West London Haemoglobinopathies Coordinating Care Centre

West London HCC
2023-24

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London Sickle Cell and Thalassemia Network and the South West London Haemoglobinopathy Network and has now subsumed and superseded their functions/operations.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 2117 patients that have registered on the NHR as of 23/24. The number of adult cases recorded on the NHR is 1380 and Paediatric cases totalling to 737.

Imperial adult cases are 512 and paediatrics 313

London North West adult cases are 441 and paediatrics 230
St George's adult cases are 443 and paediatrics 273

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

Fourth Year Outcomes

Background

In the fourth year of the West London HCC has 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 and contribution to the National education programme
- the running and integration of the Patient and Public Voice group in the functions of the HCC
- the publication of HCC wide guidelines on the management of Sickle Cell disease and development of the HCC's research and audit strategy
- Continual support Website set-up along with social media channels
- Aided in the service development of community improvement projects and Hyper Acute Unit (i.e. emergency department bypass models)

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 -23	May-23	Jun -23	Jul -23	Aug -23	Sep -23	Oct -23	Nov -23	Dec -23	Jan -24	Feb -24	Mar -24	Annual Total
Number of cases being submitted to the HCC MDT	**Adult**		5	6	0	4	4	1	2	4	5	4	0	3	38
	Children		0	4	3	3	0	3	1	2	0	0	0	0	16

Cases referred to the NHP	**Adult**	Number	**5**	**4**	**1**	**2**	**2**	3	2	2	1	3	4	5	34
		Percentage	**100%**	**67%**	**0%**	**50%**	**50%**	33%	100%	50%	20%	75%	0%	167%	**0%**
	Children	Number	**1**	**1**	**1**	**1**	**3**	**3**	**2**	**5**	**7**	**0**	**6**	**1**	31
		Percentage	**0%**	**25%**	**33%**	**0%**	**0%**	**100%**	**200%**	**250%**	**0%**	**0%**	**0%**	**0%**	**0%**

Please note some of the cases referred to the NHP are derived from BMT MDT meetings

Educational/training activities

At the start of 2023-24 Keisha Osmond-Joseph (Nurse Consultant) joined the group as joint lead of the education and training sub group, replacing Nadia Osman (Paediatric CNS at London North West). The educational and training sub group met on a quarterly basis throughout the year with Dr Mamta Sohal and Keisha Osmond-Joseph, a schedule of activity was worked on and has been delivered.

At the start of the year Keisha Osmond-Joseph 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 2023/24 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

- Hydroxycarbamide and New Treatments- Dr Steven Okoli

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 2024/25.

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.

The Clinical trials/Research team of the HCC presented to the PPV group on the 30th of May 2024

Prof. Eduardo Olivarria and Dr Steven Okoli also presented to the patient and public voice group about Bone Marrow Transplant on the 13th of November 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	54 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	65 patients (34 adults 31 paediatrics) forwarded to the national panel MDT please note this included an extensive number of BMT and gene therapy cases that were not discussed at the HCC MDT due to patients being from out of region	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	128	128 adverse Events were recorded across the HCC Of these 100% were uploaded to the NHR Of these 128 were discussed in the HCC MDT	93 Adverse events recorded on the NHR at Imperial 23/24 discussed at the HCCMDT (84 in adults, 9 in	13 Adverse events recorded on the NHR at London Northwest 23/24 discussed at the HCCMDT (13 in Adults,	15 Adverse events recorded on the NHR at St. Georges 23/24 discussed at the HCCMDT (10 in Adults, 5 in Paeds)

			Paeds)	0 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: 97% Percentage of adult patients: 98% Percentage of Paediatric patients: 93.6% There are a total of 1,895 patients recorded on local databases of the SHTs in the WLHCC** Of these 1,226 are adult patients, 669 are paediatric patients Recorded on the NHR are 1,833 patients of which 1,207 adults and 626 paediatric patients	434 adult patients are recorded on the local database 422 on adult patients NHR 240 paediatric patients are recorded on the local database 197 on paediatrics patients NHR	397 adult patients are recorded on the local database 397 on adult patient NHR 189 on paediatric patients 189 on paediatric patients NHR	395 adult patients are recorded on the local database 388 on adult patients NHR 240 paediatric patients 240 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 23-24, 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	HCC Stipulated audits

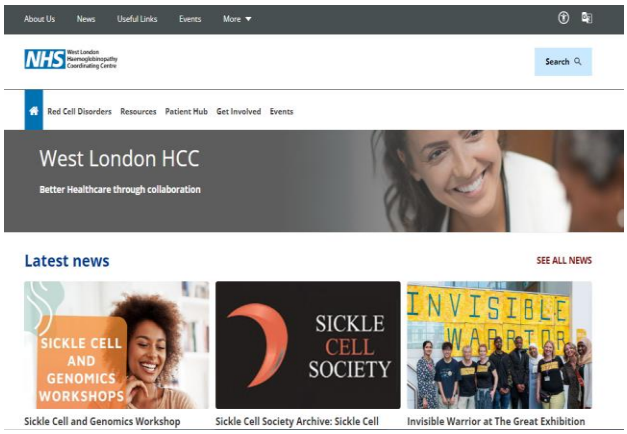
be undertaken	
22-23 Quarter 1	The number of patients who are on and have been asked about Hydroxycarbamide
22-23 Quarter 2	Time to analgesia and pain management in emergency settings, audit of the NICE guidelines To include audit of competencies https://www.nice.org.uk/guidance/cg143
22-23 Quarter 3	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.



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.

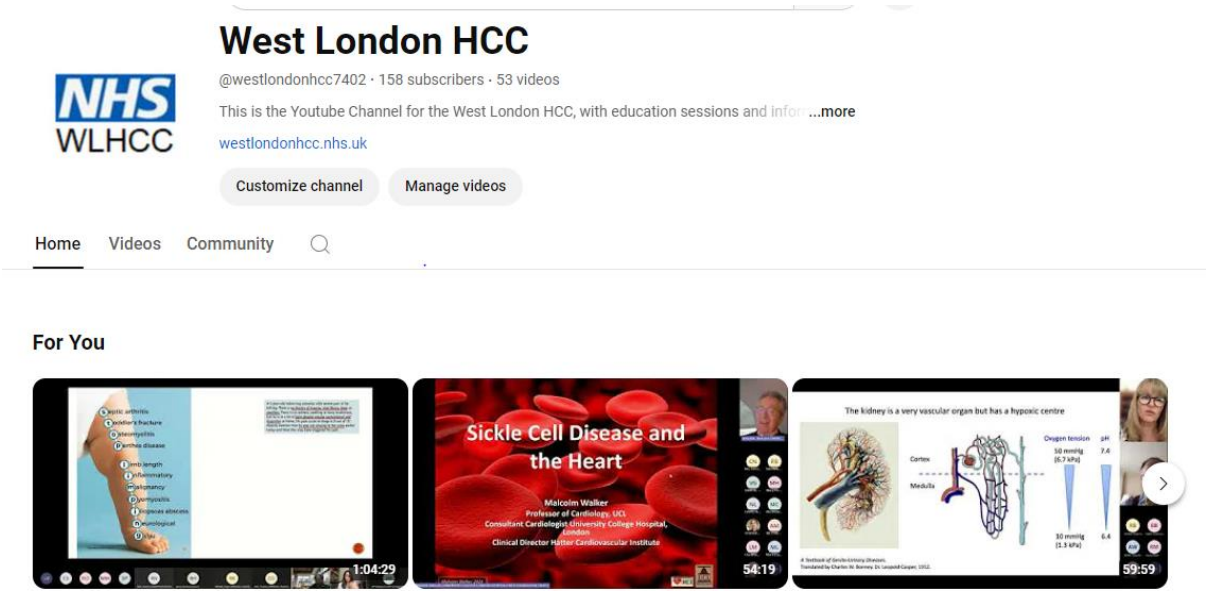
This account can retweet any Sickle related content on the feed but also promote any HCC events being hosted within the network. It can also share any relevant news that may be of interest to our patients.

https://twitter.com/HCCWestLondon

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

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 are being worked on.

Service level agreements between LHTs and SHTs and the HCC detailing individual escalation/referral pathways are being worked on. With some of these being completed in 23/24.

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.


