



# QUESTIONNAIRE SURVEY RESULTS SICKLE CELL DISORDERS & THALASSAEMIA IN SHEFFIELD

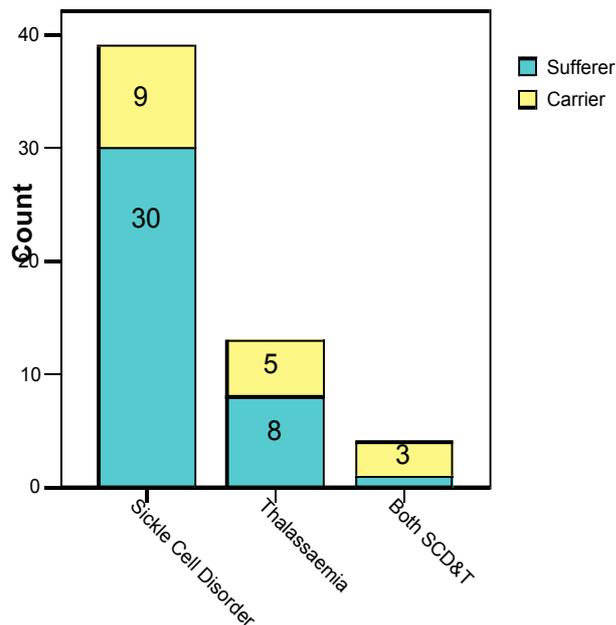
## SUMMARY

**Julia Keenan**  
Dec 2004

 <p>NORMAL RED BLOOD CELL</p> <p>THALASSAEMIA RED BLOOD CELL</p> <p>SICKLED RED BLOOD CELL</p>	<p>In Oct 2003, you were invited to take part in a questionnaire survey about sickle cell and thalassaemia in Sheffield.</p> <p>So far 59 individual carriers and sufferers have completed the questionnaire. This booklet is a summary of those results.</p> <p><i>Thank you very much to all that have taken part.</i></p>
---	--

*Help with translation or interpretation is available upon request.*

## Who in Sheffield is affected by these disorders?



**Respondent's type of Disorder**

- Nearly 70% of survey participants are affected by a SC gene, 23% by a thalassaemia gene, and a small, youthful proportion (7%) are affected by both disorders.

