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Health and Social Care Delivery Research

Extended Research Article

Intersecting factors of disadvantage and discrimination and their effect on daily life during the coronavirus pandemic: the CICADA-ME mixed-methods study

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This article

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Abstract

Background: The COVID-19 pandemic exacerbated pre-existing societal inequities. Our study addresses the dearth of studies on how intersecting factors of disadvantage and discrimination affected pandemic daily life for disabled people from minoritised ethnic groups, aiming to improve their experiences and social, health and well-being outcomes.

Objectives: Through an intersectionality lens, to:

1. explore and compare, by location and time, survey and qualitative data on changing needs for social, health and well-being outcomes
2. relate coping strategies/solutions to these
3. explore formal and informal network issues/affordances
4. gain insights from synthesising our data
5. contextualise and explore transferability of findings
6. co-create outputs with stakeholders.

Design: Mixed-methods, asset-based, underpinned by embodiment disability models and intersectionality, integrating three strands:

1. (secondary): analysis of existing cohort/panel data, literature review
2. (primary: quantitative): new survey (*n* = 4326), three times over 18 months
3. (primary: qualitative): semistructured interviews (*n* = 271), interviewee co-create workshops (*n* = 104) 5 and 10 months later, mixed stakeholder co-design workshops (*n* = 30) for rapid-impact solutions to issues, key informant interviews (*n* = 4).

Setting: United Kingdom and Republic of Ireland.

Participants: Strand 2: community-dwelling migrants, White British comparators, with/without disability.

Strand 3: focus on Arab, South Asian, African, Central/East European, or White British heritage with/without disability.

Results: We found strong adherence to pandemic restrictions (where accommodation, economic situations and disability allowed) due to COVID-19 vulnerabilities. High vaccine hesitancy (despite eventual uptake) resulted from side-effect concerns and (mis)trust in the government. Many relied on food banks, local organisations, communities and informal networks. Pandemic-related income loss was common, particularly affecting undocumented migrants. Participants reported a crisis in mental health care, non-holistic social and housing care, and inaccessible, poor-quality and discriminatory remote health/social care. They preferred private care (which they could not easily afford), community or self-help online support. Lower socioeconomic status, mental health and mobility issues reduced well-being. Individual and community assets and coping strategies mitigated some issues, adapted over different pandemic phases, and focused on empowerment, self-reflection, self-care and social connectivity. Technology needs cut across these.

Limitations: We could not explore area-level social distancing and infection rates. Data collection was largely online, possibly excluding some older, digitally deprived or more disabled participants. Participants engaged differently in online and face-to-face co-create workshops. Our qualitative data over-represent England and South Asian people and use contestable categories.

Conclusions: Different intersecting factors led to different experiences, with low socioeconomic status particularly significant. Overall, disability and minoritised ethnic identities led to worse pandemic experiences. Our co-design work shows how to build on the assets and strengths; simple changes in professional communication and understanding should improve experience. Minoritised groups can easily be involved in policy and practice decision-making, reducing marginalisation, with better care and outcomes.

Future work: More research is needed on: (1) the impact of the post-pandemic economic situation and migration policies on migrant mental health/well-being; (2) supporting empowerment strategies across disadvantaged intersecting identities; and (3) technological deprivation and the cultural and disability-relevant acceptability of remote consultations. We found some differences in the devolved nations, which need elucidation.

Study registration: This study is registered as ISRCTN40370, PROSPERO CRD42021262590 and CRD42022355254.

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Contents

List of tables

List of figures

List of boxes

List of supplementary materials

Report Supplementary Material 1 Table of characteristics of studies included in the ethnicity and vaccine uptake review

Report Supplementary Material 2 Corpus linguistics summary results

Report Supplementary Material 3 Systematic review searches

Supplementary material can be found on the NIHR Journals Library report page (https://doi.org/10.3310/KYTF4381).

Supplementary material has been provided by the authors to support the report and any files provided at submission will have been seen by peer reviewers, but not extensively reviewed. Any supplementary material provided at a later stage in the process may not have been peer reviewed.

List of abbreviations

A&E	accident and emergency
ADL	activities of daily living
CEV	clinically extremely vulnerable
CFIR	Consolidated Framework for Implementation Research
CLS	Centre for Longitudinal Studies
CRN	Clinical Research Network
EPPI-Centre	Evidence for Policy and Practice Information and Co-ordinating Centre (a division of University College London)
GP	general practitioner
HRA	Health Research Authority
ID	intellectual disability (also known as learning disability)
MCS	Millennium Cohort Study
MCSP	Millennium Cohort Study parent
NI	Northern Ireland
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health and Care Research
ONS	Office for National Statistics
PHQ	Patient Health Questionnaire
PPI	patient and public involvement
QOCS	Quality of Care and Support Scale
QoL	quality of life
RoI	Republic of Ireland
SWEMWBS	Short Warwick–Edinburgh Mental Well-Being Scale
UCL	University College London
WHO	World Health Organization
WHOQOL-BREF	WHO Quality of Life Brief Form

Plain language summary

Many disabled people from minoritised ethnic groups face barriers to accessing appropriate support, health and social care or vital 'resources', such as medicine and food. We wanted to understand how to improve these experiences, considering how different combinations of ethnicity and disability interacted with factors such as citizenship and income during the COVID-19 pandemic. This is known as an intersectional approach.

We summarised relevant articles and data from existing surveys, and surveyed 4326 United Kingdom and Republic of Ireland residents three times over 2021–2. In 2021–2 we interviewed 231 disabled Arab, South Asian, African or Central/East European migrants across England, Scotland and Wales, 20 who were not disabled, and 20 disabled/non-disabled White British people (total *n* = 271). In group work 5 and 10 months later, interviewees, lay and central team members and partners shared knowledge and discussed post-interview changes. We co-designed simple solutions to issues in workshops with charity, health and social care staff, community leaders and participants. We asked policy-makers, general practitioners and community leaders how to put these into immediate practice.

We found challenges greatest in: those with economic, mental health, hand loss or mobility issues; undocumented migrants; or people living alone or in substandard accommodation. Participants mistrusted National Health Service and social care, preferring informal support from friends, family and neighbours, and private care even when not affordable. Most issues could be reduced if people felt more empowered, had better technology access and were supported in self-care, and if health and social care professionals improved their communication and their understanding of people's day-to-day needs and beliefs.

Our study is unusual because we used an intersectional approach, successfully involved lay (community or peer) co-researchers, initiated a professional 'community of practice' to exchange ideas, and dramatised our data for a public theatre show. We showed that, with appropriate approaches, minoritised groups, including migrants refused visas, can easily be involved in policy and practice decision-making, with better care and outcomes for all.

Scientific summary

Introduction

The COVID-19 pandemic exposed and exacerbated multiple pre-existing societal inequities for people from minoritised ethnic groups in the UK and those with poor health or disability. Mortality statistics captured public and government attention. But the ways in which intersecting factors of disadvantage and discrimination affected other aspects of their pandemic experience have been largely ignored. For example, international concern about pandemic-induced mental health issues has sidelined the especially poor pandemic-related mental health of people from some minoritised ethnic groups.

Objectives

Our aim was to address the gaps by contributing and informing evidence-based formal and informal strategies, guidelines, recommendations and interventions for health and social care policy and practice, to mitigate inequities and improve the experiences and social, health and well-being outcomes of minoritised ethnic groups at the intersection with disabling chronic conditions or impairments.

This necessitated in-depth understanding of relevant influences on mental and physical health, coping, access to resources, and informal and formal social and healthcare support from different intersecting combinations of disability and ethnicity. Citizenship status is also critical; many recent refugees and undocumented migrants will have 'no recourse' to support. Though the study centres on these intersections, we necessarily also explore other categories of societal difference (e.g. age, gender) that interact with them under institutional and structural conditions to create specific health outcomes and experiences.

We included comparison with people self-identifying as of White British heritage, with/without disability, and non-disabled people from minoritised ethnic groups to help unpack intersectional patterns.

Our objectives, using an intersectionality lens, were to:

1. explore and compare, by location and time, survey and qualitative data on changing need for social, health and well-being outcomes
2. relate pandemic coping strategies/solutions to objective 1 findings, including what worked well or less well, and touchpoints (where experiences might best be improved)
3. explore formal and informal network issues/affordances in health and social care solutions
4. gain insights from convergence synthesis of our mixed-methods data
5. contextualise and explore transferability of findings
6. co-create with stakeholders identified strategies and interventions, and plans for rapid pathways to impact.

Methods

We used a transformative, convergent parallel mixed-methods design integrating three strands – quantitative, qualitative and a secondary data strand – across three phases over 18 months, to answer the study objectives.

Strands 2 and 3 involved concurrent primary data collection, with repeated measures in three 'waves' over 18 months. This allowed us to explore experiences and attitudes within changing pandemic contexts, relations between these, intersectional identities and health and well-being, and enhanced the ecological validity of our work. Our data synthesis followed a triangulation design; qualitative data were merged and compared with quantitative data.

Strand 1: secondary data analyses

We analysed existing cohort and panel data and undertook a scoping literature review, and fed these into the other strands, though they were not dependent on this.

Strand 2: primary survey and quantitative analysis

We developed a new survey for community-dwelling migrants and UK/Republic of Ireland-born children of migrants, also White British comparators, all with/without disability. In wave 1, we used data from 4326 respondents, of whom 3498 completed wave 2 and 3100 wave 3. Approximately half our sample were of minoritised ethnicity and approximately half had a chronic condition or disability; we intentionally oversampled from these groups for good statistical power and a sound understanding.

Strand 3: primary qualitative methods

Strand 3 aimed for in-depth understanding, with semistructured interviews (n = 271), follow-on co-create workshops with interviewees (n = 104) to explore changes 5 and 10 months later and exchange knowledge, and stakeholder workshops with health professionals, community leaders, charity leads and participants (n = 30) to co-design simple-to-implement solutions to issues. We asked policy-makers, general practitioners (GPs) and community leaders (n = 4) how to put these into immediate practice. The interviews were undertaken by a core academic research team, eight community researchers recruited from UK migrant charities, and partners Bromley-by-Bow Community Centre and Born In Bradford.

From the 271 interviews, a core data set of 218 met our initial criteria of living in England, being significantly impacted by a chronic condition or disability, and being of Arab, South Asian, African or Central/East European or White British heritage. Our criteria were expanded on advisory group advice, enabling limited comparison with other ethnic groups, people with non-disabling conditions, and people from Scotland and Wales. We recorded conditions at recruitment but grouped them for comparative analyses. The groups ‘food-relevant’, ‘neurodivergent’, ‘cancer’ and ‘brain hyperexcitability’ (e.g. migraines, epilepsy) followed advisory group advice, and we also used adaptations of the UK Government Statistical Service ‘harmonised’ themes: mental health, mobility, dexterity, stamina/breathing/fatigue, sensorial (hearing/vision loss), cognitive (intellectual/memory impairment). We included long COVID and other multisystemic conditions (which may belong to more than one group, so that our overall conditions denominator exceeds 271). We recognise the complexities and inadequacies of our categorisations, discussed in a study output (a toolkit). However, our intersectionality approach means these were starting points to be challenged and deconstructed.

Topics across the strands

The three strands considered the same topics, chosen for a holistic understanding of the context of people’s lives, their responses to adversity and health and social inequities, their strengths and assets, and effects on their networks:

1. intersectionalities
2. behavioural responses to COVID risk reduction measures by individuals and their formal (e.g. health/social care) and informal (e.g. friends, family, community) support networks
3. access to resources, formal support and care
4. social networks (informal support and care)
5. physical and mental health consequences of the pandemic, coping and attitudes regarding these
6. mental and physical well-being/quality of life as core outcomes
7. local/regional differences in responses linked to policies/interventions and associated impacts
8. future policy.

Theoretical underpinning

This study took a strengths and asset-based approach, underpinned by embodiment models of disability and intersectionality. Our exploration of social influences on health and well-being was framed by the social ecological model.

Analyses

We used corpus linguistics, framework, latent growth modelling and structural equation modelling for outputs reported here.

Findings

Generally strong adherence to COVID-19 containment measures left people feeling lonely and imprisoned, exacerbated in undocumented migrants by deportation fears. However, crowded accommodation, 24-hour proximity to family, economic precarity, and some disabilities prevented adherence for several and created stress. Vaccine uptake was quick for White British participants but those from minoritised ethnic groups hesitated, though most eventually took it. In our review and strand 3 data, the main hesitancy factors were a lack of appropriate information and fear of side effects. White British participants were more influenced by mass media, and minoritised ethnic groups by social media and local communities; misinformation was most common within the Arab and least common within the Central/East European group. Unexpectedly, experience of COVID-19 and community responsibility were not influential. African and undocumented migrants in particular used traditional remedies instead of or alongside the vaccine.

Informal networks shopped or cooked for participants. Food parcels were sometimes culturally inappropriate. Despite generally good medication access, costs of private medication and transport to pharmacies were problematic for some.

An increased treatment burden, combined with symptoms and everyday lifework, reduced patients' capacity to access health care or carry out self-care. They felt abandonment by health care, increased distrust of formal care, and increased dependence on informal relational networks, augmented by COVID-19 fears and unclear information on what people should do. Strand 3 data show that remote services were convenient and efficient but problematic, with no holistic care, a crisis in mental health care, and a disregard for comorbidities and intersecting factors of disadvantage, for example housing needs. Difficulties making GP appointments by phone or e-Consult-style triage were exacerbated in those digitally impoverished, with complex health needs, not fluent in English, and with some specific disabilities. Our data highlighted power differentials, issues with diagnosis and monitoring, and impaired patient–clinician relationships leading to perceived ethnic discrimination and being 'fobbed off'. Some self-medicated instead, or researched coping strategies or online therapy. Several refused face-to-face care when offered it, through COVID-19 fears.

Language, culture, socioeconomic and disability intersections with condition were often not considered in medical care, and so could exclude, cross religious and cultural lines, result in inappropriate and potentially harmful intervention, or destroy clinician–patient relationships with perceptions of discrimination. We found intersections between ethnicity and mental health in perceptions of being fobbed off by health providers. Non-specific appointment times for remote consultations were particularly problematic for those with combinations from among low income, disability, or lack of support networks, child care or English language fluency. Often, service management of expectations would have improved experiences. While the intersection of different minoritising factors tended to worsen experiences, participants with more disabling conditions mostly focused on disability discrimination only.

As a novel contribution, we defined three treatment backlog categories that left people suffering for years, worsening their condition and NHS expectations: deferrals of initial help-seeking processes; secondary or social care waiting lists (including when GP referrals had not progressed in the system due to a lack of capacity); and delays when existing treatment, monitoring plans or social care were reduced or cancelled. These left people in limbo; some took further action to get NHS care.

Many had never registered with a GP, irrespective of residency status, trusting private care more though it was not affordable. Sometimes the private doctor was a family member or friend. A few consulted doctors in their country of origin. Our survey showed community help was most likely to have physical and psychological benefits for those with chronic conditions in 2021, and social and mental well-being benefits in 2022; people reduced NHS help-seeking and increased community help-seeking. NHS help improved their psychological well-being in 2021 and physical well-being in 2022. Our interview data supported the importance of informal social networks for practical and emotional support. Cultural differences in family support, and differences in technology and social media use, including effects on entrepreneurship, empowerment and communication of appropriate information, should be considered in policy and practice.

Psychological well-being was worst in the 'minoritised ethnic–chronic conditions' group in our survey, possibly reflecting poorer access to health care. Sixty-six interview participants had one or more clinically diagnosed mental ill health conditions. Most had comorbidities, which were disproportionately common in minoritised ethnic groups. Central/East European and African participants were reluctant to seek help for mental ill health because of pride or stigmatisation. Relationships with comorbidity-related job loss and experiences of conflict zones should be disambiguated in studies reporting mental health effects of the pandemic.

Coping was enhanced by combinations of: adequate housing; spirituality; access to green spaces, technology, social support and education; adequate health; knowledge about UK systems; skills; English language fluency; and income stability. Hence, local and national policy should focus on facilitating informal connections, community and individual empowerment, and opportunities for self-care and self-improvement.

Socioeconomic status and diasporic densities were significant intersecting factors by location.

Our survey suggested healthy White British people experience more well-being advantage in England than elsewhere in the UK. Overall, considerations of the transferability of findings should encompass convergences and divergences across our ethnicity, disability and citizenship categories, rather than location.

Mobility and stamina issues intersected with cramped housing conditions, particularly in multigenerational South Asian migrant households. Other important intersectional factors were religion, and economic precarity from pandemic job loss, precarious work (e.g. zero-hour contracts) and reduced work hours intersecting with disability. Several families unexpectedly lost their breadwinners to COVID-19. These issues, combined in 2022 with the cost-of-living crisis, left participants pessimistic about the future.

Citizenship status intersected with socioeconomic status in income, employment prospects, accessing private health care, and feelings of imprisonment. Undocumented migrants and those on non-work visas were particularly affected, unable to claim welfare assistance, and felt imprisoned through deportation fears, but impacts were great for those with visas, due sometimes to a lack of information, or racism.

Issues with online food shopping could result from digital poverty, socioeconomic status and minimum spends, non-familiarity, inaccessible websites, differences to in-person shopping and the person's impairment all intersecting.

Our survey showed that overall, well-being was not significantly affected by 2021–2 COVID restrictions. This contrasts with our secondary cohort analysis for the 2020 first lockdown. We found that while non-disabled people (including from minoritised ethnic groups) recovered after the first lockdown, well-being worsened in disabled people. Perhaps by 2021 people had learnt coping measures, an interpretation supported by our qualitative data. Many strand 3 participants reported loneliness, suicidality and addiction issues caused by lockdowns and other infection containment measures, but there were improvements once the country opened up and the vaccine was available. A few found it hard to readjust. Participant anxieties about contracting COVID-19 from people lax in infection containment measures pertained throughout but escalated when the country opened up in mid-2021.

Several were initially engaged with government action in early 2020, but most ended up critical, due to delays in government action, failure to follow scientific advice, inconsistent messaging, and eventually also politicians breaking rules to suit themselves.

Early in the pandemic, online and in-person shopping were problematic for everyone, but disabled people in the process of being diagnosed and others who had been online shopping for years and were suddenly deprioritised as not on the 'clinically extremely vulnerable' (CEV) list were especially disadvantaged. Eventually, charities got the lists expanded to include other disabilities.

Treatment delays left many in limbo, particularly in later interviews, suggesting the longer the wait, the more likely this feeling was to develop, or that services became less certain later in the pandemic. Existing patients given a revised date were initially less likely to feel in limbo, a novel finding.

Conclusions

We showed that structural adversities cut across minoritised groups, including those often viewed as 'white'. There is a need to look at intersecting factors, specific contexts and individual and community strengths and assets, rather than considering some groups as inherently more disadvantaged. We also showed that low socioeconomic status is a problematic product of racial and disability discrimination that cuts across experiences and groups.

Synthesising our qualitative and survey data revealed an intersection for people of all ethnicities of lower socioeconomic status, mental health, hand loss and mobility issues, lack of outdoor spaces, cramped accommodation or dependency on others to get outside leading to poor psychological and mental well-being. Participants generally mistrusted NHS and social care, preferring informal networks and private care despite the cost. While these challenges have a structural basis, our work shows that relatively simple changes supporting empowerment, social connectivity, self-care, communication and understanding would rapidly improve the lives of disabled people from minoritised ethnic groups. We are developing some ideas for local and regional implementation. We have shown that with appropriate approaches, minoritised groups, including undocumented migrants, can easily be involved in policy and practice decision-making. This would reduce structural barriers and marginalisation, with better care and outcomes for all.

Study registration

This study is registered as ISRCTN40370, PROSPERO CRD42021262590 and CRD42022355254.

Funding

This award was funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme (NIHR award ref: NIHR132914) and is published in full in Health and Social Care Delivery Research; Vol. 13, No. 2. See the NIHR Funding and Awards website for further award information.

Approvals

Full Institute of Education, University College London, research ethics approval (UCL IoE REC 1450 COVID-19) for this study was obtained before the study commenced and an amendment approved 30 July 2021, and subsequently Health Research Authority (HRA) approval (IRAS project ID: 310741; protocol number: NIHR132914; REC reference: 22/SW/0002) was obtained to recruit in the final 6 months of the study.

Chapter 1 Background and rationale

Navigating the report

This report presents the results of a mixed-methods study (*Figure 1*) conducted in 2021 and 2022 exploring the experiences of people from minoritised ethnic groups who also have a long-term health condition or disability, as they navigated their daily lives in the context of the COVID-19 pandemic. First in this chapter, we provide a brief overview of the problem we sought to address and how this shaped the study design. We also position the study within the field. We continue with a descriptive overview of the different phases of the pandemic, as context within which to understand our findings, particularly our qualitative work, where participants make frequent reference to events on this timeline. The chapter ends with an explanation of key definitions. In *Chapter 2* we explain the study aims and objectives and describe its methodology and theoretical framework. *Chapters 3*–*11* focus on the methods and findings. The final chapter integrates findings and draws conclusions and recommendations for future research.

Intersecting inequities and the pandemic

The COVID-19 pandemic both exposed and exacerbated multiple pre-existing societal inequities (see *Box 1*). The greater risks and challenges faced by people from minoritised ethnic groups, those with chronic health conditions/disabilities, older people, the impoverished, and 'essential' workers are well recognised.[1–9] For example, non-white ethnic groups constituted 13% of the UK population, but by May 2020 comprised 33% of critically ill COVID-19 patients.[1,4,6] Similarly, disabled people constituted 16% of the population, but by July 2020 represented 59% of COVID deaths.[1] These statistics captured public and government attention. But as *Box 1* shows, death was but one impact of COVID-19 that disproportionately affected these groups because of intersecting factors of disadvantage and discrimination. Even pre-pandemic, people in the UK from minoritised ethnic groups or with poor health or disability were more likely to live in poverty, being poorly paid or on zero-hour contracts, and were often essential workers.[2] Thus, during the pandemic, they were at risk in multiple ways.

Our particular interest is in the intersection of health or disability, ethnicity and citizenship status, because:

1. People of minoritised ethnicity who are chronically ill/disabled typically have worse health outcomes than others,[2,13] even outside the pandemic, and resettled refugees have particularly poor outcomes.[14,15] This is not a simple relationship, as *Box 1* indicates.
2. Chronic conditions, such as diabetes and cardiovascular disease, are disproportionately common in some minoritised ethnic groups[16] and often less well managed – one reason for their increased vulnerability to COVID-19.[12] For example, while fewer than 25% of working-age White British households include someone with a health condition that increases their COVID-19 risks, the figure for Pakistani and Bangladeshi households is nearly 33%.[17] This may itself be linked to pre-existing patterns of persistent disadvantage and discrimination such as noted in *Box 1*.[17,18]

BOX 1 Inequities for people from minoritised ethnic groups (including migrants) and those with chronic conditions/disabilities increasing their risk of poor pandemic health outcomes[1–12]

- **Increased risk of isolation, abuse or neglect, poor access to informal emotional and well-being support** due to, for example, COVID-19 measures, changed activities, priorities, attitudes of others, a state of 'normalised absence and pathologised presence'.[3]
- **Inequitable formal treatment, support and care** from attitudinal, structural, policy, cultural, linguistic, communication and economic barriers including difficulties implementing COVID-19 measures and risk of severe illness.
- **Living conditions and environment,** for example: home schooling and associated resources; absent parents holding multiple jobs; overcrowding; lack of garden or open spaces.[4,5]
- **Lack of access to resources** such as food and medication because of physical, language or technology barriers.
- **Psychosocial factors raising COVID-19 risk, reducing capacity to cope** with social, economic and psychosocial pandemic impacts, including worries about people 'back home'.
- **Unemployment/reduced income,** for example: zero-hour contracts, key worker roles, no recourse to public welfare.

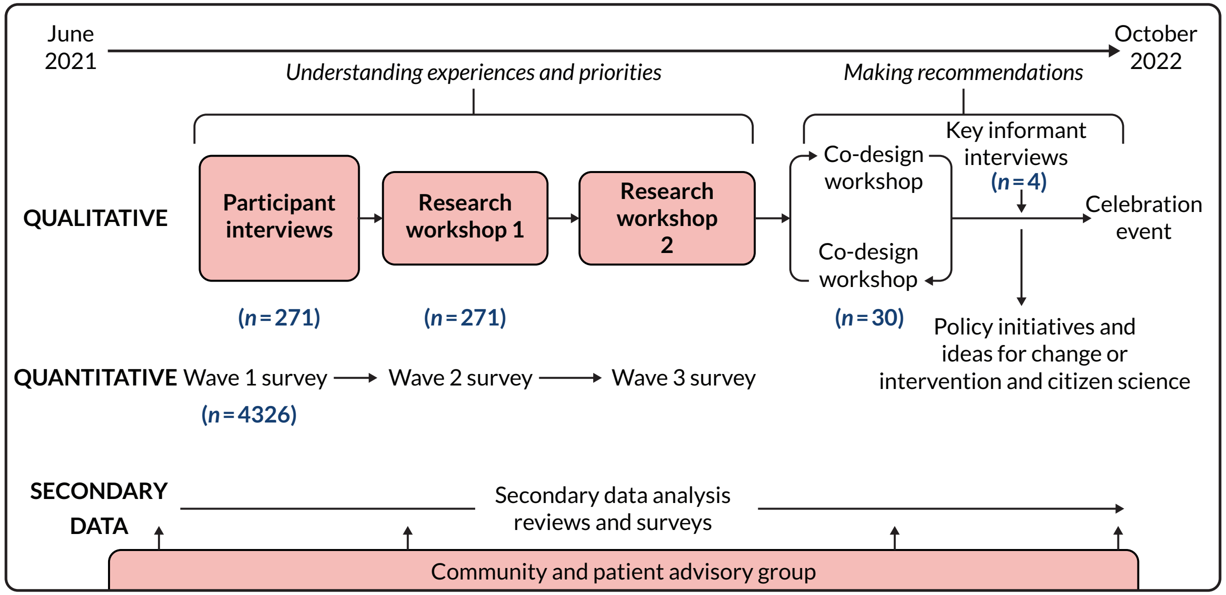


FIGURE 1 CICADA study design.

3. The estimated 1% of the population who are recent refugees, and the 1% undocumented migrants,[6] had an extraordinarily high pre-pandemic prevalence of post-traumatic stress disorder and depression,[13] and UK minoritised ethnic groups reported particularly poor mental health during the pandemic's first lockdown.[19] Yet concern about pandemic-induced mental health issues tends to a population-wide focus, so the needs of minoritised people get diluted.

Impact on study design considerations

The pandemic's greater impact on people from minoritised ethnicities and those with disabling chronic conditions or impairments (who we refer to more simply as 'disabled people' throughout) is a human tragedy and care issue, costly at personal, community, healthcare, economic, societal, and human rights levels. At the study's core, therefore, was a desire to improve support and access to care, services, and resources for these made-vulnerable populations and thence improve their health, social care and well-being outcomes. This necessitated a deeper understanding of relevant influences from different intersecting combinations of disability, ethnicity and citizenship status. Citizenship status affects the support available to people from minoritised ethnicities; many recent refugees and undocumented migrants will have 'no recourse' to normal welfare support (see *Chapter 10* for more details). Though the study centres on these intersections, we necessarily (as *Box 1* shows) also explore other categories of societal difference (e.g. age, gender) that interact with them under institutional and structural conditions to create specific health outcomes and experiences.[20,21] The study and outputs are designed to be both jointly and independently applicable to people with disabilities or those of minoritised ethnic status (insofar as intersectionalities affect this).

The study was longitudinal; all primary data across quantitative and qualitative strands were collected thrice over 18 months. Thus we could explore:

- relationships between: health and social care outcomes; access to resources, coping, and social and healthcare support; and various intersectionalities, and
- changes in these with time and varying pandemic contexts.

We took an asset-based approach, exploring what helped people cope during the period about which we collected data (Spring 2020 to Autumn 2022), to develop ideas for positive change.

Existing literature and studies

The WHO COVID-19 Research Database contained, in January 2023, 762,627 studies, with only 4753 registered as considering ethnicities, 4535 disabilities and 4947 chronic illness (with overlapping content across subcategories). Most of these subcategory studies considered one specific ethnic or racial group or disability or chronic condition.[22] Most are effectively audits of patient footfall and service delivery. Small pandemic surveys have shown the negative impact of reduced access to treatment on patients' symptomatic control, for example in Parkinson's disease,[23] migraine,[24] rheumatology[25] and chronic refractory neuropathic pain[26] and their increased reliance on support networks.[27] There are a handful of excellent UK analyses of population-level statistics[17] or of specific structural inequities, such as accommodation quality.[18] But there remains a dearth of in-depth studies of experience; those that exist tend to concentrate on COVID-19 infections or migrant (including healthcare staff) working, or engagement with pandemic information, as nationwide pressing policy concerns. These topics provide contextual information in our analysis but are not our focus. The evidence base on the COVID-19 pandemic lived experiences of our groups of interest thus remains small despite the greater impact of COVID-19 on these groups.

The pandemic experiences of minoritised ethnic groups

Pandemic-related racial and ethnic stigmatisation is described in several studies.[28–32] In UK-based qualitative research, racially minoritised young people said they felt blamed in government messaging for both rising COVID-19 cases and poorer COVID-19 outcomes.[33] Evidence also suggests that social cohesion (the strength of social networks) reduced during the pandemic in: people living in the 10% most (compared to the 10% least) deprived neighbourhoods; those with less than A-level education (compared to degree holders); those aged under 35 years (compared with over 35 years); and Pakistani, Bangladeshi and black people.[34]

Four studies considered populations at the study sites. Allen *et al.*[35] inferred the local impact of the pandemic in Manchester and Greater Manchester, by mapping rapid review findings onto data on the pre-COVID-19 economic and ethnic composition of the local population. Their deficit approach focused on reasons for reduced economic resilience. Primary survey data of mothers in Bradford similarly showed that financial insecurity and minoritised ethnicity intersected to produce a worse experience during the March 2020 England lockdown.[36] The pandemic experiences of people from the Muslim community in the north-west of England were explored in 25 in-depth qualitative interviews and four focus groups (n = 22). Infection containment restrictions impacting on income and human interaction caused psychological distress. The authors highlighted a need for culturally appropriate information, improved local communication channels and practical support for those whose usual support systems may be disrupted.[37] Finlay, Hopkins and Benwell undertook interviews with 50 South Asian, African and Arab refugees and asylum seekers (30 in Glasgow, 20 in Newcastle–Gateshead), a nationwide survey (95 respondents) and 20 service provider interviews. They explored 2020–1 experiences of the closure of public spaces, digital exclusion, caring responsibilities, housing and accommodation, prolongation of the asylum process, finances, employment, and health and well-being, showing that pandemic impacts overlapped and combined with other pre-existing challenges and inequalities, leaving many asylum seekers and refugees highly vulnerable.[38]

The pandemic experiences of people with chronic conditions or disabilities

Social functioning in the first months of the pandemic was reduced in people with treatment-resistant psychotic disorders or diagnosed anxiety disorder in Galway–Roscommon in the Republic of Ireland (RoI), according to two related qualitative interview studies.[39,40] Semistructured interviews with 22 clinicians/managers (12 from RoI; 10 from Northern Ireland [NI]) and 16 families (RoI, n = 10; NI, n = 6) where parents had prior mental illness suggested improved mental health in 60% of families, due to a respite from daily stresses and the 'normalisation' of mental distress in the general population. The remaining 40%, typically with more severe/enduring mental illness, reported challenges and increased mental distress from: unmanageable child behaviours; fear of relapse/hospitalisation; financial difficulties; absence of child care; or a lack of routine.[41]

A National Institute for Health and Care Research (NIHR)-funded project, similar in design to CICADA, focused on adults with intellectual disability (ID). It reported social isolation and reduced access to services/supports and online community activities, particularly in those with severe/profound ID.[42] Other challenges were: changes to/loss of routine; loss of support, clubs, or services; decreased health, well-being, or fitness; and worries about COVID-19 infections. Relatively few reported positives, such as: digital inclusion; more time spent with important people; improved health, well-being, and fitness; or a slower pace of life.[43] An Irish longitudinal survey showed more older adults with ID stayed connected with family and reported higher rates of contact in 2020 than in a comparable pre-pandemic sample.[44] People with dementia and their carers were interviewed in three studies[45–48] at some of our locations: one covering Gateshead, south London and Sussex; another south-east England; and another London. Challenges included:

- reduced support, with carer check-up calls reassuring but limited in scope and content[45,46]
- decreased social interaction[45–48]
- deteriorating cognitive and physical health[45–47]
- difficulties getting out and understanding COVID-19 restrictions[45,46]
- losing simple routines[46–48]
- not accessing healthcare services, to minimise COVID-19 risk or reduce NHS burden, or due to technological barriers or lack of trust[47]
- difficult remote consultations: lacking memory prompts; issues evaluating new difficulties; rescheduling/missed calls; exclusion of the voice of the person with dementia.[45]

In a longitudinal descriptive qualitative study, January–July 2021, participants with cancer described isolation and caution about keeping safe, but said national public health constraints reduced their normal sense of missing out and of having to explain their diagnosis.[49] One Irish study considered the extra family support people with eating disorders needed during the first year of the pandemic.[50] Adults with audiometric hearing loss living in Glasgow, Scotland, found both affordances and difficulties caused by different aspects of the first lockdown, such as mask-wearing and increased use of digitisation with captioning.[51]

Charities and non-governmental organisations specialising in a specific disability, or disabilities more broadly – organisations both of and for disabled people[52] – have surveyed members during the pandemic; international surveys include one by the COVID-19 Disability Rights Monitor.[53] These highlighted the inequities disabled people faced and their isolation.

A few studies published in peer-reviewed journals also considered disability more broadly. A comparison of data from the English Longitudinal Study of Ageing from 2018–9 and June–July 2020 (all respondents aged 52 years or older) suggested physically disabled respondents were at particular risk for emotional distress and poor quality of life (QoL) during the pandemic.[54] Similar results pertained in a small online cross-sectional national survey of adults in Ireland during the first lockdown.[55] In the University College London (UCL) UK COVID-19 Social Survey,[19] 38.2% of 51,417 analysed respondents had pre-existing physical conditions (with a narrower definition than ours), 19.9% pre-existing mental health conditions and 12% were from 'BAME' [*sic*] groups. This study found good support and resource access protective for pandemic mental health, which informed the study design. In 2020, Shakespeare conducted 69 in-depth telephone interviews with a range of disabled people and parents of disabled children, across England and Scotland, as well as with 28 key informants, repeated at 6 months.[56] This study, smaller than ours and single-method, has a different sampling frame and limited ability to consider intersectionalities, but provides detail on the navigation of social and environmental barriers, the use of new technologies, and participants' view on leadership and communication. Wildman *et al.* undertook in-depth interviews in May–July 2020 with 29 White British participants, many multimorbid, in urban north-east England. Participants reported the pandemic public health response increased the work they had to do to manage their conditions. Mental distress increased from fear of infection, social isolation and distancing and loss of usual support, poor housing, and the stresses of financial precarity.[57]

The intersection of health state and ethnicity and pandemic experiences

There are minimal published data on the intersection of disability with ethnicity, and no study includes our participant range. One study interviewed refugees and asylum seekers ($n = 40$) in Scotland and Newcastle–Gateshead (one of the study sites) and staff in organisations providing services for them ($n = 20$), combined with a UK-wide two-wave survey of asylum seekers and asylum services. Healthcare access was shown to be complicated by citizenship status, though the focus on asylum services differed from the study.[58]

Poppleton specifically explored Central and East Europeans' experiences of health, well-being, and primary care in the UK, with the aim of culturally adapting services to improve access to and quality of their mental health care.[59] He found his participants' health expectations often differed from those of the UK general population, risking dissatisfaction with services. Awan explored how males of South Asian origin with long-term conditions understand, experience and seek help for emotional distress, with fieldwork during the pandemic, including consideration of the impact on participants of remote consultations.[60] Carpentieri and Sheard's NIHR-funded study reported on the long COVID experiences of 40 Bradford participants, of whom 25 were Pakistani or Kashmiri.[61] They found mistrust and fear of services, issues accessing primary care or receiving (perceived) inadequate support and the use of alternatives, but also positive experiences. Ziebland's UK Economic and Social Research Council-funded project involved narrative interviews between March 2020 and November 2021 with 70 adults who had COVID-19, of whom 45 came from minoritised ethnic backgrounds.[62] These revealed: disadvantage (employment, housing, and caring responsibilities); unequal access to care, welfare, and support; fears about quality of health care and vaccine safety; feeling blamed for spreading COVID-19 by the media and public health messaging; and an increase in direct racism. In autumn 2022 the Voluntary Organisations Disability Group established the Commission on COVID-19, Disablism and Systemic Racism as a response to the dearth of information.

Conclusions

No pre-pandemic studies and only a few studies recently completed consider the everyday experiences of people with disabilities from minoritised ethnic groups, and only some consider intersectionality, despite the need. All are complementary to the study; none has considered our breadth of ethnicities or conditions or focused on strengths, assets and the practical generation of solutions to the same depth. The breadth of our sampling, longitudinal design, our intersectional considerations and triangulation of different method streams mean our work should provide unique transferable knowledge to inform the future support of minoritised ethnic groups and disabled people.

The COVID-19 pandemic: context for the study

The first confirmed case of COVID-19 in the UK was reported on 31 January 2020. On 30 January 2020, the World Health Organization (WHO) categorised COVID-19 as a public health emergency of international concern. On 11 March 2020, it declared a pandemic.[63] Initially, the UK government focused on increasing health and care system capacity to manage COVID-19 illness. On 3 March 2020, it published its coronavirus action plan.[64] By 16 March 2020, it started encouraging the public to avoid non-essential contact, work from home where possible and avoid hospitality, social venues or mass gatherings. This became enforceable on 23 March 2020 as COVID-19 spread, first in London, then rapidly elsewhere. A UK-wide lockdown was decreed, with non-essential businesses and venues closed, prohibition of gatherings of more than two people in public, and the requirement to stay home except to shop for necessities, take one form of exercise a day, get medical or social care, or commute to work where this was necessary. Face-to-face teaching in schools and universities stopped, except for vulnerable children and those of critical (key) workers. Police, army and COVID wardens patrolled, looking for people breaking lockdown. Though necessary at the time, there is considerable evidence – to which we add – that lockdowns affected people's mental health and well-being in various ways.[19]

The government compiled a list of people identified as 'clinically extremely vulnerable' (CEV) to the virus; the NHS initially identified around 2.2 million people, with specific cancers, severe respiratory conditions and some rare diseases significantly increasing infection risk (e.g. homozygous sickle cell), and people undergoing immunosuppressive therapies. In March 2020, the government advised this CEV group to stay home for 12 weeks,[65] gave the CEV list to supermarkets to prioritise online slots for them, and set up a system of food parcels.

Initially the public was asked to conserve mask supplies for health and social care professional use due to shortages in personal protective equipment. There was little clear evidence on mask effectiveness at the time. In June 2020 England and Scotland, followed by NI and Wales in July 2020, made it a requirement for face masks of any type (including home-made) to be worn in public spaces – starting with public transport and then moving in Scotland on 10 July and England on 24 July to include other spaces, such as supermarkets, restaurants and performance venues. In Wales, mask-wearing was recommended from 9 June 2020, mandated on public transport on 27 July, and mandated in other settings in mid-September 2020.

As the number of cases fell through May and early June 2020, restrictions were eased in all four UK nations. Limits were removed regarding the frequency of outdoor exercise, social contact outdoors was allowed with a limited number of other households, and schools began reopening. By the end of June 2020, non-essential shops and other businesses could reopen. NI was the first UK nation to allow indoor social contact, in groups of six people, from 23 June 2020. Contact tracing was prominent in all four UK nations during May and June 2020, with people expected to leave contact details at all public spaces visited; QR codes appeared everywhere for the purpose, linked to a special government smartphone app. From June to September 2020, the UK experienced low rates of COVID-19 hospitalisation. Pandemic fatigue, detrimental impacts from lockdowns, and the summer weather (which was thought to reduce transmissions) reduced concern among the public and government alike. The UK government turned to promoting economic growth, with its 'Eat Out to Help Out' scheme, for example, encouraging more social mixing to benefit the hospitality sector and the wider economy. Public messaging became confusing. Workers were encouraged to stop homeworking, but many were concerned about this.

The second COVID-19 wave began with a sustained rise in cases from September 2020. Attempts were made to contain it with local hotspot lockdowns that did not disrupt economic and social recovery elsewhere, then a system of tiers in England with areas categorised by COVID-19 prevalence. Those living in 'tier one' areas could mix with up to six people from different households inside or outside, whereas those in 'tier four' could meet with one person outdoors.[66]

On 2 December 2020, the second national lockdown ended in England. The prime minister on 15 December declared the relaxation of rules over Christmas, then on 19 December backtracked and mandated people across London and the south-east to stay home from 21 December 2020.

In early 2021, with the country still in lockdown, the COVID-19 vaccine was slowly rolled out. Restrictions eased in all four nations between March and May 2021 with schools reopening and limited outdoor social mixing permitted. Spread of the COVID-19 Delta variant caused a third wave in May 2021, when the study started. The public response was limited, partly due to confidence in the vaccine. The UK government's gradual easing of restrictions culminated in England in the so-called 'Freedom Day' on 19 July 2021.[67] By 16 August 2021, people in England with two vaccinations were no longer legally required to self-isolate if identified as a close contact of a positive COVID-19 case. But as COVID-19 infections and hospitalisations remained high, amid concerns about the winter burden on the NHS, from 8 December 2021 mask-wearing was mandated in public places in England, and working from home guidance and daily testing for close contacts reintroduced. COVID-19 vaccine booster doses were rolled out in early 2022 and the UK moved to its 'living with COVID' phase.[68] In December 2022, the government announced the end of regular COVID-19 infections modelling data and a move to monitoring COVID-19 in the same way as influenza. In May 2023 the WHO downgraded COVID-19 to an established and ongoing health issue.[69]

Terms used in this report

Refugee

The UK follows the 1951 United Nations (UN) Convention Relating to the Status of Refugees definition of a refugee as anyone who:

> *owing to well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country; or who, not having a nationality and being outside the country of his former habitual residence as a result of such events, is unable or, owing to such fear, is unwilling to return to it.*[70]

In the UK, refugees are usually given 5 years' leave to remain, and must then apply for extensions.[70]

Asylum seeker

This is someone who has formally applied for recognition as a refugee; requests can be rejected. In the UK, asylum seekers are not allowed to work, cannot choose where to be housed and cannot claim mainstream welfare benefits, though they are eligible for destitution asylum benefits.[70]

Migrant

The usual policy definition of a migrant is the UN definition, based on residency:

> *A person who moves to a country other than that of his or her usual residence for a period of at least a year [. . .] so that the country of destination effectively becomes his or her new country of usual residence.*[71]

Our definition, developed with our patient and public involvement (PPI) group, is: 'A person who moves to reside in a country other than that of his or her usual residence and is not born there', 'foreign-born' being the definition used in national surveys of workers and the labour market. We include asylum seekers and refugees (both groups sometimes being excluded in definitions). The UN definition problematically pivots on intention and only a minimum stay is defined; some will stay longer or less than intended. We specified in recruitment materials that participants must have experienced the UK/RoI context of the pandemic for at least 3 months. The UN definition combines recent migrants and those arriving decades ago; we include this range to dissect false homogenisations, which can problematise policy and practice. Migrants typically come to the UK/RoI to work, study or join family, but some are escaping poverty, political unrest, gang violence, natural disasters or other serious circumstances, and may not fit the legal definition of a refugee.

Undocumented migrant

These are people entering the country outside regulatory norms without the necessary authorisation or documents required under immigration regulations, or who have remained in a country without the relevant documents (e.g. entering as a tourist but never leaving).[72] They have no legal status.

Minoritised ethnicity

Selvarajah *et al.*[73] critique the term 'ethnic minority' as disguising power differentials, for example in South Africa, where white people are a cultural majority and a numerical minority, and in minoritising in many countries people from Asia, a global majority. We use the term 'minoritised ethnicity' to emphasise active processes of stigmatisation and oppression that racialised society bestows on particular ethnic groups as 'others'[73–75] rather than to necessarily ascribe to them a 'minority' status. These processes of power are what 'diminish minoritised people's capability to lead healthy lives'.[73] This study seeks to promote healthy lives, so it must necessarily emphasise this minoritisation, though we sometimes use the term 'ethnic minority', for example, verbatim from a participant or the literature. In our usage these terms encompass migrants and UK/RoI-born children of migrants. Some sources refer to these as 'second-generation', but this is othering and disliked by, for example, those affected by the Windrush scandal, as the term sidelines their historical citizenship and rights and instead foregrounds their movement to the UK. One of our outputs, a toolkit[76] for researchers wishing to engage disabled people or people from minoritised ethnicities in their research, discusses terminology in more depth.

Disability

Section 6(1) of the Equality Act 2010[77] says a person is disabled if they have a physical or mental impairment that has or is likely to have a substantial and long-term (chronic) adverse effect on their ability to carry out normal day-to-day activities, such as getting dressed (note that this does not apply to NI).[78] Schedule 1 of the Act specifies that 'long-term' means 12 months or for the rest of the person's life.

We have added to this definition any health condition with no expected cure (though it can be held in check or 'managed'), for example, diabetes, chronic pain, depression. We recorded conditions at recruitment but grouped them for comparative analyses into categories adapted from the UK Government Statistical Service 'harmonised' themes,[79] as shown in *Table 1*.

Impact categories 'mental health', 'mobility', 'stamina/breathing/fatigue', 'sensorial (hearing/vision loss)' and 'cognitive: developmental/intellectual' resulted.[79] We added 'food-relevant' and 'cancer', and a 'brain hyperexcitability' group (e.g. migraines, epilepsy) at the request of our advisory group. We include long COVID and other multisystemic conditions (which may belong to more than one group); our categorisation by impact not diagnosis enables a practical focus and a flexibility to changing understandings of long COVID and other 'contested conditions', such as fibromyalgia, chronic fatigue syndrome and Ehlers–Danlos syndromes. A contested chronic condition is one with non-specific but distressing symptoms (e.g. pain, headache, nausea) and limited or controversial physical signs (e.g. lacking a definitive blood test), making it hard to diagnose and compounding the patient's distress.[80]

We note, as indicated in the table caption, that these categorisations are imperfect and that an intersectional analysis, as described shortly in this chapter, uses common categories only to highlight their problematic use as absolute, discrete, descriptors. During analysis we explored this in the data and undertook sensitivity analyses which considered findings with and without different 'problematised' data. For example, someone may be considered 'completely' blind or may have central but no peripheral vision, and their experiences would be compared in the data against each other and the entire data set to explore any divergences.

The WHO defines a long-term condition as requiring ongoing management over years,[81] and the UK government specifies at least 12 months for disability. We use the shorter period of 3 months to strike a balance between capturing new diagnoses or conditions and ensuring participants have had some experience of the pandemic in their ill health or disability state.

While we combine chronic conditions with impairments/disabilities for an inclusive impact-led approach, this combination has been problematised (see e.g. Suleman *et al.*[82]). Not everyone with a chronic illness is disabled by it, and not everyone who is disabled because of an impairment is ill. The effects on personal and social identities of 'chronic illness' and an impairment leading to disability are often very different. During the pandemic, people with some chronic illnesses were put into the CEV category and many with impairments were not, even when disabling factors (such as social and environmental factors) increased their risks.[83] Our rationale is that we have focused in our core analysis on people whose activities of daily living (ADL) are impacted because of their condition/impairment. We also recruited people who, it transpired at interview, had impairments that did not affect daily living, and we compared these to our core group in a sensitivity analysis, described in our analyses.

TABLE 1 How our impact categories were derived

UK government theme name	CICADA impact name	Comments
Vision (e.g. blindness or partial sight) Hearing (e.g. deafness or partial hearing)	Sensorial	We focused on blindness in recruitment but included people with hearing impairments when they were specified. While being blind or deaf have different impacts, these were teased out in analysis. Only two participants specified being disabled by hearing loss.
Mobility (e.g. walking short distances or climbing stairs)	Mobility	This covers structural nerve or musculoskeletal issues that affect lower limb function, including paralysis (-plegias), loss of the lower limbs, arthritis, or multiple sclerosis.
Dexterity (e.g. carrying objects, using technology)	Dexterity	This was represented in the data by hand/upper limb loss or partial loss; conditions like multiple sclerosis and arthritis may be relevant but were not mentioned in relation to dexterity in our data.
Learning or understanding or concentrating Memory	Cognitive (e.g. dementia, ID)	We wished to separate neurodivergence more clearly than the government definition [which describes one common impact of being neurodivergent here, but confusingly lists neurodivergence itself under a separate impact theme (see below)].
Mental health	Mental health	
Stamina or breathing or fatigue	Stamina/breathing/fatigue	We included activity-limiting cardiovascular conditions, excepting strokes which would fall under cognitive, dexterity or mobility. We note that physiological stamina, breathing and fatigue issues frequently have very different aetiology and nuanced impacts, and we do not imply these lie within an individual's locus of control by using the term 'stamina'. However, this label helps distinguish conditions that indirectly affect mobility from, for example, structural musculoskeletal conditions. Some condition complexes (i.e. condition plus common comorbidity), such as Ehlers–Danlos syndromes (collagen issues) and associated postural orthostatic tachycardia syndrome might affect a person in both ways.
Socially or behaviourally (e.g. associated with autism or attention deficit hyperactivity disorder)	Neurodivergence	See the comment on our cognitive label above.
	Food-relevant (e.g. diabetes, eating disorders)	These may not be considered impairments in government surveys but may be disabling in daily life, especially for lower socioeconomic groups or in times of food scarcity.
	Cancer	This may not be considered an impairment in government surveys but involved special considerations during the pandemic. Cancer has various impacts (e.g. fatigue, pain) and can disrupt any type of body function depending on where a tumour grows, so this is not a clear impact category.
	Brain hyperexcitability group (e.g. migraines, epilepsy)	Requested by our advisory group; the name attempts to describe the type of impact rather than implying any common aetiology.

We note the limitations of these categories, which intersectional research expects to problematise, and considered individual stories of symptoms and impact to categorise participants, rather than making assumptions based on diagnostic labels per se.

Post-COVID-19 syndrome

Post-COVID-19 syndrome is defined by the National Institute for Health and Care Excellence (NICE)[83] as:

> *signs and symptoms that develop during or following an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis. It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body.*

This is more commonly called 'long COVID' in everyday talk and in this report (other terms are 'long-term COVID-19'; 'long-haul COVID'; or 'post-acute sequelae of COVID', but the NICE guidelines point out that includes symptoms that occur 4–12 weeks after infection too). The Zoe study[84] is a useful source of understanding; in June 2022 this reported three long COVID symptom patterns:

- fatigue, 'brain-fog' and headache (the most common symptom cluster)
- respiratory symptoms, such as chest pain and severe shortness of breath (mostly in those affected pre vaccines)
- diverse symptoms including heart palpitations, muscle ache and pain, and changes in skin and hair.

Almost three-quarters (72%; 1.4 million) of people with long COVID in the Zoe report said long COVID had reduced their ability to carry out daily activities, and 21% (400,000 people) reported having had long COVID for over 2 years after their first suspected infection.

Chapter 2 Study aims and objectives, design and theoretical framing

In this chapter, the study's aims and objectives are described, followed by a summary of the study design, the theoretical framing and reasoning for the mixed-methods three-strand approach. Full details about each strand, and protocol deviations, are given in subsequent chapters. Early outputs and impact are detailed in *Appendix 1* and ethics approval in *Appendix 2*.

Aim and objectives

Aim: to contribute and inform evidence-based formal and informal strategies, guidelines, recommendations and interventions for health and social care policy and practice, to mitigate inequities and improve the experiences and social, health and well-being outcomes of minoritised ethnic groups at the intersection with disabling chronic conditions or impairments.

Objectives (using an intersectionality lens) were to:

1. explore and compare, by location and time, survey and qualitative data on changing patterns of need for social, health and well-being outcomes
2. relate pandemic coping strategies/solutions to objective 1 findings, including what worked well or less well, and touchpoints (where experiences might best be improved)
3. explore formal and informal network issues/affordances in health and social care solutions
4. gain insights from synthesis of our mixed-methods data
5. contextualise and explore transferability of findings
6. co-create outputs with stakeholders that include identified strategies, interventions and touchpoints, and plans for rapid pathways to impact.

Study design

The study adopts a transformative, convergent parallel mixed-methods design (see *Figure 1*), integrating three strands (primary quantitative, primary qualitative and secondary data strands) across three phases over 18 months, to answer the study objectives. Qualitative data were merged, and qualitative and quantitative data triangulated.

The study protocol is published[85] and parts of this report – notably in this chapter and *Chapter 4* – are reproduced with permission from Rivas *et al.*[85] This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY 4.0) licence, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by/4.0/, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Research Protocols*, is properly cited. The complete bibliographic information, a link to the original publication on www.researchprotocols.org, as well as this copyright and license information must be included. See: http://creativecommons.org/licenses/by/4.0/. The text below includes minor additions and formatting changes to the original text.

Topics across all strands

The three strands were interlinked and complementary. They considered the same topics:

1. intersectionalities[86]
2. behavioural responses to COVID risk-containment measures by individuals, and their formal (e.g. health/social care) or informal (e.g. friends, family, community) support and care networks

3. access to resources, formal support and care
4. social networks (informal support and care)
5. physical and mental health consequences of the pandemic, coping and attitudes regarding these
6. mental and physical well-being/QoL as core outcomes
7. local/regional differences in responses linked to policies/interventions and associated impacts
8. future policy implementation for people with disabilities and minoritised ethnic groups.

In all cases we considered what worked well and less well for health, well-being and social care outcomes.

These topics were chosen to develop a holistic understanding of the context of people's lives, their responses to adversity and health and social inequities including their strengths and assets, and effects of their networks. In the qualitative work they formed the basis of our topic guides. In our primary survey they informed the selection of component instruments (questionnaires); those chosen were mostly validated in minoritised ethnic groups, including recent migrants. Instruments were augmented by single questions. These considered variables that, for wave 1, were based on prior research evidence on key moderators and mediators of pandemic health and well-being, and for subsequent waves also reflected our own early findings.

