

# Barriers to Participation for Marginalised Groups in Mental Health Research

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# General Barriers to participation for marginalised groups

People belonging to marginalised and/or vulnerable groups are less likely to take part in participatory research due to:

- Lack of access to resources (time, money, mobility, education...)
- Lack of access to information (how to participate, aims and objectives...)
- Lack of accessible participation formats (e.g. sign language translation)
- Power or resources differentials (within patient community and between patients and researchers)
- Inappropriate or insufficient incentives (e.g. monetary rewards whilst claiming benefits)
- Researcher bias/stereotyping
- Lack of researcher skill in outreach-based recruitment and involvement methods
- Lack of trauma-informed methodologies
- “Consultation fatigue” on part of patients as a result of negative experiences

# Barriers to participation in mental health research

In mental health research, additional barriers can prevent people with lived experience from participating in research:

- Mental health stigma (patients perceived as unreliable or lacking insight)
- Informed Consent challenges
- Issues with confidentiality in group settings
- Lack of trust due to negative experiences with services
- Lack of accessibility in PPIE activities (e.g. in-person meetings requiring travel only)
- Conflict within patient communities or between researchers and patients (e.g. controversial or politicised MH topics)
- Lack of researcher training and resources
- Neurotypical bias (e.g. expectation of small talk/eye contact at meetings)

# Barriers to participation for Black people and PoC

People who are racialised or who are marginalised due to their ethnicity may face additional barriers to participation:

- Structural and institutional racism extend into research and PPIE contexts
- Mistrust in medical research due to long history of abuses, betrayal and trauma
- Barriers to mental health care lead to lack of information
- Suspicion of being exploited or “data mined” without fair compensation and respect
- Resource and power imbalances between researchers and patients
- Lack of appreciation of differences between communities

In mental health research also:

- Lack of cultural knowledge in MH research (e.g. culturally different interpretations of symptoms)
- In some communities, cultural taboos around mental health
- Racial stereotypes can impact (mis)diagnosis

→ Compounding effect of mental health stigma and minority status

“Black African-, Asian- and Caribbean-heritage people remain significantly under-represented in our public involvement community” (NIHR Race Equality Public Action Group)

# **(Some) ways to overcome these barriers**

For marginalised groups you are not a member of:

- Listen and double check interpretations with participants
- Interpret as little as possible, communicate data as authentic as possible
- Defer to lived experience
- Acknowledge own positionality, complicity in structural racism and history of ethical misconduct in medical research

For marginalised groups you are a member of:

- Be open about experience without generalising to others
- Speak as a peer, not an authority
- Approach accessibility from a lived experience perspective, including in methods training
- Acknowledge and manage difficult topics such as self harm
- Recognise a crisis and have a response plan