

What was said at The London Forum



On 15th February 2024



**Robert chaired the meeting with help
from Greenwich Rep Lorraine Mason**

Who else was at the meeting



People came from:

Greenwich
Waltham Forest
Hackney
Barking and Dagenham

Lambeth
Southwark
Bromley

We had apologies from:

Lewisham
Ealing
Haringey

We looked at what was said at the London Forum in November



<https://advocacyingreenwich.org.uk/london-forum/>

We went through what was said at the London Learning Disability and Autism Partnership Board in December





I attended the London Learning
Disability and Autism Strategic Partnership
Board on Teams on 14th December 2023.



It was also attended by health and social
care bosses from across London.

This is what we talked about



I asked everyone in a poll if they would like to have the partnership board meetings face to face or stay online.

Most people said they would like to do hybrid meetings

Which means some people can come to the meeting in person and some people could stay online.



Jane Clegg said that can cause problems so they are going to sort out how they can have hybrid meetings.



Gemma Sharples came along to talk about why young people and children have long waiting times to see a speech and language therapist



They asked for a report to be written to find out why there were long waiting lists

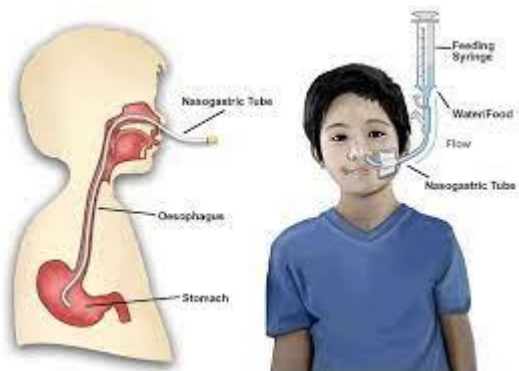
The report gave ideas of what the NHS could do to reduce long waiting times for young people to access Speech and Language services.



The main thing the report said was that there was not enough speech and language therapists and more needed to be employed.



We talked about the transfer of care project and the delay in young people not being able to leave hospital even though they are ready to go home.



They found out that a lot of the time the care provider who would be supporting them in the community says they cannot support the person, and, in most cases, it is because the young person has a nasogastric (NG) feeding Tube.

The Transfer of care project is working with providers to make sure they can support young people who have a NG feeding tube.



Gareth Harry who is the head of NHS in England came along to give an update about the Service development fund and Annual health checks.



Service development fund (SDF) is money given to boroughs to help people with a learning disability or Autism to stay in their communities and get support, so they don't get admitted to hospital.

The money should also be used to help speed up discharges from hospital and provide community support.



The next London Partnership Board is
14th March and **Robert** will be going to tell
them what you say today.

LeDeR update – Jane Kachika



- Jane Kachika from NHS England gave us an update from the Learning disability mortality review (LeDeR)

Tackling premature mortality for autistic people and people with a learning disability

Updates

Jane Kachika

LeDeR Coordinator, Learning Disabilities and Autism Programme

NHS England – London Region

February 2024

AGE AT DEATH



62.9* years old was the median age at death for people with a learning disability in 2022. This is an **increase from 2018**, where the median age at death was 61.8 years. This increase was seen despite the COVID-19 pandemic, showing a continuous improvement between 2018 and 2022.

62.9 YEARS

TREATMENT AND PREVENTION

The use of **appropriate medical treatment and prevention**, such as the use of vaccines to protect against COVID-19 and pneumococcus and mental health treatments (medications), are associated with **reduction** in the risk of an earlier age at death.



