



UK National
Screening Committee



Screening Programmes

Sickle Cell and Thalassaemia

**Towards a
Communication Strategy
for the
NHS Sickle Cell & Thalassaemia
Screening Programme:
A Planning Framework
based on
Preliminary Community Consultation**

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Summary and Major Recommendations

Summary

1. Policy background

- 1.1 The NHS Plan has committed to implementing “effective and appropriate screening programmes for women and children, including a new national linked antenatal and newborn screening programme for haemoglobinopathies”, by 2004. A national screening programme for haemoglobinopathies (sickle cell disorder and thalassaemia) is recognized as an important step towards achieving newly established national inequalities targets.
- 1.2 Commitment to national haemoglobinopathy screening is part of a wider policy shift reflecting increased recognition of the role of public services in reducing ethnic inequalities in health, including The Race Relations (Amendment) Act 2000, which assigns statutory duties to the Department of Health and NHS bodies to promote racial equality and prevent discrimination.

2. Haemoglobinopathies in the UK

- 2.1 The haemoglobinopathies, including sickle cell disorder and thalassaemia, are common recessively-inherited blood conditions. If two healthy carriers of the sickle cell or thalassaemia gene variant have a child, there is a 1 in 4 chance with each pregnancy that their child will have a sickle cell disorder or thalassaemia.
- 2.2 In the UK, it is estimated that: 170,000 people are healthy carriers of the sickle cell gene variant; over 12,500 people have a sickle cell disorder; 150,000 people are healthy carriers of the thalassaemia gene variant; and over 700 people have thalassaemia. The highest prevalence of sickle cell disorders are found amongst: Black Caribbeans, Black Africans and Black British; those with the highest prevalence of thalassaemia are Cypriots, Indians, Pakistanis, Bangladeshis, Chinese, and Other Asian groups. Both gene variants are also (less commonly) found in the North European population.

3. Haemoglobinopathy Screening Programme

- 3.1 The aim of the NHS Haemoglobinopathy Screening Programme is to identify couples who carry the sickle cell or thalassaemia gene variant, and enable them to make informed choices in planning to have children, through antenatal screening. A second aim is to reduce the health risks of children who are born with sickle cell disorder, through newborn screening.
- 3.2 Preconceptual screening (carrier testing for individuals or couples before pregnancy) does not currently feature in the NHS Programme.
- 3.3 This programme represents the first systematic national attempt at addressing the complex issues of genetic screening and reproductive choice. Successful implementation will yield valuable lessons for other conditions.

4. Communication Strategy

- 4.1 Adequately resourced national education programmes for both the public and health professionals will be an essential component of this national screening programme. A communication strategy provides a necessary framework for the systematic sharing of public health information.
- 4.2 Preliminary analysis, including needs assessment of possible primary and secondary audiences, is an important first stage in developing a communication strategy. Such an analysis also needs to consider policy and service delivery issues which may enhance or inhibit the aims of a communication programme.
- 4.3 This report presents a preliminary analysis and framework to inform planning of a communication strategy with and for the ethnic groups¹ with the highest prevalence of haemoglobinopathies in the UK. It is anticipated that this will form part of a wider strategy addressing the communication needs of all stakeholders.

5. Community Consultation

- 5.1 Key informant interviews were conducted with 35 individuals from the high prevalence populations in London, Leicester and Bradford. Participants were selectively recruited by networking through haemoglobinopathy counsellors and researchers, and other contacts working in ethnicity and health, and were drawn from voluntary sector and community-based organisations, faith-based organisations, the public sector (mainly community development), and academia.
- 5.2 The main criterion for selection was that participants should have extensive knowledge and experience of community information and service needs, and socio-cultural norms and values. Individuals directly involved in sickle cell and thalassaemia issues were deliberately not sought, as their experience and views would probably be quite atypical of the wider community.

6. Community Consultation Findings:

Community Awareness and Ownership

- 6.1 Participants reported that the Black British and African-Caribbean communities have mostly heard of sickle cell and know that it is an inherited condition. However they assessed that few community members have a good understanding of the mechanism for inheritance and the possibility of carrier testing. A strong sense of ownership of sickle cell as a Black health

¹ The exception is the Cypriot community: they have a carrier rate of 16% for thalassaemia but are believed to be relatively well informed about the condition, and have shown greatly reduced birth prevalence, due to extensive community-initiated education campaigns over a period of decades (Gill and Modell, 1998). Thus they were not included in the terms of reference for this consultancy.

issue amongst these communities was reported. Many participants were familiar with current issues around experiences of living with sickle cell.

- 6.2 There is less awareness amongst African communities, according to participants, although most felt that community members have at least heard of the condition. However some recent immigrants from rural African may not have heard of sickle cell at all, and those not fluent in English may also be less aware. Participants indicated that there are some myths and stigma associated with sickle cell in some African communities. Overall there was little ownership of the issue in comparison with the Black British and African-Caribbean communities.
- 6.3 Awareness of thalassaemia amongst the South Asian and Chinese communities was reported to be very low. Few of the participants had any previous contact with thalassaemia (in contrast, most Black participants had some personal familiarity with sickle cell disorders). There was no awareness of the experiences and needs of people living with thalassaemia, who were reported to be 'invisible' within the communities. There was no identification of thalassaemia as an Asian health issue.
- 6.4 South Asian and Chinese participants reported that the issue of disability is rarely discussed in their communities. Some suggested there is a tendency to blame the parents of children with inherited conditions.

Community Perspectives on Screening

- 6.5 The principle of genetic testing to know if one is a carrier of an inherited condition was accepted as valuable across all ethnic groups.
- 6.6 Participants from the Black communities were very positive about the expressed commitment to introduce universal newborn screening.
- 6.7 In general, participants felt that genetic testing for carrier status is more useful earlier in life, because it gives people a greater range of choices. There was significant interest in preconceptional screening for young people, although this does not currently feature in the planned NHS Programme.
- 6.8 South Asian participants were particularly interested in the possibilities for offering carrier screening for young people in the context of arranged marriage, enabling parents to negotiate to avoid the marriage of two carriers.
- 6.9 School-based screening programmes were identified as a good possible approach to mainstreaming awareness of sickle cell and thalassaemia. However there were some concerns from the Black communities about the possibility of a poorly-managed programme increasing racialisation and alienating Black youth.
- 6.10 Antenatal screening with the aim of providing parents with advance warning of a child with thalassaemia or sickle cell, was generally welcomed.

6.11 Antenatal screening with the aim of promoting informed reproductive choice for couples, was welcomed by about half of the participants. Other participants expressed concerns about offering the choice of termination of an affected pregnancy, which they felt would be unacceptable to their communities. Objections were based on concerns about coercion, as well as cultural and faith-based values.

6.12 There was a strong consensus across ethnic groups that the care and support services to meet the needs of people living with sickle cell and thalassaemia, and their families, must be prioritised equally with screening services.

7. Main Conclusions from Community Consultation

7.1 All high prevalence ethnic groups have a very inadequate understanding of sickle cell and thalassaemia, which will limit uptake of screening. Specifically:

- Thalassaemia is 'invisible' within the South Asian and Chinese communities
- African communities generally have a poor understanding of sickle cell disorders, and myths and stereotypes about the condition are prevalent. There may be a complete lack of awareness amongst some communities of recent immigrants.
- All groups are unaware of the mechanisms of genetic inheritance of these conditions, including the Black Caribbean/ Black British communities who have mostly heard of sickle cell disorders.

7.2 Partially as a result of very low levels of awareness, there is little or no 'ownership' of sickle cell and thalassaemia amongst UK Black African, and South Asian and Chinese, communities respectively.

7.3 In the interest of equity and human rights, there is a strong consensus amongst participants that screening and care for haemoglobinopathies must be given equal priority.

7.4 Universal newborn screening for sickle cell disorders is likely to be very well received by the Black communities. Implementation of this programme presents an ideal opportunity to raise awareness of carrier status and care and entitlement issues, and to stimulate greater 'ownership' by African communities.

7.5 There is strong support for preconceptual/premarital carrier screening targeting young people, but this should be delivered in the context of family and community.

7.6 Antenatal screening with the aim of providing advanced diagnosis of an affected child, allowing family and providers to prepare to provide the best possible care, is widely supported. Antenatal diagnosis with the aim of providing informed reproductive choice for couples is less consistently supported. However, the mixed views expressed do not represent a wholesale rejection of the principle of reproductive choice. The view that offering termination as a choice is contrary to community values was expressed by participants of different faiths and ethnicities, based on concerns about institutional coercion as well as faith-based and cultural values.

Major Recommendations for Communication Strategy

Services

1. The Department of Health should make a clear and public commitment that equal priority will be given to the delivery of high quality services for both screening and care services for haemoglobinopathies.
2. Central guidance should be issued to Strategic Health Authorities and Primary Care Trusts, highlighting the opportunity to make progress towards addressing health inequalities and implementing Race Equality Schemes², by implementing haemoglobinopathy screening programmes and engaging with community groups on communication initiatives.
3. A major dimension of service quality should include providers who are trained and equipped to deliver appropriate services to ethnically diverse communities. This includes a comprehensive understanding of ethnicity and health issues, including racialisation, and coverage of 'sensitive' topics such as consanguinity and termination.
4. Recruitment and development of staff from all of the high prevalence ethnic communities into genetics counselling and health communication/ community development positions, should be prioritised. This will ensure the availability of individuals with detailed knowledge of socio-cultural context and fluency in community languages.
5. It is strongly recommended that significant progress with the above should be achieved before generating increased demand for services through communication interventions.

Strategy

1. The high-prevalence ethnic populations for sickle cell and thalassaemia respectively have different communication needs. This should be recognised by developing: either two separate, but overlapping and closely co-ordinated, communication strategies; or, two distinct strands within one overarching strategy.
2. The communication strategy for high prevalence ethnic populations must be located within a holistic communication framework addressing the needs of all stakeholders, including health professionals and users of antenatal and newborn services³.
3. Major objectives for the communication strategy should include:
 - Increase basic awareness of sickle cell/ thalassaemia including pattern of inheritance and the option of carrier testing
 - Stimulate community ownership of the issues and increase participation in planning and management of services
 - Raise community awareness of the needs of people living with thalassaemia and sickle cell

² As required of all public authorities under the Race Relations (Amendment) Act 2000.

³ The issue of awareness and responses of the wider UK population towards screening for haemoglobinopathies, in regions of varying prevalence, has not formed part of this work, but needs to be addressed. Consultation with service users will be needed.

4. Three main approaches should be combined in the communication strategy:

- Community development / group work
- Interpersonal (one-on-one)
- Mass media

The former two are very important in developing community ownership and building trust, particularly with the more marginalized and underprivileged groups.

5. The main target audiences should include:

- Unmarried young people (for Chinese community especially newly arrived students and asylum seekers)
- Parents of unmarried young people
- Elders
- Community & Faith Leaders
- Health Professionals
- Community-Based Organisations

6. Early attention should be given to developing a strategic approach to engagement with the mainstream media including anticipating and responding to racist backlash coverage.

The following recommendations relate to specific sub-objectives and activities for the communication strategy:

7. Implementation of universal newborn screening for sickle cell disorders presents an ideal opportunity to begin to address recommended strategy objectives with the Black Caribbean, African and Black British communities, using the main approaches described above.

8. Communication about antenatal screening must be developed with extensive community input and careful attention to use of language. Further consultation with faith-based organisation, religious scholars and community groups is highly recommended (see 5.3.1), to build consensus around the way forward on communication for this component of the screening programme

9. Preliminary work with the high-prevalence populations for thalassaemia should involve collaboration with existing Chinese and South Asian voluntary sector groups active on disability issues (see Appendix Nine) and service users' groups, to raise community awareness of thalassaemia (including carrier screening) with a focus on people living with the condition. This could also incorporate further investigation of community attitudes towards disability in general (see consultation findings and discussion).

10. Commission a systematic review of the effectiveness of international programmes of preconceptual screening for sickle cell and thalassaemia.

11. Informed by the findings of a systematic review (above), consider piloting school-based programmes in high-prevalence areas, linking with family genetics counselling services and Primary Care Trusts. Agencies such as Naz Project and Blackliners, with expertise in working with young people from minority ethnic groups, should be consulted. The possibility of involving Marriage Bureaus serving the South Asian communities to raise awareness of pre-marital carrier screening should also be explored. All pilots need to be carefully monitored and evaluated.

Advocacy

1. A series of national seminars for religious thinkers and leaders from the different faiths to discuss screening issues should be organized through the National Steering Committee. Work done by the King's Fund engaging Faith Leaders on Mental Health issue may provide useful pointers (see Appendix Nine).
2. Community-based, voluntary sector and service users' organisations should be supported to systematically engage with health services organisations at the level at which services are coordinated as part of community development initiatives.

Service Users' Participation

1. People living with thalassaemia and sickle cell, and their families, need to be involved from the early stages of strategy development. Ideally this should be organized through local service users' groups and parent support groups.

Community Development

1. Small grants scheme for community communication initiatives by community-based organizations (including users' and parents' groups, faith-based organisations, cultural groups, HIV prevention organizations, Black Health Fora, etc)
2. Encourage collaboration (with an emphasis on sharing of skills and knowledge) between more established voluntary sector organizations (such as the main Sickle Cell and Thalassaemia charities), Community-Based Organisations, and Service User groups

Facilitation & Capacity Building

1. Ensure availability of strategically placed staff at local levels to facilitate community participation. These may be sickle cell/ thalassaemia counsellors, or specially trained community development/ health outreach workers based in Trusts or Voluntary Agencies with a remit for ethnicity and health issues.
2. Provide training to such staff where necessary to ensure adequate skills in community development and health communication
3. Training for Community Based Organisations should also be provided, to promote the development of quality interventions at community level and to better equip CBOs to contribute to the planning and management of haemoglobinopathy services

Mass Media & Materials

1. A significant investment is needed in developing genetics counselling resources in minority ethnic languages. The process of translating abstract genetics concepts needs to involve expertise from a range of sectors including community groups, religious scholars, health professionals (with haemoglobinopathy and genetics counsellors) and medical anthropologists.
2. Development of messages and materials for mass media and small group communication, ensuring rigorous pre-testing of materials developed and thorough documentation of results.

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and especially,

All of those who took part in the consultation (listed on the next page).

The author takes sole responsibility for any errors, omissions and interpretations.

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⁴ If a participant's name does not appear, this is at his or her request



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Introduction

The NHS Plan has committed to implementing “effective and appropriate screening programmes for women and children, including a new national linked antenatal and neonatal screening programme for haemoglobinopathies”, by 2004. A national screening programme for haemoglobinopathies (sickle cell disorder and thalassaemia) is recognized as an important step towards achieving newly established national inequalities targets. Commitment to national haemoglobinopathy screening is part of a wider policy shift reflecting increased recognition of the role of public services in reducing ethnic inequalities in health (and other aspects of life). A central principle in the NHS Plan is that ‘the NHS has to be redesigned around the needs of the patient’, which presents an important opportunity for making progress in addressing the health needs of ethnic minority groups (Kingsley, 2000). The Race Relations (Amendment) Act 2000, which assigns statutory duties to the Department of Health and NHS bodies (and other public authorities) to promote racial equality and prevent discrimination, is another important example of increased commitment to addressing ethnic inequalities through public sector reform.

The NHS Haemoglobinopathy Screening Programme represents the first attempt at addressing the complex issues of genetic screening and reproductive choice in a national programme. Successful implementation will yield valuable lessons for other conditions.

Adequately resourced national education programmes for both the public and health professionals will be an essential component of a national screening programme for haemoglobinopathies (Streetly, 2000). This report presents a preliminary analysis to inform planning of a communication strategy with and for those whose need for information is arguably the most urgent, the ethnic groups⁵ with the highest prevalence of sickle cell or thalassaemia carriers in the UK. It is anticipated that this will form part of a wider strategy addressing the communication needs of all stakeholders. Analysis is based on consultation with 35 individuals across England, as well as a rapid review of relevant health communication initiatives and socio-demographic data from secondary sources.

