King's Fund

Department of Health

Facing up to Difference

A toolkit for creating culturally competent health services for black and minority ethnic communities

Jeff Chandra

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1 Auditing your existing services

2 Towards organisational competence

3 Towards service competence

4 References and helpful information

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Foreword

The NHS as a public service aims to judge its results under three headings – equity, efficiency, and responsiveness, so improving the health care for people from ethnic minorities is a firm principle of the service we should offer.

To ensure that appropriate and sensitive services are provided a continuing dialogue between health authorities and local ethnic minority communities is essential. For this reason purchasers and local ethnic minority communities are increasingly engaging in discussions about health needs and how the quality of the services being provided can be improved.

This toolkit is aimed to strengthen this activity - it is a comprehensive guide for purchasers to help them in commissioning services for ethnic minority groups and provides examples of good practice which have been developed with successful results.

I recommend this report to both health authorities and trusts.

Julia Cumberlege.

BARONESS CUMBERLEGE

Acknowledgements

This toolkit was commissioned and funded by the Department of Health and undertaken by myself with unfailing support from Fitzroy Ambursley and Bo Nowak of the King's Fund Management College.

Rukshana Kapasi and Ruth Wain helped greatly in the overall design of the toolkit and in contributing to particular sections. Kathy Molan deserves a gold star for turning often untidy manuscript, via the word processor, into something sensible.

I also owe a particular vote of thanks to Veena Bahl, who commissioned this Department of Health project, for her support and encouragement throughout.

Thank you also to all the purchasers and providers who responded to my questionnaire and met with me. Some of their work is included in the good practice examples listed in this publication, though this is only a selection of the good work being done. Where responses to the questionnaire came from family health service authorities, they are listed under the appropriate health authority name (in line with the reorganisation from 1 April 1996).

Finally, I am greatly indebted to all those, too numerous to mention here, who are striving in their own organisations to improve services for black and minority ethnic communities and who freely shared their work and ideas with me. Although the sole responsibility for the toolkit rests with me they may well discern how their ideas shaped the final product.

Jeff Chandra

About the author

Jeff Chandra is a director of Josam Associates, a management consultancy working with public sector organisations. Previously chief executive of Walsall and South Birmingham health authorities, and assistant director of social services at Cheshire County Council, Jeff Chandra is also a final stage assessor for the NHS Management Training Scheme.

Introduction

Defining cultural competence

Authorities and trusts frequently talk about the need to provide services in a culturally sensitive manner. Many authorities and trusts have even built in general statements to this effect in their policy documents. However, it is all too often the case that local users and community groups perceive services as anything but culturally sensitive.

The concept of cultural sensitivity seems inadequate to define both what purchasers and providers should be aiming for and what users have a right to expect. This toolkit therefore coins the term 'cultural competence' to denote services perceived by black and minority ethnic users as being in harmony with their cultural and religious beliefs and not just provided by people who are, or are assumed to be, 'culturally sensitive'.

The purpose of this toolkit

This toolkit aims to support purchasers and providers who seek to develop culturally competent services. It aims to:

- enable individual health authorities and trusts to assess how far they have progressed towards cultural competence, and to decide priorities for further action
- identify ways of ensuring that the health needs of black and minority ethnic communities are viewed as an integral part of the commissioning process
- identify examples of good practice already being achieved by purchasers and providers
- propose the adoption of some quality standards in service provision
- point to useful sources of further information.

It is important to emphasise that except in a few instances where genetic factors are relevant, health experience is determined by factors associated with ethnicity (e.g. racism, social and economic circumstances and discrimination) rather than ethnicity itself. This toolkit is an attempt to move beyond victim blaming – which is inherent in assuming that ethnicity is itself the cause of poor health – towards the achievement of health gain through positive action.

How to use this toolkit

This toolkit is neither prescriptive nor exhaustive, and does not offer a 'blueprint' for culturally competent services. What it does offer is summarised below.

Part 1: Auditing your existing services

This section invites you to undertake a self-assessment of your organisation's strengths and weaknesses in terms of commissioning services for black and minority ethnic communities. The questions and scoring sheet may help you to achieve a better understanding of your organisation's

position and identify the priorities for your future work. It also refers you to other sections of the toolkit which you may find helpful in moving forward.

Part 2: Towards organisational competence

Organisations perceived as being closest to achieving culturally competent services often exhibit a number of common characteristics. These characteristics are explored in Part 2, with each chapter focusing on a necessary skill or process, and giving examples of good practice.

Chapter 1	**Defining the population** Looks at how culturally competent organisations can turn existing demographic data (e.g. census, lifestyle, epidemiological and research data) into useful information on which to base purchasing and providing decisions. Sets out the availability, limitations and use of data to isolate and address the links between ethnicity and health.
Chapter 2	**Policy and legislation** Looks at how race legislation and NHS policy can be used proactively to deliver culturally competent services.
Chapter 3	**Energising the organisation** Addresses the need to remodel management processes and responsibilities so that black and minority ethnic health issues are an integral part of the organisation's agenda.
Chapter 4	**Developing and implementing a commissioning strategy** Argues that a culturally competent purchaser must take ethnicity issues into account when preparing its main policy documents, including purchasing intentions and business/practice plans.
Chapter 5	**Using the contracting process** Looks as how contracts can be used to specify how providers should offer culturally competent services.
Chapter 6	**User consultation and participation** Cultural competence requires the active involvement and participation of black and minority ethnic communities in the design and delivery of services. This chapter looks at how to open and continue effective dialogue with users and communities.
Chapter 7	**Improving communications** Highlights the role of effective communications in eliminating barriers. A culturally competent organisation must use interpreting, translation, audio and video tapes, and the local media to get its message across.
Chapter 8	**Staffing the service for cultural competence** Discrimination on the grounds of ethnicity and colour remain unattractive features of NHS employment practice in many places. Yet this chapter argues that one of the most effective ways of achieving culturally competent services is to recruit, train and retain staff from the minority ethnic communities themselves.

Chapter 9	**Ethnic monitoring** Argues that purchasers should set standards for the ethnic monitoring of admitted patients, analyse and use the data to inform purchasing decisions, and extend ethnic monitoring into community and primary care settings.
Chapter 10	**Ethnicity and health standards** Proposes core standards which purchasers should ask providers to meet, as part of delivering culturally competent services.

Part 3: Towards service competence

This part addresses the specific actions which may be helpful in addressing the five key areas of the *Health of the Nation* strategy, as well as the disease and care groups where evidence suggests black and minority ethnic people are particularly vulnerable. It looks at how services can be made more accessible to black and minority ethnic communities, and ways to take account of the cultural and religious sensitivities of particular groups. It also recognises that new services may sometimes be needed.

Chapter 11	**Coronary heart disease**
Chapter 12	**Strokes in older people**
Chapter 13	**Cancers**
Chapter 14	**Mental illness**
Chapter 15	**Sexual health**
Chapter 16	**Accidents**
Chapter 17	**Diabetes**
Chapter 18	**Haemoglobinopathies**
Chapter 19	**Maternal and child health**

Part 4: References and helpful information

This part includes references, NHS documents, additional reading, useful contacts and religious organisations which might be of use in addressing issues of black and minority ethnic health.

HOW THIS TOOLKIT WAS CREATED

In order to create this toolkit it was necessary to obtain a snapshot of the position purchasers and providers have reached in identifying effective ways of improving the health of people from these communities, as well as in making services more accessible, appropriate and culturally competent.

A questionnaire was sent to 104 health authorities and trusts in January 1995, with a covering letter setting out the nature of the exercise being undertaken. These purchasers and providers were chosen on the basis of:

- geographical spread across the country
- those with statistically large and particularly small minority ethnic populations
- and some of those regarded as being amongst the more innovative organisations in this field.

The questionnaire was designed to elicit information about: strategy and policy; user and community involvement; changes made to service delivery; evaluation of service provision; equal opportunities; and alliances with local authorities. Fifty two questionnaires were sent to purchasers, and the same number to providers.

A total of 69 of the 104 questionnaires (66 per cent) were returned with almost equal numbers of purchasers (65 per cent) and providers (67 per cent) responding.

The survey was backed up by personal interviews with chief executives, executive and non-executive directors and senior staff in a smaller number of purchasing and providing organisations.

A number of interviews were also conducted with representatives of local minority ethnic communities in order to discover their views on the effectiveness of existing consultation mechanisms with the local health agencies, and their perceptions of the health services provided.

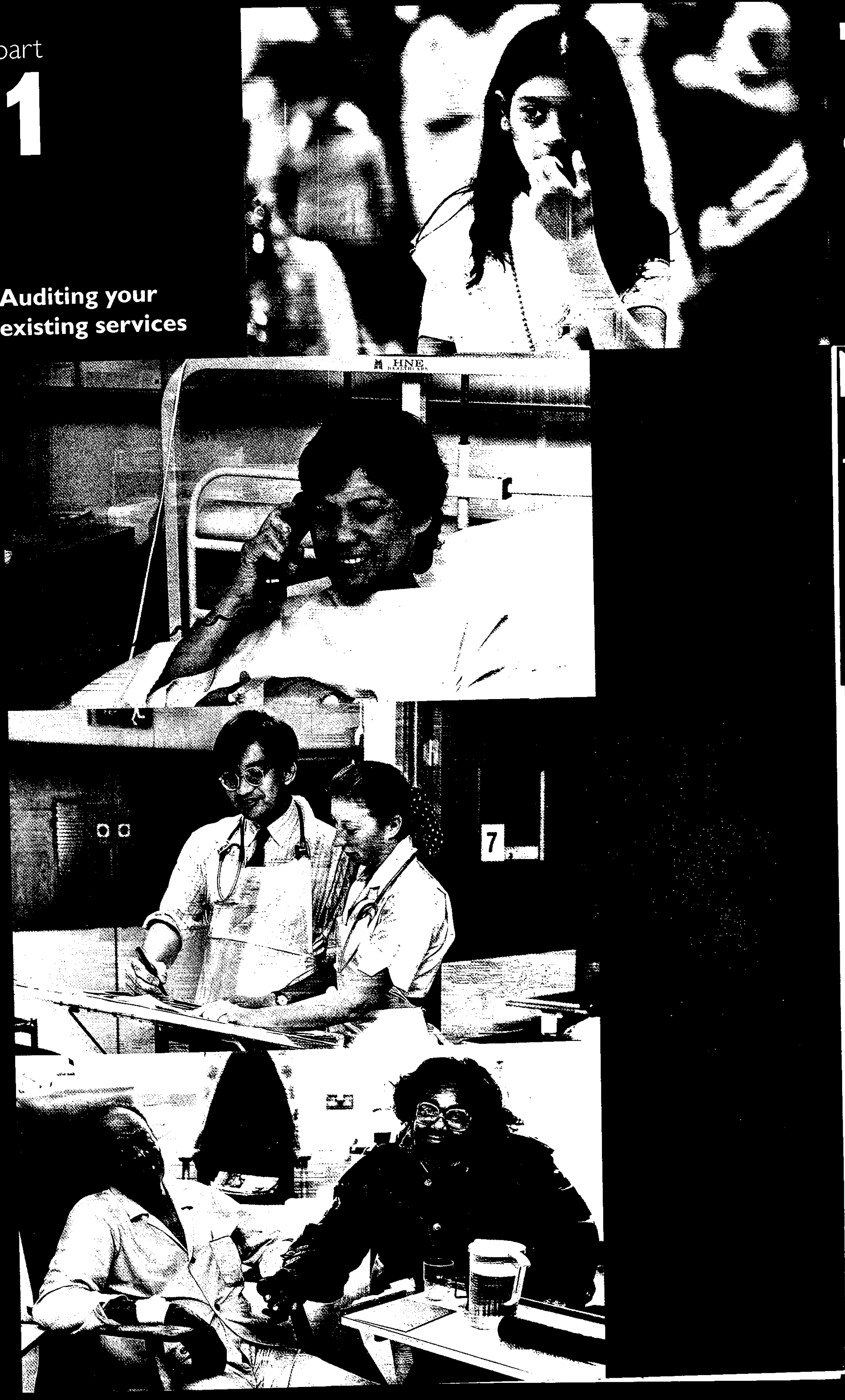
WHO ARE WE TALKING ABOUT?

It should be emphasised that terms such as 'black', 'race' and 'ethnicity' have all been favoured or rejected at different times and in different contexts and that there is no universally accepted phraseology. The term 'black and minority ethnic' is used for preference throughout this toolkit to underline the common experience of discrimination and racism suffered by non-white groups in Britain. This short-hand should not minimise the diversity of language, culture and religion which exists within the minority groups themselves and which can be significant in influencing health and access to health services. The term African Caribbean is used throughout the toolkit to refer to people of Caribbean origin.

part

1

Auditing your existing services



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Part 1

Auditing your existing services

Part 1 of the toolkit is designed to help purchasers identify their strengths and weaknesses in commissioning services for black and minority ethnic groups.

Providers could gain some help from completing sections B, C, D, E and F (and also the chapters in Part 3 which relate to services they provide).

The first six sections in Part 1 relate to **organisational competence**. The issues raised by these questions are then covered in more detail in Part 2, *Towards organisational competence.*

The remaining nine sections cover **service competence** in relation to specific diseases and care groups. The issues raised by these questions are covered in more detail in Part 3, *Towards service competence.*

Each section has five questions to be answered as either 'yes' or 'no'. To obtain a score for each section award five points for a 'yes' answer and 0 points for a 'no' answer.

The key to your score (see page 15) will provide a pointer to where you may consider investing further time and effort in developing services for black and minority ethnic communities. The scoring and reference sheet (see page 14) refers you to sections of the toolkit where you might find further useful information.

A Defining the population

1 Do you know how the ethnic composition of your district will change over the next five years? yes no

2 Do you know the age/gender profile of the main black and minority ethnic groups in your area? yes no

3 Do you know the geographical distribution of the black and minority ethnic groups in your area? yes no

4 Do you know the socio-economic characteristics of local black and minority ethnic communities? yes no

5 Have you used the above information to set priorities for local action? yes no

Score for this section

B Energising the organisation

1 Can you identify one statutory and one NHS policy requirement to address issues of black and minority ethnic health? yes no

2 Does a member of the board have specific responsibility for black and minority ethnic health issues? yes no

3 Do you have a strategy for improving black and minority ethnic health, with a timetable for implementation, targets and clear accountability for delivery? yes no

4 Do your key documents (e.g. purchasing intentions, business plans/annual practice plans) incorporate the strategy for black and minority ethnic health? yes no

5 Do you include standards in contracts with providers to address the specific needs of black and minority ethnic communities? yes no

Score for this section

C User involvement

1	Do members of your board participate in any regular forum with black and minority ethnic groups?	yes	no
2	Do you have a participation strategy for each of the black and minority ethnic groups in your district?	yes	no
3	Do the methods of participation include at least three of the following: ● local focus groups with community organisations, users and carers; ● patient surveys and questionnaires; ● one to one interviews with users/carers; ● suggestion boxes; ● recorded language lines for complaints and feedback?	yes	no
4	Do you involve members of the local black and minority ethnic communities in the monitoring of standards?	yes	no
5	Is there a budget allocated to facilitate the participation of your local black and minority ethnic population in the commissioning of local health services?	yes	no
	Score for this section	☐	

D Improving communications

1	Do your residents have easy access to trained interpreters when they use the NHS services which you purchase?	yes	no
2	Do you require providers to have policies and quality standards for their interpreting and translation services?	yes	no
3	Do your residents have access to trained advocates, particularly older people, mental health service users and mothers?	yes	no

4 Do you require providers to improve communications with black and minority ethnic groups through at least three of the following:

- signage in health premises, in appropriate languages;
- use of pictorial signs;
- audio tapes;
- video tapes;
- dance;
- theatre;
- local minority ethnic TV, radio and newspapers? yes ☐ no ☐

5 Are directors and staff given opportunities to learn something of the customs, cultural and religious norms of their black and minority ethnic patients? yes ☐ no ☐

Score for this section ☐

E Staffing for cultural competence

1 Do you and your providers have equal opportunity policies in operation? yes ☐ no ☐

2 Do you require your providers to implement action plans for *Ethnic Minority Staff in the NHS; a Programme of Action*, EL(94)12? yes ☐ no ☐

3 Are you aware how the law can be used proactively to make services culturally competent, e.g. Section 5(2)d of the Race Relations Act 1976? yes ☐ no ☐

4 Is anti-discriminatory training provided to staff? yes ☐ no ☐

5 Is performance on EL(94)12 and equal opportunity policies regularly reported to the board and positive action taken? yes ☐ no ☐

Score for this section ☐

F Ethnic monitoring

1	Do you have a mechanism for storing and analysing the ethnicity data from providers?	yes	no
2	Have you set standards for the quality of the ethnic monitoring data being collected?	yes	no
3	Do you link the analysis of ethnic monitoring data with local community views, census data, primary care data and epidemiological information?	yes	no
4	Have you developed a strategy for the use of ethnic monitoring data in the commissioning process?	yes	no
5	Do you make available to the public and to providers the results of your monitoring programme?	yes	no
	Score for this section	☐	

G Coronary heart disease (CHD)

1	Do you know which black and minority ethnic groups are at particularly high risk from CHD?	yes	no
2	Have you tailored any CHD awareness/prevention campaigns to meet the needs of particular black and minority ethnic groups?	yes	no
3	Do you have any specific treatment and rehabilitation initiatives which target black and minority ethnic groups?	yes	no
4	Do you monitor access rates by black and minority ethnic groups to secondary and tertiary services?	yes	no
5	Have you included specific standards for improving CHD services for black and minority ethnic groups?	yes	no
	Score for this section	☐	

2 Towards organisational competence
3 Towards service competence
4 References and helpful information

H Strokes in older people

1	Do you know which black and minority ethnic groups are at high risk from stroke?	yes	no
2	Do you have any specific treatment and rehabilitation initiatives in relation to stroke services which target black and minority ethnic groups?	yes	no
3	Have you tailored any stroke awareness/prevention campaigns to meet the needs of particular ethnic minority groups?	yes	no
4	Do you monitor access to stroke services by ethnicity?	yes	no
5	Have you included specific standards in contracts for improving stroke services for black and minority ethnic groups?	yes	no

Score for this section ☐

I Cancers

1	Do you know which black and minority ethnic groups are particularly at risk from cervical cancer/breast cancer in the local population?	yes	no
2	Do you provide specially adapted health information material on cancers, in any language other than English?	yes	no
3	Do you have any specific prevention or treatment initiatives which target black and minority ethnic groups?	yes	no
4	Do you monitor the uptake of cancer/breast screening services for different black and minority ethnic groups?	yes	no
5	Have you included specific standards in contracts for improving cancer services for black and minority ethnic groups?	yes	no

Score for this section ☐

J Mental illness

1	Have you asked providers to tailor any mental health awareness campaigns to meet the needs of particular black and minority ethnic groups?	yes	no
2	Do your providers have a multi-cultural team which is equipped to address the specific needs of black and minority ethnic groups?	yes	no
3	Do you have any specific initiatives which target black and minority ethnic groups?	yes	no
4	Have you included the need for advocates in contracts with providers?	yes	no
5	Have you included standards for improving mental health services for black and minority ethnic groups?	yes	no
	Score for this section	☐	

K Sexual health

1	Do you know which black and minority ethnic groups have particularly low access rates to aspects of the sexual health services?	yes	no
2	Have you asked providers to tailor any awareness campaigns to meet the needs of particular black and minority ethnic groups?	yes	no
3	Do you have any specific initiatives which target black and minority ethnic groups?	yes	no
4	Have you considered providing access to sexual health services in the evenings/nights and in locations accessible to target users?	yes	no
5	Have you included standards in contracts for improving sexual health services for black and minority ethnic groups?	yes	no
	Score for this section	☐	

L Accidents

1 Do you provide any specific accident prevention awareness material suitable for use by black and minority ethnic groups? yes no

2 Do you have a multi-agency team analysing accidents by ethnicity? yes no

3 Do you have any specific initiatives which target black and minority ethnic groups in order to improve their knowledge of accident prevention? yes no

4 Do you monitor the use of accident and emergency departments for accidents by black and minority ethnic groups? yes no

5 Have you specified targets for a reduction in accidents? yes no

Score for this section ☐

M Diabetes

1 Do you specify the establishment of diabetic registers which contain information on ethnicity? yes no

2 Do your providers make available information on diabetes on audio and video tapes, produced in different languages? yes no

3 Do you specify the need for a diabetic liaison nurse/worker to work with black and minority ethnic communities? yes no

4 Do you specify the need for dietetic, chiropody and ophthalmic advice and expertise to be available in primary care settings, and targeted at black and minority ethnic groups? yes no

5 Have you included standards for improving diabetic services for black and minority ethnic groups? yes no

Score for this section ☐

N Haemoglobinopathies

1	Do you have a haemoglobinopathy register within your district?	yes	no
2	Have you tailored awareness campaigns to meet the needs of particular black and minority ethnic groups?	yes	no
3	Do you have a genetic/pre-conception care counselling service available for your residents?	yes	no
4	Have you asked providers to develop a protocol for the management of haemoglobinopathies, particularly in accident and emergency departments?	yes	no
5	Have you included standards for improving haemoglobinopathy services for black and minority ethnic groups?	yes	no

Score for this section ☐

O Maternal and child health

1	Do you analyse information on births by ethnicity?	yes	no
2	Do you provide information on local maternity services in the appropriate languages and in a variety of formats (e.g. audio tape, video cassettes)?	yes	no
3	Do you require providers to offer advocacy/linkworker support to mothers to help them to understand and make informed choices about their care?	yes	no
4	Do you have a mechanism through which you are able to receive feedback from mothers from black and minority ethnic communities about the appropriateness of their care?	yes	no
5	Do you require maternity services staff to receive training in the cultural norms and expectations of black and minority ethnic mothers and their families around childbirth?	yes	no

Score for this section ☐

2 Towards organisational competence
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Scoring sheet and toolkit reference

	Competencies	*Score*	*Refer to:*
	Organisational competence		
A	Defining the population		Part 2: Chapter 1
B	Energising the organisation		Part 2: Chapters 2, 3, 4, 5 and 10
C	User involvement		Part 2: Chapter 6
D	Improving communications		Part 2: Chapter 7
E	Staffing for cultural competence		Part 2: Chapter 8
F	Ethnic monitoring		Part 2: Chapter 9
	Score for organisational competence (i.e. the total for A to F)	☐	
	Service competence		
G	Coronary heart disease		Part 3: Chapter 11
H	Strokes in older people		Part 3: Chapter 12
I	Cancers		Part 3; Chapter 13
J	Mental illness		Part 3: Chapter 14
K	Sexual health		Part 3: Chapter 15
L	Accidents		Part 3: Chapter 16
M	Diabetes		Part 3: Chapter 17
N	Haemoglobinopathies		Part 3: Chapter 18
O	Maternal and child health		Part 3: Chapter 19
	Score for service competence (i.e. the total for G to O)	☐	
	Overall total	☐	

Key to your score

You should now have a score for each section, subtotals for organisational and service competence and an overall total. The following is a guide to enable you to identify the key areas you may need to work on as an organisation.

Overall score

If you have scored over 55

Your agency is actively meeting the needs of black and minority ethnic communities. Your organisation has been successful in addressing issues at a number of levels in the organisation from having a strategic overview to tackling some of the practical realities of improving services for your black and minority ethnic population at the point of service delivery. However, it is important for you to look back at each section and identify any weaknesses on which the toolkit document may be able to offer you ideas and guidance for future development.

If you have scored between 30 and 50

Your agency has clearly begun to address the needs of black and minority ethnic communities and has established a foundation to build on. However, your score highlights that you have a number of areas in which you need to improve your performance. It may be that you have undertaken a number of projects to meet the specific needs of different minority ethnic communities in your district which have not been co-ordinated at a strategic level; or it may be that your agency has developed a coherent strategy/policy which has not always translated into action at a service delivery level.

Your score indicates that you need to go back to each section and identify the areas with the lowest scores for further work and development. Specific sections of the toolkit may facilitate this process; providing you with checklists and key questions to examine in determining the way forward.

If your score is 25 or below

Your agency is at the starting block in this area of work. It may be that you have just begun planning a number of initiatives; or you may feel that the size of your minority ethnic population is so small that you do not need to undertake any specific work in this area.

Your score suggests that you need to work through the toolkit guidance in the chapters relating to your lowest scores to ensure that, if you are at the planning stages of doing specific work, you develop this area of work coherently and that it becomes integral to your commissioning processes. On the other hand if you feel your black and minority ethnic population is a small percentage of your overall population, it is still important that you go back to each section and identify areas where you have not taken any action and the possible impact this may have in preventing access to and use of services. It is important to remember that small and dispersed black and minority ethnic populations may be the most vulnerable and isolated groups and are often the groups which have poorer access to appropriate and culturally competent services.

Scores for organisational and service competence

Whilst the above scores help to position your organisation in overall terms, the scores for each of the two parts (organisational competence and service competence) may also help to identify priorities for further work.

A score of 15 or less for **organisational competence** suggests that early attention to this issue is required at board level if significant progress is to be achieved. The lowest scores in that section give an indication of the issues which the board should address.

A score of 20 or below in the **service competence** section suggests at best a patchy response to the specific needs of black and minority ethnic groups. The lowest scores suggest the areas of highest priority for attention.

part

2

Towards organisational competence

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4 References and helpful information

Part 2

Towards organisational competence

Organisations perceived as being closest to achieving culturally competent services often exhibit a number of common characteristics. These characteristics are explored here, with each chapter focusing on a necessary skill or process, and giving examples of good practice.

How you scored in Part 1 will indicate which chapters in Part 2 are most relevant to your organisation.

