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One virus, many lives: a qualitative study of lived experiences and quality of life of adults from diverse backgrounds living in the UK during the COVID-19 pandemic

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ABSTRACT

Objectives The coronavirus disease 2019 (COVID-19) pandemic has had far-reaching consequences for people’s lives. In the UK, more than 23 million have been infected and nearly 185,000 lost their lives. Previous research has looked at differential outcomes of COVID-19, based on socio-demographic factors such as age, sex, ethnicity and deprivation. We conducted a qualitative study with a diverse sample of adults living in the UK, to understand their lived experiences and quality of life (QoL) during the pandemic.

Methods Participants were recruited with the help of civil society partners and community organisations. Semi-structured interviews were conducted between May and July 2021. Interviews were recorded with permission and transcribed. Transcripts were analysed following an inductive analytical approach as outlined in the Framework Method.

Results 18 participants (≥16 years) representing different ethnicities, sexes, migration and employment statuses and educational qualifications took part. Five key themes and 14 subthemes were identified and presented using the QoL framework. The five key themes describe how COVID-19 affected the following aspects of QoL: (1) financial and economic, (2) physical health, (3) social, (4) mental health and (5) personal fulfilment and affective well-being. The narratives illustrated inequities in the impact of COVID-19 for individuals with intersecting social, economic, and health disparities.

Conclusion Our findings demonstrate the multidimensional and differential impact of the pandemic on different population groups, with most of the negative economic impacts being borne by people in low-paid and insecure jobs. Similarly, adverse social, physical and mental health impacts particularly affected people already experiencing displacement, violence, physical and mental illnesses or even those living alone. These findings indicate that COVID-19 impacts have been influenced by intersecting health and socioeconomic inequalities, which pre-existed. These inequities should be taken into consideration while designing pandemic recovery and rebuilding packages.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ One of the few qualitative studies conducted in the UK that has adopted a comprehensive approach to understand the general population’s quality of life and lived experiences during the pandemic.
⇒ Our study includes participants from various ‘underserved’ groups such as ethnic and cultural minorities, migrants (including asylum seekers and refugees) and factory workers, who are under-represented in the other evidence in this area.
⇒ The qualitative design of the study enabled greater exploration of individual experiences, which augmented the richness and breadth of the data.
⇒ As a qualitative study the findings may not be generalisable.
⇒ Our study was a single time-point study hence longitudinal impacts, especially in light of the recent cost of living crisis, need further exploration.

INTRODUCTION

The coronavirus disease 2019 (COVID-19) pandemic has had devastating and overarching impacts on peoples’ lives all over the world. In the UK, more than 23 million people have been infected, and nearly 185,000 have lost their lives so far in the pandemic.1 Apart from the direct health costs, measures such as lockdowns and restrictions have had a considerable impact on the economy and society at large. The country’s Gross Domestic Product (GDP) had fallen by 25% in April 2020, as compared with February 2020, and was at 0.5% below the pre-pandemic level in October 2021.2,3 Although GDP growth has picked up since then, the impact of the pandemic on inflation and price rise is increasingly evident now.4,5 Related to these financial downturns, employment rates in the UK have also seen a dip since pre-pandemic levels, and ethnic
minority workers, young workers and those in low-paid jobs have been most affected. The closure of schools and educational institutions has also negatively affected children’s learning and attainment, mental health, nutrition and general well-being. While some of these losses may eventually recover, many of the impacts could be irreversible and lead to permanent damage to health and quality of life (QoL) more widely.

Although the pandemic has affected almost everyone, experiences and outcomes have varied depending on individual and social contexts. For example, in the UK, death rates from COVID-19 at the start of the pandemic was highest for people from black African, Bangladeshi, black Caribbean and Pakistani ethnicities. Similarly, data from the Office for National Statistics, UK showed that people who lived in the most deprived areas of England and Wales were two times more likely to die after contracting COVID-19. While previous research has looked at differential outcomes of COVID-19, based on socio-demographic factors, qualitative studies examining differences in the impact of the pandemic on holistic QoL are needed to explicate the socioeconomic gradients of health.

