

West London Haemoglobinopathies Coordinating Care Centre

West London HCC
2020-21

Final Report Quarter 4

Table of Contents

Annual Report.....	4
Background.....	4
Aim.....	4
Overview of the West London HCC	5
Structure of the HCC	5
Status of HCC Staffing/Recruitment.....	6
First Year Outcomes.....	7
Background.....	7
MDT of the HCC.....	8
Educational/training activities	9
Future developments	9
Collaborations with other HCCs that have been beneficial	10
Publications.....	10
Audit and data collection.....	10
Website and Social media work.....	12
Harmonisation of Network clinical guidelines	13
Service level agreements.....	13
Evidence of HCC meetings and actions achieved.....	13
Attendance of a representative from each of the HCCs at the National Haemoglobinopathy Panel (NHP).....	14
Patient and Public Voice Group.....	14
Finances of the HCC	15
Specialist Haemoglobinopathy Teams status 20-21	16
Imperial College Healthcare NHS Trust Adult Haemoglobinopathy Service	16
Imperial College Healthcare NHS Trust Paediatric Haemoglobinopathy Service.....	17
London North West University Healthcare NHS Trust Adult Haemoglobinopathy Service	18
London North West University Healthcare NHS Trust Paediatric Haemoglobinopathy Service	20
St George's University Hospitals NHS Foundation Trust-Adult Haemoglobinopathy Service	21
St George's University Hospitals NHS Foundation Trust- Paediatric Haemoglobinopathy Service	22

Patients within the Network	24
Adults	24
Paediatrics.....	24
Progress for 85% target of total registered patients attending for annual review	25
TCDs: Proportion of patients undergoing TCD.....	26
Pain relief: % of patients receiving pain relief within 30 minutes	27
Neonatal screening: Entry into specialist care and proportion of patients commencing antibiotic prophylaxis	28
Sickle Cell Disease and length of stay data 20-21.....	29
Appendix 1-service specification.....	34
Appendix 2-Network Organogram.....	35
Appendix 3-Network Structure	36
Appendix 4- Key Positions within the Network	37
Appendix 5-Maps of the HCC.....	39
Appendix 6- HCC MDT 2020/21 attendance	41
Appendix 7- Educational/training activities that have taken place.....	44
Appendix 8- Training sessions feedback.....	47
Details of the sessions.....	47
Appendix 9- Details of future sessions being planned by the Education Subgroup	49
Appendix 10- NHP Meeting Attendance.....	51
Appendix 11- adverse events recoded on NHR	52
Appendix 12- Covid-19 National data collection effort	53

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.

Evolution to a unified HCC structure in West London has been facilitated by consensus between key stakeholders in the North West London Sickle Cell and Thalassaemia Network formed in 2018 (built on the North West London Haemoglobinopathy Managed Clinical Network launched in 2003 and the Imperial Paediatric Red Cell Disorders Network established in 2010) and the South West London Haemoglobinopathy Network. The West London HCC builds on the strengths of both networks.

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 hired an 8b HCC Manager to support the administrative functions of the HCC. The HCC Manager, Ralph Brown, took up post on 22nd October 2020. On 25th March 2021 a Band 4 WTE 0.6 was recruited into post.

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 and a 0.5 WTE Band 8a Network manager in post. London North West University Healthcare NHS Trust (LNWHT) has a WTE Band 5 data manager in post. The approved position descriptions from each Trust are embedded below. St George's University Hospitals NHS Foundation Trust (SGHT) also have data management support which covers the South West London network



HCC Manager JD
B8b.docx.pdf



HCC Administration
Assistant JD B4 WTE

First Year Outcomes

Background

As the first year of establishment the West London HCC has achieved a number of achievements have been reached, these included;

- the establishment and effective delivery of a regular MDT meeting
- the implementation of an education schedule which has hosted a number of different virtual events
- the creation of the Patient and Public Voice group
- the set-up of subgroups to work on HCC wide guidelines and develop the HCC's research strategy
- Infrastructure for national database of COVID-19 in haemoglobinopathies and rare anaemias

The COVID-19 pandemic had a significant impact on the operation of the HCC with many staff being re-deployed during the COVID-19 surges to support ICU, vaccine delivery and other activities.

At the request of Imperial College Healthcare Trust all non-essential meetings were suspended during the second wave of the COVID-19 pandemic. This meant that no HCC meetings other than the MDT were held in January and February of 2021. Consultant staff at both SGHT and ICHT, and a consultant paediatrician at LNWHT were redeployed to mitigate the burden on ICUs during this period.

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 a very difficult year.

MDT of the HCC

The HCC MDT (multi-disciplinary team) has been established and has operated effectively throughout the year. The HCC MDT (multi-disciplinary team) has been established and has operated effectively throughout the year. Forty-eight 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,

One case has 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.

Educational/training activities

An educational and training sub group have been set-up which 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.

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 (7) which details the education sessions undertaken in 2020/21 and the number of attendees, 17 education sessions have taken place within the first year of the HCC. Appendix (8) 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 wave of the COVID-19 pandemic:

- Laboratory Aspects of Haemoglobinopathies (difficult cases, challenges of diagnosis)
- Management of Sickle Emergencies
- Nutritional support for Sickle Cell sufferers
- Physiotherapy in Sickle Cell Disease
- Child Health

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

Dr Sohal and Dr Oni are working on the education schedule for 21/22 with support from the Network Manager and aim to obtain formal recognition for CPD.

Collaborations with other HCCs that have been beneficial

The W London HCC has provided 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 contributed to the publication of articles (see below) in peer reviewed journals and presentation at the European Haematology Association Congress (2020). 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.

Publications

Real-time national survey of COVID-19 in hemoglobinopathy and rare inherited anemia patients, *Haematologica: the Hematology Journal*, Vol:105, ISSN:0390-6078, Pages:2651-2654 <http://hdl.handle.net/10044/1/84128>

Protecting vulnerable patients with inherited anaemias from unnecessary death during the COVID-19 pandemic, *British Journal of Haematology*, Vol:189, ISSN:0007-1048, Pages:635-639 <https://onlinelibrary.wiley.com/doi/full/10.1111/bjh.16687>

Audit and data collection

Due to the disruption caused by Covid-19 the ability of the services to collect data has been curtailed,

This was reflected by NHS England's request that the data from the SHTs to the SSQD (specialised services quality dashboard) be voluntary for the year 2020/21, this position will be reviewed in June of 2021.

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	48 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	1 (2.08%) 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 23	N/A –unable to validate data in time for draft report, due to late submission of Month 12 data for 20/21 and availability of time related to COVID-19 Pandemic		
Proportion of serious events entered on to NHR system by SHTs and reviewed at the HCC morbidity /mortality meetings	104	16 adverse Events were recorded across the HCC on the NHR* Of these 12 were discussed in the HCC MDT	11 Adverse events recorded on the NHR at Imperial 20/21 (6 in adults, 5 in Paeds)	1 Adverse event recorded on the NHR at London Northwest 20/21 (1 in Adults, 0 in Paeds)	4 Adverse events recorded on the NHR at St. Georges 20/21 (4 in Adults, 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: 82.3% Percentage of adult patients: 88.3% Percentage of Paediatric patients: 71.3% There are a total of 1,964 patients recorded on local databases across the HCC.** Of these 1,277 are adult patients, 687 are paediatric patients Recorded on the NHR are 1,617 patients of which 1,127 adults and 490 paediatric patients	551 adult patients are recorded on the local database 499 on adult patients NHR 280 paediatric patients are recorded on the local database 177 on paediatrics patients NHR	306 adult patients are recorded on the local database 344 on adult patient NHR 181 on paediatric patients 173 on paediatric patients NHR	420 adult patients are recorded on the local database 284 on adult patients NHR 226 paediatric patients are recorded on the local database 140 on paediatric patients NHR

