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Shepherd, V., Royston, R., Totsika, V. et al. (2025) How to Include People with a Learning Disability in Research. A Clinical Trial Example. Report. White Rose Libraries

<https://doi.org/10.48785/100/398>

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**No Research
About Us
Without Us**



How to include people with a learning disability in research

A clinical trial example





No Research
About Us
Without Us

An easy-read report from the No Research About Us, Without Us research project

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Who we are



We are a group of people who worked together in 2024 to 2025 to do research

Lots of people were in our group:



people with learning disabilities



researchers from universities



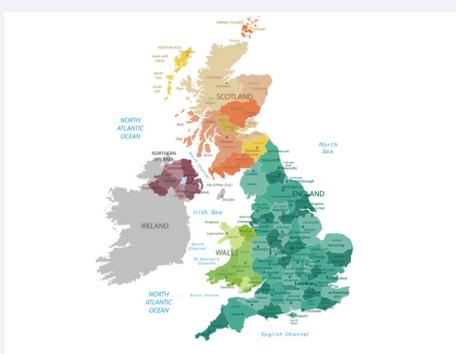
people from learning disability charities



experts who make information easier to understand



NHS researchers



We come from Wales, Scotland and England.



We worked together to:



Discover more about what stops people with learning disabilities taking part in research.



Work out ways to improve things.



We called our research:

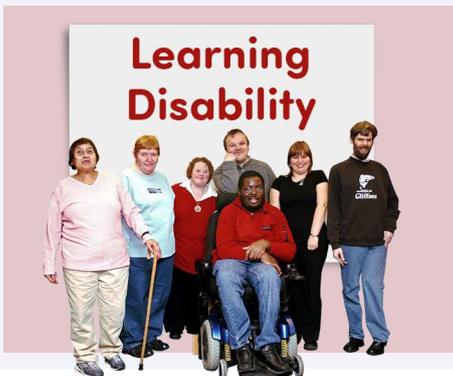
“No research about us, without us: removing research barriers for people with learning disabilities”



Some of us worked in a small group to look closely at a clinical trial that had already happened.



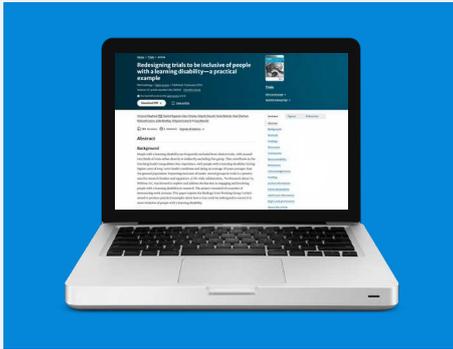
Just below, you can read about what a clinical trial does.



We wanted to see how well the trial had included people with a learning disability.



We wrote a report about what we found out.



You can read our full paper here:

[Website link to full paper](#)



This is our easy-read version of the report.

What did we do?



We looked at a clinical trial.



Clinical trials compare a new medical treatment to the usual care that is already available.



This could be something like a new medicine or a vaccine.



In a clinical trial, some people will get the new treatment, whilst others will get their usual care.



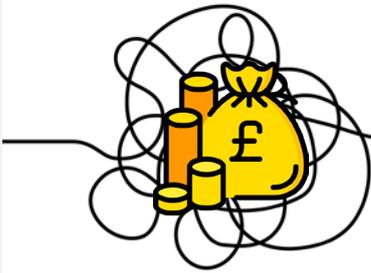
The person taking part in the trial and the researchers do not know who gets the new treatment and who gets the usual treatment.



The researchers will only find out what treatment someone has had at the end of the trial.



This means we can be sure if it is the new treatment that is making a difference.



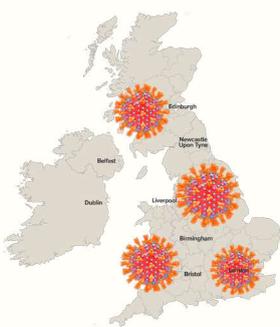
Clinical trials are complicated and expensive.



