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About the authors

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Introduction

The Department of Health has expressed a clear determination to 'promote race equality [and] do more to meet the needs of black and minority ethnic people' in the NHS in England (Department of Health 2005d). Where patients are concerned, this commitment involves addressing underlying inequalities in health, inequities in access to services and differences in experience of services. Where staff are concerned, it involves combating discrimination and overcoming barriers to career progression for all professional groups.

Underlying this commitment is a legal obligation under the Race Relations Amendment Act (2000) for public bodies– including NHS organisations – 'to eliminate unlawful discrimination, and promote equality of opportunity and good relations between persons of different racial groups' (Commission for Racial Equality 2002a). Organisations are legally obliged to explain how they plan to achieve these objectives in a 'race equality scheme', a public document that should be a 'strategy and a timetabled and realistic action plan' (Commission for Racial Equality 2002a).

The primary aim of this research was to use race equality schemes to find out what activities PCTs in England are reporting to carry out in their efforts to address any inequities in access to NHS services that patients from ethnic minority backgrounds may be experiencing. The authors chose to look at PCTs rather than other NHS organisations because PCTs are responsible for handling 83 per cent of the NHS budget (£79.2 billion in 2006/7) and are considered by the government to have a key role in the NHS system.

> PCTs will ensure access and choice to a range of high-quality health services and ensure that the government's commitments to health, reducing health inequalities and health services are delivered for local people. As custodians of their population's health budget, they are responsible for ensuring prioritisation and value for money in ways which have maximum impact on health and secure all necessary health services.
> (Department of Health 2005b)

By looking at the content of PCTs' race equality schemes, the authors hoped to gauge how effective the legal duty appears to have been at PCT level and find out whether common themes emerged from the documents about what good practice exists and what barriers to change remain.

For the purposes of this briefing, equity of access is understood primarily as the uptake or utilisation of a service in proportion to need (although it is recognised that a more comprehensive definition of need would also include the quality and experience of services (Szczepura 2005)). Action to eliminate discrimination for staff was not a focus of this research as NHS compliance with the legal duties regarding employment has been audited more recently by other organisations (*see* pp 5–6).

Background

Challenges of evaluating race equality in health care

The Department of Health's commitment to promoting race equality is not only driven by a legal imperative, but is also a response to a growing body of evidence which suggests that some staff and patients from ethnic minority groups have experienced discrimination and, compared with the 'majority' population, poorer access to and experience of services. Action to reduce inequities in access to NHS services, based on the insights of the research evidence, has been clouded by gaps in routine data. It has been difficult to get a clear, evidence-based picture of levels of access to NHS health care services by different ethnic groups because of the difficulties – both conceptual and practical – of collecting and collating routine data from patients about their 'ethnicity', which in turn has hampered the assessment of need and the evaluation of interventions designed to correct inequities.

Partly because of these data problems, the government's attempts to improve access to and experience of services among ethnic minority groups have generally not involved setting centrally driven, measurable national targets or standards[1] (a technique used to drive changes elsewhere in the NHS, such as cutting waiting times or improving performance in specific clinical areas). National level, quantifiable standards that relate specifically to ethnic minority patients have been articulated only for mental health services (Department of Health 2005c). For all other services and clinical areas, the government has taken a much less prescriptive approach, setting out general guidance for trusts (Department of Health 2005f) and introducing development initiatives, such as the Race for Health and Pacesetters programmes (Race for Health 2007; NHS Networks 2007), targeted at specific trusts or groups of trusts.

Research suggests that many local NHS bodies have been active in promoting race equality for patients for some time (often in close partnership with community and voluntary sector organisations) (Alexander 1999; London Health Observatory 2004). However, the non-prescriptive approach of the government on this issue means that trusts' responses vary widely, making it more difficult for researchers to get a sense of the type, scale and effectiveness of particular initiatives.

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1. One exception has been the drive to improve the quality of ethnicity coding in Hospital Episode Statistics for inpatients, which has been included in the Healthcare Commission's performance monitoring for hospital trusts since 2001 and has resulted in big improvements in the completeness of data in recent years (Department of Health 2005a).

The history of the Race Relations Amendment Act

In the absence of any central targets promoting race equality in the NHS, the Race Relations Amendment Act (2000) is, in theory, the main driver for change at a national level. The Race Relations Amendment Act was drafted in 1999 and came into effect in 2000. At this point, official health policy documents calling for systematic action at a national level on ethnicity and access to health services had only recently begun to emerge.

In the 1980s there were single-issue initiatives, including the national 'Stop Rickets Campaign' in 1981 (aimed at the 'Asian' community), and Department of Health-funded projects to develop best practice with a local focus (Hopkins and Bahl 1993). From the early 1990s a more comprehensive national perspective began to develop, with a brief acknowledgement of 'ethnic' variations in health in the White Paper *Health of the Nation* (Department of Health 1991) and a commitment to respect the 'privacy, dignity and religious and cultural beliefs' of patients in the *Patients' Charter* of the same year (Johnson 1993). The 1990s also saw the creation of an Ethnic Health Unit (1993–7). Although short-lived, this aimed, for the first time, to help the NHS as a whole meet the needs of an ethnically diverse society (Bhopal 2007).

In 1999, the author of an overview of action on race equality, commissioned by the Department of Health, noted that 'the last two years has seen increased effort on the part of politicians, planners and service providers to improve the health status and social well-being of these citizens' but acknowledged that most action on race equality still tended to be local in focus and short term in nature across the NHS in England (Alexander 1999).

It was against this backdrop in health that the Race Relations Amendment Act was passed, driven by a failure in the criminal justice system – that is, the flawed police response to the murder of the teenager Stephen Lawrence. The Macpherson Inquiry into the event popularised the concept of 'institutional racism' when it was published in February 1999. The Inquiry suggested that the police (and other organisations in the public sector) needed to expand their understanding of 'racism' beyond the existing notion of direct discrimination against a person because of their race or ethnicity (already illegal under the 1976 Act) to include a recognition of institutional racism. This is a passive and collective form of racism that, in the opinion of the Inquiry, was present in the police service's response to the murder of Stephen Lawrence (Macpherson of Cluny 1999).

As a result of the Inquiry, the Race Relations Amendment Act was drafted with a requirement for organisations and public bodies, including the NHS, to take 'positive action' to combat racism, rather than simply wait for instances of discrimination to occur and then take action (Bhavanani *et al* 2005). The Act places a general duty on all public bodies to eliminate unlawful discrimination, promote equality of opportunity and promote good race relations between people from different racial groups (Commission for Race Equality 2002a). To achieve this, the Act sets out specific duties for public bodies, which include preparing and publishing a race equality scheme.

