the inequalities in care for people with a learning disability and autistic people, so that they can live as long, as happily and as healthily as others.

Anyone can notify LeDeR about the death of a person with a learning disability or an autistic person – via the [LeDeR website](#). This includes family doctors (GPs), health and social care staff, family members, friends and carers. Everyone with a learning disability aged four and over who dies and every adult (aged 18 and over) with a diagnosis of autism is eligible for a LeDeR review.

The [LeDeR website](#) gives more information, including about how we work with other review processes such as safeguarding, reviews of deaths of people in hospital and child death reviews.

Acknowledgements

This LeDeR action from learning report includes examples of the vital work underway across the NHS and our partners, driven by self-advocates and self-advocacy groups, parents/carers, the charity and voluntary sectors, and our colleagues in social care. None of these efforts would be possible without family members, health and social care staff and many others contributing to a LeDeR review by sharing their experience of the life and death of a loved one or someone in their care. We would like to express our sincere gratitude to you all.

We highly value our independent advisory group whose members include people with a learning disability, parents and carers, and representatives from the charity and voluntary sectors. They inform and enrich our work. We would like to recognise and thank everyone whose work, campaigning or self-advocacy continues to inform, challenge, change and reduce health inequalities among people with a learning disability and autistic people.

Finally, we are grateful to the LeDeR workforce across England for their continued efforts to complete LeDeR reviews, address local LeDeR findings and improve the health and lives of people with a learning disability and autistic people.



What you will find in this report

This LeDeR action from learning report showcases some of the national and local action over the past 12 months across health and social care services in response to learning from LeDeR reviews and to recommendations from our previous academic partner, The University of Bristol. It also provides updates on the commitments we made in our [last action from learning report](#).

The accompanying '[LeDeR 2022 supporting resources document](#)' contains guidance, networks, data and other materials referenced in this report.

Co-production & family involvement

Working with people with lived experience and delivering services in partnership with other organisations is central to the work of the NHS England Learning Disability and Autism Programme. Our national team employs people with a learning disability, autistic people and family carers to ensure that every aspect of our work is directly informed by their insight.

An independent advisory group (IAG) is integral to LeDeR. This steers our action from learning work and includes people with a learning disability, parents and other family members of a person with a learning disability, and a representative from the following organisations:

[Association of Directors of Adult Social Services \(ADASS\)](#)

[Care England](#)

[Department of Health and Social Care \(DHSC\)](#)

[Dimensions](#)

[Health and Wellbeing Alliance](#)

[Inclusion North](#)

[Learning Disability England](#)

[Learning Disability Professional Senate](#)

[Local Government Association \(LGA\)](#)

[Mencap](#)

[Office for Health Improvement and Disparities \(OHID\)](#)

[Pathways Associates](#)

[Race Equality Foundation](#)

[Royal College of General Practitioners \(RCGP\)](#)

[Royal College of Psychiatrists](#)

[Stop People Dying too Young](#)

[Voluntary Organisations of Disability Groups \(VODG\)](#)

We are also guided by our new academic partnership – made up of individuals from King's College London, University of Central Lancashire, Kingston University and St George's, University of London. They produced this year's LeDeR annual report.



See me - Andrew's story

Mixit, a local drama group in the North East, were asked to produce a film about the person at the centre of one LeDeR review. This encourages everyone working in health and social care, as well as the public, to challenge preconceived ideas they may have around what is best for a person with a learning disability, and instead listen to that person.

The film, [See me – Andrew's Story](#), portrays Andrew's experiences, a man with Down's syndrome who died in early 2020 at the age of 51.

Andrew lived with his foster family who he had known since childhood after his father died. His mother died in childbirth. Andrew's verbal communication was limited but he would sing when he was happy and could make his needs known through non-verbal cues. He loved going to watch musicals and being out in the community in his wheelchair. He was popular around the town and loved going to the supermarket.

When Andrew was admitted to hospital with a urinary tract infection (UTI), he did not recover as expected and staff were not asking why. Andrew's family did not feel they were listened to and their concerns were ignored. Changes in Andrew's behaviour were attributed to him having dementia, and further questions were not asked. Unfortunately, this meant two pathological hip breaks went undiagnosed for several weeks. (Pathological breaks can occur in weakened bones).

County Durham Clinical Commissioning Group (CCG) and County Durham and Darlington NHS Foundation Trust (CDDFT) have shared Andrew's story as a learning tool. Its purpose is to emphasise that reasonable adjustments should be made for people with a learning disability and nothing should be assumed from their having a learning disability.

The film was made with the consent and support of Andrew's family, who want to share his story in the hope of changing attitudes towards people with a learning disability in health and care settings. While Andrew was non-verbal, this film gives him a voice. The viewer is urged to see the person, not their learning disability, and to adapt their behaviour, ask the right questions, look the right way and, ultimately, 'See Me'.

“Now is the time to listen harder and see, that there is a person inside, that person is me.”

Action from learning in 2021/22

Safe and wellbeing reviews

As part of the NHS response to the [Safeguarding adults review \(SAR\)](#) published in September 2021 concerning the deaths of Joanna, 'Jon' and Ben at Cawston Park in Norfolk, a national review was undertaken from December 2021 to check the [quality of care and wellbeing](#) of all adults, children and young people with a learning disability and autistic people being cared for in an NHS or independent mental health inpatient setting.

A series of webinars [explaining the safe and wellbeing reviews](#) were run for patients, family carers, and senior colleagues in integrated care systems (ICSs), commissioners, clinicians and multidisciplinary teams working in mental health inpatient hospitals. The people being cared for in an inpatient setting and their families/carers were informed about the review visit and asked to consent to this. Visits were carried out face-to-face with the person in hospital, providing consent had been given or granted.

Everyone involved in the care of a person with a learning disability or an autistic person had an important role in these safe and wellbeing reviews, including the person themselves, their family or carers, ICSs, mental health providers, commissioners and NHS England regional teams. Each ICS had an oversight panel to scrutinise the reviews; this panel included at least one medical director, an expert by experience and a senior clinician.

While all individual reviews of care were expected to be completed early in 2022, some were delayed due to the Omicron variant of COVID-19. NHS England regional teams and integrated care boards (ICBs) have in real time shared the emerging findings, themes and actions in their regional delivery plans. The key findings will be evaluated, and the learning fed into relevant national Learning Disability and Autism Programme workstreams and will inform and support the work of regions and systems.

Assessing a community's needs in Staffordshire and Stoke-on-Trent

To better understand the needs of people with a learning disability in the area, the learning disability and autism programme in Staffordshire and Stoke-on-Trent CCGs worked with experts by experience, parents, carers, the police, the Department for Work and Pensions, local authorities, housing providers and NHS colleagues to create a joint strategic needs assessment (JSNA).

The JSNA sets out a three-year roadmap for learning disability and autism services, connecting all stakeholders in the local health and social care system to improve the wellbeing, livelihood and lifespan of people with a learning disability and autistic people. It also makes recommendations for improvements and plans for the future.

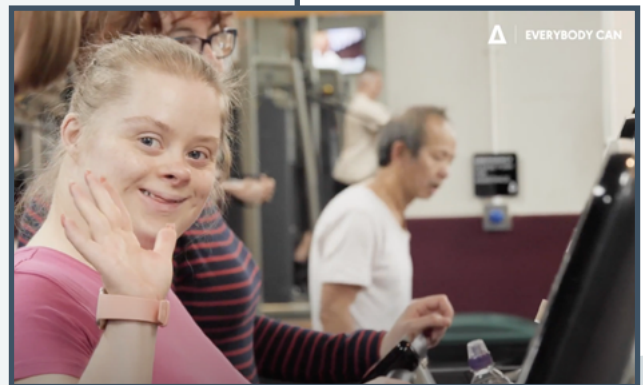
The team studied local LeDeR reviews, and national, regional and local health and care data for people with a learning disability and autistic people (including children). Regular workshops with experts by experience, family members and carers also gave insights into where improvement is needed, and these were shared at meetings with representatives from all stakeholders to inform action plans.

The final JSNA document (to be published in autumn 2022) will give the current and projected numbers of people with a learning disability and autistic people in the area, insights into people's experiences and plans for better, sustainable services across localities. Recommendations from this will be action oriented, informing strategic services, eg across social care and housing systems, through to individualised care in annual health checks, inpatient services and mental health services. In the meantime, the team is using the intelligence and insights gathered to date to inform their operational and implementation plans for 2022/23.

Getting active in Tameside

The charitable trust and life-enhancing social enterprise, Active Tameside, is working with the NHS mental health team and the local council in Greater Manchester to provide fun social care activities for children and adults with a learning disability and autistic people. Its work makes positive and empowering changes to lives through social care, community interaction, education and employment.

'[Everybody Can](#)' is a service for anyone over the age of three, including Tameside residents in supported living. It offers a host of person-centred activities to help people live healthier lives. The council refers people to the service and they receive a free leisure pass to access a range of services, eg community support seven days a week and off-peak gym and swim membership.



The team works with more than 320 adults and 27 children who have a learning disability or who are autistic to support their independence and life skills, including by supporting them on shopping trips and with making healthy food choices and weight management. The nutrition team at Active Tameside runs cooking sessions and 'Fuel for Fun' – healthier eating sessions with all schools in the borough, which includes four for children with special educational needs. Active Tameside helps its members to progress into volunteering and paid opportunities, eg in its community cafés and internships in local hospitals.

Its [annual report](#) video showcases more of its great work in 2021 and its [Everybody Can brochure](#) details how Active Tameside works with the local population.

The 'Everybody Can' service video showing person-centred activities to help people live healthier lives

COVID-19 vaccinations and treatment

The UK's COVID-19 vaccination rollout is the largest vaccination programme in NHS history. Vaccination is particularly important for people with a learning disability as they are [highly vulnerable](#) to the virus². Increased efforts to raise awareness and the uptake of the vaccine for people with a learning disability have been essential.

By the end of March 2022:

- 72% of people with a learning disability had received at least three COVID-19 vaccinations, helping to maintain the vital protection they secured from their first two doses
- 89% of people with a learning disability had received at least one dose and
- 86% at least two doses of COVID-19 vaccine.

[Data analysis](#) shows some people from minority ethnic groups and some younger people are more hesitant in taking up vaccinations. We worked with the [UK Health Security Agency \(UKHSA\)](#), the national COVID-19 immunisation programme, local authorities, voluntary sector organisations and across the NHS to ensure COVID-19 vaccinations for all eligible people with a learning disability or who are autistic are appropriately delivered.

In the last 12 months we:

- produced a series of [short animated films](#) about the safety of COVID-19 vaccination for people from minority ethnic groups
- helped plan and develop the [national booking service](#) call and recall offer
- produced training materials and guidance for vaccination sites
- reinforced stakeholder and community champion engagement
- cascaded the offer of primary dose vaccinations to at-risk children ([aged 5 to 11 years](#)) and booster vaccinations to eligible young people and adults (aged 12 years and over) with a learning disability
- ensured any offer of vaccination considers the communication and access needs of individuals who have a learning disability
- supported many individual reasonable adjustment needs by enabling vaccinations at home
- updated and shared vaccination easy read materials
- commissioned Misfits Theatre Company to produce a short video about the importance of having the [COVID-19 booster](#).

² COVID-19: People with learning disabilities are highly vulnerable. BMJ 2021; 374: n1701.

Vaccination and primary care

We asked GP practices and primary care networks (PCNs) to prioritise people in at-risk groups, including people with a learning disability, for primary and booster doses of the COVID-19 vaccine.

People were invited to attend one of the vaccination sites for their vaccination and if this was difficult due to their specific needs, a roving team vaccinated them in their home.



To support primary care colleagues we:

- provided GPs with tools to help them identify people on the learning disability register as soon as they became eligible for a vaccine and to invite them to get this, and provided them with easy read templates for a booster letter
- cascaded a top tips guide to vaccinating people with a learning disability
- developed an easy read guide to the [COVID-19 booster vaccination](#)
- shared a film explaining what the COVID-19 vaccine is and does, produced with Skills for People and Learning Disability England.

NHS England regional teams

Our regional teams have worked with the national NHS COVID-19 vaccination programme to ensure people with a learning disability and autistic people have appropriate and timely access to vaccinations. By receiving data on the uptake of both boosters and primary doses broken down by PCN, age, ethnicity and level of deprivation in the area, they have known where additional support may be needed.

