



Surrey Heartlands

HEALTH AND CARE PARTNERSHIP



Surrey Heartlands LeDeR strategy

2021-2024



The Surrey ICS vision

Everyone with a learning disability and/or Autism should have access to high quality health and social care services that meet their individual needs. By learning from past experience, we can continually improve services to ensure people stay healthy, are supported to make informed decisions and get the support they need if they become unwell or are approaching the end of their life.

This vision will help to ensure Surrey is a uniquely special place where everyone has a great start to life, people live healthy and fulfilling lives, are enabled to achieve their full potential and contribute to their community, and no one is left behind.

Foreword

The new national [LeDeR policy](#) outlines local delivery expectations required from each clinical commissioning group (CCG) and then, from July 2022, Integrated Care Systems (ICSs).

One key expectation is to have a three-year LeDeR strategy demonstrating how the CCG then ICS will act strategically to tackle the areas of health inequality experienced by people with a learning disability and autistic people.

The areas of strategic focus will be identified through the thematic learning from LeDeR reviews and must also include reference to how the ICS will reduce health inequalities faced by people from Black, Asian and Minority Ethnic backgrounds who have a learning disability.

The LeDeR strategy will be reflected strategically within the Surrey Learning Disability and Autism 3-year delivery plan - 2021 to 2024, 3-year delivery plan 2020 -2023 (our system response to the NHS Long-Term Plan) and our system wide 5 year All Age Autism Strategy agreed in September 2021, with local progress and outcomes also being monitored through the current governance oversight arrangements for these strategies as well as through the LeDeR governance route. Further to this, the LeDeR work will also link in with the Surrey Heartlands Palliative and End of life care strategy.

The LeDeR strategy will be updated annually by the ICS to reflect learning from both the prior year and the review process and shared with the NHS England Regional Team, which will form part of the governance arrangements and ensure continual improvement.

Surrey as a whole (including areas outside of Surrey ICS) has invested in convening roles to consider longer term transformation and the learning from LeDeR and tackling inequalities will be included within their remit to ensure longer term approaches where needed (e.g. to 2030 aligned to the Health and Well Being Strategy timescale).

The current ambition is to bring together a system wide dashboard through which all progress is jointly monitored.

What is LeDeR?

LeDeR is the national review programme which reviews the deaths of people with learning disabilities and autism across England. The programme started in 2018 and has found that people with learning disabilities die earlier than people who don't have learning disabilities. They are also three times more likely to die from an avoidable cause (University of Bristol, 2019).

The aim of the programme is to improve care, reduce health inequalities and prevent premature mortality of people with a learning disability and autistic people (aged four years and over) by:

- Reviewing information about the health and social care support people received during their life.
- Driving local service improvement, through the dissemination of learning from LeDeR reviews about good quality care and areas requiring improvement.
- Supporting local service improvements based on themes emerging from LeDeR reviews at a regional and national level
- Influencing national service improvements that target commonly arising themes in the analysis of LeDeR reviews.

The programme is commissioned by NHS England and delivered locally by Integrated Care Systems (ICS). Surrey Heartlands ICS are responsible for delivering the LeDeR programme across Surrey Heartlands.

How does the review programme work?

The death of anyone with a learning disability who was registered with a Surrey Heartlands General Practitioner (GP) is reviewed. Since February 2022, the deaths of autistic people who do not have a learning disability will also be reviewed.

Anyone can tell LeDeR that someone with a learning disability or an Autistic person has died. You can do this via the NHS England website <https://leder.nhs.uk/report>. Alternatively, you can phone us to tell us and we can fill out the form with you over the phone.

Our phone number is: 0300 561 1606.

Involving families, loved ones and carers.

Surrey Heartlands ICS values the input of people with lived experience. This means that we actively engage with people with learning disabilities and autistic people and their families and carers so that we can truly understand their priorities for change. As part of the review process, we will speak to people who knew the person well to gain a rounded insight into their life and death.

We are confident, that by working together, we can improve services and address the health inequalities faced by people with learning disabilities and autistic people.

