



**A GUIDE FOR CO-RESEARCHERS
WORKING ON CO-PRODUCED
RESEARCH PROJECTS**

INTRODUCTION

You may have been given this booklet by a member of our research team because you are interested in joining a project as a co-researcher. It will tell you exactly what the terms **co-researcher** and **co-produced** mean, and will help you to decide if being a co-researcher is something you would like to give your time to. It will also give you some idea of what to expect if you get involved in a research project.

There are many possible reasons to get involved in co-producing a research project. For instance, to:

- * use your skills and experience to help shape a piece of research
- * help produce new knowledge that will benefit a community you identify with
- * help ensure that the voices of people with experiences like yours are heard
- * do something new that is rewarding and stimulating
- * gain new skills that will enhance your CV

MEET SYDNIE

Sydnie was a **co-researcher** on a York-based **co-produced** research project entitled 'York Food Poverty Alliance'. Here is what she says about the experience:

Being actively involved in York Food Poverty Alliance has helped me not feel alone and vulnerable or isolated, but empowered and encouraged that others are there to talk to and share their own experiences... This has been an empowering and encouraging journey, one which [has given me the opportunity to] help others like myself and my two children.



FIRST THINGS FIRST – WHAT IS RESEARCH?

You may already have some idea of what working on a research project involves, such as looking through dusty books in libraries. However, reading books and reports is only a small part of research. The purpose of research is to better understand the world we live in so we can make it a better place to live. Doing research therefore includes a whole range of activities including: collecting information about what is already known about a particular topic, doing surveys, interviewing people, making sense of the results, and passing on the findings.

WHAT IS CO-PRODUCED RESEARCH?

You may have heard the term **co-production** and wondered what this is. In **co-production** academics and members of the community work together to design and develop new approaches to addressing the opportunities and challenges that matter to them. In the past, professional academic researchers were often considered the only people with the right skills and experience to do academic research.

In recent years however, there has been an increasing recognition that different types of expertise are needed, particularly when exploring the big challenges that society faces today, for example around health and wellbeing, new technologies, the environment and social care.

More and more researchers are realising that people with lived experience of a particular situation, health condition or disability have vital insights and perspectives which cannot be gained from any other source. This trend is known as **public involvement** in research. In a **co-produced project** however, barriers are broken down one step further, and people with lived experience become **co-researchers** – that is, they become **equal partners** in shaping research and discovering new knowledge. This makes the research stronger and more effective at delivering change.

There is no single way to do co-production, but there is always an underlying commitment to recognising the equal value of each team member's particular skills, and to listening to, respecting and valuing everyone's contribution.





WHAT IS A CO-RESEARCHER?

In contrast to a professional researcher, it is unlikely that a **co-researcher** does research as their main job. Rather a **co-researcher** will bring their varied and valuable life experiences to a particular research project. You may have experience of a specific situation, health condition or disability. In this respect you are an **expert by experience**. Professional researchers will value your expertise, as you will bring an equal but different perspective into the research project which will help to shape and deliver a piece of research. There is no substitute for getting those with first-hand experience of a situation, health condition or disability to share their knowledge with professional researchers and work together on a study.

In practice the distinction between a professional researcher and a co-researcher can be blurred and some co-researchers may have had professional research training or have been in a paid academic role previously. However, many people come to the role of co-researcher having not worked within an academic environment before and academic experience is not expected.

DIVERSITY

We welcome the involvement of everyone with relevant expertise and experience to join the team as a co-researcher and value diversity in terms of disability, sex, gender reassignment, sexual orientation, pregnancy and maternity, race, religion or belief, marriage and civil partnership. You are also welcome if you are homeless, an asylum seeker, a migrant, a member of the travelling community, a carer, or care leaver. We value people's experience because of their diverse backgrounds. This diversity is something we consider to be positive, and want to encourage, because it reflects the varied communities we live in and makes for richer, more relevant research.

