

Evaluation of ARC funded Prevention, including Behavioural Risk Factors National Priority Consortium Public Involvement & Community Engagement Group

Introduction

The Consortium PICE group is a public/community advisory group that was established to support the work of the NIHR Prevention, including Behavioural Risk Factors National Consortium, which is co-ordinated by the ARC North East & North Cumbria. The group was initially formed to gain the input of members of the public into decisions regarding the Consortium's funding of research projects. The group has since evolved and its members now give regular feedback to the projects, that were successful in receiving funding, on their PICE activities.

For this evaluation, I met with Rosemary, Sam, Susan and Steve on a Zoom call. Felicity Shenton (PICE Manager) and Ruth Wilson (Consortium Project Manager) started the meeting but then logged off to allow the PICE group members to speak honestly and openly about their experiences. I would like to say a huge thank you to everyone for meeting with me and for their contributions to this evaluation.

Evidence of Dialogue and Change

I started by asking all the group members how they first got involved with this PICE group. Sam told me that she was part of the ARC West Midlands and the opportunity came up:

"I thought it seemed a nice way of seeing an overview of all the projects."

Rosemary was a member of the Diversity in Research group with the Oxford NIHR BRC and then joined the Health Behaviour Panel, who referred her to the PICE Prevention group.

Susan was involved in the PPI work of a tobacco in hospitals project. She was asked by Angela Wearn if she would like to be the project's representative in this group.

Steve was involved in ARC public contribution work and so receives emails about opportunities. He decided that this would be one he would like to pursue.

Priority setting for funding projects

The group's first role was to give their input into decisions regarding which research projects should be awarded funding by the ARC.

Sam described this process as, ***“looking at all the projects and stratifying them. We got a lot of projects, a lot of information.”***

Steve added: ***“I can't remember how many we went through, I think there were about eight to ten that we rated.”***

Sam: ***“We put forward our views, what were the strengths and weaknesses.”***

Sam: ***“We picked out the projects that we thought should be prioritised. We picked out the projects that were most impactful, with the best benefit to service users.”*** This exemplifies the importance of including members of the public when making decisions about funding health research projects; it is important that the needs of patients are at the forefront, rather than academics' personal interests.

These views were taken on board by the Consortium Management Group when making final decisions about funding. Some examples of projects that the PICE group endorsed and were then successful in receiving funding are:

- Evaluation of the national rollout of the NHS Enhanced Service Incentive for weight management in primary care;
- Supporting the NHS Long Term Plan: An evaluation of the implementation and impact of NHS-funded tobacco dependence services;
- Effectiveness of NHS-based multi-tiered lifestyle interventions to achieve type 2 diabetes prevention across glycaemic risk tiers;
- A mixed-methods evaluation of cross-regional workplace health initiatives including a cluster randomised controlled trial of a behaviour change intervention.

Susan told me she felt really listened to during this process: ***“Definitely, I've never felt any other way.”***

This sentiment was echoed by Sam and Steve.

Sam: ***“We were really part of the project team, we had an equal say.”***

Steve: ***“For me, I’ve always felt that our contributions have been influential.”***

As part of this process, the group reviewed paperwork with the projects’ proposals, as well as films explaining the projects, created by the research teams. The PICE group had asked for these films to be made as they felt they would be able to make a more informed decision if they could hear directly from the research teams. The ARC responded to this request and asked the projects to make short films.

Sam: ***“I remember the films being played and the paperwork as well. This was interesting as the films often gave a different flavour.”*** She told me that some films were better than others at getting the project’s core message across. She thought that the use of film was beneficial in supplementing the paperwork: ***“It wasn’t too much of an information overload. It’s a good way of doing it for those who don’t like a lot of paperwork.”***

Susan corroborated this: ***“Definitely it was easier because then you could look at the paperwork and understand it.”***

Steve: ***“The personality of the researchers came through a lot more on video, you got a better sense of it.”***

This indicates that a fresh approach can bring real benefits. By having to create a film, the research academics really had to consider what the core message of their proposal was and how to communicate that clearly to a wider audience. Thus, the PICE group’s suggestion positively impacted themselves and the research teams.

