WM QRS West Midlands Quality Review Service

UK Forum on Haemoglobin Disorders

Health Services for People with Haemoglobin Disorders

North Central London Network

University College London Hospitals NHS Foundation Trust
Whittington Health NHS

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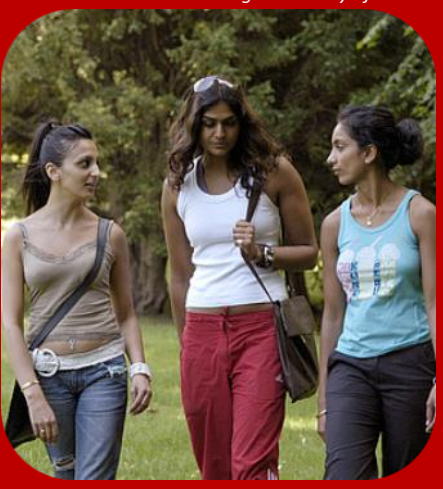

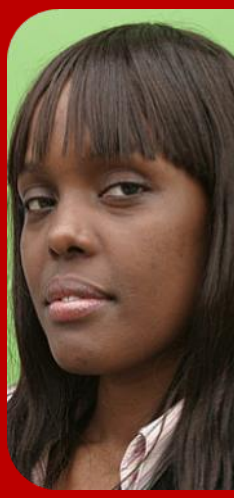

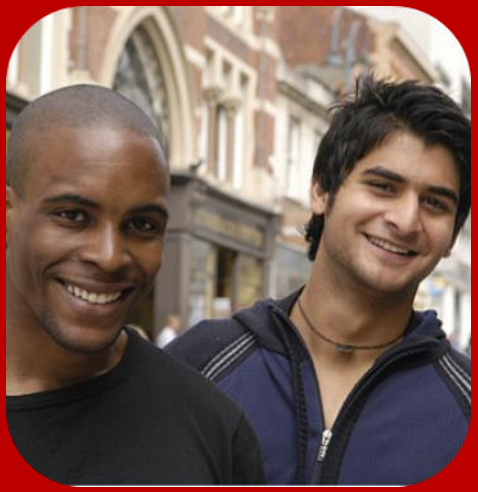

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INDEX

Introduction **3**

Haemoglobin Disorders Services in North Central London Network **4**

Adult Services – University College Hospital 4

Children and Young People – University College Hospital 6

Adult Services – Whittington Hospital 7

Children and Young People – Whittington Hospital 8

Views of Service Users and Carers 9

Review Visit Findings **10**

Network 10

Specialist Team: University College London Hospitals NHS Foundation Trust: Adults 12

Specialist Team: University College London Hospitals NHS Foundation Trust: Services for Children and Young People 13

Specialist team: Whittington Health NHS - Adult Services 15

Specialist team: Whittington Health NHS - Services for Children and Young People 16

Commissioning 17

Appendix 1 Membership of Visiting Team **18**

Appendix 2 Compliance with the Quality Standards **19**

Specialist Services for People with Haemoglobin Disorders - Adults 20

Specialist Services for People with Haemoglobin Disorders – Children and Young People 46

Haemoglobin Disorders Clinical Network 74

Commissioning 78

INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in University College London Hospitals NHS Foundation Trust and Whittington Health NHS (part of the North Central London Network), which took place on 26th November 2015. The purpose of the visit was to review compliance with the Quality Standards for Health Services for People with Haemoglobin Disorders V2, 2014 which were developed by the UK Forum on Haemoglobin Disorders working with the West Midlands Quality Review Service (WMQRS). The peer review visit was organised by WMQRS on behalf of the UK Forum on Haemoglobin Disorders. The Quality Standards refer to the following types of specialised service for people with haemoglobin disorders:

Specialist Haemoglobinopathy Centre (SHC)

Accredited Local Haemoglobinopathy Team (A-LHT): A Local Team to which the Specialist Centre has delegated the responsibility for carrying out annual reviews

Local Haemoglobinopathy Teams (LHT): These are sometimes also called 'Linked Providers'

The aim of the Standards and the review programme is to help providers and commissioners of services to improve clinical outcomes and service users' and carers' experiences by improving the quality of services. The report also gives external assurance of the care which can be used as part of organisations' Quality Accounts. For commissioners, the report gives assurance of the quality of services commissioned and identifies areas where developments may be needed.

The report reflects the situation at the time of the visit. The text of this report identifies the main issues raised during the course of the visit. Appendix 1 lists the visiting team and Appendix 2 gives details of compliance with each of the standards and the percentage of standards met.

This report describes services provided or commissioned by the following organisations:

- University College London Hospitals NHS Foundation Trust
- Whittington Health NHS [The Whittington Hospital NHS Trust]
- NHS England Specialised Commissioning
- NHS Camden Clinical Commissioning Group (CCG), NHS Islington CCG, NHS Barnet CCG, NHS Central London (Westminster) CCG, NHS Enfield CCG and NHS Haringey CCG.

Most of the issues identified by quality reviews can be resolved by providers' and commissioners' own governance arrangements. Many can be tackled by the use of appropriate service improvement approaches; some require commissioner input. Individual organisations are responsible for taking action and monitoring this through their usual governance mechanisms. The lead commissioner for the service concerned is responsible for ensuring action plans are in place and monitoring their implementation liaising, as appropriate, with other commissioners. The lead commissioner in relation to this report is NHS England; Specialised Cancer and Blood.

Acknowledgements

We would like to thank the staff of University College London Hospitals NHS Foundation Trust and Whittington Health NHS for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks too to the users and carers who took time to come and meet the review team. Thanks are also due to the visiting team (Appendix 1) and their employing organisations for the time and expertise they contributed to this review. The NHS Sickle Cell and Thalassaemia Screening Programme funded this peer review programme.

About West Midlands Quality Review Service

WMQRS is a collaborative venture between NHS organisations in the West Midlands to help improve the quality of health services by developing evidence-based Quality Standards, carrying out developmental and supportive quality reviews - often through peer review visits, producing comparative information on the quality of services and providing development and learning for all involved. More detail about the work of WMQRS is available on www.wmqrs.nhs.uk

HAEMOGLOBIN DISORDERS SERVICES IN NORTH CENTRAL LONDON NETWORK

The North Central London Haemoglobinopathy Network consisted of two specialist centres, University College London Hospitals NHS Foundation Trust (UCLH) and Whittington Health NHS (WH), providing care for children and adults with haemoglobinopathies.

Adults

Trust	Reviewed as:	No. of adults with sickle cell disease	No. of adults with thalassaemia	No. of adults on long term red cell transfusions
University College London Hospitals NHS Foundation Trust	SHT	251	150	210 (106 SCD, 104 Thal)
Whittington Health NHS	SHT	239	197	155
Luton and Dunstable University Hospital NHS Foundation Trust	LHT	43	15	42
Royal Free London NHS Foundation Trust	LHT	12	0	10

Children and Young People

Trust	Reviewed as:	No. of children with sickle cell disease	No. of children with thalassaemia	No. of children on long term red cell transfusions
University College London Hospitals NHS Foundation Trust	SHT	49	20	14
Whittington Health NHS	SHT	120	21	20
Luton and Dunstable University Hospital NHS Foundation Trust	LHT	<5	0	0
Royal Free London NHS Foundation Trust	LHT	12	0	8

ADULT SERVICES – UNIVERSITY COLLEGE HOSPITAL

Emergency Care

Adults who were acutely unwell were encouraged to call the advice line. During the day this was answered by one of the haematology administrators who dealt with administrative queries and passed on clinical queries to the clinical nurse specialist (CNS). Out of hours the advice line was answered by a senior staff nurse on the adult haematology ward. Patients were advised to attend day care, see their GP or attend the Emergency Department (ED).

ED staff began initial management following triage and assessment of patients. The haematology Senior House Officer (SHO) was called to complete the clerking and admissions process. The red cell haematology Specialist Registrar was contacted about all admissions, even if patients were admitted under another medical team.

The red cell CNS was informed by email about any patients who were seen in ED but not admitted, in order to ensure they were offered follow-up.

In-Patient Care

The haematology in-patient service was situated on two floors. Floor 16 South had 22 in-patient beds in side rooms and Floor 13 North had 24 in-patient beds comprising one female and one male bay and side rooms. The majority of patients were cared for on these wards.

If the patient developed an infection that carried a high likelihood of transmission, for example, a respiratory illness, they were moved to either an alternative haematology ward or a specialist isolation ward within the tower (T8). Haematology nurses provided an outreach service to both the patients and the nurses on T8. In-patients were under the care of the Red Cell Team and were reviewed daily by them, or by the on-call haematology team at the weekend. An 'overnight transfusion bed' on the haematology ward was well-utilised and enabled patients to receive their transfusions when the day unit was closed.

Day Care

The haematology day care unit provided services for patients with sickle cell disease and thalassaemia including blood tests, blood transfusion, both manual and automated red cell exchange transfusion, Pamidronate transfusion for the thalassaemia patients and management of indwelling lines (for example, vortex ports and port-a-caths). The unit had a rapid access service for patients with sickle cell disease and thalassaemia with health related problems including pain management. Advice was also provided over the telephone, where appropriate.

Out-Patient Care

The haematology out-patient department was on the fourth floor of the UCLH Macmillan Cancer Centre. Red cell clinics were held on Wednesday mornings and evenings. The clinics were multi-disciplinary and were staffed by haematology medical staff (consultants and Specialist Registrar), a clinical psychologist, data manager, a clinical nurse specialist and a consultant in fertility and bone health. In addition a consultant andrologist attended the clinic once a month and a consultant endocrinologist once every two months.

Community-based Care

Community services were based at the Community Sickle Cell Centre in Camden and Islington. A community matron there worked with patients with sickle cell disease in both hospital and community settings and was responsible for leading the care co-ordination of adult patients with sickle cell disease and patients with complex care needs.

