Report name: Project Board Advisory Group Annual Report 15 January 2020

Agenda Item No:		**Paper No:**	

Purpose of Report:
Sickle Cell and Thalassaemia Screening Programme – Year one 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 15 August 2018 to 31st August 2019.

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: **First 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**

15 August 2018 – 31 August 2019

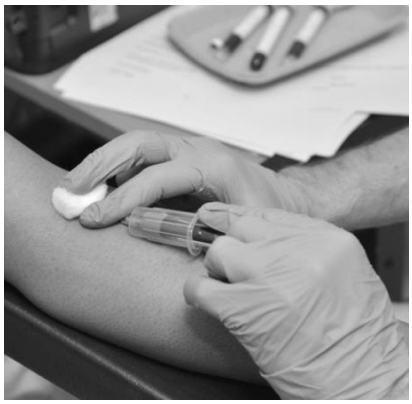


Table of Contents

Executive Summary	4-7
Purpose of Document	8
Background	8
Sickle Cell & Thalassaemia Screening Programme -Overview	10
Year 1 Project Overview Rationale Aims & Objectives Project Advisory Group Membership	11 12 12 14
Project Plan	15-22
Project Monitoring	22
Discussion	23-24
Appendix 1- Focus Group presentation on Paediatric Standards	25-26
Appendix 2 – Service user feedback on Paediatric Standards	27-30
Appendix 3- Outreach and other Activities undertaken by Sickle Cell Society and UK Thalassaemia Society	31-34
Appendix 4 – Feedback on Posters	35-38
Appendix 5 – Year 1 Finance Report	39
Appendix 6– UK Thalassaemia All Party Parliamentary Group	40
Appendix 7 – UKTS Patients and New Parents Education Day agenda	41-42
Appendix 8 –Sheffield Patient Education Day	43
Appendix 9 – Photo Gallery	44

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 (NHSSCTSP) 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 NHSSCTSP in the first year of a collaborative project commissioned by the Programme for the period 15th August 2018 to 31 August 2019.

The Societies were tasked with addressing and supporting Screening Programme challenges highlighted in recent trends and performance data. These challenges include:

- regional variation in early offer of antenatal sickle cell and thalassaemia screening test by 10 weeks 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

Four projects were identified for year 1 as follows:

- Review and update publication 'Sickle cell disease in childhood: standards and guidelines for clinical care'.
- Support the Newborn Outcomes (NBO) System (in development) which will automate the collection of outcome data and link to the NHR.
- Implement the findings from the previous year (i.e. 2017 -18) by supporting actions and recommendations from 'Parents Stories' – personal experiences of sickle cell and thalassaemia screening.
- Define a year 2 work-plan.

Project 1

The SCS formed a Standards Working Group (SWG) which produced and consulted on various drafts of an updated 'Sickle cell disease in childhood: standards and guidelines for clinical care' publication and this feedback is currently being incorporated in the final publication. A final PDF version of the publication will be put on the SCS website by end of November 2019 as well as widely shared to numerous stakeholders. Hard copies of the publication will be launched in early 2020. The Project Advisory Group (PAG) earlier decided that the 'Sickle cell disease in childhood: standards and guidelines for clinical care' publication should remain focused on the clinical management of sickle cell and that an update of the existing 'Parent's Guide to Managing Sickle Cell Disease' ('Parent's Handbook') should be produced to include the wider determinants of health relevant to living with sickle cell. Some of this work on the 'Parent's Handbook' has commenced in year 1 to produce the updated edition in April 2020.

Project 2

SCS and UKTS have supported NBO system by using their extensive networks to raise awareness and help improve families understanding and trust for the use of their data. This has been over 29 events including health professional talks, parent support groups and Patient Education Days, as shown in Appendix 3. The Societies have also educated parents on the importance of prophylaxis penicillin and getting their affected babies into timely paediatric care. Additionally, service users have been informed about registration on the NHR and the role this will subsequently play in improving commissioning and targeting of resources. The UKTS were explicitly tasked with revising and making the existing NHR patient information leaflet more user-friendly. A draft leaflet has been produced and piloted among service users and another focus group to obtain more user feedback is planned for year 2.

Project 3

In addition to the NOS, the Societies have used extensive outreach to raise awareness to the public and health professionals of the findings and recommendations from the 'Parents' Stories' (See Appendix 3 for more detail). The public has been urged to present early in pregnancy and made aware they can go directly to the nurse specialist at Sickle Cell & Thalassaemia Centres or hospital maternity units. Screening providers are also urged to provide this direct access, particularly for known 'at –risk' couples.

Project 4

A work plan for year 2 has been agreed and includes the production of a new edition of the 'Parents' Handbook' and providing the service user perspective on the 1) new update of the sickle cell and thalassaemia counselling competencies and 2) on the reporting methods used to deliver newborn sickle cell carrier results.

Conclusion

This project has once again demonstrated 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.

Purpose of Document

This document is a report on the first year of a collaborative project between the Sickle Cell Society (SCS), the UK Thalassaemia Society (UKTS) and the NHS Sickle Cell and Thalassaemia Screening Programme from 15 August 2018 to 31 August 2019.

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.

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. It should be noted that this figure is old and no accurate data is available (K. Maxwell & A. Streetly- 'Living with Sickle Pain' 1997.).

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, 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 concern throughout the Mediterranean, Middle East, the

[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.

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 carry a gene for sickle cell or thalassaemia. If the mother is found to be a carrier, screening is offered to the father. The woman must be offered sickle cell and thalassaemia (SCT) screening early, within 10 weeks of her pregnancy.

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. 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 in which the SCS and UKTS won with a proposal to explore the reasons for variation in performance by screening providers and find ways to improve performance which is driven by service user needs. Iyamide Thomas from the Sickle Cell Society (lead organisation on the project) and Romaine Maharaj from

[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]

UK Thalassaemia Society were tasked to deliver this new tender expected to last a period of 3 to5 years.

The Sickle Cell and Thalassaemia Screening Programme –an overview

The NHS Sickle Cell and Thalassaemia Screening Programme is a linked antenatal and new-born genetic Screening Programme that identifies people who are carriers for sickle cell, thalassaemia and other haemoglobin disorders and babies with a haemoglobin disorder. The 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 offer screening to:

- all pregnant women
- fathers-to-be, where antenatal screening shows the mother is a genetic carrier
- all new-born babies (for sickle cell as part of the New-born Blood Spot Screening Programme)

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 NHSSCTSP 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 new-born screen positive results to parents

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

Year 1 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 which 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
- the 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
- the timeliness of prenatal diagnosis (PND) was 40% which is below the acceptable standard (50%)

The new-born 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 panning 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 and ways to improve performance.

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

- raising public and professional awareness of the screening pathway and the new resources
- ensuring that parents and patients understand the benefits of NHR registration and are assured that information is kept strictly confidential
- raising public and professional awareness about how data is held in the new-born outcome system and develop resources to improve enrolment into care and adherence to treatment – particularly penicillin prophylaxis and immunisation programmes
- undergoing engagement work to build upon the success of past outreach work and use this to inform projects to address screening service issues with views and feedback from the public and relevant health professionals.

Project Aims and Objectives

The current tender specifies that there will be 4 projects each year. The 4 projects for year 1 (15th August 2018 to the 31st August 2019) were identified as follows:

1. Review /update 'Sickle cell disease in childhood: standards and guidelines for clinical care'. Review and update of 'a parents guide to managing sickle cell'
2. Support newborn outcome systems
3. Implement findings from previous year by supporting 'parents' stories' actions and recommendations.
4. Produce Year 2 work plan

Publications relating to the project

In addition to the 4 projects each year, the SCS and UKTS will attend Programme Advisory Group meetings (usually 2 per year) and other sub-committee / Advisory groups as required. It was decided that a Project Advisory Group (PAG) would be formed to provide monitoring and evaluation of the project to ensure timely achievement of the outputs and targets. Members of the group also approve the project workstreams and deliverables each year.

Project Advisory Group

Table 1 – 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
Oddy Cooper	Trustee, UK Thalassaemia Society
Cathy Coppinger	Programme Manager, NHS SCT Screening Programme (Retired from Post July 2019)
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 (Commenced post August 2019)
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	Co-opted Member UK Thalassaemia Society
Romaine Maharaj	Executive Director, UK Thalassaemia Society
Jamili Miah	Project Lead - NHS Sickle and Thalassaemia Screening Programme
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

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 1 (15 August 2018 -31 August 2019).

