NHS Frimley Integrated Care Board (ICB) LeDeR Annual Report 2022/2023

“Learning from the Lives and Deaths of People with Learning Disabilities and Autism”

For the period 1st April 2022 – 31st March 2023

NHS England and NHS Improvement

Contents

Executive Summary

- LeDeR is a service improvement programme for people with a learning disability and, more recently, autistic people. It was established in 2017 and is funded by NHS England. ICBs are required to review the deaths of people with a learning disability or who are autistic, with the learning outcomes implemented to improve overall care, reduce health inequalities and prevent further people from an early death.
- In 2022/23 Frimley ICB continued to operate a unified LeDeR programme covering its five places; Slough, the Royal Borough of Windsor & Maidenhead, Bracknell Forest, Surrey Heath, and North-East Hampshire & Farnham. The programme also maintained an interface with region and neighbouring ICB programmes via the monthly Regional Local Area Co-ordinators Group.
- In 2023/23, we developed new Strategy and Policy Framework documents, which reflect our overall aims and ambitions, out governance arrangements, and standard operating processes. These were ratified by the LeDeR Steering Group.
- We revised our quality assurance and sign-off processes to make them more efficient, while retaining a focus on quality. This involved reviewing our Quality Assurance Checklist and expanding the monthly LeDeR Sign-Off Group to ensure a broad level of expertise.
- While the focus has remained on quality, our biggest challenge has been the timeliness of completion of reviews. There are several factors contributing to this, notably the timeliness of the availability of Structured Judgement Reviews (SJRs) from providers, and reviewer capacity. Agreement was reached to recruit three more reviewers, and these will be in post in 2023/24 Quarter 2. We continue to work with providers on the flow of SJRs. A new national Key Performance Indicator on completion of reviews within 6 months makes these improvement measures more pressing.
- In 2022/23, the Frimley programme received 34 case notifications. Of these, 21 were designated ‘initial reviews’ and 13 required ‘focused reviews’, which go into greater depth. A focused review is mandated for cases involving people with a diagnosis of autism (without Learning Disabilities), and for people who belonged to a minority ethnic group. Focused reviews are also triggered where significant issues with care and treatment are identified.
- 35 cases were completed; some of these being cases notified before the start of the financial year.
- Key findings from the programme are summarised on the next slide.

Key Findings

Demographics

- **Note on prevalence:** As of April 2023, Frimley ICB had a Learning Disabilities and Autistic People GP Register prevalence of 0.45% of the total population against national average of 0.58%. Work is continuing to ensure that all people who meet the criteria are recorded on GP registers.
- **Gender:** The split of cases notified was 50% male and 50% female. This reflects the overall population split in Frimley ICS.
- **Adults / Children Profile of Notified Cases:** 32 adults and 2 children. Child deaths were reviewed via the Child Death Overview Panel (CDOP) process which feeds back to LeDeR. (Note: From July 2023, national policy has changed to exclude child deaths age 4-17 years from the LeDeR notification and review process. Learning from these cases will flow via the CDOP route.)
- **Age:** The average age of adult deaths was 58 years (60 for men, 59 for women); lower than last year. Age range 18-85 years. For comparison, life expectancy for the general population in Frimley ICS is 81 years for men and 84 years for women.
- **Ethnicity:** White ethnicity accounted for 77% of deaths; Asian or Asian British 12%, Mixed/Multiple ethnicity groups 3%, Black or Black British 0%, any other ethnic group 3%, with 6% not stated. The overall percentage of the Frimley population recorded as belonging to a minority ethnic group is c. 21%.
- **Level of Learning Disability:** Of the completed cases, where recorded, the mix was: 6 mild, 3 mild/moderate, 14 moderate, 1 moderate / severe, 6 severe, 2 profound, and 3 unknown / unstated.
- **Cause of Death:** Of the completed cases and cases in progress where the cause has been confirmed, the main cause of death was pneumonia; 43% of cases. The types of pneumonia recorded were Aspiration Pneumonia – 4; Pneumonia – 3; COVID Pneumonia – 2; Bilateral Pneumonia – 1; Bronchopneumonia – 2; Suspected Bronchopneumonia and Aortic Stenosis – 1; Hospital Acquired Pneumonia – 1; Community Acquired Pneumonia – 1. Other causes of death varied by category without a consistent identifiable theme.
- **COVID-19:** Of the completed cases, 2 were deaths confirmed as relating to COVID-19.

Learning (more detail on learning is included in the main report below)

- We identify learning through the analysis of case outcomes at the LeDeR Steering Group. Learning falls into two broad categories; specific learning outcomes for providers, and thematic learning for the system.
- The Learning into Action Group takes on thematic learning and selects priorities to work on. In 2022/23 the key priorities continued to be, a) Quality auditing of Annual Health Checks, b) Improving cancer screening uptake; c) Improving early detection of deterioration.

Introduction

This is the annual report of the NHS Frimley Integrated Care Board (ICB) LeDeR Programme for 2022/23. It presents information about the lives and deaths of people with learning disabilities and autistic people in the Frimley ICB area (aged 4 and over) notified to and completed by the LeDeR programme from 1st April 2022 to 31st March 2023. Also included are some comparative data and historical learning from previous years.

