



UK National
Screening Committee



Screening Programmes

Sickle Cell and Thalassaemia

SICKLE CELL AND THALASSAEMIA

QUALITATIVE RESEARCH REPORT

JUNE 2004





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Prepared by Populus for

MEDIA STRATEGY

METHODOLOGY

Two focus groups of women between the ages of 22 and 32 were held in central London on 21 June 2004. The groups were recruited from within the ethnic communities where sickle cell and thalassaemia are particularly prevalent.

Group One comprised 10 Black women in their mid to late 20s. Six of the group had not had children but planned to do so in the future while 4 had children. None suffered from sickle cell disorder.

Group Two comprised 10 Asian women aged from 22 to 32. Seven of the group had not had children but planned to do so in the future while three had children. None of the group carried the thalassaemia gene.

Discussion in both groups was led by a moderator who followed a Discussion Guide (attached at the end of the report). This report follows order of the Discussion Guide. To avoid confusion, quotes taken from Group 1 are labelled (1) and those from Group 2 are labelled (2).

EXECUTIVE SUMMARY

A. KNOWLEDGE, AWARENESS AND EXPERIENCE

- A1 All members of both groups had heard of sickle cell and Thalassaemia respectively. However, there was a marked difference in knowledge, with Group 1 both better informed about sickle cell and more likely to know sufferers personally than was the case with Group 2 and Thalassaemia.
- A2 Both groups believed that general awareness of the respective conditions in their communities was low and could be improved. Participants in Group 2 in particular felt awareness among the Asian community was very low indeed given the seriousness of Thalassaemia.
- A3 Although sufferers of either condition would face obvious difficulties in their everyday lives, neither group thought that they would necessarily be unable to work. Two participants who had known sickle cell sufferers at school offered contrasting accounts of the degree of sympathy and support offered by teachers.

B. THE NHS: TESTING

- B1 Participants assumed that the NHS would offer good care to sufferers of sickle cell disorder or Thalassaemia. However, both groups felt that it could do more to increase awareness of the conditions, and that the services available may vary between regions or boroughs.
- B2 There was a clear difference in experience of testing between the two groups. Four participants from Group 1 had been tested for sickle cell, usually because of pregnancy or plans to have children. In Group 2, although participants who had had children had been asked about their family's medical history, none had been tested (apart from one lady who assumed she must have been when she became a blood donor).
- B3 The majority in each group who had not been tested cited their lack of awareness, confusion about the causes, or a feeling that they were not currently at risk. Very few participants in Group 1 knew whether their partner had the sickle cell trait and nobody in Group 2 knew whether their partner was a healthy carrier of Thalassaemia.
- B4 Both groups reacted positively to the proposal to test newborn babies, provided testing was only carried out with the parents' consent. However, several participants suggested that testing should be made

available to everyone, emphasising that it was important for people to know whether they carried either condition before deciding whether to have children.

C. THE NHS: SCREENING

- C1 Both groups welcomed the proposal to make universal screening universally available. They suggested that screening would enable parents to prepare practically and emotionally for bringing up a child with either condition, or allow them to consider whether or not to continue with the pregnancy.
- C2 However, most participants said that whether or not they themselves would allow their unborn baby to be screened would depend upon the procedure involved and the attendant risks (most assumed it would involve an amniocentesis). Some also questioned the reliability of the result, or said that they would probably not have the test since they would continue with their pregnancy even in the event of a positive result.
- C3 Both groups felt that universal screening for sickle cell and Thalassaemia would inevitably mean some couples would decide to abort. However, even those who said they would not themselves consider a termination said that it was important to offer screening in order to give people information and choice.
- C4 Throughout the discussion it was clear that many of the opinions expressed were based on what participants acknowledged was an incomplete understanding of the conditions required for sickle cell or Thalassaemia to be inherited: for example, whether one or both parents needed to have the trait or be a carrier, whether the either condition can skip generations, and the probability of inheritance in each case.
- C5 For these reasons, participants reiterated that promoting awareness the respective communities was at least as high a priority as introducing universal testing and screening. They suggested an information campaign channelled through doctors' surgery, schools, local authorities and the media.

1. KNOWLEDGE, AWARENESS AND EXPERIENCE

1.1 All members of both groups had heard of sickle cell and Thalassaemia respectively. However, there was a marked difference in knowledge and awareness between the two groups.

