Report November 2022

Review of the Mayor of London's Health Inequalities Test

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About the report

This review was commissioned and funded by the Greater London Authority through a competitive tender process. The GLA sought a review of the 'health inequalities and prevention of ill health' test of the Mayor's six tests, with a particular focus on: inequalities in access to, experience of, and outcomes from health services; the disproportionate impact of Covid-19 on particular groups in London; and providing clarity to the NHS about what response and action the Mayor expects from the test. The overarching aim of the review was to develop recommendations for the future of the test as it is applied to major health care reconfigurations in London, taking into account the remit the Mayor has with regards to the NHS and his interest in reducing health inequalities in the capital.

Acknowledgements

We are grateful to the over two dozen senior NHS managers and leaders who agreed to be interviewed for this review to help inform our understanding, both of existing NHS action on health and health care inequalities, as well as opportunities and challenges for further progress. Our approach and questioning was also informed by patients and clinicians who shared their experiences and views on what needed to change and we are indebted for the time they gave us for this.

We would also like to thank the health team at the GLA, particularly Tom Coffey, Abisola Babalola, Charlotte Hall and Jill Wiltshire, who provided useful support and insight throughout the review, including around the relationship between the NHS and local government in London. Professor Richard Cookson at the University of York and Dr John Ford at the University of Cambridge generously gave us the benefit of their time, expertise and critical approach to health inequalities. This report has also benefited from the expertise and input of multiple colleagues at the Nuffield Trust, in particular: Nigel Edwards, Helen Buckingham, Sarah Scobie, Chris Sherlaw-Johnson, Eilís Keeble, Rebecca Rosen, Louella Vaughan, Leonora Merry, Rowan Dennison, Mark Dayan and Meilir Jones. Any flaws or oversights in the report remain the authors' own.

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Contents

	Executive summary	2
	Introduction	6
1	The impact of the coronavirus pandemic	13
2	Survey of the evidence base	26
3	Health and health care inequalities in major NHS service reconfigurations	40
4	Is the Health Inequalities Test fit for purpose? Recommendations for change	49
	Glossary of terms	54

Executive summary

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This review of the Mayor's Health Inequalities Test was undertaken to make proposals to help strengthen the test as a tool to leverage focus and change on health and health care inequalities, as well as provide clarity to the NHS about what is expected in response to the test.

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The Mayor's Health Inequalities Test is part of a framework of six tests applied to major NHS service reconfigurations, which the Mayor uses to seek reassurance that such changes will result in equitable, sustainable and high-quality NHS services for Londoners. The Health Inequalities Test is being reviewed in the light of the unequal impact of the Covid-19 pandemic in London, which highlighted the devastating impact structural inequalities have on the health of people living in deprivation and across London's minoritised ethnic communities.

The review draws a distinction between health inequalities and health care inequalities, which are both within the scope of the test. The former are indicated by the unequal distribution of disease and healthy life expectancy at birth between different social groups, and are in large part driven by systematic inequalities in the social determinants of health such as housing and wealth. It is widely accepted that action to address health inequalities will require coordinated action and changes beyond the scope of individual clinical services acting alone, including in the economy, and in central and local government. However, there is also a clear role for the NHS in addressing health inequalities through its work in preventative care, and through its status as an "anchor institution" in the communities it serves – able to reshape some of the social determinants of health as a large employer and consumer.

Health care inequalities by contrast are indicated by unequal rates of access (relative to need) to health care services, and in inequalities in the experience and outcomes that different social groups obtain from those services. Action to address these inequalities falls squarely under the NHS's control, and so forms the focus of this review. As health care services are a microcosm of the societies they serve and stem from, the same social groups which tend to experience the worst health inequalities are also most at risk of experiencing

health care inequalities. This means the NHS can miss opportunities to ameliorate health inequalities, and underlines the importance of bringing special focus to the inequalities in health care access, experience and outcome which are encountered by groups who also face the poorest levels of health status or healthy life expectancy.

To understand this context in the capital, the review explores the impact of the Covid-19 pandemic on health and health care inequalities in London and considers the dynamic it exposed whereby already disadvantaged groups were further disadvantaged when their life circumstances were not fully considered in the design of public services and policy. This marginalising dynamic was apparent during the early stages of the Covid-19 pandemic when "lockdown" policy was poorly tailored to people unable to claim or live on furlough payments, or who were in insecure employment, or in key worker jobs, or who lived in multi-generational households, with older people unable to isolate from school-age children and those working outside the home. The intersection of ethnicity and deprivation meant this dynamic disproportionately affected London's minoritised ethnic groups, who experienced death rates far higher than white groups.

The NHS vaccination response to the pandemic represented an attempt to disrupt this dynamic by involving minoritised communities in the design and delivery of the vaccine. Although this experience offered valuable lessons and relationships the NHS is now keen to build on, calls to tackle the significantly higher risk from Covid-19 faced by minoritised ethnic groups by prioritising those groups for earlier vaccination were not adopted in government policy. This was in part due to concerns this might fuel further racist stigmatisation, and in part due to the absence of robust data on ethnicity and individual-level deprivation. This serves to highlight how action on health and health care inequalities will have to grapple with the legacies of historic neglect and marginalisation, which can at times narrow the options for action.

The report presents a review of recent evidence of health care inequalities in the NHS in England, as such inequalities form a major part of the problem the Health Inequalities Test has been devised to help address. The evidence presented shows how inequalities are driven by obstacles that exist along multiple "steps" or domains of patient access: from the information services provide about themselves, through to the hidden indirect costs of attending) (2) (3) (4) (

clinics, and service flexibility and accommodation to different social needs. NHS services wanting to address health care inequalities will need to carefully scrutinise the multiple steps of service access to understand where obstacles for specific groups can emerge. They will need to be guided in this through analysis of their own data and also through sustained engagement with groups who experience these inequalities. The Health Inequalities Test can be used as a tool to support this work.

The review considers how health care inequalities were formally considered in major health care reconfigurations before the pandemic. The approach found was dominated by the "protected characteristic" framework of the 2010 Equality Act. Although this effectively includes minoritised ethnicities, it excludes socio-economic deprivation and so is poorly suited to capturing the way structural inequalities overlap and compound – particularly the dynamic between racism and deprivation – and how these impact on health and health care. Equalities impact assessments published as part of major reconfiguration schemes also tended to focus on the impact of proposed changes on the status quo – considering for example whether existing rates of access for specific groups might be worsened by the changes – rather than undertaking a thorough baseline analysis to ascertain the extent to which status quo levels of access was equitable.

There has been a marked change in the NHS approach to health and health care inequalities since the pandemic, with the Core20PLUS5 approach highlighting the centrality of structural inequalities, particularly the role of racism and deprivation, and also calling for urgent NHS action on inequalities in health care access, experience and outcomes. The review recommends the Mayor build on the Core20PLUS5 approach and uses the Health Inequalities Test as a mechanism to reinforce and champion the focused attention and action the approach is designed to bring.

This will require some revisions to the current Health Inequalities Test, including to help embed the emphasis now seen in national policy on the structural drivers of inequalities, particularly as they relate to minoritised ethnic groups and people experiencing economic deprivation. Revisions are also needed to reflect the heightened ambition and urgency now found within the NHS to tackle health and health care inequalities, which is an ambition and urgency the Mayor shares. The review's recommendations for revisions to the Health Inequalities Test are set out below, with significant changes shown in bold.

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Overarching test:

The proposed changes **make best use of the opportunities available to the health system to reduce health and health care inequalities which have been set out transparently** together with an **evidenced** plan for further action. The plans clearly set out proposed action to prevent ill health, including **targeting action and resources to improve the healthy life expectancies of the worst off, including groups who experience wider structural inequalities.**

Supplementary questions:

- 1 Do proposals set out the current systemic health and health care inequalities issues in their local population – including those driven by socio-economic deprivation and structural racism? Is the contribution of these inequalities to the Healthy Life Expectancy gap considered?
- 2 Do proposals consider their impact on the health and health care inequalities **identified in their baseline analyses** in a systematic, documented way?
- **3** Do proposals ensure that services **become more accessible** to vulnerable groups, **including those identified as experiencing the worst health and health care inequalities?**
- 4 Do proposals ensure that unwarranted variations in health care outcomes **are reduced**?
- 5 How is health and health care equity weighted in the options appraisal process for the proposed changes? Do proposals set out specific, measurable goals for narrowing health and health care inequalities? Where data and information gaps exist on inequalities and population groups, is there a plan to address these?

Introduction

This is a report to the Mayor of London reviewing the content and application of his Health Inequalities Test.

The Health Inequalities Test is part of a six test framework the Mayor developed in response to the 2017 King's Fund and Nuffield Trust report into the five London Sustainability and Transformation Plans, drawn up by London's clinical commissioning groups (CCGs) which had grouped together into what would later become the five London integrated care systems (ICS).¹ The health systems faced significant financial and workforce constraints – including a £4.1 billion funding shortfall – which were expected to lead to a series of major reconfigurations of health services in the capital – particularly of acute hospital services. As a consequence, the Mayor sought reassurance from the NHS in the form of six tests designed to ensure that service quality, equity and sustainability were maintained, and where possible improved.

In addition to tests scrutinising the robustness of financial plans; assumptions about the demand and supply of hospital capacity – including bed numbers; integration with adult social care services; and meaningfulness of patient, public and clinical engagement, the Mayor's "Health Inequalities and Prevention of Ill Health Test" set the following expectation of mayor health service reconfigurations:

The impact of any proposed changes on health inequalities has been fully considered at [a health system] level. The proposed changes do not widen health inequalities and, where possible, set out how they will narrow the inequalities gap. Plans clearly set out proposed action to prevent ill health.²

Ham, C, Alderwick, H, Evans, N, Gainsbury, S (2017) Sustainability and transformation plans in London: An independent analysis of the October 2016 STPs, Published by Mayor of London, <u>https://www.london.gov.uk/sites/default/files/kings_fund_stp_report_march_2017.pdf</u>

² Mayor of London (2017) 'Six tests framework – major hospital service reconfigurations', https://www.london.gov.uk/sites/default/files/final_six_tests_framework - for_website.pdf



The Mayor's six tests are applied to major service reconfigurations alongside the statutory consultation processes which accompany large scale change. To date, the test framework has been applied to three mayor acute service reconfiguration proposals – Moorfields Eye Hospital, North Central London Adult Elective Orthopaedics, and Sutton, Epsom and St Helier's Improving Healthcare Together programme.³

Although the Mayor cannot instruct NHS organisations, the tests are an example of the Mayor seeking to use his combined roles as champion, challenger and partner to the NHS to help encourage improvement through constructive dialogue and support. With regards to the Health Inequalities Test in particular, a set of supplementary questions – to be asked where applicable – help frame the Mayor's vision of what "good" reconfiguration proposals might be expected to do with regard to health inequalities. These questions ask:

Do proposals:

- Set out the health inequalities issues in their local population?
- Consider their impact on health inequalities in a systematic, documented way?
- Ensure that services do not become less accessible to vulnerable groups?
- Ensure that unwarranted variations in outcomes do not worsen?
- Set out specific, measurable goals for narrowing health inequalities and mechanisms for achieving this, for example, through credible plans to: – make services more accessible to vulnerable groups? – reduce unwarranted variation in outcomes?⁴

The purpose of this review is to assess whether the current Health Inequalities Test would benefit from refinements in order to improve its relevance and effectiveness. Since the original publication of the six tests, London and the rest of the world has been struck by the Covid-19 pandemic, which has both exacerbated and exposed existing health inequalities, raising public awareness of the moral case for change. This has led to a strengthening of the approach to

³ For more information on the use of the six tests to date, see <u>The Mayor's Six Tests | London City Hall</u>

⁴ Mayor of London (2017) 'Six tests framework – major hospital service reconfigurations' <u>https://www.london.</u> gov.uk/sites/default/files/final_six_tests_framework - for_website.pdf

health inequalities within both the NHS and the GLA⁵, and it is important to ensure the Mayor's Health Inequalities Test matches the heightened ambition for change now seen, and encourages emerging good practice.

The current review has also been commissioned in response to requests from the NHS for more clarity on what is within the scope of the test as it is applied to service reconfigurations and the Mayor's desire to ensure that inequalities in health care access, experience and outcomes are fully captured by the test, alongside inequalities in the levels of health that different population groups in the capital currently experience.

To add clarity to the discussion of health inequalities, it is useful here to briefly consider what is meant by the terms "health inequalities" and "health care inequalities".

