



Leicester, Leicestershire  
and Rutland



# LLR LeDeR Annual Report Summary 2025

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4<sup>th</sup> March 2026



LeDeR – Learning from lives and deaths

NHS Leicester, Leicestershire and Rutland is the operating name of  
Leicester, Leicestershire and Rutland Integrated Care Board

A proud partner in the:



Leicester, Leicestershire  
and Rutland  
Health and Wellbeing Partnership

# Reviews of deaths in 2024/25

A total of 90 deaths of people with a LD and Autistic people were notified\* to the LLR LeDeR Programme in 2024/25.

## Of those

- 4 people were autistic.
- 15 were adults with LD and autism.
- 58 were adults with LD.
- 13 were out of scope.

## Ethnicity

- 89% were 'White'
- 6% were 'Asian or Asian British'
- 3% were 'Black, African, Caribbean or Black British'
- 2% were 'Other ethnic group'

## Age at death

Median age at death for those whose deaths were notified\* to LeDeR in 2024/25, was **61yrs.**

*"She was a massive character with red hair and green eyes."*

# National Context



## KEY OVERALL DEMOGRAPHICS FROM THE LEDER REPORT

### SEX

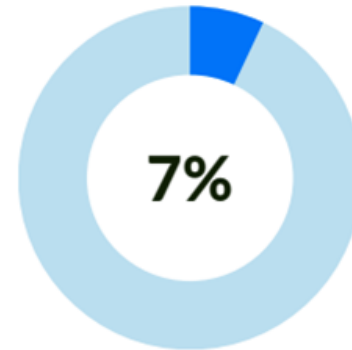
54.7% of adults notified with a learning disability who died in 2023 were male.



79.5% of autistic adults who died in 2021-2023 were male.



### ETHNICITY



7% of adults notified to LeDeR in 2023 were from an ethnic minority group.

### AGE AT DEATH

In 2023, adults with a learning disability on average die 19.5 years younger than the general population.

MEDIAN AGE AT DEATH OF ADULTS WITH A LEARNING DISABILITY WHOSE DEATH WERE NOTIFIED TO LEDER BETWEEN 2018 - 2023

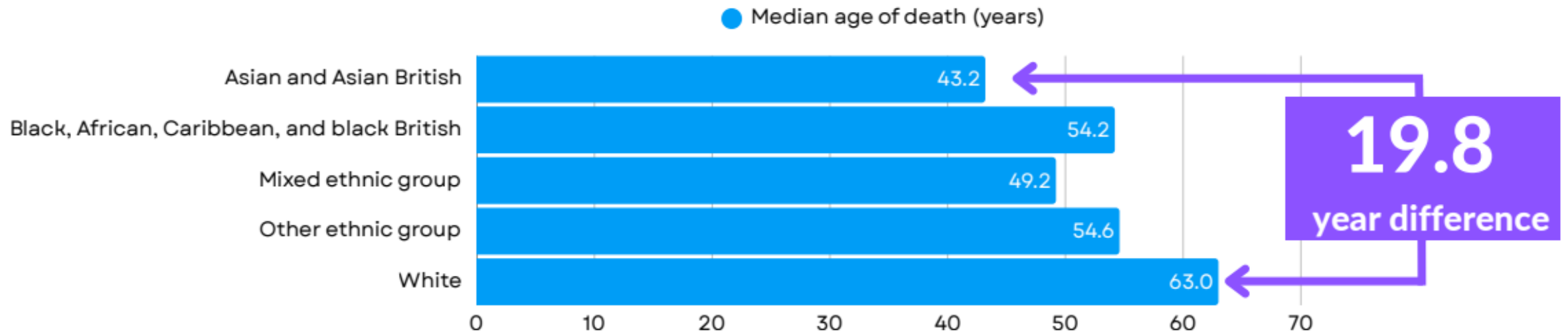
# 62.5

\*Note: Age at death is not the same as life expectancy.

