

Lessons from the COVID-19 pandemic to improve the health and social care and wellbeing of minoritised ethnic groups with chronic conditions or impairments: protocol for the mixed methods intersectional asset-based study CICADA

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Abstract

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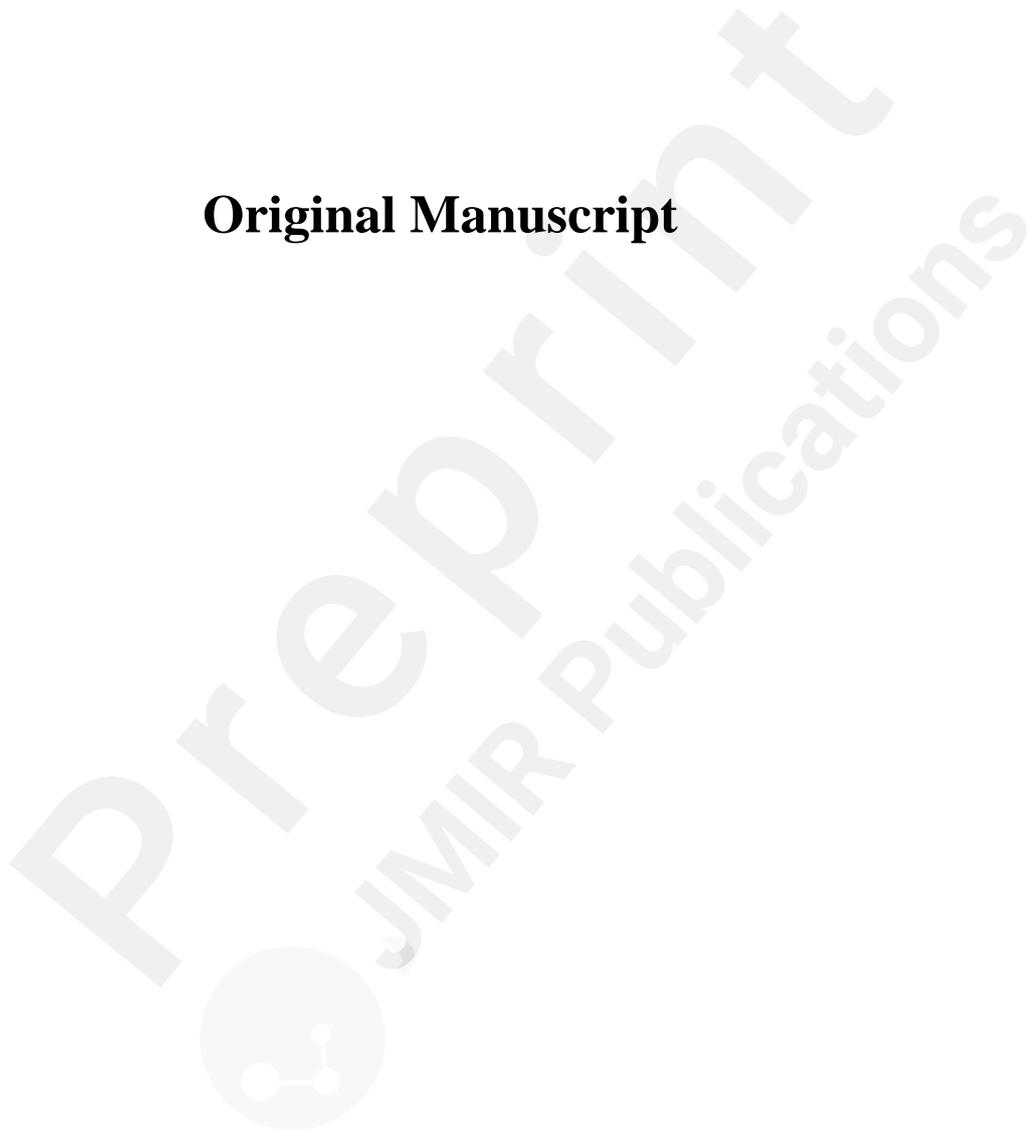
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Original Manuscript



Lessons from the COVID-19 pandemic to improve the health and social care and wellbeing of minoritised ethnic groups with chronic conditions or impairments: protocol for the mixed methods intersectional asset-based study CICADA

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Abstract

Background

The pandemic has inequitably impacted the experiences of people living with ill health/impairments or from minoritised ethnic groups across all areas of life. Given possible parallels in inequities for disabled people and people from minoritised ethnic backgrounds, their existence before the pandemic and increase since, and the discriminations that each group faces, our interest is in understanding the interplay between being disabled AND being from a minoritised ethnic group.

Objective

The overarching aim of the CICADA project, building on this understanding, is to improve pandemic and longer-term support networks and access to and experiences of care, services and resources for these under-served groups, both during the pandemic and longer term, reducing inequities and enhancing social, health and wellbeing outcomes.

Methods

This mixed methods study involves three 'sweeps' of a new UK survey, secondary analyses of existing cohort and panel surveys, a rapid scoping review, a more granular review, and qualitative insights from over 200 semi-structured interviews including social network/map/photo elicitation methods, and two subsequent sets of remote participatory research workshops. Separate stakeholder co-creation meetings, running through the study, will develop analyses and outputs. Our longitudinal study design enables us to explore significant relationships between variables in the survey data we

collect, and also changes in variables with time, including consideration of varying pandemic contexts. The qualitative data will provide more granular detail. We will take a strengths and assets-based approach, underpinned by the social model of disability and by intersectional considerations, to challenge discrimination. Our exploration of the social determinants of health and wellbeing is framed by the social ecological model.

Results

The CICADA project was funded by the Health and Social Care Delivery Research (HSDR) Programme of the National Institute for Health and Care Research (NIHR) in March 2021 and began in May 2021. Further work within the project (84 interviews) was commissioned in March 2022, focussing on mental health specifically in North-East England, Greater Manchester and the North-West Coast. Data collection began in August 2021, with the last participants due to be recruited in September 2022. As of January 2022, 5,792 survey respondents and 227 interviewees had provided data. From April 2022, the time of article submission, we will recruit participants for the sub-study and wave 2 of the surveys and qualitative work. We expect results to be published by winter 2022.

Conclusions

In studying the experiences of disabled people with impairments and those living with chronic conditions who come from certain minoritised ethnic groups, we are aiming for transformative research to improve their health and wellbeing.

Keywords: Racism, minoritised ethnic group, disabled, social care, intersectional, pandemic, social networks, public health, migrant, COVID-19.

Introduction

Background and rationale

The particular challenges faced by vulnerable groups during the COVID-19 pandemic, including people from minoritised ethnic backgrounds and people with underlying health conditions/impairments [1-7], are now well recognised. In the UK, while 17.2% of the population are recorded as disabled, they represented 59.5% of all UK COVID-19 deaths to November 2020 [8]. Similarly, though 13% of the UK population are from minoritised ethnic backgrounds, they represented 33% of critically ill COVID-19 patients between February and August 2020 [5,6]. This was partly because chronic conditions such as diabetes and cardiovascular disease are disproportionately prevalent in some minoritised ethnic groups [9] as well as being risk factors for serious illness or death from COVID-19 [10]. Moreover, perceived discrimination and perceived lower socioeconomic status are also associated with greater COVID-19 health risk [11]. These findings show the importance of considering different intersecting factors that compromise good health outcomes.

Box 1: Inequities for minoritized ethnic groups, and those with chronic conditions/impairments, increasing their risk of poor pandemic health and wellbeing outcomes [1,2,11]

1. **Increased risk of isolation, abuse or neglect, poor access to informal emotional and wellbeing support**, due e.g. to national pandemic responses, stigma, changed activities, priorities, attitudes of others, a state of ‘normalized absence, pathologized presence’ [12].
2. **Inequitable formal treatment, support and care** from attitudinal, structural, policy, cultural, linguistic, communication and economic barriers, leading e.g. to difficulties implementing recommended COVID-19 avoidance strategies, vaccine mistrust, and risk of severe illness.
3. **Psychosocial factors raising COVID-19 risks, reducing capacity to cope** with social, economic and psychological pandemic impacts, including worries about people ‘back home’.
4. **Unemployment/reduced income** (e.g., zero-hour contracts; over-representation in the unskilled service sector; ‘no recourse’ to welfare).