Theoretical framework

This study takes a strengths-and-asset-based approach, underpinned by embodiment models of disability and intersectional considerations.[87,88] Our exploration of social influences on health and well-being is framed by the social ecological model.[89]

Disability models

Medical or biopsychosocial models of disability conflate pathoanatomical diagnostic criteria with disability itself, making them inseparable. This focus on deficits locates the problem within the individual and leads to their disenfranchisement and marginalisation as deviations from the 'norm' of ableness. Disabled people are seen as needing cure or rehabilitation or, failing this, care outside normal society.[90,91] This leads to ableism (discrimination by focusing on non-disabled people)[52] and disablism ('discriminatory, oppressive, or abusive behaviors arising from the belief that disabled people are inferior to others'[92]).

The CICADA study resists the use of deficit-focused disability models. We acknowledge the social model of disability because of its currency, its usefulness in driving transformative outputs, and its continued relevance to much needed revisions in discriminatory statute and law[93] notwithstanding the UN Convention on the Rights of Persons with Disabilities.[94] In the social model, physiological problems of the body are called impairments. These are decoupled from disability, which is seen as the result of environmental and social barriers to equitable opportunities and participation in society, caused by exclusionary social oppression and prejudices.[52] This theory has driven the concept of 'reasonable adjustments' in areas such as education and employment but less so in access to medical and social care.

The social model has limitations.[95,96] Siebers argues for: (1) more complex understandings of embodied variation and (2) more dynamic problematisation of the liminal spaces occupied by lived reality.[95] Arendt calls for more account of the ways people with impairments internalise and make meaning of their lived experiences.[96] In other words, Siebers and Arendt call attention to how experiences and disability vary with context and how individuals with 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.[95] This was our overall interest.

Within this report we use the term 'disabled people' as preferred by most disability activists in the UK, though many academics and professionals use the person-first term 'people with disabilities'. Terminology issues are discussed in our toolkit.[76]

Intersectionality

The multiple social categories of 'identity, difference, and disadvantage',[97] such as gender, racial/ethnic minoritisation, disability and housing, are considered as mutually constitutive systems of oppression[97] in CICADA. In other words, we recognise that they interact under discriminatory institutional and structural conditions[98–101] to create poorer health and care outcomes.[102,103] We foreground citizenship status alongside ethnicity and disability, adding an important layer of complexity.[99] Variations in citizenship are rarely considered in health and social care research, though some studies exist on the ways health outcomes are shaped for undocumented migrants through their structural construction as 'illegal' within the 'hostile environment' (see *Chapter 10*).[58,104,105] We used a wider lens than these, considering both individual experiences of day-to-day discrimination and the wider context, and we emphasise this using the term 'minoritised ethnic groups'.

Shifting identities in the face of racism among recent migrants can include the racialisation process of 'becoming white'. Neglected in the health literature,[106] this is explored in CICADA by including recent migrants of Arab or Central and East European heritage. These may experience the tensions of being symbolically included in a white ethnic category but simultaneously excluded from many of its benefits,[106] in a manner often made invisible, not least because of the lack of its exploration.

Through considerations such as these, built into the study design, intersectionality theory allows us to develop complex nuanced insights into differences, while minimising the risks of essentialising some combinations as inherently problematic, or considering the minoritised experience as homogeneous.

Social ecological approach

Intersectionality conceptualises how an individual's social interactions are shaped through their multiple subject positions (e.g. as a female disabled migrant). The social ecological model[89] highlights their position within personal, community, regional and national (policy and society) ecosystems of norms and practices (*Table 2* shows how this relates to our work). The model levels thus range from smaller, proximal settings of local influence to larger, distal settings with indirect influence. Potential discrimination and oppression of individuals occurs across the levels.[107] In CICADA, this necessitated the involvement of multiple stakeholders in the development of potential strategies and recommendations, to ensure they will apply and have impact both within and across the different levels. This also fits with the new UK NHS tiered Integrated Care Plan.[108] Bronfenbrenner represented interactional flux through time by the 'chronosystem';[109] our longitudinal study incorporates this. The Consolidated Framework for Implementation Research (CFIR)[110] also underpinned our work, an amalgamation of implementation theories across different levels of the social ecological model, which we used to explore the implementation feasibility of our outputs. The CFIR is operationalised with definitions and a codebook, flexible (the user selects relevant themes from a taxonomy pool of 39), and facilitates actionable findings across multilevel implementation contexts. CFIR draws on theories of behaviour change, improvement science, and diffusion theory.[110]

Asset-based approach

Strengths-/asset-based approaches involve a holistic focus on both personal strengths that people have at their disposal (internal factors such as self-efficacy and external factors such as money) and social and community networks. This is more inclusive, with greater transformative potential, than more common deficit-focused approaches to intervention development,[111] which are ableist and white-centric, locating the failure of interventions in failings of the individual. A strengths-based model instead suggests structural barriers. A few small cross-sectional analyses indicate some chronic conditions and impairments may confer resilience to mental health or well-being effects of the pandemic,[112,113] and it is important to draw on strategies that enable this. In a UK pandemic analysis of chronic fatigue, for example, some Reddit users reported more severe symptoms but also more accessible opportunities to interact with others, through online video calls[114] The term 'resilience' is often disliked by minoritised groups as it implies that hardships are beneficial.[115] Our approach instead looks for assets and strengths associated with positive outcomes in adversity, and areas of behaviour and community development needs, where further resources could develop or add to assets and strengths. We are mindful to ensure this does not reduce the need for state intervention (we have been careful not to deproblematise contexts or suggest that improvements should be a community, rather than a policy, responsibility). A strengths-based approach does not try to take the focus away from the structural causes of inequalities, but rather aims to empower communities and individuals[116] in meaningful and sustainable ways. It is based on salutogenic theory,[117]

TABLE 2 How we applied the social ecological model to CICADA

Social ecological level of influence	Examples of what we considered within each level
Micro	Personal factors, such as gender, age, race, that intersect to create individual identities. Psychosocial factors, such as empowerment.
Meso	Organisations (formal networks) such as migrant charities, food banks, individual health and social care clinics and centres and staff. Usually geographically close though would include individual service providers outside the UK if part of a person's usual formal network. Community (informal networks) such as neighbours, faith institutions, local social groups, local charities. Typically geographically close. Interpersonal (emotionally close informal networks), such as neighbours, friends, family. Need not be geographically close.
Macro	National laws and national policy, cultural norms, international influences.

Source: Adapted from Bronfenbrenner; arrows show the bidirectional flows of interactions between levels as a complex system.[89]

which positions people as co-producers of health, rather than consumers of health services[118] and recognises the need to consider intersectionalities.

Mixed-methods approach

Our convergent parallel mixed-methods design allowed us to consider, integrate, compare and contrast multiple approaches and data types that could be mutually informative, as suited to an intersectional study, and to choose methods to provide the best available data. Historically, qualitative methods have been the tool-in-trade of intersectional researchers, but their interest in mixed-methods research is increasing (e.g. Bowleg and Bauer[119]). Our first strand, involving analysis of existing cohort and panel data, and a scoping literature review, fed into the other strands, though they were not dependent on this. We used survey-based methods to obtain national data (strand 2), and qualitative methods (strand 3) for in-depth understanding. Strands 2 and 3, designed to run concurrently, involved repeated measures over three periods or 'waves' of data collection over 18 months. This allowed us to explore experiences and attitudes within changing pandemic contexts; the relations between these, intersectional identities and health and well-being; and enhanced the ecological validity of our quantitative and qualitative assessments.[120] Our data synthesis followed a triangulation design.[121]

Chapter 3 Reviews of existing information

We undertook a scoping review to make preliminary sense of the large, complex and heterogeneous pandemic evidence base[122] for our work, and to provide a resource for other researchers to use, for example when developing pandemic grant applications. We also used the scoping review to develop more systematic smaller reviews. Our first, on vaccine uptake, is briefly described in this chapter

The scoping and systematic review searches reflected the novel and unstable nature of the pandemic, and the interest in getting information out to policy-makers and practitioners speedily in preprints, grey literature, blogs and other rapid disseminations.

Scoping review

Methods

The purpose of the review and a specific question (subsequently slightly modified; see *Protocol changes* below) were established:

> *Since January 2000, what information is there in the social and healthcare literatures and associated websites, grey literature, blogs, Reddit and Twitter on pandemic-relevant daily life, health and social care experiences of people with chronic conditions or impairments or from minoritised ethnic groups worldwide?*

This drove the inclusion criteria:

- people with disability, impairment, chronic health condition, or from an ethnic minority in their country of residence
- experiences of the COVID-19 pandemic relating to the eight topics of the study (see *Chapter 2*)
- worldwide settings
- sources dated 2000 or later.

Exclusion criteria were:

- focus on experiences of COVID-19 infection or intervention development
- not fitting the inclusion criteria.

We were language-inclusive; the team collectively was sufficiently fluent in many languages, and Google Translate (Google Inc., Mountain View, CA, USA) was used for screening others; we did not need to involve formal translators.

The scoping review, begun in July 2021, was updated on 15 September 2022. Searches were conducted in:

- Academic electronic databases: MEDLINE, EMBASE, CINAHL, PsycInfo, ASSIA, Sociological Abstracts, Web of Science, Scopus
- Grey literature sources: ProQuest Dissertations, Thesis Global and professional body, governmental and third-sector organisation websites, Google Advanced, blogsearchengine.org
- Reddit and Twitter
- The UCL Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre)'s COVID-19 Living Map of Evidence, the WHO Global Research Database on COVID-19, the COVID-19 Rapid Evidence Reviews Group (CORRE), and LitCOVID, who collate evidence on COVID-19 from a worldwide data set, albeit mostly clinical rather than experiential.

For articles, reports, and longer texts, the search strategy (detailed in *Report Supplementary Material 3*) used controlled subject headings and keywords such as:

1. COVID-19 OR COVID OR SARS-CoV-2 or pandemic
2. long-term OR post-acute OR long-tail OR persistent OR chronic COVID OR long Covid OR post$discharge OR prolonged symptoms OR long haul
3. ethnic* OR minority ethnic* or variants thereof including specific groups
4. chronic OR long$term OR underlying OR (names for chronic conditions or chronic health states) OR disab*
5. specific terms related to our eight study topics (see *Chapter 2*) (e.g. synonyms of 'well-being').

Within each concept, keywords were combined using Boolean and positional search operators. Identified articles were screened for relevance, then mapped by topic (*Figure 2*).

Scoping reviews do not require critical appraisal, risk of bias assessments, a formal synthesis of findings or the generation of a 'summary of findings' table.[122,123]

Protocol changes

1. Studies from 2000 to 2022 were originally included to ensure COVID-19-relevant work *and* draw on knowledge from past pandemics. But given the volume of material (over 32,000 in July 2021 after title screening) and having inspected some studies of past pandemics, we restricted final searches to the period January 2020 to September 2022.
2. We used the advanced Twitter search function on selected hashtags and people who frequently tweeted about our eight topics. We found fewer than 10 relevant tweets, so do not report these here. To put this in context, an analysis of UK tweets on health care posted between January 2018 and October 2020, extracted using the more thorough Twitter application programming interface, found only 637 relevant tweets *for the general population.*[124]

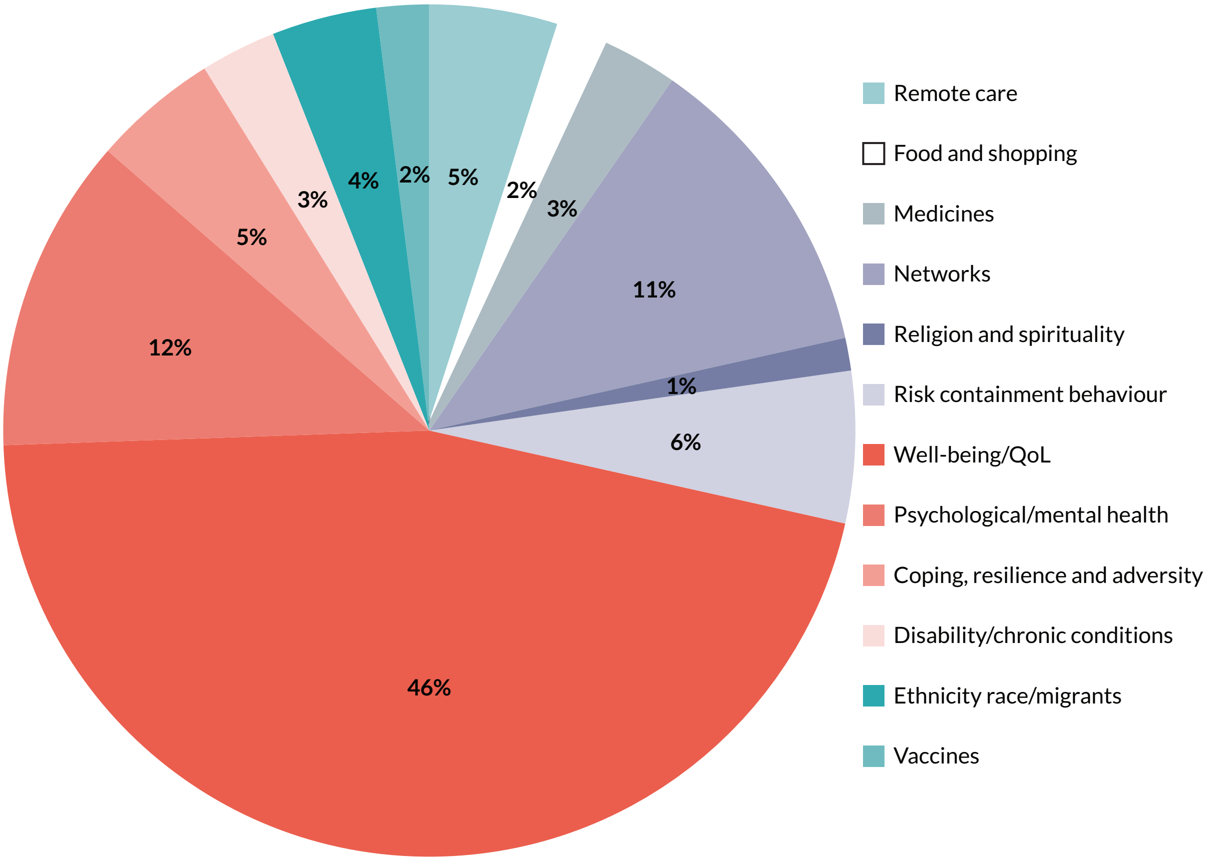


FIGURE 2 Proportionate spread of topics in the scoping review; categories are not mutually exclusive. This showed well-being was preponderate.

3. The UCL EPPI-Centre Living Map review team advised against our planned Living Map of Evidence since policy-makers and practitioners had become less interested in rapidly changing pandemic evidence.

Findings

We found 48,717 potentially relevant articles. The pie chart (see *Figure 2*) shows the spread by topic; disabilities or race/ethnicity are central to all represented papers. Approximately 5% of the total were of direct relevance, and we are using them in systematic reviews. In this report, due to the volume of material, we will not summarise the scoping review further.

Systematic review methods

Two systematic reviews were conducted before the end of primary data collection, with final search dates of 15 September 2022, to explore individual, contextual, and specific factors for COVID-19 vaccine acceptance, intention and hesitancy. One focused on adults from minoritised ethnic groups globally (summarised here) and the other on adults with disabilities. The protocol was registered on PROSPERO (CRD42022355254). We began with vaccines rather than other study topics because this was the highest priority at the time. However, the scoping review enabled us to review other topics informally (e.g. to inform analyses and new grant applications) and other formal reviews are planned.

Searches

The searches were identical to the scoping review except that one review excluded the disability search terms, and the other the ethnicity and citizenship search terms, and each search included the term 'AND vaccin*' (note that using terms for immunisation led to no further relevant articles).

Inclusion criteria are shown in *Table 3*.

We excluded studies:

- that focused on children and young adults under the age of 18 years, healthcare professionals, students and pregnant women, unless they also included separate data for our included population;
- reporting that that reported rates of vaccine uptake or acceptance, but not barriers and facilitators or attitudes influencing acceptance and uptake.

Screening and data extraction

Articles were double-screened on title and abstract, then full text, by three researchers (AM, KA, ZZ). Discrepancies were discussed until consensus. No discrepancies needed adjudication by CR.

The following extracted data were managed by the software programme EPPI-Reviewer.[128]

- article provenance and publication details
- study aims, rationale and data 'thickness'[129] related to our aims
- study methods
- country and population
- underpinning theory
- data collection and analysis methods
- reported results and author conclusions of relevance to our domain of interest
- strengths and limitations (author-reported or reviewer-determined).

Data synthesis

Framework synthesis was used to combine and analyse the different data sources. This involves developing an analytical coding framework top-down (which can then be extended inductively as the work progresses), as columns on a matrix. Each included article forms a row on the matrix, and data are extracted in the relevant code cells for its row. This enables quick comparisons of sources and a rapid data summary. More details are as follows.

TABLE 3 Review inclusion criteria

	Ethnicity review	Disability review
Setting	Studies relevant to minoritised ethnic groups in the Western world, and their ancestral countries, or other international studies with transferable knowledge. We define the Western world as the UK, Norway, Iceland, Switzerland, the USA, Canada, Australia, and New Zealand and the EU14 countries (Austria, Belgium, Denmark, Finland, France, Germany, Greece, RoI, Italy, Luxembourg, the Netherlands, Portugal, Spain and Sweden).[125] By 'minoritised groups' we mean people living in the Western world who originated from EU8 countries (Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Slovakia or Slovenia) or EU2 countries (Bulgaria, Romania) or who were represented in ONS data[126] or the list of migrant origin provided by Statista[127] because of our interest in being comprehensive within our focus on UK relevance. This means some countries (e.g. Saudi Arabia) are excluded but other countries from the same region (e.g. Iraq) are included.	No limits
Population	Adults (18 + years) from the included ethnic groups/countries.	Adults (18 + years) living with any disability or their carers
Phenomenon of interest	Adults offered or reflecting on COVID-19 vaccination, and for the disability review other adult-administered vaccines that may provide insight to acceptance (e.g. influenza vaccine, H1N1).	
Date	January 2020-September 2022	
Language	Searches were in databases that primarily index articles in English, but we did not exclude articles by language.	
Data type	Empirical data concerning barriers and facilitators to vaccine acceptance and uptake.	
Condition or domain	COVID vaccine uptake beliefs, attitudes or perceptions, intent, barriers, facilitators to acceptance, and predictors of intent.	

ONS, Office for National Statistics.

Familiarisation and analytical framework formation

The '3C' model of vaccine hesitancy was developed by the WHO Strategic Advisory Group of Experts on Immunisation (SAGE) Working Group to map three main influences on vaccine uptake: confidence, complacency and convenience.[130] We piloted this as a conceptual framework along with the '5C' model, which adds 'calculation' and 'collective responsibility',[131] and decided the 5C model was most suited to our data. This was subsequently modified through inductive theme development as synthesis progressed.[85] We also included demographic variables as potential moderators.

Indexing and charting

Microsoft Excel® (Microsoft Corporation, Redmond, WA, USA) was used to index and chart the extracted data from EPPI-Reviewer with articles as rows and codes as columns. This reflected the aim of the systematic review, summarised the included studies, enabled the risk of bias assessment, and facilitated synthesis.

Mapping and interpretation

Key findings were mapped, interpreted and summarised from included studies to form the synthesis. Team discussions and double-indexing and charting of some articles ensured consistency.

Quality assessment

We used the Mixed Methods Appraisal Tool (v2018) (MMAT)[132] to assess the quality of included studies. Instead of reporting an overall quality score for each study, we used a principle of 'good enough' quality[133] to decide whether the study could contribute to the synthesis. We did this by completing the MMAT ratings, then calculating the percentage of fulfilled relevant criteria. Studies with 'yes' responses to all five study-based questions were marked as 'very good' quality (100% fulfilled criteria); studies with 'yes' responses to only two questions were marked 'good enough' (40%); and the remainder were marked 'good quality' (60–80%). A detailed description was included for any study of poor methodological quality (20% score), rather than excluding it. Grey literature reports that were appraised using the

AACODS checklist[134] and considered to offer significant and authoritative contributions to the subject of interest were also included.[135]

Systematic review findings

Here we summarise the ethnicity review as an example. The initial literature search retrieved 7517 records. After screening titles, abstracts and full papers, 93 studies were deemed eligible: 71 cross-sectional quantitative survey-based, 15 qualitative, 1 cohort-based and 4 mixed-methods studies, 1 secondary data analysis and 1 article commentary (*Figure 3*). The countries represented are shown in *Table 4* and a summary table of studies in *Report Supplementary Material 1*.

Ninety-two of the included studies were of good or very good quality (80–100% quality). Only one was 'poor quality' (20%), with limited generalisability and potential reporting bias regarding the intervention and outcomes.

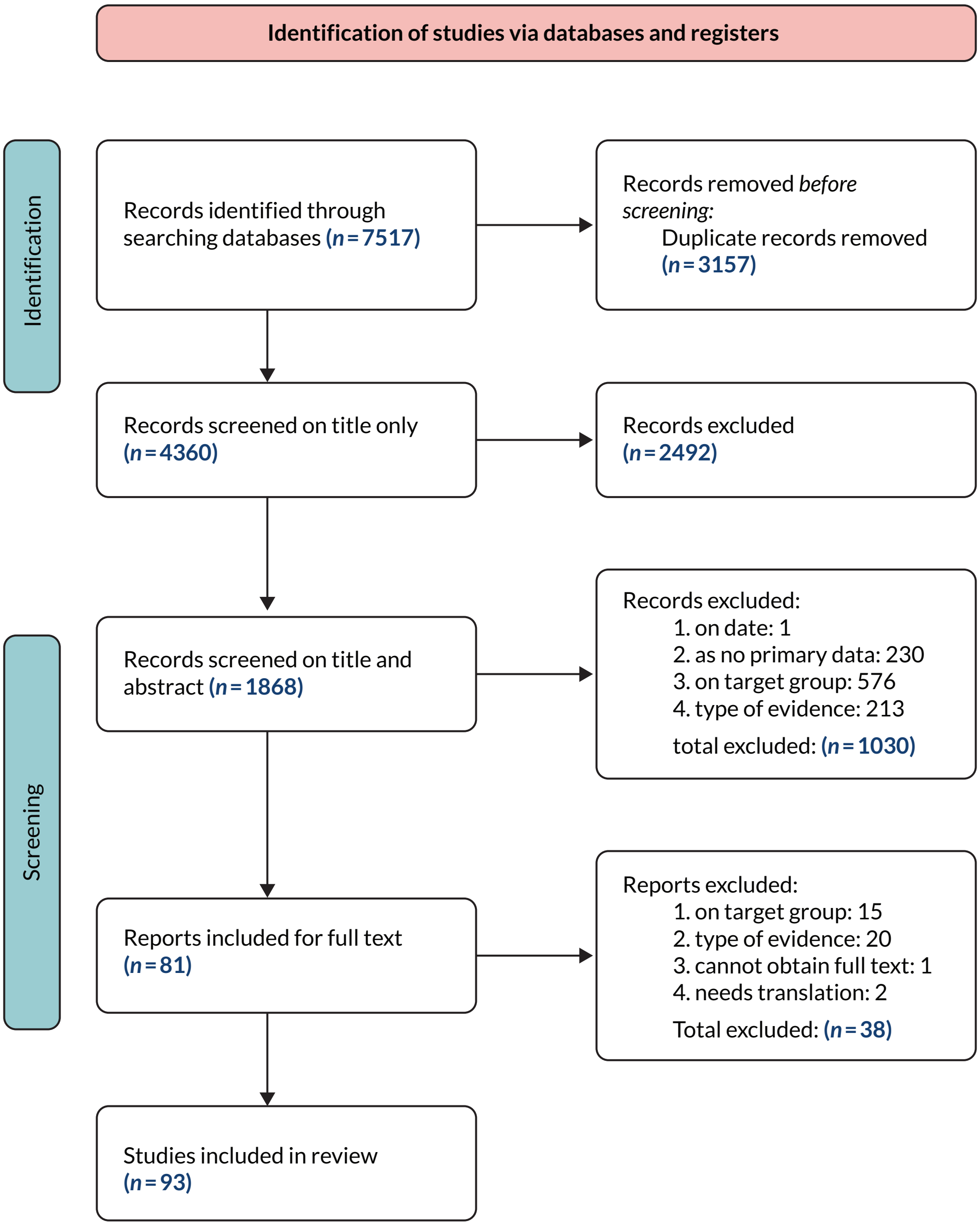


FIGURE 3 Preferred Reporting Items for Systematic Reviews and Meta-Analyses diagram of the review.

TABLE 4 Included studies by country[a]

Country	Number of studies
Western world countries	
UK	6
USA	19
Ancestral countries	
Asian	
Bangladesh	4
China	22
Hong Kong	3
India	7
Japan	2
Malaysia	2
Nepal	1
Pakistan	5
Latin American	
Brazil	1
Colombia	1
African and Caribbean	
Ghana	1
Nigeria	2
South Africa	1
Uganda	1
European	
France	1
Poland	1
Romania	2
Russia	1
Arab nations and Turkey	
Turkey	1
Iraq	2
Multiple countries	7

a Note that our inclusion criteria are global but not worldwide. For example, only some Arab countries were included, based on UK migration statistics.

Themes emerging from the evidence additional to constructs of the 5C model of vaccine acceptance, that we mapped onto it (*Figure 4*) were:

- vaccine decision delay
- past vaccine and COVID-19 experiences
- intersecting factors (i.e. factors cutting across different constraints as well as intersecting with each other)
- sources of information.

In the discussion below, we draw comparisons between minoritised ethnic communities in Western countries and their corresponding ancestral countries, when data were present.

The full review is intended for publication. Here we present a summary of findings. Overall, our results indicate vaccine acceptance, and reasons for this varied across countries, ethnic groups, health systems and population subgroups. In the USA and UK, vaccine hesitancy was higher in minoritised ethnic groups compared to the majority white population.[135–137] In some ethnic groups, for example, Black African, Caribbean and Pakistani, the hesitancy was reflected in their ancestral countries. However, this was not true for all ethnic groups, suggesting the need to treat minoritised ethnic communities as diverse, heterogeneous groups with unique contextual factors that influence vaccine uptake. Key factors influencing vaccine uptake in minoritised groups are expanded on below.

Calculation

Lack of tailored or appropriate public health information could increase reliance on less credible sources of information, leading to misinformation in communities and lower likelihood of immediately accepting the COVID-19 vaccine.[138] Participants who attended to social media information were less likely to receive the vaccine than participants using information from more reliable sources.[139–141] This was seen in Western countries and mirrored in most ancestral countries except mainland China, Taiwan and Bangladesh, where social media exposure reduced vaccine hesitancy.[142–144] Some studies specifically showed vaccine intention in the UK and USA was reduced by those relying on social media because of myths and misinformation related to the vaccine.[137,145] In the UK, for example, individuals from black, Arab and Asian minoritised ethnic groups subscribed to the belief that the COVID-19 vaccine could implant microchips for tracking purposes.[145] This was congruent with our findings from ancestral countries like Russia, Romania and Nigeria, where individuals who believed conspiracy theories had reduced intent to vaccinate against COVID-19.[140,145–147]

Lack of confidence

Lack of trust or confidence in the vaccine primarily manifested as concerns about side effects, found in studies from Bangladesh, Turkey, Nigeria and the UK.[136,137,145,148,149] Women specifically worried about the vaccine's effect on fertility.[148] Lack of trust in the government and the healthcare system due to systemic racism and marginalisation was a recurring concern among minoritised ethnic groups, reflected in their ancestral countries.[135,150] In Pakistan, for example, mistrust was attributed to negative experiences with foreign-led vaccine campaigns and a perception they could be a 'Western plot'.[149,151] In African communities, individuals were more likely to deny the vaccine due to lack of trust in their own healthcare system and the government. Lower likelihood of vaccine acceptance has been linked to medical mistrust in the past, a legacy of the Tuskegee study.[136,151,152]

Complacency

Worry about the risks from COVID-19[153,154] or having been tested for[154] or having previously had COVID-19[153] increased willingness to take the vaccine by Indian people in India[153] and by Hispanic, black and white people in the USA.[154] However, this theme was not a focus of most studies.

Collective responsibility

This factor was reported in one qualitative US study of black and 'Latinx' participants, specifically in relation to family and friends.[155]

Constraints

In the USA, logistical barriers like accessing test sites, language and transportation issues were disproportionately more common in minoritised ethnic groups, which reduced their access to vaccines.[151] Language barriers especially impacted access in rural areas due to lack of information.[151]

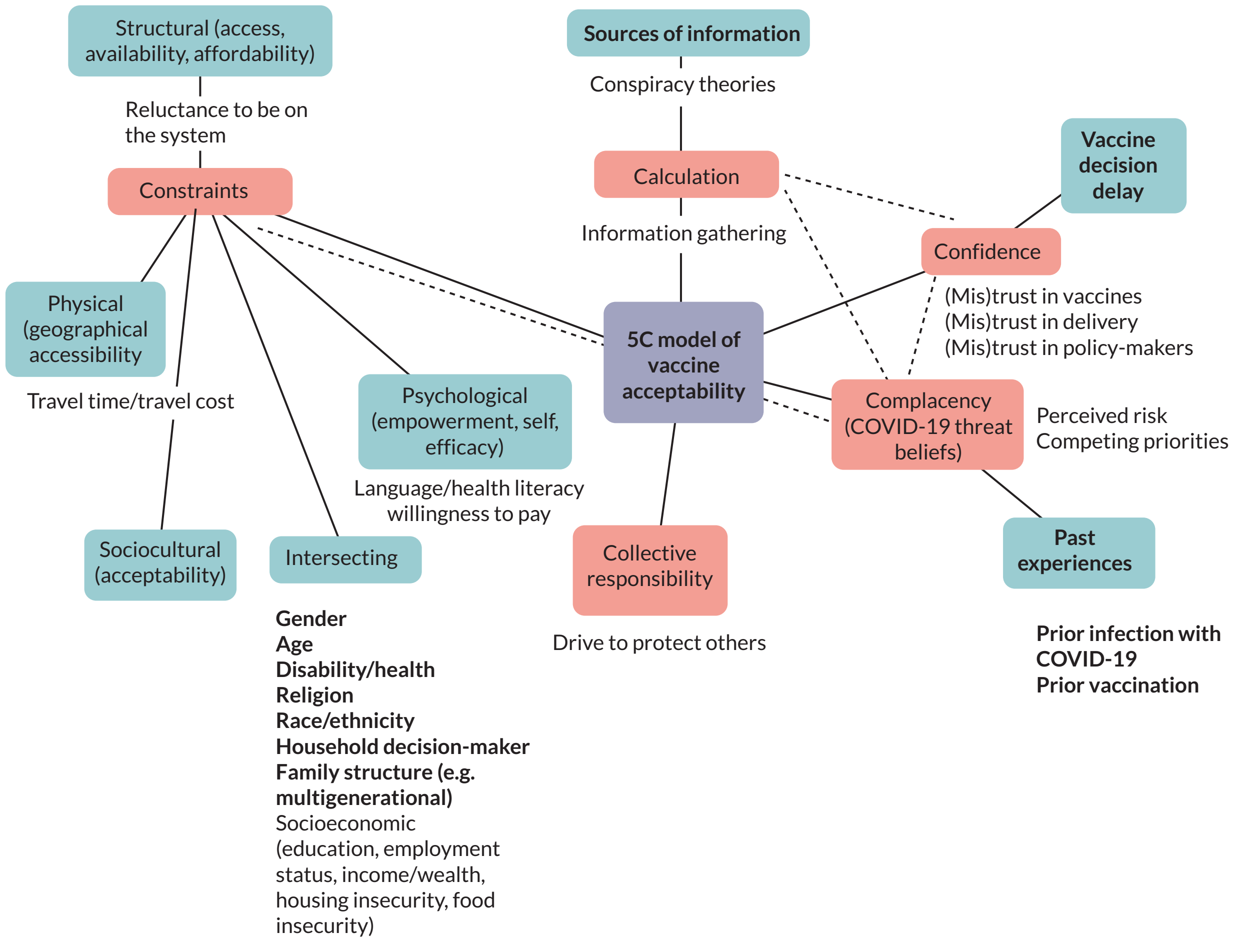


FIGURE 4 Conceptual map of themes emerging from data, mapped onto the 5C model of vaccine acceptance. Items in bold emerged from the review; the remainder are key concepts from the original theory.[131] Dotted lines indicate the strongest links between concepts, as determined for the original theory.

In ancestral countries, financial barriers such as a higher vaccine cost significantly decreased vaccine acceptance.[156,157] Additionally, if vaccination centres were geographically inaccessible or travel time too much, participants expressed unwillingness to get the vaccine.[158,159]

Intersecting factors

Data from the USA and UK suggested individuals from minoritised ethnic groups and with affiliation to religions other than Christianity had lower likelihood of vaccine acceptance.[160,161] Most studies in Western and ancestral countries found Muslim communities had lower uptake than Christians and Hindus, due to concerns over the halal status of the vaccine.[137,162–164] Furthermore, individuals holding strong religious beliefs were more likely to be exposed to conspiracy theories and the spread of misinformation.[140,159] For example, some Muslims in Pakistan believed the COVID-19 vaccine was a tool for ethnic cleansing created by the Jews to reduce the Muslim population.[159] Some Christians in Nigeria held the belief that COVID-19 was a way of introducing '666 controls' on the world.[140] Religious heads and social media platforms like TikTok® (ByteDance Ltd, Shanghai, China) disseminated this misinformation, further driving vaccine hesitancy.[140,159]

Conclusion

This review shows how vaccine hesitancy is a multidimensional concept and that its reasons vary across ethnic groups due to individual, specific, and contextual factors. This complexity was recognised by the developers of the 5C model, who commented that individual contexts would influence the causal factors leading to psychological responses, for example to loss of confidence. They argued for more research to understand this.[132] It is imperative that the factors influencing vaccine uptake in minoritised ethnic groups are acknowledged during implementation of public health interventions. This review also shows the need for involvement of community champions and religious or cultural leaders to address concerns regarding the vaccine and to debunk misinformation. Finally, to improve vaccine uptake, it is crucial to organise culturally appropriate tailored approaches for minoritised ethnic groups in Western countries that include careful understanding of the sociocultural context in their corresponding ancestral countries.

Chapter 4 Secondary data analysis of cohort studies

This chapter describes our secondary analysis of a subset (those with disabilities) of the three COVID-19 waves of Centre for Longitudinal Studies (CLS) cohort studies. Part of UCL, the CLS ran COVID-19 surveys within the nationally representative cohort studies it curates, with respondents aged 19–74 years: the Millennium Cohort Study (MCS; people born 2000–2 across England, Scotland, Wales and NI), Next Steps (born 1989–90), the 1970 British Cohort Study, the 1958 National Child Development Study, and also the MRC's National Survey of Health and Development (1946 British birth cohort). Wave 1 of its COVID-19 survey, with over 18,000 respondents, occurred in May 2020; wave 2, with almost 26,000 respondents, in September 2020; and wave 3, with 28,000 respondents, between February and March 2021. These included items on health (including COVID-19), health behaviours, demographics, mental health, social connectedness and health care, hence were relevant to our aims. While the primary cohort studies are nationally representative, there was bias in responses to the COVID-19 surveys. However, the CLS application of non-response weights so reduced this bias in all cohorts that it essentially eliminated it.[165] Therefore, these data, as analysed by us, may be considered as nationally representative.

Methods

After reviewing the different variables collected for the different cohorts, we focused on the MCS, for it used the same mental well-being scales as we did in our own survey (see *Chapter 5*). The MCS also provided the advantage that the parents of the main cohort respondent (19/20 years of age) are interviewed independently. This allowed us to study within-family dynamics during the pandemic.

In terms of the study aims, the MCS specifically checked for the conditions and impairments listed in *Table 5*, which we have mapped onto our impact categories (see *Chapter 1*, *Table 1*). We grouped them into a single category for initial analyses – 'long-standing conditions' – though we are continuing to analyse the data in other ways. For the MCS this category therefore excludes being blind, and our definition of 'brain', as well as our 'cognitive' conditions.[166]

Ethnicity data for the MCS are recorded simply as white, Indian/Pakistani/Bangladeshi, Black Caribbean/Black African, or mixed/other and therefore lack the nuances of our primary data. Technical information on the CLS surveys and their handling of missing data is available on their website and in their user guide.[165] Here we provide details of our own analysis of these data.

TABLE 5 Millennium Cohort Study condition mapped against our impact categories

MCS condition	Our impact category
Cystic fibrosis, asthma, chronic obstructive pulmonary disease, wheezy bronchitis, high blood pressure, heart disease (congenital or acquired), HIV/immunodeficiency	Stamina (conditions limiting this, such as breathing issues and conditions leading to fatigue)
Diabetes, obesity	Food-relevant
Recurrent backache, prolapsed disc, sciatica or other back problem, condition affecting the brain and nerves (e.g. Parkinson's, multiple sclerosis)	Mobility
Cancer	Cancer
Problems with hearing	Sensorial (hearing/vision loss)
–	Cognitive: developmental/intellectual
–	Brain hyperexcitability
Depression or other emotional, nervous or psychiatric problems	Mental health

We also drew on the UCL CLS COVID-19 Longitudinal Research and Evidence Tracker which trawls for COVID-19 longitudinal research and evidence (e.g. briefing notes, reports, articles) to obtain further useful information and context during analysis.

Two key analyses were undertaken on the UCL COVID-19 survey with MCS cohort members (MCSs) and their parents (MCSPs):

1. differences in mental health, including anxiety symptoms, psychological distress and mental well-being and help-seeking behaviours between chronic condition and healthy groups
2. family dynamics between family members' health conditions and individuals' mental health.

Differences in mental health between chronic condition and healthy groups

The aims of this analysis were: (1) to understand the differences in mental health and help-seeking behaviours between people with and without chronic conditions, and (2) to understand the role of perceived social support in mediating the association between mental health and health status. For this, we conducted two-step structural equation modelling with:

- mental health outcomes (i.e. mental well-being measured by the Short Warwick–Edinburgh Mental Well-Being Scale [SWEMWBS[132]] and psychological distress measured by Kessler-6[167]) as outcome variables
- social support (perceived social support measured by the Social Provision Scale[168]), social reliance (a single question on whether the participant can rely on others when being sick), and loneliness (the UCLA Loneliness Scale, short form[169]) as mediators
- chronic health condition as independent variable.

The family dynamics between family members' health conditions and individuals' mental health

We measured associations between both children's and parents' existing health conditions, their ethnicity, and their mental health outcomes (i.e. mental well-being assessed by SWEMWBS, psychological distress measured by Kessler-6, and depressed mood/anhedonia assessed by Patient Health Questionnaire [PHQ][170]). Our first research question explored how family members' health conditions influenced individuals' own mental health. Our second question examined the association between ethnicity and individuals' mental health, hypothesising that people from minoritised ethnic groups ('BAME' being the actual category used for MCSs and MCSPs) would suffer from poorer mental health than the non-minoritised ethnic group. Finally, we explored the intersection of chronic health conditions and minoritised ethnic group identity on parents' and children's mental health.

Secondary quantitative analysis findings

The differences in mental health between chronic condition and healthy groups

In the first step of our analysis, we found non-linear trajectories of mental health outcomes (see *Figures 5* and *6*) that differed between groups. The chronic health groups (MCSs and MCSPs) diverged from the equivalent non-chronic health groups across the three waves and most notably in wave 2 when restrictions were relaxed. In wave 2, compared with wave 1 which coincided with the first UK lockdown, the non-chronic health group showed an increasing SWEMWBS in MCSs (difference = 0.07, 95% confidence interval [CI] 0.04 to 0.11) and lower Kessler-6 scores both in MCSs (difference = −0.05, 95% CI −0.09 to −0.01) and MCSPs (difference = −0.04, 95% CI −0.08 to −0.00). Concurrently, mental well-being worsened in the MCSP chronic health group: the difference between wave 2 and wave 1 in SWEMWBS was −0.10 (95% CI −0.13 to −0.07) and psychological distress worsened in the MCS chronic health group: the difference between wave 2 and wave 1 in Kessler-6 score was 0.09 (95% CI 0.03 to 0.16).

In the second step, our mediation analysis showed that perceived social support, social support for sickness, and loneliness mediate the link between chronic health status and mental health outcomes (i.e. well-being and psychological distress) (*Table 6*). The paths from chronic health status to SWEMWBS in all waves are effectively halved in M2 (mediation model) compared to M1 (association between chronic illness and an outcome) for the MCS sample and in

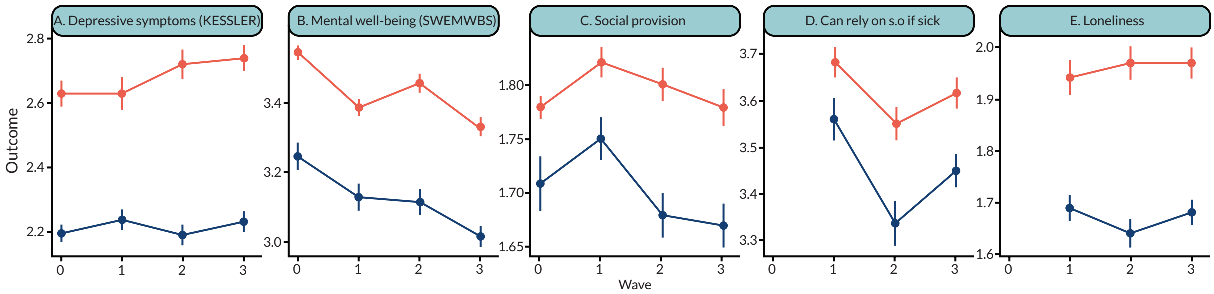


FIGURE 5 Millennium Cohort Study trajectories of mental health outcomes (child). s.o, someone.

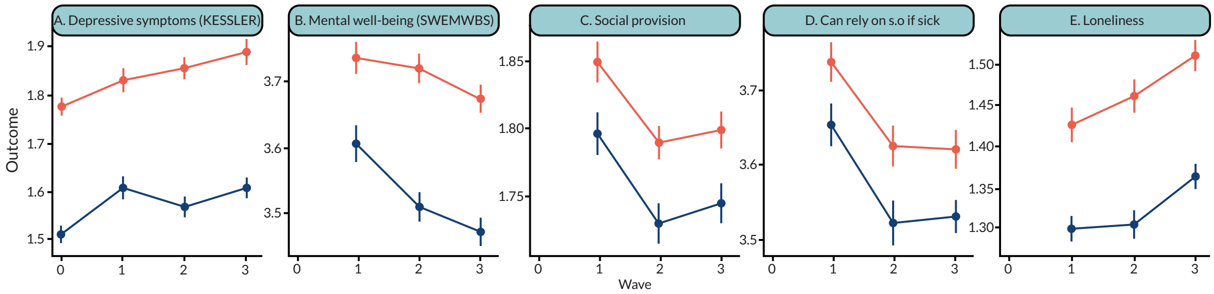


FIGURE 6 Millennium Cohort Study trajectories of mental health outcomes (parent). s.o, someone.

TABLE 6 Estimated path coefficients and fit measures for models in *Figures 5* and *6* where the outcome variable is mental well-being (SWEMWBS)[a]

	MCS sample				MCSP sample			
	M1		M2		M3		M4	
	Coefficient	SE	Coefficient	SE	Coefficient	SE	Coefficient	SE
SWEMWBS 0 on								
Chronic illness 0	−0.30*	0.021	−0.28*	0.02				
Social provision 0			0.46*	0.02				
SWEMWBS 1 on								
Chronic illness 1	−0.26*	0.025	−0.15*	0.02	−0.13*	0.02	−0.06*	0.02
Can rely on someone 1			0.04*	0.01			0.079*	0.01
Social provision 1			0.46*	0.02			0.22*	0.01
Loneliness 1			−0.42*	0.01			−0.50*	0.01
SWEMWBS 2 on								
Chronic illness 2	−0.35*	0.03	−0.17*	0.02	−0.21*	0.02	−0.12*	0.01
Can rely on someone 2			0.04*	0.01			0.08*	0.01
Social provision 2			0.46*	0.02			0.22*	0.01
Loneliness 2			−0.42*	0.01			−0.50*	0.01

TABLE 6 Estimated path coefficients and fit measures for models in *Figures 5* and *6* where the outcome variable is mental well-being (SWEMWBS)[a] (*continued*)

	MCS sample				**MCSP sample**			
	M1		**M2**		**M3**		**M4**	
	Coefficient	**SE**	**Coefficient**	**SE**	**Coefficient**	**SE**	**Coefficient**	**SE**
SWEMWBS 3 on								
Chronic illness 3	−0.32*	0.03	−0.16*	0.02	−0.20*	0.02	−0.12*	0.01
Can rely on someone 3			0.04*	0.01			0.08*	0.01
Social provision 3			0.46*	0.02			0.22*	0.01
Loneliness 3			−0.42*	0.01			−0.50*	0.01
Can rely on someone 1 on								
Chronic illness 1			−0.09*	0.03			−0.08*	0.02
Can rely on someone 2 on								
Chronic illness 2			−0.15*	0.03			−0.08*	0.02
Can rely on someone 3 on								
Chronic illness 3			−0.13*	0.02			−0.07*	0.02
Social provision 0 on								
Chronic illness 0			−0.06*	0.01				
Social provision 1 on								
Chronic illness 1			−0.06*	0.01			−0.05*	0.01
Social provision 2 on								
Chronic illness 2			−0.10*	0.01			−0.05*	0.01
Social provision 3 on								
Chronic illness 3			−0.09*	0.01			−0.05*	0.01
Loneliness 1 on								
Chronic illness 1			0.22*	0.02			0.12*	0.01
Loneliness 2 on								
Chronic illness 2			0.29*	0.02			0.14*	0.01
Loneliness 3 on								
Chronic illness 3			0.26*	0.02			0.14*	0.01
N	5552		5552		7479		7479	
χ^2(df)	273.393 (12)		987.854 (79)		81.726 (6)		420.358 (48)	
CFI	0.961		0.959		0.990		0.985	
RMSEA (90% CI)	0.062 (0.056 to 0.069)		0.043 (0.041 to 0.046)		0.041 (0.033 to 0.049)		0.032 (0.029 to 0.035)	

*$p < 0.01$.
CFI, comparative fit index; df, degrees of freedom; RMSEA, root mean square error of approximation; SE, standard error.
a Other parameters (covariances, variances, means) are suppressed for brevity. Fitted with full information maximum likelihood.

M4 (mediation model) compared to M3 (association between chronic illness and an outcome) for the MCSP sample (with an exception in wave 0 for which we only have a single mediator in MCS). The paths from chronic illness to Kessler-6 in all waves also decrease but not as strongly as for SWEMWBS when mediators are considered, again for both MCS and MCSP samples (*Table 7*). The direct paths from chronic illness to SWEMWBS and Kessler-6 remain strong and statistically significant for all waves after including mediators in the model. These results show partial mediation.

Family dynamics between family members' health conditions and individuals' mental health

We found that the child, mother, and father were most negatively influenced by their own chronic illness (*Figures 7–9*). Additionally, a mother's chronic illness affects the child's mental well-being, but their father's illness status has insignificant effects on this. The mothers are influenced negatively by their child's chronic illness for all outcomes (see *Figures 7–9*), and by the father's chronic illness for Kessler and PHQ (see *Figures 8* and *9*). The fathers are influenced by the mothers' chronic illness for all outcomes as also by their child's chronic illness, particularly for Kessler and PHQ (see *Figures 8* and *9*).

Having minoritised ethnic group status generally has a negative effect on mental well-being (*Figures 10–12*), but this is insignificant in some cases. We found significant interaction between chronic illness and minoritised ethnic group status (one of our intersectional foci) for SWEMWBS and PHQ (see *Figures 10* and *12*). This interaction was insignificant for Kessler (see *Figure 11*). In *Figure 10*, SWEMWBS is used in its original scale (not reverse-coded), so a higher score indicates better well-being. The figure shows that having a chronic illness is detrimental for well-being, but this negative effect is generally smaller for the minoritised ethnic group respondents than the White British sample.

TABLE 7 Estimated path coefficients and fit measures for models in *Figures 5* and *6* where the outcome variable is depressive symptoms (Kessler)[a]

	MCS sample				**MCSP sample**			
	M1		**M2**		**M3**		**M4**	
	Coefficient	**SE**	**Coefficient**	**SE**	**Coefficient**	**SE**	**Coefficient**	**SE**
Kessler 0 on								
Chronic illness 0/1	0.43*	0.03	0.43*	0.03				
Social provision 0			−0.47*	0.02				
Kessler 1 on								
Can rely on someone 1			−0.00	0.01			−0.05*	0.01
Social provision 1			−0.47*	0.02			−0.08*	0.01
Loneliness 1			0.56*	0.01			0.47*	0.01
Kessler 2 on								
Chronic illness 2	0.53*	0.03	0.36*	0.03	0.29*	0.02	0.22*	0.02
Can rely on someone 2			−0.00	0.01			−0.05*	0.01
Social provision 2			−0.47*	0.02			−0.08*	0.01
Loneliness 2			0.56*	0.01			0.47*	0.01

TABLE 7 Estimated path coefficients and fit measures for models in *Figures 5* and *6* where the outcome variable is depressive symptoms (Kessler)[a] (*continued*)

	MCS sample				MCSP sample			
	M1		M2		M3		M4	
	Coefficient	SE	Coefficient	SE	Coefficient	SE	Coefficient	SE
Kessler 3 on								
Chronic illness 3	0.51*	0.02	0.37*	0.02	0.28*	0.02	0.22*	0.01
Can rely on someone 3			−0.00	0.01			−0.05*	0.01
Social provision 3			−0.47*	0.02			−0.08*	0.01
Loneliness 3			0.56*	0.01			0.47*	0.01
Can rely on 1 on								
Chronic illness 1			−0.09*	0.03			−0.08*	0.02
Can rely on 2 on								
Chronic illness 2			−0.14*	0.03			−0.07*	0.02
Can rely on 3 on								
Chronic illness 3			−0.13*	0.02			−0.07*	0.02
Social provision 0 on								
Chronic illness 0			−0.06*	0.01				
Social provision 1 on								
Chronic illness 1			−0.06*	0.01			−0.05*	0.01
Social provision 2 on								
Chronic illness 2			−0.09*	0.01			−0.05*	0.01
Social provision 3 on								
Chronic illness 3			−0.10*	0.01			−0.05*	0.01
Loneliness 1 on								
Chronic illness 1			0.22*	0.02			0.12*	0.01
Loneliness 2 on								
Chronic illness 2			0.28*	0.02			0.14*	0.01
Loneliness 3 on								
Chronic illness 3			0.26*	0.02			0.14*	0.01
N	5552		5552		7496		7496	
χ^2(df)	515.763 (12)		1586.850 (79)		166.285 (8)		1670.899 (59)	
CFI	0.942		0.932		0.986		0.944	
RMSEA	0.087 (0.081 to 0.092)		0.059 (0.056 to 0.062)		0.051 (0.045 to 0.058)		0.060 (0.058 to 0.063)	

*$p < 0.01$.

CFI, comparative fit index; df, degrees of freedom; RMSEA, root mean square error of approximation; SE, standard error.

[a] Other parameters (covariances, variances, means) are suppressed for brevity. Fitted with full information maximum likelihood.

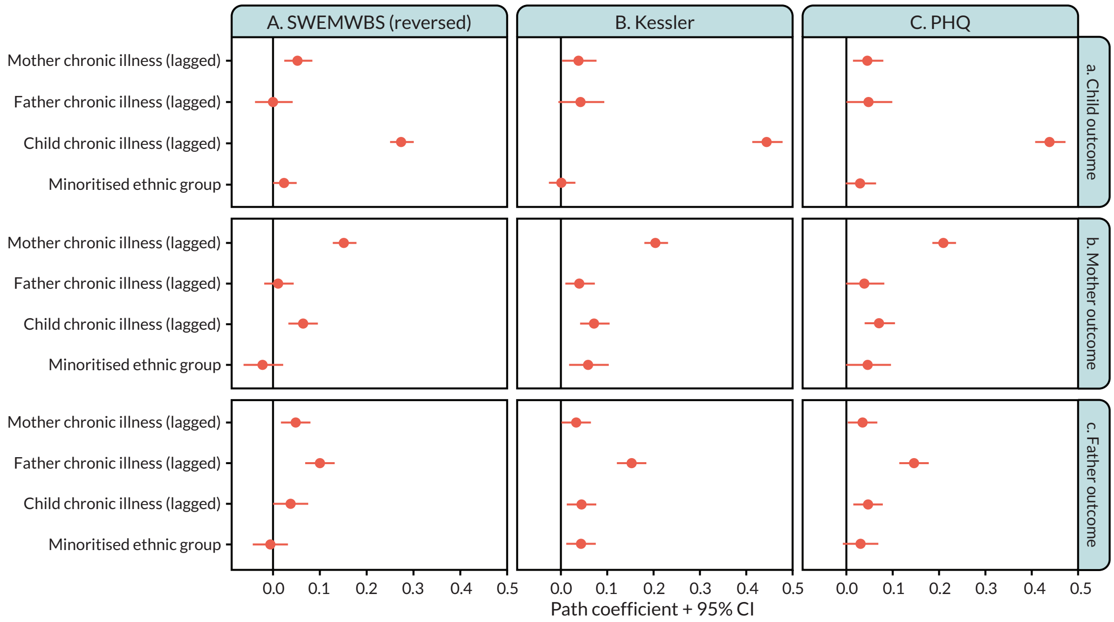


FIGURE 7 Family dynamics between family members' health conditions and individuals' mental health.