Defining health and health care inequalities

The Mayor shares the established definition of health inequalities as "avoidable and unfair differences in health; [the] result of systemic differences in the determinants of health and wellbeing".⁶ This common definition serves to underline that by "health inequalities" analysts do not mean to highlight randomly-distributed differences in health between individuals, or differences that might not be avoidable such the differences in health enjoyed by a 28-year-old and that experienced by an 82-year-old. Rather, "health inequalities" are taken to refer to differences in the distribution of disease, or in life expectancy, that are patterned by a social characteristic – for example gender, ethnicity, geography, social class or deprivation. This patterning indicates that the differences are both systematic and that they can be viewed as unfair, as they can be seen to be associated with structural dynamics such

⁵ See specifically the Mayor's updated implementation plan for his Health Inequalities Strategy, published December 2021. <u>https://www.london.gov.uk/publications/health-inequalities-strategy-implementation-plan-2021-24</u> [last accessed September 2022]

⁶ Greater London Authority (2018) The London Health Inequalities Strategy <u>https://www.london.gov.uk/sites/</u> <u>default/files/health_strategy_2018_low_res_fal.pdf</u>. See also Public Health England (2018) *Health Profile for England: 2018 <u>https://www.gov.uk/government/publications/health-profile-for-england-2018</u> [last accessed September 2022]; and Whitehead, M (1991). 'The concepts and principles of equity and health', <i>Health promotion international*, 6(3), 217-228



as exclusion, marginalisation and deprivation, rather than with free personal choice, or with natural biological or random variation.⁷

It should be noted here that "fairness" and "unfairness" are subjective value judgements and therefore inherently contestable. For example, people sometimes disagree about the precise way in which poverty leads to poor health and whether or not this is really "unfair", with some arguing there is more scope for personal responsibility and others arguing there is less.⁸ This in part explains why action to tackle health inequalities can be elusive, as the changes needed to address them require sustained political and public support. This also in part highlights further the significance of the Covid-19 pandemic which has raised public awareness of the direct impact of social inequalities on health, building a stronger public consensus that change is needed, creating an opportunity for more meaningful action.⁹

The social patterning observed in the distribution of health – often revealed in a socio-economic gradient, whereby poorer groups suffer incrementally worse health status than those who are one step more affluent than them – underlines the influence of where people are born, grow, live and work on their health. These "social determinants of health" largely lie outside the direct control of clinicians and, although estimates vary quite widely, are thought to have more influence on an average individual's health than does their access to health care services.¹⁰

The Mayor's Health Inequalities Strategy for London rightly focuses on these social determinants of health and the need for coordinated action and partnership across local government, businesses, schools, the voluntary sector as well as the NHS to reduce how deprivation, poor air quality, bad diet and

- 7 Marmot, M (2015) *The Health Gap: The Challenge of an Unequal World*, Bloomsbury. See also Braveman, P and Gruskin, S. (2003) 'Defining Equity in Health', *Journal of Epidemiology and Community Health*, 57, pp254-258
- 8 For an analysis of this, see Kane et al (2022) 'Building public understanding of health and health inequalities', https://www.health.org.uk/publications/long-reads/building-public-understanding-of-health-and-healthinequalities
- 9 This was a key and consistent message set out in Public Health England's 2020 report Beyond the Data: Understanding the impact of COVID-19 on BAME groups https://assets.publishing.service.gov.uk/government/ uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_ beyond_the_data.pdf
- 10 Buck, D and Maguire, D, 2015 *Inequalities in life expectancy: Changes over time and implications for policy,* King's Fund, <u>https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/inequalities-in-life-expectancy-kings-fund-aug15.pdf</u>

a host of other factors drive inequalities in health in London.¹¹ The Mayor's key measure of that inequality is the gap between healthy life expectancy at birth for people living in different London boroughs, which the latest available data records as 13.5 years between men living in Newham and those living in Richmond – a measure of inequality which doubles when considered at the level of small neighbourhoods.¹²

Health *care* inequalities differ from the health – or health status – inequalities described above, in that they relate to inequalities in the levels of access and standards of experience and outcome that different social groups receive from health care interventions or services, relative to their need. As health services and systems are a microcosm of society at large, the same social groups who tend to experience health status inequalities often also experience health care inequalities , entailing that the health service misses opportunities to ameliorate and address underlying inequalities in health, and at times risks exacerbating them.

It is common practice in government and the NHS to use the term "health inequalities" to refer both to health status and to health care inequalities. By contrast, this review distinguishes between the two forms of inequality, but this is intended to emphasise rather than de-emphasise the dynamic and overlap between them. As the purpose of the Health Inequalities Test is to challenge and support the NHS in addressing inequalities, it is useful to focus this review on health care inequalities,¹³ as these are under the direct control and agency of the NHS itself. However, when considering which health care inequalities to prioritise for action and resource, NHS organisations may want to pay heed to where their most significant health status inequalities are and how more inclusive health care interventions can contribute to reducing them.

¹¹ Greater London Authority (2018) *The London Health Inequalities Strategy* <u>https://www.london.gov.uk/sites/</u> <u>default/files/health_strategy_2018_low_res_fa1.pdf</u>

¹² The latest borough-level data on healthy life expectancy at birth is from 2016-2018 https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/ datasets/healthstatelifeexpectancyatbirthandatage65bylocalareasuk. The latest neighbourhood level data is for the years 2009 to 2013 https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/ healthandlifeexpectancies/articles/healthexpectanciesatbirthformiddlelayersuperoutputareasmsoasengland/ 2015-09-25[both last accessed September 2022]

¹³ See Cookson, R., et al. (2021) 'The inverse care law re-examined: a global perspective', *The Lancet*, February 2021, <u>https://doi.org/10.1016/S0140-6736(21)00243-9</u>; and Tudor-Hart, J (1971) 'The inverse care law', *The Lancet*, 1 (7696) pp:405–412

Structure of this report

As the experience of the Covid-19 pandemic has served as a catalyst for change, it is appropriate that this report opens in Chapter 1 with an outline of the impact the pandemic had on health inequalities in London. As will be shown, the pandemic has served not only to illustrate pre-existing systematic inequalities in health across London and Britain as a whole, but also highlighted how public policy responses and services can themselves risk exacerbating those inequalities if they fail to take adequate account of the way different population groups live their lives and circumstances. This report will then briefly consider the NHS Covid-19 vaccination response as an attempt to address the health inequalities exposed, highlighting the difficulties and nuances involved in practical attempts to reverse decades-long experiences and processes of marginalisation and exclusion, and new ways of working the NHS is developing to do this.

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In Chapter 2, the report will summarise a survey of recent evidence on health care inequalities in England undertaken as part of this review. The purpose of the evidence survey is to consider the wide array of circumstances and drivers which can result in health care inequalities, as these form the context against which the Health Inequalities Test will be applied and, if it is successful, represent the "problem" the Test is intended to help address.

In Chapter 3, the report briefly outlines how health and health care inequalities have tended to be addressed through major acute care reconfigurations up until 2020. This chapter shows how the approach seen in acute care reconfigurations prior to the pandemic was broadly consistent with national policy at the time, which lacked a strong emphasis on structural inequalities and tended to focus on the NHS's "health inequalities" role with regards to prevention, with less emphasis on inequalities in care access, experience and outcome. The chapter then sets out the approach developed by NHS England in response to the Covid-19 pandemic, which put a renewed emphasis on structural drivers of health and health care inequalities, and stepped-up ambition for change.

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Finally, in Chapter 4 the report turns back to each of the component questions within the current Health Inequalities Test to assess whether, in the light of the evidence and context reviewed, the test offers the sufficient challenge and support required to ensure it can be an effective tool in tackling health and health care inequalities. This chapter concludes with recommendations for revisions to the test to strengthen it in this regard.

In addition to published policy documents, peer-reviewed academic papers and official data sets, this review makes use of a series of interviews conducted by the Nuffield Trust with a selection of NHS senior managers and leaders, predominantly based in London. Interviewees included those whose remits were centred on addressing health and health care inequalities as well as those whose remits were focused on other significant operational priorities, such as finance and clinical service reconfiguration, which the Health Inequalities Test also seeks to influence. The review team also benefited from insights gathered from a variety of NHS and local government stakeholders, including representatives of organisations working with disabled Londoners, minoritised ethic groups and Londoners living in deprivation. At times, quotations from these interviews are included in the body of the report, particularly when they articulate common themes or sentiment which were expressed by a number of interviewees. To maintain the integrity of the oftencandid comments, interviewees are not identified, although their broad role and position is described.

1 The impact of the coronavirus pandemic

As is well documented, the biggest absolute determinant of risk of death from Covid-19 was, and remains, age. Those aged 70-79 faced, on average, more than an eight-fold increased risk of a Covid-related death in the early months of the pandemic in England than 50-59-year-olds. For those aged over 80, the additional risk was 38 times that of 50-59-year-olds.¹⁴

While it is important not to minimise the trauma of losing loved ones at any age, adjusting Covid-19 deaths by age illustrates how heavily and unevenly the burden of premature death fell on particular communities and sections of the population.

For adults living in areas ranked as within the most deprived fifth of England's neighbourhoods¹⁵, the risk of dying prematurely – defined as dying before 70 years of age – during the first quarter year of the pandemic was almost three times that of adults living in the least deprived fifth.¹⁶ After controlling for the higher prevalence in those neighbourhoods of smoking, obesity and other diseases identified as risk factors in Covid-19, the heightened relative risk in the most deprived areas reduced, but was still twice the risk faced by those living in the least deprived areas. For all Covid-related deaths, including those in the over 70s – the risk faced by those living in the most deprived areas¹⁷

16 Williamson J, et al (2020b) 'Post-publication supplement to "Factors associated with COVID-19-related death using OpenSAFELY", <u>https://www.opensafely.org/assets/age_interactions_report_v1.2.pdf</u>

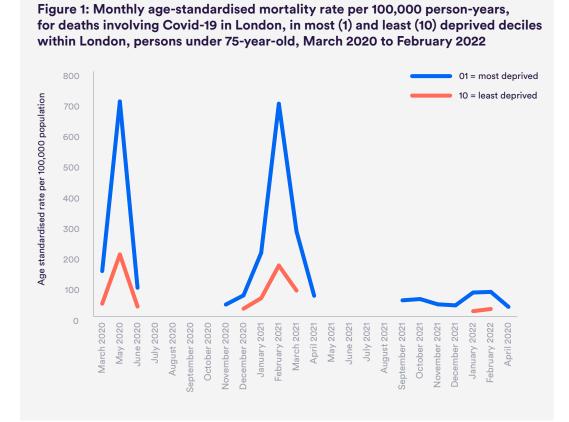
¹⁴ Williamson J, Walker J, Bhaskaran K, Bacon S, Bates C, Morton CE, Curtis HJ, Mehrkar A, Evans D, Inglesby P, Cockburn J, McDonald HI, MacKenna B, Tomlinson L, Douglas IJ, Rentsch CT, Mathur R, Wong AYS, Grieve R, Harrison D, Forbes H, Schultze A, Croker R, Parry J, Hester F, Harper S, Perera R, Evans SJW, Smeeth L, Goldacre B. (2020a) 'Factors associated with COVID-19-related death using OpenSAFELY', *Nature*, August, 584(7821):430-436 <u>https://pubmed.ncbi.nlm.nih.gov/32640463/</u>

¹⁵ Unless otherwise stated, throughout this report, deprivation is indicated by an area's score on the Index of Multiple Deprivation (IMD) while geographical units are either Lower Super Output Areas or Middle Super Output Areas – referred to as "neighbourhoods" for ease.

¹⁷ Williamson J, et al (2020b) 'Post-publication supplement to "Factors associated with COVID-19-related death using OpenSAFELY"

was 1.8 times higher than the least deprived, again after adjusting for known clinical risk factors.¹⁸

London experiences the highest level of individual-level income inequality in England, with its richest and poorest residents also tending to be "clustered" in separate, segregated areas or enclaves, creating significant spatial inequalities across the capital, as well as inequalities between individuals.¹⁹ The consequence of that during the first and second waves of the pandemic was a stark reflection of the national trend, showing a Covid-related death rate more than twice as high for those living in the most deprived tenth of London's neighbourhoods than for those living in the least deprived tenth.



Source: Covid-19 Health Inequalities Monitoring for England (CHIME) tool, OHID

¹⁸ Williamson J, et al (2020a) 'Factors associated with COVID-19-related death using OpenSAFELY'

¹⁹ Rae, A and Nyanzu, E (2019) An English Atlas of Inequality, University of Sheffield/Nuffield Foundation http://alasdairrae.github.io/atlasofinequality/reports/atlas_of_inequality_18_nov_2019_FINAL.pdf

The national policy response

The initial core policy response to the pandemic was national "lockdown", announced on March 23 2020, with the public advised to work from home where possible, avoid non-household contacts and public transport, limit trips outside to once a day and shield the clinically vulnerable and over 70s. For non-essential jobs which could not be done from home, a government-backed furlough scheme offered 80% of pre-pandemic pay to those who stayed at home.

