

**Access to Genetic Services  
by Minority Ethnic Populations**  
a pilot study

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## Summary

Inequity in health service provision (including genetics) to minority ethnic populations is well documented. That people from these groups continue to experience problems in accessing and receiving adequate and appropriate genetic services has also been increasingly highlighted over the years.

This four-month pilot study, funded by the Nuffield Foundation, was undertaken to ascertain current provision of genetic services to minority ethnic populations and to examine relevant issues underpinning the provision. Its aim was to develop proposals for further work based on the findings.

The research methods were a literature survey, consultation with health professionals and a survey of regional genetic centres. The issues explored in the survey were ethnic monitoring; referrals for haemoglobin disorders; provision for genetic counselling in minority ethnic languages and the availability of resources to aid genetic counselling with minority ethnic families.

The devising of an equitable and comprehensive genetic service for a multiethnic population, opposed to one that is relatively homogenous, requires a fundamental shift in perspective which accounts for the issues raised by multiethnicity. This report considers two examples of such issues: ethnicity in the context of ethnic monitoring and the debate surrounding customary consanguineous marriage and genetics.

The main issues that emerged from the study were:

1. The complexities of genetic service delivery to a multiethnic population from the perspective of health professionals and families have not been sufficiently explored in order to devise and implement appropriate strategies. Amongst other issues, this has particular implications for the education and training of health professionals.
2. Ethnic monitoring has been adopted by only a few regional genetic centres (RGCs). Adoption of the practice has been on an ad-hoc basis and is presently unsatisfactory.
3. The split between RGCs and services for haemoglobin disorders prevents sharing of expertise and the development of an integrated service. Two examples of collaboration between the services revealed much improved standards in service delivery to the local population.
4. The provision of linguistically and culturally appropriate genetic counselling remains inadequate. Additional approaches to first-language genetic counselling need to be explored.
5. There is a dearth of culturally appropriate resources for health professionals and families to aid in the time-consuming process of genetic counselling.

## Recommendations

1. Development of a range of education and training materials on genetic service delivery in a multiethnic context for health professionals working with minority ethnic populations.

2. Investigation of issues related to ethnic monitoring in genetic services with the aim of formulating guidelines on the ethnic categories relevant in Britain and development of associated training for health professionals.
3. Exploration of the feasibility of distance genetic counselling in a multicultural context.
4. Assessment of the nature and definition of the format of education tools required by professionals and families to aid genetic counselling in a multicultural context.
5. Exploration, in one region, of the possibilities for collaboration between an RGC, services for haemoglobin disorders, paediatricians, Primary Care Groups and community organisations, with a view to developing a framework of good practice.

1. Background

1.1 Key requirements of genetic services

The following detail the requirements developed by the Genetic Interest Group in collaboration with both professionals and service users (1). They have been designed to complement professional guidelines:

1.1.1 Availability

A fully-resourced, comprehensive genetic service, covering both rare and common disorders, should be available throughout the country.

1.1.2 Access and equity

Genetic services appropriate to individual needs should be accessible to all on an equitable basis. Services should be provided in response to clinical need - not ability to pay, geographical location, age, ethnic or cultural background, disability, or whether a condition is common or rare.

1.1.3 Partnership with users and professional collaboration

The genetic services should work in partnership with service users and in collaboration with health professionals in primary and secondary health care and other services to ensure genetic services are delivered effectively and users' needs are met.

1.1.4 Information

The provision of information is central in almost every aspect of the work of the genetic services. It is particularly important that information given to users of the service and their families is accurate, clear, appropriate and well communicated.

1.1.5 Counselling and support

Individuals and families need high quality, non-directive genetic counselling appropriate to their individual needs, and support to enable them to make their own informed choices.

1.1.6 Long-term follow up and contact of at-risk relatives

Systems are needed to facilitate efficient, effective long-term follow up of service users and their families and contact of at-risk relatives.

1.1.7 Standards for clinical and laboratory services

Specific standards are needed for practice and procedures in clinical, counselling and laboratory services, to ensure they are supportive to people who use them.

1.1.8 Monitoring and evaluation

Clinical and laboratory genetic services should be systematically monitored and evaluated, and service users should be involved in these processes.

<b>HUB</b> <i>regional centre</i>	<b>SPOKE</b> <i>district hospital and community</i>
<b>Patients and families</b>	
<ul style="list-style-type: none"> <li>● Genetic clinics, specialist and general</li> <li>● Genetic register contact</li> <li>● Information and literature source</li> </ul>	<ul style="list-style-type: none"> <li>● General genetic clinics</li> <li>● Home visits</li> <li>● Link to centre activities and information</li> </ul>
<b>Consultants</b>	
<ul style="list-style-type: none"> <li>● Organisational base, specialty clinics</li> <li>● Expert advisory role</li> </ul>	<ul style="list-style-type: none"> <li>● District clinics</li> </ul>
<b>Clinical genetic trainees</b>	
<ul style="list-style-type: none"> <li>● Main training base</li> </ul>	<ul style="list-style-type: none"> <li>● District experience</li> </ul>
<b>Nurse specialists/genetic associates</b>	
<ul style="list-style-type: none"> <li>● Specialist clinics</li> <li>● Training and research activities</li> <li>● Genetic registers</li> </ul>	<ul style="list-style-type: none"> <li>● District clinics</li> <li>● Home visits</li> </ul>
<b>Educational activities</b>	
<ul style="list-style-type: none"> <li>● Undergraduate</li> <li>● Postgraduate</li> </ul>	<ul style="list-style-type: none"> <li>● Professional/public education</li> </ul>
<b>Other activities</b>	
<ul style="list-style-type: none"> <li>● Management/service development</li> <li>● Research and development</li> </ul>	

Table 1: Clinical genetic services: the hub and spoke model

Source: (6)

1.2 Genetic services in Britain

1.2.1 In Britain genetic services are organised through 27 regional genetic centres (RGCs), the first clinical genetics service having been established in 1946. Twenty one RGCs service the population in England with four in Scotland and one each in Wales and Northern Ireland. Despite successive changes directed towards organisational structures in the NHS, the regional level has remained the main level of organisation for genetic services (2).

1.2.2 Over the past few decades genetic services have evolved into a hub and spoke model of service delivery (table 1). However, historically, the development of genetic services has not been the result of strategic planning, reflecting clear policies, but a consequence of the initiatives of individual clinicians, usually in teaching hospitals (4). Consequently, there is large variation in the range of services provided and the patterns of care differ from one region to another. Currently, on a national level RGCs form a co-ordinated service, but at the local level, the required links between different specialisms are organised, if at all, on an ad-hoc basis(2).

1.2.3 Underfunding has seriously undermined the growing need for service development in this field. This is particularly so now, given the increasing demand for genetic services due to advances in the application of genetic knowledge in common conditions such as cancer and diabetes (2). A survey conducted by the Genetic Interest Group showed that the workload of RGCs has risen by 50 and 100% (5).

1.3 Community Genetics

1.3.1 Community genetics is an advancing discipline, reflecting the approach of some professionals that outreach work in the community is an essential part of delivering a comprehensive genetics service, in which increased collaboration between RGCs, specialist hospital disciplines and Primary Care will also play an important role (6,7). The structures and networks involved in delivering a comprehensive community genetics service are illustrated in fig 1.