*Data entry to the NHR of adverse events recorded locally at the SHTs was severely encumbered by the

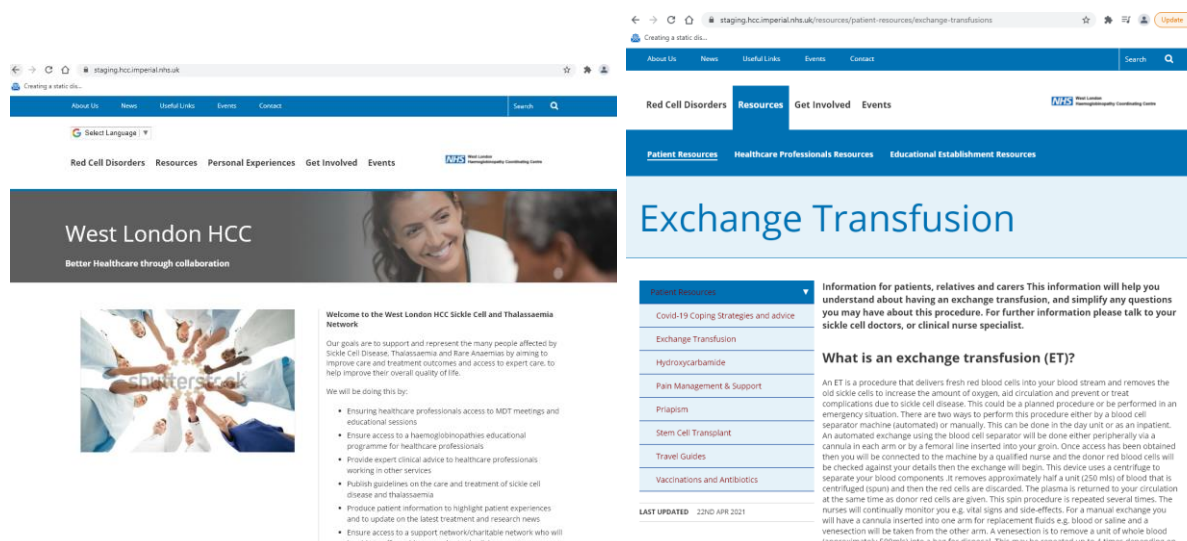
**missing some patients from adult LHTs this data will be collected in 21/22

Website and Social media work

Commercial web developers BeingOnline (who have experience with working with NHS services) have worked together with the HCC to establish a website, the time table for the website delivery is below, with the aim that an early version of the website will be accessible middle of May 2021

The project plan for the initial phase of the website, additional content will be added to this as the HCC continues/grows

	Working days	Week Commencing												
		2 11-Jan	3 18-Jan	4 25-Jan	5 01-Feb	6 08-Feb	7 15-Feb	8 22-Feb	9 01-Mar	10 08-Mar	11 15-Mar	12 22-Mar	13 29-Mar	
Project Kick Off & Scoping	1													
Sitecore CMS Development	6													
Interface design	3													
Front End Development	3													
Testing	2													
Content Population														
Deployment	1													



Further work is needed to validate the website content. The network manager will form a sub-group of clinicians to review this on a regular basis.

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

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 much of this work has been delayed but this will be worked on in depth in 2021/22. Once the guidelines have been agreed they will be hosted on the HCC website

The following guidelines will be harmonised:

- Adult guidelines for sickle cell disease
- Paediatric 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) has been finalised and signed.

SLAs for the involvement of the Scottish Paediatric and Adult Haemoglobinopathies network (SPAHA) and South Wales Haemoglobinopathy teams in HCC MDT and educational activities have been drafted and will be finalised in 2021.

Evidence of HCC meetings and actions achieved

Mobilisation/Steering group meetings have been held on a monthly basis throughout 2020/21 (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.



2020-02-05 Lot 10
HCC Mobilisation M



2020-07-10 West
London HCC Mobili:



2020-08-21 West
London HCC Mobili:



2020-10-23 West
London HCC Mobili:



2020-11-25 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 2020/21.

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 started through informal invitations via the different clinical services in the HCC, the group comprises of patient and parent representatives from paediatric and adult services. Dr Kofi Ani acts as the clinical representative for the group

The first meeting was on the 23rd of September of last year and has had four further meetings since. A few meetings have been suspended due to Covid redeployment the next meeting Thursday the 18th of March

The agenda of meetings held so far has included;

- Explanation of the HCC and aims of the PPV group,
- Discussion of the terms of reference which are due to be finalised shortly,
- Input into the HCC educational programme (which it is hoped will positively impact patient involvement and quality of care),
- Input to HCC the website due to commence including future development of apps,
- User feedback on the emergency pathways of the SHTs and LHTs in the HCC,
- How to highlight sickle crisis to A&E staff like the F.A.S.T. messaging for stroke

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.

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) in the current contract provides the HCC with £215,000 per annum. This has been included as part of the block funding in place during Covid-19. During the year the Network manager has checked with NHSE as to whether this will increase in line with inflation or with the agenda for change uplift in salaries in the subsequent years the HCC is contractually due to run for, NHSE have indicated that this will not occur.

Due to some misunderstandings and issues around the original draft budgeting the projected cost of or the draft budgets for the HCC actually overruns the £215,000

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 as not occurred due to Covid-19 restrictions. So this has resulted in a budget underspend of £66,101.

However, because of the expected overruns of the budget in the next two years (the total value of which cannot be worked out yet due to variability in NHS pay uplifts). The projection is that the overall position is around £20,000 underspent at the end of the current contract. All of this underspend needs to be invested in the HCC to ensure that it can catch-up on the work that was missed out in the year 20/21 due to the effects of the pandemic and to improve outcomes for patients as is stated in the aim of the HCC.

Year	NHSE contract	Projected Cost	Actual spend	Spend against NHSE budget *
2020/21*	£215,000	£235,591.68	£148,898.46	£66,101.51
2021/22	£215,000	£234,408.21	~£18,081.53	£19,408.21
2022/23	£215,000	£240,988.43		£25,988.43
Overall position				£20,704.87

*Please note that the financial year 2020/21 has not finished and there may be some minor variation related to the cost of ICT and the incoming Band 4 (0.6WTE) administrator. 21/22 is based on a 1% uplift of pay & 22/23 projections are based on a 2.1% uplift

Specialist Haemoglobinopathy Teams status 20-21

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 20/21:

- HCC coordinated national data collection on COVID-19 in haemoglobinopathy and rare anaemia patients
- Redeployment of staff to support COVID-19 ICU surge response
- Full-time CNS post vacant for the entirety of 20/21. Appointee unable to take up appointment due to pandemic. Eventually recruited into post May 2021. Funding for second part-time CNS post ended in June 2020
- The service transitioned many clinic appointments to video or telephone consultations. This has had a positive impact on reducing DNA rates and improving patient/parent satisfaction
- Suspension of group pain management programme (PMP)
- 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 suspended in 20/21
- Limited access to routine diagnostic imaging e.g. for monitoring of iron overload pulmonary hypertension etc
- The Renal and Haematology Triage Unit which acts as the emergency pathway for sickle cell patients saw a reduced number of adults presenting. There were fewer admissions to the ward
- Day care pain service suspended
- Increase in emergency apheresis activity
- Home delivery of medicines by hospital pharmacy introduced
- Recruitment of an additional Red Cell consultant to support the haemoglobinopathy service
- Reappointment of specialist physiotherapist as core member of multidisciplinary team for sickle cell patients
- Clinical trial activity curtailed with respect to new interventional studies

Targets for 2021/22:

- Work in collaboration with SHT at LNWUH to progress the agenda for collaborative working through the Clinical Haematology review of the NW London Specialist Services Programme
- Completion of annual reviews for the patient population for 21/22
- Reinstate PMP with combination of F2F and virtual attendance
- Reappointment of specialist social worker