NHS Frimley ICB delivers the LeDeR programme for the Frimley Integrated Care System (ICS) area, comprising the local areas of Slough, Windsor & Maidenhead, Bracknell Forest, North East Hampshire & Farnham, and Surrey Heath. The programme has developed a structure in collaboration with stakeholders for the process of undertaking reviews and putting the learning into action. This report contains information about the types of cases notified to the programme, performance, demographics, equality, learning themes, and actions being taken to improve services and the quality of life for people with learning disabilities and autism in Frimley.

Acknowledgements

We would like to thank family members, carers, service providers, reviewers, and ICS colleagues who have contributed to the review of the lives and deaths of people with learning disabilities in Frimley and worked to put service improvements in place.

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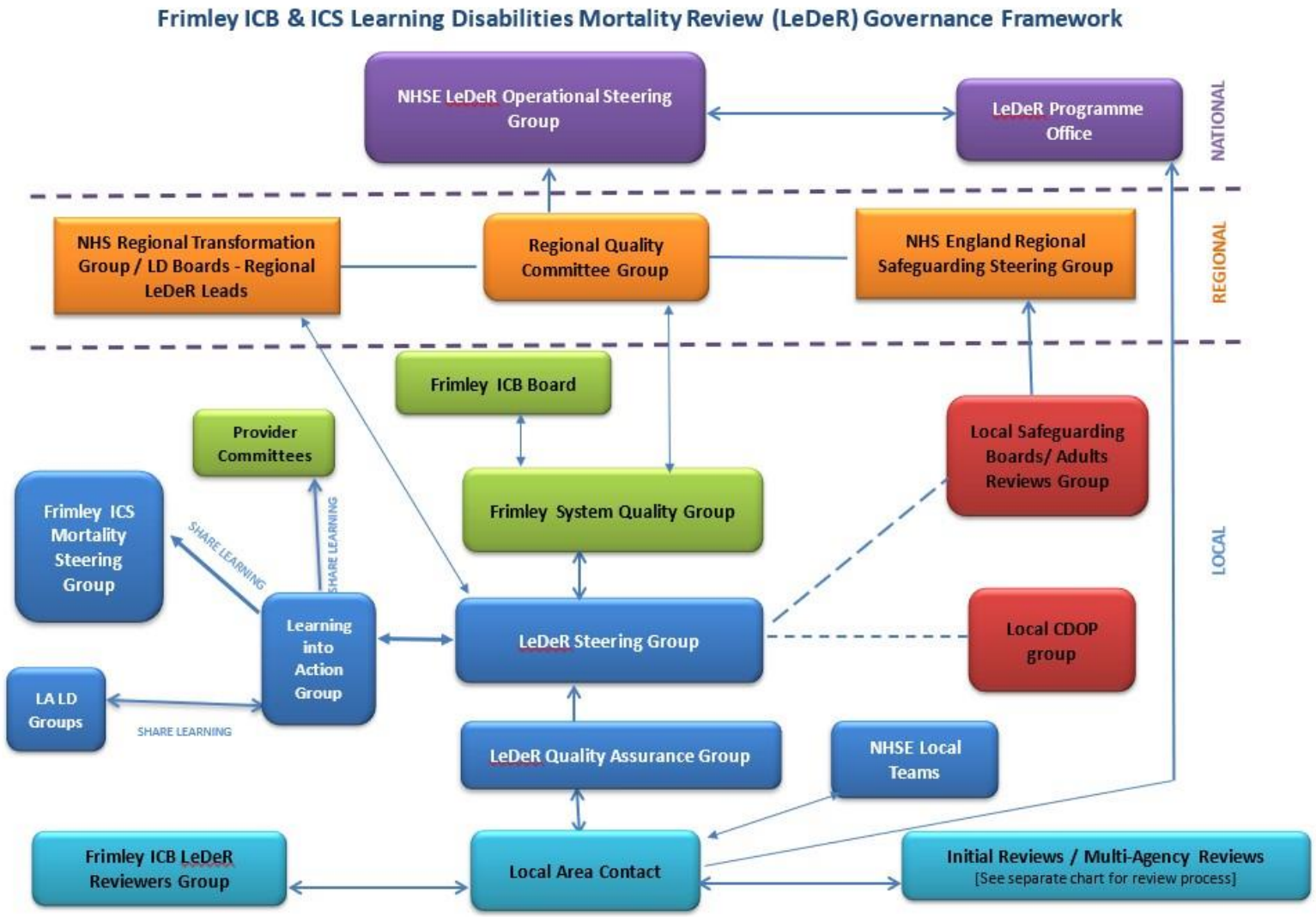
Governance Structure 2022/23



Frimley ICB Strategic Priorities 2023-2026

A new strategy was drafted in which we have identified fourteen areas we need to work on. This is what we will do over the next three years to improve health outcomes for persons with a learning disability and/or autistic people.

