



Meeting: **Health Overview and Scrutiny Committee**

Date/Time: **Wednesday, 17 January 2024 at 2.00 pm**

Location: **Sparkenhoe Committee Room, County Hall, Glenfield**

Contact: **Mr. E. Walters (0116 3052583)**

Email: **Euan.Walters@leics.gov.uk**

Membership

Mr. J. Morgan CC (Chairman)

Mr. M. H. Charlesworth CC Ms. Betty Newton CC
Mr. D. Harrison CC Mr. T. J. Pendleton CC
Mr. R. Hills CC Mrs B. Seaton CC

Please note: this meeting will be filmed for live or subsequent broadcast via You Tube at <https://www.youtube.com/@committeemeetingsatleicest9269/playlists>

<u>Item</u>	<u>Report by</u>
1. Minutes of the meeting held on 1 November 2023.	(Pages 5 - 14)
2. Question Time.	
3. Questions asked by members under Standing Order 7(3) and 7(5).	
4. To advise of any other items which the Chairman has decided to take as urgent elsewhere on the agenda.	
5. Declarations of interest in respect of items on the agenda.	
6. Declarations of the Party Whip in accordance with Overview and Scrutiny Procedure Rule 16.	
7. Presentation of Petitions under Standing Order 35.	



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|-----|---|--|-----------------|
| 8. | Public Health Medium Term Financial Strategy 2024/25 to 2027/28. | Director of Public Health and
Director of
Corporate
Resources | (Pages 15 - 26) |
| 9. | Vaping and Young People. | Director of Public Health | (Pages 27 - 32) |
| 10. | LLR LeDeR Annual Report 2022/23. | Leicestershire
Partnership NHS
Trust | (Pages 33 - 88) |
| 11. | Noting the work programme of the Leicester, Leicestershire and Rutland Joint Health Scrutiny Committee. | | (Pages 89 - 90) |
| 12. | Date of next meeting. | | |

The next meeting of the Committee is scheduled to take place on Wednesday 6 March 2024 at 2.00pm.

13. Any other items which the Chairman has decided to take as urgent.

QUESTIONING BY MEMBERS OF OVERVIEW AND SCRUTINY

The ability to ask good, pertinent questions lies at the heart of successful and effective scrutiny. To support members with this, a range of resources, including guides to questioning, are available via the Centre for Governance and Scrutiny website www.cfgs.org.uk. The following questions have been agreed by Scrutiny members as a good starting point for developing questions:

- Who was consulted and what were they consulted on? What is the process for and quality of the consultation?
- How have the voices of local people and frontline staff been heard?
- What does success look like?
- What is the history of the service and what will be different this time?
- What happens once the money is spent?
- If the service model is changing, has the previous service model been evaluated?
- What evaluation arrangements are in place – will there be an annual review?

Members are reminded that, to ensure questioning during meetings remains appropriately focused that:

- (a) they can use the officer contact details at the bottom of each report to ask questions of clarification or raise any related patch issues which might not be best addressed through the formal meeting;
- (b) they must speak only as a County Councillor and not on behalf of any other local authority when considering matters which also affect district or parish/town councils (see Articles 2.03(b) of the Council's Constitution).



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Minutes of a meeting of the Health Overview and Scrutiny Committee held at County Hall, Glenfield on Wednesday, 1 November 2023.

PRESENT

Mrs B. Seaton CC (in the Chair)

Mr. R. G. Allen CC

Mr. D. Harrison CC

Mr. M. H. Charlesworth CC

Mr. J. Miah CC

Mrs. H. J. Fryer CC

Mr. T. J. Pendleton CC

In attendance

Mrs. L. Richardson – Cabinet Lead Member for Health and Wellbeing

Mrs. C.M. Radford CC – Cabinet Lead Member for Adults and Communities (item 33 refers)

Jon Melbourne, Chief Operating Officer, University Hospitals of Leicester NHS Trust (item 32 refers)

Kay Darby, Deputy Director, Vaccination Programme (item 32 refers).

Rachna Vyas, Chief Operating Officer, NHS Leicester, Leicestershire & Rutland (item 32 refers).

Hanif Moti, Local Dental Committee (item 34 refers).

Sarah May, Local Dental Committee (item 34 refers).

Ket Chudasama, Deputy Chief Strategy and Planning Officer, Integrated Care Board (item 34 refers).

Dianne Wells, Senior Commissioning Manager, Pharmacy, Optometry and Dental.

Liz Gundel, Deputy Head of Primary Care – East Midlands Primary Care.

25. Minutes of the previous meeting.

The minutes of the meeting held on 13 September 2023 were taken as read, confirmed and signed.

26. Question Time.

The Chief Executive reported that no questions had been received under Standing Order 34.

27. Questions asked by members.

The Chief Executive reported that no questions had been received under Standing Order 7(3) and 7(5).

28. Urgent items.

There were no urgent items for consideration.

29. Declarations of interest.

The Chairman invited members who wished to do so to declare any interest in respect of items on the agenda for the meeting.

Mr. D. Harrison CC and Mr. R. Allen CC declared non-registerable interests in Agenda item 9: Outcome of consultation on the Leicester, Leicestershire and Rutland Joint Living Well With Dementia Strategy 2024-28 as they both had close relatives that suffered from dementia.

30. Declarations of the Party Whip.

There were no declarations of the party whip in accordance with Overview and Scrutiny Procedure Rule 16.

31. Presentation of Petitions.

The Chief Executive reported that no petitions had been received under Standing Order 35.

32. Winter Plan 2023/24.

The Committee considered a report of University Hospitals of Leicester NHS Trust (UHL) which summarised planning to manage winter pressures across Leicester, Leicestershire and Rutland (LLR) in 2023/ 2024 and provided an update on the Covid-19 and flu vaccination programme for the eligible population. A copy of the report, marked 'Agenda Item 8', is filed with these minutes.

The Committee welcomed to the meeting for this item Jon Melbourne, Chief Operating Officer, University Hospitals of Leicester NHS Trust, Kay Darby, Deputy Director, Vaccination Programme, and Rachna Vyas, Chief Operating Officer, NHS Leicester, Leicestershire & Rutland.

Arising from discussions the following points were noted:

- (i) Members welcomed the ambitions set out in the winter plan but stated that more detail should have been provided on the actions that would be put in place to achieve the goals. In particular members requested more data and evidence to help reassure them that targets would be reached. In response it was clarified that there were other documents held by UHL which had not been provided to the Committee that provided the further detail, actions and timescales. Future reports to the Committee on winter pressures would contain the further information requested.
- (ii) Ambulance handover times at Leicester Royal Infirmary Emergency Department had improved significantly since 2022.
- (iii) There had been a significant increase in the workforce for handling 999 and 111 telephone calls for the East Midlands area. Capacity in Primary Care had also been expanded.
- (iv) The discharge from hospital process was critical to flow through the hospital. Reassurance was given that there was close working taking place between UHL and the Adults and Communities Department at Leicestershire County Council

regarding discharge and social care. The NHS had agreed to fund additional capacity in social care. Social care staff were working on wards assessing people for discharge. People receiving home care were also being reviewed to help improve the flow.

- (v) The County Council was implementing a new intake service which would mean that every patient discharged from hospital into social care would be referred into the reablement service before receiving any other social care service. This would ensure that the patient's needs were properly assessed before further care was commissioned. The aim was that this would be implemented over winter 2023/24.
- (vi) Members welcomed the use of virtual wards which allowed people to be safely monitored from the comfort of their own home. It was planned to have 236 virtual beds in total by the end of autumn 2023.
- (vii) Recruitment at UHL was progressing better than planned and the number of vacancies was reducing. A member asked how UHL's financial situation would be affected should all the vacancies be filled. In response it was explained that the financial impact was not entirely clear but regardless UHL would continue to try and fill all the vacancies. UHL wanted substantive staff in post who would remain with the Trust for the long term.
- (viii) Part of the Winter Plan was to expand new services in the community, as up to 20% of emergency admissions could be avoided with the right care in place. There had been progress so far with a significant increase in people treated in the community. Currently 94% of patients were able to access urgent community response within 2 hours.
- (ix) Members welcomed the improvement in the length of waiting lists for elective care procedures.
- (x) Covid-19 vaccination uptake was 43% across LLR and 46% in Leicestershire. The Covid vaccination campaign would continue until 18th December with a strong equalities plan to drive uptake. Flu vaccination uptake was increasing and stood at 39% for LLR overall and 55% in Leicestershire. The flu campaign would continue until the end of March 2024.

RESOLVED:

- (a) That the update on planning to manage winter pressures across LLR in 2023/ 2024 and the Covid-19 and flu vaccination programme be noted;
- (b) That officers be invited to provide a further report to the Committee on winter pressures in advance of the 2024/25 winter.

33. Outcome of consultation on the Leicester, Leicestershire and Rutland Joint Living Well With Dementia Strategy 2024-28.

The Committee considered a joint report of the Directors of Adults and Communities and Public Health which presented the outcome of the consultation on the draft Leicester, Leicestershire and Rutland (LLR) Joint Living Well with Dementia Strategy 2024-28 following a formal consultation exercise. A copy of the report, marked 'Agenda Item 9', is filed with these minutes.

The Committee welcomed to the meeting for this item Mrs. C.M. Radford CC – Cabinet Lead Member for Adults and Communities.

Arising from discussions the following points were noted:

- (i) Diagnosis rates for dementia had reduced substantially as a result of services closing due to the pandemic. Members noted the barriers to improving diagnosis rates including a reluctance on the part of individuals to get tested which needed to be overcome. Members welcomed the action which was being undertaken to encourage people to come forward for a diagnosis.
- (ii) It was usually friends or relatives of dementia sufferers that spotted the signs of dementia first rather than the sufferer themselves and the Committee questioned whether there was sufficient awareness in communities of the signs that somebody might be suffering from dementia. Members raised particular concerns about those people living alone where the signs were less likely to be spotted. Adverts relating to dementia often featured couples and more needed to be done to reach out to those people that lived alone. Concerns were raised that where groups and activities were put on in communities to target dementia sufferers, single people would be reluctant to attend those events by themselves. A further reason for targeting those people that lived alone was that the speed that dementia developed was impacted by social isolation and a lack of mental stimulation.
- (iii) The dementia work was being carried out partnership approach through the LLR Dementia Programme Board with LLR councils, the ICB, Leicestershire Partnership NHS Trust (LPT), University Hospitals of Leicester (UHL), the voluntary sector and other allied professionals all part of the partnership. Each organisation involved had its own Action Plan which the Board would hold them to account for.
- (iv) Two thirds of people with dementia were women. It was suggested that the reason for this was that women lived longer or it could be that they were more willing to come forward for diagnosis. The issue would be tackled in LLR as part of the delivery plan for the Dementia Strategy.
- (v) Members were disappointed that Admiral Nurse provision in the county had ceased earlier in 2023 and praised the support that Admiral Nurses provided to people suffering from dementia and their families. In response it was clarified that the Admiral Nurse service was not commissioned by the County Council and had been discontinued by Primary Care Networks when Voluntary, Community Social Enterprise funding was removed. The Committee noted that Healthwatch was campaigning for Admiral Nurses to be re-instated in Leicestershire and members supported this campaign.

RESOLVED:

- (a) That the draft Leicester, Leicestershire and Rutland Joint Living Well with Dementia Strategy 2024-28 be supported and recommended it to Cabinet.
- (b) That the comments now made be submitted to the Cabinet for consideration at its meeting on 24 November 2023.

34. Intermediate Minor Oral Surgery

The Committee considered two reports; one from the Local Dental Committee (LDC) which raised concerns about the discontinued procurement process for Intermediate Minor Oral Surgery (IMOS) in Leicestershire, and one from the Integrated Care Board which responded to those concerns. Copies of the two reports, marked 'Agenda Item 10', are filed with these minutes.

The Committee welcomed to the meeting for this item Hanif Moti and Sarah May from the Local Dental Committee, Ket Chudasama, Deputy Chief Strategy and Planning Officer, Integrated Care Board, Dianne Wells, Senior Commissioning Manager, Pharmacy, Optometry and Dental, and Liz Gundel, Deputy Head of Primary Care – East Midlands Primary Care Team.

In presenting the Local Dental Committee report Hanif Moti emphasised the following points:

- (i) With regards to the engagement and consultation process that was undertaken to seek views and feedback from patients, public, dental profession and key stakeholders, the Local Dental Committee felt that the number of responses received was insufficient. Although 5,000 patients across the East Midlands who had received treatment under the IMOS pathway were contacted to complete the online engagement survey only 20 patients responded. There were only 29 responses from the public and 17 responses from dental professionals. Hanif Moti submitted that the consultation process was flawed and it should not have been possible to draw any meaningful conclusions from it.
- (ii) There were currently 10 oral surgery sites in Leicester, Leicestershire and Rutland but in the future there would only be four and patients would be expected to travel to the sites which was unreasonable for those suffering from dental pain etc.
- (iii) Currently providers were paid £174 for a typical case, a fee which had remained unchanged since 2012. This would be reduced to £141.42 under the new contracts. The fee was already lower than other areas of the country and the reduction would make the payment even less competitive.
- (iv) In the view of the Local Dental Committee the only problem with the current service was the lack of sedation facilities at the sites in Leicestershire.
- (v) In summary Hanif Moti submitted that the whole process needed reconsideration before the procurement process took place.

Arising from discussions the following points were noted:

- (i) Members expressed concerns that not one bidder in Leicestershire had been successful under the procurement process and questioned whether the process and the relevant documents were too complicated. In response reassurance was given that lessons had been learnt from the first procurement exercise and would be incorporated into the re-procurement process. The documentation would be reviewed and revised. The people writing the bids were clinical experts not procurement experts therefore they required help. Engagement and education events were taking place to support contractors to enable their bids to be more successful.

- (ii) No dates had been set for when the re-procurement would take place and it would not be within the next month.
- (iii) Most of the services were previously delivered in the Leicestershire east area though it was questioned whether this was just where dentists referred patients to or whether it was where patients actually wanted to go.
- (iv) Members shared the concerns of the Local Dental Committee regarding the remuneration for the service.
- (v) A member questioned whether any of the current providers had bid under the 2022/23 procurement process and noted that if they did and were not successful this raised questions about whether the current service was adequate. In response reassurance was given that there were no clinical concerns about the current service.

RESOLVED:

- (i) That the concerns raised by the Local Dental Committee and the responses from the Integrated Care Board to those concerns be noted;
- (ii) That the Integrated Care Board be requested to provide a further report to a future meeting of the Committee regarding the re-procurement process.

35. Review of Homeless Support Service.

The Committee considered a report of the Director of Public Health which informed of the outcome of the consultation on the proposed delivery model for homeless support and presented the recommendation that Cabinet would be asked to approve. A copy of the report, marked 'Agenda Item 11', is filed with these minutes.

Arising from discussions the following points were noted:

- (i) The proposal was to cease funding a dedicated homeless support service, and instead to provide support via the Council's existing public health services where eligibility was wider. The driver behind the change in model was not just budgetary pressures. The current contract was due to end in March 2024 and therefore the provision would have required reviewing regardless of any requirements of the Medium Term Financial Strategy. The new model would support many more people than were currently supported through the Falcon Centre. The Committee welcomed this approach and was of the view that the use of First Contact Plus had the potential to achieve far more holistic outcomes.
- (ii) The existing model was not designed for individuals who had more complex health needs. The staff were not trained to deliver more complex support (it had been intended that those individuals would receive that support from the NHS).
- (iii) In response to a question from a member, it was clarified that under the proposed model people that were already homeless or rough sleeping would be dealt with by the District Council Rough Sleeping Initiative. Should a person have both a housing and a health problem they would be dealt with by the relevant District Council

housing team for the housing need and then referred onto First Contact Plus who would carry out a triage process and ascertain what type of health and wellbeing support the individual needed.

- (iv) The Committee welcomed the format of the consultation that had taken place and the number of responses that had been received.
- (v) The review of homeless support services would result in a saving of £300,000 by 1 April 2024. In response to a concern raised by a member that the £300,000 saving could be negated by an increase in demand for the service, it was explained that Covid-19 funding had been used to increase capacity in the First Contact Plus team and Local Area Co-ordinators in Leicestershire and therefore there was confidence that the demand could be managed.

RESOLVED:

- (a) That the outcome of the consultation on the proposed delivery model for homeless support be noted;
- (b) That the proposed new model for homeless support be supported.

36. Whole School Approach to Food and Nutrition.

The Committee considered a report of the Director of Public Health which sought views of the Committee on 'Whole School Approach to Food and Nutrition' (WSAF&N), known to schools as the Food for Life (FFL) programme, as part of engagement on a new offer. A copy of the report, marked 'Agenda Item 12', is filed with these minutes.

Arising from discussions the following points were noted:

- (i) Members recognised the financial pressures Public Health was facing and that the County Council's Medium-Term Financial Strategy 2023/24 – 2026/27 included a target of saving £150,000 by 2024/25 through a review of the WSAF&N programme.
- (ii) Feedback had been received from schools as part of the engagement. Whilst the feedback was generally understanding of the changes, some schools had concerns about the loss of staff support under the new proposals. A member raised concerns that some schools would be disproportionately affected and suggested that those schools should continue to receive targeted support. In response reassurance was given that support would be still available for children in those areas with the highest obesity levels.
- (iii) The programme targeted some of the most vulnerable children in Leicestershire who could go on to develop more complex health issues and members felt it was important that some elements of the programme were still in place going forward.

RESOLVED:

That the proposed change to the service offer for Whole School Approach to Food and Nutrition be supported.

37. Physical Activity Programme.

The Committee considered a report of the Director of Public Health which sought views around the proposed reductions to physical activity programmes as part of consultation. A copy of the report, marked 'Agenda Item 13', is filed with these minutes.

Members noted that whilst it was unfortunate that the physical activity programmes had to be reduced, there were many alternative options in communities for the public to get involved in physical activity.

RESOLVED

That the proposed reductions to physical activity programmes be supported.

38. Director of Public Health Annual Report.

The Committee considered a report of the Director of Public Health which presented the Director of Public Health's Annual Report for 2023. A copy of the report, marked 'Agenda Item 14', is filed with these minutes.

The Committee raised concerns about the prevalence of vaping in Leicestershire particularly amongst children and suggested that it should be covered in the Annual Report. In response the Cabinet Lead Member for Health provided reassurance that she shared the concerns about vaping, was monitoring the issue, and work was being carried out to tackle the issue in conjunction with the Trading Standards department at the County Council.

RESOLVED:

- (a) That the Annual Report of the Director of Public Health be welcomed;
- (b) That the comments now made be submitted to the Cabinet for consideration at its meeting on 24 November 2023.

39. Noting the work programme of the Leicester, Leicestershire and Rutland Joint Health Scrutiny Committee.

The Committee considered the work programme of the Leicester, Leicestershire and Rutland Joint Health Scrutiny Committee a copy of which, marked 'Agenda Item 15', is filed with these minutes.

RESOLVED:

That the work programme of the Leicester, Leicestershire and Rutland Joint Health Scrutiny Committee be noted.

40. Date of next meeting.

RESOLVED:

That the next meeting of the Committee take place on Wednesday 17 January 2024 at 2.00pm.

2.00 - 4.26 pm
01 November 2023

CHAIRMAN

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HEALTH OVERVIEW AND SCRUTINY COMMITTEE

17th JANUARY 2024

MEDIUM TERM FINANCIAL STRATEGY 2024/25 – 2027/28

JOINT REPORT OF THE DIRECTOR OF PUBLIC HEALTH AND THE DIRECTOR OF CORPORATE RESOURCES

Purpose of Report

1. The purpose of this report is to:
 - a) provide information on the proposed 2024/25 to 2027/28 Medium Term Financial Strategy (MTFS) as it relates to Public Health; and
 - b) ask the Committee to consider any issues as part of the consultation process and make any recommendations to the Scrutiny Commission and the Cabinet accordingly.

