Report Name: Project Board Advisory Group Annual Report 23 July 2020

Agenda Item No:		**Paper No:**	

Purpose of Report:
Sickle Cell and Thalassaemia Screening Programme – Year Two 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 September 2019 to 31 July 2020.

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

Recommendations / Actions:
Please review and bring comments for discussion at the meeting.

Next Steps:
N/A

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

Annual Report: **Second 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 September 2019 – 31 July 2020

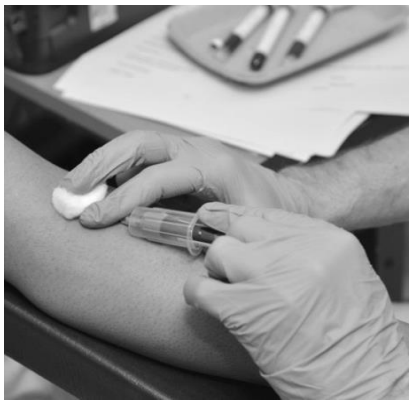


Table of Contents

Executive Summary

Introduction

Sickle cell disease and thalassaemia are severe genetic blood disorders 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. 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 screening and the offer of PND is important for women and couples who have an increased chance of having a baby affected by sickle cell disease or thalassaemia. It helps give women and couples time to make personal informed choices.

The NHS Newborn Blood Spot Screening Programme uses the heel prick test to detect babies with sickle cell conditions, 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), UK Thalassaemia Society (UKTS) and the NHS SCT Screening Programme in the second year of a collaborative project commissioned by the Programme for the period 1 September 2019 to 31 July 2020. It must be said that the unprecedented **COVID-19 pandemic** of 2020 has affected delivery of some project objectives and caused changes in the work plan previously proposed for Year 2. One positive change made has been the Societies major input to revision of the NHS SCT Screening Programme E-learning resource to support health professionals who are part of the screening pathway. These changes are more fully outlined in a 'Restore' document (**Appendix 1**). Overall, the two Societies have had to think of innovative ways to continue delivering their services, particularly to their client group who were included in the Government's official 'clinically extremely vulnerable group' and asked to shield for 12 weeks. These included patients with sickle cell disease and high-risk patients with thalassaemia. The general effect of COVID-19 on our service delivery has been closure of the offices with staff working mainly from home, cancellation of all planned face-to-face meetings or events due to social distancing. Where possible,

meetings /events have been held by video conferencing (such as Zoom) and these have been very successful!

Overall, the tender tasked the Societies with addressing and supporting Screening Programme challenges highlighted in recent trends and performance data. These challenges included:

- regional variation in early offer of antenatal sickle cell and thalassaemia screening so that carrier or affected women are identified by 10 weeks + 0 days gestation.
- improving uptake of father testing
- timeliness of PND test by 12+6 weeks gestation
- timely entry into care, acceptance of penicillin and adherence to treatment for affected babies
- raising awareness about the National Haemoglobinopathy Register (NHR)

Work Activities and Outcome

At the end of Year 1, four projects were identified for Year 2 (as below) although as stated earlier there have been some changes to the work plan due to the COVID-19 pandemic.

- review and update of 'A Parent's Guide to Managing Sickle Cell Disease'
- provide service user perspective in review and update of sickle cell and thalassaemia counselling competences
- provide service user perspective on the reporting methods used to deliver newborn carrier results
- produce Year 3 work plan

Project 1 - Review and update of 'A Parent's Guide to Managing Sickle Cell Disease'

The SCS formed a Parents' Handbook Group (PHG) of clinicians (some of who were involved on the Handbook's previous editorial team) to update the existing *'Parent's Guide to Managing Sickle Cell Disease'* ('Parent's Handbook') which was last updated as a third edition in 2012. This fourth edition as before will include the wider determinants of health relevant to living with sickle cell and incorporate feedback from successful parent / young people consultations conducted (**Appendix 2**) . The updated edition is expected to be launched (online) by November 2020 with a view to a joint face-to-face launch with other NHS SCT Screening Programme publications in January 2021.

Project 2 - Provide service user perspective in the review and update of sickle cell and thalassaemia counselling competences

The SCS and UKTS as part of a working group were able to provide service user perspective in the review and updating of sickle cell and thalassaemia counselling competences which are now complete and due to be launched online in Autumn 2020 with a view to a face-to-face launch in January 2021. The Society representatives are also part of an SCT Counselling Skills and Knowledge Manuscript Task and Finish Group writing an article on the competences which is to be submitted to the 'Nursing Times'.

Project 3 - **Provide service user perspective on the reporting methods used to deliver newborn carrier results.**

The SCS and UKTS were to solicit views from service users on their preferred methods of communication of newborn carrier results such as whether these were to be via an Electronic Child Health Record (ECHR) or by hard copy. On 24 January 2020, SCS /UKTS/ NHS SCT Screening Programme held a meeting to plan this work part of which was to include user consultation via face-to-face focus groups. UKTS produced a draft questionnaire for use in the consultation but given the current situation with COVID-19, this work stream has now been postponed to Year 3 with the likely possibility the focus groups will take place online.

Project 4 – **Produce Year 3 work plan**

A workplan for Year 3 has been discussed with NHS SCT Screening Programme. It includes work carried over beyond Year 2 because of COVID -19 as well as new work that recently evolved (E-Learning) (See 'Restore' Document in Appendix 1). As such, Year 3 should see the publication and joint launch of hard copy new editions of the 'Parents' Handbook', *Sickle Cell Disease in Childhood: Standards and Recommendations for Clinical Care*' ('Paediatric Standards') and sickle cell and thalassaemia counselling competencies. Work will continue on reviewing and updating the Screening Programme's E-Learning Resource. The focus group consultations on reporting methods used to deliver newborn carrier results will also be part of Year 3 as well as focus groups by UKTS to review a new Alpha Thalassaemia leaflet that is being produced by Public Health England (PHE).

In addition to the projects described above, the publication and launch of the 'Paediatric Standards' was carried over to the early part of Year 2. The final PDF of the Paediatric Standards and its Executive Summary were published on the Sickle Cell Society (SCS) website in Year 2 (November 2019) and this online 'launch' was carried by several press. A physical launch planned for 15 June 2020 had to be postponed; however, we aim to have hard copies printed by November 2020.

Conclusion

This project continues to demonstrate the benefits of collaborative working between the Screening Programme (providers of service) and the Sickle Cell and UK Thalassaemia Societies (which represent users of the service) and how this can help improve screening service provision. Patient Societies are an incredibly valuable resource for health care professionals. They can work very flexibly within their respective communities and from a culturally sensitive perspective, thus gaining trust and useful information from their service users. This collaboration thus ensures the Screening Programme provides a service that is underpinned by the needs of its users. Even in the COVID-19 pandemic, project partners were able to adapt to the restrictions imposed, adjust work accordingly such that the Societies still provided valuable input to the Programme's service specification.

Purpose of Document

This document is a report on the second year of a collaborative project between the Sickle Cell Society (SCS), the UK Thalassaemia Society (UKTS) and the NHS SCT Screening Programme from 1 September 2019 to 31 July 2020.

The Societies give the insight to service user needs and can raise awareness of early screening within prevalent communities. The aim is to improve the quality of care of pregnant women, babies and families with sickle cell or thalassaemia in England. The success of this work was demonstrated by the recent publication of 'Parent Stories' which documented personal experiences of the NHS SCT Screening Programme (https://www.sicklecellsociety.org/resource/parents-stories/).

Background

Sickle cell disease (SCD) and thalassaemia are autosomal recessive inherited blood disorders caused by mutations in the genes responsible for haemoglobin production. Disorders of haemoglobin synthesis (thalassaemia) and structure (e.g., sickle-cell disease) were among the first molecular diseases to be identified and have been investigated and characterised in detail over the past 40 years.

Sickle cell disease is a lifelong genetic condition most prevalent amongst people of African, African-Caribbean, Mediterranean, Middle East and Asian origin. In the UK, approximately 12 500 to 15 000 people are living with sickle cell disease. (Dormandy E, James J, Inusa B, Rees D. "How many people have sickle cell disease in the UK? "*Journal of Public Health*, Volume 40, Issue 3, 1 September 2018, Pages e291–e295, https://doi.org/10.1093/pubmed/fdx172).

