



**West London
Haemoglobinopathy Coordinating Centre**

A partnership between



West London Haemoglobinopathy Coordinating Centre for Sickle Cell Disease

Standard Operating Procedure

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0.1	Ralph Brown	06/07/2020	First Draft
1.0	Ralph Brown	06/10/2021	Finalised first Standard Operating procedure
2.0	Ralph Brown	17/10/2022	Additon of bi-annual HCC Business meeting Minor amendments to the document reflecting changing roles and changes to nomeclature of meetings

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1.0 Summary

The West London HCC led by Imperial College Healthcare NHS Trust (ICHT) is responsible as the Haemoglobinopathy Coordinating Centre (HCC) to support the provision of specialist and non-specialist haemoglobinopathy services to adults and children with Sickle Cell Disease (SCD). ICHT works in collaboration with London North West University Healthcare NHS Trust and St George's University Hospitals NHS Foundation Trust covering Sickle Cell networks across West London to provide expert opinion and management for complex patients. This includes i) governance to improve access to services and expertise; and ii) leadership to improve patient experience and outcome.

2.0 Introduction

The West London HCC's service ethos is to provide a high-quality service, in line with the requirements laid out by the Specialist Commissioning Board, offering a caring, adaptable and patient centred approach to management and long-term care of patients with Sickle Cell Disease (SCD), and to build on and spread best practice throughout the West London HCC. Practice across the West London HCC will be subject to peer review and compliance with the Quality Standard for Health Services for People with Haemoglobin Disorders V4, 2018.

3.0 Purpose

The West London HCC's overall aim is to reduce levels of morbidity and mortality and improve the experience of all Sickle Cell Disease (SCD) patients by reducing inequities and improving timely access to high quality expert care. The West London HCC is a crucial component in delivering the requirements laid out by the Specialist Commissioning Board and aims to provide strategic direction for the network and oversee the implementation of best practice for Sickle Cell Disease (SCD) patient care.

The objectives and responsibilities (see also Section 8) of the West London HCC are to:

- Identify the current and future needs of haemoglobinopathy patients.
- Raise the profile and importance of good haemoglobinopathy care throughout the network, sharing knowledge within the network in providing appropriate care for patients including transfer of patients where appropriate.
- Support hospitals within the network in securing appropriate staffing as set out by the Quality Standards, facilitating work force planning and implementation to accommodate the changing needs of the service.
- Support hospitals within the network in accessing and developing training and documentation and evidence of the above thus adhering to the Quality Standards.
- Monitor progress against the peer review Quality Standards.
- Support provision of a high quality service to patients managed in the linked hospitals across the network, by sharing of clinical guidelines across the network, and by seeing each individually at least once each year, for a comprehensive annual review, and by offering advice, support and training to health care professionals running the local services.
- Co-ordinating a central data management role, ensuring and advising in-putting patient information on the National Haemoglobinopathy Register (NHR) at specialist and local centres.
- Publishing guidelines on the care and treatment of Sickle Cell Disease.

- Increasing the understanding of a patient's experience of Sickle Cell via patient forum/awareness events.
- Offer education, awareness and learning for patients, their carers and the public.
- Agree and implement an annual programme of audit and research across the network.
- Collect, analyse and learn from performance, research and audit data ensuring benefits are imbedded in on-going service improvement.
- Provide evidence of practice to external and internal bodies as required.

4.0 Responsibilities

Key roles	Responsibilities
HCC Clinical Director	Overall lead, driving the HCC strategy and ensuring delivery against all aspects of the service specification. Responsible for leading the HCC in achieving the stated aims set out by the NHSE.
HCC Deputy Clinical Director	Supporting the Clinical HCC Director in all facets of HCC business with major contribution to clinical direction and engagement and deputise for the director when required
HCC Manager	Will act as coordinator/organiser for the HCC activities and be the lead for development and delivery of communication, network meetings and service support with a key focus on data collection and management, they will also be a key component in the delivery of operational management and governance across the network
HCC Administrator	The HCC Administration Assistant is responsible for assisting the HCC manager in the operational management and development of the West London Haemoglobinopathy Coordinating Centre (HCC) in particular with the management of education sessions and communications via the HCC website and social media channels
HCC Data Management (comprising of SHT teams)	Ensuring data collection and entry at a Trust and national level
HCC Training and Education Leads	The HCC training and education leads will be involved in the production of a training and development plan for all healthcare staff in the network and the on-going support of training and education activities through the HCC. The HCC training and education leads will also attend the Training and Education Sub-group and will complete along with the HCC Manager any actions derived from those discussions.
HCC MDT Leads	The HCC MDT Leads will work in consort via the steering group will make decisions in conjunction with the HCC Clinical Director and deputy about the direction of the HCC and work on how the stipulations on the outcomes from NHSE can be achieved. They will also set out the structure of the MDT meetings and be responsible for response to referrals. The Leads will also direct and guide a network MDT for elective queries and discussion of complex patients
HCC Research leads	The HCC research leads will contribute towards the sharing of Clinical trials access across the HCC and work on deriving research opportunities from the data accrued through the HCC, they will also direct and guide the network research portfolio

TCD lead	The TCD lead will advise the HCC on the best approach in ensuring all eligible patients receive Transcranial Doppler scans via training, organisation of patient pathways, etc.
Paediatric guidelines lead	The paediatric guideline lead will work on the standardisation and distribution of guidance related to adult sickle cell patients across the HCC, they will also haed up the guidelines sub-group
Adult guidelines lead	The adult guideline lead will work on the standardisation and distribution of guidance related to adult sickle cell patients across the HCC, they will also haed up the guidelines sub-group
SW London Network Clinical SHT Representatives	Ensure a two-way exchange of information on service performance and service issues between the HCC and Trust
NWLSCTN Clinical SHT Representative	Ensure a two-way exchange of information on service performance and service issues between the HCC and Trust
Psychology representative	Ensure the discipline of clinical psychology is reflected in service development and patient care
LHT representatives	Ensure a two-way exchange of information on service performance and service issues between the HCC and Trust

Committee	Basic discription
HCC Steering Group Meeting	Provision of clinical leadership and to make all decisions relating to the HCC
Operational Meeting	This meeting serves to review the ongoing operations of the HCC on a week by week basis, the attendees comprise of the Clinical Lead, Deputy Lead and HCC Manager with other invited to join when appropriate
MDT Leads Sub-group	This meeting is set up on an ad-hoc basis to discuss the wor of the HCC MDT and any organisational and governance issues associated with the running of the MDT
Paediatric Sub-group	The purpose of this subgroup is to work on the Paediatric clinical guidelines of the HCC, work on development of tertiary pathways, to work on paediatric education and to serve as a forum for the sharing of best practice between the Paediatric clincians within the HCC
Adult Guidelines Sub-group	The purpose of this subgroup is to work on the adult clinical guidelines of the HCC, work on development of tertiary pathways, to work on adult education and to serve as a forum for the sharing of best practice between the adult clincians within the HCC
Training and Education Sub-group	This subgroups function is to organise the teaching schedule of the HCC and to get education sessions set-up, the group will also find out from HCC members areas of education they would like to have more information on
Data Management Sub-group	The aim of this subgroup is to create reporting mechanisms for data that has been requested by NHSE for the HCC and the SSQD
Nurses, Midwives and counselling Health Visitors Subgroup	The group provides a forum for sharing knowledge, good practice, education and development of specialist nurses, clinical nurse specialists, specialist midwives and new born counselling health visitors (SpNMHV) subgroup members of the West London Sickle HCC.

HCC Business meeting	This forum allows for the dissemination of information about the activities of the HCC and updates about the future activities/direction of the HCC to all members of the HCC
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5.0 Scope

The West London HCC will set up and lead a networked approach for haemoglobinopathy services supporting both adults and children with Sickle Cell Disease. The geographical reach of the West London HCC for Sickle Cell Disease covers North West, West and South West London extending across to cover Buckinghamshire, Berkshire and Surrey. Please see Appendix 12- Maps of the MDT

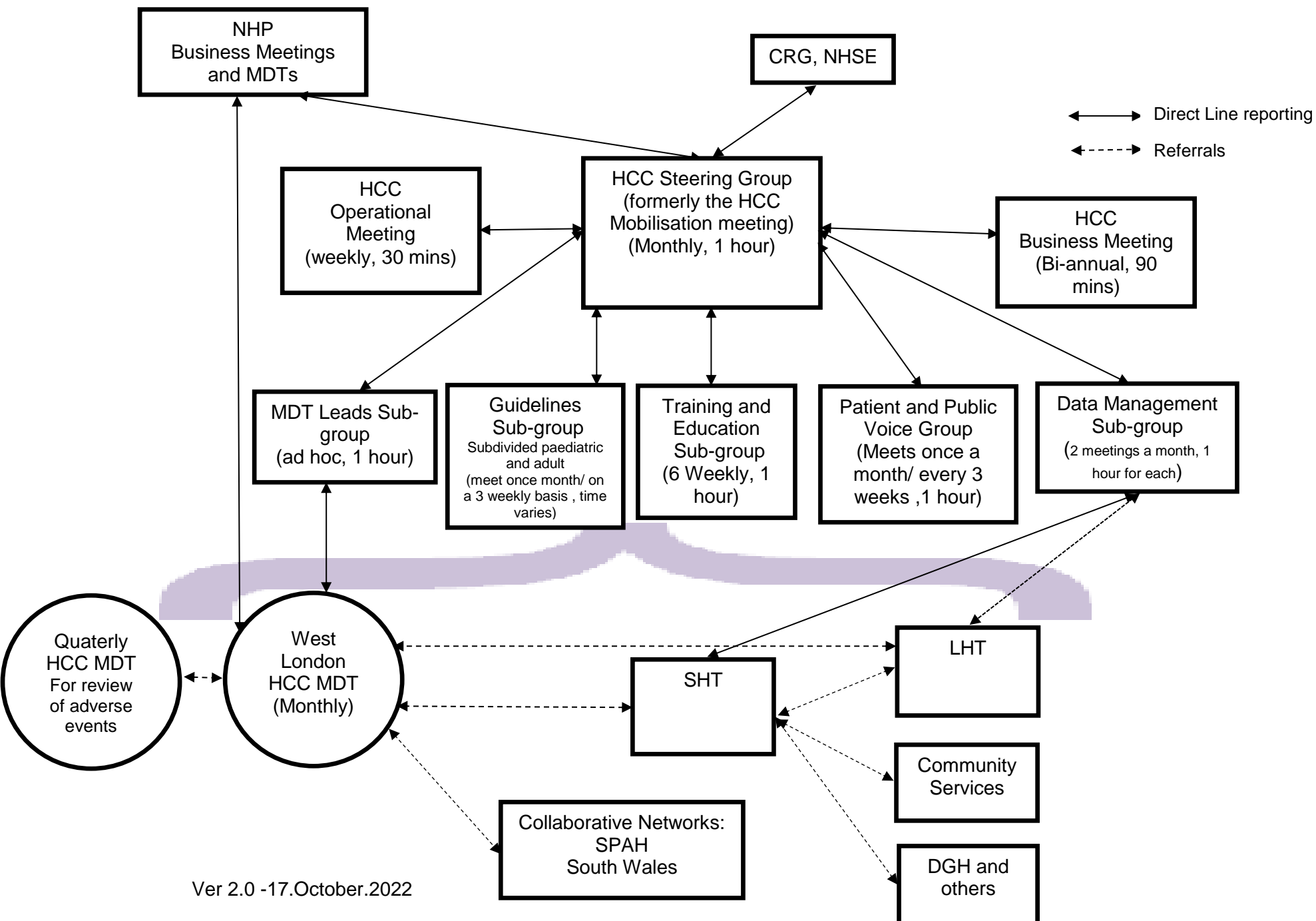
6.0 Definitions

The following defined terms are used in this standard operating procedure:

CNS	Clinical Nurse Specialist
CRG	Clinical Reference Group
HCC	Haemoglobinopathy Coordinating Centre
HCC GC	HCC Governance Committee
LHT	Local Haemoglobinopathy Team
MDT	Multi-Disciplinary Team
M&M	Morbidity and Mortality
NHP	National Haemoglobinopathy Panel
NHSE	NHS England
NHR	National Haemoglobinopathy Register
NWLSCTN	North West London Sickle Cell Thalassaemia Network
RCN	Royal College of Nursing
SCD	Sickle Cell Disease
SHT	Specialist Haemoglobinopathy Team
SSQD	Specialised Services Quality Dashboard
SW London Network	South West London
TCD	Trans Cranial Doppler

7.0 Organisation of the West London HCC

Please see the figure below/across the page which shows how the different meetings and groups within the HCC interact:



7.1 HCC Steering Group

Frequency: Once a month

Duration: 1.5 Hours/1 hour depending on availability

The HCC Steering Group is the central steering committee of the West London HCC and is responsible for the overview of management, finance and governance of the HCC; as well as for keeping an overview of the functioning of the network arrangements. The meeting is updated via the reports from the operational meeting on management, finance and governance of the HCC; as well as for keeping an overview of the functioning of the network arrangements. The HCC Management Meeting reports to the National Haemoglobinopathy Panel (NHP) and commissioners, and forms the primary contact for the NHP, NHS England and the Clinical Reference Group (CRG). The HCC Steering group is responsible for the annual HCC report.

The members of the HCC Management Meeting will comprise: Clinical Director, Deputy Clinical Director, HCC Network Manager, HCC Audit Lead, MDT Sub group lead, Guidelines Sub-group lead, Training and Education lead, HCC Data Lead, LHT reps (ask each SHT to invite LHT reps- mix of adult and paed (not both)), Patient and Public Voice Group representative/s. Other members from national patient bodies, professional bodies and other clinical specialists may be identified and invited as appropriate.

The HCC Steering Group meets on a monthly basis.

A special version of the meeting will be held on a bi-annual basis where sharing network-wide matters, achievements, results and ambitions will occur. These versions of the meeting will be open to all stakeholders who will be encouraged to attend.

7.2 HCC Operational Meeting

Frequency: Once a week initially, twice a month post the set-up period

Duration: 30 minutes

The HCC Operational Meeting is the main body for monitoring and overseeing the functions of the HCC and directing compliance with clinical standards and reports on a frequent basis.

The members of the Operational Meeting will comprise; HCC Clinical Director, HCC Deputy Clinical Director, HCC Manager and further administrative posts, other HCC representatives as and when required.

The Operational Meeting meets once a week initially and twice monthly after an initial agreed period.

7.3 Patient and Public Voice Group

Frequency: One a month/ Once every three weeks depending on availability

Duration: 1 hour

The Patient and Public voice group will act as the patient forum for the HCC and will feed into the HCC Steering group via a nominated representative. The group will comprise of a patient representatives from Paediatric and Adult services of the 3 SHTs with a view that adolescent

patient representatives may also be asked to attend the group at future meetings. The Patient and Public voice group will lead on decisions made by the HCC around education and engagement of the patient population and patient involvement in the aims and running of the HCC.

The HCC Deputy Clinical Director and the HCC Manager will attend this meeting with the patient representatives, other HCC representatives will be present as and when required.

7.4 MDT Leads Sub-group

Frequency: Ad hoc/ Matters Arising

Duration: 1 hour

The MDT Leads Sub-group is the body for discussions about the structure, running and parameters of the HCC MDT meetings. The body will give instructions around inclusion/exclusion criteria for cases being referred to the MDT and make sure that outcome of cases are being recorded. The MDTs leads subgroup will also organise the Rota of HCC members to answer queries about cases submitted to the MDT email address.

The Sub-group will comprise of the HCC Network Manager (supporting in an administrative capacity) and the respective MDT leads from the SHTs.

7.5 Adult/Paediatric Guidelines Sub-groups

Frequency: Adult- Once every 3 weeks/ Paediatric- varies normally Once a Month

Duration: Adult 1 hour/ Paediatric- varies between 1 hour and 2 hours

The aim of the HCC Guidelines Sub-groups is to produce standard guidelines on the treatment of Sickle Cell Disease that will be distributed across the HCC specialist/non-specialist teams and available for all. The sub group are divided between Paediatric and Adult teams depending on the specific set of guidelines being worked on.

The Groups also act as a forum to work on; the development of tertiary pathways across the HCC, the development of individual education sessions and to serve as a forum for the sharing of best practice between the clinicians within the HCC

The Sub-group will comprise of the HCC Network Manager (supporting in an administrative capacity) and the respective adult and paediatric Guideline leads from the SHTs.

7.7 Training and Education Sub-group

Frequency: 6 Weekly

Duration: 1 hour

The training and education sub-group will be the main forum for setting the education schedule of the West London HCC and for working out how to deliver sessions to the different groups in the education schedule

The sub group consists of the HCC Training and Education Leads and supporting SHT members along with the HCC Manager (who supports in an administrative capacity)

7.8 Data Sub-group

Frequency: 2 meetings a month

Duration: 1 hour each

The Data Sub-group will work on improving data collection through the HCC members and provide data for reports and presentations required by the HCC Steering Group for presentation the NHSE.

The Data Sub Groups member ship includes; the HCC Data Lead, the HCC Manager, Data Managers and SHT leads when required.

The first meeting of the month (which takes palce on Wednesday mornings) is a forum for the data managers to discuss best practice and any issues they are having with the HCC Manager, who will aim to support/flag to the steering group.

The second meeting will involve ongoing data collection for the previous months activities for the required data submission by NHSE and trought the SSQD for both the SHTs and the HCC. Consultants can attend this meeting optionally in addition to the data managers and HCC Manager who are core attendees.

7.9 West London HCC Daily management

The HCC Manager, additional administrative post, SHT data managers of the West London HCC. Responsibilities include; preparation of paperwork for the HCC Steering Group meeting and the Governance Committee and provide data directly to the Data Sub-group and operational meeting. The daily management is the primary platform for communication with the SHTs and LHTs with regards to non-clinical matters. All clinical matters will be discussed via the West London HCC Multidisciplinary Team Meeting (MDT); see section 10.

7.10 West London HCC Business meeting

Frequency: 2 meetings a year

Duration: 1.5 hour each

This meeting is the point at which the HCC's activites over the the previous 6 months are reviewed and the agenda of the HCC over the forthcoming months is laid out. All members of

the HCC (in particular the LHT leads are invite to the meeting). Due to stipulations by the peer review standards the following sections must be covered in the agenda:

HA-702S:a. Agree network-wide patient and carer information

HA-702S:b. Agree network-wide policies, procedures and guidelines, including revisions as required

HA-702S:c. Agree the annual network education and training programme

HA-702S:d. Agree the annual network audit plan, review results of network audits undertaken and agree action plans

HA-702S:e. Review and agree learning from any positive feedback or complaints involving liaison between teams

HA-702S:f. Review and agree learning from any critical incidents or 'near misses', including those involving liaison between teams

HA-702S:g. Review progress with patient experience and clinical outcomes (QS HA-797) across the network and agree any network-wide actions to improve performance

8.0 The HCC and Local Network Arrangements with the SHTs of the West London HCC

The following defined terms are used in this standard operating procedure:

The West London HCC together with the SHTs will be responsible for:

- Supporting local providers to register all consented patients on the National Haemoglobinopathy Register (NHR).
- Organising a minimum of two meetings a year for all healthcare staff involved in the delivery of care for haemoglobinopathy patients in the defined network.
- Ensuring local and national protocols and pathways are in place.
- Identification of Trans Cranial Doppler (TCD) screening lead who has the responsibility for ensuring the network has adequate numbers of appropriately trained practitioners.
- Ensuring nationally agreed quality assurance requirements are met for local providers including TCD, Magnetic Resonance Imaging and quality review programmes.
- Ensuring NICE guidelines are followed for automated red cell transfusions.
- Working in partnership with NHS Blood and Transplant to ensure adequate supplies of blood with special requirements available in timely manner to meet patient needs.
- HCCs will support local workforce planning and will be able to escalate this to a national level, including the national haemoglobinopathies Clinical Reference Group (CRG).

8.1 Governance and development

Work will be implemented, and decisions affected through a cycle of network-wide meetings, network-wide educational sessions, MDT meetings, the HCC Meeting members and site visits. The HCC Meeting members will comprise patient representatives, alongside clinical and managerial representatives, from all the Trusts within the HCC to maintain ownership and transparency of process. Structure and models of reporting will align with peer review.

The West London HCC will develop a universal policy towards guideline development based on national standards, resulting in all linked hospitals having up to date copies of the approved clinical guidelines for inclusion onto their intranets.

The West London HCC aims to practice evidence-based medicine and be an active participant in the development of clinical guidelines. This will be aligned to leading on a comprehensive and inclusive research portfolio; and the West London HCC will co-ordinate and publicise research trials within its geographical area.

8.1.1 LHT/SHT Catch-ups

The HCC will undertake catch-ups with SHTs and LHTs. Site visits serve the following purposes:

- Introduction and reinforcement of the network structure
- Review of local services in line with peer review parameters
- Data management

Catch-ups may be of an informal nature by the management team to provide local support and education.

8.1.2 Data management

Data management, including recording information on the NHR, is one of the key activities of the network. SHTs should appoint a data manager as part of the specialist commissioning contract, but LHTs will not have an obligation to do so. The HCC management team will support local data managers with a uniform way of recording data and governance information. Also, where SHTs struggle to get information from the LHTs within their network, the HCC will provide support and if necessary, escalate concerns to the commissioners and / or NHP/CRG.

9.0 Education and Training

Education and training will be agreed for the Network in a rolling annual programme of local and central education for all staff within the Network. Different teaching modalities will be utilised to deliver this, as follows:

- 1) Electronic teaching sessions through Microsoft Teams and Zoom
- 2) Face-to-face teaching:
 - Areas with high staff turnover e.g. A&E
- 3) Formal whole/half day training
- 4) Haematology and other speciality training days:
 - Teaching delivered by experts in the field for targeted staff groups e.g. acute medicine
- 5) Network specific training days, with the aim of introducing this to other HCCs:
 - Themed days to complement current national programmes
- 6) E- learning:
 - Enable access to portfolio of remote training options
- 7) Patient education:
 - Local patient support groups, national family days, central repository of information and support contact numbers alongside the teaching provided through Teams and Zoom

The programme will include an awareness and implementation of guidelines and policies covering acute management, escalation policies, effective clinical practice and updates regarding research. In some instances, a complementary breadth of topic coverage at national level will be affected through joint working with other HCCs across the country.

Senior staff members within the West London HCC are keen educators actively participating in education provision. Consultants are trained as educational supervisors and senior nurses regularly supervise junior staff in clinical areas. This will be expanded and made available to all centres in the Network.

