SICKLE CELL SOCIETY

UNITED KINGDOM THALASSAEMIA SOCIETY
UKTS

ABRIDGED VERSION

Report Name: Project Board Advisory Group Annual Report

Purpose of Report:
Sickle Cell and Thalassaemia Screening Programme – Year Five annual report: To update the NHS Sickle Cell and Thalassaemia Screening Programme on progress made in the collaborative project with the Sickle Cell Society and UK Thalassaemia Society to support the delivery of screening services and ensuring these are underpinned by service user needs – for the period 1 August 2022 to 31 July 2023.

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: **Fifth 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 2022 to 31 July 2023

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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 have completed a fifth year of a collaborative project commissioned by the NHS SCT Screening Programme for the period 1st August 2022 to 31st July 2023. 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 contract subsequently went to public tender for its renewal beyond 1 August 2023 and once again SCS and UKTS won the contract and can continue taking the work forward for another 2-3 years.

The unprecedented **COVID-19 pandemic** of 2020 had caused significant changes to the work plan, in particular to our method of outreach. It led to new 'hybrid' working practices, which meant events were simultaneously carried out in-person and online using video conferencing facilities. This was particularly useful in improving national (and sometimes international) access to our events and has subsequently continued. We continued our quarterly monitoring of changes to the workplan using the 'Restore' document that was created at the start of the pandemic, however in Year 5 this was renamed to 'Review' document. **(Appendix 1)**

As Year 5 was the last year of that current NHS contract, the Project Advisory Group suggested it would be pertinent to look back at the work and achievements of the preceding four years and include as a summary within this report:

Summary of Years 1-4: 15 August 2018 – 31 July 2022

Objectives, Outputs and Achievements

Reviewed and updated the *'Sickle cell disease in childhood: standards and guidelines for clinical care'* publication which was last updated in October 2010
Publication produced and launched as part of an online conference in January 2021 and disseminated to paediatric departments via the Haemoglobinopathies Co-ordinating Centres (HCC's).
Reviewed and Updated *'A parent's guide to managing sickle cell disease'* - a book particularly targeted at parents when they have just had a child with sickle cell.

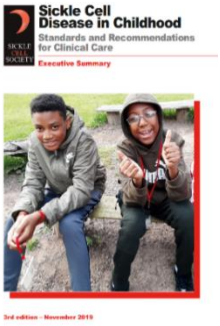
Output / Achievement

SCS organised multi-disciplinary working groups that produced both publications which were then launched as part of an online conference on 28th January 2021 attended by over 250 people. The hard copy resources were subsequently disseminated to paediatric departments and other departments via the HCC's as well as via the SCS networks. The 'Paediatric Standards' and 'Parents Guide' are also available on the SCS website.

A parent's guide to managing sickle cell disease

Sickle Cell Disease in Childhood
Standards and Recommendations for Clinical Care

3rd edition – November 2019



Sickle Cell Disease in Childhood
Standards and Recommendations for Clinical Care
Executive Summary

3rd edition – November 2019

Supported the Newborn Outcomes (NBO) System - which is an automated system that supports the referral of babies diagnosed with sickle cell into treatment. The NOS also links to the National Haemoglobinopathy Register (NHR)

Output / Achievement - SCS and UKTS supported NBO system by using their extensive networks to raise awareness and help improve families understanding and trust for the use of their data. This was done over 29 events including health professional talks, parent support groups and Patient Education Days. The Societies also educated parents on the importance of prophylaxis penicillin (if their child has sickle cell) and getting their affected babies into timely paediatric care. Additionally, service users have been informed about registration on the National Haemoglobinopathy Registry (NHR) and the role this will subsequently play in improving commissioning and targeting of resources. UKTS drafted a more user-friendly version of the existing NHR patient information leaflet.

Implemented the findings from 'Parents Stories' – personal experiences of sickle cell and thalassaemia screening.

Output / Achievement

Public Health England

Parents' Stories

The Parents Stories highlighted a number of issues for the public and health professionals which needed more awareness to be raised. As such, SCS /UKTS used extensive outreach to implement recommendations as follows: 1) the public were urged to present early in pregnancy and made aware they can go directly to the nurse specialist at Sickle Cell & Thalassaemia Centres or hospital maternity units. 2) Screening providers were to provide fast track direct access, particularly for known 'at –risk' couples.

Provided service user perspective in the review and update of sickle cell and thalassaemia counselling competences

Output / Achievement

SCS / UKTS were part of a Manuscript Task and Finish that produced *SCT Counselling Knowledge and Skills* (previously 'Nurse Counsellor Counselling Competences') launched at an online conference on 28th January 2021

Provided service user perspective on the reporting methods used to deliver newborn carrier results.

Output / Achievement

SCS / UKTS conducted focus group discussions with fathers, mothers and non-parents which gave valuable service user feedback on: the reporting methods used to deliver carrier results and the methods used to deliver newborn screen positive results for sickle cell and thalassaemia. Very useful feedback was obtained from the focus groups, subsequently resulting in a Year 5 of a launch of a report ' *'It's in Our Genes: Service User Experiences and Feedback on the Communication of Screening Results for Sickle Cell and Thalassaemia'* .

Provided input into the revision of the Screening Programme e-learning resource targeted at health professionals involved in the screening pathway

Output / Achievement

SCS and UKTS contributed their service user expertise, and resources to the revised Screening Programme's 2016 e-Learning Resource used to train health professionals. The Societies produced a film illustrating their work with service users and with the NHS SCT Screening Programme. The video, featuring interviews with staff members at both Societies, gives an insight into challenges faced by users across the screening pathway and is designed to help the Screening Programme address inequalities linked to culture, religion and language.

Reviewed Screening Programme newborn carrier leaflets and Alpha thalassaemia leaflet

Output / Achievement

SCS / UKTS reviewed and gave feedback on the Screening Programme's newborn screening information leaflets which are now on the www.gov.uk website. UKTS also reviewed the now completed Alpha Thalassaemia leaflet produced as an HTML document.

Raise awareness of SCT and Screening through increased online presence, specific social media campaigns and dissemination of screening awareness posters

Output / Achievement

The Societies successfully raised awareness of sickle cell and thalassaemia as well as screening issues in-person and 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 Day, National Thalassaemia Day, Rare Disease Day and International Newborn Screening Day. SCS / UKTS produced posters which were disseminated both online and at hospitals, health centres, GP practices and other health care settings.

Review Screening Programme Standards

Output / Achievement

The Screening Programme has a set of standards which are used to monitor performance. The Screening Programme are conducting an ongoing review of Standard 5 (monitors 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 2 parts: S05a (women at risk), and S05b (couples at risk). This splitting of the standard, however, risks women being counted twice. The proposal is to have one standard and remove the word 'couples'. SCS / UKTS have been helping with this review as the timely offer of prenatal diagnosis is important since a late prenatal diagnosis of an affected foetus can reduce parents' choice to terminate a pregnancy in certain cultures and religions.

'Preconception, Antenatal, Newborn and Maternity' Task and Finish Group

Output / Achievement

As a result of the Sickle Cell Society's *'No Ones Listening'* Report produced at the end of 2022, NHS England and NHS Improvement (NHSEI) reviewed the Sickle Cell Pathway so as to improve user experience and address existing inequalities. SCS was part of the Task and Finish work stream for **'Preconception, Antenatal, Newborn and Maternity**'. All workstreams were completed and resulted in recommendations now being implemented by NHS England. One such improvement is the piloting of hyper acute units that will offer 24/7 haemoglobinopathy services to patients.