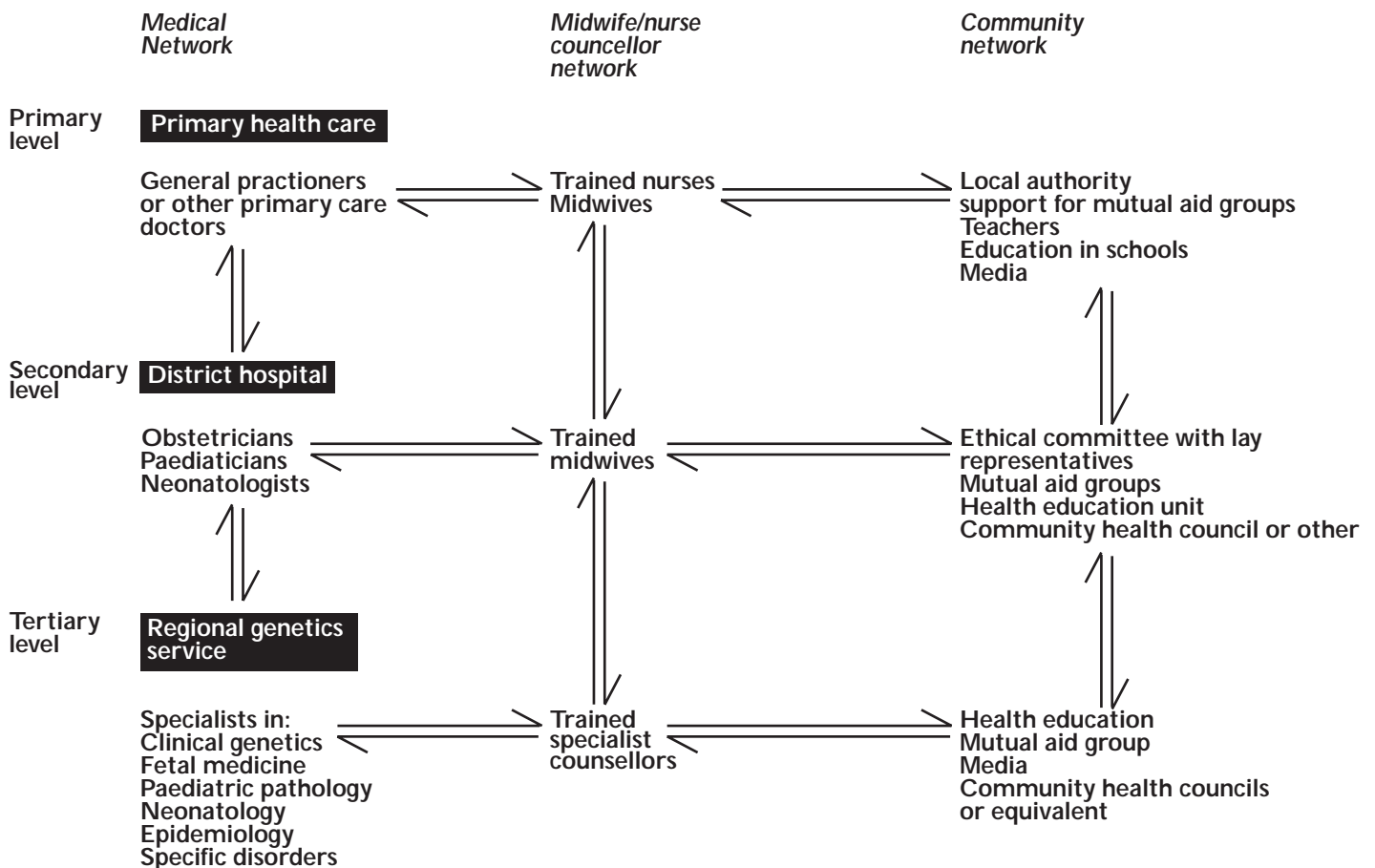


Figure 1: Community genetics network Source: (7)

#### 1.4 Development of genetic services for minority ethnic populations

1.4.1 Most of the experience in providing services for minority ethnic populations has not evolved through the RGCs, but rather through the haematology service, the haemoglobin disorders (thalassaemia and sickle cell) being the most common recessive conditions among minority populations in Britain (8). The development of haemoglobin disorder services began as a response to the treatment needs of patients. Subsequently, sickle cell and thalassaemia counsellors have been appointed on an ad-hoc basis by some hospital Trusts and community organisations to address the genetic counselling needs of affected families and communities (9).

1.4.2 There is no formal, established link between between RGCs and services for haemoglobin disorders. Because of this separation, the lessons learned, through research and experience about service delivery to linguistically and culturally diverse minority ethnic populations, have not filtered through into RGC practice. Equally, haemoglobin disorder services also suffer through lack of contact with specialist counselling services, particularly with reference to family studies.

1.4.3 Although services for haemoglobin disorders are viewed as having made progress in devising appropriate services, they still remain under resourced and highly inadequate (10,11). The thalassaemia module of the recent National Confidential Enquiry into Counselling for Genetic Disorders has shown gross deficiencies and inequity in service delivery to minority ethnic

populations (12). The enquiry highlighted marked variation between regions and between ethnic groups in meeting basic standards of care in genetic counselling, eg, standards were met for 80% of North Thames cases and 31% for West Midlands. There was also marked variation by ethnic group, eg, standards were met for 81% of Mediterranean and 46% of Pakistani couples (tables 2 and 3).

1.4.4 Protocol for the management of haemoglobin disorders and guidelines for service delivery have been recommended in the SMAC report (10) as well as subsequent publications (11,13). Concern, however, has been expressed by health professionals at the lack of interest in adopting the recommendations by service providers.

1.4.5 Presently, central funding is being considered for clinical genetic services (not including haemoglobin disorder services), whilst similar funding for thalassaemia has just been refused (14). Given this disparity between the two services there is concern that haemoglobin disorder services may become marginalised from mainstream genetic counselling services (9).

1.4.6 Primary care is one area where there is no separation between haemoglobin disorders and other genetic disorders; everyone at-risk is likely to present at the GP surgery in the first instance. This requires Primary Care Groups to be especially alert to families' genetic needs in order to refer them to the appropriate services, particularly as the importance of genetic components in common disorders such as diabetes and cancer, as well as rare disorders, are being increasingly recognised (6,7).

Regional Health Authority	Standards Met		Total
	No	Yes	
North Thames	10(20%)	40	50
West Midlands	18 (69%)	8	26
South Thames	5(45%)	6	11
North West & Mersey	8 (62%)	5	13
Northern & Yorkshire	3 (23%)	10	13
Trent	3 (30%)	7	10
Oxford and Anglia	6(50%)	6	12
Wales	1 (100%)	0	1
Scotland	0(0%)	1	1
Total	54(39%)	83	137 (100%)

Table 2: Regional variation in standards met for genetic counselling (12).

Ethnic Group	Standards Met		Total
	No	Yes	
Mediterranean	7(19%)	30	37
Asian Indian	11(34%)	21	32
Pakistani	30(54%)	26	56
Bangladeshi	3 (60%)	2	5
S.E.Asian/Chinese	3 (50%)	3	6
Iraqi	0 (0%)	1	1
Total	54 (39%)	83	137(100%)

Table 3: Ethnic variations in standards met for genetic counselling (12).

## 1.5 Equity and genetic service provision

1.5.1 Virtually all NHS documents refer to the importance of equity in service provision, yet there has been no serious consideration of how to comprehensively meet the challenge of delivering an equitable genetic service in the context of a multiethnic society. Hence, there are serious gaps in service provision for at-risk and affected minority ethnic families, who consequently struggle to deal with the burdensome realities of chronic genetic conditions and the related implications for other family members (15,16,17).

## 1.6 Ethnic composition of Britain's population

1.6.1 Smaje (18) offers a succinct account of the historical roots and extent of ethnic diversity in contemporary Britain, from which the following is taken. The account is an indication of the extent of diversity relating to ethnic origin in Britain, not always obvious when looking at most ethnicity related investigations including the 1991 Census.

1.6.2 The ethnicity of the majority population in Britain is defined as Anglo Saxon. Significant numbers of Jews, Gypsies, Irish and African people have also settled here dating back to medieval times. The more recent settlements have been mainly in the 19th and 20th centuries. After the famines of the 1840s there was large scale migration of Irish people and of Jews who were fleeing persecution from Eastern Europe. The colonial trade between Africa, Britain and the Caribbean in the latter part of the twentieth resulted in large population settlements in Liverpool and Cardiff. Around the same time smaller numbers of Chinese and South Asian people also made homes in Britain.

1.6.3 More recently, during and after the two World Wars there was considerable migration of people from Europe, notably Poles and Germans and Austrian Jews, plus continued migration from Ireland and of Chinese people, mainly from rural Hong Kong. The 1950s and 1960s were characterised by a booming economy and labour shortages which were filled by the British Government's active encouragement of migration from the "New Commonwealth", Britain's former colonies of the Caribbean, particularly Jamaica, India and Pakistan. Migrants originating in India were mainly Muslim Bengalis, Hindu Gujeratis and Sikh Punjabis. Those originating from Pakistan were mainly from the rural areas in the Punjab and Azad Kashmir. A large number were from the Mirpur District in Azad Kashmir where much displacement of village populations took place due to the Mangla Dam project. Smaller numbers also came from the cities in Pakistan of which many were people who had initially migrated from India to Pakistan after the partition of the Indian subcontinent in 1947 (19). During this period migrations also occurred from Sri Lanka and Cyprus.