What have we done so far?

In June 2021, Surrey Heartlands ICS published our second LeDeR annual report. This report, coupled with the learning from the national LeDeR reports and the 2019 Surrey LeDeR report, has shaped this overarching three-year LeDeR strategy which outlines our approach.

Each ICS annual report will influence and guide the aligned annual priorities and subsequent workplan which will seek to deliver the local identified service improvements and any regional or national thematic improvements relevant to Surrey ICS.

The workplan priorities for 2021/22 are:

- To work to ensure that we hear the voices of people with lived experience and others from minority groups to help improve access to services, reduce health inequalities and prevent premature mortality.
- To maintain focus on LeDeR priorities during a time of changing landscapes within the Surrey Clinical Commissioning Group / Integrated Care System (CCG / ICS).
- To improve the uptake of cancer screening across Surrey Heartlands CCG / ICS and ensure that the Mental Capacity Act (MCA) is followed when making decisions around screening.
- To increase confidence and skills in identifying when a family member may be deteriorating through the expansion of the delivery of Restore 2 Mini training to family carers.
- To increase awareness and expand the use of the ReSPECT documentation.
- To support the implementation of the Oliver McGowan training.
- To work with the medication management team to ensure that people with learning disabilities and autism receive the right medication to meet their needs and medication is reviewed regularly.
- To work to ensure that people with learning disabilities and autism receive good bowel management. Surrey Heartlands CCG / ICS will work with both health and social care colleagues to improve awareness and management of constipation to implement best practice across the system.

These recommendations are being taken forward by the Surrey LeDeR Governance Group as part of wider programmes of improvement work across the ICS and progress will be reported within future reports.

The work plan includes actions required, key metrics associated with these priority actions to give assurance of progress and the intended outcomes.

Our Approach for the duration of the three-year strategy

How we will ensure we are improving?

- We will continue to engage with people with learning disabilities and autistic people and their families to improve our understanding of their experience and agree how we can make improvements to local health and social care services.
- Surrey Heartlands ICS will commit to using a holistic approach to the LeDeR reviews and will value equally all sources of information.
- Surrey Heartlands ICS will ensure that the learning from LeDeR will be used to improve knowledge and skills of the workforce across all partner organisations in the ICS.
- We will work to increase our understanding of the needs of people with learning disabilities and autistic people who are from Black and Minority Ethnic communities and take action to address any areas of need identified.
- We will continue to develop a system of learning and will ensure that the learning from LeDeR reviews informs the wider health inequalities and quality improvement work that is underway in Surrey Heartlands ICS.

1. People with learning disabilities and autistic people will have access to the services and support they require

| What will we do? | How will we do this? | When will we achieve this? | How will we measure this? |
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| We will work to ensure that people with learning disabilities and autistic people have access to the support they require when accessing health services. | Reviewing the current commissioning of learning disability liaison services and evaluating the current pilot of extended hours within the liaison service. | <ul style="list-style-type: none"> • Q2 2022/ 2023 | <ul style="list-style-type: none"> • Feedback from the pilot evaluation and referral data |
| | We will promote the available support services across the Surrey Heartlands ICS through the Surrey learning disability and autism information hub and will review the current Surrey Heartlands Learning disability and autism webpages. | <ul style="list-style-type: none"> • Q1 2022/ 2023 | <ul style="list-style-type: none"> • Webpage visitor data. • Feedback from local expert by experience groups after initial amendments • Regular audit |
| | We will support the implementation of the Oliver McGowan training across health and social care. | <ul style="list-style-type: none"> • Q1-4 2022/ 2023 | <ul style="list-style-type: none"> • Training uptake / data |