Work Activities and Outcomes for Year 5

The following projects were identified for Year 5

- Analyse transcripts from focus groups and produce report on service user perspective on the reporting methods used to deliver newborn results - 'Parents Stories 2'
- Hold national conference to launch Parents Stories 2 and Protocol for communicating newborn results
- Continue to provide input to the NHS SCT Screening Programme e-Learning resource for health professionals in the screening pathway
- Review of Screening Programme literature and resources
- Conduct ongoing outreach to raise awareness of sickle cell, thalassaemia and screening
- Work with NHS England and NHS Improvement (NHSEI) and Transition Team on priorities for the new organisation
- Produce Year 6 work plan

Project 1 – Analyse transcripts from focus groups and produce report on service user perspective on the reporting methods used to deliver newborn results

Continuing the workstream from Year 4, UKTS and SCS concluded a series of focus groups with parents and prospective parents around their experience of receiving their newborn child's positive screening results and carrier results.

Analysis of the focus group discussions culminated in the production of a report: *'It's in Our Genes: Service User Experiences and Feedback on the Communication of Screening Results for Sickle Cell and Thalassaemia'* ('Parents Stories 2')

Project 2 - Hold National Conference to launch Parents Stories 2 and Protocol for communicating newborn results

SCS / UKTS organised a successful 'hybrid' national conference on 18 April 2023 to launch the '*It's in Our Genes…' report*, and to discuss the Screening Programme's forthcoming *Protocol for Reporting newborn screening results for sickle cell disease and thalassaemia major to parents'*, review which has been informed by the report.

The successful event was attended by a spectrum of up to 160 stakeholders from across the screening pathway, including health professionals, medical students, researchers, scientists, service users and representatives from the NHS SCT Screening Programme The presentations made at the conference were filmed and are available on the Societies' related YouTube channels.

Project 3 – Continue to provide input into the NHS SCT Screening Programme e-Learning Resource for Health Professionals in the Screening Pathway.

SCS and UKTS concluded intensive work on the Screening Programme e-Learning resource in Year 4 by participating in the development and review of two new sections of the e-Learning suite. The new sections were designed to give health professionals a window into the patient experience of living with sickle cell and thalassaemia. Included in the e-Learning resource is a 'Society Stories' film showcasing SCS and UKTS collaboration with the NHS SCT Screening Programme. The Societies work hand in hand to support the NHS SCT Screening Programme to ensure its service provision takes on board user needs and addresses any health inequalities.

Project 4:

Review of Screening Programme Literature

SCS and UKTS continued to review and provide feedback on various resources for the screening programme over the course of Year 5. Examples included: *Sickle Cell and Thalassaemia Screening Information for Fathers*' and the *'Protocol for Reporting newborn screening results for sickle cell disease and thalassaemia major to parents'* (new version to be launched in early 2024).

In addition to producing a 4th Edition of the "*Standards for the Clinical Care of Children and Adults living with Thalassaemia in the UK" c*omprising enhanced sections on screening and inheritance, UKTS also began the process of updating their leaflets on ‘*Beta Thalassaemia Trait*’, ‘*Alpha Thalassaemia Trait’* and related publications such as ‘*My Baby has Thalassaemia’*.

SCS revised their *'Sickle Cell Disorder and Sickle Cell Trait'* leaflet, which now includes a page on screening and preconception testing.

Project 5 – Raising Awareness of sickle cell and thalassaemia and importance of screening particularly developing and progressing an outreach strategy for informing young adults about preconception testing and pre-implantation genetic testing (PGT)

During Year 5 the Societies took every opportunity to raise awareness of haemoglobinopathies and the work of the screening programme using online platforms (Zoom or Microsoft Teams) as well as social and broadcast media, newsletters and websites. Face-to-Face awareness raising made a welcome return and in some cases this was simultaneously combined with video-conferencing in what has now become known as ‘hybrid’ events. Young adults at universities were particularly targeted and two such individuals gave their perspective of preconception screening at the national conference on 18 April. Plans have been made for SCS /UKTS to produce a preconception information leaflet in Year 6. UKTS are currently conducting a series of visits to high-prevalence cities, speaking to patients, to families and to health professionals to learn more about service provision and share awareness of haemoglobinopathies and screening. UKTS visits have included specifically targeting of higher education, where team members have delivered awareness sessions and resources centring around the haemoglobinopathies and screening.

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

NHS SCT Screening Programme transferred from Public Health England (PHE) to NHS England and Improvement (now just NHSE) on 1st October 2021 and have worked with the transition team to establish various operational processes, as some governance roles and responsibilities from PHE became lost in the transfer. A lead former PHE staff member from the Antenatal and Newborn Screening Programme - and who knows the programme and its history - remains employed by NHSE and is supportive of our collaborative project. NHSE put out a tender in July 2023 to continue the Screening Engagement Project and this was subsequently won by SCS and UKTS in September 2023.

Project 7– Produce Year 6 Workplan

During Year 5, the emergence of key themes (arising both out of new developments in screening and from the immediate work of the SCS/UKTS/Screening programme partnership) provided clear direction for possible future work and continued collaboration.

While these themes were discussed at Project Advisory Group meetings in the latter part of Year 5, uncertainty around the future of the contract and the NHSE structure put plans on hold until confirmation of a successful outcome of the tender process was announced in late summer 2023.

Chief among the aims now agreed by the partnership for Year 6 is to build on the findings and productivity of Year 5 work, and to combat any inequality in access, language and awareness of reproductive choice. Much of the work for Year 6 is to continue based on the findings and methodologies explored in Project Area 1, to be joined by themes around support for parents and health professionals faced with choices about PND, and developments in NIPT.

Other Related Work

NHSE Inequalities Improvement Programme

As a result of the SCS *'No One's Listening Report*' NHSE created an Inequalities Improvement Programme reviewing the sickle cell pathway. SCS was part of its Task and Finish work stream for ‘Preconception, Antenatal, Newborn and Maternity’ and the Patients Advisory Group. As a result of recommendations from the various workstreams, NHSE committed to making several changes that would benefit haemoglobinopathy patients, such as 24 hour hyper acute units.

Great Ormond St Hospital Global Partnership e-Learning Project

Great Ormond St Hospital has a Global Partnership e-Learning project that will also be accessible to an international workforce of health professionals. SCS is part of the working group developing this resource and will particularly be involved in writing the sections on community care, awareness and social aspects of SCD including reasons to get tested.

King's College 'PERICLES' project

SCS is part of a King’s College project investigating stakeholders' views on prenatal therapy for sickle cell disease and has provided its expertise and helped with recruitment.

Conclusion

The 4-year summary and Year 5 report show 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). Such a partnership where the service user voice is represented, continues to prove essential in the improvement of screening service provision and the identification and addressing of health inequalities.

Examples are the development of a fast-track system so at-risk carrier couples could access antenatal care quicker, which came about from work done for ‘Parent Stories’.