The Symposium

A Consortium Symposium was held in York in November 2022, which the PICE members were invited to attend.

Sam: ***“I went to the symposium in York. It was great. We were really fully included. I thought it was a nice opportunity to be invited to.”***

Rosemary: ***“We got to see the full range of projects.”***

Felicity ensured that every PICE member could attend the symposium if they wished, regardless of their financial situation or their project’s budget. Susan told me that, initially, only those whose projects would individually fund them would have been able to go.

“In the end, Felicity said, ‘we will pay for anyone that wants to go’. She was inclusive of everyone.”

Sam also added: ***“I was asked how I needed help to get there.”***

However, the PICE group also played a very active role in planning the event. They were involved in a planning group which made key decisions about the venue, catering and agenda. Sam and Susan did not have time to be involved in the discussions planning the symposium but were invited to be. However, they both attended on the day. This suggests the flexibility of the PICE group. Members can participate on terms that suit them and if they choose not to engage in one element of activity they are not prevented from engaging in the work they are interested in and able to pursue.

Rosemary and Steve were part of the planning group.

Rosemary: ***“I was involved in the symposium. We had a panel. We had a discussion about how we wanted to handle it. Some of us were evaluators, some of us were judges. Steve chaired the panel.”***

Rosemary: ***“We had a meeting with Steve and the others to talk about what we wanted to focus on. We were very much involved in the set-up and all that.”***

Steve: ***“We were involved in the preparation, developing their presentation material. We co-produced and managed the panel.”***

A key part of the PICE members’ work was organising a panel for the symposium. They were given creative control for this.

Rosemary: ***“We had a meeting about what we wanted to talk about and how we wanted to do it. We ran our panel the way we wanted to do it.”***

The PICE members decided who they wanted to be on the panel: ***“We wanted to show our diversity. We chose who would sit there.”*** Steve told me that, ***“We wanted diversity to be the tone of our presentation.”*** For example, they invited Ian Atkinson, a wheelchair user from Gateshead who founded an equality-based training and peer mentoring company: Empowerment Consultancy and Training CIC.

“It was great to have that perspective added.”

“It was great to have him on the panel.”

On the day, their panel was well received by those in attendance.

Steve: ***“It felt like the response we got was very respectful. I felt very comfortable.”***

Rosemary: ***“They were really listening, they were asking genuine questions. It wasn’t tokenistic.”***

Susan: ***“We really felt valued, to be quite honest. I felt quite important.”***

Steve and Rosemary both gave a very positive account of the experience of planning and managing their own panel.

Steve: ***“It wasn’t tokenistic at all, it was genuine co-production.”***

Rosemary: ***“It was nice to be given the floor and told, ‘this is your time’.”***

The PICE members could attend any of the event’s sessions; they chose different sessions according to their own interests. They could also give feedback on the poster’s projects had created about their research.

“We were asked to give a response to the posters all around the room. We gave marks on that.”

Susan: ***“It was amazing, we got to see all the projects and mark their posters.”***

Steve: ***“My memory is that we were given slips of paper and we gave marks out of ten against some criteria.”*** He gave the examples of how clear the posters were to read and the evidence of public involvement the posters displayed.

Rosemary: ***“They made sure that the research projects really had to show how they had involved community members.”***

The group members thought it was really important that they were included in this examination process. As Susan articulated, ***“100% as it was for the public. It was really important for us to be involved.”***

Overall, regarding the symposium, Steve told me: ***“I think things were done differently based on our involvement. Otherwise it would have been more academic and less accessible.”***

It was apparent from our discussion that the involvement of the PICE members in the symposium was far more than merely attendance. Their views were genuinely taken into account when decisions were being made about the event.

Regular meetings

The group currently meets once a quarter. They previously met more frequently than this but had a meeting to decide how they wanted to proceed.

“We had a meeting, we had a discussion about how we want to meet.”

“As PICE, we had a discussion about how we want to do it, we went for quarterly.”

“We were asked whether we thought it fitted with the research process. It made sense to me personally.”

