



Our Round Table talk was the last part of our Bringing People's Experience to Life event, which brought together academics, researchers and the participatory arts community to talk about how we can innovate within healthcare and patient and public engagement and involvement.

The panel was expertly chaired by Dr Paul Clarkson, who is a senior lecturer of social care at the University of Manchester and deputy director of Social Care and Society. Paul has worked closely with Made by Mortals over the past year, and together we have been successful in gaining funding for PPIE for a research project for 2022.

He was joined by Rob Conyers, head of patient experience at Tameside and Glossop Integrated Care NHS Foundation Trust; Julie Farley, business manager at Oldham Safeguarding Adults Board, Dr Hazel Moreby, Research Fellow at Lancaster University Research Design Service, which is part of the funding body NIHR; Annie Keane, PHD and manager at Vocal (Manchester University Hospital NHS Foundation Trust) and Jess Drinkwater, a GP and clinical lecturer at the University of Manchester.

Dr Paul Clarkson: What are your experiences of working with participatory arts and immersive experiences, and what benefits you think it might have within healthcare?

Rob Conyers is head of patient experience at Tameside and Glossop Integrated Care Foundation Trust. Rob has worked with Made by Mortals over the summer of 2021 in a commission that uses our 'Hidden' programme as a training resource for hospital staff. He said:

"In terms of using immersive experiences and how we use those methods at the NHS, I've not come across many examples at all.

"In the NHS, over in the acute side, we usually look at patient stories and feedback and we come at it from a solution-focused point of view. And we think about what we need to do better and what we need to change. And that is absolutely an important process to go through.

"When I first spoke with Paul at Made by Mortals, he introduced something completely different - an immersive experience where people had time to think about somebody else's life and what it would be like if they came to use our services.

"This immersive experience could help us think about someone else's life and how we interact with those people in order to understand their perspective. We got really excited because there was lots we could do with Made By Mortals.

“Sadly then Covid hit, but I knew it was something we would come back to. During Covid, we got the opportunity to apply for funding and we decided to get creative about how we would use that funding, which would link in with the existing Hidden project that Made by Mortals were working on.

“We thought about how we could create some reflective space for people to understand other people’s lives, rather than to just be solutions-focused, and just create an environment where you can talk about your experiences. The project was all about the power of participation and understanding where someone is coming from and putting yourself in their shoes.

“We didn’t tell the staff that you would learn a particular skill, what we said was this was an opportunity for people to be in a safe space, bring their own experiences to that forum, talk and reflect and then use that to inform your future practice. That’s been the power of these sessions.

“However, it’s a difficult sell within the NHS team - people want to know what the outcome of the project will be and how are you going to evidence that you’ve made a change.

“But we don’t know what the impact will be until we’ve run the project, so you have to get creative about how you do that.

“Made by Mortals have been so enthusiastic and have so much expertise. So we used their language about how they were going to support our staff and volunteers. We were lucky enough to get the funding and do some sessions, and we’ve taken those skills back into the organisation to continue to have more sessions. This has been hugely successful and made us think about creating that learning environment.”

Annie Keane is the public programmes manager for Vocal, at the University of Manchester Foundation Trust. Her role is to bring people and health research together to make sure people have a say in health research, and she has lots of experience around PPIE. She said:

“Our focus is in translational research which is aimed at identifying new medicine or treatments to help people with specific conditions.

“We use creative methods a lot in our work. One of the approaches we have is to work with small groups of patients with particular conditions. For example, we might create content through creative practice, like singing, storytelling, stories and poems.

“We’ve worked with a singing project with respiratory patients and we’ve done a storytelling project with people who had radiotherapy about their experience, sharing those experiences online or through exhibitions.

“We’re also raising awareness that people can have a say in research, that patients and researchers can collaborate on research funding, and patients can give researchers advice on how they can conduct their research.

“We’ve also worked with different artists to create interactive sculptures which we’ve used at events, which help people to understand the patients’ experiences, their stories and promote the idea of research generally.

“Creative methods are a really important part of our work, and the value is that it makes the work that we do much more inclusive and accessible. Everyone comes with their own experiences and we work over a period of weeks or months so people can share their experience with others. Anyone who’s been involved in participatory arts knows that that bonding within that group is really important.

