

## Retracing the Oregon trail: the experience of rationing and the Oregon health plan

Chris Ham

A decade ago the state of Oregon attracted worldwide interest when it began an ambitious attempt to set priorities for health care on a systematic basis. Stimulated by the death of a 7 year old boy who had been waiting for a bone marrow transplant operation, and led by John Kitzhaber, a doctor turned politician, Oregon passed legislation in 1989 designed to provide access to health insurance for all residents. A key part of the strategy was to increase eligibility for Medicaid, a publicly funded programme of health care for people with low incomes, by including in the programme all citizens with an income at or below 100% of the federally defined poverty level. To keep the costs of this policy within affordable limits, the legislature determined that the services provided should constitute a basic healthcare package, and it sought to ensure that Medicaid recipients were, whenever possible, enrolled in managed care plans. These plans, often known as health maintenance organisations, have developed rapidly as an alternative to fee for service medicine, and provide services to those enrolled on a prepaid basis. By managing the use of services by both patients and doctors, health maintenance organisations seek to reduce the overall cost of providing care while maintaining high standards of provision.

As well as focusing on expanding Medicaid enrolment, politicians in Oregon legislated to provide assistance to residents with pre-existing medical conditions who were unable to buy insurance coverage, and they also took action to help people working in small businesses obtain insurance. More importantly, the employer mandate was introduced, which was designed to ensure that in time the basic healthcare package offered under Medicaid would be available to workers who were not entitled to Medicaid. The purpose of the employer mandate was to move towards universal coverage by requiring businesses to offer protection to uninsured people who were working and whose incomes placed them above the federal poverty level. The mandate was also intended to avoid a reduction in the services available to those eligible for Medicaid by building a wider constituency of support for the package.

Among this diverse range of initiatives, it was the attempt to define the basic healthcare package that attracted the most interest outside Oregon. The architects of the Oregon health plan sought to raise the threshold for inclusion in Medicaid from people who earned around 50% or less of the federal poverty level

### Summary points

The basic healthcare package available to those eligible for Medicaid coverage under the Oregon health plan has been expanded. Enrolment in Medicaid has increased by over 100 000 since 1994 but eligibility criteria have been tightened in response to rising costs

The proportion of the population that remains uninsured has fallen from 18% in 1993 to 11% in 1996 as a result of implementation of the plan and economic growth

Providers of safety net services may not be able to continue to provide such services under the plan's payment arrangements. The delivery of services through managed care plans may put those who receive Medicaid at a disadvantage

The employer mandate to provide health insurance lapsed in 1996 and the problem of providing health insurance to people who are working and yet are still uninsured remains

Explicit priority setting tends to result in inflation of the basic healthcare package. Defining a list of services to be covered must go together with the development of clinical guidelines

to include those who earned up to 100% by restricting the services that would be funded. The task of determining what should be on the list was entrusted to a health services commission whose 11 members comprised professional and lay people. The conclusions of the commission were reported to the legislature which then had to decide whether to accept the conclusions and also agree the level of funding that would be made available. The work of the commission was conducted in public and included considering the advice of experts and consulting with the community. It was partly for this reason that the Oregon experience acted as a magnet for those policy makers and health professionals from other healthcare systems where priority setting or rationing were undertaken covertly rather than overtly.<sup>1</sup>

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## Genesis

During its development, the Oregon health plan attracted a range of commentary.<sup>2-5</sup> One of the main concerns of critics was that by concentrating on Medicaid, Oregon was rationing services only for the poor (most of whom were women and children) and was therefore accentuating the inequities in the US healthcare system. Critics believed that the development of the Oregon health plan distracted attention from the bigger and more important question of how to ensure universal healthcare coverage, a question that called for examination of more radical options, such as the introduction of national health insurance.<sup>6</sup> Supporters of the plan, while acknowledging the force of these arguments, contended that reform had to start somewhere and that politicians in Oregon deserved credit for their willingness to make progress by seeking to extend insurance coverage to the most vulnerable residents.<sup>7</sup> Other commentators maintained that explicit priority setting was preferable to implicit priority setting because it resulted in greater public accountability for decisions.<sup>5</sup> Yet other commentators drew on the experience of Oregon to highlight the technical challenges of priority setting<sup>8</sup> including the complexity of the formula originally used by the health services commission to rank services, the anomalies that resulted from cost effectiveness analyses, and the difficulty of organising consultations with the public to ensure that those involved were representative of the population.

Undeterred by these challenges, the commission refined its methods; research evidence and professional opinions on the effectiveness of different treatments were used together with the values derived from the public consultations to draw up a list of around 700 pairs of conditions and treatments to be given priority for funding. These conditions were categorised according to the ICD-9 (international classification of diseases, ninth revision) and they were then associated with their appropriate treatments from *Current Procedural Terminology*.<sup>9</sup> When the first list was submitted by the Oregon legislature to the federal government for approval, it was rejected as being inconsistent with the Americans with Disabilities Act 1990.

This was because the ranking of condition-treatment pairs was based in part on an assessment of the potential for restoring a full quality of life, an

outcome not possible for people with disabilities. Only after extensive revision to avoid discrimination of this kind was agreement given by the Health Care Financing Administration for the list to become operational from February 1994. The Oregon health plan was launched with funds available from the legislature to provide 565 out of 696 treatments on the final priority list. The treatments included the bulk of preventative and curative services, with high priority being attached to palliative care as a result of values identified during the public consultations. The principal exclusions were the treatment of self limiting conditions and conditions where no effective interventions were available.

Four years on, how has the Oregon health plan fared? Have the objectives of its architects been achieved? And what experience has been accumulated along the way?