1.6.4 The late 1960s and early 70s saw the arrival of people from the Sylhet region of Bangladesh, East African Asians (originally from India) who were expelled from East Africa and Cypriots fleeing the Turkish invasion in 1974.

1.6.5 There are also an estimated 120,000 refugees in Britain of whom over 80% reside in the Greater London conurbation. Their main countries of origin include Somalia, Nigeria, India, the former USSR and Yugoslavia, Turkey, Sri Lanka, Iraq, Iran, Columbia, China and Pakistan. Additionally, there are smaller numbers of students from overseas. Both categories are entitled to NHS services (20).

1.6.6 Immigration legislation passed in the 1960s and subsequently, terminated large scale primary migration from the New Commonwealth. Most migration from these areas since the 1960s has been of the dependants of the, predominantly male, earlier migrants. Another category of more recent arrivals are the spouses of the British born children of earlier migrants (21).

1.6.7 Although there is considerable diversity in Britain's ethnic make-up the presence of populations originally from the Indian subcontinent and the Caribbean have come to define the current popular image of the ethnic composition of Britain:

*"These migrations were not numerically the largest in Britain but in important respects they were definitive of the ethnic composition of Britain today. Although Gypsy, Jewish and Irish populations have all been subjected to explicit "racial" stereotyping and discrimination in Britain at various times.....it was the arrival of large numbers of people of different skin colours in post-war Britain that ignited colonial ideologies of "race". Hence increasingly from the 1950s, the "problem" of immigration has been characterised largely in terms of skin colour" (18).*

1.6.8 Given the relevance of place of origin in genetics, the considerable diversity of genetic origin in Britain's population must not be submerged beneath popular notions of difference based on physical appearance alone, thereby resulting in non-detection of people's risk status simply because their physical appearance does not tie in with popular perceptions of how people of a specific geographical origin look.

## 1.7 Demographic data

1.7.1 The age distribution of minority ethnic populations is comparatively younger than the white population, indicating a need for emphasis on maternal and child health (appendix 2, tables 4 and 5).

1.7.2 The best indicator for genetic services, insofar as their major focus is childhood disorders and reproductive risk, is annual number of births rather than number of residents (appendix 2, tables 6 and 7).

1.7.3 Consanguineous marriage, practiced by some minority ethnic populations increases the frequency of rare recessively inherited disorders. Given the larger numbers of women of reproductive age there is likely to be an increased need for genetic services in these groups (22,23,24).

## 1.8 Ethnicity and genetics

1.8.1 "In its original usage, to be ethnic was to be heathen. Deriving from the Greek work ethnos - nation - contemporary usage has often preserved the exclusionary sentiments implicit in this conflation of religion and nationality. To be ethnic is to be different, foreign and marginal: not "one of us". More recently, social scientists have extended the concept of ethnicity to encompass all of the ways in which people seek to differentiate themselves from others. In this sense, ethnicity has largely replaced "race" - differentiation according to physical appearance - as the appropriate way to think about human difference " (18).

1.8.2 The precise meaning of the term ethnicity as a variable in health research, however, is hotly debated (25, 26, 27). A number of definitions abound for this complex social phenomenon for which there still appears to be little consensus. The debate indicates caution in categorising populations and points to a consideration

of their social significance as well as precision in the terminology used. It appears that each field needs to examine its use of the term “ethnic” or “ethnicity” to define its precise meaning in the context in which it is being used rather than an unthinking use of existing terminologies. So, in the field of genetics precisely which variable is being noted when recording ethnicity, and what purpose does this form of data collection serve? This is an unresearched area that requires further consideration to reach a consensus of opinion that can inform practice. The following offers a preliminary introduction.

**1.8.3** Categories presently used by researchers and service providers for monitoring ethnicity vary considerably; the lack of consensus itself diminishes the usefulness of data. The categories are also criticized for being too broad to be useful. For example, the term white indicates English, Irish, Turkish Cypriot and Jewish people originally from Eastern and Central Europe. The term Indian encompasses Sikh Punjabis, Hindu Gujeratis and Bengali Muslims who differ at a number of levels from one another. Thus the usage of broad terms renders invisible whole communities leading to political invisibility and prevention from being included in the development of a policy agenda (28). Cultural assumptions are also made on the basis of ethnicity related data rather than accurate information seeking. For example, the practice of consanguineous marriage is generally thought to have significance in relation to Muslims of Pakistani origin whereas it is also practiced amongst Irish travelers (24), amongst others. Attention to the genetic and service delivery implications for this group, Irish travelers in this case, are subsumed if they are ethnically defined as white.

**1.8.4** Simply to record ethnic origin may not be enough in the context of genetic service delivery. Are the variables being inferred from this term largely related to geographical origin and popular notions of cultural differences? In which case, would it not be more useful to also ask questions related to specific variables? Which other variables impinge on genetic service delivery? Most importantly, how will the data collected impact on service delivery? In other words, once collected, how will the information about minority ethnic families be used to improve their experience of genetic conditions? These questions, amongst others, need to be addressed as an integral part of developing an appropriate genetic service for minority ethnic populations.

**1.8.5** In conclusion, given that ethnicity related data is essential for gathering accurate information on genetic epidemiology, planning appropriate services for an ethnically diverse population and conducting an effective audit, genetics service providers need to examine the precise relevance of ethnicity based data in the genetics field and practice caution in using terminologies borrowed from other disciplines. In place of broad categories data needs to sufficiently refined to be useful, and this is only possible when there is clarity about its use value.

## **1.9 Ethnicity - asking the question**

**1.9.1** Health professionals collecting data on ethnicity related issues do so against a historical backdrop of racism against minority ethnic populations, and of ethnocentrism wherein minority cultures are perceived as less desirable than the white norm (29, 30). Questions relating to country of birth, marriage patterns, religion, language and so on are reminiscent of the interrogations carried out by immigration authorities. Even if such

interrogations have not been the direct experience of each individual, they nevertheless are a part of the historical cultural experience of the groups as a whole, of which there is a general awareness.

**1.9.2** In the context of genetics, the background of racism is supplemented by the history of eugenics and its powerful legacy (31). This backdrop affects the perceptions of people regardless of which ethnic group they belong to. The difference lies in the dynamics that operate when a white genetics professional is the one asking the questions of someone from a minority ethnic population, bringing into play the power relations that already exist between the two groupings in the wider society. The result is a reticence and discomfort on the part of white professionals in asking ethnicity related questions and for respondents to regard the questions and the person asking them with suspicion (22). The questions need to be asked. How to ask them with sensitivity, allaying any fears, is a training and education issue that needs to be addressed.

**1.9.3** Consultation with health professionals reveals that lack of knowledge and understanding about why ethnicity related data is being collected and how it will feed back into service delivery undermines their confidence in asking pertinent, ethnicity related questions. It is an issue that has also been noted in fields other than genetics (27). Clear guidelines and training of health professionals on the collection of ethnicity related data are an essential component of operationalising a policy on ethnic monitoring.

## **1.10 Genetics and minority ethnic culture - the case of consanguineous marriage**

**1.10.1** Consanguineous marriage forms part of the cultural practices of a number of minority ethnic populations in Britain including people originally from Pakistan, the Middle East and Irish travelers (23, 24). The issue of consanguineous marriage and its genetic implications has assumed an exaggerated importance beyond its clinical relevance to rare recessively inherited conditions, causing confusion amongst health professionals and communities practicing the marriage pattern (15,16,32,33). As Bunday and Roberts (34) note:

*“Once a consanguineous couple has produced a child with a recessive defect, the risk of its recurrence is virtually the same (1 in 4) as for any other parents of a child with this condition, though there is an increased risk of some other defect. It is doubtful whether in counselling the fact that the parents are consanguineous need even be mentioned. If one is asked whether this tragedy is due to their relationship, one can only say that this has contributed, but point out that that if they had both chosen other partners they might have produced children with some other condition, for everybody carries bad genes for some disorder or other “*

**1.10.2** However, health professionals citing consanguineous marriage as the “cause” of genetic conditions is not a rare occurrence. Darr (15), in a study of thirty one British Pakistani families at risk for thalassaemia, reported that virtually every family in a consanguineous marriage had been told by a health professional that the condition was caused by their marriage pattern. A more recent study encompassing the eight District Health Authorities in the Northern and Yorkshire and North Western regions by Atkin (16) shows that Pakistani families are still subjected to the same misinformation. Consultation with Asian genetic specialist workers (appendix 1) also reveals the same situation in other parts of the country.

