ABRIDGED VERSION

Report Name: Project Board Advisory Group Annual Report final version 10 August 2021

Agenda Item No:		**Paper No:**	

Purpose of Report:
Sickle Cell and Thalassaemia Screening Programme – Year Three annual report: To update the NHS Sickle Cell and Thalassaemia Screening Programme on progress made in the collaborative project with the Sickle Cell and UK Thalassaemia Societies to support the delivery of screening services and ensuring these are underpinned by service user needs – for the period 1 August 2020 to 31 July 2021.

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

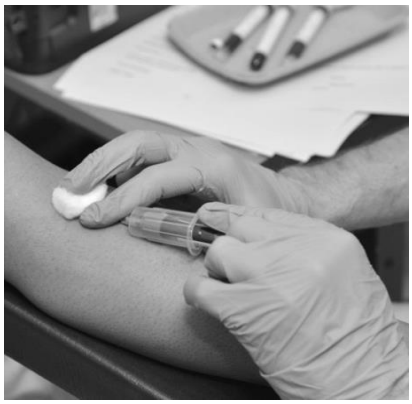
Recommendations / Actions:
N/A

Next Steps:
N/A

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

Annual Report: **Third 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 2020 – 31 July 2021



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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, 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 affected by sickle cell disease or thalassaemia. It helps give 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, 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 third year of a collaborative project commissioned by the Programme for the period 1 August 2020 to 31 July 2021. The tender commenced in August 2018 and overall tasked the Societies with addressing and supporting Screening Programme challenges highlighted in their trends and performance data. 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 avoids generating inequalities.

The unprecedented **COVID-19 pandemic** of 2020 caused significant changes in the work plan previously proposed for Year 2 and the Societies were subsequently tasked to have major input to revision of the NHS SCT Screening Programme E-learning resource to support health professionals who are part of the screening pathway. This E-Learning resource review has continued to Year 3. The workplan changes are outlined and monitored quarterly using a ‘Restore’ document (**Appendix 1**). In Year 3, the Societies

continued to use innovative ways to deliver their services, particularly to their client group who were officially classed as 'clinically extremely vulnerable' and were shielding. These included all patients with sickle cell disease and high-risk patients with thalassaemia. The general effect of COVID-19 on service delivery has been closure of the Society offices to the public with staff working mainly from home, cancellation of all planned face-to-face meetings or events due to social distancing. All meetings /events in Year 3 were successfully held by video conferencing using Zoom or Microsoft Teams. It is envisaged that when face-to-face meetings start, these might be combined with a video conferencing option, to improve accessibility ('hybrid' meetings).

Work Activities and Outcome

The following projects were identified for Year 3, which took on board changes to the work plan due to the COVID-19 pandemic:

- publication and launch of new editions of *Sickle Cell Disease in Childhood: Standards and Recommendations for Clinical Care*' ('Paediatric Standards'), *'A Parent's Guide to Managing Sickle Cell Disease'* ('Parents Handbook') and *SCT Counselling Knowledge and Skills* ('Counselling Competences')
- contribute to articles in 'Nursing Times' as part of an SCT Counselling Skills and Knowledge Manuscript Task and Finish Group
- continue to provide input into the revision of the Screening Programme E-learning resource targeted at health professionals involved in the screening pathway
- provide service user perspective on the reporting methods used to deliver newborn carrier results
- raise awareness of sickle cell and thalasaemia, including the importance of screening, through increased online presence, specific social media campaigns and dissemination of screening awareness posters.
- review Screening Programme newborn carrier leaflets and Alpha thalassaemia leaflet
- produce Year 4 work plan

Project 1 – Publication and launch of Sickle Cell Disease in Childhood: Standards and Recommendations for Clinical Care', 'A Parent's Guide to Managing Sickle Cell Disease' and SCT Counselling Skills and Knowledge

On Thursday, 28th January 2021, over 250 people from around the UK attended an online event hosted by Public Health England to launch new editions of sickle cell and thalassaemia publications produced as part of a collaborative project between the Sickle Cell Society, UK Thalassaemia Society and NHS Sickle

Cell & Thalassaemia Screening Programme. Attendees gave very positive feedback of how useful and informative the event had been.

Project 2 – Contribute to articles in 'Nursing Times' as part of an SCT Counselling Skills and Knowledge Manuscript Task and Finish Group

SCS /UKTS are part of an SCT Counselling Skills and Knowledge Manuscript Task and Finish Group currently writing articles on the 'Counselling Competences' which is to be submitted to the 'Nursing Times'. The Societies are also writing blogs on how the Competences will impact their service users.

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 have contributed their expertise and service user viewpoint to the revision of the Screening Programme's 2016 E-Learning Resource used to train health professionals, which is getting a complete overhaul. Included will be new videos recorded by the Societies which have taken on board the work SCS and UKTS are doing with users and this will specifically help the Screening Programme address inequalities that might arise due to culture, religion etc.

Project 4 – Provide service user perspective on the reporting methods used to deliver newborn carrier results

SCS /UKTS are conducting focus groups which will give valuable service user feedback on: 1) the reporting methods used to deliver newborn sickle cell carrier result 2) the methods used to deliver new-born positive (i.e., baby has the condition) screening results for sickle cell and thalassaemia. Each Society will hold three focus groups (mothers, fathers and pre-conception). To date SCS has held a focus group with ten mothers of children with sickle cell and UKTS have held a focus group with three mothers. Recruitment for the remaining focus groups discussions with fathers and preconception people at risk are currently taking place and this evaluation of reporting methods is expected to be completed in the first half of Year 4.

Project 5 – Raise awareness of SCT and Screening through increased online presence, specific social media campaigns and dissemination of screening awareness posters

In Year 3, the Societies have continued to raise awareness of screening issues using their various social media and other platforms such as their newsletters and websites. Special screening graphics were designed for World Sickle Cell/Thalassaemia Days and Rare Disease Day and the dissemination of the screening posters have continued both online and hard copy deliveries to hospitals, health centres, GP practices and other health care settings.

