'Narrowing the gap between knowledge and experience'

Participatory Research and Education in Social Care

at the University of Birmingham:

A Scoping Exercise

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Introduction

This short scoping exercise aimed to explore the views of Birmingham-based academics and researchers about participatory research and education in social care. It was commissioned as part of a programme of work which included another scoping exercise which looked at the views of the voluntary and community sector on participatory research, as well as a series of training and events. The programme aimed to both better understand participatory research in Birmingham and to do some capacity building work (see appendices for a detailed overview). The report offers some provisional conclusions.

Methods

Eighteen interviews took place between February and June 2022 on Zoom. A simple topic guide was used to guide the conversations (see appendices). The interviews were recorded, and a transcript was created using transcribing software. A thematic analysis of the interviews was then undertaken using the qualitative data software MAXQDA. The quotations used are intended to be representative and were chosen on the basis of brevity and clarity of expression. The number of mentions is how many times a topic is mentioned overall in all the interviews. If a participant mentions the topic more than once that is also included in the total.

Sample

The sample of academics, other university staff and experts by experience with an interest in participation in social care education and research at the University of Birmingham was assembled. This was achieved by a combination of drawing on the authors' networks and contacts, internet searches using the terms University of Birmingham, research and participation (plus synonyms) and by asking interviewees to recommend further participants.

The sample consisted of 18 people

- Thirteen academics including six professors, seven researchers and educators
- Two public involvement managers
- One research support manager
- Two experts by experience

Findings

Defining Participatory research

Participants did have a shared understanding of participatory research. This included a commitment to valuing lived experience, to involving experts by experience throughout the research process and to avoid a tokenistic or tick box approach.

> Lived experience is a form of evidence and a form of expertise that often isn't valued enough. (Academic 1)

> For me, it's about working with people with lived experience throughout the whole research process. So it's about working with people with lived experience to decide what topics need to be addressed. [And to work with them]… in the design, the analysis, delivery. (Academic 2)

> A doorway into the lives of people that wouldn't ordinarily engage in research. (Academic 10)

However, there was not a common definition or even a terminology which all participants shared. There was also a range of different terms which people used to describe research with people with lived experience. These include, 'public and patient involvement', 'co research', 'peer research', 'community research' 'co-production', 'participatory research' and 'action research'.

Many participants put forward a moral argument for why participation in research was important:

> I mean, ultimately, it's about if I'm going to do research about social care, morally and ethically, I think we should be working with people with experience of social care, as opposed to us as the all-powerful researchers or academics and saying what we think should be done. (Academic 3)

Participants only occasionally talked about a theoretical dimension to participatory research. One academic participant did mention

> Peter Beresford, who talked about narrowing the gap between knowledge and experience. And that reliable research is where you've narrowed the gap between what you then produce as knowledge and lived experience. (Academic 2)

And another talked about Arnstein's ladder of participation. Several participants talked about 'a whole spectrum of involvement' which can include consultation at one end and co-production of research at the other.

Experience

Many participants had a long involvement in participatory research. For some participants participatory research was a major focus of their work for others it was less central.

Topics

The topics investigated by participants included; Older people, Learning disabilities, Autism, Mental health, Young people, Crime reduction, Voluntary sector collaboration, Social enterprises, sexual and gender based violence, Undocumented migrants, Asylum seekers and refugees.

Funders

Research funding came from a range of sources including the Economic and Social Research Council (ESRC), the National Institute for Health Research (NIHR), the School for Social Care Research NIHR, local partnerships, teaching partnerships, the Welcome Trust, the Joseph Rowentree Foundation, the European Regional ERDF and the Youth Endowment Fund.

A participant who worked in research support management estimated that of the 10 million raised annually by the College of Social Sciences at least 10% goes toward costs associated with the involvement of people with lived experience.

Methods used in participatory research

One participant explained his balanced approach to thinking through when to apply participatory methods.

> I think there's a really strong political and ethical case to be made for participatory research. There are some topics where you can't answer the question very well, unless the research is participatory. It just has to be participatory to be a good study. There are possibly some other topics where full-on participatory research might not be the best way of carrying out the study. So I'm sort of passionate about it on principle. But I also pick and choose a bit when I think it's a good way of answering a particular kind of question. (Academic 1)

The methods and approaches of including people with lived experience varied considerably and included the following.

