

West London Haemoglobinopathies Coordinating Care Centre

West London HCC
2024-25

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 10,474 patients (as of June 2025), not including those from neighbouring areas that are part of the London ODNs, which equates to 59% 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 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)
- St George's Hospital (St George's University Hospitals NHS Foundation 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 Hospital (Bedfordshire Hospitals NHS Foundation Trust)
- Bedford Hospital (Bedfordshire Hospitals NHS Foundation Trust)
- Kingston Hospital (Kingston Hospital NHS Foundation Trust)
- St Helier Hospital (Epsom and St Helier University Hospitals NHS Trust)
- East Surrey Hospital (Surrey and Sussex Healthcare NHS Trust)
- St. Peter's Hospital (Ashford and St. Peter's Hospitals NHS Foundation Trust)
- Royal Surrey County Hospital (Royal Surrey County Hospital NHS Foundation Trust)

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

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

In total there have been 2096 haemoglobinopathy patients that have registered on the NHR under West London as HCC as of 24/25. The number of adult haemoglobinopathy cases recorded on the NHR is 1459 and Paediatric haemoglobinopathy cases totalling to 637.

Imperial adult cases are 511 and paediatrics 205

London North West adult cases are 417 and paediatrics 136

St George's adult cases are 490 and paediatrics 215

LHT without SHT assignment adult cases are 4 and paediatrics 2

Cardiff and Vale University Health Board adult cases are 33 and Paediatric are 78

Other non-West London HCC SHT adult cases are 4 and paediatric 1

The West London HCC covers Sickle Cell patients only with a handful of cases coded as Thalassaemia or Rare Inherited Anaemia, which diagnosis will be confirmed after communicating with the corresponding SHTs.

Structure of the HCC

The HCC incorporated the activities of the previous clinical networks in North West and South West London when it was set-up 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).

The HCC has a defined Standard operating procedure, which is used as a tool to implement the actions and functions of the Network.

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 7 WTE 1.0 Nurse Practice Developer, a Band 6 WTE 1.0 Senior Data Manager, a Band 4 WTE 0.6 administration assistant, a Band 5 WTE 0.6 patient and public voice group patient liaison lead and MDT coordinator. The approved positions descriptions from each Trust are embedded below.

Please note the HCC also manages two Project managers for the Sickle Cell Community projects in North West London and South West London respectively however these posts are not part of the budget of the HCC.

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 George's 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



West London HCC
Practice developeme



JD West London
HCC Sickle Cell MDT



JD West London
HCC Senior Data Ma

Fifth Year Outcomes

Background

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

- The continuation and effective delivery of a regular MDT meeting and Urgent/emergency ad hoc MDTs
- The implementation of an education schedule which has hosted a number of different virtual events and an in person education day
- Further integration of the Patient and Public Voice group in the functions of the HCC
- Continual support Website set-up along with social media channels
- Actively supported the service development of Community Improvement Projects and Hyper Acute Unit (i.e. emergency department bypass models)
- Finalisation of the majority of service level agreements with adult services
- Supporting clinical staff within the network to attend ASCAT (The Academy for Sickle Cell and Thalassaemia academic meeting)

MDT of the HCC

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

Four 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
- Management of complex transfusion issues (inc. Hyperhaemolysis)
- Difficult chelation issues
- Complex Psychology/Safeguarding concerns
- Candidates for bone marrow transplant/gene therapy referral
- Peri-operative management
- Unplanned PICU/ICU admissions
- Missed Children from the newborn screening programme
- Management of Multi-organ failure and Fat embolism syndrome
- Complex transition issues
- Renal Transplant Planning
- Severe Covid-19 complications and potential PIMS-TS cases
- Potential trial/Novel therapy candidates (inc. patients who are legible for Crizanlizumab)
- Pregnancy complications
- Death

Considerations would also be made for the following case presentations made as to the following:

- Consideration of stem cell transplantation
- Plan to commence long term transfusion/change from simple or manual exchange transfusion to automated transfusion
- Lack of response to hydroxycarbamide
- Other chronic/acute complications e.g.:
 - Renal dysfunction
 - Neurological disease (e.g. stroke, TIA)

- Urological complications
- Respiratory disease
- Pulmonary hypertension
- Obstetric complications
- Orthopaedic disease

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 -24	May- 24	Jun -24	Jul -24	Aug -24	Sep -24	Oct -24	Nov -24	Dec -24	Jan -25	Feb -25	Mar -25	Annual Total
Number of cases being submitted to the HCC MDT	Adult	3	10	6	4	-	13	7	2	5	0	4	4	59
	Children	0	0	2	4	-	2	2	1	2	3	4	2	21
Cases referred to the NHP	Adult	-	-	-	1	-	-	-	-	-	-	1	-	2
	Children	-	-	-	-	-	1	1	-	-	-	-	-	2

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

Educational/training activities

Keisha Osmond-Joseph (Nurse Consultant) and Dr Mamta Sohal are the leads for the education and training sub group. The educational and training sub group met on a quarterly basis throughout the year with a schedule of activity was worked on and has been delivered.

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

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

- Service users and carers

Programmes were then developed to be of educational value to the different groups identified. Please see Appendix (8) which details the education day and sessions undertaken in 2024/25 and the number of attendees.

In terms of operation of the sessions, the Network Manager sends out invites and instructions on how to register. The education leads and the Network administrator 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 HCC has hired an adult nurse practice development educator who will be involved in the coordination and review of Education within the HCC

The following sessions are due to take place:

- Management of Sickle Emergencies
- Patient experiences in Emergency Departments
- Hyperhaemolysis
- Child Health
- Antenatal Screening of Haemoglobinopathies
- Sickle Cell for School Nurses and Teachers

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

Dr Mamta Sohal (Imperial) and Keisha Osmond-Joseph (London North West) will be working on the education schedule for 25/26 with support from the Network Manager and the practice nurse educator.

Collaborations with other HCCs that have been beneficial

The HCC contributes to a national pain audit and a services status review that have been led by the East London HCC and National Haemoglobinopathy panel respectively, we expect outcomes from that work to be built upon in 2025/26.

The HCC also has been involved in supporting other HCC's regarding data sharing and development of Specialised Services Quality Dashboard returns.

Research/Clinical Trials

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

The Clinical trials/Research team of the HCC presented to the Patient and Public Voice group of the HCC on the 30th of May 2024 in order to give further information to the patients on the types of trails available for patients to go on

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

Audit and data collection

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

Indicator Reference Number	Description	Target	Numerator	Denominator	%
HAEMCC09bi	Proportion of patient deaths discussed at Haemoglobinopathy Coordinating Centres (HCC) morbidity/mortality meetings	100%	11	11	100.00%
HAEMCC09c	Proportion of serious adverse events that are discussed at the HCC morbidity/mortality meetings	NA	30	30	100.00%
HAEMCC10a	Proportion of patients with Haemoglobinopathies within the HCC network recorded on the National Haemoglobinopathy Registry (NHR)	80%	2084*	2179*	95.64%*
HAEMCC13	Proportion of Specialised Haematology Teams (SHTs) within the HCC network with a clinical representative at all HCC multi-disciplinary Team (MDT) meetings	100%	3	3	100.00%
HAEMCC14	Proportion of Local Haemoglobinopathy Teams (LHTs) within the HCC network with a clinical representative at all HCC MDT meetings	100%	1	8	12.50%
HAEMCC15	Proportion of patients with thalassaemia or rare inherited anaemia (RIAs) within the HCC network who have had a serious adverse event	NA	4	284	1.41%
HAEMCC16	Proportion of patients with sickle cell within the Haemoglobinopathy Coordinating Centre (HCC) network	NA	26	1895	1.37%

	who have had a serious adverse event				
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* Revision in number made in the subsequent part of the reports with additional information on patient population available.

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	80 patients cases have been discussed in the HCC MDT	N/A	N/A	N/A
The proportion of patients that are referred for clinical advice and guidance to the national panel	102	4 patients (2 adults 2 paediatrics) were forwarded to the national panel MDT please note this does not include an extensive number of BMT and gene therapy cases that were not discussed at the HCC MDT due to patients being from out of region	N/A	N/A	N/A
Average length of stay for patients following emergency admission across HCC referring organisations.	103	Please see page 39	N/A	N/A	N/A
Proportion of Serious adverse events entered on to NHR system by SHTs and reviewed at the HCC morbidity /mortality meetings	128	30 Serious adverse events were recorded across the HCC	18 (16 adults, 2 paed) Serious adverse events were recorded	6 (5 adults, 1 paed) Serious adverse events were recorded	6 (5 adults, 1 paed) Serious adverse events were recorded

		Of these 100% were uploaded to the NHR Of these 100% were discussed in the HCC MDT	18 (100%) Serious adverse events were uploaded 18 (100%) Serious adverse events were discussed in the HCC MDT	6 (100%) Serious adverse events were uploaded 6 (100%) Serious adverse events were discussed in the HCC MDT	6 (100%) Serious adverse events were uploaded 6 (100%) Serious adverse events were discussed in the HCC MDT
Service Specification	No.	HCC	Imperial	London Northwest	St. Georges
Proportion of patients entered on to the NHR database across the HCC	105	Total upload percentage: 81% (1,910/2,355**) Percentage of Adult patients: 90% (1,437/1,589) Percentage of Paediatric patients: 62% (473/766)	Local database: 453 Adult Sickle cell 167 Adult Thalassaemia or Rare Inherited Anaemia Recorded on NHR: 446 Adult Sickle cell 81 Adult Thalassaemia or Rare Inherited Anaemia Local database: 218 Paed	Local database: 399 Adult Sickle cell 54 Adult Thalassaemia or Rare Inherited Anaemia Recorded on NHR: 399 Adult Sickle cell 54 Adult Thalassaemia or Rare Inherited Anaemia Local database: 131 Paed	Local database: 418 Adult Sickle cell 57 Adult Thalassaemia or Rare Inherited Anaemia Recorded on NHR: 416 Adult Sickle cell 56 Adult Thalassaemia or Rare Inherited Anaemia Local database: 208 Paed

			Sickle cell	Sickle cell	Sickle cell
			57 Paed	26 Paed	45 Paed
			Thalassaemia or Rare Inherited Anaemia	Thalassaemia or Rare Inherited Anaemia	Thalassaemia or Rare Inherited Anaemia
			Recorded on NHR:	Recorded on NHR:	Recorded on NHR:
			198 Paed Sickle cell	131 Paed Sickle cell	153 Paed Sickle cell
			37 Paed	26 Paed	30 Paed
			Thalassaemia or Rare Inherited Anaemia	Thalassaemia or Rare Inherited Anaemia	Thalassaemia or Rare Inherited Anaemia

**missing patients from the LHTs as not completed data sets/readily available databases, this is being worked on in 25/26. Upload of Thalassaemia or Rare Inherited Anaemia patients into London, South Central and South West or London and South East to be discussed with the network in 25/26. St George's is recruiting a Paediatric data manager in 25/26 Quarter 1.

An audit schedule was agreed for the year 24-25, however due to staff challenges at the SHTs and LHTs the ability of services to complete this was very challenged, so a decision was reached to concentrate on the audit related to the Time to analgesia and pain management in emergency settings, audit of the NICE guidelines

Quarter when the Audits will be undertaken	HCC Stipulated audits
24-25 Quarter 1	The number of patients who are on and have been asked about Hydroxycarbamide
24-25 Quarter 2	Time to analgesia and pain management in emergency settings, audit of the NICE guidelines To include audit of competencies https://www.nice.org.uk/guidance/cg143

24-25 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)
24-25 Quarter 4	Acute admissions to inappropriate settings, including patient and clinical feedback on these admissions

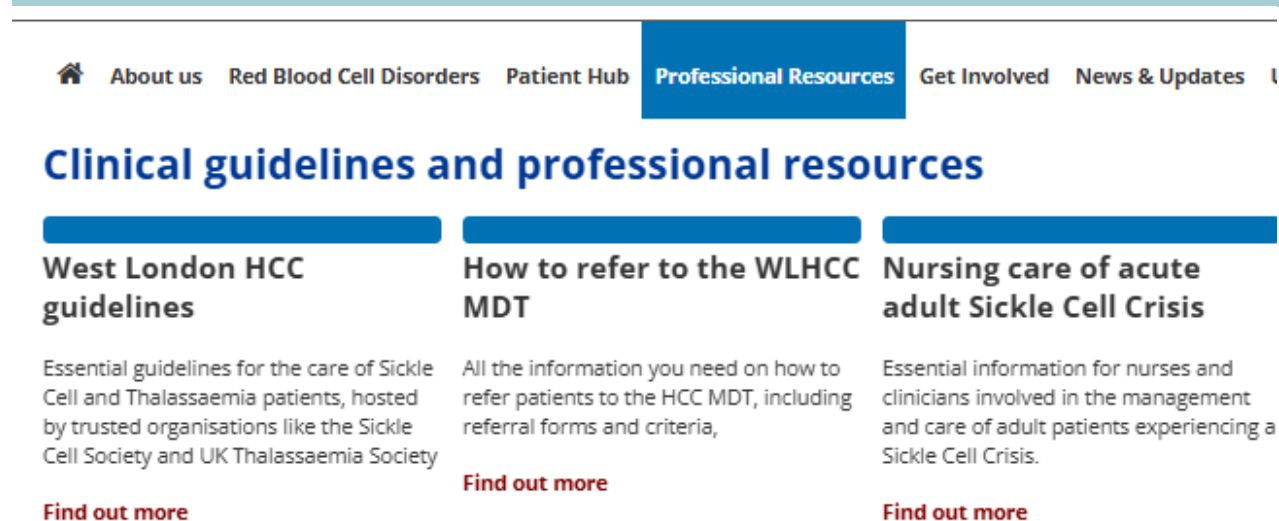
The outcomes of this audit were shared with the Steering group and Patient and Public voice group of the HCC and reviewed as part of the Peer review of the West London HCC

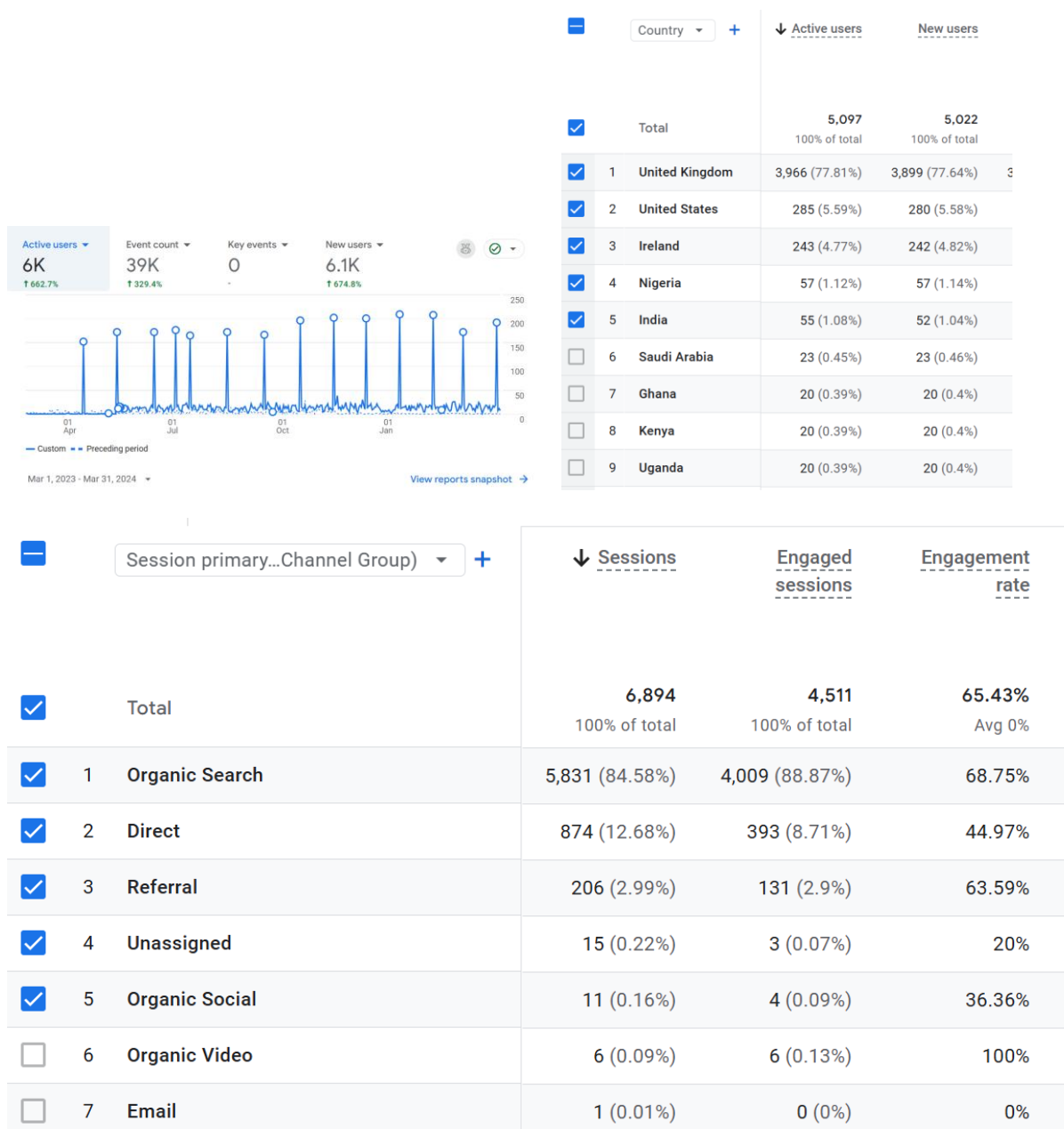
Website and Social media work

The HCC currently collaborates with commercial web development firm BeingOnline to maintain and enhance its website, originally launched in 2021. Through ongoing meetings and regular communication, we ensure the site remains up-to-date, visually appealing, and user-friendly.

