

Sexual health—a Health of the Nation failure

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The Health of the Nation initiative was launched five years ago in July 1992 with the publication of a white paper.¹ The five key areas—coronary heart disease and stroke, cancers, mental illness, accidents, and HIV/AIDS and sexual health—were given priority and specific objectives, and targets were set. For HIV/AIDS and sexual health the objective was to reduce the incidence of HIV infection and of other sexually transmitted diseases, with specific targets related to gonorrhoea and conceptions among teenagers. These specific targets were to reduce the incidence of gonorrhoea among men and women aged 15-64 years by at least 20% by 1995 (from 61 new cases per 100 000 population in 1990 to no more than 49) and to reduce the rate of conceptions among girls aged under 16 by at least 50% by the year 2000 (from 9.5 per 1000 girls aged 13-15 in 1989 to no more than 4.8). A closer examination of the incidence of sexually transmitted diseases, HIV infection, and conception rates suggests that there is still a long way to go.

The targets

Gonorrhoea

Although the target for gonorrhoea has been achieved ahead of time (fig 1), the incidence was declining so rapidly before the target had been defined, and continued to do so afterwards, that it was almost certain to continue declining without any new initiatives. The decline was therefore probably a poor indicator of effective health promotion and improved service delivery by departments of genitourinary medicine.

Caution is needed when claiming success for the Health of the Nation programme. New cases of gonorrhoea among homosexual men have not shown a rapid decline (fig 2).² Cases of gonorrhoea seen in genitourinary medicine clinics in the Thames regions, reported as acquired through homosexual contact, declined in 1992 and 1993 but rose by 26% in 1994 and by a further 9% in 1995. Outside the Thames regions, levels have remained fairly stable. Some cases of gonorrhoea will be acquired through non-rectal and “safe sex”—namely, orogenital contact—and thus the number of cases of gonorrhoea alone, without site of infection, may mask adoption of safer sex practices. However, the numbers of cases of genital warts, chlamydial infections, and herpes also acquired through homosexual intercourse have not declined markedly between 1990 and 1994. The number of cases of genital warts increased in the Thames regions between 1990 and 1995 by almost 50%, from 572 to

Summary points

Gonorrhoea is a poor indicator of behaviour change, but despite this, new cases among homosexual men have not shown a decline since the Health of the Nation was launched in 1992

Genital herpes, warts, and chlamydial infections also show no decline in homosexual men and heterosexual men and women

The total number of newly reported cases of AIDS and HIV infection continues to rise, with substantial increases in 1996; new cases of HIV infection are particularly common in young homosexual men (aged less than 30 years)

Pregnancy has not declined in girls aged under 16 (currently 8.2 per 1000 girls); the Health of the Nation target is 4.8 by the year 2000

The Health of the Nation targets can be achieved only by clear, easily available sex education and contraceptive advice for young people and by programmes of education for particular groups such as young homosexual men and certain ethnic minorities. This needs to be combined with an infrastructure of open access service for sexually transmitted diseases

Government interdepartmental initiatives are required that recognise that poor sexual health can be driven by poverty and young people's social alienation

See editorial by Johnson et al and pp 1715, 1719, 1747, 1751

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853. Chlamydial and herpes infections have not shown a dramatic decline. Ascertainment bias will be a problem in judgments of the altering rates and incidence for sexually transmitted diseases, and possibly particularly so for chlamydial infections, which have received considerable attention in the lay and medical press, leading to an increase in chlamydia screening. These trends, however, do not support there having been major alterations in sexual behaviour during the Health of the Nation initiative.

In 1996 a study carried out in six genitourinary medicine clinics (two in London and four elsewhere) showed that homosexual men, despite knowing that they were HIV positive, continued to practise unsafe

sex.³ The proportion of homosexual and bisexual men with HIV infection and sexually transmitted disease who were aware of their HIV infection before the clinic visit increased from 40% in 1990 to 55% in 1993 (fig 3). The authors acknowledged that the targets for gonorrhoea as set in Health of the Nation have been achieved but commented that high levels of sexual ill health continued. They said that new targets for HIV prevention, particularly ones focusing on homosexual and bisexual men, are required.

Gonorrhoea also presents a public health problem among young people, especially young women and people from ethnic minorities. Young women aged 16-19 have higher incidences of gonorrhoea, chlamydia, and genital warts than other age groups and men, particularly in the Thames regions.⁴ Low and colleagues have highlighted the problem in ethnic minorities in a report of gonorrhoea in adults resident in the London Borough of Lambeth, Southwark, and Lewisham attending 11 departments of genitourinary medicine between January 1994 and December 1995.⁵ They showed that the high rates of gonorrhoea in 15-19 year old women (138 per 100 000) and in men (292 per 100 000), nearly three and six times greater respectively than the Health of the Nation target of 49 per 100 000. Rates of gonorrhoea were 12 times higher in black ethnic groups than in white people, with particularly high rates in black women aged 15-19 (1710) and black men aged 20-24 (1685). Low et al calculated that these high rates of gonorrhoea in non-white people rivalled those seen in poor urban

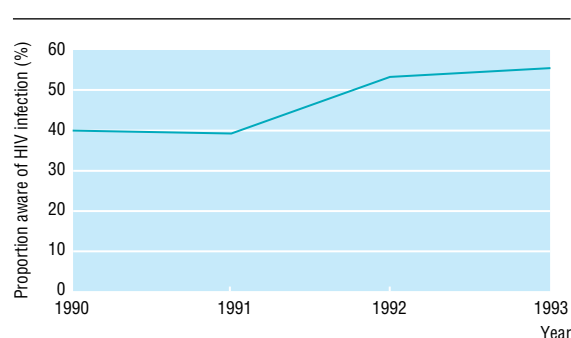


Fig 3 Proportion of homosexual and bisexual men with HIV infection and sexually transmitted disease who were aware of their HIV infection before their clinic visit (Catchpole et al³)

areas in the United States.” It has been indicated earlier that low national rates of gonorrhoea conceal what is occurring among homosexual men. Likewise, Low et al have shown how such generic rates mask an inner city epidemic that is associated with poverty and ethnic group. Similar increased rates of gonorrhoea have also been found in Leeds, where age specific incidence rates in black men and women were considerably higher than in white people.⁶

Thus, even though it is claimed that gonorrhoea targets have been achieved, these are too crude to show that considerable levels of new infections are occurring in homosexual men and ethnic minorities, particularly in the Thames regions. Also, gonorrhoea is not optimal for monitoring behaviour as its incidence is susceptible to vigorous case detection and contact tracing.

Other sexually transmitted diseases

Other sexually transmitted diseases confirm that no real reduction has been seen nationally and among heterosexual and homosexual people. Once again, ascertainment bias could affect these trends.

In England in 1995 the three commonest conditions seen in genitourinary medicine departments were anogenital warts (first presentation; 51 260 cases), chlamydial infection (39 289 cases), and genital herpes (first attack; 27 065 cases). These conditions show hardly any change since 1988; in fact, both genital warts and chlamydial infection have recently increased slightly.

If these other sexually transmitted diseases are used as proxy measures of sexual behaviour, it seems that the incidence of sexually transmitted diseases as a whole has not declined and has even increased slightly. The only caveat to this is that routine national data can be subject to ascertainment or treatment bias, or both. Other markers might be used to obtain good trend data on sexual behaviour. For example, antibody to herpes simplex virus type 2 is strongly related to sexual lifestyle and could be a suitable objective, serological marker of patterns of sexual behaviour in different populations.⁷ This underlines the fact that no data exist on trends in sexual behaviour and that we are continually using proxy outcome measures.