Beta Thalassaemia major is a life-threatening, genetically inherited and progressive form of anaemia commonly found throughout Northern Africa, the Mediterranean Basin, the Middle East, Asia, South East Asia and Melanesia to the Pacific Islands[1]. However, due to migration, thalassaemia multiplied globally to Northern Europe, Australia and the North and South Americas[2]. Thalassaemia is a serious public health

[1] De Sanctis V, Kattamis C, Canatan D, Soliman AT, Elsedfy H, Karimi M, Daar S, Wali Y, Yassin M, Soliman N, Sobti P, Al Jaouni S, El Kholy M, Fiscina B, Angastiniotis M (2017) β-Thalassemia Distribution in the Old World: an Ancient Disease Seen from a Historical Standpoint. Mediterr J Hematol Infect Dis. 2017 Feb 20;9(1)

[2] Angastiniotis, M., Modell, B.(1998) Global Epidemiology of Hemoglobin Disorders. Annals of the New York Academy of Sciences, 850:251-269.

concern throughout the Mediterranean, Middle East, the Indian Subcontinent and South Asia[3]. In the UK, approximately 1685 people are living with a moderate to severe form of thalassaemia[4].

Parents who are carriers of the sickle cell or thalassaemia gene can pass these health conditions to their baby. All pregnant women in England are offered antenatal screening (a blood test or in low prevalence areas, a screening questionnaire to identify family origins and then, if appropriate, a blood test) to find out if they are carriers of sickle cell or thalassaemia. If the mother is found to be a carrier, screening is offered to the father. The woman should be identified as a carrier or affected by 10 weeks+ 0 days of gestation to allow the baby's biological father to be offered testing and to offer PND to women at risk of having an affected child by 12+ 0 days gestation.

Outreach projects carried out by SCS and UKTS have proved successful in raising awareness of the importance of early SCT screening. In April 2016, the Programme commissioned SCS and UKTS to explore ways of achieving specific programme targets as follows:

- improving the timeliness of antenatal screening
- improving access and timeliness of counselling and offer of PND access for women with an increased chance of having an affected baby; and
- improving performance in coverage, timeliness of transition into care, adherence to treatment and data collection in newborn screening

Project objectives were delivered in a timely, cost-effective manner while ensuring the patient and carer voices were heard throughout by policymakers. The collaborative work resulted in an update of the parent and healthcare professional educational resources and a publication of 'Parents' Stories' which described experiences of parents who went through the screening pathway. Guidelines on the offer of counselling and prenatal diagnosis were revised and the Programme introduced new measures to monitor the implementation of performance standards.

Consequently, in June 2018 the Screening Programme opened a new tender won by the SCS and UKTS. This tender was to explore the reasons for variation in performance by screening providers and find ways to improve performance that would be led by the needs of service users. Iyamide Thomas from the Sickle Cell Society (lead organisation on the project) and Romaine Maharaj from UK Thalassaemia Society were tasked to deliver this new tender expected to last a period of 3 to 5 years.

[3] Weatherall, D.(2004) The Thalassaemias: The Role of Molecular Genetics in an Evolving Global Health Problem. *Am J Hum Genet* 74(3): 385–392.
[4] National Haemoglobinopathy Register – Number of Patients by Diagnosis [http://nhr.mdsas.com/wp-content/uploads/2019/10/NumberPatientsDiagnosis.pdf]

The Sickle Cell and Thalassaemia Screening Programme –an overview

The NHS Sickle Cell and Thalassaemia Screening Programme is a linked antenatal and newborn genetic Screening Programme that identifies people who are carriers for sickle cell, thalassaemia and other haemoglobin disorders and babies with a haemoglobin disorder. The NHS SCT Screening Programme was implemented based on recommendations from the UK National Screening Committee (UK NSC) regarding systematic population screening in pregnancy for genetic conditions. A formal Sickle Cell and Thalassaemia Screening Programme was established in 2008 and became part of the population screening programmes within Public Health England Health Improvement Directorate in 2013.

At present, the Sickle Cell and Thalassaemia Programme offers screening to:

- all pregnant women
- fathers-to-be, where antenatal screening shows the mother is a genetic carrier
- all newborn babies (for sickle cell as part of the New-born Blood Spot Screening Programme). Newborn screening can also identify babies with thalassaemia disorders but it is recognised that some babies may be missed by the routine laboratory methods used in newborn screening laboratories.

Public Health England collects data on the nine Sickle Cell and Thalassaemia Programme Standards, which ultimately aims to give a high-level overview of the quality of screening programmes at crucial points on the screening pathway. The Sickle Cell Society and UK Thalassaemia Society's collaborative work with the NHS SCT Screening Programme is expected to help support the following Programme Standards as the Societies have used their extensive public and professional community networks to raise awareness of the pertinent issues and brought user expertise to policymaking committees:

Standard 1- coverage: antenatal screening
Standard 2- test: timeliness of antenatal screening
Standard 3 - test: completion of family origin questionnaire (FOQ)
Standard 4 - test: turnaround time
Standard 5 -referral: timely offer of prenatal diagnosis (PND) to women at risk of having an infant with sickle cell disease or thalassaemia
Standard 6- diagnosis/intervention: timeliness of prenatal diagnosis (PND)

Standard 7- test: timely reporting of prenatal diagnosis (PND) results to parents

Standard 8 - test: reporting newborn screen positive results to parents

Standard 9 - intervention/treatment: timely follow-up, diagnosis and treatment of newborn infants with a positive screening result

Year 2 Project Overview

The Programme identified areas/projects in which the SCS and UKTS could support them. Trend and performance data highlighted the regional differences in performance standards that might cause regional differences in women's screening experiences and care. For example:

- coverage- the proportion of pregnant women being offered antenatal screening for sickle cell and thalassaemia is approximately 99.3%nationally, however, there is regional variation
- since 2015 there has been a gradual increase in the uptake of father testing, but this was highly variable regionally
- timeliness of antenatal screening is improving and went above the acceptable level specified in the Programme standards; however, the proportion of samples tested and results available by 10 weeks gestation differed significantly by region
- timeliness of prenatal diagnosis (PND) was 40%, which is below the acceptable standard (50%)

The newborn screening element of the Programme was established in England in 2006. The first evaluation undertaken for 2010 to 2016 showed scope for improvement. Though test performances and coverage appeared excellent, there were a few challenges highlighted by the initial assessment. The problems identified were:

- timeliness of care, acceptance of penicillin and adherence to treatment
- ensuring appropriate information is shared on the National Haemoglobinopathy Registry (NHR). The NHR aids the planning and targeting of haemoglobinopathy services.

Following the previous collaboration in 2016, where the SCS and UKTS engaged with parents about the antenatal screening pathway, parent and healthcare professional educational resources were updated. Guidelines on the offer of counselling and prenatal diagnosis were revised and consequently the programme introduced new methods in which the new standards would be monitored and implemented.

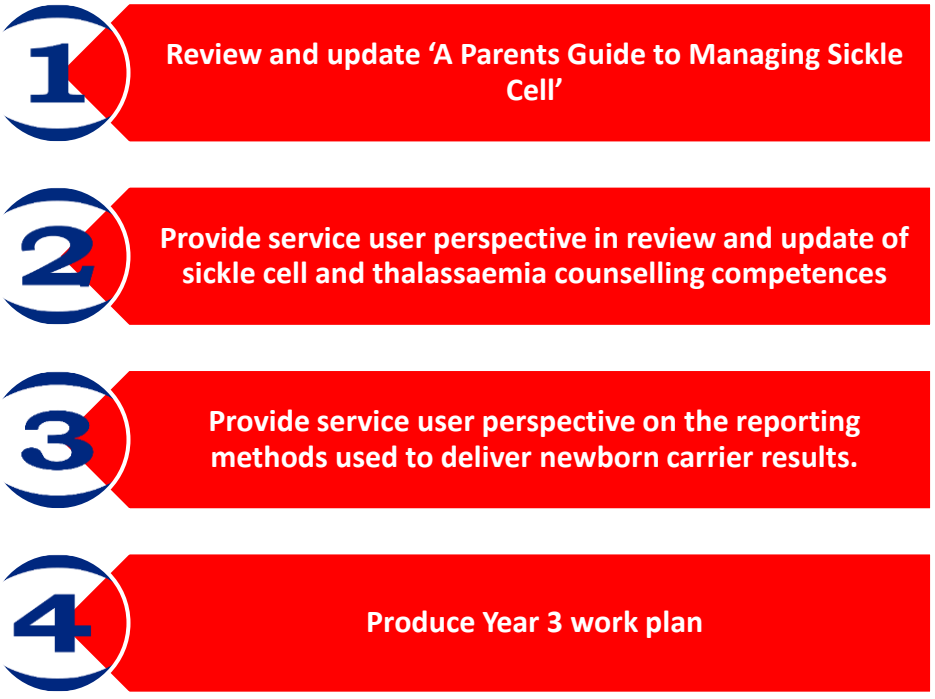
The **rationale** of the project is to explore reasons for the difference in service delivery, ways to improve performance and ensure that service provision is user-focussed.