2023-04-21 West London HCC Steerin


2023-07-12 West London HCC Steerin


2023-08-02 West London HCC Steerin


2023-09-06 West London HCC Steerin


2023-10-11 West London HCC Steerin

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 2023/24

Please see Appendix (**10**) 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 this year was on the 25th of May of this year and 6 meetings along with a patient and public voice group away day were held,

The agenda of meetings held so far has included;

- Co-design on service improvements
- Input into the HCC educational programme (which it is hoped will positively impact patient involvement and quality of care),
- Review of data from emergency department pathways
- Feedback to the HCC's approach to the 'APPG report: No one's listening' findings
- Input to HCC the website

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 25.05.2023-

PPV HCC meeting minutes 29.06.2023-

PPV HCC meeting minutes 27.07.2023-

PPV HCC meeting minutes 31.08.2023-

PPV HCC meeting minutes 30.11.2023-

PPV HCC meeting minutes 25.01.2024-

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.

Finances of the HCC

NHS England (NHSE) uplifted the amount of funds given by to the HCC by £11,322 for the year 23/24 to £245,106 (4.7% uplift, rate of inflation 23-24 4.7%). NHSE are looking to uplift the budget of the HCC for 2024/25 post discussions with national commissioners, HCC and clinical teams. Some uplift was given towards the quarter 4 budget of 23/24 in 24/25 however this is not reflected in the figures below.

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 21/22 the HCC was fully staffed and this resulted in an overspend, the original budget of the HCC was not adhered to in an attempt to control the overspend.

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.

During the financial year 23/24 there was an expectation that there will be an overspend on the HCC budget because of increased staffing costs related to inflationary pressures in the wider economy. The figure in the below table indicates this, however there was an uplift to the HCC's budget in quarter 4 which is not included below that covered the loss.

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*	£245,107	£265,537.50	£254,295.05	-£9,188.19

*Please note does not include Q4 uplift from NHSE

Specialist Haemoglobinopathy Teams status 23-24

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 23/24 with work progressing in 24/25

Service updates and challenges in 23/24:

• 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 successfully 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 (its remained fairly flat)

• Expansion of clinical trials team and study portfolio

• Joint working with London North West University Healthcare NHS Trust with a view to consolidate inpatient services at Hammersmith Hospital and expand ambulatory care including a day pain service at Central Middlesex Hospital

• Successful MedTech funding bid has secured an additional apheresis machine and there has been an uplift in apheresis staffing through business planning

• 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 2024/25:

• Hyper Acute Unit and Community projects to be established and recruitment to posts to start

• Apppointment of key posts within the multidisciplinay 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 24/25

• Implementation of the specialist pain management programme

Imperial College Healthcare NHS Trust Paediatric Haemoglobinopathy Service

Service updates and challenges of 23/24 with work progressing in 24/25

Service updates and challenges in 23/24:

Achievements

- Combined team of Haemoglobinopathy matron and Band 6 CNS working well to support the needs of patients
- Expansion of apheresis team following additional funding to enable two Band 7 and one Band 6 positions to be created -recent recruitment into these posts.
- Growth & development of the adolescent transition service involving paediatric and adult teams (increased CNS involvement in patient education & improving patient experience (pe-transition tours of the adult service now well embedded). Plans to have regular psychology presence at the clinic have given the go-ahead (pending recruitment)
- Ongoing support for unwell sickle patients requiring PICU care & emergency RBC exchange from across London
- Ongoing SHT outreach support for Haemoglobinopathy clinics in Northwick Park, Ealing & Bedford. Additional emergency support has also been offered to St George's hospital and its LHTs/GPs to cover maternity leave
- Opening of paediatric gene therapy studies for Thalassaemia (first patient has received this therapy)

Challenges

- Ongoing staffing pressures relating to lack of junior doctor cover (exacerbated at times of industrial action). This results in frequent suboptimal cover of evening/weekend rota & consultants having to act down. The additional pressures have been particularly apparent given the burdens placed on our service by external, unpredictable factors (such as the need to support the Georges' service).
- Paucity of psychology support for sickle cell service (although as outlined above this is in process of being addressed).
- Staffing of on-call apheresis service remains limited to a small body of staff. Recent issue with proposed change to the out-of-hours contract for specialist nurses which has resulted in threat to the continuation of this service - currently in process of consultation
- Challenge in offering a safe, robust paedatric priapism service within our HCC due to lack of specialist urology expertise (has been raised as a Clinical governance issue and is under discussion at a senior management level)

Targets for 2023/24:

- To formalise SLAs for outreach clinics and support offered to other HCC networks

- To recruit into psychology post to enable expansion this service. Coupled with this, to begin to refer patients to the newly developed London-wide peer support service which offers an alternative mode of support for patients
- To negotiate a mutually agreeable apheresis out of hours contract for specialist nurses
- To continue to run the gene therapy studies and enable further paediatric patients to benefit from this novel treatment approach

London North West University Healthcare NHS Trust Adult Haemoglobinopathy Service

Service updates and challenges of 23/24 with work progressing in 24/25

Service updates and challenges:

The wider Haematology team have lost three consultants which has led to pressures on the haemoglobinopathy service.

Out-patient service

- All haemoglobinopathy clinics are MDT and include an acute CNS, nurse consultant, 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, transfusions, and voxelotor.
- There are two consultant haematologists who attend the clinics, and a registrar who supports remotely. The latter position is subject to staffing and availability. A third consultant is on sabbatical until January.
- Routine investigations including Annual blood tests, Echocardiogram, audiometry and T2*MRI, and Ophthalmology reviews are being carried out.
- Elective Red Cell Exchange is carried out both at Northwick Park Hospital and Central Middlesex Hospital
- Routine surgery including orthopaedics is being carried out
- Work is being done to protect time for annual reviews, and formalising blood order sets, discussion of treatment options and blood transfusion

Nurse-Led Clinic

• There is a 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

• The psychologist is present during outpatient clinics. Additional psychology clinics are available 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 time a week. Patients admitted to the Medical Daycare unit are reviewed by the psychologist as required.

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.

In-Patient Care

• Patients with Sickle cell are treated on Drake Ward, James Ward and Dryden ward (the latter for HDU care). Staff in all these wards are trained in the care of patients with sickle cell, and in the use of PCAs. James Ward is preferred for those who are Covid positive on admission. There is ongoing teaching for all staff. The new Emergency Department pathway for sickle cell care introduced last year is being monitored and audited. There are weekly Multi-Disciplinary Team Meetings to monitor patient care.

• 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 HCC is progressing to consolidate inpatient care at Imperial and outpatient care at an expanded comprehensive centre at CMH.

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.
- Transition clinics run once every 3 months. These are MDT clinics as well. Clinics are run by Consultant haematologist from adult team, consultant paediatrician, haemaglobinopathy CNS (adult and paediatrics), community CNS and psychologist.

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 time 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.

In-patient service

- Acutely unwell haemoglobinopathy patients are seen in the A&E department and admitted to Jack’s Place. Patient aged 0-18year are eligible f

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

Service updates and challenges of 23/24 with work progressing in 24/25

- 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. Apheresis new space is still pending
- Business case for third substantive red cell consultant underway. – BC are halted however successful HAU bid will along us to recruit a 3rd consultant
- 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 (e.g. Sickle cell alert cards, education and training). HAU – ED bypass model – really well received by our patient engagement group

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

Service updates and challenges of 23/24 with work progressing in 24/25

- Apheresis – is provided by the adult haematology staff for the age range 13-18 years of age.

  The adult services have no funding or capacity to expand the service for paediatrics. All children outside this age group with sickle cell disease will need to be managed by NHSBT.

  The SLA with NHSBT went on halt in 2023, and there is no final consensus.
- Annual reviews and upload on to the National Haemoglobinopathy Registry remains compromised due to limited consultant availability to complete these. NHR is being uploaded by the CNS.
- Haemoglobinopathy clinics were compromised for few months with acute shortage and the activity has picked up now with some improvement in staffing.

- The transition clinics were affected which is picking up again. .
- Because of the new phlebotomy system since early 2024, where it is required by the parents to book the tests online has compromised on the availability of the results in timely fashion.
- There is a dedicated pain nurse and a dedicated paediatric pain team for inpatients.

Staffing –

- Consultants-The haematology service and haemoglobinopathy service has struggled with shortage of consultant staff over 2023/2024 and it ran into acute crisis towards the end of the year with no paediatric haematologist on site for few months. Partial cover was provided by the general paediatric consultant with haemoglobinopathy interest, managing the on-site service provision, who also managed to liaise with St Mary's team for discussion of the cases and a regular MDT was established. Care of the complex cases was transferred to St Mary's hospital for short-term period. The on call services were provided by the St Mary's team.