Imperial College Healthcare NHS Trust Paediatric Haemoglobinopathy Service

Service updates and challenges in 20/21:

- Suspension of Trans Cranial Doppler scanning (service suspended from mid-March 20-Jun 20 with limited access, then service opened up then was constricted again from Nov 20 to Mar 21)
- Redeployment of staff to support Covid-19 ICU work
- Red Cell CNS being away from the service due to ill health, returning on a phased return from May 21
- The service was forced to conduct many clinic appointments via video consultations, but this has been positive in reducing DNA rates and improving patient/parent satisfaction
- Significant additional work relating to communication to patients about risk associated with Covid-19 and shielding advice was undertaken
- BMT programme was suspended during Covid-19 surges, lot of patients were worked-up during this period and in the period between surges a large number of patients underwent BMT resulting in a very small shortfall on usual activity in a normal given year
- Annual reviews and the work required to upload them to the National Haemoglobinopathy Registry was curtailed in 20/21
- Outreach clinics to LHTs continued during the pandemic to support colleagues
- Elective surgical work was suspended for significant chunks of the year this is being worked on by the surgical teams during 21/22
- A&E saw a reduced number of children presenting. Fewer admissions to the ward.

Targets for 2021/22:

- Getting caught up on the work backlog related to Transcranial Doppler scanning
- Catch-up required on in person investigations for patients, including sleep studies and lung function tests
- A desire to expand the Red Cell exchange programme and maintain the out of hour's service is resulting in staffing pressures and there is a need to expedite training for more members of nursing staff to fulfil this
- Adult CNS is joining the adult team so there is an expected improvement to the facilitation of transition of paediatric patients to adult services
- Completion of annual reviews for the patient population for 21/22

London North West University Healthcare NHS Trust Adult Haemoglobinopathy Service

Service updates and challenges.

Out-patient service

- Prior to the Covid-19 pandemic Out Patient clinics were provided only at the Central Middlesex Hospital (CMH) site. All adult sickle patients in Ealing Hospital had also been moved to the CMH clinic following the merger of the two Trusts in 2016.
- During the COVID pandemic as part of Trust wide general re-organisation the Thalassaemia patients receiving transfusion at Ealing Hospital were moved to CMH. All out-patient service consultations carried out on the telephone for most patients. Patients on Hydroxycarbamide, who required blood tests were seen in the Medical Day Unit 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 required Community follow up were referred to the Community Specialist Nurse who followed up the majority on the telephone.
- During outpatient clinics the Clinical Psychologist also consulted with the patients on the phone or via AttendAnyWhere video consultation.
- Routine investigations like Annual blood tests, Echocardiogram, audiometry and T2*MRI were suspended. Ophthalmology reviews were deferred for stable patients and patients with significant retinopathy previously were reviewed
- Elective Red Cell Exchange Transferred from CMH to Northwick Park (NPH) site during the 2nd wave. Patients were informed of the change and are kept up to date
- Psychology service- Face to face appointments were suspended from mid-March 2020 until end July 2020. Psychological support was offered virtually via video consultations (AttendAnywhere) and telephone.
- Medical Day Care (CMH)
- Walk –in-Service for pain relief with subcutaneous Morphine for Sickle Pain crisis was suspended during the 1st and 2nd lock-downs. All patients with pain crises were seen in A&E at NPH only.
- Elective top up transfusions continued for all Sickle and Thalassaemia patients during the Pandemic.

In-Patient-Care

- The dedicated ward (Carroll Ward) for sickle acute admissions was converted as part of acute short stay admission linked to A&E. Sickle patients were subsequently admitted into various wards in the hospital including a Surgical ward (Sainsbury's). The persistent and frequent moving of patients to any ward within

the hospital has created significant challenges for the specialist team. The Sickle Cell and Thalassaemia Acute Clinical Nurse Specialist (CNS) has been struggling to provide sufficient educational input for nursing staff to enable them to provide safe and effective care to this group of complex patients. Teaching various wards about Patient Controlled Analgesia (PCA) use has been difficult when patients are relocated frequently. Not unexpectedly, there were serious incidents of opioid toxicity experienced by many patients leading to an influx of DATIX reports.

- Patients are now admitted to Sainsbury's ward pending COVID-19 swab PCR result. If result is negative, patients are transferred to Drake ward a dedicated Haematology Ward where staff have been given additional training in caring for the patient group and management of PCA. PCA use is avoided as much as possible if patients are admitted to other wards for example due to unavailability of a bed on Drake Ward. This has the potential of sub-optimal pain control for the patients but carries much less chance of Opiate toxicity and associated complications.

Pharmacy service

- NPH- Drive through pharmacy service was initiated. Patients could collect their medications such as Hydroxycarbamide without having to come into the hospital. Pharmacy also ran a delivery to home service for all shielding patients during the lock down periods.
- Ealing Hospital had some home delivery service during the lock down periods

Multi- Disciplinary Team meetings

- These continued virtually including with Local Haemoglobinopathy Teams. There were more frequent HCC MDTs during the 1st wave of the pandemic. During this time, Sickle and Thalassaemia patients with features suggestive of or confirmed COVID-19 infection were discussed with further advice on their management.

Vision for post COVID-19 pandemic

- Work in collaboration with SHT at ICH to progress the agenda for collaborative working through the Clinical Haematology review of the NW London Specialist Services Programme
- It is envisaged telephone and virtual clinics will be maintained for some OPD consultations
- There will be a return to face-to-face consultations for outpatient clinic annual reviews and management of complex patients including those on hydroxyurea.

- A dedicated ward for care of inpatients will be re-established and staff will be adequately trained in care and management of the patient with sickle cell and thalassaemia experiencing an acute illness.
- A substantive consultant haematologist will be appointed to manage the patient group and adequate time (PA) will be allocated for the specialist consultant and service.
- A&E department will be supported to meet NICE pain management standards.

London North West University Healthcare NHS Trust Paediatric Haemoglobinopathy Service

Service updates and challenges 20/21

- Community services- Face to face visits suspended from late March 2020-June 2021. New born affected patient visits offered through-out. Some patients declined face to face visits and this was done on the phone or on video calls.

Teaching- schools, HV's SN etc has been given via MS Teams.

World Sickle cell day on 19th June 2020- zoom call held with patients. Well attended.

- Out-patient service

Ealing Hospital- original out-patient was taken over for adult Covid ward. Out-patient services run from temporary clinic and re-located to new facility in December 2020. Consultations carried on the phone for most patients. Patients on Hydroxycarbamide, who required blood tests were seen in clinic, face to face.

Central Middlesex Hospital- Out-patient clinic-located to new facility at CMH due to Covid and relocation of other adult services into original paediatric clinic space. Patients seen face to face as required. Majority of consultations done over the phone.

- Paediatric audiology and ophthalmology clinics suspended in first and second lock down. Assessments carried out in between lockdown periods.
- Ferriscans temporarily suspended during the initial lockdown. However services re-started in summer 2020. Continued from then on. Urgent MRI/MRA done as required.

- Paediatric Day Care

Ealing- No anaesthetic availability due to Covid-19 rota, therefore blood transfusions no longer carried out in Ealing. Ealing patients on transfusion programme have their transfusions at Northwick Park.

Northwick Park- PDCU re-located to temporary facility. All transfusions done at NPH.

- A&E saw a reduced number of children presenting. Fewer admissions to the ward.

- Trans-cranial Doppler service- temporarily suspended from March- September. New unit opened in NPH Vascular department. Scanning resumed in October, increased lists done to catch up. All patients eligible for scanning had scans by March 2021. Now routine lists done.
- Psychology service- Face to face appointments suspended from mid-March 2020 until end July 2020. Psychological support was offered virtually via video consultations (AttendAnywhere) and telephone. Neuropsychological assessments could not be done virtually.
- Pharmacy service

Northwick Park Hospital- Drive through pharmacy service initiated, where patients could pick up medication such as Hydroxycarbamide without having to come into the hospital. Pharmacy also ran a delivery to home service for all shielding patients during the lock down periods. Ealing- home delivery service during the lock down periods

- MDT's continued virtually including with LHT.