# Ethnicity

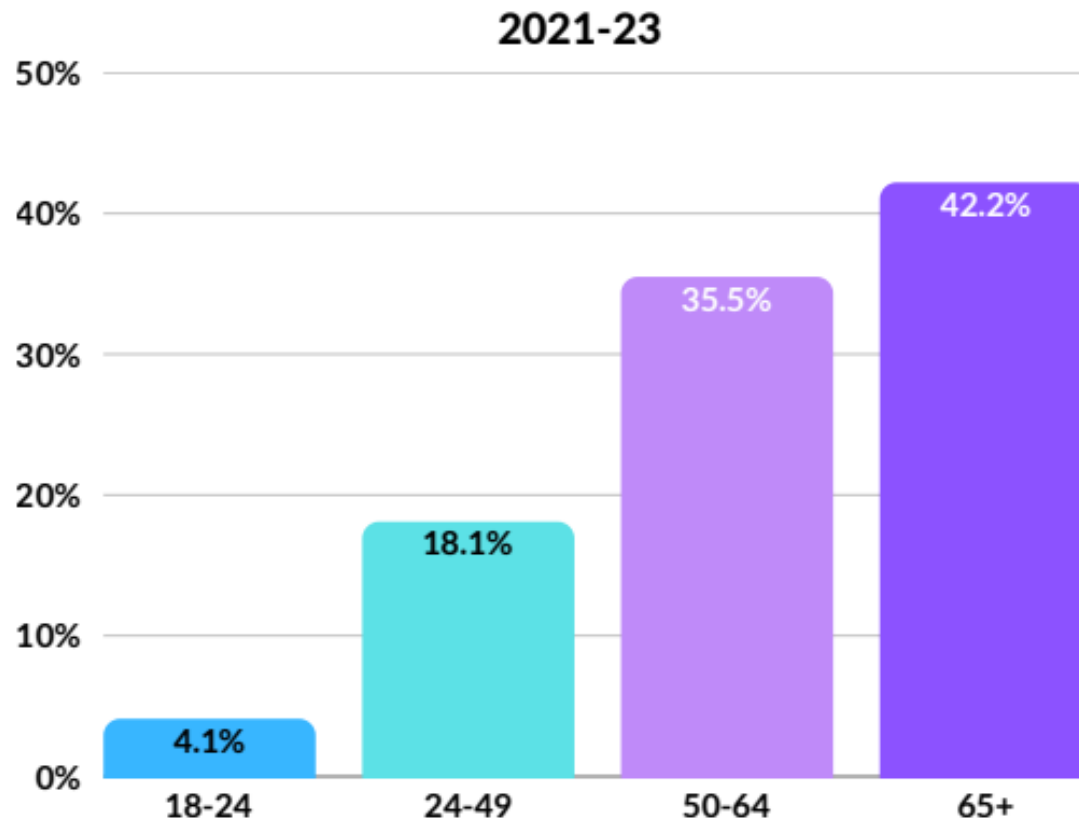
## AGE AT DEATH

Adults from all ethnic groups who were notified to LeDeR from January 2021- December 2023 had a younger median age at death compared to White adults who died.



