

# West London Haemoglobinopathies Coordinating Care Centre

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West London HCC  
2021-22

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Sickle Cell and Thalassaemia Network and the South West London Haemoglobinopathy Network and has now subsumed and superseded their functions/operations.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.

## Structure of the HCC

The HCC encompasses the pre-existing clinical networks in North West and South West London networks 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

## Second Year Outcomes

### Background

In the second 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
- Infrastructure for national database of COVID-19 in haemoglobinopathies and rare anaemias

The continuation of the COVID-19 pandemic has significantly impacted on the operation of the HCC with many staff having significant workload pressure related to backlog of work from 20/21 and additional support being needed to be given patient populations.

Consultant staff at SGHT were redeployed to mitigate the burden on medical wards during the Covid-19 2021/22 winter surge.

The HCC leads wish to extend their thanks in this report for the hard work undertaken by all members of the HCC in support of the COVID-19 response and delivery of clinical services during the pandemic and their contributions to the HCC during another difficult year.

## MDT of the HCC

The HCC MDT (multi-disciplinary team) has continued its operations effectively throughout the year. Fifty-one 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,

Two 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 -21	May-21	Jun -21	Jul -21	Aug -21	Sep -21	Oct -21	Nov -21	Dec -21	Jan -22	Feb -22	Mar -22	Annual Total
Number of cases being submitted to the HCC MDT	Adult		0	3	2	3	4	1	1	1	0	3	6	5	29
	Children		0	2	2	0	1	3	4	1	1	3	4	1	22

Cases referred to the NHP	Adult	Number	0	0	0	1	0	0	0	0	0	0	0	0	1	
		Percentage	0%	0%	0%	33%	0%	0%	0%	0%	0%	0%	0%	0%	0%	3%
	Children	Number	0	0	0	0	0	0	0	0	0	0	0	1	0	1
		Percentage	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	25%	0%	5%

## Educational/training activities

An educational and training sub group has been meeting continuously throughout the year with Dr Mamta Sohal and Dr Lola Oni lead, a schedule of activity was worked on and has been delivered with only some disruption from the pandemic surges. With Dr Lola Oni's retirement, Jacqui Bowyer took over up until the end of the financial year 21/22.

At the start of the year Dr Lola Oni 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 2021/22 and the number of attendees, 19 education sessions have taken place within the first year of the HCC. Appendix (9) also relays some of the feedback received about the sessions that have taken place.

In terms of operation of the sessions, the Network Manager sends out invites and instructions on how to register. Dr Oni 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 but were postponed/paused due to the second/third wave of the COVID-19 pandemic:

- Management of Sickle Emergencies
- Patient experiences in Emergency Departments
- Hyperhaemolysis
- Child Health

Further details of future sessions can be found in Appendix (10)

Dr Sohal and Jacqui's replacement will be working on the education schedule for 22/23 with support from the Network Manager.

## Collaborations with other HCCs that have been beneficial

The West London HCC has continued to provide infrastructure support for the national COVID-19 database, providing a detailed breakdown of cases reported by all HCCs with patient outcomes to the NHP and CRG since the start of the pandemic. This work has informed guidance on shielding for patients carers and voluntary sector organisations and will contribute to the publication of further articles in peer reviewed journals. High level data has been shared with colleagues internationally and with the SCTAPPG. HCC members have contributed to National Haemoglobinopathy Panel (NHP) guidance on the care of patients with sickle cell disease, thalassaemia, Diamond Blackfan anaemia (DBA) and other rare inherited anaemias.

Please see Appendix (12) for further details on outcomes.

## 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 13. 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.

## Audit and data collection

NHS England's request that the data from the SHTs to the SSQD (specialised services quality dashboard) be voluntary for the year 2021/22 is due to the ongoing work pressures from Covid-19, as of the next financial year reporting will return to normal.

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	51 patients 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	2 (3.9%) 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	138 adverse Events were recorded across the HCC  Of these 86.2% were uploaded to the NHR  Of these 138 were discussed in the HCC MDT	88 Adverse events recorded on the NHR at Imperial 21/22  (53 in adults, 35 in Paeds)	20 Adverse event recorded on the NHR at London Northwest 21/22  discussed at the HCCMDT (20 in Adults, 0 in Paeds)	30 Adverse events recorded on the NHR at St. Georges 21/22  discussed at the HCCMDT (11 in Adults, 19 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: 90%  Percentage of adult patients: 93%  Percentage of Paediatric patients: 84%	468 adult patients are recorded on the local database  443 on adult patients NHR	441 adult patients are recorded on the local database  441 on adult patient NHR	403 adult patients are recorded on the local database  339 on adult patients NHR

		<p>There are a total of 2,085 patients recorded on local databases across the HCC.**</p> <p>Of these 1,312 are adult patients, 773 are paediatric patients</p> <p>Recorded on the NHR are 1,866 patients of which 1,223 adults and 642 paediatric patients</p>	<p>313 paediatric patients are recorded on the local database</p> <p>198 on paediatrics patients NHR</p>	<p>230 on paediatric patients</p> <p>230 on paediatric patients NHR</p>	<p>230 paediatric patients</p> <p>214 on paediatric patients NHR</p>
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\*\*missing patients from the LHTs as not completed data sets/readily available databases, this is being worked on in 22/23

An audit schedule has been agreed for the year 22-23, when hopefully Covid disruption will be less of an issue in completing this:

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

## 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 also have an events page where visitors can see and sign up to any events that the HCC Network are hosting or any other relevant events. There is also a news page, which is update regularly with any relevant and up to date news articles, a useful links page has been set-up with of helpful hyperlinks to different services, and a resources section for both consultants and patients.

The screenshot displays the West London HCC website. At the top, there is a navigation bar with links for 'About Us', 'News', 'Useful Links', 'Events', and 'Contact', along with a search icon. Below this is a secondary navigation bar with 'Red Cell Disorders', 'Resources', 'Personal Experiences', 'Get Involved', and 'Events'. The main header features the NHS logo and the text 'West London Haemoglobinopathy Coordinating Centre'. A large hero image shows a smiling woman with the text 'West London HCC' and 'Better Healthcare through collaboration'. Below the hero image is a 'Latest news' section with three articles: 'Exchange Transfusions Changed My Life', 'Invisible Warrior: Current and Future Sickle Cell Disease Treatments', and 'Invisible Warrior Workshop'. To the right, there is a 'Patient Resources' sidebar with a dropdown menu and a list of resources including 'Covid-19 Coping Strategies and advice', 'Exchange Transfusion', 'Hydroxycarbamide', 'Pain Management & Support', 'Pregnancy in SCD', 'Priapism', 'Stem Cell Transplant', 'Travel Guides', 'Vaccinations', and 'Citizens Guidance and Advice'. A 'Vaccinations' section is also visible, featuring an image of a family and text about the importance of vaccinations for patients with sickle cell disease.

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>

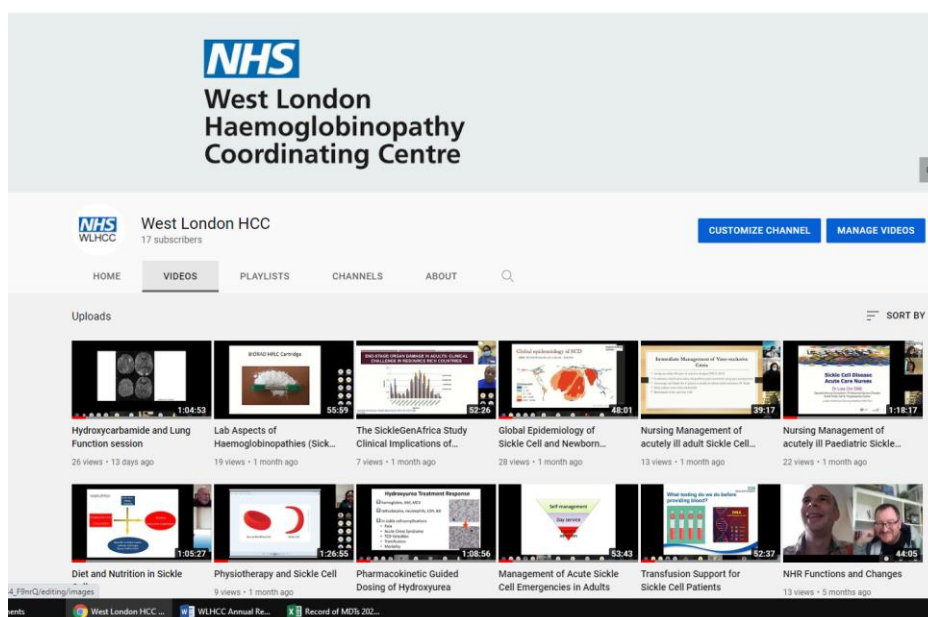
# West London Haemoglobinopathy Coordinating Centre



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 21 subscribers and 1140 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 set up to work on the harmonisation of clinical guidelines across providers in the HCC. Due to the pandemic and workload

pressures much of this work has been delayed but this will be worked on in depth in 2022/23. 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.