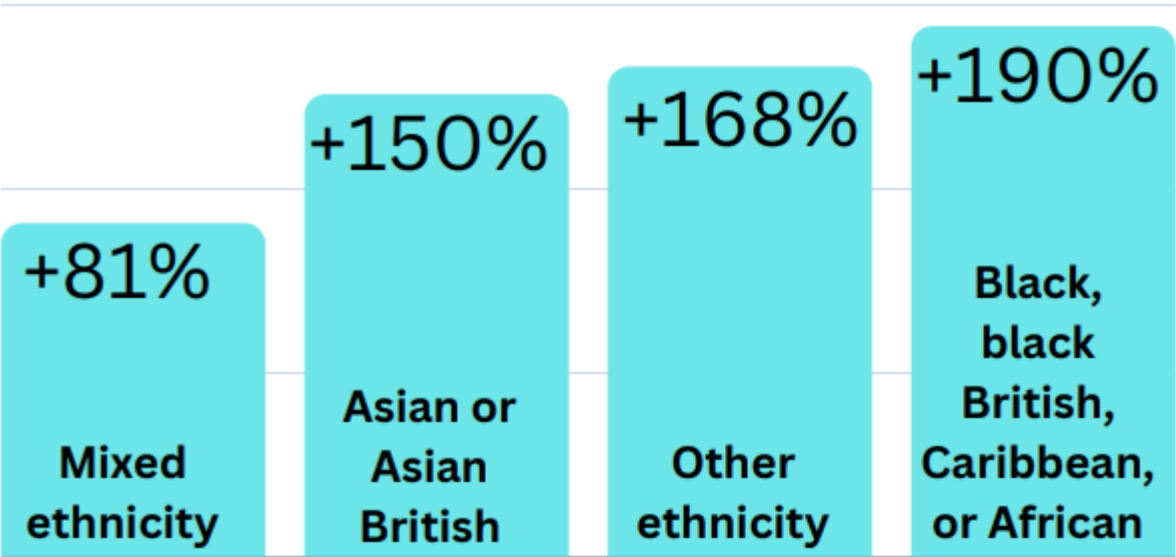
*Calculation based on adult (>18 years old) data only for both 2022 and 2018.

KEY FINDINGS OF FACTORS ASSOCIATED WITH AGE AT DEATH

■ **AGE AND ETHNICITY**

People from all ethnic minority groups died at a **younger age** in comparison to people of white ethnicity, when adjusting for sex, region of England, deprivation, place of death, and type of accommodation.

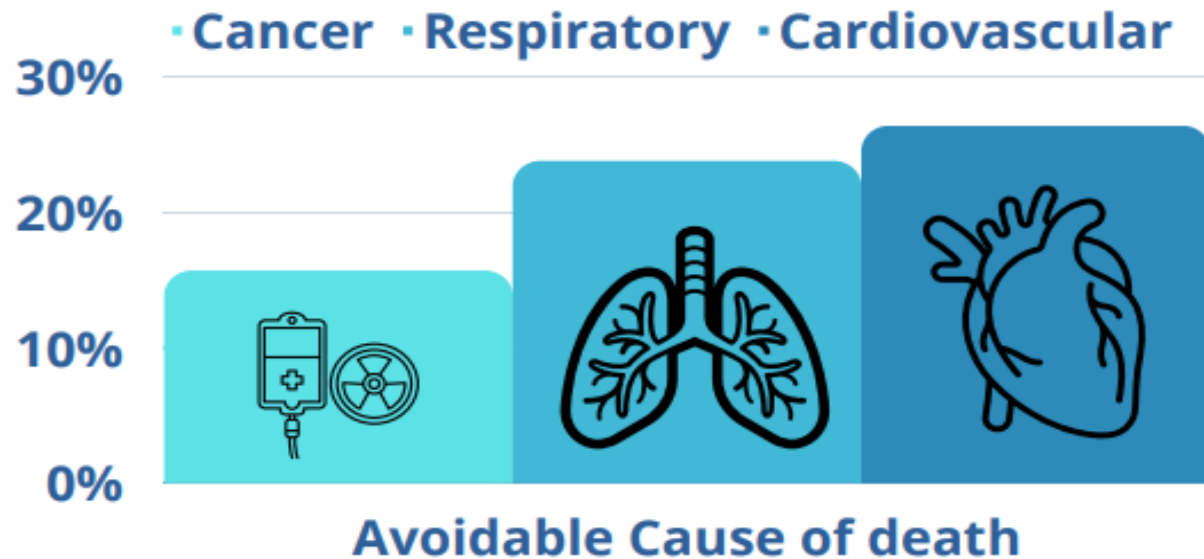
% increased risk of dying earlier by ethnic minority group, in comparison with people from white ethnicity backgrounds, when adjusting for other demographic factors



