Care of People with Inherited and Acquired Haemophilia and other Bleeding Disorders

Imperial College Healthcare NHS Trust

Visit Date: 8th April 2019

Report Date: July.2019

8831

Index

Introduction

This report presents the findings of the peer review of Services for People with Inherited and Acquired Haemophilia and other Bleeding Disorders at Hammersmith Hospital Haemophilia Centre which took place on 8th April 2019.

The purpose of the visit was to review compliance with the Quality Standards for Inherited and Acquired Haemophilia and other Bleeding Disorders (V1 July 2018), which were developed by the UK Haemophilia Centres Doctors' Organisation (UKHCDO) Peer Review Working Group working with the Quality Review Service (QRS).

The peer review visit was organised by QRS on behalf of the UKHCDO.

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 and Annual Governance Statement. 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:

- Imperial College Healthcare NHS Trust
- NHS England (London)

Most of the issues identified by quality reviews can be resolved by providers' and commissioners' own governance arrangements. 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.

Acknowledgements

We would like to thank the team at the Hammersmith Hospital Haemophilia Centre for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. We are grateful, too, to the patients who took time to 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.

About Quality Review Service

QRS is a collaborative venture by NHS organisations 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 QRS is available at www.wmqrs.nhs.uk

Hammersmith Hospital Haemophilia Centre

Patients with bleeding disorders had been cared for at Hammersmith Hospital for over 60 years, but the service lacked a dedicated specialist during the 1970s and early 1980s. Following the merger of the Charing Cross, Westminster and St Mary's Trusts and medical schools, which was completed in 2007, the haematology service was consolidated at Hammersmith Hospital.

This entailed the transfer of a relatively small number of patients from the other sites. The Haemophilia Centre served west London and a population of approximately 1.5m, although historical referral patterns meant that some patients from west London attended more central hospitals in north and south London (Royal Free and St Thomas's). Although the Centre was a Haemophilia Centre (rather than a Comprehensive Care Centre (CCC)) it was close in size to a CCC and had the appropriate laboratory, clinical and administrative support.

The two haemostasis Clinical Nurse Specialists (CNSs) were based at Hammersmith Hospital and provided anticoagulation services as well as haemophilia care. The Centre had its own outpatient and clinical facilities and was close to the rest of the haematology day care area and the outpatient and inpatient areas.

At the time of the review, Imperial College Healthcare NHS Trust (ICHNT) provided care for approximately 470 adult patients with haemophilia and other inherited bleeding disorders within a specialised haematology service. ICHNT comprised five hospitals: Charing Cross; Hammersmith; St Mary's; Queen Charlotte's; and Chelsea and Western Eye Hospitals. The haematology service was provided across the sites; the Haemophilia Centre and dedicated outpatient clinics for patients with haemophilia and other inherited bleeding disorders were located in the Garry Weston Centre at Hammersmith Hospital. There was a unified telephone and IT system so that patient details could be accessed across all of the hospital sites. The haematology consultants and Specialist Registrars (SpRs) had responsibility for all sites, and visited to supervise care as appropriate.

ICHNT constituted the clinical half of the Imperial Academic Health Sciences Centre, and many of the haematology consultants had part-time academic contracts for research or teaching. The haemostasis service establishment consisted of four consultants, plus a further consultant who was based at Royal Brompton Hospital, had three PAs at Hammersmith Hospital and also participated in the on-call service. Two consultants (1.1 Whole Time Equivalent) took the lead in haemophilia, but all consultants took part in haemostasis attendance and on-call services. One post was vacant at the time of the review.

The two CNSs who were supervised by the lead CNS for non-malignant haematology. They worked collaboratively to influence the structured development of service improvements and patient experience.

Similar site specialisation of other services meant that the coagulation service had to support patients on the other sites, and this sometimes required travel between sites to maintain care of patients under review. However, cross-site management was facilitated by the development of the Trust-wide IT system. A reconfiguration was under way at the time of the review to restore resident consultant haematology support on each site.

At the time of the review the following numbers of patients were registered at the Hammersmith Centre:

Condition		Number of patients (show breakdown Severe, Moderate and Mild)	Number of patients who had an annual review in the last year	Number of inpatient admissions in the last year
Haemophilia A	**Adults**	Severe: 33 Moderate: 4 Mild: 42	Severe: 33 Moderate: 4 Mild: 29	5
Haemophilia B	**Adults**	Severe: 6 Moderate: 7 Mild: 4	Severe: 4 Moderate: 6 Mild: 2	1
von Willebrand Disease	**Adults**	113	63	7
Other	**Adults**	266	153	19

Emergency Care

There was a 24 hour on-call service in place with a consultant rota for haemostasis and thrombosis, a haematology SpR on site 24/7 who was the first point of contact via the switchboard, and a specialist biomedical scientist.