They all told me that meeting once a quarter worked well for them. However, they told me that the research team engages with them more frequently than this, which they appreciated. Steve told me that: ***“They remember you in between meetings. They send important updates.”*** He contrasted this to other groups he has been involved with where, ***“they just remember you the week before a meeting.”***

They described the nature of the quarterly meetings to me:

“Where the projects are up to, any training as well.”

“Any issues that are emerging, we are asked our views on them.”

The members I spoke to are involved in so many different PICE groups and projects and could not remember specific examples related to this one. I followed this up with Felicity and she informed me that the group made some suggestions around recruitment to individual project teams and these suggestions were always followed up. They also gave advice around the timescales of the projects' reporting.

The PICE group provides a significant benefit to the projects that fall under the Prevention remit. The group members are the experts on how to engage with members of the public and their own communities and so can give invaluable insight when researchers are experiencing issues.

Documentation

The PICE members also told me how their group has had input into the documentation that ARC research projects use.

“I think we’ve had a lot of influence over the draft paperwork.” They elaborated on the advice they gave; firstly, a reduction in the use of any jargon and secondly, that projects remember to think about their audiences beyond their academic circles when completing paperwork.

Rosemary told me about the improvements the PICE group made to the Project Reporting Form.

“We actually changed the form quite a bit. We said we don’t understand what was going on. We did input on the report template itself. We are the ones that are going to read it so we should have a say.”

Their amendments made the form ***“less of a box-ticking exercise”***, as they asked projects to detail explicitly what they had done, rather than just provide numbers. ***“For me, it was the part for social media. They used to just say, ‘social media engagement’ and give numbers. We wanted them to say what they mean by that. If it just says ‘social media’, we don’t know what they are doing to do be honest.”***

I asked them if they felt like their contributions to meetings are taken into account; they all agreed strongly: ***“100 per cent.”*** The fact that the PICE team are able to make changes like the one above means that they want to say involved and engaged with the group. Susan told me: ***“You know that you are being listened to, otherwise I wouldn’t be involved.”*** She contrasted this to other experiences she has had as a public contributor: ***“So many times you’re just a token, I want to be heard.”***

The PICE group’s contributions to the documentation used by the ARC highlights that the group is not merely there to problem solve for the research projects. Rather, the PICE members can put forward their own agendas and make recommendations on the organisation and operation of the ARC.

Recommendations

Knowledge Mobilisation

Steve would like the PICE group to be involved in discussions about projects’ knowledge mobilisation as this is something he is very passionate about. He described

knowledge mobilisation as how research is applied in practice; what practical changes will occur that will benefit patients and the public. Therefore, he recommends that these discussions are built into the agendas for the PICE group's meetings.

Conclusion

From our discussion, it was apparent that Rosemary, Susan, Sam and Steve felt genuinely listened to by Felicity, Ruth and those working for the ARC. The PICE group members have the opportunity to put forward their views on a range of topics affecting the ARC, such as the documentation used, the symposium and the work of the individual research projects. The ARC responds to this dialogue by implementing tangible change. As the ARC makes these changes, the PICE group reciprocates with continued engagement.

I asked members whether they believe their group deserves the Dialogue and Change award; they unanimously decided yes.

Sam: ***"I think they do [deserve the award]. They really tried to involve us early on and at different stages."***

Steve: ***"For me it does, it's the best example of the groups I've worked with."***

Susan: ***"It's about prevention, it's going to make a change."***

Rosemary: ***"I think they make a serious effort to include people and to listen to people. I believe they deserve the award. I like the way they take up advice. We haven't squabbled once about what we've asked them to do. I commend them, they really try to listen to us."***

Steve: ***"It feels respectful and effective."***

As such, I am pleased to recommend that the Prevention, including Behavioural Risk Factors National Priority Consortium Public Involvement & Community Engagement Group receives the Dialogue and Change Award. Well done!

This report has been endorsed by all:

Steve: ***"Thanks for producing a good summary of our discussion. I have no amendments to suggest and I am happy to endorse the recommendation about achieving the award."***

Sam: ***“Thank you for sending out the report, I fully endorse the team getting the Dialogue and Change award.”***

Susan: ***“I agree with this.”***

Rosemary: ***“I confirm that the report is accurate.”***

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