However, it soon became clear that an individual's ability to take part in, and benefit from government lockdown measures and guidance, depended on their occupation, income level and security, household living arrangements and wider material circumstances.²⁰ As one doctor from the Muslim community in London commented to a joint NHS-GLA and Public Health England engagement study: *"[W]e were telling people to isolate if they had symptoms, and if they were [...] in insecure employment it was very difficult for them to isolate because they didn't have any income and patients told me point blank that they were not going to isolate because for them it was a choice between their lives and their livelihoods."²¹*

Indeed, when one of the first epidemiological studies on the impact of Covid-19 across England conducted sensitivity tests on their data and looked at deaths associated with coronavirus infections likely contracted before national lockdown, they found the relative risk of death for those living in the most deprived fifth of neighbourhoods compared to the least deprived fifth actually increased after the start of lockdown, as inequalities in how well people were able to protect themselves and their families from catching the virus and make use of government policy interventions became manifest.²²

21 OHID and GLA (2021a) Beyond the Data: One Year On

22 Williamson J, et al (2020a) 'Factors associated with COVID-19-related death using OpenSAFELY'

²⁰ See for example: 'The demographic impact of the first phase of Covid-19 in London, February-June 2020', July 2020, GLA/Mayor of London, <u>https://data.london.gov.uk/dataset/briefing--demographic-impact-of-covid-19</u> [last accessed September 2022]; Office for Health Improvement and Disparities and GLA, (2021a) *Beyond the Data: One Year On*, <u>https://www.london.gov.uk/sites/default/files/beyond the data one year on</u> <u>report 2021.pdf</u>; and Reed, S, et al (2021) 'Tackling Covid-19: A case for better financial support to self-isolate', Nuffield Trust, <u>https://www.nuffieldtrust.org.uk/files/2021-05/tackling-covid-19-6.pdf</u>

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These inequalities were most starkly revealed in disparities in the impact of

Covid-19 between different ethnic groups, where the intersection of ethnicity and deprivation compounded the risk faced by members of almost all Britain's minoritised ethnic groups.²³

The Office for Health Improvement and Disparities and others have recognised that the intersection of ethnicity and deprivation is driven by structural racism.²⁴ In London, as in the rest of the UK, this dynamic entails that people from minoritised ethnic groups are over-represented in the most deprived areas.²⁵ The table below illustrates this using London's neighbourhood level population by ethnicity from the 2011 census, showing the proportion of each ethnic group living in each of London's deprivation deciles, with 1 indicating the 10% most deprived neighbourhoods in London, and 10 the least. As is shown, people with Bangladeshi, Black African, Black other, Black Caribbean, Pakistani, mixed, Arab and other non-white ethnicities are concentrated in the poorest neighbourhoods in London, while other groups are either more evenly spread; concentrated in the middle of the deprivation scale; or, in the case of the White English/Welsh/Scottish or Northern Irish ethnic group, are skewed towards the least deprived neighbourhoods.

²³ Nafilyan, V., et al (2021) 'Ethnic differences in COVID-19 mortality during the first two waves of the coronavirus pandemic: a nationwide cohort study of 29 million adults in England', *European Journal of Epidemiology*, 36(6):605-617 <u>https://pubmed.ncbi.nlm.nih.gov/34132940/</u>

²⁴ OHID and GLA (2021b) Beyond the Data: One Year On: A Companion Narrative drawn from Data and Literature, https://www.london.gov.uk/sites/default/files/beyond the data one year on - companion narrative from data and literature.pdf

²⁵ Throughout this report we use the terms "minoritised" or "marginalised" to highlight the fact that in some areas of London (and elsewhere in England) people identifying as belonging to ethnicities other than White English/British are in the statistical majority, and yet continue to experience disadvantage due to the processes associated with structural racism which systematically renders their interests and wellbeing as "minority" or "marginal" concerns. A parallel phenomenon is experienced by women, who make up the statistical majority of the overall population, and yet are systematically considered as secondary in social and economic policy – see for example Criado Perez, C. (2019) *Invisible Women: Exposing Data Bias in a World Designed for Men*, Random House

Figure 2: Where London's different ethnic groups live, by neighbourhood deprivation level

Percentage of ethnic group living in each neighbourhood deprivation decile (1 = most deprived, 10 = least deprived)

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2011 Census ethnic group	1	2	3	4	5	6	7	8	9	10
Bangladeshi	16%	28%	15%	13%	9%	6%	6%	4%	3%	1%
Black African	22%	17%	15%	12%	10%	8%	6%	4%	3%	2%
Other Black	21%	16%	14%	13%	12%	10%	6%	4%	3%	2%
Black Caribbean	19%	15%	13%	13%	12%	10%	6%	5%	3%	2%
Any other non-white ethnic group	16%	11%	13%	11%	11%	9%	9%	8%	6%	5%
Pakistani	8%	9%	16%	15%	16%	10%	11%	6%	5%	4%
Mixed/multiple ethnic groups	13%	12%	12%	11%	11%	10%	9%	8%	7%	6%
Arab	13%	10%	11%	9%	11%	12%	12%	8%	7%	5%
Other white (inc Irish and Traveller)	10%	9%	11%	11%	10%	11%	10%	10%	9%	7%
Other Asian	9%	9%	11%	11%	14%	11%	11%	9%	8%	6%
Chinese	9%	10%	10%	10%	10%	13%	11%	11%	9%	8%
Indian	5%	6%	11%	11%	16%	13%	12%	11%	9%	6%
White English/Welsh/ Scottish/Northern Irish/British	7%	8%	8%	9%	9%	9%	11%	11%	13%	15%

Sources: Census 2011 ethnicity counts for London Middle Super Output Areas (ONS); IMD 2019 calculated for MSOA and ranked by London-specific deprivation decile; Nuffield Trust's own analysis. Note that data availability means the table mixes data from two different time periods and is therefore for illustrative purposes only.

This racialised dimension to deprivation – reflecting the impact of structural racism and generational cycles of exclusion and disadvantage – played a significant part in the disproportionate death toll from Covid-19 experienced by Black and Asian Londoners, which saw Black Londoners facing a 2.5 to 3 times higher risk of dying than White Londoners around the peak of the first wave of the pandemic, and South Asian Londoners around twice the risk.²⁶ These excess risks slightly diminished by the time of the second wave but remained at least 1.5 times higher than for White Londoners, with the proportion of positive Covid-19 cases among Black and Asian Londoners significantly larger than their population share.²⁷

27 ibid

²⁶ Fenton, K (2021) 'Tackling London's ongoing COVID-19 health inequalities', UK Health Security Agency, 3/2/21 <u>https://ukhsa.blog.gov.uk/2021/02/03/tackling-londons-covid-19-health-inequalities/</u> [last accessed September 2022]

Epidemiological analysis has highlighted the role not only played by deprivation in the additional risk from Covid-19 faced by London's minoritised ethnic groups, but also that played by occupation and household composition.²⁸

Although the particular individual risk factors, and the dynamics within and between them vary between Britain's minoritised ethnic groups (with evidence of a modest role played by genetics for South Asian groups ²⁹), the pattern that emerges is one of intersecting and compounding disadvantage, where economic deprivation is exacerbated by a racialised pattern in both insecure, low paid, employment and in public-facing and non-furloughed key worker occupations, all of which were least likely to be able to lock down and avoid multiple non-household contacts.³⁰

A further factor – particularly relevant during the second wave of Covid-19 – is the far greater tendency for South Asian families to live in multigenerational households, spanning grandchildren and grandparents.³¹ While bringing significant health and wider socio-economic benefits in other circumstances, in the context of an airborne pandemic, this household structure further heightened the risk faced by older generations, unable to shield themselves from younger family members leaving the home to attend school and work.³² This feature of life for particular minoritised ethnic groups in London was highlighted by another participant in the joint NHS-GLA-PHE engagement study, who commented: *"We had key workers who were bus drivers and nurses living in households with three generations of households and so there wasn't*

- 28 Nafilyan, V., et al (2021) 'Ethnic differences in COVID-19 mortality during the first two waves of the coronavirus pandemic: a nationwide cohort study of 29 million adults in England'; and Martin, C., et al (2020) 'Sociodemographic heterogeneity in the prevalence of COVID-19 during lockdown is associated with ethnicity and household size: Results from an observational cohort study', *EClinical Medicine*, August 2020, 25:100466. doi: 10.1016/j.eclinm.2020.100466
- 29 Downes, D., et al (2021) 'Identification of LZTFL1 as a candidate effector gene at a COVID-19 risk locus', *Nature Genetics*, 53:1606–1615, <u>https://doi.org/10.1038/s41588-021-00955-3</u>
- 30 Office for National Statistics (2020a) 'Why have Black and South Asian people been hit hardest by COVID-19?', 14/12/2020, www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/ articles/whyhaveblackandsouthasianpeoplebeenhithardestbycovid19/2020-12-14 [last accessed July 2022]; Platt, L and Warwick R (2020) 'Are some ethnic groups more vulnerable to COVID-19 than others?', Institute for Fiscal Studies, https://ifs.org.uk/publications/Are-some-ethnic-groups-more-vulnerable-COVID-19-others; and OHID and GLA (2021b) Beyond the Data: One Year On: A Companion Narrative drawn from Data and Literature
- 31 Office for National Statistics (2020a) 'Why have Black and South Asian people been hit hardest by COVID-19?'
- 32 Race Disparity Unit (2021) *Final report on progress to address COVID-19 health inequalities*, December 2021, <u>https://www.gov.uk/government/publications/final-report-on-progress-to-address-covid-19-health-inequalities</u> [Last accessed July 2022]

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provisions for them to isolate within their homes. They had to go out to work and therefore they were at risk?³³

This risk within South Asian families was particularly acute for older women exposed to school-attending children within their households – highlighting sex and gender as factors in further compounding disadvantage within this context.³⁴

The combined impact of these multiple disadvantages faced by a significant proportion of London's population was for the city as a whole to experience the largest regional-level fall in life expectancy at birth in England, losing 2.3 years off the measure for men by the end of 2020 compared to 2019, and 1.5 years for women.³⁵ While this statistic summarises the impact across London as a whole, the distribution of suffering was uneven, with the impact on life expectancy and mortality rates far higher for the poorest Londoners and those with Black and Asian ethnicities.³⁶

There were disproportionate impacts too for other, less visible groups, such as undocumented migrant workers or those without recourse to public funds who were unable to access furlough payments or sick pay. Infection rates among homeless people in the first wave of the pandemic were higher than the general population, with evidence that nationally, homeless women were at a particularly higher risk.³⁷ Disabled people also experienced a far higher mortality rate (after adjusting for age) than the general population nationally, with ONS analysis to mid-November 2020 showing again that women in this group were at particularly heightened risk, experiencing a Covid-19 mortality rate 4.1 times that of non-disabled women.³⁸

- 33 OHID and GLA (2021a) Beyond the Data: One Year On
- 34 OHID and GLA (2021b) Beyond the Data: One Year On: A Companion Narrative drawn from Data and Literature
- 35 The Wider Impacts of COVID-19 on Health (WICH) monitoring tool, hosted by PHE analytics <u>https://analytics.phe.gov.uk/apps/covid-19-indirect-effects/</u> [Last accessed September 2022]
- 36 ibid
- 37 Public Health England (2020b) Disparities in the risk and outcomes of COVID-19: August 2020 update, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/ file/908434/Disparities_in_the_risk_and_outcomes_of_COVID_August_2020_update.pdf; and OHID and GLA (2021a) Beyond the Data: One Year
- 38 Office for National Statistics (2021a) 'Updated estimates of coronavirus (COVID-19) related deaths by disability status, England: 24 January to 20 November 2020', February 2021, https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/ coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/24januaryto20november2020 [Last accessed April 2022]

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Although there is also emerging evidence of increased inequalities in access to health care services during the pandemic ³⁹, the bulk of the evidence described above relates to health status inequalities, rather than health care inequalities, with poorer and more marginalised groups experiencing a higher rate of death and hospitalisation from Covid-19. However, what is particularly instructive for this current review is the observation that the public policy interventions designed to protect people during the pandemic (those entailed by lock down policies and the "stay at home" message) can be seen at times to have increased inequalities in how the risks from the pandemic were distributed. This was because the interventions were badly tailored to the way poor and marginalised groups live their lives, which meant the policy response itself became a part of the process of marginalisation that exacerbates and reproduces inequalities, as the benefits of the policy were not accessible to those with the least advantages.