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

Service updates and challenges 20/21:

- Redeployment of both red cell consultants to general medicine and palliative care during 1st and 2nd Covid-19 surges
- Outpatient clinics changed to telephone clinics with suspension of annual reviews, resulting in a significant reduction in DNA rate.
- Outpatient clinics temporarily suspended during team redeployment. This resulted in an increase in ad hoc virtual/telephone reviews and “telephone treatment clinics” implemented (to keep track of those on treatment and arrange home delivery prescriptions, e.g. hydroxycarbamide and chelation)
- Non-urgent investigations and referrals (T2* MRIs, echocardiograms and ophthalmology referrals) suspended. No significant impact on urgent investigations/referrals which were performed with minimal delay
- Second Haemoglobinopathy CNS appointed October 2020. One CNS working off site full time due to shielding from March 2020 to April 2021, 2nd CNS redeployed December 2020 to April 2021

- Apheresis team: severe staffing shortages due to sickness during 2nd Covid surge with out-of-hours service/on call service being temporarily suspended for approximately 4 weeks but with minimal impact on elective patients undergoing red cell exchange transfusions
- Pain Management Programme continued with appointments being conducted via video consultation. Psychology appointments conducted by telephone.
- Additional work relating to communication to patients regarding risks associated with Covid-19, shielding and vaccination.

Targets 21/22:

- Continue telephone/virtual telephone clinics and restart face-to-face appointments for annual reviews
- Both CNS on site from April 2021
- Non-urgent investigations and referrals to restart
- Appoint network patient pathway manager

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

Service updates and challenges 20/21

- Apheresis – Apheresis staff were off sick/isolating and this had impact on paediatric patients.
- Annual reviews and upload on to the National Haemoglobinopathy Registry was compromised in 20/21
- Elective surgical work was suspended in 2020
- 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.
- Pre-transfusion blood test – were done through home visits due to shielding etc.
- Medicines – Home delivery rather than families coming here to pick up. Special Preparation needed to extend expiry dates
- Blood test monitoring – was done through home visits rather than come to hospital
- TCD scan – Capacity reduced, Patients also declined to come. Therefore many patient rescheduled/cancelled. So lower priority patients experienced large delay. Scanning team brought the equipment down to avoid moving patients through the hospitals.

- Clinics – changed to majority of telephone appointments and therefore assessments not as thorough as should be. Therefore more patients needing to be followed up and again patients declining to attend. Less patients reviewed due to leaving gaps between the patients.
- Outpatient Phlebotomy - Walk ins stopped, patients booked. Reduced capacity. Some had to be moved to Day case ward.
- Patient could not be discharged as could not have procedure due to being COVID positive.
- Lots of phone calls and time spent to encourage patients to come to hospital. Organise food packages and letters to employers for patients that were shielding.
- Staff had to move into hotel – emotional and psychological effect on staff well member.
- Transition clinic not affected as carried on over the phone.
- Psychological impacts – on patients
- Pain nurse - redeployed therefore no support
- Patients presenting later when clinically quite unwell

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 as of November 2020, previously was 1WTE.
- 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
- Psychology – Becs – 0.8 WTE – 25 hours for Haematology/Sickle Cell – throughout COVID
- Junior Drs – No SpR Support. Adult team used to support, but they are currently short and have been throughout COVID
- 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
- Community Nurse for sickle patients – 1 WTE - only for Wandsworth GP catchment.

Patients within the Network

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

Adults

Imperial College Healthcare NHS Trust

551 adult patients are recorded on the local database

499 of adult patients are on the NHR

London North West University Healthcare NHS Trust

306 adult patients are recorded on the local database

344 of adult patients are on the NHR

St George's Healthcare NHS Foundation Trust

420 adult patients are recorded on the local database

284 of adult patients are on the NHR

Paediatrics

Imperial College Healthcare NHS Trust

280 paediatrics patients are recorded on the local database

177 of paediatrics patients are on the NHR

London North West University Healthcare NHS Trust

181 paediatrics patients are recorded on the local database

171 of paediatrics patients are on the NHR

St George's Healthcare NHS Foundation Trust

226 paediatrics patients are recorded on the local database

140 of paediatrics patients are on the NHR (RB note Peter states this is 140)

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

Adverse events recorded at Imperial Adverse events recorded at Imperial 20/21- 71

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

Due to the effects of the Covid-19 pandemic, the release of the new NHR (national Haemoglobinopathy registry) and the reduced requirements from NHS England to collate this data for the number of annual reviews that took place across the HCC this year was infinitely lower than in previous years

Adults				
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)	499	90.6%	(0) 0%	
London North West University Healthcare NHS Trust	344	112.4%	(2) 0.6%	
St George's University Hospitals NHS Foundation Trust	284	67.6%		
Paediatrics				
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)	177	41.8%	(51) 28.8%	
London North West University Healthcare NHS Trust	173	95.6%	(6) 3.4%	
St George's University Hospitals NHS Foundation Trust	140	61.9%		

TCDs: Proportion of patients undergoing TCD

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

The data submitted from ICHNT also includes LHT hospitals within it's Paediatric Network

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	
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	0	0	0	0	0	9	21	24	27	11	5	10	107	
			Denominator	0	0	0	0	0	10	26	24	39	11	8	10	128	
			Percentage	-	-	-	-	-	90%	81%	100%	69%	100%	63%	100%	83.6%	
		ICHNT Children	Numerator	8	1	6	11	6	14	7	7	4	3	10	2	79	
			Denominator	8	1	7	11	6	14	8	8	4	12	17	9	105	
			Percentage	100%	100%	86%	100%	100%	100%	88%	88%	100%	25%	59%	22%	75.2%	
		SGUH Children	Numerator														
			Denominator														
			Percentage														

As you can see TCD services were significantly disrupted by both waves of the Pandemic in 20-21

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

Please note this data was effected by the Covid-19 Pandemic and cannot be completely validated, data does not include LAS administration of analgesia. It is strongly recommended that no conclusions or outcomes are derived from this data set without future years data sets.

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	6	6	5	12	5	10	6	6	7	9	11	10	93		
			Denominator	21	11	17	25	14	28	22	18	28	19	23	20	246		
			Percentage	29%	55%	29%	48%	36%	36%	27%	33%	25%	47%	48%	50%	37.8%		
		ICHNT Adult	Numerator	13	4	5	7	7	6	3	9	4	9	4	2			
			Denominator	28	24	32	38	44	36	34	28	25	20	28	17			
			Percentage	46%	17%	16%	18%	16%	17%	9%	32%	16%	45%	14%	12%			
		SGUH Adult	Numerator															
			Denominator															
			Percentage															
		LNWH Children	Numerator	1	1	1	0	4	2	1	5	2	0	1	4	22		
			Denominator	1	1	3	0	4	6	2	7	4	1	1	5	35		
			Percentage	100%	100%	33%	-	100%	33%	50%	71%	50%	0%	100%	80%	62.8%		
		ICHNT Children	Numerator	1	4	2	2	6	1	3	5	4	1	1	7			
			Denominator	0	0	1	0	0	1	0	3	1	0	0	0			
			Percentage	0%	0%	50%	0%	0%	100%	0%	60%	25%	0%	0%	0%			
SGUH Children	Numerator																	
	Denominator																	
	Percentage																	

