‘Lots of people who draw on care and support get asked to be ‘involved’ in social care research but want to know that their contribution will be meaningful and valued. What value does involving people with lived experience make to the research and to the individuals involved?’

An Ask IMPACT guide

IMPACT
Improving Adult Care Together

UKRI Economic and Social Research Council
The Health Foundation

Background

Social care has long believed that people who draw on care support and carers have the right to be involved in research about the support they receive – based on the principle of **‘nothing about us without us’.**

This can also improve the **quality of the research** – for example, in situations where co-researchers can build a better relationships with someone taking part, and where people who really understand the issue being researched are involved in analysis.

However, there is a risk that people get asked to ‘be involved’ with research without agreement about what this means, or in **tokenistic** ways.

This guide sets out some initial key terms, and then summarises the evidence around potential benefits to people and to the research of working together. The IMPACT website has details of the full review, together with all the sources we drew on. Where we include a particular quote in the guide below, we try to include a weblink so that anyone who wants to can see the article or report that the quote comes from.

Key terms

This guide focus 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

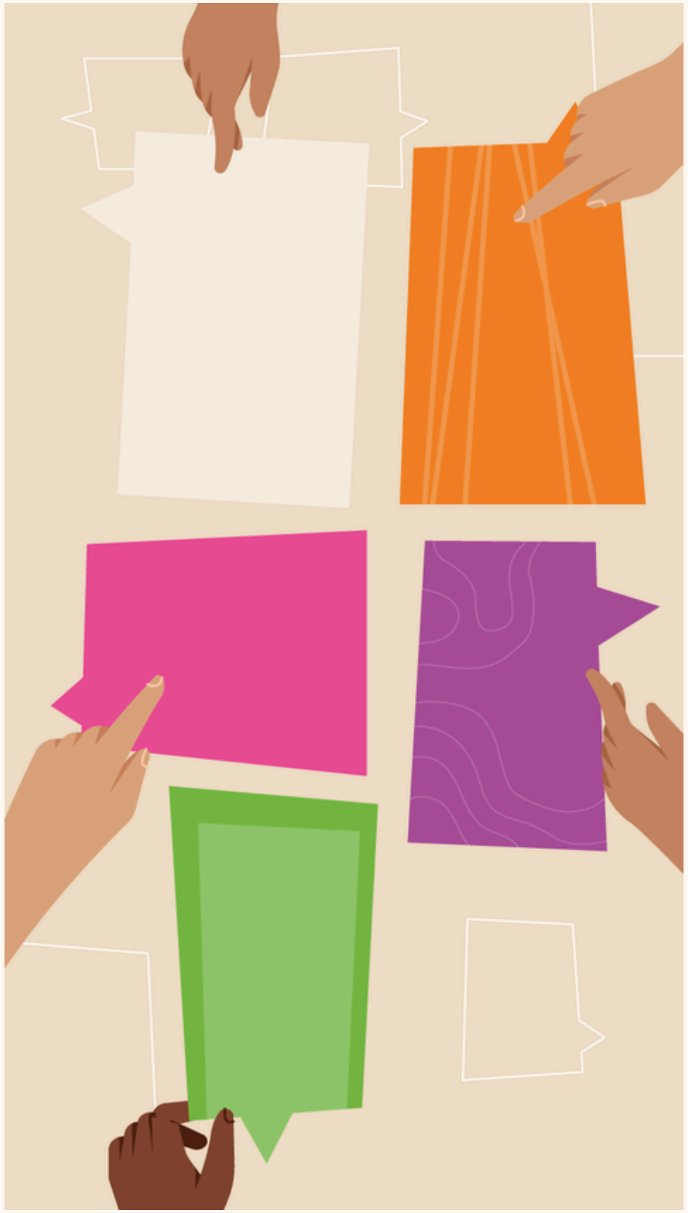
Potential benefits

For **people who draw on care and support and for carers** – potential benefits include:

- Working together to make a difference (both now and in the future)
- A sense of control and ownership
- ·Feelings of pride and of worth
- Building trust and relationships
- Developing and enhancing skills

For **adult social care research** – potential benefits include:

- Focusing on what’s important
- Creating shared knowledge
- Better data
- ‘Democratising’ research (making it more inclusive and accessible for everyone, so that more people can engage with it and help shape it)



Potential benefits, for people involved in research

Making a difference

The literature is clear that people who draw on care and support and carers want their experiences to be able to **make a difference to others**. This isn't just about our own experience, but about working with others to have a **collective voice**. It can be about making a difference now – but also (perhaps for people nearer the end of their lives in particular) about leaving a **positive legacy** for others in the future.