The vaccination campaign and vaccination inequalities

By the time vaccines became available in the UK, the above detailed inequalities by ethnicity and deprivation – as well as by age, male sex and underlying health status – were very apparent.

³⁹ The OHID and GLA (2021a) Beyond the Data: One Year On report sets out anecdotal examples from participants in community engagement exercises about a range of health care inequalities exacerbated during the pandemic. These include, for example, difficulties for groups reliant on translators, sign language or lip reading to access services; fears of immigration service repercussions for undocumented migrants in accessing testing services; and an inability for same-sex attracted people and transgender people to continue accessing bespoke health care services which required travel to other parts of London. The report also details inequalities in access and uptake of the coronavirus vaccine, which is discussed in the next section.

This led to calls for ethnicity and deprivation to be included as factors in the vaccine prioritisation schedule – in effect to prioritise low-income patients and/or those with specific ethnicities for earlier receipt of the vaccines.⁴⁰

Such calls sought an explicit and targeted reversal of the general trend in the UK for immunisation programmes to see lower uptake among deprived communities and minoritised ethnic groups.⁴¹ In general, the reasons for this long-standing health care inequality are understood to include physical and economic barriers to accessing relevant clinics (for example the cost of taking time off work, as well as the cost of travel), language and health literacy and, for minoritised ethnic groups in particular, a range of different forms of vaccine hesitancy or uncertainty, including concerns about vaccine safety and efficacy, a lack of trust in health and governmental authorities, and queries over religious permission.⁴²

- 40 Among others, these calls came from the Royal College of General Practitioners, the Mayor of Greater Manchester Andy Burnham, prominent national clinical leaders such as Dr Partha Kar, and in articles published in respected medical journals including the Lancet and Journal of the Royal Society of Medicine. (See: 'Letter to the Secretary of State for Health and Social Care, Matt Hancock' from RCGP chair Professor Martin Marshall, 30 November 2020, <u>https://www.rcgp.org.uk/News/BAME-patients-vaccination-priority</u> letter, last accessed July 2022); 'Andy Burnham: Put poverty before age in vaccine queue', The Sunday Times, 7 February 2021, <u>https:// www.thetimes.co.uk/article/andy-burnham-put-poverty-before-age-in-vaccine-queue-lqrmf3srt</u>; Kar, P (2021) 'When will leaders act on ethnicity data?', Pulse, 27 January 2021, <u>https://www.pulsetoday.co.uk/</u> <u>views/coronavirus/when-will-leaders-act-on-ethnicity-data</u>/; Hassan-Smith Z., et al (2020) 'Who should be prioritised for COVID-19 vaccines?', *The Lancet* <u>http://dx.doi.org/10.1016/S0140-6736(20)32224-8</u>; and Osama, T., et al. (2021) 'COVID-19 vaccine allocation: addressing the United Kingdom's colour-blind strategy', *Journal of the Royal Society of Medicine*, 114(5):240-243. doi:10.1177/01410768211001581)
- 41 SAGE (2020) 'Factors influencing COVID-19 vaccine uptake among minority ethnic groups', paper prepared by the ethnicity sub-group of the Scientific Advisory Group for Emergencies, December 17, 2020 <u>https://www.gov.uk/government/publications/factors-influencing-covid-19-vaccine-uptake-among-minority-ethnic-groups-17-december-2020</u> [Last accessed April 2022]; and Public Health England (2021a) *National Immunisation Programme: health equity audit*, <u>https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/957670/immnstn-equity_AUDIT_v11.pdf</u> [Last accessed April 2021]
- 42 See also Hanif, W. et al (2020) 'Cultural competence in covid-19 vaccine rollout', *British Medical Journal*, 371: m4845, doi: <u>https://doi.org/10.1136/bmj.m4845</u>. It is also important to note that the White ethnic group is not immune from vaccine hesitancy, as evidenced by the lower rates of childhood MMR vaccine update in that group – thought to the driven by erroneous perceptions of a link between the vaccine and autism. On this, see Public Health England (2021a) *National Immunisation Programme: health equity audit*

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A further factor fuelling vaccine hesitancy is the vicious circle where previous experiences of obstacles to receiving timely and appropriate health care - or indeed a whole range of public services - negatively influence future healthseeking behaviour and trust in health services and professionals.⁴³ As one South London-based GP put it at the time: "Vaccine confidence and uptake is a real trigger for anger at the moment. There is no point saying to people, 'get the vaccine, but actually we don't care that you've been smoking for 20 years and have mental health issues'. That is not an integrous way to approach communities who have been disadvantaged for so long."44

In its analysis considering the Covid-19 vaccine prioritisation schedule from an inequalities perspective, the Joint Committee on Vaccinations and Immunisation (JCVI) described how such concerns about vaccine safety created a "complex web", constraining viable policy options. It concluded that prioritisation of specific ethnic groups in the context of a rapidly developed and novel vaccine would risk both further exacerbating vaccine hesitancy and also reinforcing negative stereotypes and stigma already attached to the higher prevalence of Covid-19 within those communities.45 The JCVI further noted logistical constraints: GP records do not hold information on individuallevel deprivation, or occupation, and ethnicity coding throughout NHS records is unreliable and inconsistent, making prioritisation on these factors a practical challenge.

The JCVI instead recommended that the Covid-19 vaccination roll out proceed along age bands, with no direct adaptations for ethnicity, deprivation or sex, but with specific exceptions to the age order for elderly people and their carers

⁴³ Owolabi, B (2021) 'Tackling health inequalities in the NHS', blog post, 8 March 2021, https://www.england.nhs. uk/blog/tackling-health-inequalities-in-the-nhs/ [Last accessed April 2022]; and Campos-Matos, I. et al (2019) 'From health for all to leaving no-one behind: public health agencies, inclusion health, and health inequalities', The Lancet, Vol 4 (December), 601-603

⁴⁴ Moore, L (2021) 'Health inequality must be addressed in locality', interview with Dr Chinyere Ekhator, Integrated Care Journal, May 28, 2021, https://integratedcarejournal.com/local-approach-health-inequality/ [Last accessed September 2022]

JCVI (2020b) 'Annex A: COVID-19 vaccine and health inequalities: considerations for prioritisation and 45 implementation', Joint Committee on Vaccination and Immunisation, November 2020, updated January 6, 2021 https://www.gov.uk/government/publications/priority-groups-for-coronavirus-covid-19vaccination-advice-from-the-jcvi-30-december-2020/annex-a-covid-19-vaccine-and-health-inequalitiesconsiderations-for-prioritisation-and-implementation [Last accessed April 2022]; see also Campos-Matos, I., et al (2021) 'Maximising benefit, reducing inequalities and ensuring deliverability: Prioritisation of COVID-19 vaccination in the UK', The Lancet Regional Health - Europe, Volume 2, 2021, 100021, https://doi.org/10.1016/j. lanepe.2020.100021.

living in care homes, health and social care workers and those with specific underlying health conditions that increased their risk from Covid-19.⁴⁶

However, the JCVI did also urge local areas to maximise uptake among deprived and minoritised ethnicity groups, within the set age-based order, through multifaceted communication strategies; using local public health team community knowledge and networks; and through making the vaccine available through multiple different access points, including GPs, vaccination hubs and hospitals.⁴⁷

In London, this involved NHS organisations and borough public health teams recruiting voluntary sector, community and faith groups to help develop and disseminate culturally appropriate information and advice about the vaccine within different population groups, as well as to host vaccination clinics. Such initiatives were supported through modest central government funding, with £7.2 million ear-marked specifically to address vaccine inequalities nationally, and a further £24 million allocated for a wider "Community Champion" scheme.⁴⁸

NHS leaders in London interviewed for this review reflected both on how valuable a learning experience such community engagement was for their organisations, but also on the remaining mountain they had to climb in terms of breaking the vicious circle of neglect and mistrust. One commented: *"At first we said, 'come and have this [vaccine]; it's good for you.' But people said: 'bugger off!' We needed much better engagement with communities."* Another reflected: *"There's a number of assets in the community we just don't use – street pastors, churches, mosques. These are the people we need to use when consulting on service changes too."*

⁴⁶ JCVI (2020b) 'Annex A: COVID-19 vaccine and health inequalities: considerations for prioritisation and implementation'; and JCVI (2020a) 'Joint Committee on Vaccination and Immunisation: advice on priority groups for COVID-19 vaccination', 30 December 2020 (updated 6 January 2021) <u>https://www.gov.uk/</u> government/publications/priority-groups-for-coronavirus-covid-19-vaccination-advice-from-the-jcvi-30december-2020/joint-committee-on-vaccination-and-immunisation-advice-on-priority-groups-for-covid-19-vaccination-30-december-2020 [Last accessed April 2022]

⁴⁷ JCVI (2020b) 'Annex A: COVID-19 vaccine and health inequalities: considerations for prioritisation and implementation'

⁴⁸ NAO (2022) *The rollout of the COVID-19 vaccination programme in England,* National Audit Office, <u>www.nao.</u> <u>org.uk/wp-content/uploads/2022/02/The-rollout-of-the-COVID-19-vaccination-programme-in-England.pdf</u>

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It is hard to evaluate the success of these initiatives in the absence of evidence about what would have happened under an alternative scenario – where there were no active attempts to do things differently, to reach out, engage and involve minoritised communities. However, age-standardised double vaccination rates in the over 50s grew fastest in London between January 2021 and January 2022 for Black African and Black Caribbean people than for all other ethnic groups, outstripping growth for the same groups in the rest of England.⁴⁹ Interviewees for this review noted, however, that this was far from cause for complacency, as vaccination rates in most of London's minoritised ethnic groups started at a very low base, and remained lower than for White English Londoners for all groups other than Indian.⁵⁰

Community engagement led jointly by the NHS, GLA and PHE explored vaccine hesitancy further, highlighting lessons for the future. The feedback gathered through the engagement exercises underlined the complex nature of vaccine hesitancy, conveying both the palpable sense of stigmatisation some felt about the higher risk and prevalence experienced within minoritised ethnic groups, but also dismay at the "conflicting health messages" sent by the decision not to prioritise those same groups in the vaccination schedule.⁵¹ Perhaps most tellingly for this review, participants expressed their dismay at what they experienced as only a "sudden concern" for the health of minoritised communities when it came to uptake of the new vaccine, fuelling scepticism, as it was felt this concern had not been present before. This feedback loop between prior experience of health care services and trust in the same services was summed up by a participant in the engagement who stated: "People have lost trust with public health and not just because of Covid-19 and how it has been managed, but pre-existing health inequalities where people did not receive the right information, the right support and the right guidance". 52

There was, however, positivity about the changes the NHS made during the pandemic to engage local communities in delivering and designing health

52 OHID and GLA (2021a) Beyond the Data: One Year On

⁴⁹ PHE (2022) 'Age-standardised percentage of adults double vaccinated to January 2022' <u>https://analytics.phe.gov.uk/apps/chime/</u> [Last accessed April 2022]

⁵⁰ See also on this, Fenton, K (2022) 'London's communities remain vulnerable to COVID-19 without full vaccine protection', blog post, UK Health Security Agency, 23/3/22, <u>https://ukhsa.blog.gov.uk/2022/03/23/londonscommunities-remain-vulnerable-to-covid-19-without-full-vaccine-protection/</u> [Last accessed April 2022]

⁵¹ OHID and GLA (2021a) Beyond the Data: One Year On

care strategies and interventions, although participants in the NHS-GLA-PHE engagement noted that this needed to be strengthened and sustained, including through the proper resourcing of community organisations.⁵³

These reflections also serve to highlight how attempts to address health and health care inequalities do not have the benefit of existing in a context-free bubble, where solutions and mechanisms for change are clear-cut and easy to employ. Instead, initiatives attempting to address health care inequalities have to also grapple with the very same forces that created the inequalities in the first place. This was not only evident in the challenge the NHS faced in attempting to rapidly gain the trust of historically marginalised and overlooked communities, but also in the tools and policy options the NHS had available to address the urgent need for vaccination within those groups.

This is particularly clear in relation to successive failures within the NHS to adequately record ethnicity, with data coding particularly inconsistent for minority ethnic groups – symptomatic of institutional apathy towards ethnic differences in health and health care.⁵⁴ As we have seen, this in turn became one of several obstacles to the NHS being able to consider prioritising vaccination by ethnicity a practical possibility. Another significant obstacle was the persistence of racist attitudes throughout British society, which entailed that a further concern that needed to be balanced when developing and implementing policy was the risk that prioritising minoritised ethnic groups might become fuel for further racist stigmatisation.