1. We will work to ensure that people with learning disabilities and autistic people have access to the support they require when accessing health services.
2. We will promote a ‘Rights Based Approach’ in Frimley ICS.
3. We will work to improve the continuity of care when transitioning between primary and secondary care services.
4. We will improve application of the Mental Capacity Act across our partner organisations.
5. We will promote cancer screening.
6. We will work to ensure that people with learning disabilities and autistic people receive the right medication at the right time.
7. We will improve awareness of how to manage good bowel health.
8. We will make better use of Annual Health checks.
9. We will improve the recognition and management of pain.
10. We will ensure consistent access to End-of-Life care in Frimley ICS.
11. We will ensure RESPECT and DNACPR forms are always completed comprehensively.
12. We will actively support and encourage Advance Care Planning.
13. We will meet the health needs of BAME citizens with a learning disability.
14. We will promote system learning.

Deaths of People in our ICS: Pen Portraits

These are examples taken from reviews, showing how fulfilled people's lives can be, and the problems that can then arise when they experience deterioration.

Pen Portrait 1 (ref 13616)

This gentleman was active and independently mobile. He could also feed himself and drink by himself, eating and drinking well. He had very little communication; to all intents and purposes was non-verbal. However, staff felt that he could in fact understand some communications and interacted well with them.

He liked to go for walks outside and to be around other household activities such as baking – he did not always actively participate but did like to be present and observe. He seemed to be happy and cheerful, having a good general mood except for occasional bouts of agitation when he might slap himself or push people if he wanted them out of the way or to get out of a situation which distressed him. This tended to be in the morning or when he was tired; he settled quickly with reassurance or the offer of food or drink.

He had a positive behavioural support plan in place for staff to use. He disliked blood tests, needles and clinical examinations; they distressed him and even with sedation beforehand, procedures sometimes had to be abandoned.

He had no family except for his brother, who also resided in a care home as he also had LD. He saw him monthly. Home staff visited him in hospital.

Pen Portrait 2 (ref 14516)

This lady was always bubbly and very happy – not a sad or angry person and always tried her hardest. Things did not come easy for her; in education she was the child who worked the hardest and got the least having worked her socks off. She was very determined, worked hard to get what she got. According to her sister she did not get her Learning Disability diagnosis until she was an adult. She was always on the cusp of a diagnosis and needed help to not get overlooked.

She was not good in communicating what she wanted or her feelings and disliked taking advice. If she didn't want to discuss something, she wouldn't. Sometimes she would hang the phone up if she could not explain herself with emotional issues.

She lived near her family in a council flat. She managed her own bills and owned a car. She managed everything independently and was fully aware of what was required. She was very selective when she would answer the phone. She would not entertain her family or friends at her house but would visit others as she found it easier not to have anyone in her house.

She liked athletics and in her late teens loved trampolining. She loved going out for walks with the family and eating chocolate. She didn't need anything, never wanted anything. She was happy with simple things and had very simple needs.

She found the social isolation with COVID-19 hard, and she did not cope. The isolation during the pandemic had a real impact on her.

Pen Portraits continued:

Pen Portrait 3 (ref 16095)

This lady had a severe level of learning disability and was unable to communicate verbally in any way.

Although earlier on in life she could walk, after her left tibia and fibula fractures at the end of 2015 she found walking increasingly difficult and eventually had to rely on a wheelchair for mobilisation. She also used to feed herself but during the last year or so of her life, she lost that ability and needed support for this. She did not have any teeth and was unable to tolerate dentures, so she was on a pureed diet.

In the last few months of her life, she lost weight and her physical health deteriorated significantly. The SALT team and dieticians were involved, but she would sometimes spit out snacks and refuse meals, Her food and fluid intake were monitored. Staff tried to perform oral care for her twice daily, but she did not like this; she also did not like having personal care. She especially disliked having her face washed, and staff used pictures with her to share what was going to happen next. Other strategies were being implemented following input from the community dementia team. She also sometimes stored large tablets in her mouth, so medication types were reviewed.

She enjoyed sensory activities and engaged well with them. Due to the level of her learning disability, when assessed for capacity when required, it was felt that she was unable to consent to investigations or other actions as she could not make an informed decision. She was therefore treated in her best interests, although when her preferences were known, these were considered, such as when her room was redecorated.

Pen Portrait 4 (ref 18337)

This gentleman enjoyed parties and liked to attend church but as his mobility decreased this became more difficult. His upper limb mobility also deteriorated, and he lost the use of his hands. He required all care and needed hoist transfers. He also had a PEG inserted, which was mainly used for giving medication. He liked to go to the pub and was taken in the wheelchair.

He liked to talk about Scotland where he had some relatives; he enjoyed watching football on the TV and his favourite team was Celtic. He didn't like reading but enjoyed watching TV and particularly enjoyed films. He also liked listening to music and singing .

As his speech deteriorated, he would make noises, sometimes screeching, as he could no longer express his needs clearly, although it was reported that he could use single words such as 'tele' and 'drink'.

He enjoyed weekly visits from his next of kin. He had no other regular visitors. He was friendly and liked to shake people's hand and kiss them. When he first moved into the nursing home, he liked to chat with other residents but as his speech deteriorated, he became more difficult to understand.

During the Covid lockdown, the nursing home staff noticed that he became more withdrawn as he was not able to have any visitors or to go out. Before this the manager described him as a happy man, who knew all the staff at the nursing home well.

