

# West London Haemoglobinopathies Coordinating Care Centre

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West London HCC  
2022-23

Final Report Quarter 4

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# Annual Report

## Background

Sickle Cell Disease (SCD) and Thalassaemia are inherited red blood disorders that affect haemoglobin, the component of blood that transports oxygen. People who have these conditions require specialist care throughout their lives. In the UK, these disorders mainly affect black and minority ethnic populations with higher levels of social deprivation and poorer health outcomes.

The prevalence of haemoglobinopathies across England varies widely, with the majority of patients concentrated in urban areas, as does the expertise to manage these conditions. London centres report they treated 8726 patients (as of March 2018), not including those from neighbouring areas that are part of the London ODNs, which equates to 62% of all registered haemoglobinopathy patients.

## Aim

The aim of the service is to reduce levels of morbidity and mortality and improve the experience of all haemoglobinopathy patients by reducing inequalities and improving timely access to high quality expert care. The HCC provides a coordinated leadership function supporting NHS England's designated specialist haemoglobinopathy teams and linked local services in the delivery of clinical care. Overall, this model is predicated on the effectiveness of the HCC and driving and delivering equitable care irrespective of where the patients live through the following governance.

- To improve access to services and access to expertise and leadership
- To improve patient experience and outcomes

## Overview of the West London HCC

The West London Haemoglobinopathy Coordinating Centre (HCC) oversees and supports the safe, effective delivery of care for sickle cell and thalassaemia disorders in West London. The aim of the West London HCC is to promote clinical excellence to improve outcomes and patient experience for patients with haemoglobin disorders and maintain joint working between networks, specialist and local haemoglobinopathy teams to provide clear care pathways.

The West London HCC has built on the strengths of the two pre-existing clinical networks North West London Sickle Cell and Thalassaemia Network and the South West London Haemoglobinopathy Network and has now subsumed and superseded their functions/operations.

The West London HCC operates across a number of providers, with specialist care provided by Imperial College Healthcare NHS Trust, London North West University Healthcare NHS Trust and St George's University Hospitals NHS Foundation Trust. Patients within the HCC are cared for by a number of different specialist and non-specialist centres, including;

- Hammersmith Hospital - (Imperial College Healthcare NHS Trust)
- St. Mary's Hospital - (Imperial College Healthcare NHS Trust)
- Northwick Park Hospital - (London North West University Healthcare NHS Trust)
- Central Middlesex Hospital - (London North West University Healthcare NHS Trust)
- Ealing Hospital - (London North West University Healthcare NHS Trust)
- Chelsea & Westminster Hospital - (Chelsea & Westminster Hospitals NHS Foundation Trust)
- West Middlesex Hospital - (Chelsea & Westminster Hospitals NHS Foundation Trust)
- Hillingdon Hospital - (The Hillingdon Hospitals NHS Foundation Trust)
- Watford General Hospital - (West Hertfordshire Hospitals NHS Trust)
- Luton and Dunstable University Hospital NHS Foundation Trust
- Bedford Hospital NHS Trust
- Kingston Hospital (Kingston Hospital NHS Foundation Trust)
- St Helier Hospital (Epsom and St Helier University Hospitals NHS Trust)
- East Surrey Hospital (Surrey and Sussex Healthcare NHS Trust)
- St. Peter's Hospital (Ashford and St. Peter's Hospitals NHS Foundation Trust)
- Royal Surrey County Hospital (Royal Surrey County Hospital NHS Foundation Trust)

Please see Appendix (5) for maps of the HCC that show the hospitals within the HCC and the borders of the HCC.

Within this document there may be some variation in the patient figures given, this is in part due to different work streams being undertaken for the Specialised Service Quality dashboard data upload, returns from the National Haemoglobinopathy Registry, the demographic work undertaken for projects in the HCC, work completed by NHSE on patient numbers nationally and local reporting. The HCC team are looking to standardise and improve data accuracy over the following year.

In total there have been 1805 patients that have registered on the NHR as of 22/23. The number of adult cases recorded on the NHR is 1236 and Paediatric cases totalling to 569.

Imperial adult cases are 462 and paediatrics 235  
London North West adult cases are 446 and paediatrics 178

St George's adult cases are 427 and paediatrics 249

## Structure of the HCC

The HCC has now incorporated the activities of the previous clinical networks in North West and South West London and feeds into National Haemoglobinopathy Panel. The organogram of the HCC can be found in Appendix (2).

All of the HCC's subgroups have been established with regular meetings held. The structure of these meetings and how they feed into the Steering group of the HCC can be found in Appendix (3).

## Status of HCC Staffing/Recruitment

All HCC positions have been recruited to please see Appendix (4) which lists all staff in position across the West London network.

The West London HCC has in post a 8b HCC Manager to support the administrative functions of the HCC the HCC also has a Band 4 WTE 0.6 administration assistant. The approved position descriptions from each Trust are embedded below.

The specialist hospital teams within the HCC include key administration roles within their delivery models which support the activity of the HCC. Imperial College Healthcare NHS Trust (ICHT) has a whole time equivalent (WTE) Band 5 data manager in post. London North West University Healthcare NHS Trust (LNWHT) has a WTE Band 5 data manager in post. St George's University Hospitals NHS Foundation Trust (SGHT) adult service also have a data manager 0.5 WTE Band 5. St Georges paediatric team do not currently have data management support but this is being worked on by the management teams connected to the service.



HCC Manager JD  
B8b.docx.pdf



HCC Administration  
Assistant JD B4 WTE

## Third Year Outcomes

### Background

In the third year of the West London HCC the network has achieved a number of achievements have been reached, these include;

- the continuation and effective delivery of a regular MDT meeting and Urgent/emergency ad hoc MDTs
- the implementation of an education schedule which has hosted a number of different virtual events
- the running and integration of the Patient and Public Voice group in the functions of the HCC
- the continuation and running of subgroups to work on HCC wide guidelines and develop the HCC's research and audit strategy
- Website set-up along with social media channels

## MDT of the HCC

The HCC MDT (multi-disciplinary team) has continued its operations effectively throughout the year. One hundred cases have been referred to monthly or ad hoc urgent MDT meetings and benefited from expert input from attendees of the HCC.

The attendance, has included representatives from the Specialist Haemoglobinopathy and Local Haemoglobinopathy Teams and consultant colleagues in Scotland and Wales,

Five cases have been referred to the National Haemoglobinopathy Panel for further consideration.

MDT outcomes are recorded by the MDT lead for the HCC and then distributed by HCC Network Manager once these have been verified with the presenting consultant.

The standard operating procedure for the MDT has been drafted by the MDT subgroup. Referral criteria have been agreed and distributed to HCC Members:

Cases which manifest the following will be discussed:

- Clinically severe or unusual acute/chronic complications (e.g. liver problems, cerebrovascular disease) including failure to respond to disease modifying therapy
- Complex transfusion issues (inc. Hyperhaemolysis)
- Difficult iron chelation
- Complex Psychology/Safeguarding concerns
- Potential candidates for bone marrow transplant/gene therapy
- Post-operative complications
- Death
- Unplanned PICU/ICU admissions; issues with retrievals from DGHs
- Missed children from the newborn screening programme
- Multi-organ failure
- Fat embolism syndrome
- Complex transition patients
- Renal transplant planning
- Post COVID-19 complications
- Suspected PIMS-TS cases
- Potential candidates for novel therapies
- Pregnancy complications

Please see the Appendix (6) subdivided by year for an indication of the breakdown of attendees at the HCC MDT in terms of staffing and organisational representation. Next year the aim will be to increase the number of cases discussed at the MDT and encourage greater attendance from specialty trainees and nursing colleagues in all institutions, there will also be a drive to promote MDT attendance by local haemoglobinopathy teams and the West London HCC steering group has proposed having specific MDT meeting dates for local hospital teams to encourage case referral. There will also be a greater aim to increase the number of cases being referred to the NHP.



## MDT activity

			Apr -22	May- 22	Jun -22	Jul -22	Aug -22	Sep -22	Oct -22	Nov -22	Dec -22	Jan -23	Feb -23	Mar -23	Annual Total
Number of cases being submitted to the HCC MDT	Adult		4	8	9	3	0	19	1	13	3	10	3	6	79
	Children		0	8	1	1	0	6	1	1	0	3	0	0	21

Cases referred to the NHP	Adult	Number	0	0	0	1	0	1	1			1		1	4	
		Percentage	0%	0%	0%	33%	0%	5%	100%	0%	0%	0%	10%	0%	17%	5%
	Children	Number	0	0	1	0	0	0	0	0	0	0	0	1	0	1
		Percentage	0%	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%	25%	0%	5%

## Educational/training activities

At the end of 2021-22 Lol Oni retired as joint lead of the education and training sub group, Nadia Osman (Paediatric CNS at London North West) joined the group as Lola's replacement. The educational and training sub group met on a quarterly basis throughout the year with Dr Mamta Sohal and Nadia Osman, a schedule of activity was worked on and has been delivered.

At the start of the year Nadia Osman and Dr Mamta Sohal identified the educational activities that the HCC needed to undertake. To assist this process they stratified the target audience into five groups.

- Non-specialist clinicians and allied health care professionals that work in acute settings
- Clinicians working in the community, including primary care
- Specialist health and allied care professionals in all care settings
- Non-health care professionals e.g. commissioners and School Teachers
- Service users and carers

Programmes were then developed to be of educational value to the different groups identified. Please see Appendix (8) which details the education sessions undertaken in 2022/23 and the number of attendees, 19 education sessions have taken place within the first year of the HCC.

In terms of operation of the sessions, the Network Manager sends out invites and instructions on how to register. The education leads and the Network Manager create flyers advertising the programme with details of the title(s) and speaker(s). A certificate of attendance has been designed that is sent out to attendees and can be used for CPD purposes.

## Future developments

The following sessions are due to take place:

- Management of Sickle Emergencies
- Patient experiences in Emergency Departments
- Hyperhaemolysis
- Child Health
- Gene Therapy for SCD in Africa and the activities by the Global Gene Therapy Initiative
- Antenatal Screening of Haemoglobinopathies
- Sickle Cell for School Nurses and Teachers

Further details of future sessions can be found in Appendix (9)

Dr Mamta Sohal (Imperial) and Keisha Osmond-Joseph (London North West) will be working on the education schedule for 23/24 with support from the Network Manager.

## Collaborations with other HCCs that have been beneficial

The West London HCC contributed to the National Education Schedule with the following sessions which were well received by those who attended

- Psychology: Managing adherence to treatment Challenges in Thalassaemia and Sickle Cell Disease- Dr Kofi Anie
- Management of Pregnancy in Sickle Cell Disease- Dr Mamta Sohal

The HCC also contribute to a national pain audit and a services status review that have been lead by the East London HCC and National Haemoglobinopathy panel respectively, we expect outcomes from that work to be built upon in 2023/24.

The West London HCC will coordinate the National Education Schedule next year (2023/24).

## Research/Clinical Trials

There have been a number of clinical trials that have been undertaken across the HCC Please find a brief listing of the clinical trials in Appendix (12). Available/open clinical trials are discussed at the HCC MDT.

A research group has been set-up with its first meeting held in 2022, the aim of the group is to follow-up on the objectives set by the HCC steering group and to help with the uptake of audits.

Research team presented to the PPV group 23 February 2023

The research team have agreed that they will present to the PPV every 6 months

## Audit and data collection

The below data was submitted to the specialised services quality dashboard (SSQD)

The service specification document for the HCC requests the following direct data outcomes:

Service Specification	No.	HCC	Imperial	London Northwest	St. Georges
Number of cases referred to the HCC for specialist clinical opinion and discussion	101	100 patients cases have been discussed in the HCC MDT	N/A	N/A	N/A
The proportion of patients that are referred for clinical advice and guidance to the national panel	102	5 (5%) patient forwarded to the national panel MDT	N/A	N/A	N/A
Average length of stay for patients following emergency admission across HCC referring organisations.	103	Please see page 39	N/A	N/A	N/A
Proportion of serious events entered on to NHR system by SHTs and reviewed at the HCC morbidity /mortality meetings	104	100 adverse Events were recorded across the HCC  Of these 100% were uploaded to the NHR  Of these 100 were discussed in the HCC MDT	56 Adverse events recorded on the NHR at Imperial 22/23  (47 in adults, 9 in Paeds)	20 Adverse events recorded on the NHR at London Northwest 22/23discussed at the HCCMDT  (19 in Adults, 1 in Paeds)	24 Adverse events recorded on the NHR at St. Georges 22/23discussed at the HCCMDT  (14 in Adults, 10 in Paeds)
Service Specification	No.	HCC	Imperial	London Northwest	St. Georges
Proportion of patients entered on to the NHR database across the HCC	105	Total percentage: 93%  Percentage of adult patients: 95%	389 adult patients are recorded on	360 adult patients are recorded on	380 adult patients are recorded on

	Percentage of Paediatric patients: 93.3%	the local database	the local database	the local database
	There are a total of 1,674 patients recorded on local databases of the SHTs in the WLHCC**	372 on adult patients NHR	360 on adult patient NHR	341 on adult patients NHR
	Of these 1,129 are adult patients, 523 are paediatric patients	174 paediatric patients are recorded on the local database	145 on paediatric patients	204 paediatric patients
	Recorded on the NHR are 1,561 patients of which 1,073 adults and 488 paediatric patients	167 on paediatrics patients NHR	145 on paediatric patients NHR	176 on paediatric patients NHR

\*\*missing patients from the LHTs as not completed data sets/readily available databases, this is being worked on in 23/24

An audit schedule was agreed for the year 22-23, however due to staff challenges at the SHTs and LHTs the ability of services to complete this was very challenged, so a decision was reached to concentrate on the audit related to the Time to analgesia and pain management in emergency settings, audit of the NICE guidelines

Quarter when the Audits will be undertaken	HCC Stipulated audits
22-23 Quarter 1	The number of patients who are on and have been asked about Hydroxycarbamide
22-23 Quarter 2	Time to analgesia and pain management in emergency settings, audit of the NICE guidelines To include audit of competencies <a href="https://www.nice.org.uk/guidance/cg143">https://www.nice.org.uk/guidance/cg143</a>

22-23 Quarter 3	The patient pathway for patients needing regular transfusion, including availability of out-of-hours services and achievement of expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion (QS HC-505)
22-23 Quarter 4	Acute admissions to inappropriate settings, including patient and clinical feedback on these admissions

The outcomes of this audit were shared with the Steering group and Patient and Public voice group of the HCC

## Website and Social media work

The HCC has worked with commercial web developers BeingOnline (who have experience with working with NHS services) to establish a website.

