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The pandemic social and healthcare experiences of adults living with chronic conditions or disabilities who come from migrant and other minoritised ethnic groups

Submission date
13/06/2022

Registration date
14/06/2022

Last Edited
04/07/2022

Recruitment status
No longer recruiting

Overall study status
Completed

Condition category
Other

- ☒ Prospectively registered
- ☒ Protocol
- ☐ Statistical analysis plan
- ☐ Results
- ☐ Individual participant data
- ☐ Record updated in last year

Plain English summary of protocol
Background and study aims:
We are experiencing an unusual situation with the coronavirus pandemic. People living with long- lasting health conditions (that is, conditions that they will have had for more than 3 months) or disabilities often already find it hard to manage daily living. We believe that such challenges could be much worse for many such people during the pandemic. But others are reporting that nothing has changed much for them. There are also stories of people coping better with their conditions during the pandemic, perhaps because they do not feel under pressure to leave the house, or because other people are taking more time to support them. This study plans to understand the different situations of people living with different conditions and disabilities during the pandemic and shortly afterwards and compare these with people without these experiences. We are also interested in hearing about how racism affects this, and about the experiences of people born outside the UK. This is important to ensure that the minoritised voice is heard, as we believe that many people need better help but are not considered for this. It will also give us a better understanding of what life is like for people with long term health problems and disabilities in general.

Initial findings will be shared widely to try to ensure people with long term conditions and disabilities and racialised groups and new migrants are represented in current planning. At the end of the study, our findings will also mean we can build up a picture of the country’s neglected needs for people with long term conditions and disabilities, and minoritised ethnic groups including new migrants, as well as plan for the consequences of the pandemic on people’s health and feeling of wellbeing. Since we are also collecting data from white British people we will also be able to provide information that can help in planning for this majority group too although that is not our focus.

Who can participate?
Everyone can participate in the survey (there are two surveys, for those who consider themselves to have a chronic condition/disability or their carer, and for anyone else). The

interviews are open to people who have a long-term health problem or who consider themselves to be disabled, and from one of these groups: North Africa/the Arab League; Central- Eastern Europe; South Asia; Sub-Saharan Africa.

What does the study involve?
The study involves participants telling us about what life is or has been like during the current coronavirus pandemic. We would like to hear about experiences in the form of an interview (which takes between 40-60 minutes), and/or a survey. Participants who do the interview will be given a £20 voucher. Participants who do the survey can go in a draw, to win a £50 voucher.

What are the possible benefits and risks of participating?
We believe that this study is safe and do not expect anyone to suffer any harm or injury because of taking part. If someone becomes distressed whilst taking part, we will stop the session and ask if they want to continue. If they want to continue, we will give them time to recover before continuing. If they wish to stop, they are free to do so, and we will provide the contact details of professional people they may wish to talk to. Overall, we do not know whether anyone will experience any direct benefits from taking part in this research, but we hope that they will enjoy and value their role in helping us to develop reports to make people including the government more aware of their experiences.

Where is the study run from?
University College London (UK)

When is the study starting and how long is it expected to run for?
May 2021 to October 2022

Who is funding the study?
National Institute for Health and Care Research (NIHR) (UK).

Who is the main contact?
Professor Carol Rivas, ioe.cicada.study@ucl.ac.uk.

Contact information

Type(s)
Principal investigator

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Scientific

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Additional identifiers

Clinical Trials Information System (CTIS)
Nil known

Integrated Research Application System (IRAS)
310741

ClinicalTrials.gov (NCT)
Nil known

Protocol serial number
IRAS 303041, CPMS 51755, IRAS 310741

Study information

Scientific Title
Coronavirus Intersectionalities: pandemic social and healthcare experiences of adults living with Chronic conditions And Disabilities And Migrant status/Ethnic minoritisation

Acronym
CICADA-ME

Study objectives
People living with underlying (chronic) conditions/disabilities or from racialised groups often find it especially hard to access appropriate support, health and social care or vital needs, such as medicine and food (which we call resources). The COVID-19 pandemic has worsened their

plight but pandemic recovery gives us an opportunity to improve this and to enhance vaccination, social, health and wellbeing outcomes. Our overarching hypothesis is that people living with chronic conditions/disabilities or from racialised groups have experienced particular problems - and successes during the pandemic that health and social care can learn from as services evolve and develop in the continuation and resolution phases of the pandemic.
Our objectives are to:
O1: Explore and compare, by location and time, survey and qualitative data on changing patterns of need. Including intersections of chronic condition/disability and ancestry/citizenship state with UK pandemic contexts.
O2: Relate pandemic coping strategies/solutions to O1 findings, including what worked well or less well, and touchpoints (where experiences might best be improved), to inform health and social care policy and practice
O3: Use Social Network Analysis to explore formal and informal network issues/affordances in health and social care solutions
O4: Gain insights from comparisons and relationships across our mixed methods data, rapid framework-based synthesis of the published and grey literature, and secondary analyses of UCL's Centre for Longitudinal Studies (CLS) and ActEarly COVID-19 specific surveys.
O5: Contextualise and explore transferability of qualitative findings using the survey, and survey findings using UK census data.
O6: Co-create with stakeholders (including lay people) interim/final outputs including identified strategies, interventions and touch points, and plans for rapid pathways.

