

Health ASERT Programme Wales

Enhancing the health promotion evidence base on Minority Ethnic Groups, Refugees/Asylum seekers, and Gypsy Travellers

3.A Review of the Literature on the Health Beliefs, Health Status, and Use of Services in the Minority Ethnic Group Population and of appropriate Health and Social Care Interventions

ISBN: 07504 3758 8
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Foreword for series

As Minister for Health and Social Services, I am pleased to present the Health ASERT Programme Wales report series to you. This report series details the findings and the recommendations arising from this important research programme examining health promotion issues for minority ethnic groups, refugees/asylum seekers and Gypsy Travellers living in Wales.

This research programme demonstrates the commitment shown by the Welsh Assembly Government to promoting equality of opportunity in all aspects of Welsh life and reducing inequalities in health faced by ethnic minority and marginalised groups. In order for us to meet this commitment and develop appropriate policies and practices, it is imperative that we have access to a solid evidence base, drawn from the available literature and the views of those directly affected by our policies. The research reported here involved community members as well as key stakeholders at the national and local levels. This input, combined with the extensive review of the literature on the health beliefs and health status of these groups and their use of services and on appropriate health care interventions has culminated in a comprehensive piece of work.

One of the key conclusions of the research is that promoting good health is the responsibility of individuals, communities and Government. I wholeheartedly endorse this sentiment, which forms the approach behind the recent launch of Health Challenge Wales, a call to all people and organisations in Wales to work together for a healthier nation.

I trust that you will find this report series both enlightening and thought provoking, as indeed the Deputy Minister and I have. Furthermore we hope that you will use the report series as a source of reference material for your work.



Brian Gibbons AM
Minister for Health and Social Services



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Deputy Minister with responsibility for older people

Health ASERT Programme Wales Report Series

Health ASERT Programme Wales. Enhancing the Health Promotion Evidence Base on Minority Ethnic Groups, Asylum Seekers/Refugees and Gypsy Travellers.

1. Main Findings and Recommendations.
2. A Review of the Literature on the Health Beliefs, Health Status, and Use of Services in the Gypsy Traveller Population, and of appropriate Health Care Interventions.
3. A Review of the Literature on the Health Beliefs, Health Status, and Use of Services in the Minority Ethnic Group Population, and of appropriate Health Care Interventions.
4. A Review of the Literature on the Health Beliefs, Health Status, and Use of Services in the Refugee and Asylum Seeker Populations, and of appropriate Health Care Interventions (to be published 2006).
5. A Review of Databases and Other Statistical Sources Reporting Ethnic Group and their Potential to Enhance the Evidence Base on Health Promotion (to be published 2006).
6. Summary Primary Research Report (to be published 2006).
7. Full Length Primary Research Report (to be published 2006).

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The views expressed in this report are those of the author and not necessarily those of the Welsh Assembly Government

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Preface

The Health ASERT Programme Wales is a research programme commissioned by the Office of the Chief Medical Officer, Welsh Assembly Government to investigate health promotion issues among Minority Ethnic Groups, Refugees/Asylum seekers, and Gypsy Travellers. The acronym ASERT stands for **A**sylum **S**eekers, **E**thnic minorities, **R**efugees and **T**ravellers. Research was undertaken by the Research Centre for Transcultural Studies in Health, Middlesex University and the Centre for Health Services Studies, University of Kent at Canterbury between February 2003 and March 2004. The study aimed to enhance the evidence base on health promotion issues related to minority ethnic groups, refugees/asylum seekers and Gypsy Travellers in Wales in order to inform policy and programme development in the Welsh Assembly Government's Health Promotion Division (now known as Public Health Improvement Division) and elsewhere in the Office of the Chief Medical Officer. The study objectives were to: identify gaps in the existing evidence base of health needs and health promotion issues for the study groups; identify existing good practice of health services and promotion for the study groups; explore ways of delivering health promotion policy/programmes targeting these groups in a culturally and socially sensitive manner; identify issues for further research.

Acknowledgements

I am grateful to Ms. Kaori Onoda and Ms. Launa Harris of the Research and Evaluation Branch, Public Health Improvement Division, and other members of the Health ASERT Programme Wales Steering Group, and Welsh Assembly Government for their helpful and informative comments on an earlier draft of this report.

Executive Summary

I. Health Status, Behaviour, Wider Determinants of Health and Use of Services

1. Background and policy

The 2001 Census recorded a total population in Wales of 2.9 million, 97.9 per cent of whom were white and 2.1 per cent from minority ethnic groups. The largest minority ethnic group was Pakistanis (0.29 per cent), followed by Indians (0.28 per cent), Chinese (0.22 per cent), and Mixed: White and Black Caribbean (0.21 per cent).

2. Health conditions and generic health status

A key source on generic health status, the Policy Studies Institute Fourth National Survey of Ethnic Minorities (1993-1994), asked several questions about general health. Pakistanis and Bangladeshis were 50 per cent more likely to have described their health as fair or poor compared with whites. Caribbeans were also more likely than whites to have reported fair or poor health.

3. Women's health

Evidence suggests that ethnic minority women, especially Pakistani and Bangladeshi women, may have unmet family planning needs, use of contraception amongst those at risk of pregnancy being lower.

There is some evidence to suggest that there may be differences in the quality of antenatal care received by women from ethnic minority groups. One study found no statistically significant differences in the prevalence of domestic violence across ethnic groups (white, black, Asian, other), black women being least likely to ever have experienced physical violence.

4. Children and young persons' health

Analysis of statistics on stillbirths and infant deaths registered in England and Wales shows that in 2000, babies of mothers born in Pakistan had an infant mortality rate of 12.2 per 1,000 live births. This rate was higher than babies of mothers born in any other country and double the overall infant mortality rate (5.5 per 1,000 live births).

On measures of self-reported health for children aged 2 to 15, the 1999 Health Survey for England (HSE) reported that Indian, Chinese, and especially Pakistani and Bangladeshi children were less likely than children in the general population to report any longstanding illness. Findings on the prevalence of childhood accidents in different ethnic groups varies across national surveys and research studies. The 1999 HSE reported that annual major non-fatal accidents amongst children aged 2 to 15 were highest in the general population and in the Black Caribbean group, as were minor accident rates although showing greater variation across groups. African Caribbean girls are more likely to be overweight and African Caribbean and Pakistani girls are more likely to be obese than girls in the general population. Indian and Pakistani boys were more likely to be overweight.

5. Mental health

With respect to mental health, the EMPIRIC (Ethnic Minority Psychiatric Illness Rates in the Community) survey found that Black Caribbeans do not have significantly higher rates of psychotic illness than other groups. Although the rate of psychosis was estimated to be twice as high in the Black Caribbean group compared with the white group, the difference was not statistically significant. Moreover, though rates were low for Bangladeshi women and high for Pakistani women and Irish men, there were no marked differences in Common Mental Disorders (depression, anxiety, mixed anxiety and depression disorder, phobia, obsessive compulsive disorder and panic disorder) between the groups. Suicide rates are higher for men born in Scotland and Ireland and young Asian women. High rates of inpatient admission and of compulsory psychiatric admission have been reported amongst black groups and black patients also have more complex pathways to specialist care. Studies have identified a number of barriers to accessing services, including racism and discrimination.

6. Chronic conditions

Disease incidence data by ethnic group for coronary heart disease (CHD) are lacking but shows south Asians have moderately higher rates. There are important differences in the burden of illness across the different south Asian groups, with Pakistani and Bangladeshi groups having the highest rates. Adjusting for occupationally based social class accounts for some but not all of these differences. The latest data show that the highest mortality ratios for CHD occur amongst those born in the Indian subcontinent, although Standard Mortality Ratios (SMRs)¹ are not usually reported for the different south Asian country of birth groups. Mortality data by ethnic group are not collected. While the causes of higher CHD amongst south Asians are not fully understood with respect to the known risk factors of high blood pressure, lipids, smoking, central obesity, and insulin resistance, the contribution of socio-economic position is likely to be key and of a greater magnitude than hitherto reported. Only one study has comprehensively assessed ethnic differences in equity of access with respect to invasive management, finding that south Asian patients were less likely than white patients to receive coronary revascularisation.

Few studies are available of cancer incidence by ethnic group. There is evidence that south Asian incidence rates (for all sites combined) are significantly lower than for non-south Asians. However, rates for childhood and early adulthood cancer were similar or higher than non-south Asian rates. South Asian rates were significantly higher than non-south Asian rates for Hodgkin's disease in males, cancer of the tongue, mouth, oesophagus, thyroid gland and myeloid leukaemia in females, and cancer of the hypopharynx, liver and gall bladder in both sexes. Other studies report a low incidence of colorectal cancer amongst south Asians but significantly higher rates of oral cancer amongst south Asians and nasopharyngeal cancer amongst the Chinese. Mortality ratios for lung cancer are elevated for men and women born in Scotland and Ireland but low in both genders in other migrant groups; generally low mortality ratios for breast cancer are found in all the migrant groups. While no studies of variations in prostate cancer rates between ethnic groups have been conducted in the UK, there is some indicative evidence relating to mortality and considerable evidence from other countries that suggest that rates are substantially higher in the black groups. There have been no comprehensive studies of equity of access to cancer services for minority ethnic groups but the third of the national surveys of NHS patients suggests many areas of disadvantage. Some studies also report low uptake of breast and cervical screening in minority ethnic groups.

1. The observed number of deaths relative to the number expected if national age and sex specific mortality rates are applied, usually expressed relative to an average of 100.

SMR's for cerebrovascular disease are higher than the national average amongst all migrant groups for both men and women. The odds ratio of being hypertensive among older adults after controlling for confounding factors is higher in black men, black women, and south Asian men than in their white counterparts.

7. Disability and learning difficulties

Many studies have reported low uptake of services by minority ethnic adults with disabilities. A higher prevalence of learning difficulties in south Asian communities has been reported which is likely to be related to a complex set of factors including high levels of material deprivation, poor access to maternal health care, diagnostic misclassification, and higher rates of environmental or genetic risk factors.

8. Injury

National surveys show that the overall relative risk of having an accident is much lower for all ethnic minority groups than the white group (but not statistically different in the case of the Chinese). However, mortality data show elevated rates for men born in Scotland, Ireland, and the Caribbean and in Pakistani and Irish migrant children.

9. Diabetes and renal complications

Many studies have reported a much higher prevalence of diagnosed non-insulin dependent diabetes (type 2 diabetes) among south Asians. Mortality directly associated with diabetes amongst south Asian migrants is around three and a half times that in the general population; those born in the Caribbean have a similar excess, recent data reporting a rate three and a half times the national rate among men and a sixfold excess amongst women. Diabetic nephropathy and end stage renal failure are significantly more common in south Asian diabetics than in white diabetics: relative risks of up to 14 have been reported in studies.

10. Sexual health

The most recent statistics from the Public Health Laboratory Service's Communicable Disease Surveillance Centre provides important information on incidence of sexually transmitted infections (STIs) by ethnic group. For many STIs incidence is higher in the black groups. This reflects variations in sexual behaviour and sexual mixing and possibly inequalities in socio-economic status and access to/use of services. Since the mid 1990s the proportion of HIV-infected individuals (first diagnosis) who are Black African has risen from a quarter to a half. Research studies have identified the need for more research on the community norms, practices, and belief systems within the African community.

11. Oral health care

Studies report the under-use of dental services by the Bangladeshi population.

12. Lifestyle factors

Across all the national surveys there are substantial differences between minority ethnic groups and the white group in smoking patterns, for example, self-reported smoking prevalence amongst Bangladeshi men was 44 per cent in the 1999 HSE versus 27 per cent of men in the general population and 17 per cent in Chinese males. However, there are some significant inconsistencies in reported rates across surveys. The national surveys show substantial differences in reported prevalence of alcohol consumption compared with the white population (for example, the Fourth National Survey of Ethnic Minorities (1993-1994), found that only 4 per cent of Pakistani men reported drinking more than once a week compared to 69 per cent of white men) and also variations across the different ethnic groups. Again, there are inconsistencies. Amongst persons aged 16 to 59, one study showed that lifetime use of any drug was highest in the white group (34 per cent), followed by the black group (28 per cent), Indians (15 per cent), and Pakistani/Bangladeshis (10 per cent).

According to the 1999 HSE, Bangladeshi men and women were least likely to eat fruit six or more times a week (15 per cent men, 16 per cent women) and Pakistani men (7 per cent) and women (11 per cent) least likely to eat vegetables this often. Bangladeshi men and Pakistani and Bangladeshi women were much less likely to participate in vigorous physical activity than other groups.

13. Access to and use of services

Surveys and other studies have reported wide variations by ethnicity in the use of treatment and preventive services. While south Asians and African Caribbeans are more likely than the white group to have consulted their GP, for example, and at least as likely after differences in their health have been taken into account, studies consistently show the Chinese to be under-utilisers of this service.

14. Wider determinants of health

With respect to wider determinants of health, Indians, African Asians and Pakistanis have the highest levels of owner-occupation, followed by whites and Chinese, with Caribbeans and Bangladeshis having the lowest levels of owner-occupation. Data from the Quarterly Labour Force Survey show that white people are much more likely to be economically active (in employment or seeking jobs) than minority ethnic groups, with the exception of 'black other' women who have the highest female economic activity rates. Bangladeshi, black, and Pakistani pupils achieve less well than other pupils at all stages of compulsory education.

II. Health and Social Care Interventions

There are examples of good practice in a wide range of health care interventions for minority ethnic groups. There are, too, a number of good quality studies reporting on these interventions, including a number of randomised controlled trials (RCTs), although these mainly focus on US settings.

III. Recommendations

Based on this review of the literature on the health beliefs, health status, and use of services in the minority ethnic group population, and of appropriate health care interventions, a number of recommendations for policy and practice are put forward.

Data issues

1. Ethnic monitoring/data collection should be mainstreamed across all services and the needs of minority ethnic groups should be routinely addressed in health equity audits and health impact assessments.
2. Examples of effective interventions and good practice are limited and inconsistently reported. There is no central repository of updated, easily accessible good practice. The systematic collection of a minimum dataset on these examples in Wales and the UK generally is needed.

Preventive interventions

3. With respect to interventions to improve the uptake of cervical screening, the strongest evidence suggests that minority ethnic women may be more responsive to small, culturally sensitive group education rather than broad-based community strategies. The use of lay health educators, in particular, may be promising although resource intensive.
4. While there is a paucity of robust evidence, uptake of breast screening amongst minority ethnic women may be improved by a GP endorsement letter, translated literature including multilingual leaflet, and language support by linkworkers. Findings with respect to personal contact through a home visit are inconsistent.
5. Brief episodes of repeated breast self examination instruction may also be effective.
6. Small informal discussion classes emphasising the benefits – and giving practical advice – may be particularly effective in helping to increase the number of women from minority ethnic groups who breastfeed.

Coronary heart disease (CHD)

7. The development of a local evidence base through surveys and focus groups is needed.
8. Interventions that involve at risk communities and survivors of CHD, multi-agency partnerships, the innovative use of media including audio cassette tapes, video drama, and community radio/TV, the creation of infrastructures for community involvement, peer education schemes with accreditation, and training programmes for health professionals appear to be effective.

Diabetes

9. Continuing research and consultation with community members is needed to identify barriers to optimal self-care.
10. The use of pictorial flashcards in a one-to-one education programme may increase knowledge of the condition and self-caring behaviour.
11. The development of integrated, multi-professional services, the use of community-based diabetes specialist nurses to support primary health care teams, the employment of ethnic linkworkers, and the provision of accredited training for Asian diabetes support workers are identified as elements of good practice.

Mental health

12. The following have been identified as good practice in the provision of mental health services for minority ethnic groups: establishing trust between project managers and the communities they serve; strong leadership; a strong sense of community care, according with a preference for treatment in this setting by members of black and minority ethnic groups; open referral systems; adequate provision of social workers and supervisory staff; commitment to the maintenance of patient contact with patients' families and/or peer groups; a commitment to the eradication of fear in the therapeutic encounter; and a focus on social inclusion with respect to relationships, education, and employment.

Sexual health

13. There is some evidence to suggest that small group interventions delivered at the community level can be effective in influencing the sexual health and risk behaviours of members of black and minority ethnic groups.
14. Given cultural differences, specific impact and outcome evaluations of interventions are needed amongst the Black African population.

Lifestyle interventions

15. There is some evidence of the effectiveness of exercise on prescription schemes for south Asian women, especially where there is special provision, affordable costs, childcare facilities, and cultural codes of conduct.
16. There is some evidence for the effectiveness of brief behavioural counselling in general practice on the consumption of fruit and vegetables amongst adults in ethnically mixed inner city areas.
17. In relation to smoking, the training of bilingual peer educators to run smoking cessation services; the use of community-based stop smoking clinic services sited in youth, community, and neighbourhood centres; the use of trained community pharmacists, practice nurses, and health visitors to provide smoking cessation services in local pharmacies, drop-in and day centres for homeless people, and people's homes; and working with Muslim communities during Ramadam through the involvement of imams are all reported as good practice. Comprehensive evaluations

are limited and indicate that plays, poster and media campaigns, purpose designed leaflets, community outreach workers, referral to local tobacco cessation services, and the encouragement of contact with language specific help lines can all be effective.

18. Outreach work by members of the minority ethnic community, the use of video projects to gather views, and the use of bilingual, volunteer 'community interactors' to teach drug education to families may all be effective in reducing drug misuse.

Generic good practice across service settings

19. Walk-in centres – where patients can be seen without an appointment – could be more attractive to minority ethnic groups (but findings are awaited from national evaluations).
20. Barriers to accessing out-of-hours services for members of minority ethnic groups need to be addressed, including lack of awareness of out-of-hours interpreting services.
21. Campaigns are needed to make members of minority ethnic groups more aware of services like NHS Direct (as there is evidence of less awareness and under-use).
22. There is evidence that multi-lingual touch screens may be a particularly effective method for providing health information in appropriate languages to members of minority ethnic groups.
23. Linkworker and bilingual health advocacy (including interpreting) programmes have been demonstrated to have beneficial effects in a range of settings, including antenatal and infant care.
24. Further replication of the community mothers' programme in a range of minority ethnic groups is now supported.
25. Given that interpreting skills are scarce in the NHS, the use of rapid access remote interpreting services and primary care based advocacy and interpreting (including out-of-hours) services, operated on an open referral system, need to be evaluated.

I. Health Status, Behaviour, Wider Determinants of Health and Use of Services

I. Background and policy

I.1 The size and location of the minority ethnic group population in Wales

The 2001 Census recorded a total population in Wales of 2,903,085 persons, 97.9 per cent of whom were white and 2.1 per cent from minority ethnic groups (Table 1). The largest minority ethnic group was Pakistanis (0.29 per cent), followed by Indians (0.28 per cent), Chinese (0.22 per cent), and Mixed: White and Black Caribbean (0.21 per cent).

Table 1. The ethnic group composition of the population of Wales.

Ethnic group	Per cent of total population (n=2,903,085)	Per cent of population of Cardiff (n=305,353)
White – British	95.99	88.32
White – Irish	0.61	0.90
White – Other	1.28	2.36
Mixed – White & Black Caribbean	0.21	0.80
Mixed – White & Black African	0.08	0.34
Mixed – White & Asian	0.17	0.43
Mixed – Other Mixed	0.15	0.43
Asian/Asian British – Indian	0.28	1.25
Asian/Asian British – Pakistani	0.29	1.40
Asian/Asian British – Bangladeshi	0.19	0.83
Asian/Asian British – Other Asian	0.12	0.47
Black/Black British – Caribbean	0.09	0.44
Black /Black British – African	0.13	0.72
Black/Black British – Other Black	0.03	0.12
Chinese	0.22	0.60
Other ethnic group	0.18	0.60
Per cent population identifying themselves as Welsh ¹	14.39	13.17

Source: 2001 Census.

Note: ¹ People identifying themselves as Welsh appear in the final row; they are also included in the ethnic group proportions.

The unitary authority with the highest proportion of its population in minority ethnic groups (that is, other than white) is Cardiff (8.42 per cent), followed by Newport (4.83 per cent), The Vale of Glamorgan (2.16 per cent), Swansea (2.15 per cent), and Ceredigion (1.39 per cent).

Compared with the 1991 Census, there were increases in the proportion of Indian, Pakistani, Bangladeshi and Chinese people, and 0.6 per cent classified themselves in 2001 as of mixed ethnicity (a category not included in the 1991 Census question).

The 2001 Census asked a question on religion for the first time. By far the largest religious group in Wales was Christian (71.9 per cent). The other groups being Buddhist (0.2 per cent, n=5,407), Hindu (0.2 per cent, n=5,439), Jewish (0.1 per cent, n=2,256), Muslim (0.7 per cent, n=21,739), Sikh (0.1 per cent, n=2,015), other (0.2 per cent, n=6,909), no religion (18.5 per cent), and religion not stated (8.1 per cent).

In 2001 96.8 per cent of the population of Wales was born in the UK, 1.3 per cent born elsewhere in the European Union (including Republic of Ireland), and 1.9 per cent outside the European Union.

1.2 The national policy context

A major policy change that has impacted on all public and statutory organisations is the Race Relations (Amendment) Act 2000 which has introduced major changes to the 1976 Act. The legislation now covers all public functions, gives public authorities a statutory duty to promote race equality, and gives the Commission for Racial Equality (CRE) a new power to enforce compliance.

1.3 The policy context in Wales

The Welsh Assembly Government has expressed a commitment to reducing inequalities in health, including those for ethnic minority and marginalised groups in Wales in a number of recent reports and policy statements. This was demonstrated in the consultation document Well Being in Wales (Welsh Assembly Government, 2002a) which highlighted the specific needs of disadvantaged groups such as Travellers and black and minority ethnic communities and the need to improve the health of disadvantaged groups. This builds on the foundation set by the consultation document Better Health Better Wales (National Assembly for Wales, 2000a) which also gives a commitment to reduce health inequalities faced by minority ethnic groups in Wales. The NHS Plan for Wales recognised the need for health services to meet the needs of local people and for them to be delivered in culturally appropriate ways (National Assembly for Wales and NHS Wales, 2001). The Chief Medical Officer's Report for 2001/2002, Health in Wales (National Assembly for Wales, 2002), too, emphasises the disproportionate impact of health inequalities on minority ethnic and marginalised groups. Wales has representation on the US/UK Collaborative Initiative on Racial and Ethnic Health through the NHS Centre for Equality and Human Rights (formerly known as the NHS Wales Equality Unit).

Amongst specific initiatives, the Primary and Secondary Care Race and Health Projects (which began in August 2000) aimed to determine the primary and secondary care needs of black and ethnic minorities through a process of consultation and collaboration. Both of these were undertaken by the All Wales Ethnic Minority Association (AWEMA) and are now completed. Other policies to address inequalities (including those based on ethnicity) include the Welsh Assembly Government's 'Communities First'¹ programme, a comprehensive approach to area-based regeneration which applies to many of Wales' most deprived communities, healthy schools initiatives, health alliances and community food projects.

1. http://www.wales.gov.uk/themessocialdeprivation/content/comfirsthome_e.htm

There have also been collaborative initiatives with bodies like the Wales Commission for Racial Equality: a joint conference (CRE, Gwent Healthcare NHS Trust and NHS Equality Unit) on 'Creating a culturally competent service: exploring race equality in clinical governance'; collaborations between the CRE, North Wales Race Equality Network, and various health trusts in developing effective race equality schemes in the field of health; public forums held by the Wales Social Inclusion Group; and the launch of the Welsh Assembly Government's eye care initiative², the free eye health examination scheme for people at risk of eye disease (which has an ethnic minority focus).

In addition, there is a significant focus on the health of minority ethnic groups at a local level. The Welsh Assembly Government funded SHARP (Sustainable Health Action Research Programme)³ has funded seven projects across Wales for a period of five years (2000-2005). Some of these projects have an ethnic minority focus, for example: 'Barefoot' Health Workers Project, a project to support the health improvement of Somali, Yemeni, and Bangladeshi communities in the Butetown/Grangetown area of Cardiff; the Riverside element of the Triangle Project, a programme to support Local Health Alliances in Cardiff, Merthyr, and Powys in tackling health inequalities. Local initiatives have also been stimulated by the Assembly Government's Inequalities in Health Fund (IHF)⁴ for assisting disadvantaged communities, including support for action to improve access to health services for people from black and minority ethnic groups (Hutt, 2002). The Fund is supporting a total of 67 projects that are contributing to the standards of the NHS Framework for Coronary Heart Disease (CHD). Action to reduce risk factors for CHD (61 per cent); primary care action to identify those at risk for assessment/treatment (55 per cent); high quality care for everyone with an acute episode of CHD (13 per cent); and identification and treatment for those with heart failure (3 per cent). All the projects have primary care involvement through individual practices or via Local Health Boards (LHBs), some of which focus on minority ethnic groups.

At a local level a number of LHBs have initiatives focussing on black and minority ethnic communities, some of which include IHF projects. For example, the Cardiff Local Health Board's Coronary Heart Disease and Diabetes Project ('Heartlink') is an IHF project offering effective treatment and advice to individuals who are at increased risk of heart disease. The project's community focus is to raise awareness and undertake opportunistic screening sessions (taking measurements of individual's risk of developing CHD including family history, blood pressure, blood glucose levels, height and weight, and smoking status) with black and ethnic minority communities who reside in the Butetown, Grangetown and Riverside areas. Targeting is undertaken in the particular communities as well as mosques, temples, and community centres. Newport LHB has a programme of work addressing the promotion of equitable access to services, including the identification of potential barriers like language and communication; the Ethnic Minority Advisory Forum, a multi-agency forum is also concerned with developing appropriate services. The Community and Primary Care Nutrition Project is addressing the nutritional needs of specific groups locally, including people from minority ethnic groups. In addition there is some targeted work on specific conditions such as diabetes, including awareness days.

With respect to the evidence presented in this report, there are few research studies on minority ethnic groups that have been conducted in a Welsh context. Those that have been identified in the literature have been cited. Moreover, Wales has not had a dedicated national health and lifestyle survey focussing on minority ethnic groups, such as the Policy Studies Institute's Fourth National Survey of Ethnic Minorities (1993-1994) and the 1999 Health Survey for England (HSE). Consequently, much of the evidence presented relates to England. In some cases, such as the national surveys, this evidence is based on representative samples of minority ethnic groups drawn from across the country. In others, as

2. <http://www.eyecarewales.org/>

3. <http://www.cmo.wales.gov.uk/content/work/sharp/index-e.htm>

4. <http://www.cmo.wales.gov.uk/content/work/inequalities-in-health-fund/index-e.htm>

in some of the specific research studies, the populations are from metropolitan or inner city areas. Thus, the paucity of references to studies of the health of minority ethnic groups in Wales, including those living in rural areas, represents a gap in the evidence base rather than an undue focus on the other literature.

2. Health conditions and generic health status

2.1 Health conditions

Historically, much attention has been accorded to specific diseases (such as sickle cell and thalassaemia) that affect the minority ethnic group population disproportionately, at the expense of research on the main causes of morbidity and death in minority ethnic groups, that is, cancers and cardiovascular disease. This has begun to be addressed, although there is still a dearth of research studies that focuses on these conditions in minority ethnic groups. In the 1990s, national surveys by the Health Education Authority (HEA), Policy Studies Institute, and Department of Health produced a substantial body of research findings on risk factors for these main causes of poor health and also on the use of health services. However, there remain many major areas where knowledge is either substantially lacking, for example, data on the incidence of coronary heart disease and cancers by ethnic group, or fragmentary (mortality by cause for different ethnic groups, the collection of data by country of birth at death registration limiting analyses to the migrant population). The following sections focus on all the main causes of morbidity and mortality, focusing on Welsh data and research literature where this is identified.

2.2 Generic health status

The 1991 Census asked a question on limiting long-term illness. Age-standardised rates were lowest for the Chinese group but rates for the white group were lower than all other ethnic minority groups. The Fourth National Survey of Ethnic Minorities (1993-1994) (Nazroo, 1997a) asked several questions about generic health status. For 'general health', Pakistanis and Bangladeshis were 50 per cent more likely to have described their health as fair or poor compared with whites and Caribbeans were also more likely than whites to have reported fair or poor health. However, Indians, African Asians and Chinese were very similar to whites. Rates of reported long-standing illness were lowest in the Chinese and African Asian groups and highest in the Caribbean, Pakistani, Bangladeshi and white groups and similar differentials were found in measures of long-standing illness that limits work. On the whole, women reported worse health than men across all of the ethnic minority groups.

3. Women's health

3.1 Family planning

Evidence suggests that ethnic minority women, especially Pakistani and Bangladeshi women, may have unmet family planning needs, use of contraception amongst those at risk of pregnancy being lower (59 per cent among Pakistani/Bangladeshi women compared with 88 per cent in white women) (Raleigh *et al.*, 1997a). A study to investigate contraceptive usage amongst women (n=269) attending for assessment for NHS termination of pregnancy at community-based assessment clinics in inner London (Price *et al.*, 1997) reported similar findings. Amongst current users of contraception, there was a higher rate of use failure in women who were born outside the UK (61.6 per cent) compared with UK women (48.6 per cent). Non-UK women were also more likely to be using natural methods of contraception and less likely to be using the pill. The majority of the group who had never used contraception did not speak English and had limited knowledge of methods of contraception, some not knowing where to obtain help and information. The investigators recommended the routine collection of data on ethnicity and preferred language to develop strategies to improve access.

However, evidence from large national surveys does not indicate barriers in access. According to the HEA Health and Lifestyles Survey (1992/93) (Rudat, 1994), 12 per cent of women in the UK-wide survey reported to have used family planning clinics in the past year, compared with 17 per cent of African Caribbean women, 11 per cent of Indian and Pakistani women, and 16 per cent of Bangladeshi women.

3.2 Maternity and infant care

Several local studies have assessed the feeding and weaning practices of Asian babies born to mothers living in England (Harris *et al.*, 1983; Warrington and Storey, 1988; Duggan *et al.*, 1996). They suggest that early feeding practices may be contributing in part to these babies not achieving their full growth potential. The most comprehensive evidence is from a survey commissioned by the Department of Health from the Office for National Statistics (ONS) in 1994 to assess the feeding practices from birth to 15 months from a nationally representative sample of infants from Bangladeshi, Indian and Pakistani communities from across England.

