

United Kingdom Thalassaemia Society



Thalassaemia Asian Awareness Campaign

Report of a three-year campaign
1997-2000



Acknowledgements

The United Kingdom Thalassaemia Society would like to thank:

- the National Lottery Charities Board for giving funding towards the cost of the three-year Thalassaemia Asian Awareness campaign
- the Department of Health for a special grant of £75,000 in 2000
- supporters and well-wishers, both individuals and organisations, who have contributed to the success of the campaign
- the members of the National Advisory Committee
- religious advisers, and
- the members of the Project Subcommittee: Dr N Lakhani, Ms N Thapar, Mr K Charalambous, Mr C Paul, Mr D Theodotou, Mr K Sehmi and the late Ms Ruby Saluja.

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Edited by Wordworks, London W4 4DB.
Design by UK Thalassaemia Society.

Printed by Venus Printers (London) Ltd.



MESSAGE FROM OUR PATRON.

Like so many Asians when I first heard of Thalassaemia my first reaction was *thala what?* Having then obtained information and understood the relevance of this devastating condition to the Asian communities my second reaction was to ask – *well why don't we know about it then?*

Having now been involved as a Patron of the Asian Awareness Project of the UK Thalassaemia Society I have learnt much more about the condition and the challenges for health education and the public's needs to undertake screening. This project, which was designed and delivered by the UK Thalassaemia Society, has demonstrated that teamwork by dedicated individuals can make such a large difference to our lives.

Thalassaemia is the commonest inherited condition of any major racial group in the UK today. This project has shown that it is possible to provide sufficient and accurate information to the individual in

order that they take up the opportunity of asking to be screened. The public's response to the project has been remarkably positive and awareness has increased fourfold. The work is far from over, as we need to see 100% awareness and more uptake of screening.

It is now possible to mention the name *thalassaemia* to Asians in the UK without inviting the quizzical looks that one obtained four years ago, which be it a small is still a significant measure of this Project's success.

I have been most happy to be associated with the charity's work and look forward to further developments in this area of valuable work.

Yours sincerely,

A handwritten signature in black ink, reading 'Nina Wadia'. The script is fluid and cursive.

Nina Wadia
Patron.

Foreword



I am happy to provide an introduction to the final report of the Asian Awareness Campaign of the United Kingdom Thalassaemia Society. When the campaign was first discussed, it soon became apparent that an undertaking in the field of health education of this size and nature had not previously been carried out by a charitable organisation of our size. The campaign was designed in great detail to ensure that as many sources of difficulties as possible were identified in advance, and a pilot stage was incorporated into the beginning of the campaign.

The campaign, which ran over three years, provided the Society with a central leading role in health education about thalassaemia, as well as providing the means to engage the various Asian communities up and down the country in joining forces with us in this valuable work. I am most grateful to all the committee members, both from the National Advisory Committee and the Project Subcommittee as well as the local subcommittees in the five campaign areas throughout England, without whom we could not have achieved such successful results.

I would also like to pay a special tribute to the campaign's Project Manager Mr Kawaldip Sehmi, for his central role in the management and rolling out of the project.

I would also like to thank the three patrons of the project, Mr Pankash Udhas, Miss Nina Wadia and Mrs Meena Pathak, for their kind and ready assistance in helping ensure the success of this project. Many of the achievements and the results are well demonstrated in the following pages. At the end of this report we give recommendations for further work that needs to be done in this sector to build on the success of the initial campaign. I hope the information is not only useful reading but also serves as a point of reference for further work in this area in the future.

Dr Nitin Lakhani MBCGB, MRCGP, DA, DRCOG
Campaign Director

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Summary

- Beta-thalassaemia is a genetic blood disorder. A person who carries the beta-thalassaemia gene can appear perfectly healthy. However, where both partners carry the gene there is a 1 in 4 chance that their child could inherit both their genes and develop beta-thalassaemia major. This condition requires intensive medical care including monthly blood transfusions and a continuous injection for 8-12 hours each night at home. Beta-thalassaemia major has a serious impact not just on the quality of life of the sufferers and their family but also on the NHS since treatment for one person up to the age of 30 costs about £1 million.
- Up to 23 births of babies with beta-thalassaemia major occur each year in the United Kingdom. Of these births, 79% are to Asian parents who originate from India, Pakistan and Bangladesh. Up to 1 in 7 Asians may be carriers of the thalassaemia gene.
- Beta-thalassaemia major can be prevented – by diagnosing and screening potential at-risk couples, and offering them counselling both before and during pregnancy.
- A survey carried out by the United Kingdom Thalassaemia Society in 1995 found that only 25% of South Asians living in England were aware of thalassaemia, and only 4% had had the blood test to find out if they carry the gene. The Society successfully applied to the National Lottery Charities Board for funding to run a three-year Thalassaemia Asian Awareness Campaign. The total budget for the campaign was £214,478. Of this amount, £30,000 was to be contributed by the Society.
- The Society planned, organised and ran the three-year campaign, starting in July 1997. The first year consisted of a pilot campaign in West London. Learning from the lessons from the pilot, the campaign was extended, in Year 2 to East and North London and the Midlands, and in Year 3 to North and North West England.
- The campaign made use of Asian TV, press, and radio. Significant social and cultural events were also targeted, such as melas, religious events and sports days.
- One important feature of the programme was that it was very sensitive to the needs of individual Asian communities. In each geographical area covered by the campaign, a local subcommittee was established, including representatives from the local Asian community, health professionals and members of the public, to help inform the development of campaign materials and adverts, and advise on the best use of local media.
- By the end of the campaign in 2000, overall awareness of thalassaemia among the Asian population in England had increased from 25% to 60%, and the proportion of people who had taken the test to find out if they carried the gene had risen from 4% to 10%. While this represents a considerable achievement for a small voluntary organisation to have achieved on the relatively small campaign budget, it means that 40% of the target audience are still unaware of the condition and therefore at risk of passing the thalassaemia gene on to future generations. More work still needs to be done.

1. Introduction

About beta-thalassaemia

Beta-thalassaemia is a genetic blood disorder that can be inherited from parents. There are two forms of thalassaemia:

- thalassaemia carrier (also known as thalassaemia minor or thalassaemia trait), and
- thalassaemia major (also known as beta-thalassaemia major).

