justice studio.

Justice Studio: Response

Covid-19 impacts on groups with protected characteristics

April 2020

1. Executive summary

Justice Studio's response sets out our opinion and evidence. We begin by setting out who we are, and then address key concerns and recommendations around the disproportionate effects of Covid-19 with regard to two populations with protected characteristics, namely:

- Age (older adults): Dependency, perceived isolation and aging
- Race/ethnicity: Exposure, susceptibility and access

2. About Justice Studio

Justice Studio was founded in 2011 as a consultancy dedicated to advancing social justice and the voices of those less heard. We have worked in over 30 countries internationally, and extensively in the UK. A large proportion of our work is focused on the human rights of those with protected characteristics. Our clients include the EHRC, London Councils, DFID, charities and local government.

3. Primary concerns and recommendations: Older adults

3.1 **Social isolation and loneliness are two different concepts yet are interrelated.**[1] Generally, social isolation is an objective absence of social contacts or interaction between an individual and their social network (Gardener et al 99). Loneliness, however, is a subjective feeling of being alone: perceived social isolation. It is perceived isolation that can most severely impact older adults. It has shown to be a risk factor, or contribute to cognitive decline, depressive cognition, poorer executive function and overall cognitive function.[2]

3.2 **Older adults' wellbeing is supported by social networks which are compromised during lockdown.**[3] Changing social networks may compromise their ability to live independently at home, otherwise known as 'aging in place'. We have already seen the effects of this in our pan-country research into the experiences of older people during the covid 19 lockdown. **One of our research participants Doris**[4] is 77 and lives in London,

[1] Cacioppo, S. JP Capitanio, J.Tj Cacioppo. (2014). Toward a neurology of loneliness. Psychology Bulletin. Nov 140(6):1464-504 https://www.ncbi.nlm.nih.gov/pubmed/25222636

[2] Cacioppo, J.T., L.C. Hawkley. (2009). Perceived social isolation and cognition. Trends in Cognitive Science 13(10):447-454).

[3] Vos, W. H., van Boekel, L. C., Janssen, M. M., Leenders, R., & Luijkx, K. G. (2020). Exploring the impact of social network change: Experiences of older adults ageing in place. *Health & social care in the community*, *28*(1), 116–126. https://doi.org/10.1111/hsc.12846

[4] All names used are pseudonyms.

where she is an active member of her local community and pensioner groups. She has angina and survived a stroke just last year. Whilst she initially thought she might not survive a recent heart episode she made a remarkable recovery—only to be find herself in lockdown shortly thereafter. Doris is now feeling low and is anxious that society will change for the worse due to the virus and the isolation. She wonders if living in social isolation, depending on others for every need, yet not having her social network of positive support, is what it means to 'get old'; she also worries about how quickly she has arrived at being 'old'. She feels that older people 'nowadays' are much younger than they used to be—they are more connected, more active, and more visible. She fears that society might regress after this period, and that older people will truly 'be old' again. Doris's worries reflect those of several other interview participants, who until the lockdown had been living independently and within a vibrant social network of support keeping them 'young'.

3.3 **Positive aging principles are thwarted by the current directive to remain socially distanced and reliant on others for basic needs.** In the literature, prevention of loneliness is often coupled with preventing social isolation, as social isolation often precedes loneliness. Prevention of both social isolation and loneliness typically entail the promotion of independence. During the social distancing measures, aging is 'fast forwarded' and dependency on others is accelerated. The entry of carers/caregivers into the network in these conditions has been shown to be distressing and stoke fears of dependency. Social networks are both direct and indirect support systems for aging in place as they provide social outlets and buffer against stressful events.

3.4 **Loneliness can 'fertilise' other diseases.**[5] According to research undertaken at the Social Genomics Core Laboratory at the University of California, Los Angeles, loneliness can affect immune system cells, causing them to promote inflammation; sustained inflammation can, in turn, increase the risk of chronic diseases. This can lead to the build-up of plaque in arteries, the spreading of cancer cells and inflammation of the brain (leading to Alzheimer's disease). In short, "loneliness acts as a fertiliser for other diseases" and cause significant "wear and tear on the body".[6]