1.2 Although the black participants in Group 1 did not feel they had a detailed understanding of sickle cell, they were able to give a basic explanation of the condition:

“It’s a blood disorder. It affects how oxygen travels round your body”. (1)

“It’s about the shape of the cell. Instead of being round it’s a sickle shape”. (1)

“It’s to do with haemoglobin”. (1)

1.3 They also had some knowledge of symptoms. One participant who worked in a hospital said she had observed that people were more likely to suffer in the winter.

“Aches in joints”. (1)

“It affects your circulation”. (1)

“You get viruses more. And you get weak. If you’ve been really active you can be laid up in hospital for six months”. (1)

1.4 Group 2, comprising participants from an Asian background, were much less knowledgeable about Thalassaemia than the first group had been about sickle cell.

“It’s a blood condition.” (2)

“It could be genetic. It could be something you pass on if one or both of you have it”. (2)

“Is it your bones, or your muscles?” (2)

“Red blood cells”. (2)

1.5 Group 2 had very little idea of the symptoms of Thalassaemia and were shocked to hear of the requirement for monthly blood transfusions and daily drug infusions.

1.6 Group 1 knew that black people were most susceptible to sickle cell, but suggested that Greeks, Indians and “some Caucasians” could also suffer.

- Some members of the Group 2 did not know that Thalassaemia was associated with people from Asian backgrounds.
- 1.7 Two participants in the Group 1 had had friends at school who suffered from sickle cell, one knew the young daughter of an acquaintance who suffered, and a third had three close friends who were sufferers, one of whom had died.
- 1.8 This amounted to more direct experience than that represented in Group 2, which included three people who knew of people with Thalassaemia, and one who had known a sufferer at primary school.
- 1.9 Both groups thought that awareness of the two conditions among black and Asian communities respectively was low and should be improved – particularly given their seriousness, which some participants (particularly in Group 2) had not fully appreciated until this discussion.
- “We need to be more informed. If you live with it, it’s serious”. (1)
- “Awareness is low. Considering it’s extremely relevant to black people, awareness is almost zilch. We should have awareness at 10, like with mumps and measles”. (1)
- “Unless you’re personally affected you’re not really going to find out”. (1)
- “They need to explain in layman’s terms what’s happening. You can’t read an encyclopaedia. You can’t even check for it”. (1)
- “They should do a really good campaign and let everyone know what it is, white or black”. (1)
- “My parents probably wouldn’t even know how to say it”. (2)
- “We all have massive families. You’d know if Auntie So-and-So had had it, but they’ve never heard of it”. (2)
- “It’s a concern if it’s increasing in the Asian community, but if tonight hadn’t happened I would never have known”. (2)
- 1.10 When asked to guess the number of people suffering from sickle cell and Thalassaemia respectively, both groups offered wild overestimates. When told the actual figures, some suggested that the official figures might represent only reported cases and that the true number of sufferers could be much higher given the lack of awareness they perceived.
- 1.11 Both groups believed that the respective conditions were very serious and potentially life-threatening. Neither group thought that the condition in

question could be cured, but both could be controlled, managed and treated.

“It’s definitely serious if you’re not looking after yourself”. (1)

- 1.12 Neither group thought that sufferers would necessarily be unable to work, although they would face obvious difficulties in their day-to-day lives.

“A lot of the time they are in hospital, and they have phases of being really weak, having blood transfusions”. (1)

“They have ups and downs. All three of my friends were ravers – they would party hard and then have to go into hospital. Two had children even though they shouldn’t have, but they wanted to live life as much as possible.” (1)

“Someone at school had it. We’d have been 10 or younger. She was off for months. They told us but we just thought she was sick. She did come back though”. (2)

“The quality of life is restricted, if you have to be treated all the time. With the transfusions you can’t go too far, probably”. (2)

“It’s probably like someone with diabetes. A normal life in lots of ways but with dialysis every day. You could probably still go to work but you’d need lots of time off”. (2)

- 1.13 The two participants in the Group 1 who had known sickle cell sufferers at school reported mixed experiences.