More recently as reported for Year 5, user feedback from the focus groups will influence NHS SCT Screening Programme policy and practice around the communication of antenatal and newborn screening results.

Following the successful tender bid in Year 5, SCS/UKTS look forward to continuing their collaborative work with the Screening Programme.

Purpose of Document

This document reports on progress made in the fifth 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 2022 to 31 July 2023. It is an abridged report, with standard information from previous reports 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'*, *'SCT Counselling Knowledge and Skills'* and now in Year 5 *'It's in Our Genes: Service User Experiences and Feedback on the Communication of Screening Results for Sickle Cell and Thalassaemia'*, all demonstrate the success of this collaborative work.

Year 5 Aims and Objectives

Projects for Year 5 (1st August 2022 to 31st July 2023) include continuation and development of Year 4 workstreams, such as the service user focus groups on communication of screening results, and on the Screening Programme's e-learning Resource. Outreach work is also included throughout the contract. The chart below outlines the projects for Year 5.

1. **Analyse transcripts from focus groups and produce report on service user perspective on the reporting methods used to deliver newborn results**
2. **Hold National Conference to launch Parents Stories 2 and Protocol for communicating newborn results**
3. **Continue to provide input into the NHS SCT Screening Programme e-Learning Resource for Health Professionals in the Screening Pathway**
4. **Review of Screening Programme Literature**
5. **Raising Awareness of sickle cell and thalassaemia and importance of screening**
6. **Work with NHSE and Transition Team on priorities for the new organisation**
7. **Produce Year 6 Workplan**

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

In addition to pursuit of the workstreams identified, the SCS and UKTS attend the NHS SCT Screening Advisory Board meetings (usually two per year) and other sub-committee/Advisory group meetings as required. SCS/UKTS presented updates at the NHS SCT Screening Board meetings held on 22 November 2022 and 6 July 2023.

Project Advisory Group –and Project Monitoring

The Project Advisory Group (PAG) officially the ‘SCT Service Engagement, Outreach and Programme Development Advisory Group hold quarterly meetings that 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 5, meetings were held on 13th October 2022, 18th January 2023, 29th March 2023 and 11th July 2023. Two new members joined the group in Year 5 and one service user member left. For full details of PAG membership please see (**Appendix 2).**

In addition to the PAG meetings, SCS /UKTS met with NHS SCT Screening Programme regularly to review work progress and monitor deliverables.

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 5.

Project 1 – **Analyse transcripts from focus groups and produce report on service user perspective on the reporting methods used to deliver newborn results**

Year 4 saw the completion of focus groups with mothers and fathers who had been recently diagnosed with a baby with sickle cell disease and beta thalassaemia major, and pre-conception adults with and without a known sickle cell and thalassaemia trait. Between September 2022 and January 2023, SCS and UKTS began the intensive process of qualitative data analysis from the transcribed focus group interviews. Academics Professor Karl Atkin (University of York), Dr. Maria Berghs (De Monfort University), together with NHS SCT Screening Programme Manager Amanda Hogan and Clinical Project Coordinator Carol Nicholls were consulted throughout the process for their expert feedback and advice. The process culminated in the production of the *'It's in Our Genes: Service User Experiences and Feedback on the Communication of Screening Results for Sickle Cell and Thalassaemia'* report (available for download here: https://www.sicklecellsociety.org/resource/its-in-our-genes/)

The *'It's in Our Genes*' report contains vital service user feedback as well as key recommendations and learning for health professionals, some of which has been incorporated into the NHS SCT Screening Programme's : *'Protocol for Reporting newborn screening results for sickle cell disease and thalassaemia major to parents'* due out soon.

The *'It's in Our Genes*' report is being well received and an abstract submitted to the **London Maternity and Midwifery Festival 2024** was accepted and SCS / UKTS will be co-presenting the work on the focus groups at the conference on 6 February 2024.
The report has since been distributed in hard copy to focus group contributors, and to 71 SCT units.

The workplan for Year 6 contains workstreams designed to build on the developments of Year 4 and 5, enquiring further into the experience of families and of the health professionals who care for them, and developing a suite of resources to support them.

Project 2 - Hold National Conference to launch Parents Stories 2 and Protocol for communicating newborn results

On 18th April 2023, over 160 participants, including health professionals, researchers, medical students and service users, and representatives from the NHS SCT Screening Programme attended a hybrid conference organized by SCS and UKTS to launch the "*It's in Our Genes"* report and discuss its findings.

Conference organisers: Roanna Maharaj (UKTS), Iyamide Thomas (SCS) and Romaine Maharaj (UKTS)

The conference (See **Appendix 3** for programme) was chaired by Dr Elizabeth Dormandy, former Chair of the Engagement Project Advisory Group and Scientific Advisor, Sickle Cell Society (Retired). NHS Sickle Cell & Thalassaemia Screening Programme Manager Amanda Hogan gave an overview of the service user consultation project and its central role in the Screening Programme's service delivery. Amanda's overview was followed by illuminating presentations: *'Antenatal Screening and Counselling', 'Newborn Screening', 'Service user experiences of the screening pathway', 'Service User Stories- a Collaborative Project', 'NHS SCT Screening Programme Protocol for Communicating Newborn Screening Results', 'e-Learning Resource'* and *'Preconception Screening Outreach'*.

Among the day's highlights were powerful stories from two service users of their screening experiences and a discussion by two UCL 5th Year medical students of their hopes for future developments around preconception testing.

Sarah Barnes, Lead Clinical Nurse Specialist for Haemoglobinopathies Antenatal and Newborn Screening, Leicester Royal Infirmary talks about some challenges in delivering newborn screening results

Cross section of conference participants

Roanna gives the thalassaemia perspective

Iyamide gives feedback from mothers

Medical students talk about preconception outreach

John James, CEO Sickle Cell Society summing up

The conference was deemed very successful and this is what some of the participants had to say:

"We need more of these opportunities"
" Very informative, thanks so much"
"How can we work better to link with the Societies"
"Can't wait for e-learning"

Recordings of the conference presentations, including a six minute overview of the day, can now be accessed from the Society YouTube channels. These recordings were promoted nationally and internationally by the Societies and their related stakeholders. Conference playlist:https://youtube.com/playlist?list=PLEzW18YMN3V9D2kikmLA2WmVE7KpMtpXI&feature=shared

A Certificate of Attendance was sent to all conference attendees. In the buildup to the conference, SCS and UKTS held 3 meetings with NHSSCT Screening Programme (April 3rd, 5th and 12th) and a conference debriefing session on 19th April.

Project 3 – Continue to provide input into the NHS SCT Screening Programme e-Learning Resource for Health Professionals in the Screening Pathway.

During Year 5, SCS and UKTS contributed their expertise and service user viewpoint to the continued overhaul and development of the Screening Programme's 2016 eLearning resource training resource. SCS /UKTS were not only involved in planning the contents of each e-Learning module but also provided blogs, publications, posters service user stories and voice recordings.

SCS *'No One's Listening'* report, which showed inequalities in sickle cell service provision and gaps in clinical knowledge, together with recommendations from this report, will be used in a new lifestyle section to be added to the e-Learning resource. The UKTS's Clinical Standards (4th Edition, published 2023), which includes an enhanced section on screening and inheritance, will also be made available via the eLearning for health professionals studying the conditions and the screening pathway.

