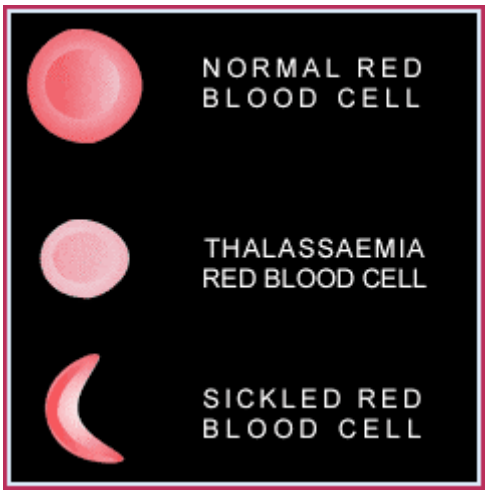
Sickle cell and thalassaemia in Sheffield

Final Report

Executive Summary



Julia Keenan

Department of Geography

University of Sheffield

Sheffield Sickle Cell & Thalassaemia Foundation

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

The University Of Sheffield.

Sickle cell and thalassaemia in Sheffield

Julia Keenan, Dept. of Geography, University of Sheffield

Contents

List of abbreviations

SSCAT	(The) Sheffield Sickle Cell and Thalassaemia (Foundation)
ERSC	(The) Economic and Social Research Council
CVS	(The) Community Voluntary Sector
PCT	Primary Care Trust
DoH	Department of Health

Sickle cell and thalassaemia in Sheffield

1. Introduction

This summary documents the findings from a collaborative research project into the experiences of people in Sheffield living with, 'carrying' or seen to be 'at risk' from the inherited blood 'disorders': sickle cell and thalassaemia and the service provision for such individuals and families. The research was conducted as part of a Ph.D research studentship and has been funded by the Economic and Social Research Council (ESRC) and The Sheffield Sickle Cell and Thalassaemia Foundation (SSCAT Foundation) under the ESRC 'CASE Award' programme.

This summary draws upon data collected in 2004-2005 and highlights the main findings of the research as well as making recommendations.

1.1 About the conditions

Sickle cell and thalassaemia are inherited blood conditions[1]. Red blood cells are usually round in shape. For those with a sickle cell disorder, these cells become a sickle or half-moon in shape under certain conditions. When this happens, these cells can get stuck in blood vessels and cause excruciating pain; this 'crisis' is often seen to define the condition. People with sickle cell disorders are also more likely to get infections and to experience problems of anaemia, organ damage and complications such as stroke. Those born with thalassaemia major have a reduced number of red blood cells and can experience fatal anaemia unless they receive regular monthly blood transfusions and undertake almost daily chelation therapy to remove the excess of iron in the blood built up as a result of repeated transfusions. Issues of compliance feature strongly in the narratives of those living with thalassaemia. Early diagnosis is vital for treatment of these conditions[2].

For evolutionary reasons, genes for sickle cell disorders are most prevalent amongst African-Caribbean and Western African ethnic origin groups and those for thalassaemia in Cypriots, South Asian, Chinese, and also amongst African-Caribbean people but actually ***can occur in any population***. This group of conditions follow a pattern of inheritance[3]. You must inherit two 'abnormal' genes (one from each parent) to have a condition. 'Carrying' one gene, or a *trait*, is medically understood to have no negative impact upon health. This is significant in terms of public health because unless tested, those 'at risk' who carry a trait could partner and have an affected child.

Evolutionary mechanisms and various geographical migrations explain why different UK population groups show genetic differences, but cannot fully account for the fact that persons living with the same genetic conditions in different places have differing experiences and accounts of health. Something else is going on and clearly, both ***where you live*** and the ***circumstances under which you live*** matter greatly.

---

[1] With this group of conditions (haemoglobinopathies) it is the alpha and beta haemoglobin genes of red blood cells which are different. There are therefore many different gene variants that can lead to clinical conditions and thus many different types of haemoglobinopathies. Traits for sickling disorders and thalassaemias can also combine e.g. sickle beta thalassaemia.

[2] Without treatment, those with thalassaemia die before the age of two years and up to 30% of deaths of those with a sickle cell disorders occur before diagnosis (Midence & Elander, 1994).

[3] This pattern is called autosomal recessive and is the same as for haemophilia and cystic fibrosis.

