

Developing Innovative,
Inclusive and Diverse
Public Partnerships



No Research About Us Without Us



An easy-read summary
of our application

National Institute for Health and Care Research
NIHR

The NIHR is The National Institute for Health and Care Research.

Health research



Social care research

The NIHR uses public money to do health research and social care research.



The NIHR works with the NHS and social care services to try to find new and better ways to care for people.



The NIHR has offered some funding to develop partnerships together.



The funding will help to tackle the barriers that stop some people getting involved in research.

Learning Disability



Our community is the learning disability community.



We have connected lots of people in our project so far.



This includes people from England, Scotland and Wales.



People with a learning disability



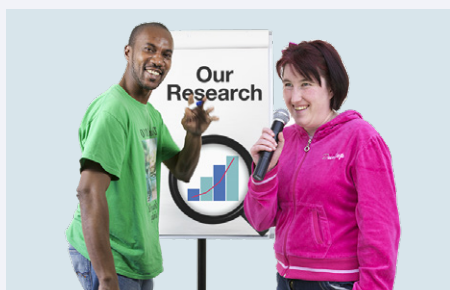
Support workers



Learning disability organisations



Accessible communication experts



Professional researchers



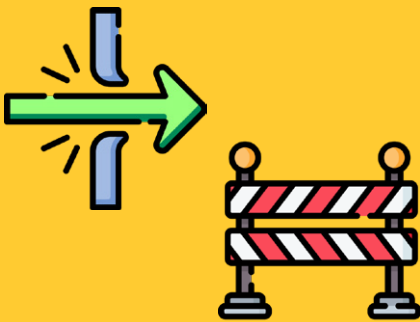
The NHS



In our project we plan to:



Look at the barriers to research for people with a learning disability.



Explore ways of overcoming some of the barriers.



Make recommendations for future research.



Here are a few facts:

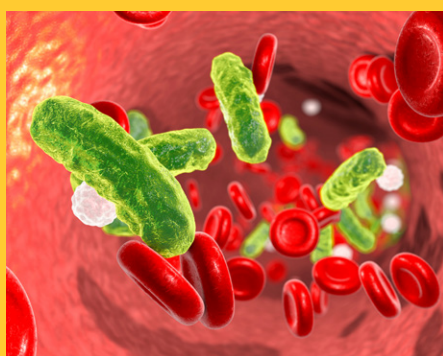


People with learning disabilities die, on average, 15-20 years earlier than the general population.



Some people die for reasons which shouldn't have happened.

People with learning disabilities die more often for this reason.



An example of this is an infection in the blood.



**When we look at research studies,
we often find that:**



**People with a learning disability are
excluded from research.**



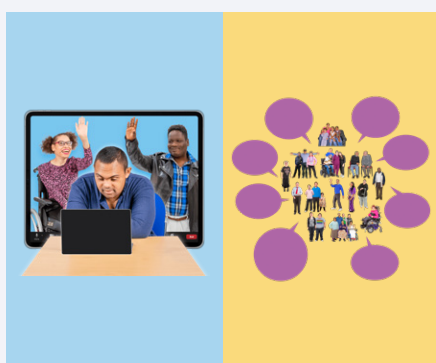
**Not enough work is done to support
people with learning disability to
understand and take part in research.**



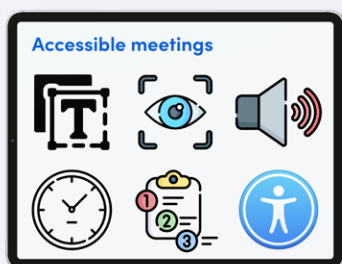
Our partnership is made up of about 25 people.



We have met on Zoom several times over the summer.



These meetings helped us to get to know each other and to co-produce our ideas.



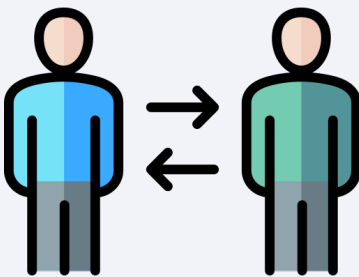
We made the meetings accessible for people with a learning disability.



This included making easy-read meeting agendas and notes.



We also planned plenty of time for meeting discussions.



Our project is led by 2 people.



Gary Bourlet who is the co-founder of Learning Disability England



Dr. Amy M. Russell from the University of Leeds



Our project will:




Look into what we know already about barriers faced by people with a learning disability.




Look at how projects that work in co-production can work well.




Agree together how we want to evaluate working together and keep diaries of how things are going.




Look at some NIHR research studies that did not include people with a learning disability.



Look carefully at 3-4 of these studies and decide how inclusion could have happened better.



Agree on the most important areas to work on.



Set up some working groups for each of these important areas.

Accessible



Information

We will look at how research teams can create accessible information.



RE Design

We will re-design a study which has excluded people with learning disabilities to make it more accessible and inclusive.



We will also write some guidance for other projects that want to make research more accessible to people with a learning disability.



We will create guidance for researchers and for self-advocacy organisations about how best to include people with a learning disability.



We will describe research which needs future funding.



An example is how people who approve research do not understand how to support people with a learning disability.



We will work together to look at what it was like to work together.



We will decide what worked well and what we would change.

We will write what we agree into a report.