**1.10.3** The genetic implications of consanguineous marriage have been regularly presented at meetings for over a decade. There has been less focus on misinformation about the subject prevalent among health professionals and its consequent impact on the families at the receiving end of the information.

**1.10.4** Citing consanguineous marriage as the cause of a genetic disorder places the burden of responsibility on the parents shoulders and simultaneously away from the health professional. It also implies that the marriage pattern of the community has caused them to have an affected child and the sole option available to them and to other people in their community is to change that marriage pattern. Coupled with the absence of information on the real options available, the result of such communication only produces guilt and despair in parents. As consanguineous marriage is highly favoured, particularly, though not exclusively, amongst the Muslim population of Pakistani origin in Britain, such statements are seen as an attack on what is viewed as a positive social practice (15,22, 23). That the exaggerated statements regarding the medical implications of consanguineous marriage are false become apparent to parents very quickly, as they are surrounded by couples who are first cousins but who do not have children with inherited disorders. This in turn produces mistrust of health professionals, whose advice in the future will not be considered sound. Erroneous comments of this nature cause strong reactions in parents. A mother of a thalassaemic child, on being told what she knew to be false information about the link between genetic disorders and consanguineous marriage said:

*“I nearly hit him (the doctor) with my handbag. I didn’t, instead I vowed never to go back to him (15).”*

Another mother with two thalassaemic children who was told that her sons’ disorder was caused by consanguineous marriage and that all her future children would be thalassaemic, gathered the courage to become pregnant again as she had no unaffected children. She doubted the first part of the doctor’s statement and therefore had little faith in the validity of the second. However, she did not inform her GP until she went into labour, foregoing antenatal care (ibid). Another mother said:

*“If we have children with inherited disorders because of our marriages then why do the English have them, too (ibid)*

One mother confessed to having told the nurse they were unrelated because “ they frown on you and question you if you are married to your first cousin” (ibid).

**1.10.5** The implicit message in this interaction between health professionals and minority ethnic families is “Your culture’s the problem. Change your culture and you won’t have the problem!” Presenting minority ethnic cultures as problematic is not restricted to the debate surrounding consanguineous marriage. The notion that there is little point in offering prenatal diagnosis to Muslim families because it is against their religion is also well known (15, 35), although inadequate service delivery has been shown to have a greater impact on uptake of prenatal diagnosis than religious beliefs (15,35,36). Another example is the case of health professionals’ dismissal of the need for strong painkillers by sickle cell sufferers based on stereotypical assumptions about Afro-Caribbean people’s leniency towards drug use (36). Simplistic notions of the role of culture in determining access to healthcare and the politics of victim blaming are well documented practices in health and social welfare (37,38,39). As Ahmed (39) notes:

*“The effect of an emphasis entirely on cultural difference to explain*

*inequalities and differences in health status or use of health care services is to pathologise “culture”, making it the cause of as well as the solution to inequalities in health and healthcare (29,37).”*

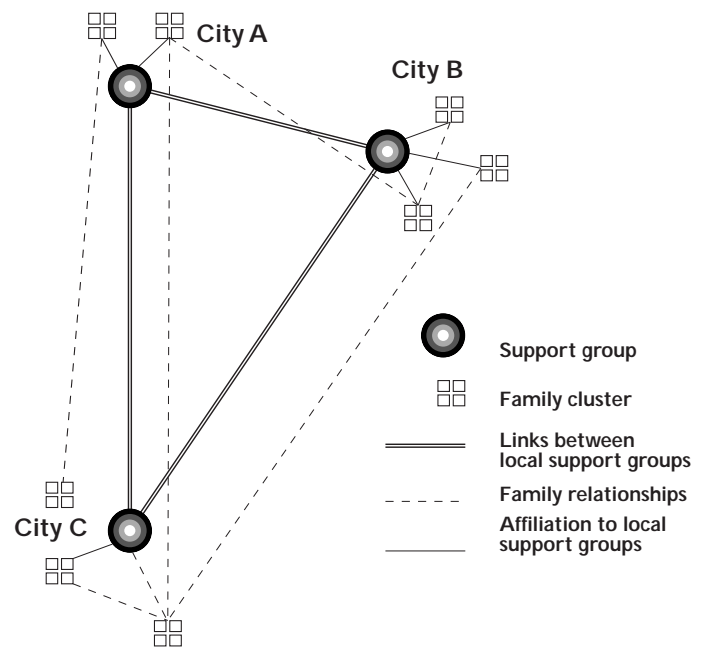
**1.10.6** The preoccupation with cultural differences ignores the wider context of poverty, poor housing, high unemployment and racism, within which most minority ethnic families live, as determinants of access to healthcare (38,39,40). Notwithstanding the need to address the structural inequalities and racism, health professionals are nevertheless vehicles for perpetuating ideologies, albeit as part of a much larger structure. As Ahmed (39) goes on to say:

*“Professional ideologies reinforce (perhaps even construct) the dominant notions of normalcy and, as main arbiters of definitions of and solutions to problems in health and social services, act as potent mechanisms for social control. Although under challenge from increasing consumerism and managerialism, and some blurring of boundaries between professional and lay knowledge in health and social services, medical and professional power remains an important tool for exerting social control by allowing the exercise of racist power through the hierarchical relationship between practitioners and patients and between service providers and users. This happens in psychiatry, general practice, community health services, obstetrics and social work as well as other fields (29,38,40,41)”*

It appears this is precisely what is happening in the field of genetics, too. Again, the complexities of the factors impinging on genetic service delivery and the consequent training needs of health professionals and other service providers need to be addressed.

**1.11 Genetics and consanguineous marriage - a positive approach**

**1.11.1** The emphasis on consanguineous marriage as a negative entity has also diverted attention from the relevance of kinship patterns (42) and the positive application of consanguineous marriage in genetics. As Darr (29) illustrates, the kinship networks



**Fig 2: Model showing possible networks of information and support formed through genetic counselling and support groups, based on existing kinship networks (33).**

established by consanguineous marriage, which are also channels of information and support, offer an opportunity to deliver a genetic counselling service by making positive use of these networks (fig 2). In communities that practice consanguineous marriage, rare recessively inherited conditions manifest in family clusters rather than randomly in the population. The prospective detection of a gene or the birth of an affected child identifies a family that is transmitting that gene. Genetic counselling focussed on the at-risk extended family may be particularly successful in detecting couples at risk of having affected children and advising them prospectively.

## 2. Survey of service delivery to minority ethnic populations through regional genetic centres.

A questionnaire was sent to all the regional genetic centres in Britain, twenty seven in total. There were 23 replies, a response rate of 85%. The questions were designed to elicit information on the following issues:

- ethnic monitoring
- referrals for haemoglobin disorders
- provision for genetic counselling in minority ethnic languages
- availability of resources to aid genetic counselling with minority ethnic families

### Survey Findings and discussion

#### 2.1 Ethnic monitoring

2.1.1 Seventeen of the twenty seven RGCs serve regions with a high prevalence of minority ethnic populations. However, only five of all RGCs record the ethnicity of people referred to them. One other recorded religion and stated an awareness of the need for recording ethnicity. One other had recorded ethnicity only for one year during an audit. Except in one centre where figures had been collected since 1983, ethnic monitoring in the other four was a recently introduced practice. Four of the centres used systems from which information was retrievable whilst one did not. The ethnic categories used varied from one centre to another.

2.1.2 A reason for not adopting an ethnic monitoring policy mentioned by some RGCs was that they were in areas with a low prevalence of minority ethnic populations. However, statistical knowledge of population make-up is based on the census data, which as previously mentioned, only records broad categories and many people's ethnicity is subsumed under those, making them invisible. This view also ignores those members of minority ethnic groups who reside in low prevalence areas, travelers, the mobile student population and the impact of mixed marriages.