Policy Framework and Previous Decisions

2. The County Council agreed the current MTFS in February 2023. This has been the subject of a comprehensive review and revision in light of the current economic circumstances. The draft MTFS proposed for 2024/25 to 2027/28 was considered by the Cabinet on 19th December 2023.

Background

3. The MTFS is set out in the report to Cabinet on 19th December 2023, a copy of which has been circulated to all members of the County Council. This report highlights the implications for the Public Health Department.
4. Reports such as this one are being presented to the relevant Overview and Scrutiny Committees. The views of this Committee will be reported to the Scrutiny Commission on 29th January 2024. The Cabinet will consider the results of the scrutiny process on the 9th February 2024 before recommending an MTFS, including a budget and capital programme for 2024/25, to the County Council on the 21st February 2024.

Service Transformation

5. Funding for Public Health activities comes from the specific Public Health grant, The indicative 2024/25 PH settlement for Leicestershire is £27.444m, a 1.3%

increase on the 2023/24 grant. The uplift to the grant includes additional funding to support local authorities to implement their duties under the Botulinum Toxin and Cosmetic Fillers (Children) Act 2021 and the impact of the NHS pay settlements. The grant also includes funding to cover the costs of routine pre-exposure prophylaxis (PrEP) commissioning.

6. The Department and the services it commissions and delivers continue to be structured in line with statutory duties and the Public Health Strategy. The Department will consider the in-house provision of services as a preferred option, where appropriate, recognising that specialised health improvement treatment services will continue to be externally commissioned through the NHS and third sector markets.

Proposed Revenue Budget

7. Table 1 below summarises the proposed 2024/25 revenue budget and provisional budgets for the next three years thereafter. The proposed 2024/25 revenue budget is shown in detail in Appendix A.

Table 1 – Revenue Budget 2024/25 to 2027/28

	2024/25 £000	2025/26 £000	2026/27 £000	2027/28 £000
Original prior year budget	-1,806	-2,606	-2,696	-2,696
Budget transfers and adjustments	0	0	0	0
Add proposed growth (Appendix B)	0	0	0	0
Less proposed savings (Appendix B)	-800	-90	0	0
Proposed/Provisional budget	-2,606	-2,696	-2,696	-2,696

8. Detailed service budgets have been compiled on the basis of no pay or price inflation.
9. The total gross proposed budget for 2024/25 is £30.4m with contributions from health, transfers and various other income sources totalling £5.5m. The indicative ring-fenced grant allocation for 2024/25 is proposed to be £27.4m.
10. The proposed net budget for 2024/25 of - £2.606m is distributed as shown in Table 2 below:

Table 2 - Net Budget 2024/25

	£000	%
Public Health Leadership	2,715	10.93
Local Area Co-ordination	1,003	4.04
Quit Ready	479	1.93
First Contact Plus	102	0.41
Other Public Health Services	179	0.72
Programme Delivery	788	3.17
Public Health Advice	11	0.04

Weight Management Service	306	1.23
Mental Health	28	0.11
Children's Public Health 0-19	8,759	35.27
Domestic Violence	379	1.53
Sexual Health	4,247	17.10
NHS Health Check Programme	450	1.81
Substance Misuse	4,029	16.22
Physical Activity	896	3.61
Obesity Programmes	10	0.04
Health Protection	388	1.56
Tobacco Control	70	0.28
Active Together (formerly Leicestershire and Rutland Sport)	0	
Total	24,838	100.0
Public Health Ring Fenced Grant	-27,444	
Total Net Budgeted Spend	-2,606	

Budget Changes and Adjustments

11. Growth and savings have been categorised in the appendices under the following classification;
 - * item unchanged from previous MTFS
 - ** item included in the previous MTFS, but amendments have been made
 - No stars - new item
12. This star rating is included in the descriptions set out for growth and savings below.
13. Savings have also been classified as 'Eff' or 'SR' dependent on whether the saving is seen as efficiency or service reduction or a mixture of both. 'Inc' denotes those savings that are funding related and/or generate more income.

GROWTH

14. There is a specific spend pressure arising from the extension of the Integrated Sexual Health Service following the failed procurement process during 2023. However, given the tight financial position of the Council's financial position overall, it was not possible to provide growth for this and instead this will need to be contained within the Public Health grant. The department has reduced funding in demand led services with the aim of balancing those areas during the year.

SAVINGS

15. Details of proposed savings are set out in Appendix B and total £0.80m in 2024/25 rising to £0.89m per annum by 2025/26. These are detailed in the following paragraphs.

16. *PH1: Eff/SR Redesign of integrated lifestyle service pathways; £100,000 in 2024/25

Opportunities for the redesigning of integrated lifestyle service pathways are underway with potential changes to service delivery being reviewed with support from the Transformation Unit and Strategic Finance. At this stage, no risks have been identified.

17. *PH2: Eff/SR Review of commissioned services; £90,000 in 2025/26

The department is working with the Transformation Unit to identify opportunities for savings across its portfolio of commissioned services. A saving of £35,000 was delivered in 2022/23 and work is underway to identify the remainder of the saving for this line.

18. *PH3: SR Internal infrastructure (physical activity); £100,000 in 2024/25

This savings line has been combined with PH10 and a consultation has been undertaken on the full amount of the two savings combined. The saving will be made for both in 2024/25.

19. *PH4: Eff/SR Review approach to homelessness support; £300,000 in 2024/25

A revised delivery model has been approved by Cabinet following the outcome of the public consultation. The department will cease to fund a dedicated homelessness support service and will, instead, provide support via the Council's existing public health services.

20. *PH5: SR Review schools sustainable food award and gold food accreditation; £150,000 in 2024/25

The service will be decommissioned in its current form and the work will be dispersed to other internal teams to deliver alongside existing programmes. The remainder of the budget will be refocused on the elements of the existing contract that have the biggest impact.

21. *PH6: SR Review sport & physical activity programmes; £150,000 in 2024/25

100% saving being proposed with the decommissioning of the existing contract.

22. Considering the scale of the challenge faced by the Council to balance the MTFs, existing financial control measures are being reinforced and new ones being applied to ensure a tight focus on eliminating non-essential spend.

Savings under Development

23. Service Efficiencies

A review of the costs of each interaction with service users to see what opportunities there are to provide services more efficiently whilst still delivering desired outcomes. This includes working with Pharmacies to look at opportunities to work collaboratively to dispense Pharmacotherapy products.

24. Commercialisation of elements of the school offer

This work stream has now been focusing on the workplace health offer and has already generated income of £18,500. The programme is still in its infancy but is growing exponentially with increased targets for 2024/25.

External Influences

25. Demand Led Activity

Sexual Health services are required to be provided on an open access basis and therefore there is a risk to the achievement of the MTFs if activity is higher than predicted. Health Checks are also demand driven and there has been an increase in activity in 2023/24 above the level anticipated which has led to an increase in the budget allocation for 2024/25.

26. Inflation

The department continues to be at risk of inflationary pressures. Although there has been an increase to the Public Health Grant in 2023/24, there is an ongoing requirement for the Department to meet increased provider costs as well as internal staff pay awards which are not funded by the central contingency.

27. Public Health Grant

The future mechanism for Public Health funding is uncertain and there is increased scrutiny from the Office for Health Improvement and Disparities (OHID) in relation to grant spend. If the grant is cut by national government, growth will be needed to maintain existing service levels. There would also be a risk to being able to deliver the MTFs savings as planned. We are working nationally to lobby for a fairer funding process for PH as well as designing the

mitigation review process to ensure spend is allocated to appropriate services within the authority.

Other Funding Sources

28. There are several funding sources that contribute to the overall budget for Public Health.

<u>Funding Source</u>	<u>Description</u>	<u>Value £000</u>	<u>RISK RAG</u>
Public Health Grant	Public Health Grant Allocation 2024/25 (indicative allocation).	27,444	G
Sport England Grant	Active Together receive funding to deliver a number of programmes. Funding varies each year, according to the programmes supported.	689	G
Better Care Fund	Funding allocation for First Contact Plus.	188	G
Rutland County Council	The provision of Public Health support to the authority and a section 113 agreement for Mike Sandys as the DPH.	318	G
Office of the Police and Crime Commissioner	This funding is a contribution to the (drugs) treatment contract.	145	G
Integrated Care Board	To meet the costs of contraceptive devices which are fitted to treat an existing medical condition.	100	G

Background Papers

Cabinet 19th December 2023 - Medium Term Financial Strategy 2024/25 to 2027/28
<https://politics.leics.gov.uk/documents/g7081/Public%20reports%20pack%20Tuesday%2019-Dec-2023%2014.00%20Cabinet.pdf?T=10>

Circulation under Local Issues Alert Procedure

None.

Officers to Contact

Mike Sandys, Director of Public Health
 Tel: 0116 305 4239
 E-mail: mike.sandys@leics.gov.uk

Declan Keegan, Director of Corporate Resources, Corporate Resources Department
 Tel: 0116 305 7668
 E-mail: declan.keegan@leics.gov.uk

List of Appendices

Appendix A – Revenue Budget 2024/25
 Appendix B – Growth & Savings 2024/25 – 2027/28

Equality implications

29. Public authorities are required by law to have due regard to the need to:
- Eliminate unlawful discrimination, harassment and victimisation;
 - Advance equality of opportunity between people who share protected characteristics and those who do not; and
 - Foster good relations between people who share protected characteristics and those who do not.
30. Many aspects of the County Council's MTFs may affect service users who have a protected characteristic under equalities legislation. An assessment of the impact of the proposals on the protected groups must be undertaken at a formative stage prior to any final decisions being made. Such assessments will be undertaken in light of the potential impact of proposals and the timing of any proposed changes. Those assessments will be revised as the proposals are developed to ensure decision makers have information to understand the effect of any service change, policy or practice on people who have a protected characteristic.
31. Proposals in relation to savings arising out of a reduction in posts will be subject to the County Council Organisational Change policy which requires an Equality Impact Assessment to be undertaken as part of the action plan.

Human Rights Implications

32. There are no human rights implications arising from the recommendations in this report.

PUBLIC HEALTH DEPARTMENT**REVENUE BUDGET 2024/25**

Net Budget 2023/24 £		*	Employees £	Running Expenses £	Internal Income £	Gross Budget	External Income £	Net Budget £
-27,086,931	Public Health Ring-Fenced Grant		0	0	0	0	-27,443,857	-27,443,857
	Department							
2,885,956	Public Health Leadership	B	3,077,857	619,899	-724,229	2,973,527	-257,858	2,715,669
1,098,107	Local Area Co-ordination	B	1,854,380	132,885	-643,624	1,343,641	-340,938	1,002,703
473,214	Quit Ready	B	936,293	408,442	-74,687	1,270,048	-791,410	478,638
350,328	First Contact Plus	B	400,772	0	-110,719	290,053	-187,845	102,208
142,480	Other Public Health Services	B	30,334	179,750	-31,334	178,750	0	178,750
794,406	Programme Delivery	B	1,057,207	383,250	-622,222	818,235	-30,588	787,647
310,720	Public Health Advice	B	0	10,720	0	10,720	0	10,720
337,841	Weight Management Service	B	316,110	33,250	-33,428	315,932	-10,000	305,932
48,050	Mental Health	B	50,920	97,500	0	148,420	-120,920	27,500
6,441,102	Total		7,723,873	1,865,696	-2,240,243	7,349,326	-1,739,559	5,609,767
8,559,341	0-19 Childrens Public Health	S	83,794	9,406,548	-731,000	8,759,342	0	8,759,342
	Health Related Harms							
384,703	Domestic Violence	S	0	416,383	-37,500	378,883	0	378,883
4,042,045	Sexual Health	S	0	4,347,070	0	4,347,070	-100,000	4,247,070
400,000	NHS Health Check programme	S	0	450,000	0	450,000	0	450,000
4,028,806	Substance Misuse	S	0	5,922,535	-120,000	5,802,535	-1,773,729	4,028,806
8,855,554	Total		0	11,135,988	-157,500	10,978,488	-1,873,729	9,104,759
	Physical Activity and Obesity							
1,145,951	Physical Activity	B	0	895,951	0	895,951	0	895,951
190,000	Obesity Programmes	B	0	10,000	0	10,000	0	10,000
1,335,951	Total		0	905,951	0	905,951	0	905,951
18,873	Health Protection	B	580,088	39,950	-185,564	434,474	-46,547	387,927
70,000	Tobacco Control	B	0	70,000	0	70,000	0	70,000
0	Active Together	B	1,353,050	1,250,370	-718,794	1,884,626	-1,884,626	0
-1,806,110	TOTAL PUBLIC HEALTH		9,740,805	24,674,503	-4,033,101	30,382,207	-32,988,318	-2,606,111

* S/D/B : indicates that the service is Statutory, Discretionary or a combination of Both

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APPENDIX B

2024/25	2025/26	2026/27	2027/28
£000	£000	£000	£000

References

GROWTH

Demand & cost increases

TOTAL

0	0	0	0
----------	----------	----------	----------

SAVINGS

*	PH1	Eff/SR	Redesign of integrated lifestyle service pathways	-100	-100	-100	-100
*	PH2	Eff/SR	Review of Commissioned services	0	-90	-90	-90
*	PH5	SR	Internal Infrastructure	-100	-100	-100	-100
*	PH8	Eff/SR	Review approach to homelessness support	-300	-300	-300	-300
*	PH9	SR	Review schools sustainable food award and gold food accreditation.	-150	-150	-150	-150
*	PH10	SR	Review Sport & Physical Activity programmes	-150	-150	-150	-150
			TOTAL	-800	-890	-890	-890

* items unchanged from previous Medium Term Financial Strategy

** items included in the previous Medium Term Financial Strategy which have been amended

Eff = Efficiency saving; SR = Service reduction; Inc = Income

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HEALTH OVERVIEW AND SCRUTINY COMMITTEE:

17th JANUARY 2024

VAPING AND YOUNG PEOPLE

REPORT OF THE DIRECTOR OF PUBLIC HEALTH

Purpose of Report

1. The purpose of this report is to inform the Health Overview and Scrutiny Committee of the work that is currently being carried out relating to vaping and young people in Leicestershire and to provide information on how the additional Government Smokefree Generation (SFG) ringfenced funding will help contribute towards this over the next few years.

Policy Framework and Previous Decisions

2. Additional funding has been allocated to Local Authority Stop Smoking services through the Smokefree Generation Programme, a government funded programme, resulting in an additional estimated £716K being allocated to Leicestershire Public Health from 2024/25 to 2028/29 in line with the current grant conditions. Confirmation of the exact funding allocation will be communicated to Local Authorities through the formal grant agreement process. This is part of the government's plan to further reduce smoking prevalence and work towards a smokefree generation by 2030.

Background

3. E-cigarettes also known as vapes are battery-powered devices that deliver nicotine by heating a solution containing nicotine, flavourings and other additives. The primary function of vapes is to deliver nicotine. Smokers are not addicted to tobacco but are addicted to nicotine. E-Cigarettes are regulated as consumer products under the UK Tobacco Related Products Regulations (2016) and there are an estimated 3.6 million E-cigarette users in Great Britain.
4. There has been an increase in vaping prevalence amongst young people nationally as well as locally. In 2023, 20.5% children nationally had tried vaping, up from 15.8% in 2022 and 13.9% in 2020 before the first Covid lockdown. Quit Ready Stop Smoking Service in November 2022 conducted a survey to assess the local situation with vaping in young people. There were over 1100 respondents targeted at young people under the age of 18 years old with 25% of children using vapes and the majority using vapes for 6 months or more. It has become evident that there has been an increase in young people vaping and this has raised concern amongst schools, parents and public health. Currently there is no national direction on what

support will be available to help young people stop vaping, but the consensus for adults, remains that smokers are better off vaping than smoking but that non-smokers should not vape.

5. Selling vapes to children is illegal but giving them out for free is not. 2.1% of children who tried vaping have reported obtaining their first vape from an E-Cigarette company. The increase in disposable vapes has happened concurrently with higher levels of youth use (ASH, 2023 findings).
6. Vaping however is not for children and whilst it can help people quit smoking, national and local guidance states that those who do not smoke should not vape. The health effects of vaping are not currently well understood and more research is needed on its long term effects. Vaping has been associated with an increasing number of reported lung complaints and conditions worldwide.
7. There is a need to reduce the number of young people accessing vape products and the amount of non-compliant products i.e. products that are not tobacco product directive compliant, available for sale. Leicestershire Trading Standards have reported receiving a total of 84 complaints regarding vapes, 63 relating to children under the age of 18 years old being sold vapes. The remaining complaints referred to counterfeit vapes. The Public Health Department will need to continually work closely with our Trading Standards colleagues to support compliance with regulations and to take enforcement action when necessary.

Proposals/Options

8. The Council's Quit Ready (QR) Stop Smoking Service are currently working with schools and have recently produced a toolkit for secondary schools. This includes a lesson plan for teachers and or student support staff. The toolkit also includes a support pack for teachers which includes the local survey results, how to support young people and where to go for help and the laws and guidance around vaping in young people and vaping and the environment.
9. The toolkits have been distributed to schools via the Council's Teen Health Service with an intention to distribute this to all secondary schools. This will include the young person's tobacco specialist following up with schools to offer them the opportunity to promote the resources, provide support for any pupils identified as smokers and help shape and contribute to the schools' policies on vaping and smoking. Quit Ready will be approaching the School Heads via the Education Effectiveness Team.
10. Quit Ready will be working with schools and young people via a competition to design a poster and or Tik Tok video highlighting the risks of vaping and choosing not to vape if you don't smoke. The winning school will be provided with a voucher presented by Public Health's lead member, Mrs Richardson, with the school being able to use this towards purchasing resources for the school. The winning video and or poster will be advertised via the Communications team and forms part of the current marketing plan.
11. The Quit Ready team currently works in partnership with Trading Standards to promote the Tobacco Product Directive (TPD) around vaping and E-cigarettes with

local businesses. Trading Standards also follow up on illicit vapes (i.e. those not TPD compliant) reported via the anonymous helpline. This is reported quarterly into Public Health.

12. The stop smoking team is linked into the regional tobacco control work around vaping and will contribute to the recently announced “swap to stop” national scheme and “illicit vapes enforcement squad” initiatives that are due to come into effect.
13. To support existing smokers to quit, the government have doubled existing local authority spend, through the implementation of the Smokefree generation fund. Leicestershire has an annual spend of £580K via the public health grant. The funding provided through the Smokefree Generation fund will see an additional estimated £716K adding to the existing Public Health grant. The funding will be delivered through a new section 31 grant and ringfenced for the purposes of local authority-led stop smoking services. To receive the funding local authorities must maintain their existing spend on stop smoking support through the existing Public Health grant.
14. The Smokefree Generation (SFG) monies will be funding service expansion. This will include additional stop smoking advisors and Young Person Tobacco Specialist posts, with the aim for the specialists to help support the planned work with schools and help young people give up smoking. The team is to be in place in the upcoming financial year (2024/2025). The criteria for the SFG funding is to be used for smoking cessation purposes only and not for vaping or towards tobacco enforcement. We plan on providing young people with smoking cessation support. This work will include helping schools develop policies around smoking and vaping and adopt a proportionate response to exclusion and punishment. The Young Person Tobacco Specialists will work directly with schools and settings for young people, supporting both the smoke free policies and delivering smoking cessation support.
15. The National Institute for Health and Care Excellence (NICE) guidance recommends a co-ordinated whole school approach to smoking and vaping. The school’s response should not be at the point where young people take up smoking or vaping but rather have strategies in place to prevent the uptake of smoking and or vaping, by educating young people of the impact caused through smoking and/or vaping. Most young vapers also smoke or have smoked in the past, and it is important to recognise and communicate to young people that the level of risk from smoking is far worse than vaping. Furthermore, schools and parents should make contact with Trading Standards should they have concerns on underage sales of vapes and tobacco by reporting via the anonymous helpline.
16. To tackle the issue, collective support and buy-in from partner organisations and groups including schools, youth council, looked after children and Trading Standards will be needed. The dedicated resource through SFG will help with this.