Following a recent comprehensive revamp, the website now offers improved navigation and a host of new features designed to increase engagement. Enhanced internal linking makes it easier for users to discover relevant content that might otherwise be overlooked. We've also introduced widgets across key pages to highlight missed news stories and display live Twitter activity. New sections have been added to serve both HCC members and the general public, offering resources ranging from healthcare training and mentoring programmes to nutritional guidance. Social media integration has also been expanded, with embedded YouTube videos featured on relevant pages to enrich user experience.

As the role of digital engagement continues to evolve, we are actively developing our social media strategy and further refining our website to better serve both the public and healthcare professionals. Our goal is to strengthen our connection with the Sickle Cell Community through a more interactive, accessible, and informative online presence.





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

Year	Active users	Visits by users
2021	153	2,700
2022	823	8,900
2023	4,200	27,000
2024	5,800	45,000

The HCC maintains an active Twitter account to share news, events, and relevant updates across the sickle cell network. This platform serves as a key communication tool, enabling us to engage directly with patients, healthcare providers, and the wider sickle cell community.

Through regular posts and retweets, we amplify important sickle cell-related content, promote HCC-hosted events within the network, and highlight news stories that may be of interest to our followers. By staying active on Twitter, we aim to keep our community informed, connected, and engaged with the latest developments in sickle cell care and advocacy.

Twitter link: <https://twitter.com/HCCWestLondon>



The HCC has an established 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 225 subscribers and 16,138 views.

The HCC currently has plans to eventually expand our social media presence by using other platforms such as Instagram. We are in talks with the relevant teams to start on creating a social media strategy.

West London HCC
 @westlondonhcc7402 · 225 subscribers · 61 videos
 This is the Youtube Channel for the West London HCC, with education sessions and info...more
[westlondonhcc.nhs.uk](https://www.youtube.com/channel/UCHWNWQhQEJnqOgw34_F9nrQ)
 Customize channel Manage videos

Home Videos Posts

For You



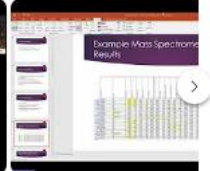
Sickle Cell: Gene therapy talk to patient group and discussion
52 views · 1 month ago



Sickle Cell: A Psychologist's Perspective on Pain
16 views · 5 months ago



Sickle Cell: A Socio-Cultural Perspective- Exploring the Intersection Culture, Society & Healthcare
36 views · 5 months ago



Lab Results and Newborn Screening
108 views · 1 year ago

Videos



Sickle Cell: Gene therapy talk



Sickle Cell: Management of



Thalassemia: Overview and



Sickle Cell: Allogenic Stem



Sickle Cell: A Psychologist's



Sickle Cell: the Current

Link to youtube channel:

https://www.youtube.com/channel/UCHWNWQhQEJnqOgw34_F9nrQ

Harmonisation of Network clinical guidelines

The HCC completed and published clinical guidelines in 23/24 these have been published on the HCC's website and can be found here:



HCC Adult Sickle Cell Guideline versic



HCC Paediatric Sickle Cell guideline



WLHCC-SOP-001 ver 3.0 West London

[Link to West London HCC Guidelines for the Management Of Sickle Cell Disease In Adults](#)

[Link to West London HCC Guidelines for the Management Of Sickle Cell Disease In Paediatrics](#)

Work is ongoing to create transition guidelines for the network.

The following guidelines are being harmonised by the respective subgroups:

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

Service level agreements

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

SLAs for the involvement of the Scottish Paediatric and Adult Haemoglobinopathies network (SPAH) and South Wales Haemoglobinopathy teams in HCC MDT and educational activities are being worked on.

Service level agreements between LHTs and SHTs and the HCC detailing individual escalation/referral pathways are in place for adult services. Paediatric SLAs with SHTs and the HCC will be worked on in 25/26.

Evidence of HCC meetings and actions achieved

Steering group meetings have been held on a monthly basis throughout 2024/25. 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 2024/25

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 continues to work closely with Clinical and Management teams of the HCC on co-design, review and patient engagement work. In 24/25 Vice Chairs were added to the group (Sonia Meikle and Ade Sawyer) to help support the work of the chair.

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

This year the HCC hired Georgia Adebawale as a patient liaison support for the patient and public voice group, Georgia joins the PPV group meetings and works with the chair and vice chairs on the agenda for the meeting and minutes produced thereafter.

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

The first meeting this year was on the 25th of May of this year and 9 meetings along with a patient and public voice group away day were held,

The agenda of meetings held so far has included;

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

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



PPV HCC meeting
minutes 11.04.2024-



PPV HCC meeting
minutes 30.05.2024-



PPV HCC meeting
minutes 24.06.2024-



PPV HCC meeting
Minutes 12.09.2024.



PPV HCC meeting
Minutes 31.10.2024.



PPV HCC meeting
Minutes 12.12.2024



PPV HCC meeting
minutes 30.01.2025.



PPV HCC Meeting
Minutes 27.02.2025



PPV HCC Meeting
Minutes 27.03.2025

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

Finances of the HCC

NHS England (NHSE) uplifted the amount of funds given by to the HCC by £274,017 for the year 24/25 to £519,124 (52.7% uplift, rate of inflation 24-25 3.4%). This uplift was undertaken post a review undertaken by the National Haemoglobinopathy Panel of the networks and Haemoglobinopathy services and post discussions with national commissioners. The HCC has used this funding to recruit a senior data manager, nurse practice developer, paediatric psychology provision in North West London and a combined post that includes MDT coordination and support of the Patient and Public Voice group. The Patient and Public Voice group is now fully funded and the HCC also distributes funds to the Invisible Warrior project housed by Imperial College that the HCC has worked with in the past. Due to the length of time it took to recruit some roles the HCC had a significant underspend that is being used to support one off projects, training and a data post to support the evaluation of the implementation of the Sickle Cell hyper acute units.

NHSE supported the HCC by confirming deferment of £110,000 of the HCC's underspend into 25/26, to support continued one off spend.

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 early November and the administrator not yet being in post until late March. Additionally a significant number of ancillary costs that normally would have been associated with the setting up of meetings did not occur due to Covid-19 restrictions. This resulted in a budget underspend of £66,101. In 21/22 the HCC was fully staffed and this resulted in an overspend, the original budget of the HCC was not adhered to in an attempt to control the overspend.

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

During the financial year 23/24 there was an overspend on the HCC budget because of increased staffing costs related to inflationary pressures in the wider economy and staff costs. There was an uplift to the HCC's budget in quarter 4 which is not included below that covered the loss.

Year	NHSE contract	Projected Cost (against initial budget)	Actual spend	Spend against NHSE budget	Comments
2020/21	£215,000	£235,591.68	£148,898.46	£66,101.51	
2021/22	£220,200	£234,408.21	£221,515.01	-£1,315.01	
2022/23	£233,522	£243,220.94	£228,153.86	£5,368.14	
2023/24	£245,107	£265,537.50	£254,295.05	-£9,188.19	An additional uplift was given by Q4
2024/25	£519,124	£505,432.48	£407,428.09	£111,695.91	NHS confirmed deferment of £110,00 to 25/26

Specialist Haemoglobinopathy Teams status 24-25

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

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

Imperial College Healthcare NHS Trust Adult Haemoglobinopathy Service

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

No update relayed

Imperial College Healthcare NHS Trust Paediatric Haemoglobinopathy Service

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

Service updates and challenges in 24/25

Achievements

- Combined specialist nurse team led by Haemoglobinopathy matron, two Band 7 apheresis nurses and 2 Band 6 nurses working well to support the needs of patients across in-patient and out-patient (including apheresis) care.
- Recruitment of a dedicated Band 6 psychologist for the paediatric sickle service - 3 days/week. Due to begin in post in Sept 2025.
- Ongoing development of the adolescent transition service involving paediatric and adult teams (CNS involvement in patient education & improving patient experience). Plans to have regular psychology presence at the clinic
- Regular meeting between Paediatric haematology /A&E clinicians and data management colleagues to review patient attendance at A&E (with focus on time of delivery of analgesia for patients in pain crisis) with an attempt to improve clinical practice
- Ongoing SHT outreach support for Haemoglobinopathy clinics in Northwick Park, Ealing & Bedford. Agreement for long term support of St George's hospital and its LHTs out of hours service (based on plan to recruit a joint post between the two Trusts - currently under development)
- Ongoing recruitment of paediatric patients to newly commissioned gene therapy for sickle & Thalassaemia

Challenges

- Intermittent staffing pressures relating to lack of resident doctor cover (exacerbated at times of industrial action)
- Staffing of on-call apheresis service remains limited to a small body of staff. Longstanding issue with proposed change to the out-of-hours contract for specialist nurses which has resulted in threat to the continuation of this service.
- Challenge in offering a safe, robust paediatric priapism service within our HCC due to lack of specialist urology expertise (recognised as a Clinical governance issue and the development of an SLA is in process with the Evelina hospital).

Targets for 2024/25:

- Recruitment of a new joint Paediatric Haematology consultant post between SMH & George (& development of a business case for a similar post between SMH & Royal London Hospital also underway)
- Development of formal SLA to recognise role played by SMH in providing tertiary care to Bedford (to align with care provided to Luton as Bedford/Luton are a joint Trust)
- Working with adult haemoglobinopathy team to develop joint educational sessions for patients
- To negotiate a mutually agreeable apheresis out of hours contract for specialist nurses
- Set up formal SLA with Evelina for a priapism referral pathway
- To continue to engage and recruit patients to the Peer support service

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

Service updates and challenges:

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

Out-patient service

- All haemoglobinopathy clinics are MDT and include an acute CNS, nurse consultant, community CNS, and psychologist. Outpatient clinic consultations are hybrid combining face-to-face at Central Middlesex Hospital (CMH) with telephone. Face-to-face appointments are prioritised for new patients, annual reviews, and management of complex patients including those on hydroxycarbamide, transfusions[CH1] .
- There are two consultant haematologists who attend the clinics, and a consultant and registrar who support remotely. The latter position is subject to staffing and availability.
- Routine investigations including Annual blood tests, Echocardiogram, audiometry and T2*MRI, and Ophthalmology reviews are being carried out
- Elective Red Cell Exchange is carried out both at Northwick Park Hospital and Central Middlesex Hospital
- Routine surgery including orthopaedics is being carried out
- Work is being done to protect time for annual reviews, and formalising blood order sets, discussion of treatment options and blood transfusion. A physicians' assistant does a weekly clinic during which she collates important information for annual reviews. We are also starting a similar nurse-led service in the community to support annual review compliance.

Nurse-Led Clinic

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

Psychology Service

- There is currently no psychology present during outpatient clinics. LNWH are currently considering options for inpatient psychology provision with -house team and other outside provider. Two part-time psychologists have been recruited for community psychology provision.

Medical Day Care (CMH- Central Middlesex Hospital)

- Walk-in-Service for acute pain management resumed. This allows for daytime treatment, and patients who require subsequent hospital admissions are transferred to NPH.
- Elective top-up transfusions have continued for all sickle cell and thalassaemia patients.

In-Patient Care

- Patients with Sickle cell are treated on Drake Ward, James Ward and Dryden ward (the latter for HDU care). Staff in all these wards are trained in the care of patients with sickle cell, and in the use of PCAs. James Ward is preferred for those who are Covid positive on admission. There is ongoing teaching for all staff. The new Emergency Department pathway for sickle cell care introduced last year is being monitored and audited and the roll out of ACTNOW has been completed with continued improvement work including new LAS ACTNOW handover, dedicated doctor and nurse at pitstop and sickle cell alert on CERNER. There are weekly Multi-Disciplinary Team Meetings to monitor patient care.

Future Plans

- Work in collaboration with Imperial College Healthcare NHS Trust HCC is progressing to consolidate inpatient care at Imperial and outpatient care at an expanded comprehensive centre at CMH.

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

Out-Patient Service

- The lead of service undertakes a joint Endocrine clinic where our haemoglobinopathy patients who have issues with growth and puberty are seen with a consultant endocrinologist.
- All paediatric haemoglobinopathy clinics are face-to-face MDT clinics and include an acute CNS, community CNS, and psychologist.
- There are two consultant paediatricians, and a consultant paediatric haematologist from Imperial College Healthcare NHS Trust who attends the clinics twice monthly.
- Ealing Hospital – clinics are held once a month.
- Affected newborn home visits are being carried out as previously, and patients who require community follow up have routine home visits and telephone consultations as required.
- Transition clinics run once every 3 months. These are MDT clinics as well. Clinics are run by Consultant haematologist from adult team, consultant paediatrician, haemoglobinopathy CNS (adult and paediatrics), community CNS and psychologist.

Psychology Service

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

Paediatric Day Care

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

Admissions

- Patients 0-17 years are seen in paediatric A&E and admitted to Jack's Place. After 18 years they are seen in adult A&E and admitted under adults

Transcranial Doppler Service

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

Multi-Disciplinary Team Meetings

- Local and HCC MDTs are conducted virtually and monthly for both.
- We carry out a Safeguarding MDT joint with the safeguarding team. This is to discuss any child or family that may have additional needs or safeguarding concerns.

Workshops

- Transition workshops are for young people 16-18years. These are nurse led and aimed at patients who are transitioning and just moved up to adults.

Vision for Recovery

- More collaboration with Imperial College Healthcare NHS Trust SHT.

In-patient service

- The lead of service has a joint Endocrine clinic where our haemoglobinopathy patients who have issues with growth and puberty are seen with a consultant endocrinologist.
- Acutely unwell haemoglobinopathy patients are seen in the A&E department and admitted to Jack's Place. Patient aged 0-18 year are eligible for admission to Jack's Place.

Service updates and challenges of 24/25 with work progressing in 25/26

- 2 Haemoglobinopathy CNS – working on site
- Band 8a lead haemoglobinopathy nurse in post as of April 2025
- Band 8b 0.2 WTE haemoglobinopathy pharmacist in post as of July 2025
- Third substantive red cell consultant in post as of May 2025
- 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. Expansion of red cell treatment clinics to x2 per month (facilitated by recruitment of a third substantive red cell consultant)
- Quarterly dedicated thalassaemia clinics
- Sickle Cell ED bypass unit operational 7 days/week, 9am to 5pm from May 2025, with a plan to be operational 24/7 from August 2025
- Rapid access "Hot" clinic operational Monday to Friday as of January 2025
- Apheresis service: staffing shortages now resolved. Medtech funding approved. Apheresis new space is still pending
- Transition clinic moved from Friday to Tuesday to enable attendance of paediatric haematology CNS, as per peer review recommendation
- Consultant neurologist with an interest in sickle cell disease appointed to the Trust – will be setting up a monthly sickle-neurology clinic - still in progress
- Social prescriber in post as of early 2025
- Consultant due to go on maternity leave September 2025 - vacancy out to advert but currently unfilled

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

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

No update relayed

Patients within the Network

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

Adults Sickle Cell Patients

Imperial College Healthcare NHS Trust

453 adult patients are recorded on the local database

446 of adult patients are on the NHR

London North West University Healthcare NHS Trust

399 adult patients are recorded on the local database

399 of adult patients are on the NHR

St George's Healthcare NHS Foundation Trust

418 adult patients are recorded on the local database

416 of adult patients are on the NHR

Paediatric Sickle Cell Patients

Imperial College Healthcare NHS Trust

218 paediatrics patients are recorded on the local database

198 of paediatrics patients are on the NHR

London North West University Healthcare NHS Trust

131 paediatrics patients are recorded on the local database

131 of paediatrics patients are on the NHR

St George's Healthcare NHS Foundation Trust

208 paediatrics patients are recorded on the local database

153 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 80% target of total registered Sickle Cell patients attending for annual review 24/25

Due to staffing challenges relating to consultant and data management support the attainment of the 80% target, by some of the services wasn't met..