The West London HCC will oversee and support the production of a training and development plan for all healthcare staff in its network, organising a schedule for the year to facilitate this. The West London HCC will ensure that, with the right oversight, training, protocols and audit, high quality care can be delivered locally by haematologists, paediatricians, pharmacists, primary care, community services and third sector organisations ensuring that very complex patients can access the expert clinical teams they need. In areas of low prevalence, HCCs responsible for different geographical areas may necessarily work together.

The programme will include acute management, patient management, an overview and update on trials and research. Best practice will be shared and where possible education and training will be delivered on the same occasion for centres within the same geographical region and in collaboration with other Sickle Cell HCCs.

Assessment of programme success aligns to the NHS Outcomes Framework Domains, namely:

- 1) Preventing people from dying prematurely:**
Morbidity & Mortality (M&M) review, audit of acute patient management, quantity and quality of NHR inputs, SSQD
- 2) Enhancing quality of life for people with long-term conditions:**
Patient education days, length of stay audit/frequent attendances, patient feedback and input into care frameworks
- 3) Helping people to recover from episodes of ill-health or following injury:**
Further develop links with community care
- 4) Ensuring people have a positive experience of care:**
Review of patient reported outcomes; A&E education; development of community patients' ability and confidence in self-management
- 5) Treating and caring for people in safe environment and protecting them from avoidable harm:**
M&M review, NHR inputs, SSQD

Members of the Network will be encouraged to attend academic meetings, such as the UK Forum on Haemoglobin Disorders, British Society for Haematology.

10.0 Monitoring and Audit

The West London HCC is required as the HCC for North West, West and South West London, Buckinghamshire, Berkshire and Surrey South Central and South West of England to work collaboratively within the Network to fulfil an annual programme of data collection work. The annual programme of work, endorsed collectively, will include targets and indicators to be monitored, as well as a clinical audit programme.

Targets include:

- a) Number of patients under active care in the HCC at the start of each year
- b) Number of new patients accepted by HCC services during the course of the year:
 - i. Births
 - ii. Transferred from another service
 - iii. Moved into the UK
- c) For babies identified by the screening service:
 - i. Date seen in clinic
 - ii. Date offered and prescribed penicillin
- d) Number of patients under the care of the constituent parts of the HCC who had their comprehensive annual review undertaken and documented in the last year
- e) Number of network patients on long-term transfusion

- f) Number of network patients on chelation therapy
- g) Number of network patients on hydroxycarbamide
- h) Number of paediatric patients (Hb SS and Hb SC) who have had Trans-Cranial Doppler ultrasonography undertaken within the last year
- j) Number of network patients whose care was transferred to another service during the year
- k) Number of network patients who died during the year
- l) Number of network patients lost to follow up during the year

10.1 Clinical Audit

The West London HCC will establish a programme and schedule of clinical audits, such as

- 1) SSQD targets
- 2) Acute pain management (pain audit, ACS management)

Resulting information will be analysed to find if there is any variation between different sites and find the reasons for any variance and fed back to the HCC Steering Group.

These audits will be against national standards. Each Trust representative will contribute information on their individual Trust's haemoglobinopathy service performance and service issues and will feedback from the meeting to their Department and Executives, as necessary. The HCC Steering Group will act as a gateway to escalating any issues to a higher level; for example, commissioning bodies or the Haemoglobinopathy CRG as outlined above. Each SHT will continue to provide service information to the Service Quality Dashboard and to the NHR and this will be monitored by the West London HCC.

The NHR will be a cornerstone of this process. The aim is that it will act as the national repository for patient information and will also host guidelines, protocols and educational materials.

11.0 Multidisciplinary Team Meetings

Where SHTs and LHTs feel they need clinical support for patients with complex needs, they may refer to West London HCC MDT and/or the NHP. West London HCC MDT will offer additional clinical specialist support and specialist advice for the management of very complex patients as part of the regional MDT meetings for non-urgent cases or through the provision of telephone or email advice for outpatient/inpatient care.

An adverse event collation version of the MDT will also be held once a quarter to enable collection of data and review of events within SHTs and LHTs to see if there are trends and learning points that can be worked on.

Process of Referral- Adults

The HCC Network Manager (or deputy) will forward out invitations for the scheduled HCC MDT in advance of the meeting. Included in the invitation will be case referral forms and adverse event report form for the MDT and criteria for referral, referrals to the MDT will be submitted at latest the day before the MDT to allow time for the coordinator to collect the case and circulate the cases in advance to the attendees. A reminder/call for cases will be sent out to clinicians two weeks in advance of the HCC MDT occurring. Patient identifiers should be anonymised. Referrals will be collated, anonymised if further required and a patient list created. The HCC Network Manager (or deputy) will respond to referral email with confirmation that patient is on the list.

Any issues with referrals to be clarified with lead clinician and referring team (e.g. doesn't meet the criteria, information not clear). Referrals that don't meet the criteria will be returned to clinician with a request for clarification. It is incumbent on the clinicians referring that they collect all necessary medical information (scans, results, notes etc.) in advance of presenting the case at the meeting.

The Meeting is chaired by the West London HCC MDT Lead or nominated deputy.

Cases are presented by the referring clinician.

Criteria for patient referrals

The criteria for patients being referred to the MDT are as follows:

Criteria for patient referrals

It is suggested the following cases should be referred to the MDT:

- 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
- Pregnancy complications
- Death

Considerations should be 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

Significant complications (known previously on the NHR as adverse events) to be submitted to the MDT for discussion will be derived from the following categories (please see appendix 1 for full list)

- Cardiorespiratory complications, including:
 - Pulmonary hypertension
 - Severe acute chest syndrome
 - Pulmonary embolism
- Multi Organ Failure, including; Fat embolism syndrome
- Genitourinary complications, including:
 - Acute renal failure
 - Severe Priapism
 - Sickle Nephropathy
- Orthopaedic complications, including:
 - Osteomyelitis/ Septic arthritis
 - Severe AVN associated with significant functional limitation
 - Recurrent leg ulcers

Structure/Frequency of the meetings

HCC MDTs will occur alternately on the first Wednesday of the month between 1-2pm and the first Friday of the month between 2-3pm. The date and time and calendar invites of the MDTs will be set far in advance to give sufficient notice to the attendees, the distribution list for the MDT will be reviewed twice a year to ensure that it is being circulated to the correct members of the HCC and that it is accurate. Additional MDTs will be held at a HCC level that

will mainly deal with adverse events, at these meetings if any of the events are deemed to be significant cases they will be referred to the HCC MDT, it is proposed that these meetings will occur on a quarterly basis and will be supported by the HCC administration team with the outcomes recorded. Local MDTs with LHTs will continue as they have done previously, cases from these will again be reviewed as to whether they can be referred to the HCC MDT.

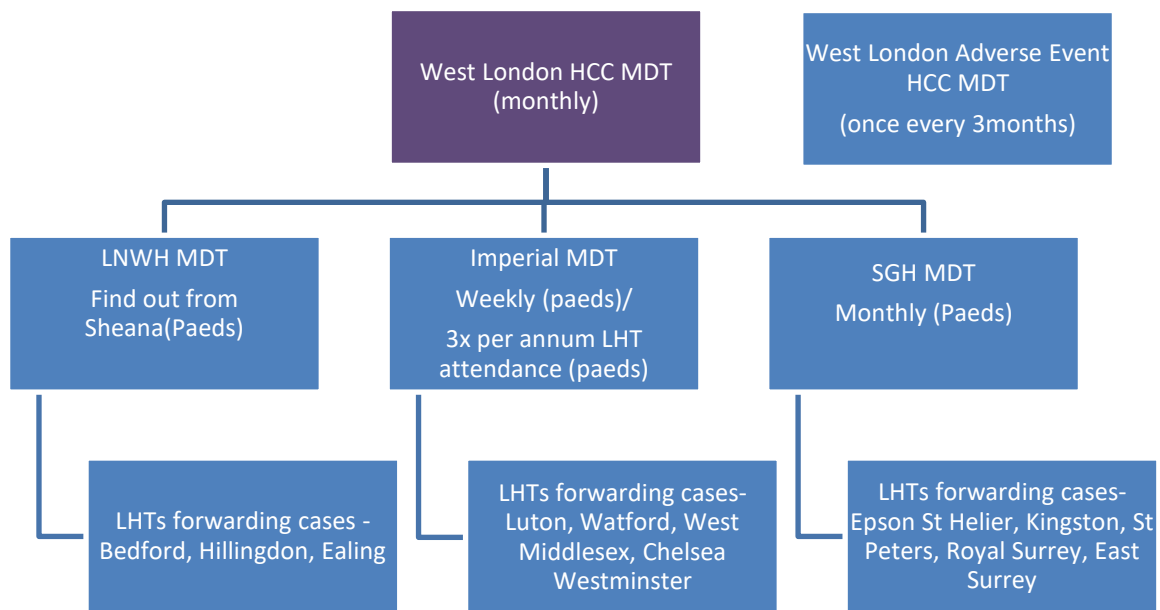
Reminders of the meeting will be sent out by the HCC Manager either the night before or the early morning of the meeting.

A 5 minute segment on the current research on trials within the HCC and how to refer patients to these will be held at the end of the MDT

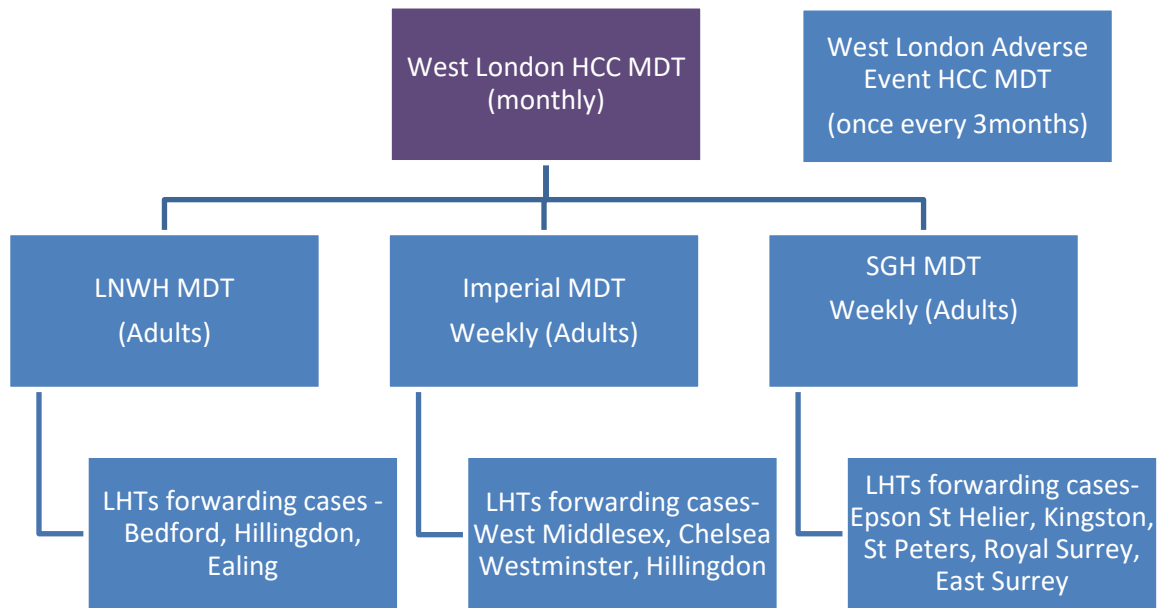
Urgent Cases

If a case requires immediate input and cannot wait for the usual MDT timescale and referral process a smaller version of the MDT will be held within a shorter timeframe and will be labelled urgent. The referral process and collection of data related to the case will be the same as the normal MDT pathway.