COVID treatment

Antiviral treatments are now available for some at-risk patients infected with the virus. We have worked to ensure the clinical policy and guidance for COVID-19 antiviral treatment considers and meets the needs of all those eligible* for treatment across all elements of the care pathway.

Our work to address COVID-19 health inequalities among minority ethnic groups is cited in the DHSC publication, '[Final report on progress to address COVID-19 health inequalities](#)', published in December 2021.

* Please note not all people with a learning disability are eligible for COVID-19 antiviral treatments. Eligibility in the community is set out in our [clinical commissioning policy](#).

Action from Learning in 2021/22: management of medical conditions

Respiratory conditions

LeDeR reviews have consistently identified the increased risk of poor respiratory health among people with a learning disability, resulting in increased health needs, reduced quality of life and higher avoidable mortality rates. People with dysphagia (swallowing difficulties) are also at an increased risk of respiratory conditions. Preventing, diagnosing and managing poor respiratory health is a priority in the care of people with a learning disability.

Bacterial pneumonia – a lung infection – was the stated cause of death in 24% of adult and 20% of child deaths notified to LeDeR in 2019³, and aspiration pneumonia* in 17% of adult and 3% of child deaths.

*NHS.uk defines aspiration pneumonia as ‘pneumonia caused by breathing in vomit, a foreign object, such as a peanut, or a harmful substance, such as smoke or a chemical’.

³ We have quoted the 2019 data here because of the impact of COVID-19 on respiratory deaths data in 2020.



Two respiratory care projects commissioned by the national LeDeR team are at the point of delivery:

- **The British Thoracic Society (BTS)** – whose members include doctors, nurses and respiratory physiotherapists and which champions ‘Better lung health for all’, produced guidance on pneumonia and aspiration pneumonia. This went out for extensive public consultation in April 2022, and publication is expected in Autumn 2022. This guidance was co-produced with people with lived experience and will help healthcare professionals improve the care of people with a learning disability who have or are at risk of pneumonia.
- **The NHS RightCare programme**, which makes recommendations to improve healthcare, has developed a RightCare pathway scenario for aspiration pneumonia care. The guide identifies best practice in preventing and treating aspiration pneumonia and is for use by providers and commissioners in planning and delivering evidence-based care. This work will also be published in Autumn 2022.



In addition, the 2022/23 commissioning for quality and innovation scheme ([CQUIN](#)), contains a new indicator for community acquired pneumonia (CAP). This CQUIN scheme applies to all providers who are commissioned to deliver acute services via the Aligned Payment and Incentives Rules ([API](#)) of the National Tariff.

This important step should mean that more people will receive the right treatment for their pneumonia and more quickly. When a person arrives at hospital for example, one of the CAP CQUIN requirements is for a lung X-ray to be taken within 4 hours of admission to make sure they get the right treatment. The CQUIN combined with the BTS guidelines and our RightCare scenario work should make a real impact on how pneumonia is prevented, identified and responded to.

A new pathway for respiratory health in Berkshire

Learning from local LeDeR reviews inspired Berkshire Healthcare NHS Foundation Trust to develop a respiratory health pathway that supports those who are not respiratory specialists to escalate concerns and, where appropriate, request a referral. It is for use in social care settings, by families, clinicians, dentists and community learning disability teams.

The pathway supports the identification of people at risk of respiratory complications, decision-making on when to refer to a specialist, keeping people in optimal health, identification of signs of deterioration in a timely manner, and incorporating existing medical decisions. It is a personalised resource.

After a patient's assessment, a meeting is held with all agencies involved in the person's care – the person, their family and paid carers, health and social care staff and advocates – and a care activity review document or 'CARD' is completed. This structured process discusses the reason for an individual's respiratory risk and how to manage this risk, and identifies any gaps in the care plan. It also considers social and environmental factors that may apply, as well as any other medical or physical conditions the person has. Actions are agreed and a review date is set.

The management of respiratory conditions can be complex, especially in people with a learning disability. Once the CARD is completed, multi-agency guidelines are produced based on all the individual's needs. Health management strategies are identified; for example, around oral care, food and fluids, chest management, postural support, medication or referral to a GP or acute care. Any information collected as part of the pathway will be shared, so should the person be admitted to hospital it can be reviewed and updated by acute care staff. It can also be used to plan care when the person is discharged from hospital.

The team is auditing the pathway's use and, in the meantime, have shared the information about and resources for this initiative with other NHS trusts.

Seasonal flu vaccination

In part due to the work of CIPOLD* and LeDeR we know that children and adults with a learning disability are a clinically 'at-risk' group. Yet LeDeR reviews still highlight that some people with a learning disability miss out on annual health checks and flu vaccination. They and their carers (a family member or support worker) are eligible for a free flu vaccine each year.

*CIPOLD was the Confidential Inquiry into the Deaths of People with a Learning Disability. It investigated the avoidable or premature deaths of people with a learning disability through a series of retrospective reviews of deaths.



What we did over winter 2021/22

We worked with colleagues in the [NHS Immunisation Management Service \(NIMS\)](#), NHS Digital and UKHSA to maximise access to and uptake of flu vaccinations among people with a learning disability. This included:

- reviewing the [easy read materials about flu vaccines](#) and how people can protect themselves from flu
- promoting a [letter template to GPs](#) for use in inviting eligible patients and their carers for their annual flu vaccination
- working with NHS England regional colleagues providing COVID-19 vaccination clinics, to identify a pathway where both the flu vaccination and a COVID-19 booster could be administered at the same visit.

We also supported the NHS national flu 'call and recall' service in identifying groups of eligible individuals according to clinical priority (using the [Joint Committee on Vaccines and Immunisations \(JCVI\) guidance](#)) and reminding them of the flu vaccine offer. Between October and December 2021, this service sent over 140,000 easy read flu reminder letters to people with a learning disability who were in an eligible group and aged 16 years and over.

By the end of February 2022, 75% of eligible people with a learning disability had received a flu vaccination⁴.

Regional initiatives continued to drive uptake of the flu vaccination over winter 2021/22. For example, the learning disability charity Bradford Talking Media created an [easy read booklet about flu](#), published in September 2021. It describes the symptoms of flu; how people can protect themselves from getting it by having the flu vaccine and the option of a nasal spray instead of an injection for children.

⁴ [Network Contract DES \(MI\)](#) – February 2022.

Identifying and managing deterioration in health

Some people with a learning disability and autistic people cannot easily communicate that they feel unwell and their health may deteriorate very quickly. The earlier we can spot a health concern and start treatment the better.

We have developed several initiatives to help identify and manage deterioration in health and to prevent avoidable deaths.

Emergency care

We are supporting the NHS Urgent and Emergency Care Programme team with the development of their new strategy to ensure that people with lived experience inform how services should be shaped at every stage – from prevention to emergency admission to hospital, including the adoption of reasonable adjustments.



Acute care toolkit

We commissioned the [Royal College of Physicians \(RCP\)](#) and the [Society for Acute Medicine \(SAM\)](#) to produce an [acute care toolkit](#) that provides practical guidance for all healthcare professionals working in acute settings on how to care for people with a learning disability. This was co-produced with people with lived experience and published on 1 April 2022 to coincide with Medicine 2022, the RCP annual event. We will be promoting the toolkit more widely with the RCP to healthcare professionals working in acute care.

Evaluating training for carers on 'soft signs' of deterioration in people's health

We commissioned Northumbria University to evaluate the tools used to identify signs of deterioration in people with a learning disability. This focused on the Restore2™ Mini tool as this tool was identified as the most widely used in focus groups with carers. [The Restore2™](#) Mini early warning system uses 'soft signs' to document a person's condition and detect acute illness early. 'Soft signs' will vary between individuals but include increased anxiety, skin colour changes, withdrawal or reduced awareness.

Initial findings indicate that carers value using the Restore2™ Mini tool. Carers report the tool and training arms them with a better understanding of the language healthcare professionals use and gives them more confidence to 'speak up' and get their message across to healthcare professionals.

Identifying risks to physical health

With funding from NHS England, Cheshire and Wirral Partnership NHS Foundation Trust have developed a tool that helps clinicians to proactively identify those with a learning disability who are at risk of premature mortality or preventable deaths. It was piloted within the trust and in three GP practices. The trust's community learning disability health teams now use the 'decision support tool for physical health' or 'DST-PH' with all people known to have a learning disability. Guidelines on how to use the tool are also available for clinical staff in community learning disability teams and for primary care health staff.

The tool assesses a person's mobility, nutrition and physical and mental health needs. Risks to their health are scored and actions developed to reduce these. This information is available to the community learning disability team to advise them on actions they could take to avoid acute hospital admissions and improve the health outcomes of people with a learning disability. The tool is updated as and when a person's health needs change.

As an example, for a man who has Down's syndrome and difficulty communicating, the team looking after him used the tool when he began declining food and having outbursts which were out of character. This helped them understand his deterioration and develop an action plan; his health has significantly improved since the implementation of this co-ordinated approach to his care.

The DST-PH proved to be an effective tool during the pandemic and further pilots have been rolled out across sites in London and the South East. Due to the demand for training on the tool, the trust is currently creating a video training session and this will be available through the Cheshire and Wirral Partnership NHS Foundation Trust and the [CANDDID website](#). The team believe the tool has improved health outcomes in the short term and may have prevented admission to hospital or reduced the length of hospital stays. They are currently completing research on the impact of using the DST-PH.

The tool was presented to the National Learning Disabilities Senate, the Royal College of General Practitioners and ADASS. The development team have recognised the potential use of the tool in GP surgeries; they are working with Innovation Agency to explore opportunities with the NHS Transformation Unit around making the tool available digitally. This development would mean that GPs are able to calculate a person's risk level swiftly enabling more efficient individualised care planning.

Stop Look Care in Sussex

[Stop Look Care](#) is a tool and handbook recognised by [NICE](#) for use by care workers and carers to prevent, identify and respond to deterioration among older people in the care sector. However, little was known about its use in social care settings with people who have a learning disability. The Sussex learning disability and autism and Stop, Look, Care teams used LeDeR case studies to develop a training package specifically for people who care for people with a learning disability. One case study focused on oral care and the prevention of chest infections among people with a learning disability who might also be autistic; another considered the active health support one person with a mild learning disability required to prevent constipation.



This Stop Look Care booklet is used in the training of care workers and carers in Sussex on helping to prevent, identify and respond to deterioration in people with a learning disability

ECHO LeDeR training in South Yorkshire and Bassetlaw

This remote training helps anyone who works with or cares for someone with a learning disability across South Yorkshire and Bassetlaw ICS understand the issues around premature mortality for this group. It is based on learning from LeDeR reviews and in 2021 more than 900 people took up this training, including care co-ordinators, speech and language therapists, nurses, social workers, healthcare assistants and support workers.

The short courses were led by St Luke's Hospice (Sheffield) and provided by Project ECHO, a virtual learning and support service that includes those who have lived experience among its trainers.

The ECHO training focused on issues such as: do not attempt cardiopulmonary resuscitation (DNACPR), the Mental Capacity Act and best interests decisions, reasonable adjustments, cancer screening, annual health checks (AHCs) and flu vaccinations. The training also covered the early identification of deterioration in physical health and early intervention by GPs and hospitals.

Participants said the training improved their professional practice and in one case had an impact on their personal life. They valued, and felt their learning was enhanced by, hearing the lived experiences of people with a learning disability.

A formal evaluation of the LeDeR ECHO programme was completed in March 2022 and the programme for 2022/23 is in development.

“The patient story was most interesting. It was really valuable to hear about the experience of dysphagia and swallow rehabilitation in the patient’s own words.”

Participant on the dysphagia training session led by St Luke’s Hospice

“It was really valuable to hear how individuals feel after their seizures, after speaking to service users on the training who shared their own experiences.”

Participant on the epilepsy training session led by St Luke’s Hospice



Mental Capacity Act and Best Interests

LEDER reviews have evidenced that applying the Mental Capacity Act 2005, to physical health issues is a significant factor in reducing or preventing avoidable death's in people with a learning disability.

