Westmorland & Furness Council

NIHR | National Institute for Health and Care Research

People First

Community Change Lab

Co-Evaluation of the Accessible Research Training Materials Project

Co-created by:
Kaz Stuart, Elizabeth Harper, Tim Baty, Ricardo Mendes, Jacob Fern-Kendrick, Hannah Mackay, Vic Adams, Mark O'Farrell, James Hughes, Mary Docton, Hannah Maiden.

Introduction

About this project

Westmorland and Furness Council and People First in Carlisle applied for a National Institute for Health and Care grant for a Public and Community Partnership.

We were awarded £10,000 to co-create research training that was accessible to people with learning disabilities. From our work in different settings we think the materials are accessible to anyone and everyone, not just people with learning disabilities.

A team of seven people with learning disabilities and neurodiversity, one person from Westmorland and Furness Council and one person from People First worked together to test out accessible learning materials and to design this pack.

What is Co-Research

Co-research is when people with lived experience do research with researchers. Co-research is an equal partnership. People do what they are able to and what they enjoy – no one has to take part in everything. Co-research can use any tools and techniques and its focus is making people's lives better.

Why Co-Research Matters

About 2.5% of the population have a learning disability, but they are very underrepresented in research, for example, less than 1% of medical

THE CONTENT OF THIS EVALUATION IS LISENCED UNDER A CREATIVE COMMONS ATTRIBUTION LICENSE TO BE USED NONCOMMERCIALLY AND ALL USE AND ADAPTATIONS TO BE CREDITED TO THE AUTHORS.

trials include people with learning disabilities, despite them experiencing a significantly higher prevalence of many conditions (Shepherd et al., 2026).

People with learning disabilities have lives 19 years shorter than the rest of the population and 39% of their deaths are avoidable (2024 Learning from Lives and Deaths Report). This highlights the need for more research into the inequalities they experience, and people with learning disabilities are best placed to design and do this research.

A review of health and social care research that included people with learning disabilities found only 17 papers written in the UK since 2000 (Hewitt et al., 2023). They only involved people with learning disabilities in the design process, they did not do the research themselves.

A search for research accessible research materials only found materials that related to consent and withdrawal. This suggests that good support is provided for people with learning disabilities to take part in research, but not for them to do it themselves.

We believe, that with the right training and support, people with learning disabilities and other needs can design, conduct, analyse, write up and communicate research themselves. There are no excuses for not involving people with lived experience as co-researchers.

THE CONTENT OF THIS EVALUATION IS LISENCED UNDER A CREATIVE COMMONS ATTRIBUTION LICENSE TO BE USED NONCOMMERCIALLY AND ALL USE AND ADAPTATIONS TO BE CREDITED TO THE AUTHORS.

Our Aims

Our aims were co-produced as a research team during one of our design sessions. As a group we aim to:

- Create accessible research training materials
- Break down the barriers to research
- Increase the opportunities to co-research
- Enable more people to co-research
- Reduce box ticking tokenistic approaches
- Create higher quality research – more lived experience
- Embed changes in practice in local authorities and council's, the voluntary sector, universities and research bodies.

THE CONTENT OF THIS EVALUATION IS LISENCED UNDER A CREATIVE COMMONS ATTRIBUTION LICENSE TO BE USED NONCOMMERCIALLY AND ALL USE AND ADAPTATIONS TO BE CREDITED TO THE AUTHORS.

Credits and thanks

Thanks to the National Institute for Health and Care Research Specialist Centre for Public Health for their Public Community Partnerships Research Grant.

Thank you to Westmorland and Furness Council for believing in the work and being lead partner in the grant process.

Thank you to Cumberland Council Health Determinant Collaboration Co-Researchers for reviewing the pack of materials.

Thank you to People First for providing all the venues, support, infrastructure and consultant time to make the project a reality.

Note:

This study/project is supported by the National Institute for Health and Care Research (NIHR) RSS Specialist Centre for Public Health (SCPH) (Grant Reference Number NIHR 205426-PH). The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

THE CONTENT OF THIS EVALUATION IS LISENCED UNDER A CREATIVE COMMONS ATTRIBUTION LICENSE TO BE USED NONCOMMERCIALLY AND ALL USE AND ADAPTATIONS TO BE CREDITED TO THE AUTHORS.

How we co-evaluated the project (our method)

At the end of every session we reviewed the project together. Kaz noted down everything we said so we had a record of our reflections.

