

## Ethnic minorities and their perceptions of the quality of primary care

Greater personalisation of care is needed



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### RESEARCH, p 684

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Societies are becoming more culturally diverse and this trend—which is driven by a combination of political and economic forces, globalisation, and improved access to travel—is set to continue. More than two decades of research, mainly from English language speaking countries, shows that ethnic minority people tend to have poorer outcomes than the white majority population for a range of diseases.<sup>1</sup> Research from the UK has, for example, shown that the risk of an emergency admission among South Asians with asthma is three times higher than the risk in white people, and is twice as high in black individuals.<sup>2</sup> Similar inequalities have also been noted with respect to risk of developing diabetes, ischaemic heart disease, and stroke.<sup>3-6</sup> In the linked study, Mead and Roland assess why patients from ethnic minorities also tend to give lower evaluations of primary health care than white patients.<sup>7</sup>

The factors underpinning inequalities in health outcomes are complex, multi-faceted, and not well understood, which partly explains the limited progress in reducing them.<sup>8</sup> Part of the explanation does, however, seem to lie in differences in the quality of care received, which has been the dominant explanation of findings from previous patient surveys of primary care provision. On the other hand, Mead and Roland's analysis suggests that some of the differences in ratings of care might be explained by higher expectations in some ethnic minority groups.<sup>7</sup>

The General Practice Assessment Questionnaire (GPAQ) is a national (English) patient survey for primary care that was undertaken as part of the quality and outcomes framework. The national use of this tool reflects the increasing importance being assigned by policy makers to patient reported outcome measures. Mead and Roland have performed an innovative and potentially important secondary analysis of this dataset, investigating various parameters of care among the four main ethnic groupings in the UK. The major strengths of this study include the fact that the instruments used in the survey allowed assessment both of perceptions of care and also patient reports of actual care received. In addition, a large number of patients (including ethnic minority patients) completed the questionnaire and were included in the sample, and the authors adjusted for a range of potentially important confounding factors.

But despite these strengths, this secondary analysis has some important limitations (many of which the authors acknowledge). These shortcomings include the lack of a

clear sampling frame, the resulting difficulties in trying to ascertain the response rate—let alone compare the characteristics of responding and non-responding patients—the failure to validate the instruments across cultures, the crude ethnic groupings used, and the substantial risk of residual confounding. It is also important to highlight that the dataset used did not involve any objective assessment of the actual quality of care delivered.

Given these limitations, one should be cautious about the suggestion that higher expectations of care in ethnic minority groups is a key factor underpinning the differences in perceptions of care. Indeed, the data suggest that, if anything, issues with patient reports of the quality of care are likely to be an important problem. This is particularly evident in Mead and Roland's data from Chinese and black respondents' assessments of receptionist and general practitioner communication, but also in data from Asian patients.<sup>8</sup> This explanation is further supported by a large body of evidence showing inequalities in various process measures of care such as provision of preventative care, the responsiveness of services, and referrals for specialist assessment and care provision.<sup>9,10</sup>

That said, the hypothesis about possible ethnic differences in expectations of care is intriguing and warrants further exploration in qualitative studies and descriptive studies using appropriately validated instruments in carefully defined population groups. Any residual differences in perceptions of care that are not adequately explained by structural factors (for example, socioeconomic considerations and the characteristics of the practice and general practitioner), discrimination, or differences in actual quality of care are more likely to be explained by differences in expectations of the types and models of care provided by health services (such as preferences with respect to evening and weekend opening) than by higher expectations.<sup>11</sup> This possibility should, therefore, be a consideration for future research.

Given the increased importance assigned to responsiveness and personalisation of care, the key practical message of this work is that practices need to identify and understand the priorities of their communities and tailor care accordingly. The emphasis thus needs to be on judging care providers by their success in meeting the needs of their local populations rather than on adjusting patient evaluations for the ethnic profile of the practice populations.<sup>12</sup>

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## Meeting the health needs of trafficked persons

International guidance provides advice on safe and appropriate treatment



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In April 2009, the Council of Europe Convention on Action against Trafficking in Human Beings came into force in the United Kingdom.<sup>1</sup> The convention requires the state to provide minimum standards of care, including medical services, to all people identified as “trafficked.” Meeting the needs and protecting the safety of such people can be a challenge for doctors.