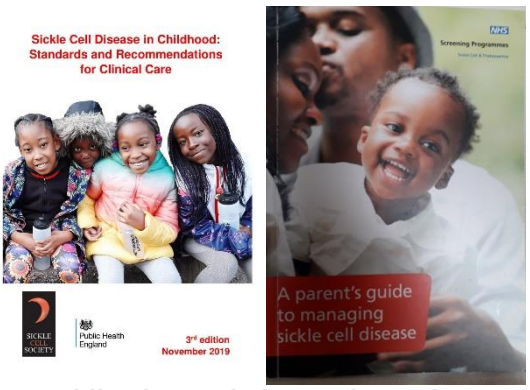
Based on the contract specification with the Programme, the Societies focused on:

- raising public and professional awareness of the screening pathway and producing posters that would help do this
- raising awareness of the new Paediatric Standards currently available online to all stakeholders. i.e. health and other professionals and service users
- producing a handbook for parents to help in managing their child with sickle cell
- ensuring that parents and patients understand the benefits of NHR registration and are assured that information is kept strictly confidential
- under-going engagement and user consultation work and using this feedback to inform projects that will address screening service issues
- providing input to health professional E-learning Resource

Project Aims and Objectives

The current tender specifies that there will be four projects each year. The four projects for Year 2 (1 September 2019 - 31st July 2020) were as identified below. In addition to these projects, new work on an E-learning Resource was identified to temporarily replace Project 3 and the publication of the *'Sickle Cell Disease in Childhood: Standards and Recommendations for Clinical Care'* was carried over to the early part of Year 2.





Publications relating to the project

In addition to the four projects each year, the SCS and UKTS attend the NHS SCT Screening Programme Advisory Group meetings (usually 2 per year) and other sub-committee / Advisory groups as required. SCS / UKTS attended the NHS SCT Screening Programme Advisory Group meeting on 14 November 2019 and the one scheduled for May 2020 was postponed because of the pandemic.

Project Advisory Group

The Societies also facilitate and attend Project Advisory Group (PAG) meetings (usually 3 a year) which provide monitoring and evaluation of the project to ensure timely achievement of the outputs and targets. Members of the group (**Appendix 3**) also approve the project work streams and deliverables each year. In Year 2 the UKTS PAG membership changed; Oddy Cooper was replaced as trustee by Roanna Maharaj and Teresa Choudhary, the UKTS National Co-ordinator joined as a new member. From NHS SCT Screening Programme, Jessamy Wilson-Pepper, PHE Project Support Officer, antenatal and newborn bloodspot screening also replaced Jamili Miah.

Project Plan

The following project work-streams show how Sickle Cell Society and UK Thalassaemia Society have worked to support the NHS Sickle Cell and Thalassaemia Screening Programme in Year 2 (1September 2019 -31 July 2020).

Project 1A – Review and update 'Sickle Cell Disease in Childhood: Standards and Guidelines for Clinical Care' (also known as 'Paediatric Standards')

(Responsibility: Sickle Cell Society: By November 2019)

The Final PDF of the Paediatric Standards and its Executive Summary were published on the Sickle Cell Society (SCS) website in November 2019. The link and accompanying information was shared to various stakeholders and service users, particularly those who participated in the consultation, (e.g. Sickle Cell & Thalassaemia Association of Nurses, Midwives and Allied Professionals (STANMAP), UK Haematology Forum and British Society of Haematology). Further dissemination was also done via the SCS networks and The Voice, African Voice, Brent and Kilburn Times published a press release as indicated below.

The press release was also edited and accepted as a PHE Blog authored by Iyamide Thomas, (**Appendix 4)** however due to PHE's COVID-19 priorities its publication is still delayed.

The Voice:

https://www.voice-online.co.uk/news/uk-news/2020/02/08/new-sickle-cell-guidelines-for-children-get-government-backing/

African Voice:

http://africanvoiceonline.co.uk/new-standards-for-care-of-uk-children-with-sickle-cell/

Brent and Kilburn Times:

https://www.kilburntimes.co.uk/news/health/sickle-cell-society-publishes-updated-care-standards-1-6504292

There were plans to launch a hard copy of the Paediatric Standards at the House of Commons on 15 June 2020 however the COVID-19 pandemic caused a delay to this launch. At a meeting of UKTS, SCS and the NHS SCT Screening Programme held on 21 April it was decided that the Paediatric Standards, Parents' Handbook and Counselling Competences should all be launched at one event possibly in November, dependent on the pandemic and social distancing guidelines. This has since been updated to a launch in January 2021 in line with the Counselling Competences new date. The SCS has received emails from clinicians which indicate the hard copy of the Paediatric Standards is eagerly awaited (see example email excerpts below) and we plan to produce these by November.

Excerpt from emails received from a Paediatric Haematologist on 14 July 2020:

" I am one of the haematologists in Sheffield. Do you happen to have paper copies of the latest childhood standards that could be sent to me? I would be very grateful".

When told of the Paediatric Standards Launch postponement:

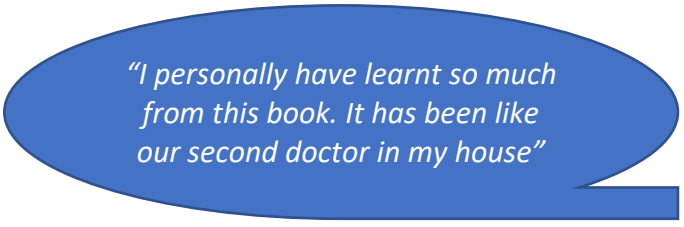
"Thank you for letting me know. I'm glad I haven't missed the official launch (I thought I must have!). Hopefully we will all be able to get together for this"!

Project 1B – Review and update of 'A Parent's Guide to Managing Sickle Cell Disease'

(Responsibility: Sickle Cell Society. Timescale: By October / November 2020)

Reviewing and updating the 2012 (3rd edition) of *'A Parent's Guide to Managing Sickle Cell Disease'* ('Parents Handbook) came about when the Project Advisory Group (PAG) decided that the scope of the Paediatric Standards being produced should mainly focus on the clinical management of sickle cell across acute, primary and community care. The Parents Handbook will therefore be updated to include the wider determinants of health relevant to living with sickle cell, with additional information from a parents' consultation. The editorial team consists of Dr. Lola Oni, Joan Walters, Prof. David Rees, Dr Olu Wilkey and Iyamide Thomas. Dr. Moira Dick has offered help with proofing manuscripts. The team have held meetings on 28th May 2019, 7 February 2020 and 2 July 2020 (the latter done by Zoom conferencing). The long duration between the first two meetings was to allow for consultation with parents using a questionnaire at clinics in Brent and Milton Keynes Sickle Cell & Thalassaemia Centres (SCaT), as well as online. The consultation was to solicit parents' opinion on any changes they wanted to see in the new Handbook and whether it should be produced in printed or electronic format. 51 questionnaires were completed nationally **(Appendix 2**) and additionally, very comprehensive feedback was emailed from a sickle cell researcher in Leeds.

Some things parents said about the Handbook:



Progress and decisions made from the editorial team meetings so far:

- each team member will continue to revise their allotted sections of the Parents Handbook and send these to Lola Oni. Revised updated sections will take on board relevant feedback from the parents who have overwhelmingly expressed that both a printed and internet copy would be useful.
- Dr Oni will oversee the updated sections, adding these to the master copy. COVID-19 priorities delayed clinicians reviewing their sections although some have already sent to Dr Oni. The last team member is expected to send her updates at the end of July, after which Dr Oni will produce the first draft to be reviewed at a team meeting to be held by 10 September.
- three thousand copies will be printed and distributed to the 10 Haemoglobinopathy Coordinating Centres, Brent SCaT and Sickle Cell Society for dissemination. A French version is also planned.

- the production timeline was discussed at the meeting on 2 July and Iyamide reminded the team of the previous deadline set for publication of the Handbook (by Black History Month October 2020). However, this was prior to the pandemic and if the first draft is now only being proofed in September, team members think a final publication launch in January is more realistic. This also fits in with the launch of the Counselling Competences now postponed to January. The final Parents Handbook will be available online before this official launch.