		Sickle Cell		Thalassaemia / Rare Inherited Anaemia	
		Adult	Paediatric	Adult	Paediatric
Imperial College Healthcare NHS Trust	No. of patients active at SHTs and linked LHTs	453	218	167	57
	No. (%) of patients registered on the NHR	446 (98.5%)	198 (90.8%)	81 (48.5%)	37 (64.9%)
	No. (%) of Annual Reviews uploaded to the NHR	386 (85.2%)	201 (92.2%)	65 (33.0%)	34 (59.6%)
London North West University Healthcare NHS Trust	No. of patients active on the at SHTs and linked LHTs	399*	131*	54*	26*
	No. (%) of patients registered on the NHR	399 (100%)	131 (100%)	54 (100%)	26 (100%)
	No. (%) of Annual Reviews uploaded to the NHR	321 (80.5%)	92 (70.2%)	44 (81.5%)	16 (61.5%)
St George's University Hospitals NHS Foundation Trust	No. of patients active on the at SHTs and linked LHTs	418	208	57	45
	No. (%) of patients registered on the NHR	416 (99.5%)	153 (73.5%)	56 (98.2%)	30 (66.7%)
	No. (%) of Annual Reviews uploaded to the NHR	50 (11.9%)	0 (0%)#	14 (24.5%)	0 (0%)#

* The patient listing is created best to the London North West's knowledge and all known cases are updated into the NHR.

St George's Paediatrics are looking to recruit a data manager to support the clinical team with the submission for the specialised services quality dashboard at year end.

TCDs: Proportion of patients undergoing TCD 24/25

In 2024/2025 the Transcranial Doppler services were re-established/continues and caught up on some of the backlog from the pandemic year,

Ref	Description	Trust/ Patient Type		Total
HAEM02i	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 national guidelines	LNWUH Children	Numerator	62
			Denominator	73
			Percentage	85%
		ICHNT Children	Numerator	108
			Denominator	111
			Percentage	97%
		SGUH Children	Numerator	N/A
			Denominator	N/A
			Percentage	N/A

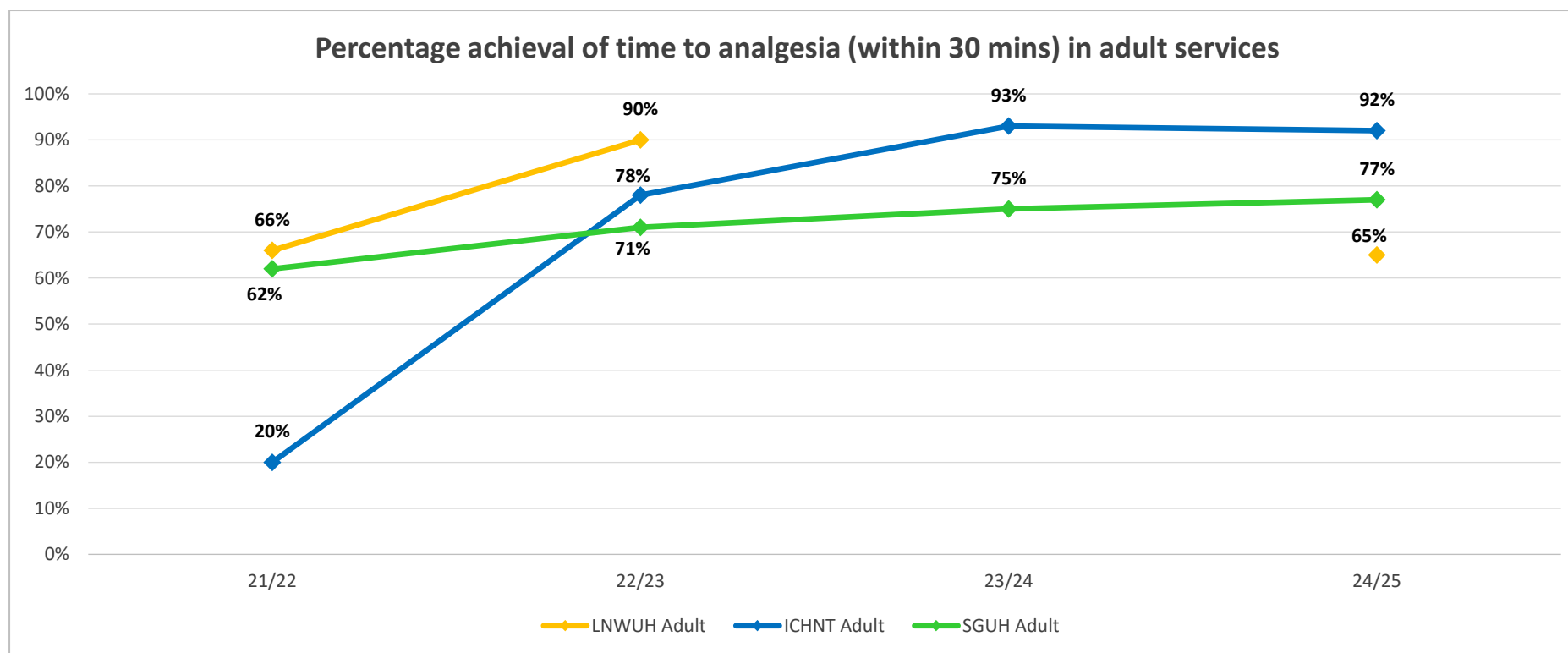
Please note the data submitted from Imperial College Healthcare NHS Trust (ICHNT) also includes data from the LHT hospitals within its Paediatric Network in Northwest London, the data uploaded to the Specialised Services Quality Dashboard related to patients solely at St Marys Hospital.

St George's Paediatrics are looking to recruit a data manager to support the clinical team with the submission for the specialised services quality dashboard at year end.

Pain relief: Percentage of patients receiving pain relief within 30 minutes 24/25

Ref	Description	Trust/ Patient Type		Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25	Total		
HAEM 03ii	Percentage of patients given pain relief by any healthcare professional within half an hour of presentations with sickle crisis , as per NICE guidelines	LNWUH Adult	Numerator	31*												31		
			Denominator	48*												48		
			Percentage	65%*												65%		
		ICHNT Adult	Numerator	51	41	51	65	58	74	70	64	69	75	59	60	737		
			Denominator	53	48	62	72	63	81	77	67	72	82	61	64	802		
			Percentage	96%	85%	82%	90%	92%	91%	91%	96%	96%	91%	97%	94%	92%		
		SGUH Adult	Numerator	12	14	18	15	18	16	16	14	19	16	15	15	188		
			Denominator	17	19	21	18	24	18	25	18	21	24	19	21	245		
			Percentage	71%	74%	86%	83%	75%	89%	64%	78%	90%	67%	79%	71%	77%		
		LNWUH Children	Numerator	31*												31		
			Denominator	48*												48		
			Percentage	65%*												65%		
		ICHNT Children	Numerator	3	2	3	6	0	4	4	1	2	2	3	1	31		
			Denominator	6	4	4	8	0	4	5	1	2	4	3	2	43		
			Percentage	50%	50%	75%	75%	NA	100%	80%	100%	100%	50%	100%	50%	72%		
		SGUH Children	Numerator	0	4	3	1	2	3	3	3	4	2	1	0	26		
			Denominator	2	4	5	1	2	5	4	4	4	3	1	0	35		
			Percentage	0%	100%	60%	100%	100%	60%	75%	75%	100%	67%	100%	NA	74%		

Remarks: * LNWH undertook a 10% random sampling audit due to reduced auditing capacity. Combined numbers of Adult and Paediatric admissions.



Neonatal screening: Entry into specialist care and proportion of patients commencing antibiotic prophylaxis 24/25

Ref	Description	Trust/ Patient Type		Total
HAEM04Ai	Proportion of paediatric patients with sickle cell identified by neonatal screening entered onto the care pathway	LNWUH Children	Numerator	22
			Denominator	22
			Percentage	100%
		ICHNT Children	Numerator	5
			Denominator	5
			Percentage	100%
		SGUH Children	Numerator	N/A
			Denominator	N/A
			Percentage	N/A

HAEM04Bii	Proportion of eligible paediatric patients offered/prescribed antibiotics at or before 3 months of age as per screening programme guidelines	LNWUH Children	Numerator	22
			Denominator	22
			Percentage	100%
		ICHNT Children	Numerator	5
			Denominator	5
			Percentage	100%
		SGUH Children	Numerator	N/A
			Denominator	N/A
			Percentage	N/A

St George's Paediatrics are looking to recruit a data manager to support the clinical team with the submission for the specialised services quality dashboard at year end.

Sickle Cell Disease and length of stay data 24/25

The 24/25 non-elective admission data is extracted from SUS dataset, with filtering criteria as followed:

SHT: filtering eligible cases with Service_Line_Desc equals to "Sickle Cell Anaemia".

LHT: filtering ineligible cases with HRG_Desc irrelevant to "Sickle cell".

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

	ICHT	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	58	41	17	41	58	67	73
Distinct Pt count	n	37	32	14	29	44	39	48
Average LOS	n	4.8	3.1	3.1	3.6	3.4	5.0	4.3
Median LOS	n	3	2	1	2	2	2	2
Readmit in 7 days	n	4	1	-	2	4	8	11
	%	7%	2%	0%	5%	7%	12%	15%
Readmit in 28 days	n	5	3	1	2	8	18	21
	%	9%	7%	6%	5%	14%	27%	29%
LOS>20 days	n	-	-	-	-	-	3	4
	%	0%	0%	0%	0%	0%	4%	5%

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

	ICHT	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	55	34	13	31	41	51	55
Distinct Pt count	n	35	29	11	23	31	32	41
Average LOS	n	5.1	3.7	4.0	4.7	4.8	6.6	5.8
Median LOS	n	4	3	2	3	3	4	3
Readmit in 7 days	n	4	1	-	2	4	7	7
	%	7%	3%	0%	6%	10%	14%	13%
Readmit in 28 days	n	5	3	1	2	6	14	15
	%	9%	9%	8%	6%	15%	27%	27%
LOS>20 days	n	-	-	-	-	-	3	4
	%	0%	0%	0%	0%	0%	6%	7%

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

	ICHT	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	444	481	416	550	599	679	826
Distinct Pt count	n	141	148	121	162	162	163	201
Average LOS	n	5.2	5.0	4.4	4.7	5.5	4.6	4.8
Median LOS	n	2	2	1	2	3	2	1
Readmit in 7 days	n	100	124	105	118	146	198	264
	%	23%	26%	25%	21%	24%	29%	32%
Readmit in 28 days	n	193	225	218	261	301	402	473
	%	43%	47%	52%	47%	50%	59%	57%
LOS>20 days	n	26	24	10	18	28	20	29
	%	6%	5%	2%	3%	5%	3%	4%

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

	ICHT	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	305	331	251	385	416	445	549
Distinct Pt count	n	119	124	97	139	137	133	178
Average LOS	n	7.6	7.3	7.3	6.7	8.0	7.0	7.2
Median LOS	n	5	4	4	4	6	6	5
Readmit in 7 days	n	75	88	60	76	93	135	142
	%	25%	27%	24%	20%	22%	30%	26%
Readmit in 28 days	n	130	151	125	180	201	248	270
	%	43%	46%	50%	47%	48%	56%	49%
LOS>20 days	n	26	24	10	18	28	20	29
	%	9%	7%	4%	5%	7%	4%	5%

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

	SGUH	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	42	43	30	46	36	43	47
Distinct Pt count	n	32	28	19	33	27	25	32
Average LOS	n	3.1	2.3	4.1	4.1	3.4	3.8	4.0
Median LOS	n	2	2	3	3.5	3	3	3
Readmit in 7 days	n	1	2	3	1	-	3	-
	%	2%	5%	10%	2%	0%	7%	0%
Readmit in 28 days	n	1	4	4	4	3	6	4
	%	2%	9%	13%	9%	8%	14%	9%
LOS>20 days	n	-	-	-	-	-	-	1
	%	0%	0%	0%	0%	0%	0%	2%

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

	SGUH	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	36	39	28	45	35	40	45
Distinct Pt count	n	27	26	18	32	26	23	30
Average LOS	n	3.7	2.6	4.4	4.2	3.5	4.1	4.2
Median LOS	n	2	2	3	2	3	3	3
Readmit in 7 days	n	1	2	3	1	-	3	-
	%	3%	5%	11%	2%	0%	8%	0%
Readmit in 28 days	n	1	4	4	4	3	5	4
	%	3%	10%	14%	9%	9%	13%	9%
LOS>20 days	n	-	-	-	-	-	-	1
	%	0%	0%	0%	0%	0%	0%	2%

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

	SGUH	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	250	224	135	182	176	220	188
Distinct Pt count	n	111	116	69	98	97	104	94
Average LOS	n	5.3	5.0	5.0	5.5	7.4	5.6	7.2
Median LOS	n	4	3	3	4	4	4	6
Readmit in 7 days	n	35	12	12	16	9	13	22
	%	14%	5%	9%	9%	5%	6%	12%
Readmit in 28 days	n	74	44	26	33	20	45	53
	%	30%	20%	19%	18%	11%	20%	28%
LOS>20 days	n	6	6	1	4	11	3	10
	%	2%	3%	1%	2%	6%	1%	5%

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

	SGUH	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	234	199	125	171	168	213	185
Distinct Pt count	n	106	107	67	95	95	101	93
Average LOS	n	5.7	5.6	5.4	5.9	7.8	5.8	7.4
Median LOS	n	4	4	4	4	5	4	6
Readmit in 7 days	n	35	11	11	15	7	13	21
	%	15%	6%	9%	9%	4%	6%	11%
Readmit in 28 days	n	74	37	21	32	18	44	52
	%	32%	19%	17%	19%	11%	21%	28%
LOS>20 days	n	6	6	1	4	11	3	10
	%	3%	3%	1%	2%	7%	1%	5%

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

	LNWH	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	76	86	33	46	64	23	40
Distinct Pt count	n	42	36	21	29	36	17	33
Average LOS	n	3.0	2.8	3.5	3.5	2.9	3.2	2.7
Median LOS	n	3	2.5	3	1	2.5	2	2
Readmit in 7 days	n	6	11	2	1	2	1	3
	%	8%	13%	6%	2%	3%	4%	8%
Readmit in 28 days	n	14	25	4	6	9	1	3
	%	18%	29%	12%	13%	14%	4%	8%
LOS>20 days	n	-	-	-	1	-	-	-
	%	0%	0%	0%	2%	0%	0%	0%