This survey collected data for 2,382 mothers in all (Thomas and Avery, 1997; Watt, 2000). The incidence of breastfeeding was much higher for Asian mothers (90 per cent Bangladeshi, 82 per cent Indian, and 76 per cent Pakistani mothers) compared with a small sample of white mothers living in the same areas, 62 per cent of whom had ever breastfed. However, there were important differences in the duration of breastfeeding. Of mothers who started to breastfeed, Pakistani and Bangladeshi mothers ceased breastfeeding much sooner than either Indian or white mothers. At 4 months, of those who started to breastfeed, 39 per cent of white, 34 per cent of Indian, 25 per cent of Bangladeshi, and 21 per cent of Pakistani mothers were still breastfeeding, whilst 10 per cent of Bangladeshi, 24 per cent of Pakistani, 18 per cent of Indian, and 38 per cent of white mothers reported that their babies were only ever bottle fed. At 15 months old at least 90 per cent of the Asian children and 75 per cent of the white children were still using a bottle some of the time. Moreover, Bangladeshi mothers were most likely to add something sweet to their baby's bottle, for example, baby rusks, baby rice or cereals. Watt (2000) concluded that up to 5 months old Bangladeshi and Pakistani babies may consume a diet higher in non-milk extrinsic sugars than white and Indian babies. These findings were similar to those in an earlier small local survey that revealed that most inner city Asian infants from Leeds were still feeding from a bottle at the age of 2 years and that two thirds of the milk feeds were sweetened (Williams *et al.*, 1989).

There is some evidence to suggest that there may be differences in the quality of antenatal care received by women from ethnic minority groups. Rowe and Garcia (2003) undertook a systematic review of social class, ethnicity and attendance for antenatal care in the United Kingdom and identified five studies. They report that 'the evidence for an association between ethnicity and late or poor attendance for antenatal care may be slightly stronger than for social class'. Petrou *et al.* (2001) and Kupek *et al.* (2002) suggest that women of south Asian origin are more likely to initiate care later and have fewer antenatal visits. Three earlier studies of poorer quality (Clarke and Clayton, 1983; Chisholm, 1989; Firdous and Bhopal, 1989) report similar findings. There are many US studies that report an association between minority status and the late initiation of prenatal care.

The reasons for late booking amongst ethnic minority women have not been fully explored but may include barriers perceived by the woman, such as language and cultural issues. There may also be institutional/provider barriers to equitable access for such women, including institutional racism. For some groups, especially Black Africans, high levels of geographical mobility may also result in late booking.

Further, in another systematic review, Rowe *et al.* (2004) also suggest that south Asian women are less likely to be offered and to receive prenatal screening, again indicating that there may be inequity in access to antenatal care for women from minority ethnic groups.

The use of some obstetric interventions varies by ethnic group, several studies reporting such differences in the use of caesarean section, particularly the use of higher rates in black women (Ventura *et al.*, 2001; Cleary *et al.*, 1996; Vangen *et al.*, 2000). The National Sentinel Caesarean Section Audit (Thomas and Paranjothy, 2001) reported that caesarean section rate was higher in Black African women (31 per cent) and Black Caribbean women (24 per cent) than white women (21 per cent) and women from other ethnic groups (20 per cent). Adjustment for other risk factors did not remove this association. Differences in maternal medical conditions explain some of the variation, this being the primary indication for caesarean section for 5 per cent of Black African women, 3 per cent of Black Caribbean women, and 2 per cent of other women. There was also a higher proportion of caesarean section rates for foetal distress for Black African (29 per cent) and Black Caribbean (32 per cent) women than for all other women (22 per cent).

The maternal mortality rate has long been recognised as an indicator of the quality of maternity care. Drife (2003) reports findings from the Confidential Enquiry into Maternal Deaths in the United Kingdom (2001), which first examined the effect of ethnic origin in the 1990s. In 1994-1996 black women had three times the risk of death compared to white women, with Asian women somewhere between. However, in 1997-1999 it was Asian women whose mortality rate was three times that of white women, with black women between. The enquiry found that no single disease or group of diseases accounted for this increase but that: 'in some cases, the care received by women from ethnic minority groups was of an exceptionally high standard. In other cases it was poor. Some of these women were recently arrived immigrants pregnant on arrival in the UK and many did not speak English. Several were late in booking and others were poor attenders at antenatal clinics. A number constantly moved address during their pregnancy making community follow up difficult'.

3.3 Domestic violence

A study undertaken by Richardson *et al.* (2002) found no statistically significant differences in the prevalence of domestic violence across ethnic groups (white, black, Asian, other), black women being least likely to ever have experienced physical violence. Other studies (British Medical Association, 1998) also report a similar prevalence across the different ethnic groups. However, there are a number of issues specific to minority ethnic women. Such women may face greater difficulties in seeking protection from domestic violence because of the experience of racism and possibly low expectations (Henwood, 2000). Difficulties for women being abused may also arise from erroneous assumptions and attitudes of some people working in health care agencies about the cultural norms of different ethnic groups. For example, about the acceptability of domestic violence within some cultures, the mechanisms which exist to deal with it, and stereotyped assumptions about the roles of men and women in the different ethnic communities (British Medical Association, 1998).

Only one report of interventions addressing domestic violence that include minority ethnic groups has been identified. Burton *et al.* (1998) have reported on the Domestic Violence Intervention Project which encompasses a Violence Prevention Project working with men and a Women's Support Service working with partners of men and women who self refer. The Women's Support Service, a proactive approach where the service made initial contact, was effective in reaching women from minority ethnic groups who currently under-use other types of provision.

3.4 Forced marriages

A particular form of domestic violence against women is that of forced marriages. A Working Group on forced marriages was established by the Home Office in August 1999 and is working towards a strategy to protect women who are forced to marry against their will. The working group, which undertook its work in the broader context of government policies on domestic violence, family breakdown and social exclusion, has now reported (Home Office, 2000). It draws a clear distinction between arranged marriages – where the families of both spouses take a leading role in arranging the marriage but the choice whether to accept the arrangement remains with the individuals – and forced marriage – in which at least one party does not consent to the marriage and some element of duress is involved. Most cases involve young women and girls aged 13 to 30 years, although there is evidence to suggest that around 15 per cent of victims are male. Around 200 cases of forced marriage are reported to the Foreign and Commonwealth Office each year but probably many others are not reported. Although the majority of cases of forced marriage in Britain involve south Asian families, cases also occur in families from east Asia, the Middle East, Europe, and Africa. Some cases involve an overseas element and some take place exclusively within the UK. Guidelines have now been issued for the police to deal with cases of forced marriage and health care professionals will need to take these into account in developing protocols for dealing with domestic violence.

3.5 Screening

There is only limited evidence on participation rates in cervical screening among different ethnic groups, mainly from an early stage in the programme. The strongest evidence of low uptake comes from the HEA Health and Lifestyles Survey (1992/93) (Rudat, 1994), although caution is required in interpreting findings as the minority ethnic group sample was drawn from inner city areas and the UK sample from all areas. Amongst the UK sample of 16 to 74 year old women, 60 per cent reported to

ever have been screened for cancer of the cervix (in response to the question 'Have you ever had any screening for any type of cancer? If yes, What type of cancer?'). Rates were lower in all the minority ethnic groups, substantially so in the case of the south Asian groups: African Caribbean (54 per cent), Indian (37 per cent), Pakistani (32 per cent), and Bangladeshi (28 per cent). When women were specifically asked if they 'Had ever had a cervical smear test?', significantly higher rates were reported, 15 per cent of UK wide women reporting never to have had a smear compared with 13 per cent of African Caribbean women but 30 per cent of Indian women, 46 per cent of Pakistanis, and 60 per cent of Bangladeshis (uptake being particularly low in the youngest and oldest age bands of south Asian women).

Findings from other studies include a range of uptake rates, not all low. A study of cervical cancer screening coverage of south Asian women in Wakefield (Sutton *et al.*, 2001) found only small differences: 67 per cent of south Asians and 75 per cent of non-Asians had acceptable (not overdue) cervical screening histories ($\chi^2=13.75$, $p<0.001$). Similarly, a comparison of uptake of cervical screening among Asian and non-Asian women aged 50 to 64 living in the same restricted geographical area of Oldham, reported no difference in response to a test invitation (uptake, 61.5 per cent in Asians and 60.6 per cent in non-Asians), although non-Asian women were more likely to have had a previous smear (Bradley and Friedman, 1993). Very low rates are reported for the Chinese in other surveys. Sproston *et al.* (1999), for example, reported that only 20 per cent of the Chinese women sampled (unweighted base, $n=542$) had used this service within the last year. In a study of variations in cervical smear uptake rates across 126 general practices in Merton, Sutton and Wandsworth (Majeed *et al.*, 1994), uptake rates varied from 16.5 per cent to 94.1 per cent and were negatively correlated with the estimated percentage of the practice population from ethnic minority groups (and also with variables associated with social deprivation).

Reasons for low uptake of screening are likely to be complicated. In a survey of the cervical screening service in a London district, Doyle (1991) reported easily identifiable differences between ethnic minorities and women from UK backgrounds related to the choice of screening venues and indicators of more fundamental problems of access to and equity in the service for some minority ethnic groups. In the UK, the reluctance of Asian women to show for cervical screening for cultural reasons has been reported by Bentham *et al.* (1995). Naish *et al.* (1994) investigated the factors that deter ethnic minority women in east London from attending their GP for cervical screening through established community groups and specially convened groups of Bengali, Kurdish, Turkish, Urdu and Punjabi, and Chinese speaking women. Administrative and language barriers, inadequate surgery premises, and concerns about sterility were more important than attitudinal barriers to cervical screening (e.g. fear of cancer) which some reported were not deterrents. Moreover, once these women understood the purpose of the test and the call and recall procedures, they were enthusiastic about cervical cytology screening.

Several studies report lack of knowledge about cervical screening. Using focus groups amongst smear takers and minority ethnic women, Chiu *et al.* (1999) report a divergence in perceptions held by these groups regarding cervical screening, contributing to negative experiences and dysfunctional clinical communication. The majority of women who had undergone screening did not understand the purpose of the programme or the procedure of the test, a situation compounded by language difficulties and practices like opportunistic screening at postnatal examination. Similar findings were reported by Box (1998) in a questionnaire survey ($n=172$) and in-depth interviews ($n=17$) with black and ethnic minority women in Newham, east London. Many of these women were unaware of the screening service or held misconceptions about the smear test. Initial or repeat attendance for screening was inhibited by fear, embarrassment, previous negative experiences, and language difficulties. According to a study amongst Asian women in Leicester (McAvoy and Raza, 1988), knowledge about cervical cytology was poor, only half of the subjects stating that they knew what a cervical smear was and over three quarters being

unaware of how often a woman normally should have a test. Of the women who responded, 59 per cent said that they had never had a cervical smear, and only around a third (35 per cent) of those at risk claimed to have had one.

Recent research into attitudes towards HPV (human papillomavirus) testing among Indian, Pakistani, African Caribbean, and white British women in the context of cervical cancer prevention suggests that the psychosocial impact may be a barrier (McCaffery *et al.*, 2003). Some women expressed anxiety, confusion and stigma about HPV as a Sexually Transmitted Infection (STI) and concern (in cases of positive testing) about their sexual relationships in terms of trust and fidelity. The research demonstrated the need for information about HPV and public education for the whole community.

Few studies have reported uptake rates for breast screening by ethnic group. Again, one of the main sources is Rudat (1994), who reported figures and likely underestimates (in response to the question 'Have you ever had any screening for any type of cancer?') showing similar differences to those for cervical screening: UK population, 21 per cent, African Caribbean, 14 per cent, Indian and Pakistani, 7 per cent, and Bangladeshi, 4 per cent. A multivariate analysis of small area data for four east London inner city boroughs showed that lowest uptake rates were found in wards with a greater than 20 per cent concentration of Bangladeshi women (Boomla, 1994). Very low rates are reported for the Chinese in other surveys. For example, Sproston *et al.* (1999) reported that only 9 per cent of the Chinese women sampled had used this service within the last year.

There has been little research on reasons for low uptake by women from minority ethnic groups. There may be difficulties in understanding the letter of invitation to the local NHS mammography screening unit (although now leaflets about the breast screening programme are available in 17 languages). For example, Rudat (1994) reported that only 47 per cent of Indian, 15 per cent of Pakistani, and 10 per cent of Bangladeshi born women aged 50 to 74 in the HEA Health and Lifestyles Survey (1992/93) could speak English and fewer could read it. Focus group research by Pfeffer (2004) has addressed issues of compliance in an ethnically diverse and socially deprived population in east London. Factors affecting uptake were reported to be complex, including women's ideas about the aetiology of breast cancer, fear of the diagnosis, beliefs about breast cancer and the value of early diagnosis, understanding of the letter of invitation and of the breast screening programme as a citizenship right, and the gender of health care professionals (as mediating different kinds of concerns including faith). A joint study by the US National Cancer Institute and the Health Care Financing Administration (NCI, 1999) showed that ethnic minority women in the United States were nearly twice as likely as white women to be unaware at what age they should start getting mammograms, and also twice as likely to be unaware that these were covered by Medicare⁵.

5. If you have Medicare and are aged 40 or older, Medicare pays for most of the cost of a screening mammogram every 12 months. If needed, Medicare will pay for a diagnostic mammogram at any time. (<http://www.cancer.gov/cancertopics/breasthealth/page2>)

4. Children and young persons' health

The main source of evidence on the health of children in minority ethnic groups is the 1999 HSE. The Fourth National Survey of Ethnic Minorities (1993-1994) asked only about the health of adults (aged 16 and over).

4.1 Generic physical and mental health

On measures of self-reported health for children aged 2 to 15, the 1999 HSE (Nazroo *et al.*, 2001) reported that Indian, Chinese, and especially Pakistani and Bangladeshi children were less likely than children in the general population to report any longstanding illness, although differences were less marked for limiting longstanding illness. Further, Black Caribbean, Indian, Pakistani, Bangladeshi and Chinese children were less likely than other groups to report having had acute sickness in the two weeks prior to the interview. However, Pakistani and Bangladeshi boys were less likely to report 'good' or 'very good' health than boys in the general population (91 per cent of whom so reported).

Two measures of psychological health were used in the 1999 HSE: the GHQ-12 (Goldberg, 1978; Goldberg and Williams, 1988), for children aged 13 to 15 and the Strengths and Difficulties Questionnaire (SDQ) (Goodman *et al.*, 1998), for children aged 4 to 15. For the GHQ-12 scores were similar across minority ethnic groups and the general population, girls scoring higher than boys in all the groups. On the SDQ, 12 per cent of boys and 8 per cent of girls in the general population had high Total Deviance scores, a similar pattern being found in the minority ethnic groups, with the exception of Pakistani boys and Indian, Pakistani, and Irish girls who were more likely to have high scores. The higher scores on these scales are indicative of poorer psychological health.

4.2 Stillbirths and perinatal and infant mortality

As ethnic group is not currently recorded on birth and death certificates, there is a paucity of data on birth outcomes stratified by ethnic group. Most studies report country of birth of mother (country of birth of parents is collected at birth registration) but this is now a poor proxy for ethnicity as a substantial proportion of fertility in minority ethnic group populations is accounted for by mothers born in the United Kingdom. Analysis of statistics on stillbirths and infant deaths registered in England and Wales, linked to their corresponding birth records, shows that in 2000 babies of mothers born in Pakistan had an infant mortality rate⁶ of 12.2 per 1,000 live births (Anon., 2001). This rate was higher than babies of mothers born in any other country and double the overall infant mortality rate (5.5 per 1,000 live births). Similarly, stillbirth⁷ and perinatal rates⁸ were significantly higher for these mothers, 9.5 and 15.4 respectively, compared with 5.3 and 8.1 overall. Rates for other groups were also elevated for stillbirths (east Africa, 8.0; rest of Africa, 9.4; Caribbean, 8.5), for perinatal deaths (rest of Africa, 14.9; Caribbean, 15.1), and for infant deaths (Mediterranean, 9.6; Caribbean, 10.4).

6. Infant Mortality Rate - calculated as the number of deaths of infants in the first year of life per 1,000 live births.

7. Stillbirth Rate - calculated as the number of stillbirths (a baby born dead after 24 weeks of gestation) per 1,000 live births and stillbirths.

8. Perinatal Mortality Rate - calculated as the number of stillbirths plus the number of liveborn babies who die before the end of the first seven days of life per 1,000 live births and stillbirths.

4.3 Tobacco and alcohol use

The 1999 HSE assessed tobacco use and exposure to tobacco smoke through self-reports among children aged 8 to 15 and measurements of the cotinine levels in informants' saliva (those aged 4 to 15) (Nazroo *et al.*, 2001). Compared with the general population (in which 19 per cent of boys and 21 per cent of girls reported ever having smoked a cigarette), Irish girls were more likely, and Indian, Pakistani, Chinese and Bangladeshi children were less likely, to report ever having smoked. With respect to saliva cotinine levels of 15 ng/ml or more, Pakistani and Chinese boys and Black Caribbean, Indian, Pakistani and Chinese girls were less likely to show high cotinine levels than the general population. Both self-reported smoking and cotinine levels increased with age across all groups, with the exception of Pakistani children and Indian girls (in whom they remained low).

Compared with the general population (in which 40 per cent of boys and 32 per cent of girls aged 8 to 15 reported ever having drunk alcohol), Indian and Chinese children were much less likely to report having drunk alcohol. Reported rates of alcohol use were especially low among Pakistani and Bangladeshi children. The prevalence of self-reported drinking increased with age, except among Pakistani and Bangladeshi children (in whom it remained low).

4.4 Asthma

Asthma is the most common chronic childhood disease in Britain and its prevalence has increased over recent decades although the reasons for this are unclear. The most robust evidence on respiratory symptoms and lung function is provided by the 1999 HSE (Nazroo *et al.*, 2001). For both boys and girls aged 2 to 15, respiratory symptoms were more common in the general population and the Black Caribbean and Irish groups than in the Indian, Pakistani, Bangladeshi and Chinese groups. Bangladeshi children were least likely to have respiratory symptoms. Lung function was assessed in those aged 7 to 15 by measuring forced expiratory volume in one second (FEV₁). For boys it was lower for Bangladeshis, Indians and Black Caribbeans than the general population and for girls lower in all minority ethnic groups except the Irish than for girls in the general population.

There is some evidence of inequity of treatment. Duran-Tauleria *et al.* (1996) assessed the influence of ethnic group on prescription of drugs for asthma among representative samples of children aged 5 to 11 years in primary schools in England and Scotland in 1990-1991. Evidence was found that children with reported asthma attacks from ethnic minority groups were less likely to be prescribed drugs for asthma and to use the appropriate method of administration. Of children with reported asthma attacks in inner city areas, 75 per cent had received a β_2 agonist (the most effective of the bronchodilators for the relief of bronchospasm) and were inhaled in 69 per cent of cases, with an even lower percentage in ethnic minority groups. Children of Afro-Caribbean and Indian subcontinent origin who had asthma were less likely to receive β_2 agonists and those from the Indian subcontinent were less likely to receive anti-inflammatory drugs. Antibiotics were less prescribed and antitussives more prescribed in children from ethnic minority groups than in white children. The investigators recommend the implementation of indicators and targets to monitor inequalities in treatment of asthma in minority ethnic groups.

4.5 Accidents and injury

Findings on the prevalence of childhood accidents in different ethnic groups varies across national surveys and research studies. The 1999 HSE (Nazroo *et al.*, 2001) reported that annual major non-fatal accidents amongst children aged 2 to 15 were highest in the general population and in the Black Caribbean group, as were minor accident rates, although showing greater variation across groups.

In an ecological study in Leicester (Tobin *et al.*, 2002), investigators reported that south Asian children were less likely than white children to utilise hospital services (attend a fracture clinic, be admitted or to have a prolonged stay) as a result of an accident. For a district with 70 per cent of its children from south Asian groups, this represents a 40 per cent lower rate of accident admissions. The reasons were likely to be related to differential exposure to accident hazards across ethnic groups rather than different thresholds of hospital attendance, as hospital utilisation rates were also lower for serious accidents in south Asian children.

Alwash and McCarthy's (1988) investigation into the severity of injuries from home accidents amongst 402 children aged under 5 treated in the Accident and Emergency (A&E) department of an inner London hospital found a strong correlation between the parent's social class and the severity of the accident but no correlation with ethnic group as indicated by the parents' country of birth.

4.6 Physical activity, diet, and obesity

The 1999 HSE (Nazroo *et al.*, 2001) assessed physical activity amongst children aged 2 to 15 in terms of, sports and exercise, active play, and walking and amongst children aged 8 to 15 for housework and gardening. The differences across the ethnic groups were not marked, the largest – for sports and exercise – being the lower rates in Indian, Pakistani, Bangladeshi and Chinese children compared with the general population. This survey also reported on anthropometric measures – height, weight, and Body Mass Index (BMI) – for children aged 2 to 15. Mean BMI was higher for Black Caribbean boys and girls and for Indian boys than for children in the general population. For Bangladeshi boys it was lower. Further secondary analysis of HSE data by Saxena *et al.* (2003) found marked differences between the ethnic groups in overweight and obesity. African Caribbean girls were more likely to be overweight [Odds Ratio (OR) 1.73, 95 per cent CI 1.29 to 2.33]. African Caribbean and Pakistani girls were more likely to be obese than girls in the general population [OR 2.74, 95 per cent CI 1.74 to 4.31 and 1.71, 1.06 to 2.76, respectively]. Indian and Pakistani boys were more likely to be overweight [OR 1.55, 95 per cent CI 1.12 to 2.17 and 1.36, 1.01 to 1.83, respectively]. The 1999 HSE did not enquire about diet in children.

4.7 Blood pressure

According to the 1999 HSE (Nazroo *et al.*, 2001), amongst children aged 5 to 15 systolic blood pressure was higher for Pakistani boys than for boys in other groups and lower for Black Caribbean girls than for girls in other groups. Diastolic blood pressure was higher in Indian, Pakistani, and Chinese boys than those in other groups and higher in Bangladeshi, Pakistani, and Chinese girls than those in other groups.

4.8 Sexual health

Low's (2002) review of the sexual health of young people from minority ethnic groups cites data (for the whole population in 1999) from the Public Health Laboratory Service and Scottish ISD(D)5 Collaborative Group that shows that some STIs are frequent amongst teenagers. Women under 20 account for 40 per cent of new cases of gonorrhoea, 36 per cent of chlamydia, 29 per cent of genital warts, 20 per cent of herpes simplex, and 2 per cent of HIV/AIDS in women of all ages. In men the proportions are much lower. Low *et al.* (2001) provide ethnic specific data for gonorrhoea and chlamydia in 15 to 19 year olds in SE London (1994-1995). The highest rates of chlamydia in women and gonorrhoea in women and men are all found in Black Caribbean teenagers, followed by black other; rates in the Black African, Asian/other and white groups being quite low by comparison. Although HIV/AIDS is not common amongst teenagers in the UK, a disproportionate number are from Black African backgrounds.

Low's (2002) review suggests that levels of contraceptive use are similar between Black Caribbean and white young women who become pregnant as teenagers and that methods of contraception amongst non-pregnant teenagers from Black Caribbean and Black African backgrounds are similar to those from white backgrounds. In women from south Asian backgrounds, education and employment influence contraceptive use, many of those who were not educated in Britain and not employed, lacking knowledge about contraception before their first pregnancy (Hennink *et al.*, 1998). In a recent survey exercise by the Teenage Pregnancy Unit, Rochdale Metropolitan Borough Council, of 2,000 14 to 15 year-olds, Pakistani girls and boys showed consistently poorer knowledge about contraception and STIs than their white counterparts (Rochdale Primary Care Trust, 2005).

Only limited data are available on sexual lifestyles, notably from Improving Sexual Health Study in south east London (Low, 2002) which focused on 16 to 25 year olds from different ethnic groups. Black African women reported much lower levels of sexual experience than either Caribbean or white women; amongst men white men had the least experience. Concurrent partnerships were common amongst all those who were sexually experienced, Black Caribbean men reporting the most concurrent partnerships. Young south Asian women are less sexually experienced than white women, although south Asian and white men are similar (Bradby and Williams, 1999).

4.9 Teenage pregnancy

The UK Government has accorded importance to a reduction in teenage conceptions, the Teenage Pregnancy Strategy target is for a 50 per cent reduction in conception rates to under 18 year olds by 2010. Guidance to local teenage pregnancy co-ordinators was issued in April 2001 to highlight the need for better tailored contraceptive and sexual health advice for young people from minority ethnic communities to access the necessary information and support to make appropriate choices about their sexual health. In 2001 the Department of Health consulted on an NHS performance indicator that measured the number of people under 18 from ethnic minorities who register with an NHS funded community clinic or GP practice which provides contraceptive services. Other recent initiatives include the collection of examples of good practice with respect to prevention issues, the commissioning by the Department of Health of research on minority ethnic young people's experience of teenage parenthood, and the commissioning of guides providing advice on working effectively with different communities on issues relating to teenage pregnancy (Department of Health *et al.*, 2002).

There are, however, information barriers to monitoring teenage conception rates amongst minority ethnic groups over time. Ethnic group is not recorded at birth registration (although ONS is currently

consulting on the introduction of this). The Birth Notification Data Set (BND) may provide this information as ethnic group is a mandatory field but the BND has only been operating for 12 months. Also ethnic group is not recorded on pregnancy termination.

There is evidence from some national surveys that some black and minority ethnic groups are at much greater risk of teenage parenthood than the national average. However, data from the Labour Force Survey, albeit based on small numbers, suggests a marked change in patterns between 1976-1982 and 1990-1996, with a substantial fall in fertility rates in all south Asian groups but stable rates in white and Black Caribbean women (although no information is available for Africans and Chinese) (Berthoud, 2001). By the 1990s teenage birth rates amongst Pakistani women had fallen by 50 per cent to 30 per 1,000, the same rate for white women. The rate for Indian women was just 7 per 1,000.

National data have not (until very recently) been routinely collected about rates of abortion in different ethnic groups for any age group. However, Low (2002) reports figures for 15 to 19 year old women (n=43,528, 11.5 per cent in minority ethnic groups, 1996-2000) from the British Pregnancy Advisory Service that carries out around a quarter of abortions in women under 20 years old in England and Wales and about half of NHS Agency and non-NHS abortions in this age group. Compared with the distribution of the teenage population, women from black ethnic groups are over-represented and those from south Asian ethnic groups under-represented. Clements *et al.* (1998) suggested that abortion rates were similar in black and white women but lower in Asian than white women in a Wessex study.

Low (2002) has reviewed the limited literature on attitudes towards teenage pregnancy, parenthood and abortion, especially the contribution of social versus cultural factors. Phoenix (1988) emphasises the similarities between young, mainly UK born black and white working class women in attitudes towards being pregnant themselves, teenage pregnancy and abortion in general. She attributes these to similarities in their experiences of growing up in the same country. In a study also carried out in the 1980s, Ineichen (1984) emphasised the influence of traditional Caribbean pro-fertility beliefs upon the attitudes of young British born Black Caribbean women. With respect to south Asian communities, Low (2002) cites the work of Katbamna (2000) who found that Gujarati and Bangladeshi women who wanted to delay conception and have small families faced conflicts with cultural and religious traditions. Further, community attitudes are critical of unmarried motherhood and less tolerant towards abortion.

4.10 The use of health services

The 1999 HSE (Nazroo *et al.*, 2001) reported that the proportion of children aged 2 to 15 who were involved in consulting a GP within the previous two weeks ranged from 5 per cent (Irish) to 16 per cent (Pakistani) for boys and 9 per cent (Bangladeshi) to 16 per cent (Indian) for girls.

The 1999 HSE also reported on dental visits. Compared with children in the general population, those in all minority ethnic groups were less likely to have visited a dentist and the differences were most marked in Pakistani and Bangladeshi children. Moreover, in all the minority ethnic groups the reason for the last visit to the dentist was less likely to be a routine check up and more likely to be due to problems with teeth than in the general population.

According to the 1999 HSE, Bangladeshi, Indian, Pakistani and Chinese boys and girls were less likely to have been to a hospital outpatient clinic in the past year than children in other groups.

Uptake of immunisation was not investigated in the 1999 HSE. However, a study undertaken by Martineau *et al.* (1997) in Newcastle amongst south Asian children found that, overall, rates of

immunisation uptake were high for all groups of children (and there were no sex differences). Indeed, south Asians in Newcastle had higher immunisation rates than Europeans. Bhopal *et al.* (1988) reported a similar finding on immunisation uptake amongst Asian children in Glasgow. Findings vary with respect to the Jewish community. Cuninghame *et al.* (1994) reported that in Hackney, uptake for all immunisations in the strictly orthodox Jewish community was not significantly different from that of the district, responding parents having positive attitudes to the value and safety of immunisations. However, in a study undertaken in Gateshead (Purdy *et al.*, 2000), rates of childhood immunisations were significantly lower in the orthodox Jewish population.

In an attempt using a matched case control study design to assess the effectiveness of BCG vaccination against tuberculosis (TB) in the first year of life in children of Indian subcontinent ethnic origin in England (Rodrigues *et al.*, 1991), BCG vaccination in infancy was found to be associated with a substantial protective efficacy but lower than has been found for the secondary school age BCG programme. The investigators conclude that vaccination of infants considered to be at relatively higher risk of TB is likely to reduce the incidence of childhood TB.

In the 1999 HSE information on prescribed medication (as well as consultation rates) was recorded. The only significant differences were the lower rates among Indian and Pakistani children compared with the general population.

5. Mental health

5.1 Prevalence

There is a lack of population based evidence on the prevalence of psychiatric illness. The most reliable estimates are based on the EMPIRIC (Ethnic Minority Psychiatric Illness Rates in the Community) Survey, carried out among ethnic minority adults aged 16 to 74 living in England in 2000 (Joint Health Surveys Unit, National Centre for Social Research and University College London, 2002). The ethnic groups covered were Bangladeshi, Caribbean, Indian, Irish and Pakistani people, as well as the general population white group for comparison.

Many studies, based largely on treatment rates, have reported that Black Caribbean people are between three and five times more likely to suffer from psychotic illness (including schizophrenia) than other population groups. The EMPIRIC survey found that Black Caribbeans do not have significantly higher rates of psychotic illness than other groups. Although the rate of psychosis was estimated to be twice as high in the Black Caribbean group compared with the white group, the difference was not statistically significant. Moreover, though rates were low for Bangladeshi women and high for Pakistani women and Irish men, there were no marked differences in Common Mental Disorders (depression, anxiety, mixed anxiety and depression disorder, phobia, obsessive compulsive disorder and panic disorder) between the groups. Across most ethnic groups women had higher rates of Common Mental Disorders than men, with the exception of the Bangladeshi and Irish groups. In general respondents across the ethnic groups were consistent in describing their mental health, factors precipitating mental illness including marital relationships and family problems, work and money problems, and racism and discrimination.