⁵ The exception is the Cypriot community: they have a carrier rate of 16% for thalassaemia but are believed to be relatively well informed about the condition, and have shown greatly reduced birth prevalence, due to extensive community-initiated education campaigns over a period of decades (Gill and Modell, 1998). Thus they were not included in the terms of reference for this consultancy.

1. Background

1.1 Haemoglobinopathies in the UK

The haemoglobinopathies, including sickle cell disorder and thalassaemia, are common recessively-inherited blood conditions mainly affecting people with origins in Africa, the Caribbean, Asia, the Middle East, and the Mediterranean, but also found in the Northern European population. Someone may be a healthy carrier of the gene variant that causes sickle cell or thalassaemia and not know it. If two carriers have a child, there is a 1 in 4 chance with each pregnancy that their child will have a sickle cell disorder or thalassaemia. In the UK, it is estimated that: 170,000 people are healthy carriers of the sickle cell gene variant; over 12,500 people have a sickle cell disorder; 150,000 people are healthy carriers of the thalassaemia gene variant; and over 700 people have thalassaemia.

The distribution of the sickle cell and thalassaemia gene variants within the UK population is extremely unequal, with the large majority of carriers concentrated within eight minority ethnic categories. The table below shows the average and range of estimated percentage carrier rates of the sickle cell and beta-thalassaemia gene variants for each of these categories (Davies et al, 2000):

	Sickle Cell (Hb S)	Beta – Thalassaemia
Black Caribbean	11%	0.9%
Black African	20% (10-28%)	0.9%
Indian	1%	3.5% (2.5-4.5%)
Pakistani	-	4.5% (3.5-5.5%)
Bangladeshi	-	3% (2-4%)
Chinese	-	3% (1-4%)
Other Asian		3% (1-4%)
Cypriot	0.75%	16%
North Europeans	0.05%	0.1%

Table 1: Average and range (in brackets) of estimated percentage carrier rates in UK ethnic groups

It is important to bear in mind whilst interpreting these figures that ethnic groups vary in their genetic heterogeneity (as the range of carrier rates indicates). Some ethnic groups may show relatively constant carrier rates, others may show significant variation with pockets of very high and very low prevalence.

1.2 Screening Programme Aims & Current Service Provision

The aim of the NHS Sickle Cell & Thalassaemia Screening Programme is to identify couples who carry the sickle cell or thalassaemia gene variant, and enable them to make informed choices in planning to have children, through antenatal screening. A second aim is to reduce the health risks of children who are born with sickle cell disorder, through newborn screening.

Individuals and couples may also decide to have genetic testing to determine if they are sickle cell or thalassaemia carriers before marriage, or before having children. This is called preconceptual screening, and does not currently feature in the NHS Programme.

Antenatal screening involves the genetic testing of a pregnant woman with her consent. If she is found to be a sickle cell or thalassaemia carrier, her partner will also be offered testing. If both partners are carriers, the couple will be given counselling and offered testing to determine if the unborn foetus has sickle cell disorder or thalassaemia. This test gives advance notice to the couple, enabling them to prepare to provide the best possible care for their child after birth. Alternatively, some couples may choose to terminate an affected pregnancy.

Newborn screening involves newborn babies. A baby found to have a sickle cell disorder will be given early treatment which can save his or her life.

Although antenatal and preconceptual screening for sickle cell and thalassaemia are currently available in most parts of the UK, services are characterized by poor coordination, variable quality (particularly in genetic counselling) and inconsistent outcomes (Anionwu and Atkin, 2001). Specialist sickle cell and thalassaemia centres are typically understaffed, struggling to provide an impossibly diverse range of services, and face challenges in coordinating with primary care services (Streetly et al, 1997). Regional Genetics Centres lack the human and material resources to provide culturally and linguistically appropriate services for ethnic minorities, and only a very small minority of Centres practice ethnic monitoring (Darr, 1999; Pritti Mehta, personal communication). Some RGCs are counselling haemoglobinopathy carrier couples and individuals, and some are working in coordination with sickle cell and thalassaemia centres, including mutual referrals (preliminary results of a survey of genetic counsellors – Chris Barnes, personal communication).

1.3 Communication Strategy

Internationally, public health programmes are increasingly strategic and systematic in their approach to communication, drawing on a range of conceptual models including behavioural sciences, social learning theory and social

marketing (Piotrow et al, 1997). There are several main elements to a well-designed health communication strategy (*ibid.*):

- It is based on the understanding that behavioural change is not solely about individual-decision making, but occurs in a socio-cultural context, follows a systematic process including: preliminary analysis; strategic programme design; development, pretesting and revision and production of messages and materials; management, implementation and monitoring; impact evaluation; and planning for continuity.
- Audience participation is facilitated throughout the process from planning to evaluation
- Targets a range of audiences, and monitors and evaluates changes at a range of levels (individual, household, community, region, etc)
- Concern with sustainability through building the capacity of partner organizations, collaboration with other programmes and facilitating cost-sharing arrangements
- Recognises the value of mass-media in raising awareness, influencing norms, providing information and supporting individual behaviour change
- Recognises the complementary value of entertainment-based approaches to engage audiences at community level.

A preliminary analysis is the crucial first stage in developing a communication strategy, and is typically concerned with needs assessment of possible primary and secondary audiences. Piotrow *et al* assert that ‘The phrase “the general public” does not belong in any communication plan’ (*ibid*: 30). Rather a comprehensive analysis should assist in identifying different sub-sections or ‘audience segments’, identifying differential information and service needs based on an analysis of current understandings, behaviours and expectations. As well as investigating audiences’ perspectives, it is important that a preliminary analysis also looks at policy and service delivery issues which may enhance or inhibit the aims of a communication programme (*ibid.*).

1.4 Sociological Approaches to Genetics

Before analyzing communication needs for the screening programme, it is relevant to appreciate the extent to which knowledge and information about genetics and screening is socially constructed. Medical literature and information often presents genetics as a straightforward subject, and yet concepts such as ‘genetic inheritance’, ‘screening programme’ and ‘informed choice’ may have very diverse meanings, depending on one’s perspective. A glimpse at the sociological literature on genetics (see Conrad and Gabe, 1999) includes analyses of a range of complex and often controversial themes. These include modern genetic science’s historical origins in eugenics (Bradby 1996), and concerns about eugenic outcomes of current policy (Shakespeare 1995); genetic screening and social control (Lippman, 1991); the absence of disabled voices in genetics discourse (Shakespeare, 1999); debate about health professionals’

roles and judgement in genetics counselling (Williams et al, 2002); and differences in lay and professional perspectives on genetics (Kerr 1997, 1998).

1.5 Genetics, Ethnicity, and Haemoglobinopathy Screening

The genetic screening of ethnic minority populations demands a further broadening of analytical perspective, as Anionwu and Atkin (2001) have comprehensively discussed. Concerns about state control, and eugenicist overtones and outcomes, are magnified when target populations have historically experienced the sharp end of institutional and individual racism in health service delivery. Groups already experiencing the effects of racialisation in media and popular discourse, may be understandably fearful about bearing further stigma which may result from ascription of genetic risk. And the already challenging practice of bridging the gap between professional and lay persons' perspectives during genetic counselling, gains another layer of complexity where language barriers are introduced (Darr, 1999), especially where the service user's language may have no directly translatable equivalents for the abstract biomedical concepts used in genetics.

2. Macro-Profiling of High-Prevalence Ethnic Groups

At this juncture, it is relevant to emphasise that each of the high-prevalence ethnic groups or populations is not homogenous, but rather may be characterized by variations including economic, cultural, educational, gender, linguistic, religious, and inter-generational differences. Similarly, in designing a health communication programme, it is not appropriate to aim to reach an entire population with one message and one medium. Rather, the more precisely one can define audience 'segments' and identify their particular needs, the more effective the communication programme will be (Piotrow, 1997). Thus each of the different ethnic groups identified includes a variety of different potential audiences. The community consultation findings presented later in this report provide a basis for beginning to define these different audiences, and identify appropriate communication channels to reach them.

As a starting point however, available sources of secondary data can inform a more macro-level "mapping" of the various high-prevalence ethnic groups. The danger of population-level data is that it often tends to 'flatten' intra-group variation and may lead to stereotyped representations of particular ethnic groups. Thus this macro-level analysis should be read as just that; the community consultation findings presented later in the report provide a slightly more nuanced picture, and more extensive local-level consultation and pilot testing of interventions will provide a yet more precise understanding of the different communication needs of the various segments of the high prevalence populations.

2.1 Population Data

Data on population size, distribution and demographic profile is important to inform planning of a health communication strategy. Data from the 2001 census when available will of course be the most up-to-date source of information on the relative size and structure of the UK's different ethnic groups. However as census data often under-enumerates particular sub-groups of the whole population (such as inner-city residents, younger people, and refugees) which include disproportionate numbers of individuals from minority ethnic groups. Thus census data needs to be interpreted critically, and supplemented by other information sources where available.

The table below lists the Strategic Health Authorities with a significant presence of one or more high-prevalence ethnic groups. This gives a rough impression only, given that the data is now more than ten years out of date. Pending availability of the 2001 census data, health authority data and other locally-available data may give a more accurate picture.

Table 2: Significant presence of high-prevalence minority ethnic groups in Strategic Health Authorities (adapted from National Institute for Ethnic Studies in Health and Social Policy, 1997 and Elam et al, 2001)

SHA	African	African-Caribbean	Bangladeshi	Chinese	Indian	Pakistani
North East London	√	√	√	√	√	√
North Central London	√	√	√	√	√	
North West London	√	√	√	√	√	√
South East London	√	√	√	√	√	
South West London	√	√		√	√	
West Yorkshire		√		√	√	√
West Midlands	√	√	√	√	√	√
Bedfordshire & Hertfordshire	√	√		√	√	
Leicestershire Northamptonshire & Rutland		√	√	√	√	√
Cheshire & Merseyside	√	√		√		
Coventry, Warwickshire, Herefordshire & Worcestershire		√			√	
Thames Valley	√	√	√	√	√	√
Greater Manchester	√	√	√	√	√	√
Trent	√	√	√	√	√	√
Cumbria & Lancashire					√	√
South Yorkshire	√	√			√	√
Avon Gloucestershire & Wiltshire		√				

2.2 Language & Literacy

Languages spoken and read by members of an ethnic group may vary with age, educational level, generation, gender, and other factors. Clearly a detailed understanding of the preferred language/s of communication and literacy levels of different sub-sections of each ethnic group is an essential prerequisite to planning a communication strategy.

The Health Education Authority's report Black and Minority Ethnic Groups in England (2000) presents data on the ability to read and write English and South Asian languages for the Indian, Pakistani and Bangladeshi populations. Over 90% of all men and women in the youngest age group surveyed (16-29) report that they can read English and speak English either very well or fairly well; the exception is Bangladeshi women for whom the figure is slightly lower (86%), perhaps a reflection of the fact that Bangladeshi women in this age group are more likely than their peers to have been born outside of the UK. A majority of Indian and Pakistani men and women aged 16-29 describe English as the language they understand best. For Bangladeshis the proportion preferring English is less, 40% and 34% for women and men respectively, with slightly larger percentages of each preferring Bengali. The second most preferred languages for 16-29 year old Indians are Gujarati (19% of women, 8% of men) and Punjabi (6% of women, 5% of men); for Pakistanis, Punjabi (28% of women and 16% of men) and Urdu (13% of women and 26% of men).

Across all groups, ability to understand English declined with age, particularly for women. Similarly, the proportion speaking a South Asian language best increased with age.

For the Chinese population, fluency in English is reported to be 100% for young men aged 16-24 and 98% for women in that age group (Modood *et al*, 1997). This falls to 82% for both sexes aged 25-44, and 50% and 47% for men and women respectively aged 45-64. The most widely spoken dialect is Cantonese (*ibid.*).

Unfortunately there is no systematic survey data available on preferred spoken languages and literacy levels for the UK Black African population. Data from the 1991 census indicates that over one-third of Africans were born in the UK, who should thus be fully literate in English. The four largest African national groups represented in the UK are Nigerians, Ghanaians, Ugandans, Somalis, and Sierra Leoneans (Elam *et al*, 2001). Whilst all of these except Somalia are Commonwealth countries where English is widely spoken and the main language of education, it is not safe to assume that all recent migrants will be highly literate in English. Experience from HIV prevention work with the Ugandan community for instance indicates that a significant proportion of the community prefer communication in Luo or Luganda. Probably the largest African group who are

likely to have low literacy in English is the Somali community, of whom nearly 15,000 entered the UK between 1992 – 1997, primarily as asylum seekers (Elam et al, *ibid*). Other groups with special language needs may include recent migrants from the francophone Democratic Republic of Congo (formerly Zaire) and Ethiopia. Elam et al (*ibid*) also identify Swahili (spoken in Tanzania and parts of Kenya, Uganda, and DRC), Luganda (spoken in Uganda), Yoruba (spoken in South-Western Nigeria), Luo (spoken in Western Kenya and Eastern Uganda) and Ibo (spoken in South-Eastern Nigeria) as African languages for which there may be significant demand in community resources.

The Black Caribbean population speaks English of course, although one fifth report regularly speaking Patois-Creole, mainly within the family (Modood *et al*, 1997).

2.3 Religion

It can be risky to make assumptions about individual values and behaviour on the basis of reported religious affiliation. However knowledge of the major faiths in a particular ethnic group may be useful as a first step towards identifying community organisations which act as significant channels of influence and communication. Major faiths may also be significant in defining ‘community values’ which, whilst not necessarily adhered to by all, may be important in determining how issues are framed in public discussion and what is deemed ‘acceptable’ at a community level.

A large majority (over 95%) of Pakistanis and Bangladeshis of all age groups describe themselves as adherents of Islam. Amongst Indians, two fifths self-identify as Hindu, one-third as Sikhs, and one-fifth as Muslims. Only 1% or less of each group reported having no religious affiliation (HEA, 2000).

Amongst Black Caribbeans, the largest affiliation was to Anglicanism (30% of women and 20% of men), followed by Catholicism (16% of men and women) and Pentecostalism (13% of women and 8% of men). Amongst the younger age group (16-29 years) relatively high percentages reported having no religious affiliation (16% of women and 35% of men), whereas older age groups reported higher rates of affiliation to other churches (HEA, 2000).

Amongst the Chinese population, 58% describe themselves as having no religious affiliation, whilst 23% identify as Christian and 19% as Other (mainly Buddhist) (Modood *et al*, 1997).

2.4 Use of Health Services

Survey findings reported by Modood et al (op cit) indicate that almost all ethnic minority groups make more frequent use of primary health care services than do the white population, even after adjusting for self-reported level of health (ie taking into account the hypothesis that greater levels of ill health might account for higher rates of service use). Exceptions are Black Caribbean men, and the Chinese population in general, both of whom use health services less than the white population. Nazroo (1997) suggests that language barriers might be a major factor deterring the Chinese population from making greater use of GP services, as nearly one third of Chinese survey respondents who had consulted a GP in the past one month could not understand the language spoken by the GP.

High rates of GP utilization for most ethnic minority groups suggest that this might be an important channel of communication. However findings also show that the quality of primary health care service provision for ethnic minority groups is lower than average (Nazroo, *ibid.*), and that language differences and other communication barriers in particular might limit the value of health information conveyed via GPs. Intergenerational differences in language preference (described above) indicate that such barriers are probably more pronounced for older generations in most communities, excepting recent arrivals.

3. Rapid Review of Relevant Health Communication Interventions

Previous and ongoing health communication interventions aiming to reach any of the high prevalence communities may yield lessons applicable to the Haemoglobinopathy Screening Programme. Unfortunately, many such projects aimed at minority ethnic groups are inadequately evaluated, and there is thus a paucity of data available about the relative success of different initiatives.