The vaccine response experience serves to illustrate how action on health and health care inequalities will at times involve challenging vested interests, controversy, and the need to balance competing concerns and priorities. Any revisions to the Mayor's Health Inequalities Test will need to help the Mayor in his twin roles to both challenge and support the NHS to navigate this terrain – for example, acknowledging that for progress to be made on inequalities, trade-offs against other organisational priorities may need to be made, or risks taken, which should be set out transparently, with reasons well evidenced and potential mitigations identified in advance.

⁵³ OHID and GLA (2021a) Beyond the Data: One Year On

⁵⁴ Scobie, S, Spencer, J and Raleigh, V (2021) Ethnicity coding in English health service datasets, The Nuffield Trust, www.nuffieldtrust.org.uk/files/2021-06/1622731816_nuffield-trust-ethnicity-coding-web.pdf; and Chinembiri, O (2021) 'Ethnicity coding in health care', Blog post, NHS Race and Health Observatory, www.nhsrho.org/blog/ethnicity-coding-in-health-care/ [Last accessed April 2022]

2 Survey of the evidence base

Inequalities in uptake of the coronavirus vaccine form only one specific example of the health care inequality that exists in London today. As the Mayor's Health Inequalities Test is primarily intended as a policy tool to leverage progress on health and health care inequalities, it is important to also understand the broader range of health care inequalities that form the problem the test is designed to help tackle.

For this purpose, this review conducted a rapid survey of recent research on inequalities in access to, experience of and outcomes from NHS care. The intention was not to systematise or exhaust the vast literature and evidence base, but rather to illustrate the breadth of the available evidence. In the main, the evidence presented is England-wide, although where relevant evidence from London is available, this has been included.

Before turning to this evidence, it is important to note some of the methodological constraints which both academic and NHS service analysis of health care inequalities face. These constraints are also directly relevant to the Health Inequalities Test, as the Mayor will want to support the NHS in improving its ability to understand health care inequalities and measure progress on reducing it.

Adjusting for need

In order to assess whether health care use or availability is equitable, data on use and availability has to be adjusted for patient need. In practice, this is often proxied in analysis by using data on prior use (for example showing the population "average" for people of a given sex and age, or diagnosis), survey data on self-reported health status, clinical registry or other disease register data, modelled epidemiological estimates of need, or a combination of any of those. $\left(1\right)\left(2\right)\left(3\right)\left(4\right)\left(\uparrow\right)$

Similar adjustments are made when exploring health care outcomes, as differences in the underlying health status of compared patient groups (which might explain differences in outcome) need to be considered. None of these methods of adjusting data are perfect, or immune from bias. For example, some more deprived groups are known to under-report ill health in surveys, while data on health care resource use (such as Hospital Episode Statistics) run the risk of baking in historic under (and over) use relative to need as the measure of need itself.⁵⁵ A further complication is that health care need is not always reliably indicated by ill health, as it is possible that a disease may not be ameliorable by health care services. What an individual might rather need is adult social care services, for example. Data quality and availability on adult social care services remains a challenge.

Identifying population groups of interest

It goes without saying that for an evidence base on health care inequalities to be formed, population groups of interest (i.e. those suspected of experiencing health care inequalities) have to be identified. And while it is the case that minority ethnic groups have long experienced marginalisation and discrimination in Britain, as already noted in the preceding chapter, exploring the impact of this on health care is hindered by the fact that the NHS has not consistently coded ethnicity in its datasets, with the health care records of minority ethnic patients affected disproportionately.⁵⁶

Data quality on ethnicity is worst in London, with more patients with ethnicity not stated (14%), or recorded in one of the "other" categories (24%), compared with 8.5% not stated and 8.8% "other" across England as a whole. While researchers interested in looking at health care use and needs by ethnicity use a number of workarounds to try to fill these gaps (see, for example, Petersen et al., 2021; and PHE 2021b), these are imperfect and cannot rectify all the knowledge gaps. In many cases, robust findings can only be reported at the level of very broad ethnic groups, which risks missing important differences

⁵⁵ For a discussion on this, see Cookson, R, Propper, C, Asaria, M and Raine, R (2016) 'Socio-economic inequalities in health care in England', *Fiscal Studies*, vol 37. No-34, pp371-403

⁵⁶ Scobie, S et al (2021) *Ethnicity coding in English health service datasets*, Nuffield Trust. https://www.nuffieldtrust.org.uk/research/ethnicity-coding-in-english-health-service-datasets

and indicates that action is needed to improve data quality at its source, by developing and implementing up to date guidance on ethnicity coding for health service providers and GPs.⁵⁷

A not dissimilar knowledge gap exists for a variety of other characteristics which we know often lead to people being marginalised or discriminated against in society, including sexual orientation, disability and gender identity where this differs from sex, or is non-binary.⁵⁸ There are also important gaps for so-called "inclusion groups", which are generally defined in health inequalities policy as groups of people at the margins of society who experience multiple disadvantages, beyond the commonly identified structural drivers of inequality such as racism, sexism and the economy. These include migrant workers and asylum seekers, people who sell sex, homeless people, those currently or previously involved with the criminal justice system and drug users, but many other discrete groups can be thought of in this way, with different groups becoming particularly significant depending on what health care service is being considered. Information which can identify inclusion groups is not consistently recorded in health records and so makes them "effectively invisible" to policy-makers and service planners.⁵⁹

Finally, the other very significant driver of health inequalities – socio-economic status – is also not recorded in routine administrative health records. Whereas ideally analysts might prefer to have individual data on patient income, wealth or occupation, instead they often have to rely on inputting this from information about the deprivation level of the small area (Lower Super Output Area, or "neighbourhood") the patient lives in, again building in the potential for error.

Analysts routinely adjust their data to try and avoid the pitfalls associated with each of these methodological problems and carry out sensitivity checks to

⁵⁷ For further analysis and recommendations, see Scobie, S et al (2021) *Ethnicity coding in English health service datasets*

⁵⁸ A trend to conflate the terms sex and gender, especially when combined with sensitivities around collecting data on sex at all, risks also undermining our ability to both adjust health data for expected and known differences between the biological sexes, as well as identify inequities between them.

⁵⁹ Campos-Matos, I; Stannard, J; de Sousa, E; O'Connor, R; & Newton, J (2019) 'From health for all to leaving no-one behind: public health agencies, inclusion health, and health inequalities', *The Lancet*, Vol 4 (December), 601-603

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ensure the pattern they identify is as close to an accurate reflection of reality as possible, rather than an artefact of the less-than-ideal data. However, scope for error and uncertainty often remains.

What is "access"?

While health care experience and outcome are largely self-explanatory terms, opinions differ on how health care "access" should be measured or defined.⁶⁰ In practice, most quantitative analyses of health care inequalities in England are led by data availability and so use one of two implicit definitions of health care access: actual service use or uptake (such as hospital procedures undergone, or outpatient appointments attended) or resource provision/ availability (as measured, for example, in terms of doctors per head in a given location, or outpatient appointments made but not necessarily attended, or the physical availability of specific services within a geographical range).

While useful for providing a means to measure inequalities, these narrow definitions of access are limited in how much they can tell us about the multiple drivers of health care inequalities. To understand these better, the conceptual framework developed by Levesque and co-authors is useful.⁶¹ This views health care "access" as spanning multiple domains or steps along what might be thought of as an access pathway, beginning with the patient's awareness of a service's existence and their need for it – which is in part influenced by the service's own outreach and information dissemination. At the end of the "access" pathway is the patient's receipt of appropriate, timely, health care, which is determined both by the availability of high-quality health care as well as by the patient's ability to engage with that care, for example through adhering to treatment regimes. In this sense, health care experience, quality and outcome are viewed as part of the health care "access" pathway, as readily available access to poor quality health care – or poorly trained clinicians – cannot be properly be seen as "good" access to health care.

⁶⁰ For a summary of the different approaches, see Cookson, R, et al (2016) 'Socio-economic inequalities in health care in England'

⁶¹ Levesque, J. F., Harris, M. F., & Russell, G. (2013) 'Patient-centred access to health care: conceptualising access at the interface of health systems and populations', *International Journal for Equity in Health*, 12, 18. https://doi.org/10.1186/1475-9276-12-18

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By conceiving access in this way, the Levesque framework broadens the focus from the simple availability of services to reflect also on the process of the patient seeking and obtaining care and how this is influenced by the norms and processes of the service provider itself 62, as well as by "feedback loops" between different steps and experiences in the access pathway - all factors which the foregoing analysis of the pandemic has highlighted as driving health care inequalities.

Although in practice marginalised groups often experience obstacles across multiple steps in the access pathway, it is instructive to illustrate the evidence for each step separately.

Access step 1: Service approachability

Approachability refers to the extent to which services can make themselves known to potential patients through their outreach and information. That in turn influences the patient's ability to perceive that they may need it, which is further mediated by their health literacy, beliefs, and trust in health care professionals, which are factors which can themselves be influenced by the information and outreach provided by the service.

An example of access inequalities driven by failures in service approachability is given in Woof and co-authors' study of the views of British Pakistani women on breast cancer screening.63 British Pakistani women experience very low rates of preventative breast cancer screening compared to White British women, and the interview-based study found this was driven by a lack of understanding of the need for and relevance of a screening, as opposed to a symptomatic, service for breast cancer - caused in part by the lack of a direct translation into community languages for common terms used by the services, such as "mammogram" or "screening", with the literal translation bringing to mind a physical screen or curtain. When asked how services could become more approachable, participants talked about their preference for information

⁶² These factors in accessing care are sometimes referred to as relating to a patient's "candidacy" - see Dixon-Woods, M, et al. (2006) 'Conducting a critical interpretive synthesis of the literature on access to health care by vulnerable groups', BMC Medical Research Methodology 6, 35 (2006). https://doi.org/10.1186/1471-2288-6-35

⁶³ Woof VG, Ruane H, Ulph F, French DP, Qureshi N, Khan N, Evans DG, Donnelly LS, (2020) 'Engagement barriers and service inequities in the NHS Breast Screening Programme: Views from British-Pakistani women', J Med Screen. 2020 Sep;27(3):130-137. doi: 10.1177/0969141319887405

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to be available in both written and spoken form in their own language, and the value of outreach through familiar community centres to increase awareness and understanding of the service, and specifically to reassure women that screenings would be conducted by female mammographers only.

Access step 2: Service acceptability

Concerns about the presence of male mammographers highlight a second dimension of care access, which relates to service acceptability. This refers to the cultural and social factors which determine whether or not a patient is able to see a service as acceptable to them. The acceptability of a service will be influenced both by the patient's own social and cultural values but also by those projected by the service and professionals who work in it. For example, a woman may be fully aware of her need to receive breast cancer screening (see the service as theoretically "approachable"), but still feel unable to seek it if she is concerned doing so will be offensive to her religious or cultural values. She might also feel unable to seek care if she is fears she will face prejudicial treatment if she does so.

A recent review by the Race and Health Observatory explored ethnic inequalities in mental health care, finding evidence of multiple barriers to seeking help for mental health problems, rooted in a distrust of both primary care and mental health care providers, and fear of discrimination.⁶⁴ Meechan and co-authors⁶⁵ used interviews with young Black teenage boys aged 16–18 from a South London school to explore this further. They found boys felt that formal support (such as GPs or mental health services) were unrelatable; they feared receiving a diagnosis considered stigmatising, and they lacked trust. To address these obstacles, the researchers recommended the promotion of more Black role models, increased representation among staff within services and better education for mental health staff on the diversity and the range of mental health experiences in the communities they serve.

⁶⁴ Kapadia, D, Zhang, J, Salway, S, Nazroo, J, Booth, A, Villarroel-Williams, N, Bécares, L & Esmail, A, (2022) Ethnic Inequalities in Healthcare: A Rapid Evidence Review, NHS Race and Health Observatory, <u>https://www.nhsrho.org/wp-content/uploads/2022/02/RHO-Rapid-Review-Final-Report_v.7.pdf</u>

⁶⁵ Meechan, H, John, M and Hanna, P (2021) 'Understandings of mental health and support for Black male adolescents living in the UK', *Children and Youth Services Review*, Volume 129, 2021, 106192, <u>https://doi.org/10.1016/j.childyouth.2021.106192</u>.

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A further study by Prajapati and Liebling provides an example where patients – in this case South Asians living in the UK – were aware of what mental health services were available, but struggled to see the service as acceptable as they felt they conflicted with their cultural values to seek help from within the family, not beyond it.⁶⁶ The review also found that some felt caught in a "dilemma" where White clinicians could not be trusted because they did not understand their culture, but the prospect of using South Asian clinicians and support staff also raised concerns about the potential for stigma within a close-knit community – a concern also noted by the Race and Health Observatory.⁶⁷

Access step 3: Service availability and accommodation of patient needs

The availability of services does not just depend on their physical (or virtual) existence, but also that they are appropriately staffed and able to accommodate the needs of different social groups, such that they are able to reach them – for example through offering a flexible range of appointment times. For individuals and groups of patients, the extent to which services are genuinely available will depend on factors such as their physical mobility (or technological capabilities, in the case of virtual services) and occupational flexibility.

