We live in a world where discussion of race gets caught up in a maze of debates about what’s politically correct, what’s part of “woke” culture, and what’s simply unacceptable in 2020. In this febrile environment, it’s not always easy to be a doctor from an ethnic minority in the NHS.

Whatever your view on Brexit, the 2016 referendum has opened wounds that will take decades to heal. And many doctors from ethnic minorities feel a sense of déjà vu as controversies erupt about immigrants, race, ethnicity, and religion. It’s not easy to say whether the UK is racist—it’s largely more accepting than other countries, but, as a qualifying argument, that holds little leverage for those at the sharp end.

I’ve been part of the NHS for 20 years and continue to work with people who, in the main, accept me for who I am—with strong emphasis on the word “accept.” But is the system or the NHS itself racist? Yes, it is, if you look at any dataset. Top jobs still go largely to people who are white: even in 2020, it’s an occasion to rejoice when someone from an ethnic minority background actually “makes it.”

My struggle to establish myself has been far greater than that of my white peers. Even in a national role, the subtle hints, negativity, or indeed downright racist comments have come from senior people, academics with titles, clinical commissioning group executives, and managers—people who didn’t bat an eyelid, believing it was OK to behave as they had. At other times I’ve heard excuses made in terms of “unconscious bias”: a term I think is used to hide outright racism in a system looking to justify prejudice.

I’m not sure what we can do to change things. From a personal perspective, my approach has fundamentally altered over the past few years: from a position of looking to be embraced, giving everyone the benefit of the doubt and wondering what else could be done, a more clarified and carefree approach has taken hold.

There’s a saying in Punjabi: “Sadda haq, aithe rakh.” Loosely translated, this means, “Give me what’s mine—right now, right here.” As a member of an ethnic minority and contributing as much as anyone else, I no longer need to justify my presence; nor do I hesitate to call out racism, however big the name is. I belong, as much as anyone else, and I’m not looking for anyone’s permission or acceptance.

What would my advice be to any ethnic minority healthcare professional? Do your job, and do your bit to make sure that people from minority backgrounds aren’t deprived of opportunities or access to services. Make sure, especially, that people aren’t being deprived just because a policy has been set by someone with no cultural awareness. Define yourself by your outcomes: people can either accept you or not. And don’t apologise for being who you are—be proud of what you are and where you come from. The rest will follow.

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Define yourself by your outcomes: people can either accept you or not
A s medical students, our vocabulary expands exponentially to accommodate written exams and clinical assessments, but nothing prepared me for the slang I encountered on the wards in my foundation years. It was here that I first came across the term “Bibi-itis.” A decade later I found it was still being used.

It happened in the doctors’ office. I was scrolling through a list of patient referrals on my computer wondering out loud what undiagnosed entity awaited me in the emergency department. Beside me, my colleague asserted that the crucial diagnostic clue could be found in the patient’s name. In fact, he went on, that based on my race and gender, if my name appeared on a list of referrals it would herald an upcoming case of “Bibi-itis.” I turned to my registrar colleague and silence hung between us for a few seconds as I contemplated an appropriate response.

I have a tendency to brush microaggressive comments away without too much evaluation. But today was different. Things escalated, voices rose, I accused him of prejudice, and I was accused of ignorance in return. I felt shaken. A registrar bystander remained passive throughout, making me question my reaction.

“Bibi-itis” or “Mrs Bibi” is a derogatory term, derived from the surname “Bibi.” It refers to female patients of south Asian heritage who are said to present with exaggerated subjective complaints, backed up by few objective findings. Usually, the term is applied to older women with limited English. It also used to refer to seemingly inexplicable complaints in south Asian women.

It’s used by white doctors as well as those from minority groups. In part, the use of the term is compounded by the belief that older Asian women express psychological distress through physical symptoms. The term serves as an example of casual clinical stereotyping that can cause unrecognised bias leading to missed diagnoses, delayed treatment, and preventable unwanted outcomes.