Project 6 – Review Screening NHS SCT Screening Programme newborn carrier leaflets and Alpha Thalassaemia leaflet

SCS / UKTS reviewed and gave feedback on the Screening Programme's newborn carrier leaflets which are now on the GOV.UK website. UKTS also gave feedback on the now completed Alpha Thalassaemia leaflet produced as an HTML document.

Project 7 – Produce Year 4 Workplan

The Screening Programme has proposed some new work for Year 4 and discussed this with the Societies and at a Project Advisory Group meeting. The workplan might include review of newborn screening 'declines', a video of 'Society Stories' and a review of NHS SCT Screening Programme Standards. Work will continue on the E-Learning Resource and the focus group consultations on reporting methods used to deliver newborn carrier results.

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 flexibly within their respective communities and by adapting a culturally sensitive perspective, gain trust and generate useful insights from their service users, able to inform policy and practice. This collaboration ensures the Screening Programme provides a service that is underpinned by the needs of its users. Even as the COVID-19 pandemic continues, project partners continue to adapt to the restrictions imposed, adjust work accordingly such that the Societies still provided valuable input to the Programme's service specification. Through their website, newsletters and social media posts the Societies are able to reach thousands of families affected by sickle cell and other stakeholders as demonstrated by social media figures later in this report.

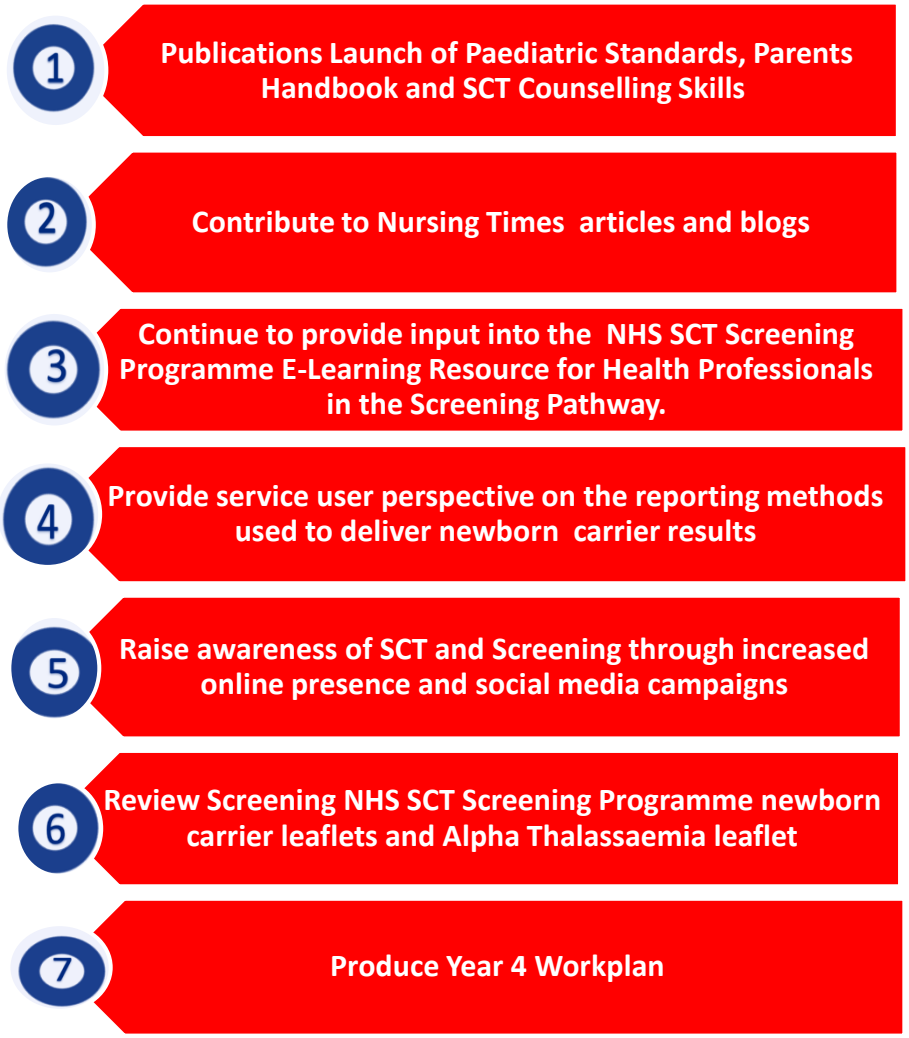
Purpose of Document

This document is a report on progress made in the third 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 2020 to 31 July 2021. It is an abridged report as standard information already in previous reports has been omitted or shortened.

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 past collaborative work was demonstrated by the publication of 'Parent Stories' which documented personal experiences of the NHS SCT Screening Programme (https://www.sicklecellsociety.org/resource/parents-stories/).

Year 3 Aims and Objectives

The current contract specifies that there will be four main projects each year. The main projects for Year 3 (1 August 2020 - 31st July 2021) follow, in addition to work such as the publications launch carried over to the early part of Year 3. Outreach work is also included throughout the contract.



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 meetings on 12 November 2020 and 20 May 2021.

