Funding for PPI activities final report

Please complete all sections of this report. We would like to publish these reports on the PPI pages of the NDPCHS and ARC Oxford & Thames Valley websites, so please ensure you do not include any details which could identify the PPI contributors you worked with, or disclose any personal or confidential information.

The reports may also be used to identify and inform future PPI development and training needs.

Please briefly describe your project and the PPI activities that you carried out with this funding.
Think about:
What was the aim/purpose of your PPI activities?
If things didn't go as you planned, why do you think this was?
Did you do anything differently from how you planned? If yes, why was this? *eg Doing individual interviews instead of a group discussion.*
(max. 150 words)

This funding was to cover the PPI contribution towards an SPCR FR13 application. This application was for a collaborative study called REDUCE-HF. This is an electronic health records study in OpenSAFELY; using big data, machine learning and community co-production to reduce inequalities in the primary care diagnosis of heart failure that Emily McFadden and I co-led.

This study will examine who is most at risk of heart failure diagnosis in hospital (and therefore who is not being diagnosed with heart failure in primary care) with a specific focus on the intersection of multiple long-term conditions, health inequalities and social determinants of health.

This funding was initially required to fund meetings with both PPI contributors our PPI co-applicant. I also requested some extra funding to cover feedback on the plain English summary which I found much more difficult to write then I had anticipated. This extra funding also covered time for our PPI co-applicant to look over and feedback on the whole application.

What was the impact of the PPI on your project? Think about:
Did it change or validate anything you will do?
Did anything unexpected happen?
(max. 150 words)

This funding was really crucial to our application. Most importantly, it allowed us to us to meet with new PPI contributors who had not been previously included in our heart disease patient advisory group and this improved the diversity of the PPI representation in the application. This increased diversity in PPI was vital as the REDUCE-HF study focuses on the intersection of multiple long-term conditions, health inequalities and social determinants of health it is therefore essential that this application was discussed with those who have lived experience of intersectional disadvantage.

This project was inspired from the start from our PPI co-applicant. After listening to the findings of the qualitative component of my DPhil he was very clear that we needed to shift focus and look at reducing inequalities within the primary care diagnosis of heart failure.

In terms of this specific funding we made a number of changes to the application and work package (WP) design based on PPI feedback:

- Our PPI co-applicant was invited to join the team at the expression of interest stage. When discussing his priorities, he advised of the need to involve 'invisible populations' so 'no-one is left behind' in research, specifically identifying people living in nursing homes/care homes and people with learning disabilities as important communities to consider in the REDUCE-HF analysis. We have ensured these groups will be included.

- The PPI strategy for the whole grant was designed closely with our PPI co-applicant who was able to talk about the need for specific requirements such as ensuring disability access and hearing loops in our in-person venue used for the WP5 PPIE event.

- Issues of possible geographical inequalities in relation to HF diagnosis were raised by our co-applicant and another contributor living in rural Wales, who described how healthcare access was hugely variable; they felt that these disparities should be a key focus. We have one WP that will generate heat maps of England so any geographical disparities in heart failure diagnosis will be illustrated. We are also looking at trying to get data for Scotland and Wales but there are feasibility and financial constraints that could make this more difficult, we will not be able to include it in this project but will look into getting additional grant funding to cover this.

- The application was also discussed with the wider heart disease patient advisory group. They advised that strong community engagement was essential for dissemination, but also for changing people’s consulting behaviour around symptoms of breathlessness, and the importance of presenting with breathlessness and requesting a heart blood test in primary care. They were enthusiastic about PPIE to inform the design of future intervention studies so that solutions “work with communities” and are “trusted by them.” In response to this advice and guided by other co-applications with experience of health inequalities research, we have now incorporated Citizens Panels, co-production and co-design into the project and added a whole new WP (WP5) to reflect this.