  The service is still struggling with limited improvement, staying at 0.6 WTE for haemoglobinopathies however with more sickle clinics created. The on-call services are provided by the St Mary's paediatric haematology as a part of HCC with agreed SLA between the two centres.
- Nursing – The haemoglobinopathy CNS has returned from maternity at 0.8 WTE and work in progress for 0.2 WTE.
- Psychology –New psychologist in post at 0.5 WTE.
- 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 area.
- No data management support for team. The SSQD data has been provided by the CNS and adverse events data provided by Dr Malik.
- No SHT lead at present (on maternity; no cover). SHT lead Dr Thomas will be back from maternity leave in February 2025.
- The haemoglobinopathy services support for HCC (HCC &adverse events MDT), covered by Dr Malik currently, however will be joined by Dr Emma Sage.
- Business and steering meetings covered by the managers.

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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
434 adult patients are recorded on the local database
422 of adult patients are on the NHR

London North West University Healthcare NHS Trust
397 adult patients are recorded on the local database
397 of adult patients are on the NHR

St George's Healthcare NHS Foundation Trust
395 adult patients are recorded on the local database
388 of adult patients are on the NHR

Paediatric Sickle Cell Patients

Imperial College Healthcare NHS Trust
240 paediatrics patients are recorded on the local database
197 of paediatrics patients are on the NHR

London North West University Healthcare NHS Trust
189 paediatrics patients are recorded on the local database
189 of paediatrics patients are on the NHR

St George's Healthcare NHS Foundation Trust
240 paediatrics patients are recorded on the local database
240 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

23/24

No. of patients at each centre	No. of patients active on the at SHTs and linked LHTs	Percentage of patients registered on the NHR	Percentage of annual reviews uploaded to NHR*
Adults			
Hammersmith Hospital (Imperial College Healthcare NHS Trust)	434	(422) 97%	(427) 98%
London North West University Healthcare NHS Trust	397	(397) 100%	(381) 96%
St George's University Hospitals NHS Foundation Trust	395	(388) 98%	(0) 0%
Paediatrics			
No. of patients at each centre	No. of patients active on the at SHTs and linked LHTs	Percentage of patients registered on the NHR	Percentage of annual reviews uploaded to NHR*
St Mary's Hospital (Imperial College Healthcare NHS Trust)	240	(197) 82%	(185) 77%
London North West University Healthcare NHS Trust	189	(189) 100%	(154) 81%
St George's University Hospitals NHS Foundation Trust	240	(240) 100%	(0) 0%

TCDs: Proportion of patients undergoing TCD

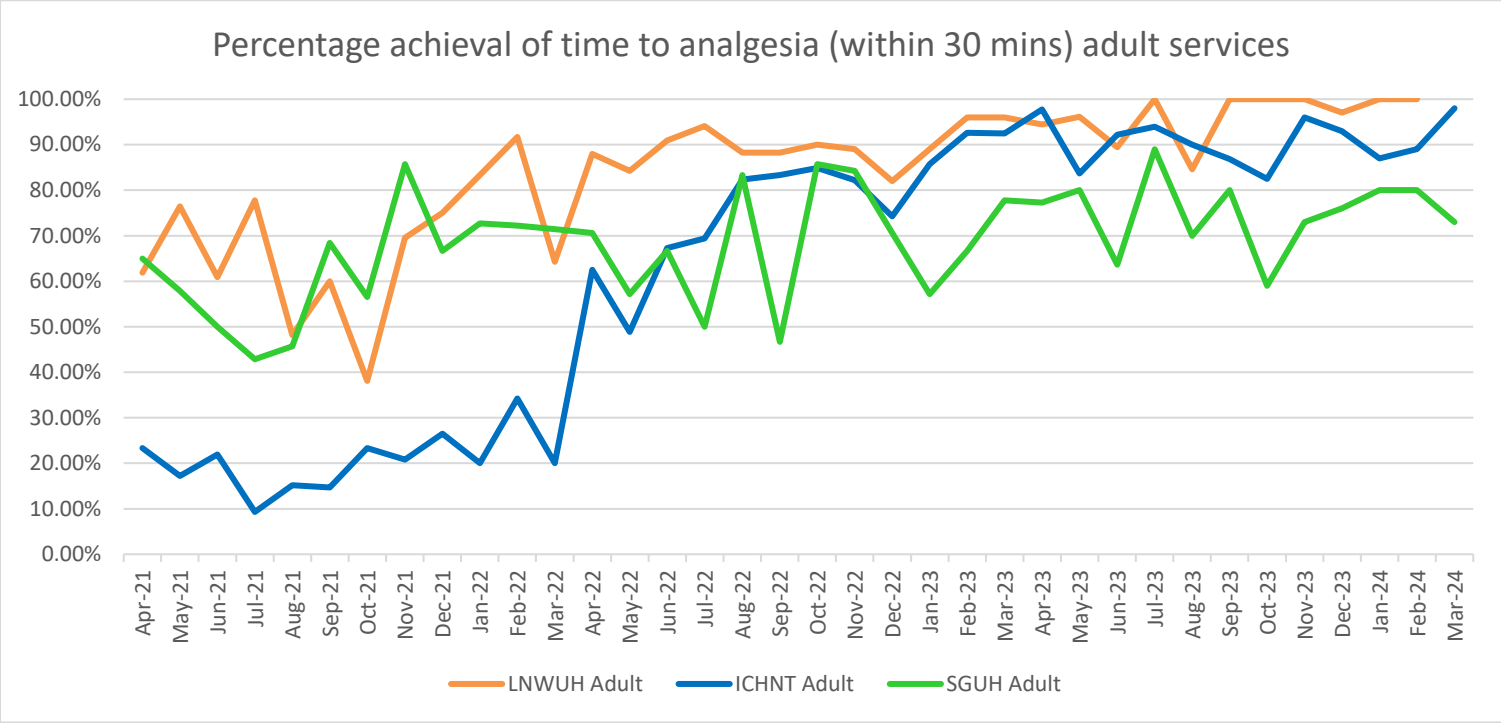
In 2023/2024 the Transcranial Doppler services were re-established/continues and caught up on some of the backlog from the pandemic year,

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	**LNWUH Children**	Numerator	107
			Denominator	108
			Percentage	**99%**
		ICHNT Children	Numerator	95
			Denominator	102
			Percentage	**93%**
		SGUH Children	Numerator	126
			Denominator	135
			Percentage	**93%**

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 23/24

Ref	Description	Trust/ Patient Type		Apr-23	May-23	Jun-23	Jul-23	Aug-23	Sep-23	Oct-23	Nov-23	Dec-23	Jan-24	Feb-24	Mar-24	Total
HAEM03i	Percentage of patients given pain relief within half an hour of presentations with sickle crisis , as per NICE guidelines	**LNWUH Adult**	Numerator	17	25	17	23	11	7	7	24	33	25	33	35	257
			Denominator	18	26	19	23	13	7	7	24	34	25	33	36	265
			Percentage	**94%**	**96%**	**89%**	**100%**	**85%**	**100%**	**100%**	**100%**	**97%**	**100%**	**100%**	**97%**	
		ICHNT Adult	Numerator	44	42	47	62	47	33	52	55	39	40	57	51	569
			Denominator	45	49	50	65	50	38	55	56	42	46	64	52	612
			Percentage	**98%**	**86%**	**94%**	**95%**	**94%**	**87%**	**95%**	**98%**	**93%**	**87%**	**89%**	**98%**	
		SGUH Adult	Numerator	17	16	14	17	14	16	16	11	16	16	16	19	188
			Denominator	22	20	22	19	20	20	27	15	21	20	20	26	252
			Percentage	**77%**	**80%**	**64%**	**89%**	**70%**	**80%**	**59%**	**73%**	**76%**	**80%**	**80%**	**73%**	
		LNWUH Children	Numerator	3	2	2	1	1	0	0	1	2	6	6	10	34
			Denominator	4	2	2	1	1	0	0	1	2	6	6	10	35
			Percentage	**75%**	**100%**	**100%**	**100%**	**100%**	**-**	**-**	**100%**	**100%**	**100%**	**100%**	**100%**	
		ICHNT Children	Numerator	0	0	0	1	4	1	2	1	2	3	1	2	17
			Denominator	1	3	2	3	5	2	3	5	5	7	3	2	41
			Percentage	**0%**	**0%**	**0%**	**33%**	**80%**	**50%**	**67%**	**20%**	**40%**	**43%**	**33%**	**100%**	
		SGUH Children	Numerator	4	1	0	3	2	0	0	2	4	3	5	2	26
			Denominator	6	3	1	4	5	1	1	2	5	3	7	2	40
			Percentage	**67%**	**33%**	**0%**	**75%**	**40%**	**0%**	**0%**	**100%**	**80%**	**100%**	**71%**	**100%**	