3.1 HIV Prevention with African Communities

A substantial amount of work on HIV prevention and sexual health with African communities, mainly in London, has been undertaken in recent years. Much of this work has been characterized by the development of a co-ordinated approach involving the statutory and voluntary sectors and African Community Based Organisations (CBOs) (National AIDS Trust, 2001). Major achievements include:

- Development of an African community-based HIV-prevention sector
- Establishment of the African HIV Policy Network, a consortium giving a voice to African communities in HIV and Sexual Health policy and linking African CBOs through regional forums
- Establishment of the African HIV Research Forum, promoting interest and collaboration in HIV research for, by and with African communities
- A range of national interventions, including a media campaign, radio programme, website, development and dissemination of information resources, African AIDS Helpline, capacity building programme and evaluation project

This work has generated a range of lessons about community-voluntary-statutory sector collaboration in the context of developing a health communication programme, targeting minority ethnic communities, and addressing complex and sensitive issues. Many of these lessons⁶ are highly relevant to the development of a communication strategy for the Haemoglobinopathy Screening Programme, including the following:

1. The commissioning model of lead commissioners working across Health Authorities, developed for African HIV Prevention in London, may be usefully adapted to accommodate more decentralized commissioning by Primary Care Trusts (PCTs). This may be relevant for the Screening Programme to consider in implementing the communication strategy, as it allows for sharing of information and expertise on this specialist issue, which may be lacking in some PCTs.

⁶ For more detailed information see [HIV Prevention and African Communities Living in England: A Framework for Action](#) and [The Evaluation Report for the National African HIV Prevention Projects](#) (full_references in Appendix 9, Useful Resources & Contacts)

2. It is important to work with a collectivist model of behavioural change, building consensus within communities – in effect, facilitating a renegotiation of cultural values - to support individual behavioural change.
3. Full community involvement is essential to ensure that interventions are both culturally appropriate and effective.
4. Partnership needs to be based on a commitment to regular consultation and joint decision-making.
5. Capacity building of community based organizations has been recognized as a legitimate use of HIV prevention funds.
6. Credibility is an important dimension determining the effectiveness of information interventions targeting African communities, which may be suspicious of sources deemed to be “non-African”, “official” or “interfering”.
7. Commissioners need to provide adequate guidelines and resources (technical and financial) to support the meaningful evaluation of new initiatives. Community Based Organisations in particular may often lack capacity to undertake sufficiently rigorous monitoring and evaluation.
8. Information derived from evaluation of new initiatives needs to be collated and made available to relevant organizations.

3.2 NHS Asian Tobacco Campaign

This national campaign has been targeting older people (mainly over 50) in the Bangladeshi, Pakistani and Indian communities since August 2001. The campaign has utilized television, radio and press advertising in both community languages and English. A major component was an outreach programme, including a Ramadan campaign, operating in cities with large South Asian populations. The post-evaluation report should be available through the Department of Health (see Appendix 9 for specific contact details).

Verbal feedback from a Community Development worker who was actively involved in the Ramadan campaign in Bradford included the following observations (Nafees Nazir, personal communication).

1. Based on the large volume of phone calls to the newly-established smoking cessation helpline, the campaign was highly successful. Although two full-time counsellors were appointed to deal with the demand for smoking cessation counselling, there was still a waiting list more than 3 months after the campaign had ended.
2. Although nationally funded, the campaign allowed for local adaptation, including involvement of locally-based outreach workers, and space on printed materials for local contact information.
3. Reaching people on their ‘home ground’ (in the Mosques), in a way which made them feel valued, was important. Information packs included a gift of dates (commonly used to break the fast during Ramadan), which was familiar, appropriate and valuable in that context.

4. The campaign was adequately resourced to allow production of quality printed materials - in colour, with appealing graphics, and information in Urdu and Gujarati – which contributed to the respectful approach of the campaign.

3.3 Chinese National Healthy Living Centre

The Chinese National Healthy Living Centre, based in Soho, London, has experience of developing health information interventions and support services targeting the Chinese population on a range of issues. Relevant interventions include:

- ◆ Smoking cessation campaign through radio and nationally-distributed Chinese newspapers and magazines: evaluation expected at the end of 2002.
- ◆ Development of bilingual health resources (printed and video) on a wide range of issues
- ◆ Establishment of a Cantonese health helpline
- ◆ Development of a disability support service, including support for carers

The CNHLC is linked with all Chinese community centers in the UK, including partnerships with major centers in Manchester and Birmingham.

Relevant lessons learned (Eddie Chan, personal communication) about health information targeting the Chinese population are:

1. Most second- and third-generation Chinese speak fluent English and use mainstream services well.
2. Groups with special needs include first-generation and newly arrived immigrants.
3. New arrivals include asylum seekers and students, many of whom have very low levels of literacy in English. Many of the new arrivals speak Mandarin, rather than Cantonese (more commonly spoken amongst the established UK Chinese community).
4. Chinese Community Centres are probably the most effective channel to use in reaching newly-arrived and first generation Chinese people.
5. Even for those fluent in English, medical jargon in health communication is off-putting, and use of Cantonese and Mandarin in health communication can be more reassuring and helps to build trust.

The CNHLC is developing a London-wide bilingual health advocacy service during 2002, to be staffed by trained volunteers. This service will be run as a 3-year pilot and there are hopes to expand it to Birmingham and Manchester.

(For contact details see Appendix nine.)

4. Community Consultation

4.1 Methods

Aim:

Rapid collection and analysis of data on community perspectives, to inform preliminary planning of a Communication Strategy for the NHS Haemoglobinopathy Screening Programme which is relevant, acceptable and accessible to the high-prevalence communities.

Objectives:

Investigate, analyse and document:

1. Community knowledge of and attitudes towards genetic screening for sickle cell and thalassaemia disorders
2. Community views on appropriate audiences, messages and channels for communication about the haemoglobinopathy screening programme.
3. Approaches for increasing community participation in the development and delivery of the Communication Strategy, and NHS Haemoglobinopathy Services more generally.

Key Informant Interviews

Time constraints did not allow for a systematic survey of Knowledge and Attitudes in the many high-prevalence ethnic groups. It was agreed to use a key-informant interview approach, purposively sampling individuals from each ethnic group with extensive knowledge and experience of community information and service needs, and norms and values with respect to communication channels, marital patterns, childbearing, and other relevant aspects of socio-cultural life. Individuals directly involved in sickle cell and thalassaemia issues were deliberately not sought⁷ as their experience and views would probably be quite atypical of the wider community⁸. Interview participants were recruited through networking and snowballing, via haemoglobinopathy counsellors and researchers, and other contacts with individuals involved with ethnicity & health issues, across England. Voluntary sector partners⁹ were also consulted regarding recruitment of interview participants and during drafting of the interview schedule.

Potential participants were approached by phone or letter in the first instance, and normally were sent background information about the NHS Screening Programme and the Community Consultation, and an information sheet about

⁷ The one exception was the mother of a son with thalassaemia who is actively involved in a range of community development activities.

⁸ It is however recommended that people living with sickle cell disorders, and their families, be actively involved in subsequent stages of consultation and planning of the Communication Strategy.

⁹ The Sickle Cell Society and the UK Thalassaemia Society, both of whom are represented on the Steering Committee for the NHS Haemoglobinopathies Screening Programme

their right to confidentiality and anonymity, before an interview was arranged. Unfortunately time constraints meant that not all contacts could be followed up, and the researcher was not able to visit as many centers as was initially hoped. A total of thirty interviews were conducted in London (21), Leicester (5) and Bradford (4), in the participant's office or home as chosen by him or her. Interviews lasted between 1 and 3 hours, 2 hours was the average.

At the beginning of each meeting, the researcher provided verbal background information, which included:

1. A brief description of what sickle cell disorder/ beta-thalassaemia major is
2. The basic principles of how sickle cell/ thalassaemia variant genes are inherited, using a diagramme to enhance the explanation
3. Current procedures and services for genetic testing for sickle cell / thalassaemia, including the main types of screening in the UK (antenatal and newborn) and gaps in existing service provision
4. Undertaking by the Department of Health to expand and improve screening services for sickle cell and thalassaemia¹⁰
5. Rationale for a Communication Strategy and the purpose and scope of the current consultation
6. Explanation of how the interview discussion will be recorded, highlighting the participant's rights to confidentiality and anonymity.

The participant was then invited to briefly describe the work of his or her organization and experience of community engagement, and to clarify specifically which community/ies s/he would be speaking about for the purposes of this consultation.

Interviews were semi-structured: the interviewer asked open-ended questions in an informal conversational format, and participants were encouraged to direct the discussion to topics they saw as relevant. The interviewer then responded with further questions as appropriate. Scenario questions were used to explore family and community responses to some of the different possible outcomes of antenatal screening. Major themes covered in the interviews included:

1. Community knowledge of sickle cell/ thalassaemia and attitudes towards those living with the condition
2. Assessment of previous health communication campaigns reaching the community (haemoglobinopathies and/or other issues)
3. Perspectives on the value of genetic screening for sickle cell/ thalassaemia at different life stages
4. Decision-making about carrier screening
5. Audiences and channels of communication
6. Community participation

The complete interview schedule is presented in Appendix Six

¹⁰ As set out in the NHS Plan

Participants' responses were recorded in note form by the researcher on prepared response sheets. Participants were invited to confirm their satisfaction with the accuracy of the recorded responses at the end of the interview.

Participants' Characteristics

Thirty interviews were conducted with 35 participants (four interviews involved either 2 or 3 participants at their request; in all cases they were members or staff of the same organization). Table one below shows a breakdown of the self-identified ethnicity of participants (including the range of nationalities of origin for African participants). Table two below shows how participants' various organizations may be categorized by sector. A full list of participants and their organisations is provided at the beginning of this report.

Table 3 Consultation Participants (Sickle Cell & Thalassaemia): Ethnicity

Sickle Cell 15 interviews, 18 participants	African (Nigerian, Ugandan, Somali, Sierra Leonean)	7
	African-Caribbean	7
	Black British	4
Thalassaemia 15 interviews, 17 participants	Pakistani	7
	Bangladeshi	4
	Indian	4
	South Asian	1
	Chinese	1

Table 4 Consultation Participants: Sector

Voluntary Sector ¹¹	12
Community-Based Organisations ¹²	6
Faith-Based Organisations	7
Public Sector (Community Development)	8
Parent of child with thalassaemia	1
Academic	1

^{11, 2} The distinction between voluntary sector and community-based organizations was based on a subjective assessment by the researcher. Organisations with public sector funding, office space and salaried staff were classified as voluntary sector. Those staffed entirely by volunteers, meeting in private houses, with little or no external funding, and serving largely as 'self-help' groups, were classified as community-based. It is acknowledged that this distinction is somewhat arbitrary.

4.2 Community Knowledge & 'Ownership' of Sickle Cell & Thalassaemia

This section provides an analysis of consultation participants' views regarding their communities' levels of knowledge about sickle cell and thalassaemia conditions, including awareness of genetic testing for carrier status. It also considers the issue of community 'ownership', that is the extent to which members of a particular community recognize sickle cell or thalassaemia as a health and social issue of particular relevance to them, worthy of community awareness, discussion and action.

4.2.1 Knowledge & Ownership of Sickle Cell

Thirteen out of eighteen consultation participants reported some previous personal contact with sickle cell disorders. In three cases, individuals were themselves a carrier and/or had a close relative with sickle trait. Others had friends, family members or clients with sickle cell disorder. This relatively high level of personal familiarity with sickle cell (not a selection criterion for participation in this consultation) probably reflects both the high prevalence of the condition amongst the UK Black population, and the extent to which sickle cell is acknowledge and discussed within the Black communities.

Most participants said that members of their communities have heard of sickle cell disorders, and have some basic awareness about the condition. (Exceptions are described below.) That sickle cell 'runs in families', and is not contagious, were commonly mentioned as facts known by most people. Community attitudes towards people living with the condition were described as sympathetic and supportive. Because it is widely understood that sickle cell is an inherited condition, participants were of the opinion that there is no negative judgement of people living with the condition (some contrasted this to people living with HIV/AIDS, whom some community members may judge as having brought their suffering on themselves). A few participants commented that community attitudes towards people living with sickle cell are sympathetic but perhaps not sufficiently empowering.

Although most community members reportedly know that sickle cell is inherited, according to the consultation participants there is little understanding of the specific mechanism by which sickle cell is passed on from parents to children. As a result, they indicated that few people would be aware of the possibility of seeking testing in order to know their carrier status, and taking decisions about partners or reproduction on that basis.

Variation between Communities

There were some consistent differences between the accounts of participants identifying as Caribbean or Black British (including British-born people of African descent), and those identifying as African (all first generation).

Black British and Caribbean participants were more likely to describe sickle cell disorders as a 'Black Health Issue', and to display knowledge of current social issues related to sickle cell disorders, such as employment, benefits entitlement, and the stigmatisation of sickle cell patients as drug users. Most of these participants are aware of the UK Black community's historical struggles for improvements in services for sickle cell, and all of the London-based participants in this category were aware of previous information campaigns initiated by the voluntary sector and sickle cell centers. This awareness of social history and political context led to quite a strong sense of community 'ownership' of the issue of sickle cell disorders amongst most Caribbeans and Black British participants.

The level of understanding of sickle cell disorders was less consistent amongst African participants compared to the Caribbeans and Black British. Although some participants (particularly those in professional contact with health services) were quite knowledgeable, others had only a vague understanding of the nature and implications on the condition. One Somali Community Development worker, in spite of many years' professional experience, had never heard of sickle cell disorders, and expressed the view that knowledge must be very low generally in her community. Other participants commented that they would expect recent migrants from rural Africa to be generally uninformed about sickle cell. Several African participants reported the existence of various community myths about sickle cell, such as the expectation that young people with sickle cell disorders will die at a predetermined age, and that women cannot menstruate or give birth. Some also commented that individuals from families known to carry sickle cell disorders may be stigmatized, and thus find it difficult to marry.

Most African participants were not aware of any information campaigns about sickle cell disorders in the UK. The few who had been exposed to such campaigns reported that they were perceived as being controlled by and targeted at the Black Caribbean community.

In spite of some basic awareness of the condition, the consensus amongst African participants was that there is relatively little 'ownership' of sickle cell disorders as an issue by the African communities.

4.2.2 Knowledge & Ownership of Thalassaemia

In contrast to the Black communities, less than one third (5/17) of participants reported previous personal contact with thalassaemia. This probably reflects both the lower prevalence of the condition compared with sickle cell disorders, and the much lower overall awareness within the South Asian and Chinese communities. Many participants were themselves learning about thalassaemia for the first time in the course of this consultation, including several individuals who are professionally involved in community health and development. Only the

Chinese participant was aware that there is a word for thalassaemia in his first language (which may be directly translated as “Mediterranean lack of blood” - T08). The consensus was that members of the South Asian and Chinese communities generally have little or no knowledge of thalassaemia, and that many, if not most, community members have probably never heard of this condition.

Because of the generally low awareness and lack of personal contact with the condition, most participants found it difficult to comment on how people living with thalassaemia are perceived within their respective communities. Many simply commented that those affected by the condition are ‘invisible’. Many participants commented that disabilities and inherited conditions generally are not widely discussed in their community and are taboo subjects. Participants from the Pakistani and Chinese communities reported that some community members may interpret childhood disability as a form of divine punishment for parental or ancestral bad deeds. Several Pakistani participants, all involved with community based organisations active on disability issues, reported that parents (and especially mothers) are often blamed for their child’s disability. One woman commented:

“Our experience is that disabilities are frowned on in this community. People are not aware of these conditions being genetically inherited, and there is a tendency to blame the parents. Religion teaches us that people with special needs are special, and should be treated as such. They are a gift given by God for people to look after. People who are ignorant of religion see disability as punishment by God.” (T12)

A minority of participants was aware of information campaigns about thalassaemia reaching their community. Four (out of seventeen) participants had been exposed to the UK Thalassaemia Society’ advertisement on Z-TV, and one had heard the radio jingle. Responses ranged from “very positive”, to “confusing”, to “offensive” (the latter in relation to the message that thalassaemia is a “lethal” condition).

All consultation participants agreed that there is no sense of ownership of thalassaemia by the South Asian or Chinese communities, underlined by the fact that even community-based health and disability organizations have almost no awareness of the issue.

Several Pakistani participants commented on the ‘very negative’ and ‘insensitive’ portrayal in the media and by health professionals, of inherited conditions (including thalassaemia) affecting the Pakistani community. They reported that accounts which attribute inherited conditions to consanguineous marriage (customary within the UK Pakistani population) are interpreted as an attack on community values, and serve to alienate people from health services and genetic testing in particular.