Similar findings have been reported in some of the national surveys and in local research studies. In the Fourth National Survey of Ethnic Minorities (1993-1994) (Nazroo, 1997b), estimated rates of mental illness were derived from responses to the Clinical Interview Schedule (CIS-R) (Lewis *et al.*, 1992) and Psychosis Screening Questionnaire (PSQ) (Bebbington and Nayani, 1995) questionnaires. Similar findings were reported for the three outcomes of neurotic depression, suicidal thoughts, and non-affective psychosis. Compared to the white British group, the white minority and Caribbean groups had higher rates, the Indian/African Asian and Pakistani groups had similar or slightly higher rates, and the Bangladeshi and Chinese groups had considerably lower rates. However, there were important differences by gender. Rates of neurotic disorder were particularly low for women in the south Asian groups. For psychosis, there were also significant gender variations, rates for Caribbean females being just over twice those of women in the white British group and rates for males being almost the same.

Local research studies and those focusing on particular ethnic groups report broadly similar findings. For example, Shaw *et al.* (1999) screened patients registered in general practices in central Manchester for anxiety and depressive illness using the GHQ-12 (Goldberg, 1978; Goldberg and Williams, 1988) and standardised psychiatric assessment. Of these patients, 13 per cent of African Caribbeans (95 per cent CI, 10 per cent to 16 per cent) and 14 per cent (10 per cent to 18 per cent) of white Europeans had one or more disorders based on one month period prevalences (although anxiety disorders were significantly less common among African Caribbeans and depressive disorders were significantly more common among African Caribbean women than white women). A separate study of the Chinese population in England (Sproston *et al.*, 1999) found that the proportion of people scoring 4 or more on the CHQ-12 (the Chinese equivalent of the GHQ-12: see Chan, 1985) (an indicator of possible psychiatric morbidity) was 7 per cent, considerably lower than among people in the general population (as reported, for example, in the 1995 HSE). This finding is consistent with the Fourth National Survey of Ethnic Minorities (1993-1994).

5.2 Suicide and self-harm

The evidence on suicide shows marked differences by country of birth group. Data for men aged 20 to 64 in England and Wales (1991-1993) show that rates were elevated for those born in Scotland (SMR⁹ 149) and born in Ireland (135) groups but low in the Caribbean (59), east African (75) and Indian subcontinent (73) groups (Harding and Maxwell, 1997). Adjusting for social class made very little difference to these rates. However, rates of suicide amongst young Asian women are more than twice those of young white women (Raleigh and Balarajan, 1992; Raleigh, 1996). Rates of inception of deliberate self-harm have also been reported to be much higher amongst south Asian women, especially those aged 18 to 24 (Bhugra, 2002).

Young south Asian women are a group at high risk of deliberate self-harm and suicide. Two studies have sought to identify the complex set of factors that might be contributing to these outcomes. Chew-Graham *et al.* (2002) (see also Chantler *et al.*, 2003) conducted focus groups amongst south Asian women, experiences such as racism, stereotyping of these women, Asian communities and Islam, and the concept of *izzat* (honour) in Asian family life being major influences in the lives of the participants and contributors to mental distress. Self-harm was seen by these women as a usable coping strategy to deal with mental distress. The investigators reported that services tended to be accessed only at a point of desperation rather than prior to crisis points. This need for services to be able to respond rapidly when Asian women ask for help clearly has importance in the commissioning of mental health services (see also mental health interventions that address these issues). Burr (2002) focussed in particular on stereotypes of south Asian cultures as a factor in the high rates of suicide amongst south Asian women. Focus groups and individual interviews with mental health carers revealed that cultural difference was constructed in terms of fixed and immutable categories which operated to diminish British south Asian communities and to potentially misdirect diagnosis and also treatment pathways.

5.3 The use of mental health services

The literature on the use of services for mental health problems reveals a number of important findings. A recent systematic review of studies comparing use of mental health services by more than one ethnic group (Bhui *et al.*, 2003) found higher rates of in-patient admission among black patients. Many studies have reported higher rates of admission for schizophrenia amongst the Black Caribbean population. However, King *et al.* (1994) compared annual incidences of psychosis in people from different ethnic groups amongst those who had made contact with a wide range of community and hospital services within the catchment area of a London district psychiatric hospital. The incidence ratio for schizophrenia in all ethnic minority groups compared with the white population was 3.6 (95 per cent CI 1.9 to 7.1) and that for non-affective psychosis was 3.7 (95 per cent CI 2.2 to 6.2). Raised incidences of schizophrenia were not specific to the African Caribbean population but found in all ethnic minority groups.

A significant body of research also reports higher rates of compulsory psychiatric admission amongst the black groups compared with white and other groups (Kendrick, 2003). A recent review of 33 studies found in the literature that reported rates of compulsory admission for whites and African Caribbeans or other black groups, 26 (79 per cent) reported significantly higher rates of compulsory detention among African Caribbeans (Morgan *et al.*, 2004). For example, Davies *et al.* (1996) reported that, in a representative group of people with psychotic disorders in south London, nearly half of the white patients had been detained under the Mental Health Act 1983 compared with 70 per cent and 69 per

9. SMR (Standardised Mortality Ratio) - the observed number of deaths relative to the number expected if national age and sex specific mortality rates are applied, usually expressed relative to an average of 100.

cent of Black Caribbean and Black African patients, respectively. Also, black patients were more likely than white patients to have been admitted to a psychiatric intensive care facility or prison. Bhui *et al.*'s (2003) systematic review reports a pooled Odds Ratio for compulsory admission, black patients compared with white patients, of 4.31 (95 per cent CI 3.33 to 5.58) (see also Kendrick, 2003).

Further, black patients had more complex pathways to specialist care, Bhui *et al.* (2003) finding some evidence of ethnic variations in primary care assessments. In their study of the prevalence of common mental disorders amongst African Caribbeans and Europeans, Shaw *et al.* (1999) found that medical help seeking was similar in the two groups but African Caribbeans were more likely to seek additional help from non-medical sources. A comprehensive review of 45 papers mapping variations in pathways to, and mode of contact with, mental health services between ethnic groups in the UK (Morgan *et al.*, 2004) provides some key findings in this area. Of the 26 studies that reported rates of criminal justice referral, there were no significant differences between white and African Caribbean/black patients in only five. In only four of the eleven studies reporting rates of GP involvement were there no marked differences.

5.4 Barriers

Several studies have reported barriers encountered by people from minority ethnic groups in accessing appropriate NHS care for mental health problems. Li *et al.* (1999) interviewed attenders at Chinese community centres who screened positive on the CHQ-12. The main barriers identified were language, interviewees' perceptions of symptoms somatic rather than psychiatric in origin, lack of knowledge about statutory services, and lack of access to bilingual health professionals. There were long delays before these people made contact with health professionals (mainly GPs), little use being made of community psychiatric services. Unemployment, social exclusion, widespread discrimination, and limited care and support from family and friends were commonly experienced. The investigators concluded that health advocates and better use of bilingual skills were essential to maximise the effectiveness of health professional-patient contacts. Sproston *et al.* (1999) also found an association between Chinese people scoring 4 or more on the CHQ-12 and those categorised as having a severe lack of social support.

6. Chronic conditions

6.1 Coronary heart disease (CHD)

The literature on CHD amongst minority ethnic groups is probably more extensive than that on some other major diseases (notably cancer). Moreover, there have been important reviews of the literature on such matters as risk in south Asians (Bhopal, 2000). Nevertheless, there remain a number of important gaps.

In his review of CHD risk in south Asians, Bhopal (2000) reported that only one study could potentially provide disease incidence data. Tunstall-Pedoe *et al.* (1975) reported attack rates (including recurrences) for men amongst a mainly Bangladeshi born study population. There was a 30 per cent excess but the 95 per cent CI (calculated by Bhopal) for the standardised attack rate included one (i.e. not statistically significant).

Around six studies have reported CHD prevalence in minority ethnic groups, including several of the major national surveys. In the HEA Health and Lifestyles Survey (1992/1993) (Rudat, 1994) Indians had a lower prevalence of self-reported heart disease than Bangladeshis but there were methodological weaknesses (the national sample was drawn from populations mainly living in inner city areas and the data for the general population was not directly comparable in sampling terms). In the Fourth National Survey of Ethnic Minorities (1993-1994), Nazroo's (1997a) analysis of self-report of angina, heart attack including heart murmur, a damaged heart or a rapid heart, or severe chest pain showed that while Indian and African Asian groups combined had a lower prevalence ratio for diagnosed angina or heart attack than the white population, that for Pakistanis and Bangladeshis combined was higher (prevalence ratios adjusted for standard of living being 0.67 and 1.24, respectively). There were only small and statistically non-significant differences between the white group and Caribbeans and Chinese.

The most recent data on mortality are for the years around the 1991 census. Wild and McKeigue (1997) report Standardised Mortality Ratios (SMRs) for selected migrant groups aged between 20 to 69 years of age in England and Wales in the period 1989-1992. Ischaemic heart disease (CHD) was the main cause of death for men and women for all the country of birth groups (except the relatively young female migrants from west Africa).

Amongst men:

- rates were highest for south Asia (combining Indians, Pakistanis, and Bangladeshis) (SMR 146, 95 per cent CI 141 to 151);
- rates were also elevated for east Africa (SMR 131, 95 per cent CI 118 to 145), Scotland (SMR 120, 95 per cent CI 116 to 124) and Ireland (SMR 124, 95 per cent CI 120 to 127);
- however, rates were very low for both Caribbean (SMR 46, 95 per cent CI 42 to 49) and west African (SMR 56, 95 per cent CI 44 to 70) groups.

Similar differentials were found amongst women:

- south Asia, SMR 151 (95 per cent CI 141 to 162);
- east Africa, SMR 105 (95 per cent CI 82 to 132);
- Scotland, SMR 130 (95 per cent CI 122 to 137);
- Ireland, SMR 120 (95 per cent CI 114 to 126);
- the Caribbean, SMR 71 (95 per cent CI 61 to 80);
- west Africa, SMR 62 (95 per cent CI 35 to 100).

A tabulation of SMRs by different age groups shows that differences between men in the different country of birth groups were even greater for the youngest (20 to 44) group. In comparison with data for 1970-1972, the SMRs for Caribbean migrants fell more steeply than the population as a whole, but less so for south Asian migrants.

Similar ratios are reported in other studies, the differences in mortality across the different groups persisting when adjusted for social class. Harding and Maxwell (1997) report adjusted SMRs for men aged 20 to 64 in England and Wales (1991-1993) of:

- Caribbean – 56;
- west/south Africa – 79;
- east Africa – 188;
- Indian sub-continent – 165 (150 unadjusted);
- Scotland – 121;
- Ireland – 115.

Balarajan (1996) also reported SMRs for south Asian men in the 140-150 range. Finally, Bardsley *et al.* (2000) showed proportional mortality ratios (all ages) of:

- 143 (95 per cent CI 126 to 161) for London residents born in Pakistan;
- 133 (95 per cent CI 127 to 140) for those born in India;
- 128 (95 per cent CI 112 to 144) for those born in Bangladesh.

Intermediate ratios:

- for those born in Ireland (85, 95 per cent CI 82 to 89);
- for those born in Scotland (90, 95 per cent CI 85 to 96).

As well as very low ratios for:

- London residents born in the Caribbean and West Indies (68, 95 per cent CI 63 to 74);
- London residents born in the rest of Africa (excluding eastern Africa) (85, 95 per cent CI 77 to 93).

Earlier cross-sectional studies around the time of the 1971 and 1981 Censuses also show an excess mortality for south Asians. Marmot *et al.* (1984) report an SMR for Indian subcontinent born males and females aged more than 20 years of 115 (109 to 121).

A comprehensive review of sources on the health beliefs and behaviours of south Asian communities with respect to CHD was undertaken by Beishon and Nazroo (1997). Their main finding was that most groups appeared well informed on the factors related to cardiovascular health and that differences based on gender and generational status were greater than those between ethnic groups. In general, women had less access to health related information and were less well informed than men, especially Bangladeshi women, and this was also true of non-UK-born south Asians. The greatest need was found in non-UK-born Bangladeshi women who often had limited English language and literacy skills and rarely attended community centres or mosques. Culture and religion were also important determinants of health-related behaviour. South Asian respondents were often unaware of the benefits of taking appropriate exercise. Cost, time and accessibility were also important factors.

With respect to smoking, even those smokers who were not convinced of the health risks wanted to cut down or give up smoking but self-efficacy was an important consideration. Smokers had little

confidence in their ability to stop smoking so the introduction of interventions that develop confidence in ability to change health-related behaviour may be important. Indeed, the systems of health beliefs relating to CHD in general encompassed a sense of personal vulnerability, balancing risks, judging relative benefits and risks, and uncontrollable risks which were not mutually exclusive and showed little difference between the ethnic groups.

The investigators concluded that clearer messages needed to be given, targeted at the specific sections of the south Asian communities most in need of it and who experience most difficulty in getting it, notably, non-UK-born Muslim women and Bangladeshi women in general. Further, these women may be in a position to encourage health behaviour change among partners, children, and the wider family network. However, limited language and literacy skills indicate that written materials may not be an effective health promotion format. Radio programmes in community languages, the use of health advocates within these communities, and the channelling of health messages through children and men may be more effective. Parents could be encouraged to attend health promotion functions in schools and community centres and places of worship could be appropriate settings. The use of health advocates trained to offer affordable women only sports or exercise facilities within local community centres and school halls, with on-site child care, may prove effective. Also, south Asian families could be encouraged to lower the fat content in traditional recipes and there may be scope to encourage healthy eating with south Asian schoolchildren. Finally, clear guidelines are needed on safe drinking limits.

6.2 Cancer

Several large national surveys have assessed some of the main risk factors for cancers (e.g., smoking and drinking) but the literature on the incidence, prevalence, survival, mortality, and treatment of cancer in the different ethnic groups is limited.

Very few studies of cancer incidence by ethnic group in Britain have been reported, as recording of ethnic group on cancer registry databases is very poor. The most comprehensive evidence is that reported by Harding and Rosato (1999), based on the Longitudinal Study (LS), for Scottish, Irish, West Indian, and south Asian migrants in England and Wales:

- the incidence of all malignant neoplasms was low among West Indians (female SIR [standardised incidence ratio] = 67, male SIR = 70) and Indians (female SIR=32, male SIR=52), a pattern consistent among south Asians for Hindus, Sikhs and Muslims;
- low incidence of breast cancer was found in West Indian and south Asian females (SIR=55 and 45, respectively).

Raised cancer incidence for a number of sites was found in Scottish and Irish migrants:

- lung cancer in Scottish females (SIR=149) and Northern Irish females (SIR=193);
- oral cavity and pharynx (SIR=321), oesophageal (SIR=219) and liver (SIR=373) cancers in Irish Republic migrants;
- laryngeal (SIR=229) and renal (SIR=203) cancers in Scottish males;
- oral cancer (SIR=259) for males from the Irish Republic;
- prostate cancer (SIR=129) and leukaemia (SIR=252) in men aged 15 to 64 from the Irish Republic;
- stomach cancer (SIR=200) in Northern Irish males.

Although the risks of the main cancers are lower among West Indians and south Asians, they are still a cause for concern. As Harding and Rosato (1999) have reported, amongst all LS members and all migrant groups breast cancer was the most common malignancy in females (with the exception of Northern Irish women for whom lung cancer was the most common) and lung cancer in males. Amongst the south Asian population the primacy of lung cancer in males has been reported (Bhopal and Rankin, 1996) whilst, amongst south Asian women, the position of breast cancer has been confirmed by Winter *et al.* (1999) (using cancer registry data), with lung cancer ranking second (Bhopal and Rankin, 1996). Moreover, with respect to south Asian women, their characterisation as having a low breast cancer risk relative to non-south Asians may be misleading for two reasons. A recent study (Smith *et al.*, 2003a) shows that breast cancer incidence is rising faster among south Asian women in England than among non-south Asians. Further, there is evidence of heterogeneity of breast cancer risk across the different south Asian communities with a raised risk for Pakistani/Indian Muslims (McCormack *et al.*, 2004).

In addition to the findings of Harding and Rosato (1999), a number of studies have focussed on particular ethnic groups. One study has used a computerised naming algorithm to investigate incident cancer cases in the south Asian population of England as compared with non-south Asian (356,555 cases registered between 1990-1992, including 3,845 classified as English south Asian) and Indian subcontinent rates (Winter *et al.*, 1999). English south Asian incidence rates for all sites combined were significantly lower than non-south Asian rates but rates for childhood and early adult cancer (between 0 to 29 years of age) were similar or higher than non-south Asian rates. English south Asian rates were significantly higher than non-south Asian rates for Hodgkin's disease in males, cancer of the tongue, mouth, oesophagus, thyroid gland and myeloid leukaemia in females, and cancer of the hypopharynx, liver and gall bladder in both sexes. With respect to comparisons with the Indian subcontinent, English south Asian incidence rates for all sites combined were higher and substantially so for a number of common sites including lung cancer in males, breast cancer in females, and lymphoma in both sexes, results which the investigators conclude are consistent with a transition from a lower risk country to the country of residence involving detrimental changes in lifestyle and other exposures.

These investigators have also analysed cancer incidence among English south Asian and non-south Asian children for the same period (1990-1992) (Cummins, *et al.*, 2001). They report standardised incidence ratios that show:

- significant overall excesses in south Asians (131), mainly due to higher rates in south Asian boys.

Specific excesses for:

- leukaemia (141);
- lymphoid leukaemia (141);
- lymphoma (172);
- hepatic tumours (375).

Another study of cancer incidence amongst south Asians (in Leicester), using cancer registry data, raises concerns about rates in children (Smith *et al.*, 2003a). While south Asians in this city have lower rates of cancer than the rest of the population, younger south Asians (and especially children) are at increased risk and cancer incidence rates are increasing in the group against a falling national trend.

There have been a small number of incidence studies of specific cancers. Two studies have also investigated the incidence of colorectal cancer (the second commonest solid tumour after lung cancer) in Asian patients. Barker and Baker (1990) demonstrated a low incidence of colorectal carcinoma in Bradford Asians (mainly Muslims from Pakistan), comparable to the low rates seen in India. Gee and

Mayberry (2000) reported a relative frequency of colorectal carcinoma in Asians (mainly Gujarati Hindus) in Leicester compared to Europeans over the decade 1981-1991 of 0.16 (Asian/European, 95 per cent CI 0.04 to 0.75). Moreover, the analysis showed an increased relative frequency amongst the younger age groups, raising concerns that the incidence of colorectal cancer will become closer to that of the host population. The overall incidence in the Asian population of Leicester of 9 per 100,000 per year is directly comparable to that on the incidence of the disease in India.

Smith *et al.* (2003b) investigated changes in lung cancer in south Asians during the 1990s. Although the incidence of this cancer is much lower than amongst non-Asians, it still remains the commonest cancer for south Asian men and the second commonest for south Asian women. After adjusting for age and deprivation, lung cancer rates were found to be lower for south Asians than non-south Asians (incidence ratio for men 0.41, 95 per cent CI 0.31 to 0.54, for women, 0.32, 0.20 to 0.50). The adjusted incidence increased over time for south Asian men (increase in risk of 43 per cent, 1990-1994 1.43 [0.84 to 2.44]) but decreased 19 per cent for non-south Asian men (0.81, 0.72 to 0.91). For women there were slight increases in lung cancer incidence over time for both south Asians and non-south Asians and no evidence of differing patterns over time. These figures are cause for concern, given the higher smoking rates among UK south Asians aged 30 to 49 than those aged 50 to 74.

Warnakulasuriya *et al.* (1999) investigated the incidence of oral and pharyngeal cancers among residents of the Thames regions using country of birth and distinctive names recorded in cancer registry data (1896-1991) to identify south Asians and Chinese. Figures of relative incidence showed that oral cancer was significantly higher among Asians (40.9 per cent) and nasopharyngeal cancer among Chinese (67.2 per cent). The investigators found that the migrant populations were significantly younger compared to the rest of the population at the time of cancer diagnosis, although no significant differences were found for the stage of presentation. However, in addition to identifying the south Asian and Chinese as high risk groups, Warnakulasuriya *et al.* (1999) report significant differences in cumulative rates of survival among the three groups studied and recommend targeted prevention.

The most recent data on mortality, relate to deaths by country of birth for the period 1989-1992, based on 1991 Census denominator data (ethnic group is not recorded at death registration) (Wild and McKeigue, 1997).

- Mortality ratios for lung cancer were elevated for men from Scotland (SMR 149, 95 per cent CI 141 to 157) and Ireland (SMR 151, 95 per cent CI 143 to 158).
- They were also high for women from Scotland (SMR 169, 95 per cent CI 156 to 182) and Ireland (SMR 147, 95 per cent CI 136 to 158).
- However, they were low in both men and women in other migrant groups (east Africa, west Africa, Caribbean, and south Asia).
- In south Asians, for example, the SMR for men was 45 (95 per cent CI 41 to 51) and that for women 33 (95 per cent CI 27 to 41).

Between 1970-1972 and 1989-1991 the mortality ratios in men declined by 18 per cent (Scottish) and 41 per cent (south Asian), but increased in women (64 per cent, Scottish, and 25 per cent, Irish).

Generally low rates of mortality from breast cancer were reported for women from migrants groups (Wild and McKeigue, 1997):

- Scotland – SMR 114 (105 to 124);
- Ireland – SMR 92 (85 to 99);
- east Africa – SMR 84 (65 to 107);
- west Africa – SMR 125 (91 to 168);

- Caribbean – SMR 75 (65 to 87);
- south Asia – SMR 59 (52 to 66).

Moreover, over the period 1971-1991 low rates in Caribbean and Asian women persisted.

Only limited evidence is available on survival. Differences in breast cancer survival between south Asian and non-south Asian women in south east England were investigated by Dos Santos Silva *et al.* (2003). The 10-year relative survival rates were 72.6 per cent (95 per cent CI 69.0, 75.9 per cent) and 65.2 per cent (64.5, 65.8 per cent) for south Asians and non-south Asians, respectively. The excess mortality rates experienced by south Asians were 82 per cent (72, 94 per cent) of those experienced by non-south Asians ($p=0.004$). Adjusting for age, differences in stage at presentation, and socio-economic deprivation, this was reduced to 72 per cent (63, 82 per cent), ($p<0.001$).

Survival following cancer (acute lymphoblastic leukaemia, acute non-lymphocytic leukaemia, Hodgkin's disease, non-Hodgkin's lymphoma, astrocytoma, primitive neuroectodermal tumour, neuroblastoma, Wilms' tumour, osteosarcoma, Ewing's sarcoma and rhabdomyosarcoma) was analysed by ethnic group among children diagnosed in Britain during 1981-1996 by Stiller *et al.* (2000). There were no significant differences in survival between white children and non-white over the study period; however, among children with acute lymphoblastic leukaemia, the relative risk of death allowing for period of diagnosis, age and white blood count was 1.25 for south Asian children compared with whites ($p=0.057$).

For many cancer sites there is no robust evidence on variations in cancer burdens by ethnic group. Selley *et al.* (1997) report that no studies of variations in prostate cancer rates between ethnic groups have been conducted in the UK. However, there is some indicative evidence from the UK and considerable evidence from other countries (both in terms of national incidence rates and differences between ethnic groups) that suggest that rates are substantially higher in the black groups. Proportional admission ratios by ethnic group for prostate cancer, in Greater London, 1997-1998, show high rates in the black groups (Caribbean: 2.34; African: 1.26, other: 1.16), compared with the white group (1.07) and all other groups (<0.8), although only the Black Caribbean ratio was statistically significant (Bardsley *et al.*, 2000). The highest incidence rates for clinically evident prostate cancer are found amongst the black population in the USA (100.2 per 100,000), substantially higher than that for whites (51.9 per 100,000). Prostate cancer is rare in Asia, with the lowest rates amongst Japanese men.

6.3 Stroke

A small number of studies have attempted to identify differences in the incidence of stroke by ethnicity. The Northern Manhattan stroke study (Sacco *et al.*, 1998) showed a 2.4-fold increase in black people (2.2 in black people and 0.9 in white people per 1,000). Another US study reported an incidence of first stroke that required admission to hospital or that was fatal and resulted in necropsy of 2.9 per 1,000 among black people, 1.6 times greater than the rate reported in white people (Broderick *et al.*, 1998).

Only two British studies have been identified. In 1989-1990 a community stroke register in south London was used by Wolfe *et al.* (1993) to show that ethnicity was associated with incidence of stroke in residents aged under 75 years. Stewart *et al.* (1999) used a prospective community stroke register with multiple notification sources to identify ethnic differences in the incidence of first ever stroke amongst a multi-ethnic population of 234,533 in south London. The crude annual incidence rate was 1.3 strokes per 1,000 population per year (95 per cent CI 1.20 to 1.41) and 1.25 per 1,000 population per year (1.15 to 1.35) age adjusted to the standard European population. Age and sex adjusted incidence rates were significantly higher in the black compared with the white population ($p<0.0001$), with an

incidence ratio of 2.21 (1.77 to 2.76) (that is, more than twice as high). Multivariable analysis showed that these higher rates were not explained by confounding factors such as social class, age and sex: increasing age, male sex, black ethnic group, and lower social class in people aged 35 to 64 were independently associated with an increase in stroke incidence. The study also reported that the excess incidence was found in all pathological types of stroke and that black people tend to have their first stroke at a younger age than white people.

The excess incidence of stroke among black people is not readily explained. Differences in genetic, physiological, and behavioural risk factors may account for some of the difference but require further investigation. Studies suggest that a higher prevalence of hypertension and diabetes among black people compared with white people and ethnic differences in genetic predisposition to hypertension may be contributory factors but are not adequate explanations alone.

A number of studies report higher mortality from stroke in black compared with white populations in both the USA (Otten *et al.*, 1990) and Britain. The most recent data are an analysis of mortality for adults aged 20 to 69 in England and Wales for the period 1989-1992 (Wild and McKeigue, 1997). SMRs for cerebrovascular disease were higher than the national average amongst all migrant groups and for both men and women.

The highest SMRs for men were amongst:

- west African migrants – 271 (95 per cent CI 210 to 344).

However the ratios were substantially elevated for:

- south Asia – 155 (95 per cent CI 143 to 168);
- Caribbean – 226 (95 per cent CI 198 to 256);
- Irish – 138 (95 per cent CI 128 to 148);
- and Scottish – 125 (95 per cent CI 115 to 136) country of birth groups.

For women the highest SMRs were also for:

- west African migrants – 181 (95 per cent CI 118 to 265).

Rates were also significantly higher for:

- south Asian – 141;
- Caribbean – 157;
- Irish – 123;
- and Scottish – 125, country of birth groups.

While the investigators report a greater than average decline in age standardised mortality between 1970-1972 and 1989-1992 for Caribbean migrants (men and women), Scottish, Irish and south Asian migrants showed smaller declines than the national average. Similar differences are reported in a subsequent study of male migrant mortality in England and Wales for the years 1991-1993 that also adjusted for social class (Harding and Maxwell, 1997). SMRs by country of birth were:

- Caribbean – 169;
- west/south Africa – 315;
- east Africa – 113;
- Indian sub-continent – 163;

- Scotland – 111;
- and Ireland – 130.

Differences in social class distributions explained some of the excess among Caribbean (SMR reduced to 146) and Irish men (SMR reduced to 124).

6.4 Hypertension

The most robust information on the prevalence of hypertension and blood pressure levels among ethnic groups in England is the combined data collected in the HSE, 1991-1996, reported by Primatesta *et al.* (2000) and the findings of the 1999 HSE (Karlsen *et al.*, 2001), although the Fourth National Survey of Ethnic Minorities (1993-1994) also reported on diagnosed hypertension and findings are available from several research studies. There is a degree of inconsistency across these various studies.

With respect to the combined HSE data, the investigators compare blood pressure (BP) levels, hypertension rates (systolic BP \geq 160 mm Hg or diastolic BP \geq 95 mm Hg, or those on antihypertensive medication), hypertension treatment and control rates in people of white (n=30,619), black (n=295), and south Asian (n=529) origin in two age groups. Those aged 16 to 39 (younger age group) and those aged 40 or older (older age group). Age-adjusted mean BP levels and hypertension rates of older adults were highest amongst the black population; south Asian men showed BP levels and hypertension rates similar to black men and south Asian women had mean BP levels and hypertension rates similar to white women. The investigators report the odds ratio of being hypertensive among older adults after controlling for confounding factors (age, BMI, smoking, alcohol consumption, and social class) was higher in black men (2.0, 95 per cent CI 1.4 to 2.9), black women (1.7, 1.2 to 2.5), and south Asian men (1.9, 1.4 to 2.4) than in their white counterparts. Treatment rates amongst those with hypertension were highest among black men and women. Amongst those on antihypertensive medication, the odds of having blood pressure controlled did not differ among the three groups of older men but was reduced in older south Asian women compared with white women.

The 1999 HSE (Karlsen *et al.*, 2001) found that, compared with men in the general population, age-standardised ratios of mean systolic blood pressure (SBP) were significantly low for Chinese, Pakistani, and Bangladeshi men but the same for Black Caribbean, Indian, and Irish men. Compared with women in the general population, age-standardised ratios of mean SBP were significantly low for Bangladeshi and Chinese women, similar for Black Caribbean, Indian, and Irish women, and high for Pakistani women. The only significant differences in age-adjusted ratios of mean diastolic blood pressure were a higher figure for Indian men. Standardised risk ratios for the prevalence of high blood pressure in men were significantly low for Bangladeshi and Chinese men (0.74), the higher figure for Black Caribbean men (1.11) being no longer statistically significant once age was controlled for. After age-standardisation, only Irish women had a lower prevalence of high blood pressure than women in the general population, while Pakistani and Black Caribbean women were significantly more likely to have high blood pressure. These findings are different to those in some other studies that report higher rates of raised blood pressure amongst Black Caribbean and south Asian groups.

