

The Family Legacy: An Innovative Approach to Raising Awareness of Sickle Cell Disease & Testing

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Screening Programmes

Sickle Cell and Thalassaemia



SICKLE
CELL
SOCIETY

Why do Outreach on Sickle Cell Disease (SCD) and Testing?

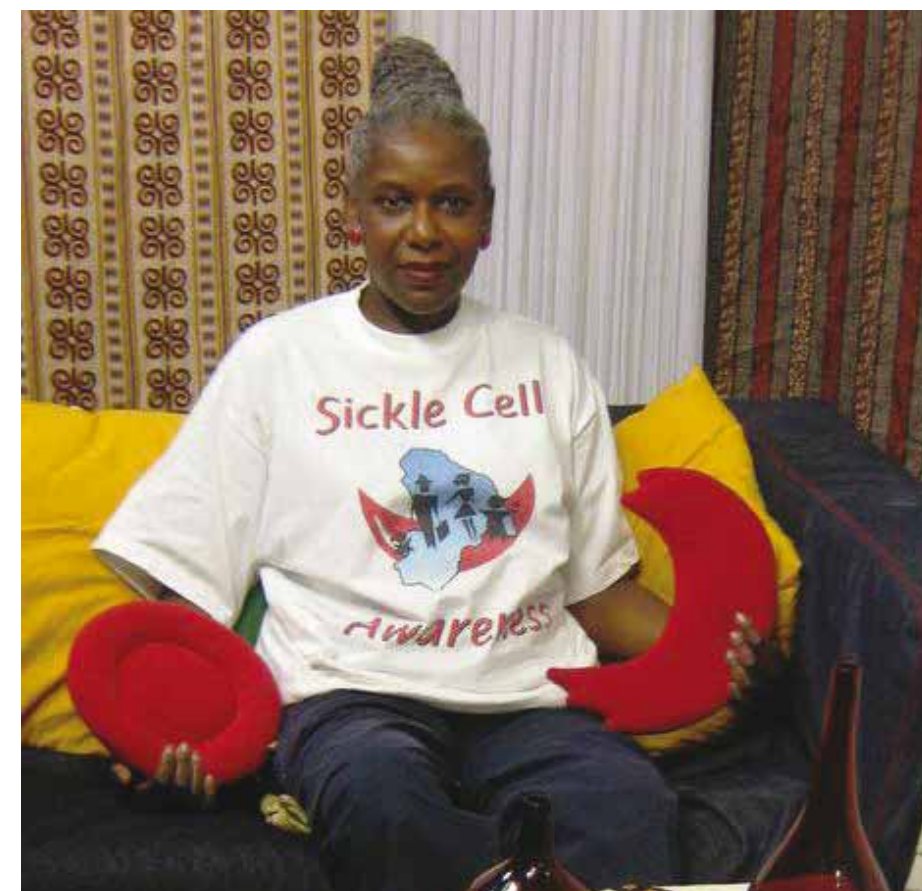
2001 UK National Health Service Sickle Cell and Thalassaemia Screening Programme (NHSSCTSP) - **Worlds' first linked programme of antenatal and newborn screening for sickle cell disease (SCD) and thalassaemia.**

2004 In high risk Africans and Caribbeans, found:

- SCD Awareness low
- Little or no knowledge of how inherited
- Lots of myths and stigma

2008 NHSSCTSP introduced 3 outreach projects so people could make informed choices about sickle cell disease and thalassaemia during pregnancy and before conception.

2009 Sickle Cell Society commissioned to deliver 'Family Legacy' (DVD) project.



"I am honoured to have contributed to the original idea of a DVD drama and to have served as an expert advisor on its production"

Iyamide Thomas
Sickle Cell Society (UK)



OBJECTIVES

- Raise awareness of SCD and testing
- Challenge stigma and misunderstanding
- Explain about SCD
- Explain basic screening choices

'Edutainment' Nollywood Style- The Screening Programme Scores a UK first!