“The teachers didn’t really mention it. There was one black teacher who spoke to her but the white ones didn’t really acknowledge it. She was off quite a lot, so she didn’t have time to complete her coursework, so she was suspended quite a lot. They didn’t do anything – they didn’t even send her coursework to her in hospital. They didn’t try hard enough”. (1)

“My school was the opposite. The teachers were aware and no-one was allowed to touch her, she couldn’t play. So she missed out a lot in the playground. They were being over-careful. She missed a lot of school, but they had a school room in the hospital so she was never really behind...The black kids tried to fit in with her, like walk around the playground linking arms instead of running around”. (1)

2. THE NHS: TESTING

- 2.1 There were mixed views as to how well the NHS deals with sickle cell and Thalassaemia. Although participants tended to the view that the NHS

offers good care to sufferers, some felt that some doctors were ignorant of the conditions and that services available may vary from one region or borough to another. There was also a widespread feeling that the NHS could do more to raise awareness of the conditions.

“It’s getting better. When my mum was growing up they didn’t test. But in Lewisham now I think they do test black people”. (1)

“The level of testing probably depends on which borough you live in. Friends have been tested for things in some areas but not in others. I don’t know how they make that decision”. (2)

“With the little girl I know, they know she’s going to be back so they personalise it for her, make it comfortable for her parents and so on”. (1)

“We have a sickle cell nurse at our hospital, so they’re working on it. Someone who’s able to talk to you and discuss it and has a greater understanding. But that might just be from half a day at university”. (1)

“I sat down with my doctor and he didn’t know anything. He said ‘read this’.” (1)

“In the doctor’s surgery you don’t find leaflets talking about sickle cell”. (1)

“I should think they provide good care for people that have it. There is probably a certain hospital that deals with that care”. (2)

“It’s probably hospitals in areas where there are lots of Asians. Doctors there are more likely to have an open mind to it”. (2)

- 2.2 There was a marked difference between the two groups in experience of testing for sickle cell or Thalassaemia. In Group 1, four participants had been tested for sickle cell (two because they were pregnant, one because she was planning to start a family, and one because she had been diagnosed with multiple sclerosis), and two were found to have the trait.
- 2.3 In Group 2, none had been tested for Thalassaemia, although one participant who was a blood donor assumed that her blood would have been tested at the time of her donations and that she would have been informed if she were a carrier. The participants who had had children said that they had not been offered a test, although they had been asked about their family’s medical history, and one had been asked specifically whether there had been a history of Thalassaemia.

2.4 In both groups, those who had not been tested cited a lack of awareness, confusion about the causes, or a lack of any current feeling of being at risk.

“I wasn’t aware enough to look deeper into it”. (1)

“If I decide I’m going to have children, I will”. (1)

“Because my family don’t suffer I assumed I wouldn’t have the trait”. (1)

“If only 700 people have it I’m sure people think it’s really rare”. (2)

“It would be the last thing I thought of until today”. (2)

2.5 Very few people in Group 1, and nobody in Group 2, knew whether their partner had the sickle cell trait or was a Thalassaemia carrier.

“I don’t know if my daughter has got the trait, let alone anyone else”.

“My partner had a very serious condition and was tested but didn’t have the trait. His dad did – he wouldn’t have been tested otherwise”. (1)

“When I asked if my husband should be tested too, they said ‘only if your result’s positive’. But from what I’ve heard today that doesn’t matter”. (2)

“My partner is mixed race but has no black genes. I didn’t realise until today that that doesn’t matter”. (1)

2.6 Both groups reacted positively to the proposal to test newborn babies, although some were concerned that testing should only happen with the parents’ consent.

“When they give them injections they could do it at the same time”. (1)

“I’d like to know. I would like my child to have all the tests. My daughter had all the immunisations and things and I was happy that I’d done my job. I’d want every little test that was relevant”. (2)

“They take blood for this, that and the other, so they might as well test for Thalassaemia”. (2)

“They should definitely ask permission...but I can’t see anyone saying ‘no, I don’t want my child to be tested’.” (2)

2.7 However, several participants made the point that although testing babies would mean the next generation might be better informed about sickle cell and Thalassaemia, testing should be made available to everyone. Some emphasised that it was important for people to know whether they carried either condition before deciding whether to have children.

