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

Royal Free London NHS Foundation Trust

Visit Date: 17th January 2019 Report Date: May 2019

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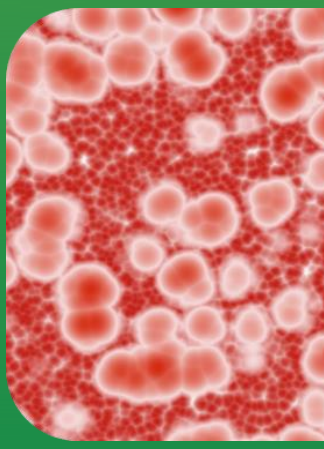

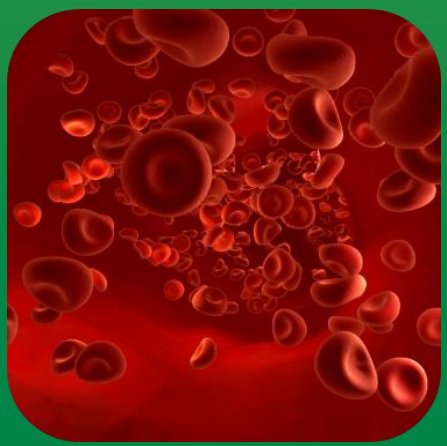

UKAS INSPECTION 8831

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 the Royal Free London NHS Foundation Trust on the 17th January 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 Centre 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:

- Royal Free London NHS Foundation 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.

ACKNOWLEDGMENTS

We would like to thank the team at the Royal Free London Comprehensive Care Centre for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks also to the users and carers who took time to come and meet the review team.

Thanks are also due to the visiting team (**Appendix 1**) and their employing organisations for the time and expertise they contributed to this review.

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

ROYAL FREE LONDON NHS FOUNDATION TRUST

The Katharine Dormandy Haemophilia & Thrombosis Centre was housed in a purpose-built facility on the ground floor of the main building of the Royal Free Hospital in Hampstead, North London.

Registered bleeding disorders patients were mainly from the London Boroughs north of the River Thames and Hertfordshire, Bedfordshire and Essex. However, as the Centre had been established since 1964 many patients who had moved out of London still chose to have their Comprehensive Haemophilia Care there and the catchment area did include all of Greater London and the Home Counties with a few patients choosing to come from further afield, where shared care arrangements were in place with the local Haemophilia Centres such as Truro in Cornwall.

The Centre was the Hub of the North London Adult Haemophilia Network with spokes at Hammersmith hospital Haemophilia Centre and the Royal London Hospital Comprehensive Care Centre. The Centre was a spoke of the North London Paediatric Haemophilia Network working in close liaison with Great Ormond Street Hospital (GOSH) to ensure that adolescents and young adults registered there receive equitable care. A weekly clinic for adolescents and young adults was held weekly by a GOSH consultant.

The service was Consultant led operating between 9am-5pm on weekdays with consultant-led on-call advice available outside of these hours. A Haemophilia Clinical Nurse Specialist (CNS) was also available from 9am-1pm on Saturdays & Sundays to ensure continuity of care and to avoid A&E attendance wherever possible. There was a daily 9am “board round” which acted as a Multi-Disciplinary Team (MDT) handover and communication session. There was a full weekly MDT to review all in-patients and complex out-patients as well as any planned surgery or obstetric deliveries and to review the psychosocial needs of patients who had been seen in clinics or at other times.

The service offered all aspects of a holistic Comprehensive Care Centre as described in the National Service Specification B05/S/a with full time Consultants in Haemostasis & Thrombosis supported by a very experienced specialist nursing and allied health professional team. Alongside the clinical team was a highly skilled clinical trials team who managed all aspects of commercial and investigator led studies, including gene therapy. There was a 24/7 UK Accreditation Service (UKAS) accredited Haemostasis Laboratory with a team of experienced senior biomedical scientists offering all aspects of diagnosis and treatment monitoring.