Chapter 1 Defining the population 19

Chapter 2 Policy and legislation 27

Chapter 3 Energising the organisation 34

Chapter 4 Developing and implementing a commissioning strategy 40

Chapter 5 Using the contracting process 46

Chapter 6 User consultation and participation 50

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Chapter 8 Staffing the service for cultural competence 65

Chapter 9 Ethnic monitoring 72

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Chapter 1

Defining the population

SUMMARY

This chapter identifies some of the basic data available to illustrate the relationship between ethnicity and health. An understanding of this relationship is essential to a proper assessment of health needs. However, inappropriate terminology can obscure rather than illuminate the variations in health, and health experience, of different communities.

This chapter sets out the availability, limitations and uses of demographic data and some of the techniques which might be used to convert the data into useful information for purchasing and providing decisions.

Who are we talking about?

Defining race and ethnicity

Everyone belongs to an ethnic group but the term 'ethnicity' has different meanings among different groups and these change over time. It was first used to mean nationality (from the Greek word 'ethnos' meaning nation) and the meaning later expanded to include religion. Social scientists now use it to describe some of the cultural features by which groups of people distinguish themselves – such as customs, family structures, language, lifestyle. Ethnicity has largely replaced 'race' (differentiation according to physical appearance) as the appropriate way to think of human difference (Smaje, 1995). Although no terminology is static or acceptable to everyone, the phrase 'black and minority ethnic' is used for preference throughout this document.

Black and minority ethnic groups

The largest minority ethnic groups in Britain have their origins in the Indian subcontinent and in the Caribbean, with smaller numbers of Africans, Chinese and others. The research on variations in health has generally concentrated on the largest minority groups, and whilst this toolkit reflects this bias, much of the guidance here will be equally relevant to the needs of smaller groups.

There is extensive evidence of the negative effects of individual and institutional racism experienced by members of these groups and yet it is a fundamental value of the NHS that it should meet the needs of all sections of the community equally. Providing the same service in the face of differing need does not give an equitable service and this has been recognised in Standard 1 of the *Patient's Charter*.

This toolkit is premised on the belief that a significant health gain would result by reducing the variations in health which currently exist in many of these groups. This was also the view taken in the report *Variations in Health, HSG(95)54*. The variations in health and how to address them are covered in Part 3.

Limitations of ethnic statistics in health studies

Changing definitions

The main source of demographic information is the decennial census. The 1981 census asked for country of birth and mother and father's country of birth. At the time this picked up most but by no means all of the black and minority ethnic population. The 1991 census put the emphasis on ethnicity rather than country of birth, recognising the limitations of the 1981 data and also the increasing numbers of black and minority ethnic people born in Britain.

Underestimation of the black and minority ethnic population

The national census is thought to underestimate the size of the black and minority ethnic population for a variety of reasons, and this can have potentially significant consequences for health and healthcare provision for these groups. Population projections produced by the Office of Population Censuses and Surveys in the inter-census years, are based on the decennial census and are for the population of the UK as a whole. There are no similar national projections for black and minority ethnic groups. So the proportions and age-distributions of the black and minority ethnic populations remain static in the inter-census years even though these populations are particularly mobile and have a disproportionately young age structure. Local authorities do produce more detailed population projections in the inter-census years. Purchasers should consider the use of these projections to influence their ethnicity and health strategy (see Chapter 4).

Relevance to health needs

In recent years more emphasis has been placed on an individual's preferred ethnicity rather than 'race'. In assessing health needs, there are times when one is more relevant than the other. 'Race' is of more importance in diseases of genetic origin whereas, for factors such as 'lifestyle', the group with which the person identifies is likely to be of greater significance.

Changing cultural identity

As second and third generations of black and minority ethnic groups grow up, the cultural identities and lifestyles may change. This could result in a shift from one set of health issues to another.

Religion

Religion is an important aspect of ethnicity. Although it has been a data item on data sets such as Common Minimum Data Set for many years, it is often ignored and therefore is not readily available for analysis.

Data quality issues

All information on ethnicity, however collected, has to be used in the light of its limitations. Ethnicity is a sensitive issue and the categories used by the Office of Population Censuses and Surveys are rigidly defined, so its use in health studies is fraught with difficulties.

Limitations can arise from: the difficulty of classifying individuals of mixed ethnicity; the increasing number of second and third generations of black and minority ethnic groups; changes in people's self-classification over time; classifications not refined enough to be useful.

Using census data

Sources

A considerable amount of information on the black and minority ethnic communities is readily available from the 1991 census and can be accessed using one of several software packages. Census tables 6, 9, 43, 49, 51 and 93 all contain information relevant to addressing the health needs of black and minority ethnic groups. The categories under which the information appears in these tables are shown below.

1991 CENSUS, TABLE 6: ETHNIC GROUP BY AGE

- Age group (0–4; 5–15; 16–29; 30–pensionable age; pensionable age and over; total persons by gender)
- Ethnic group (white; black Caribbean; black African; black other; Indian; Pakistani; Bangladeshi; Chinese; other)
- Other information (limiting long-term illness).

1991 CENSUS, TABLE 9: ECONOMIC POSITION AND ETHNIC GROUP

- Age group (16 and over)
- Ethnic group (white; black groups; Indian, Pakistani and Bangladeshi; Chinese and other groups)
- Economic position (economically active; unemployed; economically inactive)

1991 CENSUS, TABLE 43: HOUSEHOLD COMPOSITION AND ETHNIC GROUP

- Ethnic group (white; black groups; Indian, Pakistani and Bangladeshi; Chinese and other groups)
- Household composition (households with adults and dependent children; single adult households)

1991 CENSUS, TABLE 49: ETHNIC GROUPS AND HOUSING

- Ethnic group (white; black groups; Indian, Pakistani and Bangladeshi; Chinese and other groups)
- Other information

  Overcrowding (households with 1–1.5 persons per room; households with over 1.5 persons per room)

  House tenure (owner occupied; rented privately; rented from a housing association; rented from a local authority; rented from a new town or Scottish homes)
- Amenities (no central heating; no car)

1991 CENSUS, TABLE 51: COUNTRY OF BIRTH AND ETHNIC GROUP

- Ethnic group (white; black groups; Indian, Pakistani and Bangladeshi; Chinese and other groups)
- Country of birth (UK; new Commonwealth; rest of the world)

1991 CENSUS, TABLE 93: SOCIO-ECONOMIC GROUP, SOCIAL CLASS AND ETHNIC GROUP (10 % SAMPLE)

- Ethnic group (white; black Caribbean; black African; black other; Indian; Pakistani; Bangladeshi; Chinese; other groups)
- Socio-economic group (employers and managers; professional workers; intermediate non-manual workers [foremen, supervisors, skilled and own account]; professional service and semi-skilled manual workers; unskilled manual workers; farmers and agricultural workers; members of armed forces and inadequately described)
- Social class as defined by occupation (professional etc. occupations; managerial and technical; skilled occupations – non-manual; skilled occupations – manual; partly skilled occupations; unskilled occupations)

Using the data

The data can be analysed in a number of ways to help focus on specific issues within a district, locality or GP practice area. It can be used to:

- calculate the proportion of each black and minority ethnic group within a district, and by ward, using the data from table 6;
- provide age and gender profiles;

- estimate the size of the 'at risk' population;
- provide the denominator figures for the calculation of rates;
- produce specific population projections in the inter-census years by using it as a baseline;
- give information at the locality level on the size of the ethnic population;
- compare specific health indicators in localities with a similar ethnic profile;
- determine levels of migration within the area using table 51;
- monitor deprivation factors such as car ownership, house tenure, lack of central heating and overcrowding.

Collecting other information

A geographical information system, a digitised mapping package or a map can be used to build up a useful bank of knowledge about a local community. This can include the location of meeting places and places of worship, and the names of religious leaders, young people, elders, community groups and others who are known to provide links with the local community.

Quantifying health problems

Using death certificates

Historically, information on the health experiences of black and minority ethnic communities has been based on mortality data from death certificates, as other data are scarce. The cause of death was related to ethnic origin by using the place of birth.

Using small area statistics

The census can be used to look at the black and minority ethnic populations of defined small areas such as electoral wards. A geographical analysis can be carried out by ward and the health experiences of people in wards with different ethnic mixes can be compared. Such studies have again mostly been based on mortality data. The different population profile of the black and minority ethnic populations means that rates must be standardised by age. An additional problem is that the small numbers involved results in large confidence intervals. Also, any differences cannot be automatically ascribed to ethnicity either in total or in part as there are many other confounding factors, such as deprivation levels, which could be causal. The introduction of GP links will extend the ability to collect information at practice level.

Using a geographical information system, more sophisticated analyses can be carried out. An aggregation of smaller geographical areas (such as enumeration districts with specific levels of minority ethnic communities) or even user-defined geographical areas can be analysed. The health authority population register can be used to estimate the base population more accurately,

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particularly in inter-census years, and it can give information on a locality smaller than a census enumeration district.

Such analyses cannot identify causal relationships but can highlight areas where more information could help purchasing decisions.

Using names

The health authority population register can be searched by name to identify particular ethnic populations. This can identify groups who have names distinctly different from the majority population and with a high degree of endogamy. It has been used with some success on the Chinese and South Asian population (Coldman *et al.*, 1988; Ecob and Williams, 1991; Nicholl *et al.*, 1986).

Using dedicated studies

Surveys on health status have often been incorporated into lifestyle studies which have been carried out in many districts. The response rate from black and minority ethnic communities is usually low, however, and as these communities form a small proportion of population, a low response usually means that no firm conclusions can be drawn.

More recent health and lifestyle surveys have used face-to-face interviews rather than postal methods – e.g. a national survey by the Health Education Authority (1995) and local ones by individual authorities, such as Avon (Avon Health, 1995) and Walsall (Walsall Health, 1996). These have successfully collected data from black and minority ethnic communities but before any findings are transferred to other populations the methods of sampling used must be taken into account.

Using recorded ethnicity data

As from April 1995, ethnic data is being collected for all in-patient episodes as part of the CMDS. These data can be used by purchasers and providers to provide information on the uptake of services by the black and minority ethnic communities (see Chapter 9). Such analysis will be enhanced when new NHS numbers are introduced. This will allow the calculation of service uptake by patient rather than just by episode.

Service implications

Collecting ethnic data in primary care

Admitted patients account for a very small proportion of contacts with the NHS but little ethnic data exists in primary care. Chapter 9 recommends the collection of ethnicity data by requesting information on ethnicity, preferred language and religion at the point of registration with a GP. As it would only be identified by NHS number, confidentiality can be maintained. There are political and professional implications attached to this method of collecting ethnicity information but more reliable data are needed.

Confounding factors

Socio-economic status is an important confounding variable which has to be taken into consideration when examining differences in health. Research shows that minority ethnic groups overall have a lower socio-economic profile than the indigenous population but suggests that this does not fully explain the differences between groups. Nevertheless, this information can provide useful pointers about the priorities purchasers should follow.

Patterns of disease

The health of a population can be examined by:

- measuring the frequency of a disease – its incidence or prevalence;
- comparing populations by using measures such as relative risk or standardised ratios.

Most studies on the health of ethnic minorities use the second method and concentrate on relative risk more than absolute risk.

Measurements

Although absolute measures are the best indicators to assess health needs, epidemiological comparisons are useful as they can suggest likely disease mechanisms and thus suitable changes to service provision.

Once a difference has been identified in a particular group, the next stage is to identify the causes and put in place mechanisms to address them – for example, employ a female gynaecologist for women who prefer not to be treated by a male doctor.

For the future, the challenge is to be alert to any new health problems that may emerge as black and minority ethnic groups lose their original cultural identity and take on either the indigenous culture or a new identity.

Good practice examples

Camden and Islington Health Authority undertook a comprehensive health needs assessment for black and minority ethnic communities covering a broad cross-section of interest groups and specific diseases and conditions. The research was shaped by a multi-agency steering group. The recommendations provided a resumé of issues for black and minority ethnic communities which were common to all areas of health care: diseases/illnesses requiring special attention and areas for further research.

Dorset Health Authority has undertaken a detailed needs assessment of all minority ethnic and migrant groups which make up approximately 5.9 per cent of the Dorset population. The needs assessment highlights issues for, and a profile of, all resident minority groups under the OPCS classification, as well as a range of other subgroups within minority ethnic communities to whom health services may be virtually inaccessible (e.g. minority ethnic homeless people; foreign students; seasonal workers; sailors; minorities in prisons; new entrants to the UK).

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Enfield and Haringey Health Authority has collated and reviewed all the needs assessment work they have undertaken since 1988 (a total of 15 projects, studies and seminars), highlighted their recommendations and identified future developments it needs to address as a result.

Warwickshire Health Authority has produced an ethnicity data pack which includes ethnicity data contained in the census, mapped by locality, and also local ethnicity and health data. This has been made available to commissioning teams and providers to help in developing initiatives addressing black and minority ethnic health issues.

Chapter 2

Policy and legislation

SUMMARY

Race relations legislation confers on the NHS a duty to provide health care in a non-discriminatory manner, and the Race Relations Act 1976 can be used proactively to help deliver culturally competent services.

Addressing the health needs of black and minority ethnic groups is central, not incidental, to the achievement of the main planks of NHS policy as set out in recent planning and priority guidance.

Policy development

There has been increasing recognition over the last 15 years of the relationship between ethnicity and health. Some of the significant milestones over the past 15 years are:

1981 Development of interpreting and advocacy services

1983 Stop Rickets Campaign (1983)

1985 *Health Care in Multiracial Britain* (Mares et *al.*, 1985)

1987 *The Asian Mother and Baby Campaign* (Bahl, 1987)

1988 *Action not Words* (NAHA, 1988)

1989 Department of Health appoints ethnic health adviser

1990 *Working for Patients* white paper published

1991 Health and race information exchange (SHARE) established by
King's Fund and Department of Health

1992 *Health of the Nation*
Chief Medical Officer's report (1991) *On the State of the Public Health for the Year 1991*

1993 *Equality across the Board* (NAHAT and King's Fund Centre, 1993)
Ethnic Health Unit established

1994 *Collection of Ethnic Group Data for Admitted Patients*, EL(94)77
Ethnic Minority Staff in the NHS: a Programme of Action, EL(94)12
Priorities and Planning Guidance for the NHS 1995/96, EL(94)55, Priority F

1995 *Health and Lifestyles Survey of Black and Minority Ethnic Groups* (Health Education Authority, 1995)
Priorities and Planning Guidance for the NHS 1996/97, EL(95)68

Nevertheless, despite this increasingly specific focus, there is clear evidence that the issue of black and minority ethnic health has not become integral to the commissioning of health by purchasers. Reasons for this include the restructuring of the NHS which has been in progress through the early 1990s, and the pressures of competing agendas on purchasers and providers. The survey for this project found that, in addition, many senior managers and boards feel 'uncomfortable' dealing with issues of race and ethnicity, both in terms of employment and service delivery, and have sometimes been deterred from moving ahead by real or perceived difficulties in interacting with black and minority ethnic communities.

However, this survey also found that 88 per cent of respondents, both purchasers and providers, indicated that their organisation was in the process of developing a strategy to address black and minority ethnic health issues, although few had such a strategy in place. From a position two years ago, when hardly any evidence existed of systematic work in this field, such a response indicates how the issue has moved towards the mainstream, particularly for districts with sizeable communities.

The inclusion of a chapter in the Chief Medical Officer's report, *On the State of the Public Health for the Year 1991*, devoted to black and minority ethnic health, was undoubtedly a turning point in raising national awareness of the need for action and this was buttressed by the ethnicity and health data published in support of the *Health of the Nation* strategy (Balarajan and Soni Raleigh, 1993).

Ministerial commitment over recent years has also been instrumental in raising the profile of this issue. The work of the Ethnic Health Task Force, which was personally chaired by Baroness Cumberlege, Parliamentary Under Secretary of State, led in 1993 to the establishment of the Ethnic Health Unit with a remit to help the NHS improve services for black and minority ethnic groups.

Much more direct requirement for purchasers to address this issue is contained in Priority F of the *Priorities and Planning Guidance for the NHS 1995/96* which requires them to:

> *'Improve the performance of the NHS for the specific client groups of* ***minority ethnic people****, older people, children, people with physical disabilities and people with severe mental illness.'*

The effect of this inclusion within the corporate contract process was to move this issue, perhaps for the first time, from being one which was relevant but peripheral, to one which was an integral part of the performance management process. There is little doubt that this guidance was a significant factor in stimulating purchasers and providers to bring black and minority ethnic health closer to the mainstream agenda.

At least one region has moved further to include work on black and minority ethnic health as part of its corporate contract with health authorities. The relevant part of the West Midlands Corporate Contract is shown below, and the region has been monitoring progress at its quarterly and annual review meetings with purchasers.

WEST MIDLANDS CORPORATE CONTRACTS 1995/96

- Health Authorities should have functional monitoring procedures, in accordance with the requirement in *Collection of Ethnic Group Data for Admitted Patients*, EL(94)77, to provide quarterly data on the ethnicity of the population receiving in-patient care. Health authorities will be required to produce this data for their quarterly reviews.
- Health authorities will be required to develop commissioning action plans for meeting the needs of black and minority ethnic communities within their locality. The regional office will issue guidance to support these plans during the course of 1995, and they will be the basis against which health authorities' progress will be measured in 1996/1997 and subsequent years.
- A named board member – either executive or non-executive – should take responsibility for ensuring the above objectives are met.
- Districts will be required to provide baseline information on the employment of staff in their commissioning and provider units in accordance with *Ethnic Minority Staff in the NHS: a Programme of Action*, EL(94)12, and to produce six-monthly reviews of recruitment and employment trends.

Key elements of policy

Below is an extract from the most recent national guidance on the purpose of the NHS and the main national policies aimed at delivering the mission of the NHS.

PRIORITIES AND PLANNING GUIDANCE FOR THE NHS 1996/97, EL(95)68

Extract from overview

- The purpose of the NHS is to secure through the resources available the greatest possible improvement to the physical and mental health of the people of England......a service available to all on the basis of clinical need, regardless of the ability to pay. In seeking to achieve this purpose the NHS, as a public service, aims to judge its results under three headings: equity, efficiency and responsiveness.
- The main Government policies for meeting the purpose of the NHS and for delivering these results are: *Health of the Nation*, community care, the *Patient's Charter* and moves towards a primary care-led NHS.

Although not quite so explicit, *An Accountability Framework for GP Fundholding*, EL(95)54 places a general responsibility on GP fundholders to:

> *'Play their full part in meeting national priorities and objectives (for example, Health of the Nation, Patient's Charter, community care and efficiency targets).'*

Why black and minority ethnic health is a mainstream issue

It is sometimes argued that where the black and minority ethnic population is relatively small, addressing issues of black and minority ethnic health has to be a low priority. This is certainly true in the sense that small black and minority ethnic population may not be statistically significant in terms of overall *Health of the Nation* targets for that district. Nevertheless, this argument cannot be sustained if set against all the above key policies taken together.

It is also possible that some of the smaller black and minority ethnic communities are at even greater disadvantage because of their isolation. Some of the major reasons why black and minority ethnic health needs to be addressed whatever the relative population size are highlighted below.

RELEVANCE OF KEY POLICIES TO BLACK AND MINORITY ETHNIC HEALTH

Health of the Nation	Higher rates of heart disease amongst Asians and African Caribbeans Diabetes 4+ times more prevalent amongst Asians Diagnosis of schizophrenia six times higher in African Caribbean people than similar groups in country of origin High rates of perinatal mortality amongst some Pakistani born women Low uptake rates for breast and cervical screening
Patient's Charter	Delivery on charter standard in respect of privacy, dignity, religious and cultural beliefs Language and communications barriers lead to poorer access Service delivery model is still 'Eurocentric'
Care in the community	Often incorrect assumptions about extended family networks Intergenerational conflicts Need to raise awareness of services available Increasing number of older people
Primary care-led NHS	Raise awareness of role of professions working in primary care settings Address community's expectations of GPs in relation to treatment offered Quality of primary care services Annual practice plans to be consistent with national priorities Role of alternative therapies/traditional remedies

In addition, the *Priorities and Planning Guidance for the NHS 1996/97*, EL(95)68, identifies medium term priorities the achievement of which could be directly dependent on addressing issues of black and minority ethnic health. Examples are:

Priority	*Subject*	*Refer to:*
B	Mental health	Part 2, Chapters 9 and 10 Part 3, Chapter 14
D	Involving users	Part 2, Chapter 6
E	Continuing health care needs of vulnerable people	Part 2, Chapter 4 Part 3, Chapters 12 and 14
F	NHS as a good employer	Part 2, Chapter 8

Lawful and unlawful actions in service delivery

The Race Relations Act 1976 places a duty on health service organisations to ensure that health services are provided and delivered free from unlawful discrimination.

There can now be little dispute that issues of employment of black and minority ethnic people and services to black and minority ethnic communities are 'two sides of the same coin' (Virginia Bottomley, former Secretary of State for Health). The legislative aspects of equal opportunities in employment are referred to in Chapter 8; this chapter concentrates on service provision in a non-discriminatory manner. Below are some examples of unlawful discrimination in service delivery.

UNLAWFUL DISCRIMINATION IN SERVICE DELIVERY (COMMISSION FOR RACIAL EQUALITY)

Direct discrimination [Section 1(1)(a) of the Race Relations Act 1976]

Direct discrimination is defined as treating a person less favourably than another on grounds of race and includes the segregation of people on racial grounds.

Examples of direct discrimination

- A receptionist on an appointments desk tells African Caribbean patients that a particular consultant has no appointments available for a considerable period but she concurrently makes appointments for white patients with the same consultant. She does so only on the basis of their colour.
- The service is delivered by an ethnically mixed group of professionals but all African Caribbean patients are referred to African Caribbean doctors, solely because of their colour and not because of their particular needs.

cont'd

UNLAWFUL DISCRIMINATION IN SERVICE DELIVERY (COMMISSION FOR RACIAL EQUALITY) cont'd

Indirect discrimination [Section 1(1)(b) of the Race Relations Act 1976]

Indirect racial discrimination consists of applying, in the circumstances covered in the Act, a requirement or condition which, although applied equally to people of all racial groups, is such that a considerably smaller proportion from a particular racial group can comply with it than others, and which cannot be shown to be justifiable irrespective of the colour, race, nationality, or ethnic or national origins of the person to whom it is applied and which is to the detriment of the person concerned because she or he cannot comply with it.

Examples of indirect discrimination

- Allocating beds to Bangladeshi female patients on a mixed sex ward, when the staff are aware of the cultural needs of these patients but choose to ignore them. Consequently, those women from this community are unable to use the service or have to put up with insensitive and inappropriate provision.
- Staff in a hospital serving a multi-ethnic population attempt to obtain consent to an operation from a patient who speaks limited English. No access to an interpreter is offered. Staff assume that the patient understands the implication of the operation because the patient signs the consent form. The operation leads to complications which the patient was not warned about. When the patient realises the implications of the operation which they were unaware of, he/she is distraught.

Unlawful discrimination (Section 20 of the Race Relations Act 1976)

Section 20 of the Race Relations Act 1976 makes it unlawful for anyone concerned with the provision of health-care services to discriminate on racial grounds by refusing or deliberately omitting to provide the services; or as regards their quality; or the manner in which, or the terms on which, they are provided.

Example of unlawful discrimination under section 20

- Non-English speaking patients are not offered the counselling service offered to other patients for dealing with psychological trauma after a major operation because there is no provision of the service in languages spoken by these patients.

Using the law proactively

Under Section 35 of the Race Relations Act 1976 it is lawful to provide access to facilities or services to people from a particular racial group in order to meet their needs in respect of education, training, welfare or access to any other ancillary benefits, as shown below:

EXAMPLE OF LAWFUL ACTION UNDER SECTION 35

An NHS trust provides counselling services in different languages for dealing with psychological trauma after a major operation and also provides information leaflets explaining such a service in different languages such that it becomes accessible to all the different ethnic groups who may wish to use it.

Good practice examples

Coventry Health Authority has set up a working group on equal opportunities which has commitment at board level as it is chaired by an authority member; it has representatives of senior management and staff groups.

Birmingham Women's Healthcare NHS Trust has an equal opportunities group which has a clear policy and specific targets and reports twice yearly to the executive board and the Trust board.

Bradford Hospitals NHS Trust has an equity of service delivery policy which includes consultation on service planning and delivery, confidentiality, information to patients, patient complaints procedure, facilities for specific conditions, advocacy and other standards.

King's Healthcare NHS Trust has a Customer Care Manager whose remit is to ensure that everyone in the community served, including black and minority ethnic communities, women and people with disabilities have the health service they need. The Customer Care Manager reviews progress and implementation of the fair access policy, and reviews overall progress at King's Healthcare in the development of practice/services.

Royal Hospitals NHS Trust has an equal opportunities policy which encompasses staffing as well as service provision, with regular monitoring reports to the board. The Trust has established an Equal Opportunities Department to ensure a high profile for these issues.

United Leeds NHS Trust has a service equality steering group comprising senior managers across disciplines. It has also established an equal access advisory group for minority ethnic groups to improve the provision of services within the Trust.

Chapter 3

Energising the organisation

SUMMARY

Although ethnicity has risen up the health agenda over recent years, there is little evidence that purchasers and providers are dealing with this issue in a coherent and systematic way.

A paradigm shift is proposed to remodel organisational processes so that they help to create a culturally competent organisation.

This chapter identifies some of the characteristics which appear to be present in those organisations which have moved closest to planning and commissioning culturally competent services for black and minority ethnic communities. These features include: board level accountability for minority ethnic health matters; senior management leadership on this issue within the executive team; a corporate level open dialogue with local communities; a coherent strategy for ethnicity and health; a commitment to action; and robust monitoring arrangements.

Where is the NHS now?