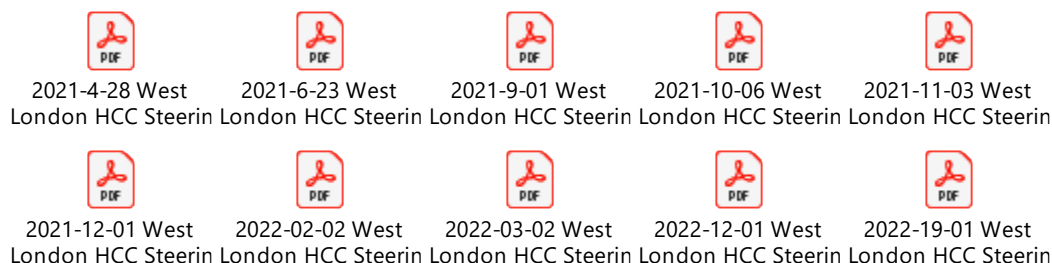
SLAs for the involvement of the Scottish Paediatric and Adult Haemoglobinopathies network (SPAH) and South Wales Haemoglobinopathy teams in HCC MDT and educational activities have been drafted and sent out to the centres.

Service level agreements between LHTs and SHTs and the HCC detailing individual escalation/referral pathways will be implemented during 2022-23.

## Evidence of HCC meetings and actions achieved

Mobilisation/Steering group meetings have been held on a monthly basis throughout 2021/22 (Covid surge permitting). 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 2021/22.

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 Ani acts as the clinical representative for the group but no longer attends meetings on a regular basis in order to encourage greater discussion.

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 18th of March of last year and has had six 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 18.03.2021-



PPV HCC meeting  
minutes 28.10.2021.



PPV HCC meeting  
minutes 25.11.2021.



PPV HCC meeting  
minutes 27.01.2022.



PPV HCC meeting  
minutes 24.02.2022.



PPV HCC meeting  
minutes 31.03.2022.

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) requested its member organisations to provide a response detailing how recommendations from the APPG report will be implemented.

The request was forwarded to the Haematology teams of the service but with a request that Trust management teams are engaged. A template for the response based on the recommendations of the APPG report was created and forwarded.

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

Some of the returned reports were presented at the West London HCC steering group meeting on the 2nd of March. A combined listing of actions from these reports is being worked on with oversight from the patient and public voice group.

## Finances of the HCC

NHS England (NHSE) uplifted the amount of funds given by to the HCC by £5,200 for the year 21/22 to £220,200 (2.36% uplift, rate of inflation 21-22 5.5%). NHSE are looking to uplift the budget of the HCC for 2022/23 by 1.7% leading to a budget of £223,943.40.

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 2021/22 there has been a slight overspend against the budget of the HCC which has been absorbed by Imperial College Healthcare NHS Trust's Haematology department, this overspend as previously noted is caused by miscalculations when the contract/service was drawn up relating to mid spine point assumptions against salary of the contributors of the HCC. This overspend occurred despite 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,

The projection is that the overall position of the HCC spend across the three years is around £45,509.06 underspent at the end of the current contract.

Year	NHSE contract	Projected Cost (against initial budget)	Actual spend	Spend against NHSE budget
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*	£223,943	£243,220.94		£19,277.44
<b>Overall position</b>				<b>£45,509.06</b>

\*Please note that the financial year 2022/23 has not finished (the 22/23 projected cost figure above assumes a 3% pay uplift and spending the entirety of the ICT and sundries budget) and there is also a need to validate some of the costings in 2021/22, so this should not be viewed as a finalised figure.

## Specialist Haemoglobinopathy Teams status 21-22

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 in 21/22:

- Vulnerable patient vaccination programme has been rolled out throughout the year at Hammersmith
- The service has moved to a longer term hybrid model of alternating face to face and video clinic reviews where appropriate
- No clinics were closed during 21/22
- HCC coordinated national data collection on COVID-19 in haemoglobinopathy and rare anaemia patients
- Significant additional communication to patients about risk associated with COVID-19 shielding advice and vaccination was undertaken
- Vacant specialist social worker post at a time of increased economic hardship for patients
- Annual reviews and the work required to upload them to the National Haemoglobinopathy Registry difficult to achieve
- Day care pain service suspended
- Increase in apheresis activity
- Clinical trial activity restarted with respect to new interventional studies

Targets for 2022/23:

- Business case development allied healthcare professional staffing for second Band 7 Haemoglobinopathy CNS, Haemoglobinopathy specialist Physio, Social worker to support Haemoglobinopathy service underway in part to address adolescent service staffing shortfall
  - Business case being developed for apheresis unit expansion, including an additional 6 apheresis trained nursing staff
  - To consolidate joint working with London North West
  - Completion of annual reviews for the patient population for 22/23

- Emergency pathways working group has been set-up to look at improving the emergency pathways
- Implementation of the specialist pain clinic

## Imperial College Healthcare NHS Trust Paediatric Haemoglobinopathy Service

### Service updates and challenges in 21/22:

- Paediatric Vulnerable patient vaccination programme has been rolled out throughout the year at St Mary's
- Trans Cranial Doppler scanning (continued through the year) with backlog caught up from suspensions in service during 20/21
- Small waiting list for iron overload MRI investigations
- Red Cell CNS being away from the service due to ill health, returned on a phased return from May 21
- Expansion of paediatric RBC exchange service across the HCC – staff training programme extended to PICU colleagues
- The service has moved to a longer term hybrid model of alternating face to face and video clinic reviews where appropriate
- No clinics were closed during 21/22
- BMT programme has been in continuous operation this year
- Outreach clinics to LHTs continued during the year
- Elective surgical work has been caught up with, there was a short backlog that has now been resolved in 21/22
- A&E attendance has recovered and is back to pre-pandemic levels
- Sleep studies, ECHOs and lung function test investigations have been running with the backlog from the previous year having been caught up

### Targets for 2022/23:

- Business case development for new Haemoglobinopathy CNS underway in part to address adolescent service staffing shortfall and to support the growing numbers of patients on Hydroxycarbamide

- Support of LHTs in expansion of Haemoglobinopathy staffing (dedicated hospital based CNS, increased consultant PAs)
- Work has commenced on the integration of Imperial & London NW Paediatric Haemoglobinopathy programmes – transfer of acute admissions from LNW to SMH where required, outreach clinic support, transfer of elective patients for surgery/specialist investigations, telephone & email advice
- The service will work to create a long term solution to staffing of the Red Cell exchange programme, including maintaining the out of hours service
- Completion of annual reviews for the patient population for 22/23

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

Service updates and challenges of 21/22 with work progressing in 22/23

### Out-patient service

- During the COVID pandemic as part of Trust wide general re-organisation the Thalassaemia patients receiving transfusion at Ealing Hospital were moved to Central Middlesex Hospital (CMH). This has remained in place.
- All haemoglobinopathy clinics are MDT and include an acute CNS, community CNS, and psychologist. Outpatient clinic consultations are being carried out by telephone for most patients.
- Patients on Hydroxycarbamide, who require blood tests were seen in the Medical Day Unit at CMH where they had blood tests and were issued with prescriptions. Prescriptions were extended from 3 months to 4 months for patients who were stable and had been on the same dose for more than 6 months prior to the pandemic.
- Patients who require Community follow up by the Community Specialist Nurse are followed up with routine home visits and telephone consultations as required.
- Routine investigations including Annual blood tests, Echocardiogram, audiometry and T2\*MRI, and Ophthalmology reviews are being carried out.
- Elective Red Cell Exchange Transferred from CMH to Northwick Park (NPH) hospital during the 2nd wave, this has remained at NPH
- Routine surgery including orthopaedics is being carried out albeit with long waiting lists

### 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 (AttendAnywhere) as required by patients. Psychological support is also offered for inpatients, and the psychologist attends consultant ward rounds three times a week.

### Medical Day Care (CMH)

- Walk –in-Service for pain relief with subcutaneous opioids for acute sickle cell pain crisis was suspended and has not been resumed because of difficulties in testing patients for Covid prior to admission. All patients with pain crises were seen in A&E at NPH only.

- 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

- The dedicated ward (Carroll Ward) for sickle acute admissions was converted to a Clinical Decision Unit as part of the Covid pathway linked to the A&E Department. Drake Ward (Haematology) has recently been expanded to accommodate sickle cell patients. James Ward is also being used as a backup for sickle cell patients, and for those who are Covid positive on admission. There is ongoing teaching for all staff, and the A&E pathway is being improved to help reduce the time to first analgesia (NICE guideline).
- Multi-Disciplinary Team Meetings
- Local and HCC MDTs have continued virtually and are being conducted monthly for both.

#### Vision for Recovery

- Work in collaboration with Imperial College Healthcare NHS Trust SHT to progress the agenda for collaborative working through the Clinical Haematology review of the North West London Specialist Services Programme
- It is envisaged telephone and virtual clinics will be maintained for some outpatient clinic consultations.
- There will be a return to face-to-face outpatient clinic consultations, starting with new patients, annual reviews, and management of complex patients including those on hydroxycarbamide.
- Additional substantive consultant haematologist to be appointed to manage the patient group with adequate time (PA) to meet peer review quality standards.

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

Service updates and challenges of 21/22 with work progressing in 22/23

#### Out-Patient Service

- All paediatric haemoglobinopathy clinics are face-to-face MDT clinics and include an acute CNS, community CNS, and psychologist.
- An additional consultant paediatrician has joined the team, and a consultant paediatric haematologist from Imperial College Healthcare NHS Trust now attends the clinics twice monthly.



- Central Middlesex Hospital - Out-patient clinics moved to Northwick Park Hospital (NPH) in October 2021 after a parent/patient consultation event was organised.
- Ealing Hospital – clinics continue to be held once a month
- Patients who require Community follow up have routine home visits and telephone consultations as required. Affected newborn visits have been offered through-out.