QoL is a multidimensional concept and is defined by the WHO as, ‘individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. In the context of COVID-19, factors such as loss of social contact, economic constraints, concerns about well-being and existing physical and/or mental health conditions are all likely to have a bearing on a person’s QoL. Most studies examining QoL during the pandemic have been either conducted among COVID-19 patients or focused on health-related QoL of people with pre-existing physical or mental health conditions. We conducted a qualitative study with adults from diverse backgrounds living in the UK, to understand their lived experiences and holistic QoL during the pandemic. In this study, we highlight the range of socioeconomic and health impacts that individuals, families and communities have endured during the pandemic, which in turn can be useful in understanding the socioeconomic gradient of health in general and also informing recovery and rebuilding efforts in post-pandemic times.

**METHODS**

**Research design**

We designed our research as a rapid qualitative inquiry to understand people’s experiences of living through the COVID-19 pandemic and the changes that have come about in their lives on account of it. This is to understand how an individual’s ‘real-life’ context influenced his/her experiences of the pandemic. We wanted to explore how the social, cultural, political and historical contexts that people occupy have determined how different individuals have experienced the pandemic and what impacts it has had on people’s QoL.

**Study setting, participants and recruitment**

The study was conducted with 18 participants living in the UK, and predominantly in Leicester, which is one of the most ethnically diverse cities in England and also ranks very high in the deprivation index. Leicester was also one of the worst COVID-19 affected areas in the country with high case and mortality rates and had to endure longer lockdown and restriction measures on account of this. Participants were adults (>16 years) from different ethnicities, migration statuses, employment statuses and educational qualifications. This enabled us to acquire data saturation by means of having a ‘thick’ data set that is, ‘many layered, intricate, detailed (and), nuanced’. The sample size was not pre-fixed but was determined by how many participants were recruited during the recruitment and data collection period, which was roughly 4 months. Participant recruitment was supported by civil society partners and community organisations that had worked with the research team on previous projects. These included charities working with homeless people and migrants, educational institutions, ethnic and religious groups and employing organisations such as factories. Participants with basic English speaking skills (as interviews were to be in English due to time and resource limitations) were identified and approached by these organisations from among their service users, client groups or staff and the participant information sheet was shared with them prior to participation. These organisations shared the contact details of prospective participants (who expressed interest) with the research team who then made contact to formally recruit them into the study.

**Data collection**

Data for this study were collected, both remotely and in-person, by two female researchers, MG and FW, who are both experienced in conducting qualitative research with culturally and ethnically diverse communities. Interviews were conducted between May and July 2021, and hence, at the time of data collection participants had endured three national lockdowns, and those from Leicester had experienced additional regional lockdowns between the second and third national lockdowns. Interested participants gave consent online or on paper, and filled in a short demographic questionnaire, which included information on age, sex, ethnicity, qualification, employment status, job role (if employed), home postcode and country of birth. Participants were invited to take part in a one-to-one interview, which was conducted in English and was either through Microsoft Teams, or over the telephone or in-person. Participants were offered the choice of mode that they would prefer to be interviewed and while the majority of interviews were conducted online, some participants also opted to be interviewed telephonically or face-to-face. Although we did not perceive any major differences in the data collected through the
three different modes, in retrospect, the telephonic ones probably took longer to establish the initial rapport as non-verbal cues such as smiles and nods could not be exchanged with participants. Despite this limitation, in all the modes, both the interviewers used vocables such as ‘uh-huh’ or where required probed and offered gentle encouragement to demonstrate their involvement and interest which helped with the flow of the discussions.

