



UK National  
Screening Committee



# Screening Programmes

Sickle Cell and Thalassaemia

## **NHS SICKLE CELL AND THALASSAEMIA SCREENING PROGRAMME**

### **SCOPING PROJECTS TO INFORM OUTREACH**

**February 2007**





**ETHNOS**

RESEARCH AND  
CONSULTANCY

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## 1.0. INTRODUCTION

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### 1.1. Introduction

This report documents the scoping process supporting the identification of community organisations to develop public outreach projects for the NHS Sickle Cell & Thalassaemia (SC&T) Screening Programme. The report represents learning and guidance for the Programme itself, as well as for other programmes and bodies which may be looking to engage with the black and minority ethnic (BME) sector to raise awareness of health conditions. It is hoped that the approach to scoping detailed in this report will provide a useful template for engaging with BME community organisations which, due to a range of factors (e.g. lack of capacity, personnel, structural under-funding etc), may be disadvantaged by a solely paper-based tendering process. Adopting a grounded scoping approach allows the identification of appropriate grassroots community-based organisations with which meaningful partnerships can then be constructed.

### 1.2. Background

The NHS SC&T Screening Programme aims to offer effective and appropriate antenatal and neonatal screening programmes for sickle cell and thalassaemia. The aims of the programme are to enable informed reproductive choice and to ensure that appropriate care is planned and delivered for affected children. Currently, it appears that relatively few people have a sufficient understanding of the conditions, of risk levels in their group, of care options, of ethnical considerations, etc. to make informed decisions. There is therefore a great need for public education around these issues.

ETHNOS Research and Consultancy was commissioned to explore how the Screening Programme can support the delivery of public education by engaging with ethnic minority populations at a local level. The specific aims of the project are:

- To explore how the Screening Programme can develop and support a sustainable programme of public outreach
- To identify partner organisations in selected areas and advise on their capacity and possible areas for joint working
- To suggest types of intervention and resources needed to support them

The actual delivery of projects is intended to follow on from this scoping process, supported by the Programme itself.

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### 1.3. Research design

It was decided at a meeting between the Programme and ETHNOS that the interventions should be selected based on a combination of the following criteria:

- The interventions should target communities that are known to be disproportionately affected by SC&T;
- The interventions should target communities that have the least awareness and knowledge of SC&T and that are the least likely to understand and accept the message of the Screening Programme;
- The interventions should be developed both in areas where the target communities are well established and supported by a developed and capable BME community and voluntary sector, and in areas where this is not the case, with a view to developing capacity in such areas;
- The interventions should be developed by partnerships that involve the Programme itself, and statutory, community and voluntary organisations that have expertise either in working with the target communities, or in devising and delivering health outreach programmes, or in the conditions SC&T.

With these criteria in mind, the research was planned in two phases:

- **Phase One**

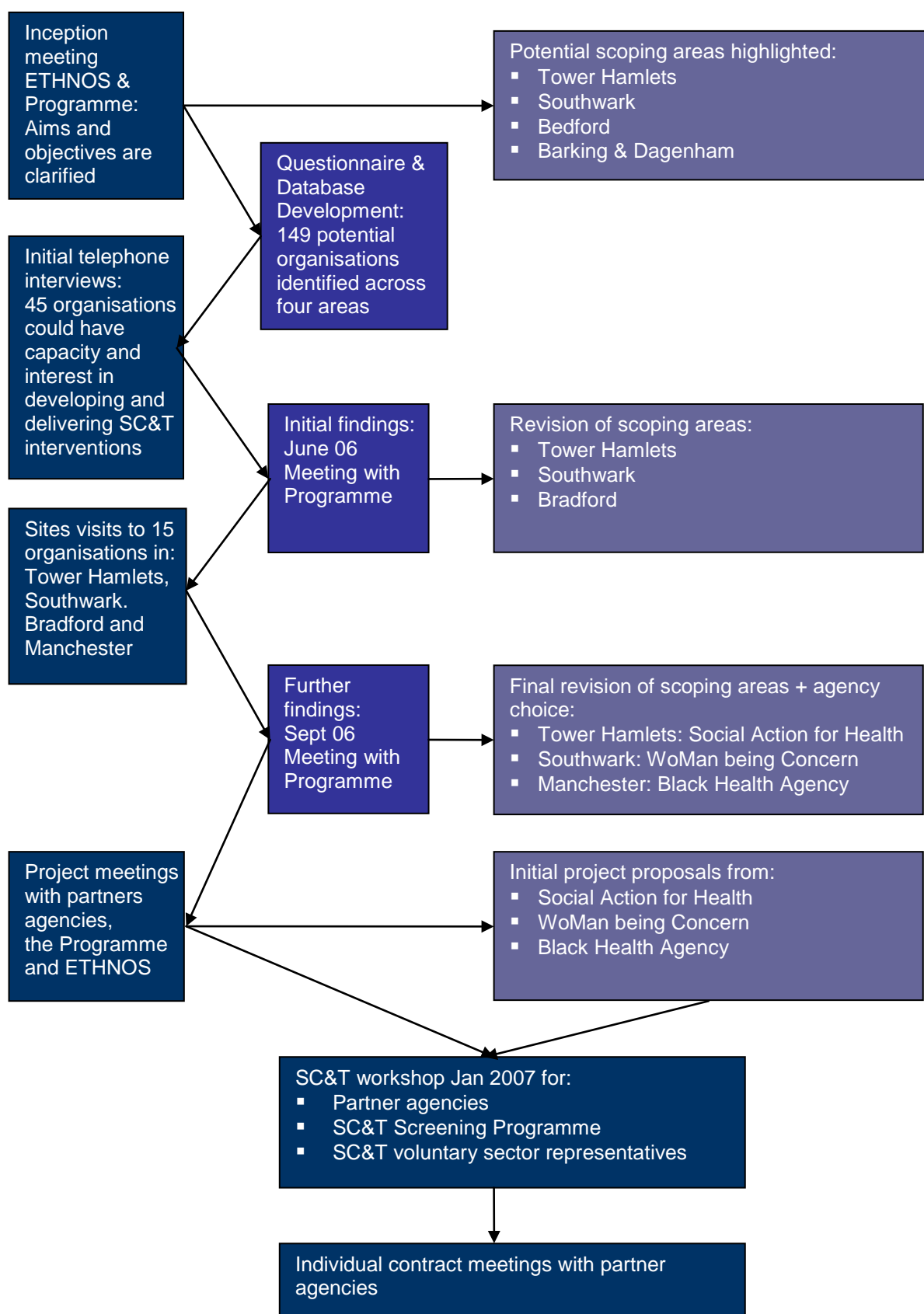
Phase one consisted of a scoping exercise to identify potential partners to help deliver public education on SC&T to target audiences. Telephone interviews with identified organisations would enable recommendations to be made to the Programme about which ones should be considered as potential partners in possible projects in each chosen geographical area. Following on from telephone interviews, face-to-face interviews were conducted with a number of voluntary and community, statutory and other related organisations in each of the areas. Based on these interviews, recommendations were made to the Programme regarding potential partner agencies which could best deliver innovative community-based projects to raise awareness of SC&T.

- **Phase Two**

Phase two consisted of working in close collaboration with the identified partners to establish their capacity and requirements from the Programme, to develop interventions, to identify target audiences and to create a detailed action plan. Finally, a workshop was conducted with partner agencies to obtain detailed information about the partner organisations' planned intervention, division of labour within their project, their current pooled resources, the resources they would require from the Screening Programme, their capacity-building needs, their project management structure, etc. Screening Programme staff were present at these workshops in order to gain a close understanding of the nature of the projects and partner agencies that they will be supporting.