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. Revised Timescale: By November 2019)

On 30 October 2018 the SCS held a meeting with various stakeholders including the Clinical Leads writing the Standards, representatives from the Programme and NHS England and a sickle cell service user to define and finalise the scope of the updated Paediatric Standards.

Agreed time line and process from this meeting were:

- a decision was made for the scope of the Standards to mainly focus on the clinical management of sickle cell across acute, primary and community care.
- the SCS would investigate the possibility of updating the current 'Parent's Guide to managing sickle cell disease' to include the wider determinants of health relevant to living with sickle cell (e.g. education, housing)
- the SCS would recruit a Medical Writer for proof-reading, formatting and reference checking the Standards
- Dr Moira Dick and Professor David Reese confirmed as the principal writers and will circulate the first draft to a Peer Review Group and other clinicians for comment

The SCS subsequently convened a Standards Working Group (SWG) of relevant health professionals as indicated in the Programme project specification e.g. UK Haemoglobinopathy Forum, Sickle Cell & Thalassaemia Association of Nurses, Midwives and Allied Professionals (STANMAP) tasked with producing the final document of the Standards which would have undergone peer review and consultation by relevant stakeholders, including health professionals and sickle cell service users. The SWG was chaired by Dr Moira Dick and held its first meeting on 3 May 2019.

Key outputs / outcomes from the SWG were:

- first draft of 'Standards' section was sent for 3-week consultation to health professionals and other stakeholders such as UK Haemoglobinopathy Forum, STANMAP, NHS England and British Society for Haematology, NHR (26 February – 22 March 2019)
- the SWG reviewed the latest Standards draft prepared by the Medical Writer which incorporated consultation feedback and replaced 'guidelines' with 'recommendations' in the publication title as this was deemed a better description.

- a 3-week online consultation on the 'Recommendations' for health professionals and other stakeholders was conducted and ended on 5 July. Over 30 responses received.
- a focus group consultation on Standards and Recommendations with 10 sickle cell service users was held in London on 13 July. (See Appendix 1 and 2 for further information)
- an online consultation on 'Standards' and 'Recommendations' targeted at service users was held ending 12 August. 16 responses received with 8 from outside London.
- the Medical Writer made changes to the document to incorporate consultation feedback

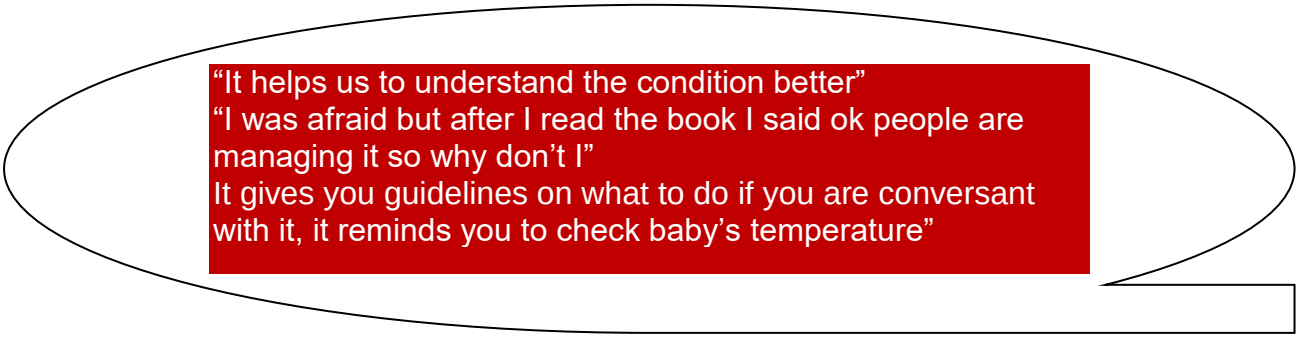
The final *'Sickle Cell Disease in Childhood: Standards and Recommendations for Clinical Care'* publication will initially go on the Sickle Cell Society website as a PDF document by mid-November after which hard copies will be printed for a launch in early 2020.

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

(Responsibility: Sickle Cell Society. Timescale: By April 2020)

At the meeting held in October 2018 to define and finalise the scope of the Paediatric Standards it was decided that as an alternative to broadening the Standards to include the wider determinants of health relevant to living with sickle cell, the SCS should investigate the feasibility of revising and updating the existing 'A Parent's Guide to Managing Sickle Cell Disease' ('Parents' Handbook). The updated publication should include feedback from parents of children and young people with sickle cell. This led to 'Project 1B' being added as a year 1 objective. The Project Advisory Group subsequently carried over production of the Parents' Handbook to April 2020 as part of a year 2 work-plan since there had just been a reprint of the current edition and other objectives in year 1 took priority. However, the following outputs were achieved in year 1:

- the SCS investigated and concluded there was enough in the budget to reproduce an updated Parents' Handbook.
- A writing group was formed which included members of the previous editorial team of Dr. Lola Oni, Joan Walters, Prof. David Rees and Iyamide Thomas. Additional members include paediatrician Dr Olu Wilkey (who replaces Dr Moira Dick) and nurse specialist Nicolette Petrou.
- the writing group held its first meeting on 28 May 2019.
- A new questionnaire has been developed after discussion by the writing group and a pilot among a group of parents and this will shortly be used to obtain wider feedback from parents. Below is some parents' feedback from the initial pilot:



Project 2 – Supporting Newborn Outcome (NBO) Systems

(Responsibility: Sickle Cell Society and UK Thalassaemia Society. Timescale: By end of year 1 and ongoing to year 2)

The SCS and UKTS have supported the Screening Programme in implementation of the NBO system. The system is an automated system that supports the referral of babies diagnosed with sickle cell or thalassaemia into treatment. The Societies were tasked with using their various networks to raise public awareness of all the relevant NBO system issues such as the 3-month pathway into care, penicillin prophylaxis and immunisation, especially in high-risk communities.
(Appendix 3 shows the outreach activities that the SCS and UKTS have carried out to raise such awareness).

The NBO also links into the National Haemoglobinopathy Registry (NHR), a confidential database comprising of people living with sickle cell disease and those living with a moderate to severe form of thalassaemia in England. The SCS and UKTS has and will continue to educate those living with or affected by sickle cell anaemia and thalassaemia on the benefits of enrolling into NHR and how their personal data will help commissioners to plan better services around their care.

In year 1, the UKTS were specifically tasked with revising the existing NHR Patient information leaflets/ posters to make them more user-friendly.

The following has been achieved by the UKTS thus far:

- draft of new screening posters was presented to Project Advisory Group (PAG) for review in April and July 2019
- drafts of revised NHR leaflets and posters were presented to Project Advisory Group for review in April and July
- revised literature was then sent to a graphic designer at Public Health England who gave an insight into fonts and wording. The edited version of the poster and leaflet were then sent to the NHR which yielded a positive and favourable response.

- UKTS then facilitated a focus group discussion with 18 people to test posters on members of the public (See Appendix 4 for feedback on the posters). This feedback was then presented at the October PAG Meeting. The SCS has also planned to host a focus group in the coming months. (Posters will be finalised pending feedback from SCS.)
- the UKTS has created an ambassador programme which presently comprises of 32 regional leaders from a range of backgrounds including ethnic, cultural, religious, gender, age and sexual orientation. The main role of the ambassador programme is to increase the geographical reach of the UKTS in order to provide/ disseminate awareness, education, information and support to people with thalassaemia, their families and the general public within the regions. Additionally, ambassadors work closely with the UKTS to advise on upcoming programmes and campaigns to ensure inclusivity. All ambassadors required to undergo extensive training and one to one meetings and reflections with the programme lead before they represent the society. This is to ensure the UKTS' objectives, viewpoints are represented and upheld at all times. Subsequently, ambassadors are expected to attend regular meetings in order to keep abreast with the society's work and to provide regular feedback to the society within their regions. The ambassador programme is still growing.

