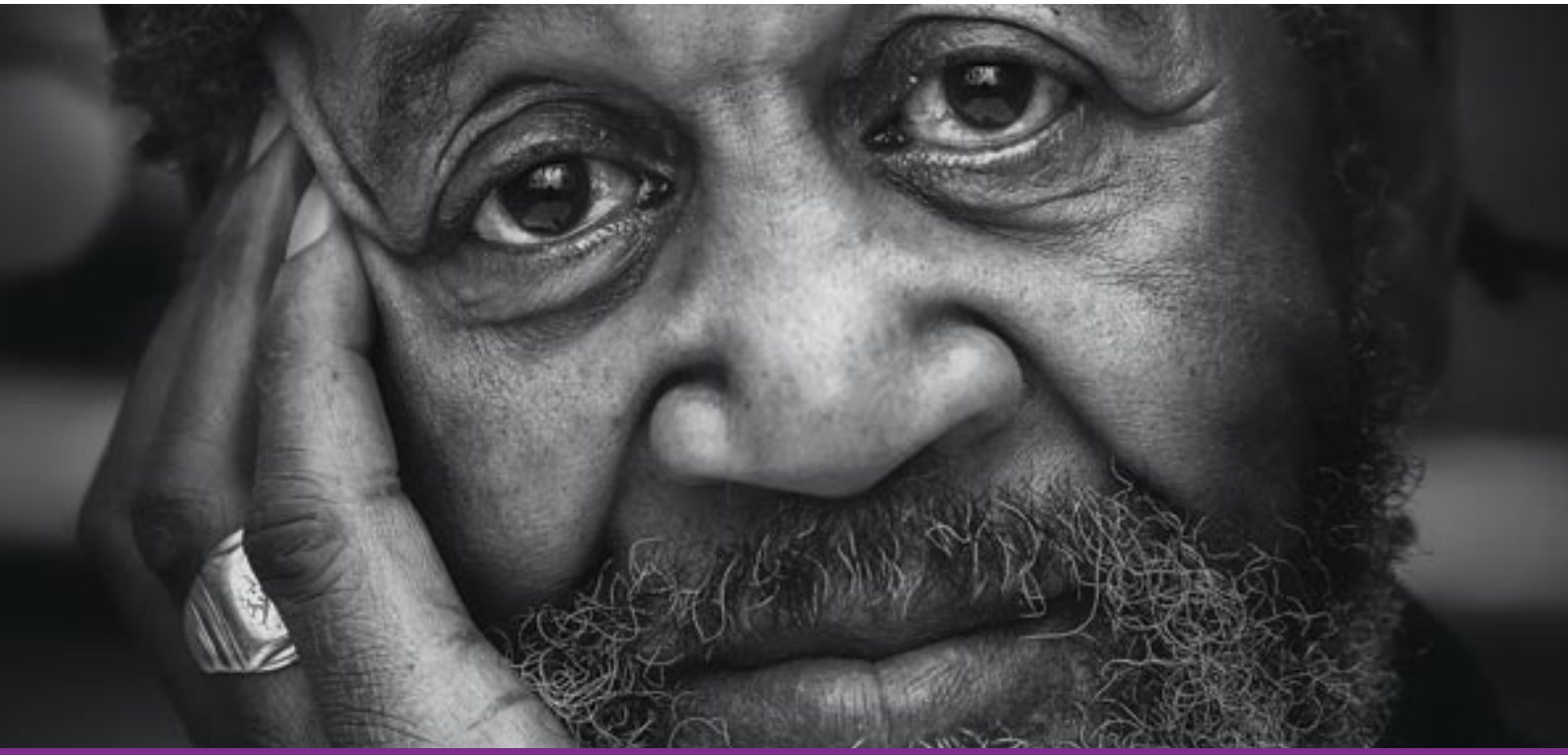
Collaboratives on addressing racial inequity in covid recovery



Long Term Conditions

Briefing Paper

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Introduction

What do we mean by long term conditions?

