**The Participatory PhD Group - Su Conquer and Peter Beresford**

Su Conquer and Peter Beresford led a session exploring the activities of the Participatory PhD Group, which was set up to support people engaged in undertaking participatory doctoral research and making this research more supportive and consistent in line with the rising interest in participation, and user involvement in research and practice.

Peter introduced himself as a service user researcher with an interest in issues of participation which relate to learning, education, research, policy and practice. Within the context of knowledge creation there are barriers and exclusions relating to peoples’ lived experience, and their experiential knowledge that have not been recognised as of equal value to other means of knowing, and the concept of epistemic injustice - what some people know from their direct experience not being counted was referenced.

PhD’s are how people tend to become part of the research world and a key training area for future research and researchers. It was discussed that while PhD’s are meant to be what one person does many people who undertake PhD’s are very keen to make them a more collaborative collective effort, and yet when they may be a very joint activity such as through a participatory PhD, this does not work with the system, and user involvement in PhDs, is not fully acknowledged and valued. However, it is important to recognise the value and contributions of people with lived experience in research and for that inclusion to be on equal terms

There are many barriers and exclusions when people bring their lived experience to research and this needs to be addressed. It was felt that currently the lived experience of people on the receiving end of policy, practice and research tends to be marginalised.

The participation PhD Network came about from a tweet Peter put out asking other people if they felt it was an issue around making it difficult for people to be part of a who had lived experience, and it got a massive response from a whole range of perspectives including service users, user researchers, supervisors, conventional researchers, examiners, and academics etc. The interest led to a meeting with around 40 to 50 people responding in an active way and there have been several meetings since where they have been working towards a paper and also understanding peoples’ experiences and where they stand in the issue.

People come from all different role such as PhD students, aspiring PhD students, people with lived experience who have had or not had the opportunity to undertake PhD research, supervisory teams, examiners, and people who just have an interest from the research and participation world. It’s been a great learning experience with open and frank discussions around the aims of the group, leading towards wanting to support the future of participatory PhDs becoming more business as usual and supporting institutions to have more accessible ways to provide and support PhD students in their research and planning for their research. Most of the discussions have been around how to overcome barriers and challenges, with the desire to make things within academia less top down and more equalised in the relationships that PhD’s bring about.

It has been lovely the way that people have wanted to be a part of it and they have found out how many good things are going on towards more participation, much more than what may have been realised which has been encouraging, but there is still more that is needed as while PhD’s are hard it is even harder doing a participatory PhD as the system in not geared up towards it.

One of the important parts of the participatory PhD group was rethinking what we mean by PhD and enabling other researchers and PhD students around the country to have the same approach. One of the things they identified at the start was how each institution looks differently at that, and how members of the public can be involved and at what stage and how they can be recognised for it such as being acknowledged in the PhD thesis or being part of academic papers and so on.

Su spoke of how she enabled her PhD to be participatory and some of the challenges involved. Su was working in her local Healthwatch and bringing her lived experience to service design within the health and care world. she got the role of co-production coordinator and when the opportunity to do a funded PhD looking at coproduction within integrated care systems came about, because of her background in participation, and her work role there was no other way she could think of approaching a PhD than participatory, and she went with that in mind from the proposal stage and it was not until she got to undertaking of the PhD itself that she realised there was no guidance or training, or encouragement to take that kind of PhD. Su didn’t know that it was going to be as difficult as it was, and this is reflected in her write up where there is a lot about the methodology of participatory research

Su started with a coproduction advisory group, with the name chosen as they wanted to move away from the terms of patient and public and it was more about the advisory element of that group. As the PhD was about coproduction in itself that made it an appropriate name as well. There were 6 members (2 representing the lived experience as a service user, 2 representing lived experience as a carer, family carer, and 2 representing the workforce so either a system or service leader within the integrated care system) and they began with discussing the aims of the research and devising the research questions. Over time they developed their concept definitions which did shift over the research, but Su was constantly in communication with those members. They signed up for 6 month periods of time so they had the choice to leave or stay, and she did have 4 of the 6 stay throughout the PhD from start to finish and 2 came on board along the way, so it was great not to have too much overturn and nice to have that group as a consistent support. A PhD is complex and so bringing someone new to that space did bring up challenges which were easily overcome with group agreements and consistent communication and transparency and that they were all learning as well as going through the challenges and barriers just like Su was.