Produced 24-minute British Nigerian DVD drama called the 'Family Legacy'

Drama educates about SCD, testing and associated myths

Story from real-life experiences of African and Caribbean Communities



Family Legacy Community sessions

- Introduction
- Film screening
- Living with sickle cell
- Discussion
- Evaluation
- Leaflets
- Food & Networking

The Mountain goes to Mohammed - to priority population wherever they are:

- | | | |
|------------------------|------------------------|------------------------------|
| • Family Homes | • Hospitals | • Black History Month Events |
| • Churches & Mosques | • Local Government | • Broadcast & Print Media |
| • Restaurants | • Community Events | • Barbershops |
| • Schools and Colleges | • Alumni Organisations | |
| • Libraries | • Francophone Events | |



50% of fathers-to-be whose partners carry the sickle cell gene are not accepting their invitation to be tested.

Coming to a GP Practice near You!

One minute film trailer on promotional TV at:

- GP Practices
- Health Centres
- Colleges

June 2010 Independent Evaluation

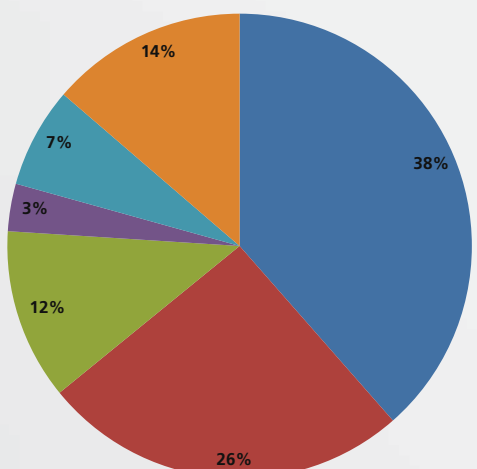
- Analyzed participant feedback forms
- Interviewed outreach workers
- Interviewed participants

Results from 1059 participant feedback forms by Feb 2012 showed:

- **76%** of respondents were Black African, Black Caribbean or Black British
- **31%** responded they were male, and **62%** said they were female
- The majority of respondents were aged between 16 and 49 years
- **74%** said they knew before that a blood test was available for sickle cell
- Only **50%** of respondents knew whether they were carriers
- **53%** of respondents who did not know their status said the film made them want to find out and **20%** were unsure
- **90%** agreed that screening should be offered to both men and women before starting a family (i.e. pre-conception screening)
- **68%** said that they had learnt something new from the session
- **84%** thought that the film captured the key issues and gave useful information on caring for someone with sickle cell disease

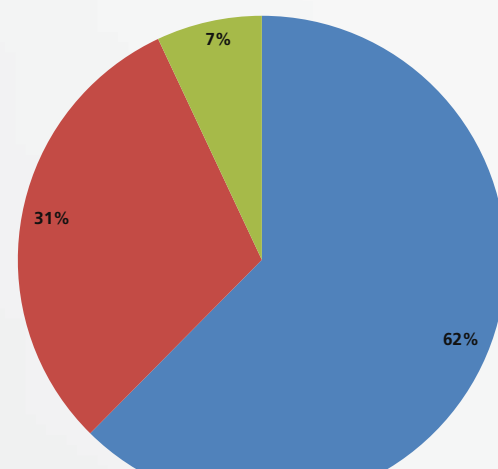
Which of the following best describes you?