In addition the service was staffed by two full-time haemoglobinopathy specialist nurses for sickle cell disease and thalassaemia who had experience in counselling and supporting families affected by these conditions.

The community service was also responsible for health education and promotion. Health professionals, voluntary groups, carers and individuals were able to arrange for the counsellor to provide support or to facilitate educational training sessions. A 'Red Cells R Us Support Group' met once a month to discuss health and social issues. The group was primarily a forum for sickle cell disease and thalassaemia service users to get to know each other. The counsellors acted as facilitators in organising guest speakers who provided an overview of care and management of sickle cell disease. The aim of the group was to provide information, peer support and raise awareness about sickle cell disease and thalassaemia. In addition a Young Persons Support Group and a Parent and Child Support Group met regularly at the Centre.

Return to *Index*

CHILDREN AND YOUNG PEOPLE – UNIVERSITY COLLEGE HOSPITAL

Emergency Care

Children had a 'paediatric passport' which facilitated rapid triage and assessment by the UCLH ED staff. The duty paediatric team was primarily responsible for the admission, although the haematology red cell Specialist Registrar or paediatric haemoglobinopathy clinical nurse specialist was always contacted. All patients were assessed by the paediatric consultant within 12 hours of admission. The red cell consultants provided support on a 1:3 on-call rota. Protocols and care plans were available electronically. If admission was required patients were admitted to paediatric wards T11 paediatric or T12 adolescent wards until their 19th birthday, although the adult haematology team provided all their care for those over 18.

In-Patient Care

Patients were admitted to wards through planned admissions, from clinic or via the ED. Adolescents were admitted to the adolescent unit T12 adolescent on Floor 12 South which consisted of 22 in-patient beds and side rooms. Facilities were age-appropriate and included a designated day room. Younger children were admitted to the general paediatrics ward on Floor 11 South T11 ward which had 16 in-patient beds and side rooms. This was co-located with the day care facilities. A school room was available from Monday to Friday for use by children and a school teacher was available. Play therapy services were available on the ward.

Patients were jointly managed by the general paediatrics team and the red cell team with daily consultant review. Emergency exchange transfusions were organised on the ward. Patients aged 13 years or older were moved to day care for this procedure.

Day Care

The paediatric day care unit offered a wide range of services including blood tests and cannulation, blood transfusion, manual and automated red cell exchange transfusion, venesection, and management of indwelling lines, (for example vortex ports and port-a-caths). Ward reviews were organised if required.

Day care was situated on T11 ward on the 11th Floor from Monday to Friday between 7.30am and 8pm and on T12 ward on the 12th floor from Monday to Friday between 7.45am and 3.45pm. Saturday transfusions were provided if required.

The apheresis team was based in the Apheresis Unit in the Cancer Centre on the fourth floor. A ratio of 2:1 machines to nurses was used in addition to a dedicated apheresis co-ordinator responsible for facilitating routine automated red cell exchange. The team was able to perform exchanges on children aged 13 years or older in the Cancer Centre, and this was preferentially organised in a side room. If a younger child required this procedure it was performed on the paediatric in-patient ward. One nurse was the apheresis lead for red cell patients. It was planned that the paediatric CNS appointed just prior to the visit would lead the paediatric component of this service.

Out-Patient Care

The paediatric out-patient department was located on the lower ground floor, Elizabeth Garrett Anderson Building. Red cell clinics were held on Monday afternoons. The paediatric haematology consultant and one registrar attended the clinic. Every three months they were joined by the paediatric endocrinologist for the growth clinic. A visiting paediatric haematologist was responsible for the Trans-cranial Doppler scans and attended ten clinics a year. Phlebotomy was provided by clinic nurses who also helped with vaccinations where needed. Play therapy services were available.

Community-Based Care

Community care was provided by the community team based at the Camden and Islington Sickle Cell and Thalassaemia Centre. The community services had become an integral part of Whittington Health NHS when it became an integrated care organisation in 2011 resulting in much more integrated working between

haemoglobinopathy staff in the community and acute sectors. The community services were organised with a high level of patient engagement and included a support group that had been continuously in operation at the centre since 1989. This group 'Red Cells R Us' met once a month to discuss health and social issues. A Young Persons Support Group and a Parent and Child Support Group also met regularly at the Centre. An integrated care community matron and a clinical psychologist worked with patients with sickle cell disease in the hospital and community settings. The service also had 1.6 w.t.e. genetic counsellors, one administrator and a full-time haemoglobinopathy specialist nurse who had been appointed and was due to start in January 2016. The service was responsible for health education and health promotion for patients with sickle cell disease and thalassaemia disorders, coordination of antenatal and neonatal screening and genetic counselling.

Return to *Index*

ADULT SERVICES – WHITTINGTON HOSPITAL

Emergency Care

Acutely ill patients with sickle cell disease and thalassaemia were advised to attend the Emergency Department. Patients with uncomplicated sickle cell crises were usually looked after by the on-call medical team until they were 'handed over' to the haematology team after the 'post-take' ward round the following day. The haematology team took over the care of patients with more complex needs during normal working hours. The haematology service had a 24/7 on-call rota. Thalassaemia patients requiring emergency care were seen by the haematology team during normal working hours. Most patients with sickle cell disease had individualised pain protocols which were followed when they presented with sickle cell crisis. The protocols were stored in electronic form on the hospital computer shared drive and were easily accessible in all clinical areas. Those without a pain protocol were treated using a generic protocol which was also stored electronically on the shared drive.

In-Patient Care

Acutely ill patients with sickle cell disease and thalassaemia requiring in-patient care were admitted initially to one of two acute assessment units (AAU), either Mary Seacole North (16 beds) or Mary Seacole South (18 beds). Once stable, patients were transferred, usually to Victoria Ward. Although the AAU wards were not specific to patients with haemoglobin disorders, they were staffed by doctors and nurses who were experienced in the care of haemoglobinopathy patients. Victoria Ward was a 33-bedded ward general medical ward. If there were no beds on Victoria Ward then the patient spent their entire admission on AAU. All haemoglobinopathy patients were reviewed at least once daily by the haematology team.

Day Care

The thalassaemia unit was open every day between 9am and 5pm and offered transfusion services for patients with sickle cell disease and thalassaemia. The unit was purpose-built with seven double sofa beds, one reclining chair and three armchairs for phlebotomy patients or for visitors. It accommodated up to ten patients. Amenities available to patients and visitors included televisions, DVDs, free Wi-Fi, refreshments and a garden. The unit had a dedicated secure blood transfusion fridge which ensured timely transfusions as staff did not have to wait for blood to be transported from the main transfusion laboratory. The unit also had a quiet room and a separate procedure room. Small numbers of patients with sickle cell disease and thalassaemia were also seen on the Ambulatory Care Unit.

Out-Patient Care

The sickle cell clinic took place once a week. The majority of thalassaemia patients were seen in a weekly afternoon to evening clinic. A combined diabetes and thalassaemia clinic was held every three months. In addition, a nurse-led annual review clinic took place weekly with a consultant review for patients if needed at the same time.

Community-Based Care

Community care was provided by the community team based at the Camden and Islington Sickle Cell and Thalassaemia Centre. The community services had become an integral part of Whittington Health NHS when it became an integrated care organisation in 2011 resulting in much more integrated working between haemoglobinopathy staff in the community and acute sectors.

Return to *Index*

CHILDREN AND YOUNG PEOPLE – WHITTINGTON HOSPITAL

Emergency Care

Children affected by haemoglobin disorders were issued 'Emergency Cards' which gave them to direct access to the paediatric department, by-passing the ED. Parents were encouraged to telephone the senior nurse on duty who was available 24/7 for telephone advice. Assessment could be coordinated on the ward, Children's Ambulatory Unit (CAU) or in the out-patient clinic. During normal working hours the paediatric haemoglobinopathy nurse was also available for telephone advice. A consultant-led emergency referral clinic was held in the Children's Ambulatory Unit every weekday morning from 10am to noon. All affected families and local GPs were aware of this service. In the ED the duty paediatric team was responsible for assessment and management of children and young people with haemoglobin disorders.

In-Patient Care

Children and young people up to their seventeenth birthday were admitted directly to Ifor Ward. The ward had a playroom with outdoor play area, a parent's room with kitchen facilities, access to educational provision both at the bedside and in a separate schoolroom, additional isolation cubicles for children and facilities for one parent to stay at their child's bedside. A high dependency unit was available on the ward including support for non-invasive ventilation and exchange transfusion. Funding had been approved for an adolescent bay on Ifor ward.

Day Care

Ambulatory management of children was coordinated in two areas. The acute Children's Ambulatory Unit was utilised for acute presentations and Roses Day Unit for elective attendances. The CAU facility was open seven days a week from 7.30am to 8.30pm. For children resident in the London Borough of Islington, an enhanced 'Hospital at Home' service operated daily from 7.30am to 10.30pm. This service provided community children's nursing input including administration of multiple doses of Intravenous therapy.

Children attended Roses Day Care three days prior to their planned transfusions for their pre-transfusion bloods to be taken. The unit was open from Monday to Friday from 7.30am to 7.30pm. Most children were cannulated by the nurses, with duty medical staff available for the more challenging cannulations. Children's community nurses also performed monitoring blood tests on patients at home or at school and the results were sent to the lead clinician and CNS.

Out-Patient Care

Out-patient clinics were held in Clinic 4D in the out-patient department. On Mondays from 2.30pm to 5.30pm, patients with sickle cell disease were seen by a joint team comprising a consultant paediatrician, a consultant haematologist, CNS, a clinical psychologist (when in post) and a family psychotherapist. Every two months on Thursdays, children with thalassaemia and sickle cell disease with transfusional iron overload were seen by the joint paediatric and adult team comprising a consultant paediatrician, a consultant haematologist and CNS. This clinic ran from 3.30pm to 8pm. Tertiary and new referrals of older children were seen initially by the consultant haematologist before being seen in the next available joint clinic. Every three months on Thursdays between 9am and 4pm a joint specialist endocrine clinic was held on site with a consultant paediatric endocrinologist

and visiting specialist from Great Ormond Street Hospital who reviewed and advised on the investigation and management of children and young people with iron overload-related endocrinopathy.