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| <p>We will promote reasonable adjustments across Surrey and ensure that all staff within health and social care services understand their responsibility to make reasonable adjustments for people with learning disabilities and autistic people.</p> | <p>We will raise awareness of the right to have reasonable adjustments made under the Equality Act 2010 through the Surrey information hub?</p> | <ul style="list-style-type: none"> • Q1 2022/ 2023 | <ul style="list-style-type: none"> • We will obtain feedback from local expert by experience groups |
| | <p>We will work to ensure that electronic care records in health and social care services in Surrey clearly communicate the reasonable adjustments that individuals require.</p> | <ul style="list-style-type: none"> • Q4 2022 / 2023 | <ul style="list-style-type: none"> • Feedback from local system partners and service users |
| | <p>We will work with the Q- exchange programme to empower people to access health services. Their programme aims to assist people with learning disabilities and Autism to choose their preferred appointment format, use care passports and access existing life skills programmes delivered by our voluntary partners.</p> | <ul style="list-style-type: none"> • Q4 2022 / 2023 | <ul style="list-style-type: none"> • Final report on the programme |
| <p>We will work to improve the transition process for people leaving children's services and transitioning into adult services.</p> | <p>We are currently reviewing the local all age learning disability and autism operational planning statements for 2022 / 2023 and are working with the Learning Disability Partnership Board, Preparing for Adulthood and SEND programme leads to develop a delivery plan. Through this plan we will develop a process to identify young people with learning disabilities and autistic people who should be invited for an annual health check from the age of 14 years old.</p> | <ul style="list-style-type: none"> • Q4 2021 / 2022 | <ul style="list-style-type: none"> • Annual health check data • Delivery plan |

2. Early identification, preventing deterioration and staying well

| What will we do? | How will we do this? | When will we achieve this? | How will we measure this? |
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| <p>We will promote cancer screening in Surrey amongst people with a Learning Disability and Autistic people, ensuring that the principles of the Mental Capacity Act are applied, where applicable, demonstrating an increase in uptake in all areas of cancer screening over the next 3 years.</p> | <p>We will increase awareness of cancer screening in Surrey through ensuring there are links to easy read cancer screening leaflets and education targeted to family carers and paid care staff.</p> | <ul style="list-style-type: none"> • Q2 2022/2023 | <ul style="list-style-type: none"> • Webpage visitor data • Service user feedback • Findings from LeDeR reviews • Screening uptake data |
| | <p>We will raise awareness of the need for clear documentation of the Mental Capacity Act process within GP records when making decisions about screening and other areas of choice through the facilitation of education sessions.</p> | <ul style="list-style-type: none"> • Q2 2022 / 2023 | <ul style="list-style-type: none"> • Training attendance data • Audit |
| | <p>We will develop a process which promotes reasonable adjustments to ensure that everyone with a learning disability and autistic people can access the screening they require.</p> | <ul style="list-style-type: none"> • Q2 2022/2023 | <ul style="list-style-type: none"> • Reporting ability • Screening uptake data |
| <p>We will work to ensure that people with learning disabilities and autistic people receive the right medication at the right time.</p> | <p>We will work with prescribers and local medication management teams to audit medication prescribing for people with learning disabilities and promote best practice.</p> | <ul style="list-style-type: none"> • Q1 2022/2023 | <ul style="list-style-type: none"> • Medication audit findings • LeDeR review findings |

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| <p>We will work to ensure that people with learning disabilities and autistic people receive the vaccinations they require.</p> | <p>We will achieve this through supporting primary care networks and other local immunisation teams to ensure that reasonable adjustments are made where they are required, and that vaccination uptake is discussed routinely as part of the annual health check process.</p> | <ul style="list-style-type: none"> • Ongoing annually | <ul style="list-style-type: none"> • Vaccine uptake data • Feedback from local experts by experience and care providers • Annual health check data |
| <p>We will improve awareness of how to manage good bowel health and constipation across Surrey.</p> | <p>We will provide education sessions to highlight the high prevalence of constipation in people with learning disabilities and autistic people and how to maintain good bowel health.</p> | <ul style="list-style-type: none"> • Q1 2022 / 2023 | <ul style="list-style-type: none"> • Training data • LeDeR data |
| | <p>We will undertake an audit of medication prescribing to treat constipation to help us better understand areas where further work may be required.</p> | <ul style="list-style-type: none"> • Q4 2021/ 2022 | <ul style="list-style-type: none"> • Medication audit |
| | <p>We will disseminate best practice guidance for the management of constipation to ensure that people are prescribed the correct medication and receive regular medication reviews.</p> | <ul style="list-style-type: none"> • Q4 2021 / 2022 | <ul style="list-style-type: none"> • LeDeR findings / themes |

