



# INVOLVING PEOPLE FROM UNDER-REPRESENTED ETHNIC BACKGROUNDS IN MULTIPLE LONG-TERM CONDITIONS RESEARCH

## OBJECTIVE

Dr Shoba Poduval, an Academic GP at the Institute of Health Informatics, wanted to know how to focus research on ethnic inequalities in multiple long-term conditions whilst preparing a fellowship application. Patient and Public Involvement (PPI) were consulted to develop research ideas and questions. A particular focus was taken to under-representation of global majority communities in research and PPI due to systemic barriers (including lack of accessibility, lack of alignment with community goals, unequal relationships and lack of sense of “ownership” of the research). Addressing these barriers was central to the project, and an equity-centred anti-racist approach was taken to ensure reciprocity between the researcher and the group, detailed below.

## FUNDING & RECRUITMENT

After securing a University College London hospital (UCLH) Biomedical Research Centre (BRC) Innovation Grant (project ref BRC1254/PPI/SP/104990), the researcher recruited five members of the public from global majority ethnic backgrounds who were affected by multiple long-term conditions to take part in discussion workshops. Community organisations were vital to recruitment, as they were able to share flyers via their established WhatsApp and email networks.

## PREPARATION

- Interested participants were able to discuss what the project involved with the researcher prior to taking part.
- The researcher identified that the most convenient means of holding the workshops was via Zoom. Anyone having trouble with Zoom was given support.
- A WhatsApp group was set up and polls were used to agree dates for the workshops.
- The researcher asked the group about skills and interests they would like to develop related to PPI and long-term conditions, and speakers with relevant expertise were invited.

## WORKSHOPS



Three online Zoom workshops were held. The workshops were organised in two parts to allow mutual exchange of skills and experience:

- Firstly, the researcher shared information and training on PPI and research methods (including NIHR resources) and asked the group for their input on the research question and methods using open-ended questions. A co-production approach was taken respecting the values and knowledge of the whole group. The group’s input was documented using an interactive Zoom whiteboard which was sent to the group for further thoughts after each workshop.
- Secondly, two expert speakers (Mita Vaghela and Dawn White) joined two of the workshops to facilitate learning on issues related to long-term conditions management that the group expressed an interest in (supporting health and wellbeing through physical activity, mindfulness and nutrition). This involved a chair-based yoga session and a ‘story circle’ discussing cultural influences on eating habits and nutrition.

PPI feedback: “I was fully able to contribute to the discussions about Shoba’s research. The discussions were inclusive, engaging and fun. Everyone had something to say. There was little or no need for prompting.”

## TRAINING AND SUPPORT

**Pre-reading-** in addition to an outline workshop plan, the researcher also shared relevant training materials in advance of the workshops. This included NIHR’s [‘Starting out guide – why and how to get involved in research’](#).

**Communication with the researcher-** diverse channels of communication were used to ensure continuous feedback including giving participants time to add to workshop notes using a shared Zoom whiteboard, and post-workshop evaluation questionnaires using MS teams. The researcher used email, WhatsApp and telephone to communicate with the group and with individuals in-between workshops. This made the researcher more accessible and meant participants could have one-to-one conversations when needed.

**Expenses-** funding from the UCLH BRC Innovation Grant allowed payments to be made to participants as a thank you for their time, and for the expert speakers. The researcher made sure payments made promptly after each workshop to ensure that the group was compensated, and the value of their time was acknowledged.





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## IMPACTS TO THE RESEARCHER

- Learning about active partnership in research and addressing barriers to involvement in PPI for people from global majority ethnic groups
- Understanding barriers and facilitators to ethnicity data collection and other types of data that are relevant to the experiences of people affected by long-term conditions from global majority communities

This learning helped to develop and inform the direction of the research in the planning stages, and identified preferences for the research design.

## IMPACTS TO THE PPI

- Learning about research and PPI
- Building capacity to take part in future research
- Being part of a supportive group
- Sharing knowledge and experience about health and wellbeing with expert speakers

PPI feedback: “I gained some useful tips around food, health and exercise. I also gained life experiences and was able to relate to the others in terms of their own personal experiences.”

## PPI FEEDBACK

“What I found useful was not only learning new things and picking up lifestyle tips. It was also good to see and hear that other women, share exactly the same thoughts and ideas as yourself even though you had never met them before this setting.”

“Ditto! I would say the examples of learning something new; picking up lifestyle tips and advice and also the chance to reflect on my health and lifestyle was enlightening.”



## CHALLENGES

- Due to the group being geographically spread out, it was not convenient to hold the workshops in-person. This meant the workshops were held online on Zoom.
- Due to the time commitment, not everyone was able to attend all the workshops.
- The payment forms required by academic institutions can be overly complex. Payment can take several weeks and researchers need to make sure they are completed and submitted early to ensure prompt payment.

## TIPS FOR RESEARCHERS

- The group expressed the need for researchers to involve them throughout the research cycle and to demonstrate evidence of impact and change for their communities.
- Don't present too much information or information that is too complex.
- Establish preferred means of communication and use diverse approaches.
- Make sure PPI are made to feel valued and compensated adequately for their time with payments. Adequately cost this into grant applications and use [NIHR PPI payment guidance](#).





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## PPI FEEDBACK

“I absolutely feel that it was a good approach to improving inclusion and diversity and counteracting racism in research. Other Researchers who want to make their research groups more diverse should do the following: link up with both local groups and national charities across the UK. For example, The Royal Free Hospital Kidney Patients Association as well as the National Kidney Federation. There are so many others patient groups, Hospital forums and charities.”

## ACKNOWLEDGEMENTS

With thanks to Dr. Nadine Fontaine-Palmer (Director, Mabadiliko), Mita Vaghela (Director, Ovada), Dawn White (UCL MASc Creative Health candidate), Patience Renias-Zuva (Patient and Public Involvement Manager, [NIHR UCLH BRC](#)), UCL Institute of Health Informatics.

[Mabadiliko](#) is a Community Interest Company (CIC) whose vision is a society where health equity is the norm, achieved through the democratisation of decision-making across the entire health ecosystem. They strive to centre the voices of seldom listed to and marginalised communities and create safe and brave spaces to challenge the status quo and enable systemic transformation.

Mita Vaghela is an artist and Director at [OVADA](#). OVADA is an artist-led arts centre in Oxford (email: [director@ovada.org.uk](mailto:director@ovada.org.uk)).

Dawn White is a passionate Yoga enthusiast which led to studying the MASc Creative Health at UCL. Dawn is also a sound bath/healing practitioner (Linked in: [www.linkedin.com/in/dawn-white-02570814](https://www.linkedin.com/in/dawn-white-02570814); Instagram: @YogaDawn\_).

With particular thanks to the PPI group, for sharing their valuable time, honest advice, significant experience, and their input into the research.

## ABOUT THE RESEARCHER

[Shoba Poduval](#) is an Academic GP and Clinical Lecturer at the [Institute of Health Informatics](#), University College London. Shoba's interests are in long-term conditions and health inequalities affecting people from global majority and low income backgrounds. Examples of previous PPI and public engagement projects can be found on the [‘Diverse Voices’ website](#) including:

[Diverse Voices – A UCL Community Engagement Project](#) (Video)

[Diverse Voices – A UCL Community Engagement Project](#) (Blog)

[Community Storytelling- Disruptive thinking on community engagement](#) (Blog)

[Oh Pod! x UCL: Demystifying Health Research at UCL](#) (Video)

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