The topic guide was designed to explore individuals’ experiences of the pandemic with opportunities to probe in-depth about their economic, social and cultural contexts (see online supplemental file 1). The topic guide was developed from prompts in the literature, and also informed by the research team’s ongoing as well as past engagements with some of these communities. Interviews lasted for 45–60 mins, and participants were given shopping vouchers as a token of appreciation. Interviews were recorded with prior permission and recordings were transcribed by professional transcribers, and transcripts were checked for accuracy by the research team.

Data analysis

The study adopted an inductive approach following the Framework Method enumerated by Gale et al. Data analysis began with the transcription of the interviews, followed by reading of a set of transcripts each by three researchers, MG, IQ and JC, to further familiarise themselves with the interviews and immerse themselves in the data. In the next stage, the researchers conducted manual line-by-line coding of three transcripts each. This preliminary coding was discussed to arrive at a ‘working analytical framework’ which was then applied to all the remaining transcripts with modifications made to the framework until saturation was reached and no new codes emerged from the data. Thereafter, using a Microsoft Excel sheet, data was charted into various categories corresponding with the codes. Finally, the wider team (MG, IQ, JC, AA-O LN and MP) had joint discussions to interpret the charted data, and rearrange categories, collapse codes and identify connections among codes to arrive at the various themes and subthemes of the QoL framework. The QoL categories used in the analysis have evolved from the data and not been determined a priori.

The research team also individually and collectively reflected on their own influences regularly during the study period. Study team members were mindful of their own values, lived experiences and perspectives which could have influenced and added bias to the study results and findings. Importantly, the researchers from this study also recognised their own positionality in that they too, just like their participants, had also lived experiences of the COVID-19 pandemic. This helped them comprehend the participants’ experiences better but at the same time they needed to be alert not to influence participants’ responses by asking leading questions or projecting their own experiences. The interview team were also mindful of the different social and cultural backgrounds of the participants and at times the interviewer’s own ethnic minority background or being a woman or being from a migrant background brought greater acceptance from some participants. Furthermore, reflexive group meetings enabled the team to also identify new areas (eg, difficult relationships) to be probed in upcoming interviews and data interpretation.

Patient and public involvement

Patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

RESULTS

Demographic data

We recruited 18 participants from diverse social and economic backgrounds, such as asylum seekers, factory workers, full-time family carers and frontline workers, to form our sample. Participants’ demographic characteristics are provided in table 1.

Five key themes and 14 subthemes were identified from the data describing how COVID-19 affected the following aspects of QoL: (1) financial and economic, (2) physical health, (3) social, (4) mental health and (5) personal fulfilment and affective well-being. Online supplemental table 1 provides an overview of these themes and subthemes as QoL categories and subcategories with illustrative quotes. These categories and subcategories are also detailed in the following paragraphs.

QoL category 1: financial and economic

Change in household income, unemployment and job precarity

Almost one-third of our participants reported a reduction in their household income due to the pandemic. Participants who were furloughed (The furlough scheme was launched in the UK in March 2020 to support employers wherein they received funds from the government to cover the majority of wages for employees not working due to COVID-19 restrictions and employees were getting at least 80% of their gross pay), had lost work, moved to a lower paying job or saw a change in their family circumstances such as divorce or separation said that the pandemic had resulted in a reduction to their household income. The majority of these were women with lower educational qualifications and limited skills and mainly working in low-paid jobs and/or on insecure contracts. Some of the jobs held prior to the COVID-19 pandemic ceased to exist afterwards due to redundancy and staff restructuring.

Despite changes in household income, living expenses such as rent and mortgages remained unchanged. Some participants who had lost their jobs or were furloughed also discussed the uncertainty around their employment and how they found it difficult to find new jobs. The loss of income from self-isolation (due to shielding or infection) concerned some of our working participants. Some of our participants also experienced housing difficulties either due to crowding or changes in their housing circumstances.
The pandemic also resulted in increased financial benefits for some participants due to new working opportunities and longer shifts. Others also experienced reduced expenses from not eating out or savings on travel costs due to working from home. Sometimes, though, these extra work-shifts were not voluntarily opted for by participants and were rather the result of having to keep services running.

