

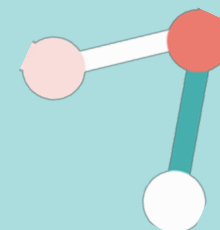


# Bringing together the NIHR for the underserved

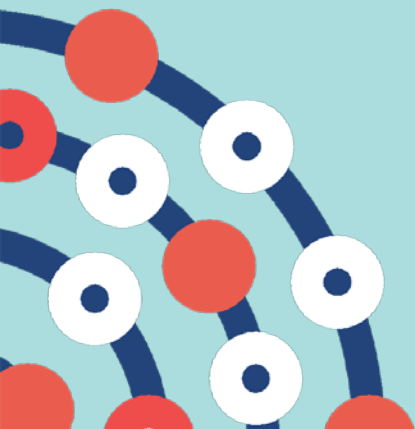
Best research for best health. By everyone  
for everyone.

Laurie Oliva, Head of Public Engagement, NIHR Clinical Research Network





# Participant Perspective

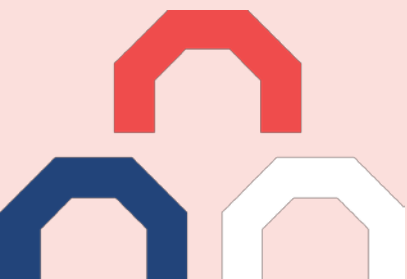


“I didn’t know this was a thing. I would have liked to take part in research to help myself or my baby or to just be part of helping learn stuff for other women, for my future daughters you know. If the research is about women, then all women should be involved. From all walks of life and cultures. Otherwise, it is not about all of us. Just some.”

Black African participant in MBRRACE UK PPIE project



# Inclusion at NIHR



# Inclusion at the NIHR



To read about the NIHRs current work on equality, diversity and inclusion:

<https://www.nihr.ac.uk/about-us/our-contribution-to-research/equality-diversity-and-inclusion.htm>

## Open Letter to NIHR from Chief Scientific Advisor

“...at the more applied, clinical and public health end of the (research) spectrum there is a strong scientific need for research to be conducted with and in the populations most affected. Research activity should go to populations who need it, and we would like to encourage the best researchers, wherever they are based, to undertake clinical and public health research in the areas of England with the greatest health needs.”

# National Standards for Public Involvement

**Standard 1: INCLUSIVE OPPORTUNITIES.** We offer public involvement opportunities that are accessible and that reach people and groups according to research needs.

The standards were created through partnership work between Chief Scientist Office (Scotland), Health and Care Research Wales, the Public Health Agency (Northern Ireland) and the National Institute for Health Research (England) and set out ‘what good looks like’ in patient and public involvement in clinical research.

# Working with partners to serve the public

## Centre for BME Health

“To reduce ethnic health inequalities”

The screenshot shows the homepage of the Centre for BME Health. At the top, there is a dark blue banner with the text "CORONAVIRUS (COVID-19) - GUIDANCE FOR PEOPLE WITH DIABETES - [CLICK HERE](#)". Below this is the Centre for BME Health logo, which features a stylized tree icon and the text "Centre for BME Health" and "reducing health inequalities". To the right of the logo, there is a link "Enquire online to find out more" and a green button labeled "Get involved". Below the logo and link is a navigation menu with the following items: "About", "Resources", "News & Events", "Gallery", "Community Involvement", "Services", "Research", "Collaboration", and "Terms of Use". The main content area features a large heading "Welcome to the Centre For BME Health" and a paragraph: "The Centre for Black and Minority Ethnic (BME) Health has one clear vision: 'To reduce ethnic health inequalities'. We do this by working with patients, the public, community and voluntary sectors, researchers, health and social care organisations. [Learn More](#)". To the right of this text is a photograph of a diverse group of people sitting around a table, engaged in a discussion. Below the main content area is a row of four colored buttons: "Community Involvement" (blue), "Services" (green), "Research" (yellow), and "Collaboration" (red). Each button has a white right-pointing arrow.