The resource now includes "Society Stories" – a short film showcasing the Societies' impact and expertise in supporting and advising the NH SCT Screening Programme. It highlights their joint contribution to the Screening Programme's need to address health inequalities.

A presentation of the updated e-Learning resource tool was given by Emma Proctor, Senior Quality Assurance Advisor (ANNB screening programmes) NHS England at the conference on 18th April 2023.

Project 4:

Review of Screening Programme Literature

SCS and UKTS continued to review and provide feedback on various resources for the screening programme over the course of Year 5. Service user feedback from the focus groups has contributed to a revision of the Screening Programme's *'Protocol for Reporting newborn screening results for sickle cell disease and thalassaemia major to parents'*, and accompanying guidance resources, which have now undergone significant review by SCS and UKTS, and are due for release in early 2024.

Health professionals giving results are reminded they should not be using the phrase *"no news is good news"* to parents waiting for newborn results, and that it is important for parents to be told that these results are sometimes delayed.

UKTS also began the process of updating their leaflets on "*Beta thalassaemia trait*", "*Alpha thalassaemia trait*" and related publications such as " *My baby has thalassaemia*" and the "*Standards for the Clinical Care of Children and Adults living with Thalassaemia in the UK* - 4TH Edition 2023).

SCS revised their *'Sickle Cell Disorder and Sickle Cell Trait'* leaflet and it now includes a page on screening and preconception testing

Project 5 – Raising Awareness of sickle cell and thalassaemia and importance of screening particularly developing and progressing an outreach strategy for informing young adults about preconception testing and pre-implantation genetic testing (PGT)

Outreach is a continuous work-stream each year for the SCS and UKTS, who use their respective networks to raise awareness amongst the public and health professionals about screening issues pertaining to that year's work, as well as general screening awareness, particularly within at-risk communities.

Addressing inequalities is one of the reasons the NHS SCT Screening Programme works so closely with the SCS and UKTS, and it is important to mention this to health practitioners and other stakeholders. As a result of the Sickle Cell Society's *'No Ones Listening'* Report produced at the end of last year, the NHS England and NHS Improvement (NHSEI) commenced a review of the Sickle Cell Pathway so as to improve user experience and address existing inequalities. SCS was represented on the Task and Finish work stream for **'Preconception, Antenatal, Newborn and Maternity**' and other workstreams, contributing towards recommendations, some of which are now being piloted e.g. 24 hour hyper-acute units.

The SCS and UKTS have sections on their websites on NHS SCT Screening Programme which is continuously updated with relevant new information. The SCS graphic below is used to inform people about its collaboration with the NHS SCT Screening Programme and UKTS and signpost them to project information on the website.

The UKTS graphic depicts the importance of screening in pregnancy.

Liked by **dr.anisha.radia** and **others**

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

From awareness events, the focus groups and 18 April conference feedback is that young people who have not yet had children are now more aware of the conditions and want to know their haemoglobin genotype. SCS/UKTS have therefore targeted students at universities and colleges, and have conducted awareness training sessions with medical students and nurses. A preconception leaflet is proposed as part of the Year 6 workplan.

UKTS / SCS Higher Education Outreach

UKTS are currently partnering with Universities in the field of Medical and Nursing practice to educate student and graduate students about thalassaemia, day to day life for families affected by the condition, the NHS SCT Screening Programme , and cultural competencies. Over the past year UKTS has worked with the University of Leeds’ Medical School, and with undergraduate and graduate nurses and health visitors at Middlesex University in London.

SCS worked with medical students at University College London on strategies to raise awareness of Haemoglobinopathies and preconception testing. Two UCL Medical students were invited to give a presentation at the 18th April conference; a slide (below) from their overview highlights areas they prioritised for attention.

Areas of focus

The areas we believe are important to focus on in order to reduce the number of future sickle patients as well as empowering young people in their family planning decisions

Preconception screening

- Early detection
- Family planning
- Medical advice
- Informed decision making
- Receiving results
- Advocacy and awareness

SCS also had a query from a student from another university wanting support to create a sickle cell awareness and testing project at the university. She also asked about the logistics of running a test drive on campus in September when they have their new student intake. SCS will pick up this discussion going forward.

In commemoration of Rare Disease Day on 28 February, University of London's Royal Holloway College held their annual event on 27 February 2023 at which SCS ran an awareness stall. It was a very productive day with many students and school children coming to find out about sickle cell, screening, blood donation. Interestingly, one young student had heard about sickle cell as her father was a haematologist. SCS also shared specially designed screening graphics for RDD on their social media platforms.

SCS awareness for Rare Disease Day

OTHER OUTREACH

SCS

Subsequent to the Covid-19 pandemic, SCS carry out a combination of in-person and online outreach. Podcasts have also successfully been used to reach wider audiences. As part of raising awareness of sickle cell for the October 2022 Black History Month, Iyamide was interviewed for a comprehensive podcast covering sickle cell, its history, screening, blood donation and more by the Department of Environment, Food and Rural Affairs (DEFRA) who shared this podcast with their 30,000 Defra group staff members and to an external audience through promotion via their social media channels. This podcast is available here:

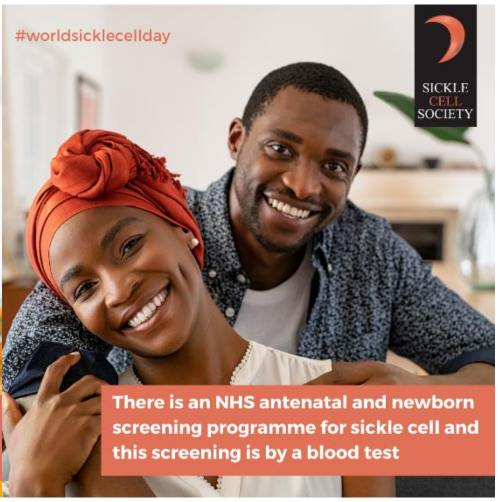
Let’s talk about Sickle Cell

Defra speak with Sickle Cell Society as part of Black History Month 2022

https://www.youtube.com/watch?v=FWDFNm4wCe8

On 1st October 2022 the start of Black History Month, Iyamide did a pre-recorded presentation on sickle cell for the Thackary Museum of Medicine in Leeds as part of their ‘Insights Lecture’ series and feedback is that it was well received by the packed hall. The presentation was also put on their website.

19 June is World Sickle Cell Day (WSCD) and the SCS has an annual awareness campaign of events, talks print, broadcast and social media. In 2023 these eye-catching graphics were used to educate the public about screening:



Events included ‘hybrid’ talks to staff at AVIVA Insurance and Wells Fargo International Finance Services which had a real stage coach in their lobby!

In addition to our WSCD 2023 theme of ‘Celebrating Progress’ we still had our usual ‘wear something red’ directive and these sickle cell nurses we work with in SE London were only too happy to oblige.

UKTS

UKTS resumed all face to face outreach in 2021. During Year 5, UKTS outreach has seen particularly strong activity during September (for their month of learning), October (for

National Thalassaemia Day), February (Rare disease month and Valentine's Day), May (International Thalassaemia Day) and in Summer (UKTS Fun Run/Walk).

