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Access to healthcare for ethnic minority populations

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3. Language and cultural barriers
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5. Cultural competence

B) Five key references for further reading, placed in text box.

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Szczepura A, Johnson M, Gumber G, Jones K, Clay D. *A review of the research evidence on ethnicity and communication*. Centre for Health Services Studies, University of Warwick, Coventry, UK. April 2004. ISBN: 0-9535430-3-X.

Institute of Medicine, Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Smedley BD, Stith AY, Nelson AR (Eds). Washington DC: National Academies Press; 2003.

Audit Commission. What seems to be the matter: Communication between hospitals and patients. Audit Commission report. HMSO. 1994.

US National Center for Cultural Competence.

<http://www.omhrc.gov/omh/programs/2pgprograms/finalreport.pdf>.

Summary:

This paper reviews the research evidence on access to healthcare by ethnic minority populations, and discusses what might need to be done to improve access to services. Research on the process of care, and the quality of care received, is considered as well as studies examining uptake of services. Changes in legal context are increasing the pressure on health care organisations to examine and adapt their services to ensure equitable access. Examples presented include a new UK population cancer screening programme. The main challenges for clinicians, managers and policy makers in ensuring equitable access are discussed.

96 words

1 INTRODUCTION

In most health care systems, it is acknowledged that black and minority ethnic (BME) populations have until now experienced poorer health and barriers to accessing certain services. Closing the health gap for individuals in these population groups is now an important priority. In the UK, as in other countries, the growth of various ethnic communities and linguistic groups, each with its own cultural traits and health profiles, presents a complex challenge to health care practitioners and policy makers in terms of achieving equitable access. This paper presents some of the research evidence on access by ethnic minority populations, and considers what might need to be done to improve the situation. The discussion is based on a number of reviews undertaken by the author examining the evidence on population diversity and variations in service uptake, health outcomes, effective patient communication, and involvement in decision-making [1-4].

At the same time, evidence of good practice is also beginning to emerge in some parts of the world. One of the largest BME populations is found in the United States, with nearly 1 in 2 Americans expected to be a member of a racial or ethnic minority group by 2050 [5]. Findings from the US 2000 Census similarly indicate major health disparities, with 'settled' groups such as Black Americans and American Indians, as well as more recent immigrant groups such as Asians and Hispanics, at higher risk of missing the benefits of health care. As a result, the US Agency for Healthcare Research and Quality has recently been asked to produce an annual National Healthcare Disparities Report that will consider 'disparities in health care delivery as it relates to racial factors' plus an annual National Health Care Quality Report; both reports will use a common framework because it is recognised that 'disparities often present as *inequalities in quality*', in other words even if certain groups use a service they may still experience inferior quality care and, therefore, poorer access [6]. The publication of these US reports provides the first comprehensive snapshot of disparities and quality of care for ethnic minority groups in the United States; performance measures underlying both reports will be used to monitor progress towards improved health care delivery for these and other disadvantaged groups [7].

In the UK, a similar need to close the health gap for ethnic minorities is recognised by bodies such as the Department of Health and professional associations. Furthermore, following the implementation of the Race Relations Amendment Act 2000 in April 2001, a statutory duty has been laid upon the NHS and other UK public service agencies to ‘have due regard to the need to eliminate unlawful discrimination’, and to ensure that every new action or policy considers the implications for racial equality [8]. The NHS has, since April 1996, expected that all hospital trusts would record data relating to the ethnic origin of all ‘admitted patients’ (including day cases). Although there has been a steady growth in collection of this data, levels of completion remain low, and this makes disparities in health care access difficult to monitor in the UK. Thus, a consistent message from the literature on access is the need for better ethnic monitoring data in the NHS, and for greater use to be made of this data in order to justify its collection. Low completion levels may partly be due to the perceived sensitivity of this area on the part of healthcare workers [9-10], and also possibly because the information collected may be insufficiently detailed for clinical care and health service planning purposes [2].

The slow implementation of ethnic monitoring data recording in the NHS means that, unlike the USA, it has not been possible to develop a UK overview of disparities in service access for BME populations or to monitor these nationally [7]. At the same time, there is evidence from the 2001 and earlier Censuses that health disparities exist in the UK and that levels of long-term illness are higher in most black and minority ethnic groups than in the general population, especially for older age groups [11-12]. Furthermore, in terms of service quality indicators, analysis of responses to the patient satisfaction surveys undertaken on behalf of the NHS shows distinct differences for ethnic minority groups [13]. But, UK data on ethnic minority groups and disparities in health and quality of care has not been integrated, unlike the initiative set in motion by the Department of Health and Human Sciences in the USA.

Poor implementation of ethnic monitoring data recording in the NHS means that it has not been possible to develop a UK overview of disparities in service access or to monitor these nationally.

2 UK POPULATION DIVERSITY

The UK has a relatively large black and minority ethnic population and this is gradually increasing in size. In the 2001 Census, the BME population was 7.9% (or 4.6 million), having risen from a figure of 5.5% in 1991 and 4.2% in 1981. The South Asian group accounts for approximately half of this population (2 million people). There are also 1.15 million 'Black' people, including nearly 0.6 million from the more established 'Black-Caribbean' population and nearly half a million 'Black Africans'. These populations are more youthful in age structure than the white population, which means that ethnic minority population growth will remain rapid over the coming years.