1.2 Study focus

This research explored how individuals, families and communities in Sheffield respond to a variety of policies which encourage them to take responsibility for the genetic, medical and social risks and uncertainties associated with sickle cell and thalassaemia by educating themselves and making accordingly 'informed choices'. Such active engagements are commonly understood to empower both individuals and communities. With its specific geographical focus upon Sheffield, research such as this is able to analyse how larger scale changes in the governance of health work out in and through place.

1.3 Methods

The programme of research designed adopts predominantly qualitative methods, as such methods are capable of investigating context and meaning and producing place and subject-centred analyses of dimensions of health and health care. Qualitative approaches also allow greater sensitivity to non-biomedical or alternative 'ways of knowing' about health that people might have, and to the politics of research and relations of power.

A postal questionnaire survey (59 responses) provided initial background information describing the demographics of the Sheffield population living with or carrying these conditions, as well as their basic service needs and usage. 13 of these individuals or households then took part in one or more in-depth, tape recorded interviews. Recruitment of individuals and households was purposive, based on identifying information rich households willing to discuss the research topics. Research findings presented are thus illustrative and broadly representative as opposed to being statistically representative. The aim was to recruit households affected by a variety of haemoglobinopathies which would show a balance and variety in household form and composition, to include those households with members living with the condition, those with carriers only etc. Reflecting the broader Sheffield demographic, most of those living with thalassaemia are under 16 years old and most of those with sickle cell in the 36-45 years age range.

Many of the issues or concerns voiced in individual or household interviews were then incorporated into interview schedules to be discussed with 21 health or social care professionals. Over this same period, participant observation was undertaken at 13 local events where the SSCAT Foundation was represented, to engage with the public and/or professionals to raise awareness and distribute materials about these conditions. Content analysis of these materials was also undertaken, and informs the overall analysis presented here.

Standard NHS Ethics and Governance procedures were adhered to with ethical permission granted from the South Sheffield Medical Ethics Committee (SSREC/03/196) and research conducted under the governance of The Sheffield Health and Social Research Consortium.

2. The Sheffield context

Sickle cell and thalassaemia are the most common genetic conditions in the UK[4]. Despite their prevalence, in research and policy terms these conditions and the issues surrounding them, have been ***repeatedly sidelined, under-resourced and ignored*** (see Anionwu & Atkin, 2001). Awareness and understanding of haemoglobinopathies is poor amongst the general public, but also amongst service providers of health, education and other forms of social support (Royal College of Physicians, 1989). Coupled with the fact that those living with the haemoglobinopathies do not always display symptoms which mark them as having a chronic condition, it is not unsurprising to learn that ***these conditions and needs those living with them (and their carers) are often described as being invisible***.

Perhaps the main reason, however, that haemoglobinopathies are ignored in the UK is because these conditions predominantly affect Black and ethnic minority communities and have become racialised. The politics surrounding sickle cell and thalassaemia suggests that it is ***institutional racism which keeps these issues off health and social care agendas*** (Anionwu & Atkin, 2001; Dyson, 2005).

Although 20% of all children born with a major haemoglobin disorder are born outside major UK conurbations associated with the residency of many minority ethnic groups within the UK (Modell & Anionwu, 1996), approximately two-thirds of those with a haemoglobinopathy in the UK live in Greater London. ***In Greater London, longer established services exist and are generally better integrated and more responsive to community needs than elsewhere.***

There are thought to be anywhere between 70-160 people living with a haemoglobinopathy in Sheffield[5]. Within the context of Sheffield Haematology Departments ***the current case load for haemoglobinopathies (including expanding laboratory screening) is seen to be growing, but small.*** Adult hospital provision is described as being *'piggy backed'* (Medical service provider, 2/12/04) onto general haematology services, as opposed to being a discrete, specialised unit. A report in 1995, by Bingham, concluded that although Sheffield was deemed to have service needs equivalent to Leicester, Nottingham and Southern Derbyshire, all these cites had more developed services, however the ***arrival of asylum seekers and refugees*** in the region in more recent years[6] will increase numbers affected or 'at risk'.