SO WHY GET INVOLVED?

BENEFITS TO YOU

Personal benefits:

- You may learn new skills and enjoy sharing your knowledge and skills with others.
- It can feel good contributing to making a difference to the communities you care about.
- It can be rewarding working with a team of people with a range of perspectives.
- Involvement can give you a new purpose and make you feel more empowered.
- It can be rewarding to see your contributions acknowledged (for example, in publications).
- Involvement can build personal confidence and self-worth.
- It can offer opportunities to engage with lots of different people.
- It can stimulate your mind in a different way.

I feel listened to and respected



I feel wanted and needed

It feels exciting and rewarding when my ideas are recognised

It improves my self-esteem, confidence and dignity

It gives me social opportunities and the chance to meet other people with lived experience



I can learn new work related skills such as chairing a meeting and interviewing skills

It feels good to make a difference to people's lives



I find it positive and rewarding

It gives me a sense of purpose and makes me feel empowered

I enjoy working together as a team

I find it stimulating and interesting

It has encouraged me to look after myself and speak up for myself.


Work related benefits:

- ✦ We will cover all of your out-of-pocket expenses, and will be clear if the role is paid or voluntary.
- ✦ You can use your existing skills and learn new ones, such as chairing meetings or preparing reports.
- ✦ You can put your involvement in the project on your CV.
- ✦ You can ask the professional researchers for a reference.
- ✦ Being involved may lead to further opportunities to work on research projects.



BENEFITS TO SOCIETY

- ✦ You can improve things for others who are in a similar situation to yourself by shaping research to focus on things that matter most in the community.
- ✦ Your involvement sends a clear message to society that communities and their members are valued for their skills and expertise.
- ✦ The research you help to co-produce may provide information which can, in time, improve policies and services.
- ✦ You can be a role model for other people in a similar situation, showing others that they too can get involved in research.
- ✦ Your involvement can make the research more relevant to people in a similar situation to yourself.
- ✦ Your involvement can make the research stronger and more likely to be implemented successfully.
- ✦ The community can share ownership of the research.

An illustration of a man with dark skin and short grey hair, wearing black-rimmed glasses and a light blue patterned short-sleeved shirt. He has a prosthetic right arm that is bright green and black, with a cylindrical base. He is looking upwards and to the right with a slight smile. The background is a textured orange-brown color. Three yellow speech bubbles are positioned around him, each containing text.

I can provide information that can, in time, improve policies and services

I can speak up for other people with lived experience

I can improve the situation for people in similar circumstances to myself

WHAT YOU CAN EXPECT IF YOU GET INVOLVED

As a co-researcher, the research team may seek your expertise before a project begins to see what questions or issues are most important to address. We may seek your input when a project is underway to help guide and influence how the research is carried out. We may ask you to help with gathering information such as interviewing other people with experience of a similar health condition, disability, or situation to your own. We may involve you in making sense of the results and sharing them with other researchers and interested people. We may also seek your perspective at the end of a project to find out what went well and what could have been improved. You will be provided with training, mentoring by a team member, and buddying with another co-researcher to support you in your role.

- ✦ You can expect the project lead, or another designated member of the project team, to welcome you and talk to you about the project and how you can help shape it.
- ✦ You can expect an induction to the role which will give you an overview of why the research project has come about and an opportunity to discuss further how you would like to be involved. You will also find out what to do if you are unhappy about anything.
- ✦ You can expect the project lead to give you an idea of what the time commitment is likely to be before you start, so you can judge whether you can fit this role in alongside other commitments.
- ✦ You can expect specialist training if you are asked to do something that requires a particular skill, such as interviewing people or making sense of the results. You can add these skills to your CV.
- ✦ You may want to contribute in some ways, but not in others. For example, you may be happy to share your experiences within the project team, so we can get to know you, but not want these experiences written about publicly. This is fine. Where possible, let the project lead or your mentor know about your preferences. The team may want to make public some information about the project's co-researchers, but will do so only with their clear agreement.
- ✦ Your situation, health condition or impairment may fluctuate. You can expect us to recruit several co-researchers to allow you to dip in and out of the project if necessary, depending on your changing needs. You can leave the project at any time or pause your involvement if you need to do so. However, if you are experiencing any difficulties, you should speak to a member of the team or your mentor, as they may be able to help.