The website consists of pages for both members of the HCC and members of the public. This is linked to the social media information to some of the pages by embedding some of the YouTube videos on the relevant pages. There is an events page where visitors can see and sign up to any events that the HCC Network are hosting or any other relevant red blood cell community events. There is also a news page, which is updated regularly with any relevant and up to date news articles, a useful links page has been set-up with loads of helpful hyperlinks to different services, and a resources section for both consultants and patients.

The screenshot displays the West London HCC website. The header features the NHS logo and the text 'West London Haemoglobinopathy Coordinating Centre'. The navigation menu includes 'About Us', 'News', 'Useful Links', 'Events', and 'Contact'. The main content area is titled 'New Treatments' and includes a 'Patient Resources' dropdown menu with options like 'Covid-19 Coping Strategies and advice', 'New Treatments', 'Exchange Transfusion', 'Hydroxycarbamide', and 'Pain Management & Support'. The 'Latest news' section features three articles: 'HCC Teaching session Antenatal Screening of Haemoglobinopathies', 'Gene Therapy for SCD in Africa and the activities by the Global Gene Therapy Initiative', and 'Sickle Cell Education Series Episode 3: Treatments, How are they meant to treat me?'. The footer includes the text 'Better Healthcare through collaboration'.

Website content will be constantly reviewed. This will take place in the form of ad hoc sub groups from the steering group committee.

The HCC have created a twitter social media account, so that sickle cell news events and other relevant information across the network can be communicated all sickle cell with the services patients.

This account can retweet any Sickle related content on the feed but also promote any HCC events being hosted within the network. It can also share any relevant news that may be of interest to our patients.

<https://twitter.com/HCCWestLondon>

# West London Haemoglobinopathy Coordinating Centre

NHS  
WLHCC

Edit profile

## West London HCC Network

@HCCWestLondon

West London's Haemoglobinopathy (Sickle Cell, Thalassemia and Rare Anaemias) Network

West London [westlondonhcc.nhs.uk](https://westlondonhcc.nhs.uk) Joined July 2021

194 Following 173 Followers

Tweets Replies Media Likes

You Retweeted



Invisible Warrior\_SCD @InvisWarriorSCD · 18h

Discover the inspiring stories of NHS staff and patients who are involved in health research at the Humans of Health Research exhibition

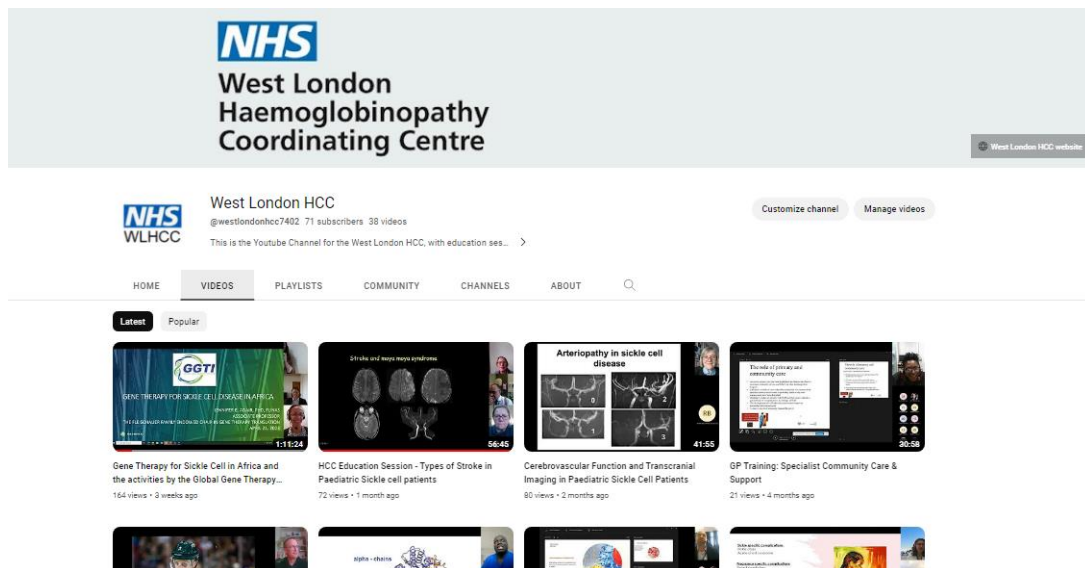
White City Community Centre

30 May - 3 June

The HCC has established of a YouTube channel so that education sessions and talks can be distributed and accessed by others:

Adobe software is used to edit the recorded teams meetings, which then get uploaded onto the YouTube channel. We have 71 subscribers and 4371 views.

The HCC plans to eventually expand our social media presence by using other platforms such as Instagram.



Link to youtube channel:

[https://www.youtube.com/channel/UCHWNWQhQEJnqOgw34\\_F9nrQ](https://www.youtube.com/channel/UCHWNWQhQEJnqOgw34_F9nrQ)

## Harmonisation of Network clinical guidelines

As part of the HCC's work sub-groups have been working on the harmonisation of clinical guidelines across providers in the HCC. The adult guideline is very close to distribution/completion and the paediatric guideline only requires an additional couple of subsections to be reviewed. Once the guidelines have been agreed they will be hosted on the HCC website.

The following guidelines are being harmonised by the respective subgroups:

- Paediatric guidelines for sickle cell disease
- Adult guidelines for sickle cell disease
- Transition from paediatric to adult services guideline
- Care of pregnant women with sickle cell disease

## Service level agreements

The Service Level Agreement (SLA) that constitutes the agreement between Imperial College Healthcare NHS Trust (ICHT) and St Georges University Hospitals NHS Foundation Trust (SGHFT) and London North West University Healthcare Trust (collectively the Partnership) with regard to the Provision of a Haemoglobinopathy Coordinating Centre (HCC) is in place.

SLAs for the involvement of the Scottish Paediatric and Adult Haemoglobinopathies network (SPAH) and South Wales Haemoglobinopathy teams in HCC MDT and educational activities have been drafted and sent out to the centres.

Service level agreements between LHTs and SHTs and the HCC detailing individual escalation/referral pathways are being worked on.

## Evidence of HCC meetings and actions achieved

/Steering group meetings have been held on a monthly basis throughout 2022/23. These meetings were used to discuss HCC actions and plans and ensure service specification deliverables were on target. Meetings will continue to be held on a regular basis in order to drive further actions and HCC work plans.

The minutes from all Steering group meetings held in the previous year are embedded below.





## Attendance of a representative from each of the HCCs at the National Haemoglobinopathy Panel (NHP)

The HCC has had at least one representative attend each of the National Haemoglobinopathy Panel meetings in the year 2022/23

Please see Appendix (11) to see which members of the West London HCC have attended the meetings of the National Haemoglobinopathy Panel.

## Patient and Public Voice Group

The patient and public voice group has continued through year and has become established with the confirmation of the terms of reference and regular monthly meetings taking place post the second and third waves. Dr Kofi Anie acts as the clinical facilitator to the group but no longer attends meetings on a regular basis in order to encourage greater freedom of expression.

Ralph Brown joins the meetings in order to feedback information on the HCC's activities.

The Chair of the PPV group Patrick Ojeer also attends the HCC Steering group meetings and ensures along with the network manager that the concerns and actions of the PPV group are highlighted in the Steering group.

The first meeting was on the 28th of March of last year and has had ten further meetings since.

The agenda of meetings held so far has included;

- Terms of reference were finalised
- Input into the HCC educational programme (which it is hoped will positively impact patient involvement and quality of care),
- Input to HCC the website
- User feedback on the emergency pathways of the SHTs and LHTs in the HCC
- Feedback to the HCC's approach to the 'APPG report: No one's listening' findings
- Improvement from incidents report

The group is keen to explore links with other HCC's to identify common themes and solutions. The network manager and group members are pursuing this.



PPV HCC meeting minutes 28.04.2022.



PPV HCC meeting minutes 26.05.2022.



PPV HCC meeting minutes 30.06.2022.



PPV HCC meeting minutes 28.07.2022.



PPV HCC meeting minutes 01.09.2022.



PPV HCC meeting minutes 29.09.2022.



PPV HCC meeting minutes 28.10.2022.



PPV HCC meeting agenda 01.12.2022.



PPV HCC meeting agenda 26.01.2023.



PPV HCC meeting agenda 23.02.2023-



PPV HCC meeting agenda 23.03.2023-

The overall aim of the PPV group is to be an integral part of the West London HCC. The group will play a leading role in achieving the strategic aim of the HCC to engage patients and the public in order for their views to affect decisions taken about the planning, improvement, monitoring and evaluation of services within the HCC.

## APPG report: No One's Listening

The All-Party Parliamentary Group (APPG) published a report on sickle cell disease care in the UK in conjunction with the Sickle Cell Society in late 2021. A number of recommendations were made from the report for NHS Trusts to follow. This report was critical of the standard of medical provision for patients with sickle cell disease, and generated national media attention. In order to address these critiques and drive improvements, the West London Haemoglobinopathy Coordinating Centre (HCC) has requested its member organisations to provide updates on the responses given in 2021/22 detailing how recommendations from the APPG report will be implemented.

Emergency department leads are also to encourage engagement with the APPG response.

A combined list actions derived from the updates to the report responses is held by the HCC, this is then presented at the Patient and Public voice group and the steering group for review.

## Finances of the HCC

NHS England (NHSE) uplifted the amount of funds given by to the HCC by £11,322 for the year 22/23 to £233,522 (5.7% uplift, rate of inflation 22-23 6.1%). NHSE are looking to uplift the budget of the HCC for 2023/24 by 1.3% leading to a budget of £236,650 (this may be subject to change given inflationary pressures).

As per the last annual report and the information relayed at business meetings due to some misunderstandings and issues around the original draft budgeting related to banding midpoints and salary costs of experienced members of staff the projected cost of or the draft budgets for the HCC actually overruns the amount allotted by NHSE.

In 2020/21 there was a significant underspend against the budget, in part this was due to a network manager not being recruited into post until late October and the administrator not yet being in post until late March. Additionally a significant number of ancillary costs that normally would have been associated with the setting up of meetings did not occur due to Covid-19 restrictions. This resulted in a budget underspend of £66,101. In 2022/23 the aforementioned budgetary issues resulted in a slight overspend against the HCC budget.

In 2022/23 there was a slight underspend against the budget of the HCC. This under spend occurred due to minimal spending on ICT and sundries that was originally set aside in the budget which has been mitigated because of the adoption of Microsoft Teams and Zoom, which the HCC had started using prior to the pandemic.

Due to the reduced uplift for the HCC in 23/24 there is an expectation that there will be a overspend on the HCC budget because of increased staffing costs related to inflationary pressures in the wider economy.

Year	NHSE contract	Projected Cost (against initial budget)	Actual spend	Spend against NHSE budget 23/24 predicted
2020/21	£215,000	£235,591.68	£148,898.46	£66,101.51
2021/22	£220,200	£234,408.21	£221,515.01	-£1,315.01
2022/23	£233,522	£243,220.94	£228,153.86	£5,368.14
2023/24*	£236,650	£255,437		-£15,111.56
<b>Overall position</b>				<b>£45,509.06</b>

Work is being undertaken between HCC Network Manager, GMs and finance teams to reduce potential overhead caused by pay uplifts in 2023/24.

\*Please note that the financial year 2023/24 has not finished (the 22/23 projected cost figure above assumes a 5% pay uplift for Agenda for change staff and a 2.1% uplift for consulting staff and limited spending of the ICT) and there is also a need to validate some of the costings in 2022/23, so this should not be viewed as a finalised figure.

## Specialist Haemoglobinopathy Teams status 22-23

NHS England London specialist commissioning team have requested an update from the HCC on the status of the services of the respective SHTs.

The past year has been challenging for the haemoglobinopathy services at Imperial, London North West and St Georges. The 3 SHTs have fed back as to their major operations for the year.