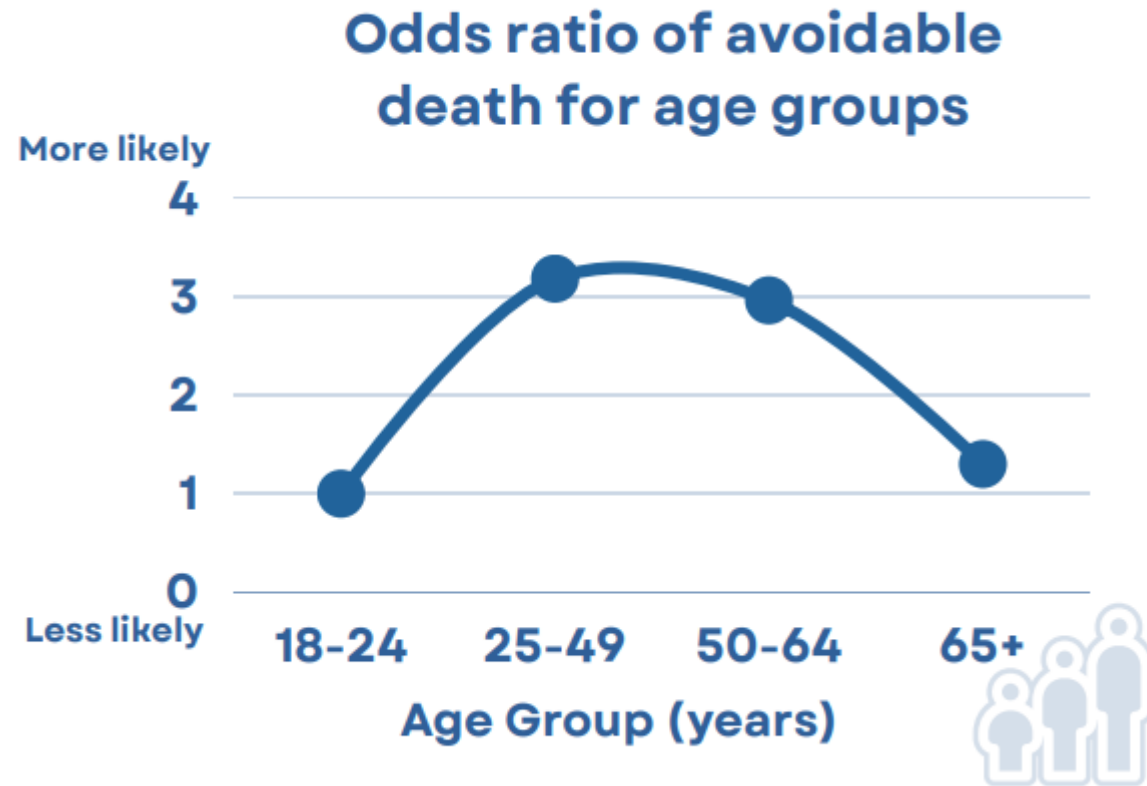
KEY FINDINGS OF AVOIDABLE MORTALITY – 42% OF DEATHS WERE AVOIDABLE

■ TOP 3 CAUSES OF AVOIDABLE DEATHS**

26.4% of avoidable deaths were linked to cardiovascular conditions, 23.8% to respiratory conditions (excluding COVID-19), and 15.7% to cancers.