<https://centreforbmehealth.org.uk/>



# INCLUDE resource on NIHR Learn

Exit activity

## Equality, Diversity and Inclusion Course

Menu

- Welcome
- Course Objectives
- Why Inclusion matters
  - Watch this video
  - Underserved Groups
  - Reading
- Important Dates
  - Equality, Diversity and Inclusion
  - Milestones
- Summary
  - Summary
  - Thank you

### Equality and Diversity V6 No Qs

**NIHR** | National Institute for Health Research

## Welcome

Welcome to this course on equality, diversity and inclusion (EDI) in health and social care research.

Widening access to research to more, and different, patient and public groups is a priority for the NIHR and research has shown there are benefits for doing so for the quality of research, for research participants and for the wider populations who benefit from the findings of the research.

This course has been developed to give you more information about why some groups are underserved in clinical research, why this matters, and what can be done about it. It has been co-produced by the NIHR Clinical Research Network's Public Engagement team and public contributors. There has also been expert input to some of the materials from the Clinical Research Network's Cluster E team who are currently leading work around improving access to research for underserved groups through the INCLUDE project.

This course should take approximately 15 minutes to complete. You can complete the course in your own time. You can work through the course in order or navigate to different sections using the menu.

You can revisit the course and complete it as many times as you wish.

PREV NEXT



"Place patients at the centre of the research process"

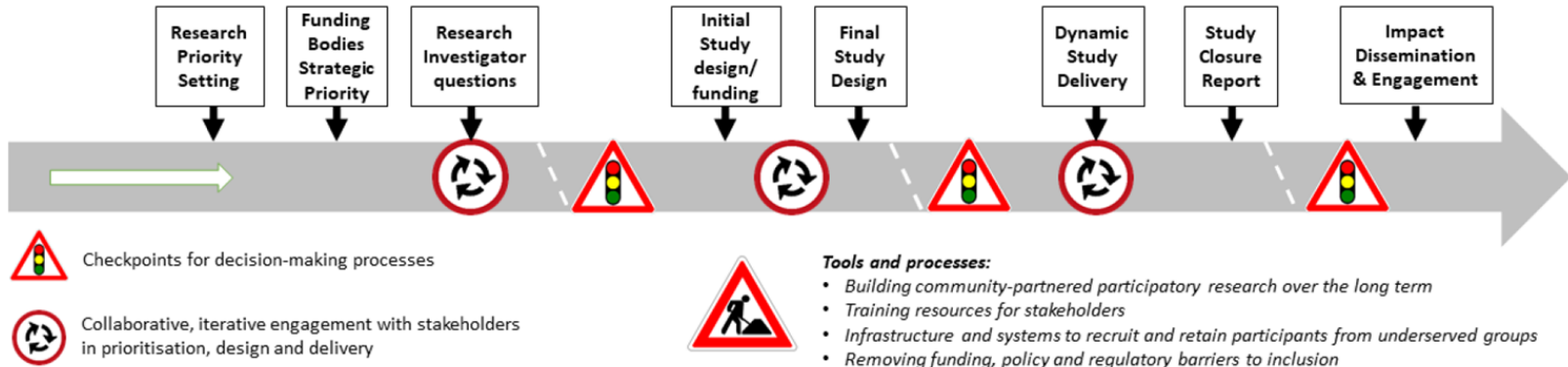
Learning from the CRN's inclusion-themed 2020 Small Grant Scheme



# PPIE as an enabler at every stage



Involved stakeholders: Patients, public, funders, clinicians, researchers, regulators, industry, policymakers



What research questions and health outcomes matter?

Which patient and public groups are affected by this research? How will this study reach them?

How can we make sure we don't exclude people 'by design'?

How can we tackle recruitment challenges?

Why are people dropping out of this study?

What's most important in these findings for people to know about and how can we let them know?

