

Widening Participation in Patient and Public Involvement (PPI)



Listening to the voices of communities
underserved by research



Demographics of participants



20 people took part in focus groups and online interviews - 10 women and 10 men



People from ethnic minority backgrounds including black African, black Caribbean and Southeast Asian



People from a low socioeconomic background



People with disabilities or long-term health conditions



People with learning difficulties or a neurodiversity



Full time carers



People who identify as LGBTQ+



People aged from 20-70



Themes

TRUST

A blue icon depicting two hands shaking, symbolizing trust, agreement, or partnership.

DIVERSITY

A red icon showing a group of stylized human figures of different heights and colors, representing diversity.

LANGUAGE

A green icon consisting of two overlapping speech bubbles, representing communication and language.

COMMUNICATION

An orange icon showing three communication tools: a rotary telephone, a smartphone, and an envelope, representing various methods of communication.

FLEXIBILITY

A pink icon showing a central vertical line with three arrows branching out to the left, right, and up, symbolizing flexibility and multiple options.

ELIMINATING HIERARCHIES

A purple icon showing a simple organizational chart with one person at the top and three people below, representing a flat structure that eliminates traditional hierarchies.

COMMUNITY

An orange icon showing four hands joined together in a square, symbolizing community, support, and unity.

RECOGNITION

A dark blue icon of a circular medal with a ribbon, representing recognition, achievement, and awards.



TRUST



- A general lack of trust in science and researchers and a fear of medical research.
- The need for trusted people within a community to act as conduits to help researchers engage with certain groups.

- TAKE TIME TO BUILD RELATIONSHIPS
- ENSURE CONTINUITY OF COMMUNICATION
- TRUST IS GAINED, NOT INHERENT

“Relationships have to be grown over time. Build an environment and connections that are long-lasting.”

“Trust in what’s being said and what’s being done, but also trust in the person who you are sharing and discussing information with.”



DIVERSITY



- A lack of diversity in imagery used.
- Feeling that there is a lack of diversity in the staff doing the research which can lead to a lack of trust.

- CONSIDER WHAT IMAGES AND GRAPHICS ARE USED
- TRY TO REFLECT THE COMMUNITY
- INVEST IN CULTURAL COMPETENCE

“If I see a picture of someone like me, it means there's something in it for me.”

“When you look around and there is no diversity on the staff, you think ‘is this for me?’”



LANGUAGE



- The use of jargon and scientific terminology.
- Language barriers for those who do not speak English as a first language.

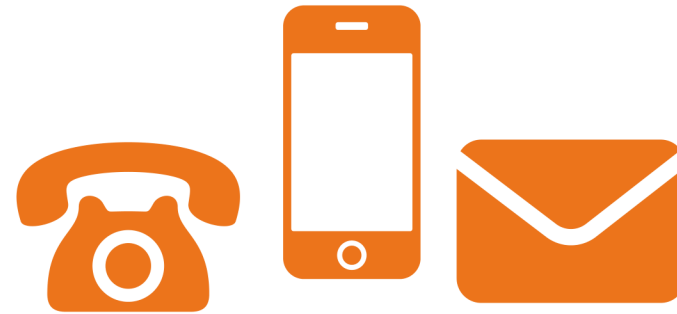
- **USE SIMPLE LANGUAGE AND PHRASES**
- **CONSIDER TRANSLATION**
- **ALTERNATIVES TO WRITTEN MATERIALS**

“Researchers use big words. It needs to be simple language.”

“Use language that everyone can understand. We want to know what we're getting into before signing up.”



COMMUNICATION



- A lack of information about what projects involve.
- Not providing flexible ways to get in touch

- PROVIDE CLEAR INFORMATION ON WHAT IS INVOLVED
- PROVIDE CHOICE IN HOW TO COMMUNICATE
- CONSIDER DIGITAL POVERTY - OFFER CALL BACKS, PRINTING, DIGITAL HELP, ETC

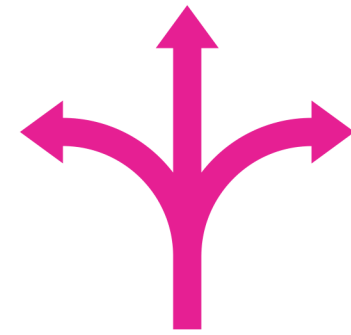
“Some people don’t have access to digital technologies.”

“How it's advertised is important.”

“I don’t trust my personal information on social media.”



FLEXIBILITY



- Expecting public contributors to fit into the research world.
- Meetings only held at university/hospital sites.

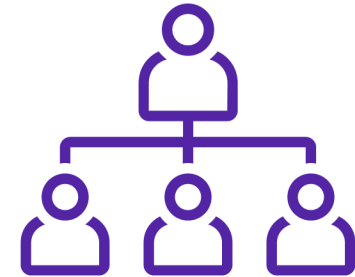
- USE COMMUNITY / FAMILIAR LOCATIONS
- CONSIDER EVENING / WEEKEND MEETINGS
- BE MINDFUL OF ACCESSIBILITY

“It's not really accessible for people who are working full time, managing their families, people who are carers.”

“You need to cater for people's mental health, physical disabilities, finances - so everyone can participate in the same way.”



ELIMINATING HIERARCHIES



- A feeling of inherent hierarchies within research.
- A need to bring equity to PPI meetings and events in order for people to feel comfortable and able to speak their opinions.

- GO INTO COMMUNITIES
- GIVE A BIT OF YOURSELF
- GIVE COMMUNITIES OWNERSHIP

“Researchers are stuck in universities, in hospitals. It all seems so secretive.”

“When you drop the badges and the hierarchy it creates a level playing field. The barriers start to disappear.”



COMMUNITY



- Faith or community leaders can help gain the trust of under-served communities.
- Taking research out of universities and into the community.

- FIND A TRUSTED INDIVIDUAL / COMMUNITY LEADER
- DON'T UNDERESTIMATE THE POWER OF COMMUNITIES

“If you want to reach these groups, you’ve got to work through trusted professionals who are in the community.”

“By going into the community, you’re making a massive change.”



RECOGNITION



- What is in it for me?
- Not necessarily monetary, but may be about recognition, altruism, a feeling of helping others.

- INCENTIVE IS IMPORTANT
- BE AWARE OF TAX AND BENEFIT IMPLICATIONS
- CONSIDER ALTERNATIVE FORMS OF RECOGNITION

“I want to do it because it’s doing some good.”

“I’m on a low income so if someone says, ‘we’ll give you a voucher’, that’s going to pay for my shopping this week.”

“Incentive can be anything, even from just saying ‘Thank you’. It’s about recognition.”