Purpose of the Act

- Protects the person's rights by making sure people are acting in the person's best interests, where they lack capacity to do so themselves.
- Make sure that the person's wishes around their care are considered.
- To ensure effective and timely diagnosis and treatment are provided.
- Makes sure the clinician is fulfilling their duty of care obligations to the person.

One of the slides used in the training on establishing mental capacity and best interests.

Me on my best day!

The community learning disability nursing service in Hertfordshire has created a resource that allows people with a learning disability to record how they usually are when well, so that should they become ill those caring for them can see the difference. The video '[Me on my best day!](#)' explains to a person with a learning disability what they should record, so that if they need to attend hospital the doctors and nurses treating them will know how they normally communicate and their level of intellectual capacity, and can then tailor their communication with the person appropriately. It will help support hospital staff assess acute deterioration.

AHSN networks and annual health checks

We have worked with several [AHSNs](#) to improve the uptake of AHCs. For example, the West of England AHSN has supported our South West team in creating a [suite of free videos to help healthcare professionals](#) increase their uptake by people with a learning disability, and another [for parents/carers](#) and people who have a learning disability. The AHSN ran two face-to-face events to raise awareness and share ideas on AHCs and at these the Misfits Theatre Company performed a play its members had written about these important health checks.

'Good Health – Good Lives' in the Midlands

A new initiative is being developed in the Midlands to help carers recognise the signs of physical deterioration in people with a learning disability in supported living settings.

The East and West Midlands Academic Health Science Networks (AHSN), ADASS and others worked with NHS England to test three existing tools and a new accessible tool, 'Keeping Well', at four pilot sites. These monitor a person's health and signs of deterioration.

The team asked people with a learning disability for their consent to participate in the pilot and have surveyed and interviewed paid care staff, health colleagues, commissioners and families/unpaid carers. They have also interviewed GPs and practice receptionists to gain their understanding of deterioration tools, good practice and areas for improvement.

The themes emerging from the pilot scheme will be used to: adapt treatment pathways and health escalation processes, refine the deterioration tools and improve collaborative approaches. The next steps will also see more people with a learning disability delivering training to healthcare professionals on accessibility and reasonable adjustments. The pilot's findings will be shared with commissioners and providers in the Midlands and nationally to raise awareness of the deterioration tools and how they are best applied.

Diabetes

Diabetes is the serious long-term health condition caused by the pancreas not producing enough insulin, or the body not effectively using the insulin it produces. Insulin controls the amount of sugar in the blood.

If not well managed, diabetes can be life threatening and can have life-changing consequences: blindness, need for limb amputation, and nerve damage.

People with a learning disability are at nearly double the risk of developing diabetes as the general adult population⁵, and it is important they are supported to reduce this risk. Particular health conditions, such as Down's syndrome and Prader-Willi syndrome, increase the risk, as does being overweight or obese. We know that some medications given to people with a learning disability can lead to weight gain and many people with a learning disability are not supported to cook or prepare food for themselves, which increases their dependence on others to provide healthy nutritious meals that support weight management.

⁵ Why is improving diabetes care for people with a learning disability important? www.diabetes.org.uk



Management of diabetes in people with a learning disability can be complex. It generally involves taking medication, lifestyle changes and regular blood tests to monitor the condition.

New accessible diabetes training in the North East

LeDeR learning in the North East highlighted diabetes as a major issue for people with a learning disability. This inspired a new pilot training course for people with a learning disability who have [type 2 diabetes](#), developed by [Skills for People](#) and [Diabetes UK](#), and funded by the Northern England Diabetes Clinical Network and Cumbria and North East Learning Disability Network. This addresses the lack in the North East of an accessible version of the education programme currently offered to individuals in the general population diagnosed with type 2 diabetes to support their understanding and management of the condition.

One of its core elements is assigning a buddy to provide support with the learning outside the training course.

The initial pilot of this training course was delivered in December 2021 over six weeks to five people with a learning disability and type 2 diabetes. Evaluation was completed in February 2022. Overall, participants found the course understandable and accessible.

The learning disability charity [Your Voice Counts](#), supported by Skills for People, is developing the course into a 'train the trainer' model and will host the first course before a wider rollout. It is working with PCNs to identify people who may benefit from the course and refer them to it. South Tyneside CCG funded this phase and the trainers will be expected to join a 'community of practice' to share learning. The aspiration is that the course will in future be available to anyone who wants to go on it.

Constipation

People with a learning disability are at greater risk of constipation; 10% of the general population and 20–50% of people with a learning disability are affected⁶. Constipation can be exacerbated when people find it difficult to communicate to others that they are constipated.

Constipation was one of the 10 most frequently reported long-term health conditions among people with a learning disability who died in 2020 (55%). Over a third of those whose deaths were reviewed in the [2020 annual report](#) were usually prescribed laxatives (38%)⁷. Appropriate use of laxatives can be helpful but should not be a substitute for a healthy diet, adequate hydration and regular appropriate physical activity.

⁶ LeDeR bulletin, January 2019: [Constipation: Dying for a poo](#).

⁷ [LeDeR Annual Report 2020](#), University of Bristol.



Understanding and managing constipation: a review

To inform our national work, we commissioned the South West NHS regional team to work with their local health community to review the management of constipation in adults and children with a learning disability and autistic people. This was completed in January 2022. We asked them to:

- determine if constipation or its complications increases hospitalisation or death in people with a learning disability and autistic people
- identify national and international best practice guidance and standards for constipation and bowel continence
- review the academic literature to explore approaches, models of care and services for effectively managing constipation and bowel continence
- outline best practices to improve constipation outcomes for adults and children with a learning disability and/or who are autistic.

The team surveyed parents and carers of young people with a learning disability and autistic people who experience constipation, looking at the impact on them and the young person and their experience of living with and managing the condition. As well as the academic literature review, they conducted a rapid evidence review of case studies, LeDeR findings and hospital data.

One key finding was that better recognition and management of constipation may reduce hospital admission and improve the quality of life.

This review's recommendations are informing and defining the work in the South West region and wider LeDeR strategies in 2022/23. An established bowel and bladder project group in the South West is taking forward this work and will share developments with the region's health inequalities improvement group and nationally with LeDeR regional co-ordinators.

A new national campaign about constipation

We have commissioned Arden and Greater East Midlands Commissioning Support Unit (CSU) to help us deliver a national campaign promoting awareness of the risks that constipation can pose to people with a learning disability. This will be targeted at people with a learning disability, their paid and unpaid carers, and general practice and pharmacy staff to help them prevent, recognise and treat constipation in people with a learning disability.

We will produce accessible materials and content for GP practices and websites used by social care staff. Materials will be distributed across stakeholder networks, to professional bodies and through other NHS England channels and relevant social media platforms.

Poobusters

LeDeR funding in Derbyshire has been used to produce a fun video with a serious message. 'Poobusters' is an [accessible short film](#) for people with a learning disability and their carers showing why constipation is an issue and what to do about it. The learning disability health facilitation team at Derbyshire Healthcare NHS Foundation Trust worked with Derbyshire learning disability representatives and the University of Derby to produce the film.

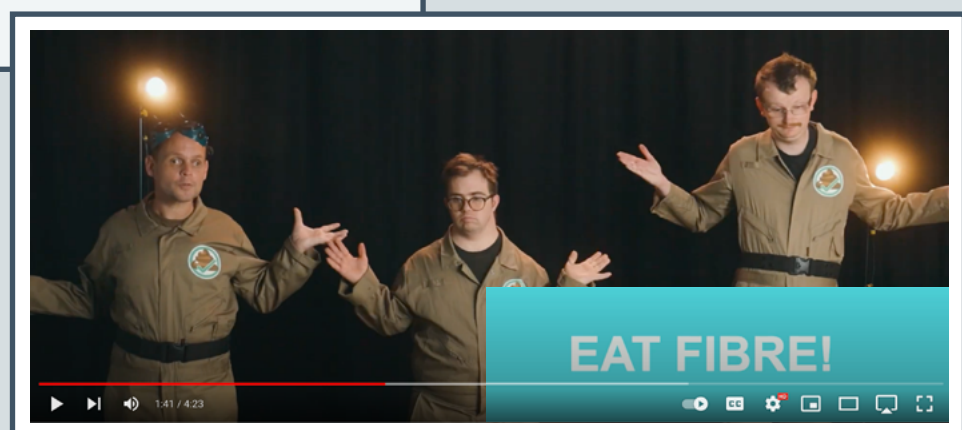
This film and [easy read information leaflets](#) have been shared across Derbyshire learning disability networks, care providers, acute trusts and community teams, and with individuals who have a learning disability and their carers. These resources are now used in regional LeDeR training for care provider teams.

"The Poobusters video was amazing, we all did a great job, it felt great being part of it, I felt like a professional actor. It is important, because it is good for people to know that if they are struggling to go, it helps them understand that they need to talk to someone."

Dan

"I liked the film and enjoyed taking part. It's important to know what you should do if you can't go for a poo."

Adam



Eat fibre! One of the messages from the Poobusters actors (from left to right) Adam, Daniel and Dan who are all members of Derbyshire's learning disability health facilitation team.

Poo matters!

In 2020/21, constipation was a factor in 80 of the 100 LeDeR reviews into the lives and deaths of a person with a learning disability conducted by NHS Bristol, North Somerset and South Gloucester (BNSSG) CCG. In response, the local learning disability team, with self-advocacy group [North Somerset People First](#) and the [Sirona](#) community learning disability nurse, developed the 'Poo Matters' training on constipation for carers.

More than 40 people – care home staff, family members and other carers – attended the autumn 2021 sessions. The training was co-presented with people with a learning disability from the Poo Matters group and self-advocates shared their anxieties and difficulties understanding words like 'constipation' or 'stool.' It covered lifestyles, healthy eating, the importance of drinking lots of water and how to discuss constipation with a GP.

The training is being expanded across the area and more people with a learning disability will be involved.

"I didn't know what constipation meant... and I would never talk to my GP about not being able to poo as it's rude."

Sean, who has a learning disability and is a key member of the Poo Matters project.

Come dine with me

NHS BNSSG has also cooked up a creative initiative to address constipation and obesity, and to improve general health among people with a learning disability. Their new 'Healthy Me' partnership with the [Square Food Foundation](#), a cookery school and community kitchen in Bristol, brings together people with a learning disability and their support staff to discuss what food is healthy, and cook healthy recipes over a six-week course. The first course started in February 2022 and further courses will run throughout the year. Participants can make healthier 'takeaway' meals and use produce they may have grown themselves, eg in a community garden. Staff are trained in how food is central to health, and participants can go online to find recipes to follow at home.

The scheme also includes educational sessions with care home managers to get them on board; they are also given recipe kits to try out at home. There is a plan to invite system leaders to the community kitchen to share a meal with the trainee cooks.

Cancer

Local LeDeR reviews highlight the need to improve access to cancer screening for people with a learning disability. [The 2018 LeDeR report](#) showed that gaps in services and support for accessing cancer screening may have contributed to the death of some people with a learning disability.

However, in the [latest cancer screening figures](#) the difference in the proportion of people with a learning disability and the proportion without who are screened for cancer has remained steady. We are continuing our work to change this.



In the last year we have:

- Worked with the Office for Health Improvement and Disparities to publish guidance for providers, commissioners and other partners on cancer screening: [Population screening: supporting people with a learning disability](#). This includes steps that services could take to improve the experience for people with a learning disability at breast cancer services – including checking they can access a mobile breast clinic.
- Asked GPs to advise us who on their register is known to have a learning disability so that the screening programme can use this information to tailor screening invitations for people with a learning disability and to enable the screening unit to identify any reasonable adjustments required.
- Checked the accessibility of NHS cancer screening services' invitation and follow-up letters.
- Audited those patients exempted from the cervical screening register (at the request of carers or others) to discover the reasons why and then address these where appropriate.
- Improved the communications and posters in the [Help Us Help You – Cervical Screening Saves Lives](#) campaign in February 2022 by including people with a learning disability.
- Worked with [public health commissioning and operations](#) to ensure that all screening and screening campaigns are fully accessible and appeal to people with a learning disability, and include their voices.
- Shared [guidance for healthcare staff](#) and an [easy read guide to bowel cancer screening](#), and encouraged the take up of home testing for people with a learning disability.
- Worked with the [national cancer patient experience survey 2022](#) – as well as [the GP patient survey 2022](#) – to ensure the questions are accessible to people with a learning disability and who are autistic.
- Carried out a benchmarking survey via the [NHS Benchmarking Network](#) about access to cancer services for people with a learning disability.