Advisory groups and panels (8 mentions)

Several participants talked about how they used advisory groups or panels. These include groups which have national roles and others which have more specific local functions. Some consisted entirely of people with lived experience and others also involved a wider range of stakeholders such as voluntary and community sector staff. Sometimes the groups were established for a particular project and were active in a range of project activities. In other cases, there was a standing panel which represented a particular constituency or identity group such as young people with mental health issues or adults with a diagnosis of autism. These panels were used as a general sounding board for grant ideas as well as advising on a variety of studies and engaging in a range of research activities.

The Institute of mental health youth advisory panel is core funded by the Institute and employs a full-time equivalent to support. The panel is integrated into the Institute research cycle:

> …they advise on the everything from the pre-design phase of looking at a research idea right through to monitoring and evaluating projects that are live. So they're embedded across the research life cycle, on the Institute for mental health. (Academic 5)

Community research (1 mention)

One participant described her approach as Community research. It appears that community research is distinguished by its approach of involving community members and community organisation staff.

> So it's been nearly 20 years where we've been developing this methodology to work with members of communities, but also members of organisations that work with specific groups. (Academic 10)

The training for community researchers is well established. It involves an accredited six-month course which covers all aspects of the research cycle. Hundreds of people have been trained in the UK and internationally. Community researchers once trained often become involved in other projects, the training of other people and in community activism.

Co-researchers and peer researchers (7 mentions)

The engagement of co-researchers who are also sometimes called peer researchers was a common approach. A co-researcher was generally a person with lived experience who conducted data collection such as interviewing in collaboration with an academic researcher. Often this meant that research subjects were interviewed by a pair consisting of a person with lived experience and an academic. There were mixed experiences of these pairings. Sometimes it worked well as both parties brought different, skills, perspectives, and identities to the work. In other examples it works less well. When for example the co-researcher felt superfluous or was not able possibly due to a lack of training and support to complete validated tools with research subjects.   Sometimes co-researchers also got involved in other aspects of studies such as analysis and dissemination.

> The co-researchers are involved in carrying out interviews with survivors. We usually have one member of the academic team and a co-researcher, and we both interview the survivor together. (Academic 11)

> I can remember going up to Leeds and doing some interviews alongside a lady that had lived experience. So I mean, that was good. I mean, she was good. And it worked really well. And it was quite nice as well. I mean, generally, when you do qualitative research, you sort of travel off to these far-flung places…So it was actually quite nice. Just to have somebody with you. We got on well, and that was valuable. And she did a really good job. (Academic 9)

Participation in student education (4 mentions)

Some participants were also active as educators

> We've just developed a new master's in mental health. And the youth advisory group at the University of Birmingham, co developed some of the learning objectives for the students across all of the modules.. (Academic 5)

The involvement of people who draw on social care services in the University of Birmingham social work degree is well developed and sophisticated. There is a panel of 32 people with lived experience who following extensive training get involved in many aspects of the

programme. Including admissions, teaching, using their life stories and role-playing members of a fictional family. The programme is regularly reviewed by the panel.

Co-authoring papers (1 mention)

> …lots of young people… helped to decide what should go into the chapter for this edited collection on children and young people's mental well being... They wrote the vignettes, and they gave me the ideas and I would write up a section and take it back to them for discussion. It was a very iterative process over a series of meetings so that we co authored a chapter…[and] they were all added as authors. (Academic 5)

Highly participative studies (4 mentions)

Some participants described studies which were highly participatory and in which people with lived experience were involved in number of levels and roles. For example:

> The first strand was having co-researchers who had lived experience who worked alongside the project team as equals. So, they conducted interviews or designed the research instruments. And then the second strand was having a reference group, who were a more lay reference group who were experts by experience but didn't have any formal academic training. In fact, some of them had not completed any formal education, including school, and so they had a very different take on the research and how to produce research. And they worked across a range of activities to design, guide and shape, the whole research journey from the point of funding being awarded onwards. I wasn't involved prior to that in the design of the research because I was hired into the project, but I understand that there was involvement in the bid as well. (Academic 5)

Benefits

Capacity building of organisations, communities and individuals (7 mentions)

One of the benefits of participatory research some participants referred to was how people's involvement built the capacity of organisations, communities, and individuals. For individuals participatory research is an opportunity to learn new skills, develop networks, enhance wellbeing and employability. Belonging to a particular network can also become a part of a positive identity.