Percentage achieval of time to analgesia (within 30 mins) adult services
100.00%
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50.00%
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30.00%
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LNWUH Adult
ICHNT Adult
SGUH Adult

Neonatal screening: Entry into specialist care and proportion of patients commencing antibiotic prophylaxis 23/24

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	4	2	0	0	1	5	1	4	0	3	1	1	22
			Denominator	4	2	0	0	1	5	1	4	0	3	1	1	22
			Percentage	**100%**	**100%**	**-**	**-**	**100%**	**100%**	**100%**	**100%**	**-**	**100%**	**100%**	**100%**	**100%**
		ICHNT Children	Numerator	7												7
			Denominator	7												7
			Percentage													**100%**
		SGUH Children	Numerator	0	1	0	0	1	2	1	0	0	2	0	1	8
			Denominator	0	1	0	0	1	2	1	0	0	2	0	1	8
			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	4	2	0	0	1	5	1	4	0	3	1	1	22
			Denominator	4	2	0	0	1	5	1	4	0	3	1	1	22
			Percentage	**100%**	**100%**	**#DIV/0!**	**#DIV/0!**	**100%**	**100%**	**100%**	**100%**	**#DIV/0!**	**100%**	**100%**	**100%**	**100%**
		ICHNT Children	Numerator	6												6
			Denominator	7												7
			Percentage													**86%**
		SGUH Children	Numerator	7												7
			Denominator	8												8
			Percentage													**88%**

Sickle Cell Disease and length of stay data 23/24

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 24-25. 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
2023/24	98	56	19	19.38%	2.99	1.5	1

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
2023/24	61	32	14	22.9%	4.80	3	1

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	Number of readmissions within 7 days	Percentage of patients being readmitted within 7 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%	70	16%	5.2	2	27
2019/20	481	147	218	82.9%	69	14%	5.03	2	24
2020/21	417	120	212	103.4%	36	9%	4.17	1	9
2021/22	553	161	250	82.5%	60	11%	4.7	2	18
2022/23	601	163	286	91.4%	77	13%	5.53	3	28
2023/24*	675	161	379		162		4.58	2	19

*Need to work on methodology within future data management support

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
2023/24*	441	113	187		7.02	5	19

*Need to work on methodology within future data management support

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
2023/24	47	28	7	14.89%	3.8	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
2023/24	44	27	7	15.90%	4.07	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	Number of readmissions within 7 days	Percentage of patients being readmitted within 7 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%	61	24%	5.5	4	7
2019/20	224	116	31	16.1%	20	9%	5	3	6
2020/21	137	69	22	19.1%	16	12%	5	3	2
2021/22	218	106	51	23.3%	19	9%	6.5	4	8
2022/23	177	98	18	10.1%	11	6%	7.45	4	11
2023/24	209	98	35	16.7%	11	6%	5.67	4	2

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
2023/24	202	93	35	17.3%	5.87	4.5	2

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 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	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
2023/24	23	17	1	4.34%	3.17	2	0

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

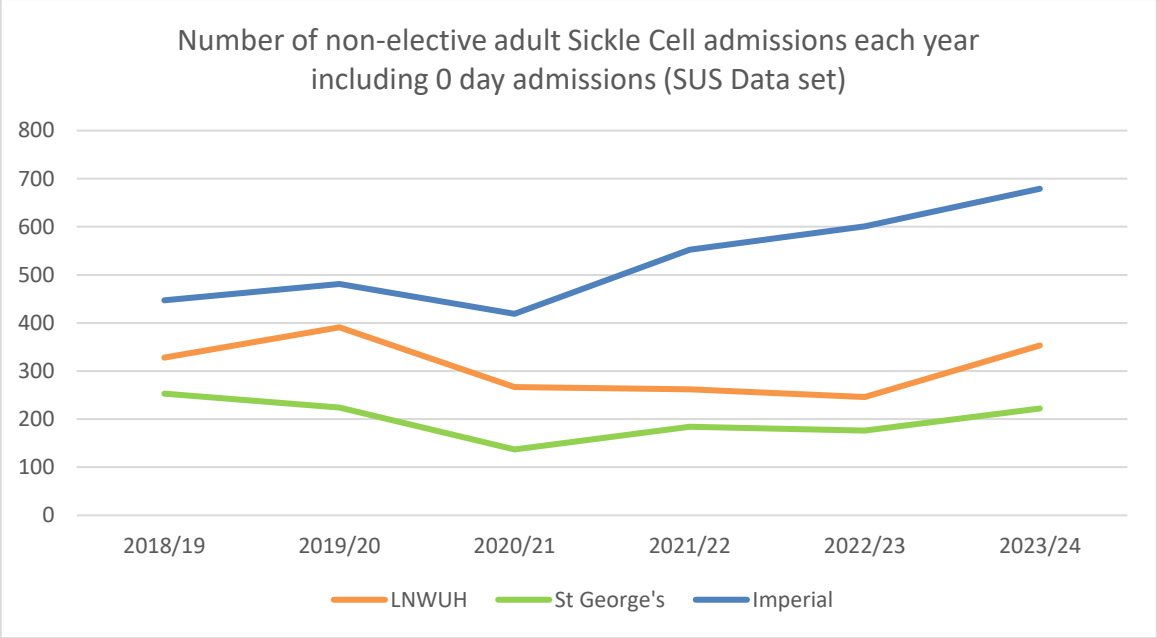
Year	Number of Non-elective admissions	Number of Unique patients	Number of readmissions within 28 days	Percentage of patients being readmitted within 28 days	Average Length of Stay (Mean)	Average Length of Stay (Median)	Admissions resulting in length of stay of over 20 days
2018/19	64	35	9	16.3%	3.53	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
2023/24	21	15	1		3.47	2	0

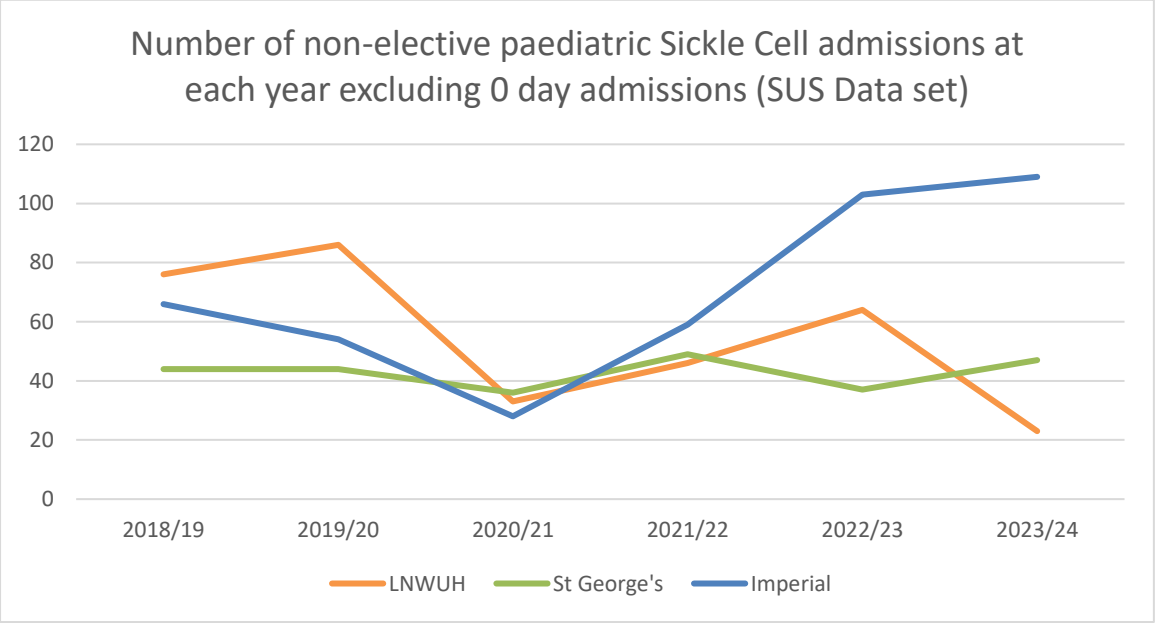
Number of non-elective adult Sickle Cell admissions at London North West each year including 0 day admissions*