Project 2 – Provide Service User Perspective in review of Sickle Cell & Thalassaemia Counselling Competences

(Responsibility: Sickle Cell Society and UK Thalassaemia Society. Timescale: By end of Year 2)

The NHS SCT Screening Programme Counselling Competences were developed with the aim of contributing towards the sustainable provision of high quality, competent counselling for couples at risk of having a baby with sickle cell or thalassaemia and for counselling individuals, together with their families and carers, who are affected by these inherited and lifelong conditions. The competences are aimed at Sickle Cell & Thalassaemia (SCT) specialist nurse counsellors as well as other health professionals such as genetic counsellors, or specialist midwives or health visitors working in high prevalence areas. The SCS and UKTS (and a service user parent volunteer from the SCS.) were members of the 'SCT Counselling Skills and Knowledge Working Group' to provide expert service user advice and input to the development of the updated Counselling Competences. In Year 2 SCS / UKTS representatives attended Working Group meetings on 16 September 2019, 4 Nov 2019, 13 January 2020 and 9 March 2020 which was the final meeting. The updated Counselling Competences will be available online before autumn with a view to an official launch in January 2021.
The SCS and UKTS are also part of a SCT Counselling Skills and Knowledge Manuscript Task and Finish Group researching, writing and publishing a 'fit for purpose' article in professional journals (e.g. *The Nursing Standard, The Nursing Times)* on their experience of reviewing and updating the 2013 SCT Counselling Competences. SCS / UKTS attended the Task and Finish Group meeting on 9 July where members were attributed various sections to write. SCS / UKTS were asked to contribute information on the relevance of screening and testing to patient care, the wider family and future generations and the gaps in healthcare for Black, Asian and Minority Ethnic (BAME) groups.

These service user views on counselling taken from 'Parents Stories' indicate the need for sustaining the provision of good counselling:

"Although we were given the wrong advice by the GP, once we were referred to the SCT Centre we had excellent support. The counsellor spent over 2 hours with us explaining about the risk to the baby and also about how thalassaemia can be managed".

"We need more awareness about sickle cell among midwives. I already had a child with sickle cell and told her I was at risk but she didn't seem to know much about the condition and said she would contact a more senior nurse".
The sickle cell centre was very helpful and got me a quick appointment for PND. I liked the counselling and their telephone number is direct and not all around the houses".

Project 3 –Provide Service User Perspective on the Reporting Methods used to Deliver New-born Screening Carrier Results (Electronic Child Health Record (ECHR) Project)

(Responsibility: Sickle Cell Society and UK Thalassaemia Society. Timescale: Year 3)

NHS SCT Screening Programme, SCS and UKTS held a meeting on 24 January to discuss various aspects of the Year 2 work-plan. At this meeting, Amanda Hogan (NHS SCT Screening Programme's Programme Manager) suggested that the Societies look at how women receive their positive or carrier results (phone, letter etc) and what their understanding is of pre-natal diagnosis (PND). The meeting decided the following:

The Societies would run focus groups each with 8-12 individuals (women / 'at-risk' couples) who have been through the screening pathway to investigate:

- views on delivery of results by electronic record rather than hard copy
- views on preference of results to be delivered – carriers / normal
- do women want a carrier leaflet?

The results of this consultation with parents could then form the basis of a 'Parents Stories 2' publication.

Through PND focus groups with carriers and health professionals, SCS / UKTS could investigate views on having PND if a non-invasive blood test was used. The UKTS have produced a first draft questionnaire for the consultation which needs to be further reviewed and the plan was to hold these focus groups in London and North of England beginning from early April, however the COVID-19 pandemic caused all face-to-face meetings to be postponed. As such, the focus groups have been deferred to Year 3 and if it is still unsafe for them to be conducted face-to-face, they will be done virtually, especially now the Societies have good experience of virtual meetings!

Participation in the Rethinking Strategies for Positive New-born Screening Result Delivery 'RESPOND' project

The SCS /UKTS have been on the Steering Committee of a research project led by City University of London to determine effective and acceptable methods that healthcare professionals can use to communicate positive new born screening results to parents (i.e. if the baby is a 'carrier' or has the condition) . The SCS has been involved since the project's inception as sickle cell is one of the nine newborn screening (NBS) conditions being looked at. Phase 1 of the study involved a national survey of newborn screening laboratories and representatives of clinical teams to determine communication practices used for giving positive NBS results. In a 'co-design'

Phase 2 the researchers engaged screening staff and parents to gather their experiences, from which suggested ways to improve the communication of results will be tested. Phase 1 and 2 are now complete and the study protocol published. At the start of Year 2 the SCS designed and distributed graphics (see below) to help with the recruitment of parents for the co-design workshops. More recently the SCS recruited parents (10) and health professionals (14) to participate in 4 online events open to parents and carers of children affected by one of the 9 screened conditions, as well as Screening Co-ordinators, Screening Nurse Specialists and Midwives involved in the newborn screening process. These events were to update attendees on the study progress so far and get feedback. SCS attended a Steering Committee held on 20 January 2020. SCS / UKTS took part in the parents' online event held on 7 July and the health professionals' event held on 15th July. The events were very good and informative and the researchers have formed a Basecamp online chat forum for participants of the events, which will be useful for exchanging ideas.

Project 3B – Update of NHS SCT Screening Programme E-Learning Resource (additional objective for Year 2/3)

One of the changes to the work programme because of the COVID-19 pandemic was for the SCS / UKTS to bring their expertise and service user perspective to the review and update of the Screening Programme's E-learning resource. This resource was produced in 2016 'to support frontline antenatal and newborn practitioners making the offer of sickle cell and thalassaemia screening and explaining the results to women and their families'. The E-Learning resource features:

- 9 units explaining the two conditions and the whole screening pathway
- video contributions from leading practitioners
- real life film clips of midwives with at-risk couples

The Screening Programme Leads at SCS (Iyamide) and UKTS (Elaine Miller) had recorded video talking heads for the E-Learning Resource first edition. However, the Screening Programme has now identified the need to focus on work SCS and UKTS are doing with users specifically around inequalities, as this wealth of information can be used in the E-Learning resource. As such, the Programme has asked the Societies to help review the entire E-Learning resource content as it undergoes a major overhaul. SCS /

UKTS / NHS SCT Screening Programme have had online Zoom meetings on May 20, 26 June 5, 23 to discuss the E-Learning resource. So far the modules that SCS and UKTS have reviewed and suggested changes to are:

- antenatal and New-born screening for sickle cell, thalassaemia and other haemoglobin variants
- understanding haemoglobinopathies
- about sickle cell disease
- about thalassaemia

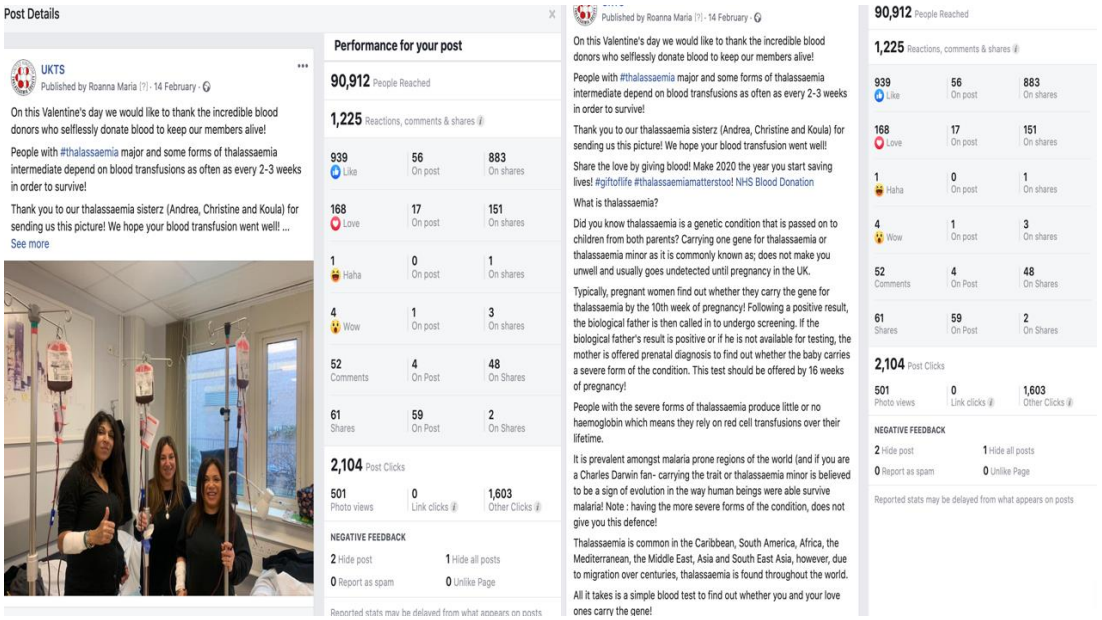
The Societies have given NHS SCT Screening Programme feedback of recent service user experiences of the screening pathway and have suggested a new module that teaches health professionals terminology and statements that should not be used with new parents waiting for heel prick results e.g. *"no news is good news"*. The Screening Programme during these Zoom calls have observed the wealth of expertise and user stories the Societies have and Amanda Hogan, NHS SCT Screening Programme Programme Manager suggested future work could investigate these 'Society Stories'.