## Implementation

Priority setting in Oregon did not end in 1994. There is a legal requirement to keep the basic healthcare package under review; this continues to be the responsibility of the health services commission. Supported by a full time project director and a part time medical director, the members of the commission, who are volunteers, undertake a formal review every two years and propose changes to the package based on their review. Much of the work of the commission is done in subcommittees that evaluate outcomes, mental health and chemical dependency services, and dental services. The commission is advised by 70 provider groups that bring together doctors from throughout the state, and they in turn make use of recommendations emanating from national expert groups such as those run by the National Institutes of Health. Any changes proposed by the commission and agreed by the legislature have to be approved by the Health Care Financing Administration. This process can be both time consuming and extended, as illustrated by the fact that in January 1998 the Health Care Financing Administration had still to approve revisions to the funding list drawn up by the health services commission in May 1997.

### Changes to the list

One of the most important changes made in the last four years has been the full integration of mental health and chemical dependency services into the basic healthcare package. This has increased the length of the priority list from 696 to 743. Elderly and disabled people whose incomes are below the federal poverty level have also been integrated into the plan. A number of changes have occurred as services have been moved up or down the list in the light of experience and as a result of changes in the coding of diseases. More importantly, adjustments have occurred as new evidence has become available on the effectiveness of particular treatments. Cochlear implants, for example, have moved from being unfunded to being funded services, as have bone marrow transplant operations for breast cancer. These transplantations were included in the list for the first time in 1997 and will be funded when the list is approved by the Health Care Financing Administration; for these treatments there is a stipulation that women should agree to enter into a clinical trial of the treatment's long term



MARK MCCONNELL

effectiveness. Inclusion of bone marrow transplantation for treatment of breast cancer was controversial and was only agreed by a narrow majority of members of the commission.

The health services commission has begun developing guidelines for the provision of some services on the list. In certain cases, these guidelines are meant to ensure that the cost of providing services is kept within the available budget. For example, the guidelines for adult dental care—a treatment that does not have to be provided under Medicaid—are intended to avoid the overprovision of services. In other cases guidelines have been developed to ensure that services are provided in accordance with the recommendations of national expert groups, for example in preventive services, where the guidelines are based on a report by the US task force on prevention. Guidelines also have a role in the provision of services that fall below the cut off point for funding where it has been recognised that more severely ill patients would benefit from earlier intervention rather than waiting for treatment of complications arising from the original diagnosis. Such services include treatment of uncomplicated hernias in adults, treatment of severe rhinitis, tonsillectomies, and adenoidectomies. The adoption of guidelines for these services demonstrates the difficulty of ruling out whole categories of care or treatment from funding.

■ *“Strict adherence to a defined set of core services is likely to be problematic”*

The experience in Oregon suggests that strict adherence to a defined set of core services is likely to be problematic. This observation is reinforced by the fact that doctors in managed care plans have the freedom to decide whether treatments not listed in the basic package should be provided. Only those doctors delivering care to the 15% of Oregon's population who are covered by Medicaid and receiving services under fee for service arrangements are subject to scrutiny to ensure that they are not providing treatments that fall below the threshold for funding. For the bulk of patients covered by Medicaid, this means that the list of funded services acts mainly as a cost containment instrument. Managed care plans carry the risk and expense of providing services that fall below the cut off for funding when doctors nevertheless determine that such treatments are needed; the plans are responsible for making their own arrangements for monitoring whether this happens.<sup>10</sup> No data exist to assess the extent to which doctors in managed care plans offer unfunded services to Medicaid patients, but the existence of this freedom is a potentially important safety valve for clinicians and patients.

The changes to the basic package and the adoption of guidelines have increased the scope of the services that are funded. In part, this has resulted from developments in healthcare technology and the availability of evidence which challenges earlier decisions to exclude treatments. It has also been driven by the experience of implementing the original list of services and the need to make adjustments based on advice received from clinicians. This advice has been instrumental in developing guidelines that give doctors greater discretion in offering services that initially fell

below the funding threshold. Expansion of the basic package has been helped by the Health Care Financing Administration's reluctance, as the ultimate arbiter of the content of the package, to approve further restrictions in funded services. Taken together, these factors mean that in Oregon explicit priority setting has expanded the range of services provided.

**Financing the plan**

The addition of treatments to the list has created problems for the funding of Medicaid, especially since the number of people enrolled has increased, in line with the intentions of the politicians in Oregon. In 1994, during the early phase of implementation, the helpline set up to provide residents with information on the plan received 4000 calls each day; only 5000 calls each week had been expected. An additional 130 000 people were subsequently enrolled in Medicaid, taking the total number covered to over 400 000. The backlog of need that was revealed in areas such as dental care, reminiscent of what happened when the NHS was set up in 1948, made accurate budgeting difficult. A deficit of \$18m (£11.25m) resulted and led to the consideration of radical options for change, including limiting funding to include only the first 505 treatments on the priority list; this would have eliminated a number of potentially effective treatments, such as those for oesophageal cancer.

This option was not implemented, but other changes were. Most importantly, eligibility criteria were tightened to exclude those with liquid assets of \$5000 (£3100) or more, to introduce contributions of up to \$28 (£17.50) each month for families at the high end of the (admittedly low) income range (a yearly income of \$16 500 (£10 300) for a family of four), to exclude full time college students, and to require people's incomes to be assessed over three months rather than just one month. These changes helped put Medicaid on sounder financial footing, but at the expense of reducing enrolment by around 15 000. The eligibility restrictions agreed by the legislature have been criticised by citizens' action groups as being inconsistent with the fundamental purpose of the health plan.

■ *“In Oregon explicit priority setting has expanded the range of services provided.”*

Changes in the economy and the labour market, which have taken people out of poverty, have reduced the number of people dependent on Medicaid. On one level, this reflects the strong performance of the Oregon economy and the additional jobs that have been created. At another, it has resulted from action by the state government to move people out of welfare and into work. Paradoxically, these developments have in turn created problems; those above the poverty level and in work do not always have private health insurance. The position of those who are working and yet are still uninsured is a particular concern of citizens' action groups. These groups have challenged claims made by the state government about the extent to which the proportion of the population without insurance has fallen, arguing that official figures do not reflect the true numbers.