The Fourth National Survey of Ethnic Minorities (1993-1994) (Nazroo, 1997a) asked respondents whether they had been diagnosed as having hypertension. People from white, Pakistani and Bangladeshi groups reported similar rates of diagnosed hypertension while Indians, African Asians, and Chinese had lower rates. Black Caribbeans reported rates almost 50 per cent higher than white informants (although, for men, the Caribbean rate was not significantly higher than the white rate, for women it was almost 80 per cent higher). Some research studies (Cappuccio *et al.*, 1997; Chaturvedi *et al.*, 1993)

showed higher rates of raised blood pressure among people of Black Caribbean and south Asian origin. A study by Cruickshank *et al.* (1983) of a work based population reported somewhat different findings.

Deaths from hypertensive disease are smaller in number than those from cerebrovascular disease. However, Wild and McKeigue (1997) report that they showed a similar pattern of differences across the different migrant groups though actual differences were more pronounced.

SMRs were:

- 813 for west African men (95 per cent CI 503 to 1242, 21 deaths);
- 373 for Caribbean men (95 per cent CI 296 to 462, 82 deaths);
- 944 for west African women (95 per cent CI 432 to 1792, 9 deaths);
- 668 for Caribbean women (95 per cent CI 542 to 840, 73 deaths).

Earlier mortality studies (Marmot *et al.*, 1984; Balarajan and Bulusu, 1990) also showed that the difference between Caribbean and white women was greater than that between Caribbean and white men.

A HEA (1998) report suggested that GPs should consider the development of screening policies aimed at the early diagnosis of the condition among African Caribbean patients as around 50 per cent of African Caribbean hypertensive patients do not receive adequate blood pressure control, are untreated or undetected (Cappuccio *et al.*, 1997). Further, according to the HEA, research findings show that organ damage starts earlier and progresses more rapidly in African Caribbean hypertensives. Other issues raised by the HEA include the need for awareness that antihypertensive drugs vary in their effects on different ethnic groups, the need to explain the health risks of untreated hypertension, and the contribution that changes in lifestyle (including levels of physical activity) can make to the prevention, reduction or control of hypertension.

7. Disability and learning difficulties

7.1 Disability

Many studies have relied upon census and survey measures of limiting long-term illness as a proxy measure of disability in minority ethnic groups. However, there is in addition a limited literature that reports directly on disability in minority ethnic groups in adults, young people, and children.

Two studies have been identified that address the needs of adults. Shah and Priestley (2001) held group discussions with 28 disabled people from black and minority ethnic groups and 5 key informants (service providers and advocates) in Leeds. Although improvements in the health care experiences of black disabled people were reported, remaining concerns included diet, religious observance, gender roles, staffing, racism, social isolation, and trust. Local black-led user groups have been successful in making cultural competence work. Barriers to access included lack of interpreting services, poor provision of information (the research suggesting that community-led development and advocacy are most effective), poor physical access in some cases (e.g. dental surgeries), and lack of familiarity, knowledge and trust in using services. Also, the myth that black families 'look after their own' created difficulty for some. The investigators recommend comprehensive ethnic monitoring (including smaller areas of disability specialism like blind registration, low vision clinic), an audit of cultural competence and sensitivity in disability services, positive action to recruit black and minority ethnic staff in specialist disability service areas, further implementation of cultural competence initiatives (e.g. PATH (Positive Action Training in Housing) trainees)¹⁰ in hospital and residential services and cultural competency training for outreach workers, the raising of awareness of interpreting services and booking procedures for interpreters, addressing problems of isolation in community health care assessments, better access to advocacy and support services for disabled black people (including black-led advocacy services), and greater promotion and dissemination of good practice on cultural sensitivity.

Vernon (2002) conducted in-depth interviews with 28 Asian disabled people aged 18 to 40 in the north of England and reported a widespread lack of confidence in existing provision and a consequent low up-take of community care services relative to need. Interviewees reported feelings of isolation, forced dependency on their families, frustration at limited mobility in their homes, and community services that were difficult to reach and inappropriate (for example, lacking Asian food choices and prayer areas). Some felt they had been discriminated against because of their disability and race, by both service providers and their own communities. Participants identified non-discriminatory decision-making by managers, practical and culturally sensitive support at home, and personal consultation about their needs as ways that care services could be improved.

Two studies address the needs of disabled young people, one young Asians and the other a multicultural population of young people. Hussain *et al.* (2002) interviewed 29 young Asian people with disabilities and members of their families in the West Midlands and West Yorkshire. Many felt excluded from services by cultural insensitivity and by stereotypes of culture and disability and families encountered problems in obtaining practical, social and financial support. The interviewees reported that they missed out on social opportunities, were discriminated against in education and employment, felt a lack of understanding in their own communities, and low expectations of achievement and over-protectiveness (especially for young disabled women) within their families. The investigators argued that services need to become more sensitive to the cultural and religious values of these young people and their families.

10. These are black led schemes, which aim to train black people so that, when fully trained, they may compete on equal terms with others for work as housing professionals.
(http://www.odpm.gov.uk/stellent/groups/odpm_housing/documents/page/odpm_house_603973.hcsp)

Similar issues were identified in a study of 65 young adults with physical disabilities from different ethnic backgrounds (40 per cent from ethnic minority groups) living in an area of deprivation in south east London (Doyle *et al.*, 1994). The majority of the interviewees were living with informal carers and most had complex disabilities and were wheelchair users. The level of contact with statutory services was diminishing and access to respite care and organised social outlets was strictly limited (especially for those with complex disabilities). Few had received advice about carers or independent living and around a half did not know where to go for family planning advice. Those from ethnic minorities were less optimistic about their future prospects, perceiving that poverty, disability, and ethnic background would result in their isolation.

Only one (national) research study was found on minority ethnic families caring for disabled children. Chamba *et al.* (1999) surveyed by postal questionnaire around 600 Black African/Caribbean, Indian, Pakistani, and Bangladeshi parents caring for a severely disabled child and compared their findings with an earlier survey of white parents (n=1,000). Several key findings were reported. Such families were in a more disadvantaged position than their white counterparts. Many of these families were in difficult circumstances because of low levels of employment, particularly among mothers (and especially lone mothers). Fewer ethnic minority than white families were receiving disability benefits and these were less likely to be awarded at the higher rates of Disability Living Allowance. Despite needs for more information, poor interpreting support and limited availability of translated materials restricted access (especially for Bangladeshi families). Telephone help lines (in English and other languages) were not popular.

Indian and Black African/Caribbean families reported least support from their extended family and lower than that amongst white families (and also lower partner support amongst minority ethnic mothers). Families with a key worker were more likely to describe their contact with professionals as positive. Two thirds of parents reported a need for more breaks from care, but just a quarter of families received short-term breaks and many families were unaware of such schemes. Reported levels of unmet need for children and parents were greater than in white families, those for their children comprising skills for future independence, help with learning abilities, communication, physical abilities, and learning about culture/religion, access to social/leisure activities, and emotional/counselling support. Parents' unmet needs included money, help in planning the child's future and during school holidays, personal guidance about available services, skills to help the child, a break from care, and help with behaviour/sleep problems.

The Department of Health (2001a) has undertaken its own research into service provision for adults with physical disabilities and sensory impairments from minority ethnic groups through a postal survey of all social services authorities in England (which were asked to liaise with their partner health authorities) (60 per cent response rate), a sub-set of authorities being selected for follow-up visits. Some of the issues uncovered in the research studies are reflected by provider responses: low uptake of services by minority ethnic adults with disabilities, reliance on Census data rather than local research to estimate numbers of disabled in these groups, poor recording of ethnicity of service recipients, a lower level of knowledge amongst these communities about their entitlements and the services available, staff lacking awareness of ethnic and cultural issues, an over-concentration on practical needs to the neglect of emotional and psychological needs, and the neglect of needs of carers (especially young carers) in black and minority ethnic families. Interpretation services were reported to be widespread but not in all languages and with poorer development of signing skills and other forms of communication with hearing impaired minority ethnic adults. Access to advocacy was reported to be patchy and very few authorities made specialist provision for the assessment of the needs of black and minority ethnic disabled adults.

The ways in which services are commissioned and provided reflect only a partial response to needs. Some authorities had looked to develop more customised services although many lacked strategies for determining the appropriate balance between investment in ethnic specific schemes and more culturally appropriate generic services. The reviewing of care plans for minority ethnic adults to ensure that services met their requirements needed to be prioritised. Some authorities had engaged in the more meaningful involvement of minority ethnic adults and their carers in the planning and commissioning process. However, service providers (including not-for-profit black and minority ethnic organisations) were found to be at an early stage in customising their services for different individuals and communities.

Many authorities are now auditing the cultural appropriateness of their services using the Race Equality Commission's standards, although there is wide variation in the extent to which service specifications address the cultural needs of users and evidence of under-resourcing in contract compliance and quality assurance. Moreover, many of the initiatives for ethnic specific schemes are only funded in the short term and few authorities have plans for the integration of these schemes into mainstream funding. There is, too, a dearth of staff with the necessary combination of skills to meet the needs of these users and the multiple short term nature of many of the schemes does not make the best use of them.

7.2 Learning difficulties

Two studies report on service needs amongst adults and children with learning difficulties. Mir *et al.* (2001) conducted a scoping study of services for people with learning difficulties from minority ethnic communities, including interviews with key respondents. They report a higher prevalence of learning difficulties in south Asian communities which is likely to be related to a complex set of factors including high levels of material deprivation, poor access to maternal health care, diagnostic misclassification, and higher rates of environmental or genetic risk factors. Partnership and joint ventures with minority ethnic communities are needed to provide services that respond to the needs and values of the different communities. The concept of advocacy or self-advocacy needs to be developed through supporting resources and engagement with the particular family structures found in different communities. Restrictive attitudes towards disability within minority ethnic communities need to be addressed and support groups can increase empowerment although many are small-scale and isolated. The investigators call for a wide range of initiatives, including support networks for minority ethnic carers and people with learning difficulties, outreach schemes, appropriate publicity to increase awareness of service provision, bilingual staff and interpreters, recruitment of ethnic minority staff at all levels, training in cultural competency/awareness, the collection of accurate and ongoing information about unmet need, patterns of service use, and service performance, and integrated rather than specialist services. They also point to remaining gaps, especially in relation to the views of people with learning difficulties.

One of the few studies to solicit those views was conducted in Huddersfield and involved interviews/discussions with 22 children aged 7 to 19 years, semi-structured interviews with 38 parents/carers, 43 staff from a range of disciplines, and several focus groups with providers (Department of Health, 2003). A major area of concern was difficulties in verbal communications between carers and professionals, especially disadvantaged by the lack of linkworkers and bilingual support. The collection of information from ethnic minority families for case notes was reported to be haphazard and poor, with knowledge of individual family's cultural needs often lacking. There was a lack of translated material and virtually no access to recorded verbal instruction. Respite care needs were under developed, there being an erroneous perception that all Asians have extended family support. The children interviewed expressed difficulties in obtaining family support with homework when their parents did not speak/read English.

Other specific needs identified were for support groups sensitive to the culture of minority ethnic families, the development of an advocacy service to help with the complexities of such matters as Special Educational Needs (SEN) reviews and medical diagnosis, the need to involve families in shaping services, and a customer affairs function in trusts managed by carers and patients themselves. While there was little evidence of individual racism, there was some institutional racism that the investigators felt could be tackled by cultural competency training.

8. Injury

Most of the large national surveys on the health of minority ethnic groups have reported on accidents and injury. The Fourth National Survey of Ethnic Minorities (1993-1994) (Nazroo, 1997a) asked about the number of accidents respondents had had in the last 12 months that had resulted in hospital treatment and where the accidents had occurred. The overall relative risk of having such an accident was much lower for all ethnic minority groups than the white group (but not statistically different in the case of the Chinese). With respect to location, Caribbeans reported a similar rate of home accidents to whites and, for road/pavement accidents, the rates for Caribbeans and Pakistani/Bangladeshis were not much below the white rate. The results need to be interpreted carefully as the question asked about accidents requiring hospital treatment and did not include anyone under 16 years of age.

These findings are in broad accord with those for adults in the 1999 HSE (Erens *et al.*, 2001) which collected data on both 'major' accidents (involving a hospital visit or doctor consultation) and 'minor' accidents (all other accidents causing pain or discomfort for more than 24 hours). Amongst men, Bangladeshis had the lowest accident rates, the age-standardised major accident rate being 31 per cent of the equivalent general population rate and the minor accident rate 11 per cent. The accident rates for Black Caribbean and Irish men were fairly close to those for the general population while those for Indian, Pakistani and Chinese men were between 18 and 55 per cent of the general population rate. The relationships for women were similar to those for men, Bangladeshi women having the lowest rates (32 per cent of the general population rate for major accidents and 14 per cent for minor accidents). The rates for Black Caribbean and Irish women were close to the general population, and Indian, Pakistani, and Chinese women had rates 16-68 per cent of the general population rate. Some association was found between the major accident rate and social class for men within minority ethnic groups, Black Caribbean, Indian, Pakistani, and Irish men having higher major accident rates in manual compared with non-manual households (although the reverse was true amongst Chinese men).

Studies of mortality have reported different findings. SMRs by social class and country of birth for men aged 20 to 64 in England and Wales – accidents and injury (minus suicides) – show elevated rates amongst Caribbean-born (121) and the born in Scotland (177) and Ireland (189) groups, but low rates in the east Africa (86) and Indian subcontinent groups (80) (Harding and Maxwell, 1997). Adjusting for social class made little difference to the Scotland and Ireland rates. Rates are elevated for the born in Ireland group among the young (aged under 15, aged 15 to 24) and old (aged 65 and over). Accidental deaths in children are also high amongst Pakistani migrants (Balarajan, 1995).

9. Diabetes and renal complications

9.1 Diabetes

Non-insulin dependent diabetes (known as Type 2, in which the β -cells are not able to produce enough insulin for the body's needs) carries significant morbidity and mortality and is also a risk factor for cardiovascular disease and renal failure. Insulin resistance has been implicated as a possible contributor to higher reported rates of CHD amongst south Asian migrants (McKeigue *et al.*, 1991). Many studies have reported a much higher prevalence of diagnosed non-insulin dependent diabetes among south Asians (McKeigue and Sevak, 1994; McKeigue *et al.*, 1991; Simmons *et al.*, 1989) and a raised rate amongst Black Caribbeans (McKeigue *et al.*, 1991; Odugbesan *et al.*, 1989). In Asians in the middle years of life the prevalence has been put at up to five times that of whites. Moreover, the age at presentation is significantly earlier, placing Asians at greater risk of complications (which relate to duration of diabetes). Mortality directly associated with diabetes amongst south Asian migrants is around three and a half times that in the general population (Raleigh *et al.*, 1997b). Those born in the Caribbean have a similar excess (Balarajan and Bulusu, 1990), recent data reporting a rate three and a half times the national rate among men and a sixfold excess amongst women. The knowledge base on diabetes amongst minority ethnic groups has been significantly improved in recent years by its inclusion as a topic in most of the large-scale national surveys.

In the Fourth National Survey of Ethnic Minorities (1993-1994) all respondents were asked if they had ever had diabetes (Nazroo, 1997a). All minority ethnic groups reported higher rates than whites but differences were small and in the case of the Chinese group not significant. The rates for Indians and African Asians and Caribbeans were similar (three times the white rate) but significantly higher in the Pakistani and Bangladeshi group (over five times the white rate). Moreover, once socio-economic status had been partially controlled for, the difference between the white and all minority ethnic groups in the rate of diagnosis of diabetes remained large.

There are a number of important areas that health promotion initiatives can address in preventing non-insulin dependent diabetes from developing and in ensuring appropriate use of services in those with the condition. Non-insulin dependent diabetes remains undiagnosed in up to 40 per cent of Asian diabetics (Simmons *et al.*, 1989; UK Prospective Diabetes Study Group, 1994). Several studies report inadequate quality of healthcare for Asian and African Caribbean diabetics and poor compliance (Cruickshank, 1989; Goodwin *et al.*, 1987; Close *et al.*, 1995; Hawthorne, 1990, 1997; and Benett, 1994), arising from patients' lack of knowledge about the disease and its management through the inappropriateness of health information.

A study undertaken in Nottingham on the knowledge of diabetes and its complications among south Asians attending a hospital diabetic clinic compared them with matched white diabetic patients (Hawthorne, 1990). The south Asian diabetic patients knew less about the disease and its complications than their white counterparts. One third did not know why it was important to keep their blood sugar concentration low (known as control), 72 per cent did not know that poor control resulted in complications, and 58 per cent could not name a single complication. For their white counterparts the figures were 16 per cent, 55 per cent and 10 per cent respectively.

Hawthorne (1997) reports on a more recent study of 200 randomly selected south Asian patients attending Manchester Diabetes Centre in 1993-1994, that found similar results. Of these patients, 168 (84 per cent) could not name any diabetic complications, 99 (50 per cent) were unsure of the reasons for monitoring and controlling glucose concentrations, 175 (88 per cent) did not know the purpose of attendances at the clinic to screen for early complications, and 183 (92 per cent) did not know what a

chiropract did or how to see one. Additionally, older women with no experience of formal education had poorer diabetic control than the rest as well as less knowledge of diabetes. The investigator argues that the educational requirements of these patients need to be urgently addressed to prevent further morbidity. A further study (Benett, 1994) at the Manchester diabetes centre similarly showed deficiencies in the care of African Caribbean patients compared with their white counterparts.

Further, there is scope to address health promotion activity to the known risk factors for development of insulin resistance and non-insulin dependent diabetes, notably, low physical activity and obesity, common amongst both Asians and African Caribbeans (Cruickshank, 1989; Rudat, 1994).

9.2 Renal complications

Diabetic nephropathy (damage to the nerves) and end stage renal failure are significantly more common in south Asian diabetics than in white diabetics: relative risks of up to 14 have been reported in studies (Burden *et al.*, 1992). Recent reviews, both national (Health Care Strategy Unit, 1994) and of specialist services in London (Roderick *et al.*, 1994), show a 3- to 4-fold higher rate of uptake of renal replacement among south Asians than whites, analyses adjusting for area of residence showing that this excess was not explained by higher referral rates resulting from inner city residence and proximity to renal units. Amongst Asians and African Caribbeans who develop end stage renal failure, non-insulin dependent diabetes is the major underlying cause (Raleigh, 1997). The relative risk of end stage renal failure secondary to diabetes has been reported to be 5.8 times greater in Asians and 6.5 times greater in African Caribbeans than in whites (Roderick *et al.*, 1996). Further, the higher prevalence of end stage renal failure is reflected in a 3- to 4-fold excess mortality from renal disease among Asians and African Caribbeans (Raleigh *et al.*, 1997b).

Here, too, there are issues for health promotion additional to the preventive strategies reported for diabetes. The higher rates of end stage renal failure amongst Asians and Caribbeans has resulted in a greater demand for transplants with only a limited supply of suitable organs. However, there are problems of cross-racial tissue type matching and a reluctance to donate. Randhawa (1998) has reported that the proportions of Asians on transplant waiting lists is growing rapidly with longer waiting times for a transplant. There is, consequently, a need for educational interventions to address religious concerns about organ donation, to raise awareness about the need for organ donation, and to address concerns about the medical consequences of transplantation. In an interview study with Sikhs (n=22) in Coventry, Exley *et al.* (1996) reported some misgivings amongst interviewees in relation to mutilation, reincarnation, and the technical aspects of the transplantation process but an overall supportive attitude to transplantation located in the altruistic tradition within Sikhism.

10. Sexual health

The most recent statistics from the Public Health Laboratory Service's Communicable Disease Surveillance Centre (PHLS CDSC, 2002; PHLS *et al.*, 2002; PHLS, 2002) provide important information on incidence of Sexually Transmitted Infections (STIs) by ethnic group. This includes data collected from various enhanced surveillance systems (the Programme of Enhanced STI Surveillance [ProgrESS] and the Gonococcal Resistance to Antimicrobials Surveillance Programme [GRASP]).

10.1 Genital chlamydial infection

Genital chlamydial infection became the most common STI seen in Genito-Urinary Medicine (GUM) clinics in the UK in 2001, with rates of diagnosis continuing to rise in all age groups. The ProgrESS surveillance initiative provides information on rates of diagnosed uncomplicated genital chlamydial infection in London by sex and ethnic group (2000). The highest rates were seen in black ethnic groups (notably, Black Caribbean and black other [that is, groups comprising black British, black mixed and black unspecified ethnic groups]). In the black other group the rate for females reached 1,500 per 100,000 population (1.5 per cent) and in men over 1,100 per 100,000. Rates were around 0.9 per cent in Black Caribbeans but under 0.125 per cent in the white, south Asian and Chinese groups.

10.2 Gonorrhoea

Rates of diagnosed gonorrhoea have increased substantially in all age groups since 1995 and are particularly high in the youngest age groups. Data from the ProgrESS initiative for 2001 show that the highest rates of diagnoses of uncomplicated gonorrhoea in London residents were seen in the Black Caribbean and black other ethnic groups, especially amongst males where rates exceeded 800 per 100,000 (0.8 per cent) (those amongst females were around 0.4 per cent and 0.7 per cent, respectively). This distribution has also been reported in other studies (Low *et al.*, 1997). Rates in the white, south Asian, and Chinese ethnic groups were substantially lower (0.1 per cent in both males and females). The PHLS and other studies report that the high rates in the Black Caribbean and black other groups reflect variations in sexual behaviour and sexual mixing between and within ethnic groups and, possibly, inequalities in socio-economic status and access to and use of services (Fenton *et al.*, 1997; Rogstad *et al.*, 1998).

10.3 Genital warts

Genital warts (manifestations of infection with some types of the human papillomavirus) are the most prevalent viral STI diagnosed in the UK and the commonest STI diagnosed in Wales. Rates for this infection have also been increasing and, while overall numbers are broadly comparable across the sexes, in those under 20 a much higher proportion of diagnoses were seen in females than males. Data from the ProgrESS initiative for 2001 again shows important differences in rates of diagnosed genital warts in London by ethnic group. Disproportionately high rates are reported for Black Caribbean and black other males (around 0.2 per cent and 0.3 per cent) and females (around 0.15 per cent and 0.3 per cent). However, the variation by ethnic group was not as pronounced as for bacterial STIs, with rates in the white group of around 0.1 per cent and less than 0.05 per cent in the south Asian and Chinese groups.

10.4 Genital herpes simplex virus

Diagnoses of genital herpes simplex virus (caused by either HSV types 1 or 2) have also been rising and show a more pronounced female to male diagnostic ratio (1.6:1), with a particularly high increase in HSV-1 infection in young women. ProgRESS data for 2001 (rates of diagnoses of genital herpes simplex virus infection, first attack) shows that the highest rates in London were in the Black Caribbean and black other groups (around 0.1 per cent and 0.2 per cent in males and 0.15 per cent and 0.3 per cent in females), while rates were less than 0.05 per cent in other ethnic groups.

10.5 Syphilis

Rates of diagnoses of syphilis infection have also increased and this has been especially marked in males since 1998. Diagnoses in men who have sex with men have significantly contributed to this rise. Moreover, the burden of syphilis does not fall mainly on teenagers but is seen across most age groups. In 2001 the Enhanced Laboratory Service for Infectious Syphilis was started in London, the increase in diagnoses associated with being aged between 25 and 44, being HIV positive, white ethnic identity, and having attended sex on premises' bars.

10.6 HIV/AIDS

The information and the accompanying tables presented in this section are taken from a report published by PHLS CDSC (2002). Information on ethnicity has been requested on the AIDS reporting forms completed by clinicians since surveillance began in the early 1980s (PHLS CDSC, 2002). It was first requested on the report form for diagnoses of HIV infection from microbiology laboratories in 1993 when the ethnic categorisation was aligned with that used in the 1991 UK National Census (Office of Population Censuses and Surveys *et al.*, 1993). The completeness of this information has improved dramatically in recent years. The proportion of new HIV diagnoses where ethnicity was reported rose from 44 per cent (1,150/2,636) in 1995 to 85 per cent (3,094/3,654) in 2000 (Table 2) (PHLS CDSC, 2002). The data reflect increasing diagnoses of infections acquired through sex between men and women, the majority of which have probably been acquired in Africa (CDSC, 2001). Over the period 1995-2001 and among those for whom ethnicity is recorded, the proportion of Black Africans has risen from 25 per cent to 51 per cent and the proportion recorded as of white ethnicity has declined from 67 per cent to 40 per cent (PHLS CDSC, 2002) (Table 2).

Table 2. HIV infected individuals* by ethnicity and year of first diagnosis in the UK: data to the end of 2001.

Ethnic group	Year of diagnosis** (per cent's subtotal)						
	1995	1996	1997	1998	1999	2000	2001
White	775 67.4%	1024 67%	1127 60.4%	1155 55.6%	1133 49.6%	1431 46.3%	1009 39.6%
Black African	282 24.5%	369 24.1%	542 29%	685 33%	880 38.5%	1318 42.6%	1302 51%
Black Caribbean	31	41	68	77	100	112	109
Black other	8	20	21	20	34	34	18
Indian/Pakistani/Bangladeshi	18	25	39	41	41	66	29
Other***/mixed	36	49	69	100	97	133	84
Subtotal	1150	1528	1866	2078	2285	3094	2551
Not known	1486	1155	855	712	729	560	791
Total	2636	2683	2721	2790	3014	3654	3342

* Individuals with laboratory reports or clinician reports of infection plus those with AIDS or death for whom no matching laboratory report has been received.

** Numbers, particularly for recent years, will increase as further reports are received.

*** Includes Chinese and south east Asian

Source: Taken from: PHLS CDSC. CDR Weekly. Volume 12, Number 9, 28 February 2002. Published by: PHLS Communicable Disease Surveillance Centre.
www.hpa.org.uk/cdr/archives/2002/cdr0902.pdf

The annual survey of prevalent HIV infections diagnosed (SOPHID) records the ethnicity of patients seen for HIV-related care in England, Wales, and Northern Ireland during the preceding year. In 2000 the survey recorded 21,717 individuals seen for HIV-related care (Table 3). Information on ethnicity was available for 20,111 (93 per cent) individuals, 65 per cent of whom were white, 24 per cent Black African, 4 per cent other or mixed, 3 per cent Black Caribbean, 1 per cent Indian/Pakistani/Bangladeshi, 2 per cent black other, and 1 per cent other Asian (PHLS CDSC, 2002). The table shows that only 1.6 per cent of the UK total of individuals was resident in Wales (n=332), of whom 89.2 per cent were white. Of those in minority ethnic groups, 36 per cent were Black African and 44 per cent other/mixed.

Table 3: Individuals seen for HIV-related care in 2000 by ethnicity and country of residence when last seen*.

NHS executive region of residence	Ethnic Group							Total
	White	Black Caribbean	Black African	BlackOther/ unspecified	Indian/Pakistani/ Bangladeshi	Other/ mixed**	Not known	
England total	12410	521	4865	312	292	965	1490	20855
Wales	296	3	13	–	2	16	2	332
Northern Ireland	97	–	5	–	–	2	–	104
Total	12803	524	4883	312	294	983	1492	21291
Other/ Abroad	38	1	12	2	3	6	5	67
Not known	144	7	74	6	3	16	109	359
Total	12985	532	4969	320	300	1005	1606	21717

*Patients seen for statutory medical HIV-related care at services in England, Wales and Northern Ireland in 2000 (includes 288 children born to HIV infected mothers in 2000 whose HIV infection status had not been confirmed: 223 resident in London, 24 in South East, nine in West Midlands, eight Northern and Yorkshire, seven in Trent, six in South West, five in Eastern, four in North West, and two where region was not reported).

**Includes 167 of other Asian/Oriental ethnicity.

Source: Taken from: PHLS CDSC. CDR Weekly. Volume 12, Number 9, 28 February 2002. Published by: PHLS Communicable Disease Surveillance Centre. www.hpa.org.uk/cdr/archives/2002/cdr0902.pdf

Of the 10,411 individuals seen for HIV-related care in 2000 who probably acquired HIV infection through sex between men and for whom ethnicity was recorded, 9,325 (90 per cent) were white, 541 (5 per cent) other or mixed, 202 (2 per cent) Black Caribbean, and 137 (1 per cent) Black African (Table 4). Among the 6,552 categorised as infected through sex between men and women for whom ethnicity was recorded, 3,881 (59 per cent) were of Black African ethnicity, 1,867 (28 per cent) white, 241 (4 per cent) Black Caribbean, 241 (4 per cent) other or mixed, and 175 (3 per cent) Indian/Pakistani/Bangladeshi. Ethnicity in this group was not recorded for 210 individuals. Of those exposed to HIV by routes other than sexual contact for whom ethnicity was recorded, 90 per cent of those categorised as infected through injecting drug user were white, as were 84 per cent of those infected through blood or blood products. Of the children of recorded ethnicity born to HIV infected mothers, 71 per cent were Black African. (PHLS CDSC, 2002).

Table 4: Individuals seen for HIV-related care in 2000 by ethnicity and exposure category in England, Wales, and Northern Ireland*.

Exposure	Ethnic Group							Total
	White	Black Caribbean	Black African	Black other	Indian/Pakistani/Bangladeshi	Other**/Mixed	Not Known	
Sex between men	9325	202	137	137	69	541	969	11380
Sex between men and women	1867	241	3881	147	175	241	210	6762
Injecting drug use	749	4	16	0	6	61	36	872
Blood/blood products	365	7	34	2	14	14	27	463
Mother to infant	87	13	493	3	8	86	133	823
Not known	592	65	408	31	28	62	231	1417
Total	12985	532	4969	320	300	1005	1606	21717

* Patients seen for statutory medical HIV-related care at services in England, Wales and Northern Ireland in 2000 (includes 288 children born to HIV infected mothers in 2000 whose HIV infection status had not been confirmed: 223 resident in London, 24 in South East, nine in West Midlands, eight Northern and Yorkshire, seven in Trent, six in South West, five in Eastern, four in North West, and two where region was not reported).

** Includes Chinese and south east Asian

Source: Taken from: PHLS Communicable Disease Surveillance Centre. CDR Weekly. Volume 12, Number 9, 28 February 2002. Published by: PHLS Communicable Disease Surveillance Centre. www.hpa.org.uk/cdr/archives/2002/cdr0902.pdf

In conclusion, ethnicity data from the ProgreSS and GRASP programmes, have enabled more comprehensive surveillance of trends by ethnic group to be presented. High rates of infection are observed in the Black Caribbean and black other ethnic groups that probably reflect variations in sexual behaviour and sexual mixing between and within ethnic groups and inequalities in socio-economic status and access to/use of health services. Moreover, the disproportionate disease burdens in these groups are increasing. The PHLS concluded that 'the inequitable distribution across ethnic groups requires urgent investigation' (PHLS *et al.*, 2002). Moreover, around half of all HIV (first diagnosis) infected individuals in the UK are now Black African.

