

## HI-COVE STUDY ARTWORK DEVELOPMENT - 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 is involved in the development of the artwork as part of the HI-COVE study. Please read this sheet carefully. Feel free to ask any questions about this part of the study.

#### Development of Artwork.

Using art to show people's experience of living with a health condition(s) helps other people and groups like friends, families, carers, non-health care and health care professionals and the public better understand people's experiences and better relate with them, especially where health conditions are misunderstood.

As part of the HI-COVE study, you have participated in a one-to-one interview talking about your experiences of living with Long Covid. We are interested in showing yours and others' experiences through art, developed with you and an Artist.

We think that showing people's experiences of Long Covid through art will help us to raise awareness about what it is like for people who do not recover quickly from Covid-19.

As part of the process, you will work with Dr. Alexa Wright, who is a Reader and Artist, from the University of Westminster, to create a piece of artwork that shows experiences of what it is like to live with Long Covid.

Alexa has worked with other groups of people to illuminate their experiences of living with chronic health conditions.

#### Who can take part?

Participated in the HI-COVE interview study.

You will need to be able to travel to London, Staffordshire or Southampton (travel will be reimbursed) for at least one in-person meeting (lasting about 60 minutes).

You do not need to have any skills in art; Alexa will create the artwork but will create this along with your ideas. Alexa will also guide this process by suggesting different art.

#### What will I be asked to do?

Your typed interview would be reviewed, by members of the research team, to identify the themes explored in your interview. You will then be asked to meet with Alexa at least once, where you will talk about these themes and to think about how you may show these through art, like the use of images, text, paintings etc. You may also be able to attend further meetings (up to four) to continue your involvement in the creation of the artwork. The first meeting will be in-person (you will be reimbursed for your travel) and the remaining meetings can take place online if this is more convenient. So that Alexa can make notes after your meeting

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you will be asked if the conversation can be audio recorded. This will be deleted once notes have been typed up.

No personal identifiable information will be shared in the artwork (e.g. name, age, gender, where you live etc.) nor will any photographs that can identify you will be taken/shared.

#### What will happen to the artwork?

The artwork will be made publicly available only after you have reviewed and agreed the final piece of artwork. All participants involved in the development of the artwork will be invited to join event towards the end of the study (likely spring/summer 2023) where we will showcase the artwork and discuss wider research findings of the project.

#### 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.

#### 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 artwork can be withdrawn at any point until it has prepared for public viewings.

#### Expenses and payments.

- All participants will be offered a £35 shopping voucher for each one-hour meeting (regardless of whether the meeting is face-to-face, or online, or whether the meeting has finished or not).
- For a face-to-face meeting, you will be reimbursed 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.



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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.

#### 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-COVestudy@westminster.ac.uk](mailto:HI-COVestudy@westminster.ac.uk)

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

[smythn@westminster.ac.uk](mailto:smythn@westminster.ac.uk)

[D.Ridge@westminster.ac.uk](mailto:D.Ridge@westminster.ac.uk)

#### What if something goes wrong?

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](mailto:D.Anand@westminster.ac.uk)

**Thank you for considering taking part.**

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