3.5 Early findings of our research into self-isolating adults over age 70 with underlying health conditions, has highlighted that for many of these people, living with limited mobility and in relative isolation is not a new experience. However, an emerging commonality in their experiences is an **isolation-related anxiety over premature aging**; while they had been largely independent until now, having to remain 'officially' isolated has commenced a period of dependency as their homes become de facto care homes and all basic needs are attended to by others, while social visits are curtailed entirely. Several participants in our research have already signalled the toll of this situation on their 'nerves', with some even reporting physical responses to these new stressors (e.g., skin rash), echoing the findings of the Genomics Core Laboratory, above. With limited access to social media, these people are now experiencing a sudden social isolation, coupled with ultimate reliance on others for basic needs; these two elements are oft-cited factors in premature aging and related diseases, and even perceived social isolation may contribute to faster cognitive decline, depressive cognition, and poorer cognitive performance.[7]

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[5] Statement by Steve Cole, Ph.D., director of the Social Genomics Core Laboratory at the University of California, Los Angeles, reported by the National Institute on Aging at https://www.nia.nih.gov/news/social-isolation-loneliness-older-people-pose-health-risks. See also: Cacioppo JT and Cacioppo S. Older adults reporting social isolation or loneliness show poorer cognitive function 4 years later. *Evidence-Based Nursing* 2014;17(2):59-60.

[6] Statement by Steve Cole, Ph.D., director of the Social Genomics Core Laboratory at the University of California, Los Angeles, reported by the National Institute on Aging at https://www.nia.nih.gov/news/social-isolation-loneliness-older-people-pose-health-risks. See also: Cacioppo JT and Cacioppo S. Older adults reporting social isolation or loneliness show poorer cognitive function 4 years later. *Evidence-Based Nursing* 2014;17(2):59-60.

[7] Cacioppo, J.T., and L.C. Hawkley. (2009). Perceived social isolation and cognition. Trends in Cognitive Science. 13(10):447-454. doi: 10.1016/j.tics.2009.06.005

4. Primary concerns and recommendations: Race/ethnicity

4.1 **Covid-19 does not discriminate, but our social structures do, and as such, the pandemic is exacerbating previous inequalities**. From our previous research into the outcomes of black and minority ethnic (BAME) men with prostate cancer we know that supports for avoiding and recovering from illness, including access to information, healthcare, and underlying conditions related to environmental quality, have been historically prejudiced. Ethnicity is not an absolute biological category,[8] and so the differences in ethnic groups and coronavirus impacts are less likely to be the result of genetic predisposition, and more likely to result from societal, political and cultural marginalisation—positions which are magnified by the current crisis, and which manifest in differential outcomes including immune responses, risk levels for infection, and morbidity and mortality rates.

4.2 **BAME groups have been disproportionately affected in previous outbreaks and pandemics, and emerging evidence suggests the same is true of Covid-19.**[9,10,11,12] Race, ethnicity, and socioeconomic status are reliable proxies for the complex socio-biological-environmental factors that determine health outcomes.[13,14] An extensive body of research has documented how, in the UK and other white-majority countries, black, Asian and minority ethnic communities have borne the impacts of previous influenza epidemics.[15,16] Despite representing just 14% of the UK population, 35% of critically ill Covid-18 patients are BAME according to early analysis of available data.[17]

4.3 **Based on extant research and comparable studies, we are concerned that these disparities may be attributed to three primary factors:**

4.3.1 **Disparities in the risk of exposure:** Frontline workers[18], wage workers, and those in the 'gig economy' are disproportionately BAME individuals. Between 60% and 70% of healthcare and social workers deaths have been BAME individuals.[19] A very recent report states that while Asian and black personnel

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[8] Lee, C. "Race" and "ethnicity" in biomedical research: How do scientists construct and explain differences in health? Social Science Medicine 28:1183-1190.

[9] Rutter, P.D., Mytton, O.T., Mak, M. *et al.* Socio-economic disparities in mortality due to pandemic influenza in England. *Int J Public Health* **57,** 745–750 (2012). https://doi.org/10.1007/s00038-012-0337-1

[10] Lin, L., Savoia, E., Agboola, F. *et al.* What have we learned about communication inequalities during the H1N1 pandemic: a systematic review of the literature. *BMC Public Health* **14,** 484 (2014). https://doi.org/10.1186/1471-2458-14-484.