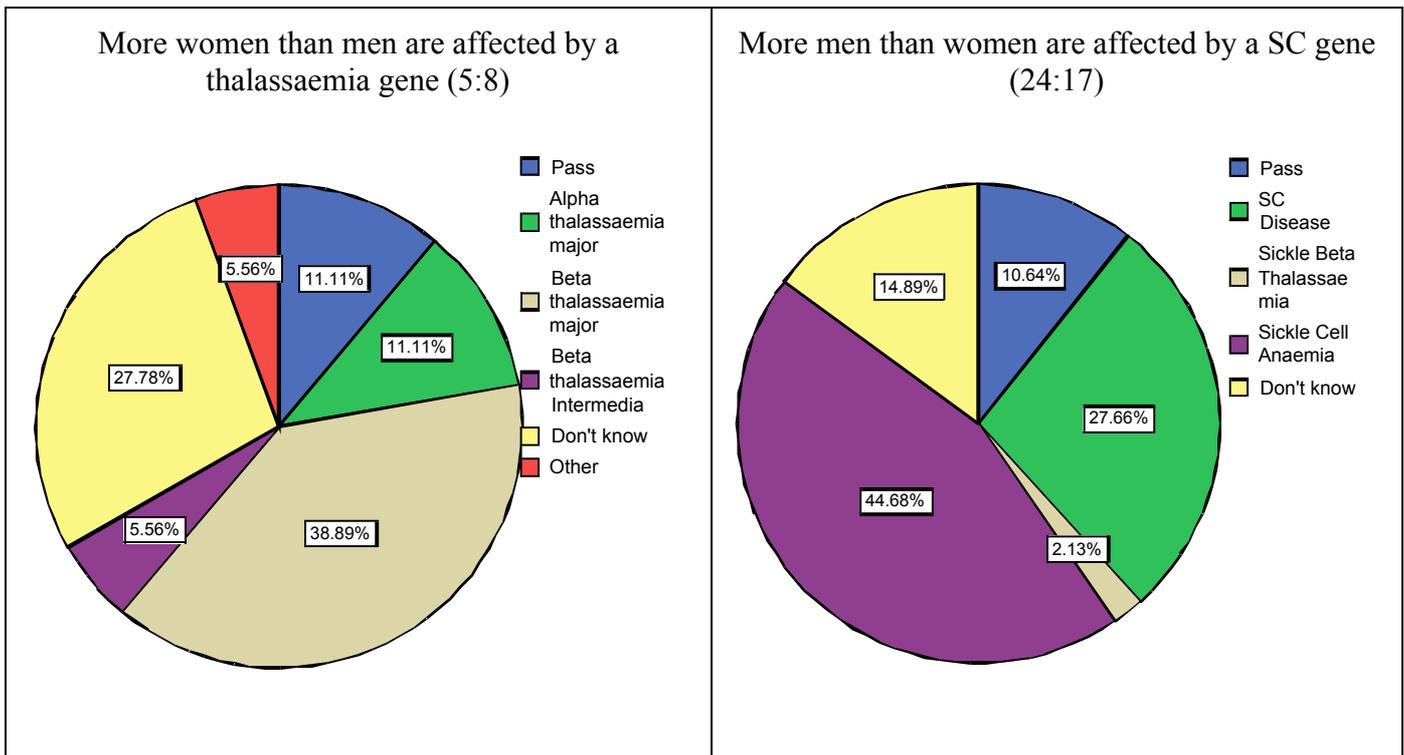
Age	Sickle Cell Disorder	Thalassaemia	Both SCD&T	Total
<b>Under 10</b>	<b>9</b>	<b>3</b>	<b>3</b>	<b>15</b>
10-18	5	3	0	8
19-25	6	2	0	8
26-35	5	2	1	8
<b>36-45</b>	<b>15</b>	<b>2</b>	<b>0</b>	<b>17</b>
66+	1	1	0	2
Total	41	13	4	58

- Most participants are in the age categories: 35-46 and Under 10.
- Those with a thalassaemia gene are, on average, younger than those with an SC gene.
- Most participants with a SC gene identify themselves as Black and Black British: Caribbean, and most affected by a Thalassaemia gene as Asian and Asian British: Pakistani. In the younger generation however, there is much greater diversity than this.

- Overall, the cultural diversity of persons affected by these disorders in Sheffield is increasing, with the youngest group showing greater variety in both ethnicity and language. Other significant ethnicities affected are carriers of dual/mixed ethnicity and Black Africans, and 'Other' Black ethnicities affected by a SCD.
- There are nine different first languages used by survey participants, two-thirds however have English as a first language, with the second most significant language being French.
- Follow up interviews with participants has shown that asylum seekers and refugees living in Sheffield are affected by these disorders.
- Those requiring interpretation to access services mainly use a qualified interpreter. However there are still instances where a family member is being used, which is not recognised best practice.
- Religious beliefs and practices may influence how people see themselves, their wellbeing and reproductive decisions. Of those affected by a Thalassaemia, 91% identify themselves as being Muslim. Of those affected by a SCD, 63% identify themselves as being Christian, 27% are of no religion, and 10% are Muslim.
- The majority of participants live in the inner city postal districts of Sheffield which have high levels of deprivation. Those affected by a SC gene are more geographically dispersed than those affected by a Thalassaemia gene. There are some people living in outlying areas of Sheffield.

## How are people affected?

- For those suffering from these conditions early detection is important. Those sufferers under the age of 35 have generally had a diagnosis in time to get treatment. The situation for those over 35 is less clear.
- There are many types of these disorders. However, many participants do not know what type of blood disorder they carry or suffer from. This can affect the ability to fully assess the implications of passing these disorders on.