## MIRACLE Migrants' Involvement in Research and Community Engagement

Mayuri Gogoi<sup>1</sup>, Helen Eboral<sup>2</sup>, Fatimah Wobi<sup>2</sup>, Manish Pareek<sup>1,3</sup>

<sup>1</sup> Department of Respiratory Sciences, University of Leicester

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<sup>3</sup> Department of Infection and HIV Medicine, University Hospitals of Leicester NHS Trust, Leicester, UK



# PPIE can challenge assumptions

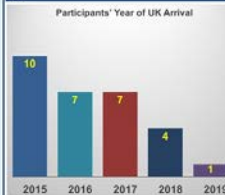
Understanding about the importance of research amongst the group was high and participants believed that involvement in research enhances their knowledge and capacities.

However participants simply didn't know how to get involved in research.

### MIRACLE PARTICIPANT DETAILS

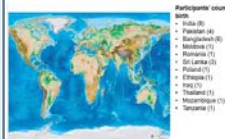
- The project was carried out with recent migrant learners attending ESOL and other employment related courses in Leicester College (LC).
- The project had a total of twenty nine (29) participants.
- We got more female participants (n=28) as compared to male (n=1) because of the skewed enrolment profiles in the courses like Health and Social Care, Child Care etc.

### MIRACLE participants' time in the UK



Out of the 29 participants, 10 participants had come to the UK in 2015, 7 each in 2016 and 2017, 4 in 2018 and 1 participant had come very recently in 2019.

### Participants originally from 12 countries took part in MIRACLE



The MIRACLE workshops were attended by participants born in 12 different countries. Apart from migrating from their countries of origin, some of the participants were also nationals of other European countries such as Belgium, Italy, Spain and Portugal where they had migrated to before coming to the UK.

### University of Leicester does 'MIRACLE' to understand migrants' involvement in research and community engagement

It is now widely acknowledged that personal and public involvement and engagement (PPIE) in health and social care research is inevitable to make these systems more robust and efficient. This project is an attempt at understanding PPIE of a group which has hitherto remain underrepresented in health care research i.e. migrants or foreign-born people. Although, nearly 14 percent of UK's current population are comprised of people born abroad, their involvement in health and social care research remains sub-optimal. This

### Ways of engagement

Five engagements workshops were conducted with a total of twenty nine (29) participants. These workshops were held at two Leicester College campuses and moderated by a member of the MIRACLE team. Due to limitations in budget, sessions were conducted in English and all participants had functional level of English. The sessions were transcribed and themes were identified from the transcripts.

### Recommendations

Suggestions to improve of foreign-born people's involvement in research include:

- Fitting around people's needs;
- Employing new and innovative ways of engagement;
- Creating formal organisations and/or creating community champions

### Next Steps

We are planning a new set of engagements for the migrant learners at ESOL LC to create learning and capacity building opportunities in PPIE. For this we are planning to organise a 'Experience a Day in Research' for the migrant learners in partnership with University of Leicester, University Hospitals Leicester NHS Trust and, Centre for BME Research. We are also planning to work with the East Midlands Research Champion team to link the learners to local activities and groups working on research involvement.

### WORKSHOP FINDINGS

#### Perception and Understanding of Research

- Understanding about importance of research is high.
- Participants wish to be involved in research and therefore shape research and clinical delivery, particularly in areas such as diabetes, cardiovascular diseases and cancer.
- However participants are currently lacking the knowledge and awareness of ways to get involved.

#### Barriers to involvement



#### Participants shared several barriers to involvement, which include:

- Lack of information about research and how to get involved in research.
- Limited English language skills.
- Participants felt that they lacked 'specialist knowledge' to be involved in research.
- Language barrier and perceived lack of knowledge giving rise to shyness and low level of confidence.
- Getting a job and looking after family are high in priority and puts constraint on people's time.
- Precarious status of immigration may make people insecure and suspicious of research and researchers.

