‘The evidence suggests that co-research can benefit the research itself and everyone involved – but what are some of the challenges and how can we overcome them?‘

An Ask IMPACT guide

IMPACT
Improving Adult Care Together

UKRI Economic and Social Research Council

The Health Foundation

Background

In 2025, a previous **Ask IMPACT guide** set out the potential **benefits of co-research** for people who draw on care and support and for the research itself.

However, members of our Co-production Advisory Group and other people who draw on care and support, practitioners and researchers who reviewed the draft guide also wanted to know more about the potential **barriers and challenges** when undertaking co-research - and any insights from the evidence on **how to overcome these.**

We therefore re-analysed and updated the initial review to inform a second guide.

Key issues from the evidence include:
- Power imbalances
- Skills and training
- Academic pressures and systems
- Communication
- Involvement at different stages of the research
- Dealing with distressing issues
- Working in groups
- Being perceived as ‘too close’ to the issues being researched
- Over-protectiveness and paternalism
- Funding and University processes

Things that help are planning ahead - thinking and/or being clear about:
- The importance of relationships
- Clarity of roles and responsibilities
- Amplifying seldom heard voices
- Resources, access and training

Creating inclusive and safe spaces

Key terms

As in our previous guide, we use a number of key terms, that sometimes get used in different ways or aren't always clarified from the start.

This guide focuses on research 'with' people rather than 'on' them – using Peter Beresford's definition of 'collaborative or partnership research' as situations where "service users and/or their organisations and researchers and/or their organisations jointly develop and undertake projects."

This is different to 'user involvement research' (where input from people using services is added to existing approaches) and to 'user-controlled research' (where people using services and their organisations initiative and control the research).

The term 'co-researchers' is often used to mean people who have lived experience of the topic that is being researched, who bring this with them as part of the research team. They often work alongside researchers from other backgrounds (some of whom might be researchers at a University who work on a range of social care topics, without necessarily having lived experience of the specific topic or situation being researched).

We also build on SCIE's definition of co-production as "working in partnership by sharing power between people who draw on care and support, carers, families and citizens."

The National Institute for Health and Care Research is clear that co-producing research should be based on a series of key principles:

- Sharing of power – the research is jointly owned and people work together to achieve a joint understanding
- Including all perspectives and skills – make sure the research team includes all those who can make a contribution
- Respecting and valuing the knowledge of all those working together on the research – everyone is of equal importance
- Reciprocity – everybody benefits from working together
- Building and maintaining relationships – an emphasis on relationships is key to sharing power

While lots of the literature talks about academics/University-based researchers and co-researchers/researchers with lived experience, we recognise that we all bring different elements of our identity to work, and that lots of people might have both lived experience and formal academic training and experience.

Barriers and challenges

Power imbalances

"Academics felt responsible for directing and taking charge of the processes that were not working. Although their actions often sought to challenge conventions in order to include co-researcher perspectives more effectively, the tendency for the academic team to lead on key methodological decisions disrupted the "co" in this co-research study." (Allen et al., 2018)

The relationship between University-based academics and co-researchers is often one based on **power imbalances** - and this needs to be acknowledged and addressed from the outset. Imbalances can relate to things like employment status, pay, social standing and previous access to training and information.

This can also be subtle and well-meaning. For example, while the researchers in the quote above were probably trying to solve some practical issues in order to develop a more collaborative relationship, the danger is that they may have a tendency to **'take charge'**.

If relationships don't feel equal, people can feel **disillusioned**, and attempts to work together can quickly feel tokenistic or 'tick box'. This can be particularly the case if co-researchers have previously had negative experiences of being involved in research, reinforcing these feelings.

One way of guarding against this is being clear on the nature of people's involvement, agreeing what's possible or not within the confines of the research, and the basis on which we will be working together.

Skills and training

"It may be that formal training is offered by research teams, at colleges or universities, but we found very little literature or descriptions of such courses or programmes." (Tuffrey-Wijne et al., 2020)

For those wanting to be involved in co-research there is often a lack of confidence and a **"fear of getting it wrong"** (NIHR, 2021). Research methods and processes can be complex, and often there is a sense of "learning on the job" (Daly Lynn et al., 2021).