Paediatric



Adult



Adult referrals outside the MDT meeting- Email

There is an associated email for referrals to the MDT leads outside of the meetings the email is as follows:

MDT West London HCC- MDTADVICE (IMPERIAL COLLEGE HEALTHCARE NHS TRUST)
imperial.wlhcc.mdtadvice@nhs.net

The email is checked by an administrator who then forwards any emails to the adult and paediatric consultant who is on the respective rota at the time.

Turn around time to respond will be 48 hours of receipt of an email.

This will be reviewed at 6 month intervals to look at activity through the email account.

Paediatric referrals outside the MDT meeting

An informal discussion would be held between the respective SHT paediatric Leads within the HCC in the event of an urgent referral for the LHTs. Clinical advice will be given at this time and if required the case would be discussed at either the HCC MDT or the quarterly/biannual network MDTs

Collecting the outcomes

The West London HCC MDT Lead records the case outcomes of the discussion, the outcomes will then be circulated within one week post the MDT to all the MDT attendees by the Network Manager (or deputy).

The Network manager will send the outcome of the MDT discussion to the referring consultant for confirmation. Once confirmed and validated via email exchange the outcomes will then be stored in the MDT folders of the HCC network server, which has restricted access and sent to the MDT attendees.

The number of patients discussed at MDTs and the numbers referred onto the NHP will also be recorded. Information on deaths and patients referred for Gene therapies and stem cell transplant will be collected for NHSE data requirements.

Governance of the MDT

The West London HCC will be responsible for the governance of the MDT. This includes developing and agreeing terms of reference, minute taking and, where appropriate, onward referrals to the NHP. Frequency of meetings will depend on the number and mix of referred cases but will be expected to be at least monthly. Clinical and laboratory transfusion expertise should be available within MDTs for patients with complex transfusion needs.

The clinical responsibility of a patient remains with the treating clinician. The West London HCC will establish shared care agreements with SHTs and LHTs, which will describe how the provision of specialist expert support, advice and oversight will be made available to local treating clinicians.

Onward Referrals to the NHP

The NHP will work alongside the Specialised Haemoglobinopathies Clinical CRG, all HCCs, the SHTs and other key bodies in haemoglobinopathies care in order to:

- Drive the delivery of a nationally consistent approach to care envisaged by the CRG and approved by commissioners
- Coordinate the actions taken at SHT and HCC levels to deliver access to specialist oversight and to reduce unwarranted variation
- Provide SHTs and HCCs access to national expert clinical opinion with regard to the treatment of complex patients
- Support the introduction of commissioned innovative therapies by acting as a national panel to consider individual patients most able to benefit and to enable patients to have access to these therapies, irrespective of where they live

Referrals will be accepted directly or via the SHT or HCC MDT arrangements, depending on what is most appropriate for the patient and the local network. Frequency of meetings will depend on the clinical needs of complex patients. The NHP is expected to use available technologies to improve the efficiency of meetings.

Again, the clinical responsibility of a patient remains with the treating clinician. The NHP will establish shared care agreements with the HCCs which will describe how the provision of specialist expert support, advice and oversight will be made available to local treating clinicians.

The National Haemoglobinopathies CRG will be available to provide support and advice as required.

Wherever possible, national templates will be produced. The West London HCC will ensure that an MDT for the consideration of very complex patients is in place and linked to the NHP.

In all cases, the care provider should be notified in accordance with the specification for care and should in turn notify the West London HCC.

Elective issues that require escalation to the West London HCC will normally be via the the West London HCC MDT. There is a mechanism in place for providing advice on emergencies that occur outside of normal working hours.

12.0 Research

The West London HCC through its Research Leads will direct and guide the network research portfolio to facilitate active participation in research relating to the care of patients with haemoglobin disorders. The West London HCC will encourage SHTs to participate in appropriate trials and research. To this end it will work with clinical research leads across the network to identify suitable collaborative studies and produce an annual response to trial recruitment. As part of this research focus, the West London HCC will ensure that patients within the network are informed about and have access to clinical trials where possible.

A clinical and research focus underpins an aim to practice evidence-based medicine and participate actively in the development of clinical guidelines. The HCC will ensure that research and development, audit and educational activities within its network are linked. It will also co-ordinate and publicise research trials within its geographical area.

As noted in the MDT section above the current status of clinical trials and research will be discussed in the MDTs for a 5 minute slot at the end in order to improve recruitment

13.0 Annual Report

The West London HCC will publish an annual report in the first quarter of each year. The report will set out, amongst other things, a review of the performance of the West London HCC across the three main areas being clinical activity (to include annual reviews, number of MDT case discussions, M&M reviews, staffing levels throughout the network), governance activity and educational activity. The clinical section will cover SSQD data for the region, results of audits, complaints and adverse events (and improvements in practice highlighted), achievements in regard to programme of work, service compliments and a summary of patient feedback. The report will also describe key objectives and any improvement plan for the following year. This is in line with the NHSE Outcomes Framework Domains which underpin the report structure. The Report will be distributed to all key stakeholders within the West London HCC aiming for transparency of performance.

14.0 Dissemination and Communication

Due to the large geographical nature of the West London HCC, the HCC will use web-based tools to communicate effectively and in a timely manner with all providers across the network as well as establishing a robust system to record data with robust governance measures to contribute and enhance clinical care remotely.

The West London HCC will achieve this through the following:

- **Teleconference facilities for Multidisciplinary Team Meetings (MDT):** This will enable clinicians to dial in to discuss their patients as per the MDT referral criteria. This is for outpatient and elective decision-making rather than acute issues

- **Development of a website:** This will have two main strands. A patient focused section with information for patients and carers e.g. patient information leaflets, patient support organisations, local support group meeting dates etc. and a secure clinician focused section which will serve as a repository for clinical guidelines, meeting dates, contact details and forms for referrals. This would include the on-call rota for the HCC for acute situations. TRCN will develop a universal policy towards guideline development, resulting in all linked hospitals having up-to-date copies of the approved clinical guidelines for inclusion onto their intranets
- **Twitter and social media:** Increasingly patients and clinicians use social media as a source of clinical information and support. TRCN will use this to publicise meetings, trials and other events as well as highlight current research and changes to guidelines

15.0 References:

This SOP has been developed on the basis of the Haemoglobinopathy Coordinating Centre Service Specification which was formed from clinical consensus, taking into account other examples of networks and multi-disciplinary teams.

The standards, guidelines and quality requirements referred to include:

- The National Haemoglobinopathy Project: A guide to Effectively Commissioning High Quality Sickle cell and Thalassaemia Services (2011), East Midlands Specialised Commissioning Group.
- Quality Standards. Health Services for people with Haemoglobin Disorders v3.1. 7. Dec 2017 <http://www.wmqrs.nhs.uk/review-programmes/view/haemoglobin-disorders-2014-16-reviews-adults-and-children>
- Royal College of Nursing – Caring for people with sickle cell disease and thalassaemia syndromes – a framework for nursing staff (2011).
- Sickle Cell Disease in Childhood – standards and guidelines for clinical care – second edition (2010). First edition 2006.
- Trans-cranial Doppler Scanning for Children with Sickle Cell Disease –standards and guidance (2009). Page 10 of 13
- Specialised Services National Definitions Set (SSNDS) 3rd edition – specialised haemoglobinopathy services (all ages) – Definition No. 38 (2009).
- NHS Sickle Cell and Thalassaemia Screening Programme.
- Handbook for New-born Laboratories January 2017, Handbook for antenatal laboratories Nov 2017
- Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK (2016) third edition. (2008) – second edition. First edition, 2005. <http://ukts.org/standards/Standards-2016final.pdf>
- Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK (2018) second edition. First edition 2008.
- Standards for the Linked Antenatal and New-born Screening Programme Second Edition (2011), NHS Sickle Cell and Thalassaemia Screening Programme.
- Sickle cell disease: managing acute painful episodes in hospital, NICE (2012).
- The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report, A Sickle Crisis? (2008).

- Understanding the Contribution of sickle cell and thalassaemia specialist nurses: a summary report (2012), NHS Sickle Cell and Thalassaemia Screening Programme.
- Transition: Getting it Right for Young People, improving the transition of young people with long term conditions (2006), Department of Health. Gateway reference 5914.
- Spectra Optia for automatic red blood cell exchange in patients with sickle cell disease, NICE Medical technologies guidance [MTG28], March 2016

16.0 Document Development

16.1 Responsibility for Document Development

The HCC Manager for West London HCC was the primary author

16.2 Equality Impact Assessment (EIA) –

All staff to receive equality and diversity training included in mandatory training. This will be monitored by practice educator for medical and nursing staff. All ward managers in clinical haematology will be responsible for assessing the EIA annually.

The author of this policy has undertaken an Equality Impact Assessment (EIA) and has concluded that there is no negative impact on any of the protected equalities groups. The completed EIA form is available from the Policy Compliance Officer.

17.0 Approval and Ratification (required)

16.1 Approval

This guideline will be approved at the HCC Steering Group Meeting

16.2 Ratification

This policy will be ratified by the Quality and Safety Patient Experience Committee

18.0 Dissemination and Implementation (required)

18.1 Dissemination

The SOP will be uploaded on the West London HCC website. The document and its linked location will be emailed to the relevant staff.

18.2 Implementation

All staff joining the West London HCC during their induction will receive information about the HCC and will be advised to read the guidelines and SOPs relevant to We This will be monitored in relevant training records.

19.0 Document Control including Archiving Arrangements

19.1 Register/Library of Procedural Documents

The author of the procedural document is responsible for updating documents onto the appropriate site on the HCC's website.

A register/library of procedural documents and the library of Clinical Guidelines is maintained in the HCC folders. Ownership of the original procedure document (together with supporting documents such as the Dissemination Plan) will remain with the author/s. Members of staff will be trained locally to upload documents on to the Internet. Where no local member of staff has been trained, the communications team will upload documents.

19.2 Archiving Arrangements

Every document that is uploaded has an individual ID which is assigned by the HCC documents management system.

A spreadsheet exists of all the policies. This is managed by the HCC administrative team. The HCC documents management system assigns named person/persons to each policy and a review date and expiry date can be added so that the document details are emailed on a specified date to be checked or expired from the system. Once the author updates the policy, they can upload the new version if they have an account or this should be returned to the HCC manager who will upload the new version. The old policy is archived automatically. Archived versions can be requested from the author or from the HCC Manager.

Appendices

APPENDIX 1 - CLINICAL GUIDELINES

Clinical Guidelines

HN-502/503/504/505/506/507/508

All clinical guidelines are ratified by the Haemoglobinopathy Coordinating Centre and adapted subsequently by the SHT or LHT, approved through local governance routes.

Name of Guideline:	Which Quality Standard is incorporated within it:
HCC Adult Sickle Cell Guideline	HN502/503/504/505/506/507/508/
HCC Paediatric Sickle Cell Guideline	HN502/503/504/505/506/507/508/
Transition of adolescents with haemoglobinopathies into adult services	HN501

A further breakdown of where the quality standards sit within guidelines is available in the Operational Policies of the Specialist Haemoglobinopathy Teams and Local Haemoglobinopathy Teams.