In addition, UKTS participated in several outreach events such as the Nowuz Music and Cultural Show in London and AHMA Eid Milan in Manchester to raise awareness of thalassaemia and sickle cell and to educated the public about the work of the Societies. During these events alone the team managed to hand out over 750 carrier leaflets and 500 flyers on thalassaemia/ importance of screening/ informed decision making.

Other face to face outreach events included Screening Days held at the UKTS office in Southgate and in other regions of the country such as Manchester and Cardiff where anyone in the community could be screening for thalassaemia and sickle cell trait.

Additionally, UKTS carried out other events in Bristol, Birmingham, Bradford and Manchester.

UKTS was also featured in Kurdish, Afghanistani, Iranian, Indian, Bangladeshi, Pakistani, Turkish, Greek and My London newspapers who covered events and highlighted the need to raise awareness of thalassaemia. Interviews with patients were also featured: in one instance, 7 British Asian newspapers simultaneously featured an article on Roanna Maharaj’s life with thalassaemia in July 2023.

All articles can be found here :

Weekly Desh (Bangladeshi)
https://www.weeklydesh.co.uk/2023/07/27/50499/

Potrika (#Bangladeshi)
https://potrika.com/?p=7571

Urdu Times (#Urdu)
http://urdutimesuk.com

Asian Express (#English)
https://www.asianexpress.co.uk/2023/07/supporting-our-childrens-health/

Asian Sunday / Asian Standard (English)

https://www.asiansunday.co.uk/supporting-our-childrens-health/
https://www.asianstandard.co.uk/advertorial-supporting-our-childrens-health/

Asian Leader (English)
https://asianleader.co.uk/supporting-our-childrens-health/

UKTS has also continued meeting with High Commissioners and High Representatives of countries where thalassaemia is prevalence, such as Iran, India and Pakistan.

UKTS has a dedicated weekly screening social media post to target pregnant mothers, expecting parents, and the pre-conceptual groups. From March to June, UKTS ran their Global Art and Poetry competition to spread awareness of thalassaemia, educate on patterns of inheritance, the importance of blood donation and lastly to highlight the work of the society. UKTS received 1649 entries from 68 countries. On the week of voting (June 1-8th), the UKTS recorded over 132,000 hits to their website.

UKTS host a monthly "Let's Talk Thalassaemia" programme on London Greek Radio, where Romaine and Roanna Maharaj receive regular questions from callers about thalassaemia, inheritance and testing from callers. UKTS also gave interviews on Alaraby TV in September, and in November on popular

Bangladeshi Television network NTV to raise awareness of thalassaemia amongst the Bangladeshi community in the UK and Europe.

During Year 5, both Societies have invested time in forming relationships service providers in the wider public sector, sharing information about issues affecting those affected by haemoglobinopathies, including inheritance, screening and onward signposting for both employees and their clients. This has led to a wide circulation of key messages via hitherto unexplored channels. An initial training session provided by Romaine Maharaj for Department of Work and Pensions staff, featuring education about the challenges life with haemoglobinopathies, has was so well received that a series of sessions with DWP units, Home Office and citizens advice bureau employees around the country is now scheduled for Year 6.

(For a detailed list of SCS and UKTS outreach activities, see **Appendix 4).**

The impact of social media

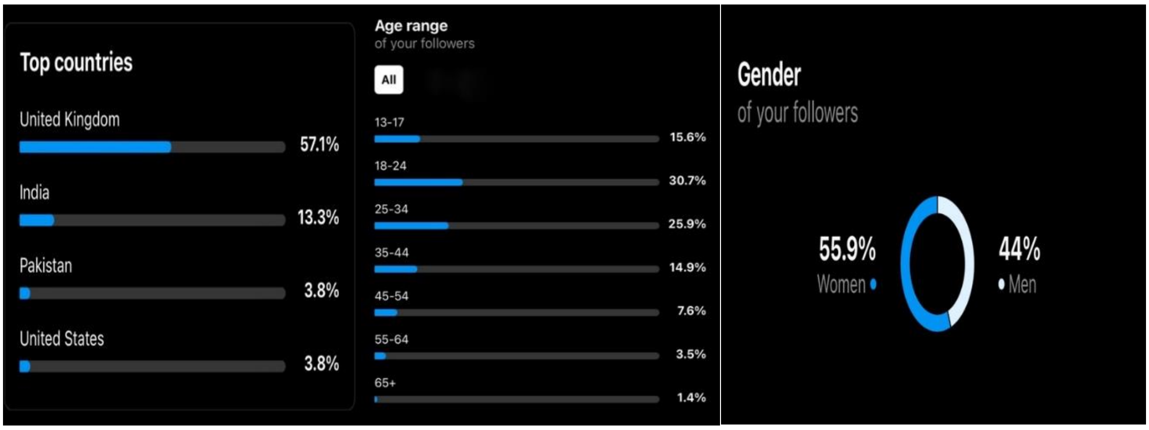
Rising to the meet challenges posed by the to the COVID-19 pandemic, the SCS /UKTS conducted highly successful virtual outreach campaigns in order to continue raising awareness within target groups.

In addition to posts and articles in newsletters, websites, print and broadcast media, the Societies' use of Social media came into its own during the pandemic as an effective tool for educating the public about sickle cell and thalassaemia. A series of specially created graphics and campaigns shared our messages about haemoglobinopathies and screening with a wider audience than ever before.

Since the pandemic period, SCS/UKTS social media reach has continued to grow and to develop, with frequent, high impact posts often carefully pitched to coincide with current events and significant dates such as national/international Sickle Cell and Thalassaemia days. Social media has helped the Societies to build community and to share information in new and exciting ways, which in turn have come to form a vital element of SCS/UKTS workstreams with the Screening Programme.

Examples of UKTS Instagram Posts in Year 5

Social Media Insights for the UKTS



Examples of SCS Instagram Posts

42 likes

sicklecelluk The Sickle Cell Society as a 'service user' or 'patient organisation' has always played an essential role, from raising awareness and lobbying for a screening programme to helping with its development and ensuring it is serving the needs of its users.

82 likes

sicklecelluk If you are expecting a baby or thinking about planning for the future, you can request to be screened for SCD. Sickle cell can affect anyone, but it predominantly affects those of African or Caribbean heritage. Sickle Cell Disorder is inherited from both parents, but Sickle Cell trait can be inherited from just one parent.

There is an NHS screening programme which is done via a blood test. Ensure you and your loved ones know what help is available for anyone wanting to test for sickle cell

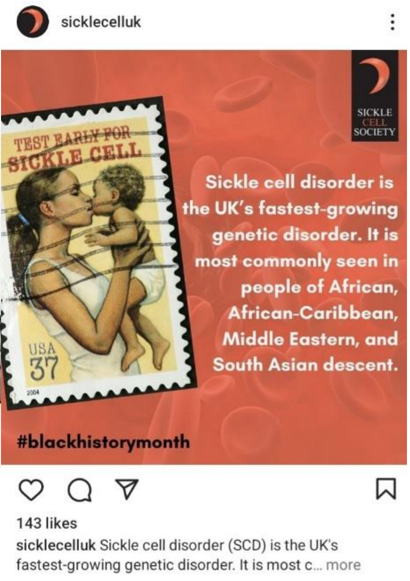
CAN SICKLE CELL CARRIERS HAVE CHILDREN?