Control and ownership

"It is exciting to be part of the team that helps to set the research agenda and to have a real influence over the research done at the University. We certainly feel a great sense of ownership over what is being done at the University and that is very powerful." (Bowker et al., 2019, p.22)

"For researchers to ask us what we want researched and not decide for us what they are going to research for us. There's this perception that we can't choose the research, when we're the best people to ask in the first place." (Davies et al., 2021, p.144)

Control and ownership over both the research agenda and its outcomes were highly valued by co-researchers. In bringing their life experiences to the table, co-researchers were able to help focus the research on **issues that really matter** to themselves and other people who draw on care and support. They particularly valued helping to create **practical resources** that would be useful to others in improving care and support.

Feeling proud

“We just want to say that people with learning disabilities CAN do research. Because we can! We broke through the barriers! We've gone out there and we've achieved something special. It is right for people with a learning disability to be heard and to be seen, and not just to be walked over. To be able to take part in doing things. It's like a book, don't always judge a book by the cover. Always look inside to see what a person can do. It is good for people to get the opportunity to go out in the world and to do normal things that other people do.” (Tuffrey-Wijne et al., 2020, p.313)

“It’s so hard to measure value, but I’ve seen it for myself in my own group of ‘Minds and Voices’ of how peoples’ confidence has improved, how their opinion of themselves at the beginning of the project might have been zero if they were asked if they felt like a researcher, but how now, they can see the valuable contributions they make are real.” (Davies et al., 2021, p.145)

Being part of research – and seeing what could be achieved – gave people a sense of pride, confidence and self-worth. Knowing they could contribute to something like a research study – and that their contribution makes a difference – was important to people. As one co-researcher put it, carrying out my first interview had been “the best day of my life.” (Hollinrake et al., 2019, p.757)

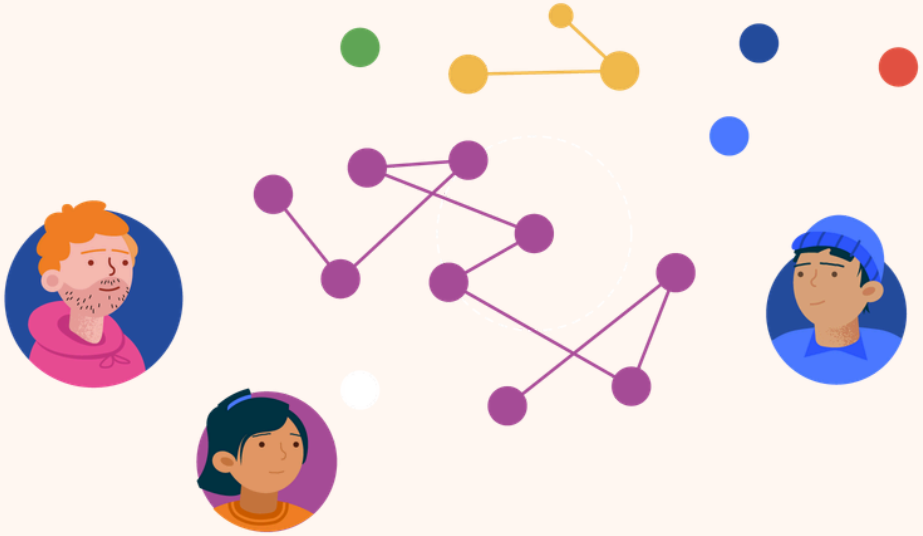
Part of feeling like this was the attitudes of other research team members, who had a key role to play in making everyone feel equally important and part of the team.

Trust and relationships

“One of the things I’ve enjoyed most about doing the research has actually been working with the people on the team. Because one of the things that, I suppose sort of is invisible, but it was the socialising aspect. It was the fact we stopped for lunch, and so you could sit and chat.” (Ward et al., 2020, p.7)

Several studies talk about opportunities to get to know different people and **building trust** with each other, often facilitated by the creation of **inclusive, safe environments.**

As with all workplaces and teams, people valued the social side of working together – having fun, chatting, getting to know new people. For some people who might be isolated or feel cut off from relationships, this could be a positive experience in its own right.



Developing and enhancing skills

People taking part in co-research talked about **personal growth** and a boost to their confidence – but also about the importance of **training** to enhance existing skills and develop new ones.

Different projects involved training and support for co-researchers to help develop **research skills** (such as carrying out interviews, raising sensitive issues, role playing different situations, not asking leading questions, reflecting on our own biases etc). In some studies, this included some initial workshops – but also recognising that the nature and pace of training might depend on the needs of the individual.

Some people also welcomed training that helped them learn and practise new skills, but which also built their **confidence**.

Scope to develop these initial skills 'on the job' and with ongoing support was also important.

For some people, the research was an opportunity to use skills and experiences developed during their **working lives**, feeling as if these were still valuable to others.