**Increased cost of living**
The cost of living also reportedly increased for some participants during the pandemic. Changes in working circumstances due to working from home and additional costs such as increased food prices were burdening factors on household finances. Some participants also reported an increase in the cost of energy bills from staying home. For most participants, having to work from home or having to home-school children also meant that they had to pay for internet services and/or buy additional equipment or electronic devices.

**Lack of social security**
Several of our participants were already in economically and socially vulnerable positions before the pandemic. For instance, two of our participants were asylum seekers, one was a recent migrant who worked as a part-time server, one was a full-time carer, one was a taxi driver and one experienced domestic violence. For most of these participants, the pandemic had not only aggravated their financial hardships by way of job-loss or salary cuts, but many also said that public funds such as Universal Credit or childcare benefits were either not available to them or were unsustainable. Furthermore, the closure of communal kitchens and charities during the pandemic severely impacted some of our participants who relied on charitable support.

**QoL category 2: physical health**

**Risk and safety**
Risk to personal physical health was perceived to be low by most of our participants, and many stressed on the hygiene and behavioural changes that they had adopted to protect themselves. However, for participants who themselves or their family members had any comorbid conditions such as diabetes, the risk was perceived to be greater. Moreover, those in frontline jobs such as health or social care acknowledged the exposure risks at work and worried that they might bring the infection home or pass it on at work. These participants, though, felt that they had the appropriate levels of personal protective equipment (PPE) at their workplaces and spoke positively of their employers’ decisions to enforce strict PPE guidance for the benefit of all.

**Access to healthcare services**
Several participants shared that accessing healthcare services or advice was difficult during the pandemic. They were either unable to make bookings for consultations
with their general practitioner (GP) or were required to wait several weeks for an appointment. A few participants also mentioned that they faced inconvenience due to unclear direction and information from healthcare providers, which resulted in them shuttling between GP surgeries and/or pharmacies. Unable to get appointments, some participants also expressed concern that their symptoms and conditions had since worsened. Participants with mental health needs also found that booking appointments and consultations with mental health services were fraught with similar access issues as GP surgeries. One of the participants who had witnessed an acquaintance commit suicide attributed it to the lack of timely help and support from mental health services, and feared that there are others who may take this extreme step if help is further delayed.

COVID-19 vaccination
Among our participants, almost half had at least one dose of the COVID-19 vaccine. While about one-third of participants had not been eligible at the time of interview, some others had declined to get the vaccine. COVID-19 vaccine hesitancy, that is, delay, refusal or even scepticism about the vaccine, was found to be higher among female and ethnic minority participants. One of the most cited reasons for this hesitancy was doubt surrounding the vaccine’s safety, especially given its rapid development. Reports of blood clots from the AstraZeneca vaccine also concerned some. Some participants also shared how they had encountered rumours and misinformation about the vaccine, which had made them question the safety and efficacy of the vaccine.

QoL category 3: social
Loss of community and relationships
A profound social impact of the pandemic that participants experienced was the loss of community interaction due to restrictions on gathering, visiting and stay-at-home orders. Participants who were living by themselves found this social isolation most challenging, with some likening it to being in prison. Lockdown changes also seemed to have taken a toll on interpersonal relations of some participants and one participant reported going through a divorce and another reported a break-up with her boyfriend during the pandemic.

Challenges to family functioning
Participants living with families described how changes like closure of schools and working-from-home affected them negatively and added to their stress. Several of our female participants spoke about the problems they encountered in home-schooling their children, and how it led to greater frustrations for them and the children alike. Moreover, some participants also shared that restrictions on meeting and visiting people outside the household meant that care responsibilities could not be shared with extended family or friends like before. Some participants also shared how their household routines changed to accommodate every member’s working-from-home or home-schooling needs.