APPENDIX 2 - ROLES AND KEY CONTACT DETAILS

WEST LONDON HCC CORE TEAM

Key Role	Name	Email Address
Clinical HCC director	Prof. Mark Layton	mLAYTON@nhs.net m.layton@imperial.ac.uk
Deputy Clinical HCC director	Dr Kofie Anie	kofi.anie@nhs.net
HCC MDT Steering Group	Dr Julia Sikorska Dr Asad Luqmani Dr Kirstin Lund Dr Alisson Thomas	j.sikorska@nhs.net asad.luqmani@nhs.net kirstin.lund@nhs.net alison.thomas6@nhs.net
HCC Training and Education	Dr Nadia Osman Dr Mamta Sohal	Nadia.osman@nhs.net mamta.sohal@nhs.net
Paediatric guidelines and sub group	Dr Kirstin Lund	kirstin.lund@nhs.net
Adult Guidelines Sub group	Dr Mamta Sohal	mamta.sohal@nhs.net
HCC Research leads	Dr Kofi Anie Dr Josu de la Fuente	kofi.anie@nhs.net josu.delafuente@nhs.net
TCD lead	Nazia Saeed	nazia.saeed@nhs.net
SW London Network Clinical SHT Representative	Dr Alisson Thomas	alison.thomas6@nhs.net
SW London Network Clinical SHT Representative	Dr Julia Sikorska	j.sikorska@nhs.net
NWLSCTN Clinical SHT Representative	Dr Asad Luqmani	asad.luqmani@nhs.net
NWLSCTN Clinical SHT Representative	Dr Kirstin Lund	kirstin.lund@nhs.net
NWLSCTN Clinical SHT Representative	Dr Muhsin Almusawy	Muhsin.almusawy@nhs.net
NWLSCTN Clinical SHT Representative	Dr Sheana Wijemanne	sheana.wijemanne@nhs.net
HCC Manager 8b	Ralph Brown	Ralph.brown@nhs.net
Administrator (0.6) B4	Eniola Kuseju	eniola.kuseju@nhs.net
HCC Data Managers	Provided by existing SHT posts	c.oke@nhs.net

APPENDIX 3 – TERMS OF REFERENCE Steering Group Meeting

The West London HCC Steering Group Meeting

TERMS OF REFERENCE

1.	Purpose The purpose of the Haemoglobinopathy Coordinating Centre Steering Group is to oversee the management, finance and governance of the West London HCC as well as for keeping an overview of the functioning of the network arrangements.
2.	Responsibilities 2.1. The West London Steering Group will report to the National Haemoglobinopathy Panel (NHP) and commissioners, and forms the primary contact for the NHP, NHS England, ICBs within the geography of the WLHCC and the Clinical Reference Group (CRG). 2.2. Responsible for the mobilisation, governance and education activity for the West London HCC. 2.3. Publish the annual report of WLHCC in the first quarter of each year. The report will set out, amongst other things, a review of the performance of the Network across the three main areas being clinical activity (to include annual reviews, number of MDT case discussions, M&M reviews, staffing levels throughout the network), governance activity and educational activity. The report will also be submitted to respective trust boards within the HCC, for review and comment. 2.4. Identify opportunities for continual improvement, including support required, in the quality of services offered to patients. 2.5. Other matters that may affect the functioning or performance of the West London HCC may also be discussed. 2.6. Support the provision of a coordinated clinical leadership function, confirming the effectiveness and alignment of the strategic direction of the coordinating service with agreed clinical standards, protocols and pathways. 2.7. Collate matters for discussion at the meeting from HCC leads, Specialist Haemoglobinopathy Team (SHT), Local Haemoglobinopathy Team (LHT) and patient representative and act to facilitate the attendance of other individuals at the Governance meeting, as required. 2.8. The HCC GC will be responsible for monitoring and directing compliance with clinical standards.

	<p>2.9. Pressing Ad Hoc issues raised by the PPV group will be discussed in the WLHCC Steering group with the Clinical Lead or Deputy Clinical Lead of the WLHCC contacting trust boards and other bodies as appropriate</p>
3.	<p>Membership</p> <p>The HCC Steering Group members will comprise:</p> <ul style="list-style-type: none"> • WLHCC Clinical Lead • WLHCC Deputy Clinical Lead • WLHCC Network Manager • WLHCC Patient and Public Voice Group Chair • WLHCC SHT Clinical Leads or nominated deputies • WLHCC SHT General managers or nominated deputies • WLHCC Training Leads • WLHCC Research Leads <p>Other members from national patient bodies, professional bodies and other clinical specialists may be identified and invited as appropriate.</p>
4.	<p>Quorum and expected attendance</p> <p>4.1. The quorum for any meeting of the Operational Committee shall be two-thirds of its membership, including either the Clinical Lead or the Deputy Clinical Lead, at the time of the meeting.</p>
5.	<p>Frequency of Meetings</p> <p>5.1. Meetings will be held once a month after an initial agreed period.</p>
6.	<p>Agenda and Reporting</p> <p>6.1. <i>The West London HCC Network Manager will provide administrative support, prepare an agenda and/or collate any additional documents for discussion or approval at the meeting.</i></p> <p>6.2. <i>Minutes will be taken for each meeting and an action tracker created to monitor actions from previous meetings. All agendas, minutes, action trackers and attachments will be stored on West London HCC local shared drive and will be distributed in advance of meetings.</i></p> <p>6.3. <i>The agenda shall be formed of standing items along with reviews of ongoing patient experience or quality improvement projects. The standing agenda will align with the Care Quality Commission's key lines of enquiry, as detailed in the service specification for the HCC, and will encompass the following:</i></p> <ul style="list-style-type: none"> • Risk Management • Morbidity/mortality levels

	<ul style="list-style-type: none"> • Information Governance • Quality Performance Indicators • Clinical Effectiveness • Guidelines and audit • Compliance with quality standards • Patient Information • Patient Experience Metrics • Engagement with SHTs and LHTs • Training and education
<p>7.</p>	<p>Review of Terms of Reference</p> <p>7.1. The Terms of Reference for the Steering Group Committee will be reviewed annually and approved by the West London HCC Clinical Lead and the West London HCC Deputy Clinical Lead.</p>

APPENDIX 4 – TERMS OF REFERENCE- Operational Meeting

The West London Haemoglobinopathy Care Centre Operational Meeting

TERMS OF REFERENCE

1.	Purpose The purpose of the Haemoglobinopathy Coordinating Centre Governance Committee (HCC GC) is to provide clinical leadership to ensure safe, equitable world-class haemoglobinopathy care and approve policies, guidelines or recommendations relating to The Red Cell Network (TRCN).
2.	Responsibilities 2.1. The HCC GC will report to TRCN Operational Committee and have primary responsibility for reviewing quality dashboards, clinical guidelines, audit and levels of morbidity and mortality across the whole of The Red Cell Network in line with applicable quality standards, ensuring actions to deliver a consistent approach to care. Chance for input from the deputy and deputy lead of the HCC, into the regular running of the HCC 2.2. The HCC GC will be responsible for monitoring and directing compliance with clinical standards. 2.3. Identify opportunities for continual improvement, including support required, in the quality of services offered to patients. 2.4. Support the provision of a coordinated clinical leadership function, confirming the effectiveness and alignment of the strategic direction of the coordinating service with agreed clinical standards, protocols and pathways. 2.5. Collate matters for discussion at the meeting from HCC leads, Specialist Haemoglobinopathy Team (SHT), Local Haemoglobinopathy Team (LHT) and patient representative and act to facilitate the attendance of other individuals at the Governance meeting, as required. 2.6. Other matters that may affect the functioning or performance of TRCN may also be discussed.
3.	Membership The HCC GC members will comprise:

	<ul style="list-style-type: none"> • TRCN Clinical Lead (Chair) • TRCN Deputy Clinical Lead • TRCN Governance Lead • TRCN Network Matron • TRCN Business and Quality Manager • TRCN Service Manager • TRCN Data Managers • SHT Clinical Lead or Deputy Clinical Lead • SHT Clinical Nurse Specialist • LHT Clinical Lead or Deputy Clinical Lead • SHT/LHT Clinical Psychologist • SHT/LHT Pharmacist • Patient Representative/s <p>Other members from national patient bodies, professional bodies and other clinical specialists may be identified and invited as appropriate.</p>
<p>4.</p>	<p>Quorum and expected attendance</p> <p>4.1. The quorum for any meeting of the HCC GC shall be two-thirds of its membership, including either the Clinical Lead or the Deputy Clinical Lead, at the time of the meeting.</p>
<p>5.</p>	<p>Frequency of Meetings</p> <p>5.1. Meetings will be held every two months at a time convenient for panel members with dates and times circulated in advance of meetings.</p>
<p>6.</p>	<p>Agenda and Reporting</p> <p>6.1. WLHCC Network Manager (or nominated deputy) will prepare an agenda in consultation with the Chair and prepare and/or collate any additional documents for discussion or approval at the meeting.</p> <p>6.2. Minutes will be taken for each meeting and an action tracker created to monitor actions from previous meetings. All agendas, minutes, action trackers and attachments will be stored on TRCN website and will be distributed in advance of meetings.</p> <p>6.3. The agenda shall be formed of standing items along with reviews of ongoing patient experience or quality improvement projects. The standing agenda will align with the Care Quality Commission’s key lines of enquiry, as detailed in the service specification for the HCC, and will encompass the following:</p> <ul style="list-style-type: none"> • Risk Management • Morbidity/mortality levels • Information Governance • Quality Performance Indicators • Clinical Effectiveness

	<ul style="list-style-type: none"> • Guidelines and audit • Compliance with quality standards • Patient Information • Patient Experience Metrics • Engagement with SHTs and LHTs • Training and education <p>6.4. Reporting of the actions and activities of the HCC GC will be made to the Division via the Haematology Clinical Governance Committee and to the HCC leadership team by means of the HCC Operational Committee.</p>
<p>7.</p>	<p>Review of Terms of Reference</p> <p>7.1. The Terms of Reference of the HCC GC will be reviewed annually and approved by the TRCN Governance Lead and by all core members of the Committee.</p>

APPENDIX 5 – TERMS OF REFERENCE- Paediatric Sub Group

The West London Haemoglobinopathy Coordinating Centre Paediatric Sub-group

TERMS OF REFERENCE

1.	Purpose The purpose of the Paediatric Sub group is to improve outcomes for paediatric patients in the West London by improving pathways of care and creating guidance that can be accessible by all healthcare professionals in the HCC. The group will also act as a forum for the discussion of best practice of Haemoglobinopathies in paediatrics.
2.	Responsibilities 2.1. The Paediatric Sub-group will report to the West London HCC Steering Group and have responsibility for reviewing paediatric clinical guidelines, pathways to care, audit, quality Performance Indicators and compliance with quality standards and ensuring actions to deliver a consistent approach to care.
3.	Membership The Paediatric Sub-group members will comprise: <ul style="list-style-type: none">• Paediatric guidelines and sub group lead (Chair)• SW London Network Clinical SHT Representative• NWLSCT Clinical SHT Representative• West London HCC Network Manager Other members from West London patient bodies, professional bodies, administrative specialists and other clinical specialists may be identified and invited as appropriate.
4.	Quorum and expected attendance 4.1. The quorum for any meeting of the Paediatric Sub-group shall be two-thirds of its membership, including the Paediatric guidelines and sub group lead, at the time of the meeting.
5.	Frequency of Meetings 5.1. Meetings will be held every month at a time convenient for panel members with dates and times circulated in advance of meetings.