Consultation

17. A consultation has not taken place however in November 2022 a survey was conducted to gain feedback on the use and prevalence of E-cigarettes amongst young people in Leicestershire. This was disseminated through partners who currently engage with young people and families and through schools via the School

Sport Physical Activity Network (SPAN). The purpose was to gather baseline information on the use of E-cigarettes i.e. looking at localities, age, sex, ethnicity and reasons for using E-cigarettes as well as to establish how many users were current smokers, ex-smokers or never smoked.

Resource Implications

18. The work outlined will be funded by the Public Health grant and the expansion of the team and additional work will be funded through the SFG money.

Timetable for Implementation

19. The aim is for Quit Ready support to be expanded from April 2024 to commence delivery of services once funding has been received from HM Government.

Conclusions

20. Whilst we recognise that vaping is not risk-free but is a safer alternative to smoking, children should not be vaping. Our stance as a public health department is if you do not smoke do not vape. Children who are smokers should be offered licensed nicotine replacement therapy alongside behavioural support and intervention. Work is underway to support young people to give up smoking and to raise education and awareness of the risks of vaping and smoking. The Smokefree Generation funding stream will help strengthen the smoking cessation offer for children, reduce smoking and vaping prevalence, and raise awareness of the issue more widely thus working towards creating a smokefree generation by 2030.

Circulation under the Local Issues Alert Procedure

21. None

Equality Implications

22. Over two thirds of people trying smoking go on to become daily smokers. Therefore, it is vital that we prevent smoking initiation. Furthermore, reducing smoking in adults especially in deprived communities reduces youth exposure to smoking role models and access to tobacco products and vapes, this is key in reducing smoking initiation. Young people who grow up in smoking households are 4 times more likely to become smokers themselves and smoking in young people from disadvantaged communities are twice as common in disadvantaged communities transferring health inequalities from generation to generation.

Human Rights Implications

23. There are no human rights implications arising from the recommendations in this report.

Other Relevant Impact Assessments

24. Not applicable.

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HEALTH OVERVIEW AND SCRUTINY COMMITTEE: 17th JANUARY 2024

LLR LeDeR ANNUAL REPORT 2022/23

REPORT OF LEICESTERSHIRE PARTNERSHIP NHS TRUST

Purpose of report

1. This report provides a summary of the LLR LeDeR Annual Report 2022/23 and offers key actions from learning for all partners.

Background

2. The 'Learning From Lives and Deaths of People with a Learning Disability and Autistic People' (LeDeR) Programme was launched in 2016/17. Since being established, deaths of people with a learning disability, and from January 2022 autistic people, have been reviewed with the findings presented in the LeDeR annual reports, where action from learning has been captured.
3. The LeDeR programme aims are to:
 - a) improve care for people with a learning disability (LD) and autistic people;
 - b) reduce health inequalities for people with a learning disability and autistic people; and
 - c) prevent people with a learning disability and autistic people dying prematurely.
4. Within Leicestershire, Leicester and Rutland (LLR) a new team was established to solely focus on this programme. The leadership of the Learning Disability & Autism Programme is a joint programme with shared responsibility. Heather Pick, Assistant Director, Adults and Communities, Leicestershire County Council and David Williams, Director of Strategy and Partnerships, Leicestershire Partnership NHS Trust are joint Senior Responsible Officers (SROs) for this work.

The 2022/23 LLR LeDeR report:

5. The report covers the financial year 2022/23 for Leicestershire, Leicester and Rutland.
6. This is the first time a LeDeR report has included reviews for autistic people. Quality of care was also measured for the first time in this report. This was measured using six themes set out nationally, and further examined by sub-themes. The report also focuses on preventative healthcare; an area which the LLR LeDeR programme team have actively been involved with in supporting the learning into action part of the report.

7. Of note within the report:
 - a) A total of 83 deaths were notified to the LeDeR Programme during 2022/23.
 - b) The median age at death was 62.
 - c) This is over 20 years younger than the general population.
 - d) From 1 July 2023, any deaths of people under 18 years of age, reviews are no longer carried out by LeDeR, but by the Child Deaths Overview Panel only (CDOP), there is very close working between LeDeR and CDOP
8. The report is supplemented by top ten learning into action points. These are followed by plans for the forthcoming year, with appendices containing more detail in relation to various sections of the report.

Learning into Action:

9. The aforementioned top ten learning into action points recommended across the LLR system from this year include:
 - 1) Report the deaths of those people autism (with or without a learning disability) to the LeDeR Programme.
 - 2) Report the deaths of those from Leicester City and from diverse ethnic backgrounds to the LeDeR Programme.
 - 3) There is an emerging theme around the widespread misuse of the Mental Capacity Act. All services should review their practices to ensure compliance with this important legislation.
 - 4) The practice of estimating someone's weight is a significant risk for people. People should be weighed using appropriate weighing equipment and the weight should be recorded accurately.
 - 5) Clear plans should be created for every person with behaviour that challenges, highlighting the support they require and anticipating the support they are likely to need in the years ahead. This should be reflected in future commissioning considerations in LLR for provision of residential care for those with learning disabilities as physical health and nursing care needs increase particularly towards the end of their life.
 - 6) Care providers must be competent and confident in talking about end-of-life matters and having these meaningful conversations at the right time.
 - 7) Screening inequalities exist, and every effort should be made to improve the uptake. Barriers to non-invasive bowel screening should be rectified.
 - 8) Better understanding of the STOMP/STAMP agenda across generic, physical, and mental health services.
 - 9) Aspiration pneumonia happens as a consequence of a precipitating event. Identification of risk factors and ongoing management are key. The changing of pathway at discharge to LD MDT is imperative.

10) There is specialist support for people in the community who have been unable to have blood taken from standard phlebotomy, which is not always accessed appropriately. Intervention by these teams does not guarantee successful outcomes but the availability should be widely known.

10. A list of achievements in partner services in response to learning from LeDeR is given from page 37 in the LeDer Annual Report.

The Impact of the COVID pandemic on Annual Health Checks:

11. People with a learning disability often have poorer physical and mental health than other people; this doesn't need to be the case. An annual health check can help people to stay well, prevent poor health and identify issues early and provide treatment.
12. Across LLR, Annual Health Checks attendance reduced during the COVID pandemic as many people did not want to attend in person. This trend was countrywide. As a result, GPs offered phone appointments to cover the main parts of the check. This was on the understanding that the physical parts of the check would be carried out later (e.g. weight, blood pressure etc.).
13. Despite the challenge of accessing GPs face to face during this period, there was an annual increase in the proportion of people accessing a check. This increased from 52% in 2018/19, to over 80% in 2022/23. We have been able to maintain this improvement trajectory and expect to exceed last year's figure.

Proposals/Options

14. The Health Overview and Scrutiny Committee is invited to:
 - a) Share the annual report widely.
 - b) Promote the key learning points across all services, noting a whole LLR system response is required.
 - c) Note the considerable disparity in life expectancy for people with a learning disability and autistic people.
 - d) Recognise that one third of deaths were potentially preventable.

Appendices

Appendix A - LeDeR annual report 2023/24

Appendix B – Presentation slides

Background papers

Report to Committee on 31 August 2022:

<https://democracy.leics.gov.uk/documents/s170836/2022%20August%20LCC%20HOSC%20paper%20LeDeR.pdf>

LLR LeDeR Annual Report 2022:

<https://democracy.leics.gov.uk/documents/s170837/Appendix%20A%20-%20LLR%20LeDeR%20Annual%20Report%202022.pdf>

Equality Implications

15. Due regard to equality and diversity in any subsequent decision-making following this paper and noted recommendations may be required.

Human Rights Implications

16. There are no human rights implications arising from the recommendations in this report itself.

Officer(s) to Contact

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Leicester, Leicestershire and Rutland LeDeR Annual Report 2023



**Leicester, Leicestershire
and Rutland**

Health and Wellbeing Partnership

Contents

Foreword	4
Acknowledgements.....	4
Executive Summary	5
Introduction.....	7
Glossary of abbreviations	8
Reviews of deaths.....	9
Deaths notified to the LLR LeDeR programme	9
Referrals received in-year	9
Age at death in 2022/23	9
Month of death.....	10
Reviews completed in-year.....	10
Equality Impact & Demographic Data.....	10
Important Statements from LeDeR.....	13
Causes and Circumstances of Death.....	13
Cause of death by demographic group.....	14
Leading Causes of Death.....	15
Respiratory Deaths.....	15
Cancer	15
Quality of Care	16
Six Key Themes.....	17
Top areas of learning	18
End of Life Care	18
Care Co-ordination.....	18
Communication.....	19
STOMP/STAMP.....	19
Behaviours that Challenge	21
Repeated hospital admission at End of Life.....	22
Safeguarding	23
Preventative Healthcare	24
Venepuncture	24
Vaccinations	24

Screening.....	26
LD Annual Health Check.....	29
Thematic Analysis	30
Aspiration Pneumonia.....	30
SMART Actions	32
Covid-19	32
Ethnic Minority.....	32
LLR CDOP LeDeR themed review	35
Recommendations	36
Learning into Action.....	37
GP and Primary Care	37
LPT FYPC / LDA	37
Acute Care.....	37
Leicestershire County Council.....	38
Leicester City Council	38
Top Ten Learning into Action.....	39
Plan for 2023/24.....	40
Appendix I	42
Appendix II	43
Appendix III	44

Foreword

This LeDeR Report would not have been possible without the dedications, commitment and passion of many people and organisations across Leicester, Leicestershire and Rutland (LLR), who have notified deaths of people with a learning disability and autistic people, conducted reviews, and coded and analysed the information. Most importantly though, we wish to acknowledge the people for whom this report is created: people with a learning disability and autistic people, their families, their friends, their colleagues, carers, and all staff and service providers whose lives are affected by this report. Also, our LeDeR Reviewers as without their expertise, experience and passion we would not be where we are today. Whilst many people can no longer be with us today, we hope that this report honours their legacy.

We must not rest upon the contents of this report. Instead, all partners across the Leicester, Leicestershire and Rutland health and social care sector must embrace the findings of this report; everyone has a role to play. Only then will we ensure that every person with a learning disability and autistic people receive the high quality of care that they deserve. Only then will we address health inequality and inequity.

Caroline Trevithick, Chief Nurse & Executive Director, Leicester, Leicestershire and Rutland Integrated Care Board

Heather Pick, Assistant Director (Adults & Communities), Leicestershire County Council

David Williams, Director of Strategy and Business Development, Leicestershire Partnership NHS Trust

Acknowledgements

Leicester, Leicestershire and Rutland Integrated Care Partnership would like to acknowledge the support provided to the LeDeR programme by the following organisations, groups and individuals:

NHS England National Team (NHSE)	Primary Care Services
NHS England Regional Team	Leicester City Council
LLR LeDeR Team	Leicestershire County Council
LLR LeDeR Experts by Experience	Rutland County Council
LPT Talk and Listen Group	Leicester, Leicestershire and Rutland Child Death Overview Panel (CDOP)
All family members' contributions	LDA Collaborative
Leicestershire Partnership Trust	DeMontfort University
University Hospitals of Leicester	

Executive Summary

The 2023 LeDeR Annual report for Leicester, Leicestershire and Rutland takes us through changes to how the LeDeR process works, including changes to the process since last year and more to come in the new working year.

The 'Reviews of Deaths' section explains how data is presented and breaks down some of the demographics by which comparisons were made. The report then looks at causes of death by demographic group, further examining the leading causes of death in LLR.

Quality of care is measured for the first time by six themes set out nationally and further examined by sub-theme.

Preventative healthcare has featured heavily in 2022/23 and LLR LeDeR has been actively involved in supporting working groups to which the programme contributes learning into action.

Thematic analysis carried out throughout the year is described, and has also been shared with national teams, notably the authors of the new 'Right Care' report.

CDOP cases and changes to policy are explained, followed by some achievements and LeDeR contributions made in the local system.

Learning into Action detail is followed by top ten learning into action, which is also highlighted below. Followed by plans for the forthcoming year, with appendices containing more detail in relation to various sections of the report.

In all, it has been a very challenging and positive year for LLR LeDeR.

Throughout the report, there are direct quotes from friends and family, shown in coloured bands across the pages. The first is shown on the next page.

Top Ten Learning into Action Points

1. Report the deaths of those people autism (with or without a learning disability) to the LeDeR Programme.
2. Report the deaths of those from Leicester City and from diverse ethnic backgrounds to the LeDeR Programme.
3. There is an emerging theme around the widespread misuse of the Mental Capacity Act. All services should review their practices to ensure compliance with this important legislation.
4. The practice of estimating someone's weight is a significant risk for people. People should be weighed using appropriate weighing equipment and the weight should be recorded accurately.

5. Clear plans should be created for every person with behaviour that challenges highlighting the support they require and anticipating the support they are likely to need in the years ahead. This should be reflected in future commissioning considerations in LLR for provision of residential care for those with learning disabilities as physical health and nursing care needs increase particularly towards the end of their life.
6. Care providers must be competent and confident in talking about end-of-life matters and having these meaningful conversations at the right time.
7. Screening inequalities exist, and every effort should be made to improve the uptake. Barriers to non-invasive bowel screening should be rectified.
8. Better understanding of the STOMP/STAMP agenda across generic, physical, and mental health services.
9. Aspiration pneumonia happens as a consequence of a precipitating event. Identification of risk factors and ongoing management are key. The changing of pathway at discharge to LD MDT is imperative.
10. There is specialist support for people in the community who have been unable to have blood taken from standard phlebotomy, which is not always accessed appropriately. Intervention by these teams does not guarantee successful outcomes but the availability should be widely known.

Having a direct payment and personal assistants ensured that every day she was well enough, she had the opportunity to go out and live her life to the max. Her car has been the only Motability car returned with 100,000 on the clock which is the maximum allowance allowed!

Introduction

The LeDeR Programme was changed from a National perspective in June 2021, when the University of Bristol's involvement came to an end and the King's College London became the new lead academic partner. The LeDeR web-based platform was launched by South Central and West Commissioning Support Unit and remains the responsibility of this team. The changes to the LeDeR web-based platform from a national level means that we continue to complete initial or focused reviews for people. This has changed the amount and type of data available at different stages of data collection. Where possible we have drawn comparisons over time but have also highlighted where, due to the transition in the system of data collection, this was not possible. For the first time since its expansion, this report will include LeDeR reviews of autistic people. As this is the first time, there is no comparable data. Notifying a death to LeDeR is not mandatory and, therefore we would not expect LeDeR to have data on all people with a learning disability and autistic people who have died in LLR. Some data contains relatively small numbers of cases, so some findings must be interpreted with a degree of caution.

National context¹

Learning from Lives and Deaths - people with a learning disability and autistic people (LeDeR), previously known as The English Learning Disabilities Mortality Review (LeDeR) programme, was established as a pilot in 2015 and rolled out nationally in 2017. The aims are to:

1. improve care for people with a learning disability and autistic people.
2. reduce health inequalities for people with a learning disability and autistic people and
3. prevent people with a learning disability and autistic people dying prematurely.

Since being established, deaths of people with a learning disability, and from January 2022 autistic people, have been reviewed with the findings presented in the LeDeR annual reports, where the action from learning has been captured.

¹ *National LeDeR Report 2021*

Glossary of abbreviations

ALN	–	Acute Liaison Nurse
ASC	–	Adult Social Care
ASD	–	Autistic Spectrum Disorder
CDOP	–	Child Death Overview Panel
DoLS	–	Deprivation of Liberty Safeguards
DNACPR	–	Do Not Attempt Cardio-Pulmonary Resuscitation
DVT	–	Deep Vein Thrombosis
EBE	–	Expert by Experience
ECG	–	Electrocardiogram
GP	–	General Practitioner
ICS	–	Integrated Care System
IMCA	–	Independent Mental Capacity Advocate
LTC	–	Long Term Health Conditions
LeDeR	–	Learning from Lives and Deaths Review Programme
LD	–	Learning Disability
MCA	–	Mental Capacity Act
MDT	–	Multi Disciplinary Team
MHA	–	Mental Health Act
MCCD	–	Medical Certificate of Cause of Death
NHS	–	National Health Service
NICE	–	National Institute for Health and Care Excellence
ONS	–	Office for National Statistics
PBS	–	Positive Behaviour Support
PEG	–	Percutaneous Endoscopic Gastrostomy
PCLN	–	Primary Care Liaison Nurse
ReSPECT	–	Recommended Summary Plan for Emergency Care and Treatment
SJR	–	Structured Judgement Review
SMART	–	Specific Measurable Actionable Realistic Timebound
STAMP	–	Supporting Treatment and Appropriate Medication Treatment in Paediatrics
STOMP	–	Stopping the Over Medication of People with LD and Autistic People
WTE	–	Whole Time Equivalent
WHO	–	World Health Organisation

Reviews of deaths

Deaths notified to the LLR LeDeR programme

A total of 83 deaths of people with a LD and Autistic people were notified to the LLR LeDeR Programme from 1st April 2022 – 31st March 2023. Of those people:

- 3 people were autistic.
- 6 were children with a learning disability.
- 2 were out of scope for a LeDeR review.
- 72 were adults with a learning disability.

Referrals received in-year

Figure 11 below shows a total of 83 deaths referred to LLR LeDeR in 2022/23, broken down into initial and focused categories. At end of year, 22 cases remained in progress and 55 had been completed.

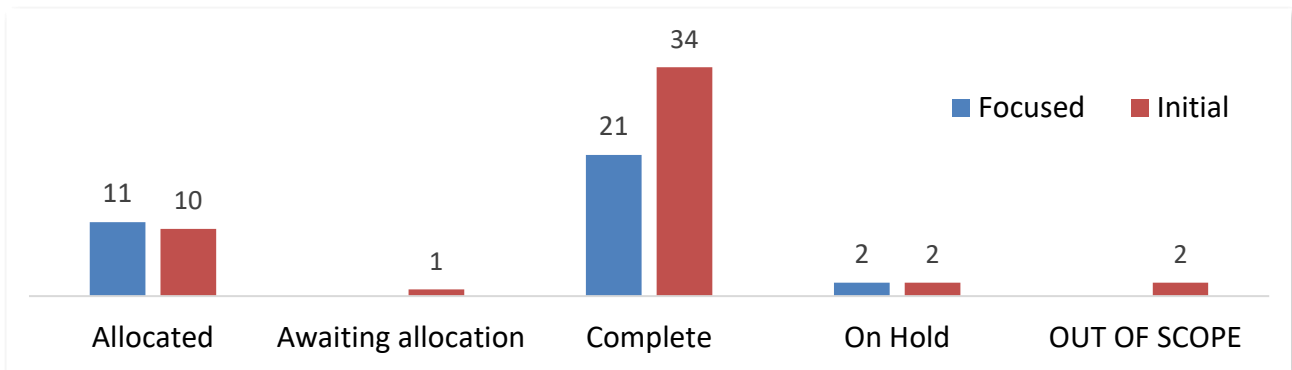


Figure 1. Referrals received by type, 2022/23

Age at death in 2022/23

Median age at death for those who passed away and their deaths notified to LeDeR in 2022/23, the median age at death was 62.

The median age at death in 2022/23, was 62.

