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

1948
NHS Founded.

2010
Equality Act and Public Sector Duty

2015
Going the Extra Mile

2019
National Standards for Public Involvement

2006
NIHR Founded

2012
Health and Social Care Act

2017
Open Letter to NIHR from Chief Scientific Advisor

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

https://centreforbmehealth.org.uk/
Equality, Diversity and Inclusion Course

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.
"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?
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.
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
"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)