Both phases are presented diagrammatically below. They are described in detail in the remainder of the report.

**Diagramme 1: Summary of the Scoping Project**



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## 2.0. SCOPING: PHASE ONE

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### 2.1. Selection of areas for scoping

In an inception meeting between the NHS SC&T Screening Programme and ETHNOS in February 2006, the Programme identified a number of geographical areas within which they wanted ETHNOS to scope possible organisations to engage in a number of community-based health promotion pilots.

A number of areas around England were chosen based on the size of the ethnic communities disproportionately affected by SC&T (e.g. Pakistanis, Bangladeshis, Black Africans, Black Caribbeans) and the differing nature of the local communities themselves (e.g. settled or recent communities, traditional or more acculturated communities). After discussion with ETHNOS, the initial areas selected by the Programme were:

- Tower Hamlets for the Bangladeshi population
- Southwark for the Black African (settled) population
- Blackburn and Darwen for the Pakistani population
- Bedford for the Black African (recent) population
- Barking and Dagenham for the Black African (recent) population

### 2.2. Development of scoping questionnaire

A questionnaire was developed to conduct telephone interviews with potential partners within each area. It was developed as a template that would support consistent administration across different members of the scoping team with the gathering of common and comparable information (see Appendix 1).

The questionnaire was designed to gather the following information:

- Organisation type and remit
- Target audiences
- Key skills and main activities currently provided
- Involvement in multi-agency partnerships
- Local knowledge base
- Perceived need for public education on SC&T in their target audiences
- Perceived interest in the Screening Programme
- Perceived priorities for the Screening Programme
- Current strategies to access target audiences
- Interest in partnering with the Screening Programme
- Staffing levels
- Length of time in existence
- Current funding
- Capacity-building needs

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### 2.3. Development of scoping database

Through web-based literature search, telephone enquiries and the accumulated knowledge and experience forged through previous ethnic minority health work within ETHNOS itself, there were an initial total of 149 organisations identified across the five areas that could form potential partners for the Screening Programme as part of the first phase. The scoping team were able to make contact with 85 from the 149 organisations. From these initial contacts, the questionnaire was completed with 45 organisations. The total breakdown of contacted organisations can be seen in Table 1 below. Each completed interview lasted between 15 and 30 minutes and followed the questionnaire as described above (see Appendix 1).

### 2.4. Initial findings

From the scoping interviews, there were a number of key points that could be identified across the range of organisations contacted.

- **Size of organisations**

The size of organisations varied. Some were run on a voluntary basis by motivated individuals, while others were large, long-established, and well-resourced organisations with several full-time equivalent employees as well as volunteers. This variety had implications for the Programme and the potential partners it could engage. For example, very small organisations would require a significant amount of capacity-building and ‘pump-priming’ in order to be able to support a project. While smaller organisations could be paired with larger organisations to support this, it would be unlikely that they would be able to support a pilot project on their own, or in partnership with other small-sized organisations since the level of requisite project management would be too high.

- **Knowledge of SC&T**

While a minority of smaller organisations had specialist knowledge of SC&T, the majority did not and they looked to the Programme or other agencies to supply this expertise. Some of the larger organisations had extensive experience of conducting health-related projects at a community level, while others had much more limited experience of conducting health-related projects.

All organisations expressed an interest in working with the Programme to raise awareness of SC&T. All felt that there was a very low level of awareness of SC&T within their target communities and that work was needed to promote this. Many organisations noted that, for their community, there were limited available (financial) resources. What resources were available tended to be channelled towards prioritised areas (e.g. CHD and diabetes for South Asian communities, sexual health and HIV for African communities). As a consequence, other conditions became lower priority areas for community



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groups, even though associated health outcomes may be no less pressing for BME communities themselves.

- **Community-based approach to health promotion**

All organisations spoken to agreed that a community-based approach would be the most effective means of raising awareness of SC&T. A number of different strategies were identified within this approach, with differential emphases made according to different ethnic communities. The approaches included:

- a) **Outreach:** This was mentioned by all organisations interviewed. Suggested strategies included engaging with people in the communities where they live, either through formal (e.g. places of worship, community centres) or informal (e.g. hairdressers, ethnic food shops) networks, in order to disseminate SC&T promotional material as widely as possible
- b) **Workshops/seminars:** A common approach across many organisations has been the setting up of workshops at local community centres, places of worship and other relevant ethnic community spaces to disseminate SC&T and other health information to an audience of assembled local people. This intersects with the outreach approaches as identified above, but it includes a focused discussion on SC&T. The success of such an approach depends on the networks that organisations have into their community of interest. However, this approach requires communities to have some nominal knowledge of the issues or conditions at hand.
- c) **Peer education programmes:** Organisations suggested training people to be peer educators, an approach which had proved particularly successful with younger people in the context of HIV/AIDS and safer sex messages. However, very few agencies had the level of expertise and personnel capacity required to facilitate such groups in relation to SC&T.
- d) **Training programmes:** Organisations identified that this could encompass the development of training programmes for community workers as well as the production of training packs that could then be given as a product to other community groups. However, again, very few agencies had the level of infrastructure, personnel and expertise to engage in the production of such packs or in the training process.
- e) **Drama-based interventions:** Some agencies identified how engaging (particularly young) people to produce a drama that illustrated multiple SC&T case studies and narratives could be a very effective and potentially culturally-sensitive way of raising awareness around SC&T. Agencies identified that production of a drama performance in DVD format or development of a Powerpoint presentation illustrated with drama vignettes would be an effective way to communicate about SC&T across community groups and to enhance the acceptability of the Programme.

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- f) Developing local media campaigns:** This approach was seen as cross-cutting of other approaches in communicating the awareness-raising message across local ethnic media (e.g. newspapers, magazines, radio), through drama, interviews with experts, interviews with sufferers, etc. Some organisations also suggested targeting of local mainstream media to promote awareness of SC&T.
- g) Other:** Organisations identified a number of miscellaneous approaches such as one-off conferences, roadshows, stands at fetes and community festivals etc as ways that they had engaged the local communities to raise awareness of health conditions. They also mentioned some approaches (e.g. such as working with schools) that are beyond the remit of the pilots that could be considered by the Screening Programme.

▪ **Geographical differences in infrastructure of community organisations**

The scoping exercise revealed that the structure of the voluntary and community sector differed markedly from region to region. This had implications for those organisations that the Screening Programme could potentially partner with. While there existed a few large and well-established organisations (e.g. Social Action for Health in Tower Hamlets), in other areas, there were a number of small to medium-sized organisations that had experience of health promotion projects focused on African communities (e.g. Southwark, Manchester).

At the time of scoping, Blackburn and Darwen had no single ethnic organisation that could act as a lead agency since the collapse of a local ethnic health forum in June 2006. Consequently, in this area, there were a number of smaller Asian organisations that could be brought together to form a consortium to deliver on projects but no obvious lead agency with the requisite experience and capacity. However, creating a consortium configuration would have required much time and effort to manage.

Within Bedford and Barking and Dagenham there were simply very few ethnic community-based organisations that had the capacity to deliver on the requirements of the Screening Programme (at least with respect to Black African communities). In these areas, a lot of work would be required to develop the capacity of existing organisations in order to function as a partner of the Screening Programme.