Year	Number of Non-elective admissions	Number of Unique patients	Number of re-admissions within 28 days	Percentage of patients being readmitted within 28 days	Number of readmissions within 7 days	Percentage of patients being readmitted within 7 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			41	13%	3.11	2	3
2019/20	391	126			27	7%	2	1	1
2020/21	259	85			18	7%	2.61	2	0
2021/22	261	112	75	40.3%	25	10%	2.79	2	0
2022/23	245	106	83	33.8%	22	9%	3.6	3	2
2023/24	375	114	144	38.4%	71	18.9%	3.76	2	6

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
2023/24	237	88	78	32.91%	4.68	3	6


Number of non-elective adult Sickle Cell admissions each year including 0 day admissions (SUS Data set)
800
700
600
500
400
300
200
100
0
2018/19
2019/20
2020/21
2021/22
2022/23
2023/24
LNWUH
St George's
Imperial


Number of non-elective paediatric Sickle Cell admissions at each year excluding 0 day admissions (SUS Data set)
120
100
80
60
40
20
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2018/19
2019/20
2020/21
2021/22
2022/23
2023/24
LNWUH
St George's
Imperial

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-23	May23	Jun-23	Jul-23	Aug-23	Sep-23	Oct-23	Nov-23	Dec-23	Jan-24	Feb-24	Mar-24	Annual Total
HAEMCC08b	**Proportion of patients that have admissions resulting in length of stay of over 20 days**	**HCC Adult**	Numerator	1	2	2	0	1	6	1	3	6	3	2	5	32
			Denominator	120	124	119	154	99	98	134	109	118	138	114	103	1430
			Percentage	**1%**	**2%**	**2%**	**0%**	**1%**	**6%**	**1%**	**3%**	**5%**	**2%**	**2%**	**5%**	**2%**
		HCC Children	Numerator	0	0	0	1	1	0	1	1	0	0	0	0	4
			Denominator	28	34	24	41	25	20	22	21	25	23	26	25	314
			Percentage	**0%**	**0%**	**0%**	**2%**	**4%**	**0%**	**5%**	**5%**	**0%**	**0%**	**0%**	**0%**	**1%**

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)

				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
Proportion of significant complications (as defined by National Haemoglobinopathy Registry) that are discussed at the HCC morbidity / mortality meetings	Numerator: Of those in the denominator, the number of significant complications discussed at HCC morbidity / mortality meeting Denominator: The total number of regional significant complications in the reporting period	**HCC Adult**	Numerator	4	9	4	11	12	6	4	16	11	8	11	6	102
			Denominator	4	9	4	11	12	6	4	16	11	8	11	6	102
			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) 23/24

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
HAEMCC09b	**Proportion of patient deaths discussed at HCC morbidity/mortality meetings**	Numerator: Of those in the denominator, the number of deaths discussed at HCC morbidity / mortality meeting Denominator: The total number of regional deaths in the reporting period	**HCC Adult**	Numerator	0	0	0	1	0	0	0	1	1	2	0	0	5
				Denominator	0	0	0	1	0	0	0	1	1	2	0	0	5
				Percentage	-	-	-	**100%**	-	-	-	**100%**	**100%**	**100%**	-	-	
			HCC Children	Numerator	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
				Percentage													

Proportion of patients registered on the National Haemoglobinopathy Register across the HCC network (HAEMCC10) 23/24

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

Proportion of patients registered on the National Haemoglobinopathy Register across the HCC network	Numerator: Of those in the denominator, the number of patients on NHR Denominator: The total number of patients in network (at time of submission)	**HCC Adult**	Numerator	1380
			Denominator	1396
			Percentage	**99%**
		HCC Children	Numerator	737
			Denominator	816
			Percentage	**90%**

Proportion of patients referred for gene therapy and haematopoeitic stem cell transplantation (HAEMCC12) 23/24

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

				Apr -23	May-23	Jun -23	Jul -23	Aug -23	Sep -23	Oct -23	Nov -23	Dec -23	Jan -24	Feb -24	Mar -24	Annual Total
Proportion of patients referred for gene therapy and haematopoeitic stem cell transplantation	Numerator: Of those in the denominator, the number of patients referred for gene therapy and haematopoeitic stem cell transplantation Denominator: The total number of patients in network (at time of submission)	**HCC Adult**	Numerator	0	0	0	0	0	1	0	0	0	2	2	1	6
			Denominator	0	0	0	0	0	1	0	0	0	2	2	1	6
			Percentage	-	-	-	-	-	**100%**	-	-	-	**100%**	**100%**	**100%**	**100%**
		Children	Numerator	0	0	0	0	2	0	1	1	0	0	0	0	4
			Denominator	0	0	0	0	2	0	1	1	0	0	0	0	4
			Percentage	-	-	-	-	**100%**	-	**100%**	**100%**	-	-	-	-	-

Appendix 1-Service Specification

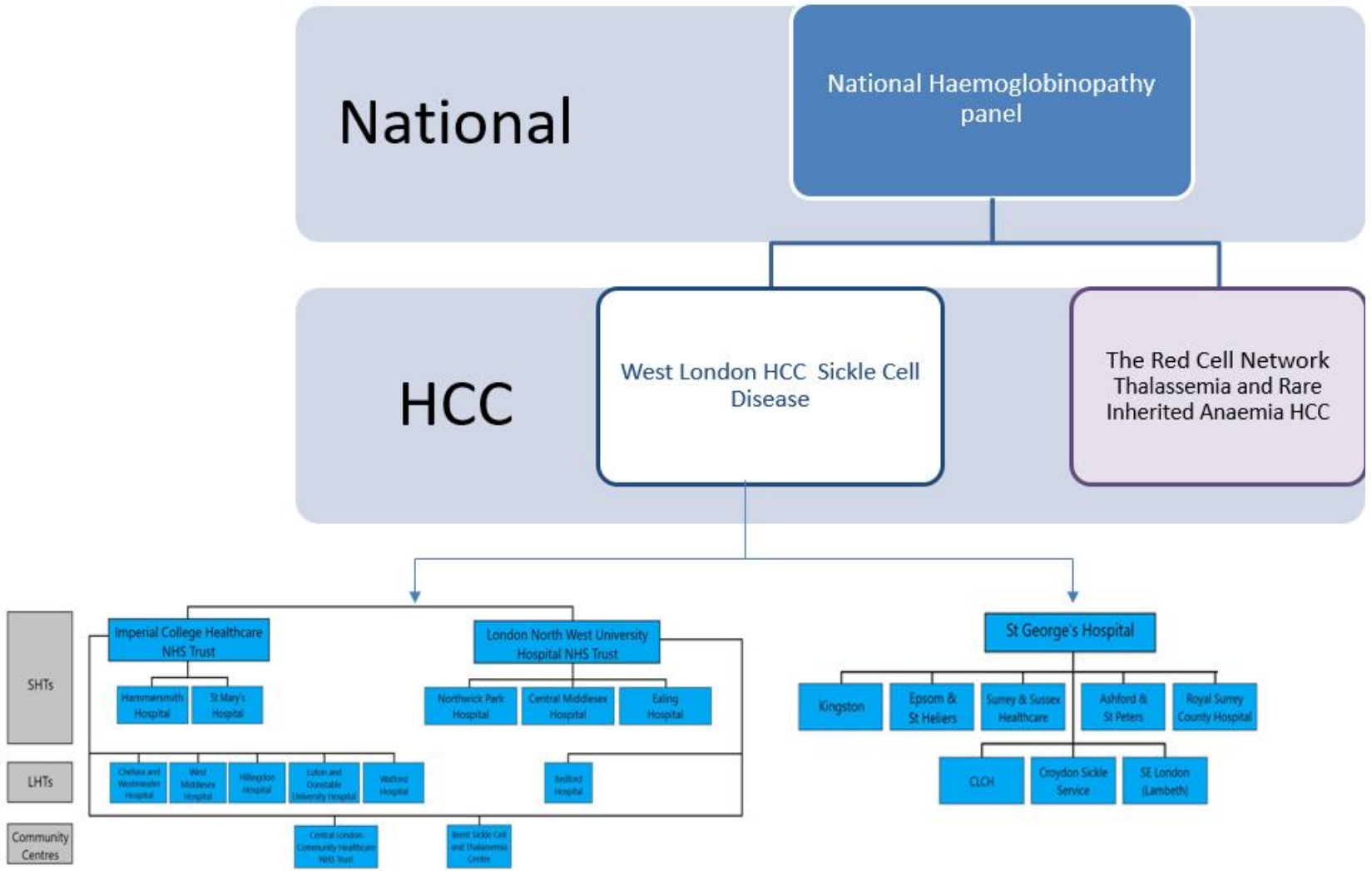
A copy of the NHS England Service specification is embedded below.