Casual clinical stereotyping
Consider, for example, the dogged pursuit of tuberculosis in an Afghan woman. A biopsy eventually shows a rare tumour affecting her central nervous system, but also poor prognosis, ethambutol induced optic neuropathy, and disability. Then there is the Afro-Caribbean woman presenting with whole body pain. An initial assessment leads to a presumed diagnosis of a functional disorder. But the following day the woman is

Ethnic minority NHS staff need to lead on climate action
I recently achieved a significant, albeit distressing, personal milestone: putting our family home in India up for sale. This family base of nearly 100 years is inseparable from cherished memories of grandparents and summer holidays, and, for my British and biracial children and grandchildren, the opportunity to get to know and love the Indian side of their heritage. The passing of one very elderly grandparent and the increasing impracticality of leaving the other alone in a large home were convincing enough arguments in favour of a sale. But an even stronger justification is the threat posed by the climate crisis.

A question which has concerned me for many years, is whether a time will come when international travel becomes as exceptional as it was a century ago. The history of the UK is woven around emigration and travel and much needed capacity in the NHS has been filled by black and minority ethnic health professionals migrating to the UK from the developing world. In past decades they have been able to care for family in their countries of origin and to enjoy regular returns to their culture and heritage as often as they wished.

This status quo must change if we are to avoid dangerous levels of global warming, but how will the risks of climate breakdown affect NHS policy for international recruitment, especially when this is set to increase? How will overseas health professionals manage to care for elderly relatives in distant countries?

The voices of ethnic minority doctors seem muted. There is an acknowledged lack of diversity in environmental campaigns in the UK. The evidence is mixed as to how climate discourse and action could be made more inclusive. But it is recognised that the socioeconomic inequalities, alienation, and racism that define the everyday lives of ethnic minority people denies them the psychological safety for activism and the luxury of protest, especially if it risks prison and deportation.

The racism that defines their everyday lives denies people the psychological safety for activism and the luxury of protest.
A starting point is self-reflection and awareness, teamed with the containment of infectious behaviour transferred to intensive care with Guillain-Barré syndrome, where she is appropriately treated. But her care does little to persuade her family that she is in capable hands.

The situation I found myself in illustrates how women from minority groups within the medical workforce can be marginalised and how this in turn can translate into the marginalisation of women patients. Racial bias in clinical encounters is rarely discussed on the job. Doctors want to be accused of racism as much as they want to be accused of negligence. But the privilege of our professional position demands a wider consideration of uncomfortable topics. A starting point is self-reflection and awareness, teamed with the containment of infectious behaviour. The viral use of racist terms serves as one example. Approaching patients as people and not patterns reflecting prevalence figures is also important.

The term “Bibi-itis” has no place in the medical, or any other, environment. It profiles a group of women through a lens of prejudice, many of whom may already be disadvantaged by society. It undermines the delivery of clinical care, reinforces perceived differences, and consolidates barriers. Let’s ditch it. Let’s aspire to a higher level of diagnostic skill.

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The NHS, with its duty of care for everyone’s health and wellbeing, must lead the way in examining the environmental impact of its recruitment strategies while ethnic minority health professionals need to enhance their own knowledge about climate change, to share their narratives. They must demand a place at the top table of these discussions as a means to achieve low carbon solutions which acknowledge the challenges ahead.

As for me, climate anxiety has been my constant companion since the late 1980s but I no longer feel alone. Staff from overseas face a bleak future in terms of separation from their families. Yet I have real hope that we who come from countries facing the worst burdens of the climate emergency have the opportunity to help shape the collective activism necessary to create a better and more equal NHS which demonstrates its leadership in climate action.

Mala Rao, senior clinical fellow, Imperial College London

ACUTE PERSPECTIVE David Oliver

What doctors told me on Twitter

When I was asked to write a column for this issue, I was hesitant. As a white, male, middle class British doctor, what could I offer? I could emphasise that I work alongside doctors, nurses, and allied professionals from ethnic minority backgrounds and that, without their commitment, our health and care services would collapse. I could write about data: 13.1% of the NHS workforce have non-British nationality, and 20.7% of NHS doctors are from ethnic minority backgrounds. Or I could describe the mismatch between their numbers in the rank and file and in leadership positions.