“The children who are tested will grow up knowing about it. They’ll be the new wave, but they need to educate the old wave too”. (1)

“It’s important to know whether you’ve got it if you’re having children. And it’s just important, anyway”. (1)

“There are lots who have the trait but don’t know”. (1)

“There is a sector of people who don’t want kids, or not at this stage. What about them?” (1)

“Not everyone plans it [pregnancy]. You need awareness”. (1)

“I think they think the beginning is the child, but it’s the parents. Or the grandparents”. (1)

“What about the gay community?” (1)

“It’s important [to be tested] because it’s life-threatening”. (2)

3. THE NHS: SCREENING

3.1 Participants in both groups welcomed the prospect of universal screening of unborn babies during the first trimester being made available, provided screening was only carried out with the mother’s consent. It was widely believed that screening would give parents time to learn about the condition and prepare practically and emotionally to care for a child with a potentially serious illness, or allow them to consider whether or not to continue with the pregnancy.

“It’s the right thing as long as it isn’t ‘you have to have the test’. It should be ‘this is the disorder, this is how it affects people, now do you want the test?’ ” (1)

“It would mean they could give it medicine in time when it’s born”. (1)

“Knowledge is power”. (1)

“It makes the road easier”. (2)

“You could read up on what to expect”. (2)

“You can decide where to live, whether you need to move. You could change your lifestyle”. (1)

“It’s a way of getting yourself acquainted with the ins and outs of it. Otherwise it would be a bombshell in the first week, when there are so many other things going on. At least you’d be prepared”. (2)

“If you had a history of genetic diseases in your family you would at least have the option of terminating.” (2)

“To abort or not to abort. That’s what it boils down to”. (1)

- 3.2 However, whether they themselves would allow their unborn baby to be screened would depend upon the procedure involved (most assumed an amniocentesis would be required), the risk to the child, the reliability of the test result, and – in some cases – whether or not they would be inclined to terminate their pregnancy in the event of a positive result.

“If there is consent. It isn’t ethical to do it behind the mother’s back”. (2)

“It depends how the tests are done – whether it’s safe”. (2)

“What’s involved? What’s the procedure?” (1)

“Is the needle the only way of testing?” (1)

“They wanted to test my unborn baby but there is a high risk of abortion”. (1)

“It’s a difficult one. If it meant harming the baby in the first trimester, that’s a difficult stage as it is. I wouldn’t have it. I would rather let it grow the best it can”. (2)

“The percentage who have Thalassaemia is still quite low so it’s not worth the risk”. (2)

“They need to let mothers know what the risk is, if there is a risk. If it was 0.1 per cent I’d go ahead but if it was 30 per cent, or even 10 per cent...” (2)

“You can have your tests and you’re never sure”. (2)

“There is a difference between a carrier and a full-blown carrier”. (2)

“There must be some people who have sickle cell who don’t even have a crisis. It depends how you look after yourself. Your diet and things”. (1)

“I wouldn’t even consider an abortion in that situation so any risk is a greater risk”. (2)

- 3.3 One participant in Group 1, who’s partner had the trait, said that she had been put under considerable pressure by the Sickle Cell Society to screen her baby and terminate her pregnancy. She resisted, and was glad that she had:

“When I was pregnant they wanted to do the test, because the baby’s father has the trait – he has AS and I have SS – and they said there was a one-in-four chance sickle cell could kill the baby. But I said no, and the Sickle Cell Society kept ringing me up and faxing me, saying it would

have the worst sort of sickle cell, and I should abort it. But the baby was born – and he doesn't even have the trait!"

This participant's view of the Society was not helped by her view that its staff were not particularly well informed.

"When I spoke to the Sickle Cell Society she was just reading out of a text book. So I was asking 'why should I get rid of my baby?' and she was like, turn to page 8". (1)

- 3.4 Both groups accepted that universal availability of screening for sickle cell and Thalassaemia would inevitably mean that some couples would decide to abort (particularly since participants in Group 2 knew that some hospitals refused to tell Asian couples the sex of their baby in case they decided to terminate on that basis alone). However, even those who said they would not themselves consider a termination said it was important to offer screening in order to give people information and choice.