#### Psychology Service

- Additional psychological support apart from clinics is offered face-to-face or virtually via video consultations (AttendAnywhere) as required by patients. Psychological support is also offered for inpatients, and the psychologist attends consultant ward rounds three time a week. Neuropsychological assessments continue to be carried out face-to-face.

#### Paediatric Day Care

- Blood transfusions are no longer carried out at Ealing Hospital, however blood tests can be done at Ealing. All transfusions are done at Northwick Park.

#### Transcranial Doppler Service

- This is carried out at NPH Vascular department on Saturdays and historically has been ideal for the children and families.

#### Multi-Disciplinary Team Meetings

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

#### Vision for Recovery

- More collaboration with Imperial College Healthcare NHS Trust SHT.

**Service updates and challenges of 21/22 with work progressing in 22/23**

- Haemoglobinopathies patient pathway manager appointed November 2021
- Data Manager (0.6 WTE) appointed January 2022 (vacancy in December 2021)
- 2 Haemoglobinopathy CNS – now working on site
  - 0.8 WTE band 7
  - 1 WTE band 7 has left the Trust – post advertised March 2022
- Face-to-face appointments to be restarted mid-2022 (currently majority of appointments remain as telephone appointments)
- Annual reviews and entry onto NHR restarted January 2022
- 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 (due to staff sickness and vacancies) and relocation of the apheresis unit during 2021/22 to increase bed capacity
  - Vacancy for apheresis manager currently out to advert
  - Apheresis nurse specialists recruited to fill the 2 vacancies– starting March 2022
  - Apheresis service moved back to original space in February 2022
- Business case for third substantive red cell consultant with a view to appointing 2022/23
- Surveillance T2\* MRI scans, echocardiograms, ophthalmology referrals restarted 2021/22 – to continue
- Pain Management Programme has continued throughout the pandemic via telephone and video consultations – to continue 2022/23 with a view to increasing face-to-face appointments
- Consultant neurologist with an interest in sickle cell disease appointed to the Trust – will be setting up a monthly sickle-neurology clinic
- Face-to-face transition clinics restarted 2021/22 – to continue on alternate months.
- 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 21/22 with work progressing in 22/23

- Apheresis - Staffing numbers have reduced and recruitment in process for this. Negotiations with NHSBT to potentially provide paediatric service (including OOH).
- 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.
- Elective surgical work has now improved.
- Transfusions - Limited by reduction in day case capacity due to COVID and social distancing. Patients were not the appropriate cohort or were not comfortable in open bays during COVID. Therefore, reduced numbers booked, patients needed to be rescheduled. – This has now improved.
- Medicines – Home delivery rather than families coming here to pick up. Special Preparation needed to extend expiry dates. Home delivery remains a good service – helpful for families. Ideal to continue.
- TCD scan – Capacity reduced, Patients also declined to come. Therefore many patients rescheduled/cancelled. So lower priority patients experienced large delay. Scanning team brought the equipment down to avoid moving patients through the hospitals. This has improved, however, some still outstanding.
- Clinics – changed to majority of telephone appointments and therefore assessments not as thorough as should be. Appointments now can be F2F or telephone when of benefit to family.
- Outpatient Phlebotomy - Walk ins stopped, patients booked. Reduced capacity. Some had to be moved to Day case ward. Improved. However, limited phlebotomy hours and we must rely on day case ward staff completing tests.
- Lots of phone calls and time spent to encourage patients to come to hospital.
- Transition clinic not affected as carried on over the phone. No significant change to this.
- Psychological impacts – on patients, still remains.
- Pain nurse - redeployed therefore no support. This is now resolved.
- Patients presenting later when clinically quite unwell - improving for A&E attendance but remains some hesitation from families.

## Positives learnt

Reduction in need for face to face for some clinically more well patients

- Home delivery of Medicine would be good to continue
- Online meetings saving time

## Staffing –

- Consultant – 2 WTE for full haematology service (not just haemoglobinopathy service) as of November 2020, previously was 1WTE. Recruitment for third consultant is ongoing.
- Nursing - 1 WTE B7 Haemoglobinopathy Nurse (Roald Dahl post), but is vacant as of Wednesday 12th May. Backfilling with Staff bank for 3 days (22.5 hours per week). HON chasing Roald Dahl for ongoing funding. Band 7 CNS 1 WTE since 21/02/22. Cross cover general haematology due to reduced nurse staffing in other haematology post.
- Psychology – BeCs – 0.6 WTE – 25 hours for Haematology/Sickle Cell – throughout COVID. Remains 0.6 WTE.
- Junior Drs – Adult team used to support, but they are currently short and have been throughout COVID. Remains as no consistency SpR support; support when they can but rota remains short.
- Social Worker – No establish at St George's. Currently relying on the Roald Dahl social work team, which can only be done as long as Roald Dahl nurse is funded. Social worker via Roald Dahl charity only.
- 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).

## 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

427 adult patients are recorded on the local database

361 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

374 adult patients are recorded on the local database

313 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

157 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

230 paediatrics patients are recorded on the local database

214 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 the effects of the Covid-19 pandemic and staffing challenges relating to consultant and data management support the attainment of the 85% target, by some of the services wasn't met

<b>Adults</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*	Percentage of annual reviews for patient cohort
Hammersmith Hospital (Imperial College Healthcare NHS Trust)	361	86.4%	(356) 99%	
London North West University Healthcare NHS Trust	397	100%	(134) 33.7%	
St George's University Hospitals NHS Foundation Trust	313	84%	(35) 11.1%	
<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*	Percentage of annual reviews for patient cohort
St Mary's Hospital (Imperial College Healthcare NHS Trust)	157	65.4%	(125) 80%	
London North West University Healthcare NHS Trust	189	100%	(103) 53%	
St George's University Hospitals NHS Foundation Trust	193	85.4%	(0) 0%	

## TCDs: Proportion of patients undergoing TCD

In 2021/2022 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		Apr- 21	May- 21	Jun- 21	Jul-21	Aug- 21	Sep- 21	Oct- 21	Nov- 21	Dec- 21	Jan- 22	Feb- 22	Mar- 22	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	LNWH Children	Numerator	20	9	9	11	8	11	8	12	13	10	7	9	127	
			Denominator	23	9	9	11	8	11	8	12	13	10	7	9	130	
			Percentage	87%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	98%
		ICHNT Children	Numerator	5	12	9	13	17	7	7	11	3	4	6	2	96	
			Denominator	5	12	9	13	19	7	10	11	3	5	6	6	106	
			Percentage	100%	100%	100%	100%	89%	100%	70%	100%	100%	80%	100%	33%	91%	
		SGUH Children	Numerator	164													164
			Denominator	174													174
			Percentage														

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 note that for the Imperial adult service this data does not include LAS administration of analgesia, the data for the Imperial adult service will in the future be validated further

Ref	Description	Trust/ Patient Type		Apr- 20	May- 20	Jun- 20	Jul- 20	Aug- 20	Sep- 20	Oct- 20	Nov- 20	Dec-20	Jan- 21	Feb- 21	Mar- 21	Total
HAEM03i	Percentage of patients given pain relief within half an hour of presentations with sickle crisis , as per NICE guidelines	LNWH Adult	Numerator	13	13	14	21	13	12	8	16	9	15	11	9	154
			Denominator	21	17	23	27	27	20	21	23	12	18	12	14	235
			Percentage	62%	76%	61%	78%	48%	60%	38%	70%	75%	83%	92%	64%	66%
		ICHNT Adult	Numerator	7	5	9	4	5	5	7	10	9	8	13	9	91
			Denominator	30	29	41	43	33	34	30	48	34	40	38	45	445
			Percentage	23%	17%	22%	9%	15%	15%	23%	21%	26%	20%	34%	20%	20%
		SGUH Adult	Numerator	12	11	11	6	11	13	13	12	14	8	13	10	134
			Denominator	16	19	22	14	26	19	23	14	21	11	18	14	217
			Percentage	75%	58%	50%	43%	42%	68%	57%	86%	67%	73%	72%	71%	62%
		LNWH Children	Numerator	1	4	1	1	3	0	2	1	3	2	5	8	31
			Denominator	1	5	2	2	4	0	2	1	3	2	5	8	35
			Percentage	100%	80%	50%	50%	75%	-	100%	100%	100%	100%	100%	100%	89%
		ICHNT Children	Numerator	1	0	1	3	1	0	0	0	3	0	0	0	9
			Denominator	1	2	1	5	1	0	0	0	3	6	1	0	19
			Percentage	100%	0%	100%	60%	100%	-	-	-	100%	0%	0%	-	47%
		SGUH Children	Numerator	2	1	0	2	3	3	1	0	1	1	2	0	16
			Denominator	7	3	2	3	6	6	3	0	3	3	4	0	40
			Percentage	29%	33%	0%	67%	50%	50%	33%	-	33%	33%	50%	-	40%



