ABRIDGED VERSION

Report Name: Project Board Advisory Group Annual Report

Purpose of Report:

Sickle Cell and Thalassaemia Screening Programme – Year Four annual report:

To update the NHS Sickle Cell and Thalassaemia Screening Programme on progress made in the collaborative project with the Sickle Cell and UK Thalassaemia Societies to support the delivery of screening services and ensuring these are underpinned by service user needs – for the period 1 August 2021 to 31 July 2022.

For Approval:		**For Information:**	✓	**For Discussion:**	

Recommendations / Actions:

N/A

Next Steps:

N/A

Engagement, Outreach and Programme Development for the NHS Sickle Cell and Thalassaemia Screening Programme

Annual Report: **Fourth year update of a collaborative project between the NHS Sickle Cell and Thalassaemia Screening Programme, the Sickle Cell Society and the United Kingdom Thalassaemia Society**

1 August 2021 to 31 July 2022

Table of Contents

Executive Summary

Introduction

Sickle cell disease and thalassaemia are severe genetic blood conditions that can be passed on from parents to children through altered haemoglobin genes. Haemoglobin is the oxygen-carrying component of red blood cells. Sickle cell and thalassaemia are mainly prevalent in tropical and subtropical regions of the world where there is a high incidence of malaria. However, due to migration, the conditions are now more commonly observed in other areas of the world, including the UK. The NHS Sickle Cell and Thalassaemia Screening Programme (NHS SCT Screening Programme) offers antenatal screening to identify carriers of unusual haemoglobinopathies to facilitate early offer of counselling and prenatal diagnosis (PND). Early access to timely screening and the offer of PND is important for women and couples who have an increased chance of having a baby with sickle cell disease or thalassaemia. It gives women and couples the opportunity to make personal informed choices. This is supported by the NHS Newborn Blood Spot Screening Programme, which uses the heel prick test to detect babies with sickle cell conditions and beta thalassaemia major, so they can receive prompt treatment. This procedure also identifies babies who are genetic carriers for sickle cell.

This report documents the achievements by the Sickle Cell Society (SCS), United Kingdom Thalassaemia Society (UKTS) and the NHS SCT Screening Programme. The Societies have direct contact with users of the screening service and can also help ensure that NHS SCT Screening Programme service provision addresses user needs and preferences and reduces inequalities.

The Societies are now in the fourth year of a collaborative project commissioned by the Programme for the period 1st August 2021 to 31st July 2022. The contract commenced in August 2018 and overall tasked the Societies with addressing and supporting Screening Programme challenges highlighted in their trends and performance data.

The unprecedented **COVID-19 pandemic** of 2020 caused significant changes in the work plan previously proposed for Year 2 and one big change was for the Societies to have major input in the revision of the NHS SCT Screening Programme E-learning resource which supports health professionals who are part of the screening pathway. This E-Learning resource review continued to Year 4 as it was a major overhaul which included newly recorded videos and graphics. Changes to the workplan are outlined and monitored quarterly using a 'Restore' document (**Appendix 1**). In Year 4, the Societies continued to follow the Government's directives in relation to COVID-19 to ensure their service user group of individuals with sickle cell and thalassaemia remained safe. For the early part of Year 4 the Society offices mainly remained closed to the public with staff working from home or on a rota basis. Additionally, most meetings and events were successfully held by video conferencing using Zoom or Microsoft Teams rather than face-to-face. However, some face-to-face outreach began during the latter part of Year 4 and also 'hybrid meetings' which allowed a video conferencing option, to improve accessibility.

Work Activities and Outcome

The following projects were identified for Year 4, which took on board changes to the work plan due to the COVID-19 pandemic:

- provide service user perspectives on the reporting methods used to deliver newborn carrier results
- continue to provide input into the revision of the Screening Programme E-learning resource targeted at health professionals involved in the screening pathway
- raise awareness of sickle cell and thalassaemia, including the importance of screening, through increased online presence, specific social media campaigns and dissemination of screening awareness literature
- participate in the production of articles and blogs for Nursing Times
- review Screening Programme Standards 5
- work with NHS England and NHS Improvement (NHSEI) and Transition Team on priorities for the new organisation
- produce Year 5 work plan

Project 1 – Provide service user perspective on the reporting methods used to deliver newborn carrier results

SCS / UKTS have conducted focus group discussions with fathers, mothers and non-parents which will give valuable service user feedback on: the reporting methods used to deliver newborn sickle cell carrier result; and the methods used to deliver newborn screen positive (i.e., baby has the condition) results for sickle cell and thalassaemia. The evaluation of feedback from the focus group discussions will form the basis of a publication '*Parents Stories -2*' and inform the Screening Programme's review of their '*Protocol for Reporting newborn screening results for sickle cell disease to parents*' targeted at health professionals. The focus group feedback from UKTS will give useful insight from parents who receive a thalassaemia diagnosis for their newborn child and it is envisaged this will now also be part of the revised protocol.

Project 2 – Continue to provide input into the NHS SCT Screening Programme e-Learning Resource for Health Professionals in the Screening Pathway.

The Screening Programme's 2016 e-Learning Resource used to train health professionals is getting a complete overhaul and SCS and UKTS have contributed their expertise and service user viewpoint to this (e.g., voiceovers, blogs). New videos recorded by the Societies showcase their work particularly their efforts to help the Screening Programme address inequality. In addition to the e-Learning Resource, SCS /UKTS presented at three training sessions the NHS SCT Screening Programme conducted for nurses, midwives and health visitors.

Project 3 – Raise awareness of SCT and Screening through increased online presence, specific social media campaigns and dissemination of screening awareness literature

In Year 4, the Societies continued to successfully raise awareness of screening issues using various online platforms (Zoom or Microsoft Teams) as well as social and broadcast media, newsletters and websites. Special screening graphics were designed for World Sickle Cell /Thalassaemia Days, Rare Disease Day and International Newborn Screening Day. The dissemination of screening posters, leaflets and other resources have continued both online and hard copy deliveries to hospitals, health centres, GP practices and other health care settings. Additionally, some face-to-face outreach has now begun.

Project 4 – Participate in the production of articles /blogs for Nursing Times

SCS /UKTS were part of an SCT Counselling Skills and Knowledge Manuscript Task and Finish Group planning to write articles/blogs for the Nursing Times. However due to clinical responsibilities, illness and retirement of the lead writers, no more progress was made with this in Year 4. SCS /UKTS had already contributed to the draft articles. UKTS wrote a blog depicting a service users' experience which is awaiting approval, following which SCS will go ahead with their blog. We anticipate this project might recommence in Year 5.

Project 5 – Review NHS SCT Screening Programme Standard 5

The Screening Programme is reviewing Standard 5 which is the timely offer of prenatal diagnosis to women at risk of having a baby with sickle cell or thalassaemia. SCS/UKTS and the Advisory team members were asked to give comments as currently Standard 5 is reported in 2 parts: S05a (women at risk), and S05b (couples at risk). This means women may be counted twice. The proposal is to have one standard and remove the word "couples".

Project 6 – Work with NHSEI and Transition Team on priorities for the new organisation

NHS SCT Screening Programme transferred from Public Health England (PHE) to NHSEI on 1st October 2021 and have been working with the transition team to establish various operational processes, as some governance roles and responsibilities from PHE became lost in the transfer. However, a lead PHE staff member from the Antenatal and Newborn Screening Programme - and who knows the programme and its history - is employed by NHSEI. They remain supportive of our collaborative project.