**Unadjusted analyses.

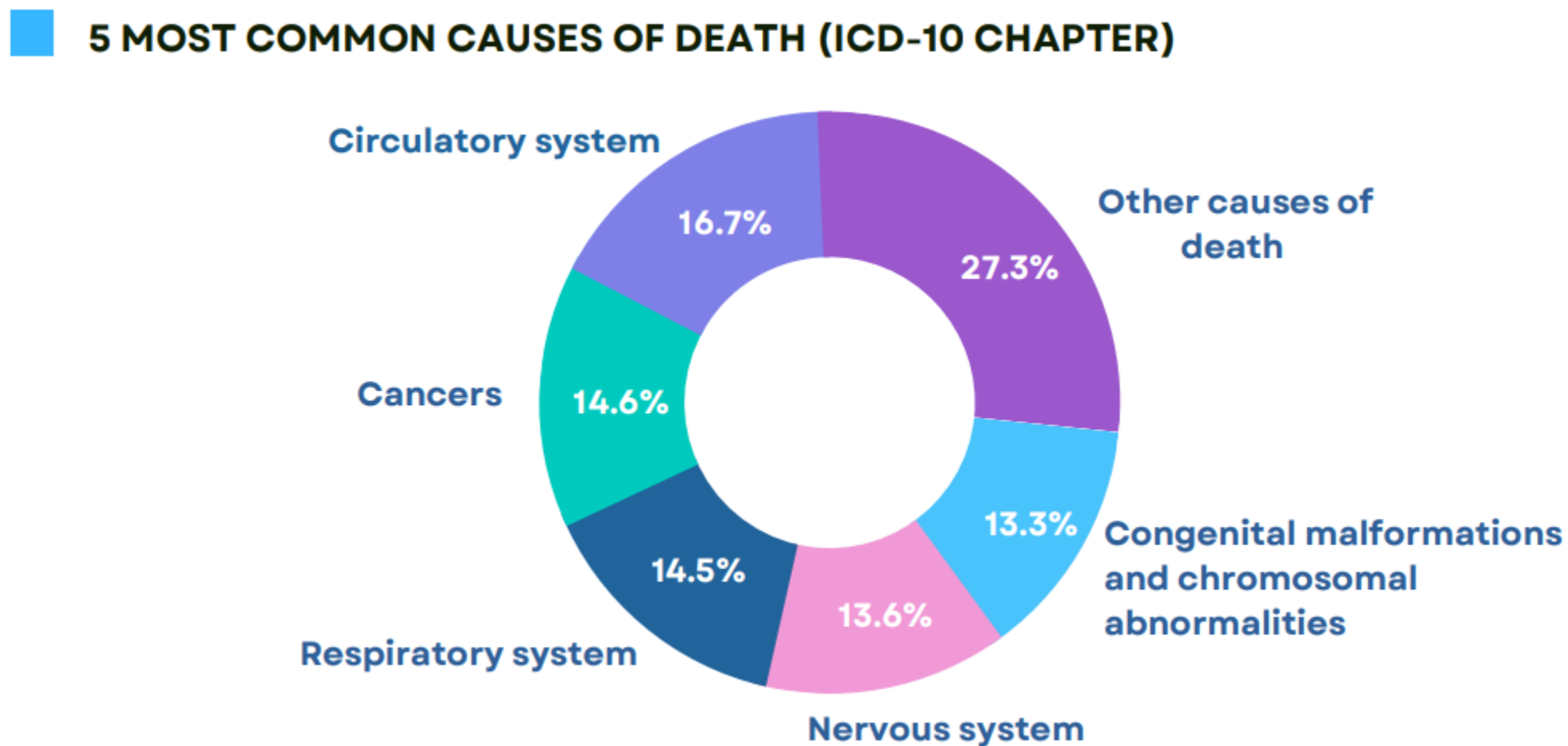


AGE AND AVOIDABLE DEATHS*

Deaths were more likely to be classified as avoidable with increasing age, peaking in the 25-49 age group before decreasing again for those who died over the age of 65 years.