Black African Black Caribbean Black British Asian European Other



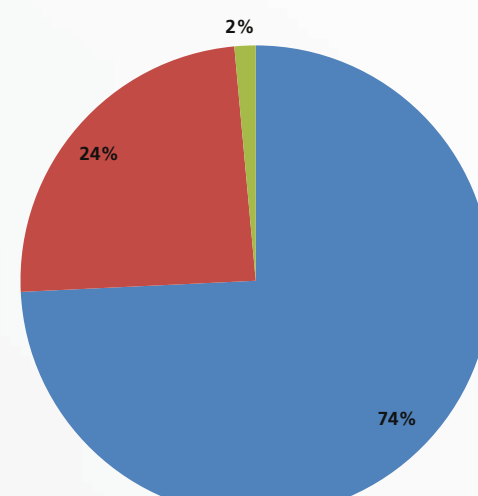
Gender

Female Male Blank



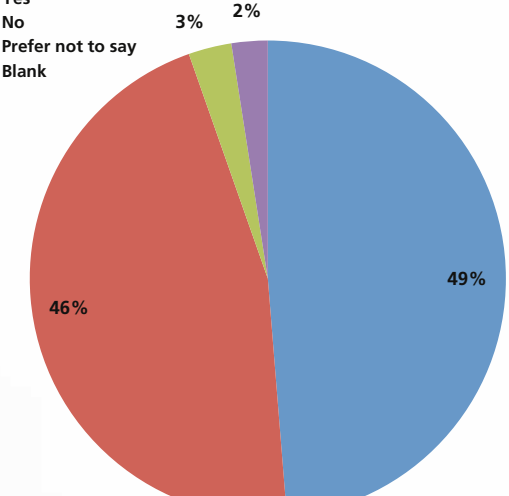
Before watching Family Legacy did you know that a blood test for sickle cell was available?

Yes No Blank

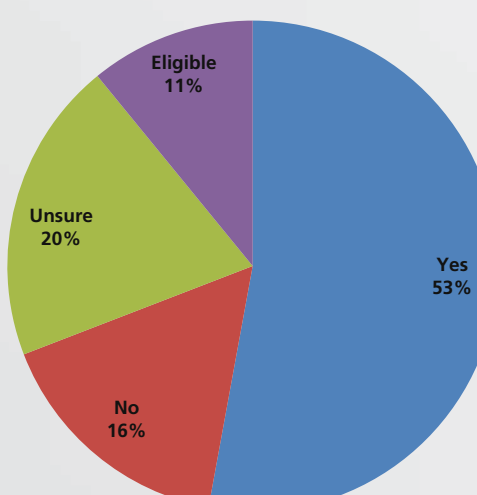


Do you know whether you carry the sickle cell gene?

Yes No Prefer not to say Blank

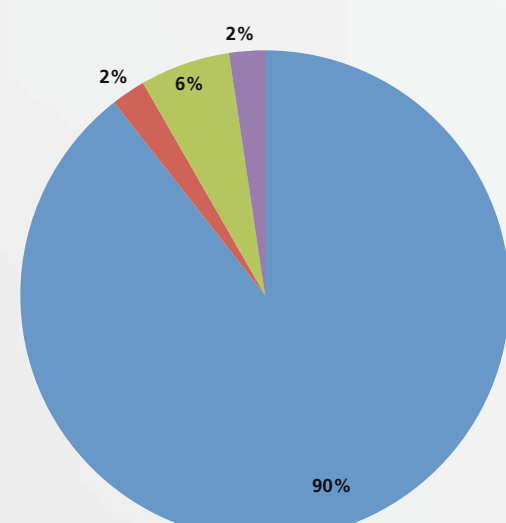


If no, has watching the Family Legacy made you want to find out?



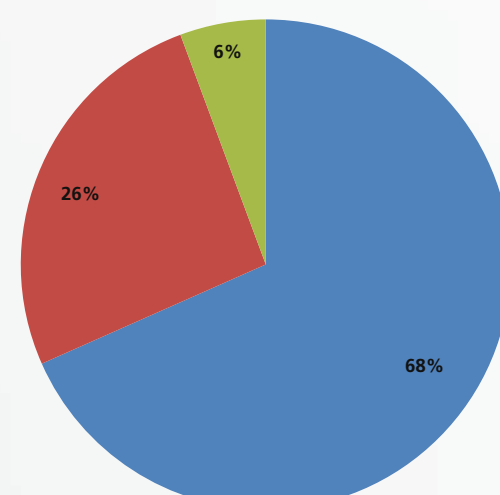
Do you think screening for SCD should be offered to both men and women before they decide to start a family?