Race equality schemes

According to the official guidance, an organisation's race equality scheme should: demonstrate how the organisation has assessed which of its current functions and policies

are relevant to the general duty (*see* appendix, p 27); explain what arrangements have been put in place to assess and consult on proposed policies; monitor the impact of existing policies; train staff; and make sure that the public has access to information and services (Commission for Race Equality 2002b). Specific additional guidance was issued for education (Commission for Race Equality 2002c) but not for health. All organisations were required to revise the schemes within three years. All types of NHS trusts (primary care, acute, mental health and care trusts) should have published, by May 2005, a second edition of a race equality scheme to cover the period 2005–8.

The role of the legislation in health care

What role was the legislation and its accompanying duties expected to play in achieving 'race equality' in access to NHS services? First, the Act was seen as a good opportunity to codify what was already being done to promote race equality in general. Guidance from the Department of Health, issued in 2002, argued that, for some trusts, producing a race equality scheme would provide an opportunity to 'review and bring this work together in a strategic framework' (Kingsley and Pawar 2002).

Second, and more importantly, the legislation was seen as a powerful tool to compel all trusts to consider whether people were accessing their services equitably. Guidance from the Commission for Racial Equality (CRE) explained how organisations should work out which of their functions were relevant to race equality and then monitor their impact – which, in the case of health provision, would cover a substantial part of NHS trust activities.

> *Identify, by racial group, those who use, or might use, the services or facilities you provide, and ask whether any of them have particular needs or priorities.*
> (Commission for Racial Equality 2002a)

In addition, the guidance from the CRE specified that: 'public authorities must set out in their race equality scheme their arrangements for making sure that the public have *access to information and the services* they provide' (2002a).

What is notable about the CRE and early Department of Health guidance is that there is very little detailed, prescriptive advice about how trusts should tackle their legal obligations to promote race equality in relation to access to health services (in contrast with employment, where the law is specific and prescriptive about monitoring many aspects of staff recruitment and training).

In its guidance of 2002, the Department of Health offered suggestions about the questions trusts might ask when developing their race equality schemes about, for example, interpreting and language provision or using available research to build up a picture of health needs locally.

> *Do not try to do everything at once. Focus in on the greatest areas of concern. For example:*
> - *if you have a significant African-Caribbean community, mental health service provision may be an issue*

- *for South Asian communities and asylum seekers, language provision may be an issue.*

Look at the research and compare it with your local population.
(Kingsley and Pawar 2002)

Two years later, in 2004, the Department of Health and the CRE began the first attempts to add some detail about what outcomes the NHS should be achieving as a result of race equality schemes (Commission for Race Equality 2004). This document divided up the functions of trusts into a number of domains, including strategy and services, with suggested outcomes for each. The expected outcome for strategy and services was that 'There is equitable access to services for all races and ethnic groups'. The document also suggested some limited concrete and measurable indicators for access:

The organisation can demonstrate:
- *inequalities in access are narrowing, eg GP registration, waiting times, referrals and elective/acute admissions per 100,000 population (age and sex standardised) reflect ethnicity profile of local population and expected morbidity*
- *inequalities in quality of care are narrowing, eg lengths of stay, complication rates*
- *any disproportionality in formal and informal complaints is narrowing*
- *gaps in 'market penetration' of service information between different ethnic groups are narrowing.*
(Commission for Race Equality 2004)

Previous evaluations of race equality schemes in the English NHS

There have been several published studies that attempt to assess how well NHS trusts, including PCTs, have complied with the legislation. The first used a combination of surveys and analysis of race equality schemes and was published in 2002, not long after the legislation had come into force. The study found that the NHS was lagging behind other authorities and judged that only a third of the 23 schemes analysed could be classified as 'mainly developed or fully developed' (Commission for Racial Equality 2002d). Access to services was not explored in any detail. In the same year, a survey of strategic health authorities (SHAs) (new organisations at the time) was published, which found limited awareness of the law and strategies to comply with it, particularly among SHAs in rural areas or areas with small ethnic minorities (Bhatt 2002).

In 2005, the NHS-based London Race Equality Group commissioned the independent 1990 Trust to carry out a more in-depth study of all trusts in London, based on scrutiny of 79 race equality schemes. The review commented that although 'there was some good practice in all areas and across types of trust, it was disappointing that not more progress had been made since the 2002 schemes'. It found that there were a 'significant number' of trusts where the race equality schemes were inaccessible or unavailable on websites, only a minority of trusts had prioritised their functions and policies well, and there was a lack of evidence about whether trusts were monitoring the impact of their services on users (The 1990 Trust 2005).

The London Health Observatory has also reviewed 'several hundred' race equality schemes from different types of trusts via their websites as preparatory work for a toolkit for the NHS on how to analyse ethnic data (London Health Observatory 2006). This report found that 'only a small number' of trusts presented analyses of workforce or patient statistics. It describe this finding as 'significant', speculating that:

> One reason for this lack of progress may be the difficulties in achieving routine ethnic monitoring to a level where organisations can have confidence in the quality and completeness of the data collected.
> (London Health Observatory 2006)

The most recent audit of compliance was conducted by the Healthcare Commission, based on a scrutiny of all NHS trust websites. The scope of the report was a quantitative analysis of indicators of trust compliance with certain aspects of the legislation, as opposed to a qualitative analysis of the schemes themselves. The Healthcare Commission attempted to locate a race equality scheme, full employment monitoring statistics and the outcomes of race equality impact assessment for every NHS trust in England on the web within a time span of 30 minutes per trust. The Healthcare Commission found that at the time of the research (March 2006) only one per cent of trusts (7 out of 570) had complied in full with the legislation (that is, they had published all three elements); and 40 per cent of trusts did not appear to have published a race equality scheme at all (Healthcare Commission 2006a).

Methods

In order to carry out this study, a full list of PCTs and their websites was accessed from the main NHS website – www.nhs.uk. There were 303 PCTs in existence during the period of the research. PCTs have since been reorganised, bringing the total number down to 152. Attempts were made to locate a race equality scheme for each PCT via their website rather than using a web search engine, on the assumption that the public are most likely to assume that a PCT's website is the main point of access for PCT documents. Websites were accessed between March and August 2006. Websites that did not appear to be functioning were retried on at least three occasions during this period.

Once a website had been successfully accessed, a series of questions were then asked. The first set of questions related to basic compliance with the publication elements of the law. The questions were as follows.
■ Is there an up-to-date race equality scheme (2005–8) available on the website?
■ Has an action plan been published?
■ Have employment figures been published (and at what level of detail)?

In addition, websites, race equality schemes and public health annual reports were searched for detail about the ethnic minority population in each area.