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

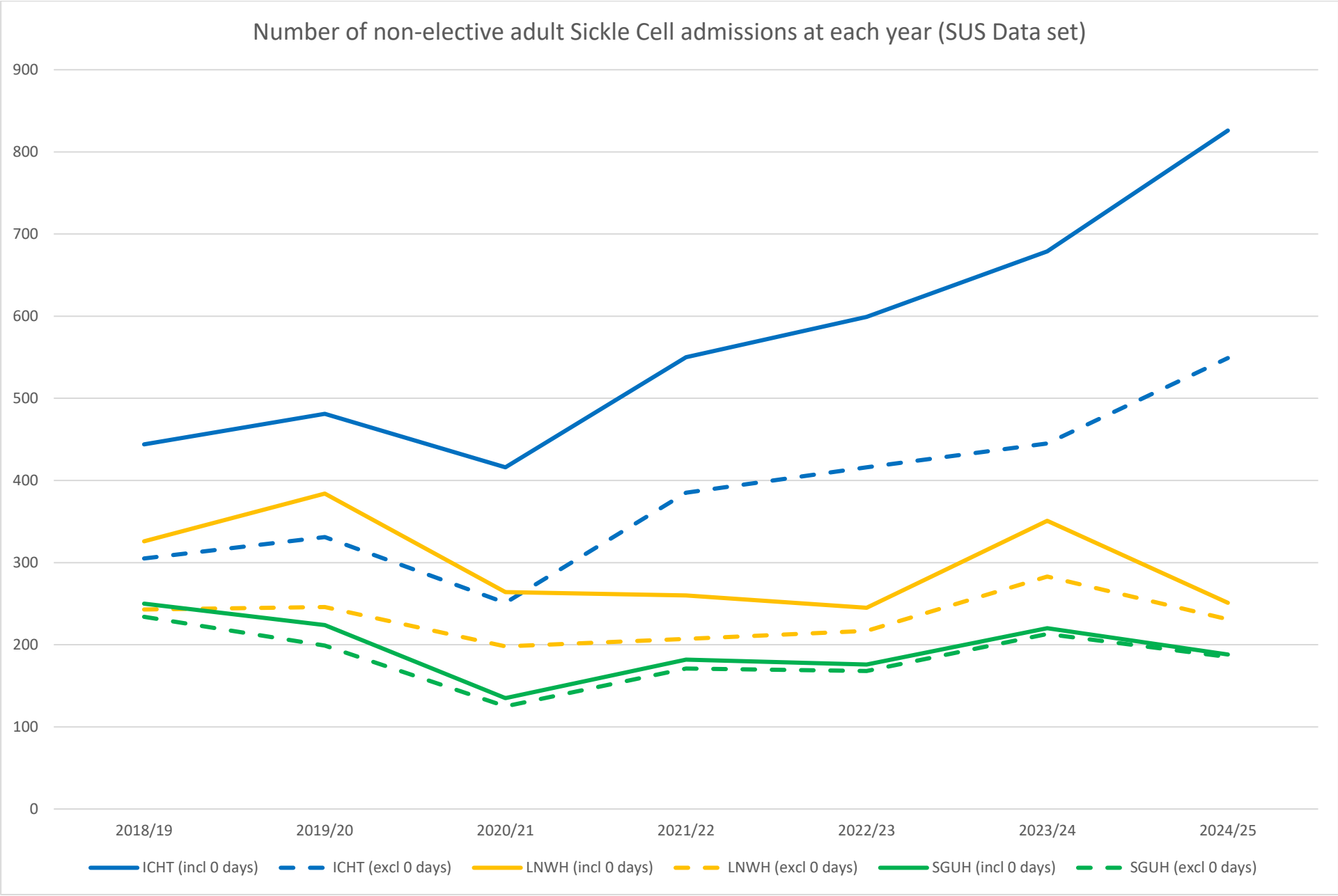
	LNWH	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	64	70	28	38	55	21	33
Distinct Pt count	n	35	32	18	23	31	15	26
Average LOS	n	3.5	3.5	4.1	4.3	3.4	3.5	3.2
Median LOS	n	3	3	3	1	3	2	3
Readmit in 7 days	n	6	10	2	1	2	1	3
	%	9%	14%	7%	3%	4%	5%	9%
Readmit in 28 days	n	12	20	4	6	9	1	3
	%	19%	29%	14%	16%	16%	5%	9%
LOS>20 days	n	-	-	-	1	-	-	-
	%	0%	0%	0%	3%	0%	0%	0%

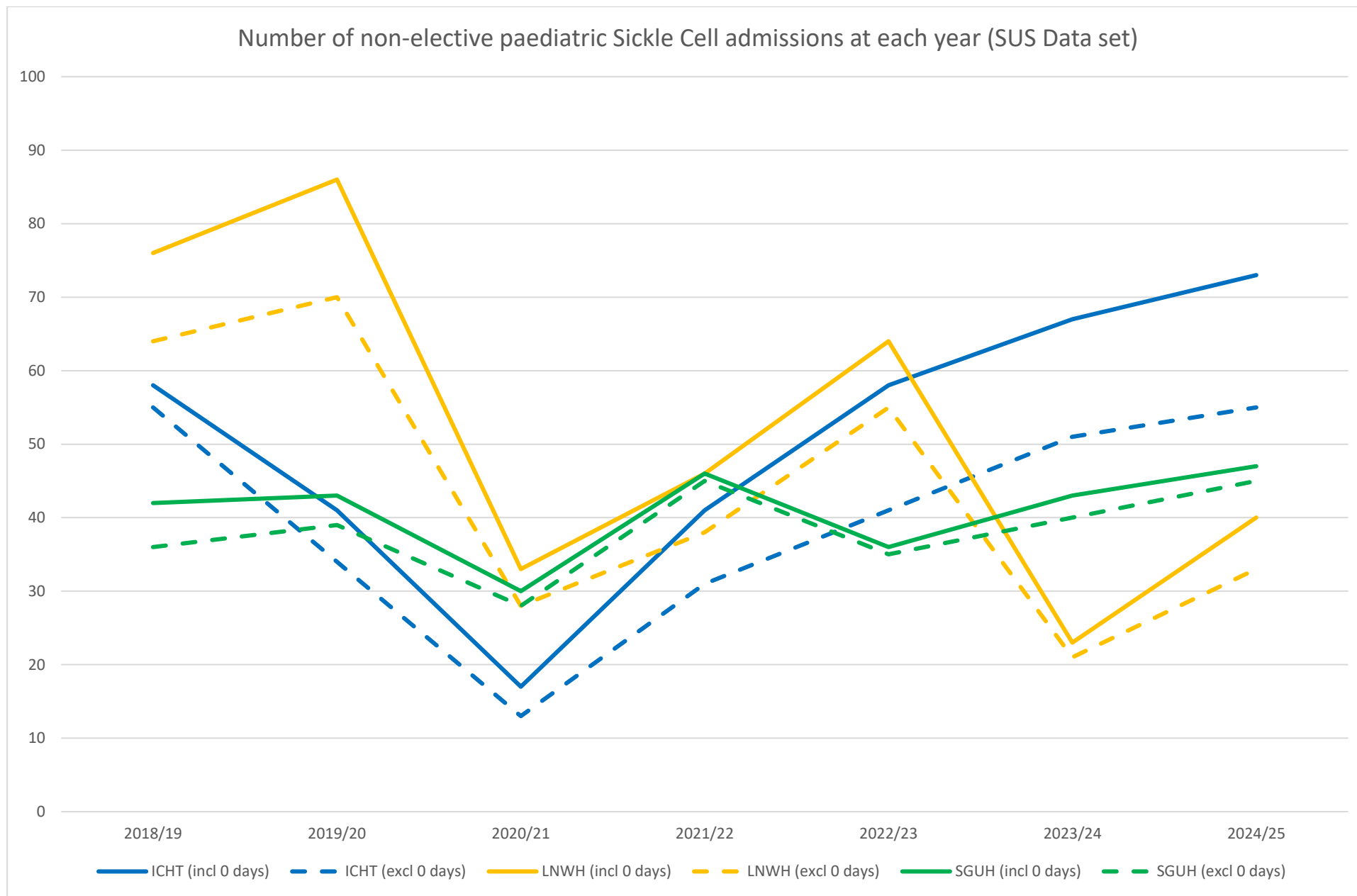
Number of non-elective **adult** Sickle Cell admissions at **London North West** each year **including 0 day admissions**

	LNWH	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	326	384	264	260	245	351	251
Distinct Pt count	n	136	127	86	113	106	115	87
Average LOS	n	3.1	2.0	2.6	2.8	3.6	4.2	4.5
Median LOS	n	2	1	2	2	3	2	3
Readmit in 7 days	n	49	62	40	29	21	67	53
	%	15%	16%	15%	11%	9%	19%	21%
Readmit in 28 days	n	111	155	98	88	86	158	115
	%	34%	40%	37%	34%	35%	45%	46%
LOS>20 days	n	3	-	1	-	2	7	4
	%	1%	0%	0%	0%	1%	2%	2%

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

	LNWH	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	243	246	198	207	217	283	231
Distinct Pt count	n	113	98	70	93	92	99	80
Average LOS	n	4.2	3.2	3.5	3.5	4.1	5.2	4.9
Median LOS	n	3	2	3	3	3	3	4
Readmit in 7 days	n	39	38	29	24	19	56	46
	%	16%	15%	15%	12%	9%	20%	20%
Readmit in 28 days	n	85	96	70	71	81	133	107
	%	35%	39%	35%	34%	37%	47%	46%
LOS>20 days	n	3	-	1	-	2	7	4
	%	1%	0%	1%	0%	1%	2%	2%





Number of non-elective **paediatric** Sickle Cell admissions at **Bedfordshire Hospitals NHS Foundation Trust** each year **including 0 day admissions**

	Bedfordshire	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	55	47	28	35	71	65	79
Distinct patient count	n	26	22	16	26	34	36	44
Average LOS	n	2.5	2.9	2.5	2.8	3.3	3.4	3.2
Median LOS	n	2	2	2	2	3	2	3
Readmit in 7 days	n	8	2	-	1	4	7	5
	%	15%	4%	0%	3%	6%	11%	6%
Readmit in 28 days	n	13	11	1	2	16	18	16
	%	24%	23%	4%	6%	23%	28%	20%
LOS>20 days	n	-	-	-	-	-	1	-
	%	0%	0%	0%	0%	0%	2%	0%

Number of non-elective **paediatric** Sickle Cell admissions at **Bedfordshire Hospitals NHS Foundation Trust** each year **excluding 0 day admissions**

	Bedfordshire	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	46	40	18	29	62	53	70
Distinct patient count	n	23	18	9	23	33	31	41
Average LOS	n	2.9	3.4	3.8	3.4	3.8	4.2	3.6
Median LOS	n	2	3	4	3	3	3	3
Readmit in 7 days	n	7	2	-	1	2	6	5
	%	15%	5%	0%	3%	3%	11%	7%
Readmit in 28 days	n	10	10	1	2	13	17	14
	%	22%	25%	6%	7%	21%	32%	20%
LOS>20 days	n	-	-	-	-	-	1	-
	%	0%	0%	0%	0%	0%	2%	0%

Number of non-elective **paediatric** Sickle Cell admissions at **West Hertfordshire Teaching Hospitals NHS Trust** each year **including 0 day admissions**

	West Hertfordshire	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	9	18	9	11	7	9	13
Distinct patient count	n	5	9	5	7	7	6	11
Average LOS	n	2.7	2.6	1.8	2.3	2.1	4.4	2.0
Median LOS	n	1	1	1	3	1	4	2
Readmit in 7 days	n	1	2	1	-	-	1	-
	%	11%	11%	11%	0%	0%	11%	0%
Readmit in 28 days	n	2	6	1	2	-	2	-
	%	22%	33%	11%	18%	0%	22%	0%
LOS>20 days	n	-	-	-	-	-	-	-
	%	0%	0%	0%	0%	0%	0%	0%

Number of non-elective **paediatric** Sickle Cell admissions at **West Hertfordshire Teaching Hospitals NHS Trust** each year **excluding 0 day admissions**

	West Hertfordshire	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	6	14	5	9	6	9	10
Distinct patient count	n	3	7	3	7	6	6	9
Average LOS	n	4.0	3.4	3.2	2.8	2.5	4.4	2.6
Median LOS	n	1.5	1.5	3	3	2	4	2
Readmit in 7 days	n	1	2	-	-	-	1	-
	%	17%	14%	0%	0%	0%	11%	0%
Readmit in 28 days	n	2	5	-	2	-	2	-
	%	33%	36%	0%	22%	0%	22%	0%
LOS>20 days	n	-	-	-	-	-	-	-
	%	0%	0%	0%	0%	0%	0%	0%

Number of non-elective **adult** Sickle Cell admissions at **West Hertfordshire Teaching Hospitals NHS Trust** each year **including 0 day admissions**

	West Hertfordshire	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	21	25	23	29	49	30	29
Distinct patient count	n	13	10	14	11	13	11	17
Average LOS	n	3.3	3.0	3.4	2.3	2.3	2.7	3.2
Median LOS	n	3	2	2	1	2	2	3
Readmit in 7 days	n	2	8	1	6	19	9	2
	%	10%	32%	4%	21%	39%	30%	7%
Readmit in 28 days	n	4	10	4	12	29	11	4
	%	19%	40%	17%	41%	59%	37%	14%
LOS>20 days	n	-	-	-	-	-	-	-
	%	0%	0%	0%	0%	0%	0%	0%

Number of non-elective **adult** Sickle Cell admissions at **West Hertfordshire Teaching Hospitals NHS Trust** each year **excluding 0 day admissions**

	West Hertfordshire	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	20	23	20	19	44	28	25
Distinct patient count	n	12	9	12	11	11	11	13
Average LOS	n	3.5	3.2	4.0	3.6	2.6	2.9	3.7
Median LOS	n	3	3	3	3	2	2	3
Readmit in 7 days	n	2	8	1	5	16	8	2
	%	10%	35%	5%	26%	36%	29%	8%
Readmit in 28 days	n	4	10	4	7	26	10	4
	%	20%	43%	20%	37%	59%	36%	16%
LOS>20 days	n	-	-	-	-	-	-	-
	%	0%	0%	0%	0%	0%	0%	0%

Number of non-elective **paediatric** Sickle Cell admissions at **The Hillingdon Hospitals NHS Foundation Trust** each year **including 0 day admissions**

	The Hillingdon	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	17	8	4	3	3	6	12
Distinct patient count	n	11	5	2	3	3	6	10
Average LOS	n	2.8	2.1	2.3	3.7	3.0	2.2	3.5
Median LOS	n	2	1.5	1	3	4	1	3.5
Readmit in 7 days	n	-	-	-	-	-	-	1
	%	0%	0%	0%	0%	0%	0%	8%
Readmit in 28 days	n	-	-	1	-	-	-	1
	%	0%	0%	25%	0%	0%	0%	8%
LOS>20 days	n	-	-	-	-	-	-	-
	%	0%	0%	0%	0%	0%	0%	0%

Number of non-elective **paediatric** Sickle Cell admissions at **The Hillingdon Hospitals NHS Foundation Trust** each year **excluding 0 day admissions**

	The Hillingdon	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	14	7	3	2	3	6	11
Distinct patient count	n	9	5	1	2	3	6	10
Average LOS	n	3.4	2.4	3.0	5.5	3.0	2.2	3.8
Median LOS	n	2	2	1	5.5	4	1	4
Readmit in 7 days	n	-	-	-	-	-	-	1
	%	0%	0%	0%	0%	0%	0%	9%
Readmit in 28 days	n	-	-	1	-	-	-	1
	%	0%	0%	33%	0%	0%	0%	9%
LOS>20 days	n	-	-	-	-	-	-	-
	%	0%	0%	0%	0%	0%	0%	0%

Number of non-elective **adult** Sickle Cell admissions at **The Hillingdon Hospitals NHS Foundation Trust** each year **including 0 day admissions**

	The Hillingdon	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	25	12	13	22	20	13	28
Distinct patient count	n	12	8	11	15	16	13	20
Average LOS	n	3.4	3.2	2.3	3.0	3.4	1.3	2.5
Median LOS	n	3	3	1	2.5	2	1	2
Readmit in 7 days	n	2	-	1	2	1	-	1
	%	8%	0%	8%	9%	5%	0%	4%
Readmit in 28 days	n	5	1	1	3	1	-	3
	%	20%	8%	8%	14%	5%	0%	11%
LOS>20 days	n	-	-	-	-	-	-	-
	%	0%	0%	0%	0%	0%	0%	0%

Number of non-elective **adult** Sickle Cell admissions at **The Hillingdon Hospitals NHS Foundation Trust** each year **excluding 0 day admissions**

	The Hillingdon	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	24	10	8	19	19	9	28
Distinct patient count	n	12	6	8	13	15	9	20
Average LOS	n	3.5	3.8	3.8	3.4	3.6	1.9	2.5
Median LOS	n	3	3.5	3.5	3	2	2	2
Readmit in 7 days	n	1	-	1	2	1	-	1
	%	4%	0%	13%	11%	5%	0%	4%
Readmit in 28 days	n	4	1	1	2	1	-	3
	%	17%	10%	13%	11%	5%	0%	11%
LOS>20 days	n	-	-	-	-	-	-	-
	%	0%	0%	0%	0%	0%	0%	0%

Number of non-elective **paediatric** Sickle Cell admissions at **Chelsea and Westminster Hospital NHS Foundation Trust** each year **including 0 day admissions**

