



HI-COVE STUDY PARTICIPANT INFORMATION SHEET

HI-COVE: Hearing from the unheard: impact of Long Covid in black and minority ethnic groups in the UK.

Please read this sheet, it explains what the HI-COVE study is about. And what taking part in the study will be like. If you want to take part, please read this sheet carefully. Feel free to ask the researcher any questions about the study.

What is the study about?

Some people do not recover quickly after getting Covid-19. Some experience ongoing symptoms for months or more, like:

- severe tiredness;
- trouble breathing;
- chest problems;
- memory or thinking problems;
- aches and pains.

There are many other symptoms, all can cause disruption to your life and how you feel. Sometimes, this is called **Long Covid**.

We want to hear about your experiences of not recovering quickly from COVID-19. What are your symptoms, and how do they affect your lifestyle? What kinds of help did you get? What is it like trying to get help (e.g., from work, doctors, family etc)? We also want to know about your recovery (or not): How has it affected your daily life and the people around you? We want to work out how to help people from all walks of life better cope with their symptoms. We hope to help people to recover better from COVID-19.

Who is organising and/or funding this project?

The research is funded by the National Institute for Health Research (NIHR).

It is hosted by Midlands Partnership NHS Foundation Trust.

The research is led by the University of Westminster, with help from Keele University, Queen Mary University of London and the University of Southampton.

Why are we conducting this study?

It can be hard to get help if you experience ongoing symptoms of COVID-19 that do not seem to get better, especially for people who are Black or come from an ethnic minority.

Healthcare is not always designed to suit people from ethnic minorities, which may mean worse effects of COVID-19.

This study seeks to raise awareness about what it is like for people who do not recover quickly from COVID-19.

We especially want to hear from people from Arab, Black and South Asian ethnic minority backgrounds, since people from these groups tend to suffer worse consequences of COVID-19 (e.g., more infections which are more severe).

HI-COVE STUDY

PARTICIPANT INFORMATION SHEET

We seek to understand your views and experiences. Where do you find support (e.g., religion, family, NHS or more traditional healthcare)? What do you want and need from the NHS? Findings will help us to ensure services are better for you. We will also find out more about how people can manage their symptoms at home.

What will happen during the study?

You are being invited to take part in an interview which will explore your views and experiences of COVID-19. We will ask you about

- a) the symptoms you have experienced and may continue to experience;
- b) how long you have experienced these symptoms and how they impact your daily life;
- c) the type of support and treatment you are getting and/or prefer;
- d) what other support you have had (such as friend, family, community, healthcare services);
- e) any challenges you may have experienced in getting support.

During the interview:

- you do not have to answer any questions you don't want to;
- you can stop the interview at any point, no questions asked;
- with your permission, we will audio record the interview. The recording will be typed up. If you prefer, the interview does not have to be recorded, the researcher will take notes instead;
- at the end of the interview, we will ask you general questions about you, such as your age, gender, marital status, ethnicity (this is so we interview people from a wide variety of backgrounds with different experiences of COVID-19);
- remember, you do not have to answer questions you do not want to.

After the interview:

- audio recordings will be stored securely on University of Westminster system for a period of 3 years after publication of the research results, then deleted. Only members of the research team at the University of Westminster will have access to these recordings;
- for interviews not conducted in English, they will be first translated into English by a professional translator, who will sign a confidentiality agreement;
- audio recordings will be typed up by a professional transcriber who will sign a confidentiality agreement;
- typed up interviews or notes will be anonymised (information that could identify you will be removed);
- these 'anonymised' typed up interviews will be stored securely on the University of Westminster system, and shared with members of the research team who will store them on their university secure systems.

Who can take part in the study?

We are interested to hear from individuals who are;

- aged over 18 years;
- from an Arab, Black, South Asian or mixed backgrounds;
- live in the UK;
- have not recovered quickly from a COVID-19 infection (i.e. for 12 week or longer)*.

*You do not have to have received a diagnosis from your healthcare provider or have accessed any healthcare for your symptoms connected to COVID-19. You will be asked to complete a few questions to confirm your eligibility to take part in the study.

HI-COVE STUDY

PARTICIPANT INFORMATION SHEET

How long will it take to be involved in the study?

The interview will usually last around an hour; during which time you can

- take short breaks (the timing of the interview may go over the one hour);
- you could also pause the interview and continue it on another day.