### Imperial College Healthcare NHS Trust Adult Haemoglobinopathy Service

#### **Service updates and challenges of 22/23 with work progressing in 23/24**

Service updates and challenges in 22/23:

- The service has resumed a significant proportion of face to face clinical appointments, but continues to offer a hybrid model including virtual appointments where appropriate
- Partnership with CNWL NHS Trust to recruit a specialist social worker post
- Completion of Annual reviews and upload to the National Haemoglobinopathy Registry remains a challenge due to service pressures
- Increase in apheresis activity
- Expansion of clinical trials team and study portfolio
- Joint working with London North West University Healthcare NHS Trust to consolidate inpatient services at Hammersmith Hospital and expand ambulatory care including a day pain service at Central Middlesex Hospital
- Business case for expansion of apheresis service development
- Funding approved for second Haemoglobinopathy Clinical Nurse Specialist post
- Successful bid for social prescribing link worker was submitted
- Working group on the emergency pathways for Sickle Cell patients established resulting in a significant improvement of time to analgesia

Targets for 2023/24:

- Hyper Acute Unit and Community projects to be established and recruitment to posts to start
- Appointment of key posts within the multidisciplinary team including: Band 7 Haemoglobinopathy CNS, Haemoglobinopathy specialist Physio, social prescribing link worker, Social worker to support Haemoglobinopathy service underway in part to address adolescent service staffing shortfall
- To consolidate joint working with London North West

- Completion of annual reviews for the patient population for 23/24
- Implementation of the specialist pain management programme

## Imperial College Healthcare NHS Trust Paediatric Haemoglobinopathy Service

### Service updates and challenges of 22/23 with work progressing in 23/24

Service updates and challenges in 22/23:

#### Achievements

- New Haemoglobinopathy CNS started in post (October 2022) - providing support for paediatric and adolescent clinic and has completed in house RBC exchange training
- Promotion of previous Haemoglobinopathy CNS to matron of Haemoglobinopathy service
- Set up of adolescent transition working group comprising staff from paediatric and adult teams to address service improvements relating to improving staffing (CNS & psychology support), patient education & improving patient experience (set up of tour of the adult service)
- Increasing transfers of unwell sickle patients for PICU support/ emergency RBC exchange from UCLH and its LHTs
- SHT outreach support for Haemoglobinopathy clinics in Northwick Park, Ealing & Bedford - has led to increasing elective referrals for surgery and RBC exchange from these centres
- Increase in local consultant Haemoglobinopathy clinic cover with Dr Toni Petterson providing additional clinic slots
- Site initiation visit/Preceptorship meetings ahead of opening of paediatric gene therapy studies for Thalassaemia/Sickle cell anaemia

#### Challenges

- Challenges relating to junior doctor pressures including industrial action and gaps in junior doctor staffing - suboptimal cover of evening/weekend rota - consultants frequently acting down
- Insufficient psychology support for sickle cell service - significant waiting list for neuropsychometric testing
- Staffing of on-call apheresis service remains limited to a small body of staff despite increase of training opportunities. Insufficient availability of trained staff to regularly participate in apheresis procedures to enable them to maintain their competencies

Targets for 2023/24:

- Business case in development for new specialist apheresis CNS post
- SLA in development to harmonise services offered to Bedford/Luton
- Continuing work to improve adolescent transition service
- Gene therapy study is now open and hope to admit the first patients for treatment in the near future

**Service updates and challenges of 22/23 with work progressing in 23/24**

Two additional substantive consultant haematologists were appointed to manage haemoglobinopathy patients.

Out-patient service

- All haemoglobinopathy clinics are MDT and include an acute CNS, community CNS, and psychologist. Outpatient clinic consultations are hybrid combining face-to-face at Central Middlesex Hospital (CMH) with telephone. Face-to-face appointments are prioritised for new patients, annual reviews, and management of complex patients including those on hydroxycarbamide.
- There are three consultant haematologists who attend the clinics.
- Routine investigations including Annual blood tests, Echocardiogram, audiometry and T2\*MRI, and Ophthalmology reviews are being carried out.
- Elective Red Cell Exchange remains at Northwick Park Hospital (NPH)
- Routine surgery including orthopaedics is being carried out albeit with long waiting lists

Nurse-Led Clinic

- There is a recently established Nurse Consultant Telephone Clinic for patients on treatment. This allows patients to be seen in between consultant clinics.
- Patients who require Community follow up by the Community Specialist Nurse are followed up with routine home visits and telephone consultations as required.

Psychology Service

- Virtual consultations are being carried out during outpatient clinic appointments. Additional psychological support is offered face-to-face or virtually via video consultations (DrDoctor) as required by patients. Neuropsychological assessment clinics are available face-to-face. Psychological support is also offered for inpatients, and the psychologist attends consultant ward rounds three times a week.

Medical Day Care (CMH- Central Middlesex Hospital)

- Walk-in-Service for acute pain management resumed. This allows for daytime treatment, and patients who require subsequent hospital admissions are transferred to NPH.



- Elective top-up transfusions have continued for all sickle cell and thalassaemia patients. Covid tests are done prior to admission at the same time as pre-transfusion bloods are done.

#### In-Patient Care

- Drake Ward (Haematology) has recently been expanded to accommodate patients with sickle cell disease. James Ward is also being used as a backup for patients with sickle cell disease, and for those who are Covid positive on admission. There is ongoing teaching for all staff. A Darzi Improvement Fellow for Sickle Cell Disease was appointed for one year to help improve the inpatient pathway. A new Emergency Department pathway for sickle cell care was introduced, which includes a Sickle Cell Emergency Call Protocol and Sickle Cell Care Bundle (copy attached). This was facilitated by the Darzi Fellow and has also helped to substantially improve compliance with the NICE guideline for management of acute sickle cell pain. Multi-Disciplinary Team Meetings
- Local and HCC MDTs have continued virtually and are being conducted monthly for both.

#### Future Plans

- Work in collaboration with Imperial College Healthcare NHS Trust SHT is progressing to consolidate inpatient and outpatient care.

### London North West University Healthcare NHS Trust Paediatric Haemoglobinopathy Service

#### **Service updates and challenges of 22/23 with work progressing in 23/24**

#### Out-Patient Service

- All paediatric haemoglobinopathy clinics are face-to-face MDT clinics and include an acute CNS, community CNS, and psychologist.
- There are two consultant paediatricians, and a consultant paediatric haematologist from Imperial College Healthcare NHS Trust who attends the clinics twice monthly.
- Ealing Hospital – clinics are held once a month.
- Affected newborn home visits are being carried out as previously, and patients who require community follow up have routine home visits and telephone consultations as required.

### Psychology Service

- Additional psychology clinics are available to support patients. These are offered face-to-face or virtually via video consultations (DrDoctor) as required by patients. Psychological support is also offered for inpatients, and the psychologist attends consultant ward rounds three times a week. Neuropsychological assessment clinics are available face-to-face.

### Paediatric Day Care

- All transfusions are done at Northwick Park Hospital including children from Ealing, however blood tests can be done at Ealing.

### Transcranial Doppler Service

- This is carried out at the Northwick Park Hospital Vascular Department on Saturdays and historically has been ideal for the children and families.

### Multi-Disciplinary Team Meetings

- Local and HCC MDTs are conducted virtually and monthly for both.

### Vision for Recovery

- More collaboration with Imperial College Healthcare NHS Trust SHT.

## St George's University Hospitals NHS Foundation Trust-Adult Haemoglobinopathy Service

### **Service updates and challenges of 22/23 with work progressing in 23/24**

- 2 Haemoglobinopathy CNS – now working on site
- Monthly Red Cell Treatment Clinics to continue (positive feedback from patients) – enables the team to keep track of patients receiving hydroxycarbamide and iron chelation which can be delivered via home delivery prescriptions
- Apheresis service: significant disruption due to severe staffing shortages and space. Business case currently sitting with St George's exc team for review and sign off to increase staffing and additional machines.
- Business case for third substantive red cell consultant underway.
- Consultant neurologist with an interest in sickle cell disease appointed to the Trust – will be setting up a monthly sickle-neurology clinic
- Ongoing QI projects being undertaken in collaboration with ED team (ED-Sickle working party) to improve care for patients with sickle cell disease at the Trust (eg. Sickle cell alert cards, education and training).

## St George's University Hospitals NHS Foundation Trust-Paediatric Haemoglobinopathy Service

### **Service updates and challenges of 22/23 with work progressing in 23/24**

- Apheresis - Staffing numbers have reduced and recruitment in process for this. Negotiations with NHSBT to potentially provide paed's service (including OOH).

Still no SLA finalised with NHSBT

There is no out of hours provision -adult apheresis team try to help if there is capacity

- Annual reviews and upload on to the National Haemoglobinopathy Registry remains compromised due to limited consultant availability to complete these. There is also no middle grade doctor (SpR) to complete these.
- Medicines –There is no further home delivery which was in operation during the pandemic
- Clinics – Mostly face to face appointments. Appointments can be telephone when of benefit to family.

- Phlebotomy is not affected due to COVID, however there is time limitation in the paediatric phlebotomy services
- Transition clinic not affected as carried on over the phone. No significant change to this. Trying to establish face to face transition clinic
- Pain nurse - We have dedicated paediatric pain team for inpatient

#### Staffing –

- Consultant – Several changes in the consultant cover- still ongoing changes- not full 3 consultants persistently
- Nursing - Full haemoglobinopathy CNS post in place since 2022- CNS on maternity leave and there is CNS full time in post for maternity cover
- Psychology –Psychologist will be moving to another trust by July 2023- will be advertising for the post
- Junior Drs –No support from the haematology SPRs (they provide cover to adult haem)Paediatric junior doctors help in the inpatient areas
- Social Worker – No social worker
- Community Nurse for sickle patients – 1 WTE - only for Wandsworth GP or housing catchment - remains but under separate Trust and management.
- No data management support for team (no audits/service evaluation/peer review 2022 etc).
- No SHT lead at present (on long leave; no cover). SHT lead Dr Thomas back from maternity leave 16 May 2023
- The haemoglobinopathy services support for HCC (MDT.adverse events MDT, paediatric guidelines) covered by Dr Malik.
- Business and steering meetings covered by the managers.

## Patients within the Network

Work is being undertaken to clarify the number of patients within the network

### Adults Sickle Cell Patients

#### Imperial College Healthcare NHS Trust

389 adult patients are recorded on the local database

372 of adult patients are on the NHR

#### London North West University Healthcare NHS Trust

360 adult patients are recorded on the local database

360 of adult patients are on the NHR

#### St George's Healthcare NHS Foundation Trust

380 adult patients are recorded on the local database

341 of adult patients are on the NHR

### Paediatric Sickle Cell Patients

#### Imperial College Healthcare NHS Trust

174 paediatrics patients are recorded on the local database

167 of paediatrics patients are on the NHR

#### London North West University Healthcare NHS Trust

145 paediatrics patients are recorded on the local database

145 of paediatrics patients are on the NHR

#### St George's Healthcare NHS Foundation Trust

204 paediatrics patients are recorded on the local database

176 of paediatrics patients are on the NHR

Work continues to be done to establish the total number of patients within the entire West London Haemoglobinopathy Care Centres.

## Progress for 85% target of total registered Sickle Cell patients attending for annual review

Due to staffing challenges relating to consultant and data management support the attainment of the 85% target, by some of the services wasn't met

22/23

No. of patients at each centre	No. of patients active on the NHR from all linked centres to SHTs	Percentage of patients registered on the NHR	Percentage of annual reviews uploaded to NHR*
<b>Adults</b>			
Hammersmith Hospital (Imperial College Healthcare NHS Trust)	434	96%	(392) 90%
London North West University Healthcare NHS Trust	484	100%	(384) 79.3%
St George's University Hospitals NHS Foundation Trust	407	90%	(7) 2%
<b>Paediatrics</b>			
No. of patients at each centre	No. of patients active on the NHR	Percentage of patients registered on the NHR	Percentage of annual reviews uploaded to NHR*
St Mary's Hospital (Imperial College Healthcare NHS Trust)	219	96%	(203) 93%
London North West University Healthcare NHS Trust	188	100%	(155) 100%
St George's University Hospitals NHS Foundation Trust	248	86%	(0) 0%

## TCDs: Proportion of patients undergoing TCD

In 2022/2023 the Transcranial Doppler services were re-established/continues and caught up on some of the backlog from the pandemic year,

Ref	Description	Trust/ Patient Type		Total
HAEM02	Proportion of children (aged between 2 and 16 years old) within at risk group (S/S and S/bets 0 Thal) receiving Trans Cranial Doppler monitoring within Trust	<b>LNWUH Children</b>	Numerator	88
			Denominator	98
			<b>Percentage</b>	<b>89.8%</b>
		<b>ICHNT Children</b>	Numerator	50
			Denominator	52
			<b>Percentage</b>	<b>96.2%</b>
		<b>SGUH Children</b>	Numerator	100
			Denominator	110
			<b>Percentage</b>	<b>90.9%</b>

Please note the data submitted from Imperial College Healthcare NHS Trust (ICHNT) also includes data from the LHT hospitals within its Paediatric Network in Northwest London, the data uploaded to the Specialised Services Quality Dashboard related to patients solely at St Marys Hospital.