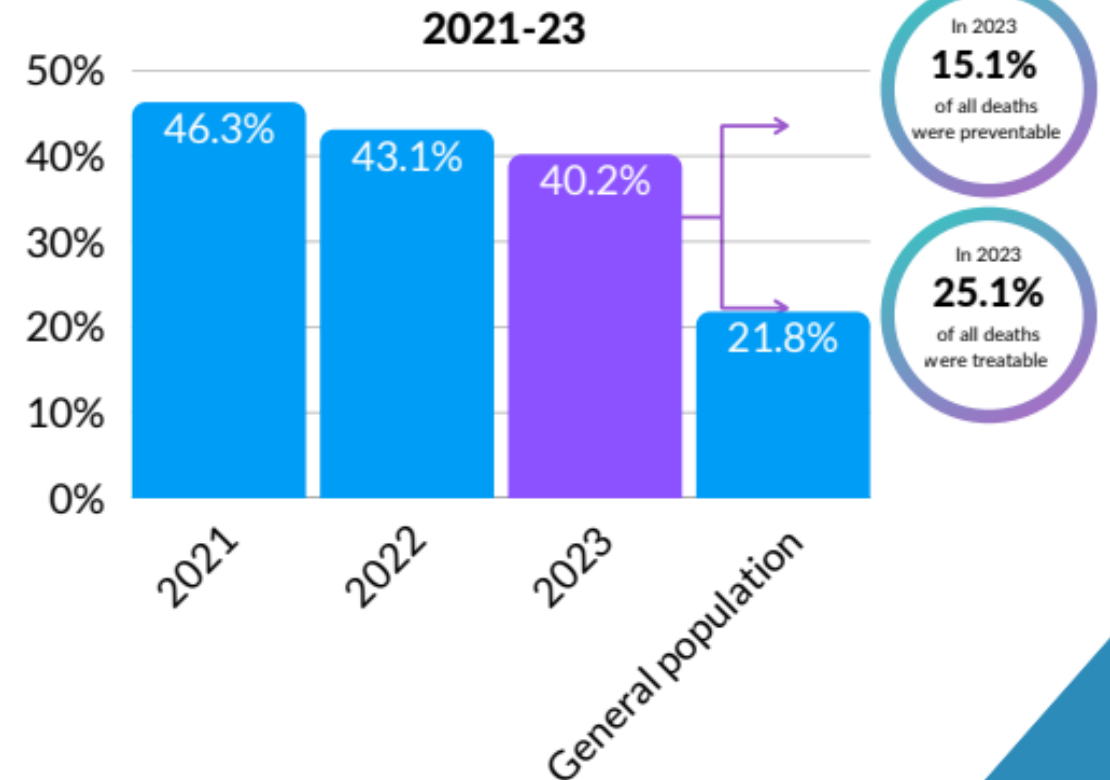
## DEATHS BEFORE 65

Nearly **60%** of adults with a learning disability who had a LeDeR review died before the age of 65 years.



## AVOIDABLE DEATHS

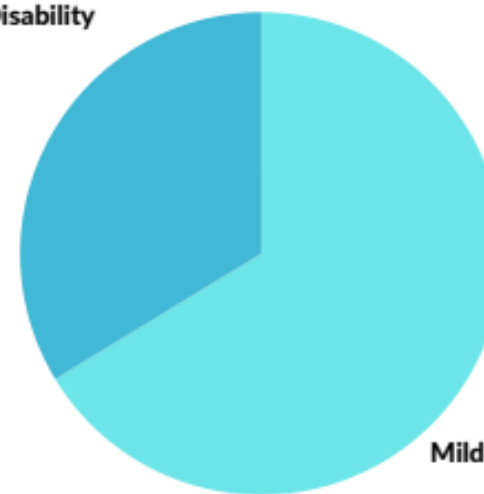
Avoidable deaths have declined since 2021, however, the rate for adults with a learning disability who died in 2023 is still nearly **double the rate compared to the general population** (data for 2022).



## LEVEL OF LEARNING DISABILITY IN THE LeDeR DATA BETWEEN 2021-2023

Of the 3,970 adults with learning disability who had a level of learning disability recorded in their initial review form, over two thirds were recorded as having a mild to moderate learning disability, and one third a severe or profound learning disability.

Severe or Profound learning Disability  
33.7%



Mild or Moderate learning disability  
66.3%

## Median age at death

Mild or moderate

**64.9**  
years

**7.3**  
years  
difference

**57.6**  
years

Severe or profound

**Table 3.8:** Avoidable mortality by the level of learning disability for adults who died from January 2021 to December 2023 and for whom a LeDeR review was completed using the latest version of the initial review form.

	Mild or moderate, Number (% of all deaths)	Severe or profound, Number (% of all deaths)	General adult* population, (% of all deaths)
<b>Avoidable deaths (preventable and treatable)</b>	1,127 (43.0%)	525 (39.6%)	21.8%
<b>Preventable**</b>	490 (18.7%)	163.5 (12.3%)	14.2%
<b>Treatable**</b>	637 (24.3%)	361.5 (27.3%)	7.6%