Experiences of stigma and discrimination
Some of our participants stated that the COVID-19 pandemic had increased stigma and discrimination against individuals from ethnic minority backgrounds. Participants spoke of their experiences of being targeted, stigmatised and discriminated against in public, based on their religious, cultural or ethnic background during or even before the pandemic. For one participant, past experiences of being judged or discriminated against made her opt out of seeking support, even for essential healthcare needs.

QoL category 4: mental health
Isolation
As mentioned earlier, the limitations on socialising were challenging for most of our participants, and had a significant negative impact on their overall well-being and mental health. Many of our study participants described that their experiences of isolating, shielding or working-from-home made them feel lonely, depressed, frustrated and anxious. Some participants described how being stuck at home during the lockdown days made them feel demotivated and lose sense of time and routine. Some participants also believed that lockdown loneliness was amplified for people with limited digital skills, such as the elderly and those with existing mental health conditions.

Fears and worries
Most participants reported being fearful of the pandemic, and worried about their health and financial circumstances. Fear around the well-being of loved-ones bothered many participants, and for those who had family abroad, the travel restrictions added to their worries. Participants with children also worried about their children’s education and well-being. Some of our participants believed that the media coverage of the pandemic had added further anxiety. Participants who worked in health and social care settings also described how they had personally witnessed or known of people dying from COVID-19, which made them fearful of infection and also inadvertently spreading infection to others.

Pre-existing mental health conditions
Participants who or whose family members had pre-pandemic diagnoses of mental health conditions reported worsening of these conditions during the pandemic. The restrictions on face-to-face consultations left them unable to access counselling or other forms of psychotherapy regularly. Some of these participants also remarked that remote consultations, which were initiated after a while, were not very helpful. Support groups were also temporarily disbanded, which disadvantaged some participants. One participant also said that in lieu of face-to-face consultations and therapies, he was instead prescribed pharmaceutical drugs to treat his anxieties and depression, which he believed was not in his best interest.
QoL category 5: personal fulfilment and affective well-being

Opportunities for personal and professional development

While the pandemic may have largely negatively impacted the lives of our participants, COVID-19 also provided new opportunities to some of our participants to reflect on their personal circumstances and pursue new personal development targets and ambitions. Other participants had also used the COVID-19 pandemic, and social isolation as a chance to improve social relations. Some of our participants also used the opportunity of working from home or on furlough to undertake career development activities or pursue career changes.

Affective well-being

Several of our participants mentioned that their religious beliefs had helped them cope with their anxieties, stress and fears. For some participants, volunteering also gave them a sense of purpose and helped them live through the pandemic. Many also reported that people had generally become more empathetic, kind and willing to support each other. Some participants also counted it as a blessing to have their family around and be able to spend time with them. However, some participants also reported negative affectivity, and shared about feeling sad at the prolonging of the pandemic or agonising about the future.

DISCUSSION

In this study we describe the lived experiences and QoL of adults living in the UK during the COVID-19 pandemic. Our findings expose the differential impact of the pandemic on people’s lives depending on their circumstances. Interviews revealed that economic impacts of the pandemic were not uniform for all participants, and while a few benefitted from increased income and greater work opportunities, others who were in low-paid jobs, and/or on part-time or temporary contracts faced job losses, or reduction in income. This finding is in line with previous research, which has reported how certain groups have borne the burden of economic constraints brought in by the pandemic. Individuals from ethnic minority communities, migrants and single parents face multiple intersecting disadvantages, exacerbating their economic and financial difficulties during the pandemic. Furthermore, food insecurity due to the closure of food banks and communal kitchens, increased expenses for food and heating, and difficulties in accessing social security experienced by some of our participants were also elucidated by other researchers. It is very likely that these conditions may have worsened in recent times owing to the burgeoning cost of living crisis that the country is witnessing. However, the generations of entrenched intersecting inequalities based on ethnicity, gender, education, age and more that had led to the disproportionate impact of the pandemic on certain groups would continue to be exacerbated by these recent economic downturns. This indicates that recovery and rebuilding efforts after the pandemic have to be multi-sectoral (including health, education, housing, financial security, etc), coordinated and targeted at those most in need.