Ethics approval required

Old ethics approval format

Ethics approval(s)

Approved 21/07/2020, University College London (UCL) Research Ethics Committee (Room 502, 20 Bedford Way, London, WC1H 0AL, UK; no telephone number provided; ioe.researchethics@ucl.ac.uk), ref: 1372

Study design

Mixed methods (primary surveys (3 waves) and secondary cohort/panel data analysis qualitative interviews and primary data generation workshops (3 waves) mapping and systematic reviews.

Primary study design

Other

Study type(s)

Quality of life

Health condition(s) or problem(s) studied

Pandemic-relevant experiences of living with diagnosed and undiagnosed chronic conditions or disabilities (considering the full range) with a particular focus on racialised/minoritised ethnic groups.

Interventions

We aim to survey 4,000 community-dwelling people in the UK from racialised groups and for contrast 1000 white British, 3 times over 15 months. We will compare their health, social networks (who they have contact with) and how these help or hinder them, ways they cope with pandemic changes and associated access to support, care and resources. We will consider how intersectional factors affect this and determine relationships between measured variables and

their trajectories.
We will also interview 210 people about the same topics. We will probe for coping strategies and ideas to inform health and social care policy and practice including vaccination. Interviewees will also describe their networks using special brief questionnaires, photos and maps. For the interviews we will focus on people of Arab, Central and East European, South Asian or African ancestry with chronic condition/disability as more likely to have limited citizenship rights, or to die from COVID-19. We will train local lay people to help undertake these interviews remotely; a transformative community migrant-majority research-active group will be our main London co-researcher.
After each of surveys 2 and 3, interviewees will be invited to research workshops to discuss findings and more recent changes, using video vignettes built from earlier study findings.
Over the 18-month study we will hold 5 participatory sessions with people with disabilities/from racialised groups and key informants working together to help analyse our data and co-create solutions to issues, pragmatically including 'life hacks' and service adaptations for rapid impact. Some may be tested in the community for proof-of-concept/feasibility, in new sub-studies. At 16 months we will interview 15-25 key informants such as support staff and community leaders to help us put our work into immediate practice. We will also review published and informal (e.g. blog) articles about pandemic experiences, and data from other complementary COVID-19 cohort and panel data and surveys.

Intervention Type
Other

Primary outcome(s)
1. Resource access measured using QOCS–ID at 4, 10, and 16 months by online survey
2. Formal/informal care measured using de novo questions and QOCS-ID at 4, 10, and 16 months by online survey
3. Quality of life measured using WHOQOL-BREF-ID at 4, 10, and 16 months by online survey
4. Control of life measured using 'control of life' validated questionnaire at 4, 10, and 16 months by online survey
5. Physical and mental health measured using WHO ADS at 4, 10, and 16 months ; Vulnerability Assessment Framework at 10 and 16 months, Global Mental Health Assessment Tool at 10 and 16 months by online survey
6. Social networks measured using an adapted Close persons questionnaire (for online work) at 4, 10, and 16 months by both online survey and as part of semi-structured interview (using closed questions, open questions, photographs taken by participants to represent their networks (no personal identifying information of anyone), and maps drawn of networks

The survey at 4 months also includes demographic data; the same respondents will complete the survey also at 10 and 16 months hence this is only collected at 4 months.

Key secondary outcome(s))
1. Fear of death using the Templer Death Anxiety Scale (1970) at 10 and 16 months by online survey
2. Thematic qualitative data from survey freetext, interviews and workshops:
2.1 Patient experiences of heath and social care and other forms of formal and informal support during the pandemic, and their perspectives on the impacts on their health
2.2 Consideration of the impacts of their identity (e.g. as disabled, as from a specific race, as of low income) on these experiences.
2.3 Consideration of their beliefs (health beliefs, covid beliefs, vaccination beliefs) and how this affect other themes

2.4 Consideration of coping mechanisms and strategies and assets used in relation to their access to and use of resources, services and support as this affects their health and wellbeing.