Summary

Our secondary analysis showed that unlike people without chronic conditions, mental well-being and psychological distress in the chronic health group did not recover when the first lockdown ended, and in fact worsened. Perceived social support, social support for sickness, and reduced loneliness were beneficial. While having a chronic illness is detrimental for well-being, this negative effect is generally smaller for the minoritised ethnic group respondents than the White British sample. Children's mental well-being was affected by a mother's but not father's chronic illness, while mothers' and fathers' well-being was affected by the health of all three family members.

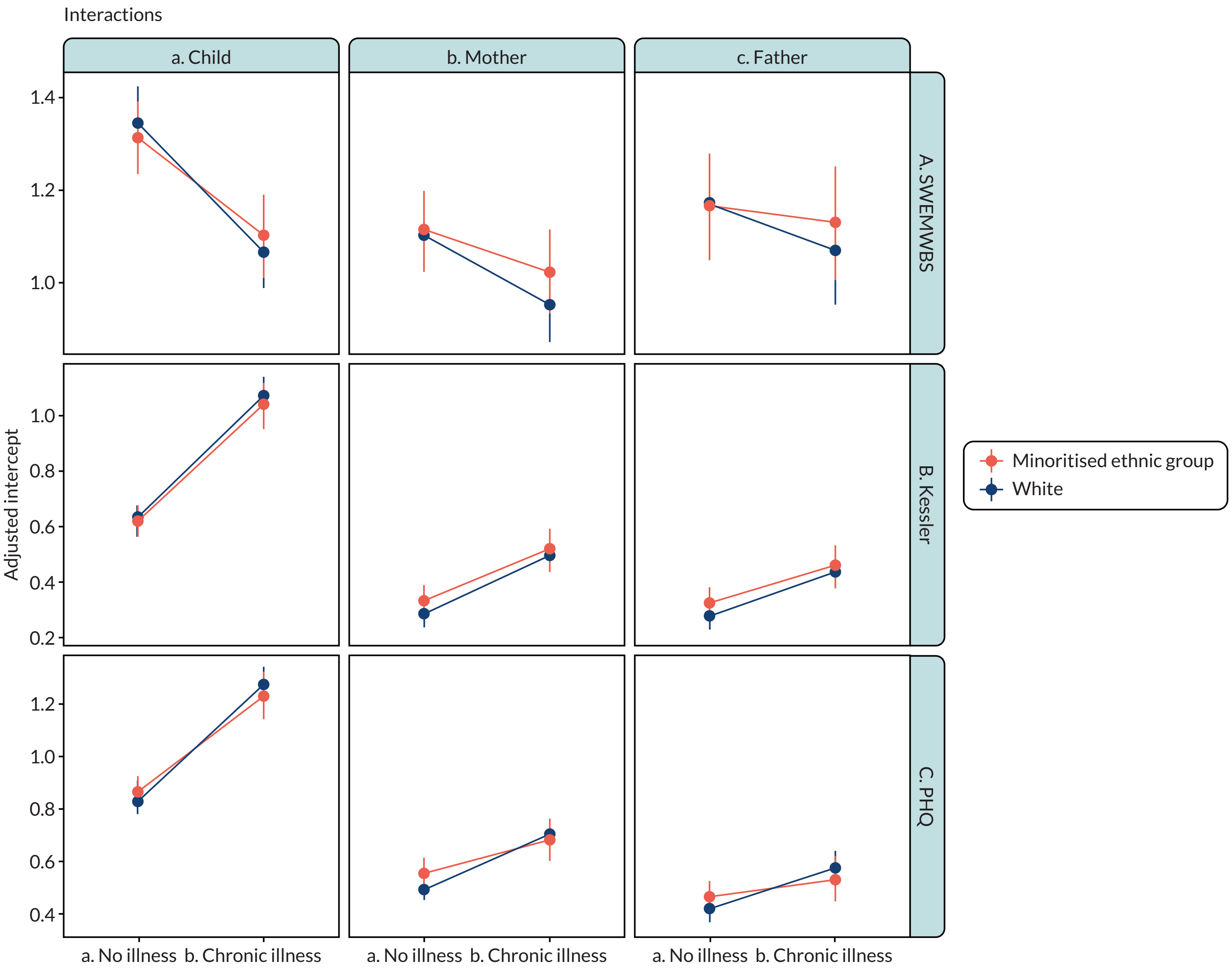


FIGURE 8 Minoritised ethnic group status and mental well-being.

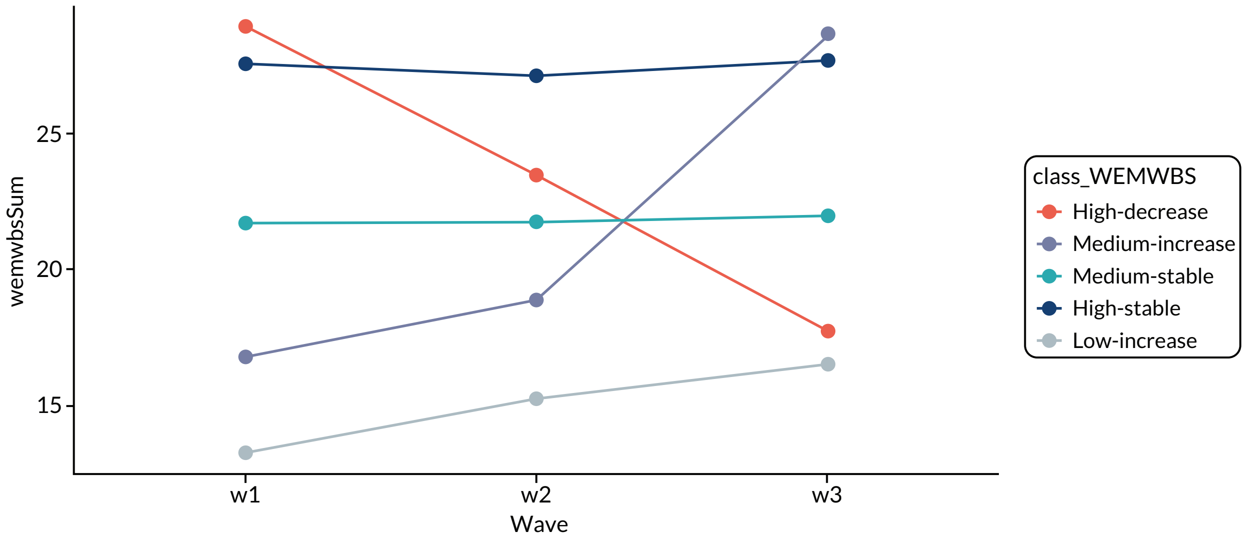


FIGURE 9 Mental well-being.

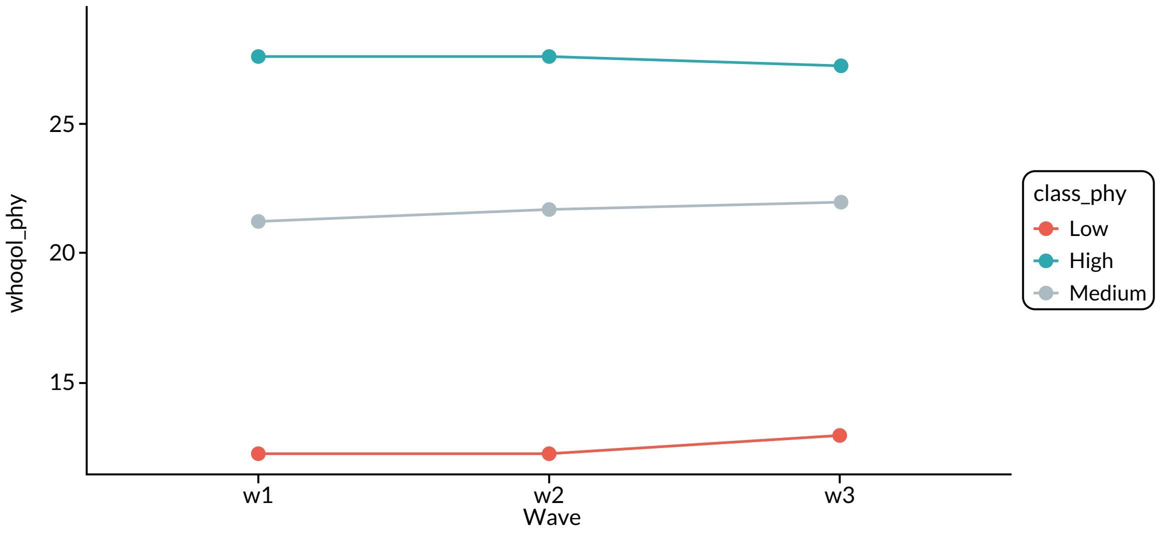


FIGURE 10 Physical QoL.

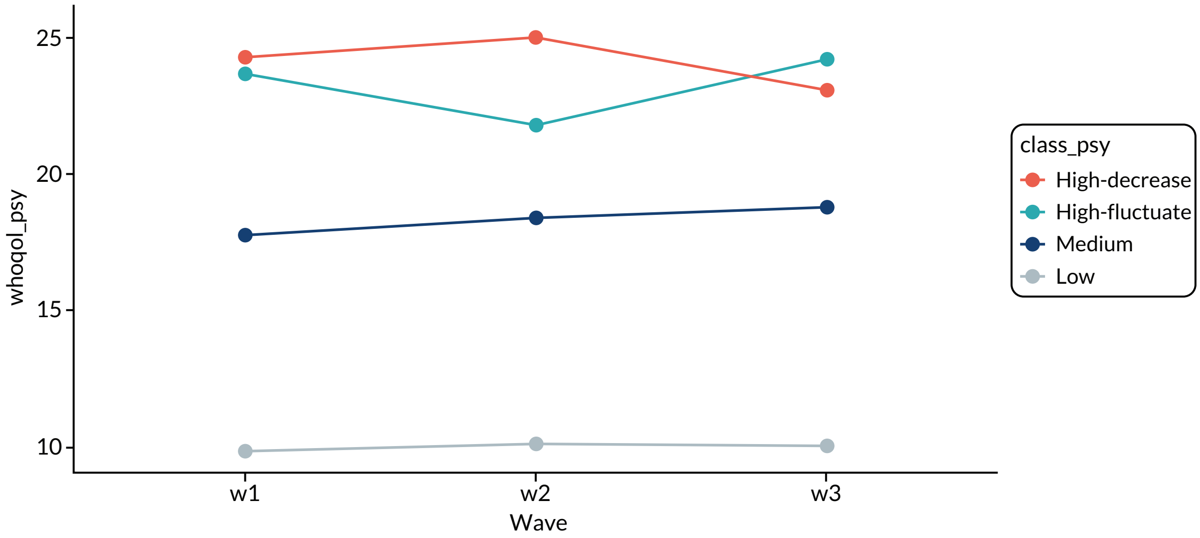


FIGURE 11 Psychological QoL.

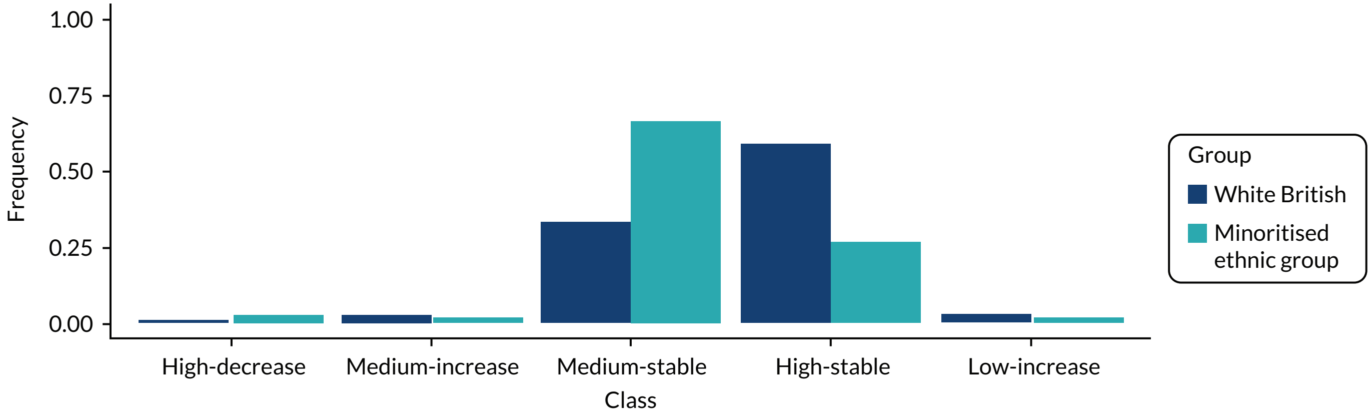


FIGURE 12 Mental well-being multinomial logistic regression.

Chapter 5 Primary survey

Introduction

This chapter describes analysis of our primary survey, which considered our eight core topics (*Box 2*), informed by our secondary analyses, in three waves, for community-dwelling migrants and UK/RoI-born children of migrants and indigenous White British comparators, all with/without disability, across the UK's four nations and RoI. This enabled us to determine relationships between the chronic condition status of the respondent and our chosen outcome variables as well as their trajectories relevant to our aims. We scoped other COVID-19 surveys, to consider the possibility of collaborating on comparisons by date, but these had considerable differences to ours. For example, two surveys undertaken for ActEarly considered pregnant women and families with young children, with a focus on childhood;[36] our survey is thus unique and extends and enlarges their scope.

Methods

Analysis exploited all three data waves, with these research questions:

1. How do outcomes (QoL, control of life, physical and mental health, and social networks) and outcome trajectories differ across subgroups?
2. What are these outcomes and outcome trajectories in terms of intersectionalities?
3. To what extent can pandemic prevalence and adherence to social distancing at the area level explain differences in outcomes and outcome trajectories across subgroups and intersectionalities?
4. How do the outcomes inter-relate within and across survey waves, and how does this differ across subgroups and in terms of intersectionalities?

We developed the final survey format with our PPI group and piloted it with $N = 30$ before fielding it at scale. The survey was completely online. To minimise respondent burden, each wave was completable within 25 minutes. Surveys began with informed consent/screening questions. Then the study topics were explored, based on validated

BOX 2 Our eight topics and corresponding survey instruments/items

Topics	Questions
Intersectionalities	Demographics including year of birth, gender, ethnicity, relationship status, area code of postcode, urban/rural dwelling, accommodation type, household income, education, employment status, religiosity.[171]
Behavioural responses	'Control of life' (including COVID-19-related).[81]
Access to resources, support, care	QOCS, ID[172] Vulnerability Assessment Framework for care needs.[173]
Social networks	Developed from the close persons questionnaire.[173]
Mental and physical well-being and QoL	• WHOQOL-BREF[81] • SWEMWBS[132] • Templer Death Anxiety Scale.[174]
Coping	Including tolerance to uncertainty, positive appraisal style, attitudes to being ill/disabled (WHO ADS).[81] Global Mental Health Assessment Tool.[175]
Local and regional differences	Within-survey analysis.
Future policies	Free-text comment boxes.

QOCS, Quality of Care and Support Scale. WHOQOL-BREF, WHO Quality of Life Brief Form.

questionnaires, mostly validated in migrant and minoritised ethnic groups as well as a general population (see *Box 2*). Surveys differed in different waves:

- Theoretically stable concepts (e.g. tolerance to uncertainty, demographic characteristics) were measured only in wave 1.
- Key topics identified in prior wave(s), work package 3 qualitative work and our co-production and engagement work were added in wave 2 and/or 3 (e.g. worries about the Ukraine–Russia conflict, increasing energy bills).
- Key outcome and exposure variables that we expected to change during the pandemic (e.g. QoL, access to care, mental health, networks) were measured in all three waves to study trajectories.

Study data were collected and managed using REDCap (Vanderbilt University, Nashville, TN, USA) electronic data capture tools hosted at UCL.[177] REDCap (Research Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies.

For wave 1, we recruited via:

- National networks (e.g. academic, NHS, third sector) including our existing networks and mailing lists, and large databases of adults interested in health research across the UK/RoI. These included the UCL Loneliness network, Contact, Help, Advice and Information Network [(CHAIN) https://www.chain-network.org.uk/], the NIHR Research Design Service public involvement groups and networks registries, the UKRI Mental Health Research Networks, the COVID-19 Research Involvement Group, and the COVID-19 Support Group. The survey link was shared via university websites.
- Clinical Research Networks (CRNs).
- Posters and leaflets left in clinics and community centres of co-applicants and collaborators.
- Media channels for these national networks, including Twitter accounts, newsletters.
- The various social media patient and migrant groups and charities we were connected with and specialist third-sector organisations.
- Our lay co-researchers (see *Chapter 6*).
- An online forum, Reddit, to reach a wider population, and paid-for enhanced project Facebook and Twitter exposure.

This strategy enabled good reach and access across the spread of disability, minoritised ethnicities and citizenship states, and connection with people already wishing to take part in research. We recognise our recruitment, being non-randomised, could exhibit some selection bias, for example to those already interested in research participation or who were active users of third-sector sites and had online access. Online survey completion is likely to have introduced respondent bias, particularly given that we were targeting recent migrants. We will have excluded many experiencing digital poverty, poor Wi-Fi availability and poor computer literacy, though our charity partners and lay co-researchers supported some people to complete face to face. We compared respondent demographics to whole-population estimates where possible (though formal data were limited) to explore *representativeness*.

In wave 2, we e-mailed invitations through the REDCap system to participants who were not excluded in the wave 1 survey analysis. Invitations were followed by e-mail reminders. This process was repeated for wave 3. Thus, the same wave 1 people were invited in both the second and third waves.

The primary aim of the quantitative data was to describe the trajectories of key variables and outcomes and the links between them, among minoritised ethnicity and disability communities, compared to White British people. It was not used to test a particular treatment or focus on a single effect. Considering power in structural equation modelling, the required sample size depends on several factors. First, it increases with the number of latent variables, but at a decreasing rate (i.e. the required sample size difference between a model with two latent variables versus a model with a single latent variable is larger than that between a model with three latent variables versus a model with two latent variables). Second, required sample size decreases strongly as the loadings on latent variables increase. Finally, power increases as the number of items used to measure each latent variable increases. In our basic structural equation modelling, we had six core latent variables per wave: QoL, control of life, access to care, coping mechanisms, mental health, and social networks. Each was measured by several items (the average number being more than eight). In a worst-case scenario with average loadings of around 0.5 and an item missingness of 20% (as suggested from prior studies), a sample size of 800 per subgroup per wave would yield useful analyses. We had four main subgroups (i.e. minoritised ethnicity, minoritised ethnicity + disability, White British, White British + disability). Hence, a sufficient target sample size is 800 × 4 = 3200, though we aimed for 5000 for stronger data.

To be included in the final analytical sample, respondents needed to be over 18 years old, have spent 75% of their time in the UK/RoI during the pandemic and correctly answered an attention check question, as well as having no difficulties in reading English text (presumed from completion and responses to free-text questions).

We required completion of almost every question on every page for participants to proceed, so we could undertake the association analyses required. This means there should generally be no missing items in any measures, though this requirement may lead to completion attrition, with respondents giving up and logging off. We mitigated that in questionnaire design. There was the risk of attrition between waves. Participants were asked to provide an e-mail address on enrolling and were recontacted using REDCap automated processes for wave 2/3 follow-up questionnaires (with reminders) to explore trajectories over time. This automatic process makes for efficient and secure wave 2/3 recruitment to reduce the risk of missing respondents. Indeed, attrition rates after wave 1 were relatively low: 19% in wave 2 and 28% in wave 3. Data were anonymised prior to analysis; however, the researcher controlled reminders. Careful design of the covering letter/page on between-wave reminders can improve return rates from those with lower education levels or who speak languages other than English at home, so we ensured they were designed with full PPI input. Incentives appear effective in some online surveys, and we sent a £2 Amazon (Amazon.com, Inc., Bellevue, WA, USA) voucher to each participant when they provided valid responses. For missing data, panel attrition and item non-response, we used full information maximum likelihood, multiple imputation with chained equations for unbiased estimates under assumptions of missing at random (i.e. missingness depending on observable data only) and multivariate normality; and pattern mixture models to address missing not at random (i.e. missingness depending on unobserved data) assuming correct model specification. Those techniques, under the specified assumptions, mitigate loss of statistical power caused by missing data and possible biases due to systematic missingness.[85]

A descriptive statistical summary was updated with each wave. For research question 1, we exploited the longitudinal nature of the data using latent growth class modelling to (1) estimate change in QoL, mental and physical health over time and (2) identify subgroups of the trajectories. For research question 2, we applied multinomial logistic regression to measure differences in subgroup memberships between those with disabilities versus without, White British versus minoritised ethnicity, and citizenship versus without. We tested interactions of disability and ethnicity in the multinomial logistic regression to study intersectionality.

For research question 3, we had planned to include area-level matched data on pandemic prevalence and adherence to social distancing in the multinomial logistic regression model as covariates, to explore the extent to which they can explain differences in outcomes between each subgroup, and differences compared with intersectional combinations. In addition, we planned to fit the latent growth class models separately by residential area, to examine the impact of the change in pandemic prevalence and social distancing across the waves on the outcomes. Because we needed to keep the survey live for longer and data collection took much longer than planned due to our efforts to mobilise charities and organisations in reaching suitable respondents, merging our survey with external data on pandemic prevalence and area-level statistics on social distancing adherence was delayed. To address this question, we therefore estimated well-being trajectories, conditional on chronic health conditions and ethnicity, separately for different parts of the UK/RoI (i.e. England, NI, Scotland, Wales, Isle of Man, and RoI). We also intended to match respondents' area code of postcode with area-level (1) registered COVID-19 cases, hospitalisations and deaths [Office for National Statistics (ONS) https://bit.ly/2NOydC8] and (2) social distancing adherence (Google Community Mobility https://bit.ly/2AqRwyk). Because of the way the pandemic and associated behaviours changed shape, this was not appropriate, as case monitoring changed and social distancing measures broke down.

For research question 4, we estimated a developmental cascade model, including all three data waves and key variables, to explore how the key variables were associated, both within survey wave and over time. We fitted our models using structural equation modelling, which offered useful tools for dealing with missing data due to non-response and attrition; the full information maximum likelihood estimation was used to address attrition.

Primary data survey findings

Demographics and descriptives

We surpassed our minimum targets:

1. Although data collection was slow at first, we exceeded the minimum of 3200 responses in wave 1. The strategies used to achieve this were to keep the survey live for longer than originally planned and to reach out to several additional charities for chronic health groups and for specific ethnicities who contributed significantly to advertising the survey.
2. Minoritised ethnic group participants were reached through charities and networks for specific ethnicities, which enabled us to collect data on 2186 ethnic minority participants.
3. We collected data on 2193 disabled people.disabilities

In wave 1, the survey link received over 5000 clicks, with 4326 valid when applying the inclusion criteria and hence included in the analytical sample. In wave 2, invitations were sent to those 4326 participants, and 3498 completed wave 2 with valid responses. For wave 3, invitations were sent to the same 4326 participants, with 3100 valid responses.

Table 8 presents the sample demographics of our three-wave data including country of residence, age, gender, ethnicity, health condition, living area/setting, reason for migration, relationship status, education, employment and income level. Overall, the demographic distribution does not significantly differ across the three waves; that is, the attrition of the sample seems equally distributed. The population distribution regarding country of residence was similar to the government census population estimates in 2021 (https://census.gov.uk/), showing that more than 85% of survey respondents were from England. However, compared with the population estimates, we have fewer respondents from Scotland and Wales (ours: 5.8% from Scotland and 3% from Wales; government estimates: 8% from Scotland and 5% from Wales). Our respondents are also younger than the population in census estimates, with median ages of 35 and 40 years, respectively. Our male/female ratio is similar to the estimates, with approximately equal sizes of the male and female populations. In line with the research goals, we oversampled people from minoritised ethnic groups and disabled people, leading to higher proportions of these than in the general population.

In sum, although the younger median age, and higher minoritised ethnicity and chronic health ratios, mean our sample is not fully representative of the general population, reflecting anticipated biases for example due to online completion, the oversampled participants from minoritised ethnic groups and disabled groups provide good statistical power for data analysis, leading to a sound understanding of these groups

Research question 1: outcome trajectories

We applied a latent growth class model to identify the trajectory classes on our outcome variables of interest, including mental well-being (measured by SWEMWBS) and four aspects of QoL (physical QoL, psychological QoL, social relationships, and environment, measured by WHOQOL).

Our results showed five trajectory subgroups of mental well-being (*Figure 13*). Over half of our sample (52%) falls in the medium-stable group (i.e. with medium well-being scores that were consistent at different waves) and around 40% is in the high-stable group, suggesting that most people's mental well-being might not be affected significantly by the COVID restrictions and later changes. Around 7% of our sample spread across the other three groups: 1.5% high-decrease (meaning their well-being decreased in waves 2/3 from a high level at wave 1), 2.2% medium-increase and 3.4% low-increase, showing that some people could be susceptible to changes and few people showed an adverse outcome.

We found three trajectory subgroups of physical QoL (*Figure 14*). The medium group has the most people in our sample (68%), followed by the high (29%) and low (2.8%) groups. Overall, the physical aspect of QoL was good and remained at a similar level across the three waves.

TABLE 8 Demographics for the three waves

	Wave 1	Wave 2	Wave 3
Sample	4326	3425	3031
Country of residence			
England	3734 (86.3%)	2971 (86.7%)	2745 (90.6%)
Isle of Man	24 (0.6%)	15 (0.4%)	12 (0.4%)
NI	71 (1.6%)	58 (1.7%)	37 (1.2%)
RoI	119 (2.8%)	99 (2.9%)	42 (1.4%)
Scotland	249 (5.8%)	181 (5.3%)	114 (3.8%)
Wales	129 (3.0%)	101 (2.9%)	81 (2.7%)
Age (years)			
Mean (standard deviation)	36 (9.7)	35.7 (9.4)	35.6 (9.3)
min < med < max	18 < 35 < 96	18 < 34 < 96	18 < 35 < 96
Gender			
Female	2100 (48.7%)	1647 (48.1%)	1484 (49.0%)
Male	2190 (50.7%)	1761 (51.5%)	1531 (50.5%)
Non-confirmation	14 (0.3%)	8 (0.2%)	9 (0.3%)
Trans-female	5 (0.1%)	1 (0.0%)	
Trans-male	7 (0.2%)	4 (0.1%)	5 (0.2%)
Ethnicity			
Arab/Turkish	123 (2.9%)	102 (3.0%)	106 (3.5%)
Black	743 (17.3%)	617 (18.2%)	548 (18.2%)
Chinese	86 (2.0%)	71 (2.1%)	56 (1.9%)
European Union	169 (3.9%)	122 (3.6%)	99 (3.3%)
Mixed other	57 (1.3%)	43 (1.3%)	34 (1.1%)
Mixed (black–white)	302 (7.0%)	232 (6.8%)	197 (6.6%)
Other mixed	9 (0.2%)	7 (0.2%)	5 (0.2%)
Southeast Asian	223 (5.2%)	187 (5.5%)	180 (6.0%)
South Asian	248 (5.8%)	203 (6.0%)	184 (6.1%)
White British	2140 (49.9%)	1663 (49.0%)	1463 (48.7%)
White (USA)	186 (4.3%)	148 (4.4%)	133 (4.4%)
Carer/chronic health			
Carer	206 (4.8%)	145 (4.2%)	141 (4.7%)
Chronic health	2193 (50.8%)	1629 (47.6%)	1457 (48.1%)
Carer with chronic health	232 (5.4%)	194 (5.7%)	90 (3.0%)
Non-chronic health	1690 (39.1%)	1454 (42.5%)	1340 (44.3%)

continued

TABLE 8 Demographics for the three waves (*continued*)

	Wave 1	Wave 2	Wave 3
Living area setting			
City	1916 (44.3%)	1530 (44.7%)	1378 (45.5%)
Large town	1072 (24.8%)	872 (25.5%)	815 (26.9%)
Small town	847 (19.6%)	682 (19.9%)	551 (18.2%)
Suburbs	266 (6.1%)	192 (5.6%)	159 (5.2%)
Village or hamlet	184 (4.3%)	115 (3.4%)	101 (3.3%)
Isolated rural dwelling	41 (0.9%)	34 (1.0%)	27 (0.9%)
Reason for migration			
Asylum/refugee	474 (21.7%)	416 (23.6%)	387 (24.7%)
Better income	759 (34.7%)	637 (36.2%)	573 (36.5%)
Join family	247 (11.3%)	197 (11.2%)	183 (11.7%)
Not relevant (UK/RoI origin)	153 (7.0%)	114 (6.5%)	67 (4.3%)
Other	14 (0.6%)	1 (0.1%)	2 (0.1%)
Study	113 (5.2%)	86 (4.9%)	81 (5.2%)
Work	426 (19.5%)	311 (17.7%)	275 (17.5%)
Relationship status			
Married but live apart	278 (6.4%)	188 (5.5%)	177 (5.8%)
Married live together	3031 (70.1%)	2514 (73.4%)	2223 (73.3%)
Separated	76 (1.8%)	50 (1.5%)	45 (1.5%)
Single	767 (17.7%)	560 (16.4%)	478 (15.8%)
Single (divorced/widowed)	174 (4.0%)	113 (3.3%)	108 (3.6%)
Education			
A level	845 (19.5%)	606 (17.7%)	481 (15.9%)
General Certificate of Secondary Education	634 (14.7%)	542 (15.8%)	477 (15.7%)
No qualification	50 (1.2%)	39 (1.1%)	37 (1.2%)
Post-16 vocational course	752 (17.4%)	637 (18.6%)	575 (19.0%)
Postgraduate	252 (5.8%)	154 (4.5%)	132 (4.4%)
Undergraduate	1793 (41.4%)	1447 (42.2%)	1329 (43.8%)
Employ			
Full-time	2334 (54.0%)	1931 (56.4%)	1763 (58.2%)
Homemaker	85 (2.0%)	63 (1.8%)	57 (1.9%)
No work (health issue)	201 (4.6%)	123 (3.6%)	100 (3.3%)
No work (visa issue)	8 (0.2%)	7 (0.2%)	6 (0.2%)
Part-time	827 (19.1%)	647 (18.9%)	541 (17.8%)
Retired	67 (1.5%)	41 (1.2%)	32 (1.1%)
School	73 (1.7%)	50 (1.5%)	46 (1.5%)

TABLE 8 Demographics for the three waves (*continued*)

	Wave 1	Wave 2	Wave 3
Self-employed	209 (4.8%)	152 (4.4%)	141 (4.7%)
Several jobs	185 (4.3%)	142 (4.1%)	123 (4.1%)
Unemployed	117 (2.7%)	94 (2.7%)	69 (2.3%)
University	220 (5.1%)	175 (5.1%)	153 (5.0%)
Income level			
Less than £16,000 a year (£310 a week)	411 (10.7%)	327 (10.7%)	293 (10.7%)
£16,000–29,999 a year (£310–579 a week)	1134 (29.5%)	916 (30.0%)	842 (30.8%)
£30,000–59,999 a year (£580–1149 a week)	1164 (30.2%)	889 (29.1%)	703 (25.7%)
£60,000–89,999 a year (£1500–1729 a week)	637 (16.5%)	489 (16.0%)	470 (17.2%)
£90,000–119,999 a year (£1730–2299 a week)	403 (10.5%)	370 (12.1%)	370 (13.5%)
More than £120,000 a year (£2300 a week)	17 (0.4%)	11 (0.4%)	9 (0.3%)
Prefer not to say	84 (2.2%)	49 (1.6%)	44 (1.6%)
Type of health condition			
No	1896 (43.9%)	1599 (46.7%)	1481 (48.9%)
Physical	1335 (30.9%)	1039 (30.4%)	843 (27.8%)
Mental	175 (4.0%)	143 (4.2%)	108 (3.6%)
Both	915 (21.2%)	641 (18.7%)	596 (19.7%)

We identify four subgroups of psychological QoL, with 72% in the medium group, 14% in the high-fluctuate, 11% in the high-decrease and 2% in the low group (see *Figure 11*). This shows that most individuals reported good or moderate psychological QoL and few individuals suffered from adverse psychological QoL.

The latent growth class analysis shows only one trajectory subgroup regarding social relationship, so multinomial logistic regression was not conducted on this.

The latent growth class analysis shows two trajectory subgroups regarding environmental QoL, but this model fails to fulfil the model selection criteria. Due to there being no subgroups of environmental QoL, multinomial logistic regression was not conducted.

Research question 2: the trajectories of outcomes by chronic health status and ethnicity and the role of their intersectionality

For each outcome variable for which the latent growth class models identified more than one class, we carried out a multinomial logistic regression to study the associations between the trajectory membership and exposure (i.e. belonging to a minoritised ethnicity and having a chronic health condition).

The analysis shows that having a minoritised ethnic identity or chronic health condition increases the possibility of having a medium-stable level of mental well-being. Conversely, White British people or people without chronic health conditions are more likely to belong to the high-stable mental well-being class (see *Figure 12*).

We also found an interaction between ethnicity and health condition on mental well-being (see *Figure 13*). White British people are more likely to have high mental well-being across three time points, while people in other groups are more likely to have medium-stable mental well-being. The low ratio of the low-increase group and increasing numbers of

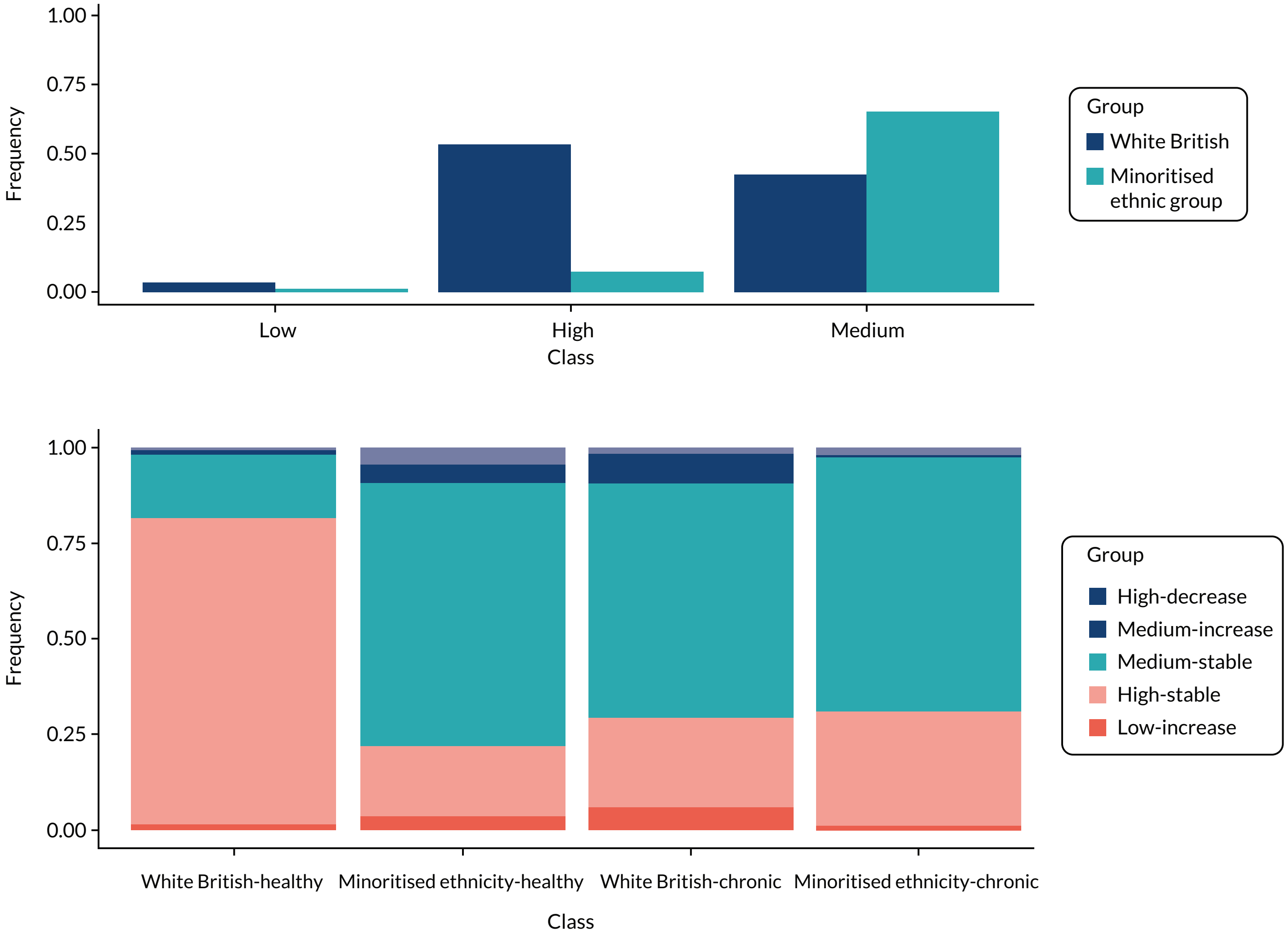


FIGURE 13 Interaction of ethnicity and health status on mental well-being, multinomial logistic regression for our primary survey.

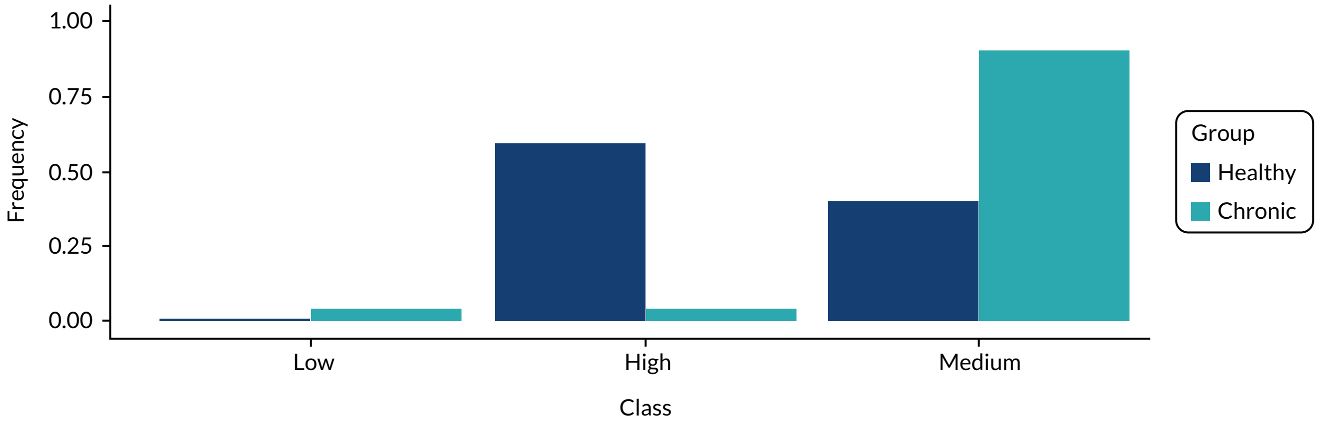


FIGURE 14 Physical QoL, multinomial logistic regression for our primary survey.

high-stable individuals in the non-white–chronic group suggest that the effects of disadvantaged identities (i.e. those adversely affected by structural discrimination) are not additive but mitigate or otherwise intersect with each other in complex ways.

The multinomial logistic regression results (see *Figure 14*) show differences in WHOQOL-physical between the White British and minoritised ethnic groups and between people with and without chronic health conditions. White British people or people without chronic health conditions have a higher chance of being in both high and medium groups, while people with disadvantaged identities are mostly in the medium group.

We also found an interaction effect between ethnicity and health condition on physical QoL (*Figure 15*). White British people show good physical QoL across three time points, while people in other groups are more likely to have a medium level of physical QoL. Interestingly, being a non-white healthy individual increases the possibility of having high physical QoL compared with other disadvantaged groups, whereas being White British with chronic health conditions increases the possibility of being in the low physical QoL group.

The multinomial logistic regression on psychological QoL (*Figure 16*) also shows similar results with the above three outcomes, suggesting that disadvantaged identities are associated with specific trajectory classes. To be more specific, most of the disadvantaged individuals (i.e. people with chronic health conditions or from a minoritised ethnic background) are in the medium group, while their counterparts have an increased chance of belonging to the high-increase or high-fluctuate classes.

An interaction between ethnicity and health condition on psychological QoL was found (*Figure 17*). White British people are more likely to have high psychological QoL with diverse patterns across three time points, while people in other groups are more likely to have medium psychological QoL. Having one of the disadvantaged identities could increase the chance of having high psychological QoL compared with having both disadvantaged identities. However, being White British with chronic health conditions would also increase the possibility of having low psychological QoL across three waves compared with non-white healthy and non-white chronic groups.

Research question 3: regional differences

The country of residence within the UK/RoI is included in the multinomial logistic regression as a predictor to study regional differences in the associations between the trajectory classes of the outcome, ethnicity and chronic health conditions. As a caveat, in some areas, such as the Isle of Man, we have a small sample size, hence the results for these small groups needs to be interpreted bearing this in mind.

We found the effects of ethnicity, health conditions and their interaction on mental well-being outcomes differed with country (*Figure 18*). Overall, in each country, most people were in the medium group. No individual from RoI or Wales was in the high-decrease group, and no individual from the Isle of Man was in the low-increase group.

The healthy White British people were mostly in the high-stable group in England. Other areas have fewer (NI, Scotland and Wales) or no (Isle of Man and RoI) healthy White British individuals in this group. This suggests the healthy White British people do not experience the same advantage in other parts of the UK/RoI as they do in England, though sample sizes should be borne in mind.

Healthy non-white individuals show different mental health trajectories across countries too. Most healthy non-white individuals from England, NI and Scotland showed a medium-stable trajectory of mental well-being. The shares of medium-increase and medium-stable classes were approximately equal in the Isle of Man. In Wales, however, medium-stable and low-increase groups were of similar prevalence. The prevalences of medium-increase, medium-stable and low-increase groups were similar in the RoI. Although healthy minoritised ethnic group individuals are overall less likely to belong to the high mental well-being class in wave 1 compared with healthy White British people, they show stable or increasing levels of mental well-being, suggesting their resilience during this period.

Most White British people with chronic health conditions in all areas are in the medium-stable groups. However, living in England, the Isle of Man, or NI might benefit their mental well-being, leading them to manifest an increased likelihood of belonging to a high-stable trajectory.

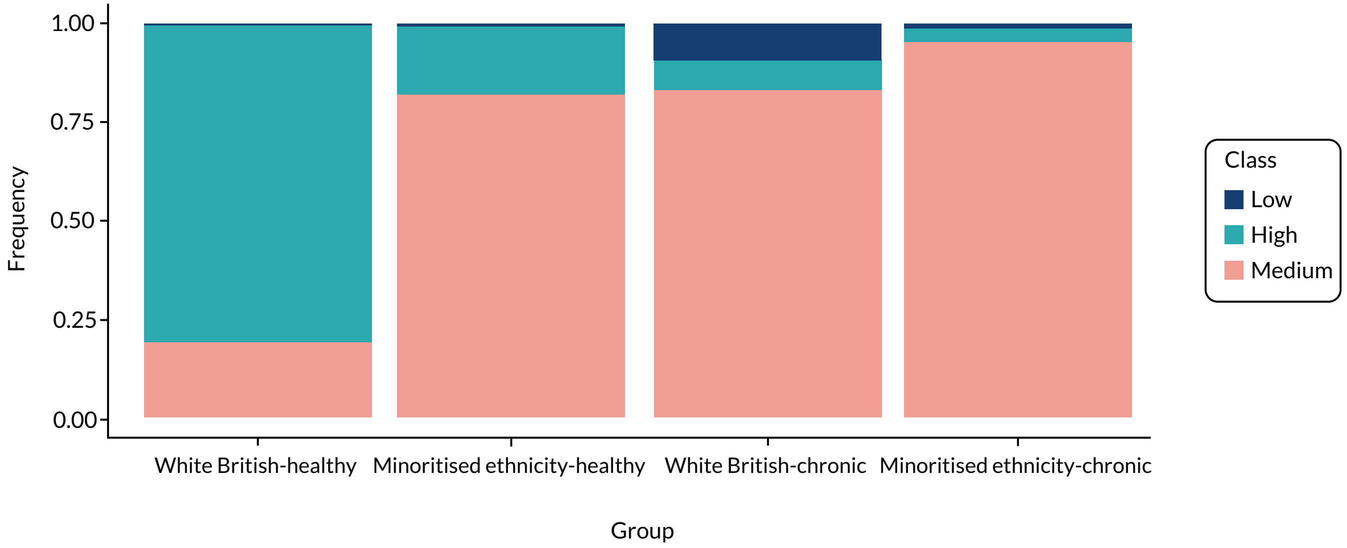


FIGURE 15 Interaction of ethnicity and health status on physical well-being, multinomial logistic regression for our primary survey.

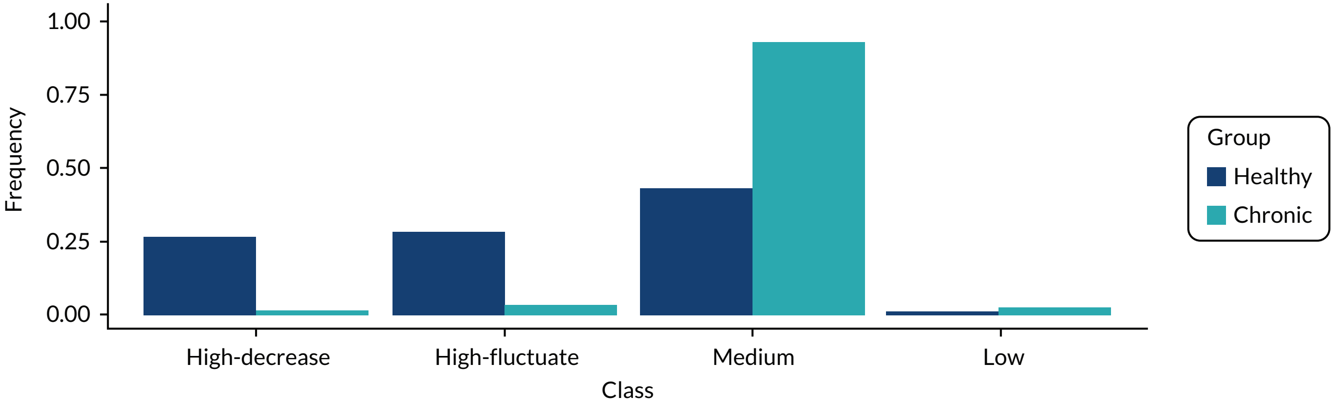


FIGURE 16 Psychological QoL, multinomial logistic regression for our primary survey.

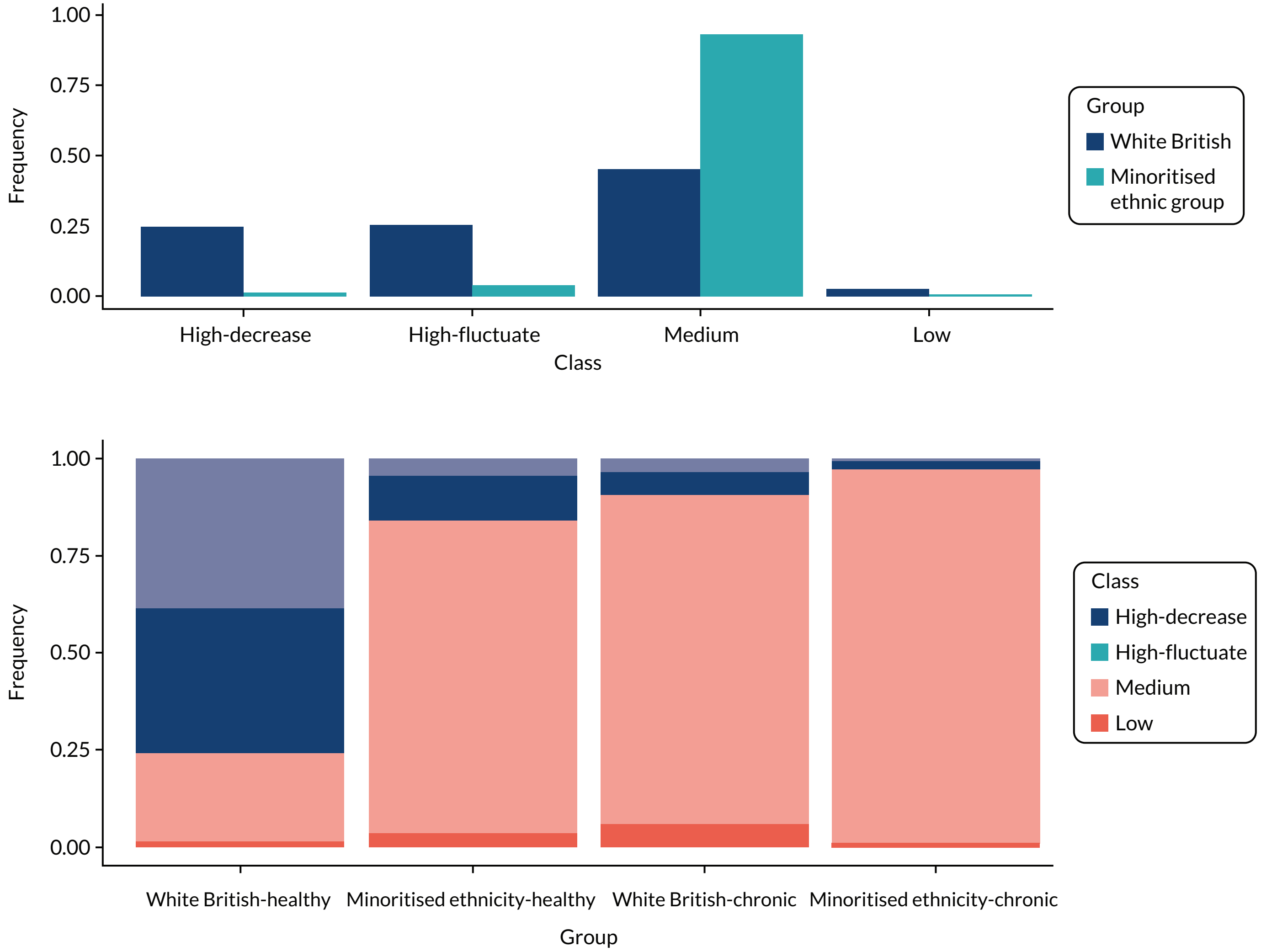


FIGURE 17 Interaction of ethnicity and health status on psychological well-being, multinomial logistic regression for our primary survey.

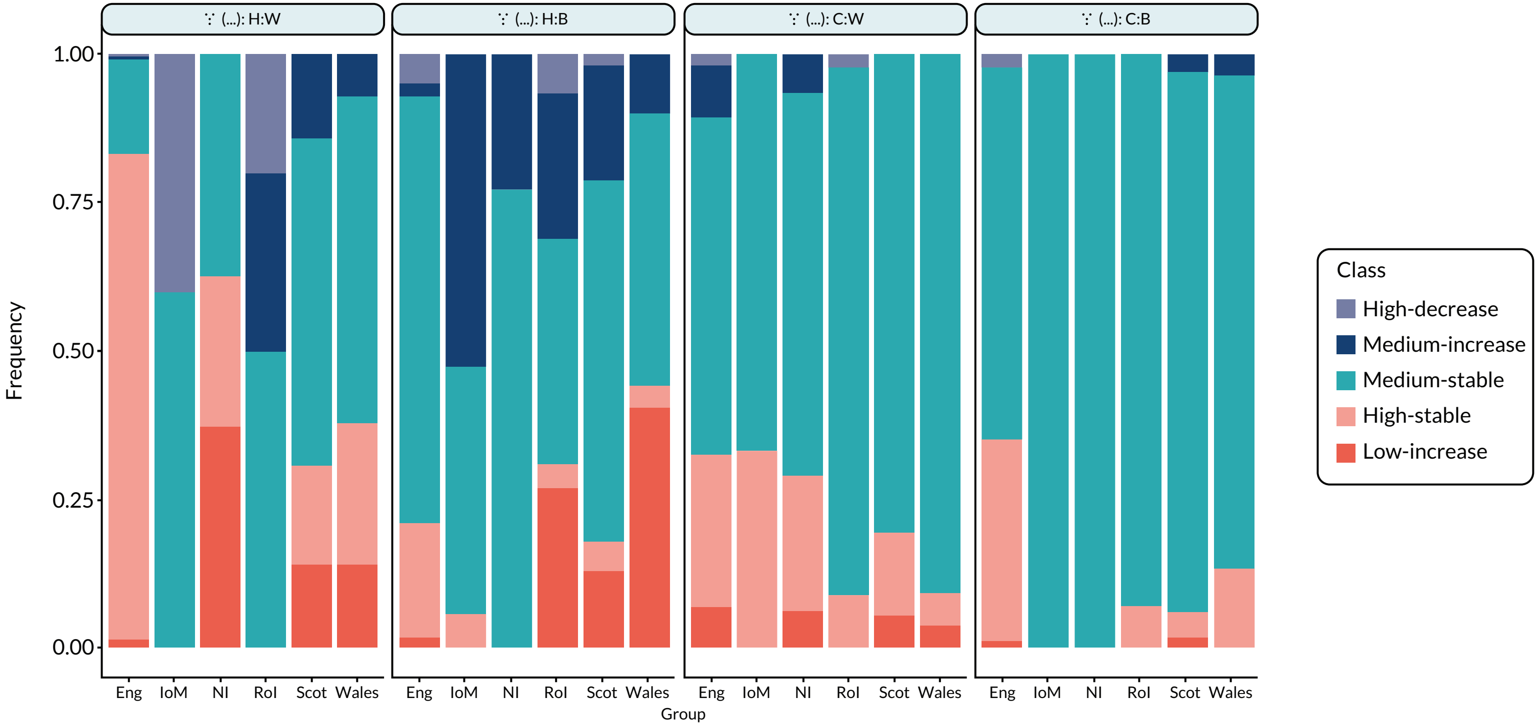


FIGURE 18 Effects of ethnicity, health conditions and their interaction on mental well-being outcomes across different countries of the UK/RoI. C:B, minoritised ethnic group with chronic health conditions; C:W, White British with chronic health conditions; H:B, healthy non-white; H:W, healthy White British.