Month of death

The 83 deaths referred to LeDeR in this time-period as shown in **Figure 2. Month of death**, with more deaths occurring in December than any other month. This is broken down in **Figure 3.**

Month of death by gender

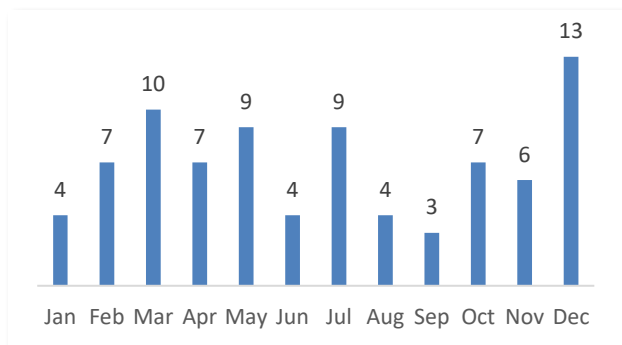


Figure 2. Month of death

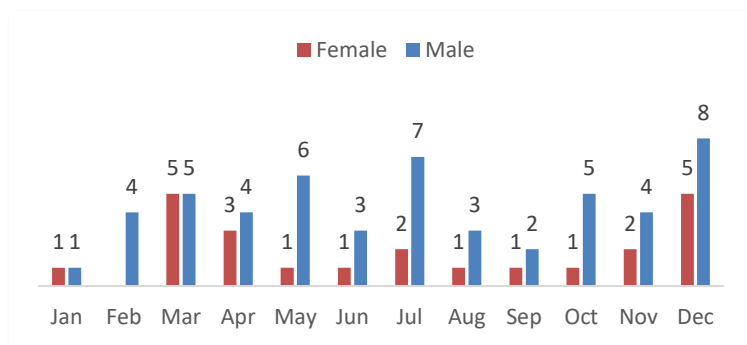


Figure 3. Month of death by gender

Reviews completed in-year

Analysis from this point covers all reviews that were completed within the 12 months from April 2022 to March 2023, rather than those received in that period.

This is because previous reports did the same, and it is possible only to report accurately on cases that were completed at the time of writing.

In 2022/23, the LLR LeDeR programme completed 94 reviews, 50 of which were initial, 44 focused (*Figure 4. Reviews completed in 2022/23.*)

It is worth noting that a number of those had been on hold for a significant period as they awaited statutory processes including Coroner's Inquests and Child Death Overview Panel (CDOP). Historically, such cases were placed 'on' hold for long periods before LeDeR was able to review them. In recent months, LLR LeDeR worked closely with LLR CDOP on 11 cases and was able finally to complete those CDOP reviews.

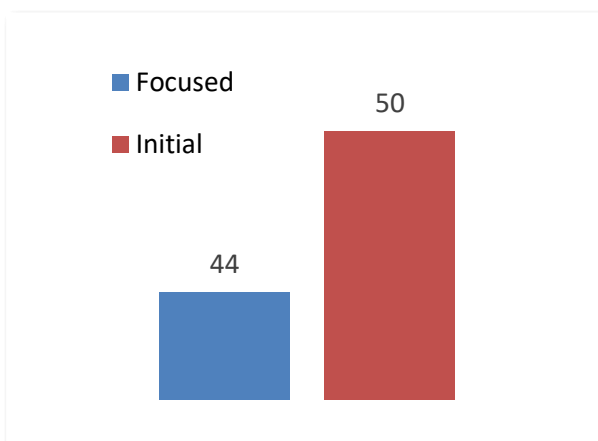


Figure 4. Reviews completed in 2022/23

Equality Impact & Demographic Data

Age Group

Deaths were broken down by age group (see *Figure 5. LLR LeDeR Deaths by age group*) and is clear to see that 12% were under 18 years of age. Again, this is due to a number of referrals received pre-2022/23 that had been on hold and were completed in year, as explained in the previous

paragraph. Comparison between Figure 5 and 6 is shown for comparing deaths by age with the general population, highlighting the level of disparity. With age at death for people with a LD is 51-60yrs and for the general population this is 85-89yrs.

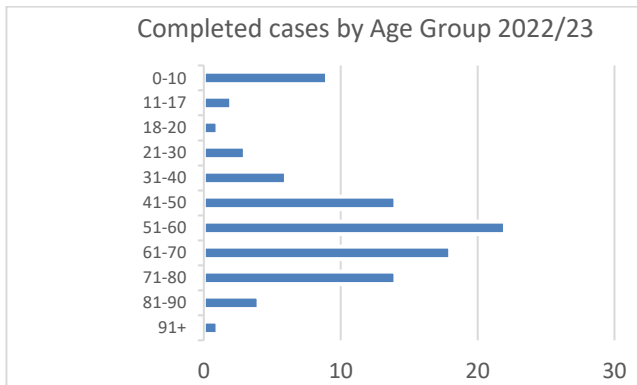


Figure 5. LLR LeDeR Deaths by age group

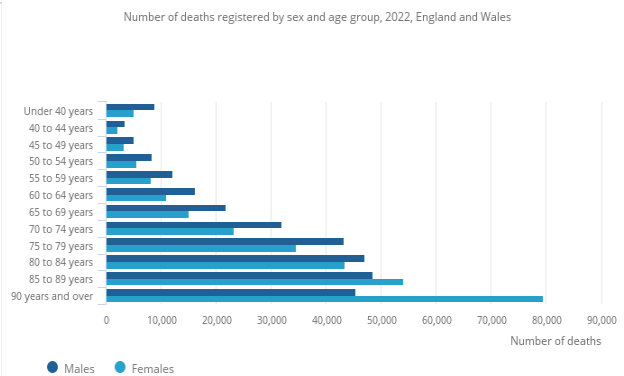


Figure 6. Death registration summary by age ONS

Median age at death in completed reviews

Due to the number of outstanding CDOP cases completed after being on hold (see previous paragraph), the mean age at death for reviews completed in 2022/23 is disproportionately affected. Taking all completed cases into account, median age at death in LLR was 54 years. Only one CDOP death was notified in this year and so the remaining 10 are skewing the median age at death. If the 10 CDOP cases that had been on hold are removed from pre-March 2022, the median age at death for reviews completed in 2022/23 completed reviews was therefore 58.

It is important to note that From July 2023, CDOP deaths will no longer be referred to LeDeR and so LeDeR will report only on deaths of people aged 18 or over.

Ethnicity

The vast majority of deaths were of ‘White’ people (82%), with ‘Asian or Asian British’ comprising 12% and ‘Black, African, Caribbean or Black British’ 1%. The remaining 5% had preferred not to state Ethnic Group. (see

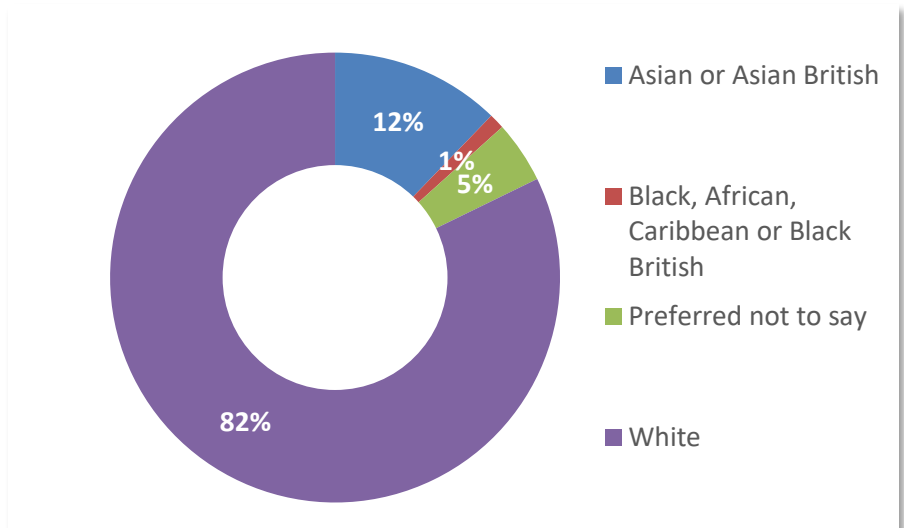


Figure 7. Cases completed 2022/23 by Ethnic Group

Figure 7. Cases completed 2022/23 by Ethnic Group

Breaking this down further and omitting the 'White' ethnic group allows us to see a clearer picture within different ethnicities, as shown in *Figure 8. Cases completed 2022/23 by Ethnicity.*

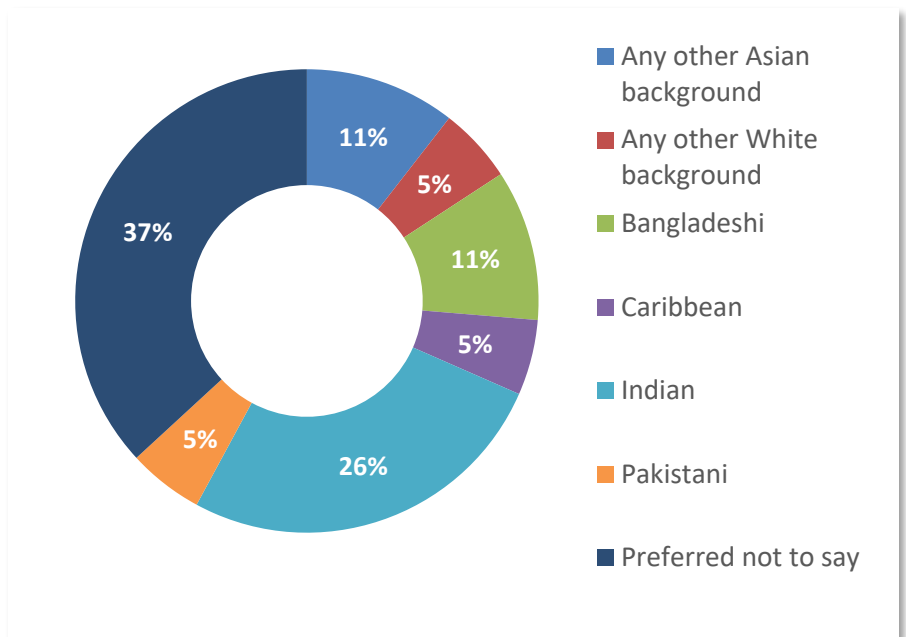


Figure 8. Cases completed 2022/23 by Ethnicity.

Gender and ICS Place

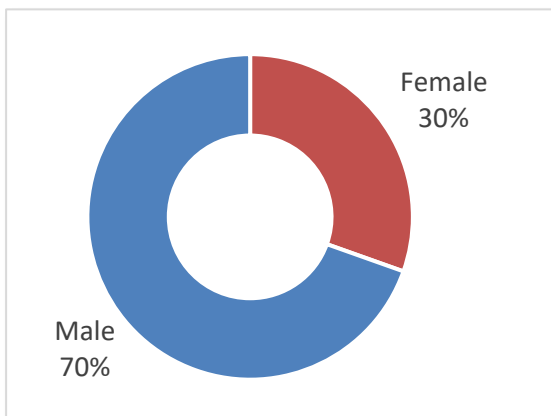


Figure 9. Deaths by Gender

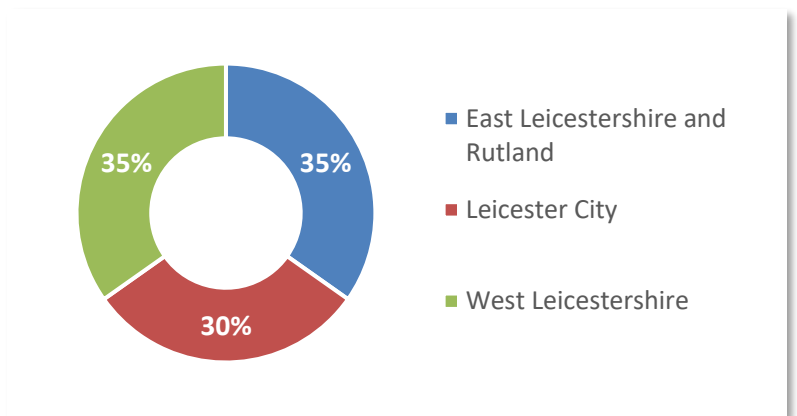


Figure 1. Deaths by ICS Place

As shown in *Figure 9. Deaths by Gender*, 70% of reviews completed in 2022/234 were of males, and 30% of females. Those people were resident across all three ICS places, almost evenly, as illustrated in *Figure 1. Deaths by ICS Place.*

Intersectionality

The LLR LeDeR team engaged in the pilot LeDeR Intersectionality train the trainer programme run by the National LeDeR Team. This was to train the remaining LeDeR workforce in culture, race and religion sufficiently to enable the reviewers to consider these factors when carrying out LeDeR reviews and make suggestions to improve services to reduce premature mortality for people with a LD and Autistic people from minority ethnic communities.

Important Statements from LeDeR

Although a lot of positive, encouraging and at times courageous work and breakthroughs have been seen in the past year for the LLR LeDeR Programme and LLR Health and Social Care System, there are two areas that require serious attention.

1. *There remains a systemic culture of acceptance with the misuse of the Mental Capacity Act (2005) for People with a Learning Disability and Autistic people. LLR LeDeR urges our local system to act now and enforce the MCA and ensure it becomes intrinsic to our everyday care and support to people with a LD and Autistic people.*
2. *Secondly, there is no doubt that some people with a Learning Disability receive inconsistent care regarding some of the basic healthcare observations. LLR LeDeR has seen the cases of a number of people who died as a consequence of malnutrition, all of whom were not weighed when they should have been. LLR LeDeR urges the seriousness of rectifying this failure.*

"The Home had two 55-inch TVs delivered and staff saw him trying to take one and put it in his room and he insisted he wanted one, so the Home contacted his Social Worker to get authorisation to get one for him. He also wanted one of the office chairs from the staff office so he helped himself to it and would sit on his swivel chair watching Family Guy and Mrs Browns Boys on his 55-inch TV to his heart's content!"

Causes and Circumstances of Death

In this section, we summarise the circumstances and most common causes of death of people with a LD and autistic people.

Cause of death by demographic group

Age Group

It is clearly shown in Figure 2. Cause of Death by Age that the most frequent Cause of Death (CoD) was respiratory illness and that this affected most age groups, notably prominent in people aged between 41 and 70.

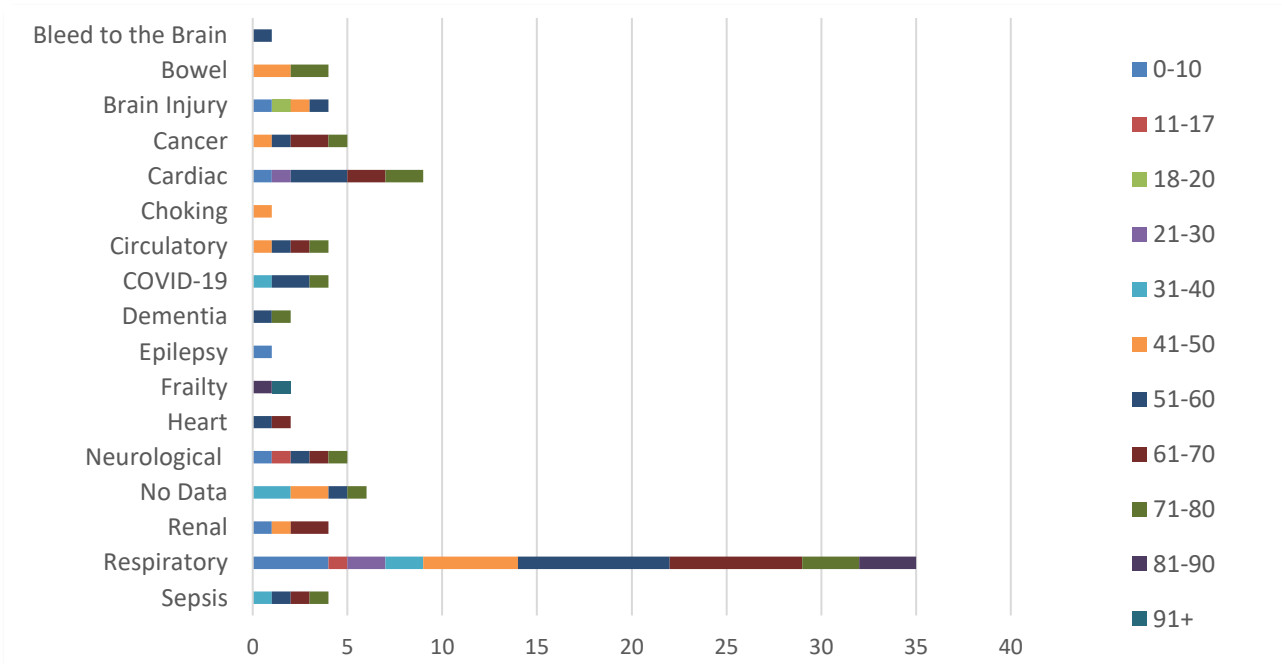


Figure 2. Cause of Death by Age

Breaking down of CoD by Ethnicity is also shown in *Figure 3. Cause of Death by Ethnicity*

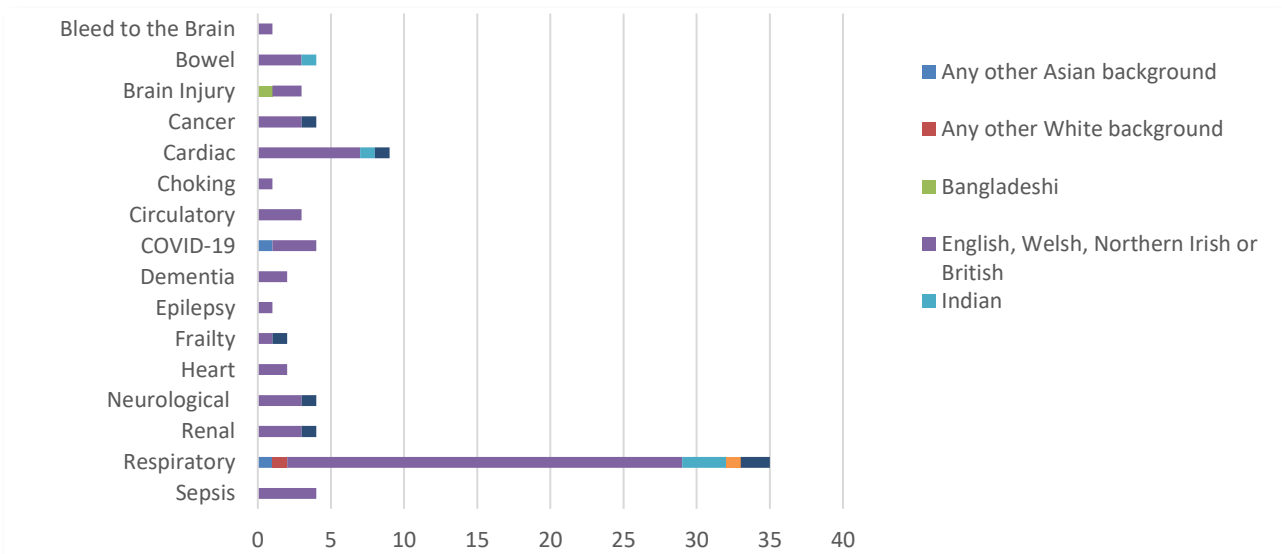


Figure 3. Cause of Death by Ethnicity

Leading Causes of Death

Causes of death in reviews completed in 2022/23 are laid out effectively in Figure 43. Causes of Death, shown below. Respiratory remains the leading cause of death, followed by Cardiac and Cancer.