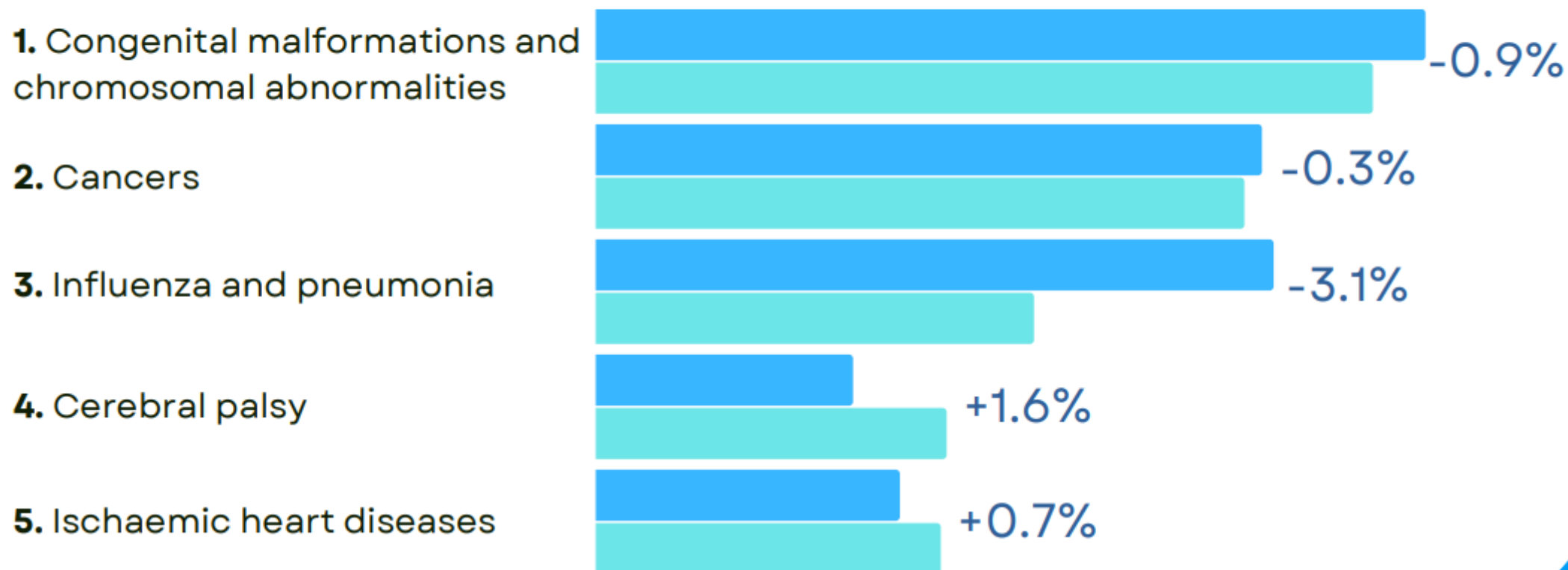
*note: deaths of people aged 75+ are defined by the OECD as not being avoidable.

KEY FINDINGS ON CAUSES AND CIRCUMSTANCES OF DEATH – LeDeR 2022 Report



KEY FINDINGS ON CAUSES AND CIRCUMSTANCES OF DEATH

5 MOST COMMON LEADING CAUSES OF DEATH (2022 VS 2018 AND 2019)



KEY FINDINGS OF FACTORS ASSOCIATED WITH AGE AT DEATH

■ EPILEPSY AND AGE AT DEATH

Epilepsy was the long-term condition that was most **strongly associated with dying at a younger age**. This was followed by deep vein thrombosis, and degenerative diseases.



■ CARE AND PREMATURE DEATH

Appropriate care was associated with **reductions in premature death**. For instance, care packages that meet a person's needs and have an appropriate use of Deprivation of Liberty safeguards to deliver care are associated with a reduced risk of a premature death.

