NIHR Policy Research Unit Children and Families

How can we make research studies more accessible and culturally relevant to Black people with mental health issues who are also survivors of violence and abuse?

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Background

As they developed the core outcome sets, Claire and Emma realised they had not involved a wide enough group of survivors. With a 'Listen & Learn' grant from UCL Public Engagement, Claire and Emma held a listening event with Ursula and Allia on 21st July 2021 to understand how they could have engaged Black survivors more effectively. What follows is a summary of learning and what researchers can do to make their studies more accessible and culturally relevant.

Researchers and Relationship-Building

- White researchers are a barrier: don't understand language, culture, experience
 of racism; use token black staff members without any power to change things to
 make initial connections.
- Older professionals can diminish the feelings and experiences of young people.
- Researchers parachute into Black organisations without trying to build a relationship first and expect support and input. 'They pillage our lived experiences, trauma, knowledge, skills and pain. The expect us to give them all of this for free or expect us to volunteer or time for free. They then parachute back out and turn everything they've pillaged from us into funding bids, and we never share in that or know what they do with the information they have.'
- Lack of lived experience researchers who are open about their experiences of violence and abuse: sharing experience is important for relationship-building

What can we do?

→ 'Educate, educate, educate – your PhD can't help you!': Bring in trainers on microaggressions, make training ongoing learn about importance of community, church and family. Support black colleagues in the workplace and learn how we might put research participants on edge through missing body language/sounds/ gestures. Learn about Black culture, history and how to talk about racism.

 \longrightarrow Build relationships over time: ask for an initial meeting, talk outside the research, build trust first.

→ Think about language: words like 'victim' are not straightforward, people might not understand or feel it applies; likewise, BAME is problematic – be specific and say African-Caribbean.

 \rightarrow Recruit researchers from a range of ages and cultures, who are 'out' about their lived experience at all levels.







Mental Health

- Eurocentric approach to mental health is a barrier and results in white organisations and the ones holding the funding labelling Black communities as 'difficult to engage' when it's the approach that's a problem.
- Problem with stereotypes of strength, not allowed to be vulnerable c.f. backlash against Naomi Osaka.
- 'We are forced to be comfortable with whiteness', this involves code switching and 'making ourselves small'.
- Approaches to professionals are different: 'GPs are a waste of time'; health services are inaccessible and alienating. Very difficult to access Black mental health professionals. More likely to talk openly to a hairdresser.

What can we do?

 \rightarrow Don't come in and tell us how you're going to do it, fit in with us.

 \rightarrow Be an ally by 'walking beside', be prepared to be the 'only white in the village'in a black majority space so you have some idea of what it feels like.

→ Need to take a collaborative approach and use events to build connections. Needs to be an organisation like Adira that hosts the event: relaxed, free food, free tickets, engaging, think about publicity.

 \rightarrow Strengthen the Black research community: offer placements (but with support), needs to be meaningful.







Research Process: 'Don't mine our pain and trauma'

 \rightarrow Be aware you can 'open a pandora's box of harm' when you go in too quickly too fast.

→ Don't ask participants to provide input for free and be flexible around vouchers/payments 'I can't eat vouchers'. Be upfront and transparent so people can say no.

 \rightarrow Don't have information about incentives in the first contact/advert, talk about these after participants have made an initial contact.

 \rightarrow Don't act as if you're the black person and as if you've lived it, you haven't.

 \rightarrow For shared experiences of violence and abuse, acknowledge the difference but you can still connect on the pain.

 \rightarrow Think about the setting: is the place informal, comfortable, and familiar? Health or formal research settings might not work, specially for young people.







The NIHR Children and Families Policy Research Unit is hosted by UCL Great Ormond Street Institute of Child Health