The survey conducted for this project found increasing awareness amongst purchasers and providers of the need to address issues of black and minority ethnic health. The awareness has resulted in a number of *ad hoc* projects, but has not yet affected organisational strategies, processes and outcomes in a way which would lead to sustained progress in addressing the issues. A summary of the findings of the survey is given below.

OVERALL FINDINGS OF THE SURVEY

- Ethnicity is now on the health agenda at a high level in many organisations
- A large number of initiatives exists: researching health needs, hearing 'local voices' and developing culturally sensitive services

However

- The tendency to rhetoric in mission statements is frequently not backed up by action plans
- There is limited use of targets and measures of success
- There is little or no consideration of primary care issues as they affect minority ethnic groups
- There is limited consideration of integration with local authority community care plans

cont'd

OVERALL FINDINGS OF THE SURVEY cont'd

- There is insufficient communication, co-operation and coherence between purchasers and providers
- Organisations still seem to be struggling with removing even the simplest barriers to progress
- Many directors and senior managers tend to feel 'uncomfortable' in dealing with issues of ethnicity both in terms of employment and service delivery.

The survey results together with the personal interviews do show, however, that some organisations have been successful in grasping the issues and demonstrating significant progress. This chapter identifies some of the organisational themes which emerge from the experience of those who are perceived by local communities as being closest to planning and commissioning culturally competent services.

Paradigm shift

Those who have made progress, whether purchaser or provider, recognised that what was required was a significant cultural change in their organisation. They embarked on the task of organisational transformation not just because of the ethnicity issue but from their commitment to making their organisations responsive to the needs of all residents, and a desire to offer genuine choice for patients. The paradigm shift – inherent in any successful attempt to transform the way in which issues of minority ethnic health are addressed by purchasers and providers – is set out below.

PARADIGM SHIFT REQUIRED

From	To
Issue treated **separately**	**Integrated** into purchaser/provider mainstream agendas
Seeing black and minority ethnic communities as **homogeneous**	Reality of extensive **diversity**, even amongst people originating in the same part of the world
Emphasis on **consultation**	Emphasis on **action** to address the issues
Eurocentric model of care	Culturally sensitive or, better, **culturally competent** services
Issue treated as a **problem**	Recognised as part of the **solution** which contributes directly to organisational objectives (as set out in *Priorities and Planning Guidance for the NHS 1996/97)*, EL(95)68
Funding on a **project** basis	Funding from **mainstream budgets**
Employment and service delivery considered separately	Composition of workforce **directly related** to quality of service for black and minority ethnic people

Framework for achieving the shift

There can be no single prescription for achieving these organisational shifts. What follows are some of the organisational competencies emerging from the research which make for success in addressing black and minority ethnic health issues as an integral part of the commissioning process. Purchasers need to include GPs fully in this process both as co-purchasers and as primary care providers. A number of the features are equally applicable to provider organisations. Each of the elements below contributes to success but taken together they constitute a powerful dynamic for achieving change.

Board level commitment

A non-executive director with a brief for black and minority ethnic health issues can help to ensure that ethnic health issues are recognised in strategies, policies and resource decisions. In some trusts and authorities, the chairperson acts as the 'product champion' driving this issue forward, but many non-executive directors, whether they are from the black and minority ethnic community or not, also help their organisations to take a strategic view. Where the number of people from these communities is significant, such an arrangement recognises that they can exert pressure on both purchasers and providers through their choice of where they receive services. Where numbers are smaller, a 'product champion' at board level can be a great potential benefit and ensure that these issues do not fall off the agenda.

The board itself needs to consider establishing a subcommittee specifically to address this issue, chaired by a board member. Many organisations have brought together issues of equal opportunity in employment and access to services within such a forum.

Executive team leadership

Within an organisation, as well as externally to the local black and minority ethnic communities, the chief executive is a visible representation of the stance of the organisation and so can determine its success. Local communities can tell quickly from their exposure to this person, or lack of it, whether to trust the organisation to deliver – and trust is a fundamental requirement of any effective links with local black and minority ethnic communities.

Internally, the chief executive's views will either encourage or deter staff from incorporating this issue as an integral part of their work. This does not imply that the chief executive must do everything personally but does demand visible leadership on this issue and active support to those in the organisation who are addressing black and minority ethnic health issues.

Few organisations have achieved full integration of this issue within their commissioning or service delivery processes, so many purchasers and providers have found it helpful to identify one senior manager with the responsibility for undertaking the detailed work necessary to:

- foster the dialogue with local black and minority ethnic groups;
- develop a coherent strategy and implementation plan;

- provide information and advice to other departments/directorates/locality staff in the organisation;
- achieve co-ordination between purchasers and providers.

Participation in influencing decisions

Most successful organisations have found it helpful to have a forum at corporate level which brings together representatives from the major local black and minority ethnic groups. The structure and membership of the forum can be decided locally but its involvement in the development of strategies, policies and initiatives and in monitoring quality standards can foster participation. Such a forum complements rather than replaces any locality consultation or participation mechanisms which may exist.

Coherent strategy

The survey showed that work on black and minority ethnic issues was characterised by:

- time-limited projects;
- projects funded through 'soft' monies;
- projects not related to the main priorities;
- initiatives geographically unrelated to where black and minority ethnic groups lived or received services;
- no evaluation of outcomes;
- projects abandoned or modified because the short-term postholder left for another job.

The next chapter proposes the elements of a coherent strategy for addressing black and minority ethnic issues.

Commitment to action

One of the strongest messages from the survey is the need for action. The research for this toolkit repeatedly showed 'focus group fatigue' amongst black and minority ethnic groups. The communities felt that they had made the same points time and time again but little action had followed. So action must follow consultation, even if the response is not what the consultees might wish to hear, and, to be effective, consultations must be linked to each other in a web which recognises the diversity of the local communities and groups – rather than using each consultation in isolation. Chapter 6 suggests some ways of developing such a web.

The barriers to action are, in many cases, not lack of commitment in principle but perceived difficulties – often more imagined than real. Some ways of addressing the difficulties are set out in the box :

OVERCOMING BARRIERS TO ACTION

Lack of information	There is now an extensive literature on health variations linked to ethnicity and the potential for health gain (see Part 2, Chapter 10; Part 3; and Part 4)
	Further targeted research is needed, in particular on the Chinese, Vietnamese, and those from Africa and the Middle-East, as well as on specific conditions, including obtaining recent data on heart disease amongst Asians
Lack of resources	The scale of new resources to achieve culturally competent services is trivial compared with overall commissioning budgets
	People from black and minority ethnic communities are not separate but part of the population for whom authorities are funded
	Better targeting by redeployment of existing resources could mean additional resources are not required
	The key to action is organisational commitment not resources
Lack of 'know-how'	Excellence is already being achieved in some places in the country
	Expertise can be 'imported' from elsewhere until an organisation develops the skills
	Most organisations have individuals who would become involved if encouraged
	This toolkit is one step in bridging this 'know-how' gap

Measuring progress

A feedback loop is essential to measure progress against the targets and milestones contained in the strategy and commissioning action plans. Feedback should be at least every six months to enable relevant action to be taken and the momentum to be maintained. The reporting should be to the board itself, through any subcommittee or implementation group which may have been established.

Good practice examples

Avon Health Authority has co-facilitated the Bristol Racial Equality Council (BREC) health working group, which provides a forum for local trusts, Avon Health Authority, Avon Social Services, BREC members and officers. The group is chaired by the chair of Avon Health Authority. The aim of the group is: 'to support the implementation of racial equality policies by local health and social care organisations and practices to ensure equality of access and care in the delivery of services'.

Kensington & Chelsea and Westminster Health Authority has a health and community care forum on ethnicity which meets quarterly, feeds into the joint community care planning mechanisms and has active involvement from the commissioning managers.

Enfield & Haringey Health Authority has a health and ethnicity liaison committee which is a formal subcommittee of the Health Authority with Community Health Council and Race Equality Council members.

Northamptonshire Health Authority has developed proposals with the social services department for each of the key community care service areas, such as mental health and learning disabilities. Each development proposal identifies services to black and minority ethnic communities not only across the agencies but also across private and voluntary sector organisations.

West Yorkshire Health Authority has set up a black and minority ethnic health forum under Health for All, a multi-agency initiative set up to develop a strategy and draw up an action plan in response to the findings of the report *Ethnic Minority Healthcare in and around Dewsbury*. This report had sought to elicit patients' perceptions of the services provided by GPs and out-patient clinics and to explore issues at the interface between primary and secondary care.

Central Middlesex Hospital NHS Trust's commitment to addressing the needs of black and minority ethnic service users is reflected in their business plan, which combines their statement of intent with practical measures to be undertaken in the next year.

North Manchester Healthcare NHS Trust has set up a patient service subcommittee for black and minority ethnic groups. The committee comprises all key managers in the Trust together with black and minority ethnic communities and voluntary sector representatives.

Portsmouth Hospitals NHS Trust set up an equal voice working group comprising staff and minority ethnic users of services, to arrive at ways of understanding, communicating and implementing changes acceptable to users.

Riverside Mental Health NHS Trust has each non-executive director taking a specialist area of interest and working closely with one of the executive directors. For example, one of the non-executive directors chairs the quality council.

Chapter 4

Developing and implementing a commissioning strategy

SUMMARY

To move beyond an *ad hoc* approach to ethnicity and health it is essential to develop a clear and coherent strategy, prepared with the involvement of the main stakeholders, particularly the communities concerned and preferably in partnership with GPs and providers. This strategy must show how the actions proposed will help to address the key objectives of the organisation.

Ethnicity issues must be included within the main policy processes and documents of the organisation (e.g. purchasing intentions, strategic and business plans, practice plans and contracts). The strategy must encompass not only the overall objectives but also a commissioning action plan which demonstrates the specific actions required to make services culturally competent, including targets, milestones, monitoring arrangements and accountability for delivery.

Integration with mainstream commissioning

Nationally, most activity to address minority ethnic health issues is through short-term, time-limited projects often funded by short-term grants. Such work has an important role but there is a conspicuous lack of a strategic approach – except in a few purchasing organisations. Significant progress towards a culturally competent service is unlikely without a strategic approach by purchasers which integrates the ethnic dimension within the mainstream commissioning processes.

Developing an ethnic health strategy – who is involved?

It is the responsibility of purchasers to develop a strategy on ethnicity and health. A successful strategy, however, requires that everyone crucial to its success is able to contribute to its formulation and is committed to its outcomes. The earlier such involvement occurs the better the chance of success.

A judgement on who to involve in the development of a strategy should be based on local circumstances but the following are almost certainly important stakeholders.

Users and the community

The issue is not whether to involve users and the community but how to involve them and when. The 'how' depends on the effectiveness of the mechanisms which exist for a dialogue with local black and minority ethnic groups and some pointers are included in Chapter 6. 'When' to invite comment is equally important in order to ensure a positive response.

One of the most frequent criticisms of the NHS by black and minority ethnic groups is not lack of consultation but that consultation is not followed by action. Undertaking another round of consultations without acknowledging previously expressed views is likely to be perceived as yet another manifestation of NHS 'deafness' to local voices. Unless purchasers are wholly unaware of some of the local black and minority ethnic health issues, they should base their talks on – at least – an outline of what action they propose taking to respond to views already expressed.

Providers

It is equally important to involve providers in the development of a strategy. Trusts, and in some cases voluntary organisations, may be those most affected by purchaser strategies so their involvement can make implementation more effective. Where providers do not have an organisational framework or focus for addressing black and minority ethnic health issues, involving some of their senior executives can help to stimulate a more strategic perspective on these issues within the provider organisation itself.

GPs and primary care staff

General practitioners and other primary and community care staff have a crucial role in any strategy both as providers and as purchasers of services. Involving them as fully as possible will be essential in achieving a primary care-led NHS for black and minority ethnic groups.

Other stakeholders

Joint work with local authorities, particularly in relation to community care, is not optional. In particular, the *Good Practice Guide on Race, Culture and Community Care* (Social Services Inspectorate, 1996) recognises the significance of ethnicity. The Community Health Council and, in appropriate cases, the local Racial Equality Council can be helpful in creating broad support for the strategy.

What should a strategy cover?

Although the final content of any strategy must reflect local circumstances, many elements are likely to be common to all. These are summarised below.

KEY ELEMENTS OF AN ETHNICITY AND HEALTH STRATEGY

Aim/mission/values

- Purchaser committed to addressing the needs of all sections of the community
- Purchaser committed to addressing black and minority ethnic health issues as an integral part of delivering on the key national policies as outlined in, for example, *Health of the Nation, Patient's Charter*, care in the community and moves towards a primary care-led NHS
- Achieve a consistent, coherent and corporate approach

Service provision (see Part 3)

- Make existing services more accessible, acceptable, appropriate and culturally competent
- Meet gaps in services
- Adapt services where necessary

Communications (see Chapter 7)

- Develop a communications strategy which is both linguistically and culturally acceptable (e.g. translated health promotion information)
- Provide audio/video tapes of policies and standards in appropriate languages
- Make a commitment to advocacy

Employment and training (see Chapter 8)

- Make a commitment to equal opportunities
- Plan to achieve the goals in *Ethnic Minority Staff in the NHS:* a *Programme of Action, EL(94)12*
- Identify posts for appointment of staff with particular ethnic/language/cultural background
- Provide anti-discriminatory training for all staff

Commissioning action plan (see opposite)

Monitoring

- Reporting arrangements
- Personal visits, including those from members of the black and minority ethnic community

Implementing the strategy – a commissioning action plan

A strategy needs a timetable and an action plan for implementation if it is to be more than just a statement of good intentions. Some of the key elements of a such a commissioning action plan are shown below:

KEY ELEMENTS OF A COMMISSIONING ACTION PLAN

Understanding community needs

- Relate qualitative and quantitative research on minority ethnic health to the local population
- Recognise the significance of gender/age/geographical distribution of each black and minority ethnic community
- Use ethnic monitoring data to identify patterns of usage which suggest commissioning priorities or which require further investigation
- Take into account the views of local clinicians and other professionals, including GPs and other primary care staff
- Take into account the views of local communities and users

Commissioning, contracting and monitoring

- On the basis of information collected, identify the key priorities to be addressed and the targets to be achieved over the next three years or so
- Identify how each of these priorities helps to deliver on the key NHS policies:
    - *Health of the Nation*
    - *Patient's Charter*
    - care in the community
    - primary care-led NHS
    - and medium-term priorities
- Identify how these priorities will be addressed within the purchaser's
    - strategic plan/health strategy
    - purchasing intentions
    - corporate contracts/business plans/annual practice plans
- Set out the **specific** developments proposed, resources identified, targets and standards to be achieved, timetable and accountability for delivery
- Propose contracting arrangements:
    - for specific diseases/care groups/outcomes
    - for commissioning new providers (e.g. local black and minority ethnic voluntary groups)
    - in terms of incentives and penalties
- Outline monitoring arrangements, involving users and the local community
- Set up formal evaluation of processes and achievements

cont'd

KEY ELEMENTS OF A COMMISSIONING ACTION PLAN cont'd

Developing the organisation

- Set up board level accountability for black and minority ethnic issues
- Designate someone with overall responsibility for delivery on the commissioning action plan and include in individual performance reviews of relevant managers
- Establish a continuing dialogue with users and the community, so they know what is being done and what is required
- Build alliances with providers, local authority etc.
- Recruit, select, train and develop staff in accordance with *Ethnic Minority Staff in the NHS: a Programme of Action*, EL(94)12; this applies to purchasers and providers, including primary care staff
- Carry out research and development
- Implement the information management and training strategy – including ethnic monitoring data in primary and community care
- Evaluate commissioning processes and outcomes annually

Good practice examples

Ealing, Hammersmith and Hounslow Health Authority has developed a corporate ethnicity and health strategy covering areas such as involvement/consultation; access; commissioning and service provision; health promotion; employment; monitoring and implementation. One of the key aims of this approach is to encourage all health authority directorates to produce implementation action plans for racial and 'geographical' inequalities in health care, designed to develop a comprehensive and integrated approach to meet the needs of black and minority ethnic communities. Specific targets are included and the achievement of them is linked to the individual performance reviews of managers.

Warwickshire Health Authority has developed a strategy and commissioning action plan in consultation with local black and minority ethnic groups, which sets out the specific initiatives it will take over the next three years to improve health and access to health services.

Bradford Community Health NHS Trust has adopted a long-term ethnicity equality action plan (1994–1997) comprising three phases: service audit, service targets over three years, and employment targets. This applies benchmarking principles to produce a checklist for action and audit of performance on racial equality. It also aims to develop market intelligence in order to anticipate and influence purchaser strategy.

Central Middlesex Hospital NHS Trust (in conjunction with the Trust executive and its main commissioning agencies) has identified key priorities for future action on ethnicity and health to provide equal access to services. For each priority, the Trust has reviewed the 'current status' to inform future action. The components included under current status describe factors such as district health authority committees; voluntary sector/consumer links; contractual obligations; and services.

Leeds Community and Mental Health Services NHS Trust produced a service equality strategy, outlining corporate objectives. The strategy advocates that service users, carers and the local race equality council will be consulted as part of its development, and will be involved in the monitoring of the policies.

North Mersey Community NHS Trust has an Equality Programme which has developed eight goals around access, service planning and provision, employment, monitoring and evaluation. Specific action will be taken to address needs, identify gaps in the service and identify issues for black and minority ethnic communities. One goal is to research and identify gaps in service provision for black and minority ethnic communities. Another goal is to develop positive action programmes to increase the number of black and minority ethnic staff employed by the Trust, setting clear targets for this increase. The equality action programme is Trust-wide. However, to engender ownership, each directorate has developed specific local action plans.

Portsmouth Hospitals NHS Trust has produced a plan of action for 'improving access to acute health care by black and minority ethnic communities'. The action plan was based on local research (undertaken by Hampshire Social Services and Portsmouth Polytechnic and jointly funded by the health authority) and national guidance requirements. The Trust has assigned a priority rating to each recommendation.

Chapter 5

Using the contracting process

SUMMARY

This chapter sets out ways in which purchasers can stimulate the provision of culturally competent services.

The contracting process can be used to specify how providers should deliver culturally competent services. Service specifications and quality standards must clearly state the objectives to be achieved and should be formally recorded either in contracts, or schedules attached to contracts.

The black and minority ethnic voluntary sector could play a much greater role in the provision of culturally competent services. Purchasers need to invest the management time necessary to equip the voluntary sector to become an effective partner in the delivery of culturally competent services and, where appropriate, a preferred provider of some services.

Contracts driving change

The fundamental purpose of contracts between purchasers and providers is to be explicit about what is expected in terms of the quality, quantity and cost of services. If black and minority ethnic health issues are viewed as an integral part of the commissioning process, it follows that the expectations of purchasers (in terms of the acceptability, appropriateness and cultural competence of services) are an integral part of the contracting process. Although there are many ways in which this can be achieved, every contract could benefit by including the points outlined below.

CORE ELEMENTS OF CONTRACTS

Purchaser mission	Purchasers need to make explicit their commitment to achieving equality of opportunity for staff, and to securing services which meet the needs and wishes of each member of their population
Expectations of providers	Purchasers should make clear that they would prefer to purchase from providers who have adopted and are actively implementing processes of equal opportunity for staff and provision of culturally competent services for their black and minority ethnic residents. Providers should undertake to comply with Section 20 of the 1976 Race Relations Act to ensure that the provision of services is not racially discriminatory

cont'd

CORE ELEMENTS OF CONTRACTS cont'd

Standards	Purchasers should set out the core ethnicity and health quality standards which providers should meet (see Chapter 10)
Monitoring performance	Purchasers should be specific about the ways in which provider performance is to be reported and monitored, and how variations from the contract are to be addressed
Incentives and penalties	Purchasers may offer to reward providers for achieving cultural competence and penalise them for failing to do so

Contracting for specific diseases

One way of ensuring that known needs are addressed is to contract with providers for specific services relating to the treatment of specific diseases. Some examples are given below.

EXAMPLES OF SPECIFIC CONTRACTS WHICH CAN BE DEVELOPED USING ETHNIC MONITORING DATA

- Diseases occurring only or principally in minority ethnic groups (e.g. thalassaemia, sickle cell, Tay-Sachs)
    - Contract and monitor for cases of each disease to be treated
    - Specify volume (min/max), threshold, quality
- Diseases with a relatively high incidence in minority ethnic groups (e.g. diabetes, heart disease, stroke)
    - Contract and monitor for cases to be treated from black and minority ethnic groups
    - Specify volume, threshold, quality
- Services with relatively low use by, or poor outcome for, black and minority ethnic groups (e.g. antenatal care, rehabilitation services for those who have suffered a heart attack)
    - Contract and monitor for translation services, interpreters, outreach and advocacy staff

Commissioning new providers

Black and minority ethnic voluntary organisations may not yet be extensive in the health sector but they could help to improve access to services and bring pressure to bear on health agencies to provide culturally competent services. They have enormous untapped potential for the direct delivery of services, if encouraged and funded appropriately. Some of the benefits of using the voluntary sector in this way are set out below.

BENEFITS OF ENCOURAGING SERVICE PROVISION BY VOLUNTARY ORGANISATIONS

- They are language and culture-specific, user-friendly and accessible
- They are an integral part of a community's networks
- They are aware of many of the difficulties being encountered by individuals within their communities
- They have the potential for influencing, positively or negatively, the perceptions of a community about the work of the health agencies
- This approach promotes partnership in achieving change

The pitfalls of using voluntary groups stem from their often limited administrative resources and lack of experience in providing services. Also, many voluntary organisations see their prime role as a pressure group and do not wish to become service providers.

'Capacity building' to provide services within black and minority ethnic communities themselves therefore requires an innovative but no less rigorous approach to developing contracts. Greatest potential may exist in the provision of services for older people and in mental health services. Some of the basic requirements for effective development of the voluntary sector are shown below.

DEVELOPING THE VOLUNTARY SECTOR

- Identify the groups which exist locally, their purpose and whether any operate in the areas covered by the ethnicity and health strategy
- Invest management time in helping the group to develop the necessary skills to become/develop as a service provider, including how to manage relationships with a statutory agency
- Use flexible contracts, but ones which recognise the true costs of service delivery and 'set-up' costs
- Set clear standards of service performance, financial viability and probity
- Monitor through regular reports against standards, personal visits etc.

Good practice examples

Kensington & Chelsea and Westminster Health Authority developed a number of black and minority ethnic initiatives by using a project-based approach to stimulate and develop work (e.g. an equal access to healthcare project). Race and health managers in the organisation have then developed and implemented an 'exit strategy' to integrate this work into mainstream service provision. This has assured continuity and a longer term commitment from the organisation to make ethnicity and health part of its core business.

Leicestershire Health Authority has developed a 12 point checklist setting out its expectations of providers in delivering services to black and minority ethnic groups. The issues covered include communication, diet, worship, patient records and care plans, and employment.

Redbridge and Waltham Forest Health Authority tendered jointly with the London Borough of Waltham Forest for domicilary care services with the aim of increasing the number of black and minority ethnic service providers.

Sheffield Health Authority has negotiated service agreements with each of its providers which focus on how the purchaser expects providers to offer appropriate and sensitive services to black and minority ethnic communities. They covers all key areas such as responsibility, communication, ethnic monitoring, diet, religion, practitioner gender, complaints, staff training, privacy, dignity and bereavement. The authority has adopted an 'enabling' approach by employing a development officer for black and minority ethnic communities, who works in conjunction with providers.

Chapter 6

User consultation and participation

SUMMARY

The disappointment most frequently voiced by many black and minority ethnic groups is that the NHS does not appear to respond to the views of local communities. This chapter discusses some of the factors which contribute to effective consultation and participation.

Genuine participation needs to go beyond undue reliance on the views of individuals in formal leadership positions. Rather it needs to seek out those who are genuinely opinion-formers within the community concerned. Effective participation does take time and effort, and success depends on demonstrating that action will follow.

What is consultation and participation?

Consultation and participation can be seen as part of a spectrum of activities carried out to ensure that people have some influence over the services they receive. Consultation implies seeking people's advice. It can be done in a tokenistic way (as when proposals are sent out with no real opportunity for change) or it can be a constructive activity (such as a series of meetings for groups to agree the overall aims and details of a service development).

Participation implies more active involvement and influence than consultation. Participative planning groups encourage and enable service users to be full and contributing members, or to give them equal powers of decision-making.

At what points should we consult?

Planning

It is particularly important that black and minority ethnic communities have an opportunity to be involved in planning and shaping the future direction of services. This will ensure that services meet real needs rather than needs based on stereotypes and 'common knowledge'.

Service delivery

Black and minority ethnic service users must have confidence that service providers communicate with them effectively, treat them with respect, build on individual strengths and meet individual needs. Ongoing liaison with groups of service users can help achieve this sensitivity at the individual level. For some services it may be appropriate to encourage and facilitate service users to deliver services, such as advocacy services.

Monitoring and evaluating

This will ensure that services respond effectively to the changing needs of local people. Black and minority ethnic users can be involved in various ways such as by setting standards and conducting independent monitoring exercises, as well as by participating in exercises such as quality review visits.

Developing a strategy for consultation

The strategy can be made relevant to the needs of black and minority ethnic users by taking into account that:

- racism and its resultant indirect and direct discrimination is a real experience for users and carers;
- many black and minority ethnic people do not use services so 'non-users' or 'potential users' should be consulted;
- there is great cultural, religious and linguistic diversity within black and minority ethnic groups, with some different needs and some common needs; any strategy should to be targeted to the particular minority ethnic groups being consulted;
- the priorities of black and minority ethnic service users (e.g. sickle cell and male circumcision) may contrast with local epidemiological information about the illnesses/diseases which should be their primary concern (e.g. diabetes or coronary heart disease).