> It's about networking and friendship. Sharing experience. (Expert by experience 1)

> We're hoping it's kind of a capacity building exercise for those organisations, getting to learn some research skills which they can then take back into their organisation. Especially because you're enabling them to… pursue their own research. (Academic 6)

Sometimes, if we can provide support and training sometimes around doing that it can increase people's confidence and skills. And sometimes it's a gateway for them to doing other things as well. (Academic 4)

We've kind of built up over time a kind of community of people. And therefore, there's been peer support between them... I think people have enjoyed the experience of being involved. (Academic 7)

Advisory Group membership forms a positive part of their identity. So we create a sense of community. (Public involvement manager 2)

Recruitment and dissemination (5 mentions)

Participants said that enhancing the recruitment of research contributors was a benefit of participatory research.

In one of our projects, we were really struggling to recruit people, and actually, having people with lived experience as part of the project enabled us to recruit participants, because they had networks and contacts. And they brought people in that we would never find… this project would not have succeeded unless we had people participating in it (Academic 8)

Participants said that the involvement of experts by experience can strengthen the impact of research dissemination.

Dissemination is probably where it's most powerful in terms of getting messages across. (Academic 2)

And also they were brilliant at helping us design the output so that they would be accessible. (Academic 3)

Brings in diverse strengths, perspectives and challenge (18 mentions)

Lots of academic participants spoke about how participatory approaches led to the involvement of a wider range of people. And how this brings with it a greater diversity of perspectives.

It provides a doorway into the lives of people that wouldn't ordinarily engage in research. (Academic 10)

Yeah, there's those benefits, obviously, being able to match your researchers up in terms of language, gender, ethnic groups, and so on. So that people may feel that they've got a rapport and are able to relate to the person that they're talking to. (Academic 10)

Academic participants also spoke about how the diversity of perspectives produces constructive challenge.

…it makes you challenge your own assumptions. And it really kind of puts up front and centre, people's real-life experiences and the things that are important to them. (Academic 7)

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For me, it's, to try and make work enjoyable, I really enjoy that diversity of opinion and viewpoints. And I enjoy being challenged…[it's a reminder] of the day-to-day nuts and bolts reality of somebody's life. I think, actually it keeps you honest. (Academic 8)

I think the benefits are huge really, I mean, certainly important in terms of shifting and challenging thinking. And that doesn't always have to be a very explicit knocking everything out of the water kind of challenge. But I think there's something really healthy and important about people who might not do research day to day [and] the questions that they bring. (Academic 11)

Participants who use services said that one of the benefits is the opportunity to contribute to something important which has the potential to make positive change.

I think the benefits are being part of something which is so unique, and so important, and something which at some point is going to affect somebody, and just being part of it, and knowing that I personally have contributed, and it's part of a legacy, I know, will be important for me to leave behind. (Expert by experience 2)

There's a whole lot of motivation, and passion about wanting to use your experience to, improve people's knowledge and make the care better. So there's an awful lot of passion that goes with it. (Expert by experience 1)

Enriches/changes research or policy or teaching (10 mentions)

For academic participants taking a participatory approach can have far reaching impacts on research and teaching.

So the benefits are about closing the gap between knowledge and experience. So we're getting the benefit of lived experience in every aspect of the research, both in terms of how we do it, the sense that we make of what we find, and then the outcomes. (Academic 3)

I think it's much richer, and I think you, you have a broader perspective of what's the impact and the process of receiving and/or accessing services. (Academic 8)

So we've got the benefits for the students... you know, years after [they have left the teaching programme], I, see students in the street, and they will still ask about the service users or tell me how [their input into teaching] impacted on how they treat people now. (Public involvement manager 1)

Academic participants also talked about how participatory methods have far reaching impacts and lead to change.

I can think of some, some very clear examples. So this project that I mentioned, where the PhD student had to pause the project and re-evaluate it. I'm not sure what would have happened if she hadn't presented that to the [expert by experience panel]. So that was a massive change in the direction of the project, hugely beneficial to the project in the end. (Academic 13)

And I do feel that when we have people with lived experience, who are part of the research team, they are very strongly committed to getting change as a result of the

research. And it's not to say that we aren't because we are, but given the nature of research funding, and universities, there's a real push to move on to the next thing. And I think service users are really good at holding us to account. (Academic 3)

I want my research to be impactful. That's why I do research…I do it partly to be academically useful, but mainly to be practically useful. And if you want your research to be useful and impactful, you've got to engage people. (Academic 6)

Challenges

Costs (5 mentions)

Several participants mentioned the challenge of funding participation.

