

Exploring barriers and facilitators to Black people’s participation in psychiatric and psychological research in the UK

Repeated Assessment of Mental Health in Pandemics Study in collaboration with #WOKEWeekly UK

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The RAMP study is a longitudinal research project examining mental health in the UK in the wake of the COVID-19 pandemic: <https://rampstudy.co.uk/>

#WOKEWeekly UK is a community organisation who host debates and discussion centered around and beyond the UK Black community: <https://www.wokeweekly.co.uk>

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Background and planning

Despite reports indicating that profound racial inequalities exist in the UK for accessing mental health treatment, receiving appropriate care, and reaching equal health outcomes¹, Black people are still grossly under-represented in clinical and health research². Studies continue to draw their samples from almost entirely Western, educated, industrialized, rich and democratic (WEIRD) societies³, which impacts the ability of research to produce valid and generalisable knowledge that improves understandings of the aetiology and treatment of psychiatric disorders among Black communities. Notably, this is also true of COVID-19 research where despite the disproportionate burden of morbidity and mortality for the disease⁴, few studies have considered the mental health of Black people⁵. This is significant as the grief associated with COVID-19 deaths and stress of unemployment and social isolation may increase the risk of anxiety, depression, posttraumatic stress and substance abuse amongst these communities^{6,7}.

By including Black communities in psychiatric and psychological research, researchers can account for the diversity of human experiences to affect policies, the allocations of resources and address existing mental health inequalities⁸. However, reasons for the under-representation of Black people in mental health research are multifaceted and largely informed by epidemiological or clinical control/intervention trials in the US⁹. Few UK studies have sought to understand the influencers of Black people's participation in mental health research. This impedes investigators' abilities to develop and employ strategies which

¹ The Mental Health Act Review African and Caribbean Group. (2019). *Independent Review of the Mental Health Act 1983: supporting documents*. United Kingdom. Retrieved from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/778898/Independent_Review_of_the_Mental_Health_Act_1983_-_supporting_documents.pdf

² Smart, A., & Harrison, E. (2017). The under-representation of minority ethnic groups in UK medical research. *Ethnicity & Health*, 22(1), 65-82. doi:10.1080/13557858.2016.1182126

³ Henrich, J., Heine, S. J., & Norenzayan, A. (2010). The weirdest people in the world? *Behavioural and brain sciences*, 33(2-3), 61-83. doi:10.1017/S0140525X0999152X

⁴ Public Health England. (2020). Beyond the data: Understanding the impact of COVID-19 on BAME groups. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_beyond_the_data.pdf

⁵ O'Connor, R. C., Wetherall, K., Cleare, S., McClelland, H., Melson, A. J., Niedzwiedz, C. L., & Robb, K. A. (2020). Mental health and well-being during the COVID-19 pandemic: longitudinal analyses of adults in the UK COVID-19 Mental Health & Wellbeing study. *The British Journal of Psychiatry*, 1-8. doi:10.1192/bjp.2020.212

⁶ Lob, E., Frank, P., Steptoe, A., & Fancourt, D. (2020). Levels of severity of depressive symptoms among at-risk groups in the UK during the COVID-19 pandemic. *JAMA Network Open*, 3(10), e2026064-e2026064. doi:10.1001/jamanetworkopen.2020.26064

⁷ Chandola, T., Kumari, M., Booker, C. L., & Benzeval, M. (2020). The mental health impact of COVID-19 and lockdown-related stressors among adults in the UK. *Psychological medicine*, 1-10. doi:10.1017/S0033291720005048

⁸ Bhopal, R., Wild, S., Kai, J., & Gill, P. S. (2007). Health Care Needs Assessment: Black and Minority ethnic Groups. The Epidemiologically Based Needs Assessment reviews. Abingdon: Radcliffe Medical Press Ltd. Retrieved from <https://era.ed.ac.uk/bitstream/handle/1842/2740/HNA+health-care+needs+assessment.pdf?sequence=1>

⁹ George, S., Duran, N., & Norris, K. (2014). A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. *American Journal of Public Health*, 104(2), e16-e31. doi: 10.2105/AJPH.2013.301706

successfully recruit Black people, and thus lead to research findings which can inform health care practices and policies¹⁰.

Aims and logistics

The Repeated Assessment of Mental Health in Pandemic (RAMP) study investigators aimed to explore the barriers to Black people's participation in psychiatric and psychological research using a focus group design. This was particularly relevant to RAMP researchers as demographic data from their own study revealed that only 76 out of 8,651 participants identified as Black or Black British. Considering data was included in reports to UK government departments on the mental health and wellbeing impact of COVID-19, it became imperative for RAMP researchers to understand the processes for devising and implementing inclusive study designs.