Equality Impact

The public sector Equality Duty, part of the Equality Act (2010), requires public bodies to consider all individuals when delivering services, and that public bodies have due regard to the need to eliminate discrimination and advance equality of opportunity. The LeDeR programme seeks to support and enhance the ICB's fulfilment of this duty by identifying any areas for improvement and translating these into actions to ensure that individuals receive optimal care and treatment with proper consideration of personal circumstances and allowance made for any reasonable adjustments. Reviewers are alert to any indications that an individual's care and treatment may have been adversely affected due to protected characteristics or other factors affecting equality of provision.

Ethnicity

The table shows the ethnicity breakdown of the people whose lives and deaths we reviewed this year.

The percentage of the Frimley ICS population recorded as belonging to a minority ethnic group is c. 21% (with significant local variation; Slough being the highest at c. 55%).

The total number of cases reviewed in 2022/23 involving individuals from minority ethnic groups was 6 (17.65%). In 2021//2 it was 15%. The percentage reported for minority ethnicities was therefore lower than their representation in the general population. In future, the availability of reliable data on the ethnicity of people on LD registers will make this metric more informative.

Ethnicity	White				Mixed/Multiple ethnicity groups				Asian or Asian British				Black or Black British			Other Ethnic Groups		
	British	Irish	Traveller or Gypsy	Any other White background	White & Black Caribbean	White & Black African	White & Asian	Any other mixed background	Indian	Pakistani	Bangladeshi	Any other Asian background	Caribbean	African	Any other Black background	Chinese	Any other ethnic group	Not stated
No. of reported deaths	25	1	0	0	0	0	0	1	0	0	1	3	0	0	0	0	1	2
% of all reported deaths	74%	3%	0%	0%	0%	0%	0%	3%	0%	0%	3%	9%	0%	0%	0%	0%	3%	6%

Data Set: Performance

	Notifications No. & %		Completions No. & %		Focused Reviews (including in progress)	% of all Reviews completed within 6 months of notification:
2021/22	41	100%	24	59%	4	62%
2022/23	34	100%	35	103% ↑*	12↑	17%↓

*This includes completion of cases notified in the previous year, so the figure can exceed 100% of the number of cases notified in-year.

Performance Narrative

- The number of cases notified to the ICB in 2022/23 decreased by 7, compared to the previous year.
- The number of cases completed in 2022/3 increased by 44%, compared to 2021/22.
- The number of focused reviews increased by 67%, compared to the previous year.
- The percentage compliance for reviews completed within 6 months of notification fell by 45% in 2022/23, compared to the previous year.
- Compliance with timeliness of completion is a significant risk. This has also increased the backlog of cases awaiting allocation to a reviewer. Revisions to the governance QA and sign-off process, and recruitment of more reviewers aims to address this.

Local Reviewer Arrangements

The programme utilised the skills of four reviewers employed on bank contracts, supported by funding from NHSEI. These reviewers are experienced senior NHS clinicians who have recently retired from service and who have the time and knowledge to devote to case reviews.

Reviewers are supported by a monthly supervision group and have access to specialist advice from key people within the ICB, including Safeguarding leads and LD & Autism specialists.

Approval was granted to increase the bank of reviewers to six, and recruitment proceeded after the end of the financial year. The full complement of reviewers will be in post by September 2023.

Data Set: Demographics (from local data)

Gender

Analysis shows that an equal number of male and female cases were reported. However, there were an additional two cases involving people who were male at birth but identified as female. For comparison, the male / female composition of the Frimley ICS general population according to GP registrations is 407,000 male and 405,000 female – roughly a 50/50 split. (These figures do not account for people who identify as non-binary, a subset not currently shown in the available data.)

	2021/22		2022/23*	
	Male	Female	Male	Female
No.	26	15	16	16
%	63%	37%	50%	50%

*A further 2 people were male by birth but identified as female. These reviews have not yet been completed.

Level of Learning Disability(if known)

The information below shows the breakdown of this information for all of the people whose reviews were completed and signed-off in 2022/23, and for whom the level of learning disability had been recorded.

Level of Learning Disability	2021/22	2023/24
Mild	7	6
Mild- Moderate*	1	3
Moderate	6	14
Moderate- Severe*	1	1
Severe	8	6
Profound/Multiple	0	2
Unknown	1	3

*Level of learning disability varied between two categories in documentation provided so an in-between classification has been added.

Data Set: Demographics, Age(local data)

All Adults with learning disabilities / autistic notified in 2022-2023:

- There was a total of 34 deaths
- The range of age at death was 18 – 85
- The average age of death was 58 (cf. 64 in 2021/2)

Women with learning disabilities / autistic women notified in 2022-2023:

- There was a total of 15 deaths
- The range of age at death was 24 – 85
- The average age of death was 59 (cf. 62 in 2021/2)
- Female life expectancy in the general population of Frimley ICS is 84 years

Men with learning disabilities / autistic men notified in 2022-2023*:

- There was a total of 15 deaths
- The range of age at death was 18 - 79
- The average age of death was 60 (cf. 68 in 2021/2)
- Male life expectancy in the general population of Frimley ICS is 81 years

*A further 2 people were male by birth but identified as female. These reviews have not yet been completed.

