# NATIONAL INSTITUTE FOR HEALTH AND CLINICAL **EXCELLENCE**

# NICE'S EQUALITY SCHEME AND ACTION PLAN 2007-2010

# 1. Introduction

The National Institute for Health and Clinical Excellence (NICE) is committed to promoting equality and eliminating unlawful discrimination. We aim to comply fully with all legal obligations to:

- promote race and disability equality and equality of opportunity between men and women, and
- eliminate unlawful discrimination on grounds of race, disability, age, sex and gender, sexual orientation, and religion or belief in the way we carry out our functions and in our employment policies and practices.

This document sets out how NICE is meeting these obligations on equality and discrimination and what we still need to do. Under race equality and disability equality legislation NICE is required to produce race equality and disability equality schemes setting out in detail the action it is taking. The Department of Health recently noted that some NHS organisations are moving towards a single equality scheme, 1 and our Board has decided that this is the approach we should adopt. For these reasons, and because the various pieces of legislation have key features in common, we have decided to bring together in one document our race equality and disability equality schemes and our plan for promoting equality of opportunity between men and women. We also include the action we are taking to eliminate age discrimination and to tackle all forms of unlawful discrimination and harassment in employment. In implementing and monitoring this scheme we need to be aware of and take steps to avoid the risk that a single scheme approach may result in a superficial consideration of each distinctive experience of equality and failure to comply with the distinctive legal requirements of the three duties (see section 2 below).2

Many of the scheme's action points highlight issues for further consideration where significant resources or operational changes may be required. These issues will be considered as necessary by our senior management team and the Board, and we will report on progress in our annual equalities report.

We will revise the document to take full account of any guidance published when the requirement in the Equality Act 2006 to promote equality between

<sup>1</sup> Department of Health (2006) Creating a Disability Equality Scheme: A Practical Guide for the NHS.

www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/Public

ationsPolicyAndGuidanceArticle/fs/en?CONTENT\_ID=4139666&chk=B6%2BbZY

Disability Rights Commission (2006) Preparing and publishing your Disability Equality Scheme: Disability Rights Commission's position on single equality schemes. www.drc.org.uk/employers\_and\_service\_provider/disability\_equality\_duty/explaining\_the\_dut y/single equality schemes.aspx

the sexes comes into force in April 2007, and subsequently in response to the commencement of remaining anti-discrimination requirements.

# 2. The duty to promote equality and eliminate discrimination

# 2.1 Race equality

The Race Relations (Amendment) Act 2000 makes the promotion of race equality central to the work of 'public authorities' such as NICE. The Act places a general duty on NICE to carry out its functions with due regard to the need to:

- · eliminate unlawful racial discrimination
- promote equality of opportunity
- promote good relations between persons of different racial groups.

In meeting this duty, we need to be governed by the following principles:

- Promoting race equality is obligatory
- We must promote race equality in all relevant functions
- The weight we give to race equality in a function should be proportionate to its relevance for that function
- The elements of the duty are complementary in other words, we need to meet the duty imposed by each element in order to meet the whole duty.

There are additional 'specific duties' which are intended to satisfy the general duty. These are contained in the Race Relations Act 1976 (Statutory Duties) Order 2001 and they require us to:

- describe in a race equality scheme how we will meet the general duty; and
- monitor our employment and recruitment practices by gathering data on the racial profile of our staff and those who wish to work at NICE.

NICE's race equality scheme should include a statement of the functions and policies assessed as relevant to our duty to promote race equality, and our arrangements for:

- assessing and consulting on the likely impact of any policies we propose on promoting race equality
- monitoring any adverse impact of our policies
- publishing the results of assessments, consultations and monitoring
- ensuring public access to our information and services
- training staff in connection with the duty to promote race equality.

We must also review our scheme every three years.

# 2.2 Disability equality

The Disability Discrimination Act 1995 makes it unlawful to discriminate in areas including employment, access to goods and services, education and

transport against disabled people or people who have or have had in the past a disability. For the purposes of the Act, a person has a disability if 'he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities'. Guidance from the Department of Work and Pensions gives examples of the wide range of impairments that might result in disability. These are in addition to the case of people who are deemed to meet the definition of disability without having to show they have an impairment: that is, people who have cancer, HIV infection or multiple sclerosis, and people who are certified as blind or partially sighted or are registered as such.<sup>3</sup>

The Disability Discrimination Act 2005 amends the 1995 Act by requiring a public authority, such as NICE, to have due regard in carrying out its functions to the need to:

- eliminate unlawful discrimination against and harassment of disabled people
- promote equality of opportunity between disabled people and other people
- take steps to take account of the disabilities of disabled people, even where it involves treating them more favourably than other people
- promote positive attitudes towards disabled people
- encourage the participation of disabled people in public life.

We must also make reasonable adjustments to both the physical and sensory features of our premises, as well as to the design of policies and services where those features make it impossible or unreasonably difficult for disabled people to make use of our services.

As with the race equality legislation, these primary duties are reinforced by regulations – The Disability Discrimination (Public Authorities) (Statutory Duties) Regulations 2005. These require NICE and other public authorities to prepare a Disability Equality Scheme. The scheme must show:

- how disabled people have been involved in developing the scheme
- the arrangements for assessing the impact of current and future policies and procedures on disability equality and how the results will be used for improvement, and specifically within a three-year period
- a three-year action plan on how we intend to promote disability equality and accommodate it within our functions and policies

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<sup>&</sup>lt;sup>3</sup> See Department of Work and Pensions (2006) *Disability Discrimination Act – Guidance on matters to be taken into account in determining questions relating to the definition of disability.*www.drc-gb.org/the law/legislation codes regulation/guidance.aspx. Paragraph A6 lists the following impairments: sensory impairments, such as those affecting sight or hearing; impairment with fluctuating or recurring effects such as rheumatoid arthritis, ME/CFS, fibromyalgia, depression and epilepsy; progressive, such as motor neurone disease, muscular dystrophy, forms of dementia and lupus (SLE), organ specific, including respiratory conditions, such as asthma and cardiovascular disease; developmental, such as autistic spectrum disorders, dyslexia and dyspraxia; learning difficulties; mental health conditions and mental illness, such as depression, schizophrenia, eating disorders, bipolar affective disorders, obsessive compulsive disorders, as well as personality disorders and some self-harming behaviour; and impairment produced by injury to the body or brain.

- how the action plan will be monitored and reviewed
- how we will involve and work with partners to make improvements
- how and where the results of impact assessments and monitoring will be published.

Guidance for healthcare organisations from the Disability Rights Commission (DRC) advises that, when drafting clinical guidelines, standards and good practice guides, public authorities should take into account how these may be relevant to a wide range of disabled people. For example, it states that, in relation to guidance on health promotion, NICE must make sure the guidance is relevant to promoting good health for disabled people; and where a particular health inequality is well known, NICE may need to produce specific guidance for a group of disabled people.<sup>4</sup>

We should note three important points about the disability equality duty. First, DRC guidance advises that work on disability should follow a social model of disability rather than a medical model. A social model approach states that people with impairments are disabled by physical and social barriers. The 'problem' of disability results, therefore, from social structures and attitudes, rather than from, in the medical model view, an individual's personal functional limitations. This approach enables a focus on understanding and dismantling the barriers which exclude and limit the life chances of disabled people.<sup>5</sup>

Second, the disability equality duty differs from other equality legislation in that it is not merely about treating disabled and non-disabled people in the same way. Rather, it requires us to consider treating disabled people more favourably than other people, for example, by providing additional dedicated services or facilities, and does not restrict positive discrimination in favour of disabled people in any way.<sup>6</sup>

Third, the new duties are not meant to over-burden public authorities – we are expected to take action proportionate to our functions and resources. There is recognition that it will not always be possible for organisations to adopt the course of action that will best promote disability equality. However, we must ensure that we have due regard to the requirement to promote disability equality alongside other competing requirements.

<sup>&</sup>lt;sup>4</sup> Disability Rights Commission (2006) *Health and the Disability Equality Duty. Guidance for public authorities working in the health sectors in England and Wales.* <a href="www.drc-gb.org/library/publications/disability">www.drc-gb.org/library/publications/disability equality duty/health and the ded.aspx</a>
<sup>5</sup> Disability Rights Commission (2006) *The Disability Equality Duty: Guidance on gathering* 

<sup>&</sup>lt;sup>5</sup> Disability Rights Commission (2006) *The Disability Equality Duty: Guidance on gathering and analysing evidence to inform action.*<a href="https://www.drc.org.uk/library/publications/disability\_equality\_duty/guidance\_on\_evidence\_gathering\_aspx">www.drc.org.uk/library/publications/disability\_equality\_duty/guidance\_on\_evidence\_gathering\_aspx</a>

<sup>&</sup>lt;sup>6</sup> See 3 above.

# 2.3 Promoting equality between men and women

When the Equality Act 2006 comes into force in April 2007, NICE will have to have regard in carrying out its functions to the need to:

- eliminate unlawful sex discrimination and harassment
- promote equality of opportunity between men and women.

As yet, there is no formal guidance to help organisations implement the legislation.

