Queen Square
MDC
UCL Movement
Disorders Centre

QUEEN SQUARE INSTITUTE OF NEUROLOGY
UCL

Participant Information Sheet For Diversity and Inclusion in Movement Disorders Research Studies

UCL Research Ethics Committee Approval ID Number: *Pending*

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of Study: Barriers and Enablers to Diversity and Inclusion in Movement Disorders Research

Department: Clinical and Movement Neurosciences

Name and Contact Details of the Researcher(s): Sonia Gandhi (Sonia.gandhi@ucl.ac.uk), Henry Houlden (h.houlden@ucl.ac.uk), Angeliki Zarkali (a.zarkali@ucl.ac.uk), Angelina Manoharan (a.manoharan@ucl.ac.uk), Hannah Collins (hannah.collins@ucl.ac.uk).

Name and Contact Details of the Principal Researcher: Amit Batla (a.batla@ucl.ac.uk)

1. Invitation Paragraph

You are being invited to take part in a study investigating barriers that may prevent people from different ethnic backgrounds from participating in movement disorders research studies. This study is being conducted by consultant neurologists and researchers at the University College London Queen Square Movement Disorders Centre. Before you decided whether to take part it is important for you to understand why this research is being done and what your participation will involve. Please take the time to read the following information sheet carefully and discuss it with others if you wish. Ask members of the research team if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for taking the time to consider participating in this study.

2. What is the project's purpose?

It is well known that ethnic minority groups are underrepresented in many areas of research in the UK, including movement disorders such as Parkinson's disease, atypical parkinsonism, dystonia, and other rare movement disorders. Movement disorders such as Parkinson's can have a wide spectrum of symptoms that may manifest differently across ethnicities. Lack of proportionate ethnic representation in Parkinson's research raises concerns about the applicability of the results to the wider population. If specific ethnic groups are excluded, researchers are unable to determine whether potential treatments (e.g. new drugs) differ in outcomes based on ethnicity.

Despite our awareness of the importance of ethnic inclusion, we have only included under 5% of patients in our research and less than 10% of active participants in our patient public involvement and engagement (PPIE) activities. We have observed some previously reported barriers, like language and mistrust in the medical community due to historical mistreatment but we anticipate that there may be other barriers that could be reversible, and identification and addressing these may positively contribute to improving research inclusion. This project aims to identify the barriers that people with movement disorders from different ethnic backgrounds may face when deciding to participate in research at UCL.

3. Why have I been chosen?

A total of 20 participants will take part in this study. You have been chosen to participate in this study because you have been diagnosed with a movement disorder.

Inclusion criteria:

- Diagnosis of a movement disorder.
- Self identifies as a member of an underrepresented ethnic group.
- Ability to understand and consent to participation in the study.
- Ability to travel to UCL campus to attend in-person focus group.
- Aged 18+ years old.

Exclusion criteria:

- Diagnosis of dementia or other mental impairment preventing informed consent.
- Unable to consent in English.

4. Do I have to take part?

Participation in this study is voluntary and it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You can withdraw at any time without giving a reason and you will still be compensated for your time. If you decide to withdraw you will be asked what you wish to happen to the data you have provided up that point.

5. What will happen to me if I take part?

If you decide to take part in this study you will be asked to complete a questionnaire and provide details about your sex, age, ethnicity, and medical condition. You will be invited to join a half-day group discussion with other people with movement disorders and their carers to discuss thoughts about participating in research and your likeliness to participate in future research.

You may also be invited to join an additional focus group with researchers and movement disorders consultants where results of the previous focus groups will be discussed and data will be analysed.

You will be compensated for you time and travel expenses (with receipt) according to the study policy. The study will run until 31st July 2025 which is the last date you can request to have your data removed from the study.

6. Will I be recorded and how will the recorded media be used?

Focus group discussions will be audio recorded to ensure the views of all participants are completely and accurately captured. Audio recordings will be anonymously transcribed following the focus group and destroyed immediately following transcription. Recordings and transcripts will be stored securely on an encrypted UCL device. The audio recordings of your activities during focus group discussions will be used only for analysis by the research team, and nothing discussed during the focus group will be quoted or directly attributed to you. No other use of the audio recording or transcript will be made, and no one outside the project will have access to the original recordings or transcript. Transcriptions will be retained and archived by UCL for no less than 10 years per the University's data retention policy.

7. What are the possible disadvantages and risks of taking part?

There are no specific disadvantages of taking part in this study. However, some participants may be uncomfortable with discussions relating to their health and medical condition. Some individuals may find the discussions on racial inequality distressing. The research team will be available during the focus groups for support and further guidance in case needed. The contact information for the study team will be provided should you need support following the focus group.

8. What are the possible benefits of taking part?

Whilst there are no immediate benefits for participating in the study, we hope that this project will enable the UCL Movement Disorders Centre to identify and address barriers preventing people with movement disorders from underrepresented backgrounds from participating in research. Increasing the diversity of research participants will help research become more representative for all communities including people from minority ethnic backgrounds.

9. What if something goes wrong?

If you wish to make a complaint or need additional support, please contact the principal researcher of this study, Dr. Amit Batla (a.batla@ucl.ac.uk). If you feel that your complaint cannot be resolved by a member of the research team or your complaint has not been handled to your satisfaction, you can contact the Chair of the UCL Research Ethics Committee (ethics@ucl.ac.uk).

10. Will my taking part in this project be kept confidential?

All information collected during the course of the research will be kept strictly confidential. You will not be able to be identified in any ensuing reports or publications. Your information will be pseudo-anonymised and stored securely in an online database called REDCap, and paper copies of questionnaire results will be stored in a secure facility at the National Hospital for Neurology and Neurosurgery.

11. Limits to confidentiality

Confidentiality will be adhered to as much as possible but cannot be guaranteed due to the small number of participants taking part in this study. Confidentiality may be breached if there are compelling and legitimate reasons for doing so such as the disclosure of intent to do harm to yourself or others, in such cases the University is obliged to contact relevant statutory bodies/agencies. The research team will inform you of any decisions that might limit your confidentiality.

12. What will happen to the results of the research project?

The results of this study will be presented in the form of a report and provided to our funder, the UCL Centre for Equality Research in Brain Sciences, presented at conferences, and published in an academic journal. The study report will be available from October 2025 and will be shared with you should you request a copy. It is possible that the results of this study will be used in future research, but you will not be able to be identified in any reports, publications, or conference presentations.

Data will be retained and archived by UCL for no less than 10 years per the University's data retention policy.

13. Local Data Protection Privacy Notice

Notice:

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data and can be contacted at data-protection@ucl.ac.uk.

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice. For participants in health and care research studies, click here.

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The categories of personal data used are participant age and sex. The categories of special category personal data are ethnicity and medical diagnosis.

The lawful basis that would be used to process your *personal data* (e.g. age, sex) will be performance of a task in the public interest. The lawful basis used to process *special category personal data* (e.g. ethnicity, medical information) will be for scientific and historical research or statistical purposes.

Your personal data other than age, gender and ethnicity will not be used for research. We will anonymise all other personal data you provide. If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

Your personal data can only be accessed by members of the research team and will not be transferred outside of the EEA.

14. Who is organising and funding the research?

This research study is being funded by the UCL Centre for Equality Research in Brain Sciences.

15. Contact for further information

For further information about this study, please contact the principal researcher Dr. Amit Batla (a.batla@ucl.ac.uk). You will be given a copy of this information sheet and a signed consent form to keep.

Thank you for reading this information sheet and for considering to take part in this research study.