Document 3a-Haemoglobinopathy

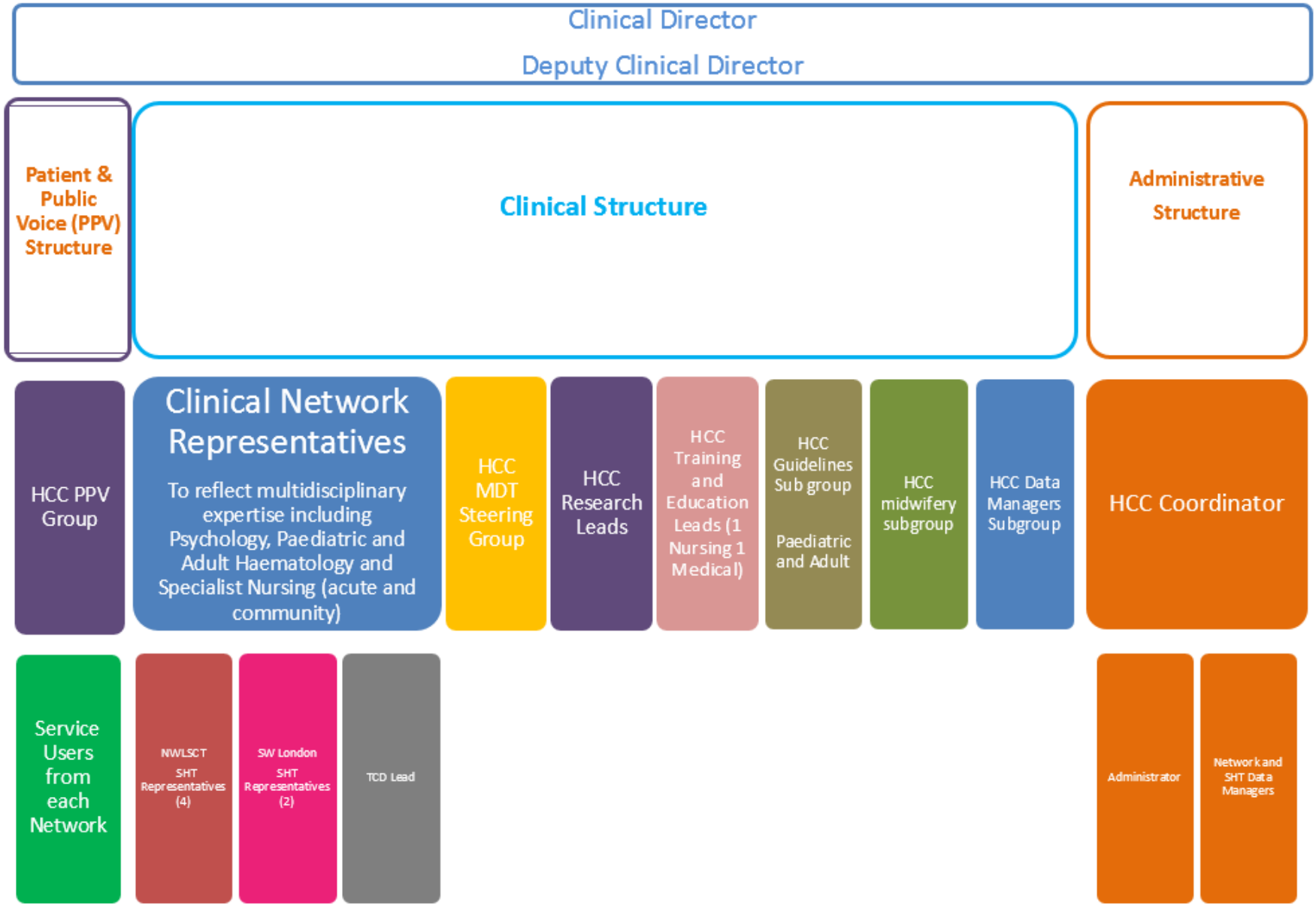
Embed a copy of the peer review standards

QS Haemoglobin Disorders V5 202111

Appendix 2-Network Organogram



Appendix 3-Network Structure



Appendix 4- Key Positions within the Network

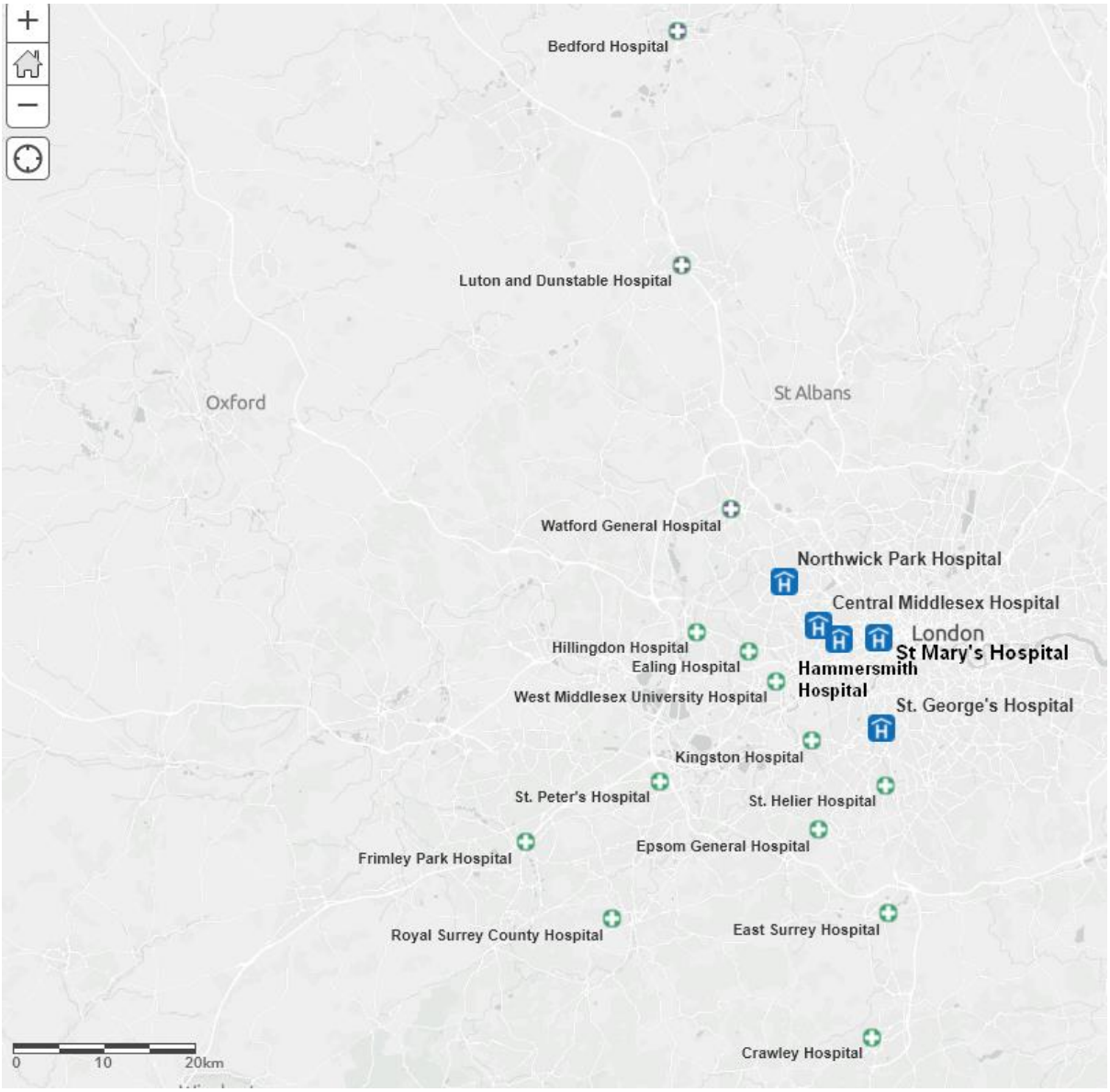
The below table details the key clinical and administrative positions within the West London HCC network

