

Participant Information Sheet

Helping you decide whether or not to join our study.

We would like to invite you to join our study and want you to know what is involved before you decide. Please read this information sheet carefully.

This information is also available online: www.bristol.ac.uk/black-brown-bioethics

Invitation and Brief Summary

You are invited to participate in a study that is being conducted by researchers at the University of Bristol in collaboration with researchers at the University of Oxford. The study is funded by the Institute of Medical Ethics. The study is being conducted as part of a wider project, 'Black and Brown in Bioethics', which aims to work towards equity for people of colour within the UK bioethics community.

Part 1 of this information sheet tells you the purpose of the study and what will happen if you take part. Part 2 gives you more detailed information about the conduct of the study.

Before you decide whether to take part it is important that you understand why the research is being done and what it will involve. Please read this information carefully and discuss it with others if you wish.

Part 1

1. What is the 'Being Black and Brown in Bioethics' study?

- The full title of the study is 'Being Black and Brown in Bioethics (BBBB): A qualitative study into the experiences of postgraduate researchers in in racially minoritised groups'.

2. What is the study about?

- There is growing evidence of racial inequity in academia and healthcare. Bioethics postgraduate researchers (PGRs) are students working at the intersection of these two systems, yet the experiences of minoritised ethnic Postgraduate researchers (PGRs) working in bioethics, which is at the intersection of academia and healthcare, are comparatively underexplored. Indeed, much of the literature on racism within academia focuses on and reflects the culture within US institutions.
- This study follows on from existing efforts to engage with meaningful and high-quality inclusive research. We hope that by learning from both positive and negative experiences, this study will take important initial steps in improving research culture within UK bioethics.

3. What are the study aims?

- This study aims to understand the experiences of PGRs from minoritised ethnic backgrounds working in UK bioethics, by investigating whether and to what extent they are affected by (in)direct racism.
- The study also aims to identify possible strategies for reducing racial inequity in bioethics.

4. Who is organising this study?

- The study is being led by Harleen Kaur Johal (Principal Investigator), a PhD Candidate and NIHR Academic Clinical Fellow, with an interest in racial disparities.
- The wider research team includes:
 - Nako Abdullah (Research Associate) – PhD Candidate, University of Bristol
 - Matimba Swana (Co-Investigator) – PhD Candidate, University of Bristol
 - Kumeri Bandara (Co-Investigator) – DPhil Candidate, University of Oxford
 - Mehrunisha Suleman (Co-Investigator and Academic Advisor) – Director of Medical Ethics and Law Education at the Ethox Centre, University of Oxford
 - Zuzana Deans (Co-Investigator and Academic Advisor) – Senior Lecturer at the Centre for Ethics in Medicine, University of Bristol

5. Who is funding the study?

- The study is funded by the Institute of Medical Ethics, a charity which promotes and supports the impartial study and understanding of medical ethics and its integration into clinical practice through education, research, and publication.

6. Who has been invited to take part?

- All PGRs, who identify themselves as being from a minoritised ethnic background and are currently undertaking research in bioethics, are invited to participate.
- Former PGRs, that completed their studies in bioethics within the last three years, are also invited to participate.
- Your postgraduate research degree could be at either master's or doctoral level.
- Postgraduate taught students in bioethics, are not eligible to participate.
- Other criteria that determine your eligibility are:
 - You must be an adult.
 - You must be able to understand and consent to participating in the research.
 - The institution, at which you have undertaken your postgraduate research degree, must be in the UK.

7. Why have I been asked to take part?

- We want to make sure that the voices of PGRs from minoritised ethnic backgrounds working in UK bioethics are heard, and that their experiences are understood.
- The findings of this study will be published and shared with higher education institutions and relevant organisations (e.g., the Institute of Medical Ethics, the European Association of Centres of Medical Ethics) to ensure that common barriers to racialised higher education experience can be identified and addressed.

8. How do I participate?

- The study is being conducted online in three phases: a survey, a follow-up interview, and a workshop.
- To take part in the study, you will first need to complete the online survey. and provide an overview of your PGR experience.
- After completing the survey, you can express your interest in participating in an online follow-up interview. Participation in an interview is optional.

- After completing the survey, you can also express your interest in participating in the online workshop. Participation in this workshop is optional.

9. What will taking part involve?

- The survey:
 - The survey is being conducted online and will take up to 20 minutes to complete.
 - This will involve completing: an eligibility check, a pre-survey consent form, questions about your background and demographic information, and questions about racism that you have (in)directly experienced as a PGR in UK bioethics.
 - You will be asked to confirm your consent after completing the survey.
 - The survey is anonymous.
 - After completing the survey, you will have the option to express your interest in participating in an interview and the online workshop, by completing a separate form. If you do express an interest in participating in either of these, you will be asked to provide your contact details.
- The in-depth interview:
 - If you indicate that you would like to participate in an online in-depth interview, a member of the research team will then contact you via email and answer any further questions you may have about the study, including addressing any concerns.
 - If you are still interested in participating, the researcher will arrange a time (at least five days later) to meet with you online. You will have this time to think about whether you want to take part or not.
 - When you meet with the researcher, they will give you a further opportunity to ask questions about the interview part of the study and explore any concerns that you may have.
 - If you are happy to take part, they will ask for your consent electronically (either as a verbal recording or on an electronically signed form). A copy of your consent will be given to you and the original will be kept by the researcher.
 - With your agreement, the researcher will ask you more detailed questions about your experiences of being a PGR in bioethics in the UK.
 - This discussion will take place as part of an interview, which is expected to take 45- 60 minutes.
 - If you agree, the interview will be audio recorded for later analysis by the researcher.
- The workshop:
 - After your participation in the survey, interview, or both, you will be able to express your interest in attending an online workshop where the study findings will be shared.
 - The research team will also seek feedback from participants on their experiences of participating in the study. Participants will be asked how they would improve the study if it was replicated in the future.
 - Discussions will be facilitated in small groups via breakout rooms.