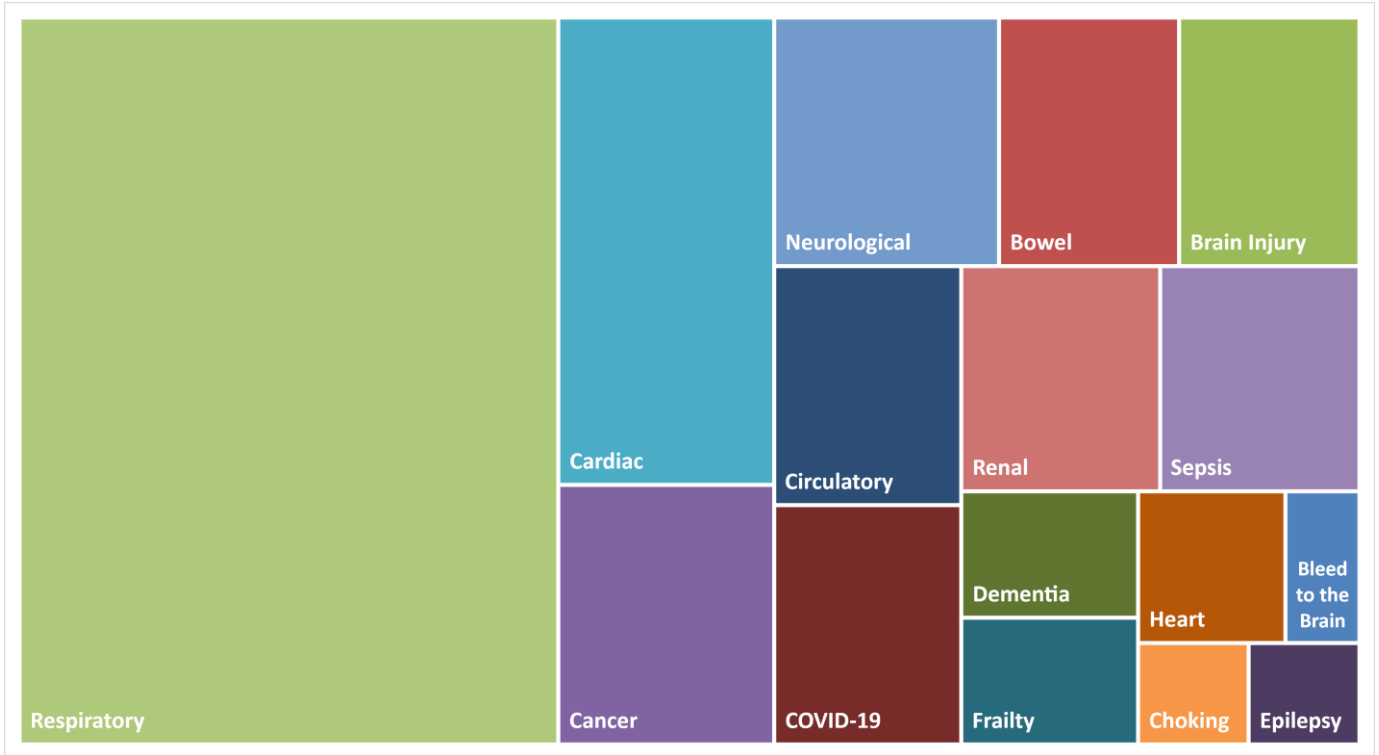


Figure 43. Causes of Death

Respiratory Deaths

Deaths from respiratory causes remains the leading cause of death for those in LLR reported to LeDeR. The Respiratory themed analysis can be found in the LeDeR 2021 – 2022 annual report. This year we were able to concentrate the Respiratory themed analysis further by analysing the deaths of those from Aspiration Pneumonia.

Cancer

Although deaths from cancer remain relatively low LLR LeDeR made the decision to revisit all the deaths from cancer reported into the LLR LeDeR Programme since 2017 up to the end of March 2023. This was to identify any inequity and offer assurance and safety in our local population. Analysis identified there were even numbers of males and females who sadly died from cancer or as a contributory factor. Since 2016, the total number of deaths from cancer is 3%, rising to 4% when including cancer listed as a contributory cause of death. There are no trends observed in the type of cancer causing the deaths of those people who have sadly died and received a LeDeR Review. Cancer screening information can be found in the section on Preventative Healthcare.

Quality of Care

High quality health and social care is of paramount importance for people with a LD and Autistic people. However, evidence has demonstrated that this is sometimes not the case and sadly, the impact on this has the potential to contribute to early or avoidable mortality. Focused LeDeR Reviews are graded in two areas, the overall quality of care the person received and the availability and effectiveness of services. The score is an overall judgement on the care the person received, it is not reflective of one service but of all the services who worked with the person as an entirety. This is the first year that grading of care has been implemented by the LLR LeDeR Programme in line with the LeDeR Policy (2021).

The breakdown of the grading can be found in *Appendix I*.

Context for grading of care 2022/23

Scoring of 1 for Quality of Care: This is related to a case that was on hold for several years following a police investigation, safeguarding enquiry and patient safety review. The actions taken from this were addressed by the relevant authorities and LLR LeDeR was satisfied by those reports and actions to redress the findings locally which reflected the grading of care at the time.

Scoring of 2 for Quality of Care: Those reviews were reflected with onward referrals and investigations to the necessary safeguarding, patient liaison and complaints boards required.

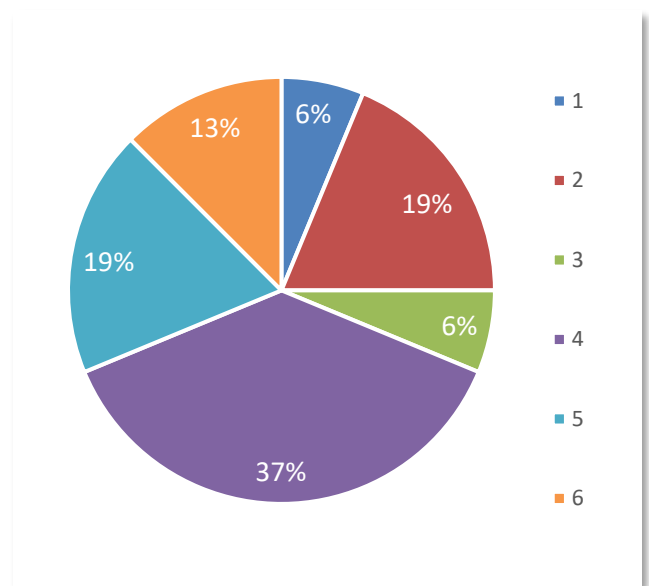


Figure 54. Grading of care

Scoring of 6 is outstanding and care we wish to celebrate and learn from; this can be demonstrated by the following:

Outstanding Positive Behaviour Support and Functional Analysis assessments from the Outreach (now known as Crisis Response Intensive Support Team - CRIST) and Community LD Teams reviewed as and when required and re-referrals picked up quickly. The outcome here was that acute hospital admission was completely avoided due to the high standards of community care delivered.

Some examples of positive learning related to availability and effectiveness of services:

- Regarding the communication between the lady's carers and her GP practice there was clear evidence of good communication between the care provider and GP calls were responded to very promptly and requests for home visits were always met positively.
- The LD Annual Health Check was started via telephone call and finalised with a second appointment that was face-to-face to conduct the physical health and wellbeing checks. The GP and Nurse worked together to carry out a high-quality LD Health Checks.

It is important to recognise a level of bias, as initial reviews are not graded and generally do not alert or amount to lives and deaths that have caused concern. Therefore, focused reviews are more likely to lean towards care that requires a higher level of learning into action.

Overall, the Quality of Care was favourable to higher standards, two thirds of people had satisfactory or good quality care. Although this leaves one third of people in receipt of care falling short of expected good practice.

Six Key Themes

Nationally it was requested for the first time, that all systems theme each of the learning into action into the one of six themes. As this was the first year, there is no comparable data.

In LLR, *Table 1. 6 Key Themes - learning points* shows the number of actions (learning points) related to the 6 key themes.

Theme	No. of learning points
Equality and Disability Issues including reasonable adjustments	97
All statutory duties related issues including Mental Capacity Act including end of life planning issues and DNACPR.	87
Quality of care issues in care delivery, serious incidents, and multi-agency investigations	140
Care Coordination issues including pathway issues and transition	145
Information Sharing including family involvement and documentation issues	170
Skills, knowledge and competency issues including training requirements, carers training and education.	85
Grand Total	724

Table 1. 6 Key Themes - learning points

The area of highest concentration is with regards to information sharing, including family involvement and documentation issues. This is broken down again in *Table 2. Sub-themes - learning points*. (Please note only top 10 sub themes included.)

Sub theme	No. of learning points
End of Life Care	67
Care coordination	67
Communication	59
Care Planning	57
Reasonable adjustments	53
Deteriorating Patient	47
Family Involvement	47
MCA	45
Diagnostic Overshadowing	33
Person Centred Care	28

Table 2. Sub-themes - learning points

Top areas of learning

End of Life Care, Care Co-Ordination, and Communication.

End of Life Care

Learning

“Updating of records was not completed when decisions had been made about End-of-Life Care and no hospital admissions. This prevented them from remaining in a familiar environment with familiar people supporting them. They died in hospital when they could have died at home.”

“The provider felt that they had to advocate for them to receive end of life care with them at home rather than in a hospital setting.”

“Conversations around end-of-life planning and respect form prior to last episode of care: Opportunities were missed to listen to them and gather their wishes as to how they wanted to be treated at EoL. They did not have a ReSPECT form completed until they were admitted into hospital at their last episode of care. Their family member stated that this is something that they would have liked to have been involved in creating.”

Positive Practice

“They died a dignified death at home as planned for by those closest to them. They had an advanced care plan RESPECT form and DNACPR. All professionals involved in their life were aware their health was deteriorating and was for comfort care at home. They were actively treated wherever required and the multidisciplinary team (LD Team, family and GP) worked in co-ordination with care and compassion for them.”

“It was acknowledged that they were coming to the end of their life, and they were supported to die at home. They had an advanced care plan describing their wants and wishes for the end of their life and this was explained in an easy read manner by the care home and GP. Their RESPECT form and DNACPR were all explained to them, and they were able to be in control and supported in a personalised and dignified manner with the necessary reasonable adjustments provided.”

“They died surrounded by the people they loved the most.”

Care Co-ordination

Learning

“They were losing weight, demonstrated in regular weight records and a referral was made to dieticians. They were eating and drinking as normal. The referral was declined, presumably due to the primary care options not being exhausted prior to the referral. Build up drinks were prescribed, the weight loss continued, and a cancer diagnosis was suspected by the GP. The GP requested a blood test due to concerns of cancer and wanting to instigate the 2-week wait pathway however there were delays in taking the bloods. During this time, they had laboured breathing and were taken to hospital where they sadly passed away. The cancer was looked at and suspected after they passed away.”

Positive Practice

“The Acute Liaison Team supported them in hospital. Providing valuable information and raising best interests concerns with the ward consultant and suggesting a need for an IMCA.”

“Good evidence of care co-ordination from the GP liaising with their family and carers and implementing the end-of-life care pathway in a timely and appropriate manner following their initial Alzheimer's diagnosis.”

Communication

Learning

“There was no clear communication or discussion with their family or the care provider as to what was causing the urinary retention. They were discharged back to the care provider with a medical procedure in situ with no clear plan in place in relation to the presenting complaint and management of it. The care provider did not feel equipped or informed as to how to manage the rapid change in care needs.”

Positive Practice

“Regarding the communication between the carers and GP practice there was clear evidence of good communication between the care provider and GP. Calls were responded to very promptly and requests for home visits were always met positively.”

The decision has been made nationally to end the 6 key themes for this year only and as we enter into the new financial year 2023 – 2024, 10 key themes have been identified for LeDeR to map against instead, this will not be comparable for next year.

STOMP/STAMP

LLR LeDeR continues to see people with a LD and autistic people prescribed psychotropic medication, without the recommended STOMP or STAMP reviews.

Learning

- Some people were under Mental Health Psychiatry services, as opposed to LD Psychiatry, there needs to be more awareness across other directorates regarding the LDA agenda.
- Some people were prescribed Antiepileptic medication with no evidence of an epilepsy diagnosis nor prescription for behavioural management. On record analysis there were historical diagnosis of childhood epilepsy but never a review of the epilepsy or medication into adulthood. People are then living potentially unnecessarily with the side effects of antiepileptic medication.

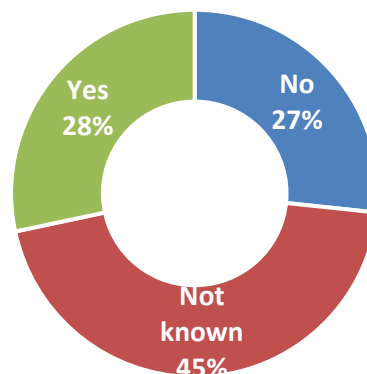


Figure 15. STOMP/STAMP review carried out for people on psychotropic medication at time of death.

- When a person's activities of daily living change, the impact of the psychotropic medication should be reviewed in line with STOMP. Often people with a LD communicate with their behaviour and this can be a sign of something underlying.
- Awareness in Primary Healthcare services that there are alternative options when prescribing psychotropic medication to people with a LD and a referral to Community LD Team should be considered, particularly in relation to PBS.

Positive Practice

- Some people had their medication reviewed in line with STOMP, this included clear rationale and decision making documented.
- There is evidence this year that some people had their STOMP medication with good effect, that reduced the medication they took to optimise their mental health and side effects.
- Psychiatry led MDT's when the person's presentation felt likely to be dementia avoided the need to for psychotropic medication and the care pathway implemented.
- Evidence of ongoing alternative management of behaviours that challenge for some people who experienced this their entire life and were never prescribed psychotropic medication. The stable and consistent support team were paramount in those circumstances.

An audit was conducted in 2021-22, data was collected by LPT, on local LLR prescribing practices in line with PBS guidance. Findings highlighted the need to improve physical and psychosocial health and ECG monitoring, as well improving review of medication within the 6 weeks of initiation, consent and MCA practice. Therefore, the past year has seen a benchmarking exercise against the NICE guidance NG11 (2015), and STOMP and the learning has been added to the STOMP trust wide action plan. The audit findings are comparable to what the findings are in LLR LeDeR.

For the next several years:

- LPT have delivered a new model service delivery to offer Intensive Support underpinned by PBS principles, the service is called CRIST as previously mentioned.
- The STOMP forum is led by the Clinical Director to lead improvements around polypharmacy and pharmacological interventions.
- Sponsorship of the implementation of the role of the Advanced Clinical Practitioner, in line with building the right support and STOMP. The intention is to recruit to in the next financial year.

Behaviours that Challenge

LLR LeDeR analysis highlights that more people did not have a PBS plan where behaviours that challenge were present than did. When considering this it would be anticipated that more people would have a PBS plan in place than would not. However, it should also be noted that not all behaviours that challenge presents risks and support needs that require PBS input.

Due to the ongoing evidence of Winterbourne View and Whorlton Hall enquiries and lengthy admissions to assessment and treatment hospitals for people with a LD and Autistic people with behaviours that challenge, the LLR LeDeR Programme advise that this is an area for consideration and review. The more that is understood by the behaviours that challenge and the communication needs that are being presented can only increase community care and avoidable hospital admissions.

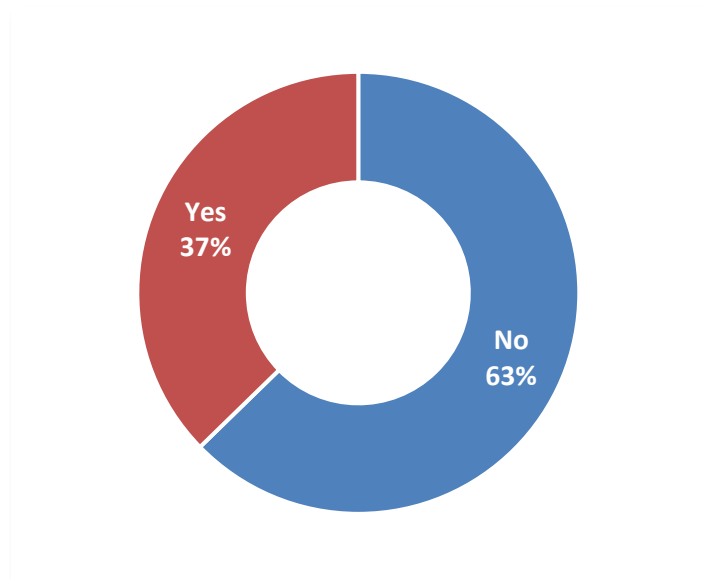


Figure 6. People with challenging behaviour who had a PBS plan in place.

Learning

“They received extensive support from Specialist LD and Autism services having displayed challenging behaviour for some time refusing to leave their bedroom. Although behaviours were common, they had escalated in frequency. Advice and recommendations were provided to supporting staff at their care setting; however, the care staff did not follow the suggested reasonable adjustments and the behaviour continued, he did not leave his bedroom until admission to hospital.”

Positive Practice

“When their personality was understood and they were listened to and cared for in a personalised way, their challenging behaviour reduced. Community LD team particularly Outreach prevented a mental health hospital admission for them. The care from the LD team was paramount and resulted in them finally having a settled and happy life (despite years of moving from placement to placement).”

“He lived in the pursuit of happiness”.

Repeated hospital admission at End of Life

It is evident to see that the EOL care of people with a LD and Autistic people in LLR is not where it needs to be yet. There are more people having repeated hospital admissions during their EOL care, than not. People with a LD and Autistic people can find hospital admissions particularly stressful and challenging, which should be avoided when it is unnecessary, in order to provide the appropriate care to the person in the community, as would be expected for all.

It has been observed through the LeDeR governance panels that the lack of 'specialised nursing care provision for people with a LD' is showing an impact. The programme has heard the care of some people with a LD who

experience behaviours that challenge and have physical healthcare needs requiring nursing care. Some people are having either their behavioural and LD needs met, or their nursing care needs met. Whereas they require both, behavioural care and management and nursing care.

Without care provision skilled in both of these areas, we will continue to see people with a LD having avoidable and repeated hospital admissions, becoming 'stuck' in hospital care having had notice handed in on their placement and frustrated care providers unable to provide the home for life and death that people with a LD and autistic people deserve.

This should be balanced with some outstanding care that has also been seen:

- Panel members describe this particular care home as brave and as a standout service. They were not a nursing care home and were not equipped to manage those needs alone (all other residents were mobile and independent). They wanted to meet the person's needs in a person-centred way, which ultimately meant they were reliant and trusting on community services supporting them all through the EOL care for them. This is not an ordinary position to take and should be commended. The person died peacefully at their care home.