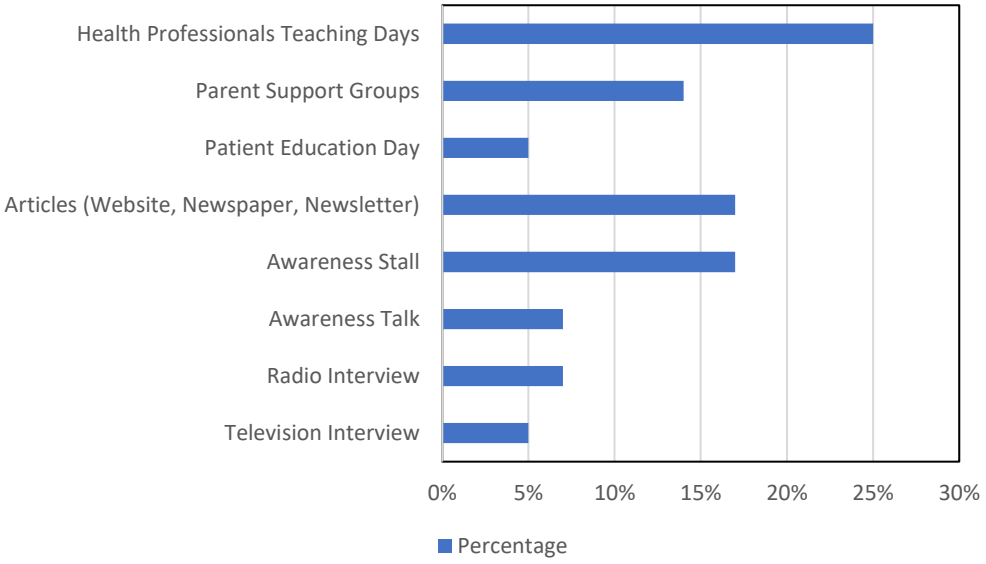
Project 3 – Implement findings from previous year by supporting the actions and recommendations from 'Parents' Stories'

(Responsibility: Sickle Cell Society and UK Thalassaemia Society. Timescale: By end of year 1)

For this workstream the SCS and UKTS have used their networks to raise awareness to the public and health professionals of recommendations from the 'Parents' Stories produced in the previous year. This included raising awareness of early presentation in pregnancy and direct access to specialist nurse counsellors and maternity services especially for known 'at-risk' couples. SCS and the UKTS hosted or took part in outreach events across the country. A table displaying a more detailed summary of the outreach activities and number of participants is included in Appendix 3.

Outreach Work

The bar chart below summarises the outreach work undertaken over year 1.



Bar graph 1: Showing outreach and awareness work undertaken by the Sickle Cell Society and the UK Thalassaemia Society between August 2018 to August 2019.

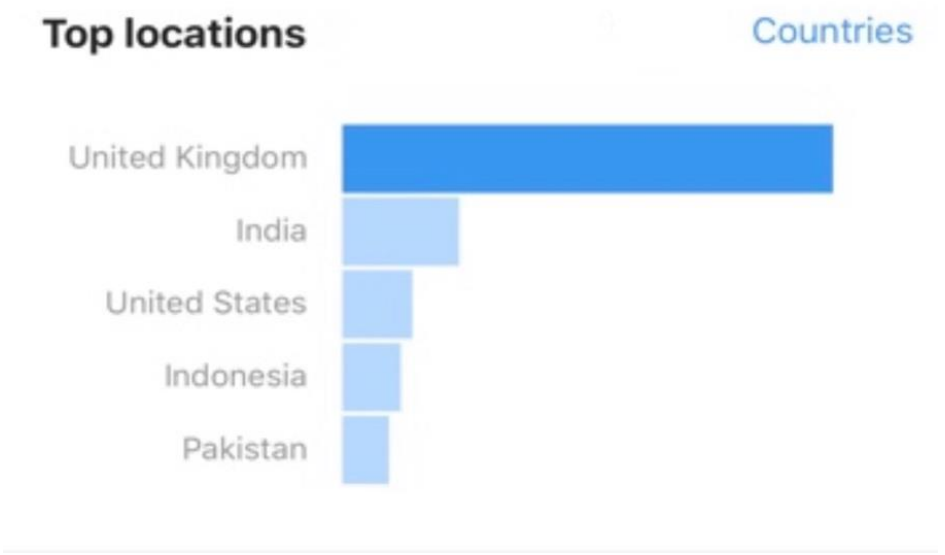
The impact of Social Media

As digital technology and the use of social media continues to rise amongst the younger population and the SCS and UKTS have used this medium to raise much needed awareness by having regular social media posts on Facebook, Twitter and Instagram that targets activities outlined in the project such as:

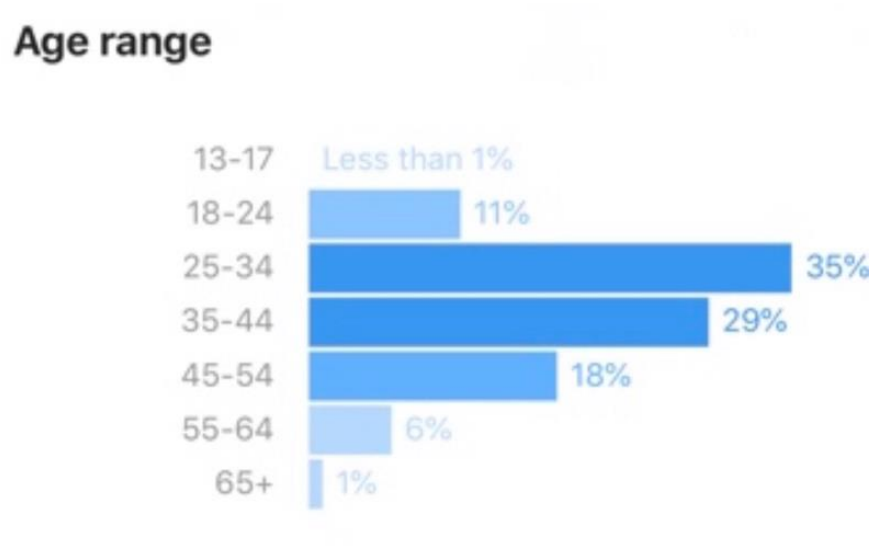
- the importance of early screening in pregnancy
- the importance of new-born testing
- the importance having patients enrolled unto the NHR

An Example of a Facebook post (including number of times post was viewed and shared) with regards to early screening is seen below.

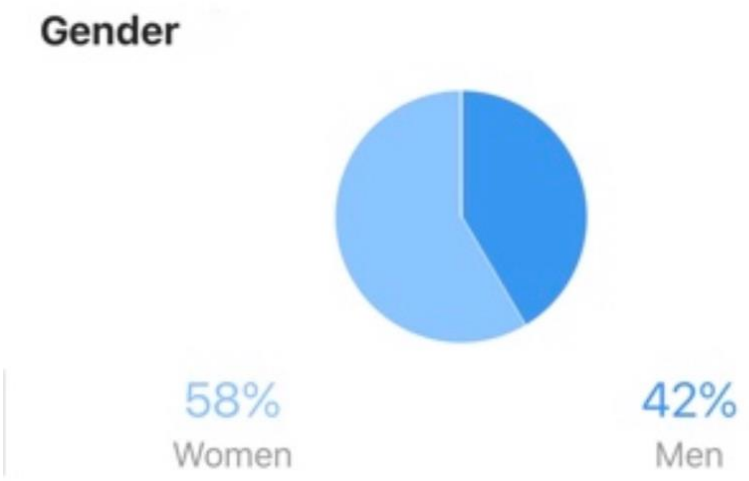
The charts below show the cumulative data obtained by the UKTS across the 3-social media platform with regards to posts targeting the screening agendas.



Bar Graph 2- Showing UKTS cumulative data of top countries who viewed posts with regards to a screening and NHR agenda.



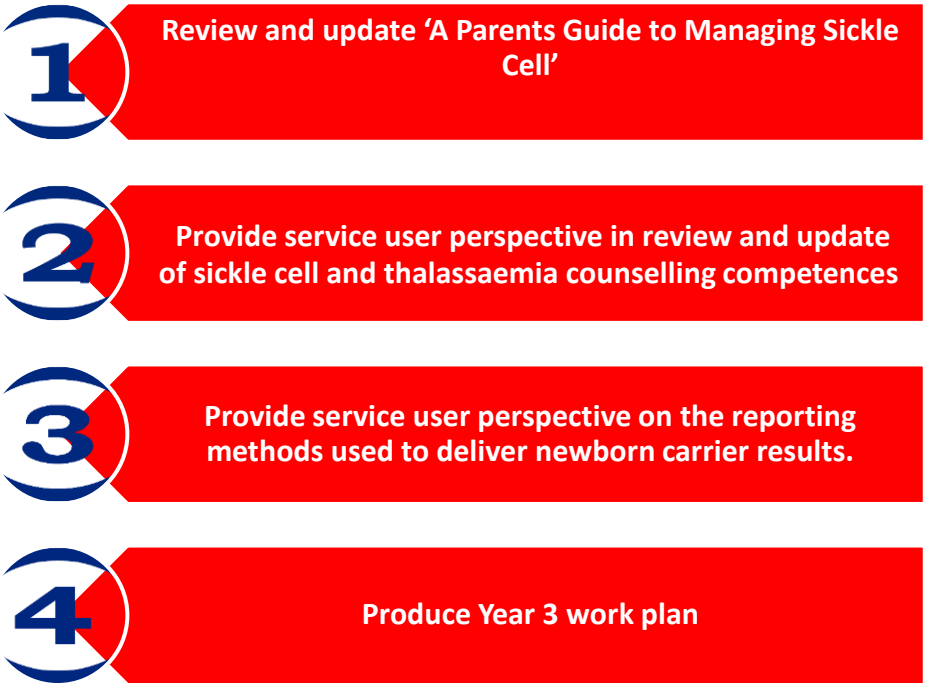
Bar Graph 3- Showing UKTS cumulative data of percentages of age ranges of people who viewed posts with regards to a screening and NHR agenda.