4.3 Community Perspectives on Carrier Screening for Sickle Cell & Thalassaemia Traits

This section gives an account of participants' interpretations of community attitudes towards carrier screening for sickle cell and thalassaemia. Discussion was structured by considering the different possible life stages¹³ at which genetic testing for sickle cell and thalassaemia traits might be offered to individuals and couples, focusing on:

- factors which might influence decision-making about seeking or accepting testing
- the social implications of knowing one's carrier status, including decision-making about partners and reproduction

An analysis of responses shows that most participants made implicit or explicit reference to one or more of four key considerations in assessing the value of screening:

1. How relevant and useful will the information provided be to the individual or couple at their particular life stage, in terms of both their ability to interpret the information, and the range of choices available to them?
2. In the context of community values, is it appropriate and acceptable for the individual to be offered this information at this stage? What would be the short and long-term implications of individual knowledge of carrier status for their family and community? (Might sharing the knowledge with family and more widely eventually lead to stigmatisation of the family and affect the marriageability of other family members? At community level, could widespread carrier screening affect culturally-determined patterns of marriage?)
3. Will quality services be provided, offering comprehensive support to the screened individual/ couple and their family, regardless of decisions taken?
4. Will the screening service be racially stigmatizing? (Will the existence of a screening programme for a condition mainly affecting minority ethnic populations promote unfavourable associations and fault against affected communities?)

Whilst responses reflect several common themes across all ethnic groups, some important differences also emerged. To aid clarity, the findings for sickle cell and thalassaemia are presented separately, but the consistency of many of the findings across these two groups should be noted.

¹³ Including newborn, childhood, adolescence, pre-marital, post-marital but pre-conception, antenatal.

4.3.1 Screening for Sickle Cell Trait

Value of Carrier Testing

All participants expressed the view that in principle, it is good for individuals to be offered the choice of testing to know whether they are carriers of the sickle cell gene, on the basis that this knowledge can encourage people to take responsibility for making relevant decisions. However it was recognized that some people may not want this responsibility and thus may prefer to remain ignorant of their carrier status. The importance of not coercing people into being tested was highlighted, as was the importance of providing comprehensive information and counselling as part of the testing service. Several participants commented that screening and counselling services should be delivered by Black professionals, in order to encourage greater trust.

Preferred Timing

All participants advocated that ideally, individuals should have the choice of knowing their sickle cell status “as early as possible”, and expressed support for the intention to establish universal newborn screening for sickle cell disorders. Beyond supporting the prioritization of newborn screening, participants recommended offering “catch-up” opportunities for carrier testing at strategic or opportunistic points throughout life, in order to reach more recent immigrants and others not tested at birth, and to reinforce information about carrier status. The findings presented below document participants’ views on the relative value of screening at different life stages.

Pre-marital screening

Participants were mostly of the opinion that it is more useful to offer testing to single individuals rather than couples, as the former will have a more acceptable range of choices available if diagnosed as a carrier.

Genuine prevention is about offering people testing before they start having a family. (S07)

Some held the view that knowledge of carrier status would definitely influence individuals’ decision-making in developing partner relationships. Others were doubtful that it would. Community development workers cited the difficulties that young Black people experience in discussing sexually transmitted infections with partners, as an illustration of how challenging it may be to discuss sensitive health issues in the context of a sexual relationship. Still, the consensus was that it would be ideal for individuals to have this knowledge in order to at least have the possibility of making informed choices about both partnerships and reproduction.

Some Africans expressed concern about the possible stigma attached to carrier status, and the implications for marriageability. It was suggested that African women in particular might suffer reduced self-esteem if the diagnosis of carrier

status was not sensitively conveyed. African-Caribbeans and Black British were less concerned about such stigma.

Targeting Adolescents

About half of the participants were strongly in favour of offering testing for sickle cell trait during adolescence. Many favoured a school-based education campaign including the option of testing through school nurses. Reasons advanced in support of this approach were:

1. There is a precedent of universal school-based health programmes such as rubella vaccinations
2. If properly managed, this could be a good mechanism for mainstreaming awareness of haemoglobinopathies, thus helping to de-stigmatise and de-racialise these conditions.
3. Education could be provided in the context of pro-reproductive family life & sexual health education, with an emphasis on relationship skills and responsible parenting
4. At this life stage, young people identified as carriers would not be faced with the 'unacceptable' choice of considering termination of a serious relationship or pregnancy
5. Many Black people have children before or outside of marriage, thus this may be the best opportunity to reach a significant number of young people before child-bearing.

Other participants were less enthusiastic about targeting young people through a school-based programme, and advanced the following reasons:

1. The school curriculum is already overloaded with too many competing priorities, and it would be difficult to give adequate time to this complex topic
2. Many young Black people are experiencing tensions in school, and may feel further stigmatized or picked-upon by the introduction of teaching on this topic.

A young person might feel "Is this something else they can blame me for? Is this going to be another stick they can hit me with?" (S09)

3. Young people will not see this as a priority concern and so there would be little impact.
4. Schools lack the expertise to deliver such a programme, and funding and managing an outside agency would be difficult.
5. If not well taught, such a programme could lead to increased racialisation of sickle cell disorders and stigmatisation of Black people.

Opportunistic Testing

About half of the participants stressed the importance of offering testing at a variety of life stages and service delivery points, such as before dental treatment, during immigration procedures and as part of the standard health check during GP registration. Some expressed the view that only this approach would indicate

a true commitment to the mainstreaming of sickle cell services. This could be particularly useful in reaching young Black men, many of whom may rarely come into contact with health services. It was suggested that quality written information, clearly stating the individual's genetic status and indicating where further information and advice may be sought, should be provided as part of this service.

Marriage preparation

Most participants from the Black communities did not see this as a relevant or appropriate time to encourage testing. As mentioned, many Black couples may give birth before marriage or outside of marriage. Apart from this consideration, most felt it was simply too late. As one African woman said, it would be "as good as finishing someone's life" to identify a carrier couple at this stage.

Married Couples, Pre-Conception

Again, this was not felt to be a particularly useful stage at which to offer testing, and many expressed concerns about the de-stabilising effect that the communication of carrier status could have on a relationship.

A woman who is fortunate to have a husband and desperate to have a child, won't want to risk rocking the marital boat (by considering carrier testing for sickle cell). (S05)

Antenatal Screening

All participants viewed antenatal screening as a potentially valuable service, but held divergent views as to what should be the overall aim of antenatal screening.

About two-thirds of participants, and particularly Africans, expressed the view that the most relevant overall aim of antenatal screening for their communities would be to provide an advance diagnosis of a child with a sickle cell disorder, enabling parents and service providers to prepare to provide optimum care.

This is a good aim. If you know, then you are prepared. Services can provide whatever care is needed, and parents can accept the child. (S08)

In Black African cultures, it is very important to have a child. Having a child with sickle cell is better than having no child at all. (S03)

Just under half of the participants expressed the view that informed reproductive choice for couples should be the main aim of antenatal screening. Three community development workers with particular expertise in young people's health service needs thought this aim would be the most relevant and acceptable to them. Some supported the aim of informed choice, but expressed concerns about the possibility of coercion by health professionals limiting actual choice, given the historical backdrop of racism resulting in sub-standard health services for Black people.

I am pro-choice, but it has to be the choice of the woman, not the State or the Health Authority – which has been Black women’s experience. (S09)

About half of the participants supported the aim of advanced diagnosis of an affected child, but did not accept informed reproductive choice as an overall aim for antenatal screening because of opposition to the option of termination. Many expressed the view that religious and cultural values would prevent most Black couples from considering termination of an affected foetus:

It is good for people to be informed in advance (of their carrier status and the risk to the unborn child), but not to be given the choice of abortion. People should be encouraged to keep their babies. The church can play a role in providing spiritual support. (S06)

It is morally wrong in God’s eyes to terminate a pregnancy. The world is full of people who would be glad to look after a sickle cell child. (S02)

In the Somali community we are fully Muslim, and termination is not accepted, regardless of illness or disability. Whatever it takes, the child should be fully supported. (S12)

The reported prevalence of such values explains why some participants argued that the concept of reproductive ‘choice’ including termination is not relevant to their communities.

For some people there is no choice, even with the provision of information. Providers have to detach themselves from the outcome of providing the information. (S04)

Many Participants were concerned that antenatal screening services should not be developed within the framework of an implicit ‘prevention’ agenda, which is morally unacceptable to most.

As a Christian, I believe that the business of producing children and reducing births should not be calculated. (S08)

Prevention is not an acceptable aim (of screening) at the antenatal stage. (S07)

Most participants view screening and care for sickle cell disorders as inextricably linked, and the views expressed around ante-natal screening highlight this concern. Participants expect that the Department of Health should show equal commitment to the care of children and families affected by sickle cell disorders, as to the provision of screening services.

People need information, for mental preparation, and support (speaker's emphasis). If you are giving the choice, you need to offer sufficient care. (S07)

Screening is important, but care is crucial. (S14)

4.3.2 Screening for Thalassaemia Trait

Value of Carrier Testing

All participants held the view that it is good for individuals to be given the choice of testing to know if they are carriers of the thalassaemia gene. It was argued that such knowledge enables individuals to understand the possible implications for themselves and their families, and to make informed choices about the steps they may wish to take. As with the Black communities, participants also stressed that some individuals would certainly not want to have this knowledge and would prefer to 'leave it to God', and that such views should be respected. The importance of providing a quality counselling service was frequently mentioned, as was the need to view testing of individuals as an opportunity to encourage other family members to come for testing.

Preferred Timing

The overwhelming concern of all South Asian participants was that screening should be offered with due consideration for family relations in general, and marriage in particular. This is unsurprising given that in all of the relevant cultures, marriage is generally viewed as an inter-generational concern to be arranged between families.

In the Chinese community, marriages are not arranged but it is still common for parents to "vet" their child's prospective partner before marriage. After marriage, according to the Chinese participant, young people normally make decisions about marriage and reproduction with little reference to older generations. It was suggested that a young couple planning children after marriage would be at the most appropriate lifestage at which carrier screening should be offered.

Promoting Carrier Testing for Young People: School-based & Premarital Screening

In comparison with participants from the Black communities, amongst South Asians there was a stronger consensus that adolescence is the ideal time to encourage testing. Some supported the idea of a school-based programme, for similar reasons as those advanced for sickle cell: a good way to reach young people at a stage in life when less is at stake; a natural part of their development and beginning to take control of their own life; and an opportunity to 'mainstream' the condition, building on the precedent of existing school-based health programmes:

Like testing for rubella, in a normal natural way. (T03)

However, participants expressed serious concerns that adolescents should not be targeted in isolation of their families. Any programme aiming to inform and educate young people about thalassaemia screening should also involve parents, in a way which makes them feel valued and respected. This will be essential if such a programme is to have an impact, as parents and elders will usually play a significant role in making decisions about a young person's choice of marital partner.

Participants reported that in their communities, a significant number of marriages are arranged between families, although increasingly with significant input from the young people involved. Mechanisms for arranging marriages vary between cultures. For Pakistani families, and a minority of Bangladeshis, participants reported that cross-cousin (consanguineous) marriage is customary. It was reported that some Indian families (both Hindu and Sikh) make use of marriage bureaus, which are also becoming more popular with Pakistani and Bangladeshi Muslims.

Some participants suggested that an arranged marriage presents an ideal opportunity to encourage carrier screening in the context of an existing cultural practice. They predicted that if parents were informed of their child's carrier status, and had a clear understanding of the implications, many parents would then want to confirm the carrier status of a prospective spouse before marriage. (Some participants also pointed out that UK-born South Asians are increasingly assertive about their choice of marital partner, and that informed young people may be able to exert significant leverage during the pre-marital negotiation process.) Although potentially challenging to manage, it was argued that this approach would be preferable to the much greater trauma and distress which might occur after marriage, if it were then found that both members of a couple are carriers.

Not to risk the marriage, not to risk the coming child. That (testing young people before marriage) should be a better option. Parents would then definitely consider (the carrier status of) their child in planning a marriage. (T07)

I would want my daughter tested before marriage – if it were available, during the teenage years – instead of going through the trauma of testing in the immediate premarital stage. It would be even worse to be tested after marriage, and there would be the threat of divorce, because it is paramount that a couple must have children. (T12)

There are huge possibilities for young people to influence their choice of partner, discourse about potential marriages is constantly ongoing. Health conditions may well feature in these discussion, and there is a tendency towards greater openness. (T09)

Some participants from the Pakistani community in Bradford suggested that genetic counselling in the context of arranged marriage needs to provide reassurance that it is okay for cousins to marry, provided that they are not both thalassaemia carriers.

Not all participants were optimistic about the opportunities for encouraging carrier screening during the process of arranging a marriage. Some cited preexisting difficulties in inter-generational communication as a barrier, and said that to introduce the issue of carrier testing for thalassaemia would constitute an unacceptable additional burden for young people, during what is already a stressful and difficult process. Some female participants expressed concerns about the implications for young women in particular, for whom public knowledge of carrier status could carry greater stigma.

Married Couples, pre-Conception

A few participants suggested that it may also be valuable to encourage a couple to undergo carrier testing after marriage, particularly if one partner has come from abroad and premarital testing could not be arranged¹⁴. The majority expressed the view that the pressure to produce children after marriage is so great, that a newly married couple would be reluctant to even acknowledge the possibility of a risk to the well-being of their unborn children. The consensus was that whilst it would be useful to have knowledge of carrier status at this stage, family expectations may limit the range of choices available in practice for many couples.

Antenatal Screening

Almost all participants viewed antenatal screening as a potentially valuable service, but as with Sickle Cell Disorders, held divergent views regarding the most relevant and acceptable overall aim of antenatal screening.

Three respondents from the Pakistani and Bangladeshi communities commented that the concept of antenatal screening is fundamentally irrelevant to most people in their community. They expressed the view that the majority would not find it useful to have advance knowledge of an affected child, but rather would find it inappropriate to be given such information.

I don't think that the option (of advance diagnosis of a child with thalassaemia) would be valued, except by the educated middle class. I'm not sure whether antenatal screening will meet the needs of the Bangladeshi community. (T04)

Most people would not want to know, they would say you're playing God. (T12)

All other participants reported that their communities would view advance diagnosis of an affected child as an acceptable aim of antenatal screening, and

¹⁴ Although some participants reported that carrier screening for thalassaemia is now available in the Indian sub-continent.

that carrier testing and the option of foetal diagnosis would be valued by most people. Some commented that it would be useful to prepare the family at large for arrival of the child, and could provide an important opportunity to raise awareness of the presence of the thalassaemia gene in the family. Some participants hoped that antenatal counselling for whole families might address the perceived tendency (reported by members of all of the major South Asian ethnic groups) for women to be blamed for the birth of a disabled child. This might have the effect of minimizing conflict within the family after the birth.

Half of the participants¹⁵ also thought that informed reproductive choice for a couple was a relevant and acceptable aim for antenatal screening. The consensus among these participants was that although it would not be acceptable to present termination of the affected foetus as an option at community level, individual couples would value this choice.

A married couple will rarely go for an abortion, but choice is very important. (T07)

As a community, Bangladeshis would not even want to consider the choice of termination, but it is good for individuals to be offered this choice. The concept of 'informed choice' may be quite relevant for those who are UK-born, but for many Bangladeshi-born¹⁶ this concept could be offensive. (T05)

Some sections of the community would find this (informed choice) an unacceptable aim (of antenatal screening), but the choice should be made available. Those understanding the implications would probably consider the option (of termination). (T11)

The younger generation of the Chinese community would want to have that option (informed choice). Some of the older generation might object (to the option of termination) and may put a lot of pressure on a younger couple. (T08)

Those supporting the aim of informed reproductive choice cautioned that the topic of termination of pregnancy must be very sensitively introduced, with careful attention to use of community languages in communicating about this issue.

Opposition to the principle of informed choice was not necessarily or exclusively based on religious values. Some participants, mainly from the Black communities, expressed particular concerns about the possibility of coercion by the state or individual health professionals:

¹⁵ Including all Indian and Chinese participants, and some of the British-born Pakistani and Bangladeshi contributors.