The emergency access and walk-in service was available Monday to Friday 9.00am to 5.00pm, and in the event of a bleed at home or in the community patients contacted the Haemophilia Centre in hours.

Patients could attend the Centre at any time and would be seen by the haemophilia team during the day. Initial assessment and administration of clotting factors were coordinated by the nursing team. Patients were reviewed by the coagulation SpR with support from the attending haemostasis consultant.

Renal and Haematology Triage Unit (RHTU), Hammersmith Hospital

All registered haemophilia and bleeding disorder patients were issued with a patient access card that provided contact details and access to the RHTU triage service at Hammersmith Hospital should they require urgent assessment of bleeds or other problems related to their bleeding disorder out of hours i.e. between 5.00pm and 9.00am on weekdays or during the weekend.

Patients initially contacted the RHTU helpline by telephone. This helpline was operational 24/7, including at weekends and on bank holidays. The unit was located in B block on the Hammersmith Hospital site. An initial patient assessment was carried out using a standard telephone triage tool, and appropriate advice given to patients, including advice to attend the RHTU or another acute care setting as appropriate. The RHTU nursing team were able to gain additional support from the haematology SpR and the Senior House Officer on call. The RHTU was co-located on the Hammersmith site with the haemophilia centre.

Emergency Departments at Charing Cross and St Mary's Hospitals

ICHNT had Emergency Departments (EDs) located at St Mary's Hospital (which included a major trauma centre) and at Charing Cross Hospital. When a patient known to have haemophilia or a bleeding disorder attended the ED, the haematology SpR was notified by the ED triage nurse. The patient would be reviewed by the ED doctor in charge, who acted as the point of communication with the haematology SpR and/or the haemostasis consultant. Patients were assessed and treated with clotting factor concentrates within 30 minutes of arrival.

Stocks of concentrate were maintained in the transfusion laboratory on each site. Patients were told that if they were very unwell, they were to dial 999 and present their access passport to the London Ambulance Service (LAS). They would then be taken to St Mary's ED, with the LAS team giving advance notification of their arrival.

Ward Care

There were three inpatient wards exclusively for patients with haematological disorders: Fraser Gamble, Dacie and Weston Wards, all at the Hammersmith site. Dacie and Weston Wards consisted of single rooms with high efficiency particulate air filtration and en-suite facilities, and were used predominantly for immuno-compromised patients. Fraser Gamble Ward consisted of twenty-five funded beds with an additional four beds used as escalation beds for the department, giving a maximum bed capacity of twenty-nine beds (five side rooms with en-suite facilities and up to six four-bedded bays equipped with en-suite facilities). It specialised in the management of patients with non-malignant haematological disorders including haemophilia / bleeding disorders and other non-malignant blood disorders.

Day Unit Care

Most day care for bleeding disorders was provided within the Haemophilia Centre, using the treatment and consulting rooms available. The Haemophilia Centre was open from 9.00am to 5.00pm, five days a week, and received walk-in patients. For longer procedures requiring observation and a bed, such as platelet, iron or intravenous immunoglobulin (IVIg)[1] infusions, patients attended the haematology day care unit on the ground floor of the same building as the Haemophilia Centre. This unit was open from 8.00am to 8.00pm, seven days a week (i.e. including weekends), and accommodated out of hours appointments and treatments.

Outpatient Care

There were three outpatient consulting rooms located within the Haemophilia Centre and staffed by the haemophilia team. These were adjacent to the Centre's own waiting room and office facilities. Within the Centre there were treatment rooms and a phlebotomy room, which also housed the fridges containing factor concentrate supplies.

Community-based Care

When appropriate, patients were visited at home by staff from the Centre. The majority of patients with severe haemophilia self-administered their prophylaxis, and supplies were provided by home delivery.

Return to Index

[1] **IVIg** is manufactured from human plasma. It contains IgG antibodies and is used in the treatment of several immunological, haematological and neurological illnesses.

Review Visit Findings

Achievements

This well-respected and long-established service was providing care at a high level. There was strong medical leadership, although this was non-hierarchical, and all team members felt included and respected. They were enthusiastic and helpful to one other, and new team members were integrating well. The core team members were well supported by a highly involved quality team, and the valued input of the data manager, senior nursing team, secretary and general managers was notable.

Strong liaison with the coagulation laboratory, where there was a dynamic lead, was evident, and weekly joint meetings were held to review and discuss results. This also provided an excellent learning opportunity for both biomedical scientists and haematologists in training.

There was an outstanding research portfolio, the site being the UK centre for dosing in gene therapy studies in haemophilia.

Patients were especially vocal in their gratitude for the high quality of care they received.