	Chelsea and Westminster	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	39	35	20	38	30	19	13
Distinct patient count	n	26	20	11	20	14	13	9
Average LOS	n	1.8	3.1	1.8	3.9	3.1	2.7	2.8
Median LOS	n	1	3	1.5	2	2	2	3
Readmit in 7 days	n	3	4	1	6	2	-	-
	%	8%	11%	5%	16%	7%	0%	0%
Readmit in 28 days	n	5	5	1	11	5	1	-
	%	13%	14%	5%	29%	17%	5%	0%
LOS>20 days	n	-	-	-	1	-	-	-
	%	0%	0%	0%	3%	0%	0%	0%

Number of non-elective **paediatric** Sickle Cell admissions at **Chelsea and Westminster Hospital NHS Foundation Trust** each year **excluding 0 day admissions**

	Chelsea and Westminster	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	28	31	15	34	27	17	11
Distinct patient count	n	20	19	10	18	13	12	8
Average LOS	n	2.6	3.5	2.3	4.4	3.4	3.1	3.4
Median LOS	n	2	3	2	2	3	2	3
Readmit in 7 days	n	3	3	-	6	2	-	-
	%	11%	10%	0%	18%	7%	0%	0%
Readmit in 28 days	n	4	4	-	11	4	1	-
	%	14%	13%	0%	32%	15%	6%	0%
LOS>20 days	n	-	-	-	1	-	-	-
	%	0%	0%	0%	3%	0%	0%	0%

Number of non-elective **adult** Sickle Cell admissions at **Chelsea and Westminster Hospital NHS Foundation Trust** each year **including 0 day admissions**

	Chelsea and Westminster	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	106	69	47	78	96	78	65
Distinct patient count	n	44	39	26	35	38	36	38
Average LOS	n	4.0	3.9	3.1	2.7	4.0	3.8	4.8
Median LOS	n	2	2	2	1	2	2	2
Readmit in 7 days	n	14	3	3	5	31	15	8
	%	13%	4%	6%	6%	32%	19%	12%
Readmit in 28 days	n	34	9	8	18	44	24	11
	%	32%	13%	17%	23%	46%	31%	17%
LOS>20 days	n	3	2	-	-	1	1	1
	%	3%	3%	0%	0%	1%	1%	2%

Number of non-elective **adult** Sickle Cell admissions at **Chelsea and Westminster Hospital NHS Foundation Trust** each year **excluding 0 day admissions**

	Chelsea and Westminster	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	86	56	35	61	79	62	49
Distinct patient count	n	36	33	22	31	32	34	33
Average LOS	n	4.9	4.8	4.2	3.5	4.9	4.8	6.3
Median LOS	n	3	3	3	2	3	3	4
Readmit in 7 days	n	11	3	2	5	22	11	5
	%	13%	5%	6%	8%	28%	18%	10%
Readmit in 28 days	n	28	9	3	16	34	15	6
	%	33%	16%	9%	26%	43%	24%	12%
LOS>20 days	n	3	2	-	-	1	1	1
	%	3%	4%	0%	0%	1%	2%	2%

Number of non-elective **paediatric** Sickle Cell admissions at **Kingston and Richmond NHS Foundation Trust** each year **including 0 day admissions**

	Kingston	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	6	9	5	9	10	11	10
Distinct patient count	n	4	4	3	6	7	6	6
Average LOS	n	2.8	4.2	3.4	2.9	2.2	3.1	1.6
Median LOS	n	2	4	4	3	2	2	1
Readmit in 7 days	n	-	-	-	1	-	-	1
	%	0%	0%	0%	11%	0%	0%	10%
Readmit in 28 days	n	-	2	-	2	-	1	1
	%	0%	22%	0%	22%	0%	9%	10%
LOS>20 days	n	-	-	-	-	-	-	-
	%	0%	0%	0%	0%	0%	0%	0%

Number of non-elective **paediatric** Sickle Cell admissions at **Kingston and Richmond NHS Foundation Trust** each year **excluding 0 day admissions**

	Kingston	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	5	7	4	7	10	10	8
Distinct patient count	n	4	3	2	5	7	6	5
Average LOS	n	3.4	5.4	4.3	3.7	2.2	3.4	2.0
Median LOS	n	2	5	4.5	3	2	2.5	1
Readmit in 7 days	n	-	-	-	-	-	-	1
	%	0%	0%	0%	0%	0%	0%	13%
Readmit in 28 days	n	-	2	-	1	-	1	1
	%	0%	29%	0%	14%	0%	10%	13%
LOS>20 days	n	-	-	-	-	-	-	-
	%	0%	0%	0%	0%	0%	0%	0%

Number of non-elective **adult** Sickle Cell admissions at **Kingston and Richmond NHS Foundation Trust** each year **including 0 day admissions**

	Kingston	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	23	25	20	28	27	40	20
Distinct patient count	n	12	6	5	15	10	11	4
Average LOS	n	3.4	2.4	1.2	3.8	3.1	3.2	2.7
Median LOS	n	3	2	1	2	2	2	2
Readmit in 7 days	n	3	11	7	3	6	14	3
	%	13%	44%	35%	11%	22%	35%	15%
Readmit in 28 days	n	6	14	14	9	13	22	12
	%	26%	56%	70%	32%	48%	55%	60%
LOS>20 days	n	-	-	-	1	-	1	-
	%	0%	0%	0%	4%	0%	3%	0%

Number of non-elective **adult** Sickle Cell admissions at **Kingston and Richmond NHS Foundation Trust** each year **excluding 0 day admissions**

	Kingston	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	15	23	13	25	22	37	16
Distinct patient count	n	9	6	4	15	10	10	4
Average LOS	n	5.3	2.7	1.8	4.2	3.8	3.5	3.3
Median LOS	n	4	2	1	2	3	2	2.5
Readmit in 7 days	n	2	11	5	3	3	13	2
	%	13%	48%	38%	12%	14%	35%	13%
Readmit in 28 days	n	4	13	9	7	8	20	8
	%	27%	57%	69%	28%	36%	54%	50%
LOS>20 days	n	-	-	-	1	-	1	-
	%	0%	0%	0%	4%	0%	3%	0%

Number of non-elective **paediatric** Sickle Cell admissions at **Epsom and St Helier University Hospitals NHS Trust** each year **including 0 day admissions**

	Epsom and St Helier's	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	20	10	5	16	13	13	7
Distinct patient count	n	11	9	4	13	9	11	6
Average LOS	n	3.9	3.3	6.2	2.1	4.0	2.8	4.6
Median LOS	n	3	3	6	1.5	2.5	2	5
Readmit in 7 days	n	2	-	1	-	-	-	-
	%	10%	0%	20%	0%	0%	0%	0%
Readmit in 28 days	n	4	-	1	-	-	-	-
	%	20%	0%	20%	0%	0%	0%	0%
LOS>20 days	n	-	-	-	-	-	-	-
	%	0%	0%	0%	0%	0%	0%	0%

Number of non-elective **paediatric** Sickle Cell admissions at **Epsom and St Helier University Hospitals NHS Trust** each year **excluding 0 day admissions**

	Epsom and St Helier's	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	20	9	4	15	12	12	7
Distinct patient count	n	11	8	3	12	9	10	6
Average LOS	n	3.9	3.7	7.8	2.3	4.3	3.0	4.6
Median LOS	n	3	3	7.5	1.5	3	2	5
Readmit in 7 days	n	2	-	1	-	-	-	-
	%	10%	0%	25%	0%	0%	0%	0%
Readmit in 28 days	n	4	-	1	-	-	-	-
	%	20%	0%	25%	0%	0%	0%	0%
LOS>20 days	n	-	-	-	-	-	-	-
	%	0%	0%	0%	0%	0%	0%	0%

Number of non-elective **adult** Sickle Cell admissions at **Epsom and St Helier University Hospitals NHS Trust** each year **including 0 day admissions**

	Epsom and St Helier's	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	46	50	36	36	33	32	45
Distinct patient count	n	23	23	16	18	14	22	23
Average LOS	n	4.2	4.5	5.1	6.6	8.0	7.4	7.4
Median LOS	n	3.5	4	5	6.5	7	6	6
Readmit in 7 days	n	4	9	3	8	3	1	3
	%	9%	18%	8%	22%	9%	3%	7%
Readmit in 28 days	n	6	17	17	17	8	6	13
	%	13%	34%	47%	47%	24%	19%	29%
LOS>20 days	n	-	-	-	-	2	2	2
	%	0%	0%	0%	0%	6%	6%	4%

Number of non-elective **adult** Sickle Cell admissions at **Epsom and St Helier University Hospitals NHS Trust** each year **excluding 0 day admissions**

	Epsom and St Helier's	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	36	42	34	36	31	31	44
Distinct patient count	n	18	19	14	18	14	21	22
Average LOS	n	5.4	5.3	5.4	6.6	8.5	7.6	7.6
Median LOS	n	4.5	5	5	6.5	7	6	6
Readmit in 7 days	n	4	8	3	8	2	1	3
	%	11%	19%	9%	22%	6%	3%	7%
Readmit in 28 days	n	6	16	17	17	7	6	13
	%	17%	38%	50%	47%	23%	19%	30%
LOS>20 days	n	-	-	-	-	2	2	2
	%	0%	0%	0%	0%	6%	6%	5%

Number of non-elective **paediatric** Sickle Cell admissions at **Ashford and St Peter's Hospitals NHS Foundation Trust** each year **including 0 day admissions**

	Ashford and St Peter	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	4	-	1	3	6	5	10
Distinct patient count	n	3	-	1	2	4	4	6
Average LOS	n	1.3	-	3.0	2.3	3.0	3.0	5.3
Median LOS	n	1	-	3	3	2	2.5	5.5
Readmit in 7 days	n	-	-	-	-	1	-	1
	%	0%	0%	0%	0%	17%	0%	10%
Readmit in 28 days	n	-	-	-	-	2	-	1
	%	0%	0%	0%	0%	33%	0%	10%
LOS>20 days	n	-	-	-	-	-	-	-
	%	0%	0%	0%	0%	0%	0%	0%

Number of non-elective **paediatric** Sickle Cell admissions at **Ashford and St Peter's Hospitals NHS Foundation Trust** each year **excluding 0 day admissions**

	Ashford and St Peter	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	3	-	1	2	5	4	10
Distinct patient count	n	3	-	1	1	3	3	6
Average LOS	n	1.7	-	3.0	3.5	3.6	3.8	5.3
Median LOS	n	1	-	3	3.5	3	3	5.5
Readmit in 7 days	n	-	-	-	-	1	-	1
	%	0%	0%	0%	0%	20%	0%	10%
Readmit in 28 days	n	-	-	-	-	2	-	1
	%	0%	0%	0%	0%	40%	0%	10%
LOS>20 days	n	-	-	-	-	-	-	-
	%	0%	0%	0%	0%	0%	0%	0%

Number of non-elective **adult** Sickle Cell admissions at **Ashford and St Peter's Hospitals NHS Foundation Trust** each year **including 0 day admissions**

	Ashford and St Peter	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	9	6	3	1	8	27	12
Distinct patient count	n	7	6	2	1	6	8	7
Average LOS	n	3.0	1.8	1.3	2.0	3.1	2.4	3.4
Median LOS	n	3	1.5	1	1	2	1	2
Readmit in 7 days	n	-	-	-	-	2	14	-
	%	0%	0%	0%	0%	25%	52%	0%
Readmit in 28 days	n	-	-	-	-	2	19	1
	%	0%	0%	0%	0%	25%	70%	8%
LOS>20 days	n	-	-	-	-	-	-	-
	%	0%	0%	0%	0%	0%	0%	0%

Number of non-elective **adult** Sickle Cell admissions at **Ashford and St Peter's Hospitals NHS Foundation Trust** each year **excluding 0 day admissions**

	Ashford and St Peter	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	9	5	2	1	7	26	10
Distinct patient count	n	7	5	1	1	6	8	7
Average LOS	n	3.0	2.2	2.0	2.0	3.6	2.5	4.1
Median LOS	n	3	2	2	2	2	1	2.5
Readmit in 7 days	n	-	-	-	-	2	13	-
	%	0%	0%	0%	0%	29%	50%	0%
Readmit in 28 days	n	-	-	-	-	2	18	-
	%	0%	0%	0%	0%	29%	69%	0%
LOS>20 days	n	-	-	-	-	-	-	-
	%	0%	0%	0%	0%	0%	0%	0%

Number of non-elective **paediatric** Sickle Cell admissions at **Royal Surrey County Hospital NHS Foundation Trust** each year **including 0 day admissions**

	Royal Surrey	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	1	6	2	6	7	11	7
Distinct patient count	n	1	2	1	3	1	9	5
Average LOS	n	2.0	0.8	0.5	2.0	1.9	2.5	2.1
Median LOS	n	2	0.5	0.5	1	0	1	2
Readmit in 7 days	n	-	1	1	-	-	-	-
	%	0%	17%	50%	0%	0%	0%	0%
Readmit in 28 days	n	-	2	1	1	-	-	-
	%	0%	33%	50%	17%	0%	0%	0%
LOS>20 days	n	-	-	-	-	-	-	-
	%	0%	0%	0%	0%	0%	0%	0%

Number of non-elective **paediatric** Sickle Cell admissions at **Royal Surrey County Hospital NHS Foundation Trust** each year **excluding 0 day admissions**

	Royal Surrey	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	1	3	1	6	1	6	6
Distinct patient count	n	1	2	1	3	1	6	5
Average LOS	n	2.0	1.7	1.0	2.0	13.0	4.5	2.5
Median LOS	n	2	2	1	1	-	5	2
Readmit in 7 days	n	-	-	-	-	-	-	-
	%	0%	0%	0%	0%	0%	0%	0%
Readmit in 28 days	n	-	-	-	1	-	-	-
	%	0%	0%	0%	17%	0%	0%	0%
LOS>20 days	n	-	-	-	-	-	-	-
	%	0%	0%	0%	0%	0%	0%	0%

Number of non-elective **adult** Sickle Cell admissions at **Royal Surrey County Hospital NHS Foundation Trust** each year **including 0 day admissions**

	Royal Surrey	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	16	23	3	5	15	18	14
Distinct patient count	n	5	10	3	3	10	7	7
Average LOS	n	1.3	2.0	4.0	7.6	5.3	4.0	3.2
Median LOS	n	1	1	3	5	4.5	3.5	2.5
Readmit in 7 days	n	3	3	-	-	-	1	2
	%	19%	13%	0%	0%	0%	6%	14%
Readmit in 28 days	n	5	5	-	-	1	5	2
	%	31%	22%	0%	0%	7%	28%	14%
LOS>20 days	n	-	-	-	-	-	-	-
	%	0%	0%	0%	0%	0%	0%	0%

Number of non-elective **adult** Sickle Cell admissions at **The Royal Surrey County Hospital NHS Foundation Trust** each year **excluding 0 day admissions**

	Royal Surrey	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	10	16	3	5	15	17	11
Distinct patient count	n	4	8	3	3	10	6	5
Average LOS	n	2.1	2.8	4.0	7.6	5.3	4.2	4.1
Median LOS	n	1.5	2	3	5	4	4	3
Readmit in 7 days	n	2	3	-	-	-	1	2
	%	20%	19%	0%	0%	0%	6%	18%
Readmit in 28 days	n	3	5	-	-	1	5	2
	%	30%	31%	0%	0%	7%	29%	18%
LOS>20 days	n	-	-	-	-	-	-	-
	%	0%	0%	0%	0%	0%	0%	0%

Number of non-elective **paediatric** Sickle Cell admissions at **Surrey and Sussex Healthcare NHS Trust** each year **including 0 day admissions**

	SASH	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	23	23	7	16	23	29	31
Distinct patient count	n	11	10	5	9	12	14	14
Average LOS	n	2.8	3.3	2.0	2.9	1.9	2.8	2.3
Median LOS	n	2	2	1	2	1	1	2
Readmit in 7 days	n	1	3	1	2	-	2	2
	%	4%	13%	14%	13%	0%	7%	6%
Readmit in 28 days	n	3	8	1	4	1	5	5
	%	13%	35%	14%	25%	4%	17%	16%
LOS>20 days	n	-	-	-	-	-	1	-
	%	0%	0%	0%	0%	0%	3%	0%

Number of non-elective **paediatric** Sickle Cell admissions at **Surrey and Sussex Healthcare NHS Trust** each year **excluding 0 day admissions**