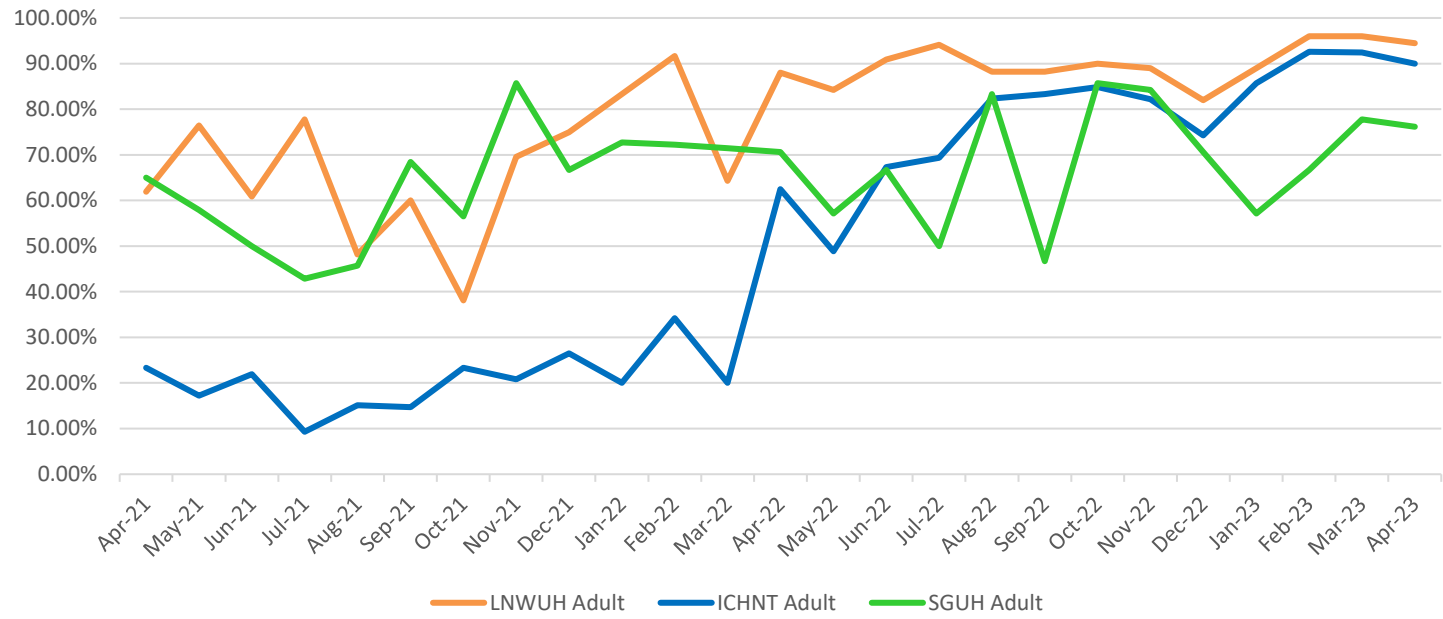
## Pain relief: % of patients receiving pain relief within 30 minutes

Please

Ref	Description	Trust/ Patient Type		Apr-22	May-22	Jun-22	Jul-22	Aug-22	Sep-22	Oct-22	Nov-22	Dec-22	Jan-23	Feb-23	Mar-23	Total	
HAEM03i	Percentage of patients given pain relief within half an hour of presentations with sickle crisis , as per NICE guidelines	LNWUH Adult	Numerator	22	16	20	16	15	15	19	17	14	17	25	22	218	
			Denominator	25	19	22	17	17	17	21	19	17	19	26	23	242	
			Percentage	88%	84%	91%	94%	88%	88%	90%	89%	82%	89%	96%	96%		
		ICHNT Adult	Numerator	20	20	34	35	43	45	28	37	29	36	50	49	426	
			Denominator	32	47	52	49	51	54	33	46	35	42	55	53	549	
			Percentage	63%	43%	65%	71%	84%	83%	85%	80%	83%	86%	91%	92%		
		SGUH Adult	Numerator	12	8	12	9	10	7	12	16	12	8	12	21	139	
			Denominator	17	14	18	18	12	15	14	19	17	14	18	27	203	
			Percentage	71%	57%	67%	50%	83%	47%	86%	84%	71%	57%	67%	78%		
		LNWUH Children	Numerator	3	2	4	2	5	3	5	3	2	4	2	2	37	
			Denominator	3	2	4	2	5	3	5	4	3	4	3	3	41	
			Percentage	100%	100%	100%	100%	100%	100%	100%	75%	67%	100%	67%	67%		
		ICHNT Children	Numerator	2	1	1	0	0	3	0	1	0	2	0	2	12	
			Denominator	2	1	1	0	1	4	2	2	0	2	0	2	17	
			Percentage	100%	100%	100%	#DIV/0!	0%	75%	0%	50%	#DIV/0!	100%	#DIV/0!	100.00%		
SGUH Children	Numerator	0	0	2	1	2	0	1	1					7			
	Denominator	1	1	2	2	2	1	2	2					13			
	Percentage	0%	0%	100%	50%	100%	0%	50%	50%								



Percentage achieval of time to analgesia (within 30 mins) adult services



## Neonatal screening: Entry into specialist care and proportion of patients commencing antibiotic prophylaxis

Ref	Description	Trust/ Patient Type		Apr-22	May-22	Jun-22	Jul-22	Aug-22	Sep-22	Oct-22	Nov-22	Dec-22	Jan-23	Feb-23	Mar-23	Total	
HAEM04A	Proportion of paediatric patients with possible sickle cell disease identified by neonatal screening, who have been entered into the care pathway.	LNWUH Children	Numerator	3	4	3	0	1	1	1	0	0	1	1	2	17	
			Denominator	3	4	3	0	1	1	1	0	0	1	1	2	17	
			Percentage	100%	100%	100%	-	100%	100%	100%	-	-	100%	100%	100%	100%	
		ICHNT Children	Numerator	5													5
			Denominator	5													5
			Percentage														
		SGUH Children	Numerator	1	0	0	1	2	0	2	2	0	1	0	0	9	
			Denominator	1	0	0	1	2	0	2	2	0	1	0	0	9	
			Percentage	100%	-	-	100%	100%	-	100%	100%	-	100%	-	-	100%	

HAEM04B	Percentage of eligible children beginning Penicillin at our before 3 months of age as per screening programme guidelines	LNWUH Children	Numerator	3	4	3	0	1	1	1	0	0	1	1	2	17	
			Denominator	3	4	3	0	1	1	1	0	0	1	1	2	17	
			Percentage	100%	100%	100%	-	100%	100%	100%	-	-	100%	100%	100%	100%	
		ICHNT Children	Numerator	1													1
			Denominator	3													3
			Percentage														
		SGUH Children	Numerator	1	0	0	1	2	0	2	2	0	1	0	0	9	
			Denominator	1	0	0	1	2	0	2	2	0	1	0	0	9	
			Percentage	100%	-	-	100%	100%	-	100%	100%	-	100%	-	-	100%	

## Sickle Cell Disease and length of stay data 22-23

Please note this centrally held data needs to be validated by the data management teams and clinicians of the respective trusts, this is work that is being worked on in 23-24. It is strongly recommended that no conclusions or outcomes are derived from this data set,

### Number of non-elective Imperial paediatric Sickle Cell admissions each year including 0 day admissions\*

Year	Number of Non-elective admissions	Number of Unique patients	Number of readmissions within 28 days	Percentage of patients being readmitted within 28 days	Average Length of Stay (Mean)	Average Length of Stay (Median)	Admissions resulting in length of stay of over 20 days
2018/19	64	39	7	12.28%	4.87	3.5	0
2019/20	48	35	2	4.35%	3.85	3	1
2020/21	26	21	1	4%	3.19	2	0
2021/22	55	38	6	12.24%	4.62	3	1
2022/23	96	62	10	10.4%	2.56	1	0

### Number of non-elective Imperial paediatric Sickle Cell admissions each year excluding 0 day admissions

Year	Number of Non-elective admissions	Number of Unique patients	Number of readmissions within 28 days	Percentage of patients being readmitted within 28 days	Average Length of Stay (Mean)	Average Length of Stay (Median)	Admissions resulting in length of stay of over 20 days
2018/19	61	39	7	12.96%	5.1	4	0
2019/20	41	32	1	2.5%	4.5	4	1
2020/21	21	17	1	5%	2.8	2	0
2021/22	42	32	3	7.1%	6.1	4	1

2022/23	56	41	4	9.8%	4.39	2.5	0
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Number of non-elective adult Sickle Cell admissions at Imperial each year including 0 day admissions\*

Year	Number of Non-elective admissions	Number of Unique patients	Number of readmissions within 28 days	Percentage of patients being readmitted within 28 days	Average Length of Stay	Average Length of Stay	Admissions resulting in length of stay of over 20 days
					Mean	Median	
2018/19	446	139	192	75.6%	5.2	2	27
2019/20	481	147	218	82.9%	5.03	2	24
2020/21	417	120	212	103.4%	4.17	1	9
2021/22	553	161	250	82.5%	4.7	2	18
2022/23	601	163	286	91.4%	5.53	3	28

Number of non-elective adult Sickle Cell admissions at Imperial each year excluding 0 day admissions

Year	Number of Non-elective admissions	Number of Unique patients	Number of readmissions within 28 days	Percentage of patients being readmitted within 28 days	Average Length of Stay	Average Length of Stay	Admissions resulting in length of stay of over 20 days
					Mean	Median	
2018/19	306	118	114	59.3%	7.6	5	27
2019/20	331	124	116	53.9%	7.3	4	24
2020/21	250	96	92	58.2%	6.9	4	9
2021/22	387	137	133	52.35%	6.71	4	18
2022/23	417	137	163	52.1%	7.97	6	28

Number of non-elective paediatric Sickle Cell admissions at St Georges each year including 0 day admissions\*

Year	Number of Non-elective admissions	Number of Unique patients	Number of readmissions within 28 days	Percentage of patients being readmitted within 28 days	Average Length of Stay (Mean)	Average Length of Stay (Median)	Admissions resulting in length of stay of over 20 days
2018/19	44	33	1	2.3%	3.1	2	0
2019/20	44	29	3	7.3%	2.4	2	0
2020/21	35	24	5	16.7%	6.1	4	1
2021/22	49	35	5	10.2%	4.3	4	0
2022/23	37	27	2	5.4%	3.4	3	0

Number of non-elective paediatric Sickle Cell admissions at St Georges each year excluding 0 day admissions

Year	Number of Non-elective admissions	Number of Unique patients	Number of readmissions within 28 days	Percentage of patients being readmitted within 28 days	Average Length of Stay (Mean)	Average Length of Stay (Median)	Admissions resulting in length of stay of over 20 days
2018/19	38	30	1	2.7%	3.6	2	0
2019/20	40	27	2	5.3%	2.8	2	0
2020/21	33	23	5	17.7%	6.5	4	1
2021/22	48	34	5	10.4%	4.4	4	0
2022/23	36	26	2	5.6%	3.5	3	0

Number of non-elective adult Sickle Cell admissions at St Georges each year including 0 day admissions\*

Year	Number of Non-elective admissions	Number of Unique patients	Number of readmissions within 28 days	Percentage of patients being readmitted within 28 days	Average Length of Stay (Mean)	Average Length of Stay (Median)	Admissions resulting in length of stay of over 20 days
2018/19	253	111	64	33.9%	5.5	4	7
2019/20	224	116	31	16.1%	5	3	6
2020/21	137	69	22	19.1%	5	3	2
2021/22	218	106	51	23.3%	6.5	4	8
2022/23	177	98	18	10.1%	7.45	4	11

Number of non-elective adult Sickle Cell admissions at St Georges each year excluding 0 day admissions

Year	Number of Non-elective admissions	Number of Unique patients	Number of readmissions within 28 days	Percentage of patients being readmitted within 28 days	Average Length of Stay (Mean)	Average Length of Stay (Median)	Admissions resulting in length of stay of over 20 days
2018/19	237	106	59	33.15%	5.9	4	7
2019/20	199	107	23	13.1%	5.6	4	6
2020/21	127	65	12	10.4%	5.4	4	2
2021/22	199	105	43	21.6%	7.21	5	8
2022/23	169	96	18	10.6%	7.8	5	11

Number of non-elective paediatric Sickle Cell admissions at London North West each year including 0 day admissions\*

Year	Number of Non-elective admissions	Number of Unique patients	Number of readmissions within 28 days	Percentage of patients being readmitted	Average Length of Stay (Mean)	Average Length of Stay (Median)	Admissions resulting in length of stay of over 20 days
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				within 28 days			
2018/19	76	42	11	16.9%	2.97	3	0
2019/20	86	36	22	34.3%	2.81	2.5	0
2020/21	33	21	4	13.8%	3.45	3	0
2021/22	48	29	7	17.1%	3.52	1	1
2022/23	64	36	8	12.5%	2.89	2.5	0

Number of non-elective paediatric Sickle Cell admissions at London North West each year excluding 0 day admissions

Year	Number of Non-elective admissions	Number of Unique patients	Number of readmissions within 28 days	Percentage of patients being readmitted within 28 days	Average Length of Stay (Mean)	Average Length of Stay (Median)	Admissions resulting in length of stay of over 20 days
2018/19	64	35	9	16.3%	3.53	3	0
2019/20	70	32	17	32%	3.46	3	0
2020/21	28	18	4	16.6%	4.07	3	0
2021/22	38	23	7	22.5%	4.26	2	1
2022/23	55	31	8	14.6%	3.36	3	0