Human trafficking involves the movement of people by force, coercion, or deception into situations of exploitation.<sup>2</sup> Trafficked persons are often subjected to physical violence, sexual abuse, psychological violence, and severe deprivation. Trafficking of women and girls for sexual exploitation receives the greatest attention, but men, women, and children are also trafficked and exploited in, for example, agriculture, construction, contract cleaning, and domestic service.<sup>3</sup> Usually, trafficked persons agree to a job opportunity and are misled about their pay, work, conditions, or repayment obligations, and they find themselves in situations akin to “slavery.”<sup>4</sup>

Globally, about 2.5 million people are estimated to be in situations of forced labour as a result of trafficking,<sup>3</sup> although statistics on trafficking are notoriously unreliable.<sup>5</sup> The UK anticipates identifying about 860 trafficked persons each year,<sup>6</sup> but the actual number is thought to be much higher.<sup>7</sup> As the UK augments its law enforcement efforts to tackle human trafficking, health practitioners may see an increasing number of trafficked persons.

Women who are trafficked into the sex industry may face physical and psychological abuse, confinement, and rape. Many have suffered traumatic events similar to those experienced by survivors of torture.<sup>8,9</sup> Yet, abuse related to trafficking is best viewed as a continuum, because some people will experience inhuman cruelty and deprivation, whereas others will be controlled through various levels of coercion, threat, or intimidation. Existing research on health focuses on women trafficked for forced prostitution.<sup>9,10</sup> A survey of 192 women in post-trafficking service settings in Europe found that 78% had been physically assaulted while trafficked, and that 57% reported symptoms suggestive of post-traumatic

stress disorder.<sup>9</sup> Similar research on the health of people trafficked for various forms of labour exploitation has not yet been conducted.

Providing medical services for people who are still being trafficked or who have escaped can pose many ethical, safety, and medical challenges. For example, trafficked persons may be sought by traffickers and may be at risk of retribution. They are also likely to present with complex physical and psychological symptoms resulting from a history of repetitive abuse, deprivation, or hazards related to their forced labour. Legal circumstances (for example, participation in a criminal prosecution) or problems related to the provision of care (for example, insecure immigration status) may affect their health. Other complexities include language differences and diverse cultural expressions of ill health.

The UK has recently taken steps to establish a system of identification, care, and referral of trafficked persons, known as a “national referral mechanism.” However, to date, actions have focused mainly on law enforcement and have neglected to define the role of the medical sector or provide guidance for health practitioners.<sup>11</sup> Recently, international guidance, *Caring for Trafficked Persons: Guidance for Health Providers*, was developed by the International Organization for Migration and the London School of Hygiene and Tropical Medicine. This guidance offers non-clinical advice on safe and appropriate treatment approaches for trafficked persons (box).<sup>12</sup> One of the first recommendations is for providers to take account of the security risks to the patient, themselves, and other medical staff, especially in relation to organised criminal gangs. Providers are encouraged to keep an up to date contact list of trustworthy referral options, including shelters, psychological support services, and legal aid.

Providers are also urged to learn about and apply “trauma-informed” care practices, which include acknowledging that violent or life threatening experiences may affect people’s health and their responses to medical care, especially physical examinations and invasive procedures.

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Doctors will become more involved as more trafficked persons are identified. Practitioners should draw on existing guidance for similarly vulnerable populations, including migrants, refugees, and victims of sexual abuse and other forms of violence, while also recognising the unique characteristics of human trafficking. Representatives from the Department of Health, NHS, and primary care trusts should work with the Home Office, UK Human Trafficking Centre, and state and non-governmental support services to ensure that the role of the health sector is clearly defined and providers are adequately trained and resourced to care for victims.

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## Age based discrimination in health and social care services

Will be against the law if the 2009 equality bill is enacted

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The 2009 Equality Bill will, if enacted, make age based discrimination in the provision of health care and social care illegal for the first time in the United Kingdom. In a speech in 2008, the then health secretary, Alan Johnson, said, "Old age is the new middle age. Health and social care services need to adapt to the changing needs of today's older people . . . to promote health in old age and help older people to maintain independence and quality of life."<sup>1</sup> People over 65 already account for more than 60% of hospital bed days and most expenditure on health and social care. In 2007 there were 8.2 million people aged over 65 in England and Wales, but this is projected to increase to 11.6 million by 2026—an increase of 46%—with similar projected rises in the prevalence of disability and dependency.<sup>2</sup> Core users of health care will continue to be older people, many of whom will be frail, have long term conditions, and rely on support from social services or informal carers. A demographic shift in the ratio of retired to working people and multiple competing demands on health services and local government make this a challenging situation.