To ensure that focus group questions and processes were relevant to Black communities, RAMP researchers approached #WOKEWeekly to co-design and facilitate the session. #WOKEWeekly were uniquely placed to deliver the focus group, as an organisation that regularly hosts debates and discussions on a range of subjects relevant to the UK Black community. Their audience regularly includes Black-centric university societies such as African & Caribbean Societies and Black, Asian and Minority Ethnic societies.

Following two consultation meetings held with RAMP investigators and #WOKEWeekly executives on 10 November 2020 and 3 December 2020, focus group questions, participants, recruitment, facilitators and processes were identified and agreed by both parties. Fostering a collaborative approach to designing the session ensured that the focus group adopted culturally sensitive, appropriate and ethical strategies for engaging participants. For example, #WOKEWeekly executives stressed the importance of facilitating open conversations and mutual knowledge sharing amongst researchers and participants. Correspondingly, the main aim of the session was confirmed:

Aims:

- To discuss the barriers and facilitators of Black people's participation in psychiatric and psychological research.

It was also important for RAMP investigators to demonstrate how outputs of the session will be used to inform future research. Thus, preliminary plans for disseminating the sessions findings amongst the academic community were communicated. These included:

- Delivering presentations to academics at the Social, Genetic & Developmental Psychiatry Centre (SGDP), King's College London on strategies for reducing the barriers and facilitating Black people's participation in psychiatric and psychological research.

¹⁰ Redwood, S., & Gill, P. S. (2013). Under-representation of minority ethnic groups in research—call for action. *British Journal of General Practice*, (612), 342-343. doi:10.3399/bjgp13X668456

- Informing and advising academics at the SGDP, King’s College London on how to effectively enhance ethnic diversity in research samples via a bespoke handbook (currently in preparation).

The focus group was scheduled for the 7th December 2020, 17:00 to 19:00 GMT and advertised via #WOKEWeekly’s and RAMP’s social media platforms (including Twitter, Instagram and Facebook) from 13 November 2020 to 6 December 2020. Participants' sign up was facilitated using Eventbrite and a £25 Amazon voucher offered as reimbursement for time spent participating. Zoom was the preferred conferencing platform for focus group hosting due to its convenience for participants.

Ethical considerations

Informed consent was indicated via participants remaining on the zoom call after the aims of study were communicated. Participants could leave the session at any point by leaving the zoom call. Field notes collected did not record any identifying characteristics of participants and were stored in a word document that only RAMP researchers had access to. A mental health practitioner of Black ethnicity was commissioned to support participant wellbeing following any sensitive or triggering discussions.

Participants

A total of 11 individuals attended the focus group session. Summaries of participants ethnic background and age were provided by #WOKEWeekly to maintain confidentiality of participant identities. A summary of their demographic characteristics can be found in Table 1.

Table 1
Demographic Characteristics of Focus Group Participants

| Ethnicity | Count |
|-------------------------|-------|
| Black British African | 9 |
| Black British Caribbean | 1 |
| Black African | 1 |
| Age | Count |
| 17 | 1 |
| 19 | 1 |
| 21 | 2 |
| 22 | 2 |
| 23 | 2 |
| 24 | 1 |
| 25 | 1 |
| 25> | 1 |

Findings and recommendations

Several thoughts, opinions and experiences on the barriers to Black people’s participations in psychiatric and psychological research were discussed. These are grouped into themes and discussed below with reference to previous research. Recommendations on strategies for researchers to implement immediately and long-term are presented subsequently. Whilst categorised according to the barrier it most closely relates to, it should be acknowledged that recommendations may lead to benefits across a range of themes.

Action and social change

The paucity of research aiming to seek and action transformative change within Black communities acted as a significant barrier to engagement within research. Participants emphasised that ‘research is not just a pile of paper’ and that ‘you [researchers] need to do something with those papers’ otherwise ‘what is the point?’. Another participant enquired ‘how much research do you need to do before you make a difference?’. These observations indicate the value of research which is conducted for the purposes of creating social change. Specifically, findings which helped address the continued social injustices experienced by racialised minority groups were perceived as ‘tangible outcomes’ which if demonstrated by research, would encourage participation.

Recommendations

- Investigators should practice participatory action approaches to research which supports development of knowledge for social change and participant empowerment¹¹. This includes collaborating with participants during the design, implementation, interpretation and dissemination phases to understand how research can be used to have a social impact.