The BME population is principally located in England, where one in eleven of the population is currently from such groups; just over half (4.6%) are of south Asian origin (including Indian, Pakistani, and Bangladeshi groups), 2.3% are of Caribbean and African origin, and the remainder of various origins including Chinese, Arabs and 'mixed' backgrounds. According to the 2001 Census, nearly half (45%) of the minority ethnic population lives in the Greater London area, where they form 29% of the population overall. A further 13% of the BME population is resident in the West Midlands. Certain minorities are even more concentrated in London - for example, 78% of the Black African population lives in London, as does nearly two thirds of the Caribbean origin population (61%). Information on certain ethnic minority groups such as asylum seekers and seasonal or migrant workers is more difficult to find. These groups are likely to be poorly recorded in sources such as the Census and other national datasets (e.g. Labour Force Survey, for migrant workers). However, estimates are available of the numbers of refugees and asylum seekers in London [14]; and research also highlights issues relating to their access to health and services [15]. In contrast, there is little information available on seasonal and migrant workers or their health needs, although clearly this group will become increasingly important as the UK encourages such workers, especially from other parts of the EU and eastern Europe.

3 ACCESS TO HEALTH CARE VERSUS SERVICE PROVISION

Appropriate access to healthcare for a diverse population requires more than simply providing the service. Provision alone cannot ensure access to care for all individuals, regardless of their religion, culture or ethnic background. This has recently been acknowledged in the NHS, as has the requirement for a major re-think of concepts previously held about access to services by BME groups:

Diversity is a fairly new word in Britain. Prior to recognition of diversity, the idea was that some services for black and minority ethnic groups could be provided, but the quality of services and whether they reached the population was not an issue. When black and minority ethnic groups raised the issue of services not reaching them, the standard answer was, “but we are providing the services of a link worker or an advocate and we are meeting your religious and cultural needs.” [16]

The same author had previously in 1996 identified a need for improvements in access to cancer screening and treatment programmes for ethnic minorities, when presenting the Department of Health's perspective on these services:

'The Government's 'Health of the Nation' report produced in 1993 by the Department of Health identifies key areas, including cancer, where improvements in mortality and morbidity could be achieved, and an essential element relates to the needs of black and minority ethnic people. It is, for example, now well recognised that in terms of screening, treatment and palliation, cancer services are not always accessible and sensitive to the needs of this section of the population.' [15].

A recent review on access to, and uptake of, NHS services by ethnic minorities [2] has identified the following three dimensions of equitable access:

- having equal access via appropriate information;
- having access to services that are relevant, timely and sensitive to the individual's needs;
- being able to use the health service with ease, and having confidence that you will be treated with respect.

In summary, access is clearly linked to equal care, since it is accepted that 'access-related factors may be the most significant barriers to equitable care' [7, 18]. Equitable access has been defined as 'care that does not vary in quality because of personal characteristics, such as gender, ethnicity, geographical location and socio-economic status' [19]. Adequate access is also linked to timeliness and the quality of services, as exemplified by definitions such as 'the timely use of personal health services to achieve the best health outcomes' [20]. Thus, definitions of 'access' that are limited to service uptake or 'receipt of care' are clearly inadequate unless they also consider the *process* of accessing care, and the *quality* of care received by ethnic minority groups.

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4 LINGUISTIC AND CULTURAL COMPETENCE

In countries and regions that have experience of population diversity (especially the USA, Australia, Canada and also the United Kingdom) consideration is now being given to developing linguistic and cultural competence in health care organisations. In particular, it is acknowledged that, in a range of clinical areas where access is demonstrated to be poor, health care services now need to develop policies and structures to begin to address such disparities. Policies should focus on both linguistic

and cultural competence; and they should have the capacity to adapt to the changing cultural contexts of the communities served.

Extensive evidence is emerging on the need for cultural competence, as well as linguistic competence, in health care organisations.

4.1 Linguistic Competence

Linguistic competence describes the capacity of an organisation and its personnel to communicate effectively, and convey information in a manner that is easily understood by diverse audiences including persons of limited English proficiency, and those who have low literacy skills or are not literate [21-22]. This is clearly of key importance in ensuring equitable access for many ethnic minority populations. Improved access for such populations might require provision of: bilingual/bicultural staff; foreign language interpreting services; link-workers/advocates; materials developed and tested for specific cultural, ethnic and linguistic groups; translation services including those of: (i) legally binding documents (e.g. consent forms), (ii) hospital signage, (iii) health education materials, (iv) public awareness materials and campaigns; and ethnic media in languages other than English e.g. television, radio, Internet, newspapers, periodicals.

4.2 Cultural Competence

Although language barriers may be important, it is also well documented that various dimensions of culture can influence successful health care delivery to ethnic minority populations [21]. Cultural differences are also likely to be more persistent than language needs in immigrant groups. Cultural dimensions might include:

- patients' health, healing, and wellness belief systems;

- how illness, disease, and their causes are perceived;
- the behaviour of patients/consumers seeking health care, and their attitudes toward health care providers;
- the views and values of those delivering health care.

Thus, healthcare organisations and their staff need to be culturally as well as linguistically competent. Improved responsiveness to the health beliefs, practices, and cultural needs of patients is clearly required in order to provide equitable access to health care services for diverse populations. Such provision should also recognise that the provider and the ethnic minority patient each bring their own individual learned patterns of language and culture to the health care experience.

Appropriate access to healthcare requires more than simply providing a service. Provision alone does not ensure access for all individuals, regardless of their religion, culture or ethnic background.

5 STUDIES OF DISPARITY IN ACCESS TO HEALTHCARE FOR ETHNIC MINORITY POPULATIONS

Reviews of evidence on the use of NHS services by ethnic minorities would appear to provide evidence of the presence of access problems [2, 23]. However, the findings may not be conclusive. For example, studies often rely on receipt of care or uptake levels as a measure of access, and this does not allow for variations in levels of need in different populations [19]. Also, studies of access should ideally control for income and other social factors to check whether the differences in uptake observed might be explained by factors other than ethnicity. Even though there are relatively few rigorous studies of this type, it is generally accepted that ethnic differences in access to health services cannot simply be reduced to socio-economic factors [24].