\* Over the age of 20

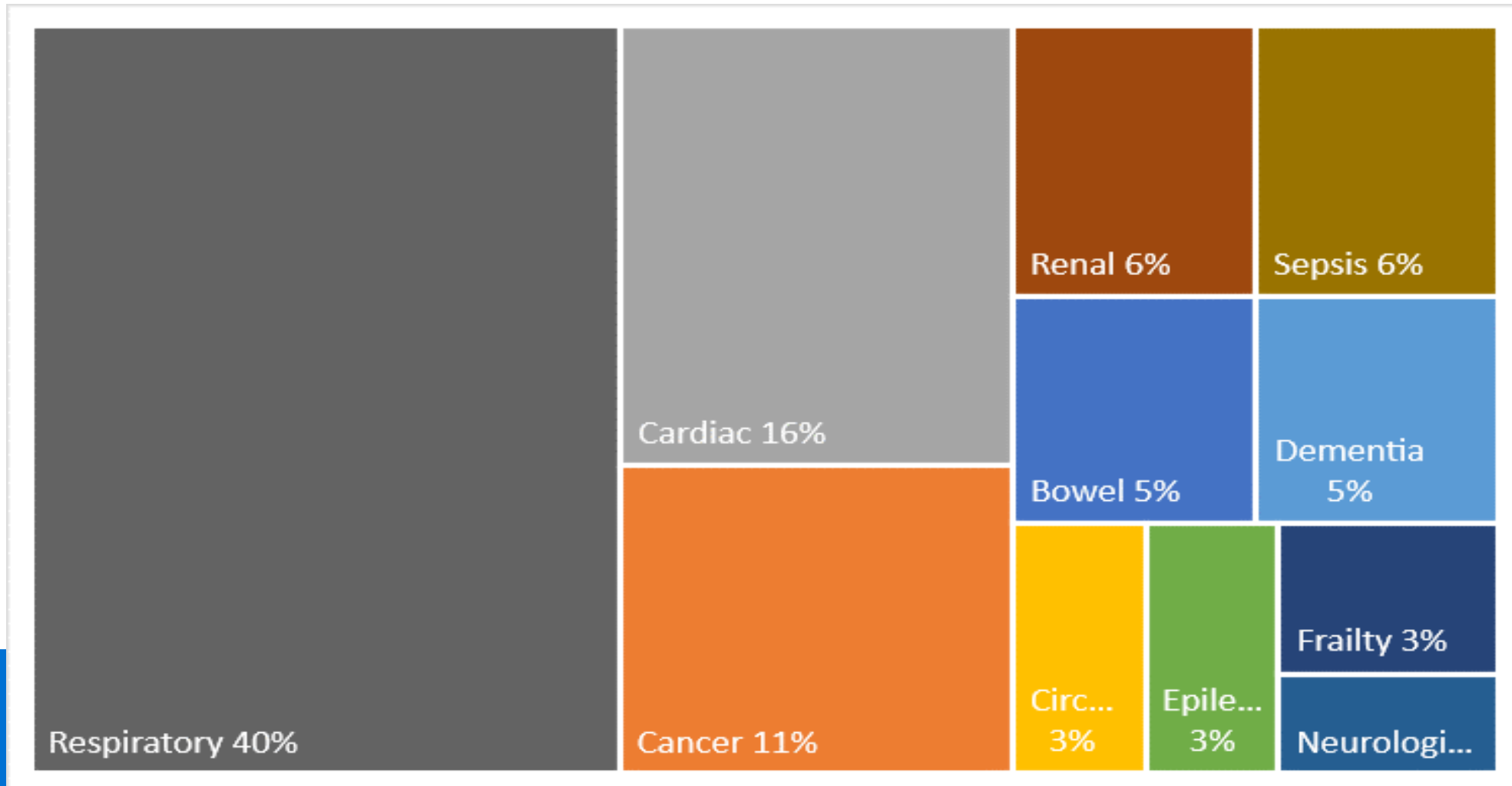
\*\*Causes of death classed as equally preventable and treatable have been counted as 0.5 in preventable and 0.5 in treatable. There were 60 deaths that were categorised as equally preventable and treatable for adults with a severe or profound learning disability. 195 deaths for adults with a mild or moderate learning disability were categorised as equally preventable and treatable.



Mild or moderate (% of avoidable deaths)		Severe or profound (% of avoidable deaths)	
Cause of avoidable death	Number (%)	Cause of avoidable death	Number (%)
Influenza and pneumonia	144 (12.8%)	Influenza and pneumonia	99 (18.9%)
Ischaemic heart diseases	129 (11.4%)	Epilepsy	67 (12.8%)
Cancer of the digestive organs	107 (9.5%)	Cerebrovascular diseases	44 (8.4%)
<b>Total avoidable deaths (% of avoidable deaths)</b>	<b>1,127 (43.0% of all deaths)</b>	<b>Total avoidable deaths (% of avoidable deaths)</b>	<b>525 (39.6% of all deaths)</b>

# Causes of death

**Respiratory** remains the leading cause of death for those in LLR



# National Context

What did people with a learning disability die of in 2023?