Most people from minoritised ethnic groups and with chronic health conditions are in the medium-stable group across different areas. People in these groups across six areas have high or medium levels of mental well-being in wave 1 and remain so over time.

We found the effects of ethnicity, health conditions and their interaction on WHOQOL-physical also differed with country (*Figure 19*). Overall, for each country except England and the Isle of Man, most people were in the medium group. No individual from the RoI or Wales was in the low group.

Among healthy White British groups, those in England and the Isle of Man have a higher chance of belonging to the high physical QoL class, while people in other areas belong to the classes with medium or high levels of physical QoL. Although most healthy White British individuals show medium or high levels of physical QoL, around 10% of individuals in NI manifest poor physical QoL.

Most healthy minoritised ethnic group individuals have medium levels of physical QoL, and around 10–40% appear to have a good level of physical QoL.

Interestingly, non-white respondents with a chronic condition seem to maintain a medium level of physical QoL compared with white respondents with a chronic condition. Their chances of being in the other two groups (high or low) were lower in either case.

Regarding psychological QoL, the effects of ethnicity, health conditions and their interaction differ across regions of the UK/RoI (*Figure 20*). Most people have a medium level of psychological QoL, apart from the healthy White British people in England. The class distribution in England is like that in Wales but significantly different from that in Scotland.

Although the healthy White British individuals in England are more likely to have a high level of psychological QoL, those in other areas show medium or high-decreasing levels of psychological QoL. Around 10% of those in Wales or Scotland even suffered from poor psychological QoL. This result is like the findings regarding mental well-being (SWEMWBS), in that healthy White British individuals outside England may not experience the same advantage regarding psychological well-being.

Most healthy non-white individuals also have moderate levels of psychological QoL, except those in the Isle of Man with half of healthy non-white individuals having a good level of psychological QoL. The risk of belonging to the low group is small among healthy non-white individuals in all areas. Healthy non-white individuals in NI are all in the medium group.

The two chronic health groups also have a moderate level of psychological QoL. Both groups show few people with low or high levels of trajectories.

Research question 4: the relationships between the key variables across three waves

In this section, we assess whether help from community and the NHS mediates the associations between health conditions and the five outcomes by utilising structural equation modelling. We also compare the model fit indices of the original structural equation modelling model with those of the multilevel structural equation modelling model with participants nested in ethnic groups, to evaluate the intersectionality effects.

Table 9 presents the mediation analysis results on five outcomes. Since the multilevel models with participants nested in two ethnic groups do not perform better than the original models, they are not presented in the table. The poorer fitness of the multilevel model suggests that the mediation effects of help from the community and from the NHS on the associations between health conditions and five outcomes do not significantly differ between the two ethnic groups.

Having chronic health conditions could reduce NHS help-seeking but increase community help-seeking. The mediation effects of community help-seeking on the association between chronic health and health outcome vary across the five outcomes and waves. Community help-seeking significantly mediates the effects of chronic health conditions on mental

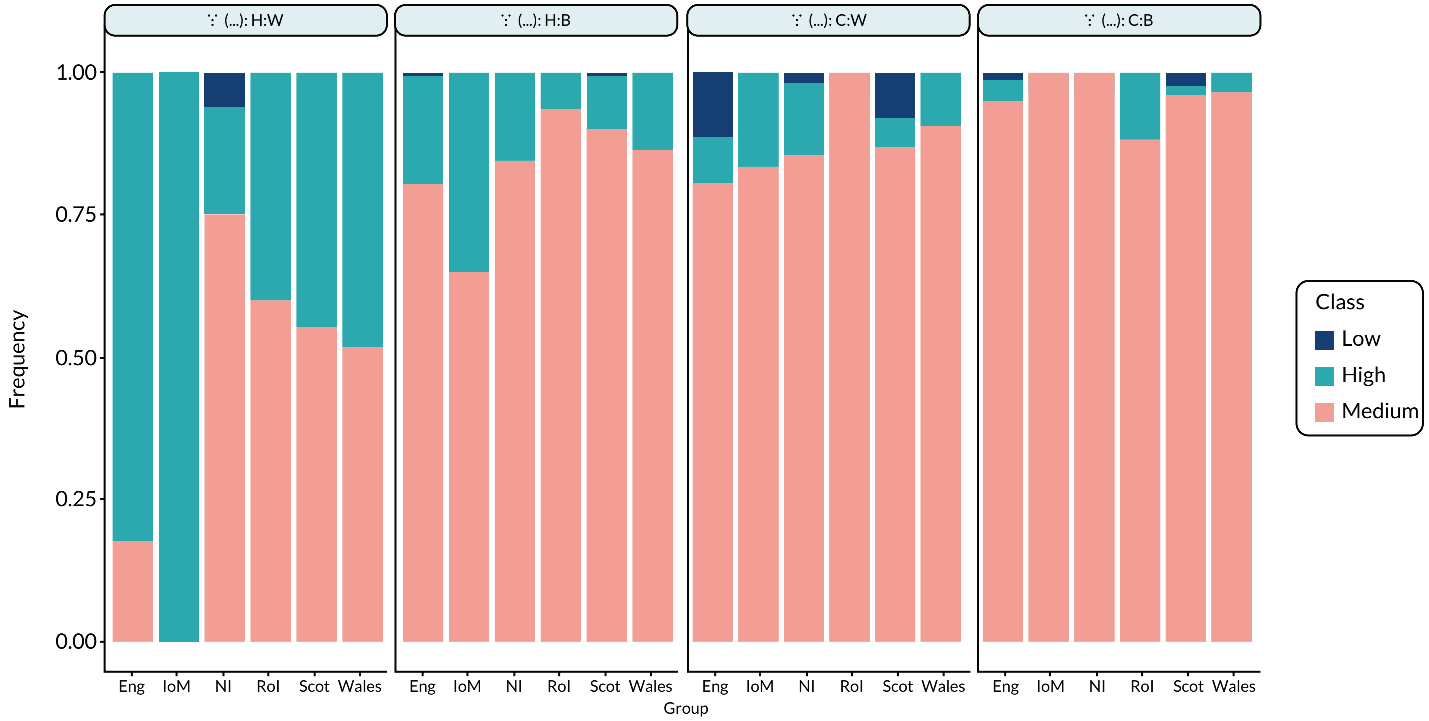


FIGURE 19 Effects of ethnicity, health conditions and their interaction on physical well-being outcomes across different countries of the UK/RoI. C:B, minoritised ethnic group with chronic health conditions; C:W, White British with chronic health conditions; H:B, healthy non-white; H:W, healthy White British.

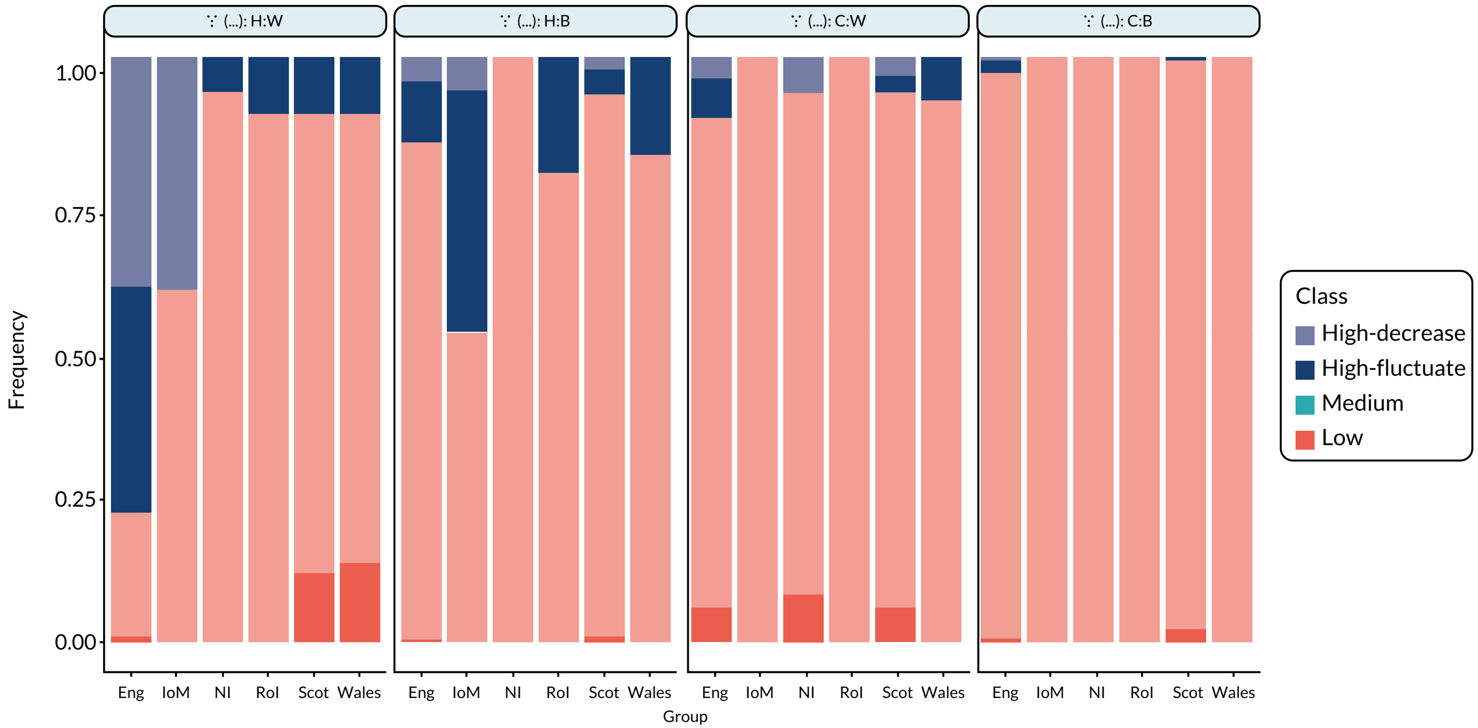


FIGURE 20 Effects of ethnicity, health conditions and their interaction on psychological well-being outcomes across different countries of the UK/RoI. C:B, minoritised ethnic group with chronic health conditions; C:W, White British with chronic health conditions; H:B, healthy non-white; H:W, healthy White British.

TABLE 9 Mediation analysis results on five well-being outcomes

	Coefficient	SE		Coefficient	SE		Coefficient	SE		Coefficient	SE		Coefficient	SE
SWEMWBS.w1 on			WHOQOL_phy.w1 on			WHOQOL_psy.w1 on			WHOQOL_soc.w1 on			WHOQOL_env.w1 on		
Help (community).w1	−0.09	0.15	Help (community).w1	−0.48*	0.14	Help (community).w1	−0.46*	0.13	Help (community).w1	−0.17	0.10	Help (community).w1	−1.46*	0.19
Help (NHS).w1	−0.07	−0.07	Help (NHS).w1	0.15	0.12	Help (NHS).w1	0.40*	0.11	Help (NHS).w1	0.27*	0.08	Help (NHS).w1	0.86*	0.15
Chronic.w1	−2.29*	0.17	Chronic.w1	−4.71*	0.14	Chronic.w1	−4.41*	0.12	Chronic.w1	−2.36*	0.09	Chronic.w1	−5.59*	0.17
SWEMWBS.w2 on			WHOQOL_phy.w2 on			WHOQOL_psy.w2 on			WHOQOL_soc.w2 on			WHOQOL_env.w2 on		
Help (community).w2	−0.65*	0.14	Help (community).w2	−0.36*	0.14	Help (community).w2	−0.28*	0.13	Help (community).w2	−0.34*	0.10	Help (community).w2	−0.14	0.18
Help (NHS).w2	−0.20	0.11	Help (NHS).w2	−0.14	0.12	Help (NHS).w2	0.21*	0.11	Help (NHS).w2	0.05	0.08	Help (NHS).w2	0.46*	0.15
Chronic.w1	−2.39*	0.16	Chronic.w1	−3.90*	0.15	Chronic.w1	−3.41*	0.13	Chronic.w1	−1.19*	0.09	Chronic.w1	−3.74*	0.17
SWEMWBS.w3 on			WHOQOL_phy.w3 on			WHOQOL_psy.w3 on			WHOQOL_soc.w3 on			WHOQOL_env.w3 on		
Help (community).w3	−0.54*	0.16	Help (community).w3	−0.13	0.14	Help (community).w3	0.02	0.14	Help (community).w3	0.22*	0.09	Help (community).w3	0.57*	0.20
Help (NHS).w3	0.17	0.14	Help (NHS).w3	−0.40*	0.13	Help (NHS).w3	−0.02	0.12	Help (NHS).w3	−0.21*	0.08	Help (NHS).w3	−0.31*	0.16
Chronic.w1	−1.78*	0.16	Chronic.w1	−3.74*	0.15	Chronic.w1	−3.07*	0.14	Chronic.w1	−1.26*	0.09	Chronic.w1	−3.46*	0.18
Help (community).w1 on			Help (community).w1 on			Help (community).w1 on			Help (community).w1 on			Help (community).w1 on		
Chronic.w1	0.25*	0.02	Chronic.w1	0.25*	0.02	Chronic.w1	0.25*	0.02	Chronic.w1	0.25*	0.02	Chronic.w1	0.25*	0.02
Help (community).w2 on			Help (community).w2 on			Help (community).w2 on			Help (community).w2 on			Help (community).w2 on		
Chronic.w1	0.29*	0.02	Chronic.w1	0.29*	0.02	Chronic.w1	0.29*	0.02	Chronic.w1	0.29*	0.02	Chronic.w1	0.29*	0.02
Help (community).w3 on			Help (community).w3 on			Help (community).w3 on			Help (community).w3 on			Help (community).w3 on		
Chronic.w1	0.22*	0.02	Chronic.w1	0.22*	0.02	Chronic.w1	0.22*	0.02	Chronic.w1	0.22*	0.02	Chronic.w1	0.22*	0.02
Help (NHS).w1 on			Help (NHS).w1 on			Help (NHS).w1 on			Help (NHS).w1 on			Help (NHS).w1 on		
Chronic.w1	−0.10*	0.02	Chronic.w1	−0.10*	0.02	Chronic.w1	−0.10*	0.02	Chronic.w1	−0.10*	0.02	Chronic.w1	−0.10−	0.02

TABLE 9 Mediation analysis results on five well-being outcomes (*continued*)

	Coefficient	SE		Coefficient	SE		Coefficient	SE		Coefficient	SE		Coefficient	SE
Help (NHS).w2 on			Help (NHS).w2 on			Help (NHS).w2 on			Help (NHS).w2 on			Help (NHS).w2 on		
Chronic.w1	−0.11*	0.02	Chronic.w1	−0.11*	0.02	Chronic.w1	−0.11*	0.02	Chronic.w1	−0.11*	0.02	Chronic.w1	−0.11*	0.02
Help (NHS).w3 on			Help (NHS).w3 on			Help (NHS).w3 on			Help (NHS).w3 on			Help (NHS).w3 on		
Chronic.w1	−0.21*	0.02	Chronic.w1	−0.21*	0.02	Chronic.w1	−0.21*	0.02	Chronic.w1	−0.21*	0.02	Chronic.w1	−0.21*	0.02
N	2844		2842.00			2842			2842			2842		
χ^2(df)	231.69(21)		243.9(21)			238.68(21)			157.466(21)			221.377(21)		
CFI	0.95		0.96			0.96			0.959			0.956		
RMSEA (90% CI)	0.059 (0.053 to 0.066)		0.061 (0.054 to 0.068)			0.06 (0.054 to 0.067)			0.048 (0.041 to 0.055)			0.058 (0.052 to 0.065)		

*$p < 0.01$.

well-being and social QoL in waves 2 and 3 but not wave 1. Additionally, it mediates the associations between health conditions and physical QoL and between health conditions and psychological QoL in waves 1 and 2 but not wave 3. Finally, the effect of health conditions on environmental QoL was significantly mediated by community help in waves 1 and 3 but the mediation effects were the opposite.

The mediation effects of NHS help on the links between chronic health and health outcome also differ across outcomes and waves. NHS help-seeking mediates the associations between health conditions and physical QoL in wave 3 but not waves 1 and 2. In contrast, it mediates the effect of chronic health conditions on psychological QoL in wave 1 but not later waves. Additionally, the mediation effects of NHS help were significant in waves 1 and 2 regarding environmental QoL and in waves 1 and 3 regarding social QoL, but the effects on the association between health condition and social QoL in waves 1 and 3 were the opposite.

Summary

Our primary data show the mental well-being of only around 7% of our sample was significantly affected by 2021–2 COVID restrictions and few people showed an adverse outcome. Psychological and physical QoL were also good. We found these nuances:

- White British people are more likely to have better and more stable mental well-being.
- Most White British people with chronic health conditions, and minoritised ethnic groups with chronic health conditions, in all areas, are in the medium-stable groups.
- Although healthy non-white individuals are overall less likely to belong to the high mental well-being class in wave 1 compared with healthy White British people, they show stable or increasing levels of mental well-being, suggesting their resilience during this period.
- The significant numbers in the non-white–chronic group with better and more stable well-being suggest that the effects of disadvantaged identities are not simply additive, supporting the importance of an intersectionality framework.

We found a gradient of disadvantage for psychological QoL, which tended to be best in White British people without chronic health conditions and worst in the non-white–chronic group (though with some White British people with chronic illness also falling here), with the others falling between.

Concerning physical QoL:

- White British people are more likely to have better and more stable physical QoL.
- However, being White British with chronic health conditions increases the possibility of being in the low physical QoL group.
- Being from a non-white healthy group increases the possibility of having high physical QoL compared with other groups disadvantaged by structural inequalities.
- Most healthy non-white individuals with or without a chronic condition have medium levels of physical QoL, and around 10–40% appear to have a good level.
- Around 10% of individuals in NI manifest poor physical QoL.

Data also suggested healthy White British people do not experience the same advantage in other parts of the UK/RoI as they do in England for mental and psychological well-being, though sample sizes should be borne in mind.

Having chronic health conditions could reduce NHS help-seeking but increase community help-seeking, perhaps because of NHS changes in the pandemic, fear of COVID-19 infection or a greater need for practical rather than health support. Community help is most likely to have physical and psychological benefits for those with chronic conditions in 2021 and social and mental well-being benefits in our wave 3 data. Similarly, NHS help improves physical QoL in those with chronic conditions in our wave 3 data but psychological QoL in wave 1, and in those with chronic conditions it reduced social QoL in wave 2.

Chapter 6 Qualitative interview and co-create workshop methods

Here we provide more detail on the methods used for our qualitative strand, and in subsequent chapters the key findings. We used interviews, and follow-on co-create workshops focused on knowledge exchange, for an in-depth longitudinal exploration of the experiences of four groups of purposively sampled community-dwelling migrants and, for comparison, native White British people, all with/without disability. Our topic guide focus is shown in *Chapter 5*, *Box 2*. Participants received thank you vouchers (online, posted or by hand depending on extant pandemic guidance/personal request) following NIHR guidance.

Interview methods

Interviewers and modes of interview

Interviews were remote by default due to pandemic considerations, using the method of respondents' choosing, usually Microsoft Teams® (Microsoft Corporation, Redmond, WA, USA) or Zoom (Zoom Video Communications, San Jose, CA, USA). We trained 11 lay community members as co-researchers, primarily to undertake interviews locally at our different sites. Three dropped out because of other commitments but eight remained engaged through the project; one joined the central team more formally to work fully alongside them. All interviewers (central and lay) conducted some interviews by phone and some face to face (following strict UCL pandemic and lone working risk assessments and guidance). Participants were supported to provide maps of their local networks.

Lay (often called peer or community) co-researchers, supported by the central team, were important contributors, being:

- sensitive to local situations and contexts, particularly relevant while England was subdivided by tiers of COVID risk
- sensitive to cultural needs
- networked with and trusted within local communities, extending our reach.

Undocumented migrants were recruited by both lay researchers and a central team member with relevant contacts from previous research.

Lay co-researchers from collaborator Bromley-by-Bow Community Centre recruited and interviewed 34 of our London participants independently; they had direct experience of similar work with, and access to, local migrant groups. Collaborators Born In Bradford, part of the ActEarly research-ready city collaboratory,[178] provided direct access to suitable participants and co-researchers in Yorkshire as well as a lay co-researcher, and undertook some work alongside the central team. Born In Bradford (https://borninbradford.nhs.uk/) regularly tracks the lives of over 40,000 Bradfordians, using findings for health and well-being intervention; we ensured we did not sample the same people, to avoid research burden.

An expert in migrant mental health/safeguarding crisis assessments was on our advisory team, and we developed a protocol for clear signposting to sources of help when these might be needed. We actively addressed migrant concerns about anonymity and disability needs, as detailed in our toolkit.[76]

Interview sampling

Our initial target was 210 interviews using purposive quota sampling (*Table 10*) for maximal diversity and sufficient numbers for rich data for each group. Purposive quota sampling must be constantly monitored. If aimed-for numbers were not achieved, our plan was to re-evaluate strategies and explore data saturation and theoretical sampling. Recruitment used the same channels as strand 2 (primary survey), plus posters, adverts, snowballing and direct approaches to attract those who lacked resources or technology to respond to online recruitment, for example via our clinical co-applicants, collaborators, lay co-researchers and in 2022, following Health Research Authority (HRA) ethics approval (IRAS project ID: 310741, Protocol number: NIHR132914, REC reference: 22/SW/0002), CRNs. We

TABLE 10 Interview sampling[a]

	Aimed-for people born outside the UK from parents not born in the UK				Born in UK from parents not born in UK	Native White British	
Condition/ethnicity	**Middle Eastern Arabs/ North African**	**Sub-Saharan African**	**Central/East European**	**South Asian**	**Second generation**	**White British**	**Totals**
Mental health	5 + 2	5 + 2	5 + 2	5 + 2	5 + 2	5	40
Mobility	5 + 2	5 + 2	5 + 2	5 + 2	5 + 2	5	40
Stamina/breathing/fatigue (incl. heart)	5 + 2	5 + 2	5 + 2	5 + 2	5 + 2	5	40
Sensorial	5 + 2	5 + 2	5 + 2	5 + 2	5 + 2	5	40
Cognitive	5 + 2	5 + 2	5 + 2	5 + 2	5 + 2	5	40
Food-relevant	5 + 2	5 + 2	5 + 2	5 + 2	5 + 2	5	40
No condition/disability	5 + 2	5 + 2	5 + 2	5 + 2	5 + 2	5	40
Total	42	42	42	42	42	42	280

[a] Figures following the + sign represent top-up recruitment aims. We later added a brain hyperexcitability and a cancer category in our analyses.

considered recruiting from long COVID specialist clinics, but either their set-up was delayed in our locations of interest or none were planned. We received top-up funding to collect up to 80 more interviews focusing on participants with mental ill health from Manchester and north-west England. Our consent process was in English as default. Translated study documents were provided via lay co-researchers if required to ensure fully informed consent. Braille and other formats, for example for neurodivergent people, were offered but not taken up. Participant information materials were piloted within relevant communities.

Inclusion criteria were:

- Ethnicity: Middle Eastern and North African Arab; sub-Saharan African; Central/East European; South Asian
- Diverse citizenship states, focused on refugees/migrant adults (including skilled migration, humanitarian or family streams) aged 18 + years born outside the UK (undocumented, on temporary visas, with indefinite leave to remain, with British citizenship)
- Condition – any disability (following the study definition, see *Chapter 1*), including self-diagnosed.

For more detail on our ethnicity choices, please see *Appendix 3*. We excluded:

- Residents of detention centres/closed facilities linked to national migration policies, as complex cases with specific considerations (ethics reviewers required their exclusion).
- Carers without disabilities, though some participants with disabilities were inevitably also carers, for example because of structural factors increasing familial risks or because some conditions are heritable.

We initially excluded mental ill health beginning during the pandemic and apparently caused by it, as other studies had focused on this. However, the distinction between prior or pandemic-related mental ill health was often unclear in interviews.

Our PPI advisers had suggested we only interview participants able to communicate in English so findings would not focus on language fluency. But we revisited this as per protocol, and lay co-researchers sometimes undertook interviews in their own language and provided translations. This was so undocumented migrants could feel confident their details (including voice recordings) would not spread beyond lay co-researchers; thus we could not undertake quality checks, such as back-translation.

We originally chose five sites in England for maximal sampling diversity in migrant population density, proportion of EU to non-EU migrants, and reasons for migration (*Table 11*). With the top-up funding we added Manchester and the north-west coast. Our UK/RoI survey enabled contextualisation and evaluation of transferability of our interview findings. We aimed within sites to recruit from a mix of local communities well served by immigrant-specific services, and less service-rich communities.

Follow-on co-create workshop methods (May and September 2022)

We did not invite the full interview cohort to these, as we excluded:

- those undocumented individuals whom we retained no contact details for
- White British people, as we were interested in foregrounding specifically the intersection of minoritised ethnic group with disabilities and citizenship
- non-English speakers (except at Bromley-by-Bow Community Centre and in Bradford, where an interpreter was present)
- ethnicities outside our four key categories (e.g. 'mixed race')
- people not living in the core locations
- people without a disability or who said they had one at screening but whose interview clarified their ADL were unaffected.

This was a post hoc decision based on consideration of the data already collected.

The remaining interview participants were directed to an Eventbrite (Eventbrite, Inc., San Francisco, CA, USA) booking system via e-mail or text; we booked their Eventbrite place for them on request. We offered face-to-face sessions in a central town in each core region (Leicester, London, Bradford, Liverpool, Newcastle), which became possible as the country opened up. We also offered online sessions across regions, capped at 20 per session or 8 per breakout room. To be inclusive, we also offered repeat interviews. We had planned to mix ethnic groups within each workshop where possible, but on reviewing our interview data on community connections, we decided to mix conditions instead.

We offered £40 for participation in the May workshops. These used a topic guide to explore our interpretation of interview themes and consider subsequent change through knowledge exchange co-creation. Our PPI group recorded short vignettes using verbatim interview extracts to prompt for assets and strengths, issues and potential solutions. Accessibility transcripts were provided in advance if needed. PPI members and lay co-researchers helped facilitate

TABLE 11 Relevant features of chosen sites

Site	% of residents born abroad[179]	Non-EU % of all residents born abroad[179]	Majority reason for coming[179]
London	38	68	Work, asylum seekers, refugees
South-east England	13.5	58	Work or to join family
Gateshead–Newcastle	13	84	Work or to join family
West Midlands	18	75	Work, also many to join family
Yorkshire	10	56	Work and family
Manchester and north-west coast	36	42	Work, asylum seekers, refugees, family

discussions. Small breakout groups focused on different topic combinations, so all topics were considered at least twice (*Table 12*). We ensured workshops were accessible and inclusive. While we avoided complex interactive software tools in remote workshops, we introduced simple tools for structure, controlled by facilitators (see *Chapter 12*), and visual stimuli using quotes, data summaries and simple cartoon drawings (see *Appendix 4*).

The face-to-face May workshops provided richer data than their online equivalent, so in September we prioritised the face-to-face format with an intensive recruitment drive. We also offered online sessions capped at eight participants to avoid using breakout rooms, and individual remote interviews for those unable to attend face-to-face sessions. We offered £40 for participation in face-to-face workshops and £20 for online contributions as the country had entirely opened up and this reflected the different time considerations involved for participants. Vignettes were updated to incorporate May workshop data and shortened (as we had found they needed to be quick and punchy). In discussion we prompted for assets, intervention and change, structuring the sessions to enable effective knowledge exchange using four co-creation techniques: journey mapping, structured brainstorming,[180] dot voting and a vision cone (see *Appendix 5*). The journey maps focused on access to either primary or secondary health care, with participants reflecting on their experiences of: deciding to seek care; booking; having the consultation; and the follow-up period. The vision cone guided participants to think about the present, then reflect collectively on how this compared to the past – during the pandemic in our case – and then discuss their feelings about the future. Structured brainstorming was used to collate ideas and suggestions for improving health, care and well-being. Each person was asked to suggest three ideas; their group then collectively negotiated the most important, supported by facilitators from among our central team, lay co-researchers and PPI group, for discussion and development. In face-to-face sessions, participants were divided into different tables and then tables contributed to the whole-group discussion. Ideas from these sessions were subsequently added to those from the co-design workshops (see *Chapter 12*) and semistructured interviews to shape study outputs.

Co-design workshop methods

The co-design workshops built on the practical coping strategies used by people from minoritised ethnic groups with disabilities during the pandemic that were identified from the interviews and knowledge exchange co-create workshops. Their aim was to produce a series of service design proposals to either form recommendations for policy and practice or develop interventions to mitigate health inequalities and improve health and well-being for the study population. This matches the study's assets-and-strengths-based approach. Design and delivery of the workshops were led by a design researcher (AT), with contributions by the core team, lay researchers and PPI members. Three workshops were planned, to explore the broad themes described below. Our co-design lead decided, having seen the interview data, and after PPI input, that these workshops would be most productive if they were 1–2 weeks apart, to keep the process fresh.

Participants were purposively sampled stakeholders from relevant communities, charities, health and social care and policy sectors, and researchers, with professional or personal expertise or experience of health and social care for disabled people from minoritised ethnic backgrounds. They had to have some practical understanding of how services are commissioned, developed and/or deployed, key to identifying gaps or possibilities for new service proposals.

TABLE 12 Example of topic distribution in a workshop

	Subgroup 1	Subgroup 2	Subgroup 3	Subgroup 4	Subgroup 5
Theme 1	X	X			
Theme 2	X		X		
Theme 3		X	X		
Theme 4				X	X
Theme 5				X	X

The workshops followed a participatory design approach. Different creative tools, such as illustration, physical modelling and future-focused discussions, enabled workshop participants to empathise with study participants' experiences and encouraged ideation to develop actions for their future support.

It was important that discussions moved beyond the limitations of current service provisions, so activities were imaginative as well as future-focused. We used a phrase directly from the interview data to frame the discussions: 'the new world after the pandemic'.

While participants interacted, an illustrator captured insights, reflections and ideas through live drawing, documenting the creative process. This gave participants something to reflect on through the workshop series and forms a key part of the creative outputs.

Participants were divided into groups of six to eight mixed stakeholders, each with a CICADA facilitator. The workshops comprised the following stages:

1. Listen to the theme

The facilitator introduced the theme by reading out a short description. Participants were given illustrative quotes from the data, with examples of coping strategies highlighted within contextual information.

Theme 1: embracing technology
Theme 2: alternative sources of medical advice and care
Theme 3: looking after ourselves
Theme 4: navigating the system and COVID-19 recommendations
Theme 5: coping financially
Theme 6: supporting each other

2. Individually model a coping strategy

Participants were asked to create a plasticine model to represent a coping strategy in the data they wanted to explore. The activity of physical modelling facilitated ideas generation and helped people think differently about problems.

3. Discuss unique behaviours or strategies interviewees drew on to cope

Participants used their individual models to discuss the coping strategies and started to incorporate examples from their experiences working in this space. Different perspectives were shared about pandemic responses, health and social care service limitations, and community and cultural awareness. Models helped participants report to their group, contributing to final collective idea creation.

Facilitators used prompting phrases such as 'If we knew that then, what would we have done differently?' or 'What can we change in our current practice now we know this?'.

4. Think about the 'post-pandemic world'

Discussions then opened up to encourage participant thinking about future services or interventions. Facilitators used prompts such as 'From *your* experience from policy/commissioning/funding/service use/service design, how would this knowledge change practice?'. They discussed what might work, or not, what already exists, and what does not.

5. Create new models

Facilitators then supported participants to create new models together, building on the individual coping strategies discussed and linking these to wider relevant issues. Facilitators gave short presentations to share models between groups. The new models became physical embodiments of the ideas created collaboratively as a group. All models were exhibited on a table, alongside illustrations of the discussions, which became visual summaries of the discussions, creating new interpretations of the CICADA data.

Following the workshops, the design researcher led the CICADA team. including one community co-researcher, through a design activity to iterate and refine the workshop proposals. They reviewed workshop transcripts, photographs of the models, facilitator notes and reflections. Ideas were plotted on a spectrum to gauge feasibility within the scope of the CICADA study. A further discussion critiqued the proposals in terms of feasibility, originality, appropriateness and scale of impact. A series of proposals resulted that the study team could take forward as study outputs, and also broader recommendations for policy and practice.

Key informant interview method

Recruited through our central team, collaborator and advisory group networks and e-mails to local service providers and organisations, 10–15 interviews were planned for October 2022 with key informants, for example: welfare, social and healthcare staff; settlement and ethno-specific services; charities; and community leaders. To support implementation into policy and practice, the topic guides included perceptions of local service needs, area-level characteristics, barriers to and facilitators of community member service access, current community-led responses, impacts and effects of the pandemic, and future planning. We focused on implementation of our co-design workshop outputs, so each topic guide was individualised to match the expertise and experience of the key informant.

Analysis of qualitative interviews and follow-on workshops

All qualitative data sessions were recorded, if this was consented to, and transcribed (in three cases researchers were asked to make written notes instead, and one interview was by e-mail).

Corpus linguistics

All interview data underwent corpus linguistics analysis using #LancsBox [Brezina V, Weill-Tessier, P, & McEnery, A (2020). #LancsBox v.5.x.],[181] developed at Lancaster University, for a bird's-eye view of the data and broad summary comparisons. This also quantifies qualitative data, but with limited validity and reliability with our data set as it was relatively small for this. We considered the core data set of 218 (i.e. data that matched our initial inclusion criteria) and did not balance word or interview numbers per group across the different comparisons. Corpus linguistics analysis often compares text with a language standard, but we compared subsets of the data, removing interview questions from the transcripts.

1. We evaluated the top 100 most frequent words generated for each corpus for each comparison (by ethnicity, condition, place, and gender). We cleaned the data of:
    - filler words, hedges (modal verbs, e.g. 'may', 'might'), lexical verbs (e.g. 'suggest', 'appear') and adverbs (e.g. 'likely', 'possible')
    - attitude markers, such as 'important(ly)' and 'surprising(ly)'
    - engagement words ('imagine you are')
    - words that on inspection were used often, in a wide range of ways (three or more), with no clear pattern, for example, 'gone'
    - words occurring < 10 times
    - names of places or ethnicity provided at the interview start
    - words for which examinations of clusters showed the word to have meanings not significant for the analysis.

2. We chose keywords generated by the different comparisons, from the 10 most different words by word frequency, that had a dispersion statistic of 1.5 or less. This excludes words which clump together in one or two interviews and are less dispersed across interviews.[179]
3. We considered these words in context across the different groups (so-called concordance analysis) and by topic/sentiment.

Framework

Our main interview analysis used the framework thematic approach (originally developed for rapid policy guidance[182]). Workshop and key informant data were subsequently added. Using deductive themes developed from the topic guide meant we could map our framework analysis to the survey for added insight. Inductive (bottom-up) themes were added as analysis progressed. NVivo® 12 (QSR International, Warrington, UK) was used to manage initial frameworks but these were subsequently moved into Microsoft Excel where we added network maps provided with some interviews, the chat and Miro boards from online workshops, and outputs of the workshop co-production tools. We will undertake discourse analysis on a data subset produced from participant pairs matched within typologies identified from framework analysis, as a longer-term dissemination aim.

We ensured credibility (with workshop validation and an inter-rater reliability exercise between three core team members until we achieved values of 75% or more for the key themes), transferability (with full description), confirmability (using illustrative extracts), and dependability (via transparent methods and archiving of anonymised data for secondary analyses).

Protocol deviations

Networks

We planned to explore informal support networks for: education; health, social care and legal matters; well-being; and social/cultural activities in strand 3 using:

- a brief questionnaire preceding the first interview
- results translated into Network Canvas Interviewer to develop ego (participant)-centric network maps
- participant sketch maps of their local area and places significant to them[183]
- photographs by participants of significance to their health care and social interactions.

We stopped after collecting these data from 10 participants, having given them clear instructions, with a focus on ethical issues (e.g. to avoid identifiable photos of other people). The quality of photos and sketch maps was too variable to be useful, and this was an extra burden for participants with uncertain benefit. This approach would, we believe, have been successful if we could have guided participants in person.

Students

We originally excluded student migrants as likely to have structured educational institution support. However, despite screening interviewees, some student interviews crept into the data, which we included.

Sites

We initially interview-sampled in England only, due to differences in the devolved nations in responses to the pandemic and health and social care systems. When data were accidentally collected by community co-researchers from the devolved nations, our advisory panel suggested we ensure five participants were recruited from each nation to enable an exploration of transferability; neither we nor the community co-researchers were successful in recruiting from NI or RoI. This means that while some of our findings may be more relevant to NHS England, we could begin to consider whether principles are similar across the four nations but remained somewhat limited in this.

Ethnic categories

Our original ethnic categories were Arab, sub-Saharan African, East European, Indian and Pakistani. While not homogeneous, these groups were chosen to be diverse but focused enough to ensure rich data and given that:

1. 74% of refugees resettled in the UK 2010–20 were Arab and Turkish people, 19% sub-Saharan African[177] (who were also the most likely to die from COVID-19 in the UK[12]).
2. Recent migrants by choice up to 2020 were mostly born in Poland or India.[179]
3. The second highest UK COVID-19 mortality rates by ethnicity were for people of Pakistani origin.[12]

We modified our categories after early discussion with our advisory group and collaborators, who included people from these ethnic groups. Full details of the ethnicities included are provided in *Appendix 3*.

Chapter 7 Demographics and 'big picture' corpus linguistics findings for interviews

In this chapter, we consider participant demographics and potential for transferability of findings as well as corpus linguistics findings. In *Chapters 8*–*11* we consider our in-depth framework analyses, in which we juxtapose extracts from key informant interviews with those of our other interviewees, for insights augmenting and confirming our interview data. *Chapter 8* considers COVID-19 infection control measures, and *Chapter 9* other challenges of daily living. *Chapter 10* looks at health and social care, and *Chapter 11* considers the coping strategies people used. *Chapter 12* focuses on changes noted in the workshops of 2022. Key informant comments on co-design workshop proposals are considered in *Appendix 6*.

Demographics and transferability

Interviews lasted 25–90 minutes, and workshops 2 hours. Detailed demographics of the interviewees are shown in *Table 13* (public participants) and *Table 14* (key informants). We recruited our first 210 participants a month earlier than expected (6 were later excluded because of corrupted or deleted files), from July to October 2021. We recruited 67 more in our top-up work, mostly in May–September 2022, stopping short of our planned 80 because CRN involvement to fill gaps in the data only began shortly before the project end date, due to HRA approval delays.

TABLE 13 Public participant demographics (*n* = 271)

Ethnicity	South Asian	35.42%
	North African	17.71%
	Other Arab League	8.86%
	Central/East European	9.96%
	African	11.07%
	Undocumented[a]	2.21%
	Native White – British, Irish	7.38%
	Caribbean	0.74%
	Southern European	3.32%
	Mixed race	3.32%
Age (years)	18–24	11.44%
	25–34	36.90%
	35–44	18.82%
	45–54	11.44%
	55–64	5.54%
	65–74	2.216%
	75 +	0.37%
	Unknown	12.55%

TABLE 13 Public participant demographics ($n = 271$) (*continued*)

Gender	Male	46.49%
	Female	51.66%
	Gender non-conforming	1.11%
Site	South England	7.75%
	London	39.85%
	Midlands	11.07%
	Manchester and north-west coast	13.28%
	Yorkshire	11.81%
	Cumbria and Newcastle area	6.27%
	Scotland, Wales	8.86%
	Unknown	0.37%
Condition		*N*% alone (*N*% including with other conditions)
	Dexterity	1.12% (1.38%)
	Mental health	7.01% (31.75%)
	Mobility	12.92% (35.59%)
	Stamina/breathing/fatigue (incl. heart, lung)	16.24% (43.88%)
	Sensorial (3/16 deaf)	1.85% (6.48%)
	Cognitive	1.48% (11.20%)
	Food-relevant	6.64% (22.65%)
	Brain hyperexcitability (migraines, epilepsy)	2.58% (3.44%)
	Cancer	5.17% (6.77%)
	No condition/impairment (across ethnic groups)	9.59%
	2 + conditions	33.58%

[a] Note that 'undocumented' figures are a minimum as some participants did not wish us to know their citizenship status. This also means we have not written identifying details for undocumented migrants in the text and in some cases, we have not disclosed their undocumented status for disaggregated data.

TABLE 14 Key informants interviewed[a]

Role	Comments
Member of Parliament	London-based, Labour
Community group worker	London-based, develops and delivers community mental health and works to empower women and black people
Primary care GP	Manchester GP, working in a deprived ethnically diverse area where, however, many patients could communicate in English
Charity representative	London health and well-being charity

GP, general practitioner.

[a] When writing this report, we had complete interviews and transcripts from four key informants because of changes in government and healthcare staff burnout; interviews were repeatedly rearranged and cancelled due to work crises.

Figure 21 indicates the spread of conditions and the largest gaps in our data – in particular, we did not recruit African or Central/East European participants with sensory loss.

Our samples appear broadly representative of national data:[17]

- South Asian and Central/East European ethnicities were our largest and smallest samples by ethnicity, in a 3.4 : 1 ratio. Census 2021 data show a South Asian : Polish ratio of 3 : 1.
- Considering condition plus ethnicity, Census 2021 data show White British and Bangladeshi families are the most likely to receive the care (8% and 10%) and mobility component (7% and 8%) of the Disability Living Allowance.[184]
- More participants lived in London than elsewhere, but with good representation across sites corresponding to national census data. While we used quota sampling to drive recruitment, we were aware ab initio that recruitment characteristics were unlikely to be evenly spread across sites.[17]

We had a spread of ages, but with more participants aged 54 years and under and fewer older participants, which may partly reflect pandemic restrictions and reliance mostly on the internet for interviewing. Females slightly outnumbered males.

We had substantial representation across disabilities and conditions. Ab initio we sampled public participants using a comorbidity approach; that is, we aimed for equal numbers of participants for each 'index' impact category while recognising many might have co-occurring (so-called comorbid) conditions. Thus, our initial choice of unit of analysis was condition, not person. We had assumed that one – the index condition identified at screening – would dominate, but this was not clear in practice. Given this, and since particular clusters of comorbidities are common, in analysis we use a multimorbidity approach, where the experiences of a person with multiple conditions are considered more holistically.[185]

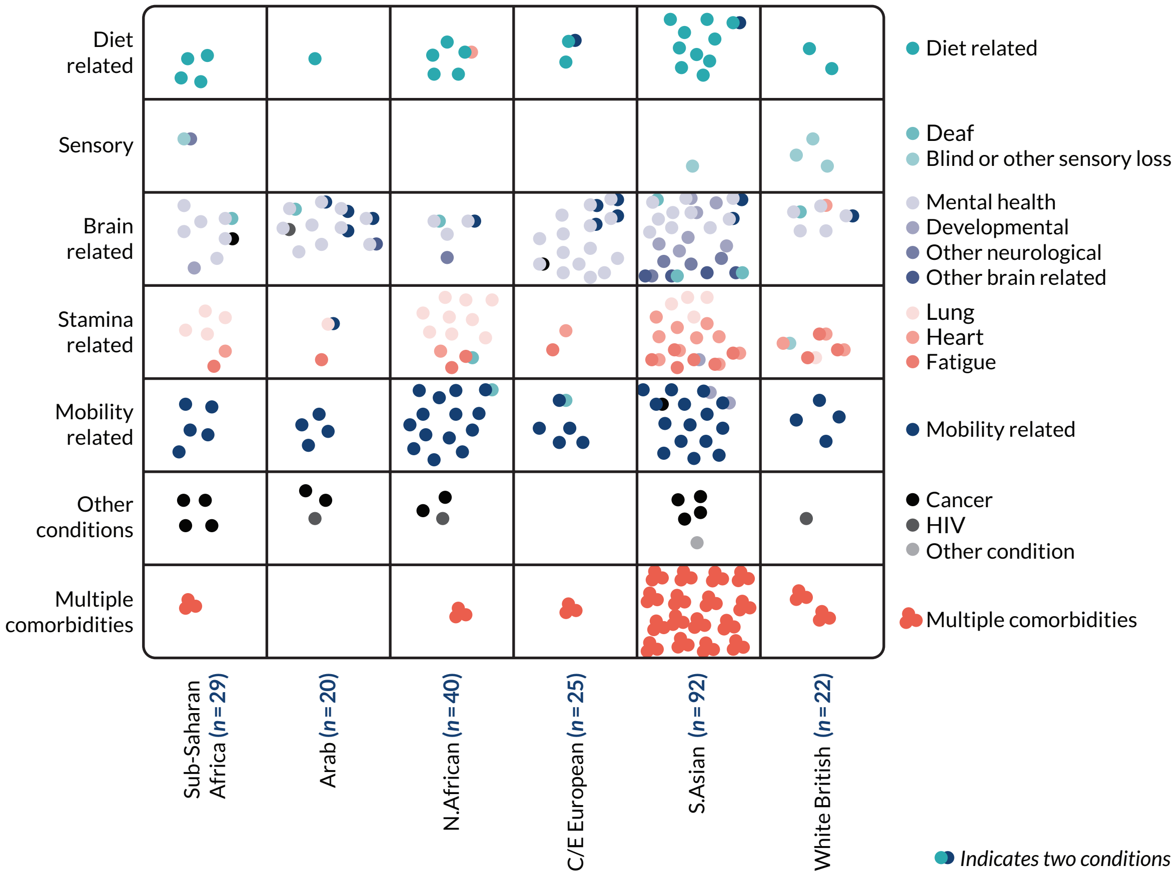


FIGURE 21 Illustration of the distribution of conditions by ethnic grouping.

In our core interview data set (the data that matched our initial inclusion criteria), 29% (63/218) of participants had two coexisting conditions and 10% (21/218) had multiple comorbidities (see *Figure 21*). This is significantly less than the 78.7% of white patients, 60.2% of South Asian patients or 60.1% of black patients recorded by Kuan *et al.*, in their 2010–5 population-based study in England.[186] However, adjusting for within-study sample size differences, multiple comorbidities are most common among South Asian participants in our data, indicating complementarity with the Kuan *et al.* data. In our strand 2 survey data, 39% of white participants had multiple comorbidities, followed by mixed race black/white (36%) and South Asian (31%) groups with a similar but not identical pattern, whereas Arab/Turkish people in the survey were most likely to have two conditions (35%), followed by Chinese (21%) and South-east Asian survey respondents (18%).

Kuan *et al.* identified multimorbidity clusters that varied with age or sex between different ethnic groups.[187] They recorded the following clusters across ethnic groups:

- Depression + one or more from among the other impact areas in the study excepting brain hyperexcitability. In our sample this was supported for White British, Arab and South Asian people but not African participants, weakly supported among North African participants, and partially supported among Central and East European participants.
- Heart failure + one or more from among: other cardiovascular issues, osteoarthritis, chronic kidney disease, type 2 diabetes, or chronic obstructive pulmonary disease. This was not found in the study, perhaps because heart failure is often fatal.

Participants were categorised by the condition impacting their life most significantly. Note that while we have grouped participants by impact in *Figure 21*, we have counted the number of conditions per participant rather than number of impact types per participant to construct the diagram.

Some differences could be explained by data collection year, but since the national prevalence of recorded disabilities has increased over the years of the study, this is unlikely. Methodological differences are more likely explanations, some of which transcend the quantitative–qualitative paradigms, as summarised in *Table 15*. Kuan's data set will have included people without significantly impacted ADL, while ours will have excluded these and also people who are most severely impacted. We included self-identified conditions not formally diagnosed, which differs from most studies including that of Kuan *et al.* but is important to identify contested and newly emergent conditions. In strand 3 we focused only on conditions impacting ADL.

Whereas Kuan *et al.* reported greater multimorbidity among white respondents, they noted this might be due to their more frequent consultations, preferential access to health care or bias in recording diagnostic codes, all structural inequalities that we are exploring. Our survey data also raise similar possibilities.

Corpus linguistics

In this section we do not include illustrative interview extracts, which are provided in subsequent chapters where comparable topics are explored in more depth. Questions we asked of comparisons were:

1. What are the most frequently used words in each?
2. Which words hold the greatest significance in each?
3. What topics tend to be favoured in each?
4. How do these appear in their actual context?

Overall keyword results will be published elsewhere. Summary data are provided in *Report Supplementary Material 2*. Note this is a comparative word frequency analysis so based on likelihood of talk on a topic, rather than its total presence/absence.

Community support was emphasised by all but South Asian interviewees, who were the most likely to live in diasporic communities with larger local family networks, reflected in the words they used about family. Talk of family members

TABLE 15 Differences between our qualitative data and those of Kuan *et al.*[187] (in the absence of any more comparable large qualitative data set). These show complementarity, and also the unique insights of our data set

Kuan *et al.*[187]	Pros (+) and cons (X)	CICADA qualitative strand	Pros (+) and cons (X)
Aimed for national representation.	+ National overview for planning.	Both quantitative and qualitative primary strands intentionally oversampled for our index groups, to provide insights in specific groups that complement national panel and cohort data sets.	+ Deeper understanding of issues. X Stopped sampling once a quota was reached, which means those slowest to respond will have been excluded (note that some quotas were not filled).
Data from electronic health records on the Clinical Practice Research Datalink linked with Hospital Episode Statistics 'admitted patient' care data set'	+ Large data set. + Retrospective study 2010–5; includes people who progressed in illness and died from their condition. X Potential over-representation of white people due to more frequent consultations, preferential access to health care or bias in recording of diagnostic codes. X Only includes people who have used these services.	Convenience (purposive) sampling.	+ Included migrants not registered in NHS data sets (e.g. the undocumented). X A self-selected sample. X Primary data collection methods likely mean the most disabled or sickest people could not contribute. X Cross-sectional interviews embedded within a longitudinal design of two follow-ups where some dropouts could conceivably have had heart failure (we obtained incomplete information on reasons for dropout); notably, some participants had myocardial infarction and other conditions clinically associated with heart failure but had not progressed to this at interview.
Excluded self-identified conditions that are not formally diagnosed.	X Means people with 'contested' or difficult-to-diagnose conditions were excluded.	Included self-identified conditions that are not formally diagnosed.	+ Included people with 'contested' or difficult-to-diagnose conditions.
Considered 308 health conditions.	X Not all health conditions are disabling, so this gives a picture only of diagnoses, not impact. This can lead to a watering-down of impact for the most disabled, and disablism in policy and practice.[91]	Only considered conditions impacting ADL rather than all conditions.	+ Gave insights into the experiences of those who most need to be targeted in policy and practice.

differed across groups. Central/East European and South Asian children supported participants practically, whereas White British people positioned themselves as carers of children. African and North African participants spoke of supportive wider relatives, practically and financially (though 'auntie' can simply mean an older person, in our sample this word was clearly used about relatives).

White British people more often described good living conditions and green environments. Compared with White British people, those from minoritised ethnic groups talked more about:

- Stress and anxiety, especially Central/East European people.
- Vaccinations, but Central/East European people were worried strangers were not vaccinated, White British people described being up to date with vaccination, African interviewees said it gave them confidence, and South Asian and Arab participants distrusted it and were particularly nervous to go outside and risk infection. African interviewees used traditional remedies to boost their immunities.
- Connecting technologies, though different groups used different media and in different ways. Central/East European participants often held online gatherings and used Facebook (Facebook, Inc., Menlo Park, CA, USA) groups, African participants networked via WhatsApp (Facebook, Inc., Menlo Park, CA, USA) and South Asian interviewees via Zoom.
- Language issues – mentioned most by Central/East European and South Asian participants.

- Racism and disablism – highlighted by African and North African participants, but not South Asian participants due to strong diasporic localities.
- COVID-19 containment measures (especially South Asian and North African participants).
- Waiting lists (except South Asian participants, who focused more on tests).
- Private healthcare cost (African and Arab participants).

Central/East European participants talked positively about relatively short waiting list times and stabilising medical conditions but negatively about remote health care and lack of funds for community support. Arab participants tended to use positive sentiments more than other groups. North African participants tended to be more positive than South Asian participants.

Considering disabilities, people with cancer talked the most about vaccines, perhaps because they are immunocompromised by treatment, and neurodivergent people talked least about being online, perhaps because they used the internet often pre pandemic, though these explanations are speculative. People with sensory loss or mental ill health talked the most expansively about other people, and people with cancer or dietary issues the least. Only the neurodivergent group focused on interactions in the home, and neurodivergent participants and those with mental health issues more often mentioned lockdowns.

Compared with men, women talked more about issues accessing health care, general practitioners (GPs) and mental health, suggesting – when considered with our other data – the day-to-day burden fell on them; men talked more about hospitals and vaccines and rarely used negative words, perhaps because the social norm is for them to appear strong.

Comparing sites, including Scotland and Wales, people in the Midlands and Yorkshire most often mentioned food, and in Yorkshire also shopping, while those in Newcastle most often mentioned giving as well as receiving support. People in Scotland and Wales talked about support least often. South-eastern respondents most often talked about phone calls (for medical care), and the remainder (excepting Manchester) online informal support. Those in Manchester and Yorkshire most often and those in the Midlands and south-east least often described vaccination. Negative words were most used in the Midlands and Yorkshire, and more positive words in Manchester and Newcastle. Those in the Midlands, Yorkshire and Scotland and Wales used more healthcare words, but ‘mental’ was mentioned least in Manchester and Newcastle, and ‘the government’ most in Midlands, Newcastle and Scotland and Wales. People in Manchester and Yorkshire most often mentioned the word ‘old’. Thus, there was considerable diversity across sites that may have partly reflected local demographics and service provision.[17]

The main difference we found between those with and without disabilities was that those with disabilities were more likely to focus on disability discrimination than racism.

Chapter 8 COVID-19 and government guidance and rules: interview findings

Understanding the analyses in Chapters 8–12

In *Chapters 8–11* we mostly report on the main interview data but include key informant data where useful and relevant to the same periods. To do so, we merged data on a theme-by-theme and category-by-category basis. Workshop data focusing on changes since the interviews are reported separately in *Chapter 12*.