Despite the acknowledged importance of groups, like the SCCAT Foundation, in providing culturally appropriate services for individuals and families affected by sickle cell and thalassaemia (Anionwu & Atkin 2001:112), some individuals working within mainstream service provision viewed the early activities of the SSCAT Foundation (in the late 1980s and 1990s) negatively. The SSCAT Foundation battled to establish itself and gain funding (Registered Charity & Registered Company) and at the time of writing provides support to c.50 people living with these conditions (out of

[4] Recent estimates suggest that around 12,500 people currently have some sort of sickle cell disorder in the UK (Streetly *et al.*, 1997), and this is expected to rise above 15,000 by 2010. Beta thalassaemia also currently affects around 750 UK citizens (Modell *et al.*, 2000).

[5] This figure is difficult to accurately assess because not all of those affected (by a sickle cell disorder) will access mainstream services.

[6] Sheffield, as part of the Yorkshire and Humber Consortium, has become a major centre for the settlement of asylum seekers under NASS, second only to Leeds (Home Office, 2006:31)

a total of between 70-160) and is better connected with mainstream services. Initially funded by The National Lottery in 1997, this client-centred service is now predominantly funded by the Sheffield NHS Primary Care Trust.

With regards to public health and those seen to be at greatest risk, Black and minority ethnic groups account for a growing percentage of the Sheffield population (currently 8.8%) (2001 Census) and most of the ethnic groups seen to be at greatest risk from these conditions are represented in Sheffield. Of particular significance is the increase in local and national population of those identifying as being of a mixed ethnic group, as this may affect how they interpret information targeted at them regarding genetic risk. This group is also relatively young e.g. the White and Black Caribbean group has an average age of only 16 (Sheffield City Council, 2003). In South Yorkshire it is estimated that the percentage per annum of pregnant women carrying significant haemoglobinopathy variants is 1%. The estimated total number of conceptions per annum with sickle cell disorders is 2 and the number of conceptions per annum with beta thalassaemia is 1 (NHS Sickle Cell and Thalassaemia Screening Programme, 2004). ***Sheffield has a growing 'at risk' population with respect to genetic ancestry, which shows an increasingly strong diversity in terms of ethnicity, culture and mobility*** (see also Keenan, 2004).

3. Policy context for the study

Changes in four areas of policy are particularly as relevant to the politics of service provision for sickle cell and thalassaemia, and the experiences of people in Sheffield.

3.1 The NHS screening programme for sickle cell and thalassaemia

Current testing and screening technologies in England have not been the result of public health initiatives by the NHS, but sought through long-fought community action beginning in the 1980s. The *governmental commitment* to improve service provision in England finally came in the 2000 'NHS Plan', to develop '…effective and appropriate screening programmes for women and children including a new national linked antenatal and neonatal screening programme for haemoglobinopathy and sickle cell disease by 2004' (DoH, 2000:109). During the course of this research (2002-2006), this long-awaited national NHS Sickle & Thalassaemia Screening Programme has been 'rolled out' across England. In the antenatal setting, sickle cell and thalassaemia screening is now offered to all pregnant women as an integral part of early antenatal care (in the first trimester). All newborn babies born in England, irrespective of the ethnic origins of their biological parents, will be routinely offered testing for sickle cell as an integral part of the newborn bloodspot screening programme. In line with other recessively inherited conditions, the current emphasis is firmly upon professionals providing information and non-directed counselling to enable 'informed decision making' and 'reproductive choice'. As well as identifying babies who will require vital early treatment and care, screening will also identify carriers of sickle cell disorders and some carriers of thalassaemia, who should then be given information about this. A new post of haemoglobinopathies nurse counsellor has been created to help implement these changes in Sheffield[7].

[7] Sheffield PCT will need to find funding for this post after the central funding associated with implementing this policy ends.

Basic screening technologies for the identification of these genes have been available (in an 'ad hoc' way) since the 1970s, but what is 'new', here is the expanded, universal scope of the screening tests, requirements for their more formalised co-ordination, their technical ability to identify many haemoglobin variants and the commitment to providing adequate counselling. Individuals and families in England should now have access to technologies, expert knowledge and services which support carrier testing and informed reproductive decision making, however service delivery models and professional responsibilities in relation to these commitments can vary between regional health authorities.