Sometimes, the recognition of **pre-existing skills and experiences** can be overlooked by the wider social care system, and co-research was felt to be one way of **challenging negative stereotypes and prejudices:**

"Too often we're getting a diagnosis and told we're incapable, but we're turning around and saying: 'we are capable, and we can do the things that academics can do'." (Davies et al., 2021, p.134)

Some people involved in research felt that the skills they gained could also benefit others in the longer-term. As Kamlesh, a disabled researcher on a project around digital technologies, said:

"I believe recruiting disabled lay researchers like myself didn't just benefit us as individuals or stick true to the principles of co-production. I think it has and will continue to have a positive impact on the wider disabled community since we're bringing these skills and this knowledge back with us. I'm now in a much better position to support other fellow disabled people." (Sarre et al., 2023, p.2834)

Others talked about having the confidence to get involved in future research; the benefit from learning research skills and being exposed to insights from the latest research; and benefits in terms of **future employment.**

Reading all these articles and reports, we wonder whether research teams could do more to help co-researchers plan for future paid work and **develop their careers.**

Potential benefits, for the research

Focusing on what's important

"Above all, the hope underlying the Dementia Enquirers programme is that the project can influence mainstream research, while bringing new respect for the skills, expertise and resilience of those who are living with dementia." (Davies et al., 2021, p.137)

Collaborative research helps to focus on **things that matter to people** who draw on care and support and carers – and to make the research more **relevant**. This guards against the danger that research only gets shaped by what is of interest to academics, or by their assumptions around what's important.

'Relevance' is also one of three key ways that the quality of UK research is judged.

Creating shared knowledge

"It's something about trying to recognise that we've all got something to offer." (Ward et al., 2020, p.4)

"The dual perspective of lived experience of mental health difficulties and being a researcher was felt… to have achieved franker, richer, and higher quality data collection than would have been achieved by typical non-lived experience university researchers." (Lambley, 2021, p.6)

Genuine collaboration and a commitment to working together as equal partners helps to create **deeper, more complete insights** into the topic being researched. The literature talks about "new, shared knowledge" (Sarre et al., 2023) and a "collective story" (Hollinrake et al., 2019). As a researcher in the briefing produced by Ward et al (2020, p.5) said:

"It's about recognising the expertise of people. It's about recognising that research is comprised in many different knowledges and that those different types of knowledge contribute to the value and the depth and the roundedness of the research."

This is an important part of **validating research findings**, especially when it comes to understanding the experiences of **seldom-heard groups.**

For academic researchers, this has meant that they have gained **valuable insights** and **enhanced their own knowledge** in a way that might not otherwise have been possible. As one academic team member in a collaborative project said:

"Had we gone in as an academic research team [without lived experience] we would have got very different results. Without the shared understanding it would have been harder to get the depth we got in our interviews. A team of typical university researchers would just not have got the same results." (Lambley, 2021, p.6)]

Better data

“I think when we met people, because we weren’t from the university, we weren’t from the Local Authority, we were there effectively as volunteers, that gave us a relationship with the interviewees that was really quite special and I think they felt that they were able to be fairly candid with us both positively and negatively and I think that was really valuable.” (Ward et al., 2020, p.7)

"I think it’s easier to be interviewed by a person of a similar age… It enables them to be more relaxed and open with their views.” (Buffel, 2019, p.542)

For some topics, the sharing of life experiences between co-researchers and people taking part in the research can help to generate a stronger relationship, **greater openness and better data**.

This might be where there is scope for **trust, empathy and mutual understanding** based on similar experiences, or through the sharing of certain characteristics, such as age, ethnicity or local knowledge.

This isn’t automatic – and some people can feel reluctant to talk to someone who they see as being from their own community (for example, through concerns about confidentiality). However, collaborative research – when thoughtfully conducted – can generate **better understandings.**

‘Democratising’ research

This doesn’t just improve individual studies, but has the potential to ‘**democratise research**’ more generally. (This is an unusual phrase – but it can mean making the research more inclusive and accessible, so that a wider range of people can engage with it and are involved in shaping it).

As Mikulak et al (2021, p.59) argue:

“[Collaborative research has the] potential to open academic practice up for questioning and probing from non-academic collaborators, which in turn might expose its dead angles and limitations. It can also challenge and motivate academic researchers to make research processes more transparent and accessible, in effect demystifying research, making room for more democratic practices of knowledge production and sharing.”

Summary, final thoughts and next steps

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, lots of research talks about co-production but fails to deliver - and a second Ask IMPACT guide will explore some of the **barriers to meaningful co-research** and (in particular) **how these can be overcome.**

As part of this, and from our reading so far, we wonder whether there is scope for even more emphasis on **equity and inclusion**. For example:

- 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?

A number of articles talk about involvement in **qualitative research** (often with interviews, group discussions or observations), and we also wonder if more evidence is needed in future about co-research which involves lots of numbers and statistics (**quantitative research**).

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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