The expanding literature on HIV and African communities in the UK clearly shows that there is a lack of relevant social research and interventions relating to these communities. Mclean (2002) has drawn attention to neglect of the complex social factors – migration, different languages, racism, social exclusion, different social and family norms, poverty, asylum, separation from family, and different gender norms that complicate the picture of HIV in African communities in the UK. There are, too, the wide diversity of cultures and societies subsumed under the heading of 'African'. Issues identified as requiring research are the patterns of socialising and social mixing, the significance of national and tribal associations, the extent to which the different communities are established in the UK, the role of religion in shaping peoples' understandings of HIV, the implications of disclosing HIV status to partners

and children within traditional cultural values, the social implications of not breastfeeding, the impact of migration on health, and beliefs about masculinity and traditional gender roles and behaviour change. McClean (2002) sums up the picture:

‘We have the precious expertise that lies in African community organisations about community norms, practices and belief systems. And we have a growing expertise across the sector about what works in HIV prevention. But what we don’t have is the insight and knowledge about culture, community and behaviour that comes from a national programme of social research into the UK’s African communities’.

The National African HIV Prevention Network outlines as key priority areas for HIV social research in African communities:

- the epidemiological and demographic features of the African HIV epidemic;
- a better understanding of the sexual behaviours and attitudes of Africans with/at risk of HIV, in the context of cultural practices and beliefs;
- more understanding of attitudes, beliefs and practices surrounding breast-feeding, pregnancy and termination, experiences of antenatal testing, male approaches to condom use, experiences and behaviours of African men, sexual negotiation and masculinity;
- more information on subgroups like asylum seekers and visitors, Africans who inject drugs, African men who have sex with African men, and African sex workers;
- patterns of service use by African communities, evaluation of HIV prevention interventions, and the development of research tools to reflect African community experience.

The African HIV Research Forum, too, has questioned the value of HIV prevention and care programmes that are substantially ‘blind’ to the needs of the African communities and identified the need for research-led prevention programmes for gay men in African communities. The Department of Health is to publish a National Prevention (and Social Care) Framework for prevention with African communities and fund the Forum to commission and manage national HIV health promotion with African communities in England. (Since the completion of this review, this framework has been published; Department of Health *et al.*, 2004).

Some of these issues are now beginning to be addressed. The findings of a 1999 survey on the needs of black gay men have recently been reported (Worrall and Kirk, 2001). As a population black gay men are younger, less ‘gay identified’, better educated, and suffer less discrimination and unemployment than gay men as a whole. While they are less likely to access GUM services, they are reported to have comparable HIV testing histories and levels of sexual behaviour and risk to other gay men. Their ‘unique needs’ were identified as the need for support from within their own communities, for anti-homophobia and anti-racism interventions, and for work to deal with their perceived lack of visibility within the gay communities and their own ethnic communities. Moreover, the survey found that these needs did not vary substantially between the different black groups (Caribbeans, Africans, etc.) and that, for most black men, culture and ethnicity were more important than sexuality. An example of culturally appropriate service provision is the use of language: ‘Black men respond better to medicalised ‘toned down’ language, whereas white gay men prefer to see colloquial terms used to describe sexual behaviour’.

11. Oral healthcare

The literature on the prevalence of dental caries and other indicators of dental health across ethnic groups is limited and inconsistent in the differences reported. The series of nationally co-ordinated dental epidemiological surveys commissioned by individual health authorities to standardised national protocols and diagnostic standards (involving the dental examination in state schools of children in the specified age-group) (Mitropoulos *et al.*, 1992) does not collect data on ethnic group. A recent study of dental caries and treatment experience of adults (n=928) from a range of minority ethnic groups living in the South Thames Region (Robinson *et al.*, 2000), found more of these participants were dentate or had 18 or more sound and untreated teeth than the adult population living in the same area (although the comparator was data published in 1991). In the sample as a whole, duration of residence in the UK predicted caries or treatment experience and age and history of visiting a UK dentist predicted increased DMFT¹¹.

A number of the large national surveys of the health of minority ethnic groups have asked about the use of dental services. The Fourth National Survey of Ethnic Minorities (1993-1994) (Nazroo, 1997a) reported marked differences in the percentage who had used dentists in the past year: more than three fifths of white respondents (62 per cent), around half for most minority ethnic groups (Caribbean 53 per cent, Indian 45 per cent, African Asian 46 per cent, Pakistani 50 per cent, and Chinese 47 per cent), but only a quarter of Bangladeshi respondents (a figure consistent with that reported by Rudat (1994) in the HEA Health and Lifestyles Survey [1992/93]). Cost may have been a barrier as a significant number of respondents paid for their dental care privately, Pakistanis and Bangladeshis being far less likely to have done so. The national surveys show some inconsistencies in the use of dental services by gender.

The use of dentists by the Chinese group is reported in other surveys. Although there was no separate Chinese sample in the HEA Health and Lifestyles Survey (1992/93), Sproston *et al.* (1999) found that 56 per cent of the Chinese group had visited the dentist in the year before the interview (48 per cent of men and 63 per cent of women), still below that for the white group in the Fourth National Survey of Ethnic Minorities (1993-1994). The main reason for non-use was lack of need (73 per cent), although 12 per cent reported expense.

Recent qualitative research used focus groups to identify barriers to the regular use of dental services by members of minority ethnic groups in the United Kingdom (Newton *et al.*, 2001) and reported issues such as language, a mistrust of dentists, cost, anxiety, cultural misunderstandings, and concern about standards of hygiene. These findings confirm previous research identifying barriers to regular attendance although, importantly, this study suggests that the nature of the perceived barriers varies across ethnic groups (though mistrust of dentists was common to all groups).

11. The number of decayed, missing, and filled teeth, used to describe the amount – the prevalence – of dental caries in an individual.

12. Lifestyle factors

12.1 Exercise

Of the large national surveys, the 1999 HSE included a question set on exercise and the Fourth National Survey of Ethnic Minorities (1993-1994) included questions on perceived obesity. According to the 1999 HSE (Teers, 2001) 33 per cent of men in the general population met the current recommended guidelines for participation in physical activity¹². The highest age-standardised ratios relating to this guideline were for Black Caribbean (1.13) and Irish men (0.97), lower ratios being found amongst Indian (0.86), Chinese (0.62), Pakistani (0.70), and Bangladeshi (0.55) men. In the general population, 21 per cent of women met the guideline, age-standardised ratios again being highest amongst Black Caribbean (1.21) and Irish (1.15) women, but much lower amongst women in other groups (Chinese, 0.74, Indian, 0.67, Pakistani, 0.63, and Bangladeshi, 0.35). These differences are also reflected in figures for participation in vigorous activity in the last four weeks. In the general population, 32 per cent of men had taken part in this, relative to this Bangladeshi men having an age-standardised ratio of 0.45 (compared with 1.17 for Black Caribbean men). In the general population, 24 per cent of women had engaged in any vigorous activity. Relative to this, Pakistani women (with an age-standardised ratio of 0.29) and Bangladeshi women (0.27) were between 3 and 4 times less likely to have taken part in such activity. Thus, Black Caribbean men had the highest levels of participation in physical activity but high levels were also found amongst Irish men and men in the general population. Amongst women participation was similar in Black Caribbeans, Irish, and the general population but lower in the other groups (especially Bangladeshis).

Hayes *et al.* (2002) assessed the type and level of physical activity, as measured by a multidimensional index, and its relationship with selected cardiovascular disease and diabetes risk factors in a cross-sectional, population-based study of European, Indian, Pakistani, and Bangladeshi men and women aged 25 to 75 and resident in Newcastle upon Tyne. Europeans (defined as people with ancestral origins in European countries, excluding individuals from ethnic minority groups) were found to be more physically active than Indians, Pakistanis and Bangladeshis. Of European men, 52 per cent did not meet current guidelines¹² for participation in physical activity on the physical activity index, compared with 71 per cent of Indians, 88 per cent of Pakistanis, and 87 per cent of Bangladeshis. The investigators reported similar findings for women. European men and women participated more frequently in moderate and vigorous sport and recreational activities. Moreover, with respect to the extent to which differences in level of physical activity might contribute to differences in the prevalence of diabetes and cardiovascular disease risk markers, such levels were inversely correlated with BMI, waist measurement, systolic blood pressure, and blood glucose and insulin in all ethnic groups (but did not correlate with high-density lipoprotein cholesterol).

In an earlier study of 288 male manual workers aged 20 to 65 employed in two factories in the textile industry of Bradford, West Yorkshire, Knight *et al.* (1993) found that the frequency of exercise in leisure time was low in both Asian men and non-Asian men, with 44.4 per cent of non-Asian and 21.1 per cent of Asian men taking moderate exercise weekly, and even fewer, regular strenuous exercise (16.3 per cent and 8.6 per cent, respectively).

The Fourth National Survey of Ethnic Minorities (1993-1994) (Nazroo, 1997a) asked if respondents considered themselves to be overweight and whether they had tried to lose weight. While 40 per cent of white men considered themselves overweight, the proportions amongst ethnic minority men varied from 18-21 per cent, with the exception of Bangladeshis (7 per cent) and Chinese (11 per cent).

12. Defined as a target of at least five episodes of moderate activity of 30 minutes duration per week. (Blair *et al.*, 1995).

Amongst women, 50 per cent of Black Caribbeans considered themselves overweight (similar to whites, 44 per cent) and 22-33 per cent of south Asians, but with lower rates in the Bangladeshi (14 per cent) and Chinese (12 per cent) groups. Around a quarter of white men had seriously tried to lose weight and 14-16 per cent of men in minority ethnic groups, with the exception of Bangladeshi (10 per cent) and Chinese (5 per cent) men. Similar proportions of white and Caribbean women (44-46 per cent) had tried to lose weight and 22-27 per cent amongst other groups, with the exception of Bangladeshi and Chinese women (11 per cent).

Many investigators emphasise the importance of measures to increase physical activity in minority ethnic group populations. However, the potential barriers to participation have received only limited attention, although this was a topic included in the HEA Health and Lifestyles Survey (1994). Johnson *et al.* (2000) reported that Bangladeshi people and Pakistani women were the least likely to be personally taking active exercise for the sake of their health and that there was a relatively low level of awareness or knowledge about the health-related benefits of exercise. White people gave more excuses for not exercising (including being 'not sporty types') and Indian women were most likely 'not to have time'. For minority ethnic groups, modesty, avoidance of mixed sex activity, and fear of going out alone were also important. African Caribbean men and women were much more likely to engage in leisure sports while Asian women were very much less likely to do so. Low levels of knowledge about the actual levels of effective physical activity (i.e. the level necessary to confer health benefits), reported across the sample, may be a barrier to participation, as may unemployment and patterns of employment amongst those in work. The investigators conclude that, given the complex patterns of variation observed, it may be important to consider the needs and potential to increase participation of each ethnic group (and gender within the groups) separately.

12.2 Smoking and tobacco use

Data on prevalence are available from the two HEA Health and Lifestyles surveys (1992/93 and 1994), the Fourth National Survey of Ethnic Minorities (1993-1994), the 1999 HSE, and the Chinese Health and Lifestyles Survey (1998). Across all these surveys there are substantial differences between minority ethnic groups and the white group in smoking patterns. For example, self-reported smoking prevalence amongst Bangladeshi men was 44 per cent in the 1999 HSE, compared with 27 per cent of men in the general population and 17 per cent of Chinese males. However, there are important inconsistencies across the surveys, with generally higher self-reported smoking rates in the Fourth National Survey of Ethnic Minorities (1993-1994) compared with the other national studies for Caribbeans, Pakistanis, Chinese, and the white population and higher rates in the 1999 HSE for Indians and Bangladeshis. Amongst the most marked of the differences in prevalence of cigarette smoking are: 1 per cent in Bangladeshi women (1999 HSE) versus 6 per cent (Johnson *et al.*, 2000); 17 per cent in Chinese men (1999 HSE) versus 31 per cent (Fourth National Survey of Ethnic Minorities [1993-1994]); and 29 per cent in African Caribbean men (Rudat, 1994) versus 42 per cent (Fourth National Survey of Ethnic Minorities [1993-1994]). There are also important discrepancies with respect to cotinine measures, significantly higher prevalences being found for most ethnic minority males compared with self-reported consumption levels. According to the 1999 HSE, self-reported cigarette smoking prevalence for Bangladeshi males was 44 per cent, self-reported use of any tobacco products 53 per cent, and cotinine adjusted rate 59 per cent; even greater discrepancies were found amongst Bangladeshi women, with rates of 1 per cent, 27 per cent, and 38 per cent, respectively.

Some of the national studies also report on the use of smokeless tobacco products such as paan and hookah¹³. The Fourth National Survey of Ethnic Minorities (1993-1994) reported high prevalences of

13. These products – paan, betel nut/sopari, and hookah – are chewed with/without tobacco and are thought to be linked to an increased risk of mouth and throat cancers.

paan use amongst Bangladeshi males (45 per cent) and females (54 per cent), but substantially lower rates amongst Indians and Pakistanis. Broadly consistent findings are reported in the HEA Health and Lifestyles Survey (1992/93) (Rudat, 1994) and in the 1999 HSE. In the HEA Health and Lifestyles Survey (1994) (Johnson *et al.*, 2000), particularly high rates (over 80 per cent) of chewing tobacco were found in Bangladeshi women over the age of 30. Many Bangladeshis (especially women) consumed tobacco through both smoking and chewing.

A number of local studies report the prevalence of smoking amongst minority ethnic groups, such as a cross-sectional, population-based study of 480 Chinese and 625 European men and women aged 25 to 64 in Newcastle upon Tyne (White *et al.*, 2001). Age-adjusted findings are reported for a number of measures: smoking was less common in Chinese (24 per cent) than European men (35 per cent) ($p=0.00002$) and among Chinese women (1 per cent) compared with European women (33 per cent) ($p<0.00001$); number of cigarettes smoked was similar among Chinese and European male smokers; median age at starting smoking was higher among Chinese (18.5 years) compared with European men (15 years) ($p=0.00001$); and smoking most common in older Chinese and in younger Europeans.

Tobacco consumption in minority ethnic groups raises important health promotion issues for a variety of reasons. Smoking rates vary widely both within (by gender) and between minority ethnic groups. Social, cultural, and religious factors account for some of these differences. For example, Sikhs are prohibited from smoking by their religion, and there are social taboos that make it unacceptable for women from some ethnic groups to smoke. While smoking is a significant risk behaviour in all groups, some groups are disproportionately affected. For example, Johnson *et al.* (2000) report especially high smoking rates in Bangladeshi men aged 30 to 49 (54 per cent) and aged 50 to 74 (70 per cent) and in African Caribbean (21 per cent) women and Bangladeshi women aged 50 to 74 (14 per cent). Smoking is a risk factor for a number of conditions that affect south Asians disproportionately, particularly cardiovascular diseases. While half to three quarters of current smokers in all ethnic groups had attempted to stop smoking, such attempts were a more recent phenomenon compared with the wider population (Johnson *et al.*, 2000). In addition, their knowledge of the health risks is poor – around a quarter of Bangladeshis, Pakistanis and Indians associated smoking with CHD and about half know about the link with lung cancer. Knowledge of risks associated with other respiratory illnesses and throat and mouth cancers was also very low. The investigators conclude that sensitively targeted programmes that meet the information needs of individual groups are needed to improve knowledge about the health risks of smoking. They also identify the need for further research into the most effective methods of helping each group to obtain such information ahead of developing health promotion programmes. Research is also needed on the extent of knowledge in the different ethnic groups about the link between chewing tobacco products and disease.

12.3 Alcohol use

As with smoking, the main sources of evidence on the prevalence of drinking amongst ethnic groups are the large national health surveys undertaken by the HEA, the Policy Studies Institute, and HSE. These sources show substantial differences in reported prevalence compared with the white population and also variations across the different ethnic groups. For example, the Fourth National Survey of Ethnic Minorities (1993-1994) found that only 4 per cent of Pakistani men reported drinking more than once a week compared to 69 per cent of white men. Some of these differences are clearly related to cultural and religious practices, for example, Muslims are prohibited from consuming alcohol, and it is socially unacceptable for women from several minority ethnic groups to drink. In some cases, too, the inconsistencies between survey findings are notable, especially for Indian women, but generally less so than for smoking.

There is some consistency in findings for alcohol consumption amongst men. The Fourth National Survey of Ethnic Minorities (1993-1994) (Nazroo, 1997a) showed that amongst men current alcohol use was highest in the white (92 per cent) and Caribbean groups (87 per cent). Both this survey and others reported that 66 per cent of Indian men reported currently consuming alcohol and 68-73 per cent of Chinese men (68 per cent in the 1999 HSE; 69 per cent in the Fourth National Survey of Ethnic Minorities (1993-1994); and 73 per cent in the Chinese Health and Lifestyles Survey (1998) [Sproston *et al.*, 1999]). Much lower proportions of Pakistani (8 per cent in the Fourth National Survey of Ethnic Minorities [1993-1994]) and Bangladeshi (3 per cent) men did so (Nazroo, 1997a). The national surveys report similar findings for Pakistani, Bangladeshi, African Caribbean, Chinese, and white females. For example, in the Fourth National Survey of Ethnic Minorities (1993-1994), less than 1 per cent Pakistani, 2 per cent Bangladeshi, 74 per cent Caribbean, and 51 per cent Chinese women currently consumed alcohol. However, for Indian women there were disparities in reported prevalence levels: 18 per cent (Nazroo, 1997a) vs. 35 per cent in the 1999 HSE.

The cross-sectional, population-based study of Chinese and European men and women aged 25 to 64 in Newcastle upon Tyne also provides some findings on alcohol consumption (White *et al.*, 2001). The prevalence of alcohol consumption was lower among Chinese men (63 per cent) than European men (93 per cent) ($p < 0.00001$) and among Chinese (29 per cent) compared to European women (89 per cent) ($p < 0.00001$). Median alcohol consumption was significantly lower among Chinese men (2 units per week) than European men (16 units per week) ($p < 0.00001$) and among Chinese women (1 unit per week) compared to European women (6 units per week) ($p < 0.00001$). Among alcohol drinkers Chinese men were less likely to drink above recommended limits¹⁴ than European men (1 per cent vs. 39 per cent; $p < 0.00001$).

Several studies have identified difficulties experienced by people from minority ethnic groups in accessing specialist alcohol services. Based on the use of alcohol screening questionnaires in community and primary care settings and an analysis of those in contact with specialist and psychiatric services in a multi-ethnic area, Commander *et al.* (1999) reported that around half of those with alcohol morbidity in the community never consulted their doctor and only half of those who did had their problem identified. Case recognition was particularly poor for Asians, as well as women and young people. Deficits in access to specialist services for ethnic minorities arose at the point of referral from primary care.

With respect to the Irish, Harrison and Carr-Hill (1992) have identified the need for alcohol agencies to prioritise the development of culturally sensitive alcohol services and outreach services. Foster (2003) suggests that Irish alcohol users tend to use generic mental health services rather than alcohol specialist treatment services and may be discriminated against in accessing integrated drug and alcohol services because of their age (arguing that they tend to be older: aged 45 and over). Further, Foster *et al.* (1998) have shown significantly poorer short-term relapse rates (3 months) in socially deprived Irish subjects compared with their English and Scottish equivalents.

Other issues for health educators and promoters include the importance of maintaining the low levels of alcohol consumption in some ethnic groups. In the Chinese Health and Lifestyles Survey (1998), for example, younger people were more likely to drink than older people (Sproston *et al.*, 1999). Further, some alcohol-related disorders are appearing earlier in some ethnic groups. A study of ethnic

14. At this time current advice about sensible drinking was: there is no significant health risk for men (of all ages) who regularly consume between 3 and 4 units a day and for women (of all ages) who regularly consume between 2 and 3 units a day; regular drinking of 4 or more units a day for men, or 3 or more a day for women, is likely to result in increasing health risk and is not advised; the health of men aged over 40 and of post-menopausal women can benefit from drinking between 1 and 2 units a day. (Department of Health, 1995).

differences in cirrhosis of the liver in Birmingham (Douds *et al.*, 2003) found south Asian non-Muslim males with alcoholic cirrhosis over-represented and younger at diagnosis than white alcoholic cirrhotics. Moreover, south Asian men who abuse alcohol may be more susceptible to alcohol-related liver damage and acetaldehyde-mediated haemoglobin modification than European men who abuse alcohol to a similar extent for a considerably longer period (Wickramasinghe *et al.*, 1995).

12.4 Illicit drug use

The HEA Health and Lifestyles Surveys (1992/93 and 1994) did not ask about drug misuse and findings are limited to a few national and local studies (Aujean *et al.*, 2001). The 2000 British Crime Survey (Ramsay *et al.*, 2001) included an ethnic booster sample to enable variations in drug use across ethnic groups to be analysed. Amongst persons aged 16 to 59 lifetime use of any drug was highest in the white group (34 per cent), followed by the black group (28 per cent), Indians (15 per cent) and Pakistani/Bangladeshi (10 per cent). The white group also reported statistically significant higher lifetime rates of cannabis, amphetamine, ecstasy and Class A drugs than other ethnic groups. For Indian respondents aged 16 to 29 lifetime use of Class A drugs and amphetamines was equal to or surpassed that of the black group. For respondents in the 30 to 59 age group, lifetime drug use was slightly higher in the white than black group and Asian drug use was about a third of the level in the white group. High lifetime use was also reported in the 'mixed ethnicity' group. Among the different ethnic groups there were no statistically significant changes in the use of heroin in any age group but small increases in the Indian and white group. In the Indian group the proportion using crack, cocaine, and ecstasy had increased significantly.

The evidence base on drug use amongst minority ethnic groups is poor. Although the English and Welsh Regional Drug Misuse Databases collect information on ethnicity, deficiencies in completeness currently preclude analysis by ethnic group (Department of Health, 2001b). In Scotland only 17 out of 11,123 people recorded on the Scottish Drug Misuse Database were reported to be of Indian subcontinent or Afro-Caribbean ethnic origin (Information and Statistics Division, 2000). Moreover, with respect to data collected from service agencies, it is possible that drug users from minority ethnic groups will be more likely to remain unknown, reflecting high levels of social exclusion and barriers to access to healthcare services (Awiah *et al.*, 1990).

The Nightlife in Europe and Recreational Drug Use study (Calafat *et al.*, 1999) provides some qualitative findings. Panel members reported that stimulants like amphetamines and ecstasy were unpopular and little used amongst minority ethnic groups compared with cannabis and cocaine, as they were perceived as 'a white man's drug'. There was growing evidence that heroin use was increasing amongst young people from minority ethnic groups (especially from SE Asia). Heavy cannabis use was described in African Caribbean, Asian and black British communities and was perceived to be the drug of choice in this population, its use being more widespread than in the white group. Panel members thought that drug usage in Asian youth may be attributed to the Afro-Caribbean/black American culture that many Asians identify with. Also, cannabis use is harder for parents and families to detect than alcohol (the use of which is opposed in Asian culture).

Additionally, research on delivering drug services to minority ethnic communities to support the UK Government's 10-year drug strategy¹⁵ (UKADCU, 1998) has been reported by Sangster *et al.* (2002). Based on around 100 interviews with professionals, a community consultation involving 13 group discussions with around 100 people from a range of communities, interviews with 14 experts in the area of ethnicity and drugs, and analysis of statistical data, the investigators report overall lower levels of drug use within minority ethnic communities and especially in south Asian and Black African

15. There is also a Welsh drug strategy (National Assembly for Wales, 2000b).

communities. Similar levels of cannabis use were reported for Black Caribbeans and whites but lower levels of hallucinant drugs amongst Black Caribbeans. Problematic drug use amongst African Caribbean users was found to focus on crack and cannabis. There was also concern about the role of khat¹⁶ in Somali communities (see also Griffiths, 1998).

The research also focused on the delivery of drug services to minority ethnic groups, notably, institutional failings to do with the image of the services and their isolation from the community and an inability to respond to the specific patterns of drug use and service needs shown by the different ethnic communities, failings that were particularly acute in specialist residential services. Interviews accorded particular importance to the role of cultural competence in relation to the planning, commissioning and delivery of drug services. Most also felt that it was important that mainstream providers develop appropriate ways of working with minority ethnic communities. There was some evidence in the research of under-representation of minority ethnic communities (especially south Asians) in presentation to drug services outside London and of Black Africans, Pakistanis, and Bangladeshis in London. Concern was also expressed about the low number of Turkish people attending drug services. Black and minority ethnic users tended to use a small number of services that had a particular commitment to their needs. African Caribbeans mainly used voluntary-sector drug agencies as these provided crack services. Minority ethnic users were less likely than whites to consult their GPs about drug use, possibly for reasons of anonymity. The investigators call for organised needs assessment, community consultation, greater cultural competency, the tackling of institutional racism, and improved systems of data collection to underpin national and regional strategies.

12.5 Diet and nutrition

The Department of Health's healthy eating initiatives have focused on a diet rich in fruit and vegetables, with reduced salt intake and saturated and total fat as this can lower blood pressure and reduce the risk of cardiovascular disease. The 1999 HSE focussed on the consumption of various types of food and overall fat and fibre consumption across minority ethnic groups. The proportion of Chinese men and women who ate fruit and vegetables six or more times a week (men 46 per cent fruit, 53 per cent vegetables; women 60 per cent fruit, 69 per cent vegetables) was much higher than in the other ethnic minority groups. Bangladeshi men and women were least likely to eat fruit six or more times a week (15 per cent men, 16 per cent women) and Pakistani men (7 per cent) and women (11 per cent) least likely to eat vegetables this often. Amongst men the proportion with an adjusted high fat consumption score was greatest among Irish and Bangladeshi men (22 per cent and 21 per cent respectively), and low amongst Indians (11 per cent), Chinese (12 per cent) and Black Caribbeans (12 per cent). Amongst women the highest proportion with a high fat score was found amongst Bangladeshis (27 per cent), followed by Irish (14 per cent), Pakistani (13 per cent), Chinese and Black Caribbeans (9 per cent), and Indian (8 per cent) women. The proportion with a low fibre score was greatest among Bangladeshis (79 per cent of men and 82 per cent of women). Indian men (39 per cent) and women (42 per cent) and Irish women (41 per cent) were less likely than other minority ethnic groups to have low fibre intake.

The HEA Health and Lifestyles Survey (1994) (Johnson *et al.*, 2000) focused on self-reports of the consumption of traditional foods and understanding of terms used in healthy eating messages. Traditional foods (which around half in each ethnic group perceived to be healthier than western diets)

16. Khat (qat) is a green-leafed shrub that has been chewed for centuries by people who live in the Horn of Africa and Arabian Peninsula. It is a stimulant drug with effects similar to amphetamine.
http://www.drugscope.org.uk/druginfo/drugsearch/ds_results.asp?file=percent5Cwippercent5CIpercent5CIpercent5CIpercent5Ckhat.html

constituted a major component of the meals eaten at home by south Asians but was less common amongst African Caribbean people. Only small proportions in each ethnic group (varying from 10 per cent to 17 per cent) reported a preference for British or European style food. Dietary restrictions for cultural or religious reasons were uncommon among African Caribbeans (22 per cent) but widespread among Indians (80 per cent), Pakistanis (97 per cent), and Bangladeshis (97 per cent).

The survey explored people's understandings of some key dietary terms commonly used in health education messages. A large proportion (75 per cent and above) of African Caribbeans reported understanding the terms 'starchy foods', 'dietary fibre', and 'fat', and about half reported an understanding of the term 'saturated fat'. The south Asian groups reported lower rates of perceived understanding of each term. However, amongst those reporting an understanding of the individual dietary terms, knowledge of foods high in starch, dietary fibre, fat, and saturated fat was patchy or poor across all ethnic groups. Additionally, knowledge of the links between diet and cardiovascular disease was poor, especially amongst Bangladeshis. The investigators conclude that key nutrition messages relating to CHD prevention may not have been heard or understood by a substantial proportion of the minority ethnic group population.

13. Access to and use of services

13.1 Healthcare utilisation and access

Surveys and other studies have reported wide variations by ethnicity in the use of treatment and preventive services. While south Asians and African Caribbeans are more likely than the white group to have consulted their GP (Erens *et al.*, 2001), and at least as likely after differences in their health have been taken into account (Nazroo, 1997a), studies consistently show the Chinese underutilise this service (Nazroo, 1997a; Erens *et al.*, 2001; Sproston *et al.*, 1999). The Chinese may underutilise hospital casualty or outpatient department services, around 12 per cent (both men and women) having attended in the previous 3 months, compared with 15 per cent of men and 16 per cent of women in the general population (Sproston *et al.*, 1999). For hospital inpatient visits HSE findings (Erens *et al.*, 2001) show that, whilst all other ethnic minority groups had rates similar to that for the general population, the Chinese were least likely to report using this service, the relative use for Chinese men being 0.4 and for women 0.5. Use of this service by the Chinese was also lowest in the Fourth National Survey of Ethnic Minorities (1993-1994) (Nazroo, 1997a), although this group's use of inpatient hospital day treatment has been reported in another survey to be slightly higher than in the general population (men: 8 per cent versus 6 per cent; women: 10 per cent versus 7 per cent) (Sproston *et al.*, 1999).

Ethnic minorities are less likely to visit the dentist than the white group, the rates being particularly low for the Bangladeshi group (Rudat, 1994; Nazroo, 1997a), and it is possible that costs may be a barrier. South Asian women (especially Bangladeshis) are less likely to have visited an optician than white women and, amongst men, African Caribbeans and Bangladeshis are the least likely to have used opticians (Rudat, 1994). The use by the Chinese of this service is also low (Watt *et al.*, 1993).

With respect to preventive services, there is evidence that women from ethnic minority groups use antenatal services less intensively (Petrou *et al.*, 2001) and a higher proportion book too late for screening to be useful (Ades *et al.*, 2000). Also, women in some ethnic groups have low uptake of potentially life saving cervical cancer smears. The percentage of women aged 16 to 74 reporting having a cervical smear in the previous 5 years being below the UK average of 77 per cent in the south Asian groups, especially the Bangladeshis (33 per cent) (Rudat, 1994). Evidence also suggests that ethnic minority women, especially Pakistani and Bangladeshi women, may have unmet family planning needs. However, studies suggest that minority ethnic groups may have higher immunisation rates than Europeans in two reported studies.