Examination of the research literature on access identifies a consistent pattern in most disease areas in terms of the evidence available [2]. Most articles focus on the differential uptake of services or receipt of care; there are fewer papers reporting research on *process*, including barriers to accessing care and factors influencing these; and there is very little peer-reviewed literature on the evaluation of interventions to improve access. The latter group are found mainly in the 'grey' literature.

Ethnic differences in access to health services cannot simply be reduced to socio-economic factors.

The available evidence thus falls into three main categories, and provides different types of evidence as follows:

- *Quantitative analyses of uptake or receipt of care:* such research can demonstrate apparent *inequalities* and raise questions about the causes of these, using methods such as secondary analysis of data collected for other purposes [25], or questionnaire based surveys [26-28]. These studies do not usually offer an explanation, but they can flag up the presence of disparities that require further investigation.

Analysis of uptake figures can demonstrate apparent inequalities and raise questions about the causes of these.

- *Process-oriented research:* this can provide potential *explanations*, often using focus groups or semi-structured interviews to explore possible reasons for any disparities identified through quantitative analyses [29]. By identifying barriers to access, such research can also build up an evidence base for possible intervention studies. Yet other studies in this area present descriptions of '*good practice*' [e.g. 30-31]. Although such research does not usually provide evidence of effectiveness, it can once again provide evidence for the types of interventions that might be worth evaluating, as well as demonstrating their feasibility. It is perhaps significant that most of the literature reporting process-oriented research comes to a similar conclusion, namely the

essentially rational behaviour of patients, and the need for evaluation of interventions to improve access.

- *Intervention studies:* this research requires the actual implementation and assessment of interventions designed to improve access and uptake. Such studies form a small minority of published studies on access. Where such research has been undertaken very few, if any, studies consider the cost or the cost-effectiveness of the interventions evaluated. Some research has been undertaken to estimate the cost of providing interpreter, advocacy and translation services, and this has been used to allocate some resources to different areas in the NHS [4].

By identifying barriers to access, researchers can build up an evidence base for possible intervention studies. At present, there are very few intervention studies and virtually none consider the costs or cost-effectiveness of interventions.

6 FACTORS INFLUENCING ACCESS TO HEALTHCARE BY ETHNIC MINORITY GROUPS

Explanations offered by researchers for reported disparities in access to health services fall into two main groups. The first group are linked to intrinsic or 'personal' factors; these include the particular needs of ethnic minority individuals which must be met as part of ensuring equitable access. The second group are associated with extrinsic or organisational factors; these focus on the organisation itself and its health care delivery and planning systems.

6.1 Intrinsic or personal factors

- *Cultural differences:* This is offered as a key explanation for disparities in access to health services by BME populations. This explanation recognises that individuals identify themselves with a social group on cultural grounds, and that diverse racial and ethnic groups may respond

differently because of their particular health beliefs and behaviours [32]. Cultural dimensions highlighted include: religion which may affect compliance or access to services; gender which is frequently mentioned as an obstacle to service access by women; differential presentation including ‘somatisation’ of symptoms which is reported to lead to misunderstandings, misdiagnosis, or incorrect referrals; ‘fatalism’ or shyness which may also lead to a reluctance to seek help resulting in late presentation; and other cultural factors such as family dynamics may mean people cannot easily attend or take up services without the support of family members [2]. It is recognised also that health professionals need to take into account these types of cultural beliefs and values when communicating with patients or users [33]. Linked to this, there may be a need for visual representation (i.e. pictorial reference to ethnic groups, cultures) in posters and other health care materials.

- *Language and literacy*: Clearly poor linguistic competence will be a major barrier to access for some people. In such cases interpreting services are required in order to adequately diagnose, consent, and treat these individuals. This can be a complex organisational task [1]. For example, recent surveys indicate that over three hundred languages are used in London homes [34-35]. Furthermore, high levels of need appear to exist among UK adults, with only 14% of Bengalis, 29% of Gujeratis, 26% of Punjabis, 41% of Chinese and 32% of refugees reported to have a survival level of competence in the use of English in 1996 [36]. In the most populous South Asian groups in the UK (Indian, Pakistani, Bangladeshi) there is also good evidence that ability to speak English is lower for women than men, is much poorer for those born outside the UK, and declines with increasing age [37-39]. Differences in *literacy* might be another important factor. Firstly, although people may be able to speak English they might not be able to read it. Estimates differ but there is general agreement that fewer than one third of older Bangladeshi and Pakistani women (50-75 years of age) can read English; and fewer than two thirds of older men [37, 38]. Another study has estimated that fewer than half of South Asian adults can read a school timetable or telephone directory [36]. Furthermore, even if letters or patient information leaflets are translated, individuals may not be able to read their own language. Over half of older

Bangladeshi and Pakistani women are illiterate in any language, and approximately 20% of older men [37]. In some cases, there may be no written form of their own language (e.g. this is the case for Sylhetti, which more than one in two 'over-50s' of Bangladeshi origin report as their main language) [37].

Poor linguistic competence is a major barrier to access for many with high levels of need among older ethnic minority adults.

- *'Newness' or user ignorance:* this factor is related to the migrant status of individuals in the BME population, and demonstrates itself through unfamiliarity with the NHS and limited knowledge of available services. Additional dimensions such as the lack of 'grandparenting' within the social group (i.e. family, friends or other networks providing expert advice) are also identified as important. User ignorance has been offered as an explanation for patterns of poor access to services reported for new populations as they first come into contact with different forms of health care. For example, much of the initial literature on user ignorance in the UK was linked to studies of access to antenatal care and obstetric care [40-41], and subsequently to low uptake of services for older people [42-46].