In *Chapters 8–12*, we use the phrases 'some' or 'a few' when under 10 participants made a particular comment. Where helpful and representing 10 or more participants (e.g. 'several' or 'many'), we give specific percentages to indicate the weight of a theme. The phrase 'the majority' means over 50% and 'almost all' means at least 90%. However, it should be noted that to obtain these figures we counted participants who made any mention of each topic; as we used semistructured interviews, with the conversational flow directed by participants, lack of a mention cannot be taken as lack of an experience or perception. This is usual in this type of qualitative work, but it means that counts are indicative of theme importance rather than absolute. When we report 'x% of the core data set', this has the denominator 218; where we say 'x% of the (entire) data set' the denominator is 271.

We mostly, however, report participants with topic mentions as a proportion of one of the categories used. Thus 'x% of South Asian interviewees' has the denominator 93 since we recruited 93 South Asian participants. This approach corrects for category sample sizes, which is more in keeping with our intersectional approach to deconstructing categories as non-homogeneous; 8/93 and 8/271 have very different import. The former measure indicates how important a topic is for South Asian participants specifically, and the latter measure tells us the contribution to a topic made by South Asian people as a proportion of our ethnically mixed sample, without taking account of the bias to South Asian participants in our sampling. We did not do statistical tests on these data as this would be methodologically incorrect; the percentages we specify can only be taken as likely indications rather than precise measures.

Our themes in these chapters are descriptive and largely developed top-down. We provide our basic coding frame in *Appendix 7*. Each chapter considers a particular frame, and the – largely descriptive – subheadings have been developed from the frames by reading separate codes to look for patterns in the data. We intend to publish more conceptual analyses subsequently.

Several participants were carers as well as needing care, and some illustrative extracts refer to this.

A health crisis

In early 2020, a few participants had doubted the pandemic was genuine: 'At first I thought it was a political move from the government to gain profits or to control people' (P25, North African). A few others considered it 'a punishment from God' (P192, South Asian). Some framed it as a plot to kill people from minoritised ethnic groups: 'I was hesitant very much knowing that of course this is a new thing. We don't know what this means, this means they are creating the virus to kill people' (P62, Central/East European). Overall, however, as the pandemic developed, most recognised it as a developing public health crisis which required compliance with public health guidance. Often participants followed this in extremis, fearing COVID-19 infection, due to acknowledged vulnerabilities associated with both health and ethnicity. Many drew additional strength from spirituality. Twenty [19 (8.23%) core participants and one of mixed race] sought alternative or additional protection from traditional home remedies, represented across all core minoritised ethnic groups but proportionately most common among African (16.67%) and undocumented (30%) participants.

The majority who expressed an opinion about the government ended up criticising it, especially the White British (no positive comments), Central/East European, non-core ethnic group and South Asian participants and those with multimorbidity or mobility issues (with 5.50, 5.00, 2.67, 3.56 and 3.25 times as many anti- as pro-government comments, respectively). Critics said the government waited too long to act, did not respond to scientific advice, had inconsistent messaging, and eventually also that it broke its own rules. Lack of trust in the government was a significant obstacle to mobilising public COVID containment behaviours in the broader population, leading to 'solution aversion'.[188] This increased anxiety for participants, especially those on the CEV list. Anxiety escalated when the country opened up mid-2021, with CEV participants worried about encountering infected others on public transport and about family members picking up infection.

A few across ethnic categories complained the government was designing policies for the mainstream population and excluding migrants, who could not necessarily follow the rules because of poor accommodation or economic precarity. There was a common reticence to give personal data in restaurants and shops, which was temporarily mandated for track and trace, because of fear as to what the government would do with the data. This was evident irrespective of citizenship or socioeconomic status.

> *The issues people of colour have with police and accessing services, I have not had to deal with. So it comes from the privilege an upper middle-class background [. . .] [After COVID] there have been times when police had stopped . . . an amount of terror. And because you are brown, and you hear the stories . . . even if you have not faced it before, the fear still exists . . . When you had to give your details at restaurants or cafes, it felt very much like surveillance. As someone who doesn't trust the authorities, because of where I come from, I did not believe the details would just be used for track and trace*
>
> *P67, South Asian, mental health*

Shielding and social distancing

A few participants found benefits from shielding and social distancing: one with asthma welcomed reduced exposure to pollution, while some neurodivergent participants and one with schizophrenia appreciated a more controlled personal space and reduced distractions and social interaction. These findings cannot be extrapolated to all people with these conditions.

Many shielded even if not CEV, which isolated those living alone. Local and global social distancing measures also kept participants away from faith gatherings, and physically separated friends and family, including families living in a participant's country of origin:

> *My parents normally would come, which is linked to ethnicity or culture, for a couple of months in the summer every year, so they didn't do that, so that was different . . . so that was a loss for us not to have them home.*
>
> *P16, South Asian, stamina/mental health*

Loneliness was stated by approximately 17% of core participants. It was especially reported by Arab (34.78%), Central/East European (22.22%) and African (20.00%) participants, who tended to live in areas with low densities of people of similar heritage, and White British (20.00%) interviewees, despite South Asian participants explaining they strongly felt the loss of their previously frequent community interactions. The loneliest by disability category had mental health, sensorial and cancer issues, neurodivergence, and multimorbidities (31.58%, 40.00%, 21.43%, 20.00% and 23.08%, respectively); in other words, they belonged to groups that may already have felt lonely pre pandemic. The high rate among some neurodivergent participants, when juxtaposed with comments from some others from this group who welcomed staying at home, emphasises the dangers of over-generalising without considering heterogeneities and intersectionalities. Those with no disabilities or with migraines/epilepsy were the least lonely (5% and 9.09%, respectively). Considering location, participants were least lonely in the Midlands (where recruitment was more scattered across rural areas) and the south-east. This is an unexpected finding.

Eleven (4.06%) participants (seven of whom had prior mental health issues) said the pandemic had made them suicidal. Proportionately more lived in the south-east (14.29%) and were White British or from non-core ethnic groups, with a few more from South Asia and one Arab (with no disabilities). Seven (2.58%, from seven different ethnic groups), spread across London, Newcastle and the south-east, had turned to alcohol to cope with the pandemic, of whom four had prior mental health issues.

The pandemic could also create stress when people lived with others, especially in multigenerational households, because of the burden placed on others to avoid contracting the virus.[189] Stress from inadequate housing and domestic violence are considered in *Chapter 9*. The health and social care of the 66 participants with clinically diagnosed mental ill health is described in *Chapter 10*.

> *I stayed mostly in my room from the beginning as I have teenage grandchildren who don't listen, keep going in and out the house. You know what boys are like, they have their own mind! My son said it was causing arguments and I'd be safer staying in my room.*
>
> *P167, South Asian, arthritis*

Mask-wearing and sanitising

Mask-wearing issues were common across ethnic groups (mean 19.48%, range 10.00–30.00%) though least for White British, Central/East European and African participants. Muslims lacked suitable masks to wear with headscarves, an issue especially noted by those from Yorkshire.

Mask issues were common across all but the food-relevant and sensorial disability groups (with a disabilities mean of 19.59%) but particularly reported by those with dexterity issues, brain hyperexcitability or cancer. Hand or arm amputation or cerebral palsy with associated sialorrhea (excessive salivation) made putting on a mask a challenge.

> *Since I have one hand, I first hang it on my first ear either the left or the right then using the hand I put it on the next ear but in places where it's open and the wind blows it might be a challenge because now if you put it on the left ear and the wind blows you see the mask will be blown off.*
>
> *P52, North African, amputee*

A few participants said they discarded the masks when sweating in the hot summer of 2020. Several with mental health issues said they often forgot their masks. Most with respiratory conditions said masks left them feeling unable to breathe or 'suffocating'. While some reflected on the dispensation given to disabled people to not wear a mask, many instead withdrew contact with others, increasing their isolation.

Hand or arm amputation or sight impairment made sanitising or handwashing an additional challenge outside the home, increasing risk of infection.

> *I'm single-handed. I do wash my hand, but you know when you get [in the] workplace, people expect you to wash your hands like other people wash hands, but the company doesn't have the equipment for people like me. So, it becomes quite a problem.*
>
> *P90, South Asian, amputee*

> *There are many places I have to touch [. . .] a door or gate, they have the numbers to type and enter [. . .] It's a bus, or a bus stop, or something we just have to touch. We rely on touch. It means everywhere you have to sanitise, and you can't sanitise every second.*
>
> *P5, South Asian, blind*

COVID-19 vaccination

Most participants reported having had or being about to have the COVID-19 vaccine. This helped reduce fear, conferring confidence and freedom, as 'a protective shield', particularly in the light of personal vulnerabilities, and hence positively influenced mental health. The decision-making process, however, was complex, as predicted by the 5C[131] model. Most who chose the COVID-19 vaccine did so anxiously, influenced by the different concepts across the 5C model, as part of their decision-making process, 'weighing up', 'debating' and 'deliberating' the options. The following account is structured by the 5C model (see *Chapter 3*, *Figure 4*).

Calculation

Eleven participants across several ethnic groups (but proportionately most commonly Central/East European and mixed race participants) and with and without disabilities, described actively researching vaccines, for example via the internet. Trusted formal sources of information also positively influenced vaccine uptake, for example, community private 'family doctors', faith leaders, a trusted NHS GP:

> *There was so much misinformation . . . in the Pakistani community rumours were being spread that they [vaccines] were not halal, but the imams from the mosque did radio talks on the community channel, that there was no harm in them, and they were permissible.*
>
> *P194, South Asian*

Ten mixed race, South Asian and Central/East European participants with various disabilities explicitly reported insufficient information from the NHS. However, it was clear from people's fears that the need for better information was far more pervasive. This included scientific information about vaccine types, evidence of benefit, and risks of interaction with different conditions. The mass media confounded this issue by creating confusion and highlighting risk factors.

> *I was worried, especially 'cos I'm 30 years old [. . .] I was really scared 'cos I wanted to get a vaccine but on the other hand [. . .] after hearing the news about blood clots*
>
> *P23, mixed race*

Excepting the White British and Southern European participants, who took the vaccine when first offered, and those who undertook research, many looked to the community, neighbours, family and friends for evidence the vaccine was safe, waiting to see what others did and how they fared. Across minoritised ethnic groups, a few talked about their communities being guinea pigs or that people not born in the UK got different vaccines. This was most common within the Arab (30.43%) and least common among the Central/East European (3.70%), groups among the core ethnicities, not discussed by our white participants and only mentioned by mixed race (11%) participants among our non-core ethnic groups.

> *I was a bit anxious because I didn't, obviously didn't, want to be guinea pigs. And there was talk of testing it on BAME [sic] first to see if it worked.*
>
> *P3, South Asian*

Some, especially African participants (10%) referred rather to others in their communities who spread misinformation they reported not falling for. Those who got vaccinated did so against the backdrop of these circulating beliefs:

> *As science shows, vaccinations are good, so I'm pro-vaccinations but I understand that if you start to read about things people say, you can get anxious about stuff . . . when you read statistics and stuff like that.*
>
> *P185, Central/East European, mental health*

Confidence

Fear of side effects was reported by 44 participants across ethnic groups as one of the most significant factors affecting vaccine uptake, despite the vaccine having been available for many months by the time of the interviews. This affected a mean of 18.18% and a range of 11.11–30.43% of participants across all the core minoritised ethnic groups (particularly those from Arab or North African groups), 5% of White British and 11.11% of South European participants. Additionally, a fear of blood clots was specified by seven people (three from Central/East Europe with mental health issues), while many others said they experienced clotting as a side effect. Fear of side effects cut across all disability types except dexterity, with a mean of 15.10%. People with diabetes in the food-relevant category (22.22% fearing side effects) may ironically have been affected by reports that COVID-19 infection triggered diabetes.[190] A proportion (16.67%) of those not disabled by their condition and 26.92% of those with no impairment or chronic health condition were concerned the vaccine would tip them into dependency. A few participants (one each from South Asia, Central/East Europe, North Africa and Africa) with diabetes, mobility issues, cancer or multimorbidity demonstrated an intersection between disability, living alone or in poverty, and ethnicity. They feared side effects would worsen their condition or incapacitate them and so prevent their being able to look after themselves financially or practically (as also found by Baz *et al.*[61]). We have placed this concern within the 'confidence' theme of the 5C model since it relates to trust, but it also links with the 'intersecting factors' theme identified in our systematic review in relation to constraints (see *Chapter 3*).

A few across all ethnicity and disability categories were concerned the vaccines had been developed too quickly, lacked trust in the government, and declared uncertainty about the effectiveness of the vaccine.

Many White British participants, like many others, struggled with side effects post vaccination, but pre vaccination they did not fear side effects, and unlike the minoritised ethnic groups they did not express distrust in vaccination in general.

Complacency

Undocumented and Central/East European participants and those with sensorial impairments, mental ill health or neurodivergence were more likely to not have had the vaccine at the time of interview (35 participants), concerned that the vaccines would not be effective enough to justify the risks. Only one, interviewed after December 2021, from Central Europe, who had had COVID-19, was adamantly against the vaccine; they had no disabilities or health conditions and considered it had minimal benefits. A few who had had COVID-19 said this had not influenced their decision either way.

Collective responsibility

COVID-19 deaths in relatives and friends did not appear to consistently affect decisions to vaccinate. Only four from South Asia were mainly motivated by a social responsibility to the community.

Constraints

A few across all the core minoritised ethnic groups showed a preference for natural remedies and spirituality rather than vaccination. Personal beliefs about biomedicine, personal circumstances, such as whether support was present at home, and personal self-efficacy to disregard social pressures and misinformation, all influenced vaccination decisions.

A few South Asian and North African male participants said they made the vaccination decision for their family. A few others described being expected to follow the decision of the head of the family, which could conflict with their own.

> *So, first vaccine, my parents were completely 'no' and said you shouldn't have it. They were refusing to even support me to have it. So, I had to find my own way to [the centre] to receive vaccine and get back. I was frozen stiff, because I had to wait outside the vaccine centre for a taxi.*
>
> *P6, South Asian, autism*

Eleven per cent of Central/East European and mixed race participants complained that personal choice had been removed. Twenty participants (most notably 22.22% of the Central/East Europeans) had to take the vaccine to travel or work, and a few across the minoritised ethnic groups said they took it so they could receive medical care or socialise without worrying about COVID-19. Undocumented migrants and asylum seekers worried interaction with health care and government vaccination programmes would lead to deportation.

Once the decision to vaccinate was made, a few spoke of the inconvenience, with geographical constraints intersecting with disability (particularly mobility issues), economic precarity or carer need. This complicated both transport and queuing; issues around social distancing were also mentioned by a few.

> *[It is difficult] getting to the vaccination. I hate to use public transport. You must wait in the line for long – standing alone is difficult for me.*
>
> *P150, African, respiratory*

A few deaf, autistic or intellectually disabled participants found it difficult to communicate with centre staff, including the rare situation when they became anxious at the vaccination centre. Language issues were not mentioned specifically in relation to vaccination.

> *There was a bit of a palaver because they said you don't look well. I said no I'm autistic – I'm fine [. . .] it was just that I'm not good with needles.*
>
> *P9, South Asian, autism*

Other individual comments were that it was hard to book online, and culturally problematic to have to expose your upper arm. Good practices, such as home visits and careful infection containment at centres, were also described. Nonetheless, participants often appeared unaware of special adjustments some centres made for disability, or their extent. Our data suggest a need for several improvements:

- Support for neurodivergent individuals who wanted the vaccine but found the process daunting even though the government introduced a policy of streamlining them through vaccine centres.
- Practical support for those unable to stand at all or for long; some chairs were available in centres but not in the queues.
- Appointments for the clinically vulnerable, where the density of other patients was limited to reduce infection risk; not everyone could get home visits from nursing staff (though this was appreciated when available) and pharmacies and GPs as options were often busy.
- Provision for carers to stay with individuals; the government made an exception for formal but not informal carers.

Chapter 9 Adversity experiences: interview findings

The COVID-19 pandemic had substantial and unequal effects for our participants, exacerbated by macro-level social security policy and the national economic situation. Lower socioeconomic status was a key factor influencing coping, being a structural issue underlying other adversities. While this is an assets-based study, the adversities people experienced must be understood to contextualise coping strategies; in this chapter we consider those listed in *Table 16*.

Accommodation

In the UK, less-affluent urban neighbourhoods frequently contain more multiple-occupancy homes, higher population densities, and limited access to outdoor space.[18] These factors are linked to unfavourable health outcomes generally;[18] and for COVID-19, with individuals unable to self-isolate with COVID-19 infection, whole households could succumb, limiting their access to food and medication (see below).

Participants with mobility and stamina issues spoke the most about constrained physical activity, either inside or outside the home, partly because of their condition, partly because of shielding. This intersected with cramped housing conditions to reduce well-being. Poor living conditions and 24-hour proximity to family (see also *Domestic violence and threats to personal safety* below) added to people's stress.

> *[Normally] I can sit there [outside], I can go out, and try and do those little things myself and have that ability of control. So, you know, housing does play a big part of that because if I don't have access to that then I'm limited. But like I said, the lockdown I had to literally stay indoors, so I didn't get that.*
>
> *P203, South Asian, mobility/stamina/cognitive*

> *I was super stressed about everything. I was anxious about COVID [. . .] I was anxious going outside, but then staying at home also made me more anxious because I'm stuck inside with the same people. It's like a lose situation on both sides.*
>
> *P43, South Asian, mental health/respiratory*

Income and employment

Our data highlight the severe economic effects of lockdowns and pandemic job loss or a reduction in work hours (see also Baz *et al.*[61]), for example where a business closed down, or people on zero-hour contracts had less work. Most participants or their family members lost their jobs or had their hours reduced; they often worked in the hospitality or other industries severely impacted by the pandemic. A major social stressor,[192] this affected living standards and access to quality healthcare services, especially when participants paid for this, as well as family dynamics when the

TABLE 16 Adversity categories, amended from Wright *et al.*[191]

Type of adversity	Adversity experience
Poor accommodation	Living in cramped, poorly maintained spaces
Financial difficulty	A major cut in household income
Loss of paid work	Lost job or cannot do paid work
Poor diet	Cannot access sufficient or appropriate food
Uncontrolled illness	Cannot access required medication
COVID-19 illness	Currently or previously suspected or diagnosed COVID-19
Threats to personal safety	Experienced abuse

breadwinner became unemployed. This has particular significance for migrants on family visas and undocumented migrants (who could not work legally and had no recourse to public funds; see also Finlay *et al.*[38]).

> *I was anxious of what was going to happen and if I could remain in the country. I coped because my wife was also working so she chipped in and covered for me.*
>
> *P143, South Asian*

> *So, whereas they've [migrants] been working and many have been working very hard, working for perhaps two jobs or three jobs to support themselves and their families, and all of that ended in the pandemic. And then for that large group who had no recourse to public funds, they couldn't get any income from work, and they couldn't get any income from Social Security either. So, they were completely stuck.*
>
> *Politician informant*

Fears of COVID-19 infection limited the activities of several participants who ran their own business. Those with shops but no online outlets were compromised by lockdowns and reduced footfall.

> *But lack of business created pressure – I didn't have an online platform while competitors started trading online. There was a lot of stock in the shop which wasn't selling, which was a pressure, especially as others were making it work.*
>
> *P16, South Asian, stamina/mental health*

A few across core ethnic groups, all with mobility or dexterity issues (three due to lost arms or legs), said their vulnerability and general health were major factors in employers' decisions. Others had to resign because of the risks. Some were taken back later in the pandemic, for example when vaccines became available.

> *I couldn't go on with the job because it was a high risk for me. Like being exposed*
>
> *P120, South Asian, cancer*

> *Yes. I work as a delivery man. So, during the pandemic, we had to be stopped from our job for some period of time, since movement was restricted [. . .] those people who are, their health was good, they continued with their work.*
>
> *P145, Arab, mobility/anxiety*

> *During the pandemic so many people have really suffered because of the number of hours we used to work reduced to something like two hours to three hours only, but before then we were working like eight hours, you know. This was bad for me financially. Then later the manager asked me to stay at home due to my vulnerability.*
>
> *P90, South Asian, mobility*

Some people allowed to work from home felt a benefit even with reduced hours:

> *With regards to my fibromyalgia and everything and the fact that I can now work from home, that really helps [. . .] there's flexibility [. . .] So it's like when I'm feeling this wiped-out, to be able to just freshen up in the morning and just sit at home on my laptop and work, it just helps me recover as well because I'm not using additional energy to basically travel into work.*
>
> *P205, South Asian, mobility*

A few who lost their jobs found new jobs, some did casual work, and some, across core ethnic groups, used entrepreneurial skills to set up their own business. Others found the job market competitive and felt disadvantaged racially or health-wise.

> *I was sacked and started a new business, so I've been running my business for like four to five months there. I am a trader, I sell electronic devices, TVs and radios and all that.*
>
> *P250, African, depression*

Access to food

Most, but not all, participants across groups struggled to access appropriate food, aligning with national survey data which showed 60% of disabled people could not access essential supplies, including food, in the early months of the pandemic.[193] Many needed special diets, without which existing conditions and symptoms were exacerbated, laying the path to longer-term problems.

> *Lack of food was difficult because of disorder so worried about there being enough food. There wasn't enough food for me to keep eating.*
>
> *P93, African, eating disorder*

> *Quality of food was affected, meat and fresh vegetables and fruits, I have vitamin D deficiency now.*
>
> *P87, North African, mobility/sensorial*

In-person shopping

In-person shopping was complicated by fear of COVID-19, being CEV or having to self-isolate with COVID-19. Many spoke about queues ('I think the change was having to queue outside the supermarkets', P247) and long waits, caused by social distancing inside shops and constraints on the number allowed inside at once. A few said they used the early-morning slots supermarkets dedicated to disabled people, older people and key workers. However, people could not use these if they had companion or guide dogs, or if they needed:

- support to get up, washed and dressed
- medical technologies such as feeding tubes or oxygen tanks
- assistance with mobility or transport
- manipulation therapy for musculoskeletal problems to move.

These lengthened the time needed to leave the house and made them dependent on assistance.[194]

A blind participant felt a social pariah because feeling his way around shelves made other shoppers worry he was spreading COVID-19. For minoritised ethnic groups, especially the undocumented, police presence and check and trace measures provided further stress.

> *There was police in front of the supermarket just to make sure that the queues were okay. I spent the next 20 minutes talking myself out of a panic attack because there was police there and I didn't know what to do, and I didn't know whether or not I was actually going to get told off, whether I was going to get arrested because they were just arresting people left, right and centre, because no one was sure what they were actually meant to be doing. It was chaotic.*
>
> *P276, Central/East European*

Panic and bulk buys

Some people without disabilities said they bulk-bought, mostly to reduce the frequency of shopping trips, and for money savings. However, one acknowledged this required good finances while others with disabilities and fewer resources talked about not being able to stockpile. Panic-buying by others, emptying shelves, was more than an inconvenience for those requiring special diets; it could lead to deteriorating health.

> *Because there was only three of us and no car, there was absolutely no chance that we would be hauling 30 boxes of milk from Tesco to here. That was not happening.*
>
> *P276, Central/East European, autistic/depression*

> *You know these selfish people that went out and bought everything so nobody else [. . .] Pretty much anybody that I could try and get to go and get stuff couldn't get half the stuff that I actually needed.*
>
> *P227, White British, stamina/depression*

Costs

Rising costs combined with pandemic-related financial issues further limited diets. Some replaced fresh foods with nutritional supplements. Two described how supply and demand patterns were exploited by local small businesses.

> *Because of my low finances [. . .] even though I know diet is a major way of helping me, but I couldn't choose what I need or what I want to eat. I just decided to throw caution to the air during the pandemic and just survive.*
>
> *P264, Arab, cancer*

> *Shopping-wise people went mad and started buying toilet paper and chapatti bags ran out, then prices were put up by Asian shopkeepers, a large sack of flour used to cost £12 went up to £20.*
>
> *P190, South Asian, multimorbidity*

Formal support: government parcels and community food banks

To enable CEV people to access food during lockdowns and shielding, the government worked with national food distributors, local authorities and local voluntary groups to establish a national service of free, weekly, standardised food box deliveries, often described by participants as coming from 'the council'. CEV people had to sign up for this via the gov.uk website. Those with food insecurity could also get free food and basic items from non-profit organisations called food banks. Mostly these distribute food donated by members of the public using volunteers. In London, participants said Tower Hamlets council also provided hot meals at community centres. Two participants volunteered at a food bank and were given free food in return. The UK has over 2500 food banks; over 1170 are run independently, including in schools (described by several participants), universities, hospitals, and Salvation Army centres, with the remainder run by the Trussell Trust, a Christian organisation. The Food Standards Agency ran a monthly COVID-19 consumer tracker for 19 months, showing 8% of respondents used a food bank or food charity in April 2020, and 11% in October 2021. In May 2021 the figure was 2.5% of all UK households.[195]

> *Only support I'd say we received is – I think we had four different food bank type places support us initially. So, when my dad was alive, we had the government shielding boxes that turned up to our house once a week. I mean they were okay, but they were quite basic. Almost like you live in World War II or something. But we were very thankful and grateful for the food banks and the charities that helped with food and drink, and stuff.*
>
> *P7, South Asian, multimorbidity*

Our politician informant commended as considerable assets the local food bank, church and mosque food initiatives, as a testament to the power of local organisations and communities coming together to help those in need. He suggested rural communities would have fewer resources and condemned national policy linked to crisis food bank use, especially for undocumented migrants. Community support from local charities, religious institutions and community groups could be particularly important in rural areas where shops might be at a distance or not deliver. But offers of help were not always accepted by participants fearful of catching COVID-19 from others, and some who might have been eligible were unaware of these services.

As demand increased, so did caps on use; consequently, one person said they were helped to move from food bank to food bank. The demand also meant food banks could run out of supplies. One participant argued for a food bank triage system to ensure the neediest get food, including whole households with COVID-19.

> *We called a few food banks. But I didn't get a good response from them, they said, 'We are very busy.' Because it's for aged people, old people who are living in a care home or something and they are very busy with them [. . .] they need to do the assessment or something of the family structure [. . .] So they need to prioritise the vulnerable, the second category, whole family. If the whole family isolate, how are they going to do shopping?*
>
> *P216, South Asian, food-relevant*

Some had issues with food parcel deliveries because of their disabilities, for example, answering the door in time, or carrying them from the ground floor of blocks of flats, or because of maintenance issues such as lifts or entrance gates not working.

Informal support

Friends, family, neighbours, carers and even colleagues shopped for participants or topped up essentials from their own stocks, irrespective of formal support, or cooked them meals, for example when participants had deteriorating health or COVID-19 ('They'd just leave it outside and I take it in', P221). Sometimes this support broke down, when informal supporters were too scared of COVID-19, were also vulnerable or struggling, were too busy, or were anxious they could transmit COVID-19 to the participant. A few across ethnic groups, because of their disability, went to live with their parents, citing food as the reason:

> *The pandemic was a burden to me because I'm paralysed. I can't walk and I have a kid also. I had lack of food. I didn't have anything to eat during the lockdown. My kids didn't have anything to eat so we went to my parents' house. Food was the main problem.*
>
> *P34, North African, mobility*

> *But four people are COVID positive, we can't go outside. And we needed food. So I had to call one of my neighbours to give some milk and some things. And some other neighbours also gave some food.*
>
> *P216, South Asian, food-relevant*

Participants often communicated with their support networks by phone call or text to avoid COVID-19 infection. One Bangladeshi woman in London organised a residential group that optimised support between people on the same housing estate:

> *It was like 'Is anyone going to Iceland today if you are can you pick me up this?' And if you lived on the same block and you were going past the person's house, you'd just leave it on their doorway and just drop it off.*
>
> *P222, South Asian, brain hyperexcitability*

Online shopping

The various challenges meant participants – with few exceptions – moved to online shopping. Nationally a May 2021 poll found the number of disabled people shopping online increased by 20% in the pandemic;[194] proportionately more of our sample did so. Some so liked the benefits that they continued once others returned to in-person shopping.

However, early in the pandemic, online shopping was characterised by websites crashing or long waits (of hours at times) just to get onto the site. Participants competed with the general public for supermarket slots, leading to a version of panic-buying in which participants booked any free slots just in case they could not get another for weeks. A few benefitted from being on the CEV list but this excluded others at high risk, including people in the process of being diagnosed. Some vulnerable participants who had been online shopping for years were suddenly cut out. Eventually charities got the lists expanded to other disabilities, but participants spoke about the difficulties before this.

A few participants complained of receiving inappropriate substitutions for missing items – early in the pandemic this could mean most things because of stock issues – compromising dietary needs. A few had problems meeting the minimum spend, which could be higher than their weekly shopping budget. Some found online shopping technologically challenging or the process overwhelming 'like going through a maze, I find it really difficult so that was something quite hard to manage' (P207, South Asian, mental health), which made them dependent on others. This could result from non-familiarity with the process, inaccessible websites, the poor emulation of in-person shopping and the person's impairment all intersecting. Conversely, online shopping facilitated several people helping others, ordering for them, or buying extras in their own shopping to give to friends and neighbours in need.

> *I'm not good with technology. So I can't order online. I have to rely on other people to order for me. And that will take ages. And also, it will not be 100% sure that I'll be getting the same stuff.*
>
> *P5, South Asian, sensorial/brain hyperexcitability*

> *The pensioner she needed help. So what I would do sometimes when I would get my Amazon Fresh delivery or my Iceland shop, I would get something for her as well, like toiletries and tissue paper, fruit and vegetables. And I would put it in the*

> *bag and then leave it outside her door, ring the doorbell and then just tell her from outside that that bag was for her. So I did that for a couple of months.*
>
> *P211, South Asian, food-relevant/mental health*

Cultural needs

A few participants said pandemic restrictions or infection fears stopped their accessing shops with culturally relevant ingredients or halal foods ('the options were limited to cook our traditional food', P68, North African).

> *It's a very very very long time now to enjoy even cooking while eating not enjoying at all. There are only few shops that sell Indian food like pulses, flour, etc. I haven't been there since the pandemic started and it's unfortunate many Asian people don't believe in taking the vaccine and that is why we hear the virus is spreading quite a lot. So I don't go to that side of town. So no variety for me, we are just surviving on what I get at the supermarket.*
>
> *P12, South Asian*

The standardised government food boxes included coffee, tea bags, biscuits, bread, cereal, tinned vegetables, potatoes, long-life milk, tinned protein (fish, meat excluding pork), fresh fruit, pasta sauce, pasta, and rice (as well as toilet tissue, hand soap or shower gel). These were predominantly foods not normally eaten by our participants, sometimes causing cultural and sometimes religious issues.

> *A lot of the food banks they don't really care about your ethnicity. They don't care about your religion, your culture, the dietary needs. So, it's hard because we're a Muslim Bengali family and they give you stuff in tins, and obviously we were grateful that they were giving us food but at the same time my mum and dad used to get really upset because they would give us the wrong food. Or they'd give us non-halal meat. And they'd give us animal products, and things that we couldn't use or eat that had to be disposed of. So, it was quite stressful because it caused a lot of tension in our house [. . .] My family, my mum and dad, they eat rice and curry. That's their main food, their staple food.*
>
> *P7, South Asian, multimorbidity*

Food banks were more variable than food parcels, hence some did supply culturally appropriate foods, especially if linked to a local community group. This was reported in two areas where there was a large South Asian diaspora: Bradford (Yorkshire) and Tower Hamlets (London).

Access to pharmaceuticals

Few participants had issues getting medication. Several collected it from a pharmacist, sent a friend or relative, or went without temporarily. A few sourced medications abroad (see *Chapter 10*). Many got medication delivered; those on repeat prescriptions were used to this from before the pandemic, others learnt the process, then switched permanently to it, but a few were unaware they were eligible. Sometimes delivery errors damaged participant trust but were also ascribed to difficulties with online ordering. Occasionally brand or packaging changes caused confusion; in person, a pharmacist could have clarified changes at point of collection. Several said supply and transport issues sometimes caused delays and shortages, specifying asthma inhalers, pain medication and insulin.

> *Sometimes [my auntie] would just go and come back empty-handed, so, I would just survive by limiting my feeding habits and just being cautious of what I took.*
>
> *P75, African, food-relevant*

Several said their medication – and the cost of transport to get it – strained their finances. Several said their GP had changed repeat prescription ordering, in variable ways. Phoning the GP instead of going in person was seen as a positive change; filling in an e-form instead of e-mailing was viewed negatively.

Experiences of COVID-19 infection and its impact

Exposure to COVID-related bereavement (partners, friends and parents) and its associated impact was described by only 17 participants, from South Asia, Africa and North Africa. This included distant loved ones contracting the virus in countries of birth, where COVID-19 may have been less successfully contained or treated than in the UK. Nonetheless, a majority across the core minoritised ethnic groups made more general reference to COVID-19 vulnerabilities associated with ethnicity in their interviews.

The impact of close deaths was compounded by their sudden, unexpected nature, with people unable to be with their loved one when they died, say goodbye, or attend funerals, an important rite of passage, because of travel restrictions or caps on the number allowed to congregate. Social distancing rules also meant they could not seek comfort with friends and family. One African participant reported being barred by her church from the funerals of close family members for her own safety due to her disability. This left people feeling guilty, depressed, anxious, and lonely. The Pakistani participant below explained that telephone conversations are no substitute; for Muslims, as in many religions, community interaction and shared mourning are important.[196]

> *So many people in our community (Baradari) passed away. We could not pay our respects to their family or do the burial prayer (Janazah). It was really hard to deal with because the Pakistani community supports each other when there is a death in the family.*
>
> *P176, South Asian*

Death of the family breadwinner was specified in a few cases and created severe financial hardship for families with limited or no access to social support funds. People who contracted COVID-19 sometimes were reticent to tell others, to minimise anxiety in precarity.

> *What was hard was accepting that I had contracted the virus and telling it to my people [. . .] knowing it will stress them. Maybe they think I'm going to die, [that] I'm going to leave them. I'm the sole provider of my family, so it was a little bit difficult telling them.*
>
> *P145, North African*

Some described not being taken seriously. One participant explained this resulted from myths about COVID-19, but one undocumented female said: 'the hard thing was to tell my family. They didn't really care about it. I have to do a lot to convince family members. This was upsetting but they hardly listen to ladies in my culture' (P66, Undocumented). She received no care or support and resorted to prayer.

Domestic violence and threats to personal safety

The rise in domestic violence against women during the pandemic[197] was reflected in a few accounts. Many migrant women who lack legal status or have no access to public funds remain with or reliant on domestic violence perpetrators, lacking other options.[198,199]

> *My husband has a lot of behavioural issues and threw something at me. He's hitting my carer. So, then I had to report it and then they put me on MARAC [multiagency risk assessment conference] [. . .] and I had to say no, that's his autism. That's him asking for help, getting the emotional, psychological support [. . .]. But they want to call the police on them, or they want to put my case to MARAC. But I don't get any outcome. So, not a very good experience.*
>
> *P64, South Asian, multimorbidity*

Chapter 10 Access to health and social care: interview findings

Our data show overwhelming dissatisfaction with health and social care, but 23% of participants praised at least some aspects. Often this was a recognition of professionals doing their best under the circumstances. But some received almost normal care during the pandemic, because their condition required it or because of the dedication of individual GPs or the particular structure and ownership of the local primary care hub. These satisfaction data should be borne in mind when considering subsequent sections.

The move to remote care

The NHS move to greater use of remote consultations was accelerated by the COVID-19 pandemic to minimise infection risks for staff and patients. In England face-to-face GP appointments formed just under 80% of all consultations in March 2020 and 46% in March 2021, with similar trends in the devolved nations.[200] Most were replaced by telehealth (telephone, text messaging, photographs), despite NHS England's promotion of video consultations.[201] Digital triage systems were also implemented, for example, e-Consult.[200]

The benefits

The changes were mostly criticised by participants, but a few reported advantages, though getting used to remote care took time. It obviated the need for anxiety-inducing social interaction or travel logistics for some with neurodivergence, mental health conditions, fatigue or mobility issues or caring responsibilities, or those who simply were afraid of COVID-19 infection (see also *Chapter 8*). Some liked its time-efficiency (a point confirmed more generally in the literature[202]), and that going to the doctor's or the clinic did not require time off work or day patient attendance. Some found the consultation style conducive to discussions of intimate need (but see later in this chapter for alternative perspectives). Others liked the NHS app as a paperless system holding all test results in one place. These benefits were felt across the ethnic groups.

> *So even when I had some eye problems as well, I call the hospital. They did a video call [. . .] I clicked the photo and sent over the WhatsApp. And I was happy. And it was safe that I didn't have to go to the hospital with my kids [. . .] So yeah, it was good. It was done. Like they told me the solution.*
>
> *P10, South Asian, multimorbidity*

> *I'm less emotive than when I'm talking to somebody face to face. It gives me a chance to consider what I'm really trying to give over [. . .]. It's just a different way of getting the same result.*
>
> *P229, White British, stamina*

> *It's something you can be flexible with you can do it anytime I'm anywhere. So you can even be at job, you don't have to go to the doctor, and you just do an appointment with him over the phone maybe.*
>
> *P264, Arab, cancer*

> *The last [blood tests] I had the other week was at the London. So he does it all on the system, you haven't got to walk along there with a bit of paper. So I just turned up, took a seat and waited.*
>
> *P228, White British, fatigue/mobility*

> *My unit gave me remote support. My nurse called and sometimes if I needed physical support – like video calls for meals that would be provided [. . .] otherwise, I would have had to have gone in as a day patient.*
>
> *P9, South Asian, food-relevant/cognitive*

Our GP key informant also saw efficiency benefits from a hybrid of face-to-face and telehealth work for patients and his own time management ('You can move your calls around between those face-to-face patients') but noted he was influenced by the relatively young age profile of his catchment.

> *A lot of people prefer to be on the phone because it's just easier to work around in normal day-to-day life. They could be in Sainsbury's waiting for you to call them or taking their kid to school or something. They don't want to be in the surgery. More often are people kind of annoyed that I want them to come in, than are relieved. We just bring them in for a quick examination if we haven't got what we need to from their history.*
>
> *GP informant*

Making appointments

Phoning the general practitioner

Across all groups, 12% of our core sample reported difficulties making GP appointments. The main frustrations were:

1. the volume of calls to the GP practice being unmatched by practice staff capacity
2. gatekeeping by receptionists, once they answered the phone
3. technological issues (irrespective of digital literacy and digital poverty).

> *They probably weren't working at the GP surgery, people were probably working from home on a phone line. And when they called, the calls wouldn't come through to my mobile, it would just go straight to voicemail. [Author comment: iPhones can be set to do this for unknown numbers].*
>
> *P206, South Asian, food-relevant/respiratory*

> *It's been so bad that I couldn't get an appointment with my GP because the lines open at eight and you call at eight o'clock you're number 29. And by the time they get to you, because you've been on the line for so long the line cuts off automatically. So you dial up again and then you're number 30 in the queue. And then it's just a vicious circle.*
>
> *P211, South Asian, food-relevant/mental health*

> *And I said it's a Friday, if the doctor doesn't call me in time the chemist will close so I won't get my prescription. But they don't care, it's just the receptionists, wrong people are in the wrong job, they have no empathy, they don't care they're just there to do their job and clock off and finish. You know, they're not even flipping qualified and the way they interrogate you is just like what the hell. I don't want to speak to you lot, I know more about my condition than you ever will. I just want you to [. . .] I want an appointment with the doctor. It's a simple request but it's just so difficult now.*
>
> *P203, South Asian, mobility/stamina/cognitive*

Some tried for a month before succeeding. A few said family members or other health services intervened to get them appointments, others gave up ('the palaver of going through and getting that done is just, I couldn't do it', P16, South Asian, stamina/mental health) and self-medicated or otherwise took care into their own hands:

> *I wanted to make an appointment at doctor's as I do have health condition issues, but unfortunately it was not possible. I was waiting on call one hour and between I lost signal three times and [. . .] then I've been told there can't do any appointment that moment I have to try to call only in the morning. I was trying it for one, two week. Then because I struggled, I medicate myself and start using medication what I had left.*
>
> *P72, Central/East European, mobility*

Consequently, urgent needs were not met in a timely fashion, with adverse or potentially adverse effects on health. Some frustrated participants felt they had no choice but to go to Accident and Emergency (A&E):

> *One side is saying you have to save NHS money and do not go to A&E, but on other side GP do not want to give you an appointment [. . .]. After they are surprised we are going to emergency department.*
>
> *P175, Central/East European, stamina/mobility*

Online general practitioner triage systems

General practitioners set up online booking systems as an alternative to phoning in, which 16 participants complained about. Many others were unaware of this or lacked appropriate technologies, as noted in other studies.[203] Several reported the online form was tedious and difficult to fill in. It excluded some by language (see *Immigration and the National Health Service* later in this chapter) and others by condition (see *Chapter 12*, September workshops). Some older people felt disempowered, having to ask their children for help. While phone-in booking resulted in same-day appointments, online triage led to two- to three-day waits.

> *You had to go fill in this online form that took forever. Questions after questions after questions [. . .]. And for every little thing I had to fill out a form.*
>
> *P206, South Asian, multimorbidity*

> *I had a sudden rash, my face swelled up, I needed to be seen face to face, now I called them, and they said I had to fill in a form, I said look can't you just put me on the call list, they're like no, no, it's not a simple yes/no, it's a lot of details you have to give [. . .] she would not budge I had to do it that way.*
>
> *P203, South Asian, mobility/stamina/cognitive*

Our GP-linked charity informant said GPs disliked e-consult too, though their notion that 'you can just go on the website' sits in tension with participant complaints.

> *I think our GPs' view is that e-consult in trying to solve a problem has created another problem. One of our GPs was telling me this morning, 'I had to turn e-consult off because by eight o'clock in the morning you've got 50 patients on e-consult already and it just keeps coming.' You've got two doctors on surgery who are seeing physical patients and then you've got e-consult coming through just continually and basically anybody at home on a smartphone or a laptop can just go on to the website and go on to e-consult just sitting in your living room. It's like the sorcerer's apprentice. It's created this thing that is just unstoppable. Anybody with an idle moment can just be on their phone or laptop or iPad at home – crazy. It's the same for the doctors as having [that] patient in the waiting room. They've got to deal with it. It's just created a monster.*
>
> *Charity informant*

By contrast, our charity informant understood frustration with e-consult and was concerned about digital exclusion associated with lack of hardware, access to Wi-Fi, language and literacy and skills barriers.

> *A lot of people just hate the fact that they feel gatekeepered. So their access to general practice [. . .] You can't just rock up and say 'I want to see somebody'. It's now got to go through e-consult or you phone up and you're told 'No sorry, go through e-consult' and then you've got to fill in a whole load of boxes and wait for a callback. So the idea that the client can drive the contact and how that contact is driven by their own sense of urgency, is all now being mediated by a web-based interface where the clinicians are making the judgement call about how urgent or how important [the need is].*
>
> *Charity informant*

No specified health and social care appointment times

A few participants, looking after children or with precarious income on zero-hour contracts, found the vague scheduling of phone appointments ('the doctor will call you sometime today/this morning') impractical and disruptive. Community services and social care staff also phoned unpredictably and often at awkward times for participants. As in the key informant quote above, this highlighted power differentials, with the professional dictating the timing. Note the difference from what our GP informant says above, though he does add 'we need to be a bit more flexible and say maybe have reception ask, are there times they [patient] can or can't make in that morning'.

> *I was walking with my children on the road and then GP called me to discuss something and then my child started to cry. And they said that they would call in the window of like three hours so it's not like I could stay at home and wait for it. And then GP got annoyed because I couldn't hear her properly [. . .] I knew it's urgent thing so it was very stressful and it wasn't a nice experience and [. . .] my English is not too bad but then I couldn't understand what she was saying and it was making me feel stupid and not being able to express what help do I need.*
>
> *P185, Central/East European, mental health*

In the consultation

Continuity of care

A few participants said it was rare when they could consult the same doctor on consecutive occasions, a particular issue when a locum or unknown doctor phoned, with complaints of discrimination and breakdowns in communication. Similar issues were reported across secondary care and social services.

> *When I arrived from Slovakia [after a brief holiday] and informed them I had a stroke, doctor replied to me to go back to Slovakia get treatment [. . .] when I have been here for 17 years [. . .]. I also do not know which doctor I am speaking to, I don't know his name, when I am asking about names, I was told that is not important for you [. . .] That makes me feel so uncomfortable and I am not sure if I do speak with doctor or not.*
>
> *P175, Central/East European, stamina/mobility*

This lack of continuity:

- made it difficult to monitor changes in a person's condition or situation – something already made harder through remote working (see later)
- could increase patient anxiety
- wasted time and irritated participants, who had to keep re-explaining things.

> *I think I've only spoken to the same one twice in the past 18 months or so which has been really hard because each time you have to go over your story again and try to remember things that you need to mention [. . .]. There's so much to think about and also not knowing because it's a telephone consult how long you actually have.*
>
> *P79, South Asian, multimorbidity*

Describing symptoms

Eleven participants suggested that some physical issues, especially mobility issues and pain, must be seen to be understood because of their nature or easier articulation through gestures. Seven more described similar issues with secondary care and allied health care:

> *I've also had one telephone consultation with rheumatology regarding my Raynaud's in my hands, which is very difficult to describe, because normally you would show them how your hands are, but you can't do that over the phone.*
>
> *P79, South Asian, multimorbidity*

One participant was asked to read her own blood pressure for the GP, and worried this was not reliable. Often the complaint was about review or monitoring of established conditions, which contrasts with the literature, where both patients and GPs considered the problem worse for new or developing conditions.[203,204] Our GP informant agreed:

> *Just seeing someone's face if they're describing a mental health problem, seeing someone's face if they're describing the impact of chronic pain on their life, what it is they can't do. You're really getting a sense of something that you're missing when it's just on the phone.*
>
> *GP informant*

A few participants also felt symptom description was hampered by their health illiteracy, lack of English language fluency or education, or the functional limitations of their condition. A blind participant said:

> *'Do you have any rashes on your stomach?' How can I say? I can't see. So, it's very terrible and horrible. [. . .] So not possible for me to do over the phone and [. . .] blood pressure, 'buy device and do it at home', but how can I take a machine if I can't see?*
>
> *P5, South Asian, sensorial*

The failing clinician–patient relationship

Telehealth mostly compromised the patient relationship with GPs and mental health services, with difficulty establishing rapport or talking frankly about personal matters (but other perspectives are also described in this chapter, e.g. the section on mental health). These issues have been reported in other studies, from the perspectives of GPs[203] and patients.[204,205] One summed it up thus:

> *I wasn't given the time and attention I would have gotten before. With speaking to GPs, they were a lot more abrupt.*
>
> *P67, South Asian, mental health*

A couple of participants said face-to-face appointments could be extended simply by not leaving the room, something not possible in telehealth. While 7% of patients in a US retrospective observational study said remote consultations should be longer,[204] two US studies involving healthcare staff – one survey and one qualitative interview-based – attributed consultation brevity to patient reticence or preference.[202,203] Our participants instead cited discomfort, feeling unwelcome and alienated, and staff abruptness.

Decision-making within health and social care

Some participants argued telehealth made clinical decisions inadequate at best and potentially risky, illustrating this with reports of errors. This is supported by studies of UK and Romanian GP perspectives.[203,205,206] Poor decision-making could seem marginalising or gaslighting to a patient, for example when their condition was downgraded or denied or where reasonable adjustments were not considered when arranging care.

> *[The consultant] didn't know I was a wheelchair user, I had to tell her.*
>
> *P2, African, mobility*

> *When I got the call, it was very short, cannot explain my problem . . . I have very bad constipation during a pandemic, but I was neglected by my GP and ended up in hospitalisation where I had an enema three time, a CT [computerised tomography] scan and was referred to a colorectal specialist for treatment.*
>
> *P191, South Asian, multimorbidity*

Similar issues were described with other NHS services, such as physiotherapy, chronic obstructive pulmonary disease rehabilitation and mental health care; 12 participants across ethnic groups gave examples of how they felt these were unsuited to telehealth.

> *And [group therapy] was helpful, but it wasn't as helpful as they used to be in person, because I feel like a lot is lost when it's, you know, online, like you don't see the body language and eye contact like you don't really feel like they're speaking to people as much.*
>
> *P43, South Asian, mental health/respiratory*

> *I am not always able to do these exercises by myself because nobody corrects me. And when I got physical therapy over the phone, it was horrible. [. . .] Where really nothing can be comprehended. [. . .] I think that physiotherapy must go and see and be and touch.*
>
> *P278, Central/East European, mental health/mobility*

Face-to-face appointments were thought to encourage more holistic care and consideration of intersectional factors affecting experiences and mental health; but staff using telehealth could, and reportedly did not, ask relevant questions. This was considered particularly problematic with social care assessments, which were also complicated by people's connectivity issues contingent on financial precarity.

> *Social care workers [would] not visit during the pandemic. They were told not to, for example, if you ask for a Care Act assessment which is by law you can ask for, many social care officers or workers were doing it over the phone [. . .] you really can't tell what the person needs over the phone. And many people can't use Zoom. Especially people who are on benefits, they don't have the kind of income for them to even pay for their Wi-Fi or have good Wi-Fi.*
>
> *P2, African, mobility*

Seven South Asian and Central/East European participants described being given, or sometimes they claimed 'fobbed off' by GPs with, medications they did not want because of the different power dynamics and feelings of discomfort with telehealth, or lack of trust; similar findings are reported in other studies.[61,205,206] As with difficulties booking appointments, this led some – especially with mental health problems and anxiety – to self-medicate differently, or research coping strategies or online videos.

> *[on the phone] You can talk with him for 2–3 minutes and you have no chance to tell him all your problems and after he will prescribe you stupid tablets even you did not ask about them.*
>
> *P175, Central/East European, stamina/mobility*

Challenges with photos and video consultations

Colour or proportions could be distorted from reality in photos and videos. Photos of rashes were seen as particularly problematic (instead attributed in a US-based qualitative study of clinicians to patients' inability to explain them remotely[203]), with issues exacerbated by different skin tones.

> *I had a small infection in my arm, for which I needed antibiotics [. . .] I'd called the GP and they'd had a video call, and they were like, 'Oh, hold your arm up to the camera,' sort of thing. It was an under-the-skin infection on my arm. There wasn't any break in the skin or anything, so you couldn't see anything on the camera. They were like, 'Oh, there doesn't seem to be anything there.' I'm like, 'Okay, well my arm is throbbing and it's red.'*
>
> *P277, Central/East European, mental health*

Online video consultations for mental health care, physiotherapy and occupational therapy were considered better than telehealth by the few who had them, but less good than face-to-face sessions. There was a lack of privacy,[202,204] distraction from family, and technology issues.

> *When they did give me a session with a Zoom call, it helped me in the first session, the second one because I had to be in a quiet place but because of the kids in the house, and you are not thinking, looking at the children, they are talking to you, you're not focusing, it affects the whole of the household, I think.*
>
> *P210, South Asian, cognitive/mental health*

Face-to-face appointments

Participants continued to attend hospital or clinics in person when critical, life-saving care was needed, such as for a heart attack. They might also attend for X-rays and specialist tests. Some attended the GP for routine testing or monitoring or to receive routine intramuscular or intravenous medication, or if they had cancer or suspected cancer. Face-to-face appointments in allied health care (e.g. physiotherapy) were infrequently mentioned but occurred. A few had home visits from the doctor for therapy, or from a nurse for tests or vaccination, if they were older or had mobility issues, or cancer.

Sometimes face-to-face GP, physiotherapy and social care appointments might be adapted to be:

- more spaced out than before the pandemic
- hybrid; for example, a physiotherapist might suggest exercises to do at home, with only occasional face-to-face follow-up.

Fear of in-person care

Forty-four participants said when offered face-to-face care they avoided it through fear of catching COVID-19 (see also *Chapter 8*). Proportionately and numerically, this was most notable in those with multimorbidities (17.58%, $n = 16$) though it occurred in people with other conditions; it was found across several ethnic groups. These participants reacted by:

1. stopping all healthcare access
2. only using remote care
3. modifying their medication intake to reduce visits: 'I tried to take medications, dosages that could last me longer. So, I didn't have to book appointments to go and get my prescriptions.' (P265, South Asian, epilepsy)
4. getting the vaccine (see *Chapter 8*)
5. using less busy services as routes into needed care:

> *My wife did a bit of research for me and so we went to a GP unit. There was hardly anyone there, we went in first thing, they took a look at my ECG and told me to go the ambulatory emergency unit straight away. So I didn't have to wait in the long A&E with people coughing and spluttering.*
>
> *P238, White British, sensorial*

Some perceived healthcare staff as also reducing contact time with patients because of their own fear of COVID-19; some GPs were said to only see patients who were vaccinated or could prove they currently tested negative for coronavirus.

Failure to return to face-to-face appointments for all

Many participants interviewed in 2022 were frustrated that only some GPs had fully resumed face-to-face consultations ('Why can't we see doctors like before, it's like they don't care about us.' P167, South Asian) and that 'the rest of the country' (i.e. all other services, including secondary care) had returned to face-to-face delivery. GP practices operate as independent contractors embedded within the NHS as quasi-employees, and so can make individual choices about care delivery.

> *When you go out it's unbelievable, the people have become as it was before the pandemic, before the COVID. Then if everything has gone back to normal then why don't the services and the hospitals and the GPs go back to normal?*
>
> *P208, South Asian, epilepsy*

> *My GP practice is working only over the phone [. . .] neighbour [. . .] she has a different GP practice from different area of Bradford, and she said she is able to have an appointment face to face.*
>
> *P175, Central/East European, stamina/mobility*

The backlog in secondary and social care: waiting lists, deferrals and delays

Many participants bewailed the backlog in secondary and social care as COVID-19 impacted service delivery.[207] We have subdivided this into 'deferrals', 'waiting lists' and 'delays' to reflect our data (see *Table 17* and *Figure 22*). We define deferrals as occurring when patients, knowing about extended waiting lists, or unable to book a GP appointment (see earlier in this chapter) or fearing COVID-19, put off help-seeking, or where primary care diagnostic tests and reviews or discussion of their results are held back by healthcare providers. We define waiting lists as lists joined when a person is newly booked into secondary or social care for a diagnosis or procedure or support following a successful GP referral, or where GP referrals have been delayed, cancelled or refused due to a lack of capacity in primary, secondary or social care. We define delays as occurring when existing treatment or monitoring plans or social care visits are less frequent or temporarily abandoned or cancelled. All three backlog subtypes left people suffering for months to years, often in chronic pain or with mental ill health, without diagnoses to enable support, without therapy, and without rehabilitation and enablement measures such as home equipment. Consequently, their condition and expectations of the NHS worsened.