Community-Based Care

Community care was provided by the community team which was based at the Camden and Islington Sickle Cell and Thalassaemia Centre. The community services had become an integral part of Whittington Health NHS when it became an integrated care organisation which had improved integrated working between haemoglobinopathy staff in the community and acute sectors. The community services were organised with a high level of patient engagement and a support group had been continuously in operation at the centre since 1989. This group 'Red Cells R Us' met once a month to discuss health and social issues. A Young Persons Support Group and a Parent and Child Support Group also met regularly at the Centre.

The service was staffed by full-time haemoglobinopathy specialist nurses for sickle cell and thalassaemia. An integrated care community matron and a clinical psychologist worked with patients with sickle cell disease in hospital and community settings. The service was responsible for health education and health promotion on sickle cell and thalassaemia disorders, coordination of antenatal and neonatal screening and genetic counselling.

Return to *Index*

Views of Service Users and Carers

University College London Hospitals NHS Foundation Trust

The visiting team met a number of patients and carers with both sickle cell disease and thalassaemia and received feedback from them. They also reviewed responses to 28 questionnaires.

Common themes raised by patients and carers were:

Children and young people's services

- Staff were extremely pleasant and their efforts were appreciated but the systems in place were not robust and frequently failed
- Problems with prescribing of medicines and ordering of blood were reported
- The lack of an experienced clinical nurse specialist (CNS) was viewed as particularly problematic

Adult services

- Overall feedback was positive
- Patients were happy with the team and they felt that the consultant had helped them in a lot of ways
- Patients felt that the CNS had too much work for one person
- Patients welcomed the many strategies that had been put in place, for example, regular meetings with the haematology consultant to discuss issues and patients being reminded when to attend for blood tests and clinic appointments

Whittington Health NHS

The visiting team met a number of patients and carers with both sickle cell disease and thalassaemia and received feedback from them. They also reviewed responses to over 50 questionnaires.

Common themes raised by patients and carers were:

- Overall the feedback was very positive and the patients and carers mentioned that the staff exceeded their job descriptions which was highly appreciated

- Most of the patients with sickle cell disease reported that they had care plans and that they were asked to cooperate in designing the plans
- The patients felt that their treatment in the ED was dependent on whether they were lucky enough to find a staff member on duty who knew them
- The medical staff often had difficulty accessing their information out of hours
- Patients reported being left in severe pain as there could be long waits for analgesia
- The adult patients would welcome an "emergency card" similar to that used by the paediatric patients. The parents of children with sickle cell disease reported that this worked extremely well for them
- Praise for the dedication and concern for the patients provided by the CNS for children and young people who always responded to their needs
- Patients welcomed the fact that a CNS for the adult patients with sickle cell disease was expected to start shortly after the visit which they expected would resolve many of the issues reported

Return to *Index*

REVIEW VISIT FINDINGS

NETWORK

General Comments and Achievements

The North Central London Haemoglobinopathy Network consisted of two specialist centres, University College London Hospitals NHS Foundation Trust (UCLH) and Whittington Health NHS (WH). The two centres had formed the Joint Red Cell Unit in 2004 and had been developing an integrated service since then. They saw the largest number of thalassaemia patients in the UK. In addition to providing high quality care to their local patients the centres also provided a tertiary level of care to patients from across the UK. This service functioned as a national resource for patients with thalassaemia and other iron-loading conditions, providing both supra-specialist review and phone or email advice.

UCLH provided a large automated apheresis service which was expanding rapidly and the number of patients had almost doubled since the previous peer review visit for adult services in 2012. A large number of patients from outside the hospital catchment area were accommodated and many of these patients had complex medical and nursing needs which had led to a disproportionate increase in workload.

Adult services were linked with two local hospitals, the Royal Free London NHS Foundation Trust and the Luton and Dunstable NHS Foundation Trust. Out-patients with haemoglobinopathies attended one of the specialist centres for routine care. Two of the consultants at WH had sessions at the Royal Free Hospital to review in-patients, most frequently those admitted under the renal or liver teams. Barnet Hospital did not offer routine care for patients with haemoglobinopathies but had approximately 12 acute admissions per year of patients with sickle cell disease. They used the protocols and an escalation policy from WH and would call them for advice. Luton and Dunstable NHS Foundation Trust provided care for a relatively large number of patients with haemoglobinopathies. Patients were under the care of one haematology consultant with insufficient time in their job plan and no cover for absence. One of the consultants at WH attended specialist sickle cell disease and thalassaemia outreach clinics at Luton and Dunstable Hospital once a month. Patients from either local centre who required automated exchange or intensive care were referred to UCLH.

The paediatric service at Luton and Dunstable Hospital was supported by an outreach clinic from Imperial NHS Foundation Trust. Local hospitals did not have formal links to either specialist centre for paediatric services. Neither specialist centre had a paediatric intensive care unit.

Progress since Last Visit

A good degree of integration of adult services across the network was evident, in particular, the haematology team working across sites. Protocols were shared with some local modifications.

Good Practice

1 Communication between the two specialist centres and local centres for adult services was good and local centres felt well supported.

2 A good range of supra-specialist clinics was available for example, endocrine and cardiology clinics were held and were open to patients across the network and beyond.

Immediate Risks: No immediate risks were identified.

Concerns

1 A sizeable and growing population of patients lived in the Luton area. The reviewers considered that consultant and nursing time and community provision was insufficient to meet the needs of this population.

Further Consideration

1 A review of the network links should be considered to harmonise referral pathways.

Return to *Index*

NETWORK CONFIGURATION

These centres had a small formal network however they provided tertiary care for a large number of patients across the UK. At UCLH over 60% of out-patient appointments were allocated for patients outside the local area.

The network configuration at the time of the review was as follows:

Specialist Haemoglobinopathy Centre	Local Haemoglobinopathy Teams
University College London Hospitals NHS Foundation Trust: University College Hospital	• Luton and Dunstable University Hospital NHS Foundation Trust • Royal Free London NHS Foundation Trust (Royal Free Hospital, Barnet Hospital)
Whittington Health NHS: Whittington Hospital	

Return to *Index*

SPECIALIST TEAM: UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST: ADULTS

General Comments and Achievements

This was an excellent integrated paediatric and adult red cell service delivered by a highly committed and cohesive team of health professionals. The transition of local patients from paediatric to adult services was therefore good. The service promoted a 'one stop' approach to patient care with good multi-disciplinary working allowing for efficient and streamlined management. The team had an admirable track record in education and research. Facilities at the UCLH site overall were very good. It provided a highly specialist service particularly for thalassaemia and in effect, functioned as a national reference centre receiving large numbers of referrals from across the UK.

The apheresis service was efficient and effective. The number of patients was increasing and a service was provided for a large number of tertiary patients. The team was proactive at offering disease modifying therapy, either transfusion or hydroxycarbamide. The day unit provided an excellent service and patients commented positively on their ability to access acute pain treatment via the day unit.

Progress since Last Visit

Since the last review which took place in 2012, a full-time haemoglobinopathy consultant had been appointed. The supra-specialist clinics with a diabetologist and andrologist had been developed. The red cell apheresis service had expanded and weekly multi-disciplinary meetings were taking place.

Good Practice

1 The thalassaemia service provided high quality care, particularly the supra-specialist clinics for example, endocrinology and cardiology.

2 The service participated in an expanding programme of haemoglobin disorders research which was directly benefitting patients. It included publication of more than 65 peer reviewed articles since the last review and the numbers of clinical trials had increased.

3 An educational programme including an MSc in Haemoglobinopathies and an International Fellowship in Thalassaemia had been developed.

4 The guidelines were clear, comprehensive and easily available electronically. The reviewers considered that the guidelines on iron chelation, pregnancy in thalassaemia and the management of acute complications of thalassaemia were particularly noteworthy. The annual review proforma for thalassaemia was also very thorough. A good pre-operative guideline and proforma had been developed.

5 The patient leaflets were comprehensive and of high quality. The leaflet about psychology and the welcome pack were particularly noted by reviewers.

6 Patient engagement was particularly good with an active community-based user group, a young person's support group and a parent and child support group. These groups met regularly at the community centre.

7 Access to alternative and holistic therapies was facilitated through the Macmillan Centre and was highly valued by families.

8 A meeting was held every three months between patients and staff with the aim of improving communication.

Immediate Risks: No immediate risks were identified.

Concerns

1 The clinical nurse specialist (CNS) had a high workload in view of the number of patients with complex conditions and had limited time for service development. Review of CNS provision may enable planned service developments, including extension of the role to cover out-patient clinics.

2 Whilst many patients accessed emergency care via the day unit, those who used the ED commented that they often waited over 30 minutes for analgesia.

Further Consideration

1 The service had successfully incorporated large numbers of referrals into its apheresis service but these were often complex patients requiring multi-disciplinary resource. Reviewers suggest that the Trust should review the sustainability of this service and ensure it is adequately resourced.

2 It was not clear how the planned move of malignant haematology services from the Royal Free Hospital to UCLH would impact on the resources available to haemoglobinopathy patients. The red cell service had to change the times of its out-patient clinics which would impact on the one-stop cardiology clinic. Reviewers were also told of concerns about increased pressure on day care and in-patient facilities following the move.

3 Although the ED had good links with community services to facilitate ambulatory and outreach work, this was not specific to haemoglobinopathies. Patients felt that resources based at WH integrated community service were less accessible for UCLH patients.

4 Adult patients could not access transfusions at the weekends. It may be helpful to consider developing this aspect of the service.

5 Reviewers were told of problems accessing treatment for patients with leg ulcers and liaison with psychiatry services for in-patients. Further work to improve links with these services may be helpful.