Outreach Work

This is a continuous work-stream each year for the SCS and UKTS to use their respective networks to raise awareness to the public and health professionals on screening issues pertaining to that year's work, as well as general screening awareness to at-risk communities. Screening awareness posters were finalised and are at the printers. UKTS has once again concentrated more on outreach this year and **Appendix 5** gives a detailed summary of outreach activities for Year 2. SCS and UKTS have used digital technology and social media (e.g. Zoom, Facebook, Twitter, Instagram) to raise awareness of the conditions and screening issues (which is a good way to target young people) particularly in the second half of Year 2 when the world was gripped by the COVID-19 pandemic. Below are some examples of the use and impact of digital technology and social media.

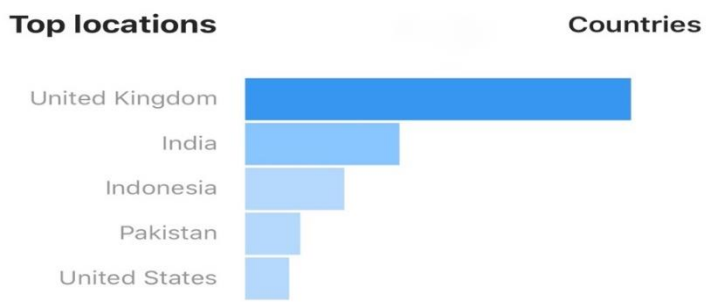
The impact of Social Media

An example of a UKTS Facebook post (including number of people who saw the post 90,912 and the number of times people interacted with it 2,104) about early screening can be seen below.

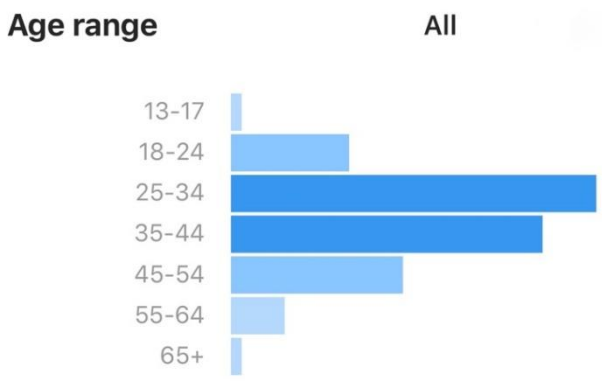


The charts below show the cumulative data obtained by the UKTS across the 3-social media platform with regards to posts targeting the screening agendas.

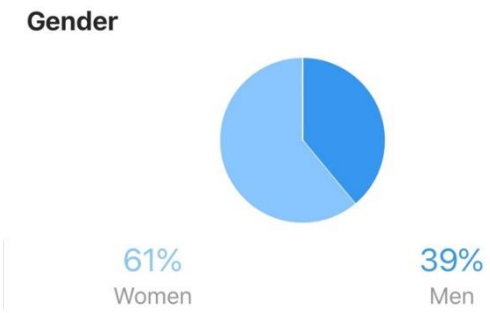
Bar Graph 1- Showing UKTS cumulative data of top countries who viewed posts with regards to the screening agenda.



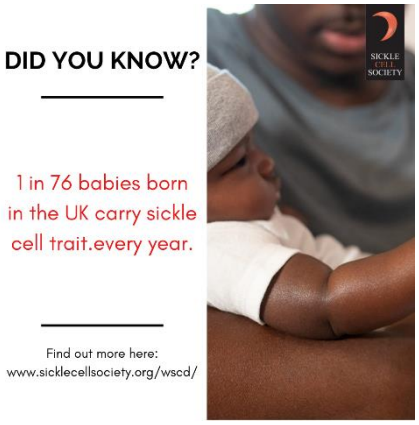
Bar Graph 2- Showing UKTS cumulative data of percentages of age ranges of people who viewed posts with regards to the screening agenda.



Pie Chart Showing UKTS the percentage of men and women who viewed posts with regards to the screening agenda.

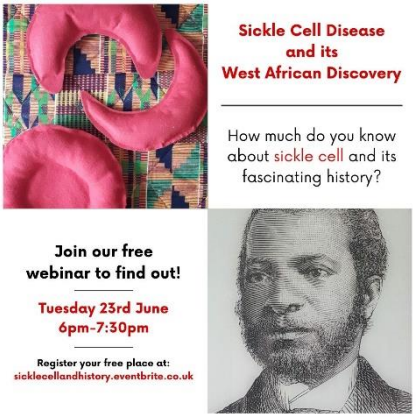


Sickle Cell Society Instagram posts to commemorate World Sickle Cell Day included the following graphics:



143 Instagram 'Likes'

57 Instagram 'Likes'



150 Instagram 'Likes'

PROJECT 4: PRODUCE YEAR 3 WORKPLAN

1. Provide service user perspective on the reporting methods used to deliver newborn carrier results
2. Continue to provide input into the revision of the Screening Programme E-learning resource targeted at health professionals involved in screening pathway
3. Alpha Thalassaemia leaflet
4. Produce Year 4 work plan

Part of year 3 will also involve implementing the findings from the previous year, including the dissemination of the new screening posters and NHR patient information literature. The SCS and UKTS will work with the NHS SCT Screening Programme to develop a detailed project plan linked to the Programme objectives for 20 /21.

Project Monitoring

- **monitoring and evaluation**: The Project Advisory Group (including a representative from the Programme) to hold meetings to monitor achievement of outputs/targets and advising on SCS/UKTS progress reports
    - This was done by quarterly updates using the Red Amber Green (R.A.G) reporting system showing performance against the agreed outputs. In Year 2 the PAG held full meetings on 17 October 2019 and 15 January 2020. Due to the pandemic, the meeting scheduled for 21 April was changed to an online meeting of a smaller sub-group consisting of the PAG Chair, UKTS, SCS and NHS SCT Screening Programme only. At this meeting, changes were made to the work plan (because of the implications of the pandemic) and the minutes shared to the wider PAG membership. The PAG meeting of 23 July was held by Zoom conferencing.
- **monitoring and evaluation:** SCS / UKTS performance review meetings with the Programme are held 3 monthly

The Programme has met with SCS /UKTS to review work progress using a milestone tracker to monitor what is being delivered. A face-to-face meeting was held on 24 January 2020. Zoom meetings to discuss progress and the Year 2 report were then held on 15 May and 6 July 2020.

Discussion

Once again, this Year 2 report has shown the benefits of collaborative working between the Screening Programme and the Sickle Cell and UK Thalassaemia Societies (which represent users of the service). It has shown how the Societies can provide valuable service user input to the Programme that will ultimately help improve its service provision (e.g. review of the E-Learning resource for health professionals along the screening pathway). The Societies have also shown value for money in delivering Year 2 of this collaborative project. (**See Appendix 7 finance report**). The unprecedented COVID-19 pandemic brought its challenges as the Societies and Screening Programme had to change how they worked in order to follow Government directives such as ‘stay at home’ and ‘social distancing’. Additionally service users with sickle cell and some high risk patients with thalassaemia were placed on the clinically extremely vulnerable group’ and asked to shield for 12 weeks.

However, in the face of adversity good things can sometimes develop and the Societies / Screening Programme partnership was able to adapt to the changes brought by the pandemic. (See Restore Document). The project work streams that involved face-to-face contact were deferred and in its place was substituted the important review and overhaul of the Screening Programme E-Learning Resource for health professionals, which the Societies have been able to contribute immensely to via online Zoom meetings. The Societies and Screening Programme held 12 virtual meetings over the April- July 'lockdown' period, many of which involved detailed review of the E-learning modules. These meetings also helped keep the Societies' focus on the workplan to ensure core milestones were still met. During these online meetings (which on average lasted two hours), the Screening Programme again observed the wealth of knowledge and user stories the Societies have between them, the fact they can work very flexibly within their respective communities from a culturally sensitive perspective and gain trust from their service users. The Programme has identified that there are inequalities faced by the high-risk sickle cell and thalassaemia communities in accessing services such as PND because cultural needs are not adequately met or there is a lack of understanding by both health professionals and the users they serve. As such, Amanda Hogan, (NHS SCT Screening Programme Programme Manager) has stated that using the SCS / UKTS (and possibly producing a 'Society Stories' publication) can help the Programme's work on redressing these inequalities and can be part of the Screening Programme's future 5 year plan.