A person who is a thalassaemia carrier may appear perfectly healthy. However, when two people who are thalassaemia carriers have a child, there is a 1 in 4 chance, at each pregnancy, that they will have a baby with beta-thalassaemia major.

Beta-thalassaemia major is a serious blood disorder where the baby is unable to produce enough red cells in the blood. Without treatment, the child eventually dies. Treatment involves monthly blood transfusions and a 'continuous injection' for 8-12 hours each night at home. Even with treatment, people with beta-thalassaemia major face many health complications such as diabetes, growth and sexual development problems, and heart problems.

Beta-thalassaemia major has a serious impact not just on the quality of life of the sufferers and their family but also on the NHS since treatment for one person up to the age of 30 costs about £1 million.¹

It is estimated that up to 1 in 7 Asians may be carriers of the thalassaemia gene.² Individuals can find out if they carry the gene by having a special type of blood test called haemoglobin electrophoresis. Those who are found to be a carrier can be offered advice and counselling. This is particularly important for those planning a pregnancy.

If both partners are thalassaemia carriers, tests can be carried out during early pregnancy to determine if the baby has beta-thalassaemia major. If the tests reveal that the pregnancy is affected, the couple should then be offered counselling and support to help them make an informed choice about whether to continue or terminate the pregnancy.

Why a campaign was needed

In the late 1980s, the United Kingdom Thalassaemia Society became aware that of all babies in the UK born with beta-thalassaemia major, 79% were born to Asian parents.³ In 1995 the Society, on its own initiative and using its own funds, carried out an independent national survey. This revealed that only 5% of South Asians in England were aware of thalassaemia, and only 4% had had the blood test to find out if they carried thalassaemia gene.⁴

The Society therefore applied to the National Lottery Charities Board for a grant of £184,478 to run a project to improve awareness of thalassaemia in the Asian community and to emphasise the importance of screening. This would be supplemented by £30,000, to be raised by the United Kingdom Thalassaemia Society. The campaign would use the community media and would be aimed at 16-40 year old South Asians in London and the South East, the Midlands and North and North West England.

The funding application was successful and, in 1997, the United Kingdom Thalassaemia Society embarked on a major national thalassaemia awareness campaign targeted at South Asians. The three-year campaign had a total budget of £214,478.



Our Patron Mr Pankaj Udhas with children who have thalassaemia.



From the launch of our Campaign in Parliament.

2 Planning the campaign

Defining the problem

Defining current awareness

The first step was to measure current awareness of thalassaemia among the target group. This was compiled from:

- the national independent survey commissioned by the United Kingdom Thalassaemia Society in 1995⁴
- focus group interviews
- a literature review, and
- anecdotal evidence collected during contact with various institutions and professionals, and from calls to the United Kingdom Thalassaemia Society helpline.

From these sources we identified the following problems:

- *The word.* The word 'thalassaemia' is a mouthful. Furthermore, it has no direct translation into any South Asian languages.
- *Haematology.* Many respondents found it difficult to understand the functions of red and white blood cells and that blood was 'made' in the bone marrow.
- *Types of thalassaemia.* Many respondents were unaware that there were two types of thalassaemia. The different names used for the two types created further confusion: one type is called 'thalassaemia carrier', 'thalassaemia minor' or 'thalassaemia trait', and the other is known as 'thalassaemia major' or 'beta-thalassaemia major'.
- *Genetic disorders.* Most respondents thought that genetic disorders were passed down from a parent (or parents) to a child, and that the child would only get the disorder if a parent had it. Many found it difficult to understand the concept of an 'ill-health causing agent' such as the thalassaemia gene.
- *Tests.* The target audience needed to be informed of the different tests available:
 - the blood test to determine whether a person carries the gene, and
 - tests which can be used during pregnancy – such as CVS (chorionic villus sampling) and amniocentesis – to find out if the unborn child has acquired the gene. The campaign also had to stress the importance of having these tests early in the pregnancy.

Defining and measuring risk

One of the most important tasks of the campaign was to communicate the 'level of risk' of thalassaemia to the Asian community in the UK.

The UK South Asian communities are not a homogenous group. The 1991 census and statistics collected for public health epidemiology define ethnicity to a narrow national origin – for example Pakistani, or Indian. However, focus group participants wanted to know the risk level for their own community – for example for Punjabi Pakistani or Sindhi Pakistani rather than simply for Pakistanis. They were not happy with generalisations. It proved difficult to collect data for individual communities as there were no large-scale studies. The main source of information was therefore taken to be an article by DJ Weatherall from the British Journal of Haematology.² This was simplified into the statement: 'Up to 1 in 7 Asians may be at risk.'

The other important aspect of the campaign was to communicate the level of severity of beta-thalassaemia major. In the 1995 survey none of the respondents had linked thalassaemia to serious ill health and life-threatening symptoms.⁴



The campaign had to communicate the true impact of beta-thalassaemia major. The impact was a combination of risk probability, level of severity, the cost in terms of human suffering, and the fact that there is no satisfactory and safe, easy cure for the condition.

The final statement that defined the problem was:

“Thalassaemia is a high risk condition which may affect up to 1 in 7 of the Asian community. It has a huge impact and is a disrupting life-threatening condition that costs up to £1 million to treat. For the foreseeable future there is no safe and reliable cure available. The mainstay of prevention is preconception screening of 16-40 year olds and, where both partners are carriers, prenatal screening to give each parent an informed choice about termination of pregnancy.”

It was thought that the at-risk public would only be aware of and make an informed choice:

- if they had a complete understanding about the risk profile of thalassaemia – expressed in terms of probability, severity and impact
 - if they associated this risk directly to their community and daily life so that they took ownership
- if they were able to close the gap between the real level of threat and what they perceived this to be, and
 - if they realised that people could avoid having a child with beta-thalassaemia major if they got accurate and timely information.

Defining the target audience

Before starting the campaign we needed to identify the key target audience: where they lived, what their issues were, what type of messages they respond to, and how we might deliver our message to them. We did this by examining existing data about the at-risk target group.