The financial model that we've got is not very sustainable. Because if I just failed to get a grant, then the advisory panel would cease to be funded. (Academic 13)

We have to battle for the budget every year, (Public involvement manager 1)

Ethic approval (4 mentions)

Several participants mentioned how the university and research processes such as ethical permissions and grant funding can obstruct participatory approaches

We were advised that we couldn't recruit the co-researchers until we got our ethics approval. But by the time you got your ethics approval, you've basically written everything that your project is about, all of your research instruments are done…So we found that was a source of frustration that a lot of things have to be confirmed [before we are able to involve people with lived experience]. And obviously, you've written the grant as well. And that's got a lot of detail that you then have to deliver against. (Academic 7)

The ethics system is a bit of a nightmare, it feels like you got to fight your way through. And if you feel that some funders would be sympathetic, and others wouldn't you're trying to navigate each of those different systems to then get to a situation that's really participative, and then adds value to everyone involved, and to the study. So I think you've got to really want to do it and get quite slick at navigating those different systems. (Academic 1)

Power and knowledge differentials (13 mentions)

Some participants acknowledged the differences in power between academics and people who use services.

We need to work with the power imbalances that you get. That takes time and, resource. And, and if you don't do it, well, it can also cause some difficulties. (Academic 1)

Participants said that the complex technical nature of research methods can make participation challenging.

We had some real challenges. With research tools, particularly with quantitative methods. Co-researchers didn't quite understand the tools, it was quite hard. There's a whole extra level of training [that's needed] (Academic 2)

I think at the data analysis point, we struggle to involve people meaningfully because of the volume of analysis that's involved. We've tried various things for example printing out transcripts and sending them to people but if you've got hundreds of transcripts and they're all about 25 pages each it's an overwhelming amount of material. I guess what we've tended to do is share with people samples of things to sense check. We couldn't really describe the actual analysis phase as being done collectively. (Academic 7)

Participants also acknowledged that some of the challenges could be overcome through training and developing better understanding of some of the likely issues.

In terms of the data collection on one of the studies, I think we probably haven't got the training for one of our participants with learning disabilities quite right. In the first interview, which they were doing jointly with an academic, before they did some by themselves. The academic needed to step in quite a lot to keep the interview on track and help the person fully concentrate on what they were being told by the interviewee rather than interjecting with their own experiences. Now, we have anticipated that issue and we've role played it, and they've been trained, and the person is doing it alongside another more experienced researcher. (Academic 1)

However, there are some quantitative elements of studies in which it is extremely challenging to have full and equal participation

One of the issues is that the people with lived experience didn't understand fully the sort of analysis and what the trial statistician was doing, but that doesn't mean to say that they shouldn't be doing it. I mean, you each have your role in a multidisciplinary team. And there are, by default, people who have expertise and I think this idea that, that the people with lived experience need to somehow understand the ins and outs of everything that's going on in a project, it isn't valid…I think there can be a real role in terms of making sure that you're using the right tool for the right job, and that you're setting out to ask the right people. I think once you've selected it and the tool is validated, it's often copyrighted, you haven't got scope to start messing around with that. So once you've picked a tool that seems appropriate, I think you've just got to run with it as it is. (Academic 9)

Time/lack of admin support (10 mentions)

Participants reported that time is a challenge. This is an issue which has several dimensions.

From the perspective of someone who uses services and takes part in research it is about not being able do things at short notice.

> Another problem, a big issue is the time situation. It's because I am slow. And I have to know where I'm at and what I'm doing. I can't cope with immediate deadlines or, you know, doing things off the cuff, and I need to prepare for meetings…if somebody says, will you give a talk about something tomorrow? You know, I can't do it at all. (Expert by experience 1)

For academic participants there is pressure to get things done to meet deadlines.

