



## South Thames Sickle Cell and Thalassaemia Network Terms of Reference

Final Version June 2017

### 1. Introduction

This group supports the governance arrangements for the Operational Delivery Networks for Haemoglobinopathies covering the South Thames Sickle Cell and Thalassaemia Network.

Having solid governance arrangements underpinning the network will drive improved patient outcomes through the development of sustainable networks to deliver high quality care.

The South Thames Sickle Cell and Thalassaemia Network (STSTN) launched in October 2011, although consultants from hospitals within the network had been meeting informally before that time. South East and South West London remain separate networks, but continue to work together, and provide guidance and support.

The network is coordinated by a part-time Network Support Manager. Historically this role was funded by King's College Charity and Roald Dahl's Marvellous Children's Charity, but it is now joint-funded by King's College Hospital and Guy's and St Thomas' Hospital. The network has strong links with hospitals across South East London and beyond.

### 2. Network

#### Tertiary Centres

King's College Hospital NHS Foundation Trust  
Guy's and St Thomas' Hospital NHS Foundation Trust

#### Secondary Centres

Lewisham and Greenwich NHS Foundation Trust  
Croydon Health Services NHS Trust

#### Local Centres

Brighton and Sussex University Hospitals NHS Trust  
Dartford and Gravesham NHS Trust  
East Kent Hospitals University NHS Foundation Trust  
East Sussex Healthcare NHS Trust  
Maidstone and Tunbridge Wells NHS Trust  
Medway NHS Foundation Trust

The network covers the geographical location of South London and South East England.

In 2015-16 we provided care to 4,100 patients by network

### 3. Purpose of the Group

**Mission Statement:** To improve the patient experience by offering better treatment outcomes for people with sickle cell disease and thalassaemia.

In order to achieve this mission, the group will have the following purpose:



- To increase understanding of a patient's experience of SCD and thalassaemia by offering patient awareness and feedback events
- To establish and maintain joint methods of working throughout the network
- To collaborate in specialist clinics including renal, obstetrics, orthopaedics, pulmonary hypotension, neurology and urology
- To provide a peer support network and educational programme for consultants, GPs, nurses, trainees and other healthcare professionals
- To publish guidelines on the care/treatment of SCD and thalassaemia
- To develop consistent pathways of care to provide equitable care across the network
- To produce patient information sheets and a quarterly newsletter to highlight patient experiences and to update on the latest research and treatment news
- To promote clinical excellence and improve clinical care
- To function as a forum and feed into the National Haemoglobinopathy Registry, which will facilitate research into red blood cell disorders
- To disseminate information and raise awareness of ongoing research in the UK and internationally
- To provide expert clinical advice to healthcare professionals working in other services
- To support the implementation and delivery of CQUINs
- To assess the implications of national Clinical Reference Group (CRG) recommendations
- To review, comment and advise on peer review reports on service provision
- To support any providers with action plans against reports (for example commissioner action plans for improvement)
- To support the wider development of Pan London Protocols (as applicable) to reduce variation across the region
- To share learning from clinical incidents / serious incidents /service improvements
- To support audits that may be used to improve patient outcomes and experience
- To actively participate in the National Service Review as required

#### **4. Reporting**

It is the responsibility of the Specialist Centre(s) to report directly within each Trusts Local Clinical and Managerial groups and report to NHS England London Region as the specialist commissioner.

All members of the group will receive the meeting notes, the meeting notes will be sent to the NHS England London Quality Group for information, and the Programme of Care Lead for Blood & Infection will disseminate to the MDTs within NHS England London Region.

#### **5. Working Arrangements**

The network will convene quarterly each year.

Administrative support will be provided by the Network Support Manager, Eleanor Bagglely:

- Administering and co-ordinating meeting agendas, papers and information as required.



- The meeting will be recorded in meeting notes and an action log. The meetings will be sent out in draft format within 20 working days of the meeting date and agreed at the following meeting.
- Circulating papers for the next meeting 5 days prior to the next meeting date.
- Meeting notes will be required as evidence by NHS England and be sent in via the CQUIN reports.

## 6. Membership

The group membership will take on a truly multidisciplinary approach with the following membership:

### Adult Leads

Tertiary centre: Jo Howard/ Moji Awogbade

Secondary centre: Tullie Yeghen/ Stella Kotsiopolou

### Paediatric Leads

Tertiary centre: Subarna Chakravorty/Alison Thomas/Maria Pelidis

Secondary centre: Sarah Wilkinson/Julie Lord

### Research and Development Leads

David Rees/ Baba Inusa

### Audit and Governance Lead

Sara Stuart-Smith

### Quality Information and Guidelines Leads

Rachel Kesse Adu /Sue Height/Moira Dick/Baba Inusa/Alison Thomas

### Nursing Leads

Nkechi Anyanwu/Neil Westerdale

### Patient Involvement

Donna Prendergast (Sickle Cell Society)

### Psychology Leads

Heather Rawle/Gary Bridges

If appropriate, meetings may also involve the following:

- Representation from NHS England London
- Patient Representation
- Provider Management (General / Service Manager)
- Public Health England
- CCG Leads
- Primary Care representatives

It is expected that each provider will send at least one representative to each meeting. All members will receive the dates and invitation to the meeting, with a steer on the agenda on the target audience, e.g.: management need not attend all forums, however are welcome and for specific items it would be beneficial to the Network.

## 7. Chair



***Jo Howard, GSTT***

There will be one clinical chair for this group, for a time frame of 1 year

### **8. Frequency & Longevity**

The forum will run as long as deemed a useful resource; the Terms of Reference will be reviewed at each meeting to ensure the group maintains to function effectively.