At the end of the project we filled in evaluation forms individually and then worked out what they meant (analysis) together. We used three different forms so we could see which form we liked the best as part of the project, and to ensure we evaluated every aspect of the project. One of the forms reflected our project objectives. The two other forms were developed from the Learning Disabled and Autistic Adult Research Group's ACCESS framework and the other from the Listen, Respect Include International Guidance for Inclusive Participation. Both can be found in our materials.

We also did some creative work to help us reflect on and identify what we had each gained by taking part in the project.

After this we discussed each part of the evaluation report and what we thought should be included. Liz wrote down all the points we made. Kaz and Liz drafted this report which we all read and suggested changes.

THE CONTENT OF THIS EVALUATION IS LISENCED UNDER A CREATIVE COMMONS ATTRIBUTION LICENSE TO BE USED NONCOMMERCIALLY AND ALL USE AND ADAPTATIONS TO BE CREDITED TO THE AUTHORS.

Evaluation of how we co-designed the materials (our process)

Our working process

Kaz and Liz had written the grant application and this set out the structure of the project. We had ten sessions that covered each stage of the research process.

Each week Kaz and Liz would design some activities and some information that would help people with learning disabilities to understand research.

We would all try out the activities and read the information. We were very honest about what needed changing. After each session Kaz wrote everything up into our accessible research training materials pack.

When the pack was completed, we sent it to Cumberland Council Health Determinant Research Collaboration Co-Researchers to review it. They gave us feedback which we used to create the final pack.

What did we enjoy the most?

In our reflections and discussions we consistently said that the most enjoyable things were:

- The role play activities (the bad interview, the bad focus group)
- Interactive games (paper's got talent)
- The opportunity to shape the materials

THE CONTENT OF THIS EVALUATION IS LISENCED UNDER A CREATIVE COMMONS ATTRIBUTION LICENSE TO BE USED NONCOMMERCIALLY AND ALL USE AND ADAPTATIONS TO BE CREDITED TO THE AUTHORS.

- Kaz and Liz acting on our feedback
- Moving around and doing different things.

What went badly or was not enjoyable?

We consistently said ‘nothing’ to this question. Everyone said they enjoyed being together and the activities.

Was the project accessible?

Discussing the project showed that the team were not sure what they were signing up to. They had never taken part in research before and did not know what to expect. They had to place a lot of trust in Kaz and Liz and be willing to give it a go. In the future we might set up a meeting or a test session so people can ‘have a go’ before committing to the project.

We had asked people to ‘sign up’ to take part in the project by filling in a simple form. People said they didn’t get any feedback on whether they had filled in the form well or not and they were not sure why they were given a place. We would do this better by providing feedback in the future.

Everyone found the building accessible and the spaces nice to work in. However, we also noted “it could be difficult to access if commuting in from a rural town”. Public transport links are poor in Cumbria.

Our weekly reflections showed the group always found the resources accessible. Written materials were always in an Easy Read format, and we enjoyed doing things in different ways. The team commented that they thought there was a good balance in the materials, they were not “dumbed down or patronizing”.

THE CONTENT OF THIS EVALUATION IS LISENCED UNDER A CREATIVE COMMONS ATTRIBUTION LICENSE TO BE USED NONCOMMERCIALLY AND ALL USE AND ADAPTATIONS TO BE CREDITED TO THE AUTHORS.

Our discussions also showed that the way we set up the project was accessible. People felt the space was safe and they were allowed to "be themselves". They commented it was "flexible and learning disabled and neurodivergent friendly". Flexibility was provided in allowing people to look after their own needs, in giving people choice in what to take part in and the variety of activities in each session.

Were the activities and project meaningful?

The team consistently commented that they felt they were "really listened to" and that they enjoyed "using our knowledge" and having "lived experience valued". The team said they felt they were "making a difference". In one evaluation the team noted that "our contributions were clearly implemented in the outcomes of the project", indicating they felt their views were meaningful.

The team were particularly pleased in how they had steered the use of language in the research training materials. Kaz and Liz had been tempted to take out technical research language as it is inaccessible, but the team had advised that it was included in brackets after the simpler words so that people could learn research language as they used the materials to help people to go to be involved in research in the future.

Did people have opportunity to be involved in different ways?