## **2.5. Initial findings: implications for the Screening Programme**

The profile of the community and voluntary sector in each of the potential areas (as described above) was presented at a meeting between ETHNOS and the Programme in June 2006. Given the differences in the community infrastructure of the differing areas, the Programme decided that the research should focus on areas where there are well-established community organisations that have the capacity to deliver on projects and are easy to partner for the Screening

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Programme. This meant identifying other areas in which further scoping work could take place. After deliberation, the following areas were identified:

- Tower Hamlets for the Bangladeshi population
- Southwark for the Black African population
- Bradford for the Pakistani population

## **2.6. Face-to-face interviews with organisations**

Potential partner organisations were identified and face-to-face interviews arranged in each of the three areas identified by the Screening Programme. The aim of the interviews was to gain further information about the organisations, their experience in conducting health promotion projects with their local communities.

Interviews were conducted with the following organisations:

### **a) Bradford**

- Bradford Voluntary Services
- Bradford PCT Equalities facilitator
- Bradford Keighley Voluntary Services
- Bradford Director of Children's Centres and Sure Start

### **b) Southwark**

- Health First
- Regional Care Advisor for Sickle Cell Society (South London)
- WoMan Being Concern
- African Advocacy Foundation
- Neovenator

### **c) Tower Hamlets**

- Social Action for Health

The interviews revealed that both Tower Hamlets and Southwark had organisations that have the capacity and experience to develop innovative projects to enhance people's awareness and understanding of SC&T and help make the message of the Programme acceptable to the target communities. However, this was not the case in Bradford.

Although Bradford had many community organisations, these tended to work with a narrow focus on certain communities or issues. There was little work occurring across groups. In order to access the wider Pakistani population, contacts suggested a range of local community and children's centres would have to be included in a partnership. In a similar situation to Blackburn, there appeared to be no overarching agency which could deliver a project. It was

decided that it would be impractical for the Programme to seek to develop capacity to the extent required in Bradford. Another area with a large concentration of Pakistani people had to be found, preferably based on the north of England. Based on these criteria, Manchester was selected. We followed the same process as elsewhere – identification of potential partner organisations, and telephone discussions followed by face-to-face interviews. This resulted in the identification of the potential organisations:

- Manchester Race and Health Forum
- Black Health Agency
- Manchester Sickle Cell and Thalassaemia Centre Manager
- Manchester Thalassaemia Support Group
- Pakistani Resource Centre

To sum up, the number of organisations contacted in each area for the scoping exercise can be represented in Table 1.

**Table 1: Total Organisations Contacted Per Area**

	Agencies identified	Contacts made	Telephone interviews	Face- to-face interviews
<b>Tower Hamlets</b>	41	22	8	1
<b>Southwark</b>	30	19	11	5
<b>Blackburn &amp; Darwen</b>	17	8	4	n/a
<b>Barking &amp; Dagenham</b>	16	1	1	n/a
<b>Bedford</b>	12	7	2	n/a
<b>Bradford</b>	28	23	14	4
<b>Manchester</b>	5	5	5	5
<b>TOTAL</b>	<b>149</b>	<b>85</b>	<b>45</b>	<b>15</b>

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## 3.0. SCOPING: PHASE TWO

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### 3.1. Partner organisations and potential projects

Face-to-face interviews generated a menu of potential outreach activities that agencies could potentially carry out with funding from the Programme. These were presented to the Programme during September 2006. For each area, partner organisations were identified together with their suggested projects. As can be seen below, some organisations were well placed to produce materials but did not have the community contacts to disseminate them; other organisations had extensive contacts with the local community and were very well placed to disseminate materials but lacked the skills to produce them.

#### 3.1.1. Tower Hamlets

Social Action for Health (SAfH) has been conducting health promotion activities for many years. Using a community development approach, SAfH's aim is to increase local people's active participating in improving their own health and well being. They have conducted numerous projects with the local Bangladeshi population as well as other ethnic minority groups resident in the Tower Hamlets area. Recently, they have extended their activities to cover other areas of London such as Hackney.

SAfH is a large, well organised, well resourced organisation. It has an annual turnover of over a million pounds with a large number of full-time, part-time and voluntary staff. The organisation has extensive experience of working with the statutory sector and would be an easy organisation to partner for the SC&T programme. Their Director, Elizabeth Bayliss, expressed a keen interest in the SC&T initiative. SAfH envisaged that their participation in the project could take many forms, including:

#### a) The development of training programme for community workers

The aim would be to train local people to raise awareness of SC&T amongst the Bangladeshi population. A training programme would be developed together with relevant training materials. The community workers would be taught various ways of communicating SC&T information to Bangladeshis. This could include a storytelling approach which has been used successfully in raising awareness of diabetes.

#### b) A local media campaign

The focus here would be to develop a local media campaign to raise awareness of SC&T. The campaign would make use of local radio and print media directly aimed at the Bangladeshi population together with leaflets and posters. A toolkit would be developed on ways of engaging with local media that could be used in other parts of the country and with different populations.

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### **c) A forum theatre**

This approach would use actors drawn from the local community (rather than paid professionals). Individuals would be trained to perform live theatre describing and dramatising various issues linked to SC&T. This would normally consist of a 'troupe' of 10-12 people who would then go out to community centres to present their scenarios.

### **3.1.2. Southwark**

Southwark has a robust voluntary and community sector working with the Black African population. Two types of interventions were suggested; drama on DVD and local workshops.

#### **a) A drama on DVD**

The key organisation to partner with would be WoMan Being Concern (WBC). The main focus of this organisation is on community participation. It has wide informal networks into African communities. The organisation has been established for about 5 years. It has 2 full time staff and 30 volunteers. WBC has been involved in a number of health campaigns, including work on SC&T for Lambeth, Southwark and Lewisham PCT. It is coordinated by Mr Mohammad Haji-Kela. Executive members include medical practitioners, community trainers and, significantly, a lecturer in film at Westminster University.

The organisation is keen on developing a drama based intervention. They have experience of this, having already produced a film on fistulas in Africa and a drama on HIV in the UK. They suggest producing a drama that would be filmed and produced on DVD. The DVDs could be given directly to individuals or used in group situations. While WBC would be good for producing the Drama DVD they identified wider African community contacts for the dissemination phase.

Ms Iyamide Thomas is the Regional Care Advisor for South London on sickle cell. She has a long-standing interest in developing drama on sickle cell as she believes it is a powerful tool to dispel cultural myths and taboos. She is also in charge of programming for a new FM African radio station – another medium through which drama could be distributed as there will be 3 slots on health per week. She could help provide case studies for a drama-based intervention.

#### **b) Workshops, posters**

African Advocacy Foundation has a London-wide remit. It has 4 full time and 30 part-time or voluntary staff. The organisation has the capacity to work on an SC&T project though they would require expert knowledge about the condition. It represents some 11 African community groups in the area and so has good grassroots coverage. They produce regular newsletters and have developed various brochures. They suggest running workshops on SC&T and developing

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awareness raising posters. The organisation would be able to develop workshops and posters and to disseminate their outputs in the African community.

**c) Dissemination only**

Neovenator Community Organisation has been established for some 6 years. It is run by 8 volunteers. It has a focus on West African communities and has done much work on raising awareness of HIV and AIDS. The organisation was mentioned by a number of the other community organisations that were contacted during the scoping phase as one that has good reach into the African community. This organisation would be good for disseminating materials but does not have the capacity to develop them.