<p>6.</p>	<p>Agenda and Reporting</p> <p>6.1. HCC Network Manager and Paediatric guidelines and sub group lead (or nominated deputy) will prepare an agenda and prepare and/or collate any additional documents for discussion or approval at the meeting.</p> <p>6.2. Minutes/Actions list will be taken for each meeting and an action tracker created to monitor actions from previous meetings. All agendas, minutes/actions, action trackers and attachments will be stored in HCC folders and will be distributed in advance of meetings.</p> <p>6.3. The agenda shall be formed of standing items along with any best practice discussions of treatments in paediatric haemoglobinopathies.</p> <ul style="list-style-type: none"> • Clinical Guidelines • Pathways for care • Engagement with SHTs and LHTs • Training and education • Data and Audit • Quality Performance Indicators and compliance with quality standards • Clinical Effectiveness • Patient Information • Patient Experience Metrics <p>6.4. Reporting of the actions and activities of the Paediatric Sub-group will be made to the HCC leadership team by means of the HCC Steering Group</p>
<p>7.</p>	<p>Review of Terms of Reference</p> <p>The Terms of Reference of the Paediatric Sub-group will be reviewed annually and approved by the Paediatric guidelines and sub group lead and by all core members of the Committee.</p>

APPENDIX 6 – TERMS OF REFERENCE- Adult Guidelines Sub Group

The West London Haemoglobinopathy Coordinating Centre Adult guidelines Sub group

TERMS OF REFERENCE

1.	Purpose The purpose of the Adult guideline Sub group is to improve outcomes for adult haemoglobinopathy patients in the West London by improving pathways of care and creating guidance that can be accessible by all healthcare professionals in the HCC. The group will also act as a forum for the discussion of best practice of Haemoglobinopathies in adult patients.
2.	Responsibilities 2.1. The Adult guidelines Sub-group will report to the West London HCC Steering Group and have responsibility for reviewing clinical guidelines and pathways to care- ensuring actions deliver a consistent approach to care.
3.	Membership The Adult guideline Sub-group members will comprise: <ul style="list-style-type: none">• Adult Guidelines Sub group lead (Chair)• SW London Network Clinical SHT Representative• NWLSCT Clinical SHT Representative• West London HCC Network Manager Other members from West London professional bodies, administrative specialists and other clinical specialists may be identified and invited as appropriate.
4.	Quorum and expected attendance 4.1. The quorum for any meeting of the Adult Guidelines Sub-group shall be two-thirds of its membership, including the Adult Guidelines Sub group lead , at the time of the meeting.
5.	Frequency of Meetings 5.1. Meetings will be held every month at a time convenient for panel members with dates and times circulated in advance of meetings.
6.	Agenda and Reporting

	<p>6.1. HCC Network Manager and Adult guidelines and sub group lead (or nominated deputy) will prepare an agenda and prepare and/or collate any additional documents for discussion or approval at the meeting.</p> <p>6.2. Minutes/Actions list will be taken for each meeting and an action tracker created to monitor actions from previous meetings. All agendas, minutes/actions, action trackers and attachments will be stored in HCC folders and will be distributed in advance of meetings.</p> <p>6.3. The agenda shall be formed of standing items along with any best practice discussions of treatments in paediatric haemoglobinopathies.</p> <ul style="list-style-type: none"> • Clinical Guidelines • Pathways for care • Applicability to SHTs and LHTs • Clinical Effectiveness <p>6.4. Reporting of the actions and activities of the Adult guideline Sub-group will be made to the HCC leadership team by means of the HCC Steering Group</p>
<p>7.</p>	<p>Review of Terms of Reference</p> <p>The Terms of Reference of the Adult guideline Sub-group will be reviewed annually and approved by the Adult guidelines and sub group lead and by all core members of the Sub group.</p>

APPENDIX 7 – TERMS OF REFERENCE- Training and Education Sub group

The West London Haemoglobinopathy Coordinating Centre Training and Education Sub group

TERMS OF REFERENCE

1.	Purpose The purpose of the Training and Education Sub group is to improve outcomes for haemoglobinopathy patients in the West London by improving education and training that can be accessible by all healthcare professionals and patients in the HCC. The group will also act as a forum for the discussion of best practice education of Haemoglobinopathies.
2.	Responsibilities 2.1. The Training and Education Sub-group will report to the West London HCC Steering Group and have responsibility for creating a education schedule for the HCC each year.
3.	Membership The Training and Education Sub-group members will comprise: <ul style="list-style-type: none">• HCC Training and Education Lead (Conjoint Chair)• HCC Training and Education Lead (Conjoint Chair)• West London HCC Network Manager Other members from West London professional bodies, administrative specialists and other clinical specialists may be identified and invited as appropriate.
4.	Quorum and expected attendance 4.1. The quorum for any meeting of the Training and Education Sub-group shall be 100% of its membership.
5.	Frequency of Meetings 5.1. Meetings will be held every 6 weeks at a time convenient for panel members with dates and times circulated in advance of meetings.
6.	Agenda and Reporting <ul style="list-style-type: none">○ HCC Network Manager with discussion (or nominated deputy) will prepare an agenda and prepare and/or collate any additional documents for discussion or approval at the meeting.

	<ul style="list-style-type: none"> ○ Minutes/Actions list will be taken for each meeting and an action tracker created to monitor actions from previous meetings. All agendas, minutes/actions, action trackers and attachments will be stored in HCC folders and will be distributed in advance of meetings. ○ The agenda shall be formed of standing items along with any best practice discussions of treatments in paediatric haemoglobinopathies. ● Upcoming training sessions status ● Suggested training sessions from the HCC members and patients ● Operational discussion on who to contact for proposed training sessions ● Attendance at sessions- maximising audience ● Continuous professional development ○ Reporting of the actions and activities of the Adult guideline Sub-group will be made to the HCC leadership team by means of the HCC Steering Group
7.	<p>Review of Terms of Reference</p> <p>The Terms of Reference of the Training and Education Sub-group will be reviewed annually and approved by the HCC Training and Education leads and by all core members of the Sub group.</p>

APPENDIX 8 – TERMS OF REFERENCE- Data Management Sub group

The West London Haemoglobinopathy Coordinating Centre Data Management Sub group

TERMS OF REFERENCE

1.	Purpose The purpose of the Data Management Sub group is to improve outcomes for haemoglobinopathy patients in the West London by using data collection methods and tools to accrue data on outcomes for patients in the West London region. The group will also act as a forum for the discussion of best practice in data management Haemoglobinopathies.
2.	Responsibilities 2.1. The Data Management Sub-group will report to the West London HCC Steering Group and have responsibility for creating an education schedule for the HCC each year.
3.	Membership The Training and Education Sub-group members will comprise: <ul style="list-style-type: none">• West London HCC Network Manager• Data Manager London North West University Healthcare NHS Trust Adults and Paediatrics• Data Manager Imperial College Healthcare NHS Trust Adults and Paediatrics• Data Manager St George's University Hospitals NHS Foundation Trust Paediatrics• Data Manager St George's University Hospitals NHS Foundation Trust Adults Other members from West London professional bodies, administrative specialists and other clinical specialists may be identified and invited as appropriate.
4.	Quorum and expected attendance 4.1. The quorum for any meeting of the Data Management Sub-group shall be 60% of its membership.
5.	Frequency of Meetings 5.1. 2 separate Meetings will be held every 4 weeks at a time convenient for panel members with dates and times circulated in advance of meetings. The meetings are subdivided in the following manner:

Monthly Data Management: Catch-up meeting

This will be held on the Third Wednesday of each month and in effect will act as a session for the data managers to share information and best practice with each other, it will also to let the HCC staff know if there are any issues with data accrual that the HCC can help with,

Through the catch-up meeting we will try and standardise the local data bases being used by the services to enable easy return of the data at the end of each month before the data collection meeting,

Monthly Data Management: data collection meeting

This meeting will be on the first Wednesday of each month and will require data from the previous month to be submitted in advance based on the requirement/schedule in the attached spreadsheet, please let me have any feedback on the timeframes in the document as these can be changed in the event that services think there is a more efficient way of updating the dashboard on an ongoing basis,

The rationale behind having the monthly data collection is to keep on top of the requirements requested by NHSE.

6.

Agenda and Reporting

- HCC Network Manager with dicussion (or nominated deputy) will prepare an agenda and prepare and/or collate any additional documents for discussion or approval at the meeting.
- Minutes/Actions list will be taken for each meeting and an action tracker created to monitor actions from previous meetings. All agendas, minutes/actions, action trackers and attachments will be stored in HCC folders and will be distributed in advance of meetings.
 - The agenda shall be formed of standing items
 - Data required for NHSE as part of the HCC service specification
 - Data required for the NHSE Specialised Services Quality Dashboard
 - Status of audits collecting data related to the NHSE requirements /directions from the HCC steering group
 - Returns from the Annual survey of patients in the HCC
 - Operational discussion on who to contact for help in accruing the data and support the HCC can give in processing the data
 - Work on collecting data from the Local Haemoglobinopahty Teams (LHTs)
 - Forum for exchanging ideas and information/courses avaiaible to data managers
 - Demographic data of the West London Haemoglobinopathy cohort
 - Feedback and progress on the use of the National Haemaoglobinopathy Registry (NHR)
 - Reporting of the actions and activities of the Data Management Sub-group will be made to the HCC leadership team by means of the HCC Steering Group

The listing of SSQD data be collected is below

Frequency	Ref	Description	
Monthly	HAEMO 2	Proportion of children (aged between 2 and 16 years old) within at risk group (S/S and S/bets 0 Thal) receiving Trans Cranial Doppler monitoring within Trust	Numerator: Of those in the denominator, the number of paediatric patients undergoing TCD monitoring within national guidelines Denominator: The total number of paediatric patients who are eligible for TCD monitoring in the reporting period
Monthly	HAEMO 3i	Percentage of patients given pain relief within half an hour of presentations with sickle crisis , as per NICE guidelines	Numerator: Of those in the denominator, the number of patients that receive pain relief within 30 minutes of presentation with a sickle cell crisis Denominator: The total number of events (patients presenting with sickle cell crisis) in the reporting period
Monthly	HAEMO 4A	Proportion of paediatric patients with possible sickle cell disease identified by neonatal screening, who have been entered into the care pathway.	Numerator: Of those in the denominator, the number of paediatric patients entered into the care pathway Denominator: The total number of paediatric patients with possible sickle cell disease, identified by neonatal screening in the reporting period
Monthly	HAEMO 4B	Percentage of eligible children beginning Penicillin at our before 3 months of age as per screening programme guidelines	Numerator: Of those in the denominator, the number of paediatric patients beginning antibiotics at or before 3 months of age as per screening programme guidelines Denominator: The total number of paediatric patients eligible to begin antibiotics in the reporting period