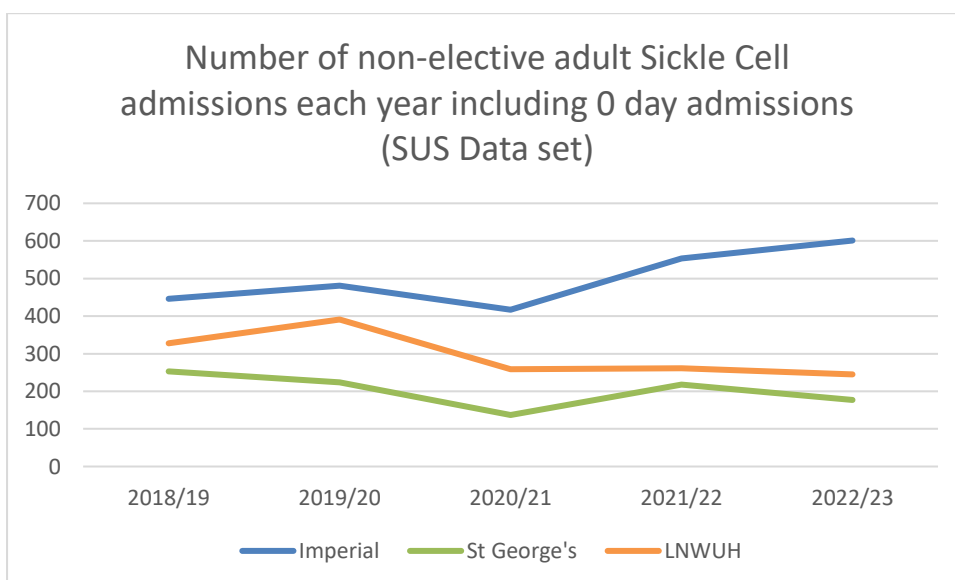
Number of non-elective adult Sickle Cell admissions at London North West each year including 0 day admissions\*

Year	Number of Non-elective admissions	Number of Unique patients	Number of readmissions within 28 days	Percentage of patients being readmitted within 28 days	Average Length of Stay (Mean)	Average Length of Stay (Median)	Admissions resulting in length of stay of over 20 days
2018/19	328	135			3.11	2	3

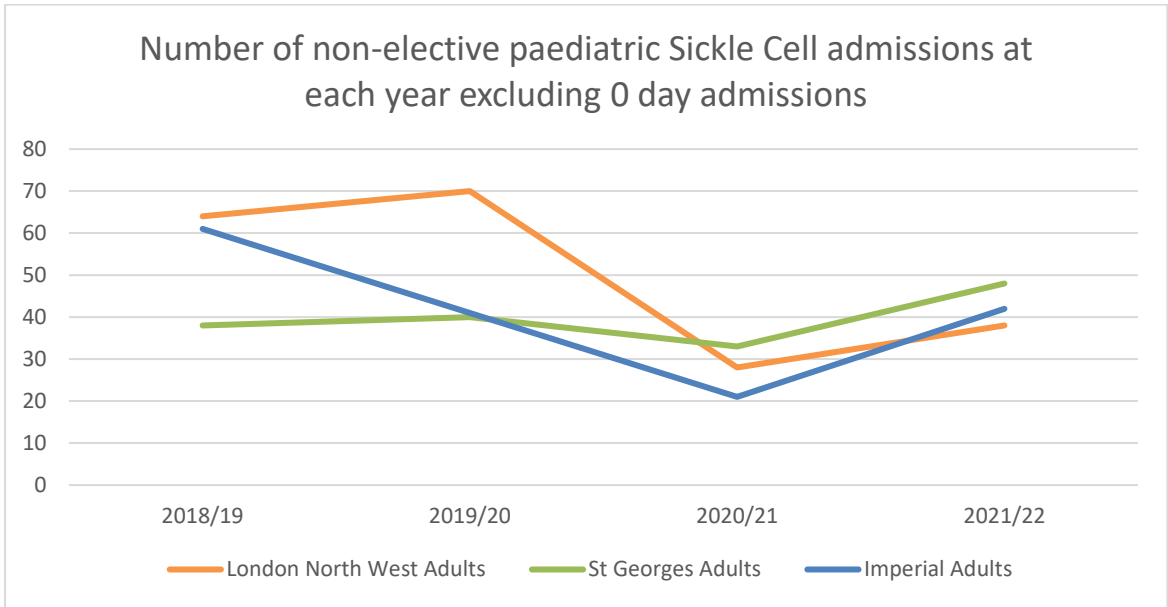
2019/20	391	126			2	1	1
2020/21	259	85			2.61	2	0
2021/22	261	112	75	40.3%	2.79	2	0
2022/23	245	106	83	33.8%	3.6	3	2

Number of non-elective adult Sickle Cell admissions at London North West each year excluding 0 day admissions

Year	Number of Non-elective admissions	Number of Unique patients	Number of readmissions within 28 days	Percentage of patients being readmitted within 28 days	Average Length of Stay (Mean)	Average Length of Stay (Median)	Admissions resulting in length of stay of over 20 days
2018/19	231	111			3.58	3	3
2019/20	246	98			3.18	2	1
2020/21	191	67			3.36	3	0
2021/22	206	93	55	26.6%	3.5	3	0
2022/23	216	92	73	33.7%	4.1	3	2







## Proportion of patients that have admissions resulting in length of stay of over 20 days (HAEMCC08b)

Please note the below data includes information from the LHTs (Local Haemoglobinopathy teams) as well as the SHTs (Specialist Haemoglobinopathy Teams)

				Apr-22	May22	Jun-22	Jul-22	Aug-22	Sep-22	Oct-22	Nov-22	Dec-22	Jan-23	Feb-23	Mar-23	Annual Total		
HAEMCC08b	Proportion of patients that have admissions resulting in length of stay of over 20 days	HCC Adult	Numerator	5	2	1	5	6	7	3	7	2	3	0	6	47		
			Denominator	89	102	113	113	110	110	105	97	106	93	119	138	1295		
			Percentage	6%	2%	1%	4%	5%	6%	3%	7%	2%	3%	0%	4%	4%		
		HCC Children	Numerator	1	0	0	0	0	0	0	0	0	0	0	0	0	0	1
			Denominator	16	26	31	32	31	29	37	26	22	37	41	37	365		
			Percentage	6%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	

## Proportion of significant complications (as defined by National Haemoglobinopathy Registry) that are discussed at the HCC morbidity / mortality meetings (HAEMCC09a)

Please note the below data includes information from the SHTs (Specialist Haemoglobinopathy Teams), Covid-19 cases were also discussed at the HCC adverse event MDTs but have not been included in these figures

Proportion of significant complications (as defined by National Haemoglobinopathy Registry) that are discussed at the HCC morbidity / mortality meetings	<p>Numerator: Of those in the denominator, the number of significant complications discussed at HCC morbidity / mortality meeting</p> <p>Denominator: The total number of regional significant complications in the reporting period</p>		Apr-22	May-22	Jun-22	Jul-22	Aug-22	Sep-22	Oct-22	Nov-22	Dec-22	Jan-23	Feb-23	Mar-23	Annual Total	
		HCC Adult	Numerator	4	4	8	1	1	8	10	15	3	2	17	9	82
			Denominator	4	4	8	1	1	8	10	15	3	2	17	9	82
			Percentage	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%
HCC Children	Numerator	2	1	2	2	1	2	2	4	3	2	1	4	26		
	Denominator	2	1	2	2	1	2	2	4	3	2	1	4	26		
	Percentage	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%		

## Proportion of patient deaths discussed at HCC morbidity/mortality meetings (HAEMCC09b)

At the HCC MDT meetings patient deaths are presented as cases by the respective consultants of the service where the patient passed away. Work is being undertaken by the research group to see if mortality rate can be worked on as a defined metric from the HCC.

					Apr -22	May -22	Jun -22	Jul -22	Aug -22	Sep -22	Oct -22	Nov -22	Dec -22	Jan -23	Feb -23	Mar -23	Annual Total			
HAEM CC09b	<b>Proportion of patient deaths discussed at HCC morbidity/mortality meetings</b>	<p><b>Numerator:</b> Of those in the denominator, the number of deaths discussed at HCC morbidity / mortality meeting</p> <p><b>Denominator:</b> The total number of regional deaths in the reporting period</p>	<b>HCC Adult</b>	Numerator	0	0	0	0	0	2	0	1	0	0	0	3	6			
				Denominator	0	0	3	0	1	2	1	2	0	2	0	3	14			
				<b>Percentage</b>			0%		0%	100%	0%	50%		0%		100%				
			<b>HCC Children</b>	Numerator	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
				Denominator	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
				<b>Percentage</b>																

## Proportion of patients registered on the National Haemoglobinopathy Register across the HCC network (HAEMCC10)

Please note these numbers are derived from the HCC's SHTs there are some patients registered at the LHTs who have not been uploaded to the NHR due to lack of data management support, HCC will work on establishing patient numbers at the LHTs and seeing if there are ways these patients can be uploaded to the NHR

<b>Proportion of patients registered on the National Haemoglobinopathy Register across the HCC network</b>	<b>Numerator:</b> Of those in the denominator, the number of patients on NHR	<b>HCC Adult</b>	Numerator	1236
			Denominator	1335
			<b>Percentage</b>	<b>93%</b>
	<b>Denominator:</b> The total number of patients in network (at time of submission)	<b>HCC Children</b>	Numerator	569
			Denominator	662
			<b>Percentage</b>	<b>86%</b>

## Proportion of patients referred for gene therapy and haematopoietic stem cell transplantation (HAEMCC12)

At the HCC MDT this year 9 patients have been put forward for discussion on the option of Stem Cell Transplant

				Apr -22	May- 22	Jun -22	Jul -22	Aug -22	Sep -22	Oct -22	Nov -22	Dec -22	Jan -23	Feb -23	Mar -23	Annual Total		
<b>Proportion of patients referred for gene therapy and haematopoietic stem cell transplantation</b>	<p><b>Numerator:</b> Of those in the denominator, the number of patients referred for gene therapy and haematopoietic stem cell transplantation</p> <p><b>Denominator:</b> The total number of patients in network (at time of submission)</p>	<b>HCC Adult</b>	Numerator	0	0	0	0	0	0	1	0	0	0	0	1	2		
			Denominator	0	0	0	0	0	0	1	0	0	0	0	0	1	2	
			<b>Percentage</b>	-	-	-	-	-	-	-	<b>100%</b>	-	-	-	-	<b>100%</b>	-	
		<b>Children</b>	Numerator	0	0	0	0	0	0	0	0	0	0	0	0	2	0	2
			Denominator	0	0	0	0	0	0	0	0	0	0	0	0	2	0	2
																		-
			<b>Percentage</b>	-	-	-	-	-	-	-	-	-	-	-	-	<b>100%</b>	-	

## Appendix 1-Service Specification

A copy of the NHS England Service specification is embedded below.



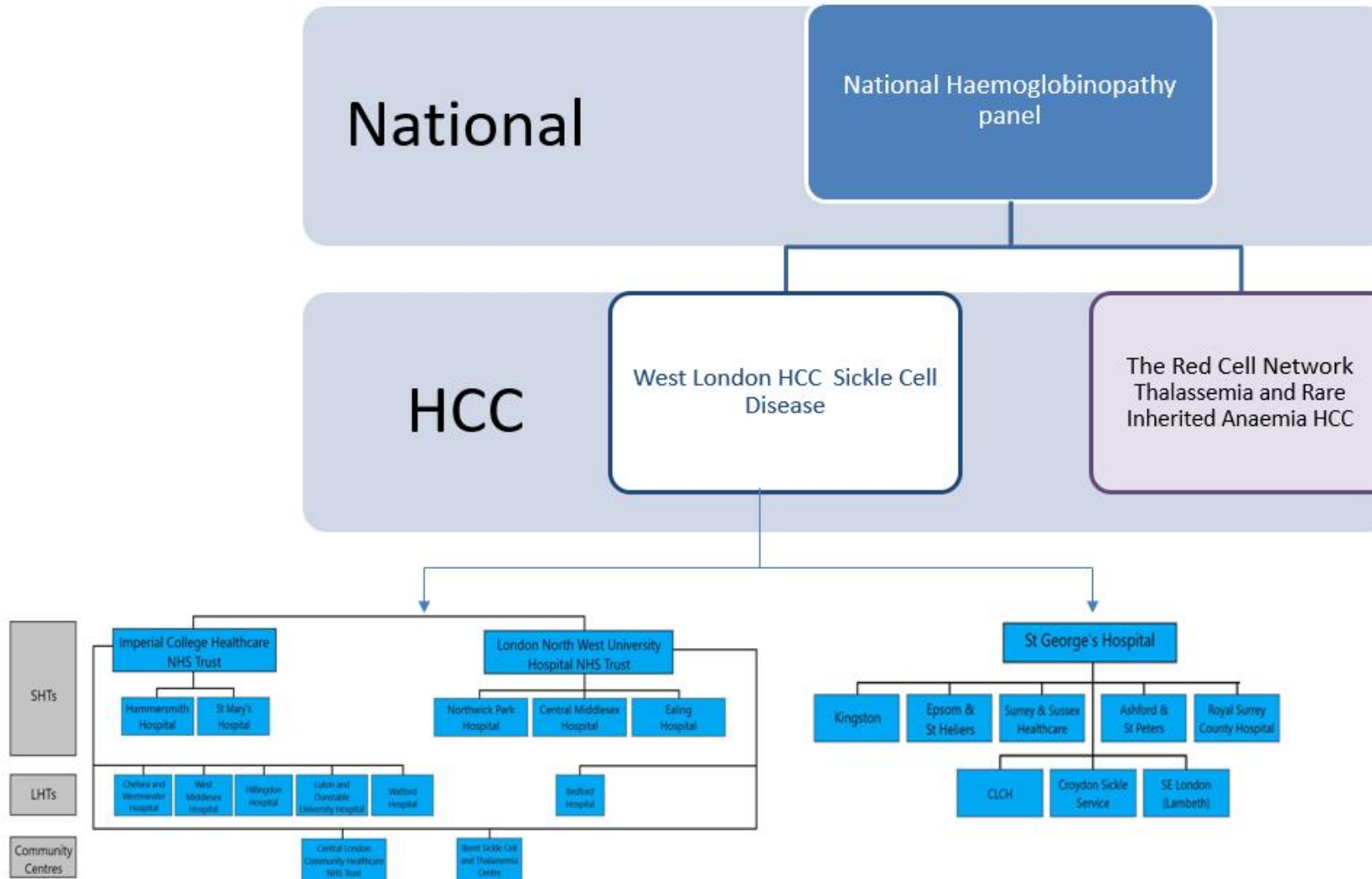
Document 3a-  
Haemoglobinopath;