Demographic information

The 1991 census indicated that the key areas for us to work in were: West London, North London, East London, Birmingham, Coventry, Leicester, Bradford and Manchester.

Our own survey carried out in 1995 revealed varying degrees of awareness of thalassaemia: 29% of Indians were aware of the condition, 22% of Pakistanis, 13% of Bangladeshis, and 17% of Sri Lankans.⁴ Awareness levels were: 23% in the South, 24% in the North and 26% in the Midlands. Awareness levels were much lower among men (19%) than amongst women (29%).



Information needs

The 1995 survey and anecdotal evidence helped us to work out which segments of the population were most at risk. These were, in order of risk:

- pregnant women who had not been screened
- couples planning a family
- young single individuals planning to settle down, and
- 16-20 year olds in college or university.

Sources of information used by the target audience

Mainstream media and its high advertising prices were beyond the campaign budget. We had to make do with the more cost-effective, newly emerging Asian media. We had to determine a promotional strategy that could identify the best route to reach our targets.

The 1995 survey had revealed that, among those who were aware of thalassaemia, 21% had heard about it from TV, 16% from the press, 30% from friends, 17% from relatives, 7% from college, 5% from teachers, 13% from doctors and 10% from other medical sources.

Significantly, when asked about which media they regularly used, we found that there was a low level of penetration among survey respondents. Among the target group, only 42% regularly listened to a local Asian radio station and 39% watched Asian TV. This meant that we could not reach up to 60% of our target audience using these media.

Festivals and other promotion routes

The annual melas and religious festivals therefore had an important role to play in the communication strategy for the campaign. Diwali, Idd and Vaisakhi festivals have a very big impact on the cultural life of the Asian community and are attended by a large proportion of the community. The local borough council melas in summer and the special community sports days also play a large role.

Style of message

Testing of pilot versions of the campaign publications in focus groups revealed that we had two distinct segments:

- Some people liked a full frontal, simple, and blunt message backed by colourful imagery.
- Others liked a subtle, thoughtful, tongue-in-cheek humour-filled message with abstract imagery.

The communities based around industry, car plants and major production centres responded differently to the communities based around commuter belts that served the financial services and other service-based commerce.

Social class

It proved difficult to define the social class of the target audience. The focus groups included families from a wide range of social classes but in some cases even within an individual family there were family members with A or B occupations (such as doctor or lawyer) as well as C1/C2 occupations (such as factory worker, a cleaner) in the same household.

In the 1995 survey, awareness of thalassaemia was higher in social classes A and B where 41% of respondents were aware of thalassaemia, compared with 32% among social class C1 and 21% in C2.⁴

Employers

Traditional employers for South Asians include: London Transport, British Rail, the Post Office, British Airports Authority (BAA) and local government. Other industries with a high proportion of South Asian workforce were the restaurant trade, assembly work, and foundry and component manufacturers in the industrial belt of Birmingham.

In West London, A further 12% were employed in the ethnic food/spice import export businesses. The local borough councils employ up to 8%. Of the employees at Heathrow BAA (the airlines and air service subcontractors), 23% are South Asians.

Fifty per cent of the target audience passed through the local tube stations, railway stations and bus stations on the way to their workplace.

GPs, health professionals and carers/educators

These were segmented into three groups:

- those who were unaware that thalassaemia affected Asians
- those who were unaware of the detailed clinical and screening requirements of thalassaemia, and
- those who had a partial knowledge of the above problems.

The United Kingdom Thalassaemia Society helpline was a very valuable source of information about the accuracy and appropriateness of advice that health professionals around the country were giving to patients. This highlighted the need for a coherent and standard message to be put across to the at-risk group.

The core issue for the awareness campaign was for GPs and health professionals to appreciate the risk involved and opportunistically screen those at risk before they plan a pregnancy. They should do this in a timely and accurate manner. If the person and their partner are at-risk of having an affected pregnancy, health professionals should be able to offer prenatal counselling and screening services. At all stages the couple should be informed and counselled properly.

The strategy for the campaign

In line with initial planning findings, we decided on a 'pull strategy' rather than a 'push strategy' (see box below).

<p><u>'Push strategy'</u></p> <p>The United Kingdom Thalassaemia Society pushes the message through to Department of Health.</p> <p>The Department of Health pushes to NHS.</p> <p>The NHS pushes to local health authorities.</p> <p>The local health authorities push to GPs.</p> <p>GPs push the message to their 'customers'.</p> <p><u>Advantages</u> Cheap. Uses other people's money.</p> <p><u>Disadvantages</u> Time-consuming, and involves political wrangling as there is competition with other causes to attract the attention of the Department of Health and the health care system.</p> <p>Loss of control, and quality of message compromised.</p> <p>Remoteness from 'consumer'.</p>	<p><u>Pull strategy'</u></p> <p>The United Kingdom Thalassaemia Society promotes the message directly through the media to the Public.</p> <p>The public then pulls services from the GP.</p> <p>The GPs pull resources from their local health authorities.</p> <p>Local health authorities pull resources from the NHS.</p> <p>NHS pulls resources from the Department of Health.</p> <p><u>Disadvantages</u> Expensive.</p> <p><u>Advantages</u> Fast and to target.</p> <p>Control is maintained, and quality of message is assured.</p> <p>Close contact with the public.</p>
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Key tasks of the communication strategy

Our initial findings and planning exercise had revealed that we had to:

- communicate the level of risk to the at-risk target group
- help those at risk to understand the impact of the risk, and
- motivate those at risk to acquire timely and accurate information to get screened.

We planned a three-burst campaign which would: **introduce** the message; **remind** the audience of the message; and **reinforce** the message.

The message was to be targeted at each carefully identified segment and perform three key tasks. It would:

- get attention
- hold interest, and
- arouse desire.

Getting attention

We planned to start the campaign with a brightly coloured and emotive message that would be directed at a mass audience. As no respondents in the 1995 survey were aware of the impact of beta-thalassaemia major, we decided to push the life-threatening aspects of thalassaemia. An emotive message would be directed at the self-interest of the individual and his or her partner.