6 Patient-controlled analgesia (PCA) was not available on all medical wards and patients placed on non-haematology out-lying wards were not able to use this method of analgesia.

7 Despite the three-monthly patient and staff meetings, some patients commented that it was difficult to provide feedback about the service.

8 Guidelines for when the local centres should refer for specialist advice were not seen. Guidelines on when tertiary advice should be sought may also be helpful.

Return to *Index*

SPECIALIST TEAM: UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST: SERVICES FOR CHILDREN AND YOUNG PEOPLE

General Comments and Achievements

This was an excellent integrated paediatric and adult red cell service delivered by a highly committed and cohesive team of health professionals. The transition of local patients from paediatric to adult services was therefore good. The paediatric service was small and managed patients proactively with few in-patient admissions. A considerable number of children, particularly adolescents, were seen from other regions, primarily for automated exchange. The service promoted a 'one stop' approach to patient care with good multi-disciplinary working allowing for efficient and streamlined management. The team had an admirable

track record in education and research. Facilities at the UCLH site overall were very good. Rates of 'did not attend' in the paediatric clinic were very low.

Progress since Last Visit

Since the last review visit, which took place in 2010, there had been a number of significant improvements. All protocols for the management of acutely presenting children were easily accessible electronically. A paediatric clinical nurse specialist (CNS) had been appointed and was going to lead on the paediatric automated exchange service.

Good Practice

1 Clinical guidelines were clear, comprehensive and easily available electronically. The reviewers considered that the escalation policy, transition guidelines and organisation policy were particularly noteworthy.

2 Use of the emergency access card allowed for rapid assessment and admission if required.

3 The service provided a high degree of flexibility for elective transfusion therapy with provision of evening and weekend transfusions.

4 Patient engagement was particularly good with an active community-based user group, a young person's support group and a parent and child support group. These groups met regularly at the community centre.

5 Access to alternative and holistic therapies was facilitated through the Macmillan Centre and was highly valued by families.

Immediate Risks: No immediate risks were identified.

Concerns: No concerns were identified.

Further Consideration

1 The children's ED was small and cramped. This was in contrast to all other facilities which were generally of a high standard.

2 Although the ED had good links with community services to facilitate ambulatory and outreach work, this was not specific to haemoglobinopathies with resources based at the WH integrated community patients felt that services were less accessible for UCLH patients.

3 The log book of activity was seen and a formal competence assessment had been organised for the Trans-Cranial Doppler scanning service but this service was provided by a visiting paediatric haematologist and no cover was available in her absence. A review of the service with appropriate cross cover arrangements and internal quality assurance may be helpful to ensure this service is sustainable in the longer term.

Return to *Index*

SPECIALIST TEAM: WHITTINGTON HEALTH NHS - ADULT SERVICES

General Comments and Achievements

This was an excellent integrated paediatric and adult red cell service delivered by a highly committed and cohesive team of health professionals. The transition of local patients from paediatric to adult services was therefore good. Patient and carer feedback was highly complimentary of the service and they valued the close working between community and acute services. The service had responded proactively to patient feedback with timely action plans and implementation of changes. The appointment of a data manager prior to the visit had helped with data collection including entry onto the national haemoglobin registry (NHR).

Progress since last visit

Since the last review which took place in 2012, a data manager had been appointed and the ambulatory care for children and adults had been established. An adult CNS had been appointed and was due to start in 2016.

Good Practice

1 The thalassaemia service, particularly the supra-specialist clinics (endocrinology) provided high quality care. The joint thalassaemia diabetic clinic was runner up in the British Medical Journal diabetes team of year awards in 2014.

2 Patients had been involved in the development of the excellent facilities for thalassaemia day care. The nurse-led annual review programme was comprehensive and provided patient-focussed flexible care. Extended hours and weekend transfusions were available.

3 An educational programme including an MSc in Haemoglobinopathies had been developed.

4 The guidelines were clear, comprehensive and easily available electronically. The reviewers felt the guidelines on iron chelation, pregnancy in thalassaemia and the management of acute complications of thalassaemia were particularly noteworthy. The annual review proforma for thalassaemia was also very thorough.

5 The patient leaflets were comprehensive and of high quality. Reviewers considered that the pregnancy leaflet was particularly noteworthy.

6 Patients were well supported by the community matron who provided high quality care at home.

7 Patient engagement was particularly good with an active community-based user group, a young person's support group and a parent and child support group. These groups met regularly at the community centre.

8 The transition process was fully integrated into care, with a clear process for transition including a welcome event when patients moved to adult care.

9 Care plans for thalassaemia were well structured and clearly laid out. Most patients with sickle cell disease had personalised care plans.

10 Joint paediatric and adult multi-disciplinary meetings were held.

Immediate Risks: No immediate risks were identified.

Concerns

1 Access to a psychologist with an interest in haemoglobinopathies and a neuro psychology was not available.

2 The consultants had a high workload with large patient numbers at three sites plus outreach clinics.

3 Patients reported that they often waited for over 30 minutes for analgesia and that care in Emergency Department (ED) was inconsistent. This may be improved by increased training of staff in ED.

Further Consideration

1 Reviewers suggested that consultant job plans should be reviewed and additional support should be considered to ensure the service is sustainable. At UCLH three consultants were delivering the red cell service, equating to just over two w.t.e. whilst at WH there were three w.t.e. consultants for all of adult haematology and for paediatric services two lead consultants were available for haematology. Little time was therefore available specifically for the care of patients with red cell disorders.

2 Reviewers felt that the service may benefit from additional support to facilitate participation in research projects.

3 An adult clinical nurse specialist (CNS) was not in post at the time of the visit although one had been appointed and was due to start in January 2016.

4 Patient-controlled analgesia (PCA) was not available on all medical wards and patients placed on non-haematology out-lying wards were not able to use this method of analgesia.

5 Reviewers suggested that the provision of automated apheresis at Whittington Hospital could enable care closer to home for patients who attended UCLH for their transfusions and this development should be considered.

6 Increasing development of the ambulatory care unit for the management of acute pain crisis would improve patient access.

7 Guidelines for when the local centres should refer for specialist advice were not seen. Guidelines on when tertiary advice should be sought may also be helpful.

Return to *Index*

SPECIALIST TEAM: WHITTINGTON HEALTH NHS - SERVICES FOR CHILDREN AND YOUNG PEOPLE

General Comments and Achievements

This was an excellent integrated paediatric and adult red cell service delivered by a highly committed and cohesive team of health professionals. The transition of local patients from paediatric to adult services was therefore good. Patient and carer feedback was highly complimentary of the service and they valued the close working between community and acute services. The service had responded proactively to patient feedback with timely action plans and implementation of changes. The appointment of a data manager prior to the visit had helped with data collection including entry onto the national haemoglobinopathy registry (NHR). The ambulatory care service allowed for robust delivery of scheduled and unscheduled care. The 'Hospital at Home' service allowed children to be treated at home, thereby avoiding frequent hospital visits.

Progress since last visit

Since the last review visit, which took place in 2010, a data manager had been appointed. The paediatric sickle clinics had changed to afternoons to suit children attending hospital. The ambulatory care for children and adults had become established.

Good Practice

1 The guidelines were clear, comprehensive and easily available electronically.

2 Care plans were well-structured and clearly laid out.

3 The use of the emergency access card allowed for rapid assessment and admission directly through the paediatric department, avoiding the busy ED.

4 The ambulatory paediatric care model was well-established and allowed many patient with acute complications to be treated as day patients

5 Patient engagement was particularly good with an active community-based user group, a young person's support group and a parent and child support group. These groups met regularly at the community centre.

6 Joint paediatric and adult multi-disciplinary meetings were held.

7 The transition process was fully integrated into care, with a clear process for transition including a welcome event when patients moved to adult care.

Immediate Risks: No immediate risks were identified.

Concern

1 Access to a psychologist with an interest in haemoglobinopathies and a neuro psychology was not available.

Further Consideration

1 The log book of activity was seen and a formal competence assessment had been organised for the Trans-Cranial Doppler scanning service but this service was provided by the lead nurse and no cover was available in her absence. A review of the service with appropriate cross cover arrangements and internal quality assurance may be helpful to ensure this service is sustainable in the longer term.

2 Reviewers considered that the service may benefit from additional support to facilitate participation in research projects.

Return to *Index*

COMMISSIONING

Immediate Risks: No immediate risks were identified.

Concerns: No concerns were identified.

Further Consideration

1 The Joint Red Cell Service provided a highly-valued advisory role in the management of thalassaemia patients in the UK. The numbers of babies born with thalassaemia in the area had markedly decreased in the years before the review visit however the workload was increasing in part due to large numbers of tertiary patients. These often had more complex needs which required input from the whole multi-disciplinary team. It was not clear that the tariff associated with these services reflected the complexity of care provided. Careful long-term planning of this service will be required with national input to ensure the excellent national service is supported in the long-term.

Return to *Index*

APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Clinical Leads

Dr Jo Howard	Consultant Haematologist	Guy's and St Thomas' NHS Foundation Trust
Dr Banu Kaya	Consultant Haematologist	Barts Health NHS Trust

Visiting Team

Nkechi Anyanwu	Clinical Nurse Manager (Haemoglobinopathies)	Guy's and St Thomas' NHS Foundation Trust
Aldine Thomas	Clinical Nurse Specialist	Barts Health NHS Trust
Charlotte Gabi	Clinical Nurse Specialist	Barts Health NHS Trust
Kim Newell	Clinical Nurse Specialist	Barts Health NHS Trust
Elaine Miller	Co-ordinator	UK Thalassaemia Society
Sia Nyandemo	Service User	Not applicable
Patrick Ojeer	Carer and Patient Leader	Not applicable

Return to *Index*

APPENDIX 2 COMPLIANCE WITH THE QUALITY STANDARDS

Analyses of percentage compliance with the Quality Standards should be viewed with caution as they give the same weight to each of the Quality Standards. Also, the number of Quality Standards applicable to each service varied depending on the nature of the service provided. Percentage compliance also takes no account of 'working towards' a particular Quality Standard. Reviewers often comment that it is better to have a 'No, but', where there is real commitment to achieving a particular standard, than a 'Yes, but' – where a 'box has been ticked' but the commitment to implementation is lacking. With these caveats, table 1 summarises the percentage compliance for each of the services reviewed.