Project 7– Produce Year 5 Workplan

The Screening Programme has proposed some new work for Year 5. This was discussed with the Societies and at Project Advisory Group meetings. The workplan may include review of newborn screening "declines" (i.e., those who decline a test) and work to explore parents views on Non-invasive Prenatal Testing (NIPT) and Diagnosis (NIPT). Work will also complete the e-Learning Resource and organise focus group consultations on the reporting methods used to deliver newborn carrier results.

Conclusion

This project continues to demonstrate the benefits of collaborative working between the NHS SCT Screening Programme (as service providers) and the Sickle Cell and UK Thalassaemia Societies (which represent service users). This partnership has been used to improve screening service provision and address inequalities. In particular, the service user focus group discussions conducted by the Societies has generated useful insights, which will inform NHS SCT Screening Programme policy and practice and specifically enable them to update their '*Protocol for Reporting newborn screening results for sickle cell disease to parents'* (last updated in 2012). This new publication targeted at health professionals will be launched next April together with the '*Parents Stories-2'*, a report of the focus group discussions. Despite Government COVID-19 directives being lifted, the pandemic is not over and project partners are working with caution, to keep their clinically vulnerable user group safe. As such our virtual outreach continues, although some face-to face activity is slowly returning. Through their website, newsletters and social media posts, the Societies are reaching thousands of families affected by sickle cell and thalassaemia as well as other stakeholders, as demonstrated later in this report.

Purpose of Document

This document reports on progress made in the fourth year of a collaborative project between the Sickle Cell Society (SCS), the UK Thalassaemia Society (UKTS) and the NHS SCT Screening Programme from 1 August 2021 to 31 July 2022. It is an abridged report as standard information already in previous reports has been omitted or shortened.

The Societies provide insight in service user needs and can raise awareness of early screening within prevalent communities. The aim of this partnership is to improve the quality of care of pregnant women, babies and families at risk of sickle cell or thalassaemia in England. The publication of 'Parent Stories' which documented personal experiences of the NHS SCT Screening Programme (https://www.sicklecellsociety.org/resource/parents-stories/) and updated editions of a Parent's Handbook, Paediatric Standards and SCT Counselling Skills, demonstrate the success of previous collaborative work.

Year 4 Aims and Objectives

The main projects for Year 4 (1st August 2021 to 31st July 2022) include some previous project work continued from Year 3, such as the E-learning Resource. Outreach work is also included throughout the Contract. The chart below outlines the projects for Year 4.

1. **Provide service user perspective on the reporting methods used to deliver newborn carrier results**
2. **Continue to provide input into the NHS SCT Screening Programme e-Learning Resource for Health Professionals in the Screening Pathway**
3. **Raise awareness of SCT and Screening through increased online presence, specific social media campaigns and dissemination of screening awareness literature**
4. **Participate in the production of articles /blogs for Nursing Times**
5. **Review NHS SCT Screening Programme Standard 5**
6. **Work with NHSEI and Transition Team on priorities for the new organisation**
7. **Produce Year 5 Workplan**

Diagram 1: SCS& UKTS Workplan for Year 4 (1 August 2021- 31 July 2022)

In addition to the various projects, the SCS and UKTS attend the annual NHS SCT Screening Programme Advisory Group meetings (usually two per year) and other sub-committee/Advisory group meetings as required. SCS/UKTS presented their updates at the NHS SCT Screening Programme Advisory Group meetings on 25th November 2021. The May 2022 meeting has been postponed to November 2022.

Project Advisory Group –and Project Monitoring

The Project Advisory Group (PAG) name was changed to ‘SCT Service Engagement, Outreach and Programme Development Advisory Group’ to properly reflect the remit of the project. Societies facilitate and attend these Advisory Group meetings usually held four times a year. These meetings provide monitoring and evaluation of the project to ensure timely achievement of outputs and targets. Members of the group also approve the project work streams and deliverables each year. In Year 4, meetings were held on 14th October 2021, 19th January 2022, 21st April 2022 and 14th July 2022. Due to various members retiring, the group has a vacancy for a screening midwife representative and will be recruiting shortly. For full details of PAG membership please see **Appendix 2.**

In addition to the PAG meetings, SCS /UKTS meet with NHS SCT Screening Programme regularly to review work progress and monitor what is being delivered.

Project Plan

The following project work-streams show how Sickle Cell Society and United Kingdom Thalassaemia Society have worked to support the NHS Sickle Cell and Thalassaemia Screening Programme in Year 4.

Project 1 – Provide service user perspective on the reporting methods used to deliver newborn carrier results

SCS /UKTS have conducted online focus group discussions. These have given valuable service user feedback on: 1) the reporting methods used to deliver newborn sickle cell carrier results; and 2) the methods used to deliver new-born positive screening results (i.e., baby has the condition) for sickle cell and thalassaemia (see **Appendix 3** for a sample focus group programme). The Societies were tasked to each hold a focus group discussion with mothers; one with fathers (children had to be three years or under); and one with pre-conception individuals who may be at risk of having a child with the conditions. However, due to difficulty recruiting men, this format was changed and UKTS held individual interviews with fathers, whereas SCS did a combined focus group for fathers and non-fathers. This method worked well. To date the SCS has interviewed 10 mothers, 3 fathers and 7 preconception individuals and the UKTS has interviewed 4 mothers, 4 fathers and 7 preconception individuals. During the discussion, participants provided a wealth of information on various aspects of sickle cell and thalassaemia and some gave their experiences of the newborn screening programme communication pathway and how they would wish to see it develop further. Some of the focus group discussions have been transcribed and meetings are planned between the Screening Programme, SCS, UKTS and Dr Maria Berghs and Professor Karl Atkin, who assisted with conducting two of the focus group discussions and will give the project team advice regarding analysis. The data will form the basis of a report ‘Parent Stories-2’, which will be launched at a conference in April

2023. Importantly, the feedback from the focus group discussions will inform the Screening Programme's review of their '*Protocol for Reporting newborn screening results for sickle cell disease to parents'* targeted at health professionals, which was last updated in 2012. This new protocol will also be launched at the conference in April 2023.

Do you or someone you know have sickle cell or trait and have not yet had a child?

Take part in an online focus group to tell us:

- What you know about sickle cell
- What you know about screening for sickle cell
- How you think parents should receive their baby's newborn screening results
- What information you might need on sickle cell or screening

For your help you will get a thank-you gift voucher!

Please register your interest at:
iyamide.thomas@sicklecellsociety.org

For more info go to:
www.sicklecellsociety.org/have-your-say-on-screening/

ARE YOU PLANNING TO HAVE CHILDREN AND MIGHT BE A CARRIER OF THALASSAEMIA OR SICKLECELL BUT HAVEN'T YET BEEN TESTED?