As Box 1 shows, the pandemic has inequitably impacted the experiences of people living with ill health/impairments or from minoritised ethnic groups across all areas of life and not only in relation to COVID-19 illness. Given parallels in the inequities for disabled people and people from minoritised ethnic backgrounds, the increase in these inequities since the pandemic, and the discrimination that each group faces, we were interested in understanding the interplay between being disabled AND being from a minoritised ethnic group. This has been a neglected area in research and policy. Certainly before COVID-19 vaccination programmes were rolled out, there was more focus on the COVID-19 mortality of discriminated-against groups than on their general health and wellbeing during the pandemic. Moreover, international concern about pandemic-induced mental health issues has tended to take a population-wide focus, side-lining the especially poor pandemic-related mental health experienced by some people from different minoritised ethnic groups [13; for an example of this see 14].

Most peer-reviewed published articles on chronic conditions/impairments and the pandemic have been survey or audit-based considerations of reduced patient footfall for, or access to,

consultations. In a global COVID-19 survey, 17% of 548 respondent rheumatologists estimated that 25% of their patients had no access to telehealth [15] and therefore little clinical support. It is increasingly recognised worldwide that the rapid move to remote healthcare has accentuated inequities for some. Problems with pandemic telehealth services are currently under scrutiny in the UK and have been experienced by CICADA study clinical team members, though remote consultations also have benefits.

Interviews in Italy with representatives from seven voluntary organisations that specialised in disability highlighted bureaucratic challenges, and shortfalls in advice, coordinated care plans and inter-agency coordination to compensate for reduced services in the pandemic [16]. Similar issues have been reported in the grey literature. Systemic pre-pandemic failures were perceived by respondents to a European Federation of Neurological Associations (EFNA) global survey to have led to the collapse of normal neurology care pathways during the pandemic [17]. Healthcare services for people with rare and complex conditions have fared especially badly according to the European H-CARE Survey [18]. In the UK, the organisation National Voices collated 2020 data from a range of third sector pandemic surveys specialising in disability and health conditions, reporting: issues with mental health, managing symptoms and/or deteriorating health and finances; access to medication, food, health and social care; impacts on carers; and problems with accessing or understanding information [19].

There are several examples in peer-reviewed journals of small surveys internationally that have shown how reduced access to treatment negatively impacts patients' symptomatic control, for example in the cases of Parkinson's Disease [20], migraine [21], rheumatology [22] and chronic refractory neuropathic pain [23], leading to an increased reliance on support networks [24].

Even within these studies, there is very little recognition of the way the particular challenges faced as a result of belonging to a minoritised ethnic group might intersect with, or be compounded by, the challenges faced by having underlying health conditions/impairments. Minoritised ethnic groups with a chronic condition or impairment are more likely to die from COVID-19 [3-8,10,24], in the historical context of poorer health outcomes more generally [4,7,25-27]. The unifying explanation is ingrained racism. Twenty-five percent of doctors responding in a US survey reported that pre-existing socioeconomic issues caused by structural racism, combined with institutional racism, when added to pandemic constraints on care, made it even more challenging to care for Black asthma patients than others in the pandemic [28]. Another US survey showed pandemic telehealth was used by Black patients more than by White patients. This was attributed to the need of Black patients to compensate for prior health and health care disparities caused by systemic racism [29].

Aim and research questions

Given the current evidence gaps and the pressing need for these to be filled, the broad questions underlying this research project are therefore:

1. Are the pandemic-related issues faced in different aspects of daily living, summative, additive or broadly similar in people from minoritised ethnic groups who also have chronic conditions/impairments as compared to people belonging to either one of these two categories?
2. What can we learn about how different people successfully draw on different assets, coping strategies and other strengths or developed solutions to deal with these issues in different pandemic contexts?
3. Which intersecting social categories are the most significant in shaping these answers?
4. How can a systematic, living map of existing evidence contribute to understandings about the pandemic-relevant experiences of having an impairment/chronic condition and belonging to a minoritised ethnic group?

In aiming to answer these questions, we will undertake primary and secondary research to improve our understanding of the pandemic-related issues faced by minoritised ethnic groups with chronic conditions/impairments in different aspects of daily living, and the different assets, strengths and solutions they have drawn on. To better understand their particular experiences, we compare them with people self-identifying as being of White British ancestry, with and without chronic conditions/impairments, and people from minoritised ethnic groups with no chronic conditions/impairments. We will use our findings to help to mitigate inequities and improve their experiences, support networks, and access to and experiences of care, services and resources. We plan to achieve this by developing and informing evidence-based formal and informal strategies, guidelines, recommendations and interventions for health and social care policy and practice. These outputs are intended to improve social, health and wellbeing outcomes for under-served groups, both during the COVID-19 pandemic and longer term.

Theoretical underpinnings

We will take a strengths and assets-based approach, underpinned by the social model of disability and by intersectional considerations to challenge discrimination [30,31]. Our exploration of the social determinants of health and wellbeing is framed by the social ecological model [32,33].

Disability models

Medical or biopsychosocial models of disability have led to the continued disenfranchisement and marginalisation of people with physiological impairments, through the conflation of patho-anatomical diagnostic criteria with disability itself [34,35]. In other words, the two are inseparable and the person with the diagnosis is only seen as dysfunctional. This leads to ableism (discrimination in favour of non-disabled people) [36] and disableism (“discriminatory, oppressive, or abusive behaviors arising from the belief that disabled people are inferior to others” [37, p.9]).

The CICADA study resists the use of these deficit-focused disability models, instead taking as its

starting point the social model of disability because of its currency, its usefulness in driving transformative outputs, and its relevance to much-needed revisions in continuing discriminatory statute and law [38]. This continued discrimination is despite the UN Convention on the Rights of Persons with Disabilities [39]. In the social model, impairments, as physiological problems of the body, are decoupled from disability, which results from exclusionary social oppression and prejudices [36]. Society, by accommodating impairments through the removal of iniquitous barriers to inclusion, can enable the full participation of all, across every area of life.

While important, the social model has limitations which are the topic of much discussion [40,41]. For example, Siebers [40] argues for: (a) more complex understandings of embodied variation; and (b) more dynamic problematisation of the liminal spaces occupied by lived reality than that afforded by the social model. Arendt's [41] criticism of the social model is that more account needs to be taken of the ways people with impairments internalise and make meaning of their lived experiences. We will therefore also draw on alternative non-deficit models in our analyses. Our overall interest is in how individuals with chronic conditions or impairments experience and make meaning of the world through their embodiment within it at the intersection with various other simultaneously and variably interacting social factors.

Intersectionality

Rather than separately considering the multiple social categories of “identity, difference, and disadvantage” [42, p.171] such as gender, racial/ethnic minoritisation, disability and occupation, we consider them as co-existing interacting systems of oppression. In other words, they work together (are mutually constitutive) under discriminatory institutional and structural conditions to create [43-46] lower levels of physical and mental health, poor access to quality health care, and poorer health outcomes [47-50]. Citizenship status adds an infrequently considered further important layer of complexity that we explore in the CICADA study [49]. There is a particular lack of research on the

ways health outcomes are shaped for undocumented migrants through their structural construction as 'illegal' [50] within a hostile environment [51] with 'no recourse' to welfare and housing support.

