WM QRS West Midlands Quality Review Service

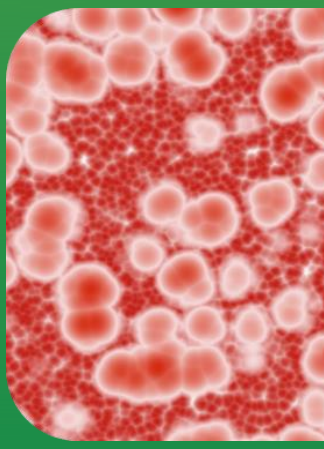
UKHCDO UNITED KINGDOM HAEMOPHILIA CENTRES DOCTORS' ORGANISATION

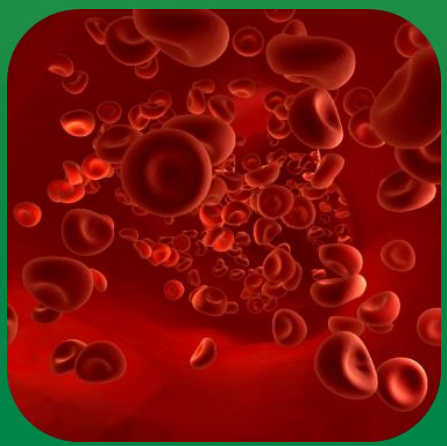
Care of People with Inherited and Acquired Haemophilia and other Bleeding Disorders

Barts Health NHS Trust

Visit Date: 14th December 2018 Report Date: May 2019

Images courtesy of NHS Photo Library





UKAS INSPECTION 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 Barts Health NHS Trust (The Royal London Hospital) on the 14th December 2018.

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 West Midlands Quality Review Service (WMQRS).

The peer review visit was organised by WMQRS 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:

- Barts Health NHS Trust
- NHSE 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 Royal London Hospital Haemophilia Centre 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 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 West Midlands Quality Review Service

WMQRS 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 WMQRS is available at www.wmqrs.nhs.uk

THE ROYAL LONDON HOSPITAL (RLH)

The Haemophilia Comprehensive Care Centre (CCC) at The Royal London Hospital (RLH) treated both adult and paediatric patients. The hospital served a population of 2.5 million with a significant increase in numbers predicted over the next 5-10 years. Birth rate and family size was increasing, resulting in a growth in numbers of young patients treated. East London is recognised as an area of high social deprivation.

Historically, RLH had a skewed ratio of moderate/mild: severe haemophilia when compared to other large centres in London such as the Royal Free Hospital and Guys & St Thomas Hospitals who had similar total numbers of patients with haemophilia.

The RLH Haemophilia Centre was an integrated unit within the Haematology Day Unit (HDU). It provided care for all patients with Inherited and Acquired Bleeding Disorders, from cradle to grave. The Centre did not provide the hospital thrombosis / anticoagulant service which is entirely separate at nursing level and largely so at a senior medical level.

Previously the haemophilia offices were situated at a distance from the clinical area for both adults and paediatric care. With the redevelopment of the RLH site and the opening of the new build, the HDU and haemophilia offices were relocated to the ground floor of the south tower in January 2012. This provided integration of both administrative and clinical services. Due to further redevelopment of the site and the requirement for outpatients space the HDU was taken over to be redesigned as a general outpatient service. At the end of 2014 the Centre was transferred to a redesigned part of the second floor as a final HDU incorporating the Haemophilia Centre. The HDU provided share clinical space, with one clinical room allocated to the Haemophilia Centre sole use and two offices for all staff to use.

Within the main hospital building, the Haemophilia Centre was in close proximity to both paediatric and adult services, imaging and pathology. The laboratory service was in the Pathology and Pharmacy building which was adjacent to the south tower. All acute services were provided on the RLH site. Some specialised services, most notably cardiology and cancer services, were predominantly provided at the Smithfield site and occasionally patients from the RLH service required treatment at that site. Orthopaedic services and other major surgical services, HIV, Hepatology and Obstetrics / Gynaecology services were provided on the RLH site within the main building. The RLH site was also a large and busy designated trauma unit.

The RLH Centre was part of the North London adult haemophilia network and also the North London paediatric haemophilia network. The 'hubs' for these networks were the Royal Free Hospital and Great Ormond Street Hospital for Children respectively. The financial arrangements and integration with the hub varied according to the network. The adult network had a board which had responsibility for strategy and approach. It was chaired for 3 years on rotation by Centre Directors from the three sites, in sequence: Royal London Hospital; Imperial College Healthcare Trust and the Royal Free Hospital.