**3.1.3. Manchester**

The Black Health Agency was the main ethnic health organisation spanning a range of ethnic communities. Set up 16 years ago, it relaunched under its present name in 2002. It has 68 full time staff working in 20 languages and a range of health matters. BHA has Pakistani workers and volunteers who provide links into the community. It has a lot of experience of local health awareness raising activities. They suggested the following projects:

**a) Support materials for community workers**

BHA believes there are individuals working with local communities to raise awareness of SC&T, such as Mrs Rasul. However, they do not have the necessary materials to support them in their awareness-raising work. Thus, BHA would like to produce a range of culturally sensitive materials that could be used by community organisations and individuals. These would include such things as what information to give people and how best to do this together with information booklets that could be handed out to people from the community. The local Sickle Cell Centre also suggested involving Rehana Khan, a scientist based at Manchester hospital Genetics Department who has researched how to raise awareness of SC&T amongst Asian populations.

**b) Local media campaign and outreach**

BHA suggested conducting a local media awareness campaign together with outreach with the range of local community organisations, institutions and networks that they had amassed over time. In addition, smaller Asian community organisations would be involved in this process. Promotional materials would be produced for the campaign. The whole process would itself be documented so that it would function as an instructive 'how-to-do' guide for other organisations to deliver in their local communities.

BHA has the experience and capacity to carry out these projects. They would also be able to disseminate them through their links with other community organisations. Once such organisations would be the Pakistani Resource

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Centre. The Pakistani Resource Centre was established some 40 years ago. It has very good links into the Pakistani community. Its focus is wide-ranging and includes social and legal welfare as well as health. They have conducted workshops with local Pakistanis on raising awareness of such issues as diabetes and hereditary illnesses. The organisation would be good for disseminating rather than producing resources.



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## 4.0. PROJECT DEVELOPMENT

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### 4.1. Selection of partner agencies

Following presentation of the different potential options for public outreach projects, the Screening Programme decided that the following organisations should be enlisted in the development and dissemination of resources:

- Social Action for Health: focussing on the Bangladeshi community in Tower Hamlets
- WoMan Being Concern: focussing on the African communities in Southwark
- Black Health Agency: focussing on the Pakistani community in Manchester

As discussed in chapter 3, each organisation had offered a menu of different potential activities that they could do within each project. The task at hand was now to specify the activities that could be practically be achieved by organisations in the context of local agencies' capacity and expertise and the overall budget that may be available for each project.

### 4.2. Meetings to formalise partner agency activities

In December 2006, three meetings were convened by ETHNOS with the aim of bringing together key members of the Programme and the partner agencies.

Key Programme members were:

- Programme Implementation Manager: Sandra Anglin
- Communications Consultant: Liz Aram
- Communications Administrator: Kemi Johnson

Project coordinators and/or senior management from each of the three lead agencies also attended the meetings. In addition, a consultant to the Programme (Peter Finegold) attended the meeting with the Manchester agency. The emphasis of meetings was informal. From the Programme's perspective, these meetings aimed to:

- Establish a relationship and dialogue with lead agency partners
- Explore lead agency ideas for the projects and support needed
- Clarify the aims and objectives of the project
- Ensure that the partner agencies feel fully involved with setting objectives and agree that they are realistic and achievable.

Prior to each meeting agencies were sent a brief. This brief asked them asked to consider:

- the likely resource inputs that the agencies could provide (e.g. experienced personnel, administrative support etc)
- the kinds of inputs that they would expect the Programme to provide (financial, clinical expertise etc)
- thoughts on personnel who would be involved from their organisation, who would manage the project from an agency perspective and if there were other agencies or individuals who might be involved,
- potential project timeline in order to have successful impact
- rough idea of financial support needed
- preliminary thoughts about realistic aims and objectives for the project and it might be evaluated
- ideas about how the work might be sustained in the medium and longer term and what resources/support this would entail
- issues of transferability: the correct balance of specific relevance to the local population vs. providing wider learning and relevance across other contexts
- language and translation issues for this project
- potential communication challenges
- role and relationship with SC+T voluntary sector

In addition, a set of further specific questions were put to each partner concerning their specific projects. This can be seen in Appendix B.

Each meeting was extremely useful in identifying the specific activities that agencies could realistically lead on within their project. On the basis of the discussions, agencies were asked by the Programme to submit a short proposal on their projects outlining their potential activities. Agencies were also asked to confirm their attendance at a workshop that would bring all partners together. This is discussed in more detail below.

### **4.3. Project proposals**

#### **4.3.1. Black Health Agency**

The focus of the BHA proposal is on training outreach workers to deliver awareness-raising of thalassaemia amongst the Pakistani community within Manchester. This will be facilitated in conjunction with supporting partner agencies such as Manchester Sickle Cell and Thalassaemia Centre and the local Sickle Cell Society. They anticipate training Community Development Workers for them to better understand the biomedical issues concerning Sickle Cell and Thalassaemia, with specific training and information resources (e.g. Pegasus) provided by Screening Programme. Using those existing BHA workers already engaged in targeted health promotion with Pakistani communities, a Community Development Worker would lead on facilitating Thalassaemia awareness and related screening issues. Examples of existing BHA projects and related workers includes 'Reaching Out' and 'Routes' whose workers/volunteers are fluent in South Asian languages such as Urdu and Punjabi. There would be production of a training manual in order to maximise the mainstream profile of the project both locally regionally and nationally.

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### 4.3.2. Wo Man Being Concern

The project aim is to develop and produce culturally sensitive information, education and communication material in the form of a drama edited on a DVD, with the aim of raising awareness and enlightening African and Caribbean communities on Sickle Cell and Thalassaemia in Southwark. The project will identify voluntary and statutory organisations such as SLAWO, Neovenator, NHS (Health First) and people affected with and by SC&T. Community members will be recruited to serve as actors. The drama will be made into a DVD formats with information prompts/links relating to issues raised in the drama at intervals. The intention is for the DVD to be played on a computer and/or DVD player by groups or individuals. Voice over and/or subtitles in French and possibly one other African language will be included to ensure we reach a wide range of communities.

The DVD will be distributed through various workshops with BME community groups within and beyond the African Health Forum, statutory organisations, and individuals. Various workshops will be organised in partnership with community based organisations, on how to use the DVD as an effective medium to raise awareness on issues related to SC&T with a focus on health professionals working with Africans in various locations, as well as opinion leaders and their communities at informal gatherings such as parties, naming ceremonies, cultural restaurants, barber shops and homes of friend and families.

### 4.3.3. Social Action for Health

Social Action for Health has an established spiral of participation approach to their community outreach work. This starts at the very basic grassroots approach within the community (e.g. talking to community and religious leaders) and then builds upwards (e.g. once an issue has been approved, then holding workshops and groups etc). It is this approach that it proposes to adopt in developing an outreach health literacy project in Tower Hamlets targeting excluded Bengali and Somali communities.

The 2 elements to the project will aim to:

- Establish what the Islamic religious position is in relation to knowledge gained through ante-natal screening
- Include within Health Guide sessions on maternity, specific information on screening for sickle cell and thalassaemia

Discussions will take place with Imams about the Islamic religious view of the practical implications of screening so that health Guides can inform people accurately if asked. Bengali and Somali Health Guides will be trained by health professionals in the specific issues around screening so that they can enable people to make informed choices. They will run community health guide sessions, with a focus on maternity and the pathways to care and support that are currently being developed by health guides in consultation with local

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people. The Health Guides will run sessions in various community settings. They will draw participants together, encouraging them to share their experiences and talk about their concerns, helping them to explore these so that they are empowered to make informed decisions about the risks associated with sickle cell and thalassaemia. Documentation of this whole process will be kept for reporting. This will provide invaluable feedback to policy makers so that they can be informed of the issues and experience of local people, to contribute to the learning about how best to develop the process of screening of genetic disorders in all communities.