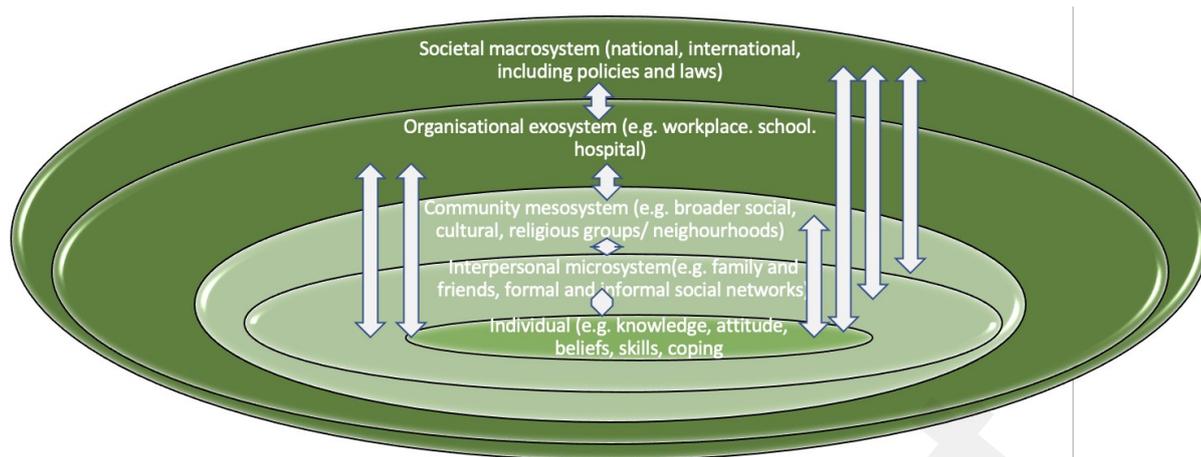
We consider both individual experiences of day-to-day discrimination and the wider context. We use the term minoritised ethnic groups to emphasise the stigmatisation and oppression that racialised society bestows on particular ethnic groups as racialised "others" [52] rather than to necessarily ascribe to them a "minority" status. An alternative term, 'racialised communities', is also used in some study documents to indicate the nature of this oppression.

Shifting identities among people who have recently migrated, in the face of racism, can include the racialisation process of "becoming White". This process tends to be neglected in the health literature [53] and is one which we also consider. We hypothesise negative consequences for recent immigrants of Arab or Central and East European ancestry, who may experience the tensions of being symbolically included in a White ethnic category but are excluded from many of its benefits [53], in a manner that is often invisible because of the lack of its exploration.

Through considerations such as these, built into the study design, intersectionality theory will allow us to develop complex nuanced insights into differences, while minimising the risks of: a) essentialising some combinations as inherently problematic; or b) considering the minoritised experience as homogenous.

Social ecological approach

Figure 1: The Social-ecological Model (adapted from Bronfenbrenner [32]); arrows show the bidirectional flows of interactions between levels as a complex system.



Intersectionality conceptualises the ways an individual's social interactions are shaped by their multiple subject positions (for example, as a female, a recent migrant, a disabled person). The social ecological model (SM) [32,33] highlights the ways this individual is positioned at the centre of a system of mutually influencing sets of social determinants incorporating their personal, community, regional and national (policy and society) ecosystems of norms and practices. Embodied experiences of migration, citizenship, chronic conditions and impairments are necessarily intersectional with areas of potential discrimination and oppression across the different levels of the SM. Hence the need for a range of comparisons and involvement of multiple stakeholders in our study that ensures any potential strategies and recommendations we develop will apply both within and across the different levels [54]. This also fits with the new UK National Health Service tiered Integrated Care plan [55]; the CICADA study is set in the UK.

Intersectional interactions across the levels of the SM are in constant flux, which Bronfenbrenner represented by the chronosystem in a development of his original model [56]. Recognising the importance of these changes over time, our study is longitudinal. Our work is also underpinned by the Consolidated Framework for Implementation Research (CFIR) [57]. This is an amalgamation of various implementation theories that target different levels of the SM, and we use it to comprehensively explore the feasibility of implementation of our recommendations and other

outputs. The CFIR is easy to operationalise, flexible (the user selects relevant themes from a pool of 39) and facilitates actionable findings across multilevel implementation contexts.

Assets-based approach

Our intersectional and critical disabilities approaches facilitate the interrogation of our data for participant assets and strengths as well as the barriers they face. For example, small cross-sectional analyses suggest some chronic conditions and impairments may confer resilience to mental health or wellbeing effects of the pandemic [58,59]. In a UK analysis of chronic fatigue during the pandemic, Reddit reported more severe symptoms in some people but also more accessible opportunities to interact (through online videocalls) [60]. Strengths/asset-based approaches involve a holistic focus on both personal strengths (internal factors such as resilience and external factors such as material assets) and social and community networks. This opens up spaces for individuals who experience disadvantage to be viewed as important partners in the development of change processes rather than problems to be acted upon. Our approach falls under a branch of asset-based work sometimes termed Positive Deviance. This looks for positive outcomes in the face of adversity, as well as behaviour and community development needs, where further support could develop or add to assets and strengths. We are mindful to ensure this does not reduce the need for state intervention (we will take pains not to deproblematise contexts or suggest improvements should be a community, rather than a policy, responsibility). A strengths-approach does not try to take the focus away from the structural causes of inequalities [61], but rather aims to empower communities and individuals [61] in meaningful and sustainable ways. It is based on salutogenic theory [62], which positions people as co-producers of health, rather than consumers of health services [63], and recognises the need to consider that individuals have intersectional identities. This approach has greater transformative potential than deficit-focused approaches [64].

Methods

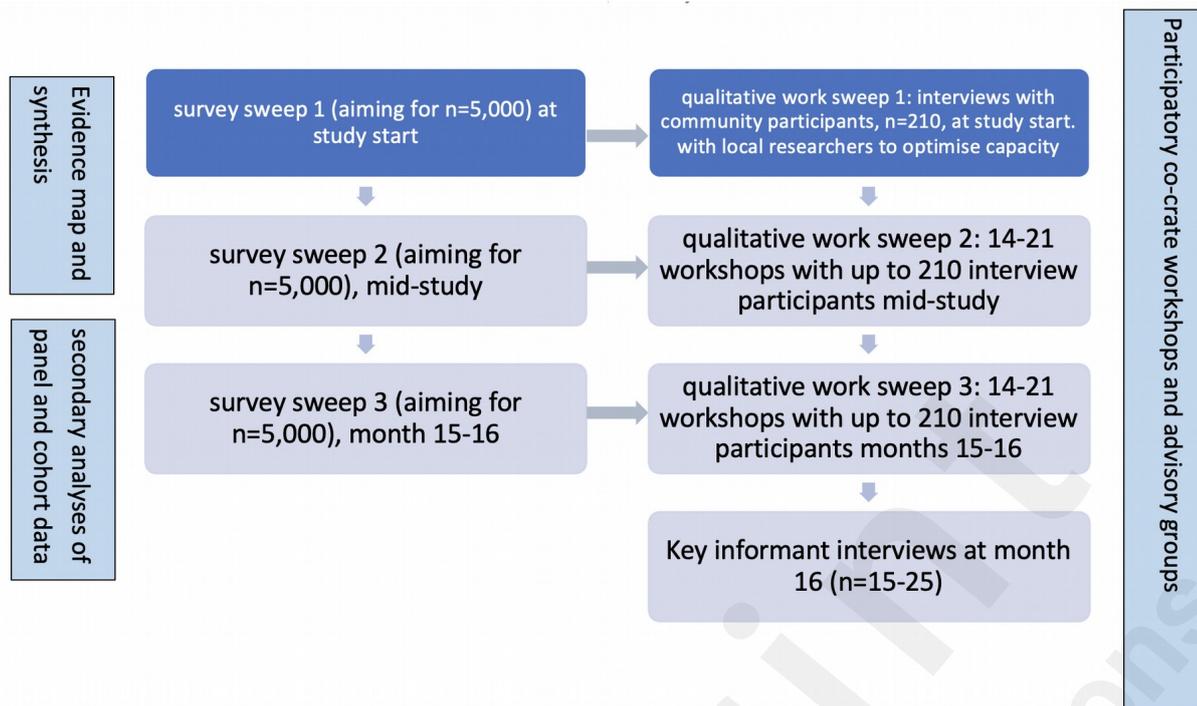
Ethics approval

The study has Institute of Education, University College London, Research Ethics Approval (UCL IoE REC 1372, and amendment 1450 Covid-19, Data protection registration number: Z6364106/2020/06/24) and will follow FAIR Open Science principles of accountability and transparency [65]. We also have NHS ethics approval to recruit participants at NHS sites (IRAS: 310741, CPMS ID: 51755 – CICADA recruitment).