Cultural competence and representation

Cultural competence in research refers to ‘the ability of researchers and research staff to provide high quality research that takes into account the culture and diversity of a population’¹². In line with previous research, observed lack of cultural competence amongst research staff was suggested as an obstacle for Black people when participating in research¹³. Participants noted that investigators often failed to incorporate the cultural perspectives and experiences of Black people, and thus wrongly assumed their lived experiences. As an example, one participant highlighted that when partaking in a study, ‘African foods’ was not

¹¹ Kidd, S. A., & Kral, M. J. (2005). Practicing participatory action research. *Journal of Counselling Psychology*, 52(2), 187. doi: 10.1037/0022-0167.52.2.187

¹² Harvard Clinical and Translational Science Centre. (2010). Cultural competence in research. Retrieved from <https://catalyst.harvard.edu/pdf/diversity/CCR-annotated-bibliography-10-12-10ver2-FINAL.pdf>

¹³ Hughson, J. A., Woodward-Kron, R., Parker, A., Hajek, J., Bresin, A., Knoch, U., & Story, D. (2016). A review of approaches to improve participation of culturally and linguistically diverse populations in clinical trials. *Trials*, 17(1), 263. doi: 10.1186/s13063-016-1384-3

included as an option for types of food consumed. This highlights the need for research to acknowledge and respond to cultural differences within their study design and implementation. A culturally matched research team which reflected the ‘lived experience’ of Black communities was emphasised as a solution to perceived lack of cultural competence amongst investigators. It would also assure participants that data would be contextualised according to the Black communities’ socio-cultural experiences i.e., historical and systematic racism.

Recommendations

- Studies should aim to recruit a ‘lived experience’ representative or ensure lived experience amongst its research team when developing research ideas, conducting research, and exploring applicability of research findings.
- Research staff should equip themselves with cultural competence skills, and knowledge of the Black communities’ cultural experiences and perspectives to enhance interaction and communication with Black populations¹⁴. This can be facilitated through attending cultural competence training, events hosted by Black communities or collaborating with Black-led mental health charities. Undertaking these actions will require a budget incorporated in research grants.

Mistrust of system

A history of systemic racism in the healthcare system has led to mistrust in clinical and health research amongst Black communities¹⁵. This was mentioned in focus group discussions where one participant expressed that witnessing their friends and family receive ‘inadequate medical care’ based on their ethnicity increased reluctance to engage in health-related research. The disproportionate mortality of Black women compared to White women during pregnancy or childbirth in the UK was referenced as a further example¹⁶. The metaphor of feeling like a ‘guinea pig’ to reference experiences of participants' input in research being disregarded due to their race was often restated. For instance, a participant expressed that they ‘fear [feared] that my response may not be taken seriously as a Black person’ as ‘it is common in society that our [Black peoples’] opinions have been pushed aside or dumbed down’. There was further worry over whether findings will be ‘misused’ by researchers to propagate narratives which ‘damage’ the community. Demonstrating how research will not perpetuate these injustices should be a key activity for investigators aiming to recruit Black people.

¹⁴ Harvard Clinical and Translational Science Centre. (2010). Cultural competence in research. Retrieved from <https://catalyst.harvard.edu/pdf/diversity/CCR-annotated-bibliography-10-12-10ver2-FINAL.pdf>

¹⁵ Scharff, D. P., Mathews, K. J., Jackson, P., Hoffsuemmer, J., Martin, E., & Edwards, D. (2010). More than Tuskegee: understanding mistrust about research participation. *Journal of Health Care for the Poor and Underserved*, 21(3), 879. doi: 10.1353/hpu.0.0323

¹⁶ Knight, M., Bunch, K., Kenyon, S., Tuffnell, D., & Kurinczuk, J. (2020). A national population-based cohort study to investigate inequalities in maternal mortality in the United Kingdom, 2009-17. *Paediatric and Perinatal Epidemiology*, 34(4), 392-398. doi: 10.1111/ppe.12640

Recommendations

- A visible demonstration of the research teams’ commitments to excellence in research by advancing equity, diversity and inclusion (EDI) should be observed by participants. This can be exemplified through an EDI statement which acknowledges present challenges faced by Black ethnic minority groups in mental health and current or future staff involvement in EDI research and activities i.e., mentorship, education and community service.

Altruism

Participating in research to increase scientific knowledge on Black people’s mental health and thus acquire ‘insights’ to support the Black community and its future generations was a common theme. Focus group participants highlighted that by engaging in research they wanted to stop ‘future generations from experiencing the same injustices’ they experienced and ‘help future people of similar characteristics’. They emphasised that their ‘opinions have value’ and would want it ‘to contribute to something bigger and better’ for their community. Previous research has also cited altruism towards the Black community as a strong facilitator for Black people’s participation in research¹⁷. Implications from this would suggest that psychiatric and psychological research needs to demonstrate its direct and long-term benefit to Black communities i.e., addressing racial disparities in mental health care.

