

Investing in You – Dialogue and Change Membership Award

Evaluation of NIHR Health and Care Inequalities National Consortium Public Involvement & Community Engagement Group



Introduction

This is a Public Involvement and Community Engagement (PICE) advisory group that was established to support the work of the NIHR Health and Care Inequalities National Consortium which is co-ordinated by the ARC North East & North Cumbria.

The PICE group involves contributors from several geographical areas of the country including areas of social/economic deprivation, ethnically minoritized communities, cultural diversity as well as disability, age, gender, and sexual orientation.

The group met first in mid- December 2020. They were provided with written guidance and copies of all of the research proposals for projects that were looking for Consortium funding. Priority setting meetings in January, and follow-up meetings in February and March reported on progress with the final short-list of projects submitted to NIHR in March 2020.

Once approved the successful research projects presented to a combined group of Stakeholder Board and PICE groups in July and September so that the PICE group could see which projects were going ahead, hear directly from the teams and make suggestions about future PICE activities. The group continue to comment on documentation, agreed a Terms of Reference, co-developed the Communications Strategy and receive ongoing progress reports. They completed a Skills Audit and a PICE Training session was delivered. The group continues to meet regularly to review progress across all of the research projects.

I met with David, Lisa, Gaby, Ian and Sandra over Zoom on 20th April 2023 and then met with Amelia separately via Zoom on 5th May 2023. Thanks to all of you for making the time to talk to me and to Ruth, Stephanie and Felicity for helping to organise the meetings.

Evidence of Dialogue and Change

Prioritising Projects

The group were involved in prioritising project proposals to be funded. Sandra's understanding was they were one of three groups that had their say. ***"We were given all the bids. Stakeholders, the board and the PICE group all had a third of a responsibility to put our views forward."***

"I don't think all priorities got to fruition. I assume others [other groups] didn't get all their priorities either." - Sandra

“We had an equal part in choosing, we were listened to on our views.” – Sandra

“I noticed some research was already subject to NICE guidance and there it was the following week in the report and then as it happens, that was one of the projects that wasn’t funded.” – David

“Being involved right from the beginning was important.” – Lisa

It may be the length of time since the work was done, but it is important that the PICE group are kept informed of how the final decisions were made and how their contributions factored into this. This was picked up by Amelia who was less sure about the weight that the feedback from the PICE group held and felt, ***“we didn’t get the final say.”*** The project team shared that it was the PICE group’s top 3 projects and the stakeholder group’s top 3 projects that were funded, although one team was unable to progress with their project. She suggested that all of the groups coming together to agree the final decisions would have been useful. This would also have given the opportunity for more dialogue, as there had been within the PICE group, ***“we could have negotiated.”*** Amelia felt this would have been particularly important for projects where there was a difference in opinion between the groups. While their notes on the projects were shared, ***“dialogue is better than notes.”*** ***“I didn’t feel like we were making a decision, I felt like we were contributing to someone else’s decision.”***

After reviewing the proposals, there was an opportunity to ask questions of people submitting projects which helped to clarify, particularly language and jargon which was an issue, Amelia felt that they ***“weren’t writing for us.”*** The group then came together to discuss their views before making their final recommendations. ***“It was great to have a group and have discussions”***

Lisa told me, ***“The criteria were set so it was all impartial.”*** Although the group could not recall how the criteria were set. The NIHR team’s understanding is that criteria were set by the Consortium Management Group to align with the Consortium’s Strategy from the application that was submitted to NIHR.

Successful Projects

The successful projects then gave more detailed presentations to the group, which was a request from the group, where they were able to ask questions and give advice. The projects have then provided update presentations as their projects have progressed. Lisa said that it has been good to hear from the community members of projects about how their projects have been going.

There were some frustrations regarding the update presentations where the group felt that sufficient progress has not been made in the first year and put this to the research team, ***“It was put to the people that you should be ready to go when you get the funding.”*** Another project had not factored in translation costs and so had to come back to the group with a ‘second ask’ and were allocated additional funds for this. These challenges are important to maximise the use of funds for time-limited projects.

The group also asked for details and made suggestions regarding public engagement when this was not clear. ***“It’s good to understand how the research has been conducted and who it is supporting the public.”***

“When we review, we pass our recommendations via Ruth and Fizz.”

They have also been able to make recommendations to the projects: ***“We gave advice on how to structure interviews and how to ask questions.”*** ***“Quite often you get loaded questions, we had the opportunity to shape the questions.”***

“Through the process, we could request them to explain better when they used jargon and inform them about how we see that research.” – Gaby

Amelia feels that the group bring important scrutiny and accountability to the projects, and keeps a clear focus on the need for practical outcomes: ***“Is it worth spending the money if practice won’t change?”***

Symposium

Members of the group were involved in organising and facilitating a symposium on the various funded research projects in York. A subgroup was set up to organise this, with the wider group being kept informed of the discussions. The group told me they were involved in planning a range of aspects of the day, ***“down to picking the menu.”***

“I asked if I could go and look at the venue. I couldn’t but they shared photos.”