In addition, our lived experience advisors have reviewed and updated the easy read information around prostate cancer, following a request from [Prostate Cancer UK](#). We are now working with them on our cancer screening campaigns and to provide peer awareness on cancer screening.

Lung health and cancer awareness roadshows

We funded [People First Merseyside](#), a self-advocacy group run by and for adults with a learning disability, to deliver a series of 'Red Flag' lung health and cancer awareness events between May and December 2021 across the North West, Yorkshire and Humber regions. The team ran 22 roadshows and has more planned; of the 267 people who attended, 173 had a learning disability and 94 were support workers, parent carers or professionals with an interest in the subject.

The team asked attendees to share the resources with three other people, giving a potential reach of over 700 people.

Evaluation after the roadshow noted an 88% increase in awareness of the signs and symptoms that could lead to cancer among those who attended.

People First Merseyside's [free resources](#) include a poster, an accessible booklet to help people understand how to look after their lungs, and [a film starring their members](#) which anyone can use to help them recognise the signs and symptoms of cancer.

"I have realised that even if it is something small it needs checking."

A roadshow attendee who has a learning disability

"I have really enjoyed this session, you were all amazing and I would love to do training like this myself. How do I become a trainer?"

A self-advocate who was inspired by the peer trainers at a lung health and cancer awareness roadshow



People having fun while hearing the serious message around recognising the signs and symptoms of cancer at People First Merseyside's 'Red Flag' events.

Be screening aware

'[Be Cancer Aware](#)' is a co-production project that works with experts by experience from across the North East and Cumbria. As part of this, the North East and Cumbria Learning Disability Network, in partnership with Skills for People, Speak Up Together and People First Independent Advocacy, are developing training modules across the five adult [cancer screening programmes](#) (breast, bowel, cervical, abdominal aortic aneurysm and diabetic eye screening) that people with a learning disability will deliver to their peers, to increase awareness and uptake of these vital screening offers.

These were piloted in the North East and North Cumbria earlier in 2022, and the resources are now being cascaded through the national screening programme and learning disability partners for other self-advocacy organisations to use.

Cancer cervical screening

Around two women⁸ die every day from cervical cancer.

The Office of Health Improvement and Disparities delivered a cervical screening campaign in February 2022 and engaged the NHS and a number of disability organisations to ensure that its messages reached people with a learning disability. We reviewed the campaign's easy read information, and provided posters, leaflets and the easy read letter templates for inviting people to a screening and then following up.

We worked closely with NHS London to deliver a targeted cervical screening campaign at the same time, featuring a woman with a learning disability.

⁸ [Cancer Registration Statistics](#), England 2019. Data obtained from NCRAS, PHE. On average, 2,687 women were diagnosed with cervical cancer (ICD-10 C53) each year from 2017 – 2019 and 689 women died from the disease. The latest annual data is for 2019.

Targeted lung health checks in the North East

We are running a [pilot scheme](#) offering targeted lung health checks (TLHCs), with the aim of diagnosing lung cancer at an earlier stage when treatment may be more successful.

The pilot in Gateshead offers TLHCs to anyone aged 55 or over who has ever smoked or currently smokes.

The person is asked questions at an initial appointment with a healthcare professional to assess their risk of

lung cancer. Those with a higher risk are offered lung cancer screening, including a CT scan of their lungs. If they smoke, they are also offered help to stop.

The North East developed a specific pathway to ensure individuals flagged on their GP's register as having a learning disability were offered support from the community learning disability team to understand and decide whether to have a TLHC. So far this pathway has supported 25 people in Newcastle and Gateshead with the number expected to increase as the pilot is rolled out.

The region aims to expand the pilot to three more locations across the North East and Cumbria and will be including the learning disability pathway in this.



Bowel screening in Sutton

People with a learning disability are less likely to take part in bowel cancer screening compared to those without a learning disability, leaving them at a higher risk of undetected cancer⁹.

Colleagues across Sutton are working to increase uptake of bowel cancer screening among people with a learning disability. The learning disability health facilitator talked about the importance of bowel cancer screening at a borough-wide primary care meeting focusing on meeting primary targets, learning from LeDeR and improving the range and effectiveness of primary care services.

They recommended:

- promoting bowel cancer screening at AHCs and in quarterly multidisciplinary team meetings in care homes for people with a learning disability
- having a named lead for each GP practice to manage the bowel cancer screening list and follow-up with patients on the list, to ensure their screening is completed.

The cancer screening leads emailed easy read materials and NHS videos about bowel cancer screening to all GP practices in Sutton.

The team is working to increase the uptake of AHCs. If a patient attends an appointment who has not had an AHC in more than 13 months, the learning disability nurse checks whether bowel screening has been completed and if it has not, explores why not. They provide the person with easy read or other relevant information about screening and can request a screening kit is sent to them. A fortnight later the nurse checks if the patient has now been screened.

The team has seen 82% uptake of bowel cancer screening, higher than the 67% uptake in the general population in 2020/21¹⁰.

One person who was encouraged and supported to have bowel screening was found to have polyps and has since received treatment.

The team is planning to promote breast and cervical screening in the same way and is working with the local branch of Mencap to co-produce videos explaining cancer screening to service users.

⁹ Public Health England: <https://phescreening.blog.gov.uk/2020/01/31/bowel-cancer-screening-new-information-for-people-with-learning-disabilities/>

¹⁰ Public Health England: [Fingertips, Public Health Data](#)

Epilepsy

Epilepsy is a condition that affects electrical activity in the brain and this causes seizures.

Nearly one in three people with a mild to moderate learning disability has epilepsy – and those with a severe learning disability are even more likely to.

Epilepsy was the second most frequently reported potentially treatable cause of death among people with a learning disability in 2019¹¹. Warning signs are seen in 90% of people who have a diagnosis of epilepsy and die suddenly; these should inform care plans, support risk reduction and as a result reduce mortality.

Sources: Epilepsy Society and SUDEP* Action.

* SUDEP means the sudden, unexpected death of someone with epilepsy, who was otherwise healthy.

¹¹LeDeR Annual Report 2019: (Page 111) https://leder.nhs.uk/images/annual-reports/LeDeR_2019_annual_report_FINAL2.pdf



My life with epilepsy

We have funded [SUDEP Action](#) to improve and develop information and resources to support people with a learning disability and autistic people. The '[My Life with Epilepsy](#)' project is developing a 'toolkit' that helps these groups better understand and reduce their [epilepsy risks](#).

Leading epilepsy and learning disability experts from [Speakup](#) self-advocacy group, Cornwall Partnership NHS Foundation Trust and the University of Plymouth are involved, supported by Sheffield University.

The resources, which will include videos and leaflets, will be tested in one or two local healthcare settings to get feedback from people with a learning disability, autistic people and their families and carers, to make sure they are helpful to them.

As part of this project, Speakup will also review SUDEP Action's [EpSMon app](#), to see how it could be redesigned to better support people who have a learning disability or are autistic to monitor the condition. SUDEP Action will consider any recommendations when it designs the next version of EpSMon.

Epilepsy guidelines

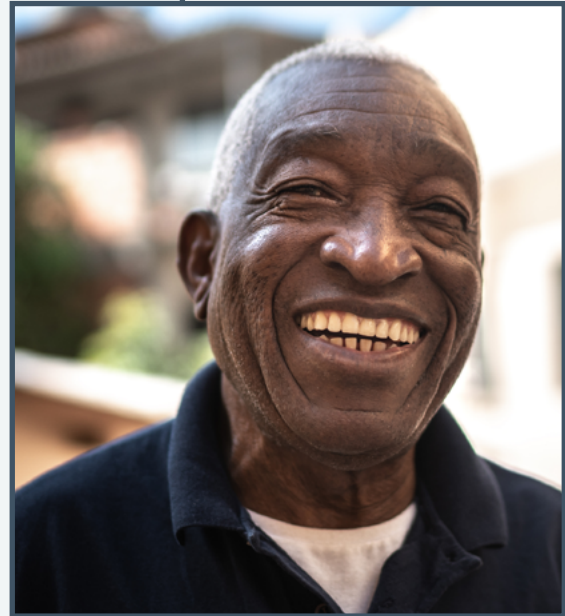
We also worked with colleagues to influence the first draft of the new [National Institute for Health and Care Excellence \(NICE\) guidelines on diagnosing and managing epilepsy](#).

"This project will help many people to improve their risk awareness, seizure control and general wellbeing, which we know reduces risk of SUDEP and premature death."

**Sammy Ashby, SUDEP Action
Deputy Chief Executive**

A review of epilepsy in Lancashire and South Cumbria

LeDeR findings on SUDEP led Lancashire and South Cumbria (LSC) LeDeR steering group, supported by NHS England, to review all reported deaths in their area that noted an epilepsy diagnosis. A task and finish group looked at the epilepsy referral pathway in each CCG, to establish how assistive technology is being used to improve epilepsy care and treatment, and to check if people with a learning disability, their family carers and providers of care are aware of the pathways and have an appropriate epilepsy care plan.



Recommendations were made for local implementation and these will be adopted through 2022/23 to improve care for people with epilepsy across the ICS.

We have also commissioned SUDEP Action and Cornwall Partnership NHS Foundation Trust to develop practical guidance and resources for both commissioners and providers of community and specialist hospital care on how to commission, deliver and oversee safe and effective epilepsy care for people with a learning disability. This work has been commissioned in response to the findings about epilepsy in the [Clive Treacey Independent Review](#).

Action from learning in 2021/22: changing how we work

LeDeR policy in action

The [LeDeR policy](#), published in June 2021, was co-produced with people with lived experience, bereaved family members, self-advocacy groups, commissioners, voluntary sector organisations and LeDeR experts (academics and LeDeR reviewers).

Under the policy, responsibility for ensuring completion of LeDeR reviews transferred from CCGs to ICBs on 1 July 2022. Crucially, ICBs will become responsible for addressing the learning identified in these reviews and improving the quality of services for people with a learning disability and/or autistic people to reduce health inequalities and premature mortality.

People who are autistic are also at an [increased](#) risk of dying earlier¹² than the general population. Since January 2022 LeDeR reviews include looking at the lives and deaths of people aged 18 and over with a clinical diagnosis of autism. The insights from these reviews will help us shed light on the specific health inequalities that autistic people may face – whether or not they also have a learning disability.

¹²Hirvikoski T, et al (2015). Premature mortality in autism spectrum disorder. *British Journal of Psychiatry*, 207(5).

¹³The diagnosis must be recorded in the person's clinical record.

Learning from lives and deaths in the South East

In Oxfordshire, the CCG steering group is responsible for the LeDeR process and is overseen by the Vulnerable Adults Mortality Panel – a subgroup of the Oxfordshire Safeguarding Adults Board (OSAB).

The [panel's last annual report](#), published in November 2021, includes the experiences or 'pen portraits' of Fred, Agnes, Stanley and Margaret, four people with a learning disability who died locally. Based on their LeDeR reviews, these findings provided insights into their lives, as well as whether best practice was followed in their care, what caused their death and any suggestions for future improvements in others' care.

The report and pen portraits have been shared in council meetings, in the ICS steering group, with safeguarding boards, in care provider forums and with learning disability charities.

The LeDeR reviews underlined the importance of family involvement and community (Fred had felt particularly isolated under COVID-19 restrictions); understanding an individual's communication needs (highlighted in Agnes' LeDeR review); consistent care and the co-ordination of complex care needs and attendance at AHCs (highlighted in Stanley's and Margaret's reviews respectively).

[My Life My Choice](#) published an [easy read version of the annual report, including the pen portraits](#).

The team is building a resource library for professionals, providers, carers and families. This will include bereavement support and guidance on conversations around planning for death, making a will, creating a funeral plan and talking about loss.

An ACE initiative in Wakefield

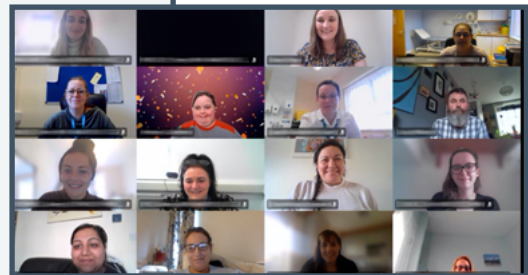
Local LeDeR findings in Wakefield led to an educational project to improve the health of people with a learning disability in the community and reduce unplanned hospital admissions. This includes training open to anyone working in primary care across the district.