Overall design

We will use a longitudinal mixed methods approach to develop a rich understanding of study participants' mental and physical health, coping strategies, access to resources, and informal and formal social and healthcare support experiences. We will explore relevant assets and strengths for wellbeing enhancement, and examine variations through the lens of intersectionality. Analyses, outputs, dissemination and implementation plans will be co-created with key stakeholders.

Figure 2: Flowchart to show the design of the CICADA study.



Our design (Figure 2) includes three ‘sweeps’ (i.e. repetitions) of a new UK survey, secondary analyses of existing cohort and panel surveys, a rapid scoping review, and a more granular review. We will incorporate qualitative insights from 210 semi-structured interviews, including network/map/photo elicitation methods, and two subsequent sets of remote participatory research workshops that roughly coincide with survey sweeps two and three, designed instead of second and third sweep interviews to minimise participant burden. Stakeholder co-creation meetings will run through the study and are key to implementation of outputs. Policymakers such as those within Public Health England (now the UK Health Security Agency), and practitioners such as clinicians and social support workers, specify an urgent need for participatory work with minoritised ethnic groups [66]. Our embedded social network analysis will provide important insights on how to improve information channels, routes into health/social care and support, resilience to stress and post-disaster recovery [13,64]. We will include consideration of new service delivery models, some of which are already planned to continue beyond the pandemic (e.g. telemedicine [67,68]). Our longitudinal study design enables us to explore significant relationships between variables in the survey data we collect, and also changes in these over time. We will include consideration of varying

pandemic contexts such as lockdowns, restrictions, and their relaxation. The qualitative data will provide more granular detail.

Primary data collection instruments and topic guides for the survey, interviews and research workshops

The left-hand column of Table 1 shows the eight topics that run through the study. These topics have informed the reviews, topic guides, research workshops and surveys. Instruments included within our surveys are shown in the right-hand column as an example of this; they are mostly validated by their developers in different newly migrated populations, and thus are particularly appropriate for use in this study.

Table 1: Our eight topics that run through all parts of the study, with the corresponding survey instruments/items

Topics across all study parts that structure our reviews, topic guides and surveys	Survey instruments/items
Intersectionalities.	A range of demographic variables [69,70].
Behavioural responses to COVID risk-reduction measures including vaccination.	‘Control of life’ (including COVID-19-related).
Access to resources, support, care, vaccines, including digital transformation, service innovations.	QOCS-ID [71], Vulnerability Assessment Framework [72] for care needs, UK government SAGE group recommended questions.
Social networks.	Developed from the close persons questionnaire [73] to contextualise other topics.
Mental and physical wellbeing/quality of life as primary outcomes.	WHOQOL-BREF-ID [71].
Coping.	Including tolerance to uncertainty, positive appraisal

	style, attitudes to being ill (WHO ADS [71]), pandemic health and mental health consequences (Global Mental Health Assessment Tool [74]), why they arose and how issues can be mitigated.
Local and regional differences in responses linked to policies/ interventions and associated impacts.	Apart from within-survey analysis, we will match respondents' area code of postcode with area-level (i) ONS registered COVID-19 cases, hospitalisations and deaths and (ii) Google data on social distancing adherence.
Vaccines, Future policies.	Freetext comment boxes.

The primary outcomes, some of which are indicated in Table 1, are as follows:

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.

Secondary outcomes are as follows:

1. fear of death using the Templer Death Anxiety Scale [75] at 10 and 16 months by online survey;

2. thematic qualitative data from survey freetext, interviews and workshops:
 - a. patient experiences of health and social care and other forms of formal and informal support during the pandemic, and their perspectives on the impacts on their health;
 - b. consideration of the impacts of their identity (e.g., disabled, from a specific ethnicity, from a low income background) on these experiences;
 - c. consideration of their beliefs (health beliefs, covid beliefs, vaccination beliefs) and how these affect other themes;
3. 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.

Surveys will vary by sweep. Key outcome and exposure variables that we expect to change over time will be measured in all three sweeps to study trajectories. Theoretically stable concepts (e.g., tolerance to uncertainty, demographic characteristics) will be measured only in one sweep. Key topics may be added to sweeps 2 and 3 that have been identified through our other work.

Review process

Our two-stage review work will:

- Stage 1: Create a systematic (living) map to summarise the pandemic-relevant experiences of living with impairments/ chronic conditions and/or being from a minoritised ethnic group across the topics in Table 1.
- Stage 2: Undertake an in-depth analysis and synthesis on specific aspects determined according to the map.

This will ground the research in current evidence and generate themes that can be incorporated in the primary data collection design.

In both stages, two reviewers will independently screen titles, abstracts and full texts against inclusion criteria, and extract data. They will compare a subset of this work to check for consistency as quality control, with any disagreements to be resolved by a third researcher. We will assess risk of bias using Cochrane-recommended checklists, also noting the provenance and publication status of sources. Data extraction will be managed in 'EPPI-Reviewer' software and will reflect the inclusion criteria and the designated aims of the review.

The review inclusion criteria, using a modified 'SPIDER' [76] framework (see letters in bold below), are as follows:

- **Sample:** People with any chronic condition/impairment, and/or from a minoritised ethnic group within their country of residence (see 'Setting' below).
- **Phenomenon of Interest:** Lived experience during the pandemic, social networks and relationships between intersectional variables and health and social care outcomes. Testimony from informal and formal carers may be included where it: a) directly relates to the topics; and b) considers the perspective of people with a chronic condition/impairment, and/or from a minoritised ethnic group.
- **Design:** All study designs.
- **Evaluation topics:** The topics listed in Table 1.
- **Research source:** All sources of research evidence, both peer-reviewed and pre-print/grey literature, augmented by data from tweets (given a fast-moving pandemic-responsive field), and websites of relevant public bodies/agencies.
- **Setting:** International studies (though the setting of our study is the UK, it is important to develop a broader knowledge that may be transferable to the UK, or may provide context, useful models or lessons to be learned).

Filter restrictions are:

- *Date:* Peer-reviewed articles published since 2000, grey literature since January 2019 and other sources since 2020 to balance currency of the data with the identification of a broad view of developing issues.
- *Language:* English.

The outcomes, and the focus of the granular review, will depend on the evidence available, and gaps in the evidence will be highlighted for future study. Reporting will follow PRISMA guidelines. The review is registered with Prospero (CRD42021262590).

Review data analysis

Reporting of the data will depend on the types of included studies, for example descriptive statistics, narrative synthesis and diagrams. We will perform subgroup analyses where appropriate.

Use of existing datasets

We will undertake secondary analysis of data relevant to the topics in Table 1 from several existing data collections, for triangulation and complementary insights. This includes the ActEarly city collaborative consortium's [77] pandemic surveys of families in Bradford and East London, and pandemic surveys within nationally representative cohort studies curated at the Centre for Longitudinal Research (CLS), University College London. None have our overall focus but include some relevant questions. The overlapping variables between the ActEarly, CLS data, and our own survey will enable us to compare and assess data quality across surveys.

To place our primary survey data within existing and prior national contexts, we will conduct our secondary quantitative analyses on three periods: before the pandemic (up to 01/01/20); pre-

relaxation of the winter-spring 2021 lockdown in the UK (up to May 12th, 2021) and thereafter (to autumn 2022). Should the data enable this, we will also subdivide the third period to match the dates of the three sweeps of our primary survey. Since these are secondary analyses, we will be mindful of and discuss relevant biases, and contextualise according to the evolution of the pandemic.