Annual- with monthly tracking	HAEM0 5	Proportion of annual reviews recorded by the NHR.	<p>Numerator: Of those in the denominator, the number of annual reviews undertaken by the centre as recorded by NHR entry.</p> <p>Denominator: The total number of registered patients eligible for annual reviews via the NHR by that centre in the reporting period.</p>
	HAEM0 6Ai	Proportion of eligible patients on <u>long term transfusion who receive cardiac MRI</u>	<p>Numerator: Of those in the denominator, the number of eligible patients on long term transfusions, who undergo cardiac T2*MRI.</p> <p>Denominator: The total number of patients eligible for cardiac T2* MRI in the reporting period.</p>
Monthly	HAEM0 7	Proportion of eligible paediatric patients (> 9 months of age) who are offered, or currently on Hydroxycarbamide	<p>Numerator: Of those in the denominator, the number of annual reviews undertaken by the centre as recorded by NHR entry.</p> <p>Denominator: The total number of paediatric patients eligible to receive Hydroxycarbamide in the reporting period</p>
Monthly	HAEM0 8	Proportion of eligible adults who are offered or currently on Hydroxycarbamide	<p>Numerator: Of those in the denominator, the total number of adults currently offered, or currently on Hydroxycarbamide</p> <p>Denominator: The total number of adults eligible to receive Hydroxycarbamide in the reporting period</p>
Annual	HAEM0 9a	Proportion of regularly transfused paediatric	Numerator: Total number of paediatric patients on

		patients on simple top-up transfusions	regular transfusions undertaken by simple top-up transfusions Denominator: The total number of paediatric patients on regular transfusions in the reporting period
Annual	HAEM09b	Proportion of regularly transfused adult patients on simple top-up transfusions	Numerator: Total number of adult patients on regular transfusions undertaken by simple top-up transfusions Denominator: The total number of adult patients on regular transfusions in the reporting period
Annual	HAEM10a	Proportion of regularly transfused paediatric patients on manual exchange transfusions	Numerator: Of those in the denominator, the number of paediatric patients on regular transfusions undertaken by manual exchange transfusions Denominator: The total number of paediatric patients on regular transfusions in the reporting period
Annual	HAEM10b	Proportion of regularly transfused adult patients on manual exchange transfusions	Numerator: Of those in the denominator, the number of adult patients on regular transfusions undertaken by manual exchange transfusions Denominator: The total number of adult patients on regular transfusions in the reporting period
Annual	HAEM11a	Proportion of regularly transfused paediatric patients on automated exchange transfusions	Numerator: Of those in the denominator, the number of paediatric patients on regular transfusions undertaken by automated exchange transfusions Denominator: The total number of paediatric patients on regular transfusions in the reporting period

Annual	HAEM1 1b	Proportion of regularly transfused adult patients on automated exchange transfusions.	Numerator: Of those in the denominator, the number of adult patients on regular transfusions undertaken by automated exchange transfusions Denominator: The total number of adult patients on regular transfusions in the reporting period
Quarterly	HAEMC C08b	Proportion of patients that have admissions resulting in length of stay of over 20 days	Numerator: Of those in the denominator, the number of admissions which resulted in length of stay of over 20 days Denominator: The total number of admissions in the reporting period
Quaretrly	HAEMC C09a	Proportion of significant complications (as defined by National Haemoglobinopathy Registry) that are discussed at the HCC morbidity / mortality meetings	Numerator: Of those in the denominator, the number of significant complications discussed at HCC morbidity / mortality meeting Denominator: The total number of regional significant complications in the reporting period
Monthly	HAEMC C09b	Proportion of patient deaths discussed at HCC morbidity/mortality meetings	Numerator: Of those in the denominator, the number of deaths discussed at HCC morbidity / mortality meeting Denominator: The total number of regional deaths in the reporting period

<p>Quarterly</p>	<p>HAEMC C10</p>	<p>Proportion of patients registered on the National Haemoglobinopathy Register across the HCC network</p>	<p>Numerator: Of those in the denominator, the number of patients on NHR Denominator: The total number of patients in network (at time of submission)</p>
<p>Monthly</p>	<p>HAEMC C12</p>	<p>Proportion of patients referred for gene therapy and haematopoietic stem cell transplantation</p>	<p>Numerator: Of those in the denominator, the number of patients referred for gene therapy and haematopoietic stem cell transplantation Denominator: The total number of patients in network (at time of submission)</p>
<p>7. Review of Terms of Reference</p> <p>The Terms of Reference of the Data Management Sub-group will be reviewed annually and approved by the West London HCC Network Manager leads and by all core members of the Data Manager Sub group.</p>			

APPENDIX 9 – TERMS OF REFERENCE- HCC MDT

The West London Haemoglobinopathy Coordinating Centre HCC MDT

TERMS OF REFERENCE

1.	Purpose The purpose of the HCC MDT is to provide multi professional input for adults and children with Sickle Cell disease served by the West London HCC
2.	Responsibilities <u>Process of Referral</u> The HCC Network Manager (or deputy) will forward out invitations for the scheduled HCC MDT in advance of the meeting. Included in the invitation will be case referral forms and adverse event report form for the MDT and criteria for referral, referrals to the MDT will be submitted at latest the day before the MDT to allow time for the coordinator to collect the case and circulate the cases in advance to the attendees. A reminder/call for cases will be sent out to clinicians two weeks in advance of the HCC MDT occurring. Patient identifiers should be anonymised. Referrals will be collated, anonymised if further required and a patient list created. The HCC Network Manager (or deputy) will respond to referral email with confirmation that patient is on the list. Any issues with referrals to be clarified with lead clinician and referring team (e.g. doesn't meet the criteria, information not clear). Referrals that don't meet the criteria will be returned to clinician with a request for clarification. It is incumbent on the clinicians referring that they collect all necessary medical information (scans, results, notes etc.) in advance of presenting the case at the meeting. The Meeting is chaired by the West London HCC MDT Lead or nominated deputy. Cases are presented by the referring clinician. In the event of rare or extremely complex cases or the consideration of Novel Therapies cases may be referred through to the National Haemoglobinopathy Panel. <u>Collecting the outcomes</u> The West London HCC MDT Lead records the case outcomes of the discussion, the outcomes will then be circulated within one week post the MDT to all the MDT attendees by the Network Manager (or deputy). The Network manager will send the outcome of the MDT discussion to the referring consultant for confirmation. Once confirmed and validated via email exchange the outcomes will then be stored in the MDT folders of the HCC network server, which has restricted access and sent to the MDT attendees.

	<p>The number of patients discussed at MDTs and the numbers referred onto the NHP will also be recorded. Information on deaths and patients referred for Gene therapies and stem cell transplant will be collected for NHSE data requirements.</p>
<p>3.</p>	<p>Criteria for patient Referrals</p> <p>Criteria for patient referrals It is suggested the following cases should be referred to the MDT:</p> <ul style="list-style-type: none"> • 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 <p>Considerations should be made as to the following:</p> <ul style="list-style-type: none"> • 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.: <ul style="list-style-type: none"> - Renal dysfunction - Neurological disease (e.g. stroke, TIA) - Urological complications - Respiratory disease - Pulmonary hypertension - Obstetric complications - Orthopaedic disease <p>Significant complications (known previously on the NHR as adverse events) to be submitted to the MDT for discussion will be derived from the following categories (please see appendix 9a for full list)</p> <ul style="list-style-type: none"> • Cardiorespiratory complications, including: <ul style="list-style-type: none"> - Pulmonary hypertension - Severe acute chest syndrome - Pulmonary embolism • Multi Organ Failure, including; Fat embolism syndrome • Genitourinary complications, including:

	<ul style="list-style-type: none"> - Acute renal failure - Severe Priapism - Sickle Nephropathy • Orthopaedic complications, including: <ul style="list-style-type: none"> - Osteomyelitis/ Septic arthritis - Severe AVN associated with significant functional limitation - Recurrent leg ulcers • Extramedullary haemopoiesis • Neurological disorders, including: <ul style="list-style-type: none"> - Stroke - Silent cerebral infarcts - Visual Loss - Moya Moya • Hepatobiliary complications: <ul style="list-style-type: none"> - Sickle hepatopathy - Cirrhosis of liver - Pancreatitis • Endocrinopathy due to iron overload or opioid use • Obstetric/ gynaecological complications, including Intrauterine death • Severe bacterial or viral infection • Cancer • ITU admission • Severe transfusion reaction including hyperhaemolysis • Death • Safeguarding issues/significant Psychosocial concerns
<p>4.</p>	<p>Membership</p> <p>The MDT HCC members will comprise:</p> <ul style="list-style-type: none"> • West London HCC MDT Lead or nominated deputy • West London HCC Consultants (including a representative of each of the SHT paediatric and adult services. SHT services- Imperial College Healthcare NHS Trust, London North West University Healthcare NHS Trust, St George's University Hospitals NHS Foundation Trust) • West London HCC Nursing Staff both Community and Hospital based • West London HCC Psychology Staff • West London HCC Junior Doctors

	<ul style="list-style-type: none"> • West London HCC Network Manager • Members of the SPAH and Welsh Haematology teams linked with the West London HCC <p>Other members from West London professional bodies, administrative specialists and other clinical specialists may be identified and invited as appropriate.</p>
<p>5.</p>	<p>Quorum and expected attendance</p> <p>The quorum for any meeting of the MDT shall be at least 8 members of the clinical teams</p> <p>Key Membership should include: Adult Consultant from Imperial College Healthcare NHS Trust Paediatric Consultant from Imperial College Healthcare NHS Trust Adult Consultant from London North West University Healthcare NHS Trust Paediatric Consultant from London North West University Healthcare NHS Trust Adult Consultant from St George's University Hospitals NHS Foundation Trust Paediatric Consultant from St George's University Hospitals NHS Foundation Trust</p>
<p>6.</p>	<p>Frequency of Meetings</p> <p>The MDT will be held every Month alternating between Wednesdays at 1pm and Fridays at 2pm</p> <p>With an additional meeting to discuss significant complications/adverse events every 3 months, this will be scheduled for 2 hours</p>
<p>7.</p>	<p>Agenda and Reporting</p> <ul style="list-style-type: none"> ○ HCC Network Manager with discussion (or nominated deputy) will prepare the patient list and prepare and/or collate any additional documents for discussion or approval at the meeting. ○ Outcomes list will be taken for each meeting and a list of all cases that have been reviewed at the MDT will be agglomerated and held by the HCC network manager and team in relation to any data requests from NHSE ○ A 5 minute section of the HCC MDT will be given over to an update on Clinical trials open within the HCC and to enable equitable access to clinical trails for patients

	<p>To satisfy the NHS England data requirements as follows information will need to be picked up from the cases going through the HCC MDT:</p> <ul style="list-style-type: none"> • Number of cases referred to the NHP • Proportion of significant complications (as defined by National Haemoglobinopathy Registry) that are discussed at the HCC morbidity / mortality meetings • Proportion of patient deaths discussed at HCC morbidity/mortality meetings • Proportion of patients referred for gene therapy and haematopoietic stem cell transplantation <p>The MDT will have separate sessions to cover significant complications/adverse event reporting this will occur once every 3 months</p>
<p>8.</p>	<p>Review of Terms of Reference</p> <p>The Terms of Reference of the HCC MDT will be reviewed annually and approved by the West London HCC Network Manager leads and by all core members of the HCC MDT Sub group and noted at the HCC Steering Group.</p>

APPENDIX 9a – Significant complications/Adverse events listed on the NHR

Cardiorespiratory:

Pneumonia
Acute chest syndrome
Angina
Cardiac arrhythmia
Pulmonary hypertension
Myocardial infarction
Asthma
Deep vein thrombosis
Restrictive lung disease
Fat embolism syndrome
Obstructive lung disease
Other thrombotic complication related to central catheter
Pulmonary embolism
Superior venocaval obstruction secondary to previous central lines

Genitourinary:

Acute renal failure
Renal stones
Haematuria
Glomerulonephritis
Chronic renal failure stage 1-5 CKD listed and has different eGFR from less than 15 to greater to 90
Hydronephrosis
Renal replacement therapy
Nephrotic syndrome
Papillary necrosis
Priapism
Renal mass/tumour

Orthopaedic:

Fracture
Acute osteomyelitis
Chronic osteomyelitis
Septic arthritis
AVN
Osteoporosis
Degenerative disc disease
Leg ulcer
Extramedullary haemopoiesis