Recent research has suggested that ethnic minority groups may be under-represented in research studies including clinical trials. Mason *et al.* (2003) found people of south Asian ethnic origin under-represented in six clinical trials conducted by the Northern and Yorkshire Clinical Trials and Research Unit. Johnson *et al.* (2002) [also Johnson, 2003] report that in the national research register of over 1,000 randomised controlled trials (RCTs), only 9 referred to ethnic minority or non-English speaking groups. However, Cooper *et al.* (2003) have demonstrated that with appropriate investment in translators, ethnic minority patients can achieve representation in clinical trials.

13.2 Quality of services

There is some evidence that ethnic minorities receive poorer quality primary healthcare. The first of the national surveys of NHS patients, for general practice (Airey *et al.*, 1999) shows that a higher proportion of ethnic minority respondents took a less favourable view of their treatment by GPs than the white population. Asian respondents were much more likely than others to be registered with a

single-handed practice (23 per cent compared with an average of 7 per cent). The number of days' wait for an appointment was generally higher – and the wait in the surgery to see the GP longer – for ethnic minorities, especially Bangladeshis, than the white population. Ethnic minority respondents were less likely to think that the GP took appropriate action on their last visit, more likely to have wanted a second opinion, and more doubtful about their GP making the right diagnosis. They also tended to be more critical of GPs' attitudes to them, of the time spent (reporting fewer minutes with the GP), and of the extent to which GPs communicated effectively with them. There was a much greater probability of ethnic minority respondents putting off visiting their GP by the inconvenience of surgery hours. Similar findings have been reported in other recent national surveys. In addition to communication difficulties, people from minority ethnic groups were more likely than whites to find physical access to their GP difficult, have longer waiting times in the surgery, feel that the time spent with them was inadequate (especially Bangladeshis), and be less satisfied with the outcome of the consultation (Rudat, 1994). They were also likely to find their preferences for doctors of a similar ethnicity and gender to themselves unmet (Modood *et al.*, 1997). A study based in only one practice found that during consultations with a GP, ethnic minority patients were less likely to receive a follow-up appointment (Gillam *et al.*, 1989).

With respect to treatment services for the main causes of mortality, only limited evidence is available. The second of the national surveys of NHS patients, which assessed the quality of NHS hospital patient care for patients treated for CHD, revealed that ethnic minority patients, particularly south Asians, expressed higher than average levels of criticism of their treatment and care and of the attitude of hospital staff (Airey *et al.*, 2000). In several indicators of access to care south Asian patients were the most likely to express dissatisfaction, but the level of dissatisfaction amongst Black Caribbean patients was also at a higher level than among patients in general.

These indicators included: waiting for assessment (as an emergency admission), length of time on the waiting list, deterioration in health whilst on the waiting list, and being made to wait for a bed after admission to hospital – south Asian patients, in particular Bangladeshi men and women, were more likely than average to report adverse treatment. With respect to information and communication – understanding doctors' explanations of their condition or treatment, doctors giving easily understood answers to their questions, being upset by the way in which information was presented, and not always being treated with respect and dignity by doctors, nurses and other hospital staff.

Of the few research studies on this topic, the delay between the onset of symptoms of ischaemic heart disease and undergoing an angiogram in one part of Britain was reported as twice as long in patients of Indian origin than in those of European origin (Shaukat *et al.*, 1993). Indian patients also are reported to be less likely to receive thrombolysis after admission with a diagnosis of myocardial infarction (Lear *et al.*, 1994). Feder *et al.* (2002) reported findings from the ACRE study (Appropriateness of Coronary Revascularisation) that showed that among patients deemed clinically appropriate for coronary artery bypass grafting, south Asians are less likely than white patients to undergo procedures. Abubakar and Kanka (2002) conducted an audit of all patients (including 53 south Asians and 1,556 whites) admitted with unstable angina or acute myocardial infarction who were linked to their HES (Hospital Episode Statistics) record to provide follow up information. They found higher access to angiography and CABG (Coronary Artery Bypass Graft surgery) among south Asian compared with white patients, but no difference in access to angiography (Odds Ratio: 0.94, CI 0.49 to 1.83) or CABG (Odds Ratio: 1.27, CI 0.62 to 2.62) between these patient groups after controlling for age, sex, and deprivation (but not for severity or appropriateness).

Scarcely any findings are available for cancer, although the third of the national surveys of NHS patients addressed this topic (Airey *et al.*, 2002). Some analysis by ethnicity has been presented for London only as very few patients (2 per cent) classified themselves as other than white (and nearly half these were in London). Even here there were around only 300 black and 150 south Asian patients, compared with

5,100 white patients. The investigators report a number of areas of disadvantage for the minority ethnic groups. Black (14 per cent) and south Asian (14 per cent) patients were nearly twice as likely as all patients (8 per cent) to report that their appointment for their first treatment had been postponed or cancelled. These groups reported waiting longer after seeing their GP but before seeing a hospital doctor for diagnosis: 37 per cent of black and 38 per cent of south Asian patients waited more than a month compared with 30 per cent of all patients.

Further, 32 per cent of south Asian patients did not completely understand their diagnosis, compared with 25 per cent of black patients and 19 per cent of all patients. Of south Asian patients 45 per cent did not completely understand the range of treatment options, compared with 39 per cent of black patients and 33 per cent of all London patients. With respect to their first hospital treatment, both black and south Asian patients showed lower levels of confidence in doctors and nurses. Seventy two per cent of black and 77 per cent of south Asian patients reported confidence in all of the doctors who treated them, compared with 83 per cent of all patients; 36 per cent of black and 42 per cent of south Asian patients did not have confidence in all the nurses, compared with 27 per cent of all patients. Thirty two per cent of black and 29 per cent of south Asian patients considered that doctors at least sometimes withheld information from them, compared with 16 per cent of all patients.

A much higher proportion (50 per cent) of south Asian patients felt that they were not always treated with respect and dignity by hospital staff than of black patients (31 per cent) and all patients (26 per cent). Of south Asian patients 22 per cent considered that hospital staff sometimes talked about them as if they were not there, higher than black (19 per cent) and all patients (16 per cent). The proportion of south Asian patients who reported being in pain all or most of the time during their first hospital treatment was more than twice the average and this group were also more likely to consider that the hospital staff did not help them all the time with their pain (36 per cent versus 23 per cent of all patients). Again, with respect to the hospital environment, south Asian patients were much more likely to be critical: only 57 per cent considered there were enough doctors on duty compared with 76 per cent of all patients and only 32 per cent considered their wards to be 'very clean' compared with 42 per cent of all patients. There were no differences with respect to opinions of hospital food, outpatient appointments or discharge procedures.

With respect to other services, there is current inconsistent antenatal and neonatal haemoglobinopathy screening practice, described in one report as 'patchy' and 'unstructured', some districts deciding eligibility for screening in an ad-hoc manner and others adopting different combinations of antenatal and neonatal strategies (Davies *et al.*, 2000). A substantial body of evidence points to widespread underprovision of interpreting services in many settings. As part of an inspection of services for ethnic minority children and families in eight local authorities, a survey of parents showed that 32 per cent disagreed with the statement that they were able to access translation/interpretation services (O'Neale, 2000). An examination of case records for 850 children revealed that there had been use of interpreters/advocates in only 15 per cent of assessments with partial use in a further 13 per cent. In surveys in London, 43 per cent of respondents in Haringey and 53 per cent in Brent and Harrow stated that they needed an interpreter when seeing a GP (Association of London Government, 2000).

Amongst research on specific ethnic groups, one important Welsh study merits mention. Research has been undertaken by Hawthorne *et al.* (2003) into the difficulties experienced by the Bangladeshi community in Cardiff in accessing appropriate primary care services in four health centres in the Grangetown area of the city. Experiences of and attitudes to working with Bangladeshi patients were explored. The investigators reported that health visitors had made significantly more effort than others to get to know their Bangladeshi patients, with consequent costs in terms of time, effort, and caseload. Common to the Primary Health Care Teams (PHCTs) were issues around communication and cultural differences and the difficulties experienced by Bangladeshi patients in using NHS services appropriately.

While PHCTs were aware of the reasons for these difficulties, they were not generally able to take account of them without outside facilitation because of their workload and systems of working.

13.3 Language barriers

Language discordance between patients and professionals has been widely documented with respect to accessing primary care, including making an appointment, communicating with doctors, and acquiring knowledge about service availability (Hawthorne, 1994; Nazroo, 1997a; Free *et al.*, 1999; Nguyen Van Tam *et al.*, 1995). Evidence is available of these barriers operating in other settings, including secondary care. In one inner city A&E department, 17 per cent of patients did not speak English as their primary language (Leman, 1997). Moreover, 42 per cent of A&E departments across the UK had to use interpreters to communicate with their patients over a seven day period (Leman, 1998).

Further, with only limited availability of professional interpreters and bilingual health advocates and linkworkers, a consequence of this discordance has been the use of children as informal interpreters. Qualitative research has demonstrated the inappropriateness of the use of children in such roles, including GPs concern about the sensitivity and complexity of the consultation and ideological opposition to the appropriateness of this task for children generally (Cohen *et al.*, 1999). However, there may be benefits as well as disadvantages. Green *et al.* (2002) explored the accounts of young people aged 9 to 18 (n=77) in four linguistic communities in London (Vietnamese/Chinese, Bengali/Sylheti, Kurdish/Turkish, and eastern Europeans) of their role as interpreters and mediators in health service settings. From the young people's perspective, many health service encounters were straightforward but some were problematic, difficulties with respect to the latter including language (especially medical terminology) and insufficient English vocabulary. Some felt they had to persuade as well as interpret and others were concerned about attitudes of healthcare providers (for example, the appearance of displeasure with the young person's presence or ignoring the interpreter). Also, the nature of the problem – if it was a personal or embarrassing one – could cause difficulties. However, almost all the participants perceived benefits, including the contribution to self-esteem and a sense of pride in helping their families or communities, rather than seeing interpreting as an inappropriate burden. Amongst disadvantages were missing school and other preferred activities.

14. Wider determinants of health

14.1 Environmental factors: housing

The Welsh Assembly Government has addressed black and minority ethnic housing issues in a number of key policy developments. In 2000 the Assembly published the report *From the Margins to the Centre – Assessing the Need for a Black and Minority Ethnic Housing Strategy in Wales* (Nyoni, 2000) and the BME housing recommendations of the National Housing Strategy Task Groups. In April 2001 the assembly published and consulted on its Draft BME Housing Strategy. The Black, Minority Ethnic Housing Action Plan for Wales was published in 2002 (Welsh Assembly Government, 2002b), the aim of which is ‘to ensure that clear directives and targets are set for social landlords and other providers of housing, to ensure that discrimination and disadvantage is eliminated across Black, Minority Ethnic communities living in Wales’. Key themes in the BME Housing Action Plan for Wales include local and regional BME housing strategies and plans, BME tenant involvement, tackling racial harassment, race equality training, and monitoring and review. Following on from the BME national housing action plan, the Housing Directorate has been awarded the Diversity Award for the ‘Best Racial Diversity Practice by a Housing Agency’ at the Black and Voluntary Sector Network Wales Diversity Awards. The award recognises commitment to tackling discrimination and disadvantage among black and minority ethnic group communities living in Wales.

The Fourth National Survey of Ethnic Minorities (1993-1994), has addressed housing issues (Modood *et al.*, 1997). Comparing Policy Studies Institute data from 1982 and 1994, rates of owner-occupation had increased for all groups except the Pakistanis. Indians, African Asians and Pakistanis continued to have the highest levels of owner-occupation, followed by whites and Chinese, with Caribbeans and Bangladeshis having the lowest levels of owner-occupation. Younger Caribbean households had particularly low rates of owner-occupation and high rates of social renting, partially reflecting the high proportion of lone parent families among young Caribbean households. The high levels of owner-occupation amongst Indians, African Asians and Pakistani households reflect survey findings that show that these groups have a preference for this tenure, possibly related to their wish for autonomy and the use of ownership as a form of investment. Council tenants from these groups were more likely to have utilised the ‘Right to Buy’ scheme to acquire their council accommodation. Since the completion of this review, a report has been published using Welsh 2001 Census data (Welsh Assembly Government, 2005). On average ethnic minorities were less likely than their white counterparts to own their own homes (58.2 per cent and 71.5 per cent respectively). Furthermore those from ethnic minority groups were less likely than their white counterparts to live in local authority rented accommodation (11.6 per cent compared with 13.8 per cent). Ethnic minority households were more than twice as likely as white households to live in private sector rented accommodation and were also more likely to live in accommodation provided by housing associations and other social landlords. Pakistani and Chinese households were more likely than other minority ethnic groups to be owner-occupiers, at a similar level to white households.

The Fourth National Survey of Ethnic Minorities (1993-1994) also looked at quality of housing. Much higher proportions of flat dwellers were found amongst the Caribbean, Bangladeshi and Chinese groups, the first two groups being in medium and high-rise accommodation. By contrast Indian and African Asian households were as likely as white households to occupy detached or semi-detached properties. However, Pakistani and Bangladeshi households tended to be concentrated in terraced housing and were more likely to lack central heating, bathrooms, and inside toilets. Moreover, the study suggests that Pakistani and Bangladeshi owner-occupiers were occupying properties with much poorer amenities than those available to social tenants from the same ethnic groups. Between 1982 and 1994 levels of overcrowding decreased considerably for all ethnic groups although differences between groups

remained, Pakistanis and Bangladeshis being most overcrowded and whites the least. Levels of satisfaction with housing to some extent reflect its quality. Whites were most likely to be 'very satisfied' and Caribbeans and Bangladeshis most likely to be 'dissatisfied'. When respondents living in similar circumstances are compared, whites were more likely than any group apart from Caribbeans to be 'dissatisfied' with their housing. In Wales ethnic minority households were more likely than white households to live in terraced dwellings (33.8 per cent compared with 29.2 per cent) and flats (12.6 per cent compared with 7.8 per cent). Furthermore ethnic minority households were less likely than white households to live in detached (21 per cent compared with 27.1 per cent) and semi-detached (23.5 per cent compared with 32.5 per cent) dwellings (Welsh Assembly Government, 2005).

14.2 Socio-economic factors: employment, income and poverty

Data from the Quarterly Labour Force Survey (undertaken by the Office for National Statistics) show that white people are much more likely to be economically active (that is, in employment or seeking jobs) than minority ethnic groups, with the exception of 'black other' women who have the highest female economic activity rates (Policy Action Team, 2000). Employment is much lower for ethnic minority men than white (80 per cent), varying from 54 per cent (Bangladeshis) to 73 per cent (Indian). Amongst women, there is a much greater difference in employment rates, varying from 13 per cent (Bangladeshis) to 66 per cent (black other), well below the 70 per cent rate for whites.

The ILO (International Labour Organisation) definition of unemployment is measured through the Labour Force Survey and covers people who are looking for work and are available for work (it is the number of people who are unemployed as a proportion of the resident economically active population of the area concerned). For men, the ILO rate was 20 per cent in the Pakistani and 21 per cent in the Bangladeshi groups, more than three times the white rate (6.5 per cent), although Indians (9 per cent) were approaching whites. Similar differentials were found amongst females. Evidence from the Fourth National Survey of Ethnic Minorities (1993-1994) (Modood *et al.*, 1997) showed that amongst men with A-level or equivalent qualifications, Caribbeans were much more likely to be unemployed than whites (23 per cent versus 12 per cent), Caribbeans, Indians/African Asians, and Pakistanis/Bangladeshis all being more likely to be unemployed amongst women.

Data from the 'New Deal' (a key part of the UK Government's strategy to get people back to employment by assisting those on benefits to look for work, including training and job preparation) have revealed that Black African, Black Caribbean, and Pakistani New Dealers are less likely to move into employment than New Dealers from Indian, Chinese and Bangladeshi groups (Cabinet Office, 2001). However, all minority ethnic groups are less successful at obtaining employment than white people. Further, a lower proportion of ethnic minority people than whites move from the New Deal into sustained unsubsidised or subsidised employment (25 per cent versus 33 per cent of whites) and a higher proportion into education and training (59 per cent versus 44 per cent of whites), despite being better qualified.

Finally, ethnic minorities are disproportionately employed in self-employment. For example, the Fourth National Survey of Ethnic Minorities (1993-1994) showed that amongst male employers and managers of small establishments, 45 per cent of the white group were self-employed compared with 70 per cent of the south Asian/Chinese groups; amongst the skilled manual and foremen, 34 per cent of the white group, compared with 51 per cent of the south Asian/Chinese groups. The reasons for these differences are likely to be complex, involving both push factors (such as racism in the labour market) and pull factors (like the geographical concentrations of particular ethnic communities providing opportunities for self-sustaining businesses).

14.3 Educational factors

Bangladeshi, black, and Pakistani pupils achieve less well than other pupils at all stages of compulsory education. Findings from the 2002 Youth Cohort Study show marked differences in the attainment of 5 or more GCSE grades A*-C in year 11 in England and Wales over the period 1992-2002 (Department for Education and Skills, 2003). The proportion of white pupils reaching this level has increased from 37 per cent to 52 per cent. Black pupils have increased from 23 per cent to 36 per cent, Pakistani pupils have increased from 26 per cent to 40 per cent, and Bangladeshi pupils have increased from 14 per cent to 41 per cent. However, both Indians (38 per cent to 60 per cent) and Chinese/other Asians (46 per cent to 64 per cent) outperformed white pupils. Data from OFSTED for 1997 show important ethnic differentials in exclusion from school. The Black Caribbean group had the highest percentage (0.58 per cent), followed by white (0.15 per cent), Pakistani (0.10 per cent), Bangladeshi (0.07 per cent), and Indian (0.04 per cent).

A substantially higher proportion of students stay on in full time education at age 16 amongst minority ethnic groups (over 85 per cent) compared with the white group (67 per cent). However, a higher proportion of white 16-year-olds are in full time employment (10 per cent) and government supported training (12 per cent) than their ethnic minority counterparts (3 per cent and 4 per cent, respectively) (Cabinet Office, 2001), a pattern also reported in the 2002 Youth Cohort Study (Department for Education and Skills, 2003). Labour Force Survey data show that amongst 18 to 24 year olds there are marked differences across the ethnic groups and by gender in the proportions who are students (Leslie and Drinkwater, 1999). Rates are highest amongst Chinese/other Asian men and women (45.7 per cent and 47.3 per cent, respectively), above those for the white group (15.2 per cent and 14.9 per cent). Amongst males, rates are particularly low amongst Black Caribbeans (11.5 per cent) but higher in the other black group (20.5 per cent). Amongst women, staying on rates are low relative to other minority ethnic groups amongst Black Caribbeans (15.6 per cent) and other black (21.8 per cent). Further, black undergraduate entrants are much more likely to be mature students: around half of black undergraduates are aged over 25 compared with a third of whites. Some 60 per cent of Black African male and Black Caribbean female students start their degrees aged over 25 years. With the exception of Chinese/Asian other students, a larger proportion of ethnic minority students are studying at the 'new' post 1992 universities, a similar pattern to that of white working class students (Owen *et al.*, 2000). However, according to admission data, even after controlling for factors like age, parental social class, appropriate entry qualifications, and number of exam sittings, students from some ethnic minority groups are still less likely than their white counterparts to gain admission to traditional universities. Amongst first degree graduates, ethnic minority students are less likely than whites to obtain an upper second or first class honours degree (53 per cent versus 37 per cent), Chinese and Indian students also underachieving at this level (Owen *et al.*, 2000).

14.4 Social support and social inclusion

The issue of minority ethnic social exclusion has been comprehensively addressed by the UK Government's Social Exclusion Unit, and this section is based on their work (Social Exclusion Unit, 2002).

Although there is a lack of data in some specific areas, the evidence base strongly confirms disproportionate disadvantage experienced by minority ethnic groups across all domains of life but with much variation within and between the different groups. People from minority ethnic groups are disproportionately represented in deprived areas, 56 per cent living in the 44 most deprived local authorities in the country, and in the main metropolitan areas. Minority ethnic groups are more likely

than the rest of the population to be poor, 34 per cent of Chinese people, over 40 per cent of African Caribbeans and Indians, and over 80 per cent of Pakistanis and Bangladeshis living in households that have incomes that are less than half the national average compared with 28 per cent of people in England and Wales.

Young people from minority ethnic groups are disproportionately at risk of experiencing the problems of deprivation and social exclusion, due to racism and discrimination, poverty, and living in deprived neighbourhoods. For example, African Caribbean young men are over-represented at all stages of the criminal justice system. Nearly half of those using Centrepoin't's temporary housing services are black. In 1991 almost a fifth of children looked after by local authorities were from a minority ethnic background (versus 9 per cent of the under 16 population). As already noted, there are marked differences in educational attainment and exclusions from school. Qualitative research suggests that there are relatively high levels of tension between white teachers and black pupils with teachers' expectations about the potential of students from minority ethnic groups being different from those for white students. Studies document greater difficulty amongst young people from minority ethnic communities in securing training places, those places being less likely to be with employers and less likely to lead to employment.

As already noted, employment rates are lower amongst minority ethnic communities, especially Bangladeshis and Pakistani women, and unemployment rates are considerably higher. Moreover, being from a minority ethnic group diminishes people's chances of employment at all levels of qualification. Rates of unemployment amongst those with degrees or higher level qualifications are significantly higher for African Caribbean than Asian people. There is strong evidence that racial discrimination plays a role as rates of unemployment are higher for people from minority ethnic groups, regardless of their qualifications, place of residence, sex or age. Also, racial discrimination appears to contribute to limiting the progress of minority ethnic employees in work.

The disadvantages of minority ethnic groups in the housing market have also been referred to. However, homelessness is an additional issue. Estimates suggest that people from minority ethnic groups comprise about 5 per cent of those sleeping rough. Voluntary organisations report disproportionately high numbers of people from minority ethnic communities amongst the single homeless population living in hostels.

Racial harassment and racial crime are widespread and under-reported, estimates suggesting around 400,000 racist incidents in England and Wales annually (around only 3 per cent of which are reported to, and recorded by, the police). One survey found that over a half of Caribbean and south Asian victims did not report racial harassment and another that just 5 per cent of racist incidences were reported to the police. There may also be shortcomings in the way statutory authorities address racial harassment. For example, less than half of local authority housing departments in England were found to have written policies and procedures on racist harassment, compared with nine out of ten of the larger housing associations.

Finally, people from minority ethnic groups, especially black people, are over-represented in the criminal justice system. In England and Wales in 1998-1999:

- black people were six times more likely to be stopped and searched by the police than white people;
- the population-based arrest rate for notifiable offences was around one and a half times higher in Asians but over four times higher amongst black people;
- in nearly all police forces there was a lower use of cautioning for suspected black offenders than for white and Asian offenders;

- higher proportions of black and Asian prisoners were remanded before trial compared with white prisoners;
- sentences were longer for young and adult black and Asian prisoners;
- people from minority ethnic groups accounted for 18 per cent of the male prison population and 24 per cent of the female prison population.

More research on the reasons behind these differences is needed.

II. Health and Social Care Interventions

The following interventions have been graded according to the strength of evidence for them. A number of schema are available, the most widely recognised being those based on the Agency for Health Care Policy and Research (AHCPR, 1992; Petrie *et al.*, 1995). The former resulting in a grade of A, B or C (see Appendix 2), has been used.

Where appropriate a grade is assigned. Those studies reported but without a grade either do not refer to specific interventions or are too brief to grade but are still of note.

I. Interventions to improve the uptake of cervical screening

There are a number of systematic literature reviews that have attempted to assess the effectiveness of community-based strategies to increase cervical cancer screening. Black *et al.* (2002) evaluated evidence of the effectiveness of interventions available to public health staff and found 42 relevant studies (1 'strong', 18 'moderate', and 23 'weak'). Of the strong and moderate studies, around half (10) were aimed at disadvantaged women. The most frequently reported intervention is mass media campaigns (alone or in combination with other strategies), followed by one-to-one education using lay health educators and letters of invitation. Thirteen of the moderate/strong studies comprised strategies that reported statistically significant increases in Pap smear rates. The investigators concluded that strategies combining mass media campaigns and direct tailored education to women and/or health care providers seemed most successful, together with accurate centralised cytology databases for recall. With respect to minority ethnic women, they found that such groups may be more responsive to small, culturally sensitive group education rather than broad-based community strategies. The use of lay health educators, in particular, may be promising although resource-intensive and issues of generalisability of findings across other cultural groups remain.

In general there is a paucity of strong evidence (based on RCTs) that relates specifically to minority ethnic groups in Britain, although several reports of provider interventions are stated to be practical or effective but lack robust evidence of such effectiveness.

Mitchell *et al.* (1997) assessed the effect of ethnic media on cervical screening rates in Australia (an intervention included on the Cochrane Controlled Trial register). The numbers of women giving Pap smears before and after the intervention were compared in areas with high and low percentages of residents of non-English speaking background. The media publicity appeared to generate an additional 6.7 per cent (95 per cent CI 4.4 to 9.2 per cent) increase in screening in areas with a high proportion of women from non-English speaking background compared with changes in screening in areas with a low proportion of women of non-English speaking background.

(Grade A)

In a recent study of cervical and breast screening practices in the San Francisco area, in which the researchers assigned lay health workers to contact and follow up more than 2,000 low income and ethnic minority women in their communities, those Latina and Chinese women reached by the intervention showed substantial increases in uptake of Pap smear screenings (reported by Boughton, 2001).

(Grade B)

Naish *et al.* (1994) advocate consultation with community groups in their own language through focus group discussions, working with bilingual health advocates who have had a short practical training in

facilitating small group discussions.

The Women's Nationwide Cancer Control Campaign (Buchanan *et al.*, 1995) claim the following methods are effective in cervical and other screening: approaches to leaders of ethnic communities, the issuing of leaflets in minority ethnic languages (with emphasis on the correct language idioms and expert peer review), focus groups (amongst the homeless), and use of video.

Only one robust UK intervention study that has taken place in a multiethnic population has been identified. Adab *et al.* (2003) report on an RCT of the effect of evidence-based information (providing women with additional information on the pros and cons of screening, compared with the NHS Cervical Screening Programme leaflet currently offered by the NHS) on women's willingness to participate in cervical cancer screening. Of the 283 women attending 3 Birmingham general practices who completed the study – 141 controls and 142 intervention – 12.6 per cent and 23.0 per cent, respectively, were from minority ethnic groups. Fewer women in the intervention (79 per cent) than the control group (88 per cent) expressed intention to attend screening after reading the information leaflet (crude Odds Ratio 0.50, 95 per cent CI 0.26 to 0.97); after adjusting for other factors the trend persisted (Odds Ratio 0.60, 95 per cent CI 0.28 to 1.29).

(Grade A)

2. Interventions to improve uptake of breast screening and breast self examination (BSE) behaviour

There have been a number of comprehensive, including systematic, reviews and some specific interventions amongst minority ethnic group women that merit particular mention. Of general reviews the Scottish Health Purchasing Information Centre (SHPIC, 1997) reported that there were few UK RCTs in this area. Some of their findings are not specific to ethnic minority women:

- public education campaigns recruit only those most likely to attend anyway;
- open-ended written invitations signed by GPs achieve uptake rates of up to 75 per cent;
- written invitations from GPs which include scheduled appointments are more effective but only cost-effective if overbooking is allowed;
- reminder letters and second invitations to non-attenders can recruit an additional 13-21 per cent of non-attenders;
- and tailored interventions (such as with reference to screening history or risk assessment) have no substantial impact on uptake.

The review found that ethnic groups require special attention but that the evidence for using linkworkers was unclear.

A more comprehensive Cochrane review was undertaken by Bonfill *et al.* (2003) of strategies for increasing the participation of women in community breast cancer screening. Based on 14 RCTs conducted in several countries (and not specific to ethnic minority women), the investigators reported that the evidence favoured five strategies:

- letter of invitation (Odds Ratio: 1.66, 95 per cent CI 1.43 to 1.92);
- mailed educational material (Odds Ratio: 2.81, 95 per cent CI 1.96 to 4.02);
- letter of invitation plus phone call (Odds Ratio: 2.53, 95 per cent CI 2.02 to 3.18);
- phone call (Odds Ratio: 1.94, 95 per cent CI 1.70 to 2.23);
- and training activities plus direct reminders for the women (Odds Ratio: 2.46, 95 per cent CI 1.72 to 3.50).

Home visits (Odds Ratio: 1.06, 95 per cent CI 0.80 to 1.40) and letters of invitation to multiple examinations plus educational materials (Odds Ratio: 0.62, 95 per cent CI 0.32 to 1.20) did not prove to be effective.

There are a small number of randomised trials that have attempted to assess the effectiveness of interventions to improve the uptake of breast screening amongst minority ethnic groups. Atri *et al.* (1997) used a controlled trial, randomised by general practice, to determine whether a two hour training programme for general practice reception staff to contact non-attenders by telephone or by sending a GP letter could improve uptake in patients who had failed to attend for breast screening and whether women from different ethnic groups benefited equally. Amongst 2,064 women aged 50 to 64 in the inner London borough of Newham who had failed to attend for screening, over half from minority ethnic groups, attendance in the intervention group was significantly better than in the control group (9 per cent vs. 4 per cent). In the logistic regression model, the adjusted Odds Ratio was 2.3 (95 per cent CI, 1.1 to 5.3, $p=0.04$) for overall rate of attendance in the intervention group compared with the control group. The response was best in Indian women: 19 per cent in the intervention group and 5 per cent in the control group (the adjusted Odds Ratio being 2.2, 95 per cent CI 1.3 to 3.8, $p=0.005$), probably because many practice staff shared their cultural and linguistic background. Costs per additional woman screened were £13 but this finding needs to be treated with caution in the absence of statistical or sensitivity analyses and the issue of generalisability was not addressed (different participant or staff backgrounds may produce other results) (NHS Centre for Reviews and Dissemination, 1998).

(Grade A)

An earlier study (Hoare *et al.*, 1994) investigated the effectiveness of a linkworker intervention – which involved linkworker follow up (1 or 2 visits) to give encouragement and explanations about breast screening – on the subsequent attendance for screening by south Asian women registered in a breast screening centre who had failed to attend. While 59 per cent of the intervention group could be contacted by linkworkers, 25 per cent were permanently or temporarily not resident at the invitation address. No difference in attendance during the following 12 months was found between the intervention and control groups (49 per cent vs. 47 per cent) (Odds Ratio: 1.07, 95 per cent CI, 0.76, 1.51).