The three-sweep primary survey

The primary survey is online and will collect quantitative and qualitative (freetext) data.

Survey sampling and recruitment

Survey sampling across the four nations of the UK will be open to any adult living in the UK, but purposively targeted via selected sites and networks to encompass all conditions/impairments and organisations supporting minoritised ethnic groups including recently arrived and undocumented migrants. Sampling will not depend on individual patient data such as that which could be obtained via electronic health records, to ensure we include people who are self-diagnosed or who perceive themselves to have a different diagnosis to the one held in the electronic record, as well as participants not registered with primary care. We will be mindful of the different biases this causes and will collect data on whether or not a diagnosis exists and whether the person agrees with this diagnosis, for in-depth understanding.

The three survey sweeps will be evenly spaced over 15 months, with each sweep open for a month. Recruitment will predominantly involve distribution of a survey link via social media, and specialist and national networks (such as academic, health service, third sector), as well as mailing lists and large databases of adults interested in health research across the UK. We recognise this strategy, being non-randomised, will be biased, for example to those already interested in research participation, or who are active users of third sector sites and have online access. We will make

available print copies for community groups involving participants lacking internet access. We will compare respondent demographics to whole population estimates where possible, to explore representativeness (though formal data are limited).

Survey numbers and power

Our new longitudinal survey will enable a description of the trajectories of key variables and outcomes and the links between them. Free-text data will also be analysed for patient experience.

The survey will not be used to test a particular treatment or focus on a single effect.

In our basic Structural Equation Modelling (SEM), we have six core latent variables (factors) per sweep:

1. quality of life,
2. control of life,
3. access to care,
4. coping mechanisms,
5. mental health, and
6. social networks.

Considering statistical power in SEM [78]:

- The required sample size increases with the number of latent variables, but at a decreasing rate (i.e., the required sample size difference between a model with one versus two latent variables is larger than that between a model with three versus two latent variables).
- The required sample size decreases strongly as the loadings on latent variables increase (i.e., the magnitude of the association between latent and observed variables, where values below 0.9 are generally taken to show confounding).
- The power increases as the number of items (questions) used to measure each latent variable increases.

In terms of our study, each latent variable will be measured by several items (the average number being more than 8). In a worst-case scenario with average loadings of around 0.5 and an item missingness of 20% (as suggested from ActEarly work), a sample size of 800 per subgroup per sweep will yield useful analyses. We have four main subgroups (i.e., self-identifying as: i) minoritised ethnicities with a chronic condition/impairment, ii) minoritised ethnicities without a chronic condition/impairment, iii) white British ancestry with a chronic condition/impairment, iv) white British ancestry without a chronic condition/impairment). Using these four comparator groups enables us to fully understand the nature of relationships between different variables and the influence of chronic condition/impairment and minoritised ethnic group categories on each, both separately and combined. Thus, the required sample size is $800 \times 4 = 3,200$, though we aim for 5,000 for a more robust sample [78].

Survey analysis

A descriptive statistical summary will be updated with each sweep. More in-depth analysis, using SPSS, R, Stata or Python, will exploit all three sweeps of the data, with these research questions (RQs):

1. How do outcomes (resource access, formal/informal care, quality of life, control of life, physical and mental health, social networks) and outcome trajectories differ by sample subgroups (minoritised group, condition/impairment, citizenship status) and intersectional combinations? This cuts across all three of our overarching research questions.
2. To what extent can COVID-19 prevalence and pandemic adherence to social distancing at the area level explain differences in outcomes and outcome trajectories across subgroups and in terms of intersectionalities (as a proxy for pandemic contextual factors)? This relates to our third overarching research question.

3. How do the outcomes inter-relate within and across survey sweeps, and how does this differ across groups of the sample and in terms of intersectionalities? This cuts across all three of our overarching research questions.

For RQ1 and RQ2, we will exploit the longitudinal nature of the data using Latent Growth Modelling (LGM), with ‘multiple group’ analysis, varying different combinations to consider the effect of intersectionalities on outcomes. Depending on geographical coverage and the numbers recruited, the LGM estimation for RQ2 could be carried out within-area, to examine the causal impact of the change in COVID-19 prevalence and pandemic social distancing across the sweeps on each key outcome, under the assumption that this is exogenous. We will examine the plausibility of this assumption and detail possible sources of endogeneity. This will be important for policy, given our unique subgroups focus. For example, our data could help clarify why specific groups may find it unfeasible to adhere to recommended behavioural responses. For RQ3 we will estimate a developmental cascade model, including all three data sweeps and key variables, to explore how the key variables are associated with one another, both within survey sweeps and over time. We will fit the LGM models using SEM; this offers useful tools for dealing with missing data due to non-response and attrition.

The **Social Network Support Module** of our model will consider how respondents are connected to others who provide support to the respondent (through relations such as friendship, kinship, exchanges, activities, etc.) [79,80]. Characteristics such as the participant network’s size, composition, and resources available will result in a latent ‘network capital’ variable created through measurement analysis within the SEM as a novel contribution. These network metrics will be used to provide a descriptive presentation of the network/s and any changes over time.

Missing data

We will require completion of almost every question on every page for participants to proceed, so we can undertake the association analyses required. This means there should generally be no *missing* items in any measures. But this requirement may lead to *completion attrition*, with respondents giving up and logging off. We will try to mitigate that in the design, which will allow participants to save responses and return to the survey later, and the survey will be developed and piloted with N=30 people from our advisory group and patient advisory group (PAG). There is also the risk of attrition *between* sweeps. Participants will be asked to provide an email address on enrolling online. The RedCap online secure system that we will use will automatically re-contact them for sweep 2/3 follow-up questionnaires (with reminders). This automatic process makes for efficient and secure second and third sweep recruitment to reduce the risk of missing respondents. Lotteries appear effective in some online surveys [81] and we are including a £50 Amazon voucher as an incentive given at random.

To handle missing data and address panel attrition and item non-response, we will use modern methods, including: Full Information Maximum Likelihood; Multiple Imputation with Chained Equations that produce unbiased estimates under assumptions of missing at random (i.e., missingness dependent on observable data only) and multivariate normality; and pattern mixture models that address missing not at random (i.e., missingness dependent on unobserved data), assuming correct model specification [82]. Those techniques, under certain assumptions, ameliorate loss of statistical power due to missing data, and possible biases due to systematic missingness.

The interviews

Interview sampling frame

Our interview sampling frame follows an intersectional approach, that allows us to consider and

compare assumed homogeneity: a) across chronic conditions/impairments irrespective of heritage, and b) across ancestries irrespective of chronic condition/impairment. The aim of this is to tease out intersectional factors and heterogeneity. To achieve this, we will use a purposive quota sampling approach. At analysis the focus may switch to other commonalities, such as shared barriers or enablers in accessing health and social care resources.

Possible attrition between sweeps (up to 20% based on ActEarly experience) may require further recruitment if theme/pattern saturation is not reached, or early saturation may lead us to more theoretical sampling.

The main interview inclusion criteria are as follows:

- Any condition/impairment, including self-diagnosis, that chronically affects daily activities; the condition should have lasted for at least 12 weeks and have no defined endpoint. These will be categorised in an adaptation of the UK Government Statistical Service harmonised data recommendations as: mental; mobility; stamina/breathing/fatigue (including heart problems); hearing/vision loss; developmental/intellectual; and food-related. These categorisations will then be analysed.
- People living in the UK who were born in, or whose parents were born in, Arabic, Central and Eastern Europe, South Asian or sub-Saharan African countries, with people of self-defined white British ancestry as comparators.
- Aged 18+
- Self-identification of migrant status (with recruitment aiming to cover the range of people whose status is categorised as: undocumented, on temporary visas, with indefinite leave to remain, or British citizens).