AIDS and HIV infection

The white paper did not set any specific target in reducing the incidence of HIV infection. The reason for this was the newness of the epidemic, as well as uncertainty about which would be the most robust

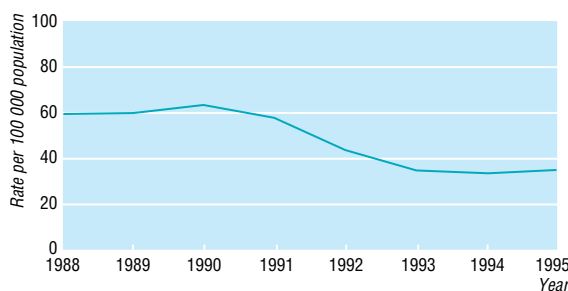


Fig 1 New cases of infection with *Neisseria gonorrhoeae* seen in genitourinary clinics in England, 1988-95

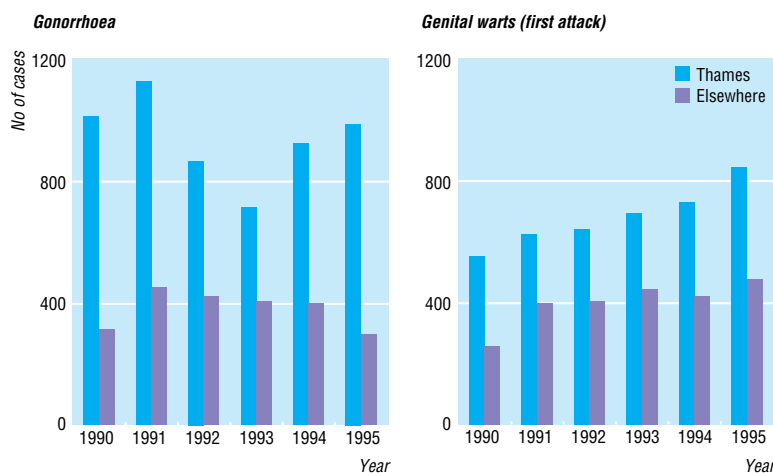


Fig 2 New cases of gonorrhoea and genital warts seen in genitourinary clinics in homosexual men, 1990-5

indicators. Although the number of reported cases of HIV infection has continued to increase since then, it gives no real sense of incidence or more recent changes in seroprevalence of HIV. National data of reported diagnosed AIDS and HIV infection give some indication of the year by year trends by means of exposure (table 1). These data show a decline in the proportion year by year of those infected by sharing injecting equipment and through homosexual intercourse, with a marked rise in infection among heterosexuals. Such trends must be interpreted with caution as they cover only those individuals who have opted to be tested or are presenting for care, or both. Despite this, the sheer volume of the new reports of cases of AIDS and diagnosed HIV infection is worrying. Altogether, 1862 cases of AIDS were reported in 1996, the highest annual total to date and 18% more than in 1995, when 1578 cases were reported. Likewise, 1996 saw the highest annual total to date of newly reported HIV infection (2986). The number of infections acquired through sex between men rose by 11% from

1474 in 1995 to 1634 in 1996—a considerable rise compared with previous years.⁸

A better indication of trends can be obtained from the unlinked anonymous HIV prevalence monitoring programme carried out in genitourinary medicine clinics and agencies for injecting drug users, and among pregnant women (table 2).⁹ HIV seroprevalence in homosexual men attending “high prevalence” genitourinary medicine clinics in the Thames region seems to be declining slowly (22.4 in 1990; 11.4 in 1995), although in the rest of the London clinics HIV seroprevalence among homosexual men has changed little. A more detailed study to explain the possible reasons for this decline in London was undertaken in one clinic. Much of the fall could be “accounted for by the changing pattern of care for HIV1 infected homosexual and bisexual men They have received care in specialist clinics alongside routine genitourinary medicine clinics and so are less likely to be tested for syphilis.”⁹ HIV seroprevalence in “high prevalence” clinics increased moderately from 1990 to 1995 both in heterosexual men (0.95% and 1.14% respectively) and in women. Among heterosexuals in other London clinics a similar increase has been found. This increase among heterosexuals is supplemented with data from the programme for anonymous testing of pregnant women—specifically, the infant dried blood spots (Guthrie test). This indicates a prevalence in inner London of 0.26% in 1995 compared with 0.14% in 1990 but unchanging low levels in the rest of England, with a prevalence of 0.12% for outer London (0.04% in 1990).

Even though the anonymous seroprevalence data show a decline in prevalence of HIV infection among homosexual men, this is not borne out by national data, new reports of HIV infection, or data from the national survey of prevalent diagnosed infections and mortality, which all show continuing substantial incidence of new infections, with the highest number of new infections occurring through sex between men.¹⁰ Thus the national data show continuing transmission. More detailed studies among homosexual men show no decline in HIV infection and sexually transmitted diseases.⁵ This is confirmed especially among young men (aged less than 30 years), in whom the incidence between January 1992 and April 1994 was 8.9 per 100 person years, compared with 7.5 between January 1988 and December 1989.¹¹ These data, as with gonorrhoea, are contrary to the crude national statistics, which suggest a decline.

Conception rates and unwanted pregnancies

The 1989 rate of conceptions among girls aged 13-15 (9.5 per 1000 girls) used by the Department of Health as its base represented the highest teenage conception rate in Europe. Teenage conceptions have slightly decreased since 1989, resulting in 1993 in the lowest level (8 per 1000) since 1982. Unfortunately, the latest figures (1994) show an increase again, to 8.2 (fig 4). These trends make it hard to see how the target of 4.8 will be achieved by the year 2000. However, with a fall in the age of first sexual intercourse, the rate among sexually active teenagers may be declining.

In England there is considerable geographical variation, with the highest rate of teenage conceptions (15.9) among girls in Barnsley, Doncaster, and southeast London. In contrast, eastern Surrey has par-

Table 1 Trends in distribution of exposure as percentage of HIV infected people in England, Wales, and Northern Ireland

Year (to end)	Sexual intercourse		Injecting drug use
	Between men	Between men and women	
1985	94	2	3
1986	84	5	10
1987	78	9	12
1988	75	12	12
1989	73	16	11
1990	71	19	8
1991	66	24	8
1992	62	28	7
1993	62	28	7
1994	61	30	7
1995	58	33	7
1996	64	30	6

Table 2 Prevalence of HIV-1 infection among attenders at two genitourinary medicine clinics in central London, 1990-5

Sex and exposure category* by year	Infected with HIV-1 (%)
Male, homosexual/bisexual:	
1990	22.4
1991	18.4
1992	20.5
1993	19.9
1994	17.6
1995	11.4
Male, heterosexual:	
1990	1.0
1991	1.2
1992	0.6
1993	1.9
1994	1.7
1995	1.1
Female, heterosexual:	
1990	0.5
1991	0.7
1992	0.8
1993	0.8
1994	0.7
1995	0.5

*Excluding injecting drug users.

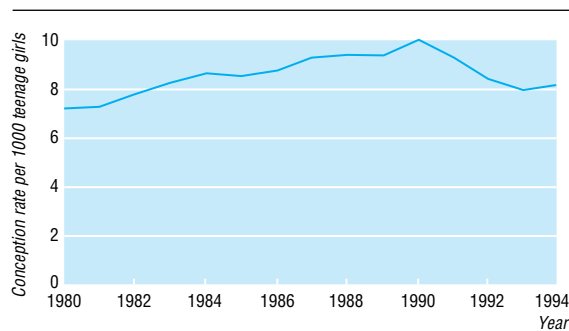


Fig 4 Teenage conception rates per 1000 teenage girls (aged 13-15 years), England

ticularly low rates (3.9). Districts with high underprivileged area scores, inner city areas, and other urban areas are more likely to have high rates of teenage conception. Studies show that the highest level of teenage births occur to the most socioeconomically disadvantaged women. The Office for National Statistics has shown in a longitudinal study that teenage birth rates among manual social classes were three times higher than among non-manual classes.¹² The reasons for unwanted teenage pregnancy are complex, with both socioeconomic factors and a failure in effective health education and contraceptive services for high risk girls playing a large part. It is thought that at least half of teenage pregnancies are unintended and 52% of conceptions end in abortion. Currently, Britain has the highest teenage birth rate in western Europe.

Discussion

The Health of the Nation is an important public health initiative and has for the first time established an agenda and targets for improving the health of the general population. The current lack of success in relation to achieving "good" sexual health is unfortunate, but such failures can indicate how we need to improve our approaches and strategies.

Health education and promotion have to be the foundation for improving sexual health. The high level of sexually transmitted diseases among young people,

some homosexual men, and ethnic minorities, and such high rates of teenage pregnancies, are indicators of both the failures and the way forward. Effective health education needs a two pronged approach, aimed in a general way at all young people and also at those identified as at particularly "high risk."

