



North Central London
Health and Care
Integrated Care System

LeDeR

Learning from lives and deaths of people with a learning disability and autistic people



Annual report 2022 to 2023



About us

We are the North Central London Integrated Care Board (NCL ICB)



We arrange health and care services for people living in



- Camden
- Islington
- Haringey
- Enfield
- and Barnet



About LeDeR reviews



When a person with a learning disability or autism dies in NCL we look into what happened – this is called a review



Many people with learning disabilities and autistic people die younger than others



This can be because of their health problems or because they didn't get good enough care



The review looks at the lives and deaths of people with a learning disability and autistic people so we can

- make changes to help them live longer and healthier lives



- fix unfair health differences among different groups of people



From January **2022** LeDeR reviews started looking at the lives and deaths of autistic people with no learning disability



There are **2** types of review for people with a learning disability and autistic people

- an **initial review** – everyone has an initial review



- and a **focused review** – some people then have a focused review which looks at health and care in more detail



A **focused review** happens if

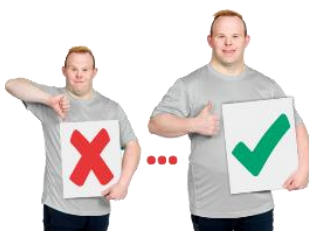
- someone was worried about the health and care someone received



- the person was an autistic adult without a learning disability



- the person was from a Black, Asian or Minority Ethnic background (**BAME**)



- or if the person's death was connected to an area we want to improve in (a priority)



Deaths in North Central London



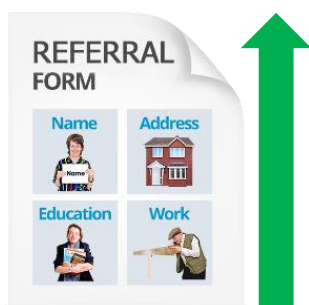
We were told about **65** people who had died



This is **25** more deaths than the year before



The report looks at LeDeR reviews for people with a learning disability and autistic people aged **18** and older



We did not receive any referrals for autistic people - we will look at ways of helping people tell us about the deaths of more autistic adults



We have **5** reviews to complete from earlier years



We have **23** reviews to finish for this year

POSITIVE SUPPORT GROUP

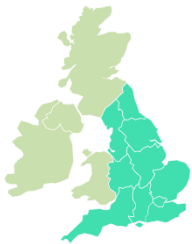
Positive Support Group (PSG) are doing all the LeDeR reviews for us



About the people who died



People with a learning disability are dying much younger than the general population



The average age of death for people with a learning disability in this country is just under **63** years old



In NCL the average age at death for people with a learning disability is **60** – this is a little bit higher than last year



Enfield has the lowest average age at death for people with a learning disability out of the **5** boroughs – we will find out why this is



People from **BAME** groups are dying at a much younger age than White people

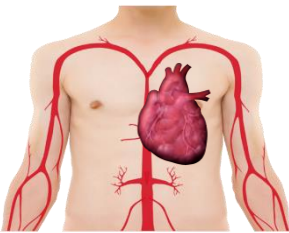


We had slightly more women die than men

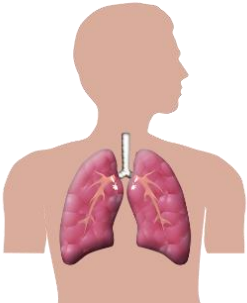


Top causes of death

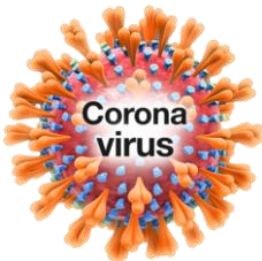
These are the top **5** main causes of death



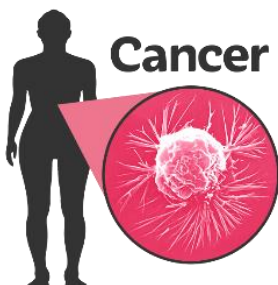
- circulatory problems – this can include heart problems or stroke