[11] Financial Times. https://www.ft.com/content/5fd6ab18-be4a-48de-b887-8478a391dd72

[12] Hutchins, S. S., Fiscella, K., Levine, R. S., Ompad, D. C., & McDonald, M. (2009). Protection of racial/ethnic minority populations during an influenza pandemic. *American journal of public health*, *99 Suppl 2*(Suppl 2), S261–S270. https://doi.org/10.2105/AJPH.2009.161505

[13] Drake, K. A., Galanter, J. M., & Burchard, E. G. (2008). Race, ethnicity and social class and the complex etiologies of asthma. *Pharmacogenomics*, *9*(4), 453–462. https://doi.org/10.2217/14622416.9.4.453

[14] Marmot MG, Shipley MJ, Rose G. Inequalities in death--specific explanations of a general pattern? Lancet. 1984;1:1003–6. A classic investigation of the effect of social class on disease. [PubMed] [Google Scholar]

[15] H Zhao, RJ Harris, J Ellis, RG Pebody. Ethnicity, deprivation and mortality due to 2009 pandemic influenza A(H1N1) in England during the 2009/2010 pandemic and the first post-pandemic season. Epidemiol Infect, 143 (2015), pp. 3375-3383.

[16] Sandra Crouse Quinn, Supriya Kumar, Vicki S. Freimuth, Donald Musa, Nestor Casteneda-Angarita, and Kelley Kidwell, 2011: Racial Disparities in Exposure, Susceptibility, and Access to Health Care in the US H1N1 Influenza Pandemic. American Journal of Public Health 101, 285_293, https://doi.org/10.2105/AJPH.2009.188029

[17] Intensive Care National Audit and Research Centre. https://www.icnarc.org/DataServices/Attachments/Download/76a7364b-4b76-ea11-9124-00505601089b

[18] Siddique H. UK government urged to investigate coronavirus deaths of BAME doctors https://www.theguardian.com/society/2020/apr/10/uk-coronavirus-deaths-bame-doctors-bma

[19] GP Online. https://www.gponline.com/government-move-faster-protect-bame-doctors-covid-19-deaths/article/1681449

make up 10% and 6% of the NHS workforce, respectively, they account for 36% and 27% of known NHS worker deaths.[20]

4.3.2 **Access to healthcare and factual information:** Significant disadvantages related to socioeconomic factors and access to basic care and information compound risk factors.[21,22] Further, many underlying conditions relevant to Covid-19 severity (such as asthma) require self-management, which is more difficult to embed in populations with lower rates of health literacy.[23] Previous examples from influenza outbreaks find relationships between ethnicity and socioeconomic deprivation and health-seeking behaviour, particularly, in access to antivirals in a pandemic.[24] Further, alarming disinformation—such as rumours that people with dark skin are not affected by coronavirus—has gained traction on social media channels since January, and has been echoed by media personalities with little or no effort to dispel such myths.[25]

4.3.3 **Susceptibility due to underlying conditions:** Emerging reports on the relationship between heart disease and Covid-19 include a letter published April 29 in the New England Journal of Medicine[26] detailing five young and middle-aged Covid-19 patients who suffered large vessel strokes across a two week period, suggesting a relationship between Covid-19 and large vessel blood clots, even in a-symptomatic patients. Similar research in the Netherlands supports this, demonstrating higher rates of thrombotic complications in 184 critical Covid-19 patients with pneumonia (31%).[27]

Heart disease and hypertension (high blood pressure), both emerging factors in the severity of Covid-19 cases, are also correlated with lower socioeconomic status[28] and with ethnic minorities. In the UK, the burden of cardiovascular disease is higher among those with South Asian heritage,[29] while occurrence of stroke is higher among African-Caribbean groups.[30] Repeated studies show hypertension is greater in Afro-Caribbean men (30.8% in 2002) and women (34.4%) compared to white men (19.4%) and women (12.9%).[31] Further, African-Caribbean ethnicity is associated with a hypercoagulable state and thus risk of venous thromboembolism, or clots in deep veins.[32]