Inequalities in the availability of services are one of the more common dimensions of health care inequalities explored in the literature, often through geographical variation.

Fisher and co-authors explored inequalities in the availability of primary care between deprived and less deprived areas before the pandemic.⁶⁸ After adjusting for patient need, they found GPs in the most deprived fifth of neighbourhoods in England were responsible for on average 10% more patients each than GPs serving the least deprived fifth. Appointment availability was broadly similar between the deprivation groups, but in poorer

⁶⁶ Prajapati R, Liebling H, (2022) 'Accessing Mental Health Services: a Systematic Review and Meta-ethnography of the Experiences of South Asian Service Users in the UK', J Racial Ethn Health Disparities. 2022 Apr;9(2):598-619. doi: 10.1007/s40615-021-00993-x

⁶⁷ Kapadia, D. et al (2022) Ethnic Inequalities in Healthcare: A Rapid Evidence Review, NHS Race and Health Observatory,

⁶⁸ Fisher R, Dunn R, Asaria M & Thorlby R (2020) 'Level or not? Comparing general practice in areas of high and low socioeconomic deprivation in England'. The Health Foundation, September 2020 <u>https://www.health.org.uk/</u> <u>publications/reports/level-or-not</u> [Last accessed April 2022]



areas, appointments were more likely to be with a nurse, meaning patients were seen by clinicians which on average had a lower, or cheaper, mix of skills in part reflecting the lower funding available to practices per patient (after needs adjustment) in the most deprived areas.^{69,70}

As the use of digital technology and remote health care grow, so too do concerns about the impact digital exclusion can have of limiting the availability of health care resources to those without the relevant technology or skills.⁷¹

The National Paediatric Diabetes Audit provides a stark example in the use of digital technologies for children and young people with type 1 diabetes. The audit found that despite digital technologies being linked to significantly better HbA1 control (a key outcome measure in diabetes management), these had much lower use in both patients living in poorer areas and those from minoritised ethnicities, particularly affecting Black children and young people. Whereas just under 40% of White children and young people with type 1 diabetes were using insulin pumps in 2019-20, the proportion among Black children was less than 27% and for Asian children just under 30%. A social gradient was also evident, with just under 32% of patients living in the most deprived areas using a pump, increasing to just over 44% of patients in the least deprived area – a gap that had grown since 2014-15.⁷²

Real time blood glucose monitors (rtCGM) are also shown to be associated with better HbA1 control but were similarly far less likely to be used by Black children and young people, with a fifth of White patients using the technology compared to only 12% of Black patients and 15% of Asian patients. Of those living in the poorest areas, only 14% were using the continuous monitoring technology compared to 25% of those in the least deprived areas. Significantly,

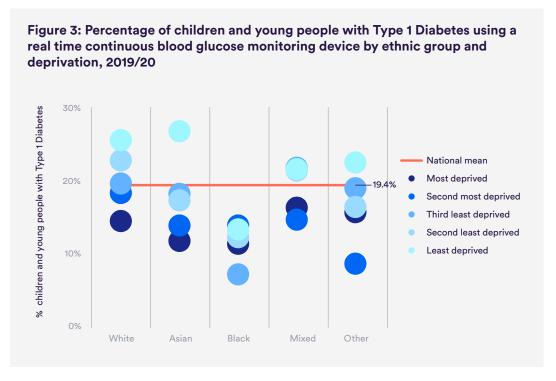
⁶⁹ Fisher R, Dunn R, Asaria M & Thorlby R (2020) 'Level or not? Comparing general practice in areas of high and low socioeconomic deprivation in England'. The Health Foundation, September 2020 <u>https://www.health.org.uk/publications/reports/level-or-not</u>

⁷⁰ see also Nussbaum C, Massou E, Fisher R, Morciano M, Harmer R, Ford J, 2021 "Inequalities in the distribution of the general practice workforce in England: a practice-level longitudinal analysis", *British Journal of General Practice* Oct 26;5(5):BJGPO.2021.0066

⁷¹ Stone E (2021) Digital exclusion & health inequalities. Briefing paper. Good Things Foundation. https://www.goodthingsfoundation.org/insights/digital-exclusion-and-health-inequalities/

⁷² National Paediatric Diabetes Audit (2021) "Annual Report 2019-20: Care Processes and Outcomes" London: Royal College of Paediatrics and Child Health, <u>https://www.rcpch.ac.uk/sites/default/files/2021-06/</u> <u>Appendix%201%20NPDA%20201920.pdf</u> [Last accessed April 2022]

unadjusted data from the audit shows that Black children and young people continued to experience rates of access to the technology significantly below the national average, even when they lived in the least deprived quintile.



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Separate research suggests that this ethnic and socio-economic divide in access to health care technology may not be driven purely – or even significantly – by patients' ability to use and afford technology, for example through having WiFi access at home, but also by unwarranted assumptions made by some clinicians about which patients would make full use of the technology and which would not.⁷³

⁷³ Farrington, C., Hovorka, R., & Murphy, H. R. (2020). Who Should Access Closed-Loop Technology? A Qualitative Study of Clinician Attitudes in England. *Diabetes technology & therapeutics*, 22(5), 404–410. https://doi.org/10.1089/dia.2019.0380

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Access step 4: Affordability

The affordability step (or obstacle) in the health care access pathway refers to direct and indirect costs of receiving health care. From a patient perspective, affordability relates to their ability to pay for care - including prescription charges - and, more significantly in the UK, the ability to shoulder the indirect and often "hidden" cost of accessing care, such as time off work, or away from caring responsibilities, or needing to rely on others for help in order to receive care.

Although the NHS is free at the point of use, for some groups living in London, this is not the case. Nellums and co-authors looked specifically at the experiences of undocumented migrant women in maternity care.⁷⁴ This found that women could be deterred from seeking care as they were unclear about what services they were entitled to, and received inconsistent information about charging, compounded by ongoing financial and legal uncertainty.

Even when patients are clear that the direct care they receive in the NHS is free at the point of use, evidence suggest that, for some, the indirect costs of receiving care may form an obstacle. This is particularly the case for patients on low incomes, for whom time spent seeking and obtaining health care is likely to represent a higher proportion of disposable income (or earning time) than for better off patients.75

There is substantial evidence of socio-economic inequalities in receipt of planned (or elective) care in NHS hospitals at a national level. Unadjusted data published by NHS Digital shows that in 2019/20, patients living in the most deprived 20% of neighbourhoods - where levels of ill health are known to be higher - made up just 18.6% of patients admitted to hospital from waiting lists.76

⁷⁴ Nellums LB, Powis J, Jones L, Miller A, Rustage K, Russell N, Friedland JS, Hargreaves S. (2021) "It's a life you're playing with": A qualitative study on experiences of NHS maternity services among undocumented migrant women in England. Social Science and Medicine, Feb;270:113610.

⁷⁵ Cookson, R, Propper, C, Asaria, M & Raine, R (2016) "Socio-economic inequalities in health care in England", Fiscal Studies, vol 37. No-34, pp371-403

⁷⁶ NHS Digital (2021) "Hospital Admitted Patient Care Activity 2020-21" https://digital.nhs.uk/data-andinformation/publications/statistical/hospital-admitted-patient-care-activity/2020-21 [Last accessed April 2022]

Work by the Strategy Unit, based in the Midlands, explored this further for selected high-volume care pathways.⁷⁷ They found that while patients in the most deprived areas received either more or about the same levels of primary care relative to need as patients in better off areas, this was not the case for secondary care. The findings are broadly consistent with earlier studies^{78,79} but there are still evidence gaps around understanding the precise drivers.

Researchers at the Institute for Fiscal Studies attempted to isolate indirect care costs as a possible driver of this inequality when they looked at elective care in over 65-year-olds only – in effect attempting to remove the influence of loss of earnings by selecting a predominantly retired sample group.⁸⁰ For elective admissions, the social gradient observed elsewhere was removed, suggesting that loss of earnings could be a factor driving inequalities for working-age people. However, for outpatient care, the gradient persisted, with patients with the highest level of education receiving 17% more outpatient hospital appointments a year than those with the lowest educational level, after adjusting for need. The gap was made up almost entirely of routine and follow-up appointments, rather than first referrals. The researchers concluded that this could be driven by more educated people finding it easier "to navigate the complex NHS bureaucracy", or feeling more able to attend and "push for" follow up appointments than less educated patients.⁸¹ This could be seen as comprising a number of Levesque's access steps, including a failure of services to accommodate different patient needs, but also an indication of the higher degree of effort or indirect relative cost required from patients with a lower socio-economic status.

81 ibid

⁷⁷ Wyatt, S and Parsons, J (2021) Socio-economic inequalities in access to planned hospital care: Causes and consequences, Strategy Unit, <u>socio-economic inequalities in access to planned hospital care - 210513.pdf</u> (strategyunitwm.nhs.uk) [Last accessed April 2022]

⁷⁸ Ryan-Ndegwa, S., Zamani, R. & Akrami, M (2021) "Assessing demographic access to hip replacement surgery in the United Kingdom: a systematic review" Int J Equity Health 20, 224 (2021). <u>https://doi.org/10.1186/s12939-021-01561-9;</u>

⁷⁹ Cookson, R, Propper, C, Asaria, M & Raine, R, 2016 "Socio-economic inequalities in health care in England", *Fiscal Studies*, vol 37. No-34, pp371-403

⁸⁰ Stoye, G., Zaranko, B., Shipley, M., McKee, M. and Brunner, E.J. (2020), "Educational Inequalities in Hospital Use Among Older Adults in England, 2004-2015" *The Milbank Quarterly*, 98: 1134-1170. <u>https://doi.org/10.1111/1468-0009.12479</u>



Access step 5: Quality and appropriate health care

The final step in the health care access pathway is the receipt of optimal, highquality care that is appropriate to the patient's clinical needs. Inequalities in health care quality are often indicated by health care outcome measures, but can also be considered by exploring different inputs or processes – such as whether or not best practice treatments are provided. The appropriateness of health care will also be influenced by a patient's ability to engage with it and be actively involved in decisions about it.

Multiple studies have identified inequalities in health care outcomes that do not appear to be related to differences in underlying health.

Outcome inequalities from maternity care for Black women in the UK are particularly stark, with a recent report showing that Black women are four times more likely to die in pregnancy or childbirth than White women in the UK.⁸² There are limitations in the data, but qualitative studies report that ethnic minority women feel underserved by community-based services that could offer them support.⁸³

⁸² MBRRACE-UK (2022) Saving Lives, Improving Mothers' Care Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2017-19. National Perinatal Epidemiology Unit (NPEU), University of Oxford. <u>https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/</u> <u>reports/maternal-report-2021/MBRRACE-UK_Maternal_Report_2021_-_FINAL_-_WEB_VERSION.pdf</u>

⁸³ Kapadia, D; Zhang, J; Salway, S; Nazroo, J; Booth, A; Villarroel-Williams, N; Bécares, L & Esmail, A, 2022 Ethnic Inequalities in Healthcare: A Rapid Evidence Review, NHS Race and Health Observatory, <u>https://www.nhsrho.org/wp-content/uploads/2022/02/RHO-Rapid-Review-Final-Report_v.7.pdf</u> [Last accessed April 2022]

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There is also a long-established trend for disproportionate numbers of people from minoritised ethnic groups to be subject to the Mental Health Act. The most recent data shows that among the five broad ethnic groups, known rates of detention for the 'Black or Black British' group were over four times those of the White group.⁸⁴ This indicates inappropriate care, particularly when coupled with evidence showing that receipt of earlier intervention services, in the community and through primary care, is disproportionately low for the same groups.^{85,86,87}

There is also evidence of inequalities around appropriate care in elective care. Wan and co-authors found a social gradient in deaths within three years of elective surgery, with just under 19% of patients from the most deprived fifth of neighbourhoods dying, compared to just under 16% of patients from the least deprived areas.⁸⁸ Patients from the most deprived areas also had a significantly greater risk of developing post-operative complications which could not be explained by underlying comorbidities or age. The researchers concluded that lower survival rates and higher post-operative complication rates should be considered when planning post-operative care for patients from deprived areas.^{89,90}