Young people have a right to sound, unbiased information that allows them to make informed choices before they have sexual intercourse. We have the highest teenage rate of conception and termination in Europe, illustrating the failure of our education programmes. The 1993 Education Act has created anomalies around sex education and contraceptive advice in schools, which present barriers to the dissemination of information to all young people. Pupils have their own rights with regard to education about sex and personal relationships, and sex education must become part of the national curriculum. That the provision of sex education in schools will bring forward the onset of sexual experience is not borne out by the evidence.¹³

Attempts to withhold information on the basis of a particular agenda of family values and morality have resulted in large numbers of young people not protecting themselves against sexually transmitted diseases and unwanted pregnancy. Socioeconomically disadvantaged people have the highest morbidity in relation to sexual health. Why should teenage birth rates be three times greater among manual social class groups than among non-manual groups? As with cancer, depression, heart disease, and other diseases, this will only be understood and tackled once health is approached across government departments and the effect of poverty and social alienation on health are acknowledged.¹⁴ Focused and targeted education that recognises the needs of specific groups is also required. The Department of Health has recognised the problem of continuing high levels of sexually transmitted diseases and HIV infection in homosexual men, especially young ones, and has commissioned the Terence Higgins Trust to mount extensive campaigns. Local health promotion units in London also recognise the need for targeted health promotion for this group. Less recognised and easily solved is the issue of high levels of sexually transmitted diseases in certain ethnic minorities; we need to talk about what is happening without apportioning blame or stigmatising groups in society. The needs of ethnic minorities with regard to sex education and services for sexually transmitted diseases and HIV infection is of urgent concern and should be acknowledged, described, and tackled. Delivery of general health education to all young people must incorporate a recognition of the considerable influences of poverty and social deprivation on health.

Primary prevention through education and health promotion must be complemented by the provision of services for sexually transmitted diseases and contraception. These services have been largely transformed as a result of extra resources made available through ringfenced money for AIDS/HIV services; recognition by the Department of Health of the pivotal role played by the specialty in caring for patients with sexually transmitted diseases and HIV infection; and one to one health promotion and condom distribution. It is encouraging that clinics are used by a wide demographic spectrum of the population and that



PETER ARRELL/IMPACT

The Health of the Nation targets for sexual health can be achieved only through easily available sex education and contraceptive advice for young people

they attract those at high risk of infection.¹⁵ The service has been at the centre of providing clinical care and health promotion for those with HIV infection and AIDS and those uninfected but with concerns and requiring testing. The decision to disaggregate services for HIV infection and AIDS is likely to destabilise this model, which is based on open access and not area of residence—an important ingredient of offering rapid, open door services to clients.

The Health of the Nation has so far failed to deliver. The agenda for success is fourfold. Firstly, it requires clear, easily obtainable sex education and contraceptive advice for young people before they start to have sexual relationships, with the ability of schools to give this without fear or hindrance from the Department of Education. Secondly, continuing and increasing programmes are needed for particular groups such as young homosexual men and certain ethnic minorities. Thirdly, governmental interdepartmental approaches should recognise that “poor” sexual health can be driven by poverty and young people’s sense of social alienation and worthlessness. Finally, the infrastructure of a good service for sexually transmitted diseases exists but needs to be protected, nurtured, expanded, and funded.

Conflict of interest: None.

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HIV and AIDS, other sexually transmitted diseases, and tuberculosis in ethnic minorities in United Kingdom: Is surveillance serving its purpose?

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Summary

Experience of disease differs across ethnic groups, and ethnicity is a relevant personal characteristic for descriptive epidemiology. Information about ethnicity and country of birth is omitted from the routine notification of many diseases. HIV infection and AIDS, other sexually transmitted diseases, and tuberculosis have different incidence rates in different ethnic groups in the United Kingdom. Omission of ethnic data from surveillance activities allows such differences in incidence to go undetected and unaddressed. Surveillance data that included ethnic details could guide interventions to reduce inequalities in health between different subpopulations.

Introduction

Disease surveillance—the routine collection, analysis, and dissemination of data about the distribution of diseases—is essential for the planning and provision of services for preventing, treating, and controlling diseases.^{1,2} Surveillance data describe the occurrence of diseases in time, place, and person. In addition to

age and sex, relevant personal characteristics may include ethnic group and country of birth, although these are omitted from many surveillance activities.

Three public health problems with wide variation in incidence and prevalence across subpopulations in the United Kingdom are HIV infection and AIDS, other sexually transmitted diseases, and tuberculosis. We discuss the need for epidemiological surveillance to incorporate data on ethnicity for more effective interventions for these unequally distributed diseases.

Ethnic minority groups in United Kingdom

The 1991 census was the first to document the ethnic distribution of the population of the United Kingdom. About 5.5% of the population belongs to self defined ethnic minority groups (table 1),³ although this may be an underestimate because of incomplete registration.⁴ The distribution of people from minority groups throughout the country is uneven, with most living in large urban centres.

In the following discussion we adhere whenever possible to the names for ethnic groups defined by the Office of Population Censuses and Surveys for the

See editorial by Johnson et al and pp 1715, 1719, 1743, 1751

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1991 census³ and use other terms only to accommodate original data cited.

Disease, race, ethnicity, and surveillance

Ethnicity is a heterogeneous concept. It is not synonymous with race, and, for public health purposes, it should be considered in sociological rather than biological or anthropological terms.^{5,6} Epidemiological analyses based on ethnic data are open to criticism. Differences in the incidence of disease among ethnic groups may mask differences in socioeconomic factors that could be more important determinants of incidence than ethnicity.⁷ Also, self assigned ethnic groups can change over time, resulting in non-comparability of routine sources of data.⁸ Surveillance data can summarise ethnic differences in experiences of disease, which, without effective interventions, indicate wide and sometimes increasing inequalities,^{9,10}

leading to further marginalisation of vulnerable groups. Misuse of ethnic data could lead to breaches of confidentiality, increased stigmatisation and discrimination, and proposals for inappropriate disease control measures.

On the other hand, failure to address ethnic differences may have severe consequences for public health. Ignoring ethnicity in surveillance may result in disparities in health going unnoticed, weakening efforts to prevent disease and giving false reassurance. For example, since non-whites contribute only 5.5% of the British population,³ overall public health targets for sexually transmitted diseases defined in the *Health of the Nation*¹¹ could be met while unchanging or worsening trends in minorities went undetected.

Sensitivity about collecting ethnic data may be compounded by official reticence to investigate minority health issues. There is little political pressure to address such problems, and publicity about differences in disease incidence among population subgroups reflects unfavourably on official services.

Table 1 Ethnic groups in the United Kingdom (data from 1991 census³)

Group	No of people	Percentage of population	
		Total population	Non-white population
Black:	890 727	1.6	29.5
Black Caribbean	499 964	0.9	16.6
Black African	212 362	0.4	7.0
Black other	178 401	0.3	5.9
Asian:	1 834 117	3.3	60.8
Indian	840 255	1.5	27.9
Pakistani	476 555	0.9	15.8
Bangladeshi	162 835	0.3	5.4
Chinese	156 938	0.3	5.2
Asian other	197 534	0.4	6.6
White	51 873 794	94.5	
Other	290 206	0.5	9.6
Total	54 888 844		

Table 2 Crude incidence of AIDS in adults and children in United Kingdom in 1994-5 by ethnic group

Ethnic group	Population size*	Cases of AIDS	
		No of cases†	Annual incidence (per 100 000)
Adults (aged ≥15 years)‡			
Black African	152 838	298	97.5
Black Caribbean	396 253	69	8.7
Black other	91 920	17	9.2
White	42 330 551	2241	2.6
South Asian	979 314	38	1.9
Children§			
Black African	59 524	55	46.2
All other	10 313 682	26	0.13

*Data from 1991 census.³

†Excludes 537 adults and 5 children of unknown ethnic group. Data from PHLS AIDS Centre et al.¹⁵

‡Includes all cases of AIDS except those resulting from mother to child transmission.

§Restricted to children infected through mother to child transmission.

Table 3 Incidence of AIDS resulting from presumed heterosexually acquired HIV infection in African and non-African adults (aged ≥15 years) in United Kingdom in 1994-5

Ethnic group	Population size*	Cases of AIDS	
		No of cases†	Annual incidence (per 100 000)
Black African	152 838	285	93.2
Other	44 362 800	241‡	0.27

*Data from 1991 census.³

†Data from PHLS AIDS Centre et al.¹⁵

‡Excludes 98 AIDS cases of unknown ethnic group.

Surveillance for HIV infection and AIDS

Surveillance for HIV infection and AIDS is conducted by the Public Health Laboratory Service Communicable Disease Surveillance Centre and the Scottish Centre for Infection and Environmental Health. Data are derived from voluntary confidential reports.¹² Information is also provided by unlinked, anonymous testing for HIV infection in various groups, including childbearing women and attenders at sexually transmitted disease (genitourinary medicine) clinics¹³ and by monitoring results from voluntary tests for HIV in selected laboratories. Surveillance reports are published on a monthly basis, with more detailed quarterly tables being circulated to a restricted readership.