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

Please note this data was effected by the Covid-19 Pandemic and is not complete

Ref	Description	Trust/ Patient Type		Apr- 20	May- 20	Jun- 20	Jul- 20	Aug- 20	Sep- 20	Oct- 20	Nov- 20	Dec- 20	Jan- 21	Feb- 21	Mar- 21	Total	
HAEM04A	Proportion of patients with possible Sickle disorders identified by neonatal screening who have been entered onto care pathway	LNWH Children	Numerator	1	0	1	0	2	2	2	2	3	1	2	0	16	
			Denominator	1	0	1	0	2	2	2	2	3	1	2	0	16	
			Percentage	100%	-	100%	-	100%	100%	100%	100%	100%	100%	100%	100%	-	100%
		ICHNT Children	Numerator	1	0	0	0	1	0	1	1	0	0	0	1	1	6
			Denominator	1	0	0	0	1	0	1	1	0	0	0	1	1	6
			Percentage	100%	-	-	-	100%	-	100%	100%	-	-	-	100%	100%	100%
		SGUH Children	Numerator	2	0	2	2	0	1	1	0	0	0	1	0	2	11
			Denominator	2	0	2	2	0	1	1	0	0	0	1	0	2	11
			Percentage	100%	-	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	LNWH Children	Numerator	1	0	1	0	2	2	1	2	2	1	2	0	14	
			Denominator	1	0	1	0	2	2	1	2	2	1	2	0	14	
			Percentage	100%	-	100%	-	100%	100%	100%	100%	100%	100%	100%	100%	-	100%
		ICHNT Children	Numerator	1	0	0	0	1	0	1	1	0	0	0	1	1	6
			Denominator	1	0	0	0	1	0	1	1	0	0	0	1	1	6
			Percentage	100%	-	-	-	100%	-	100%	100%	-	-	-	100%	100%	100%
		SGUH Children	Numerator	2	0	2	2	0	1	1	0	0	0	1	0	2	11
			Denominator	2	0	2	2	0	1	1	0	0	0	1	0	2	11
			Percentage	100%		100%	100%		100%	100%				100%		100%	100%

## Sickle Cell Disease and length of stay data 21-22

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 22-23. 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

### 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

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

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

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

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

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

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

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

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
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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

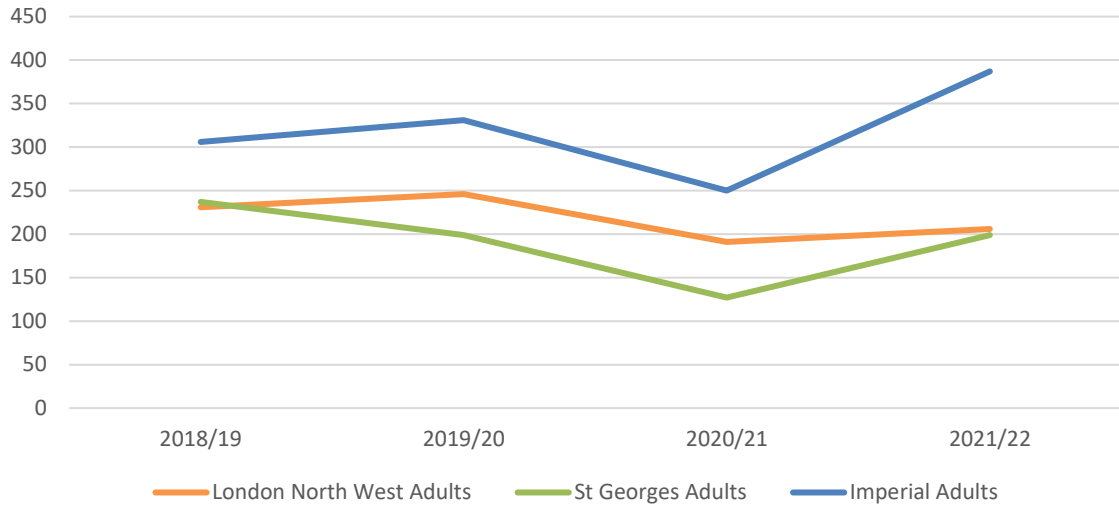
Number of non-elective adult Sickle Cell admissions at London North West each year including 0 day admissions\*

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

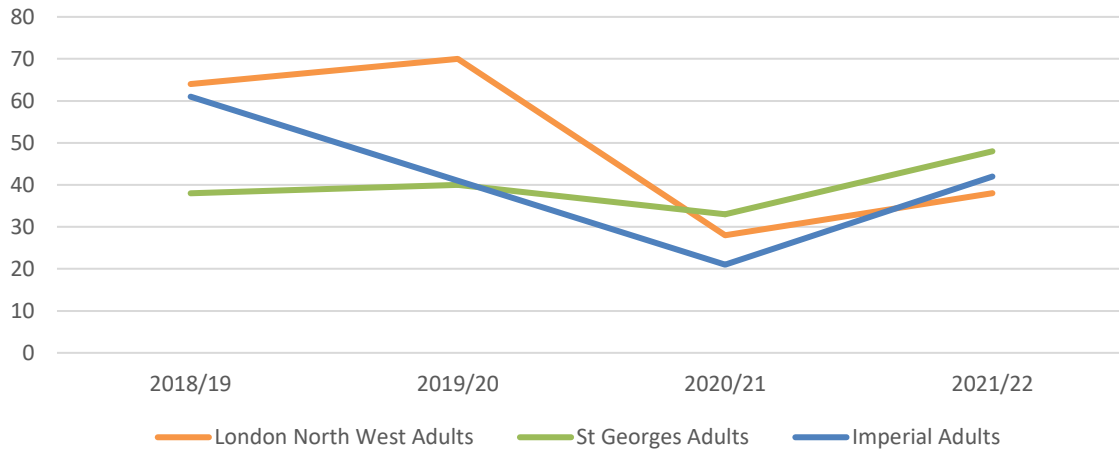
Number of non-elective adult Sickle Cell admissions at London North West each year excluding 0 day admissions

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

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



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



## 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-21	May-21	Jun-21	Jul-21	Aug-21	Sep-21	Oct-21	Nov-21	Dec-21	Jan-22	Feb-22	Mar-22	Annual Total		
<b>Proportion of patients that have admissions resulting in length of stay of over 20 days</b>	<b>Numerator:</b> Of those in the denominator, the number of admissions which resulted in length of stay of over 20 days <b>Denominator:</b> The total number of admissions in the reporting period	<b>HCC Adult</b>	Numerator	2	2	0	6	1	2	3	2	1	1	1	5	26		
			Denominator	83	89	103	106	97	74	79	107	102	107	111	96	1154		
			<b>Percentage</b>	<b>2%</b>	<b>2%</b>	<b>0%</b>	<b>6%</b>	<b>1%</b>	<b>3%</b>	<b>4%</b>	<b>2%</b>	<b>1%</b>	<b>1%</b>	<b>1%</b>	<b>5%</b>	<b>2%</b>		
		<b>HCC Children</b>	Numerator	0	1	0	1	0	2	0	0	0	0	0	0	0	0	4
			Denominator	20	37	15	26	21	11	23	29	25	39	35	28	309		
<b>Percentage</b>	<b>0%</b>		<b>3%</b>	<b>0%</b>	<b>4%</b>	<b>0%</b>	<b>18%</b>	<b>0%</b>	<b>0%</b>	<b>0%</b>	<b>0%</b>	<b>0%</b>	<b>0%</b>	<b>0%</b>	<b>1%</b>			



## 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	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		Apr-21	May-21	Jun-21	Jul-21	Aug-21	Sep-21	Oct-21	Nov-21	Dec-21	Jan-22	Feb-22	Mar-22	Annual Total
		<b>HCC Adult</b>	Numerator		1	3	4	4	11	9	8	4	5	15	11
Denominator			1	3	4	4	11	9	8	4	5	15	11	9	84
<b>Percentage</b>			<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	
<b>HCC Children</b>	Numerator		3	4	3	2	6	4	4	6	6	5	3	5	51
	Denominator		3	4	3	2	6	4	4	6	6	5	3	5	51
	<b>Percentage</b>		<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	

## 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 -21	May- 21	Jun -21	Jul- 21	Aug- 21	Sep -21	Oct -21	Nov- 21	Dec- 21	Jan -22	Feb- 22	Mar- 22	Annual Total	
<b>Proportion of patient deaths discussed at HCC morbidity/mortality meetings</b>	Numerator: Of those in the denominator, the number of deaths discussed at HCC morbidity / mortality meeting	<b>HCC Adult</b>	Numerator	0	1	0	2	1	0	1	1	1	1	1	1	10	
			Denominator	0	1	0	2	1	0	1	1	1	1	1	1	1	10
			<b>Percentage</b>	-	<b>100%</b>	-	<b>100%</b>	<b>100%</b>	-	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>
	Denominator: The total number of regional deaths in the reporting period	<b>HCC Children</b>	Numerator	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
			<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	1223
			Denominator	1312
			<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	643
			Denominator	769
			<b>Percentage</b>	<b>84%</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 -21	May- 21	Jun -21	Jul -21	Aug -21	Sep -21	Oct -21	Nov -21	Dec -21	Jan -22	Feb -22	Mar -22	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	0	0	0	0	0	0	0		
			Denominator	0	0	0	0	0	0	0	0	0	0	0	0	0	0	
			<b>Percentage</b>	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
		<b>Children</b>	Numerator	0	2	1	0	0	0	0	0	0	0	0	4	1	1	9
			Denominator	0	2	1	0	0	0	0	0	0	0	0	4	1	1	9
			<b>Percentage</b>	-	<b>100%</b>	<b>100%</b>	-	-	-	-	-	-	-	-	<b>100%</b>	<b>100%</b>	<b>100%</b>	-