“We also run patient’s panels and focus groups with researchers to ensure that people have a say, and that patient experience is really valued. A lot of people who take part in those projects, often go on to do more work with Vocal, so it gives them the opportunity to learn new skills.

“We worked on a Covid project with young people in the UK, South Africa and India, which brought together scientists and comic artists to create a narrative-based web comic that demonstrated different elements of the story of Covid through characters that were aimed at engaging young people in science. That was a fantastic project in terms of engaging young people at that time. Young people were having a really difficult time and felt that their voices weren’t being heard in the broader debates around Covid.”

Chair Paul Clarkson said: “What I’m taking from this is that there’s so many different methods by which you can help to tell those stories.”

Jess Drinkwater is a GP in Bradford and clinical lecturer at the University of Manchester. She has been working to include participatory arts within patient involvement in her GP practices. She said:

“Every general practice has a patient participation group who are involved in making improvements. However, they get frustrated when they get treated tokenistically by the GPs they’re involved with. So, I’ve been working with patients and staff to find solutions to make participation more meaningful. We started off using arts approaches and have tried participatory arts to do traditional research to develop some interventions to try to improve those things.

“We’ve had some successes, so we’ve looked at the work that’s required to create a meaningful participatory space where different stakeholders can come into it. There are four different types of work that people need to do...

“One is understanding the space. One is about identity and legitimacy in the space, one is about the work you do together and doing something credible and meaningful, and the last one is about reflection.

“As GPs, we previously totally failed to provide any way to reflect on that space in the work we were doing together. So we were looking for a way for the staff and patients in that patient participation group to reflect together.

“The second reason we went down an arts route is we were trying to do some co-analysis together. After five years of working together that was like pulling teeth, we were winding each other up and coming from different perspectives.

“They didn’t understand qualitative research and I was rubbish at explaining what qualitative research is.

“So we managed to find some funding to apply to use theatre methods to step back from a traditional qualitative approach to data analysis. We did some work that would draw on the life experience of the group to create a mini-scenario and characters.

“I also wanted to develop a forum theatre workshop, to invite external audiences, which were staff and patients in together, and reflect what it’s like to work together and why it’s frustrating when we sit in a meeting together.

“I had a friend with a background in drama and also does lots of PPI work, and we found a professor of theatre studies. It was all out of our comfort zone. We’d planned an away weekend but it all got cancelled for Covid.

“We did end up doing some more traditional qualitative analysis but we did produce a forum theatre workshop and have tested it out online. It was a little bit like the Handforth Parish Council video. People get to watch a meeting and then talk about the characters and what it’s like to be in that meeting. It could be about institutional racism, for example, and what it’s like to be the only person of colour in that room.”

Paul Clarkson added: “Jess is being modest about her work and it’s really important to look at this. We know how difficult primary care is as it’s quite different to hospital or social care research. It’s good that you’re all involved in these new methods.”

Hazel Morbey, works at the Research Design Service, which is part of the funding body NIHR as well as being a Research Fellow at Lancaster University. She said:

“The Research Design Service is a free service available to all researchers, including academics and social care practitioner researchers, from housing, care home research etc.

“We support and provide guidance and advice on submitting funding apps for research proposals. Anyone who is applying for funding knows just what a job that is.

“The NIHR funds our service and we involve ourselves from the very beginning from ideas right through to developed funding ideas. We also advise on their research question, how to pull together a team, we might be involved in putting people in touch with specialists.

“One of the key things we do is to advise on public involvement and support researchers to think through how they will gain public involvement to help both the development of their proposal but also how public involvement is going to be a central part of their study.

“For the NIHR it is not just a critical part, but a required element, to have a public involvement lead. This is a crucial component into how you are going to design research and how it will be delivered.

“It’s important to say, participatory arts are definitely not a common method of PPIE. We are seeing researchers coming to us and wanting to deliver participatory arts or other creative methods.

“I know the value and the benefit and the difference that it makes to employ different means of getting our research across. I have no doubt that supporting research to include other creative approaches is highly relevant.

“We have a Centre for Engagement and Dissemination which has a wealth of resources and materials. And we do have a small pot of money that researchers can apply for to support their public involvement, and we can help support early public involvement.”

Paul Clarkson added: “Use the NIHR pot of money and their advice, it does work!”