Pie Chart 1- Showing UKTS the percentage of men and women who viewed posts with regards to a screening and NHR agenda.

PROJECT 4: PRODUCE YEAR 2 WORKPLAN

The 4 projects for year 2 have been identified and proposed as follows:



Part of year 2 will also involve implementing the findings from the previous year, including the continuation of the work on the Newborn Outcomes (NBO) System with the dissemination of the new NHR patient information literature. The SCS and UKTS have worked with the NHSSCTSP to develop a detailed project plan linked to the Programme objectives for 19 /20.

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. The first Project Advisory Group (PAG) meeting was held on 19th September 2018 where the chair and membership were confirmed. The 4-year 1 project areas were defined, and the draft work plan agreed. Subsequent PAG meetings were held on 18th January 2019, 9th April and 8 July 2019
- **monitoring and evaluation:** SCS/UKTS performance review meetings with the Programme – 3 monthly

- The Programme has designed a milestone tracker to monitor what is being delivered before the release of each quarter's payment. SCS and UKTS completed the first such tracker backdated to the start of the contract

Discussion

In year 1 of the project, we have once again demonstrated the benefits of collaborative working between the Screening Programme 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 a valuable resource for health care professionals as they can work very flexibly within their respective communities and from a culturally sensitive perspective, thus gaining trust and depth of information from their service users. This provides assurance to NHSSCTSP that work streams are informed by the user perspective. The value of service user engagement was demonstrated during consultation on the:

- paediatric standards both online and focus groups
- parent's guide
- NHR posters and leaflets

Apart from the 4 specific projects of year 1, general engagement and outreach were also deemed essential to ensure that screening service provision continues to be underpinned by service user needs. The 2 Societies have been able to do a lot of outreach throughout the year among both health professionals and the communities most at risk. The UKTS have 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 among users of the screening service so they too can be more proactive and ask for screening, prenatal diagnosis, newborn results and follow-up care if these are not being provided promptly. In turn, we hope this will impact positively on the relevant Programme's Screening Standards.

The Societies have also shown value for money in delivering year 1 of this collaborative project. (See Appendix 5 finance report).

As we commence year 2 and the four projects identified, the Societies' will ensure the publication and dissemination of the Paediatric Standards (which was the key project from year 1) is a priority since this publication was last updated in 2010 and this new edition updates clinical recommendations in several key areas and emphasises the importance of collecting data and measuring outcomes against robust standards. The NHR posters will also be disseminated (as part of 'implementing recommendations from the previous year' which is usually one of the year's 4 projects).

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 any future advisory groups, projects or consultations and look forward to this continuing collaboration.

Learning from Year One

It is good to reflect on any learning from year 1 that will inform how the Societies and the Programme progress with year 2. One central aspect of helping improve the uptake of online consultations (particularly in the case of service users) is to extend the usual 3-week consultation period and continuously send reminders using social media avenues. The online forms should also be made 'Smartphone' friendly to enable better access. This learning will be used for any user consultations planned in Year 2 such as the online feedback on the Parent's Guide to Managing Sickle Cell Disease.

The Societies acknowledge that they were not able to complete project 1a (paediatric standards) which was clearly identified as a priority in the contract specification. Main reason for not delivering this objective within the 1-year time frame was due to staff illness. Going forward, the Societies will be careful that realistic timescales are set and that more staff are involved with each project so that cover is available in case of sickness.

Acknowledgement

The Sickle Cell Society and UK thalassaemia Society would like to thank the NHS Sickle Cell & Thalassaemia Screening Programme for their openness and willingness to work collaboratively with the voluntary sector to ensure the service user's voice is heard. Both 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.

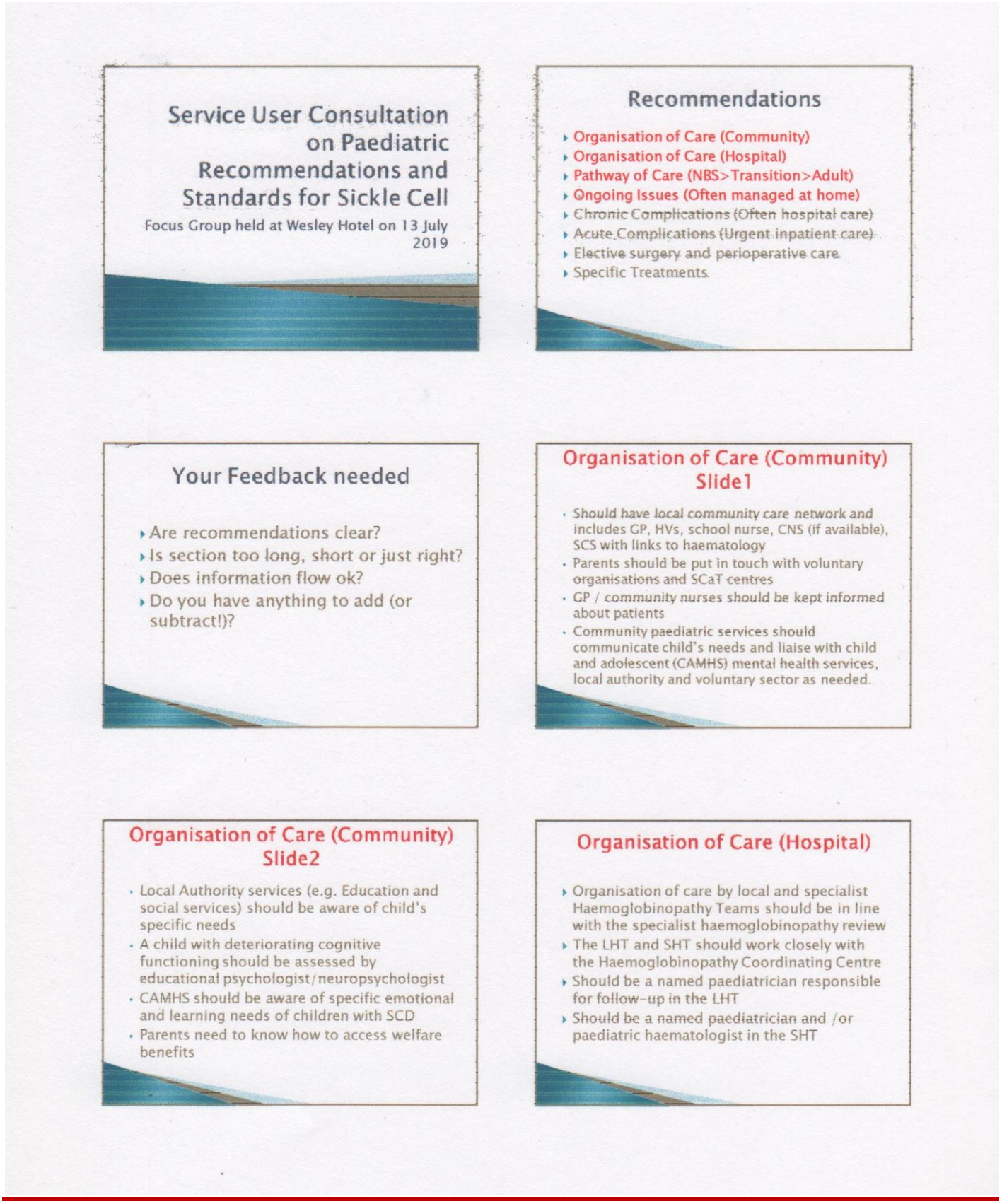
Iyamide Thomas
NHS Engagement Lead, Sickle Cell Society