KEY FINDINGS OF AVOIDABLE MORTALITY



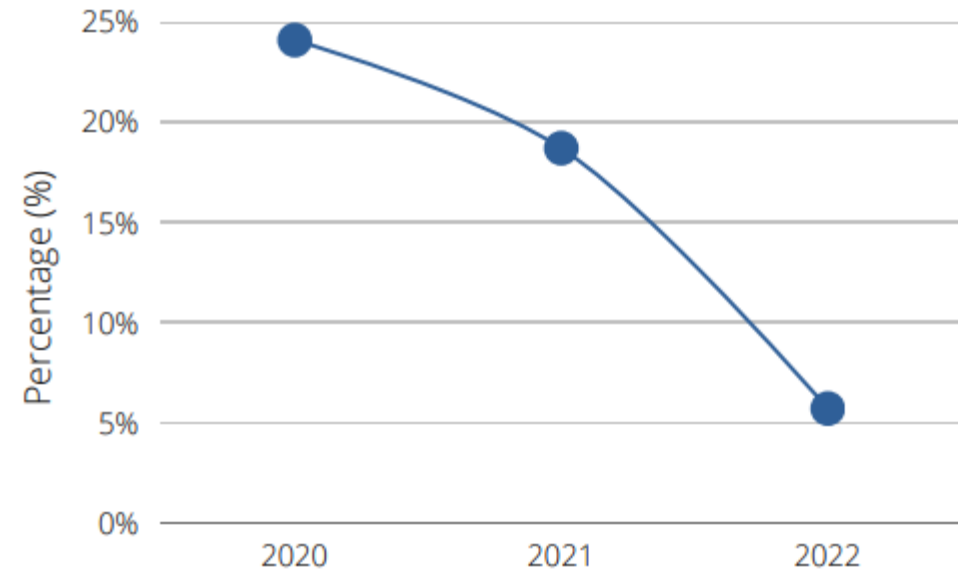
COVID-19

COVID-19 has **decreased** from 24% of all causes of death in 2020 to 19% in 2021 and **6%** in 2022 for adults with a learning disability. It has gone from the most common cause of death to the 6th most common.

1st  6th



DEATHS DUE TO COVID-19 ARE FALLING YEAR ON YEAR



THE MOST FREQUENT CAUSES OF DEATH

Underlying cause of death for autistic adults without a learning disability (grouped ICD-10 codes)	Totals in the data
Suicide, misadventure* or accidental death**	11
Respiratory conditions	8
Cadiovascular and stroke related	<5
Cancer	<5
Other	8

Note: * includes drug and alcohol related deaths that were not thought by the coroner to be intentional.
** includes falls.





LeDeR Listening Event

Themes

- Positioning LeDeR strategically with quality and nursing leads
- Engaging providers
- Establishing multi-disciplinary panels
- Sharing learning across the system
- Resourcing reviews and backlogs
- Improving reporting of autistic deaths
- Linking with health inequalities work
- Training on autism



LeDeR Listening Event

Key commitments

- Strategic focus on learning from lives and deaths
- Engaging communities in the learning process
- Sharing practical examples and resources
- Collaborative learning events
- Mapping current work across systems
- Strengthening reasonable adjustments
- Utilizing data to drive improvements
- Awareness raising across staff groups

Poll

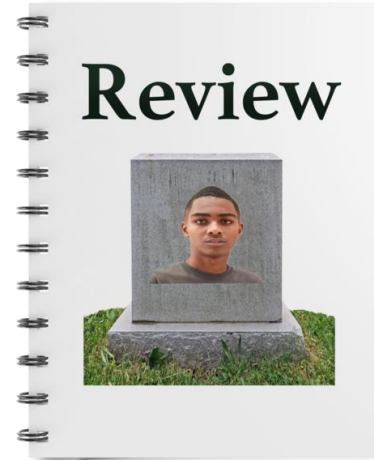


- Should it be compulsory that people with a learning disability be on a learning disability register at their GP surgery?
- Hold up your yes or no card
- If you're on zoom a poll will come up

Poll results



- 10 people said Yes
- 6 said no
- Everyone did agree that people with learning disabilities should still be told about the register and given time to understand why it's important.



