Humber and North Yorkshire
Health and Care Partnership

NHS
Humber and
North Yorkshire
Integrated Care Board (ICB)

Learning from lives and deaths – 'People with a learning disability and autistic people' (LeDeR).

Annual Report – Easy Read
1st April 2022 to 31st March 2023

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11th May 2023

Content

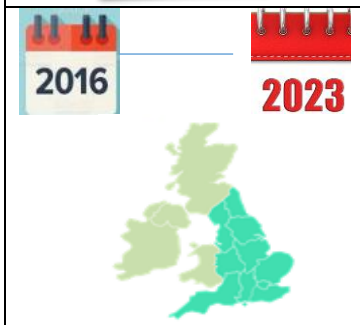
Within the past year, we have sadly lost one of our colleagues, Mr Gary Stark.

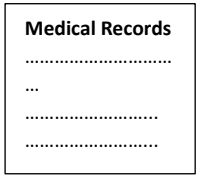
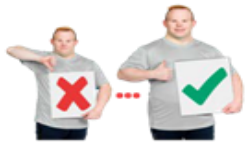
Gary was a much respected and active member of the Humber LeDeR Steering Group. He was a passionate advocate in promoting the rights of people with a learning disability to ensure equity and equality of access to services.

As the Local Area Contacts for the LeDeR Programme within the Humber, and with the kind permission of Gary's family, we would like to dedicate this year's Annual report to him.

He will not be forgotten, and we will forever be grateful for the opportunity to have known Gary and worked with him towards improving patient experience and local services.

1.0 Introduction

	On July 1st 2022, Integrated Care Systems (ICS) replaced Clinical Commissioning Groups (CCGs). The 6 CCGs in the new ICS are called the Humber and North Yorkshire Health and Care Partnership. This is the 2nd report we have written together about the number of people with a learning disability and autistic people who have sadly died in our areas.
	The LeDeR programme was set up 7 years ago. Every person in England who is over the age of 4 years, who has a learning disability and sadly dies, has their death looked at in the same way. From January 2022, autistic people who sadly die have their death looked at in the same way too.
	We look at every death to see if anything could have been done better and take the learning from the reviews to make changes to the care we provide in our local areas.
	The review is carried out by a person called a reviewer. They look at all the care the person who died received during their life.

	They do this by: Talking to the family or someone who knew the person really well and to people who supported the person during their everyday life.
	They will review the medical and care records to look at the care provided to the person.
	The completed review looks for where changes need to be made to make things better for people in our area who have learning disabilities and autistic people.
	This report tells you a little bit about people who have died in the Humber and North Yorkshire Health and Care Partnership area from 1st April 2022- 31st March 2023. It also tells you about the learning we found and where we need to make things better from reviews we did from 1st April 2022 - 31st March 2023.

2. What we know about the People who Sadly Died 1st April 2022 – 31st March 2023

	119 people who had a learning disability and sadly died, had their death reported to the LeDeR programme.
 	**Of the 119 people who died:** • 71 of them were men. • 48 of them were women.
  	• The average age of the 119 people who had died across the Humber and North Yorkshire Partnership area was 60.1 years. This is about the same age as last year's report (60.4 years). To work out the average age we add up all the ages of everyone who has died. Then we divide that number by the number of people who have died. • The average age of the men who died was 58.7 years. This is lower than last year's report (62.8 years). • The average age of the women who died was 63.2 years. This is lower than last year's report (73 years).

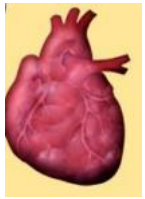
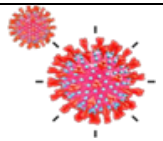
	• All of the people were identified as being white British. This is the same as last year's report. We need to do some work to make sure that all the people from our non-white British communities who sadly die are reported to the LeDeR programme so that we can review their death for any learning to improve our services.
	• 54 people died in a hospital.
	65 people died in the community. • 6 of the 65 people died in a hospice. • 36 of the 65 people died in a residential or nursing home.
	• 23 of the 65 people died in their own home or supported living accommodation.

3. What we learnt from the Reviews we Completed 1st April 2022 – 31st March 2023

	85 reviews were completed 1st April 2022 – 31st March 2023.
	28 of these were completed in the time they were meant to be finished in. This is 6 months from the time we know the person died.
	57 of the reviews were not finished in the time they should have been. • Some of the delay was because there were not enough people complete the reviews. • Some of the time the review was completed in time, but it showed there was more learning which could be found and so a deeper look at the care the person received was needed. • Sometimes the review could not be started because of other legal investigations like the coroner who is an official who looks into why somebody die.
 	**Of the 85 reviews completed:** • 46 of them were men. • 39 of them were women.