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| We will work to ensure that Annual Health Checks in Surrey are of good quality and are effective. | We will develop an audit tool for use in Surrey to evaluate the quality of annual health checks. | <ul style="list-style-type: none"> • Q4 2022 / 2023 | <ul style="list-style-type: none"> • Audit findings |
| | We will also monitor the development of health action plans across Surrey Heartlands for anyone with a learning disability who has had an annual health check. | <ul style="list-style-type: none"> • On going | <ul style="list-style-type: none"> • Annual health check data • LeDeR findings • Intelligence from local providers |
| | We will be working in partnership to develop an ICS wide plan for the pilot of health checks for autistic people. | <ul style="list-style-type: none"> • Subject to national directive | <ul style="list-style-type: none"> • Annual health check data and feedback from local service users groups. • LeDeR review findings |
| We will ensure our local family and paid care staff are skilled in identifying when the person they care for may be becoming unwell. | We will achieve this through the roll out of Restore 2 mini training across Surrey Heartlands ICS and in particular offering this to families as well as domiciliary carers. | <ul style="list-style-type: none"> • Q3 2022 / 2023 | <ul style="list-style-type: none"> • Training uptake data and feedback |
| | We will evaluate the impact of the Whzan boxes in identifying people whose condition is deteriorating and who may need further medical review. | <ul style="list-style-type: none"> • Q1 2022/2023 | <ul style="list-style-type: none"> • Evaluation data from the care home leads in each place. |

3. Supporting people to make decisions

| What will we do? | How will we do this? | When will we achieve this? | How will we measure this? |
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| We will continue to work to improve the application of the Mental Capacity Act across Surrey. | We will support clinicians and carers to empower people with learning disabilities and autistic people to enable them to make decisions about their care. | <ul style="list-style-type: none"> • Q2 2022 / 2023 | <ul style="list-style-type: none"> • LeDeR findings • Training uptake |
| | We will help people learn more about the Mental Capacity Act and the assessment and decision-making process needed should someone they care for lack capacity. | <ul style="list-style-type: none"> • Q2 2022 / 2023 | <ul style="list-style-type: none"> • LeDeR findings |

4. Palliative and end of life care

| What will we do? | How will we do this? | When will we achieve this? | How will we measure this? |
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| <p>We will be sensitive to the needs of people with learning disabilities and autistic people as they near the end of their lives. This includes involving them in decisions about how and where they would like to be cared for.</p> | <p>We will work to provide a consistently good quality service when someone with a learning disability or an autistic person is nearing the end of their life. We will achieve this through the roll out and promotion of the ReSPECT (end of life care planning) document across Surrey Heartlands ICS.</p> | <ul style="list-style-type: none"> • Q4 2021/2022 | <ul style="list-style-type: none"> • End of life care teams- Respect uptake and training data • LeDeR findings |
| | <p>We will also continue to promote the annual health check process as a key tool in identifying the need for further/early end of life care planning through the enhanced service training.</p> | <ul style="list-style-type: none"> • Q2 2022 / 2023 | <ul style="list-style-type: none"> • AHC findings • LeDeR data |
| <p>We will work to ensure that bereavement support services are available for people with learning disabilities and autistic people when someone close to them has died.</p> | <p>We will work to ensure that we put people in touch with bereavement support services that meet the needs of people with learning disabilities and autistic people through clearer information on the Surrey learning disability and autism webpages.</p> | <ul style="list-style-type: none"> • Q2 2022 / 2023 | <ul style="list-style-type: none"> • Webpage development |

We would like to thank the Surrey People Group for their valuable contribution into this strategy and the wider work of the LeDeR programme.

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