This means that **training, support and space to reflect** are really important to build in from the start.

Academic pressures and systems

"The incentives that count for career progression within academia (publications, research grants) are inherently disabling: they are individualising and competitive and do not support those academics who want to work in a collaborative way with service users and disabled people. Equally, these same issues represent significant barriers to the employment of disabled people and service users." (NIHR, 2021)

"TIME is a major issue, both a need and a barrier. Good involvement takes time and research deadlines often mitigate against this." (NIHR, 2021)

Disincentives (for academic researchers) to undertaking co-research can include **time constraints**, and the general pressures and **demands of academic life**. Other studies mention a perceived lack of support from senior academic colleagues, the amount and nature of paperwork that needs to be completed with regards to research ethics and difficulties in finding a safe, accessible research environment in which to meet and work.

Some of these barriers are about what is valued when it comes to academic advancement – so it is important to recognise this reality, whilst also encouraging research teams to challenge it in order to advance opportunities for co-research.

Of course, time can also be a disincentive for people who draw on care and support, whether from prior commitments or the time it takes to give and receive care, travel and build up skills and confidence. Some groups may also feel that they have limited time left to them and to give, for example if you are an older person living with dementia and near the end of life. Some community and user-led organisations who might support individuals to become involved in co-researchers also struggle for time and capacity, and many academic processes (for example, university ethics processes) can be experienced as a potential barrier.

Communication

There are lots of communication challenges – including **academic terminology** and **jargon**, and the difficulty of ensuring **accessible communication** which enables people to take part and share ideas in a way that works for them.

Lots of research now uses different forms of **technology** to help with communication (for example, different ways of interacting online), and this can both help and be a barrier for some people.

Involvement at different stages of the research

Genuine partnership would imply full involvement **in all aspects of the research process**, from the research design to data collection, and from analysis to writing up and sharing findings.

However, this does not always happen in practice, and it can be more common for people to be asked to be involved via brief inputs or at **particular stages** of the research, but often not in analysis or sharing findings with others.

This can lead to **academic bias** at key stages of the process (for example, when identifying overall themes and key messages), to people feeling **excluded** and to the research as being seen as **'belonging' to the academics** rather than the full team.

Equally, academics can worry about asking too much or overwhelming co-researchers – making an honest and upfront conversation about time commitment and the nature of the contribution being sought is even more important.

Lots of the literature also seems to talk about involvement in **qualitative research** (where it can be more common to focus on people's experiences of care and support, and on different voices). However, it may be that more is needed to develop approaches to co-research in more **quantitative research** (see Allen et al., 2018 for a practical example of a study that tried to include a more quantitative element, as well as a discussion of potential tensions between participatory research and quantitative outcome measures).

Dealing with distressing issues

The issues being explored in social care co-research can be very **distressing and emotive**, especially if you have **lived experience** of such issues yourself or as a carer.

This might be particularly the case for people from **marginalised communities**, whose experiences may often be rooted in historical discrimination, exclusion and racism.

This makes the way we support each other and try to create safe spaces even more important. **Training** and **clear agreements** as to how to respond when distressing issues arise are important – this shouldn't be left to chance.

Working in groups

Lots of co-research involves groups of people coming together to work on the research, and any group situation can raise issues around:

- How best to hear everyone's voice and to prevent a few voices from dominating
- How best to handle potential personality clashes and disagreements
- How and where best to meet to enable as many different people as possible to be able to take part
- How best to create an environment where everyone feels included, valued and part of a team

Being perceived as 'too close' to the issues being researched

While data and understanding can be improved when co-researchers and research participants have similar life experiences or come from similar backgrounds, this also raises potential issues around **confidentiality**. This may be especially the case if someone from a particular community feels less likely to take part in case someone else from that community finds out.

Sometimes people also worry that some people with lived experience might find it difficult to move beyond their own experiences to understand the experiences of participants (which might be similar to, but also inevitably different from, the co-researchers).

These are real risks – but **all good researchers should be identifying potential bias** in their questions, methods, evidence collection and results, **whether or not they have lived experience** of the issues at stake. In reviewing the evidence, we wonder whether there is a risk that co-researchers could be asked to live up to an even higher standard in this regard than other members of the team – more as a way of excluding their voices rather than of ensuring good research.