# 2.4 Tackling age discrimination

Age discrimination legislation is about unlawful discrimination of various forms and harassment in employment. There are no duties in relation to age comparable to those of promoting race, disability and equality between the sexes, or eliminating discrimination in the exercise of public functions.

The key employment duties are contained in the Employment Equality (Age) Regulations 2006, which implement a European Community Directive establishing a general framework for equal treatment in employment and vocational training. The general effect of the regulations is to prohibit employers from directly or indirectly discriminating against or harassing job applicants or employees in the various circumstances of employment – from recruitment to dismissal – on grounds of age, although exceptions apply. The functions of the new Commission for Equality and Human Rights, which has been established under the Equality Act 2006 and will replace the current equalities commissions, include combating unlawful age discrimination.

# 3. NICE's role and the purpose of this equality scheme

NICE came into being in April 2005, bringing together in a new organisation the functions of the former National Institute for Clinical Excellence and Health Development Agency. NICE is responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health.

We produce guidance in three areas of health:

- public health guidance on the promotion of good health and the prevention of ill health for those working in the NHS, local authorities and the wider public and voluntary sector
- health technologies guidance on the use of new and existing medicines, treatments and procedures within the NHS
- clinical practice guidance on the appropriate treatment and care of people with specific diseases and conditions within the NHS

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<sup>&</sup>lt;sup>7</sup> See www.opsi.gov.uk/si/si2006/20061031.htm#3

NICE guidance helps to improve public health and make access to healthcare more equal across the country.

NICE aims to support policy-makers, planners, commissioners, and practitioners in the NHS, local government and related parts of the public sector. Patient and carer organisations and non-governmental organisations are also important stakeholders and recipients of our guidance. We produce versions of our guidance tailored for patients and the public, and work with statutory patient and public involvement structures – for example, local patient and public involvement forums, the Independent Complaints Advisory Services (ICAS), and Patient Advice and Liaison Services (PALs) – to publicise and help disseminate NICE guidance to individual patients and carers.

Apart from a general enquiry service, NICE does not provide services directly to individual patients or members of the public. However, we do involve patients, carers and members of the public as members of all our advisory bodies.

This equality scheme explains how NICE meets its duties to promote race and disability equality and equality between men and women, and tackle age and other forms of discrimination. It builds on the race equality schemes and other policies on equality and diversity of our predecessor organisations. More specifically, the paper sets out:

- how we believe NICE can contribute to achieving equality in the NHS and beyond
- our view of NICE's responsibilities and the principles that should underpin our approach to equality
- an analysis of the various NICE functions and policies that are relevant to duties on equality and eliminating discrimination and how we are taking account of our responsibilities
- what we intend to do over the next three years to ensure that NICE's work continues to have a positive impact on race and disability equality and equality between men and women
- who is to be accountable for the actions in our equality action plan.

Our approach is based on the principle that we enhance the effectiveness of our scheme and minimise any burdens arising from compliance with the law by embedding actions to meet equality duties in our routine procedures and practice. It follows from this that assessing the equality impact of our activities at the earliest stage of projects is a strong guarantee of attention to our equality duties at all subsequent stages.

# 4. Discrimination and health variations and inequalities

This section summarises how factors such as ethnicity, disability, sex, gender and age – whether singly or in combination – influence the pattern of health in

the population. It illustrates the complexity of the picture, particularly the importance of the interaction of these factors with socioeconomic status.

# 4.4 Race and health variations and inequalities

There are striking variations in health status, prevalence of diseases, and health behaviours among the ethnic groups in the population. For example, the 2004 Health Survey for England found that:

- Bangladeshi and Pakistani men and women have the highest prevalence of bad or very bad health and Black African and Chinese men and Chinese women the lowest.
- The prevalence of heart attacks is especially high among Pakistani men and women.
- Stroke rates are highest among Bangladeshi and Pakistani women and Black Caribbean and Irish men.
- Diabetes is more common among people from Black Caribbean and many Asian communities than in the general population.
- Men from most ethnic minority groups have markedly lower obesity rates than among the general population, but obesity rates in childhood are relatively high among Black African, Black Caribbean and Pakistani boys and Black African and Caribbean girls.
- The proportion of smokers among men in minority ethnic groups ranges from 21% among Black African and Chinese men to 40% among Bangladeshi men, compared with 24% of men in the general population. Among women, the highest prevalence of smokers is in the Irish and Black Caribbean groups, and the lowest among the South Asian and Chinese groups, especially Bangladeshi women.<sup>8</sup>

Improving health in the most deprived areas – the so called 'spearhead group' of 70 local authorities and (since the recent re-structuring of the NHS) 62 primary care trusts (PCTs)<sup>9</sup> – is an important part of the government's strategy on narrowing health inequalities. These areas have nearly half (44%) of the entire black and minority ethnic population of England but only 28% of the total population, and also contain 53% of the Muslim population, a section of the population with the highest levels of ill health. <sup>10</sup>

The Healthcare Commission's patient surveys have shown that patients from some ethnic groups (along with older people and women) perceive themselves as less likely to get good quality care for coronary heart

<sup>&</sup>lt;sup>8</sup> National Statistics and Health and Social Care Information Centre (2004) *Health Survey for England 2004: The health of minority ethnic groups – headline tables*.

www.dh.gov.uk/PublicationsAndStatistics/PublishedSurvey/HealthSurveyForEngland/HealthSurveyResults/fs/en

groups – headline tables.

www.dh.gov.uk/PublicationsAndStatistics/LettersAndCirculars/DearColleagueLetters/DearColleagu

Department for Communities and Local Government (2006) *Improving Opportunity,* Strengthening Society. One year on – A progress report on the Government's strategy for race equality and community cohesion. www.communities.gov.uk/index.asp?id=1501928

disease, 11 and patients in the white British and white Irish ethnic categories report better experiences of A&E, outpatient and PCT services than other ethnic groups, with South Asian respondents reporting the worst experience. 12 They also indicate that there are differences linked to ethnicity in satisfaction with the range of health services. For example, patients from black and minority ethnic groups are more likely than white patients to report low levels of involvement and a lack of respect from medical staff. 13

The Department of Health's 2003 consultation document *Delivering Race* Equality: a framework for action recognised that mental health services were not being delivered to people from Black and minority ethnic communities experiencing mental illness and distress in a way that was appropriate to their needs. 14

These inequalities relate to variations in disease prevalence, differential access to services, differential delivery and take-up of services, and differential exposure to risk factors. However, ethnicity is only one of several linked but separate dimensions of inequality. For example, research suggests that socioeconomic disadvantage is a major contributor to the poorer health of African-Caribbean, Bangladeshi and Pakistani groups – and exposure to racism is an important part of why some groups in the population are more disadvantaged than the wider population.

There is evidence that the experience of discrimination may take an additional toll on the health of certain minority ethnic groups. Associations between ethnicity and inequalities in health status and access also need to be considered in relation to factors such as language and communication barriers.

# 4.4 Health inequalities and people with disabilities

Around 10 million people in the UK live with a limiting long-term illness or disability that restricts daily activity. 15 The chances of living in good health and without impairment are much higher for people in more advantaged circumstances than for those in poverty. Inequalities in childhood health experience persist in adulthood – self-rated health is considerably poorer for those in 'routine and manual occupations' compared with those in managerial and professional occupations, and this is also the case for long-term illnesses

<sup>&</sup>lt;sup>11</sup> Healthcare Commission (2005) Coronary heart disease – Survey of patients 2004. www.healthcarecommission.org.uk/nationalfindings/surveys/patientsurveys/nationalnhssurvey 2004-2005.cfm

<sup>&</sup>lt;sup>12</sup> Commission for Health Improvement (2004) *Unpacking the patient's perspective: Variations* in NHS patient perspective in England. Healthcare Commission. www.healthcarecommission.org.uk/nationalfindings/surveys/patientsurveys.cfm

<sup>&</sup>lt;sup>13</sup> Healthcare Commission (2006) Variations in the experiences of patients using the NHS services in England. Analysis of the Healthcare Commission's 2004/2005 surveys of patients. www.healthcarecommission.org.uk/nationalfindings/surveys/patientsurveys.cfm

14 Department of Health (2003) *Delivery Race Equality: A framework for action.* 

<sup>&</sup>lt;sup>15</sup> See www.statistics.gov.uk/cci/nugget.asp?id=1326

and impairments that limit the performance of everyday tasks and for psychological well-being.<sup>16</sup>

The Disability Rights Commission (DRC) has been particularly concerned with the health inequalities affecting people with learning disabilities and mental health problems. Its recent report, Equal treatment: Closing the Gap, 17 highlights that:

- Someone with a major mental health problem is more likely to develop a significant illness such as diabetes. CHD, stroke or respiratory disease than other citizens, more likely to develop it before the age of 55, and once they have it – more likely to die within five years.
- People with depression have higher risk of key physical illnesses than other citizens.

Area studies for the report found that people with learning disabilities:

- had higher rates of respiratory disease than the remaining population
- were more likely to be obese than the remaining population
- were more likely to die younger than other citizens, and have high rates of unmet health needs, which may contribute to an early death.