The roles in the project were explained at the start and the team felt comfortable that Kaz and Liz would be responsible for the overall process and everyone else was responsible for giving their views on activities and information.

THE CONTENT OF THIS EVALUATION IS LISENCED UNDER A CREATIVE COMMONS ATTRIBUTION LICENSE TO BE USED NONCOMMERCIALLY AND ALL USE AND ADAPTATIONS TO BE CREDITED TO THE AUTHORS.

Every activity was offered to everyone. Sometimes people chose to write things, lead things or not. Sometimes people were very active or very quiet in activities. This was all okay. The team noted they "never felt judged" and never had to explain why they did or did not want to take part in something.

People in the team reflected that; "It's been very varied, I've had lots of options", "We did lots, I've liked the thinking, talking, writing and lego today".

Was everyone supported well-enough?

We used written documents and a WhatsApp group to support people to remember to attend sessions, everyone felt this was a good approach.

Resources were designed as accessibly as possible and everyone thought this helped them to take part. Fidget toys and snacks were also provided as a standard practice to support engagement.

As already noted, the way we worked also supported people to take part. Looking after people and meeting their needs before getting the project done even if this meant we worked slowly. Everyone said they felt valued and enjoyed being able to "talk about what they wanted". Sometimes this was about issues outside the project. Every session started with a check-in and Kaz and Liz sometimes left a session to chat about an individual issue with a member of the team. Weekly reflections consistently recorded that everyone felt "supported and included". In one of the evaluations the team said there was "plenty" of time and "plenty" of support. In another evaluation, the

THE CONTENT OF THIS EVALUATION IS LISENCED UNDER A CREATIVE COMMONS ATTRIBUTION LICENSE TO BE USED NONCOMMERCIALLY AND ALL USE AND ADAPTATIONS TO BE CREDITED TO THE AUTHORS.

support level was noted as 10 out of 10, with a comment that “there was no obvious discontent”.

Were people paid and did they have their contributions recognized?

The co-designers were paid for the time and expertise they gave. They were paid at the National Institute for Health and Care Research recommended rate of £27.50 per hour. This was done via a direct payment into their bank accounts.

The co-designers were also named as co-authors of the research training materials and of this co-evaluation.

Was power shared in the project?

We reflected on this question every week. We set the project up in a way that modelled we all had equal power with a working agreement. Kaz and Liz ensured we worked in this way every week. We took every opportunity to show we were listening and responsive to people’s requests and views, from bringing in their favourite snacks to re-designing materials.

The team noted that they did not design the project or the weekly session and that they would not have wanted to; “If we’d had to plan the sessions I’d feel too responsible and worry about what to do”. They said it was good that Kaz and Liz held that power. The team said that in sessions they had lots of power. They noted that they “decided what we did and what we shared”, they “shaped the questions and the plan for next time” and were “treated equally”.

In one of the evaluation forms, one person noted; “I always felt part of decision making and felt everyone else did too”. One of the team commented

THE CONTENT OF THIS EVALUATION IS LISENCED UNDER A CREATIVE COMMONS ATTRIBUTION LICENSE TO BE USED NONCOMMERCIALLY AND ALL USE AND ADAPTATIONS TO BE CREDITED TO THE AUTHORS.

that this was different to other lived experience projects they had taken part in, which had felt tokenistic and 'tick box', whereas here, "what we say really counts".

In order to share power all the way through the project we all felt it was important this evaluation report was co-written.

THE CONTENT OF THIS EVALUATION IS LISENCED UNDER A CREATIVE COMMONS ATTRIBUTION LICENSE TO BE USED NONCOMMERCIALLY AND ALL USE AND ADAPTATIONS TO BE CREDITED TO THE AUTHORS.

Evaluation of the changes the co-design project created (our impact)

The gains we experienced as individuals

To understand the gains we made as a co-design team we each drew a 'body map', an outline of a body, and filled it with words to show what had changed for each of us. There were seven body maps.

We mapped out all the different words. We had gained 17 different outcomes. We counted how many of us had gained them, this varied between all of us (seven people) and one of us. The gains we experienced are shown in the table below:

What we gained (outcomes):	**How many of us experienced this (frequency):**
Communication / use of words	7
Empathy for and understanding of other people	7
How to do research and design work	5
Hope things will change	5
Confidence	4
Knowledge	4
Fun	4
Creativity	4
First time named as an author	4
Friends / comrades	3
Support / stability	3
Thinking outside the box	3
Calmness / slowing down	3
New experiences	2

THE CONTENT OF THIS EVALUATION IS LISENCED UNDER A CREATIVE COMMONS ATTRIBUTION LICENSE TO BE USED NONCOMMERCIALLY AND ALL USE AND ADAPTATIONS TO BE CREDITED TO THE AUTHORS.

