Lincolnshire Integrated Care Board

NHS
Lincolnshire
Integrated Care Board

Annual Report for the LeDeR Programme in Lincolnshire

April 2022 – March 2023

Contents

NHS Lincolnshire Integrated Care Board

1. Introduction | 1.1 What is LeDeR?

NHS Lincolnshire Integrated Care Board

LeDeR originally stood for The Learning from Deaths Review Programme.

It grew out of the Confidential Inquiry into Premature Deaths of People with a Learning Disability (CIPOLD) and was piloted in parts of the country in 2016. [1]

LeDeR Policy was refreshed in 2021 and saw the introduction of autism into the programme for the first time. The programme is now known as LeDeR - Learning from lives and deaths of people with a learning disability and autistic people.

LeDeR is a service improvement programme which aims to improve care, reduce health inequalities, and prevent premature Mortality of people with a learning disability and autistic people.

LeDeR Policy 2021 sets out for the NHS, the core aims and values of the LeDeR programme and the expectations of different parts of the health and social care system in delivering the programme.

1. Introduction | 1.2 Executive Summary

NHS Lincolnshire Integrated Care Board

This report presents information about the deaths of people with learning disabilities and / or autistic people aged 4 years and over notified to the LeDeR programme between 1st April 2022 and the 1st March 2023 across Lincolnshire.

LeDeR is delivered locally by NHS Lincolnshire Integrated Care Board (ICB) in association with local partners from across the Integrated Care System.

The purpose of this report is to share the findings, the learning, and local service improvement and initiatives with those involved in the LeDeR programme and those working with individuals with learning disabilities and or autistic people, and to illustrate how the Lincolnshire Integrated Care System is delivering on local actions as identified in LeDeR reviews.

Lincolnshire Integrated Care System;
- *NHS Lincolnshire Integrated Care Board*
- *Lincolnshire Partnership NHS Foundation Trust*
- *Lincolnshire County Council*
- *United Lincolnshire Hospitals Trust*
- *Lincolnshire Community Hospital Services*
- *East Midlands Ambulance Services & Transport services. - Palliative/ End of Life Care services*

1. Introduction | 1.2 Executive Summary continued

Since the programme began there have been 315 deaths reported to LeDeR in Lincolnshire covering the period 2017 to end March 2022 of which of have had a review undertaken and completed.

Lincolnshire LeDeR focus for 2023 / 2024;

The Lincolnshire LeDeR Governance Board has identified the following locally agreed criteria meeting the threshold for Focussed Review;

- Cardiovascular Disease
- Rough Sleepers
- Cancer
- Epilepsy
- Rare genetic syndromes
- Down Syndrome with emphasis upon dementia screening

1. Introduction | 1.2 Executive Summary

NHS Lincolnshire Integrated Care Board

Lincolnshire LeDeR vision and priorities for 2023 / 2024:

Reduction in the frequency of deaths that were potentially avoidable or responsive to good quality healthcare.

Quality: Ongoing and continual Quality Assurance of reviews with a robust process to measure the impact of our work in identifying both good practice and missed opportunities to improve local services for people with a learning disability and autistic people, and reduce premature mortality.
Significant changes made to the Quality Assurance process following the outcome of the LeDeR 2022 Audit (NHSE). Pre-submission discussions held with each reviewer at the 16 week point allowing the reviewer sufficient time to finalise the review. Further Quality Assurance pre sign off.

Governance: Continual strengthening of the processes in place which ensure action is taken to address the recommendations emerging from completed reviews via presentation at bi-monthly Governance Panel meetings. ~~A~~ction log to identify the actions from learning required from Focussed Reviews. Continual feedback delivered to system partners both NHS providers, the Local Authority, and community provision where positive practice is identified.

2. LeDeR in Lincolnshire | 2.1 Geography

NHS Lincolnshire Integrated Care Board

The population of Lincolnshire has increased by 11.1%, from around 93,500 in 2011 to 103,900 in 2021. This is higher than the overall increase for England (6.6%), where the population grew by nearly 3.5 million to 56,489,800. [2]

At 11.1%, Lincoln's population increase is higher than the overall increase for the East Midlands (7.7%). [2]
In 2021, Lincoln ranked 230th for total population out of 309 local authority areas in England, Moving up 19 places in a decade. [2]

As of 2021, Lincoln is the fourth most densely populated of the East Midlands' 35 local authority areas, with around 21 people living on each football pitch-sized area of land. [2]

NHS Lincolnshire Integrated Care Board (ICB) is made up of 79 GP practices across the county and 14 Primary Care Networks (PCN's). [3]

PCN's are groups of GP practices working together with other local organisations, such as community, mental health, social care, pharmacy, hospital and voluntary services. They collectively support the needs of a population that has grown, is living longer, and of which may need to access local health services more often.

2. LeDeR in Lincolnshire | 2.1 Geography

NHS Lincolnshire Integrated Care Board

It is estimated more than 14,000 adults with a learning disability currently live in Lincolnshire, with the number expected to increase to around 15,800 by 2035. [2]

Only 4,884 (34.9%) of these adults are registered as having a learning disability with GP Practices .

11,782 people are registered within Lincolnshire Practices as having a diagnosis of autism.

The number of people with a learning disability in Lincolnshire will continue to increase, in particular, the cohort of those aged over 65. Being medically better able to sustain life, complexity of needs will increase. The majority of patients that are in Lincolnshire's Transforming Care cohort are people with complex needs. [2]

2. LeDeR in Lincolnshire | 2.2 Notifications and Reviews

NHS Lincolnshire Integrated Care Board

Notifications received

*There were 49 adult notifications received in Lincolnshire between April 2022 and March 2023. A **DECREASE** of 13 from 2021-22.*

49

Notifications allocated

48 notifications were allocated for initial or focussed review during the year.