	• The average age of the 85 people across the Humber and North Yorkshire area was 57 years. To work out the average age we add up all the ages of everyone who has died. Then we divide that number by the number of people who have died.
	• The average age of the men whose death was reviewed was 56.7 years.
	• The average age of the women whose death was reviewed was 63.2 years. yyyy
	• 41 people died in hospital.
	44 people died in the community. • 4 of the 44 people died in a hospice. • 22 of the 44 people died in a residential or nursing home.
	• 18 of the 44 people died in their own home or supported living accommodation.

4. What the Completed Reviews told us was the Cause of Death 1st April 2022 – 31st March 2023

	When a person dies, Part 1a of a Death Certificate tells you what the person died of; this is called the cause of death.
 	From the 85 completed reviews, problems with people's respiratory systems were the most common cause of death within the Humber and North Yorkshire Health Care Partnership. • A number of these were caused by pneumonia. This is an infection in your lungs and is caused by germs called 'bacteria'. • Others were caused by aspiration pneumonia. This is an infection in your lungs caused by food or liquid going down 'the wrong way'.
	• The second most common causes of death recorded were related to problems with people's hearts.
	• A small number of deaths were related to COVID – 19. This is a virus which is a type of illness that can make you cough, have a high temperature and loss of taste or smell.

5. Some Examples of Good Care Found in the Reviews 1st April 2022 – 31st March 2023

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<td>Lots of the completed reviews showed good practice across all the areas within the Humber and North Yorkshire Health and Care Partnership. Here are some examples:

• Reviews identified good support from the community learning disability team nurses, supporting care home staff as well as people with learning disabilities.

• Some reviews identified good end-of-life care planning, involving the person, their family and those that cared for them. People had ReSPECT documents in place. This is a form that asks about what is important to you and the kinds of treatments you would want to have in an emergency.

• Lots of reviews identified care home staff knew the people they were caring for very well and the care they were provided with showed excellent person-centred care or holistic care being delivered.

• A review showed good discharge planning which included use of the Mental Capacity Act.</td>
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<td>• Many reviews identified good evidence of multi-disciplinary working, which provided person centred care.
• A number of reviews showed people had had their Annual Health Check and medication reviews.

• Some reviews identified that people were supported well to live independently or at home.

• Some people had access to a learning disability doctor who specialises in complex physical health and was able to coordinate the medical care the person needed.

• Reviews identified the positive role of the learning disability liaison nurse in hospitals.</td>
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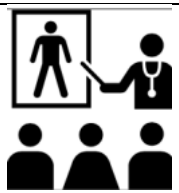
6. Some Examples of Things we need to do Better found in the Reviews 1st April 2022 – 31st March 2023

	Some of the completed reviews showed where we need to do better across all the areas within the Humber and North Yorkshire Health Care Partnership. Here are some examples: • Some reviewers had difficulty getting information from care homes and GPs to complete the reviews. • Not everyone who needs to go into hospital has an up-to-date hospital passport with them. • A review identified a lack of reasonable adjustments being made.
	• Reviews found that there was still poor application of the Mental Capacity Act. • Reviewers did not always find evidence of mental capacity assessments and Best Interests decision making.
	• Reviews showed there have been improvements in the documentation for end-of-life care, but some reviews still showed problems with the quality of the documentation completed, or it was not kept up to date.

7. Recommendations from the Completed Reviews 1st April 2022 – 31st March 2023

	There has been a lot of good work going on to make things better for people with learning disabilities and autistic people living in the Humber and North Yorkshire Health Care Partnership area. From the reviews, we found some key areas where we still need to do more work to make things better.
	• We need to make sure everyone who is 14 years old and over is on their GP learning disability register and is offered their Annual Health Check. • We need to make sure Health Check is completed really well and meets the person's needs with a health action plan completed.
	• We need to make sure all health and care staff are aware of their responsibilities and are following the Mental Capacity Act. • We need to see Best Interest Decision meetings being documented.
	• We need to keep working to make sure people coming to the end of their life are recognised early so that decisions can be made with them, and their family and plans made to stop them being taken to hospital if they do not need to go. • There needs to be earlier thought for completion of the ReSPECT document allowing good end of life conversations and early planning with people, their family and those who care for them.

	• We will be raising the profile of the hospital passport so that everyone has a hospital passport and that this is kept up to date with any changes and goes with them into hospital.
	• We will be undertaking a more in-depth review for anyone who sadly dies during 2023/2024 of heart disease.
	• We want to offer early recognition of the deteriorating patient training including the use of ‘softer signs’ to recognise deterioration to all care home providers.