An unintended and unanticipated effect of the implementation of the plan has been to bring into question the funding of safety net providers who deliver services to patients with special needs such as people with HIV or AIDS and migrant workers who do not speak English. These services were fully funded in the past and enabled providers to deliver appropriate care. The capitation payments available under the plan are less generous, and this has made it difficult to sustain these services at their previous level. Providers of safety net services in Oregon have responded by forming their own managed care plan, CareOregon, which is lobbying for capitation payments to be adjusted for risk to allow for the higher cost of treating those clients who need these services. Unless changes are made to the plan's financing, there is fear that safety net services will have to be terminated, with adverse consequences for both the providers and clients of these services.

Beyond its effects on those covered by Medicaid, the plan has had a number of other effects. Progress has been made in enabling patients in high risk groups and those who are employed in small businesses to obtain insurance coverage, thereby reducing the number of people who are uninsured. However, the employer mandate lapsed in 1996 when a waiver of federal laws could not be obtained. The failure to proceed with the mandate means that people who are working and yet are still uninsured continue to pose a challenge to those seeking to ensure universal coverage.

■ *"The main weakness of the plan is not healthcare rationing... but managed care"*

More positively, the revenue from a new tobacco tax (30 cents (18 pence) on a packet of cigarettes) has been earmarked for the maintenance and expansion of the plan. Among other schemes, this includes taking action to bring into the plan pregnant women and children up to age 19 who earn incomes of up to 170% of the federal poverty level. Other options for expanding coverage will be considered during 1998 by the Oregon health council, a group of citizens appointed by Governor John Kitzhaber to advise on reforms. The deliberations of the council will be informed by the results of a new programme of community consultations on fairness and financing in health care that are being undertaken by Oregon Health Decisions, a non-profit making organisation which organised the community meetings in 1990 and which helped to clarify the values the public believed should guide priority setting for the basic package. As in federal policy, the aim is to gradually extend health coverage in recognition of the difficulty of achieving more fundamental change.

#### Managed care

One other aspect of the implementation process merits comment. The strategy of containing the cost of Medicaid expansion by encouraging the provision of services through managed care plans has resulted in 85% of those on Medicaid receiving their care through health maintenance organisations. An explicit objective of the plan was to reimburse health insurers at a

level sufficient to make it attractive for them to treat clients with Medicaid. This objective appears to have been met with the exception of safety net services. However, citizens' action groups have expressed concern that Medicaid clients may have greater difficulties than more affluent residents in effectively gaining access to services offered in managed care plans, for example because they may lack telephones or transportation. They also argue that shortages of doctors, dentists, and other staff in some parts of the state have frustrated the attempt to translate health insurance coverage into the effective delivery of service. From this perspective, the main weakness of the plan is not healthcare rationing, since most services are now funded in the basic package, but managed care. These developments in Oregon mirror those occurring across the United States as the drive towards managed care gathers pace.

■ *"Establishing strong purchasing bodies... has not been easy... the needs of clients are still not well articulated"*

The emphasis on delivering Medicaid through a system of managed care has led to changes in the organisation of state government. The Office of Medical Assistance Programmes, the agency charged with putting the basic package into operation, has had to shift its role from paying for Medicaid services to actively purchasing them. This new role includes monitoring the performance of the 15 health plans with which it has contracts and ensuring that they are meeting the needs of Medicaid patients. The office does this by carrying out client satisfaction surveys. It is also arranging to assess standards of clinical care by commissioning an external agency to sample and review the medical records of patients with conditions such as diabetes to ensure that they are receiving appropriate care. The office also aims to develop a scorecard for monitoring performance in order to address some of the criticisms that have been levelled at managed care. Just as in the United Kingdom, establishing strong purchasing bodies that are able to negotiate on equal terms with providers has not been easy. As a consequence, the needs of clients are still not well articulated. Although this problem has been recognised, it will take time until it has been rectified to the satisfaction of those lobbying on behalf of citizens.

#### Outcome

Judged on its own terms, the Oregon health plan has achieved success in some areas but has failed in others. The most important achievement has been to increase enrolment among residents eligible for Medicaid by over 100 000 and to contribute to the reduction in the proportion of those who are uninsured from 18% in 1993 to 11% in 1996 (Office for Oregon Health Plan Policy and Research). In the same period the proportion of children who were uninsured fell from 14% to 8%. While some of the improvement is a result of a reduction in unemployment, the contribution of the plan, including the protection offered to people in high risk groups and people employed in small businesses, is estimated to have been responsible for

around two thirds of the increase in insurance coverage (D Coffman, personal communication). Not only that, but the basic package has been expanded and encompasses a great deal more than a narrow set of services. The work that has been done on clinical guidelines has begun to define more precisely the way treatments on the list should be provided and has blurred the distinction between services that are or are not funded.

Against these achievements, the tightening of the criteria for eligibility for Medicaid has contributed to a reduction in Medicaid coverage from the peak of over 400 000 in 1995. The difficulties encountered by safety net services also show that the part of the population covered by Medicaid may have been put at a disadvantage by the implementation of the plan even though others may have benefited. A particular concern of citizens' action groups is the position of those who are working but who are still uninsured. The failure to implement the employer mandate means that many people who work and whose incomes are above the federal poverty level still lack coverage in the event of illness.

The most important lesson to be learnt from Oregon's experience is that explicit priority setting tends to result in inflation of a basic healthcare package. Furthermore, defining a list of services to be funded has to go together with work on clinical guidelines to ensure that treatments both above and below the threshold for funding are provided in a way that is consistent with evidence on the effective and appropriate provision of care. Because of the rapid changes in the availability of healthcare technologies and in the evidence of their effectiveness, priority lists must be continuously reviewed. In the process, those who are charged with making decisions are dependent on the advice of experts but they must also take account of the views and values of the community. Additionally, clinical discretion remains important in the implementation of the basic package, at least in managed care plans where doctors are able to decide whether treatments beyond those included in the package should be provided in practice.