The second set of questions required a more qualitative approach, based on reading the race equality scheme and action plan (where they were available). The questions were as follows.
■ Does the PCT publish information about its demography and, if so, at what level of detail?
■ Does the PCT believe there is unmet need or inequity in access among the population it serves and, if so, how has it established this?
■ Is there evidence of activity to improve access to health care services? For example, does the race equality scheme contain details of concrete projects? Are there timescales, etc?
■ Is there evidence of activity to monitor ethnicity in relation to access to services (not just employment)?

For the purposes of this research, 'access to services' was defined as utilisation of all services for which a PCT is directly and indirectly responsible – that is, primary care, community-based services and acute hospital services; and 'ensuring equity of access' was defined as understanding whether the utilisation of services is proportionate to need.

Demographic detail about each PCT was obtained from the Office for National Statistics (www.neighbourhood.statistics.gov.uk) to enable the researchers to make some simple comparisons of PCTs by demography. This was done to help answer the question of

whether PCTs that had bigger ethnic minority populations were more likely to have published a race equality scheme than those with very small minorities.

It is clear from the early guidance issued to trusts that, among other things, race equality schemes were intended to be a record of intentions and action on race equality. It would therefore seem reasonable to use the documents as a way of building a picture of what activity is being attempted across the NHS. However, this picture will only be partial because race equality schemes may not provide an accurate representation of a PCT's activity: although it seems fair to assume that the majority of PCTs will capture their most relevant activities in their race equality schemes, a scheme may fail to reflect the number or type of activities that are really taking place, resulting in an underestimation of a PCT's activity; conversely, in their schemes, PCTs could quite easily overestimate the activities that they are carrying out. The extent of such under- or overestimation cannot be verified through this form of research.

Findings

Was the race equality scheme publicly available?

It was possible to locate an up-to-date race equality scheme (that is, dated 2005–8) via the website for 61 per cent of England's PCTs under the old structure (184 out of a total of 303). Of the remainder, 30 per cent of PCTs (n=90) did not appear to have published a race equality scheme on their website. A further 10 PCTs had an out-of-date race equality scheme (from 2002 only) and 19 had websites or links that crashed repeatedly.

Some PCTs had race equality schemes that were either available on their front pages or could be found within minutes elsewhere on their websites, usually under a 'Publications' heading. By contrast, other PCTs (that did have the document available) had located it in hard-to-find areas, filed under 'Human Resources', as appendices to board papers or sometimes listed under categories of available information in their Freedom of Information section.

Action plans

Most race equality schemes (78 per cent; n=153) also had action plans, which were designed to set out what action was to be taken, by whom and by what date. These seemed highly variable in quality: some contained full details of dates of completion and milestones, as well as named individuals responsible for particular tasks; others contained action plans devoid of any deadline dates or milestones and heavy reliance on the concept of 'ongoing'. Many of these race equality schemes named whole departments rather than individuals as being responsible for getting things done.

Employment figures

The Race Relations Amendment Act specifies that public bodies should monitor the ethnicity of their staff in post and all those who apply for jobs, training and promotion. It also specifies that the results of the monitoring should be published annually. This research found that only 29 per cent of trusts (n=87) had published any employment data and very few (n=10) had published a breakdown of the data by staff grade (although this is not specified in the act, it is recommended in the guidance).

Content of race equality schemes: general qualitative observations

Nearly all race equality schemes were presented as official documents intended for a professional readership, made available as simple Word documents or, more commonly, pdf files.

Many race equality schemes shared a similar structure and sometimes identical language, which is perhaps due to the use of a model version on the Department of Health's website. Aimed at the second wave of race equality schemes (dated 2005–8), the model version explained the rationale behind the Act (including a quote from the Macpherson Inquiry on the definition of institutional racism), and provided broad headings on a trust's role, locality and obligations under the law (Department of Health 2005a). However, some race equality schemes had deviated quite substantially from the model version, including one which had apparently been typeset and aimed at a lay audience, complete with a short historical section and quotes from users (Central Liverpool PCT). Others had added in additional comment, including one that used a quotation from the former Home Secretary Jack Straw as a call to action:

> ...the inquiry process has revealed some fundamental truths about the nature of our society – about our relationships one with another. Some of these truths are uncomfortable, but we must confront them....
> (Gedling PCT, citing Straw 1999)

A very few race equality schemes used language that is now considered to be out of date, such as 'white races', 'Caucasian' and 'oriental', or rather eccentric language, such as 'Indian sub-culture'.

Some schemes showed signs that steering groups had been involved in their production and sign-off, identified someone to contact for more information and were introduced by the chief executive of the trust. Some PCTs presented evidence of community involvement in the production of their race equality schemes. For example, both Central Liverpool PCT and Birkenhead and Wallasey PCT included feedback from users and community groups who had given their input into the production of their race equality schemes.

> We very much welcome the opportunity to respond. We would like to ensure that the needs and experiences of both the Irish community and the Irish Traveller community are effectively represented and addressed. We would like to ensure that both communities are included in all monitoring, training and consultation procedures and that resources are allocated appropriately to meet the needs of both communities.
> (Birkenhead and Wallasey PCT)

Many PCTs did not appear to have gone down this route at all or, in one case, offered evidence of more limited community involvement:

> The diabetes group, which is run by the trust, is attended by an Asian person.

Identifying the ethnic minority population

Race equality schemes, PCT websites and Public Health reports were searched for details about the demography of their areas: had PCTs identified whether they had ethnic minority people living in their catchment areas? If so, how much information did they supply about this population and where did they source the information?

Of the 284 functioning PCT websites, 64 appeared to have published no information about the ethnicity of their local population (22.5 per cent). Of the 220 PCTs that did provide ethnicity information, the 2001 Census data was the near-universal source (three PCTs cited data from the 1991 Census). The majority of PCTs gave the percentage breakdown

of their 'white' and 'non-white' populations. However, 51 PCTs also provided more details about the composition of the of the 'non-white' and 'white' categories – for example, separating out White British from White Irish and White 'other' (a category that might be used to capture people from new EU accession countries or, according to one PCT, a Korean population).

In their race equality schemes, the majority of PCTs reproduced 2001 census data as percentages aggregated to PCT level. In addition, some PCTs also provided estimated numbers of ethnic minority people (usually in the low thousands in PCTs with populations that are more than 96 per cent 'white'). Some PCTs also gave Census data at ward level to show, in some cases, the uneven distribution of some ethnic minority people, who were sometimes concentrated in just one or two wards in PCTs covering a largely 'white' population.

A small number of PCTs took a critical attitude towards the completeness of the Census data, pointing out, for example, the difference between estimates of resident numbers by geographical area (based on the Census) and the numbers on corresponding GP registers.