> The biggest challenge, I think, for me is that you generally have, a deadline, you have to get the programme together. The funders will only give so long and they're hungry for results. And the reality is, to do participatory research, well, you have to give it time, because people have to feel comfortable, they need to feel confident in what they're doing… But the funders, understandably want to get an output for the money they put in. But they're not necessarily that willing to accept that these things will be richer, but will just take a longer time. (Academic 8)

Another issue is that there can be long gaps between an expert by experience being engaged in an aspect of a project and seeing the outcomes of their involvement.

> One of the barriers is about the massive time delays that research projects have. So I'm often embarrassed about getting back in touch with people after quite a long period of time, but academic timetables are very, very slow. And I think part of good practice is keeping people warm and engaged. Things will go quiet for ages, because we're waiting for ethical approval, or, we're waiting for research sites to be signed off. People just cannot believe that we're still working on this project, you know, three years later. (Academic 7)

Some participants said that the relational elements of participatory approaches also take extra time.

> The big one has got to be time. Because it does take a lot longer, particularly to do it well. And it's about not only working with groups of people, but individuals and recognising the different pressures that individuals are under. So there's quite a lot of liaising with individuals outside of the actual main research work… It's about relating to people as people and not just somebody, you've, co-opted to do something for you. (Academic 3)

Several participants spoke about how experts by experience may have pressures on their availability and may prefer to be involved outside of office hours.

> Young people are typically of working aged and therefore busier, and are trying to fit in their involvement, around other commitments. So all of our meetings with young people are in the evenings. (Public involvement manager 2)

A linked challenge is that there is not enough administrative support available to researchers.

> And we don't have enough support on the administrative side, I do, because I have some senior administrators in my research centre, but generally, people who are time

pressured and are not able to give the proper sorts of time and attention it needs. (Academic 12)

Recruitment (4 mentions)

Some participants mentioned how difficult it can be to recruit co-researchers.

> The challenge around recruiting co-researchers is really hard. Getting the right people with the right skills. People who can understand what you're doing but it's also making sure you have a good range of people, including really vulnerable people who are excluded who aren't necessarily involved in research in any way, but they often have absolutely no knowledge of research. So it's, it's really hard to get that balance. (Academic 2)

Emotional challenges of topics (4 mentions)

Some participants spoke of the emotional demands of some topics and the need to support people with lived experience.

> I think it's about how you support people who are doing that emotionally demanding work. And how you think about that supportive structure? And what responsibility you take for it. (Academic 5)

Payments (17 mentions)

The difficulties of paying people who use services was the most frequently mentioned challenge. The forcefulness and the emotion of the language used to describe the situation is notable. Participants for example described the issue as 'horrendous', 'a complete nightmare' 'the big one' and one participant says she tries 'to block that one out.'

> The university does not appear to me to understand service users and carers. Are they a visiting lecturer? Are they a student? Well, no, actually, they're neither of those. You know, and it just seems that we have to fight a lot. (Public involvement manager 1)

Several participants mentioned how paying people fairly and promptly is a very important aspect of good participatory practice.

> I don't exactly want to call it ideological, but the fair and the ethical side of participatory research [includes] people being valued and compensated appropriately. (Academic 4)

> We've really struggled over time to with the practicalities of paying people well, and you know, why that should still be an issue in 2022, I struggle to understand. (Academic 1)

Some participants felt it had got worse over time

> I mean, it's just hopeless. It's got worse. I mean, I've been doing this for 15 years now. It's got worse, rather than better. There was a time when it was actually pretty easy. But it's hopeless at the moment. (Academic 12)

It's still incredibly complex with a lot of systems that the big research organisations have, many of which are now automated, so that there's a lot less discretion about different payment mechanisms. In the past that were manual expenses forms now it's automated, and the computer says, no. (Academic 1)

Several participants said that the issue contributed to a breakdown in trust between researchers and experts by experience and excluded some people from taking up opportunities.

The bureaucracy ruins the trust between the community researchers and the project. So on one project it took months to get paid. These are real community researchers who need to pay the rent, they can't be hanging on, so they dropped off the programme. The ones that we managed to retain at the end, and the ones we're still working with, I would say are privileged. They have the financial resilience. (Academic 10)

Participants described issues with longer term and short-term payments:

All our contributors, every 12 weeks have to re-apply and complete the forms all over again to be able to do any more work with us, so we've got 40 people every 12 weeks going, starting all over again. And then sometimes the university has lost all the details of people and we've had to ferry people in in cabs with their passports to get people re-integrated back into the system. (Public involvement manager 1)

The university systems are way too complex, particularly when people are involved in a fairly limited kind of capacity. And it's an honorarium payment or short duration of payment. It's very, very overly bureaucratic. (Academic 6)

Support requirements of co-researchers (5 mentions)

Some participants spoke about the uncertainties of working with people who may have various health conditions.