#### Facilitators to involvement



This project is funded by the National Institute for Health Research (NIHR) Clinical Research Network Patient and Public Involvement and Engagement in Research Small Grants Scheme and supported by the NIHR Local Clinical Research Network (East Midlands). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.



## Increasing access to research amongst gay, bisexual, transgender and other men who have sex with men (MSM).



### Listen ....

- Establishing effective health improvement interventions for gay, bisexual, transgender and other men who have sex with men (MSM) is a priority for the NIHR Public Health Research (PHR) programme.
- MSM remain at highest risk of sexual infections including HIV, and other risk factors for chronic disease including alcohol, smoking, and use of recreational drugs are prevalent.
- We sought to better understand how we might increase research participation amongst this diverse community:
  - Many potential research participants prefer not to engage with traditional sexual health services
  - limited disclosure of sexuality and sexual behaviour can further complicate the identification of those at risk
- We performed a pilot survey at Newcastle Pride 2019 which confirmed enthusiasm for research participation locally, with a preference for online surveys due to convenience and confidentiality.



### Involve ....

- We launched our online survey in January 2020 to an unselected local audience.
- We drew on clinical research network resources to assist with survey design and our communication strategy.
- Participation was truly confidential: we recorded no identifiable information other than an email address, which was used to facilitate compensation.
- We involved local community representatives and key healthcare workers to identify bars and other social venues frequented by potential respondents.
- Dissemination was facilitated by word of mouth and peer recruitment, participation was boosted when championed by a trusted contact.

"I hope it will bring about change that may improve the quality of life for young gay men and help put an end to HIV"  
Participant 1

"It felt good thinking that my participation could influence services for the future"  
Participant 7

"I hope the research goes well. I believe that participation is important"  
Participant 3

### Outcomes



### Challenges ....

- Anonymity was prioritised to maximise survey response, but this demanded new ways to recruit participants and identify unique respondents.
- Project participants were often not users of clinical services, thus relationships between participants and researchers had to be newly established.
- Informal peer recruitment increased our reach where we would otherwise have struggled to engage communities, however the inherent recruitment bias associated with this process must be considered.
- Clear communication within the research team and between researchers and participants is key.

### Information Flow ....



### Our Response....

- Interest in HIV prevention research is consistent with our experience amongst MSM who attend clinical services for care.
- We are encouraged by the enthusiasm for face-to-face interviews, which we had not anticipated.
- This work has strengthened our network of local peer research advocates amongst the MSM community, we want to use the priorities identified to inform the planning of future work.
- Unexpectedly, potential project participants themselves facilitated recruitment, and we are keen to consider how we might develop training and governance to support peer research in sexual health.

With thanks to our local partners:

- The Eagle
- Number 52
- The Private Shop
- Central
- Roxy's
- The Vault
- Theatre Royal
- Heavens Above
- Basement
- SHFT
- Viggo
- Tyneside Cinema
- Maple Park
- The travelling man
- Revo Co

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# PPIE can create innovative solutions to research delivery challenges

"Informal peer recruitment increased our reach where we would otherwise have struggled to engage communities" Researcher



## Diverse Voices

What barriers do our diverse communities experience when accessing research opportunities within Family and Integrated Support Services division? (Woman and child)

### Project Overview.

A few things that influenced the Diverse Voices project:

- MRRACE UK Maternal report, Saving Lives, 2019<sup>1</sup> and MRRACE UK Maternal Report, Saving Lives 2018<sup>2</sup> identified that Asian women are two times more likely to die during pregnancy and early postnatal period and Black women are five times more likely to die during pregnancy and early postnatal period when compared to white women.



- Participation in clinical trials improves outcomes in women's health<sup>3</sup>
- Do ALL women have equal access to research opportunity within FISS services?
- NHS local trust Equality Impact assessment completed. Need identified.

### What we planned for Diverse Voices.

The DIVERSE VOICES project was intended to be delivered as below.