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	0	1	2	2	3	4	0	0	2	0	0	2	16	
			Denominator	0	1	2	2	3	4	0	0	2	0	0	2	16	
			Percentage	-	100%	100%	100%	100%	100%	-	-!	100%	-	-	100%	100%	
		ICHNT Children	Numerator	0	0	0	1	2	0	1	0	0	0	0	0	0	4
			Denominator	0	0	0	1	2	0	1	0	0	0	0	0	0	4
			Percentage	-	-	-	100%	100%	-	100%	-	-	-	-	-	-	100%
		SGUH Children	Numerator														
			Denominator														
			Percentage														

HAEM04B	Percentage of eligible children beginning Penicillin at our before 3 months of age as per screening programme guidelines	LNWH Children	Numerator	0	1	2	2	3	3	0	0	2	0	0	2	15	
			Denominator	0	1	2	2	3	3	0	0	2	0	0	2	15	
			Percentage	-	100%	100%	100%	100%	100%	-	-	100%	-!	-	100%	100%	
		ICHNT Children	Numerator	0	0	0	1	2	0	1	0	0	0	0	0	0	4
			Denominator	0	0	0	1	2	0	1	0	0	0	0	0	0	4
			Percentage	-	-	-	100%	100%	-	100%	-	-	-	-	-	-	100%
		SGUH Children	Numerator														
			Denominator														
			Percentage														

Sickle Cell Disease and length of stay data 20-21

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 21-22. 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)
2018/19	64	39	7	12.28%	4.87	3.5
2019/20	48	35	2	4.35%	3.85	3
2020/21	26	21	1	4%	3.19	2

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)
2018/19	61	39	7	12.96%	5.1	4
2019/20	41	32	1	2.5%	4.5	4
2020/21	21	17	1	5%	2.8	2

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
					Mean	Median
2018/19	446	139	192	75.6%	5.2	2
2019/20	481	147	218	82.9%	5.03	2
2020/21	417	120	212	103.4%	4.17	1

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
					Mean	Median
2018/19	306	118	114	59.3%	7.6	5
2019/20	331	124	116	53.9%	7.3	4
2020/21	250	96	92	58.2%	6.9	4

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)
2018/19	44	33	1	2.3%	3.1	2
2019/20	44	29	3	7.3%	2.4	2
2020/21	35	24	5	16.7%	6.1	4

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)
2018/19	38	30	1	2.7%	3.6	2
2019/20	40	27	2	5.3%	2.8	2
2020/21	33	23	5	17.7%	6.5	4

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)
2018/19	253	111	64	33.9%	5.5	4
2019/20	224	116	31	16.1%	5	3
2020/21	137	69	22	19.1%	5	3

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)
2018/19	237	106	59	33.15%	5.9	4
2019/20	199	107	23	13.1%	5.6	4
2020/21	127	65	12	10.4%	5.4	4