Most common:



Cancer



Lung infections (pneumonia)



Heart problems.

Of each,  
10 people with a learning disability  
who died in 2023.



4 people **should** probably **still be** alive today.



# Important Statements

## The Mental Capacity Act (2005)



The system in LLR continues to be unsuccessful in the correct and complete application of the Mental Capacity Act (MCA) (2005), in practise, for people with a LD and autistic people.

## Cancer



LLR LeDeR have seen a rise in people with a LD dying from cancer particularly in the past year. It is a concern that most of those people had a stage 4 cancer diagnosis, which means the cancer was at the most advanced stage.

# System Planning for 2025/26

The Clinical Executive are clear that in order to address these challenges all services, partnerships and collaboratives in LLR need to examine their response to this agenda. Please can I therefore ask that in your plans for the remainder of the year and for 2025/26 you ensure:

1. The Reasonable Adjustment Digital Flag (RADF) is fully implemented in your pathways and that staff in related services are accessing the RADF e-learning resource.
2. Improvement plans are in place across services in your pathway to improve access through reasonable adjustments.
3. Monitoring and reporting arrangements are put in place to ensure improvement plans are resulting in reduced levels of inequality of access to care for the LDA population to the services in your pathway.

*Letter from Chief Medical Officer NHS Leicester, Leicestershire & Rutland Integrated Care Board*



LeDeR – Learning from lives and deaths

# Cancer and Screening



Cervical Screening is very low this year (5% of eligible people attended).

High impact actions plans are in place and highlights the importance regarding the low cancer screening seen in LLR LeDeR.

Focused Priority Review Area for 2025 - 2026

**'All Cancer Diagnosis'**

There is an increase in deaths from cancer and those with a stage four diagnosis.

# Local Focused Priority Review Area

***Deaths of those under the age of 50yrs, with congenital conditions and/or syndromes, through the lens of intersectionality***

Median Age at Death 28yrs

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Expected deaths (44%), the person died from the condition/syndrome. Unexpected deaths (56%) were all Respiratory related. People generally survived average life expectancy for their condition.

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89% of people lived at home with family

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33% of people were from a diverse ethnic background

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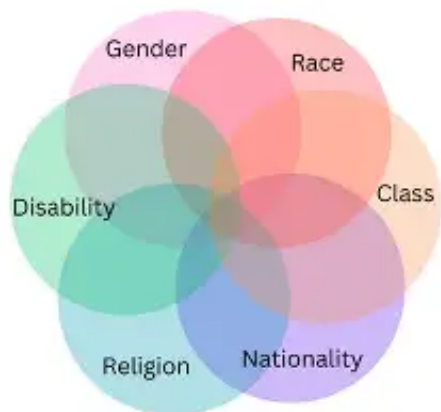
Vicarious intersectionality was observed ~ if there were language barriers experienced by the care giver; it was observed the same barriers were simultaneously observed for the person.

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MCA issues ~ appears to challenge professionals more when the care giver is an unpaid care giver, as opposed to a paid care giver. With more responsibility placed on unpaid care giver.

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Concerns with recognition of deteriorating patient and the dying patient and the difference.



# Autism



Notifications remain very low.



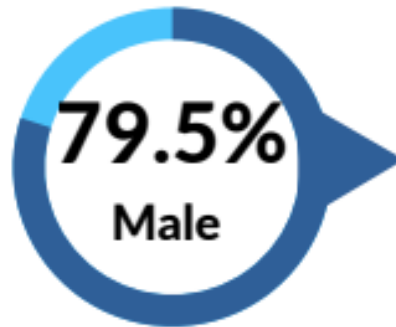
Importance of post diagnostic support service and consideration of active surveillance of health and wellbeing post discharge.



A call for autism register and autism health check.