LLR LeDeR is committed to a deeper understanding of the deteriorating patient and EOL care, particularly where there are concerns in those areas. This has been recognised by the LACs and LeDeR Steering Group and an agreement has been made to commit the local priority focused

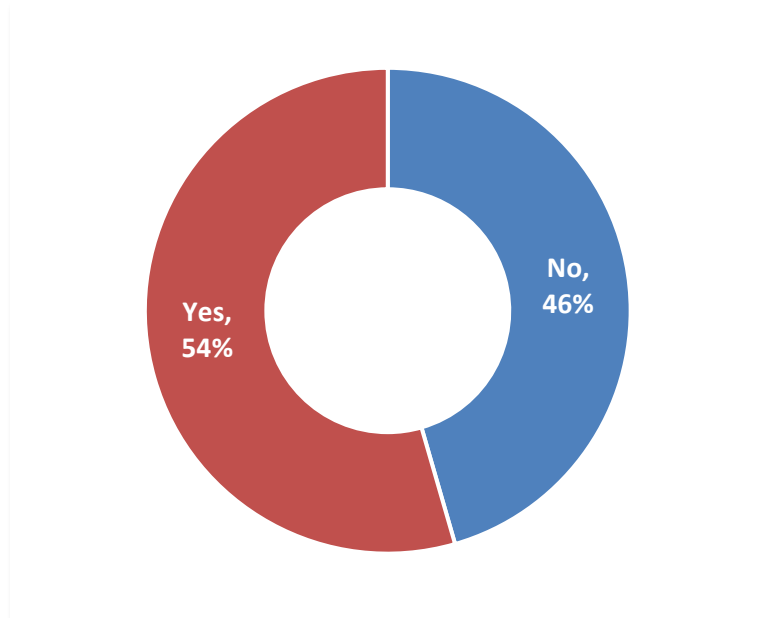


Figure 17. People on EoL pathway who had repeat hospital admissions.

review area to be *“either concerns around the deteriorating patient OR concerns around the EOL care the person received.”*

In the past year the LDA collaborative in LLR has introduced the LDA Health Inequalities group and a subgroup focusing on learning around the deteriorating person. LeDeR has been influential and a focal point in steering these groups with the learning into action. The LeDeR themes influence the future of these working groups across the system to implement the learning into action and improvements.

An example: this year has seen successful sign off and implementation of the local accessible end of life care plan.

The LDA Collaborative focus on the deteriorating patient for this year has been:

- Weight management/nutrition and hydration.
- Improving the outcomes for people with LD and epilepsy benchmarking.
- The role out of LD specific training to care homes on recognising the deteriorating person, RESTORE2 mini and SBARD.
- Venepuncture care and provision.
- Health Equity Lead Nurse post established.

Safeguarding

LLR LeDeR continue to work closely with the LLR safeguarding teams. Where a LeDeR review and Safeguarding Adults review is being conducted at the same time, the Safeguarding Adults team lead and carry out necessary communications specifically to family members, this is also on behalf of the LeDeR Team. This enables collaborative approaches, reducing stress and inconvenience to families already under stress and upset. A memorandum of understanding is being drawn up to establish this process formally during the coming year.

“A gentle person who had a good sense of humour and someone who enjoyed being sociable.”

Preventative Healthcare

Venepuncture

Venepuncture is one of easiest and the most widely used medical tests to diagnose and manage people's health. However, this can be extremely challenging if a person is not compliant with the blood taking procedure and carries risks.

Learning

"They did not have a blood test throughout their life at the GP surgery there is no evidence of a referral to the Community LD Team for desensitisation work especially after concerns were raised back in 2017 and up to the time they passed away."

"This person who had severe LDs, autism and displayed behaviours that challenge. Attempts to provide blood desensitisation support had been made over the years, but with little effect, and there were MDT discussions but there appears to have been a delayed response to best interest discussions and action around blood taking intervention. There were difficulties with the use of the Mental Capacity Act and the level of restriction that was required for successful venepuncture in the community. This person sadly died from the cancer that was in question."

"LD Team completed desensitisation work, but blood taking attempts were unsuccessful. It was decided not to do any blood tests. This was despite conventional antipsychotic medication prescribed (known to carry more side effects) most of their life. There is evidence that indicates the lack of provision available for people with a LD and behaviours that challenge with regards to blood taking when more restrictive practice under the MCA is required in community care."

"It was clearly difficult to progress through for the required blood tests and medical investigation when the person did not respond as hoped from the desensitisation."

Positive Practice

"District Nursing services would do home visits to obtain blood even though they would have been able to access the surgery. This was because it was so difficult to do a blood test and they would always have several blood vials taken to test for everything to minimise the number of times a blood test would be required. This was planned for and instigated by the GP."

"They were supported to attend all health appointments including ECG's and blood tests for metabolic monitoring."

Vaccinations

There are preventative healthcare measures that are available on rolling NHS programmes, the aim is to prevent avoidable mortality through vaccinations and screening for early detection of changes. Everyone should be given the opportunity to partake in and be aware of the available programmes. There are a number of occurrences that can affect engagement and opportunities for vaccinations for people with a LD and autistic people and therefore, reasonable adjustments are often required.

The LLR LeDeR programme, as mentioned earlier, is able to utilise only local data, manually recorded as opposed to reporting direct from the LeDeR web-based platform and the information below is reflective of this for 2022-2023.

Flu Vaccine

People with a LD, their family carers and paid supporters are entitled to a free flu vaccination.

The person’s choice, history and consent is important. Respiratory illness remains the leading cause of death for people with a LD in LLR. It is also known that if those around the person are vaccinated against flu, then the person themselves are less likely to contract it. Reasonable adjustments are pivotal in increasing the uptake of the flu vaccination for people, where required the nasal vaccine can be considered as an alternative with the planning and agreement of the GP practice and the person and support network. In LLR it is encouraging that 70% of people had their flu vaccine in the last year of life (Figure 18. Flu jabs), this should continue to be encouraged and increased. People should also be encouraged to attend their LD Annual Health Checks where further reasonable adjustments and opportunities can be discussed.

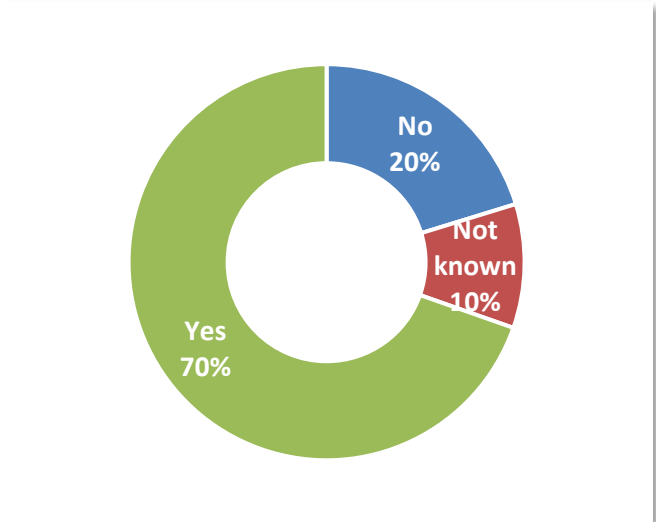
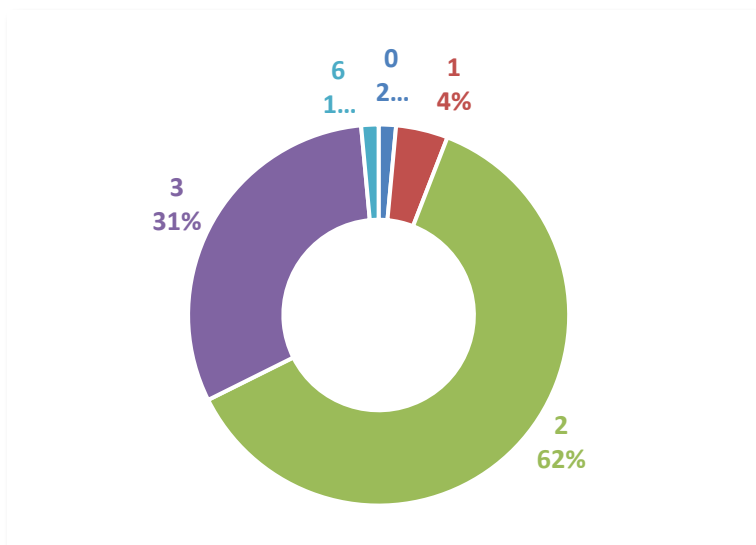


Figure 18. Flu jabs received.

Covid Vaccine

The Covid-19 pandemic struck the world in 2020 and the years that followed remained challenging for the entire population. For people with a LD and autistic people these challenges were particularly heightened and difficult; the social isolation masks, absence from families and loved ones. The change of routine and testing were demanding, tiring and for some sadly, catastrophic. The Covid vaccination programme offered some relief and protection as well as new challenges to overcome. This year has seen a decline on the number of deaths from COVID-19..

shows only 2% of people who died and not had a COVID vaccine at all. 4% had received a single vaccine, 62% had received two, 31% had received three vaccines and 1% had even received six.



In 2022 LPT was one of the lead organisations in rolling out mass Covid vaccination programmes which enabled the LD and autism leaders to influence the mobilisation of the LD and autism vaccine programme. This offer was extended until March 2023. The LD and autism vaccine programme consisted of hubs that were identified to be more accessible to the LD and autism population, that were staffed and supported by health professionals who had the skills and knowledge to overcome barriers and provide reasonable adjustments.

The teams identified a proportion of people with LD and autism who could not access the LD vaccine clinics and were able to organise a roving programme where health professionals went out to people's homes with great success.

It is important to acknowledge that there remains a portion of the population of people who did not achieve all 3 of their vaccines and some who were not successfully vaccinated. The themes for this were the complexity of restrictive practice that would have been required and would have necessitated the involvement of the Court of Protection. For some people, it was deemed not to be in their best interest by the MDT and family/carers.

There was media interest and press release which can be found in *Appendix II*.

Screening

Cancer screening is an extremely valuable and important preventative healthcare measure. However, there remain some barriers to access and even more so for people with a LD and autistic people.

Cervical Screening

In 2022-23 for those eligible for cervical screening only 19% of people attended, with 70% of people not attending. Cervical screening is known to be one of the more challenging of the screening services offered in terms of uptake, due to the intimate nature. Nevertheless, people should always be offered the appointment, never ceased from the screening register due to having a LD or autism and alternative checks can be offered such as, abdominal checks and menstrual tracking.

The LD PCLN team planned and co-ordinated a specialist project on cervical screening to increase the uptake for people with a LD in LLR.

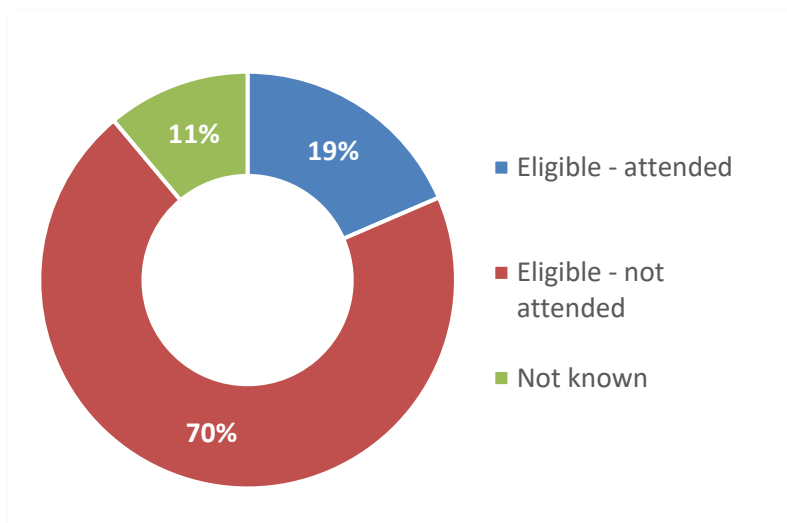


Figure 7. Cervical cancer screening attended (Where eligible)

The team were successful in securing funding for the project from the LLR Cancer Screening Network. The initial project was due to run in March 2020, however due to the Covid-19 pandemic the work was suspended for two years.

The collaborative work between LPT and UHL was a complete success, yielding 100% success rate for every person on the day. The nurses have since reflected upon this session, the tilt chair was of exceptional benefit for all who attended for cervical screening, and it is hoped that this chair can be purchased and used for primary care next year. The detail of person-centred care and reasonable adjustments, including transport was found to be of most benefit.

The team are considering locations nearer to the individuals as well as plans to run regular clinics for non-attenders. The LD PCLN team have also worked collaboratively with one Primary Care Network in LLR who have put forward a proposal to run an enhanced service for LD specialist cervical screening clinics into 2023-2024. The team are considering local data analysis and impact going forward into the next financial year.

Breast Screening

In 2022-23, 33% of people eligible for breast screening attended, with 53% of people not attending. Breast screening along with breast checking are imperative for preventative healthcare and people should be adequately supported with relevant reasonable adjustments, reminders and prompts where required. The easy read video is still available to support people with LD and autism on breast screening, on the internet, that was developed by LLR and should be used and promoted.

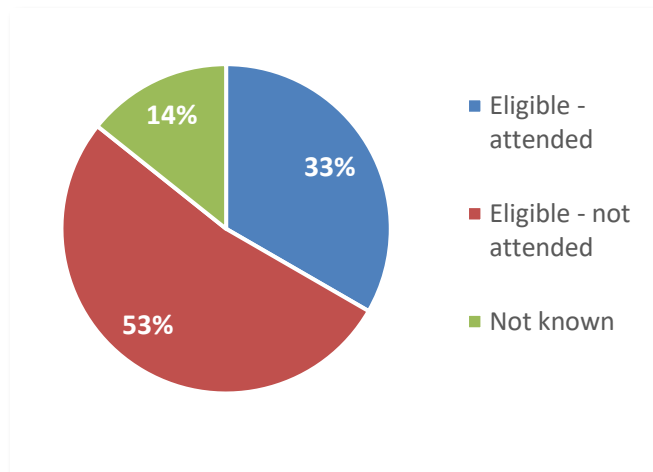


Figure 8. Breast screening attended (where eligible)

As part of the drive to increase equality for people with a LD, the LD PCLN team are working with the Breast Screening Service in LLR. The aim is to improve access by ensuring that the breast screening service are aware of individuals that have a LD and can offer them appointments at their Equality Access Clinic by using accessible letters that are more easily understood. The AHC template has also been revised and now alongside all screening questions are the links for easy read, accessible information awareness which can be printed and given during the check.

Bowel Screening

This year has seen 58% of people eligible, attend for their bowel screening appointment, leaving 32% of people not attending. Bowel screening usually yields one of the highest attendance rates due to its less invasive nature and we would be expecting this figure to rise. There has been some encouraging positive practice seen this year in LLR LeDeR with regards to supporting people with a LD to respond to the bowel screening invitation and on occasions work has been undertaken to support people in their best interests where this has been deemed necessary and appropriate. This will be continued into the next financial year.

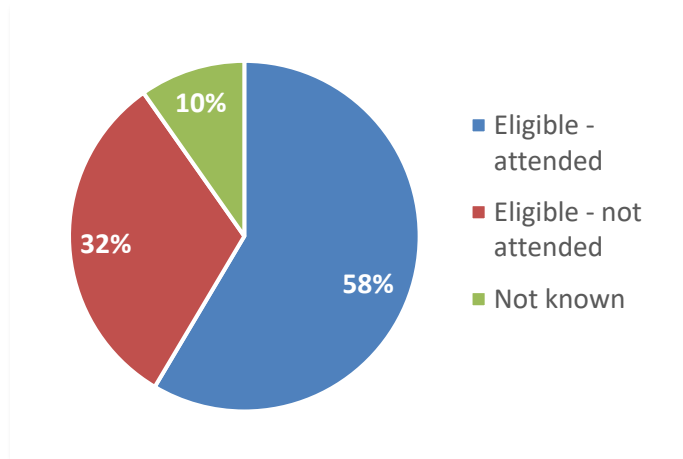


Figure 9. Bowel screening attended (where eligible)

Abdominal Aortic Aneurysm (AAA) Screening

AAA screening demonstrates that approximately half of the eligible people through the LeDeR programme are attending but half are not, further work is required to understand this better.

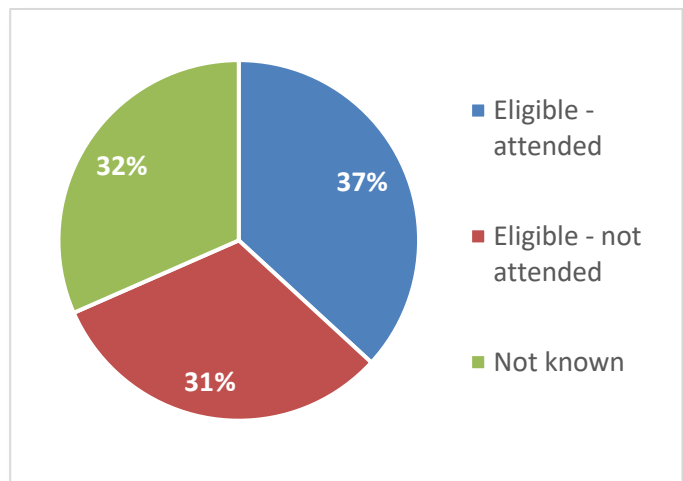


Figure 10. AAA screening attended (where eligible)

LD Annual Health Check

The past year has seen the highest achievement in LD AHCs, achieving in LLR just over 80%, which is reflected in LeDeR too. The GP practices and LD PCLN team as well as others including people with a LD and their family, friends and carers should be commended on the success in driving forward this agenda.

LLR is now second in the whole of the Midlands (and in the top ten in England) in terms of the number of annual health checks completed. Two years ago, LLR was one of the lowest performing areas in the country.

LD PCLNs, offer regular support and training on AHCs for primary care and

social care partners – including GP practices – to improve access to health care and reduce health inequalities for people with a learning disability. The team are currently running a pilot project to increase the AHC uptake for those hard-to-reach communities and people who may find accessing the AHC challenging. See [Appendix III](#) for further information.

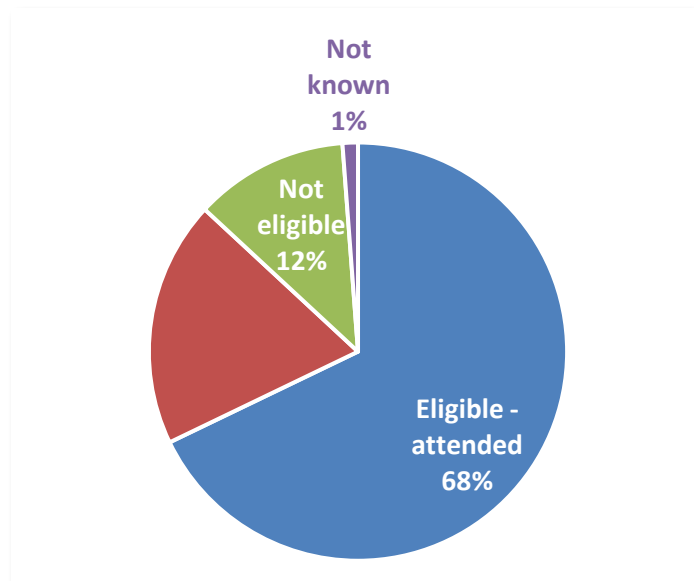


Figure 11. LD Annual Health check attendance

Thematic Analysis

Thematic analysis is a qualitative research method that can be widely used across a range of epistemologies and research questions. Lincoln and Guba's (1985) criteria for trustworthiness during each phase of thematic analysis is widely used and often viewed as the "gold standard" for qualitative research. This ensures reliability, credibility and trustworthiness in our analysis process. This framework has been adopted in LLR for the purposes of the LeDeR Learning into Action and demonstrates the systematic structure of thematic analysis undertaken for the LeDeR reviews in LLR.

There were five areas of focus for LLR LeDeR during 2022 – 2023, which were:

- Aspiration Pneumonia - *priority focused review area agreed at Steering Group.*
- Covid-19 – *Requested from Steering Group.*
- Weight - *[this was carried out but is still underway and will be explored further with completion in 2023-2024].*
- MCA - *[this work will also continue be being explored and finalised through into 2023-2024].*
- Ethnic Minority – *Mandated focused review area and agreed at Steering Group.*

Aspiration Pneumonia

Aspiration pneumonia is categorised by the Office for National Statistics (ONS86) as a preventable medical cause of death. Aspiration pneumonia results from accidental infiltration of food or other substances from the mouth or stomach into the lungs that leads to a chemical pneumonitis, lung injury, and resultant bacterial infection. [NHS website 2022](#)

It is diagnosed through a series of medical history, signs and symptoms along with clinical investigation. One of the challenges with aspiration pneumonia in people with a LD is that often no one actually sees the person breathe in an object or food or saliva. People are sometimes unable to communicate what and how the event occurred, putting them at greater risk.