Before any consultation a purchaser should:

- set aside a realistic amount of time for consultation; more development work may be needed if black and minority ethnic users are reluctant to get involved in another statutory sector exercise or to participate because of previous bad experiences of the health service;
- allocate adequate resources to cover the cost of interpreting and translation, transport and child care/respite care, and cover for voluntary sector staff – some voluntary sector organisations may rely on just one worker, who may be unable to leave the agency unless this type of support is provided;
- map out a range of formal and informal venues where users and potential users can be accessed, such as shops, faith organisations, English language classes, mother and baby clinics, employment training schemes and local festival celebrations;
- select appropriate community venues where local people feel comfortable, and which are accessible to them.

Some of the key steps in achieving a successful dialogue are set out below.

KEY STEPS IN PLANNING CONSULTATION AND PARTICIPATION

◆ Determine the aims and purpose of the consultation

  ◇ what does the purchaser want from the exercise?

  ◇ what benefits will there be for the people and organisations involved?

cont'd

KEY STEPS IN PLANNING CONSULTATION AND PARTICIPATION cont'd

what sorts of issues can be usefully addressed?

◆ Examine what consultation and participation mechanisms already exist and evaluate how effective these are in involving black and minority ethnic communities in a meaningful way

how many black service users and carers do they involve?

from which groups?

what is the gender balance?

how many specific issues for black and minority ethnic communities emerge from the consultation exercises?

are the black and minority ethnic users and carers active members of groups or just names on a list?

if key people from black and minority ethnic communities are acting as 'representatives', how do they consult the wider constituency of service users about their views/opinions?

◆ Develop a strategy for consultation following this initial audit which:

states the premise on which health authorities want to engage with users;

is part of a long-term ongoing process/development plan;

is an integral part of the structure of the authority;

addresses issues of representation and accountability;

states the points at which users will be involved;

has built in audit and review procedures to evaluate the process.

Consultation methods

Any methods developed to work with black and minority ethnic users/carers must recognise that involving them will take more time and require different approaches because:

- many such users/carers have relatively low expectations of health services;
- some such users/carers, particularly older people, feel that they have fewer rights to health services than the indigenous population;
- a large number of black and minority ethnic users and carers have low levels of knowledge about services, roles of professionals and how the NHS system works because they generally have poorer access to information;
- traditional consultation methods such as public meetings may not attract particular groups of users (e.g. black or minority ethnic women; non-users/potential users including black or minority ethnic people with learning disabilities);
- other methods, such as small focus groups, may only work immediately with existing/established groups; other individuals who may be meeting in a discussion group for the first time will require

a period of time and support before they can work together as a group;
- involvement of black and minority ethnic users should be a two-way process; such users may need information and skills building to enable them to comment constructively on issues and articulate their views on health services.

Whom should we consult?

A targeted consultation process needs to spell out who is to be consulted, for example:

- black and minority ethnic service users and carers;
- potential users/non-users and carers;
- existing community and voluntary organisations (black, minority ethnic and white);
- professionals working with minority ethnic clients (black, minority ethnic and white).

How can we reach service users/non-users and carers?

- Advertise in the local and national black and minority ethnic press, target TV and radio stations (e.g. TV Asia, local community and commercial radio stations) about initiatives, consultation exercises and events.
- Use local black and minority ethnic celebrities – sports/TV personalities, members of bands etc. – to provide information on radio stations.
- Put up notices in informal meeting places (e.g. local shops, community centres) and formal meeting places (e.g. faith institutions, employment training centres, GP surgeries, and English language classes).
- Co-opt local people and a range of community-based professionals from various health and social care/leisure agencies to undertake outreach and awareness-raising work.
- Target specific minority ethnic groups for 'open day' events at local health services.
- Have information stalls at local festivals and social gatherings (e.g. carnivals, Chinese New Year events, Idd and Diwali functions).

Working with black and minority ethnic users and carers

- Use a range of methods to consult and involve people. Examples include: public meetings; one-to-one interviews; questionnaires; suggestion boxes; recorded message language lines for complaints; small group discussions. Some of these methods may be more appropriate and effective for particular groups.
- Purchasers should continue to listen to users even if the issues have been raised many times before; raising issues previously raised should not be perceived as 'banging on the same drum' because the issues will be very real experiences for many users and are being voiced because those experiences have not changed.
- Share skills and knowledge with black and minority ethnic service users; this could be done by training volunteers and peer educators to deliver services (such as health promotion and interpreting).
- Develop a pool of skills within black and minority ethnic groups to enable effective consultation to take place.

- Feed back what has been done and delivered (big and small) so that the commitment is evident; for example, a couple of issues can be acted on to demonstrate to black and minority ethnic users that statutory agencies have listened and responded; media used to access black and minority ethnic service users could also be used to feed back actions.
- Review the consultation methods being used.

Good practice examples

Bedfordshire Health Authority undertook an innovative piece of research in which they consulted over 20 key black and minority ethnic groups and their representatives, and identified issues for those groups in specific service areas. This information was then used by the authority to:

- develop a minority ethnic advisory panel on health which involved three health authority directors and minority ethnic representatives; minority ethnic representatives were allowed to lead the development of the group and its agenda;
- develop guidelines on the most appropriate and effective way of consulting with minority ethnic communities;
- produce a framework for planning and developing services for black and minority ethnic communities through contracting;
- formulate quality standard guidelines for all acute and community services.

Bexley and Greenwich Health Anthority is commissioning a research/development project to develop effective ways of involving people from black and minority ethnic communities in influencing and informing the commissioning/purchasing of services. The project is working with a forum set up by local black and minority ethnic groups and also works with focus groups to develop user involvement at a local level.

Camden and Islington Health Authority has a local community advisory group which meets bimonthly, a health and ethnicity forum, and a refugee forum. African, African-Caribbean, South-east Asian, Chinese, Middle Eastern, Latin American, southern and eastern European groups take part.

Coventry Health Anthority facilitated a health and ethnicity consultation day to gain a greater insight and understanding of the health needs and experiences of black and minority ethnic communities. The conference was chaired and facilitated by board members and senior managers in the authority and thus was driven from the top. It has led to an 'action not words' campaign and further work, including a successful health promotion day at the GNPS Sikh temple, which is being repeated in other communities.

Ealing, Hammersmith and Hounslow Health Authority has established 'user perspective groups' with local black and minority ethnic groups, on relevant services such as diabetes and strokes.

Kensington & Chelsea and Westminster Health Authority has produced a comprehensive strategic action plan, *Listening to Local Voices*, which it intends to develop as a fundamental component of the corporate agenda. The framework produced by the Authority reviews and builds on all existing work which Kensington & Chelsea and Westminster has undertaken with other agencies and service users/carers. Its approach to consultation and participation has included health fairs, open days, road shows, publicity campaigns, carer information days, work with councils for voluntary services, race equality councils, community health councils as well as the development of specific forums such as a health and ethnicity forum, refugee forum and an equal access group. Some of the consultation work with black and minority ethnic groups formed the basis for developing generic health and race standards, which now form an integral part of the Authority's contact quality specification.

The Authority's action plan for 1994–1996 has a number of central themes:

- internal awareness of local voices;
- development of an external communications strategy;
- development of a joint inter-agency consultation timetable – in order to synchronise with local authority planning cycles;
- development of a locality focus to user/carer consultation/participation.

Northamptonshire Health Authority is setting up an innovative counselling and support service accessed via GP practices for members of black and minority ethnic communities who, because of cultural or language reasons, felt unable to use GP based counselling. This was as a direct result of consultations with users.

North West Anglia Health Authority developed a consultation framework using groups and forums within the NHS, the black and minority ethnic community, community health councils, the voluntary sector and the local authority to access minority ethnic service users. As a result they have:

- developed a resource pack for staff which is highly informative and does not focus on 'cultures' and 'differences' as being problematic, but provides clear information to enable staff to provide a sensitive service;
- undertaken training for staff;
- developed an equal access to services policy;
- set up community consultation networks.

Redbridge and Waltham Forest Health Authority has established a user involvement project for black and minority ethnic users and is running a training programme to empower users to become involved in the mental health planning process.

Birmingham Women's Healthcare NHS Trust has audited black and minority ethnic user involvement and developed specific proposals for involving black and minority ethnic users more fully in developing services and feeding back on service provision and practice. Within their approach they have identified the need to take action on the concerns already expressed before undertaking further user consultation.

Central Middlesex Hospital NHS Trust monitors satisfaction from black and minority ethnic service users by using survey questionnaires after discharge. Comments and suggestions are also invited using a leaflet made available in several languages. The Trust also plans to introduce targeted monitoring of black and minority ethnic user satisfaction.

3 Towards service competence
4 References and helpful information

Enfield Community Care NHS Trust commissioned innovative research to explore the different perceptions that providers and users have of Trust services. This focused on examining how accessible and equitable Trust services were to minority and refugee communities living in Enfield. This research was provider-driven and funded. Out of the research report, Enfield has developed a strategy and action plan focusing on the key areas of training, communication, service delivery and recruitment, and retention. This work is now under review and will assist in developing further policies. The Trust also undertakes focused/targeted consultation twice monthly with Turkish/Kurdish communities. The Trust also runs a weekly support group for Turkish women.

St George's Healthcare NHS Trust has set up a two-year project to develop local networks with black and minority ethnic groups. It focuses on the health needs of black and minority ethnic elders and carers and acts on the research findings during the life of the project. The project was developed as a result of research undertaken by the black and minority ethnic interest group. The project has a reference group comprising all key managers at provider level and has developed specific outcomes with a phased timetable.

Southern Derbyshire Health Authority has a district-wide ethnic minorities forum to bring together purchasers and providers on a quarterly basis led by the Health Commission vice-chairman, with representatives from the local Race Equality Council, health, social services and 20 representative bodies.

Chapter 7

Improving communications

SUMMARY

Poor communication between patients and service providers still remains a significant barrier to achieving culturally competent health services.

This chapter proposes the development of a strategy for improving communications between service purchasers, providers and black and minority ethnic groups. It proposes the establishment of professional interpreting and translating services within clear policies and quality standards. It recommends greater use of taped information (video and audio) and proactive use of the media and innovative approaches, such as the use of dance and theatre, to convey health messages.

Why improve communications?

> *'We are here to provide a service and we are talking about quality of care. If we can't even communicate with the patient, where are the standards and where is the quality of care?'*
> *Ward nurse in a district general hospital (1995)*

There is extensive evidence that communication problems affect accessibility to health care, and can mean less appropriate services (including potentially serious misdiagnosis) and frustration and delay for all concerned. Excessive reliance is still often placed on relatives, frequently young children, to bridge the communications gap.

The scale of the communications gap

The survey relating to black and minority ethnic groups *Health and Lifestyles* (Health Education Authority, 1995) included a section on languages spoken. The key findings of that survey were:

- although most South Asians can speak some English, only about three out of ten (32 per cent) Indians and one out of ten (10 per cent) Bangladeshis considered English to be their main spoken language;
- women were less likely than men to speak English and only a small proportion of those aged 50 or over considered English to be their main spoken language;
- about one-quarter (24 per cent) of Indians and almost half (48 per cent) of Bangladeshis were unable to read English; smaller proportions were unable to read any languages.

This research confirms that language is a significant barrier to the provision of appropriate and culturally competent health services. The survey found that the Bangladeshi community, in particular, appeared to be in the lowest socio-economic groups: living in the poorest housing, their health poorer than average, and with high levels of smoking among men and women. This group was most likely to use children and spouses as interpreters when talking to the doctor. This overall national picture of poor communication with black and minority ethnic people has been supported by specific work in health authorities.

The position is even more complex given that, in some communities, between a third and two-thirds of people may not read or write their first language. This means that indiscriminate translation of information may not communicate what is needed and will not be cost-effective. Nor is it right to assume that the communications gap is a short-term time-limited problem. There are many people with little English who came to the UK in the 1960s and 1970s (aged 20 to 30 years) who will be making increasing use of health services as they get frailer over the next 20 years.

A professional approach

There is now a widely accepted need for a much more 'professional' approach to communicating with black and minority ethnic patients and communities. The Health Education Authority has produced a book on health related resources for black and minority ethnic groups (Health Education Authority, 1994). Some key elements of such a professional approach are set out below.

KEY ELEMENTS OF A COMMUNICATIONS STRATEGY

Policies	Interpreting and translation services should be provided within agreed policies
Quality standards	Policies shall include the standards of quality expected (see Core Standards, page 80)
Professional development	Staff should be appointed to specific posts and be encouraged to reach nationally recognised standards and qualifications
Advocacy	Interpreting services should be based on an advocacy model (see below), particularly for those working in mental health and care services for older people
Use of relatives	Relatives, and in particular children, should not be used to interpret for patients; a qualified professional interpreting service should be available
Use of staff	The practice of using staff to interpret should be discouraged unless they are involved in treating that patient

Interpreting, link working and advocacy

Schemes set up to facilitate or improve communication between health professionals and users revolve principally around interpreting, link working or advocacy services. Each type of service has a different background and emphasis, but the terms are often used interchangeably. The three types of service are interrelated but distinct and each is intended to improve access to services for people from black and minority ethnic communities. They make very different demands of their workers and require different sets of professional experience, training, skills and interests. For these reasons they require different kinds of management and so it is important that the differences are recognised when establishing one or more of these services locally.

Interpreting

Interpreting is a skill based on professional language training. It emphasises the technical precision, linguistic skills and neutrality of the worker and is not limited to any particular working context. It is a discipline with a long history.

Link working

A link worker is someone who does more than interpret, they also play an active role in bridging the cultural gap between health professionals and their clients. This concept evolved from the Asian Mother and Baby Campaign launched in September 1984 (Bahl, 1987), which arose from a widely held concern about the health of the Asian mother and her baby, particularly in districts with high infant mortality rates. The campaign highlighted that language difficulties and cultural differences were both considerable barriers to the provision of fully effective antenatal and postnatal care for Asian mothers.

Advocacy

The main aspects of advocacy are:

- it facilitates linguistic and cultural communication between the service user and the health professional;
- it advises other health professionals on, and ensures delivery of, appropriate health care acceptable to the particular needs of the service user, including adherence to differing religious, cultural or dietary norms and requirements;
- it provides information, advice and support to the service user to enable them to:
  - be fully informed about their medical condition and the health care available to them;
  - voice their concerns and expectations;
  - know their rights;
  - make informed choices;
- it acts on behalf of, and in the interests of, the service user and, if so requested, to formally represent them;
- it advises the service user about, and ensures access to, other professional agencies regarding their health-related needs (e.g. home care, hospice care, housing, welfare rights).

KEY ELEMENTS OF A POLICY FOR INTERPRETING SERVICES

The sections below set out some of the headings which a policy for interpreting services should contain.

Purpose of an interpreting service

- to improve communications;
- to reduce language and cultural barriers;
- to reduce the scope for wrong diagnosis and treatment;
- to enable patients to make choices.

What the service offers

- languages covered;
- interpreting only/interpreting and advocacy;
- availability;
- principle of acceptability by users;
- choice in terms of gender/age.

How the service can be accessed

- for planned admissions;
- for emergency admissions;
- out of hours cover;
- out-patient clinics;
- arrangements for prior notice;
- any special arrangements for maternity services;
- mental health and community psychiatric services:

  arrangements for admissions under the Mental Health Act;

  attendance at out-patient clinics;

  particular issues in relation to advocacy;
- other community services:

  booking arrangements and unplanned needs;
- GP and other primary care services.

Using interpreters effectively

- do's and don'ts, publicity, training for staff.

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KEY ELEMENTS OF A POLICY FOR INTERPRETING SERVICES cont'd

Maintaining service standards (see Chapter 10)

- standards for the service, code of practice, and monitoring arrangements;
- knowledge of health and medical terminology.

Complaints procedures

- complaints by patients and staff.

Finance

- internal charge-out rates;
- minimum charges;
- financial monitoring;
- reporting.

KEY ELEMENTS OF A POLICY FOR TRANSLATION SERVICES

Purpose

Such a policy should aim to develop a systematic approach to translation beginning with careful planning and research. Scarce resources are often wasted on material that is not effective because it is poor quality, irrelevant, culturally insensitive or inadequately targeted.

Feasibility

If a document is to be translated, the decision should be made before the material is written – it will affect the style, content, choice of imagery and phraseology, timing, distribution and allocation of resources.

What should be translated?

To help decide what it is useful to translate, the following are important:

- create database of existing translated material (see also Health Education Authority, 1994);
- consult with community groups on information needs, summary or full translation, etc.;
- decide if written communication is most appropriate – consider tapes (audio or video).

Translation languages

To determine the specific target for material (e.g. gender, age, location) the following are important:

- obtain information on literacy and education levels;

cont'd

KEY ELEMENTS OF A POLICY FOR TRANSLATION SERVICES cont'd

- assess the size of the group and its particular information needs (which may be in reverse proportion to the length of time in this country);
- design (e.g. larger typefaces for older groups).

Translators

The following list highlights what to look for in a translator:

- target language is their first language;
- can translate meaning, not just text;
- aware of the particular needs of the local community;
- sound knowledge of the subject matter, and trained in use of health/medical terminology;
- good links with local professional staff;
- aware of time scales – average translation rate is 200–250 words per hour;
- require minimum training.

In addition, time should be allowed for community consultation and testing for validity.

Quality assurance

- ensure good links with professional staff and the community;
- provide opportunities for group discussion to ensure clear and common understanding of the text;
- get the translation checked by another translator;
- check for use of plain, clear language;
- allow community members to check specific meanings.

Dissemination

Agree on the most appropriate and sensitive method for making translations available (e.g. publicly or individually).

Evaluation

An evaluation of the service should be made at regular intervals.

Innovative ways of communicating

An increasing range of information about health and health care can be found on audio and video tapes in community languages – some prepared by organisations such as the Health Education Authority (1994) and others made locally for local distribution.

Health information in video rental shops located within the different communities could reach communities who would otherwise not access such information. The number of Asian cinemas is increasing and can be used for dissemination.

Several health services use community language radio stations, TV and newspapers to reach local black and minority ethnic communities. Dance and theatre have successfully promoted health in schools and colleges and also communicated culturally sensitive health messages.

Good practice examples

Many NHS trusts and health authorities now subscribe to telephone interpreting services, some of which are available 24 hours a day, 365 days a year and cover up to 140 languages.

East London and City Health Authority is seeking to implement recommendations from a MORI survey to evaluate bilingual health advocacy schemes in east London. The current health advocacy provision covers no more than 60–65 per cent of existing need.

Camden and Islington Health Authority is proposing to set up a multilingual advocacy service and also a project worker for female genital mutilation.

Leeds Health Authority through joint finance monies has funded a major advocacy and interpretation service with an emphasis on advocacy. This includes outreach/drop-in services.

Northamptonshire Health Authority has run a one-year project within which two part-time healthcare workers for black and minority ethnic communities have been appointed to work closely with primary healthcare teams to facilitate better service provision, access to services and information for individuals and groups within black and minority ethnic communities. The posts are located in a multi-agency funded access, interpreting and translating service for the county.

Kensington & Chelsea and Westminster Health Authority commissioned a needs assessment of the language and communication needs of black and minority ethnic communities. From this, a language and communication policy was produced and a service specification and contract agreed for the provision of an interpreting service in all GP practices, provided by a neighbouring authority.

Salford and Trafford Health Authority has undertaken a one-off detailed needs assessment of the communication needs of black and minority ethnic pregnant women in Salford. This highlights gaps in services, experiences and difficulties for service users as well as identifying the views and needs of service providers. The report draws out implications for the commissioning authority.

Wiltshire and Bath Health Authority has facilitated the adaptation of a translated patient information booklet onto tapes for audio use.

Birmingham Heartlands NHS Trust has identified key services which require ongoing interpreting support. It has recruited specific staff with language skills to be permanent members of the teams rather than relying on the provision of interpreters/link workers. For example, it has appointed a full time diabetes liaison nurse with language skills, a dietician with language skills and a ward clerk interpreter – in addition to using general interpreters.

North Mersey Community NHS Trust has produced concise guidance for its staff to:

- communicate its equality programme;
- provide guidelines for working with interpreters and linkworkers;
- 'celebrate' and feed back progress on the equality programme in the leaflet, *On Target*.

The Trust also produced the leaflet, *Guidelines for Staff Working with Interpreters*, which identifies the range of link workers and interpreters available, and provides a good practice checklist of points to remember when interviewing with an interpreter.

Chapter 8

Staffing the service for cultural competence

SUMMARY

Although some improvements have been achieved over recent years, discrimination on the grounds of ethnicity and colour remain an unattractive feature of NHS employment practice in many places (Beishon *et al.*, 1995).

This chapter argues that the case for equal opportunities is not simply a moral one. One of the most effective ways of achieving culturally competent services is to recruit, train and retain staff from the ethnic minority communities themselves.

The business case for fairness in employment

During 1992 and 1993 Virginia Bottomley, then Secretary of State for Health, chaired a task force to develop a national framework for attracting, retaining and developing black and minority ethnic staff in the NHS. This initiative recognised that the NHS had not achieved much progress despite many years of exhortation and reports (e.g. the King's Fund Task Force on Equal Opportunities which found a patchy adoption of equal opportunities policies [King's Fund Centre, 1991]) and some highly publicised cases of proven racial discrimination. The report of the Secretary of State's task force on staffing was published as *Ethnic Minority Staff in the NHS: a Programme of Action*, EL(94)12, and this continues to have ministerial support. In launching the document, the Secretary of State said:

> *'I want to stress that taking action to promote equality in employment is not just a matter of moral justice or of fairness to people from minority ethnic groups. It is good, sound common sense, and it makes business sense too.'*

Current position

The survey of purchasers carried out for this project showed that some 70 per cent of respondents had not developed action plans to deliver the goals set out in the *Programme of Action*. Nearly a quarter of providers had no such action plan and many chief executives were not aware of the existence of the *Programme of Action*. Yet the Secretary of State had made clear: 'I look to chairmen and chief executives to be fully accountable for meeting equal opportunities objectives'.

The eight goals

The *Programme of Action* remains current policy and its eight goals are outlined below. Each NHS organisation should have a local action plan to reach the targets.

THE EIGHT GOALS OF THE *PROGRAMME OF ACTION*

Recruitment and selection	NHS trusts and health authorities to include in their business plans a local objective to increase the proportion of minority ethnic staff in areas and grades where they are under represented, within a specified time scale, until fair representation is achieved
Staff development	To maximise the skills and potential of all personnel in a multiracial NHS workforce, with particular emphasis on the identifiable needs of people from minority ethnic groups
Racial harassment	To ensure NHS workplaces are free from harassment and discrimination, including racial harassment
Appointments to NHS boards	To increase the number of black and minority chairs and non-executive members of NHS authorities and trusts, and community health councils, to reflect the composition of the population served (see also NAHAT and King's Fund Centre, 1993)
Service delivery	To provide a better service to patients by optimal use of the workforce
Doctors	To ensure that the time spent in higher specialist training by doctors with right of residence from minority ethnic groups equates to the time spent in higher specialist training by white doctors with right of residence
Nurses	NHS authorities and trusts to set a local objective to achieve equitable representation of minority ethnic nurses at G grade (ward manager or community equivalent) within five years; progress towards achieving this objective should be reviewed annually as part of the business planning cycle
Management training schemes	Regional health authorities and the NHS management training scheme to take steps to increase each year to a locally determined level the proportion of minority ethnic applicants for the NHS management training scheme, and the proportion obtaining a place on the scheme; this will require the elimination of bias and in some instances positive action in recruitment, selection and training processes A similar requirement is placed on regional health authorities in respect of the NHS finance training scheme and other career grade training schemes, and on NHS organisations below regional health authority level where there are locally managed training and development schemes

The *Programme of Action* suggests ideas which may help purchasers and providers to achieve the goals. There are, nevertheless, a number of actions required at national level by the NHS executive and other agencies. High on this list is the task of working with the Royal Colleges and the professional and training bodies of the NHS professions to make the NHS an attractive and accessible career option for people from black and minority ethnic communities.

Ethnic monitoring of staff

Central collection of data on the ethnic group of NHS staff has been introduced in two phases:

- data on nursing and midwifery staff were collected in the non-medical workforce census, September 1993;
- data on all non-medical staff have been collected since the 1994 non-medical workforce census.

A survey in 1993 *Ethnic Monitoring Survey of NHS Workforce* (NHSME, 1993) showed the following picture.

MAIN RESULTS FROM *ETHNIC MONITORING SURVEY OF NHS WORKFORCE*

- Approximately 8 per cent of the NHS workforce is from minority ethnic groups compared with 5.9 per cent of the population as a whole
- Most minority ethnic staff are concentrated in the lower grades, especially within the nursing profession and in ancillary departments
- Medical staff groups have larger concentrations of staff in minority ethnic groups than non-medical, also concentrated in the lower grades
- Minority ethnic nurses and midwives are drawn mainly from black ethnic groups.

Comparable information is not available for primary care services. This is a gap which needs to be filled. Ethnic monitoring of staff is the key to checking progress against targets. This requires that information is not just collected but analysed, conclusions drawn and appropriate action taken. Below is a set of key points proposed by the Commission for Racial Equality in November 1993 to help organisations put into practice their commitment to equal opportunities.

EQUAL EMPLOYMENT OPPORTUNITY POLICIES

Have a policy statement, communicated to all employees and new entrants setting out top level commitment to equal opportunity in recruitment and promotion, training and development, and all aspects of employment practice. Emphasise benefits of policy to organisation and all employees, and identify member of top management accountable for its implementation.

cont'd

EQUAL EMPLOYMENT OPPORTUNITY POLICIES cont'd

Develop an action plan, setting measurable goals, including numerical targets and timetables, and accountability for achieving them. Monitor progress on a regular basis; review and update action plan in the light of findings.