Embed a copy of the peer review standards



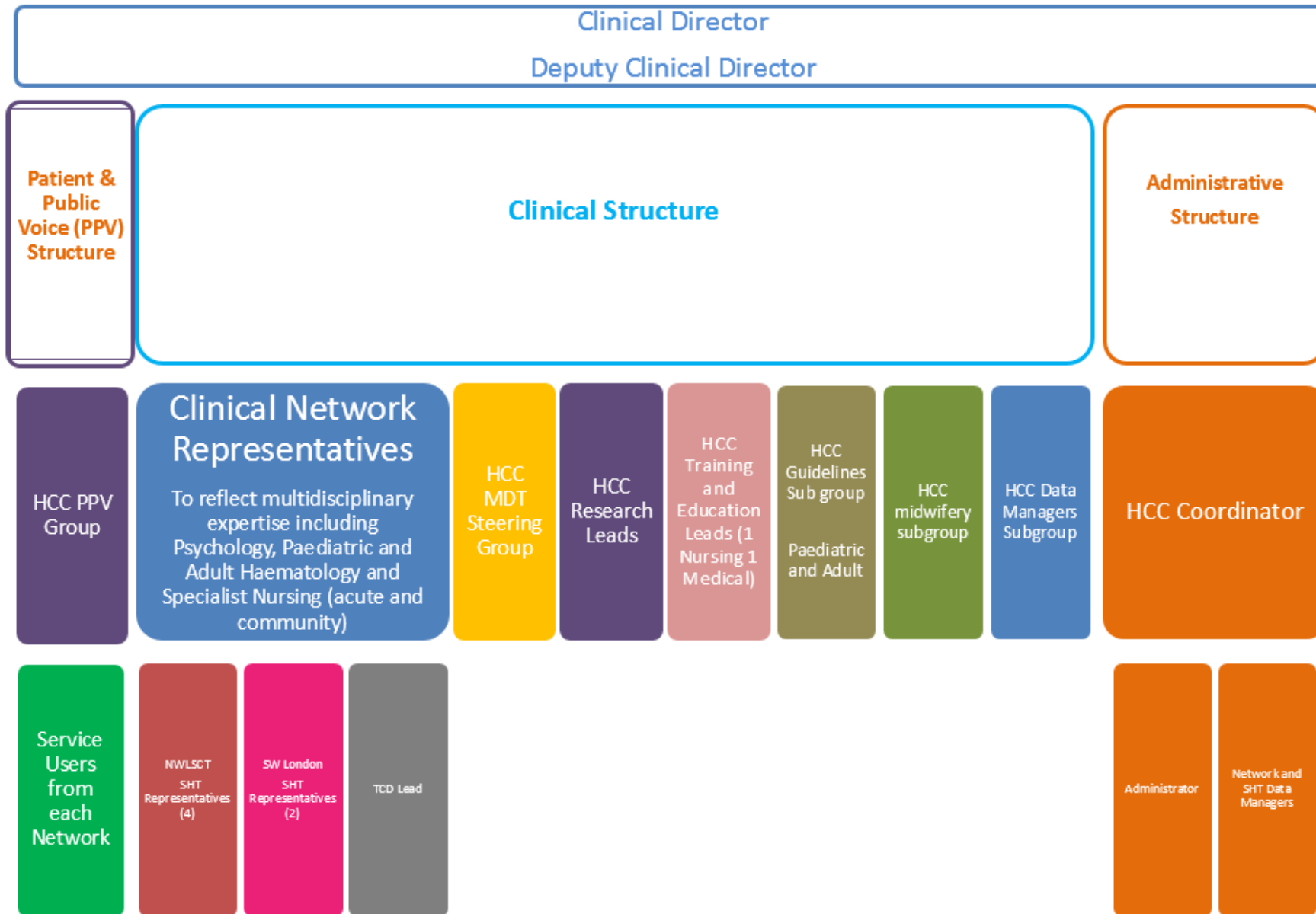
QS Haemoglobin  
Disorders V5 202111

## Appendix 2-Network Organogram





## Appendix 3-Network Structure



## Appendix 4- Key Positions within the Network

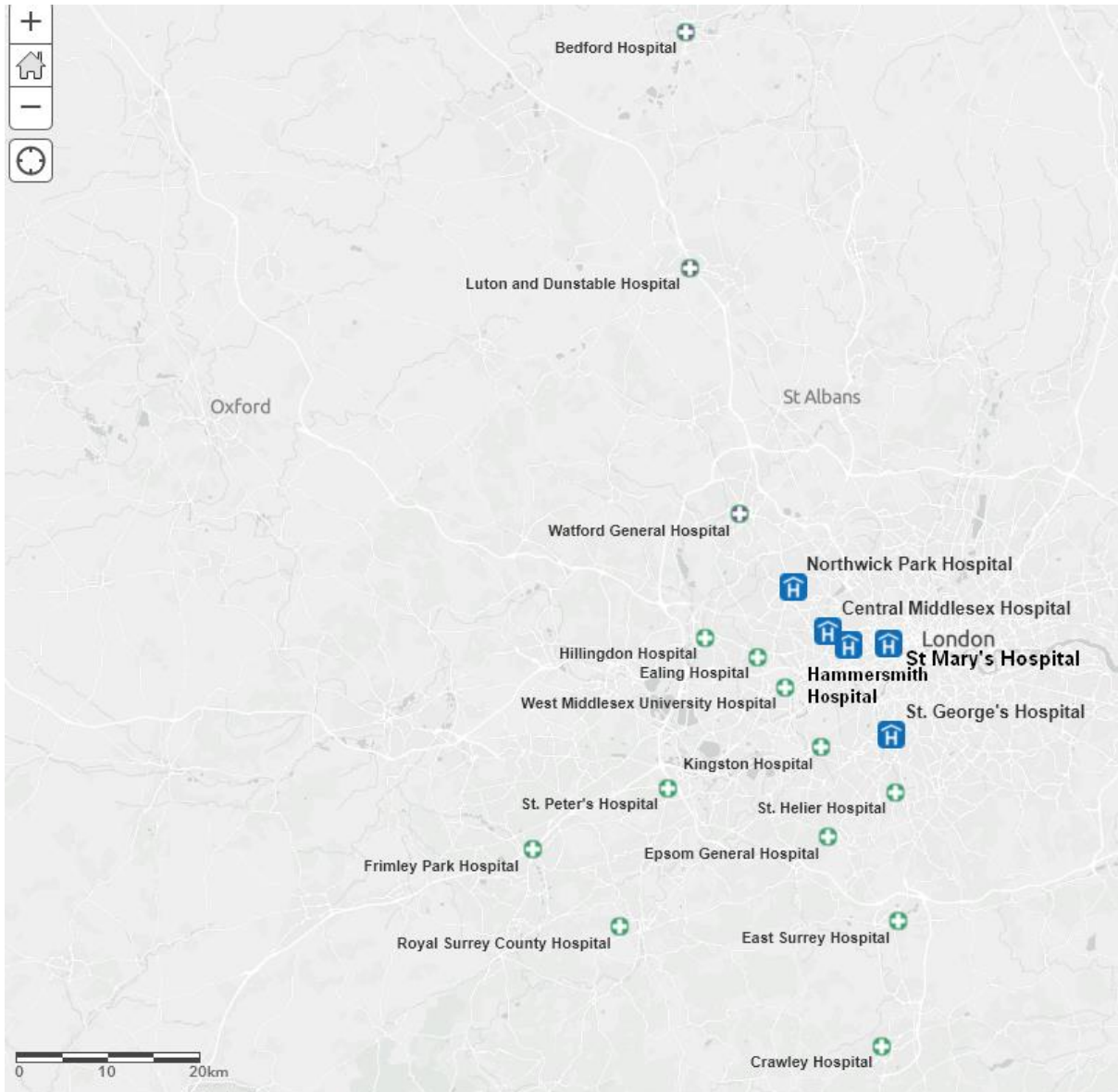
The below table details the key clinical and administrative positions within the West London HCC network

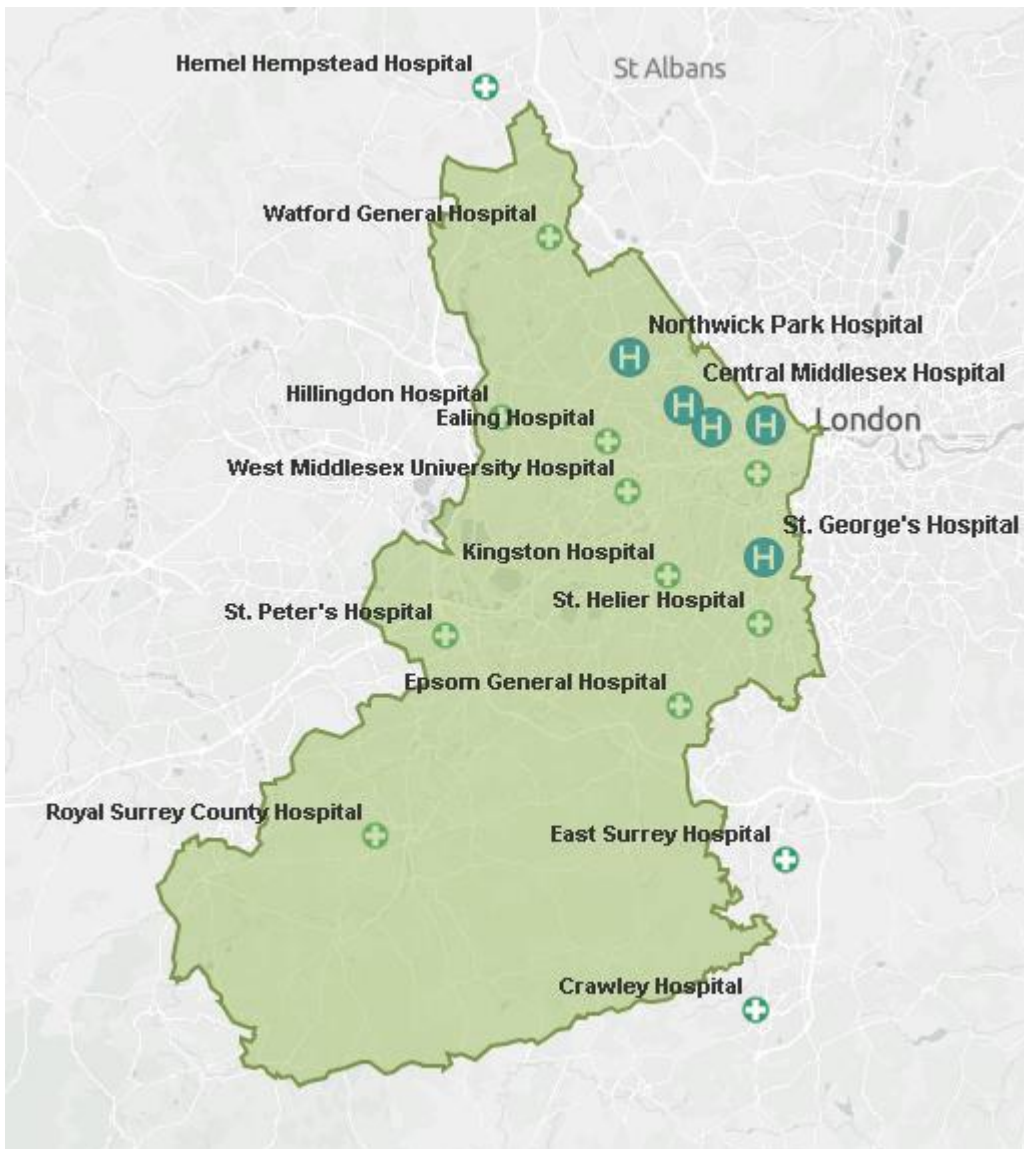
<b>Position</b>	<b>Member of Staff</b>	<b>Associated Hospital</b>
Clinical HCC Director	Mark Layton	Imperial College Healthcare NHS Trust
Deputy Clinical Network Director	Kofi Anie	London North West University Healthcare NHS Trust
HCC Coordinator	Ralph Brown	
HCC Administrator	Eniola Kuseju	
HCC MDT Steering Group	Asad Luqmani  Julia Sikorska/ Lizzie Rhodes  Alison Thomas/Rubina Malik  Kirstin Lund	Imperial College Healthcare NHS Trust  St George's University Hospitals NHS Foundation Trust  St George's University Hospitals NHS Foundation Trust  Imperial College Healthcare NHS Trust
HCC Training and Education Leads	Nadia Osman (Keisha Osmond-Joseph from Apr. 23)  Mamta Sohal	London North West University Healthcare NHS Trust  Imperial College Healthcare NHS Trust
HCC Research Leads	Kofi Anie  Fred Piel  Josu de la Fuente	London Northwest University Healthcare NHS Trust  Imperial College London  Imperial College Healthcare NHS Trust
HCC TCD Lead	Nazia Saeed	London Northwest University Healthcare NHS Trust
Paediatric guidelines and sub group lead	Kirstin Lund	Imperial College Healthcare NHS Trust
Adult Guidelines Sub group lead	Mamta Sohal	Imperial College Healthcare NHS Trust
SW London Network Clinical SHT Representative	Alison Thomas/Rubina Malik	St George's University Hospitals NHS Foundation Trust
SW London Network Clinical SHT Representative	Julia Sikorska/ Lizzie Rhodes	St George's University Hospitals NHS Foundation Trust