2.1.3 Ethnic monitoring is an essential but neglected component of genetic service delivery to a multiethnic population. Its absence reflects a grave deficiency in a Centre's ability to plan appropriate services for an ethnically diverse population, to conduct an effective audit and to gather accurate data on genetic epidemiology. However, simply recording ethnicity is of little use unless employed as a tool within a comprehensive policy that makes constructive use of the data to improve service delivery (see 1.8 and 1.9).

#### 2.2 Provision for genetic counselling in minority ethnic languages

2.2.1 Only four of all RGCs specifically employ someone trained in genetic counselling to counsel people from minority ethnic populations. One of the four employs two people. The vast majority of the others, including those in high prevalence areas who have not employed a specialist counsellors, rely on interpreters and linkworkers (who are not specifically trained in genetic counselling skills), or on members of staff employed for tasks not related to genetic counselling.

2.2.2 An essential part of a genetic counsellor's responsibility is to ensure that families receive accurate information in a way that they understand and to support them in the process of making decisions based on that information. Given the centrality of effective communication, confidentiality and on-going support in

the provision of genetic counselling, utilising the services of interpreters and linkworkers who are not trained in genetics, greatly falls short of a quality service. This practice also has the potential for doing more damage than good because of the possibilities for misunderstandings in communicating complex genetic issues. One health professional commented that, "We are often told by interpreters that there are no direct translations of the terminology and this makes explanations difficult. It has seemed on some occasions in the past that the interpreters we have used have not been able to translate in the non-directive manner which we employ during genetic counselling. In extreme circumstances we have used members of staff for translation, but we are concerned about this practice if the member is not one of the clinical team. Consultations can be stressful and the issues discussed very sensitive and require specialists skills to deliver".

2.2.3 Inaccessibility to quality genetic counselling in their mother tongue can have serious consequences for families. An example is of Mr A, not fluent in English, who understood the term "genes" to mean "germs", when an English-speaking doctor was trying to explain genetic inheritance to him. Not having grasped the genetic nature of the condition or the details of the treatment, he thought that if the condition is caused by germs, then with the present state of medicine there must be a cure, somewhere. Against the advice of their paediatrician, Mr and Mrs A returned to Pakistan with their two thalassaemic children where they also hoped to find an alternative cure for thalassaemia major. During that period, one of their children died as he was technically difficult to transfuse. Distressed, they returned to England with their other child. It was only when the couple spoke to a counsellor who explained the condition to them accurately in their mother tongue, that Mr A recounted his experience and was able to understand and contextualize his own reactions and the paediatrician's advice (15).

2.2.4 A survey conducted in 1996 (9) showed that there were 34 haemoglobinopathy counsellors in post. The employment of culturally appropriate counsellors for the local populations is one area in which experience of service delivery for haemoglobin disorders has resulted in a response to need. Anionwu (9) in an account of users, carers and professionals involved in this area noted the following as the major reasons influencing the creation of sickle and thalassaemia counselling posts:

- "increased burden that families experience due to ethnocentric, negative, patronising or racist attitudes encountered in dealings with healthcare workers;
- failure to provide information in appropriate languages prior to, during and after screening and diagnosis of the trait and the disorder;
- difficulties in obtaining support and information from people who respect the cultural background of the families".

In the above-mentioned survey only four of the thirty four haemoglobinopathy counsellors were of Asian background with the appropriate linguistic skills. Asian specialist workers attending the ASWIC Forum meetings (appendix 1) were three Asian counsellors employed by RGCs, one employed by RNIB and eight who had responsibility for haemoglobin disorders. This is not a comprehensive list of all Asian specialist workers in the genetics field; a thorough and systematic analysis of minority ethnic professionals in the genetics field is required.

2.2.5 The provision of genetic counselling to non-English speakers is a challenge for the Health Service in a linguistically and

culturally diverse population. For example, in a multiethnic area with a large concentration of people of Bangladeshi origin an RGC might employ someone who speaks Bengali, but how would the service cater for the smaller numbers of people of Turkish, Indian or Pakistani origin in the same area? Although a few organisations do employ genetics associates with relevant language skills in some regions, the supply falls greatly short of demand. It is unlikely that a genetic counsellor of the appropriate cultural background and language skills will ever be available in every region for every family. Given the importance of effective communication in genetic counselling, alternative ways of providing genetic counselling alongside existing channels need to be explored. One such approach is distance genetic counselling.

**2.2.6** Distance genetic counselling is the provision of information and support to an individual from a professional who is based at a distance, using the telephone or video-conferencing facilities. The feasibility of this service is being investigated for the Welsh population (42). This project addresses the genetic counselling needs of people living in the Welsh valleys, away from the Regional Genetic Centre in Cardiff. Distance counselling may also be an efficient way of organising a nationwide genetic counselling service for a multiethnic society, in addition to the specialist counsellors serving the major areas of settlement. Similar to the situation in Wales, the service would also be of use to minority ethnic families in low prevalence areas.

**2.2.7** It must be emphasised that the lack of priority given to the employment of genetic counsellors of appropriate cultural backgrounds needs to be rectified. Face-to face contact is by far the best way of providing information and support. However, distance genetic counselling would be an efficient supplement in providing a comprehensive, nationwide service.

### **2.3 Availability of resources to aid genetic counselling with minority ethnic families**

**2.3.1** There is a dearth of linguistically and culturally appropriate genetic education resources to assist communication between health professionals and minority ethnic families. Only five of the RGCs reported having access to and using leaflets and two used a video.

**2.3.2** Audio-visual aids are particularly relevant in the context of genetics given that the general population has little knowledge of genetic issues; the complexity of genetic concepts which require repetition and the central role of accurate information for all family members on which to base decisions. Burton (44) describes the initial impact of diagnosis of a genetic disorder:

*“Not only do they actively not want to know but they also experience a paralysis of thought processes which renders impossible comprehension of anything but the clearest, clearest information”.*

A diagnosis is usually met with shock by parents:

*“I can’t recall what we were told on that occasion. An awful lot of what he said, I lost. I’d already begun to look out of the window. The feeling I had the roof was coming in around us”.*

*“I didn’t even know what it was. I thought it was multiple sclerosis. I couldn’t remember what it was he said. I kept crying but I didn’t know” (ibid).*

A common psychological response to this type of knowledge, which to families feels as though it has been thrust upon them, is denial:

*“I felt it wasn’t it. That she hasn’t got it at all, that she couldn’t have it”.*

*“I can’t really describe how I felt about it at the time. It’s the sort of thing you don’t think about . . . .you push it more to the back of your mind and don’t think about it” (ibid).*

**2.3.3** In the process of genetic counselling, information giving is not a one-off task. The information needs to be repeated until it is understood sufficiently so that families feel confident about the facts and the decisions they make, based on those facts. If the information being given is in a language that is foreign to the affected family, parents or an individual leave a consultation knowing that something is seriously wrong but without access to information they can understand.

**2.3.4** Genetic counselling is a time consuming process; the absence of education aids to consolidate information makes it even more so. The availability of linguistically and culturally appropriate resources, such as leaflets, audiocassettes and videos would greatly enhance the efficiency with which counsellors, and other health professionals, can communicate and consolidate information. Videos have been documented as a cost-effective tool in genetic counselling (45). The resources would also provide families with accurate information they can access repeatedly in the privacy of their homes, with other family members, at a time convenient for them.

**2.3.5** The use of videos as information resources in the home may be particularly relevant for Asian families; in the mid-1980s for reasons related to the entertainment industry over 60 per cent of Asian households had videos in their homes. This number is likely to have increased as VCR continues to be an important resource for accessing entertainment in Asian languages (46).

### **2.4 Haemoglobinopathy referrals**

**2.4.1** RGCs receive few referrals for haemoglobin disorders, even though they are the most common recessive disorder for a large proportion of the minority ethnic population. Most RGCs were, however, aware of alternative diagnostic and counselling facilities for these disorders.

**2.4.2** The survey, however highlighted a uniquely successful outreach programme at Glasgow and examples of collaboration between a small number of RGCs and services for haemoglobin disorders. Insufficient information does not allow for conclusive statements based on this survey, but the Confidential Enquiry found that collaboration between the RGC and services for haemoglobin disorders at Leeds and Leicester had led to a marked improvement in services for at-risk couples [personal communication (47)]. Closer links between the two services may result in better service provision from both, in line with DoH recommendations of co-operation between organisations (48).