Monitor ethnic composition of workforce by grade, department, specialisms, location as appropriate; identify areas of under-representation and possible barriers to equal opportunity and take action to address these.

Monitor effect of employment policies and procedures, such as advertising, recruitment, promotion, take up of training and development opportunities, performance assessments, performance pay, disciplinary action, redundancy and redeployment, resignations and the reasons for them, grievances relating to discrimination and/or harassment. Analyse information and take action to identify and address possible barriers to equal opportunities.

Train all staff and key decision-makers, such as managers and those involved in selection, in their equal opportunity responsibilities under the organisation's policy and the legislation.

Ensure fair selection by advertising jobs to all sections of the community, drawing up job-related, non-discriminatory selection criteria, against which selectors are trained to assess candidates in a fair and consistent manner. Use only tests which are valid for different ethnic groups and the work in question.

Consider positive action encouragement and training, as permitted under Sections 37 and 38 of the Race Relations Act 1976, to help encourage and/or prepare people from particular ethnic groups to take up work in which they are under-represented. Consider, too, training to cover the identified special needs of particular ethnic groups in relation to their education, training or welfare.

Consider the organisation's equal opportunity image as reflected in the workforce, recruitment literature, choice of media for recruitment advertising, links with colleges, schools and local community groups.

Ensure there are fair and effective policies and procedures for handling complaints of discrimination and harassment, which are known to all employees.

Make discrimination and harassment a disciplinary offence leading, in serious cases, to dismissal.

Using the law proactively

One of the most powerful ways of making services culturally competent is to have staff from those communities providing front line services. The *Programme of Action* proposes positive action not positive discrimination, which is illegal. The Race Relations Act 1976 acknowledges the potential of positive action. This important but wholly under-used provision in the legislation is set out below:

LAWFUL EMPLOYMENT UNDER SECTION 5(2)(D) OF THE RACE RELATIONS ACT 1976

It is lawful to appoint someone from a particular racial group where the job involves providing people from that group with personal services to promote their welfare, and where those services can most effectively be provided by someone from that racial group.

Example: lawful action under Section 5(2)(d)

A consortium of NHS Trusts employs interpreters from different communities in order to facilitate communication with non-English speaking patients as and when necessary. There is a requirement for Section 5(2)(d) posts to demonstrate that the appointments represent more than just a preference and that they will fulfil a specific need.

One of the most significant developments in improving access to health care was the establishment of family link workers as an outcome of the Asian Mother and Baby Campaign during the 1980s (Bahl, 1987). These staff, many of whom came from the same minority group as their clients and who spoke the same language, have directly contributed to improved maternal and child health and to the reduction of perinatal mortality rates.

Training for developing culturally competent services

Making services culturally competent means ensuring staff are able to respond in ways which meet the *Patient's Charter* objective of respecting the patient's privacy, dignity and religious and cultural beliefs. Most NHS staff are wholly committed to this aim but are often frustrated by a lack of information and advice about caring for people from different cultures. At worst, this can lead to misdiagnosis and inappropriate treatment and at best mutual frustration and a lingering sense of unease between patients and staff.

Experience suggests that staff respond well to opportunities to learn and understand something of the language, culture and beliefs of their black and minority ethnic patients and, in particular, welcome help in removing barriers to effective treatment and care.

Approaches to training

Training that can equip health professionals with more knowledge, information and sensitivity in providing services to black and minority ethnic communities can be broadly divided into three approaches:

- cultural awareness training;
- race awareness training;
- anti-discriminatory training.

Before provider and purchaser agencies commission or undertake training for staff it is important that they fully understand the differences, advantages and disadvantages of each of these approaches.

Cultural awareness training

This aims to provide information on the customs, habits and lifestyle of black and minority ethnic people living in Britain for the purpose of understanding their culture. This type of training has been and still is popular among many health service professionals. However, as a unitary approach it can have severe limitations if it is used to enforce simplistic stereotypes to assert, for example, that:

- ethnic groups behave in similar ways;
- the different culture of groups explains why they find many services inappropriate;
- if you have professionals trained in 'cultural' knowledge then you can provide a culturally competent service;
- aspects of culture are rigid, static and do not change.

Race awareness training

This aims to raise awareness of racism and its implications with the hope of changing individual racist attitudes and behaviour. Some health workers find it useful for raising awareness of, and changing, personal attitudes as well as providing an insight into potential racial disadvantage. It can be criticised for individualising and personalising racism to the extent where institutionalised racism is not acknowledged and for generating guilt in white trainees – not considered a positive emotional motive for change. The central tenet, however, of the case against race awareness training is that it does not necessarily lead to any desired changes in behaviour. Race awareness training could become just a consciousness-raising exercise that amounts to little beyond a personal voyage of discovery.

Anti-discriminatory training

This is based on the arguments that other people can only judge your actions and not your attitudes and that trainers/employers cannot control how employees feel or think, but can expect them to act in a particular way. Thus the aims of anti-discriminatory training can be closely linked with policies, responsibilities and duties that are actually carried out. Practice can be given direction by policies and subsequently evaluated. The central tenets are that:

- organisations can indirectly discriminate in a range of ways;
- individual workers, through their training and socialisation, can discriminate indirectly or directly;
- practices should be based on clear anti-discriminatory policies and strategies;
- professionals should act in a way which does not discriminate directly or indirectly;
- services should be provided on the basis of identified needs of individuals;
- culture is dynamic and ever changing;
- services should be flexible and cater for the needs of a wide range of groups.

Recommended action

Based on the above, the anti-discriminatory model provides the best choice – this does not detract from the value of the other models as long as those using them appreciate the underlying assumptions and are able to counter any negative features.

Good practice examples

Burnley Health Care NHS Trust has developed local goals from the *Programme of Action* and, in particular, has developed a comprehensive package of initiatives around recruitment and selection including liaison with the local Race Equality Council, the Race Relations Employment Advisory Service, the Training and Enterprise Council and the Equal Opportunities Department of Burnley Borough Council.

Enfield and Haringey Health Authority has undertaken an audit of its current position in relation to all the goals identified in the *Programme of Action*. As a result of the audit it has produced a detailed action list both for the health authority and in terms of monitoring the progress of providers.

Southern Derbyshire Health Authority provides NVQ and health care assistant training to open up vocational qualifications to staff groups with high minority ethnic representation. All appointing officers have equal opportunities training. There is also positive targeting for bilingual professional staff.

Leeds Community and Mental Health NHS Trust has undertaken a comprehensive local review and action plan in relation to the *Programme of Action* goals and has allocated resources in key areas as well as identifying other areas which have resource implications. Some examples include:

- developing a bursary scheme for black and minority ethnic staff to enter training of their choice;
- piloting a 'positive action' training scheme to equip black and minority ethnic people with skills needed to apply for posts in management, professional and technical grades, in which they are currently under-represented.

Luton and Dunstable Hospital NHS Trust has developed specific responses to the goals set out in the *Programme of Action*. In particular, the Trust has produced a detailed harassment policy and procedure. This highlights the responsibilities of employees and managers and provides clear guidance on how to handle harassment cases.

Riverside Mental Health NHS Trust has set up an equal opportunities group to provide a framework for the development of equal opportunities policies and strategy. Within the action plan, the Trust includes local goals identified from the national targets developed in the *Programme of Action*. These goals have been developed from a detailed workforce review undertaken by the Trust. A senior manager is allocated responsibility for each local goal and a review date is identified.

Swindon and Marlborough NHS Trust has produced a resource book for staff, *Matching Cultural Needs*, which is available on every ward and sets out many of the cultural and religious beliefs and practices of people of different faiths.

United Bristol NHS Trust is conducting a career-tracking exercise in response to the *Programme of Action*.

Chapter 9

Ethnic monitoring

SUMMARY

After a number of years' debate and discussion, ethnic monitoring has become mandatory for admitted patients from April 1995. This is welcome but covers only a small proportion of the contacts people have with the NHS. This chapter gives pointers to successful data collection by providers and proposes ways to extend ethnic monitoring to the primary and community care settings. Some important uses of ethnic monitoring information are also identified.

Why use ethnic monitoring?

Elsewhere in this guide, particularly in Part 3, detailed evidence is given relating to the health experience of black and minority ethnic people, namely:

- worse morbidity (poorer health): e.g. the prevalence of diabetes amongst Asians, and associated complications;
- worse mortality (more deaths): e.g. from coronary heart disease amongst people from the Indian subcontinent and the African Commonwealth, or perinatal mortality amongst Pakistani babies;
- less benefit from available health services than the population as a whole as a result of: e.g. lack of knowledge about services; poor English; poor access to primary care services; poor access as a result of staff attitudes.

Many of the variations in health experience can be addressed, but this requires good information about which groups use which services (and how these patterns vary). This information is essential in order to plan effective responses to identified differences in need.

Collecting data on ethnic group

The mandatory collection of data on ethnic grouping of all patients admitted since 1 April 1995 (*Collection of Ethnic Group Data for Admitted Patients*, EL(94)77) is a recognition of the importance of such data as a basis for commissioning and providing culturally competent services. In the first few months after April 1995 the data collection was highly variable in quality – some providers did not have a reliable system in place even though a training package had been produced nationally. Chapter 10 includes quality standards for ethnic monitoring and some pointers for collecting good quality data on a continuing basis are given below.

POINTS FOR SUCCESSFUL COLLECTION OF ETHNIC GROUP DATA BY PROVIDERS

- Locate ethnic monitoring within a clear corporate ethnicity and health strategy – one to which senior management is committed.
- Consider stating within the contract of employment that staff are working in a multicultural organisation serving an ethnically diverse community.
- Make ethnic monitoring training an ongoing process, as part of staff induction, customer care training programmes, refresher study day courses etc.
- Set up an interdepartmental purchaser/provider forum to develop consistency in the implementation of ethnic monitoring across the agency and to develop and identify the use of data.
- Use any existing interpreters and advocates in appropriate key languages to assist patients.
- Update classification and coding structures for local populations; remember the classification should be workable and usable.
- Collect other useful information such as languages spoken, the need for an interpreter, and religious needs.
- Audit the data collection process.
- Provide regular feedback to staff and patients about statistics collected, use and limitations of information and any new developments arising as a result to benefit patients and the service.

Primary care and community settings

Pilot projects on ethnic monitoring in primary care have been undertaken in a number of districts including Berkshire, Birmingham, Brent and Harrow, Camden and Islington, Enfield and Haringey, and Kensington, Chelsea and Westminster. Such projects have rarely continued beyond the pilot stage because:

- collection of ethnic group data is not a national requirement in primary care settings;
- they were set up as fixed-term projects to test the mechanics of collecting data rather than as means to more effective commissioning;
- they were funded by one-off monies;
- organisational restructuring has meant lack of continuity.

Nevertheless the potential benefits of ethnic monitoring are the same, or greater, within the primary care and community settings. There are no plans currently to introduce such monitoring nationally and it will, therefore, be up to local initiative to realise these benefits. For example, at the time of writing, the West Midlands regional office is considering a large-scale exercise in introducing ethnic monitoring in primary care. Some ways of beginning the task are given below.

IMPLEMENTING ETHNIC MONITORING IN COMMUNITY SETTINGS

- Audit existing record-keeping systems and procedures (some services, such as health visiting, may not have a central record-keeping system).
- Conduct multidisciplinary seminars to brainstorm issues to be resolved such as:
    - classification and coding for mixed ethnicity children;
    - self-classification of age by children;
    - development of interdisciplinary centralised record systems;
    - procedures for classifying, for example, confused older people who are living alone and not able to self-classify.
- Set up a multidisciplinary working group to implement ethnic monitoring.
- Identify and meet staff training needs.
- Pilot ethnic monitoring in one locality initially in order to:
    - develop a standardised system of ethnic monitoring/recording;
    - develop appropriate information and administration systems for recording, storing and analysing data;
    - raise staff and patient awareness, confidence and acceptance of ethnic monitoring;
    - assess how the collection of ethnic group data across various community services can be integrated;
    - determine how data can be shared across community, primary, acute care and social services.
- Review the experience, methodology and outcomes of pilot projects.
- Use review findings to develop a programme and timetable for implementation and training.

IMPLEMENTING ETHNIC MONITORING IN PRIMARY CARE SETTINGS

- Establish a working group of all key stakeholders (i.e. health authority/DHA staff, practice managers, single-handed and group practice GPs, local medical committee representatives and patients) to oversee the implementation process.
- Set up a practical system/mechanism for recording and storing ethnic group data, for example:
    - develop a prompt card in different languages;
    - develop translated public information leaflets, posters and audio tapes in appropriate languages;
    - link new patient registrations on FP1 forms to the Exeter system;
    - clarify which staff will enter codes;

cont'd

IMPLEMENTING ETHNIC MONITORING IN PRIMARY CARE SETTINGS cont'd

  - acquire access to interpreters.
- Identify and meet the training needs of practice staff and others involved in the recording/monitoring of ethnic group or language of patients.
- Develop a step-by-step bullet-point guide which practice staff can refer to.
- Pilot ethnic monitoring in specific localities/wards or specific clinics initially.
- Monitor and analyse collection of ethnic group data.
- Review and use pilot findings to develop an implementation action plan which focuses on how GPs should use ethnic monitoring for their own purposes – until the health authority register is amended to include an ethnic group field.

How can ethnic monitoring information be used?

Ethnic monitoring can support existing initiatives intended to build a more accurate local demographic profile and more informed assessment of needs. The information can be used in a variety of ways, as shown below.

USES OF ETHNIC MONITORING INFORMATION

Information gained from ethnic monitoring can be used:

- to identify current service use and type of treatment;
- to raise awareness of gaps in services;
- to influence the development of priorities for future service provision;
- to improve access to services;
- to develop epidemiological profiles of service users by ethnic groups, mapped against existing mortality and morbidity data;
- to provide a baseline for identifying changing patterns of disease;
- to help guide service provision for the specific health needs of all ethnic groups, therefore targeting resources more effectively;
- to monitor the type of service response to any identified gaps;
- to help identify patterns of illness and need among all ethnic groups;
- to enable comprehensive service specifications to be drawn up;
- to enable better targeted health promotion and prevention programmes;
- to ensure that black and minority ethnic issues are within mainstream planning and policy development;
- to measure outcome(s) of any changes in policy.

Ethnic monitoring data can be used specifically for needs assessment, as shown below.

EXAMPLES OF NEEDS ASSESSMENT USING ETHNIC MONITORING DATA

- undertaking case fatality analyses – for example perinatal mortality among Pakistani babies;
- linking patterns of morbidity with specific minority ethnic groups – for example mouth ulcers may occur more in groups of people who chew 'Bang' or 'Khat';
- comparing national epidemiological profiles of ethnic minorities with the local profile – for example, whether the incidence of hypertension among African Caribbean women is above or below the national finding;
- comparing local profiles with epidemiological data from countries of origin of specific groups – for example, noting that diagnostic rates for schizophrenia in African Caribbeans are higher in England than they are in Jamaica;
- identifying unusual profiles – for example, the incidence of cervical cancer in some groups of Asian women;
- looking for patterns of inherited conditions – for example, congenital malformations in Pakistani babies.

Good practice examples

Dudley Health Authority has established a joint health authority/social services group to agree, for example, classification and coding issues across agencies.

Ealing, Hammersmith and Hounslow Health Authority levies a £5,000 penalty on providers who fail to collect ethnic group data. It is also piloting the collection of ethnic group data in primary care.

Heartlands NHS Trust is undertaking a two-year project in ethnic monitoring of all those who use the accident and emergency service. The steering group involves representatives of local black and minority ethnic communities.

Riverside Mental Health NHS Trust has specified additional information it collects over and above that identified in EL(94)77. For example its action plan states: 'Ethnic monitoring information should include referral routes, admissions, discharge and an audit of treatment received to ensure services are non-discriminatory.'

Chapter 10

Ethnicity and health standards

SUMMARY

The ethnicity and health quality standards suggested in this chapter have been developed to highlight how the specific needs of black and minority ethnic users and carers may need to be met. The core standards provide a basic framework through which a more meaningful assessment of the quality of services can be made. The standards can be adapted locally by purchasers and providers to suit local circumstances. Where appropriate, a reference has been made to relevant standards in the *Patient's Charter.*

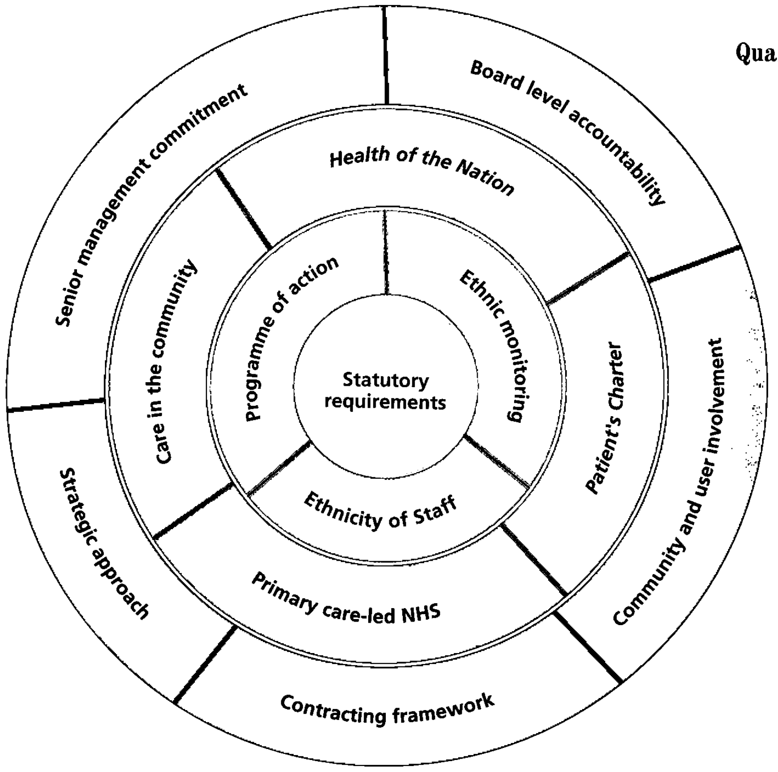
A framework for quality standards

Quality standards are the means to an end. The end is to ensure that health services are accessible, appropriate and culturally competent to meet the needs of black and minority ethnic communities.

The diagram below suggests a framework for quality standards which puts the achievement of accessible, appropriate and culturally competent services firmly within the mainstream agenda of purchasers. The four concentric circles taken together comprise the suite of quality standards required to achieve this aim.

- **Statutory.** The inner circle is the statutory standards, such as the Race Relations Act 1976 referred to in Chapter 2, which should be specifically included in purchaser contracts with providers.
- **Mandatory.** The second circle includes the mandatory requirements placed on purchasers and providers; purchasers have a key role in ensuring that these requirements are being met by providers.
- **Contractual.** The third circle comprises the key policy planks for the NHS as set out in the *Priorities and Planning Guidance for the NHS 1996/97.*
- **Organisational.** The fourth circle sets out the organisational standards which are essential to deliver success in terms of achieving culturally competent services.

A framework for quality standards for black and minority ethnic health



Quality standards → **leading to**

↓

Services which are

- accessible
- appropriate
- culturally competent

Key

● inner circle	Statutory standards
● second circle	Mandatory standards
● third circle	Contractual standards
● outer circle	Organisational standards

Statutory standards – the inner circle

The specific policy and legislation relating to services for black and minority ethnic communities is set out in Chapter 2. Thus, purchasers should state explicitly that they require providers to adhere to the relevant sections of the Race Relations Act 1976, such as Section 20, which makes it unlawful to discriminate in the provision of services on racial grounds.

Mandatory standards – the second circle

Contracts should also specify the need to meet the mandatory requirements of the health service in relation to ethnicity and health. Two of these requirements relate to the collection of data to help in the planning and provision of culturally competent services:

- *Ethnic Monitoring of Staff*;
- *Collection of Ethnic Group Data for Admitted Patients*, EL(94)77.

One requirement relates to *Ethnic Minority Staff in the NHS: a Programme of Action*, EL(94)12.

Contractual standards – the third circle

The issues in the third circle have been grouped under this heading because purchasers have contractual discretion about how they establish and enforce standards in these areas. The areas are considered below.

So far as *Health of the Nation* is concerned there are examples of innovative initiatives and projects being developed to address the variations in the health of black and minority ethnic communities. Some examples of service specifications and standards which would help to make these services culturally competent are included in Part 3.

Standard 1 in the *Patient's Charter* requires that 'patients shall receive care which shows respect for their privacy, dignity, religious and cultural beliefs'. Some of the initial work in this area was done in Liverpool, Walsall, Bradford and in Kensington, Chelsea and Westminster. In London, this work was given an impetus through the London Health and Race Forum which brought together purchasing staff from a number of inner London commissioning agencies with the agreement and support of the relevant chief executives. These standards have been published by the King's Fund (SHARE, 1996). The quality standards proposed later in this chapter build upon this work.

Care in the community and primary care services involve a wide range of quality issues and much detailed work remains to be done to establish quality standards with particular significance for black and minority ethnic communities. The research for this project found few examples of shared needs assessments between health and local authorities for these communities and also few quality standards in relation to primary care services. Some of the relevant issues are identified in Part 3.

Organisational standards – the outer circle

The organisational arrangements which improve the prospect for achieving culturally competent services were identified in Chapter 3 – board level accountability, senior management commitment, corporate level dialogue, and a strategic approach with a commitment to action. It is for boards to satisfy themselves that they have the organisational standards in place to ensure progress.

Examples of ethnicity and health – quality standards

The following are examples of quality standards which purchasers could consider including in contracts with providers. However, it is vital that, against each standard, clear arrangements are specified about how performance is to be measured and unacceptable variations addressed.

Ethnic monitoring

Core standard	*Target*
Ethnic monitoring of all in-patients should be undertaken in accordance with EL(94)77	By the middle of, for example, 1996/97, 90% of all patients should be monitored, with 100% thereafter.
Providers to establish systems for monitoring out-patient, primary care, community and allied health services	Review feasibility of providing services other than for in-patients

Communication and information

See Right 1 in the *Patient's Charter*: 'to ensure that the patient has access to detailed information about local health services'.

Core standard	*Target*
All patients to be able to communicate with staff in a language they feel comfortable with	Language to be recorded as part of any health assessment/process (admission, discharge, eligibility for services etc.)
	Information about interpreters and advocates to be proactively offered to patients
	The use of family members or friends as interpreters should be discouraged unless the patient requests this
	Each provider to have a contract with a professional language service; this should include: ● arrangements for provision out of hours ● a protocol regarding its use ● provision of dialects/languages relevant to local communities ● standards of provision ● training arrangements ● availability of dedicated bilingual staff in identified clinics (e.g. maternity, diabetic)

cont'd

Communication and information cont'd

Services which patients and their carers may need to use should be clearly signposted and enquiry points clearly marked	Clear policy on signage in different languages
To make available appropriate information to patients and their carers/relatives in an accessible format (to facilitate informed choice and their care and treatment)	Patients to have their information needs met through the development of a comprehensive information strategy which includes provision of information in a language, style and medium accessible to identified ethnic minority groups about for example: ● rights to interpreters/advocates ● confidentiality code of practice ● rights to see a female/male practitioner ● complaints/information about procedures ● consent, assessment, treatment and care plan forms ● available services and how and where to obtain them Identification of designated individuals in the organisation equipped to deal with enquiries Development of a policy on translation services which sets out: ● process for deciding which material shall be translated ● which information is better provided in audio-visual formats ● involvement of users/carers etc. Review of existing translated information for appropriateness and accessibility of imagery, concepts and languages Development of future translated materials in consultation with target audience to check style, format, contents and language Pilot testing of translated materials by service users

Religious and spiritual needs

See standard 1 in the *Patient's Charter*: 'all patients shall receive care which shows respect for their privacy, dignity, religious and cultural beliefs'. Section 5(ii)d of the Race Relations Act 1967 should be used where appropriate.