I decided to ask on Twitter about the problems ethnic minority doctors faced. Some essences can be distilled from what I was told. First, when people are new to working in our system and culture we need to answer questions, provide inductions, and give people time and patience. How would I fare if I suddenly found myself in a different set-up—even in a white majority, English speaking country?

Second, a theme was basic humanity. Time and again we don’t get people’s names right, even after correction. This extended to ethnic minority doctors being mixed up with one another, sometimes for months, despite looking different in all respects bar skin colour. We simply wouldn’t do this with white colleagues.

Third, people tweeted about so called “micro-aggressions.” Even if it’s well meaning or motivated by genuine interest, repeatedly being asked “Where are you from?” and, in some cases, “Where are you really from?” quickly gets tiresome. Other commonly reported micro-aggressions included assumptions about how doctors from a particular culture might think or act, as well as meetings dominated by white British colleagues, where other doctors were ignored or marginalised. It was also pointed out that white European doctors with foreign accents and English as a second language can sometimes face barriers and attitudes that are just as troublesome.

Some mentioned structural inequalities. How transparent are we about pay disparities, the far higher rates of ethnic minority doctors reported to the GMC, or senior appointments? Visible leadership role models matter.

Several respondents highlighted that the term “BME” lumped together people with very different cultures, religions, nationalities, backgrounds, or skin shades into one poorly differentiated group. I didn’t see many calls for affirmative action, quotas, or positive discrimination. What I saw was a call for senior doctors and NHS managers to treat all doctors with respect and decency; to create acceptable working conditions for all; to ensure a level playing field to progress; and to recognise cultural or racial differences but not make assumptions about them.

But perhaps what came through most strongly was the need to treat everybody with consideration and fairness, whatever their skin colour, gender, or nationality. That shouldn’t be too much to ask in 2020.

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I didn’t see many calls for affirmative action, quotas, or positive discrimination
Policing my privilege

I try hard, but I know that I make mistakes. I practise unfamiliar names to myself before calling patients in from the waiting room, and I ask to be corrected on pronunciation. I like to know where my patients are from, and I hope that asking this demonstrates my interest—but what if it’s construed as intrusive or, worse, as questioning their right to be here seeing a doctor? Sometimes I ask, “Where is your name from?” which is more about heritage than personal history but still could be misconstrued.

The problem with privilege, which I undoubtedly have, is that I may be blind to getting things wrong: if I’m racially insensitive, most of the time nobody will tell me. There are many possible manifestations of discrimination. When consultations are complicated by the necessity of working through an interpreter, is there a risk that I’ll fail to explore my patient’s thoughts and fears because we’re concentrating on the diabetes or hypertension numbers? Am I less likely to raise sensitive issues related to sex, drugs, or alcohol for fear of being seen as insensitive, most of the time nobody will tell me.

It’s still common for hospital doctors to write letters to patients’ GPs after outpatient consultations, and for patients to receive copies of these letters. However, Hugh Rayner, a consultant nephrologist, and Peter Rees, former chair of the Academy of Medical Royal Colleges’ lay patient committee, suggest that there are compelling reasons for hospital doctors to start discussing letters directly to patients. Hugh Rayner discusses the odd way in which these letters are written. The BMJ found that scientific articles with financial links to the indoor tanning industry were more likely to have a conclusion in favour of the practice. The authors join this podcast to discuss the difficulties of conducting research that you know will be picked apart by industry. Here, researcher Eleni Linos explores what the public can take away from this finding: “The general public needs to be aware that this is happening. Even though overall we found that very few studies have financial links to the tanning industry, these papers may be used in promotional materials to mislead people.”

As well as policing myself, I must respond when racism arises in others’ behaviour

Try hard, but I know that I make mistakes. I practise unfamiliar names to myself before calling patients in from the waiting room, and I ask to be corrected on pronunciation. I like to know where my patients are from, and I hope that asking this demonstrates my interest—but what if it’s construed as intrusive or, worse, as questioning their right to be here seeing a doctor? Sometimes I ask, “Where is your name from?” which is more about heritage than personal history but still could be misconstrued.

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As well as policing myself, I must respond when racism arises in others’ behaviour
Ethnic diversity is a global phenomenon resulting from historical and contemporary movements of people. However, healthcare policy makers, practitioners, and researchers have been slow to wake up to this reality. We urgently need to improve our understanding of, and responses to, the health needs of mobile and ethnically diverse populations.