We recognise the heterogeneity within these groups, and the way these categories are laden with assumptions, for example with regard to multimorbidities, the concept of being British, the ancestry of people who are born in particular countries, and the apparent essentialisation of specific groups. However, to ensure in-depth data whilst keeping sample numbers to a feasible level, we decided to use these problematic categorisations as tools, to organise our research so that we can then unpack and critique them [83]. The groups have been chosen to reflect recent migration waves to the UK (albeit that some people from these groups may have lived in the UK for decades) and to capture those groups most at risk of hospitalisation or death from COVID-19.

The main interview exclusion criteria are:

- Student migrants as they are likely to have structured educational institution support,
- Residents of detention centres/closed facilities linked to national migration policies (e.g., new asylum-seekers/refugees, displaced or trafficked persons), as these are deemed complex cases with specific considerations.

Interview sites

We sample from five interview sites within England, for maximal sampling diversity in migrant population density, proportion of EU to non-EU migrants, and reasons for migration, to enhance transferability, which we will explore against our four nations survey findings. This is important as we only sample in England for qualitative work, due to differences in the devolved nations' responses to the pandemic and their health and social care systems. Sites for our qualitative research are London, South-east England, North-east England, West Midlands, and Yorkshire. While this means some of our findings may be more relevant to England, we expect principles to be similar across the four nations, and we will consider this in our reporting and outputs.

Recruitment to interviews

We will recruit interview participants from adverts/links distributed through a range of platforms and networks, as well as through local lay co-researchers. We will rely on participant self-identification of citizenship status and condition/impairment. Posters, adverts and snowballing will target those who lack resources or technology to be recruited via online messages; they can contact us by telephone or email. Collaborators will provide recruitment and data collection support through organisations such as Born in Bradford (BiB) in Yorkshire, a long Covid centre [84] in Gateshead, Bromley-by-Bow community centre in East London and migrant charities in London and Canterbury.

Interview process

Respondents can choose to do interviews by phone, remote video methods or face-to-face, depending on extant pandemic restrictions. Our PAG leads will help train lay community members to undertake some interviews locally at our five sites, supported by the core team. Interviews will be recorded. Attention will be given to making the interviews fully accessible and inclusive, and all researchers will be vigilant to participant needs, such as, for example, requiring frequent breaks.

All potential participants will be informed about the study in plain English (read to them if needed) and told that interviews will be in English by default. Where a participant feels more comfortable doing so in another language, if a researcher fluent in that language is available, this will be arranged. Translated and accessible study documents will be provided if required, to ensure that participants are able to give fully informed consent.

We will probe in interviews for the same topics as covered in the survey (Table 1). For social networks, we will discuss the data from the following participant pre-interview tasks:

- a brief questionnaire, data from which we will translate into network ‘maps’ using Network Canvas™ software.
- photographs and sketch-maps of the local area where people live, and the places significant to their healthcare and social interactions, using their smartphones or disposable cameras provided by us. These data will also be thematically analysed. This ethnographic approach facilitates a safe social space to communicate difficult issues and has been used to explore migrant resettlement [85].

The two research workshops and four co-creation meetings

The two research workshops and four co-creation meetings will all be participatory and designed for participants to work in equitable partnership. They will be led by a core team member and a PAG member. They will aim for outputs relevant to the ‘real world’ that will maintain participant voices and will ensure the research outputs can be implemented. Each session will last approximately four hours (two if held remotely).

Research workshop recruitment, sampling and process

The make-up/number of research workshop groups per sweep (2 and 3) will be determined by considering any typologies (patterns in intersectionalities and outcomes) from Sweep 1 data. Participants will be recruited from Sweep 1 interviews.

Sweep 2 workshops will discuss scenarios, or structured vignettes, shown as short videos recorded by community members reading scripts. Content will be developed from Sweep 1 data into a pandemic-relevant story, with accessible transcripts provided in advance. Discussion will consider changes from previous findings. Sweep 3 workshops will follow a similar pattern, with updated vignettes. We will also use participatory scenario planning [86], a policy tool whereby participants are encouraged to explore alternative futures, their impacts and relevant action plans. To ensure inclusivity we will work with our PAG group on workshop accessibility and will offer repeat interviews as an alternative.

Co-creation meeting recruitment, sampling and process

Co-creation meeting participants will include patients and carers (our aim is that they will be representative of our interview participants), as well as key stakeholders in their support and care. They will be recruited via professional or dedicated community networks, such as government and policy, welfare, social and health care staff, migrant, settlement and racialisation-specific services, third sector organisations and community leaders. We will aim for two representatives from each of these groups per workshop, thus approximately 20 people in each. We will be assisted in this process by our PAG.

The co-creation meetings will involve discussion of findings from each data sweep, and their co-created translation into outputs to feed into the next stages or final study outputs, depending on what is appropriate at the time each workshop is held. To enable inclusion and stimulate discussion and outputs, we will use arts-based and participatory approaches, such as miro.com, Collaborative Poetics materials [87] and other co-creation tools [88,89].

Key informant interview process

To explore how outputs can be implemented in policy and practice, 15-25 interviews (up to 5 per site) will be conducted with key informants. These will be identified from earlier phases of the study. These are likely to be drawn from the same categories as our co-creation meetings.

Recruitment plans and topic guides will be informed by our other findings and co-created in our co-creation meetings, and with members of our advisory groups.

Analysis of interviews and workshops

Deductive Framework analysis of the workshop, interview, photo and key informant data will be

used for general dissemination and policy-relevant themes that can be mapped to the survey for added insight. We will also remain open to adding inductive themes throughout analysis. Data collection and analysis will be concurrent for quick outputs and to test emerging and discordant themes.

Interview data will also undergo Keyword in Context (word frequency-based) analysis to compare specific constructs. We will undertake discourse and narrative analyses on a data subset, produced from participant pairs, matched on features identified as important in earlier analysis. Coding, using NVivo, will be undertaken by the core team, with feedback from the advisory groups and co-creation meetings. We will follow good practice for transparency, quality and rigor. Anonymised data will be archived for secondary analyses.

Patient Advisory Group

We have an active Patient Advisory Group (PAG); its members will take part in the co-creation meetings, as well as advising on all stages of the study. They will be supported to be co-authors in any publications we co-produce. We have two PAG co-applicant co-leads. We will adhere to the seven principles of patient engagement [90], namely: Shared purpose; Respect and accessibility; Representativeness; Roles and responsibilities; Capacity and capability for engagement; Transparency in communication and documentation; Continuity and sustainability.

Overall data synthesis and dissemination

We will use cascaded dissemination at each data sweep, tailored to our key audiences, that emphasise practical solutions and implementation. The dissemination plan will be determined with our PAG, and through our co-creation meetings.

Overall synthesis will provide an executive overview for easy assimilation by policymakers and

practitioners. This will indicate where changes to health/social care policy and practice are likely to be most effective. Synthesis will be results-based - that is, tabulation will be derived from data analyses, with table columns for themes/topics, and rows for each distinct set of quantitative and qualitative data. Some data will need to be transformed (quantified or qualitated) for tabulation, such as network graphs. We will interrogate the tabulated data using anchor questions based on the PerSPectif [91] framework (informed, for example, by patterns of data convergence/divergence).

An overview of findings and ideas for outputs will be presented to participating communities more widely, via collaborator platforms, to give them the opportunity to reflect upon and interrogate researchers' interpretations and analysis of the data. Findings and ideas for outputs will also be distributed through trusted community channels, such as places of worship, trusted religious leaders, community champions - possibly tapping into the infrastructure developed from COVID vaccine rollout - and community groups, including collaborators such as Bromley-by-Bow. This will enable broader community input into the final project outputs. All findings will be publicly available via our website in accessible forms for lay consumption with assistance from our PAG.