Surveillance of AIDS cases, which has included ethnic status since 1989 (white, black, Asian or oriental, other), provided indirect evidence of the high proportion of cases in black Africans—the largest ethnic group among people with AIDS who were thought to have acquired HIV infection from heterosexual sex with a partner abroad.¹⁴ The categories for ethnic groups specified by the Office of Population Censuses and Surveys have been adopted for surveillance of AIDS cases since 1994.¹⁵ Data on ethnicity are not available for the unlinked anonymous studies of seroprevalence except for limited information on geographic origin of participants in surveys of sexually transmitted disease clinics that have recently been published.¹³

Table 2 shows the crude incidence of AIDS in adults and children in the United Kingdom by ethnic group, and table 3 shows the crude incidence of AIDS from presumed heterosexually acquired HIV infection in black African and non-African adults. The higher crude incidence of AIDS in adults of black minority groups are confounded by age and residence; minority populations are younger and a greater proportion live in greater London, where the incidence of AIDS is higher than in the rest of the United Kingdom.

The age adjusted relative risk for AIDS in black African adults in 1994-5 was 20 compared with non-African adults (indirect standardisation to age specific rates of AIDS in the whole United Kingdom; data not shown). For black African children, the annual

incidence of AIDS was 355 times greater than in all other children combined, reflecting ethnic differences in rates of heterosexually acquired HIV infection. The age adjusted relative risk for AIDS from presumed heterosexually acquired HIV infection in black African adults in 1994-5 was 154 compared with non-Africans (indirect standardisation; data not shown).

Surveillance data for AIDS in adults reflect much earlier patterns of HIV transmission. Our inability to link ethnic status and country of birth to data on the seroprevalence of HIV and trends in prevalence limits our understanding of recent patterns of heterosexual transmission of HIV. The current unlinked anonymous serosurveillance cannot detect changes in specific subgroups; if HIV infection were introduced, for example, by heterosexual travellers returning from the increasingly affected Indian subcontinent, this would not be recognised in a timely fashion. There are no mechanisms for differentiating changes in rates of HIV infection in indigenous versus foreign born people, for following trends in specific subgroups, or for targeting preventive measures to those ethnic groups in which new cases of HIV infection are appearing.

At present, groups most in need of HIV counselling and testing for provision of zidovudine in pregnancy to prevent transmission from mother to infant¹⁶ are defined by the ethnicity of paediatric AIDS cases or by other indirect means.¹⁷ Evaluation of services for women most at risk of infecting their infants is handicapped,¹⁸ and predicting the need for prevention and treatment of paediatric HIV infection is restricted because the blinded testing of childbearing women is conducted without ethnic data. Since ethnicity is now routinely recorded in data from surveillance of AIDS cases there is no obvious reason why this is not also done for serosurveillance.

Surveillance for sexually transmitted diseases

Data on sexually transmitted diseases are provided quarterly from sexually transmitted disease clinics in England and Wales to the Department of Health (since July 1996 to the Public Health Laboratory Service Communicable Disease Surveillance Centre) by means of specific reporting forms (KC60).¹⁹ Aggregated information is transmitted about disease episodes, diagnosis, sex of affected people, and, for some diagnoses, age and homosexually acquired infections. From 1996 the data will be compiled and analysed by the Communicable Disease Surveillance Centre, which also collates laboratory reports and results of other studies and surveys. Data on ethnic group are not routinely collected. Little information exists about sexual behaviours and attitudes of people from minority ethnic groups, and the national survey of sexual attitudes and lifestyles included too few minority respondents to allow detailed ethnic specific analyses.²⁰

Sexually transmitted diseases are distributed heterogeneously in the population, with the highest rates occurring in London and the south east.²¹ Low et al showed that the incidence of gonorrhoea in south London was eight to nine times higher in non-whites (all black, Asian, and other non-white groups combined) than in whites in all age and sex strata, and these ethnic differences persisted after adjustment for socioeconomic status.²² The disproportionately high incidence of gonorrhoea in black heterosexual men is

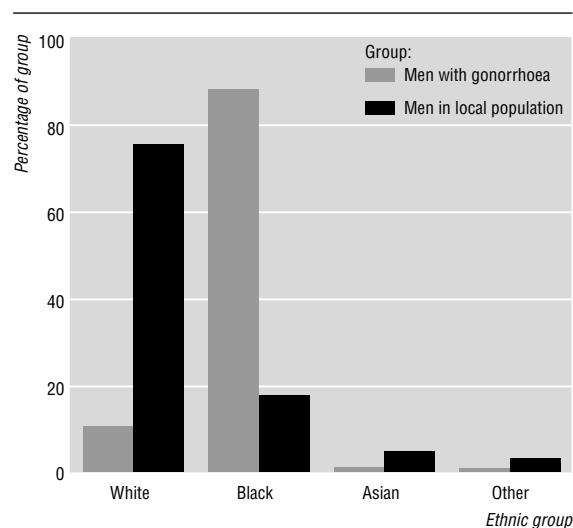


Fig 1 Ethnic distribution of heterosexual men with diagnosis of gonorrhoea in an inner London sexually transmitted disease clinic and that of local population of men aged 15-59 during 1990-2. (Data on cases of gonorrhoea from Dr David Barlow, St Thomas's Hospital, personal communication; data on local population in Lambeth, Southwark, and Lewisham from 1991 census³)

illustrated by figure 1, which shows the ethnic distribution of heterosexual men treated for gonorrhoea at an inner city London hospital and that of male residents of the surrounding area. Increased rates of gonorrhoea have also been reported for Afro-Caribbean people living in Leeds, among whom peak age specific incidence rates were 12 times higher for women and 54 times higher for men than among white people.²³

Sexually transmitted diseases increase the risk of transmission and acquisition of HIV infection in women and men,²⁴ but otherwise cause severe complications predominantly affecting women. These include pelvic inflammatory disease, recurrent pelvic pain, infertility, ectopic pregnancy, increased fetal wastage, and increased risk of carcinoma of the cervix.²⁵ Since the highest rates of sexually transmitted diseases in women occur in non-white females aged 15-19 years, the severe but unquantified complications of sexually transmitted diseases must be suffered disproportionately by young black women in inner city areas.

Lack of data on ethnicity and country of birth prevent targeting of efforts for preventing sexually transmitted diseases such as strengthening of treatment services, more intense tracing of contacts, and sexual health education for the heavily affected groups. Data for specific subgroups would also help for advising travellers from minority groups who may be potentially exposed to HIV infection overseas.

Surveillance for tuberculosis

Reporting of tuberculosis by clinicians is performed on a statutory basis to local consultants in communicable disease control, who provide weekly returns to the Office of National Statistics. Additional reports come from laboratories and from death registrations. Definitive data on tuberculosis rates are published by the Office of National Statistics. Information reported by clinicians includes the age and sex of patients, date of diagnosis, and site of disease. Data on ethnicity are examined only in national surveys of notified cases undertaken on a five yearly basis. The last survey, con-

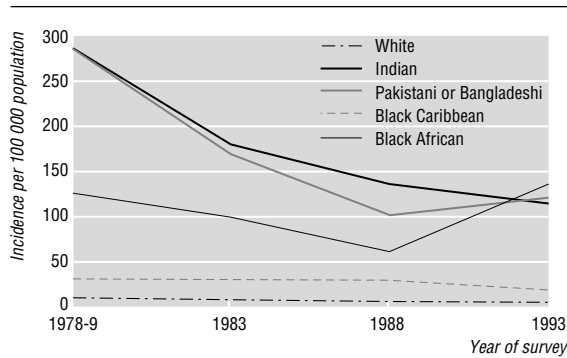


Fig 2 Incidence of tuberculosis by ethnic group in England and Wales from five yearly surveys during 1978-93 (data from Ormerod²⁷)

ducted in 1993, also aimed to examine the role of HIV infection in the epidemiology of tuberculosis.²⁶

Ormerod has summarised the data from these five yearly surveys, including results from 1993.²⁷ Figure 2 shows the disproportionately high rates of tuberculosis in different non-white groups and the changing trends. Between 1988 and 1993 the incidence of tuberculosis rose by 20% in Pakistanis and Bangladeshis, and by 124% in black Africans. In 1993 the crude incidence in black Africans was 135/100 000, 31 times higher than in whites.

HIV infection is the strongest risk factor known for tuberculosis.²⁸ Because so few patients with tuberculosis are tested for HIV infection it is currently impossible to know what proportion of cases of tuberculosis in the United Kingdom is attributable to HIV, both overall and within specific minority groups. Tuberculosis accounted for 27% of initial diagnoses of AIDS in black Africans in London compared with 5% in non-Africans²⁹; the minimum annual incidence of tuberculosis associated with HIV in black Africans is thus 27% of the incidence of AIDS (table 2). At least 19% of tuberculosis cases in black Africans are therefore likely to be in HIV infected people ((27% of African incidence of AIDS/African incidence of tuberculosis) × 100).