This message was to be channelled through popular media, high concentration route bill boards, and Adshells in gatherings and circulation space.

Holding interest

The next step was to disseminate detailed information to the target audience through workplaces, schools, colleges, community organisations and other venues.

A poster campaign was planned as a follow-up to the radio and mass media campaign. Posters were to be sent to places such as workplaces and colleges.

Arousing desire

The third message was to trigger the need for the target audience to think about getting tested because it was good for them. This burst had PR activity with endorsements by celebrities. A GP awareness campaign was also planned in order to give GPs and health professionals an opportunity to update their knowledge of screening.

Potential resistance to the campaign messages

We were aware that there might be resistance to the adverts and the communication strategy. Three levels of potential resistance were identified: the individual, the family, and the community. These issues had to be kept in mind at all stages of campaign planning.

The individual

- Age: Young people are more flexible than adults.
- Occupation and economic circumstance: Social classes A and B are better informed and easier to engage.

- Lifestyle and personality: The 'fundamental' and the 'radical liberal' acted in different ways.
- Gender and self-concept: Women are better informed and more civic-minded and more likely to participate actively.
- Psychological make-up: Motivation, perception, learning, existing knowledge, skills and attitudes would all affect resistance to the message.

The family

Each individual may respond to a set of family values. These values may have origins in a unique set of circumstances and depend on the family's values. We recognised that there might be different reactions in rural and urban settings and in different parts of the country. The role and status of individuals in family decision-making had to be kept in mind.

The community

We also recognised that each community – with its different origins, reference groups and sub-cultures – would react differently to the campaign. For example, UK Mirpuri communities in Bradford have evolved differently to Bangladeshi communities in Tower Hamlets.

The Faiths

We were aware of the different religious denominations within the Asian population and made it one of our top priorities to liaise and keep communication channels open with all the major faiths giving information about the campaign.



3 Year 1 – The pilot campaign

Choosing the area for the pilot project

West London – Hounslow, Hayes, Ealing and Southall – was chosen as the pilot project area. The main reason for this choice was that West London has a catchment area that extends beyond the physical boundaries of West London. This area ‘drives’ events elsewhere. The spice wholesalers, ‘cash and carry’ firms and the Western International fruit market attract people from all over the UK. Because of the presence of the importer/exporter belt around Heathrow Airport along with the fabric importers in Southall, up to 45% of UK Asian population visit the area once a year.

The three main religious groups and temples are busiest during the festivals of Diwali, Idd and Vaishaki. Twelve per cent of the Asian population from Birmingham and the Midlands travel to London using the Bharat coach service, which terminates in Southall. Of the employees at BAA (the airlines and air service subcontractors) and British Airways at Heathrow, 28% are South Asians.

The administration structure

The campaign was to be run with a Project Manager, supported by two office staff of the United Kingdom Thalassaemia Society. The overall administration structure for the pilot campaign is shown in the diagram below.

National Advisory Committee

The campaign had a National Advisory Committee which was responsible for the overall running of the campaign. This committee included:

- the President of the UK Thalassaemia Society, who was also the Campaign Director
- members of the Project Subcommittee
- the Project Manager of the Asian Awareness Campaign
- the Public Relations and Media Adviser of the UK Thalassaemia Society
- a Consultant Haematologist
- a Clinical Lecturer in Reproductive Medicine
- a Professor in Clinical Genetics
- a Lecturer in General Practice
- 2 nurses associated and working with beta-thalassaemia.
- 2 parents of children with thalassaemia
- a primary school headteacher
- a broadcaster/journalist, and
- religious advisers from the three main faiths.

The power, influence and reach that the National Advisory Committee had in the UK Asian communities, in medical and public health and other aspects of public life would provide a valuable asset in planning and carrying out the campaign.

The Project Subcommittee

This was made up of:

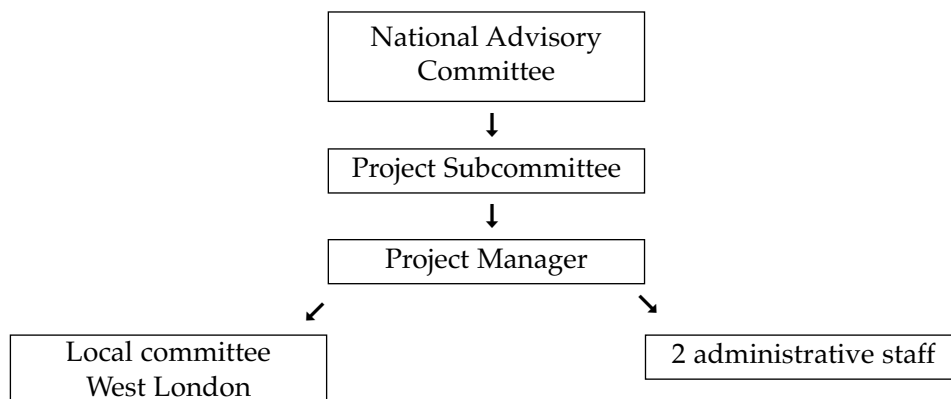
- the President of the UK Thalassaemia Society, who was also the Campaign Director
- 3 patient members of the UK Thalassaemia Society's Management Committee
- the Co-ordinator of the UK Thalassaemia Society's office
- the Project Manager of the Asian Awareness Campaign, and
- the Public Relations and Media Adviser of the UK Thalassaemia Society.



Local committee

A local committee for the West London pilot area was established. This committee ideally should have had about 10 members: 2 patients, 2 parents, 2 local health professionals, 2 students and 2 lay members. However there was low take-up by patients and parents. This local committee advised on the best ways of making links to the local Asian community, and how best to use the local media. It also helped to develop radio and press adverts, and to assemble a media plan, advising on which local papers and radio stations to use.

Administration structure for the pilot campaign



Planning the pilot campaign

The pilot campaign, which ran from July 1997 to June 1998, focussed on the following areas:

- a mass audience programme through radio, local press and TV
- colleges
- shopping malls, libraries and major employers, and
- a programme for GPs and primary health care staff.