The core team was supplemented by close working relationships with the Viral Hepatology & Infectious Diseases Teams and joint clinics were held in the Centre with the Orthopaedic and Obstetrics / Gynaecology Consultants. While most services were available at the Royal Free site, a close link was maintained with the Haemostasis Consultants at University College Hospital for Neurosurgery and Ear Nose and Throat (ENT) surgery. The routine dental needs of patients with bleeding disorders were managed by general dental practitioners in the Community, however specialist services for those with complex needs were arranged with network partners at the Royal London Dental Hospital. Similarly, in accordance with commissioning arrangements in the North London Sector. Cardiac Surgery was also managed at the Royal London hospital.

The Table below summarises the conditions and severity of patients managed by the Centre at the time of the review:

Condition		No. patients (show breakdown Severe, Moderate and Mild)	No. patients who had an annual review in last year	No. in-patient admissions in last year
Haemophilia A	Adults	**TOTAL: 338** Severe : 143 Moderate: 35 Mild : 160	244	22
	Children	**Total: 14** Severe: 5 Moderate: 3 Mild: 6	11	0
Haemophilia B	Adults	**Total: 86** Severe: 36 Moderate: 18 Mild:32	58	4
	Children	**Total: 3** Severe: 0 Moderate: 1 Mild:2	3	0
Von Willebrand	Adults	**Total: 346** Severe: 50 Moderate: 7 Mild:40 Not classified: 249	174	5
	Children	**Total: 17** Severe:5 Moderate: 01 Mild:1 No Severity :10	15	0
Other	Adults	563 patients	337	10
	Children	59 Patients	57	0

WARD CARE

Patients requiring admission due to bleeding complications were most frequently admitted to 11 East Ward which was a mixed haematology/oncology ward. Nurses on 11 East were familiar with the administration of clotting factor products and had a good understanding of the complex needs of this patient group – they were most frequently looking after those with acquired haemophilia, although there were occasional admissions of those with other bleeding disorders. The Haemophilia CNS & Specialist Registrar (SpR) attended the Ward MDT weekly when there were in-patients. There were dedicated Physiotherapists and Occupational Therapists and a pharmacist on 11 East who also participated in the MDT and the care of patients. Physiotherapists throughout the Trust were trained by, and liaised with, the Haemophilia Clinical Specialist Physiotherapist.

Most elective admissions were for orthopaedic surgery – the orthopaedic ward nursing staff were very familiar with administration of clotting factor concentrates by bolus or continuous infusions and had good liaison with the specialist nursing team. The in-patient orthopaedic physiotherapists were trained by and liaised with the Haemophilia Clinical Specialist physiotherapist

All in-patients were seen at least daily by a Haemophilia registrar and a Haemophilia CNS. There were Consultant ward rounds at least twice each week and whenever required.

Day Unit Care

Most day unit care was provided within the Haemophilia Centre, although in some cases (e.g. Rituximab or iron infusion) patients attended the Haematology / Oncology day unit. The Clinical Nurse Specialist (CNS) team operated a "walk-in" service every day for those with urgent clinical needs relating to their bleeding disorder. The CNS triaged patients and assessed the need for further assessment and management by the specialist physiotherapist or the haematology registrar with the guidance of the on-call Consultant. There was also a telephone advice line in operation by the Haemophilia CNS and Physiotherapists whenever the Centre was open and from 9-1pm on Saturdays and Sundays. When the Centre was closed at weekends, the Specialist Nurses were able to see patients in the treatment room on 11 East to ensure the safety of patients in line with the Trust 'Lone Worker' policy.

Outpatient Care

All out-patient care for Haemophilia and Inherited Bleeding Disorders took place in the Haemophilia Centre. Patients who were referred to other services attended the relevant clinics/departments. Patients were reviewed according to service specification in routine out-patient clinics – all with severe haemophilia were seen in MDT clinics at least twice yearly.

Community based care

Since the move of the very young children to Great Ormond Street > 10 years ago the requirement for regular community visits, such as supporting schools and home treatment training, had lessened. However, it was still offered on an ad-hoc basis when the need was identified by the MDT although this was increasingly difficult to achieve as there had been no increase in nursing staff levels for more than 10 years despite a significant increase in the complex patient caseload. Close links had been developed with many of the haematology Day Units in District General Hospitals to try to achieve delivery of care close to home whenever possible and some good examples of this were demonstrated for an adolescent with significant learning needs and a very complex patient with Acquired Haemophilia where the education of nursing staff close to the patients' homes had meant fewer admissions and less disruption to family life.