Project Advisory Group –and Project Monitoring

The Societies also facilitate and attend Project Advisory Group (PAG) meetings (usually 4 times a year). These meetings provide monitoring and evaluation of the project to ensure timely achievement of the outputs and targets. Members of the group also approve the project work streams and deliverables each year. In Year 3, meetings were held on 14 October 2020, 20 January 2021, 14 April 2021 and 7 July 2021. Membership of the group changed during Year 3 due to retirements (Brigid Keane, Professor Simon Dyson, and Moira Dick) and new members (Dr Maria Berghs, Louise Smith, Rowena Clayton and Patricia Connell). We thank Brigid, Simon and Moira for their invaluable contribution to the group and wish them good luck in their retirement. At the end of Year 3, Dr. Elizabeth Dormandy who has chaired the PAG meetings since their inception stepped down as chair. We thank her for her stewardship and invaluable contribution to the group and wish her all the best as she steps down as a group member. For full details of PAG membership please see **Appendix 2.**

In addition to the PAG meetings, SCS /UKTS meet with NHS SCT Screening Programme quarterly to review work progress using a milestone tracker to monitor what is being delivered. SCS /UKTS also attend and give updates to the biannual NHS SCT Screening Programme Advisory Group meetings.

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 3.

Project 1 – Publication and launch of Sickle Cell Disease in Childhood: Standards and Recommendations for Clinical Care', 'A Parent's Guide to Managing Sickle Cell Disease' and SCT Counselling Skills and Knowledge

Over 250 people from around the UK attended an online event on Thursday, 28th January 2021 hosted by Public Health England to launch new editions of sickle cell and thalassaemia publications produced as part of this collaborative project between the Screening Programme and the Societies. The publications were:

'A Parent's Guide to Managing Sickle Cell Disease' (4th Edition) –' Parents Handbook'

'Sickle Cell Disease in Childhood: Standards and Recommendations for Clinical Care' (3rd Edition) which has a full document and an 'Executive Summary' - 'Paediatric Standards'

'Sickle Cell & Thalassaemia Counselling, Knowledge & Skills Guidelines' (2020) – 'Counselling Competences'

The Paediatric Standards and Parents Handbook are available to download from the Sickle Cell Society website and the majority of printed hard copies are being distributed via the Haemoglobinopathy Coordinating Centres (HCC). The Counselling Competences are available on GOV.UK website:

https://www.sicklecellsociety.org/resource/parentsguide/
https://www.sicklecellsociety.org/resource/paediatricstandardsresource/
https://www.gov.uk/government/publications/sickle-cell-and-thalassaemia-counselling-knowledge-and-skills

The event was chaired by Dame Elizabeth Anionwu, a founder and current patron of the Sickle Cell Society. Presentations were given on the above publications as well as on the new Sickle Cell and Thalassaemia Laboratory Handbook and Screening Programme information leaflets. Two service users Laurel Brumant and Roanna Maharaj gave insightful talks on living with sickle cell and thalassaemia respectively.

Below is feedback from some of the attendees, which encapsulates this first PHE online publications launch:

"Thank you everyone , been very useful and informative. This way maybe new and different, but this platform allows us to take part much easier than attending".

"Great informative afternoon-well done all. Thanks very much. Patient experiences very powerful".
"Many thanks for a very useful session. it will enhance my work with our families".

Project 2 – Contribute to articles in 'Nursing Times' as part of an SCT Counselling Skills and Knowledge Manuscript Task and Finish Group

SCS /UKTS are part of an SCT Counselling Skills and Knowledge Manuscript Task and Finish Group currently writing articles on the 'Counselling Competences' which are to be submitted to the 'Nursing Times'. SCS / UKTS were allocated to contribute information on: The relevance of screening and testing to patient care, the wider family and future generations, the global prevalence of both conditions and the gaps in healthcare provision for Black, Asian and Minority Ethnic (BAME) groups. Additionally, SCS and UKTS were also asked to write blogs on the work and experiences of living with the relevant conditions. UKTS submitted their draft blog to PHE for review in May to ensure it fits the ask from the Societies. Potential title of one of the Nursing Times article is: *'(Defining/Refining) the knowledge and skills required for high quality sickle cell and thalassaemia counselling services'* and that of the blogs might be: *'Lived experience of parents and individuals with thalassaemia / sickle cell'.*

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 have contributed their expertise and service user viewpoint to the revision of the Screening Programme's 2016 E-Learning Resource used to train health professionals, which is getting a complete overhaul. Throughout April 2020 - June 2021, SCS /UKTS/ NHS SCT Screening Programme have had online Zoom meetings 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

On 17 June 2021 the Societies filmed face-to-face interviews on their work with service users as well as their experiences with those who had used the screening pathway. These interviews will be edited for the E-learning resource such that they show the Screening Programme by working with the Sickle Cell Society and UK Thalassaemia Societies are addressing inequalities that might arise due to culture, stigma, language, religion, as the Societies can feedback the individual user needs which the Programme cannot access, since they have no direct relationship with service users. The film will also include some of the outreach the Societies do on behalf of the Screening Programme and will probably be called 'Society Stories'.

UKTS, SCS and Screening Programme socially- distanced photocall at E-Learning filming

Project 4 – Provide service user perspective on the reporting methods used to deliver newborn carrier results

SCS /UKTS are conducting focus groups which will give valuable service user feedback on: 1) the reporting methods used to deliver newborn sickle cell carrier result 2) the methods used to deliver new-born positive (i.e., baby has the condition) screening results for sickle cell and thalassaemia (See **Appendix 3** for sample focus group programme). Each Society will hold three focus groups: two each with mothers and fathers whose children are under three years old and one each with pre-conception individuals who might be at risk of having a child with the conditions. To date SCS has held a focus group with 10 mothers of children with sickle cell and UKTS has held a focus group with 3 mothers. Recruitment for the remaining focus discussion groups is currently taking place. However, recruitment particularly for UKTS has been difficult due to the pandemic and people's availability. Identifying fathers is also proving difficult. Additionally, UKTS found that parents with recently diagnosed children were less willing to participate due to how stressful their children's new lives were and learning how to cope. The Screening Programme, SCS and UKTS are to discuss publishing data and creating 'Parents Stories 2' based on the information obtained in the focus groups.