At the time of the visit the following Haemophilia patients were registered at the Centre

Condition		No. patients (show breakdown Severe, Moderate and Mild)	No. patients who had an annual review in last year
Haemophilia A	Adults = 237	Severe = 63 Moderate = 29 Mild = 145	All severe and severe moderate patients are reviewed 6 monthly / alternating between the joint: Consultant/nurse/physiotherapy Outcomes Clinic and general MDT clinic All mild and mild moderate patients are reviewed annually in either face to face clinic and/or telephone clinic
	Children = 65	Severe = 21 Moderate = 7 Mild = 37	All patients are reviewed annually in Paediatric clinic Moderate and Mild
Haemophilia B	Adults = 53	Severe = 13 Moderate = 13 Mild = 29	All severe and severe moderate patients are reviewed 6 monthly / alternating between the joint: Consultant/nurse/physiotherapy Outcomes Clinic and general MDT clinic All mild and mild moderate patients are reviewed annually in either face to face clinic and/or telephone clinic All patients are reviewed annually in Paediatric clinic Moderate and Mild
	Children = 12	Severe = 2 Moderate = 1 Mild = 9	All severe and severe moderate patients are reviewed 6 monthly / alternating between the joint: Consultant/nurse/physiotherapy Outcomes Clinic and general MDT clinic All mild and mild moderate patients are reviewed annually in either face to face clinic and/or telephone clinic All patients are reviewed annually in Paediatric clinic Moderate and Mild

EMERGENCY CARE

The RLH had a major trauma centre. Patients could attend directly or typically were encouraged to call the centre or Specialist Registrar (SpR) on call ahead of attending. On registration in A+E the patients Electronic Patient Record would highlight that they had a bleeding disorder and A+E staff could contact the Haemophilia Centre or SpR on call to inform them of the patients' arrival, as per protocol. Admission would take place, if required.

If patients lived at a distance, they were asked to call the Centre for advice and, if appropriate, patients were advised to attend their local A&E where the team called ahead to provide clinical details for the patient. The team asked A+E to call back on arrival and patients were strongly encouraged to ask A+E to call the team at the RLH after assessment. A joint decision was then made. Transfer to RLH could be made, as an emergency, if required.

Ward Based Care

Patients were admitted to general wards dependent on their specific clinical need and if care was shared with a subspecialty the preferred ward within that speciality e.g. orthopaedics, ENT etc. Otherwise patients were admitted to a general medical ward, most frequently 11C which had a high proportion of haematology patients. Medical cover was provided by haemophilia consultants and SpRs and the ward nursing staff were fully supported by the Haemophilia Centre specialist nursing team and physiotherapists.

Day unit Care

Day care was provided within the Haematology Day Unit (HDU) for adults and the paediatric day unit for children. The HDU was the site of the Centre offices and store/fridges. In both areas other patients attended with broad paediatric issues, or non-malignant haematology, haemoglobinopathy and anticoagulation on the HDU.

Out-patient Care

Outpatient clinics were in the children's facilities or general medical outpatient clinics. The physiotherapy led outcomes clinic was held on the HDU.

Community-based Care

There was no formal community-based care. This was provided, as required, by the hospital-based team.

Return to *Index*

REVIEW VISIT FINDINGS

Achievements

Reviewers reported that this was an outstanding Comprehensive Care Centre team, staffed by dedicated, patient-focussed and hardworking individuals who delivered excellent services, within a number of constraints. There was strong leadership, and members of the team communicated well and were highly supportive of one another. Staff were very positive about their work, and retention rates within the team were high.

Education and training, offered to senior trainees and Consultants from elsewhere in the UK and across Europe, was very highly rated.

The nursing team was very experienced, working flexibly across adult and children's services, though each also had a sub-specialty lead role too. The achievements of the physiotherapy team were also considered noteworthy: leading the 'outcomes clinics' with appropriate time for comprehensive musculoskeletal assessment; direct access for patients and availability to see patients flexibly at other times and undertaking school visits. The Musculoskeletal (MSK) pathway overall was felt to be very strong.

The laboratory service was excellent, being UK Accreditation Service (UKAS) accredited for all relevant investigations. The laboratory lead attended Multi-disciplinary (MDT) meetings and also held laboratory meetings, the outcomes of which fed into the wider MDT.

Non-clinical team members were also evidently committed to delivering good patient care and felt integral to that process. Reviewers noted that the Data Manager in particular provided valuable support to the team. The success of the service was reflected by overwhelmingly positive feedback about the team from patients who attended the review in person as well as in the written feedback seen by reviewers.

