Údarás Náisiúnta Míchumais
National Disability Authority

How to do collaborative research with people with disabilities

A guide for researchers

This is an Easy to Read version of the guide

April 2023

What is this guide about?

This guide is about collaborative research.

Collaborative research is when professional researchers do research with people who are not professional researchers.

This guide is about researchers working with people with disabilities to do research.

There can be different levels of collaborative research.
A lower level would be a group where people with disabilities give advice to researchers.

A higher level would be when people with disabilities have full control over the research.

We hope this guide will help researchers to do more collaborative research with people with disabilities.

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National Disability Authority

This guide was put together by the National Disability Authority.

We would like to thank the Disabled Persons' Organisations, people with disabilities, voluntary and community organisations, and professional researchers, who helped us to put this guide together.

Collaborative research

What is a research participant?

A research participant is a person who volunteers to take part in a research project.

They are given information about the research, they think about this, and make a choice to take part.
This is called consent.

Research participants do not make decisions about the research.

They are not involved in planning or doing the research, for example, they do not decide what the research is about or study the data.
Data is the information we collect during research.

A collaborative researcher is different to a research participant.

A collaborative researcher is often called a co-researcher.

A co-researcher is involved in making decisions about the research.

For example, they may help decide what to research.

A co-researcher will help to run the research project.

For example, they might design a survey, collect and study the data, or share the research findings.

The values of collaborative research

The research is owned by the whole research team. They work together so everyone can understand the research.

The research team includes all different types of people.

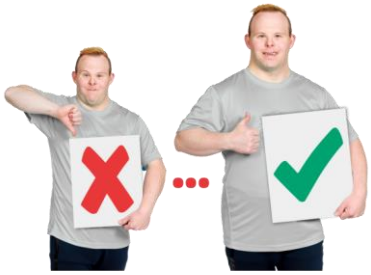
The knowledge of every person on the research team is important and is respected.

Everybody benefits from working together.

The way the research is done, the materials used, and the environment are as accessible as possible to everyone.

There is trust and a good relationship between the professional researchers and co-researchers.

Professional researchers and co-researchers talk about research decisions and how the research is going.



Everyone understands the commitments involved in collaborative research.
The research plan and ways of working can change if people need them to.

Ethics

Ethics means making sure that a research project has the right values and ways of working.

We need to think about the ethics in collaborative research projects.

There can be challenges if the co-researchers know the research participants, but that doesn't mean that the research can't happen.
It is a good idea to ask co-researchers and researcher participants if they are comfortable taking part when they know each other.

It is not usually a good idea to have the same people as co-researchers and research participants.

It is important to avoid tokenism.
This is when researchers want to look like they have involved people with disabilities but do not do this in a meaningful way.

The voice of the co-researcher must be heard.
They must have a chance to share their views and ideas.

It is important to have a good relationship between the professional researchers and co-researchers.
There should be respect, trust, and honesty.

Professional researchers need to find the right balance between giving support and taking too much control.

Professional researchers should give support to co-researchers when they need it.
They should make sure that the work plan is fair and achievable.

If co-researchers are under the age of 18, it is important to know how to keep them safe.
Researchers must know about safeguarding policies.

Doing collaborative research

Why should we do collaborative research?

When professional researchers and people with disabilities work together, it can help to make sure that research is in line with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

When we include people with disabilities, they can say if money is being spent on the right kind of research.

Co-researchers can help to make sure that research is about things that are important to people with disabilities.

People with disabilities may be more likely to take part in research when their peers are co-researchers in the project.

Co-researchers bring different skills, ideas, questions, experiences, and understanding to the research.

Co-researchers can help to make sure that information about the research is accessible.

Collaborative research gives people with disabilities a voice and a way to stand up for themselves and their communities.

Co-researchers can get experience, research skills, confidence, and control.

Professional researchers can learn new skills and learn about the lives of people with disabilities.

Who should be involved in collaborative research?

Professional researchers should think about including people with disabilities even if the project is not about disability.

Professional researchers should know why they are involving people with disabilities in the research project.

Professional researchers should think about the skills that co-researchers will need to do the research.

Where possible, professional researchers should involve more than one person with a disability. The number of co-researchers you need will depend on the size of the research project.

What should co-researchers know before deciding to be involved?

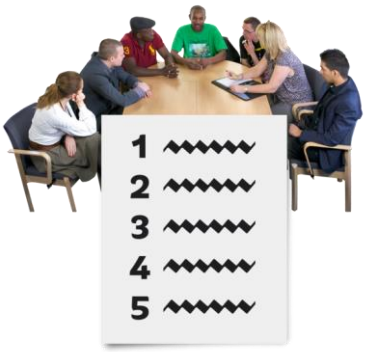
Co-researchers need to know why the research is being done.

They need to understand why they are asked to be involved.

Co-researchers need to know the plan for the research.

They need to know what their role will be.

Professional researchers should not ask co-researchers to do too much in a small amount of time.



Researchers should be open from the beginning about what is possible in the research project.

Involving co-researchers at every stage of collaborative research

Involving people at every stage of the research process

There are many different ways that professional researchers and people with disabilities can work together.

People with disabilities can get involved in all stages of the research process.

It is important to include people with disabilities when deciding what to research.

Co-researchers can be involved in writing funding and ethics applications.

Professional Researchers should use Plain English or Easy-to-Read forms.

They should break forms down into smaller pieces.

Co-researchers can help study other research and writing.

This is called a literature review.

Co-researchers can help put together information for research participants.

They can teach other researchers how to make information accessible.

Co-researchers can help find people to take part in the research.

Co-researchers can help with getting consent from research participants.

Co-researchers can collect information, for example, during interviews or in surveys.

Co-researchers can study the information collected. This is called data analysis.

Co-researchers can write research reports

Co-researchers can share the information and learning from the research project.

Co-researchers can give advice on the best ways to present the learning from the research project.
For example, have a community event, make a podcast or a video, make a website, have an art exhibition, do a theatre performance.

Co-researchers can say how they think the research project went.

They can think about how it went for them.
For example, did they feel included and listened to, or did they learn new skills?

It is important to support co-researchers at the end of the research project.

The research team should mark the end of the project with a celebration event.

The professional researchers should keep co-researchers updated after the project has ended. For example, will there be follow on projects, or did the research bring any changes in plans or policies?

Supporting co-researchers to do research

Research organisations can do more to make sure that collaborative research happens.

Where possible, co-researchers should be paid for their work.

Payment should be made in a simple and quick way that suits the co-researcher.

There should be a payment for expenses.

This makes sure that people with disabilities can take part.

Expenses could include travel, meals, support staff, printing, childcare, or technology (such as smart phones, laptops, apps, Internet access, assistive technology).

Professional researchers must talk to co-researchers, before and during the research project, to find out how they can make things accessible.

All information and materials should be accessible.

Co-researchers need time to look at and understand information.
It is important not to send too much information at once.

Co-researchers should be given plenty of notice of meetings.

The research team should work together to think about how often and when meetings will happen.

Meetings should be organised in a way that helps people to take part.

The whole research team should have Disability Equality Training, which is led by or includes people with disabilities.

Co-researchers may need, or want, some training and upskilling.
Researchers and co-researchers should work together to decide what training is needed.

The timeline for the project work should be flexible. For example, some co-researchers have other jobs, or are in education.

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