We discuss waiting lists before deferrals below because deferrals were a consequence of the waiting lists.

Prolonged waiting lists

Extended waiting lists for secondary health care and social care were acknowledged as due to the pandemic and some participants were pragmatic about this, though not happy about the consequences. Social care waiting list issues tended to centre around the lack of a dedicated formal carer, or unsuitable housing. Waiting times were particularly

TABLE 17 Different categories of backlog in care found in our data

	Described by the BMA[207]	Arising from our data
Deferrals		
Patients who have not yet seen their GP about symptoms that would ordinarily lead to a referral, due to concerns of burdening the health service, issues making an appointment, or fears around COVID-19 infection.	Yes	Yes
Patients for whom primary care diagnostic tests or assessments, or non-routine assessments or discussion of the results of these, have been cancelled, postponed or delayed.	No	Yes
Waiting lists		
New patients on a secondary care treatment/social care waiting list who would have expected to have been seen by the time of interview were it not for the pandemic.	Yes	Yes
Patients who had GP referrals delayed, cancelled or refused due to a lack of capacity in primary, secondary or social care.[3]	Yes	Yes
Delays		
Existing patients who have had planned management or interventions or support cancelled.	Not disambiguated from the 'cancelled' group but our data show specific differences.	Yes
Existing patients who have had management or interventions or support delayed or postponed (but with the expectation they will happen eventually).		Yes
Patients whose regular management or monitoring or review consultations or social care meetings were less frequent but continued.	No	Yes

BMA, British Medical Association.

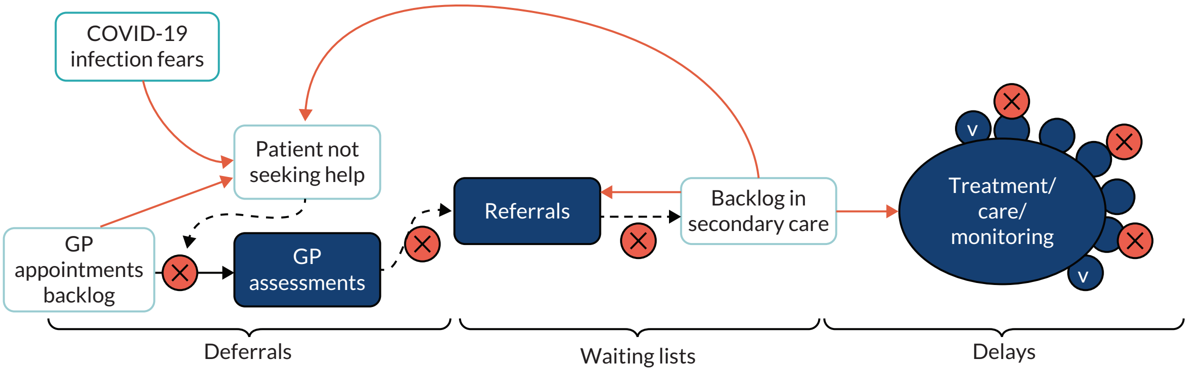


FIGURE 22 Processes impacting on health and social care service delivery. Solid (red) arrows are negative feedback loops. Filled (blue) shapes are the usual pathway to care. Unfilled shapes are issues in the normal process. x (red) shapes and dashed arrows show where these disrupt the process, leading to delays and cancellations

exacerbated in those who needed interpreters (see *Language barriers*), though the significance of this varied depending on who was being consulted and what for:

> *Getting an interpreter was, is quite difficult . . . So for the normal hospital [. . .] [don't] need it . . . because they don't speak much. The problem is the mental health support if it's on the phone or not on the phone. If it's face to face then it's face-to-face interpreter. But that's sometimes difficult, they're not available. So they book in advance but that takes, there are waiting lists for that, so, it just makes everything longer. For GP don't really need an interpreter because it's really simple.*
>
> *P236, South Asian*

Waiting times mostly exceeded 6 months; participants believed critical conditions were prioritised; the longest specified times were for endometriosis (1 year) and talking therapies (up to 2 years). The NHS Constitution includes a right for patients to start consultant-led elective treatment within 18 weeks of a GP referral.[208]

Participants usually described the wait as absolute; that is, patients were not offered interim care, nor given indications of waiting times, seen as especially problematic for mental health issues. Participants felt treated dispassionately, forgotten and neglected. Many felt in limbo, particularly in our later interviews.

> *Right now I'm in limbo, nothing has really been done to be honest to help me [. . .] I called them up last week and they said 'You are on the waiting list' and [. . .] they said 'We can't give you an estimate, the list is very long but you are on the waiting list'. [. . .] So another six weeks later, I made another appointment with the GP saying my condition [. . .] was getting worse but I haven't heard anything back from the pain clinic [. . .]. So she gave me their number and I called them directly. They said 'You are on the waiting list but we don't know how long it's going to take'. [. . .] It's like talking to a robot on the other end of the phone. I don't blame them because they're just doing their job, they're just telling you the facts but nobody knows what you're going through day in and day out so you just need a bit of compassion or a bit of sympathy to say, 'You're on a long waiting list but there's something else that we can do for you'.*
>
> *P205, South Asian, stamina/respiratory*

This feeling of limbo led us to distinguish between new patients and cancellations with no clear new date, and existing patients given a revised date (see *Table 17*), who were initially less likely to feel in limbo. But revised dates could be broken, leading to an anxiety-provoking helter-skelter of hopes and disappointments.

> *They told me that they would put me on the waiting list for [cognitive behavioural] therapy. [. . .] They send me message that I will get my therapy in like [. . .] three months' time so I was like oh yes, wow, what happened. This is great [. . .] then after these three months, [. . .] they sent me like all your therapy will start in four weeks. And then two months later they were sending another text saying it was starting in four weeks. And being a person suffering from anxiety, I would really prefer if they told me it was starting six months' time [. . .] not like I think, okay, we'll start soon, I'll get help soon and then no I didn't [. . .] So it gives me more anxiety.*
>
> *P185, Central/East European, mental health*

A similar situation occurred for social, council and formal community care. Since these often involve more complex processes than other care, with multidisciplinary teams and private sector provision, sometimes professional networks or processes could break down, exacerbating feelings of neglect.

Our key informants explained, however, that any neglect went against key practice drivers. The GP admitted pandemic challenges caused a short period of limbo, quickly followed by intensive check-up calls. The charity representative similarly said:

> *There is a quality expectation of practice-driven contact for patients with long-term conditions and every GP practice has a call and recall team who spend their whole lives literally phoning up thousands of patients with long-term conditions and then triaging.*
>
> *Charity informant*

Primary care deferrals

Some participants had stopped help-seeking unless for crisis care ('unless it is very very very crucial, I just keep quiet and sit at home.' P12, South Asian, sensorial) because of waiting lists and difficulties getting an appointment with a GP, and therefore a referral, in the first place. This was most frequently mentioned for mental health care.

> *Going back to the GPs, now because of the COVID they take ages to do a referral, more than six weeks [. . .] I've been going through psychology for a while and then that stopped [. . .] So because the GP has to refer me every time I've given up.*
>
> *P208, South Asian, epilepsy*

Participants reported long-deferred primary care diagnostic tests and non-routine assessments. This means conditions or their progression being confirmed at a later and more serious stage, resulting in a worse prognosis and unnecessary suffering for patients. It might also mean intermittent or relapsing–remitting conditions are not picked up, resulting in dismissed needs and diagnoses not being made.

> *And then when I was feeling really washed out and everything a few weeks ago, my GP asked me to do a blood test. The blood test isn't until the 10th of November [weeks after the interview] and it's like it's not going to be a true reflection of how I was feeling at the time because I was just completely wiped out. And I don't know how I'm going to feel in November when they take my blood test.*
>
> *P205, South Asian, stamina/respiratory*

These issues are acknowledged by the English government; the Elective Recovery Plan commits to 9 million more tests and checks by 2025 and has invested in expanding its network of community diagnostic centres.[209]

Delays

Delays were described for chemotherapy, gender-reassignment therapy, podiatry and rehabilitation physiotherapy. Inevitably, participant health suffered; many spoke of prolonged pain. Occasionally cancellations were last-minute decisions because the clinician had COVID-19. These were described as poorly done, with the inconvenience pushed onto the patient, particularly upsetting for those with mental health or fatigue issues. One patient was even told to repeat the referral process because cancellation by the hospital made the prior test results out of date.

> *I got an appointment and then they cancelled it the day before, and then I have to rebook it and I have to wait for hours on the phone to try to rebook it and then the phone goes off, things like that, it's been really frustrating.*
>
> *P16, South Asian, stamina/mental health*

> *For me to go out of the house, I work at this thing with my doctor. We plan it, we organise it, we pace it. So that's what I do, I plan, organise, pace my week. I've already now trained my brain three, four days earlier saying, I'm going to do this doctor's appointment. It's going to be okay, I'm not going to exert myself, I'm not going to overdo it, I'm going to take it easy because I need to save that energy for the next two days' time. I need to now get ready and get out my house and go to an appointment.*
>
> *P234, South Asian, fatigue/mobility*

Our data suggest that, except for crisis needs such as chemotherapy, health and social care delays often lasted the entire pandemic, only beginning to be addressed in 2022. As with waiting lists, what was deemed critical and therefore prioritised was unclear. For example, while one participant with cancer got new appointments fairly quickly, another said their kidney dialysis ceased.

As with long waiting lists, long delays led people to enter a liminal space, lower their expectations, and even feel hopeless and suicidal:

> *The appointments have just come to a stop. [. . .] So, I did feel sometimes that I'd be better off just killing myself to put an end to all of this.*
>
> *P161, South Asian, mobility*

Social care delays were typically contingent on the presence of particular staff, or staff social distancing or shielding, whereas in health care, the needs of COVID-19 patients played a greater role.

> *I had a support worker coming in [. . .] I think she's been off sick herself [. . .] It's difficult.*
>
> *P159, African, multimorbidity*

> *The health and social routine or package we had as a family before COVID-19 was completely removed during the pandemic and until now. [. . .] In our borough the social services lost their senior decision-makers, those who are experienced, due to COVID-19 illness, shielding or difficulty with digital access. I believe this was a major knock to the*

> *services. Junior officers could not make quick decisions, avoided responding to our queries, this delayed our housing move, arranging transport for my dad, safety in the house, door locks, mobility options.*
>
> *P68, North African, cognitive/mobility*

Routine monitoring tests and reviews had resumed, where they had been deferred, in 2022, but with backlogs leading to long wait times in our data.

> *And for the past three months I've been trying to book an annual review. And they didn't have any clinics set up so they're still not inviting anybody in [. . .] There's got to be a backlog and they won't see me straight away. They're saying it should be coming up soon [. . .] But it's been [18 months, because of prior deferral], it's been a long time.*
>
> *P206, South Asian, multimorbidity*

Strategies to shorten waits

Participants often felt they had to take action to get NHS help. Many said that this was not easy and could take an additional toll on their health. See *Chapter 11* for more details of effective strategies used:

> *I think part of my anxiety and mental health was the fact that I had to deal with all that, that I felt that every part of getting help was a struggle, yes. And I had to ask many times again and again for help, and yes, it added up to my depression and hopelessness and anxiety the fact that I really had to do so many things. It was hard for me to go through all of that and feeling on every step it's like you have to fight to get help.*
>
> *P185, Central/East European, mental health*

Some White British and Central/East European participants felt empowered to use their own interim solutions, particularly those seeking psychological or psychiatric support. For example, one used church-based counselling support till she received NHS support after 7 months (P220, White British). Another 'found everything on my own on the internet' (P95, Central/East European, stamina/mental health). One described how 'a place became available on the ACT [acceptance and commitment therapy] group so I accepted that so that I could be doing something whilst I'm kind of waiting for individual therapy' (P227, White British, depression).

A few others across the ethnic groups, eligible for free NHS care, including a few White British people, turned to private care explicitly because of waiting times ('it feels like I cannot rely any more on the NHS.' P279), although this was not possible for maintenance of existing NHS equipment. (This is additional to those seeking private care because of their migrant status or beliefs; see *Immigration and the National Health Service*.)

> *I was referred to a colorectal specialist for treatment but unfortunately, they put me on a very long waiting list. Luckily my husband managed to make an appointment with a private specialist where I have a colonoscopy and emergency blood test. It cost lots of money.*
>
> *P191, South Asian, multimorbidity*

> *COVID-19 has affected follow-up to review my CPAP [continuous positive airway pressure] machine and my health. It could not be assessed outside the NHS otherwise I would have looked into that.*
>
> *P154, North African, stamina*

Immigration and the National Health Service

The NHS is government-funded, and free at the point of use for British citizens excepting a set fee for prescription medications. UK migrants have varying degrees of entitlement to NHS care; the rules are complex to navigate and understand. The Doctors of the World 'short guide' is 11 pages long and specifies that the complexities mean many people cannot get care (even when entitled to it) or are wrongly charged.[210] The immigration health surcharge must be paid to get most visas; without visas, foreign nationals must pay a 'point-of-access' charge. Thus, NHS Trusts must check a person's immigration status as part of their care process – a deterrent to migrants even if they have funds to pay for care. As a minimum, all overseas nationals in the UK, including undocumented migrants, can access free GP services, and A&E care. Many migrants are unaware of this, while others are afraid to access it because of Theresa May's 'hostile environment' (this was rebranded the 'compliant environment' by the Conservative government, in line with their social order as opposed to social justice approach to governance). It aims to drive undocumented migrants from the UK. Their access to all public services is restricted (with 'no recourse to public funds'). Immigration enforcement teams track, detain and deport them, creating a 'climate of fear'.[211]

Consequently, our data show some migrants avoid health care altogether and others use private care whether or not they can really afford it. They are afraid of detention, separation from family, and deportation to their unsafe country of origin or another place such as, in 2022, Rwanda.[66]

In March 2020, to protect community health during the pandemic, the government gave a temporary reprieve to migrants, with the 2020–1 'Everyone In' scheme. This did not allay the fears of many migrants, and was misunderstood as negligent care by some, including healthcare professionals.

The following sections should be read in this context. We first consider how access to care was affected by immigration rules, then barriers caused by language and culture. Some such barriers have already been referred to elsewhere in this report.

Never using a National Health Service general practitioner

Many participants had never registered with a GP, typically saying: 'I don't have a family doctor. I just go to the hospital'. Undocumented migrants often had 'no care from anywhere' (P78, South Asian, cognitive), being afraid of being identified, but people on visas or with British passports also sometimes did not have an NHS GP.

Some obtained A&E point-of-access free care, then paid the same clinician for private care thereafter. It is unclear whether this was billing for services or a special arrangement, but descriptions suggest the latter. Sometimes NHS staff wrongly interpreted the immigration rules, pushing participants to private care; COVID-19 care was a charge exemption:

> *I had some breathing difficulty [because of my lung condition] and my parents took me to the hospital. They refused to take me saying I had COVID, so my parents had to look for a private clinic. The private clinic was helpful. They're in business, yes, it's about money.*
>
> *P25, North African, respiratory*

In several cases, the private doctor was a friend, family member or neighbour who also worked for the NHS, particularly described by North African and South Asian participants.

> *I occasionally talk to a friend or a family member. They are also doctors. If I have a headache, rashes, or stomach aches, I only ask for the name of the medication.*
>
> *P96, South Asian, respiratory*

Private care was viewed positively across groups; doctors used conventional therapies, and provided clarification and motivation. Meetings were typically every 4–7 days online, and every 2–4 weeks in person. While face-to-face care was preferred, participants did not complain about remote care, unlike NHS patients, and seemed largely satisfied. However, private care strained people in economic precarity and frequently meant difficult choices about which care to pay for, or premature cessation of essential care. In total, 34 from minoritised ethnic groups (mostly African, North African, Arab and undocumented) described private care they could not really afford. Often family members or friends helped pay:

> *There are some things like medications and then there are supplements. [. . .] CT scans, X-rays, I have to pay the doctor to get through all those [. . .] there was [mental health] support, but I didn't go for it because I was discouraged because [. . .] I didn't have the financial if maybe the therapist or those people need me to pay them I couldn't.*
>
> *P264, Arab, cancer*

A few used doctors in their country of origin, by phone or online, some of whom sent medicines to the UK, which were delayed during parts of the pandemic.

> *I also take LPZ [heartburn medicine called lansoprazole] . . . I usually get my supply from Lebanon because what you have here in the UK it is not quite, not saying it does not help but it's not something I'm used to. [. . .] So, I preferred bringing my own supply every time I go back and forth, and I visit quite often. But during the pandemic that became more problematic [. . .] so I resorted to informal acquaintances, and I just asked them.*
>
> *P19, Arab, food-relevant*

Our GP informant bewailed: 'They come back with test results that may or may not mean anything and drugs that we may or may not be licensed to give in this country.' One talked about a doctor in her country of origin and a 'doctor in a garage' here, an NHS doctor working privately. She describes the double bind of not being allowed to work or have free NHS care, but having to work to pay for the private care she is forced to use. Our politician key informant lamented similar cycles of need in other undocumented migrants.

> *I have a doctor in [country]. He told me that my diabetes is affecting my eyes, and it may affect other parts of my body. I meet him on WhatsApp or FaceTime. He is a very good doctor who tells me the right medicine to eat when I was having COVID. He is [. . .] always available when I need support. He recently told me to pray to God when I had the infection. For medicines, I send him money and he post medicines to me. It takes time to come but I manage somehow. In 2020, the medicines took time to come to me. I had to wait for a month for medications which affected my health [. . .]. Then I went to my doctor [the private doctor] in [area of UK] for medicines. They charged me £60 for 10 minutes. It is expensive for me, but I have to ask for his help. He gives me medicines and checks my eyes, but I have to work hard to pay him for every visit. His clinic is in a garage in [town]. It is a small room, and he has a bed and medical instruments to see a patient.*
>
> *Undocumented*

Eligible for National Health Service care but uses private care at least sometimes

Several participants were eligible for free NHS care but still paid every time – because they lacked awareness of free care or trust in the NHS or were loyal to private doctors from their own communities – and a few paid some of the time, for example when waiting times were too long.

> *Sometimes he is very understanding and sometimes when I'm in a position to, I usually pay for my visits.*
>
> *P76, North African, respiratory, visa*

> *I'm used to the family doctor, and I don't want to maybe betray him, it's like betrayal you know you have been with him for like 20 years and you have started accessing other services, so that's why maybe I am not that curious, I don't want to know.*
>
> *P250, African, mental health, Right to Remain*

One lady, on a long NHS waiting list, returned to Poland since private care was cheaper there. She could not sustain this, so her problems returned.

> *Then at the first lockdown I was in Poland [. . .] I went there and made a private appointment with a lady for physiotherapy, and I had to pay because here in England it took too long and over the phone. [. . .] in England it was only privately, and it was cheaper in Poland. Airline tickets were cheaper during COVID, so it was more profitable for me to come to Poland. So, I flew once a month for two weeks [at a time]. I rinsed out of all my savings. It helped me and I thought I would go back to work but because there is no continuation it gets worse, and everything comes back.*
>
> *P184, Central/East European, mobility/mental health*

Our GP informant was concerned about these issues, providing an alternative perspective:

> *People are paying for really inappropriate tests that private medical care will give them, and the NHS probably wouldn't. Not because they don't need it but because it's not indicated. I almost have to beg some people, who I know don't have the money, not to waste it, because it is not a fruitful avenue to pursue in terms of finding a health problem. So, if they really think they have brain cancer, I will send you for a scan, but you don't have brain cancer. Occasionally you have to do stuff that isn't indicated on the NHS, as long as it's cheap enough, and you're not sending them for MRI [magnetic resonance imaging] scans and expensive things. It is going to create a problem for people who do need it. Just to convince*

> *them they don't have a health problem that they claimed they did to start with. That happens a lot, and people in Eastern Europe, and particularly Nigerian, but also Indian and Pakistani families will, 'I'm just flying back to get some medical care.' You're literally in a country with free medical care, why would you do that? Of course, it's mixed in with seeing their own family and doing other things, but they're still spending a lot of money on health care when they needn't.*
>
> *GP informant*

Language barriers

Section 13G of the National Health Service Act 2006 ('NHS Act') states NHS England, 'in the exercise of its functions, must have regard to the need to reduce inequalities between patients with respect to their ability to access health services'.[212] Failure to provide adequate free interpretation and translation support breaches this Act. Primary care commissioning guidance[213] also requires, for patients needing language support:

- Adapted online booking systems, for example, video explanations.
- Increased consultation times for interpretation.
- No unnecessarily longer wait for appointments because of adjustments; small delays are permissible but can have knock-on effects: 'because of the language barrier they said they will call me back with an interpreter, and they did after an hour or hour and half, but then there was no available appointment left by the time' (P95, Central/East European, stamina/mental health).
- Language and communication needs recorded, clearly flagged in the patient's record and shared with other services with referrals.

Yet many CICADA participants described language issues in primary care (e.g. accessing care, describing symptoms) (see also Finlay *et al.*[38]) that led them to go straight to A&E, where they could encounter the same issues. Flagging of communication needs only happened late in some participants' patient journeys:

> *My first session with the [mental health] therapist I have online. She was very nice and asked me because I explained that some of my troubles come from the fact that I can't communicate everything what I want to say in English because this is not my first language. And this is part of why I'm anxious about communicating institutions because it's hard for me to communicate. So, she asked me if I would prefer to have therapist that speaks Polish, so this was the moment when it's like, all right, there are some open doors. [. . .] But again, I had to go through all this part when there was no one speaking Polish, or no one was wanting to speak Polish.*
>
> *P185, Central/East European, mental health*

One participant wondered why a receptionist refused to interpret at point of contact with primary care. This may reflect what other patients think. In fact, NHS interpreting is regulated to ensure patient safety.[213] Staff 'should not, other than where immediate and necessary treatment is required, take on the role of an interpreter unless this is part of their defined job role, and they are qualified to do so'.[213] However, professionals and primary care staff 'may use their language and communication skills to assist patients in making appointments or identifying communication requirements' (language brokering).

Our seven Roma participants all described the complication of interpreters speaking a different language to them. The first extract below shows GPs apparently falsely assumed all Roma spoke one language, which led to errors compromising care. The second extract shows similar issues with language dialects, in this case Arabic.

> *In my experience the interpreter explained my health problem to the doctor the complete opposite [. . .] I received an invitation from GP for a head examination, but I never had a problem with my head. I went to the doctor for a back examination [. . .] they sometimes give us interpreter who speaks Slovak. Slovak is similar to Czech but not the same as Czech language. Therefore, interpreter in Czech should be available for the Czech nationals. However, the best solution would be an interpreter from the Czech Republic who speaks the Czech language but also the Romani language, so that communication with the patient from the Romani community/nation is improved and inaccurate data towards the doctor do not occur, as this is a complication and could escalate medical appointments.*
>
> *P72, Central/East European, mobility*

> *They need to [. . .] use translation from the same community. [. . .] They used to get me Arabic-speaking translators who speak differently. They could not understand my language and I did not understand their Arabic accent.*
>
> *P87, North African, mobility/sensorial*

Consequently, some participants wanted to or did resort to family interpreters, against NHS guidance.[213]

> *I'd change that everywhere I go to the doctor's, I wouldn't have an interpreter that they assign to me but rather that someone from my family would be translating for me because I speak a different dialect than them, which gets me confused because I can't understand them, and I don't trust them . . . my daughter that lives with me helps me.*
>
> *P97, Central/East European, mobility/mental health*

> *Fortunately, I have a son [. . .] he communicated [for me]. Doctors offer translators but those cannot be trusted. They distort reality.*
>
> *P72, Central/East European, mobility*

Our GP informant, while acknowledging the issues with family interpreters, suggested BMA recommendations should be balanced with patient needs:

> *On one side, you think it's inappropriate [for children to interpret for their families] and you don't know really what you're getting out of it, and the parent doesn't want a formal interpreter because some of these communities are not huge, and it might be someone that they know or a friend of a friend. On the flip side, some of these children are astonishingly capable young children [. . .]. Maybe there's a sense that we obviously need to safeguard our patients, and particularly children and particularly make sure we're gaining good information and doing good medicine and communicating appropriately via an uncertain quantity. On the flip side, maybe we do need to have confidence in some of these communities that they function in certain ways.*
>
> *GP informant*

The problems of hospitalisation with no English and no interpreters were exacerbated during the pandemic when interpreters were overstretched and multiple family members might be ill at once, or when family were forbidden to accompany patients. At best this meant patients and their families lacked information (contrary to the NHS Act) and some patients became afraid, not knowing what was happening (explained by P167 below), a situation worsened by lack of trust in the NHS and circulating myths. It could lead to deteriorating illness and even death.

> *My mother-in-law and father-in-law [suffered badly from COVID-19 and] were hospitalised [. . .]. My mother-in-law has been in hospital for nearly 2 months [. . .]. If I could not speak this little English as I do, we would know [. . .] nothing about them. I tried to translate between them. We were only able to get an interpreter at one time at this whole time, and it was still difficult to get one. So, I tried to translate, however I do not speak English very well [. . .]. The pandemic made me realise how much [interpreters] needed. As we needed them for more than one member of the family at the same time.*
>
> *P95, Central/East European, multimorbidity*

> *I was scared because I couldn't speak or understand English. They told me I would see a Pakistani doctor. Once he came and explained I felt more at ease (sah pirya).*
>
> *P167, South Asian, mobility*

> *She called an ambulance [because she had COVID] [. . .] UTC [urgent treatment centre] was really, really busy she was left to sit on the wheelchair outside, but she was on her own not knowing what was happening, very unwell, been waiting for a long time [. . .] because of her language barrier she couldn't ask for help, or she couldn't go to reception, she ended up crying and then a passer-by gave her his phone and she called her husband and asked him to take her back. So, she went back home. And then she only just deteriorated, worse, worse and worse and then [. . .] she was taken to hospital, and she passed away in March after a long battle with COVID.*
>
> *P235, South Asian, fatigue/mobility, about a neighbour*

Three Pakistani participants specified the same circulating rumour about hospitalisation, evidently linked to the greater mortality rate in minoritised ethnic groups and conspiracy theories about this:

> *A lot of people were saying don't go into hospital, especially the old people [because] they give you a lethal injection and you die. It may not be COVID, but they put that on the death certificate. So, especially in the Pakistani community people were afraid to go to hospital if they were ill.*
>
> *P176, South Asian, multimorbidity*

Participants also complained of false assumptions when they spoke English:

1. Being 'othered' as migrant, with racist discrimination and ghosting when they spoke imperfect or accented English.
2. Having needed language support removed when they were conversationally articulate.

This could aggravate healthcare problems and disempower patients.

> *When I went to GP practice, I have been told I never had a stroke showed them all my paperwork translated in English and diagnosis are multiple sclerosis and stroke and they said that cannot be true. I had a stroke in Slovakia, and I had to translate my hospital report in English, and they denied, and I said only you are a doctor's and in Slovakia we have no doctors? I was sent to CT scan, and they did apologise after results from CT scan and said there was a stroke.*
>
> *P175, Central/East European, stamina/mobility*

> *I ask my doctor for an interpreter, and I am not always able to get one, because the lady at the reception is able to say that my English is good. Well, maybe blood sampling is good, but when it needs an explanation of some result, from a blood test or something, some medical terms can stress me out so much that you tell me that I know, and I don't know. And I don't know if it happens sometimes because I used to come there and asked for too many things. For example, blood sampling needs to be tested or that needs to be tested. So then I thought it was maybe because I'm Polish. Well, if I say now three times that I need this translator, they already know that it is me [i.e. that she needs one]. And if you call the doctor, you already know it's me.*
>
> *P278, Central/East European, mobility/mental health*

Our community worker informant said people chose GPs with language in common including idiomatic use of English, whom they trusted better, even paying to do so, which adds nuance to our finding that participants eligible for NHS care turned to private care:

> *We have in West London a GP from one of the islands. People will save their pension money – particularly for the older people – to go to see him rather than go to their doctor because they do not think [the GP will understand what they say], a lot of GPs. With trauma or distress, very often they can become practically incoherent or the language you use they do not understand. They cannot express themselves, so they use a lot of colloquialisms and a lot of home language. The doctors, they only have a few minutes, so people then don't go to their doctor. They don't trust them and they will go to see this doctor that people know. He must be so popular! He sees people privately and then people get a private prescription, but they trust him. Even if what he prescribed was no different to what their GP might prescribe, the point is they go to his catchment area, they're prepared to pay, they want to be listened to, they want somebody to respect that what they come with is important. The fact they can trust that individual, talking.*
>
> *Community worker informant*

Ableism

The UK government Equality Act 2010 places a legal duty on all service providers, and an additional duty on public sector bodies, to make 'reasonable adjustments' that avoid putting disabled people at a substantial disadvantage compared to those not disabled. The Equality and Human Rights Commission states: 'Anything which is more than minor or trivial is a substantial disadvantage'. The 'Accessible Information Standard' of 2016 specifies requirements for accessible information and communication support for people with a disability, impairment or sensory loss from all NHS providers (including independent contractors and commissioned services). Specific needs must be identified, recorded, flagged, shared and met.[75,214,215]

Ironically, we found participants were often unable, because of their disability or condition, to do the therapy or use equipment provided to help them manage it.

> *I've got deformity in the hand, so I have gripping issues, so I wasn't able to do that therapy myself.*
>
> *P234, South Asian, stamina/mobility*

> *I've got a wheelchair. I've got nobody to push me. Now it's a self-propelling wheelchair, but I can't propel it, because fibromyalgia in both arms.*
>
> *P64, South Asian, multimorbidity*

> *The support health-wise, health access was appalling, because I also have other physical conditions, I have a nerve condition in my elbows and I have the back condition, so just trying to get appointments has been impossible.*
>
> *P16, South Asian, stamina/mental health*

Culture

Some participants specified that healthcare professionals should respect cultural norms and remain alert to the impacts of culture on help-seeking or misunderstandings about care. Later in this chapter we consider this in relation to mental health specifically.

> *My husband came home, and my son said the hospital said there was nothing further they could do for him, the cancer had spread, and nurses would come home to take care of him, administering injections. We did not want care staff to come for his personal care, we the family took care of that. It's matter of dignity [. . .]. Then my husband passed away.*
>
> *P189, South Asian*

> *Things like the treatment I got was very British, Western, and I eat with my fingers in my culture, and I wasn't allowed to do that because they said that's an anorexic thing.*
>
> *P9, South Asian, cognitive/food-relevant*

Several said doctors should embrace traditional approaches and prayer in tandem with the medicalised. The triumvirate of God, individual effort, and professional support has been noted in other studies of minoritised ethnic groups.[216]

> *For my husband for instance [. . .] I would get him the spiritual help, but I would do it as a Muslim. [. . .] But also, medically I would want that intervention as well [. . .] so it's balanced. And then working with both would allow his healing quicker. Whereas I think previously it was just like medical, medical, well we need to give you these tablets and then people weren't understanding, no, no, no.*
>
> *P243, South Asian*

Other intersectional factors

National Health Service guidance on remote communication is weaker than for other aspects of care and does not consider the intersection of language issues with sensorial impairments, age, digital poverty or inadequate digital skills (see also Finlay *et al.*[38]). Our data showed this could exacerbate issues.

> *I don't know how to use smartphones or e-mail, [social services] could not help me, no carer, nobody to help with booking appointments, nobody will help me to send e-mails. They were very useless I want to reach to human rights organisations. I feel that there were violations of my rights. Because I am an old lady from minority group and don't speak English, I am deaf, so they give up and get frustrated.*
>
> *P87, North African, mobility/sensorial*

Impacts on mental health

Demographic considerations

A total of 66 participants had one or more clinically diagnosed mental ill health conditions, of whom 19 had no other comorbidities, comprising 10% of African, 6% of Arab/North African, 4% of South Asian, 15% of Central/East European, 2% of White British and 33% of mixed race participants.

Very few African participants talked about mental health. Those with Central and East European heritage spoke of not help-seeking because of pride, not wanting to seem a burden on the state (encompassing any condition), or the taboo attached to mental health:

> *I'm very self-sufficient so I decline all help. I have difficulties with accepting help. It creates shame and feelings of guilt and inadequacy, so I haven't ever spoken to anyone about my issues before.*
>
> *P170, Central/East European, mental health/stamina*

> *I don't think I'm seen as mentally ill enough to get the help, or I don't portray myself as mentally ill enough, because I don't wear it on my sleeve, but I think because I don't – well, I think for an Eastern European culture it's not very normal to speak about mental health, or to discuss it with people. So I think I'm still in that mindset of if you don't speak about it, it doesn't exist, sort of thing. So I think I struggle finding help for it, but I think that's more of my own issue than an outside factor.*
>
> *P277, Central/East European, mental health*

Comorbidities with mental ill health

In this section we provide a numerical overview of comorbidity data for those interviewees with mental health issues to explore the pervasiveness and highlight the association with some morbidities.

Mental health issues occurred in 47 people with other conditions, specifically 25% of South Asian, 41% of Central/East European, 14% of Arab/North African and 15% of White British participants. *Figure 23* shows numbers of comorbidities with the participant as the unit of analysis. *Figure 24* uses condition category as the unit of analysis. While there appear to be patterns, when corrected for the demographics of the total interview sample, several did not reach statistical significance ($p = 0.5$ and 0.6 on the chi-squared test), but they have clinical and experiential significance to our participants. For mobility, the chi-squared statistic with Yates correction is 20.3429 and the p-value < 0.00001. For stamina (including cardiovascular conditions), the chi-squared statistic with Yates correction is 5.4449 and the p-value 0.019626. These statistical analyses have the caveat that we used quota rather than random sampling, but they do show similarities to national data. Cohort studies, for example, show strong associations between conditions, such as diabetes and cardiovascular conditions and mental ill health, with a two-way effect.[217]

Mental health care

The Office for National Statistics (ONS) has reported that 46% of disabled people reported a negative impact on their mental health from COVID-19, compared with 29% of non-disabled people.[126] Issues discussed in previous sections as particularly affecting mental health care included:

- Damaged clinician–patient relationships, perceived dispassion by health and social care staff, and difficulties talking about mental health on the phone, led participants to self-research coping strategies or look for online help videos.
- The use of interpreters further exacerbated these issues.

Moreover, complaints about waiting lists and referrals were most common for mental health care. Central and East European migrants stated they were used to different systems in their countries of origin that bypassed the GP, speeding up the process and making it more likely a specialist would be seen. This is common in many other countries outside the UK.

> *For most of the things that should be available literally just by yourself, you need to actually go to your GP and be like, 'Hey, can you refer me to this?' I don't want to go to my GP every issue that I have. [. . .] It's also the fact that everything takes forever. If I am having, say if I want to get in touch with someone about my depressive episodes, I need to go to my GP, get them to actually have a conversation with me, for them to decide whether or not I actually need that help [. . .]*

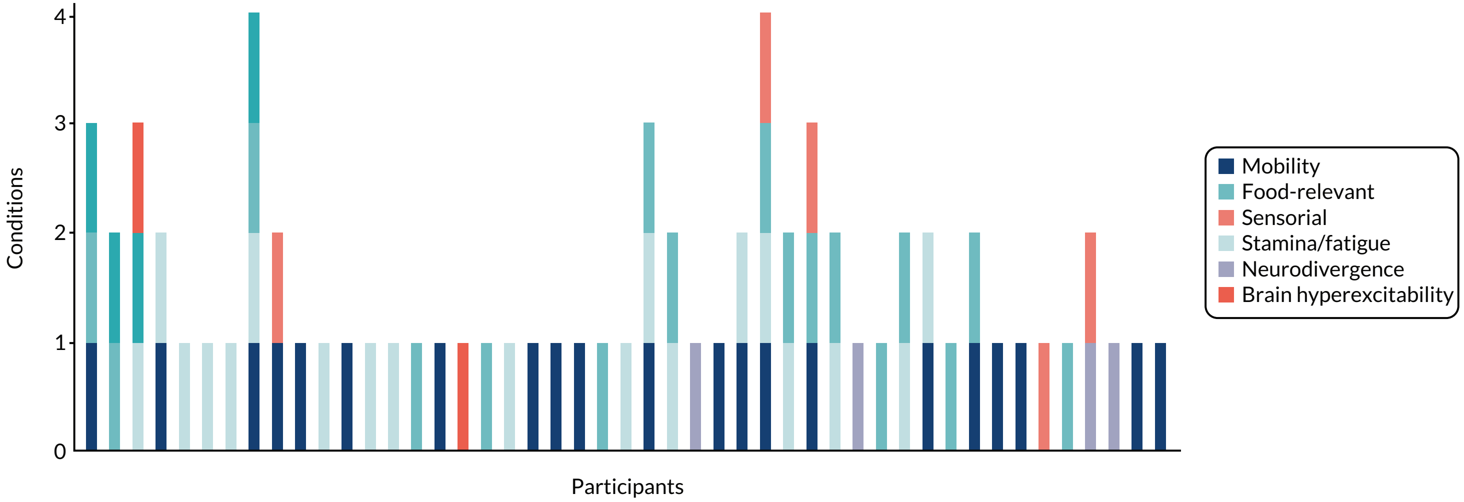


FIGURE 23 Morbidities occurring with mental health issues per participant.

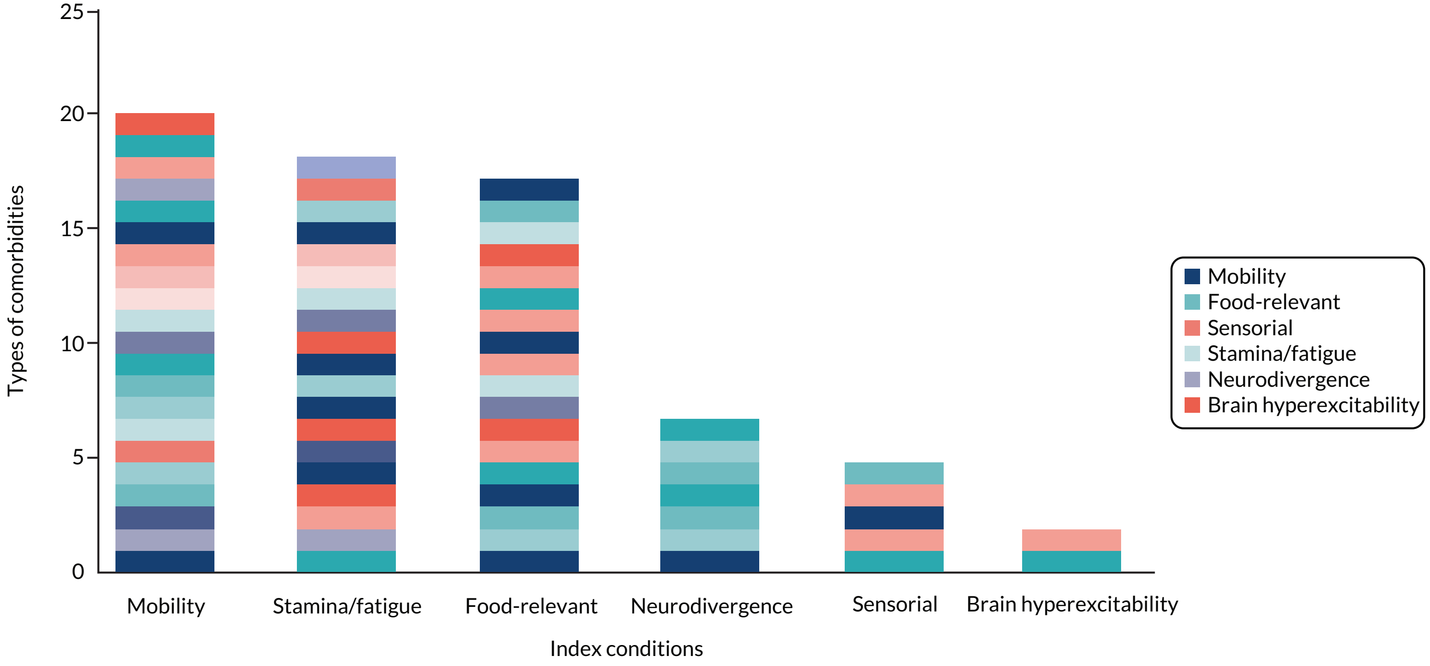


FIGURE 24 Morbidities occurring with mental health issues by type.

> *The fact is, GPs should not be the ones to decide whether or not you need outside mental health support [. . .] I get that the health-care system here works different, but it's really not good. Especially for mental health, it's really not good.*
>
> *P276, Central/East European, cognitive/mental health*

What constituted 'critical' for mental health care needs, to get people off waiting lists, was open to interpretation:

> *And if you are suicidal you're not about to tell anyone. That comes out during counselling. So the crisis team were talking to me about whether I was suicidal [. . .] And I know that there was a panic within me that was just on the horizon. But because I wasn't actually then I didn't get the immediate help.*
>
> *P220, White British, mental health*

> *And the doctor decided that because [. . .] our family [. . .] we're supportive, he feels like [my sister] can't be put on an emergency list so they put her on a long waiting list [. . .] she had mentioned that she was feeling suicidal. [. . .] She was self-harming which was kind of bad. But yeah, the doctors said it's not bad [. . .] And then after, she did attempt.*
>
> *P43, South Asian, mental health/respiratory*

These issues emanated from a crisis in the specialty caused by the pandemic: 'They said [. . .] that they don't have enough space for mental support for her because so many people are coming to the doctors about it' (P43, South Asian, mental health/respiratory). Contributory factors were loneliness, social isolation and stress from remote work, job loss, closed schools, stay-at-home orders, closed businesses, physical distancing, adversity experiences and infection fear (see *Chapters 8* and *9* for details). Many adults – our participants and the general population – experienced new mental health issues or exacerbations of existing ones, including suicidality[19,54,55] (see also strand 2 data). Deterioration in other conditions because of poor healthcare access was also linked to worsened mental health.

Many were anxious of others not following infection containment measures (see also *Chapter 8*). Some claimed to have become reclusive, worried they had lost their social abilities after a year of sparse social interaction, and frightened to spend time with others. The following excerpt describes a social gradient in confidence. COVID-19 vaccination, in enabling people to socialise more confidently, indirectly helped to address many of these issues.

> *There are a lot of people in my town who are not following the government guidelines and sanitising hands. You won't believe there are about 30 people living in the same house. This is a hot spot in Leicester. You must be reading in the newspaper. I am paranoid and sad to see this situation. The local leaders first should check the housing and immigration in this area [. . .] Because of the worst compliance policies, I am suffering from mental health issues. They are affecting me a lot.*
>
> *P200, South Asian, stamina*

Intersectional factors

Many participants – particularly those with mental ill health – believed waiting lists were purposely extended for minoritised ethnicities because they were vulnerable to being fobbed off with incorrect information and were considered a nuisance and less important than White British people. Others highlighted structural barriers to access, such as lack of knowledge of the system and language problems.

> *I've been struggling to get any help; I've been under the mental health team for three or four years and I've not had any help or treatment from them for the last three years. I've been on waiting lists. I've been waiting. I've been chasing. I've been complaining. Again, it's the thing about ethnic minorities. They don't take us seriously in anything, in the services in this country, we're just seen as a pest. Or we're just seen as like a bother, or we're just seen as like – and if you complain or if you raise any issues, they will just use it against you, or they'll take advantage and lengthen things out on purpose.*
>
> *P7, South Asian, multimorbidity*

> *Because I don't know how the system works, sometimes I can feel that maybe they can just – how to say this – they don't treat me like an English person let's say, because I don't know how to fight for my rights, I don't know where to go, I don't know what I can and what I can't, so I don't know the system properly, so they can say to me, 'Yes we do it like this,' but actually if there would be an English person they know that no it's not right, you can still do something, that they can do it.*
>
> *P196, Central/East European, mental health*

Chapter 11 Coping strategies, strengths and assets: interview findings

Here, following previous chapters on issues and adversity, we focus on coping strategies and assets in line with our strengths-based approach. Our intersectional focus recognises that people will cope differently depending on intersecting personal, structural and environmental factors and their dynamism. The three main themes in this chapter, ‘increasing connections’, ‘becoming empowered’ and ‘reflection and self-care’, have been developed inductively from the coping data.

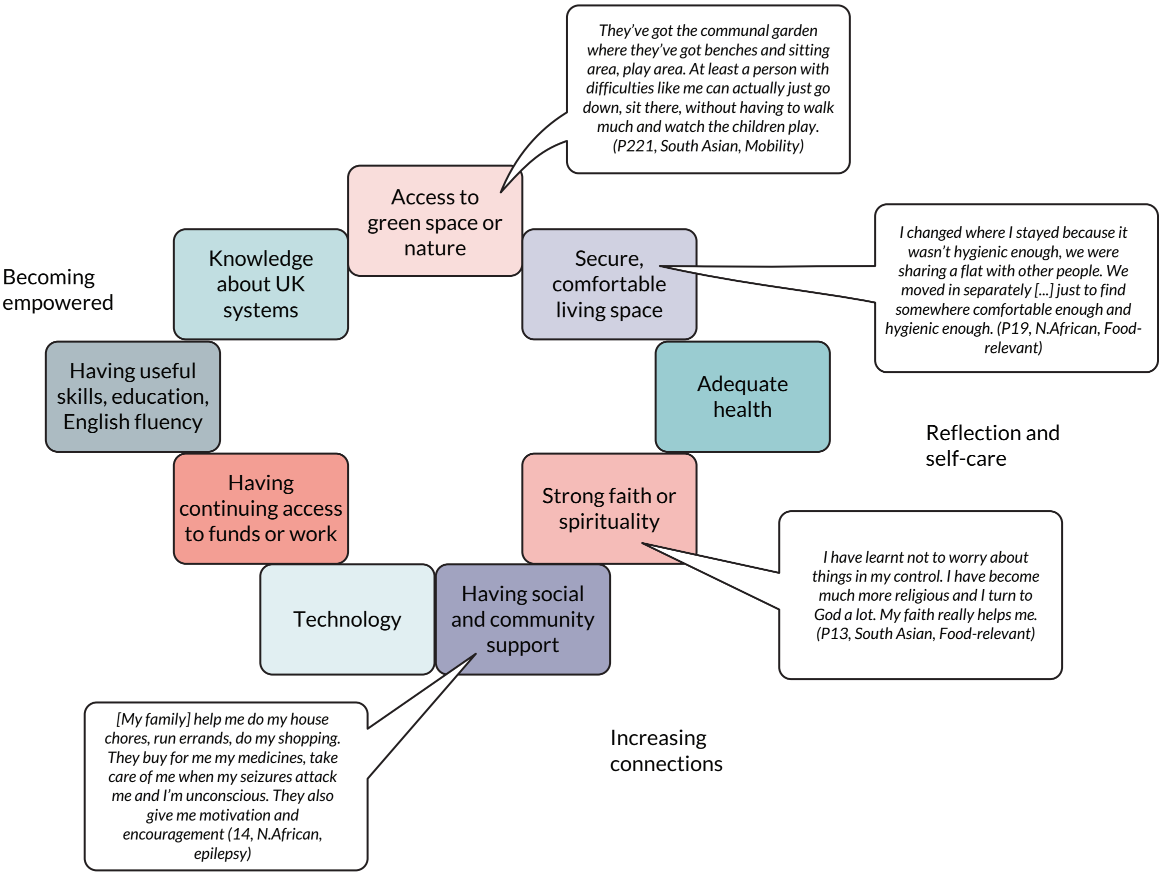
Assets associated with ability to cope

Assets associated with improved coping included access to green spaces and technology; a secure and adequate standard living environment; a strong faith or sense of spirituality; social support (from friends, family, neighbours, community); adequate health; knowledge about UK systems; education, skills and English language fluency; and access to work or a stable income throughout the pandemic (*Figure 25*). Correspondingly, key coping strategies drew on these, increasing connections, becoming empowered, and undertaking reflection and self-care.

The importance of increasing connections

Family and friends

Having *practical support* from family and friends was vital for many and the only reason some managed. Support included delivering care normally provided by health professionals, such as weekly physical therapy, and practical



They’ve got the communal garden where they’ve got benches and sitting area, play area. At least a person with difficulties like me can actually just go down, sit there, without having to walk much and watch the children play. (P221, South Asian, Mobility)

I changed where I stayed because it wasn’t hygienic enough, we were sharing a flat with other people. We moved in separately [...] just to find somewhere comfortable enough and hygienic enough. (P19, N.African, Food-relevant)

I have learnt not to worry about things in my control. I have become much more religious and I turn to God a lot. My faith really helps me. (P13, South Asian, Food-relevant)

[My family] help me do my house chores, run errands, do my shopping. They buy for me my medicines, take care of me when my seizures attack me and I’m unconscious. They also give me motivation and encouragement (14, N.African, epilepsy)

FIGURE 25 Assets associated with improved ability to cope, and strategy themes developed inductively from the data.

assistance for shielding participants and others unable to access medication and food without help. Recent migrants were often dependent on family and friends for financial assistance for basic needs and to fund medications and care (see *Chapter 9*). For conditions needing regular support, this could be a considerable burden but was essential.

In multigenerational households, older participants were practically supported by younger family members to navigate online doctor's appointments and technology and communicate with healthcare teams.

Family and friend *emotional support* was important across ethnicities and health conditions. Many described strengthened bonds, 'withdrawing into the family unit' and 'drawing the family around'. Walking, eating and chatting together helped mitigate low mood and challenges. Despite one participant being unable to access care for her diabetes, or financial support, because she was undocumented, the extract below illustrates the importance of shared rituals and bonding during this time:

> *The beautiful thing was I made a lot of sweets and cooked food for my family. We all used to eat together. We watched television together. I enjoyed my time with family members [. . .] we used to eat sweets and have dinner together and chat all night. I think we should have the pandemic for people to realise the support we can give.*
>
> *Undocumented, mobility/food-relevant*

For people not living with family or friends, or without family or friends in the UK, daily online connectivity provided some emotional support, with suggestions this strengthened bonds with family abroad. Nevertheless, this did not assuage loneliness for those without the physical presence of others.

Community connection

Community emotional and practical support, via neighbours, charity groups, faith institutions or other informal networks, supplemented family and friend support or compensated for its lack, though some participants lacked community support. Neighbourhood ethnic diversity appeared to influence the degree of connectivity, with participants of minoritised ethnicity living in mainly white neighbourhoods feeling less supported. We heard many stories of informal WhatsApp networks developed to support people in the immediate communal housing or neighbourhood. Participants also supported others practically, emotionally and by sharing reliable COVID-19 information, finding this rewarding. Charities and informal networks, for example on Facebook, facilitated ties and support between people with similar conditions, and when access to health care was restricted, provided lived experience-related advice and other useful condition-related COVID-19 information, as a substitute. Charities also provided mental health support and therapy.

> *We got this Facebook page [. . .] so, if you post a question, they will try to help you or answer your question, maybe someone has a similar experience and then they can guide you.*
>
> *P12, South Asian, sensorial*

> *We have this organisation where we talk with people, they have some people who are disabled like me, like maybe hands are not working, so we shall come together and maybe try to talk, and exchange ideas on how to solve some problems, and talk of many stories. With that I just feel relieved [. . .] the situation I'm suffering from fades away.*
>
> *P33, North African, mobility*

Faith institutions offered solace for some, connecting online for social interaction, religious festivals and prayer. They also provided practical support with food parcels, pandemic-related advice, financial assistance (occasionally) and, if required, personal guidance and support.

Support from a carer or health professional

Some with disabilities requiring close therapeutic support relied on a therapist, clinician, formal carer or social worker, although generally ties appeared weaker than for informal networks.

See *Chapter 10* for further detail on health and social care.

Empowerment

Technology

The affordances of digital technology were a vital part of coping with the pandemic and becoming more empowered for almost all participants. The digitally impoverished usually had access to at least some technology such as WhatsApp. The digitally literate with good technology access were advantaged with access to work, education, digital books, music, health and social care (see *Chapter 10*) and for faith meetings, social connection to reduce isolation and separation from friends and family, relaxation, access to food shopping and other necessities (*Figure 26*), videos (educational, health care and for pleasure), films and TV. Social media, commonly Zoom and WhatsApp, was a 'saviour' connecting friends and family in this country and back home. Apps like TikTok and YouTube (YouTube, LLC, San Bruno, CA, USA), and online courses run through charities and other organisations, helped people learn new hobbies (e.g. sewing, crochet, knitting, drawing). These also facilitated self-care.