Good Practice

1. Patients requiring acute assessment and treatment had 24 hour access every day to a triage service used only by haematology and renal patients.
2. Some of the written material supporting the service, including a comprehensive operational policy and MDT proforma, was outstanding.
3. Clinical service leads in the supporting specialisms in the hospital had signed a written agreement accepting their responsibility for providing the necessary services for this patient group.
4. A great deal of work had gone into designing and refining a comprehensive database known as 'Powerform' within the Trust's IT system, onto which all clinically relevant material had been condensed and entered by senior clinical staff, in advance of a change over from paper to electronic records. There was remote access to this and other IT systems for medical staff on duty out of hours.
5. A haematologist in training carried a dedicated 'bleep' for the service at all times, in rotation, facilitating access to the clinical team, and supporting continuity. Time spent in this role was also a valuable training opportunity.
6. A recent patient survey had resulted in high response rates and very positive feedback about the services. Comments had been carefully analysed and presented, and some changes made in response to patient and carer suggestions.
7. Although parking spaces on the site were limited, blue badge holders could request exemption from paying for parking when using the Centre.
8. Special provision had been made for one patient who was unable to attend the Centre for reviews because of mental health difficulties, and he was visited instead for assessment and discussion in his home.

Immediate Risks: No immediate risks were identified at the time of the visit.

Concerns

1. **Staffing**

   Provision of some key support staff was not sufficient.

   a. A locum physiotherapist, who was enthusiastic and had good plans for what was required, was only available for two sessions per week (0.2 Whole Time Equivalent). Although this had increased recently (from one session), there was no cover for other days. She was able to offer some long-term joint health assessment and care, but was seldom able to help manage acute joint bleeds. There had been a discussion with the Royal Free Hospital about a shared post, and it will be important to secure permanent funding and to ensure that provision is increased, as well as to ensure cover can be provided when the physiotherapist is not on site.

   b. There was no psychologist on the team. Patients could be referred, if needed, to a network psychologist based at the Royal Free Hospital, but this did not happen frequently. In practice it was inconvenient for patients and did not meet the expectation that a psychologist is an integral part of the on-site team. Without this, reviewers observed that there was likely to be an unmet need for this support within the patient group.

2. **Consultant cover at Charing Cross Hospital**

   The review team learned that there was no consultant haematologist based at Charing Cross Hospital and only a single haematologist working part-time at the St Mary's Hospital site. Senior medical staff in this service were frequently contacted (during working hours and out of hours) for advice about inpatients on these sites. This resulted in regular interruptions for the medical team during clinics and other scheduled activities, and distracted from the focus of their specialist work.

Further Consideration

1. The two long-serving CNSs had left the service in recent months, and two new appointees were in post. They were well supported by their nurse manager. However, no nurse working within the Centre had yet attended the Haemnet 'Contemporary Care of People with Bleeding Disorders' course, and the nurses were not yet undertaking all aspects of the role. It was noted that it was important that the two new CNSs were enrolled on this as soon as possible, although it was acknowledged that the course had not been run in the months since they came into post. In the meantime, they had visited other large Centres in the network, and had continued contact with senior experienced haemophilia nurses, for education and guidance. This should continue to be encouraged at every opportunity. They were also encouraged to register with Haemnet as this is a useful online forum for haemophilia nurses.

2. The team included a 0.5 wte WTE social worker, who was managed by a senior nurse. Supervision by a more senior social worker is recommended. In addition, in the other half of the role, the social worker worked with the haemoglobin disorders team, and it was noted that this service took up over 50% of his time. This meant that he was not always able to undertake some of the work which the inherited and acquired bleeding disorder patients would have found valuable, and he was not always available to see patients attending clinic appointments.

3. The Centre did not care for children, and it was agreed that transition practice started at the paediatric centre from early teens. However, some consideration might be given to liaising on the process of transition, so that young people attending the Hammersmith Hospital Haemophilia Centre for the first time would at least have met some team members in advance. This could be achieved by one of the team members joining the paediatric team a couple of times a year where they could jointly see the young people before formal transfer to the adult service. In addition, one of the haemophilia nurses could be a link nurse for transition and could attend the paediatric clinics when a patient is due to transition.

4. The excellent current working relationship between the clinical and laboratory teams was noted as a key achievement. Care and effort will be needed to maintain the high quality of the service once the laboratory 'hub' moves to Charing Cross Hospital; this move was scheduled to take place within 12 months of this review.

5. The combined diagnostic and clinical management guidelines were detailed and comprehensive. However, it was noted that specific detail on what samples were required for each test, where they were to be sent, and within what hours, was lacking and would provide additional useful guidance for new team members. It was noted that these details, and instructions for specimen transfer, would become increasingly important when some tests are not available on site following the planned laboratory move.