TAKE PART IN A VIRTUAL FOCUS GROUP

DETAILS BELOW:

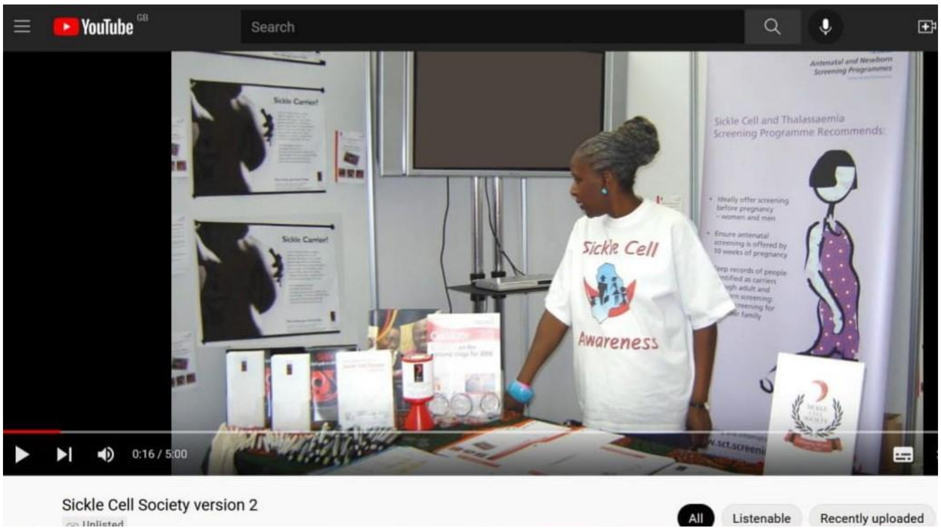
Examples of SCS & UKTS focus group recruitment graphics

SCS Participation in Related Research

SCS are part of a research project at King's College London investigating stakeholders' views on prenatal therapy for sickle cell disease (https://www.kcl.ac.uk/research/pericles) and will be helping with the recruitment for focus groups and/or interviews. SCS has had input on a short, animated video which will also be used for recruitment. Some of the participants from the screening focus group discussions will be eligible to participate. Recruitment for the screening focus group discussions has created learning, which SCS is using with the King's researchers.

Project 2 – Continue to provide input into the NHS SCT Screening Programme e-Learning Resource for Health Professionals in the Screening Pathway

The Screening Programme's 2016 e-Learning Resource used to train health professionals is being overhauled. SCS and UKTS have contributed their expertise and service user viewpoint to this overhaul. SCS /UKTS have endorsed the short edits of new videos (recorded in June 2021), which aim to showcase the Societies' work, particularly what they do to help the NHS SCT Screening Programme address inequality. It is hoped that slightly longer edits of the video footage will be available for use as 'Society Stories', which can be placed on the project team websites. The Societies also provided resources for the e-Learning such as "Parent Guides", service user experience blogs, voiceovers, posters and the SCS *"No One's Listening"* report which details failures in secondary care for patients with sickle cell. In addition to contributing to the e-Learning Resource, SCS /UKTS presented at three training sessions, which the NHS SCT Screening Programme conducted for nurses, midwives and health visitors in the North of England on 8th, 31st March and 5th April 2022.



Clip from E-Learning video showing Iyamide Thomas (SCS) raising awareness of screening and sickle cell

Project 3 – Raise awareness of SCT and Screening through increased online presence, specific social media campaigns and dissemination of screening awareness literature

Outreach is a continuous work-stream. The SCS and UKTS use their respective networks to raise awareness among the public and health professionals on screening issues pertaining to that year's work, as well as general screening awareness particularly to at-risk communities. SCS /UKTS also have sections on their websites about NHS SCT Screening Programme. SCS created the graphic below to alert their network of the SCS collaboration with the NHS SCT Screening Programme and the new website screening section.

Addressing inequalities is one of the reasons the NHS SCT Screening Programme works so closely with the SCS and UKTS. It is important to mention this to other health practitioners and stakeholders. On 22 September, Iyamide participated in a focus group discussion, which was part of the Race and Health Observatory major review into ethnic inequalities in healthcare. By contributing to the three main discussion topics (maternal and neonatal healthcare; genetic testing and genomic medicine; and digital access to healthcare), she spotlighted the work NHS SCT Screening Programme have done in partnership with SCS /UKTS, such as the Family Legacy outreach, Parent Stories, fast-tracking at risk couples, e-Learning and counselling competences.

A final report was produced and given media coverage: https://www.theguardian.com/society/2022/feb/13/radical-action-needed-to-tackle-racial-health-inequality-in-nhs-says-damning-report; and https://www.nhsrho.org/news/new-review-calls-for-radical-action-on-stark-ethnic-inequalities-across-healthcare/. The Observatory Report found that while some positive relationships with midwives occurred, poor communication between women and maternity health providers was the norm. Additionally, women who did not have English as a first language often lacked access to quality interpreting services.

Due to the COVID-19 pandemic most of Year 4 SCS /UKTS outreach was successfully achieved virtually. This was done via posts and articles in newsletters, websites, social, print and broadcast media, which allowed the Societies to continue raising awareness to their target groups. SCS/UKTS also attended a selection of virtual workshops, national and international conferences and gave their input on screening for sickle cell and thalassaemia. UKTS resumed some face-to-face outreach in September 2021 and SCS in May 2022. SCS increased their outreach during Black History Month (October 2021) and ran awareness campaigns for World Sickle Cell Day and Rare Disease Day. For World Sickle Cell Day, the SCS repeated it's 'Wear Something Red' campaign, which saw many don red, including at church since it fell on a Sunday. Iyamide gave a brief talk at All Saints Church and spoke about fathers and screening as it was also Fathers' Day!

UKTS increased their outreach during September (for their month of learning), October (for National Thalassaemia Day), February (Rare disease month and Valentine's Day) and May (International Thalassaemia Day). UKTS also has a dedicated weekly screening social media post to target pregnant mothers, expecting parents, and pre-conceptual populations. From March to June, UKTS ran their Global Art and Poetry competition to spread awareness of thalassaemia; educate communities on the patterns of inheritance and the importance of blood donation; and highlight the work of the society. UKTS received 747 entries from 49 countries. On the week of voting (June 1-8th), the UKTS recorded over 98,000 hits to their website. **Appendix 4** provides a detailed list of SCS and UKTS outreach activities.

World Sickle Cell Day Commemoration

UKTS International Day celebrations

SCS participated in several conferences and workshops (see below). At one successful event organised by a group of Manchester health professionals (attended by 54 people), Iyamide gave her presentation in Krio (Sierra Leone’s lingua franca). One parent of a child with sickle cell spoke about the child’s father refusing a screening test in the UK as he said a test, he took in Africa was negative. Screening was extensively discussed at the events listed below. One theme that came from the Invisible Warrior Workshop on dating was that young people wanted to have more information on preconception screening and options available to those who are carriers, including Pre-implantation Genetic Diagnosis (PGD). Following the ‘Sickle Cell and Dating’ workshop, Iyamide took part in an interview published by The Voice newspaper on *"Dating with Sickle Cell Remains a Taboo"* and spoke about screening. The interviewer was also very interested in preconception screening and how to raise awareness. As such, SCS /UKTS will prepare a strategy for further preconception outreach work as some of this was done in previous outreach projects using the Family Legacy and Thalassaemia DVDs. At a European Sickle Cell Summit held in September (see flyer below), Professor Corrina McMahon (Clinical Director of the Red Cell, general Haematology Laboratory and Blood transfusion laboratories at Children's Health Ireland) said she would be very keen to receive an update on the focus group discussions, exploring communication of newborn screening results.

Sickle Cell Workshop: Screening

Antenatal and newborn screening are important to identify sickle cell disease.

Who, how and where can you request screening?

What are the emotional effects of this process?

Join our exciting workshop with Dr. Lola Oni who will discuss screening with a psychologist, patients, family and friends, and the doctors of the future.

With Special Guest
Dr Lola Oni OBE FRCN
Specialist Nurse Consultant

1st November | **7pm-8.30pm GMT** | **Online workshop**

Patients, family, friends, and medical students are invited to sign up by emailing: invisiblewarrior.scd@imperial.ac.uk

- Explore the impact of SCD on patients, friends, and family.
- Meet and chat with others in similar positions.
- Inspire and inform the next generation of doctors.

Invisible Warrior Workshop: Sickle Cell and Dating

What does sickle cell mean for finding a partner?