## Appendix 1-service specification

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



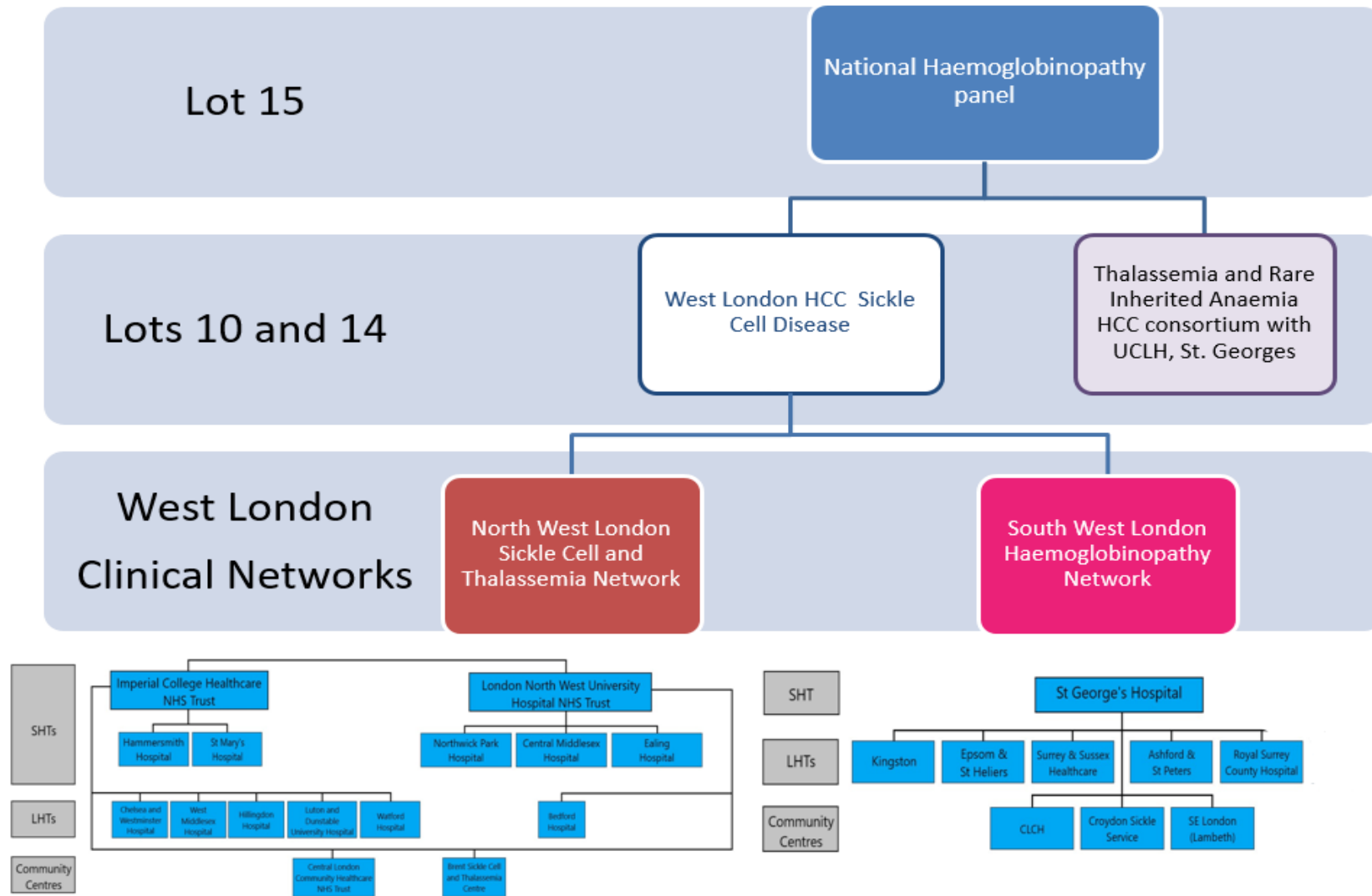
Document 3a-  
Haemoglobinopath;

Embed a copy of the peer review standards

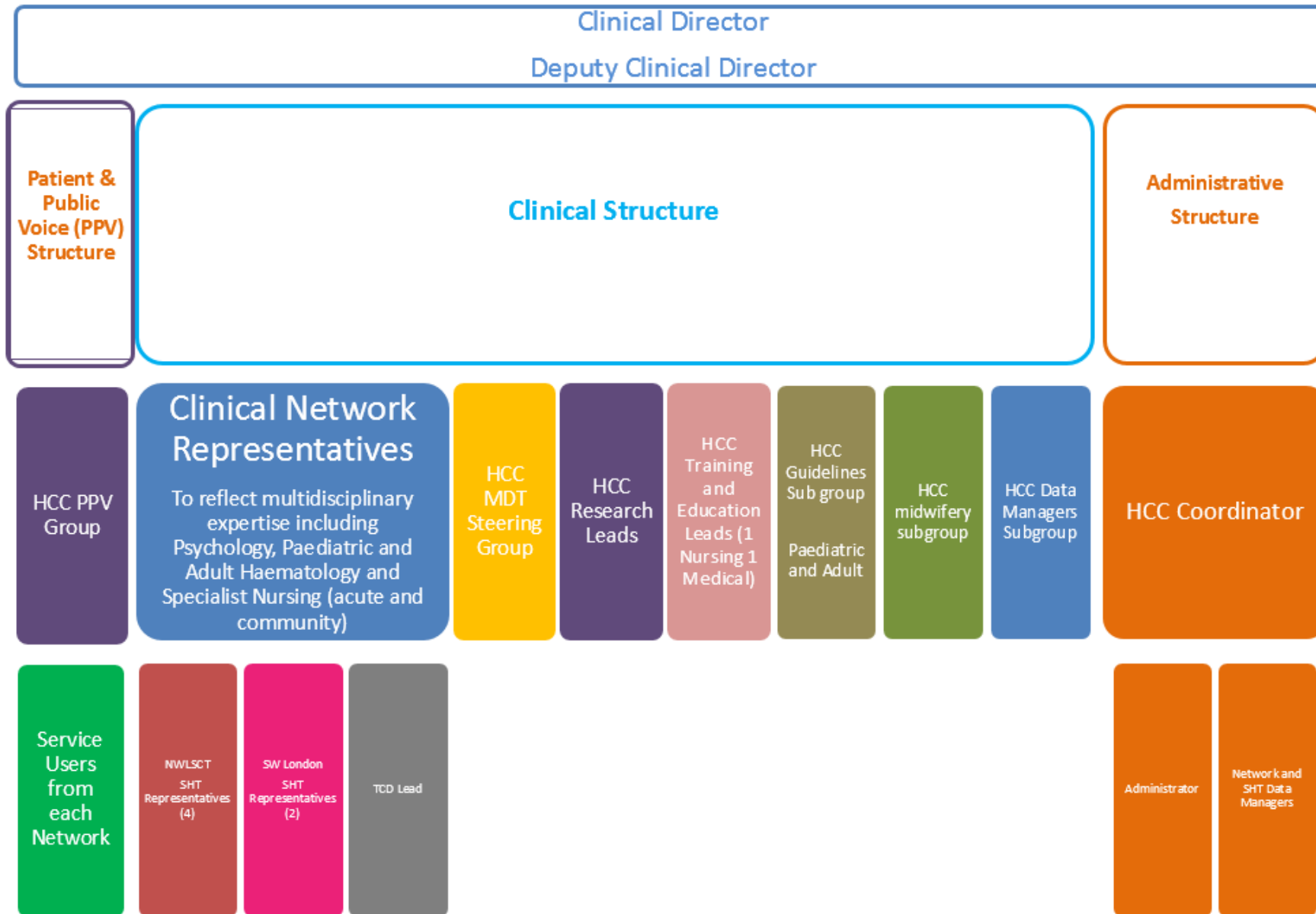


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## Appendix 2-Network Organogram