Where is the UK is the research taking place?

Interviews can be held online, over the telephone or face-to-face:

- online or telephone interviews can be conducted with people living in the UK;
- Face-to-face interviews can be held if you can travel to London, Staffordshire and Southampton (travel will be reimbursed).

Do I have to take part in the study?

No, your participation is entirely voluntary. You can stop taking part at any time without having to provide an explanation. If you decide to take part, you do not have to answer any question. Additionally, your interview data can be withdrawn at any point until it has been analysed.

Expenses and payments.

- all participants will be offered a £35 shopping voucher for their time (regardless of whether the interview is face-to-face, online or over the telephone, or whether the interview has finished or not).
- for a face-to-face interview, you will receive money for your travel costs.

Disclosing safeguarding issues.

The information you give us will be treated in confidence. In the unlikely event that you tell us that you (or others) are at risk of serious harm, as researchers, we may have a duty to tell someone in authority. We would only do this with your knowledge.

What happens to the information?

This research is being conducted in accordance with the University of Westminster Code of Practice Governing the Ethical Conduct of Research and the British Psychological Society (BPS) Code of ethics.

If you provide any personally identifiable data, it will be treated confidentially and in accordance with the University of Westminster ethical guidelines and British Psychological Society code of human research ethics.

Note in exceptional circumstances, the duty of confidentiality may be overridden by more compelling duties such as to protect the individual from harm.

All data will be securely stored and managed in accordance with the Data Protection Regulation 2018 and the General Data Protection Act 2018. You will not be personally identifiable in any reports that arise from this study.

Your anonymised data may be used for future research and may undergo secondary analysis. This future research may be unrelated to the goals of this study and may be conducted by researchers unrelated to this research project.

HI-COVE STUDY

PARTICIPANT INFORMATION SHEET

What are the possible benefits, disadvantages and risks of taking part?

Benefits:

- contribute to the development and improvement of better healthcare and at-home management of COVID-19;
- ensure professionals are more sensitive to people from different walks of life, so that more people can get good care.
- You will be offered £35 shopping voucher for your time.

Disadvantages/risks: There are no serious risks involved in taking part in the interview. Talking about some health issues can be difficult, but you can choose what you want to tell us. You may say “pass” to any question you do not want to answer. The interviews are more like a conversation, to put you at ease. Many times, participants say they find our interviews to be helpful.

What will happen to the results of the research project?

The results of our research will be written up and used to promote good healthcare for people who do not recover quickly from COVID-19. We hope that it will also help people from all kinds of different backgrounds to look after themselves better too.

We are also interested in showing the findings in a piece of artwork developed with our participants and an Artist. We are looking to involve up to 8 participants in this part of the research, you will need to be able to travel to London, Staffordshire or Southampton (travel will be reimbursed) to talk about your experiences of Long Covid with an Artist. This will be a creative activity and no artwork skills are needed. You will receive a £35 shopping voucher for each one-hour meeting with the Artist. If you are interested, please talk with the researcher.

What happens next?

If you would like to ask any further questions before deciding to take part, please get in touch with the research team:

HI-COVStudy@westminster.ac.uk

Dr. Nina Smyth email and Prof. Damien Ridge - Study Principal Investigators

smythn@westminster.ac.uk

D.Ridge@westminster.ac.uk

Before the interview you will be asked to:

- complete pre-interview questions to check you are eligible to participate in the study;
- complete the consent form agreeing to your involvement in the study*
- the researcher will go through the consent form with you before the interview starts to make sure you are happy with everything and to address any further questions that you might have.

*You do not have to provide your full name; we just require your initials and your signature on the consent form. If you have any problems signing the consent form electronically, you can send an email saying that you have read the information sheet and consent to being interviewed. If you are having a face-to-face interview, the researcher will print out copy for you to sign on the day. Alternatively, we can audio-record your verbal consent (stored separately to the interview) prior to the interview.

What if something goes wrong?

HI-COVE STUDY PARTICIPANT INFORMATION SHEET

This research has been approved by the University of Westminster Ethics Committee. If you have concerns about this research, please contact: Professor Dibyesh Anand (Head of School of Social Sciences) – email: D.Anand@westminster.ac.uk

Thank you for considering taking part.