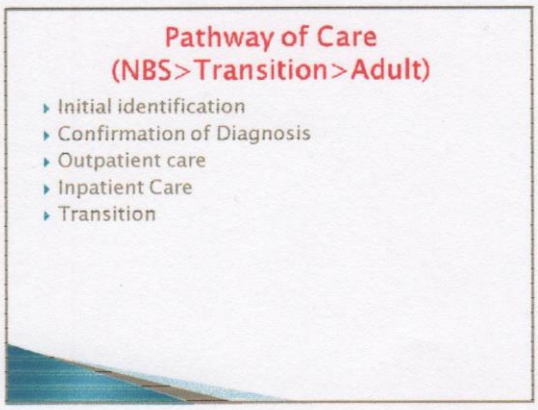
Romaine Maharaj
Executive Director, UK Thalassaemia Society

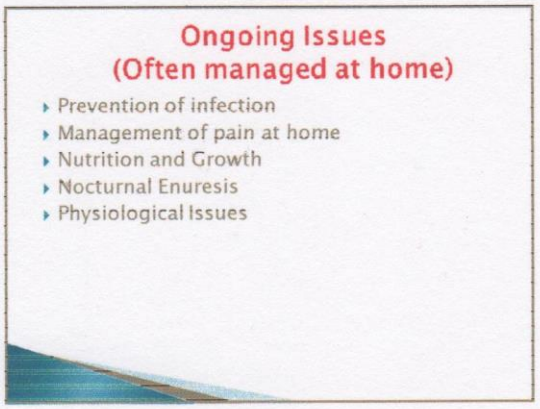
November 2019

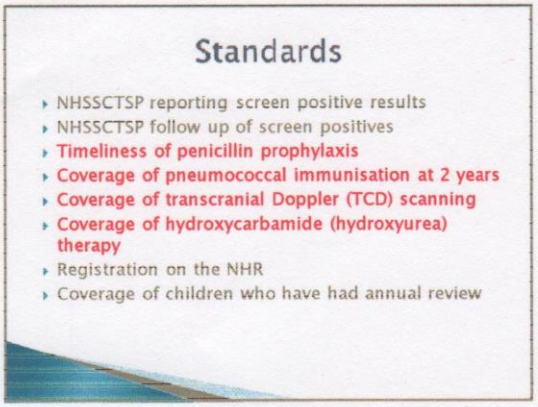
Appendices

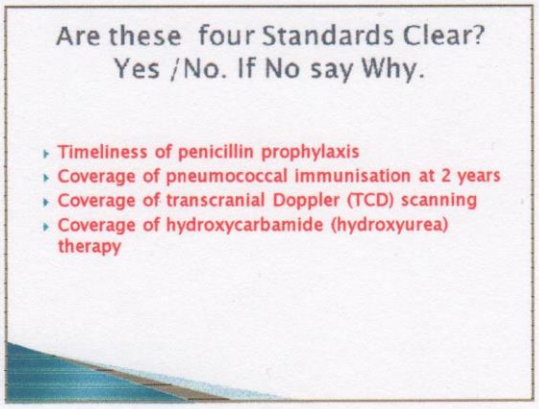
Appendix 1: Focus Group presentation on Paediatric Standards

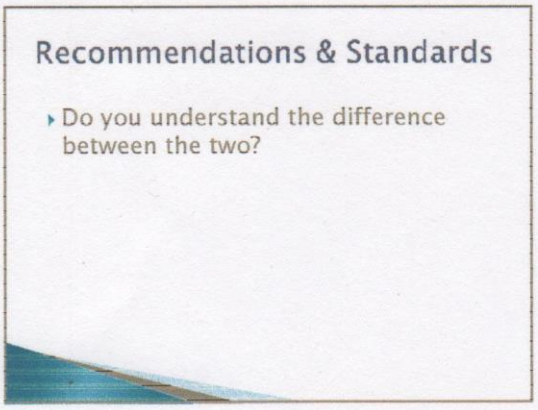



Pathway of Care
(NBS>Transition>Adult)
Initial identification
Confirmation of Diagnosis
Outpatient care
Inpatient Care
Transition


Ongoing Issues
(Often managed at home)
Prevention of infection
Management of pain at home
Nutrition and Growth
Nocturnal Enuresis
Physiological Issues


Standards
NHSSCTSP reporting screen positive results
NHSSCTSP follow up of screen positives
Timeliness of penicillin prophylaxis
Coverage of pneumococcal immunisation at 2 years
Coverage of transcranial Doppler (TCD) scanning
Coverage of hydroxycarbamide (hydroxyurea) therapy
Registration on the NHR
Coverage of children who have had annual review


Are these four Standards Clear?
Yes /No. If No say Why.
Timeliness of penicillin prophylaxis
Coverage of pneumococcal immunisation at 2 years
Coverage of transcranial Doppler (TCD) scanning
Coverage of hydroxycarbamide (hydroxyurea) therapy


Recommendations & Standards
Do you understand the difference between the two?

Appendix 2

Service User Feedback on Paediatric Standards

Ten parents attended a Sickle Cell Society focus group held on 13 July 2019 to give their feedback on relevant parts of the draft document '*Sickle Cell in Childhood-Standards and Recommendations for Clinical Care'*. They had been sent the document in advance and the Executive Summary was also distributed to each parent on the day. Overall the parents felt it was a much needed publication and were pleased that it spelt out certain aspects of care (e.g. cognitive functioning, nutrition and growth) which some of their children had issues with. However, some parents were concerned that the existence of such a document did not guarantee the recommendations would be followed and asked how this was to be monitored. Below are excerpts from the discussion which shows some of the issues parents were concerned about or aware of in relation to organisation of care of their children with sickle cell. Items in red are the Standards and Recommendations discussed. (Thanks go to Dr. Maria Berghs, Lecturer in Health & Wellbeing in Society, Social Study of Thalassaemia and Sickle Cell Unit, De Montfort University who helped record the focus group discussion)

Organisation of care – community

Discussion on availability of sickle cell & thalassaemia centres

Iyamide Thomas (**IT**): "How many of you have access to a sickle cell and thalassemia centre as there isn't one everywhere"?
(It is noted that only 4 out of the 10 participants who have access to specialist Sickle Cell and Thalassaemia Centres.)
Mother A: *"*Well, I would not say that we have a centre, it's just for everything. We have a section, and have our community nurse in there. It is not like in London. But where we were before, it was just sickle cell and then I think regional funding….That is in Essex not far from Brentwood*"*.
Mother D: *"*I have not used the sickle cell community services, where I live they have the sickle cell services but because I usually go all the way to King's College for my care I was not included in my local area*"*.

Discussion on Local Authority Services e.g. education, social services, educational psychologists

Mother E: "The point being raised about the local authorities is a good one. Many of the local authorities are not linked up to the GPs or the local schools. What I am trying to say is that they might have to give them the responsibility. For example, in terms of cognitive functioning I had to push for my daughter's test to be done, only because, when I teach her she does not retain it enough and I was a bit worried and I had to push for that. If parents are not made aware of this, they would not know. I did not know it was one of the requirements that would be accepted here*"*.

Parents were then asked if they think it is important to have their children assessed for cognitive functioning.

Mother E: *"*If it is made a requirement, they should put an age at which this test should be done. And from that they could say, every parent, it is your responsibility or the sickle cell nurse or someone".
Mother E: "Just as the clinician would recommend immunisations such as pneumococcal vaccine, he should recommend assessments".

Welfare Benefits

Mother E: "The welfare benefit is it a new thing or has it always been in the Standards? If it has always been there, we have not been aware of it".
Mother C: "Sometimes we are also discouraged from it. It feels as if it's okay but then when your child goes into hospital that's when it is serious and you might need extra benefit and taking time off work. Oh, now I am struggling to pay this".
Mother E: "Well, I was only told about this last year because we were in and out of hospital, in fact because I am a teacher as well, I had to resign and I only do part time voluntary as an accountant So I was asked to apply for welfare benefit. I applied for it and I was rejected".
Mother E: "They gave me someone to fill the forms for us. In fact the first thing that he says to us, and I think that is the stereotype. He came to my office and I had to go to the car to get something and he said, "Oh, I don't think you are getting it." That is a stereotype. You do not know whether it is my mom that gave me the car. You do not know anything about it. I don't know what he filled in my form, I did not get it".
Mother A: "It does not matter what you fill out on that form or how much you earn. Its tax free and it has nothing to do with your money or how rich you are".
Father A: "You have to focus on the child who is sick and then they are talking clinical language and they throw all these terminologies at you but if there is an advocate who understand these things and who could go to a school and say where is the care plan for this child. They could go to local authorities and say where are the special educational needs for this child? They could go to all these other services which we are talking about and then they could speak for every parent who is going through the same journey as what we have gone through. But ten years ago there was nothing, nothing! We had to fight all the way. What (name) is talking about is true. I had to resign from my job".
Mother F: "The point is that you as a parent or as a support group have to fight for the advocate. How do you do that? By coming together, by having the support groups, writing to your MPs and telling them that you need an advocate. It is not just enough to be here. About 15 years ago we were fighting, we had the support group and we were the ones that wrote a letter to the chairperson at Guys and St Thomas', we got the child psychologist there. He is still there tomorrow because the position was going to be cancelled after a year or two years. I wrote, I signed the letter, we fought as a support group it is not enough for us to just sit". "If you want to have a voice, you have to come together. We have to join in unity. We cannot just sit and say we need an advocate, we have to fight. We have to fight for the standards. I am calling for us to stand united and have that voice".