- We also discussed this project with people with lived experience of MLTC and deprivation from a community group in northern England. One patient and adult daughter spoke to us about the application, this patient only spoke Urdu but her daughter was able to translate. She explained how her hypertension was detected through a routine blood pressure check during her diabetes review and she felt that annual reviews for LTCs should be used for HF diagnosis. She explained that she had a lot of support from family who live with her, and that without this she might not go to the doctors. She advised that we should look specifically at people who live alone as they might find it harder to get help. The study team also agreed that annual chronic disease reviews were a potentially important opportunity in which to detect heart failure and this will be discussed in WP5 in which a future implementation study will be co-designed.

- The above patient's daughter worked in a GP surgery in a deprived area, she advised of the need to include migrant populations as she felt this population were particularly vulnerable. Our WP and protocol have been expanded to incorporate this feedback as feasible within the available electronic health record data, adding household composition/size and migrant status as additional exposures.

Changes were also made to the lay summary following feedback from PPI contributors:

The first paragraph of the lay summary, prior to circulation, was as follows:

"The NHS was founded on the principle of providing fair and equal healthcare for all, but major health inequalities persist and are worsening. Addressing these inequalities is a priority, especially in primary care."

Following a lot of feedback and multiple iterations, the final lay summary read:

"Some people are healthier than others because of things like where they live, how much money they have or the healthcare they get. This is unfair. Everyone should have the same chance to be healthy and get good NHS care. One way to help is by finding health problems early so treatment can start sooner. This is particularly important for General Practitioners (GPs), the first doctors people usually see."

Finally, the most important impact of this funding was that it really did help to build a strong application that closely aligned with patient and public priorities and those with lived experience of intersectional disadvantage.

What was the impact of the PPI on you? Think about:
Did it make you think about anything differently?
Did it increase your confidence at doing PPI?
What did you find challenging?
(max. 150 words)

This project definitely helped to further increase my confidence in doing PPI. It was more challenging to speak to people outside of Oxford with very different lived experience but was very rewarding and enjoyable.

I think doing lots of PPI at this early, pre-funding stage is so vital and I've learnt how important it is from this application and will make sure that I follow this for future grants. It was fantastic to be able to create a whole new workpackage or change analysis methods based on the PPI feedback and the earlier this is received the more it can help to build a good project.

This was my first experience of working with a PPI co-applicant and I will definitely repeat that in the future. It was so much better to co-design a PPI strategy directly with a PPI co-applicant.

What was the impact of the PPI on your PPI contributors?
How do you know what the impact on them was – did you ask them?
(max. 150 words)

The PPI contributors said that they really enjoyed being a part of this. Particularly for the patients and public living away from Oxford who we had not spoken to before, they said were very pleased to be involved, to be listened to and in the words of our PPI co-applicant that their "voices were heard."

On finding out that the project had been funded, our PPI co-applicant said he was "really pleased that this important research has been funded."

What are the next steps? (max. 150 words)

I'm delighted to report that we did get this grant and am aware that without this PPI funding it would have likely been a very different outcome. The project will start in June for 18 months and we are delighted that this is going ahead. The reviewers' feedback was very positive and included statements such as: "the project is well designed with a clear pathway to impact" and "the EDI section is very good – the team has thought about communication to the public through creative methods." We were very pleased to get this feedback but totally acknowledge that it was a team effort, only possible with this PPI grant funding and working closely to build the project with our PPI co-applicant and wider team of collaborators in Nottingham, Keele and Bristol.

Did you spend all the funding that you were awarded? If not, why not?

Yes

Please also include a copy of the feedback you sent to your PPI contributors (either paste the text here or send as a separate document).

Our PPI co-applicant reviewed the whole application so he was able to directly see his input into the co-design of the PPIE strategy and the data-analysis plan. The PPI contributors were individually emailed and we thanked them directly for their time, advice and guidance. This below was from one feedback email to two of our PPI contributors:

"I wanted you and your mum to know that our conversation has directly led to some changes in how the study is going to be designed. You specifically mentioned that you felt that migrant populations were a group who we should focus on and we have been able to add this into the analysis plan. Your mum was concerned about people that live alone and other patient contributors have raised this concern too and household size will now be included in this study. "