



UK National
Screening Committee



Screening Programmes

Sickle Cell and Thalassaemia

Running outreach sessions on sickle cell and thalassaemia

A step by step guide

Introduction

These notes are written for people presenting outreach sessions as part of the project funded by the NHS Sickle Cell and Thalassaemia Screening Programme and managed by the Sickle Cell Society and the UK Thalassaemia Society.

The guide provides a step by step guide on how to set up and facilitate a session using resources developed for this project. We envisage that a session will consist of:

- Showing of either the Family Legacy DVD or the UKTS DVD
- Showing a short powerpoint presentation to ensure the audience have understood the key messages
- Running a question and answer session
- Ensuring that participants fill in an evaluation form
- You filling in paperwork to record the event and any expenses incurred and claiming your own reimbursement
- (Plus ideally personal story from service user)

We welcome your suggestions for this briefing and we will be updating it regularly in response to feedback.

Step one: scoping your event

Target audiences

Our priority is people who are at higher risk of being carriers and who are of child bearing age. We want to target both men and women – we are particularly keen to reach young men.

We are not looking to target “the usual suspects” ie people in the sickle cell and thalassaemia world who will already be broadly familiar with the issues. Rather, the aim is to reach out to people for whom the messages are relevant but who may not be aware of the issues.

You may have good ideas of where to go based on your knowledge of the local area. It is also worth making contact with local voluntary sector groups that engage with our target communities. Some examples of settings where we have successfully delivered sessions so far include:



- ✚ Schools and colleges – including special interest groups eg Muslim groups, ones with health interest, African societies
- ✚ Student unions
- ✚ Youth groups
- ✚ Community events (e.g. Black History Month, Melas)
- ✚ Sure Start centres
- ✚ Drop in centres run by relevant voluntary sector organisations eg ones targeting people from higher risk communities
- ✚ Churches and mosques
- ✚ Barber shops
- ✚ Hairdressers
- ✚ Restaurants
- ✚ Cinemas (for Family Legacy) eg special seasons focusing on target communities
- ✚ Family home (with caution – see notes below)

Remember – we will have translated versions of the UKTS DVD (Urdu and Bengali) and we have a French version of the Family Legacy so we are also keen to find communities where the translations would be helpful. We will be happy to discuss with you how we deal with any translation issues.

Once you have identified a potential place to deliver a session, it would be helpful to have a very preliminary discussion to establish whether in principle they are happy to receive a session and what the costs would be. Please note: we are looking for a minimum of 10 people to attend the session and preferably more.

Step 2: getting formal agreement from the project

Please email your proposal to:

Sickle cell event: iyamide.thomas@sicklecellsociety.org and

Thalassaemia event: Elaine@ukts.org

We need to know:

- Where you propose to go
- Who will attend
- Estimate of costs involved

The kind of costs we have envisaged when setting the budgets include room hire, hire of projection equipment, light refreshments for participants, small payment in the form of £30 voucher for service user, some administration costs for setting up the event. Some events will cost more than others – in many instances we hope that some of the elements above will be free – eg use of room and you using your own equipment to show the DVD.

We will liaise and you will get a formal go ahead email from one of the voluntary sector partners. The partners will be available to talk through any issues with you and help you to set up the event. **Please do not go ahead with your event until we have confirmed it with you** (We have to watch the overall budget and ensure events are suitable. In addition, unless a facilitator is registered as self-employed or doing sessions under the umbrella of their workplace, there will be a limit to the number of sessions they will be allowed to undertake for tax reasons.)

PHE gateway number: 2014540

If you do not have any administrative support or time, we have provided in the budget for the voluntary sector partners to help you.

Note: if you have an event which you feel would be valid but which does not exactly fit this model eg media opportunity, attendance at large community event, do please run this past us as well.

Step 3 – organising your event

Clarifying what the event is

It is important that the person at the venue to which you are going understands clearly the nature and purpose of the session. The Sickle Cell Society has provided some specific briefing sheets for the following settings: 1) Barbers and hairdressers, 2) Schools and colleges, 3) Family home, 4) Restaurant, 5) Community Event /organisation) Please ask Lyamide Thomas for copies of these. We can help develop versions for thalassaemia events.

Equipment

You will need to ensure there is suitable equipment to play a DVD and project it so people can see it. Do not forget to check the sound – lack of sound is a very easy bear trap to fall into! You will also need to be able to show the powerpoint presentation. The Screening Programme has bought several DVD players and projectors and it may be possible to lend these to you. Otherwise, we accept if the venue does not possess the relevant equipment that it may be necessary to hire it.

Refreshments

We have allowed for tea, coffee, soft drinks, biscuits and other small snacks – not a full three course meal! You will need to show receipts for the cost of refreshments

Venue

If a venue needs to be booked and paid for, invoices should be raised through the Sickle Cell Society or UKTS. Sometimes, there is an equivalent hosting fee – eg for a barber shop or for a family home screening. The cost of the venue needs to be agreed in step 2. (We are thinking in the order of £50 but hoping that this can often be free).