Table 1 - Percentage of Quality Standards met

Adult Services	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders: University College London Hospitals NHS Foundation Trust	44	42	95
Specialist Services for People with Haemoglobin Disorders: Whittington Health NHS	43	39	91
Haemoglobin Disorders Clinical Network	9	9	100
Commissioning	3	0	0
Total	**99**	**90**	**91**

Service for Children and Young People	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders: University College London Hospitals NHS Foundation Trust	49	46	94
Specialist Services for People with Haemoglobin Disorders: Whittington Health NHS	49	42	86
Haemoglobin Disorders Clinical Network	9	9	100
Commissioning	3	0	0
Total	**110**	**97**	**88**

Pathway and Service Letters

HN-	Specialist services for People with Haemoglobin Disorders
HY-	Haemoglobin Disorders: Network
HZ-	Haemoglobin Disorders: Commissioning

Topic Sections

Each section covers the following topics:

-100	Information and Support for Patients and Carers
-200	Staffing
-300	Support Services
-400	Facilities and Equipment
-500	Guidelines and Protocols
-600	Service Organisation and Liaison with Other Services
-700	Governance

SPECIALIST SERVICES FOR PEOPLE WITH HAEMOGLOBIN DISORDERS - ADULTS

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-101 All	**Haemoglobin Disorder Service Information** Written information should be offered to patients and, where appropriate, their carers covering at least: a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the service e. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent) v. Give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns vi. Get involved in improving services (QS HN-199)	Y	Some patients reported that it was difficult to give feedback about the service. Information for 'h' 'v' and 'vi' was not seen.	Y	Patient information was good.

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-102 All	**Information about Haemoglobin Disorders** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of the condition (SC or T), how it might affect the individual and treatment b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Splenic palpation and Trans-Cranial Doppler scanning (children only) e. Transfusion and iron chelation f. Possible complications, including priapism and complications during pregnancy g. Health promotion, including: i. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Stopping smoking h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions	Y	Patient information was good.	Y	

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-103 All	**Information for Primary Health Care Team** Written information should be sent to the patient's primary health care team covering available local services and a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC) b. Side effects of medication, including chelator agents [SC and T] c. Guidance for GPs on hydroxycarbamide and iron chelation therapy (if being prescribed by GPs). d. Immunisations e. Indications and arrangements for seeking advice from the specialist service	Y	Generic information for GPs was available on antibiotics and vaccination but it was fairly brief.	Y	
HN-104 All	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Plan for management in the Emergency Department iii. Planned acute and long-term management of their condition, including medication iv. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed The care plan and details of any changes should be copied to the patients' GP and their local / specialist team consultant (if applicable).	Y		Y	Letters to patients were comprehensive. The annual review proforma was excellent.

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-105 All	**School Care Plan (Paediatric Services Only)** A School Care Plan should be agreed for each child or young person covering, at least: a. School attended b. Medication, including arrangements for giving / supervising medication by school staff c. What to do in an emergency whilst in school d. Arrangements for liaison with the school	N/A		N/A	
HN-106 SHC (A-LHT)	**Transition to Adult Services** Young people transferring to the care of adult services should be offered written information covering at least: a. Their involvement in the decision about transfer and, with their agreement, involvement of their family or carer b. A joint meeting between children's and adult services to plan the transfer c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Arrangements for monitoring during the time immediately after transfer	Y		Y	Transition was integrated into the service and a good self-assessment for adolescents was provided. Welcome events were organised.

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-107 SHC	**Information about Trans-Cranial Doppler Ultrasound** Written information should be offered to patients and their carers covering: a. Reason for the scan and information about the procedure b. Details of where and when the scan will take place and how to change an appointment c. Staff who will be present and will perform the scan d. Any side effects e. Informing staff if the child is unwell or has been unwell in the last week f. How, when and by whom results will be communicated	N/A		N/A	
HN-199 All	**Involving Patients and Carers** The service's involvement of patients and carers should include: a. Mechanisms for receiving feedback from patients and carers b. An annual patient survey (or equivalent) c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service d. Examples of changes made as a result of feedback and involvement of patients and carers	N	A summary of 28 patient surveys was seen. No other patient feedback or examples of changes resulting from patient feedback were seen.	Y	A support group was in place. Surveys from 69 patients were seen.

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-201 All	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services within the network. The lead consultant should undertake Continuing Professional Development of relevance to this role and should have session/s identified for this role within their job plan.	Y		Y	
HN-202 All	**Cover for Lead Consultant** Cover for absences of the lead consultant should be available. In SHCs this should be a named deputy within the SHC with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHC. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHC advice and support.	Y		Y	

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-203 All	**Lead Nurse** A lead nurse should have appropriate time available for their leadership role and: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. RCN competences in caring for people with haemoglobin disorders d. Competences in the care of children and young people (children's services only)	Y		Y	

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-204 All	**Staffing Levels and Competences** The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Medical staffing for clinics and regular reviews b. Medical staffing for emergency care, in and out of hours c. Nurse staffing on the ward and day unit d. Clinical nurse specialist/s with responsibility for the acute service e. Clinical nurse specialist/s with responsibility for the community service f. Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion. g. Clinical or health psychologist with an interest in haemoglobin disorders Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	Y	The clinical nurse specialist for acute service had a large workload which limited capacity to develop the service.	N	At the time of the visit an adult clinical nurse specialist was not yet in post so insufficient support was available. An appointment had been made and a CNS was due to start in post shortly after the visit.
HN-205 All	**Competences and Training** A training plan should ensure that all staff are developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders (QS HN-204).	Y		Y	

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-206 SHC	**Specialist Advice** During normal working hours a consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients.	Y		Y	
HN-207 All	**Training for Emergency Department Staff** The service should offer regular training in the care of patients with haemoglobin disorders to: a. Clinical staff in the Emergency Department b. Nursing staff on general wards to which patients with haemoglobin disorders may be admitted	N	Evidence was not seen on the visit.	N	Evidence of comprehensive training was not seen.
HN-208 All	**Safeguarding Training** All staff caring for people with haemoglobinopathies should have undertaken appropriate training in: a. Safeguarding children and/or vulnerable adults (as applicable) b. Equality and diversity	Y		Y	
HN-209 SHC	**Doctors in Training** The service should ensure that doctors in training have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.	Y		Y	

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-210 SHC	**Trans-Cranial Doppler Ultrasound Competences (Paediatric Services Only)** Sufficient staff with appropriate competences for Trans-Cranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.	N/A		N/A	
HN-299 All	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	Y		Y	
HN-301 All	**Support Services** Timely access to the following services should be available: a. Psychologist with an interest in haemoglobinopathies b. Social worker c. Leg ulcer service d. Play specialist (children's services only) e. Chronic pain team f. Dietetics g. Physiotherapy h. Occupational therapy i. Mental health services (adult and CAMHS) In Specialist Centre's these staff should have specific competences in the care of people with haemoglobin disorders and sufficient time for patient care and for attending multi-disciplinary meetings (HN-602) if required.	Y	Service provision for 'c' had changed from a very good service to one that where access was more difficult. In-patient psychiatric support was limited to risk assessment.	N	Access to a psychologist with an interest in haemoglobinopathies was not available.

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-302 SHC	**Specialist On-site Support** Access to the following specialist staff and services should be available on the same hospital site as the specialist team: a. Manual exchange transfusion (24/7) b. Acute pain team including specialist monitoring of patients with complex analgesia needs c. Consultant obstetrician with an interest in care of people with haemoglobin disorders d. Respiratory physician with interest in chronic sickle lung disease e. High dependency care, including non-invasive ventilation f. Intensive care (note 2)	Y		Y	

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-303 SHC A-LHT	**Specialist Services - Network** Access to the following specialist staff and services should be available: a. Erythrocytopheresis b. Pulmonary hypertension team c. Fertility, contraception and sexual health services, including pre-implantation genetic diagnosis d. Consultant cardiologist e. Consultant endocrinologist f. Consultant hepatologist g. Consultant neurologist h. Consultant ophthalmologist i. Consultant nephrologist j. Consultant urologist with expertise in managing priapism and erectile dysfunction k. Orthopaedic service l. Specialist imaging, including i. MRI tissue iron quantification of the heart and liver ii. Trans-Cranial Doppler ultrasonography (children) m. Neuropsychologist n. DNA studies o. Polysomnography and ENT surgery p. Bone marrow transplantation services Specialist services should have an appropriate level of specialist expertise in the care of people with haemoglobin disorders.	Y		N	Access to 'm' was not available.

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-304 All	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y		Y	
HN-401 All	**Facilities Available** The environment and facilities in phlebotomy, out-patient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child friendly environment, including toys and books / magazines for children and young people of all ages.	Y	Facilities were of a high standard.	Y	Facilities were excellent particularly the day unit.
HN-402 All	**Facilities for Out of Hours Care** Facilities should be available for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	Y	Overnight and evening transfusions were available but not weekend transfusions.	Y	Access to transfusion outside normal working hours was excellent.