The team's research portfolio was exceptional, involving medical, nursing, physiotherapy and laboratory members, and included a number of studies for which the team was a global lead including bioengineered novel therapies for haemophilia and the first potentially curative gene therapy for Haemophilia A. Clinical trials were chosen for their potential to make radical changes to patients' lives and outcomes. Patients also described favourably their experience of taking part in these studies.

Good Practice

1. Reviewers saw and heard that the team made every effort to be contactable, telling patients 'any time, any place, anywhere'. There was also a generic e-mail address available to patients which was checked and responded to daily by the team.
2. Telephone and 'skype' clinics were available which improved the patient experience by reducing the need for patients to travel for all consultations.
3. Reviewers were also told that patients were offered a 1-hour appointment every 6 months so that clinicians and patients had time to go through any issues regarding their treatment/physiotherapy requirements etc.
4. Reviewers noted that some of the written information provided to patients was felt to be very good, including the patient service information booklet and the 'Haemophilia Centre Guidelines' for new team members.
5. The Centre supplied (free-of-charge) doses of all major concentrates / medications likely to be needed in an emergency to its five large linked District General Hospitals at Chelmsford, Colchester, Basildon, Romford and Southend. These were rotated when nearing their expiry date for use back in the centre to reduce wastage.

6. Reviewers heard that a large number of patients were on pharmacokinetic dosing, ensuring optimal factor levels while allowing for cost savings on some patients who need less frequent dosing.

7. Dental services worked closely with the Centre team and were notable for having educated patients and local community dentists about the procedures which could safely be carried out without the need for concentrate cover. There was also a novel laser diode treatment in place for reducing gum bleeding which had been shown to reduce bed days as well as the need for concentrate for this complication. Reviewers noted the significant contribution, in terms of the support, commitment and enthusiasm that the dental team had made to developing this service

8. Reviewers were impressed by the transition practice within the Centre. This was aided by the same staff working across paediatric and adult services, but also with a named nurse leading on the process and plentiful, age appropriate material. Patients who met the review team described the process as being smooth and trouble free.

9. Reviewers saw that there was a very high level of compliance with Haemtrack ®.1

10. Homecare medication prescriptions and stock control was 'Hackett compliant' 2 which required considerable nursing and management time, but reduced waste.

11. The availability of point-of-care ultrasound by the physiotherapy team to examine joints during any consultation was unusual and considered to be an enhanced provision and an excellent addition.

12. When a new patient was referred from another Centre, they were immediately sent a 'bridging letter' by the Centre which introduced them to the service and provided contact numbers, so that the patient could access care or advice even before their first appointment.

13. Many patients used a comprehensive 'app' developed by the service which included a great deal of information and guidance. Reviewers felt that this was an extremely valuable resource for patients making information easily accessible though the review team did note that the same material could be made available in hard copy for any patients or carers who were not familiar or comfortable using 'apps'.

14. A shared 'baby calendar' spreadsheet allowed all team members to track anticipated births and therefore provide timely and appropriate care for parents.

15. Reviewers saw that the team used 'Progeny', which is a software system designed for use in other long-term conditions, that had been adapted by one of the clinical nurse specialists on the team for use in Inherited & Acquired Bleeding Disorders. This allowed linkage of affected family members with specific genetic mutations across a broad family tree which helped to provide appropriate interventions.

16. The team were routinely seeking patient feedback and had a 50% response rate which was felt to be a positive achievement.

Immediate Risks: None

[1] **Haemtrack** - Haemtrack is a secure recording system developed connecting patients and clinicians through the Haemtrack phone apps and website. Haemtrack enables patients to record all therapies as they occur, and allows clinicians to see up-to-date therapy information to help monitor, optimise and improve patient care

[2] **Hackett Compliant** – is a Department of Health framework for maintaining standards in home care. These standards aim to help patients experience a consistent quality of homecare services, irrespective of homecare provider, that will protect them from incidents of avoidable harm and help them to get the best outcomes from their medicines.

Concerns

1. **Facilities**

   The facilities from which the service was provided were limited, with only a single clinic room available. This meant that sometimes staff had to ask other teams to vacate clinic rooms so they could see patients which sometime caused delays. Reviewers also heard that sometimes up to ten team members could be sharing a cramped, dark office, where they may need to talk to patients, or take calls for clinical advice.