A major area of concern was the patchiness of the response from primary care services and from government. In primary care, these high risk groups were less likely to receive some of the expected, evidence-based checks and treatments than other patients, and efforts to target their needs specifically were ad hoc. For example, people with mental health problems with heart disease receive cholesterol checks and statins less often than others with heart disease; people with learning disabilities with diabetes receive fewer measurements of their body mass index than others with diabetes; and they have very low cervical and breast cancer screening rates. At government level, these groups have not been systematically targeted by programmes to reduce health inequalities, which have mainly focused on socially deprived areas.

Furthermore, people with learning disabilities and people with mental health problems experience 'diagnostic overshadowing' - i.e. reports of physical ill health are viewed as part of the mental health problem or learning disability and so not investigated or treated. (This also means that levels of ill health may be higher than the DRC's figures suggest.)

Healthcare Commission patient surveys have found that patients who describe themselves as having a disability that affected their day-to-day

<sup>&</sup>lt;sup>16</sup> Nocon A (2006) Background evidence for the DRC's formal investigation into health inequalities experienced by people with learning disabilities or mental health problems. See link to 'evidence paper 2006' at www.drc-

gb.org/newsroom/health\_investigation/research\_and\_evidence.aspx

Disability Rights Commission (2006) Equal treatment: Closing the gap. www.drcgb.org/newsroom/health investigation.aspx

activities are significantly more likely to have a negative experience of healthcare services than patients without a disability. 18

# 4.3 Health variations and inequalities between men and women

Biological (or sex) differences between men and women affect their need for healthcare. There is growing evidence that these differences go beyond the reproductive system and that there are genetic, hormonal and metabolic variations affecting male and female patterns of heart disease, infections and a range of auto-immune problems. Health is also shaped by social gender – differences in living and working conditions of women and men and access to resources put them at differential risk of developing some health problems, while protecting them from others. <sup>19</sup>

The following are examples of variations and inequalities relating to sex and gender:<sup>20</sup>

- Average life expectancy at birth is greater for women than men (81.8 years compared with 76.7 years)
- Women can expect to spend more years free of disability than men (63 years compared with 60.9 years)
- Although women can expect to live longer than men, they are also more likely to spend more years in poor health or with a disability
- Differences between men and women in mortality are in general smaller in areas of relative affluence and greater in the most deprived areas
- Women have greater morbidity than men from poor mental health, and psychosocial heath in women is strongly influenced by socioeconomic status
- Men are twice as likely as women to drink more than the recommended daily limits for alcohol consumption
- Death rates from circulatory diseases have declined more rapidly in men than in women in the last 30 years
- Women with angina are less likely to be referred to a specialist or to have revascularisation than men.

# 4.4 Age discrimination and health

Policy developments such as the national service framework (NSF) for older people, the children's NSF, and national healthcare standards emphasising the need to treat patients with dignity and respect and provide equitable access to services and treatment reflect a moral duty to tackle age

<sup>&</sup>lt;sup>18</sup> See 9 above.

<sup>&</sup>lt;sup>19</sup> Doyal L et al (2003) *Promoting gender equality in health*. Equal Opportunities Commission. <u>www.eoc.org.uk/Default.aspx?page=15570</u>

<sup>&</sup>lt;sup>20</sup> Sources: Department of Health (2002) *Tackling health inequalities. 2002 cross-cutting review.* 

www.dh.gov.uk/PublicationsAndStatistics/PublicationsPublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT\_ID=4098280&chk=o/%2BsLZ; National Statistics website 'Focus on gender' <a href="https://www.statistics.gov.uk/focuson/gender/">www.statistics.gov.uk/focuson/gender/</a>

discrimination in the NHS.<sup>21</sup> The National Director for Older People's report on the next steps for the NSF for older people describes an improving overall situation but notes that, although overt age discrimination is now uncommon in the care system, there are still deep-rooted negative attitudes and behaviours towards older people.<sup>22</sup> Recent Healthcare Commission surveys have found that older people are more positive about the range of NHS services they receive than other patient groups.<sup>23</sup>

A common feature of the children's and older people's NSFs – and of policy across government concerned with children and older people – is the emphasis on involving children and older people in planning and delivering services as a safeguard against discrimination.

# 5. NICE's commitment to equality

NICE is committed to promoting equality and tackling discrimination as part of its role of developing evidence-based guidance for improving public health, making access to healthcare more equal, and reducing health inequalities. The inclusion of public health in our remit following the public health white paper, *Choosing Health*, <sup>24</sup> has enabled us to sharpen our focus on all aspects of health inequality, including health inequalities associated with ethnicity or affecting disabled people.

Our guidance is an important element in the national healthcare standards, *Standards for Better Health*, <sup>25</sup> which define the level of quality all organisations providing NHS care must meet or aspire to. It also progressively adds substance to all the national service frameworks, thereby supporting efforts to ensure equity in access to services.

NICE must ensure that it helps healthcare organisations to satisfy the requirement in the current NHS planning framework to interpret and implement the healthcare standards in ways which:

- challenge discrimination
- promote equality of access and quality of services

21 Department of Health (2001) National Service Framework for Older People; Department of Health (2004) National Service Framework for Children, Young People and Maternity Services: Department of Health (2004) Standards for Better Health.

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Services; Department of Health (2004) Standards for Better Health.

22 Philp I (2006) A New Ambition for Old Age. Next Steps in Implementing the National Service Framework for Older People.

www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/Public ationsPolicyAndGuidanceArticle/fs/en?CONTENT\_ID=4133941&chk=UKWFIL

23 See 9 above.

<sup>&</sup>lt;sup>24</sup> HM Government (2004) *Choosing Health – Making healthy choices easier*.

www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/Public

ationsPAmpGBrowsableDocument/fs/en?CONTENT\_ID=4097491&chk=KPBy7H

<sup>25</sup> Department of Health (2004) Standard for Data the first fo

<sup>&</sup>lt;sup>25</sup> Department of Health (2004) *Standards for Better Health*. <u>www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT\_ID=4086665&chk=iXDWU6</u>

- support the provision of services appropriate to individual needs, preferences and choices
- respect and protect human rights
- further the NHS's reputation as a model employer
- enable NHS organisations to contribute to economic success and community cohesion.<sup>26</sup>

Our Board is committed to ensuring that we comply fully with the general and specific duties contained in equalities and anti-discrimination legislation and meet the standards with regard to equality expected of all NHS organisations. It is conscious that discrimination can occur inadvertently and has stated that NICE and its advisory bodies should be especially vigilant in avoiding all forms of discrimination.

NICE has a primary legal and moral responsibility for ensuring the promotion of race and disability equality and the elimination of discrimination on age and other grounds and that this is met by an effective policy, which is continually monitored.

*NICE's services*: We will take all reasonable steps to communicate our work to all sections of the community, taking account of our primary remit to provide guidance to the NHS and other public sector service providers.

Stakeholders and contractors: We will promote race and disability equality by ensuring that the need to comply with race and disability equality duties is built into expectations of working arrangements and performance requirements for the delivery of services to NICE.

Equal opportunities: We are working to promote equal opportunities in service provision and employment. It is our agreed policy to work towards ensuring that no recipient of our services and no present or future employee or job applicant receives less favourable treatment on grounds of age, gender, race, gender reassignment, religion or beliefs, colour, HIV status, sexual orientation, disability, ethnic origin/race (taking account also of Gypsy Travellers), nationality, national origin, marital status, social and employment status, domestic circumstances, nationality, trade union membership, or political affiliation.<sup>27</sup> Our policy works to ensure that no present or future employee or job applicant is disadvantaged by any conditions or requirements that cannot be shown to be justified and that the needs of particular groups are identified and addressed within legal parameters. 28 We implement the policy in accordance with the statutory requirements in relevant legislation. In addition, we take full account of all available guidance, in particular, the statutory codes of practice on the duties to promote race equality and disability equality.

<sup>28</sup> See www.nice.org.uk/page.aspx?o=94062

<sup>&</sup>lt;sup>26</sup> Department of Health (2004) *National Standards, Local Action. Health and Social Care Standards and Planning Framework 2005/06-2007/08.*<sup>27</sup> NICE (2002) Frank (2003) Fr

<sup>&</sup>lt;sup>27</sup> NICE (2003) Equality and Diversity Policy. <a href="https://www.nice.org.uk/page.aspx?o=94060">www.nice.org.uk/page.aspx?o=94060</a>

We aim to ensure through this equality scheme and action plan that the duties to promote race and disability equality and equality between men and women, and eliminate age discrimination are embedded in the processes and standard operating procedures that underpin the production and dissemination of NICE guidance, and in the services and products aimed at supporting its implementation.

# 6. Involving disabled people in NICE's equality scheme

We are required by legislation to show how disabled people have been involved in developing this equality scheme. So far, we have involved disabled people in projects that will inform the scheme:

- We commissioned DISC (Disability Camden) to carry out a disability audit
  of NICE's London office, which has informed actions to make the building
  as accessible as possible see section 14.
- Specific initiatives have focused on meeting the needs of disabled people

   for example, our communications teams set up a user group to help
   develop the new NICE website that included people able to comment on
   the needs of people with visual and hearing impairments see section 9.5.
- We involve disabled people by including people with a patient, carer or community viewpoint, including users of mental health services, in our advisory bodies – see section 9.4.
- We have acted on feedback from people with disabilities who have engaged with NICE in the past to inform the content of this scheme

We now need to establish a more systematic approach to involving disabled people in shaping the actions proposed in this scheme and assessing our progress in implementing them. We also believe that this good practice should be extended to other groups affected by the equality scheme.