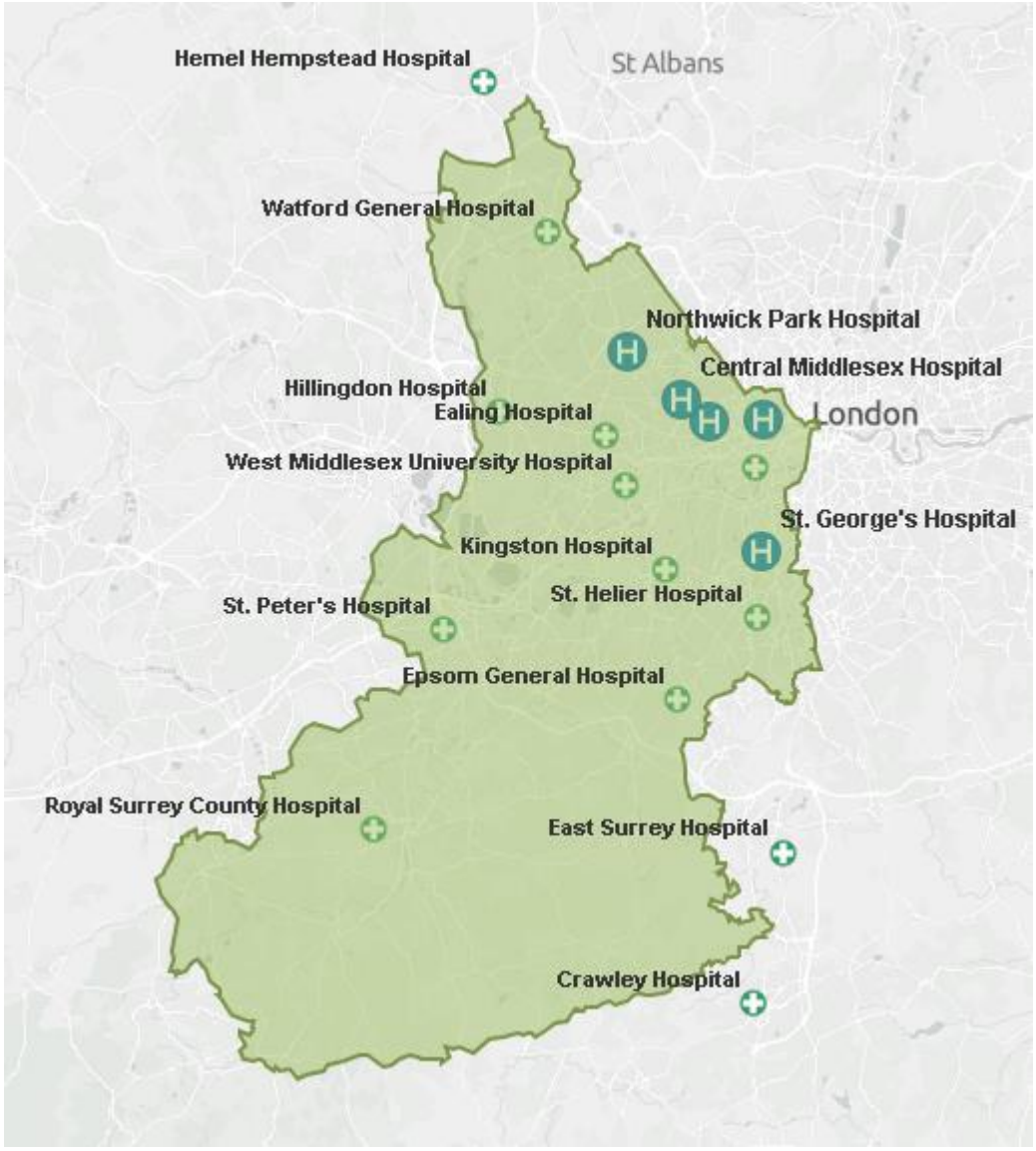
Position	Member of Staff	Associated Hospital
Clinical HCC Director	Mark Layton	Imperial College Healthcare NHS Trust
Deputy Clinical Network Director	Kofi Anie	London North West University Healthcare NHS Trust
HCC Coordinator	Ralph Brown	
HCC Administrator	Eniola Kuseju	
HCC MDT Steering Group	Asad Luqmani 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	Keisha Osmond-Joseph 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

Position	Person	Associated Organisation
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 2023/24 attendance

MDT Attendance	Friday	Wednesday	Friday	Wednesday	Friday	Wednesday	Friday	Wednesday	Wednesday	Wednesday	Friday	Wednesday
	27.03.2024	21.02.2024	19.01.2024	21.12.2023	17.11.2023	18.10.2023	15.09.2023	30.08.2023	26.07.2023	21.06.2023	02.06.2023	26.04.2023
Cases	3	5	4	3	6	3	4	4	7	3	10	5
Attendance	22	20	33	27	30	31	32	33	40	29	26	29
Job Types												
Haematology Consultants	7	8	9	8	7	10	8	9	9	10	10	10
Paediatric Haematology and General Paediatric Consultants	1	2	4	4	3	3	4	2	5	5	2	3
SpRs/Trainee Doctors		1	5		4	1			1	1		
Nursing Staff	6	2	7	7	9	4	7	6	6	6	5	7
Psychologists	1	1	1				1	1	2			
Other Allied Health Professionals	7	4	7	8	7	13	12	15	17	7	10	8
SHTs												
Imperial College Healthcare NHS Trust	8	12	16	11	14	17	11	14	20	13	5	9
London North West University Healthcare NHS Trust	1	1	7	5	5	1	3	3	3	2	1	7
St George's University Hospitals NHS Foundation Trust	4	2	1	3	3	1	2	2	1	3	2	
LHTs												
Luton And Dunstable University Hospital NHS Foundation Trust												

Central London Community Healthcare NHS Trust	4	2	3	2	2	1	2	3	3	3		2
Ealing Community Partners												
Kingston Hospital NHS Foundation Trust												
West Hertfordshire Hospitals NHS Trust	1		1	1		2	1	2	1	1	2	2
Royal Surrey										1		
Chelsea and Westminister Hospital NHS Foundation Trust		1	1	1	1	1	1	1				
Epsom and St Helier University Hospital NHS Trust			1				1					
Ashford and St Peter's Hospitals NHS Foundation Trust								2	2			
Other												
Cambridgeshire Community Services NHS Trust									1			
Buckinghamshire Healthcare NHS Trust												
Barts Health NHS Trust						1					1	
Whittington Health NHS Trust												
Hounslow And Richmond Community Healthcare NHS Trust												
Royal Cornwall Hospitals NHS Trust												
The Royal Marsden NHS Fundation Trust - RPY												
Kings College Hospital NHS Foundation Trust												
Other Trusts	1	1	1				3	2	2	2	1	1

SPAH and Welsh Partners												
NHS Greater Glasgow and Clyde			1			1	3	1		1	2	
Cardiff And Vale UHB	1			2	2	3	3	1	2	2	5	4
NHS Grampian												1
NHS Lothian					1						1	
NHS Tayside												
NHSBT	1		1		1	1	2	1				
Aneurin Bevan UHB											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	7	0	7
St Mary's Hospital- Imperial College Healthcare NHS Trust	0	1	1
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
Total Imperial	7	1	8
St George's University Hospitals NHS Foundation Trust	16	5	21
London North West University Healthcare NHS Trust, Northwick Park Hospital	10	0	10
LHT			
West Middlesex Hospital	0	0	0
West Hertfordshire Hospital NHS Trust	1	3	4
SPAH			
Glasgow Royal Infirmary	1	0	1
Royal Hospital for Children, Glasgow	0	4	4
ARI, Aberdeen	0	0	0
RHSC Edinburgh	0	0	0
Ninewells Hospital Dundee	0	0	0
Welsh Centres			
Noah's Ark Children's Hospital for Wales, Cardiff and Vale UHB	0		
Cardiff and Vale UHB	0	1	1
Cardiff CAVUHB	0	1	1
Cardiff UHW	1	1	2

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)
21/04/2023	Gene Therapy for SCD in Africa and the activities by the Global Gene Therapy Initiative	Professor Jennifer Adair Professor Julie Makanni Professor Tassos Karadimitris	All HCC Members	Time: 16:00-17:00 60 mins in Length Teams	89
17/05/2023 & 07/06/2023	Antenatal Screening of Haemoglobinopathies	Paula Sullivan Joyce Adu-Admankwah Shauna Fahy	All HCC Members	Time: 14:00-15:30 90 mins in Length Teams	46
13/07/2023	School Nurses	Dr Layan Allawi Dr Elizabeth Olukoga Dr Rebekah Easton	All HCC Members	Time: 12:00-13:00 60 mins in Length Teams	124
14/07/2023	Key Findings from the Fatigue in Sickle Cell Disease project	Brenda Poku	All HCC Members	Time: 16:00-17:00 60 mins in Length Teams	32
21/07/2023	Autologous Therapy	Thomas Blair	All HCC Members	Time: 15:30-16:30 60 mins in Length Teams	41