As a country with a colonial past, a long history of migration, well established minority ethnic groups, and high investment in health related research, the UK should be leading the way in evidence informed, equitable healthcare. In reality, however, the UK has significant shortcomings. We believe the health system’s failure to respond to ethnic diversification reflects a deeper, politically led, ambivalence towards the notion of multiethnic UK. Policy makers, practitioners, and researchers can and should challenge the persistent marginalisation of this agenda.

There is widespread evidence that UK policy responses to ethnic diversity are ambivalent, fragmented, confused, and often harmful. This is despite the apparently strong legal framework of the 2010 Equalities Act.

Practitioners often feel ill equipped and poorly supported to meet the needs of ethnically diverse patient groups

Failure of policy and practice

There are, nevertheless, some positive examples, such as the Desmond diabetes programme adaptation, which responds to diversity in the patient’s preferred language, dietary, and religious practices. There are, nevertheless, some positive examples, such as the Desmond diabetes programme adaptation, which responds to diversity in the patient’s preferred language, dietary, and religious practices. Unfortunately, scale-up of such innovations is patchy. Spread is often hampered by short term funding, unrealistic targets, expectations of cost savings, and failure to share learning.

Some important health problems that disproportionately affect ethnic minority groups are ignored by national policy (for example, the higher risk of hepatitis B among people who have migrated from east Asia). Other health policies can stigmatise ethnic minority populations rather than promote culturally competent action on inequity. One example is safeguarding legislation against female genital mutilation, which has led to negative stereotyping of the Somali community in Bristol.

Research reveals large ethnic inequalities in healthcare. Lower uptake and poorer satisfaction with care have been documented among ethnic minority groups across diverse NHS contexts. Maternity and mental health services show particularly worrying and persistent ethnic inequalities in experiences and outcomes. We also know that healthcare practitioners often feel ill equipped and poorly supported to meet the needs of ethnically diverse patient groups.

Increasingly stringent rules around entitlement to NHS care for migrants have also prompted concern. There are, nevertheless, some positive examples, such as the Desmond diabetes programme adaptation, which responds to diversity in the patient’s preferred language, dietary, and religious practices. Unfortunately, scale-up of such innovations is patchy. Spread is often hampered by short term funding, unrealistic targets, expectations of cost savings, and failure to share learning.

KEY MESSAGES

- The UK population is increasingly diverse as a result of both immigration and natural growth
- Health policy and healthcare for minority groups is patchy, sometimes stigmatising, and rarely culturally sensitive
- Important gaps in routine data, national surveys, and commissioned research mean there is inadequate evidence on how to meet the health needs of these groups
- Well designed research with meaningful involvement of patients and the public is required to inform action
- Stronger national leadership is needed plus support for local innovators who can lead the way towards an evidence informed, inclusive, and equitable health system

The NHS must take urgent action to better understand and provide for the health needs of migrants and ethnic minority people, say Sarah Salway and colleagues.
Inadequate data

Progress on this agenda requires much more investment in generating and applying evidence, and our recent work confirms this picture. Using desk based reviews, interviews, group discussions, and deliberative stakeholder workshops, we found a combination of data gaps, low demand for evidence, and a failure to act on available knowledge. The resultant reinforcing cycle perpetuates the marginalisation of ethnic minority and migrant health.

Participants in our workshops voiced concerns about inadequacy of data. Poor data availability and quality undermines our ability to describe and understand health and healthcare among ethnic groups and by migrant status. A recent Public Health England technical report confirms substantial data gaps, as does the Race Disparity Audit. The Health Survey for England, one of our most important resources, has not focused on ethnic minority people since 2004. Other data collection initiatives have ceased (such as the Citizenship Survey).

In England, joint strategic needs assessments are central to establishing local authority health profiles and priority action plans. We reviewed assessment documents from 32 local authority areas, selected to provide geographical distribution and with varied demographic profiles, and found a combination of data gaps and missed opportunities to use data. Some local authorities had taken targeted “deep dive” assessments to understand their local population. However, ethnicity and migration were not embedded in the assessment processes. This was true even in areas with long established ethnic minority populations and high ethnic diversity. Racism was rarely identified as an important determinant of poor health.