As we are dealing with real life things change, you know, so I mentioned to you all the sessions we've got coming up. This week, one person's broken their hip and another person has cancer. (Public involvement manager 1)

You know, we've worked on studies where people have got ill… So you need to make sure there's cover and contingencies and, and so on. Of course, that could happen to any member of the research team, but perhaps it is more likely if someone's got a pre-existing condition. (Academic 1)

Some participants expressed how they felt responsible for expert by experience's welfare

But then yeah, at the same time, you want people to be able to express themselves and commit themselves to what they want to commit to, but sometimes, particularly around mental health, you need to be wary about over committing people. And very wary about, ensuring that people aren't biting off more than they can chew, but also careful about not making that decision for them. So a large part of my role, and my colleague's role is a degree of mentorship. (Public involvement manager 2)

What would help?

Participants described a range of things that could improve participatory research. Some of these elements could be provided or facilitated by the development of a network whilst others may require improvements in research support and administrative systems.

> What do people want to help them? And how could people work together? And is there anything that we can do to help facilitate that? (Academic 2)

Sharing contacts, mutual support and know how (24 mentions)

When asked what would help the most common reply was about greater sharing of contacts, support and know how.

Some participants spoke about how a network for experts by experience involved in participatory research projects across the university and how this could be helpful and supportive.

> I think particularly about support and ongoing skills for people who have been involved in research after the project ends, that's something I'm very conscious of, how they can, if they want to, stay engaged with research. A network could support survivors, to get involved with things with other studies and activities. (Academic 11)

An expert by experience participant said that it would be helpful to have both more technical and practical support

> …to talk through, difficulties on using NVivo, and SPSS. And people just to talk it through with and present my ideas, see what people thought that that would be really good. (Expert by experience 1)

Academic participants wondered if a network could expand the range of people who use services to whom they could offer opportunities.

> I think what can easily happen is that you do draw on the same people for different research projects, because you've got the relationships, and that's not necessarily getting diversity of involvement. There are people whose voices are not heard. (Academic 3)

> If there was a central website that they could log into, and if they could see, the current projects that are looking for some comments from a participatory group or something like that, then people from our group could volunteer for those positions. That could work quite nicely. (Academic 13)

Several academic participants expressed the need for mutual support and were conscious that there was not much sharing across departments.

> You know, we can seem to be doing this in silos, and we've all got lots of good practice, just small things that we could share. (Academic 10)

For me, it's having those networks of other people that are trying participatory approaches, so you can have those kind of honest conversations with each other and share mutual support as much as anything. (Academic 6)

I think more collaboration, I think more working with other groups, sharing expertise, sharing, learning, having opportunities that can be shared across multiple groups. (Academic 12)

I just wonder whether there's something there in terms of a sort of community of practice, peer support, that's partly practical, how do you get around barriers? But that's partly about emotional support. That's challenging and improving your own practice by reflecting critically together. (Academic 1)

So I think learning across different projects, you might only have one project in a department at any one time. So actually, being able to connect with other people who have done it in the past or in a different discipline, that would certainly be helpful. (Academic 11)

More administrative support/time to build relationships, better systems (10 mentions)

There was general agreement among participants that some aspects of participatory research require extra time and support.

I think mainly when there's been differences of opinion, or a disagreement can be quite constructive. But it has to be given time for it to be constructive. So you have to factor that in, I think or make time for it. So it's time to build relationships and trust really within a group. (Academic 11)

Some participants said that their commitment to demonstrate good practice in participatory research was not adequately supported by the university's administrative systems.

I feel there are a group of us that try and do this almost despite rather than enabled by the wider context and the institutional structures. (Academic 12)

Some participants said that more administrative and practical support could help with some of the time-consuming aspects of participatory research.