Yes, and can have a normal pregnancy. Your partner should get tested before you plan your family, so you know whether you are both carriers, and at risk of having a child with the full sickle cell condition. More info here https://www.sicklecellsociety.org/screeningprogramme/

SICKLE CELL AWARENESS MONTH, SEPTEMBER 2023
TEXT SCSDONATE2DAY TO 70085 TO DONATE £5

110 likes

sicklecelluk It's Sickle Cell Awareness Month, so we're publishing a series of sickle cell facts to help more… more



Sickle cell disorder is the UK's fastest-growing genetic disorder. It is most commonly seen in people of African, African-Caribbean, Middle Eastern, and South Asian descent.

#blackhistorymonth

143 likes

sicklecelluk Sickle cell disorder (SCD) is the UK's fastest-growing genetic disorder. It is most c… more

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

SCS /UKTS will continue to work with NHS SCT Screening Programme (now sitting within a newly restructured NHS England), and adapt to ensure the viability and success of their collaboration with the Programme.

Project 7– Produce Year 6 Workplan

Key areas for possible future work were identified throughout Year 5, with feedback from families during the Newborn Carrier Results project proving particularly fertile.

In September 2023, the NHS SCT Screening Programme confirmed the success of the Societies' joint tender submission to continue their collaborative work with the Screening Programme. A planning meeting between SCS/UKT and the Screening Programme then took place on 8 November 2023 at which major themes for work during Year 6 and beyond were discussed. Further planning with the Project Advisory Group will prioritise these going forward.

One main area for Year 6 will be to build on the findings and productivity of year 5 work, and continue to ensure no inequality exists in service provision in access, language, or of awareness of reproductive choice.

Discussion

The Year 5 report evidences the continuing benefits of collaborative partnership between the NHS SCT Screening Programme, the Sickle Cell and the UK Thalassaemia Societies, representing users of the service.

Working with the Societies has demonstrably aided the Screening Programme to identify and to address inequalities faced by the high-risk sickle cell and thalassaemia communities in accessing services (such as PND), and to make relevant policy changes.

During Years 4 and 5, the Societies' direct relationship with the target communities has enabled SCS/UKTS to conduct insightful focus groups with users of the screening service, and to feedback user needs to the Screening Programme.

The Societies learned a great deal from participants the possible impact of a haemoglobinopathy screening diagnosis on the immediate and the wider family in terms of disclosure, communication, timeliness, stigma, knowledge and understanding.

The focus groups also yielded feedback around the language that was used for communicating health messages, and the support families may need once their baby had a positive diagnosis. The work has further helped to clarify the existence, causes and effects of inequalities linked to meeting the cultural needs of target communities, and to a lack of understanding in both health professionals and the users they serve.

The Societies were able to share these valuable findings with NHS SCT Screening Programme, the most immediate effects being shown in the Programme's review of its *Protocol for Reporting newborn screening results for sickle cell disease and thalassaemia major to parents*.

In the longer term, the findings are expected to help the Programme adapt its service, and to impact positively on the relevant Screening Programme Standards, particularly Standards 8 and 9 on time taken to give newborn results and follow up with a consultant respectively.

The SCS /UKTS contribution to the review of the Screening Programme's e-Learning resource, and to training events for health professionals has been 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 SCS *'No One's Listening'* report which showed inequalities in service provision and gaps in haemoglobinopathy clinical knowledge and its recommendations will help inform the e-Learning resource to improve services.

The Societies input to a review of Screening Standard 5 (Timely offer of Prenatal Diagnosis) has been significant, and will help to ensure that any proposed changes are piloted before roll-out, resulting in better quality service provision to users.

In Year 5, NHS SCT Screening Programme had become part of a restructured NHSE and still worked collaboratively and successfully with SCS and UKTS. At the end of Year 5 in July 2023, NHSE put out a tender for their new contract for ‘Engagement, Outreach and Programme Development’ and the SCS /UKTS tender application was successful. This means that this programme of work can once again rely on support from the Patient Organisations (i.e. SCS / UKTS), particularly as their work continues to provide value for money to the Screening Programme (**Appendix 5**).

Learning from Year 5

Learning from Year 5 showed the benefits of continuing to work in the new ‘hybrid’ way of holding events simultaneously in-person and online, as was effectively shown in the national conference held on 18 April attended by over 160 participants from across the country. The Societies have also carried out outreach events in this hybrid format, some of which have included international participants joining online. The focus group work and *"It's In Our Genes"* publication, highlighted the importance of providing appropriate support to families throughout the screening process and after receiving a new diagnosis. This work emphasised that the commonly used phrase "*no news is good news*" can be very harmful and is not reassuring as possibly meant. As such, this should not be used by health professionals as was shown not only from service user feedback but also from one of the health professionals who reported this of colleagues at the 18 April conference.

Some learning that came from the sickle cell focus groups is that parents waiting for newborn results should be told if there is a technical delay in reporting results as it was already thought 28 days was itself an inequality compared to reporting other newborn screening results. The learning that the UK Thalassaemia Society has gained from their outreach work in the community has been invaluable in terms of supporting families during screening and improving the communication and follow-up of new diagnoses.

The focus group work highlighted the significance of timely and clear communication, as well as the need for ongoing support during the diagnostic journey. By challenging the notion that silence implies a negative result, the Societies continue to advocate for more proactive and compassionate approaches to delivering test results and ensuring families have the necessary information and support they require.

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
NHS Engagement Lead, Sickle Cell Society

Romaine Maharaj
Executive Director, UK Thalassaemia Society

Appendices

Appendix 1

‘Review’ Document (Formerly ‘Restore’)

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 NHS England (NHSE), 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 NHS Sickle Cell and Thalassaemia Screening Programme (NHS SCT Screening Programme) 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 changed since the start of the COVID-19 pandemic and many of the planned outreach and face to face work were affected. In addition, a new work stream was 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 review document is specific to the Societies’ workplan and contract with NHSE.

Shared Learning

During the pandemic, the SCS and UKTS had the opportunity to work very closely with the dedicated NHS SCT Screening Programme led by Amanda Hogan. The group held regular virtual meetings which provided useful insights and learning opportunities to all who were present. 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 their 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.

Fully Restored		
Produce report on service user perspective on the reporting methods used to deliver newborn results - 'Parents Stories 2'	Unaffected and Completed	"It's in Our Genes" report launched on 18th April 2023. Copies are available on UKTS/ SCS websites.
E-learning modules under review	Unaffected and completed	This SCS and UKTS have been providing feedback on the current online modules used to train specialist haemoglobinopathy nurses and genetic counsellors. This was launched on 18th April 2023
Joint Hybrid Conference to launch publications	Unaffected and Completed	Conference was held in London on 18th April 2023 with virtual option available. Publications CSK competencies and e-learning resources were also launched.
Review of Screening Programme's literature and resources	Unaffected and Completed	NHSE is in the process of finalising documents to make them more accessible (language, html ready etc.) See workplan for more detail.
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.