#### Action

1. We will build on work carried out to date by involving disabled people in a structured, systematic and significant way in the actions on NICE's disability equality duty emerging from this scheme and in reviews of the scheme, and we will extend this approach to other groups affected by the equality scheme.

# 7. Functions and policies assessed as relevant to equality duties

In line with legislation and guidance from the Commission for Race Equality, the Disability Rights Commission, and the Department of Health, we have analysed NICE's functions and identified changes that would be likely to have a positive impact on equality or, at least, eliminate the risk of an inadvertent negative impact. This has not been an entirely straightforward task as NICE, unlike frontline healthcare organisations, influences the world mainly through others, which makes it difficult to evaluate our impact on race and disability equality, equality between men and women, and on health inequalities more generally.

NICE's overarching function is the production and provision of guidance to the NHS and others. Underpinning it is a number of other functions, each of which must contribute to the goal of promoting equality. These are:

- 1) Guidance development (see sections 8 and 9), which includes:
  - Topic selection
  - Involving stakeholders
  - Guidance scoping
  - Appraising the evidence base
  - Establishing advisory bodies
  - Public involvement through consultation
  - Making guidance recommendations
  - Making research recommendations
  - Accountability arrangements.
- 2) Dissemination of guidance, including information for patients and the public, and using channels such as local NHS trusts and patient and other stakeholder organisations (see section 10)
- 3) Support for implementation of guidance, and impact monitoring (see section 11)
- 4) Procurement of services connected with guidance development and other functions, such as the services of collaborating centres (see section 12)
- 5) Employment, recruitment and human resources policies and practices, including monitoring (see sections 13 and 14)
- 6) Corporate accountability for equality impact, including the role of the Board and the Citizens Council and Partners Council (see section 15)
- 7) Cross-organisational functions, particularly the Patient and Public Involvement Programme (PPIP) and Communications (see section 16).

# 8. NICE's overarching function – production and provision of guidance

# 8.1 Principles informing production and provision of guidance

NICE's overarching function is to provide the NHS and others with evidence-based guidance on the clinical effectiveness and cost effectiveness of the clinical and public health interventions referred to it by the Department of Health for appraisal. This guidance is informed by principles based on the ethical principles, preferences, culture and aspirations that should underpin the nature and extent of the care provided by the NHS.<sup>29</sup> The document *Social Value Judgements – principles for the development of NICE guidelines* 

<sup>&</sup>lt;sup>29</sup> NICE (2005) Social value judgements – principles for the development of NICE guidelines. www.nice.org.uk/page.aspx?o=svjquidance

sets out these principles and is periodically reviewed and augmented in light of advice from NICE's Citizens Council (see section 15). Currently, the most directly relevant principles are as follows:

- Race equality: 'NICE clinical guidance should only recommend the use of an intervention for a particular racial (ethnic) group if there is clear evidence of differences between racial (ethnic) groups in the clinical effectiveness of the intervention that cannot be identified by any other means'.
- Age: 'NICE clinical guidance should only recommend the use of a therapeutic or preventive measure for a particular age group when there is clear evidence of differences in the clinical effectiveness of the measure in different age groups that cannot be identified by any other means.'
- Gender and sexual orientation: 'In setting priorities there is no case for the Institute or its advisory bodies to distinguish between individuals on the basis of gender or sexual orientation unless these are indicators for the benefits or risks of preventative or therapeutic interventions.'

# 8.2 General approach to promoting equality through guidance

There are three main ways in which we promote equality through the guidance function. First, we build on the above principles by ensuring through a process of screening for equality relevance that our guidance gives proper weight to the various equality considerations that might be important for a given health topic or intervention. Thus in relation to race, disability, sex and gender, age, and socioeconomic status we look for evidence of variations and inequalities in, for example:

- mortality and disease patterns
- health-related behaviour
- access to and uptake of clinical and preventive services and public health programmes
- experiences of and attitudes to services
- diagnostic overshadowing in the case of people with learning disabilities or mental health problems, or neglect of the health needs of disabled people with co-existing impairments
- the effectiveness of clinical, preventive and public health interventions.

Second, we ensure that, for any given health topic or intervention, people – that is, patients, carers, and (in the case of public health guidance) community members – from the groups affected by these variations and inequalities, representative organisations, and professionals with particular expertise are involved in the development of guidance. Those affected include disabled people with co-existing impairments related to the health topic in question, along with organisations of disabled people and professionals with expertise in the health of disabled people.

Third, it is essential that patients, carers and members of the public from all ethnic groups – whatever their age, sex or sexual orientation – have equal

access to opportunities for involvement in the development of NICE guidance in general, and that it is as easy as possible for disabled people to participate.

As noted in section 7, a number of functions and related processes underpin the production of guidance. We must make sure that the importance of our equality duties and the need for assessing relevance to equality is embedded in quality assurance mechanisms, particularly the various manuals governing the way we carry out our work, and in final sign-off procedures for guidance recommendations. In this way we can eliminate the risk that relevant issues of ethnicity, disability, equality between men and women, or age discrimination might be neglected in the development of guidance.

# 8.3 Statements of standards of patient-centred care

All NICE guidance on clinical practice contains a standard section on the need for healthcare professionals to take account of the individual patient's needs and preferences; their responsibility for following guidance on consent to examination and treatment, including codes of practice on working with patients who lack the capacity to understand the options on offer; and the need for treatment, care and information to be culturally appropriate and in a form that is accessible to people who have additional needs, such as people with physical, cognitive or sensory disabilities, and people who do not speak or read English.

A statement of this sort, revised in the light of new equality duties and in versions suitable for each type of guidance and implementation advice, can play a part in demonstrating NICE's commitment to promoting equality and supporting the NHS and other public sector organisations which must also meet equality duties.

Any statement should take account of the Mental Capacity Act 2005, which comes into effect in April 2007. The Act's definition of a person who lacks capacity focuses on the particular time at which a decision about treatment and care has to be made and the particular matter to be decided, and not on any theoretical ability to make decisions generally. Thus determinations of capacity should not merely be made on the basis of a person's age, appearance (including skin colour) or unjustified assumptions about capacity based on the person's condition (for example, a physical or learning disability) or behaviour. The statement should also refer to the social model of disability and its focus on removing barriers to participation of disabled people – see section 2.2.

#### **Action**

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2. We will ensure that all guidance and implementation advice contains a statement that includes appropriately tailored references to how professional and organisational practice should reflect equality requirements and the provisions of the Mental Capacity Act 2005.

<sup>&</sup>lt;sup>30</sup> See 'Explanatory Notes to Mental Capacity Act' at www.opsi.gov.uk/acts/en2005/2005en09.htm

# 8.4 Terminology in this scheme

Three internal centres (the Centre for Health Technology Evaluation, the Centre for Clinical Practice, and the Centre for Public Health Excellence) are responsible for producing the various kinds of NICE guidance. There are differences in the procedures that govern the work of these centres. For example, the structure of NICE advisory bodies (our advisory and guidance development committees), and mechanisms for involving stakeholders and consulting more widely vary from centre to centre. These differences are not significant as far as NICE's equality duties are concerned, so we have not described them in detail in this scheme. Instead, we use the term guidance to cover public health intervention guidance and public health programme guidance, technology appraisals, clinical guidelines, and interventional procedures guidance. Also, we discuss the relevant generic processes using terminology that may not exactly match that used in descriptions of the work of these centres on our website and in the manuals describing their methods and procedures.31

In the next section we describe the progress we have made in relation to key processes in guidance development and our proposals for further action.

# 9. Functions and processes underpinning guidance

# 9.1 Topic selection

Does the process of deciding on topics to be referred to NICE take account of implications for equalities?

Suggestions on topics for guidance come from a number of sources, including patients, carers, and the public. Our website provides information on making suggestions and encourages and enables people to make suggestions online. However, it is the Department of Health which makes the final decision about the topics to be referred to NICE.

Since September 2006, NICE coordinates the early stages of the topic selection procedure, sifts topic suggestions for appropriateness and produces a detailed 'topic profile' of all candidate topics using criteria laid down by the Department of Health. Expert 'consideration panels' consider these topics against the criteria, assess their relative priority, and refer them to the Department of Health committee that in turn makes recommendations to Ministers. The criteria reflect the government's interest in narrowing health inequalities and ensuring that the needs of sub-groups in the population are recognised.<sup>32</sup> Topic selection represents the earliest opportunity in the guidance development process to assess the potential impact of a topic on equalities. (It is important to note that the Department of Health's equality

<sup>&</sup>lt;sup>31</sup> See <a href="www.nice.org.uk/page.aspx?o=114218">www.nice.org.uk/page.aspx?o=114218</a> for technology appraisals, www.nice.org.uk/page.aspx?o=114219 for clinical guidelines, and www.nice.org.uk/page.aspx?o=295452 for public health guidance <sup>32</sup> See www.nice.org.uk/page.aspx?o=364841

scheme contains a commitment to conduct equality impact assessments of its own policies.<sup>33</sup>)

We advertise through our website for members of these expert consideration panels, and are monitoring the ethnicity, country of birth, age, and marital status of applicants and whether they consider themselves to be disabled. The panels are made up of health, social care and public health professionals. academics and researchers, as well as people who bring a patient, carer, and/or a community viewpoint.