More administrative support would definitely help to build people's capacity, being able to know how to connect up with different communities. And what would be helpful is a kind of facilitator or broker somebody who's got a relationship with those communities who we can engage with to help us to connect with people. That would be really good. So we're not just starting from scratch…I think there's also probably some support needed in terms of making documents more accessible. (Academic 8)

I mean, I suppose we need to get better at costing in the kind of administrative support that makes all this possible…And I think we have got a bit better at doing that. But just having somebody that can help people process forms and get set up on systems. And all of that is obviously really important. (Academic 7)

Some participants said it would be helpful if the university developed a more systematic approach to meeting the needs of participatory researchers

It would be brilliant if the university could produce a kind of protocol or guidelines for if you're employing somebody with lived experience. Here's, you know, a couple different ways to do it. Pros and cons. Here's who to contact. And actually, there's a there's a person in research finance, who was a designated person for this. And when you when you ask them the question, they won't look like they've never heard of this idea ever before. And is completely flummoxed by it. I think it would be really helpful not always having to start back at the beginning. (Academic 7)

Celebrating expertise in participatory research (5 mentions)

Several participants said that one thing that could help is to celebrate and value the expertise in participation that has developed in the university.

I don't think people necessarily say, my university is really good at participatory research. I think that's something that leads to a virtuous cycle. Because if you say, at this institution, this is something we really value, and we put time and effort and energy into it Then people start to go, oh, that sounds really good. I'd like to be part of that. (Academic 8)

But when you think about all the sorts of praise that goes into publications, or winning research grants, as important as they are, I think where people are genuinely trying to work around participation to make a difference it should be celebrated. And being proud, you know, and it being a sort of strength to our approach. (Academic 12)

The main thing is celebrating it actually, you know, for some really great research that has made a real difference to people's lives. And it was co-produced, and the co-production was a key part of making it successful. You know, we should just be shouting that from the rooftops. (Academic 1)

Funds to support bids (2 mentions)

I do think there's a challenge so I've recently bidded for some funding, for which we were unsuccessful. But it goes to show the challenges, I think of engaging at an early stage, because we did a lot of work to build a network, with potential partners, to build those relationships to engage people in the conversation about what this proposal would focus on how it would do it. And it was unsuccessful. So people are putting in a lot of time, you feel it's hard not to generate expectations. And then it's not successful. So yeah, this then means we don't engage people until we're more confident that the research is going to happen by then it's already too late [for people to have an influence]. So I do think there is something definitely there in terms of really wanting to engage people at that stage and having funds to do that. (Academic 6)

Resources/guidance/protocols (8 mentions)

One participant used this analogy to describe tackling the practical aspects of participatory research projects.

It is kind of like getting a piece of Ikea furniture without the instructions. (Public involvement manager 2)

Participants said that one of the reasons participatory approaches are not more widespread is because of the challenging practical aspects of studies and the lack of systems and guidance.

> I think a lot of it is about resources and practical tips and guidance. I think a lot of the issues we face in involvement and participatory approaches that we can say quite broadly, is I'll be wanting to do this, then there's so many little niggly practical implications to doing certain things that a lot of people kind of give up or stick to what's always been done. And the reason it's always been done is because it's probably relatively easy compared to the alternative. So that's why I like going to forums to discuss these things. But then I ultimately find that we have the same conversation over and over again, over the space of a few years. What would be helpful is to have, a working group who sit down and like really nail it out and say, okay, these are the things that we've established. (Public involvement manager 2)

Participants said they would find resources such as guidance or protocols very helpful, especially if they were all collected together.

> Some good practice guidelines. And that if, if they were accessible to us, we would definitely use them and try to tick off whether we're actually doing them or not. (Academic 13)

> Resources are helpful…if you build a repository of those types of resources, and obviously, that's fantastically helpful. (Academic 6)

> It would be a useful thing for me if everything was in the same place. (Academic 3)

Training (**8 mentions)**

Participants identified training as an important part of developing participatory skills.

> I've been on some great training in the, in the past, I went on a fantastic training a few years ago on doing action research, which I found really useful. training is always useful. (Academic 6)

Several participants said that they felt there was a lot of participatory research expertise in Birmingham university which could be shared through training.