> *According to the Office of National Statistics, the 2002 mid-year estimates for the number of residents in Wandsworth is 269,300. The PCT is, however, responsible for a registered population of 314,000.*
> (Wandsworth PCT)

There was also a concern that the Census might undercount some groups or miss them out entirely. This approach was particularly evident where PCTs believed they had significant populations of travellers, gypsy communities, asylum seekers, refugees and people who had come to work in the UK from Europe and beyond. An example of these concerns comes from Cherwell Vale PCT.

> *Recent survey work with Chinese communities in Banbury indicates that the latest census underestimates the number of Chinese people in these two towns, failing to capture a significant transient migrant worker population.*
> (Cherwell Vale PCT)

Identifying the health needs of the ethnic minority population

Nearly all of the race equality schemes contained a section that outlined health inequalities and set out reasons to be 'concerned' about ethnic minority people. Most commonly, this section took the form of a list of facts about the higher prevalence of disease among broad ethnic groups reproduced from national research, with a tendency to link certain diseases with particular ethnic groups without further explanation. The most commonly cited health problems were higher diabetes and coronary heart disease among 'Asians', stroke, hypertension and mental ill health among 'Afro-Caribbeans', higher incidence of communicable diseases and sexual health problems among 'Africans'. Most race equality schemes listed these without attribution, but a few PCTs provided references, suggesting some research.

Most PCTs reproduced the list without commenting on the reasons for the links between certain groups and conditions beyond making statements such as:

The main reason why people's ethnic origins are important is that some health problems are specific to particular groups.

A small proportion of PCTs went beyond the 'condition list' approach to inequalities by also acknowledging the role of socio-economic disadvantage as a contributory factor to ill health.

The experience of health inequality is very real, but also complicated, for black and minority ethnic communities. [...] Members of the black and minority ethnic communities in South Kirklees disproportionately experience certain health issues and medical conditions. [...] On the other hand, black and minority ethnic communities disproportionately experience the sorts of social and economic disadvantage – such as, for example, unemployment, low income and poor housing – which themselves also generate health inequalities.
(South Huddersfield PCT)

It was common for PCTs to reproduce the national-level prevalence data with no attempt to apply it to their locality. Nevertheless, there were a few that did attempt to provide a local interpretation of the national data. One example was City and Hackney PCT, which provided a list, giving examples of local prevalence, that included:

Mental ill health is linked with both social exclusion and ethnicity. Hackney has in excess of four times the national rate for schizophrenia. Mental health problems may be both a cause and consequence of social exclusion. For example 76% of adults with long-term mental health problems are unemployed and two-thirds of men under 35 who commit suicide are unemployed.
(City and Hackney PCT)

According to the race equality schemes examined, only a few PCTs showed evidence of using a wide variety of data sources to build a picture of local health needs. One of these, Croydon PCT, provided the following list in their race equality scheme as source material for assessing health needs:

- *data on general practice computer systems (MIQUEST)*
- *data on directly provided or community services, such as health visiting, district nursing, school nursing (ePEX)*
- *hospital episode statistics*
- *Public Health Birth File and Public Health Mortality File*
- *Birth Survey*
- *Survey data – based on survey sent to 10% (31,000) of the Croydon population*
- *Cancer Registry data*
- *Survey of Prevalent HIV Infections Diagnosed (SOPHID).*
(Croydon PCT)

The PCTs that had attempted more detailed needs analysis all drew attention to the striking lack of ethnicity coding in many of the key data sets.

*One of the problems is that the routine information we have available on health status
itself is pretty limited and we often have to resort to using mortality rates as an indicator
of community health status. For ethnic monitoring, analysis of mortality is complicated
by the fact that death certificates do not record ethnic group but country of birth.*
(Hammersmith and Fulham PCT)

It is not clear from the race equality schemes exactly how many PCTs have attempted to
conduct 'Health Equity Audits' on specific topics relevant to ethnic minorities (to get an
answer to this would require fuller research of PCT public health departments, which would
add to an earlier baseline study (Aspinall 2005a)). From the race equality schemes that did
mention equity audits, the following topics were reported to have been investigated:
coronary heart disease (by 12 PCTs); diabetes (by 3 PCTs); smoking cessation (by 3 PCTs);
stroke (by 2 PCTs); and older people, cancer, immunisation, cervical screening, exercise,
obesity, cancer, flu and access to GP services (by 1 PCT each).

Understanding potential inequities in access to services

Most PCTs listed 'access to services' as part of their function, although a minority did not
(*see* below). Many limited their responsibility to services directly delivered by the PCT,
such as district nursing. Regardless of the scope of services mentioned, only a small
minority of race equality schemes attempted to explain what was meant by *equity* or
inequity in access to services – key concepts if an organisation needs to demonstrate,
as the law implies, that its services are being accessed fairly by all in proportion to need.
Examples of explanations from two race equality schemes are given below. Both employ
the idea of services being accessed in proportion to need, albeit expressed in rather
different languages.

*'Equals should be treated equally and un-equals should be treated unequally according
to their inequalities' (Aristotle's formal principle of justice). To Heart of Birmingham PCT
this means that we do things differently for those whose life chances and opportunities
are limited as a result of inequalities experienced, because to treat the un-equal
individual the same as those who do not experience the inequalities, means that we
continue to exacerbate inequalities.*
(Heart of Birmingham PCT)

*In relation to ethnic minorities the key question is whether the uptake of services for
specific ethnic groups is higher or lower than would be expected, given known
differences and similarities in the prevalence of particular health problems.*
(Hammersmith and Fulham PCT)

Those PCTs that did attempt to quantify the scale of inequities all reported major data gaps
about local mortality or morbidity rates by ethnicity – a problem compounded by a lack of
ethnicity data about service uptake. For example, Croydon PCT reported the early findings
from a health equity audit devoted exclusively to ethnicity.

*The most important finding to date is the low level of ethnic coding in many service
areas. A key, and recurring, recommendation is that ethnic coding must be improved in
order to enable us to accurately assess health outcomes and access to services
according to ethnic group.*
(Croydon PCT)

As a result of this data deficit, some PCTs appeared to have commissioned their own surveys to gauge needs or relied on more informal evidence drawn from user groups or BME networks, consultations or ad hoc contact with the community and voluntary sector.

> *Anecdotal evidence in Derby suggests that people from black and minority ethnic communities:*
> - *have a low take up of cardiac rehabilitation services*
> - *are less likely to attend appointments regarding cardiovascular disease, and*
> - *lack the provision of information in different languages.*
>
> (Central Derby PCT)

Other PCTs had commissioned specific studies – often combining research methods, such as surveys and focus groups with staff and patients – that explore gaps in service delivery and unmet needs. For example, Rotherham PCT had conducted a survey on the needs of young ethnic minority men and traveller communities. In addition, a few PCTs (Central Liverpool and Wolverhampton PCTs, for example) had commissioned work from university departments to investigate specific conditions. However, judging by the evidence in the race equality schemes, these sorts of bespoke studies on access problems are uncommon.