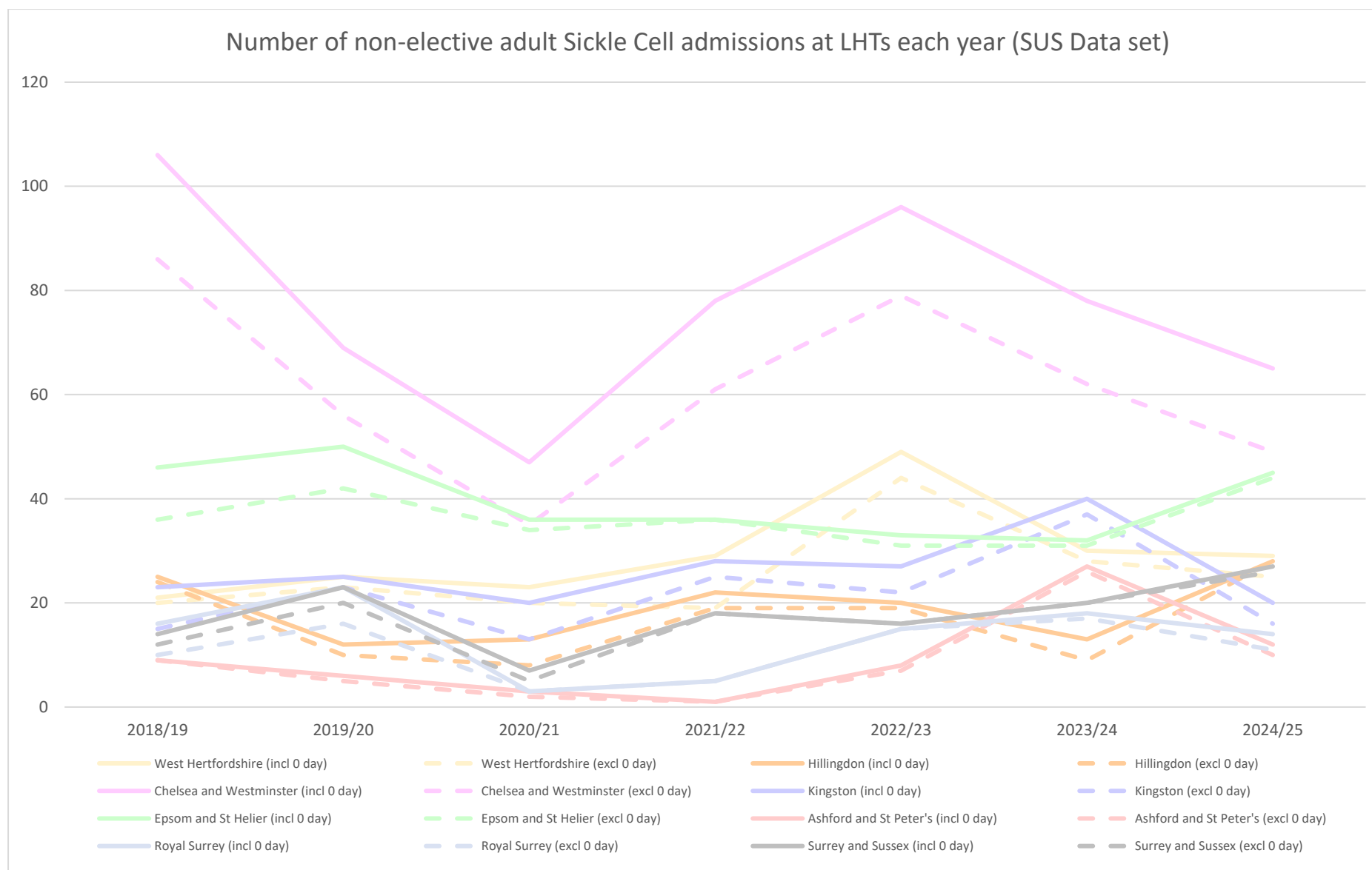
	SASH	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	19	22	6	15	14	18	21
Distinct patient count	n	11	10	5	9	9	13	11
Average LOS	n	3.4	3.5	2.3	3.1	3.1	4.4	3.3
Median LOS	n	3	2.5	2	2	2	2	3
Readmit in 7 days	n	1	3	1	2	-	2	2
	%	5%	14%	17%	13%	0%	11%	10%
Readmit in 28 days	n	2	7	1	4	1	2	5
	%	11%	32%	17%	27%	7%	11%	24%
LOS>20 days	n	-	-	-	-	-	1	-
	%	0%	0%	0%	0%	0%	6%	0%

Number of non-elective **adult** Sickle Cell admissions at **Surrey and Sussex Healthcare NHS Trust** each year **including 0 day admissions**

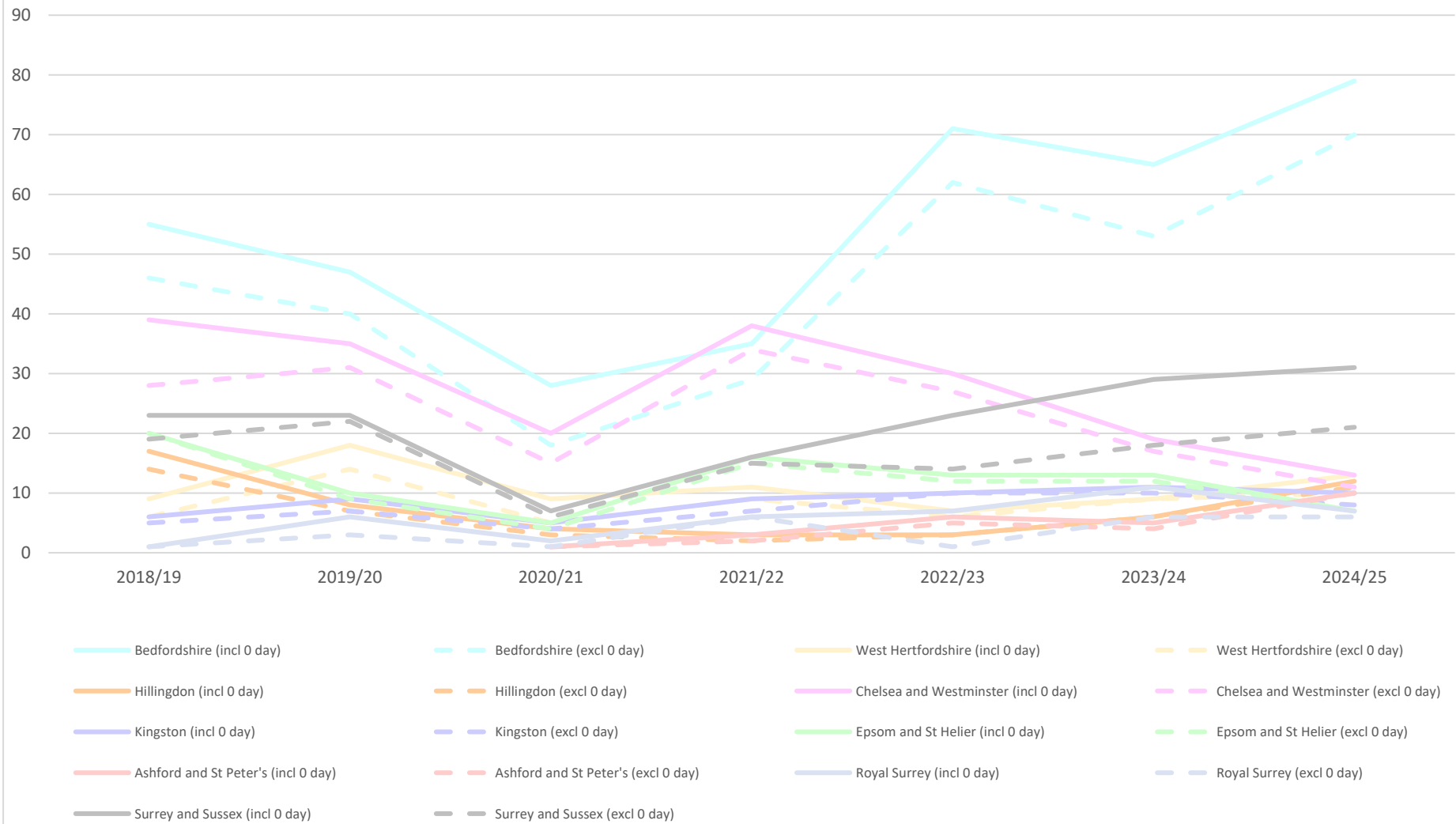
	SASH	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	14	23	7	18	16	20	27
Distinct patient count	n	11	14	5	7	14	10	17
Average LOS	n	3.0	4.6	2.9	5.2	4.4	5.1	4.6
Median LOS	n	3	1	3	4.5	3	5	4
Readmit in 7 days	n	-	2	-	-	-	2	-
	%	0%	9%	0%	0%	0%	10%	0%
Readmit in 28 days	n	2	5	2	4	-	3	3
	%	14%	22%	29%	22%	0%	15%	11%
LOS>20 days	n	-	1	-	-	-	-	-
	%	0%	4%	0%	0%	0%	0%	0%

Number of non-elective **adult** Sickle Cell admissions at **Surrey and Sussex Healthcare NHS Trust** each year **excluding 0 day admissions**

	SASH	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
No. of admission	n	12	20	5	18	16	20	26
Distinct patient count	n	10	13	4	7	14	10	16
Average LOS	n	3.5	5.3	4.0	5.2	4.4	5.1	4.8
Median LOS	n	2	4	3	4.5	3	5	4
Readmit in 7 days	n	-	2	-	-	-	2	-
	%	0%	10%	0%	0%	0%	10%	0%
Readmit in 28 days	n	2	4	2	4	-	3	3
	%	17%	20%	40%	22%	0%	15%	12%
LOS>20 days	n	-	1	-	-	-	-	-
	%	0%	5%	0%	0%	0%	0%	0%



Number of non-elective paediatric Sickle Cell admissions at LHTs each year (SUS Data set)



Proportion of patient deaths discussed at Haemoglobinopathy Coordinating Centres (HCC) morbidity/mortality meetings 24/25 (HAEMCC09bi)

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.

Service Specification	HCC	Imperial	London Northwest	St. Georges
Proportion of patient deaths discussed at Haemoglobinopathy Coordinating Centres (HCC) morbidity/mortality meetings	11 Deaths recorded across the HCC 100 % were uploaded to the NHR 100% were discussed in the HCC MDT	6 Deaths recorded (6 Adults, 0 Paeds)	3 Deaths recorded (2 Adults, 1 Paeds)	2 Deaths recorded (2 Adults, 0 Paeds)

Proportion of serious adverse events (as defined by National Haemoglobinopathy Registry) that are discussed at the HCC morbidity/mortality meetings 24/25 (HAEMCC09c)

Please note the below data includes information from the SHTs (Specialist Haemoglobinopathy Teams)

Service Specification	HCC	Imperial	London Northwest	St. Georges
Proportion of serious adverse events that are discussed at the HCC morbidity/mortality meetings	30 Serious Adverse Events recorded across the HCC 100 % were uploaded to the NHR 100% were discussed in the HCC MDT	18 Serious Adverse Events recorded (16 in Adults, 2 in Paeds)	6 Serious Adverse Events recorded (5 in Adults, 1 in Paeds)	6 Serious Adverse Events recorded (5 in Adults, 1 in Paeds)