The increased incidence of tuberculosis in specific subpopulations went undetected between the five yearly surveys because ethnic specific data were not collected routinely. Current surveillance practice would not detect the emergence of HIV associated tuberculosis in other populations at risk such as Asians, nor changes in tuberculosis epidemiology such as an increasing proportion of cases independent of HIV infection in foreign born people, as has occurred in the United States.³⁰ There have been repeated calls for routine notification of ethnicity and country of birth for all persons with tuberculosis^{31 32} and the offering of HIV testing to all affected people,³³ and collection of data on ethnicity is included in proposals for enhanced routine notification of tuberculosis in England and Wales (J Watson, personal communication). Data on ethnicity were important in defining and evaluating the response to epidemic tuberculosis, much of it multidrug resistant, in New York City.³⁴

Discussion

Sexual behaviour and sexually transmitted diseases fuel the transmission of HIV,²⁴ which leads to

opportunistic illnesses that include tuberculosis.²⁸ To understand incidence rates, trends, and interactions of these diseases, we need surveillance data that take account of relevant descriptive information, including ethnicity and country of birth. It is also important that data sets for specific diseases can be matched in a confidential fashion (such as on soundex code³⁵ and date of birth) to study epidemiological associations.

The differences in disease rates between ethnic groups in the United Kingdom are of similar size, and in some cases greater, as disparities between blacks and whites in the United States, where surveillance routinely documents ethnicity.⁵ The roots of these inequalities are complex and include exposure to infections abroad, socioeconomic disadvantages, unequal access to health services, and other factors such as behaviour. The size of these disparities in health indices in the United Kingdom may cause surprise and would be widely discussed if they applied to other essentials such as education, housing, or employment.

Surveillance systems in the United Kingdom are sometimes failing to capture and communicate differences in disease incidence of more than 20-fold in different subpopulations. Despite the potential for misuse or misinterpretation of ethnic data, descriptive epidemiology for public health must be objective and complete. The development of interventions to reduce health inequalities among different ethnic groups in the United Kingdom—as for HIV infection and AIDS, other sexually transmitted diseases, and tuberculosis—requires data on ethnicity and country of birth to be included in routine surveillance activities.

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Is research into ethnicity and health racist, unsound, or important science?

Raj Bhopal

Summary

Much historical research on race, intelligence, and health was racist, unethical, and ineffective. The concepts of race and ethnicity are difficult to define but continue to be applied to the study of the health of immigrant and ethnic minority groups in the hope of advancing understanding of causes of disease. While a morass of associations has been generated, race and ethnicity in health research have seldom given fundamental new understanding of disease. Most such research is "black box epidemiology." Researchers have not overcome the many conceptual and technical problems of research into ethnicity and health. By emphasising the negative aspects of the health of ethnic minority groups, research may have damaged their social standing and deflected attention from their health priorities. Unless researchers recognise the difficulties with research into ethnicity and health and correct its weaknesses, 20th century research in this subject may suffer the same ignominious fate as that of race science in the 19th century.

Introduction

Epidemiology aids health policy and planning and helps discover the laws governing health and disease. As with other sciences,¹⁻³ epidemiology has been beguiled by ethnicity and race^{4,5} and has become racialised. Racialisation consists of the idea that race is a primary, natural, and neutral means of grouping humans and that racial groups are distinct in other ways, such as their behaviours.⁶ Racialism is the belief in the superiority of some races. In this paper I draw lessons

from the racialised research of the 19th century, discuss the terms race and ethnicity, and analyse the value of and problems with research into ethnicity and health.

Research on race: a historical look

Racialised research has an inglorious history: scientists have been besotted by race and ethnicity, while politicians and social commentators have encouraged them.¹⁻¹¹ In the 19th century scientists ranked races on their biological and social worth, particularly using measurements of the size and shape of the head and the contents of the brain to measure intelligence (northern European groups always ranked top).⁷ Such research was used to justify slavery, imperialism, anti-immigration policy, and the social status quo.^{1 6-12} One underlying value of this research was that biology determined social position—that is, biological determinism. The power behind scientific racism is shown by the prowess of some of the researchers, who included Louis Agassiz, Francis Galton, Paul Broca, and John Down (see Gould⁷ for details of their contributions).

Medical practitioners contributed to racialised science. "Diseases" such as drapetomania (irrational and pathological desire of slaves to run away) and dysaesthesia Aethiopica (rascality) were invented.⁶ To quote a textbook, "the pelves becomes increasingly lower and broader the more civilised the race from which it is obtained," and, "coloured children weigh considerably less than white, a fact which, in large cities at least, is indicative of the physical degeneration which characterises the race."¹³ The importance of race research and the innate inequality of races was considered self evident, and few scientists questioned whether their work was ethical.^{1 2 7 11}

See editorial by Johnson et al and pp 1715, 1719, 1743, 1747

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Current views on race and ethnicity

Humans are one species: races are not biologically distinct, there is little variation in genetic composition between geographically separated groups, and the physical characteristics distinguishing races result from a small number of genes that do not relate closely to either behaviours or disease.² Massive effort over 150 years to classify races has largely failed, though we use crude classifications which trace their heritage to Linnaeus, based on the division of populations as *Homo Afer* (synonyms, black, Negro, Negroid), *Homo Europaeus* (synonyms, white, Caucasian, Caucasoid), *Homo Asiaticus* (Mongoloid), and *Homo Americanus* (American Indian). Variants of these classifications also have a grouping for Australian aborigines.^{2 3 12 14} Most complex classification has been forgotten.²

Haddon and Huxley recommended that the race be replaced by ethnic type,¹ an idea enjoying much support^{4 5 15 16} and some criticism.¹⁷ None the less, race remains important in modern thinking, though increasingly it reflects geographical, social, and class divisions rather than biological ones.^{16 18 19} The term race is often used alongside ethnicity.^{4 6} While arguing for abandoning race, Huth did not see problems with ethnic identification.¹⁵

Ethnicity

The taboo surrounding research into race,^{1 2 11} greater understanding of social and cultural factors in health and disease,^{4 6 15 17 19 20} and the need to describe the health and health care of people from ethnic minorities created the spur for new terminology,^{16 17} and ethnicity is at the fore. In the context of health it means a group that people belong to because of shared characteristics, including ancestral and geographical origins, cultural traditions, and languages.^{5 6 15 17 19} Ethnicity is a complex idea that has become a euphemism for race, and writers have not separated the concepts clearly.^{5 21 22} For example, a paper by Hopkinson constructed around race uses the ethnic groups as classified by the census.²² Inability to use a clear definition of ethnicity echoes the past, when a

consensus on the definition of race could not be achieved but was too important an idea to discard.¹

Ethnicity is a fluid concept and depends on context. For practical and theoretical reasons, the current preference is for self assessment of ethnicity.^{17 19} People change their self assessment over time, as is their prerogative. The alternatives include skin colour, birthplace, ancestry, names, geographical origins, or a mixture of these. Ethnicity is not measurable with accuracy or validity.¹⁷ The question on ethnicity in the 1991 census worked only in that people were willing to answer it, and the classification was arbitrary.

Research into ethnicity and health

Expectations of researchers

Scientists want to discover the causes and processes of disease, while health policy makers and planners want to meet the needs of ethnic minority groups. Historical analysis reveals motives such as a wish to reverse the health and social disadvantages of ethnic minority groups, curiosity about racial and ethnic variation, and an interest in ranking races and ethnic groups.

Studies of migrant groups help to separate the effects of environmental and genetic factors.^{4 5 20 23 24} Leaving aside problems of bias and the difficulties of making comparable measurements across long distances, studies of migration could be a powerful means of generating and testing hypotheses. When both migrants and their offspring are compared with other ethnic groups the design is enriched. Changing circumstances within and between generations in different migrant and ethnic groups can be linked to changing health.