48

Reviews completed

*There were 44 reviews completed and signed off in the year. That is an **INCREASE** of 9 from the previous year.*

44

Reviews completed within 6 months

57% of reviews signed off between April 2022 and March 2023 were completed within 6 months.

Reasons for 6-month breaches

The most common reasons for the 6-month time limit on reviews being completed in Lincolnshire for 2022-23 were:

1. On Hold with the Coroner
2. Reviewer Workload

Child reviews

*There were 2 child reviews received during the year, 4.17% of the total notifications. A **DECREASE** of 8.50% from 2021-22.*

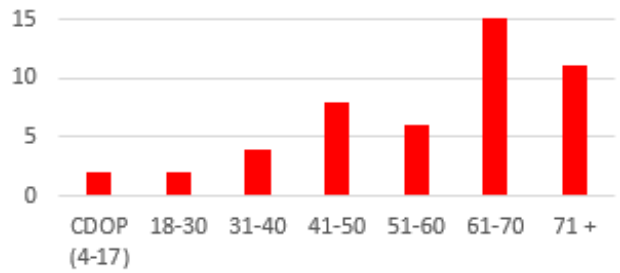
2. LeDeR in Lincolnshire | 2.3 Demographics

NHS Lincolnshire Integrated Care Board

Sex

61% of people in the Lincolnshire data who died in 2022-23 were male and 39% female.

Age



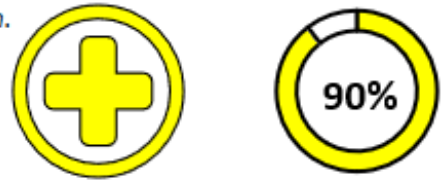
Age at death

The median age of death for people with a Learning Disability or Autism was 57. The average life expectancy for the general Lincolnshire population is 81.

57 Years

Diagnosis

43 of LeDeR reviews in 2022-23 were for patients diagnosed with a LD (90%). The remaining 10% were diagnosed with a LD & Autism.



Ethnicity

100% of people who died in 2022-23 in Lincolnshire identified as "White British".

100%

Early death

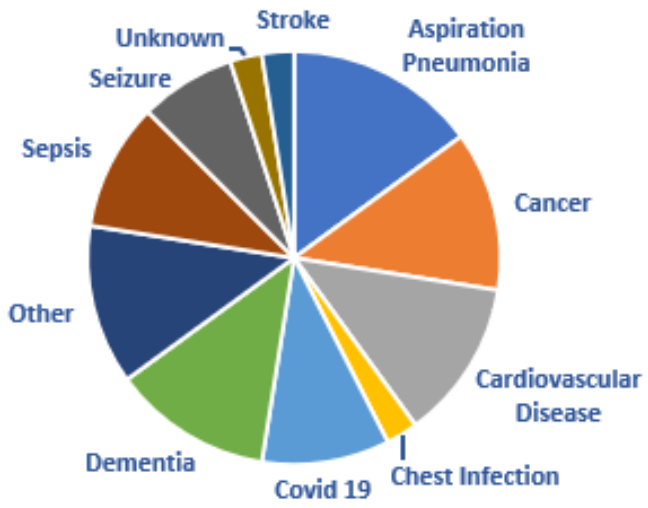
More than 6 out of 10 of those who died in Lincolnshire with a LD and/or Autism died before they were 65. This compares to around 1 out of 10 in the general population.

2. LeDeR in Lincolnshire | 2.4 Deaths

NHS Lincolnshire Integrated Care Board

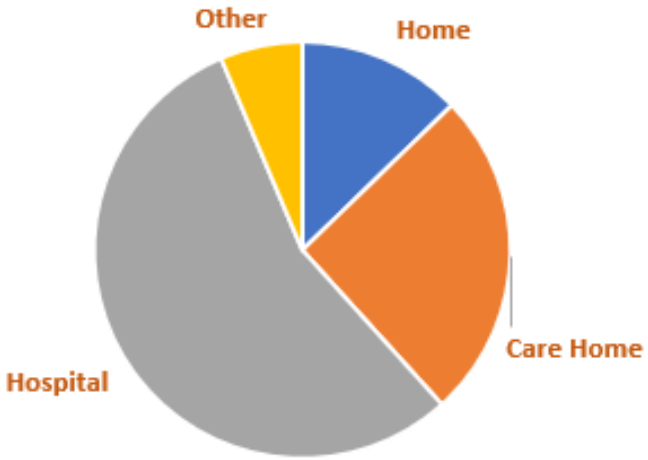
Cause of death

The top 4 causes of death for people diagnosed with a Learning Disability and/or autism in Lincolnshire were Aspiration Pneumonia, Cancer, Cardiovascular Disease and Dementia.



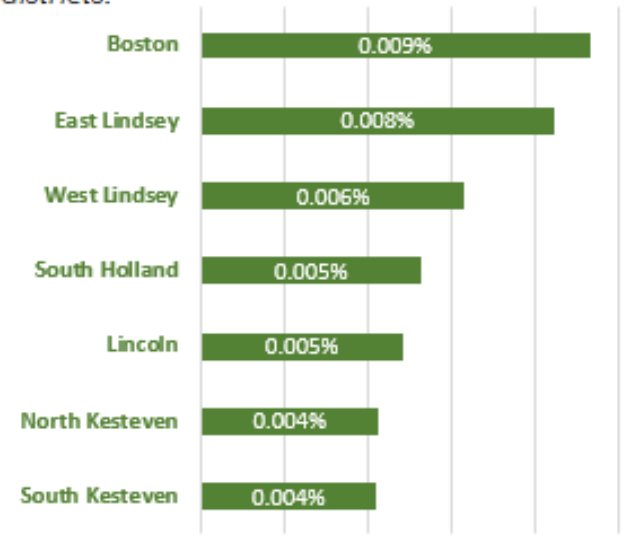
Place of death

*55% of deaths occurred in a hospital setting. An **INCREASE** of 2% from 2021-22. Deaths in a care home setting **DECREASED** from 34% in 2021-22 to 26% in 2022-23.*



Lincolnshire districts

The 2 highest percentage of deaths per population in Lincolnshire were Boston and East Lindsey, more than double that of some districts.