- Project team will identify minority and under-served communities (Examples - BAME, LGBTQ, Teenage parents, Low income families).
- Project team will identify community leaders/gatekeepers for these communities. Snowball sampling will be used to ensure we identify stakeholders who may not currently be known to us from our under-served groups.
- We will undertake a series of interviews with community leaders and gatekeepers. The focus of the interviews will explore maternity research, communication and communication barriers, as well as barriers to participation in research with regards the communities that they represent.
- We will use thematic analysis to identify the barriers and facilitators to under-served groups engaging in Midwifery Research.
- Key themes and analysis from this project will be shared with Local Maternity Services and relevant service user groups. Outcomes will influence future delivery of the Reproductive Health/FISS research within our NHS trust.

### What actually happened.

DIVERSE VOICES project evolved due to external factors. We changed and adapted along the way.

- Project team changed when the Patient Research Ambassador (PRA) who was key to the project inception was unable to be part of the project delivery.
- Identifying participants and snowball sampling took much longer than anticipated.
- A combination of interviews and focus groups were used. The introduction of focus groups was requested by women representatives in our communities.

### Outcomes.

Assessing research opportunities, common themes - all communities.

#### Communication

- Spoken - Language barriers and assumptions about language barriers.
- Availability and timing of interpreters.
- Written - Ability to speak and read a second language. Terminology used. Lengthy written information.
- Methods of communication - Ease of use eg text and email. Post sent to houses of multiple occupancy.
- Dynamics of interaction - Wanting to please the Health Care Professionals.

#### Health Care Professionals (HCPs)

- Lack of continuity of care: Impact on building trusting and open relationships.
- Cultural difference to the opinion of HCPs.
- Consistent information and advice from multidisciplinary team.

#### Service Provision

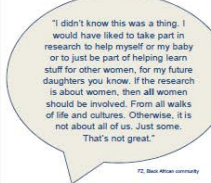
- One centre service eg hospital. No research opportunity in community settings.
- 3-4 service providers for shift workers, rural communities, women with caring responsibilities and others.

#### Cost

- Financial cost. Associated travel and parking.
- Paternal for cost to ensure time away from work or caring responsibilities.
- Time cost of additional or frequent appointments.

#### Cultural

- Health literacy.
- Navigating NHS services particularly if recently arrived in UK.
- Managing family expectations.



FR, Black African community

### Groups Involved.



### What we heard - Barriers

"Lots of people do shift type agricultural work so it is hard to get to appointments all 6 to 8 times. Appointments not needing travel to the city centre would help." SR (Lithuanian migrant to UK)

"I don't ever answer my phone. I prefer to text and I don't think that's just a teenager thing. If stuff, info and appointments could be text or emailed then it's right there on my phone." MD (Teenage parent community)

"Talking to a total stranger about some very personal things can be quite difficult for women from certain cultures and backgrounds." FR (South Asian community)

### What we heard - Enablers

"Research that has translations of all documents that the patient might see or need to read, as well as having interpreters so that we are not left out." SR (South Asian community)

"Better ways of contacting me. Being able to text me or email me instead of posting letters." MD (Teenage parent community)

"You could make sure that information and adverts are seen in the places that we go, not just the hospital. Community centres and churches. We all talk loads and share information, if someone has seen it we will all talk about it." FZ (Black African community)

"It would be helpful to see and speak to the same person so that you could build a relationship, trust them, and have better conversations about parts of your care." SR (South Asian community)

### Next Steps.

- Continue the project and engage with women from other diverse communities.
- Use feedback to shape the way that research opportunities are offered within our NHS trust.
- Share feedback with service user groups and Maternity/FISS service managers and commissioners.
- Share across CDN Factors team

# PPIE can remind us of the basics

"It would be helpful to see and speak to the same person so that you could build a relationship, trust them, and have better conversations about parts of your care." (South Asian community)

"Better ways of contacting me. Being able to text me or email me instead of posting letters." (Teenage parent community)