Long-term conditions are health problems for which there is currently no cure, and which are managed with drugs and other treatment. Examples include diabetes, chronic obstructive pulmonary disease, arthritis, and hypertension. An estimated 20 million people in England have a long term condition and these numbers are expected to increase.[1] It is not uncommon for people to be affected by more than one health difficulty. The medical term for this is multi-morbidity.

Links between long term conditions and deprivation

Long term conditions are clearly linked to socio-economic status, with higher proportions of people with long term conditions living in more deprived areas.[2] This paper concentrates upon long term physical health conditions. A separate Briefing Paper in this series examines mental health and wellbeing[3] but it is worth emphasising here that living with a combination of long term physical and mental health conditions appears to be particularly difficult. People affected this way are more likely to live in areas of socio-economic deprivation and have fewer resources of all kinds. This often leads to significantly poorer health outcomes and reduced quality of life and contributes to generating and maintaining inequalities.[4,5]

The risk of developing a long term condition rises with age

The risk of acquiring a long term condition increases with age. For example, only about 1% of people in the UK aged 20-24 report they have problems with their heart, circulation or high blood pressure compared with 48% of those aged 65-99.[6]

While smaller proportions of young people have a long term condition, it is important not to overlook the problems that people in this age group face. Among high income countries, the UK has one of the highest rates of young people living with conditions such as asthma or diabetes. Unfortunately, young people in the UK tend to receive less support when compared with similar countries. For young people with a long term condition in the UK, a major barrier is that most services have not done enough to encourage young people to engage with their services and become better at managing their condition themselves.[7] Furthermore, long term conditions which develop in adolescence can become more severe as time passes.

1. Why we need better information on ethnicity and long term conditions

Socio-economic status in the UK differs by ethnic group and gender. For example, Indian men make up the highest proportion of people in higher managerial and professional backgrounds while women from Bangladeshi and Pakistani heritage are more likely to have never worked or be long term unemployed.[8,9]

Despite all the evidence we have for the strong links between socio-economic status and long term conditions highlighted at the beginning of this paper, very little research about long term conditions has examined links between ethnicity and long term care conditions. There are three reasons for this.

Self-report and sample size

Studies based upon representative samples of the general population which use a self-report question such as 'Do you have any physical or mental health conditions or illnesses lasting or expected to last 12 months or more?'[10] include large numbers of people who do not have any long term conditions. Furthermore, self-ratings may actually under - rather than overestimate – the proportion of people with a long term condition.[11] Ethnic groups in the UK, as do long term conditions, vary in size so they sometimes include only a few people from a particular group with a particular condition.

Under-representation of different ethnic groups in clinical trials and other research studies

Some studies of people with long term conditions have been especially designed to ensure that they include enough people from different black and ethnic minority groups to enable comparisons.[12,13] Unfortunately, these are the exceptions. The consequences of this are particularly serious because it means that interventions cannot be tailored to the needs of different ethnic groups and may perpetuate, rather than reduce health inequalities.[14,15]

Health records and death certificates lack data on ethnicity

Although GPs are now contractually required to record patients' ethnicity where patients give their permission to do so,[16] ethnicity is often recorded inaccurately on patients' health records[17] which creates the risk of incorrect conclusions being drawn from flawed data.[18] Many researchers have called for better harmonisation in recording ethnicity and an end to the practice in which people whose origins lie in the Indian sub-continent are recorded as 'South Asian' as if they were a single ethnic group.[19,20]

If a long term condition has contributed to a person's death, then it is recorded on the death certificate. Scotland introduced an ethnicity category for death registration in 2012 but this has yet to take place in England, although the Westminster government has promised to make this change.[21] Once this happens, it will be possible to get more accurate information on whether long term conditions contribute to the different levels of life expectancy among people from different ethnic groups in England.[22]

2. Some ethnic groups are more affected than others

Poor health is caused by a wide range of factors, including biological factors (such as age, gender, and hereditary factors) and wider social determinants. These include education, employment, income and poverty, housing, and the local environment. Experiences of racism and racial discrimination also have a damaging impact of people's health.[23,24]

