

Newsletter

CICADA-ME: Coronavirus Intersectionalities: Chronic Conditions and Disabilities and Migrants / Ethnic minoritisation



Written by the study's lead qualitative researchers Lorna Collins and Kusha Anand

Project description

We aim to develop a rich intersectional understanding of the mental and physical health, coping, access to resources, and informal and formal social and health care support experiences, and relevant assets and strengths, of minoritised ethnic groups at the intersection with chronic health conditions/impairments longitudinally over 18 months. The study is funded by the National Institute for Health Research (NIHR). Check our website for more details: <https://cicada-study.org.uk/home/>

“I am delighted the NIHR is funding such a large study with a focus on improving the health and social wellbeing of some of the least heard people in the community. This study is unusual because of its particular focus on migrants, refugees, asylum seekers and the undocumented, specifically those who have illnesses and impairments that are made more disabling because of the widening inequalities that the pandemic has caused. The study's premise is that the interplay of impairment and migrant status creates extra disadvantage, but that those affected also have strengths and assets that we can learn from. I am very excited to be working with such an excellent group of people on this study, the co-applicants, collaborators, my colleagues in our core research team, and especially the community co-researchers, from whom we are already learning a great deal.” Prof Carol Rivas (Principal Investigator)

CICADA-ME Patient and Public Involvement (PPI)

The CICADA-ME team wishes to make sure that the patient and public voice is heard throughout the project – we want to make a desired difference and to ensure that our research is accountable, transparent, and relevant to the public. We use NIHR

INVOLVE definitions, namely that patient and public involvement is where patients and members of the public are actively involved in the activities, organisation, and governance of research projects. The Patient/Public Advisory Group (PAG) intends to meet face to face approximately four times during the project for 2 hours each time.

“Myself and my family are familiar with the challenges that come with living with serious medical conditions, and this led me to develop an interest in patient engagement and public involvement and I have recently graduated from a funded 14 month training course with EUPATI, the European Patient’s Academy on Therapeutic Innovation. I wanted to be able to apply some of the knowledge and skills from this to support research that is patient centric and truly reflects things that matter to patients. By engaging different patients in the PAG, we hope to help prioritize 2-3 cross cutting topics and themes and engage disease specific groups and patient advocates, as there is a need to ensure those living with disability and their needs are communicated in order to support evidence in a striking way that can ensure political will and public acceptance. If we view Covid 19 as a syndemic that co-occurs with many communicable and non communicable diseases, then we may be ultimately able to use this as an opportunity to do better and support many patients.” Jenny Camaradou (PPI Lead)

Lay Researcher recruitment and training

Our latest task in the CICADA study has been recruiting lay researchers to conduct interviews for the project. We have located our lay researchers from and around five main sites: London, Southeast England/Canterbury, Gateshead/Newcastle, West Midlands/Birmingham, and Yorkshire/Leeds.

Lay Researchers become partners, offering specialist knowledge and contacts. Their task is to interview 5-10 people (each), who fit into two categories: chronic disability and having an ancestry with minoritised ethnic status in the UK. Disability groupings in the study cover mental health, mobility, stamina/breathing, fatigue (including heart), hearing or vision loss, developmental or intellectual, and specialist dietary needs. The idea behind this is to consider disabilities in terms of the functional impact of the social and environmental barriers that lead to disability. The actual conditions can include diabetes, Chronic Obstructive Pulmonary Disease (COPD), and other long-term conditions, not just conditions that are more usually considered as disabilities. Disabilities can also be diagnosed or undiagnosed.

The other main category is ancestry (and connected citizenship status). We are focusing specifically on four ancestral groups with minoritized ethnic status in the UK: Arab, South Asian, Black African, and Central-Eastern European. This focus helps us get into the real detail across a range of some of the largest migrant groups in the UK. We are especially interested in hearing the voices of those without citizenship, such as asylum seekers and refugees.

Our Lay Researchers have been sourced from different groups who support migrants or refugees: Kent Refugee Action Network (KRAN); MedAct Migrant Solidarity Group (MSG); Polish migrant organisations. Our thanks to collaborators KRAN and MSG and to Roch Dunin-Wąsowicz for support with this.

We are also collaborating with Born in Bradford (BiB) for recruiting Lay Researchers, and the interviews. Aamnah Rahman is BiB's Community Engagement Research Fellow and acts as the liaison between BiB, UCL, and the local communities of Bradford to recruit and support local lay researchers. She says:

“I am happy to support this initiative as I see the importance of the research but more importantly how local people will be empowered and encouraged to get involved to benefit the community.”

Our next task is to train the Lay Researchers. Carol, Lorna and Kusha have created a training package which includes a guide to doing interviews (preparation, topics, the process, technology, data management, and storing), as well as ethics, protocol, and the chance to practice doing role plays. We also have a section in the training run by our other PPI lead, Sarabajaya Kumar, who is going to talk about running interviews with the disabled. Following the training, Lay Researchers will be supported to recruit and conduct their interviews. A number of Lay Researchers are also going to translate and transcribe their interviews if they are conducted in another language (e.g., Arabic, Polish). There is energy amongst the group, which vivifies the project, from the start. We are excited to be collaborating with these people; they enrich our data collection.



Artwork by Lorna Collins

“A rough sketch of the CICADA logo (watercolour). I’m trying to capture the flaky, messy virus particle.”