Filming of Societies Stories	Unaffected and Completed	Both SCS and UKTS were filmed to create a platform which highlighted the work, education, experience and support that the societies' offer for families, health care professionals, government officials and members of the public.
Production of Year 5 Report	Unaffected and Ongoing	Work on the Year 5 report is currently underway. It contains a "lookback" at both year 4 and year 5 work, key points, highlights and lessons learned. A communication strategy, including wider dissemination of the Y5 report, and a paper building on the work of the It's In Our Genes report, with publication in relevant trade press, will form part of Year 6 work
Development of Year 6 workstreams	Unaffected and Ongoing	A working group meeting was held on 8 November 2023 to discuss and develop ideas for Year 6 workstreams. The list of proposed areas for development over the course of the new contract was produced at the meeting, together with the minutes of the meeting, have now been circulated to the wider PAG group, asking for member's comments as to prioritisation of workstreams. Members will further discuss, and will begin to schedule plans for Year 6 work at the PAG meeting on 16th January 2024

Authors: United Kingdom Thalassaemia Society and the Sickle Cell Society

Appendix 2

Membership of Project Advisory Group (PAG) in Year 5	
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, NHSE
Amanda Hogan	Newborn Implementation Pathway Lead, NHS Newborn Screening Programme, NHSE
Nafisa Varachia	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
Carol Nicholls	Clinical Project Coordinator – Sickle Cell and Thalassaemia Screening
Jessamy Willson-Pepper	Project Support Officer, NHS ANNB Screening Programmes, UKTS
Nadia Permalloo	Head of Quality Assurance Service, Screening, NHSE
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

SICKLE CELL SOCIETY

Information, Counselling and Caring for those with Sickle Cell Disorders and their families

Charity Reg: 104 6631
Company Reg: 284 0865
www.sicklecellsociety.org

UNITED KINGDOM THALASSAEMIA SOCIETY
UKTS

Appendix 3

Service User Experiences of Sickle Cell and Thalassaemia Screening Pathway

A conference chaired by Dr Elizabeth Dormandy
18 April 2023
Brewer & Smith Room, Mary Ward House,
5-7 Tavistock Place, London WC1H 9SN

PROGRAMME

10.30am – 11.00am	**Registration , tea and coffee**
11.00 -11.10	**Welcome and Purpose of the Day** - Elizabeth Dormandy, Former Chair of Engagement Project Advisory Group and Scientific Advisor, Sickle Cell Society (Retired)
11.10 – 11.20	**Project Overview** - Amanda Hogan, NHS Sickle Cell & Thalassaemia Screening Programme Manager
11.20 – 11.35	**Antenatal Screening and Counselling** – Joyce Adu-Amankwah, Specialist Haemoglobinopathies Midwife, St Georges Hospital
11.35 – 11.50	**Newborn Screening –** Sarah Barnes, Lead Clinical Nurse Specialist for Haemoglobinopathies Antenatal and Newborn Screening, Leicester Royal Infirmary
11.50 – 12.10	**Service user experiences of the screening pathway** – Service users
12.10 – 12.30	**Service User Stories- a Collaborative Project** – Iyamide Thomas, NHS Engagement Lead, Sickle Cell Society (SCS), Roanna Maharaj, Vice-Chair, UK Thalassaemia Society (UKTS)
12.30 -12.40	**NHS SCT Screening Programme Protocol for Communicating Newborn Screening Results** –Carol Nicholls, Clinical Project Coordinator – Sickle Cell and Thalassaemia Screening programme
12.40 -12.50	**Question and Answer session –** Dr Elizabeth Dormandy
12.50 – 13.45	**Lunch / Networking/ Interviews**
13.45 – 14.00	**e-Learning Resource** – Emma Proctor, Senior Quality Assurance Advisor (ANNB screening programmes) NHS England
14.00 – 14.20	**Preconception Screening Outreach** – Iyamide Thomas (SCS), Roanna Maharaj (UKTS), Bimpe Adeyemi and Zenni Enechi (UCL Medical Students),
14.20 – 14.45	**Plenary Discussion –** Participants and speakers
14.45 -15.00	**Next Steps and Closing Remarks –** John James, CEO, (SCS)

Appendix 4

Year 5 Outreach and other activities undertaken by Sickle Cell Society and United Kingdom Thalassaemia Society

Dates	Activity and Feedback	No of Participants
2 August 2022	UKTS- Screening Talk at UKTS	Estimated as > 35
15 August	SCS- discussed importance of screening as part of a radio show called One2One mentoring	N/Avail
20 August	UKTS- Sunday Mail Newspaper article about a thalassaemia interview with patient Roanna Maharaj	Estimated reach > 200,000
01-30 September	UKTS- Month of Learning Campaign – featuring screening, caring for a child with thalassaemia etc	Estimated as > 50,000
17 September 2022	Virtual Thalassaemia Patient Conference	>200
27 September	IT recorded a comprehensive Black History Month podcast covering sickle cell, its history, screening, blood donation etc for Department of Environment, Food and Rural Affairs (DEFRA) who will be sharing it with 30,000 Defra group staff members, and an external audience through promotion via their social media channels as part of their Black History Month awareness. Podcast link also put on SCS website. Link to also go on NHSSCT Screening Programme e-Learning resource.	Estimated 30,000 staff
1 October 2022	Thackary Museum of Medicine in Leeds played a pre-recorded sickle cell presentation from IT as part of its Insights Lecture series and feedback is that it was well received by the packed hall. It will also be put on their website	100+
2 October	UKTS supported the #teamukts runners at the London Marathon and in Southgate by providing leaflets, advice and social media campaigns	>2500
15 October	SCS presentation on SCD and related inequalities highlighted in 'No One's Listening' report at Museum of Liverpool. Lots of family and sickle cell advocates	60
17 October	SCS APPG	
19 October	UKTS – National Thalassaemia Day social media, parliament, 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 > 500,000
23 October	UKTS- Divali Event in Trafalgar Square	>500

November 2022	IT screening project article in SCS winter edition newsletter.	~3000 circulation
4 November	UKTS/ SCS – attended George Marsh Reopening hosted by North Middlesex Hospital	Estimated as > 35
8 November	UKTS- attended West Midlands Haemoglobinopathy Coordinating Centre regional meetings for patients, parents and health care professionals	Estimated as > 25
9 November	UKTS- attended the Mayor of Enfield's for the council committee meeting to talk about the work of the society and the need for awareness in the borough	Estimated as > 25
23 November	SCS Presentation on No One's Listening Report at UK Forum for Haemoglobinopathy Disorders	~
26 November	UKTS- Dinner and Dance- there was a chance to raise awareness at the dinner and dance with speeches and leaflets and cards to take away.	Estimated reach = 300
26 November	SCS presentation on No One's Listening Report at British Pharmaceutical Students Association	
27 November	UKTS – was interviewed by Bangladeshi TV- NTV Europe at their studios in London to talk about thalassaemia and the importance of screening. UKTS was also able to talk about some of the common myths and stigmas facing the community.	Estimated reach >300,000
28 November	IT participated in an SCS 'Sickle Cell Back to Basics' online event held on 28 November to discuss various topics including genotype, screening etc.	20
29 November	UKTS- Transfusion webinar for thalassaemia community	Estimated as > 80
29 November	UKTS- APPG meeting for thalassaemia in Parliament and awareness session with MPs	Estimated as > 25
6 December 2022	UKTS- attended and presented at Ladies of all Nations International conference in London	Estimated reach > 500
19 December	SCS APPG which included a one-year anniversary presentation of 'No One's Listening' report progress. Discussion included	