Core standard	*Target*
Providers to observe the religious and spiritual beliefs of patients in accordance with their identified needs	Record requirements in nursing and community care documents

cont'd

Religious and spiritual needs cont'd

Providers to facilitate the spiritual and religious well-being of patients and their carers	Provide translated information about available religious facilities Employ on a permanent, sessional or voluntary basis qualified individuals who reflect the religious profile of the community Staff and patients to have immediate access to a list of local religious leaders and contact details Staff to provide open access for visits to patients by their own religious and spiritual leaders Patients to have protection from uninvited religious or cultural representatives Staff to be aware of the direction of Mecca for Muslim prayer
Providers to ensure access to multi-faith facilities for all in-patients	Provide a suitably equipped room(s) at each hospital site where patients/carers/relatives can fulfil their religious and spiritual requirements

Bereavement

Core standard	*Target*
Providers to have in place procedures to ensure the sensitive handling of the dying/deceased patient and relatives	Patients, carers and relatives to have open access to visits from religious and spiritual leaders All staff to check with carers/ relatives or, in their absence, his/her appropriate religious priests regarding care and handling of the dying/deceased Providers to have a protocol to enable: ● release of bodies within 24 hours to allow religious funeral rites to be carried out as soon as possible after death ● private viewing of bodies in room with only appropriate religious symbols visible ● Laying out of bodies in appropriate positions in accordance with religious/cultural beliefs ● informed consent to post-mortems ● provision of bereavement counselling by trained counsellors and/or local faith institutions

Gender

See standard 1 in the *Patient's Charter*

Core standard	*Target*
Patients should have a choice of staff of their own gender, with information made readily available about this option	Review current arrangements to ensure that the access to male/female staffing ratio is appropriate for relevant service areas
Single sex facilities to be provided wherever feasible	Review the need to provide single sex facilities and develop a timetable to put this into effect Where mixed sex facilities are the only option, patients should be told in advance

Diet

Core standard	*Target*
Meals should meet the religious/cultural requirements of service users	Review existing dietary provision in conjunction with service users and community-based organisations and identify gaps to address
Information about the availability and provision of appropriate diets should be given to all patients on admission	Record dietary requirements for all in-patients in nursing assessment documentation on admission Provide menus in pictorial and translated formats Identify appropriate local suppliers who can provide specific dietary requirements within 24 hours Undertake training for all key staff groups who prepare and service food and raise awareness of religious and cultural significance of providing an appropriate diet Meal times to be sensitive to the needs of patients fasting during religious festivals Provide genuine choice – 'Asian menu' is not acceptable

Personal care

Core Standard	*Target*
To provide appropriate personal care elements of: requirements	All nursing staff to receive awareness/ physical sensitivity to meet individual cultural/religious training which includes key ● appropriate hair and skin care ● significant personal cleanliness/hygiene for specific minority ethnic groups ● diet ● gender of care worker

cont'd

Personal care cont'd

	All hospital facilities to offer a choice of showers or baths for minority ethnic users
	All in-patient facilities to have available small jugs or bidets for washing after use of toilets
	Staff to respect patient wishes to be called by their preferred name, and training provided in understanding naming systems

General anti-discriminatory training

Core Standard	*Target*
Provider to demonstrate that steps are being taken to equip staff to respond appropriately to the differing individual, social, cultural, religious and other needs of black and minority ethnic users	Develop an action plan to implement training identifying ● timetable ● target staff groups ● officer responsible for training
	Provide anti-discriminatory training as an integral part of the induction programme for all staff
	Design courses to enable participants to identify individual and organisational action points at the end of each course
	Make information about cultural diversity easily accessible to staff on wards, in out-patient departments and other health points

Employment

Core Standard	*Target*
Provider to achieve the eight goals set out in *Ethnic Minority Staff in the NHS: a Programme of Action*, EL(94)12	An action plan in place which has: ● a timetable for the achievement of each of the goals ● clear responsibility at senior level ● equal opportunity policy as its core

Complaints

Core standard	*Target*
The complaints procedure should be accessible to minority ethnic users who do not read English or their spoken language	Information on complaints procedures for hospital and primary care services available in suitable translated format/medium (e.g. audio/video cassettes)
	Complaints panel which is representative of local population
Ethnic monitoring of complaints introduced and maintained	Ethnic monitoring undertaken for all patient complaints
	Complaints procedures which state how specific complaints relating to discrimination and harassment will be handled in all appropriate languages

Good practice examples

Bedfordshire Health Authority has produced guidelines and quality standard compliance standards for all acute and community service contracts which are specific to meeting the needs of black and minority ethnic communities. These have been developed in consultation with South Bedfordshire Ethnic Minority Health Advisory Panel. The guidance provides advice in the provision of all mainstream services and in the provision of specific services, such as protocols for haemoglobinopathies, accident and emergency, paediatrics, maternity and mental health.

Dorset Health Authority uses a framework for quality which covers context, commitment, content, consultation and co-operation, and draws on this structure in identifying quality standards.

Camden and Islington Health Authority has developed specific quality standards for Maternity Services which cover:

- antenatal care
- care in labour
- postnatal care
- supervision of midwifery practice.

The needs of black and minority ethnic women are integrated throughout, for example by:

- provision of an advocacy service with expressed individual need and continuity of the same advocate/community health adviser throughout pregnancy, labour and postnatal care;
- a philosophy of care to demonstrate that all women including women from black and minority ethnic communities and those with physical, sensory or learning disabilities have effective control, independence and equal participation at all stages of their maternity care;
- requiring protocols for women who have miscarriages, stillbirth or neonatal death which respect religious and cultural beliefs, and introducing arrangements for religious rites *in situ*.

East London and City Health Authority has developed quality standards to reflect a balance of user, professional and organisational indices of quality and have considered these against a structure, process, outcome framework, so that a grid of quality indices will exist.

Enfield and Haringey Health Authority has developed specific quality specifications for health and ethnicity which define monitoring and reporting requirements. They fall into three distinct categories:

- structure and process;
- individual care (e.g. it states: 'providers must ensure that effective two-way communication occurs between staff and users/carers: this will involve actively engaging the use of bilingual health advocates who can offer professional interpreting at the same time');
- service development.

Central Middlesex Hospital NHS Trust works to the core ethnicity and health standards set by Brent and Harrow Health Authority – the majority of which have a 100 per cent performance compliance.

Gloucestershire Royal NHS Trust has developed a number of innovative models such as:

- diets produced by local people known to communities, using local suppliers;
- a fast-track death certificate and bereavement service for Muslim patients who die in hospital – including protocols which prevent culturally inappropriate post-mortem and fast-track post-mortem where the coroner's advice is sought;
- dispersal of antenatal midwifery clinics to familiar meeting places within local communities;
- use of local Chinese community association to provide interpreters and advocates for patients in the Trust.

North Manchester Healthcare NHS Trust has developed detailed requirements around appropriate *Patient's Charter* rights for black and minority ethnic communities. For example, staff undertake a multifaceted programme of training which includes:

- ethnicity discrimination awareness;
- religious and cultural awareness;
- medical records and the Asian naming systems;
- equal opportunities recruitment and selection.

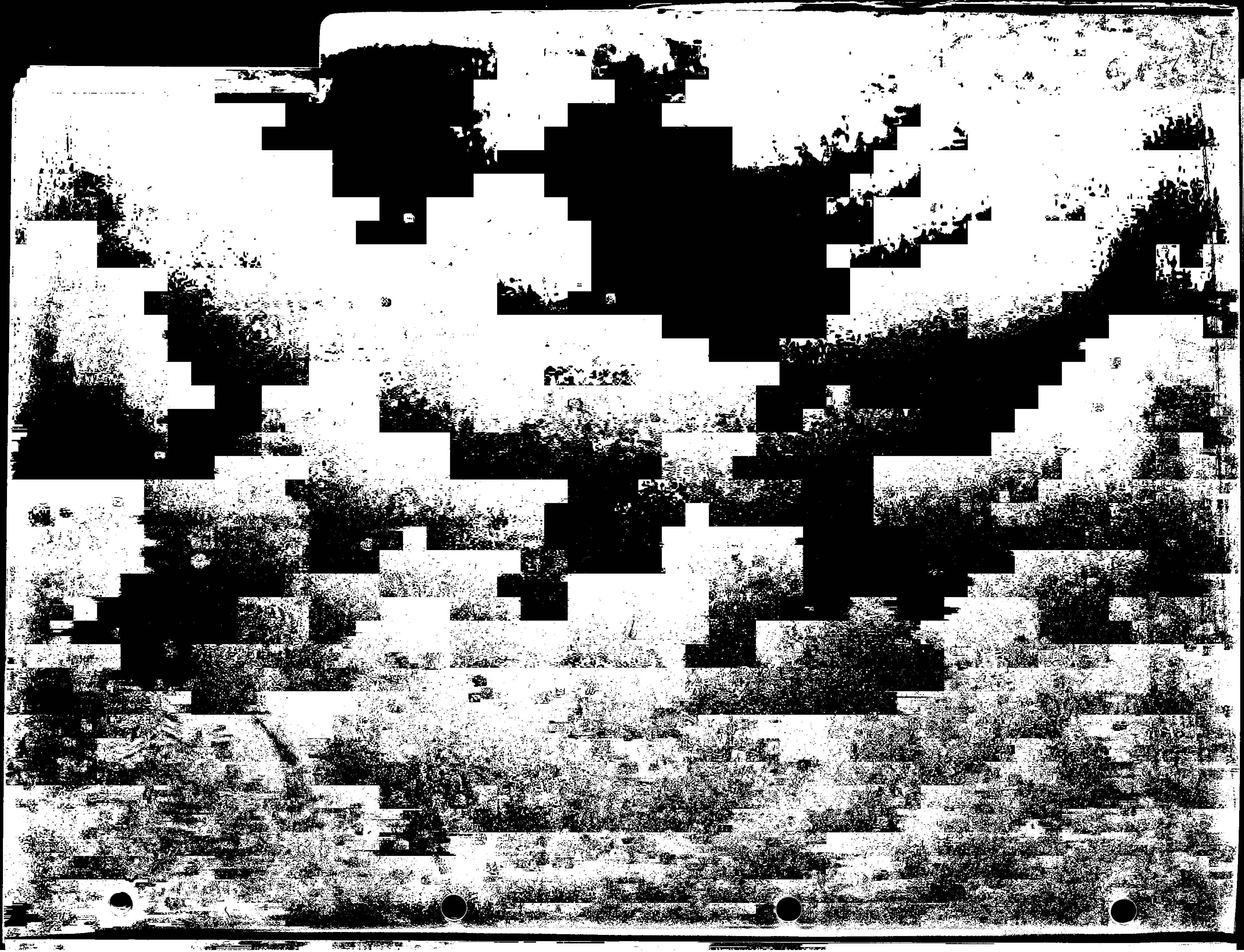
It has also developed an equal access policy which is comprehensive, encompassing all key areas of service provision such as food, washing, worship/spiritual, practical care, care of the dying, communication and health records.

3 Towards service competence

4 References and helpful information

part 3

Towards service competence



Part 3

Towards service competence

The services examined in this part of the toolkit have been chosen for one or more of the following reasons:

- the health issues are particularly relevant to one or more black and minority ethnic groups (i.e. there is a higher morbidity and/or mortality level, or poorer access);
- they are of significance nationally (i.e. they relate to *Health of the Nation* targets);
- they are areas where health gain is thought to be achievable.

Many other health services could also have been included here, but a judgement on priorities had to be made for reasons of space.

Each chapter summarises the evidence linking health to ethnicity and recommends how to make service provision culturally competent, in order to achieve maximum health gain.

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Chapter 11

Coronary heart disease

Health needs assessment – the evidence

Mortality

Coronary heart disease mortality between 1979 and 1983 among people born in the Indian subcontinent was, after adjusting for age, higher than the national average by 36 per cent for men and 46 per cent for women; with the risk of mortality from coronary heart disease being 65 per cent higher in the age group 20–49 years (Balarajan and Soni Raleigh, 1993).

Men born in the African Commonwealth (many of whom are of Indian subcontinent origin) also had high mortality from coronary heart disease; it was again highest among the young. In contrast, African Caribbeans had low mortality from coronary heart disease during this period (Balarajan, 1991).

Morbidity

Morbidity data is scarce, although research suggests a greater prevalence of ischaemic ECG abnormalities among South Asian men, which was highly significant statistically and consistent with mortality data (McKeigue, 1993). The research also suggests that black and minority ethnic communities experience greater delays in accessing tertiary care, under-diagnosis of coronary heart disease, less surgical intervention and poorer coding of records (Smaje, 1995).

Limitations of the data available

The mortality data are out of date and, as they are based on place of birth, only relate to those born abroad.

Future trends

Higher mortality from coronary heart disease is likely to persist within the South Asian populations, while coronary heart disease mortality may rise among the African Caribbean population (Smaje, 1995).

Possible causes

Possible reasons for the high coronary heart disease mortality found in certain black and minority ethnic groups are shown below.

POSSIBLE CAUSES OF HIGH CORONARY HEART DISEASE IN A BLACK OR MINORITY ETHNIC GROUPS

Underlying mechanism

There is a common pattern of raised rates of coronary heart disease in expatriate South Asian populations throughout the world. This contrasts with the available evidence of lower heart disease rates in the Indian subcontinent. Also the data from expatriate populations suggest that the high incidence may persist beyond the first generation. These findings may be explained by a common underlying disease mechanism (McKeigue *et al.*, 1989).

Deprivation

Williams *et al.* (1994) – and a major review by the Coronary Prevention Group (1986) – suggest that factors such as lack of social support, stress, lifestyle change and the effects of racism play a significant role in raised coronary heart disease rates (Fox and Shapiro, 1988).

Use of ghee

The use of a traditional cooking fat, ghee, has been implicated (Jacobson, 1987).

Smoking

Unlike previous research, the data recently published in *Health and Lifestyles Survey: Black and Minority Ethnic Groups in England* (Health Education Authority, 1995) show that smoking is a considerable risk factor. Data for African Caribbean men and for Pakistani men show a similar prevalence to the UK average. Indian men show the lowest smoking prevalence; among Bangladeshis a significantly higher rate is recorded – regular smoking is found in 46 per cent of men aged 30–49 years and 56 per cent aged 50–74 years.

Insulin resistance

McKeigue (1993) has argued that up to two-thirds of the excess coronary risk among South Asian men could be explained by the hypothesis that they metabolise insulin in such a way that several features of coronary heart disease are manifested.

Service uptake

There is little research evidence about the uptake of services by black and minority ethnic groups. Anecdotal evidence and local knowledge in areas where there is a large black and minority ethnic population supports the belief that uptake is low amongst these groups.

Setting targets

The *Health of the Nation* target is to reduce the death rate from coronary heart disease in people under 65 by at least 40 per cent and in people aged 65–74 by at least 30 per cent by the year 2000. To achieve this target the Asian population must be targeted, as the data for 1979–1983 show the death rate for this group to be considerably higher than nationally. Only comparative statistics are available so, without baseline data, a specific target cannot be set – but the reduction must be more than the national target of 40 per cent.

Service implications

The actions which the various services should take are shown below.

RECOMMENDED ACTION

Prevention

Increase awareness of coronary heart disease, particularly within high risk groups. Provide information in appropriate languages on:

- symptoms;
- the importance of seeking medical advice;
- having regular check-ups;
- training for a healthy heart.

Make health promotion material easily available in a culturally acceptable and accessible format.

Train members of a local community to become 'Look After Your Heart' tutors, so that they tailor the programme and directly access their community.

Use local Asian radio broadcasts to increase awareness and promote healthy lifestyles.

Provide loan videos in different languages.

Primary care

Monitor the use of primary care services by black and minority ethnic groups.

Monitor risk factors in high risk groups by screening both systematically and opportunistically to maximise coverage.

Hold clinics/awareness sessions in acceptable venues in the community, such as religious meeting places and community centres.

Monitor outcome of GP consultations – to determine, for example, whether patients are able to communicate effectively with their GPs.

Monitor the referral rates to secondary care.

Secondary care

Monitor patient satisfaction and their understanding of:

- what is going on;
- their condition (and whether they feel 'in control');
- the need to be an active participant in their treatment both while in hospital and post-discharge.

cont'd

RECOMMENDED ACTION cont'd

Tertiary care

Monitor the referral rate for coronary artery bypass grafts and angioplasty.

Monitor the outcome of the referral, whether it was appropriate and timely and whether the intervention added life to years, years to life or both.

Rehabilitation

Monitor the uptake of rehabilitation:

- is it appropriate?
- is it offered?
- is it taken up?
- reasons for non-compliance.

The rehabilitation service needs to be appropriate, for example:

- exercise regimes should be tailored to the dress code of Asian women;
- if the local demand is great enough then Asian women-only exercise sessions should be provided;
- dietary advice should be given by professionals aware of cultural dietary habits.

Good practice examples

Ealing, Hammersmith and Hounslow Health Authority has established a multiagency group, Ethnic Heart Health, which has an action plan to increase awareness among South Asians. For example, the Authority funds a journalist to broadcast an hour and a half of health information weekly on Sunrise Radio (which approximately 50 per cent of the local Asian population listens to regularly).

Walsall Health Authority is working with community representatives, the local College of Arts and Technology and local primary and secondary care providers to establish a 'together our health' project. The aim is to train mature students from the Asian communities to be employed as support workers to accompany patients and provide interpreting skills, advocacy and support to Asian people whilst they are receiving health services.

Barton House Health Centre in East London set up a Bangladeshi family screening clinic. One of the functions of the clinic is to screen every adult for cardiovascular risk factors. Clinics conclude with a health education session covering smoking, exercise and diet.

St George's Healthcare NHS Trust has identified key *Health of the Nation* areas for black and minority ethnic communities and taken action to determine the nature and extent of impact of various issues. For example, they have employed an Asian research fellow who is focusing on diabetes and heart disease in the South Asian population.

Chapter 12

Strokes in older people

Health needs assessment – the evidence

Mortality

Stroke mortality rates among African Caribbean men and women were 76 and 110 per cent higher respectively, and for men and women from the Asian subcontinent 53 and 25 per cent higher than the UK average between 1979 and 1983 (Balarajan, 1991).

In 1970–1972 and 1979–1983 there was a large drop in stroke mortality in most groups whereas there was only a small drop for men from the Indian subcontinent (Balarajan, 1991).

Mortality from hypertensive disease in England and Wales in 1979–1983 was four times greater than average in African Caribbean men and seven times greater in African Caribbean women (Balarajan, 1991).

Morbidity

There is little morbidity data available nationally.

Future trends

The incidence and mortality from cardiovascular disease is likely to increase considerably as the African Caribbean and South Asian populations age.

Service uptake

There has been some research carried out on the use of services by the older black and minority ethnic populations with strokes. General and specific research indicates that there is:

- low uptake of community health and social services, such as meals on wheels, home helps, day centres and lunch clubs, and health visiting and district nursing (AFFOR, 1981; Donaldson, 1986; Evers *et al.*, 1988; Home Office, 1989);
- lack of knowledge or contact between the older black and minority ethnic population and community health services (AFFOR, 1981; Evers *et al.*, 1988; Home Office, 1989; Kapasi, 1995);
- lack of information about the role and function of community support services, stroke prevention and health lifestyles, rights and entitlements, and access to interpreters (Kapasi, 1995);
- lack of appropriate follow-up care and services in the community, particularly respite care and home care assistance (Carers Network, 1994; Kapasi, 1995).

Possible causes

Possible causes of high incidence of cardiovascular disease include:

Hypertension

This is an important risk factor (Cruickshank *et al.*, 1980). There is no evidence of any ethnic difference in the risk of mortality for a given level of blood pressure (Lancet, 1992). In terms of the Asian population, a greater prevalence of hypertension due to insulin resistance may cause some of the excess mortality from cardiovascular disease (Smaje, 1995).

Obesity

Generalised obesity is known to be a problem in the African Caribbean population.

Competing cause

A low incidence of coronary heart disease amongst African Caribbeans means that there are more people 'available' to die from cardiovascular disease (Cruickshank, 1993).

Sickle cell disorder

There may be a link with sickle cell disorders (Brozovic *et al.*, 1989; Diggs, 1992).

Setting targets

The *Health of the Nation* target is to reduce the death rate for stroke in people less than 65 years old by at least 40 per cent by the year 2000. No baseline data are available, but the available evidence makes it clear that focusing on the Asian and African Caribbean population is crucial to meeting these targets.

Service implications

The actions which the various services should take are shown below.

RECOMMENDED ACTION

Prevention

Raise awareness of the effect of obesity on risk of cardiovascular disease.

Ensure regular health checks for 'at risk' groups.

Provide information about how to access and use services.

Primary care

Make the services accessible, particularly to the older age group – the language barrier is particularly significant for stroke services.

Control hypertension through clinical management.

cont'd

RECOMMENDED ACTION cont'd

Identify the 'at risk' population, monitor and manage obesity problems and hypertension.

Provide support for carers.

Secondary care

Provide culturally sensitive services in hospital settings.

Review hospital discharge procedures to ensure that there is adequate and appropriate support after discharge.

Community care

Make a wide range of facilities available which offer real choices to both users and their carers, both to ensure continuity and flexibility of care and to be sensitive to ethnicity and culture.

Increase the number of black and minority ethnic staff who provide direct services at key points – such as discharge planners, home care assistants, meals on wheels staff and community nurses. The relative proportion of these should be monitored in relation to ethnic mix of the local community.

Provide a range of appropriate short break options for users and their carers in private nursing homes, residential homes and individual home care settings – such as care 24-hours a day at home, day sitting services, night sitting services and home visiting services, as well as long-term care. Local communities could be given support to set up and run such services.

Rehabilitation

Provide rehabilitation services in hospitals and the community in a culturally appropriate way.

Chapter 13

Cancers

Health needs assessment – the evidence

Mortality from most cancer sites in most black and minority ethnic groups is lower than for the general population, with the exception of cervical cancer in Caribbean-born women (Balarajan and Bulusu, 1990).

The evidence for the incidence of cervical cancer in black and minority ethnic groups is based on small-scale studies and is contradictory. However, cervical cancer is the commonest form of malignancy in the Indian subcontinent with a rate 1.5 times higher than the current incident rate in the UK.

American studies have shown that the pattern of malignancy one or two generations after migration becomes the same as the majority community. In this case, it would be expected that the most common sites for males would be lung and prostate and for women, breast, lung and cervix.

Future trends

Cancer is mainly a disease of older people. As the black and minority ethnic population ages, there will be a large increase in the number of cancers.

Service uptake

Cervical screening

The *Health and Lifestyles Survey: Black and Minority Ethnic Groups in England* (Health Education Authority, 1995) showed the uptake among African Caribbean women to be similar to the UK average (81 per cent report being tested in the last five years, and a further six per cent more than five years ago).

The figures for women from the South Asian communities are significantly lower. Among Indian women, 63 per cent report being tested in the past five years and three per cent more than five years ago. Only 40 per cent of Bangladeshi women said they had ever had a cervical smear. The survey showed that high proportions of women are not aware of the purpose of cervical screening.

One study showed that only 35 per cent of 309 eligible Asian women reported ever having a smear. This uptake is about half that of the indigenous population. Less than half of Pakistani women (45 per cent) have had a test in the past five years and only 33 per cent of Bangladeshi women (McAvoy and Raza, 1988).

Breast screening

Evidence is sparse and confounded by socio-economic status, but there seems to be less uptake – particularly among South Asian women. A survey in London suggests that uptake rates may be associated with length of residence in Britain (Hoare, 1993). Uptake could be low as South Asian women may underestimate the value of receiving health care when they are well (Hoare, 1993).

Detection

American studies of experience and outcome of breast cancer treatment have shown that black and minority ethnic people are consistently diagnosed at a later clinical stage (McWorther and Mayer, 1987) and tend to have poor experiences and survival rates (Axtell and Myers, 1978; Nemeto *et al.*, 1980; Bassett and Kreiger, 1986).

Hospice care

People from the new Commonwealth and Pakistan had less involvement with hospices than white people (Dervi Rees, 1986; National Council for Hospice and Specialist Palliative Care Services, 1995).

Setting targets

The *Health of the Nation* targets are to reduce the death rate from breast cancer in the population invited for screening by at least 25 per cent, and to reduce the incidence of invasive cervical cancer by at least 20 per cent by the year 2000. Baseline data are not available for the black and ethnic minorities for either of these targets but evidence suggests that the low uptake of screening needs to be redressed.

Service implications

The actions which the various services should take are shown below.

RECOMMENDED ACTION

Information

Make available in relevant languages all leaflets about cancer prevention, cancer services and coping with cancer. There is a lack of knowledge about cancer, especially among non-English-speaking and older people. The lack of material in the relevant language and poor dissemination often means that such people do not know what services are available and where to go for them. Carers from black and minority ethnic communities do not therefore have access to the information and support they need to carry out their tasks (Baxter and Baxter, 1988; Shabina, 1987). Viewing a short video in the appropriate language at home has been found to be very effective in persuading women to attend for cervical smears (McAvoy, 1989).

Provide instructions with medicines in the language which the patient/carer speaks.

cont'd

RECOMMENDED ACTION cont'd

Translate screening results – women are often confused about the terminology used (e.g. positive and negative).

Use all appropriate media to make cancer information accessible.

Publicise how to get information in relevant media.

Use link workers, advocates and interpreters to help maintain close links between health authorities and black and minority ethnic communities.

Form alliances between health authorities and voluntary organisations in the black and minority ethnic community.

Develop grass roots health initiatives.

Recognise that naming systems are different in different cultures and take care when recording women's names, to avoid confusion.

Screening and early detection

Use methods which are imaginative, innovative and sensitive to different cultures to inform black and minority ethnic communities about screening services. Evaluate these methods and share the lessons learned.

Offer clear reasons for screening services, in a language which is easily understood. Recognise that non-English speakers cannot understand all the terminology.

Offer women the choice of a woman doctor – and respect their choice.

Monitor ethnicity as part of the screening service, to produce more accurate records on uptake.

Encourage women to bring a relative or friend to screening clinics.

Primary care

Provide a link worker for patients with poor understanding of English – someone who they could invite to attend a consultation with them.

GPs should use general consultations to discuss the benefits of screening to those who do not use the service.

Make available in waiting rooms leaflets on cancer in black and minority ethnic languages – particularly the *European 10-Point Code* and *Can You Avoid Cancer?*

Secondary care

Make available, as and when required, trained interpreters, link workers, and/or advocates.

Respect patient's personal, cultural and religious beliefs.

Reflect the make-up of the local population in the appointment of management and care staff.

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RECOMMENDED ACTION cont'd

Provide regular training for staff to raise awareness of the needs of the black and minority ethnic community.

Terminal care

Provide culturally specific day care, hospital and hospice provision for people from black and minority ethnic backgrounds who are dying of cancer.

Actively recruit black and minority ethnic nurses to be trained as specialist nurses – such as Marie Curie and Macmillan nurses.

Make counselling services available through people with a specific understanding of people from black and minority ethnic communities, and where their own language is spoken. A cross-cultural counselling service should be developed to meet the bereavement needs of black and minority ethnic groups.

Training

Improve the training of all health professionals to include better interpersonal, communication and cross-cultural skills.

Good practice examples

Northampton Health Authority targeted all black and minority ethnic patients due to attend the mobile breast screening unit at a particular location and approached each person individually to arrange a visit to talk informally about the purpose, relevance and procedure of breast screening. Health promotion leaflets in appropriate languages were also distributed to all GP surgeries.