Julie Farley, is the chair of Oldham Safeguarding Adults Board and using her experience of working alongside [Made by Mortals on the 2019 Rats in the Sofa](#) project, she explained:

“One of the strengths of using participatory arts is that it’s a third person conversation. It’s one thing to get services users’ own lived experience, but that can make people feel they’ve been labelled as the victims.

“So the benefits of using this type of co-produced theatre is that it’s about creating a third-person scenario exploring the issues and exploring the solutions, using the actor’s lived experience.

“We also ask the follow up question ‘why would it work’, and it’s this ‘why’ that provides the insight that you don’t get from other methods and that was the added value.”

Our chair Paul went on to ask the panel about challenges and barriers around using innovative PPIE in research.

Dr Jess Drinkwater started off by saying, “We were putting a grant together and asking someone in the medical schools for advice, and people were asking what the theatre part was. They said, can you call it theatre science?!”

“You have to write for your audience, and recognise that it does have to be science-based. I’ve also had issues with people asking ‘what’s the tangible outcome?’

“Within general practice, it’s almost an easier sell as GPs do a lot of role play in training, so they can understand how it can be useful. But equally that means they hate role playing!

“The GPs that I work with think I’m really strange. We got an audience for a workshop and they really loved it. There is something about how we sell it.

“It’s so interesting to see what Made by Mortals do, as the theatre work is at a really professional level and that really helps.”

Rob Conyers added, “My experience is very similar to Jess’s. When we talk about doing an immersive and interactive session - that really appeals to some people but not to others.

“And you have to recognise that people have really busy work lives so it can be hard to convince them to come to a session where there’s no guarantees that you’ll come out with a new skill or learn about a piece of new equipment, for example.

“A lot of people are in agreement that it’s a good thing to do, but then actually saying that will take time out of their diary to come along is difficult. So, using the right language is really important.

“The other challenge I had was that when I started to pitch this, initially, the managers who were interested, wanted to send people who they thought needed some performance improvement within their roles. They saw it as a means to support those people.

“And while we’re happy for those people to come along – there’s no barriers in terms of coming along, what we wanted to make was not an environment where you had to come because your manager had told you to come. It was important for everyone’s development, regardless of whether it was identified as an issue.

“We wanted people to come along and feel it was a safe space. This is hard in the NHS as it is so protective of our time. It’s not something we completely overcame so it still is a barrier.

“When I spoke to someone from the Tate Modern, they said, don’t think about improvement as one big bang, it’s like creating lots of small fires. Small fires create the heat. By keeping them small fires going, and keeping the constant messaging you end up getting the heat and the traction that you want. We’ve not overcome all of the barriers, but we know that if we keep on this track we’ll make some improvement long term.

Annie Keane explained the challenges she had faced,

“Any creative process has challenges, because you’re trying to do something new. And that is really the definition of a creative process.

“From our point of view, one of the challenges is getting the researchers involved, as well as the patients. The researchers are part of the group as well so our intention is that they’re involved and sharing their stories too. That’s really important in this type of work because using creative processes together creates an equity for people in different roles. So selling this process to researchers can be hard, and their time is really limited, so there’s logistical issues around that.

“There are other practical challenges around recruiting people to do something new – we’re always trying to diversify the people who we work with, with unrepresented communities and with people who don’t usually take part in PPIE. There’s a long process to get people onboard and try something new.

“The other challenge is holding all those elements together. Making sure the experience for participants is meaningful, making sure content produced is something that we can use in different formats, that it’s engaging and that the whole thing makes sense to external audiences.”

In conclusion to this really interesting discussion, Dr Paul Clarkson added his own experience,

“One of my own challenges is that the research funder didn’t really understand Made by Mortals and what they did. It was a learning experience for us. The feedback was that they didn’t understand how an arts organisation was involved in PPIE.

“We had to present that the actual structure of Made By Mortals is made up of people with lived experience and it’s a collaborative organisation that also happens to be a public involvement organisation. That is a lesson that you really need to make it very explicit what the organisation you’re working with does.

“Funders are still stuck in traditional model of PPIE, which is go and consult with a group of patients, not even really listen to them, just run a few focus groups.

“It often hasn’t been co-produced, and is not collaborative. As researchers we’re moving away from this style, but the funders haven’t moved as quickly as us researchers. That’s a challenge.

“However, the solution to this is the more success we have, the findings we can create, the more it builds those small fires and eventually all bids will include participatory ideas. We need to change the paradigm and move away from traditional route which is now process-dominated.”