## 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

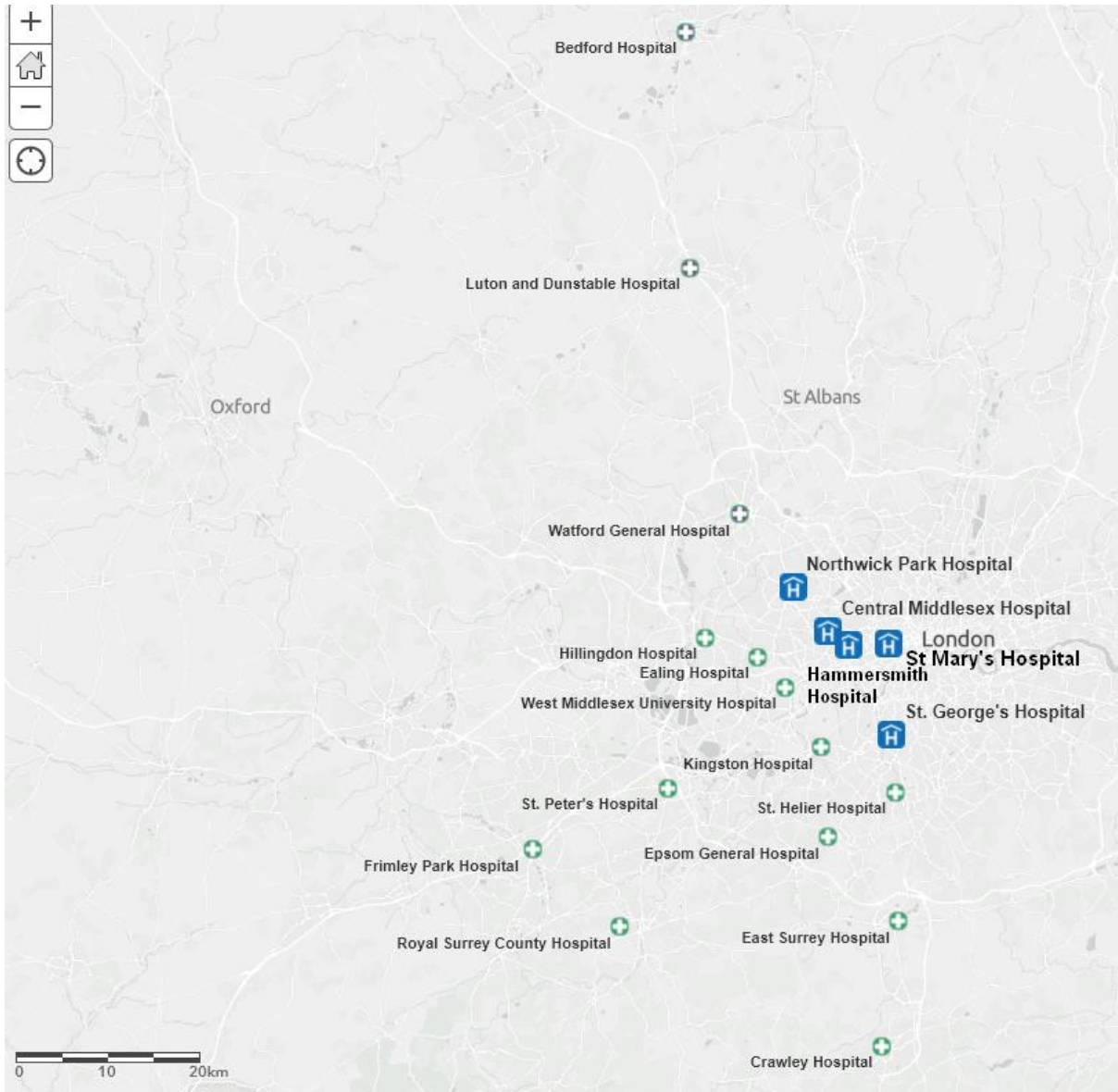
<b>Position</b>	<b>Member of Staff</b>	<b>Associated Hospital</b>
Clinical HCC Director	Mark Layton	Imperial College Healthcare NHS Trust
Deputy Clinical Network Director	Kofi Anie	London North West University Healthcare NHS Trust
HCC Coordinator	Ralph Brown	
HCC Administrator	Eniola Kuseju	
HCC MDT Steering Group	Asad Luqmani	Imperial College Healthcare NHS Trust
	Julia Sikorska	St George's University Hospitals NHS Foundation Trust
	Alison Thomas	St George's University Hospitals NHS Foundation Trust
	Kirstin Lund	Imperial College Healthcare NHS Trust
HCC Training and Education Leads	Lola Oni/Jacqui Bowyer	London North West University Healthcare NHS Trust
	Mamta Sohal	Imperial College Healthcare NHS Trust
HCC Research Leads	Kofi Anie	London Northwest University Healthcare NHS Trust
	Fred Piel	Imperial College London
	Josu de la Fuente	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	St George's University Hospitals NHS Foundation Trust
SW London Network Clinical SHT Representative	Julia Sikorska	St George's University Hospitals NHS Foundation Trust

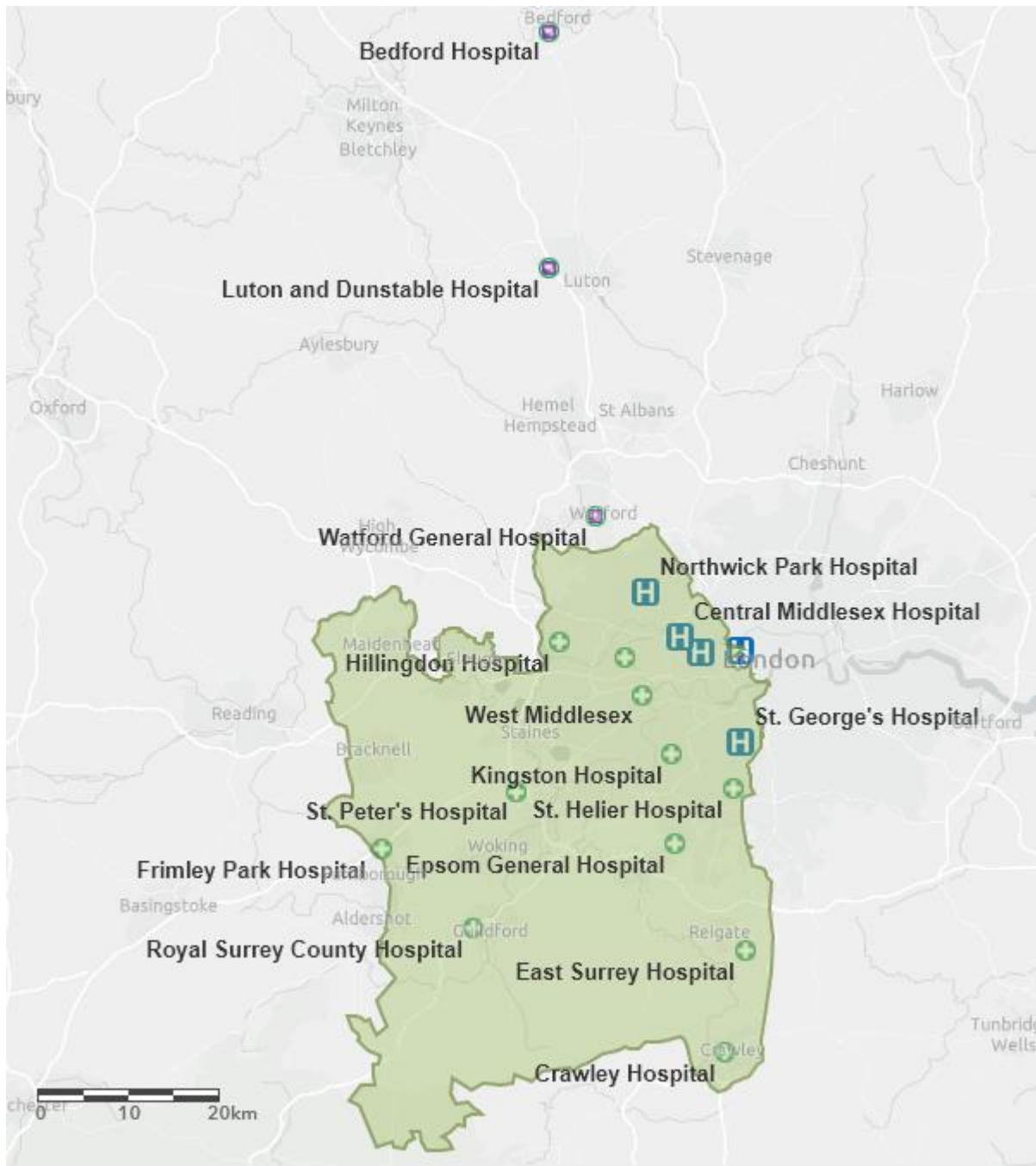
Key Positions within the Network continued



<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 taken from the original bid documents given out to the respective bidding organisations

**Appendix 6- HCC MDT 2021/22 attendance**  
**2021/22 Table:**

MDT Attendance	Friday - Adverse event MDT	Friday	Wednesday	Friday	Friday - Adverse event MDT	Friday	Wednesday	Friday - Adverse event MDT	Friday	Wednesday	Friday	Wednesday	Friday
	01.04.2022	18.03.2022	23.02.2022	21.01.2022	14.01.2022	19.11.2021	20.10.2021	08.10.2021	17.09.2021	18.08.2021	16.07.2021	16.06.2021	07.05.2021
Cases		5	10	6		2	4	4-ad hoc	4	5	3	4	5
Attendance	25	31	27	32	28	28	30	25	28	33	36	34	38
<u>Job Types</u>													
Haematology Consultants	8	6	7	9	11	11	10	7	7	6	9	9	8
Paediatric Haematology and General Paediatric Consultants	3	5	1	5	6	4	3	4	5	8	8	9	13
SpRs/Trainee Doctors	0	1	0	1	0	0	0	0	2	4	1	0	1
Nursing Staff	6	5	7	7	6	6	10	9	11	9	13	8	10
Psychologists		1	2	1	1	1	2	1		2	2	1	1
Other Allied Health Professionals	8	13	10	8	4	6	5	4	3	4	3	7	5
<u>SHTs</u>													
Imperial College Healthcare NHS Trust	7	10	9	13	12	9	10	6	10	15	14	13	9
London North West University Healthcare NHS Trust	4	6	5	5	5	13	6	7	6	9	11	8	7

St George's University Hospitals NHS Foundation Trust	1	2	6	3	3	3	3	4	3	4	1	3	2
LHTs													
Luton And Dunstable University Hospital NHS Foundation Trust							1				1	1	1
Central London Community Healthcare NHS Trust	1	1	2	1	2		3	3	2		1	1	1
Ealing Community Partners	1	1		1	1	1	1	1	1		1	1	
Frimley Health NHS Foundation Trust	1		1										
Kingston Hospital NHS Foundation Trust		1		1							1		
West Hertfordshire Hospitals NHS Trust					1				1				1
Royal Surrey													1
Chelsea and Westminster Hospital NHS Foundation Trust													1
Epsom and St Helier University Hospital NHS Trust	1	1								1			1
Ashford and St Peter's Hospitals NHS Foundation Trust													1
Other													
Cambridgeshire Community Services NHS Trust							1				1		1
Buckinghamshire Healthcare NHS Trust													
Barts Health NHS Trust	1	1											1