6.2 Extrinsic or organisational factors

- *Differential needs and provision:* In some cases, barriers to access may be linked to poor provision of certain services required specifically for ethnic minority groups. In the UK, this might include services for 'ethnic' diseases such as haemoglobinopathies i.e. sickle cell disease among people of West African origin and West Indian descent, and thalassaemia among populations of South Asian and Mediterranean origin [47-48]. Access to such 'minority' services may be poor because they are not required by the majority white population and therefore provision is poor [49]. In other cases, low levels of uptake of services (and apparent poor access) may be due to the relative rarity of certain diseases in ethnic minority populations (e.g. cystic fibrosis). Both examples are linked to variations in the level of *need* for certain services in ethnic

minority populations. However, even where need appears to be low, service provision should take account of the fact that diverse populations may still be at risk [3], and also that their risk profile may change over time, especially for conditions that are linked to lifestyle and environmental factors as well as genetic makeup [50].

- *Location:* The location of health services may result in poor access for certain mobile populations (e.g. traveller gypsies, refugees etc). Also, as settled ethnic populations move, for example through the process of suburbanisation, there may be a lag in providing appropriate services (e.g. advocacy/ link workers) in these new locations [2]. Isolated minorities in areas not equipped to meet their language needs may also experience barriers in accessing routine services; for example, because of poor levels of interpreting provision in A&E departments [51-52].
- *Staff training needs:* Finally, health care staff may have strong stereotypical views, lack cultural awareness and ability, or generally manage patients from diverse backgrounds in an unsuitable manner, which can create barriers and generate resentment. The literature suggests that institutional racism should be addressed as part of any intervention to improve access for ethnic minority users. In addition, health care organisations may need to improve the diversity of their workforce, something which cannot be achieved by merely recruiting more ethnic minority individuals; it is recognised that diversity training for the existing majority workforce should be an integral part of this activity [53-54]. Other forms of training may also be required. For example, the training of clinicians to recognise key symptoms e.g. sickle cell crisis [48]; administrative training to cope with distinctive naming systems [9]; and last, but not least, training in the use of interpreters [55-56].

7 A CASE EXAMPLE: ACCESS TO NHS POPULATION CANCER SCREENING PROGRAMMES

One example of poor access to health care by BME populations, and the need for policies and structures to address this, is that provided by cancer screening programmes in the UK.

7.1 Cervical and breast cancer screening

The two existing UK cancer screening programmes (cervical and breast) have consistently demonstrated low uptake by ethnic minority groups over a number of years, particularly for South Asians. Hoare reviewed the UK evidence on uptake of *breast* cancer screening in 1996 and showed lower uptake among ethnic minority women [57]. There is similar evidence of lower uptake of *cervical* cancer screening by South Asian women (Indian, Pakistani and Bangladeshi), although uptake in the African Caribbean population has been reported to be high [58]. Furthermore, UK studies that have compared cervical and breast cancer screening in diverse populations consistently indicate that breast screening uptake is lower [59-60].

The four main reasons identified by researchers for low uptake in both programmes appear to be a lack of knowledge among women from the ethnic communities about screening services; language barriers; inaccurate screening registers, including poor awareness of minority ethnic naming systems, compounded for Asian women by extended visits to the Indian subcontinent; and a lack of referral/recommendations by healthcare professionals and physicians. Early articles (from 1991 onwards) on cervical cancer screening identified administration, language needs, and poor knowledge of the screening service as important barriers [61-64]. A more recent (1999) paper also highlighted professional perceptions and poor communication [64]. Furthermore, as might be expected, cervical cancer screening rates appear to be more strongly associated with practice characteristics than do breast screening rates; for example, cervical smear uptake rates are higher in practices with a female partner [62], although a similar effect is not apparent for breast screening [65]. For breast cancer

screening, early research (from 1992 onwards) similarly identified poor health information, errors in the screening register, and lack of knowledge of screening as important factors [66-68]. Later papers continued to report lack of knowledge [59] plus the need for active physician encouragement [65] as important factors. Research has also highlighted the need for more attention to broader questions of power relations [64] and indirect discriminations [67]. At the same time, some early research did report comparable uptake of cervical cancer screening among South Asian women [69]. However, more recent research (2001) appears to indicate that the disparities in uptake of both cervical and breast cancer screening observed earlier have not yet been rectified [70].

Although there is considerable literature on disparities in screening uptake, there is little research reporting attempts to improve access to cancer screening for ethnic minority populations. The UK literature reports only one trial for cervical cancer screening; this found that home visits were more effective than a postal leaflet, with some evidence that home viewed videos may be particularly effective in one of the most hard to reach groups, Urdu speaking Pakistani Moslems [71]. Slightly more UK trials of interventions to improve breast cancer screening uptake have been reported. Based on these, it would appear that the use of a reminder letter has only a limited role in improving uptake [72-73]. Unlike cervical cancer screening, there also appears to be no evidence that home visits by an NHS linkworker are effective in improving access to mammography [74-75]. However, there is some evidence that training practice receptionists to follow up non-attenders can have a significant effect (55% vs 31%, $p < 0.01$) [76]. International studies provide similar evidence on potential interventions to increase cervical cancer screening uptake by ethnic minorities. A limited positive impact has been reported from the USA for linkworkers [77-78], and little benefit has been observed from translated reminder letters in Australia [79-80].

However, there does appear to be some consistent evidence to show that complex, multi-strategies are able to improve uptake of cancer screening by ethnic minority groups [76, 81-82]. Such interventions might include practice receptionist training, follow-up letters in various languages, offers of transport, health advocates on site, and (for breast screening) mobile units available for longer. A similar sized

positive impact has been reported by several of these studies (with initial uptake rising from ca 30% to 50%). None of these studies has considered cost or cost-effectiveness.

From the research discussed above, it is apparent that the evidence of poor levels of uptake by South Asians for the two existing cancer screening programmes has been available for some time. However, little research has been carried out to identify effective interventions to improve access in these population groups.