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-501 SHC A-LHT	**Transition Guidelines** Network-agreed guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams	Y		Y	Guidelines were adequate but brief.
HN-502 All	**Monitoring Checklists** Checklists should be in use for: a. First out-patient appointment (SHC & A-LHT only) b. Routine monitoring c. Annual review (SHC & A-LHT only) Use of the checklists should cover both clinical practice and information for patients and families.	Y	Checklists were good for thalassaemia. The checklists were all seen but they were not in the patients' notes.	Y	

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-503 LHT	**Clinical Guidelines: LHT Management and Referral** Network-agreed guidelines on routine out-patient monitoring and management between annual reviews should be in use which specify the indications for telephone advice, early referral and immediate transfer to the Specialist Centre.	N/A	Guidelines for LHT management and referral were not seen.	N/A	Guidelines for LHT management and referral were not seen.
HN-504 All	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion b. Offering access to exchange transfusion to patients on long-term transfusions c. Protocol for carrying out an exchange transfusion d. Hospital transfusion policy e. Investigations and vaccinations prior to first transfusion f. Review by specialist nurse or doctor prior to transfusion to ensure each transfusion is appropriate. g. Areas where transfusions will usually be given h. Recommended number of cannulation attempts	Y		Y	

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-505 All	**Chelation Therapy** Network-agreed clinical guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug/s, dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Where prescribing is undertaken through shared care arrangements with GPs, guidelines for GPs on prescribing, monitoring and indications for seeking advice from and referral back to the LHT/SHC. g. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible.	Y	The guidelines were comprehensive.	Y	The guidelines were very good.

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-506 All	**Clinical Guidelines: Acute Complications** Network-agreed clinical guidelines on the management of acute complications should be in use covering at least: **For patients with sickle cell disease:** a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision k. Acute splenic sequestration (children only) **For patients with thalassaemia:** l. Fever, infection and overwhelming sepsis m. Cardiac, hepatic or endocrine decompensation	Y	The guidelines on the management of acute complications of thalassaemia were good.	Y	
HN-507 All	**Specialist Management Guidelines** Network-agreed clinical guidelines should be in use covering the care of patients with sickle cell disease and thalassaemia: a. During anaesthesia and surgery b. Who are pregnant c. Receiving hydroxycarbamide therapy	Y	The guidelines about thalassaemia in pregnancy were comprehensive. The pre-operative plan was good.	Y	

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-508 All	**Clinical Guidelines: Chronic complications** Network-agreed clinical guidelines on the management of chronic complications should be in use covering at least: a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain i. Liver disease j. Growth delay / delayed puberty (children only) k. Enuresis (children only)	Y		Y	
HN-509 SHC	**Referral for Consideration of Bone Marrow Transplantation** Guidelines for referral for consideration of bone marrow transplantation should be in use.	Y		Y	
HN-510 All	**Thalassaemia Intermedia** Network-agreed clinical guidelines for the management of thalassaemia intermedia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy	Y		Y	

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-511 All	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, clinic and ward areas.	Y		Y	

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-512 SHC	**Trans-Cranial Doppler Ultrasound Guidelines (Paediatric Services Only)** Guidelines on Trans-Cranial Doppler ultrasound should be in use covering at least: a. Identification of ultrasound equipment and maintenance arrangements b. Identification of staff performing Trans-Cranial Doppler ultrasound (QS HN-210) c. Arrangements for supervision of doctors in training performing Trans-Cranial Doppler ultrasound d. Ensuring all patients are given relevant information (QS HN-107) e. Use of an imaging consent procedure f. Guidelines on cleaning ultrasound probes g. Arrangements for recording and storing images and ensuring availability of images for subsequent review h. Reporting format, including whether mode performed was imaging or non-imaging i. Arrangements for documentation and communication of results j. Internal systems to assure quality, accuracy and verification of results k. Participation in the National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler ultrasound (when established) or local peer review arrangements (until NQAS established)	N/A		N/A	

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-601 All	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. 'Fail-safe' arrangements for ensuring all children with significant haemoglobinopathy disorders who have been identified through screening programmes are followed up by a specialist SHC (SHC only) b. Ensuring all patients are reviewed by a senior haematology decision-maker within 12 hours of acute admission c. Patient discussion at multi-disciplinary team meetings (QS HN-602) d. Out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population e. Arrangements for liaison with community paediatricians and with schools (children's services only) f. 'Fail-safe' arrangements for ensuring all children and young people have Trans-Cranial Doppler ultrasound when indicated g. Follow up of patients who do not attend h. Transfer of care of patients who move to another area, including communication with all SHC, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHC, LHT and community services who will be taking over their care. i. Accessing specialist advice (QS HN-206) j. Two-way communication of patient information between SHC and LHTs k. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together	Y		Y	

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-602 All	**Multi-Disciplinary Meetings** Multi-disciplinary team meetings should be held regularly involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, other members of the service team (QS HN-204) and representatives of support services (QS HN-301).	Y		Y	
HN-603 All	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services.	Y		N/A	Whittington Health NHS provided integrated care.
HN-604 All	**Network Review and Learning Meetings** At least one representative of the team should attend each Network Review and Learning Meeting (QS HY-798).	Y		Y	
HN-605 SHC	**Neonatal screening programme review meetings** The SHC should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results (HN-704), identify issues of mutual concern and agree action.	N/A		N/A	

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-701 SHC	**Data Collection** Data on all patients, following patient or parental consent, should be entered into the National Haemoglobinopathy Registry. Data should include annual updates and serious adverse events.	Y		Y	
HN-702 All	**Annual Data Collection - Activity** The service should monitor on an annual basis: a. Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances b. Length of in-patient stays c. Re-admission rate d. 'Did not attend' rate for out-patient appointments	Y		Y	

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-703 SHC	**Annual Data Collection – Network Patient Data** The SHC should monitor on an annual basis, separately for sickle cell disease and thalassaemia: a. Number of patients under active care in the network at the start of each year b. Number of new patients accepted by network 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 network patients 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 (HbSS and HbSB) who have had Trans-Cranial Doppler ultrasonography undertaken within the last year i. Number of pregnancies in network patients 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	Y		Y	

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-704 All	**Audit** Clinical audits covering the following areas should have been undertaken within the last two years: **Achievement of screening follow-up standards:** a. At least 90% of infants with a positive screening result attend a local clinic by three months of age b. At least 90% of cases of HbSS and HbSC have confirmation of result documented in clinical notes by six months of age c. Less than 10% of cases on registers lost to follow up within the past year **For patients with sickle cell disease:** d. Proportion of patients with recommended immunisations up to date e. Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required f. Compliance with NICE Clinical Guideline on the management of acute pain, including proportion of patients attending in acute pain who received first analgesia within 30 minutes of arrival, and achieved adequate pain control within two hours of arrival g. Availability of extended red cell phenotype in all patients h. Proportion of children: i. at risk of stroke who have been offered and/or are on long-term transfusion programmes ii. who have had a stroke **For patients with thalassaemia:** i. Evidence of effective monitoring of iron overload, including imaging (QS HN-505) j. Proportion of patients who have developed new iron-related complications in the preceding 12 months **All patients:** k. Waiting times for transfusion	Y		Y	

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-705 All	**Guidelines Audit** The service should have a rolling programme of audit, including: a. Audit of implementation of clinical guidelines (QS HN-500s). b. Participation in agreed network-wide audits.	Y		Y	
HN-706 SHC	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	Y		Y	Research was limited by the lack of nurse support.
HN-707 SHC	**Trans-Cranial Doppler Quality Assurance (Paediatric Services Only)** The service should monitor and review at least annually: a. Whether all staff performing Trans-Cranial Doppler ultrasound have undertaken 40 procedures in the last year (QS HN-210 and HN-512) b. Results of internal quality assurance systems (QS HN-512) c. Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established) d. Results of 'fail-safe' arrangements and any action required	N/A		N/A	

	Adults	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-798 All	**Review and Learning** The service should have appropriate multi-disciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, audit results, incidents and 'near misses'. This should include: a. Review of any patient with a serious adverse event or who died b. Review of any patients requiring admission to a critical care facility	Y		Y	
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y		Y	

Return to *Index*

SERVICES FOR PEOPLE WITH HAEMOGLOBIN DISORDERS – CHILDREN AND YOUNG PEOPLE

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-101 All	**Haemoglobin Disorder Service Information** Written information should be offered to patients and, where appropriate, their carers covering at least: a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the service e. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent) v. Give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns vi. Get involved in improving services (QS HN-199)	Y	Information was available detailing the services provided.	Y	Information was available detailing the services provided.

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-102 All	**Information about Haemoglobin Disorders** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of the condition (SC or T), how it might affect the individual and treatment b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Splenic palpation and Trans-Cranial Doppler scanning (children only) e. Transfusion and iron chelation f. Possible complications, including priapism and complications during pregnancy g. Health promotion, including: i. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Stopping smoking h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions	Y	Paediatric-specific information was available but 'iv' was generic.	Y	Detailed information was available.

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-103 All	**Information for Primary Health Care Team** Written information should be sent to the patient's primary health care team covering available local services and a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC) b. Side effects of medication, including chelator agents [SC and T] c. Guidance for GPs on hydroxycarbamide and iron chelation therapy (if being prescribed by GPs). d. Immunisations e. Indications and arrangements for seeking advice from the specialist service	Y	This was detailed in the clinic correspondence. Additionally a GP information leaflet was available. Some information relating to the role of the GP in general health maintenance may be helpful.	Y	This was detailed in the clinic correspondence. Additionally a GP information leaflet was available. Some information relating to the role of the GP in general health maintenance may be helpful.
HN-104 All	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Plan for management in the Emergency Department iii. Planned acute and long-term management of their condition, including medication iv. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed The care plan and details of any changes should be copied to the patients' GP and their local / specialist team consultant (if applicable).	Y	The reviewers were able to see electronic and printed examples.	Y	Care plans were well structured. The annual review care plan was particularly good.