2. LeDeR in Lincolnshire | 2.5 Positive Practices: Reviewers findings

NHS Lincolnshire Integrated Care Board

"*The GP was responsive and proactive with all care needs, and with EOL care too.*"

"Mum reported that care in hospital was compassionate at EOL, ULHT provided a knitted comforter for Mum and for Brian, and provided a hand cast for Mum to take out with her, which would be expected on a C/YP ward, but this was in A&E."

"Consistency across his care due to residing at the home since 1991. The home made it a home for life, reasonable adjustments made to allow him to remain there at the end of his life."

"Regular annual health checks completed, good engagement with the LD community team and GP practice."

"Weekly G.P ward rounds at nursing home environment. A&E liaison with home i.e.: communication needs/preferences. Access to all required and indicated health specialities."

2. LeDeR in Lincolnshire | 2.6 Actions for Learning : Reviewers findings

NHS Lincolnshire Integrated Care Board

"More evidence of reasoned clinical decision making required moving forwards".

"Lack of risk versus benefit decision making".

"Individual was prescribed Buccal Midazolam as a rescue medication as per her PRN protocol. Ward staff reported that this couldn't be administered as there wasn't anyone available to write this up".

"No evidence of who was involved in any best interest decision in relation to the RESPECT form".

"Inconsistent information in relation to Jean's speech recorded within the health action plan".

"The LD liaison was not informed that the patient had been admitted to hospital".

"Inconsistencies within assessments of capacity pertaining to hospital/end-of-life care, lack of familial consultation or best interests' assessments pertaining towards care provision".

2. LeDeR in Lincolnshire | 2.7 Action From Learning from Focussed Reviews

NHS Lincolnshire Integrated Care Board

E was a 71-year-old man who had learning disabilities, epilepsy, dementia, and Glaucoma. E had a brother who kept regular contact with him. Family and staff said E was always in a good mood and loved to be around people. He had a really loving relationship with his nephew and looked forward to him visiting and taking him out. E liked food which he said was not mucky food , like meat and vegetables. E had regular annual health checks with the GP along with medication reviews.
E presented with signs typical of a TIA and spent time in hospital before being returned back home to his care home. E was still not presenting as himself, staff were concerned and called for an ambulance. E stayed in hospital the night and returned home on 15th June on an end-of-life pathway, and sadly E passed away on 23rd June 2022.

Learning. Improved oversight of discharge for End-Of-Life Care with clear pathway as per the Gold Standards Framework

Actions agreed at Governance Panel. Identified opportunity to improve upon contact time and provision of the LD bundle (Early recognition of patients with learning disabilities, effective communication with patients, carers, family members and clinicians, dignified, person-centred care and treatment) for provision of support in patients in EOL – actions disseminated by the Specialist Safeguarding Learning Disability Nurse and fed back to next panel.

Positive Practice. Provider was proactive in managing EOL and keeping the patient comfortable from leaving hospital to death.

2. LeDeR in Lincolnshire | 2.7 Action From Learning from Focussed Reviews

NHS Lincolnshire Integrated Care Board

C was 62 years old with a diagnosis of learning disability, Epilepsy, and Tuberose sclerosis. Described as loving life and enjoyed engaging in many activities including trips out and singing and dancing, C enjoyed living with her peers and being supported by staff at her CSL placement where she had lived for more than 20 years.

C was independently mobile and was always encouraged by her support staff to maintain her independence. C communicated verbally and was able to make her needs known however this declined when she was feeling physically un-well and staff who knew her well would anticipate her needs.

C died at home following a series of hospital inpatient admissions, and during her final admission experienced a prolonged seizure lasting 45 minutes.

Learning. For medical professionals to evaluate medications that will continue to be required alongside anticipatory medications

Actions agreed at Governance Panel. GP link to discuss further with GP colleagues within Lincolnshire.
With kind permission of the family, the review was shared at the Lincolnshire Purple Light Epilepsy webinars.

Positive Practice. The Care provider had very informative care plans and hospital passport which was given to the hospital to support the admission of C.

2. LeDeR in Lincolnshire | 2.8 Governance

NHS Lincolnshire Integrated Care Board

Lincolnshire's LeDeR Governance panel meet bi-monthly.

The panel considers the issues, concerns and areas of good practice and learning identified in LeDeR reviews and agree a set of SMART actions to address those issues including both strategic and practical activity that will reduce premature mortality, improve the quality of services and reduce health inequalities.

All Focussed Reviews are presented to the Governance Panel via a Power Point Presentation Template and the case is presented by the LeDeR Reviewer or, a Senior LeDeR Reviewer or the LAC.

Actions for learning are disseminated across the ICS by a designated Governance Panel member and the completed actions are updated at the next governance panel.

A new process has been developed for x1 slide to be presented from each Initial Review so as to ensure that positive practices are disseminated across the ICS and fed back to individual services.