Key Positions within the Network continued

<b>Position</b>	<b>Person</b>	<b>Associated Organisation</b>
NWLSCT Clinical SHT Representative	Asad Luqmani	Imperial College Healthcare NHS Trust
NWLSCT Clinical SHT Representative	Kirstin Lund	Imperial College Healthcare NHS Trust
NWLSCT Clinical SHT Representative	Lola Oni/Jacqui Bowyer	London Northwest University Healthcare NHS Trust
NWLSCT Clinical SHT Representative	Sheana Wijemanne	London Northwest University Healthcare NHS Trust
Patient/Carer representatives	Patrick Ojeer  Sonia Meikle	

## Appendix 5-Maps of the HCC





Please note in this map the boundary of the HCC is due to be discussed with some of the surrounding network (this is applicable for the districts of Hertsmere and Reigate & Banstead)

## Appendix 6- HCC MDT 2022/23 attendance

MDT Attendance	Friday	Wednesday	Friday	Wednesday	Friday	Wednesday	Friday	Friday	Friday	Wednesday	Wednesday	Wednesday	Friday	Friday
	17.03.2023	22.02.2023	20.01.2023	21.12.2022	18.11.2022	19.10.2022	23.09.2022	16.09.2022	15.07.2022	15.06.2022	20.05.2022	14.05.2022	20.04.2022	01.04.2022
Cases	6	2	13	13	14	2	6	20	2	7	16		4	15
Attendance	21	27	29	21	30	21	22	29	22	25	36	21	25	25
<u>Job Types</u>														
Haematology Consultants	5	8	7	8	11	9	2	9	7	7	9	2	8	9
Paediatric Haematology and General Paediatric Consultants	3	3	4	1	5	4	4	4	3	3	8	2	3	3
SpR/Trainee Doctors	1	1	2	1										
Nursing Staff	5	5	9	4	9	5	7	6	4	5	7	9	6	7
Psychologists		1	1	1		1	1	1	1		1	1		
Other Allied Health Professionals	7	9	6	6	5	2	8	9	7	10	11	6	8	6
<u>SHTs</u>														
Imperial College Healthcare NHS Trust	9	12	8	8	8	6	5	7	4	10	12	3	7	7
London North West University Healthcare NHS Trust	1	4	9	4	6	4	5	7	7	2	7	9	4	4
St George's University Hospitals NHS Foundation Trust	2	2	3	2	2	2	1	2		2	2	1	1	1
<u>LHTs</u>														
Luton And Dunstable University Hospital NHS Foundation Trust						1		1						

Central London Community Healthcare NHS Trust	1	1		2	3	2	1	1				1	1	1
Ealing Community Partners	1	1							1		1	1	1	1
Kingston Hospital NHS Foundation Trust	2	2			2	1								1
West Hertfordshire Hospitals NHS Trust	2	1			2	1			1	1				
Royal Surrey														
Chelsea and Westminster Hospital NHS Foundation Trust		1	1	1		1	2	1		1	1		1	1
Epsom and St Helier University Hospital NHS Trust											1	1		
Ashford and St Peter's Hospitals NHS Foundation Trust														
Other														
Cambridgeshire Community Services NHS Trust								1	1			2		
Buckinghamshire Healthcare NHS Trust														
Barts Health NHS Trust														
Whittington Health NHS Trust														
Hounslow And Richmond Community Healthcare NHS Trust														
Royal Cornwall Hospitals NHS Trust														
The Royal Marsden NHS Foundation Trust - RPY					1		1	1	1	1	1	1	1	1
Kings College Hospital NHS Foundation Trust													1	1
Other Trusts	1		2	2	2	1	1			2				

SPAH and Welsh Partners														
NHS Greater Glasgow and Clyde	1	1	1	1	3	1		2	2		3		1	2
Cardiff And Vale UHB	2	3	2		3	1	2	2	2	4	4	1	2	2
NHS Grampian		1						1	1				2	2
NHS Lothian			2								2			
NHS Tayside														
NHSBT														
Aneurin Bevan UHB						1	1	1		1	1		1	1
NHS Lanarkshire			1											



## Appendix 7- MDT origin of cases

Where cases came from	Total Adults per centre	Total Paeds per centre	Total Cases all ages per centre
Hammersmith Hospital- Imperial College Healthcare Trust	18	0	18
St Mary's Hospital- Imperial College Healthcare NHS Trust	1	6	7
Whittington/St Mary's Imperial College Healthcare NHS Trust Joint case	0	0	0
Buckinghamshire Healthcare NHS Trust/Imperial College Healthcare Trust Joint case	0	0	0
<b>Total Imperial</b>	<b>19</b>	<b>6</b>	<b>25</b>
St George's University Hospitals NHS Foundation Trust	30	8	38
London North West University Healthcare NHS Trust, Northwick Park Hospital	34	5	39
LHT	0	0	0
West Middlesex Hospital	1	0	1
West Hertfordshire Hospital NHS Trust	0	0	0
SPAH	0	0	0
Glasgow Royal Infirmary	4	0	4
Royal Hospital for Children, Glasgow	0	2	2
ARI, Aberdeen	1	0	1
RHSC Edinburgh	0	1	1
Ninewells Hospital Dundee	0	0	0
Welsh Centres	0	0	0
Noah's Ark Children's Hospital for Wales, Cardiff and Vale UHB	0	1	1
Cardiff and Vale UHB	0	5	5
	<b>89</b>	<b>28</b>	<b>117</b>

Please note of the 53 cases recorded here this includes cases that were brought back to the MDT which is why the figure is higher than the 51 in the body of the text of the report

## Appendix 8- Educational/training activities that have taken place

Date	Topic	Speaker	Target audience	Timing/Web platform	Attendees (number excludes presenters)
17/06/2022	Renal Function and Sickle Cell	Prof Claire Sharpe	All HCC Members and Nephrology teams	Time: 16:00-17:00 60 mins in Length Teams	22
24/06/2022	Ophthalmology and Sickle Cell	Evelyn Mensah	All HCC Members and Ophthalmology teams	Time: 16:00-17:00 60 mins in Length Teams	31
28/06/2022	Diagnosis and Management of Thalassaemia	Asad Luqmani	All HCC Members	Time: 60 mins in Length Teams	
01/07/2022	Psychology of Treatment Adherence	Kofi Anie	All HCC Members	Time: 60 mins in Length Teams	80
23/09/2022	Management of Pregnancy in Sickle Cell Disease	Mamta Sohal	Maternity teams and HCC Members	Time: 16:00-17:00 60 mins in Length Teams	85

11/10/2022	Dentistry for Sickle Cell Patients	Navdeep Kumar	All HCC Members and Dentistry teams	Time: 16:00-17:00 60 mins in Length Teams	23
02/12/2022	Gene Therapy Vertex	Dr Thomas Blair	All HCC Members	Time: 16:00-17:00 60 mins in Length Teams	36
14/12/2022	GP Study session	Mushin Almusawy, Steven Okoli, Jeremy Anderson, Keisha Osmond-Joseph	General Practitioners and Primary care staff	Time: 13:00-15:30 120 mins in Length Teams	43
27/01/2023	Sickle Cell in Emergency Departments	Nadia Osman, Catherine Mkandawire	Paediatric Emergency teams and HCC Members	Time: 16:00-17:00 60 mins in Length Teams	23
03/02/2023	Cerebrovascular Function in Paediatric Sickle Cell Patients and Transcranial Doppler Imaging	Prof. Fenella Kirkham, Prof. Dawn Saunders	Transcranial Doppler practitioners and HCC Members	Time: 16:00-17:00 60 mins in Length Teams	31

17/03/2023	Types of Stroke in Paediatric Sickle cell patients	Prof Fenella Kirkham, Prof. Dawn Saunders		Time: 16:00-17:00 60 mins in Length Teams	21
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## Appendix 9- Details of future sessions being planned by the Education Subgroup

Title of Proposed Session	Speakers	Target audience	Other details
GPs- Hub for West London	Division between 3 consultant speakers from the SHTs	General Practitioners and Primary care staff	
Ophthalmology and Sickle Cell	Dr Evelyn Mensah	All HCC Members	
Renal and Haemoglobinopathies	Prof Claire Sharpe	All HCC Members and Nephrology teams	
Disease modifying agents and trials recruitment	Prof Mark Layton	All HCC Members	
Transcranial Doppler Scans	TCD practitioners	All HCC Members	
Hyper Haemolysis	Dr Ahmad Khoder	All HCC Members	
Paediatric Emergency Department Nursing session		Nursing staff Emergency departments and HCC members	

## Appendix 10- NHP Meeting Attendance

NHP MDT attendance	
4 <sup>th</sup> April 2022	Mark Layton
27 <sup>th</sup> April 2022	Josu de la Fuente, Kofi Anie
23 <sup>rd</sup> May 2022	Josu de la Fuente, Kofi Anie, Mark Layton
29 <sup>th</sup> June 2022	Josu de la Fuente
25 <sup>th</sup> July 2022	Mark Layton
26 <sup>th</sup> September 2022	Josu de la Fuente
26 <sup>th</sup> October 2022	Kofi Anie, Mark Layton
28 <sup>th</sup> November 2022	Kofi Anie, Mark Layton
21 <sup>st</sup> December 2022	Kofi Anie, Mark Layton
23 <sup>rd</sup> January 2023	Josu de la Fuente, Kofi Anie, Mark Layton
22 <sup>nd</sup> February 2023	Josu de la Fuente, Kofi Anie, Mark Layton
27 <sup>th</sup> March 2023	Kofi Anie

NHP Business Meetings attendance	
April 2022	Kofi Anie, Mark Layton
November 2022	Mark Layton

## Appendix 11- Clinical Research within the West London HCC

### Open Trials

Title of Study	SHT the Study is being run from	Sponsor	PI (Principal Investigator) /Contact details of Lead Clinician(s)	Status of the Trial
CLIMB - Thal – 111 A Phase 1/2 study of the safety and efficacy of a single dose of autologous CRISPR-Cas9 Modified CD34+ human hematopoietic stem and progenitor Cells (CTX001) in subjects with transfusion-dependent $\beta$ thalassemia	Imperial College Healthcare NHS Trust	CRISPR Therapeutics/VERTEX	Prof Josu de la Fuente	Paused during Covid-19 surges, other than enrolled patients  18 to 35 years closed to recruitment, but there may be expanded recruitment from April. Open 12 to 17 years and expected to open later on in the year 4 to 11 years
CLIMB - SCD -121 A Phase 1/2 study of the safety and efficacy of a single dose of autologous CRISPR-Cas9 Modified CD34+ human hematopoietic stem and progenitor Cells (CTX001) in subjects with SCD	Imperial College Healthcare NHS Trust	CRISPR Therapeutics/VERTEX	Prof Josu de la Fuente	Paused during Covid-19 surges, other than enrolled patients Open 12 to 35 years of age. Finalising apheresis arrangements for children and young people.
CTX001 – 131 Long-term follow up study (2 to 15 years) of haemoglobinopathy patients having had CTX001	Imperial College Healthcare NHS Trust	CRISPR Therapeutics/VERTEX	Prof Josu de la Fuente	Open Remained open during Covid-19 surges
HGB-210: A Phase 3 Study Evaluating Gene Therapy by Transplantation of Autologous CD34+ Stem Cells Transduced Ex Vivo with the LentiGlobin BB305 Lentiviral	Imperial College Healthcare NHS Trust	Bluebird bio	Prof Josu de la Fuente	Paused but hoped to be opened in 2021 for 4 to 17 years of age.