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-105 All	**School Care Plan (Paediatric Services Only)** A School Care Plan should be agreed for each child or young person covering, at least: a. School attended b. Medication, including arrangements for giving / supervising medication by school staff c. What to do in an emergency whilst in school d. Arrangements for liaison with the school	Y		Y	
HN-106 SHC (A-LHT)	**Transition to Adult Services** Young people transferring to the care of adult services should be offered written information covering at least: a. Their involvement in the decision about transfer and, with their agreement, involvement of their family or carer b. A joint meeting between children's and adult services to plan the transfer c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Arrangements for monitoring during the time immediately after transfer	Y		Y	

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-107 SHC	**Information about Trans-Cranial Doppler Ultrasound** Written information should be offered to patients and their carers covering: a. Reason for the scan and information about the procedure b. Details of where and when the scan will take place and how to change an appointment c. Staff who will be present and will perform the scan d. Any side effects e. Informing staff if the child is unwell or has been unwell in the last week f. How, when and by whom results will be communicated	Y		Y	
HN-199 All	**Involving Patients and Carers** The service's involvement of patients and carers should include: a. Mechanisms for receiving feedback from patients and carers b. An annual patient survey (or equivalent) c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service d. Examples of changes made as a result of feedback and involvement of patients and carers	Y	Different mechanisms of feedback were explained. The reviewers were able to see results of a survey carried out shortly before the visit with responses from 28 individuals	Y	The reviewers were able to see surveys results detailing more than 50 responses.

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-201 All	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services within the network. The lead consultant should undertake Continuing Professional Development of relevance to this role and should have session/s identified for this role within their job plan.	Y		Y	
HN-202 All	**Cover for Lead Consultant** Cover for absences of the lead consultant should be available. In SHCs this should be a named deputy within the SHC with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHC. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHC advice and support.	Y		Y	

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-203 All	**Lead Nurse** A lead nurse should have appropriate time available for their leadership role and: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. RCN competences in caring for people with haemoglobin disorders d. Competences in the care of children and young people (children's services only)	Y	The lead nurse had been appointed just prior to the visit.	Y	

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-204 All	**Staffing Levels and Competences** The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Medical staffing for clinics and regular reviews b. Medical staffing for emergency care, in and out of hours c. Nurse staffing on the ward and day unit d. Clinical nurse specialist/s with responsibility for the acute service e. Clinical nurse specialist/s with responsibility for the community service f. Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion. g. Clinical or health psychologist with an interest in haemoglobin disorders Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	Y		N	Access to a psychologist with an interest in haemoglobinopathies was not available.
HN-205 All	**Competences and Training** A training plan should ensure that all staff are developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders (QS HN-204).	Y		Y	

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-206 SHC	**Specialist Advice** During normal working hours a consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients.	Y	The red cell consultants participated in a 1:3 on call rota.	Y	
HN-207 All	**Training for Emergency Department Staff** The service should offer regular training in the care of patients with haemoglobin disorders to: a. Clinical staff in the Emergency Department b. Nursing staff on general wards to which patients with haemoglobin disorders may be admitted	Y		Y	
HN-208 All	**Safeguarding Training** All staff caring for people with haemoglobinopathies should have undertaken appropriate training in: a. Safeguarding children and/or vulnerable adults (as applicable) b. Equality and diversity	Y		Y	
HN-209 SHC	**Doctors in Training** The service should ensure that doctors in training have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.	Y		Y	

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-210 SHC	**Trans-Cranial Doppler Ultrasound Competences (Paediatric Services Only)** Sufficient staff with appropriate competences for Trans-Cranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.	N	Evidence of the formal competence assessment was available, however a log book of activity was not seen. Cover for absence was not available. See further consideration section of report.	N	The log book of activity was seen and a formal competence assessment had been organised. This service was provided by the lead nurse and no cover was available in her absence. See further consideration section of report.
HN-299 All	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	Y		Y	A data manager had been appointed just prior to the visit.
HN-301 All	**Support Services** Timely access to the following services should be available: a. Psychologist with an interest in haemoglobinopathies b. Social worker c. Leg ulcer service d. Play specialist (children's services only) e. Chronic pain team f. Dietetics g. Physiotherapy h. Occupational therapy i. Mental health services (adult and CAMHS) In Specialist Centre's these staff should have specific competences in the care of people with haemoglobin disorders and sufficient time for patient care and for attending multi-disciplinary meetings (HN-602) if required.	Y	However a good leg ulcer service previously provided by the vascular service was no longer available. The Trust had initiated a new chronic pain service prior to the visit.	N	Access to a psychologist with an interest in haemoglobinopathies was insufficient for the needs of the population and access to a neuro psychology was not available.

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-302 SHC	**Specialist On-site Support** Access to the following specialist staff and services should be available on the same hospital site as the specialist team: a. Manual exchange transfusion (24/7) b. Acute pain team including specialist monitoring of patients with complex analgesia needs c. Consultant obstetrician with an interest in care of people with haemoglobin disorders d. Respiratory physician with interest in chronic sickle lung disease e. High dependency care, including non-invasive ventilation f. Intensive care (note 2)	Y	Paediatric intensive care support was not available on site.	Y	Paediatric intensive care was not available on site.

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-303 SHC A-LHT	**Specialist Services - Network** Access to the following specialist staff and services should be available: a. Erythrocytopheresis b. Pulmonary hypertension team c. Fertility, contraception and sexual health services, including pre-implantation genetic diagnosis d. Consultant cardiologist e. Consultant endocrinologist f. Consultant hepatologist g. Consultant neurologist h. Consultant ophthalmologist i. Consultant nephrologist j. Consultant urologist with expertise in managing priapism and erectile dysfunction k. Orthopaedic service l. Specialist imaging, including i. MRI tissue iron quantification of the heart and liver ii. Trans-Cranial Doppler ultrasonography (children) m. Neuropsychologist n. DNA studies o. Polysomnography and ENT surgery p. Bone marrow transplantation services Specialist services should have an appropriate level of specialist expertise in the care of people with haemoglobin disorders.	Y	Support was available on site for liver and renal patients. However more complex patients and those requiring transplantation were managed at the Royal Free Hospital.	N	Insufficient time was allocated for neuro- and health psychology input for the needs of the population.

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-304 All	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y		Y	
HN-401 All	**Facilities Available** The environment and facilities in phlebotomy, out-patient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child friendly environment, including toys and books / magazines for children and young people of all ages.	Y	Facilities were generally very good however the paediatric ED was fairly cramped.	Y	
HN-402 All	**Facilities for Out of Hours Care** Facilities should be available for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	Y	Transfusions for children were available in the evenings and at weekends.	Y	

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-501 SHC A-LHT	**Transition Guidelines** Network-agreed guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams	Y	A good transition package was used, (see good practice section in this report). The same document was not shared across the network.	Y	Transition guidelines were available however these were in different formats across the network.
HN-502 All	**Monitoring Checklists** Checklists should be in use for: a. First out-patient appointment (SHC & A-LHT only) b. Routine monitoring c. Annual review (SHC & A-LHT only) Use of the checklists should cover both clinical practice and information for patients and families.	Y	The guidelines were of a high standard, (see good practice section of the main report).	Y	

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-503 LHT	**Clinical Guidelines: LHT Management and Referral** Network-agreed guidelines on routine out-patient monitoring and management between annual reviews should be in use which specify the indications for telephone advice, early referral and immediate transfer to the Specialist Centre.	N/A	The specialist centre was not formally linked with any local centre for paediatric services.	N/A	The specialist centre was not formally linked with any local centre for paediatric services.
HN-504 All	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion b. Offering access to exchange transfusion to patients on long-term transfusions c. Protocol for carrying out an exchange transfusion d. Hospital transfusion policy e. Investigations and vaccinations prior to first transfusion f. Review by specialist nurse or doctor prior to transfusion to ensure each transfusion is appropriate. g. Areas where transfusions will usually be given h. Recommended number of cannulation attempts	Y		Y	

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-505 All	**Chelation Therapy** Network-agreed clinical guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug/s, dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Where prescribing is undertaken through shared care arrangements with GPs, guidelines for GPs on prescribing, monitoring and indications for seeking advice from and referral back to the LHT/SHC g. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible	Y		Y	

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-506 All	**Clinical Guidelines: Acute Complications** Network-agreed clinical guidelines on the management of acute complications should be in use covering at least: **For patients with sickle cell disease:** a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision k. Acute splenic sequestration (children only) **For patients with thalassaemia:** l. Fever, infection and overwhelming sepsis m. Cardiac, hepatic or endocrine decompensation	Y	The guidelines were of a high standard, (see good practice section of the main report).	Y	The guidelines were clear and comprehensive.
HN-507 All	**Specialist Management Guidelines** Network-agreed clinical guidelines should be in use covering the care of patients with sickle cell disease and thalassaemia: a. During anaesthesia and surgery b. Who are pregnant c. Receiving hydroxycarbamide therapy	Y		Y	

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-508 All	**Clinical Guidelines: Chronic complications** Network-agreed clinical guidelines on the management of chronic complications should be in use covering at least: a. Renal disease d. Orthopaedic problems e. Retinopathy f. Cardiological complications / pulmonary hypertension g. Chronic respiratory disease h. Endocrinopathies i. Neurological complications j. Chronic pain k. Liver disease l. Growth delay / delayed puberty (children only) m. Enuresis (children only)	Y	The guidelines were of a high standard, (see good practice section of the main report).	Y	Guidelines were clear and comprehensive.
HN-509 SHC	**Referral for Consideration of Bone Marrow Transplantation** Guidelines for referral for consideration of bone marrow transplantation should be in use.	Y		Y	
HN-510 All	**Thalassaemia Intermedia** Network-agreed clinical guidelines for the management of thalassaemia intermedia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy	Y	The guidelines were of a high standard, see good practice section of the main report.	Y	Guidelines were clear and comprehensive.