Whether the outcome looks like a glass half full or a glass half empty depends on your perspective. The 1996 award to the state of the prestigious Innovations in American Government prize by the Ford Founda-

tion brought national recognition to Oregon and testifies to the progress made by the state. It also indicates that in a country where government sponsored change in health care is notoriously difficult to achieve, Oregon has done better than most in terms of increasing access among the most vulnerable residents. However, the extent of unfinished business is daunting and illuminates the obstacles that have to be overcome even when the political commitment to change is strong.

For the future, much hinges on the strength of the economy. The Oregon health plan has been implemented in favourable economic circumstances; a downturn in the economic cycle would probably increase the number of families in poverty and at the same time put pressure on tax revenues. At that point, the balance that has been struck between the comprehensiveness of the basic package and eligibility for Medicaid would have to be reviewed. In a context in which the Health Care Financing Administration has been resistant to reductions in the list of funded services, there may be little choice but to further tighten eligibility criteria, especially if Oregon remains a fiscally conservative state.<sup>11</sup> Were criteria to be tightened the longer term sustainability of the health plan would be put to the test.

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### *Fifty years ago*

## The new NHS: The Octopus

The Public Relations Department of the Association has got out a most effective folder, the principal feature of which is a pictorial design illustrating the arrangements under the new Act. The picture, which is in colours, admirably done by F K Henrion, the distinguished poster artist, well conveys the strong jaws and unattractive countenance (officially, of course, not personally) of the Minister of Health, while his sucker-bearing arms hold all the things which he can determine—by regulation, appointment, provision, control, approval, whatever it is—in relation to hospitals, general practice, and local authority services. For example, in general practice it is shown that he controls entry into the public medical service through the Medical Practices Committee; that he regulates the Executive Council, which

consults the Local Medical Committee, and contracts with the general practitioner; also that he appoints the Central Health Services Council and controls dismissal from public medical practice through a tribunal. There is more in the design than meets the eye—and the eye has quite a lot to meet it. It is said that on occasion the octopus will devour its own arms, which may, for anything we know, be the fate of these appointed or approved bodies. The folder, which includes a number of other facts tersely set out, is being sent to every member of the profession, and in a larger size it is available on application for exhibition at divisional or other meetings. (*Heard at headquarters*, 17 January 1948, p 11 (suppl). See also editorial by Gordon Macpherson, 3 January 1998, p 6.)



# Spectre of racism in health and health care: lessons from history and the United States

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Inequalities in health and health care in relation to race and ethnicity pose ethical problems of which racism is the most disquieting.<sup>1 2</sup> One controversial inequality is the poor health of African Americans—their life expectancy in 1993 was 7.1 years less than that of white Americans. La Veist et al have shown that the disparity has increased over this century.<sup>3</sup> The deficit arises from excess mortality in relation to many causes of death, and is partly explained by differences in income.<sup>4</sup>

Empirical evidence is scarce and hard to interpret, but much public opinion and some scholarly analysis in the United States and the United Kingdom place racism at the hub of ethnic and racial inequalities in health and health care.<sup>2 3 5-11</sup> Health professions, governed by ethical codes that emphasise their humanitarian duties, find the charge that health care is racist hard to bear. It is less vocal in the United Kingdom than in the United States, but the issues are similar enough for us to learn from the experience there. This essay takes a historical perspective in order to disentangle the argument and counter argument that characterise the current debate. I have used the terms found in most of the publications cited—my understanding of these terms used is given in the box.

## History of scientific racism

Hippocrates contrasted the feebleness of the Asiatic races to the hardness of the Europeans.<sup>12</sup> Hippocrates' concept of race was of human groups shaped by ancestry in different geographical conditions, especially climate. In the 19th century, racial differences in

### Terminology

**Race**—The group a person belongs to as a result of a mix of physical features, ancestry, and geographical origins, as identified by others or, increasingly, as self identified. The importance of social factors in the creation and perpetuation of racial categories has led to a broadening of the concept to include social and political heritage, making its usage similar to ethnicity. Race and ethnicity are increasingly used synonymously

**Ethnicity**—The group a person belongs to as a result of a mix of cultural factors, including language, diet, religion, ancestry, and race

**Racism**—A belief that some races are superior to others, used to devise and justify actions that create inequality between racial groups

**White**—People with European ancestral origins known in the 19th century as caucasoid (in the United States, white includes people from the Middle East and north Africa)

**Black**—People with African ancestral origins (in the United States, excluding some parts of north Africa) and who fall into the racial group known in the 19th century as negroid

**African American**—People who fall into the category black and live in the United States

### Summary points

Inequalities in the health and health care of ethnic and racial minority groups are evident

Racism is the most disturbing of the explanations for these inequalities

Pinpointing the specific role of racism is difficult

The history of racism in science and medicine shows that people and institutions behave according to the ethos of their times and warns of dangers to avoid in the future

Inequalities result from inextricably linked, complex factors including historical and current racism

Action to reverse inequalities should not have to wait for reliable answers to questions on causes and mechanisms

anatomical, physiological, behavioural, and health status were avidly sought.<sup>13-16</sup> The idea of races as distinct species gave way to that of races as biological subspecies. This is the defining feature of the 20th century concept of race, supported by many dictionaries and encyclopaedias and permeating biomedical thinking. However, the view that race is a social and not a biological reality is emergent.