2. **Staffing**

   a. Some of the clinical staff did not have enough time in their job-plans to manage this large clinical service. Nursing provision was felt be reviewers to be low and did not currently allow for adequate community work and home visits. Consultant Programmed Activity (PA) sessions (1.9 WTE) meant that they were often putting in extra unpaid time, and with growing patient numbers this is unlikely to be sustainable.

   b. The lack of any dedicated psychologist time, and of a social worker on the team, were cause for significant concern. Patients could be referred to see the psychologist at the Royal Free Hospital, but in practice this pathway was seldom used and would be very inconvenient for patients. Efforts to try novel ways to address the lack of psychology input, by holding funded 'support group' sessions, were noted but did not substitute for a psychologist as an integrated member of the core team. Reviewers also heard that the lack of social work support to work with families in this area of high social deprivation was a problem.

3. **Homecare issues**

   Reviewers saw patient feedback that highlighted that the current homecare delivery provider was not working well for a large number of patients. This was the main criticism of the service by patients in face to face and written feedback. The team had met the providers and were hopeful that some of the problems with communication and deliveries could be improved. Further patient satisfaction audits in the near future will be required to assure the issues have been adequately addressed.

Further Consideration

1. **IT issues**

   a. Some of the ward PCs did not support all of the necessary applications, and when they did access to them could be very slow so that team members described sometimes 'giving up' and having to come back to their office to access them.

   b. Reviewers saw that the CERNER® patient record system has an excellent front page which provided all the necessary information about a patient's condition, comorbidities and treatment but this was not accessible remotely for a Consultant on call. If called by a linked hospital Emergency Department (ED) to which a patient had presented, the Consultant had to call in to the Royal London Hospital ED asking staff there to check the record which would then be read over the phone to them, before then calling the local hospital back with details. Remote access would allow the team to see details and give advice without the need for an intermediary and reduce the risk that they may not have accurately read off all the necessary details. This is currently being piloted, is technically feasible, and reviewers felt that this should be rolled out as soon as possible due to the benefits it brings.

2. The 'Haemophilia Centre Guidelines' contained an excellent flowchart for patients requiring surgery, and reviewers felt that this could usefully also be included in the clinical guideline for surgery preparation.

3. Reviewers heard that some patient activity was not being captured within formal activity figures; this included ad hoc telephone conversations. Only face to face and formal telephone clinic activity was being

included in hospital activity records. The team should consider capturing this additional activity so that the demand upon resources needed is fully understood.

4. Reviewers did not see a training matrix or training plan which outlined the record of training that staff required or had completed. The team should consider developing such a plan to ensure that there is an accurate record for all staff groups of the training required for their respective roles and whether this has been completed.

5. Patients with whom the reviewers met with talked appreciatively about some evening education and discussion meetings which had been taking place 3-6 monthly, however they indicated that none had been organised for over a year. Patients acknowledged that this was likely to be due to the many other demands on the team's time, but they would appreciate the sessions being restarted.

6. The lack of adequate nursing time to offer community and home visits is noted under the Concerns section earlier in this report. Resource requirements should be reviewed to ensure that adequate capacity is available for community activity.

7. Document control: not all guidelines and other documents seen be reviewers had full details of authorship and review dates. Reviewers felt that this should be addressed so that all members of the team can be confident that they are accessing the latest version of all relevant procedures and guidelines.

8. Reviewers heard that patients had Consultants mobile phone numbers which therefore provided them with 24/7 access. Whilst this clearly improved accessibility for patients and was appreciated by them, consideration should be given to the impact upon staff if they are being regularly contacted by patients and always seen as 'on call'.

General Comments

Barts Health Haemophilia Comprehensive Care Centre was commissioned as a 'spoke' of the North London Networks for paediatric and adult haemophilia services. It was described that to some extent the adult network functioned at a financial and administrative but not clinical level, while the paediatric centres worked well as a clinical but not administrative network. Some of the expected 'managed network' responsibilities, including review and learning, education, workforce planning, and governance across the North London centres were lacking.

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. An interesting contribution to the discussion, raised during this review, was that additional / alternative focus might be given – instead of always looking 'inwards' to link the large London CCCs in networks - to formalising the links between the large London CCC's and the peripheral hospitals who link with them. For this CCC this would be the hospitals at Chelmsford, Colchester, Basildon, Romford and Southend. It was felt that working together with these hospital teams sharing of protocols, guidelines, education, and review and learning meetings could give rise to real improvements in patient experience and outcomes.

NETWORK

The team had self-assessed compliance with the eight network standards [HY-199 – 798] but on review compliance was assessed by reviewers not to be complete for seven of them.