Whittington Health NHS Trust				1								1	3
Hounslow And Richmond Community Healthcare NHS Trust	1												1
Royal Cornwall Hospitals NHS Trust					1								
SPAH and Welsh Partners	1	1	1	4									
NHS Greater Glasgow and Clyde	2	3	1	1							2		2
Cardiff And Vale UHB	2			1	1	2	3	3	3	4	2	3	3
NHS Grampian				1	1							1	
NHS Lothian												1	1
NHS Tayside													
NHSBT	1	1	1	1			1		1	1		1	
Aneurin Bevan UHB							1	1	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	9	0	9
St Mary's Hospital- Imperial College Healthcare NHS Trust	0	3	3
Whittington/St Mary's Imperial College Healthcare NHS Trust Joint case	0	1	1
Buckinghamshire Healthcare NHS Trust/Imperial College Healthcare Trust Joint case	0	1	1
<b>Total Imperial</b>	<b>9</b>	<b>5</b>	<b>14</b>
St George's University Hospitals NHS Foundation Trust	12	5	17
London North West University Healthcare NHS Trust, Northwick Park Hospital	8	4	12
LHT	0	0	0
West Middlesex Hospital	1	0	1
West Hertfordshire Hospital NHS Trust	1	0	1
SPAH	0	0	0
Glasgow Royal Infirmary	0	2	2
Royal Hospital for Children, Glasgow	0	3	3
ARI, Aberdeen	0	1	1
RHSC Edinburgh	0	0	0
Ninewells Hospital Dundee	0	0	0
Welsh Centres	0	0	0
Noah's Ark Children's Hospital for Wales, Cardiff and Vale UHB	0	0	0
Cardiff and Vale UHB	0	2	2
	<b>31</b>	<b>22</b>	<b>53</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)
19/04/2021	Pain Management	Kofi Anie, Jeremy Anderson, Rebecca Mcloughlin	West London HCC Members: Acute and community doctors, nurses, Junior Doctors and all specialists	Time: 15:00-16:30 90 mins in Length Teams	30
21/05/21	Gene Therapy and BMT	Josu de la Fuente	West London HCC Members: Acute and community doctors, nurses, Junior Doctors and all specialists	Time: 16:00-17:00 60 mins in Length Teams	40
17/06/21	Sickle Cell GP Study Session	Asad Luqmani, Steven Okoli, Jeremy Anderson, Lola Oni	GP Liaisons	Time: 12:55-15:30 155 mins in Length Teams	66
18/06/2021	Observational Studies including Psychology and Patient Experience	Jeremy Anderson	West London HCC Members: Acute and community doctors, nurses, Junior Doctors and all specialists	Time: 16:00-17:00 60 mins in Length Teams	52



17/09/21	Transfusion Therapy	Sara Wright	Junior Doctors	Time: 16:00-17:00 60 mins in Length Teams	47
24/09/2021	Management of Acute Sickle Cell Emergencies in Adults	Mamta Sohal	Junior Doctors/Emergency Urgent care Settings	Time: 16:00-17:00 60 mins in Length Teams	30
12/11/21	Laboratory Aspects of Haemoglobinopathies including Difficult Cases and Challenges of Diagnosis	Amanda Hann, Julia Sikorska	Junior Doctors	Time: 15:30-17:00 90 mins in Length Teams	40
19/11/2021	Community Healthcare professionals	Alan Jackson	West London HCC Members: Acute and community doctors, nurses, Junior Doctors and all specialists, Dietitians	Time: 16:00-17:00 60 mins in Length Teams	62
24/11/2021	Physiotherapy and Sickle Cell Anaemia	Mercy Ibidapo, Zara Ewing, Rebecca McLoughlin	Physiotherapists	Time: 15:00-16:30 90 mins in Length Teams	45

26/11/2021	Sickle Gen Africa - Study Clinical Implications of Hemopexin Deficiency in SCD	Solomon Ofori-Acquah	West London HCC Members: Acute and community doctors, nurses, Junior Doctors and all specialists	Time: 15:00-16:00 60 mins in Length Teams	22
17/12/2021	Nursing Management of Acutely Ill Sickle Cell Patients in Hospital	Lola Oni	Nurses	Time: 15:30-17:00 90 mins in Length Teams	65
14/01/2022	Pharmacokinetic Guided Dosing of Hydroxyurea	Patrick McGann	West London HCC Members: Acute and community doctors, nurses, Junior Doctors and all specialists	Time: 16:00-17:00 60 mins in Length Teams	46
21/01/2022	Global Epidemiology of SCD and Newborn Screening With POCT Presentation	Fred Piel	West London HCC Members: Acute and community doctors, nurses, Junior Doctors and all specialists	Time: 16:00-17:00 60 mins in Length Teams	50
04/02/2022	Hydroxycarbamide and Lung Function	Subarna Chakravorty	West London HCC Members: Acute and community doctors, nurses, Junior Doctors and all specialists	Time: 16:00-17:00 60 mins in Length Teams	45

25/02/2022	Paediatric Sickle Cell Emergency Department Teaching Session	Cardiff and Vale Emergency Unit Team	West London HCC Members: Acute and community doctors, nurses, Junior Doctors and all specialists, Emergency department attendees	Time: 16:00-17:00 60 mins in Length Teams	36
04/03/2022	Transfusion Reactions in Sickle Cell	Fatts Chowdhury	West London HCC Members: Acute and community doctors, nurses, Junior Doctors and all specialists	Time: 16:00-17:00 60 mins in Length Teams	26
08/03/2022	Midwifery and Sickle Cell	HCC Midwifery team	Midwives	Time: 10:00-11:30 90 mins in Length Teams	53
09/03/2022	Sickle Cell in Schools Teaching session		School Teachers/ Schools Nurses/ Community Nurses	Time: 15:30-16:30 60 mins in Length Teams	125
31/03/2022	Midwifery and Sickle Cell	HCC Midwifery team	Midwives	Time: 14:00-15:30 90 mins in Length Teams	65

## Appendix 9- Training sessions feedback

### Details of the sessions

Title of the sessions: **School Care**

Dates delivered: 09/03/2022

Delivered by: Barbara Bailey, Jacqui Bowyer

Content: Sickle Cell; biology, pathology, pathophysiology, genetics, clinical manifestation, prevention and management of illness, management of children and adolescents in a learning environment and school care plans

Number of School nurses and Teachers reached: 125

Comments from attendees:

*"This was fantastic! Very educative. Thank you. Thank you so much for this opportunity. Thank you once again"*

*"Thank you very much for a very informative training session"*

*"Thank you Barbara, very practical advice on supporting these children in schools."*

Title of the sessions: **Midwives**

Dates delivered: 08/03/2022, 31/03/2022

Delivered by: Helen Hoskin, Paula Sullivan, Carmen Martos-Ordonez, Joyce Adu-Admankwah, Shauna Fahy

Content: Sickle Cell; biology, prevalence, genetics, pathophysiology, clinical manifestation; difference in iron deficiency anaemia and anaemia due to alpha thalassaemia in pregnancy; the new revised Public Health England sickle cell & thalassaemia counselling competencies

Number of Midwives reached: 118

Comments from attendees:

*"Yes the session was very useful as relevant to our everyday practise and a level that was easy to understand"*

*"Really very useful. As we are experiencing a small but growing increase in incidences it was really helpful to have some formal tutorials."*

*"Very easy to understand and follow. Excellent updates sent also."*

Title of the sessions: **Difficult Transfusions**

Dates delivered: 04/03/2022

Delivered by: Fatts Chowdhury

Content: Case presentations, Challenges of Provision of Blood for Patients with SCD, Extended Matching, Patient Prioritisation, Modelling for Future Demand Planning, Hyperhaemolysis – Transfusion Lab aspects

Comments from attendees:

*“Thank you so much really useful and informative”*

*“Thanks for extensive good cases”*

*“Thanks so much, that was really informative”*

## Appendix 10- 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 11- NHP Meeting Attendance

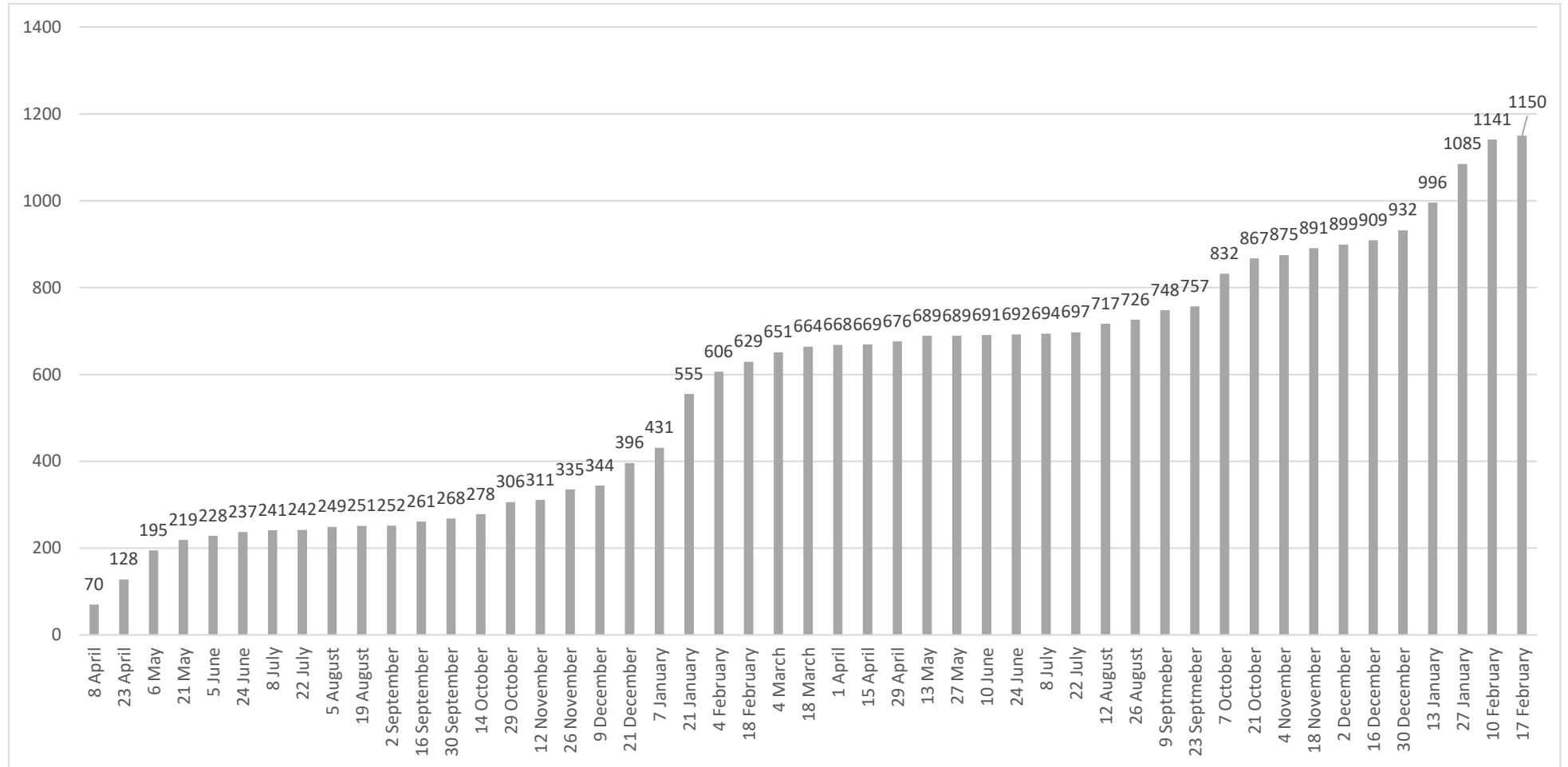
NHP MDT attendance	
April 2021	Josu de la Fuente
May 2021	Josu de la Fuente, Mark Layton
24th January 2022	Kofi Anie, Mark Layton
3rd February 2022	Josu de la Fuente, Mark Layton

NHP Business Meetings attendance	
March-21	Kofi Anie, Mark Layton, Josu de la Fuente

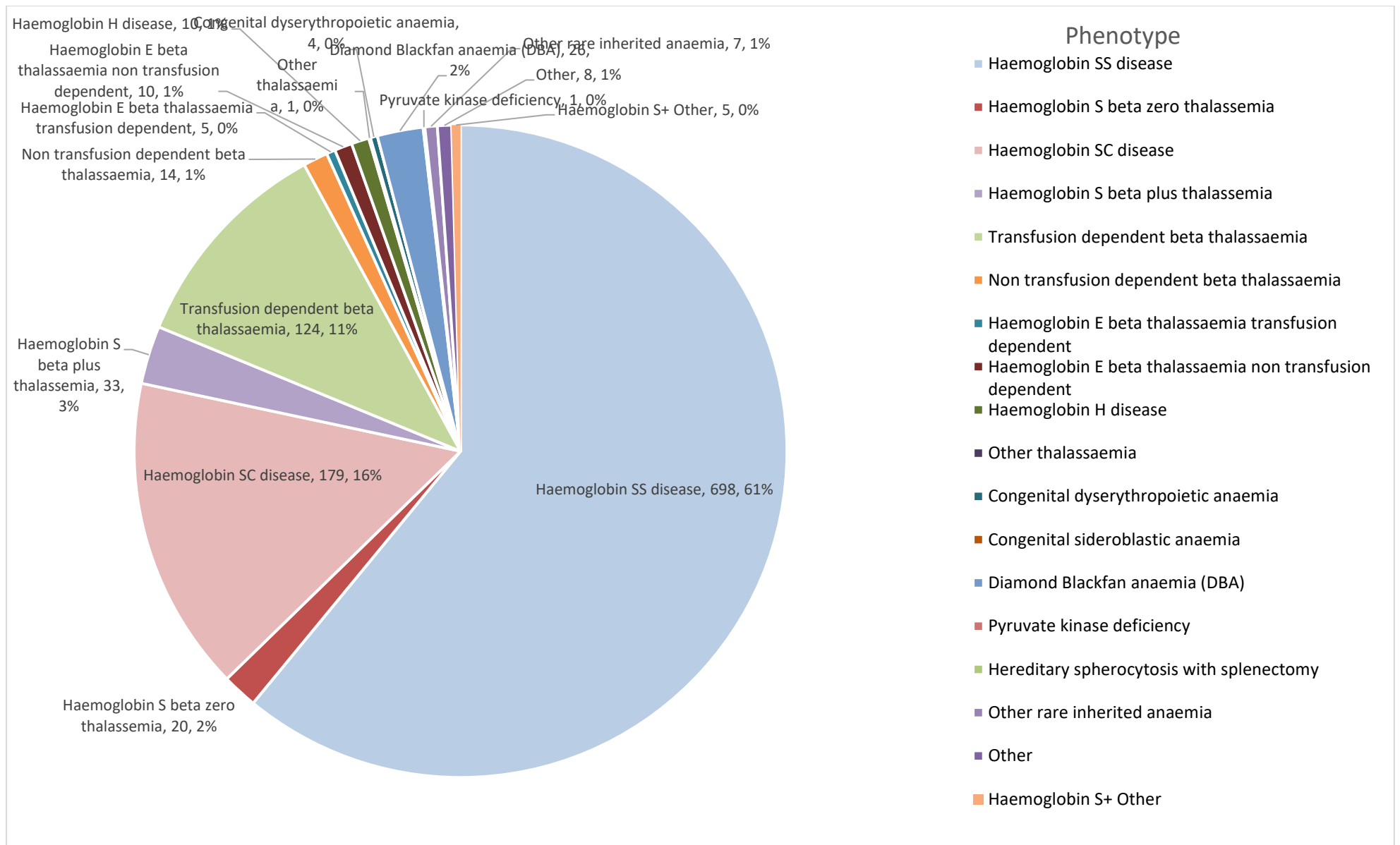
Please note NHP attendance listings (June to Dec 2021) were lost after zoom account closure and changeover of NHP manager/coordinator

## Appendix 12- Covid-19 National data collection effort

Taken from update to the National Clinical Reference Group on the 17<sup>th</sup> of February 2022







## Appendix 13- 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 Vector in Subjects with Severe Sickle Cell Disease.	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.

Title of Study	SHT the Study is being run from	Sponsor	PI (Principal Investigator) /Contact details of Lead Clinician(s)	Status of the Trial
<p>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</p>	<p>Imperial College Healthcare NHS Trust</p>	<p>Apellis</p>	<p>Prof Josu de la Fuente</p>	<p>12 to 17 years.</p>
<p>COVID-19 in patients with inherited anaemias in England</p>	<p>NHP wide</p>	<p>Imperial College Healthcare NHS Trust</p>	<p>Prof Josu de la Fuente Prof Mark Layton</p>	<p>IRAS granted</p>
<p>Study to assess the effect of long-term treatment with GBT440 in participants who have completed treatment in study GBT440-031</p>	<p>Imperial College Healthcare NHS Trust</p>	<p>Global Blood Therapeutics</p>	<p>Prof Mark Layton</p>	<p>Open  Remained open during Covid-19 surges  Closed to recruitment – in follow-up</p>
<p>Pyruvate Kinase Deficiency Global Longitudinal Registry (PEAK Registry)</p>	<p>Imperial College Healthcare NHS Trust</p>	<p>Agios</p>	<p>Prof Mark Layton</p>	<p>Open Remained open during Covid-19 surges  Open to recruitment</p>
<p>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)</p>	<p>Imperial College Healthcare NHS Trust</p>	<p>Novartis</p>	<p>Dr Asad Luqmani</p>	<p>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 now on treatment.</p>

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 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</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

Title of Study	SHT the Study is being run from	Sponsor	PI (Principal Investigator) /Contact details of Lead Clinician(s)	Status of the Trial
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 opens to recruitment on 20th April 2022
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 opens to recruitment on 25th April 2022

## 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
AG348-C-015 Pyruvate Kinase Deficiency Global Longitudinal Registry: Patient-Reported Outcomes linked to 008	Imperial College Healthcare NHS Trust	Agios	Prof Mark Layton	SIV pending.
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	Trial in set-up stage
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	Site selected
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	
Paed Voxelotor study	Imperial College Healthcare NHS Trust	GBT	Dr Kirstin Lund	

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, 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)</b>	<b>Status of the Trial</b>

			<b>/Contact details of Lead Clinician(s)</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 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 Cell	Roald Dahl's Marvellous Children's Charity./ LNWH NHS Trust.	Patricia Kiilu	Study Is Now Closed