Children with learning disabilities / autistic children notified in 2022/2023:

- There was a total of 2 deaths notified (cf. 10 in 2021/2).
- Age data is redacted due to low numbers

Data Set: Cause of Death.

Cause of Death – Completed Cases

The most common cause of death this year, as with the previous year, was pneumonia (sub-types listed below). The number of deaths from pneumonia was 15 which is 43% of all completed cases for 2022/23. The table below shows the top primary and secondary causes of death for cases completed in 2022/23.

No	Primary Cause of Death (1a)	No	Secondary Cause of Death (1b, 1c)
1	**Pneumonia - 15 cases** Comprising: • Aspiration Pneumonia – 4 • Pneumonia – 3 • COVID Pneumonia – 2 • Bilateral Pneumonia – 1 • Bronchopneumonia – 2 • Suspected Bronchopneumonia and Aortic Stenosis – 1 • Hospital Acquired Pneumonia – 1 • Community Acquired Pneumonia - 1	1	**1 case each (1b):** • Cerebral palsy • Chronic Kidney Disease • Complete Heart Block • Diabetes Mellitus • Gastric Perforation • Heart Failure • Hiatus Hernia • Historic brain injury with epilepsy • Hypertrophic cardiomyopathy with Fredrich ataxia • Large Volume Pericardial Effusion • Metastatic Lung-Non-Small Cell Carcinoma • Oesophageal Dilatation • Oropharyngeal Dysphagia • Perforation of ascending colon • Pneumonia (including bilateral) • Streptococcal Pneumoniae Infection • Traumatic subdural haematoma • Urinary Tract Infection
2	**1 case each:** • Acute cardiorespiratory failure • Cancer – Metastatic Adenocarcinoma • Cardiac Tamponade • Disease Progression - Autosomal Recessive Hypomyelinating Leukodystrophy Type 10 • Drowning • End Stage Dementia • Faecal Peritonitis • Frailty of old age • Hanging • Ischaemic Heart Disease • Lactic Acidosis • Mitochondrial Metabolic disorder • Multi organ failure • Peritonitis • Pulmonary Oedema • Sepsis • Severe cardiac failure • Sudden Unexpected Death in Epilepsy • Suspected heart attack • Upper Respiratory Tract Infection		**1 case each (1c):** • Colonic Neuropathic Dysmotility, Cerebral Palsy • End stage liver cirrhosis • Hypothyroidism, Obesity • Large Volume Pericardial Effusion • Pearsons (mitochondrial disease) • Perinephric abscess • Arterial Hypertension • Type 2 Diabetes • Upper gastrointestinal tract haemorrhage

DNACPR – Do not attempt cardio-pulmonary resuscitation

A DNACPR decision is designed to protect people from unnecessary suffering by receiving CPR that they don't want, that won't work or where the harm to them outweighs the benefits

The DNACPR decision-making process should always take account of the benefits, risks and burdens of CPR and consider the individual person's wishes and preferences, the views of the healthcare team and, when appropriate, those close to the person.
Hospital trusts and other providers are legally obliged to have a clear DNACPR policy for staff to follow. It must be accessible so that patients and/or their families are able to understand the decision-making process.

Over the past two years, we have seen some improvement in the consistency of appropriate application of DNACPR. However, some cases have raised questions about the timing of the measure being put into place (usually whether it could have been considered sooner). We have not seen any cases where resuscitation was attempted contrary to DNACPR instructions. Some cases have shown a lack of properly documented evidence of timely and appropriate formal assessment of mental capacity.

Data Set: Cause of Death.

Annual Health Checks (AHCs)

A theme that has emerged in our LeDeR reviews since the inception of the programme is a lack of consistency in completion of annual health checks (AHCs) in primary care.
In some cases, the lack of a formally documented AHC was offset by other evidence showing a good standard of GP knowledge, involvement and support for the patient. In other cases, lack of evidence of an AHC carried out in the past year pointed towards missed opportunities for an holistic appraisal of the individual's state of health, any recent changes in their condition, and a chance to co-ordinate support and interventions across multiple disciplines and agencies.

In a time when, for the general patient population, getting to see a single named GP consistently is not operationally feasible, these findings underline the importance of ensuring that this does happen for people with learning disabilities. This gives consistency of care and treatment and an intimate knowledge of the person's circumstances by a named GP who will be more likely to be able, with the help of carers and those who know the individual well, to spot subtle changes in condition or behaviour that may point towards something clinically significant.

This was an area in which we wanted to drive improvement in 2022/3. In 2022/23, the ICB prioritised support and monitoring of GP AHCs and (as shown in the next slide) the ICB has exceeded the national target for the percentage completed over the past year. Community Teams for People with Learning Disabilities have also worked closely with GPs to improve the accuracy of GP LD registers and AHC uptake.

To further support this work, the LeDeR Learning into Action (LiA) Group organised an audit of the quality (not just the number) of AHCs. This is discussed later in the report.