Results

The CICADA project was funded by the Health and Social Care Delivery Research (HSDR) Programme of the National Institute for Health and Care Research (NIHR) in March 2021 and began in May 2021. Further work within the project was commissioned in March 2022. This will provide a subset of data focussed on mental health specifically in North-East England and will add Greater Manchester and the North-West Coast to our sites, where the NIHR has identified a particular need. Data collection began in August 2021, with the last participants due to be recruited in September 2022. As of January 2022, at the close of wave 1, we had 5,792 survey respondents with usable data from 4,300, and 227 interviews. We plan to collect 84 further interviews for the newly funded sub-study. At the time of submission, beginning April 2022, we are recruiting participants for the sub-

study and wave 2 of the surveys and qualitative work. We expect all results to be submitted for publication by winter of 2022.

Discussion

Anticipated findings and potential impact

In undertaking this study, we will fill a gap in the evidence about the pandemic experiences of disabled people and people living with chronic conditions, particularly those from minoritised ethnic groups. We expect to contribute considerable new knowledge through our mixed methods approach. We consider issues, such as those relating to: access to health and social care and resources; formal and informal networks of support; discrimination and marginalisation. However, we are particularly interested in the strengths and assets that have improved our participants' capacity to cope with the pandemic.

We believe this is important, as many iniquitous pandemic health and wellbeing challenges, such as those faced by minoritised ethnic groups at the intersection with chronic conditions/impairments and insecure citizenship status, can be mitigated by small adjustments to: health and social care service policy and delivery; formal networks such as community health services; and informal networks such as family and friends [24]. We expect to provide recommendations for these adjustments and for potential interventions, through our longitudinal mixed methods analyses. We may also produce some simple interventions ourselves. To attempt to tease out the impact of the pandemic, we will: a) model relationships between mediating variables (including social network features) and health and social outcomes; and b) explore participant current and recent experiences and recall of pre-pandemic experiences and inequities.

Building on prior research

We are undertaking both primary research and secondary data analyses. While the design and focus of our study is unique, the pandemic has fostered the development of a number of contemporary studies looking at particular disabilities, particular 'stakeholders' in disability experiences (e.g. disabled people, health and social care services staff, carers, young people) and particular racial and ethnic groups. Our scoping review, which was begun in 2021, and which includes grey literature, will be updated in autumn 2022 to ensure our findings are reported in the context of these other studies. We will publish our reviews. Our secondary analyses of other panel data will help to contextualise our own findings; for example, we are analysing data from a survey that began before ours and overlapped with our own and which includes some relevant data.

Strengths and limitations

We will provide rich quantitative and qualitative data, with a large sample size for qualitative interviews, providing in-depth information through quota sampling. Our creative participatory and equitable approach will be key to co-creating our outputs, with relevant stakeholders. This will include members of the populations we hope will benefit, third sector organisations, clinicians, social care staff and policy staff. This will ensure outputs that have real credibility, real-world relevance and value, can be implemented and are sustainable.

Whilst the ideal study design would include an experimental evaluation of outputs, we cannot undertake full feasibility testing and trialling of any interventions we suggest, as this is an 18-month study. We may, however, explore implementation enablers and barriers, and acceptability in small proof-of-concept evaluations; these are likely to require ethical review amendment.

We are not using randomised sampling in any part of the study, which is likely to introduce bias. However, rigorous synthesis of the multiple types of data we produce, our strong patient

representation, our participatory approach across stakeholder groups, our overall rigor and adherence to principles of Open Science, and a reflexive approach to biases, should help to contextualise findings within these limitations.

We focus on specific minoritised ethnic groups and specific sites within England in our qualitative work. This has benefits in terms of the depth of analysis for particular groups and settings but could reduce transferability of findings to other groups and settings, which we will explore through our survey, and other existing datasets. Categorisations are laden with assumptions that need to be explored.

The survey, being primarily digital, will exclude people with poor access to the digital world, though we do offer alternatives such as paper-based copies. There is also the potential for pandemic survey fatigue.

In studying the experiences of disabled people with impairments and those living with chronic conditions who come from certain minoritised ethnic groups, we are aiming for transformative research. We are sensitive to the social constructionist nature of terms that are used to categorise particular groups, which can result in tensions. However, we need to disseminate our findings using terms that have meaning to our key audiences. We intend to report on the issues and tensions as part of our wider push for change.

Conclusions

Current understandings and considerations are limited with regard to the health and social care and support received by disabled people or those living with chronic conditions who are from certain minoritised ethnic groups. Inequities existing before the pandemic have been made worse by it, and public and policy awareness of this provides an opportunity for change. This study, using an

intersectional assets-based approach, and drawing on participatory and mixed methods, aims to fill a gap in the evidence, to help to inform changes that reduce inequities.

List of abbreviations

PPI: Patient and Public Involvement

SM: Social ecological model

SEM: Structural equation modelling

CFIR: Consolidated Framework for Implementation Research

NGO: Non-government organisation

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

CLS: Centre for Longitudinal Research (London)

UK: United Kingdom

US: United States

EU: European Union

SPSS: Statistical Package for the Social Sciences

RQ: Research Question

LGM: Latent Growth Modelling

PerSPectif: Perspective, Setting, Phenomenon of interest/problem, Environment, (optional Comparison), Time/timing, Findings

BiB: Born in Bradford

Conflicts of interest

The authors declare that they have no competing interests.

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Authors' contributions

CR conceived the study idea, overall methodology and conceptualisations, and the initial study design, and wrote the first draft of the manuscript. She leads on the study overall. OA and BN contributed to the design of the quantitative methods and VR, JC and SK to theoretical conceptualisations. OA, LB, LG, RD, JC and SK provided substantial revisions to the original draft. KA and WF are undertaking data collection. All authors read, edited and approved the final manuscript.