PANORAMIC

Platform Adaptive trial of NOvel
antiviRals for eArly treatMent of
COVID-19 In the Community

We looked at a clinical trial called PANORAMIC.



The PANORAMIC trial happened during the Covid-19 pandemic.



It wanted to quickly find treatments for people who were ill from Covid-19.



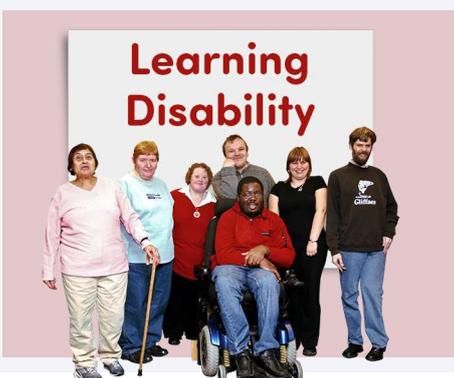
The trial started before the Covid-19 vaccine was available.



The trial used different medicines to see which ones worked and which ones did not work.



Over 26,000 people took part in the trial.



It was important to include people with learning disability in clinical trials about Covid-19.



We looked at what the PANORAMIC trial did to make sure people with a learning disability were included.



The PANORAMIC website had lots of information about the trial. This meant we could carefully look at how the trial had worked in real life.



We found out:



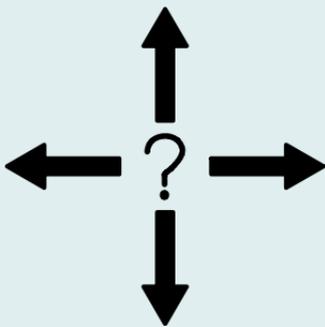
Who the researchers wanted in the trial



How they asked people to join



How they told people **what the trial was about**



What the trial asked people to do



What **risks** there were to people who joined



How people **agreed to join**

WHAT'S
NEXT?



What happened **after** people joined the trial

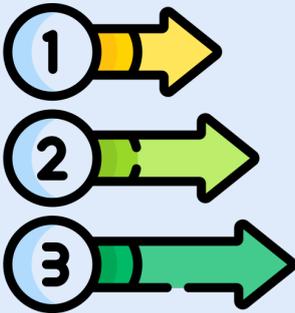


We tested **PANORAMIC** to see how well it included people with a learning disability.



We did this by using a **checklist**.

The checklist is a **guide for researchers**.



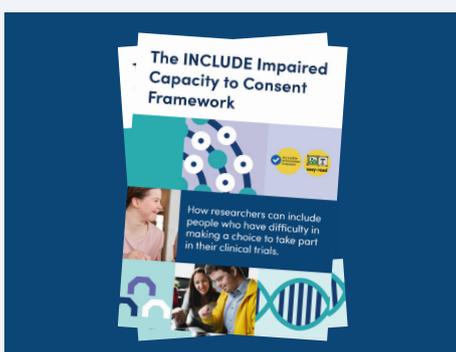
It goes through all the different steps in a clinical trial.



It guides researchers to think about how to include people in trials who have difficulty making decisions.



This includes many people with a learning disability.



Here is a link to an [easy-read version of the checklist.](#)

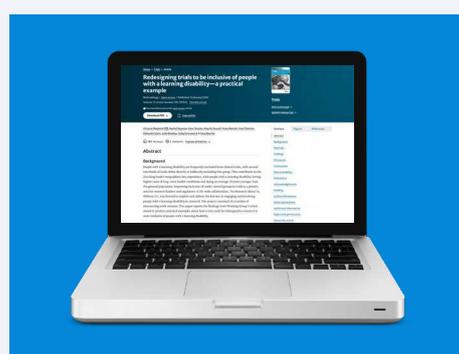
What did we do?



We found lots of ways that the PANORAMIC trial did not support people with a learning disability to take part.



Our report sets out many ways they could have avoided this.