Regarding involvement on the day, there was a PICE panel that some of the group were part of, ***“questions from the audience to get the message across about public involvement.”*** ***“The message that people stay involved longer if they are involved in the beginning.”*** There was a suggestion that more time could have been given to hear from public contributors.

The importance of public involvement in the discussions was highlighted by a number of people. ***“It was inspiring for early researchers to hearing from PICE members about the importance.”***

They also felt that in a less formal role, public members at the event asked the best questions! When a presenter explained a set back as being a typical scenario, they were challenged by a public contributor, ***“Why are you wasting your time if you know that’s always the case?”*** Sandra felt that having an equal standing at the event meant that people felt confident to speak up and ask questions, ***“able to have that opinion, without thinking, ‘who am I to say that?’”*** Ian agreed, ***“The community group were valued as equally as the academic group.”***

Other members of the group were involved in scoring presentations and posters. Sandra said: ***“It was really interesting to know that our influence meant someone would win based on what we said.”*** Amelia would have liked more time to have been allotted for the poster review as it had to be done in the break and during lunch,

“when you wanted to talk.” There were access issues for another poster judge who could not get to some of the posters as they were mounted higher than was viewable for a wheelchair user.

As a result of some of the access issues at the symposium, Ian is now assisting in planning a more local event. **“They took a lot of learning from that for the next event and work with us to go along [to the venue for the next event] to make sure the rooms are suitable and there will be a break out room for people who might need time away.”**

Terms of Reference

The information provided by the NIHR team said that the group had been involved in developing the terms of reference for the group. The group could not recall the detail of those initial conversations, however it led to an interesting discussion about how the group has developed.

“As the group has moved forward, the process has adapted to make it easier and easier to get involved [...] This has led to us being better involved.” – David

“If you were to write [the terms of reference] out now, they would be brilliant. It is worth doing.” – David

“If you look back at the terms of reference from the start to what it’s become...it needs to be movable.” – Ian

Group Meetings

David highlighted the nature of discussion in the groups and how this is recorded to reflect their contributions. **“Often ideas emerge from conversations that you can’t attribute to a particular person but in the reports, you can see those voices”** – David

“Our views were not only recorded but action was being taken. I would read reports and remember that someone said that [...] When comments were raised, you could see them answering these questions in their responses [...] That’s why I’ve stayed involved.” – David

General Discussion

Throughout my conversations, members of the group shared positive reflections on their involvement in the group and how their views are taken on board and acted on:

“I would never have dreamed of being involved at this level.” – Sandra

“Nowhere else apart from places I work have I had my opinions sought and acted upon.” – David

“It’s a model for future projects, not just NIHR research.” – David

“The team have been so supportive. They have taken things on board, responded to questions, nothing has been too much.” – Lisa

“The model that was used could be rolled out.” – Ian

“Before we used to know that researchers did research to us, not with us.” – Gaby

“Researchers now understand they can work with the public if they help them understand what they are doing.” – Gaby

Amelia spoke about the importance of the public role in seeing communities more holistically and bringing this perspective to the discussions. ***“If you go at it from the perspective of a health professions to the public saying we want to change you or research how to change you,”*** which ultimately will not result in the best outcomes for the public.

Further Opportunities

As a result of their involvement in this group, both Lisa and David have been involved in supporting early-career researchers. ***“I was asked if I would review an early-career research project. I kept in touch and have been directly involved in offering support,”*** – Lisa

Gaby also had a meeting with Fizz and a PhD student at Northumbria Uni, ***“I gave advice on how to approach people if you come to my community.”***

Recommendations

- Opportunities for the PICE panel to meet with the Stakeholder panel and board, especially when decisions are being made.
- The group recommended that the terms of reference are reviewed to capture the progress that has been made since the group first form.

Conclusion

This is a relatively new group that has been established to support the work of the NIHR, which has a commitment to public involvement and community engagement in research. There have been learning opportunities and the group has developed together. There are some recommendations made above for how the work of the group could be further embedded and solidified.

The Investing in You – Dialogue and Change Award is made when there is evidence that members of the public have been meaningfully involved in discussions that shape how research is being carried out. David, Ian, Gaby, Sandra, Lisa and Amelia all agreed that based on their experiences, the project should receive the Dialogue and

Change award. I am pleased to recommend that the Health and Care Inequalities National Consortium Public Involvement and Community Engagement Group receives this award. Well done.

This report has been read and endorsed by the members of the group.

Emma Rogan
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Investing in Children
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