Access: range of action

Regardless of whether PCTs had analysed the specific question of what sort of inequities in access might exist, many race equality schemes offered some evidence of action taken to ensure that people from ethnic minority backgrounds could access services equitably. As might be expected, there was a wide spectrum of activity to improve access.

After an initial analysis of the broad themes emerging from the race equality schemes, it was possible to group the 184 PCTs with race equality schemes into three broad categories.

- The first category consisted of PCTs who offered no evidence of action of any kind to ensure or improve access, including those who did not interpret 'access to services' as a function relevant to the legal duty. This applied to 20 per cent of PCTs with race equality schemes (n=37).

- The second category consisted of PCTs who interpreted access purely as a language problem and offered as evidence of action (to solve the problem) the availability of generic NHS telephone-based interpreting services and provision of NHS documents in other languages. Forty per cent of PCTs with race equality schemes (n=74) fell into this category.

- The third category consisted of PCTs who offered evidence of some sort of bespoke services or interventions *in addition* to the generic interpreting/communication examples from previous group. Forty per cent of PCTs with race equality schemes (n=73) fell into this category. There was a huge range of activity within this group, including PCTs that had provided a single outreach or link worker for a particular community or group, to PCTs with multiple initiatives, using a range of voluntary sector providers across a range of disease areas, aimed at several different ethnic groups.

It also became clear, as websites were searched for race equality schemes, that a further 12 PCTs had evidence of activity at a level equivalent to the third category, despite not having put race equality schemes in the public domain via the website.

Efforts to improve access included many preventative schemes run directly by PCTs, such as smoking cessation initiatives targeted at high risk groups and measures to boost uptake of breast screening and immunisation. Some PCTs had developed different techniques for getting health messages across, such as advertising on local radio or making videos or CDs. Peer or lay advocates and link workers were also used by PCTs, sometimes in conjunction with local authority schemes such as Sure Start, particularly to get educational messages across about health promotion.

Sometimes PCTs had targeted primary care services or staff at entire groups, such as refugees and asylum seekers or travellers, with the creation of mobile clinics or dedicated GP services. A few PCTs had also aimed services at migrant workers (for example, Herefordshire and East Cambridgeshire PCTs).

In terms of disease areas, initiatives to improve the primary care of diabetes, chronic heart disease and stroke, and access to mental health services were the most commonly mentioned in the race equality schemes. In addition, there were examples of initiatives to improve cancer (Bristol PCT) and access to palliative care (North Bradford PCT). While the bulk of activity appears to have been targeted at improving the knowledge or health-seeking behaviour of ethnic minority groups themselves (via dedicated staff serving specific communities), some PCTs also offered detailed evidence of changing the behaviour of mainstream staff through training – for example, Birkenhead and Wallasey PCT, which has produced a detailed training manual for all its PCT staff.

While the race equality schemes gave a strong sense of the breadth and methods of initiatives to improve access, they did not offer much comment on the effectiveness of initiatives. There did not appear to be examples in the schemes of targets or milestones relating to quantifiable outcomes in relation to initiatives on access. However, it is possible that such targets do exist but are to be found elsewhere in PCT websites.

Monitoring access

Race equality schemes were scrutinised for evidence of what kind of monitoring was taking place to ensure equity in access to services. Thirty-five per cent of PCT schemes either gave no details of how services were being monitored, or interpreted monitoring exclusively as an employment requirement. Just over half of the race equality schemes (52 per cent) identified the importance of monitoring uptake of services by ethnicity and included some evidence of monitoring a proportion of services delivered by the PCT, such as district nursing or smoking cessation services. The most comprehensive example of this was Heart of Birmingham PCT, whose race equality scheme lists in considerable detail the current monitoring arrangements for its directly delivered services, which range from physiotherapy to dental services:

> *Dental Services Priorities/Actions: Computerised system is in place, but usage can be patchy. Coding sheets have been translated into Urdu and Punjabi. Importance of this will be reinforced at staff meetings and by email.*
> (Heart of Birmingham PCT)

In some cases, race equality schemes referred to 'plans' to devise ways of monitoring the ethnicity of patients using GP services, which represent possibly the biggest gap in ethnicity monitoring in the NHS. However, only 13 per cent of PCTs (n=24) offered any

concrete evidence of attempts to monitor patients using primary care delivered by GPs, either by referring to pilots underway in some GP practices or plans to start pilots or initiatives with target dates. Ten of these PCTs were in London, including Lambeth, Islington and Camden, where the former SHAs had set targets for GP-level monitoring. Other PCTs offering concrete evidence of ethnic monitoring included urban areas such as Central Liverpool (home to one of the earliest GP monitoring schemes), as well as a number of more rural PCTs such as Cherwell Vale PCT in Oxfordshire.

Even in the minority of PCTs where some GP-level monitoring was taking place, it was not clear from their race equality schemes how the data was being used. This could be a reflection of the fact that many projects are still at an early stage of development. For example, Lambeth's Public Health report of 2004–5 notes that:

> *Two projects are about to start in Lambeth that look at access to care and quality of care for people with schizophrenia and heart disease. The Lambeth PCT Datanet Project has developed an expanded minimum dataset (known as a patient profile) for primary care. Staff are being trained and IT systems upgraded to use this. Thirty-one practices are involved so far and more are joining.*
> (Lambeth PCT)

There were also a few PCTs (including Croydon, Ellesmere Port, Cheshire West and Islington) that referred to monitoring of patterns of access to acute hospital care by ethnicity using Hospital Episode Statistics (HES).

> *In North Central London, admission rates have some variations across ethnic groups. Considering the largest ethnic groups and largest disease categories (with at least 200 admissions per disease category in each group), it shows that, for example, White British and White Irish people had higher admission rates for cancers, while Asian people had a lower admission rate. In circulatory diseases, Asian people had the highest admission rates and Black African people the lowest. This information can help us to plan and develop services.*
> (Islington PCT)

Some health equity audits also contained evidence of analysis of routine HES data alongside Census profiles at ward level (Ealing PCT on coronary heart disease for example). Evidence of this sort of monitoring in the race equality schemes (and Public Health reports) was rare; it may be more widespread than this but unreported in the documents under review.

One PCT (Rotherham) mentioned monitoring Choose and Book and one PCT (South West Oxfordshire) mentioned monitoring the uptake of Language Line (a major NHS provider of interpreter services) to get an idea of service uptake.