6. The impressive research portfolio was noted, but involvement of non-medical team members in research appeared to be limited. As physiotherapy support for the service increases, and the CNSs gain experience, more multi-professional research studies might be considered.

7. The long-serving consultants in post knew their patients and families well and were careful to discuss testing and counselling of potential carrier / mildly affected females in a timely way, before they reach the age of family planning. However, inclusion of a prompt to discuss and recall these young adults may be helpful to ensure a more robust process.

8. If one of the fridges storing concentrate malfunctioned and the required temperature range was exceeded, the review team considered that it might be more appropriate to alert the site manager, or perhaps the blood transfusion biomedical scientist, rather than the haematologist in training as was the practice at the time of the review. This was particularly important out of hours when that individual may be busy attending to a clinically urgent matter and therefore not best placed to manage this issue promptly.

9. Signage to the Centre across the extensive hospital site was not good, and a patient who had been attending for years remarked that he frequently still got lost when trying to access it.

10. Availability of car parking for patients attending the Centre was limited, and the review team learned that this problem may become worse as an adjacent sporting facility is to be increasingly used for large football events.

General Comments

The Royal Free London Haemophilia Comprehensive Care Centre was commissioned as the hub of the North London Network for adult haemophilia services, with the Hammersmith Hospital Haemophilia Centre offering services as a linked part of the network. The reviewers learned that this functioned at an administrative level, with data being submitted by Imperial College Healthcare NHS Trust to NHS England by the Royal Free Hospital. Meetings of the Network Board had continued with three meetings having been held in 2018.

However, some 'managed network' activities, including review and learning, education, workforce planning, and governance across the north London centres, were lacking. Some previous meetings, including a 'network MDT' at which the management of particularly difficult patients had been discussed and which was reported to be a valued opportunity for clinical discussion and education around these clinically complex conditions, had been disbanded. It was also noted that, while commissioning efforts had been directed towards joined-up working between the large specialist London centres, more 'outward looking' working with the smaller general hospitals, to whose Emergency Departments this Centre's patients often presented, may well have more direct benefit for care quality and outcomes. This should ensure that patients who presented acutely with traumatic or spontaneous bleeds were optimally managed.

There has been much discussion, over several years, between commissioners and provider specialists about the optimal model and configuration of services for inherited and acquired bleeding disorders across London. It is

evident that further discussion will be necessary, possibly partly informed by some of the findings of these peer review visits.

Return to Index

APPENDIX 1 Membership of Visiting Team

Visiting Team		
Dr Catherine Bagot	Consultant Haematologist	Glasgow Royal Infirmary, NHS Greater Glasgow and Clyde
Sarah Bowman	Haemophilia Social Worker	Sheffield Teaching Hospitals NHS Foundation Trust
Emma Franklin	Haemophilia Centre Manager, Adult CNS	University Hospitals Bristol NHS Foundation Trust
Graham Knight	Patient Representative	
Anna Wells	Advanced Practice Physiotherapist in Haemophilia / Professional Lead for Physiotherapy	Hampshire Hospitals NHS Foundation Trust

QRS Team		
Dr Anne Yardumian	Consultant Haematologist	Programme Clinical Lead
Rachael Blackburn	Assistant Director	Quality Review Service

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

	Number of Applicable QS	Number of QS Met	% met
Comprehensive Care Centre	37	31	84%
Network	8	2	25%
Commissioning *	3	1	33%
Total	48	34	71%

* The Centre did not complete the commissioning standards at they were a Haemophilia Centre. The compliances for this section were therefore taken from the Royal Free CCC, which was the Comprehensive Care Centre that this Centre was linked to.

Return to Index

Haemophilia Comprehensive Care Centres and Haemophilia Centres

Ref	Standard	Met?	Comments
HP-101	**Service Information** Written information should be offered to patients and, where appropriate, their carers covering at least: a. Brief description of the service 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 vi. Get involved in improving services (QS HP-199)	Y	There was a comprehensive range of documentation in place covering all aspects of this standard.

Ref	Standard	Met?	Comments
HP-102	**Condition-Specific Information** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of their condition and how it might affect them b. How their condition is diagnosed c. Genetics of inherited bleeding disorders d. Testing for carrier status and the implications of being a carrier e. Problems, symptoms and signs for which emergency advice should be sought f. Out of hours services g. 'On demand' clotting factor treatment h. Prophylaxis i. Self infusion (or infusion by parent or carer) j. Home therapy and use of Haemtrack k. How to manage bleeding at home l. Ports, fistulae and in-dwelling access devices (if applicable) m. Possible complications, including inhibitors and long term joint damage n. Approach to elective and emergency surgery o. Women's health issues p. Health promotion, including smoking cessation, health eating, weight management, exercise, alcohol use, sexual and reproductive health, and mental and emotional health and well-being q. Dental care r. Travel advice s. Vaccination advice t. National Haemophilia Database, its purpose and benefits u. Sources of further advice and information Information should be available covering: 1. Haemophilia A 2. Haemophilia B 3. Von Willebrand Disease 4. Acquired haemophilia 5. Inherited platelet disorders 6. Other less common and rare bleeding disorders	Y	There was a plentiful supply of useful and informative information available to patients and carers.