Advocating for self and others

Empowered participants coped better than others; they were able, for example, to advocate for health and social care rights for themselves and their community (see *Chapter 10*), thus increasing connections, health and living standards. A few mobilised local support networks, fought for service access, volunteered for local support services, such as food banks, and supported others informally. They explained the value of good English, education, and knowing your rights:

> *They wouldn't dare speak to a Caucasian person [. . .] in that manner and then when I've spoken to them [the council] on their behalf, I see the complete tone change and when I say this is unacceptable, can I raise it further, can I speak to the manager and then I get that and then the people who I help they're like, oh thank you so much I know if you hadn't come and if you hadn't spoken to them, I would have not got nowhere.*
>
> *P203, South Asian, mobility/stamina/cognitive*

Some took control of their own health and social care, when services did not meet their needs, finding contact details and e-mailing hospital consultants, raising formal complaints, contacting charities and social services themselves. Several said phrases, such as 'You have to be very, very pushy to get your own appointment, because otherwise, nothing' (P193, Central/East European, mobility/food-relevant) or raised or threatened to raise complaints ('Because I think when they hear liability and things like that they start paying attention.' P222, South Asian, brain hyperexcitability). Sometimes this was draining, or they felt viewed as a problem because of their empowerment:

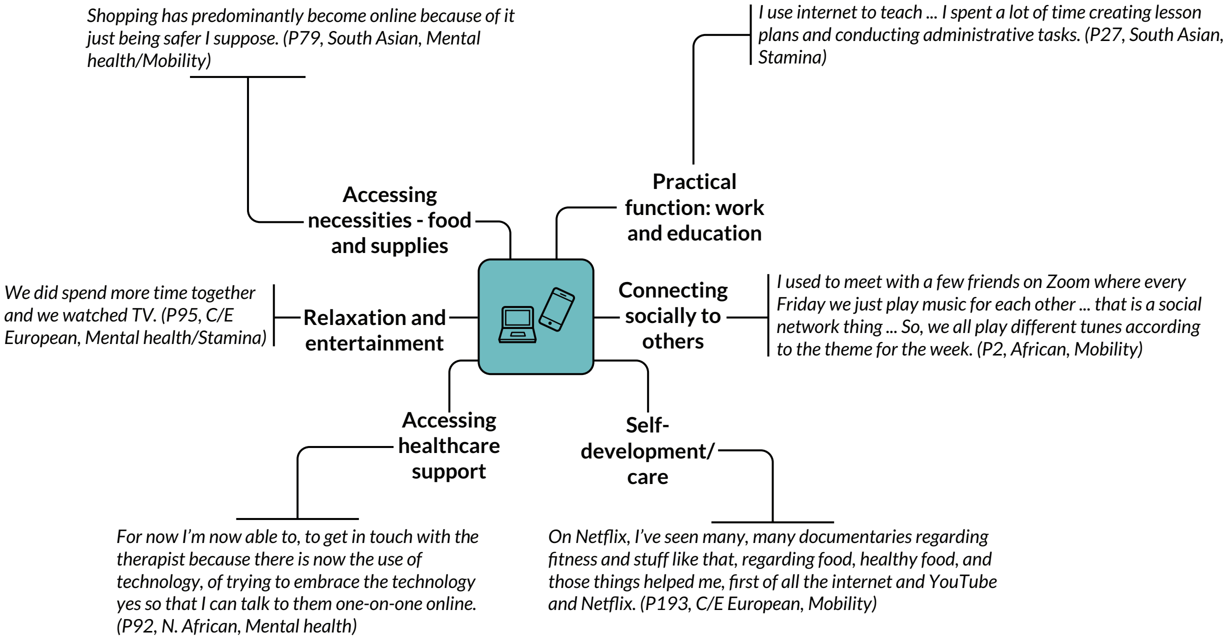
> *But what I need to do now is put all the e-mails together and do an official complaint [. . .] when it comes to [housing association], they've been really terrible and previously I've actually sued them and I had a payout [. . .]. But last year I haven't had that room for capacity to do that fight, to do that thing [. . .]. But I think definitely ombudsman is the way to go.*
>
> *P234, South Asian, stamina/mobility*

> *I had to fight really hard the last six months with their service that provides a nurse [. . .]. They stereotype us. I'm not the norm Indian woman. An Indian woman doesn't make complaints. An Indian woman takes whatever the GP says and doesn't challenge them [. . .] They put a label on me, I'm too challenging, I'm too neurotic.*
>
> *P64, South Asian, multimorbidity*

Empowerment sometimes involved playing the system rather than complaining; for example, some bypassed a stage in the process of getting to secondary care:

> *My wife came with an idea that we should at least go to the counsellor at the nearest hospital [for stress] [. . .] we didn't call anybody, we went there physically me and my wife, it was just psychological support.*
>
> *P260, Arab, mental health*

> *And it was so bad one morning that I called the paramedics, I didn't go through on 111 because – I just, you know, did a typical nurse thing [as an ex-nurse] I just called them and they said, 'Oh yes, no fine, we'll be over just to see'.*
>
> *P183, White British, stamina*



Shopping has predominantly become online because of it just being safer I suppose. (P79, South Asian, Mental health/Mobility)

I use internet to teach ... I spent a lot of time creating lesson plans and conducting administrative tasks. (P27, South Asian, Stamina)

We did spend more time together and we watched TV. (P95, C/E European, Mental health/Stamina)

I used to meet with a few friends on Zoom where every Friday we just play music for each other ... that is a social network thing ... So, we all play different tunes according to the theme for the week. (P2, African, Mobility)

For now I'm now able to, to get in touch with the therapist because there is now the use of technology, of trying to embrace the technology yes so that I can talk to them one-on-one online. (P92, N. African, Mental health)

On Netflix, I've seen many, many documentaries regarding fitness and stuff like that, regarding food, healthy food, and those things helped me, first of all the internet and YouTube and Netflix. (P193, C/E European, Mobility)

FIGURE 26 People used technology and digital tools in various ways to cope.

Reflection and self-care

Positive reflection and self-care were associated with enhanced mental and physical well-being by participants. It was undertaken by 43 people across the core ethnic groups, including 33.33% of African, 18.28% of South Asian, 17.39% of Arab and 15% of White British participants.

Strategies included hobbies, mindfulness, yoga, meditation and positive affirmation, and personal spirituality. These might also be offered by formal support services.

> *I would say self-help spiritual healing [helped me]. So, I believe in spiritual things, like karma and affirmations, and I'm doing a lot of work on myself, like rewiring, reprogramming. So, building things up to not see things from a one-pointed lens, not take things so black and white. So, I've been using the time to kind of work on the foundations with myself.*
>
> *P9, South Asian, cognitive/food-relevant*

With at least one example across all core ethnicities including White British (5% of all White British), religious faith was emphasised by 23.33% of African, 10.42% of North African and 16.13% of South Asian participants and increased in several South Asian participants during the pandemic. People used prayer to cope with COVID-19 infection, to ask God for coping tools, and for situational factors.

> *I prayed to God, but I don't know when COVID left my body. After 40 days of praying, one day I felt that I don't have any COVID. I felt better.*
>
> *Undocumented, mobility/food-relevant*

Some, particularly those whose disability made them housebound, struggled with positive self-reflection until an epiphany:

> *I knew at that point [. . .] I have to take control. And I forced myself to walk around more and slowly but surely, I started to improve and started showering, and then going to the toilet, and changing myself. Going down and sitting with my father. So, yes, I got myself in a much better position.*
>
> *P11, South Asian, mobility*

Those with financial stability and adequate accommodation used lockdown as an opportunity to focus on their self-care, following traditional recommendations for natural tonics and herbs to boost immunity, taking supplements, eating well and exercising:

> *The pandemic meant that I didn't really have to go anywhere or focus too much on other things because I could do it from home. I actually focused a lot more on my diet and my exercise. Because the only thing you could really do in the pandemic was go out for a jog or whatever.*
>
> *P26, South Asian, stamina*

Traditional remedies appeared comforting and emotion-supporting as well as being ascribed physical benefits – 'the ginger garlic drink [. . .] is good for my body and immunity [. . .] I think this makes me more confident and settled' (P100, African, cancer). People had more time to cook and think about healthy eating but could not always access the foods they needed or wanted (see *Chapter 9*).

Walking was the most popular exercise across ethnicities, even for people who struggled to walk without help. People with conditions managed by healthy lifestyles, for example diabetes, in difficult living conditions walked 10,000 steps in the flat or compound. Walking helped families bond in lockdown and meet others outside, even though they said they would all walk 2 m apart wearing masks. One person mentioned the gym.

> *I felt the advice on NHS's website and by NHS doctors are very helpful [. . .] However, sometimes it is not tailored to our condition and experiences in life, so I also started speaking to the gym instructor on how to stay healthy during lockdowns.*
>
> *P200, South Asian, stamina*

Intersectionalities

Challenges with technology included balancing excessive screen time of children and young adults; sharing time on limited Wi-Fi or hardware; stress from online learning, for example some students could not find anywhere quiet to study and sit exams in multigenerational households; sight impairment; and digital poverty. This highlights the intersectional impact of ethnicity, socioeconomic status and some health conditions.

> *With the kids being at home as well it was not easy, we have three-bedroomed house and only one computer, so the children were arguing who needed to use the computer. I had to do a timetable so they could do their classes and homework [. . .]. The youngest one, getting him to do his schoolwork is a headache, in the end we gave up, what can you do? We tried to get a laptop from the school but there was none.*
>
> *P190, South Asian, multimorbidity*

Chapter 12 Workshop findings

Co-create workshops

Participation and demographics

In April 2022, 134 interview participants were invited to workshops; 104 attended, mostly online at the participants' request. We ran the first session on Microsoft Teams; but outside the work environment, Teams is uncommon, so participants were unfamiliar with the technology. Participants got disconnected and had to rejoin each time we used breakout rooms, so we moved to Zoom. Free-flowing conversation was challenging; participants mostly kept cameras off, concerned about anonymity. Many used the chat box, but that created discordance, with parallel conversations, which was difficult for facilitators to manage.

We addressed this iteratively. We split the second session into two parallel workshops of 10 people, but this had little benefit, so we returned to workshops of 20 with breakout groups. We added facilitators from our PPI group, a Miro whiteboard and polls. The Miro visual maps (see *Appendix 4*) structured discussion on different services and how things had changed, and became useful additional data. Two workshops were held face to face, in London and Bradford, and used a comparable approach (*Figure 27*).

In September 2022, we held two London face-to-face sessions (*n* = 22), two small online sessions with participants from the Midlands (*n* = 11) – converted from a local face-to-face session at their request – and two individual remote interviews. We got minimal interest in face-to-face sessions as people had moved back into their usual routines. We discontinued online workshops because the burden of attendance appeared greater than the benefits, with a combination of: technology barriers, privacy concerns in this population, and the potential for participants to not fully invest in the process with other distractions around them.

FIGURE 27 Activities to facilitate discussion in the face-to-face workshops.

At their request, we did not retain demographic data for undocumented participants or those recruited by our charity partners. Demographic information for the remaining workshop participants is summarised in *Table 18*. Compared with those invited, this suggests the invitation was more likely to be taken up by Arab and North African people than those from South Asia, and by men compared to women.

Longitudinal reflections on health, well-being and COVID-19

Findings from the two sets of workshops are summarised in *Figure 28*. We sense-checked data on the core topics focused on in the interviews and survey. Then we simply asked participants, with some structuring to orient to relevant themes, to talk about changes. We developed change themes bottom-up from the data, which we report here.

In April participants focused on transition from the pandemic to a world opening up, but not back to normal. Overall, they indicated being less able to *bounce back* than the general population.

While participants had begun to reintegrate socially by September, continued pandemic impacts, combined with new issues, such as the cost-of-living crisis, created pessimism for the future.

Reintegration fears

In April 2022, people talked about feeling unsettled, social pressures and learning to reintegrate, having adjusted to social isolation. One blind participant highlighted changes in the environment, such as new cycle lanes, complicating reintegration. CEV participants worried about wider community disregard of COVID containment measures; their families worried about bringing infection home to them. Multigenerational households worried children would be infected at school. Overall, we found reluctance to reintegrate, and continuing precautions, such as wearing masks and avoiding people who did not.

TABLE 18 Demographic data for a subset (*n* = 75) of workshop attendees

Characteristic	% (*n*)
Gender	
Female	32 (24)
Ethnicity	
Arab/N. African	41 (31)
Black/Black British	23 (17)
South Asian	23 (17)
C/E. European	5 (7)
Other	4 (5)
Age (years)	
	Mean 31.6 (standard deviation 9.3)
Location	
South England	5 (4)
London	48 (36)
Midlands	16 (12)
North-west	13 (10)
Yorkshire	11 (8)
Withheld	7 (5)

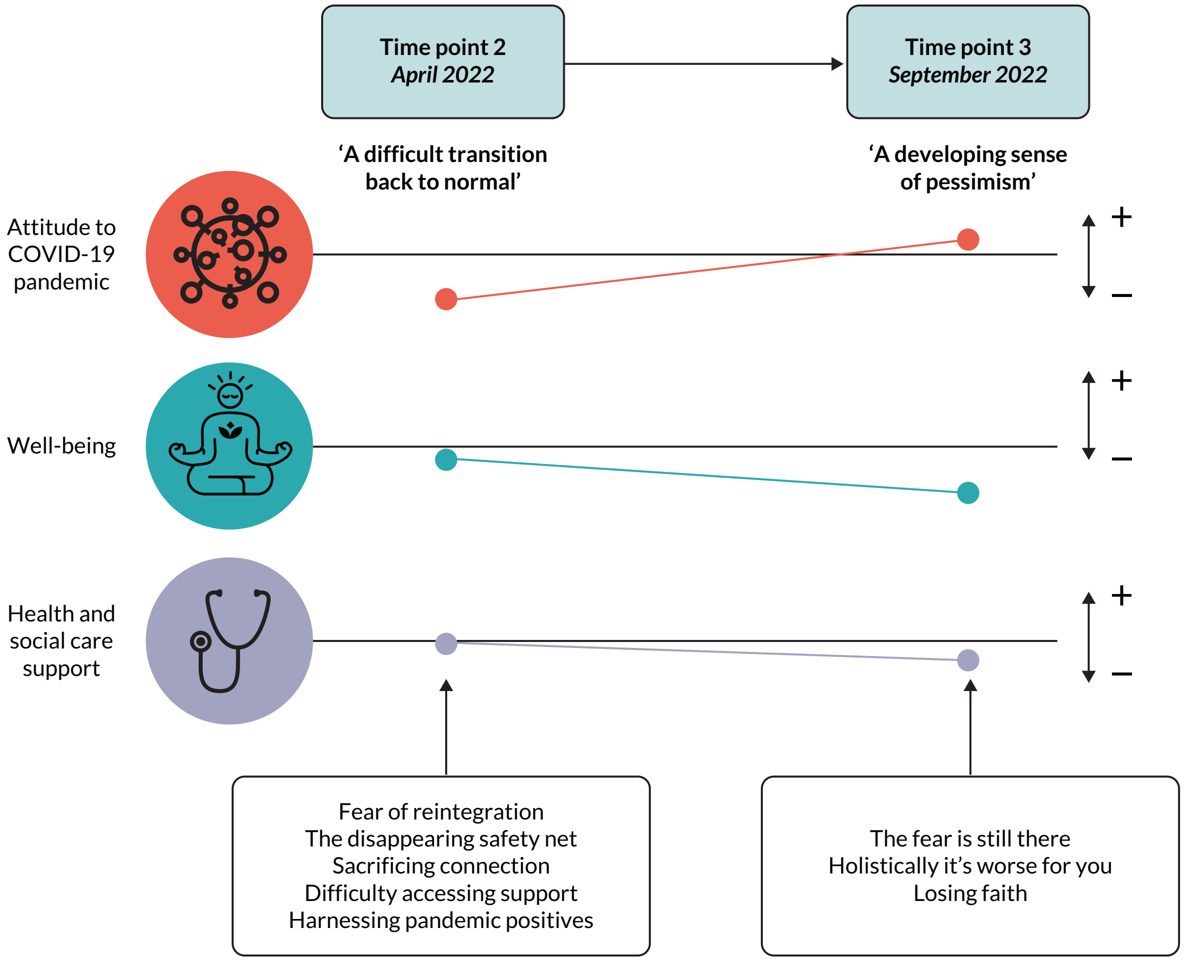


FIGURE 28 Schematic illustrating changes in attitudes at two time points.

In September 2022, most still feared infection but were more resigned to 'living with COVID'. For example, the dot voting activity (*Figure 29*) suggested that most in the Tower Hamlets workshop continued sanitising and social distancing; responses about mask-wearing were more disparate. Similar responses occurred across the workshops.

Younger participants reported that most of their contemporaries no longer took any precautions. CEV participants said mask-wearing was now 'a lifetime thing'.

Finances

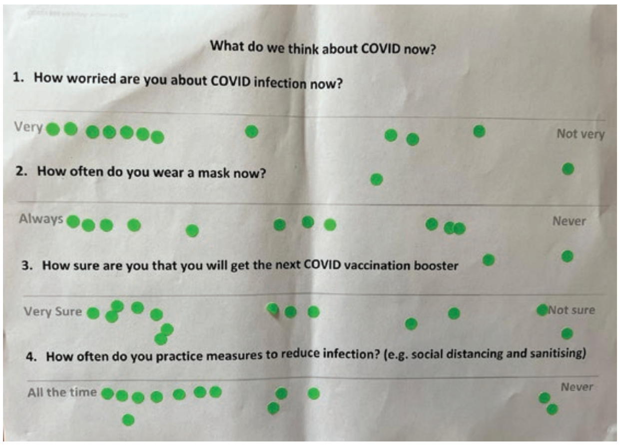
In April 2022, we heard that during the pandemic, many participants, on the poverty line, had been reliant for coping on:

- food banks and financial support for lost earnings
- charity laptops for children's home study
- online free-of-charge courses and classes.

People saw this safety net disappearing, and were anxious about coping, particularly given rising prices and withdrawal of bonus Universal Credit payments.

People felt institutions lacked empathy with their plight, exacerbating distrust of the establishment. For example, one London group questioned why schools took back children's laptops.

> *Devices came to a lot of households at that point where they needed it [. . .]. So there was a pot of money that was allowed into communities to provide those devices. But what is really sad in the community at the moment is a lot of those*



What do we think about COVID now?

1. How worried are you about COVID infection now?

Very — Not very

2. How often do you wear a mask now?

Always — Never

3. How sure are you that you will get the next COVID vaccination booster

Very Sure — Not sure

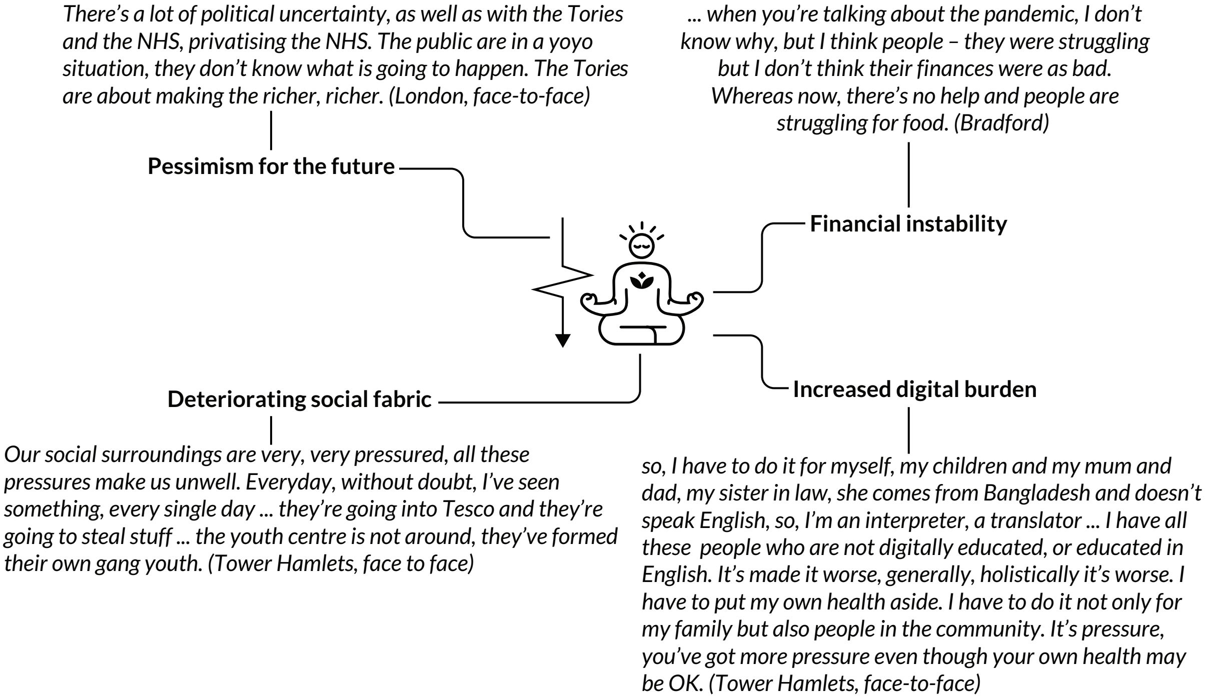
4. How often do you practice measures to reduce infection? (e.g. social distancing and sanitising)

All the time — Never

FIGURE 29 Dot voting on how you feel about COVID-19 currently (in-person workshop). Reproduced with permission from Rivat *et al.*[218] This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY 4.0) licence, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by/4.0/.

> *devices have been asked to be taken back by many of the schools [. . .] but what's happened to those devices? That's my question! Schools have taken the devices back from children who should have been left that device from a household that needed that device [. . .] and then they had to give them away to staff and some staff members had to go home with three, four tablets and laptops because the government is not taking this back, they will be scrapped, they will be put in the bin.*
>
> *Tower Hamlets, April*

In September 2022 (*Figure 30*), all workshops reported increased financial instability from the combination of pandemic impacts and the cost-of-living crisis. Fuel poverty was often mentioned ('the fuel worry will take me to my grave'). People using energy meters felt particularly disadvantaged as they could not go on fixed-price tariffs or vary their payments by arrangement.



There's a lot of political uncertainty, as well as with the Tories and the NHS, privatising the NHS. The public are in a yoyo situation, they don't know what is going to happen. The Tories are about making the richer, richer. (London, face-to-face)

Pessimism for the future

... when you're talking about the pandemic, I don't know why, but I think people – they were struggling but I don't think their finances were as bad. Whereas now, there's no help and people are struggling for food. (Bradford)

Financial instability

Deteriorating social fabric

Our social surroundings are very, very pressured, all these pressures make us unwell. Everyday, without doubt, I've seen something, every single day ... they're going into Tesco and they're going to steal stuff ... the youth centre is not around, they've formed their own gang youth. (Tower Hamlets, face to face)

Increased digital burden

so, I have to do it for myself, my children and my mum and dad, my sister in law, she comes from Bangladesh and doesn't speak English, so, I'm an interpreter, a translator ... I have all these people who are not digitally educated, or educated in English. It's made it worse, generally, holistically it's worse. I have to put my own health aside. I have to do it not only for my family but also people in the community. It's pressure, you've got more pressure even though your own health may be OK. (Tower Hamlets, face-to-face)

FIGURE 30 General well-being was reported to have declined since pre-pandemic days.

> *I feel during lockdown there was real help with food parcels from the council and my sons got support with wages when they had to work from home. But prices in the UK are going up . . . My joints get stiff when it is cold, up until May we had the heating on, but my son kept saying we need to use heating less.*
>
> *Non-English-speaking, online, September*

Many were in poorly maintained rental accommodation, with inefficient, fuel-guzzling boilers. Food prices and quality were thought worse post pandemic and food banks described as 'normalised', resulting in some authorities instigating a 12-week use cap – creating further anxiety.

Social connection

In April 2022, groups mourned the loss of interpersonal connections made during the pandemic, as people returned to previous routines or took on extra work to mitigate financial difficulties. The elderly and those staying home because of their disability were especially affected.

> *Being disabled, I had a lot of people around me during the pandemic, but currently, people are trying to go back to their normal lives and my social support system of my family is dwindling and I am kind of left alone.*
>
> *Online, April*

By September, mental health effects from social distancing and isolation were not mentioned, and people expressed relief at mixing again. However, participants also reported a deteriorating social fabric, with declines in interactional quality the new normal. For example, shop staff did not speak to customers, and violent crime and stabbing, including hate crime and racism, were thought to be increasing, driven by social unrest and poverty. Community support was withdrawn. In one face-to-face group, participants reflected that the message from the pandemic was that 'society doesn't value older people'.

Health and social care support

In April 2022, people were frustrated about continued restricted access to services and health care, a particular challenge for disabled people. Participants recognised some benefits of a hybrid online/face-to-face system, but the prevailing processes did not work for most. There was also frustration with mental health support and access to social care and other government departments.

By September, health status was mostly closer to pre-pandemic levels (excepting those diagnosed during the pandemic and some with multiple complex comorbidities). People reported some positive stories of good healthcare interactions for acute health issues and in secondary care (e.g. COVID-19 related paralysis and suspected cancer). Overall, though, the April themes continued. The new norm of hybrid care and online triage increasingly disadvantaged those with mental health issues, sensory disabilities and complex chronic conditions. For example, telephone consultations were no longer possible for a deaf participant as her partner had returned to work; the insistence on same-day appointments meant taxis and carers could not be planned and organised. Two years of largely remote care meant lost rapport with primary care teams. People missed one-to-one interaction but also felt hostility from front-line reception staff and felt healthcare staff were 'desensitised'. There was frustration that hybrid processes were not 'joined up', leaving people without medication and with lost test results. Collectively these factors meant people continued to go straight to A&E, seek private care, self-treat and on occasion 'game the system', such as by exaggerating symptoms on online triage forms to get an appointment. There was less frustration about secondary care, beyond extended waiting times. Access to social care was less mentioned, with less reliance on this than during the pandemic, but challenges remained, created by online access and budget cuts.

Other well-being points

In April 2022, participants wanted to continue the positive coping strategies they had discovered during the pandemic (see *Chapter 11*) but found this hard. Online learning was no longer free, they had competing pressures, such as the need to earn money, or they needed help with activities and their families had gone back to work. Their stories highlight the potential value of social prescribing.

> *I am suffering from the chronic depression from last 13 years [. . .]. So, what I started doing is meditation and listening music more and using video calls, that sort of things [. . .]. And doing exercise at home. So, these kind of things helped me a lot. And actually, this COVID thing has helped me a lot. Like it was a blessing in disguise that year, I have lost a lot of weight by exercising at home. I was always shy to go to gym because I was so overweight. Now I am not following the same pattern or routine because the life is coming back to normal a bit. So earlier when it was complete lockdown I followed [those] strategies regularly, on a regular basis.*
>
> *Leicester, April*

In September 2022, the new hybrid, partially digital world increased the care burden of members of minoritised ethnic communities who were tech-literate with English language skills (see *Figure 30*) supporting elders in the family and wider community – 'now we do everything. We are their advocates, their translators'.

Participants described 'deep uncertainty' in the future, disenchantment, disillusion and distrust in mainstream media. All groups discussed political uncertainty and worry, including possible privatisation of the NHS. One participant proclaimed a general disenfranchisement: 'people are moaning on social media but no one's going on the streets to complain. Once there is a crash there will be some sort of revolution'.

Ideas for change

Participants were enthusiastic, most providing more than the three ideas for change originally requested. A summary is provided in *Appendix 6*, *Table 19*.

Co-design workshops

Ideas for change from the co-create workshops were taken into the co-design workshops, described here.

Findings and proposals

We recruited 12–16 people for each workshop; the same people could not necessarily attend them all. Two workshops took place, in June and July 2022. Attendees were four charity leads, two social workers, three community leads, two patients, three clinicians, and two service managers.

Participants used their hands to animate points in their discussions in abstract ways or were very literal in the creation of scale models of objects; *Figure 31* shows examples of some models. For example, one made a model of a nose and wore it as a badge.

While the process worked well overall, no policy participants took part. Although willing to attend, timescales and the fast-changing political landscape prevailed (workshops took place just when the prime minister Boris Johnson resigned). We planned the third workshop to discuss outputs at our final event3; this was not held as planned due to train strikes, government changes and the Queen's death in 2022. Overall, participants enjoyed the experience and produced useful outputs.

Here we summarise results of our proposal development activity. Fuller findings and detail on proposals are to be published elsewhere.

Easy access: patient engagement campaign:

- **Who is it for?** GP practices and all patients – to reduce patient frustration and improve satisfaction.
- **What would it involve?** Developing a toolkit for GP practices to allow interaction with patient groups to improve online triage forms. May include workshop plan, letters, posters.

Guide to your local GP services:

- **Who is it for?** Migrants from North Africa and Central/Eastern Europe.
- **What is it?** A guide to accessing your local GP practice, what to expect, key staff functions.

FIGURE 31 Examples of models created in the workshop discussions.

The holistic umbrella: guide to understanding cultural health beliefs and motivations:

- **Who is it for?** GPs, staff, nurses.
- **What is it?** Data about hacks and approaches people used to help them in the pandemic, to help sensitise staff.

Social prescribing within chronic condition community hubs: supporting charities:

- **Who is it for?** Bromley-by-Bow Community Centre and their users with chronic conditions (primarily Bangladeshi).
- **What will it do?** Use our data to add weight to the Bromley-by-Bow Community Centre case to get support for community prescribing (including providing walking groups, creative classes, tech training, language).

Evidence-based soundbites:

- **What will it do?** Use our data to suggest useful ways to get reliable information out to minority ethnic and migrant communities.
- **Who is it for?** Policy-makers, information providers, Department of Health and Social Care.
- **What is it?** Document to suggest approaches to access people who may not trust government sources, or where information doesn't reach. Needs to be adapted to each context.

Nuancing the community ambassador role:

- **Who is it for?** Charities, policy-makers, local health authorities.
- **What is it?** Sharing our learning on how these roles may be developed to be more effective.

Key informant comments on the proposals

Co-design proposals were universally considered useful and feasible; in *Appendix 6*, *Table 19* we structure initial feedback from our four key informant interviews using the CFIR (many domains/constructs were not relevant since we presented initial ideas, not developed interventions).[110] There was consensus on the need for more work to develop the proposals, which we have planned.

Chapter 13 Discussion

Here we synthesise and discuss findings by core topic (see *Box 2* and *Chapter 2*) and objectives across our strands, considering the intersection of ethnicity, disability, citizenship status, and other factors where relevant. Objective 4, synthesis of our data, underpins this discussion, and topic 1 (intersectionality) follows the remainder as it draws on and cuts across the other topics. For qualitative–quantitative synthesis we used a matrix comparing findings. We treated strands 1, 2 and 3 as interdependent; that is, we compared similarities and differences between quantitative and qualitative results (triangulation) but focused on corroborations.[219] For qualitative–qualitative synthesis (of interview and workshop data) we merged data theme by theme and category by category based on our framework analysis.

Topic 2: behavioural responses to COVID risk reduction

Our qualitative data showed those with greater vulnerability to COVID-19 adhered strongly to COVID-19 containment measures. Social distancing, shielding and lockdowns could lead to participants, from the minoritised ethnic groups especially, feeling lonely and imprisoned, exacerbated in undocumented migrants by fear of detection and deportation, particularly during track and trace times. However, crowded accommodation, economic precarity, and (particularly for mask-wearing) some disabilities prevented adherence for several participants, as also found in a Netherlands study for African migrants.[220] Poor living conditions and 24-hour proximity to family also created stress.

Vaccine uptake was quick for the White British and Southern European participants, but those from minoritised ethnic groups took time to weigh up different factors, though almost all eventually took it. This deliberation, despite wanting to reduce their vulnerability to morbidities and mortality, should be considered by policy-makers for future vaccination campaigns. Our systematic review showed that reasons for vaccine hesitancy among Black African, Caribbean and Pakistani migrants were similar in the UK and their ancestral countries, but that, as predicted by the 5C model,[161] while the same broad factors may operate across populations, their characterisation is different in each. In both the review and our strand 3 data the main factors were a lack of appropriate information (the calculation theme in the 5C model) and lack of confidence in the vaccine; fear of side effects was significant in our interview data for the minoritised ethnic groups, corroborating other UK studies,[135–138] but not for the White British participants. White British participants were more likely to be influenced by mass media, and minoritised ethnic groups by social media and local communities.[135–138] Our core interview data suggested misinformation was most common within the Arab community and least common among the Central/East European group. African and undocumented migrants were the most likely to prefer traditional remedies to boost their immune systems, or to take the vaccine in parallel. Our concordance analysis showed South Asian and Arab participants particularly distrusted the vaccine and were also particularly nervous to risk infection outside. Unexpectedly, complacency (experience of COVID-19) and community responsibility were not prominent themes in either the review or the strand 3 data.

Topic 3, objective 3: access to resources, formal support and care

Food and medication

Our strand 3 data highlighted the issues many had with online food shopping, especially those in poverty, technologically impoverished or with disabilities affecting online navigation, as well as issues with non-familiarity with the process and the poor emulation of in-person shopping, and lack of stock, which could be critical for those needing special diets. Food banks and local food initiatives were sometimes more culturally appropriate than the government food boxes. Informal networks shopped or cooked for participants. Many were already using online prescription repeats and had good access to medication, though with some delays and shortages in the pandemic. The cost of private medication, and transport to pharmacies, was problematic for some.

Health and social care

Strand 3 data show that remote services were convenient and efficient but lacking in multiple ways. Our findings corroborate studies for people with ID,[42] dementia,[45–47] and South Asian heritage[60,61] but add nuances, which we now describe. There was a lack of holistic care and a disregard for comorbidities and intersecting factors of structural disadvantage, such as social and housing care needs. Difficulties making GP appointments by phone or via e-consult-style triage were exacerbated in those digitally impoverished, with complex health needs or not fluent in English. An informant comment that GPs felt overwhelmed because patients 'can just go on the website' encouraging more trivial help-seeking sits in tension with participant complaints of lack of online accessibility. Our data highlighted power differentials, with GP triaging decisions dictating the timing of callbacks. Non-specific remote appointment times were particularly detrimental to those lacking income or support networks. Impaired patient–clinician relationships led to perceptions of ethnic discrimination, and migrants' lack of knowledge of UK processes was seen to make them more vulnerable to being 'fobbed off' by GPs with tablets without referrals, as reported by South Asian and Central/East European participants. This illustrated the different power dynamics in remote care, and patient feelings of discomfort with telehealth; similar findings occur in other studies.[61,204,206] As with difficulties booking appointments, this led some – especially those with mental health problems and anxiety – to self-medicate differently, or research coping strategies or online videos. Issues with diagnosis and monitoring noted in the literature[203,204] were confirmed, particularly for some conditions that are hard to describe verbally or where the patient could not see. Face-to-face care continued for those most needing it. However, several participants – especially with multimorbidities – refused it through fear of COVID-19 (as found in a dementia study[47]), stopping all health care, only using remote care, reducing visits by self-medicating with reduced doses, getting vaccine protection, or choosing less busy services.

Our findings sit in tension with a systematic review of the literature on remote consultations which focused on the general population.[202] We do not support its findings – at least in our index group – of better monitoring of cases, increased insights into the home environment, or empowerment to discuss more personal issues (our findings were equivocal). We did, however, find some similar benefits – convenience, reduced risk of COVID-19 infection – and the same issues of compromised clinical decision-making, privacy concerns, technology barriers, loss of rapport, too-short consultation times, language barriers and difficulty booking consultations.

As a novel contribution, we defined three categories of treatment backlog that left people suffering for months to years, worsening their condition and expectations of the NHS. First, deferrals occurred when patients put off help-seeking because of known NHS issues or fear of COVID-19, or where primary care diagnostic processes were frozen by healthcare providers. Deferrals raise concerns regarding the pandemic's health legacy.[202] Second, secondary or social care waiting lists were joined following a GP referral, including when GP referrals had not progressed in the system due to a lack of capacity. Third, delays occurred when existing treatment, monitoring plans or social care were reduced or cancelled. These backlogs left people in limbo. Last-minute cancellations were described as poorly done. We found several participants were sufficiently empowered to take further action to get NHS care.

Private care

Another new and important finding is that many participants had never registered with a GP, irrespective of residency status. They trusted private care more (though they could not often afford it), as it better matched their expectations from their countries of origin. Poppleton[59] has described this for Central/East Europeans; we found they commonly spoke of better systems outside the UK, but this phenomenon cut across the ethnic groups. Our concordance analysis shows the financial burden was particularly described by Arab and African participants. Sometimes, the private doctor was a friend, family member or neighbour who worked for the NHS. A few used doctors in their country of origin, by phone or online, some of whom sent medicines to the UK. The issues inherent in these practices remain to be explored, though it is important for health and social care services to work alongside existing habits, processes and structures rather than criticising and discouraging them.

Patient burden and help-seeking

May *et al.*[221] described the increasing reliance of health services on individuals' self-management of their conditions, making patients increasingly accountable for this work. Overall, we found from strand 2 and strand 3 data that the pandemic increased this treatment burden, leading to a feeling of abandonment by health care, increased distrust in formal care, and increased dependence on informal relational networks. This was augmented by fear of COVID-19 and unclear information on what people should do. Similar reports of increased self-management work and linked issues were identified in a study of White British participants, many of whom were multimorbid.[57]

Our strand 2 survey data showed that NHS help improved psychological well-being in wave 1 (late 2021) and physical well-being in wave 3 (late 2022) in those with chronic conditions but reduced social well-being between these waves for unclear reasons; perhaps participants were exhorted to self-isolate early 2022 or perhaps this relates to vaccination pressures. Alternatively, the strand 3 data support the feedback loop described by Shippee *et al.*[222] whereby increased patient workload[221] from an increase in the burden of symptoms, treatment and everyday lifework caused by the pandemic reduces a patient's capacity to access health care or carry out self-care. Thus, many strand 3 participants described giving up on the NHS; others said exhortations by NHS staff to self-care did not consider the constraints of their disabilities that hindered this. They were also worried about COVID-19 infection in health-care settings. Correspondingly, in strand 2, we found having chronic health conditions could reduce help-seeking from the NHS but increase help-seeking from the community, with social and mental well-being benefits by late 2022. Increased community help-seeking may, however, also be explained if people with established disability are not in a health crisis, have learnt how to self-manage their situation, and need help for structural rather than specific health barriers. For example, many reported language barriers, interpreters with the wrong language or dialect, being 'othered' as migrant, with racist discrimination and ghosting when they spoke imperfect or accented English, and having necessary language support removed because they were conversationally articulate. This would also help explain reduced social well-being associated with NHS support, which therefore seems to have multifaceted causes.

Topic 4, objective 3: informal social networks

Our strand 1 cohort analysis showed that perceived social support, social support for sickness, and reduced loneliness were beneficial to well-being. Strand 2 data showed that community help was most likely to have physical and psychological benefits for those with chronic conditions in wave 1 (2021) and social and mental well-being benefits in wave 3 (2022). The changed benefits may reflect an opening-up of health care and the country by wave 3 and may have encouraged a shift from NHS to community support in those with chronic health conditions, as discussed in the previous paragraph. Our strand 3 data supported the importance of informal social networks for well-being, particularly for practical and emotional support. This accords with other studies, for example of ID,[42] dementia[45–48] and cancer.[49] Our concordance analysis showed that community support was emphasised by all but South Asian interviewees, but that this did not indicate its absence; South Asian participants were the most likely to live in supportive diasporic communities with larger local supportive family networks. They both sought community help and gave it; other studies have shown social cohesion reduced in South Asian and black people in the pandemic,[34] which may reflect the constraints on this caused by infection containment measures. The differences in family support between ethnic groups should be considered in policy and practice, and the nuances form a contribution of the study. Central/East European and South Asian children supported participants practically, and communications and advice should target them as well as, and differently to, older generations, whereas White British people positioned themselves as carers of children. African and North African participants spoke of supportive wider relatives, who, with friends, gave practical and financial support. Our data on employment show the effects on entrepreneurship and empowerment from this which might be better supported by policy. Differences in the use of technology should also be considered, particularly in relation to communications and the provision of credible and appropriate information. Our concordance analysis showed different groups preferred different media, used in different ways: Central/East European participants often held online gatherings and used Facebook groups, African participants networked via WhatsApp, and South Asian interviewees via Zoom, though they also set up ethnicity non-specific neighbourhood support WhatsApp groups during the pandemic. All groups used YouTube and similar online media for mental health care, self-care and empowerment (e.g. the development of hobbies, learning new skills for new employment).

Topic 5: mental and physical well-being and quality of life

Many strand 3 participants reported a pandemic-related crisis in and difficulty obtaining mental health care, causing many to turn to self-care or private care. Psychological well-being was worst in the 'minoritised ethnic–chronic conditions' group in our strand 2 data, possibly reflecting poorer access to NHS or private care. However, they had moderately good to good physical well-being, whereas White British respondents with chronic health conditions tended to poor physical well-being. This may reflect the greater number of comorbidities reported by White British respondents, though this higher prevalence may also be an artefact of structural limitations on access to support and diagnosis for people of minoritised ethnicity. It may alternatively be linked to differences in informal support networks. Our strand 3 data revealed that people of all ethnicities with lower socioeconomic status, mental health and mobility issues found physical mobility harder because of lack of outdoor spaces, cramped accommodation or dependency on others to get outside. Similarly, poor psychological and mental well-being in strand 2 was significantly associated with mobility and stamina/fatigue issues.

Like us, Poppleton *et al.*[59] reported Central and East European reluctance to seek help for mental ill health because of pride, or the taboo attached to mental health. Peñuela-O'Brien *et al.* found mental health stigma intersected with female gender, and the performance of whiteness to assimilate, so those most assimilated were more help-seeking.[223] Very few Africans talked about mental health, as also reported in the literature.[217] Mental health services and policies in Africa are limited, with a low proportion of residents there receiving mental health care. The global annual rate of visits to mental health outpatient facilities is 1051 per 100,000 population; in Africa it is 14 per 100,000[224] despite particularly high need driven by conflict and deprivation.[225] Many Africans consult traditional healers, who believe in supernatural causes and remedies, before medical practitioners. There is stigmatisation of mentally ill people, and reluctance or delay in help-seeking.[226] Nonetheless, traditional remedies and stigmatisation both occur in other regions than Africa and Central and Eastern Europe,[227] suggesting complex factors at play.

Despite these issues, in strand 3 we successfully interviewed participants with mental health issues across the range of ethnicities. Sixty-six participants had one or more clinically diagnosed mental ill health conditions. Most had comorbidities, particularly mobility and stamina (including cardiovascular conditions). Similarly, cohort studies show strong associations between conditions, such as diabetes and cardiovascular conditions and mental ill health, with a two-way effect;[228] and a pandemic study of White British participants showed similar factors influencing mental distress, with multimorbidity intersecting with fear of infection given greater vulnerability, social isolation and loss of usual support, poor housing, and the stresses of financial precarity.[57] Our qualitative data show the mobility group were particularly isolated in the pandemic, and more likely to lose their jobs, some participants having moreover lost limbs in conflict zones, all factors decreasing mental health. These relationships should be disambiguated in studies reporting mental health effects of the pandemic, particularly since they are disproportionately common in minoritised ethnic groups.

Loneliness was especially reported by Arab, Central and East European and African participants (who tended to live in areas with low densities of people of similar heritage), and White British interviewees, despite South Asian participants lamenting the loss of their previously frequent community interactions. The loneliest by disability category encompassed groups that may already have felt lonely pre pandemic, as indicated by some (with mental health, sensorial and cancer issues, neurodivergence and multimorbidities). Notably, those with no disabilities were the least lonely. Some people turned to alcohol, and a few felt suicidal (particularly those living in the south-east or who were White British or from non-core ethnic groups, possibly suggesting these had less social capital).

Topics 6 and 8, objective 2: coping and future policies

Coping, our strand 3 data show, was enhanced by combinations of adequate housing, access to green spaces, technology access, spirituality, social support, adequate health, knowledge about UK systems, education, skills and English language fluency, and income stability. This means key strategies that need better supporting by local and national policies should focus on facilitating informal connections, community and individual empowerment, and opportunities for self-care and self-improvement. Strand 3 showed these strategies were associated with reported mental and physical well-being. Some assets, such as access to technology and to courses (for hobbies, self-development or skill development), cut across strategies and should be prioritised. Others, such as spirituality, and self-care involving traditional remedies, should be better accommodated by formal services for their psychosocial benefits. Walking and dietary considerations were both mentioned by many across groups, indicating the importance of social prescribing. Stories of empowered participants, advocating for others, raising complaints, or otherwise dealing with health and social care issues, highlight pervasive challenges of White British centrism, racism and disability discrimination and the importance of capacity-building within communities. Our chapter on assets and coping strategies, our co-create work, which drew on these assets and strategies, and our knowledge exchange activities (see *Appendix 1*) show where relatively simple changes might be made with rapid impact in improving the lives of people with disabilities from minoritised ethnic groups. We are developing some of the ideas for local and regional implementation. These include a blueprint for a GP patient engagement campaign, a culturally informed guide to UK primary care service provision, a guide for GPs to understanding cultural health beliefs and motivations, support for social prescribing within chronic condition community hubs, the provision of evidence-based soundbites in culturally and disability-accessible ways, and modification of existing models for community ambassadors. Broader change suggestions from participants are provided in *Appendix 9*.

Topic 7, objective 5: local and regional differences

We have contextualised and explored geographical differences, particularly in our survey data (see *Chapter 3*) and our comparison of themes by region (see *Chapters 8–11*). These showed the importance of socioeconomic status and diasporic densities as significant intersecting factors, and more satisfaction in the devolved nations where government policies and formal care were operationalised differently. These were not simple relationships; for example, participants were least lonely in the Midlands (where recruitment was more scattered across rural areas) and the south-east. This is an unexpected finding that needs further exploration.

Our strand 2 data suggested healthy White British people do not experience the same advantage in other parts of the UK as they do in England for mental, physical and psychological well-being, though sample sizes should be borne in mind. Overall, considerations of transferability of findings need to encompass convergences and divergences across our ethnicity, disability and citizenship categories, rather than location, as discussed earlier in this discussion.

Topic 1: intersectionalities

Most systematic review studies of vaccine hesitancy showed an intersection with ethnicity and religion, with concerns over the halal status of the vaccine,[137,162–164] and individuals holding strong religious beliefs more likely to be exposed to conspiracy theories and the spread of misinformation. through religious leaders and social media platforms.[140,159] In our strand 3 interview data, local imams promoted accurate information to compensate for similar circulating misinformation, showing the importance of good relationships between community leaders and policy-makers, at least locally.

Strand 3 data highlighted the intersectional importance of participants' economic situations. We found across our data sets a severe economic effect for participants from lockdowns, pandemic job loss, precarious work (e.g. zero-hour contracts) and reduced work hours. Disabilities were factors in some employers' decisions, while some participants resigned because of the risks. The employment issues are confirmed by UK government statistics.[229] As found in other reports, the need to continue working could override fears about COVID-19,[230,231] and several families unexpectedly lost their breadwinners to COVID-19.[231] Pandemic-related economic precarity particularly affected undocumented migrants and those on non-work visas as they could not claim welfare assistance. These issues combined in 2022 with the cost-of-living crisis, leaving participants worried and pessimistic about the future. Primary survey data of mothers in Bradford and qualitative data considering the Muslim community in north-west England similarly showed financial insecurity with lost income and minoritised ethnicity intersecting to produce a worse experience.[36,37]

Our findings on the intersection of citizenship status with disability in worsening access to health care accords with other work on asylum seekers specifically,[38] but we have focused on intersectionality and have a broader range of citizenship states in our data. We have discussed how citizenship status also intersects with socioeconomic status in income, employment prospects and accessing private health care during the pandemic, and feelings of imprisonment; undocumented migrants are the most excluded, but the impacts are great for those with visa status, due sometimes to a lack of information, sometimes to racism.

We found intersections between ethnicity and mental health in perceptions of being fobbed off by health providers, though as with all intersecting relationships we report, the very nature of intersectionality means many other intersecting factors were also important, such as language fluency and degree of assimilation in the UK. We found language, culture and even disability were often not taken account of in medical care, and so could exclude, or cross religious and cultural lines, or result in inappropriate and potentially harmful intervention, or destroy clinician–patient relationships and lead to perceptions of discrimination. Our data confirm other work[216] showing that religion, culture, and the biomedical should be harnessed in tandem. There was a lack of holistic care that considered intersecting factors, despite the common coexistence of disabilities and social and housing care needs. Non-specific appointment times for remote consultations were particularly detrimental to those with combinations from among low income, disability, lack of support networks, child-care needs and lack of English language fluency. In many cases, service management of expectations would have improved experiences. NHS guidance on remote communication is weaker than for other aspects of care and does not consider the intersection of language issues with sensory loss (e.g. deafness, sight problems), age or inadequate digital skills. Our data showed this could exacerbate issues, and e-triaging was especially problematic for those with digital poverty, multimorbidities, or lack of English language fluency, as well as some specific disabilities, such as blindness, musculoskeletal conditions and neurodivergence. While strand 3 data suggested that the intersection of different minoritising factors tended to worsen experiences, participants with more disabling conditions mostly focused on disability discrimination only; and in our strand 2 data, the significant number of people in the minoritised ethnic–chronic group with better and more stable well-being shows that disadvantaged identities are not simply additive. This is likely to be dynamic and to depend on intersecting factors and contexts.

Aside from remote care, other technology-associated challenges included balancing excessive screen time for children and young adults; sharing time on limited Wi-Fi or hardware; stress from online learning and exams in multigenerational households; sight impairment; and digital poverty. Some found online shopping technologically challenging or the process overwhelming, as noted for topic 3, intersecting with their impairment, which made them dependent on others. These technology-related issues highlight the intersectional impact of ethnicity, socioeconomic status and some disabilities and health conditions.

Mobility and stamina issues intersected with cramped housing conditions, particularly likely in multigenerational South Asian migrant households, to reduce well-being during shielding, social distancing and lockdowns. This should be considered also in the context of informal support networks as we describe above; the type of support people received or lost during the pandemic, and from whom, seemed to intersect with diasporic densities, whereby South Asian communities were the largest, most established and least scattered.

Objective 1: changing patterns of need

Strand 2 survey data showed that overall, mental, physical and psychological well-being were not significantly affected by 2021–2 COVID restrictions. This contrasts with the literature[19] and our strand 1 secondary cohort analysis for the 2020 first lockdown, during which most people had worse mental well-being and psychological distress. Our secondary analysis shows that while people without disabilities (including from minoritised ethnic groups) recovered when the first lockdown ended, well-being worsened in those with disabilities. These data suggest that either those with disabilities started 2021 already at a peak of poor well-being (which is not indicated by our strand 2 data) or that by 2021 people had become more used to and less restricted by the restrictions and had learnt coping measures, an interpretation supported by our primary data. Many strand 3 participants reported loneliness, suicidality and addiction issues caused by lockdowns and other infection containment measures, but also often improvements once the country opened up and the vaccine was available. A few, however, found it hard to readjust. Participant anxieties about contracting COVID-19 from people lax in infection containment measures pertained throughout but escalated when the country opened up mid-2021.

We found several participants were initially engaged with government action in the first lockdown, but most ended up criticising it. This was fed by delays in government action or failure to follow scientific advice, inconsistent messaging, and eventually also politicians (including the then prime minister) breaking rules to suit themselves.[232]

Excepting the White British and Southern European participants, who took the vaccine when first offered, and those who researched the vaccine using official sources, many waited to see what others did and how they fared, but intended to take it, so that by the end of the study only one participant seemed to remain a vaccine-denier.

Early in the pandemic, while online and in-person shopping were problematic for everyone, disabled people in the process of being diagnosed and others who had been online shopping for years and were suddenly deprioritised as not on the CEV list were especially disadvantaged. Eventually charities got the lists expanded to other disabilities.

Treatment delays left many feeling in limbo, particularly in our later interviews, suggesting that the longer the wait, the more likely this feeling was to develop, or else that services had become less certain as the pandemic wore on. Existing patients given a revised date were initially less likely to feel in limbo, a novel finding.

Strengths and limitations and methodological issues

Ours is the most in-depth study of the lived experiences of people from minoritised ethnic groups with disabilities that we are aware of, in the context of their health and social care. While the study was framed by the pandemic, many findings are applicable more generally. We successfully applied a range of participatory and collaborative approaches to give voice to these minoritised groups, including the successful use of community co-researchers, a rare success in the field a tthe time of the study. We successfully included undocumented migrants and others with precarious status. We were complimented by participants for the research design, which led them to trust us above other researchers from their experience who had used community groups as gatekeepers but undertook all research themselves. Participants felt listened to and heard. Our engagement and knowledge exchange activities have been widely lauded, and our innovative inclusive intersectional methods praised. We recruited across a wide range of disabilities and ethnic groups. We included migrants who have undergone degrees of performed whiteness[106,223] and have shown they have common experiences with other migrants and considerable discrimination but also differences, including greater empowerment in general. We triangulated data across several methods and approaches, with good agreement between these, and our data generally confirm the findings of smaller and more focused studies, showing both the viability of our approach (one large study enabling intersectional considerations, rather than several smaller, more homogeneous, explorations) and the credibility of findings from our work and that of others in the field.

Nonetheless, the study has limitations. The complexity and inclusiveness that was praised by participants and advisers, and has been a strength of the study, has also led to challenges in integrating the findings into a coherent whole that includes focused recommendations. We therefore consider this report as an overview of our work, with more focused smaller outputs to follow it. Comparisons by category are as flawed as the categories themselves, which we expected to problematise ab initio because of our intersectional approach. They do, however, map onto government administrative data, which is important for impact. We recruited people who (it transpired at interview) had impairments that did not affect daily living, and we compared these to our core group in a sensitivity analysis, described in our analyses.

The use of counts and percentages in the qualitative chapters should be taken as indicative only and as needing further unpacking intersectionally, which we plan in further analyses of the data. The MCS, on which we based our secondary analysis, though nationally representative, comprises 89% white families, and millennium-generation family dynamics are significantly different to 1970s family dynamics, limiting transferability to older families.[233] *It excludes blindness, epilepsy, migraines, ID and dementia*.[166] Ethnicity data for MCS are recorded simply as white, Indian/Pakistani/Bangladeshi, Black Caribbean/Black African, or mixed/other and therefore lack the nuances of our primary data. We could not match respondents' area code or postcode with area-level registered COVID-19 cases, hospitalisations and deaths and social distancing adherence, due to changes in case monitoring and social distancing measures. Our survey was only completed online though we offered alternatives, suggesting some respondent bias, though our findings agree with other survey data. It was not age- or gender-representative of the population. Participants in online follow-on workshops did not engage though face-to-face ones were successful, reducing inclusivity. Our interviews were largely online and thus may have excluded some older and more disabled participants. We did not use formalised translation facilities for participant information sheets/consent, but we made sure consent was fully informed. We had formal translators/interpreters in London and Yorkshire only; these and our lay researchers ensured full informed consent for those less fluent in English. Community co-researchers and advisers endorsed this approach, including undertaking some interviews in another language than English and translating it; they knew local ways of talking, which a formal translator/interpreter may not. Mismatches of dialect and language were noted in relation to other services in the data (see *Chapter 10*). Moreover, many interviewees were undocumented and did not want to involve any formal agency. We focused in our qualitative data on England, though we have limited data from Wales and Scotland showing similar accounts and our survey was UK/RoI-wide. Our qualitative data have stronger representation by South Asians than others, though we corrected for this in analyses.