Yes No Unsure Blank



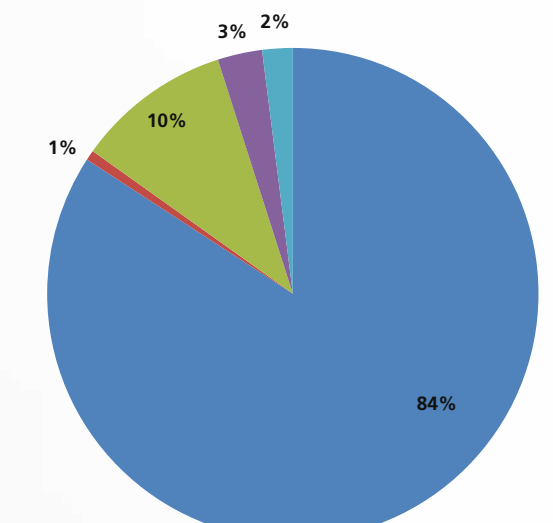
Having watched Family Legacy, did you learn anything new?

Yes Blank No



Do you think the film captured key issues around screening and caring for someone with sickle cell?

Yes No Partly Don't Know Blank



Discussion

Screening Programmes

Sickle Cell and Thalassaemia

What the Independent Evaluators Said

JUNE 2010

“These results clearly show that the sessions were meeting their objectives in raising awareness of SCD”

“The dissemination phase has been very successful”

“Innovative ideas for circulation now and in the future aim to ensure that the message reaches an ever widening audience”

“Extensive media coverage has meant that the DVD has now been seen by a wide audience both in the UK and abroad”

“Participants were very positive about the value of the sessions in raising awareness and 78% said they had learned something new”

What the Public are Saying

“This film was watched by my two sons aged 10 years and 7 years whom both found it very interesting, and learned a great deal that I could not have told them about the disease myself. Thank You. I will be passing on this information to all that I can”.

(Female, age 30 to 39, Black Caribbean in UK)

“I learnt that people could be ignorant and challenge the possibility that they carry the gene, but might change their minds through persuasion to get tested.”

(Male, age 40 to 49, Black African living in Ghana)

“I am a sickle cell sufferer and the film brought back many memories for me, as when I found out I was pregnant my partner also refused to take the blood test saying he did not have such illnesses in his family. I found the film very informative”.

(Female, age 40 to 49, Black British in the UK)

“Very nice film that tackled the issue of sickle cell disease and how it affects families. Nice acting. I am doing a play on sickle cell disease and breast cancer”.

(Male, age 16 to 21, Mixed White and Caribbean in UK)

Lessons Learnt and Tips on Good Outreach

- ✓ Consider culture and traditions of target group.
- ✓ Use experts such as retired sickle cell nurses to help deliver sessions.
- ✓ Grassroots communities often need incentives (e.g. food, hosting fees).
- ✓ Arrange family home sessions with ‘credible’ individuals.
- ✓ Be innovative – even if you are doing it for the Government!

Conclusions and Implications for Public Health

- Project demonstrates substantial information need amongst priority populations
- Proactive outreach is an effective way to engage audiences outside normal channels
- Contributing to NHSSCTSP core objectives of supporting informed choice, engaging men, developing materials for public and hearing their views
- NHSSCTSP to continue investing in outreach work and integrate into overall communications strategy
- NHSSCTSP now extending project around UK