How to discuss your genetics and talk about testing?

What are the moral, ethical and cultural dilemmas?

Join our exciting workshop to discuss these and other questions with a psychologist, patients, family and friends, and the doctors of the future.

13th December | **7.30pm-9.00pm GMT** | **Online workshop**

Patients, family, friends and medical students are invited to sign up by emailing: invisiblewarrior.scd@imperial.ac.uk

- Explore the impact of SCD on patients, friends, and family.
- Meet and chat with others in similar positions.
- Inspire and inform the next generation of doctors.

INAUGURAL
EUROPEAN SICKLE CELL SUMMIT 2021
24TH SEPT. 2021.
TIME: 9:50AM UK time.

Prof. Corrina McMahon
Lead Consultant Haematologist
Paediatric Sickle Cell Centre
Children's Health Ireland

Iyamide Thomas
NHS Engagement Lead
Sickle Cell Society
United Kingdom

Prof. Corrine Pondarre
Head of Paediatric Sickle Cell Disease
Centre Creteil Hospital. France

Dr. Gulcin Gumus
Research and Policy Manager
EURORDIS-Rare Disease Europe

Mrs Lanre Tunji-ajayi
Founder/President
Sickle Cell Awareness Group
of Ontario-SCAGO. Canada

Session: NEW BORN SCREENING

Topic: NEWBORN AND MATERNAL SCREENING – A MULTI-NATIONAL REVIEW AND COMPARISON

SPONSORED BY: NOVARTIS VERTEX
SUPPORTED BY: EURORDIS RMC sickle cell

Wɛl Bɔdi Bɛtɛ Pas Gɛntri
presents
Sickle Cell
(Facts, History and Impact) in Krio

By: Ms Iyamide Thomas (NHS Engagement Lead, UK Sickle Cell Society)

Date: 3rd July 2022

Time: 18:00 (UK), 17:00 (SaLone time), 19:00 (Central Europe time), 13:00 (EDT - US time)

Zoom details: 740 546 7486

Your Host
T J Fullah

Our Team
Dr M Kamara
Dr A Hanciles-Amu
Dr MZ Turay
Ms R Kamara
Dr C Bell
Ms A Jalloh
Dr R Conteh
Mrs F Kamara
Dr A sesay
Ms F Koroma

Made with PosterMyWall.com

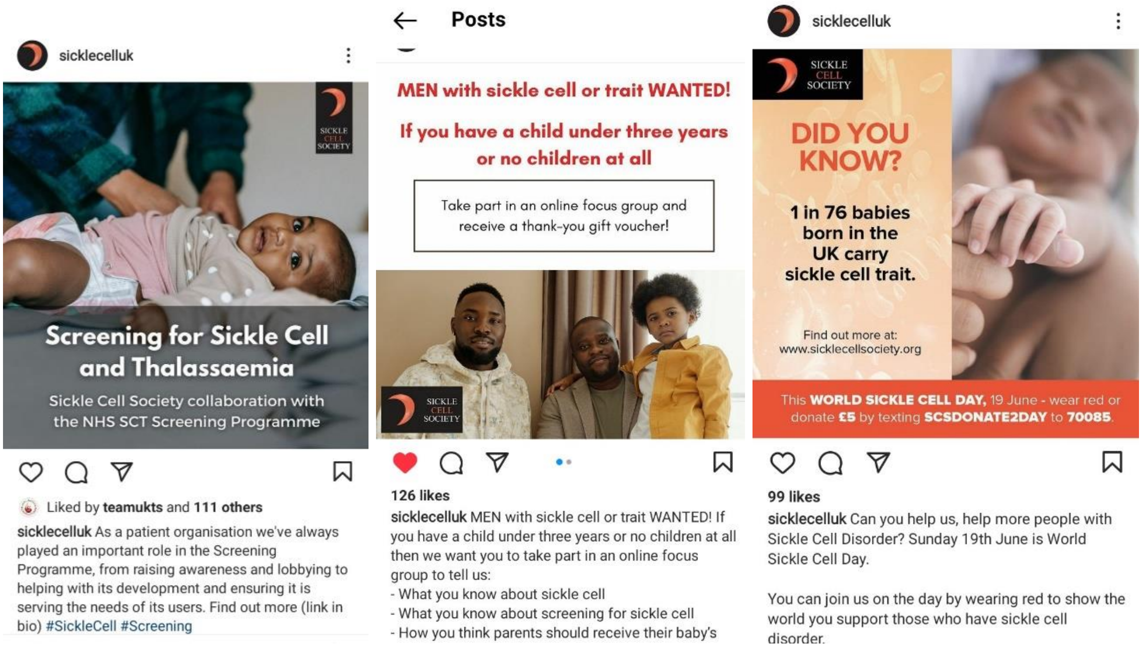
Flyers of some of the events SCS participated in

UKTS participated in several outreach events such as the Nowuz Music and Cultural Show in London, which is an event attended by all Middle Eastern communities. The team handed out over 306 carrier leaflets and 250 flyers on thalassaemia/importance of screening/ informed decision making. Additionally, there were several interviews done with the Kurdish, Afghanistan, Iranian and "My London" teams who covered the event. Other face-to-face outreach events included UKTS Nostalgia Game Night, UKTS Fun Run Walk, AHMA Eid Milan in Manchester, Coventry White Collar Boxing, UKTS AGM and Rumi Mosque Breakfast Club. UKTS have also met various High Commissioners and High Representatives of countries where thalassaemia has a high prevalence. In June 2022 UKTS met with the High Representative, His Excellency Karwan Jamal of the Kurdistan Regional Government.

Examples of UKTS outreach

The impact of Social Media

Social media has value, when educating the public about sickle cell and thalassaemia. Both Societies have worked to create campaigns that target a variety of audiences. Examples of some of their social media graphics are below:



Liked by **teamukts** and **111 others**

sicklecelluk As a patient organisation we've always played an important role in the Screening Programme, from raising awareness and lobbying to helping with its development and ensuring it is serving the needs of its users. Find out more (link in bio) #SickleCell #Screening

126 likes

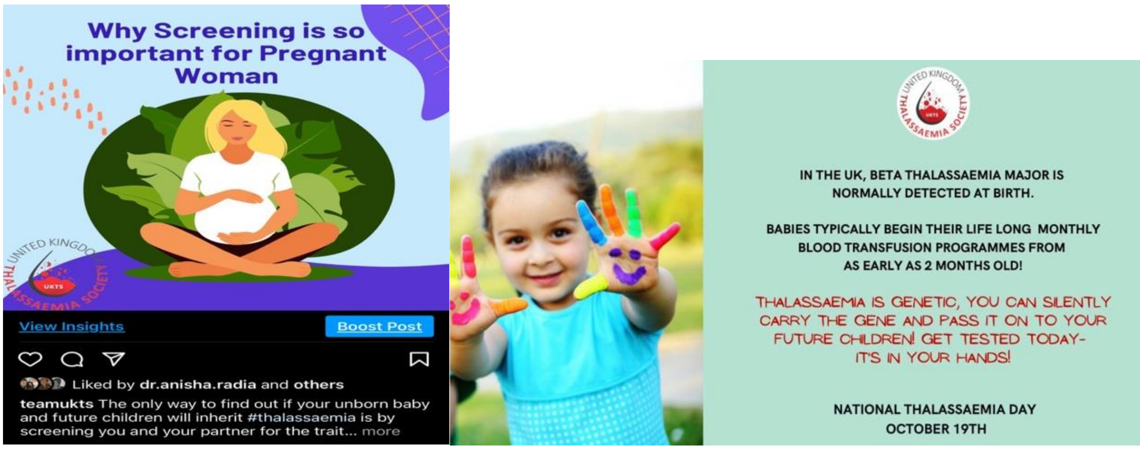
sicklecelluk MEN with sickle cell or trait WANTED! If you have a child under three years or no children at all then we want you to take part in an online focus group to tell us:
- What you know about sickle cell
- What you know about screening for sickle cell
- How you think parents should receive their baby's

99 likes

sicklecelluk Can you help us, help more people with Sickle Cell Disorder? Sunday 19th June is World Sickle Cell Day.