Appendix 1-Service Specification

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



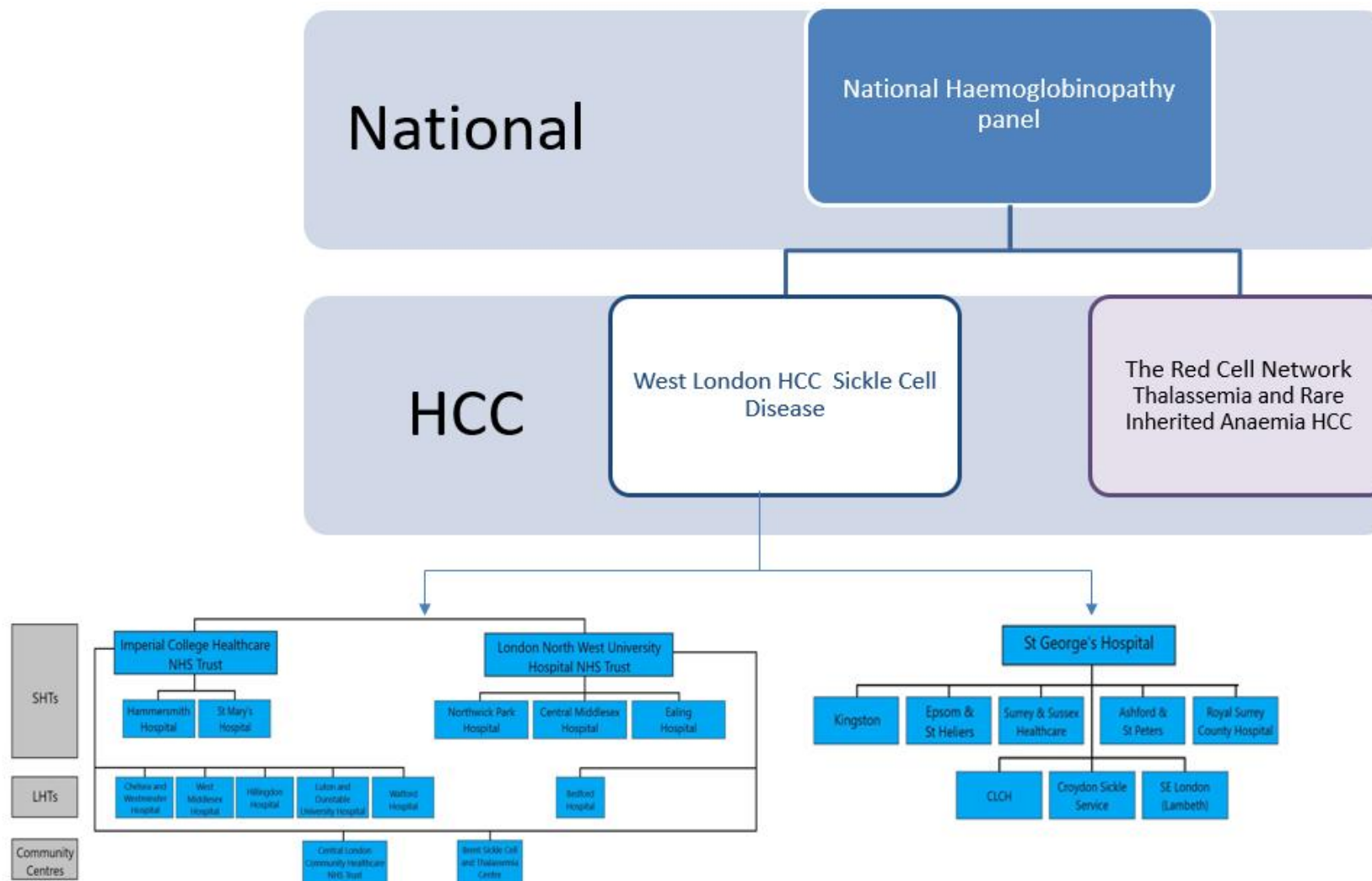
haemoglobinopath
y-coordinating-cent

Embed a copy of the peer review standards

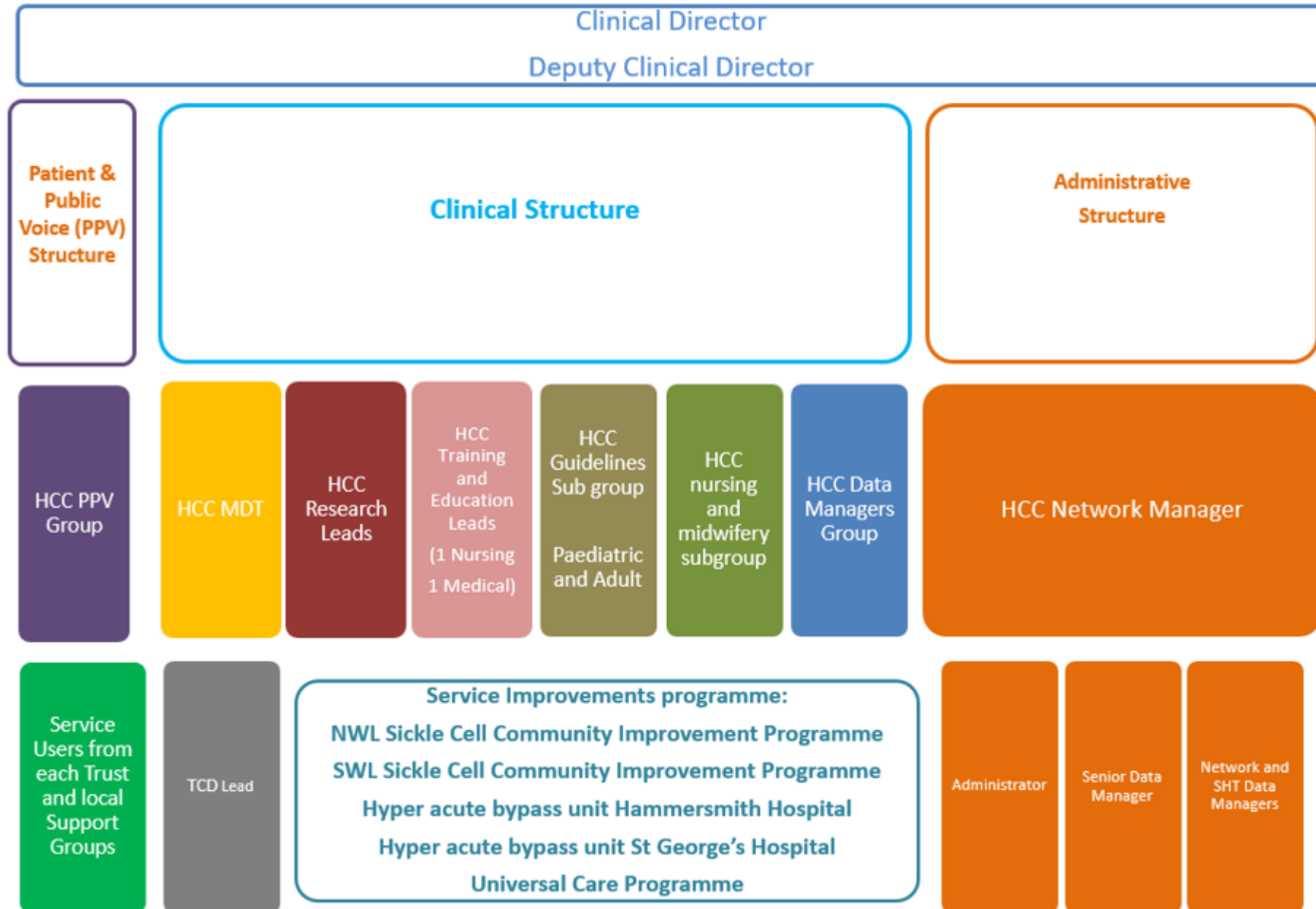


QS Haemoglobin
Disorders V5 202111

Appendix 2-Network Organogram



Appendix 3-Network Structure



Appendix 4- Key Positions within the Network

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

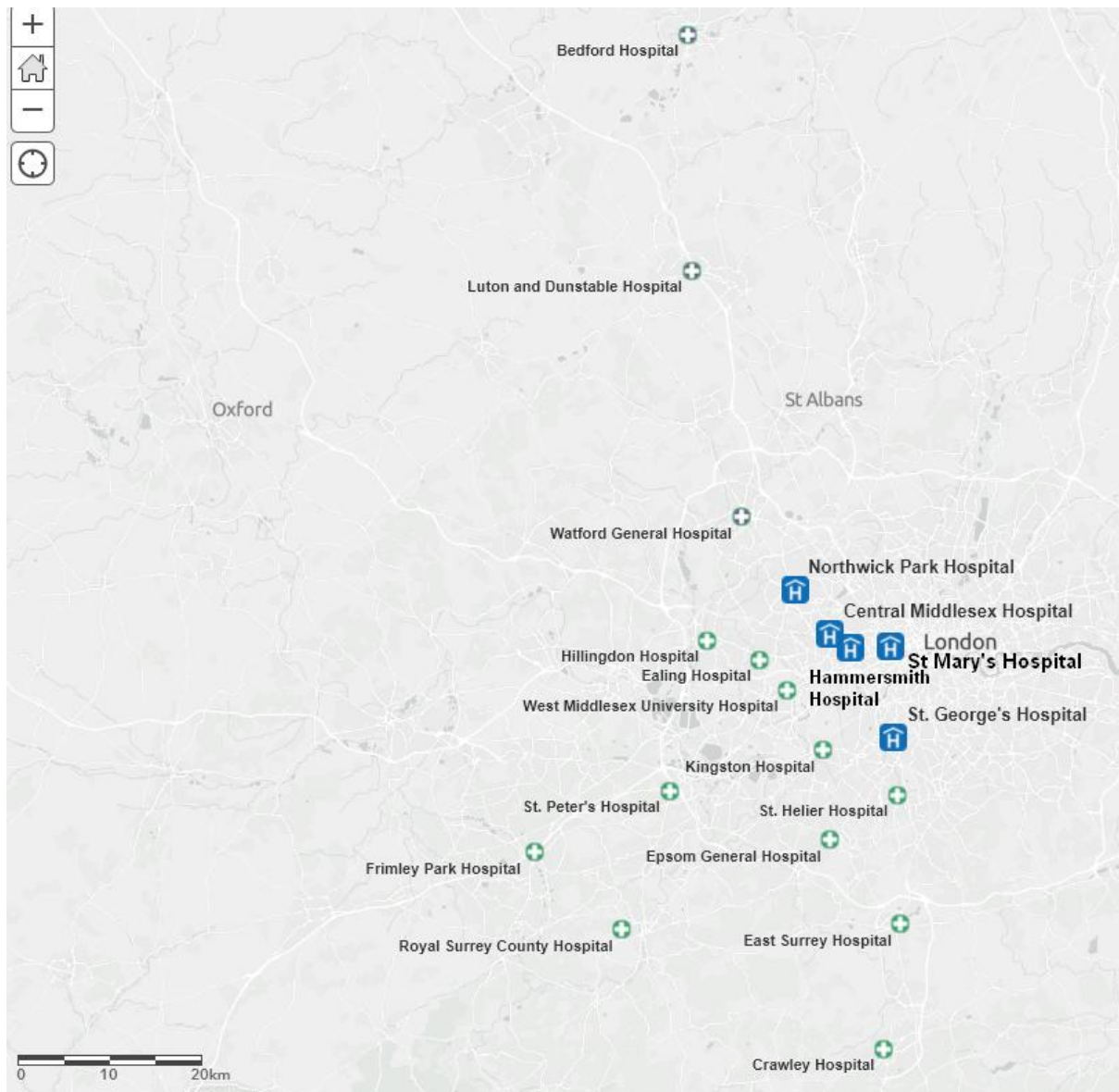
Position	Member of Staff	Associated Hospital
Clinical HCC Director	Mark Layton	Imperial College Healthcare NHS Trust
Deputy Clinical Network Director	Kofi Anie	London North West University Healthcare NHS Trust
HCC Coordinator	Ralph Brown	Imperial College Healthcare NHS Trust
HCC Senior Data Manager	Cindy Hong	Imperial College Healthcare NHS Trust
PPV Liaison	Georgia Adebawale	Imperial College Healthcare NHS Trust
HCC Administrator/Social Media Manager	Eniola Kuseju	Imperial College Healthcare NHS Trust
HCC Practice Development Nurse	Jomcy Pyli	Imperial College Healthcare NHS Trust
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	Keisha Osmond-Joseph	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

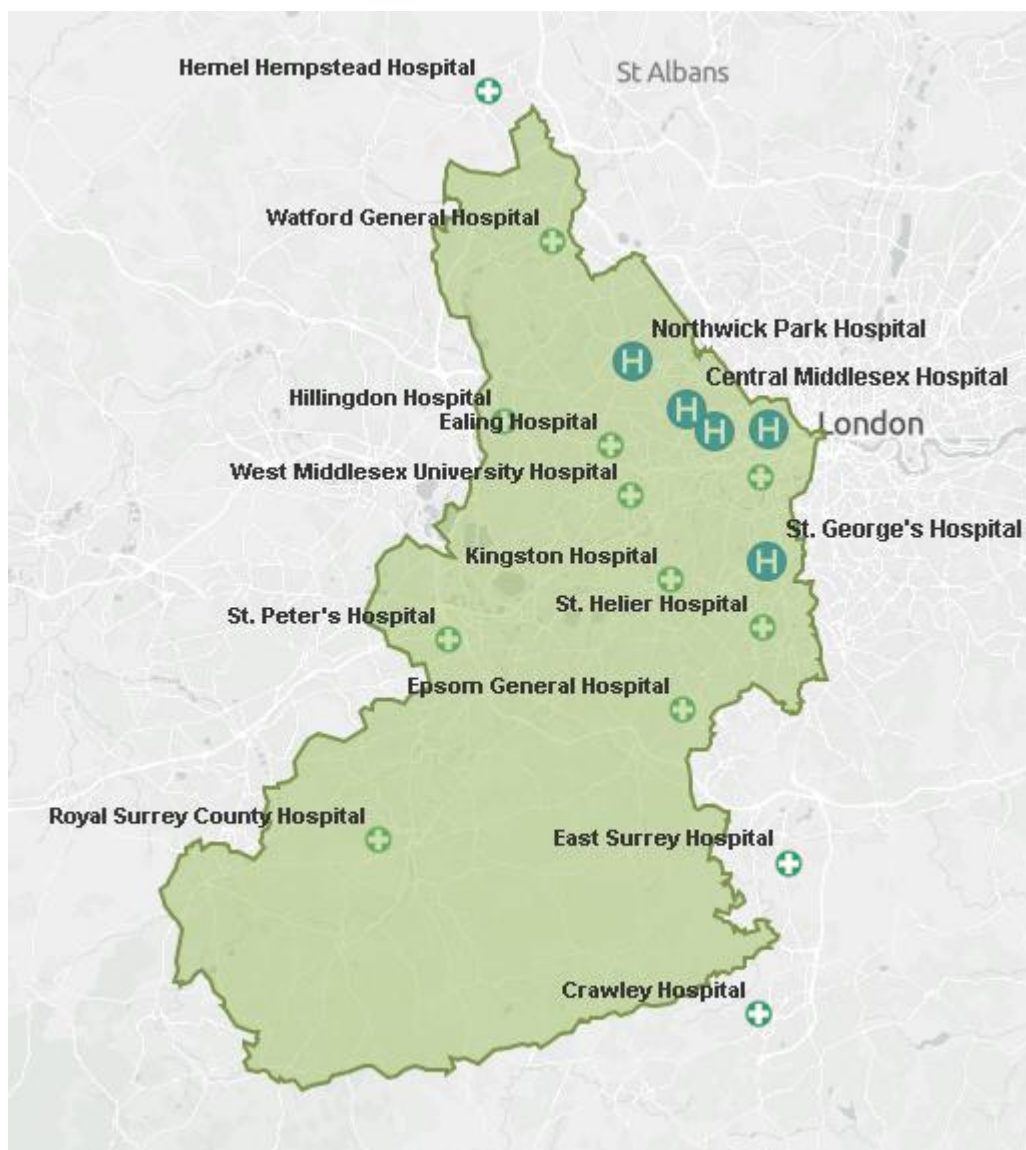
Adult Guidelines Sub group lead	Mamta Sohal	Imperial College Healthcare NHS Trust
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Key Positions within the Network continued

Position	Person	Title
Patient/Carer representatives	Patrick Ojeer	Chair of the Patient and Public Voice group
	Sonia Meikle	Vice chair of the Patient and Public Voice group
	Ade Sawyer	Vice chair of the Patient and Public Voice group

Appendix 5-Maps of the HCC





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

Appendix 6- HCC MDT 2024/25 attendance

MDT Attendance	Wednesday	Friday	Wednesday	Wednesday	Friday	Wednesday	Wednesday	Friday	Wednesday	Friday	Wednesday
	19.03.2025	28.02.2025	29.01.2025	18.12.24	15.11.24	16.10.2024	04.09.2024	19.07.2024	19.06.2024	17.05.2024	17.04.2024
Cases	6	8	3	7	3	9	15	8	8	10	3
Attendance	33	29	34	36	28	29	43	34	35	30	22
<u>Job Types</u>											
Haematology Consultants	10	8	7	9	8	7	13	12	9	10	7
Paediatric Haematology and General Paediatric Consultants	3	4	3	3	4	4	7	3	6	2	1
SpRs/Trainee Doctors	1		1		1	3		3	2	2	
Nursing Staff	14	11	14	11	9	8	9	8	8	6	6
Psychologists		1	1	1			1			1	1
Other Allied Health Professionals	4	5	8	12	6	7	13	8	10	9	7
<u>SHTs</u>											
Imperial College Healthcare NHS Trust	13	8	12	13	10	11	12	12	12	7	8
London North West University Healthcare NHS Trust	4	8	4	3	4	3	7	5	2	7	2
St George's University Hospitals NHS Foundation Trust	2	4	6	6	3	3	5	5	4	3	4
<u>LHTs</u>											
Luton And Dunstable University Hospital NHS Foundation Trust											
Central London Community Healthcare NHS Trust	3	1	3	6	3	4	1	1	4	3	4
Ealing Community Partners											
Kingston Hospital NHS Foundation Trust											
West Hertfordshire Hospitals NHS Trust	1	2	1		3	1	2	1	3	2	1
Royal Surrey								1			
Chelsea and Westminster Hospital NHS Foundation Trust		2	1	1	1	1	1	1	1	1	

Epsom and St Helier University Hospital NHS Trust								1			
Ashford and St Peter's Hospitals NHS Foundation Trust							1				
<u>Other</u>											
Cambridgeshire Community Services NHS Trust											
Buckinghamshire Healthcare NHS Trust					3						
Barts Health NHS Trust											
Whittington Health NHS Trust											
Hounslow And Richmond Community Healthcare NHS Trust											
Royal Cornwall Hospitals NHS Trust											
The Royal Marsden NHS Foundation Trust											
Kings College Hospital NHS Foundation Trust											
Other Trusts	6				1	2	4	1	3	3	1
<u>SPAH and Welsh Partners</u>											
NHS Greater Glasgow and Clyde				1			5	3	1	2	
Cardiff And Vale UHB	3	3	4	2	2	1	5	1	3		1
NHS Grampian				1		1					
NHS Lothian									1	1	
NHS Tayside											
NHSBT		1		2	1	1		2	1	1	1
Aneurin Bevan UHB											
NHS Lanarkshire											

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	15		15
St Mary's Hospital- Imperial College Healthcare NHS Trust		4	4
Whittington/St Mary's Imperial College Healthcare NHS Trust Joint case			
Buckinghamshire Healthcare NHS Trust/Imperial College Healthcare Trust Joint case			
Total Imperial			
St George's University Hospitals NHS Foundation Trust	19	9	28
London North West University Healthcare NHS Trust, Northwick Park Hospital	17	1	18
LHT			
West Middlesex Hospital			
West Hertfordshire Hospital NHS Trust	2	1	3
SPAH			
Glasgow Royal Infirmary			
Royal Hospital for Children, Glasgow			
ARI, Aberdeen			
RHSC Edinburgh			
Ninewells Hospital Dundee			
Welsh Centres			
Noah's Ark Children's Hospital for Wales, Cardiff and Vale UHB			
Cardiff and Vale UHB			
Cardiff CAVUHB			
Cardiff UHW		2	2
	59	21	80

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

West London HCC Training Day, 15.Jan.25

Time	Minutes	Content	Speaker/Facilitator
10:00 – 10:15	15 mins	Welcome and Introduction	Morning session Chair: Prof Mark Layton
10:15 – 10:45	30 mins	<u>Managing an acute Sickle Cell Crisis</u>	Afo Arigbe (Clinical Nurse Specialist, Imperial College Healthcare NHS Trust) and Caroline Cheo (Clinical Nurse Specialist, Imperial College Healthcare NHS Trust)
10:45 – 11:15	30 mins	<u>Understanding chronic pain</u>	Dr Jeremy Anderson (Consultant Clinical Psychologist for Haemoglobinopathies, Imperial College Healthcare NHS Trust) /St Georges Pain management team- Rebecca McLoughlin (Specialist Haemoglobinopathy physiotherapist, St George's University Hospitals NHS Foundation Trust)
11:15 – 11:30		Coffee	
11:30 – 12:30	1 hr	<u>Equality Diversity and inclusion in the workplace</u>	Nana Boyake (Equity and Inclusion Lead, Imperial College Healthcare NHS Trust)
12:30 – 13:30		Lunch/ networking	