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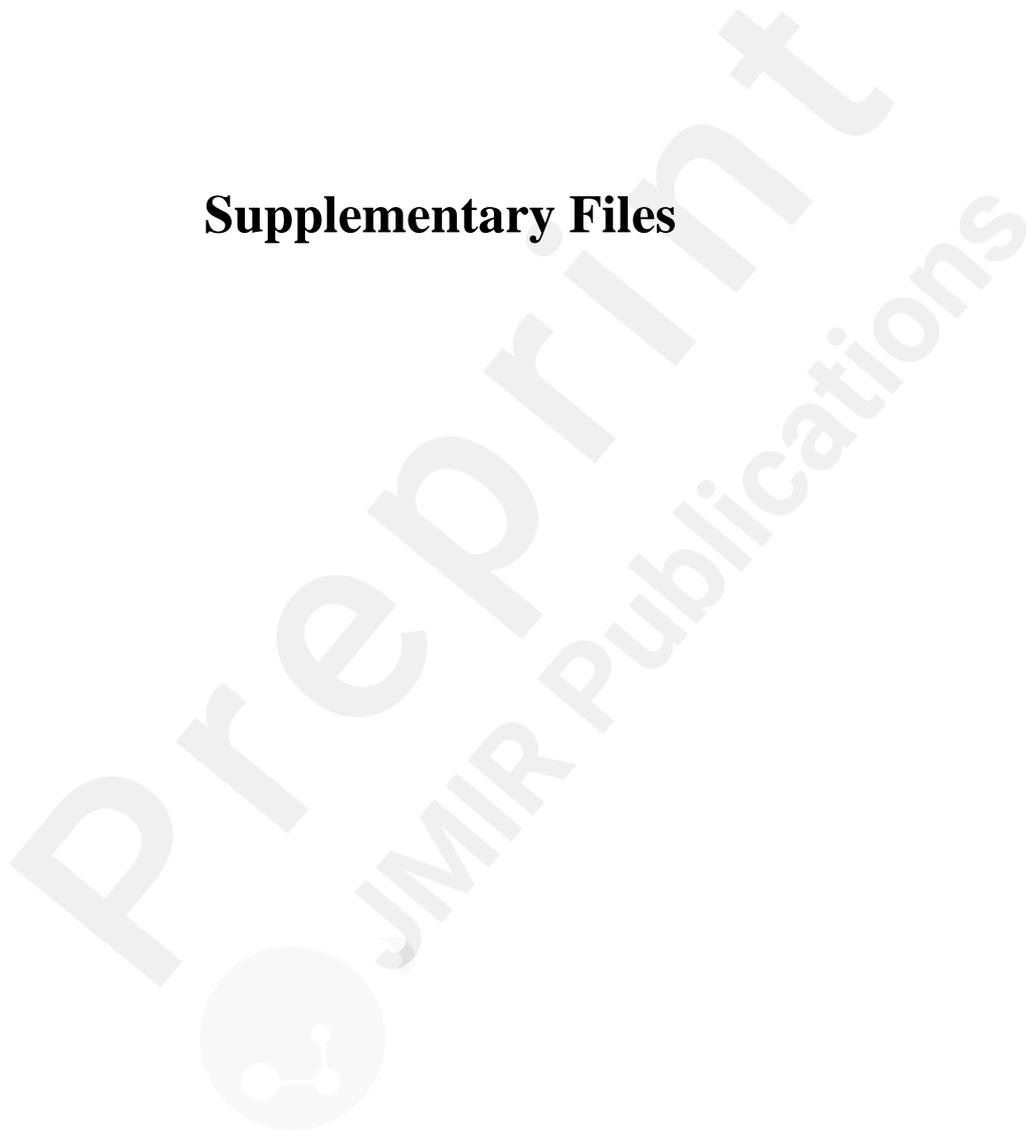
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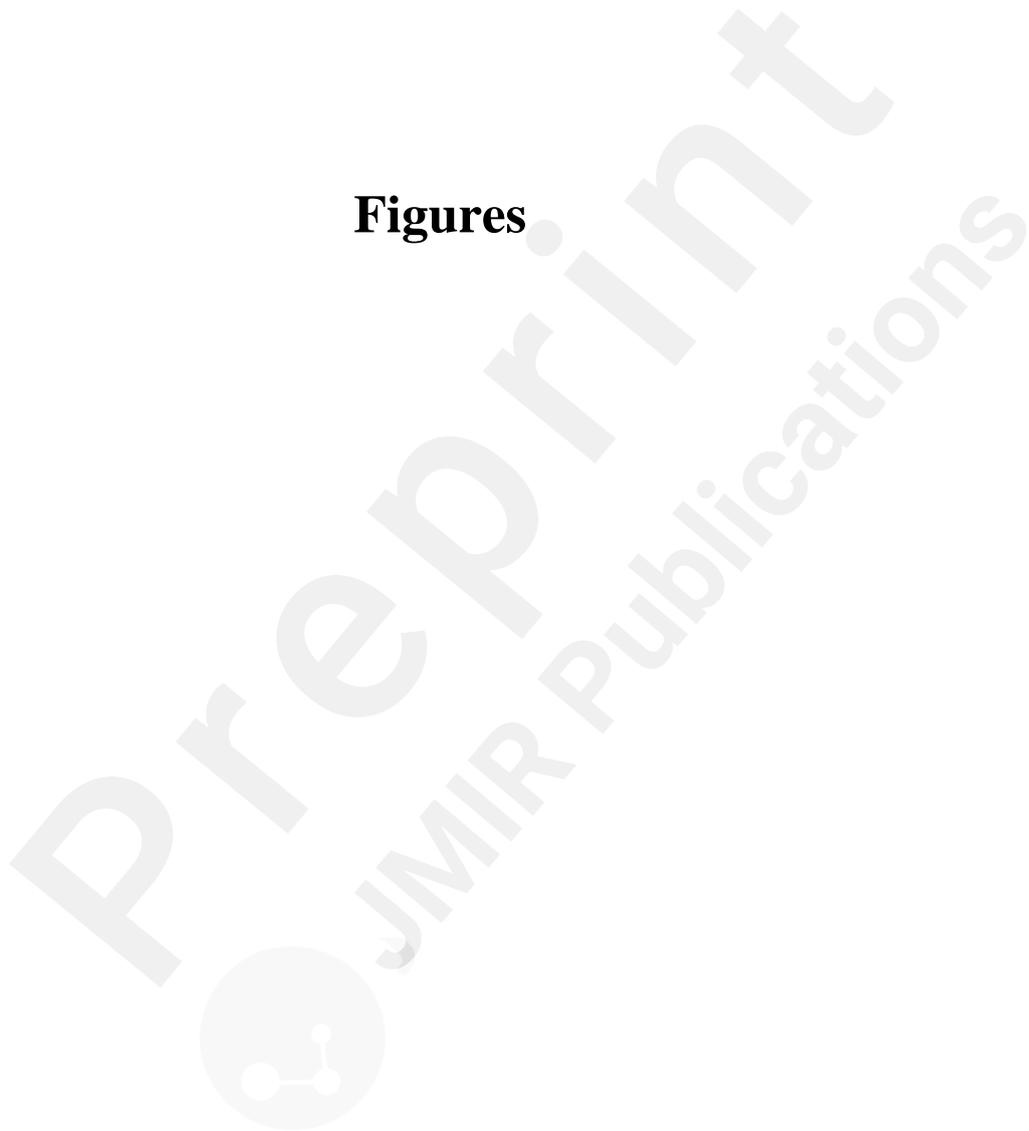
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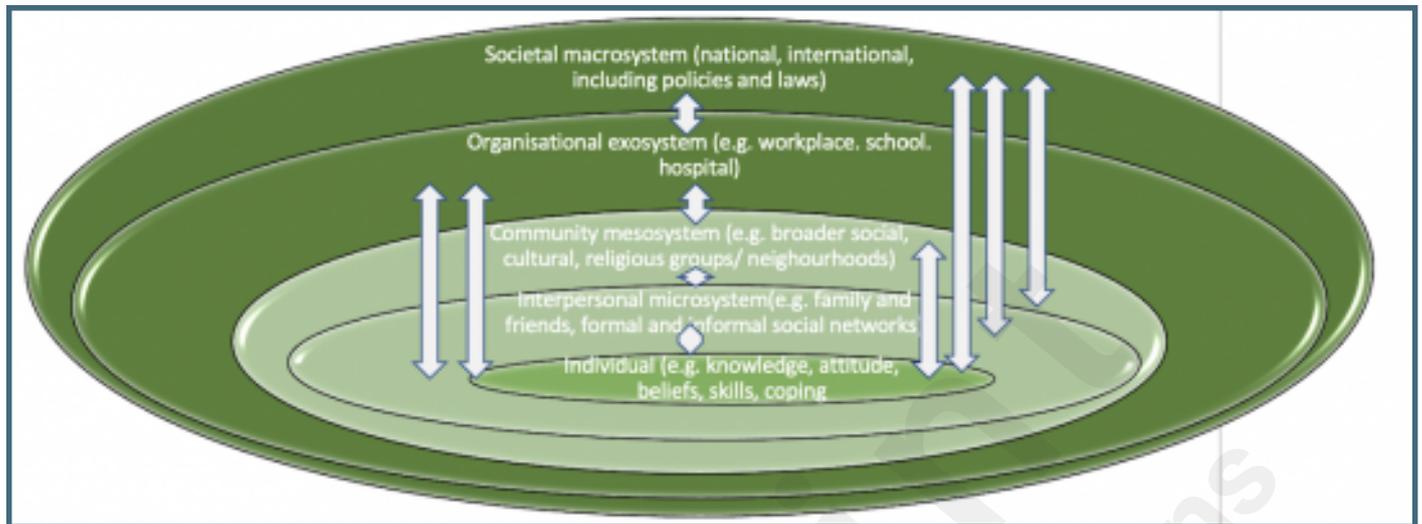
Supplementary Files



Figures



The Social-ecological Model (adapted from Bronfenbrenner [33]); arrows show the bidirectional flows of interactions between levels as a complex system.



Flowchart to show the design of the CICADA study.