Overall, many PCTs acknowledged major shortcomings in their ability to monitor uptake of services and some PCTs expressed frustration with the deficiencies of the data available to them – for example:

> *The lack of robust data, and the lack of consistent systems for analysing and reporting on the data in a form which helps practitioners and managers improve their services, presents a serious risk to the PCT's ability to achieve its aspirations around equality.*
> (Westminster PCT)

Demography and race equality schemes

There appeared to be no obvious relationship between the ethnic diversity of a population served by a PCT and the likelihood of them having an accessible, published race equality scheme (based on the supposition that having low densities of ethnic minority people might reduce an organisation's interest in pursuing race equality). When describing their demographic make-up, many PCTs conceptualised their demography as having a 'below' or 'above' average proportion of ethnic minority people when compared with England as a whole. When PCTs were split into two groups – one with an above the national average proportion of 'non-White British' people (13 per cent according to the 2001 Census categories) and one group with a below the national average proportion of 'non-White British' people, then only a slight difference emerged in the proportions of those PCTs with accessible race equality schemes, compared to those without.

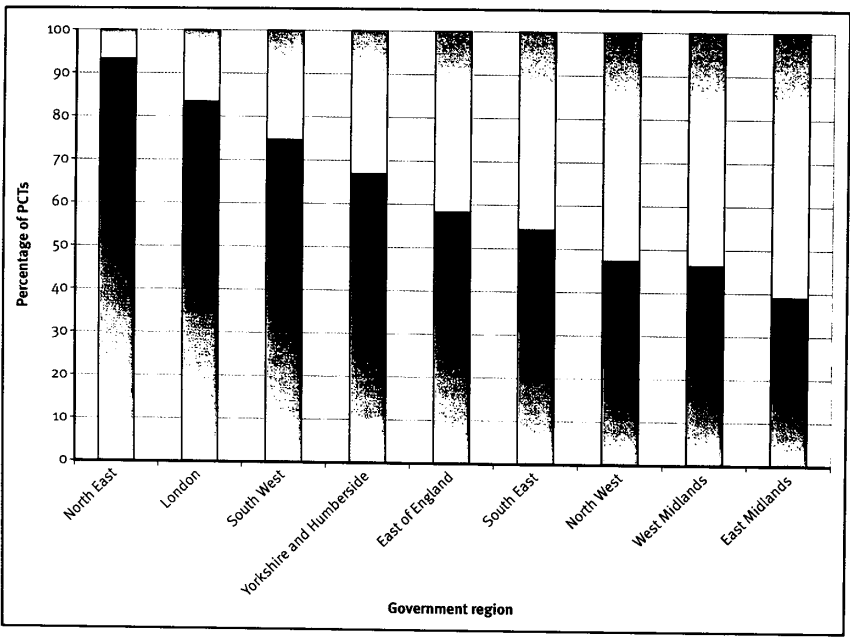|	Percentage	Number
PCTs with 'above average' minority population		70
With accessible race equality scheme	66%	46
Without accessible race equality scheme	34%	24
PCTs with 'below average' minority population		233
With accessible race equality scheme	59%	138
Without accessible race equality scheme	41%	95

When grouped by geographic area, such as Government Region, there is, again, no neat 'fit' between with the geography of diversity and the availability of race equality schemes (*see* Figure 1, overleaf). For example, London's performance (home to 44 per cent of England's ethnic minorities) is strong relative to the rest of England, with more than 80 per cent of trusts with a publicly available race equality scheme. But London is outperformed by the North East, where more than 90 per cent of trusts have a publicly available race equality scheme. Meanwhile, the West Midlands has a low percentage of PCTs with a race equality scheme, despite relatively high concentrations of ethnic minority populations.

There was a more obvious connection between the concentrations of ethnic minority groups in an area and the likelihood that PCTs have taken action to improve services and improve monitoring. This is perhaps to be expected, given that investment in extra services or monitoring is much more likely to be a function of the demographic makeup of PCTs. As Figure 2 (*see* overleaf) demonstrates, a greater proportion of the PCTs with above average ethnic minority populations fall into the categories of action rather than no action on access.

Similarly, PCTs with above average ethnic minority populations were more likely to have gone beyond the minimum level of monitoring, showing evidence of PCT- and GP-level monitoring of service uptake (*see* Figure 3, p 19).
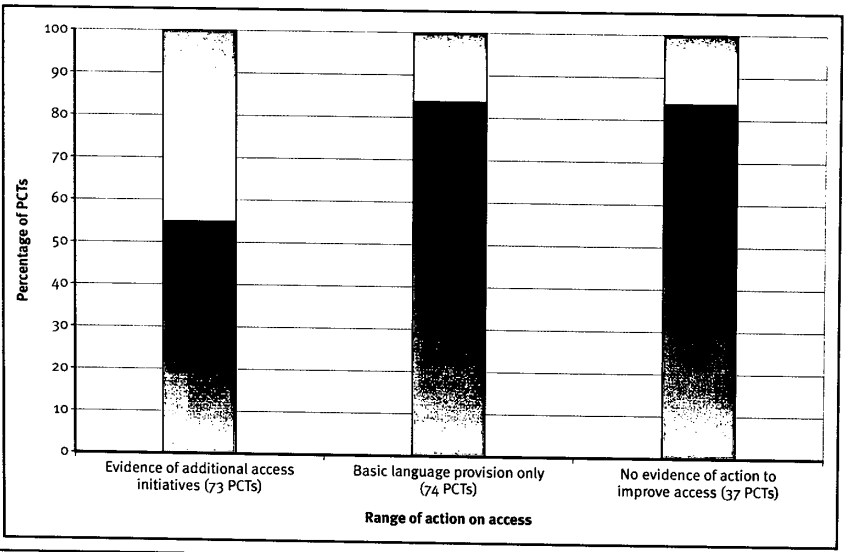
What is notable from this analysis is that there are outliers in both groups, including PCTs with very good initiatives on access and monitoring despite having predominantly 'white' (often rural) populations, while a few, more diverse, PCTs appear to have more limited

1 AVAILABILITY OF RACE EQUALITY SCHEMES (RES) BY REGION

Percentage of PCTs

North East, London, South West, Yorkshire and Humberside, East of England, South East, North West, West Midlands, East Midlands