Ref	Standard	Met?	Comments
HP-103	**Plan of Care** Each patient and, where appropriate, their carer should discuss and agree their Plan of Care, and should be offered a written record covering at least: a. Agreed goals, including life-style goals b. Self-management c. Planned assessments, therapeutic and/or rehabilitation interventions d. Early warning signs of problems, including acute exacerbations, and what to do if these occur e. Agreed arrangements with school or other education provider and preparation for adult life (children and young people only) f. Planned review date and how to access a review more quickly, if necessary g. Who to contact with queries or for advice The Plan of Care should be communicated to the patient's GP and to relevant other services involved in their care.	Y	
HP-104	**Review of Plan of Care** A formal review of the patient's Plan of Care should take place at least six monthly for patients with severe or moderate haemophilia and at least annually for other patients. This review should involve the patient, where appropriate their carer, and appropriate members of the multi-disciplinary team. Haemtrack results should be reviewed (if applicable) and the outcome of the review should be communicated in writing to the patient and their GP.	Y	
HP-105	**Contact for Queries and Advice** Each patient and, where appropriate, their carer should have a contact point within the service for queries and advice. A clear system for triage of urgent clinical problems should be in place. If advice and support is not immediately available for non-urgent enquiries, then the timescales for a response should be clear. Response times should be no longer than the end of the next working day. All contacts for advice and a sample of actual response time should be documented.	Y	
HP-106	**Haemtrack (Patients on Home Therapy)** All patients on home treatment should be encouraged to use electronic recording of their treatment through Haemtrack.	Y	

Ref	Standard	Met?	Comments
HP-194	**Environment** The environment and facilities in out-patient clinics, wards and day units should be appropriate for the number of patients with inherited and acquired bleeding disorders and accessible by people with severe mobility problems. 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	
HP-195	**Transition to Adult Services and Preparation for Adult Life** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards f. Advice for young people going away from home to study, including: i. registering with a GP ii. how to access emergency and routine care iii. how to access support from their Comprehensive Care Centre iv. communication with their new GP	N	However, see Quality Standard HP-595 below in relation to transition practice.
HP-198	**Carers' Needs** Carers should be offered information on: a. How to access an assessment of their own needs b. What to do in an emergency c. Services available to provide support	N	Reviewers did not see any evidence of proactive support for carers in identifying and responding to their own personal needs.
HP-199	**Involving Patients and Carers** The service should have: a. Mechanisms for receiving regular feedback from patients and carers about treatment and care they receive b. Mechanisms for involving patients and carers in decisions about the organisation of the service c. Examples of changes made as a result of feedback and involvement of patients and carers	Y	

Ref	Standard	Met?	Comments
HP-201	**Lead Consultant and Lead Nurse** A nominated lead consultant and lead nurse should have responsibility for staffing, training, guidelines and protocols, service organisation, governance and for liaison with other services. The lead consultant and lead nurse should be registered healthcare professionals with appropriate specialist competences and should undertake regular clinical work within the service and specific time allocated for their leadership role.	N	Reviewers noted that, although there was a lead nurse in place, he/she did not have the required haemophilia nurse qualification, although reviewers recognised that this is only available in September every year. Reviewers did acknowledge, however, that every effort had been made by the team to gain experience at the time of the review including visiting other centres to shadow more experienced nursing staff.