Over-protectiveness and paternalism

Some groups – such as people living with dementia or people with learning disabilities – can experience **stereotypical attitudes**, with an assumption that they do not have the capabilities to undertake co-research.

This can replicate people's experiences in health and social care services and broader society.

The resources that have been reviewed for this guide suggest that lots of different people and groups can be involved in co-research if it's based on **good relationships, accessible approaches** and a commitment to **seeing each other as individual people**, rather than responding to people's labels and conditions.

Funding and University processes

"When you are properly paid in a timely fashion, you feel valued. Payment shouldn't be an afterthought. This shows the power balance. The researchers get paid on time. They are up there, and we are down here.' 'You shouldn't feel like you have to chase or beg." (Griffiths et al., 2024, p.718)

Having the **time** and **space** to build relationships, undertake training and take part in research depends on **funding** so that people who are contributing their lived experience and skills are properly paid for their work and expertise.

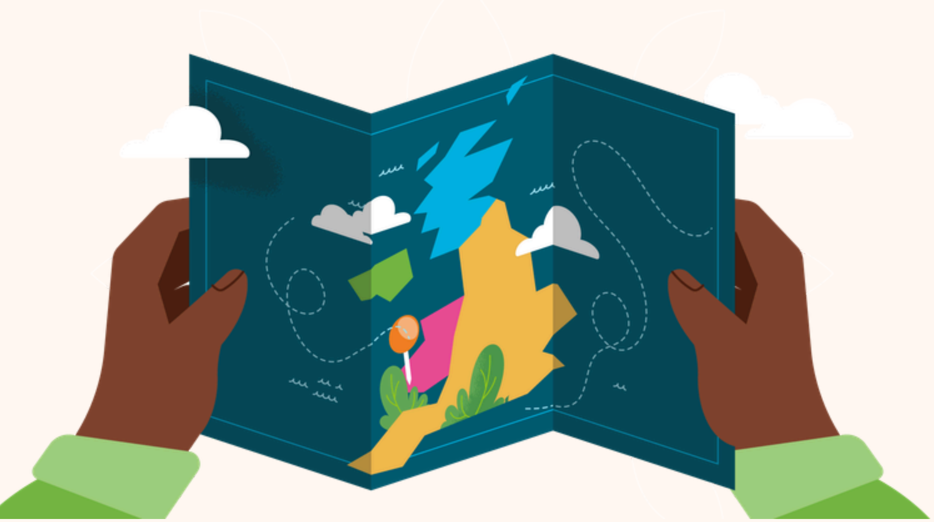
In practice, this is often more complex than it may sound, potentially involving the difficulty of navigating **University systems and processes** (which may not have been designed with co-research in mind) and of the **benefits system** (where there can be a series of barriers to people undertaking paid work).

However, **proper and timely payment** is really important, both in practical terms (enabling people to take part) and symbolically (so that everyone is being appropriately paid for their time and expertise).

Things that might help

Overcoming these barriers requires a commitment to doing things differently and to **planning** for co-research at the early stage of the process. This is an important step towards addressing the structural limitations and barriers identified in the evidence – laying a foundation to be able to demonstrate the value of co-production to answering the research questions and ensuring co-production at all stages of the research endeavour.

For example, guarding against poor communication or jargon may not necessarily be about specific tools – but about being mindful of the risks and conscious of attempts to be more accessible.



Relationships

Most of the issues raised in this guide and our review revolve around **time, space, skills and commitment** in terms of building more inclusive, trusting, two-way **relationships**.

This is partly about **values** – a commitment to principles of 'nothing about us without us' and mutual respect between academics and co-researchers. However, it is also about building in (and funding) opportunities to get to know each as people, spend time together, work and plan together, and reflect on ways of tackling power imbalances. This in turn can help to demystify unhelpful stereotypical attitudes.

Like co-production itself, co-research is often a journey we go on together, without necessarily knowing in advance where we may end up and where there isn't really a map - but where we commit to travelling together.

Agreeing roles and responsibilities

Spending time working through and being clear about **mutually agreed roles, responsibilities and ground rules** is time well spent.