A set of campaign materials were developed including posters, flyers, leaflets, factsheets and a campaign newsletter. Adverts for Adshells and hoardings were also produced. These were all piloted with a focus group before production. A selection of the materials is shown below. A radio script was produced and broadcast on local Asian radio stations. There was one burst of TV advertising, with 54 spots of a specially made advert broadcast on Zee TV. Press adverts were featured in local newspapers. Details of the media used are given on the next page.

Publications produced for the pilot stage of the Thalassaemia Asian Awareness Campaign



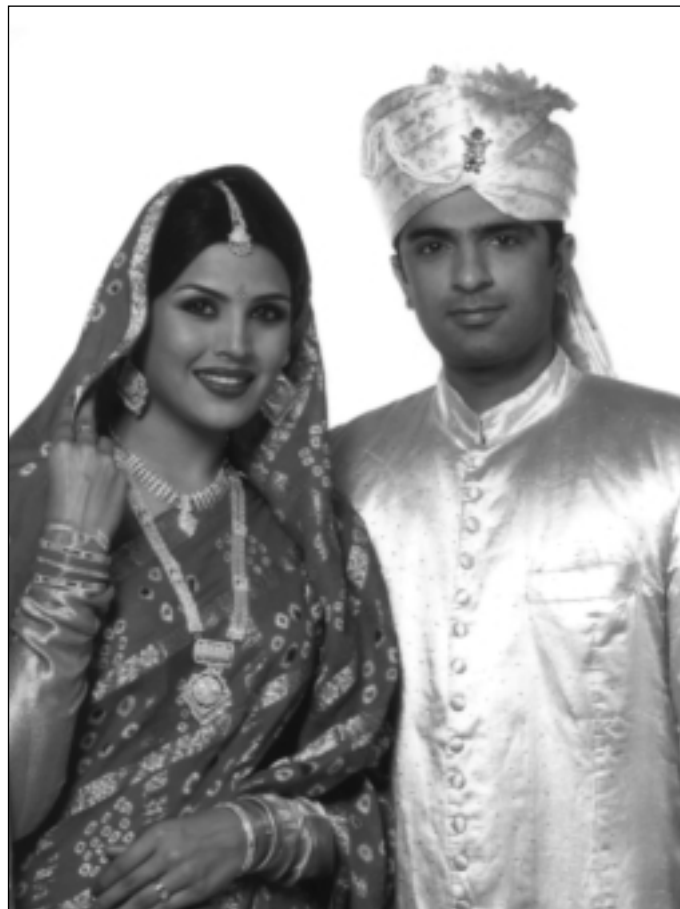
Media used in the pilot stage of the Thalassaemia Asian Awareness Campaign in West London

TV	Radio Press	Press
Zee TV	Asia Radio Sunrise	Asian Times East newspaper Eastern Eye Leader newspaper: versions in Hounslow, Southall, Harrow, Skyport

Posters were sent to key Asian organisations, local colleges, schools and local authorities. Thalassaemia exhibitions were held at local cultural events, college health fairs and sports days, as well as in local libraries and shopping centres. Talks and lectures were given. Posters were also sent to GPs surgeries and health centres.

The campaign materials showed a freephone helpline number. People who called this number heard a recorded message giving information about thalassaemia and the importance of having a blood test, and a phone number they could call for further information.

A Parliamentary Launch was held in January 1998 to raise awareness of thalassaemia among parliamentarians. A booklet giving information on thalassaemia and an outline of the Asian Awareness Campaign was prepared for this purpose.



How the money was spent

	YEAR 1 July 1997 – June 1998	
	Amount spent	% of total budget spent
Radio/TV production	£1,566	2.5%
Press production	£1,118	1.8%
TV advertisements	£3,500	5.5%
Radio advertisements	£6,610	10.5%
Press adverts	£7,381	11.7%
Adshell poster sites	£474	0.7%
Newsletters	£975	1.5%
Printing inserts	£3,095	4.9%
Printing leaflets	£750	1.2%
PR: Parliamentary work	£3,158	5.0%
PR: GPs and health professionals	£3,653	5.8%
PR: communities	£493	0.8%
Helpline	£633	1.0%
Survey/audit	£5,828	9.2%
Administration		
Advertising post	£1,415	2.2%
National Advisory Committee expenses	£108	0.2%
Local committee expenses	£585	0.9%
General administration	£999	1.6%
Total operations	£42,346	67%
Total salaries	£20,899	33%
Total campaign expenditure in Year 1	£63,245	

Results of the pilot year

An independent survey was commissioned at the end of the first year to audit how the campaign had performed in the West London Asian community and how our adverts and publicity were perceived. The survey of 115 respondents⁵ found that:

- Total awareness of thalassaemia had increased marginally since the 1995 survey, from 25% to 32%.
- Nearly half of those aware of thalassaemia heard about it first from the television – a much higher proportion than in the 1995 survey.
- About 2 in every 5 of those aware of the disorder (13% of all respondents) claimed to have seen some advertising or publicity about thalassaemia.
- TV was the most commonly mentioned medium where respondents had seen the campaign publicity (TV 11%, local newspaper 2%, posters 2%, ethnic newspapers 1%, radio 1%).

Feelings on the publicity were mixed. Generally it was seen as a good idea, but many felt it did not give enough information. Despite the increased awareness of the disease, concern about thalassaemia remained low and was unchanged since 1995. Of the respondents aware of the disorder, less than one-third were concerned about the effect thalassaemia might have on their family.

The survey also asked respondents about the media they used most often. Results were similar to those in the 1995 survey, with Eastern Eye, Cineblitz and Stardust being the three most commonly read publications. The most commonly listened to radio station was Sunrise which 64% of respondents regularly listened to. A higher proportion of respondents watched an Asian TV station than had done in 1995: 47% of respondents watched Zee TV (compared with 37% in 1995).

People calling the UK Thalassaemia Society for extra information were asked where they had seen the advert giving the helpline number. Forty-three per cent had seen the helpline number on Zee TV, 31% heard it on the radio, 21% saw it in the press, and 5% found out about it from another source.

3. Years 2 and 3 – The main campaign

We had learnt some important lessons from the pilot year. In the light of the findings of the post-pilot survey, we decided to add new elements to the promotional mix and make certain changes to the messages.