72 Colorectal cancer screening

The NHS is currently considering the introduction of a new population cancer screening programme; colorectal cancer (CRC) screening using a self administered faecal occult blood test (FOBT), followed by colonoscopy for those who screen positive. Colorectal cancer is the second most common cause of all cancer deaths in the UK, with 5 year survival approximately 40% and 16,170 deaths in 2001 [83]. In 2000, the UK National Screening Committee established a Pilot to assess the feasibility of introducing this third cancer screening programme [84]. At that time there was no evidence on likely CRC screening uptake levels for UK ethnic minority population groups. The original Nottingham trial of FOBT screening did not record uptake by ethnic group [85], and a subsequent trial of mass screening by flexible sigmoidoscopy had also not provided any data on ethnic uptakes [86].

However, in the USA uptake of CRC screening by ethnic minority groups is reported to be even lower than uptake of breast and cervical cancer screening [87]. Similarly, a Swedish study of CRC screening in a diverse population has identified lower uptake levels among older (age > 64 yrs) immigrants; with uptakes of 44% versus 69% for the whole age group [88]. Research emerging from the USA has consistently identified lower FOBT uptake levels for a range of ethnic minority groups, both in established populations such as African Americans [89-92] and in more recent immigrant populations, including Koreans, Japanese, Chinese and South-East Asians [93-95]. A few studies have separated socio-demographic characteristics (e.g. income or education level) from ethnic

diversity, and found that socio-demographic factors cannot fully explain the observed variations in uptake, especially for older people [87].

Most US studies conclude that interventions should be developed to enhance knowledge, improve risk perception, and facilitate access to CRC screening for minority populations, but there remains little or no research examining what form of intervention might be most effective or cost-effective [96-97].

In summary, the introduction of CRC screening in the UK will represent a major challenge in terms of ensuring equitable access for BME populations. Preliminary analysis of data from the UK Pilot indicates very low uptake by South Asians [98]. Uptakes are particularly low for Muslims and Sikhs; both groups include red meat eaters and are therefore at greater risk of colorectal cancer than the other mostly vegetarian South Asian groups. Even if other demographic factors (age, gender and deprivation) are taken into account in a multivariate analysis, the ethnic minority populations continue to exhibit particularly poor uptakes. Research from other countries on barriers to uptake of CRC screening by ethnic minorities identifies older age [87-92, 99], and shorter acculturation or length of residence [88, 100-101] as significant predictors of low FOBt uptake, both of which may be related to cultural and language needs.

8 CONCLUSIONS

A substantial research base now exists to demonstrate disparities in access to health care services for ethnic minority populations in different parts of the world. Healthcare organisations and their staff need to be culturally, as well as linguistically, competent when delivering services. Improved responsiveness to the health beliefs, practices, and cultural needs of patients is clearly required in order to provide equitable access to health care for diverse populations. Such provision should also recognise that the provider and the ethnic minority patient each bring their own individual learned patterns of language and culture to the health care experience.

In conclusion, ensuring equitable access to health care services by ethnic minorities will represent a major challenge for clinicians, managers and policy makers in the coming decades. At the same time, it is clear that the changing legal context in countries like the UK following the Race Relations Amendment Act 2000, and in the remainder of Europe following Human Rights legislation, increases the pressure on health care organisations to examine and adapt services in order to ensure equitable access for local ethnic minority populations. The example presented, of a new UK colorectal cancer screening programme, serves to demonstrate the paucity of evidence on interventions to assure access for ethnic minority populations. Finally, in order to fully address issues of access, inequalities in the quality of care received, as well as disparities in uptake of care, need to be examined and addressed.

Following the implementation of the Race Relations Amendment Act 2000, the NHS must consider the implications for racial equality of every action or policy. Access to services should be viewed in the context of this major new requirement.

REFERENCES

1. Szczepura A, Johnson M, Gumber G, Jones K, Clay D. *A review of the research evidence on ethnicity and communication*. Centre for Health Services Studies, University of Warwick, Coventry, UK. April 2004. ISBN: 0-9535430-3-X.
2. Atkinson M, Clark M, Clay D, Johnson M, Szczepura A. *Systematic review of ethnicity and health service access for London*. Centre for Health Services Studies, University of Warwick, Coventry, UK. February 2001. ISBN 0-9535-4300-6.
3. Johnson MRD, Clark MD, Owens D, Szczepura A. *The Unavoidable Costs of Ethnicity: A review of evidence on health costs*. Centre for Health Services Studies, University of Warwick, Coventry, UK. June 1999. ISBN 0953 5430 05.
4. Szczepura A, Clark MD, Johnson MRD, Owen D. *Assessment of the costs to the NHS arising from the need for interpreter, advocacy and translation services*. Centre for Health Services Studies, University of Warwick, Coventry. September 1999. ISSN 0964-7902.
5. U.S. Bureau of the Census. Population projections of the United States by age, sex, race, and Hispanic origin: 1995 to 2050. Current Population reports, No. P25-1130. Issued February 1996; revised April 1999.
Available at: <http://www.census.gov/prod/1/pop/p25-1130>
6. Institute of Medicine, Committee on Guidance for Designing a National Healthcare Disparities Report, *Guidance for Designing a National Healthcare Disparities Report*. Swift EK (Ed). Washington DC: National Academies Press; 2002.