That some races are superior to others, a tenet of racism, was widely believed, especially in the 19th century,<sup>17-20</sup> but is clear in Hippocratic writings.<sup>12</sup> In the 19th century, differences between races were usually assumed to be biological, were interpreted to show the superiority of white races, and were used to justify policies that subordinated "coloured" groups.<sup>13-22</sup> These policies included slavery,<sup>20</sup> social inequality,<sup>15 19</sup> eugenics,<sup>21</sup> immigration control,<sup>15 21</sup> and the unequal practice of medicine.<sup>22 23</sup> John Down's theory of "mongolism" (trisomy 21 or Down's syndrome) was that these infants were from an inferior, Mongoloid, race.<sup>24</sup>

Dr J M Smith argued that the environment was responsible for health disparities, showing that poor white families had patterns of diseases similar to black ones.<sup>9</sup> Challenges such as this are still needed. For example, the suggestion that the higher prevalence of hypertension in black people is caused by biological factors is challenged only rarely with the alternative view that it is a response to racism or other environmental factors.<sup>5-8 26 27</sup>

Modern genetics undermined the biological concept of race,<sup>14</sup> and Nazi racism undermined eugenics.<sup>28</sup> Races are now considered to be based on a few physical features (such as colour and facial features)

that are of little direct importance to health but serve important social purposes.<sup>2 5 22 26 27</sup> None the less, the idea of the biological basis of health differences in relation to race<sup>26 27</sup> and ethnicity<sup>29</sup> remains strong.

Gamble has argued that the Tuskegee syphilis study has left a legacy of mistrust.<sup>30</sup> This study in Alabama lasted from 1932-72, and deceived and bribed 600 black subjects into cooperating with research that examined the progression of syphilis without treatment, even once a cure was available.<sup>31</sup> The study was conducted by the US Public Health Service with the backing of the medical and scientific establishment. In May 1997, President Clinton apologised, on behalf of America, to the survivors of this experiment. Tuskegee was not a unique racist medical experiment.<sup>30</sup>

### Contemporary research in the US

Osborne concluded that much American health research on race and ethnicity is itself racist by contributing to the idea that some human groups are inferior.<sup>32</sup> The review of racism, sexism, and class by Krieger et al concluded that racial/ethnic differences in health have not been explained.<sup>3</sup> They criticised research on racial differences, particularly as racism—which they defined as “an oppressive system of racial relations, justified by ideology, in which one social group benefits from dominating another”—was rarely studied. Krieger et al contended that much modern research supported the assumptions needed to justify racism. They explained that racism is important because it leads to socioeconomic inequalities that underlie health inequalities, and, by implication, that racism underlies unexplained inequities in health care, including treatment for heart disease,<sup>33</sup> renal failure,<sup>34</sup> bladder cancer,<sup>35</sup> and pneumonia.<sup>36</sup> These inequalities have been documented in numerous studies.

Gornick et al, for example, showed that black people had fewer mammograms, immunisations, and ambulatory care visits than white people, but greater mortality and more admissions to hospital.<sup>37</sup> Commenting on this, Geiger wrote that “investigators tend to invoke unspecified cultural differences, undocumented patient preferences, or a lack of information about the need for care as reasons for the differences. The alternative explanation is racism, that is, racially discriminatory rationing by physicians and health care institutions. We don’t yet know enough to make that charge definitively.”<sup>38</sup>

The consistent and repeated findings that black Americans receive less health care than white Americans—particularly where this involves expensive new technology—is an indictment of American health care.<sup>39</sup> These inequalities are not wholly a result of differences in socioeconomic circumstances.<sup>4 5 38 39</sup> Escarce et al explained their finding that white patients were more likely than black patients to receive services in terms of the following factors: different disease patterns; different level of contact with doctors, especially specialists; financial and organisational barriers; patients’ preferences; and the fact that doctors managed their patients differently on the basis of race.<sup>40</sup>



In May 1997, President Clinton apologised to the survivors of the Tuskegee experiment—black men deceived and bribed into cooperating with research into the progression of syphilis

The difficulty in interpreting these findings is considered in the context of heart disease, which has been studied in detail. Differences between black and white patients have been publicised since 1984.<sup>33</sup> As the box shows, white patients in the United States receive more intensive medical attention in the treatment of heart disease than do black patients.

Thus, extensive published reports do not yield a clear conclusion on the role of racism. The studies are mainly on quantity, not quality, of care, but Ayanian et al were not clear whether white patients had too many interventions or black patients too few.<sup>45</sup> A study examining outcomes showed no differences between black and white patients, and thus evoked a different reaction from studies examining quantity of care.<sup>47</sup> Despite at least 15 years of attention and much research, no definitive explanation has emerged. Admittedly, these

#### Racial inequalities in treating heart disease

- Wenneker and Epstein showed that black patients had lower rates for coronary angiography and coronary artery bypass grafting than white patients after adjustment for confounding factors<sup>41</sup>
- Hannan et al showed that black patients had fewer cardiac procedures than white ones after adjustment for disease severity<sup>42</sup>
- Goldberg et al reported that coronary artery bypass rates in black men and women were a quarter and a third respectively of rates in white men and women<sup>43</sup>
- Whittle et al showed inequalities between black and white patients in invasive cardiac procedures<sup>44</sup>
- Ayanian et al reported that black patients had fewer coronary revascularisation procedures than white patients<sup>45</sup>
- Carlisle et al showed that in Los Angeles invasive cardiac procedures were less common in Latin American and black patients than in white patients, but not in Asian patients compared with white patients<sup>46</sup>
- Peterson et al showed that black patients had fewer cardiac procedures yet better short term survival and equivalent intermediate survival rates<sup>47</sup>