"People should have a choice. Just because some people will want to abort doesn't mean they shouldn't screen". (1)

"You have a choice anyway, so why not have another thing to test?" (2)

- 3.5 Throughout the discussion of whether or not to screen it was clear that many of the opinions expressed were based on what the participants acknowledged was an incomplete understanding of the conditions required for sickle cell or Thalassaemia to be inherited. Before they could say for certain whether they would undergo screening, for example, they would want to know whether sufficient information could be gleaned from testing the parents instead. Can the condition be passed on if only one parent has the trait? Does it make a difference if just one or both parents are a sufferer? Do they have to be of the same ethnic background? Can the condition skip generations? And what is the probability of passing the condition on in each circumstance?

"Instead of screening the baby, why not just screen the parents and go on from there?" (2)

"If it could jump a generation I would be more inclined to have the baby screened, especially if my parents had it. But if you know they could just test you, there is no need to touch the baby". (2)

"I know of a little mixed-race girl who's got it. But her brother and sister are both black and they don't have it! Her mum is white and doesn't know what to do". (1)

“I was told that both parents have to be black”. (1)

“I thought both had to have the trait to pass it on, but if one does there is a 50–50 chance the child will. It was on *Casualty*”. (1)

“Is it true that you can develop it if you’re not born with it?” (1)

“People would have their partner tested before they had children if they realised how serious it was”. (1)

“There are some diseases that can miss a generation and come back. Maybe this is a similar thing”. (2)

“How is it passed on? Do there have to be two carriers? If one of you is healthy is that OK? If I know I don’t have it, I wouldn’t be so concerned”. (2)

“If it has to be two carriers, I probably wouldn’t be so concerned”. (2)

“If you and your husband were both carriers you could pass it on”. (2)

“If the parents are tested it shouldn’t be necessary”. (2)

“If I hadn’t been screened, I would still want my child to be. But if I had and my partner had, I wouldn’t bother”. (2)

“I’d ask to have myself and my partner tested and go from there. If we were both positive, I would be more inclined to have my baby tested. But if you’re both negative, you’ve saved the risk”. (2)

3.6 Although testing and screening were both seen to be valuable, Group 1 in particular felt that the first priority should be promoting awareness. Many felt that to introduce the subject at the screening or testing stage is “a bit down the line – it’s like giving sex education after you get pregnant”.

“[Screening is all very well but] it’s informing people before. The council could do workshops and events. When we [a local authority] put a magazine out, we can get hundreds of calls about a tiny article”. (1)

“Sickle cell can defy the rules. If you’re tested and you both have it, the baby might have it or it might not. But if there was awareness you would know how to manage it”. (1)

“We need knowledge in the community”. (1)

“There are so many people in the black community who haven’t had a test”. (1)

“Teenage pregnancy is on the up. Two 16 year-olds are not going to know what sickle cell is. Many of them don’t even know about contraception!” (1)

“They should start a campaign about sickle cell. They will be giving screening to people who don’t know about it”. (1)

- 3.7 Participants therefore reiterated their concern at the lack of awareness of sickle cell and Thalassaemia among their respective communities and hoped to see an information campaign channelled through doctors’ surgeries, schools, local authorities and the media.

“They should have workshops and things. Educate us”. (1)

“They should have case studies and things. When I was told I had MS, I had to seek my own emotional support as well as consultancy”. (1)

“It should be in a medical context. At the GP’s. If you’re sitting in a doctor’s surgery, you’re thinking about your health so you’re more likely to pick a leaflet up”. (2)

“You get STD notices on toilet doors!” (2)

“Outdoor media works. Adverts on tubes and buses, with an 0800 number or a website”. (1)

“Not like those old Aids adverts. The way teenagers talk”. (1)

“It’s worth hitting the radios, like they do for not having enough blood type for a particular race, or bone marrow. There are specific Indian media agencies”. (2)

“They could do something at the Mobo Awards. Someone famous must have had it. Ian Wright or someone”. (1)

“There should be awareness. We all know about breast cancer. It should be part of our consciousness”. (1)

4. LOGO

- 4.1 Each group was shown the logo of the new sickle cell and Thalassaemia campaign. Most took a neutral view of the logo itself, comparing it to various objects.