#### Action

- 3. In preparing each topic profile for the selection process, we will seek within available resources to identify any issues relevant to race, disability and sex/gender equality and age discrimination that should be considered.
- 4. We will formally record the conclusions of these assessments of potential equality impact, including where no relevant issues are identified.
- 5. We will highlight gaps in information about a topic that prevent assessment of potential equality impact.
- 6. We will review the extent to which our methods for involving people and organisations in making topic suggestions are reaching a wide range of patients, carers and members of the public, particularly people from black and minority ethnic groups and disabled people; and whether there are ways of providing access to the process in addition to NICE's website.
- 7. We will consider whether we can include additional prompts and examples in our online 'suggest a topic' form that would encourage people wanting to highlight issues they regard as important in relation to equality.
- 8. We will consider whether the online 'suggest a topic' form should include a confidential section in which respondents can volunteer information for monitoring purposes about their ethnicity, country of birth, age, and sex or gender, and whether in light of the legal definition of a disabled person and related guidance they consider themselves to be disabled.
- 9. In addition to seeking information for monitoring purposes from applicants for membership of expert consideration panels, we will monitor the composition of the panels themselves and publish data about them in our annual equalities report.

# 9.2 Involving stakeholders

What efforts are made to find and ensure the involvement of all relevant stakeholders in the topics referred to NICE?

At a very early stage in developing guidance, we publish on our website and via the media an open invitation to interested national organisations to register as stakeholders and we make direct contact with key stakeholders. Stakeholders include organisations representing patients, carers or

<sup>&</sup>lt;sup>33</sup> Department of Health (2006) Single Equality Scheme 2006-09. www.dh.gov.uk/PublicationsAndStatistics/PublicationsPublicationsPolicyAndGuidance/Public ationsPolicyAndGuidanceArticle/fs/en?CONTENT\_ID=4140896&chk=WUpH/B

communities affected by the topic, as well as health, social care and children's services commissioners and providers, health professionals and professionals in sectors such as education and local government, academics, professional bodies and trade unions, non-governmental organisations, and relevant industries.

The purpose of formal registration is to stimulate active engagement – stakeholders can be sure that they will be alerted to all the documentation about the guidance and to opportunities to comment at key stages, from taking part in a consultation meeting about the initial scoping of the guidance through to consultations on final drafts.

We consult both internally and externally when identifying and recruiting stakeholders and use the expertise of the Patient and Public Involvement Programme to identify organisations that represent relevant patient, carer or lay constituencies (see section 16). These organisations predominantly represent people affected by the various diseases and conditions that lead to the impairments from which a disability may arise. In addition, we also carry out targeted activities to enable more groups representing the interests of black and minority ethnic groups to understand how the stakeholder role can influence NICE guidance production and to register as stakeholders.

#### Action

- 10. We will reinforce our commitment to recruiting the widest possible range of topic-relevant stakeholders, including national organisations representing relevant black and minority ethnic groups and disabled people, by highlighting it as an action in manuals of procedures in the next review of these manuals. (The manuals of methods and procedures of our guidance centres are reviewed on a three-year cycle.)
- 11. We will review the effectiveness of our arrangements for recruiting stakeholders representing the views of people with mental health problems and learning disabilities about health topics affecting them, and consider whether additional measures are required.
- 12. We will continue to develop links with national networks concerned with the health of people from ethnic minority groups (including those within organisations representing a wider patient population), and with the rights and health of disabled people.

# 9.3 Guidance scoping

How does NICE ensure a continuing focus on the impact of guidance on equality during the development process?

At an early stage of the process, NICE prepares a scoping document about the guidance topic. The scope is a formal document defining precisely what guidance will and will not cover, whom in the population it is intended for, the settings in which use of the intervention in question is appropriate, and other matters to be included or excluded. It is based on an analysis of a range of scientific literature and other information, as well as contributions from stakeholders and comments from the public. The topic profile from the new topic selection procedure will be an important input to the scope in the future.

The scope thus constitutes a detailed brief for the various academic and professional agencies and collaborating centres to which we contract the tasks of evaluating the evidence and making draft recommendations. It is an important guarantee that where an impact on any aspect of equality has been identified as a factor in a topic, that factor is given due prominence in the search for evidence and the resulting guidance and recommendations. We consult widely with groups representing professionals, patients and carers, black and minority ethnic groups, disability groups, and public interest groups who can comment on the scope to let us know if any issues requiring specific attention have been inappropriately omitted.

At present, our centres' manuals of methods and procedures express in various ways the requirement to consider in scopes the relevance of topics to sub-groups in the population, minority ethnic groups, equity in service provision, and health inequalities, including those affecting disabled people.

#### Action

- 13. In the next review of the manuals of our guidance centres we will seek to make them more consistent in describing how impact on equalities will be assessed in the scoping process.
- 14. We will improve our practice so that we formally record the conclusions of these assessments of impact on equalities, including where no impact is identified.

# 9.4 Composition of advisory bodies involved in guidance development

How does NICE try to ensure that the advisory bodies involved in guidance development reflect the diversity of the population? How does NICE ensure that, where equality impacts have been identified, relevant organisations have the opportunity to nominate lay members?

Independent advisory bodies play a crucial role in producing NICE guidance. Broadly, these advisory bodies either steer the production of individual items of guidance, and disband when the task is complete, or are standing committees overseeing whole categories of guidance over a fixed period. They are made up of people from a range of interests and backgrounds. All advisory bodies include at least two people whose role is to provide a patient/public perspective. The criteria in the person specifications for these roles explicitly include personal experience of the condition or public health topic. We proactively encourage organisations representing black and minority ethnic groups to nominate people to sit on these advisory bodies. We also advertise for members through our website.

Given the particular inequalities affecting people with mental health problems and learning disabilities, we need to explore whether our current arrangements for appointing members of advisory bodies provide us with expert and lay views on the implications of guidance for people with disabilities.

All advisory bodies working on guidance on clinical practice in mental health include mental health service users and carers as full members, and service users are invited as patient experts to meetings of the technology appraisal advisory body considering mental health medicines and treatments.

It is not feasible to run our standing advisory bodies in ways that would make it possible for people with significant learning disabilities or cognitive impairments to participate as full members. However, we have encouraged groups that represent the views of people with learning disabilities to join advisory bodies developing guidance that impacts specifically on the needs of people with learning disabilities, for example, that on long-acting reversible contraception.

We have commissioned work with children and young people to inform guidance topics that cover children's conditions (for example, type 1 diabetes, depression in children, and children's cancers). There is potential to do this more systematically.

We support disabled people to attend advisory body meetings by identifying in advance member's needs in relation to access and support, paying for carers who need to accompany patient members and for carers who are their supporters. There are inconsistencies according to type of guidance in our policies for paying lay members for the time they spend on advisory bodies. This may affect the age and social class profile of some of our advisory bodies and our ability to recruit younger people, who may not be able to afford the necessary time off work.

#### **Action**

- 15. The manuals of our guidance centres vary in how they express the need to reflect the diversity of the population on advisory bodies. In the next review of these manuals we will consider how we can achieve more consistency among centres.
- 16. We will make nominating organisations aware of our commitment to promoting equality and tackling discrimination and encourage them to operate within that spirit.
- 17. We will consider the feasibility for all advisory bodies of a confidential section in application forms, similar to that for monitoring applicants for expert consideration panels (see section 9.1), which would invite people who are nominating themselves to provide information about their ethnicity, country of birth, age, sex/gender, and whether in light of the legal definition of a disabled person and related guidance they consider themselves to be disabled.
- 18. Once the necessary information is available, we will monitor the

composition of advisory bodies in order to assess our success in recruiting disabled people and people from black and minority ethnic groups, and achieving a balance between the sexes. We will report monitoring data in our annual equalities report.

19. We will review our policies on paying lay members of advisory bodies in view of the need to achieve a representative membership, and seek to arrive at a consistent approach across guidance types.

# 9.5 Involving all sectors of the public in consultations on draft guidance

How does NICE encourage responses to consultations on draft guidance from all sectors of the public, including ethnic minority groups and people with disabilities?

We encourage the public and interested organisations, including those registered as stakeholders, to comment on guidance by publicising consultations through the media, and enabling them to respond via our website. The site gives guidance on standard features that can be switched on by people with visual impairments and people who have difficulty using a mouse. It also has special features including a 'vision impaired' button that converts the entire site into text-only mode using contrasting colours but retaining normal navigability, and information about products such as speaking browsers. The site aims to achieve at least the minimum standards defined by the World Wide Web Consortium (W3C).<sup>34</sup> We monitor it regularly and address any non-compliance issues brought to our attention.

As noted in section 9.2, we encourage groups representing ethnic minority interests to register as stakeholders and respond to consultations. We also work with organisations that represent wider patient or public groups to encourage them to include the views of their own internal ethnic minority group networks (where they exist) when they formulate their responses.