You can read about them in our full report:

[Website link to full paper](#)



Here are just 6 examples:



Finding 1



The trial rules said only some people with a learning disability were allowed to take part.



For example, people with a severe disability who were living in a care home or, people with a mild or moderate learning disability with Down's Syndrome.



This excluded other people with learning disabilities.



For example, people with **any** mild, moderate or severe learning disability who lived at home with their family or in supported living.



Right away, this meant most people with a learning disability could not take part.



68% of people with a learning disability who died from Covid-19 in the first wave in England had a mild or moderate disability.



ACTION NEEDED!



Future trials should include people with mild and moderate learning disabilities as well as people with severe learning disabilities.



This includes people who can understand what it means to take part in a trial.



Future trials should include people who live independently or with family as well people who live in a care home.



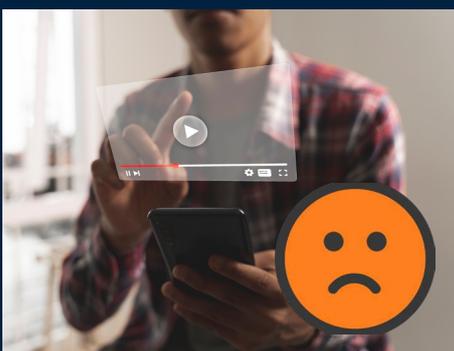
People should be given support and adjustments funded by the trial to help them to take part.



Finding 2



There were videos to let people know what PANORAMIC was about on the trial website.



But there was not a video for people with a learning disability.



Only one piece of information about PANORAMIC was in easy read.



This was checked by someone with a learning disability and a member of their family.



Our research team had self-advocates with a learning disability.



They said this easy-read information sheet could have been better.



ACTION NEEDED!



Better resources should be used to support people with learning disability to understand what a clinical trial is about.



Better support is needed for them to decide if they want to take part.



Researchers can make information accessible by using videos, easy read, and by having phone and video conversations.



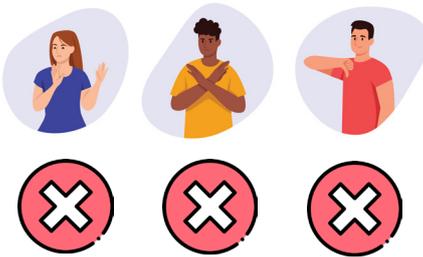
Researchers should ask for help from experts by experience and accessible design experts when designing a trial.



Funders must agree that this means extra cost, including for carers.



Finding 3



The PANORAMIC team did not ask for help from a community organisation, or other experts, who worked with people with a learning disability.



ACTION NEEDED!



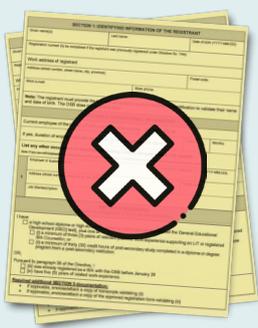
A larger advisory group of people with a learning disability and their carers should be consulted all the way through a trial.



A learning disability organisation should help with the advisory group involvement.



Finding 4



The form asking people if they understand and agree to join the trial was too complicated.



This is called a consent form.



ACTION NEEDED!



The consent form should use accessible language for everyone.



There should be an easy read consent form for people with a learning disability.



Finding 5



It is very important that a person understands what they are asked to do in a clinical trial.



It was not clear how the researchers knew if someone had difficulty making decisions.



There was no information about what support could be given to someone in this situation.



ACTION NEEDED!



Some people will need more help to understand what is happening in a clinical trial.



Better support is needed for them to decide if they want to take part.



For example: talking mats, sign language, Photosymbols and other communication aids.



Funders must agree that this means extra cost, including for carers.