3. Highlights | 3.1 Focus upon Epilepsy – The Purple Light Toolkit

NHS Lincolnshire Integrated Care Board

Research suggests that epilepsy is more common in adults with a learning disability than those without a learning disability; and is more common amongst men and those with a higher level of impairment [4]

Successive LeDeR reports and national reviews, such as the Clive Treacy Independent Review and Norfolk Safeguarding Review into the deaths of Joanna, Jon and Ben, make an urgent and compelling case for action to tackle premature avoidable death and improve quality of life for people with learning disability, autism or both who suffer from epilepsy. [5]

NHSE Midlands Learning Disability & Autism Programme invited all ICSs in the region to participate in an important benchmarking review of epilepsy services and support for people of all ages with a learning disability, autism or both. This was viewed as a critical part of a regional programme of work to reduce premature avoidable death associated with epilepsy for this vulnerable cohort.

The Purple Light Toolkit has been implemented as a resource supporting service improvement in epilepsy across Lincolnshire.

3. Highlights | 3.1 The Purple Light Toolkit - Epilepsy Webinars

Two repeat Webinars were shared in January 2023 to share the learning from “My life with Epilepsy: a tribute to the learnings from the life of Clive Treacy programme” and to review the lived experiences of Lincolnshire citizens with epilepsy and learning disabilities and/ or autistic people. [4]

The Webinars provided the opportunity to reflect about the effectiveness of epilepsy services and support for Lincolnshire citizens with a learning disability, autism or both, and via Breakout Sessions to provide guidance, best practice and learning from local LeDeR cases, on how epilepsy services and support for people with a learning disability and/or autistic people can be improved, and to network and share information about improvement work taking place across Lincolnshire [4].

3. Highlights | 3.2 Profile upon Virginia House Day Care Centre

NHS Lincolnshire Integrated Care Board

Virginia House is a day care centre situated in a residential area of the Louth and offers community based day services for people with disabilities who are eligible for Adult Social Care:

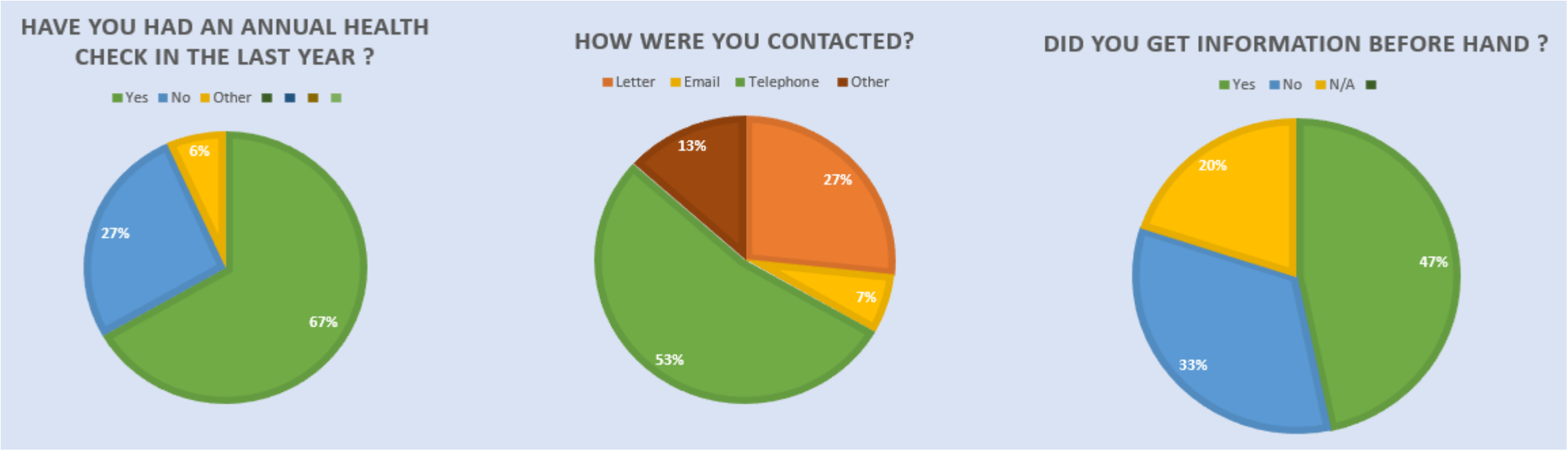
- The service helps people to live independent and fulfilling lives. We will help people using the service, to develop friendships and to do the everyday things that are important to them. We will also ensure people can be part of and make important contributions to their local communities. We also provides a level of support for the wider family.
- Day opportunities help people to:
- Make positive contributions to the community
- Make friends
- Develop relationships
- The people we support have personalised activity plans which reflect their interests.
- Take part in various interest and activities to improve wellbeing.
- It is a chance for the people we support to meet others, build confidence, learn new skills and to live life to the full.

3. Highlights | 3.2 Virginia House Day Care Centre Annual Health Checks Project

NHS Lincolnshire Integrated Care Board

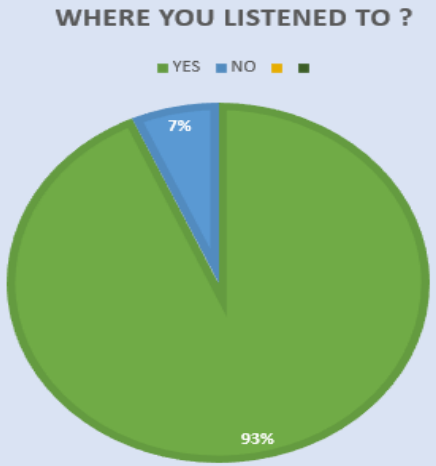
Virginia House undertook an independent study of the experience of service users and their family / carers of the quality of Annual learning disability health checks they received.