7. Committee on National Statistics. *Eliminating Health Disparities*. The National Academies Press, Washington DC, USA; 2004.
8. Parliament. Race Relations (Amendment) Act 2000: Elizabeth II: Chapter 34. London: Stationery Office, 2000.
9. Bhatti-Sinclair K, Wheal A. Analysis of the external audit on ethnically sensitive practice. *J.Clin.Effect.*, 1998; **3(1)**: 6-9.
10. Bhatti-Sinclair, K. & Wheal, A. Using external audit to review ethnically sensitive practice. *J.Clin.Effect.* 1998; **3(1)**: 2-5.
11. Szczepura A, Gumber G, Clay D, Davie R, Elias P, Johnson M, Walker I, Owen D. *Review of the occupational health and safety of Britain's ethnic minorities. Research Report 221*. Health & Safety Executive, Norwich. HMSO ISBN 0 7176 2842 6, 2004.
12. Owen, D. (1993). *Ethnic Minorities in Great Britain: Housing and Family characteristics 1991* Census Statistical Paper 4, Coventry: Centre for Research in Ethnic Relations National Ethnic Minority Data Archive
13. Commission for Health Improvement. *Unpacking the patient's perspective: Variations in NHS patient experience in England*. CHI, February 2004
14. Storkey, M. and Bardsley, M. Estimating the numbers of refugees and asylum seekers in London. Chapter 2 of Aldous, J. et.al. *Refugee Health in London: Key issues for public health*. London: Health of Londoners Project, 1999, pp11-26.

15. Aldous J, Bardsley M, Daniell R et al. *Refugee Health in London: Key issues for public health*. London: Health of Londoners Project, 1999. East London & City Health Authority
16. Bahl V. Improving access and quality for ethnic minority women. *Womens Health Issues* 2001;**11(4)**:348-54.
17. Bahl V. Cancer and ethnic minorities: the Department of Health's perspective. *British Journal of Cancer*. 1996;**74**:S10.
18. Institute of Medicine, Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Smedley BD, Stith AY, Nelson AR (Eds). Washington DC: National Academies Press; 2003.
19. Institute of Medicine, Committee on Monitoring Access to Personal Health Care Services. *Access to Health Care in America*. Millman (Ed). Washington DC: National Academy Press; 1993.
20. Fiscella K, Franks P, Gold MR, Clancy CM. Inequalities in quality: Addressing socioeconomic, racial, and ethnic disparities in health care. *JAMA*. 2000;**283**:2579-84.
21. US National Center for Cultural Competence.
<http://www.omhrc.gov/omh/programs/2pgprograms/finalreport.pdf>.
22. Anderson, L. M., Scrimshaw, S. C., Fullilove, M. T., Fielding, J. E., and Normand, J. Culturally competent healthcare systems. A systematic review. *Am.J.Prev.Med* 2003;**24**: 68 - 79.
23. Smaje C, Le Grand J. Ethnicity equity and the use of health services in the British NHS. *Social Science and Medicine* 1997 **45(3)**:485-496

24. Davey-Smith G. Ethnicity, socio-economic position and health. *ESRC Health Variations Newsletter*. Vol 6, July 2000
25. Gill P, Scrivener G, Lloyd D, Dowell T. The effect of patient ethnicity on prescribing rates. *Health Trends*. 1995;**27(4)**:111-113.
26. Leisten R, Richardson, J., *Access to Health: A minority ethnic perspective*. BHA / Nene College Northampton 1994
27. Richardson J, Leisten R, Calviou A. Lost For Words. Health services are inaccessible to many people from ethnic minorities because of inappropriate health information. *Nursing Times* 1994;**90(13)**: 31-33.
28. Madhok R, Bhopal R, Ramaiah R. Quality of hospital service: A study comparing 'Asian' and 'non-Asian' patients in Middlesbrough. *Journal of Public Health Medicine* 1992;**14(3)**:271-279.
- 29 Sheldon H. *Consulting with local Black and Minority Ethnic Groups*. London: Lewisham Hospital NHS Trust. 1996
30. Bowes A, Domokos T. Health Visitors' Work in a Multi-Ethnic Society: a Qualitative Study of Social Exclusion. *Jnl.Soc.Pol.* 1998;**27(4)**:498-506.
31. Shah R. Improving services to Asian families and children with disabilities. *Child: care, health and development*. 1997;**23(1)**:41-46.
32. Brach C, Fraser I. Can cultural competency reduce racial and ethnic health disparities? A review and conceptual model. *Medical Care Research and Review* 2000;**57 Suppl 1**: 181-217.

33. Stewart ALN-S, Perez-Stable A, Posner EJ, Bindman SF, Pinderhughes AB, Washington HL, Interpersonal Processes of Care in Diverse Populations. *Milbank Quarterly* 1999;**77(3)**: 305-340.
34. Baker P, Mohieldeen Y. The languages of London's schoolchildren. In Baker P, Eversley J (Eds) *Multilingual Capital – The languages of London schoolchildren and their relevance to economic, social and educational policies*. London: Battlebridge, 2000.
35. Storkey M. Using the schools' language data to estimate the total number of speaker of London's top 40 languages. In Baker P, Eversley J (Eds) *Multilingual Capital – The languages of London schoolchildren and their relevance to economic, social and educational policies*. London: Battlebridge, 2000.
36. Carr-Hill R, Passingham S, Wolf A, Kent N. Lost Opportunities: the language skills of linguistic minorities in England and Wales. London: Basic Skills Agency, 1996.
37. Rudat K. *Black and Minority Ethnic Groups in England: Health & Lifestyles* London: Health Education Authority, 1994.
38. Johnson MRD, Owen D, Blackburn C, Rehman H, Nazroo J *Black and Minority Ethnic Groups in England: The second health & lifestyles survey* London: Health Education Authority, 2000.
39. Modood T, Berthoud R, Lakey J, Nazroo J, Smith P, Virdee S, Beishon. *Ethnic Minorities in Britain: Diversity and Disadvantage* London: Policy Studies Institute, 1997.
40. Hayes L. Unequal access to midwifery care: a continuing problem? *Journal of Advanced Nursing* 1995;**21**:702-707.