#### **4.4. Workshop**

In January 2007, a workshop was held involving the three lead agencies, representatives of the SC&T voluntary sector, local clinical experts and key Programme team members. The workshop provided an opportunity to:

- Consider the aims and objectives of outreach in the context of the wider strategic vision for SC+T screening
- Review the planned activities (with each organisation presenting a short overview of their project plan)
- Share ideas and expertise and identify potential synergies across projects
- Consider issues such as appropriate partner involvement (particularly the voluntary sector in SC+T), project sustainability, and principles underpinning evaluation (eg what success would look like).

Presentations were made by Programme members and each of the three local delivery agencies. This was followed by a session in which delegates broke into small groups to consider a number of issues relating to each of the 3 projects (see appendix C).

##### **4.4.1. Workshop outcomes**

The workshop was well attended by the three delivery agencies, local and national sickle cell voluntary sector and service representatives as well as the Programme Secretariat. In informal feedback, delegates identified that the usual process for their involvement with commissioners was to be assessed on the strength of their submissions alone, sometimes supported by a following interview. This process was felt to favour larger, well-established agencies over smaller and more narrowly focused ones. Agencies felt the scoping process added value because it assessed capacity and other competency issues that meant that the most appropriate agencies were identified, rather than ones who could simply field the best proposals. Delegates welcomed the opportunity to hear from Programme and other local agency staff. This enabled participants to learn about the wider context of the SC&T programme and where their own outreach work fitted in. It provided them with an opportunity to detail their proposal and to open them to expert scrutiny.

In the second half of the workshop, the delegates were split into 3 smaller groups, the first focusing on the Social Action for Health project (Tower Hamlets), the second on the WoMan Being Concern (Southwark) project and the third on Black Health Agency (Manchester). The relevant delivery agency representatives and local partners were involved in each group. Each group was asked to consider a number of questions in relation to their project in addition to any that they raised themselves. Feedback on each theme under each project is outlined below.

### **WoMan Being Concern (WBC) drama DVD project**

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#### ***Evaluation and monitoring***

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A mixture of quantitative and qualitative methods would be used to:

- Identify how many people have accessed or watched DVD
- Identify how many organisations have enquired about the DVD
- Evaluate the networks that have engaged in disseminating work
- Assess the level of knowledge of SC&T and screening in the target community

A benchmark is needed against which evaluation can take place. This could use:

- Uptake of screening
- User feedback (e.g. through an internet site or various other formats)

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#### ***Involvement of the SC&T voluntary sector***

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- Work with the SC&T sector to identify and deliver appropriate evaluation indices and methods
- Train community members (actors, people disseminating the DVD)
- Work with Iyamide Thomas to develop the script
- Ante Natal Clinic – accessing of clinic would be useful. ETHNOS have experience of best routes in and WBC could ask them for advice.

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#### ***Balancing key messages with local consultation***

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A number of issues are relevant to the balance of national-level Programme messages with local-level issues:

- Local communities wanting to sweep such issues under the carpet
- Macho perspective that will have to be negotiated in trying to engage men
- Perception of SC&T stigmatises or blames women for the condition
- Barriers to involvement of men in ante-natal clinics with stereotypes/set perceptions
- Widespread misperceptions and myths surrounding SC&T
- Need to spell out risks extremely clearly in terms of pre-natal diagnosis
- Religious issues or objections that may arise for this project. Religious issues need to be considered *in conjunction* with existing clinical and medical knowledge and how this is used by people (what balance is struck). This will differ from person to person
- Wider health beliefs are important. For example, there is a perception that penicillin should not be given to children amongst some African communities.

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#### ***Expert patient programme***

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This option was felt to be too formalised for the context of the drama DVD project at present. Those who disseminate DVD or actors who are trained up in SC&T were felt to need an informal training package. For some, there was lack of clarity over what an expert patient programme would comprise of.

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### ***Sustainability***

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- Production of a DVD was in itself is a positive tool for sustainability since it could be used as a promotional tool in other communities beyond the life of the project.
  - Forging collaborative links and workstreams with Southwark PCT was important in that it may allow the project to tap into resources (if under the remit of relevant National Service Frameworks). There is an SC&T board at Southwark PCT of which Iyamide Thomas is a member (the Partnership Action board). Patient and public involvement group (PPI) at PCT is also an important forum to contact.
  - Embedding the project in wider networks. WBC have access to the African Health Forum (regional), the African HIV Networks(National) and Minorities in Europe (European)
- 

### ***Synergies***

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- Health guides and training: there is the possibility of joint work across the projects or at least each set of training informing the others since there will be common elements to the training that workers from all 3 projects will receive
  - Cultural issues: for example, Islamic considerations will resonate across focus communities in each project. Mutual learning could be facilitated around the differing ways that links are made with religious leaders for instance.
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### ***Meeting up again***

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- Informal network meeting would be best, perhaps once every 3 months.
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## **Social Action for Health (SAfH)**

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### ***Evaluation and monitoring***

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Outcome measure identified included:

- Number of sessions conducted by the Health Guides
- Number of people attending sessions
- Increase in knowledge about SC&T amongst those attending

There was discussion about the possibility of producing case studies describing the experiences of individuals who had attended a screening programme and been identified as a carrier. However, there was uncertainty as to whether this would be possible due to confidentiality issues.

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### ***Involvement of the SC&T voluntary sector***

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- SAfH have extensive experience of working sensitively with their local mosque on health issues. They intend to consult with key members of the mosque as part of the SC&T project. Working with mosques was thought to be an important skill to transfer to other agencies working with Muslim communities. There was however uncertainty as to how this could be done or this aspect of the project evaluated.
  - The involvement of the SC&T voluntary sector was thought to be important especially in helping the Health Guides develop their expertise in SC&T.
- 

### ***Balancing key messages with local consultation***

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The main issues identified by the project were:

- Avoiding stigmatisation of individuals affected by the condition
  - Involving men
  - Dealing with any objections raised by religious leaders to the issue of termination
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### ***Sustainability***

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SAfH have a number of Health Guides working with the local community on various health issues. It was felt that once trained on SC&T, these Health Guides would continue to promote SC&T after completion of the project. Discussion would also take place with the local PCT to determine what support they would be able to provide for the continuation of the project.

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### ***Synergies***

- Although working with the Bangladeshi and Somali communities in relation to this project, there is a large Caribbean and African population within the areas SAfH operate. SAfH could disseminate the DVDs produced by WBC amongst these population.
  - SAfH are keen to share their experiences of working with local communities and to learn from the other project. There was a suggestion that individuals from each of the three projects could spend time with other project to share the learning.
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## **Black Health Agency**

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### ***Evaluation and monitoring***

- For BHA, success would be to produce a reproductive training package which could be taught and understood by the health workers, via optimum training. The Health Workers in turn, could relay their knowledge to various community groups, with the help of learning resources such as pictorial flip cards and leaflets.
  - Proposed evaluation techniques were to conduct a comparable analysis on the quality of access into the maternity services for new arrivals from Pakistan, with the general population in Manchester and measure the outcome.
- 

### ***Balancing key messages with local consultation***

- The group discussed the importance of looking at existing work around community engagement in the Manchester area. Suggestions were made for the Black Health Agency to make contact with Rehana Khan of the North West Genetics Knowledge Park organisation who has produced some pertinent work.
  - There were some concerns that if GPs do not subscribe to the idea of early antenatal screening for SC&T, this could cause a backlash when the Programme is trying to raise awareness through the community outreach programme. Presuming that the project is successful, women and their families may become discouraged if they do not receive the service and additional knowledge that they have been promised.
  - BHA suggested recruiting GP representatives to its proposed steering group. BHA have formed relationships with some GPs in the area and would endeavour to involve them to overcome the problem anticipated above.
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### ***Sustainability***

BHA could identify organisations to take over the work when the project ceases. One area felt to be of importance was that of targetting schools. Suggestions were made for BHA to contact Kate Matherson who has done a lot of work with schools and has formed strong networks in this area.