- lung problems



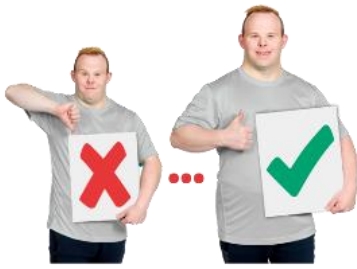
- Covid



- Cancer



- nervous system problems – this includes things like Alzheimer's or seizures (fits)



Things we need to do better



We need to understand why people from **BAME** groups die at a younger age than White people



We need to reduce inequalities and help people from these groups live longer



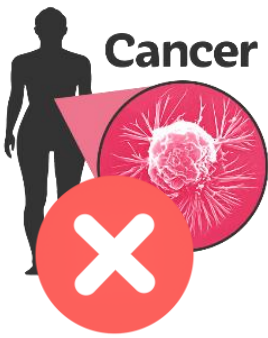
Not everyone had an Annual Health Check



Not everyone who had an Annual Health Check had a Health Action Plan



Not everyone had good reasonable adjustments

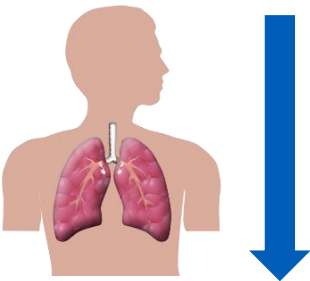


Cancer

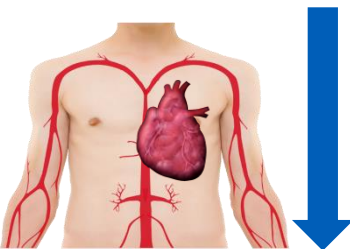
Not enough people had health screening appointments for cancer



We need better support for people in hospital when the learning disability liaison nurses are not on duty



We need to lower the number of deaths from lung problems



More people died from circulatory problems than usual – we need to lower the number of deaths from circulatory problems



Some people died from something that could have been stopped - we need to help people stay as healthy as possible



If someone needs help with their health, we should make sure they get it straight away



Things that have gone well



Some people got good emotional support from carers when they were in hospital



Some people got good support from voluntary organisations to do things in the community and develop friendships



Some people moving to a hospice had carefully written communication books and hospital passports to make sure everyone understood their needs



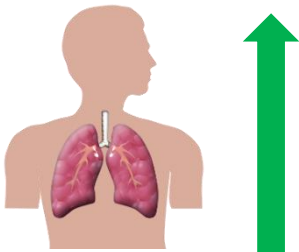
Staff teams worked well together to make sure people got the right support when they were in hospital



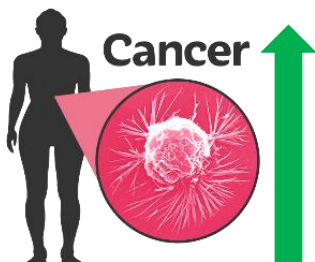
How we are making things better



We will look closer at all focused reviews where the death was because of a problem with the heart and how blood moves around the body



We will improve how we help people who have a problem with how they breathe or who have lots of chest infections



We will increase the number of people going for cancer screening by sharing easy read accessible information



We will make sure our teams know to report the deaths of autistic people without a learning disability



We will study all focused reviews for **BAME** residents to find out why they die younger and work out how to prevent early avoidable deaths



We will help more people get their Annual Health Check



We will make sure more reasonable adjustments are in place where needed



We will make sure the remaining reviews are finished



We will make sure important lessons and main points from earlier reviews are shared with everyone involved



We will set up a NCL area LeDeR meeting to talk about common issues and problems



We will make sure experts by experience are involved in meetings and in producing action plans



More information

You will find more information about the work being done at these websites



North Central London
Health and Care
Integrated Care System

The NCL ICB LeDeR programme



About the LeDeR Programme

nclhealthandcare.org.uk/icb/about/leder-programme/



The NHS England LeDeR programme

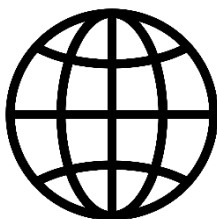


LeDeR - NHS

leder.nhs.uk



The NHS England Learning Disability and Autism Programme



NHS England - Learning disability and autism

england.nhs.uk/learning-disabilities/