Apart from the four specific projects of Year 2, the Societies conducted general engagement and outreach **(Appendix 5)** among both health professionals and the communities most at risk until March 2020. When the pandemic lockdown began, some events (e.g. World Sickle Cell Day event on 23 June) took place online. The UKTS have once again concentrated on outreach this year and have spread the messages from the Parents' Stories, the NHR and Newborn Outcome (NBO) System to communities at-risk of thalassaemia using a variety of forums and broadcast media. This engagement with the at-risk communities will raise awareness of screening among users so they too can be more proactive and ask for screening, prenatal diagnosis, newborn results and follow-up care if these are not being promptly provided. In turn, we hope this will impact positively on the relevant Screening Programme Standards.

As we commence Year 3 we will fulfil the revised work programme as detailed in the Restore document and make any required changes as we continue to be impacted by the COVID-19 pandemic. Both the SCS and the UKTS have staff members with many years' experience of working with the Screening Programme who can be relied upon to contribute to the Screening Programme's service development and we look forward to a long successful collaboration. The SCS will also try to source an additional experienced individual to help (Iyamide) with the delivery of this work to mitigate against illness etc.

Learning from Year 2

The most important learning from Year 2 is without a doubt how a project can adapt to unexpected changes such as a once in a lifetime pandemic! The NHS SCT Screening Programme/SCS /UKTS were able to produce a Restore document and adapt to unpredicted changes using social media and video conferencing platforms to continue delivering outputs that would ultimately ensure screening service provision considerate to user needs. It is always good to use learning from a previous year to inform work for the following year and in Year 2 this was done when we used learning from Year 1 and extended the Parents Handbook consultation beyond the usual 3-week period and sent reminders via social media avenues. As such, 51 parents participated in the survey. Though the pandemic caused deferral of some of the Year 2 projects, it is still important to set realistic timelines for the various projects, especially if their delivery involves a multi-disciplinary team of clinicians whose priorities might change due to other pressures. One example is the case of the Parents Handbook, where the timeline anticipated by the PAG was not met by the editorial team of clinicians (even before the COVID-19 pandemic) and has had to change a few times. It is best for any production timelines to be jointly set with a publication's editorial team.

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 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

'Restore' Document

Purpose

This 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 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 newborn 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.

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 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 fifteen virtual meetings held over the April to July 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 weekly 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 resource, 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 as 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 health-care professionals, which 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: projects that have been maintained but have been suspended or stopped (highlighted in red), projects that have been partially restored yet are still somewhat affected (yellow) and projects that have been unaffected including new work undertaken by the Societies (green).

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 or ceased)			
1.	Electronic Child Health Record (ECHR) Project: Service user perspective on the methods used to deliver new-born screening for sickle cell and thalassaemia	Maintained	
2.	National Haemoglobinopathy Registry (NHR) Posters	Suspended	NHR is redesigning their process to obtain consent
3.	Outreach (Face to face)	Suspended	All face-to-face contact is delayed until it is safer to do so. We plan to resume face to face contact with others in late 2020
4.	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 will be moved to Year 4
Partial restoration - phase back (Affected, Ongoing)			
5.	Parents Handbook	Affected	Editorial team comprises of mostly clinicians whom are all front-line staff and have been occupied with COVID-19 related issues- so there has been a delay. Editorial meetings/timeline- Thursday 2nd July and early September to proof first draft. Online Launch possibly in November with a view to launch hard copy in January 2021 with the Paediatric Standards and Counselling Competences.
6.	Alpha thalassaemia leaflet	Affected	PHE is still working on the document to make it more accessible (language, html ready etc.) It will be sent to UKTS when it has been completed. Deadline late 2020

7.	Focus groups on carrier results: mothers	Affected	UKTS developed draft questionnaires to capture experience of mothers Focus groups were planned in London and North of England in late March-April. If it is not safe to conduct face to face, the focus groups will be conducted virtually in October/November.
8.	Focus groups of new-born carrier results	Affected	Focus groups were planned in London and North of England in late March-April. If it is not safe to conduct face to face, the focus groups will be conducted virtually in October/ November.
Fully restore service- (Completed/ Unaffected)			
9.	Paediatric Standards	Completed	Launched online on November 2019 with a view to a hard copy launch in January 2021.
10.	Counselling Competencies	Completed	Will become available online at the end of July. Launch- January 2021, if not will be launched online
11.	Awareness Posters	Completed	Posters have been sent to the printers, but printing has been delayed. We hope to receive them by late July.
12.	Outreach (Social media, virtual)	Unaffected	Both SCS and UKTS have increased their online presence and have been developing social media campaigns to raise awareness
13.	E-learning modules under review (new project added)	Unaffected	This SCS and UKTS have been providing feedback on the current online modules used to train specialist haemoglobinopathy nurses and genetic counsellors. PHE has plans to update all the units.

Appendix 2

Summary of Parents' Handbook Consultation

51 questionnaires were completed with half of these being via the Sickle Cell and Thalassaemia centres of Brent and Milton Keynes whilst the others were completed online including by parents in Aylesbury, Birmingham, Oxford and Reading. 20% of respondents stated they knew nothing about sickle cell prior to being given the Parents Handbook. Of those given the Handbook 97% stated they found it useful with some parents giving the following reasons when asked what the most important knowledge gained from the book was:

''The different signs and symptoms of the disease and what to look out for"

"Pain management, this helped me to understand the types of pain and what to do"

"Knowing when to go to the hospital. Having the book as a reference point to always go to to further understanding".

Parents who did not find the book useful gave the following information that might have helped:

"*Sometimes have difficulty reading the English"*

"*How children who were not born in this country but are now living here can be helped since those children do not have social workers to guide them on certain social things they might be qualified for*".

90% (of 47 responses) felt that a printed copy of the book should be given to all parents of newly diagnosed children with sickle cell.

67% (of 43 responses) felt their child's sickle cell would have been harder to manage if they had not been given the Parents Handbook. One parent stated:

"It will be harder to manage because on the internet there are different things about SCD and this can be very confusing for someone who isn't aware of the disease. The booklet helps because you can find all information in one place and it is very handy".

Information parents stated (in their own words) they would like included in the book:

- "How to break bad news to child with condition about inherited chronic illness"
- "Direct references to legal /statutory support for parents to access when making bids to employers for flexible working"

The raw data from the consultation can be downloaded directly from:

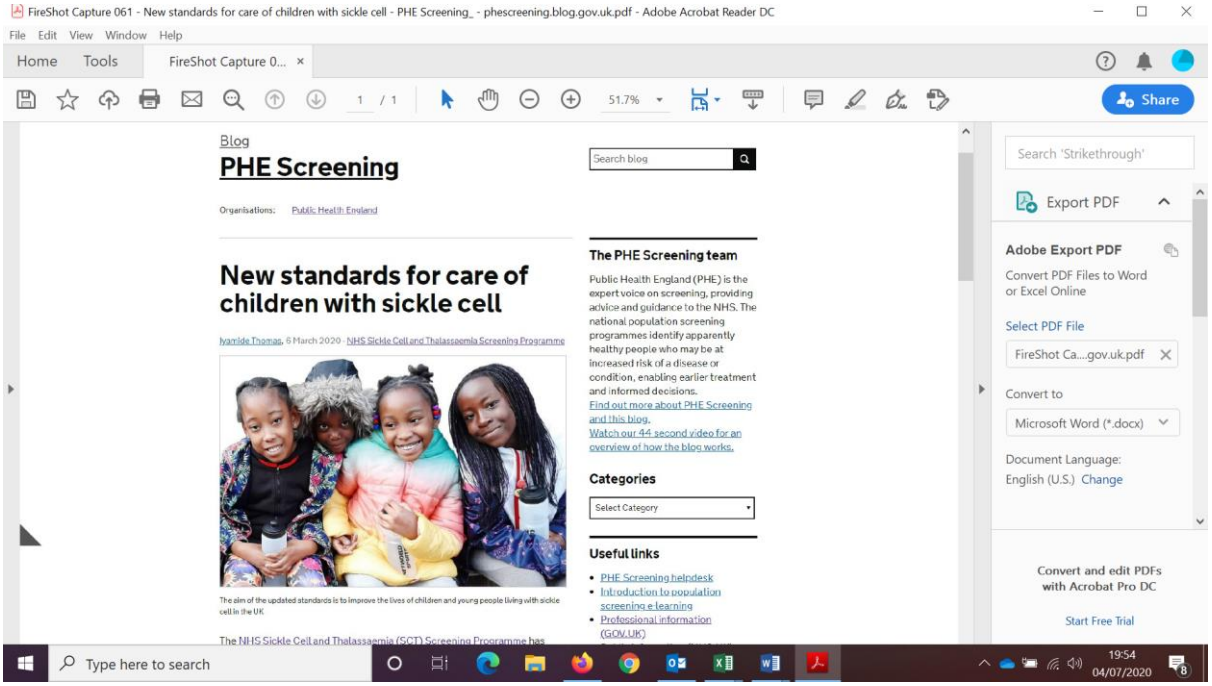
https://www.sicklecellsociety.org/wp-content/uploads/2020/07/Parents-Handbook-Consultation-Final-PDF-version.pdf