Recommendations

- Researchers should aim to engage with Black communities by attending Black issue focused events, consulting Black-led mental health charities or key representatives and hosting public and patient involvement events to gauge an understanding of how research can specifically benefit Black communities. Subsequently, key themes identified should be integrated within the study aims and communicated on advertisement platforms.

Concerns with research processes

The focus group highlighted that lack of experience, knowledge and awareness of research processes and its translation into policies impacted their engagement in psychiatric and psychological research. Misgivings around how data is kept confidential were of particular concern. This was due to fears around the possible disclosure of participants or associates immigrational status. Apprehensions around data usage is commonly observed in clinical and health research¹⁸. Increasing the visibility and usefulness of research within early, secondary and higher education was suggested.

¹⁷ Farmer, D. F., Jackson, S. A., Camacho, F., & Hall, M. A. (2007). Attitudes of African American and low socioeconomic status white women toward medical research. *Journal of Health Care for the Poor and Underserved*, 18(1), 85-99. doi: 10.1353/hpu.2007.0008

¹⁸ Freimuth, V. S., Quinn, S. C., Thomas, S. B., Cole, G., Zook, E., & Duncan, T. (2001). African Americans’ views on research and the Tuskegee Syphilis Study. *Social Science & Medicine*, 52(5), 797-808. doi:10.1016/S0277-9536(00)00178-7

Recommendations

- Research teams should employ education outreach officers or host events/workshops/training sessions which inform the public on the utility of research, the design and implementation process. This approach supports the development of research skills and knowledge and acts as an essential part of EDI activity¹⁹.
- Information on how data is kept confidential and anonymous should be presented in clear, visible and innovative formats i.e., descriptive videos or illustrations to effectively address concerns with participating²⁰.

Monetary and non-monetary incentives

Monetary and non-monetary incentives are known to positively influence participation in clinical and health research²¹. Focus group participants emphasised this during discussions and indicated that ‘money’, ‘amazon vouchers’, ‘food’ and the opportunity to network with ‘link minded’ individuals facilitated participation in research. The value of incentives was particularly noted by one participant who used Maslow’s Hierarchy of Needs to argue that supporting one’s basic and psychological needs will motivate individuals to participate in studies. This would ensure that participation was worthwhile and reimbursement for any time or financial losses to the individual was provided.

Recommendations

- Budgets for culturally appropriate monetary and non-monetary incentives in research should be included in grant applications.
- Study designs should incorporate opportunities for participants to network with each other, potentially after the research study at dissemination events. This would provide opportunities for researchers to engage with the communities and individuals they are investigating.

Cultural barriers

Negative perceptions of and stigma against mental health is prevalent among Black communities²². This has been shown to act as a barrier to participating in mental health related research²³. Focus group participants acknowledged this by stating their reluctance to ‘share experiences’ of psychological distress or be ‘vulnerable’ in mental health-related

¹⁹ Santoyo-Olsson, J., Cabrera, J., Freyre, R., Grossman, M., Alvarez, N., Mathur, D., ... & Stewart, A. L. (2011). An innovative multi phased strategy to recruit underserved adults into a randomized trial of a community-based diabetes risk reduction program. *The Gerontologist*, 51, S82-S93. doi: 10.1093/geront/gnr026

²⁰ McDougall, G. J., Simpson, G., & Friend, M. L. (2015). Strategies for research recruitment and retention of older adults of racial and ethnic minorities. *Journal of Gerontological Nursing*, 41(5), 14-23. doi: 10.3928/00989134-20150325-01

²¹ George, S., Duran, N., & Norris, K. (2014). A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. *American Journal of Public Health*, 104(2), e16-e31. doi: 10.2105/AJPH.2013.301706

²² Memon, A., Taylor, K., Mohebati, L. M., Sundin, J., Cooper, M., Scanlon, T., & de Visser, R. (2016). Perceived barriers to accessing mental health services among black and minority ethnic (BME) communities: a qualitative study in Southeast England. *British Medical Journal Open*, 6(11).

²³ Murphy, E., & Thompson, A. (2009). An exploration of attitudes among black Americans towards psychiatric genetic research. *Psychiatry: Interpersonal and Biological Processes*, 72(2), 177-194. doi: 10.1521/psyc.2009.72.2.177

research. Cultural expectations to not disclose issues relating to oneself or familial background was also mentioned. These findings suggest that considerable mental health literacy and practical support to raise awareness and combat stigma of mental health is required amongst Black communities before recruiting to research.