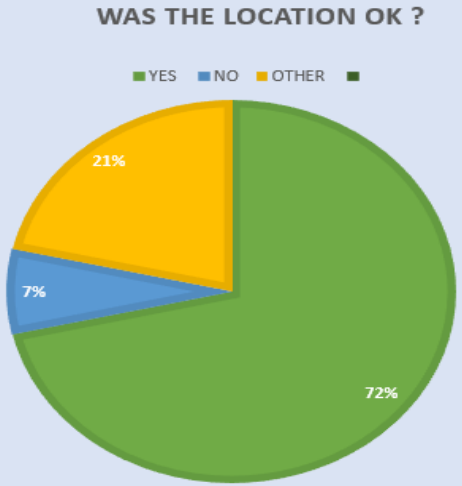
This is the feedback received from their study.

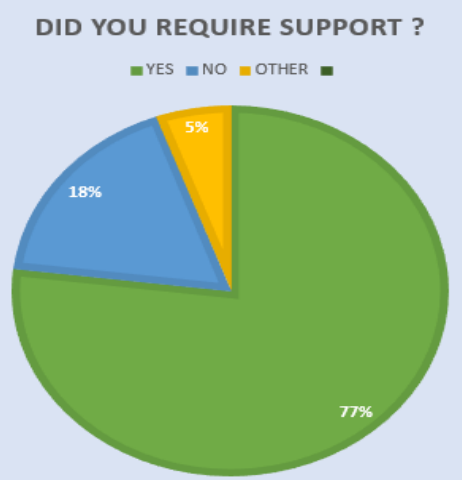


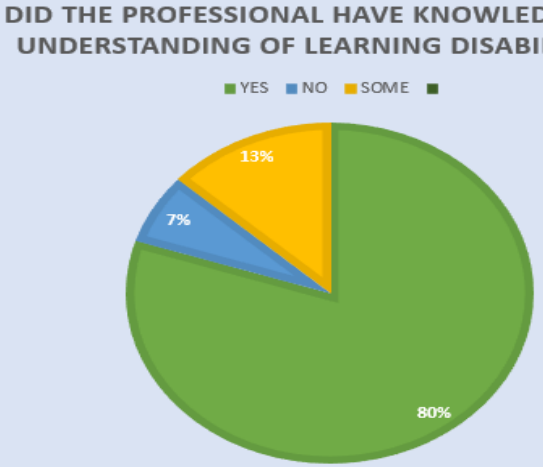
3. Highlights | 3.2 Virginia House Day Care Centre Annual Health Checks Project

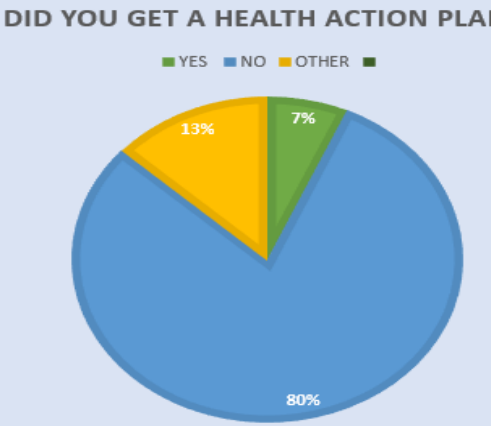
NHS Lincolnshire Integrated Care Board











3. Highlights | 3.2 Virginia House Day Care Centre Annual Health Checks Project

NHS Lincolnshire Integrated Care Board

WHAT COULD HAVE BEEN IMPROVED?

- To be able to choose the environment that suits my needs.
- Accessibility
- Access to a hoist
- Face to Face
- Access to appropriate professionals -e.g. phlebotomist .
- The receptionist of the surgery to have an understanding of Learning Disabilities .
- GP to update their systems to allow an appropriate adult to speak on behalf of the individual.
- All professionals to read and adhere to health passports .
- Working together – being available for " best interest meetings "

3. Highlights | 3.2 Virginia House Day Care Centre Annual Health Checks Project

NHS Lincolnshire Integrated Care Board

NEXT STEPS ?

- Supporting parents and carers to appointments.
- Continuing to work with NHS .
- Contact GP surgeries directly
- Look at working with GP surgeries to improve accessibility .
- All individuals who access Virginia house to have an annual health check and a health passport .
- All individuals to have a personalised health plan

3. Highlights | 3.3 Lincolnshire GP Practice Awards

NHS Lincolnshire Integrated Care Board

LD Friendly Practice Quality Mark

The aim of the Lincolnshire Learning Disability Friendly Practice Quality Mark is to improve health outcomes for people with a learning disability living in Lincolnshire by supporting GP practices to improve care quality and patient experience. Everyone is entitled to good health care, and it is vital that LD patients have equitable access to services too.

The Quality Mark aims to recognise good practice in providing accessible health care to people with a learning disability and encourage continuous quality improvement.

Awarding the Quality Mark follows a simple process:

- Practices apply and provide the required evidence that they meet the standard
- An LD Health Check Network panel, including experts-by-experience, reviews applications and approves or provides feedback - the panel may seek views of patients registered at the practice (and their carers)
- A register of LD Friendly Practices is maintained by NHS Lincolnshire ICB

3. Highlights | 3.3 Lincolnshire GP Practice Awards

NHS Lincolnshire Integrated Care Board

Congratulations to Parkside Medical Centre Boston who were awarded the LD Friendly Practice Quality Mark in September 2022

Parkside Medical Practice boasts X2 Learning Disability Champions;
Non-Clinical Lead (Hannah Padley) and Clinical (Sandra Smith)

Pre-Health Check questionnaire:
In this we added a picture of Sandra Smith
for familiarity and added that she is located in an upstairs room accessible via the stairs or lift, but states to let us know if the patient would prefer a downstairs room.

We invite patients in their Birthday month.