The message from most publications on ethnicity and health is that this opportunity must not be missed.^{4 5 20 23 24} In *Biocultural Aspects of Disease* Henry Rothschild offered ethnicity as a paradigm for understanding diseases of complex aetiology.²⁰ Marmot and colleagues' report *Immigrant Mortality in England and Wales* opens with the statement: "Studies of mortality of immigrants are useful for pointing to particular disease problems of immigrants, investigating aetiology and validating international differences in disease."²³

Black box epidemiology

Does such research discover aetiology? Thousands of associations between racial and ethnic groups and disease have been published with the promise that they will help in elucidating aetiology. The data are usually published in the style of aetiological epidemiology to show relative frequency of disease by means of standardised mortality ratios or similar measures (see Senior and Bhopal¹⁷ for a fuller discussion). Few variations have been explained in a way that gives new insight into aetiology.^{4 5 19 23}

Most ethnicity and health research is "black box" epidemiology—what Skrabanek described as epidemiology where the causal mechanism behind an association remains unknown and hidden ("black") but the inference is that the causal mechanism is within the association ("box").²⁵ Skrabanek argued that science must open and understand the black box. He cited a review of 35 case-control studies of coffee drinking and bladder cancer which failed to provide important information and likened such epidemiology to repeat-



Ethnicity is a fluid concept. At Ellis Island millions of Europeans swapped European identities for American ones

edly punching a soft pillow. David Savitz defended black box epidemiology, particularly for exploring new subjects, arguing that epidemiology may not be needed when other sciences have elucidated causal paths.²⁶

Many studies have investigated patterns of cancer in immigrant, racial, and ethnic minority populations.^{4 23 24 27-31} Marmot and colleagues' analysis of cancers in immigrants in England and Wales found many differences, but, overall, immigrants had lower cancer rates.²³ The researchers' aetiological focus is illustrated by their emphasis on causal hypotheses, of which many of interest were developed. They noted that international data for cancers of the large intestine and female breast showed high correlations with heart disease and fat consumption. Their observation of low rates of these two cancers in Indian immigrants but high rates of heart disease led them to question the assumption that dietary fat was the common factor in cancer of the large bowel and breast, and they queried whether the high fibre content of the Indian diet modified the effect of fat on large bowel cancer.

Balarajan and colleagues' study of immigrant populations by region of origin also found many differences from which they developed aetiological hypotheses, and they urged that data on ethnicity and health be used to develop more.²⁴ Donaldson and Clayton found numerous ethnic differences in patterns of cancer registration in Leicestershire health district.²⁸ The authors rightly concluded: "The results indicate the need for formal epidemiological study to test specific aetiological hypotheses which may account for these apparent differences." This type of work has been repeated—for example, by Barker and Baker in Bradford,²⁹ by Matheson et al in Scotland,³⁰ and by Balarajan and Bulusu.³ Similar work has been done on children. The conclusion is almost invariable—differences exist and need detailed study.²⁷

However, there has been little progression beyond this black box epidemiology, since few studies have explored the ideas generated.²⁷ One exception is the study of diabetes and insulin resistance in south Asian communities as the possible basis of their surprisingly high rates of coronary heart disease. Marmot et al observed that "The high rate of diabetes could contribute to the high rate of ischaemic heart disease in Indians. This explanation would then pose the problem of why immigrants from the Caribbean, with their high rate of diabetes, do not also have a high rate of ischaemic heart disease."²³ This question is being pursued tenaciously.³²

We need to move from the repetitious demonstration of disease variations that have already been shown in research into ethnicity and health or in work on international variations or in social and sex variations—that is, stop punching the pillow²⁵—and move to new territory.²⁶ Studies of ethnicity and health should be able to provide models and contexts for advancing aetiological knowledge if questions for research are clearly articulated and pursued with sound methods.

Is such research unsound epidemiology?

Much research into ethnicity and health is unsound.¹ The key variables of ethnicity and race are vaguely defined, and the underlying concepts are poorly understood and hard to measure.¹⁷ There is inconsistent use of terminology: for example, Asian, white, Cau-

Basic errors in epidemiological studies of ethnicity

- *Inventing ethnic groups*—A study labelled a group as Urdus on the basis of the language spoken, thus inventing an ethnic group³⁵
- *Not comparing like with like*—Inner city populations are different from whole population samples,³⁶ but studies of ethnicity and health continue to focus on them for convenience—as in the recent Health Education Authority survey, in which the comparison population was not an inner city sample³⁷
- *Lumping groups together*—A paper on smoking and drinking habits in British residents born in the Indian subcontinent did not describe sex and regional variations, creating the impression that smoking and drinking were unimportant in the "Asian" population.³⁸ As has been shown,³⁷ and long known by people knowledgeable about populations of Indian origin, smoking and drinking are important problems in some subgroups. Heterogeneity in the prevalence of disease and risk factors has even been shown among different Hindu castes in one city in Tanzania.³⁹ Yet journals still publish comparisons as crude as white and non-white.¹⁹ The British attitude before 1940 was to blur the racial specificity of colonial populations¹¹
- *Not adjusting for confounding factors*—Inferences can change radically once interacting and confounding factors are accounted for: Lillie-Blanton et al challenged the observation that crack smoking was commoner in African Americans and Hispanic Americans and showed that once social and cultural factors were accounted for there were no differences⁴⁰

casian, and Hispanic are common terms in research but have inconsistent and non-specific meanings.³³ There are difficulties in collecting comparable data across cultural groups: for example, do questions on stress or alcohol consumption have equivalence across cultures? There are problems in recruiting representative and comparable population samples.

Data need to be adjusted for known confounding variables and interpreted with the recognition that adjustment is probably incomplete. These issues have been detailed elsewhere.^{17 34} Rigour is needed for sound epidemiology in ethnicity and health, but the literature is littered with elementary errors (see box).

There is little evidence that criticism of the methods and concepts of research into ethnicity and health^{17 19 34 41-45} has paid dividends. For example, while Marmot and colleagues' analysis of mortality in immigrants attempted to analyse ethnicity because country of birth was too crude,²³ an update using mortality data for 1980-2 did not even though there were then far more British born people in ethnic minority groups.²⁴

While methodological errors may be apparent, it is more difficult to judge whether the research questions are valuable and whether the conceptual basis of the research (largely comparative) is sound.

Harm from such research

Osborne⁴⁶ answered yes to the disturbing question of whether race based research in medicine is racist. His review cites projects that focused on differences between blacks and whites in diseases associated with promiscuity, underachievement, and antisocial behaviour and which implied that the underlying explanation lay in race rather than class, lifestyle, or socioeconomic status.

Perceiving ethnic minorities as unhealthy—The perception that the health of ethnic minority groups is poor⁴⁷ can augment the belief that immigrants and ethnic minorities are a burden. The perception is at least partially false for some migrant groups, especially men, as shown in table 1.^{23 24} There are variations by cause of disease, but overall standardised mortality ratios hover around the average for England

Table 1 Standardised mortality ratio (standardised to population of England and Wales) for all causes of death in England and Wales among people aged 20-69 by country of birth

Country of birth	Men	Women
Indian subcontinent		
During 1970-2*	99	111
During 1979-83†	106	105
Caribbean Commonwealth countries		
During 1970-2*	95	131
During 1979-83†	79	105
African Commonwealth countries		
During 1970-2*	133	144
During 1979-83†	109	114

*Data from Marmot et al.²³†Data from Balarajan and Bulusu.³¹

and Wales. Bearing in mind inaccuracy in the denominator, the fact that those born in Britain have not usually been included, and that some deaths and illnesses are among visitors rather than residents, it is not clear whether the true rates are higher in most ethnic minority groups. The perception of poorer health arises from a focus on differences where the excess of disease is in the ethnic minority population.^{17 47} For many causes, morbidity and mortality are lower.