(Grade A)

Amongst the few non-randomised UK intervention studies, three inner city general practices in Cardiff, with a low uptake in the previous round of breast screening and a high proportion of ethnic minority women on their lists, were targeted to receive interventions to increase uptake (Bell *et al.*, 1999). The interventions comprised:

- identification of ethnic language groups;
- GP endorsement letter;
- translated literature including multilingual leaflet, GP letter, and screening invitation;
- transport to the screening centre;
- and language support.

Of 369 women invited, 187 attended for screening, an uptake of 50.7 per cent compared with that of 35.2 per cent in the previous screening round, a statistically significant increase of 15.5 per cent. (95 per cent CI 8.2 to 22.5). Translated literature, GP endorsement letter and language support by linkworkers were beneficial, although the provision of free transport was ineffective and underutilised. Uptake was highest amongst Urdu and Gujarati speaking groups and lowest for the hardest to reach groups of Bengali and Somali speakers. While the attendance rate amongst ethnic minority groups can be increased, these interventions have cost implications.

(Grade B)

There are a few notable randomised trials involving multiethnic populations from other countries. Besides the Atri *et al.* (1997) and Hoare *et al.* (1994) trials, three of the trials reported in Bonfill *et al.*'s (2003) Cochrane review related to multiethnic populations. Bodiya *et al.* (1999) reported an RCT involving a reminder letter (and a reminder letter plus a reminder phone call) from the radiology department amongst a multiethnic population in Michigan, USA. With respect to attendance to the mammogram invitation during the following 12 months the interventions were effective (Odds Ratio: 2.57, 95 per cent CI, 1.46 to 4.53 for letter plus phone call; Odds Ratio: 1.08, 95 per cent CI 0.61 to 1.89 for letter only).

(Grade A)

Janz *et al.* (1997) reported similar results (Odds Ratio: 2.14, 95 per cent CI, 1.57 to 2.93) for an RCT assessing the effectiveness of a physician letter plus phone call to non-responders amongst a Michigan, USA population with a high percentage of low socio-economic, minority women.

(Grade A)

Finally, in a breast cancer screening intervention (home visit plus educational material) among low income black women in inner city Atlanta, Sung *et al.* (1992) did not find that the intervention was effective (Odds Ratio: 1.04, 95 per cent CI, 0.65 to 1.67), yielding results similar to the home visit trial reported by Hoare *et al.* (1994).

(Grade A)

Whilst Bonfill *et al.* (2003) reported that home visits have not proven to be effective, a different conclusion was reached by Seow *et al.* (1998), not referenced in the Cochrane review. In a randomised trial of three methods to improve mammography uptake, these investigators found that response to a second reminder was generally low (7.0 per cent) and that additional print material did not improve screening attendance (7.6 per cent) in this group of initial non-attenders. However, personal contact with the family through a home visit significantly increased uptake (13.3 per cent) and as a method might be helpful for women who have less frequent contact with the health care system.

(Grade A)

Brief episodes of repeated breast self examination (BSE) instruction linked to the Canadian National Breast Screening Study were evaluated in around 90,000 participants (Baines and To, 1990). Among those eligible for re-screening (approximately 72 per cent), measured BSE competence scores significantly improved over time and correlated directly with reported BSE frequencies. Among all participants the proportion reporting BSE frequencies of 12 per year or more increased over time from around 20 per cent on entry to 50 to 64 per cent at final screen; also, reports of zero frequency fell from 50 per cent to 10 to 15 per cent. Educational status, age, and ethnic origin had negligible/no influence on BSE competence.

(Grade B)

3. Interventions to promote physical activity

Carroll *et al.* (2002) provide some evidence on the effectiveness of exercise on prescription schemes (EoP) – initiatives based in primary care by which GPs prescribe exercise as the preferred course of treatment for a range of conditions including CHD – for south Asian women. EoP schemes have been available in England and Wales since the early 1990s (Health Development Agency, 1998). Although there are many service models, key features include a preliminary fitness assessment and a recommended programme of physical activity over a period of weeks. In a survey of health authorities with south Asian populations of at least 0.5 per cent, some schemes were identified in which special provision was made for south Asian Muslim women (but none in many schemes).

The perceived barriers to exercise for such women were access to facilities, cost, childcare facilities, cultural codes of conduct, and language. Many schemes suffered from shortcomings, including communication and co-operation between all the participating parties and the need for clarification of procedures. The investigators undertook and evaluated a pilot intervention programme with special provision for south Asian women, which was seen as being successful both by providers and participants. They conclude that specific consideration should be given to the needs of south Asian Muslim women with respect to the use of local community facilities and the employment of bilingual and sympathetic staff. Costs to these women should be kept low, the provision of childcare facilities should be considered, and EoP schemes should be set up on a long- rather than short-term basis. Further trials with large samples, clear criteria for groups and intervention programmes, and with outcome measures at specific intervals up to one year are recommended. However, there is conflicting evidence about the effectiveness of EoP schemes in the wider community, Harland *et al.* (1999) recommending that national and local government, health authorities, and primary health care teams should be cautious about current and future expenditure on, and implementation of, exercise prescription or referral schemes.

4. Interventions on smoking cessation

Until recently, ethnic minorities have not been accorded special attention in national policies on smoking reduction or cessation (Raw *et al.*, 1998; West *et al.*, 2000). However, in August 2001 the Department of Health launched the NHS Asian Tobacco Information Campaign to reduce the high level of smoking and chewing tobacco in Asian communities, with a budget of £1 million. A specialist Asian language phonenumber has been set up to give free advice on how to give up smoking. The service operates in a variety of languages, including Urdu, Punjabi, Hindi, Gujarati, and Bengali. It has also funded 19 local projects and national advertising campaigns in the appropriate mother tongue language have appeared on specialist Asian TV and radio, and in the press. Other local smoking cessation services are also increasing.

There is a lack of robust evaluations of smoking cessation schemes targeted at minority ethnic groups. Farren and Naidoo (1996) report that knowledge of the health risks of smoking is high, as is the desire and motivation to quit, indicating that there is potential for targeted campaigns to achieve good results. They discuss innovative targeted campaigns with a national coverage, including the Ramadan Project, a resource pack funded by the Department of Health and No Smoking Day, and local activities which target black and minority ethnic smokers in the workplace or cultural centres.

The Health Development Agency collected details on a wide range of specific local initiatives. These included Bradford Community Health Trust's handing out of 5,000 packets of dates to people by linking with five local mosques and visiting them during Friday prayers in Ramadan. Labels with details of the smoking cessation service were put on the packets in Urdu and Bengali, along with a message about smoking and health, and distributed to people attending prayers. The imams in some of the mosques also provided support, by talking to those in prayer about smoking and health. The smoking cessation team also took the West Yorkshire NHS no smoking double-decker bus – with the team's two Asian linkworkers (one male and one female) and supporting literature in relevant languages – on a tour of the main areas where the Asian community live. In all, 14 mosques were covered, reaching over 2,000 people. Other publicity included radio phone-ins on local programmes covering Ramadan and competitions. A rapid health needs assessment carried out during the tour found that only 27 per cent of the 55 respondents knew about the local stop smoking service. In the three months following the campaign (which took place from October to December 2001) the number of Asians setting a quit date went up three times compared to the year before (from 32 – or 3 per cent of the total number of

those who came forward, to 93 or 8.5 per cent of respondents).

(Grade C)

Coventry is addressing the issue of paan. Nicotine replacement therapy has been made available to local paan users on prescription. A locally funded general awareness campaign was also launched, involving the targeting of local mosques through the printing of a timetable for daily prayers during Ramadan (that carried a health message about tobacco).

In London's Tower Hamlets, another NHS funded project – the Tower Hamlets Bangladeshi Stop Tobacco Project – is working with tobacco paan retailers (Fox, 2004). A group of local Asian men were trained to visit retailers to remind them of their legal responsibilities (paan is poorly labelled both in terms of health warnings and contents), give them information about Asian smoking cessation services and persuade them to repackage the paan in plastic bags – which are provided free and carry a health warning in Bengali. Good rates of take-up (60 retailers) have been reported. Interviews with retailers before and after the project showed that they became much more aware of the health risks of chewing paan and knew about the existence of the local smoking cessation service. In addition, from April 2003 to March 2004 the project actively supported 310 people (126 women and 184 men), 62 per cent of whom gave up using tobacco over 4 weeks.

(Grade C)

5. Interventions to reduce the risk of coronary heart disease (CHD)

There is a substantial literature on interventions to reduce the risk of CHD in minority ethnic groups but few that are robust in design. McKeigue (2000) reports on RCTs for interventions – comprising exercise and dietary supplementation with Omega 3 fatty acids – that address metabolic disturbances associated with insulin resistance and central obesity in south Asian and European subjects (28 south Asian men, 12 south Asian women, 27 European men, and 20 European women). The two exercise groups received a 12 week programme with examinations 24 hours after the last session and a similar programme with examinations 5 days after the last session, the exercise programme involving three half hour sessions of walking/jogging/running and one supervised aerobic circuit session per week. In south Asians and Europeans there was a marked increase in insulin sensitivity immediately after the exercise programme but this persisted only for a few days. The investigator concluded that only a sustained increase in physical activity on a daily basis would be likely to reduce the risk of non-insulin-dependant diabetes and the risk of cardiovascular disease. There were no changes following a diet supplemented with Omega 3 fatty acids.

(Grade A)

6. Interventions for controlling the prevalence of diabetes and for blood glucose control

The World Health Organisation (WHO) Study Group (1994) has argued for resources to be focused on improving the quality of preventive care in primary settings and on public health interventions for controlling the condition. The most important of these are likely to be concerned with the promotion of physical activity and control of obesity. Measures to promote physical activity in minority ethnic groups have been previously discussed. There are reports of several major lifestyle intervention trials with type 2 diabetes patients, halving the risk in high-risk subjects, achieving rapid change in lifestyle, and conferring similar benefits in different ethnic groups (Tuomilehto and Lindstrom, 2003). In particular, the

US Diabetes Prevention Programme (Diabetes Prevention Programme Research Group, 2002) – involving weight loss/weight maintenance and physical activity goals – resulted in a reduction of 58 per cent in the incidence rate of diabetes amongst 1,079 participants (45 per cent from ethnic/racial minorities). Key components of the intervention were:

- individual case managers/‘lifestyle coaches’;
- frequent contacts with participants;
- a structured, state of the art 16-session core-curriculum that taught behavioural self-management strategies for weight loss and physical activity;
- supervised physical activity sessions;
- tailoring of materials and strategies to address ethnic diversity, and an extensive network of training, feedback, and clinical support.

(Grade A)

In addition, two RCTs have assessed culturally specific health promotion interventions and a substantial programme of health promotion work has been undertaken in Wales using a range of approaches (Leedham, 2000; Leedham and Akhtar, 2002). Of the two RCTs, Hawthorne and Tomlinson (1997) used a pictorial flashcard one-to-one education in 201 Pakistani Muslim patients in Manchester attending a hospital outpatient clinic or diabetic clinics in general practices. At 6 months all parameters of knowledge were increased in the intervention group: percentage scores for correctly identifying different food values increased from 57 per cent to 71 per cent and knowledge of one diabetic complication from 18 per cent to 78 per cent. Self-caring behaviour also improved, 92 per cent of patients doing regular glucose testing at 6 months compared with 63 per cent at the start. Attitudinal views to diabetes were more resistant to change. Haemoglobin A1c (HbA1c)¹⁷ control improved by 0.34 per cent over 6 months. The intervention thus empowered Asian diabetics to take control of their diets, learn to monitor/interpret glucose results, and understand the implications of poor glycaemic control for diabetic complications.

(Grade A)

The second RCT concerns the effectiveness of culture-specific diabetes care for Surinam south Asian patients (n=53) with type 2 diabetes in The Hague (Middelkoop *et al.*, 2001). The intervention comprised a referral of the south Asian patients to a specialist diabetes nurse and a dietician who had received training in south Asian cultural and culinary traditions. They used educational audio cassettes containing general diabetes information in appropriate languages and booklets containing general nutritional information and a carbohydrate variation list, both based on south Asian cooking. The diabetes education provided by the nurses and dieticians consisted of intensive guidance (4 to 7 visits) for 3 months and then less frequent guidance. The outcome was the difference in the change in the HbA1c level immediately after the intensive guidance, compared with waiting list controls (n=60). An adjusted difference of 0.50 per cent (p=0.004) was found in the average change in HbA1c level in favour of the intervention patients. In a controlled before and after study of 89 patients, little improvement was found in BMI but the lipid profile had improved significantly after one year. Continuity in the provision of care appears to be crucial for a lasting effect.

(Grade A)

The substantial programme of work by Diabetes UK Cymru (Leedham and Akhtar, 2002) in Wales – a three year health promotion project to help people with diabetes in minority ethnic communities manage their diabetes better – has reported key findings on good practice. This encompassed in phase I focus group sessions in Bangladeshi, Pakistani, Somali, and Chinese communities that demonstrate a very

17. The HbA1c blood test – also called glycosylated haemoglobin, glycohemoglobin, or A1c – estimates how well blood sugar has been controlled during the previous three or four months.

limited understanding of diabetes in relation to its cause, implications for lifestyle, and longer-term effects. Phase 2 has involved developing a database of culturally and language appropriate resources and materials and development work in particular communities through a series of culturally and language appropriate diabetes awareness sessions. The research recommends that health care providers should work with grassroots community partners to set up health promotion initiatives.

Also, the potential should be exploited for community-specific diabetes self-help groups: the Local Diabetes Service Advisory Groups should consider running more diabetes awareness sessions to kick start longer-term programmes. Focus group interviews revealed that people in minority ethnic groups preferred video or tape recorded messages about diabetes rather than leaflets. Participants (especially women) preferred to share their experiences at group meetings rather than attend a one-to-one session with a doctor or nurse. Diabetes UK Cymru is progressing the idea of community-specific local self-help groups of people with diabetes, carers, and other interested parties and is now setting up a Cardiff self-help group for Gujarati speakers with diabetes and their families.

(Grade B)

Two trials have reported on blood glucose control and complications in diabetes. The Diabetes Control and Complications Trial in the USA (Diabetes Control and Complications Research Group, 1993) reported evidence of the effectiveness of strict blood glucose control in reducing renal and other complications of insulin dependent diabetes.

(Grade A)

The UK Prospective Diabetes Study has assessed the relationship among self-reported ethnicity, metabolic control, and blood pressure during treatment of type 2 diabetes using an RCT (Davis *et al.*, 2001). Around 3,000 newly diagnosed type 2 diabetic patients (83 per cent white, 9 per cent Afro-Caribbean, and 8 per cent Asian of Indian origin) were recruited to the study and randomised to conventional or intensive glucose control policies. During the 9 year study period body weight increased more in white patients than the ethnic minority groups. There were no consistent ethnic differences in mean change in fasting plasma glucose or HbA1c. After adjustment for antihypertensive therapy, increase in systolic blood pressure at 9 years was greatest in Afro-Caribbean patients. Mean diastolic blood pressure, total cholesterol, and LDL cholesterol decreased progressively in each group over the 9 years.

(Grade A)

7. Interventions to promote infant breastfeeding

The Health Development Agency (HDA) reported on the effectiveness of public health interventions to promote the initiation of breastfeeding from systematic review evidence (Protheroe *et al.*, 2003). This section is based on that review.

Their report covers the way that health services are organised and antenatal instruction is delivered, attitudes of the mothers themselves, their partners and peer groups, the kind of support provided by the father, other family members and friends, and supportive environments outside the home and in the workplace. The authors cite a study showing that small informal discussion classes emphasising the benefits – and giving practical advice on how to breastfeed – can help increase the number of women who adopt this approach. Such discussion classes were found to be especially effective among women on a low income or who came from certain ethnic minority groups. Studies of low income black

American women show that one-to-one health education appears more likely than a group session to persuade those planning to bottle-feed to change their minds. Another study found that breastfeeding promotions delivered both before and after birth were more likely to succeed than antenatal or postnatal interventions alone.

(Grade C)

There is, in addition, a range of evidence relating to the population in general. The investigators (Protheroe *et al.*, 2003) found that mothers given the opportunity to talk to others who are either breastfeeding, or who have done so successfully in the past, are more likely to try breastfeeding than those who simply talked to a health professional or were given literature to read. In Scandinavia (where around 98 per cent of new mothers breastfeed) exposure to a successful breastfeeding experience has been one of the crucial components of a multi-faceted approach to promoting breastfeeding. Combined interventions that have been implemented nationally in Scandinavia over the last two decades include:

- problem solving information written by – and for – mothers;
- peer support groups;
- extended paid maternity leave with the offer of a guaranteed return to previous work;
- improvements in the breastfeeding management skills of health professionals;
- and changes in maternity ward practices to promote mother-infant contact.

The HDA indicates that there is evidence that this multi-faceted approach – supported by media campaigns, health education, training of health professionals and/or changes in government and hospital policies – is more effective than standalone interventions. For example, professional training was most likely to have an effect when implemented as part of a package of measures.

(Grade C)

With respect to the full evidence base, however, the investigators point out that the effectiveness of each individual component has not been evaluated. They urge that more research be conducted into the effects of both local and national media-based initiatives, the former appearing to have some effect in challenging negative attitudes to breastfeeding, and on how the following can impact on the uptake of breastfeeding:

- informal health education in small groups during the antenatal period;
- peer support during both the antenatal and postnatal periods;
- changes in maternity ward practices to promote mother-infant contact;
- and increased maternity leave.

They note, too, many other (including some apparently promising) intervention studies which were improperly evaluated or limited by methodological weaknesses and recommend that all future studies should be designed to permit adequate evaluation, including the impact of the programmes on different socio-economic and ethnic groups.

Since this review was undertaken, Ingram *et al.* (2003) have evaluated an intervention to assess south Asian grandmothers' ability to support successful exclusive breastfeeding daughters/daughters-in-law in an area of low exclusive breastfeeding amongst 16 south Asian families. The intervention included a leaflet covering the health benefits of breastfeeding, good positioning and attachment, feed management, and how families can support breastfeeding. The investigators report that the intervention was appreciated by the south Asian families and seemed to be influencing behaviour, particularly in giving colostrums¹⁸, water or artificial milk and the use of dummies/pacifiers. They recommend linkworkers

18. Colostrum is the first milk produced in the early days of breastfeeding and is low in fat and high in carbohydrates, protein, and antibodies.

with appropriate training and ability to speak the languages relevant to the ethnic groups in the area and the recording of details of baby-feeding method at eight weeks systematically by ethnic group. (Grade B)

8. Interventions to reduce the risk of sexual transmission of HIV/AIDS

An overview of findings and recommendations from a review of selected systematic and other reviews and meta-analyses published since 1994 was undertaken by the Health Development Agency (Ellis *et al.*, 2003). The reviewers did not find any review level evidence which contained information about inequalities relevant to the UK priority populations. Amongst key gaps in the evidence base they identified no review level evidence relevant to UK African communities (including specific sub-populations of men who have sex with men, for instance black people). They did find that there was sufficient review level evidence to conclude that small group interventions delivered at the community level can be effective in influencing the sexual risk behaviours of black and minority ethnic women. Given the cultural differences with respect to UK communities, however, the reviewers suggested that it was not possible to transfer findings to the UK's African population and were, therefore, unable to make any policy and practice recommendations specific to the African population in the UK. They make several key recommendations for research:

- a need for impact and outcome evaluations of interventions with UK African communities at all levels;
- secondary analyses/reviews of data as they become available from black and minority ethnic group studies deemed relevant to UK African communities;
- further investigation into group-level interventions with black and minority ethnic group women via impact and outcome evaluations;
- and a need to explore the added value of designing interventions specifically for these groups and where necessary involving the communities in the design, implementation and evaluation of interventions.

They also identify a need for research on the influence of HIV voluntary counselling and testing according to ethnicity.

9. Interventions to change nutrition practices amongst minority ethnic groups

A review of the research literature (1985-1996) on the effectiveness of interventions to promote healthy eating in people from minority ethnic groups was undertaken by White *et al.* (1998). Only 40 papers reporting 29 studies evaluating interventions to promote healthy eating in minority ethnic groups were identified, only two of which were conducted in the UK (compared with 23 out of 29 in the USA). Nearly all the studies included an educational element of some kind, the most common being a group or class session. Frequently, nutrition education was combined with physical activity classes. Other methods include food supplements, food policies and provision of resources. Most interventions aimed at multiethnic populations made little attempt to adapt the intervention for specific ethnic groups. Almost half the studies demonstrated some degree of effectiveness but only a quarter were judged effective for their main nutritional aims. The main categories of intervention were educational approaches (one-to-one, group or community-wide in homes, schools or community settings), policy

measures (such as school food policies), and technological measures (such as food supplements). The reviewers concluded that, apart from two UK-based studies (which evaluated food supplements for minority ethnic toddlers, both demonstrating some degree of effectiveness), few of the interventions could be directly applied to the UK. Most community-based projects to promote healthy eating in minority ethnic groups in the UK lacked formal evaluation and none had sound evidence of effectiveness.

(Grade C)

Since the review was published several important studies have been undertaken. Steptoe *et al.* (2003) used a parallel group RCT to measure the effect of brief behavioural counselling (based on the stages of change model) in general practice on the consumption of fruit and vegetables in adults (n=271) from a low income, ethnically mixed inner city area. This was compared with time matched brief nutrition education counselling. Consumption of fruit and vegetables increased from baseline to 12 months by 1.5 and 0.9 portions per day in the behavioural and nutrition groups. The proportion of participants eating five or more portions a day increased by 42 per cent and 27 per cent in the two groups. Plasma beta-carotene and alpha-tocopherol (a form of vitamin E) concentrations increased in both groups.

(Grade A)

Thus, brief individual counselling can result in sustained increases in consumption of fruit and vegetables amongst low income, ethnically mixed adults. School-based nutritional programmes have given poorer results.

Ciliska *et al.* (2000) performed a systematic review to investigate the effectiveness of community-based interventions to increase fruit and vegetable consumption amongst children aged 4 and older and reported that the most effective interventions gave clear messages about increasing fruit and vegetable consumption, incorporated multiple strategies that reinforced the messages, involved the family, were more intensive, were provided over a longer period rather than one or two contacts, and were based on a theoretical framework (Ciliska *et al.*, 2000; Atkinson and Nitzke, 2001). One of the largest of the interventions was the child and adolescent trial for cardiovascular health study, involving the randomisation of over 4,000 children from many ethnic groups (Perry *et al.*, 1998). Third grade students received 15-24 lessons with family and food service activities, post-test 24 hour recalls showing no differences between the intervention and non-intervention control groups in total servings of fruit and vegetables or cardiovascular risk factors.

(Grade A)

10. Use of linguistically and culturally appropriate health education/promotion materials

It is the UK Government's policy to see a growth in 'expert patients', that is, people who are well informed about their health and the choices open to them, as outlined in the White Paper, Saving Lives: Our Healthier Nation (Department of Health, 1999). However, the majority of health information is available only in written English format, denying access to many people in minority ethnic groups, except through English speaking members of their family. There are clearly drawbacks to the use of translated written materials including the loss of meaning in translation, the fact that the language of some ethnic groups has no written tradition or format, and that some people are not literate in their own language. It is reported, for example, that 70 per cent of the Pakistani population in Nottingham have origins in the Mirpur District in Pakistan, where people speak a local dialect (Mirpuri Punjabi) which has no written form. Finally, the high costs involved in translating high quality information in multiple languages across a wide range of subjects may represent a barrier to making such information widely available.

The scope for multimedia approaches exists as a majority of the ethnic booster for the Cabinet Office's People's Panel (n=830) felt that new technology would make dealing with government easier, although of the new technologies (touchscreen, interactive TV, personal computers, and telephone services) they much preferred to use the telephone, although less so than the Panel as a whole (59 per cent vs. 72 per cent) (Cabinet Office, 2000).

There is only limited evidence on the effectiveness of new information technology amongst minority ethnic groups in conveying health promotion messages or improving access to services. Phul *et al.* (2003) explore the provision of information by health promotion units to non-English speaking Asians in the UK – and the potential for new technology to provide better access to such information – through a questionnaire survey of a purposive sample of health promotion units (n=90). Health promotion specialists considered that videos and verbal presentations were the two most effective formats of information for use with this target group and that scope for interactivity was important. The investigators concluded that attempts were beginning to be made by health promotion units to use this technology to provide health information in Asian languages and that usefulness depended on the availability of simple, user friendly systems, such as touchscreens.

(Grade C)

Although video is used widely amongst minority ethnic groups for health education/promotion purposes, very few studies have evaluated the effectiveness of this intervention. Indeed, the results of a search by Anderson *et al.* (2003) for studies that examined the effectiveness of linguistically and culturally appropriate health education materials (on improving outcomes of client satisfaction, racial/ethnic differentials in utilisation of services or treatment and health status measures) identified only four of quality, all of which examined the effectiveness of culturally sensitive health education videos. Herek *et al.* (1998) tested HIV/AIDS educational videos (1. black announcer, multicultural message, 2. black announcer, culturally specific message, and 3. white announcer, multicultural message) amongst low income African Americans. The first was rated more credible, although no significant differences across groups in risk reduction intentions or intention to be tested for HIV were found.

(Grade B)

In Kalichman *et al.* (1993), the effectiveness of video (standard AIDS video, video matching race and gender, and video matching race and gender, and culturally-specific message) was assessed in low income, African American women. With respect to outcome – having HIV test within 2 weeks after intervention – 18 per cent in the culturally specific message group reported HIV testing and none in the other two groups. The intervention in Stevenson and Davis (1994) was HIV/AIDS video similar in race and culture compared with dissimilar video, the culturally similar video being rated more favourably (although there were no behavioural outcomes) amongst a population of 14-15 year old African American students.

(Grade B)

Finally, Sussman *et al.* (1995) compared rap format video with standard video on tobacco use prevention amongst adolescents (41 per cent African American and 45 per cent Latino). Cultural sensitivity and likeability were rated, the rap video being rated a more accurate portrayal of African American culture but with no difference in likeability by ethnic group.

(Grade B)

Thus, only one study reported a change in health behaviour, insufficient evidence to determine the effectiveness of this intervention. No UK evaluative studies have been identified.

Only one project (also evaluated) has been identified that provides access for minority ethnic groups to health information in appropriate languages via touchscreens. This intervention, the 'Three Cities'

Project, comprises multi-media touchscreen kiosks offering audio and visual health information in 5 community languages (English, Mirpuri Punjabi/Urdu, Gujarati, Bengali, and Chinese) in three cities (Nottingham, Sheffield, and Leicester Health Action Zones) (Coppel, 2002; Jackson and Peters, 2003). The project was developed at grassroots level by inviting the community to become involved in identifying key topics (notably, mental health, cancer, cardiovascular disease, diabetes, nutrition, tuberculosis, cervical screening, smoking cessation, substance/alcohol misuse, and exercise) and the languages. Locations for the kiosks are rotated and include libraries, health and medical centres, neighbourhood centres, and a mosque in minority ethnic communities.

The project has been evaluated through an analysis of computer logs and a questionnaire survey in each city conducted by bilingual interviewers. Of 1,278 'hits' during the first 6 months of the project, 13 per cent were by users aged 15 and under, 25 per cent by those aged 16 to 35, 43 per cent aged 36 to 55, 16 per cent aged 56 to 75, and 3 per cent aged 75 and over. Of 212 persons interviewed, 65 per cent used telephone audio and understood information and 55 per cent read and listened to information. Furthermore 211 said that they would recommend the touchscreen to other people and 91 per cent said that they would be able to explain how to use it to others. Of the interviewees, 70 per cent found the system easy to use and a further 27 per cent fairly easy. When comparing the touchscreen with other media, two thirds of interviewees felt it was better than pamphlets and magazines and 41 per cent better than television or video. Of the 212 people interviewed, 112 (53 per cent) said that they would tell family and friends about the touchscreen, 13 would change what they did, 31 reported that they would both tell family and change practice and 6 would ask for medical advice. This is part of a longer-term evaluation, the investigators concluding from initial evaluation that touchscreens appear to be a suitable medium for making health information available in specific languages. The project is planning to roll out copies of the software on CD to other parts of the NHS where language is an issue and is investigating alternative ways of making the information available (including the internet and digital TV).

(Grade B)

11. Training in cultural competency for health care staff

The systematic review of the literature by Anderson *et al.* (2003) identified only one study (Wade and Bernstein, 1991). The setting was a counselling (mental health) centre on a metropolitan college campus and the intervention 4 hours of cultural sensitivity training for counsellors (2 African American, 2 'Euro American') and the control counsellors with usual training (2 African American and 2 'Euro American'). Amongst 80 subjects who were lower-income African American women with a mean age of 38 residing in the community, clients in the intervention group reported greater satisfaction with counselling than did controls (standard effect size = 1.6, $p < 0.001$), independent of the race of the counsellor. Clients were asked to return for three follow up visits, those assigned to the intervention group returning for more sessions than did those assigned to the control group (absolute difference = 33 per cent, $p < 0.001$).

(Grade A)

With only one published study (and none identified for the UK in literature searches), the evidence is insufficient to determine the effectiveness of cultural competence training programmes for health care staff.

12. Linkworker interventions to improve access

In Britain, linkworker schemes had their origin in the Asian Mother and Baby Campaign in the mid 1980s where the role was developed to help combat poor perinatal health in south Asian communities. Over the last two or three decades, linkworker schemes to address the needs of minority ethnic communities in primary care have increased in number but remain patchy geographically. Moreover, the role of linkworkers varies but usually encompasses interpreting, advocacy, health education, and health promotion, with the first of these frequently being dominant. Linkworkers are often seen as ‘a cultural bridge between doctors and patients’ (Gillam and Levenson, 1999) but their role may be broader and has encompassed that of facilitator in interactions with a wider network of agencies and service providers and also in confronting individual and institutional racism in the NHS (Winkler, 1984; Cornwell *et al.*, 1984).