We send a Dementia Screening Questionnaire to patients over 35 years

We added the Poo Matters Information

All patients have an Action plan

3. Highlights | 3.3 Lincolnshire GP Practice Awards

NHS Lincolnshire Integrated Care Board

Parkside Medical Centre Boston

We added a 'Signs an Symptoms of Cancer' leaflet for the patient to tick and relevant symptoms for the clinician to review

The Pre-Health Check paperwork has reasonable adjustments listed and these are coded on the records for each appointment, the invitation (as above) details the location of the room they will be seen and how they will get to the room, but offers an option to move to a lower room

The LD team undertook refresher training as part of the Quality Improvement plan, then the full practice undertook training as part of Protected Learning Training

We joined the LD steering group, this was when the Tier programme was discussed and we immediately put ourselves forward for it.

4. Person Profile | 4.1 Mandy Hodson (Parent/Carer EbE)

NHS Lincolnshire Integrated Care Board

Mandy Hodson (Parent/Carer EbE)

My name is Mandy Hodson and I am a Parent /Carer Expert by Experience. I work for NHS Lincolnshire Integrated Care Board (ICB) Mental Health, Learning Disability and Autism Team. I have a daughter with a learning and physical disability, so she is my inspiration in everything I do.

My role with LeDer as a parent/carer, is to be a representative on the LeDer Governance panel, where we oversee the reviews completed after someone has died. I also visit or contact families and carers, if they wish me to, to offer any help and support they might need. This is a very emotional time of their lives and I believe support and communication is very important.

I am an Easy Read advocate to ensure that any information given is suitable and appropriate for the reader.

I also see LeDer as a vital thread running through the care of people with a learning disability and autistic people, therefore I am passionate about the link with Annual Health Checks being given equal provision. This will enable the appropriate care to be provided therefore preventing early deaths. I work closely with our Local Area Contact and LeDer Chairperson, reviewing and listening to people so that we can implement their voice and provide the improvements needed to allow the people of Lincolnshire with a learning disability or Autism to lead a happy and healthy life.

5. Partnerships & Collaborations | 5.1 LDAHC

NHS Lincolnshire Integrated Care Board

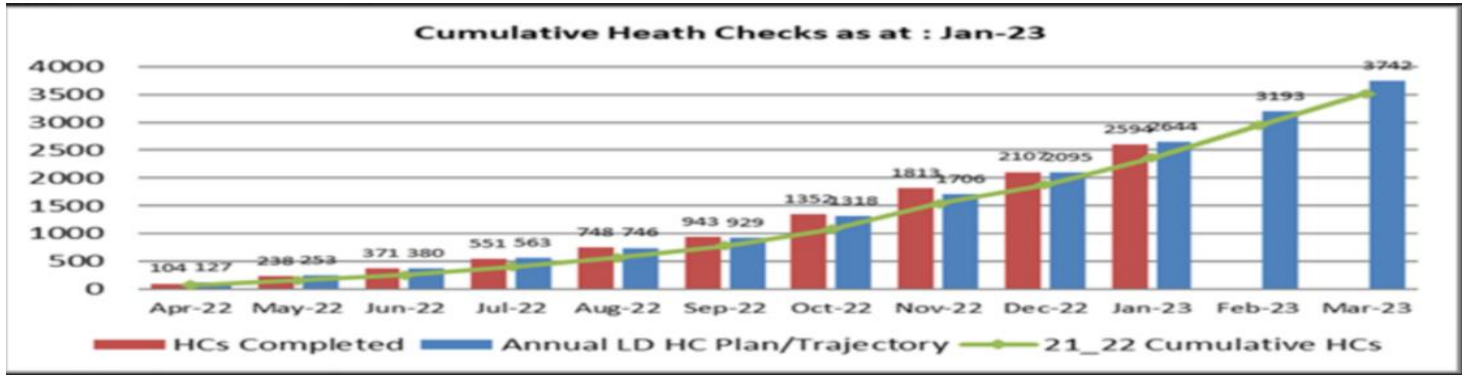
GP practice annual health checks with are an essential part of addressing health inequalities experienced by people with a learning disability [LD] aged 14 and above.

3,557 Annual Health Checks were delivered in Lincolnshire over the year, this is 82.3% of the total LD register of 4,320 (March '23 QOF register). This is 185 checks under the planned trajectory for the year but 44 checks more delivered than the previous year. Performance is significantly above the national target of 75%.

Health Action Planning following a check is also important. Data suggests people in Lincolnshire aged 14-25 years are less likely to take up the offer of a check – the ICB and LCC have worked together to promote uptake through SEND services.

The Lincolnshire LDHC Network has been focussing on improving the quality of health checks including:

Standardising templates
Introducing dementia screening
How to improve cancer screening
Sharing best practice



5. Partnerships & Collaborations | 5.2 LDAHC Co Production

NHS Lincolnshire Integrated Care Board

Virginia House's project inspired us all at the Learning Disability Partnership Board, and we discussed it further at the Healthy Lifestyle Working Group with the collective opinion that promoting physical and mental wellbeing, and avoiding premature mortality starts with the Annual Health check.

So it was at that point we agreed to build upon the amazing work that Virginia House have started, and develop the questionnaire to spread widely across the county with the intention of understanding what it is that makes an Annual Health check good, or bad, if they are meeting the needs of Lincolnshire residents, and are fit for purpose.

The project was piloted at the Voices For All event on 7th June 2023. Feedback will be collated and analysed.

We anticipate that this project will evolve in stages and inform the wider system, and primary care, and we will continue to feed back our progress via the Healthy Lifestyle Working Group and decide next steps.

5. Partnerships & Collaborations | 5.2 LDAHC Co Production

NHS Lincolnshire Integrated Care Board

LeDeR

Annual Health Check Project 2023

VoiceAbility

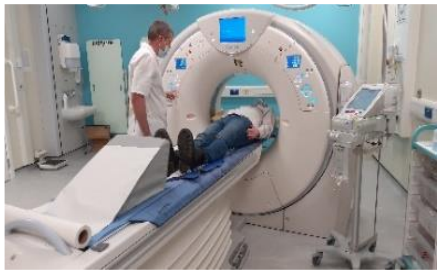
NHS

Lincolnshire COUNTY COUNCIL

Working for a better future

5. Partnerships & Collaborations | 5.3 Voices for All Lincolnshire

NHS Lincolnshire Integrated Care Board



Working together to break down barriers and promote awareness.