Our finding shows that participants felt most at risk if they or their family members had comorbid conditions like diabetes or hypertension. These findings gain significance in light of the fact that most of these comorbidities are proven risk factors for COVID-19, and the elevated prevalence of these conditions in some ethnic minority groups mean that they are at an increased risk of COVID-19 and adverse outcomes. Along with this, it was also observed that for some of our ethnic minority participants, the awareness that they (or their family members) may be at increased risk because of their ethnicity or health condition increased their apprehensions and anxieties. Additionally, a large proportion of our ethnic minority participants worked in frontline roles, had large or multigenerational households and often occupied smaller dwelling units, which increase the chances of transmission and infection.

Along with disparities in health, our findings also indicate unmet health needs due to unavailability or cancellation of appointments. While the pandemic put additional pressure on the UK National Health Service and created massive backlogs and long delays for patients, certain communities such as migrants and those living in deprived areas were known to be disproportionately affected by delays or gaps in access to healthcare services even before the pandemic. Our findings corroborate the health inequalities experienced by minoritised and marginalised communities, and highlight the risk that they may present to healthcare with more severe illness due to these delays. To address these inequalities greater investments should also be made in preventive healthcare of communities at risk of developing diseases. Support and awareness campaigns on healthy diet, healthy lifestyle, early screening, etc, should be provided to vulnerable and isolated populations through local charities and organisations which are trusted by these communities.

Among our participants, vaccine hesitancy was observed in some ethnic minority and female participants. Research has shown that vaccine hesitancy is highest in the most deprived areas of the UK, and among ethnic minority communities, which is a cause of concern as these are groups which are most at risk from COVID-19 and experience health inequalities which pre-date the pandemic. Low trust in the safety and efficacy of the vaccine has been found to have driven hesitancy among our participants, which is corroborated by evidence from previous studies. Hence, targeted public health messaging dispelling fears and myths and engagement with communities through trusted organisations and leaders is needed to improve vaccination uptake as new waves and peaks of the pandemic continue to emerge.

Our data reveal that fear and worries were reported by almost all the participants, although the sources of these fears varied, with the most common being the well-being of loved ones. This finding corroborates with other studies examining ‘fear’ among people during the pandemic.
There are other domains of fear and worry as well that participants have experienced, such as fear of being ill themselves, worrying about finances and facing uncertainty. While for most, these fears can be overcome or regulated, there is a chance that for some, these fears may have an impact on mental health and daily functioning. This is especially true for people with pre-existing mental health conditions, or those experiencing greater stressors or barriers to care, for example, asylum seekers and those experiencing domestic violence. The inadequacy and gaps in mental health services and care during the pandemic, as reported by our participants, could worsen mental health. Hence, if mental health needs and improving services are not prioritised, the likelihood of a mental health epidemic is very real.

Social isolation due to physical distancing measures has been found to have a considerable impact on the quality of life of our participants. Such stressful situations combined with personal vulnerabilities and social conditions may have negatively impacted on interpersonal relationships as indicated by some of our participants. Similarly, additional burden put on families by closure of schools, home-schooling and working from home have been shown to increase anxiety among parents and children, and disrupt family functioning. Research has also shown that the burden of unpaid care work has been borne disproportionately by women during the pandemic, impacting their health and well-being. Most of our female participants with school-aged children shared similar anxieties about managing home-schooling and household chores. Apart from this, the racial and religious discrimination faced by ethnic minority communities, both before and during the pandemic put additional strain on participants from these communities to protect themselves not just from the virus but also from the wider experiences of marginalisation and violence which were seen during the pandemic.