> There are what I would probably call more seasoned veteran individuals who have been doing this their entire life and either have come from working in a sector where it's mandatory and moved into academia, or kind of flitted between the two. And there is a lot to be said about sharing their experiences. That real world experience is something that I think would be invaluable to training academics. And it will dispel hopefully myths around difficulty of it, but it will also show how risks can be avoided. (Research support manager)

> For each project we've put our own training package together. But you think, well, if everybody worked together, there must be tools that have already been developed that people could draw on? (Academic 3)

One participant spoke about how powerful training by community researchers can be and how this can cascade knowledge.

> I am now working with two of the community researchers who are now training a group of local people in [a part of Birmingham with high deprivation]. Generally the people there are very hostile to anybody coming from outside because they've been let down so many times. The way that we work with them, it's about giving them the ownership and giving them the opportunity to make decisions and we truly make that happen. And when they see that that's happening. It's a it's an absolute game changer. So we've had a massive buzz endless hours last month working with this group that are so switched on and wanting to do stuff in the community, it's just been absolutely, amazing. (Academic 10)

One participant suggested that perhaps an accredited qualification in participatory research could be developed.

> Could that even be set up in a way that leads to some kind of qualification for people as well. I mean, that may be that may be overkill, and not what people want, but I just wonder about all the training and development needs and whether there's a way of making that easier. (Academic 1)

Conclusions

The University of Birmingham has developed considerable expertise in participatory research and education in social care and beyond, with experts by experience, community and voluntary groups. This is something to be celebrated. It is estimated that participatory elements of research studies generate at least £1 million of funding annually in the College of Social Sciences alone. The likely financial benefit to the university overall, when other departments, research centres and educational activities are included is likely to be even higher.

Many participants spoke about the moral and ethical drivers for participatory research. Among participants there is a clear articulation of the benefits of participatory research. These include introducing more diverse and authentic voices into academic activities which enrich studies and student education, providing constructive real-world challenge and increasing research impact. Participants said that the practice of participatory research also enhances the well-being, networks, and employability of individual experts by experience and builds the research capacity of community organisations.

However, there are institutional barriers to the practice of participatory research and education in the University of Birmingham These include, funding systems, the ethical permission process and especially the lack of a consistent system for employing and paying experts by experience. These barriers inhibit the further development of participatory methods and tend to confine their practice to a core group of highly committed academics. Even within this group, good practice and contacts are not widely shared, and mutual support is not generally available especially cross departmentally. And although there is a collective understanding of participatory research, there is not a widely shared terminology or commonly used set of approaches.

There is a generally held view that a participatory research and education network could facilitate the sharing of contacts, opportunities, mutual support and know how. The network it is believed could also co-ordinate the development of guidance and training and be a powerful voice for participatory research and education.

However, some of the barriers to the practice and development of participatory research and education require system wide solutions. There was a view shared by several participants that the University of Birmingham could more highly value and promote its expertise and achievements in participatory research.

Appendix

Building capacity in participatory research in social care in Birmingham

Project overview

The School of Social Policy at the University of Birmingham are leading a project that aims to build capacity and knowledge exchange in participatory research and education among social care researchers and voluntary and community sector organisations (VCSOs) in Birmingham. The project will share knowledge on participatory research, facilitate stronger connections between researchers and VCSOs, and deliver training and support to researchers on participatory methodologies.

The project is being led by Kelly Hall and Caroline Jackson at the University of Birmingham in collaboration with Communicate2U (https://www.communicate2u.co.uk/); Birmingham Voluntary Service Council (BVSC) https://www.bvsc.org/; and Co-Production Works https://coproductionworks.co.uk/.

The project objectives are to:

1. Map participatory research and education in Birmingham. Scoping work will identify social care related participatory research and education activity in Birmingham's VCSOs and higher education institutions

2. Deliver training for researchers (academic and VCSOs) in creative participatory research methods and approaches. Communicate2U will lead three half-day training workshops to researchers and VCSOs on creative research methodologies for communicating with people who may find traditional word-based communication challenging e.g. people with dementia or a learning disability. The training will be co-delivered with people with disabilities.

3. Facilitate peer learning and support for researchers and VCSOs in Birmingham through webinars and a networking workshop. The events will showcase and provide opportunities for social care practitioners, VCSOs, people with lived experience and researchers to discuss and share practice on participatory research.

4. To develop a participatory research online resource through a new webpage that will publish training videos, case studies of participatory research, good practice from HEIs and VCSOs, and links to participatory research projects in Birmingham.