Communicating risks, genetic and/or lifestyle risks, is now a key strategy in preventative public health. We read daily newspaper headlines about studies that show the risks that certain lifestyles and genes might have on our health. Such understandings can alter both strategies for life planning and expectations and obligations surrounding risk management and the prevention of illness. Some critics argue that many public health campaigns can champion individual self control rather than attending to the structural causes of ill health and health inequalities (such as poverty and racism) and how over-emphasising individual behaviours or 'choices' can generate strong cultural pressures to pass judgements on others. Although increased freedom to choose has a strong positive value within Western cultures, it also entails psychological costs such as elevated anxiety and guilt about making the right choices (Marteau, 1991; Lippman, 1992). The wider emphasis upon notions of individual choice and informed consent within debates around the new genetics also masks the fact that strong cultural pressures exist to make particular decisions. As such, despite the promise of alleviating pain and suffering, genetic testing is feared by some, as it could slowly lead to disability genocide.

3.2 Integrating services and promoting self-care in managing long-term conditions

The cost of providing care for long-term conditions can be high in an ageing population. Further to this, and building on what it terms 'examples of local excellence' the Department of Health has put forward an *NHS and Social Care Model to support local innovation and integration* (2005). This model essentially entails identifying and stratifying patients with long term conditions to match the intensity of their care to their different ascribed needs, to avoid health deterioration and emergencies and keep patients out of hospital. This model looks towards developing health and social care partnerships responsive to local needs. It also places increasing significance on promoting heightened vigilance amongst those with long-term conditions (especially those with lower level needs) towards self-care.

One of the ways, for example, in which health and social care organisations should support self care, involves 'enabling' and 'empowering' patients and their carers 'for example by implementing self monitoring or providing supporting prompts and reminders for patients to identify when they should be doing something and attending for care' (DoH, 2005:30). This model also highlights the benefits of encouraging patients to participate in community programmes, to form self-care support networks to provide peer support to one another and to inform local planning and service delivery through schemes such as the Expert Patient Programme (DoH, 2001). But to what extent do people feel able, obliged or motivated to take such responsibility for managing their own health and wellbeing?

3.3 Forging local partnerships

At the same time that the new genetics is profoundly shaping reproductive choices, and individuals being encouraged to take an active role in managing long-term conditions, the health and linked welfare needs of such people are increasingly seen to be best met by local partnerships between the state and the CVS.

The UK government has begun to acknowledge the vital role that the CVS plays in maintaining the health and well being of those specific community and client group whose interests it represents and serves. Indeed, the CVS and carers save the NHS a great deal of money. There has been a shift to promote the role of the CVS in contributing to health service planning and delivery (DoH, 2004), as part of a wider agenda to make available a choice of services for health care 'consumers' (including the private sector). A commitment to partnership between the government and CVS was made in England and the devolved nations through the development of a series of Compact Agreements (Home Office, 1998). These compacts seek to provide the principles for a working relationship and to impose certain uniform standards, but what room does this leave for creativity in this sector? What limits, or managerial cultures does it impose on what were traditionally more grassroots organisations?

Universal screening will lead to an increase in the number of newly identified carriers potentially requesting support and information. The ability of the SSCAT Foundation to stretch its annual budget and continue to meet the needs of its client base has also been tested somewhat by the additional demands of asylum seekers and refugees arriving in the region.

3.4 Entitlements of asylum seekers

Before the Immigration and Asylum Act of 1999, nearly all asylum seekers were confined to London and the South-East of England. More recently, under dispersal systems, people from a wide range of countries have been relocated to the regions. There are no statistics available on the exact numbers of asylum seekers and refugees in Sheffield, although there are undoubtedly recent flows of populations 'at risk' of these disorders settling here[8].

There has been a recognised 'learning curve' for health and social care providers in these areas, in how to deal with the needs of asylum seekers, who do not create new problems, but rather expose existing weaknesses in healthcare provision. As Johnson (2003:4) notes, healthcare providers are often unsure how asylum relates to healthcare entitlements. There are a number of rules concerning who can receive what NHS services, at what cost and for how long, however the voluntary and community sector, and many other public services, have not been given additional resources to enable them to work effectively with this new and vulnerable client group (Wilson, 2002).

[8] Most surveys, including the Census, do not collect information on immigration status; therefore disaggregating this population from other residents is difficult. The publicly available data on the asylum seeking population relate only to those asylum seekers supported by NASS, therefore the exact numbers of asylum seekers in the regions are not known.