We were also aware that our internal resources could not manage an ‘all out campaign’ that covered all the remaining geographical areas at the same time, as we would not have enough resources to service all the calls and requirements. We therefore phased the campaign to sweep the following areas in turn:

Stage 1 North London and East London

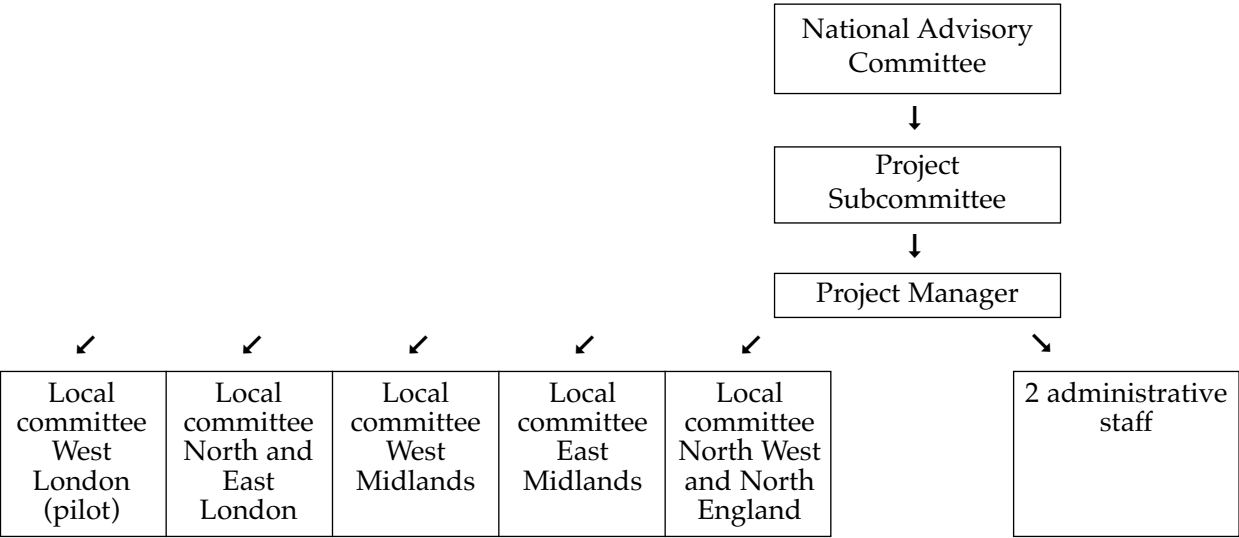
Stage 2 East Midlands and West Midlands

Stage 3 North West and North England

As before, the overall campaign was guided by the National Advisory Committee. A local committee was established for each area. The local committees had between 6 to 16 members and included representatives from the local community including people from the target age group (16-40 year-olds), both employed and unemployed, as well as some health professionals familiar with the local health care set-up.

The administration structure for Years 2 and 3 is shown overleaf.

Administration structure for Years 2 and 3 of the campaign



Planning the campaign

We established that each of the areas and communities targeted for Years 2 and 3 might be reached by:

- a single national media (Zee TV)
- regional media (for example Sunrise Radio in London or Excel Radio in the Midlands), and
- local newspapers.

We commissioned new radio and TV advertisements. These included a striking 30-second TV commercial made with the help of *Goodness Gracious Me* star and our patron Nina Wadia, United Kingdom Thalassaemia Society patron Pankaj Udhas, and new patron and Business Woman of the Year Meena Pathak. New press adverts were also produced. A selection of the new materials is shown below.

Publications produced in Years 2 and 3 of the Thalassaemia Asian Awareness Campaign



Media used

The main focus of the media campaign was TV, with adverts on Zee TV. The campaign also made use of the emerging Asian cable networks. This work was supported by radio adverts on local Asian radio stations, and press adverts both in national publications such as Eastern Eye, Cineblitz and Cineworld, and in local newspapers.

Hoardings and Adshells were also used in Year 2 at key stations, bus routes and tube stations as well as high streets and public spaces used by the target group. However, the cost of these was beyond our reach in Year 3 since the stockpiling in the car industry had led to car manufacturers buying lots of advertising space in these media and pushing prices up.

The amount spent on the different forms of media is shown on page 20.

Media used in Years 2 and 3 of the Thalassaemia Asian Awareness Campaign

TV	Radio	Press
Asia ITV Asia Net B4U Bangla TV Channel East MA TV Pakistani Sony Zee TV	Asian Spectrum Radio (London) Manchester Radio Radio Birmingham Radio Excel (Birmingham) Sabras Radio (Leicester) Sunrise Bradford Sunrise London	Cineblitz Cineworld Des Perdes Eastern Eye Snoop <i>North and East London</i> Barking and Dagenham local newspaper Brent Leader East Docklands Express Ilford Express <i>Midlands</i> Birmingham Mail Birmingham Metro Coventry News Coventry Telegraph Derby Journal East Stafford Journal Leicester Mercury Nottingham Post <i>North and North West England</i> Leeds and York Evening Post Sheffield Post Manchester News

Promotions, presentations and exhibitions

The campaign had an exhibition stand at the first ever BBC Mega Mela in 1998 where it launched a new leaflet. The campaign benefited from the presence of Pankaj Udhas at the 1999 BBC Mega Mela. We also gained considerable extra publicity as a result of thalassaemia patient Zoya Choudary who was awarded a BBC Brave Child Award.

The extensive coverage also helped us to secure a BBC Network documentary slot on the programme *East*. A 30-minute programme on Thalassaemia was produced which was accurate and well presented.

The campaign also exhibited at a wide range of other religious and cultural events. The largest of these were: the Hare Krishna Janmasthanmi (Lord Krishna's birthday celebration) which attracted 50,000 visitors in 1998 (Year 2) and 60,000 in 2000; the Bradford Mela which attracted 30,000 participants in 1998 and 45,000 in 1999; and the Nottingham Dussera Festival with 10,000 participants. Exhibitions were also staged at other events. In Year 3 of the campaign it was decided to exhibit only at events where more than 4,000 participants were expected.