			Afternoon session Chair: Dr Kofi Anie
13:30 – 14:05	35 mins	<u>Sickle Cell Disease: a sociocultural perspective</u>	Dr Kofi Anie (Consultant Clinical Psychologist, London North West University Hospitals NHS Trust)
14:05 – 14:40	35 mins	<u>Management of iron overload</u>	Dr Asad Luqmani (Consultant Haematologist, Imperial College Healthcare NHS Trust)
14:40 – 15:15	35 mins	<u>Current Treatment Landscape in Sickle Cell Care</u>	Dr Steven Okoli (Consultant Haematologist, Imperial College Healthcare NHS Trust)
15:15 – 15:30		Break	
15:30 – 16:00	30 mins	<u>Ophthalmology and Sickle Cell</u>	Dr Evelyn Mensah (Consultant Ophthalmologist London North West University Hospitals NHS Trust)
16:00 – 16:30	30 mins	<u>Stem Cell Transplant</u>	Prof Josu de la Fuente (Paediatric BMT Programme Director Imperial College Healthcare NHS Trust)
16:30 – 17:00	30 mins	<u>Update on Gene Therapies</u>	Dr Tom Blair Vertex Pharmaceuticals
17:00		End of session	

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

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

Appendix 10- NHP Meeting Attendance

NHP MDT attendance	
24 th April 2024	Josu de la Fuente, Mark Layton,
20 th May 2024	Josu de la Fuente, Kofi Anie, Mark Layton, Elizabeth Rhodes
26 th June 2024	Mark Layton
22 nd July 2024	Kofi Anie, Mark Layton,
28 th August 2024	Kofi Anie,
23 rd September 2024	Josu de la Fuente, Kofi Anie, Mark Layton
23 rd October 2024	Josu de la Fuente, Kofi Anie
25 th November 2024	Josu de la Fuente, Kofi Anie, Mark Layton
18 th December 2024	Asad Luqmani, Kofi Anie, Mark Layton
27 th January 2025	Josu de la Fuente,
26 th February 2025	Asad Luqmani, Kofi Anie, Mark Layton
24 th March 2025	Josu de la Fuente, Kofi Anie, Mark Layton

NHP Business Meetings attendance	
13 th May 2024	Josu de la Fuente, Kofi Anie, Mark Layton, Ralph Brown
13 th November 2024	Josu de la Fuente, Kofi Anie, Mark Layton, Ralph Brown

Appendix 11- Clinical Research within the West London HCC

Trials Open to Recruitment:

Title of Study (Paediatric)	SHT the Study is being run from	Sponsor	PI (Principal Investigator) /Contact details of Lead Clinician(s)	Status of the Trial
CLIMB - Thal – 111 A Phase 1/2 study of the safety and efficacy of a single dose of autologous CRISPR-Cas9 Modified CD34+ human hematopoietic stem and progenitor Cells (CTX001) in subjects with transfusion-dependent β thalassemia	Imperial College Healthcare NHS Trust	CRISPR Therapeutics/VERTEX	Prof Josu de la Fuente	Paused during Covid-19 surges, other than enrolled patients 18 to 35 years closed to recruitment, but there may be expanded recruitment from April. Open 12 to 17 years and expected to open later on in the year 4 to 11 years
CLIMB - SCD -121 A Phase 1/2 study of the safety and efficacy of a single dose of autologous CRISPR-Cas9 Modified CD34+ human hematopoietic stem and progenitor Cells (CTX001) in subjects with SCD	Imperial College Healthcare NHS Trust	CRISPR Therapeutics/VERTEX	Prof Josu de la Fuente	Paused during Covid-19 surges, other than enrolled patients Open 12 to 35 years of age. Finalising apheresis arrangements for children and young people.
CTX001 – 131 Long-term follow up study (2 to 15 years) of haemoglobinopathy patients having had CTX001	Imperial College Healthcare NHS Trust	CRISPR Therapeutics/VERTEX	Prof Josu de la Fuente	Open Remained open during Covid-19 surges
APL2-PNH-209 An open-label, single-arm, phase 2 study to evaluate the safety, pharmacokinetics, and biologic activity of pegcetocoplan in pediatric	Imperial College Healthcare NHS Trust	Apellis	Prof Josu de la Fuente	12 to 17 years.

patients with PNH				
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 (Adults)	SHT the Study is being run from	Sponsor	PI (Principal Investigator) /Contact details of Lead Clinician(s)	Status of the Trial
REDRESS: A multi-centre open randomised controlled trial to assess the effect of related haplo-donor haematopoietic stem cell transplantation versus standard of care (no transplant) on treatment failure at 24 month in adults with severe sickle cell disease	Imperial College Healthcare NHS Trust		Dr Steven Okoli	Actively recruiting. 1 patient received transplant, 3 others randomised into the recruitment arm. 1 patient in screening.
NIHR BIORESOURCES: Improving Black Health Outcomes	Imperial College Healthcare NHS Trust	NIHR/Genomics England	Dr Steven Okoli	Open to recruitment
FERVENT-1 (R7999-BTHAL-2350): A Phase 2, Two-Part, Randomized, Double-Blind, Placebo-Controlled, Multicentre Study To Evaluate The Efficacy, Safety, And Tolerability Of Subcutaneously Administered REGN7999 (TMPRSS6 inhibitor) In Participants With Iron Overload Due To Non-Transfusion Dependent B-Thalassemia	Imperial College Healthcare NHS Trust	Regeneron	Prof. Mark Layton	Open to recruitment
Hibiscus 2: A global phase 3, randomised, double-blind and placebo-controlled study evaluating the efficacy and safety of etavopivat in adolescents and adults with sickle cell	Imperial College Healthcare NHS Trust	Novo-Nordisk	Prof. Mark Layton	Open to recruitment

disease				
Floral Study: An open-label, multi-centre, rollover study to characterise long-term safety and efficacy of Etavopivat in adults and children who have sickle cell disease or thalassemia and have completed a treatment period in an Etavopivat study. Long term extension of PURPOSE.	Imperial College Healthcare NHS Trust	Novo-Nordisk	Prof. Mark Layton	Open to recruitment

Trials In Long term Follow-up

Title of Study	SHT the Study is being run from	Sponsor	PI (Principal Investigator) /Contact details of Lead Clinician(s)	Status of the Trial
Title of Study (Adults)	SHT the Study is being run from	Sponsor	PI (Principal Investigator) /Contact details of Lead Clinician(s)	Status of the Trial
Agios 10: A study to determine the efficacy safety pharmacokinetics and pharmacodynamics of AG-348 in adult participants with non-transfusion-dependent thalassaemia	Imperial College Healthcare NHS Trust	Agios	Prof Mark Layton	Closed to recruitment, patients on long term follow up.
AG348-C-017- A Phase 3, Double-blind, Randomized, Placebo-Controlled, Multicenter Study Evaluating the Efficacy and Safety of Mitapivat in Subjects With Non–Transfusion-Dependent Alpha- or Beta-Thalassemia (ENERGIZE)	Imperial College Healthcare NHS Trust	Agios	Prof Mark Layton	Closed to recruitment, patients on long term follow up.

AG348-C-018-A Phase 3, Double-Blind, Randomized, Placebo-Controlled, Multicenter Study Evaluating the Efficacy and Safety of Mitapivat in Subjects With Transfusion-Dependent Alpha- or Beta-Thalassemia (ENERGIZE-T)	Imperial College Healthcare NHS Trust	Agios	Prof Mark Layton	Closed to recruitment, patients on long term follow up.
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	Closed to recruitment, patients on long term follow up.

Studies in Set-up

Title of Study	SHT the Study is being run from	Sponsor	PI (Principal Investigator) /Contact details of Lead Clinician(s)	Status of the Trial
CSL889-2001: A Phase 2 / Phase 3, Multicenter, Randomized, Multiple-Dose, Double-Blind, Placebo-Controlled Adaptive Study to Evaluate the Safety, Efficacy and Pharmacokinetics of CSL889 in Adults and Adolescents with Sickle Cell Disease during Vaso-Occlusive Crisis.	Imperial College Healthcare NHS Trust	Behring LLC	Dr Asad Luqmani	Study in set up
GBT021601: A Phase 2/3 Randomized, Multicenter Study of GBT021601 Administered Orally to Participants with Sickle Cell Disease and an Open-Label Pharmacokinetics Study in Pediatric Participants with Sickle Cell Disease	Imperial College Healthcare NHS Trust	GBT	Dr Steven Okoli	Study in set up

Paed Voxelotor study	Imperial College Healthcare NHS Trust	GBT	Dr Kirstin Lund	
A multicentre trial evaluating the efficacy and safety of oral decitabine- tetrahydrouridine (NDec) in patients with sickle cell disease (ASCENT 1)	London North West University Healthcare NHS Trust	Novo Nordisk	Dr Muhsin Almusawy	Trial currently recruiting
Phase IB study of Crovalimab in the management of Acute Vaso-Occlusive Crises in Sickle Cell Disease (CROSSWALK SCD)	London North West University Healthcare NHS Trust	Roche	Dr Muhsin Almusawy	Trial currently recruiting
DiSC-ELEVEN: Digital Sickle Cell Disease Data Platform and Wearable Device Pilot Project	London North West University Healthcare NHS Trust	Sanius Health	Dr Kofi Anie	Data collection ongoing
CSL889-2001: A Phase 2 / Phase 3, Multicenter, Randomized, Multiple-Dose, Double-Blind, Placebo-Controlled Adaptive Study to Evaluate the Safety, Efficacy and Pharmacokinetics of CSL889 in Adults and Adolescents with Sickle Cell Disease during Vaso-Occlusive Crisis.	Imperial College Healthcare NHS Trust	Behring LLC	Dr Asad Luqmani	Study in set up
GBT021601: A Phase 2/3 Randomized, Multicenter Study of GBT021601 Administered Orally to Participants with Sickle Cell Disease and an Open-Label Pharmacokinetics Study in Pediatric Participants with Sickle Cell Disease	Imperial College Healthcare NHS Trust	GBT	Dr Steven Okoli	Study in set up

Studies/Trials closed

Title of Study	SHT the Study is being run from	Sponsor	PI (Principal Investigator) /Contact details of Lead Clinician(s)	Status of the Trial
Adherence to Iron Chelation Therapy with Deferasirox or Desferrioxamine in Thalassaemia and Sick Cell Disease.	London North West University Healthcare NHS Trust	Novartis Pharmaceuticals UK. /LNWH NHS Trust.	Dr Kofi Anie	Study was completed
Study to evaluate the effect of Voxelotor administered orally to patients with sickle cell disease	Imperial College Healthcare NHS Trust	Sponsor Global Blood Therapeutics	Prof Mark Layton	Closed
Agios 3: A study evaluating the efficacy and safety of AG348 in regularly transfused adult participants with pyruvate kinase deficiency	Imperial College Healthcare NHS Trust	Agios	Prof Mark Layton	Study closed, patients on compassionate access program.
Agios 11: A study evaluating the efficacy and safety of AG348 in not regularly transfused adult participants with pyruvate kinase deficiency Sponsor	Imperial College Healthcare NHS Trust	Agios	Prof Mark Layton	Study closed, patients on compassionate access program.
Study to assess the effect of long-term treatment with GBT440 in participants who have completed treatment in study GBT440-031	Imperial College Healthcare NHS Trust	Global Blood Therapeutics	Prof Mark Layton	Study Closed
A Phase 2b, double-blind, randomised, placebo-controlled, multicentre study to assess the efficacy and safety of VIT-2763 multiple doses in adults with sickle cell disease (ViSion Serenity)	Imperial College Healthcare NHS Trust	Vifor	Dr Asad Luqmani	Study Closed

COVID-19 in patients with inherited anaemias in England	NHP wide	Imperial College Healthcare NHS Trust	Prof Josu de la Fuente Prof Mark Layton	Study closed
AG348-C-015 Pyruvate Kinase Deficiency Global Longitudinal Registry: Patient-Reported Outcomes linked to 008	Imperial College Healthcare NHS Trust	Agios	Prof Mark Layton	Study closed
Title of Study	SHT the Study is being run from	Sponsor	PI (Principal Investigator) /Contact details of Lead Clinician(s)	Status of the Trial
TAPS2 (Transfusion Antenatally in Pregnant Women With SCD) - A Feasibility Trial of Serial Prophylactic Exchange Blood Transfusion in Pregnant Women With Sickle Cell Disease Aiming to Improve Maternal and Infant 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) https://clinicaltrials.gov/ct2/show/NCT03975894	Imperial College Healthcare NHS Trust	Guy's and St Thomas' NHS Foundation Trust	Dr Mamta Sohal	Study is now closed to recruitment.
CSL889_1001 - A Phase 1, Multi-Center, Open-Label, Single Ascending Dose Study to Evaluate the Safety, Tolerability, and Pharmacokinetics of CSL889 in Adult Patients with Stable Sickle Cell Disease	Guy's and St Thomas	Behring LLC	Prof Mark Layton	We are a PIC site; phase 2/3 now in set up.
A randomised, single-blind, placebo-controlled, Phase 1b single ascending and multiple dose first-in-man study in adult patients with non-transfusion-dependent beta-thalassaemia or low risk myelodysplastic syndrome to investigate the	Imperial College Healthcare NHS Trust		Dr Asad Luqmani	SLN124 study is no longer active at Hammersmith Hospital

safety, tolerability pharmacokinetic and pharmacodynamic response of SLN124				
A randomized, placebo-controlled, Phase 2 Study to evaluate the safety and pharmacodynamics of once-daily oral IW-1701 in patients with stable sickle cell disease	Imperial College Healthcare NHS Trust	Cyclerion	Dr Mamta Sohal	Trial has closed 20.07.2020
CATS: Children and Adolescents Telehealth in Sickle Cell.	London North West University Healthcare NHS Trust	Roald Dahl's Marvellous Children's Charity./ LNWH NHS Trust.	Patricia Kiilu	Study Is Now Closed
A Phase II multicentre randomized open label two arm study comparing the effect of crizanlizumab + standard of care to standard of care alone on renal function in sickle cell disease patients ≥ 16 years with chronic kidney disease due to sickle cell nephropathy (STEADFAST)	Imperial College Healthcare NHS Trust	Novartis	Dr Asad Luqmani	Update: The study was closed early by the sponsor due to recruitment challenges. They decided to stop recruitment due to difficulties identifying the protocol specified patient population and high screen failure rate (57%). We managed to recruit one patient before recruitment was stopped. The patient is not on treatment anymore. Study closed April 2023
A Phase 2a, Randomized, Open-Label Study to	Imperial College Healthcare NHS		Dr Steven Okoli	Study abandoned by Sponsor

Evaluate Multiple Dosing Regimens of Subcutaneous ALXN1820 in Adult Patients with Sickle Cell Disease	Trust			
Title of Study	SHT the Study is being run from	Sponsor	PI (Principal Investigator) /Contact details of Lead Clinician(s)	Status of the Trial
Adherence to Iron Chelation Therapy with Deferasirox or Desferrioxamine in Thalassaemia and Sickle Cell Disease.	London North West University Healthcare NHS Trust, Recent Studies in Sickle Cell	Novartis Pharmaceuticals UK. /LNWH NHS Trust.	Dr Kofi Anie	Study was completed
Study to evaluate the effect of Voxelotor administered orally to patients with sickle cell disease	Imperial College Healthcare NHS Trust	Sponsor Global Blood Therapeutics	Prof Mark Layton	Closed
TAPS2 Transfusion Antenatally in Pregnant Women With SCD (TAPS2) https://clinicaltrials.gov/ct2/show/NCT03975894	Imperial College Healthcare NHS Trust	Guy's and St Thomas' NHS Foundation Trust	Dr Mamta Sohal	Study is now closed to recruitment.
CSL889_1001 - A Phase 1, Multi-Center, Open-Label, Single Ascending Dose Study to Evaluate the Safety, Tolerability, and Pharmacokinetics of CSL889 in Adult Patients with Stable Sickle Cell Disease	Guy' s and St Thomas	Behring LLC	Prof Mark Layton	We are a PIC site; phase 2/3 now in set up.
Title of Study	SHT the Study is being run from	Sponsor	PI (Principal Investigator) /Contact details of Lead Clinician(s)	Status of the Trial

A randomised, single-blind, placebo-controlled, Phase 1b single ascending and multiple dose first-in-man study in adult patients with non-transfusion-dependent beta-thalassaemia or low risk myelodysplastic syndrome to investigate the safety, tolerability pharmacokinetic and pharmacodynamic response of SLN124	Imperial College Healthcare NHS Trust		Dr Asad Luqmani	SLN124 study is no longer active at Hammersmith Hospital
A randomized, placebo-controlled, Phase 2 Study to evaluate the safety and pharmacodynamics of once-daily oral IW-1701 in patients with stable sickle cell disease	Imperial College Healthcare NHS Trust	Cyclerion	Dr Mamta Sohal	Trial has closed 20.07.2020