Further detail is available in Appendix 2.

COMMISSIONING

The three Commissioning standards were assessed by the Royal London team as well as the reviewing team as not having been met.

Further detail is available in Appendix 2.

Return to *Index*

APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Visiting Team		
Simon Fletcher	Lead Research Nurse	Oxford University Hospitals NHS Foundation Trust
Sandy Jeffery	Patient / Carer representative	
Kathryn Marshall	Clinical Nurse Specialist	University Hospitals Coventry and Warwickshire NHS Trust
Joanna Nightingale	Head Biomedical Scientist	East Kent University NHS Foundation Trust
Dr Emily Symington	Consultant Haematologist	Cambridge University Hospitals NHS Foundation Trust
Anna Wells	Advanced practice Physiotherapist in Haemophilia	Hampshire Hospitals NHS Foundation Trust

WMQRS Team		
Dr Anne Yardumian	Consultant Haematologist	Programme Clinical Lead
Rachael Blackburn	Assistant Director	West Midlands 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

Adult Service	Number of Applicable QS	Number of QS Met	% met
Comprehensive Care	37	33	89
Networking	8	1	13
Commissioning	3	0	0
Total	48	34	71

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	

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 a. Haemophilia B b. Von Willebrand Disease c. Acquired haemophilia d. Inherited platelet disorders e. Other less common and rare bleeding disorders	Y	

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.	N	See Concerns section of the main report. The review team did not feel that the space available to the team was adequate for the level of service that they were providing
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	Y	See Good Practice section of main report. Transition was particularly impressive and the reviewers noted that there was a dedicated transition nurse in post
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	Y	
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.	Y	
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	Y	

Ref	Standard	Met?	Comments
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	See Further Consideration section of main report. Reviewers did not see a competency / training plan that reflected the training needs and achievements of the whole team.
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	
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	

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.	N	See also Quality Standard HP194. The review team felt that more clinic space was needed and that the office space available to the team was inadequate for the level of service that they are providing
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	However reviewers heard that not all IT systems were accessible from all terminals and that on occasions access was slow
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	
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	

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	Y	
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	

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	See Good Practice section of main report regarding physiotherapy clinics
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	

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.	N	All policies were in standard Trust format however, many local SOPs did not have robust document control including no 'developed on' and review dates

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.	N	Reviewers did not see any evidence at the time of the visit of the mechanisms for obtaining feedback. However, they were subsequently informed by the Centre that this had taken place.
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	See Centres own self-assessment (*As part of a pan London approach, it has recently been agreed a rolling programme of education will commence in January 20019 across London*) - this was not in place at the time of the review. However reviewers did see evidence of education "link" days for colleagues within the organisation. So some steps had been taken in terms of education support within the local network.
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	See Centres own self-assessment (*This is work in progress*).

Ref	Standard	Met?	Comments
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	See Centres own self-assessment (*Every month data from BH is sent to the Hub (RFH) for adults and directly to NHSE for children. Data to NHD is sent directly from BH, not via the Network. Historically the adult Network board would review high use within the centres but this has over recent times been stopped*) - this was not in place at the time of the review
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.	N	Reviewers did not see any evidence of an agreed audit programme during the course of the review
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	See Centres self-assessment *(There is no agreed research policy for the network)*- there was no agreed network research policy in place at the time of the visit
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	Minutes were available for the review team. However, it was unclear whether any of the discussions had resulted in sharing of good practice and changes to practice resulting from the analysis of this information.

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	N	See Centres own self-assessment *(Historically the Pan Thames Haemophilia Consortium used the national service specification and outcome of the 2006-2010 service review process for contracting with haemophilia centre. This has not been reviewed with the clinical teams from the participant Trusts since 2010).*
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 Centres own self-assessment *(The Commissioners do not meet with the individual Trusts. If they have met with the Hubs of the Networks since 2014 it has not involved all the participants Trusts).*

Ref	Standard	Met?	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	See Centres own self-assessment *(There are no Network review meetings that involve all participant Trusts and focus on a specific Network. However, the Commissioners do meet with all Trust via the Clinical Advisory Group and Commissioning Support Forum 3-4 times per year. This meeting was very popular and successful but had a lapse due to NHSE internal pressure late 2016 to early 2018. It has now been re-established. The role is to provide clinical support for difficult cases, developing audit and to provide a discussion forum for commissioning issues and intentions across the City, but is not network specific. It has been very successful as a forum. A key issue limiting its effectiveness is the rapid change of staff within the NHSE team and lack of corporate memory of issues).*

Return to *Index*