Project 5 – Raise awareness of SCT and Screening through increased online presence, specific social media campaigns and dissemination of screening awareness posters

Outreach 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. One major way the Societies spotlighted screening and raised awareness in Year 3 was by a UKTS special newsletter in October 2020 dedicated to screening which had comprehensive interviews with Amanda Hogan (Programme Manager) and Iyamide Thomas (SCS, NHS Engagement Lead) on the work they do with the Screening Programme. Iyamide subsequently updated her interview for the SCS Spring 2021 newsletter. The Societies continued their remote outreach work in Year 3 using their various social media and other platforms such as

newsletters, websites and broadcast media. SCS increased their outreach during October 2020 Black History Month and both Societies did awareness campaigns for World Sickle Cell / Thalassaemia Days, Rare Disease Day and the inaugural International Neonatal Screening Day of 28th June. UKTS disseminated hard copies of the screening posters produced at the end of Year 2 to every centre in the UK treating both sickle cell and thalassaemia, whilst SCS have so far disseminated the PDF posters online.

28th February was Rare Disease Day (RDD) and SCS /UKTS did much outreach to celebrate this. The SCS designed special graphics as part of their RDD campaign including a special one on screening. Additionally, Iyamide took part in a 'speed-dating' presentation event by Royal Holloway College which involved rotated 7 minute talks to 7 schools. The Screening awareness posters and other resources were also sent to be posted on Royal Holloway College's RDD website.

In celebration of Rare Disease Month of February, UKTS joined forces with 19 Branches of Santander in Kent to raise awareness of both conditions. Every day in the month of February posters (new), leaflets and other literature was handed out to members of the public in the region of Kent (serving a population of 1 million people). Employees of each branch, walked to raise awareness and money for thalassaemia and shared their achievements with their friends and family on their respective social media platforms. UKTS has since contacted other companies and institutions to extend this level of awareness to their employees, clients, and the greater community.

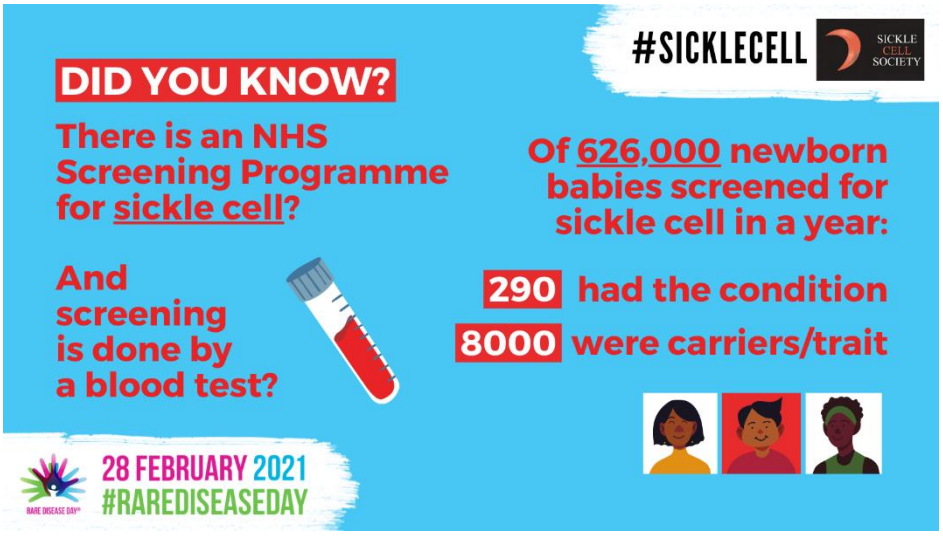
In March 2021- June 2021, UKTS ran their second annual global art competition which encouraged people from age 3 and above to enter. This year's theme was on blood donation, DNA, genetics, and thalassaemia in campaign to raise awareness. UKTS received 654 entries from 54 countries. Entries contained the inheritance patterns of thalassaemia and genetic conditions, why screening was beneficial and what life with thalassaemia is like. This can be view on their website. UKTS launched their redesigned and rewritten website in May 2021. The new website includes a more user-friendly template with headings such as 'new diagnosis', 'new parents', 'where to go', 'genetic counselling', 'where to get help', in addition to information about the entire screening pathway. The new website is a modern approach to access education and information and is still a work in progress.

19th June was World Sickle Cell Day and the SCS used its various platforms (E-newsletter, social and broadcast media) to raise awareness of sickle cell and screening. In particular, Iyamide did a screening presentation on YouTube and Facebook Live. The SCS had a 'Wear Something Red' campaign to raise awareness of sickle cell and amongst its media pack included graphics specifically with screening statistics.

Friends show support

Nurses at Brent Sickle Cell & Thalassaemia Centre

Sickle Cell Society specially designed graphics to raise awareness of sickle cell and screening:

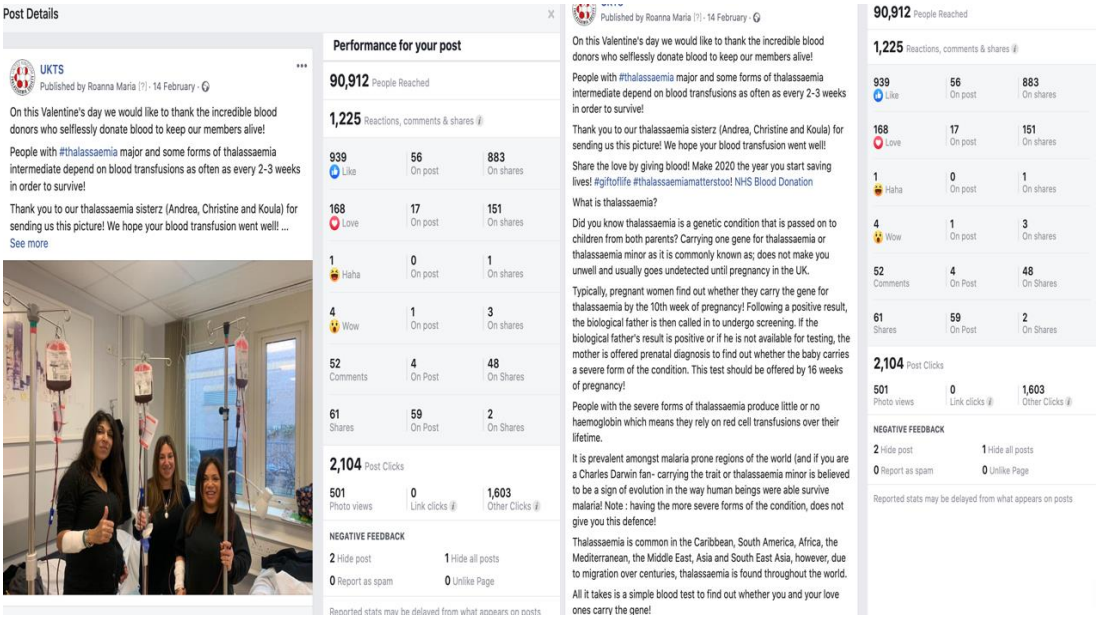


Did You Know that 28th June is
International Newborn Screening Day?

- There is a UK NHS Screening Programme that tests newborn babies for sickle cell using a heel-prick blood test.
- In 2018/19 approximately 626,000 newborn babies were screened for sickle cell disease
- 1 in 2100 of these babies tested positive for sickle cell
- 1 in 79 babies were 'carriers' or 'trait'
- Each year approximately 300 babies are born with sickle cell disease
- If parents-to-be are both carriers there is a 25% chance at each pregnancy their baby will have sickle cell.

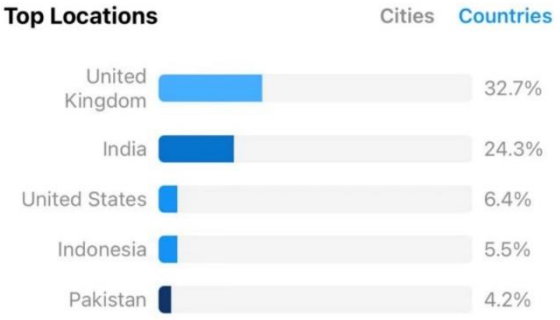
The impact of Social Media

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) with regards to early screening can be seen below.

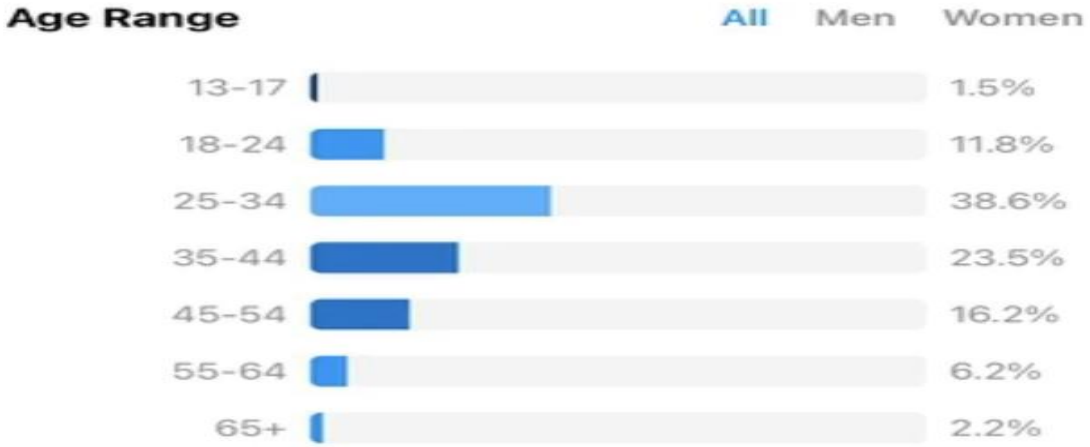


The charts below show the cumulative data obtained by the UKTS across the 3-social media platform with regards to posts targeting the screening agendas.

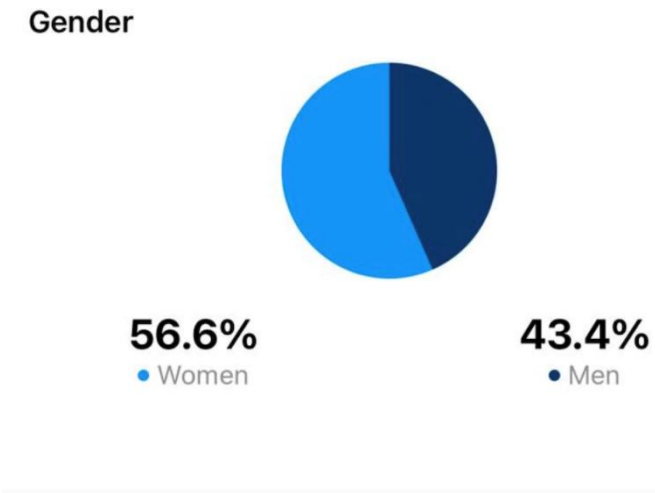
Bar Graph 1- Showing UKTS cumulative data of top countries who viewed posts with regards to the screening agenda.