### **2.5 Education and training**

**2.5.1** The need for education and training for health professionals has already been mentioned in this report. Presently, there is no specific training course to equip health professionals to deal with issues related to effective genetic service delivery to minority ethnic populations, for example, genetic epidemiology, ethnic monitoring, the relevance of kinship patterns including customary consanguineous marriage and communication dynamics in a multilingual society.

**2.5.2** All professionals consulted emphasised the need for adequate training in genetics in general and specifically on aspects of genetic service delivery to minority ethnic populations for those dealing directly with those populations.

**3. Recommendations**

**3.1** Development of a range of education and training materials on genetic service delivery in a multiethnic context for health professionals working with minority ethnic populations.

**3.2** Investigation of issues related to ethnic monitoring in genetic services with the aim of formulating guidelines on the ethnic categories relevant in Britain and development of associated training for health professionals.

**3.3** Exploration of the feasibility of distance genetic counselling in a multicultural context.

**3.4** Assessment of the nature and definition of the format of education tools required by health professionals and families to aid genetic counselling in a multicultural context.

**3.5** Exploration, in one region, of the possibilities for collaboration between an RGC, services for haemoglobin disorders, paediatricians, Primary Care Groups and community organisations, with a view to developing a framework of good practice.

A detailed proposal based on the above recommendations has been developed and funding is being sought.

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## Appendix 1

### The ASWIC Forum

The ASWIC (Asian Specialist Workers for Inherited Conditions) Forum is a national group which was set up in June 1997. It forms part of the Genetic Interest Group's programme of work with health professionals and is in recognition of the isolation in which specialist genetic workers, dealing with Asian families, are attempting to deal with the demands of providing a genetic service at the grass roots level.

The first specialist genetic associate<sup>1</sup> with the required cultural background and linguistic skills for counselling Asian families was appointed in 1986 by the Regional Genetics Centre in Leeds. This was in response to a study that revealed serious gaps in genetic service provision to the large British Pakistani population in the region (15). Since then, there have been subsequent similar appointments in other parts of the country. The background of the appointees varies from nursing and graduates from a variety of disciplines to people with community work experience. All speak at least one of the Asian languages, however, none have received specific training in counselling Asian families. A large number of the genetics associates are counsellors for the haemoglobin disorders based at a Thalassaemia and Sickle Cell Centre.

Consultation with some of the genetics associates prior to setting up the ASWIC Forum revealed that there was little knowledge of each other's work in different parts of the country; that individually they experienced problems devising a strategy for informing the Asian communities about inherited conditions; that they felt a need for specific training on genetic counselling in the Asian context; that they wished to meet other Asian specialist workers for support and to exchange ideas and that issues specific to Asians were arising out of their work which they needed to discuss.

There is no formal register of all the specialist genetics associates, therefore a list of fifteen people was compiled through the network of known genetics associates plus other health professionals and invitations sent for the first meeting. The Forum has met on five occasions and formed an ad-hoc committee. All meetings have had good attendance.

At the first meeting the Forum defined its role as the following:

- To allow specialist genetic workers to offer support to one another and exchange ideas and information. The exchange of information was particularly important with regard to the mobile student population.
- To ensure consistency of information being delivered to families and communities nationally.
- To have an input into the contents of courses for health professionals.
- To examine the dynamics between white health professionals and specialist genetic workers.
- To examine the professional status of specialist genetics workers.
- To build confidence within the community of specialist genetic workers.
- To develop co-ordination between genetics services and services for haemoglobin disorders.

Interestingly, the priorities set by the Forum in 1997 are similar to

some of the proposals for further work defined by the findings of this pilot study.

Currently, the committee are further debating the Forum's role and discussing whether it would be feasible and more pertinent to widen the Forum's membership to include all health professionals working with any minority ethnic population, rather than just Asian. This has arisen because the issues discussed at meetings affect service delivery to all minority ethnic populations. Additionally, all health professionals responsible for the care of minority ethnic families, regardless of cultural background or specialism, need a platform to address barriers to delivering an optimum service.

<sup>1</sup> The term *specialist genetic worker* and *specialist genetic associate* are used interchangeably. The term *genetic associate* is increasingly being adopted to describe the role of people in different specialisms who are responsible for genetic counselling.

### Appendix 2: Demographic data

The information contained in this appendix is taken from the Health Education Authority's publication, *Sickle Cell and Thalassaemia: achieving health gain* (13). The tables provide details of all health authorities in England. The figures are based on the 1991 census data which is known to have underestimated minority ethnic populations:

It is estimated that 20% of children under four years and men in their twenties may have been missed in London and other cities.

The 1991 census data does not include recent arrivals, such as African or Middle Eastern refugees.

People of Mediterranean origin classify themselves as white and those born in the UK are not included in the census figures for minority ethnic people. The figures in this appendix allow for people from Mediterranean communities.

The need for services at present depends primarily on the local mix of minority ethnic groups at risk, ethnicity alone will be an increasingly inadequate indicator with the passage of time and future mixing between groups.

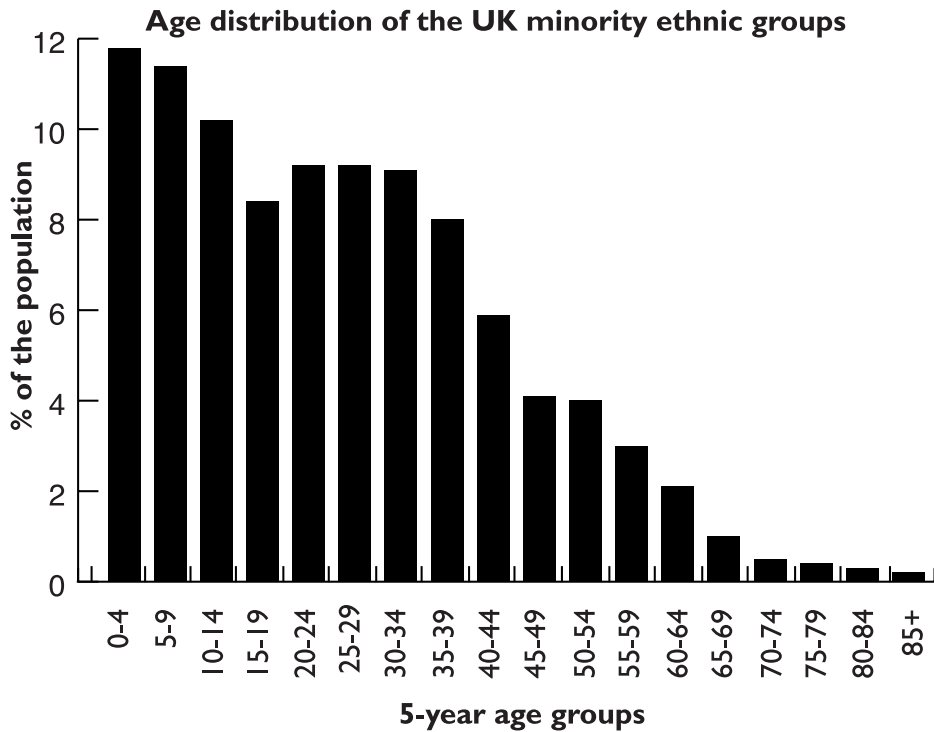
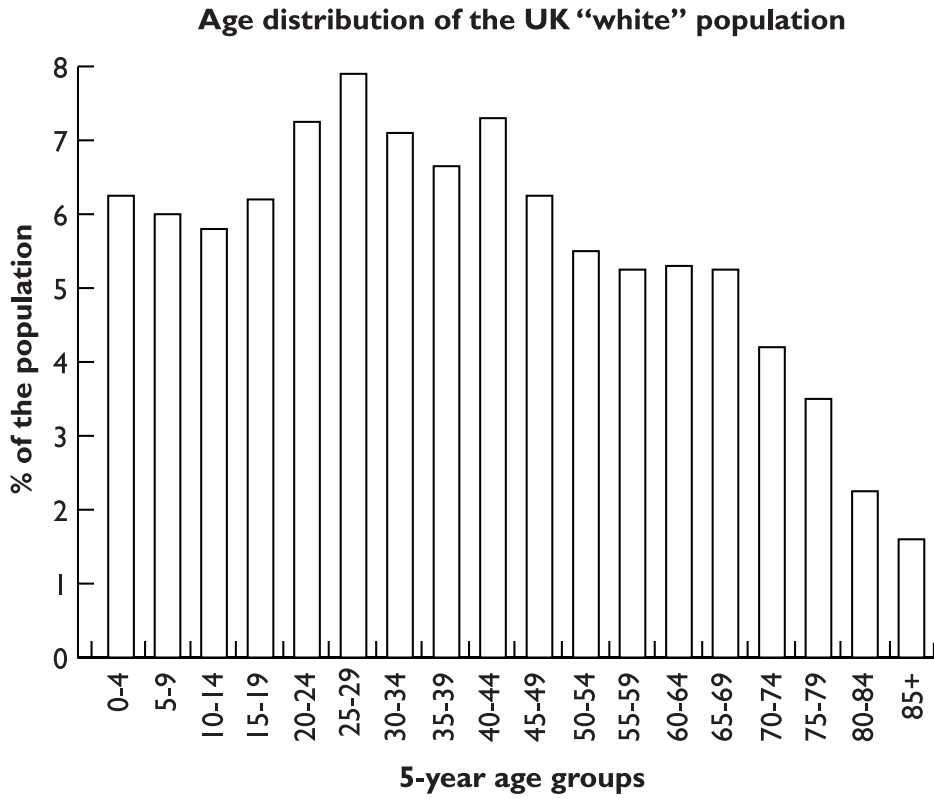
Table 4: Age distribution of UK "white" population.

