

STUDY NEWS



The impact of the pandemic on social & health related needs of people from minoritised ethnic groups living with chronic conditions & disabilities

Our objectives

We aim to develop understanding of the impact of the pandemic on social & health related needs of disabled people and minoritised ethnic groups. Our outputs will inform guidelines and suggest ways of improving experiences for the future.

Our research team

The overall study is led by Professor Carol Rivas, survey work by Dr Ozan Aksoy and co-create workshops by Dr Alison Thomson. The lead researchers are Dr Kusha Anand, Dr Amanda Moore (project manager) and Dr Fang-Wei Wu.

Our Patient & Public Involvement Team

We are lucky to have a fantastic diverse and enthusiastic patient and public involvement group. The study team meets monthly with the group leads Jenny Camaradou and Dr Sarabajaya Kumar and we held our second full group meeting in March. The group members are now playing an active role in designing and delivering the workshop phase of the study.



Study Update

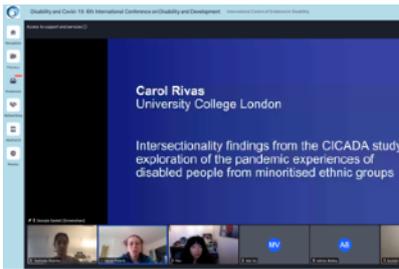
We are now half way through the study and are progressing well through our plans. You can find out a bit more below.

The Interviews

We interviewed over 230 people about their pandemic experiences. With 8 lay researchers we collected detailed accounts encompassing diverse ethnicities, disabilities and chronic conditions. People reported using doctors outside the NHS, including 'back home' ("difficult to get healthcare in England"), deteriorating health, discrimination from some communities, great support from others, and financial struggles, amongst other topics. You can see some quotes from participants on our website. In April/May we will discuss with interviewees how things have changed since 2021.

The CICADA Survey

The team is repeating a new survey 3 times over the study. The first 'wave' was distributed through charities, social media and online fora from August 2021 to January 2022. 4300 respondents met our research criteria. Half self-reported a minoritised ethnicity and half had a chronic health condition. The team is currently analysing the data.



Dissemination

The team has been working hard to share findings. Prof. Rivas gave talks at the International Conference on Disability and Development on 17th March, and at a British Medical Association Conference in 2021 and was an invited speaker at a one-day event at Queen Mary University of London, talking about our Intersectionality findings and our Methods. We are planning ways to share our findings with other audiences. See the slides on our website.

Ozan and Fang-Wei have submitted a paper for publication, using existing survey data from the UCL Centre of Longitudinal Study, collected earlier in the pandemic. They found that people with chronic health conditions had particularly poor - and worsening - mental wellbeing in the pandemic. But social support was effective at improving wellbeing.

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The co-create workshops

We are planning a series of creative workshops May-June that aim to develop future learnings from the CICADA study. They will be led by Dr Alison Thomson, a designer and researcher, based at The Wolfson Institute of Population Health at Queen Mary University of London. Alison has led a number of workshops with different patient groups using a variety of creative methods ranging from modelling with food to knitting. The workshops will bring together charity representatives, policy makers, health and social care professionals, patient representatives and community leaders to explore the question, *“How can we learn from what we’ve been through to support our communities going forward?”*

The study has gathered information on an incredibly rich and diverse range of strategies that people developed throughout the pandemic to cope with living with a long term condition. Workshop participants will learn about these innovative strategies, then work in groups to ‘model’ with plasticine the behaviours that were developed. This activity will encourage the workshop participants to think differently about some of the challenges and issues that people faced and help them work together to co-create new ideas for the future. They will then use their professional experience and expertise to pull out key learnings from these strategies that have the potential to improve existing service delivery and care. An important output of the workshops will be action points to take to existing policy recommendations. The workshops will conclude with a celebration event showcasing both the creations and the next steps for policy recommendations.