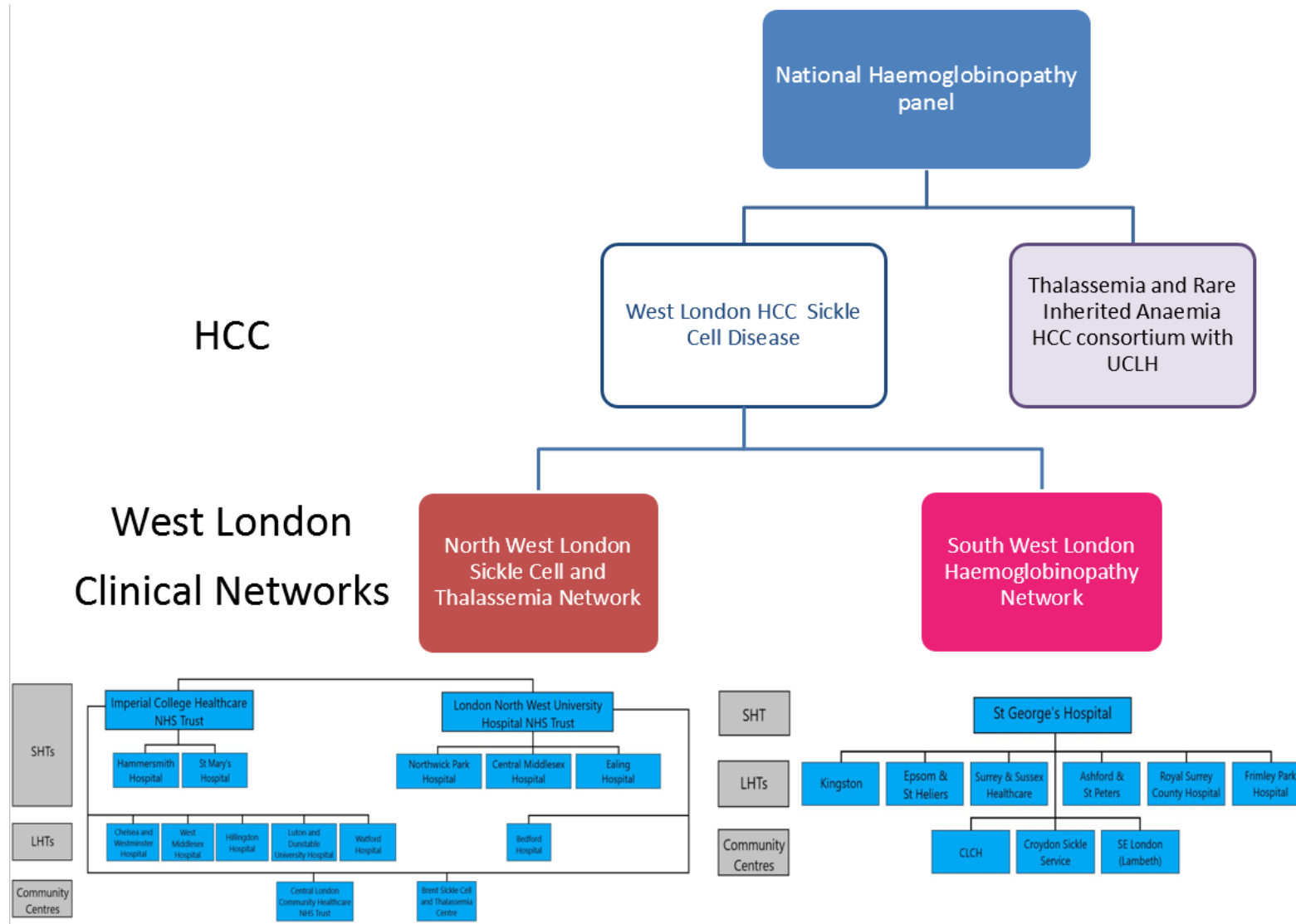
Appendix 1-service specification

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

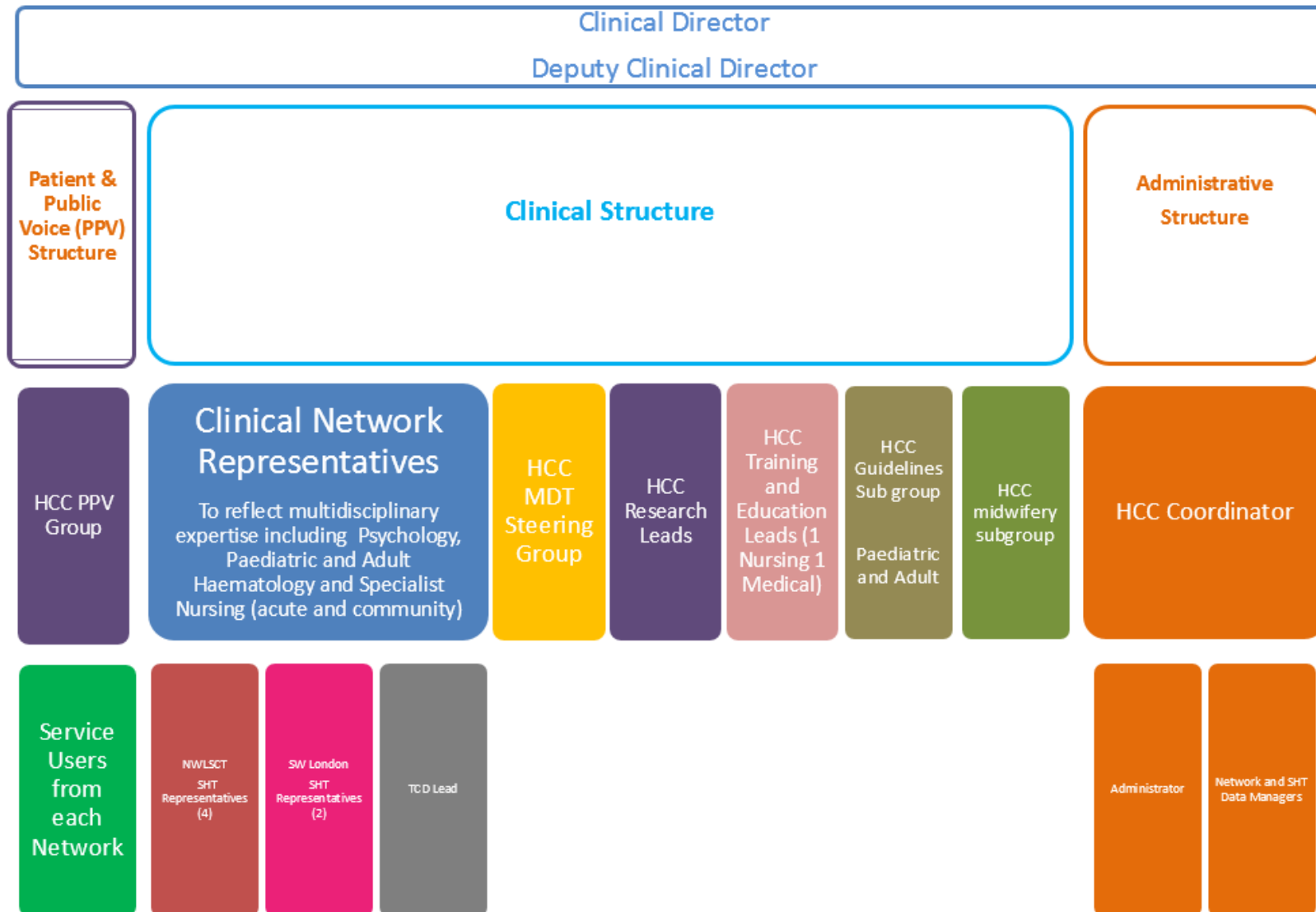


Document 3a-
Haemoglobinopath;

Appendix 2-Network Organogram



Appendix 3-Network Structure



Appendix 4- Key Positions within the Network

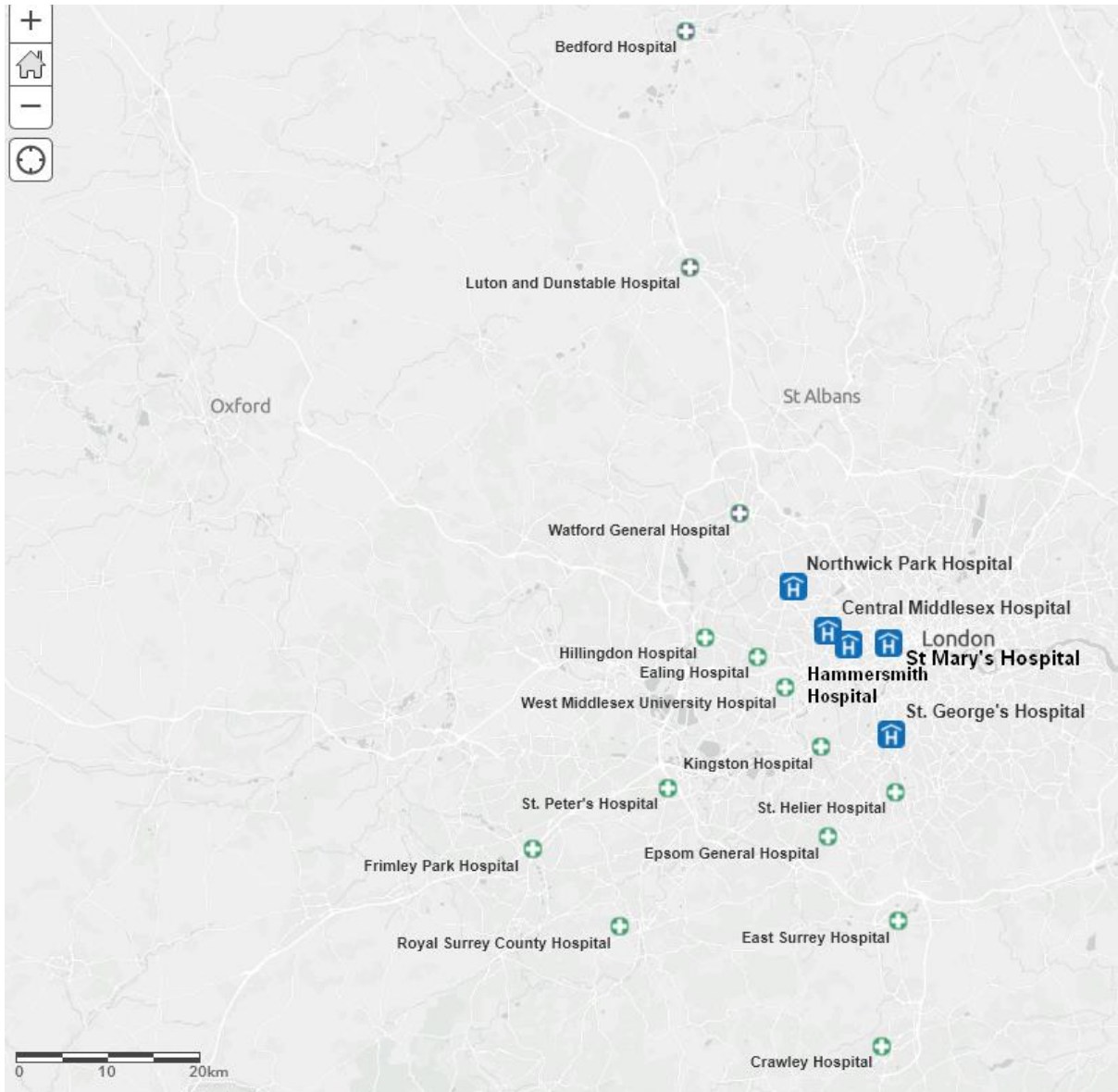
The below table details the key clinical and administrative positions within the West London HCC network