As mentioned earlier, the risk of having a long term condition rises with age. After controlling for social and economic disadvantage, people aged 60 and over from a black and minority ethnic groups were more likely to report that they had a long term condition than their White British counterparts. This was especially true of people from Pakistani backgrounds.[20]

A similar pattern exists in studies which include everybody aged 16 and over, not just those aged 60 and over. People from ethnic minority groups (especially Pakistani and Bangladeshi groups) are more likely than those from the White British group to report limiting long-term illness and poor health, with those identifying as White Gypsy and Irish Traveller reporting the poorest health. This is equally true of men and women.[23,24]

When we examine patterns in the proportion of people self-reporting a limiting long-term illness over time, it becomes clear that these are largely linked to changes in socio-economic circumstances and not to any inherent risk factor for long term conditions across different ethnic groups. These data also show that while levels of self-reported limiting longstanding illness among people from Indian and black backgrounds were improving, the position of people from Pakistani and Bangladeshi backgrounds appeared to be worsening.[19]

Some long term conditions – such as diabetes - are more common among some minority ethnic groups while other common long term conditions – such as arthritis – are not. The next sections discuss some of the main evidence about some of the long term conditions which appear to be more common among some black and minority ethnic groups.

Asthma

People from black and minority ethnic groups in England and Wales are more likely to be affected by asthma than their white counterparts. They are also more likely to be admitted to hospital for treatment. When subdivided into those born in the UK and those outside, there is a further divide. People from BAME groups born outside the UK have a lower incidence than those born in the UK, suggesting that the descendants of Asian and black Caribbean who migrated to England are even more likely to be affected than their grandparents and great grandparents.[25]

A study of asthma among people from black and minority groups in Scotland found they experienced higher rates of hospital admission and were also more likely to die of their disease when compared to White Scottish people. People from Pakistani backgrounds had the worst outcomes while those from Chinese backgrounds had the best.

Among children, a slightly different pattern has been reported, with higher rates of asthma among children from Black Caribbean backgrounds and lower rates among children from Bangladeshi backgrounds.[26]

Taken together, these studies have suggested that socio-economic disadvantage plays an important role in explaining these differences. It is possible that there are other differences – such as whether some groups are more likely than others to consult their GP about their breathing problems, or whether some groups receive poorer primary care than others but these need to be investigated more fully.[25-28]

Cancer

Overall, the proportion of people from black and minority ethnic groups affected by cancer is lower than in the white population.[29] Black women are less likely to get cancer than white women. By contrast, there is no evidence that black men are less likely to get cancer than white men. Asian, Black, Chinese, and Mixed ethnic groups have significantly lower risk of getting either breast, prostate, lung, and colorectal cancer compared to white people. However, Black people are nearly twice as likely as white people to get stomach cancer and Asian people are up to three times more likely to get liver cancer than the white population. Black men are also more likely to get prostate cancer and Black and Asian women aged 65 years and over, are at higher risk of cervical cancer compared with white women.[30]

Recent work has questioned whether these ethnic differences could be improved by better uptake of screening programmes. For example, a study of bowel cancer in Scotland suggested that there are important variations in uptake of bowel cancer screening by ethnic group and religion in Scotland, for both sexes, that require further research and targeted interventions.[31]

Cardiovascular disease

Rates of coronary heart disease are higher among people from Asian backgrounds while people from a Black Caribbean background have higher rates of high blood pressure and stroke.[32] However, these data have been criticised for misclassifying UK-born minority ethnic groups and providing insufficient detail on whether excess risk is due to increased incidence, poorer survival or both.[33]

A study of acute myocardial infarction incidence (heart attacks) in Scotland showed that while Pakistani men were the ethnic group most likely to experience a heart attack, rates among Chinese men and women were much lower. It concluded that drastic steps were needed to reduce the incidence among Pakistani men – especially considering the high rates of coronary heart disease already existing among the White Scottish population.