Oxfordshire Health Authority funded a project in which an Asian health link worker circulated a questionnaire on her visits and then invited those at risk to the cytology clinic as part of a practice's efforts to achieve its target for cervical smears.

Redbridge and Waltham Forest Health Authority has appointed a worker to improve the uptake of breast and cervical screening for Asian women.

Chapter 14

Mental illness

Health needs assessment – the evidence

African Caribbeans

High hospitalisation rates of schizophrenic disorder among African Caribbean populations has been a consistent research finding in Britain over the last three decades. Recent studies have shown that hospitalisation rates are, if anything, higher among British-born people of African Caribbean origin (Cope, 1989; Harrison, 1993).

However, research shows marked differences in the way African Caribbeans access the service so these high hospitalisation rates for schizophrenia do not necessarily demonstrate a high incidence of schizophrenia among the African Caribbean population in Britain (Smaje, 1995).

Asians

Suicide rates among young South Asian women aged 15–24 years are three times the national average and 60 per cent higher for those aged 25–34 (Balarajan and Soni Raleigh, 1993). Measures of mental distress developed by western-oriented researchers and psychiatrists may not be sensitive to symptoms shown by Asian people (Williams, 1993), leading to possible under-reporting in prevalence studies.

Service uptake

Research shows that African Caribbeans are:

- less likely to have been in prior contact with a GP and more likely to have been referred by the police or detained by them in a 'place of safety' under the 1983 Mental Health Act (Cope, 1989; Moodley and Thornicroft, 1988);
- up to three times more likely to be admitted or detained compulsorily under the 1983 Mental Health Act (Cope, 1989; Littlewood, 1986);
- more likely to be diagnosed as violent and to be detained in locked wards, secure units and special hospitals (Cope, 1989; Moodley and Thornicroft, 1988);
- more likely to receive more 'physical' treatments – such as major tranquillisers and electroconvulsive therapy in cases where it does not appear to be indicated – at a more intensive level and without earlier recourse to less radical therapy (Littlewood and Cross, 1980);
- more likely to be seen by junior staff (Littlewood and Cross, 1980);
- less likely to make voluntary contact with health services (McGovern and Cope, 1991).

The following factors have been shown for Asians.

- Asian people entering specialist mental health services often do so in acute crisis, with low levels of GP referral (Bhui *et al.*, 1993).
- Asian women are particularly disadvantaged in both primary and secondary mental health services as a result of language, cultural and religious issues (Upadhyaya *et al.*, 1989; Williams, 1993).
- Asian people suffering from mental distress present more frequently with physical symptoms (Bal, 1987) but less often with neurotic or other psychiatric traits compared with non-Asians (Hill, 1975; Cochrane and Stopes-Roe, 1977; Cochrane 1983).

Possible causes

Although the high hospitalisation rate in the African Caribbean population results from a complex set of underlying issues, three explanations for ethnic differences have been offered:

- possible underlying genetic differences;
- some factor or factors associated with the process of migration;
- racism and disadvantage in Britain has caused a genuine epidemic of schizophrenia in the African Caribbean population (Smaje, 1995).

Several theories have been proposed to explain the apparent high rate of suicides in young Asian women. They include:

- 'culture conflict' around the issue of traditional or Western-style marriage;
- marital problems among women who have recently come to Britain to join their husbands;
- inter-generational conflicts.

Setting targets

Health of the Nation targets on mental health are:

- to improve significantly the health and social functioning of mentally ill people;
- to reduce the overall suicide rate by at least 15 per cent by the year 2000;
- to reduce the suicide rate of severely mentally ill people by at least 33 per cent by the year 2000.

To meet these targets, specific initiatives must be set up for black and minority ethnic groups.

Service implications

The above evidence clearly shows that many black and minority ethnic populations are not getting the type of service they require. A range of barriers indicated in the research are currently preventing black and minority ethnic people from accessing and using services at key points.

RECOMMENDED ACTION

Assessing needs is the key to understanding and responding to the needs of particular communities, rather than treating them as a homogenous group. If little or no ethnic monitoring information is available locally, first target 'at risk' groups – such as young Asian women or African Caribbean men and women. Focus on groups which make high or low use of mental health services – for example little is known of Chinese and Vietnamese populations which may indicate unrecognised and untreated psychiatric morbidity or access barriers with little or no support (Au and Li, 1992).

Examine why a particular group, or groups, is being selected – for example, selecting the longest established black and minority ethnic group or the group with which the agency has established links will continue to leave many other needs under-served.

Talk to targeted key users/non-users and carers in the area to clarify the specific mental health issues and service-related issues for them. Audit admissions to local mental health units and collect reliable information on ethnicity, religion and the sources of and reasons for admission for all patients.

GPs could conduct practice-based audits with the support of the Medical Audit Advisory Group, looking particularly at presenting symptoms, diagnosis, treatments and referral patterns to specialist mental health services.

Prevention

Preventive work is essential in order to stop the escalation of individual mental health problems and, in the case of African Caribbean people, to reduce the number of people coming into psychiatry under a section of the Mental Health Act. Provision of information is critical to the development of effective mental health preventative services. National research and local work with mental service users suggests that the following types of information are required.

General information

General information should be provided:

- to local communities about the range of mental health problems in order to raise greater awareness and acceptance of the issues;
- to providers about community attitudes to mental illness – in some South Asian and Far-East Asian cultures it may be seen as a curse and carry a greater stigma than it does in the West; in African cultures it may be seen as a result of spiritual possession and this can result in a reluctance to use mental health services;
- to local communities about the role of GPs, community mental health teams, out-patient clinics, hospitals, secure units and the range of community support services and accommodation available.

Specific information

Specific information should be provided:

- on services, illnesses, rights and treatment options for those already using the system, to promote more informed decision making;

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RECOMMENDED ACTION cont'd

- on anxiety, stress, depression, manic depression and types of schizophrenia;
- on rights under the Mental Health Act including legal status on admission;
- on hospital/community facilities – in particular information on advocacy, interpreting and translating and specifically targeted services for black and minority ethnic populations;
- on physical treatments – such as major tranquillisers and electroconvulsive therapy as well as non-psychiatric therapies such as counselling, occupational therapy;
- for professionals to understand how racism, cultural practices and differences within black and minority ethnic communities affect treatment, care, access and choices on services.

Information for professionals

Belief in a spiritual world is widely accepted in the philosophy of East and South Asia, and Africa. Referring to spirits is not uncommon, and should not be regarded as an indication of psychosis (SHPU, 1994).

Assumptions and stereotypes should be challenged and awareness raised of how racism can have implications for service provision. The pathways of care and treatment may result in, for example, an African Caribbean person being admitted to hospital and diagnosed 'schizophrenic' through the penal justice system; here professional awareness should be raised about the process by which African Caribbean people are admitted to hospital rather than a reductive focus on the nature of their apparent disease.

African Caribbean people are often identified as a homogenous mass, but Nevisians, Barbadians and Jamaicans all come from distinct islands with individual characteristics and customs, even though they are part of the Caribbean collective.

How to provide information

Reinforce all verbal information with written/recorded information on leaflets or audio tapes. Audio tapes can relay information in languages which are essentially dialects and not written (such as Mirpuri).

Use outreach work and open days at local service venues with local groups, faith organisations and service users to develop confidence and trust in local mental health services as well as building bridges and cultivating links.

Target groups for awareness-raising information

The following should be specifically targeted:

- service users and non-users;
- carers and relatives of people diagnosed with mental illness/suspected of experiencing mental illness;
- faith organisations;
- voluntary organisations in the black and minority ethnic community;

cont'd

RECOMMENDED ACTION cont'd

- generic mental health organisations and other general 'filter' organisations such as citizens advice bureaux, advocacy schemes, and health information projects;
- mental health professionals in community mental health teams, 'special' hospitals, GPs and other primary health care staff.

Service provision

Local research and work highlights a clear need for the development of some targeted mental health services which respond specifically to the needs of particular black and minority ethnic groups by:

- providing an appropriate response to the social, cultural, family, religious and gender specific needs of individuals;
- increasing knowledge and understanding of the social, cultural and religious realities for black and minority ethnic individuals;
- providing black and minority ethnic staff to match service users with someone of the same ethnicity and gender;
- providing a service in appropriate languages.

Advocacy services

Advocacy support is particularly important in order to:

- enable black and minority ethnic users and carers to make informed decisions about care treatment once they are in the system;
- promote access to under-used services;
- build trust and help to break down reluctance by people who may not be using the services.

The two broad models of advocacy services are:

- 'professional' advocates with legal, medical or welfare rights experience;
- 'citizen advocates' – ordinary citizens who take up an issue on someone's behalf.

The steps in planning and developing an advocacy service are outlined below:

PLANNING AND DEVELOPING AN ADVOCACY SERVICE

Consult with service users and non-users to find out:

- whether advocacy is the type of support individuals need and want;
- if so, why service users want advocacy support;

cont'd

PLANNING AND DEVELOPING AN ADVOCACY SERVICE cont'd

- what is wanted/not wanted in terms of advocacy support;
- at what points in the system the needs are the greatest;
- who users want to deliver the service.

Communicate and consult with service users and carers as well as key staff groups in developing such a service. An independent advocacy service in particular may be viewed with suspicion and mistrust (by users, carers and staff) because people may be unclear about their role. They may see it as potential interference in the relationship between professional and patient.

Involve service users and carers in designing and delivering the service – for example, users could be employed as advocates and advisers. This will make the service more responsive to their needs.

Focus the brief for the service to target one or a few specific black and minority ethnic communities in identified localities so that the service and workers are not set up to be all things to all people.

If resources are limited, first pilot the new service in one locality with one target group, then review the service in terms of its applicability to other key black and minority ethnic groups.

Identify and specify the key skills/experience required from paid workers and volunteers. Recruit workers on a salary scale which takes into account the range and breadth of skills/knowledge and experience required.

Budget adequately for further support and resource needs to deliver an effective service – such as employment of sessional workers, purchase of training support for volunteers and paid workers, and interpreting and translating.

Monitor gender, age, ethnicity, languages spoken and whether the specific needs of clients are identified and met.

Involve service users, carers and professionals working with the advocacy service in reviewing and evaluating impact and effectiveness.

Community-based services

More appropriate and specific community mental health services are needed such as:

- crisis response services (e.g. crisis accommodation for young Asian women);
- residential services and housing accommodation, or halfway housing with adequate support for African Caribbean men being discharged from special hospitals, psychiatric and secure units;
- day services and supported employment;
- domiciliary services including support for informal carers;
- therapy, treatment and rehabilitation services – for example when rehabilitating black and minority ethnic women consider:
    - women's safety;

  - supporting family structures to prevent children being taken into care;
  - confidence building in the case of sexual and physical abuse;
- other community-based support services such as carer/relative groups.

Quality standards

Statutory and voluntary mental health services for black and minority ethnic communities need specific quality standards and monitoring mechanisms as the majority of changes required to improve access and sensitivity are changes to practices. Below are some examples of specific standards.

Quality standards

Point of delivery	*Quality standard*
Primary care	Literature provided and disseminated about nature of mental illness and the roles of services at all key contact points for service users and potential users (in appropriate languages). Targeted outreach work undertaken to raise awareness of issues, services and roles of professionals in conjunction with community mental health teams, advocates, link workers and voluntary sector providers from black and minority ethnic groups.
In-patient admission	A clear admissions policy and procedures in place which specify the assessment procedure. The language, age, sex and religion of all clients monitored. Patients and/or relatives/carers given verbal information (reinforced in a written format/audio tapes) on admission about the following: ● hospital facilities; ● complaints procedures; ● legal status on admission and rights; ● professionals' roles; ● rights to advocacy and interpreting.
Assessment	Explanations supported by relevant written/audio/video material in relevant languages. An advocate/interpreter proactively offered. Each patient (and carer if appropriate) involved in the development of her/his care plan; each care plan has therapeutic, recreational, social and rehabilitation components. Care plans reviewed at planned regular intervals; a timetable of review dates drawn up and adhered to; patients given advance notice of dates and given opportunity to attend or be represented by a relative, friend or advocate.

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Quality standards cont'd

Treatment	A planned programme of activities on and off the ward involving 'therapeutic' interaction of patients with nursing, paramedical and appropriate black and minority ethnic provider staff. Programme regularly reviewed and reviews recorded.
Discharge	Unit has a written discharge policy which specifies: ● all discharged patients to be referred to GP; ● all relevant agencies, including key black and minority ethnic providers, to be notified; ● discharge follow-up procedures to be undertaken by relevant staff with the appropriate language/cultural skills or staff to be accompanied by an advocate/interpreter.

Good practice examples

Liverpool Health Authority opened its advocacy project in February 1993, run by the Granby Community Mental Health Group. The project values user input by providing:

- training in advocacy for service users;
- staff training in promoting self advocacy;
- access to legal representation;
- a reference library on mental health issues;
- access to understanding medical terminology and related issues.

The remit of the project is to:

- offer a community-based service which supports and encourages black and minority ethnic people to challenge inappropriate procedures, practices and treatments;
- raise awareness of health and social services professionals and those in the voluntary and private care sectors of the needs of black and minority ethnic people with mental health problems;
- develop the confidence of black and minority ethnic people with mental health problems to demand their rights in other areas, such as legal representation, housing and welfare benefits.

Northamptonshire Health Authority has set up a counselling and support service within GP practices for black and minority ethnic communities who for cultural or language reasons feel unable to use GP counselling.

Sandwell Health Authority has developed a model for pilot advocacy services following specific consultation work with black and minority ethnic service users about the type of service required.

Wiltshire and Bath Health Authority have approved funding from an equal opportunities initiative to 'pump prime' service innovations to improve access to disadvantaged groups. The services for black and minority ethnic communities which will be developed through the 'pump primed' monies will be:

- creation of a black and minority ethnic resource for mental health care staff;
- involvement of black and minority ethnic groups to provide training for mental health staff on issues such as diet, religion, death, bereavement, culture.

The African Caribbean Mental Health Project in Manchester was begun in 1989, after concerns expressed by African Caribbean people about the way in which African Caribbean youth are admitted to psychiatric hospitals (and the Regional Forensic Unit) and what happens to them when they are admitted (diagnosis and treatment) and when they leave (after-care and housing).

Bradford Community Health NHS Trust has a Transcultural Psychiatric Unit (established 1972) comprising a multidisciplinary, multilingual health care team which delivers more appropriate and sensitive services to black and minority ethnic communities, as well as providing consultation advice and training on transcultural mental health issues to others.

Riverside Mental Health NHS Trust, as part of its work on addressing major health trends, includes a priority for 1996/97 to develop more appropriate psychotherapy for black and minority ethnic groups at the Cassel Hospital in Richmond. This programme will include:

- positive action on recruitment;
- modification of the building fabric to reflect a more multicultural setting;
- training modules for nurses and senior registrars on issues relating to the mental health of patients from different black and minority ethnic groups;
- development of procedures for bringing in therapists with specific cultural understanding appropriate to specific clients.

Servol Community Trust in Birmingham is a black-led organisation set up in 1980, catering predominantly for the needs of black communities with mental illness. Servol has four residential homes which cater for approximately 40 people, and a resource centre. Servol's policy is to ensure that residents continue to have unrestricted access to all community support services, including health, housing, social services, leisure, educational employment and training.

Chapter 15

Sexual health

Health needs assessment – the evidence

Much of the research and service development to date in the field of sexual health has focused on HIV/AIDS. This emphasis should now be refocused to include the broad range of education, advice, support, counselling, diagnosis, treatment and care provision in all areas relating to sexual health.

General sexual health

Overall fertility is relatively low among women born in the Caribbean, India and East Africa and high among women born in 'other' African countries, Pakistan and Bangladesh (OPCS, 1992).

HIV/AIDS

Heterosexual intercourse is the predominant method of transmission of HIV infection among 'black' people (CDSC, 1993). National prevention information about HIV/AIDS has been ineffective in reaching the majority of black and minority ethnic communities (Mohanty, 1989; Croall, 1991; Leicester Health Authority, 1993). Black people perceive themselves to be at low risk of HIV infection (Thakar, 1993; Kumari, 1992). Very little is known about general sexual health or the prevalence and incidence of HIV/AIDS among Britain's black and minority ethnic populations.

The size of the AIDS problem in the minority ethnic community

At the end of 1992 there were 5591 reported AIDS cases among white people, 521 among 'black' people and 119 among South Asian people, but reliable prevalence estimates cannot be made (Balarajan and Soni Raleigh, 1993). It has been suggested that there may be differences in those at risk in different groups. Balarajan and Soni Raleigh report that a greater proportion of notified cases among white people have arisen from sexual intercourse between men and from injecting drug use, whereas the main mode of infection among 'black' people appears to be intercourse between men and women. There is also a higher proportion of mother-to-infant infection (Smaje, 1995).

Service uptake

- Uptake of family planning services for some groups of Asian women is constrained by poor access to information, interpreting services and female doctors, rather than a reluctance to use services because of culture and religion (Zaklama, 1984; McAvoy and Raza, 1988).
- Black and minority ethnic users of sexual health services have highlighted that their access to mainstream services can be improved by the provision of advocates, more female practitioners, and staff training in antidiscriminatory service provision (Kapasi *et al.*, 1995).

- Mainstream genetic screening services for sickle cell and thalassaemia have failed to take specific cultural and psychosexual factors for minority groups into account when delivering the service (Nidorf, 1993).
- Service users in the West Midlands have expressed a strong preference for the location of sexual health services within generic services at a primary care level, in order to secure greater anonymity (Kapasi *et al.*, 1995).
- Counselling approaches/models used by professionals require re-examination to identify whether they are relevant to the social realities, lives and values of black and minority ethnic people (Kapasi *et al* , 1995).
- There is a low uptake of specialist HIV services by black and minority ethnic people (Kumari, 1992; Thakar, 1993) due to lack of knowledge about services, preconceived negative images of specialist services, the stigma of HIV and the inflexible approach of agencies in relation to working with black and minority ethnic community and voluntary organisations (Kapasi, 1995).
- GPs are identified in many studies as the preferred point of contact for advice, counselling and the HIV test (Thakar and BHAF, 1991; Kumari, 1992).
- Black and minority ethnic service users who are HIV positive present late for medical care (Bhatt, 1991).

Service implications

The actions which the various services should take are shown below.

RECOMMENDED ACTION

Cultural competence

Provide appropriately trained advocates and interpreters at genitourinary medicine clinics, GP practices and family planning clinics.

Provide more black and minority ethnic receptionists, female doctors, health advisors and counsellors.

Set up black and minority ethnic women/men/gay/lesbian-only support groups.

General sexual health

Provide accessible, holistic services at primary care level – such as staff skilled in providing advice/counselling in terminations, infertility, menopause and sexually transmitted diseases in a culturally appropriate way.

Set up a facility for on-site pregnancy tests and the full range of contraceptive services – including the provision of condoms and emergency contraception.

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RECOMMENDED ACTION cont'd

Specific sexual health

Provide:

- women/men/gay/lesbian-only support groups run by black and minority ethnic voluntary sector service providers;
- counselling/helpline services provided by black and minority ethnic staff;
- outreach 'safer sex' promotion work targeting young African Caribbean and Asian men;
- drop-in 'well men' or 'well women' clinics at youth clubs, GP surgeries or community centres;
- black and minority ethnic provider-led home care and meals on wheels support services for people with severe HIV disease.

Good practice examples

Birmingham Health Authority produced audio tapes for women around sexual health, providing information about thrush and HIV/AIDS. The tapes were produced following consultation with a range of black and minority ethnic women attending English language classes and health clinics. These women identified thrush as a common concern. The audio tapes have been produced with supporting information on:

- key questions women asked when the tapes were piloted;
- advice given on the tapes which may need emphasising/clarifying;
- use of tapes in different settings (e.g. discussion groups/self-help groups)
- glossary of sexual health terms and phrases used to translate them.

King's Healthcare NHS Trust, in conjunction with Health First, SELSA Outreach and Mainliners have established a working women's clinic, a drop-in sexual health clinic run on one evening per week. It is based at a GP practice in a locality where women and men sex workers are available. The clinic offers a full range of services from: sexual health check-ups and treatment; contraception and contraceptive advice; pregnancy testing and advice; referrals for abortion and other gynaecological problems; hepatitis B vaccination; needle exchange scheme; 'ugly mugs' list of punters with whom women have had a bad experience; and space for women who just want to talk and have a coffee.

Walsall Hospital NHS Trust genitourinary medicine service undertakes outreach work on an ongoing basis with local black and minority ethnic communities. This work was initiated by the Health Promotion Unit and has facilitated greater awareness and acceptance of services. For example, the GUM organised an open day for black and minority ethnic groups which was attended by people from local mosques. Mosque members talked to staff and as a result became more receptive to the work of the clinic.

Chapter 16

Accidents

Health needs assessment – the evidence

Social disadvantage associated with ethnicity, rather than ethnicity as such, is seen as the main factor in higher accident rates (RoSPA, 1993). However, there are very few data available on the occurrence of accidents in black and minority ethnic groups. A study based in a London hospital of accident and emergency admissions for child injuries in the home showed that there was no significant difference by ethnic group, but a strong socio-economic gradient in all groups, particularly as measured by house tenure, overcrowding and mother's employment status. Other research has confirmed these findings (Smaje, 1995).

Unequal access to services was perceived to occur because of:

- communication barriers, lack of translating and interpreting services;
- service providers do not generally cater for the needs of black and minority ethnic groups;
- older people from the Asian community felt that the treatment they received was uncaring and sometimes discriminatory.

Data are not routinely collected on accidents so it is impossible to estimate the size of the problem in black and minority ethnic groups, and nor is it possible to separate out the affect of deprivation and ethnicity on accident rates.

Possible causes

Asian children were found to have a higher incidence of burns than the majority population with cultural factors such as methods of cooking being seen as the probable main factor as well as social circumstance (Vipulendron *et al.*, 1989; Learmonth, 1979).

A study of road accidents reported that there were significantly more road accidents to young Asian pedestrians age 0–9 years than in the majority population. On analysis it was found that accidents involving Asians were more likely to be associated with masking, or being hidden by, a parked vehicle. This was closely linked to those Asians in the sample living in inner city areas, the type of road and the age of the casualty (Lawson and Edwards, 1991).

Research into the relationship between ethnic origin and accidents in the workplace has suggested that the high rate of accidents amongst black and minority ethnic communities could be accounted for by the nature of the work environment (Lee and Wrench, 1977; Baker, 1987).

Setting targets

The *Health of the Nation* targets on accidents are, by the year 2005, to reduce the death rate for accidents among:

- children aged under 15 by at least 33 per cent;
- young people aged 15–24 by at least 25 per cent;
- people aged 65 and over by at least 33 per cent.

The area which needs specific targeting among black and minority ethnic groups is children – particularly in relation to road safety.

Service implications

The actions which the various services should take are shown below.

RECOMMENDED ACTION

Prevention

Work with other agencies and the local community to produce a strategy for accident prevention – in which the needs of black and minority ethnic communities receive specific consideration.

Database

Develop an accident database within the accident and emergency department which collects routine information on cause of accident, injury type and severity, and common minimum data set personal details, as well as details of ethnicity and socio-economic group; this information should be rendered anonymous and made available to local authorities, police and all relevant safety organisations to form the basis of policy development.

Information

Develop an accident prevention strategy for young Asians and their parents on road safety – investigate whether they are allowed out on busy roads unaccompanied at too young an age, or whether they are not taught the dangers of crossing a road by parked cars, and develop appropriate safety campaigns.

Increase awareness of the dangers of traditional cooking methods and develop alternatives – particularly where there are young children in the family.

Develop some of the safety messages through black and minority ethnic groups' radio and TV drama series in consultation with producers – as has been successfully done with 'soaps' – as well as using the media for safety information bulletins in several languages.

Inter-agency working

Ensure that overcrowding, unsafe working conditions and other situations likely to put people at risk are priority areas for joint action between health agencies and other agencies.

Good practice examples

Accidents are not very high on most health authorities' agendas despite being one of the *Health of the Nation* target areas. Deaths from accidents are relatively few, and because population statistics on the health implications of accidents are not readily available, accidents do not get the priority they deserve. This is an obvious area to achieve health gain, and yet they continue to be ignored.

The only examples of good practice found were local initiatives linked to other campaigns such as national Child Safety Week. In **Haringey**, for example, monies were obtained to promote a Community Safety Week in which a provider safety group was set up to address issues of injury locally, particularly focusing on injuries among black and minority ethnic groups and injuries that led to police and local authorities becoming involved, such as domestic violence.

Chapter 17

Diabetes

Health needs assessment – the evidence

The prevalence of known diabetes among African Caribbeans is estimated to be double the rate among the white population (Odugbesan *et al.*, 1989), and in Asians it is four to five times higher than in non-Asians (Mather and Keen, 1985; Simmons *et al.*, 1989).

The condition remains undiagnosed in large proportions of Asian diabetics. The prevalence of known and unknown diabetes in Asians has been estimated at between 10 and 20 per cent of the population (Simmons *et al.*, 1989). Compared to national levels, mortality from diabetes is three to four times greater in Caribbean-born people, about double in African-born people and three times greater in the Asian population (Balarajan and Bulusu, 1990).

The non-insulin dependent form (NIDDM) of diabetes appears to be more highly prevalent among most black and minority ethnic populations (Smaje, 1995). Insulin-dependent diabetes mellitus (IDDM) appears to be less prevalent in both the South Asian and African Caribbean population than in the white population. South Asian and black populations have a greater incidence and poorer outcomes from diabetes complications, particularly end stage renal failure disease (Roderick *et al.*, 1994).

The size of the problem

Prevalence surveys based on WHO criteria are now available for most countries where South Asians have settled in large numbers. They show that the prevalence of diabetes in South Asian men and women aged over 40 is at least 20 per cent (Williams, 1993).