29 LLR LeDeR reviews of people who died from aspiration pneumonia were identified for analysis, time period not restricted, this only included adults with a LD. A workstream was convened which included Consultant in Respiratory Medicine, Acute LD Liaison Nurse, Specialist Respiratory Physiotherapist and Occupational Therapist and Professional Lead for LD Speech and Language Therapy. It was found that the deaths **could not be attributed to aspiration pneumonia alone**, this is because something must have precipitated the aspiration for the incident(s) to occur. The summary can be seen below.

"He loved to watch steam trains".

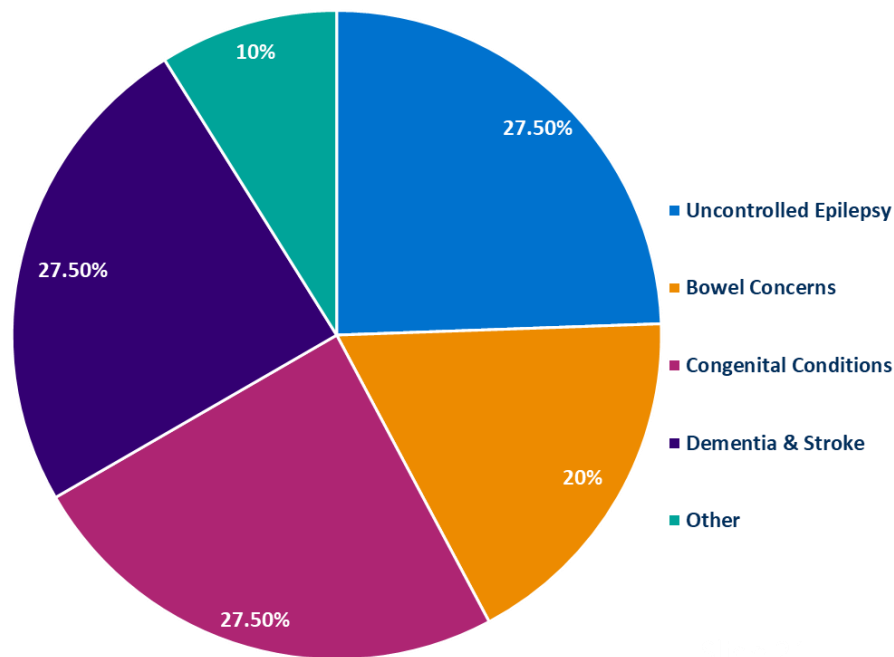


Figure 12. Percentage attributable to Aspiration Pneumonia

Sadly, 34% of the deaths were found to be potentially avoidable.

We have identified the area in the NICE Guidelines pathway that we wish to work through in LLR which is “Correct any reversible underlying problems that precipitated the aspiration”. **Error! Reference source not found.**, while *Figure 27* shows the proposed pathway.

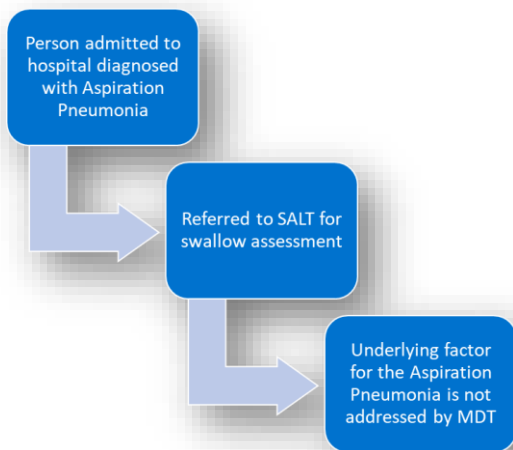


Figure 26. Current Aspiration Pneumonia pathway

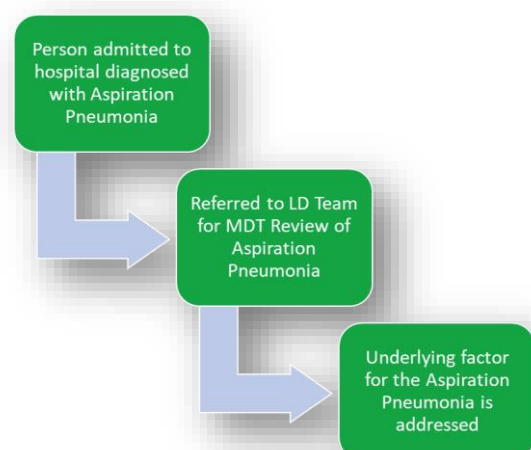


Figure 27. Proposed Aspiration Pneumonia pathway

This aims to eliminate the risk of escalation by replacing referral only to SALT with referral to LD Team for MDT review of Aspiration Pneumonia.

SMART Actions

What do we want to achieve?

To reduce preventable aspiration pneumonia deaths in people with LDs in LLR.

By creating/embedding into already existing care pathways and addressing the precipitating factors linked to increased risks to aspiration pneumonia.

A comprehensive plan has been agreed based on the findings and will be implemented with the support of the LDA Collaborative partners during 2023-24. These recommendations are ambitious and require a whole system approach. The aspiration pneumonia analysis is currently being written up as a journal article piece to enable ongoing learning and research in this area.

Covid-19

A scoping exercise was completed to review further detail to inform us on the effects of the Covid-19 pandemic. This was challenging because it is often difficult to fully understand the indiscriminate nature of Covid. However, quality of care was able to be analysed with the top 3 themes highlighted and requiring improvement in the care of people with a LD and Covid:

- The implementation of the Mental Capacity Act (MCA).
- Diagnostic overshadowing and misinterpreting signs and symptoms for behaviour and communication.
- Record keeping and clearly documenting the excellent work that is often carried out, particularly in what reasonable adjustments have been provided, the MCA and how certain decisions have been reached.

Ethnic Minority

LLR LeDeR conducted a scoping exercise on all the notifications to the LeDeR Programme since 2017 of those from a diverse ethnic background.

Due to ethnicity not currently being reliably and routinely recorded on electronic patients records (SystemOne), LLR LeDeR compared the 2020 – 2021 Census data with the LeDeR notifications for the exact same time period by way of population comparative. This information and data comparison must be used with caution as it is not without its discrepancies. Special thanks to DeMontfort University in supporting this piece.

LLR LeDeR Notifications by ethnicity

White British	85.05%
Ethnic Minority	14.94%

Census data population by ethnicity

White British	87.52%
Ethnic Minority	12.48%

The charts above show on the left the LLR LeDeR Notifications received by ethnicity during specific time period of 22/03/2020 – 21/03/2021. On the right shows the Census population by ethnicity

for the same time period. This information should be used with caution, however, demonstrates the LLR LeDeR programme are receiving the expected number of notifications of those with from a diverse ethnic background.

However, when comparing specifically LLR LeDeR Notifications from Leicester City there appears to be disparity.

Comparing the census population data of those from an ethnic minority background with the LLR LeDeR notifications received of those from an ethnic minority background, in the same time period (22/03/2020 – 21/03/2021).

Census Population - Ethnic Minority background – Leicester City	59.11%
LeDeR Notification - Ethnic Minority background – Leicester City	28.20%

We would expect to be seeing more notifications to the LLR LeDeR programme of those from an ethnic minority background from Leicester City.

The scoping exercise was then undertaken, this information includes only people with a LD whose deaths were notified to the LLR LeDeR Programme.

The top 3 main causes of death were aspiration pneumonia and covid followed by pneumonia.

Diabetes in those people from an Ethnic Minority background:

- 41% of people from an ethnic minority background had **diabetes**.
- Of those people with diabetes, 71% of people had very serious health concerns. These were concerns picked up in an emergency and had been lived with for some time, but not identified or remedied prior, including ketoacidosis (life threatening condition in diabetes).
- Almost a third of those people with diabetes had morbid obesity, this increases the risks of nephropathy, heart disease and amputation, in those with diabetes.
- 86% of people lived at home with their family and no one lived in paid care environments.
- 57% of people did not attend their LD AHC and diabetic appointments.

Covid-19 in those people from an Ethnic Minority background:

- 17.5% of people from an ethnic minority background died from Covid-19.
- Of those people who died from Covid-19 85% of people had multiple co-comorbidities.
- The average age of death was 55yrs old. The average age of death from Covid-19 in the general population is 80yrs old.
- 43% of people lived in a care home and 57% of people lived at home with family.

Conditions in those people from an Ethnic Minority background:

- 14% of people from an ethnic minority background had vitamin deficiency.
- 14% of people from an ethnic minority background had anaemia.
- 60% of people did not attend age-appropriate screening and LD Health Checks.

What else have we found out through this scoping exercise?

- There is no detail at all regarding the risk level for the person with regards to their health condition and their ethnicity in clinical records/care plans, or if they are at an increased risk to a health condition. Subsequently, there is no detail on how to reduce the risk for them.

- People were more likely to live at home with their family providing care for them.
- There were higher than expected levels of obesity observed.
- Iron deficiency and vitamin D deficiency went unnoticed, especially in care homes where risks are known to be higher, but this was not accommodated.
- Culturally appropriate health and social care to support the person's life and death, was largely not documented. Where people lived with families, they were more likely to have their cultural beliefs met during life and death.
- It is not always represented in respect forms how someone's culture should be addressed at time of death.
- Assumptions are often made about someone's cultural beliefs.
- Ethnicity is not accurately and consistently recorded. Moving forward it would be more suitable to break down the ethnic groups as opposed to grouping ethnic minorities, nobody wants to be known as "other" and this should be respectfully avoided.

Autism

This year saw the LeDeR Programme open to receiving notifications of those with a clinical diagnosis of autism, and do not have a learning disability, aged 18yrs and over. The LLR LeDeR programme has received notification of very few deaths that is not representative of the local population. This is concerning and the awareness of the LeDeR programme and the notifications of deaths of autistic people must be a priority.

In total there were 3 deaths notified to LLR LeDeR of autistic people, who were all male, there have been no notifications of females. The reviews will be completed in the coming year.

"Family was very important to him, and he enjoyed going out and socialising. On a Saturday night he and his Mum would go to the local club for a drink and a dance."

LLR CDOP LeDeR themed review

Deaths of all people with learning disabilities aged 4 years and over are reviewed as part of LeDeR programme, aiming to identify learning to reduce the increased mortality and morbidity rates seen for this cohort. During 2022-23, 10 case reviews were completed for children who had died, who met the criteria for LeDeR. A review group was convened with representation from Public Health, Childrens Social Care, UHL, LPT, ICB and the LeDeR Programme to look at these cases collectively, identify themes and learning, and to generate actions.

Of the 10 cases:

- The most common category for cause of death was:
 - Chromosomal, genetic or congenital anomalies (60%)
 - Other categories included acute or chronic medical conditions, malignancy, and infection.
- Modifiable factors were identified in 2 cases.
- Positive aspects of service delivery were noted in 7 cases.
- Mean age at death was 8.3 years (4-17yrs)
- Of the two young people who were eligible for AHCs in primary care, neither were on the GP learning disability register.

LeDeR Scope & definition: Everyone with a learning disability aged four and above who dies and every adult (aged 18 and over) with a diagnosis of autism is eligible for a LeDeR review.




Individuals with a learning disability are those who have:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with
- A significantly reduced ability to cope independently (impaired adaptive or social functioning), and
- Which is apparent before adulthood is reached and has a lasting effect on development.

"She was a lovely bubbly person and she really loved babies".

Recommendations

Key learning themes identified during the CDOP LeDeR reviews:

	<p>Children & young people being appropriately included on the GP learning disability register at the earliest opportunity.</p> <ul style="list-style-type: none"> - Ensures appropriate adjustments are made within primary care, including offer of services tailored to children and young people with a learning disability (e.g., LD vaccination clinics). - Ensures once young person is 14 years of age, they are offered an AHC. - As well as optimising overall health, can provide support with transition from child to adult services. This is also an opportunity for the GP practice to support the whole family including the needs of the parents.
	<p>Importance of communication with families.</p> <ul style="list-style-type: none"> - Complex care needs good coordination, families need to know who their lead professional is, effective transition to adult services for vulnerable young people is vital.
	<p>End of life care.</p> <ul style="list-style-type: none"> - Advanced Care Planning can be complex for children, young people and their families, whether or not they have a Learning Disability, and it is important for services to communicate and work well together to provide timely and appropriate support.

Children who have a learning disability should be on the GP Practice Learning Disability Register, to ensure that, from the age of 14 years, they are offered the opportunity for a Learning Disability Annual Health Check.

Services should ensure that:

1. At the earliest opportunity children with a learning disability are added to the GP learning disability register.
2. Inclusion in LD AHC and ensure reasonable adjustments are identified and offered at the earliest possible opportunity.
3. Individual circumstances are taken into account in terms of exceptions as it may not be appropriate for a child or young person receiving end-of-life care to be offered a LD AHC. It may be appropriate to offer a modified health check to ensure a supportive experience for the child or young person and their family.

Learning into Action

The learning into action for LLR LeDeR has a formal structured process that can be viewed in the LeDeR reporting structure at the beginning of this report. On a quarterly basis all the issues and positive practice that are highlighted from LeDeR reviews are sent to the respective service provider in order for them to develop SMART actions. The service provider then reports back to the LeDeR steering group. This is the first year it has been delivered in this way and LLR LeDeR intends to strengthen this in the coming year.

Top 3 Highlights of LLR LeDeR learning into action:

GP and Primary Care

- Improved integrated working between GP practices and LD PCLN team – enabling improved accuracy of LD registers and improved numbers of AHCs completed.
- Safeguarding, "Was Not Brought" code, is now actively in use and receiving 6 monthly updates from HIS data team, action plan will be developed from this.
- LD Primary Care Champions – seeking to establish a key person in each GP practice across LLR, including implementation of positive praise of practices demonstrating good care/positive changes for LD and Autism population.

LPT FYPC / LDA

- Accurate weight checking services for those who require alternative weighing than stand on scales. Accessible portable scales have been purchased, next step of how this will be rolled out across LLR and how wider GP networks can utilise is to be established.
- Venepuncture – seeking to establish a service appropriate for those requiring more restrictive intervention under the MCA in community care.
- Epilepsy pathway joint with UHL changes to the access to service, templates and assessments incorporating a more robust assessment of physical health and encouraging access to AHC's.

Acute Care

- Delays in access to treatment and ensuring that people with a LD are not adversely disadvantaged, there is now oversight of waiting lists by the LD ALN team.
- Limited capacity of the specialist LD ALN team to provide training and support for patients with autism and children. The capacity of the LD ALN team has been reviewed along with a business case to expand the service, which was successful and funding for an all-age LD ALN Team confirmed.
- To ensure that complex discharges are correctly identified, an audit of patients with a LD will be undertaken to confirm if they were correctly coded as a simple or complex discharge and action plan following results.

Leicestershire County Council

- Weights oversight - Care providers to understand and evidence in practice how they effectively support people with their weight management, know who they can refer to for concerns over weight management and how to make those referrals in a timely way, through training and awareness raising.
- Mental Capacity Act - Care providers to work within the Mental Capacity Act and the remit of their role. To have understanding about best interest decisions, contribute towards that decision where appropriate, working with the lead professional from health or social care, through awareness training and information.
- Reasonable adjustments - Care providers to understand reasonable adjustments and how to request this for people they support with LD and/or Autism. To make improvements through signposting care providers to LD and Autism LPT training to cover RESPECT, reasonable adjustments, hospital passports & STOMP, via Care Provider Bulletin and Provider Forums.

Leicester City Council

- Transitions care, ASC frontline staff are now discussing at point of contact with families the difference between Children's Act and Care Act. This is to ensure and support realistic support care and treatment as the child becomes an adult.
- To overcome language barriers, LD social care now have an agreement with Leicester City Council language services, that if interpreter required by phone in emergency, this can be provided. Family's preferred method of language is obtained prior to any meetings/visits and interpreter secured to enable person(s) to express views.
- ASC frontline staff are striving to secure culturally appropriate residential placements. When sourcing placements the individual's culture, language and communication needs are identified to match to the best available care provider.

"She had a wonderfully close relationship with her mother and sister and people would talk about how much her face lit up every time she saw them".

Top Ten Learning into Action

This section aims to give a final top 10 summary learning into action points from LLR LeDeR Annual Report 2022 – 2023:

1. Report the deaths of those people autism (with or without a learning disability) to the LeDeR Programme.
2. Report the deaths of those from Leicester City and from diverse ethnic backgrounds to the LeDeR Programme.
3. There is an emerging theme around the widespread misuse of the Mental Capacity Act. All services should review their practices to ensure compliance with this important legislation.
4. The practice of estimating someone's weight is a significant risk for people. People should be weighed using appropriate weighing equipment and the weight should be recorded accurately.
5. Clear plans should be created for every person with behaviour that challenges highlighting the support they require and anticipating the support they are likely to need in the years ahead. This should be reflected in future commissioning considerations in LLR for provision of residential care for those with learning disabilities as physical health and nursing care needs increase particularly towards the end of their life.
6. Care providers must be competent and confident in talking about end-of-life matters and having these meaningful conversations at the right time.
7. Screening inequalities exist and every effort should be made to improve the uptake. Barriers to non-invasive bowel screening should be rectified.
8. Better understanding of the STOMP/STAMP agenda across generic, physical, and mental health services.
9. Aspiration pneumonia happens as a consequence of a precipitating event. Identification of risk factors and ongoing management are key. The changing of pathway at discharge to LD MDT is imperative.
10. There is specialist support for people in the community who have been unable to have blood taken from standard phlebotomy, which is not always accessed appropriately. Intervention by these teams does not guarantee successful outcomes but the availability should be widely known.

Plan for 2023/24

1. LLR LeDeR projects for 2023 - 2024:
 - a. LLR LeDeR – the Mental Capacity Act through story telling.
 - b. Leading a safe programme – Review of deaths of those who live in care homes.
Weight Management – effects of poor weight management from the perspective of LLR LeDeR.

2. Restorative Supervision:
 - a. To balance the effects of compassion fatigue the LLR LeDeR Team will be engaging in 6 x restorative supervision sessions during 2023 – 2024.

3. Experts by experience:
 - a. Aim to ensure all the LLR LeDeR programme, boards, panels and where possible interviews are co-chaired by an EBE. This is from a strategy and planning perspective, creating the agenda and forming the drive and commitments of the programme.

4. Intersectionality:
 - a. The LLR LeDeR programme intends to embed intersectionality into each review, understanding local cultures, highlighting areas that are impactful for individuals on an individual and personable level, creating a diversity to the review, panels and discussions. This in turn will shape the steering group and LD&AAB.
 - b. Accurate recording of the ethnicity of people with a LD and autistic people on electronic patient records is a priority to be addressed in LLR for next year.

5. LeDeR:
 - a. To revise the membership and include more people and a wider audience i.e., registered managers of care provision for those with LDs or autistic people; mental health practitioners; Drug and Alcohol services; lay member to represent those from a diverse ethnic background etc. *[List not exhaustive]*.
 - b. To hold themed analysis:
 - i. Ethnic Minority.
 - ii. Autism only.
 - iii. Local priority focused review area, which for LLR in 2023-2024 is ‘concerns around end-of-life care and/or the deteriorating patient’.

6. Steering Group:
 - a. To hold themed steering groups directing the focus on learning into action and bringing all providers services together:
 - iv. LD AHCs.
 - v. MCA.
 - vi. EOL.
 - vii. Weight.
 - c. To receive bimonthly highlight reports from each provider service and to include positive practice. To better understand the learning into action progress more consistently.