Diabetes

The problem of the lack of ethnic diversity in clinical trials highlighted earlier could hardly be better illustrated than when we consider ethnicity and diabetes. In the UK, type 2 diabetes is disproportionately prevalent among people defined as ‘South Asians’ and outcomes (such as going on to develop cardiovascular disease subsequent to developing type 2 diabetes) are known to be poorer for this group.[34] Despite this, a review found that while we might expect to see people from an Asian background making up 11% of UK trial participants, the actual figure ranged from 0-10%.[35]

Without sufficient numbers of people from Asian backgrounds in studies of diabetes, it is impossible to develop tailored programmes that identify what improvements could be achieved by better prevention programmes, screening services, and tailored interventions, such as dietary advice.

An earlier section of this paper also highlighted the difficulties of living with a combination of physical and mental long term conditions. A study comparing the position of Asian and White people living in England found that in a population at high risk of developing Type 2 diabetes, South Asian men and women reported a higher burden of depressive symptoms than their white counterparts. This was irrespective of a number of clinical, sociodemographic, lifestyle or environmental adjustments. The authors questioned whether depression was hindering the uptake of diabetes prevention programmes among people from an Asian background and whether diabetes services should also include interventions aimed at ameliorating depression.[36]

3. Long term conditions and the coronavirus pandemic

The coronavirus pandemic (COVID-19) has highlighted longstanding ethnic inequalities in the UK. Ethnic inequalities in relation to COVID-19 mirror longstanding ethnic inequalities in health. A large body of evidence has shown that these inequalities are driven by social and economic inequalities, many of which are the result of racial discrimination.[37]

The differential death rates from COVID-19 among people from black and minority ethnic groups are stark. Unfortunately, it has not been possible to fully adjust for the impact of co-morbid long term conditions, although it is recognised that they are a contributing factor.[38,39] The other unquantifiable factor is the extent to which the suspension of many non-urgent clinical services has meant that more people have developed long term conditions or that those who already had a long term condition have seen their problems worsen. As recovery begins, it is vital that preventive measures designed to reduce the number of people affected by long term conditions and interventions designed to provide better support consider the interactions between ethnicity, gender and socio-economic circumstances.

Discussion

The fundamental role of wider social and economic factors, such as racism, poverty, and poor housing in creating and sustaining inequalities in health and wellbeing is without question [23]. The incontrovertible evidence that the pattern of socio economic status is very different for people from different ethnic groups in the UK [9] and the links between long term conditions and socio-economic deprivation means that it is crucial we improve our understanding of the links between ethnicity and long term conditions.

There is an emerging picture of differences between different ethnic groups in terms of their experiences of long term conditions. It is also important to consider other intersecting factors, such as age and gender. For example, Pakistani men have been shown to be at higher risk of poorer outcomes for respiratory[27] and coronary heart disease.[33]

Although the main emphasis in this paper has been on the frequency of long term conditions among different ethnic groups, there is emerging evidence that improvements can be achieved with interventions aimed at improving take up of screening and interventions among groups that are at risk of developing certain long term conditions. The improvements in diabetes care in Tower Hamlets provide an important example of what can be achieved with this.[40] However, research reporting the views and experiences of people with long term conditions from black and minority ethnic groups and those caring for them is notable by its absence, with a few exceptions.[41,42]

In taking things forward, while it is clear that we need more information on the rates of different long term conditions among different ethnic groups, we also need more information on their experiences of treatment and the levels of support they receive. Without this, we will not be able to achieve equitable outcomes among different ethnic groups. The coronavirus pandemic has created a heightened awareness of health inequalities among health professionals, politicians, and the general public. Support for people with long term conditions takes up an increasing proportion of health and social care budgets. It is vital that we understand more about how this should be used most effectively and fairly.

Questions

- How can we incentivise better recording of ethnicity in research?
- Do we know enough about incidence and prevalence to prioritise research about interventions that are better tailored to a diverse population of people living with a long term condition?
- Do stereotypes exist in perceptions about the ways in which different ethnic groups are affected by long term conditions? Do they affect the uptake of screening and treatment services?
- Why has there been so little research reporting on the views and experiences of people from black and minority ethnic groups? What needs to be done to improve this?

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