¹⁶ According to informants, most Bangladeshi couples marrying in the UK include one Bangladeshi-born partner

Once you put the idea of choice into someone's mind, you're saying 'If you're sensible, you will terminate this pregnancy'. (S08)

This (informed reproductive choice) sounds like 'breeding out people we don't like'. (S13)

Amongst those who argued that informed choice would not be acceptable to their community because of opposition to termination, similar accounts of false positive foetal diagnosis were relayed in three separate interviews. In each case described, a couple opting for foetal diagnosis were told that their child had a severe disability (unspecified in these accounts), and were offered the choice of a termination, which they declined. When the child was born, it was completely healthy. Participants reported that such cases are widely discussed and may serve to undermine parental confidence in foetal diagnosis and antenatal screening in general.

Several Muslim participants, including a senior Mosque official, commented that Islamic authorities may sanction termination for medical reasons during the early stages of pregnancy, before 'ensoulment' has occurred. Participants' views were that most lay people in the Pakistani and Bangladeshi communities are probably not aware of this. It was suggested that if such information could be communicated to affected couples and their families using appropriate channels, they would then have a more genuine choice of options.

4.4 Discussion & Conclusions

This preliminary consultation, involving 35 selected individuals from the high-prevalence ethnic groups, highlights the range and complexity of issues to be considered in the course of developing a communication strategy for the NHS sickle cell and thalassaemia screening programme. The consultation findings have specific implications for planning:

- The content, phasing and mode of delivery of communication
- The selection of target audiences within the high-prevalence populations
- The organization and delivery of screening services.

Three major issues, common across ethnic groups, are discussed below:

1. Lack of understanding within most of the high-prevalence communities (with the exception of Black Caribbean/ Black British who may have higher awareness) of sickle cell/ thalassaemia, including little awareness of the mechanism of inheritance amongst all communities
2. The care needs of people living with these conditions, and support for their families, should be addressed in coordination with the screening programme.
3. The challenge of promoting informed reproductive decision-making for individuals and couples, whilst respecting and working with the norms and values of different ethnic communities.

(Consultation findings relating to specific messages and channels of communication are incorporated into recommendations in section 5, and detailed in various appendices relating to the communication strategy.)

The consultation solicited the views of a small number of purposively selected individuals who are in many ways unrepresentative of their wider ethnic groups. Participants are probably more educated, of a higher socio-economic class, and more interested in and aware of community development and health issues than average. A slight majority of the participants were female, with each of the major ethnic groups represented by at least one person of each gender, with the exceptions of the Chinese (no female participant) and Indian (no male participant) populations. A significant proportion of the African participants are office-holders in faith-organisations, which play a major role in the lives of most Africans. Conversely, due to time constraints the consultation did not include any faith leaders from the Sikh, Hindu, and Chinese Christian or Buddhist communities. No representative of the Ghanaian community was involved due to time constraints, although this is the second largest African group in the UK with a high prevalence of sickle cell disorders.

The intention was to undertake a rapid 'mapping' of community perspectives, rather than a systematic in-depth survey of knowledge and attitudes. By virtue of their positions and experiences – leadership roles, actively engaged in community development services and activities – one would expect the views of the consultation participants to provide some reflection of community values

which are prominent and public, but not necessarily adhered to. Those with extensive experience of community support services at grassroots level may have a thorough knowledge of their client group's needs, but these may not be generalisable to the wider ethnic group. In most cases the consultation has involved multiple participants from each ethnic group, of different ages, gender, and regional locations; the overall consistency of their accounts, with some distinct patterns of intra-ethnic variation, tends to support this interpretation. The availability of more time would have allowed for involvement of participants from a wider geographical range, and greater intra-ethnic diversity. Such wider involvement might have produced more detailed data on the particular needs of different groups, but given the overarching consistency of themes emerging from these accounts, it is unlikely that the major findings would vary significantly.

4.4.1 Lack of Community Knowledge

Although reported levels of knowledge about the conditions vary between the communities, findings of this consultation indicate that in none of the high-prevalence communities is there widespread understanding of the principles of genetic inheritance of haemoglobinopathies. Such an understanding is clearly an essential prerequisite to awareness and uptake of screening services.

Consultation findings are consistent with previous studies showing that the UK Black Caribbean population have mostly heard of sickle cell disorder, but have a poor understanding of its mode of inheritance (Green & France-Dawson, 1997; Dyson, 1997), and that a large majority of South Asians have a very low awareness of thalassaemia (Darr, 1990; Dyson et al., 1993; Lakhani, 1999). Dyson (1997, op cit) has attributed the relatively high levels of (basic) awareness of sickle cell disorders amongst Black Caribbeans, in comparison with South Asians' lower awareness of thalassaemia, to the prominent voluntary sector-led campaigning amongst the former group. Several participants in this consultation offered a similar analysis. The low level of individual and community awareness reported by the consultation's seventeen Asian participants is all the more striking given that most are actively involved in community development activities, many in a professional capacity. These findings are in the contrast to those by the UK Thalassaemia Society that since their recent 'Asian Awareness Campaign', 60% of UK Asians are now aware of thalassaemia (UKTS, 2002).

I am not aware of any studies investigating levels of knowledge of sickle cell disorders amongst UK African communities, and it would be wrong to make a conclusive statement on the basis of this consultation, particularly given the diversity of the African population. However, the views of the eight different African participants on this issue were consistent with one another: that although many Africans may have a vague awareness of the condition because of its prevalence in their country of origin, overall knowledge is generally poor, and persisting stereotypes and myths about the condition need to be addressed. Two major explanations were offered: that UK awareness campaigns to-date have

been perceived as controlled by and targeted at Black Caribbeans; and that recent migrants, especially from rural Africa, are unlikely to have been exposed to educational information about sickle cell disorders. The extensive work on HIV prevention awareness recently undertaken with UK African communities provides some useful models and lessons for health communication interventions with Africans (see section three of this report), many of which are generalisable to other communities.

Community knowledge of sickle cell or thalassaemia is not only a prerequisite for uptake of the screening programme, it is also an essential foundation for community-initiated action in response to the issue, and active participation in planning and delivery of the programme. Contributions from the Black British and Black Caribbean participants suggest a relatively strong sense of ownership of sickle cell disorders as a Black health issue, based on years of campaigning by voluntary sector and community groups. This sense of identification with the condition was not perceived amongst African and Asian participants; as the purposive selection of consultation participants probably means that they are likely to have higher than average awareness of community health and development issues, this particular finding is quite likely to be generalisable to the wider communities.

4.4.2 Addressing Care & Support Needs of Affected Individuals & Families

The consultation revealed a strong consensus across ethnic groups that an awareness campaign about screening should also address the experiences, needs and entitlements of individuals living with sickle cell and thalassaemia.

For participants from the South Asian and Chinese communities, the ‘invisibility’ of people living with thalassaemia implies that messages encouraging uptake of screening services will hold little meaning unless communities are made more aware of the realities of living with the condition. Information resources featuring ‘real-life’ accounts from affected individuals and families were recommended.

Several South Asian participants involved with disability issues generally are concerned about a perceived lack of community support, and tendency to blame the parents of children with disabilities, and suggested that such negative community attitudes should be addressed in the context of a communication campaign. However, it is worth noting that Darr’s (1990) study of UK Pakistani families living with thalassaemia found no evidence of stigmatisation of affected families, nor of mothers or parents being blamed or blaming themselves for their child’s condition. As this consultation and Darr’s study both involved small numbers, a more systematic investigation of these issues, in collaboration with the Asian voluntary sector, should be considered to inform planning of communication on these issues.

Some participants from the Black communities discussed the need for greater awareness about social issues such as benefit entitlements, negative

stereotyping and employment opportunities – not just within the Black communities, but also targeting relevant professional groups and the wider UK society. These issues have been well documented in the literature (see Anionwu and Atkin, 2001), and would likely be brought to the fore in the event of increasing publicity about sickle cell screening, thus some consideration is warranted as to how they might be addressed within a communication framework. The implementation of universal newborn screening may provide a good opportunity to begin to address awareness of such issues, in the framework of more general awareness of the realities of living with sickle cell.

Across all ethnic groups, participants expressed concerns that the availability and quality of care and support services must reflect an investment of commitment and resources at least equivalent to the screening services. Some argued that if screening services are apparently accorded greater prioritisation than care services, this could be interpreted as evidence of racism in health policy. Many commented that if care & support services are unavailable or inadequate, the principle of informed choice is undermined. (See discussion below.)

4.4.3 Reproductive Choice and Community Norms & Values

Perhaps the single most important theme emerging from the consultation is the tension between informed reproductive choice and respect for community values. Systematic engagement with the high-prevalence ethnic communities needs to be a central plank of the communication strategy, in order to begin to resolve this tension. This presents a particular challenge for decentralized commissioning in the context of addressing inequalities in health.

Participants' contributions on who should be targeted for screening, when and how¹⁷, based on their own perceptions of community values and needs, can inform the preliminary design of interventions for further discussion and development. These are discussed in relation to two possible dimensions of a screening programme: pre-conceptual/ pre-marital carrier screening for young people (not currently an explicit component of the planned NHS programme), and antenatal screening (which the NHS has committed to implementing). The former includes a brief discussion of the issues around consanguineous marriage. This serves as a case study illustrating how an effective communication strategy may help to resolve conflicting community and health service perspectives, which otherwise may risk undermining the screening programme and increasing racial stigmatisation.

Carrier Screening for Young People (pre-conception/ pre-marriage)

¹⁷ For more details on recommended audience segments and communication channels, see Appendices One and Two.

Most participants saw this approach as particularly valuable, because of the possibilities for:

- Mainstreaming awareness of sickle cell and thalassaemia in the general population
- Minimising the perceived threat to community values posed by antenatal screening, with its attendant disruption to marital and family relations and the possibility of termination of pregnancy
- Maximising individual choice, by offering information and counselling in a setting where there is more time for individual and family reflection, and less scope for professional or institutional coercion

The main concern of the minority not in favour of school-based screening was that a poor quality programme might do more harm than good, particularly in terms of (further) alienating young Black people, and of increasing the racialisation of sickle cell disorders. It was argued that an already overstretched curriculum and lack of in-school expertise do not bode well for the delivery of a quality communication and screening intervention. Such concerns are valid and need to be taken seriously, by ensuring adequate resource commitment for a carefully monitored and evaluated pilot programme, and anticipating and addressing possibilities for unintentional racial stigma which might arise from communication interventions.

A second concern, expressed equally by those in favour of targeting young people, was to ensure thorough involvement of parents and communities in school-based programmes. As well as supporting community values by promoting family integrity and respect for elders and parents, a more widely-inclusive approach may also increase the effectiveness of an intervention targeting young people, for reasons discussed below.

A crucial question in considering preconceptional/ pre-marital screening for young people, is the extent to which genetic testing and counselling delivered in this context is likely to influence actual decision-making about partnerships. Consultation participants had mixed views on this question. Quality of information and counselling provided may be a major determinant, and there is both positive and negative evidence to support this assumption. One UK-based study (Dyson, 1997) found no differences in levels of understanding between sickle cell carriers and non-carriers after testing, with both groups showing an equally poor understanding of patterns of inheritance. This suggests that offering genetic testing with inadequate counselling may have little impact on carriers' future reproductive choices. Demographic monitoring of a high-school based thalassaemia screening programme¹⁸ in Montreal, showed that almost all carriers identified in the programme did go on to remember their status, have their

¹⁸The programme has been in existence for over 20 years, with more than 60% uptake of voluntary screening, and has identified 693 carriers out of a population of 25,274 students screened (most of Mediterranean origin). A corresponding programme exists for Tay Sachs disease.

partner tested and seek reproductive counselling (Mitchell JJ *et al.*, 1996), showing that a school-based screening programme can have an impact on future decision-making about partnerships.

Consultation participants with expertise in sexual health education with young Black people, argued that sickle cell awareness for this group needs to be presented in the context of broader teaching about relationships and health, including communication and negotiation skills, in order to have an impact on actual life choices. These topics fall within the national curriculum for secondary schools, although the quality and coverage vary between schools and boroughs.

Carrier Screening in the Context of Arranged Marriage

Several South Asian participants suggested that the practice of arranging marriage between families presents an ideal opportunity for carrier screening¹⁹ to influence partner choice. Interventions to support this could build on a school-based programme involving parents and elders, offering intra- and inter-family counselling with a specific focus on the negotiation of marriage. Such approaches to family counselling have already been used on an ad-hoc basis with Pakistani families in the North of England (Gulsan Karbani, personal communication), and necessitate the availability of skilled genetics counsellors fluent in South Asian languages, obviously with sensitive adherence to principles of confidentiality. The London-based Naz Project has addressed the issue of HIV testing for South Asians in the context of arranged marriage, in an awareness campaign targeting parents, GPs and social services (Parminder Sekhon, personal communication; see Appendix Nine).

Scaling-up such interventions would require an appreciation of inter-ethnic, regional, and other variations in practice around the arrangement and negotiation of marriages in the South Asian population. Modood *et al* (*op cit*) note a significant generational shift in the practice of arranged marriage amongst some South Asian groups, finding that only a minority of younger Sikhs, Hindus and East African Asians report arranged marriages. It is however still a majority practice amongst the Muslim Pakistani and Bangladeshi communities, particularly those in the North of England and the West Midlands (*ibid.*). Other findings from the same survey indicate that although many South Asian young people now have the last say in the selection of their marital partner, parents still make a (potentially significant) input to the process in most cases.

Consanguineous Marriage, Thalassaemia Screening & Communication

The tendency of health professionals and the media to 'blame' the cultural practice of consanguineous marriage for inherited disorders emerged as a particular concern of some Pakistani participants in Bradford. Consanguineous marriage is practiced by a majority of the Pakistani and Indian Muslim

¹⁹ Apparently such a screening programme has been running in North Manchester for many years (see Elton, 2000) and is currently being considered in Bolton (Peter Elton, personal communication)

populations in the UK, and by a small minority of Bangladeshi and East African Asians (Modood, 1997). The practice is most widespread amongst Pakistanis in the Northwest and West Midlands, whereas only about a third of Pakistanis in the South East are in consanguineous marriages (*ibid.*).

Ahmad has provided a detailed analysis of how medical and health policy discourse around consanguineous marriage has tended to promote a pathological stereotype of Muslim culture, which “provides an excellent means of blaming the victim and absolving health services and wider racial inequalities from responsibility.” Darr’s extensive study (1990) of Pakistani families affected by thalassaemia confirms that most of the related couples she worked with ‘were initially told by a health worker that the condition was “caused “ by the couple being cousins’ (*ibid*:248). Darr reports that such misinformation not only caused unnecessary distress to parents, it also had the effect of undermining their trust in health professionals, as it became evident that this was a misleading explanation of their child’s condition. The possibility of screening for thalassaemia makes health professionals’ preoccupation with consanguineous marriage less relevant in the case of this condition. Affected families need to be supported in the process of communicating their risk status within families, and negotiating to avoid an at-risk marriage (Modell and Darr, 2002).

As the NHS Haemoglobinopathy Screening Programme is implemented, media and public interest in such issues will undoubtedly increase. Programme planners should take responsibility to anticipate and address sensitive issues, which may lead to increased stigmatisation of the high prevalence communities and undermine the effectiveness of the screening programme. Customary consanguineous marriage may be such an issue. Given the evidence of health professionals’ dangerous levels of misunderstanding of this practice and its implications for thalassaemia, it is important that this ignorance be systematically addressed in the course of training for health professionals as part of the screening programme’s implementation. Community-targeted communication interventions should also address the issue directly. Credibility and trust will likely be gained by reassuring the relevant groups that the practice of consanguineous marriage can still be facilitated in the context of carrier screening and informed reproductive decision-making. (See also Darr, 1997 for a discussion of how the intra-family networks promoted through the practice of consanguinity may serve as a basis for family-oriented thalassaemia screening.)