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### ***Funding***

BHA suggested that funding could be sought from Connecting for Communities Plus and that this should be further investigated.

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At the end of the workshop, delegates agreed that the following objectives had been achieved during the day:

- A relationship between partner agencies had been established allowing agencies (and their partners) to see the project as a whole
- Agencies had been briefed on the wider context of SC+T screening
- Basic principles underpinning evaluation had been initially explored
- A level of interaction between projects had been mooted
- The core key messages had been reviewed
- Initial consideration had been given to how sustainable results could be achieved
- The role of SC+T representatives within projects had been raised and/or identified across projects
- Adopting an expert patient programme for SC&T was felt to be too formalised an approach for projects at this juncture

The next steps for the agencies, partners and the Programme will be to conduct contract meetings which detail the timeline and activities of each project in turn. This will be achieved through 3 individual meetings in Southwark, Manchester and Tower Hamlets respectively in February/March 2007.



## APPENDIX A

### NHS SICKLE CELL & THALASSAEMIA SCREENING PROGRAMME

#### OUTREACH PROJECT: TELEPHONE SURVEY

##### General introduction

My name is ----- . I am ----- at ETHNOS, a company that specialises in research with the ethnic minority populations. I am contacting you now because our company has been tasked by the NHS Sickle Cell and Thalassaemia Screening Programme with identifying organisations that could get funding from the Screening Programme in order to develop and deliver outreach programmes to improve people's knowledge and understanding of sickle cell and thalassaemia, and their uptake of antenatal and newborn screening for these conditions.

I would like to speak to the Director or Manager of your organisation, to find out whether your organisation is both willing and able to participate in outreach work with the local Black African/Pakistani/Bangladeshi population.

##### Introduction for Director

My name is ----- . I am ----- at ETHNOS, a company that specialises in research with the ethnic minority populations. I am contacting you now because our company has been tasked by the NHS Sickle Cell and Thalassaemia Screening Programme with identifying organisations that could get funding from the Screening Programme in order to develop and deliver outreach programmes to improve people's knowledge and understanding of sickle cell and thalassaemia, and their uptake of antenatal and newborn screening for these conditions.

Would you have 15 minutes to answer a few questions and to discuss your possible involvement in a public outreach project in partnership with the NHS SC&T Screening Programme and others?

The aim of today's telephone survey is only to find out more about your organisation (i.e., relevant experience, current projects and target audiences), any experience your organisation has in conducting outreach projects, and what you think your organisation could contribute to a public health education outreach programme. We are looking for organisation that would help design, develop, deliver and disseminate health information on SC&T and the Screening Programme in different formats and for different groups at high risk of SC&T.

**Note:** Sickle Cell and Thalassaemia are health conditions that disproportionately affect specific BME groups. The highest prevalence for Sickle Cell disease is amongst black Caribbean, black African and black British populations. The highest prevalence for Beta Thalassaemia is amongst Cypriot, Italian, Greek, Indian, Pakistani, Bangladeshi, Chinese and other South East Asian populations).

## 1.0. Call history

Interviewer: NC / CM / MCG / HR

Organisation ID:

Date of 1<sup>st</sup> call: \_\_\_\_\_ Time: \_\_\_\_\_

Date of 2<sup>nd</sup> call: \_\_\_\_\_ Time: \_\_\_\_\_

Date of 3<sup>rd</sup> call: \_\_\_\_\_ Time: \_\_\_\_\_

## 2.0. Description of organisation

2.1. Name of the organisation: \_\_\_\_\_

2.2. Name of the contact person: \_\_\_\_\_

2.3. Title of the contact person: \_\_\_\_\_

2.4. Geographical Area:

	Tower Hamlets
	Southwark
	Blackburn & Darwen
	Bedford
	Barking & Dagenham
	Manchester

2.5. What kind of work do you do? Is it focused on:

	SC&T specific
	Health in general
	Social welfare in general
	Other:

Comment

**2.6. What are the target audiences of your organisation?**

**Comment**

	All local population (non BME-specific)
	All BME groups
	All South Asian groups
	Black Africans only / mainly
	Pakistanis only / mainly
	Bangladeshis only / mainly
	Refugees only / mainly
	Youth (expected to be sexually active)
	Other:

**2.7. How long has your organisation been in existence?**

	Less than a year
	1 - 3 years
	4 - 5 years
	5> years

**3.0. Capacity of organisation**

**3.1. How many full-time equivalent staff have you got?**

\_\_\_\_\_

**3.2. Does your organisation have any experience of conducting any health campaigns?**

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

	None/limited
	Moderate/good
	Outstanding

**3.3. Can you briefly describe the most relevant projects you have been involved in?**

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**3.4. What are the main ways in which your organisation could conduct a health education project on SC&T for the “X” community?**

A) \_\_\_\_\_

B) \_\_\_\_\_

C) \_\_\_\_\_

#### **4.0. The NHS SC&T Screening Programme**

**4.1. Do you think there is a need for public education on SC&T in the “X” community?**

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No
<input type="checkbox"/>	Don't know

**4.2. What do you think of the key priorities in terms of reaching out to the BME communities about SC&T?**

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**Comment**

**4.3. Would you be interested in partnering with other organisations to design, develop and disseminate public health information materials on SC&T?**

**Comment**

	Yes
	No
	Maybe

**Reason:** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**4.4. Are there other organisations which you feel would be able and willing to deliver this outreach programme or to partner with your organisation?**

**A)** \_\_\_\_\_  
\_\_\_\_\_

**B)** \_\_\_\_\_  
\_\_\_\_\_

**C)** \_\_\_\_\_  
\_\_\_\_\_

**4.5. Is there anything else which we have not covered that you would want to add?**

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Many thanks for your time and expertise. We will put forward the results of this survey of organisations to the NHS Screening Programme. Together with a Steering Group, they will make a preliminary selection of organisations who could be involved in the outreach work and determine the terms of their involvement. We will contact you to let you know the outcomes of the selection process that are relevant to your own organisation.

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## Appendix B

### **Sickle Cell and Thalassaemia Screening Programme: Development of briefs for community organisations**

#### **Introduction**

As you know, ETHNOS has been supporting the scoping phase of community-based projects aimed at raising awareness of sickle cell and thalassaemia amongst a number of ethnic minority communities in different locations across the UK.

Having considered the options presented by ETHNOS, the Screening Programme now wishes to pursue the development of three projects – one with each of three organisations: Black Health Agency in Manchester, Social Action for Health (Tower Hamlets), Womanbeing Concern (Southwark).

Through discussions, each organisation identified a number of approaches it could adopt to raise awareness of sickle cell and Thalassaemia (SC+T) with their ethnic community of interest. These were presented to the Screening Programme, who would now like each agency to elaborate on this further.

#### **Suggested next steps**

The Programme has suggested a series of meetings to take this work forward.