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

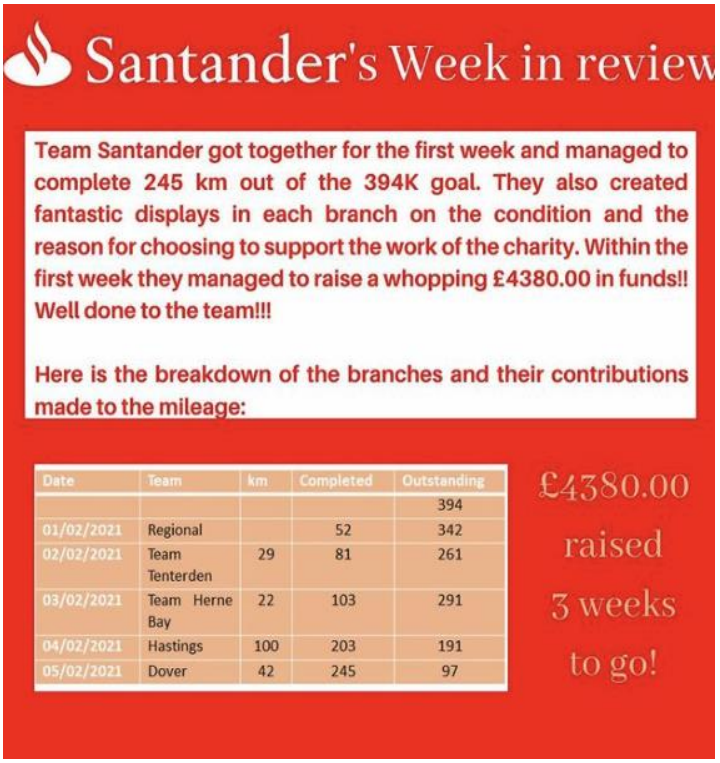


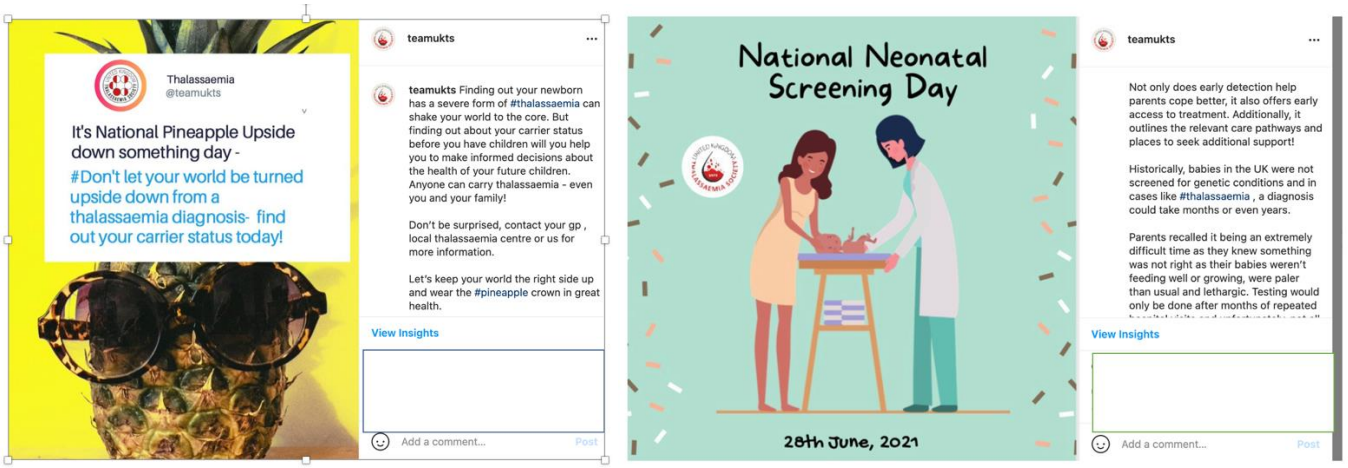
Pie Chart Showing UKTS the percentage of men and women who viewed posts with regards to the screening agenda.



There has been an increase in views by men from 39 % in 2019-2020 to 43.4 % over 2020 - 2021.

Some UKTS Screening related posts





Project 6 – Review Screening NHS SCT Screening Programme newborn carrier leaflets and Alpha Thalassaemia leaflet

SCS / UKTS reviewed and gave feedback on the Screening Programme's newborn carrier leaflets which are now on the GOV.UK website.

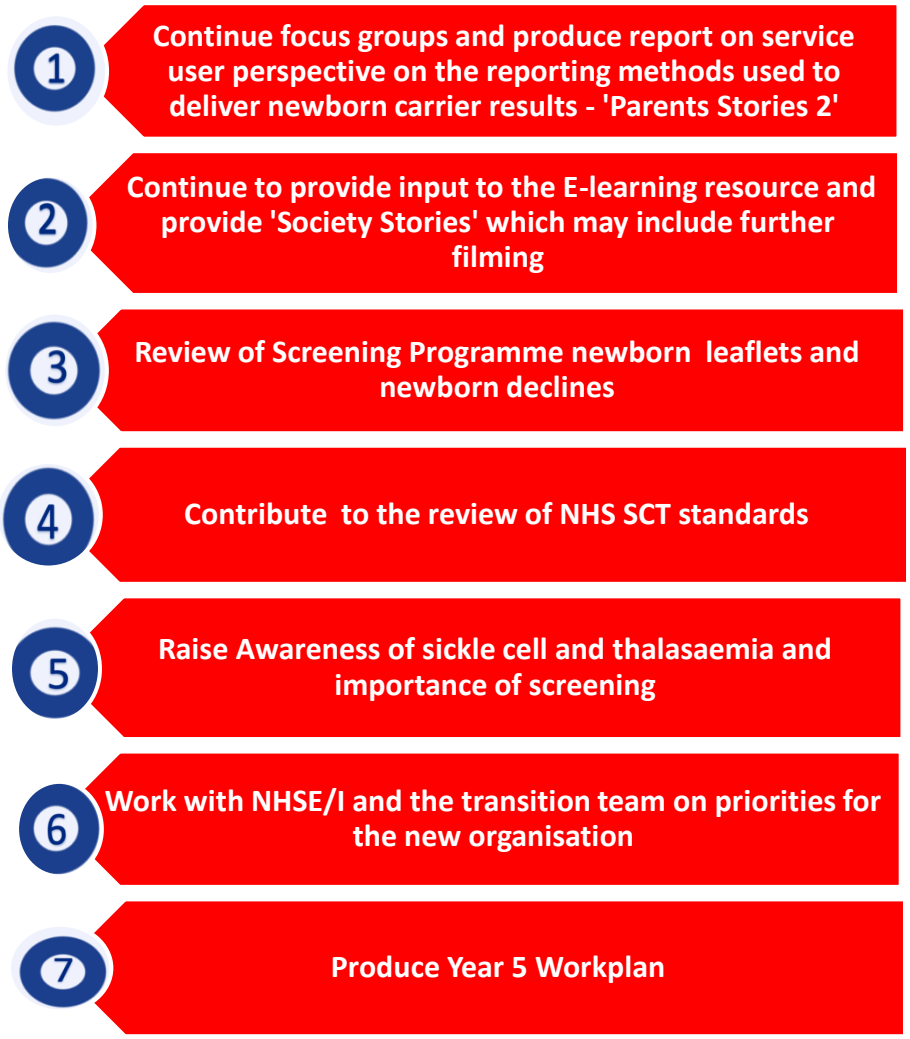
UKTS have reviewed and sent feedback on the alpha thalassaemia leaflets that were given to parents by health care professionals. Following this, the need to update the beta thalassaemia was also identified and UKTS sent their comments into NHS SCT Screening Programme for review. One of the interesting things noted was that both leaflets did not explain what the severe forms of thalassaemia was, it mainly described what being a carrier was but the implications on pregnancy was not so easily articulated. Subsequently, both leaflets were updated and sent to UKTS for feedback. UKTS returned feedback and is waiting to view finalised versions.