Ante-natal Screening

It is important to stress that the range of views expressed in this consultation in relation to antenatal screening give us little or no insight into how individuals or couples will actually respond when faced with reproductive choices in the context of antenatal screening for sickle cell disorders and thalassaemia. What the consultation findings do provide is some insight into how the topic of antenatal screening might be framed in order to maximize acceptability to the relevant

communities. They also highlight particular issues warranting further consultation.

The consistent support expressed for 'advance diagnosis of an affected child' as an aim of antenatal screening highlights the value attached to linking screening interventions with explicit care outcomes. Virtually all participants expressed the view that it would be both useful for individual couples and families, and acceptable to the wider community, for children with sickle cell or thalassaemia to be identified in the womb, to enable advance preparation for their arrival by parents, families, and service providers. That this is not a peculiar perspective is suggested by findings from other studies, showing that many couples who opt for prenatal testing (for various conditions) state that they would not consider termination (Evers-Kieboomes et al, 1993; Green et al, 1993).

'Informed reproductive choice' as an aim of antenatal screening was less consistently acceptable to the consultation participants, with about half expressing approval (roughly equal proportions Black and Asian). Most of those not supporting this aim do not entirely reject the principle of reproductive choice, as evidenced by the level of interest in prenatal testing, but do have particular concerns about the choice of termination of an affected foetus being offered (or "promoted", as some interpreted.). Even amongst those supporting informed choice as an aim, participants were concerned that the overt statement of such an aim may cause offence "at a community level".

The basis for expressed concerns about termination incorporates both religious and cultural values, as well as suspicions about the possibility of institutional coercion based on an historical analysis of racism in health services delivery. No single ethnic group demonstrated a rigid or uniform adherence to faith-based values. On the contrary, there were examples of participants from all faiths who expressed support for informed reproductive choice as an aim of antenatal screening, whilst acknowledging that the particular choice of termination is contrary to their own religious values. Several Black participants indicated that community objections to termination may be more cultural than religious, by making reference to 'African' or 'Black' values (rather than Christianity). Others, whilst articulating support for the principle of informed choice, also expressed concerns about the possibility of coercion limiting that choice for Black people.

The tendency of health professionals to stereotype South Asians as opposed to termination, and therefore to deny them the option of antenatal screening has been documented (Atkin and Ahmad, 1997). It has equally been shown that when given the option of termination, South Asian parents will exercise a range of responses depending on various factors, of which faith values may only be one (Darr 1990; Green 1992, cited in Atkin et al 1998). In this consultation, those South Asians who anticipated community opposition to the aim of informed reproductive choice, explained their views as based on community interpretations of Islamic values. However several of these individuals also acknowledged the

existence of different schools of thought within Islam regarding medical termination during early pregnancy, and those encountering this suggestion for the first time during the interview expressed interest. Darr (1990) reports on discussions with Muslim scholars, which similarly indicate varying views on the issue of termination, with some pronouncing that termination could be permissible before 10 weeks' or 3 months' gestation²⁰. More extensive consultation with key Islamic thinkers and organisations in the UK (see Appendix Nine) and Muslim communities might facilitate the emergence of a consensus which could be communicated more widely, within the relevant communities generally and to carrier couples in the context of genetic counselling.

²⁰ In discussion with Dr Abdul Majid Katme, a member of the Health Committee of the Muslim Council of Britain, he informed me that there are two alternate points of view regarding ensoulment, one recognizing that it occurs at 6 weeks after conception and one espousing 120 days.

4.4.4 Conclusions: Implications of Community Consultation

The following conclusions are reached on the basis of this consultation, notwithstanding the limitations acknowledged previously.

3. All high prevalence ethnic groups have a very inadequate understanding of sickle cell and thalassaemia, which will limit uptake of screening. Specifically:

- Thalassaemia is 'invisible' within the South Asian and Chinese communities
- African communities generally have a poor understanding of sickle cell disorders, and myths and stereotypes about the condition are prevalent. There may be a complete lack of awareness amongst some communities of recent immigrants.
- All groups are unaware of the mechanisms of genetic inheritance of these conditions, including the Black Caribbean/ Black British communities who have mostly heard of sickle cell disorders.

Action point: Raising basic awareness of sickle cell and thalassaemia at community level should be an urgent priority for communication interventions.

2. Partially as a result of very low levels of awareness, there is little or no 'ownership' of sickle cell and thalassaemia amongst UK Black African, and South Asian and Chinese, communities respectively.

Action point: Alongside raising awareness, the communication strategy should consider supporting community development activities which will encourage greater identification with the issues and stimulate community-based responses.

3. In the interest of equity and human rights, there is a strong consensus amongst participants that screening and care for haemoglobinopathies must be given equal priority.

Action point: Black, South Asian and Chinese voluntary sector and Community Based Organisations should be involved in developing communication interventions on care issues.

Action point: Management of the Haemoglobinopathies Screening Programme should use all possible opportunities to advocate for and influence improvements in care services, which must be seen to develop in parallel with the Screening Programme.

Critical point: This is essential for the credibility of the Programme and to avoid accusations of institutional racism.

4. Universal newborn screening for sickle cell disorders is likely to be very well received by the Black communities. Implementation of this programme presents an ideal opportunity to raise awareness of carrier status and care and entitlement issues.

Action point: Information and counselling provided under the newborn screening programme should target parents (and GPs) of children identified as sickle cell carriers, not just those with sickle cell disorder (Hb SS).

Action point: Communication interventions to raise awareness of the newborn screening programme should incorporate messages about the achievements, needs and entitlements of people living with sickle cell (for all Black communities), and present sickle cell as a community issue (especially for the African communities). (See Appendix Five for more details of proposed messages.)

5. There is strong support for preconceptual/premarital carrier screening targeting young people, but this must be delivered in the context of family and community.

Action point: Pilot school-based programmes in high-prevalence areas should be considered, linking with family genetics counselling services and Primary Care Trusts. The possibility of involving Marriage Bureaus serving the South Asian communities to raise awareness of pre-marital carrier screening should also be explored.

6. Confusion regarding the relevance of customary consanguineous marriage to thalassaemia requires careful attention, so not to isolate and stigmatise from the majority and other minority ethnic groups.

Action point: Training for genetics counsellors, midwives, GPs, health visitors and other staff involved in delivering the Screening Programme must provide sensitive and comprehensive coverage of this issue.

Action point: Communication for the relevant communities should provide accurate information and reassurance that consanguineous marriage does not 'cause' thalassaemia.

7. Antenatal screening with the aim of providing advanced diagnosis of an affected child, allowing family and providers to prepare to provide the best possible care, is widely supported. Antenatal diagnosis with the aim of providing informed reproductive choice for couples is less consistently supported. However, the mixed views expressed do not represent a wholesale rejection of the principle of reproductive choice, nor a consistently rigid adherence to religious values by any particular group. The view that offering

termination as a choice is contrary to community values was expressed by participants of different faiths and ethnicities, based on concerns about institutional coercion as well as faith-based and cultural values.

Action point: Communication about antenatal screening must be developed with extensive community input and careful attention to use of language. Further consultation with faith-based institutions and religious scholars is warranted, in the interests of promoting a more genuine range of choices for devout couples of all faiths.

5. Detailed Recommendations for Design of Communication Strategy/ NHS Sickle Cell & Thalassaemia Screening Programme

5.1 Services

6. The Department of Health should make a clear and public commitment that equal priority will be given to the delivery of high quality services for both screening and care services for haemoglobinopathies.

7. Strategy design should be informed by a detailed understanding of the scope and quality of services currently available (and a clear timetable for development and improvement of services where relevant).

8. Central guidance should be issued to Strategic Health Authorities and Primary Care Trusts, highlighting the opportunity to make progress towards addressing health inequalities and implementing Race Equality Schemes²¹, by implementing haemoglobinopathy screening programmes and engaging with community groups on communication initiatives.

9. The communication strategy should be integrated into service standards for the implementation of screening programmes.

10. A major dimension of service quality should include providers who are trained and equipped to deliver appropriate services to ethnically diverse communities. This includes a comprehensive understanding of ethnicity and health issues, including racialisation, and coverage of 'sensitive' topics such as consanguinity and termination.

11. Recruitment and development of staff from all of the high prevalence ethnic communities into genetics counselling and health communication/ community development positions, should be prioritised. This will ensure the availability of individuals with detailed knowledge of socio-cultural context and fluency in community languages. Obstacles which may hinder employment and development of such staff need to be investigated and addressed; for instance if nursing qualifications are an essential requirement for genetics counsellors, that will reduce the number of South Asian counsellors available (Gulsan Karbani, personal communication).

12. It is strongly recommended that significant progress with the above should be achieved before generating increased demand for services through communication interventions.

²¹ As required of all public authorities under the Race Relations (Amendment) Act 2000.

5.2 Strategy

1. The high-prevalence ethnic populations for sickle cell and thalassaemia respectively have different communication needs. This should be recognised by developing: either two separate, but overlapping and closely co-ordinated, communication strategies; or, two distinct strands within one overarching strategy.

2. The communication strategy for high prevalence ethnic populations must be located within a holistic communication framework addressing the needs of all stakeholders, including health professionals and users of antenatal and newborn services²².

3. Major objectives for the communication strategy should include:

- Increase basic awareness of sickle cell/ thalassaemia including pattern of inheritance and the option of carrier testing
- Stimulate community ownership of the issues and increase participation in planning and management of services
- Raise community awareness of the needs of people living with thalassaemia and sickle cell

4. Three main approaches should be combined in the communication strategy:

- Community development / group work
- Interpersonal (one-on-one)
- Mass media

The former two are very important in developing community ownership and building trust, particularly with the more marginalized and underprivileged groups (who may be harder to reach through mass media due to language barriers and lower literacy levels). (See Appendices One and Two for more details of communication channels.)

5. The main target audiences should include:

- Community & Faith Leaders
- Elders
- Parents of unmarried young people
- Unmarried young people (for Chinese community especially newly arrived students and asylum seekers)
- Community-Based Organisations
- Health Professionals

(See Appendices One and Two for more details of target audiences and communication channels.)

²² The issue of awareness and responses of the wider UK population towards screening for haemoglobinopathies, in regions of varying prevalence, has not formed part of this work, but needs to be addressed. Consultation with service users will be needed.

6. Early attention should be given to developing a strategic approach to engagement with the mainstream media (as well as minority ethnic media, see Appendices One and Two), including anticipating and responding to unfavourable associations and fault being apportioned to affected communities.

The following recommendations relate to specific sub-objectives and activities for the communication strategy:

7. Implementation of universal newborn screening for sickle cell disorders presents an ideal opportunity to begin to address recommended strategy objectives with the Black Caribbean, African and Black British communities, using the main approaches described above.

8. Communication about antenatal screening must be developed with extensive community input and careful attention to use of language (see recommendation 5.8.2). Further consultation with faith-based organisation, religious scholars and community groups is highly recommended (see 5.3.1), to build consensus around the way forward on communication for this component of the screening programme

9. Preliminary work with the high-prevalence populations for thalassaemia should involve collaboration with existing Chinese and South Asian voluntary sector groups active on disability issues (see Appendix Nine) and service users' groups, to raise community awareness of thalassaemia (including carrier screening) with a focus on people living with the condition. This could also incorporate further investigation of community attitudes towards disability in general (see consultation findings and discussion).

10. Highlight the need for a National NHS Research and Development Programme such as the Health Technology Assessment to commission a systematic review of the effectiveness of international programmes of preconceptual screening for sickle cell and thalassaemia.

11. Informed by the findings of a systematic review (above), consider piloting school-based programmes in high-prevalence areas, linking with family genetics counselling services and Primary Care Trusts. Agencies such as Naz Project and Blackliners, with expertise in working with young people from minority ethnic groups, should be consulted. The possibility of involving Marriage Bureaus serving the South Asian communities to raise awareness of pre-marital carrier screening should also be explored. All pilots need to be carefully monitored and evaluated.

5.3 Advocacy

1. A series of national seminars for religious thinkers and leaders from the different faiths to discuss screening issues should be organized through the National Steering Committee. Work done by the King's Fund engaging Faith Leaders on Mental Health issue may provide useful pointers (see Appendix Nine).
2. One-on-one consultations with local 'gatekeepers' (leaders of faith-based and other community organizations, local politicians, business people, media) need to be undertaken on a regular basis by haemoglobinopathy counsellors, community based organizations, community development workers and representatives of users' groups
3. Community-based, voluntary sector and service users' organisations should be supported to systematically engage with health services organisations at the level at which services are coordinated as part of community development initiatives.

5.4 Service Users' Participation

1. People living with thalassaemia and sickle cell, and their families, need to be involved from the early stages of strategy development. Ideally this should be organized through local service users' groups and parent support groups.
2. Local groups and individuals should be encouraged to define their roles/ involvement, which might include acting as spokespersons for mass media, trainers for group events, advocates with community leaders.

5.5 Community Development

1. Small grants scheme for community communication initiatives by community-based organizations (including users' and parents' groups, faith-based organisations, cultural groups, HIV prevention organizations, Black Health Fora, etc)
2. Community-based organizations can be invited to participate in competitions to develop materials for use in mass-media campaigns (eg drama for use in videos, jingles for use in radio advertisements). Such interventions could also be linked to school-based campaigns to encourage involvement of young people.
3. Encourage collaboration (with an emphasis on sharing of skills and knowledge) between more established voluntary sector organizations (such as the main Sickle Cell and Thalassaemia charities), Community-Based Organisations, and Service User groups

4. Recruit field staff (to facilitate consultation, evaluations, etc) locally whenever possible, to enhance ownership and sustainability

5.6 Facilitation & Capacity Building

1. Ensure availability of strategically placed staff at local levels to facilitate community participation. These may be sickle cell/ thalassaemia counsellors, or specially trained community development/ health outreach workers based in Trusts or Voluntary Agencies with a remit for ethnicity and health issues.
2. Provide training to such staff where necessary to ensure adequate skills in community development and health communication
3. Training for Community Based Organisations should also be provided, to promote the development of quality interventions at community level and to better equip CBOs to contribute to the planning and management of haemoglobinopathy services

5.7 Participatory Monitoring & Evaluation

1. Develop mechanisms for obtaining feedback from target communities and service users at all stages of communication and service delivery
2. Results of evaluations of services and communication interventions should be discussed at public fora involving all community stakeholders

5.8 Mass Media & Materials

1. Undertake an inventory of existing mass media and other educational materials about sickle cell and thalassaemia produced nationally and internationally.
4. Link with Genetic Interest Group and NW Thames Regional Genetics Centre, which are collaborating on a pilot project developing genetics counselling resources in minority ethnic languages. The process of translating abstract genetics concepts needs to involve expertise from a range of sectors including community groups, religious scholars, health professionals including haemoglobinopathy and genetics counsellors, and medical anthropologists.
5. Obtain data for all of the major Black and Asian media on coverage, audience profiles, costs (including availability of discounted public service air time).
6. Development of messages and materials, building on preliminary analysis presented in this report (see Appendices 3, 4 and 5) and working with audience segments as identified with partner organizations.

7. Ensure rigorous pre-testing of materials developed and thorough documentation of results.

5.9 Further Research

This work highlights a range of issues warranting further investigation, including:

1. Lay understandings of the meaning and implications of reproductive choice.
2. Value of preconceptual screening and key elements of good practice (see recommendation 5.2.5).
3. The impact and implications of knowledge of carrier status on individuals and families at different life stages.