- 84 NHS Digital (2021) "Mental Health Act Statistics, Annual Figures 2020-21" <u>https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-act-statistics-annual-figures/2020-21-annual-figures</u> [Last accessed April 2022]
- 85 Kapadia, D; Zhang, J; Salway, S; Nazroo, J; Booth, A; Villarroel-Williams, N; Bécares, L & Esmail, A, 2022 Ethnic Inequalities in Healthcare: A Rapid Evidence Review, NHS Race and Health Observatory, <u>https://www.nhsrho.org/wp-content/uploads/2022/02/RHO-Rapid-Review-Final-Report_v.7.pdf</u>
- 86 Jankovic, J., Parsons, J., Jovanovi, N. et al., 2020 "Differences in access and utilisation of mental health services in the perinatal period for women from ethnic minorities—a population-based study" BMC Med 18, 245 (2020). <u>https://doi.org/10.1186/s12916-020-01711-w</u>
- 87 Halvorsrud K, Nazroo J, Otis M, Brown Hajdukova E, Bhui K, 2018 "Ethnic inequalities and pathways to care in psychosis in England: A systematic review and meta-analysis" BMC Med. 2018;16(1):1-17
- 88 Wan Y, McGuckin D, Fowler A, Prowle J, Pearse R, Moonesinghe S, 2021 "Socioeconomic deprivation and longterm outcomes after elective surgery: analysis of prospective data from two observational studies" Br J Anaesth. 2021 Mar;126(3):642-651. doi: 10.1016/j.bja.2020.10.019
- 89 Wan Y, McGuckin D, Fowler A, Prowle J, Pearse R, Moonesinghe S (2021) "Socioeconomic deprivation and longterm outcomes after elective surgery: analysis of prospective data from two observational studies" Br J Anaesth. 2021 Mar;126(3):642-651. doi: 10.1016/j.bja.2020.10.019
- 90 Poulton T, Moonesinghe R, Raine R, Martin P; National Emergency Laparotomy Audit project team (2020) "Socioeconomic deprivation and mortality after emergency laparotomy: an observational epidemiological study", Br J Anaesth. 2020 Jan;124(1):73-83. doi: 10.1016/j.bja.2019.08.022

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NHS systems wanting to tackle health care inequalities will need to scrutinise the access pathways into each of their services to identify where obstacles may exist for specific patient groups, particularly those who experience wider structural inequalities and health inequalities, which the evidence suggests are particularly vulnerable to health care inequalities. Giving particular focus to these groups will help the NHS maximise the opportunity to close the healthy life expectancy gap, which is the Mayor's key measure of health inequalities. The Health Inequalities Test can support the NHS in this work by encouraging a culture where the elimination of health care access, experience and outcome inequalities is viewed as part of continuous striving for clinical improvement and excellence. This will need to be guided by both the interrogation of the NHS's own data and sustained work with communities and social groups experiencing lower rates of service access to identify what the particular, service and population-specific obstacles to that are and remedies to it. $1) (2) (3) (4) (\uparrow)$

3 Health and health care inequalities in major NHS service reconfigurations

Having explored above some of the forms and drivers of health care inequalities in the NHS, it is useful to consider how health and health care inequalities have been approached during major NHS service reconfigurations. It should be acknowledged that reconfigurations are far from the only point at which health and health care inequalities should be considered by NHS organisations. However, reconfigurations are particularly relevant to the Health Inequalities Test due to the consultative mechanisms they trigger, and because the disruptive nature of major service change can present an opportunity to rebuild services more inclusively.

To explore how inequalities have been approached during major service reconfigurations, this review considered four recent reconfiguration schemes – two inside London and two outside it – with consultation processes spanning between 2018 and 2020. The main way the NHS organisations and systems proposing these major service changes demonstrated their consideration of inequalities was through equalities impact assessments, which in each case were published as part of the consultative and decision-making process.

Each of the equality impact assessments considered focused their analysis on the likely impact proposed service changes would have on local population groups with the nine protected characteristics of the 2010 Equality Act.⁹¹ These are set out in part two of the Act as: age; disability; sex; gender reassignment; pregnancy and maternity; race; religion or belief; sexual orientation; marriage and civil partnership.

91 https://www.legislation.gov.uk/ukpga/2010/15/contents

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NHS organisations have a Public Sector Equality Duty (PSED) under the Equalities Act to "have due regard" to the need to eliminate direct and indirect discrimination, harassment and victimisation of people who have these characteristics, to "advance equality of opportunity" between those who share them and those who do not.

In addition to the 2010 Equality Act, the 2006 National Health Service Act (as amended by the 2012 Health and Care Act) gave NHS England and CCGs a legal duty to *"have regard to the need to… reduce inequalities between patients with respect to their ability to access health services.*" ⁹² However, unlike the protected characteristics listed in the Equality Act, NHS England legal guidance notes that there is no definition of which population groups are covered by the specific NHS duty, which has not been tested in case law. This creates practical difficulties when assessing the duty against other operational priorities, including financial balance.⁹³ By contrast, there is ample case law around the Equality Act, and NHS England legal guidance recommends that health care services and commissioners should be monitored against each of the protected characteristics of the Equality Act, as well as "inclusion health groups", which guidance does not define exhaustively, but specifically mentions refugees, asylum seekers, homeless and people who sell sex.⁹⁴

In line with this guidance, equalities impact assessments considered for this review typically did supplement the nine protected characteristics with further groups – most commonly carers and those on low income and/or living in deprived areas. However, there was little consideration of how structural drivers might cause the different groups considered to intersect – for example the over-representation of minoritised ethnic groups living in the poorest areas, compounding obstacles to good health and health care access.

92 Health and Social Care Act 2012 (legislation.gov.uk)

93 Guidance for NHS commissioners on equality and health inequalities legal duties, NHS England, 2015 <u>hlth-inqual-guid-comms-dec15.pdf (england.nhs.uk)</u>

94 Op cit.

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In place of a more systematic analysis of the structural drivers of inequalities, NHS leaders and managers interviewed for this review acknowledged a concern that equality impact assessments could at times be approached as "tick box" exercises, to show compliance with the 2010 Equality Act. This concern was underlined by the fact that two out of the four of the assessments considered for this review were carried out by public relations firms rather than epidemiologists or public health specialists.

Crucially, the approach taken in this small sample of assessments was to implicitly assume that the status quo distribution of service access and outcomes was equitable, with the analysis focused on whether proposed reconfiguration changes might result in any deterioration for the "at risk" groups considered. This was then used to establish which groups would be more affected by any changes, with those changes explored through both open and targeted surveys and through focus groups to identify potential negative impacts.

There was little or no consideration of whether or not access and outcomes at present were equitable – for example through a baseline analysis of the health system's own data on access, experience and outcome for the relevant services by different population groups. None of the assessments were therefore able to ascertain the extent to which their services were currently equitable or not, although some insights on this emerged though the focus groups – typically around service culture, stigma and discrimination; physical accessibility issues for elderly and disabled people, including parking; translation and communication difficulties for non-English speaking people and people with sensory impairments; and public transport and travel cost issues for people on low incomes.

Although these are all important issues, with many featuring as equity factors in the above survey of the recent evidence, the reliance on anecdotal reports through focus groups, together with the absence of an analysis of the structural drivers of inequalities and marginalisation, meant the impact assessments were unable to attribute specific weights to the relative importance of specific access obstacles and experiences identified, and nor did they attempt to. It is therefore not surprising that none of the assessments recommended substantial changes to published plans, or resource commitments, to address the obstacles identified. Instead, recommendations centred around equality

and diversity training for staff; better signage and communication with patients; commitments to discuss the need for improved bus routes with local providers or TfL (in London); and references to how eligible patients should be encouraged to make use of the national Healthcare Travel Costs Scheme and local patient transport services.

New policy approaches since the pandemic

The inequities exposed and exacerbated through the coronavirus pandemic have brought a refreshed approach to national policy on health and health care inequalities.

The change in approach was signalled in a 31 July 2020 letter from NHS England's chief executive and chief operating officer to all NHS chief executives, regional directors, chairs and GP practices. It stated that, alongside continued efforts on Covid-19, a priority from August was "action on inequalities and prevention".⁹⁵ The letter marked a significant change by emphasising the importance of addressing health care inequalities as part of efforts to reduce health status inequalities, alongside the NHS's role in ill health prevention.

The letter stated that post-pandemic health service recovery should be planned "in a way that inclusively supports those in greatest need". These would be guided by new organisational-level performance measures assessing service use and outcomes by people living in the most deprived neighbourhoods and those from Black and Asian communities – a reference to the dominant structural drivers of health and health care inequalities that became unignorable over the course of the pandemic.

NHS England's change in approach was followed, and to an extent codified, by the launch of the "Core20PLUS5" initiative, which sets out a method to identify target populations and disease areas in local health inequalities strategies.⁹⁶

⁹⁵ NHS England (2020) "Third phase of NHS response to COVID-19" Letter from Sir Simon Stevens and Amanda Pritchard, <u>https://www.england.nhs.uk/coronavirus/documents/third-phase-of-nhs-response-to-covid-19/</u> [Last accessed April 2022]

⁹⁶ NHS England (2021) "Core20PLUS5: An Approach to Reducing Health Inequalities". <u>https://www.england.nhs.uk/wp-content/uploads/2021/11/core20plus5-online-engage-survey-supporting-document-v1.pdf</u> [Last accessed April 2022]

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The "Core20" refers to the 20% most deprived population nationally, as measured by the Index of Multiple Deprivation, while the "PLUS" refers to other groups not already captured in the Core20 who experience poorer health care access, experience and/or outcomes.⁹⁷ The initiative gives health systems the flexibilities to define these themselves, on the basis of local data analysis, but as a guide it mentions minoritised ethnicities, protected characteristic groups, coastal communities, people with multi-morbidities and other groups frequently included under the notion of "inclusion groups". Finally, the "5" element of the initiative highlights five clinical areas assessed as either contributing the most to the life expectancy gap between the most and least deprived populations, or (in the case of maternity and severe mental illness) are outstanding Long Term Plan commitments.

In contrast to preceding approaches to health inequalities, the Core20PLUS 5 approach is clear that the intent is for action on health care access, experience and outcome inequalities, as well as broader prevention work on the wider determinants of health, and that socio-economic inequalities, alongside ethnicity, are particularly under the spotlight.

This was followed with the 2022 Health and Social Care Act. This clarified that the original health care inequalities duty would be applied to the new integrated care boards overseeing ICSs, whose performance on this duty would be assessed annually by NHS England. The Act also included a new requirement for NHS trusts to consider the wider impact of their decisions on inequalities "between individuals" in health care outcomes. The full implications of the new legislation are not yet clear, but could potentially lead to increased transparency and focus being put on health and health care inequalities, in part through an extended regulatory framework, although it should be noted that there is nothing in the legislation to suggest that it alone will lead to the greater emphasis placed on structural inequalities seen in the Core20PLUS 5 approach.

⁹⁷ See <u>Health and Care Act 2022 (legislation.gov.uk)</u> and "NHS England and NHS Improvement's Equality Objectives for 2022/23 – 2023/24", NHS England, May 2022 <u>B1588-nhsei-equality-objectives-for-2022-2023-2023-2024.pdf (england.nhs.uk)</u>

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The view from the NHS in London

All NHS managers and leaders interviewed for this report talked about the significant change in approach to health and health care inequalities that had been triggered by the pandemic. One echoed many when they expressed how Covid had created a burning platform from which it may be possible to push forward with more radical change: *"We need to capitalise on the post-Covid awareness of this,"* they said. Many commented that the shift towards population health management, which is at the centre of the earlier move towards integrated care systems, also entailed a focus on health inequalities, through its emphasis on targeted support of at-risk patient groups.

Several interviewees mentioned the significance of socio-economic deprivation being *"back on the radar"* through recent NHS England policy and welcomed it, but also highlighted how developing cultural competence in services to better serve marginalised ethnic groups was an area that would need more local work. *"It's not just about translation"* commented one national leader. Another gave a vivid example of the scale of change needed. Referring to a national target for continuity of midwife care for Black and minority ethnic women, they commented: *"Change won't come from national targets, as there's no point having continuity if you're still being bullied, or the care is culturally inappropriate or racist."*

Interviewees were enthusiastic about using data in the way outlined by NHS England to identify and target population groups underserved by health services. Several noted that while there was much room for improvement – in particular on ethnicity coding – health systems should not *"let perfection get in the way of getting on".* Interviewees were equally enthusiastic about using new ways to engage with local communities beyond *"the usual suspects"*, including through participatory research. Integrated care systems (ICSs) are at an early stage in developing work in this area, but are keen to build on momentum and relationships created during the pandemic. One area identified as a risk was relationships with local authorities, who were recognised as local experts in community engagement, who needed to be treated as equal partners as integrated care systems developed. $\left(2 \right) \left(2 \right) \left(3 \right) \left(4 \right) \left(1 \right)$

NHS managers also talked about emerging good practice. For example, the health inequalities team in North Central London has designed simple-touse "equity ratio" metrics to help services explore potential inequalities in services access and outcomes. These are not being seen as a replacement for more robust analysis, but rather as an aid to help start early conversations and to create a common metric that can be easily understood and compared across different services and trigger further investigations. Beyond London, University Hospitals Coventry and Warwickshire NHS Trust (UHCW) has developed a data dashboard which allows clinicians booking elective operating theatre slots to see other information about a patient which may be relevant to their ability to access timely elective care, including the deprivation score of where they live (as a proxy for income deprivation) and information on previous "did not attends" (DNAs) which may indicate that the patient experiences access difficulties.