Appendix 3

Membership of Project Advisory Group (PAG)	
Chair : Dr.Elizabeth Dormandy	Public Health & Screening Advisor, Advisor to the Sickle Cell Society,
Lynette Adjei	Service user representative (sickle cell)
Prof. Karl Atkin	Professor of Sociology with special interest in haemoglobinopathies, University of York
Teresa Choudhary	National Co-ordinator, UKTS
Dr. Moira Dick	Retired Consultant Paediatrician and Medical Advisor to Sickle Cell Society
Prof. Simon Dyson	Professor of Sociology with special interest in haemoglobinopathies, De Montfort University
Amanda Hogan	Programme Manager, NHS SCT Screening Programme
Adeeba Jameel	Service user representative (thalassaemia)
John James	Chief Executive Officer, Sickle Cell Society
Brigid Keane	Specialist Midwife for Haemoglobinopathies, Royal Victoria Infirmary, Newcastle
Roanna Maharaj	Trustee, 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 Development, PHE Screening Programmes
Dr. Mary Petrou	Director, Haemoglobinopathy Genetics Centre, UCL & Advisor to UKTS & SCS
Michele Salter	Trustee, Sickle Cell Society
Iyamide Thomas	NHS Engagement Lead, Sickle Cell Society

Appendix 4

PHE Blog on Paediatric Standards



Website link for full text available from:
https://documentcloud.adobe.com/link/review?uri=urn:aaid:scds:US:de2fc056-339d-40ad-8089-82af2535cae1

Appendix 5

Year 2 Outreach and other activities undertaken by Sickle Cell Society and UK Thalassaemia Society

Dates	Activity and Feedback	No of Participants
14 September, 2019	UKTS attended Sickle Cell and Thalassaemia Family day in Butetown Community Centre, Cardiff- spoke to new parents and people visiting the community centre about screening.	~150 visited stall
15 September 2019	UKTS had a stall at Cardiff Mela- which is well attended by Asians across UK due to the performers, food and clothing stalls. We had the opportunity to raise awareness of thalassaemia and how it affected the Asian community with all generations	~500
18 September 2019	UKTS went on EUROGENC TV to raise awareness of thalassaemia and why screening was imperative. (Station targeted the Turkish and Turkish Cypriot Community). Interview was done in Turkish and English and was also live streamed on Facebook.	Estimated reach as > 400
19 September 2019	UKTS went on Delite Radio (targeted at the 18-35 year olds) to raise awareness of thalassaemia and the importance of screening. Also spoke about the upcoming National Thalassaemia Day and the Screening Event which was open to the general public to find out whether they were carriers of thalassaemia and/or sickle cell.	Estimated reach > 300
20 September 2019	UKTS /SCS met with Raleen Fernandes from ARISE to talk about future collaboration with the Societies to encourage future learning and to promote screening.	
21 September 2019	UKTS went on the London Greek Radio @LGR1033 at 9am with Patron Peter Polycarpou and Vasillis Panayis to raise awareness of thalassaemia. UKTS Supported sickle cell and thalassaemia nurses at Leicester de Monfort University freshers fair.	Estimated reach > 400 >200
24 September 2019	UKTS hosted Coffee morning at HQ- to gain feedback on posters from general public	~19
26 September 2019	UKTS Patron Tonia Buxton appeared on London Greek Radio to raise awareness of thalassaemia and why it was imported to be tested.	Estimated reach > 500
7 October 2019	SCS did a Black History Month talk at the Association of Commonwealth Universities which included the history of sickle cell, the condition and screening. Good feedback from participants.	35

9 October 2019	UKTS met with Liz Odeh, Lead CNS in Haematology & Nasser Roheemun Haematology Specialist Nurse Manager at the North Middlesex Hospital to discuss the UKTS' screening event for #thalassaemia & #sicklecelldisease	~30 visited stall
10 October 2019	UKTS Attended GG2 Diversity Conference in London to raise awareness of thalassaemia	Website estimated reach > 500
18 October 2019	UKTS went live on BBC Asian Network to raise awareness of thalassaemia UKTS went live on Dilse Radio (Asian network) to raise awareness of thalassaemia. Roanna also spoke about the UKTS open day screening event	~40 ~250
18 October 2019	UKTS attended Mayor of Enfield Gala ball to provide information on thalassaemia and their upcoming screening event	~300
19 October 2019	UKTS hosted a Screening day event which was opened to the general public to test for thalassaemia and sickle cell. **(See Appendix 6**) https://londragazete.com/english/185352/ukts-launched-its-national-thalassaemia-day/	~160 stall
21 -23 October 2019	SCS/UKTS joint stall at Annual Sickle Cell and Thalassaemia Conference (ASCAT). ASCAT presents an excellent forum for raising awareness and networking with both national and international audiences who are mainly healthcare professionals. Updated Sickle Cell Adult Care Standards were in high demand as were other sickle cell and thalassaemia literature.	Stall visited by ~ 150 people
26 October 2019	SCS sickle cell awareness talk to Young Sierra Leoneans Arts and Culture Event	~ 120
28 October 2019	SCS Black History Month talk to Department of Education staff on sickle cell, its impact on education and employment and screening. Talk was done jointly with Dr. Maria Berg from De Montfort University, Leicester.	30
30 October 2019	SCS attended the All Party Parliamentary Group launch of 'A Guide to Sickle Cell and Employment' of which the SCS were joint collaborators. Meeting attended by politicians, service users, nurse specialists and	~25
1 November 2019	SCS / UKTS attended and networked at the Sickle Cell & Thalassaemia Association of Nurses, Midwives and Allied Professionals (STANMAP) conference	~ 50
11 November 2019	SCS attended PHE Screening Inequalities Conference which focussed on sharing information on actions being taken to tackle inequalities in screening, and seeking input into what further practical steps PHE need to take to address inequalities in their service delivery.	~80
20 November 2019	UKTS and Patron Tonia Buxton went on Hellenic TV to speak to the Greek and Greek Cypriot population about thalassaemia and why it was important to encourage the younger generation to test.	Estimated reach > 500
22 November 2019	SCS attended the British /Nigerian Law Forum event which was good opportunity to network and provide sickle cell and screening literature.	~ 100

7 December 2019	UKTS Charity Winter Ball- Roanna Maharaj gave a short presentation on what living with thalassaemia was like for her and why it was essential that people found out their carrier status	300
13 December 2019	UKTS attended Bond Wolfe Auction House in Birmingham to collect a donation at their annual event and was given the opportunity to speak about thalassaemia and disseminate carrier information leaflets.	~50
8 January 2020	UKTS met with Shailesh Solanki, Executive editor of the Asian Media Group to discuss raising thalassaemia awareness amongst the Asian communities	
9 February 2020	UKTS attended the AGM of the Giants group of London and delivered a short presentation about thalassaemia and why screening for the condition was important, we addressed thalassaemia myths and the work UKTS has done over the past 4 decades.	~35
12 February 2020	SCS attended the 'Future Midwife' celebratory event that launched the new midwifery standards which SCS /UKTS had participated in a roundtable for. The Standards will enable midwives of the future to provide the best and safest care to women, their babies and families. The first pre-registration midwifery programmes based on the new Standards will start in September 2020.	~ 70
14 February 2020	UKTS Social Media post on all platforms for Valentine's Day to raise awareness of thalassaemia and why screening is helpful- Over 90,000 views	-
26 February 2020	SCS at All Party Parliamentary Group (APPG) AGM attended by MPs, clinicians, service users and other stakeholders to discuss the year's programme to enhance service provision to those living with sickle cell.	20
27 February 2020	SCS gave sickle cell awareness talk to a students' event at South Bank University	~60
19 June 2020	SCS did World Sickle Cell Day (WSCD) article in All Saints Church newsletter which mentions screening. Distributed via email and Facebook.	>100 reached
19 June 2020	SCS specially created WSCD screening graphic widely shared on social media including other graphics with screening statistics.	N/A
23 June 2020	SCS online Zoom event for WSCD includes presentation on screening	65

Appendix 6

UKTS National Thalassaemia Day Event Report

19th October 2019

THE United Kingdom Thalassaemia Society (UKTS) launched their National Thalassaemia Day (UK) on Saturday the 19th October 2019. Opening its doors to the general public, inviting everyone to walk in and be tested for thalassaemia and other conditions, it also gave an option for people to learn more about the condition. UKTS offered those who attended; free screening to the general public for thalassaemia and sickle cell trait, counselling and guidance (for positive test results), free screening for Hepatitis C and other infected diseases and more.