APPENDIX ONE: Audience Segments & Communication Channels: Thalassaemia

Audiences	Channels		
	Interpersonal	Group/ Community Development	Mass Media
1a. South Asian unmarried young people (15-25)	<ul style="list-style-type: none"> • Family • Peers • School/ University Health Advisors • Providers of targeted health/ social services • Thalassaemia Counsellors 	<ul style="list-style-type: none"> • Schools (including Islamic & other supplementary schools) • Higher/ Further Education Institutions • Youth services • Designated sessions in Health and Community Centres 	<ul style="list-style-type: none"> • Cinema Houses • South Asian TV stations: Z-TV, ARY, Prime TV, Bangla TV, Ekushey TV • South Asian radio stations (Sunrise, Ramadan Stations) • English Language Asian magazines targeting women: Asian Bride, Asian Woman • Printed media (outlets as per group channels)
1b. Chinese young people (individuals and couples), especially newly arrived students and asylum seekers	<ul style="list-style-type: none"> • Family • Peers • School/ University Health Advisors • Providers of Chinese language services • Thalassaemia Counsellors 	<ul style="list-style-type: none"> • Higher/ Further Education Institutions including English as a foreign language • Chinese National Healthy Living Centres (London, Manchester, Birmingham) 	<ul style="list-style-type: none"> • Printed media (outlets as per group channels) in Cantonese • TVBSE Cantonese service • Spectrum radio Cantonese & Mandarin broadcasts
2. Parents of unmarried young people (15-25)	<ul style="list-style-type: none"> • Family • GPs (especially Asian GPs) • Thalassaemia counsellors • Marriage bureaus 	<ul style="list-style-type: none"> • Parents' groups including single-sex sessions, through schools, health centers, community centers, mosques/ temples/ gurdwaras/ churches with significant Chinese congregation 	<p style="text-align: center;">As above plus:</p> <ul style="list-style-type: none"> • Audio-Videos cassettes in community languages (Bengali, Gujarati, Hindi, Punjabi, Sylheti, Urdu, Cantonese) • Printed media through marriage

3. Elders	<ul style="list-style-type: none"> Family 	<ul style="list-style-type: none"> Designated group sessions at mosques/ temples/ gurdwaras & community centers Chinese National Healthy Living Centres (London, Manchester, Birmingham) 	bureaus, Asian grocers, sari shops, health centers, Asian videos shops <ul style="list-style-type: none"> South Asian newspapers (mainly read by men): Bangladeshi: Surma, Ntundin, Jonomat, Porthrika; Punjabi: Punjabi Times, Despardes; Pakistani: Eastern Eye, Pakistan News, Kashmir News, Daily Jung (Urdu) Cantonese newspapers
4. Community/ Faith Leaders	<ul style="list-style-type: none"> Individual advocacy meetings with Community Development workers and Thalassaemia counsellors and 	<ul style="list-style-type: none"> Umbrella Organisations Designated Seminars 	As above
5. Health Providers	<ul style="list-style-type: none"> Thalassaemia Counsellors 	<ul style="list-style-type: none"> Designated Seminars & Training Events 	<ul style="list-style-type: none"> Video cassettes
6. Community-Based Organisations		<ul style="list-style-type: none"> Designated Seminars & Training Events Engage as Partners in delivery of strategy 	<ul style="list-style-type: none"> National mail-outs of printed materials

APPENDIX TWO: Audience Segments & Communication Channels: Sickle Cell

Audiences	Channels		
	Interpersonal	Group/ Community Development	Mass Media
1. Young People (15-25)	<ul style="list-style-type: none"> • Family • Peers • School Nurses • University Health Advisors • Providers of Targeted Health/ Advice/ Welfare Services • Sickle Cell Counsellors • GPs • Family Planning Services 	<ul style="list-style-type: none"> • Schools (including supplementary schools) • Higher/ Further Education Institutions • Youth services/ youth clubs • Designated sessions in Health Centres • Social Services – Young people in care • Church youth groups/ conventions 	<ul style="list-style-type: none"> • Christian TV stations • Black & African radio stations: Choice, Premiere, Baseline (pirate), Power Gen (pirate), African Pirate stations • Black, African, Caribbean papers: The Voice, New Nations, Jamaican Gleaner, Caribbean Times, Barbados Weekend Nation, etc • Printed media & videos through Black Businesses: Hairdressing/ Barbing Salons, Foodshops, Restaurants, Taxi Firms • Printed media (outlets as per group channels)
2. Parents of unmarried young people (15-25)	<ul style="list-style-type: none"> • Family • GPs • Sickle Cell Counsellors • Family Planning Services 	<ul style="list-style-type: none"> • Parents' groups including single-sex sessions, through schools, health centers, community centers, Black-led churches, mosques with large Black/ African congregation, parents' organisations 	<p>As above plus:</p> <ul style="list-style-type: none"> • Audio-Videos cassettes in community languages (Somali, Luganda, Swahilli, French...)
3. Elders	<ul style="list-style-type: none"> • Family 	<ul style="list-style-type: none"> • Designated group sessions at Black-led/African churches/ mosques & community centres 	
4. Community/ Faith Leaders	<ul style="list-style-type: none"> • Individual advocacy meetings 	<ul style="list-style-type: none"> • Umbrella Organisations • Designated Seminars 	<ul style="list-style-type: none"> • N/A

5. Health Providers	<ul style="list-style-type: none"> • Thalassaemia Counsellors 	<ul style="list-style-type: none"> • Designated Seminars & Training Events 	<ul style="list-style-type: none"> • Video cassettes
6. Community-Based Organisations	<ul style="list-style-type: none"> • N/A 	<ul style="list-style-type: none"> • Designated Seminars & Training Events • Engage as Partners in delivery of strategy 	<ul style="list-style-type: none"> • N/A

APPENDIX THREE: Guidelines for Materials Development

1. For both sickle cell and thalassaemia, implementers need to ensure careful definition of audience segments and sub-segments, and thorough pre-testing, to ensure relevance of messages and images, and avoid causing offence or alienation of particular groups. Whilst the South Asian communities demonstrate greater heterogeneity in terms of languages and religious values, it is also important to acknowledge the special needs of the minority of the Black African community who are Muslim, or who have low literacy in English.
2. For African communities (first-generation and especially recent immigrants), use of traditional designs and pictures of men and women in traditional dress will help to stimulate recognition and a sense of personal relevance.
3. Reduce stigma associated with the conditions by using 'positive' framing:
 - Use comparative data to demonstrate the prevalence of different recessive genetic conditions in different populations (Cystic Fibrosis, Tay-Sachs, etc)
 - Highlight the selective advantage of carrier status in evolutionary terms²³
4. Ensuring that consistently good quality materials are produced will help to build trust by giving communities a sense of being valued.
5. Credibility may be jeopardized if messages are seen to be inconsistent.
6. Use 'true-life' characters and stories as much as possible: people speaking about their own condition can have a powerful impact. Submissions could be invited from users' groups for use in mass media campaigns.
7. Allow for local adaptation of nationally-developed materials, for instance by allowing space to print details of local services and contacts.
8. Availability of care services needs to be a prominent theme.
9. Messages should be seen to support community values and integrity by:
 - ◆ Encouraging intergenerational communication and respect for elders and parents (particularly important for the South Asian communities)
 - ◆ Promoting the principle of voluntary community service, and acknowledging contributions made by volunteers
 - ◆ Providing positive role models
10. Consider involvement of media figures as spokespersons, but be conscious of the boundaries of a particular personality's appeal.

²³ Evidence of psychological benefits for carriers who are given information about the evolutionary benefits of thalassaemia carrier status is presented in an unpublished paper by Karetti *et al* (see References)

11. Include simple facts & figures about prevalence, distribution, nature and inheritance of sickle cell/ thalassaemia, but avoid using clinical jargon, and don't overwhelm the audience with numerical/ technical information.

12. Always provide contact details for relevant services and sources of further information.

APPENDIX FOUR: Outline of Suggested Materials for Development

Notes:

1. A comprehensive survey of existing materials be conducted before developing any of the following from scratch.
2. All materials need to be rigorously pre-tested with sample audiences during development, and findings of this pre-testing thoroughly documented.

	Sickle Cell	Thalassaemia
1. TV	<p>Series of short vignettes on the theme of ‘a child is born (with sickle cell disorder)’, raising awareness of newborn screening programme. Could use a fantasy sequence of parent or grandparent imagining possible future life events, to introduce various variations on the theme of ‘what can this child expect in her/ his life’. Some of the children should have obviously African (first-generation) parents. Possible themes:</p> <ol style="list-style-type: none"> a) What care and support services are available for the child and her family b) Who is available as role models to show what people living with sickle cell disorders can achieve at different life stages c) What are the particular challenges s/ he may face (pain management, possibly interruption to schooling, etc) d) How the child’s community can 	<p>Series of short vignettes in community languages (to be shown on respective cable channels) treating major messages Possible storylines:</p> <ol style="list-style-type: none"> a) Challenges faced by a teenage girl living with thalassaemia with aspirations to go to university. b) Young man who is tested and discovers he is a thalassaemia carrier. Family members’ show a range of different responses to the news in the context of planning his forthcoming marriage. Eventually his parents agree to request that the intended wife be tested. c) Young married couple expecting their first child who are informed that they both carry the thalassaemia gene. <p><i>Note: the first two storylines would be suitable for development quite early on in strategy implementation, the last should await the</i></p>

	support her	<i>outcome of further community consultation with regards to antenatal screening.</i>
2. Radio	<p>In English and community languages as appropriate, based on Major themes (see Appendix 5, messages section)</p> <p>Could invite youth & user groups to develop jingles (based on prescribed themes) as a competition, and select the best for production.</p>	
3. Audio & video cassettes	<p>In English and appropriate community languages:</p> <p>Video versions of the tv vignettes, expanded to include additional technical information.</p> <p>Audio tapes – could be dramas followed by provision of simple factual information including how to access services and further information.</p> <p>Could invite youth & user groups to develop concepts for dramas (based on prescribed themes) as a competition, and select the best for production as videos.</p>	
4. Newspapers & magazines	<p>Need a mixture of features and advertisements, targeted to the different readership of different publications, but reflecting 4 major themes (appendix 5).</p>	

<p>5. Training packages for group work appropriate to range of different audiences (young people, parents, elders)</p>	<p>Content should include:</p> <ul style="list-style-type: none"> • basics of genetic inheritance • experiences of living with/ caring for someone with sickle cell/ thalassaemia • decision-making about testing and the implications of carrier status in different family/ cultural contexts • community responses and action-planning <p>Approaches should be participatory including role plays, small group discussions and presentations, etc</p>
<p>6. Posters & leaflets</p>	<p>In English/ community languages as appropriate, but with minimal text on posters. Don't overload leaflets with clinical information. Should be based on Major themes (see Appendix 5, messages section) For sickle cell, linked to newborn screening programme as appropriate.</p>
<p>5. Materials for genetic counselling with individuals, couples and families</p>	<p>Community languages; pictorial materials (with attention to Islamic sensibilities with regards to faces) for use with semi-literate and illiterate people.</p> <p>Translation of abstract genetic concepts is very complex process: suggest collaboration with Genetics Interest Group and NW Thames Regional Genetics Centre (see section 5: Recommendations), ensuring involvement of full range of stakeholders and expertise (including medical anthropologist/ linguist if possible).</p>

APPENDIX FIVE: Messages

The table below presents a series of messages grouped under four main themes:

Theme 1: Understanding the needs, capabilities and entitlements of people living with sickle cell disorders/ thalassaemia.

Theme 2: Sickle Cell/ Thalassaemia is an Issue for the (Ethnic Group) Community

Theme 3: Encouraging Young People to be tested

Theme 4: Encouraging Parents to support testing of young people (pre-marriage/ pre-conception)

These are preliminary suggestions based on the findings of this consultation and are intended only as a basis for further discussion. Clearly they will require extensive revision, refinement, adaptation (including translation where relevant) for different audience segments, and field-testing.

Themes	Sickle cell disorders	Thalassaemia
<p>Theme 1: Understanding the needs, capabilities and entitlements of people living with ...</p>	<ul style="list-style-type: none"> a) Sickle Cell is an unpredictable disorder and can cause a lot of pain and disability. b) People living with sickle cell don't need pity, they need respect, support and encouragement. c) With the right support, there is much they can achieve (education, career, marriage, children...). <p>Illustrate using real-life stories, featuring a range of individuals of different ages/ ethnicities/ gender.</p> <p>Provide information about special needs and entitlements – benefits, housing, education and employment.</p>	<ul style="list-style-type: none"> a) Thalassaemia is a challenging condition to manage. b) People living with thalassaemia don't need pity, they need respect, support and encouragement. c) With the right support, there is much they can achieve (education, career, marriage, children...) <p>Illustrate using real-life stories, featuring a range of individuals of different ages/ ethnicities/ gender.</p> <p>Provide information about special needs and entitlements – benefits, housing, education and employment.</p>

<p>Theme 2: Sickle Cell/ Thalassaemia is an Issue for the (Black/ African/ South Asian/ Indian/ Bangladeshi/ Pakistani/ Chinese) Community</p>	<p>X people in the UK are carriers of the sickle cell gene, including 1 in 10 people of Black Caribbean descent, and 1 in 4 people of West African descent.</p> <p>Include information about the evolutionary origins and advantage (protection against malaria) of the carrier state Z people in the Y community in the UK are living with sickle cell disorder.</p> <p>Sickle Cell is an unpredictable disorder and can cause a lot of pain and disability. The attitudes and actions of the wider community can make a difference to people living with sickle cell and their families: give positive and negative examples – highlight local community responses to the condition, eg development of respite services, educational support, mentoring, etc. Users’ groups and counsellors can be invited to submit local examples of successful community initiatives.</p>	<p>X% of the Y (ethnicity) community carry the gene for thalassaemia.</p> <p>Include information about the evolutionary origins and advantage (protection against malaria) of the carrier state Z people in the Y community in the UK are living with thalassaemia.</p> <p>Thalassaemia is a challenging condition to manage. The attitudes and actions of the wider community can make a difference to people living with thalassaemia and their families : give positive and negative examples – highlight local community responses to the condition, eg development of respite services, educational support, mentoring, etc. Users’ groups and counsellors can be invited to submit local examples of successful community initiatives.</p>
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<p>Theme 3: Encouraging Young People to be tested: 'It's good to know.'</p>	<p>Young Black people:</p> <p>Considering having children? Now, or in the future? If you know your sickle cell status, you are well equipped to plan your future and plan for healthy children. Get tested for the sickle cell gene NOW, before you start having children. If you have a serious partner, discuss the results with him or her. If you have sickle cell trait, there's nothing wrong with you. But if your partner also has the trait, there is a 1 in 4 chance that your child will have a sickle cell disorder.</p>	<p>Unmarried young people:</p> <p>If you know your thalassaemia status, you are well equipped to plan your future and plan for healthy children. Get tested for the thalassaemia gene <u>before you get married</u>, and discuss the results with your parents. If you're a thalassaemia carrier, there's nothing wrong with you. But if your future husband or wife also has the trait, there is a 1 in 4 chance that your child will have a sickle cell disorder.</p>
<p>Theme 4: Encouraging Parents to support testing of young people (pre- marriage/ pre- conception)</p>	<p>Could your grandchild's inheritance be sickle cell disorder?</p> <p>Don't inflict avoidable suffering on your unborn grandchildren and their parents. Encourage your son or daughter to be tested for the sickle cell gene before having children If s/he has sickle cell trait, your grandchildren may be at risk of inheriting sickle cell disorder. Encourage your son or daughter to ask their partner to be tested for sickle cell trait, BEFORE they start having children.</p>	<p>Could your grandchild's inheritance be thalassaemia?</p> <p>Don't inflict avoidable suffering on your unborn grandchildren and their parents. Ask for your son or daughter to be tested for the thalassaemia gene before marriage If s/he is a thalassaemia carrier, your grandchildren may be at risk of inheriting Beta-thalassaemia major. Ask for your child's intended husband or wife to be tested before finalizing the marriage.</p>

Appendix Six

Interview schedule COMMUNITY PERSPECTIVES ON SCREENING FOR SICKLE CELL DISORDERS

Introductions

Interview Questions:

1. Do you have any direct personal experience of sickle cell? If yes please describe.
Probe: Have you ever been close to anyone affected by this condition?
2. How would you describe your community's current level of awareness about sickle cell?
Probe for variation in level of awareness between different social groups in the community: gender, age, more recent immigrants, non-English speakers, etc.
3. How are individuals living with sickle cell perceived within the community?
4. Have there been any systematic efforts made to tell people in this particular community about sickle cell, either now or in the past?
5. If yes – please describe what was done and by whom. Do you think it was successful? Why or why not? How could it have been improved?
6. Have there been any systematic efforts made to tell people in this particular community about any other health issues, either now or in the past?
Prompt: smoking/ healthy eating/ HIV prevention/ asthma
7. If yes – please describe what was done and by whom. Do you think it was successful? Why or why not? How could it have been improved?