Exhibitions were also staged at colleges and universities, and posters and leaflets sent out to the health centres of 96 universities in the target areas.

United Kingdom Thalassaemia Society representatives also took part in radio and TV programmes including interviews and phone-ins.

Information packs were sent to each of 500 key national organisations, MPs and health departments, 50 key local organisations and 50 heads of local authorities. 1,000 media packs were distributed.

The telephone helpline publicised in the materials gave a recorded message with information about thalassaemia and the importance of having a blood test, and giving a phone number to call for further information.

Our established website was expanded as a further source of information.

Work with GPs and health professionals

The campaign took an exhibition stand at the *NHS – 50 years* show in July 1998 and a *GP and Health Professionals Fact Sheet* on thalassaemia was produced and distributed at the event.

The United Kingdom Thalassaemia Society undertook a survey of GPs and health professionals attending the event. This revealed that 68% of health professionals (including GPs) were aware of thalassaemia, 45% knew that it affected South Asians, and 34% were aware how to test carriers. The corresponding figures for GPs were 82%, 47% and 35%. This showed that there was still a good deal of information work to be done with GPs and health professionals. We decided that this work was to be a priority for Year 3.

After consulting with a GP Education expert Dr Steve Gillam of the Kings Fund on the best strategies to adopt to target GPs, we decided on:

- a 20-minute video covering key areas of thalassaemia screening and prevention strategies (This was sent to 9,000 GP practices.)
- adverts in the GP press
- exhibiting at GP conferences
- launching a primary care group factsheet to core Primary Care Groups, and
- other PR activities including articles in the GP and health professionals' press.



Blood screening and information at one of the melas we attended.



Giving a blood sample for testing; with a smile!

How the money was spent

Asian Awareness Campaign income and expenditure June 1997 - June 2000

INCOME

National Lotteries Charities Board		£184,478
United Kingdom Thalassaemia Society	£30,000	
Oshwal (a community organisation)		£7,230
Eastern Eye (weekly newspaper)		£1,770
London Borough of Hounslow	£3,500	
Maersk (pharmaceutical company)		£5,000
Norvatis (pharmaceutical company)	£2,000	
Donations from individuals		£1,285
Interest		<u>£5,120</u>
Total income		£240,383

EXPENDITURE

Administration and salaries	£90,400	
Design and advertising		£132,625
Survey		£14,107
Parliamentary launch		<u>£3,251</u>
Total expenditure		£240,383

What we would do differently next time

National Advisory Committee and local committees

The structure of local committees brought considerable advantages, particularly in being able to make contact with local Asian communities in the most appropriate way, and to make the most of local media. However, at times there was confusion and overlap over the roles and responsibilities of the National Advisory Committee and the local committees. This affected decisions over monitoring and control of budget, development and production of printed materials, scripts and imagery for TV and radio adverts.

Quality of customer care advice

Callers to the helpline heard a recorded message about thalassaemia and were given a phone number to call if they needed further information. In some cases the advice given to people calling this phone number was not fully comprehensive. Furthermore, those offering the advice were not always representative of the community served. Further training for those taking the calls would have been helpful.

Administrative support

There was inadequate administrative support for the Project Manager at certain times in Years 2 and 3 when the campaign went national.

Office accommodation

The campaign was run from the offices of the United Kingdom Thalassaemia Society, a small office and store room at the back of the United Kingdom Thalassaemia Society charity shop. This proved to be an inadequate space for running a campaign of this size and caused many difficulties.

IT systems

Incompatibility between different computer systems proved a constant problem, particularly in the follow-up to the parliamentary work in Year 1 when we were unable to respond to the MPs who wanted to find out more about thalassaemia and the possibilities for prevention as we did not have access to a good database of Society members.



5. What did the campaign achieve?

A tracking survey was carried out at the end of Year 3, in June 2000, to monitor the effects of the campaign. Interviews were carried out with 498 people aged 16-39.

The main findings were:

- Overall awareness of thalassaemia has risen from 25% in 1995, to 32% in 1997 and 60% in 2000.
- The proportion considering themselves knowledgeable about thalassaemia has almost doubled since 1995, from 21% in 1995 and 40% in 2000.
- While awareness of thalassaemia has increased substantially, the proportion aware of the two different types of thalassaemia has not: 68% of respondents in the 2000 survey did not know there were different types.
- Almost half of the Asian community in the survey had seen some advertising or publicity about thalassaemia. Thirty-five per cent of all respondents had seen advertising or publicity on the TV.
- Fifty-eight per cent of those seeing the advertising or publicity picked up on the message to get checked. Forty per cent of respondents felt that the publicity had encouraged them to have a blood test.
- However, only 1 in 10 respondents have actually been tested for thalassaemia.

The results are shown in more detail overleaf. This survey also gave information about the media used by the target group, which could prove useful for planning further campaigns (see page 31).



Even Police Officers take the test!

What the campaign achieved

	1995 survey ⁴	1998 post-pilot survey ⁵	2000 survey at end of the 3-year campaign ⁶
Awareness of thalassaemia			
Prompted awareness of thalassaemia	25%	32%	60%
Unprompted awareness of thalassaemia	5%		20%
Awareness of thalassaemia as a blood disorder affecting the Asian community	5%		25%
Rating of own knowledge of thalassaemia: very knowledgeable or fairly knowledgeable	21%		40%
Awareness of the two types of thalassaemia	17%		21%
Campaign awareness			
Saw or heard any advertising or publicity about thalassaemia		13%	43%
Saw or heard advertising or publicity on TV		73%	83%
Saw or heard advertising or publicity on radio		13%	18%
Saw or heard advertising or publicity in local newspapers		13%	4%
Saw or heard advertising or publicity in local poster		7%	4%
Saw or heard advertising or publicity in ethnic newspapers		7%	3%
Thought main message of campaign was to get checked before marriage or having children			31%
Thought main message of campaign was to get yourself checked			27%
Action in response to campaign			
Publicity has really encouraged me to have a blood test (agreed strongly or agreed slightly)			40%
Whether have had a blood test to determine if carrier of thalassaemia	4%		10%
Overall level of concern about the effect of thalassaemia on your family: very concerned or fairly concerned	30%		35%