For most secondary outcomes, semi-structured interviews are used to collect data at 3-7 months, with one interview per participant recruited to interview, lasting approximately 40 min-1 hr. Data will be analysed using framework analysis and KeyWord in Context for rapid dissemination and some themes will be explored in more depth using discourse and narrative analysis.
At 10 and 16 months analysis of the interview data will be explored with the same participants in mostly remote (video conference) arts-based workshops (one per participant per time point) to consider changes and gain further understandings of themes. The primary approach is to use vignettes of hypothetical people and discuss these, we will also use other approaches such as collage but the precise arts-based work will be co-designed with our advisory and stakeholder groups. Face to face workshops will be used when participants require or interviews as an alternative.

Completion date
31/10/2022

Eligibility

Key inclusion criteria
Survey
1. Community dwelling adults living in the UK
2. Aged 18 years or above
3. We have two versions of the survey, one for adults living with chronic conditions/disability or their carer, and one for any other adult

Main interview/research workshops inclusion criteria
1. White British comparators or people of Arab, C/E European, S Asian or sub-Saharan African ancestry, aged 18+ (undocumented, on temporary visas, indefinite leave to remain, British citizenship). Comprising people born outside the UK or whose parents were status in the UK as skilled migration, humanitarian or family streams, the ‘irregular’ or undocumented, on temporary visas, with indefinite leave to remain, or with British citizenship.
2. Any condition/disability, including self-diagnosis, that chronically affects daily activities. We have not defined chronicity using standard definitions, to avoid excluding studies and people that do not fit their tight criteria but who/which may be relevant but in general we mean by this that the condition has lasted for at least 12 weeks and has no defined end-point.

Eligibility criteria for key informant interviews
- Inclusion and exclusion criteria will be determined by our advisory and Co-create workshop members as a result of earlier analyses.

Eligibility criteria for Co-create workshops
- We will seek representation from a cross-section of relevant lay and professional stakeholders; the inclusion criterion will be that participants should be stakeholders in the health and social care of people with any condition/disability from racialised groups.

Eligibility criteria for interventions
- We will try out adaptations of two existing training programmes run by study collaborators, one for community members and one for practitioners, at key sites across the UK for proof-of-

concept. We may also evaluate other small interventions that involve expansion or adaptation of existing provision. Inclusion and exclusion criteria will be determined by our advisory and co-create workshop members as a result of earlier analyses.

Participant type(s)
All

Healthy volunteers allowed
No

Age group
Adult

Lower age limit
18 years

Sex
All

Key exclusion criteria
Main interview/research workshops
1. Student migrants as likely to have structured educational institution support
2. Residents of detention centres/closed facilities linked to national migration policies (e.g. new asylum- seekers/refugees, displaced or trafficked persons), as complex cases with specific considerations.

Date of first enrolment
01/07/2022

Date of final enrolment
31/10/2022

Locations

Countries of recruitment
United Kingdom

England

Study participating centre
University College London
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18 Woburn Square
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Sponsor information

Organisation
University College London

ROR
https://ror.org/02jx3x895

Funder(s)

Funder type
Government

Funder Name
National Institute for Health Research

Alternative Name(s)
National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
United Kingdom

Results and Publications

Individual participant data (IPD) sharing plan
The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request. All data for each participant will be referred to by an anonymous code from start of the study. All data will be identified and coded by this code only. Participants actual names will never be used or linked to the data. Data will be fully anonymised, which includes removing any directive identifiers (e.g., names) and reducing the precision of variables that can be used as indirective identifiers (e.g., date of birth).The anonymised qualitative data from interviews and workshops, and anonymised quantitative data from surveys (converted to suitable open formats for long term preservation) will be deposited for archiving and re-use according to UCL protocols existing at the time. These data will be available on request to appropriate (according to UCL archive protocols) professionals and researchers 12 months after end of the study, and for up to 25 years. Archived data will be

checked for anonymisation before sharing; raw data will never be shared but will remain in the UCL safe haven. Data that are considered by the custodian to be sensitive and not in the public interest will not be shared despite anonymisation. Other anonymised data will be freely shared according to extant UCL protocols. Given the richness of our data and its potential to address gaps in knowledge, our data have considerable potential to benefit other research groups across the world as well as practitioners. The custodian of the data to whom requests may be made is Professor Carol Rivas, c.rivas@ucl.ac.uk. Where permission for archiving has not been granted by participants (the option of data re-use is provided in the consent form), in line with UCL policy, all paper records will be held for up to 25 years in central archives, and electronic data stored on the data server for 5 years and subsequently on storage media such as external hard drives and DVDs for 20 years.

IPD sharing plan summary

Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Other files	version 2	09/09/2021	14/06/2022	No	No
Participant information sheet	Participant information sheet	11/11/2025	11/11/2025	No	Yes
Protocol file	version 1.1	05/05/2021	14/06/2022	No	No
Protocol file	version 2	13/09/2021	14/06/2022	No	No
Study website	Study website	11/11/2025	11/11/2025	No	Yes