The focus on a few "ethnic" problems (such as high birth rates, "Asian rickets," the haemoglobinopathies, and congenital defects said to be linked to consanguinity) has been at the expense of major problems.^{17 48} Health education material for ethnic minority groups in the 1980s tackled birth control, lice, child care, and spitting, but there was nothing on heart disease and little on smoking and alcohol.⁴⁸ The idea of a package of specific "ethnic" diseases has echoes in history: Negro susceptibility to particular diseases such as leprosy, tetanus, pneumonia, scurvy, and sore eyes was instrumental in "branding blacks as an exotic breed," and the differences were explained by nonsensical hypotheses on causation.⁴⁹

The comparative approach—Most research into ethnicity and health (including mine) is based on the comparative paradigm and presents data using the "white" population as the standard.¹⁷ Inevitably, attention is focused on diseases that are commoner in ethnic minority groups than in the white population, thereby displacing problems like cancer and respiratory disease that are very common but less so than in the white population from their rightful place as high priorities for ethnic minority groups. A bibliography by Karmi and McKeigue stated: "Although cancer is one of the key areas specified in the Health of the Nation white paper, it is not especially relevant to ethnic groups in Britain."⁵⁰ This shows the danger of the comparative approach. Cancers are a major cause of death and disability in ethnic minority groups, and there is an opportunity to prevent some cancers reaching the high levels seen in the general population.²⁷

Ignoring quality of services—The implications of comparative research, including the risk of ethnocentrism, is discussed in more detail elsewhere,¹⁷ and a strategy for setting priorities for ethnic minority groups is forthcoming.⁵¹ The misperception that the needs of ethnic minorities are so different from those of the majority that separate strategies are necessary (but which may not materialise) provides a rationale

for national strategy to exclude consideration of ethnic minority groups.⁵² The promise of aetiological understanding has meant a focus on variation in diseases, as opposed to the quality of services. There is a huge gap in the research record on the quality of care received by ethnic minority groups.¹⁹

Fuelling racial prejudice—Finally, racial prejudice is fuelled by research portraying ethnic minorities as inferior to the majority. Infectious diseases, population growth, and culture are common foci for publicity. Following the release of statistics on the ethnicity of single mothers, the *Sunday Express* of 13 August 1996 had the headline "The ethnic time bomb". Toni Morrison wrote that "A whip of fear broke through the heart chambers as soon as you saw a Negro's face in a paper," for this signalled exceptionally bad news.⁵³ Researchers cannot be responsible for media reporting but must be aware of the potential impact of their work on race relations.

Conclusion

With hindsight, we can see that much race oriented science in the past was unethical, invalid, racist, and inhumane though it was perceived to be of great importance.^{1 2 11} *The Bell Curve* is a reminder that research which purports to demonstrate the innate inferiority of some racial groups continues and that race science is alive.⁵⁴ Researchers need to understand how research into race and health was misused in the past. Epidemiologists should remember that warnings from disciplines incorporating anthropology and psychology may be based on harsh experience, for these disciplines played a leading part in racialising science.^{1 7 11} Epidemiologists who remain unpersuaded that racial prejudice could influence science should read about the Tuskegee syphilis study, which examined the natural course of syphilis in 600 poor "negroes" in Alabama, denying them effective treatments and hastening many deaths.⁵⁵

Knowledge of the interplay of cultural, genetic, and environmental factors is valuable, and research into race and ethnicity is one way to achieve it. Contemporary researchers also justify such research as necessary to help meet the needs of ethnic minority groups and point out that lack of data can hinder health policy.^{19 56} Inequalities in the health status of ethnic minority groups demand attention.^{15 21 23 24 31} For these reasons, scientists' interest in the relation between race, ethnicity, and health will increase.

Participation by ethnic minorities in research, policy making, and the development of services might be one safeguard against repeating the mistakes of the past. The American College of Epidemiology has called for a greater contribution to epidemiology by researchers from ethnic minority groups, who are underrepresented.^{21 57} When Jews and black people spoke on race, however, their views were interpreted as representing special interests.¹¹ A partnership between scientists from ethnic minority and ethnic majority groups is needed.

My view that the potential for testing hypotheses is rarely realised and that the aetiological value of such research has been exaggerated^{17 34 52} remains controversial. Wider and constructive debate on mounting criticisms is essential as a step towards agreement on the way forward. This debate is more advanced in the

United States than in Europe, but on both sides of the Atlantic writings intended to stimulate change^{6 19 41-46} have had surprisingly little impact.

With regard to the question in this paper's title, I believe that few people researching ethnicity and health are racist and that most hold humanitarian views. Many, however, are working to a racialised research agenda (my own work is no exception). If our work is racist as well as racialised most of it is unwittingly so, but that probably applies to much historical work. In 100 years' time will our successors judge our research to be racist—that is, bolstering the case for the innate superiority of some racial groups? Applying this to ethnicity, might our work be seen as "ethnicised" research and the fuel of "ethnicism"? Millions of people had their skulls measured by craniologists to no benefit.¹ Let us ensure that late 20th century research does not suffer a similar fate.

Most research on race, ethnicity, and migration has been black box epidemiology, which has potential in planning health care but needs to be presented and interpreted with a different perspective from that of aetiological research.¹⁷ A great deal of research on race, ethnicity, and migration is unsound because the questions posed were not relevant or answerable or because the methods were not adequate.

My message is not of despair but a call for corrective action, of the kind so ably documented by many scholars,^{6 19 41-46} but which has been deftly evaded by researchers and editors alike. The research paradigm should be adjusted away from ethnicity and race as the key to unlocking the secrets of the causes of disease²⁰ to being a tool for assessing needs and inequality and guiding practical action.

Senior and I made nine recommendations to help make ethnicity a sound epidemiological variable (see box).¹⁷ To these I would add (or re-emphasise) the following:

- Researchers, policy makers, and professionals in the subjects of race, ethnicity, and health should understand the ignoble history of race science^{1 2 7} and be aware of the perils of its return⁵⁴
- In the absence of consensus on the nature of ethnicity and race, researchers must state their understanding, describe the characteristics of both the study and comparison populations, and provide and justify the ethnic coding^{17 58 59}
- Editors must play a greater role in developing and implementing a policy on the conduct and reporting of research on race, ethnicity, and health^{15 58-60}
- There should be wide recognition that, like data on social class, information on race and ethnicity has a key role in raising awareness of inequalities and stimulating policy and action.^{19 56 57 61 62}

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Summary of recommendations to improve the value of ethnicity as an epidemiological variable (from Senior and Bhopal¹⁷)

- Ethnicity should be perceived as different from race and not as a synonym for it
- Ethnicity's complex and fluid nature should be appreciated
- The limitations of methods of classifying ethnic groups should be recognised, and reports should state explicitly how such classifications were made
- Investigators should recognise the potential influence of their personal values, including ethnocentricity
- Socioeconomic differences should be considered as an explanation of differences in health between ethnic groups
- Research on methods for ethnic classification should be given higher priority
- Ethnicity's fluid and dynamic nature means that results should not be generalised except with great caution
- Results should be applied to the planning of health services
- Observations of variations in disease should be followed by detailed examination of the relative importance of environmental, lifestyle, cultural, and genetic influences

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Save our service

Peter Richards, Michael Gumpel

The medical director and the chairman of Northwick Park Hospital and St Mark's NHS Trust sent us a copy of their letter to Frank Dobson, the new secretary of state for health; we are publishing it because we think it reflects the concerns of many hospital doctors in Britain today.

See editorial by
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BMJ 1997;314:1756-8

Dear Secretary of State,

We are writing to you on behalf of the medical staff of the Northwick Park and St Mark's NHS Trust, who welcome a new government clearly totally committed to the future of the NHS, but we are deeply concerned to bring home to you the extremely serious practical problems facing doctors, nurses, and their colleagues in the acute hospital services. With the best of intentions we cannot sustain current services with even less than current resources; we cannot maintain morale without light at the end of the tunnel.

All the points we wish to make apply to a greater or lesser extent nationwide; a few pertain particularly to our trust. Everything we have to say is based on hard evidence which we shall not attempt to present here but can produce in any degree of detail you would find helpful.

■ *"We cannot maintain morale without light at the end of the tunnel."*

We should preface our remarks by saying that Northwick Park and St Mark's is a large general hospital with several subregional, regional, and national tertiary services with a strong academic emphasis; of these St Mark's Hospital is the largest and best known. As a general hospital we offer an appropriately balanced range of services. A comparison by the Audit Commission of Northwick Park with similar hospitals in 1995-6 and a recent assessment by Arthur Andersen confirm that the cost per case here compares

favourably with other providers nationally. These audits also show that the trust uses its beds efficiently. But the current very high bed occupancy leaves no margin for surges in demand and is putting unremitting and damaging pressure on all staff.

You are familiar with the core problems but we and our patients are the ones who have to live with the human consequences from day to day. They include the following:

- Accident and emergency attendances increasing by 7% in 1996-7 and by a further estimated 10% this year, to the point at which staff are working at full stretch throughout night and day. Urgent patients are not seen soon enough, and at peak times less urgent patients may wait several hours to be seen.

- Emergency admissions increasing by 11% in 1996-7 and by a further estimated 17% this year, to the point where they build up in accident and emergency and general practitioner referral, filling all space and occupying all trolleys while they await a bed on a ward—and this at what is normally a relatively quiet time of year.

- Surgical elective beds overrun by both surgical and medical emergencies which we cannot turn away. Elective operations are cancelled at short notice, patients are highly inconvenienced, and income is lost. For example, trauma has risen from 37% to 50% of orthopaedic admissions in the past three years, with reduction of inpatient elective surgery from 30% to 28%; the pressure on operating time has reduced day cases from 33% to 22%. Not only is income lost as emergencies displace elective work but the case mix

becomes more expensive because emergencies take more theatre time and stay longer in hospital. The trauma load this year is expected to reduce orthopaedic elective income substantially. Providers work at double penalty in a purchasing system which fails to pay the full cost of emergencies; shoulders shrug responsibility all the way down to the coalface; and money does not follow patients.