Ref	Standard	Met?	Comments
HP-202	**Staffing Levels and Skill Mix** Sufficient staff with appropriate competences should be available for out-patient, day unit and in-patient care and for support to urgent care services. Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network. All staff should undertake regular Continuing Professional Development of relevance to their work in the inherited and acquired bleeding disorders services. Staff working with children and young people should have competences in caring for children as well as in the care of people with bleeding disorders. Cover for absences should be available. In HCCCs these staff should have sessional time allocated to their work with the IABD service. In HCs the arrangements for accessing staff who do not have sessional time allocated to the IABD service should be clearly defined. Staffing should include: a. Medical staff: i. Consultant specialising in the care of people with inherited and acquired bleeding disorders available during normal working hours ii. On-call consultant haematologist (24/7) iii. Arrangements for advice from a consultant specialising the care of people with inherited and acquired bleeding disorders (if not on call) b. Specialist nursing staff: i. Bleeding disorders specialist nurses (5/7) ii. Ward, out-patient and day unit staff with competences in the care of people with inherited and acquired bleeding disorders. c. Clinical specialist physiotherapist d. Biomedical Scientist and Clinical Scientist (further detail on the requirements are included in HP-303) e. Clinical or counselling specialist psychologist or appropriately trained psychotherapist f. Specialist senior social worker g. Data manager	N	Reviewers noted that the current physiotherapy resource was limited and that the current postholder was in a locum post. Psychology input was not adequate, and although there was social worker input, this was split between haemoglobinopathy (HD) and IABD, with the majority of time being spent with HD patients.
HP-203	**Service Competences and Training Plan** The competences expected for each role in the service should be identified. A training and development plan for achieving and maintaining competences should be in place.	N	Reviewers saw evidence for doctors but evidence was limited for other staff in the team. Please see the notes for this QS which requires a matrix for all team members outlining the competencies required for their role along with a plan as to how these will be achieved.

Ref	Standard	Met?	Comments
HP-204	**Competences – All Health and Social Care Professionals** All health and social care professionals working in the service should have competences appropriate to their role in: a. Safeguarding children and/or vulnerable adults b. Recognising and meeting the needs of vulnerable children and/or adults c. Dealing with challenging behaviour, violence and aggression d. Mental Capacity Act and Deprivation of Liberty Safeguards e. Resuscitation	Y	
HP-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be available.	Y	
HP-301	**Support Services** Timely access to the following support services should be available: a. Play support (children's services only) including: i. Play and distraction during any painful or invasive procedures ii. Play support to enable the child's development and well-being b. Pharmacy c. Dietetics d. Occupational Therapy e. Orthotics	Y	
HP-302	**Emergency Department – Staff Competences** Medical and nursing staff working in the Emergency Department should have competences in urgent care of people with inherited and acquired bleeding disorders including awareness of: a. Guidelines on care of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) b. Who to contact for advice	Y	

Ref	Standard	Met?	Comments
HP-303	**Laboratory Service** a. A UKAS / CPA accredited laboratory service with satisfactory External Quality Assurance performance should be available 24/7 b. A laboratory representative (senior biomedical scientist or clinical scientist) should attend inherited and acquired bleeding disorder service multi-disciplinary team meetings (QS HP-602) regularly c. The following tests should be available: i. All coagulation factor assays (24/7) ii. Inhibitor screening iii. FVIII inhibitor quantification iv. VWF antigen v. VWF activity vi. Platelet function testing d. Molecular Genetic Laboratory service for: i. detection of causative mutations in patients with inherited bleeding disorders ii. carrier detection	Y	See the Achievements section of the main report: reviewers felt that the lab manager was very engaged and dynamic. Also see the Further Consideration section in relation to maintaining proactive communication when the hub moves to Charing Cross Hospital.
HP-304	**Specialist Services** Timely access to the following specialist staff and services should be available as part of a HCCC service. HCs should be able to access these services through network arrangements: a. Obstetrics including reproductive counselling, information about pre-implantation genetic diagnosis and antenatal diagnosis b. Foetal medicine c. Vascular access (consultant surgeon or interventional radiologist with experience of venous access devices) d. Orthopaedic surgery e. Care of older people services f. Dental services g. HIV services h. Hepatology i. Medical genetics (Genetic Counselling Services) j. Pain management services k. Rheumatology Specialist services should have an appropriate level of specialist expertise in the care of people with inherited and acquired bleeding disorders.	Y	See the Good Practice section of the main report with regards to the signed agreements from support services in relation to their responsibilities to the Haemophilia Centre.

Ref	Standard	Met?	Comments
HP-402	**Facilities and Equipment** Facilities and equipment appropriate for the service provided should be available including: a. Fridges b. Storage c. Clinical rooms for staff of all disciplines to see patients and carers d. Room for multi-disciplinary discussion e. Room for educational work with patients and carers f. Office space for staff g. Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all clinical areas All equipment should be appropriately checked and maintained.	Y	See the Further Consideration section of the main report regarding who to call when the fridge breaks down.
HP-499	**IT System** IT systems should be in use for: a. Storage, retrieval and transmission of patient information, including access to the latest vCJD status and family tree b. Patient administration, clinical records and outcome information c. Data to support service improvement, audit and revalidation d. Alerting the specialist team when patients attend the Emergency Department	Y	See the Good Practice section of the main report.
HP-501	**Diagnosis Guidelines for Patients with Suspected Inherited and Acquired Bleeding Disorders** Guidelines on diagnosis should be in use covering at least a. Haemophilia A b. Haemophilia B c. Von Willebrand Disease d. Acquired haemophilia e. Inherited platelet disorders f. Other less common and rare bleeding disorders	Y	