Role of cancer screening

Another key area in which we need to ensure equality and consistency of uptake is cancer screening for people with learning disabilities. Our reviews in the past year continued to highlight that consistency is yet to be achieved. In some cases, there was an absence of clear evidence that age-appropriate screening had been carried out, and a lack of clearly documented rationale to indicate why screening may not have been undertaken for an individual.

The LeDeR LiA group identified increasing cancer screening uptake as one of its key priorities last year, and this continues to be priority heading into 2023/4. The group has analysing uptake data and disseminated resources to promote screening among healthcare professionals, carers and people with LD. This included easy-read and video resources for patients and carers. The group is exploring further options to drive increased uptake among people with LD.

IMPACT(some quotes from families/carers)

"His care package did not meet his needs for some time. The assisted living environment was not appropriate."

After he moved to a new setting, the family had "nothing but praise for the care home". (Ref 14957)

"We feel that generally he was well supported during his lifetime; thankfully, the care he received from his teens to the onset of health issues in later life could not be faulted, mainly due to the dedicated staff and the care providers.

However, "There is so much that could be said, about the care he received in the last two years of his life…the problem appears to have been with recruiting of staff and the present care provider."
(Ref 16192)

Action from Learning:
Examples of best practice and positive outcomes from the reviews

The patient's mother was identified by his GP as being very anxious about his health, and so arranged for longer appointments so that her fears could be allayed.

This gentleman was unable to take tablets easily, so these were provided in dispersible form. He also got very travel-sick, so his GP would prescribe dispersible anti-emetics prior to a trip abroad.

The GP and carers arranged for a numbing cream to be used prior to blood tests to alleviate anxiety and any pain for the patient.

This lady received excellent support from the Community Team for People with LD (CTPLD). An example was the support they gave her in preparation for eye surgery when treatment was delayed and helping with her anxiety about the procedure.

A CD player/radio was sourced by the LD liaison nurse for him to listen to in hospital. His sister was pleased about this.

The Intensive Treatment Unit (ITU) was fantastic, with hair washes, massages, lotions, taking her outside to have fresh air, and her family were given rooms so they could stay.

Action from Learning: Examples of specific areas for improvement identified by reviews

Medication alternatives were not considered when a patient was not able to tolerate their current medication. **If a drug is discontinued for no other reason than that the patient cannot tolerate it, another, more tolerable medication should be considered**

MCA/ DNACPR Documentation: While there was evidence that a discussion occurred with family, no formal documentation was found around mental capacity or DNACPR. **On-going training and awareness of Mental Capacity Assessment and Best Interest within provider organisation.**

Reasonable adjustments for clinical procedures: No other method than sedation was tried to take bloods or give immunisations. **Staff need to consider a range of options when procedures are problematic and to seek expert advice if necessary.**

Hospital Passport not in place: These passports can be of great use in enabling hospital staff to understand not only the baseline health but also preferences and behaviours. **GPs, carers and CTPLDs should ensure all patients with LD have Hospital Passports.**

Miscommunication between hospital and CTPLD: Hospital contacted wrong organisation. **Acute LD nursing team to ensure they contact relevant CTPLD teams when funding is from out of area.**

Ceilings of Care: No ceiling of care implemented on admission. **Learning identified and accepted by the hospital provider who undertook to reinforce best practice.**

Action from Learning: Examples of thematic areas for improvement identified by reviews

Cancer Screening Uptake:
LeDeR reviews show variable uptake of bowel, breast and cervical screening. The ICB has developed a data pack showing the variations and the LiA Group has disseminated promotional materials / resources in the system. Further work is planned for 2023/4.

Annual Health Checks:
With completion rates having improved, there was a need to audit the quality of AHCs. An initial phase of auditing has been carried out and learning sessions for GPs held by the GP LD Lead. Re-audits are planned for Autumn 2023.