The completeness and accuracy of ethnicity recording within routine health data systems also remains patchy. NHS ethnic categories have not been revised with census updates. Migration status is not routinely recorded. The conduct of health equity audits has dwindled in recent years. Most services simply do not routinely consider whether they are meeting the needs of different ethnic and migration status groups within their catchment populations. Equality concerns continue to be distant from the healthcare quality agenda.

The picture is even starker when we look for evidence to inform action on unmet need and health inequalities. We examined the research funded by four of the National Institute for Health Research (NIHR) funding streams (public health research, health services and delivery research, research for patient benefit, and health technology assessment) from 1995 to 2017. It could be argued that all research intended to inform the design and delivery of health services for the UK’s multietnic population should consider ethnicity. In fact, we found that only 8–10% of funded research projects mentioned ethnicity related terms in their title or abstract. Furthermore, out of 2658 funded projects, just 38 had a clear focus on health needs linked to ethnicity or migration.

Participants in our deliberative stakeholder workshops have identified several factors contributing to this low volume. These include a lack of demand for evidence from policy makers and limited visibility of this field in leading medical journals. Limited competence and confidence among researchers and low representation of ethnic minority researchers within academia also contribute. Participants also thought that charities and social science funding streams were more ready to fund such research than NIHR.

Quality is key for research. Earlier commentaries and reviews have cautioned that poorly conducted research can do more harm than good. Workshop participants reiterated the importance of underpinning all research in this field with conceptual rigour; meaningful involvement of patients and the public; and concrete plans for moving knowledge into action.

Much biomedical and health services research fails to adequately recognise the contextual and multidimensional nature of ethnic (and migrant) identities. It often falls back on untested narrow cultural or biological explanations for patterns of health and healthcare, rather than uncover a more complete causal picture. There is also a need to acknowledge that ethnic categories encompass diverse groups of people with highly variable health related assets and opportunities. Similarly, many interventions aimed at meeting the needs of migrant or ethnic minority groups lack sound theoretical underpinning. Crucially, the role of racism must be more consistently addressed if we are to develop effective interventions at individual and societal levels.

**ETHNICITY, RACE, AND RACISM**

Ethnicity can be described as a form of collective identity that draws on notions of ancestry, cultural commonality, geographical origins, and shared physical features. Ethnic identities are not fixed or natural. They are social constructs fluid across space and time. Individuals may self-identify with several or none of the ethnic categories used in government statistics or research. Processes of ethnic identification are also externally imposed. Ethnic categories acquire meaning in particular contexts. Societal structures and ideologies reinforce ethnic boundaries and the illusion that differences between ethnic groups are immutable.

The term race is used less often than ethnicity in UK health policy and research. However, these terms are used variably across the world. Both concepts are social constructions, and both invoke physical as well as cultural distinctions. Both are linked to processes of exclusion and differential access to power, resources, opportunities, and status.

Racism has a central role in shaping the health of minority ethnic and migrant people. Processes of racism are entrenched in laws, policies, and practices. They are reproduced within societal institutions and organisations. The circulation of images, language, and symbols within everyday conversation, media, and policy perpetuates an ideology of inferiority and difference. Interlocking structural and cultural processes result in differential access to health promoting resources, exposure to health risks, and access to healthcare.

**Stronger national leadership**

There are signs that some leaders in the health system are beginning to take ethnic inequality seriously. The BMJ’s theme issue is clearly one such indicator. Integrated care systems present an opportunity to enhance equity, routinely identify those who are not receiving services, and hold leaders to account. Local innovations are appearing around the country, such as drop-in GP clinics for newly arrived migrants, yet more can be done to learn from and scale up such solutions. More doctors and healthcare practitioners should be encouraged to advocate for underserved migrant and minority patient groups. More practitioners from ethnic minority groups are required at senior levels of the NHS, though there is evidence of slow improvements.
Recent publication of relevant Public Health England resources22-33 and the Race Disparity Audit23 are welcome signs. In addition, concerted effort is needed to plug data gaps and reinstate routine equity audits in order to identify who is not benefiting from services. We can learn from local authorities that are undertaking strong assessment work to increase understanding of local health needs. For example, in Nottingham and Leicester there has been good engagement with ethnic minority groups to identify health concerns.34 35 These authorities also developed clear recommendations to act on gaps in data and to implement longer term strategies around quality standards, monitoring and evaluation, financial planning, and specific provision and coordination between services.

