NHS
Herefordshire and Worcestershire
Clinical Commissioning Group

Dying to Live Longer

SpeakEasy NOW with Rachael Skinner
LeDeR Local Area Contact

Learning Disabilities Mortality Review (LeDeR) Annual Report 2020

speak easy N.O.W

Health Checkers



Why LeDeR is important

Health Checkers from SpeakEasy NOW said:



LeDeR can help to make sure that people get the right treatment at the right time and in the right place'.

LeDeR will stop people like us dying too young.



I want to live a long and healthy life. It's sad but learning from other people dying could help me do this.

Nobody should die unnecessarily.





All life is precious. Having a Learning Disability doesn't change this.

It's bad if mistakes are made but learning from them helps to stop it happening again.

People with Learning Disabilities have the right to good treatment and care the same as anyone else.

Just because someone can't talk doesn't make them invisible.

I need help to stay healthy. If my care is poor my health will suffer.



I don't always know what's good for me. I trust other people to help me.

Good support will make sure people get the care they need.

Here is a link to LeDeR Easy Read documents:



http://www.bristol.ac.uk/sps/leder/easy-read-information/

Any person can report the death of someone with a learning disability by using this link:

http://www.bristol.ac.uk/sps/leder/notify-a-death/

What we are trying to do?







We try to help the reviewers (the people doing the review) to make sure that reviews include:

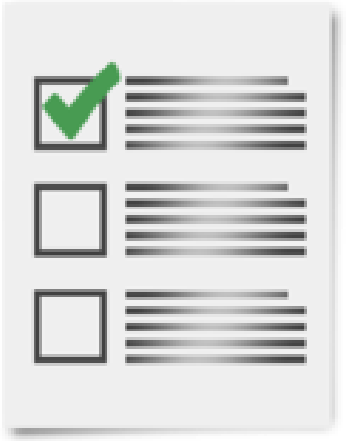
✓The right information

✓The patients loved ones are talked to

✓The review is done as quickly as possible



We make sure that during the review things that went well and things that need to change are talked about.



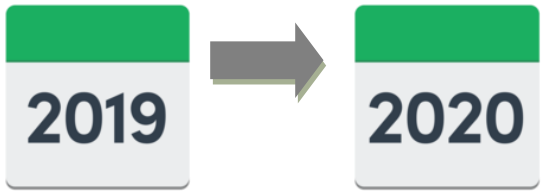
We talk about the suggestions made and agree what needs to be done to help people have healthier lives or improve services to help people who are unwell.

How many reviews have been done?

How many deaths are reported each year?

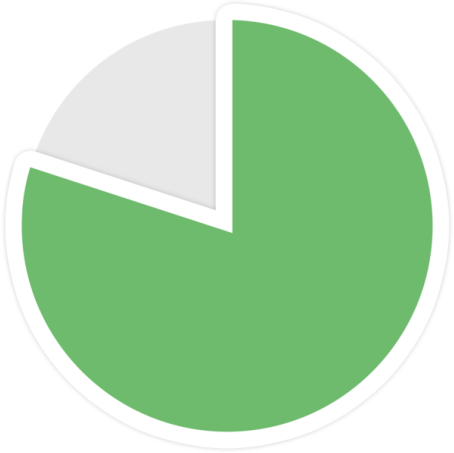


Since October 2017 there have been **113** deaths reported to LeDeR for Herefordshire and Worcestershire.



From April 2019 to March 2020 there were **39** deaths reported for Herefordshire and Worcestershire.

How many reviews have we completed?



In Herefordshire and Worcestershire, 7 or 8 out of every 10 reviews had been completed by the end of March 2020

Why is it difficult to complete all reviews quickly?



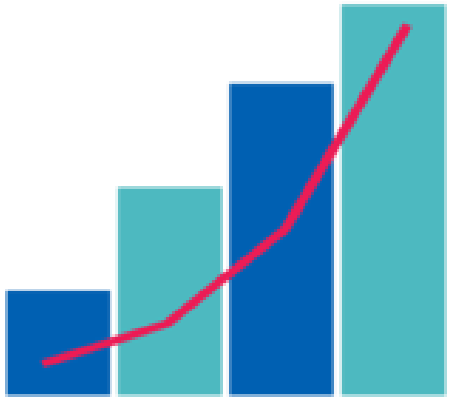
Sometimes it will take longer to complete a review because:

- It may be difficult to get care notes



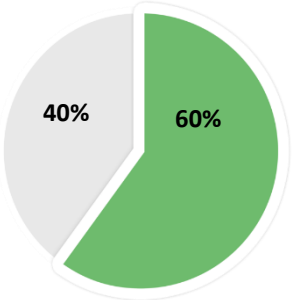
- It may be difficult to arrange for families to get involved

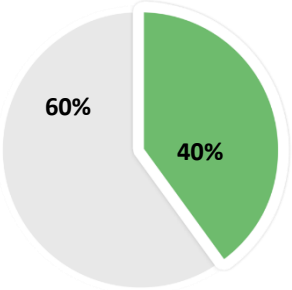
What do notifications tell us?