The LD-ACE programme, 'Learning Disability – Achieve Change through Engagement' is supported by South West Yorkshire Partnership NHS Foundation Trust, Wakefield CCG and [Connexus Healthcare](#). It is being delivered by paid carers, the CCG, specialists in the acute hospital trust and the community learning disability team, with involvement from people with lived experience, carers and families.

The training covers key areas identified in LeDeR reviews: the Mental Capacity Act (MCA), reasonable adjustments, constipation, STOMP (over medication), dementia, dysphagia and transition from children's to adult services. It also cascades wider LeDeR learning – for example, around timely referrals to specialist learning disability teams – and addresses local actions in LeDeR reviews.

A local learning disability champion network has emerged through this scheme and will continue to unite the voices of people with a learning disability, specialists and champions to highlight good practice and learning in primary care.

The number of people on the learning disability register in the district has increased and more referrals are being made to the community learning disability team. Families report better experiences – including more timely medication and improved follow-up on health action plans. The team have shared this approach with colleagues in Huddersfield and Calderdale and aim to cascade it across the ICS and to other regions.



A recent online LD-ACE session included listening to someone with lived experience talk about her experience of growing up, accessing healthcare and the AHC, and the importance of health action plans.

NHS 2022/23 standard contract

We have given advice to the NHS Contracts team developing the [NHS standard contract for 2022/23](#) for providers of NHS-funded services, including community-based and learning disability services. This is to ensure that across the NHS people with a learning disability receive better services and their care needs are met.

Changes include:

- the requirement for commissioners to agree data quality and improvement plans (DQIPs) with providers of inpatient services, stating how they will improve the recording and diagnosis of learning disability and autism in relevant data and medical record systems
- amended contract wording on the use of the [Lester tool](#), to make it clearer that providers of mental health and learning disability services are required to monitor the cardiovascular and metabolic health of people with a learning disability and/or who are autistic, and who are receiving anti-psychotic medication
- the requirement for commissioners to agree service development and improvement plans (SDIPs) with providers of mental health and learning disability services, stating how the providers will support STOMP and STAMP.

A summary of the [changes to the contract](#) can be found on our website.

Annual Health Checks (AHCs)

The NHS Long Term Plan set an ambition that by 2023/24 at least 75% of people aged 14 and over on a GP learning disability register will receive an AHC.

By the end of March 2022, 71% of those eligible had received an AHC. This represents a considerable achievement by GPs across the country and services supporting people with a learning disability to access an AHC, particularly given that some face-to-face services closed due to the pandemic. The equivalent percentage in 2019, so pre-pandemic, was 62%.

AHCs when done properly promote healthy lifestyles, support wellbeing and enable early access to additional healthcare support if this is needed. They also help spot the early signs of cancer, diabetes, respiratory and heart disease – leading to treatment starting earlier and better health outcomes. AHCs are also an opportunity to discuss vaccinations, manage and monitor known health conditions, eg epilepsy or dysphagia (swallowing difficulties), and to discuss DNACPR decisions. A good AHC leads to a health action plan for the individual.

Seven AHC pilot sites

In July 2021, we invited proposals for new and creative ways of supporting the local delivery, uptake and quality of AHCs (the responsibility to deliver AHCs remains with individual GP practices). We are [funding pilots](#) of seven of the 36 proposals we received (one in each NHS England region). Learning from the pilots will inform LeDeR strategies.

The pilot scheme from Wirral CCG, as part of ongoing work to improve health action plans, is exploring creative ways to improve the quality and uptake of health checks among 14 to 17-year olds and adults with a learning disability.

The project working group has representation from children and young people, parent/carers, commissioners, acute trusts, primary care, community learning disability teams and voluntary sector organisations, including Wirral Mencap.

Cheshire and Wirral Partnership, working with a parent and carer organisation, recruited a peer support worker in February 2022 to offer support and raise awareness about AHCs among looked after children, people from minority ethnic groups, people living in more deprived areas and those living independently.

The project will run until December 2022 when an audit will establish its impact on AHC awareness, and lessons learnt will inform the LeDeR strategy for Cheshire and Merseyside.

Additional work on AHCs

In the past year our work to improve access to, uptake and quality of AHCs has included:

- presenting at the [Council for Disabled Children](#) conference for SEND leads to elicit feedback on the potential inclusion of AHCs in the education and health care plan (EHCP) process
- finding out through the Race Equality Foundation community networks what barriers minority ethnic groups face in accessing and taking up AHCs, so we can act to overcome these
- developing an AHC learning hub with [Health Education England](#)
- commissioning co-produced information, materials and resources for children and young people from diverse backgrounds that promote the importance of AHCs.

People with a learning disability serving a prison sentence longer than a year will be offered an AHC, as outlined in the [prison health primary care service specification \(2020\)](#).

Health action plans in Manchester

In July 2021, specialist community learning disability services in Manchester were awarded funding from NHS England – and this was matched by the local primary care commissioning group – to increase the number of people having an AHC and receiving an effective health action plan. The MHCC* nursing team and the learning disability and autism team have changed the culture around AHCs across the city (89 practices) after listening to people with a learning disability to understand how AHCs could be made more meaningful and accessible. They continue to engage with people with a learning disability through a new forum. They ensure reasonable adjustments are in place before and during any appointment; have improved and embedded health action plans in conversations around any health concerns and have developed health promotion activities for individuals via their GP practice, eg healthy weight pathways; and support screening and immunisation.

The team are also exploring new support roles and have connected system partners, including social care, to reduce health inequalities among people with a learning disability or autistic people from a minority ethnic group.

The MHCC nursing team is about to recruit a project manager to identify and bridge any gaps in this new approach, and one PCN is to fund a learning disability health liaison facilitator to work with patients, families, carers, supported living, voluntary organisations and clinicians across primary and secondary care.

*MHCC (Manchester Health and Care Commissioning) is a partnership between Manchester City Council and NHS Manchester CCG.

Video series to increase the uptake of AHCs

NHS England South West has produced [four films for healthcare professionals](#) to help increase AHC uptake among people with a learning disability in the region. The films were made with support from the West of England AHSN and in collaboration with the West of England Learning Disability Collaborative.

Other films featuring members of the Misfits Theatre Company in Bristol have been produced to give [people with a learning disability, their carers and families](#) more information about AHCs, oral health and health action plans.

The NHS team is sharing the films widely with primary care staff, the learning disability and autism programme and its stakeholders across the region. So far they have had over 500 viewings.

Health inequalities and people from minority ethnic groups

Of the more than 324,000¹⁴ people on learning disability registers in England (a figure Mencap believes should be close to 1.5 million)¹⁵, an estimated one in five are of 'unknown' ethnicity.

We recognise that people with a learning disability from a minority ethnic group experience significant health inequalities and in April 2022 we created a national clinical post to engage with and focus attention on those among ethnic minority groups who have a learning disability or are autistic.

We also recognise that premature death is particularly high among younger adult men with severe, profound and multiple learning disabilities from a minority ethnic group.

But recognition is not enough: we need to build our understanding of how different ethnic groups are impacted, using the data and evidence to improve service accessibility, care pathways, treatment and care for all ethnicities.

A review into inequalities

Working with the [NHS Race and Health Observatory](#), we commissioned the University of Central Lancashire to review the causes of the inequalities that impact on health outcomes for people with a learning disability from a minority ethnic group – to give us a better understanding of the actions the NHS and its partners need to take to address these. This review is due to be published in Spring 2023.

Overcoming barriers

To inform how we should improve access to healthcare for people with a learning disability from minority ethnic groups in England, we have commissioned the [Race Equality Foundation](#) in partnership with [Learning Disability England](#) to research the inequalities people in these groups face and identify targeted actions to address these. This work is gathering insights from people with lived experience as well as the academic literature.

AHCs and minority ethnic groups

In December 2021 we ran a webinar to present the work of the nine CCGs appointed as [AHC exemplars](#) in 2020/21 to staff working in primary care, health inequalities and CCGs. This included efforts to improve the uptake of AHCs among people from minority ethnic groups.

¹⁴[Learning Disabilities QOF Prevalence 2020/21](#), Public Health Profiles, Office for Health Improvement and Disparities

¹⁵[How common is learning disability](#): Mencap.

Training for community organisations

Learning Disability England, supported by the Race Equality Foundation, is working with self-advocacy and community networks led by or open to people with a learning disability and their families from minority ethnic groups to strengthen:

- inclusive self-advocacy
- family-led or parent peer support
- local community responses to tackle health inequalities and unfair treatment.

This work will deliver co-produced training materials and resources that widen the understanding among community organisations, self-advocacy groups and family-led groups of racism and how to challenge it. They will encourage these groups to forge stronger links with local minority ethnic group organisations and to create action plans for greater engagement from minority ethnic groups with their services.

Reducing inequalities – local programmes and ICBs

Each ICB must now have a named lead who ensures that the challenges faced by people from minority ethnic groups are considered and addressed as part of the local LeDeR programme. This includes ensuring that reviewers understand the challenges faced, establishing links with organisations that represent minority ethnic groups, raising the profile of LeDeR and increasing death notifications from minority ethnic groups.

ICBs are expected to know the number of notifications they should expect for people with a learning disability from minority ethnic groups, based on the demographics of their local population, and develop action plans to increase the number of deaths reported. Their annual LeDeR action plans must also explain how they will reduce inequalities in health.

AHCs in Nottinghamshire

We have funded the Nottingham and Nottinghamshire learning disability transformation partnership's initiative to understand the barriers to and increase the uptake of AHCs among people from minority ethnic groups in the county.

A newly recruited learning disability nurse will work with local groups and people with lived experience, including the My Life Choices co-production group. Their insights will be used to target support to improve the uptake of health checks, confirm that GP learning disability registers are complete, and ensure high quality health actions plans are produced and fully understood.

Improving health in diverse and transient communities

Norfolk and Waveney CCG, with funding from NHS England, is working with charities, organisations and community groups on a 12-month pilot to support people from minority ethnic groups, including Traveller and Gypsy communities. A learning disability nurse, a GP and a support worker first focused on supporting GP surgeries in the OneNorwich PCN, advising and training their staff on AHCs and updating the learning disability register. So far 17 of 22 OneNorwich GP practices have engaged with this initiative.

The team is raising AHC awareness by phoning patients whose health checks are overdue and has conducted over 50 outreach visits so far, including one to a Traveller site. They have met religious leaders, provided easy read materials, hosted a stall at a Black History Month event, linked up with the team running the vaccination bus and attended a food bank at a mosque. They also attend the equality and diversity group meetings in the CCG.

This pilot scheme is already seeing an increase in AHC uptake among people with a learning disability in these communities: 516 people had had a health check by January 2022 – compared to 440 in January 2021. The team is now evaluating the scheme and aims to scale it up across Norfolk and Waveney.

“When we attended the Black History Month event in Norwich Forum to raise awareness of AHCs and learning disability services, the organisers told us how pleased they were to have us there as it was the first time any health services had been represented at similar events.”

Laila Ramsi, Health Improvement Support Worker for Learning Disabilities.



Laila (l) and Steph (r) from the health improvement team raising awareness of AHCs and learning disability services to visitors to the Norwich Forum’s Black History Month event in October 2021.

End of life care and advance care planning

Advance care planning helps a person who is dying to live as well as possible until they die, and to die with dignity. Care providers should ask the person about their wishes and preferences when planning their care with them, and also support the person's family, carers or other people who are important to them. Advanced care planning is voluntary and likely to require a number of person-centred conversations.

As a result of concerns raised during the pandemic, the Care Quality Commission (CQC) published the report [Protect, respect, connect – decisions about living and dying well during COVID-19](#), and we in turn worked with a coalition of partner organisations to develop [universal principles for advance care planning](#). These ensure the person is central in developing and agreeing all elements of the plan. The plan should be sharable and clearly document what matters to the person, their preferences and decisions about future care and treatment.

We have also worked this year with NHS Digital to develop a code on the clinical record that identifies a conversation about DNACPR has taken place with a person with a learning disability and/or their family and carers. This means that we will in future have more confidence that a DNACPR has been put in place appropriately.