7. Conducting High Quality LeDeR Reviews:
 - a. Receive a session on the 5 Why's is scheduled for the LLR LeDeR Team in May 2023.
8. Autism:
 - a. Support the introduction of the Autism register and autism AHC.
 - b. To work with the Patient Safety Team and Learning from Deaths team in LPT to look to improve notifications of autistic people and improve overall governance structure of LLR LeDeR programme.
 - c. Develop an autism only data collection, including additional relevant factors in autism only governance presentations.
9. The LDA Collaborative focus on the deteriorating patient workstream for next year is:
 - a. Themes from the LLR LeDeR aspiration pneumonia analysis.
 - b. EOL care for people with LD.
 - c. Continuation of improving the outcomes for people with LD and epilepsy benchmarking - this is a 3-year plan.
 - d. Continuation of the weight management and nutrition and hydration workstream.
 - e. Trialling the new plans and service delivery on for venepuncture care and provision.
10. Aristotle
 - a. To work with and alongside the Aristotle data system and teams utilising this database to reflect on findings from LeDeR.
11. Health Equity and LD PCLN team Qi projects:
 - a. Working with people with a LD in prisons ensuring the correct people are appropriately on the LD Register and appropriate LD AHC.
 - b. To re-establish the Better Health group to work collaboratively on the health equity plan which LeDeR feeds into.
 - c. Implement the transition age uptake of LD AHCs project [including CDOP analysis].
 - d. To implement the mobile vaccination unit for the coming year, to offer additional reasonable adjustments to access primary care; offer health promotion; screening and access to weighing and physical health checks.
 - e. Quality audit for LD AHCs.

"She loved having nice clothes and she had beautiful outfits and wore these with bracelets and necklaces. She had a great collection of them and wouldn't leave the home without a necklace and a bracelet."

Appendix I

Grade	Quality of Care	Availability and effectiveness of services	Grade
6	<p>This was excellent care (it exceeded expected good practice).</p> <p>Please identify in learning and recommendations what features of care made it excellent and consider how current practice could learn from this.</p>	<p>Availability and effectiveness of services was excellent and exceeded the expected standard</p>	6
5	<p>This was good care (it met expected good practice).</p> <p>Please identify in learning and recommendations what features of care that current practice could learn from</p>	<p>Availability and effectiveness of services was good and met the expected standard</p>	5
4	<p>This was satisfactory care(it fell short of expected good practice in some areas, but this did not significantly impact on the person's wellbeing). Please address these issues in your recommendations for service improvement and identify in learning and recommendations any features of care that current practice could learn from</p>	<p>Availability and effectiveness fell short of the expected standard in some areas, but this did not significantly impact on the person's wellbeing.</p>	4
3	<p>Care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to the cause of death. Please address these issues in your recommendations for service improvement and identify any features of care that current practice could learn from.</p>	<p>Availability and effectiveness fell short of the expected standard, and this did impact on the person's wellbeing but did not contribute to the cause of death.</p>	3
2	<p>Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death. Please address these issues in your recommendations for service improvement and identify any features of care that current practice could learn from.</p>	<p>Availability and effectiveness fell short of the expected standard, and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.</p>	2
1	<p>Care fell far short of expected good practice and this contributed to the cause of death. Please address these issues in your recommendations for service improvement and identify any features of care that current practice could learn from.</p>	<p>Availability and effectiveness fell far short of the expected standard, and this contributed to the cause of death.</p>	1

Appendix II

Covid 19 Coverage for LLR LD Vaccination Programme.

- 12 Oct: LD Vaccination Clinic promo interview on BBC Radio Leicester Breakfast Programme.
- 28 Oct: LD Vaccination Clinic, coverage on East Midlands Today lunchtime bulletin.
- 28 Oct: LD Vaccination Clinic, coverage on East Midlands Today evening bulletin.

13 Jan: <https://www.leicspart.nhs.uk/news/people-with-learning-disabilities-invited-to-book-in-at-specialist-covid-19-vaccination-clinics/>

06 May: <https://www.leicspart.nhs.uk/news/specialist-learning-disability-and-autism-covid-19-vaccination-clinics-open-doors-to-children-and-adults-this-spring/>

21 June: LD Week - <https://www.leicspart.nhs.uk/news/more-specialist-covid-19-vaccination-clinics-announced-this-learning-disability-awareness-week/>

21 Sept: Winter preparation - <https://www.leicspart.nhs.uk/news/specialist-learning-disability-covid-19-vaccination-clinics-reopen-ahead-of-winter-season/>

06 Oct: <https://www.leicspart.nhs.uk/news/octobers-specialist-learning-disability-covid-19-vaccination-clinic-is-announced/>

08 Nov: LD Vaccination Clinic at Highcross Shopping Centre - <https://www.leicspart.nhs.uk/news/highcross-shopping-centre-to-host-the-next-learning-disability-covid-19-vaccination-clinic/>

05 Dec: LD Vaccination clinics/last of 2022 - <https://www.leicspart.nhs.uk/news/leicestershire-partnership-nhs-trust-to-host-final-covid-19-vaccination-clinic-for-people-with-a-learning-disability-of-the-year/>

Appendix III

LD AHCs further information

Further information can be found here [Huge progress on annual health checks for people with learning disabilities across LLR - Leicestershire Partnership NHS Trust](https://www.leicspart.nhs.uk/news/huge-progress-on-annual-health-checks-for-people-with-learning-disabilities-across-llr/) [URL: <https://www.leicspart.nhs.uk/news/huge-progress-on-annual-health-checks-for-people-with-learning-disabilities-across-llr/>] (Last accessed 17/07/2023)

LLR LeDeR Annual Report 2023

Julie Gibson

LD and Autism Transformation Manager

APPENDIX B



Leicester, Leicestershire and Rutland
Health and Wellbeing Partnership

Reviews of deaths in 2022/23

83 deaths of people with a LD and Autistic people were reviewed by the LLR LeDeR Programme in 2022/23

Of those

- 3 were autistic
- 6 were children with LD
- 72 were adults with LD
- 2 were out of scope

Ethnicity

- 82% were 'White'
- 12% were 'Asian or Asian British'
- 1% were 'Black, African, Caribbean or Black British'

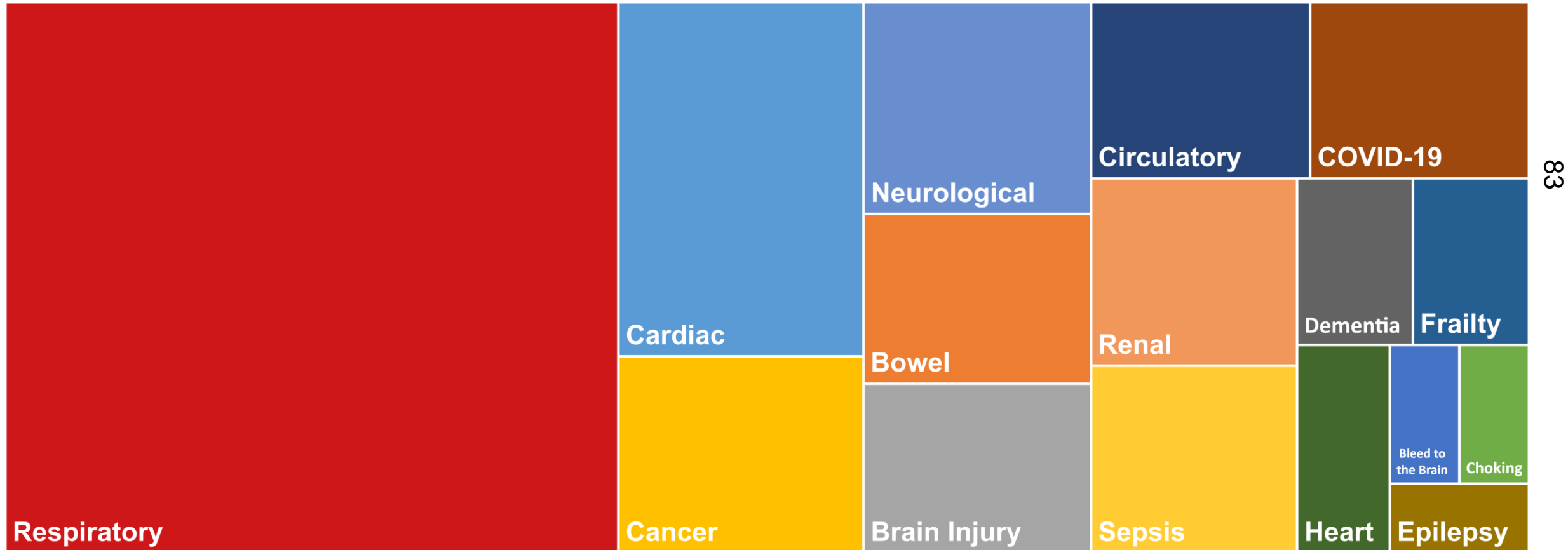
Age at death

Median age at death for those whose deaths were notified to LeDeR in 2022/23, was **62**

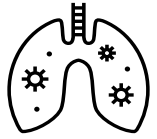
- **34% of deaths from aspiration pneumonia were avoidable**

Causes of death

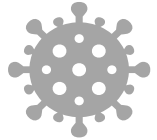
Respiratory remains the leading cause of death for those in LLR



Deeper analysis and areas of focus



Aspiration Pneumonia



Covid-19



Weight management



Mental Capacity Act
assessment



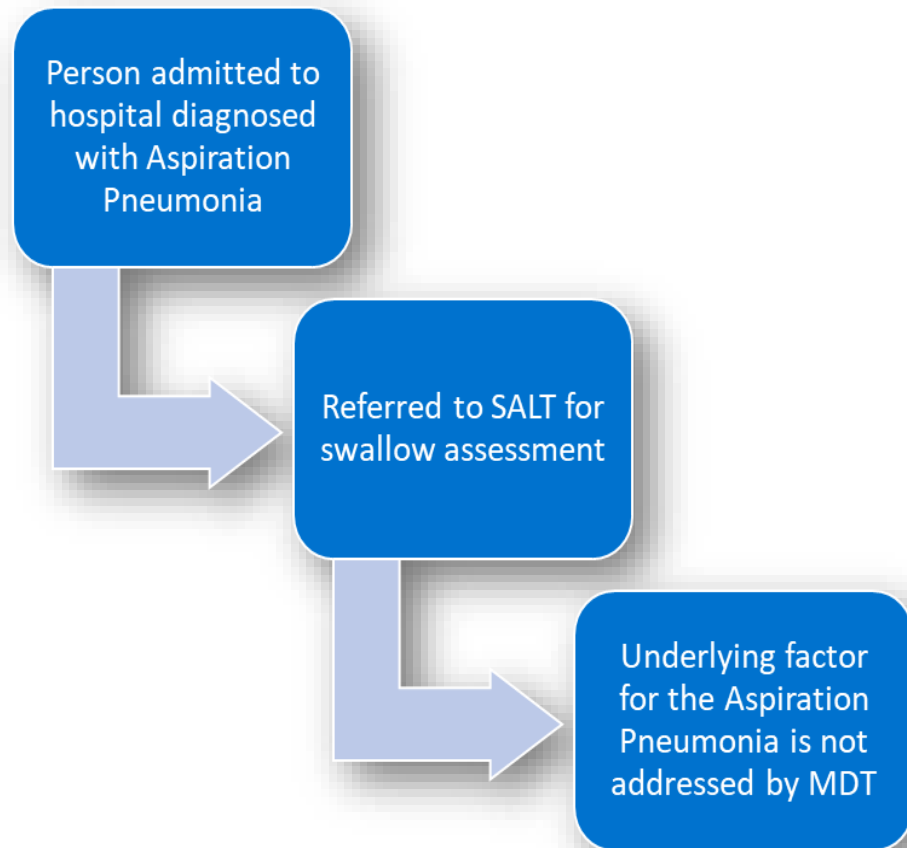
Inequalities

Venepuncture

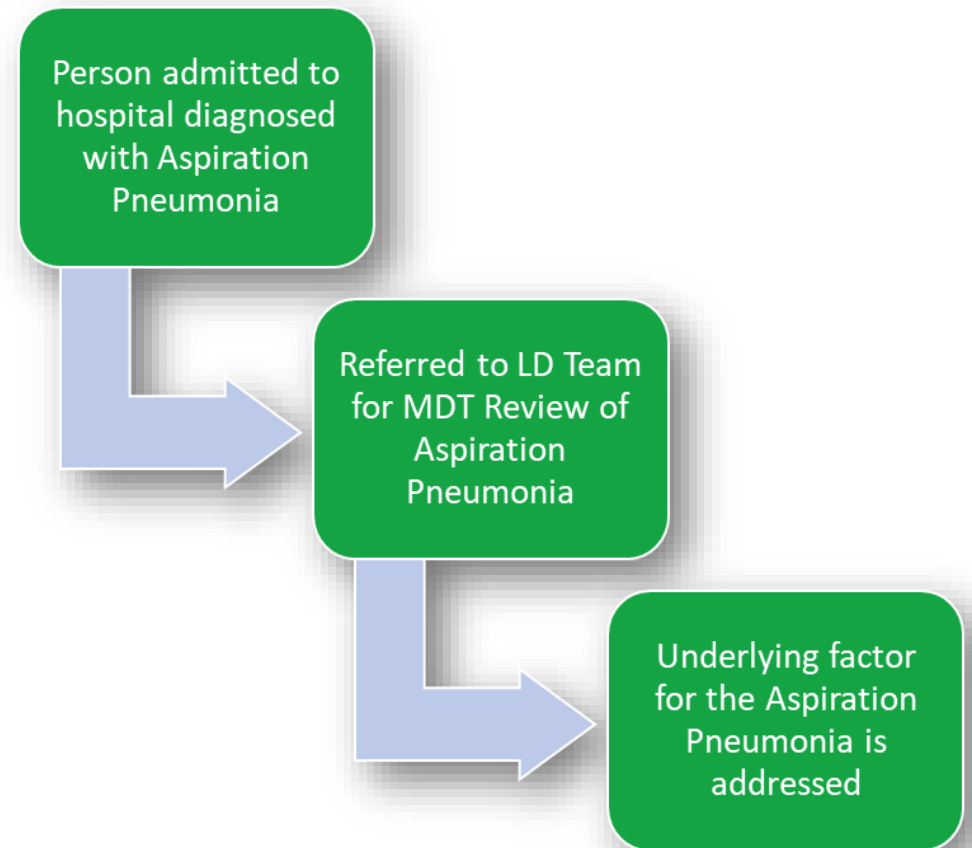
- Can be extremely challenging if a person is not compliant with the blood taking procedure and carries risks
- LLR is seeking to establish a venepuncture service appropriate for those who have received all support currently available, but require more restrictive intervention under the MCA in community care
- Successful trial with two people who had not had bloods taken for several years

Avoiding deaths from aspiration pneumonia

Current Aspiration Pneumonia pathway



Proposed Aspiration Pneumonia pathway



LeDeR 2023 TOP TEN things you can do to help

to prevent deaths of people with a learning disability and autistic people (aged 18 and over)

- 1. Tell us when an autistic person dies. Deaths of autistic people are significantly under-reported.** We cannot learn from someone's life and death if we don't know they have died. Report all deaths of autistic people (with or without a learning disability) to the LeDeR Programme. This is easy to do and takes 2 minutes at <https://leder.nhs.uk/report>
- 2. Deaths from some places and ethnic groups are under-reported.** Deaths of people in Leicester City area, and of people from diverse ethnic backgrounds are not being referred to the LeDeR Programme. This means we are unable to learn whether place of residence or ethnic background affects someone's life expectancy. Please refer all deaths to <https://leder.nhs.uk/report>
- 3. Mental Capacity Act Assessments really do make a difference.** There is widespread under-use and inappropriate use of the [Mental Capacity Act](#) across health and social care. Please review your own practices to ensure compliance with this important legislation and share your experience with others.
- 4. Weight: don't estimate, measure and record accurately.** Many of those who die early have not had their weight measured accurately or managed well. The practice of estimating someone's weight is a significant risk for people, but it is common. People **must** be weighed using appropriate weighing equipment and the weight should be recorded accurately.
- 5. Plan support for people well in advance.** Clear plans should be created for every person with behaviour that challenges highlighting the support they require and anticipating the support they are likely to need in the years ahead. The needs of people with learning disabilities as physical health and nursing care increase, particularly towards the end of their life.

Top ten continued...

6. **Talk about End of Life well in advance.** Care providers must be competent and confident in talking about end-of-life matters. Have these meaningful conversations at the right time; when people are still able to take an active part in conversations about their care.
7. **Screening, screening, screening!** Screening inequities exist, and every effort should be made to improve uptake. Barriers to non-invasive bowel screening should be rectified. Speak to your Primary Care Liaison Nurse for support.
8. **Stop prescribing psychotropic medications unless they are absolutely necessary.** The [STOMP/STAMP](#) agenda is well-established, but there's much to do. Generic, physical, and mental health services all need to understand the need to reduce unnecessary medications. In the 12 months to October 2023, over 700 people with a learning disability and autistic people in LLR have had their medications reviewed and reduced as a result.
9. **30% of deaths from aspiration pneumonia are preventable.** Aspiration pneumonia happens as a consequence of a precipitating event. Early identification of risk factors and ongoing management save lives. The learning from LeDeR shows that changing of pathway at discharge to LD MDT rather than to SALT only, **will** prevent deaths.
10. **Blood tests save lives...if you can, take some blood! If you can't, there is help available.** There is specialist support for people in the community who have been unable to have blood taken from standard phlebotomy.

And finally...spread the word!

Contact: llr.lederadmin@nhs.net

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**Leicester, Leicestershire and Rutland Joint Health Scrutiny Committee
Work Programme – 2023/24**

27 March 2024

Agenda item	Organisation/Officer responsible
CAMHS data and analysis	LPT
Gluten Free Products consultation	ICB
Update on Dental Services - plans to improve access. Follow on from report that went to June 2022 meeting.	ICB
EMAS - Clinical Operating Model and Specialist Practitioners update. Five year strategy and clinical strategy. (Information only report. Not presented)	EMAS

Future agenda items	Organisation/Officer responsible	Notes
1. Transfer of pharmacies from NHS England to ICB on 1 April 2023 plus optometrists and dentistry. Change to pharmacists prescribing medication.	ICB	
2. Leicester, Leicestershire, and Rutland Integrated Care System	ICS	This item was last taken in February 2023. Further updates to be scheduled accordingly.
3. Corporate Complaints Procedure	UHL	This item was taken in November 2022. It was requested that a full report setting out how the complaints procedure works, how the procedure has moved on including the patient experience and learning from complaints together with performance trends and dashboard data be provided to a future meeting.

Future agenda items	Organisation/Officer responsible	Notes
4. Re-procurement of the Non-Emergency Patient Transport Service (NEPTS). Contract awarded to ERS Transition Limited in June 2023 (inform Phil King when its on the agenda)	ICS	Might be worth giving ERS Transition Ltd time to settle in before scrutinising them.
5. Transfer of Haemodialysis Unit	UHL	Unit moved building in March/April 2023. A paper to be brought later in 2023
6. Transforming Care – Learning Disabilities and Autism Update	ICB/LPT	A further paper was sought for early 2024 following the report taken to JHOSC in February 2023.
7. PIFU and health inequalities	UHL	Arose out of Elective Care item at 18 December 23 meeting
8. Apprenticeships	ICB	Arose out of workforce discussion at 18 December 23 meeting
9. UHL Future Hospitals programme to include detail on modular buildings	UHL	Further report requested at 18 December 23 meeting
10. Elective Care and Operational Plan	UHL	Further report requested at 18 December 23 meeting