4. Key Findings

4.1 Genetic testing: attitudes and experiences towards knowing the risks

- Although welcomed, the new national, universal screening programme continues to disproportionately target pregnant women. This reduces both options in reproductive decision making that exist before pregnancy, and undermines men's rights as potential fathers.
- Current awareness raising materials in circulation do not fully acknowledge any potential negative consequences of testing, and presume values of freedom and autonomy in decision making to be universal.
- That people have a right 'not to know' their genetic identity is not acknowledged in awareness raising materials.
- GPs are currently best positioned to offer tests to identify carriers at an age which will allow full reproductive choice, but there have been problems reported in gaining informed consent and providing information and support, which remain only partially addressed.
- The popular simplification of haemoglobinopathies as sickling disorders and thalassaemias can cause problems in understanding genetic risk for those families affected by both variants.
- Research participants' understandings of these conditions and their inheritance pattern are broadly in line with those of Western biomedicine, but alternative understandings of genetics, inheritance and the clinical impact of these conditions exist which could affect interpretations of genetic risk.
- There is a strong belief amongst female carriers interviewed, that they suffer diluted effects of these conditions, and that these effects remain un-researched and are often dismissed by haematology staff and GPs.
- Some people report having experienced stigma associated with their being a carrier.
- The SSCAT Foundation has played an important role in addressing past deficits in statutory service provision regarding genetic counselling.

4.2 The perceived duty to do the ‘right’ thing

- In telling other relatives that might be affected by these conditions, some participants say that they would have found family (cascade) screening helpful as part of their diagnosis, to make this process easier. This service, run by a specialist genetics services, was not generally made available in Sheffield at the time of this research, although was available to families affected by other recessively inherited conditions.
- For those participants who had decided not to risk having children because they might suffers from a haemoglobinopathy, this was sometimes based upon inaccurate or incomplete understandings of inheritance risks, and was therefore not a fully informed choice.
- No participant demonstrated an awareness of new techniques of PGD (Pre-implantation Genetic Diagnostics) and the possibilities this technique presents to select an unaffected fertilised egg for implantation, should this be ethically acceptable.
- There is some evidence of routinisation of screening in antenatal and neonatal settings, with women and parents being offered and agreeing to tests without full consideration, which will be difficult to ever fully eliminate.
- The three households interviewed who had experience of being counselled through an ‘at risk’ pregnancy in Sheffield had very different accounts of this. There have been serious failings in past service provision, but the household with the most recent experience reported no complaints.
- A few participants had questioned both the accuracy of screening tests and health professionals’ knowledge and ability to accurately represent living with these conditions when a pregnancy is ‘at risk’, although professional delineations of responsibility for these matters have recently been addressed.
- Key service providers interviewed were careful to avoid stereotyping and showed awareness of the fluidity of religious or cultural practices and attitudes towards screening and termination, although no midwives were interviewed for this study.

4.3 Care of the self: managing risk and uncertainties in medical care when living with a red cell disorder

- Because of differing degrees of reliance upon them, those living with sickle cell are more able than those with thalassaemia to actively engage with the risks and uncertainties posed by blood transfusions.
- Many of those living with sickle cell feel there is often little that they can actually *actively do* to predict a crisis occurring or to limit its severity.
- Those with sickle cell are considered by some health professionals not to know enough about their condition to actively manage their health.
- Research participants reported no complaints regarding procedures for quickly accessing pain relief. Although not fully representative, this is positive.
- As found in previous research, the responses to chelation therapy of individuals with thalassaemia are constantly shifting, although not necessarily unpredictable, ways. Support given for self-management acknowledges this but necessitates close, secure relationships.
- Good, trusting relationships with specialist consultants and particularly with specialist nurses (within children's services) exist. These are highly valued, but patients and families feel vulnerable because of their dependence on such a few specialists, and do not believe there is enough research being done to find better treatments and cures for these conditions.
- Interviews with nursing staff highlight the potential for patients to encounter less-experienced care because of low admissions, and other training priorities within haematology nursing.
- Flexibility has been shown in transfer arrangements of patients between children's and adults' services, but for those with thalassaemia this can be a trying time and there is perceived to be less nursing knowledge and care shown towards them by hospitals within adult than in children's services. The continuity of care provided by the SSCAT Foundation has played a key role in supporting clients through this process.
- Hospital patients who are also clients of the SSCAT Foundation strongly value the support they receive from this organisation to manage their health and well being.