Return to *Index*

REVIEW VISIT FINDINGS

General Comments and Achievements

This was a strong service, offering excellent care, and working in a fully multi-disciplinary way. The Centre Director had been co-director for the previous five years, with the other co-director having stepped down in November 2018. The success of the services was reflected by wholeheartedly positive feedback from patients. The Physiotherapists, Nurses, and Psychologist drew special comment. The administrative and support team were also very effective. The encouragement and support for team members to undertake continuing training was noted.

The environment from which the services were provided was welcoming and well maintained, with some recently refurbished rooms in the Centre, plentiful clinical and office space, and a physiotherapy gym and hydrotherapy pool located nearby.

It had been possible to retain all the necessary laboratory staff and facilities on site in line with the NHS England B5 service specification for haemophilia, and to continue close partnership working with them, despite a management change which meant that the laboratory scientists were no longer Royal Free Hospital employees.

The impressive research portfolio was internationally recognised and included a number of studies for which the Centre was UK or global lead. The department had led the development of gene therapy in haemophilia globally over a number of years and continued to support several gene therapy studies. All staff groups contributed to research activity, so that there was a large multi-professional research output. The way in which active research had allowed the Centre's patients to have access to new and developing treatments was a great benefit.

Good Practice

1. Some of the guidelines and service descriptions authored by team members were especially good, including 'Assessment and management of musculoskeletal bleeds in patients with inherited bleeding disorders', 'Physiotherapy service for patients with Inherited Bleeding Disorders', the Emergency Department guideline and pathway, and there was a comprehensive Home Treatment policy.
2. The availability of a Clinical Nurse Specialist, on site if needed to triage, review and treat patients directly, for four hours on Saturdays and Sundays was exceptional.
3. Transition practice for young people joining the service from the Great Ormond Street Centre was excellent**.** Age at transition was highly flexible with the process starting as early as 12 years, and a Great Ormond Street (GOSH) consultant continuing to see them on the Royal Free Hospital site. A clinic took place one day a week, until they were comfortable to move wholly over to the adult team, which could last into their 20's.
4. Radioactive synovectomy [1] was available on site, and the service was also offered to patients from other Centres.

[1] **Radioactive synovectonomy -** is a very effective and gentle procedure, used for rapid and sustained pain relief of severe joint pain. Through targeted sclerotisation of the synovial membrane with radioactive substances, lasting relief from pain and inflammation is achieved in most cases.

5. It had been possible to make sufficient savings, by Lloyd's Pharmacy dispensing concentrates, to allow for employment of an additional Health Care Assistant (HCA) on the team.

6. Reviewers were informed that home delivered concentrates were labelled, for clarity, with the patient-specific dose to be used for prophylaxis, and for an acute bleed.

Immediate Risks: None

There were no Immediate Risks.

Concerns

1. **The electronic document system EDRM**

   The Trust-wide system was cumbersome, and it was time consuming to access information. Scanned hard copy records could be stored in up to eight different folders, but the types of document stored in each was not systematic. The scanned images were sometimes upside down. Older 'legacy' records were filed individually without indication of what sort of document they were. The team saw that with current records in clinical use, the filing was much clearer.

2. **Homecare issues**

   Reviewers heard that the current homecare delivery provider was not working well for a large number of patients. The re-tender for this service was due to be completed soon, and it was hoped that this could be a platform for demanding a higher level of service. Further patient satisfaction audits in the near future will be required to provide assurance that the issues have been adequately addressed.

Further Consideration

1. There was no specific 'plan of care' recorded for each patient [standard HP-103], and although some elements of it were included in the hard-copy records held in the Centre, on the local database or in clinic letters, not all parts of a care plan appeared to have been discussed and recorded for some of the patients whose records were reviewed.

2. Many guidelines, including the diagnostic guideline, and some of the clinical guidelines, were national UK Haemophilia Centre Doctors Organisation (UKHCDO) documents, without any direction or guidance as to how they were implemented locally.