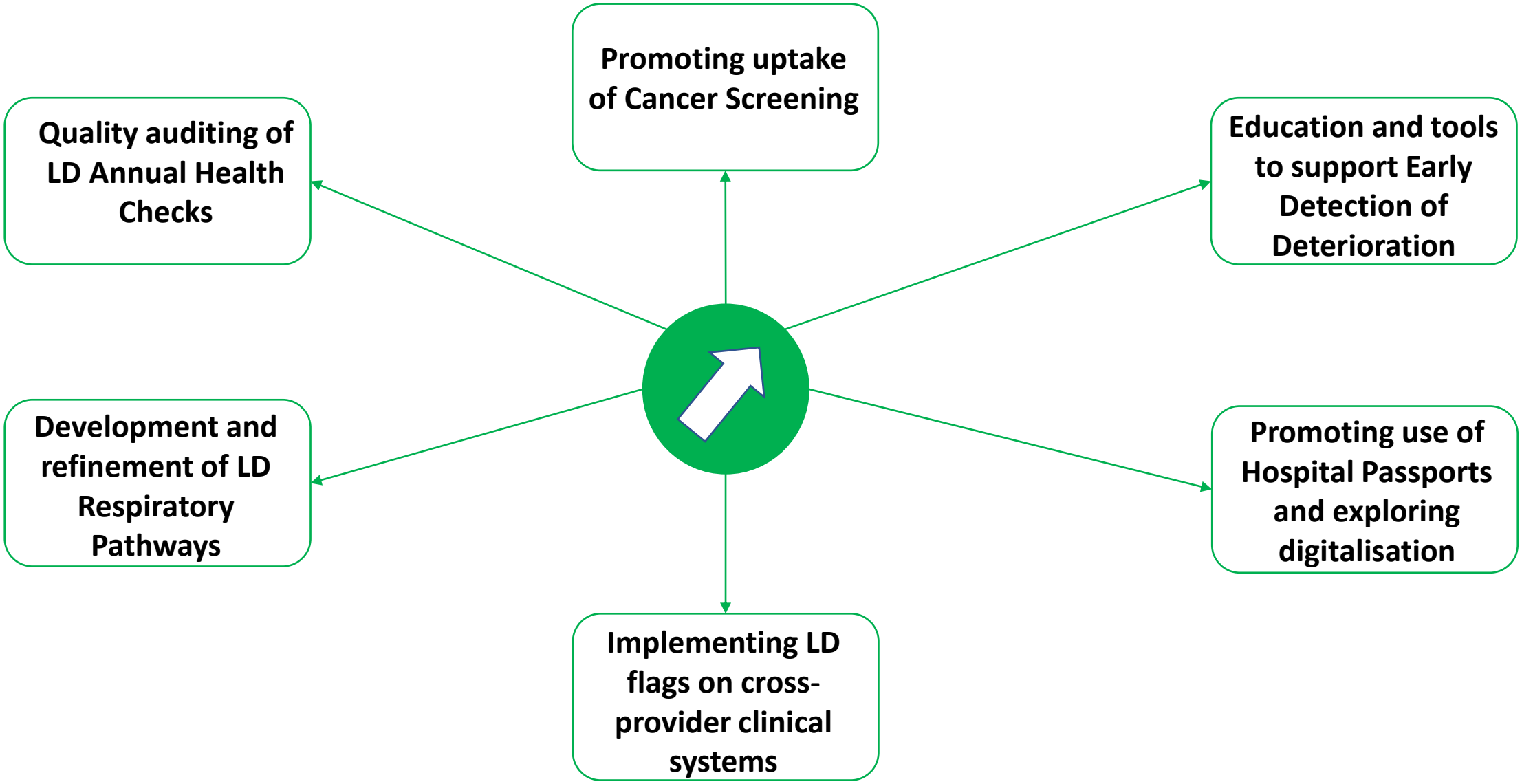
Early Detection of Deterioration:
LeDeR cases have shown that continued work is needed to ensure early detection of deterioration both in the community and in hospital settings. The LiA Group has explored pain recognition tools and digital / remote support.

Respiratory Illness:
Data show respiratory conditions to be a leading cause of death. National and regional work is progressing on LD respiratory pathways with clinical involvement at system / provider level.

Discharge and Funding Issues:
Some cases have shown delays in assessments and funding decisions where people are being discharged and require a higher level of residential care. Applications for CHC funding need to be expedited.

LD Flags on Clinical Systems:
Cross-provider flagging of LD status on clinical records will assist visibility of a person's status and need for reasonable adjustments. Progress has been made on this with care homes.

Action from Learning: Local Priorities 2022-2023



Action from Learning:
The evidence base for local priorities in 2022-2023

The three main priorities for the Learning into Action Group are set out below, along with summaries of the supporting rationale and evidence.

1. Annual Health Checks (AHCs)

Evidence suggests that providing health checks to people with learning disabilities in primary care is effective in identifying previously unrecognised health needs, including those associated with life-threatening illnesses. Ref: Annual health checks and people with learning disabilities - GOV.UK (www.gov.uk). Public Health England's Learning Disabilities Observatory has published a systematic review of evidence concerning the impact of health checks on the health and wellbeing of people with learning disabilities. The ICB has successfully promoted an increase in completion of AHCs, and in 2022-3 the national target was exceeded. We also inaugurated a quality audit, with the findings used to inform learning webinars for GPs. The audit is scheduled to be repeated in 2023-4.

2. Cancer Screening

Given that life expectancy for people with a Learning Disability is significantly lower than for the general population, the early detection of life-threatening conditions such as cancer is of vital importance. Ref: Cancer screening: making reasonable adjustments - GOV.UK (www.gov.uk). Some LeDeR cases have found ambiguity around why an individual has not had their screening; an absence of evidence of mental capacity being assessed, relevant best interest decisions documented, or support for individuals and carers to access screening. ICB-level data show lower levels of uptake for people with LD. It is therefore important that we focus on promotion of these checks and support for individuals and carers to access screening, and for clinicians to have the tools to educate and inform people on their importance. This links with the Annual Health Check work described above, as AHCs provide an opportunity to check on screening status, alongside other key issues such as medication concordance, and vaccination status. We have developed a data-pack to monitor uptake in comparison to the general population, and promotional / guidance materials have been disseminated within the system. An information pack for patients / families / carers is being developed, and we are promoting links between GPs and the Southern Bowel Screening Hub.