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[20] HSJ. https://www.hsj.co.uk/exclusive-deaths-of-nhs-staff-from-covid-19-analysed/7027471.article
[21] JAC Online. https://www.jacionline.org/article/S0091-6749(18)31732-9/abstract
[22] Asthma.org. https://www.asthma.org.uk/dd78d558/globalassets/get-involved/external-affairs-campaigns/publications/health-inequality/auk-health-inequalities-final.pdf
[23] Asthma.org. https://www.asthma.org.uk/dd78d558/globalassets/get-involved/external-affairs-campaigns/publications/health-inequality/auk-health-inequalities-final.pdf
[24] Shamil M.M. Haroon, Gregory P. Barbosa, Patrick J. Saunders, The determinants of health-seeking behaviour during the A/H1N1 influenza pandemic: an ecological study, *Journal of Public Health*, Volume 33, Issue 4, December 2011, Pages 503–510, https://doi.org/10.1093/pubmed/fdr029
[25] BBC. https://www.bbc.co.uk/news/world-us-canada-52245690
[26] New England Journal of Medicine. https://www.nejm.org/doi/full/10.1056/NEJMc2009787?query=RP
[27] Medscape. https://www.medscape.com/viewarticle/929345
[28] Individual social class, area-based deprivation, cardiovascular disease risk factors, and mortality: the Renfrew and Paisley Study. Smith GD, Hart C, Watt G, Hole D, Hawthorne V J Epidemiol Community Health. 1998 Jun; 52(6):399-405.
[29] Ethnicity and cardiovascular disease prevention in the United Kingdom: a practical approach to management. Lip GY, Barnett AH, Bradbury A, Cappuccio FP, Gill PS, Hughes E, Imray C, Jolly K, Patel K J Hum Hypertens. 2007 Mar; 21(3):183-211.
[30] Ethnic differences in incidence of stroke: prospective study with stroke register. Stewart JA, Dundas R, Howard RS, Rudd AG, Wolfe CD BMJ. 1999 Apr 10; 318(7189):967-71.
[31] Lane, D., Beevers, D. & Lip, G. Ethnic differences in blood pressure and the prevalence of hypertension in England. *J Hum Hypertens* 16, 267–273 (2002). https://doi.org/10.1038/sj.jhh.1001371
[32] Blood Coagul Fibrinolysis. 2013 Jan;24(1):40-9. doi: 10.1097/MBC.0b013e32835a07fa. African-Caribbean ethnicity is associated with a hypercoagulable state as measured by thrombin generation. Roberts LN[1], Patel RK, Chitongo P, Bonner L, Arya R.

Together, these studies suggest ethnicity may be a predictive variable in determining Covid-19 health outcomes. Again, this is not due to inherent biological differences between groups, but because of environmental and social factors that impact different groups disproportionately. It is also important to recognise that the severe cases involving blood clots highlighted above occurred in otherwise young and healthy patients with few or no Covid-19 symptoms, meaning those most affected may not be sheltering in place as they will not consider themselves at risk.

4.4 **Environmental and ecological factors exacerbate underlying conditions in BAME populations**. Environmental factors, including pollution and living conditions, are related to respiratory conditions, such as asthma. Asthma and related chronic illnesses are demonstrably influenced by socioeconomic status, and are more common in ethnic minorities.[33,34] Covid-19 affects breathing and respiratory systems and chronic asthma sufferers are considered at high risk for developing severe coronavirus symptoms. Importantly, many chronic breathing problems are caused by the pollution that characterises the poorest areas of the UK.

4.4.1 **The inequalities that correlate with BAME populations affect people with asthma and is more prevalent in deprived communities.**[35] Asthma is not only more prevalent in deprived communities, but those living in more deprived areas of the UK are more likely to require hospital treatment for asthma.[36] This is no surprise, given that 66% of anthropogenic carcinogens are emitted in the 10% most highly deprived English city wards,[37] which are also less likely to have access to green spaces and associated air quality benefits, and receive less spending on public transport.[38]

4.4.2 **Overcrowded living conditions** also make social distancing measures less attainable, and are more likely to affect BAME groups. For example, among UK Bangladeshi populations 30% are considered to live in overcrowded housing. For black Africans and Pakistanis this is 15%[39]. Some of the disparity shown in early studies of Covid-19 deaths and BAME populations may be accounted for by higher transmission rates in densely populated areas, such as large cities, where there is a higher BAME population.[40]

4.5 **Data around protected characteristics, including racial/ethnic disaggregated data in Covid-19 cases and mortalities, must be collected and analysed.** Previous studies on race, ethnicity, and viral outbreaks/epidemics have called for the collection of individual-