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-511 All	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, clinic and ward areas.	Y	Guidelines were available electronically.	Y	

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-512 SHC	**Trans-Cranial Doppler Ultrasound Guidelines (Paediatric Services Only)** Guidelines on Trans-Cranial Doppler ultrasound should be in use covering at least: a. Identification of ultrasound equipment and maintenance arrangements b. Identification of staff performing Trans-Cranial Doppler ultrasound (QS HN-210) c. Arrangements for supervision of doctors in training performing Trans-Cranial Doppler ultrasound d. Ensuring all patients are given relevant information (QS HN-107) e. Use of an imaging consent procedure f. Guidelines on cleaning ultrasound probes g. Arrangements for recording and storing images and ensuring availability of images for subsequent review h. Reporting format, including whether mode performed was imaging or non-imaging i. Arrangements for documentation and communication of results j. Internal systems to assure quality, accuracy and verification of results k. Participation in the National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler ultrasound (when established) or local peer review arrangements (until NQAS established)	Y		Y	

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-601 All	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. 'Fail-safe' arrangements for ensuring all children with significant haemoglobinopathy disorders who have been identified through screening programmes are followed up by a specialist SHC (SHC only) b. Ensuring all patients are reviewed by a senior haematology decision-maker within 12 hours of acute admission c. Patient discussion at multi-disciplinary team meetings (QS HN-602) d. Out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population e. Arrangements for liaison with community paediatricians and with schools (children's services only) f. 'Fail-safe' arrangements for ensuring all children and young people have Trans-Cranial Doppler ultrasound when indicated g. Follow up of patients who do not attend h. Transfer of care of patients who move to another area, including communication with all SHC, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHC, LHT and community services who will be taking over their care. i. Accessing specialist advice (QS HN-206) j. Two-way communication of patient information between SHC and LHTs k. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together	Y		Y	

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-602 All	**Multi-Disciplinary Meetings** Multi-disciplinary team meetings should be held regularly involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, other members of the service team (QS HN-204) and representatives of support services (QS HN-301).	Y	Meetings were clearly documented.	Y	Meetings were regular and well documented.
HN-603 All	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services.	N/A		N/A	Community services were integrated within the Trust.
HN-604 All	**Network Review and Learning Meetings** At least one representative of the team should attend each Network Review and Learning Meeting (QS HY-798).	Y		Y	
HN-605 SHC	**Neonatal screening programme review meetings** The SHC should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results (HN-704), identify issues of mutual concern and agree action.	N	Formal neonatal screening review meetings did not take place.	Y	

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-701 SHC	**Data Collection** Data on all patients, following patient or parental consent, should be entered into the National Haemoglobinopathy Registry. Data should include annual updates and serious adverse events.	Y		Y	
HN-702 All	**Annual Data Collection - Activity** The service should monitor on an annual basis: a. Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances b. Length of in-patient stays c. Re-admission rate d. 'Did not attend' rate for out-patient appointments	Y	Details were within the annual report and 'did not attend' rates were low.	Y	

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-703 SHC	**Annual Data Collection – Network Patient Data** The SHC should monitor on an annual basis, separately for sickle cell disease and thalassaemia: a. Number of patients under active care in the network at the start of each year b. Number of new patients accepted by network 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 network patients 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 (HbSS and HbSB) who have had Trans-Cranial Doppler ultrasonography undertaken within the last year i. Number of pregnancies in network patients 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	Y	Data were available for the specialist centre. There were no local hospitals with formal shared care arrangements.	Y	Data were available for the specialist centre. There were no local hospitals with formal shared care arrangements.

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-704 All	**Audit** Clinical audits covering the following areas should have been undertaken within the last two years: **Achievement of screening follow-up standards:** a. At least 90% of infants with a positive screening result attend a local clinic by three months of age b. At least 90% of cases of HbSS and HbSC have confirmation of result documented in clinical notes by six months of age c. Less than 10% of cases on registers lost to follow up within the past year **For patients with sickle cell disease:** d. Proportion of patients with recommended immunisations up to date e. Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required f. Compliance with NICE Clinical Guideline on the management of acute pain, including proportion of patients attending in acute pain who received first analgesia within 30 minutes of arrival, and achieved adequate pain control within two hours of arrival g. Availability of extended red cell phenotype in all patients h. Proportion of children: i. at risk of stroke who have been offered and/or are on long-term transfusion programmes ii. who have had a stroke **For patients with thalassaemia:** i. Evidence of effective monitoring of iron overload, including imaging (QS HN-505) j. Proportion of patients who have developed new iron-related complications in the preceding 12 months **All patients:** k. Waiting times for transfusion	Y		Y	

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-705 All	**Guidelines Audit** The service should have a rolling programme of audit, including: a. Audit of implementation of clinical guidelines (QS HN-500s). b. Participation in agreed network-wide audits.	Y		N	The service did not yet have a rolling programme of audit for guidelines.
HN-706 SHC	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	Y	The department was highly active in research activity.	N	At the time of the review active research trials were not under-way.
HN-707 SHC	**Trans-Cranial Doppler Quality Assurance (Paediatric Services Only)** The service should monitor and review at least annually: a. Whether all staff performing Trans-Cranial Doppler ultrasound have undertaken 40 procedures in the last year (QS HN-210 and HN-512) b. Results of internal quality assurance systems (QS HN-512) c. Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established) d. Results of 'fail-safe' arrangements and any action required	N	An external assessment had been organised in November 2015. However, in view of the single-handed service, there was no process for internal quality assurance. See further consideration section of report.	N	However, in view of the single handed service, the process for internal quality assurance was not yet in place. See further consideration section of report.

	Children and Young People	University College London Hospitals NHS Foundation Trust (UCL)		Whittington Health NHS (WH)	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-798 All	**Review and Learning** The service should have appropriate multi-disciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, audit results, incidents and 'near misses'. This should include: a. Review of any patient with a serious adverse event or who died b. Review of any patients requiring admission to a critical care facility	Y	Details were highlighted in the annual report, (see good practice section in this report).	Y	
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y		Y	

Return to *Index*

HAEMOGLOBIN DISORDERS CLINICAL NETWORK

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HY-199	**Involving Patients and Carers** The network should have mechanisms for involving patients and their carers from all services in the work of the network.	Y		Y	
HY-201	**Network Leads** The network should have a nominated: a. Lead consultant and deputy b. Lead specialist nurse for acute care c. Lead specialist nurse for community services d. Lead manager e. Lead for service improvement f. Lead for audit g. Lead commissioner	Y		Y	
HY-202	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HN-204 and HN-205.	Y		Y	

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HY-501	**Transition Guidelines** Network guidelines on transition to adult care should have been agreed covering: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. Communication of clinical information from paediatric to adult services e. Arrangements for monitoring during the time immediately after transfer to adult care f. Arrangements for communication with Local Haemoglobinopathy Team (if applicable) Guidelines should be explicit about transition directly to any accredited LHTs.	Y		Y	Guidelines were shared between UCLH and the WH although these were in different formats.

		Adults		Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HY-502	**Clinical Guidelines** Network guidelines should have been agreed covering: a. Annual review (QS HN-502) b. Routine monitoring (QS HN-503) c. Transfusion (QS HN-504) d. Chelation therapy, including guidelines for shared care with general practice (QS HN-505) e. Management of acute complications (QS HN-506), including indications for referral to specialist services (QS HN-303) f. Management of chronic complications (QS HN-508), including indications for referral to specialist services (QS HN-303) g. Specialist management (QS HN-507) h. Thalassaemia intermedia (QS HN-510) Guidelines should be explicit about any accredited LHTs which may take responsibility for annual reviews or any other aspect of care usually provided by SHCs.	Y	Guidelines were shared between UCLH and WH.	Y	Guidelines were shared between UCLH and WH.
HY-701	**Ongoing Monitoring** The network should monitor on a regular basis: a. Submission of data on all patients to the National Haemoglobinopathy Registry (QS HN-701) b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year.	Y		Y	

		Adults		Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QSs HN-703, HN-704, HN-705 and HN-707.	Y		Y	A network wide audit of patient transfers between wards had been undertaken.
HY-703	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with haemoglobin disorders b. A list of research trials available to all patients within the network.	Y	There was evidence of some collaboration.	Y	
HY-798	**Network Review and Learning** The SHC should meet at least twice a year with its referring LHT teams to: a. Identify any changes needed to network-wide policies, procedures and guidelines b. Review results of audits undertaken and agree action plans c. Review and agree learning from any positive feedback or complaints involving liaison between teams d. Review and agree learning from any critical incidents or 'near misses', including those involving liaison between teams e. Consider the content of future training and awareness programmes (QS HY-202)	Y	Evidence of educational meetings was available.	Y	Evidence of educational meetings was available.

Return to *Index*

COMMISSIONING

		Adults		Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HZ-601	**Commissioning of Services** Commissioners should have agreed the configuration of clinical networks based on the expected referral pattern to each SHC and LHT and, within each network, the configuration and location of services for people with haemoglobin disorders across each network, taking into account the type of patient (sickle cell and/or thalassaemia) who will be treated by each team, in particular: a. Designated SHC/s for the care of people with with sickle cell disease b. Designated SHC/s for the care of adults with thalassaemia c. Any agreements for delegation of annual reviews to accredited LHTs for care of people with sickle cell disease or thalassaemia d. Other LHTs/Linked providers for care of adults with sickle cell disease or thalassaemia e. Community care providers	N	This work had not yet been undertaken.	N	This work had not yet been undertaken.
HZ-701	**Clinical Quality Review Meetings** Commissioners should regularly review the quality of care provided by: a. Each service, in particular QS HN-703 b. Each network, in particular, achievement of QS HY-702 and QS HY-798. c. Service and network achievement of relevant QSs	N	Regular clinical quality review meetings for haemoglobin disorders services were not yet in place.	N	Regular clinical quality review meetings for haemoglobin disorders services were not yet in place.

		Adults		Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HZ-798	**Network Review and Learning** Commissioners should attend a Network Review and Learning meeting (HY-798) at least once a year for each network in their area.	N	Regular network review and learning meetings were in place but commissioners did not attend.	N	Regular network review and learning meetings were in place but commissioners did not attend.

Return to *Index*