3. Early Detection of Deterioration

LeDeR cases have shown the importance of swift recognition of deterioration, particularly in community / residential settings where 'soft signs' of deterioration may go unnoticed. The University of Bristol has published a paper on the importance of early detection of deterioration in people with LD – ref: RecognisingDeteriorationLiABulletinFINAL.pdf (bristol.ac.uk). Frimley ICS has supported early detection of deterioration with training and education for LD care homes, including use of the Restore2 and Restore Mini tools. A review of pain recognition tools was also undertaken, and further work on this is being scoped.

Action from Learning: Further Updates on LiA Work

Over the past year, GPs in Frimley ICS have made great strides in increasing the number of Annual Health Checks and Health Action Plans completed. We also need to focus on the quality of these checks. A quality audit was conducted earlier this year and the findings showed that we can improve on:

- **The use of accessible information and invites in line with the Equality Act 2010 and Accessible Information Standard.**
- **Effective and consistent use of hospital passports.**
- **Consistent application and recording of reasonable adjustments in line with the Equality Act 2010.**
- **Robust and consistent use of Health Action Plans.**
- **STOMP / STAMP (medication monitoring) considerations for every patient.**
- **Promotion of national screening programmes and making reasonable adjustments to ensure fair access.**
- **Application of the Mental Capacity Act.**

Our GP Lead for Learning Disabilities carried out quality auditing earlier this year and has delivered webinars for Primary Care, and more are planned.

Action from Learning: Further Updates on LiA Work

East Berkshire Keyworker Service commissioned: To be provided by Barnardo's and to commence from 1st June. First year will focus on people up to the age of 25 on the Dynamic Support Register, then year 2 will have a broader scope.

Dynamic Support Register (DSR): The ICB LDA team are working on the Dynamic Support Register to make it more meaningful, accessible and inclusive.

Reasonable Adjustment Digital Flag (RAF) Project: The Frimley project is focused on care homes in East Berkshire and residents now have started having reasonable adjustments on their summary care records. LD Liaison Nurses have been putting RAFs on records during register checks.

LD Care Homes ICB Support Work:

- Respect training level 1 and 2 is now complete, with a good turnout–data being compiled to draw out attendance from LD homes.
- Running symptom managements sessions on agitation, pain, breathlessness and nausea and vomiting – feedback has been positive.
- Advance care planning session for LD homes in April.
- Restore2 training is available virtually.
- Funding secured to put on SaLT training sessions (swallowing safety and assessment).

Action from Learning : LD Annual Health Checks (AHCs) – Performance 2022/23

Evidence suggests that providing annual health checks to people with learning disabilities in primary care is effective in identifying previously unrecognised health needs, including those associated with life-threatening illnesses.
Annual health checks and people with learning disabilities - GOV.UK (www.gov.uk).

Public Health England's Learning Disabilities Observatory has published a systematic review of evidence concerning the impact of health checks on the health and wellbeing of people with learning disabilities.

In 2022/3 NHS Frimley strongly promoted the uptake and completion of AHCs and was successful in surpassing the 75% target. Frimley was ranked 4th in the country and best in the region.

Mar 23	Total Register (age 14+)	Completed Health Checks (age 14+)	% Completed Health Checks	Ranking in England out of 42 ICBs
England	310,570	242,641	78.1%	-
SE Region	45,981	35,526	77.3%	-
Frimley ICB	**3,101**	**2,657**	**85.7%**	**4th**

And Highest Ranking in SE Region

Action from Learning: Evaluating the Impact

What is in place to monitor and review action plans /service improvements to ensure that they are implemented and effective in improving care, reducing inequalities & saving lives:

Frimley ICB has a LeDeR Steering Group which brings together all of the involved providers and agencies to review the learning from cases and disseminate among their staff. The group also receives updated on strategies and improvement plans from providers. We also have a 'Learning into Action Group', with clinical / operational lead membership, to work on translating learning into action across the system. This group works together with the wider LD and Autism commissioning programme, feeding back into the LeDeR steering group and the relevant commissioning / pathway groups.

How we will evidence that service improvements are making a difference to people with a learning disability and their families:

There are some key metrics used to evaluate improvements in areas such as GP annual health checks and cancer screening uptake. A new dashboard has been developed by the Analytics Team, which is routinely scrutinised by the LD+A Transformation Programme Board; this enables us to keep track of key metrics and compare them to equivalent data for the general population. Our quality audit of Annual Health Checks has, alongside the successful drive to increase the percentage of checks completed, provided evidence of how well these checks are being completed. Learning from these audits is being delivered in GP training sessions to drive improvement, and repeat auditing is planned for Autumn 2023. Improving the quality of AHCs is also aimed at giving more opportunities for the voices of people with LD, autistic people and their carers to be heard in relation to their experience of services. We have an expert-by-experience on our Steering Group to offer challenge and service-user insights.

Our new strategy sets out our 3-year aims and commitments with which we are aligning our improvement work. In terms of evaluations, we hope to see the improvement work reflected in the positive movement of key metrics and audit outcomes, and to find through LeDeR reviews evidence of more consistent practice in relation to effective AHCs, screening uptake, and early detection of deterioration, alongside other important elements such as effective management of respiratory and bowel conditions.