A number of different studies and guides give an insight into the sort of things that might be important to consider. This can include being upfront about key tasks, the time commitment/people's availability, who might do what, the training and support available, and what each partner is hoping to get out of the process.

As examples, Buffel (2019) describes how co-researchers and academic researchers worked together to build consensus around roles, group meetings, ways of working and ground rules.

Mikuluk et al (2021) describe the co-design of training for co-research involving people with learning disabilities and carers, including the materials they developed together to help people understand different parts of the research process and tips for making information and processes accessible.

Davies et al (2021) describe how people living with dementia (experts by experience) worked together with a traditional academic with expertise by research to capture learning from the DEEP (UK Network of Dementia Voices) Dementia Enquirers programme.

Seldom heard voices

One of the core benefits of co-research is the potential to include the voices of minoritised populations who are seldom heard, whether this be in relation to age, experience, ethnicity, socio-economic background or other parts of people's identity.

This involves a commitment to approaches which enable as many different people as possible to contribute, and to paying serious and thoughtful attention to **diversity, equality, inclusion and tackling power imbalances.**

People who draw on care and support who reviewed our co-research guides thought that it was important to always ask:

- Whose voices still get missed, even in co-research?
- How do things like race, disability, age, gender and sexuality shape whose knowledge is seen as valid?

However, IMPACT also finds that some people can sometimes 'tip over' from trying to value inclusion and diversity into asking co-researchers to be somehow '**representative**' of particular groups or communities (when other researchers aren't being ask to represent anyone else other than themselves). While it is important to listen to seldom heard voices, we shouldn't dismiss views that we might find difficult as coming from people who are not 'representative' of 'typical' people who draw on care and support (whoever we may see these apparently 'typical' people as being).

Resources, access and training

Making sure that there is adequate funding for co-researchers and for the time needed to build relationships is crucial.

Payment mechanisms are often difficult, but there can be scope to find ways to streamline University payment and expenses processes as much as possible, so that these don't form too great a barrier to participation. This might include a nominated person who can help with paperwork and getting payments processed.

For relationships to be more equal, several co-research teams felt that people should be a paid position with **transparent roles** and associated **contracts of employment** – although there may also be some downsides to this, depending on people's circumstances and the kind of relationship they want with the University (not all of us want to be 'employed' as such, and there might be a range of different funding and employment mechanisms to enable different people to take part in a way that works for them).

When reviewing the evidence, some of the focus seemed to be on groups coming together for a particular piece of research. There seemed to be less discussion of the support, advice and guidance that might be needed to help co-researchers move into other, perhaps more long-term or secure employment after this initial study. Instead, some accounts suggest that groups might be brought together for a particular purpose, work together then stop – which isn't how more traditional academic researchers would want to plan their own careers and employment. Helping people to think about **longer-term development and opportunities** feels a potential gap in much current practice.

Having the right **physical environment** is another important consideration – in terms of accessibility and environments which are comfortable, relaxed and feel familiar. Some co-researchers have also valued this being at a University because of its amenities and status, although this might also be inaccessible for others.

Throughout many of the sources included in this review, having access to meaningful, tailored, accessible **training and support** is seen as crucial in helping people develop new skills, build their confidence and start to work together effectively as a team. This requires time, funding and personal commitment from research teams, and needs materials that are clear, jargon free and in plain language. Some groups of people – such as some people living with dementia or some people with learning disabilities – might also need training provided in particular ways to make it accessible.

One example, from Tuffrey-Wjine et al (2020), shares the experiences of people with learning disabilities and their tutors from a research course:

- We are eight people with learning disabilities. We did a training course at a university in London. It was called “Learning how to do research.” We learned about the 10 steps in research, and we practised how to do research.
- Part of the course was doing our own research project. Then, we presented it to an audience.
- In this article, our tutors describe the course. We say what it was like for us. Most of us were nervous about doing the course, but we learnt a lot from it.
- There are not many opportunities for people with learning disabilities to learn about research. We think more people with learning disabilities should have the chance to do it. We hope this article helps other teachers to start a research course.
- We can be researchers! **Being involved in research gives us a voice.**

Another example comes from Buffel (2019), who describes how a co-research study built in time for training sessions, reflection meetings and workshops, covering different stages of the research process and focusing in particular on interviewing techniques (“how to ask questions, how to listen, how to probe, how to raise sensitive issues, how to pick up cues about when to follow up, when to move on, and when to let the participant speak without guidance or interruption”). Workshops were interactive, had plenty of time for reflection and set aside time for people to practise new skills, interviewing each other in pairs, conducting a pilot interview and then using the next workshop to explore any challenges they faced while conducting the pilot interview. Workshops were facilitated by the lead academic and a local community development worker, ensuring a mix of skills and experiences.