Linkworkers have been employed in many specific areas, including patient health checks, women’s health, and mental health (Levenson and Gillam, 1998), increasing the uptake of breast and cervical screening (Hoare *et al.*, 1994; Naish *et al.*, 1994), managing patients with diabetes and asthma (Khanchandani and Gillam, 1999; Hawthorne, 2001), assessment of depression and brief cognitive behaviour therapy (NHS Beacon Services, 1999), antenatal and maternity care (Warrier, 1996; Hicks and Hayes, 1991; Parsons and Day, 1992; Starkey, 1998), and consanguinity and genetic morbidity (Qureshi *et al.*, 2003). However, problems associated with the role include the short term nature of the schemes, lack of funds for evaluation, the generally low employment status of linkworkers and their sometimes uncertain location in the primary health care team and poorly coordinated training that is often not accredited/quality assured (Gillam and Levenson, 1999; Khanchandani and Gillam, 1999).

There is a paucity of robust evidence on the effectiveness of the linkworker role but several service evaluations. These include the role of linkworkers in the Asian Mother and Baby Campaign. In Leicestershire, for example, Mason (1990) found that they provided an important service in interpreting but were less successful as providers of health education knowledge to Asian women, improvement in knowledge only occurring in women with a good understanding of English. Khanchandani and Gillam (1999) reported that linkworkers trained in health promotion and chronic disease management had resulted in a shift in workload from the practice nurse to the linkworker and there were improvements in asthma and diabetes care. An evaluation of linkworkers in antenatal care in 20 health districts (Hicks and Hayes, 1991) revealed a mismatch between client need and service planning, resulting in many of the at risk group being denied the full and appropriate services of the linkworker. The investigators called for the systematisation of the service where it was effective and its discontinuance in other areas. There was stronger evidence of its success (a wider role than just language interpretation) in Hackney (Parsons and Day, 1992), a retrospective study of three groups of non-English speaking women – groups with and without the intervention in the same hospital and a non-intervention reference hospital – found differences in three outcomes: antenatal length of stay, induction, and mode of delivery (including a statistically significant reduction in the use of caesarean section in the intervention group that could have been attributable to improved communication).

(Grade B)

Both advantages and disadvantages have been reported in the Maternity and Health Links project set up in Bristol to provide linkworkers at a health centre, GP surgery, and maternity hospital, including English home tuition for pregnant women (Starkey, 1998). A mix of key strengths and structural weaknesses were also reported in a study of the effectiveness of three linkworker and advocacy schemes (Birmingham, Wandsworth, and Leeds) – in which linkworkers were independent of health services – in empowering minority ethnic community users of maternity services (Warrier, 1996). The study emphasised the importance of training and support for linkworkers and monitoring for quality.

There are only a few robust evaluations of the efficacy of the linkworker intervention, including two RCTs and a case note review, and these demonstrate the need for rigorous evaluation of the linkworker role in different settings. In an RCT to assess the effectiveness of a linkworker intervention (involving giving encouragement and explanations about breast screening) on the subsequent attendance for screening by 'Asian' women, Hoare *et al.* (1994) and Hoare (1996), no difference in attendance was found between the intervention group and a control group that received no visits (49 per cent vs. 47 per cent). Moreover, 59 per cent of the intervention group could not be contacted by linkworkers. This study demonstrated the importance of using linkworkers in an appropriate role and of the need for rigorous evaluation of such schemes.

(Grade A)

The effect of linkworkers in the provision of culturally appropriate one-to-one structured health education on glycaemic control and knowledge of diabetes (delivered with pictorial flashcards as a visual aid) in British Pakistani women (n=105) with type 2 diabetes has been assessed in an RCT of 200 Pakistani patients with diabetes (Hawthorne, 2001). All patients were assessed before and six months after the intervention by questionnaire and haemoglobin A1c blood tests to measure their overall blood sugar level. The women in this study – who had shown less knowledge about diabetes and had poorer glycaemic control than men – demonstrated a catch-up improvement in knowledge to equal men and glycaemic control also improved in the women receiving the intervention. However, illiterate women performed less well than their literate peers, continuing to score less on knowledge parameters and failing to show an improvement in glycaemic control.

(Grade A)

A case note review was undertaken by Dance *et al.* (1993) to evaluate the introduction of an Asian Linkworker Programme with specific reference to perinatal mortality rates and the number of low birthweight infants in the Asian community. In addition to routine antenatal care, the specific intervention comprised Asian women receiving a minimum of three home visits and two phone calls from an Asian linkworker who spoke their mother tongue, the linkworkers role being to provide basic health education/information and social support. Compared to the control group (without linkworker) (n=221), the women in the intervention group (n=464) had an improved perinatal mortality rate (12.9/1000 vs. 19.2), a lower rate of low birthweight infants (8.1 per cent vs. 11.3 per cent), had fewer low birth weight perinatal deaths, required less analgesia during labour, required less episiotomies, had shorter labours, were more inclined to breastfeed, breastfed for longer, and were more likely to attend for postnatal examination.

(Grade B)

These studies emphasise the importance of robust evaluations of effectiveness of linkworker schemes and the deployment of linkworker resources in settings where they work. Better use of these resources may result from a more strategic consideration of their role and their integration by local health boards.

13. Translation and interpreter services

Bilingual health care staff

The need for interpreter services is diminished by language concordance between health professional and patient. However, this method of addressing language difficulties (and, indeed, of improving access in general) is rarely discussed in the literature as it is clearly subject to supply factors and personal choice. The issue of public preferences amongst minority ethnic groups in the field of psychiatry, including that

for bilingual staff/workers to interpreters, has been addressed (Bhui, 1998; NHS Executive, 1994). Bhui reports on the recruitment of 210 Punjabi Asian and 188 white patients to a prevalence study based in five general practices in a London ward. All of the GPs were of Asian origin and spoke at least two Asian languages. More Punjabi Asian attenders visited their GP when the receptionists were bilingual (Odds Ratio: 2.59, 95 per cent CI 1.40 to 4.77 and Odds Ratio: 6.76, 1.80 to 25.43).

(Grade B)

Westermeyer (1990) argues that psychiatrists and other mental health professionals should develop skills and experience for conducting cross-language communication, including working with translators.

Bilingual health advocates and other interpreters in proximate consecutive interpretation

Comprehensive services have been established by some NHS trusts and there are examples of good practice. For example, the core funded City and Hackney Primary Care Trust Advocacy Services (CHAS) provides advocacy and interpreting services to users of primary and community services in the City and Hackney area. There is also an out-of-hours telephone interpreting service provided to GPs. The NHS trained staff comprises 18 permanent health advocates (12 core languages) and 15 sessional advocates (11 languages) and the service operates an open referral system. The scheme is internally evaluated through the collection of monthly quantitative data on referral and patient numbers, client ethnicity, unmet requests, and complaints. Qualitative feedback on service delivery is also obtained through annual surveys or focus groups with users and staff.

However, few robust evaluations of bilingual advocates have been undertaken and none identified in the Cochrane library. Two systematic reviews have been identified that include use of interpreter services or bilingual providers. Anderson *et al.*'s (2003) review of culturally competent health care systems included this intervention but concluded that available studies provided insufficient evidence to determine the effectiveness of these services for clients with limited English proficiency. Only one relevant study (Sarver and Baker, 2000) was identified.

Sarver and Baker (2000) used a cohort study design to assess whether patients who encountered language barriers during an emergency department visit were less likely to be referred for a follow-up appointment and less likely to complete a recommended appointment. The proportion of patients who received a follow-up appointment was 83 per cent for those without language barriers, 75 per cent for those who communicated through an interpreter (both professionally trained and untrained), and 76 per cent for those who said an interpreter should have been used but was not ($p=0.05$). The adjusted Odds Ratios for not receiving a follow up appointment was 1.92 (95 per cent CI 1.11 to 3.33) for patients who had an interpreter and 1.79 (95 per cent CI 1.00 to 3.23) for patients who said an interpreter should have been used, compared with patients without language barriers. However, appointment compliance was similar for patients who communicated through an interpreter, those who said an interpreter should have been used but was not, and those without language barriers (60 per cent, 54 per cent, and 64 per cent, respectively; $p=0.78$). One of the drawbacks of the study was that differences in effect based on whether the interpreter was professionally trained (12 per cent) or was a family member or hospital staff member serving as an ad-hoc interpreter (88 per cent) were not reported.

(Grade B)

Remote (telephone) interpreting and other uses of information management and technology

There are many different ways that technology can be used to overcome language difficulties but the most frequently used in Britain is telephone (or remote) interpreting (including 'remote-simultaneous interpretation' used in some settings in the USA). NHS Direct in England is an example of a Government supported telephone health advice service that includes a translating service. Similarly in Wales, NHS Direct Wales accesses a telephone translating service (language line).

There is a wide range of practice from remote interpreting on a shared line to the innovative use of telephone conferencing technology and several NHS organisations have invested in such technology. For example, the Broadwater Farm Medical Centre and Haringey Community Care Trust have established a hands-free telephone Turkish interpreting service to improve access for the Turkish speaking Kurdish refugee population to primary care services (NHS Beacon Services, 1999). This rapid access remote interpreting service uses BT hands-free AC4600 conference telephone technology and is available from 9am to 1.30pm via the remote link. The service is being further developed to include a visual link using an ISDN line and tele-medicine technology.

There have been few robust evaluations of telephone interpreting services and only one RCT and one other experimental study have been identified. Hornberger *et al.* (1996) assessed in an RCT the quality of communication, interpretation, and level of patient, interpreter, and physician satisfaction with two services: 'proximate-consecutive interpretation', the traditional method of an interpreter being physically present at the interview and interpreting consecutively (control), and 'remote simultaneous interpretation', interpreters trained in the skills of simultaneous interpretation linked from a remote site to the clinician and patient through standard communication technology (intervention). Amongst mothers (n=490) attending their first postpartum visit, the intervention averaged 8.3 (10 per cent) more physician utterances (95 per cent CI 4.3 to 12.4) and 9.1 (28 per cent) more mother utterances (95 per cent CI 6.1 to 12.1). On average there were 2.8 (12 per cent) fewer inaccuracies of physician utterances in experimental visits compared with control visits (95 per cent CI -5.9 to 0.4) and 3.0 (13 per cent) fewer inaccuracies of mother utterances (95 per cent CI -5.4 to 0.6). Mothers and physicians significantly preferred the remote-simultaneous service to proximate-consecutive interpretation.

Moreover, interpreters felt mothers and physicians better understood each other using the intervention but interpreters preferred to work with the proximate-consecutive method.

(Grade A)

Jones *et al.* (2003) compared three methods of providing an interpretation service during general practice consultations amongst 35 of 36 non-English speaking patients who agreed to take part, 29 of whom were female: a physically present interpreter (n=14), a remote interpreter accessed using an ISDN videoconferencing link (n=11), and a remote interpreter accessed by telephone (n=10). Mean scores on the Patient Enablement Instrument were 5.2, 2.3, and 5.1; mean scores on the Medical Interview Satisfaction Scale were 5.3, 4.9, and 5.3, respectively. The investigators reported that the visual and sound quality of remote interpreting were satisfactory and that videoconferencing and hands free telephones could deliver an acceptable interpreting service in primary care.

(Grade B)

Amongst service evaluations, a review was recently undertaken of NHS Direct that included access by members of minority ethnic groups (National Audit Office (NAO), 2002). Awareness of the service was low among amongst these groups (45 per cent vs. 52 per cent of the population), in spite of the implementation (albeit patchy) of guidelines produced by NHS Direct for sites on raising awareness

amongst minority ethnic communities. All sites have arrangements to offer interpreting facilities, a national contract having been let for provision of translation services in over 200 languages. To date, however, little use has been made of NHS Direct's interpreting facilities: only around 1,000 times during 2000-2001 out of a total of 3.5 million calls (0.03 per cent). The NAO estimated that over 600,000 people preferred to receive medical advice in Asian language alone, so there is substantial underuse of this service. The reasons offered were only anecdotal (including stakeholder feedback) and included a lack of awareness of the NHS Direct translating service, difficulties in initial contact with a caller in the pre-interpreter phase, problems with the technical nature of discussions about symptoms, and the reluctance in some cultures to involve third parties in discussions about health matters. The recruitment by some sites of bilingual nurses from minority ethnic groups may have helped to address some of these concerns.

14. Organisational arrangements to improve access to primary care services

Walk-in centres

NHS walk-in centres first announced in 1999, are a network of centres where patients do not require an appointment. They aim to improve access to a range of NHS services that include advice, information and treatment for a range of minor injuries and illnesses. By the end of 2002 there were 42 walk-in centres open, the average number of visits per site per day increasing from 30 (March 2000) to 81 (March 2002) and 92 (September 2002) (Fox, 2002). A national evaluation of these centres has been undertaken (Salisbury *et al.*, 2002a). In a comparison of 38 walk in centres and 34 neighbouring general practices (Salisbury *et al.*, 2002b), walk-in centre visitors were more likely to be owner-occupiers, to have further education, and to be white (88 per cent vs. 84 per cent; $p < 0.01$) than general practice visitors.

(Grade B)

In general few research findings are available for minority ethnic groups. Chapple *et al.* (2001) undertook a study to assess the potential use of NHS walk in centres prior to a new NHS centre being established in Wakefield to find out which groups of people would be most likely to use it. Based on a postal survey of 2,400 people and 27 semi-structured interviews, a walk-in centre would be more attractive to ethnic minorities, young people, and those currently dissatisfied with access, although people wanted a range of services, including treatment, and access to doctors as well as nurses.

Out-of-hours services

Another UK Government initiative that seeks to ensure that patients have access to good quality clinical care is that for out-of-hours care. The Report of the Independent Review of GP Out-of-Hours Services (Department of Health, 2000) was published in October 2000. In response the Department of Health set out arrangements for the managed process to select exemplar services within the terms of the implementation of the review. It invited regional offices, health authorities, PCTs, out-of-hours service providers, and NHS Direct to identify proposals for recruitment of out-of-hours service providers to the exemplar programme, only organisations that could demonstrate that they could meet and maintain the quality standards set out being accredited to provide out-of-hours services.

However, a number of studies suggest that there may be barriers to accessing out-of-hours services for members of minority ethnic groups. Salisbury (1997) assessed patients' satisfaction with out-of-hours care by a general practice co-operative compared with that by a deputising service in London. Patients from minority ethnic groups were significantly less satisfied than white patients with out-of-hours services. A study by Rashid and Jagger (1992) of around 450 Asian and 450 non-Asian patients in Leicester found differences in attitudes and perceived need for services. More Asian patients disliked management of illness by telephone than non-Asian patients, although both groups regarded home visiting as essential. Asian patients disliked deputising services more than non-Asian patients, the former expressing some support for 24-hour surgeries.

(Grade B)

Difficulties experienced by minority ethnic groups in accessing services in the out-of-hours period have also been reported (Free *et al.*, 1996; Dale *et al.*, 1996).

In a study designed specifically to examine access to and use of out-of-hours services by members of one ethnic group, the Vietnamese in south London, Free *et al.* (1999) reported many barriers to access:

- lack of knowledge about GPs' out-of-hours arrangements;
- inability to communicate with health care professionals or answering services;
- lack of awareness of out-of-hours interpreting arrangements;
- delays experienced in seeking health care services; and confusion regarding the medicines and advice given.

(Grade B)

15. Access to mental health services

There have been a number of UK-based projects that have attempted to improve access to mental health services for members of minority ethnic groups or to make those services more culturally competent. In the Nottingham Health Action Zone, the Awaaz Project aims to provide and advocate for mental health services for the Asian community using a community development approach (Kandola, 2003). The particular problems identified included stigma of mental health in the Asian community, the need to address mental health services with a culturally sensitive approach, providing a culturally appropriate service in their mother tongue, improving access to services, and raising awareness on mental health in the Asian community. The reported evaluation comprised information on contacts collected monthly on a manual basis and a case study. Client contact over 3 months included 51 clients seen, 125 visits, and 12 new referrals. The components of the intervention that appear to have been particularly successful (based on the case study for example) are the provision of a culturally appropriate service to Asian people in their mother tongue in an environment they are comfortable with, the facilitation of preventive work as GPs refer at early stages of stress and anxiety, and more direct communication with GPs on the individuals referred, although no robust evidence is offered in support of these findings.

(Grade C)

The Nottingham Health Action Zone also established an African Caribbean Family Support Project to increase uptake of the Community Child and Adolescent Clinical Psychology Service by children and young people from the African and African Caribbean communities (Hunt, 2002). The main needs addressed by the project were the under-representation of children and adolescents from African and African Caribbean communities within the Community Child and Adolescent Psychology Service and the lack of any specialised service to meet the psychological needs of children and adolescents from

these communities. A comprehensive evaluation was undertaken, including an analysis of enquiries from agencies, referrals to the project (including ethnic monitoring), and a service evaluation of views of families who had accessed the service. The project resulted in increased uptake of the service by these communities, demonstrated by: most referrals to the project being from families who had never accessed the service before, the increased percentage of referrals for these age groups from black minority ethnic communities to the service as a whole (from 6 per cent to 13 per cent), and the steady rate of referrals to the project. Of the families seen for therapeutic input by the project and subsequently discharged, 10 out of 13 had shown partial or complete resolution of difficulties. There had also been an increase in referrals to Clinical Psychology from voluntary sector groups and from parents.

(Grade C)

Overall conclusions

In conclusion, this literature review on the health and health care of minority ethnic groups has focussed mainly on studies undertaken in the United Kingdom and, in some cases, North America. There is a paucity of such literature that relates specifically to Wales although a few studies have been included in the review. The knowledge base on the health of minority ethnic communities in England has been enhanced over the last decade by a number of major health and lifestyle surveys, including the two HEA Health and Lifestyle Surveys (1992/93 and 1994), a dedicated Health and Lifestyle Survey for the Chinese community (1998), the Fourth National Survey of Ethnic Minorities (1993-1994), and the 1999 HSE. There is no similar body of survey findings for minority ethnic groups in Wales, the proportion of such respondents in the Health in Wales and Welsh Health Surveys being too small to merit reporting.

With respect to coverage of key health areas, the literature on CHD in minority ethnic groups is incomplete, especially that on incidence. Since only country of birth is recorded at death registration, our knowledge about mortality is based mainly on migrant groups although exploitation of the Longitudinal Study is beginning to provide ethnic-specific rates. Our knowledge of cancer in minority ethnic groups is also fragmentary. Studies based on cancer registry data that have utilised name recognition algorithms are beginning to yield important findings on south Asian groups but major gaps remain for other groups, e.g. prostate cancer in the Black Caribbean and Black African communities. For both these areas – CHD and cancer – there is a paucity of literature that has addressed equity of access to services, with only one good quality study on the former.

The evidence base on health and lifestyle issues has improved significantly through the national HEA Health and Lifestyle Surveys (1992/93 and 1994). However, there are worrying inconsistencies across the surveys in the prevalence figures reported for smoking and drinking and recent research (Bhopal *et al.*, 2004) indicates that insufficient attention has been accorded to issues of conceptual equivalence in translating questionnaires into minority ethnic group languages.

In the short-term this significant body of knowledge – especially that on risks in the major national surveys – could be exploited through synthetic estimation techniques to help identify where the main burdens of ill health are located among the minority ethnic group population in Wales. In addition there are data in the 2001 Census that could be utilised to produce indirectly age standardised prevalence ratios for indicators of poor health.

III. Recommendations

Based on this review of the literature on the health beliefs, health status, and use of services in the minority ethnic group population, and of appropriate health care interventions, a number of recommendations for policy and practice are put forward.

Data issues

1. Ethnic monitoring/data collection should be mainstreamed across all services and the needs of minority ethnic groups should be routinely addressed in health equity audits and health impact assessments.
2. Examples of effective interventions and good practice are limited and inconsistently reported. There is no central repository of updated, easily accessible good practice. The systematic collection of a minimum dataset on these examples in Wales and the UK generally is needed.

Preventive interventions

3. With respect to interventions to improve the uptake of cervical screening, the strongest evidence suggests that minority ethnic women may be more responsive to small, culturally sensitive group education rather than broad-based community strategies. The use of lay health educators, in particular, may be promising although resource intensive.
4. While there is a paucity of robust evidence, uptake of breast screening amongst minority ethnic women may be improved by a GP endorsement letter, translated literature including multilingual leaflet, and language support by linkworkers. Findings with respect to personal contact through a home visit are inconsistent.
5. Brief episodes of repeated breast self examination instruction may also be effective.
6. Small informal discussion classes emphasising the benefits – and giving practical advice – may be particularly effective in helping to increase the number of women from minority ethnic groups who breastfeed.

Coronary heart disease (CHD)

7. The development of a local evidence base through surveys and focus groups is needed.
8. Interventions that involve at risk communities and survivors of CHD, multi-agency partnerships, the innovative use of media including audio-cassette tapes, video drama, and community radio/TV, the creation of infrastructures for community involvement, peer education schemes with accreditation, and training programmes for health professionals appear to be effective.

Diabetes

9. Continuing research and consultation with community members is needed to identify barriers to optimal self-care.
10. The use of pictorial flashcards in a one-to-one education programme may increase knowledge of the condition and self-caring behaviour.
11. The development of integrated, multi-professional services, the use of community-based diabetes specialist nurses to support primary health care teams, the employment of ethnic linkworkers, and the provision of accredited training for Asian diabetes support workers are identified as elements of good practice.

Mental health

12. The following have been identified as good practice in the provision of mental health services for minority ethnic groups: establishing trust between project managers and the communities they serve; strong leadership; a strong sense of community care, according with a preference for treatment in this setting by members of black and minority ethnic groups; open referral systems; adequate provision of social workers and supervisory staff; commitment to the maintenance of patient contact with patients' families and/or peer groups; a commitment to the eradication of fear in the therapeutic encounter; and a focus on social inclusion with respect to relationships, education, and employment.

Sexual health

13. There is some evidence to suggest that small group interventions delivered at the community level can be effective in influencing the sexual health and risk behaviours of members of black and minority ethnic groups.
14. Given cultural differences, specific impact and outcome evaluations of interventions are needed amongst the Black African population.

Lifestyle interventions

15. There is some evidence of the effectiveness of exercise on prescription schemes for south Asian women, especially where there is special provision, affordable costs, childcare facilities, and cultural codes of conduct.
16. There is some evidence for the effectiveness of brief behavioural counselling in general practice on the consumption of fruit and vegetables amongst adults in ethnically mixed inner city areas.
17. In relation to smoking, the training of bilingual peer educators to run smoking cessation services; the use of community-based stop smoking clinic services sited in youth, community, and neighbourhood centres; the use of trained community pharmacists, practice nurses, and health visitors to provide smoking cessation services in local pharmacies, drop-in and day centres for homeless people, and people's homes; and working with Muslim communities during Ramadan

through the involvement of imams are all reported as good practice. Comprehensive evaluations are limited and indicate that plays, poster and media campaigns, purpose designed leaflets, community outreach workers, referral to local tobacco cessation services, and the encouragement of contact with language specific help lines can all be effective.

18. Outreach work by members of the minority ethnic community, the use of video projects to gather views, and the use of bilingual, volunteer 'community interactors' to teach drug education to families may all be effective in reducing drug misuse.

Generic good practice across service settings

19. Walk-in centres – where patients can be seen without an appointment – could be more attractive to minority ethnic groups (but findings are awaited from national evaluations).
20. Barriers to accessing out-of-hours services for members of minority ethnic groups need to be addressed, including lack of awareness of out-of-hours interpreting services.
21. Campaigns are needed to make members of minority ethnic groups more aware of services like NHS Direct (as there is evidence of less awareness and under-use).
22. There is evidence that multi-lingual touch screens may be a particularly effective method for providing health information in appropriate languages to members of minority ethnic groups.
23. Linkworker and bilingual health advocacy (including interpreting) programmes have been demonstrated to have beneficial effects in a range of settings, including antenatal and infant care.
24. Further replication of the community mothers' programme in a range of minority ethnic groups is now supported.
25. Given that interpreting skills are scarce in the NHS, the use of rapid access remote interpreting services and primary care based advocacy and interpreting (including out-of-hours) services, operated on an open referral system, need to be evaluated.

Appendix I: Literature search strategies

Some 40 databases were searched using a variety of search strategies, including hierarchical search algorithms, Boolean searches, use of database thesauruses (MESH, Emtree thesaurus), and key word searches: ContentsFirst; Electronic Collections Online, Index to Theses; PapersFirst; Proceedings; UnCover; Web of Sciences Proceedings; Zetoc; ArticleFirst; Best Evidence; CHID; Cochrane Library Databases (CDSR, DARE, Cochrane Controlled Trials Register; NHS Economic Evaluation Database; Health Technology Assessment Database); EMBASE; HealthPromis; HMIC; HSTAT; Medline; PubMed; National Electronic Library for Health; PsycInfo; Science Citation Index; ASSIANet; EconLit; Social Science Citation Index; Social Services Abstracts; Sociological Abstracts; British Nursing Index; CINAHL; ENB Health Care Database; CRER; National Research Register; and Regard. Searches were also undertaken of Government online databases and sites.

The review was undertaken between February 2003 and March 2004. In a small number of cases, updates have been provided prior to publication.

Appendix 2: Evidence grading of interventions

Levels of evidence and grading of recommendations

Level	Type of evidence
1a	Evidence obtained from meta-analysis of randomised controlled trials
1b	Evidence obtained from at least one randomised controlled trial
2a	Evidence obtained from at least one well designed controlled study without randomisation
2b	Evidence obtained from at least one other type of well-designed quasi-experimental study
3	Evidence obtained from well designed non-experimental descriptive studies such as comparative studies, correlation studies, and case controlled studies
4	Evidence obtained from expert committee reports of opinions and/or experiences of respected authorities

Grade	Type of recommendation
A (levels 1a, 1b)	Requires at least one randomised controlled trial as part of a body of literature of overall good quality and consistency addressing the specific recommendation
B (levels 2a, 2b, 3)	Requires availability of well conducted clinical (health services) studies but no randomised clinical trials on the topic of recommendation
C (level 4)	Requires evidence from expert committee reports or opinions and/or clinical (health services) experience of respected authorities. Indicates absence of directly applicable studies of good quality

Appendix 3: Statistical information sources on the health of minority ethnic groups in Wales

A review has been undertaken of statistical databases that might provide information on the health of the minority ethnic group population in Wales. The following databases have been identified.

1991 and 2001 Census data

These datasets are a key source of information on the socio-economic position of minority ethnic groups in Wales. Both the 1991 and 2001 Censuses contained questions on limiting long-term illness (LLTI) (any long-term illness, health problem or disability which limits the respondent's daily activities or work). Thus, it would be possible to derive indirectly age-standardised prevalence ratios by ethnic group that would permit comparisons across local authority areas taking account of different age and gender distributions.

The 2001 Census (but not that for 1991) contained a general health question, asking respondents about their health over the previous 12 months. Again, it would be possible to develop indirectly age-standardised ratios of good/fairly good/not good health by ethnic group. In the questions on economic activity both Censuses collected information on whether respondents were permanently sick/disabled. Such information might enable indirectly age-standardised permanently sick/disabled prevalence ratios to be derived for ethnic groups, although care would be needed in the choice of numerator and denominator as economic activity and employment rates differ widely across ethnic groups. Finally, the 2001 Census asked a question about carers, that is, whether respondents gave any help or support to family members, friends, neighbours or others because of long-term physical or mental ill health or disability. Again, it may be possible to develop indicators that would reflect underlying patterns of disability and ill health, although area-based carer prevalence rates outside paid employment may be subject to a wide range of determinants.

Mortality data from death registrations

The number of deaths in different country of birth groups by main causes of death (such as cancers, CHD, and stroke) in Wales is likely to be too small to yield statistically significant standardised mortality ratios (SMRs). Even in England and Wales, combined counts are too small in some of the country of birth and specific cause groups to be statistically significant. It may be possible to aggregate, say, five years of data centred around the 2001 Census year as mid-point to produce SMRs for pan-country of birth groups (like black and Asian) but these are still likely to be subject to wide confidence intervals and to be of questionable validity. Moreover, it is likely that migrant mortality in Wales would not differ significantly from that for England and Wales in terms of rates. Some use, however, could be made of proportional mortality ratios reported with confidence intervals.

Hospital episode statistics

The mandatory collection of ethnic group on all NHS hospital inpatient episodes was introduced in April 1995 in England and Wales. However, the completeness of the data has been very poor with around 40 per cent of finished consultant episodes in England lacking a valid code (Aspinall, 2000). An investigation of the Patient Episode Database Wales (PEDW) database confirms that although ethnic group is a field the level of ethnic coding on the Wales database is too poor to merit analysis. A recent

review of ethnically coded statistical data (National Statistics and National Assembly for Wales 2004: Annex B – Ethnicity: A guide to Data Sources) records for the PEDW: ‘At the moment no data is available as there are presently training issues regarding the collection of the information by trust staff ...it is not known when data will become available’.

Other routine sources of information

These have also been investigated. The Welsh Cancer Surveillance and Intelligence Unit has indicated that ethnic coding on cancer registrations is inadequate for statistical analysis purposes. Personal communications (with staff in Health Statistics and Analysis Unit, Welsh Assembly Government, and National Public Health Service) report no routine collection of ethnic data by GPs although many GP systems allow these data to be recorded. Also, the 1995 and 1998 Welsh Health Surveys cannot provide much meaningful information due to the small numbers of ethnic minority respondents.

Other ethnically-coded data sources that can be utilised include:

- the NHS Medical and Dental and Non Medical staff Censuses undertaken annually;
- the annual Survey of Prevalent HIV Infections Diagnosed (SOPHID) (diagnosed HIV-infected patients when last seen for care);
- the National Mental Health and Ethnicity Census 2005;
- children looked after by local authorities (SSDA 903 return);
- and Government social and health surveys. The latter include the Welsh Local Labour Force Survey, British Household Panel Survey, Millennium Cohort Study, and National Survey of Sexual Attitudes and Lifestyles (NATSAL) 2000: however, in some cases small numbers preclude cross-tabulation and sub-national analyses.

Since the completion of this review, the Patient Equality Monitoring Project has been set up by the NHS Centre for Equality and Human Rights. The aim of the project is to deliver a programme of change that improves the collection of equalities data within NHS Trusts across Wales. In so doing, to distinguish the impact of health service policies and practices upon different groups of patients, according to their racial group, gender, age, disability, sexual orientation, religion or belief. There are three main areas of focus for the project. The first is training NHS Wales Secondary Care Trusts with the capacity and competency to collect patient equality information. The second is working with NHS Wales information technology stakeholders to standardise arrangements for the collection and use of patient equalities data so that the information can inform service planning and improvement. The third is exploring the opportunities for the future collection of this information in a Primary Care setting. For further information please see: www.wales.nhs.uk/equality.

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ISBN: 07504 3758 8
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