Neurological disorders:

Ischaemic stroke
Silent cerebral infarcts
Seizure without diagnosis of epilepsy
Haemorrhagic stroke
Central venous thrombosis
Epilepsy
Spinal cord compression
Visual loss
Retinopathy stages I - V listed separately
Moya Moya
Chronic pain

Haematological:

Acute haemolytic event not related to blood transfusion
Agranulocytosis
Disseminated intravascular coagulation
Neutropenia
Pure red cell aplasia
Acute vaso occlusive crisis

Hepatobiliary:

Liver failure
Intrahepatic cholestasis
Cholestasis
Biliary colic
Ascending cholangitis
Acute pancreatitis
Pancreatic exocrine insufficiency
Cirrhosis of liver
Fibrosis of liver
Fatty liver disease
Hepatocellular carcinoma
Acute infective hepatitis
Hepatic mass

Endocrine:

Insulin dependent diabetes
Non-insulin dependent diabetes
Diet controlled diabetes
Hypothyroidism
Hypoparathyroidism
Adrenal insufficiency
Hypogonadotropic hypogonadism
Other endocrine complication

Obstetric/ gynaecological:

Intrauterine death
Recurrent miscarriage

Bacterial infection:

Pneumococcus
Salmonella sp.
Klebsiella sp.
Coagulase neg staphylococcus]mycoplasma
Bacterial infectious disease (other)

Viral infection:

Influenza
COVID 19
Parvovirus
Hep a
Hep b
Hep c
Hep e
Other viral illness

Other:
Cancer
Other complication not listed above
Death

APPENDIX 10 – TERMS OF REFERENCE- Specialist Nurses, Midwives and counselling Health Visitors Subgroup

<p style="text-align: center;">NHS England West London Sickle Cell Haemoglobinopathy Coordinating Centre (HCC) Specialist Nurses, Midwives and counselling Health Visitors Subgroup</p>
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TERMS OF REFERENCE

1. Purpose of Forum

- 1.1 To provide a forum for sharing knowledge, good practice, education and development of specialist nurses, clinical nurse specialists, specialist midwives and new born counselling health visitors (SpNMHV) subgroup members of the West London Sickle HCC.
- 1.2 To provide opportunities for peer support and clinical supervision for SpNMHV to keep abreast of developments in the specialist field and identify ways in which they can contribute to the developments and implementation of approved and agreed changes.
- 1.3 To provide opportunities for collaborative working with clear aims, objectives and timescales for delivery.
- 1.4 To provide a pathway for giving feedback to the HCC steering group including information about the achievements of the group and areas of concern which need to be addressed by the steering group or brought to the attention of the LHTs or SHTs.
- 1.5 Receive updates from the HCC and National Haemoglobinopathy Panel (NHP) via the chair of the SpNMHV subgroup.
- 1.6 To develop mechanisms for collecting local and regional activity data, for submission to the steering group and present at the annual general meeting of the West London HCC.
- 1.7 To contribute to the development and provision of educational resources and programmes for students, generalist nurses, midwives, HVs, allied health and other professionals in care and management of the patient group and the wider community, including raising public awareness of sickle cell.
- 1.8 To initiate and contribute to regional clinical audit and research.

2. Membership

- 2.1 Specialist Nurses, Midwives and new born carrier counselling health visitors working in the Local Haemoglobinopathy Team (LHT) hospitals and Specialist Haemoglobinopathy Team (SHT) hospitals and community care Trusts in the West London Sickle HCC Region.

2.2 Chair:

The Chair will be agreed from members of the group but ideally the chair must be a member of the West London Sickle HCC Steering group. There will also be an agreed Co-Chair from the membership. The role of the Chair and Co-Chair will be agreed and documented.

3. Quorum

- 3.1 A minimum of 3 members need to attend from the above membership. Meetings should go ahead wherever possible.
- 3.2 Attendance can be in person or via Microsoft Teams or other approved virtual platforms.
- 3.3 Attendance, apologies and minutes of meeting will be documented. Absence from the meeting will also be minuted. Minutes will be circulated in a timely manner, including action points and clear timescales for any actions required to be undertaken by a member.
- 3.4 The Chair or acting chair is responsible for checking the draft minutes prior to circulation to members of the group. During a subsequent meeting those who attended the meeting will check for accuracy, correct and agree the minutes.

4. Sharing information/resources

- 4.1 The main method of sharing information between group members will be via nhs.net email which may include confidential material. Members will respect and maintain confidentiality of identified information shared during meetings or circulated via email, especially during clinical supervision where sensitive information may be shared. However anonymised patient information must be used and patient identifiable information must not be disclosed.
- 4.2 Information relating to this forum including a copy of the terms of reference, minutes of meetings and other relevant documentation will be held by members of the subgroup and stored by the HCC administrator.

5. Frequency of meetings

The meetings will be held quarterly. Clinical supervision will be held six weekly.

6. Review terms of reference

To be reviewed in June 2022

West London Haemoglobinopathy Coordinating Centre
Patient and Public Voice Group

Terms of Reference

Role

The Patient and Public Voice (PPV) Group will act as the patient forum for the West London Haemoglobinopathy Coordinating Centre (HCC) and will feed into the HCC Steering Group via a nominated representative. The PPV Group will comprise of patient and parent representatives from Paediatric and Adult services of the three Specialist Haemoglobinopathies Team (SHT) networks with a view that representatives of children, adolescent, and adults are involved. The PPV Group will lead on decisions made by the HCC around engagement of the patient population, and patient involvement in the aims of the HCC.

Overall Aim

The PPV Group is an integral part of the West London HCC and will lead, advise, coordinate and report on progress in achieving the strategic aim of involving patients and the public in order for their views to affect decisions taken about the planning, improvement, monitoring and evaluation of all services within the West London HCC.

Supporting Objectives:

- To provide advice within the West London HCC regarding strengthening patient and public involvement in services pertaining to them.
- To evaluate the level and quality of patient and public involvement currently being undertaken identifying good practice and areas for priority work.
- To monitor progress in achieving the strategic aim for patient and public involvement and provide West London HCC with a written report
- To act as an advisory panel to meet with staff who are planning consultation and/ or patient and public initiatives.
- To reflect on the outputs and outcomes from consultations and/or patient and public initiatives.
- To hold regular meetings throughout the year to share ideas, support learning and development, address challenges and further develop patient and public involvement in specialised services.
- To initiate links with key stakeholders including but limited to other service users and the wider public.
- Coordinate and/or undertake specific patient and public consultations if requested by the West London HCC.
- To nominate patient and public representatives to represent the HCC if requested by the HCC.

1 Membership

- 1.1 The PPV Steering Group will review its membership as appropriate to ensure that it best reflects and supports the strategic aim with regard of patient and public involvement.
- 1.2 To ensure that the network is well represented with members from the SHTs and Local Haemoglobinopathy Teams (LHT), recognising the overall aim is about supporting involvement.
- 1.3 Other individuals may be co-opted for specific projects.

2 Chair role and responsibilities

- 2.1 The PPV Steering Group will be chaired by a patient or carer supported by the network manager. The chair will ensure the following is undertaken. However, some of the supporting actions may be delegated.
 - The meeting is convened.
 - Setting the agenda of the meeting in consultation.
 - Minutes for meetings are appropriately taken and subsequently distributed.
 - Ensuring the annual objectives are agreed and set and the work programme is followed through.
 - Ensure the meetings conform to all requirements for equal opportunities and to support members to participate in the meeting.

3 Quorum

- 3.1 The quorum necessary for the transaction of business shall be that the chair must be present with 5 members. Decision making rules will be determined to ensure decisions can be taken effectively.

4 Frequency of meetings and attendance requirements

- 4.1 The PPV Group will meet once a month.
- 4.2 Members should aim to attend as many meetings as possible; if they are unable to attend they shall try and send apologies in advance.

5 Objectives

The PPV Group will adopt the principles of co-design laid out in the Terms of Reference. Objectives will be reviewed in real time as commissioning intentions are communicated to providers.

6 Procedures of the West London HCC

- Each meeting will be structured with a pre-determined agenda. The PPV Group will be supported within the West London HCC with administration and communication.
- Any member of the PPV group may raise an issue with the chair, normally by written submission. The chair will decide whether the issue shall be included in the PPV Group business.
- The meeting will start and finish on time.
- Confidential information will be clearly indicated in advanced and will not be discussed outside the meeting without prior agreement.
- Plain language will be used where possible.
- All attendees will have an opportunity to contribute to the meeting. Discussions will remain on topic, and focused, if you agree to do something you are expected to do it.
- If someone cannot attend a meeting, you are expected to send their apologies.
- The PPV group will develop an annual work plan.
- Regular reports will be submitted to West London HCC Steering Group.

7 Reporting responsibilities

7.1 The PPV Group will report into the West London HCC Steering Group. It will receive reports from Task and Finish subgroups which it will use to deliver specific piece of work as required to meet the objectives of the group. It will receive quarterly and annual reports on the achievements/activities of the West London HCC. In addition to this the following duties and responsibilities will be undertaken:

- To attend meetings, workshops etc, and participate in the work of the PPV as relevant and as agreed.
- To comply of standards of conduct.
- To raise areas of unresolved concerns regard in the process of decision making or the outcome of the work.

8 Standards of Conduct

8.1 Seven principles of public life.

8.1.1 Selflessness

Holders of public office should act solely in terms of the public interest.

8.1.2 Integrity

Holders of public office must avoid placing themselves under any obligation to people or organisations that might try inappropriately to influence them in their work. They should not act or take decisions in order to gain financial or other

material benefits for themselves, their family, or their friends. They must declare and resolve any interests and relationships.

8.1.3 Objectivity

Holders of public office must act and take decisions impartially, fairly and on merit, using the best evidence and without discrimination or bias.

8.1.4 Accountability

Holders of public office are accountable to the public for their decisions and actions and must submit themselves to the scrutiny necessary to ensure this.

8.1.5 Openness

Holders of public office should act and take decisions in an open and transparent manner. Information should not be withheld from the public unless there are clear and lawful reasons for so doing.

8.1.6 Honesty

Holders of public office should be truthful.

7.1.7 Leadership

Holders of public office should exhibit these principles in their own behaviour. They should actively promote and robustly support the principles and be willing to challenge poor behaviour wherever it occurs.

9 Monitoring and Review:

- 9.1 The PPV Group will review the Terms of Reference at the outset of the first independent meeting and annually to ensure that it remain fit for purpose and is best to discharge its duties
- 9.2 Terms of reference approved 31.March.2021
- 9.3 To be reviewed 30.Sep.2021

APPENDIX 1

Current objectives of the Steering Group are to:

- Ensure commitment to working together for the improvement of health and wellbeing for the Sickle Cell population of the West London HCC, including embedded engagement with service users and the voluntary sector, and to extracting maximum value from public spend on health;
- Drive cultural change towards the management of population health and wellbeing;
- Ensure open and regular communication, early raising of risks and issues and a shared commitment to their resolution wherever possible;
- Ensure transparent sharing of data, where this does not represent a commercial conflict or contravene information governance.
- That the HCC should support in engaging with schools and young people with sickle cell disease the idea of an assembly is excellent along with the training of the first aiders, School nurses and teachers
- That the HCC should work on training in the LHTs especially in A+E departments

Work out a way to get a caption/Acronym in the style of the Stoke F.A.S.T. to promote sickle cell education on a national level

APPENDIX 12 – Maps of the MDT