Creating inclusive and safe spaces

Closely linked to building trusted relationships is the importance of creating **inclusive and safe spaces.**

This can involve thinking about the **physical or online spaces** where teams meet, as well as **the way in which meetings will be organised** and **how we will work together.**

Skills in **facilitation and group work** can help, including in situations where different groups or individuals have very different ways of working, different things they want to get out of the research and/or different views about what's important.

It is also important to make it clear in advance that the research may deal with distressing and emotive issues, and that team members may be asked to share personal experiences or to work on topics that might mirror their own lived experience. Making sure that there are regular **emotional 'check ins', access to support** and a chance to **take a break** can make a difference.

We also need to pay attention to the **practicalities** – including making sure materials are available in accessible formats, that agendas and papers are sent out in advance with enough time to prepare, having icebreakers and regular breaks, and building in time for conversation and the sharing of experiences etc.

Above all, though, this may be about **how projects are managed** and **how project leaders demonstrate inclusive behaviours** – championing co-research, valuing lived experience as a form of expertise in its own right, prioritising time and space to build more equal relationships, and paying sufficient attention to overcoming practical barriers.

Summary

Our previous guide concluded:

“Collaborative research – or ‘co-research’ – can have lots of different benefits for people who draw on care and support, carers and the research itself.

At its best, co-research draws on people’s lived experience to make a difference to others; gives a sense of control and ownership; increases a sense of pride and self-worth; enhances skills; builds trust; leads to better research which focuses on what really matters; and helps to ‘democratise’ the research process.”

However, the evidence and our experience is also clear that **“lots of research talks about co-production but fails to deliver”** - hence a second guide to explore some of the **barriers to meaningful co-research** and (in particular) **how these can be overcome**.

In reflecting on this guide, some members of the panel of people (with lived experience, practice knowledge and research experience) who read and sense-check our work felt that the evidence throughout this guide seems to point to a clear invitation to funders, universities and system leaders:

If we are serious about co-research, we need to fund time for relationships, not just outputs, and align institutional processes so that sharing power is supported rather than worked around. In short: co-research cannot keep relying on goodwill at project level while systems remain unchanged upstream (Reviewer who draws on care and support).

They also identified a number of headline messages:

- **Co-research is about sharing power, not just sharing tasks** - and power shows up in pay, timelines, decision-making and whose knowledge counts.
- **Good co-research is relational work** - it takes time, trust, emotional safety and skilled facilitation, not just good intentions.
- **Barriers to co-research are largely systemic, not individual**, sitting in funding models, academic incentives and institutional processes.
- **Equity means valuing lived experience as expertise**, without asking people to carry the burden of ‘representation’ or repeatedly re-tell harm.

About this guide and IMPACT

Ask IMPACT materials are designed to be trusted, accessible and practical. They are based on reviewing evidence – including research, lived experience and practice knowledge – that is captured on academic databases and on the websites of adult social care policy and practice organisations.

The HSMC Knowledge & Evidence Service (KES) is a specialist information service providing a range of research, communications and information literacy skills services to the health and social care community.

To find out more about KES, or about the searches behind this guide, you can contact them at: hsmc-kes@contacts.bham.ac.uk.

IMPACT is Improving Adult Care Together, the UK centre for implementing evidence in adult social care. Working across the four nations and with co-production at its heart, IMPACT draws on insights from research, lived experience and practice knowledge to make a difference to front-line services and to people's lives.

Funded by the Economic and Social Research Council (ESRC) and the Health Foundation, it is being led by Professor Jon Glasby at the University of Birmingham, with a Leadership Team of 13 other academics, people using social care services, and policy and practice partners – along with a broader consortium of key stakeholders from across the sector and across the four nations of the UK.

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