Improvements to data collection must go hand in hand with assurance of data protection. Recent data sharing between NHS Digital, the Department of Health and Social Care, and the Home Office for immigration enforcement presented substantial risks to the health and wellbeing of migrant and settled ethnic minority communities and must not resume. UK health research can learn from elsewhere. In the US, all clinical research funded by the National Institutes of Health (NIH) must include women and minority groups (when appropriate to the research question). Additionally, the National Institute on Minority Health and Health Disparities is focused on eliminating disparities.36 Recent UK developments that have the potential to influence the way evidence is generated include the Equality Diversity and Inclusion in Science (EDIS) network37 and the diversity and inclusion workstream of INVOLVE, a national advisory group set up to promote public involvement in research.38 The results of research projects examining key challenges should be widely disseminated. These include projects on the meaningful involvement of ethnic minority people,39 understanding and tackling discrimination in health services,40 and data linkage to improve understanding of ethnic health inequalities.41

We need to increase the visibility and status of research in this area. The demand for evidence among decision makers must be boosted. Effective channels for routinely applying evidence to policy and practice are also needed. The recently launched NIHR applied research collaboration (ARC) for East Midlands identifies “ethnicity and health inequalities” as a priority; we hope this may influence the other 14 regional ARCs. We should also look to countries such as Norway, where research-policy partnership structures facilitate ongoing dialogue around these health needs.42 Rather than countering discriminatory processes of wider society, the UK health system often mirrors the forces that undermine the health of migrants and ethnic minority people. We overlook, misconstrue, and respond poorly to the health needs of these groups. An inadequate knowledge base contributes to this unacceptable situation. We need radical action to increase the creation of high quality research evidence and data at local, regional, and national levels. Such knowledge must be routinely expected and used to inform action. Stronger national leadership is required. This must be coupled with greater involvement of ethnic minority people and sustained support for local innovators who can lead the way.

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Population research ignores older people from ethnic minority backgrounds

The need for data is now critical.

The UK has not collected any survey data specifically on older ethnic minority populations. But data from 2004, the last year when the Health Survey for England oversampled ethnic minority people (over 15 years ago), found that the proportion of people aged 61-70 reporting fair or bad health was 34% for white English people but 86% for Bangladeshi people, 69% for Pakistani people, 63% for Indian people, and 67% for black Caribbean people. These data show that the health of white English people aged 61-70 is equivalent to that for Caribbean people in their late 40s or early 50s, Indian people in their early 40s, Pakistani people in their late 30s, and Bangladesh people in their late 20s or early 30s.

A lifetime of disadvantage

Although there is great heterogeneity across and within ethnic minority groups in countries of origin, reasons for migration, and personal characteristics, most older people who migrated to the UK when young entered low skilled and low paid manual work. They have endured a lifetime of disadvantage and deprivation driven by experiences of structural, institutional, and interpersonal racism and discrimination.

As they approach later life, the complex interplay of social and economic disadvantages accumulated across their life negatively affects a range of outcomes. An understanding of the pathways leading to ethnic inequalities in older age requires research on these complex processes and how they link different life experiences to health and social outcomes in later life.

For the general, mainly white, British population we have several data sources to facilitate our understanding of later life outcomes. However, such data are not available for older ethnic minority people. This lack of representation in population level studies that monitor health and social circumstances is indicative of systematic discrimination and institutional racism.

The three UK national longitudinal birth cohort studies with samples suitable to study the ageing processes (the National Survey of Health and Development, National Child Development Study, and 1970 British Cohort Study) have negligible numbers of ethnic minority respondents. The UK’s largest survey of ageing, the English Longitudinal Study of Ageing (ELSA), included only just over 300 people from ethnic minorities out of a total of 7265 at its most recent data release (wave 8), and of these just under 150 were aged 65 or older.