Table 5: Age distribution of UK minority ethnic groups.

Table 6: Ethnic minority residents, proportion by ethnic group and ethnic minority births, proportion by ethnic group.

Table 7: Number of residents and percentage of residents in the UK, by RHA.

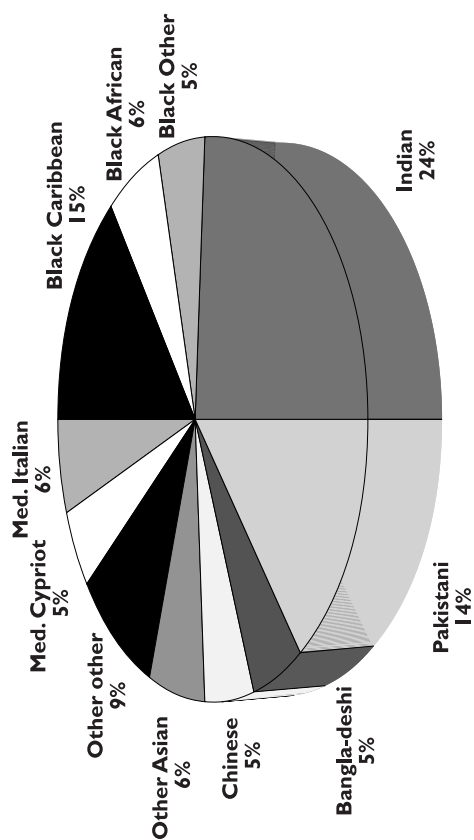
Table 8: Number of annual births and percentage of annual births in the UK, by RHA.



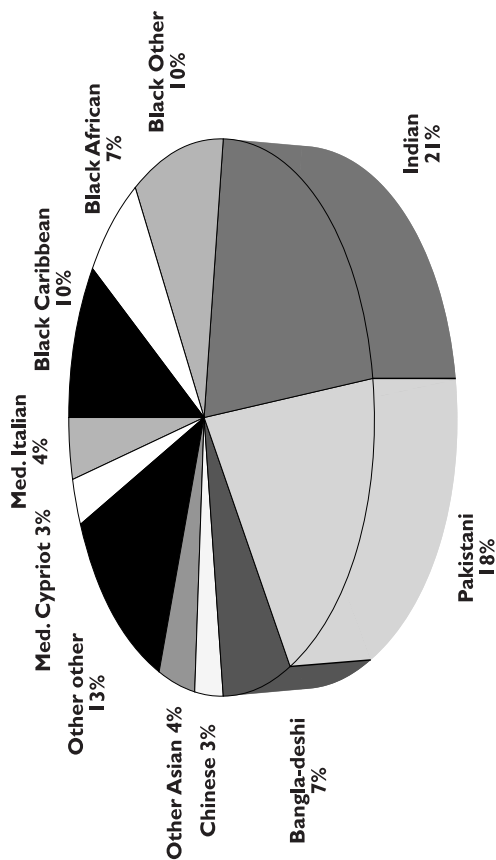
Tables 4 and 5 (13)

WHOLE UK	TOTAL	White not Med	Black Caribbean	Black African	Black Other	Indian	Pakistani	Bangla-deshi	Chinese	Other Asian	Other other	Med- Cypriot	Med. Italian
RESIDENTS	56,105,925	52,584,858	518,925	223,587	187,105	867,123	496,552	168,839	163,529	205,154	302,104	173,511	204,773
% of residents	100	93.72	0.92	0.40	0.33	1.56	0.89	0.30	0.29	0.37	0.54	0.31	0.36
ANNUAL BIRTHS	748,368	672,799	7,882	5,249	7,539	15,387	13,053	5,116	2,310	3,305	9,909	2,560	3,257
% of births	100	89.90	1.05	0.70	1.01	2.06	1.74	0.68	0.31	0.44	1.32	0.34	0.44

Ethnic minority residents, proportion by ethnic group



Ethnic minority births, proportion by ethnic group



Tables 6: (13)

Region	Residents, Number		Total Ethnic Minorities		White minus Mediterranean		Black Caribbean		African		Black Other		Indian		Pakistani		Bangladeshi		Chinese		Other Asian		Other other		Cypriot		Italian	
	Total	Total	Minorities	Total	Mediterranean	Caribbean	African	Black Other	Indian	Pakistani	Bangladeshi	Chinese	Other Asian	Other other	Cypriot	Italian												
E Anglia	2,071,423	57,574	2,013,849	2,013,849	2,697	5,164	2,697	7,500	6,684	6,055	1,681	3,886	3,890	7,813	3,830	8,371												
Mersey	2,410,553	41,367	2,369,187	2,369,187	3,539	2,984	3,539	5,360	4,710	1,765	1,158	7,524	2,175	7,536	1,744	2,874												
N Western	4,000,419	231,159	3,769,260	3,769,260	6,291	19,518	6,291	11,492	52,662	78,546	14,272	10,605	7,396	17,343	3,463	9,572												
NE Thames	3,780,564	633,203	3,147,361	3,147,361	68,381	110,846	68,381	34,046	103,175	44,536	70,202	23,073	36,778	42,841	72,617	26,708												
Northern	3,091,010	45,026	3,045,985	3,045,985	1,587	1,165	1,587	1,968	7,987	9,744	3,684	5,181	3,251	5,507	1,949	3,004												
NW Thames	3,488,058	646,745	2,841,313	2,841,313	41,510	85,029	41,510	25,102	224,202	48,980	18,917	24,131	53,568	58,661	23,816	42,829												
Oxford	2,548,794	150,213	2,398,582	2,398,582	4,869	21,186	4,869	8,887	35,557	28,551	3,713	7,017	8,523	14,446	4,448	13,016												
SWestern	3,288,339	58,511	3,229,828	3,229,828	2,119	10,216	2,119	5,185	7,896	3,449	1,523	4,658	2,900	8,622	4,959	6,984												
SE Thames	3,688,874	327,363	3,361,510	3,361,510	51,005	87,586	51,005	24,868	45,418	7,587	8,047	17,468	19,135	28,816	21,371	16,063												
SW Thames	2,984,037	242,785	2,741,252	2,741,252	19,929	41,193	19,929	12,502	49,287	18,092	5,574	12,907	27,862	26,888	8,946	19,604												
Trent	4,706,453	227,724	4,478,728	4,478,728	4,322	26,971	4,322	11,720	98,835	31,166	4,061	8,725	7,756	17,521	6,005	10,643												
W Midlands	5,265,382	458,904	4,806,478	4,806,478	5,581	81,012	5,581	19,741	163,806	102,754	20,133	9,991	11,908	25,325	6,442	12,211												
Wessex	3,119,746	64,336	3,055,410	3,055,410	2,307	5,523	2,307	4,262	11,526	2,306	3,286	6,173	5,302	9,833	5,130	8,687												
Yorkshire	3,652,238	196,529	3,455,709	3,455,709	3,723	16,088	3,723	8,052	38,417	84,981	7,449	6,273	6,122	13,791	3,818	7,814												
SCOTLAND	5,104,757	77,047	5,027,710	5,027,710	2,917	969	2,917	2,776	10,372	22,082	1,176	10,916	4,774	9,187	2,997	8,881												
WALES	2,895,411	52,715	2,842,695	2,842,695	2,810	3,475	2,810	3,643	6,588	5,957	3,961	5,003	3,813	7,974	1,978	7,513												
TOTAL	56,105,925	3,511,201	52,584,858	52,584,858	223,587	518,925	223,587	187,105	867,123	496,552	168,839	163,529	205,154	302,104	173,511	204,773												