4.4 Partnership working: meeting the health and welfare needs of local communities

- Some people living with a sickle cell disorder have not disclosed their condition to employers because of concerns about being seen, or treated, differently to others.
- Some participants with a sickle cell disorder struggle to gain appropriate employment on account of their condition, and/or because of their asylum/refugee status.
- The ignorance of educators can exacerbate the consequences of their illness for those with sickle cell disorders.
- Some are concerned that Disability Living Allowance, as not specifically designed for people with these conditions, can leave them inadequately supported and/or undermine their coping abilities through encouraging patients to adopt a disabled role.
- There are difficulties regarding the use of public funds to help those who have been refused asylum appeals, which poses an ethical dilemma to service providers.
- Medical professionals recognise that the SSCAT Foundation has a distinct and valuable role in maintaining and improving the wellbeing of patients and carers, although responsibility for patient care is rarely expressed in terms of being an equal partnership.
- There is no established system of referral from the hospital to the SSCAT Foundation, significant numbers of participants with a sickle cell disorder were not aware of the SSCAT Foundation, of what it does and how it is valued by its clients.

Table 1: The perceived level of support provided by the SSCAT Foundation as reported in questionnaire survey

	Frequency	Percentage
Excellent	11	40.7%
Good	10	37.0%
Satisfactory	5	18.5%
Poor	1	3.7%
Total	59	100.0

5. Conclusions

The new universal screening programme is welcomed. Despite the potential for stigma when identified as a carrier, there is little principled resistance amongst those with haemoglobinopathy gene(s) towards being offered screening. Indeed past and current failings in service provision to provide accurate or complete information, or support mean that participants in this research believe they have a *right* to this. The emphasis upon notions of individual choice and informed consent within screening, however, can mask that strong cultural pressures exist to make particular decisions. For those whose pregnancy is 'at risk', their autonomy to make reproductive decisions is shaped by normalising pressures of a wider society that is still inequitable, prejudiced and discriminatory. Decision making of 'informed choices' in this study have been influenced by inaccurate descriptions of the clinical conditions, and policed by comments made by family members which showed less sympathy for those whose families where a child's illness was seen to be 'preventable'. The social and economic strains of having a child within the wider context of structural inequalities, expectations of standards of living and the uncertainty of employment, state stability and health/welfare provision were also found to influence choices.

Those living with a blood disorder feel more able to take control of some aspects of their medical care more than for other areas, and have various ways of coping with the risks and uncertainties of their medical care treatment. People can, however, become disengaged from actively managing their health when they see that little is being done to find better treatments, or a cure for these racialised conditions.

It is sometimes a challenge to maintain the sense of collective identity and solidarity required for community action, particularly when numbers affected are low and people have been disenfranchised. Commitment to community participation can also change throughout the course of life. Local partnerships face many challenges in fully representing and meeting the health and welfare needs of an increasingly diverse and sometimes transient set of clients and 'at risk' communities and must continue to be imaginative in finding ways to understand needs and make sure they are met. There is also a continual battle to keep sickle cell and thalassaemia in the spotlight, particularly when local issues are competing with those which have a central governmental target attached to them. Local voices must continue to shout to be heard.

6. Key Recommendations

1. More work needs to be done and funded to raise awareness of carrier testing amongst young people, particularly about thalassaemia, in both ‘at risk’ communities and in the general population.
2. The new national, universal screening programme for haemoglobinopathies will eventually identify almost all carriers of these genes. However, the current generation of young people will still need to be offered screening before reproductive age through community initiatives and General Practices that do not currently see this as being their responsibility.
3. Carriers should routinely be given information about possible referrals to genetic counselling services and CVS organisations which could offer them support.
4. Cascade screening should be routinely made available and if sensitively handled, could be of utility in cultures where cousin marriage is a valued custom to help explain risks and identify alliances where risk is reduced.
5. There is a need to act as health communities to offset the ‘numbers’ argument within regional health and social care services and to highlight inequities in care available for other conditions such as haemophilia, that affect the ethnic majority.
6. In Sheffield, and areas with similar service provision, nursing staff and the CVS could work more closely to encourage patients to adopt more active engagements with the risks and uncertainties associated with their condition.
7. Hospital services could better support its partners in the CVS by operating a system of direct referral, so that any patient living with or carrying a haemoglobinopathy is registered with, and informed about, available support and activity and can make their own choices about their level of participation.
8. There are ways in which local partnerships in Sheffield could work more beneficially in tandem, but there needs to be recognition that the strength of the CVS ultimately lies in its ability to be creative in meeting needs, and in its independence from State services.