However, we recognise that other techniques are necessary to gather the views of particular groups or gain more depth of understanding. For example, we hold workshops to allow for more interactive input from stakeholders. Sometimes these are organised for people from a range of different interests (including patients, carers and members of the public). At other times we arrange meetings specifically for groups that represent lay interests, for example patient and carer organisations, voluntary and non-governmental organisations. In addition, our Patient and Public Involvement Programme runs workshops for organisations representing patient, carer or public interests which want to know more about how NICE guidance is produced and how to contribute to its development.

Where advisory bodies need information about the views of specific patient sub-groups, including ethnic minority groups, which is not available from the

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<sup>34</sup> See www.nice.org.uk/page.aspx?o=accessibility

published research literature or from stakeholder organisations, NICE commissions dedicated project work to collect this information.

In our policy on patient and public involvement we have made it a priority to consider how we can fully take account of the views of a diverse community by reflecting their needs and perspectives in the guidance itself, and in reaching them with guidance.<sup>35</sup>

#### Action

- 20. We will review our strategies for encouraging responses to guidance consultations from people from minority ethnic groups and organisations representing them, and from disabled people and disability groups, looking in particular at:
  - the targeting of communications about consultations
  - the scope for improving NICE's website beyond minimum standards of accessibility
  - the scope for additional strategies for topics where we have identified that ethnicity or disability is a factor
  - the role of the Patient and Public Involvement Programme
  - the responsibilities of guidance centres.
- 21. We will consider how best to monitor our success in involving in consultations organisations of black and minority ethnic groups and disabled people and individual disabled people and people from black and minority ethnic groups.

# 9.6 Making guidance recommendations

How does NICE ensure that the development of guidance recommendations takes into account the duties to promote equality?

Advisory bodies adhere to rigorous procedures in deriving recommendations from evidence. As well as evaluating the scientific evidence, they must also take account of the evolving body of social value judgements agreed by NICE's Board (see sections 8.1 and 15) and which so far include principles covering issues of race equality, age, gender and sexual orientation, and health inequalities arising from socioeconomic inequalities. The actions already listed in this section aimed at ensuring that potential impacts of guidance topics on equalities are thoroughly investigated should lead to robust application of these social value judgements in making guidance recommendations.

In developing public health guidance, we engage in an additional form of consultation when we 'field test' draft recommendations. Field testing involves group discussions with local professionals from various agencies working with the kinds of community on which the recommended interventions will be targeted. The purpose is to find out whether recommendations about interventions found by research to be effective in improving health and

<sup>&</sup>lt;sup>35</sup> See NICE's patient and public involvement policy at <a href="www.nice.org.uk/page.aspx?o=242614">www.nice.org.uk/page.aspx?o=242614</a>

narrowing health inequalities are appropriate and feasible in such local settings, and whether additional features might enhance their effectiveness.

#### Action

22. We will ensure that in the next reviews of our guidance centres' manuals of methods and procedures and our guidance on social value judgements we will highlight the importance of systematic consideration of duties to promote equality and eliminate discrimination in arriving at recommendations.

#### 9.7 Research recommendations

How does NICE ensure that gaps in evidence about topics where ethnicity or disability is a factor are filled?

When advisory bodies draw up recommendations they also make recommendations specifying the research required to fill important gaps in the evidence they have considered. When issues related to ethnicity or disability arise, research recommendations should take account of them.

NICE prioritises these recommendations and promotes them to the research community and its funders. The recommendations are openly available via our website.<sup>36</sup>

# **Action**

23. We will consider how we can include relevance to race and disability equality as a factor among the criteria for prioritising research recommendations.

# 9.8 Accountability for guidance

Who is accountable for ensuring that in developing guidance NICE takes proper account of any factor concerned with ethnicity or disability?

Ultimately, NICE's Board is responsible for ensuring that NICE guidance serves the needs of all users of NHS services and thus reflects our equality duties and objectives.

At an operational level, the directors of our guidance centres are responsible for ensuring that the guidance production process, including the part played by contractors, satisfies the quality standards in relation to equality set out in guidance manuals. See also section 15 on corporate responsibility.

<sup>&</sup>lt;sup>36</sup> See <u>www.nice.org.uk/page.aspx?o=ResearchRecommendations</u>

NICE's guidance executive – comprising executive and programme directors – receives and considers draft guidance on the Board's behalf before guidance is issued.

#### Action

- 24. The directors of NICE's guidance centres are responsible for monitoring and reporting periodically to NICE's senior management team and Board on the impact of the measures described in this section to promote equality. They will review practice in their centres in relation to equality in light of this equality scheme and amend their centres' manuals at the next review if necessary. They should seek to ensure consistency of approach among centres.
- 25. The chairs of advisory bodies have a responsibility for ensuring that questions about impact on equality are posed at key stages and that conclusions are formally recorded, including where there is no relevant evidence. We will create a standard form to enable chairs to confirm that these matters have been considered and appropriately recorded.
- 26. The centre director's report to NICE's Guidance Executive accompanying each piece of guidance will confirm that this standard procedure has been followed.
- 27. We will assess and meet the need for induction and training of chairs and members of advisory bodies, and staff from executive level managers downwards so as to ensure effective implementation of the equality measures described in this section. (We deal with the subject of training in section 14.)

# 10. Dissemination of guidance

As noted in the introduction, the main recipients of NICE guidance are NHS organisations, local government and other public bodies, patient and carer organisations and other NGOs – i.e. those whose job it is to plan, commission and deliver healthcare services, including public health, and those who can help support those activities. We have various mechanisms for alerting these organisations to consultations about new guidance and finished guidance products, and for disseminating these products to them directly, often targeting people according to their professional functions.

We also work with patient, carer and voluntary organisations, and the patient and public involvement structures within statutory organisations, and use the media to raise public awareness about our guidance. We publicise the availability of guidance by providing articles on relevant NICE guidance topics for use in the newsletters and websites of patient, carer and voluntary organisations. We provide an email alert service about new documents on the NICE website and an e-newsletter, for which members of the public can sign up.

By highlighting guidance in this way and providing direct, free access to it, we support individuals and organisations who want to understand more about treatments and services and the care they should expect to receive. As noted

in section 9.5, our website enables access to guidance for people with visual impairments and people who have difficulty using a mouse.

Most of our guidance is accompanied by a version for patients and carers aimed at helping people who use NHS services to understand the guidance and the care and treatment options available to them. To this end they are written in plain language, in accordance with standards set by the Plain English Campaign. These documents are also available on the website.

We have considered systematically producing the patient versions of our guidance in languages other than English. Having considered the best use of NHS resources, and taking into account the huge variety of languages spoken across the country, we have taken the decision not to routinely produce these versions in other languages (apart from Welsh, as part of an agreement about dissemination of NICE guidance in Wales).

We provide guidance on request in formats such as Braille and on tape, as we are required to do. Occasionally, we also provide versions of guidance in other languages in response to individual requests.

#### Action

- 28. It is essential that our communications strategy takes account of minority ethnic groups and disabled people as segments of our audience. We will review the extent to which we ensure that:
  - our press list includes print and other media that particularly serve black and minority ethnic groups and disabled people
  - there is consideration of the need to highlight any impact on race equality and/or disability equality in communications about guidance
  - there is consideration of the need for special targeting of print and other media which particularly serve black and minority ethnic groups and/or disabled people when guidance has implications for aspects of race and/or disability equality
  - we monitor the impact of our communications strategy.
- 29. We will review our policies on the provision of patient and carer versions of guidance in languages other than English and Welsh, taking account of data about uptake of the translation service and requests for written translations.
- 30. We will consider whether additional formats would remove potential barriers preventing disabled people from using guidance, and the potential for involving organisations of disabled people, or which support disabled people, both as channels of communication and as potential partners in producing appropriate versions of guidance.

Although we protect the copyright on our guidance documents, we promote free, non-commercial use, actively encouraging:

 NHS organisations to translate patient versions of guidance into languages relevant to their local patient populations  stakeholder organisations involved in individual items of guidance to provide information to relevant communities.

#### Action

31. We will continue to encourage NHS and stakeholder organisations to translate patient versions of guidance to meet the needs of their populations or communities.

Local patient organisations also help NICE by disseminating guidance to individual patients and carers. We had made a commitment to explore how links with patient forums and patient advice and liaison services (PALS) might be improved. The arrangements for involving patients and the public are to change again, with the establishment, following legislation, of local involvement networks (LINks) in every area where the local authority has responsibility for social services.

#### Action

32. We will anticipate legislation about involving patients and the public by considering how NICE might best link with the new system of local involvement networks (LINks).

# 11. Supporting implementation and monitoring the equality impact of guidance

Local organisations responsible for implementing NICE guidance have a specific responsibility for ensuring that it is implemented in ways that meet the needs of their communities.

Implementation of NICE clinical guidance is the responsibility of local NHS organisations, and responsibility for monitoring its uptake lies with the Healthcare Commission. However, we support implementation by providing local NHS organisations with support tools and advice. These implementation tools both cover generic processes of implementation and reflect the specific items of guidance that they relate to, so the race and disability equality safeguards are 'upstream' – see section 9. Similar tools will be developed for organisations responsible for implementing our public health guidance, particularly local authorities. The staff, and ultimately the director, of our Implementation Systems Directorate are responsible for ensuring that implementation tools appropriately reflect any implications for race or disability equality highlighted in guidance.