Equity, diversity and inclusion

This study had equity, diversity and inclusion at its heart. Participants came from different minoritised ethnic groups with an extensive range of chronic conditions or disabilities and citizenship states including undocumented status; quota sampling for interviews and oversampling of underserved groups in the survey facilitated this diversity. While categorising groups for analysis, we also deconstructed categories; an intersectional approach was integral to the study design. Our participant group makes the study unique and much needed to fill gaps in existing evidence. Our PPI group and lay researchers, representing the study populations, also exemplify our inclusive approach. We were sensitive to needs and adjustments through the study. All PPI and lay researchers were trained, with capacity-building throughout. Core team members, including the Chief Investigator, had lived experience of minoritised ethnicity status or chronic conditions or disabilities or both.

The impact of public involvement

At proposal stage, the PPI leads helped refine the research question, proposed methods, lay summary and public involvement sections, ensuring their relevance and appropriateness. Once the project started, they recruited nine further PPI members, ensuring a range of ethnic groups and disabilities. This group helped evaluate participant burden through the study, use of language in the lay summary and various documents, including ethics materials, recruitment posters, and the protocol paper, and accessibility and cultural needs. The leads were key in bridging researcher and PPI group speak. As the study developed, they alerted us to relevant articles, studies, policies or patient events.

Group members contributed to discussions about terminology and disability models, and were shown dissemination materials for comment, including for academic talks. One PPI lead created a video clip for a remote conference talk in 2021. All PPI members were offered co-authorship of the published protocol paper; only the leads took this up, but others wrote small blog-like website and newsletter pieces. PPI members were given the first draft of the theatre script (see *Appendix 1*) to comment on and improve and approve.

The group helped select data extracts for the workshops and recorded video and audio interpretations for these to bring the data to life. All could attend as participants, which they saw as capacity-building. Three helped facilitate the workshops, with training; their lived experience helped them empathise with participants and stimulate conversation, which was especially valuable in online workshops. They negotiated sensitivities around language and approach; for example, encouraging people to participate with cameras on in online sessions. They became immersed in the research process, including pre-briefing and debriefing sessions with the core team. They helped interpret data. One PPI member fed back:

> *The project leaders prepared me and fellow facilitators with sufficient information and knowledge to ensure that we felt confident and competent to carry out the tasks. This meant that I not only contributed to a worthy and important study, but also learnt new skills, met new friends and grew in myself.*

Patient and public involvement representatives worked alongside other stakeholders in our co-create workshops and two helped facilitate along with two lay researchers. They created a positive, trusting atmosphere which helped participants enjoy the sessions.

What went well?

- Our PPI group provided continuity from proposal through to write-up and attended and contributed to Study Management Group and Project Advisory Group meetings and activities (see *Appendix 10*), including the addition of 'public involvement' as a regular agenda item.
- Members could draw on their own networks to help with recruitment.
- The two leads split duties according to capacity and experience.
- There was mutual respect between public contributors and researchers as members of the project team and this developed into a strong relationship of trust.
- PPI members enjoyed their roles and said the opportunities we gave them were enriching. We made sure throughout that their involvement was capacity-building and never tokenistic. The group had a significant say in decision-making (e.g. contribution to project oversight groups) and dissemination (e.g. co-authoring papers and commenting on newsletters and scripts and blogs).
- One PPI lead was a point of contact for public contributors.
- The group participated in the research and co-design workshops as public members of the research team, enabling influence on theme and output development from both a project and public perspective, and stimulating discussion when it dropped.

What could have been improved?

- Reimbursement of public contributors lacked clarity despite the team's best efforts to simplify the process. This was largely because university rules changed part way through the study.
- The university needed to establish right-to-work status before PPI members could be reimbursed for time and travel and subsistence. At first, this was done remotely, but as pandemic restrictions eased, some members had to travel to the university for this, which was unexpected and onerous.
- We had not planned for times when the PPI leads were sick, leading to a heavy burden for one when the other was hospitalised; the PPI leads took this opportunity to develop clearer understanding of communication needs when sick.

Recommendations for future research

We are loath to recommend priority areas for these marginalised groups since the issues they face are pervasive. However, the pessimism our workshop participants felt and the impacts of financial as well as continuing food precarity and housing needs should be urgently explored using intersectional considerations so that the situations of the worst affected do not get diluted by the experiences of people in less severe hardship. The importance of technology to a range of strategies means this should also be a priority research area. More work is needed on the cultural acceptability and feasibility of remote consultations and how to improve them, as well as considerations of remote consultations and disability. Currently this is hampered by variability within the NHS in available technology, despite the NHS drive to its greater use.

There is a need for more assets-based research on intersectional coping strategies, which might explore some of the more significant combinations in our data through further modelling work, and also workshops and other qualitative approaches that consider transferability of coping strategies intersectionally. We are undertaking further analysis to elucidate which intersecting combinations of factors need prioritising.

Specific work is needed on the use of doctors or medicines outside the UK by migrants resident in the UK. This should ensure representation across citizenship status.

There should be more exploration of the similarities and differences in effects on well-being between different conditions, and their reasons, and the differences in empowerment between people from different migrant groups and of different socioeconomic status. The possibility that having any disadvantaged identity leads to the development of coping strategies to deal with discrimination and increase self-empowerment and resourcefulness that are helpful across additional disadvantaged identities might be explored. More work is needed on the devolved nations. In each case, studies might begin with focused quantitative work and modelling, drawing from our work, followed by qualitative methods to consider the nuances and implications.

Conclusions

We have shown that structural adversities cut across minoritised groups, including those often viewed as 'white', and that rather than considering some groups as inherently more disadvantaged depending on ethnicity or race, there is a need to look at specific contexts and individual and community strengths and assets. We have also shown that disabled White British people of low socioeconomic status will also experience many similar issues and that low socioeconomic status is a problematic product of racial and disability discrimination that cuts across experiences and groups.

Overall, our data indicated coping was especially challenging for several groups. This included people with an underlying mental health condition, or aged under 40 years with declining health associated with terminal conditions such as cancer or conditions with a lower QoL trajectory, such as multiple sclerosis. It also included people with undocumented status; those who are isolated, living alone or poorly supported socially; those in cramped, poorly maintained accommodation; those of lower socioeconomic status or in financial precarity, particularly those with job or income loss, and recent migrants funding their own health care and medications; and people with technological deprivation, less education, or food insecurity. Our data make it clear that the intersection of different factors does not simply have an additive effect. While they generally have a structural basis, we have further demonstrated how many might be partially 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.[2,111] Many of these adjustments centre on better communication practices and a better understanding of circumstances, contexts, disability constraints and day-to-day experience and needs, cultural beliefs and attitudes. Methodologically, we have shown that the voices of minoritised groups, including undocumented migrants, are easily heard if these groups are simply asked to contribute to policy and practice in appropriate ways. Doing so would enable health and social care policy and practice to draw on the strengths and assets of these communities, and break down some of the structural barriers, with more appropriate care and better outcomes for all.

Additional information

CRediT contribution statement

Carol Rivas (https://orcid.org/0000-0002-0316-8090): Conceptualisation (lead), Data curation (lead), Formal analysis (joint lead), Funding acquisition (lead), Methodology (joint lead), Supervision (joint lead), Visualisation (equal), Writing – original draft (equal), Writing – editing and reviewing (lead).

Amanda P Moore (https://orcid.org/0000-0003-2679-1907): Formal analysis (supporting), Investigation (equal), Project administration (equal), Visualisation (equal), Writing – original draft (equal).

Alison Thomson (https://orcid.org/0000-0002-9299-0130): Formal analysis (subsidiary lead), Methodology (joint lead), Writing – original draft (equal).

Kusha Anand (https://orcid.org/0000-0002-3432-3495): Formal analysis (supporting), Investigation (equal), Project administration (equal), Visualisation (equal), Writing – original draft (equal).

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Alison Fang-Wei Wu (https://orcid.org/0000-0002-8640-8351): Formal analysis (supporting), Investigation (equal), Writing – original draft (equal).

Ozan Aksoy (https://orcid.org/0000-0003-2170-6099): Formal analysis (joint lead), Methodology (joint lead), Supervision (joint lead), Visualisation (equal), Writing – original draft (equal).

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Data-sharing statement

The anonymised qualitative data from interviews and workshops, and anonymised quantitative data from surveys will be deposited for archiving and re-use according to UCL protocols existing at the time. This data will be available on request to appropriate professionals and researchers 12 months after 31 October 2022, and for up to 25 years. Archived data will be checked for anonymisation before sharing and data that is considered to be sensitive and not in the public interest will not be shared despite anonymisation. Other anonymised data will be freely shared according to extant UCL protocols, for further information please contact the corresponding author.

Ethics statement

Full Institute of Education, University College London, Research Ethics Approval (UCL IoE REC 1450 COVID-19) for this study was obtained on 21 July 2020, before the study commenced and an amendment approved 30 July 2021, and subsequently Health Research Authority approval (IRAS project ID: 310741, Protocol number: NIHR132914, REC reference: 22/SW/0002, Sponsor UCL/UCLH Joint Research Office) was obtained on 18 February 2022 to enable a change in recruitment in the final months of the study.

Information governance statement

University College London is committed to handling all personal information in line with the UK Data Protection Act (2018) and the General Data Protection Regulation (EU GDPR) 2016/679. Under the Data Protection legislation, University College London is the Data Controller, and you can find out more about how we handle personal data, including how to exercise your individual rights and the contact details for our Data Protection Officer here (www.ucl.ac.uk/legal-services/privacy/ucl-general-privacy-notice-participants-and-researchers-health-and-care-research-studies).

Disclosure of interests

Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at https://doi.org/10.3310/KYTF4381

Primary conflicts of interest: Carol Rivas was a member of the NIHR Health and Social Care Delivery Research (HSDR) Commissioning Committee (2018–22). Carol Rivas has current NIHR funding as a co-applicant with the Health Technology Assessment (HTA) programme (NIHR151372), as a co-applicant with the HS&DR programme (NIHR 157268) and as a co-applicant with the Evidence Synthesis Programme (NIHR153783). Carol Rivas reports consulting fees from Office for Students, payment from SAGE Publications, Ltd for book chapters and SAGE Methods course development, and participation on several Data Safety Monitoring Boards or Advisory Boards. Alison Thomson received a Novartis Honoraria payment for a connected presentation. No other authors have any conflict to declare.

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Appendix 1 Outputs and impact

Social media

Our project website has disseminated study news, team achievements, and outputs and celebrated team members including our PPI group. Our Twitter account feeds into it (979 impressions in January 2023 alone). We also set up a Facebook group.

Many participants were grateful for the opportunity to be heard and said during interviews that our research addressed issues of great importance to them in a sensitive and inclusive way. There were high levels of interest, with over 1794 views of our website in 6 months, leading to many requests for further information, or downloads of materials.

Teaching and education

- Intersectional and participatory methodologies used as examples in teaching across BSc Sociology and MSc Social Policy degree modules.
- Learnings on discrimination and on studies of discrimination shared in teaching and scholarly meetings.

Policy

- Policy briefs disseminated with Members of Parliament at study sites.
- We contributed to the UK Parliamentary Office of Science and Technology note on 'Invisible disabilities in education and employment'.[231]

Talks

Our Chief Investigator, Carol Rivas, was invited to give several talks:

- Royal Society of Medicine: Mental Health and Palliative Care conference plenary, 2024
- COST (European Cooperation in Science and Technology) plenary in Krakow on intersectional research, and a summer school 'lunch and learn' workshop for researchers from academia, SMEs, public institutions and other relevant organisations
- 14th Geneva Conference on Optimizing Clinical Care through Person Centered Medicine – 'Participatory research for complex interventions: involving undocumented and recent migrants', which led to involvement in the development of the International College of Person-centred Medicine annual plan of action, and an invited paper
- Wolfson Institute of Population Health (Queen Mary University London, London, UK) symposium on inequalities and social determinants of health (talk summarised in a *Lancet: Neurology* article[234])
- NIHR workshop, UCL, 22 June 2022

Team member Kusha Anand was a guest speaker at the British Sociological Association's symposium on Sociological Perspectives on the Cost-of-Living Crisis in Britain. Kusha presented the unheard voices of undocumented migrants living on the margins as part of the CICADA data set.

Other talks

- Carol Rivas (Chief Investigator) gave a talk on intersectional analysis at the 6th International Conference on Disability and Development: Disability and COVID-19, hosted by London School of Hygiene and Tropical Medicine. At the same conference, Alison Fang-Wei Wu and Kusha Anand talked on the use of disaggregated data in multimethods work.
- Carol spoke at the What Works Global Summit 2022 on our evidence syntheses.

- We had a strong presence at the British Sociology MedSoc conference with one talk in 2021 and four in 2022 by different team members, where delegates said our study made a huge impression on them. These led to further invitations to speak in small meetings and webinars.
- We had three orals at the HSR conference June 2023 and one at the COMET (communication) conference in Cork, also in June 2023.
- Carol Rivas (Chief Investigator) gave a talk at The Migration Conference, Hamburg, August 2023 on methods to involve undocumented migrants in research.

Advancement

Kusha Anand was awarded a competitive place at the National Centre for Research Methods' Reproducibility Bootcamp, organised by the UK Data Service. This included guidance on the implementation of reproducible practices across all project-related activities.

Articles and other disseminations:

- a protocol paper[111]
- a toolkit on research with migrants and disabled people[76]
- a BMC blog '"Giving voice to the under-served": the coronavirus chronic conditions and disabilities awareness study' https://blogs.biomedcentral.com/on-medicine/2022/10/26/giving-voice-to-the-under-served-the-coronavirus-chronic-conditions-and-disabilities-awareness-study-isrctn/
- two review papers in draft
- three quantitative papers submitted for publication
- draft co-create interventions/recommendations, for further development
- qualitative strand monograph
- strand 3 papers in draft
- SAGE video case study: Techniques and strategies for including people with disabilities in health/medical research
- SAGE video case study: Techniques and strategies for including ethnic minority groups in health/medical research
- NIHR final report.

Capacity-building

We endeavoured to develop capacity and are pleased to report that:

- Two lay researchers decided to pursue a research career and have been applying for positions.
- Our three postdoctoral researchers all secured other lectureship or research posts at the sponsoring university (UCL) from the day CICADA ended.

Knowledge exchange activities

Tough Cookie

We worked with 'Tough Cookie' to adapt their Mixed Mental Arts™ training programme. This is usually delivered in a corporate environment, but Tough Cookie were already developing adaptations for minoritised ethnic groups. We recommended they consider neurodivergence; but our data suggested people with chronic pain and stamina issues were most likely to benefit from our adaptation work, because of their conditions and number.

Tough Cookie is normally delivered to groups of 30, in person, over 6 weeks of half-day sessions. Adaptations were made following input from an advisory group of community leads, participant representatives and clinicians. Our participants needed something simpler, requiring shorter sessions of 2.5 hours over three sessions. They wanted sessions delivered online with adaptations to elements of language and to ensure accessibility. The feasibility evaluation was restricted to two groups of 10 people.

We undertook simple pre–post assessment of sessions, and observations of participant engagement. We were only evaluating acceptability of the programme for our participants.

While we registered our target number of participants, there was high attrition following the first session. While reports from the evaluation were reasonable, we feel the online medium did not create a trusted, safe environment for people from minoritised ethnicities. It was difficult to get buy-in from our community leads who would have preferred a co-designed programme.

The Ultimate You

The Ultimate You webinar has been designed for primary care professionals and incorporates cases from our data as exemplars. This knowledge exchange programme encourages practitioner humility with people from minoritised groups (e.g. racialised, disabled).

This webinar, while designed, has not yet been given due to illness. Knowledge exchange impact will be evaluated in a simple pre–post questionnaire.

Bromley-by-Bow Community Centre knowledge exchange event

A knowledge exchange webinar 'Bridging Two Worlds: towards holistic community-centred approaches for people with long-term health conditions' was held with our collaborators Bromley-by-Bow Community Centre, reaching 240 healthcare professionals and community members, mostly from the UK. We based this on CICADA data. It asked: 'How can primary care and personalised care work with patients with long-term health conditions to best support them and the management of their condition?' Delegates explored the lived experience of people with long-term conditions and the support structures they create and manage – and shared stories about how the structure has changed and been tested during the COVID-19 pandemic and beyond. Explanations of how ethnicity shaped people's experiences were highlighted.

Strategies considered in the webinar included self-management, advocacy for needs, learning, practical support from community, building networks and problem-solving with professionals. Delegates explored some of the opportunities presented with the advent of Integrated Care Systems and Primary Care Networks while providing practice-based examples of holistic support solutions for people with long-term conditions. It considered structural examples of why and how we must progress with initiatives such as social prescribing, and the context and opportunity for these. A community of practice formed, and examples of best practice will be summarised for dissemination.

Theatre

Cicada Stories was an interactive dramatisation of some of our participants' stories, performed on 20 September 2022 at the Bloomsbury Theatre, London. The script was based on general interview findings and verbatim text from our interviews; a professional scriptwriter provided the enveloping fictionalisation. The setting was an urban tower block; five sets of inhabitants were visited to hear their pandemic experiences. We included professional graphics for set 'wallpaper' to distinguish flats and the tower block shop. Spoken poets between scenes, and a dancer, expressed the inner worlds and emotions of stories. A question-and-answer session with the study's Chief Investigator followed, which considered learnings from the project.

When developing the performance, we originally considered forum theatre,[235] where a controversial scene is acted and the audience asked to suggest what should be done differently. This taps into cognitive processes and aims to promote deeper understanding of often taken-for-granted issues, or to develop dialogue and deliberation. Forum theatre is best suited to student and professional audiences who are used to similar processes, and who have perhaps already begun to think about the issues presented and their potential solutions.

We were producing academic outputs already, and wanted our performance to reach a different audience – ordinary members of the public, and people who had contributed to our data as participants, lay researchers and PPI members – and emotionally engage them with the stories.

We planned two performances, but the Queen's funeral meant one was cancelled. Our audience of around 200 people ranged from schoolchildren to healthcare professionals and some academics.

A study team member held post-dramatisation informal chats with the audience on the impact of the stories and to foster debate. An academic echoed the comments of service provider audience members and attending members of the public by saying:

> *The CICADA Stories performance was absolutely brilliant. The team managed to combine beautiful spoken-word poetry, with dance, drama and incredible qualitative data to create an extremely moving evening of theatre. I cannot imagine how much work went into this but it is an absolute model of how to make research come alive to an audience. Public engagement at its best.*

Appendix 2 Research governance and ethics

The study has Institute of Education, University College London, Research Ethics Approval (UCL IoE REC 1450 COVID-19) and HRA approval (IRAS project ID: 310741 Protocol number: NIHR132914 REC reference: 22/SW/0002). University College London is the Data Processor.

We intended avoiding HRA approval; this was a COVID-19 study and, operating in a changeable and fast-moving world, we planned immediate data collection. But some recruiting clinicians wanted to 'play safe'. So, although we only asked them for passive recruitment support through posters on clinic walls, halfway through the study we sought HRA approval. This took 3 months longer than normal, because staff in our local NHS Research and Development Office were either sick or on leave, or had left.

The need to approach different local CRNs following approval from the central Research Ethics Committee significantly delayed recruitment at Newcastle and Gateshead. However, when clinicians there finally started recruitment, they could access records, an option in the HRA application at clinician request. When the study ended, CRN recruitment had taken off, indicating that with speedier processes or earlier HRA application, this recruitment approach would have been successful.

Appendix 3 Ethnicities included, in detail

Arabs

Originally we considered this as an ethno-linguistic category, identifying people who speak the Arabic language as their mother tongue and who were born in and migrated from a country where Arabic is the common language. The recognised Arab world – the League of Arab States – was founded in 1945, with Arabic as the official language being the primary criterion, and consists of 22 countries: Algeria, Bahrain, the Comoros Islands, Djibouti, Egypt, Iraq, Jordan, Kuwait, Lebanon, Libya, Morocco, Mauritania, Oman, Palestine, Qatar, Saudi Arabia, Somalia, Sudan, Syria, Tunisia, the United Arab Emirates and Yemen.

This definition differs from our other categories, which were geographical, and we soon realised the benefits of subdividing it into two geographical subgroups – Middle Eastern Arabs and North African Arabs. These divisions are imperfect but recognise that Middle Eastern Arabs are more commonly considered 'white' in the UK and North African Arabs are more often a mixture of White Arabs and Black Arabs. In our analyses we found they differed in several ways.

Central and East Europeans

Eastern Europeans (with a focus on Poles) were originally chosen for their recent migration histories and because of traditionally strong differences in attitudes in countries historically associated with Eastern versus Western Europe[236] that reflect their different political histories. However, our advisory panel argued that many migrants from Central Europe are sufficiently aligned with Eastern European attitudes (though the Pew Institute says this depends on the topic) and sufficiently discriminated against in the UK that it was inappropriately exclusionary not to expand this category, especially since the two groups are often combined in policy.

Our final category encompassed countries in the geographic East that were part of the twentieth-century Soviet sphere of influence[236] and any other countries, excepting Germany, that are generally considered Central European: Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Czech Republic, Estonia, Hungary, Kosovo, Latvia, Lithuania, Montenegro, North Macedonia, Poland, Romania, Serbia, Slovakia, Slovenia, Abkhazia, Armenia, Artsakh, Azerbaijan, Belarus, Georgia, Moldova, Russia, South Ossetia, Transnistria, Ukraine.

South Asians

South Asia comprises Afghanistan, Bangladesh, Bhutan, India, Maldives, Pakistan, Nepal and Sri Lanka, all members of the South Asian Association for Regional Cooperation. The various South Asian diasporas tend to aggregate more than other diasporas, which means that at our different sites, different South Asian peoples predominated. Our Bromley-by-Bow Community Centre collaborator was in one of the most deprived areas in England, mainly Bangladeshi. Therefore, it was important to expand this category from 'Indians and Pakistanis'.

Appendix 4 Workshop whiteboards

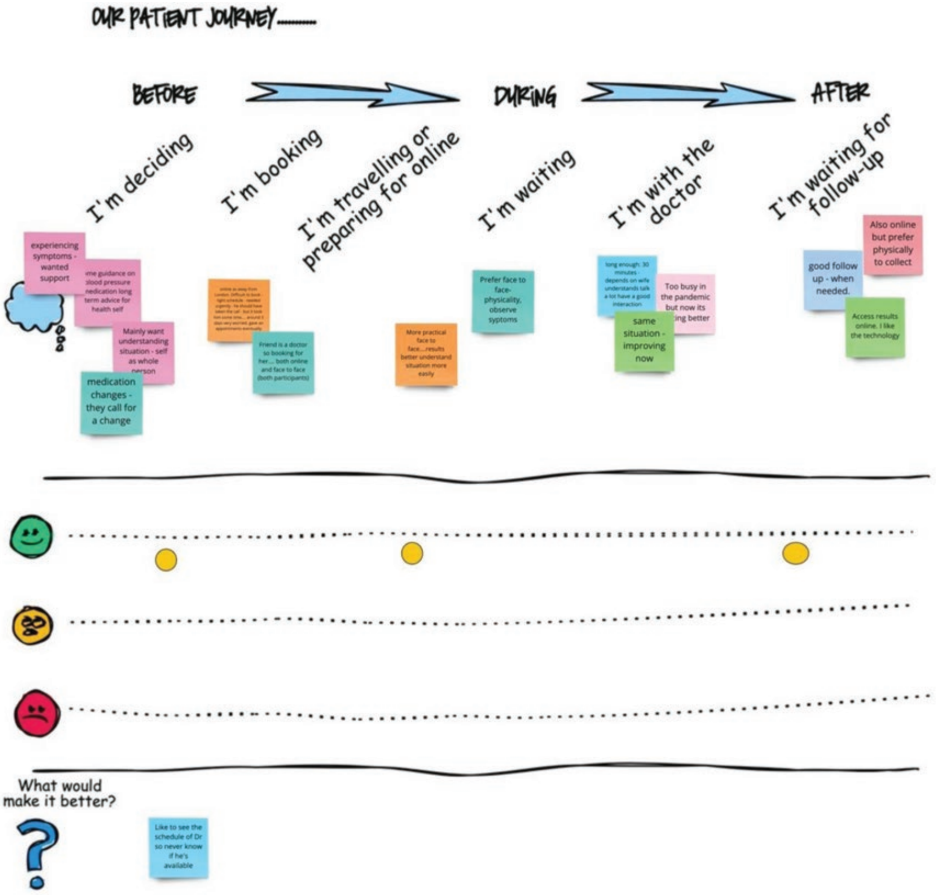


FIGURE 32 Illustration of online whiteboard for the workshops (journey mapping).

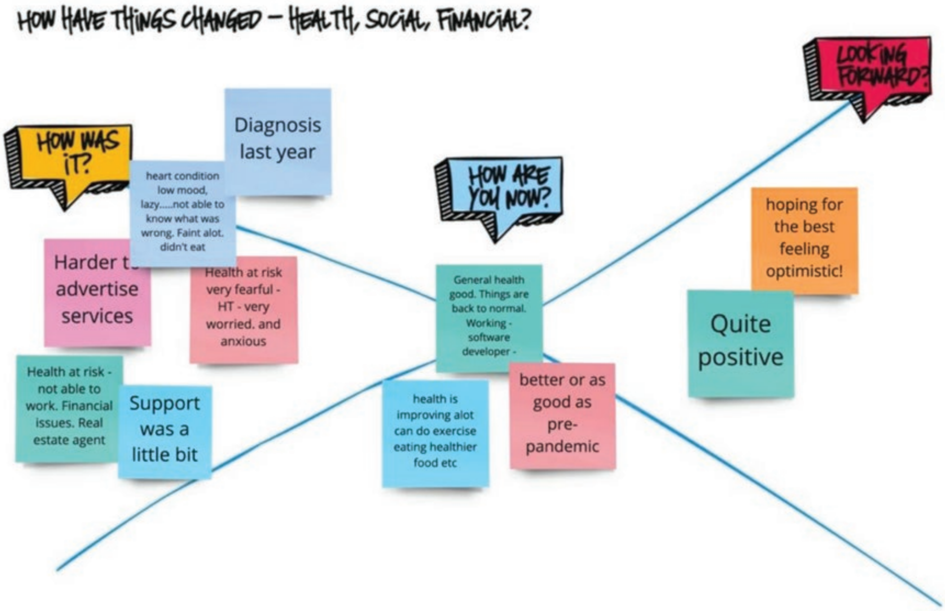
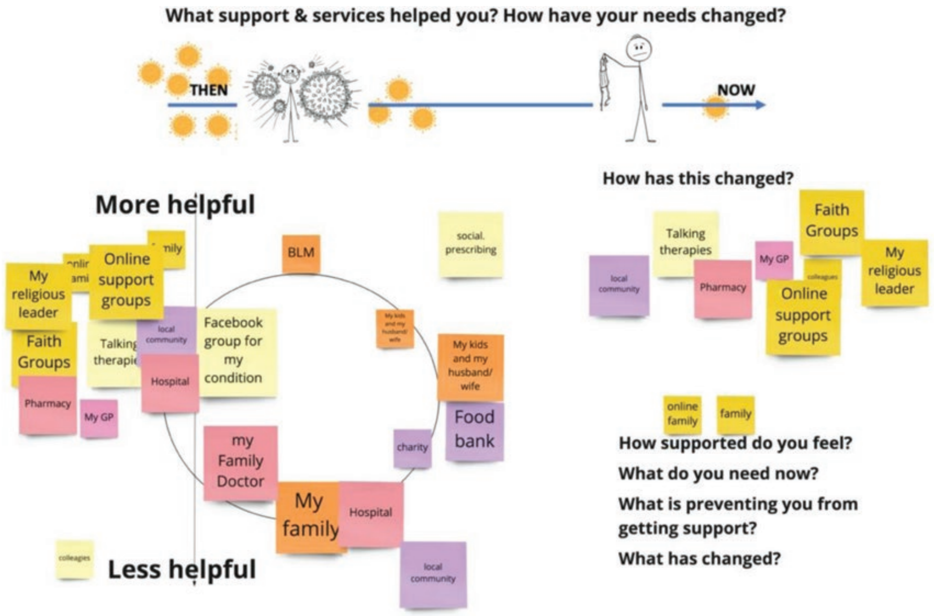


FIGURE 33 Illustration of online whiteboard for workshop (vision cone).



What support & services helped you? How have your needs changed?

How has this changed?

How supported do you feel?

What do you need now?

What is preventing you from getting support?

What has changed?

FIGURE 34 Miro online whiteboard for workshop: discussion of support and services.

Appendix 5 Themes used in the co-create workshops

Theme 1: embracing technology

This explores different ways participants used technology to help them cope. Overall, participants described using technology during the pandemic in a way that they had not done prior to this. Use included: using social media to connect and strengthen bonds between friends and family and continue engagement with faith groups; using online resources and social networking groups to develop their own health knowledge; utilising online teaching resources to develop new skills and to keep active; and using technology to access health care.

Theme 2: alternative sources of medical advice and care

This concerns sources of medical advice or care participants turned to, other than mainstream health-care services. These included taking traditional remedies; spirituality; engaging and paying for a community family doctor; Facebook condition-related support groups; and seeking medical advice from friends, family and other informal contacts.

Theme 3: looking after ourselves

Various strategies were employed to help boost health or help individuals to cope with the pandemic. For some, just having their family around was enough to help improve their health. Strategies included boosting immunity with natural remedies or lifestyle changes, taking supplements, cooking from scratch, and exercising more. Individuals also proactively sought and developed support networks and practised self-care strategies, like proactively managing their workload and reducing stress. Working from home, for some, was positive in that it helped their condition as they could manage the stimulation in their environment and have more control.

Theme 4: navigating the system and COVID recommendations

Some individuals developed their own ‘hacks’ to help them adapt to COVID recommendations. These included cultural changes such as designing something to allow you to wear a mask and a religious headscarf, things to help people cope with less support, and using online services to minimise exposure to the virus.

Theme 5: coping financially

Many participants struggled financially during the pandemic as they were unable to earn money but did not qualify for government support. Some coped by developing new skills and ventures. Others coped by accessing vouchers and receiving financial support from others.

Theme 6: supporting each other

Individuals coped both by supporting others and by being supported themselves by family friends and the community. Family and friends were particularly important, offering emotional, practical and financial support. Not everyone was supported by family, however. People found like-minded people suffering with the same condition or disability, and they supported each other.

Appendix 6 Key informant comments on co-design proposals

Initial feedback from our four key informant interviews is structured below using the CFIR (many domains/constructs were not relevant since we presented initial ideas, not developed interventions).[110]

TABLE 19 Key informant comments on co-design proposals

I. Innovation domain	
Construct name	**Feedback**
C. Innovation relative advantage	Easy Access 'This is the new normal because it's not going to go back [. . .]. E-consult now is national policy. I think our GPs' view is that e-consult in trying to solve a problem has created another problem. [. . .] The fact is our GPs also hate e-consult. I'm sure they're not unique and maybe it's the bane of every GP's life at this point. So, I would have thought there is an appetite for trying to get it more right than it is. Yes, I would have thought that would be an interesting exercise.' (KI4) '[where] I work doesn't have that, we just have [. . .] the same basic approach we had before, where people call up on the morning, then you can book them in over the next few weeks for more routine things. Receptionists tend to ask what the problem is about so they can leave a note, so that we can start to organise the day [. . .] I don't use my GP, very seldom, but they have a system where there's forms now, and I absolutely loathe it. It's the sort of thing I just feel like you put a note in a box and it just goes off into a computer and you get an answer back from someone who wasn't the person you're writing to . . . . If they tried to introduce a system like that in my own practice, I would be extremely unhappy, because of that barrier to access that it creates, and just quality. It just creates bureaucracy on the side of the practice, and it creates a poor user experience on the side on the patient.' (KI3) The politician considered e-consult especially beneficial for disabled people, those in remote areas, or with other difficulty seeing a doctor in person. However, our data suggest it creates considerable challenges for these groups. Nuanced Community Ambassador Similar existing initiatives were described by the three London informants, showing advantage. Our proposal is recognised as different to these, with a disability-specific network – considered feasible and needed. GP Guide 'This is so badly needed, yes. Difficulty being is that because GPs have just always been a herd of cats, that everyone does it in a different way. I think it's a good idea and there are probably a bunch of different formats that practices take, and it can be boiled down fairly easily.' (KI3) The Holistic Umbrella 'When you're not well, for some people you lie there and you have your blanket, your lemon and ginger and your herbal tea and herbs that you bought from home to here. . . . They need to be able to tell [the GP] what they are taking as well. What often happens is, people feel the doctors will chastise them or to treat them . . . but when you go to the doctor you should be able to tell them anything, shouldn't you?' (KI2) 'People [go] to the doctor and they said that they can't – they don't feel able to say, "Well, actually my mother died and I'm depressed. I didn't do the funeral. I can't get it out of my mind, and I don't think her spirit is resting because I am not able to do . . ." If you do that, are they just going to say you're depressed and give you antidepressants when really what you just need is somebody to acknowledge that it must be difficult [. . .] It is respecting that: this is part of my culture and it's . . . for me as a process of dealing with my bereavement [. . .]. For some people it's all about the tradition and it's all about the religion, but for so many people it's merging both religion and tradition.' (KI2) 'Having some context about those beliefs, about the other products we use, would make a massive difference to how we communicate with those people.' (KI3) Condition Community Hubs 'I think there's a lot more that we need to do around how we tailor support for people with long-term health conditions [. . .] As far as the NHS goes, they are expensive patients.' (KI4) '. . . and they don't socialise much, but I think . . . people with similar conditions and they could have . . . You know, the social aspect is really important to people's mental health, and in addition, they'd be able to cope in society. It's fantastic [idea].' (KI2)

continued

TABLE 19 Key informant comments on co-design proposals (*continued*)

I. Innovation domain	
Construct name	**Feedback**
D. Innovation adaptability	Easy Access 'They [different practices] may be working on different software platforms. The fields may be slightly different as well.' (KI4) Nuanced Community Ambassador 'Could run sessions in schools.' (KI2) GP Guide To reach everyone, recommended faith places: mosques, temples, gurdwaras, and churches. 'This pandemic highlighted their importance as essential community hubs.' (KI1) 'I don't know how you then get that to people. Ideally, you'd have the Home Office distribute it to everyone.' (KI3) The Holistic Umbrella 'Again, it's another thing of why we need people, doctors, who are actually from the same communities as those people, is that you start up a whole conversation, you don't need to do the bit where you're transactionally trying to learn what the other person is trying to communicate to you, because you already know. Your mum's probably said the same things to you. That gives patients so much better quality of care.' (KI3) 'I wonder if there's the opportunity to kind of integrate this into teaching [. . .] in sort of medical school training.' (KI4)
II. Outer setting domain	
Construct name	**Feedback**
B. Local attitudes	Various The importance of understanding language nuances '[. . .] support for those people who are speaking their language in relation to, "I know this is what we say at home. I know we would use this word or I know we would use this prayer, but has it worked for you? Do you know anybody it has worked for?" There's the big thing about media literacy and how do you establish the foundations of trust? If you're saying a few respected community leaders it might not be enough, and what if the next thing is not health advice, then I don't know. In London a whole load of imams came together and issued a statement. They had a website [. . .] really nicely laid out tiny sentences of fact checks and things like that.' (KI4)
C. Local economic, environmental, political, and/or technological conditions	Nuanced Community Ambassador 'One you share broadly as wide as possible that may be building WhatsApp networks or there are things like training volunteers to support people in certain ways.' (KI4) 'Is it a more professional role? There are also other models than just service provision. So that's kind of where I see that question. So it depends what it means and where the gap is. If it's digital exclusion (for example) then that's really specific, that's potentially a programme, like a discrete programme.' (KI4)
E. Policies and laws	'So an enormous increase in demand from food banks and a big chunk of that was because of the impact of no recourse to public funds. People just weren't able to get any income from anywhere. I raised this with the prime minister at the time and he said to me well, seems to be people who've been working hard making a contribution should get help of one sort or another [. . .] policy of the government was not to give to give that help and so lots and lots of people had a very, very, very hard time [. . .] I've tried really hard to find out from the Home Office how many people there are who've got leave to remain in the UK, but no recourse to public funds. Just so we've got some sense of the scale of this and they've, they just won't tell me. They say they don't know, which just seems a terrible reflection on them. Obvious. But of course, for people who are undocumented, by definition, there aren't any documents about them.' (KI1)
III. Inner setting domain	
Construct name	**Feedback**
2. Recipient-centredness	'There is a difference between African-Caribbean people and people from Africa. There is a difference between people from the Caribbean, who are very Christian, and people who are not; people who will talk more about spirituality [. . .]. So you can't lump people together.' (KI2)
I. Mission alignment	Nuanced Community Ambassador 'We've got heads of delivery or someone from our development team could start the conversation and see what the scope is.' (KI4) Soundbites 'So we would create WhatsApp groups, there's definite learning from that [. . .]. Again for us there's the idea of Health Creation networks – people-connected learning about their health.' (KI4)

TABLE 19 Key informant comments on co-design proposals (*continued*)

III. Inner setting domain	
Construct name	**Feedback**
J. Available resources	General Different community support resources depending on whether migrant lives in the UK in ethnically mixed areas, or in a diasporic community, or gets community support 'back home': 'Traditionally we would have men congregating, women congregating – and we have our reasoning – but coming to this society [. . .] it's difficult to get that support and that space to sit and listen.' **(**KI2**)** Nuanced Community Ambassador 'Well it feels like a big sort of question. We've had energy champions and health champions in the past. There's a huge amount of power there. I know there are some advocacy services but obviously they've got very limited capacity. There's things [to think about] like scaling and the levels of information we need to share.' (KI4) GP Guide 'We've just co-designed a resource called "Your voice in a GP appointment" which is for people with a mental health condition who are coming to a GP. We've done about 10 different workshops to create this and we're testing it now. It's taken a good six months. If you are going to do this kind of approach it takes time.' (KI4) Condition Community Hubs 'We don't have masses of capacity. The way we normally [get] evidence is we hold a workshop and turn it into key points. Then the main way we change service design is through our bid writing for the centre or the knowledge share programme.' (KI4)

Appendix 7 Codebook for thematic analysis

Name	Description
1. Intersectionalities	
1.1. Inequity	Avoidable and unfair differences in a particular condition or state or outcomes between different groups of people vs. benefits (could be in these or main benefiting groups).
1.2. Physical effects of inequities	Direct or indirect harms that accrue across all spheres of physical health – but need to be linkable to the inequity in the data vs. benefits (could be in these or main benefiting groups).
1.3. Psychological effects of inequities	Direct or indirect harms that accrue across the range of mental health areas, including but not limited to depression, anxiety, stress, and psychosis vs. benefits (could be in these or main benefiting groups).
1.4. Group or social effects of inequities	Direct or indirect harms that accrue by targeting social interventions at particular groups or parts of society, thereby worsening the experience of subsets of people within a population vs. benefits (could be in these or main benefiting groups).
1.5. Opportunity cost	The loss of one or more options, courses of action, or outcomes that is incurred by selecting an alternative one.
1.6. Place of residence/local environment	Description of features (e.g. urban/rural).
1.7. Wider determinants of health	Such as employment and environmental exposures, education, diet, gender, socioeconomic status, religion.
1.8. Social capital (including assets and negative examples)	Social relationships and networks. It includes interpersonal trust between members of a community (community spirit), civic participation, and the willingness of members of a community to assist each other and facilitate the realisation of collective community goals and the strength of their political connections, which can facilitate or complicate access to services.
1.9. Age	Events and experiences and attitudes related to age. Certain age groups can often be inequitably impacted by avoidable differences in access to services and technology and vulnerability to exploitation and to the impacts of termination or suspension of certain services such as routine healthcare services or education. Some age groups may have greater resilience or adaptability during times of crisis.
1.10. Disability or health condition	Illness, length and severity of disability or health condition or whether it is invisible or attributed to psychology ('in your head' or 'women's problems').
1.11. Citizenship status	
1.12. Family composition	Description
2. Behavioural responses to COVID risk reduction measures	To understand the context of people's lives, what responses are feasible or acceptable to them, and effects on their networks. This will help us build up a picture of potential assets and strengths and affordances (as well as issues).
2.1. Vaccination – including hesitancy and acceptance	Attitudes to the vaccine itself – COVID and generally including by individuals and their formal/informal support and care networks (e.g. friends, family, community, health/social care), attitudes towards having vaccine for other people/for themselves.
2.2. Vaccine centres and vaccine booking	Attitudes towards other people and the centres and their environment, and experiences of the centres and booking.
2.3. Attitudes and beliefs re COVID	
2.4. Other responses such as mask-wearing and social distancing	For example, for blind people.
2.5. Attitudes towards official others on the pandemic	For example, government, Members of Parliament, community leaders?
2.6. Rapid testing centres or kits	Attitudes towards rapid testing centres or kits.

Name		Description
3.	Access	Just access to, rather than experiences with (which is coded elsewhere).
3.1.	Access to formal support and care	For example, NHS (appointments), social care, shops etc., including access to mobile/in-person health services (e.g. homeless people) (access to digital infrastructure is different and covered below).
3.2.	Access to appropriate information	For example, awareness of their conditions, denial of condition by the GP.
3.3.	Access to informal support and care	For example, community, friends, family, volunteers.
3.4.	Access to digital infrastructure to access digital transformation, service innovations (online consultations)	
3.5.	Access to food needs	
3.6.	Access to medicines	
3.7.	Access to religious needs	
3.8.	Access to benefits (or financial support)	
3.9.	Access to transport	
3.10.	Access to communication	Interpreter, interpretation.
3.11.	Access to private care/family doctors	
3.12.	Access to other	Anything not covered by the above.
4.	Social network: formal and informal support and care networks descriptions	Contextualising topic 2 above for network behaviours.
4.1.	Descriptions of who is in their formal networks	
4.2.	Descriptions of who is in their informal networks	
4.3.	Frequency of contacts with informal networks	
4.4.	Frequency of contacts with formal networks	
4.5.	Strength of ties to formal networks	How good quality they are (e.g. trust, location).
4.6.	Strength of ties to informal networks	How good quality they are [e.g. obligations, reciprocations, location (could be ‘back home’)].
5.	Coping and assets	
5.1.	Physical and mental health consequences of the pandemic	So distinct from inequities though mostly linked – why they arose and what they are like.
5.2.	Social consequences of the pandemic	
5.3.	Financial consequences of the pandemic	
5.4.	COVID illness and bereavement	

continued

Name		Description
	5.5. How people coped with the pandemic (physical and mental health consequences)	Assets and strengths and also failed coping, why their illness has become severe during COVID or depression has worsened or they got long COVID; includes COVID illness (and long- or short-term effects of COVID) and bereavement.
	5.6. How people coped with the pandemic: social consequences	
	5.7. How people coped with the pandemic: financial consequences	
	5.8. Feelings about QoL and well-being	Control of life, isolation.
	5.9. Assets and strengths	For example, community, being well off, having a house.
6. Policy		Like inequity, looks at differences but rather geographically, and what we can learn of good and bad examples.
	6.1. Local/regional differences in pandemic responses	Linked to policies/interventions and including associated impacts.
	6.2. Local/regional differences in other experiences	Linked to policies/interventions and including associated impacts – can be pre-pandemic and can be about anything already considered, but policy focused, community action, evaluation, and charitable funding, lack of understanding and confusion (public health messages).
	6.3. Particular policy that targets migrants etc.	
	6.4. Particular policy that targets disabled etc.	
	6.5. Future policy implementation that is accessible to both groups	Recommendations by participants or expression of the future (e.g. their future wants and needs).
7. Racism and discrimination (covert and overt)		
	7.1. COVID and coloniality	
	7.2. COVID and capitalism	Racial capitalism, COVID and biopolitics, labour, immigration health surcharge.
	7.3. Racism in experiences of hospitalisation and vaccine take-up	Diagnosis, consultation.
	7.4. Racism and colour	
	7.5. Ableism and disablism or other comments about disability discrimination	

Appendix 8 Ideas for change

Participants were enthusiastic, most providing more than the three ideas for change originally requested. A summary is provided below.

TABLE 20 Participant ideas for policy changes

Theme	Idea
Ease financial burden	Support for child-care costs
Ease financial burden	School uniform support/open access to used uniform bank for all
Ease financial burden	Council to make houses more energy efficient
Ease financial burden	Make pre-payment meters the same price as account meters
Ease financial burden	Reduce barriers to accessing family financial support
Ease financial burden	Bring back Pharmacy First service
General health	Bring back family swimming programme
General health	Offer full health checks (annually or 5-yearly depending on health)
General health	Social prescribing: access to swimming and hydrotherapy
General health	Community growing spaces to allow growing your own food
General health	Improve bursary support to allow training of more healthcare staff
General health	Increase number of NHS dentists
General health	Improve access to secondary care appointments
General social	Youth: skill building for youth (including voluntary opportunities)
General social	Youth: community activities to reduce crime involvement
General social	Youth: young carer support
General social	Youth: improved signposting for youth services
General social	Community centre offerings: provision of classes (exercise, cooking, day trips)
General social	Parents: bring back Sure Start
General social	Community centre offerings: increase provision of classes for elderly
General social	Organise community activism
General social	Increase access to English lessons
Primary care	Improve appointment process for GP
Primary care	GP: have an assigned GP to build a relationship and who knows you
Primary care	GP: campaign to improve attitudes and interactions of reception staff
Primary care	Patient support: translators at surgeries
Primary care	Patient support: improve complaint management
Primary care	Access to advance booking, longer appointments and timed telephone consultations for those with chronic conditions
Society	Lower cost of living!
Society	Reduce food prices

Appendix 9 Broader ideas for change from the semistructured interviews

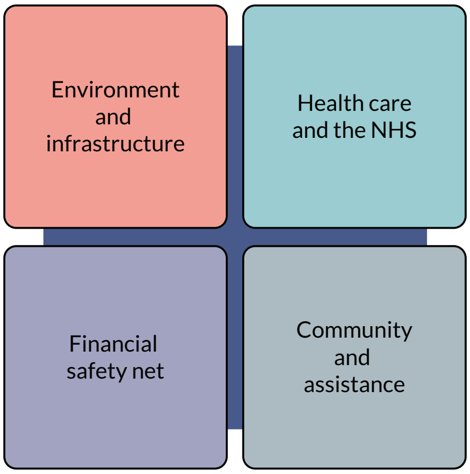


FIGURE 35 Summary of the key areas of priority for change from people with disabilities or chronic conditions.

Environment and infrastructure

South Asian participants from London proposed accessible public transportation for persons with various chronic health conditions. Participants with North African heritage from the Midlands responded that dustbins should be introduced because they have a direct impact on people's health, especially those who are deaf or have visual impairments. They also suggested that streets should be cleaned because environmental pollution has a direct impact on health.

Health care and the National Health Service

Participants with all types of disabilities and medical conditions called for a change in appointment scheduling procedures, as well as an accessible system that can be adjusted to address any problems that may arise. Participants with mental health issues called for better services by raising awareness and understanding of depression. In addition, participants from a variety of disability groups suggested that accessibility to medical equipment in the local area, faster diagnosis, and reporting can all help to improve the quality of care. This includes increasing the number of GPs (including their availability for preventative care). Regarding the quality of care and patient-centred care, participants with all types of impairments and health issues indicated further help can be obtained from GPs by implementing a better interaction plan and giving patients the option of scheduling visits face to face or online.

Financial safety net

People with disabilities of all types, of African and South Asian heritage, desire a larger safety net by expanding financing options and reducing the immigration health surcharge. They exhort the government to consider a variety of systems and actors in order to achieve societal goals as well as the balance of revenue production, expenditure, and non-economic externalities. Participants of South Asian heritage from London with numerous health conditions advocated easy access to benefits by offering instructions in a simple language and help that should be immediately available. This is true for disability benefits. In terms of coverage for medical expenses, people of African and Arab heritage who have any type of disability or health issue were the groups specifying that they need money to pay for any necessary medical charges. The flexible working hours policy thus should be changed, and others should be made aware of all limitations among participants of Arab and North African heritage.

Community and assistance

When individuals of North African heritage lacked the funds to pay their landlords' rent, they talked about community shelters assisting them. Social groups can assist people with weariness by being knowledgeable about their circumstances. Community organisations and advocates should pay attention to voices on the ground, especially those of South Asian heritage who have multiple disabilities. If local officials routinely check for rule violations by enacting local policies on compliance and checks, there would be less concern voiced about a rise in COVID infection among South Asian participants from the Midlands with heart diseases. Participants from London who have a mental health illness and are of South Asian heritage advocate for encouraging cultural sensitivity in mental health care and rejecting the 'Eurocentric perspective of thinking'. This can be accomplished through decolonising the mental health problem, retheorising the problem, and including voices from many racial and national backgrounds. Digital hubs that can teach digital literacy to persons who are having accessibility and usability issues should be established in local communities. This will lessen isolation among South Asian people who reside in the Midlands and have mobility and mental health issues.

Ideas to support migrant populations

All migrant groups call for a fundamental overhaul of the immigration system, including reasonable fees, open access to visas, and accommodations for those with impairments. Midlands residents with South Asian heritage and many chronic disabilities ask for a 'multicultural health system' by enacting 'ethnically inclusive reforms' and employing 'ethnic minority-focused therapists for Muslims'. Raising awareness of various cultures could help minimise cultural prejudices among GPs and in treatment, which should improve the health of individuals of South Asian background from the Midlands.

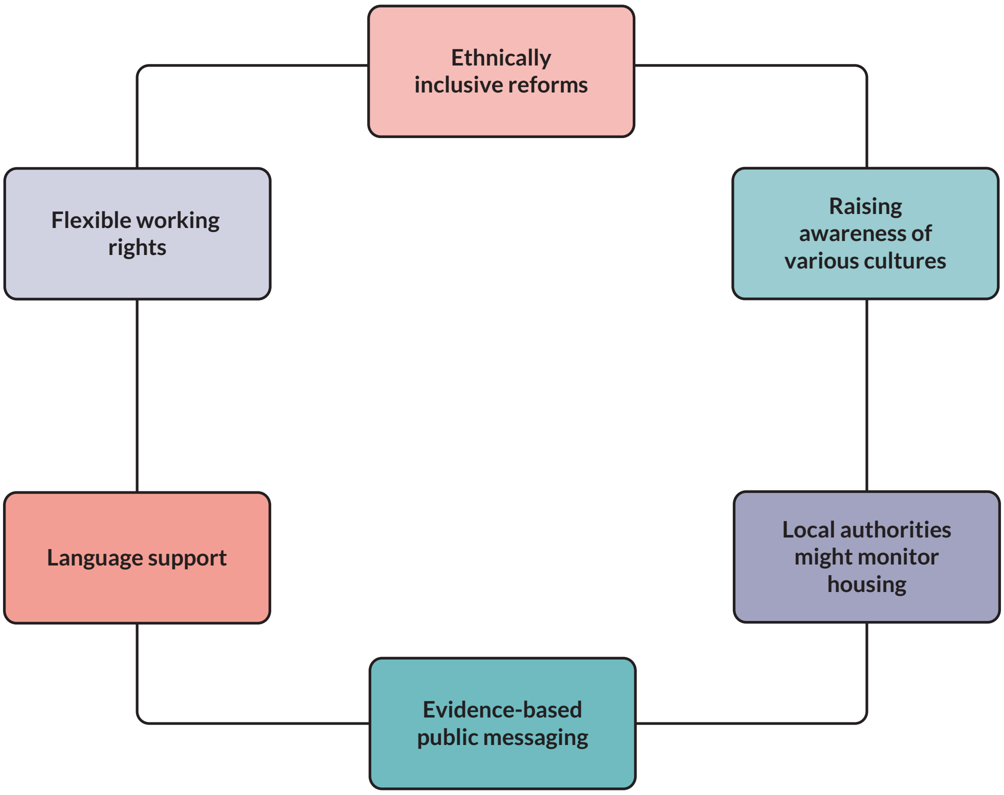


FIGURE 36 Participant suggestions for required support.

Local authorities might monitor housing, which would ease participants of South Asian heritage who reside in the Midlands. Evidence-based public messaging can lessen participants of South Asian heritage from Yorkshire's bewilderment and fear. Participants of Central European and Arab background who have numerous health issues may receive better care if there is accurate interpretation and language support. Participants of African heritage living in London should have access to 'flexible working rights' and an 'inclusive stipend system'.

Appendix 10 Study management and lay researchers

Patient and public involvement began at proposal stage with meetings with the PPI leads, who became co-applicants, then members of the Study Management and Advisory Groups once the project was funded. Both had lived experience of chronic conditions and disability, including long COVID. One was in the CEV category and South Asian. Study Management Group meetings were weekly for the core team, with others invited as needed. PPI lead meetings were 2-weekly and full PPI meetings (with 11 members) every 1–3 months, with PPI subgroup meetings (e.g. for those facilitating workshops) as needed and informal contact when small interim questions and accessibility issues arose.

Advisory group meetings were at study milestones, approximately 6-monthly. We had one independent steering committee meeting and a separate and associated Data Management Expert Committee meeting. Co-applicants/collaborators also touched base after co-create workshops to manage outputs and impact. Microsoft Teams was used between meetings. The Chief Investigator was responsible for conduct of the study, day-to-day management and decision-making, but all staff shared the same duty of care to prevent unauthorised disclosure of personal information and follow good governance. A data management plan was developed before the start of the study.

Lay researchers

This project had a strong public participatory element. People with long-term conditions or disability and from minoritised ethnic groups, who lived in our six sites across England, played significant roles as lay researchers. We recruited 12, with two online training courses (6 per course) explaining interviewing processes, participant recruitment, ethical dimensions, and including role play – interview practice. Eight went on to do interviews, undertook translating, advised us on protocols with migrants and commented on some findings. Lay researchers in Leicester, Bradford, and London helped organise face-to-face co-create workshops, increasing attendance. One helped with our systematic reviews and co-create and co-design workshops, joining all core team tasks. We provided honorary access where necessary for lay researchers and PPI members to access the Teams channels.

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