The event was opened by the Executive Director Romaine Maharaj, Chair Gabriel Theophanous, Treasurer Oddy Cooper, Patrons Peter Polycarpou and Kypros Kyprianou, volunteers and staff. Also attending was the Mayor of Enfield Kate Analou, MP for Enfield Southgate Bambos Charalambous, David Burrowes, doctors, nurses and members of the public.

Screening for thalassaemia/ sickle cell trait:

- Probable alpha thalassaemia trait – 21%
- beta thalassaemia trait – 9%
- Sickle cell trait- 3%
- Normal- 67%

Hep C screening/ Liver scans:

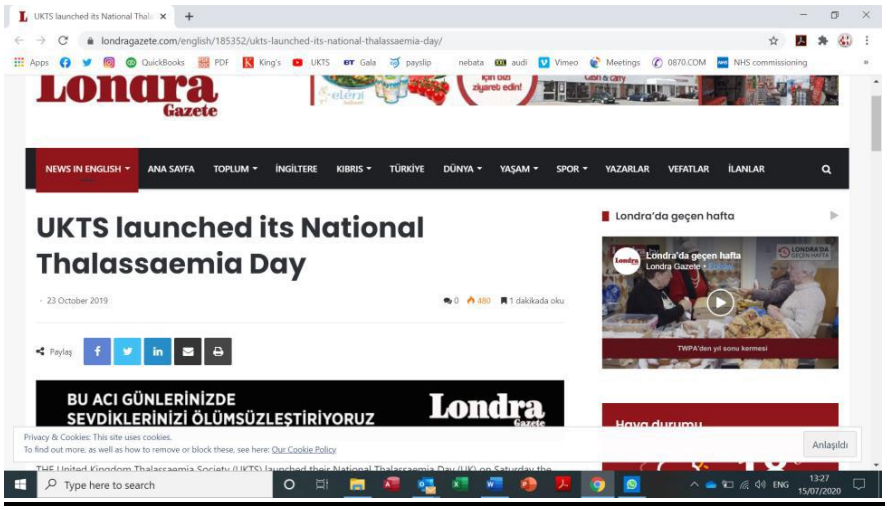
We had no positives from the 9 that were screened for Hep C but the fibroscans (liver) did show up some abnormalities. 54 people were fibro scanned, 1 of who which was unable to get a result on; 1 was cirrhotic and 5 others had abnormal results. All these people were given mini consultations to discuss the result and then given forms with the results on and relevant contact details for any follow up questions that the GPs or whatever Dr they would be giving the results to.

NHSBT/ know your type/ Registration as a blood donor:

36 people registered on the day to become donors. They did not have final figures on the amount tested.

Several articles were produced following the event, one of which is:

https://londragazete.com/english/185352/ukts-launched-its-national-thalassaemia-day/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UKTS launched its National Thalassaemia Day
23 October 2019
Londra'da geçen hafta
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Privacy & Cookies: This site uses cookies.
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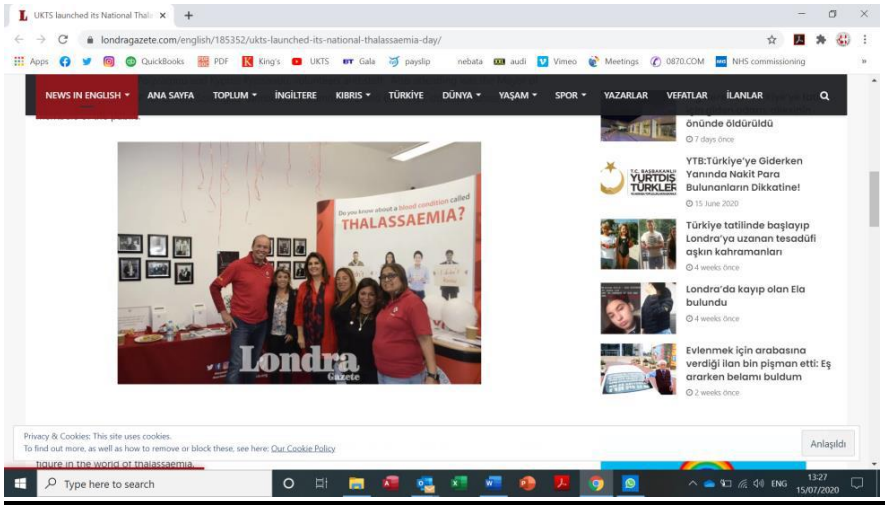
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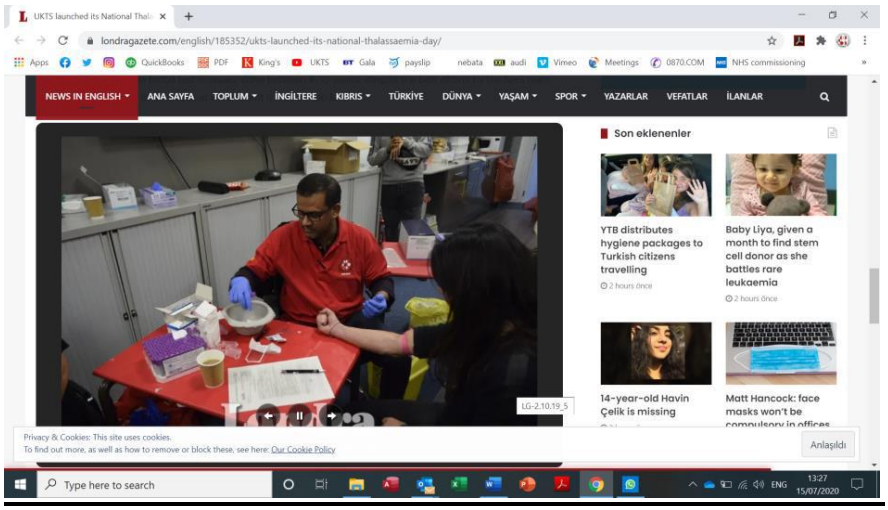
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Baby Liya, given a month to find stem cell donor as she battles rare leukaemia
14-year-old Havin Çelik is missing
Matt Hancock: face masks won't be
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Appendix 7

Year 2 Finance Report

Sickle Cell Society

PHE -Sickle Cell and Thalassaemia Screening Programme Tender 2018/21

Year 2 Finance Report August 2019 to June 2020

1. Introduction

This report provides a summary of income and expenditure related to the second year of actual income & expenditure for the tender for the SC&T Outreach Project covering 01 August 2019 to 31 June 2020. The annual operating budget for the tender covering both Sickle Cell Society (SCS) as lead organisation and UK Thalassaemia Society (UKTS) is £121,277.

Second year of the tender - from August 2019 to July 2020 - £121,277

- SCS £77,887
- UKTS. £43,390

01 August 2019 to 30 June 2020

Income of £112,087 representing 11 months from August 2019 to June 2020. Income received to date £90,957.75, £20,213 outstanding (invoice sent early June waiting payment from PHE).

Total expenditure to date £98,615 including £7,232 accrued payment to UKTS

2. Commentary

At the end of June 2020, which represents 11 months of the second year, including the debtor's amount of £20,213 the project has a surplus of £14,413 subject to any further expenses for this period.

This is mainly due to underspend on travel cost including volunteers and Scientific Advisors, venue hire & catering.

We are expecting further expenses totalling £9,300 for printing cost for the Parent Guide to Managing Sickle Cell (£4,500) Paediatric Standard for Sickle Cell (£4,000) and Medical Writer's cost (£800).

The forecast for the end of the second year 31 July 2020 is a surplus (underspend) of £4,000 if expenditure trend remains the same.

John James OBE
CEO
SCS

Appendix 8

Photo Gallery

SCS Screening graphic for World Sickle Cell Day

SCS / UKTS joint Awareness stall at ASCAT

UKTS at Cardiff Mela

Roanna (UKTS) at Delite radio interview

Roanna (UKTS) at LGR radio interview

Tweet from Young Sierra Leonean Event

Iyamide at British Nigerian Law Forum event

SCT nurses at De Montfort Fresher's Fair

Romaine meets nurses at North Middlesex Hospital

Iyamide and Roanna at STANMAP AGM

SCS reps with Lola Oni and visitors at SCT Competences