# **Action**

33. We will ensure that implementation tools reflect the implications for equality of guidance recommendations.

We have established an external reference group as a mechanism for obtaining rapid and informal feedback from a representative group of NHS staff on implementation issues, and thus for testing the usefulness of our implementation tools. People can apply to be a member of the external reference group through our website. We aim to recruit people with a range of different roles in the NHS, at various grades and career stages, and in different settings. The group's terms of reference include identifying guidance recommendations that are particularly challenging to implement.

# Action

34. We will consider how we can encourage people from ethnic groups and disabled people to volunteer for the external reference group and other standing groups, build equality monitoring into the recruitment process, and monitor the composition of these groups. We will report monitoring data in the annual equalities report.

NICE is at some remove from direct service delivery, so finding a way of assessing the equality impact of our guidance on users of healthcare services may be a major challenge. However, we need to explore whether there might be intermediate impacts that point reliably to these ultimate impacts. These might be derived from studies of the uptake of relevant items of guidance by NHS organisations and local authorities, or from surveys of the views of local professionals and other individuals with responsibilities for equality, local black and minority ethnic group organisations, and local disability organisations.

# Action

35. We have commissioned various studies on the uptake of our guidance and we monitor other sources of data. We will explore whether there is a reliable method for periodically monitoring the equality impact of NICE guidance. If we find that there is, we will consider the most appropriate way to take forward the necessary work and publish findings in our annual equalities report.

#### 12. Procurement

NICE sub-contracts important elements of the development work on guidance to a range of external organisations and collaborating centres (consortia bringing together a mix of royal medical colleges, academic centres, professional bodies and patient organisations). It also uses subcontractors for other research and development tasks in support of its guidance function, and for work related to business support functions. We seek to ensure that these contractors, most of which are themselves public authorities, are compliant with equalities legislation.

Furthermore, the contractors who develop our guidance within our network of collaborating centres must use the methods and follow the procedures set out in our guidance manuals and so must meet the quality standards in relation to equality described in section 9.6. The project managers in our guidance centres and other functional units are responsible for ensuring that work is carried out to the appropriate standard. Relevant directors have overall responsibility for ensuring compliance with requirements on race equality.

#### Action

- 36. We will review our procurement processes, including standard terms and conditions in contracts, against the standards recommended in the codes of practice and guidance on meeting race<sup>37</sup> and disability<sup>38</sup> equality duties and in guidance to the NHS from the Department of Health.<sup>39</sup>We will ensure that all project managers receive training on how equality duties are reinforced in the process of contracting.
- 37. We will consider whether we need to provide further support to contractors for example, by providing training on the equality requirements in our guidance development processes and how we might assess their training needs.
- 38. We will monitor the performance of contracts in relation to our equality duties.

# 13. NICE's employment duties - ethnic monitoring

Article 5 of the Race Relations Act 1976 (Statutory Duties) Order 2001 requires NICE to monitor and report on the ethnicity of its workforce, and the numbers applying for jobs, promotion and training according to racial group. As an organisation with over 150 full-time staff, we must specify the numbers of staff from each racial group who receive training, benefit or suffer detriment as a result of our performance assessment procedures, are involved in grievance procedures, are the subject of disciplinary procedures, or cease employment. We must also publish the results of this monitoring annually.

We have already taken steps to ensure that we have sufficient information in personnel files about racial and ethnic origin, using the ethnic classification system of the 2001 census. We have revised the ethnic monitoring form included in job application packs.

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<sup>&</sup>lt;sup>37</sup> Commission for Racial Equality (2002) *Statutory Code of Practice on the Duty to Promote Race Equality*. www.cre.gov.uk/publs/cat\_duty.html#cop

<sup>&</sup>lt;sup>38</sup> Disability Rights Commission (2005) *The Duty to Promote Disability Equality*. www.drc-gb.org/employers\_and\_service\_provider/disability\_equality\_duty/getting\_started/codes\_of\_practice.aspx

<sup>&</sup>lt;sup>39</sup> Department of Health (2006) Creating a Disability Equality Scheme: A Practical Guide for the NHS.

www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT\_ID=4139666&chk=B6%2BbZY

We bring together data from monitoring various dimensions of employment and recruitment in our annual human resources report. This report contains a detailed description of the make-up of our workforce and, where possible, compares against previous years and/or combined figures from the last year of operation of its two predecessor organisations, and, in some cases, against ethnicity data on the population of London, England and other organisations.

We gather and monitor these data in order to:

- examine whether patterns related to employment and recruitment indicate any inequalities
- consider the underlying reasons for possible inequalities
- take whatever steps are needed to remove barriers and promote equality of opportunity.

# Our 2006 monitoring report<sup>40</sup> shows that:

- The proportion of NICE's workforce of non-White ethnic origin 19.3% was higher than the proportion of the population of England of non-White ethnic origin (9%) but lower than the London population of non-White ethnic origin (28.8%).
- There has been an overall increase of 1% in the proportion of staff of non-White ethnic origin compared with the combined figures for NICE's predecessor organisations for 2005.
- We have not been successful in recruiting from the Bangladeshi population, which means that it is unrepresented in relation to the proportion in London's population.
- There was a mixed picture of the proportions of the workforce from non-White ethnic backgrounds at various levels of seniority. None of the senior management team was from a non-White ethnic background, whereas over half of administrative staff were. At associate director level, the proportion of the workforce from non-White ethnic backgrounds was below the proportion in the English population. The proportion from non-White ethnic backgrounds in the other intermediate tiers of seniority were more in line with proportions in the English population in the case of 'professional' staff, and the London population in the case of 'project managers'.
- Twenty-one percent of successful applicants through external recruitment were from ethnic minority groups, but there were no successful applicants from minority ethnic groups through internal recruitment.
- The highest proportions of applications for training and development from staff of a non-White ethnic origin were from Black African and other Asian ethnic groups, greater than the proportions employed by NICE. The proportions of applications received from staff of the Indian and Pakistani ethnic group were lower than the proportions employed by NICE.
- Staff of non-White ethnic origin took up 25% of training opportunities greater than the proportion of staff of non-White ethnic origin in the NICE workforce.

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<sup>&</sup>lt;sup>40</sup> See Annual Human Resources and Equality Report to 31 March 2006 at www.nice.org.uk/page.aspx?o=316213

#### Action

- 39. Within the last year NICE has opened an office in Manchester with around 60 staff. This has given us an opportunity to extend the geographical range of our recruitment. We will consider whether for future monitoring purposes we need to build in another local population benchmark perhaps Greater Manchester in the same way as we currently use London's population profile as an additional point of comparison.
- 40. We will ensure that the annual equalities report continues to highlight issues for consideration raised by monitoring data and reports on action taken in light of findings from the previous year's report.

Our practice in gathering and monitoring data is in the spirit of the 2001 Order but does not meet every requirement to the letter. For example:

- The Order requires that we report our findings in terms of the numbers of employees and potential employees in relation to each category of information, whereas our reporting is in percentages.
- We may have omitted certain categories of information, such as information about employees subject to disciplinary procedures and employees who have gained benefit or suffered detriment as result of performance assessment procedures. This may be a matter of interpretation or failure to record that the category did not apply in the year in question.
- In some cases data have not been broken down to the required level for example, reporting as 'non-White' employees instead of specifying racial groups.

#### Action

41. We will comply with the 2001 Order's monitoring requirements in our 2007 equalities report, while taking account of the need to respect the confidentiality of staff.

# 14. Promoting equality and tackling discrimination through employment and human resources policies

NICE's equality and diversity policy is a high-level statement of the range of employment and human resources policies on equalities and discrimination and of accountabilities for effective implementation. <sup>41</sup> The policy is elaborated in separate procedures, each of which covers race and disability equality, equality between men and women, and discrimination on grounds of age, sexual orientation, and religions and beliefs, including:

Recruitment and selection

<sup>&</sup>lt;sup>41</sup> NICE (2003) Equality and Diversity Policy. <a href="https://www.nice.org.uk/page.aspx?o=94060">www.nice.org.uk/page.aspx?o=94060</a>

- Disciplinary
- Grievance and disputes
- Racial and sexual harassment
- Job security, alternative employment and redundancy
- Maternity, special leave and flexible working.

NICE's annual staff survey, which is conducted by an independent agency, tests out the impact of some of these policies, including those on equal opportunities. This year's survey indicated concerns about staff experience of discrimination and knowledge about NICE's commitment to equal opportunities in employment and service development and signalled the need for a review of the equality and diversity policy. <sup>42</sup>The Board agreed an accompanying action plan including commitments in 2006-2007 to:

- develop a single equality scheme
- update and integrate equal opportunities policies, including the equality and diversity policy
- a new, integrated bullying and harassment policy accompanied by training
- obligatory equality and diversity training for all managers and staff
- continue to build capacity through the Black and Ethnic Minority Leadership (BEL) programme
- a training and development policy to support equal opportunities
- monitor staff turnover
- develop human resources capacity.

# Action

42. We will integrate relevant tasks and goals from the Staff Survey and Human Resources Action Plan 2006 into the action plan for this equality scheme. We will ensure that they cover the training needs highlighted in section 9.8 in relation to promoting equality in the guidance development process, and in section 12 on procurement.