**Interpretation of current thinking**

- Racial and ethnic inequalities in health and health care are abundant, but their underlying causes, and the contribution of racism, are controversial
- Racial discrimination is evident in many factors that affect health, including employment and social security, and wealth inequalities
- Minority groups find it difficult to reduce inequalities in wealth, partly because of racially discriminating actions and policies and because wealth may be accumulated over generations
- Minority racial/ethnic groups generally (but not always) have worse overall health than the majority population
- Health services are mostly staffed by members of the racial/ethnic majority, and are usually planned and delivered in relation to the needs and preferences of racial/ethnic majority users
- Health services may offer a worse service to minority groups because staff treat patients unequally on account of their race or ethnicity, policies are based on the needs of the racial/ethnic majority, and specialist resources required to meet the needs of minority groups do not exist
- That racial discrimination in health care is an obstacle to racial/ethnic minorities achieving their full health potential is sufficiently widely believed for it to be crucially important even without definitive evidence from research

studies have not been designed to unearth the role of racism. The emerging, somewhat reluctant interpretation, is that racism is important.<sup>5 39</sup> Whittle concluded, “We believe that inadequate health education, differences in patients’ preferences for invasive management, delivery systems that are unfriendly to members of certain cultures, and overt racism may all play a part.”<sup>44</sup> Perhaps, as a legacy of racism, black patients distrust invasive diagnostic and therapeutic procedures and this inhibits them from seeking or accepting this type of care. In this climate of distrust, doctors may be inhibited in advising invasive procedures. If so, even if patients’ preferences are partly responsible for the disparities, racism will not be wholly exonerated. The box shows my interpretation of current thinking on racism as a cause of health and healthcare disparities.

**Lessons from history and the US**

In planning action amid controversy and uncertainty, we can draw upon two lessons from history and two from the United States. Firstly, our attitudes, interpretations, and actions are influenced by the prevailing ethos in society.<sup>15</sup> As Gladys Reynolds candidly wrote “We the scientific community ... bring everything we have been taught by our culture—our xenophobia, our homophobia, our racism, our sexism, our ‘classism,’ our tendency to ‘otherise.’”<sup>48</sup> Most health workers and researchers are humanitarians, reflecting their professional ethos. This is an important but insufficient guard against racism.

Many scientists and policy makers of the 19th century shared the attitude that whites had a responsibility to colonise and lead coloured people, and perceived their actions as morally justifiable in the interest of

society and all racial groups.<sup>13–20</sup> (Similar paternalistic views are illustrated in *The Bell Curve*, which argues that a consequence of a lower IQ in African Americans than white Americans is a set of specific policies attuned to that observation.<sup>50</sup>) The humanitarianism of medicine did not prevent doctors participating in Nazi medicine<sup>28</sup> or in the unethical treatment of black South Africans in custody during the apartheid era. Doctors and other health professionals followed the ethos of their times.

Secondly, while important in showing inequities, seeking differentials in relation to race and ethnic group is potentially dangerous. Race science of the kind that dominated the 19th century is lurking, and *The Bell Curve* is an example,<sup>50 51</sup> but there are others.<sup>52 53</sup> Binet’s test was designed to select children for “special educational attention,” but was used for immigration control and to show racial inferiority in intelligence.<sup>15</sup> As Disraeli, the British prime minister, said to the House of Commons in 1849 “Race implies difference, difference implies superiority and superiority leads to predominance.”<sup>18</sup> Research focusing on problems more common in minority groups and data presentation designed to highlight differences when minorities are compared with the majority population portray the minorities as weaker.<sup>29 49</sup> When published reports imply that genetic factors rather than environmental ones are the cause of racial differences in health, racial minorities may be perceived as innately weaker.<sup>1 3 5 20 26 27 49</sup>

Two lessons from the United States are particularly noteworthy. Firstly, close and repeated observation and tracking of inequalities in this century has been accompanied by widening, not narrowing, of the gap between black and white people. Secondly, definitive answers on the role of racism as an explanatory factor for inequalities in health and health care have not emerged despite much debate, scholarship, and research. As a result, damaging allegations of racism in the health sector cannot be countered, and yet there is reluctance to take corrective action.

**Conclusion: action amid uncertainty**

We do not yet know to what degree racial and ethnic inequalities in health and health care are caused and maintained by racism. Should we wait to define the exact contribution of racism before we act or proceed according to the emergent (though uncertain) analysis that racism is important? Guinan has argued against delay, on the basis that we know enough.<sup>34</sup> Warren, however, has strongly advocated that racism should be researched.<sup>55</sup> The need and demand for more research was a dominant theme at the consultation on “Refining the research agenda” hosted by the National Centre for Health Statistics in May 1997 (personal observations).

There is understandable ambition to quantify the specific effects of racism, driven by such questions as “What are the causes of racial or ethnic disparities in health and health care?” and “What are the mechanisms by which the various causes operate?”<sup>56</sup> Awaiting reliable quantitative answers to these complex questions will impede policy and action. Alternatively, we could simply accept that racial and ethnic inequalities result from a complex, inextricably



linked set of factors, of which racism is an important part. The key question would then be "What actions could effectively reverse health and health care inequality?" The questions of cause and mechanism, including the role of racism, then become supportive of the quest for effective interventions.

The spectre of racism in healthcare institutions needs to be driven out. In the United Kingdom to date, the spotlight has mainly been on racism directed at ethnic minority staff.<sup>57-59</sup> With continuing disquiet about the potential adverse effects of racism on the quality of health care delivered to ethnic minority groups<sup>10 21 22 25 60 61</sup> and evidence (by self admission by the white population) of continuing racist attitudes in the United Kingdom,<sup>62</sup> the spotlight is likely to shift to racism in patient care. Knowledge of events in the United States, and particularly the difficulties there in pinpointing the role of racism and in narrowing inequalities, may help to prevent the same happening in the United Kingdom. Knowledge of the history of race in science and medicine engenders the moral drive for action, provides insight on how societies acquire and interpret data on racial differences, shows how the prevailing social attitudes affect individuals' behaviour, and gives warning of the dangers to avoid.