Personal and occupational fulfilment are important benchmarks in QoL and are dependent on an individual's spiritual fulfiment and social support. The strong association between better social support and affective well-being during crises indicates that individuals whose support systems are compromised are at higher risk of experiencing negative feelings. It was also observed in our study that participants who had limited social support (eg, more isolated participants, including those who were experiencing domestic violence or asylum seekers) had difficulties in overcoming the adverse impacts of the pandemic, which overwhelmed them emotionally. This underscores that there are intersecting factors influencing the impact of pandemic on different individuals and groups and thus, coordinated and long-term efforts are required if we wish to build back society better and fairer.

Limitations
Our study has certain limitations, including our sampling frame. Our focus was on recruiting participants from a range of socioeconomic backgrounds, and particularly from certain 'underserved' groups such ethnic minorities and migrants. However, we did not identify participants from certain other 'underserved' groups including gender minorities or people with disability. Despite this limitation, we recruited a sample which is diverse in terms of ethnicity, educational and migration status, and social and economic conditions such as survivors of domestic violence, factory workers and asylum seekers. Our ethnically and socioeconomically diverse sample meant that our data provide insight into a range of pandemic experiences, and highlight the unique issues and concerns that each of these individuals and families had encountered. However, this also means that findings may not be generalisable, and larger quantitative studies are needed to validate the findings at a population-level. Moreover, the rapidly evolving situation around COVID-19 policies and vaccination may mean that some views expressed on this topic by the participants at the time of the interview may have changed. However, we believe other areas of life such as economic instability and increasing cost of living continue to be relevant and need further studies to ascertain the full impact.

CONCLUSION
Our findings demonstrate the multidimensional impact of the COVID-19 pandemic on people’s lives. This study brings to light the differential impact of the pandemic depending on people’s intersecting socioeconomic circumstances. The data reveal that most of the negative economic impacts have been borne by people in low-paid and insecure jobs. Similarly, adverse social and mental health impacts particularly affected people experiencing displacement, violence, pre-existing mental illnesses or isolation. Thus, these findings indicate that COVID-19 responses should take into account existing health, social and economic inequalities while designing recovery and rebuilding packages.

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**Contributors**

MP: Conceptualisation; Funding Acquisition; Methodology Development; Writing-Review & Editing. LBN: Conceptualisation; Funding Acquisition; Methodology Development; Formal Analysis; Writing-Review & Editing. MG: Data Curation; Formal Analysis; Writing-Original draft and preparation; Writing-Review & Editing. JC: Formal Analysis; Writing-Original draft and preparation; Writing-Review & Editing. IG: Formal Analysis; Writing-Original draft and preparation; Writing-Review & Editing. FW: Data Curation; Writing-Review & Editing. AAO: Formal Analysis; Writing-Review & Editing. HW: Writing-Review & Editing. MS: Conceptualisation; Methodology Development; Writing-Review & Editing. MP is responsible for the overall content as the guarantor.

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**Competing interests**

MP reports grants from Sanofi, grants and personal fees from Gilead Sciences and personal fees from QIAGEN, outside the submitted work. All other authors declare no conflict of interest.

**Patient and public involvement**

Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

**Patient consent for publication**

Consent obtained directly from patient(s).

**Ethics approval**

Ethical approval for the study was granted by the Medicine and Biological Sciences Research Ethics Committee, University of Leicester, UK (Reference number 30058-cig29-Is:healthsciences). All participants provided written formal consent to participate.

**Provenance and peer review**

Not commissioned; externally peer reviewed.

**Data availability statement**

The data for this study consists of interview transcripts of participants that contain potentially identifying and sensitive information. The data cannot be shared publicly due to concerns of participant confidentiality and ethics requirements. Participants consented to the study with the understanding that only de-identified quotations would be made public, not the entirety of the transcripts. Therefore, only illustrative quotes from the transcripts have been included in this paper. Data for this study could be made available on reasonable request to the corresponding author.

**Supplemental material**

This content has been supplied by the author(s).

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