Government region

KEY
☐ Without RES
▨ With RES

2 DEMOGRAPHY OF PCTS BY RANGE OF ACTION ON ACCESS INITIATIVES

Percentage of PCTs

Evidence of additional access initiatives (73 PCTs)
Basic language provision only (74 PCTs)
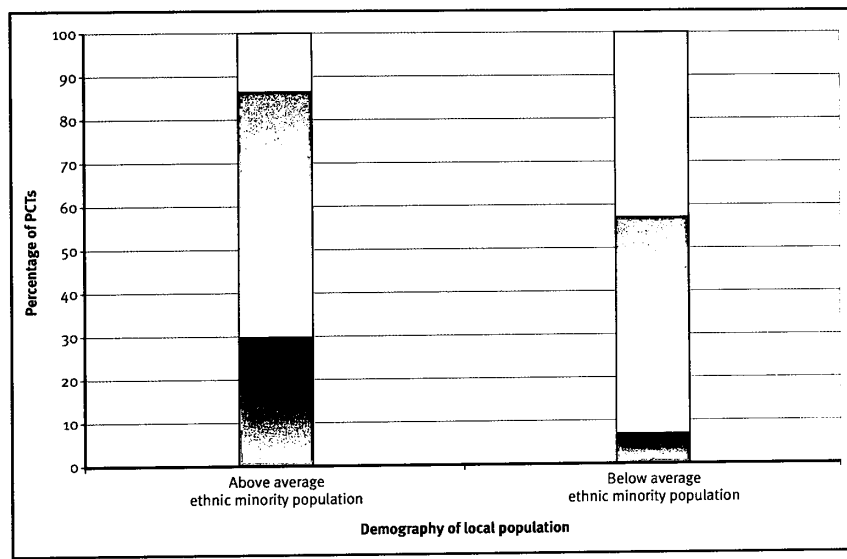No evidence of action to improve access (37 PCTs)

Range of action on access

KEY
☐ Above average ethnic minority population
▨ Below average ethnic minority population

3   **PCT ACTION TO MONITOR THE UPTAKE OF SERVICES BY DEMOGRAPHY OF LOCAL POPULATION**

evidence of activity on behalf of their ethnic minority populations, especially when compared with similar PCTs.

Some of those active, predominantly 'white', PCTs had published clear statements to explain their level of concern – for example:

> *Despite the low numbers of ethnic minority families, we are aware that we need to be just as committed to ensuring equal access to services for all our patients, clients, service users and staff, as we would if the demographic profile were different.*
> (Sedgefield PCT)

> *Small numbers should not mean that people are invisible to health services. It does mean that we need to be prepared to make changes on the basis of small numbers of people, and to understand success in terms of quality of service for individuals.*
> (Hereford PCT)

Conversely, other PCTs with similar demographic profiles used the fact of low numbers to build the opposite case – for example:

> *Most services felt that they were low risk for adverse impact, mostly due to the low percentage of patients from different racial groups that use the services.... Clinical services noted that they treat all patients as individuals, and so care is based on the individual's needs, which will include any difficulties with communication, religious and cultural needs.*

Discussion

The aim of this audit was to see if the published race equality schemes could shed light on what sort of activity has been prompted in PCTs across England in response to the requirements of the Race Relations Amendment Act.

At a superficial level, compliance with the legislation has been strikingly patchy. This research found a very similar pattern to that of the Healthcare Commission's study of August 2006: namely, that a significant minority of PCTs did not appear to have made public their race equality schemes or published employment monitoring figures. This raises immediate questions about the adequacy of efforts to monitor compliance with the legislation, even at this superficial level. Although the CRE is now considering taking action against trusts in the wake of the Healthcare Commission's audit, it appears that no action was taken against PCTs in the preceding period since the legislation came into force in 2002 (Commission for Racial Equality 2007).

However, as we have seen, the presence or absence of race equality schemes in the public domain only tells a partial story. In a very few cases, race equality schemes were absent from PCTs whose websites clearly showed a great deal of activity aimed at improving the access of ethnic minority groups to health care. More importantly, the presence of a race equality scheme in itself does not imply very much beyond basic compliance with the legislation.

It was only through close scrutiny of the content of the race equality schemes that it was possible to shed light on what sort of actions and initiatives have been tried by PCTs and what sort of barriers confront PCTs who have attempted to address the key question that lies behind the legislation – how can a PCT be sure that the NHS is being accessed equitably by all ethnic groups?

We found huge diversity in the content and style of race equality schemes, but more importantly, considerable variability in PCTs understanding of the link between ethnicity and health, as well as variations in evidence of activity to ensure or improve access to services. The outdated use of language (in some PCTs) and the 'list' approach to ethnic groups and ill health suggests a continuing gap between the insights of the research community and local NHS practice (Aspinall 2005b; Culley and Domaine 2006). There were plenty of examples of 'tickbox' race equality schemes – that is, schemes short on detail and lacking compelling evidence of any significant action towards promoting race equality at all.

However, an encouraging finding was that the quality of race equality schemes was not universally a function of a PCTs demographic make-up: there were a number of PCTs with very small ethnic minorities who had devised ways of assessing needs (often in the

absence of formal data), designed and delivered some sort of targeted services and published robust rationales for acting on behalf of small groups. There were also other PCTs, sometimes very similar in make-up, whose race equality schemes voiced a concern about their ethnic minorities, but where there was a lack of follow through. One conclusion from this audit might be that there is a great deal of untapped potential for PCTs with similar population profiles to learn from each other.

One less encouraging finding was that, in some cases, the Act appears to have been unable to focus PCTs on connecting race equality with their core business of providing and commissioning services. Aside from the small sub-set of PCTs who appeared to omit access to services completely from their relevant functions, there were many PCTs who failed to see their responsibility for race equality extending beyond the services that they provide directly themselves. Ensuring equity of access within PCT-delivered services is, of course, a valid and important task. However, these services only represent a small proportion of the spending on NHS services that takes place within a PCT's boundary.

The prospects for improvement in this area are, in theory, good. This research was conducted as PCTs were on the cusp of a major re-organisation – part of the complete overhaul of the functions and capabilities of PCTs that began in 2005 (Department of Health 2005b). PCTs (outside London) have been merged into much larger organisations (with their numbers halved to 152). There has been an intense 'fitness for purpose' exercise designed to lever up performance, accompanied, in many cases, by a change in the senior management of PCTs. In addition, there has been a welter of policy documents aimed at boosting the technical capacity of PCTs to commission services and a new vision for involving GPs in commissioning through the practice-based commissioning initiative (Department of Health 2006a). While it remains to be seen what impact these changes will have on race equality and access to services, the technical competency and role of PCTs as commissioners should, in theory, be vastly improved. This should mean that the issue of fair access to services should rise up the list of priorities for PCTs, making it less likely that race equality can be limited to a 'Human Resources' issue or ignored altogether.

Perhaps the most disconcerting finding of this audit is that so few PCTs appeared (at least in their race equality schemes) to have got to grips with the concept of 'equity of access'. Those that had were grappling with the difficulty of systematically quantifying the degree of inequity that might exist in access to services – a difficulty arising because of the enduring gaps in the data relating to ethnicity that determines need and service uptake in relation to need. Some PCTs appear to have got round this by commissioning surveys or pieces of academic research and engaging with community groups to create a more 'bottom up' approach to identifying potential service problems. While this is a legitimate approach, findings from these methods might be strengthened by quantifiable routine data, not least because it would allow a more systematic evaluation of the many and varied interventions that PCTs appear to be trying.