Sense of community / belonging	2
Make less assumptions	1
Using what I know	1

Overall, the 'body map' exercise shows that taking part in the project created a wide range of personal, social and research-related benefits. The strongest, most reported gains were improved communication and greater empathy for and understanding of other people, which were experienced by everyone.

Many of us also developed research skills, confidence, knowledge, creativity and a greater sense of hope that things could change. The findings also highlight the importance of recognition in research and connection with peers: four people identified being named as authors for the first time while others gained friendship; support and a sense of belonging. Together, these findings suggest that co-design was not only a way of producing accessible research materials, but also a positive experience that helped us develop skills, relationships, confidence and a stronger sense that our knowledge and contributions mattered.

Other wider impacts

The Cumberland Council Health Determinant Research Collaboration Co-Researchers said they felt the materials were really valuable. They wished they had been able to use them themselves. They felt they were useful to all co-researchers, not just those who are learning disabled.

We created an accessible version of the University of Cumbria ethics form as a part of the project. The universities ethics committee is reviewing the form and considering whether it can adopt it for research projects that are co-designed.

THE CONTENT OF THIS EVALUATION IS LISENCED UNDER A CREATIVE COMMONS ATTRIBUTION LICENSE TO BE USED NONCOMMERCIALLY AND ALL USE AND ADAPTATIONS TO BE CREDITED TO THE AUTHORS.

We also reached out to the Westmorland and Furness community power team to see where this project may contribute to other council workstreams. The community power team have shared news of this work with their wider contacts, and we have received interest from Westmorland and Furness' Corporate Equality, Diversity and Inclusion Adviser. They would like to work with us to better understand how we can apply easy read/ accessible materials more widely and embed community co-research into policy and practice.

THE CONTENT OF THIS EVALUATION IS LISENCED UNDER A CREATIVE COMMONS ATTRIBUTION LICENSE TO BE USED NONCOMMERCIALLY AND ALL USE AND ADAPTATIONS TO BE CREDITED TO THE AUTHORS.

Conclusion

This project set out to co-design accessible research training materials, but it achieved more than producing a resource. Our evaluation shows that the way we worked together was just as important as what we produced. People felt listened to, supported and able to contribute in ways that worked for them. They had genuine influence over the materials and the decisions we made, while having the choice not to take part in activities when they did not want to.

The project also created benefits for the people involved. Through our body-mapping exercise we identified 17 different outcomes including: improvements in communication; empathy and understanding; research skills; confidence and knowledge. Everyone identified improved communication and greater empathy and understanding of other people, and four people identified their value in being named as authors for the first time.

We also learned things that we would do differently. In particular, we could make joining a future project clearer by giving people an opportunity to try a session before committing and by providing better feedback during the sign-up process. We also recognise that travel can remain a barrier for people living in rural areas.

The impact has begun to reach beyond the original project. Co-researchers from Cumberland Council Health Determinant Research Collaboration felt the materials could be valuable to co-researchers more widely, an accessible version of the University of Cumbria ethics form is being considered by the university's ethics committee, and the work has generated interest within

THE CONTENT OF THIS EVALUATION IS LISENCED UNDER A CREATIVE COMMONS ATTRIBUTION LICENSE TO BE USED NONCOMMERCIALLY AND ALL USE AND ADAPTATIONS TO BE CREDITED TO THE AUTHORS.

Westmorland and Furness Council in using accessible materials and community co-research more widely.

Most importantly, this project showed us that accessible and meaningful co-research is possible when people are given the right support, genuine choices and real influence. People with lived experience should not simply be participants in research. They can help shape it, undertake it and communicate it. Our next challenge is to take what we have learned and help make this way of working part of everyday research practice within our other partnership organisations.

THE CONTENT OF THIS EVALUATION IS LISENCED UNDER A CREATIVE COMMONS ATTRIBUTION LICENSE TO BE USED NONCOMMERCIALLY AND ALL USE AND ADAPTATIONS TO BE CREDITED TO THE AUTHORS.