Organisation of Care – hospital

Pathway of care (from newborn screening to transition to adult care)

IT: Introduces the newborn outcomes system and explains this is being trialled. Every child diagnosed will be on an electronic pathway and their treatment recorded. If diagnosed the child should be seen by a clinician within 3 months, and should go on the National Haemoglobinopathy Registry (NHR). **IT** asks the group who had children on the register and half the group said their children were on it.

Mother E: "They should give the choice when you do the screening, when you get the first diagnosis say we want them to go straight on the register now. That is what they are trying to do".
Mother B: "Sometimes it can happen in the clinics. Mine happened when I was in the clinic".
IT: states that the sickle cell and thalassaemia centres can do it too. They can put people on the registry.
Mother E: Yes you get a card.

Mother B: Yes, you get a card like a credit card. When you are part of the register, they give you a card. They say whether you have SC or SS.
Mother E: "When I am travelling, I just put it in the bag. Like when I went to Spain and my daughter was sick, I had the card".

Inpatient care

Mother F: "The chest crisis used to be frequent over time so I had to find other ways of managing it without the visits to hospital because she was scared of hospitals. I read it here as one of the things included. I was waiting to get to that point".
Father B: "Can I just ask, with the penicillin, there are some kids that are allergic to penicillin. So, in my case, my child was allergic to penicillin and I had to fight again for him to be moved on to a different antibiotic".

Ongoing issues

IT discusses prevention of infections [Parents say this is very Important], standards and compliance and if you run out of medication health can be compromised. Long wait between prescriptions so negotiate so you can get enough prescriptions from the pharmacies. [Page 10]

Mother D: "For my child, we get it in a powder form for like a month and then I just call and renew it".

Inpatient care and Transition

Mother F: "There should be an accessible transition policy in place. I am at d) Inpatient care and where it says a key support worker should be in place. It says that they should start the progression at the early age of 13 to 14. Is that the transition period"?
Mother F: "The diabetes people are already complaining about how bad the transition is. The children cannot really manage it and when you go into the adult side you are on your own. It's quite a lot so that is why I am a little bit interested that is it is 13 to 14. My daughter is 14 and I needed to know when I should start to prepare".
Mother E: "Some will start at 15 and some at 16. Every child is unique. At times they can delay it until the child is 18".

Management of pain at home
Management of pain at home including complementary treatment are suggested in the document.

Mother F: "When I read this, it is really good. I think they need to push complementary stuff. I have used it a lot. I used the massage and it worked a lot".
Mother A: "They have always talked about massage a lot. Dr. Kofie Anie was the one who talked about that".
Mother D: "Who should be telling me which coping strategies to use when she is at home"?
Mother G: "Your paediatric doctor maybe"?
Mother D: "Normally what they say is penicillin and ibuprofen around the clock".
Mother G: " In our case it was our paediatric doctor, who we see twice a year, who will tell you what works and then you find your feet…is it a heat pad, massage, oils. You will know yourself what works but they will generally tell you, try this or try that".
Mother D: "It's good that they are giving us non-medical options, normally they say it should be treated with Paracetamol. It's like they are giving that balance which is good".

Nutrition and growth

Mother F: "I am concerned with this because I have raised it several times. With my doctor, with my GP with the nurse, that she needs to be referred and she's 14 and she still has not been referred. She is growing but she is not growing the way she's expected, maturing the way she is supposed to. Her puberty and all those things have not started. So, I need to know who I go back to again. I am pushing a lot. I am really happy that something is in the Standards about nutrition and growth because I have been pushing for it".

Standard 5: Coverage of Transcranial Doppler (TCD) Scanning

IT: Mentions this is a new standard. They do this to monitor risk of stroke. Parents say they are familiar with it. **Mother F** says that they had this a long time ago. **IT** has to explain that it is now coming in as a standard. Parents say that this is very good.

Standard 6: Coverage of hydroxycarbamide (hydroxyurea) therapy

IT: Hydroxyurea is also a new Standard and health professionals need to document that they have had that conversation with the parents.

Mother B: "You just have that conversation but it is a choice".
Mother B: "What is the age from which you can begin giving hydroxyurea? It says acceptable for children over 9 months and then over 2 to be determined? Is that just for the discussion? What is the other one about when they should give it"?
Mother A: "You can have it before age 2, I have a parent in my support group and have a young child and they have started giving it to the child".

Standard 8: Coverage of children who have had an annual review.

IT asked how many of parents go to the annual review? All say they take their children to annual review.

Mother A: "So, what I am going to say is yes, we have all these things on paper but actually in reality people don't actually have all this information and how do you ensure adherence to all this"?
Mother B: "That is always the question. You have all these things on paper how do you ensure it is monitored"?

IT explains that the Standards and Recommendations will be available on the Sickle Cell Society and other websites for anyone to access and it will also be printed so parents have a hard copy they can consult and use. Peer reviews will help monitor the measurable Standards.

Appendix 3

Year 1 Outreach and other activities undertaken by Sickle Cell Society and UK Thalassaemia Society

Dates	Activity and Feedback	No of Participants
9 October, 2018	Sickle Cell Society (SCS) did a Black History Month talk in Liverpool to Home Office BME Network and discussed sickle cell, screening and Parents Stories. Two sessions carried out (am /pm) to different staff. Very well received and good Q&A. Promise made to fundraise on Society's behalf.	~40 per session
18 October 2018	United Kingdom Thalassaemia Society (UKTS) awareness event with NHS Blood and Transplant (NHSBT) at Ernst &Young where leaflets and parent stories were distributed.	~150
22-23 October, 2018	UKTS hosted an awareness booth 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.	~150 visited stall
24 October, 2018	SCS / UKTS joint stall at ASCAT and disseminated Parent Stories. Recently updated Sickle Cell Adult Care Standards were in high demand as were other sickle cell and thalassaemia literature.	~50
26 October, 2018	SCS attended new parents' support group at SE London Sickle Cell & Thalassaemia Centre (SCaT) and also a Transition Workshop in Croydon SCaT and discussed National Haemoglobinopathy Registry (NHR), Entry into care, Newborn Outcomes System (NOS), Parents' Stories, Parents Handbook and Paediatric Standards. A few service users did not know about registration onto the NHR	10 in SE SCaT 6 in Croydon
29 October, 2018	SCS stall at Nursing Now event at St Thomas' Hospital targeted at health professionals. Discussed and distributed Parents' Stories.	~20 visited stall
31 October, 2018	SCS gave a Black History Month talk in Blackfriars to Home Office BME Network and discussed sickle cell, screening and Parents Stories.	25 participants
8 November 2018	SCS /UKTS at a Genetic Alliance UK workshop to develop a patient's charter on new-born screening. The workshop purpose was to engage patient group representatives in the newborn screening decision making process and the wider policy and technology context. We ensured that sickle cell and thalassaemia screening issues were discussed.	32
7 December, 2018	SCS attended Midwives workshop at Northwick Park Hospital and disseminated Parent Stories.	~40
12 January, 2019	UKTS conducted a focus group to get ideas for design and wording for screening posters and NHR posters	4