3 January 2023	UKTS- Members meeting	Estimated as > 40
20 January	UKTS gave their closing speech at the Infected Blood inquiry- raising awareness of thalassaemia and the screening protocol	Estimated reach > 100,000
25 January	UKTS- Educational session with specialist community public health nurses from Middlesex University	Estimated as > 15
25 January	UKTS /SCS- joined forces with the Rotary Clubs of Stratford, Canary Wharf and Bradford (UKTS only) to raise awareness of thalassaemia	Estimated reach > 500
30 January	IT participated in a Preimplantation Genetic Diagnosis Taster day online attended by various health professionals	~ 40
February 2023	IT published a post Valentine article on sickle cell (and thalassaemia) which also talks about screening and preconception testing in African Voice newspaper.	Weekly online readership of 48,000 and 100,000 printed
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 > 1,000
24 February	UKTS- Awareness Presentation on thalassaemia -Learn by Design at Southgate College	Estimated reach > 500
26 February – June 2023	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 1969 entries from 63 countries. On the week of voting (June 1-8th), the UKTS recorded over 150,000 hits to their website.	Estimated reach > 150,000
27th February	IT held a stall at Royal Holloway College as part of their annual Rare Disease Day programme. Lots of students and school children attended and learned about sickle cell and screening	~80
28 February	UKTS- Rare Disease Day. UKTS raised awareness via social media campaigns and attended events in parliament to raise the profile of thalassaemia.	Estimated reach > 5,000
3 March 2023	UKTS- attended the Metropolitan Police Greek and Cypriot Association Easter Event to speak about thalassaemia and stress in the importance of testing.	Estimated reach > 150
6 March	SCS presentation on No One's Listening Report at King's College Hospital: Sickle Cell Study Day	

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 > 200
10 March	UKTS and SCS – attended Peer review Steering Committee for Haemoglobin Disorders	Estimated reach > 15
20 March	SCS APPG	
18 April	Joint Screening Conference with SCS and UKTS to launch publications and e-learning resources.	Estimated reach >160
23 April	UKTS- London Marathon Stall	Estimated reach >1,000
28 April	SCS presentation on No One's Listening Report at Birmingham City Hospital: Patient Event	
3 May 2023	IT attended the King's Garden Party and raised some awareness of sickle cell and screening with people she networked with, one of who said his mother had sickle cell trait.	Networked with ~15 guests
8 May	UKTS- Screening Event for Eid festival in Manchester (AHMA Eid Milan in Manchester- Muslim family day)	>500
16 May	UKTS- Screening Event at UKTS office in London	>150
21 May	SCS /UKTS supported an awareness event jointly with NHSBT and the Rotary Clubs of Stratford and Canary Wharf at London Westfields	Estimated reach 500
22 May	UKTS - UKTS met with the High Representative, His Excellency Karwan Jamal of the Kurdistan Regional Government	20
23 May	UKTS- interviewed on BBC Radio 1 about thalassaemia and insight from a patient living with the condition.	Estimated reach > 100,000

23 May	UKTS Face to face event - Thalassaemia awareness presentation and blood donation promo to Rumi Mosque's breakfast club in Edmonton	Estimated reach > 50
11 June 2023	UKTS- Fun run/ walk in Southgate plus Radio coverage on LGR and Turkish Radio	Estimated reach > 100,000
12 June	UKTS- Raising awareness of thalassaemia and handing out posters and leaflets in Bradford (Pop up stall at Shopping Centre)	Estimated reach > 300
12 June	SCS APPG. Dr Dianne Addei, Senior Public Health Advisor for the National Healthcare Inequalities Improvement Programme a well-rounded summary of the National Sickle Cell Healthcare Pathway Review;	
18 June	IT also gave a short talk to All Saints Church to mark World Sickle Cell Day (WSCD) on the 19th.	~ 100
19 June	IT gave WSCD awareness online talk to staff of AVIVA.	22 staff in person and ~ 30 online
19 June –July	SCS had a big awareness campaign marking WSCD and throughout July Sickle Cell Awareness Month with the theme 'Celebrating Progress'. A wide suite of social media graphics was disseminating including on screening and preconception testing.	Unknown
19 June	IT wrote a WSCD article in African Voice newspaper which raised awareness particularly of screening and the new 'It's in Our Genes...' screening report.	To date the article now viewed 1569 times.
20 June	IT gave WSCD awareness talk to local and international staff at Wells Fargo Bank. This was a hybrid format (i.e. in-person and online)	21 in-person and 40 online
22 June	UKTS – Screening Event in Cardiff	>350
29 June	UKTS and SCS attended and presented their workstreams at STANMAP	>80
29 June	On 29 June SCS/UKTS presented at the annual Sickle Cell & Thalassaemia Midwives, Nurses and Allied Professionals (STANMAP) conference.	~50
	SCS presentation on No One’s Listening Report at RPP Advocacy and Policy Change Workshop	

2 July 2023	IT wrote sickle cell awareness article for the church newsletter to mark UK Sickle Cell Awareness Month of July	~ 250 circulation
20 July	UKTS- on London Greek Radio for monthly show	Estimated reach > 300,000
21 July	UKTS – Awareness and support event in Bristol- with Oscar Bristol	>20
31 July	Royal Society of Medicine, Beyond the Clinic: Sickle Cell Disease	
12 June 2023	UKTS- Roanna Maharaj featured in 8 Asian newspapers. Weekly Desh (Bangla) https://www.weeklydesh.co.uk/2023/07/27/50499/ Potrika (#Bangla) https://potrika.com/?p=7571 Urdu Times (#Urdu) http://urdutimesuk.com Asian Express (#English) https://www.asianexpress.co.uk/2023/07/supporting-our-childrens-health/ Asian Sunday / Asian Standard (English) https://www.asiansunday.co.uk/supporting-our-childrens-health/ https://www.asianstandard.co.uk/advertorial-supporting-our-childrens-health/ Asian Leader (English) https://asianleader.co.uk/supporting-our-childrens-health/ Garavi Gujarat (Gujarati)	Estimated reach > 500,000

Appendix 5

Sickle Cell Society

PHE -Sickle Cell and Thalassaemia Screening Programme Contract 2018/21 - Extended to 10 August 2023
Year 2 Extension Finance Report 11 Aug 2022 to 10 Aug 2023

Introduction

This report provides an actual summary of income and expenditure related to the 2nd year of the 2-year extension of the contract from 11 August 2022 to 10 August 2023. 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.

The annual operating budget from 11 August 2022 to 10 August 2023 contract covering both Sickle Cell Society (SCS) as lead organisation and UK Thalassaemia Society (UKTS) was £124,916.

- SCS £80,225
- UKTS £44,691

11 August 2022 to 10 August 2023

Total allocated income for this period 11 Aug 22 – 10 Aug 23 is £124,916, plus underspend from 2021/22 of £10,132. Therefore, the total income for this period is £135,408.

Total expenditure for this period £135,408.

Commentary

The project ended the 2nd year extension with a breakeven result.

John James OBE
CEO – SCS
Miriam Williams- Finance and Administration Manager-SCS
Iyamide Thomas – NHS Engagement Lead- SCS

NOTES