Health services are not uniformly "age proof and fit for purpose,"<sup>3,4</sup> structured, or incentivised to meet the needs of older people—especially those with complex needs—who may be a "disadvantaged majority" and potential victims of age based discrimination. Many sources provide evidence of this. Surveys of professionals, managers, and service users repeatedly show that these people see health services as inherently ageist.<sup>4-7</sup> Common conditions of old age are often less well recognised, managed, and resourced than those affecting younger people.<sup>8,9</sup> Conditions affecting all ages are often comparatively less well managed in older people.<sup>9</sup> Older people presenting "non-specifically" with falls, poor mobility, impaired

cognition, or loss of function are often labelled as "social admissions" or as having "acopia" instead of receiving a detailed assessment, diagnosis, and plan to treat the medical problems that usually underlie such presentations.<sup>8</sup> Targets, performance incentives, commissioning priorities, resources, and research funding are often skewed towards conditions of childhood and midlife. The attitudes, priorities, education, and training of staff often fail to reflect the needs of older patients. Reports of undignified care, poor communication, and patronising attitudes are still all too common.<sup>3,6</sup>

Organisational and cultural change is an iterative process requiring many approaches, but legislation is an important lever in tackling these problems. Although the NHS constitution sets out "respect and dignity," "compassion," and "everyone counts" among its principles, no current UK law protects people from age based discrimination by healthcare or social care services. The 2009 Equality Bill aims to rectify this by extending the duty for public sector equality to age, alongside the other "protected characteristics" of disability, sex reassignment, pregnancy and maternity, race, religion or belief, and sexual orientation and banning such discrimination.<sup>10</sup> The legislation will apply throughout the UK and could be used by individual older people, or more probably campaign groups and charities, to challenge apparent discrimination.

The secretary of state has commissioned a review, which reports in October, into when and how the NHS and social care system should implement the provisions in the bill in relation to age equality. At a national level, the review is supported by an advisory group representing key national stakeholders. It has issued a "call for evidence" from stakeholders for examples of age based



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discrimination or differentiation, justifiable or beneficial exceptions, and the potential effect of changing the law. It is also undertaking work in the south west of England with the NHS, local authorities, the voluntary sector, and patient representatives on the practical implementation of the bill.<sup>10 11</sup>

Key review principles are that “unjustifiable age discrimination and unfair treatment have no place in a fair society which values all its members”; that “meeting individuals’ needs should be based on their individual circumstances and not arbitrary assumptions about their age”; and that “services should be differentiated by age only when justifiable or beneficial.” (So that “differentiation” is not always “discrimination.”)

In law, to prove the existence of age based discrimination, no material difference should exist between the circumstances relating to each case (for example, in diagnosis, prognosis, or individual ability to benefit from treatment) with the test resting on relative differences in treatment between groups or individual patients and not against absolute standards such as those set out in clinical guidelines. The bill allows for justifiable exemptions where differentiation is a “proportionate means” of achieving “legitimate aims.” Emergency plans to ration hospital beds or intensive care beds by age in a flu epidemic provide a topical scenario, which could hypothetically be subjected to these tests if challenged in law.

When can age based differentiation be justified? Some services, investigations, or treatments may legitimately use aged based cut offs on the basis of patient need or evidence of benefit. The National Institute for Health and Clinical Excellence (NICE) walks a tightrope when it determines cost-benefit using quality adjusted life years, which could be seen to discriminate against people with a shorter life expectancy and those with disability. However, NICE guidelines have sometimes advocated treating older people preferentially on cost-benefit grounds and have provided key guidelines to drive quality in several common conditions of old age. Some people argue that the current amount spent on older people is

effectively “super serving them,” and that on the basis of the “fair innings” argument for life prolonging treatments, we are morally obliged to discriminate in favour of younger people.<sup>12</sup>

The current consultation and scrutiny process is a unique opportunity to contribute to the debate on whether age discrimination or differentiation can be justified in the context of our ageing population and the intrinsic NHS commitment that “everyone counts.” Older people—especially those who are frail, chronically ill, or cognitively impaired—have tended not to have the same powerful self advocacy as other vulnerable groups. If enacted, the Equality Bill will change this and will be a key bulwark against discrimination.

