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## Long COVID and self-management

People with COVID-19 often have symptoms in the long term (ie, long COVID), including fatigue, breathlessness, and neurocognitive difficulties.<sup>1</sup> The disease mechanisms causing long COVID are unknown, and there are no evidence-based treatment options. Clinical guidelines focus on symptom management, and various treatment options are being evaluated.<sup>1</sup> The scarcity of advice has often left people with long COVID feeling isolated and frustrated in their search for therapies.

Studies have reported a wide range of self-prescribed medications being used for prevention and management of acute COVID-19, including anti-retrovirals, penicillin, vitamin C, traditional medicines, and chloroquine or hydroxychloroquine.<sup>2-4</sup> Self-prescribing practices are unsurprising given the high incidence of and mortality from COVID-19, restricted access to health care during lockdowns, and few treatments and preventive therapies for COVID-19.

There is an absence of research on self-management practices among individuals with long COVID. Patients and patient advocacy groups have reported an absence of timely support and poor recognition of long COVID, partly attributable to insufficient knowledge and evidence of long COVID and overwhelmed health-care systems. Insufficient support has led to loss of faith and disappointment in health-care service delivery, leading people with long COVID to seek alternative sources of support and treatment.

People with long COVID reported turning to a vast range of over-the-counter medicines, remedies, supplements, other therapies, and dietary changes to manage relapsing and remitting symptoms. Individuals have expressed a willingness to try anything because symptoms have substantial effects on quality of life and work capability.

There are potential risks of self-prescription, such as harmful drug-drug interactions and use of inappropriate treatments.<sup>5</sup> Medicines can be used off label, in unsafe doses, and sometimes purchased in an unregulated manner overseas. Harmful drug-drug interactions are enhanced due to the complexity and multiple symptoms of long COVID leading to use of multiple treatments.

People with long COVID have sought advice from social media platforms, such as Facebook, where individuals share their self-management experiences, and online resources, including medical blogs and journals. Due to the small evidence base, these platforms are a potential source of conflicting information and misinformation.

Self-management of symptoms in the long term is often costly, with some individuals using a substantial proportion of their income, which threatens to widen existing health inequalities. Further inequalities include geographical disparities in access to clinics for long COVID, access to private health care, and health literacy.

Research is needed to understand the self-management practices that are being used to manage long COVID symptoms; factors influencing their uptake; and the benefits, harms, and costs. There is also a need to assess the potential harmful effects of polypharmacy and drug-drug interactions in these individuals. The Therapies for Long COVID (TLC) Study (ISRCTN15674970) will begin to explore self-management practices through a survey of people with long COVID. This study aims to be a first step towards understanding this important and under-researched public health issue.

JC has participated in Patient Public Involvement for University College London and University Hospitals Bristol. JC has been a National Institute for Health and Care Excellence Covid Expert Panel lay member and a patient representative for other boards and organisations in the UK and Europe. JC has also been a received honorarium from GlaxoSmithKlein for

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## Intersectionality and developing evidence-based policy

It is reassuring to see that ministers in the UK are formally acknowledging how people from minority ethnic (ie, defined here as all ethnicities other than White British) backgrounds have been disproportionately affected by COVID-19. However, crucial gaps exist in the collection, analysis, and translation of data to assess the effects of multiple intersecting factors on individuals and communities. The Science and Technology Committee and Health and Social Care Committee report, *Coronavirus: lessons learned to date*,<sup>1</sup> dedicates thirteen paragraphs to



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how ethnicity ties into disparities and makes five recommendations for how the government could avoid these inequities in the future.

This report and those preceding it<sup>2,3</sup> acknowledge poorer COVID-19 outcomes for minority ethnic people than for White British people; they also point to structural and systemic inequalities contributing to the disproportionate effect of the pandemic and the importance of socioeconomic status. The Science and Technology Committee and Health and Social Care Committee report also goes further to attribute increased exposure to the virus to an over-representation of minority ethnic staff in front-line roles, which intersects with other risk factors, such as little access to appropriate personal protective equipment. However, reports still do not make explicit recommendations about how data should be gathered and analysed to investigate how the intersections of occupational risk, ethnicity, and other social and biological factors affect health. The continued failure to strengthen the collection and interpretation of meaningful data around health inequities in diverse populations inhibits the development of evidence-based policy to protect and support minority ethnic communities and key risk groups, such as health-care workers.

Ethnicity, occupation, gender, socioeconomic status, migration status, and other sociodemographic factors—including protected characteristics—are too often considered separately and without acknowledging heterogeneity and intersectionality within populations. As a result, policy making often overlooks how multiple social identities intersect at an individual level to reflect interlocking systems of marginalisation and disadvantage and exacerbate health inequities.

One of the important obstacles in identifying and explaining the over-representation of COVID-19-related deaths in minority ethnic people has been the scarcity of available

data across these intersecting factors, for example ethnicity and occupational risk.<sup>4</sup> Early in the pandemic, research showing the disproportionate effects of COVID-19 on health-care workers from minority ethnic backgrounds had to rely on media reports, underscoring the low availability of robust primary data.<sup>5</sup> Subsequently, primary research<sup>6</sup> has been done and new data have been synthesised,<sup>7</sup> strengthening evidence for the effects of COVID-19 on minority ethnic communities. However, mechanisms are not in place for accessible collection, analysis, and translation of data to assess the effects of multiple intersecting factors on individuals and communities.

Calls for meaningful data for ethnicity<sup>6,8</sup> and the use of an intersectional framework when developing public policy<sup>9,10</sup> have largely gone unheeded, at great human cost. We should build on urgent public health responses, such as the UK research study into ethnicity and COVID-19 outcomes among health-care workers (UK-REACH; ISRCTN11811602), and demand a framework for data gathering that facilitates easy inter-sectional analysis. The upcoming independent public inquiry into the government's handling of the COVID-19 pandemic should include a review of how relevant data are collected and made accessible. Surely one of the key lessons that we should learn from the response to this pandemic is the importance of setting up a robust system for data collection, aggregation, and analysis as a pandemic-preparedness measure rather than a response. This action will not only help to ensure future responses are quicker and more effective than was the initial response to COVID-19 but also that the government is better prepared to identify and address the multiple and intersecting factors driving health inequities.

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