Vector in Subjects with Severe Sickle Cell Disease.				
<b>Title of Study</b>	<b>SHT the Study is being run from</b>	<b>Sponsor</b>	<b>PI (Principal Investigator) /Contact details of Lead Clinician(s)</b>	<b>Status of the Trial</b>
APL2-PNH-209 An open-label, single-arm, phase 2 study to evaluate the safety, pharmacokinetics, and biologic activity of pegcetocoplan in pediatric patients with PNH	Imperial College Healthcare NHS Trust	Apellis	Prof Josu de la Fuente	12 to 17 years.
COVID-19 in patients with inherited anaemias in England	NHP wide	Imperial College Healthcare NHS Trust	Prof Josu de la Fuente Prof Mark Layton	IRAS granted
Study to assess the effect of long-term treatment with GBT440 in participants who have completed treatment in study GBT440-031	Imperial College Healthcare NHS Trust	Global Blood Therapeutics	Prof Mark Layton	Open  Remained open during Covid-19 surges  Closed to recruitment – in follow-up
Pyruvate Kinase Deficiency Global Longitudinal Registry (PEAK Registry)	Imperial College Healthcare NHS Trust	Agios	Prof Mark Layton	Open Remained open during Covid-19 surges  Open to recruitment
A Phase II multicentre randomized open label two arm study comparing the effect of crizanlizumab + standard of care to standard of care alone on renal function in sickle cell disease patients ≥ 16 years with chronic kidney disease due to sickle cell nephropathy (STEADFAST)	Imperial College Healthcare NHS Trust	Novartis	Dr Asad Luqmani	Update: The study was closed early by the sponsor due to recruitment challenges. They decided to stop recruitment due to difficulties identifying the protocol specified patient population and high screen failure rate (57%). We managed to recruit one patient before recruitment was stopped.. The



				patient is not on treatment anymore.
<b>Title of Study</b>	<b>SHT the Study is being run from</b>	<b>Sponsor</b>	<b>PI (Principal Investigator) /Contact details of Lead Clinician(s)</b>	<b>Status of the Trial</b>
TAPS2 (Transfusion Antenatally in Pregnant Women With SCD) - A Feasibility Trial of Serial Prophylactic Exchange Blood Transfusion in Pregnant Women With Sickle Cell Disease Aiming to Improve Maternal and Infant Outcomes	St George's University Hospitals NHS Foundation Trust		Ms Ingrid Watt-Coote	Re-opened on the week of the 13th of July 2020
TAPS2 Transfusion Antenatally in Pregnant Women With SCD (TAPS2) <a href="https://clinicaltrials.gov/ct2/show/NCT03975894">https://clinicaltrials.gov/ct2/show/NCT03975894</a>	Imperial College Healthcare NHS Trust	Guy's and St Thomas' NHS Foundation Trust	Dr Mamta Sohal	Trial Recruiting Inclusion Criteria: <ul style="list-style-type: none"> <li>•Pregnant women with sickle cell disease (all genotypes)</li> <li>•Gestation 18+0 weeks or below</li> <li>•Singleton pregnancy</li> </ul> Exclusion Criteria: <ul style="list-style-type: none"> <li>•On long term transfusion programme prior to pregnancy for amelioration of SCD</li> <li>•Prior Hyperhaemolysis</li> <li>•Red cell phenotype or antibodies present prevent likely provision of adequate red cell units to support elective EBT programme. Study is now closed to recruitment.</li> </ul>
CSL889_1001 - A Phase 1, Multi-Center, Open-Label, Single Ascending Dose Study to Evaluate the Safety, Tolerability, and Pharmacokinetics of CSL889 in Adult Patients with Stable Sickle Cell Disease	Guy' s and St Thomas	Behring LLC	Prof Mark Layton	We are a PIC site; Trial currently recruiting

RUDY: Rare and Undiagnosed diseases Study (RUDY) - Patient and relatives online survey	Imperial College Healthcare NHS Trust	University of Oxford	Dr Jeremy Andreson	Trial currently recruiting
<b>Title of Study</b>	<b>SHT the Study is being run from</b>	<b>Sponsor</b>	<b>PI (Principal Investigator) /Contact details of Lead Clinician(s)</b>	<b>Status of the Trial</b>
AG348-C-017- A Phase 3, Double-blind, Randomized, Placebo-Controlled, Multicenter Study Evaluating the Efficacy and Safety of Mitapivat in Subjects With Non-Transfusion-Dependent Alpha- or Beta-Thalassemia (ENERGIZE)	Imperial College Healthcare NHS Trust	Agios	Prof Mark Layton	Trial currently recruiting
AG348-C-018-A Phase 3, Double-Blind, Randomized, Placebo-Controlled, Multicenter Study Evaluating the Efficacy and Safety of Mitapivat in Subjects With Transfusion-Dependent Alpha- or Beta-Thalassemia (ENERGIZE-T)	Imperial College Healthcare NHS Trust	Agios	Prof Mark Layton	Trial closed to recruitment

## Studies in Set-up

Title of Study	SHT the Study is being run from	Sponsor	PI (Principal Investigator) /Contact details of Lead Clinician(s)	Status of the Trial
Sickle cell disease and cardiovascular risk - red cell exchange trial (SCD-CARRE) Sponsor	Imperial College Healthcare NHS Trust	NIH	Prof Mark Layton	Trial in set-up stage Trial was abandoned by sponsor
AG348-C-015 Pyruvate Kinase Deficiency Global Longitudinal Registry: Patient-Reported Outcomes linked to 008	Imperial College Healthcare NHS Trust	Agios	Prof Mark Layton	Trial currently recruiting
AG348-C-020 A Phase 2/3, Double-Blind, Randomized, Placebo-Controlled, Multicenter Study to Evaluate the Efficacy and Safety of Mitapivat in Subjects With Sickle Cell Disease	Imperial College Healthcare NHS Trust	Agios	Prof Mark Layton	Recruitment is currently on pause
Forma FT-4202 (PURPOSE)- "Phase 2 Open-Label Study to Evaluate Safety and Clinical Activity of Etavopivat (FT-4202) in patients with Thalassemia or Sickle Cell Disease	Imperial College Healthcare NHS Trust	Forma Therapeutics	Prof Mark Layton	Recruitment will start soon
PRAISE study  An Adaptive, Randomized, Placebo-controlled, Double-blind, Multi-center Study of Oral FT-4202, a Pyruvate Kinase Activator in Patients with Sickle Cell Disease	Imperial College Healthcare NHS Trust	Forma Therapeutics	Prof Josu de la Fuente	Trial currently recruiting
Paed Voxelotor study	Imperial College Healthcare NHS Trust	GBT	Dr Kirstin Lund	

A multicentre trial evaluating the efficacy and safety of oral decitabine- tetrahydrouridine (NDec) in patients with sickle cell disease (ASCENT 1)	London North West University Healthcare NHS Trust	Novo Nordisk	Dr Muhsin Almusawy	Trial currently recruiting
Phase IB study of Crovalimab in the management of Acute Vaso-Occlusive Crises in Sickle Cell Disease (CROSSWALK SCD)	London North West University Healthcare NHS Trust	Roche	Dr Muhsin Almusawy	Trial currently recruiting
DiSC-ELEVEN: Digital Sickle Cell Disease Data Platform and Wearable Device Pilot Project	London North West University Healthcare NHS Trust	Sanius Health	Dr Kofi Anie	Data collection ongoing

#### Studies/Trials closed

<b>Title of Study</b>	<b>SHT the Study is being run from</b>	<b>Sponsor</b>	<b>PI (Principal Investigator) /Contact details of Lead Clinician(s)</b>	<b>Status of the Trial</b>
Adherence to Iron Chelation Therapy with Deferasirox or Desferrioxamine in Thalassaemia and Sickle Cell Disease.	London North West University Healthcare NHS Trust	Novartis Pharmaceuticals UK. /LNWH NHS Trust.	Dr Kofi Anie	Study was completed
Study to evaluate the effect of Voxelotor administered orally to patients with sickle cell disease	Imperial College Healthcare NHS Trust	Sponsor Global Blood Therapeutics	Prof Mark Layton	Closed

A study to determine the efficacy safety pharmacokinetics and pharmacodynamics of AG-348 in adult participants with non-transfusion-dependent thalassaemia	Imperial College Healthcare NHS Trust	Agios	Prof Mark Layton	Closed to recruitment
A study evaluating the efficacy and safety of AG348 in regularly transfused adult participants with pyruvate kinase deficiency	Imperial College Healthcare NHS Trust	Agios	Prof Mark Layton	Closed to recruitment And phase 3 study planned and Phase 3 study due to open
A study evaluating the efficacy and safety of AG348 in not regularly transfused adult participants with pyruvate kinase deficiency Sponsor	Imperial College Healthcare NHS Trust	Agios	Prof Mark Layton	Closed to recruitment In follow-up
<b>Title of Study</b>	<b>SHT the Study is being run from</b>	<b>Sponsor</b>	<b>PI (Principal Investigator) /Contact details of Lead Clinician(s)</b>	<b>Status of the Trial</b>
A randomised, single-blind, placebo-controlled, Phase 1b single ascending and multiple dose first-in-man study in adult patients with non-transfusion-dependent beta-thalassaemia or low risk myelodysplastic syndrome to investigate the safety, tolerability pharmacokinetic and pharmacodynamic response of SLN124	Imperial College Healthcare NHS Trust		Dr Asad Luqmani	SLN124 study is no longer active at Hammersmith Hospital
A randomized, placebo-controlled, Phase 2 Study to evaluate the safety and	Imperial College Healthcare NHS Trust	Cyclerion	Dr Mamta Sohal	Trial has closed 20.07.2020

pharmacodynamics of once-daily oral IW-1701 in patients with stable sickle cell disease				
CATS: Children and Adolescents Telehealth in Sickle Cell.	London North West University Healthcare NHS Trust	Roald Dahl's Marvellous Children's Charity./ LNWH NHS Trust.	Patricia Kiilu	Study Is Now Closed
BO42451 Roche - A RANDOMIZED DOUBLE-BLIND PHASE IIA STUDY EVALUATING THE EFFICACY, SAFETY, PHARMACOKINETICS, AND PHARMACODYNAMICS OF CROVALIMAB AS ADJUNCT TREATMENT IN PREVENTION OF VASO-OCCLUSIVE EPISODES (VOE) IN SICKLE CELL DISEASE (SCD)	Imperial College Healthcare NHS Trust		Dr Steven Okoli	Open to recruitment
A Phase 2a, Randomized, Open-Label Study to Evaluate Multiple Dosing Regimens of Subcutaneous ALXN1820 in Adult Patients with Sickle Cell Disease	Imperial College Healthcare NHS Trust		Dr Steven Okoli	Study in set-up
REDRESS: A multi-centre open randomised controlled trial to assess the effect of related haplo-donor haematopoietic stem cell transplantation versus standard of care (no	Imperial College Healthcare NHS Trust		Dr Steven Okoli	Study in set-up

transplant) on treatment failure at 24 month in adults with severe sickle cell disease				
A Phase 2b, double-blind, randomised, placebo-controlled, multicentre study to assess the efficacy and safety of VIT-2763 multiple doses in adults with sickle cell disease (ViSion Serenity)	Imperial College Healthcare NHS Trust		Dr Asad Luqmani	Study in set-up
<b>Title of Study</b>	<b>SHT the Study is being run from</b>	<b>Sponsor</b>	<b>PI (Principal Investigator) /Contact details of Lead Clinician(s)</b>	<b>Status of the Trial</b>
Adherence to Iron Chelation Therapy with Deferasirox or Desferrioxamine in Thalassaemia and Sickle Cell Disease.	London North West University Healthcare NHS Trust, Recent Studies in Sickle Cell	Novartis Pharmaceuticals UK. /LNWH NHS Trust.	Dr Kofi Anie	Study was completed
Study to evaluate the effect of Voxelotor administered orally to patients with sickle cell disease	Imperial College Healthcare NHS Trust	Sponsor Global Blood Therapeutics	Prof Mark Layton	Closed
A study to determine the efficacy safety pharmacokinetics and pharmacodynamics of AG-348 in adult participants with non-transfusion-dependent thalassaemia	Imperial College Healthcare NHS Trust	Agios	Prof Mark Layton	Closed to recruitment And phase 3 study planned and Phase 3 study due to open
A study evaluating the efficacy and safety of AG348 in regularly transfused adult participants with pyruvate kinase deficiency	Imperial College Healthcare NHS Trust	Agios	Prof Mark Layton	Closed to recruitment And phase 3 study planned and

				Phase 3 study due to open
A study evaluating the efficacy and safety of AG348 in not regularly transfused adult participants with pyruvate kinase deficiency Sponsor	Imperial College Healthcare NHS Trust	Agios	Prof Mark Layton	Closed to recruitment  In follow-up
<b>Title of Study</b>	<b>SHT the Study is being run from</b>	<b>Sponsor</b>	<b>PI (Principal Investigator) /Contact details of Lead Clinician(s)</b>	<b>Status of the Trial</b>
A randomised, single-blind, placebo-controlled, Phase 1b single ascending and multiple dose first-in-man study in adult patients with non-transfusion-dependent beta-thalassaemia or low risk myelodysplastic syndrome to investigate the safety, tolerability pharmacokinetic and pharmacodynamic response of SLN124	Imperial College Healthcare NHS Trust		Dr Asad Luqmani	SLN124 study is no longer active at Hammersmith Hospital
A randomized, placebo-controlled, Phase 2 Study to evaluate the safety and pharmacodynamics of once-daily oral IW-1701 in patients with stable sickle cell disease	Imperial College Healthcare NHS Trust	Cyclerion	Dr Mamta Sohal	Trial has closed 20.07.2020



CATS: Children and Adolescents Telehealth in Sickle Cell.	London North West University Healthcare NHS Trust, Recent Studies in Sickle Cell	Roald Dahl's Marvellous Children's Charity./ LNWH NHS Trust.	Patricia Kiilu	Study Is Now Closed
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NHR

	Total	On NHR	Percentage	SCD only	SCD only on NHR	Percentage
St Georges Adult Database:	427	372	87%	380	341	90%
St Georges Paediatric Database:	249	176	71%	204	176	86%
Imperial Adult Database:	462	418	90%	389	372	96%
Imperial Paediatric Database:	235	215	91%	174	167	96%
LNWH Adult Database:	446	446	100%	360	360	100%
LNWH Paediatric Database:	178	178	100%	145	145	100%
	Total Patients	Total Patients on NHR		Total SCD patients	Total SCD patients on NHR	
	1997	1805	90%	1674	1561	93%