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## Does improving quality of care save money?

Not necessarily, as higher quality is mainly driven by professional reasons

As the NHS enters a period of little or no real growth in funding but incessant demand and cost pressures,<sup>1</sup> the idea that improving the quality of services, treatment, and care could actually save money is an attractive proposition. But although there is plenty of evidence that poor quality health care and adverse events are costly both for the NHS in financial terms and for patients in terms of health consequences, there is, as a new report reveals, a dearth of evidence of the reverse relation: that improving quality leads to lower costs.<sup>2</sup>

In a wide ranging literature review for the Health Foundation, John Øvretveit unearths just eight reasonably robust and well researched examples—mainly

from the US—where service or clinical change has led to identifiable savings. These include annual savings of \$0.7 million from reducing deep surgical wound infection rates and \$0.3 million from earlier patient discharge and reductions in delays in dealing with pathology specimens.<sup>3 4</sup>

The poor standard of much of the evidence on quality improvement and cost will be disappointing news for those at the Department of Health pushing to extract a silver lining from the approaching financial cloud. But as Øvretveit also points out, there are numerous reports of the avoidable costs of error, adverse events, and poor quality. For example, the Department of Health has estimated that the cost of

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longer lengths of stay in hospital arising from various avoidable adverse clinical events is around £2 billion a year,<sup>5</sup> and 4-10% of patients admitted to UK hospitals develop pressure ulcers, which likewise increases length of stay and treatment costs.<sup>6</sup>

And there are also, on paper at least, obvious examples where changing clinical practice or improving the way patients move from one part of a health system to another can enhance quality of care for patients and also save money. For example, estimates suggest that around 15-30% of the 100 000 or so cases of hospital acquired infections each year in England could possibly be prevented, saving the NHS between £15 million and £30 million a year.<sup>7</sup> Past attempts to get the NHS to focus on improving quality and either saving cash or freeing up resources include the now defunct Modernisation Agency's "Ten High Impact Changes" report, which suggested measures such as reducing variations in length of stay; treating day surgery rather than inpatient surgery as the norm; optimising patient flow through the system; and managing variation in patient admission processes.<sup>8</sup>

There have been improvements in the NHS in many of these areas—for example, the average patient having a hip replacement in 2008 spent 30% less time in hospital than a patient in 1998.<sup>9</sup> However, Øvretveit notes that although identifying the cost consequences of poor care and the potential savings of getting things right is one thing, actually doing something about them is another.

Apart from detailing the lack of hard evidence on what works and what doesn't, the review also notes the cultural, financial, budgetary, and managerial barriers to improving quality with an eye to costs. The NHS, for example, is not unique among health systems in having budgetary and purchasing arrangements that can give rise to the perverse situation where providers are rewarded for poor quality of care and treatment. Without robust action by purchasers—whether insurers in the US or primary care trusts in the UK—the costs—for example,

of readmissions arising from initially poor treatment—are borne by the purchasers not the providers.

The review also rightly points out that saving money is not a prime motivating factor for clinicians, and that professional and ethical reasons for improving the quality of care do not seem to have been sufficient in producing the win-win situation of high quality at low cost.

What's needed, the review argues, is better evidence that any change will actually produce the quality and cost improvements claimed for it. This in turn requires more research and evidence of the true costs of change. In addition, the review suggests that the incentive and financial systems for providers should be redesigned so that providers can kick start change by tackling poor quality and directing support for upfront investment where it is needed.

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## Health and climate change

Will a global commitment be made at the UN climate change conference in December?