You can join us on the day by wearing red to show the world you support those who have sickle cell disorder.

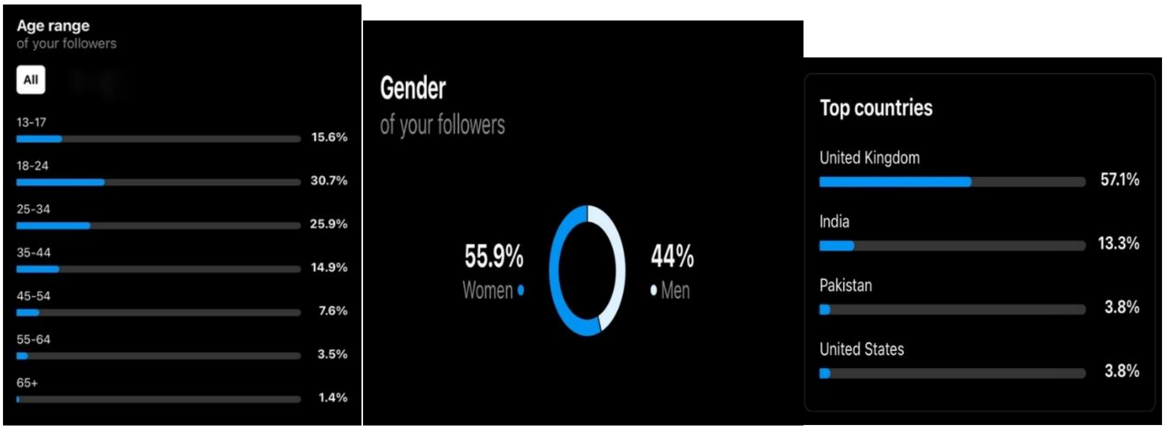
Sickle Cell Society Instagram posts in Year 4



teamukts The only way to find out if your unborn baby and future children will inherit #thalassaemia is by screening you and your partner for the trait... more

Examples of UKTS social media campaigns

Social Media Insights for the UKTS



Project 4 – Participate in the production of articles /blogs for Nursing Times

SCS/UKTS are part of the SCT Counselling Skills and Knowledge Manuscript “Task and Finish” group currently writing articles on the ‘Counselling Competences’ which are to be submitted to the Nursing Times. SCS/UKTS were tasked to contribute information on: the relevance of screening and testing to patient care, the wider family and future generations; the global prevalence of both conditions; and gaps in healthcare provision for Black, Asian and Minority Ethnic (BAME) groups. Additionally, SCS and UKTS were asked to write blogs on the experiences of living with the relevant conditions. UKTS submitted their draft blog to PHE for review in May 2021. However, there has been no progress with this project since mid-2021, due to pandemic becoming the clinical priority for group members. No submissions, therefore, have been made to Nursing Times, although it is anticipated this will be picked up in Year 5.

Project 5 – Review NHS SCT Screening Programme Standard 5

In November 2021, SCS /UKTS and members of the project advisory group gave their feedback to NHS SCT Screening Programme' review of Standard 5, which is the timely offer of prenatal diagnosis to women at risk of having a baby with sickle cell or thalassaemia. Currently, Standard 5 is reported in two parts: S05a (women at risk), and S05b (couples at risk). This risks women being counted twice. The proposal is to have one standard and remove the word "couples" so as to focus on the women. Another proposed change is to have a clear definition of what is meant by the offer of PND, as it could mean the offer of the counselling appointment or the offer of PND at the counselling appointment. Different services could be counting different things. The proposed changes of combining SCT-S05a and SCT-S05b, along with clarification of the definition, should improve the quality of the data collected and help inform and drive improvements in the early offer of PND to women at risk of having an infant with sickle cell or thalassaemia. One feedback about the proposals was that some testing of the planned changes with 2-3 trusts should take place before wider roll-out. Another view was that there should be clear timescales/standards for the invitation of the biological father for carrier testing who may or may not be in a couple, nor partner of the woman. The NHS SCT Screening Programme will incorporate the feedback into a draft document in consideration of NHSEI commissioning timelines.

Project 6 – Work with NHSEI and Transition Team on priorities for the new organisation

NHS SCT Screening Programme transitioned from Public Health England (PHE) to NHSEI on 1st October 2021 and have been working with the transition team to establish various operational processes, as the new structure did not accommodate some previous governance roles and responsibilities. The head of commissioning and operations for the Antenatal and Newborn Screening Programmes is supportive of the SCT Screening Programme and NHSEI are looking at making some of the screening team posts, currently on fixed-term contracts, permanent. There has been some discussion with NHSEI around new Integrated Care Systems (ICS), which are to replace Clinical Commissioning Groups. The transition to ICS will, however, have little impact on the day-to-day running of the NHS SCT Screening Programme.

The focus of ICS is to improve outcomes, tackle inequalities, enhance productivity and by working with SCS /UKTS ensure the Screening Programme has sufficient evidence to meet these criteria.

Project 7 – Produce Year 5 Workplan

The Screening Programme has proposed some new work for Year 5 and discussed this at a Project Advisory Group and at a separate meeting with the Societies on 22 July 2021. The proposed Year 5 workplan is shown below (Diagram two). In addition, outreach to raise awareness of screening remains a continuous work-stream. The current contract, however, ends in July 2023 and any work for Year 6 will necessitate an extension.

1. Implement Findings from Year 4
2. Analyse transcripts from focus groups and produce report on service user perspective on the reporting methods used to deliver newborn results - 'Parents Stories 2'
3. Hold two conferences to launch Parents Stories 2 and Protocol for communicating newborn results
4. Review of newborn bloodspot declines
5. Continue to provide input to the e-learning resource and provide 'Society Stories' which may include further filming
6. Conduct workshops to determine parents' views on NIPT/NIPD tests
7. Produce Year 6 Workplan

Diagram 2: SCS& UKTS Workplan for Year 5 (1 August 2022 – 31 July 2023)

Discussion

This Year 4 report once again demonstrates the benefits of collaborative partnership working between the NHS SCT Screening Programme and the Sickle Cell and UK Thalassaemia Societies (which represent users of the service). The Screening Programme identified the inequalities faced by the high-risk sickle cell and thalassaemia communities, when accessing appropriate services (such as PND) because cultural and social needs are not adequately addressed; or because of a lack of understanding on the part of health professionals and a lack of knowledge among communities. Working with SCS /UKTS helps the Screening Programme address these inequalities. The Societies have a direct relationship with the targeted communities and can feedback on individual user needs. The Programme cannot access this feedback since they have no such direct relationships with the communities.

One way the work of the Societies will help NHS SCT Screening Programme address inequalities - and make relevant policy changes - is exemplified by the planned use of feedback from the focus group discussions to inform the review of Screening Programme's *Protocol for Reporting newborn screening results for sickle cell disease to parents',* targeted at health professionals. The additional feedback now obtained from UKTS will provide useful insight from parents who receive a thalassaemia diagnosis for their newborn child. It is envisaged this feedback will be part of the revised protocol. Other valuable feedback from the focus group discussions on newborn screening should help the Programme adapt its service and hopefully impact positively on the relevant Screening Programme Standards, particularly Standard 8 (on the time taken to give newborn results) and Standard 9 (provide follow up with a consultant).