Our employment policies are in line with all current legislation. NICE's workforce is diverse and we will make necessary attempts to retain and/or widen the diversity. Where permissible, we will positively encourage underrepresented groups to apply for jobs, promotion and training. Where appropriate, we will practice lawful discrimination in favour of disabled applicants as set out in the Disability Discrimination Act 1995.

We report monitoring data on the diversity of NICE's workforce in the annual human resources report – see section 13 for those compiled for ethnic monitoring purposes. The most recent report analyses:

<sup>&</sup>lt;sup>42</sup> NICE (2006) Staff Survey and Human Resources Action Plan 2006. www.nice.org.uk/page.aspx?o=343443

- the composition of the workforce according to sex: around 70% of NICE employees are female and 30% male, far exceeding the figure for London of women in the workplace (43%) but falling below the NHS figure of 75%
- roles in NICE according to sex: in relation to their proportions in NICE's workforce, women are over-represented among administration workers (over 80%), under-represented as project managers (around 50%), proportionately represented among professional staff (around 70%), and slightly under-represented in the senior management team (just over 60%)
- the composition of the workforce according to age: the majority of NICE employees (112) are in the 30-45 age-group, and there are more in the 45-65 age-group (62) than in the under 30 age-group (22)
- composition of the workforce according to disability: there is one member
  of staff who has self-declared as disabled; there were no data on whether
  any disabled people applied for jobs at NICE
- the working patterns of the workforce: 24% of female employees work part-time compared with 2% of males and the 33% of women working part-time in the public sector
- recruitment patterns in terms of numbers of men and women and the roles occupied, and the age of recruits: external recruitment echoes the pattern of sex against role noted above, but not the overall age pattern, with an equal proportion of new employees in the under 30 and 30-45 age groups (48% respectively) and 4% in the 45-65 age-group.

These data suggest that we may need to look carefully at future trends in the age pattern of the workforce and at our performance in attracting disabled people to work at NICE. We should note the very wide range of impairments that may lead to a disability, in addition to those people who are deemed to meet the definition of disability without having to show they have an impairment: that is, people who have cancer, HIV infection or multiple sclerosis; people who are certified as blind or partially sighted or registered as such (see also section 2.2 and footnote 4).

#### Action

ACTION 43 We

43. We will examine whether there are changes we should make to our recruitment and selection processes – involving, for example, positive action and lawful discrimination - that might increase the number of disabled people applying for jobs at NICE.

We fully recognise the importance to efforts to recruit and retain disabled people of ensuring that our offices are as accessible as possible. In 2004, we asked Disability in Camden (DISC), an organisation controlled by and accountable to disabled people in the London Borough of Camden, to carry out a disability access audit report of our London office, both its internal features and the approach, entry and exit points. The audit report made over 50 recommendations, covering the approach to NICE's office, parking, reception areas, the features of the office environment, meeting rooms and

<sup>&</sup>lt;sup>43</sup> See 22 above and <a href="https://www.nice.org.uk/page.aspx?o=316213">www.nice.org.uk/page.aspx?o=316213</a>

meeting arrangements, the kitchen/cafeteria area, WCs, vertical circulation in the building, including stairs, and features and procedures for emergency exit. 44 We have implemented the majority of the recommendations, although some relating to the responsibilities of the landlord are outstanding.

#### Action

- 44. We will commission an update to our disability access audit at the London office.
- 45. We will take account of accessibility criteria in searching for a permanent base for our Manchester office and carry out an access audit to identify further improvements.

# 15. Corporate responsibility for meeting equality and anti-discrimination duties

Ultimate responsibility for ensuring that NICE meets its equality duties lies with our Board. The Board fulfils these responsibilities in the following ways:

- The Board agrees NICE's equality scheme and action plan.
- The Board receives regular reports on progress towards action plan objectives – the annual equalities report – and considers their implications for NICE's equality and anti-discrimination duties.
- The Board considers the equality implications of NICE's business and corporate plans and the account in the annual report of NICE's activity concerned with equality.
- The Board periodically reviews NICE's human resources and other policies and procedures in light of equality duties.
- The Board considers performance on equality and anti-discrimination duties in the context of risk management

In section 13 we discussed possible improvements in the annual human resources report. We also need to make sure that the Board can oversee progress on the other aspects of our equality scheme.

#### Action

46. From 2007, we will provide the Board with an annual equality report setting out monitoring information about progress against the commitments in this action plan, including progress on human resources policies and practice. The equality report will help ensure that we are open about and accountable for the performance of our various equality and anti-discrimination duties.

In the Scheme of Delegation, the chief executive is responsible for ensuring that NICE fulfils its equality duties and is accountable for this equality scheme

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<sup>&</sup>lt;sup>44</sup> DISC (2004) Disability Access Audit Report.

and action plan. Directors of our guidance centres and other NICE functional directors are accountable for the actions specified in the preceding sections.

#### Action

47. To demonstrate our commitment to equality, we will assign responsibilities for implementation of this equality scheme to a non-executive director and an executive director of NICE's Board.

The decisions of the NICE Board are informed by input from two key initiatives, the Citizens Council and the Partners Council.

The Citizens Council is a deliberative forum of 30 people established by NICE as a way of gathering in the views of the public about the values that should underpin decisions about our guidance. The Council tackles challenging questions about values – such as fairness and need – and its reports to our Board influence NICE's thinking and procedures. It has, for example, influenced the Board's statement of NICE's social value judgements, which cover the approach NICE should take to health inequalities and issues of discrimination in relation to race, age, and gender and sexual orientation – see also section 8.<sup>45</sup>

Recruitment to the Council aims to ensure that the socio-demographic characteristics of its membership reflect as far as possible those of the population of England and Wales. Thus recruitment criteria cover age, sex, ethnicity, and disability. By paying members for the time they spend at Council meetings we encourage people from the range of social groups as well as younger people to take part. We support the involvement of disabled people by paying the expenses, including accommodation, of their carers.

#### **Action**

48. In periodic reviews of the Citizens Council's membership we will ensure that:

- its composition reflects as far as possible the proportion of people from ethnic minority groups in the population;
- it includes disabled people;
- there is an appropriate balance among age-groups and between the sexes.

The Partners Council consists of nominated members from national organisations that have an interest in our guidance. Member organisations include professional bodies (e.g. the medical Royal Colleges, industry, and groups representing the interests of patients and the public). Our Patient and Public Involvement Programme has at regular intervals carried out proactive attempts to contact patient and voluntary organisations that represent minority

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<sup>&</sup>lt;sup>45</sup> See NICE (2005) Social value judgements – principles for the development of NICE guidance. www.nice.org.uk/page.aspx?o=sviguidance

ethnic groups to explain the role of the Partners Council and to encourage them to join it, but with limited success. We have also invited national organisations representing the views of people with learning disabilities to take part, but, again, without success.

#### Action

- 49. We will make nominating organisations aware of our commitment to promoting equality and tackling discrimination and encourage them to meet their own statutory duties by considering whether their mechanisms for recruiting potential nominees for the Partners Council are giving everyone with the necessary qualifications for the role the opportunity to put themselves forward.
- 50. We will continue with our efforts to elicit nominees for the Partners Council from bodies representing black and minority ethnic groups and disabled people, including people with learning disabilities.
- 51. We will monitor the composition of the Partners Council and report on it in our annual equality report.

# 16. Cross organisational functions

# 16.1 The Patient and Public Involvement Programme (PPIP)

The Patient and Public Involvement Programme (PPIP) plays a major role in ensuring that NICE meets it equality and anti-discrimination duties. It provides advice and support to NICE on patient, carer and public involvement and works with us to develop opportunities for involving patients, carers and members of the public across our work programmes, particularly in the development of guidance. The PPIP also supports that involvement in a variety of ways, for example, by running workshops for organisations interested in contributing to guidance development, giving information, training and support to patients, carers and members of the public who are interested in contributing, and working with service users to make sure that their views and experiences inform the development of guidance.

The PPIP is thus an important resource for NICE as it tries to involve people from ethnic minority groups and disabled people, mainly through the organisations representing them, in the stages of NICE guidance development discussed in section 9.

### Action

52. We will consider with the PPIP whether there should be any enhancements to its capacity or changes to its role so that it can better help other parts of the organisation – particularly NICE's guidance centres - to maximise NICE's equality impact.

# 16.2 Telephone enquiry service

Our telephone enquiry service is governed by protocols designed to make sure that there is an efficient and, as far as possible, helpful response to every kind of call, including requests for audio versions of guidance and versions in languages other than English. There will shortly be a system for monitoring calls, which should provide data about the demand for guidance in these forms.

# 16.3 Making NICE's facilities accessible

Meetings – whether consultation meetings, meetings of advisory bodies, or meetings of our Citizens and Partners Councils – are essential to NICE's work. It is vital that we adhere to agree standards such as those for greeting disabled people, the quality of audio-visual equipment in meeting rooms, and for speakers' presentations. We must also ensure external meeting venues meet the same accessibility standards.

# **Primary Author**

Nick Doyle Research and Development

# **Responsible Executive Directors**

Andrea Sutcliffe Peter Littlejohns

#### **Date**

5 December 2007