Group Work – learning Disability mortality Review and Annual Health checks

feedback



- Southwark and Barking & Dagenham suggested that NHS dentists send out an easy read reminder letter for a six-month check-up.
- A lot of people agreed and said they used to get phone call/Text message reminders from their dentists but that hasn't happened for a long time.
- We were asked to find out if we will have to start paying to go to the dentist on the NHS?

Q1. answers



- People still don't know about them
- People are unsure about what will happen
- People are discouraged
- They might not want to go
- They are frightened and upset
- Not registered by the doctor or nurse
- Don't get reminded by the doctor

Question 2

- What could the NHS do to help more people go for their annual health check?



Q2. answers



- Easy read questions
- Force the doctors to use simple language
- Use easy read
- Make the rules clearer about who can get one and who can't.

Q2. answers



- Make it easy to contact the GP
- Text messages
- Easy read letters
- Phone people up when it's their turn
- Give appointments at weekends
- Encourage to go to the hospital

Question 3

- How does your GP tell you about your annual health check?



Q3. answers



- I don't get told to go for an Annual Health Check, I would like to have a letter in easy read.
- Letters
- Phone calls
- One person said their supported living house is called but they are not. They would like to be called as well.
- Phone calls and texts
- Easy read letter

The future of London Forum



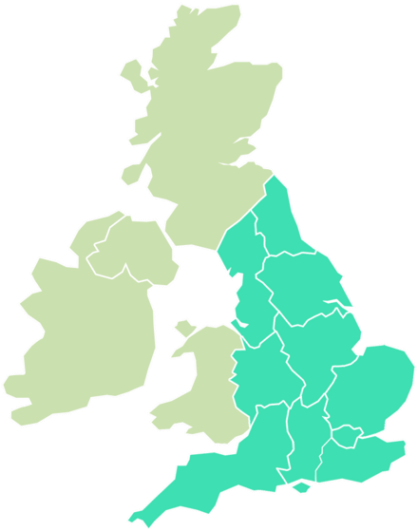
Robert - The funding for London Forum ends in March.

We are reapplying for funding, if we get the funding again, we want to know what you would change.

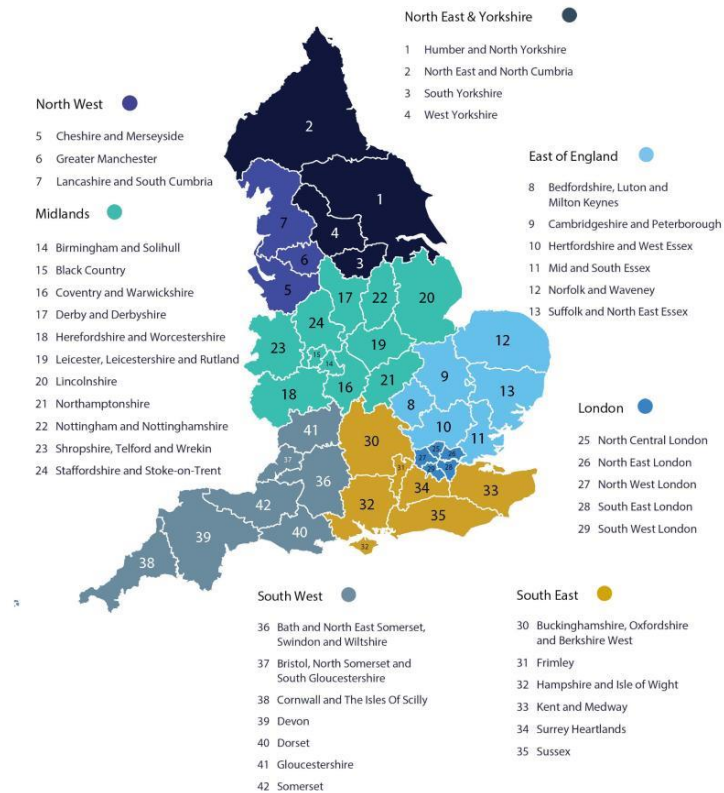
Pat - Would you like the National forum to start again?