The UHCW approach has been widely discussed within the NHS as an example of emerging good practice and innovation, and the trust's medical director told this review how service-level analysis on health care inequalities could be used to build the case for change within health care organisations. The medical director described how, when surgeons were shown the data on the social gradient in elective care access in their own hospital, they agreed to fast-track moving to weekend surgery lists, which are seen as beneficial to patients in low-income or insecure employment, who may not be able to afford to take time off during the working week. This resonated with another interviewee who commented that it was sometimes easier to win clinicians' support to make changes if they were presented with meaningful data on their own patients, enabling them to view action on health care inequalities as part of improving clinical quality.

On health status, as opposed to health care inequalities, all leaders and managers interviewed talked about the importance of seeing NHS organisations as "anchor institutions" in their areas. Interviewees described how NHS service reconfigurations should be viewed as a *"structural intervention"*, with the power to either improve or worsen the social determinants of health of its own staff and local population. In particular, they felt that when reconfiguration schemes involved service consolidation, they should consider the impact on low paid staff, whose jobs were the most likely to be put at risk, or become unfeasible if travel distances increased. |)(2)(3)(4)(4)

However, there were also concerns about how the new national approach to health care inequalities would be implemented in practice. The first was about transparency. Although NHS England has developed a Health Inequalities Dashboard to track progress on health care inequalities for deprived populations and minoritised ethnic groups, its use as an accountability mechanism for local communities and the worst affected population groups is currently limited as it is not in the public domain. One NHS manager talked about how their ICS was also reluctant to publish their own equity analyses, due to local "political sensitivities" over what it showed. Others expressed concern about a similar reluctance nationally to be transparent about slow progress on meeting the Workforce Race Equality Standard, which they felt hampered frank conversations about what was needed to improve ethnic minority representation at all levels of NHS staffing – an equality issue in its own right, but also a factor likely to hold back NHS attempts to increase the cultural competence and acceptability of services for minoritised ethnic groups.

The second concern was about shifting resources to meet the scale of the inequalities challenge. One interviewee said that despite the undoubted commitment of some prominent NHS and public health leaders, elsewhere there was "a wave of indifference; the focus is on finance and waiting times". This was echoed by others, with one stating that at ICS level "you can't get health inequalities on the agenda, it's all finance and electives". Another commented that those trying to push for health care equity initiatives to be funded found themselves on the "back foot" due to the notion that schemes should ultimately be cost-saving, by reducing demand for acute services. This left those trying to design and implement health and health care inequalities schemes charged with identifying the 'downstream' financial savings they would generate in order to justify the investment, rather than improvements in equitable access and outcomes being viewed as an end in themselves.

Other senior managers described how it was often unclear what "fairness" or "equity" meant in the provision of health care, particularly when decisions have to be made about what to prioritise. One commented: "There are no guiding principles; everybody sees it differently." This highlights a need for the Mayor, in his engagement with the NHS through the Health Inequalities Test and other avenues, to articulate his own clear vision, which centres on



the reduction of the Healthy Life Expectancy gap.⁹⁸ The renewed focus on the structural drivers of health and health care inequalities in the light of the pandemic may also contribute to a clearer understanding of the priorities for change, in so far as this can help identify how inequalities are compounded and which population groups are most at risk.

⁹⁸ For a discussion on the use of the Healthy Life Expectancy gap as a means to guide and evaluate efforts to reduce health care inequalities, see Gainsbury & Mitchell, 2022, <u>https://www.hsj.co.uk/health-inequalities/the-seemingly-fair-principle-that-is-driving-nhs-inequality/7033172.article</u>

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4 Is the Health Inequalities Test fit for purpose? Recommendations for change

Following the NHS response to the coronavirus pandemic, a mismatch has emerged between the modest ambitions implied by the original wording of the Health Inequalities Test and the policy direction now being explored by the NHS, both nationally and locally through ICSs. It is further clear from the Mayor's Health Inequalities Strategy, as well as the approach adopted by the London Recovery Board, that the Mayor is likely to want to adopt and encourage an approach to health and health inequalities which focuses on the structural drivers of inequalities – particularly the role of structural racism and socio-economic inequalities – and there is scope to better reflect this through revisions to the Health Inequalities Test.

To set out where change is needed, this report concludes by considering each of the supplementary questions in the current Health Inequalities Test and comparing it to the evidence and insights gained through the course of this review.

Supplementary question 1: "Do proposals set out the health inequalities issues in their local population?"

This question remains broadly appropriate and is expected to form a major focus of the population health management approach which health systems are adopting. However, a clarification that both health care and health status inequalities should be captured would be useful, as an understanding of the relationship between the two will help health systems and the Mayor identify priorities for action.)(2)(3)(4)(

Further, it would be advantageous to stipulate that inequalities analyses are expected to include inequalities driven by structural or systematic inequalities, including those relating to ethnicity and socio-economic deprivation. This would not preclude local health systems identifying other population groups – for example patients with particular conditions, or other Equality Act 2010 protected characteristics – but would help embed the renewed focus on structural inequalities which has followed the pandemic. The Mayor has already adopted the Healthy Life Expectancy gap as his key measure of health (in)equity and it would be useful for this to be flagged here, which again would not preclude other measures also being used (particularly where healthy life expectancy data is not available at sufficiently granular level).

None of these changes should add additional workload or information requirements to health care systems, but should instead reinforce and support existing good practice, including around population health management and Joint Strategic Needs Assessments, and ensure such practice – together with a baseline analysis of inequalities – is fully embedded in service change proposals.

Suggested revised wording: **"Do proposals set out the current systemic health** and health care inequalities in their local population – including those driven by socio-economic deprivation and structural racism? Is the contribution of these inequalities to the Healthy Life Expectancy gap considered?"

Supplementary question 2: "Do proposals consider their impact on health inequalities in a systematic, documented way?"

The review of NHS reconfigurations and interviews with NHS leaders and managers undertaken for this report identified that until recently, health inequalities have been viewed as largely "out of scope" of service reconfigurations, as health status inequalities are seen as driven by wider social determinants beyond the direct control of the NHS service. This view is now changing as a result of the "anchor institution" observation that health care providers and systems are themselves major social, economic and cultural forces in their local areas. $1)(2)(3)(4)(\uparrow)$

As shown in the preceding chapter, service reconfiguration impact assessments have tended to focus on the protected characteristics of the 2010 Equality Act and to rely on survey-based insights pertaining to protected characteristic group views on the likely impact of proposed changes on them. Although these insights can be useful, they lack the weight that could be brought through analysis linked to a more thorough understanding of relevant baseline service access and outcome inequalities, such as those expected in response to the revised supplementary question 1.

While NHS organisations will continue to need to show their compliance with the EA2010, the expectation for major service changes should be for a more thorough analysis of the impact of the proposed changes on the population groups identified in their baseline inequalities analysis as suffering the worst health and health care inequalities. This would then allow the Health Inequalities Test to act as a lever to bring focus and transparency to relevant health and health care inequalities.

Suggested revised wording: "Do proposals consider their impact on the health and health care inequalities identified in their baseline analyses in a systematic, documented way?"

Supplementary question 3: "Do proposals ensure that services do not become less accessible to vulnerable groups?

This question as currently phrased does not fully reflect the ambition shared by both the Mayor and the NHS to reduce access inequalities, rather than merely ensure they are not exacerbated.

Suggested revised wording: **"Do proposals ensure that services become more** accessible to vulnerable groups, including those identified as experiencing the worst health and health care inequalities"

Supplementary question 4: "Do proposals ensure that unwarranted variations in outcomes do not worsen?"

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This supplementary question could similarly be reworded to reflect the greater ambition now shared with regards to health care inequalities.

Suggested revised wording: **"Do proposals ensure that unwarranted variations in health care outcomes are reduced?"**

Supplementary question 5: "Do proposals set out specific, measurable goals for narrowing health inequalities and mechanisms for achieving this, for example, through credible plans to: – make services more accessible to vulnerable groups? – reduce unwarranted variation in outcomes?"

While the second part of this question would be made redundant by the greater ambition expressed in the above suggested revisions (as credible plans to reduce health inequalities would become integral to service change proposals, rather than bolt-on mitigations), the first part remains vital for ensuring transparency and accountability. This transparency may at times be uncomfortable for the NHS and its partners, but it is nonetheless necessary for ensuring that the focus and platform given to health inequalities by the pandemic continues. While it is recognised that the NHS faces competing priorities and resource constraints, it is important that where other priorities have taken precedence over health and health care equity, this is also set out transparently and reasons clearly stated.

Suggested revised wording: "How is health and health care equity weighted in the options appraisal process for the proposed changes? Do proposals set out specific, measurable goals for narrowing health and health care inequalities? Where data and information gaps exist on inequalities and population groups, is there a plan to address these?

Overarching recommendation for the Health Inequalities Test

These proposed revisions to the existing supplementary questions better reflect the heightened ambition that now exists around reducing health and health care inequalities, will help embed the focus on structural drivers of inequality, and further make it clear that both health and health care inequalities are within scope. These changes should also be reflected in the main text of the Test, which we propose be revised to read as follows:

"The proposed changes make best use of the opportunities available to the health system to reduce health and health care inequalities which have been set out transparently together with an evidenced plan for further action. The plans clearly set out proposed action to prevent ill health, including targeting action and resources to improve the healthy life expectancies of the worst off, including groups who experience wider structural inequalities."

As seen through the experience of the pandemic, a vital component in reducing health care inequalities involves addressing the impact of marginalisation which sees the needs of some communities excluded or overlooked from service design and delivery. Meaningful, ongoing public engagement and involvement in the design of services is explored through a separate part of the Mayor's six-test framework – the Patient and Public Engagement Test. This test currently references the need to engage with "harder-to-reach" and "equalities" groups and communities. While the intent is clear, it may be useful to clarify that such groups are expected to include those experiencing socio-economic deprivation and structural racism, as these have been identified as key drivers of both health and health care inequalities. 2

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Glossary of terms

Clinical commissioning groups (CCGs)

NHS organisations charged with planning, commissioning, and designing NHS services for their resident populations in England under the 2012 Health and Social Care Act. NHS commissioners are distinct from NHS providers, such as hospitals and community services, which deliver services and are typically set up as NHS trusts or NHS foundation trusts. CCGs were replaced by ICSs and integrated care boards in July 2022.

Integrated care systems (ICSs)

Partnerships of NHS and social care organisations, including both NHS commissioners and providers, and upper-tier local authorities, which plan and deliver health and social care services in their areas. At present there are 42 ICSs in England, which were placed on statutory footing by the 2022 Health and Care Act. The statutory NHS organisations overseeing ICSs are integrated care boards.

Health care access/health service access

There is no single definition of health care access or health care accessibility in the policy or academic literature. Some definitions view it as analogous to service availability, with "access" being equated with opportunity for service uptake. Other definitions align it with actual service use or uptake, with a service seen as "accessed" once it has been used. This report uses the latter definition and identifies a number of obstacles which can result in different population groups having less opportunity to access services in practice than others.

Health inequalities

Avoidable and unfair differences in health that are systematically patterned by a social characteristic such as ethnicity, gender or socio-economic position, as opposed to the result of free personal choice, or natural or random variation.



Health care inequalities

Avoidable and unfair differences in the level of health care access (relative to health care need) or quality of health care experience and outcome that are systematically patterned by a social characteristic rather than free personal choice, or natural or random variation.

Health care outcome

The health benefits patients receive from a health care intervention, which can also be used as an indicator of care quality.

Minoritised ethnic group

This report uses the term "minoritised" instead of "ethnic minority" to highlight the fact that in some areas of London (and elsewhere in England) people identifying as belonging to ethnicities other than White English/ British are in the statistical majority, and yet continue to experience disadvantages due to the processes associated with structural racism which systematically renders their interests and wellbeing as "minority" or "marginal" concerns. The term also highlights that minoritisation is an active process which organisations perpetuate when they fail to be inclusive. Nuffield Trust is an independent health charity. We aim to improve the quality of health care in the UK by providing evidence-based research and policy analysis and informing and generating debate.

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