Making care decisions in advance

The North East's LeDeR confirm and challenge group, which includes members with a learning disability, highlighted the need for better resources in this area. In response, new easy read resources about end of life care for people with a learning disability and those who are autistic have been developed in partnership with [Inclusion North](#) and the [End of Life and Palliative Care Network](#).

These resources explain [emergency health care plans](#) and form part of the Northern Cancer Alliance's [Deciding Right](#) programme resources for end of life and palliative care.

Advanced care planning in the North

The NHS learning disability and autism teams in the northern regions delivered two advance care planning and DNACPR good practice webinars to over 150 people in autumn 2021. The audience included care providers, people with a learning disability, their families, and staff from primary care, learning disability teams, mental health trusts, acute hospital trusts and advocacy groups.



They heard personal perspectives from people with a learning disability about DNACPR and end of life care, their concerns and tips on how staff could communicate better with them about critical decisions. Attendees had the chance to discuss issues of respect, the inclusion of next of kin, establishing mental capacity, clinical rationale and the importance of agreeing (and writing down) advanced care plans, eg if a person has a life-limiting condition such as dementia or is deteriorating. Learning from LeDeR reviews was a key part of the webinar.

The webinars also looked at the recommendations in the CQC's review of DNACPR, [Protect, Respect, Connect](#) (published in March 2021). The teams provided useful resources such as the [DNACPR support pack](#) developed by Turning Point and Learning Disability England that explain what DNACPR orders are, helping patients, families and carers to raise any questions and concerns.

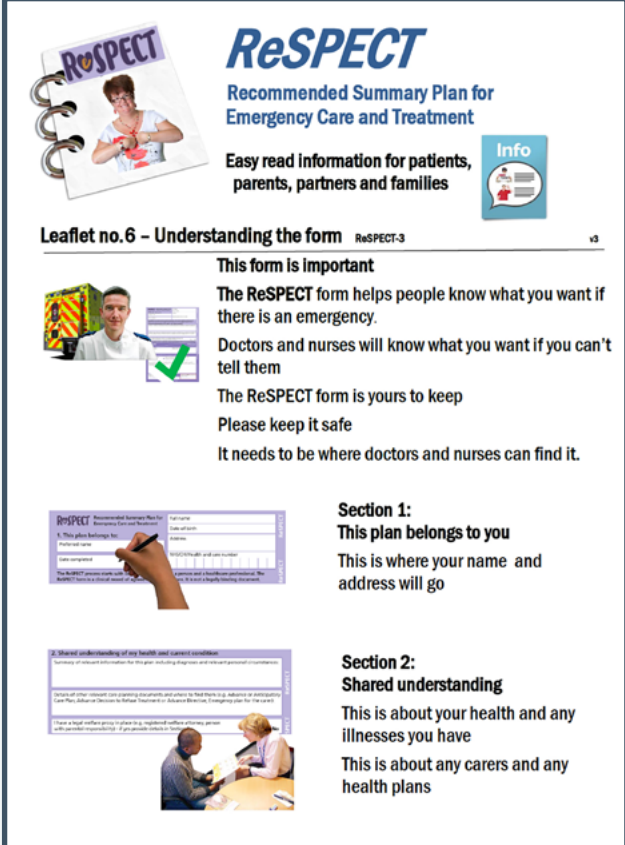
The teams have developed and circulated a discussion paper to primary care and acute trusts covering good practice and areas for consideration to ensure all patients receive a consistent approach to DNACPR. They have awarded funding to self-advocacy groups to raise awareness of this important aspect of care.

Resuscitation resources developed in Gloucestershire

The ReSPECT form is used to plan for an emergency situation and express individualised recommendations for a person's clinical care and treatment if they are unable to make or state choices. The clinician has a ReSPECT conversation with the person with a learning disability, where possible together with a family member, carer or a doctor or nurse, and this is documented on the ReSPECT form. If a person lacks capacity, a 'best interests' approach is explored – or anyone who has been legally appointed to make decisions on their behalf is engaged. The form is then kept by or with the person until it may be needed.

In May 2021, NHS Gloucestershire CCG discussed the Resuscitation Council UK's [ReSPECT* process](#) with its learning disability health action group, which includes learning disability experts by experience and experts by profession. It then worked with Resuscitation Council UK and [Inclusion Gloucestershire](#) to develop an easy read leaflet explaining the form and how it is used. The Resuscitation Council UK has also commissioned Inclusion Gloucestershire to produce a video about the ReSPECT process and how to talk to someone about their priorities and wishes in an emergency situation, to be used as a national resource for people with a learning disability or who are autistic.

*Recommended summary plan for emergency care and treatment.



The image shows a spiral-bound leaflet titled "ReSPECT Recommended Summary Plan for Emergency Care and Treatment". The cover features a photograph of a person and the text "Easy read information for patients, parents, partners and families". Below the cover, the leaflet content is displayed. It includes a section titled "Leaflet no. 6 - Understanding the form" with a sub-section "This form is important" explaining that the form helps people know what they want in an emergency and that doctors and nurses will know what they want if they can't tell them. It also states that the form is the person's to keep and should be kept safe in a place where doctors and nurses can find it. There are two main sections: "Section 1: This plan belongs to you" which is for the person's name and address, and "Section 2: Shared understanding" which is for health and illnesses, and carers and health plans. The leaflet includes small images of a person with a clipboard, a hand writing on a form, and a group of people in a meeting.

The easy read leaflet explaining the ReSPECT (form)

Reasonable adjustments

The [Equality Act 2010](#) and the [Public Sector Equality Duty](#) require that all publicly funded services make reasonable adjustments to “remove any barriers – physical or otherwise – that could make it difficult for disabled people to use their services or prevent them from using them altogether”.

Reasonable adjustments for someone with a learning disability or who is autistic could include longer appointments, providing easy read materials or having the support of a carer. They will vary from person to person.

We are pursuing a number of initiatives to raise awareness of the requirement for reasonable adjustments and to improve the quality of any adjustments made.

New resources for clinicians

We commissioned a [video](#) for healthcare professionals in primary care that explains reasonable adjustments and how they can support people with a learning disability to attend their AHC.

A reasonable adjustment digital flag

The [NHS Long Term Plan](#) requires that by 2023/24 a ‘digital flag’ in the patient record will ensure staff know a patient has a learning disability or is autistic. We commissioned NHS Digital to create the ‘[reasonable adjustment digital flag](#)’ for patient records. This is a complex process involving significant development and testing across different NHS and supplier systems.

The flag has now been built on the NHS Spine in summary care records and is expected to be piloted by the end of 2022 with ‘early adopter’ organisations to ensure that when it goes ‘live’ it works across all local NHS systems. It will eventually enable staff across health and social care to identify, record, share and view details of a person’s reasonable adjustments, so that they are known about wherever the person is treated or cared for.

Going to hospital book

The easy read book [Going to Hospital](#) advises children and young people with a learning disability or who are autistic what to expect at a hospital appointment or if they are admitted. Co-authored by Jane Rees from the NHS Learning Disability Nursing And Safeguarding team at Royal Cornwall Hospital Treliske and Angie Emrys-Jones from [Cornwall Down's Syndrome Support Group](#), it won the HSJ Patient Safety Award 2021: Learning Disabilities Initiative of the Year.

The book is easy to read, uses Makaton (signs and symbols) throughout and is sent to patients known to the learning disability team at the hospital before their visit.

The authors are now producing a version for adults – at the request of many patients, families and carers.

Reception



A page from *Going to Hospital*, a book explaining to young patients with a learning disability or autism what to expect when they attend a hospital.

New hospital liaison teams

Last year NHS Bristol, North Somerset and South Gloucester CCG (BNSSG) funded new teams of learning disability nurses in two acute hospital trusts, North Bristol Trust (NBT) and University Hospitals Bristol and Weston, to support people with a learning disability and autistic people to attend hospital. They work with clinicians to ensure that individual reasonable adjustments are in place where they are needed. The nurses can also help GPs to support patients who are distressed about attending. The team have 'reasonable adjustment boxes' that contain a range of resources to help calm or distract patients.

BNSSG has also funded a 'medi room' at NBT with calming lighting and sounds that patients in hospital can use before an operation, seven days a week. Staff also provide noise cancelling headphones, weighted blankets (to reduce anxiety) and distraction techniques, eg hand massages or nail painting, while needle-phobic patients are having a canula inserted.

A new hospital passport app

LeDeR learning in the South West has led to an innovation to improve the experience of people attending any hospital in Plymouth. Earlier this year University Hospitals Plymouth Learning Disability Liaison Team launched a hospital passport 'app' that patients with a learning disability can use. This was co-created with Derriford user group – a group of people with a learning disability who help improve the hospital's services – and built by Suvo Ltd, using feedback from a survey of people with a learning disability who use hospital services in Derriford.

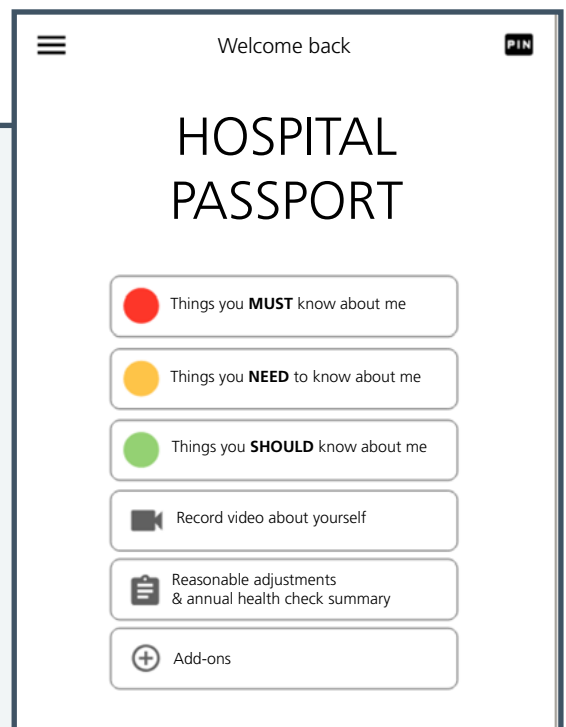
The app will not replace the paper version of hospital passports so individuals can choose whether to have a digital or paper passport.

Paper passports however can be easily damaged, lost or incomplete and don't include an overview of the person or any in-depth understanding of their physical or mental health conditions.

The app can be used on mobile phones, tablets and on desktop computers and includes vital information on any allergies, medication and details of reasonable adjustments that can make a patient's experience in hospital less stressful.

Now available for use in Plymouth, the team hopes to roll out access to the app across Devon, Cornwall and the rest of the South West region, dependent on funding.

Building on this, we have commissioned North of England Commissioning Support Unit to work with the [RIX Centre](#) to understand what other digital solutions already exist for hospital passports and whether these might be rolled out across the country for people with a learning disability and autistic people.

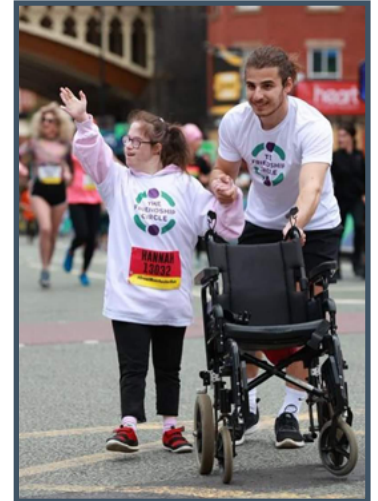


How the hospital passport app will look on a mobile phone

Social prescribing and personal health budgets (PHBs)

The NHS Long Term Plan includes plans to roll out a personalised care model across the country, to expand the choice people have in their care and the control they have over it. As part of this, 'social prescribing' will widen and diversify the range of support available to people. Link workers in PCNs will work with people to develop tailored plans and connect them to local groups and support services for both physical and mental health.

Social prescribing is an integral part of the improvements to AHCs for people with a learning disability and/or who are autistic.



Social prescribing in Suffolk

Ipswich and East Suffolk CCG is looking at how social prescribing and personal health budgets can improve the health and wellbeing of people with a learning disability as part of their AHC.