Robert - What would you like to change about the London Forum?

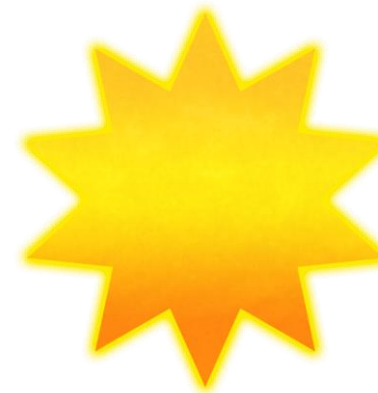
Pat - Do you want the London Forum to start at 12pm till 3pm?



National Forum feedback



- All 16 participants said they would like the National Forum to start up again.
- It would be good if it could be a hybrid meeting or take place in the summer when it is better weather for travelling.



New London forum Feedback



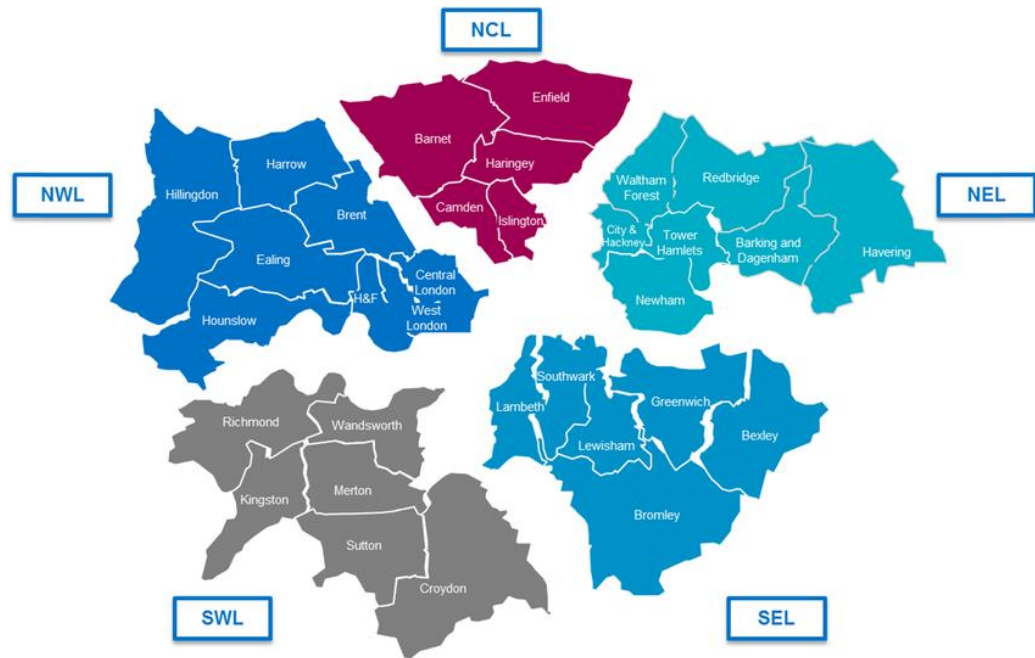
- Don't always have the meeting in Woolwich.
- Move around London to hold the event in different areas to give different self-advocacy groups the chance to host the London Forum.
- Could the forum be held in central London

New London forum Feedback



- The venues must be easy to access from public transport and be wheelchair accessible
- A lot of people were not sure about a longer meeting time of 3 hours – it would depend on the topic

New London forum Ideas



- **Some Ideas were:**

- Have a regular monthly meeting for people to talk about what is happening in their areas.
- Invite ICB's from different areas to those monthly meetings to hear from self-advocacy groups.
- Have longer meetings that professionals can come along to and take part in activity workshops with London forum members.

**We said goodbye and thank you for
coming to the meeting**



We will let everyone know if we get the funding
again.