Future trends

The incidence of IDDM is likely to increase within the South Asian and African Caribbean populations as they become more exposed to some viral infections.

Possible causes

The following factors have been suggested as affecting the incidence of diabetes.

- genetic propensity (Williams, 1994);
- environmental factors – such as exposure to some viral infections;
- lifestyle factors – such as diet.

Service implications

The actions which the various services should take are shown below.

RECOMMENDED ACTION

Health promotion

Promote awareness of diabetes and its symptoms through literature and audio tapes in appropriate languages.

Promote awareness of risk factors associated with diabetes.

Provide health promotion in a culturally sensitive way, focusing on the control of obesity and advice on diet and exercise.

Encourage members of the local community to provide classes in meeting places to promote healthy eating and the importance of exercise.

Information

Make available the British Diabetic Association leaflets in appropriate languages.

Publicise the availability of these leaflets through relevant channels.

Primary care

Monitor for the onset of diabetes in 'at risk' groups.

Give diabetic patients a defined programme of care.

Provide patients with a diabetic link worker who can speak the appropriate languages and has a knowledge of both the cultural requirements of the patient as well as a knowledge of diabetic services and diabetic patients' needs.

Carefully manage the disease to avoid complications.

Reduce complications by providing:

- support to diabetic patients to enable them to manage the disease effectively;
- regular screening for diabetic retinopathy;
- adequate provision of foot care.

GPs should keep a register of all diabetic patients, including details of ethnicity.

Secondary care

Record the fact that a patient is diabetic on all patient episodes.

Monitor the incidence of complications such as coronary heart disease and end-stage renal disease.

Provide a specialist diabetic antenatal clinic.

Good practice examples

Bedfordshire Health Promotion Agency has developed material on diabetes as well as coronary heart disease, women's health issues and childhood immunisations. This material, which includes posters, leaflets, videos and display boards, can be borrowed from the Agency and is available in Punjabi, Bengali, Urdu and English.

Coventry Health Authority has made funding available to provide dietetic advice to Asian clients in their first language and to improve acceptance of that advice. Six GP practices with high Asian populations have dietetic clinics and other GPs are able to refer patients to a specialist dietitian at a central location. The senior dietitian speaks Punjabi, Hindi and Urdu and so is able to communicate with all Asian clients. Suitable written material and teaching aids have also been produced using Asian word-processing software, and photographs have been used for visual aids.

Ealing, Hammersmith and Hounslow Health Authority has set specific objectives for diabetes among South Asian people following local needs assessment work in Hounslow. Targets are directed at a multiagency approach seeking to involve local authority organisations in addition to GPs and primary health care teams.

Birmingham Heartlands NHS Trust has identified key services which require ongoing interpreting support and have recruited specific staff with language skills to be permanent members of teams providing these services rather than just relying on the provision of generalist interpreters/link workers. For example, they have appointed a full-time diabetic liaison nurse with language skills, a dietitian with language skills and a ward clerk/interpreter specifically for diabetes patients.

Wolverhampton Healthcare NHS Trust employs an Asian health worker who gives support and advice to newly diagnosed Asian patients, relatives and carers in their own language as well as working proactively with the Asian community with regard to early detection and prevention of diabetes.

Chapter 18

Haemoglobinopathies

Health needs assessment – the evidence

Sickle cell anaemia and haemoglobin sickle cell disorder are most prevalent in African and African Caribbean populations. The genetic trait for the disease may help to protect the carrier from malaria and it is most commonly found in populations whose origins lie in areas where malaria is endemic (Anionwu, 1993). Sickle beta-thalassaemia also affects people originating from South Asia, southern Europe and the Middle East (Smaje, 1995). The nature of the symptoms in Britain may be different from that in the areas of origin, with a greater incidence of 'painful crises', but relatively little is known about the geographical variations in the symptomology of the disease (Smaje, 1995).

Currently there are about 5000 people with sickle cell disorder in the UK, mostly in the African Caribbean population. Thallasaemia affects about 600 people in the UK, the population mainly derived from the Mediterranean and Indian subcontinent. It was estimated there were five cases of sickle cell disorder per 1000 African and African Caribbean population in London in 1984 (Brozovic *et al.*, 1989).

Future trends

All the ethnic groups have a young age-distribution, and thus a relatively high birth rate. Consequently the need for counselling and screening will rise in the future.

Possible causes

Sickle cell disorder and thalassaemia are autosomal recessive inherited disorders affecting the structure or synthesis of haemoglobin, the red pigment principally responsible for the carriage of oxygen by the red cells of the blood. It is essential to distinguish between those who carry a haemoglobinopathy trait, who are more numerous, and the much smaller number of people with the disorders. A person who is a carrier usually has no symptoms and leads a normal life – but they have a genetic risk. If a carrier chooses a non-carrier partner, in each pregnancy there is a 1 in 2 chance that the child will become a carrier but no risk of the child having the disorder. If both parents are carriers, in each pregnancy, the child will have a 1 in 4 chance of inheriting an abnormal haemoglobin disorder, a 1 in 2 chance of being a carrier and a 1 in 4 chance of having two normal genes.

Service uptake

Although sickle cell anaemia is very rare in the population as a whole, some studies have suggested that in certain areas it accounts for up to 40 per cent of hospital admissions in the haematology specialty (Brozovic *et al.*, 1989). Many patients go straight to the accident and emergency department for treatment during a crisis. More than nine out of every ten hospital admissions for sickle cell disorders are for painful crisis. On average, people with sickle cell disorders admitted to hospital spend just over seven days a year in hospital (Department of Health, 1993).

Service implications

The actions which the various services should take are shown below.

RECOMMENDED ACTION

Health education/promotion

Increase awareness of haemoglobinopathies in the general population.

Make available information to black and minority ethnic groups in an easily understandable format, in language of their choice.

Increase awareness of all aspects of haemoglobinopathies in health professionals through their training.

Primary care

GPs have a major role to play in the management of the disease; they can:

- administer prophylactic antibiotics and pain killers such as short-acting oral morphine for the treatment of a mild crisis;
- act as lead in developing a disorder management protocol with the local hospital, in consultation with the patient;
- help avoid unnecessary hospital admissions by providing a coordinated service.

Develop practices which have a special interest and expertise in the management of haemoglobinopathies as it may not be possible for all GPs to be able to deliver the above.

GPs should offer haemoglobinopathy screening to all 'at risk' patients.

Offer haemoglobinopathy risk assessment to all new patients.

Encourage preconception diagnosis of carriers and provide preconception counselling.

Secondary care

Make sure that sickle cell patients receive immediate assessment and rapid treatment when they arrive in accident and emergency departments by:

- keeping a register in accident and emergency which identifies all sickle cell patients, lists their diagnosis, previous complications and usual pain treatment;
- providing experienced staff who can identify and know how to deal with patients in crisis;
- ensuring staff have been trained in the use of pain killers for sickle cell crises.

In-patient care

Screen all at risk patients preoperatively if appropriate.

If the population coming through the antenatal clinic is composed of 15 per cent or more ethnic minorities at risk from sickle cell disorder, provide universal antenatal screening and neonatal screening.

Identify a clinician and nominated deputy with responsibility for overall care.

Make available a nurse specialist who has received training in the management of sickle cell crisis.

Train staff on wards which admit sickle cell patients in the handling of patients in crisis.

Make available haemoglobinopathy counsellors.

Patient care/support

Encourage people to carry a haemoglobinopathy card and set up support groups.

Good practice examples

Manchester Health Authority has developed an action plan with specific process targets and/or objectives. One of these is the monitoring of uptake of haemoglobinopathy services by area of residence.

West Yorkshire Health Authority in conjunction with Kirklees Metropolitan Council and the charity Level Best are jointly funding a project to establish a collaborative approach to haemoglobinopathies, in particular sickle cell and thalassaemia.

Wandsworth Community Health NHS Trust has employed a nurse specialist for haemoglobinopathies to work with both in-patients and in the community, to empower patients to progressively manage their pain at home while maintaining daily activities.

Chapter 19

Maternal and child health

Health needs assessment – the evidence

The infant mortality rate is higher for most migrant groups, and is particularly high for infants of Pakistani-born mothers (70 per cent above the UK value), and Caribbean-born mothers (33 per cent above the UK figure) (Balarajan and Soni Raleigh, 1990).

Within this, it is the perinatal mortality rate (i.e. stillbirths and deaths within the first seven days) and the neonatal mortality rate (i.e. deaths within the first 28 days) which are high compared to the UK – with the highest rates being found amongst Pakistani-born mothers (80 per cent higher for both perinatal and neonatal death rates).

The infant mortality rate for infants of Pakistani-born and Caribbean-born mothers has declined but only in line with UK trends, so the disparities remain. For other black and minority ethnic groups, however, the rates have declined more rapidly than in the UK (Balarajan and Soni Raleigh, 1990).

There are significantly higher rates of congenital abnormalities in babies whose mothers were born in Pakistan, India and East Africa (mainly of Indian origin). The Pakistani rate was more than double the rate of the general population (Little and Nicholl, 1988).

Possible causes of higher perinatal mortality rates

The following causes have been identified:

- higher rates of congenital abnormalities;
- neonatal and post-neonatal infection;
- low birthweight – a major risk factor;
- mother's age and number of children;
- length of time between pregnancies;
- parental socio-economic status;
- smoking during pregnancy;
- association with the practice of consanguinity (marriage between relatives);
- association with ethnic differences in access to and use of health services;
- communication problems about reproductive health;
- quality of antenatal care;
- registration with a GP who was not on the obstetric list (recognised expertise in providing maternity

care) has been associated with higher perinatal mortality particularly in South Asian groups;

- Asian , African and African Caribbean women are at higher risk of diabetes and hypertension (Department of Health, 1993);
- Asian women who have not been immunised against rubella – as they came into this country as young adults – are therefore at greater risk of contracting rubella during pregnancy (Department of Health, 1993).

Service uptake

Women from black and minority ethnic groups tend to be late bookers and are less likely to exercise their right to choice. There are also lower rates of induced labour amongst Bangladeshi and South Asian women.

Service implications

The actions which the various services should take are shown below.

RECOMMENDED ACTION

Information

The lessons of the Asian Mother and Baby Campaign remain relevant (Bahl, 1987). Make available in appropriate languages and in a variety of media easily understood information which allows women to make informed choices; the Asian community in Britain has a higher than average video ownership – this should be exploited by the production of educational videos and the development of lending facilities.

Translate more leaflets into other languages and include images to which black and minority ethnic women can relate (NHSME,1993).

Health Visitors need to access the community in which they work, by giving talks at local community centres or meeting places.

Survey patients to ensure that their cultural and religious needs are being met.

Primary care

Put in place additional early booking mechanisms, including booking at home.

Hold clinics in local community meeting places.

Reflect the ethnic mix of the local population in recruitment.

Identify a named lead professional who will follow the patient through the system throughout her pregnancy and aftercare – an interpreter is to be available if required; the role of this person is to discuss the options for birth and delivery with the mother and develop a birth plan.

Train all staff dealing with women from black and minority ethnic groups on religious and cultural beliefs about pregnancy and childbirth.

cont'd

RECOMMENDED ACTION cont'd

Offer parentcraft classes which are appropriate to the needs of the individual and sensitive to religion and culture.

Secondary care

Train all staff dealing with women from black and minority ethnic groups on religious and cultural beliefs about pregnancy and childbirth.

All providers should adopt and implement an equal opportunities policy demonstrating that efforts are being made to recruit staff who are representative of the local population.

Offer all 'at risk' patients screening for haemoglobinopathy.

Provide religious services appropriate to all cultures and religions.

Carry out ethnic monitoring of births – for example, monitor factors such as preterm births, induced labour, Caesarean sections and congenital malformations.

Good practice examples

Hackney Health Authority has funded an advocacy project, managed by the Community Health Council, which employs a team of women helpers from different ethnic backgrounds to work with mothers-to-be. Their aim is to improve the appropriateness and accessibility of maternity services by supporting the users of the service and explaining their rights.

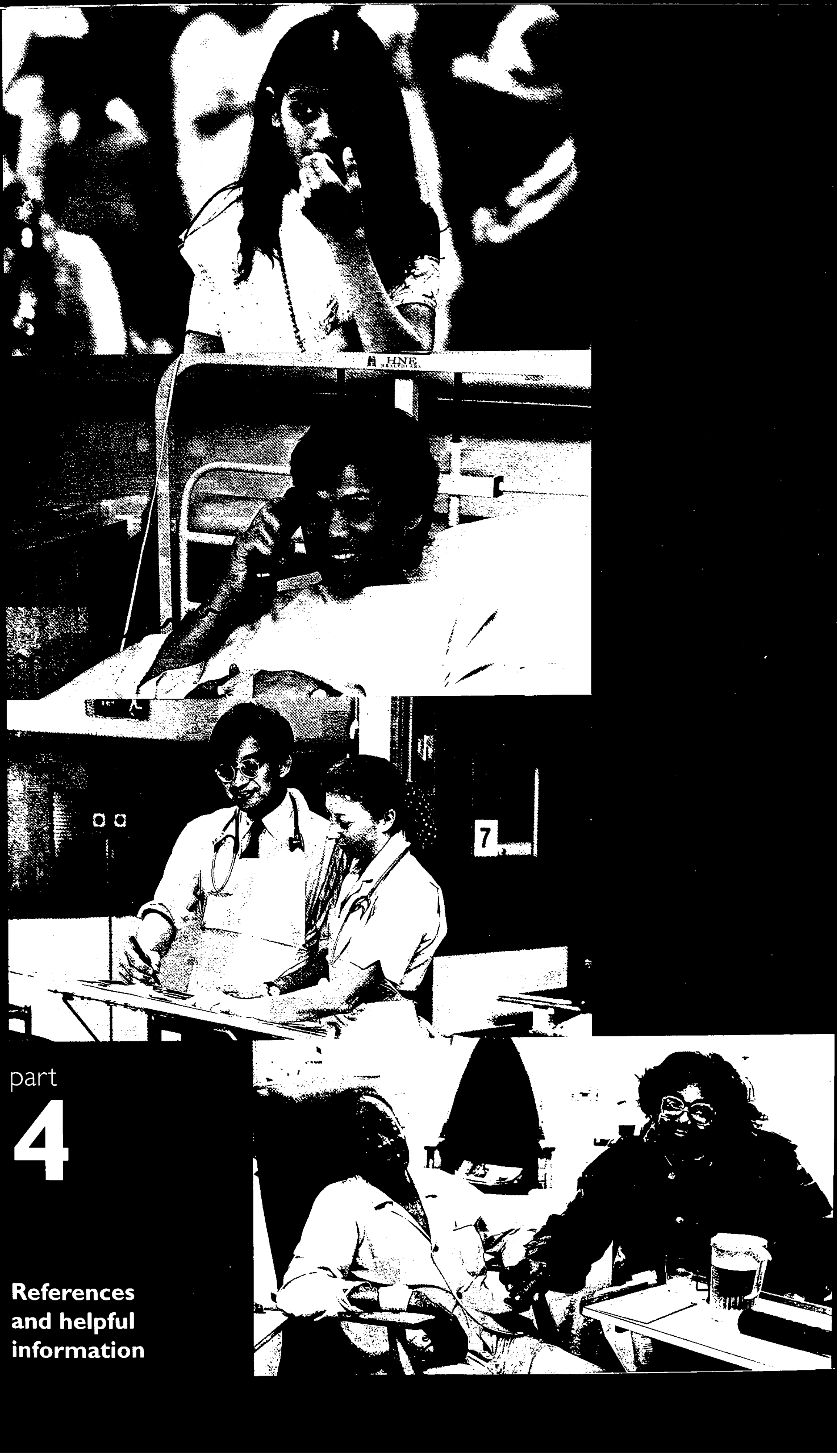
Ealing Hospitals NHS Trust, where more health workers from ethnic minorities have been employed, has shown an increase in the uptake of clinics and parentcraft classes by Asian women.

Greater Glasgow Health Board and two GP practices in the area have set up a child health clinic managed by a health visitor from the black and minority ethnic community. The clinic provides the usual routine weighing and child development checking as well as: advice on diet and anaemia due to poor diet; haemoglobinopathies; a service for the high percentage of handicapped children in the area who are the result of first cousin marriages; discussion regarding male sterilisation; and many other topics in a culturally sensitive manner.

Optimum Health NHS Trust has child health sessions for the Vietnamese and Turkish populations.

Nottingham Community NHS Trust's co-worker scheme for speech and language therapy developed a training package for co-workers from the Asian community to work with children whose first language is not English. This has helped these children to have equal access to the service.

The **Royal College of Midwives** has produced a video entitled *Rights and Choices in Maternity Care* in five languages.



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NHS documents

Relevant Health Service Guidance (HSG)

HSG(94)19	*Information to Support Health of the Nation*
HSG(94)29	*GMS GP Practice Vacancies: Revised Selection Procedures*
HSG(95)4	*Developing NHS Purchasing and GP Fundholding*
HSG(95)13	*Revised and Expanded Patient's Charter: Implementation*
HSG(95)39	*NHS Responsibilities for Meeting Healthcare Needs*
HSG(95)54	*Variations in Health: Report of the Variations Sub-group of the Chief Medical Officer's Health of the Nation Working Group*

Relevant Executive Letters (ELs)

EL(94)12	*Ethnic Minority Staff in the NHS: a Programme of Action*
EL(94)37	*Consultation on Proposals Concerning the Control of Immigration Status of Overseas Doctors and Dentists Undertaking Postgraduate Training in UK*
EL(94)55	*Priorities and Planning Guidance for the NHS 1995/96*
EL(94)62	*Monitoring and Financial Health Support for the Programme of Action on the Ethnic Minority Staff in the NHS*
EL(94)74	*Improving the Effectiveness of the NHS*
EL(94)77	*Collection of Ethnic Group Data for Admitted Patients*
EL(94)79	*Developing NHS Purchasing and GP Fundholding*
EL(94)91	*Public Expenditure on Health*
EL(94)92	*Towards a Primary-Care-Led NHS: an Accountability Framework for GP Fundholding*
EL(95)10	*The Patient's Charter: GP Practice Charters*
EL(95)27	*Education and Training in the New NHS*
EL(95)54	*An Accountability Framework for GP Fundholding*
EL(95)68	*Priorities and Planning Guidance for the NHS 1996/97*

Additional reading

There is an extensive and growing literature on ethnicity and health and what follows is a very short list of recommended reading and pointers to other bibliographies.

Commission for Racial Equality: *Race Relations Code of Practice for the Elimination of Discrimination and the Promotion of Equality of Opportunity in Employment* (1984); *Codes of Practice in Maternity Services, Primary Care Services* (1992); *A Guide on NHS Contracts and Racial Equality* (1991) and other related guides

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Useful contacts

Asian Family Counselling Service
Ms Kulbir Randhawa
74 The Avenue
West Ealing
London W13 8LB
Telephone 0181 997 5749

Asian Language Cancer Information and Support Line
Telephone 0171 713 7867 (10 am to 12.30 pm Monday and Friday, answerphone).
Information and support on any aspect of cancer in Hindi, Bengali and English.

Association of Blind Asians
Ms Sandhya Hannay, Development Officer
22 Upper Street
London N1 2NX
Telephone 0171 1226 1950

Association of Community Health Councils
Information Team
30 Drayton Park
London N5 1PB
Telephone 0171 609 8405

BHAN (Black HIV/AIDS Network)
Drop In Centre
111 Devonport Road
Shepherds Bush
London W12 8PB
Telephone 0181 749 2828
(Monday to Friday 10 am to 5.30 pm)
Fax 0181 746 2898

Blackliners
Trisha Plummer
EuroLink Business Centre
49 Effra Road
London SW2 1BZ
Telephone 0171 738 7468/0171 738 5274 Helpline
Fax 0171 738 7945

British Medical Association
BMA House
Tavistock Square
London WC1H 9JP
Telephone 0171 387 4499

British Red Cross Society (International Welfare Department)
9 Grosvenor Crescent
London SW1X 7EJ
Telephone 0171 235 5454

Cancerlink
17 Britannia Street
London WC1X 9JN
Telephone 0171 833 2451

Commission for Racial Equality
Elliot House
10/12 Allington Street
London SW1E 5EH
Telephone 0171 828 7022

Confederation of Indian Organisations
Tanzeem Ahmed
Westminster Bridge Road
London SE1 7XW
Telephone 0171 928 9889

Cypriot Advisory Service
26 Crowndale Road
London NW1 1TT
Telephone 0171 387 6617

Department of Social Security
Teletel: Advice Line
Calls free and confidential
Urdu 0800/89/188; Punjabi 0800/521/360
Chinese 0800/252/451; Welsh 0800/289/011;
Benefits Line for the Disabled 0800/882200
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Telephone 0181 682 0216

Foundation for Women's Health
Ms Enyo Afele
38 King Street
Covent Garden
London WC2E 8JT
Telephone 0171 379 6889

Good Practice in Mental Health
380 Harrow Road
London W9 2HU
Telephone 0171 289 2034

Greater London Action for Race Equality (GLARE)
Room 312
South Bank House
Black Prince Road
London SE1 7SJ
Telephone 0171 700 8135

Health Education Authority
Health Promotion Information Centre
Hamilton House, HEA Mabledon Place
London WC1H 9TX
Telephone 0171 383 3833

Joint Council for the Welfare of Immigrants
Mr C Moraes, Director
115 Old Street
London EC1V 9JR
Telephone 0171 251 8706 Advice
0171 251 8708 Office

Latin American Women's Rights Service
Julia Alazar
Wesley House, Wild Court
London WC2B 5AV
Telephone 0171 831 4145

London Chinese Health Resource Centre
Queen's House
1 Leicester Place
Leicester Square
London WC2H 7BP
Telephone 0171 287 2000

The Maternity Alliance
15 Britannia Street
London
WC1X 9PJ
Telephone 0171 837 1265

Maternity and Health Links
Shaheen Chaudhry
The Old Co-op
38-42 Chelsea Road
Easton
Bristol BS5 6AF
Telephone 0171 955 8495

Nafsiyat – The Intercultural Therapy Centre
Mr L K Thomas, Clinical Director
278 Seven Sisters Road
Finsbury Park
London N4 2HY
Telephone 0171 263 4130

National AIDS Helpline
PO Box LB400
London WC2B 6JG
Telephone 0800 567 123 Helpline

National Association for
Racial Equality Councils
8–10 Coronet Street
London N1 6HD
Telephone 0171 739 6658

National Children's Centre
Mrs Hazel Wigmore
Brian Jackson Centre
New North Parade
Huddersfield
West Yorkshire HD1 5JP
Telephone 01484 519988

National Council for Voluntary Organisations
26 Bedford Square
London WC1B 3HU
Telephone 0171 833 1818

NHS Ethnic Health Unit
7 Belmont Grove
Leeds LS2 9NP
Telephone 0113 246 7336

Organisation for Sickle Cell Anaemia Research (UK) (OSCAR)
Mr N Clare
Sickle Cell Community Centre
Tiverton Road
London N15 6RT
Telephone 0181 888 2148

Overseas Doctors Association
28–32 Princess Street
Manchester M1 4LB
Telephone 0161 236 5594

SHARE
King's Fund
11–13 Cavendish Square
London W1M 0AN
Telephone 0171 307 2400

Sickle Cell Society
Ms J Richards
54 Station Road
London NW10 4UA
Telephone 0181 961 7795 or 0181 961 4006

Standing Conference of
Ethnic Minority Senior Citizens
D B Nguyen, Development Officer
5 Westminster Bridge Road
London SE1 7XW
Telephone 0171 928 0095
Fax 0171 928 5466

Union of Turkish Women in Britain
110 Clarence Rod
Clapton E5 8JA
Telephone 0181 985 4072 or 0181 986 1358

United Kingdom Thalassaemia Society
Mr C Paul
107 Nightingale Lane
London N8 7QY
Telephone 0181 348 0437

Religious organisations

Baha'i Faith
National Spiritual Assembly of the Baha'is
of the United Kingdom
27 Rutland Gate
London SW7 1PD
Telephone 0171 584 2566

Buddhism
London Buddhist Centre
51 Roman Road
London E2 0HU
Telephone 0171 981 1225

The Buddhist Society
58 Eccleston Square
London SW1V 1PH
Telephone 0171 834 5858

Hinduism
Hindu Centre
7 Cedars Road
London E15 4NE
Telephone 081 534 8879

Hindu Cultural Society
321 Colney Hatch Lane
London N11 3DH
Telephone 0181 361 4484

National Council of Hindu Temples (UK)
26 Hillingford Avenue
Great Barr
Birmingham B43 7HS

Islam
Islamic Cultural Centre
London Central Mosque (Regent's Park)
146 Park Road
London NW4 3TL
Telephone 0171 724 3363

Institute of Ismaili Studies
19 Portland Place
London W1N 3AF
Telephone 0171 436 1736

Muslim Women's Help Line
0181 904 8193
(10 am to 4 pm Monday–Friday)

Jehovah's Witnesses
Telephone No. 0171 286 6016
Will provide name of local resource
person who can give advice on the
non-blood medical management of patients

Jews (Orthodox)
The Office of the Chief Rabbi
Alder House
Tavistock Square
London WC1H 9HL
Telephone 0171 387 1066

Jews (Progressive)
Union of Liberal and Progressive Synagogues
The Montague Centre
21 Maple Street
London W1P 6DS
Telephone 0171 580 1663

Judaism
Mr H Pinner
Secretary General of the Board
of Deputies of British Jews
Woburn House
Tavistock Square
London WC1H 0EU
Telephone 0171 387 3952

Sikhism
Sikh Cultural Society of Great Britain
88 Mollison Way
Edgware
Middlesex HA8 5QW
Telephone 0181 952 1215