“A windmill”. (1)

“Air conditioning. Glade”. (1)

“A fan”. (1)

“Looks like a Mary Quant flower”. (2)

“A Polo mint”. (2)

“It’s a bit girly”. (1)

“It’s as good as any other logo but it depends what comes with it”. (2)

“It’s like the breast cancer logo – when it was first out nobody knew what it meant”. (2)

4.2 A few picked up on the connection between the design and the disorders in question.

“The leaves do have a sickle look but what’s the bit in the middle?” (1)

“I associate the red with the red blood cell. But only because I know”. (1)

4.3 Some participants in Group 1 suggested that a new logo was unnecessary.

“What’s the point of going on about the logo if the Sickle Cell Society has already got a logo? It will confuse people”. (1)

“If one exists already why waste time with this? Why not just have one?”
(2)

Sickle Cell and Thalassaemia Focus Groups – Discussion Guide (Sickle Cell)

1. General introductory questions (7–10 minutes)

Introduce Populus; explain general purpose of the group (at this stage do not reveal who the group is being conducted for, instead say that we want to find out what people's reactions are to a number of issues to do with health and welfare). Explain and stress confidentiality and ground rules for discussion (ie that although we are taking notes no names or addresses will be passed on to anyone).

Ask group members to introduce themselves, say what they do for a living, whether they are married (with children?), interests, hobbies etc.

2. Awareness of Sickle Cell (40 minutes)

As I explained at the beginning of the group, we want to discuss your attitudes towards health – in particular your attitudes towards sickle cell disorders which are especially common among black people.

What is sickle cell disorder? [seek unprompted perceptions] [*Sickle cell disorder changes the shape of the red blood cells, which makes them less able to carry oxygen around the body*]

How common do you think it is? How many people in Britain do you think are affected by it? [*From 1991–2001 the incidence of sickle cell has increased by 45%. It is estimated that 170,000 people are healthy carriers of the sickle cell gene and over 12,500 have a sickle cell disorder*]

Do you know what the symptoms of the disorder are? What are the long term consequences of the disorder? [*The symptoms of sickle cell disorders can include severe anaemia, intense pain, damager to major organs and infections. Antibiotics can help prevent infection and improve quality of life*]

Do you know anyone who has the disorder? What are the consequences for that person? Were you at school with anyone with the disorder? If so, how were they treated (by teachers, other pupils)?

Is it a serious condition? Is it life threatening/life shortening? Can it be cured?

How would you describe the quality of life of people with the disorder? Can people with the disorder work normally, hold down employment, live the same kind of lives as the rest of us? How does it affect the way they live their lives?

How seriously do you think that the National Health Service takes the disorder?
Does it provide good care for sufferers of the condition?

3. Testing (15 minutes)

When you were recruited to come to this group you all said that you did not suffer from Sickle Cell disorder. Have you all been tested? If so, when and why? Do you think that most people you know have been tested to see whether they carry the sickle cell gene?

This next section has to be handled sensitively.

Do you know whether your husband or boyfriend carries the gene? Have they been tested?

[To those who have had children] were you / your partner tested before you had your child/children? At what stage did the test happen – during pregnancy or sometime before? If they (either partner) hadn't been tested was this something that you had thought about?

How important is it to know whether you or your partner carries the gene? Do you think that people should be tested or doesn't it really matter so long as they don't have the disorder? Do you think that screening of new born babies does currently happen? Do you think that new born babies should be tested? Do you think that blood of all new born babies should automatically be screened for the disorder?

4. Screening (20 minutes)

As well as screening new born babies, it is now possible to screen for the disorder in the early stages (first trimester) of pregnancy. Do you think that this would be a good idea? If so, why? If not, why not?

What advantages do you think there would be to knowing at a very early stage of a pregnancy that a baby will suffer from sickle cell disorder? Why do you think the Health Service is planning to introduce this antenatal screening across the country? [Seek unprompted perceptions]

The aim of antenatal screening is to offer effective and appropriate screening to enable women and couples "to make informed choices about their pregnancy". What do you think this means? What kind of choices could women and couples make? (Prompt – only if not brought up spontaneously – discussion of abortion)

What is your reaction to this? Do you think that screening will lead to couples choosing to have an abortion if their child is going to suffer from the disorder? Do you think this is right? If screening leads to some couples making this decision, would it be better not to have any screening programme at all? What do you think the advantages are of an antenatal screening programme?

5. Conclusion (5 minutes)

[Explain why the group is being held ie that the NHS is about to introduce newborn and antenatal screening for sickle cell and that it is interested in the views of people who do not have direct experience of the disorder themselves]

Show the logo –identity for the campaign. Ask for immediate reactions. If you saw this logo – what would you think it was about? How effective do you think it is? What is your instant reaction to it?