The SCS /UKTS contribution to the review of the e-Learning resource and training events for health professionals is an invaluable contribution that will help nurses, midwives, health visitors and others on the screening pathway learn about service user needs and ensure such needs are met. The Societies feedback to the review of Screening Standard 5 (timely offer of Prenatal Diagnosis) has been valuable and should ensure that any proposed changes are piloted before roll-out, thereby facilitating better screening service provision to all users.

NHS SCT Screening Programme transferred from Public Health England (PHE) to NHSEI on 1st October 2021 and has put various operational processes in place to ensure the governance roles and responsibilities from PHE are now part of NHSEI. The lead PHE staff member from the Antenatal and Newborn Screening, who knows the NHS SCT Screening Programme and its history of successfully working collaboratively with SCS /UKTS, transferred to NHSEI. This means this programme of work can rely on support, particularly as the work continues to provide value for money to the Screening Programme (**Appendix 5**)

Learning from Year 4

Learning from Year 4 showed that despite some continued restrictions associated with the COVID-19 pandemic, our project was still able to adapt to the challenges and monitor these using the Restore document (see Appendix 1). Both Societies have benefitted from the expertise and advice of the Advisory Group members, which have strengthen their work streams, particularly in the case of the focus group discussions. Due to the difficulty in recruiting men to the focus group discussions, the Societies were able to successfully alter the format and do individual father interviews (UKTS) or combine two of the focus group discussions for men (SCS). One of the biggest learning areas for UKTS is related to newborn diagnosis and the impact on families. Families with thalassaemia found coping with the diagnosis and the rigorous treatments extremely difficult. It took up to five years for families to be able to talk fully about the condition. Additionally, the Societies learned a great deal from their service users and the general public about language, appropriate care and community need, which they were able to share with NHSEI.

Acknowledgement

The Sickle Cell Society and UK Thalassaemia Society would like to thank the NHS Sickle Cell & Thalassaemia Screening Programme for their willingness to continue working collaboratively with the voluntary sector to ensure the service user voices are heard. The Societies would also like to acknowledge the Project Advisory Group members for the leadership and expertise given towards the project over the last year. Most of all, we would like to thank all the service users, particularly from the focus groups who have taken time to contribute to this project.

Iyamide Thomas	Romaine Maharaj
NHS Engagement Lead, Sickle Cell Society	Executive Director, UK Thalassaemia Society

Appendices

Appendix 1

‘Restore’ Document

Purpose

The purpose of this document is to provide guidance and clarification on how best the Sickle Cell Society (SCS) and the United Kingdom Thalassaemia Society (UKTS) plan to resume their projects with regards to the joint screening contract they hold with Public Health England (PHE), as the COVID-19 pandemic evolves, and services return to business as usual.

Despite, not being a quick return to “normality” the SCS and UKTS in collaboration with PHE have found new ways of working and have adapted their workplan to continue to prioritise antenatal and new-born screening in England as safely as possible.

Some of the Societies’ activities and focus have changed since the start of the COVID-19 pandemic and many of the planned outreach and face to face work have been affected. In addition, a new work stream has been prioritised.

This document aims to also provide a brief update on the work that has been undertaken by the SCS and UKTS, in addition to some shared learning during the COVID-19 pandemic.

Update: **SCS/UKTS will periodically update this document and bring to future PAG meetings for review.**

This restore guidance is specific to the Societies’ workplan and contract with PHE and is targeted towards PHE.

Shared Learning

During the pandemic, the SCS and UKTS had the opportunity to work very closely with the dedicated NHS Sickle Cell and Thalassaemia Screening Programme (NHS SCT Screening Programme) led by Amanda Hogan. The group held virtual meetings, on a weekly to biweekly basis, which provided useful insights and learning opportunities to all who were present. There were nineteen virtual meetings held over the August 2020 to March 2021 period. These meetings were instrumental in supporting and keeping the Societies' focus on the workplan to ensure core milestones were still met and for adaptations to be made. These regular e-meetings ensured the important work of the screening programme continued to progress into the next phase of the pandemic.

It was decided by the lead of the NHS SCT Screening Programme that the SCS and UKTS would be included in the revision of PHE's e-learning material which was utilised by specialist haemoglobinopathy nurses, midwives and other allied health professionals. This brainstorming opportunity was invaluable for all involved as it helped update and modernise the e-learning units to include factors such culture, ethnicity and religion.

The input of the SCS and UKTS to the review of the E-learning resource gave the Societies the opportunity to share some of their previous experiences gained over the years from speaking to families and healthcare professionals who the NHS SCT Screening Programme thought was insightful and very helpful to the continuation of a future tender.
The SCS and UKTS hope these e-meetings will continue in the future as it proved to be very helpful and both Societies' felt very supported by the NHS SCT Screening Programme.

The table below shows the status and details of the projects outlined as part of the SCS and UKTS workplan.

The projects have been categorised into three sections:

Red - projects that have been maintained but are currently suspended.

Yellow - projects that have been partially restored yet are still somewhat affected.

Green - projects that have been unaffected including new work undertaken by the Societies.

Table 1: Showing status and details about each project identified in the workplan.

Project		Status	Details
Not able to restore (but maintained within the Societies' workplan, suspended until further notice)			
1.	Parent Stories 2/ Society Stories- we hope to update the previous work done to give feedback on ECHR and provide more service user experiences	Maintained	This project will not be started until the focus groups and interviews have been completed.
Partial restoration - phase back (Affected, Ongoing)			

2.	Contribute to the NHS SCT Screening Programme Standards 5 Review.	Ongoing	**UKTS** & **SCS** awaiting further intruction from NHSSCTSP
3.	Manuscript work after launching updated counselling competencies	Affected	**UKTS** has written blog piece and both Societies have submitted the work required by the manuscript group. Due to clinical staff work commitments and leave, the group have not been able to meet since April/ May 2021.
4.	Electronic Child Health Record (ECHR) Project: Service user perspective on the methods used to deliver new-born screening for sickle cell and thalassaemia	Affected	**SCS** & **UKTS** have completed all focus groups and one to one interviews. Recordings have been sent to the Transcription service awaiting return. Two potential days have been blocked off in the calander for analysis. – see workplan for more details.
5.	Outreach (Face to face)	Semi- Affected	**UKTS** has been meeting with individuals and families at their HQ and has resumed face to face awareness. **SCS** have not commenced F2F outreach but continue to outreach online.

Fully restored service- (Completed/ Unaffected)

6	Alpha thalassaemia leaflet	Unaffected	A finalised version of this leaflet is now on the Gov.UK website. **UKT**S has also included the link on their website.
7.	Outreach (Social media, virtual)	Unaffected	Both **SCS** and **UKTS** have increased their online presence and have been developing specific social media campaigns to increase level of awareness. **SCS** has a screening update in their current spring newsletter. **UKTS** has a dedicated screening post on Tuesday across all social media platforms. Also a

			dedicated screening article in the quarterly magazine/ monthly email updates. UKTS is updating webpages and educational resources relating to screening. – see workplan for more details.
8.	E-learning modules under review (new project added)	Unaffected	UKTS awaits the development of the thalassaemia module.