Asking a service user to tell their story

The event is usually boosted enormously if a person with the condition can speak about their personal experience. We have allowed a payment of £30 per session which will be in the form of a suitable voucher which you can agree in advance with them. (This is simply because a voucher is much easier to administer than cash for tax purposes). The user should sign a receipt for the voucher. It is particularly useful to have a male service user if you are going to a setting aimed at men eg .barber shops, mosques. Whilst respecting their story, it is important that you 'coach' the service user so they give a balanced view of their experiences including screening where relevant. Please ensure if they inadvertently give out any information that is clinically incorrect that you correct this promptly.

Check list for you to take

- The DVD (either Family Legacy or UKTS)

- Powerpoint presentation (ideally pre-loaded onto laptop and also on separate memory stick – it is a good idea to also mail it to the venue in advance so there are various options in the event of a technology hitch. It's also a good idea to check if anyone with IT skills and knowledge of their systems will be available on the day)
- Laptop
- TV with built in DVD player and external loudspeakers or DVD projector with whiteboard or wall onto which you can project
- Evaluation questionnaires
- Frequently asked questions briefing
- Sickle cell/thalassaemia factsheets
- Some prompt questions for Q+A session
- Pens
- Refreshments
- Receipt book (it is helpful to have a book so you can keep all your receipts together)

Step 4: publicising your event

We have provided some template posters to help you advertise the event at the venue – for example on notice boards, corridors, shop windows. We encourage you to use all the networks you have as well – emailing local voluntary organisations or relevant people you know. The venue/host organisation may have other channels eg a newsletter, parish magazine in the case of a church, announcements.

In some cases such as barber shops or family homes where a 'hosting' fee of £50 is payable the host is expected to do most of the advertising. This is explained in the briefing sheet on barber shops.

Step 5: running your session

The following is a guideline – in practice you may need to be flexible. We suggest you allow at least 1.5 hours if possible.

- Introduction and aims of session – c 5 mins
- Showing of DVD (Family Legacy takes 25 mins, UKTS takes 10 mins)
- Powerpoint presentation (you can cut these short if time is limited. We suggest you principally focus on the inheritance charts if you have to choose and cut. The thal presentation is longer than the sickle one)
- Talk from service user – c 5 mins
- Question and answer - c 20 min
- Distribution and completion of evaluation forms
- Distribution of information leaflets
- Refreshments (when they have handed in evaluation forms!)

Some useful tips

- It's a good idea to have an ice breaker questions to start off the Q &A. For sickle, a good question has been: do you think 'Femi' forgave 'Simi' too quickly? This usually stimulates conversation! You can also choose other icebreakers from the discussion topics in the powerpoint presentations. However, don't worry about silences – our experience is people always have plenty to say!
- If you are unable to answer a question, signpost participant to relevant organisation or take contact details to get back with information if appropriate.
- If a participant requests a copy of the DVD, find out how they intend using it and suggest that YOU conduct a facilitated session to that audience if relevant. Copies of the DVD should only be given out selectively to individuals such as health professionals, teachers, media etc who could help promote it.

Opportunistic DVD sessions

In addition to your official facilitated sessions for which you will be reimbursed, there might be situations where you could screen the 1 minute 'trailer' of the Family Legacy or the 10 minute short version of the film both of which signpost viewers to the film's website at www.familylegacy.org.uk.

The film trailer is subtitled and can therefore be shown even in situations where sound is unavailable. Please be innovative and use such situations, encouraging people to watch the film on-line and complete the on-line evaluation form. If you have opportunities to give the DVD trailer to someone at your local TV station please do so! (Resource available: A5 flyer with website details and sickle cell facts, one minute trailer, short 10 minute version of film)

Much of this also applies to showings of the UKTS DVD which are not full sessions.

A note on sessions in family homes

We have tried these with some success but there are pitfalls. It is better to use a family whom you know personally and can trust to turn up and deliver on the day. It's a good idea to bring your own equipment. Probe them carefully on who is coming so you are sure it is a valid audience - eg not too many kids running around. Similarly it's fine to have some elders as they can be influential in the family but they are not our primary audience.

Step 6: follow up

- Please fill in details of your session on the "session record" form provided.
- Each set of evaluation forms should be coded at the top right hand corner with your initials followed by the number 1 (for session 1) number 2 for session two etc. Example – John Smith forms for his four sessions will be coded as JS1, JS2, JS3 and JS4. On the 'Session Record' the evaluation form number will be cross referenced with the venue where the session was done, thus allowing us to relate each feedback form to the setting where the session took place.

- Please fill out the claim form for your own reimbursement and send this to either Iyamide Thomas (for sickle events) or Sema Kiamil (for thalassaemia events)
Payment will be by cheque and will usually take two to four weeks to process.

Questions and contacts

In the first instance, please contact Iyamide Thomas re sickle questions, or Elaine Miller at UKTS re thalassaemia questions

Iyamide Thomas, Sickle Cell Society
54 Station Rd, London NW10 4UA
www.sicklecellsociety.org
Tel: 07841 558611 or Email: iyamide.thomas@sicklecellsociety.org

Elaine Miller, UK Thalassaemia Society
19 The Broadway, Southgate Circus, London N14 6PH
www.ukts.org
Tel: 020 8882 0011 Email: Elaine@ukts.org

And finally...

Thank you for working with us. Please don't be daunted by this list! We have found it to be quite straightforward in practice.

We see this as a learning opportunity for all of us so we welcome your feedback on every aspect of doing the outreach work. We hope to bring everyone together to share experiences at least once during the first year.

Best wishes! (Iyamide and Elaine)