Interviewer briefly remind interviewee of the principles of genetic inheritance of sickle cell, and procedures for testing – including preconceptual, newborn, and antenatal (carrier screening/ foetal testing/ option of termination).
8. Is it good for individuals to be offered testing to know whether they carry the gene for sickle cell? Why/ Why not?
9. What should be the main aim of antenatal screening? *Or if interviewee does not support the principle of genetic testing at all: Would any of the following aims justify a programme of antenatal screening?*

- a) Advance diagnosis: Telling a couple during pregnancy if the woman is carrying a child with sickle cell disorder, so that the family, health and social services can prepare to provide the child with the best possible care after birth
 - b) Informed reproductive choice: Telling a couple during pregnancy if the woman is carrying a child with sickle cell disorder (after giving the options of carrier testing and foetal testing), and allowing the couple to choose whether they want to have the child or to terminate the pregnancy
 - c) Decrease the number of children born with sickle cell disorders
 - d) Any combination of the above – In which order of priority?
 - e) Any other aim
 - f) Don't support genetic testing at all.
10. At which stage in life should an individual or couple ideally be offered testing to learn if they carry the sickle cell gene? *Or if prenatal testing is not supported: Should individuals be tested to know if they are carriers before pregnancy, at any of the following stages?*
- Prompts:*
- a) At birth ⇒ if newborn is tested at what stage should s/he be informed if s/he is carrying the sickle cell gene?
 - b) School-age children
 - c) Adolescence/ reproductive age
 - d) When preparing for marriage
 - e) After marriage but before the woman is pregnant
 - f) After the woman is pregnant
 - g) Any combination of the above

Why is this stage/ these stages ideal?

11. Should the health services be providing information to community groups about sickle cell and genetic testing? If yes, which groups within the community should the health services be specifically aiming to reach with such information?
- Probe:* as well as those to be encouraged to come for testing, who else should be informed about screening issues?
12. What would be the most effective way to reach each target group with information?
- Prompts:*
- a) Written leaflets - which language/s? – distributed where? [GP surgeries/ local shops/ community centres/ religious centres]
 - b) Mainstream National press – which papers widely read?
 - c) Ethnic minority press – names of papers?
 - d) Television
 - e) Radio
 - f) Video or audio cassettes

- g) Community-Based Organisations – religious leaders/ other significant organisations (identify specific groups/ individuals)
 - h) Schools/ Colleges/ Universities
 - i) Counselling – by GP/ Pharmacist/ Religious leader/ Other
 - j) Other?
- Probe:* Should different channels be used to reach women and men? Different age groups? If so, which?
13. What barriers might prevent the following individuals from seeking genetic testing for sickle cell:
 - a) Young adult of marriageable age
 - b) Married couple preparing to have children
 - c) Married couple expecting their first child
 14. What would be the social implications for each of these categories of people to be diagnosed as a carrier of the sickle cell gene?
 15. How would a couple's family and the wider community react if:
 - a) A couple was tested before pregnancy and both were identified as carriers of the sickle cell gene. They then went on to give birth to a child with sickle cell.
 - b) A couple was tested during pregnancy and both were identified as carriers of the sickle cell gene. They were offered testing for the foetus at 11 weeks and they declined. They went on to give birth to a child with sickle cell.
 - c) A couple was tested during pregnancy and both were identified as carriers of the sickle cell gene. They accepted testing of the foetus at eleven weeks. This testing revealed that the foetus was affected by sickle cell. The couple decided to terminate the pregnancy during the third month.
 16. *Confirm information provided in response to question 3, and probe for further information:* Could you say a bit more about how people living with sickle cell are currently viewed in your community?
 17. In what ways might a major campaign to inform the community about screening for sickle cell affect public attitudes towards individuals living with this condition?
 18. Do you think more should be done to raise awareness about and provide support for individuals living with this condition? If yes, what should be done, and by whom?
Prompt: Community organisations/ voluntary sector/ national government/ council/ health authority

19. This research may lead on to a larger community consultation before plans are finalised for a major information campaign for sickle cell screening. Which individuals, groups and organisations in this community would you recommend should be consulted in future?
20. Beyond consultation in the planning stages, how would you suggest that health services could continue to involve community representatives in the screening programme?
21. Do you have any questions you would like to ask, or any other comments to make on this issue?

Appendix Seven: Steering Committee Membership

CHAIR/ LAY MEMBER

The Right Reverend Dr John Sentamu
PROFESSIONAL ORGANISATIONS

Bishop of Birmingham

Professor Elizabeth Anionwu

National Screening Committee - Antenatal Subgroup
Director of Midwifery Affairs - Royal College of Midwives

Dr Phil Darbyshire

Consultant Paediatric Haematologist, Birmingham

Ms Joan Henthorn

Head of Laboratories, London

Dr Tracey Johnston

Obstetrician, Manchester

Ms Gulsan Karbani

Genetic Counsellor/ Research Fellow, Leeds

Ms Ann Kennefick

Heart of Birmingham PCT

Professor Theresa Marteau

National Screening Committee - Child Health Subgroup

Ms Lola Oni

Nurse Director /Lecturer, London

Dr David Rees

Consultant Haematologist, London

Professor Neva Haites

Clinical Genetics Service, Aberdeen

Dr Beatrix Wonke

UK Haemoglobinopathy Forum

Dr Moira Dick

UK Haemoglobinopathy Forum

VOLUNTARY SECTOR

Ms Janet Campbell

Sickle Cell Society

Mr George Constantinou

United Kingdom Thalassaemia Society

USERS/ PATIENT REPRESENTATIVES

Mrs Sonoo Malkani

Patient Representative Thalassaemia

Ms Carol Nwosu

Patient Representative Sickle Cell

Mrs Zanib Rasul

Patient Representative Thalassaemia

EXPERT ADVISORS

Professor Sally Davies

Director of R & D NHS London Region

Dr Jane Logan

General Practitioner, London

Professor Bernadette Modell

Emeritus Professor of Community Genetics, London

Dr John Old

Clinical Scientist, Oxford

OBSERVERS

Mrs Margaret Boyle	DoH Social Services & Public Policy, Northern Ireland
Ms Rosemary Johnson	Wales Antenatal Screening Project
Dr Rosalind Skinner	Scottish Executive

Appendix Eight: Consultant's terms of reference

Aim: Support the development of a strategy to raise public awareness, generate demand, and increase acceptability and uptake of haemoglobinopathy screening services, through analysis of secondary data and preliminary consultation with stakeholders.

Objectives

1. Develop a framework to inform the planning and delivery of a relevant, acceptable and accessible multi-media Information-Education-Communication (IEC) campaign to raise awareness and increase demand for haemoglobinopathy screening services
2. Make recommendations on approaches and opportunities for increasing voluntary sector and service user engagement in the development and delivery of an awareness campaign for haemoglobinopathy screening, with implications for haemoglobinopathy services generally.

Specific tasks

1. Undertake a rapid review of published and unpublished data on previous and current UK-based health service information campaigns targeting specific minority ethnic populations, and extract relevant lessons learned.
2. Identify useful sources of secondary data to inform the mapping of target populations (nationally and if possible regionally), including:
 - estimated size and demographic profile of specific minority ethnic populations
 - main written and spoken languages
 - literacy levels
 - appropriate channels and media for communication, including existing community networks
 - cultural (including religious) values and issues of relevance in developing content of messages
 - community-based networks, organizations, and individuals who could champion increased participation in the development and delivery of haemoglobinopathy services by service users and the voluntary sector
3. Work with the voluntary sector and haemoglobinopathy counsellors to conduct informal interviews with a selection of stakeholders, including service users, voluntary sector representatives, and religious and community leaders, to further investigate and validate issues raised in the review of interventions and regional mapping of target groups.
4. Produce a report containing specific recommendations for the detailed planning and implementation of the awareness campaign, including:
 - An analysis of major issues to be considered in the development and testing of relevant and acceptable messages and approaches
 - Sampling frame for wider consultation and pilot testing of messages, based on mapping of target populations and major issues identified
 - Specific recommendations for strengthening consumer involvement in programme development and delivery, including a list of key community stakeholders

Appendix Nine: Useful resources & contacts

This is not an exhaustive list, just some suggested starting points based on information gathered during the course of this consultancy.

1. HIV Prevention with African Communities

National AIDS Trust (2001) HIV Prevention and African Communities Living in England: A Framework for Action (Final Draft)

Bhatt C, Phellas C, Pozniak A (2000) National African HIV Prevention Projects: Evaluation Report Enfield & Haringey Health Authority

2. African Health Forum

Useful model for coordination and participation of Community-Based Organisations collaborating with Strategic Health Authority and Primary Care Trusts. Offers capacity building and training, small grants scheme, support for networking, development and dissemination of resources, etc.

Contact: Joseph Edem-Hotah, Programme Manager (African Communities)
Health First
Mary Sheridan House
15 St Thomas St
London SE1 9RY
Tel: 020 79554366 x4678

3. NHS Asian Tobacco Campaign

Evaluation report available June 2002

Caroline MaCaulay
Campaigns Manager
Tobacco Information Team
Department of Health
Tel 020 7972 5270
Email: caroline.macaulay@doh.gsi.gov.uk

4. Chinese National Healthy Living Centre

Contact: Eddie Chan, Director
29/30 Soho Square
London W1D 3QS
Tel 020 7287 0904/ 7534 6546
Email: general @cnhlc.org.uk
Web: www.cnhlc.org.uk

5. Naz Project (HIV, AIDS and sexual health services for South Asian, Middle Eastern, North African, Horn of Africa and Latin American communities)

Contact: Parminder Sekhon
Palingswick House
241 King St
London W6 9LP
Tel: 020 8741 1879
Email: naz@naz.org.uk
Web: www.naz.org.uk

6. Working with Faith-Based Organisations

King's Fund workshop report: Building Partnerships: Black Majority Churches and Mental Health Services, 11 January 2001
Organiser: Angela Greatley

Second workshop with South Asian Faith-based Leaders planned for August 2002, would be useful to get report.

Also project in the Dept of Health on Teenage Pregnancy, which is producing a report about collaboration with faith-based organisations:

INSERT DETAILS (*Allison unsure of details –SA*)

7. Asian voluntary sector groups active on Disability issues

Asian Disability Network
PO Box 432
Bradford BD5 8YA
Tel: 01274-224-444
Email: adnbradford@hotmail.com
Web: www.asiandisability.net

Parvaaz: Young People with Disabilities
Slough, Berkshire
Tel. 01753-539-642

Michael Jeewa, Director
Asian People with Disability Alliance (London)
Tel/ fax 0208-961-6773

References

Ahmad, WIU (1995) Consanguinity and related demons: Science and racism in the debate on consanguinity and birth outcome in Samson C and South N (eds) The Social Construction of Social Policy London: Macmillan

Anionwu EN and Atkin K (2001) The Politics of Sickle Cell and Thalassaemia Buckingham: Open University Press

Atkin K and Ahmad WIU (1997) Genetic Screening and Haemoglobinopathies: Ethnicity, politics and practice Social Science and Medicine 46 (3), 445-458

Atkin K, Ahmad WIU and Anionwu EN (1998) Screening and Counselling for Sickle Cell disorders and Thalassaemia: The Experience of Parents and Health Professionals Social Science and Medicine 47 (11), 1639-1651

Bradby H (1996) Genetics and Racism in Marteau T and Richards M (eds) The troubled helix: Social and psychological implications of the new human genetics Cambridge University Press

Conrad P and Gabe J (1999) Sociological perspectives on the new genetics: an overview Sociology of Health & Illness 21 (5): 505-516

Darr A (1990) The social implications of thalassaemia among Muslims of Pakistani origin in England – family experience and service delivery PhD thesis, University College, University of London

Darr A (1997) Consanguineous Marriage and Genetics: A Positive Relationship in Clarke A and Parsons E (eds) Culture, Kinship and Genes – Towards Cross-Cultural Genetics London: Macmillan

Darr A (1999) Access to Genetic Services by Minority Ethnic Populations: a pilot study London: Genetic Interest Group

Davies SC, Cronin E, Gill M, Greengross P, Hickman M, Normand C (2000) Screening for sickle cell disease and thalassaemia: a systematic review with supplementary research Health Technology Assessment 4 (3)

Elam G, McMunn A and Nazroo J (2001) Feasibility Study for Health Surveys Among Black African People Living in England prepared by the Joint Health Surveys Unit, University College London and National Centre for Social Research for the Department of Health

Elton P (2000) Screening Teenagers in some communities to prevent occurrence of a condition (letter) BMJ 6th June 2000

Gill PS and Modell B (1998) Thalassaemia in Britain: a tale of two communities (editorial) BMJ 317: 761-2

Green JM (1992) Principles and practicalities of carrier screening: Attitudes of recent parents Journal of Medical Genetics 29: 313-319

Green J and Statham H (1996) Psychosocial aspects of prenatal screening and diagnosis in Marteau T and Richards M (eds) The troubled helix: Social and psychological implications of the new human genetics Cambridge University Press

Health Education Authority (2000) Black and Minority Ethnic Groups in England: The Second Health & Lifestyles Survey London: HEA

Karetti M, Ferguson M, Yardumian A and Modell B (unpublished paper) Detecting carriers of beta thalassaemia: giving the good news (Contact: Professor Modell, Royal Free and University College Medical School, Dept of Primary Care and Population Sciences)

Kingsley S (2000) The NHS Plan – Opportunities for improving health and access to health services for black and minority ethnic populations Department of Health website

Lakhani, N (1999) Thalassaemia Society is working to improve awareness (letter) BMJ 318: 873

Lippman A (1991) Prenatal genetic testing and screening: constructing needs and reinforcing inequities American Journal of Law and Medicine 17: 15-50

Mitchell JJ, Capua A, Clow C, Scriver CR (1996) Twenty-year outcome analysis of genetic screening programs for Tay-Sachs and beta-thalassaemia disease carriers in high schools American Journal of Human Genetics 59 (4): 793-798, Oct 1996

Modell B and Darr A (2002) Genetic counselling and customary consanguineous marriage Nature Reviews: Genetics Vol 13, March 2002: 225-229

Modood T, Berthoud R, Lakey J, Nazroo J, Smith P, Virdee S, Beishon S (1997) Ethnic Minorities in Britain: Diversity and Disadvantage London: Policy Studies Institute

National AIDS Trust (for the African HIV Strategy Development Project) HIV Prevention and African Communities Living in England: A Framework for Action Pre-publication final draft Oct 2001. Funded by the Department of Health and London HIV Commissioners

National Institute for Ethnic Studies in Health and Social Policy (1997) Ethnic Diversity in England and Wales: An Analysis by Health Authorities based on the 1991 Census Department of Health

Nazroo J (1997) The Health of Britain's Ethnic Minorities: findings from a national survey London: Policy Studies Institute. Cited in Modood T, Berthoud R, Lakey J, Nazroo J, Smith P, Virdee S, Beishon S (1997) Ethnic Minorities in Britain: Diversity and Disadvantage London: Policy Studies Institute

Piotrow PT, Kincaid DL, Rimon JG, Rinehart W (1997) Health Communication: Lessons from Family Planning and Reproductive Health Westport: Praeger

Shakespeare T (1995) Back to the future? New genetics and disabled people Social Policy 46: 22-35

Shakespeare T (1999) Losing the plot? Medical and activist discourses of contemporary genetics and disability Sociology of Health & Illness 21 (5): 669-688

Streetly A, Maxwell K, Mejia A (1997) Fair Shares for London Report: Sickle Cell Disorders in Greater London – A needs assessment of screening and care services London: United Medical and Dental Schools, St Thomas's Hospital

Streetly A (2000) A national screening policy for sickle cell disease and thalassaemia major for the United Kingdom (editorial) BMJ 320: 1353-1354

United Kingdom Thalassaemia Society (2002) Thalassaemia Asian Awareness Campaign: Report of a three year campaign 1997-2000 London: UKTS

Williams C, Alderson P, and Farsides B (2002) 'Drawing the line' in prenatal screening and testing: health practitioners' discussions Health Risk & Society 4 (1): 61-75