Speak Out Leaders Pete, Michelle and David, have been working with staff at United Lincolnshire Hospital Trust, Grantham hospital.

Visiting different departments and interviewing doctors and nurses, making short films.

Michelle enjoyed pretending she had broken her arm and being filmed going through the process then having her arm put in plaster for the day.

When the films are finished they will be shared across the hospital website and with other people to help show what it is like inside different parts of the hospital. This will then help people before they visit.

Voices For All Lincolnshire

5. Partnerships & Collaborations | 5.4 LPFT Highlight

NHS Lincolnshire Integrated Care Board

Spotlight on the Acute Liaison Service Lincolnshire Partnership NHS Foundation Trust

Mikey

Through his eyes...

Young man wearing headphones sits on hospital bed fidgeting with a blood pressure cuff. Headphones connected to ipad. Room is darkened. Background shows medication and sports bottle. What can't be seen, is me, his mother. It was a turbulent hospital stay. He has very complex learning disabilities. We can communicate but his voice wasn't heard during his treatment. I am his mum and carer.

"They did not listen"……

Lorena described Mikey's unplanned surgery in 2019 as a very traumatic and bad experience.

Because "they did not listen", Mikey's dignity was compromised. "…. distressed, petrified, and beyond de-escalation".

Lorena Jane Hall

5. Partnerships & Collaborations | 5.4 LPFT Highlight

NHS Lincolnshire Integrated Care Board

Spotlight on the Acute Liaison Service Lincolnshire Partnership NHS Foundation Trust

Mikey

Mikey needed further surgery in April 2023 to replace his PEG.

Lorena was given one week's notice and declined this so as to avoid another potentially traumatic experience.

It was agreed that surgery would be planned for one month's time.

- "…….this time they listened!"
- The ALN Service supported with a care plan
- One month for careful planning
- The ALN's worked with the hospital and home pre and post operation
- Required adjustments made – admitted straight to paediatric theatre this time
- Theatre was reserved for Mikey, with no other patients to avoid triggering a distressed reaction
- Person centred, the hospital explored what Mikey would want pre and post-surgery
- Mikey went home an hour after waking up in recovery

The Acute Liaison Nurses made sure that a Mikey's learning disability was not a barrier to the hospital staff engaging with the treatment he needed to receive.

5. Partnerships & Collaborations | 5.4 LPFT Highlight

NHS Lincolnshire Integrated Care Board

Spotlight on the Acute Liaison Service Lincolnshire Partnership NHS Foundation Trust

Rachel, Assistant Physical Health Practitioner for Learning Disability provided an account of the work the Acute Liaison Service undertakes.

Lincolnshire Partnership NHS
NHS Foundation Trust

“The Acute Liaison Nurse supports hospital staff to enable patients to receive appropriate care and treatment whilst in the acute hospital setting and advises on reasonable adjustments to be considered so the person with a learning disability receives the same equitable service.
….supports family and carers of the individual whilst in hospital and offers support and teaching to hospital staff.

The Assistant Physical Health Practitioner supports the Acute Liaison Nurse and also supports the Physical Health Liaison Nurse in the community making sure reasonable adjustments are considered for individuals with a learning disability to ensure their health needs are recognised and appropriately treated in primary and secondary care.”

6. Project Updates | 6.1 RESPECT

NHS Lincolnshire Integrated Care Board

ReSPECT

Recommended Summary Plan for Emergency Care and Treatment

NHS Lincolnshire

Dying Matters Week 2023

What's New ?

- *Updated ReSPECT Policy and SOP*
- *Moving to V3.5*
- *New Training and Education package*
- *New Resources on Lincs EOL website*

Background

ReSPECT was launched in 2019 as a Lincolnshire-wide initiative, across all providers. It replaced the previous DNACPR and gave the opportunity for people to voice their wishes and choices, together with clinical balance, should they be in an emergency situation where they are unable to speak. Since September 2021, the core programme work has resumed, and this update details the developments and provides information and key links.

Why does ReSPECT matter?

In line with Dying Matters Week, having a quality ReSPECT conversation recorded on the ReSPECT form really can make a difference to people at the end of their lives. It gives them opportunity to have a voice and share their wishes and choices.

Have a Query? licb.respect.lincolnshire@NHS.net

ReSPECT – everyone's business and everyone's responsibility

Updates

ReSPECT electronic signature

- You no longer need to print off an electronic form, sign and scan in. Electronic signature or print is perfectly acceptable to validate
- **The 'Senior Responsible Clinician'** can be a Registered Practitioner with proficiency. At ULHT it will need to be a Dr or ACP who are proficient
- **How to order ReSPECT 3.5**
  All PCNs and Care Homes can access ReSPECT forms via Ruddocks direct and at no cost currently.
  Link & QR code to the website:

CLICK HERE

ReSPECT

Training and Education

The package has now been developed and accessible through the link below. It is a blended approach with eLearn and support in practice, with a focus on ReSPECT:

Awareness (Level 1)
Action (Level 2)
Authorship (Level 3)

CLICK HERE

Best Practice

Revisit ReSPECT when:

1) **There is a change of setting**
2) **There is a change of condition**
3) **There is a change of wishes/choices**

- Check out the Resus Council website for ReSPECT information e.g. GP myth-busting, ReSPECT easy-reads, videos and more

RESUS COUNCIL

- We are regularly updating the End of Life website with local ReSPECT resources:

EOL WEBSITE

- It is Best Practice to use recognised purple card/ paper for ReSPECT forms

Jenny Fryer - ReSPECT Project Manager
Contact: Jenny.fryer3@nhs.net

ReSPECT – everyone's business and everyone's responsibility

7. Credits and Acknowledgments

NHS Lincolnshire Integrated Care Board

A note from the Author;

As the Local Area Contact for LeDeR, I would like to take the opportunity to thank my Co-Authors without whom this report would not be possible;

Senior LeDer Reviewers / Improvement & Delivery Managers. Jodie Goodman, Gareth Elwick and Katrina Brown for progressing local LeDeR review activity, providing continuous clinical governance supporting our endeavour to identify opportunities for improving services in Lincolnshire.

and…

Improvement & Delivery Manager. James (Jim) Hartley for his phenomenal IT skills and overhaul of the way we input, store and analyse our data to allow us to turn our findings into insights, and in addition, identifying the performance of our data and KPI key measures.

7. Credits and Acknowledgements

NHS
Lincolnshire
Integrated Care Board

The LeDeR Governance Board would like to thank the following people without whom the reviews and continuous learning and opportunity for improvement would not be possible;

All of our dedicated LeDeR Reviewers from across the Lincolnshire Integrated Care System for their commitment to improve services:

The family members, friends and carers who at a time of bereavement have shared their stories of their loved ones with reviewers and who have agreed to reviews of their loved ones being shared to support learning.

To our system partners, for providing the information to help us undertake the reviews, by responding to feedback and continuing to support the LeDeR Programme in Lincolnshire.

7. Credits and Acknowledgements

NHS Lincolnshire Integrated Care Board

Thank you to the Lincolnshire LeDeR Governance Board Panel;

Chair: Cath Keay Head Of Commissioning NHS Lincolnshire ICB (LICB)
Deputy Chair: Mandy Hodson Parent Carer Expert By Experience NHSLICB
Board Members:
Claire Noble Senior Commissioning Manager and Local Area Contact for LeDeR in Lincolnshire *NHSLICB*
Dr Louise Roscoe Named GP for Safeguarding Children and Adults *NHS LICB*
Craig Ferris Deputy Director of Safeguarding *United Lincolnshire Hospitals NHS Trust*
Sara Apps General Manager LD Services *Lincolnshire County Council*
Sue Garratt Highly Specialist Autism Assessors *Lincolnshire Partnership NHS Partnership Trust*
Ali Balderstone Deputy Named Nurse Child Protection *Lincolnshire Community health Services NHS Trust*
Kerry Poberezniuk LD Safeguarding Nurse *Lincolnshire Partnership NHS Partnership Trust*
Emma-Kay Dominey-Hill Trust Lead for Transforming Care - *Lincolnshire Partnership NHS Foundation Trust*

And a big thank you to Bev Stevenson, Senior Admin Lead to the MHLDA Senior Team upon whom we rely upon for her effective minute taking, agenda setting, recording of actions and generally bringing it all together and keeping us on track.

7. Credits and Acknowledgements

NHS Lincolnshire Integrated Care Board

Thank you to all those who have contributed to this report by sharing their stories, projects and workstreams:

Cath Keay, Skye Cooper, Katie Faherty and The Purple Light Toolkit working group for Lincolnshire.

Debbie Dennis and Judith Blow, Virginia House Day Care Centre in Louth.

Mandy Hodson Parent Carer Expert By Experience.

Speak Out Leaders Pete, Michelle and David, Speak out Leader Facilitator Kerry for The Healthy Lifestyle Working Group and The Voices for All Group, Voiceability.

Lorena Hall for sharing Mikey's story and allowing us to learn from good practice, and to The Acute Liaison Service, Lincolnshire Partnership NHS Foundation Trust.

Lisa Baldwin Practice Manager, Hannah Padley, Sandra Smith and their team at Parkside Medical Centre for sharing their achievements with us.

Jenny Fryer ReSPECT Project Manager, NHS LICB, and the Lincolnshire ReSPECT working Group.

8. Looking forward;

NHS Lincolnshire Integrated Care Board

As our LeDeR dataset continues to develop in Lincolnshire, so will the opportunities for further statistical and thematic analysis to allow us to identify trends and develop valuable insights to understand where initiatives have been effective, and target areas where more needs to be done in terms of service improvement.

We are constantly striving for opportunities in Lincolnshire to improve health outcomes for people with a learning disability, and autistic people and to reduce health inequalities.

We hope this report illustrates our shared vision and collective goal from across the Integrated Care System, working in true co-production to reach our collective outcome.

Thank you for taking the time to read our Annual LeDeR Report for Lincolnshire 2022/2023.

Claire Noble

Senior Commissioning Manger for NHS Lincolnshire ICB

Local Area Contact for LeDeR in Lincolnshire

9. References

NHS Lincolnshire Integrated Care Board

[1] Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) policy 2021 Version 1, 23 March 2021 B0428-LeDeR-policy-2021.pdf

[2] Learning Disabilities - Lincolnshire Health Intelligence Hub (lhih.org.uk)

[3] NHSLICB Lincolnshire ICB - Supporting healthcare for the population of Lincolnshire

[4] McGrother et al. 2006; Epilepsy Society, 2019 ; Robertson et al., 2015.

[5] Lincolnshire Webinar - Epilepsy Services for People with a Learning Disability, Autism or Both. NHSE Midlands Learning Disability & Autism Programme January 2023 Catherine Keay HOC NHSLICB.

[6] MIDLANDS LEARNING DISABILITY & AUTISM PROGRAMME Benchmarking Review of Epilepsy Services & Support for People with a Learning Disability Autism or Both

NHS
Lincolnshire
Integrated Care Board

END