Some Innovative Ways of Outreach



Sinto & Biggie Barbers



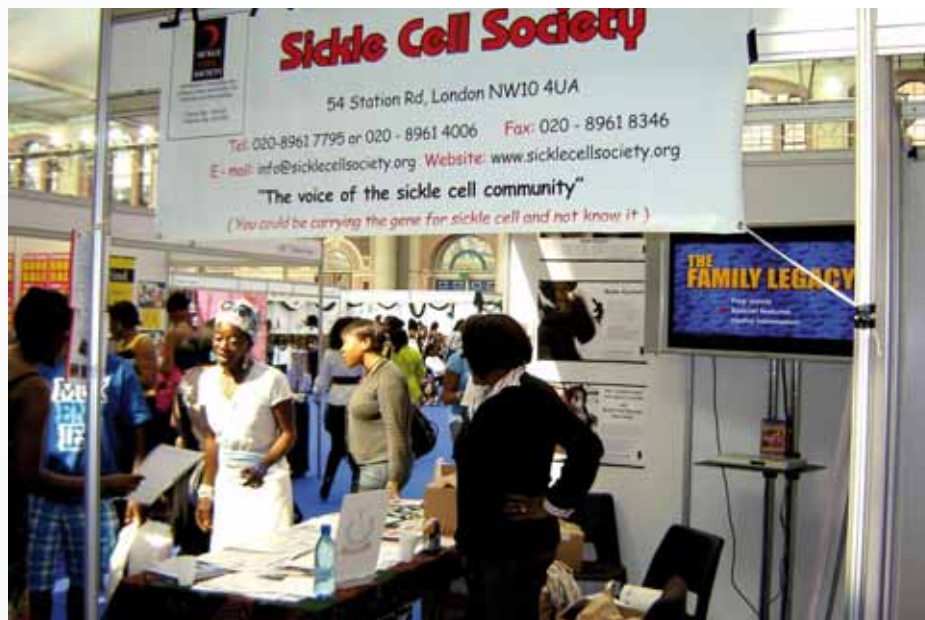
'Sinto & Biggie' - Our Pioneer Barbers



At Big Choice Barbers



'Men in Bags' at Better Cutz



Afro Hair & Beauty Show



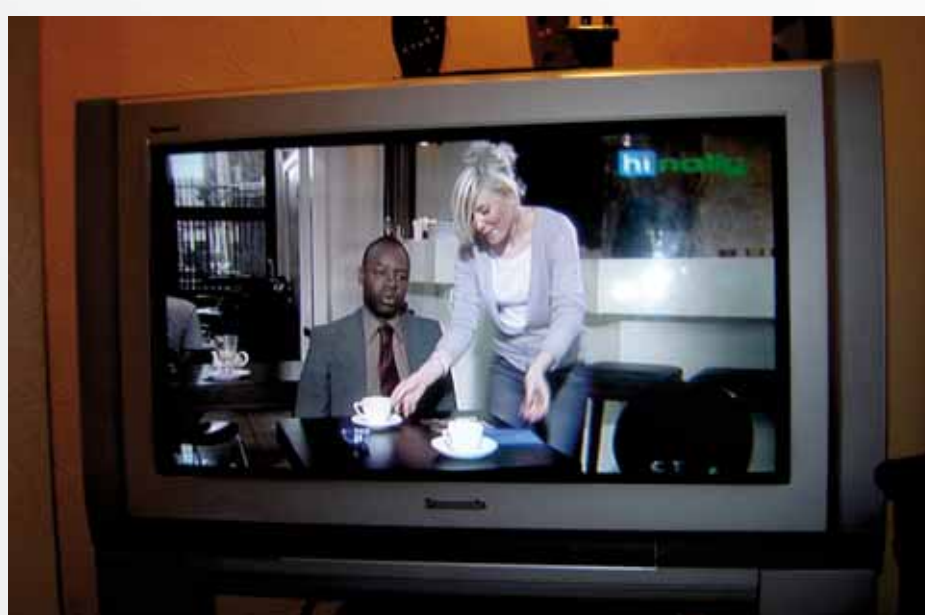
Lewisham People's Day



Expert Panel at the Africa Centre



Special session at the Africa Centre

Launch of
'Test for Dads' LeafletAde Aluko talks about
living with SCDFamily Legacy on 'Hi Nolly'
- Sky Channel 204Watch it here:
www.familylegacy.org.uk