7. Acknowledgements

This research was made possible by the grants awarded by the ESRC and The SSCAT Foundation whom I wish to thank for their support. It was supervised by Mr Randolph Prime (The SSCAT Foundation) and by Dr Deborah Sporton and Prof Gill Valentine[9] from within The Department of Geography, University of Sheffield. A Research Steering Group with further representation from Sheffield Hospitals, The SSCAT Foundation and Dr Karl Atkin, University of Leeds[10] provided invaluable guidance and support.

Most of all, I would like to thank the research participants for their time, patience and for sharing their thoughts and experiences with me.

August 2007

References

Anionwu E N and Atkin K (2001) *The Politics of Sickle Cell and Thalassaemia* OU Press, Buckingham.

Department of Health (2000) *The NHS Plan* HMSO, London.

Department of Health (2001) *The expert patient: a new approach to chronic disease management for the 21st century* HMSO, London.

Department of Health (2003) *Our Inheritance, Our Future: Realising the potential of genetics in the NHS* HMSO, London.

Department of Health (2004) *Making Partnership Work for Patients, Carers and Service Users: A Strategic Agreement between the Department of Health, the NHS and the Voluntary and Community Sector* HMSO, London.

Department of Health (2005) *Supporting People with Long Term Conditions: An NHS and Social Care Model to support local innovation and integration* HMSO, London.

Dyson S M (2005) *Ethnicity and Antenatal Screening for Sickle cell and Thalassaemia* Elsevier/Churchill Livingstone, Oxford.

Home Office (1998) *Getting it right together: compact on relations between the government and the voluntary sector in England*. Home Office, London Cm 4100.

Home Office (2006) *Asylum Statistics: 2nd Quarter United Kingdom* http://www.homeoffice.gov.uk/rds/ Accessed 13th August 2006.

[9] At the time of writing, Professor Valentine is employed by the University of Leeds.
[10] At the time of writing, Dr Atkin is employed by the University of York.

Johnson M J (2003) *Asylum Seekers in dispersal – healthcare issues* Home Office online report 13/03. Available at:www.homeoffice.gov.uk/rds/pdfs2/rdsolr1303.pdf. Accessed: 4/11/04.

Keenan J (2004) *Questionnaire Survey Results: Sickle Cell Disorders and Thalassaemia in Sheffield* Available from author.

Lippman A (1992) 'Led (astray) by genetic maps: the cartography of the human genome and health care' *Social Science and Medicine* 35(12) 1469-1476.

Marteau T (1991) 'Psychological Aspects of Prenatal Testing for Fetal Abnormalities' *The Irish Journal of Psychology* 12 (2) 121-132**.**

Modell B, Harris R and Lane B *et al* (2000) 'Informed choice in genetic screening for thalassaemia during pregnancy: audit from a national confidential inquiry' *British Medical Journal* 320 337-40.

Midence K and Elander J (1994) *Sickle Cell Disease: A Psychological Approach* Radcliffe Medical Press, Oxford.

Royal College of Physicians (1989) *Prenatal Diagnosis and Genetic Screening: Community and Service Implications* London.

Sheffield City Council (2003) 'Ethnic Origin: Sheffield City Council 2001 Census Topic Report' Corporate Policy Unit, Sheffield.

Streetly A, Maxwell K, and Mejia A (1997) *Sickle Cell Disorders in Greater London: A Needs Assessment of Screening and Care Services, the Fair Shares for London Report*, London: Department of Public Health Medicine, UMDS and St Thomas's Hospital.

Wilson J (2002) Improving the Health of Asylum Seekers: An Overview. Occasional Paper, No5- June 2002. Available at: www.nepho.org.uk/files/referece/occ_paper/oco5.pdf. Accessed: 4/11/04.

This summary is taken from a longer, more detailed report. Questionnaire results have also been reported separately.

For further information, please contact:

Julia Keenan
4th Floor
Informatics Collaboratory for the Social Sciences (ICoSS)
University of Sheffield
219 Portobello
Sheffield
S1 4DP
(Valid until September 2008)