Authors: United Kingdom Thalassaemia Society and the Sickle Cell Society

Appendix 2

Membership of Project Advisory Group (PAG) in Year 4

Chair : Rowena Clayton	Screening Lead (Retired) , West Midlands, PHE
Lynette Adjei	Service user representative (sickle cell)
Dr. Maria Berghs	Director - Unit for the Social Study of Thalassaemia and Sickle Cell (TASC)
Prof. Karl Atkin	Professor of Sociology with special interest in haemoglobinopathies, University of York
Dr. Patricia Connell	Finance and Business Manager, NHSEI
Amanda Hogan	Programme Manager, NHS SCT Screening Programme, NHSEI
Adeeba Jameel	Service user representative (thalassaemia)
John James	Chief Executive Officer, Sickle Cell Society
Roanna Maharaj	Vice -Chair, UK Thalassaemia Society
Romaine Maharaj	Executive Director, UK Thalassaemia Society
Jessamy W-Pepper	Project Support Officer, antenatal and newborn bloodspot screening
Nadia Permalloo	Head of Quality Assurance Service, Screening, NHSEI
Dr. Mary Petrou	Director, Haemoglobinopathy Genetics Centre, UCL & Advisor to UKTS & SCS
Michele Salter	Chair, Sickle Cell Society

Louise Smith**	SCT Clinical Nurse Specialist, Alder Hey Hospital, Liverpool
Iyamide Thomas	NHS Engagement Lead, Sickle Cell Society

** Unable to attend meetings but would like to receive papers and comment on relevant issues

Appendix 3

Sickle Cell Focus Group with those from an at risk community planning a family (Pre-conception)

(4 December 2021)

10.50 -11.00am Registration and Entry into Zoom Room
11am -11.15 Welcome and Introductions

Introduce the session and explain what it is all about and how grateful we are for participants to be here to give their feedback and opinions. Remind people of confidential recording and some ground rules to respect what each participant says, use 'raise hand' feature etc. Ask each participant to use a maximum of 2 minutes or less to tell us about themselves – first name, where they are from and how they found out they had sickle cell or the trait.

Background Knowledge **(Approx. 10 minutes)**

- **How much background knowledge do you have about sickle cell /trait and if any where did you find out this information? (e.g. parents, health professional, website, leaflet etc)**
- **Are you familiar with the term 'carrier'? What does it mean to you?**
- **What do you understand by the terms pre-conception and, antenatal?**

(Give explanation to participants as required).

Testing (Explain that 'testing' is different from 'screening') **(Approx. 10 minutes)**

What do you know about testing for sickle cell or thalassaemia trait for example:

When do you think someone should be tested for the sickle cell or thalassaemia gene?

Why do you think it is important for an individual to know whether they carry the 'sickle cell or thalassaemia gene?

Where in the community do you think testing should be offered?

Which health professionals need to know if you are 'trait' and why? (e.g. GP, dentist, hospital)

Antenatal Screening **(Approx. 10 minutes)**

- **What if anything do you know about the NHS antenatal screening programme for sickle cell and thalassaemia? Do you think it's only for women?**
- Which different ways do you think individuals should receive their antenatal screening results? (e.g. telephone call, email, visit)
- **What support or information do you think couples should be given if they are found to be carriers? (NB: there is antenatal counselling by nurse specialists in some areas)**

Newborn Screening – (Ask first question and then give info on newborn screening) **(Approx. 10 minutes)**

- **What if anything do you know about the NHS newborn screening programme?**
- **Which health professional would you like to give you your baby's results and why? (GP, health visitor, midwife etc)**
- **How would you like to receive these results?**
    - In person
    - Phone
    - Other (email, Whatsapp etc)

- **If your baby had sickle cell or trait what information would you find useful and why?**

- **What sources of information would you use? (e.g. the internet, religious leader, GP, Patient organisations etc)**

- Do you think most people your age have a Smartphone and / or a computer to communicate with?

- **What support do you think might be important if your baby was diagnosed with sickle cell before they had their first consultant visit in 90 days?**

Impact of Baby's sickle cell diagnosis on participants, family and friends (Approx. 10 minutes)

- What information would you need to communicate the test result to your wider family?

- **Who is it important to communicate your baby's test results with? (e.g. extended family, nursery, babysitter)**

Health Communication (Approx. 10 minutes)

Where do you get your health information from?

- Health Professional
- Internet – websites, social media, you tube etc.
- Posters – do you use QR codes?
- Leaflets
- Friends and family
- Other

How do you generally like to communicate with health professionals?

- In person
- Online
- Phone
- Email
- Text

- Other

Discussion Summary (Approx. 10 minutes)
Maria Berghs / Iyamide

Now that you are more aware of sickle cell and thalassaemia:

1) When do you think people should be made aware of the conditions and the need to get tested? (e.g. schools, college)
2) How should this awareness be made? (e.g. talks, leaflets, social media)

Ask participants if pertinent points of their feedback have been covered.

Do you have any questions?

Appendix 4

Year 4 Outreach and other activities undertaken by Sickle Cell Society and United Kingdom Thalassaemia Society

Dates	Activity and Feedback	No of Participants
1 August 2021	UKTS- Roanna Maharaj did an Instagram live with @FunwithRedBloodCells – to talk about life with thalassaemia and the importance of screening	Estimated as > 500
10 August	UKTS- Daily Mail Newspaper article about a thalassaemia interview Roanna Maharaj	Estimated reach > 2000
25 August	UKTS attended a meeting held by the National Disease Registration Service about their upcoming transition from Public Health England to the various departments.	14
26 August	UKTS hosted a Nostalgia Games & Pizza Night for Londoners aged 18-25 to educate them about thalassaemia and how they found covid lockdown. Individuals who attended had not been tested for thalassaemia prior to attending.	16
22 September	IT attended a Race Equality Foundation Focus Group as part of a major review into ethnic inequalities in healthcare. She gave an example of how the NHS SCT Screening Programme is addressing these.	10
13 September	SCS attended SE London SCT Support Group meeting which included several parents who were told about the focus groups.	15
22 September	SCS attended Race Equality Foundation workshop on health inequalities.	13
24 September	SCS attended European Sickle Cell Federation Summit and presented at newborn screening session. Recording available on their website.	~40
01-30 September 2021	UKTS- Month of Learning Campaign – featuring screening, caring for a child with thalassaemia etc	Estimated as > 500

3 October	UKTS supported the #teamukts runners at the London Marathon by providing leaflets, advice and social media campaigns	~500
5 October	SCS gave Black History Month SCD awareness talk to staff at British Library.	25
11 October	SCS gave Black History Month SCD awareness talk to SE London Sickle Cell Support Group.	20
12 October	SCS participated in a conference at King's ('Elements and Advances in Sickle Cell Care') which included relevant topics: Antenatal Haemoglobinopathy screening, Pre-implantation Genetic Diagnosis (PGD), Non-Invasive prenatal diagnosis for sickle cell, inutero therapy for sickle cell	Webinar Stats unavailable
18 October	SCS participated in BHM sickle cell talk to South London Botanical Institute given by retired sickle cell nurse	15
19 October	UKTS – National Thalassaemia Day social media, hospital awareness and radio campaigns- UKTS supported all participating trusts by sending educational information for hcps and the public. UKTS Patrons Peter Polycarpou and Bambos Charalambous MP and Chair of APPG for thalassaemia did radio interviews.	Estimated as > 1000
28 October	UKTS – Medical and Scientific Conference for Health Care Professionals	128
28 October	SCS participation in Elsevier event on health inequalities	Webinar Stats unavailable