The PhD included a systematic literature review where meta ethnography which had 7 phases for qualitative research was used in which her coproduction advisory group were part of all 7 phases and were upskilled in systematic review methodology, and really importantly in the evidence synthesis together they translated some new findings which have now been published in the international Journal of Integrated Care, the ladder of coproduction –where they added another rung of codelivery within integrated care.

Designing the main part of the PhD to explore coproduction within the integrated care system, the coproduction advisory group helped to design the study which was a multi case study using participatory action research. The group helped to devise all of the materials which went through full NHS ethics.

The advisory group took a pause when Su was doing the with the case studies, but because it was participatory action research the participants of the case studies became co researchers with Su, where she had 3 different case studies with 3 different co researcher groups over a period of 6 to 9 months. The coresearchers were exploring their own practice of coproduction within integrated care system and Su observed their exploration and their transcripts of their discussions became her data.

The co production advisory group and the coresearchers were brought together to discuss the 3 case studies in a deliberative workshop They looked at enablers, barriers, and outcomes of coproduction and together helped Su form her final findings. Now that the PhD is finished Su hopes to share it back with all of those people and invite them to all become future coauthors with her when she writes it up.

Her role now is as Coproduction lead so she is able to put all the participatory findings and everything that people in the local system said and some of the early recommendations they made into practice and she still has the same people alongside her to be critical friends and to support this work to continue, so she is not at the end of her journey, but that’s because of the participatory element of the PhD that they are able to see the fruition of the work and continue the work together.

Peter liked how the coproduction has not just been constrained within the PhD, but has been carried on especially as the PhD provided opportunities for people to develop skills and experience. He was of the opinion that PhDs can be used much more broadly in learning and not just s a stop and start thing, but can move on and develop and change things as had been done here

In discussions it was referenced that everybody comes to a PhD with different motivations and skill levels and so participatory may not be at the top of everybody’s priority list which means that they might need upskilling, encouragement and support to even think about a participatory PhD because it is in addition to undertaking a PhD it is more than you need to do to complete a PhD. The knowledge gap or that gap in peoples understanding that a participatory PhD is even an option is one of the challenges and barriers for it and it is a cultural shift in how we think about what knowledge is.

As a society we are not particularly involved, and there is lack of any participatory approaches and we need to have a cultural shift where we have our voices heard from a very young age so a shift would happen then it would be norm but at an early age. It was referenced how people develop services without asking service users what they want or would like or need and then it’s a sad situation.

Rethinking the PhD and how they are approached was also discussed with participatory approaches being seen as creating more equality and making for a more fuller picture which will challenge the exclusions that presently operate and limit what we know, how people are known about, their experience, and how identities are imposed on people.

The challenges in training and support that PhD students need was also explored alongside issues of funding. While some PhD students many have a stipend or very limited resources to spend doing their research, or be self funding , having some PPI funding costed into a PhD is a key issue especially with doing participatory research and coproduction. Thinking ahead about how this is resourced and funded is crucial.

With patient and public involvement becoming a necessary requirement in research the unintended consequences and how to stop it being tokenistic was raised. It was felt that instead of thinking about all the regulation the way to approach this was to support the desire that lots of people want to do it and also the desire that people who have wanted to do it have been denied from doing PhDs to do it. It was felt that we need to look at what works such as supported facilitation. Furthermore, if we sell it in a way that we say that we need the public that we value the public and will give feedback to the public on what happens we can get people on board.