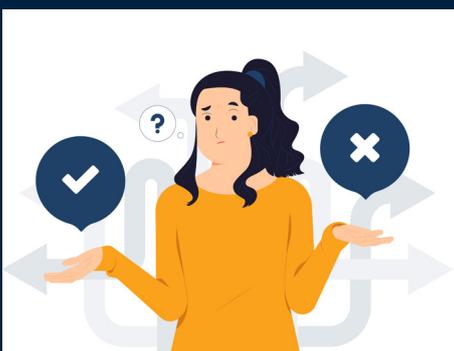
Finding 6



A clinical trial has to be clear about how it knows if it is finding out something important.



This is called the trial outcomes.



It was not clear if people with a learning disability and their carers were involved in deciding what PANORAMIC trial outcomes should be.



ACTION NEEDED!



A larger advisory group of people with a learning disability and their carers should be consulted all the way through a trial.

What should happen next?



Poorer
health



Not including people with a learning disability in research means their health is poorer than it should be.



Worse

Their experience during Covid-19 was much worse than other people's experience.



Clinical trials must change the way they work.

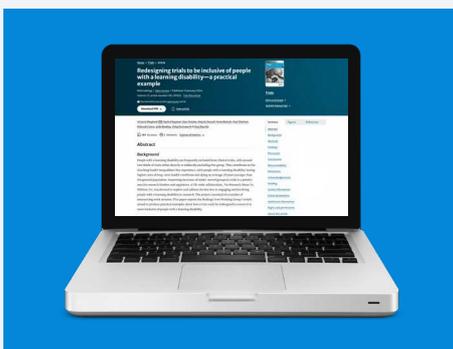


They must do more to include people with a learning disability.



It is not difficult to do this.

Our research has shown how it can be done.

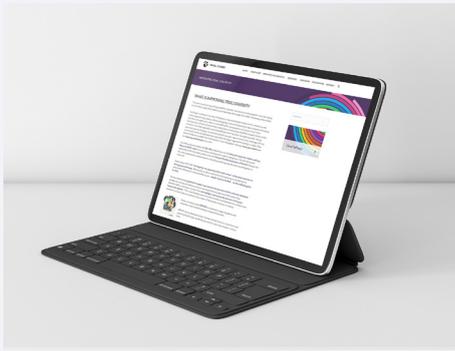


Our full report has a long list of how to do it:

[Website link to full paper](#)



Here are more links to information about including more people in research:



www.trialforge.org

Improving Trial Diversity



www.step-up-clinical-trials.co.uk

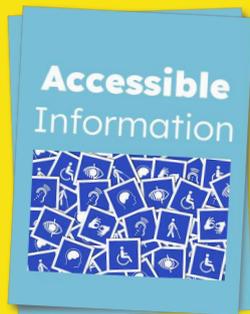
Strategies for trialists to promote equal participation in clinical trials for under-served populations



Research funders need to:



say no to clinical trial applications which do not fully consider the adjustments that people with a learning disability might need to take part



check that all research activity uses accessible information



agree to pay the cost of these adjustments, including for carers.



These fully costed adjustments will benefit people with a learning disability and many others.

To cite this easy-read please use: Shepherd, V., Royston, R., Totsika, V. Russell, AM., Marriott, A., Charlton, P., Cairns, D., Bradley, J., Farnsworth, V., Bourlet, G., Clark, M. And Thinklusive Advisory Group. (2025) Report. How to Include People with a Learning Disability in Research. A Clinical Trial Example. White Rose Libraries. Report. <https://doi.org/10.48785/100/398>

This easy-read version has been created with members of the Thinklusive Advisory Group.

The information in this booklet was adapted from an original article: Shepherd, V., Royston, R., Totsika, V. Russell, AM., Marriott, A., Charlton, P., Cairns, D., Bradley, J., Farnsworth, V. and Bourlet, G. Redesigning trials to be inclusive of people with a learning disability—a practical example. *Trials* 27, 120 (2026). <https://doi.org/10.1186/s13063-026-09446-4>

This project is funded by the NIHR Programme Development Grant 'Developing Innovative, Inclusive and Diverse Public Partnerships' (NIHR PGfAR – NIHR205211). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

To find out more visit our website:

www.learningdisabilityengland.org.uk/no-research-about-us-without-us

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