10. What are potential disadvantages of taking part in the study?

- You may find discussing the topic upsetting, and it may remind you of stressful or difficult episodes you have witnessed or personally experienced.

- Should you find the interview distressing, you will be able to stop it at any time, and the researcher will give you a chance to wind down and reflect on these emotions.
- The time it takes to participate is also a disadvantage.

11. Are there any benefits to taking part?

- There may be no direct benefits to taking part, although you may find talking about your experiences gives an outlet for your feelings.
- The main benefit of the study will be to contribute to research that aims to improving research culture within UK bioethics.
- We hope that having a better understanding of the experiences of PGRs from minoritised ethnic backgrounds working in UK bioethics, will enable us to identify possible strategies for reducing racial inequity.

12. Is the data from the study confidential?

- Yes, the data from the study is confidential. All the information you give us will be anonymised and only used for research purposes. This information will only be accessed by members of the research team when necessary for data analysis.
- We may use transcription services (e.g., UK Transcription Limited) to transcribe interviews, however we will only use services that have been approved by the University of Bristol and asked to sign a confidentiality agreement.
- You will be asked to give consent to the University of Bristol to record and process the information you give for research purposes.
- Neither your name nor personal details will be reported in any research papers or written reports. These may include some quotations from interviews. We will make sure no one can work out who you are from the reports we write.
- An exception to this confidentiality would be a disclosure of serious criminal wrongdoing (for instance something that may have harmed or presently endanger a vulnerable person). Such a disclosure could not be kept in confidence and would need to be passed on to the appropriate authorities.
- Furthermore, due to the nature of a workshop, your participation in the online workshop will be known to other workshop participants. All workshop participants will be asked to respect each other's confidentiality.

13. How will my data be stored?

- The University of Bristol is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and we will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.
- Anonymised electronic data will be stored on password protected computers for 20 years in accordance with the University of Bristol's research governance policy.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

This completes Part 1 of the information sheet.

If the information in Part 1 has interested you and you think you may wish to participate, please continue to read the additional information in Part 2 before making a final decision.

Part 2

14. What will happen if I don't want to carry on with the study?

- Your participation is voluntary and if you decide to take part you will be free to withdraw at any time, without giving a reason.
- You will not be able to withdraw your survey data, as survey responses are anonymous, and it will not be possible to identify your data following submission of your survey response.
- If you would like to withdraw your interview data, please let us know by sending an email to: bbb-study@bristol.ac.uk
- You can withdraw all of your interview data up to 7 days after your interview.
- After 7 days, your interview data will be anonymised and analysed and cannot be removed from the study completely.
- If you wish to withdraw from the study after 7 days, you can do so without giving a reason, but we will retain the use of your data in our analysis. However, we will endeavour not to use direct quotations from you in any publications, presentations, or outputs that follow.
- It will not be possible to withdraw from the study at all once the data has been presented or submitted for publication.
- Withdrawing from the study or declining participation will have no repercussions upon your employment, or future institutional treatment by the study sponsor, funder, or any affiliated organisations. Withdrawing will not have an impact on your future engagement with the Black and Brown in Bioethics network.

15. What will happen to the results of the study?

- After the workshop, when the study has concluded, a summary of the results will be posted on the Black and Brown in Bioethics website, and emailed to all participants that shared their contact details.
- The study results will be published in bioethics journals.
- The study results will also be presented at scientific conferences and research seminars to circulate them as widely as possible.
- There may also be an opportunity to attend public events, during which the findings of the study will be presented.

16. Is there anything else I should know about how my data will be used?

- In this research study we will use information from you. We will only use information that we need for the research study.
- We will let very few people within the research team know your name or contact details, and only if they really need it for this study.
- When you agree to take part in a research study, the anonymised information you provide will be treated as "controlled data" and it may be given to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations, or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research.
- Everyone involved in this study, and future studies, will keep your data safe and secure. We will also follow all privacy rules. People, who do not need to know who you are, will not be able to see your name or contact details. Your data will have a code number instead.

- This information will be anonymised. It will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.
- Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.
- You can find out more about how we use your information:
 - by asking a member of the research team
 - by sending an email to: bbbb-study@bristol.ac.uk

17. What if something goes wrong?

- If something has gone wrong or you wish to make a complaint, please contact the research team in the first instance, by sending an email to: bbbb-study@bristol.ac.uk
- If you would prefer to contact the lead researcher directly, please email: harleen.johal@bristol.ac.uk
- If you would like to raise your concerns to someone independent of the research team, please contact the University of Bristol Research Governance Team (research-governance@bristol.ac.uk).

18. Who has reviewed this study?

- This study has been given a favourable opinion for conduct by the University of Bristol Faculty of Health Sciences Research Ethics Committee (ref: 15169).

Thank you very much for taking the time to read this information sheet. Please keep this copy.

If you there is anything that you don't understand or if you would like more information, please contact us: bbbb-study@bristol.ac.uk