Firstly, we would like to arrange an informal preliminary meeting with each lead agency. This would be for key members of the Programme team to meet you. These would be Sandra Anglin, Programme Implementation Manager; Liz Aram, Communications Consultant; and Kemi Johnson, Communications Administrator. In addition, the Programme would like to invite Peter Finegold who is working as a consultant on this project. Peter specialises in public outreach work – particularly looking at scientific and genetic issues. He also has extensive experience in working with drama projects.

This first meeting would be to establish a relationship, find out more about your work, set up a dialogue, explore your ideas for the projects and the support you would need from the programme and jointly plan the second meeting – a workshop.

The other key objective for the preliminary meeting would be to start to clarify the aims of the project. As these projects are – to some extent – pilots for future work, we will need to have a strong evaluation framework so that we can learn from them. Hence it is important to have clear aims and objectives against which we can measure success. It is vital that the partner agencies feel fully involved with setting objectives and agree that they are realistic and achievable.

The second meeting would be a workshop with all the local agencies. The intention would be for all the agencies to meet each other, to get an overview of the project as a whole, to explore synergies between the various activities, and for each agency to present their project to the wider group.

After the workshop, the Programme team would meet with you again to agree the specifics of your project so that formal contracts can be developed for you and for any supporting agencies including the voluntary sector in SC+T.

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In addition to this brief, the Programme will send you some background information about sickle cell and thalassaemia screening. It may also be helpful for you to know that the Programme is organising a national steering committee to oversee the public outreach project as a whole. They will be happy to share information about this group with you if you are interested.

Thank you for reading this brief and for the planning work you are doing to prepare for the various meetings. We look forward to working with you.

### **Brief for preparatory work**

In order to make best use of the preliminary informal meetings, it would be helpful if you could consider the questions below. It would also be useful if you are able to show the Programme team any relevant examples of existing projects/resources. We would appreciate it if you could read the brief in full (ie the questions for all the agencies) as there are potentially some synergies across all three projects.

If you have questions that you would like to put to the Programme team to inform these meetings, we will be delighted to hear from you.

Before looking at the individual projects, there are some generic questions/issues that apply to all the agencies. We would be grateful if you could consider:

- the likely resource inputs that your organisation could provide (e.g. experienced personnel, and admin support etc)
- the kinds of inputs that you would expect the Programme to provide (financial, clinical expertise etc)
- thoughts on who would be involved from your organisation, which other agencies or individuals might be involved, who would manage the project from your end
- timeline that, in your experience, such a project would take in order to have successful impact
- rough idea of financial support that you would need
- your preliminary thoughts about realistic aims and objectives for the project and how we might evaluate it
- ideas about how the work might be sustained in the medium and longer term and what resources/support this would entail
- issues of transferability. We want the interventions to be specifically relevant to the local population but also to provide wider learning. What is the right balance between these two aims?
- what are the language and translation issues for this project?
- what other communication challenges might we need to consider?
- we are keen to involve the SC+T voluntary sector as they are committed to our aims and are – hopefully – going to be around in the long term. How would you see the relationship between your agency and the local/national voluntary sector?

### **More detailed questions by geographical area**

#### **TOWER HAMLETS**

ETHNOS presented a number of options suggested by SAtH to the Screening Programme. The Screening Programme has now reflected on these and it is interested in exploring the three listed options below. In principle all the options sound valuable. However, we would like to review whether all three are realistic within the resources that you have and the support that we can offer. If not, which would you see as the priority?

### **a) Development of training programme for community workers**

The aim would be to train local people to raise awareness of SC&T amongst the Bangladeshi population. A training programme would be developed together with relevant materials for the public. The community workers would be taught various ways of communicating SC&T information to Bangladeshis. This could include a storytelling approach which has been used successfully in raising awareness of diabetes (You may want to consider inviting people from the diabetes project to the preliminary meeting if appropriate.)

#### **Questions to be addressed in the meeting:**

- Further information about how community workers currently engage with local Bangladeshi populations. This should include:
- Where community workers normally go when working with the community
- What an intervention would normally consist of
- For e.g. would this be a health professional talking to lay people? (where, how)
- How many people might they be talking to? Do these tend to be established groups eg an existing women's group or people convened specially?
- How long these would operate for (e.g. training and then dissemination)
- What kind of formats did you have in mind for resources eg do they need to be hard copy or is it possible to use other formats eg tapes, DVDs, ability to project people's video or audio stories via laptop/projector etc
- Do you like to include any peer element? For example, a person who has Thalassaemia or a carer talking about their personal experience?
- What would the storytelling approach consist of?
- What support would you need to develop a training programme and supporting materials e.g. clinical support on content, design and production, piloting
- To what extent do we want to develop materials specifically for a local Bangladeshi population? Are there differences between making a project specifically Bangladeshi or more broadly "Asian"? Are there particular local issues that would not be applicable to a Bangladeshi audience elsewhere?
- The Programme has an extensive training programme, PEGASUS. This is developing training resources for a range of health professionals. We would need to involve PEGASUS to ensure that training messages are broadly consistent. It will be helpful to consider how this could best be done.
- It will be helpful for you to read the section about proposed activities in Manchester. This also involves supporting community outreach. Might there be synergies between the two programmes? What do you feel about this in principle and in practice?

### **b) Local media campaign**

Development of a local media campaign to raise awareness of SC&T. The campaign would make use of local radio and print media directly aimed at the Bangladeshi population together with leaflets and posters - if appropriate. A toolkit would be developed on ways of engaging with local media that could be used in other parts of the country and with different populations.

#### **Questions to be addressed in the meeting:**

- The Programme has a contracted media agency, Media Strategy. How would you see the relationship between your organisation and Media Strategy?



- Personal stories – ie people with the conditions and/or carers are usually vital for media work. To what extent can the agency source such people or would Media Strategy need to do it
- To what extent can your agency field spokespeople and have they received any media training?
- Can you help with contacts of local journalists? What is your relationship with local media?
- Have you ever tried any more ambitious media approaches eg tie up with local radio station?
- Should we consider any paid approaches eg buying air time?
- What kind of resources would you envisage for the toolkit?
- The voluntary sector in SC+T might be a good source of casestudies and direct patient experience. How would you see such a partnership working in your area?
- Please look at the media proposal in Manchester. Would there be synergies with this?

### **c) Forum theatre**

This approach uses actors who are drawn from the local community rather than paid professionals. Individuals are trained to perform live theatre in the form of role plays for instance of a GP and patient interaction. This would normally consist of a 'troupe' of 10-12 people who would then go out to community centres to present their scenarios.

#### **Questions to be addressed in the meeting:**

- How realistic is it to do both the community outreach project and theatre work in your area?
- Do you envisage that the two projects would work together eg the theatre is part of the community outreach intervention?
- If we do both activities, to what extent could they be developed alongside each other?
- Please look at the proposals from Womanbeing Concern below. Might there be any synergies between the two proposed drama approaches?
- We would be interested to know more about typical dramas produced in this way eg how long are they? How much detail do they tend to cover eg for SC+T we can talk about the disorders and living with them, about screening, about wider social and cultural issues, about genetics. But we wouldn't want to overwhelm our audience. It would be helpful to talk about this albeit in a preliminary way.
- To what extent can we use theatre to establish a dialogue with our audience? For example, to explore issues such as:
- Does the community see 'advice' as information on which individuals can respond voluntarily or do they see it as mandatory?
- What differences exist between generations? Are there any issues relating to the use of language in connection with these conditions that could create differences in understanding between the health system and service users?
- What are the traditional conceptualisations of these conditions? How are they perceived in comparison to e.g. infectious disease, physical disability, mental illness...etc?
- What language would the drama be in? If English, would we envisage translating it or having some way to make it accessible to people who would struggle in English? Or have it in two versions?