02/11/2023	Sickle Cell and Bone Marrow Transplant- Patient and Public Voice Group Session	Dr Steven Okoli Dr Eduardo Olivarria	All HCC Members and Dentistry teams	Time: 18:00-19:00 60 mins in Length Teams	28
21/11/2023	Transition from Paediatric to Adult Services	Dr Mamta Sohal Dr Gayathriy Sivaguru Dr Afoke Arigbe Dr Caroline Cheo Dr Kajal Rai Dr Louis William	All HCC Members	Time: 15:30-16:30 60 mins in Length Teams	32
19/01/2024	Cardiac Issues and Management in Sickle Cell Disease	Prof Malcolm Walker	All HCC Members	Time: 16:00-17:00 60 mins in Length Teams	56

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	
Transcrannial 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	
26th April 2023	Kofi Anie, Mark Layton,
22nd May 2023	Josu de la Fuente, Kofi Anie, Mark Layton, Muhsin Almusawy,
28th June 2023	Josu de la Fuente, Kofi Anie, Mark Layton
24th July 2023	Josu de la Fuente, Jeremy Anderson, Mamta Sohal, Steven Okoli
23rd August 2023	Kofi Anie, Leena Karnik, Mark Layton, Steven Okoli
25th September 2023	Kofi Anie, Mamta Sohal, Mark Layton, Steven Okoli
18th October 2023	Asad Luqmani, Josu de la Fuente, Kofi Anie, Mamta Sohal, Mark Layton
27th November 2023	Josu de la Fuente, Kofi Anie, Leena Karnik
20tht December 2023	Josu de la Fuente, Kofi Anie, Mamta Sohal, Mark Layton
22nd January 2024	Fernando Pinto, Josu de la Fuente, Mamta Sohal, Mark Layton, Steven Okoli
28th February 2024	Asad Luqmani, Elizabeth Rhodes, Fernando Pinto, Jennifer Laird, Kirstin Lund, Leena Karnik, Steven Okoli
25th March 2024	Alice Klauser, Elizabeth Rhodes, Josu de la Fuente, Kofi Anie, Mamta Sohal,

NHP Business Meetings attendance	
15th May 2023	Josu de la Fuente, Kofi Anie, Mark Leyton, Ralph Brown
15th November 2023	Josu de la Fuente, Kofi Anie, Mark Leyton, Ralph Brown

Appendix 11- Clinical Research within the West London HCC

Trials Open to Recruitment:

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 β 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 Vector in Subjects with Severe Sickle Cell	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.

Disease.				
Title of Study	**SHT the Study is being run from**	**Sponsor**	**PI (Principal Investigator) /Contact details of Lead Clinician(s)**	**Status of the Trial**
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.
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 transplant) on treatment failure at 24 month in adults with severe sickle cell disease	Imperial College Healthcare NHS Trust		Dr Steven Okoli	Actively recruiting. 1 patient has received a transplant, with another aiming to receive their transplant in July.
BO42452 Roche Crosswalk- A phase 1b acute arm trial: Randomised, placebo-controlled study evaluating the safety, pharamcokinetics, pharmacodynamics and efficacy of Crovalimab for the management of acute, uncomplicated vaso-occlusive episodes (VOE) in patietns with SCD.	Imperial College Healthcare NHS Trust	Roche	Dr Steven Okoli	Open to recruitment
Pyruvate Kinase Deficiency Global Longitudinal Registry (PEAK Registry)	Imperial College Healthcare NHS Trust	Agios	Prof Mark Layton	Open to recruitment
Sickle Cell Eye Project	Imperial College Healthcare NHS Trust	Academic study	Dr Steven Okoli	Open to recruitment
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

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	Actively recruiting
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	Actively recruiting
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	Actively recruiting
NIHR BIORESOURCES _TISSUE BANK: Improving Black Health Outcomes	Imperial College Healthcare NHS Trust	NIHR/Genomics England	Dr Steven Okoli	Open to recruitment

Trials In Long term Follow-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
Agios 10: 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, patients on long term follow up.
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	Closed to recruitment, patients on long term follow up.
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	Closed to recruitment, patients on long term follow up.
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) (Crosswalk-C)	Imperial College Healthcare NHS Trust	Roche	Dr Steven Okoli	Patients in long term follow up.
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	Remained open during Covid-19 surges Closed to recruitment – in follow-

				up

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
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
FEREVNT-1 - Regeneron R7999-BTHAL-2350: A Phase 2, Two-Part, Randomized, Double-Blind, Placebo-Controlled, Multicenter Study To	Imperial College Healthcare NHS Trust	Regeneron	Prof. Mark Layton	Study in set up

Evaluate The Efficacy, Safety, And Tolerability Of Subcutaneously Administered Regn7999 (An Inhibitor Of Tmprss6) In Participants With Iron Overload Due To Non-Transfusion Dependent B-Thalassemia				
GBT021601: A Phase 2/3 Randomized, Multicenter Study of GBT021601 Administered Orally to Participants with Sickle Cell Disease and an Open-Label Pharmacokinetics Study in Pediatric Participants with Sickle Cell Disease	Imperial College Healthcare NHS Trust	GBT	Dr Steven Okoli	Study in set up
CSL889-2001: A Phase 2 / Phase 3, Multicenter, Randomized, Multiple-Dose, Double-Blind, Placebo-Controlled Adaptive Study to Evaluate the Safety, Efficacy and Pharmacokinetics of CSL889 in Adults and Adolescents with Sickle Cell Disease during Vaso-Occlusive Crisis.	Imperial College Healthcare NHS Trust	Behring LLC	Dr Asad Luqmani	Study in set up

Studies/Trials closed

Title of Study	**SHT the Study is being run from**	**Sponsor**	**PI (Principal Investigator) /Contact details of Lead Clinician(s)**	**Status of the Trial**
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	Imperial College Healthcare NHS	Sponsor Global Blood Therapeutics	Prof Mark Layton	Closed

disease	Trust			
Agios 3: 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	Study closed, patients on compassionate access program.
Agios 11: 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	Study closed, patients on compassionate access program.
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 Closed
COVID-19 in patients with inherited anaemias in England	NHP wide	Imperial College Healthcare NHS Trust	Prof Josu de la Fuente Prof Mark Layton	Study closed
AG348-C-015 Pyruvate Kinase Deficiency Global Longitudinal Registry: Patient-Reported Outcomes linked to 008	Imperial College Healthcare NHS Trust	Agios	Prof Mark Layton	Study closed
Title of Study	**SHT the Study is being run from**	**Sponsor**	**PI (Principal Investigator) /Contact details of Lead Clinician(s)**	**Status of the Trial**
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	St George's University Hospitals NHS Foundation Trust		Ms Ingrid Watt-Coote	Re-opened on the week of the 13th of July 2020

Outcomes				
TAPS2 Transfusion Antenatally in Pregnant Women With SCD (TAPS2) https://clinicaltrials.gov/ct2/show/NCT03975894	Imperial College Healthcare NHS Trust	Guy's and St Thomas' NHS Foundation Trust	Dr Mamta Sohal	Study is now closed to recruitment.
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; phase 2/3 now in set up.
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 Hammersmtih 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	Roald Dahl's Marvellous Children's Charity./ LNWH NHS Trust.	Patricia Kiilu	Study Is Now Closed

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. Study closed April 2023
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 abandoned by Sponsor
Title of Study	**SHT the Study is being run from**	**Sponsor**	**PI (Principal Investigator) /Contact details of Lead Clinician(s)**	**Status of the Trial**
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

TAPS2 Transfusion Antenatally in Pregnant Women With SCD (TAPS2) https://clinicaltrials.gov/ct2/show/NCT03975894	Imperial College Healthcare NHS Trust	Guy's and St Thomas' NHS Foundation Trust	Dr Mamta Sohal	Study is now closed to recruitment.
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; phase 2/3 now 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**
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 Hammersmtih 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	Roald Dahl's Marvellous Children's Charity./ LNWH NHS Trust.	Patricia Kiilu	Study Is Now Closed

	Cell			

NHR

	Total	On NHR	Percentage	SCD only	SCD only on NHR	Percentage
St Georges Adult Database:	443	434	98%	395	388	98%
St Georges Paediatric Database:	273	273	100%	240	240	100%
Imperial Adult Database:	512	505	99%	434	422	97%
Imperial Paediatric Database:	313	234	75%	240	197	82%
LNWH Adult Database:	441	441	100%	397	397	100%
LNWH Paediatric Database:	230	230	100%	189	189	100%
	Total Patients	Total Patients on NHR		Total SCD patients	Total SCD patients on NHR	
	2212	2117	96%	1881	1833	97%