The largest UK household panel study, the UK Household Longitudinal Study, included 570 non-white ethnic minority participants aged 65 or older in the most recently released wave of data. Although the sample is larger than that in ELSA, it is not big enough to conduct robust analyses examining the circumstances of older people within specific ethnic minority groups (for example, there were only 32 Bangladeshi participants aged 65 or older); it is also not possible to determine period and cohort differences within ethnic minority groups or the underlying mechanisms behind ethnic health inequalities in later life. And, importantly, the topics covered by the UK Household Longitudinal Study are not focused on issues related to later life.

In order to document and understand ethnic health inequalities in later life, and identify drivers of healthy ageing for ethnic minority people, studies must include suitable sampling designs with representative and sufficiently large samples of ethnic minority groups. Surveys must include questions on ethnicity, identity, and key determinants, such as experiences of racism and discrimination.

Socially unjust

UK agencies need to commit substantial funding to adequately address this problem. The exclusion of older ethnic minority people from population based studies is a form of institutional racism and leads to a worrying and socially unjust dearth of knowledge about the health and social conditions of an already disadvantaged part of the UK population.

The need for data is now critical. But visibility alone will not lead to the disappearance of ethnic inequalities, which have persisted despite indisputable evidence. Evidence must be used to develop and implement national policies that improve the health of ethnic minority people to ensure an equitable society for all.

Lack of representation in population level studies monitoring health is indicative of systematic discrimination and institutional racism

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Communities that prefer close blood marriages need more help to access genetic services

Fear, inadequate knowledge, and cultural assumptions lead to missed opportunities for referrals

The practice of marrying close blood relatives has received intermittent, largely unhelpful, attention within UK health policy circles over past decades. Rather than conveying the increased genetic risk accurately, the tendency has been to sensationalise the matter and stigmatise people at risk. Media attention has further stoked blame and distortion. Our experience from clinical practice and research highlights the need to view this as a healthcare inequality problem. We need to tackle the persistent unmet need for genetic services that many families experience.

Close relative marriage—often between cousins—is common around the world. It is also preferred among some UK communities. The largest group affected is people identifying as Pakistani or British Pakistani. Since blood relatives are more likely to carry the same gene variants than unrelated people, a higher incidence of autosomal recessive genetic disorders ensues. This manifests as higher population rates of congenital abnormality and infant and child mortality. The risk of any congenital abnormality is around 6 per 100 births, compared with 3 per 100 births for unrelated couples. This increased risk is similar to that associated with childbearing over the age of 34. Importantly, genetic risk clusters in families. Around 8 out of 10 cousin couples are not at increased risk.

We have been working to improve access to genetic services for those families affected with these genetic disorders for more than 10 years. Qualitative studies and local population based surveys reveal poor understanding of the levels and patterns of risk among the general population. Unfamiliarity with genetic services, and the options they present, is common. It is also clear that the cascading of information among families where harmful gene traits have been identified is often poor. Multiple, unanticipated affected births (and deaths) often occur in the same family.

Keen for information
Naz’s clinical experience confirms that those affected use genetic services when offered. Family members are keen to access information. Provision of genetic counselling with a sensitivity to the patients’ cultural context can be empowering. This requires imparting medical knowledge while appreciating how such new information may be accommodated alongside existing understandings.

Currently, many families are not being offered referrals to genetic services at primary or secondary level. Referrals are crucial, as affected people are often unaware of what genetic services can offer. In the words of participants in a recent consultation, “How can we ask for something when we don’t know it exists?” Health professionals have a responsibility to ensure these families have the knowledge to make informed reproductive decisions.

However, fear of being culturally insensitive, inadequate knowledge, and assumptions about religious and cultural beliefs result in many missed opportunities to support access to genetic counselling.

Our engagement work at a community level also demonstrates that many people have an appetite for improved knowledge. Yet, while in a few places genetic literacy has been incorporated into healthy pregnancy promotion work, this is by no means universal. Furthermore, several initiatives have been poorly designed and short lived. These healthcare and public health shortcomings are a manifestation of a system that struggles to accommodate diverse needs and questions ethnic minority people’s entitlements to healthcare.