1 November	SCS participated in Invisible Warrior workshop on ‘Screening’	~25
3 November	SCS participated in the Progress Educational Trust’s ‘Newborn Screening- What Should be Screened For’ webinar	Webinar Stats unavailable
13 November	SCS participated in Croydon Support Group Meeting and discussed focus groups	20
1 December	SCS recorded a video on screening which was included in Dawn Butler MP Advent 2021	Unavailable but estimated at a few hundred views
13 December	SCS participated in Invisible Warrior workshop on ‘Sickle Cell and Dating’ which discussed stigma, preconception screening etc.	~40
14 December	SCS screening interview for The Voice newspaper.	N/A
17 December	SCS had 1:1 discussion with young lady interested in preconception screening and also availability of PGD	2
13 December	SCS participated in a workshop on VALuing the bENefits and harms of anTenatal and newborn screening programmes In health economic Assessments (VALENTIA).	48
13 January 2022	SCS / UKTS did presentations at the Sickle Cell and tThalassaemia Assoc. of Nurses Midwives and Allied Professionals (STANMAP)	>30

26-27 January	SCS/UKTS attended ASCAT International Conference	>100
8 Feb	SCS participated in Invisible Warrior workshop on ‘Improving Patient –Doctor Relationship’ bringing screening perspective when relevant	~40
24 Feb	SCS participated in Invisible Warrior workshop on ‘’Current and future SCD Treatments’ bringing screening perspective when relevant	~40
14 February	UKTS Social Media post on all platforms for Valentine’s Day to raise awareness of thalassaemia and why screening is helpful	Estimated reach > 500
26 February	UKTS- Alaraby TV interview with Dr. F Shah, Gabriel Theophanous (UKTS Chair) and Romaine Maharaj (UKTS ED)	Estimated reach > 500
26 February	UKTS- Awareness Presentation on thalassaemia -Learn by Design at Southgate College	19
26 February – June 2022	UKTS Global Art and Poetry Competition to spread awareness of thalassaemia, educate on the patterns of inheritance, the importance of blood donation and lastly highlight the work of the society. UKTS received 747 entries from 49 countries. On the week of voting (June 1-8th), the UKTS recorded over 98,000 hits to their website.	estimated reach > 100,000
28 February	Rare disease Day- UKTS AND SCS had social media campaigns and attended events to raise the profile of both conditions.	Estimated reach > 2000
1 March	UKTS- Updating Clinical Standards for children and adults – includes a section on screening , caring for newly diagnosed babies etc- 1st Meeting	

3 March	UKTS attended a workshop hosted by Dr. Nnenna Osuji, Chief Executive Officer of North Middlesex Hospital in London to discuss how the trust can improve services and the experience of people living with thalassaemia and Sickle Cell Disease.	
8 March	UKTS and SCS supported the NHSSCTSP by presenting on the work of the Societies and a service user experience at the North East Yorkshire and Humber SCT Forum	~20
13 March	Nowuz Music and Cultural Show in London (March 13th) which is an event attended by all Middle Eastern communities. The team managed to hand out over 306 carrier leaflets and 250 flyers on thalassaemia/ importance of screening/ informed decision making	Estimated reach > 300
29 March	UKTS- Roanna Maharaj attended a rare disease round table with Sajid Javid to talk about issues relating to the rare disease community such as lack of new-born screening, education etc	13
30 March	SCS had 1:1 discussion with UCL medical student on a strategy for raising awareness of preconception screening	2
31 March	UKTS and SCS supported the NHSSCTSP by presenting on the work of the Societies and a service user experience at the SCT Forum	~30
5 April	UKTS and SCS supported the NHSSCTSP by presenting on the work of the Societies and a service user experience at a second SCT Forum	~30
9 April	SCS sickle cell and blood donation awareness talk to Croydon church group	45
24 April	UKTS – Westminister Hall Debate- As part of the International Thalassaemia Day celebrations, Bambos Charalambous MP, Chair of the All Party Parliamentary Group for thalassaemia, will be taking the opportunity to raise national concerns relating to the treatment of thalassaemia in the UK. A recording of the event would also be available in the archives following the event.	Estimated reach > 500
25 April	SCS participated in Invisible Warrior workshop on ‘Being a Sickle Cell Advocate’ bringing screening perspective when relevant	~40

6 May	UKTS- Gabriel Theophanous and Roanna Maharaj did a radio interview at London Greek Radio to raise awareness of thalassaemia ahead of the UKTS 5K Fun run	Estimated reach > 250,000
8 May	UKTS- Fun Run/ Walk in Southgate for International Thalassaemia Day- with MPs, Patrons and media outlets	>300
18 May	UKTS AND SCS attended UK Forum on Haemoglobin Disorders Academic Meeting	>150
21 May	UKTS- AHMA Eid Milan in Manchester- Muslim family day – handed out leaflets, posters and providing advice	Estimated reach > 500
21 May	UKTS - Coventry White Collar Boxing- Supported an individual with thalassaemia by handing out leaflets, posters and providing advice	Estimated reach > 500
22 May	UKTS- UKTS introduction to St Monica Palmers Green Catholic Church.	100
29 May	UKTS- Ride London 100 mile race- supported our rider and gave leaflets and advice to general public	>150
13 June	UKTS met with the High Representative, His Excellency Karwan Jamal of the Kurdistan Regional Government	
15 June	UKTS - Face to face event - Red Cell Celebration Day at St Georges Hospital- handed out leaflets, posters and providing advice	44
16 -17 June	SCS attended the Global Conference on Sickle Cell Disease	Webinar numbers unavailable
19 June	SCS did a World Sickle Cell Day talk at All Saints Church and included aspects of Father screening as it was also Fathers' Day. SCS put special WSCD screening graphics on social media and website.	~100
21 June	SCS attended Royal College of Nurses WSCD talk	
26 June	UKTS- Article on Eastern Eye on Bollywood stars break stigma and speak out about having thalassaemia minor. https://www.easterneye.biz/bollywood-stars-	Estimated reach > 1000

	break-stigma-and-speak-out-about-having-thalassaemia-minor/	
28 June	UKTS social media post on International Neo-natal Screening Day	>150
28 June	UKTS Face to face event - Thalassaemia awareness presentation and blood donation promo to Rumi Mosque's breakfast club in Edmonton	32
3 July 2022	SCS sickle cell awareness talk to international audience organised by Manchester based A&E consultant	54

Appendix 5

Sickle Cell Society

PHE -Sickle Cell and Thalassaemia Screening Programme Contract 2018/21
– Extended to 10 August 2023
Year 1 Extension Finance Report August 2021 to July 2022

1. Introduction

This report provides an actual summary of income and expenditure related to the 1st year of the 2-year extension of the contract from 11 August 2021. PHE agreed to extend the contract for a further 24 months from August 2021 to August 2023 to supply services subject to the original contract terms and conditions.

2- year Extension of the contract - Effective from 11 August 2021 to 10 August 2023

The annual operating budget for August 2021 to July 2022 contract covering both Sickle Cell Society (SCS) as lead organisation and UK Thalassaemia Society (UKTS) was £124,916.

- SCS £80,225
- UKTS £44,691

August 2021 to July 2022

Total allocated income for this period Aug 21 – Jul 22 is £124,916, plus underspend from Year 3 of £9,585. Total income for this period is therefore £134,501.

Total expenditure for this period £124,424.

Commentary

Total allocated income for the year August 21 to July 22 was (£134,501), grant payment £124,916 plus underspend carried forward £9,589. Total expenditure £124,424.

A final underspend of £10,076 has been carried forward to year 2 of the extended contract.

John James OBE
CEO – SCS
Miriam Williams- Finance and Administration Manager-SCS

NOTES