# National Context

## KEY DEMOGRAPHICS OF AUTISTIC ADULTS WHO HAD A LeDeR REVIEW BETWEEN 2021 - 2023



164 notifications for 2021 and 2022



5 completed reviews for 2021



69 completed reviews for 2022



173 notifications for 2023



53 completed reviews for 2023



127 completed reviews for 2021-2023

# MENTAL HEALTH 2021-23

Had a diagnosis of depression

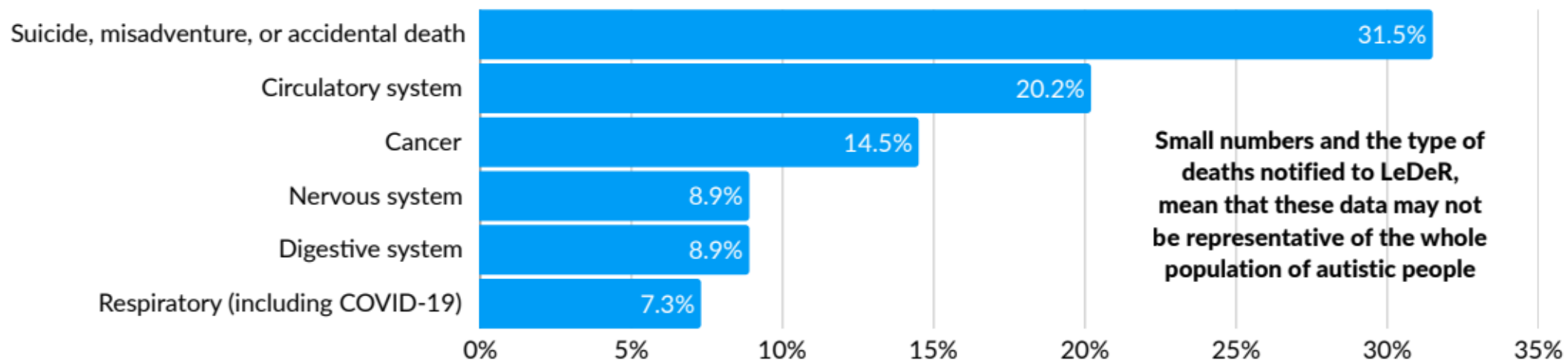
54.3%

42.5%

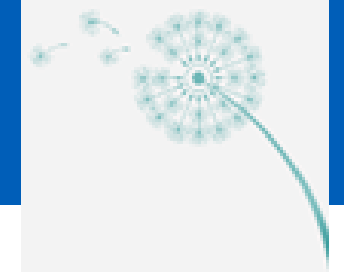
Had a diagnosis of anxiety disorder

## MOST COMMON CAUSES OF DEATH FOR AUTISTIC ADULTS WHO HAVE HAD A LeDeR REVIEW

● 2021-2023



# LeDeR CDOP



- Develop LLR wide Care Passport for children and young people with LD.

- GP LD Registers to include all children with a learning disability.

- Smoking cessation in-reach for parents and carers of children and young people with LD.



- Evaluate if the LAPPP tool would be clinically appropriate for children.

- Ensure that children and young people with a LD and a life-limiting condition are considered for the Children & Young People's Advanced Care Plan (CYPACP)

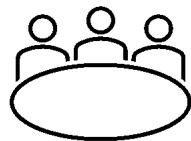


- Ensure every child and young person with a LD and medical complexity has an allocated lead medical consultant.

# Top 10 Learning into Action Points (2024–2025)

1. Report all deaths of people with LD and autistic individuals promptly to LeDeR.
2. Review and ensure compliance with the Mental Capacity Act (2005).
3. Avoid estimating weight; use suitable equipment and record accurately.
4. Create clear care plans for those with behaviours that challenge in preparation for future care needs.
5. It is important to instigate Advanced Care Plans and ReSPECT forms early enough.
6. Improve access and communication for cancer screening; implement RADF.
7. Use tools like DISDAT to identify and manage pain effectively.
8. Prevent aspiration pneumonia with holistic, multi-disciplinary care and use of LAPPP.
9. Promote cardiovascular health using 'Healthy Living Toolkits'.
10. Ensure access to specialist LD phlebotomy services when needed.

# Learning into Action



LD AHC's are at the highest they have been in LLR.

LD Community Phlebotomy & sedation clinic.

GP LD Ambassador Network.

End of life care working group.

Leicestershire Aspiration Pneumonia Protection Plan.

STOMP annual reviews increased significantly.

Healthy Living Toolkits.

ReSPECT training delivered to ED staff.

LD Week Conference in Adult Social Care.