Sickle Cell and Thalassaemia Focus Groups – Discussion Guide (Thalassaemia)

6. General introductory questions (7–10 minutes)

Introduce Populus; explain general purpose of the group (at this stage do not reveal who the group is being conducted for, instead say that we want to find out what people's reactions are to a number of issues to do with health and welfare). Explain and stress confidentiality and ground rules for discussion (ie that although we are taking notes no names or addresses will be passed on to anyone). .

Ask group members to introduce themselves, say what they do for a living, whether they are married (with children?), interests, hobbies etc.

7. Awareness of Thalassaemia (40 minutes)

As I explained at the beginning of the group, we want to discuss your attitudes towards health – in particular your attitudes towards thalassaemia which is particularly prevalent in this country among the Indian, Pakistani, Bangladeshi and Chinese communities.

What is thalassaemia? [seek unprompted perceptions] [*Thalassaemia is a genetic blood disorder. A person who carries the gene can appear perfectly healthy but those who have condition (known as beta- thalassaemia major) require intensive medical care including monthly blood transfusions and daily drug infusions (this can mean continuous injection for 8–12 hours a day)*]

How common do you think it is? How many people in Britain do you think are affected by it? [*From 1991–2001 the incidence of thalassaemia has increased by 45%. It is estimated that 150,000 people are healthy carriers of the thalassaemia gene and 700 people in the UK have the condition*]

Do you know what the symptoms of the disorder are? What are the long term consequences of the disorder? [*Those with the condition can suffer from diabetes, growth problems, problems with puberty or early menopause*]

Do you know anyone who has the condition? What are the consequences for that person? Were you at school with anyone with the condition? If so, how were they treated (by teachers, other pupils)?

Is it a serious condition? Is it life threatening/life shortening? Can it be cured?

How would you describe the quality of life of people with the condition? Can people with the condition work normally, hold down employment, live the same kind of lives as the rest of us? How does it affect the way they live their lives?

How seriously do you think that the National Health Service takes the condition? Does it provide good care for sufferers of the condition?

8. Testing (15 minutes)

When you were recruited to come to this group you all said that you did not suffer from the thalassaemia condition. Have you all been tested? If so, when and why? Do you think that most people you know have been tested to see whether they carry the thalassaemia gene?

This next section has to be handled sensitively.

Do you know whether your husband or boyfriend carries the gene? Have they been tested?

[To those who have had children] were you / your partner tested before you had your child/children? At what stage did the test happen – during pregnancy or sometime before? If they (either partner) hadn't been tested was this something that you had thought about?

How important is it to know whether you or your partner carries the gene? Do you think that people should be tested or doesn't it really matter so long as they don't have the condition? Do you think that screening of new born babies does currently happen? Do you think that new born babies should be tested? Do you think that blood of all new born babies should automatically be screened for the condition?

9. Screening (20 minutes)

As well as screening new born babies, it is now possible to screen for the condition in the early stages (first trimester) of pregnancy. Do you think that this would be a good idea? If so, why? If not, why not?

What advantages do you think there would be to knowing at a very early stage of a pregnancy that a baby will suffer from thalassaemia condition? Why do you think the Health Service is planning to introduce this antenatal screening across the country? [Seek unprompted perceptions]

The aim of antenatal screening is to offer effective and appropriate screening to enable women and couples “to make informed choices about their pregnancy”. What do you think this means? What kind of choices could women and couples make? (Prompt – only if not brought up spontaneously – discussion of abortion)

What is your reaction to this? Do you think that screening will lead to couples choosing to have an abortion if their child is going to suffer from the disorder? Do you think this is right? If screening leads to some couples making this decision, would it be better not to have any screening programme at all? What do you think the advantages are of an antenatal screening programme?

10. Conclusion (5 minutes)

[Explain why the group is being held ie that the NHS is about to introduce newborn and antenatal screening for thalassaemia and that it is interested in the views of people who do not have direct experience of the disorder themselves]

Show the logo –identity for the campaign. Ask for immediate reactions. If you saw this logo – what would you think it was about? How effective do you think it is? What is your instant reaction to it?