14 January, 2019	SCS / UKTS posted screening articles on the project on their respective websites	Website reach estimated as > 500
7 February, 2019	SCS awareness stall at NHSBT event held at City Hall attended by the London Mayor. Stall generated much interest from City Hall staff and politicians such as Helen Hayes MP for Dulwich and West Norwood and Neil Coyle MP in Southwark and, Florence Eshalomi, London Assembly member and Shaun Bailey, the Conservative Party's 2020 mayoral candidate	~30 visited stall
14 February, 2019	SCS website screening article: '*It's Valentine's Are You My Type*?' An article which raised awareness on sickle cell and in particular partner screening around Valentines.	Website reach estimated as > 500
21 February, 2019	SCS /UKTS joint presentation covering all aspects of the project given to the Sickle Cell and Thalassaemia Association of Nurses Midwives and Allied Professionals (STANMAP) Study Day. This was a good forum to let relevant health professionals know of the actions and recommendations from the Parent Stories which they need to take on board	~40
26 February, 2019	UKTS interviewed on London Greek Radio about thalassaemia within the Greek population and the need for carrier screening. Additionally information was also given on how to access information on screening for thalassaemia	
28 February, 2019	UKTS posted on their social media about why people needed to access screening for thalassaemia and on how to find out more about it.	~850
3 March, 2019	UKTS was interviewed by Hellenic TV about the importance of educating the younger Greek population of thalassaemia and early screening	~315
5 March, 2019	SCS attended Croydon parent and toddler support group and discussed Paediatric Standards & piloted Parents Handbook feedback questionnaire to several parents	10
19 March, 2019	UKTS in addition to Dr. Banu Kaya was interviewed by EURO GENC TV about the importance of early screening of thalassaemia within the Turkish and Turkish Cypriot Society.	218
23 March, 2019	SCS presented at South London Link parents' workshop and discussed NHR, NOS, Parents' Stories, Parents Guide and Paediatric Standards. Parents showed much interest in the forthcoming Paediatric Standards.	20
1 April, 2019	SCS published an article on the project in their spring newsletter covering recommendations from Parent Stories plus information on NHR and NOS.	Reach estimated as > 2000
5 April, 2019	UKTS attended the AGM & 20th anniversary of the Greek and Cypriot division (GCA) of the Metropolitan Police Service at the Cypriot High commission in London.	~120

15 April, 2019	SCS / UKTS attended Nursing and Midwifery Council (NMC) Roundtable to discuss new midwifery and nursing proficiency standards. We discussed relevant findings from the Parents' Stories.	10
17 April, 2019	UKTS visited the East Ham Sickle Cell & Thalassaemia Centre; awareness literature and parent's stories and a discussion about the possibility for future interaction between the centre and involvement in the screening programme.	~20
8 May, 2019	UKTS held a stall at the Whittington Hospital in Archway, North London UKTS launched APPG for thalassaemia in Parliament and spoke to 43 Members of Parliament (MP) about raising awareness of thalassaemia within their constituencies. (See Appendix 6 for MP list)	~100 ~50
17 May, 2019	UKTS attended the 6th Annual Charter celebration of the Lion's Club of Mercia in Coventry. At this event, UKTS gave an address about the lack of awareness of thalassaemia and the importance of early screening within Asian and South Asian communities.	300
25 May, 2019	UKTS hosted a patient awareness day at Birmingham City hospital. This included informing patients of the United Kingdom Thalassaemia Society involvement within the screening Programme; focusing on at risk communities and the importance of registering on the National Haemoglobinopathy Registry was reinforced. (See Appendix 7 for Agenda)	~150
31 May 2019	SCS attended a transition workshop in Croydon and raised awareness of National Haemoglobinopathy Registry and Paediatric Standards. Discussed with nurse specialist names of Croydon parents that could be contacted for Paediatric Standards service user consultation.	6
1 – 2 June 2019	UKTS hosted a booth at the Cypriot wine festival to raise awareness of the condition and give information on how to access screening.	~10,000
20 June, 2019	SCS interview on AYTV raising awareness of sickle cell and screening for World Sickle Cell Day.	>1000 viewership
21 June, 2019	SCS held a Patient Education Day in Sheffield and NHS England discussed the Haemoglobinopathy Review with attendees. (See Appendix 8 for Agenda)	TBC
22 June 2019	UKTS attended a new parent and patient support group with Leicestershire and South East of Leicester Sickle Cell and Thalassaemia service.- With regards to this contract, the UKTS discussed the role of NHR and why it was important to give consent and also answered questions regarding this.	~25
2 July, 2019	SCS gave a detailed one hour interview on OMEGA LIVE TV raising awareness of recommendations from Parents' Stories, NOS and NHR as well as many other issues on sickle cell. Interview is available here: https://www.youtube.com/watch?v=ERUYTzuIz2c	Video has received >3500 views

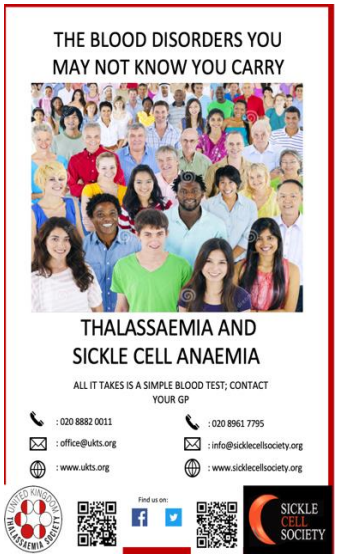
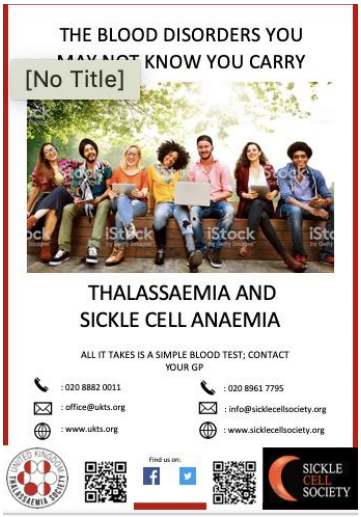
22 July, 2019	UKTS spoke about parent stories, NHR and patient experiences at the 3rd Annual Sickle Cell and Thalassaemia study day at King's College Hospital	~50
25 July, 2019	UKTS' new Patron Adil Ray OBE is interviewed on Parikiaki to raise awareness of thalassaemia and early screening in particular within the Asian and South East Asian communities.	-500
26 July, 2019	UKTS attended an Outreach day hosted by the haemoglobinopathy team at Queens Hospital in Romford. UKTS spoke to the haematology team about parent stories and the importance using of the NHR. The UKTS also had a stall at the event to give members of the public information about early screening in thalassaemia.	~150

Appendix 4

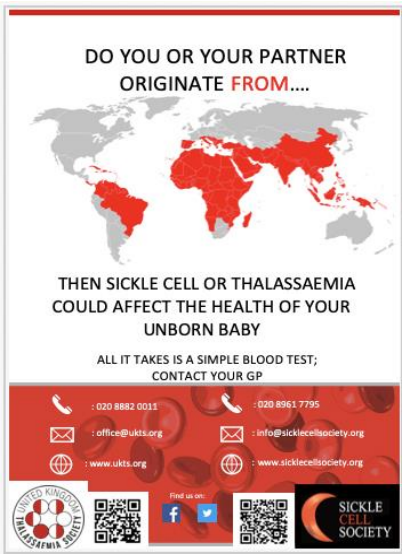
Feedback on Posters

The UKTS held a coffee morning to gain feedback on the posters created as part of the screening contract.

The coffee morning was attended by 18 people (female-16, male-2) all of whom did not have any prior knowledge of sickle cell or thalassaemia. The posters were printed on A3 sheets and distributed to everyone for their opinion. The table below summarises the feedback given.

Poster	Comments- Pros	Recommendations
	- I love the different generations in the picture - You should keep the bar codes-It gives it a professional / young people look and you are taking it seriously. - Use bolder font - Put border around picture -	- You should use a less crowded picture- something more eye-catching - There are nationalities that are not relevant - Why are there two sets of numbers? Can't there just be one? Do you need two? - Add Instagram - Think of the next step-get tested now! Be firm! -
	- I love this picture and the simplicity of the design - The wording is good but needs to be bolder and draw more attention - QR code -great idea! Very forward thinking! - Great picture!	- It doesn't give any indications of target or nationalities or symptoms - Do you need the email address? - The logos should be before the contact details - Add Instagram - One number and contact only - Can you put the logos over the contact info? - Target your audience so that they pay attention to the message- At

		University-Are you a carrier-free blood test - Headings should be bolder
Poster	**Comments- Pros**	**Recommendations**
	- I prefer this poster - I love this poster - The picture is great! - I think adults will like this image - Poster is easy to read - Poster is: Current, Ethnic, Appealing - Kids would like it - Keep the bar code! - This is good -less fussy - Nice picture with softer image-it is less scary than some GPs -	- -List of countries/ regions- were people may be from maybe? - Instagram-most young people use it - Organisation logo should be on top of contact details - Can you use less people but then make the people bigger? - Need shorter headings or something more catching/interesting - List of countries or a map! - It's a softer picture- need something scary or sick child?
	- This is a great heading! -map is a great idea- makes it engaging	-Can you also have a picture of a pregnant mother- with partner's hand over her belly? Mixed race? - too wordy- take all the wording off from wondering to what they would look like? Or learn to write English properly? - Contact us to find out more about it! -make "all it takes font" bigger. -can you use blue on the map instead of grey? -can you add regions names?