UKTS also pointed out the need to translate the leaflets into other languages as they were being contacted by members of the public and health care professionals for an increase in Arabic, Tagalog, Romanian, Farsi and Indonesian. A list of languages required was sent to NHS SCT Screening Programme

Project 7 – Produce Year 4 Workplan

The Screening Programme has proposed some new work for Year 4 and discussed this at a Project Advisory Group and also at a separate meeting with the Societies on 22 July 2021. The proposed workplan is shown below.

Year 4 Workplan



Part of Year 4 will also involve implementing the findings from Year 3.

Discussion

Once again, the benefits of collaborative working between the Screening Programme and the Sickle Cell and UK Thalassaemia Societies (which represent users of the service) has been shown in this Year 3 report. The Screening Programme by working with the Sickle Cell Society and UK Thalassaemia Societies are addressing inequalities that might arise in their service provision due to culture, religion and language barriers. The Societies can feedback on the individual user needs, which the Programme cannot access, since they have no direct relationship with the service users. This will ultimately help the Programme improve its service provision e.g., review of the E-Learning resource for health professionals where the 'Societies Stories' module will be invaluable. The Societies have also shown value for money in delivering Year 3 of this collaborative project. (**Appendix 4**). The continuing COVID-19 pandemic brought its challenges as the Societies and Screening Programme continued 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. (**Appendix 1**). For the first time Public Health England and the Societies held a virtual publications launch, which was attended by over 250 people from around the UK. Other work streams that would have involved face-to-face contact, such as the service user focus groups on newborn screening results were also conducted online and the uptake for the first of these meetings was very good (e.g., 10 of the invited 12 mums of children with sickle cell attended). The Societies and Screening Programme continued to hold virtual meetings to discuss the work streams. Meetings were also held with Project Advisory Group members (Professor Karl Atkin, University of York and Dr Maria Berghs, De Montfort University, Leicester) who input their expertise into the organisation and management of focus group discussions. Filming of the two Societies took place face-to-face and the 'Societies Stories' film will show the Screening Programme 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. These 'Societies Stories' can help the Programme's work on redressing inequalities and can be part of the Screening Programme's future 5 year plan.

The Societies continued to conduct general engagement and outreach among both health professionals and the communities most at risk using online platforms, social media 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. The valuable feedback from the focus groups on newborn screening conducted so far will help the Programme adapt its service which we hope will 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.

As we commence Year 4 we will continue producing a 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.

Learning from Year 3

The most important learning from Year 3 continues to be the fact of how a project can adapt to unexpected changes such as a COVID-19 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 is considerate to user needs. Some other learning that has come from Year 3 is the difficulty of recruiting thalassaemia service users for participation in focus groups to do with newborn screening since annual births are much smaller compared to sickle cell. Recruiting fathers for both sickle cell and thalassaemia can also be problematic. As such, timelines for focus groups should allow for these delays. Another learning has been the length of time it takes communicating and getting responses from Haemoglobinopathy Coordinating Centres (HCC) Clinical Leads which ultimately caused delays in the printing and dissemination of the Parents Handbook and Paediatric Standards since dissemination was to be through them. However, updated PDF versions of both publications were available from the Sickle Cell Society website.

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

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

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

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

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

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

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

Shared Learning

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

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

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

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

The projects have been categorised into three sections:

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

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

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

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

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

	Project	Status	Details
Not able to restore (but maintained within the Societies' workplan, suspended until further notice)			
1.	Outreach (Face to face)	Suspended	All face-to-face contact have been delayed until it is safer to do so. However, UKTS ran some face to face awareness campaigns with 19 Satander branches in the region of Kent for the entirety of the month of February.
2.	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)			
4.	Electronic Child Health Record (ECHR) Project: Service user perspective on the methods used to deliver new-born screening for sickle cell and thalassaemia	Affected	**Status moved from Suspended as work has commenced.** Study scoping and design has been completed. There has been a delay due to recruitment. SCS conducted first focus group in June 2021 UKTS will caryr out their first focus group on 3 July, 2021 – see workplan for more details.