41. Baxter C. The case for bilingual workers within the maternity services. *British Journal of Midwifery*. 1997;**5(9)**:568-572.
42. Ehtisham M, Guthrie S, Hickling J, Luck M, Ritch AES, Talbot J, Tinsley RN. *Health needs of elderly people in the inner city*, West Birmingham Health Authority, 1991.
43. Lindsay J, Jagger C, Hibbett M, Peet S, Moledina F. Knowledge, Uptake and Availability of Health and Social Services Among Asian Gujarati and White Elderly Persons. *Ethnicity and Health* 1997;**2**:59-69.
44. Iqbal H. *Palliative Care Service use by Black and Ethnic Groups in Leicester*, Leicestershire Health, 1994.
45. Penso D, Hill D. *Opening Doors: Improving access to hospice and specialist palliative care services by members of the black and ethnic minority communities*. London: National Council for Hospice and Specialist Palliative Care Services, 1995
46. Powell B. *Improving accessibility and information services for Asian communities, relating to cancer and palliative care*. Cancer Care - Ethnic Minorities Group, Leicester, 1999.
47. Modell B, Petrou M, Layton M, Varnavides L, Slater C, Ward R, Rodeck C, Nicolaides K, Gibbons S, Fiches A, Old J. Audit of prenatal diagnosis for haemoglobin disorders in the United Kingdom: the first 20 years. *BMJ*. 1997; **315**:779-785.
48. Streetly A, Maxwell K, Mejia A. *Sickle Cell Disorders in Greater London. A needs assessment of screening and care services*. London: United Medical and Dental Schools Department of Public Health Medicine, (Fair shares for London report) 1997 Jan.

49. Dyson S. Genetic Screening and ethnic minorities. *Critical Social Policy* 1999; **19(2)**:195-215.
50. Raja-Jones H. Clinical. Breast screening and ethnic minority women: a literature review. *British Journal of Nursing* 1999;**8**:1284-8.
51. Lawrenson R, Leydon G, Freeman G, Fuller J, Ballard J, Ineichen B. Are We Providing for Ethnic Diversity in Accident and Emergency (A & E) Departments? *Ethnicity and Health* 1998; **3**:117-123.
52. Leman P. Interpreter use in an inner city accident and emergency department. *J.Accid.Emerg.Med.* 1997;**14**:98-100.
53. Shaw-Taylor Y, Benesch B. Workforce diversity and cultural competence in healthcare. *J.Cult.Divers.* 1998; **5(4)**: 138 - 146.
54. Shaw-Taylor, Y. Culturally and linguistically appropriate health care for racial or ethnic minorities: analysis of the US Office of Minority Health's recommended standards. *Health Policy* 2002; **62**: 211 - 221.
55. Audit Commission. What seems to be the matter: Communication between hospitals and patients. Audit Commission report. HMSO. 1994.
56. Jones J. Unaccompanied refugee children in Enfield and Haringey; 1999 (Aug).
57. Hoare T. Breast screening and ethnic minorities. *British Journal of Cancer* 1996;**74(Supplement 29)**:S38-S41.
58. Carr-Hill R, Rudat K. Unsound barrier. *Health Service.Journal* 1995;**105(5439)**:28-9.

59. Boomla K, Moser K, Naish J. Uptake of breast screening. Accurate addresses will improve uptake rates. *BMJ* 1995;**310**:1004.
60. Rudiman R, Gilbert FJ, Ritchie LD. Comparison of uptake of breast screening, cervical screening, and childhood immunisation. *BMJ* 1995;**310**:229.
61. Doyle, Y. A survey of the cervical screening service in a London district, including reasons for non-attendance, ethnic responses and views on the quality of the service. *Soc.Sci.Med.* 1991; **32(8)**: 953-957.
62. Majeed FA. Using patient and general practice characteristics to explain variations in cervical smear uptake rates. *BMJ* 1994;**308**:1272-6.
- 63 Box V. Cervical screening: the knowledge and opinions of black and minority ethnic women and of health advocates in East London. *Health Education Journal* 1998;**57**:3-15.
64. Chiu LF. Balancing the equation: the significance of professional and lay perceptions in the promotion of cervical screening amongst minority ethnic women. *Critical Public Health* 1999;**9**:5-22.
65. Majeed FA, Cook DG, Given-Wilson R, Vecchi P, Poloniecki J. Do general practitioners influence the uptake of breast cancer screening? *Journal of Medical Screening* 1995;**2**:119-24.
66. Hoare TA. Reasons for non-attendance for breast screening by Asian women. *Health Education Journal* 1992;**51**:157-61.
67. Botha JL, Manku-Scott TK, Moledina F, Williams A. Indirect discrimination and breast screening. *Ethnicity & Disease* 1993;**3**:189-95.

68. Sutton S, Bickler G, Sancho-Aldridge J, Saidi G. Prospective study of predictors of attendance for breast screening in inner London. *Journal of Epidemiology & Community Health* 1994;**48**:65-73.
69. Bradley SN, Friedman EH. Cervical cytology screening: a comparison of uptake among 'Asian' and 'non-Asian' women in Oldham. *Journal of Public Health Medicine* 1993;**15**:46-51.
70. Sutton GC, Storer A, Rowe K. Cancer screening coverage of south Asian women in Wakefield. *Journal of Medical Screening* 2001;**8**:183-6.
71. McAvoy B, Raza R. Can health education increase uptake of cervical smear test among Asian women? *BMJ* 1991; **302**: 833-836.
72. Majeed A, Given-Wilson R, Smith E. Impact of follow up letters on non-attenders for breast screening: a general practice based study. *Journal of Medical Screening* 1997;**4**:19-20.
73. Atri J, Falshaw M, Gregg R, Robson J, Omar RZ, Dixon S. Improving uptake of breast screening in multiethnic populations: a randomised controlled trial using practice reception staff to contact non-attenders. *BMJ* 1997;**315**:1356-9.
74. Sharp DJ, Peters TJ, Bartholomew J, Shaw A. Breast screening: a randomised controlled trial in UK general practice of three interventions designed to increase uptake. *Journal of Epidemiology & Community Health* 1996;**50**:72-6.
75. Hoare T, Thomas C, Biggs A, Booth M, Bradley S, Friedman E. Can the uptake of breast screening by Asian women be increased? A randomized controlled trial of a linkworker intervention. *Journal of Public Health Medicine* 1994;**16**:179-85.