	-I really love this poster -using a map is a great idea - I prefer this poster - I like the red- it gets your attention	-Add regions e.g. South America etc. -blood cell theme in background -the health of unborn baby needs to stand out. -Could you be a carrier -use larger font
	-QR code is a great idea!	-at the first glance there is too much information -if you put the heading with a short interesting sentence, you can put the rest. -also instead of using three red colours, heading use one. -it needs to be eye catching -way too wordy -no grab -say something like we need your help-please register These are the benefits -how to register-tell your haem or doctor

General Comments

1) Have a common theme/ branding/ look to identify this as a campaign / message.

e.g. blood cells as a background image or running through so that people will know what they are looking at.

2) Simplify the contact details- there's just too much and it is confusing. This may stop people from picking up the phone or going online.

3)Target each poster-make it personal

a. student- at university? Have you had a blood test? It is super easy! Free blood test!

b. thinking of starting a family? - picture of mixed-race couple and wording “origin” say from Africa, Asia, Mediterranean, South America- Get tested it is really simple!

c) world map- if you are/ have a certain background you have a higher risk of carrying a blood disorder- Get tested – Go to your GP today! - Simple- Sorted

d. Are you a silent carrier?

e. do you know if you are a carrier?

The message needs to have a call to action and a reason why it could relate to you! For example: Are you from the regions? If so, you carry a higher risk of carrying these blood disorders. Call for action- Go to your GP and ask for a blood test! - Contact details.

Appendix 5

Sickle Cell Society

PHE -Sickle Cell and Thalassaemia Screening Programme Tender 2018/21
Finance Report – 08 July 2019

1. **Introduction**

   This report provides a summary of income and expenditure related to the first year income & expenditure for the tender for the SC&T Outreach Project covering 01 August 2018 to 30 June 2019. We are not expecting any material change in income & expenditure to have any significant effect on this overall financial position for the first year.
   The annual operating budget from the tender covering both Sickle Cell Society (SCS) as lead organisation and UK Thalassaemia Society (UKTS) is £117,745. The effective date of the Project is August 2018.

2. **August 2018 to June 2019**

   Income Received to date - £117,745 - Full payment for the 1st year.

   - SCS £75,619
   - UK TS. £42,126 (to date £31,596 has been paid to UK TS. With £10,530 outstanding – SCS is awaiting invoice from UK TS).

   Total expenditure to date is £101,289. This represents 86% of the total budget.

3. **Commentary**

   At the end of June 2019, which represents 11 months of the first year, the remaining funds to the end of the year 31 July 2019 is £16,556. The forecast for the period ending 31 July 2019 is a surplus of £8,558.

   John James
   CEO
   SCS

Appendix 6

Names of Members of Parliament who committed to actively campaign for thalassaemia in their communities- All Party Parliamentary Group for thalassaemia Launch 8th May 2019.

MPs	Constituent	Party
Barry Gardiner	Brent North	Labour
David Burrowes	Southgate South	Conservative
Alberto Costa	South Leicestershire	Conservative
Alison Thewliss	Glasgow Central	SNP
Andrew Rosindell	Romford	Conservative
Annaliese Dodds	Oxford East	Labour
Bambos Charalambous	Enflield South	Labour
Cat Smith	Lancaster and Fleetwood	Labour
Catherine West	Hornsey and Wood Green	Labour
Chi Onwurah	Newcastle Upon Tyne	Labour
Craig Tracey	North Warwickshire	Labour
Dennis Skinner	Bolsover	Labour
Ed Milliband	Doncaster North	Labour
Eleanor Smith	Wolverhampton South West	Labour
Fiona Bruce	Congleton	Conservative
John Hayes	Lincolnshire	Conservative
Jonathon Ashworth	Leicester South	Labour
Khalid Mahmood	Birmingham, Perry Barr	Labour
Maggie Throup	Erewash	Conservative
Mark Menzies	Fylde	Conservative
Martin Vickers	Cleethorpes	Conservative
Matt Rodda	Reading East	Labour
Norman Lamb	North Norfolk	Liberal Democrat
Pat McFadden	Wolverhampton South East	Labour
Preet Kaur Gill	Birmingham Edgbaston	Labour
Ruth Jones	Newport West	Labour
Stephen Crabb	Pembrokeshire	Conservative
Tanmanjeet Singh Desi	Slough	Labour
Tony Lloyd	Rochdale	Labour
Tracy Brabin	Batley and Spen	Labour
Simon Hoare	North Dorset	Conservative

Appendix 7

UKTS Patient and New Parents Education Day Programme.

Patient and Parent Support Group

UK Thalassaemia Society presents "2020 and Beyond – discuss, debate, educate"

Working together to make a positive difference!

Programme 25th May 2019

10.30 - WELCOME and OPENING – Romaine Maharaj (Executive Director, UKTS)

MORNING SESSION – chaired by Anand Ghattaura (Vice chair) & Ashkaan Bandoui (Asst Treasurer)

11.00 –11.30: Update on new developments in treatment – Dr Shivan Pancham

Information of the latest new trials including luspatercept (haemoglobin increasing drug) and the first ever gene therapy trial in the UK. (*Followed by question and answer session)*

11.30 – 12.00: Living long, looking good – Dr Emma Drasar

12.00-12-12.15: National Haemoglobinopathy Register- What is it, why should we care- Dr. Shivan Pancham

12.15- 12.30- Questions and Discussions.

12.30 – 13.30 LUNCH

AFTERNOON SESSION – chaired by Roanna Maharaj & Dr Emma Drasar

13.30 – 14.30 DISCUSSION GROUPS

My baby has thalassaemia - coming to terms with your child's diagnosis
My teenager has thalassaemia - stepping back and allowing your son/daughter to take charge
My wife/husband has thalassaemia – living with thal as a partner
My brother/sister has thalassaemia – living with thal as a sibling
Young teens group (for patients and family members from age 12)
Going away to work or study? Leaving home/living independently with thalassaemia
How to be your own advocate (effective handling of disputes with medical or nursing staff)
Understanding Personal Independence Payments
Understanding your rights regarding antenatal screening and testing
Getting started - gym workouts and fitness training
What a drag it is getting old – especially with thalassaemia!

14.30 – 15.00 COFFEE

15.00 – 16.00 FLOOR DEBATES and Role Play Exercise

Floor Debate – *What is your point of view? Do you agree or disagree with the proposition? Enjoy the battles between our star debaters - everyone is welcome to join in!*

- Question: if a new and possibly risky treatment offers the chance to be transfusion free is it a risk worth taking?

For TBC *Against TBC*

16.00 – CLOSING COMMENTS AND THANKS – Oddy Cooper (Treasurer, UK Thalassaemia Society)

Appendix 8

Sheffield Patient Education Day

South Yorkshire Sickle Cell Organisation (SYSCO) and the Sickle Cell Society (SCS)

Date: 21/06/19

Time: 12:00-16:30

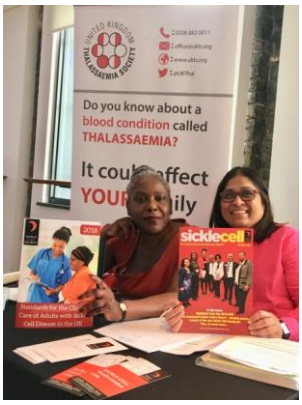
Venue: The Circle, 33 Rockingham Lane, Sheffield, S1 4FW

Capacity: 60

12:00 – 13:00	Lunch	Provided by SYSCO
13:00 – 13:20	Welcome and Introduction	SYSCO John James OBE Lord Mayor of Sheffield
13:20 – 13:50	Clinical Trials	Dr Josh Wright
13:50 – 14:30	NHS Service Review	Findings Report – John James OBE NHS Plans - Mark Thaxter How it effects South Yorkshire – Dr Josh Wright
14:30 – 14:50	Break	Provided by SYSCO
14:50 – 15:20	Paediatric Sickle Cell Services	Shaun Emmitt
15:20 – 15:50	Wider Social Support for People with Sickle Cell	Gloria Ogunbadejo SCS
15:50 – 16:00	Thanks and End	SYSCO & John James OBE
16:00 – 16:30	Networking and Stands	All – Stands: SCS

Appendix 9
Photo Gallery

SCS Paediatric Standards Focus Group



SCS/ UKTS joint Awareness stall at ASCAT

SCS awareness stall at City Hall

SCS at new parents support group in Croydon

UKTS stall at Cyprus Wine festival

UKTS interview at London Greek Radio