

About the CICADA-ME study



Why are we doing this study?

Many people from minority ethnic groups, especially those with underlying (chronic) conditions/disabilities, face barriers to accessing networks of appropriate support, health and social care or vital ‘resources’, such as medicine and food. Around 50% lived in poverty in 2019; the pandemic has worsened their plight, highlighting the need for these barriers to be removed. There is a largely unmet expressed need to explore the pandemic problems - and successes - these groups have experienced in relation to reduced services, inequalities, lifestyle changes or health neglect and vaccine uptake. This is especially as health and social care tries to return to normal – and also with the emergence of people newly disabled by post-Covid syndrome.

Our approach:

To investigate pandemic experiences and how we may further support these vulnerable groups, we are using a combination of research methods, such as:

A longitudinal survey – We are surveying over 4000 first- and second-generation, UK-based minority ethnic group members and for contrast 1000 white British individuals at three time points. Beginning during the COVID pandemic period and spanning 15 months. We

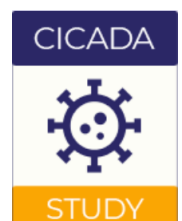
are considering access to support, care and resources in particular.

Interviews – We are conducting interviews, amongst 230 people, across 6 UK sites (London, Yorkshire, Manchester/Liverpool and the Northwest, the Southeast, the Midlands and Newcastle). We are comparing their health and social networks, how these help and hinder them and the ways they have coped with the pandemic and beyond.

Research workshops – Twice during this 15 month process the interviewees will be invited to group-based research workshops to discuss the findings and recent changes.

Co-creation stakeholder workshops – We are running participatory sessions with people with disabilities from ethnic minorities and key stakeholders (charity leaders, clinicians, commissioners, and politicians) to help make sense of the data and co-create solutions to support these communities. These include ‘life-hacks’ and service solutions for rapid impact.

In addition, our team are carrying out several evidence synthesis reviews, exploring socially and environmentally constructed barriers for people with disabilities and chronic conditions and considering barriers to vaccine uptake.



What will we do with the results?

We are aiming for immediate, readily implemented, relevant useful change to support health and social care delivery.

We aim to develop a rich intersectional understanding of the mental and physical health, coping experiences of minority ethnic groups at the intersection with chronic conditions/disabilities. We are exploring access to resources, and informal and formal social and health care support experiences, and relevant assets and strengths.

This will contribute and inform evidence-based formal and informal strategies, guidelines, recommendations and easily adopted interventions for pandemic-related and future health and social care policy and practice, to mitigate inequities and improve the experiences, health and wellbeing outcomes of these groups.

Getting involved

Charities and organisations

Charities and organisations are getting involved by helping us recruit to the study, sharing our information with their members as well as working as active partners conducting interviews and holding workshops. Charity representatives are also engaging in the development of outputs through the co-creation process. If you belong to a charity or help run and organise a charity that supports individuals from minoritised ethnic groups and/or individuals who may have disability, mental health or other chronic conditions, and would like to get involved please contact us directly to discuss how you may help.

Individuals

If you are from an ethnic minority background and have a disability or condition that influences your everyday life you can get in touch to get involved with sharing your experiences and helping contribute to

improving conditions for others. Conditions may include for example: physical and sensory disability (such as having mobility issues, blindness, deafness etc.), any chronic illness (such as diabetes, asthma, heart disease, cancer, COPD) or any other long-term condition which impacts significantly upon how you live your life.

Who we are

The study is led by Professor Carol Rivas, who is supported by Dr Kusha Anand and Dr Amanda Moore in the core research team. We also have a strong wider team of lay researchers and local charities we are working with. We have a very active team of patient and public involvement representatives, representing a range of different communities and disabilities and health conditions. Our wider team also include clinicians, social workers and charity leads. You can find out more about the Team here: <https://cicada-study.org.uk/about-us/>

Funding

This study is being run by University College London and is funded by the National Institute of Health Research. NIHR HS&DR project NIHR132914.

Ethics

The study has been approved by the University College London (UCL) Research Ethics Committee (Reference number: 1372, Data protection registration number: Z6364106/2020/06/24); HRA: IRAS 310741

Contact

If you would like to get involved or would like further information please drop us a line at ioe.cicada.study@ucl.ac.uk.

<https://cicada-study.org.uk>