I have learnt so many skills that I can use not only as a peer researcher but in my life. I never thought I would be able to travel on my own and stay away from home before but becoming a peer researcher has given me loads of confidence.

Peer researcher at *Peer Research and Understanding Homelessness: Exploring Practice, Learning and Innovation* conference by Focus Ireland, Dublin, 2019

MUTUAL RESPECT

One of the most important ideas behind co-production is mutual respect between all members of the project group, as well as other people you come into contact with while working on the project. With co-production each person and each contribution is valued equally so it is important to be respectful of different viewpoints even if you disagree with them. The group will agree a set of ground rules which promote respect and dignity as well as safeguard-related issues such as confidentiality. The more the group members can foster respect and trust the better the experience will be.



CHALLENGES

- ✦ Being involved in a research project can challenge your ways of thinking, your views of the world, and your perspective on your situation, health condition or disability. This can be daunting at first but after a while you may find it empowering.
- ✦ You may feel daunted about speaking up in team meetings. We will try to make this easier for you by creating a friendly and informal environment. It can help to know that even professional researchers can feel daunted about speaking up in certain situations. We will try to make it as easy as possible for you to contribute and work within the team. Remember you are an 'expert by experience'!
- ✦ Research projects are carried out from within particular academic disciplines, for example, social sciences, health sciences, education or medicine. These disciplines have their own traditions, methods and vocabularies which can seem slightly alien at first. You are, of course, not expected to know everything in advance. In a co-produced project, the research team is there to be guided by you and the fresh perspective you can provide. It's easy to think professional researchers are scary people in 'white lab coats' or 'professors interviewing people' who know everything. Like everyone else, however, professional researchers have many things they are uncertain about or have not thought about.
- ✦ Co-production is still quite a new way of working. To some extent the whole team will be feeling their way as they go along. You may find that there are opportunities to encourage new ways of working. As with many things, the more you are able to get involved with a variety of tasks, the more you will get out of the experience.

I was very nervous when presenting our presentation. Presenting in front of experienced and professional researchers was intimidating considering I've only been a peer researcher for four or so months. I was fully supported throughout the day which was comforting and I definitely have more knowledge on peer research now.

Peer researcher at *Peer Research and Understanding Homelessness: Exploring Practice, Learning and Innovation* conference by Focus Ireland, Dublin, 2019

THE RESEARCH TEAM'S COMMITMENT TO YOU

- ✦ If you choose to get involved, we will create a supportive, safe, welcoming, non-judgemental environment in which everyone has a fair opportunity to contribute, and respectfully listen to each other's views.
- ✦ We will provide an induction where you will be introduced to the other members of the project team, and be given the background to the project and the potential timescales. We will also discuss with you how you would like to be involved in the project.
- ✦ We will give you a mentor from among the professional researchers with whom you can raise any questions, needs or concerns, and a buddy from among your co-researchers with whom you can also talk things over.
- ✦ We will provide you with training to help you to better understand some of the different approaches that researchers may take to a topic, and what these approaches aim to achieve.
- ✦ We will provide you with training to supplement and enhance your existing skills, ensuring that you have the confidence and know-how you will need to carry out research activities related to the project.
- ✦ We will keep you up to date with the project and answer any questions you have. Within the constraints of the project's budget, we will try to involve you as much as possible.
- ✦ We will avoid using jargon and acronyms as much as possible, and if they are unavoidable we will make clear what they mean.