- What would be the process for developing the drama? How much input would you need from the Programme/clinical specialists? Would you recruit and support the actors and arrange for performances? Who would advise on the drama?
- How would we take learning from this project to inform other drama approaches in other areas? Might the actors be prepared to perform the drama outside this geographical area? Could we make a video of the drama to use in other places?

## **SOUTHWARK**

ETHNOS presented two connected approaches for Southwark; drama on DVD and local workshops to disseminate it.

### **a) Drama on DVD**

Womanbeing Concern is keen to develop a drama-based intervention. They have extensive experience of this having already produced a film on fistulas in Africa and a drama on HIV (in UK). They suggest producing a drama that would be filmed and produced on DVD. The DVDs could be given directly to individuals or used in group situations.

Ms Iyamide Thomas is the Regional Care Advisor for South London on sickle cell. She has a long-standing interest in developing drama on sickle cell as she believes it is a powerful tool to dispel myths. She is also in charge of programming for a new FM African radio station – another medium through which drama could be distributed as there will be 3 slots on health per week. She could help provide case studies for a drama-based intervention.

### **b) Workshops to disseminate**

Once produced the DVD could be disseminated locally through workshops with members of local African communities. Womanbeing Concern will need to identify the partners they would need to engage to facilitate this (e.g. Neovenator).

### **Questions to be addressed in the meeting:**

- Clarify the rationale behind putting drama on DVD. Is that because it is a cost effective way of making a drama go further? Is dramatic effect lost on a DVD? Is it more powerful to just do the drama in several places? What are the advantages of the DVD approach?
- To what extent would Womanbeing Concern be prepared to take responsibility for the project as a whole ie acting as chief contractor and subcontracting and managing dissemination agencies? If not, how would you see your role? What support would be needed from the Programme in terms of recruiting and managing dissemination agencies?
- It would be helpful if you can describe the process for developing the drama. For example, how do you set about defining the issues, developing a script, consulting about clinical issues, consulting about local cultural issues, language issues? Who would you see as the key stakeholders in this process?
- To what extent can the drama enable us to establish a dialogue with our audiences? (See similar question to Tower Hamlets above.) In what setting would the DVD be shown and by whom?
- Can you brief us on the technical issues ie do you have the technical resources to actually produce the DVDs, edit the productions etc

- Logistics: do you recruit and manage the actors?
- Please look at the Tower Hamlets proposal for drama. Do you think there would be any synergies with this project? For example, you producing DVDs of their drama?
- How have previous projects like this worked in terms of dissemination? What are your relationships with the proposed dissemination agencies?
- We would like to discuss the balance question noted in the generic questions above. So, to what extent should the content be local and sickle specific? Or, how far can it touch on wider issues eg Thalassaemia, more generic cultural issues?

## **MANCHESTER**

After discussions, with the Black Health Agency in Manchester, the following proposals were put before the Screening Programme.

### **a) Support materials for community workers**

BHA suggests producing a range of culturally sensitive materials that could be used by community organisations (e.g. by Mrs Rasul, Thalassaemia Support Group at Manchester Sickle Cell Centre). These would include: what information to give people; how best to give people information; what information booklets to give to people.

### **b) Local media campaign and outreach**

BHA suggests conducting a local media awareness campaign together with outreach with the range of local community organisations, institutions and networks that they amassed over time. In addition, smaller Asian community organisations would be involved in this process. Promotional materials would be produced for the campaign. The whole process would itself be documented so that it would function as an instructive 'how-to-do' guide for other organisations to deliver in their local communities.

### **Questions to be addressed in the meeting**

- Please read the proposals for Tower Hamlets. Clearly there may be synergies between the two areas. What are your views on this in principle and in practice?
- For the outreach project, this proposal appears to assume that we are just producing resources for workers to give out rather than training the workers themselves. Is that right? Can we rely on that knowledge being accurate/consistent/sustainable if particular people leave? If we are producing training for the workers in Tower Hamlets, does it make sense to do this here too – in part so we can compare and contrast for the sake of a learning process? And if so, could we achieve synergies across the projects?
- We are particularly keen to address the needs of the Asian population about Thalassaemia. However, there is a strong local sickle group and potentially valuable support from Anthony Mason, the regional co-ordinator of the Sickle Cell Society. How do you feel about this? Would the intervention need to be very specific to thalassaemia or could it usefully cover sickle too?
- Mrs Rasul's organisation is also active in Manchester. How would you envisage working with this group?
- Also in Manchester is the North West Genetics Park. How might they be involved?
- It would be very helpful if you could elaborate on what kind of resources you envisage. Would these be in hard copy or in a range of media or both? What exists already?

- 
- What capacity do you have to physically produce resources eg copywriting, design, production, printing?
  - What kind of outreach work is done in Manchester? Please give us a sense of who you are talking to, what settings, what numbers, what languages etc.
  - Who are the outreach workers that would use the resources? Are they in one organisation or across several eg BHA and the voluntary sector? How many are there and how would we assess the effectiveness of their interventions?
  - How would you see the process of developing the resources? What support would you need from the Programme?
  - For the media project, would you see any synergies between this and Tower Hamlets?
  - How would you see the potential relationship with the Programme's agency, Media Strategy?
  - To what extent are we looking at paying for media coverage or establishing some more formal working relationship with key media? Eg a roadshow with local radio station?
  - How do you plan to source case studies of people who have the conditions or carers?
  - What process would you envisage for dissemination?

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## APPENDIX C

### Agenda for 30 January 2007 workshop

#### 11.00 Introduction (ETHNOS)

- Round table introductions
- Overview of day
- Objectives
- Chance to share and swap experience
- Emphasis on informal and informative approach
- Housekeeping

#### 11.15 Sandra Anglin

- Wider SC&T context
- strategic vision for screening
- closer integration of screening and care
- SC&T as part of national screening programme
- SC&T in context of other agendas
- Importance and commitment to public outreach
- First of screening programmes to robustly address etc

#### 11.30 Liz Aram

- Where SC&T is with delivering screening
- Public outreach and communications strategy
- Key messages

#### 11.45 Coffee

#### 12.00 Social Action for Health

Presentation of proposal including:

- Community of interest being focused on
- Rationale and focus of project
- Staff involved, who partnering with
- Expected inputs and outputs
- Short Q&A

#### 12.15 Womanbeing Concern

Presentation of proposal as above

#### 12.30 Black Health Agency

Presentation of proposal as above

#### 12.45 Lunch

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### **13.15 Small group work**

Each group to focus on one project but to consider some cross-cutting issues:

- What would success for this project look like? E.g. learning about processes, improving knowledge of local audience, changing behaviour? How can we build in getting feedback from local audiences about both issues and this project? i.e. establishing some principles that can inform evaluation
- Is it realistic to build in some sustainability objectives? Might these be around supporting the development of local voluntary sector involvement? How could the SC+T voluntary sector be engaged in local projects/the project as a whole?
- Would it be helpful to establish an expert patient programme – for this project/across all three projects?
- How will this project balance conveying key Programme messages with responding to local information needs/wishes?
- Are there synergies across the projects? How could we achieve them – e.g. would there be value in all three agencies meeting occasionally?
- Are there other funding bodies that we should be approaching for the local project/the project as a whole?

### **14.15 Feedback from each group, discussion and action points**

### **15.15 Next steps (contract meetings) and close**