## Household Issues

- No participants affected by a Thalassaemia gene live alone. For respondents suffering from a SC disorder however, over a fifth lives independently. These respondents are predominantly in the 35-46 age range, and thus may require support to remain independent in later years.
- Although all but one of participants' homes are equipped with central heating (particularly crucial for avoiding a sickle cell crisis) over 50% of respondents, and half of all sufferers, do not have access to a car, leaving them dependent upon public transport.
- Some sickle cell sufferers, but importantly not carriers, had also experienced difficulty in accessing financial services, such as insurance and mortgages.
- Marital status patterns (over 16s) differ from the Sheffield 2001 Census averages, with fewer participants being married and more being single. 25% of those that responded are married, 66% are single and 9% are divorced. Whether or not this is a reflection of fears about passing disorders on warrants further research, as observed differences may simply be reflection of cultural differences and demographics of this group.

## Employment & Educational Issues

For those suffering from these disorders could be said to have a chronic illness with disabling effects. As such, attending work or school/college can at times prove problematic and employers/educators should be aware of and respond to sufferers' needs.

- Almost two thirds of those of working age are in paid work. Reflecting demographic differences between the two groups of disorders, almost all of those in paid work are affected by a SC gene. Most have told their employers about their condition and over a third have taken time off work because of it.
- Of the twelve respondents that told their employers about their condition (sufferer or carrier) none reported their employers overall response as being negative, which is an encouraging finding.
- Just fewer than 40% of participants are in full time education. As might be expected, all eighteen respondents in the 10-18 age range are in full time education. There are four respondents continuing post 18 education.
- Sufferers' perceptions of educators' overall response to their situation are also almost entirely positive, which is an encouraging finding.
- Sufferers have had to take time off school/college in the last twelve months because of their condition, which is to be expected. Three respondents having had up to two months off are all sickle cell sufferers. One sufferer of Thalassaemia has had up to a month off school/college in the last twelve months because of their condition.
- Catch up work is provided for only 43% of sufferers who have told their school/college about their condition. Further analysis shows that of the individuals who receive no catch up work, five are Under 10 years old, which may be a factor. Only two sufferers that have told their school/college about their condition have been offered home based teaching.

#### Support: Awareness, use and access

- There are a number of national charitable organisations specifically associated with these conditions. Many have web resources for families & service providers, run help lines, publish newsletters and lobby for recognition and resources. **Participants' awareness of, and therefore contact with, national support organisations for these conditions is poor.**
- The Sheffield Sickle Cell and Thalassaemia (SSCAT) Foundation is a client centred service, which provides culturally appropriate support to individuals and families affected by these disorders in Sheffield. It seeks to empower clients and also strives to raise awareness of the disorders amongst those 'at risk', health/social care providers and the wider population. **A third of all participants had not heard of this organisation.**

		Frequency	Percent
Valid	Excellent	11	40.7%
	Good	10	37.0%
	Satisfactory	5	18.5%
	Poor	1	3.7%
	Pass	27	
	Total	54	
Missing	System	5	
Total		59	100.0

- Over 40% of those that access The SSCAT Foundation described the level of support provided as excellent.
- Significantly, **one third of sufferers of a SC disorder had not heard of The SSCAT Foundation.** These respondents' first languages are English, suggesting that the barriers which exist in raising awareness are more than just ones of language interpretation.

#### Participants' suggestions for how The SSCAT Foundation could improve its service

#### AWARENESS RAISING

***“By providing more information and raise the public awareness of this illness.”***

Male, 26-35, Living with SCD. Ethnicity: N. African. First language: Arabic.

***“More information on what the Foundation is about. Publicise the Foundation more. I’d never heard of them until I found out my son was a carrier like myself.”***

Carer for male carrier of SCD, under 10, Ethnicity: Black Caribbean. First language: English.

#### ACCESS

***“For someone to be in the office to take your call, instead of most of the time getting the answering machine.”***

Carer for male carrier of both SCD& Thalassaemia, under 10. Ethnicity: Mixed: Caribbean/English, Scottish, Welsh or Irish. First language: English.

#### ASSESSING NEEDS

***“By meeting people and understand what they really need, understand the help they require.”***

Male 36-45, living with SC Disease.

Ethnicity: Black and Black British, Caribbean. First language: English.

***“I am a carer...and apart from the newsletter, we pretty much cope on our own.”***

Carer for male, 19-25, Living with SCD,

Ethnicity: Black and Black British, Caribbean. First language: English.