Expectations are running high for the United Nations climate change conference in Copenhagen this December. But will we get the global commitment for radical cuts in carbon dioxide emissions that the world so urgently needs? The scientific evidence that global temperatures are rising and that man is responsible has been widely accepted since the Intergovernmental Panel on Climate Change's report in 2007.<sup>1</sup> There is now equally wide consensus that we need to reduce carbon dioxide emissions to at most 50% of 1990 levels by 2050 if we are to have even a 50% chance of preventing temperatures from exceeding preindustrial levels by more than 2 degrees, considered by many to be the tipping point for catastrophic and irreversible climate change.<sup>2</sup> The economic argument that taking action

now rather than later will be cheaper has also been widely accepted since the Stern report in 2006.<sup>3</sup> The election of President Obama has shifted policy in the United States from seeking to block an agreement to seeking to find one.

So the chances of success should be good but the politics are tough. The most vocal arguments are about equity: the rich world caused the problem so why should the poor world pay to put it right? Can the rich world do enough through its own actions and through its financial and technological support for the poor to persuade the poor to join in a global agreement? The present economic climate doesn't help, giving sceptics from the rich world arguments for not acting—or at least not acting now. And the sensitive issue of population stabilisation continues

See also **LETTERS**, p 647,  
**FEATURES**, p 660,  
**PERSONAL VIEW**, p 697

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**Will Copenhagen be a landmark in climate change talks?**

to slip off the agenda but is crucial to achieving real reductions in global carbon dioxide emissions.

These arguments need to be tackled head on. Climate change is global, and emissions know no frontiers. The necessary measures should be seen not as a cost but as an opportunity. Coal fired power stations and internal combustion engines pollute the atmosphere and worsen health, and deforestation destroys biodiversity, whereas saving energy helps hard pressed household budgets, and drought resistant crops help poor farmers. So even without climate change, the case for clean power, electric cars, saving forests, energy efficiency, and new agriculture technology is strong.<sup>4</sup> Climate change makes it unanswerable.

The threat to health is especially evident in poorest countries, particularly in sub-Saharan Africa, as the recent *Lancet* and University College London report shows.<sup>4</sup> These countries are struggling to meet the Millennium Development Goals. Their poverty and lack of resources, infrastructure, and often governance, greatly increase their vulnerability to the effects of climate change. Warmer climate can lead to drought, pressure on resources (particularly water), migration, and conflict. The conflict in Darfur is as much about pressure on resources as the desert encroaches as about the internal politics of Sudan. And the implications for the health of local populations are acute: on the spread and changing patterns of disease, notably water borne diseases from inadequate and unclean supplies; on maternal and child mortality as basic health services collapse; and on malnutrition where food is scarce.<sup>5</sup> And population stabilisation will not be achieved if, for want of resources, girls are not educated and contraceptives are unavailable.<sup>6</sup>

Climate change is causing other kinds of extreme weather events too: storms, floods, and rising sea levels affecting coastal populations and islands.<sup>7</sup> Every such

event has adverse consequences for health. The poorer the country and its infrastructure, the worse are the consequences and the poorer the chances of meeting the Millennium Development Goals.

Crucially for winning hearts and minds in richer countries, what's good for the climate is good for health. The measures needed to combat climate change coincide with those needed to ensure a healthier population and reduce the burden on health services. A low carbon economy will mean less pollution. A low carbon diet (especially eating less meat) and more exercise will mean less cancer, obesity, diabetes, and heart disease.<sup>4</sup> Opportunity, surely, not cost.

This is an opportunity too to advance health equity, which is increasingly seen as necessary for a healthy and happy society. If we take climate change seriously, it will require major changes to the way we live, reducing the gap between carbon rich and carbon poor within and between countries. The Commission on Social Determinants of Health said that action to promote health must go well beyond health care.<sup>8</sup> It must focus on the conditions in which people are born, grow, live, work, and age, and in the structural drivers of those conditions—inequities in power, money, and resources. These insights give further confirmation that what is good for the climate is good for health.

A successful outcome at Copenhagen is vital for our future as a species and for our civilisation. It will require recognition by the rich countries of their obligations to the poor; and recognition by the poor countries that climate change is a global problem that requires a global solution in which we all have to play a part. It will require a new mindset: that the measures needed to mitigate the risks of climate change and adapt to its already inevitable effects provide an opportunity to achieve goals that are desirable in their own right—the achievement of the Millennium Development Goals in the poor countries and a healthier more equal society in the rich world and globally. Failure to agree radical reductions in emissions spells a global health catastrophe, which is why health professionals must put their case forcefully now and after Copenhagen ([www.climateandhealth.org](http://www.climateandhealth.org)).

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