- Nationwide this surgical tension is facing doctors with an ethical dilemma, between fairness and equity on the one hand and solvency through concentrating on fundholder patients on the other.

- Every effort to reduce inpatient stay is frustrated by increasingly elderly patients and diminishing capacity of social services to identify suitable long stay accommodation and to secure funding for it. The mean number of beds blocked by delayed discharges has increased over the last year by 55% to 5688 bed days; these figures pick up only extreme delays.

- General practitioners require a full and adequate open access service—for example, to pathology and radiology investigations and to physiotherapy—but there is no effective means of control, nor is funding clearly linked to demand.

- Reduced hours of work of trainee doctors (which we applaud) require more staff if those on duty are not to have an intolerable and unsafe workload. There is good evidence nationally that trainee doctors' morale is at breaking point and that they will look for other countries or other careers if their concerns are not addressed.

■ *"We deserve a rational sharing of national problems."*

- Increasingly stringent requirements for supervision of trainee doctors (which we applaud) have had the unwanted effect of diminishing the number of operating theatre sessions.

- Increasing emphasis on quality of outcome and risk management (which we applaud) has minimised emergency operations at night but introduced additional competition between emergency and elective operations by day. Elective operations must wait and wait. We are informed that the regional management executive finds an increase in long waits unacceptable and will impose financial sanctions: more double jeopardy. Which way are we to face—the wall? We deserve a rational sharing of national problems.

- Better teaching of trainees in outpatient clinics implies a reduction in the number of patients seen in these clinics. In fact, consultants have attempted to maintain the numbers; this responsibility, coupled with the perfectly reasonable monitoring of waiting time in outpatients, has introduced relentless pressure on the consultant staff. League tables may encourage efficiency but they seriously constrain teaching.

- No resource has been made available for the regular appraisal and counselling of trainees (which we applaud), which has become a requirement for all junior staff.

- Decreased time for teaching medical students: hospitals like Northwick Park and St Mark's are the ideal complement to the increasingly specialised and research dominated central university hospitals, but

time for teaching medical students is being progressively squeezed.

- Difficulty in capturing all income: you are familiar with the cost and inefficiency of operation of the current structure of internal market.

These are just some of the problems but sufficient to make a point. What, you will ask, have we done about them? Against the background of year on year savings we have this year had to find recurrent savings of £6m against a budget of approximately £83m to remain solvent. How have we done this? Could we go on doing it? In short, we have almost finalised our plans and have taken all possible steps to avoid harming patients, but we have reached the point at which we are beginning to question seriously our ethical credibility—both with regard to the workload imposed on our colleagues, particularly on the trainee staff, and as carers of patients.

■ *"We are beginning to question seriously our ethical credibility."*

We have taken all possible steps to increase and collect income, to reduce unnecessary expenditure and to improve facilities appropriately—for example, by improving the medical and surgical facilities to provide 143 additional beds for the 27% increase in catchment population following the closure of Edgware General Hospital.

We have been forced to make widespread and immediate savings, including reducing managerial staff, clinical secretaries (on whom the day to day communications with general practitioners vitally depends), nurses, paramedics, ancillaries, and medical clinical assistants. Estates costs have also been substantially reduced, thereby laying up trouble for tomorrow.

Most of these are short term measures which will impair our long term effectiveness; some reflect a different way of providing the services.

■ *"We have been forced to cut and cut again."*

We have made a wide ranging and rigorous review of how we provide our services and make use of our medical staff, including the following measures:

- We have partially implemented a medical manpower strategy 1996-9 which last year set out the core staff required to provide a 24 hour service of the range, quality, and complexity required for the immediate future, including the initial phase following the closure of Edgware General Hospital, taking account of the new deal, and making a token contribution to the nationally required improvements in supervised training of senior house officers and specialist registrars. Purchasers have not questioned the logic of this strategy; they question only how it can be funded.

- The medical manpower strategy also seeks to provide full internal cover for holidays and study leave through a staff establishment sufficient to avoid the use of locums, which are neither cost effective nor as satisfactory as established staff who are part of the team.

- We have developed an acute services strategy 1997-8 which:

- (a) promotes a new approach to acute medical assessment/admission and early discharge;
- (b) promotes development with general practitioners of guidelines for referral and also for multidisciplinary planned case management;
- (c) promotes the development of one-stop clinics;
- (d) seeks a full clinical and managerial partnership of services for the elderly (currently split between two trusts on one campus serving different catchment areas);
- (e) offers to explore collaborative services with neighbouring hospitals (impracticable on any really effective strategic scale until competition between trusts is abolished);
- (f) seeks an NHS Management Executive review of tertiary specialties in north west London, openly examining the opportunities for their coordinated consolidation and integration with full district general hospital services on a single campus on the lines of the St Mark's model;
- (g) clearly identifies the accountability of consultant staff for the use of all their professional time for NHS work on campus, apart from specifically agreed time for private practice (consultants are being encouraged to undertake all their private practice on site);
- (h) identifies the need for annual review of consultant work plans in the light of the rapidly evolving service strategies;
- (i) commits the trust to a major national role in medical education at all levels for which a director and manager for medical education and training have been appointed with a far more proactive and strategic function than the traditional clinical tutor model;
- (j) commits the trust to redeveloping its national commitment to NHS clinical research and development with several academic units of Imperial College on site and a total of 12 London University professors on the staff.

■ *“Ensure that ... money follows patients.”*

You will see that we have responded to the need to improve our systems, although we acknowledge we still have some way to go in developing all these themes, the majority of which will not save money but will offer better value for money. Yet despite the need to invest and to take our part of the national surge of acute hospital work, together with a substantial increase in catchment population, we have been forced to cut and cut again. In the face of enormous service stress and attempts to improve working and training conditions for trainee doctors (largely overtaken already by the intensity of workload) we are examining rigorously our way of providing the service and our accountability for the way in which we spend our time.

Please do not tell us, secretary of state, that “times are hard.” They are nothing like as hard up there in Richmond House as they are down here; nothing like as hard, for that matter, in private industry as in public service. That, we believe, is why you have been elected and that is why we welcome you. Of course you face a formidable task, a task facing every developed nation, but you have the advantage and privilege of presiding over a system of health care offering unparalleled

value for money. It has been taken for granted for far too long.

■ *“We cannot maintain services while continuing to cut costs.”*

We wish to suggest four measures which would immediately and convincingly demonstrate your determination to relieve the pressure on the acute hospital services and to lift staff morale. They do not solve all the problems, but they would show that you mean business.

(1) Abolish the annual recurrent 2.7% cost improvement imposition, a tax which has long outlived its justification and which unselectively penalises the efficient along with the less efficient and takes no account of individual circumstances.

(2) Abolish interest on loans for agreed redevelopments, such as the £15m debt we have necessarily and responsibly incurred here around the move of St Mark's to this site and provision for the closure of Edgware General Hospital. We have been left with a serious handicap of interest and capital repayments which will compromise our financial viability for years to come.

(3) Make capital more easily available, especially for schemes which would reduce revenue costs, by simplifying the bureaucracy concerned with private fundholder initiative schemes.

(4) Ensure that emergency work is properly paid for: in short, that money follows patients.

■ *“You cannot count on our loyalty and willingness to be flexible.”*

Our colleagues instructed us to protest vigorously that we cannot maintain services while continuing to cut costs. We hope that we have left you in no doubt about our concern and feeling of despair. We are convinced that we cannot now continue to make further recurrent savings without destroying the service and those who provide it. We do not seek confrontation but we, and most other hospital doctors, are not prepared to destroy what we have all worked so hard to achieve.

You can count on our loyalty and willingness to be flexible with regard to change, but not on our ability to continue to maintain a first class, or even second class service, against overwhelming odds. You should not, however, count on trainees to stay in an overstretched service in which they feel devalued and exploited, although most love their work and do it extremely well. You can count on us to do our ethical duty to patients, even if it were to bring us into conflict with a well intentioned government.

■ *“You should not count on trainees to stay in an overstretched service in which they feel devalued and exploited.”*

We look forward to receiving your personal response to our urgent and deep concerns. As we believe that wider debate on these issues before the forthcoming budget would be in the public interest, we are copying this letter to the *BMJ*, and will make it available to our local MPs.