During an AHC a person can choose to be referred to the social prescribing link worker for help with accessing individualised support with their health and wellbeing, such as a mental health support group, or a walking or knitting group to help with isolation. Link workers also help existing services adapt their communications, signpost people to activities and in some cases go with them.

The project team is also:

- identifying new link workers in primary care and the voluntary care sector
- co-producing training materials with the self-advocacy group [Ace Anglia](#) for social prescriber link workers on:
 - AHCs – what they are and why they are so important for people with a learning disability
 - supporting people referred to the social prescribing team
 - reasonable adjustments – what they are, and how to implement them and ensure any provision a person needs is provided when they attend
- delivering awareness raising sessions and [training videos](#) for NHS primary care staff on social prescribing
- creating an easy read health action plan, and an easy read health and wellbeing support plan that link workers then develop with the individual.

Social prescribing in Suffolk (continued)

The team also worked with Ipswich Borough Council and the [Fairer Access to Health and Leisure Activities](#) initiative to improve the accessibility to and reasonable adjustments at local gyms and leisure activities. Individuals can now join a bespoke weight management session via [OneLife Suffolk](#), while Public Health Suffolk has developed easy read motivational activity cards.

As the link worker role develops it should become a rich resource for supporting people to access other health provisions, eg someone who can help a person manage their anxiety about cancer screening.

STOMP–STAMP (Medication)

‘STOMP’ means stopping over-medication of people with a learning disability and/ or who are autistic with psychotropic medicines, which affect how the brain works, while ‘STAMP’ supports treatment and appropriate medication for children and young people. Both are [NHS Long Term Plan](#) commitments involving many organisations to ensure that medication is used appropriately and safely.

STOMP–STAMP helps people, with their doctor, to consider removing medication, if they no longer feel it is beneficial. It also supports non-medication alternatives.

The latest [data](#)¹⁶ shows that in people with a learning disability prescribing rates have fallen for medicines including anti-psychotics (often prescribed for behaviour thought to be challenging), anti-epileptics (where prescribed other than to treat epilepsy) and benzodiazepines. While this is good news, our efforts continue to challenge and reduce inappropriate prescribing, and ensure people have access to medication alternatives, eg [positive behavioural support](#).

¹⁶[Health and Care of People with Learning Disabilities Experimental Statistics 2020 to 2021](#) (December 2021), NHS Digital.

STOMP–STAMP is everybody’s business

Over 800 people joined a STOMP/STAMP day in July 2021. The sessions ([available online](#)) included personal stories, presentations on improving care, learning from LeDeR, alternatives to medication and sharing STOMP resources, and covered our key priorities for STOMP. These are:

Primary care:

- AHCs to include a structured medication review by a doctor or pharmacist
- our continued education and development of the primary care workforce – GPs and over 1,000 pharmacists in England (including pharmacists employed in PCNs) – to conduct these reviews and ensure the person receives the form of pharmaceutical care that best promotes their mental, physical and behavioural wellbeing.

Specialist providers, NHS trusts and private/independent providers:

- working to improve STOMP processes and pathways
- using their specialist knowledge to develop safe protocols and support less experienced primary care colleagues
- sharing expertise and capturing experiences from professionals and self-advocates.

Training and re-engagement for health and social care staff and other carers:

- in partnership with Health Education England, developing six new modules with the educational platform [MindEd](#), to help families, self-advocates and non-specialist health and social care staff to understand STOMP and how they can play their part in it. These are due to launch in 2022; another four for more specialist teams are in production for release later in the year.

Self-advocacy and families:

- provide STOMP information in different languages; it is now available in eight, including Urdu, Hindi and Polish, and the team are working with the Race Equality Foundation to explore how we can work better with people from minority ethnic groups
- provide a STOMP resource for autistic people and their families: with the National Autistic Society and their members we created [this resource](#) explaining psychotropic medicine and medication reviews.

A page from the STOMP easy read resource produced with Mixit theatre group, people with a learning disability and families and carers.

What is STOMP?

STOMP



STOMP is a project in England to stop the over use of psychotropic medicines.

There is more information about these medicines on the next page.



These medicines are used to treat mental health conditions. Sometimes they are also given to people because their behaviour is challenging.

People with a learning disability, autism or both are more likely to be given these medicines than other people.



These medicines are right for some people. They can help people stay well. Sometimes there are other ways of helping people so they need less medicine, or none at all.



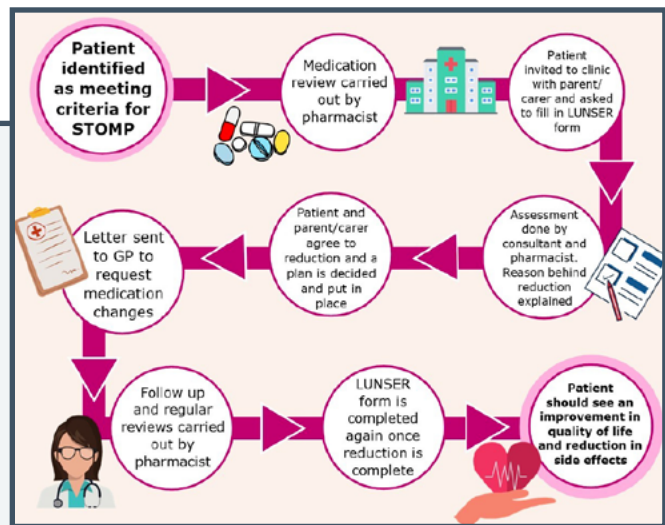
STOMP is about everyone working together to make sure people get the right medicine when they need it.

It is also about making sure that people get the other support they need. This might mean they are less likely to need this sort of medicine.

STOMP is about helping people to stay well and have a good quality of life.

A review of Jimmy's* medication

The STOMP programme in North East London Foundation Trust (NELFT) is led and developed by the advanced clinical pharmacist for learning disabilities with the support of the community learning disability teams. Two new patients are seen per borough each week.



Of the 168 people with a learning disability or who are autistic and who meet the STOMP criteria and are eligible for a medication review, so far 68 have been placed on medication reduction plans and followed up using an evidence-based assessment of medication. By reducing antipsychotic adverse effects, their quality of life has significantly improved, and feedback from patients, carers and healthcare professionals involved in the project has been positive.

Jimmy is an example success story.

Jimmy is 46 and has a mild learning disability. He lives in supported accommodation and needs minimal support for day-to-day activities. He loves gardening and going out for a walk with his girlfriend who he visits regularly. Jimmy is always eager to learn new skills and is very motivated to improve his own health. He and his girlfriend both joined a clinic to quit smoking together.

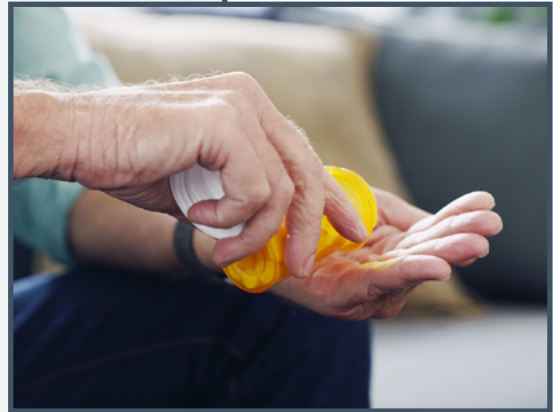
In 2012 a consultant psychiatrist prescribed Jimmy risperidone because he was often distressed and could on occasion become angry and aggressive. Jimmy did not receive any positive behaviour support, psychological support or occupational therapy.

Jimmy was identified as eligible for a STOMP review by the community learning disability team. He was referred to the STOMP clinic and had an initial consultation with a consultant, the pharmacist and the nurse in November 2020.

The patient journey in a STOMP clinic; this may vary for individuals who need additional support, eg occupational therapy. The LUNSERs form is used to measure how STOMP can improve quality of life.

A review of Jimmy's* medication (continued)

STOMP was explained to him and he was asked how he felt about having his medication reduced and receiving additional support through a behavioural specialist and occupational therapy. Jimmy and the multidisciplinary team involved in his care both agreed to this plan as he understood the medication was not the best thing for him. Over the course of five months, his dose of risperidone was gradually reduced and by June 2021 Jimmy was no longer prescribed the medication.



As his medication was being reduced Jimmy did on one occasion show signs of aggression towards another resident. This was managed with other interventions and his medication was not increased. The side effects that Jimmy had previously experienced reduced, including restlessness, weight gain, sleeping too much, mood changes, reduced sex drive and difficulty concentrating.

Jimmy has been off psychotropic medication since and he has now been discharged by the psychiatry team, but still has regular reviews from the nursing team to check that he is doing well. The GP can refer Jimmy back to the STOMP clinic should any signs of distress return.

*We have changed his name to protect his anonymity.

Terms and acronyms used

ADASS – The Association of Directors of Adult Social Services.

AHC – annual health checks. These are offered to anyone aged 14 or over who has a learning disability and are important for maintaining health and wellbeing.

AHSN – Academic Health Science Networks. There are 15 AHSNs, set up by the NHS in 2013 to help the service innovate to improve healthcare.

Autism – autism diagnostic criteria includes differences in social communication and interaction; highly focused interests or behaviours that appear to others to be repetitive or restricted; and challenges with sensory hyper- or hypo-sensitivity.

CCGs – clinical commissioning groups. These were clinically-led statutory NHS bodies responsible for planning and commissioning healthcare services locally. On 1 July 2022 they were replaced by integrated care boards as the new Health and Care Act 2022 comes into law.

CIPOLD – was the Confidential Inquiry into the Deaths of People with a Learning Disability. It investigated the avoidable or premature deaths of people with a learning disability through a series of retrospective reviews of deaths.

CQUIN – Commissioning for Quality and Innovation. This framework supports improvements in the quality of services and the creation of new, improved patterns of care.

CVD – Cardiovascular disease, is a general term for conditions affecting the heart or blood vessels. It is usually associated with a build-up of fatty deposits inside the arteries (atherosclerosis) and an increased risk of blood clots. It can also be associated with damage to arteries in organs such as the brain, heart, kidneys and eyes.

DHSC – The Department of Health and Social Care. The ministerial department that supports ministers in leading the nation's health and social care to help people live more independent, healthier and longer lives.

DNACPR – do not attempt cardiopulmonary resuscitation. A DNACPR (or a 'DNR' or a 'DNAR') is an advance decision not to attempt cardiopulmonary resuscitation should a person experience cardiac or respiratory arrest.

EHCP – education, health and care plan. An EHCP document sets out the education, healthcare and social care needs a child or young person needs beyond what a school can offer.

Health action plan – as part of a patient’s annual health check (AHC), GP practices are required to produce a health action plan. This identifies the patient’s health needs, what will happen (including what the patient needs to do), who will help and when this will be reviewed. The plan includes any key action points agreed during the AHC.

ICB – integrated care board. Every integrated care system (ICS) will be led by an NHS ICB, an organisation with responsibility for NHS functions and budgets, and an integrated care partnership (ICP), a statutory committee bringing together all system partners to produce a health and care strategy.

ICS – integrated care system. A group of health and care organisations that come together to improve the health of people in their area.

Learning disability – A learning disability affects the way a person understands information and how they communicate. This means they can have difficulty understanding new or complex information, learning new skills and coping independently.

LeDeR – Learning from lives and deaths. A service improvement programme to improve care, reduce health inequalities and prevent premature death of people with a learning disability and (from 2022) autistic people by reviewing information about the health and social care support they received up to their death. It is funded by NHS England.

LeDeR review – a LeDeR review looks at the health and social care that a person who died and had a learning disability and/or who was autistic received that may have been relevant to their overall health outcomes. Reviews are not investigations or part of a complaints process.

NHS England – formerly NHS England and NHS Improvement – supports the NHS to deliver improved care. From 1 July 2022 we are known as NHS England. In this report we have used NHS England to include activity carried out under the auspices of NHS England and NHS Improvement.

NHS pathways – a clinical tool used for assessing, triaging and directing the public to urgent and emergency care services.

NHS Spine – this supports the information technology (IT) systems for health and social care in England, linking more than 23,000 systems in 20,500 organisations.

Pulse oximeter – usually placed on a fingertip, these meters are a non-invasive way of measuring level of oxygen in someone's blood.

Restore2 and Restore2™ mini – recognise early soft signs, take observations, respond, escalate; tools used to identify deterioration in health.