	Fully restore service- (Completed/ Unaffected)		
5.	Paediatric Standards	Completed	Launched virtually on 28/01/21 with the Paediatric Standards, Parents Handbook and Counselling Competences. Hardcopy printing of full Standards and Parents Handbook delayed until dissemination confirmed. Updated versions now on SCS website.
6.	Parents Handbook	Completed	Launched virtually on 28/01/21 with the Paediatric Standards, Parents Handbook and Counselling Competences. Hardcopy printing of full Standards and Parents Handbook delayed until dissemination confirmed.
7.	Counselling Competencies	Completed	Launched virtually on 28/01/21. Links posted to relevant websites.
8.	Awareness Posters	Completed	UKTS has distributed posters to 61 units treating Thalassaemia and SCD and to GP practices in the local area. In addition, UKTS sent posters to 19 Santander branches for an awareness campaign. UKTS awaiting confirmation from SCS re: distribution to their HQ.
9.	Alpha thalassaemia leaflet	Unaffected	PHE is finalising document to make it more accessible (language, html ready etc.) See workplan for more detail. Deadline TBC
10.	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.
11.	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. One module is yet to be discussed. Filming for Society's corner took place on 17 June, 2021.

Appendix 2

Membership of Project Advisory Group (PAG) in Year 3	
Chair : Dr.Elizabeth Dormandy	Public Health & Screening Advisor, Advisor to the Sickle Cell Society,
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
Teresa Choudhary	National Co-ordinator, UKTS
Rowena Clayton	Screening Lead (Retired) , West Midlands, PHE
Dr. Patricia Connell	Finance and Business Manager, PHE
Dr. Moira Dick**	Retired Consultant Paediatrician and Medical Advisor to Sickle Cell Society
Prof. Simon Dyson**	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
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
Louise Smith	SCT Clinical Nurse Specialist, Alder Hey Hospital, Liverpool
Iyamide Thomas	NHS Engagement Lead, Sickle Cell Society

**Retired from group prior to last meeting on 7 July 2021.

Appendix 3

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

Sickle Cell Focus Group with Mothers on Communicating SCT NBS Results
12.00pm – 1.30pm, Saturday 12th June 2021

11:50 – 12:00pm **Registration and Entry into Zoom Room**
12:00 – 12:15 **Welcome and Introductions** – Iyamide Thomas
Iyamide (IT) will introduce herself and Dr. Maria Berghs and say what the day is all about and how grateful we are for participants to be here to give their feedback (good and bad) of how their babies SCT NBS results were communicated. **IT** will then remind people of confidential recording and some ground rules to respect what each participant says, use 'raise hand' feature etc. **IT** to ask each participant to use a maximum of 1 minute or less to tell us about themselves – first name, age of baby, whether baby is trait /condition and if they knew (or know) if they themselves were carriers. Ethnic origin, religion?

12:15 – 12:40 (Approx. 25 minutes)

Staff Communication

Antenatal Screening

- **Did you go for antenatal screening /counselling and if so do you think you were given enough information on sickle cell and the various options available to you? E.g. partner testing, PND**.
- What was your general experience of antenatal screening /counselling? E.g. Was it timely or delayed by the pandemic etc?

Newborn Screening

- **How did you get your baby's test results? – (phone, visit, letter)**
- **When did you get your baby's result? – (SCT 08 < 28 days)**
- How soon after your baby's SCD test result was s/he followed up at a paediatric / haematology clinic? (SCT 09 < 90 days)

- **Which health professional gave you your result?**
- **Did the health professional communicate the results to you in a satisfactory and professional way, one you understood, answering any questions you had?**
- Is there anyone who you would have preferred to give you your result?
- **What information were you given apart from your newborn baby's results? (e.g. leaflet, online resources, patient organisations)**
- Did you find any of the information useful and if so which?
- Did you seek information from any other source and if so where? (e.g. the internet, church pastor, sickle cell organisations)

12:40 – 13:05 (Approx. 25 minutes)

Improvements to Communication of Results

- **What communication worked well and what did not?**
- How would you prefer to receive sickle cell information including newborn screening results? (e.g. In person, online, hardcopy, Whatsapp, Email etc)
- Do you have a Smartphone and / or a computer?
- **What support would be important after receiving your baby's carrier or full-blown SCD results? (e.g. From diagnosis to first consultant visit and beyond)**

13:05 – 13:20 (Approx. 15 minutes)

Impact of Baby's Diagnosis on participants, family and friends

- Do you feel that you had suitable information to communicate the test result to your wider family?
- Which family members is it important to communicate with? (e.g. within extended family network)
- Is there anyone else that you think should know if your baby has the condition? (e.g. Nursery or sitter, grandparents?

13:20 – 13:30pm (Approx. 10 minutes)

Discussion Summary - Maria Berghs / Iyamide

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

The 8 questions in bold should be asked in every focus group so comparisons can be made.

Appendix 4

Finance Report

Sickle Cell Society

PHE -Sickle Cell and Thalassaemia Screening Programme Contract 2018/21
Year 3 Finance Report August 2020 to July 2021

Introduction

This report provides a summary of income and expenditure related to the third year of actual income & expenditure for the contract for the SC&T Outreach Project covering 12 months from 01 August 2020 to 31 July 2021. The annual operating budget for the contract covering both Sickle Cell Society (SCS) as lead organisation and UK Thalassaemia Society (UKTS) is £124,916.

Third year of the contract - from August 2020 to July 2021 - £124,916

- SCS £80,224
- UKTS £44,691

August 2020 to 31 July 2021

Total allocated income for this period Aug 20 – July 21 is £124,916, plus underspend from Year 2 £5,500, total income for this period £130,416. Total expenditure for the period was £120,831.
The project ended month 12 of the third year with an underspend of £9,585.

Commentary

At the end of July 2021, which represents 12 months of the third year, the project has a surplus of £9,585.

John James OBE
CEO - SCS

Notes Page