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*Managing demand***Managing demand at the interface between primary and secondary care**

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**This is the fourth of five articles on ways of managing demand for health care**

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General practitioners have acted as official gatekeepers to the United Kingdom hospital service since the inception of the NHS in 1948, but the roots of the referral system can be traced to the conflict between physicians, surgeons, and apothecaries in the 15th and 16th centuries.<sup>1</sup> Specialists and general practitioners had to compete for paying patients until the early 20th century, when the issue was resolved with the establishment of registered general practice lists, a salaried hospital service, and a formal system of referral from one to the other. The gatekeeping role (more recently called filtering) of general practitioners is arguably the most important mechanism for managing demand in the NHS. The British referral system undoubtedly contributes to the low cost of health care relative to other countries. Healthcare systems which allow patients direct access to specialists—America, Germany, France, and Sweden—tend to incur higher costs than those that channel demand via general practitioner referrals, such as Britain, Denmark, Finland, and the Netherlands.<sup>2</sup> At its best the referral system ensures that most care is contained within general practice, and when specialist care is needed patients are directed to the most appropriate specialist. However, it is also a restrictive practice, initially introduced to protect the interests of doctors, which gives general practitioners a monopoly over primary medical care and restricts patients' freedom of choice. Despite this the system has survived relatively unscathed by public criticism, a tribute to the widespread public confidence in general practitioners and to the fact that the gatekeepers have been very willing to open the gates to secondary care in response to patient demand.

**Variations in referral rates**

Evidence of wide variations in the rates at which general practitioners referred patients to specialist clinics began to emerge in the 1970s.<sup>3</sup> Later studies using more sophisticated techniques of data collection and analysis confirmed the early impression that rates were variable but failed to identify any factors that could explain the major sources of variation.<sup>4</sup> Referral rates increased steadily in line with increased consultation rates in general practice<sup>5</sup>; on average general practitioners make about 5 outpatient referrals per 100 consultations (12 referrals/100 registered patients) per year. Rates vary between individual general practitioners within practices and between practices. Estimates of the extent of variation between individual general practitioners are hard to calculate because of the difficulty in establishing a correct denominator, but it is fairly well established that rates vary between practices by at least threefold or fourfold.<sup>4</sup>

These large unexplained variations are disturbing to policymakers because they suggest inefficiencies, and few incentives seemed to exist for general

**Strategies for managing demand at the interface**

Information and audit:	Feedback of referral rates Measuring outcomes
Decision support:	Guidelines Information for patients
Financial incentives:	Practice based services Fundholding Primary care groups

practitioners to avoid referral. Some considered that many referrals were avoidable and that if a way could be found to curb the activities of the high referrers it would lead to greater efficiency.<sup>6</sup> However, practices' outpatient referral rates have been found to be strongly correlated with elective inpatient admission rates for their patients, which are equally variable.<sup>7</sup> The finding that high referring practices also had high admission rates cast doubt on the view that these practices were referring many patients unnecessarily, since specialists appeared to be concurring with general practitioners' judgements by admitting their patients to hospital in similar proportions.

Achieving a shift in the balance from secondary to primary care has been a central focus of recent policy initiatives and various attempts have been made to modify general practitioners' referral behaviour (see box).

**Information and audit**

The requirement for general practitioners to collect data on their referrals to hospital specialties and report these in their annual reports has recently been dropped. In theory these data can be obtained from provider units, but many problems exist in interpreting referral data collected in this way.<sup>8</sup> Comparative information can be a spur to action, but hopes that feedback of information on referral rates would lead general practitioners to change their referral behaviour proved overoptimistic.<sup>9</sup> General practitioners were sceptical of the data on which the feedback was based and because referral rates in themselves do not reveal anything very useful about the quality of care, it was difficult to persuade them to use information about aggregate rates as a basis for auditing their own hospital referrals.

Referral rates are unsatisfactory indicators of quality because they can hide failures to refer as well as unnecessary referrals. Patients may be harmed if referral occurs too late and delay can lead to more major treatment being required at a later stage. There are various reasons for referring patients to specialist outpatient clinics (see box on next page). The complex factors influencing referral decisions contribute to the difficulties in reaching agreement on what is an appropriate rate of referral (see box on last page).

### Reasons for referring

Diagnosis  
Investigation  
Advice on treatment  
Specialist treatment  
Second opinion  
Reassurance for the patient  
Sharing the load, or risk, of treating a difficult or demanding patient  
Deterioration in general practitioner-patient relationship, leading to desire to involve someone else in managing the problem  
Fear of litigation  
Direct requests by patients or relatives

These criteria are hard to measure and routine data cannot provide answers. General practitioners, consultants, and patients often disagree about the purpose of referrals and differ in their assessments of appropriateness.<sup>10</sup> Despite a widespread assumption that high referring general practitioners tend to refer unnecessarily, studies comparing referrals from high and low referring doctors have not confirmed this.<sup>11 12</sup>

Despite the difficulties, collating and feeding back information about referral rates is an important first step in understanding patterns of demand for secondary care. Tracer studies to follow up patients referred with particular conditions or problems can also be illuminating,<sup>13</sup> but ultimately the need is for referral decisions to be based on an understanding of the cost effectiveness of different forms of treatment and evidence on the most appropriate setting for these to be provided. It should be a priority to commission reviews and efficacy studies on treatment options for the conditions most commonly referred to specialists. The top 15 problems account for 28% of all outpatient referrals<sup>14</sup> (see figure).