Media used by the target audience, 2000

Television stations regularly viewed	
Zee TV	49%
B4U	21%
Sony TV	21%
Asia Net	11%
Asian publications read regularly	
Eastern Eye	21%
Cineblitz	13%
Stardust	12%
Daily Jung	10%
Movie	8%
Radio stations listened to regularly	
Sunrise London	33%
BBC Radio 1	18%
Asian Sound	14%
Sunrise Bradford	9%
Radio Excel	8%
Sabras	7%
Leisure activities in the past year	
Religious festivals	46%
Mela	40%
Asian videos	37%
Asian films	36%
Asian concerts	20%

6. Discussion and recommendations

To our knowledge, this was the first time that an awareness-raising campaign of this scale – with a £214,478 budget over three years – had been carried out by a small voluntary organisation in the UK. The United Kingdom Thalassaemia Society took on the organisation and monitoring of the campaign in a professional manner. It clearly defined the issues, the work to be done, who the target audience should be and the best ways of reaching them. It carried out a pilot campaign in one area in Year 1 and, learning from the lessons of the pilot, adapted the campaign before rolling it out to other areas of the UK in Years 2 and 3. A post-pilot survey was carried out to measure what the campaign had achieved. The three-year campaign was within its budget.

The campaign achieved an increase in awareness of thalassaemia. In 1995, 25% of the target audience were aware of thalassaemia. By 2000 this figure had increased to 60%. The percentage of the target audience who had been tested for thalassaemia had risen from 4% in 1995, to 10% in 2000.

While these figures represent a considerable achievement, there is still much more work to be done. Although prompted awareness of the condition has risen to 60%, this means that 40% are still unaware of thalassaemia. Similarly 90% of the target audience have still not had a blood test to find out if they are carriers of the thalassaemia gene.

One of the main reasons for the success of the campaign was the use of local committees in the different areas to help plan and implement the local campaigns. Each local committee included lay people, local medical representatives and representatives from key community groups. This group gave invaluable advice on use of local media, and help with designing and developing suitable local materials and adverts. The local committees acted as the campaign's eyes and ears and gave us invaluable access to local Asian communities.

Areas for improvement for future campaigns of this nature would include:

- clearly defining the roles and responsibilities of the National Advisory Committee and the local committees
- ensuring adequate training for those answering helpline enquirers
- ensuring adequate administrative support and office accommodation
- ensuring good IT back-up.

Recommendations for the future

OVERALL RECOMMENDATIONS

Further work needs to be done to build on the success of the initial Asian Awareness Campaign, in order to increase awareness of thalassaemia among the Asian communities.

Mainstream funding is needed to address not only awareness-raising about thalassaemia among the target population but also the wider implications of the education and continuing education of health professionals, with support for at-risk couples.

It is essential to take a long-term view of improving health education and prevention in order to reduce the number of births of children with beta-thalassaemia major. There therefore needs to be further awareness-raising about thalassaemia among politicians, decision-makers and health management professionals.

EDUCATION AND TRAINING OF HEALTH PROFESSIONALS

Further education and training for health professionals is needed in order to ensure that communities have access to thalassaemia screening and prevention services.

Primary health care workers

Health care workers – in particular GPs, practice nurses and midwives – need continuing education to help them become aware of the need for screening for thalassaemia among young Asians.

Training of health professionals

Thalassaemia should be included in undergraduate medical curricula and in the curricula for nursing and midwifery.

NHS ORGANISATION

National Institute for Clinical Excellence (NICE)

There is currently no adequate method of identifying couples at risk of having a child with beta-thalassaemia major, and no systematic screening of individuals who may be carrying the thalassaemia gene. The National Institute for Clinical Excellence should investigate this gap in present practice.

Screening

GPs should offer opportunistic screening for thalassaemia to 16-40 year old patients in at-risk groups.

Mandatory antenatal testing should be carried out for all pregnant women, regardless of ethnic origin, in order to identify at-risk pregnancies.

NHS user organisations

NHS user organisations should become more actively involved in ensuring that local health care providers offer screening for thalassaemia.

Monitoring/epidemiology

A national register of all children born with a Thalassaemia Major should be established. The register, which should be centrally funded and administered, would provide a much-needed point of reference for measuring and monitoring the effects of health education interventions as well as identifying areas of special need.

LOCAL ASIAN ORGANISATIONS

Local Asian organisations should work with the United Kingdom Thalassaemia Society to help increase awareness of thalassaemia and of the need for screening within their groups.

Local Asian organisations need to foster dialogue and debate among young Asians to encourage them to get screened for thalassaemia.

RESEARCH

Further research should be carried out to find out more about the reasons why some people, who are aware of thalassaemia and of the need for testing, are still not having the test to find out if they are carriers of the thalassaemia gene.

There should be more formal research into the most effective health education messages for at-risk groups, to help inform future health education strategies.

There is a need for a cost-benefit analysis of the various thalassaemia screening programmes. There is also a need for research into the reliability of screening tests.

Further research into the treatment of beta-thalassaemia major is needed.

MEDIA

Both the mainstream and ethnic media should be encouraged to provide space and airtime to the issues around thalassaemia and screening.

Lessons for future campaigns in this area

Staff

A campaign of this nature requires not only close teamwork but also a full resource of staff who are trained in the skills of working with health professionals and who are familiar with the target communities.

Input from the local community

To achieve good community PR it is essential to have interested and reliable input from local communities who see the need for and the benefit that can be derived from health education and screening.

Health education messages

When giving health education messages, it is important to strike the correct balance between giving enough information to encourage screening but at the same time not implying criticism of the parents of children who have been born with beta-thalassaemia major.

Using the media

Campaign workers need to have a good knowledge about the different media available, their relative costs, and which ones offer greatest reach into the target group.

There needs to be a plan for organised and continuing use of the various media, in order to retain the momentum of the campaign.

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United Kingdom Thalassaemia Society

The United Kingdom Thalassaemia Society aims to increase awareness of thalassaemia and provides advice, information and counselling to the public and to people with thalassaemia and their families. It also raises funds for research into thalassaemia.



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