[33] Forno, E., & Celedon, J. C. (2009). Asthma and ethnic minorities: socioeconomic status and beyond. *Current opinion in allergy and clinical immunology*, *9*(2), 154–160. https://doi.org/10.1097/aci.0b013e3283292207
[34] Netuveli, G. Hurwitz, B. Sheikh, A. 2005. Ethnic variations in incidence of asthma episodes in England & Wales: national study of 502,482 patients in primary care. Respiratory Research. Accessed at https://respiratory-research.biomedcentral.com/articles/10.1186/1465-9921-6-120.
[35] Asthma.org https://www.asthma.org.uk/dd78d558/globalassets/get-involved/external-affairs-campaigns/publications/health-inequality/auk-health-inequalities-final.pdf
[36] Asthma.org https://www.asthma.org.uk/dd78d558/globalassets/get-involved/external-affairs-campaigns/publications/health-inequality/auk-health-inequalities-final.pdf
[37] Marmot, M. 2010. Fair society, healthy lives. Accessed at http://www.instituteofhealthequity.org/resources-reports/fair-society-healthy-lives-the-marmot-review/fair-society-healthylives-full-report-pdf.pdf.
[38] Public Health England. 2016. Working together to promote active travel: A briefing for local authorities. Accessed at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/523460/Working_Together_to_Promote_Active_Travel_A_briefing_for_local_authorities.pdf.
[39] Gov.uk: Overcrowded households. https://www.ethnicity-facts-figures.service.gov.uk/housing/housing-conditions/overcrowded-households/latest#by-ethnicity
[40] Nuffield Trust. https://www.nuffieldtrust.org.uk/news-item/are-more-black-asian-and-minority-ethnic-people-dying-with-covid-19-than-might-be-expected

level data on ethnicity during future pandemics,[41] as well as qualitative research to examine reasons for disparities in health outcomes.

One recent report found none of the ten countries with the highest Covid-19 cases have reported ethnicity data; this includes the UK, where ethnicity has not been a required metric. Early findings among mortality rates where race/ethnicity data are available suggest this is a dire oversight. While death certificates may list country of origin, we understand that this is not shorthand for ethnic identity in any applicable sense—the way a person has lived their life, what groups they interact with, or what exposure that may have entailed. However, we support early and emerging efforts to correlate self-identifying racial/ethnic categories with health outcomes and urge decisionmakers to funnel resources toward furthering these inquiries.

4.6 **Data collection must be followed with critical, systematic analysis to determine correlations between self-identified race/ethnicity and Covid-19-related health outcomes.** Calls for urgent public health research into race and ethnicity with relation to Covid-19 has been very recently highlighted in leading journals. Much of this has drawn attention to comorbidity burdens relative to race and ethnicity, education and understanding around Covid-19, and social behaviours (such as interaction with unwell and holding social/familial gatherings).[42]

4.7 **Responses must address racial/ethnic specificities.**[43] This must include close attention to, and sustained efforts to engage with, communities that have a historic distrust of authorities and health researchers such as BAME groups which is an understandable feature of research due to historic research abuse. Already during Covid-19 concerns arising from two French doctors' suggestion that vaccine trials be undertaken on African populations in the Democratic Republic of Congo[44] have left many UK black populations worried that any covid-19 research will involve injections or vaccines etc. This is something that we encountered when recruiting for our purely qualitative peer research with older people, and steps must be taken to ensure that any research is transparent and non-abusive, invasive or exploitative. Previous research into health crises and race has made use of existing datasets to inform present-day decision-making. We support efforts to rapidly review data from previous outbreaks to save BAME lives today.[45]

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[41] Shamil M.M. Haroon, Gregory P. Barbosa, Patrick J. Saunders, The determinants of health-seeking behaviour during the A/H1N1 influenza pandemic: an ecological study, *Journal of Public Health*, Volume 33, Issue 4, December 2011, Pages 503–510, https://doi.org/10.1093/pubmed/fdr029

[42] Pareek, M. M.N. Bangash, N. Pareek, D. Pan, S. Sze, J.S. Minhas, W. Hanif, K. Khunti. 2020. The Lancet. In Press 21 April 2020 (corrected proof). https://doi.org/10.1016/ S0140-6736(20)30922-3

[43] Sonja S. Hutchins, Kevin Fiscella, Robert S. Levine, Danielle C. Ompad, and Marian McDonald, 2009: Protection of Racial/Ethnic Minority Populations During an Influenza Pandemic American Journal of Public Health 99, S261_S270, https://doi.org/10.2105/AJPH.2009.161505

[44] Quartz Africa. https://qz.com/africa/1836272/french-doctors-say-test-covid-19-vaccine-on-africans-spark-fury/

[45] Science Magazine. https://www.sciencemag.org/news/2020/04/how-can-we-save-black-and-brown-lives-during-pandemic-data-past-studies-can-point-way