SEND – special educational needs and disability. A child or young person has special educational needs and disabilities if they have a learning difficulty and/or a disability that means they need special health and education support.

Social prescribing – this is when healthcare professionals refer patients to support in the community, to improve their health and wellbeing.

SUDEP – the sudden, unexpected death of someone with epilepsy, who was otherwise healthy.

Summary care records (SCR) – an electronic record of important patient information, created from GP medical records. They can be seen and used by authorised staff in other areas of the health and care system involved in the patient's direct care.

Task and finish group – a group of people responsible for delivering a specific objective within an agreed timeframe; they report back to a wider group with any recommendations, action plan or evaluation.

UKHSA – the UK Health Security Agency; established in April 2021 to replace Public Health England. An executive agency of the Department of Health and Social Care, responsible for public health protection and infectious disease capability.

Appendix: Update on actions by NHS England and plans for the year ahead

This table shows our progress between summer 2021 and spring 2022 towards fulfilling the LeDeR commitments we made last year.

Theme	We said...	We did...
Racial inequalities	<p>NHS England recognises the significant health inequalities faced by people with a learning disability from minority ethnic groups.</p> <p>A continued focus on the deaths of all adults and children from minority ethnic groups is required.</p> <p>LeDeR steering groups to be asked to identify a lead for minority ethnic group inclusion.</p>	<p>Every death of a person from a minority ethnic group has a focused LeDeR review. All ICBs should ensure that reviewers are representative of their local population, and understand the local community's cultures and beliefs, including those around learning disability and autism, bereavement and death. Training for LeDeR reviewers and local area contacts emphasises the importance of considering factors related to ethnicity and inequalities when undertaking reviews.</p> <p>Every ICB is required to identify a named lead whose role is to ensure that the challenges faced by people from minority ethnic groups in their local area are considered and addressed as part of LeDeR.</p> <p>We are working in partnership with the Race and Health Observatory to review the causes of the inequalities that impact on health outcomes faced by people with a learning disability from a minority ethnic group, and to understand what further actions we can take to tackle these health inequalities. This will be published in Spring 2023.</p> <p>We commissioned the Race Equality Foundation in partnership with Learning Disability England to undertake work to understand the inequalities faced by people with a learning disability from minority ethnic groups and to identify targeted actions to address these.</p> <p>We also commissioned specific work from the Race Equality Foundation to identify the barriers around access to and uptake of AHCs in minority ethnic groups.</p> <p>With Learning Disability England and supported by the Race Equality Foundation, we are working with self-advocacy groups and others to challenge racism and increase engagement of people from minority ethnic groups in their services.</p> <p>We created a new post in April 2022 to focus attention on those groups who experience the greatest health inequalities, including people from minority ethnic groups.</p> <p>More details on the above actions and partnership working can be found in the main report.</p>

Theme	We said...	We did...
<p>Acute deterioration</p>	<p>We will evaluate the use of National Early Warning Score 2 (NEWS2) and Restore2™ and other early warning approaches to ensure that they meet the needs of people with a learning disability, and adapt documentation to reflect any required changes.</p> <p>We will implement at least one pilot programme using Restore2™, virtual wards and oximeters to support care staff to identify early signs of deterioration.</p>	<p>We commissioned Northumbria University to evaluate the effectiveness of early warning tools to ensure they were effective in meeting the needs of people with a learning disability.</p> <p>The university team interviewed and ran focus groups with paid and unpaid carers of people with a learning disability and/or who are autistic who provide care in the following settings:</p> <ul style="list-style-type: none"> • supported living environments • family homes • social care home providers. <p>Their findings are described in the main report.</p> <p>Pulse oximeters have been used throughout the pandemic in the South West region to monitor oxygen saturation in people with a learning disability. The Academic Health Science Network (AHSN) in the South West is now looking at rolling this out across the region, along with the Restore2™ assessment. This will lead to better identification of deterioration and better AHCs.</p> <p>At each AHC a person should have full observations taken, including pulse oximetry and soft signs. Taking this baseline makes it easier to detect subsequent deterioration. NHSX (which is now part of the NHS Transformation Directorate) has agreed to provide additional funding for this work.</p> <p>Initiated in the pandemic, the NHS is expanding its number of virtual wards across England. This NHS film explains how they work.</p>

Theme	We said...	We did...
Respiratory	<p>We have commissioned a toolkit and guidance from the British Thoracic Society (BTS) for prevention, diagnosis and management of pneumonia and aspiration pneumonia.</p> <p>NHS RightCare to provide a set of resources to support systems to improve patient outcomes for adults and children at risk of aspiration pneumonia.</p> <p>A new CQUIN standard for community acquired pneumonia.</p>	<p>The aspiration pneumonia toolkit and guidance were produced with a co-production group, and opened to public consultation in April 2022. They will be published in Autumn 2022.</p> <p>Experts by experience, respiratory consultants and a range of stakeholders worked with the LeDeR programme to create a new RightCare pathway. This will be published in Autumn 2022, alongside the BTS guidance above.</p> <p>A Commissioning for Quality and Innovation Framework (CQUIN) has been created for community acquired pneumonia for acute trusts. It means that more people will have the right treatment for their pneumonia. For example, patients will receive a chest X-ray within four hours of arrival at A&E, the severity of their pneumonia will be scored and they will receive appropriate antibiotic therapy. The CQUIN will also work in tandem with the BTS toolkit and our RightCare scenario work to make a real impact on how pneumonia is prevented, identified and treated.</p>
Theme	We said...	We did...
Constipation	<p>We will work across the system to find the most appropriate route to understanding the prevalence, causes and consequences of chronic constipation.</p>	<p>We commissioned NHS England South West to deliver a pilot project to review hospitalisation and mortality data, conduct a literature review and determine best practice approaches to improving constipation outcomes for adults and children with a learning disability. (Details of the completed pilot project, its findings and recommendations are given in the main report.)</p> <p>NHS England has also commissioned Arden and Greater East Midlands Commissioning Support Unit (CSU) to help deliver a new national campaign to promote awareness of the risks that constipation can pose to people with a learning disability (again details are given in the main report).</p>

Theme	We said...	We did...
Identifying deterioration in health	We will work with the Royal College of Physicians (RCP) to produce a toolkit on the management of deterioration in the health of people with a learning disability in acute hospital settings.	The acute care toolkits are RCP produced resources to help improve the delivery of acute care. They look at current problems and make a range of recommendations for improving quality. NHS England commissioned the RCP and the Society of Acute Medicine to produce the toolkit supporting healthcare professionals caring for people with a learning disability when they present to hospital emergency care, and this was published on 1 April 2022.
Theme	We said...	We did...
Working with local authorities, ICSs and primary care networks	<p>CCGs are already required to make arrangements so that individuals for whom services are being or may be provided are involved in planning the commissioning and any changes in the services delivered. To do this effectively local systems need to engage effectively with people who have a learning disability and their families and carers, and who are representative of their local population.</p> <p>ICSs will need to ensure that they are supported by local organisations to share information with groups that are not well connected with services, including people from minority ethnic groups, in a range of accessible ways.</p>	<p>Examples of how CCGs have engaged with people with a learning disability are described throughout this report. In addition to this 95% of ICSs have a clear strategy for meaningful involvement of people with lived experience in LeDeR governance.</p> <p>We have commissioned Learning Disability England to develop and strengthen self-advocacy and carer support for people with a learning disability and their families from minority ethnic groups.</p>
Theme	We said...	We did...
Child death reviews	A LeDeR representative should routinely and as of right be involved with the child death review meeting/process for children with a learning disability, to ensure that necessary information is collected and transferred to the wider LeDeR programme (LeDeR report recommendation 2020).	<p>NHS England is committed to learning from the deaths of children and young people with a learning disability, as well as of adults.</p> <p>We are working closely with the National Child Mortality Database (NCMD) team to share information between the national child mortality and LeDeR databases.</p> <p>We also supported a webinar for child death overview panel (CDOP) reviewers that explained the LeDeR process to them, and are working with the national programme on the revision of forms associated with child death reviews to ensure they reflect the lines of enquiry in LeDeR.</p>

Theme	We said...	We did...
<p>Mental health or criminal justice restrictions</p>	<p>NHS England to collect and collate evidence about the needs and circumstances of people who have been subject to mental health or criminal justice restrictions, and use this to inform appropriate, personalised service provision for this group of people. While waiting for this evidence, robust after-care support (as required by s117 of the Mental Health Act) must be provided.</p>	<p>NHS England has made important changes to address the health inequalities of people who have been subject to mental health restrictions or the criminal justice system.</p> <p>We have introduced a requirement for a focused LeDeR review to be completed for all deaths of people who were subject to mental health or criminal justice restrictions at the time of their death or within the previous five years, where this information is known.</p> <p>ICBs will be required to report in their annual action from learning reports on what has been done in relation to deaths of people with a learning disability who have been subject to mental health or criminal justice restrictions.</p> <p>In 2021 NHS England issued guidance on 'meeting the healthcare needs of adults with a learning disability and autistic adults in prison', which reiterates the requirement that people with a learning disability serving a sentence of more than one year receive an AHC.</p> <p>As part of the NHS response to the Safeguarding Adults Review published in September 2021 concerning the tragic deaths of Joanna, 'Jon' and Ben at Cawston Park in Norfolk, a national review was undertaken to check the quality of care and wellbeing of all adults, children and young people with a learning disability and/or autistic people being cared for in an NHS or independent mental health inpatient setting in England. The learning from this review is informing further development of the Care, Education and Treatment Review (CETR) process to ensure that people accessing CETR have high quality physical healthcare plans in place that are regularly reviewed.</p>

Learning from lives and deaths - People with a learning disability and autistic people (LeDeR):
Action from learning report 2021/22

Theme	We said...	We did...
Local systems (ICs)	We believe it is crucial that local systems understand the causes and impact of health inequalities for people with a learning disability in their local area and take action to tackle them.	The new LeDeR policy requires ICBs to produce and publish annual reports on action from learning, as well as provide NHS England regional teams with quarterly delivery reports for monitoring and assurance. ICBs are also required to demonstrate that they have a robust process in place for ensuring that the learning from local LeDeR reviews leads to prompt and effective actions to improve care, reduce health inequalities and prevent premature mortality for people with a learning disability.
Theme	We said...	We did...
COVID-19	We will remind leaders of relevant clinical organisations of the need to continue to make reasonable adjustments, including highlighting the role for staff with particular experience and expertise in learning disability and health liaison, eg learning disability nurses, in ensuring that reasonable adjustment needs are understood by frontline clinicians and implemented.	We provided GPs with tools to support their identification and invitation of people on their learning disability register who are eligible for a COVID-19 vaccine, and easy read templates for a booster invitation letter. We also cascaded a top tips guide for vaccinating people with a learning disability; this included information about the legal requirement to provide reasonable adjustments and remove barriers, and examples of reasonable adjustments.

In the year ahead the LeDeR team will take action in the following key areas:

1. Work with the cancer and cancer screening programmes to ensure that we understand the factors influencing avoidable deaths from cancer including prevention and treatment and determine actions to target awareness raising.
2. Work with the end of life care team, the CQC and others to further promote the use of appropriate documentation for DNACPR across all services over and above the SNOMED code for DNACPR documentation which is now in place.
3. Roll out quality improvement initiatives for the respiratory projects which will be completed this year around pneumonia to support pathway change and improvement.
4. Understand the prevalence of circulatory conditions as a cause of death and work with the CVD programme to take appropriate actions to tackle hypertension and CVD in people with a learning disability.
5. Consider the findings of the hospital passport digital discovery work to understand the best way to ensure that more people with a learning disability and autistic people have hospital passports which are taken account of when accessing health care.
6. Work with partners to support more carers / staff to be trained in the soft signs of deterioration.
7. Develop advice and support on sleep apnoea and continuous positive airway pressure machine usage (CPAP).
8. Deliver a social media campaign around constipation co-produced with people with lived experience and their families and carers and general practice staff.

In addition we will work across the system to ensure that LeDeR reviews are high quality and can support local service improvement; that LeDeR data is accessible to local systems for them to interrogate to support local service improvement, improved commissioning and service provision; and that King's College London are commissioned to deliver deep dives into specific areas identified to support service improvement for people with a learning disability and autistic people.

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