ACCESS AND OTHER NEEDS

We want to make sure our involvement opportunities are accessible to you. We will ask about your access needs, and any other needs and preferences you may have. However, do not be afraid to be proactive about sharing your needs. For example, you may need a hearing loop; a lip speaker or a BSL interpreter; materials in an accessible format; a meeting room and travel suitable for a wheelchair user; a carer to come with you; papers or information in a particular format; or a support worker. If you are a carer, you may need an expense payment to cover the cost of someone to take over your carer responsibilities while you are at a meeting. You may need meetings arranged at particular times of the day. Clearly state your needs to us. Leave plenty of time so we can put your requirements in place.

We will let you know if refreshments are provided, and if they are, we will ask you in advance about any specific dietary needs.

EXPENSES AND PAYMENTS

- ✦ If you get involved all your out-of-pocket costs will be covered for travel, parking, accommodation (if needed), carer and support worker costs, printing, telephone, photocopying and postage costs where appropriate.
- ✦ Your involvement in a project may be voluntary or paid. This will be made clear at the very beginning of the project so you can make an informed decision about whether or not to take part. If you decide to take on a paid position, you may need advice on how this will affect your benefits. The Social Care Institute for Excellence has some helpful information on this at: bit.ly/34drVBF, or you can talk to the project lead.
- ✦ If you decide to get involved in a research project, you can bring this booklet with you to meetings. You can refer to it to make sure you are being fully supported and draw the team's attention to any areas where they are not meeting their commitments to you.
- ✦ If anything is unclear, you should not be afraid to ask the project lead, your mentor or another member of the team.



THE SMALL PRINT

KEEPING YOU SAFE

We prioritise the safety of everyone working on a research project. We will carry out a full risk assessment of any activities which require one, and will help you and all the team to keep safe. For example, if the research involves interviewing research participants, we will have a clear policy on where interviews will be conducted, how to contact team members, and what information may be recorded. If you have any concerns about safety while participating in a research project, you should contact the project lead, your mentor, or another member of the team.

ETHICS

It is very important that research is conducted in a way that treats people with respect and consideration. All research projects are assessed by an ethics committee to ensure that the research processes and procedures are ethically correct. We take ethical considerations very seriously and are committed to fair and open treatment of co-researchers, and everyone else involved in research. If you decide to participate in a research project and have ethical concerns about the way the research is being conducted, you should contact the project lead, your mentor, or a member of the team.

CONFIDENTIALITY AND DATA PROTECTION

As with all staff who work with us, we will hold all the personal information that you give us on secure, password-protected servers. We are legally obliged to follow the comprehensive guidelines set out by the General Data Protection Regulation. More information can be found at: gov.uk/government/publications/guide-to-the-general-data-protection-regulation.

SOME DEFINITIONS

Professional researcher This is likely to be someone who has been trained in a particular research area and is employed by a university to conduct research.

Co-researcher A co-researcher is someone in a particular situation, or who has a particular health condition or disability, and who uses their experience to deliver research on a particular topic as a member of the research team.

Expert by experience If you have been given this booklet because you are in a particular situation, such as having a health concern or disability, it is likely that you are already an 'expert by experience'. This is someone who has a particular understanding of a situation or health condition by virtue of their lived experience.

Lived experience This is experience gained by living with a particular situation, health condition or disability.



LINKS

You may want to read more about co-produced projects or research projects that involve co-researchers. See the following links:

The 'Realising Just Cities' project hosted by the University of Sheffield: realisingjustcities-rjc.org

Special issue of the journal Nature on co-production of research: nature.com/collections/nnqkvntry/

'Inside, outside and in-between: The process and impact of co-producing knowledge about autism in a UK Somali community': doi.org/10.1111/hex.12939

Lab4Living: lab4living.org.uk

Projects from the McPin Foundation using co-produced and peer research methods: mcpin.org/our-work/research-2/

'Involve' guidance on co-producing a research project: invo.org.uk/wp-content/uploads/2019/04/Copro_Guidance_Feb19.pdf



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