Recommendations

- Providing culturally appropriate and sensitive mental health training sessions, workshops or information leaflets for members of the Black community should be provided by research teams before recruiting to study. This approach has been found to create much success in recruiting lower socioeconomic and ethnic minority groups in clinical and health research²⁴.

Implementation of recommendations

On 18 February 2021, RAMP investigators established plans for implementing recommendations in future studies at the Social, Genetic and Developmental Psychiatry (SGDP) centre, King’s College London. These are highlighted below with mention of actions already undertaken by the RAMP team prior to and proceeding the focus group session:

- *Action and social change* – Participatory action approaches to research are currently employed within the Repeated Assessment of Mental Health in Pandemics-Youth (RAMP-Y) study (an extension of the main RAMP study, focusing on long-term effects of the pandemic among young people). This includes the development of a patient and public advisory group which inform RAMP-Y researchers on how the study’s aims, design and findings can be used to support action and social change amongst Black communities. The advisory group will recruit members of Black British or African/Caribbean backgrounds from established research partnerships with Black community-based organisations i.e., #WOKEWeekly and Dope Black Dads. Further collaborations will be sought to ensure that a range of perspectives from the Black community are represented and findings disseminated to groups who can directly affect change e.g., Black Thrive and Thrive LDN.
- *Cultural competence and representation* – A Diversity Consultant of Black ethnicity was recruited in July 2020 to help facilitate RAMP researchers’ cultural knowledge and competence skills via diversity training and consultation on issues pertaining to Black communities. Further education and engagement with Black communities was facilitated when participating in community led events i.e., ‘Psychiatry in Depth’ or ‘In Conversation with Black Professors in Mental Health’. A Black psychiatrist was also recruited in November 2020 to support data interpretation on RAMP. It was agreed that these actions will be sustained across future research studies i.e., RAMP-Y, to support continuous learning and cultural congruence amongst research teams.

²⁴ Santoyo-Olsson, J., Cabrera, J., Freyre, R., Grossman, M., Alvarez, N., Mathur, D., & Stewart, A. L. (2011). An innovative multiphased strategy to recruit underserved adults into a randomized trial of a community-based diabetes risk reduction program. *The Gerontologist*, 51, S82-S93. doi: 10.1093/geront/gnr026

- *Mistrust of system* – RAMP researchers wish to further support and build transparent relationships with members of Black communities. As such, volunteering in widening participation schemes i.e., Brilliant Club, Aspire and King’s Scholars at King’s College London, engaging in SGDP Race Equality Working Groups and providing monetary and visible support to Black causes have been embarked upon or explored for future work. Commitments to these activities will be communicated in EDI statements via future study web and social media pages to ensure accountability.
- *Altruism* – Recruitment campaigns for future studies at the SGDP will aim to communicate the benefits of participating for Black communities. These will be informed by patient and public advisory groups and established partnerships with Black community-based organisations.
- *Concerns with research processes* – Regular (i.e., monthly) drop-in-sessions for participants to acquire knowledge on research processes and data usage will be considered as a long-term strategy for minimising research concerns amongst participants. More accessible formats for informing participants on data confidentiality and anonymity i.e., video or illustrations, have been used in the Genetic Links to Anxiety and Depression (GLAD) study and are contemplated for use in the RAMP-Y study.
- *Monetary and non-monetary incentives* – Replicating approaches used in the RAMP study, a budget for culturally appropriate monetary and non-monetary incentives will be included in future grant applications. The monetary value of incentives offered to participants will be informed by patient and public advisory groups. To support networking amongst participants and wider dissemination of results, the use of public-facing research conferences will be explored by RAMP researchers. This could provide opportunities for researchers and participants to discuss and present research interests after a study’s conclusion.
- *Cultural barriers* – Patient and public advisory groups and partnerships with Black community-based organisations will be consulted to acquire insight on methods for addressing potential cultural barriers to future research. The potential for facilitating mental health workshops and events amongst Black communities to help raise awareness and combat stigma of mental health is also plausible. This will be supported by partnering with Black community-based organisations and/or Black mental health practitioners.

RAMP investigators are overall committed to research excellence through equity, diversity and inclusion within the academic setting. Findings and recommendations from this report have thus been disseminated at SGDP centre seminars, King’s College London’s EDIT Lab and the GLAD study for wider implementation. Plans for further dissemination include sharing findings with other researchers across the Institute of Psychiatry, Psychology and Neuroscience at King’s College London, beyond academia including publishing in the Psychologist Magazine and RCPsych Insight and sharing with the RAMP study research partners.