Ref	Standard	Met?	Comments
HP-502	**Guidelines: Concentrate Use and Monitoring** Guidelines should be in use covering: a. Concentrate therapy: i. Initiation and monitoring of prophylaxis ii. Home therapy b. Use of extended half life products, including inhibitor testing and PK assessment c. Management of concentrate supplies including: i. Ordering ii. Storage iii. Stock control to ensure all stock is up to date and waste is minimised iv. Prescription and delivery for patients on home treatment v. Arrangements for emergency 'out of hours' supply vi. Recording issue to patients vii. Recording use by patients, including on Haemtrack viii. Submission of data via NHD for national tenders coordinated by CMU	Y	
HP-503	**Clinical Guidelines** The following clinical guidelines should be in use: a. Management of acute bleeding episodes, including patients with inhibitors b. Inhibitor screening c. Immune tolerance therapy d. Dental care e. Care of patients with hepatitis C f. Care of patients with HIV g. Antenatal care, delivery and care of the neonate h. Management of synovitis and target joints i. Long term surveillance of musculoskeletal health j. “For public health purposes”: care of patients at risk of vCJD who are undergoing surgery	Y	However, see the Further Consideration section of the main report in relation to physiotherapy guidelines, as there was no reference to guidelines on acute bleed management. In addition reviewers did not see any guidelines in relation to monitoring during pregnancy.
HP-504	**Emergency Department Guidelines** Guidelines on management of patients with inherited and acquired bleeding disorders in the Emergency Department should be in use.	Y	However, reviewers noted that there should be more guidance in relation to patients presenting to smaller local hospitals other than those within ICHNT.

Ref	Standard	Met?	Comments
HP-505	**Guidelines on Care of Patients requiring Surgery** Guidelines on the care of patients with inherited and acquired bleeding disorders who require surgery should be in use covering at least: a. Involvement of surgical and inherited and acquired bleeding disorders service in agreement of a written plan of care prior to, during and post-surgery b. Communication of the agreed plan of care to all staff involved in the patient's care prior to, during and post-surgery c. Documentation of care provided d. Arrangements for escalation in the event of unexpected problems	Y	
HP-595	**Guidelines on Transition and Preparing for Adult Life** Guidelines on transition of young people from paediatric to adult services should be in use covering at least: a. Taking responsibility for their own care b. Involvement of the young person and, where appropriate, their carer in planning the transfer of care c. Joint meeting between paediatric and adult services in order to plan the transfer d. Allocation of a named coordinator for the transfer of care e. A preparation period prior to transfer f. Arrangements for monitoring during the time immediately after transfer g. Advice for young people going away from home to study, including: i. registering with a GP ii. how to access emergency and routine care iii. how to access support from their Comprehensive Care Centre iv. communication with the young person's new GP	N	Reviewers heard that, although transition was mainly led by Great Ormond Street clinicians, the team at Hammersmith still needed to be involved in this process, possibly visiting the young adults at Great Ormond Street in advance of their transition to the adult service. It is necessary to have a document in place clarifying this arrangement.
HP-599	**Care of Vulnerable People** Guidelines for the care of vulnerable children, young people and adults should be in use including: a. Restraint and sedation b. Missing patients c. Mental Capacity Act and the Deprivation of Liberty Safeguards d. Safeguarding e. Information sharing f. Palliative care g. End of life care	Y	

Ref	Standard	Met?	Comments
HP-601	**Service Organisation** The service should have an operational procedure covering at least: a. Ensuring all children who are in-patients have a named consultant paediatrician and a named haematologist with expertise in caring for patients with inherited and acquired bleeding disorders responsible for their care b. Ensuring all adults are under the care of a consultant haematologist with an interest in inherited and acquired bleeding disorders, either directly or through a shared care arrangement with a general haematologist c. Responsibility for giving information and education at each stage of the patient journey d. Arrangements for involving Haemophilia Centre staff in multi-disciplinary discussions relating to their patients (QS HP-602) e. Arrangements for follow up of patients who 'do not attend' f. Arrangements for transfer of patient information when patients move areas temporarily or permanently g. Ensuring patients' plans of care are reviewed at least six monthly for patients with severe haemophilia and at least annually for other patients (QS HP-104) h. Ensuring school visits for children with severe haemophilia at least at each change of school (children's services only) i. Ensuring patients are visited at home at least annually if they are unable to attend clinics, including those in nursing homes j. Lone working	Y	
HP-602	**Multi-Disciplinary Team Meetings** Multi-disciplinary team meetings to discuss patients' plans of care should take place regularly involving: a. All core members of the specialist team (HP-202) b. Senior biomedical scientist or clinical scientist with responsibility for the Coagulation Laboratory c. HC staff who are regularly involved in the patient's care as part of network arrangements	Y	This requirement is met by the monitoring of the functional active list, but it would benefit from nursing input on a regular basis.