76. Falshaw ME, Fenton C, Parsons L, Robson J. Improving the uptake of breast screening: one initiative in east London. *Public Health* 1996;**110**:305-6.
77. Navarro AM, Senn KL, Kaplan RM, McNichols L, Campo MC, Roppe B. Por La Vida intervention model for cancer prevention in Latinas. Monograph National Cancer Institute 1995;**18**:137-145.
78. Sung JFC, Coates RJ, Williams JE, Liff JM, Greenberg RS, McGrady GA et al. Cancer screening intervention among Black women in inner-city Atlanta -- design of a study. *Public Health Reports* 1992;**107(4)**:381-8.
79. Del Mar C, Glasziou P, Adkins P, Hua T, Brown M. Do personalised letters in Vietnamese increase cervical cancer screening among Vietnamese women? A randomised controlled trial. *New Zealand Journal Public Health* 1998;**22(7)**:824-5.
80. Hunt JM, Lawton GG, Straton JAY. Pap smear screening at an urban aboriginal health service: report of a practice audit and an evaluation of recruitment strategies. *Australian and New Zealand J Public Health* 1998;**22(6)**:720-725.
81. Bell TS, Branston LK, Newcombe RG, Barton GR. Interventions to improve uptake of breast screening in inner city Cardiff general practices with ethnic minority lists. *Ethnicity & Health* 1999;**4**:277-84.
82. Kernohan EE. Evaluation of a pilot study for breast and cervical cancer screening with Bradford's minority ethnic women; a community development approach, 1991-93. *British Journal of Cancer - Supplement* 1996;**29**:S42-S46.

83. Cancer Research UK. www.cancerresearchuk.org/aboutcancer/statistics/mortality (accessed 19/11/03).
84. Garvican L. Planning for a possible national colorectal cancer screening programme. *Journal of Medical Screening* 1998;**5**:187-94.
85. Hardcastle JD, Chamberlain JO, Robinson ME et al. Randomised control trial of faecal occult blood screening for colorectal cancer. *Lancet* 1996;**348**:1472-7
86. Verne JE, Aubrey R, Love SB, Talbot IC, Northover JM. Population based randomized study of uptake and yield of screening by flexible sigmoidoscopy compared with screening by faecal occult blood testing. *BMJ* 1998;**317**:182-5.
87. Hoffman-Goetz L, Breen NL, Meissner H. The impact of social class on the use of cancer screening within three racial/ethnic groups in the United States. *Ethnicity & Disease* 1998;**8**:43-51.
88. Lindholm E, Berglund B, Haglind E, Kewenter J. Factors associated with participation in screening for colorectal cancer with faecal occult blood testing. *Scandinavian Journal of Gastroenterology* 1995;**30**:171-6.
89. Boring C, Squires T, Heath C. Cancer statistics for African Americans. *CA* 1992;**42**:7-17
90. Weinrich S. Predictors of older adults' participation in fecal occult blood screening. *Oncology Nursing Forum* 1990;**17**:715-20.
91. American Cancer Society. *Cancer in the socioeconomically disadvantaged*. Atlanta: American Cancer Society, 1990.

92. South Carolina Task force on Minority Health. Closing the gap: a call for action. Columbia: S.C. Department of Health and Environment Control, 1990.
93. Kim K, Yu ES, Chen EH, Kim J, Brintnall RA. Colorectal cancer screening. Knowledge and practices among Korean Americans. *Cancer Practice* 1998;**6**:167-75.
94. Tang TS, Solomon LJ, McCracken LM. Barriers to fecal occult blood testing and sigmoidoscopy among older Chinese-American women. *Cancer Practice* 2001;**9**:277-82.
95. Yu ESH, Kim KK, Chen EH, Brintnall RA, Liu WT. Colorectal cancer screening among Chinese Americans: a community-based study of knowledge and practice. *Journal of Psychosocial Oncology* 2001;**19**:97-112.
96. Beeker C, Kraft JM, Goldman R, Jorgensen C. Strategies for increasing colorectal cancer screening among African Americans. *Journal of Psychosocial Oncology* 2001;**19**:113-32.
97. Douglas CY. Community-based screening interventions for colorectal cancer. *Journal of Psychosocial Oncology* 2001;**19**:133-46.
98. Szczepura A, Johnson M, Orbell S, Gumber A, O'Sullivan I, Clay D, Owen D. Addressing Ethnic Diversity: Key findings from the UK Colorectal Cancer Screening Pilot. Department of Health, Oct 2003.
99. Powe BD. Fatalism among elderly African Americans. Effects on colorectal cancer screening. *Cancer Nursing* 1995;**18**:385-92.

100. Theuer CP, Taylor TH, Brewster WR, Campbell BS, Becerra JC, Anton-Culver H. The topography of colorectal cancer varies by race/ethnicity and affects the utility of flexible sigmoidoscopy. *American Surgeon* 2001;**67**:1157-61.

101. Theuer CP, Wagner JL, Taylor TH, Brewster WR, Tran D, McLaren CE et al. Racial and ethnic colorectal cancer patterns affect the cost-effectiveness of colorectal cancer screening in the United States. *Gastroenterology* 2001;**120**:848-856.