Residents, %

E Anglia	100	2.8	97.2	97.2	0.1	0.2	0.1	0.4	0.3	0.3	0.1	0.2	0.2	0.4	0.2	0.4
Mersey	100	1.7	98.3	98.3	0.1	0.1	0.2	0.2	0.2	0.1	0.0	0.3	0.1	0.3	0.1	0.1
N Western	100	5.8	94.2	94.2	0.2	0.5	0.2	0.3	1.3	2.0	0.4	0.3	0.2	0.4	0.1	0.2
NE Thames	100	16.7	83.3	83.3	1.8	2.9	1.8	0.9	2.7	1.2	1.9	0.6	1.0	1.1	1.9	0.7
Northern	100	1.5	98.5	98.5	0.1	0.0	0.1	0.1	0.3	0.3	0.1	0.2	0.1	0.2	0.1	0.1
NW Thames	100	18.5	81.5	81.5	1.2	2.4	1.2	0.7	6.4	1.4	0.5	0.7	1.5	1.7	0.7	1.2
Oxford	100	5.9	94.1	94.1	0.2	0.8	0.2	0.3	1.4	1.1	0.1	0.3	0.3	0.6	0.2	0.5
SWestern	100	1.8	98.2	98.2	0.1	0.3	0.1	0.2	0.2	0.1	0.0	0.1	0.1	0.3	0.2	0.2
SE Thames	100	8.9	91.1	91.1	1.4	2.4	1.4	0.7	1.2	0.2	0.2	0.5	0.5	0.8	0.6	0.4
SW Thames	100	8.1	91.9	91.9	0.7	1.4	0.7	0.4	1.7	0.6	0.2	0.4	0.9	0.9	0.3	0.7
Trent	100	4.8	95.2	95.2	0.1	0.6	0.1	0.2	2.1	0.7	0.1	0.2	0.2	0.4	0.1	0.2
W Midlands	100	8.7	91.3	91.3	0.1	1.5	0.1	0.4	3.1	2.0	0.4	0.2	0.2	0.5	0.1	0.2
Wessex	100	2.1	97.9	97.9	0.1	0.2	0.1	0.1	0.4	0.1	0.1	0.2	0.2	0.3	0.2	0.3
Yorkshire	100	5.4	94.6	94.6	0.1	0.4	0.1	0.2	1.1	2.3	0.2	0.2	0.2	0.4	0.1	0.2
SCOTLAND	100	1.5	98.5	98.5	0.1	0.0	0.1	0.1	0.2	0.4	0.0	0.2	0.1	0.2	0.1	0.2
WALES	100	1.8	98.2	98.2	0.1	0.1	0.1	0.1	0.2	0.2	0.1	0.2	0.1	0.1	0.1	0.3
TOTAL	100	6.3	93.7	93.7	0.4	0.9	0.4	0.3	1.5	0.9	0.3	0.3	0.4	0.5	0.3	0.4

Table 7: (13)

Annual Births, Number		Total Ethnic Minorities	White minus Mediterranean	Black Caribbean	African	Black Other	Black Indian	Pakistani	Bangladeshi	Chinese	Other Asian	Other	Cypriot	Italian
Region	Total													
E Anglia	26,497	1,265	25,232	72	49	265	117	161	49	49	54	252	57	140
Mersey	33,115	875	32,241	41	73	178	64	38	33	119	31	224	26	48
N E Thames	53,369	13,793	39,576	1,703	1,743	1,302	1,900	1,081	2,228	331	580	1,392	1,089	445
N W Thames	46,915	12,287	34,628	1,205	869	936	3,826	1,153	499	283	837	1,607	357	714
N Western	56,746	5,904	50,843	296	132	490	1,098	2,237	460	170	158	651	52	160
Northern	40,438	1,019	39,419	15	36	70	132	257	123	74	67	166	29	50
Oxford	35,578	3,320	32,258	303	84	372	630	799	109	94	123	521	67	217
S E Thames	49,779	6,977	42,803	1,469	1,403	995	723	155	204	268	266	905	321	268
S W Thames	37,421	4,450	32,972	588	393	454	739	375	141	161	417	721	134	327
S Western	41,040	1,275	39,766	141	43	213	142	84	43	66	33	287	74	116
Trent	62,225	5,158	57,067	397	94	568	1,924	811	122	126	151	699	90	177
W Midlands	72,528	10,417	62,111	1,306	101	965	2,900	2,766	602	142	232	1,103	97	204
Wessex	40,288	1,275	39,014	62	50	174	200	51	100	83	58	276	77	145
Yorkshire	50,050	4,929	45,120	224	73	346	701	2,389	236	100	128	543	57	130
SCOTLAND	63,859	1,489	62,370	11	54	86	182	548	32	168	101	301	3	5
WALES	38,517	1,167	37,351	48	54	125	110	147	134	76	68	261	30	113
TOTAL	748,368	75,568	672,799	7,882	5,249	7,539	15,387	13,053	5,116	2,310	3,305	9,909	2,560	3,257

Annual Births, %														
Region	Total													
E Anglia	100	4.8	95.2	0.3	0.2	1.0	0.4	0.6	0.2	0.2	0.2	0.9	0.2	0.5
Mersey	100	2.6	97.4	0.1	0.2	0.5	0.2	0.1	0.1	0.4	0.1	0.7	0.1	0.1
N E Thames	100	25.8	74.2	3.2	3.3	2.4	3.6	2.0	4.2	0.6	1.1	2.6	2.0	0.8
N W Thames	100	26.2	73.8	2.6	1.9	2.0	8.2	2.5	1.1	0.6	1.8	3.4	0.8	1.5
N Western	100	10.4	89.6	0.5	0.2	0.9	1.9	3.9	0.8	0.3	0.3	1.1	0.1	0.3
Northern	100	2.5	97.5	0.0	0.1	0.2	0.3	0.6	0.3	0.2	0.2	0.4	0.1	0.1
Oxford	100	9.3	90.7	0.9	0.2	1.0	1.8	2.2	0.3	0.3	0.3	1.5	0.2	0.6
S E Thames	100	14.0	86.0	3.0	2.8	2.0	1.5	0.3	0.4	0.5	0.5	1.8	0.6	0.5
S W Thames	100	11.9	88.1	1.6	1.0	1.2	2.0	1.0	0.4	0.4	1.1	1.9	0.4	0.9
S Western	100	3.0	97.0	0.3	0.1	0.5	0.3	0.2	0.1	0.2	0.1	0.7	0.2	0.3
Trent	100	8.3	91.7	0.6	0.2	0.9	3.1	1.3	0.2	0.2	0.2	1.1	0.1	0.3
W Midlands	100	14.4	85.6	1.8	0.1	1.3	4.0	3.8	0.8	0.2	0.3	1.5	0.1	0.3
Wessex	100	3.2	96.8	0.2	0.1	0.4	0.5	0.1	0.2	0.2	0.1	0.7	0.2	0.4
Yorkshire	100	9.8	90.2	0.4	0.1	0.7	1.4	4.8	0.5	0.2	0.3	1.1	0.1	0.3
SCOTLAND	100	2.3	97.7	0.0	0.1	0.1	0.3	0.9	0.0	0.3	0.2	0.5	0.0	0.0
WALES	100	3.0	97.0	0.1	0.1	0.3	0.3	0.4	0.3	0.2	0.2	0.7	0.1	0.3
TOTAL	100	10.1	89.9	1.1	0.7	1.0	2.1	1.7	0.7	0.3	0.4	1.3	0.3	0.4

Table 8: (13)

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