Ref	Standard	Met?	Comments
HP-603	**Multi-Disciplinary Clinics** The following multi-disciplinary clinic arrangements for patients with inherited and acquired bleeding disorders should be in place: a. Involvement of medical, specialist nursing and physiotherapy staff in clinics b. Availability of social work and psychology staff in clinics c. Combined clinics or other arrangements for multi-disciplinary discussion with: i. orthopaedics ii. rheumatology iii. obstetrics and gynaecology iv. paediatrics v. dental vi. HIV / hepatology	Y	However, reviewers noted that psychology and social work input for clinics was not available.
HP-604	**Liaison with Other Services** Review meetings should be held at least annually with specialist services to consider liaison arrangements and address any problems identified.	Y	
HP-701	**Data Collection** The following data should be collected: a. UK National Haemophilia Database data on all patients b. Data on concentrate use and bleeds, either through Haemtrack or an equivalent mechanism c. Data required to complete the UKHCDO National Haemophilia Dashboard or other national mechanisms	Y	
HP-702	**Audit** The services should have a rolling programme of audit covering at least: a. Clinical guidelines (QS HP-503) b. Emergency and out of hours care (QS HP-504) c. Initiation of prophylaxis in children d. Inhibitor surveillance and Immune Tolerance Induction (ITI) e. Clinical reviews including joint scores (QS HP-103 & 104) f. Concentrate use and wastage	Y	
HP-706	**Research** The service should actively participate in research relating to the care of patients with bleeding disorders.	Y	Reviewers noted that there was a wealth of research activity being undertaken, but felt that this would benefit from being more MDT-based.

Ref	Standard	Met?	Comments
HP-798	**Multi-disciplinary Review and Learning** The service should have multi-disciplinary arrangements for review of and implementing learning from: a. Positive feedback, complaints, outcomes, incidents and 'near misses' b. Morbidity and mortality c. Haemophilia Dashboard d. Review of UKHCDO Annual Report benchmarking information on concentrate use e. Ongoing reviews of service quality, safety and efficiency f. Published scientific research and guidance	Y	
HP-799	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	

Return to Index

Network

Ref	Standard	Met?	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	
HY-203	**Inherited and Acquired Bleeding Disorders Network Leads** The network should have a nominated: a. Lead consultant and deputy b. Lead specialist nurse c. Lead physiotherapist d. Lead clinical or counselling psychologist e. Lead manager	Y	
HY-204	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HP-203.	N	Reviewers agreed with the Centre's self-assessment.
HY-503	**Guidelines** Network guidelines should have been agreed covering: a. Diagnosis for patients with suspected inherited and acquired bleeding disorders (QS HP-501) b. Concentrate use and monitoring (QS HP-502) c. Clinical guidelines (QS HP-503) d. Management of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) e. Care of patients requiring surgery (QS HP-505) f. Transition and preparing for adult life (QS HP-595)	N	Reviewers agreed with the Centre's self-assessment.
HY-701	**Ongoing Monitoring** The network should monitor on a regular basis: a. Submission of data on all patients to the UK National Haemophilia Database (QS HP-701) b. Network-wide data on concentrate use and bleeds	N	Reviewers agreed with the Centre's self-assessment.
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.	N	Reviewers agreed with the Centre's self-assessment.
HY-703	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with inherited and acquired bleeding disorders b. A list of research trials available to all patients within the network.	N	Reviewers agreed with the Centre's self-assessment.

Ref	Standard	Met?	Comments
HY-798	**Network Review and Learning** Representatives of Comprehensive Care Centres and referring Haemophilia Centres should meet at least once a year 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 positive feedback, complaints, critical incidents and 'near misses', including those involving liaison between teams d. Share good practice and potential service improvements	N	Reviewers agreed with the Centre's self-assessment.

Return to Index

Commissioning

Ref	Standard	Met?	Comments
HZ-601	**Commissioning of Services** Commissioners should have agreed the configuration of clinical networks including: a. Designated Comprehensive Care Centres and Haemophilia Centres and the relationships between them b. Whether the service cares for children, adults or both c. Referral pattern to each service, taking into account the type of patients who will be treated by each team	Y	Compliances for this section were taken from the Royal Free, which was the Comprehensive Care Centre with which this Centre was linked
HZ-701	**Clinical Quality Review Meetings** Commissioners should regularly review the quality of care provided by: a. Each service, including achievement of QS HP-701 b. Each network, including achievement of QS HY-701 and QS HY-798 c. Service and network achievement of relevant QSs	N	See HZ-601
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	See HZ-601

Return to Index