We have to ensure families have the knowledge to make informed reproductive decisions

In recent months we have seen some promising signs of change. There is a growing consensus that this matter must be seen as one of healthcare inequality. We have also witnessed increased interest at regional and national level within the Maternity Transformation Programme. We need to see a similar response from those responsible for the redesign of clinical genetic services. As genomic medicine advances, a much wider range of options will become available to individuals and couples. This makes it even more important that we strive for equitable access to genetic services.

While we await policy shifts to materialise, individual healthcare professionals can do more. We must take every opportunity to enhance genetic literacy and increase access to genetic services for groups who remain underserved. Genetic professionals must also ensure a culturally competent service. Informed reproductive decision making should not be the preserve of a subset of the population.

Naz Khan, principal genetic counsellor, Manchester Centre for Genomic Medicine
Sarah Salway, professor of public health (honorary), University of Sheffield
“There’s not just a moral case for change. There’s also a business case,” says Yvonne Coghill

The RCN’s deputy president is charged with making the NHS a fairer place for ethnic minority staff tells Helen Jones that engaging with senior leaders is key to successfully transforming the service’s culture.

Coghill says that cultural change is down to leadership. “The type of leadership we have had to date has been transactional. These people made their careers on being transactional and delivering on finance, on targets. Now we need them to be more transformational; to be the type of leader who will sit down and have a cup of tea with their teams; who asks questions and listens.

“We are targeting senior leaders and talking to chief executives to get them on side and to understand not just the moral case, but the business case—if people feel valued, they are less likely to go and work for agencies or go off sick. It saves the NHS money and makes it easier to recruit, and those staff give higher quality patient care.”

Good communication is also vital, she says, “The comms world across the NHS is incredibly defensive and this agenda scares them witless. They say we want good news stories—it’s not a good news story that people have different experiences in our NHS. But what is a good news story is that the NHS is doing something about it, to make things better for staff and ultimately for patients. Comms is key.”

She also says that ethnic minority staff need role models: “a reasonable number of people who look like themselves who have made it in the NHS. We need to look at the pipeline of people coming through.”

“M"otivated, valued, and respected staff give much more, they feel appreciated and part of something. A fully included workforce improves patient safety, patient care, and patient satisfaction,” says Yvonne Coghill, director of the Workforce Race Equality Standard (WRES) for NHS England, who aims to bring about “cultural transformation” across the service.

WRES was set up in 2015 to raise awareness of and help close the race gaps in the NHS. As Coghill explains: “We knew there was a problem, but couldn’t convince people from white backgrounds because we didn’t have the data or evidence to show there is a gaping hole between the experiences of BME and white staff. Now we have that data, and nobody can argue there aren’t real issues for people and how they are treated, received, and able to progress their careers.”

The latest WRES report indicates that the proportion of ethnic minority staff in very senior managerial positions was 6.9% in 2018—much lower than the proportion of ethnic minority staff (19.1%) in NHS trusts. In addition, ethnic minority job applicants are less likely than white applicants to be appointed from shortlisting, and more likely to enter disciplinary processes when in post.

Effect is profound

Coghill started her career as a NHS nurse in 1977 and says she experienced discrimination. “I thought I was doing pretty well in my career. I was told to go and get a degree and then a masters. I applied for five director of nursing posts and didn’t get any of them. I was told that on the day someone was better than me. Those people were invariably white and even at that stage I thought it was something to do with me.

“What that does to you personally, to your self-esteem, self-confidence, and your sense of who you are and what you can deliver, is quite profound. You start to question yourself, rather than question the system,” she says.

As a result, Coghill left the NHS and says she was “incredibly lucky” to become private secretary to then NHS chief executive Nigel Crisp. “I went to work in the Department of Health, and when you are sitting at a strategic national level you can see the issues very clearly. I was shocked at the derisory number of people at a senior level who looked like me,” she says.

Since the launch of WRES, Coghill says the situation is improving, and “people’s understanding of why we are doing this has changed,” but she adds that there is “a long way to go—there are just eight BME chief executives [of 227] in the NHS.”

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