This raises the question of how improvements are to be made. One argument is that there is a great deal of data that is already coded to an adequate level (despite the perceptions of PCTs) and the challenge is to get PCTs to make better use of what they already have (London Health Observatory 2006). On the other hand, if progress is contingent on further improvements in ethnic coding (particularly in GP-delivered services), this raises a further question of who should bear the responsibility for achieving this. The legislation itself only

specifies that ethnic monitoring should be carried out for employment purposes, but it implies that there is a need for more widespread monitoring of services in order to demonstrate fair access.

As we have seen, many PCTs seem to have interpreted the need for the ethnic monitoring of services as relating narrowly to their own directly delivered services (with varying degrees of completeness). However, a minority of PCTs have been scrutinising hospital-level data and collecting ethnicity data at GP-practice level, in some cases, for several years. Very little has been published in the formal academic literature about the extent or application of this kind of monitoring; but in one of the few examples, the proponents of ethnic monitoring in primary care have made a strong case for its ability to drive evidence-based improvements for patients (Jones and Gardner 2003).

However, this sort of monitoring clearly has a cost and it is evident from our research that it is not being used on a wide scale, even in areas such as London, where city-wide targets were imposed by the former SHAs. One PCT (Westminster) reported in its race equality scheme that its main clinical body, the Professional Executive Committee (PEC), has 'significant concerns' about the usefulness of ethnic profiling in this form.

There is therefore a need to re-open the debate about what sort of ethnic monitoring is needed in primary care to permit effective commissioning, how it should be done, who should bear the cost and what benefits it might bring. It should be noted that it is only after sustained pressure from the regulator and other organisations that inpatient hospital data has now begun to reach respectable levels of completeness.

Conclusion

This research has confirmed the recent findings of the Healthcare Commission that a significant minority of trusts would appear to have placed race equality as a low order priority and failed to publish race equality schemes at all, or have published schemes that suggest very little analysis or understanding of whether ethnic minority people are getting fair access to services in the NHS. Given the limited inspection or regulatory pressure from the Commission for Racial Equality and other organisations so far, this is not necessarily a sign that the legislation itself has failed to drive change. It may be that better inspection or regulation would make the legislation more effective in the future. The Healthcare Commission has promised improvements to the way it regulates race equality in the NHS (Healthcare Commission 2006b), so it will be interesting to see what, if any, changes occur as a result.

Our analysis of the content of the race equality schemes has, however, raised a challenge in relation to compliance with the law. While it is clear that a minority of PCTs have invested in varied and imaginative services to ensure equality of access to health care, no PCT seems to be entirely confident about the scale of the inequities to be narrowed because of the gaps in the data. In other words, it might be technically impossible for PCTs to comply with the law because of the data gaps.

The government's NHS reforms envisage a revolution in the commissioning competency of PCTs (and GP practices) driven by improvements in data collection and analysis. The question of what data needs to be collected and how it can be used more appropriately in relation to ethnicity, needs to be urgently addressed if the NHS intends to deliver on its commitment to race equality.

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Appendix: Race Relations Amendment Act – general and specific duties

The following extracts are taken from the *Statutory Code of Practice on the Duty to Promote Race Equality* (Commission for Race Equality 2002c). The extracts describe the general and specific duties that are set out in the Race Relations Amendment Act, and include statements from the Act.

THE GENERAL DUTY (3.1)

3.1 [...] The duty is set out in section 71(1) of the Race Relations Act (the Act) and it applies to every public authority listed in schedule 1A to the Act (see appendix 1 of this code). Section 71(1) says:

Every body or other person specified in Schedule 1A or of a description falling within that Schedule shall, in carrying out its functions, have due regard to the need

a) to eliminate unlawful racial discrimination; and

b) to promote equality of opportunity and good relations between persons of different racial groups.*

SPECIFIC DUTIES: POLICY AND SERVICE DELIVERY (4.5–4.6)

4.5 Under the specific duties, which came into effect on 3 December 2001, the listed public authorities had to publish a race equality scheme by **31 May 2002**. The scheme is a timetabled and realistic plan, setting out the authority's arrangements for meeting the general and specific duties.

4.6 The scheme should show how the public authority plans to meet its statutory duties under section 71(1) of the Race Relations Act (the Act) and, in particular, articles 2(2) and 2(3) of the Race Relations Act 1976 (Statutory Duties) Order 2001.

2. (2) A Race Equality Scheme shall state, in particular –

(a) those of its functions and policies, or proposed policies, which that person has assessed as relevant to its performance of the duty imposed by section 71(1) of the Race Relations Act; and

(b) that person's arrangements for –

(i) assessing and consulting on the likely impact of its proposed policies on the promotion of race equality;

(ii) monitoring its policies for any adverse impact on the promotion of race equality;

(iii) publishing the results of such assessments and consultation as are mentioned in sub-paragraph (i) and of such monitoring as is mentioned in sub-paragraph (ii);

(iv) ensuring public access to information and services which it provides; and

(v) training staff in connection with the duties imposed by section 71(1) of the Race Relations Act and this Order.

(3) Such a person shall, within a period of three years from 31st May 2002, and within each further period of three years, review the assessment referred to in paragraph (2)(a).

SPECIFIC DUTIES: EMPLOYMENT (5.1–5.2)

5.1 The specific duty on employment applies to most of the public authorities bound by the general duty (see appendix 3). Schools and further and higher education institutions are not bound by the employment duty, as they have separate employment responsibilities (see chapter 6). A few, mainly advisory, agencies are also not bound by the employment duty.

5.2 Articles 5(1), 5(2), and 5(3) of the Race Relations Act 1976 (Statutory Duties) Order 2001 say the following:

> 5. *(1) A person to which this article applies shall,*
>
> > *(a) before 31st May 2002, have in place arrangements for fulfilling, as soon as is reasonably practicable, its duties under paragraph (2); and*
> >
> > *(b) fulfill those duties in accordance with such arrangements.*
>
> *(2) It shall be the duty of such a person to monitor, by reference to the racial groups to which they belong,*
>
> > *(a) the numbers of –*
> >
> > > *(i) staff in post, and*
> > >
> > > *(ii) applicants for employment, training and promotion, from each such group, and*
> >
> > *(b) where that person has 150 or more full-time staff, the numbers of staff from each such group who –*
> >
> > > *(i) receive training;*
> > >
> > > *(ii) benefit or suffer detriment as a result of its performance assessment procedures;*
> > >
> > > *(iii) are involved in grievance procedures;*
> > >
> > > *(iv) are the subject of disciplinary procedures; or*
> > >
> > > *(v) cease employment with that person.*
>
> *(3) Such a person shall publish annually the results of its monitoring under paragraph (2).*

Source: Commission for Racial Equality (2002c)