### Decision support

Attempts to modify referral behaviour have usually relied on the development of clinical guidelines designed to assist decision making about when a referral is appropriate. Good evidence exists that guidelines can help change clinical behaviour, but they are likely

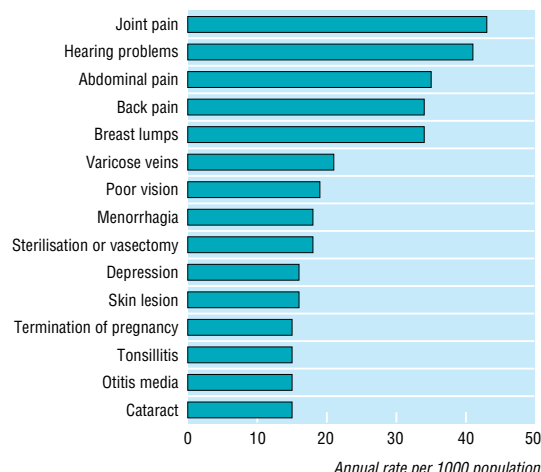
to have an impact on practice only if they are agreed by those responsible for implementing them.<sup>15</sup> The absence of evidence on the outcomes of referrals leads to widely differing opinions on when a referral is appropriate, which in turn makes it hard to achieve consensus on the need to implement referral guidelines. This type of local consensus development is difficult and time consuming, an activity for enthusiasts and therefore unlikely to have a major impact on the balance of care. Even if it were possible to eliminate referrals deemed to be inappropriate according to agreed guidelines, the effect on overall rates would probably be marginal at best.<sup>12</sup>

If achieving consensus among doctors is difficult, supporting shared decision making between doctor and patient may prove to be a more promising approach to managing demand at the interface. The development and use of information packages to allow patients to participate in decisions about their care is currently attracting interest. Research has shown that patients find it difficult to access the information they would like, that doctors consistently underestimate patients' desire for information, and that many, but not all, patients want to play a more active role in decision making about their care.<sup>16</sup>

Evidence from America suggests that fears that better informed patients will demand more treatment may prove groundless. An interactive video which provides patients with benign prostatic hypertrophy with evidence based information about the treatment options reduced demand for prostatectomy among American patients<sup>17</sup>; and patients who were better informed about the risks and benefits of screening for prostate cancer were less likely to want the tests.<sup>18 19</sup> In Britain, hysterectomy rates are strongly associated with educational level<sup>20</sup>: women with higher education, who tend to be more knowledgeable about treatment options, are much less likely to agree to hysterectomy than women without educational qualifications.<sup>21</sup> Patients may turn out to be more risk averse than their doctors, so investing in decision support systems for patients may prove to be more cost effective than developing yet more clinical guidelines.

### Financial incentives

The major thrust of government policy on primary care since 1989 has been the attempt to align clinical decisions and financial responsibility by providing incentives for general practitioners to provide more practice based services and by giving them the opportunity to manage secondary care budgets. In giving general practitioners financial incentives to perform minor operations, the government presumably hoped to remove some of the hospital workload. But evaluation of this policy showed no impact on the demand for hospital based minor surgery.<sup>22</sup> Instead general practitioners' willingness to perform these procedures seemed to encourage patients to come forward for treatment who would not otherwise have done so. The increased availability of equipment for near patient diagnostic testing in general practice has had a similarly disappointing impact, with investigation rates and costs continuing to increase.<sup>23</sup> Simply increasing the supply of services in primary care is not



Top 15 problems referred to specialist outpatient clinics

**Appropriate referrals are:**

*Necessary* for the particular patient, in the light of presenting symptoms, age, previous treatment, etc.  
*Timely*—neither too early nor too late in the course of the disease

*Effective*—the objectives of the referral are achieved  
*Cost effective*—the benefits justify the costs

enough to deliver the desired knock on effect on the demand for secondary care services.

Fundholding brought the costs of prescribing, outpatient referrals, and elective admissions under the control of general practitioners for the first time, giving them a financial incentive to modify their behaviour. The effect on referrals was not dramatic: rates continued to rise in fundholding practices, although the increase was slightly less steep than in non-fundholding practices.<sup>24</sup> Fundholders did use their financial leverage to achieve several beneficial changes, including investing in practice based services such as physiotherapy, counselling, and diagnostic equipment. They also negotiated direct access to many hospital diagnostic services, avoiding the need for specialist referral, but in general the effect has been to improve access for fundholders' patients, rather than changing the pattern of provision or modifying the demand for specialist services.

**Future developments**

In announcing their intention to give primary care groups control of almost all of the budget for hospital and community health services (compared with the 20% controlled by fundholders), this government has adopted an even more radical approach to demand management.<sup>25</sup> In theory both the incentive to deal with health problems within a primary care setting, and the scope to do so, will be much stronger. Larger primary care organisations covering populations of around 100 000 will contain a greater range of professional expertise, allowing for cross referral within the primary care group or trust, which may reduce the need for referrals to hospital based specialists. Unitary budget arrangements will encourage substitution of primary care services for secondary care. Eventually, primary care trusts may develop and run their own specialist services, thus blurring the boundaries

between primary and secondary care. The role of the gatekeeper looks set to undergo a dramatic change.

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*Fifty years ago***The new NHS: No patchwork for health centres**

The very name of health centre has a fascination for some people, and probably the greatest surprise they will experience after July 5 is to find the urban landscape very much as before instead of being decorated by 2,000 new buildings functioning as health centres, none of them more than a mile away from the house of anyone who lives in a town. An architect on the staff of the Ministry of Health was questioned on the subject at a recent conference and declared that there was no intention of making health centres out of patched-up buildings. The Minister had made it clear, he said, that in order to get his scheme launched properly health centres must be in new buildings, not existing

buildings adapted for the purpose. A private architect on the same occasion also said that it was imperative that health centres should be specially designed. To the British mode of life the health centre is a new creation and calls for a new architectural form. Even reference to America does not reveal much satisfactory information. But the Minister also holds that dwelling-houses must have precedence over health centres and even over maternity homes.

(*Heard at headquarters*, 26 June 1948, p 185 (suppl). See also editorial by Gordon Macpherson, 3 January 1998, p 6.)