#### MULTIPLE SUGGESTIONS

##### AWARENESS & CONNECTING CLIENTS

***“More awareness. Try to get the patients together more.”***

Female, 36-45, Living with SCD.

Ethnicity: Black and Black British, Caribbean. First language: English.

##### ACCESS & COUNSELLING

***“It should be easier to approach. They should have one-to-one contact and give counselling sessions.”***

Female, 19-25, Living with Beta thalassaemia major.

Ethnicity: Asian and Asian British, Pakistani. First Language: Punjabi.

##### PARENTAL SUPPORT, COUNSELLING & ADVOCACY

***“1: Provide better support to parents e.g. support groups. 2: Individual Counselling Sessions using alternative therapies. 3: Have a greater influence on medics to get more resources from the hospitals.”***

Carer for Male, Under 10, Living with Beta Thalassaemia,

Ethnicity: Asian and Asian British, Pakistani. First language: English/Punjabi.

#### SATISFACTION

***“None I can think of.”***

Male, 36-45, Living with SC Disease.

Ethnicity: Black and Black British, Caribbean. First language: English

***“I think they are excellent as they are. No improvement needs doing.”***

Female, 36-45, Living with thalassaemia.

Ethnicity: Asian and Asian British, Bangladeshi. First language: Bang lie.

## Conclusions from the survey

- People need to know, and have a written record of, exactly which type of haemoglobin disorder they suffer from or carry, as this has implications for assessing risk.
- There needs to be a greater acknowledgement of both the variety of Hb disorders and the fact that these conditions can combine to avoid confusion amongst those affected by both.
- A central database needs to be established to hold the details of carriers as well as sufferers of these conditions to keep track of carriers and keep them informed. (Owing to their pattern of inheritance, there are likely to be many more carriers in Sheffield than are represented in this survey).
- There is an increasingly strong diversity of cultures affected by these disorders in Sheffield. This needs to be acted upon both within mainstream and non-mainstream services.
- A great deal of work needs to be done to raise awareness of both national and local support organisations.
- Routine inter-agency procedures and mechanisms for informing people of The SSCAT Foundation should be established without compromising the political strength of organisations such as SSCAT Foundation in remaining independent from mainstream service providers.
- Those sufferers already living in Sheffield that do not know about The SSCAT Foundation need to hear the positive messages of those already using the service.
- More research needs to be done to find out why 31% of sufferers who have heard of SSCAT have not contacted them.
- French language resources and promotional materials (website & leaflets) should be made permanently available. (Website languages are currently Bengali, Chinese, Arabic, Somali, Urdu & English).
- Those granted refugee status and leave to remain in this country have entitlements to services. Service providers need to be aware of what these are and work in conjunction with local co-ordinators to make sure their institutional procedures and staff are trained to respond to these needs.

## **ACKNOWLEDGEMENTS**

Thanks are paid to my research steering group, who helped with the design and content of this questionnaire. Also to Elaine Greyson & Janet Wood, secretaries to Haematology Consultants at both the Sheffield's Children's Hospital and The Royal Hallamshire Hospital; and finally to The SSCAT Foundation, without whose patience and co-operation this data could not have been obtained.

## **AUTHOR DETAILS**

Julia Keenan

Postgraduate Researcher  
D Floor  
Department of Geography  
University of Sheffield  
Winter Street  
Sheffield  
S2 4EX

(0114) 222 7973

E mail: [j.keenan@sheffield.ac.uk](mailto:j.keenan@sheffield.ac.uk)

Further copies of this booklet and a full report are available upon request, and downloadable copies online at [www.shef.ac.uk/geography/pg/scdt](http://www.shef.ac.uk/geography/pg/scdt).

The research is funded by The Economic and Social Research Council (ESRC) and The SSCAT Foundation.

The project has been peer reviewed within the Department of Geography and approved by The South Sheffield Medical Ethics Committee SSREC/03/196.

A Research Steering Committee has been set up with representation from The Department of Geography, The SSCAT Foundation, The Sheffield Children's Hospital and Centre for Research into Primary Care, University of Leeds.