- The youngest person reported to have died with a learning disability was **4** years' old
- The oldest person reported to have died with a learning disability was **90** years' old
- The average age that people died was 61- this is slightly older than the average age of death in the Midlands and England which was 59

Hospital | Home







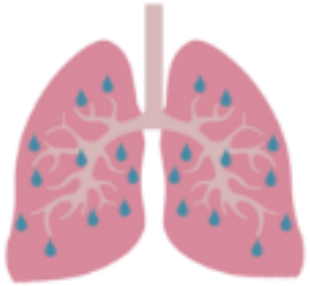


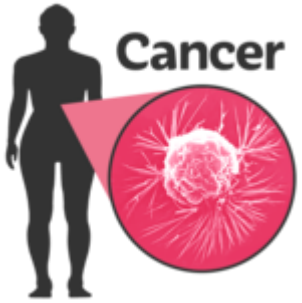
- In Herefordshire, 40% died in a hospital, 60% of people died at home in 2019 – 2020

- In Worcestershire, 60% died in a hospital, 40% died at home in 2019 – 2020
- We want to look into this to understand why

- 50 women and 63 men died

What do completed Reviews tell us?





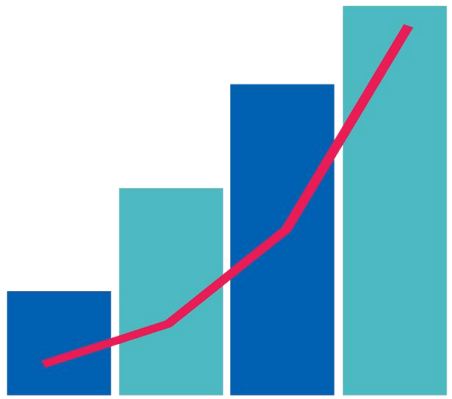


- The largest number of deaths is from respiratory problems (lung problems) 60% of people died from lung problems in Herefordshire and 26% in Worcestershire

- 13% of people died from cancer in Herefordshire and 12% in Worcestershire

- In the last report, some people in Worcestershire had died from Constipation and we were really sad about this, but this year no one has died from it

How good was peoples care?



- In Herefordshire 7 out of every 10 reviews and in Worcestershire 3 out of every 10 reviews were found to have good or excellent care.

- 1 in every 10 cases reviewed were found to have care that was so poor it may have led to the person's death

What are we finding and what are we doing about it?



- What we found:

  Annual health checks need to improve



- What we did:

We got a group of people together to work out how to help improve our annual health checks
We also asked GPs what would help.

What are we finding and what are we doing about it?



- What we found:

The ReSPECT programme should include people with a learning disability



- What we did:

The ReSPECT board have been working with the learning disability team and SpeakEasyNOW to ensure that the needs of people with learning disabilities are included.

What are we finding and what are we doing about it?



- What we found:

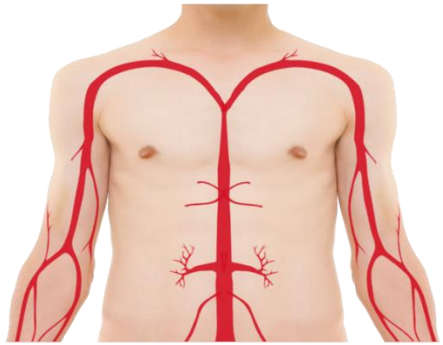
We need to train medical staff on how to communicate with people with a learning disability in hospitals



- What we did:

Acute liaison nurses are in both Herefordshire and Worcestershire to help people with learning disabilities get good support when they are in hospital and train other staff

What are we finding and what are we doing about it?





- What we found:
  Social care providers should ensure that care staff know when someone they support needs urgent medical assistance, including sepsis

- What we did:
  In Worcestershire we worked together to run workshops to help staff support healthy lifestyles and recognise when someone needs urgent help, including sepsis.
  In Herefordshire, the lead sepsis nurse delivered training to staff

What are we finding and what are we doing about it?



- What we found:

Staff need to follow the Mental Capacity Act to make the best decision when a person cannot decide for themselves.



- What we did:

We worked together to improve training to make sure it included examples where people might refuse care because they do not fully understand the impact of saying no (for example not going to cancer screening)

What are we finding and what are we doing about it?



- What we found:

People with learning disabilities, their families and carers needs to know the risks of Constipation and how to support a healthy lifestyle and a healthy bowel.



- What we did:

Teams worked together to provide training on how to recognise problems and what to do about them. The Learning Disability team go and talk to people after they have been to A&E due to constipation, to improve their care

What we want to do next



- One **Steering Group** for Herefordshire and Worcestershire



- Two **Learning into Action Groups,** one in Worcestershire and one in Herefordshire will look again at the big action plan

Next year our work will include:



✓ What we learnt from the COVID-19 pandemic



✓ Help GP's to improve annual health checks, health action plans, give more flu jabs, check people's medicines are right