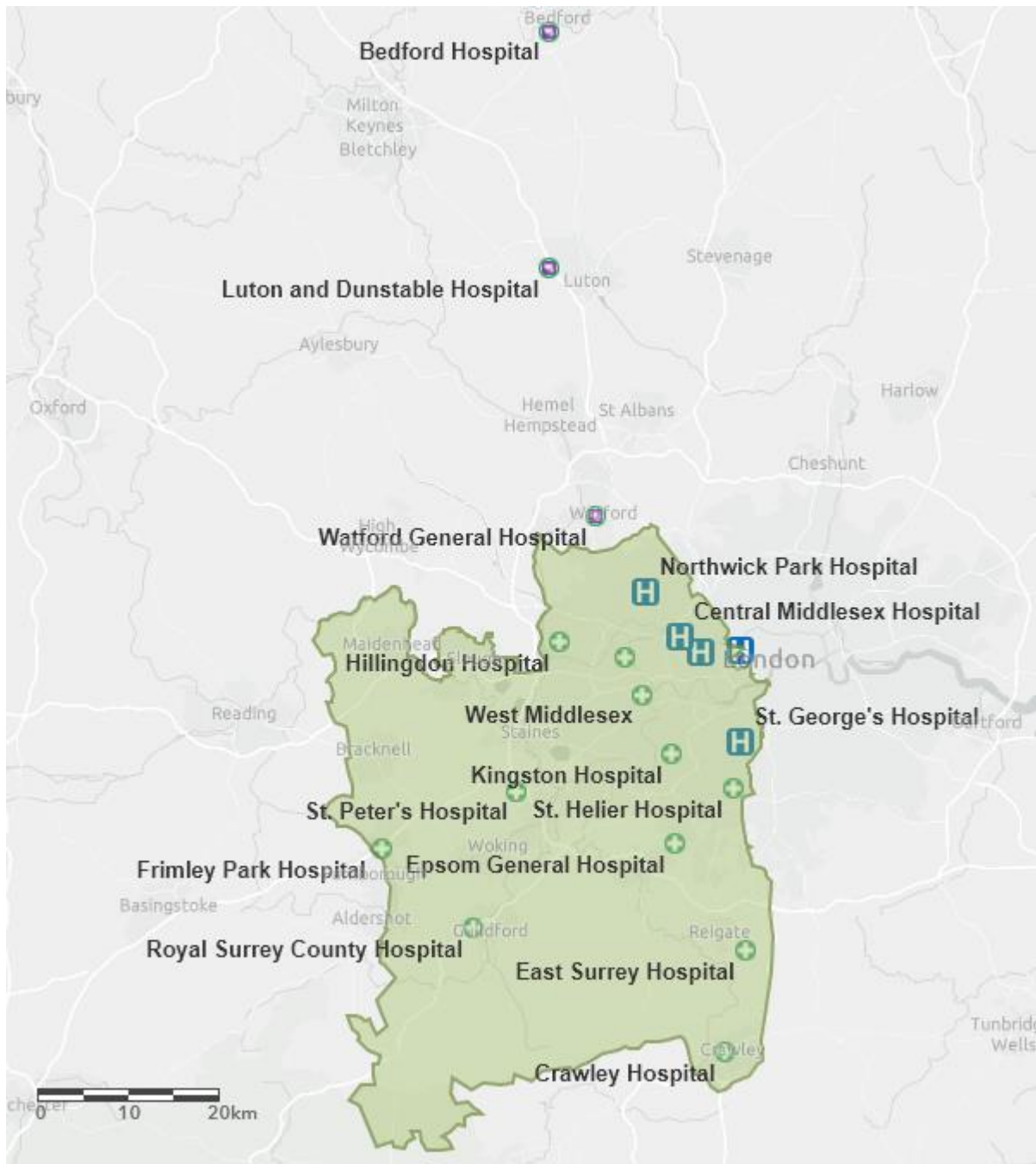
Position	Member of Staff	Associated Hospital
Clinical HCC Director	Mark Layton	Imperial College Healthcare NHS Trust
Deputy Clinical Network Director	Kofi Anie	London North West University Healthcare NHS Trust
HCC Coordinator	Ralph Brown	
HCC Administrator	To be appointed	
HCC MDT Steering Group	Asad 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	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

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	London Northwest University Healthcare NHS Trust
NWLSCT Clinical SHT Representative	Sheana Wijemanne	London Northwest University Healthcare NHS Trust
Patient/Carer representatives	Patrick Ojeer Hindatu Comma	

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 2020/21 attendance

2021 Table:

	MDT Attendance			
	Total 20/21	19.03.2021	03.02.2021	08.01.2021
Cases	48	3	2	4
Attendance		29	25	20
<u>Job Types</u>				
Haematology Consultants		10	5	4
Paediatric Haematology and General Paediatric Consultants		5	6	6
SpRs/Trainee Doctors		0	0	0
Nursing Staff		8	8	6
Psychologists		2	2	1
Other Allied Health Professionals		1	4	3
<u>SHTs</u>				
Imperial College Healthcare NHS Trust	117	11	7	7
London North West University Healthcare NHS Trust	75	7	7	7
St George's University Hospitals NHS Foundation Trust	18	2	1	0
<u>LHTs</u>				
Luton And Dunstable University Hospital NHS Foundation Trust	9			
Central London Community Healthcare NHS Trust	7	1	1	
Ealing Community Partners	7	1		1
Frimley Health NHS Foundation Trust	2			
Kingston Hospital NHS Foundation Trust	2		1	
West Hertfordshire Hospitals NHS Trust	1			
<u>Other</u>				
Cambridgeshire Community Services NHS Trust	7	1	1	1
Buckinghamshire Healthcare NHS Trust	2	1	1	
<u>SPAH and Welsh Partners</u>				
NHS Greater Glasgow and Clyde	14	2	1	
Cardiff And Vale UHB	9	1	1	1
NHS Grampian	8		2	1
NHS Lothian	6		1	1
NHS Tayside	2			
NHSBT	5		1	1

2020 Table:

	MDT Attendance										
	02.12.2020	04.11.2020	07.10.2020	16.09.2020	05.08.2020	17.07.2020	19.06.2020	29.05.2020	20.05.2020	29.04.2020	01.04.2020
Cases	6	2-only adult	3	3	5	1	7	4	3	3	2
Attendance	29	23	34	24	31	19	29	16	21		
<u>Job Types</u>											
Haematology Consultants	10	8	12	7	6	8	11	6	5		
Paediatric Haematology and General Paediatric Consultants	6	0	8	5	7	2	5	3	7		
SpRs/Trainee Doctors	2		2	2	3	2	1				
Nursing Staff	6	4	8	5	7	5	6	3	5		
Psychologists	1	2	2	2	2	1	2	1	2		
Other Allied Health Professionals											
<u>SHTs</u>											
Imperial College Healthcare NHS Trust	10	10	14	10	10	9	12	8	9		
London North West University Healthcare NHS Trust	4	6	7	5	7	4	8	5	8		
St George's University Hospitals NHS Foundation Trust	3	2	3	1	2		2	1	1		
<u>LHTs</u>											
Luton And Dunstable University Hospital NHS Foundation Trust	2		5	1					1		
Central London Community Healthcare NHS Trust	1		1	1	1	1					
Ealing Community Partners	1	1	1	1	1		1				
Frimley Health NHS Foundation Trust					2						
Kingston Hospital NHS Foundation Trust					1						
West Hertfordshire Hospitals NHS Trust					1						

Other											
Cambridgeshire Community Services NHS Trust			1	1		1	1				
SPAH and Welsh Partners											
NHS Greater Glasgow and Clyde	3		4	2	2	1	1				
Cardiff And Vale UHB	2	1	1			1			1		
NHS Grampian	1			1	2		1				
NHS Lothian	1	1		1			1				
NHS Tayside							1	1			
NHSBT	1	1			1						

Appendix 7- Educational/training activities that have taken place

Date	Topic	Speaker	Target audience	Timing/Web platform	Attendees (number excludes presenters)
27/07/2020	Community care	Lola Oni, Vesna Graham	Health Visitors Practice Nurse	Time: 10:30-12:00 - 90 mins in Length Team	20
30/07/2020	Community care	Lola Oni, Vesna Graham	Health Visitors Practice Nurse	Time: 14:00-15:30 - 90 mins in Length Teams	33
31/07/2020	International Forum on Covid-19 in Haemoglobinopathies: Clinical Case Presentation, Ghana Clinical Case Presentation, UK Guyana Covid-19 Data Presentation UK Covid-19 Data Presentation	Dr Emmanuel Asafo-Adjei, Ghana Dr Elizabeth Adegbenro Dr Michael Marks, Guyana Prof Mark Layton	African, South American and UK Clinicians working in Haemoglobinopathies	Time: 16:00-18:00 60 mins in Length Zoom	31
07/08/2020	Gene Therapy	Josu de la Fuente	West London HCC Members: Consultants, Junior Doctors	Time: 16:00-17:00 60 mins in Length Teams	49
14/09/2020	School care(inc. additional education needs)	Jacqui Bowyer, Caroline Anele	School Nurses/ SENCOs	Time: 15:00-16:30 90 mins in Length Teams	41

17/09/2020	School care(inc. additional education needs)	Jacqui Bowyer, Caroline Anele	School Nurses/ SENCOs	Time: 15:00-16:30 90 mins in Length Teams	58~
02/10/2020	Difficult transfusions	Fiona Regan	Lab staff, Consultants, Junior Doctors	Time: 16:00-17:00 60 mins in Length Teams	52
09/10/2020	Impact of Covid-19 on SCD & Thal in Adults	Mamta Sohal Mark Layton to chair	West London HCC Members: Acute and community doctors, nurses and all specialists	Time: 14:00-15:00 40 mins Mamta 20 mins questions Teams	27
16/10/2020	International Forum on Genetics Modifiers of Long-term Survival in Sickle Cell Disease in Africa'	Ambroise Wonkam- University of Cape Town		Time: 16:00-17:00 60 mins in Length Teams	34
23/10/2020	International Forum on Covid-19	Julie Panepinto, Lana Mucalo, Amanda Brandow, Ashima Singh	African, South American, US and UK Clinicians working in Haemoglobinopathies	Time: 16:00-17:00 60 mins in Length Teams	27
23/11/2020	Community Healthcare professionals	Lola Oni, Vesna Graham		Time: 14:30-16:00 90 mins in Length Teams	9

27/11/2020	Community Healthcare professionals (repeat)	Lola Oni, Vesna Graham		Time: 10:00-11:30 90 mins in Length Teams	16
07/12/2020	School Nurses- Follow-up	Jacqui Bowyer, Caroline Anele	School Staff; nurses teachers, first aiders	Time: 15:00-16:30 90 mins in Length Teams	47~
10/12/2020	School Nurses- Follow-up (repeat)	Jacqui Bowyer, Caroline Anele	School Staff; nurses teachers, first aiders	Time: 15:00-16:30 90 mins in Length Teams	30~
21/01/2021	Midwives	Helen Hoskin, Lola Oni, Carmen Martos-Ordonez	Midwives	Time: 11am-12:30pm 90 mins in Length Teams	29
12/02/2021	Midwives	Helen Hoskin, Lola Oni, Carmen Martos-Ordonez, Mamta Sohal	Midwives	Time: 2pm-3:30pm 90 mins in Length Teams	29

Appendix 8- Training sessions feedback

Details of the sessions

Title of the sessions: **Community Care**

Dates delivered: 27/07/2020, 30/07/2020, 23/11/2020, 27/11/2020

Delivered by: Lola Oni and Vesna Graham

Content: Sickle Cell; biology, pathology, pathophysiology, genetics, clinical manifestation, prevention and management of illness, community care

Number of community Healthcare professionals reached: 78

Comments from attendees:

“Very useful and informative. A good refresher. Especially because it has been quite some time since I last attended this type of update.”

“Yes, the session has very useful information relevant to my practice”

“Very useful, I learnt a lot of information about SCD”

All responders to the feedback survey said they would attend a future update

Title of the sessions: **School Care**

Dates delivered: 14/09/2020, 17/09/2020, 07/12/2020, 10/12/2020

Delivered by: Jacqui Bowyer, Caroline Anele

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: 176

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 Jacqui, very practical advice on supporting these children in schools.”

Title of the sessions: **Midwives**

Dates delivered: 21/01/2021, 12/02/2021

Delivered by: Helen Hoskin, Lola Oni, Carmen Martos-Ordonez, Mamta Sohal

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: 58

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: 02/10/2020

Delivered by: Fiona Regan

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:

“Brilliant and very useful session, thanks Fiona”

“Thanks Fiona, excellent session”

Appendix 9- Details of future sessions being planned by the Education Subgroup

Title of Proposed Session	Speakers	Target audience	Other details
Pain Management/ Psychological strategies for chronic pain	Kofi Anie and Jeremy Anderson, Jenna Love, Rebecca McLaughlin	West London HCC Members: Consultants, Junior Doctors, Community nursing staff, Nurses (Everyone)	1hour 30 mins Patient as expert in their condition Sickle Cell broadly pain introduction- develop multifaceted approach to pain management Acute to Chronic, difference between the two Acute: What can an acute pain service do? Further than injections Dependency and the 3 easy steps they can do to broaden their range for patients - incorporating tweaks to practice Therapeutic alliance -eye contact, pausing, active listening Patient quotes Chronic pain work: Pain management programme looks like: Rebecca/Jenna- overview then broader impact of pain/life management
Clinical Epidemiology, Acute Treatment and Secondary Prevention of Priapism in Sickle Cell Disease	Michael DeBaun	All HCC Members	1 hour 15 mins for discussion
GPs- Hub for North West London	Division between 3 consultant speakers from the SHTs	General Practitioners and Primary care staff	
Laboratory Aspects of Haemoglobinopathies (difficult cases, challenges of diagnosis)	Diagnostics Dan Pelling, Amanda Hann, Ade- GOSH, Debbie, Laura	Lab Staff, Junior Doctors (inc. SHOs), Consultants	

A+E/EDs for all HCC centres- Management of Sickle Emergencies session Need to get patient involvement	Mamta Sohal/SGUH speaker has session tailored for the ED's	Emergency department and acute care staff	
Nutritional support in Sickle Cell Disease		Dieticians	
Physiotherapy in Sickle Cell Disease populations		Physios	
Radiology and Sickle Cell Disease			

Appendix 10- NHP Meeting Attendance

NHP MDT attendance	
22nd April 2020	Kofi Anie, Mark Layton, Josu de la Fuente
28th May 2020	Kofi Anie, Mark Layton
29th June 2020	Kofi Anie, Josu de la Fuente
29th July 2020	Kofi Anie
27th August 2020	Kofi Anie
28th September 2020	Kofi Anie, Mark Layton, Josu de la Fuente
21st October 2020	Kofi Anie, Mark Layton, Josu de la Fuente
23rd November 2020	Kofi Anie, Mark Layton, Josu de la Fuente
21st December 2020	Kofi Anie, Mark Layton
27th January 2021	Kofi Anie, Mark Layton, Josu de la Fuente
22nd February 2021	Kofi Anie, Josu de la Fuente

NHP Business Meetings attendance	
Feb-20	Kofi Anie, Mark Layton, Josu de la Fuente
May-20	Kofi Anie, Mark Layton, Josu de la Fuente
Sep-20	Kofi Anie, Josu de la Fuente
Nov-20	Kofi Anie, Mark Layton, Josu de la Fuente

Appendix 11- adverse events recoded on NHR

St Georges

Date added to NHR	Type of Adverse Event	Details	HCC MDT discussion
08/04/2020	ACS	ICU admission (cardiac tamponade), AKI (post Covid)	Discussed at the MDT of 19.06.20
12/09/2020	Stroke	stroke	Discussed at the MDT of 04.11.20
10/11/2020	Death	RIP. JW. ICU admission – severe anaemia, multiorgan failure	Discussed at the MDT of 02.12.20
00/12/2020	Hyperhaemolysis	Treated with IVIg, Steroids and Eculizumab	Discussed at Ad Hoc emergency MDT

LNWH

Date added to NHR	Type of Adverse Event	Details	HCC MDT discussion
03/10/2020	VOC	Pain and Testicular swelling	Not discussed

Imperial

Date added to NHR	Type of Adverse Event	Details	HCC MDT discussion
12/05/2020	Fat Embolism	Fat embolism syndrome	Discussed at the MDT of 19.06.20

Appendix 12- Covid-19 National data collection effort