3. Some policies were not seen and although it was acknowledged that senior team members, who know the procedures, are readily available at all times so that systems worked in practice, it is expected that there will be some written guidance for other team members to consult as needed so that they are aware of their roles and responsibilities and to ensure consistency.

4. The local patient information leaflets that were seen by reviewers only applied to patients with severe haemophilia. Leaflets for those with mild or moderate, and other Inherited Bleeding Disorders – of whom the Centre cares for a large number – would be appropriate.

5. The lack of a social worker posed problems for some patients, and although the psychology support was reported to be very good, 0.5 Whole Time Equivalent (WTE) for a service of this size could be an under provision especially as the same professional also sees patients from other centres.

6. There was no named Rheumatologist working with the team. A senior orthopaedic surgeon with long established links with the Centre along with the physiotherapists, were felt to be providing adequate support in this regard. However, as that surgeon was due to retire in the near future, it may be timely to review the need for Rheumatology input.

7. Document control required attention. Some documents, for example the Operational Policy, had recently been updated and expanded to good effect, but both versions were drafts versions. Many of the other

documents and guidelines were still in draft form awaiting formal ratification, without a named author, issue date or review date included.

8. The increase in patients using Haemtrack [2]was noted, but patients reported that they find it difficult to use, and it may be helpful to consider some sort of demonstration or a coaching session for patients using Haemtrack. This could also help to increase the level of compliance with using Haemtrack.

9. Patients commented that, when they had given feedback or suggestions, it would be helpful if they could be informed of the team's responses or any actions planned as a result.

10. Reviewers heard from patients that they would like their appointment and follow-up information communicated to them by email (rather than by post). There may be some issues with doing this however, it would be helpful to discuss this further with patients as they would find it useful.

11. Reviewers heard from patients that during scheduled appointments they were frequently provided with new and complex written information. Patients felt that It would be helpful to have this information in advance if possible, so that they were able to read and consider it, in preparation for asking more detailed questions when they met with the clinician.

12. Carers who met the team said that they would welcome the chance to be more involved in consultations, with the patient's consent

General Comment

Royal Free London Haemophilia Comprehensive Care Centre was commissioned as the hub of the North London Network for adult haemophilia services, and as a 'spoke' in the paediatric service, with the hub being at Great Ormond Street Hospital. It was described that to some extent the adult network functioned at an administrative level. Data was being submitted by Barts Health NHS Trust and Imperial College Healthcare NHS Trust to NHS England by the Royal Free, and meetings of the Network Board had continued, with three having been held in 2018 although no dates were planned yet for 2019.

However, some of the expected 'managed network' activities, including review and learning, education, workforce planning and governance across the North London centres were not evident. Reviewers were told by the Centre Lead Consultant that there was no extra funding to the Royal Free London NHS Trust to support these activities, after an initial year of funding, and it was acknowledged that there were other possible barriers to joint working.

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.

[2] **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

NETWORK

Further information regarding compliance with the Network standards is included in Appendix 2.

COMMISSIONING

Further information regarding compliance with the Commissioning standards is included in Appendix 2.

Return to *Index*

APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Visiting Team		
Dr Amanda Clark	Consultant Haematologist	University Hospitals Bristol NHS Foundation Trust
Graham Knight	Patient reviewer	
Ruth Pink	Clinical Trials Manager	Hampshire Hospitals NHS Foundation Trust
Sayma Raza-Burton	Senior Haemophilia Specialist Nurse	Oxford University Hospitals NHS Foundation Trust
Stephanie Taylor	Physiotherapist	Oxford University Hospitals NHS Foundation Trust
Emma Warner	Clinical Nurse Specialist - Haemophilia	Cambridge University 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	30	81%
Networking	8	2	25%
Commissioning	3	1	33%
Total	48	33	69%

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.	N	Reviewers did not see a standard plan of care that covered each of the criteria in the quality standard. A template was made available to reviewers that did cover all relevant aspects. However, it was not being implemented. If this was implemented it would provide a comprehensive plan of care for patients
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.	N	Although reviewers felt assured that patients were being reviewed at appropriate intervals this standard cannot be 'met' as there was no single plan of care being used - See HP 103
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	However see Further Consideration in main report. Some patients commented that they found it difficult to use.

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	Y	Reviewers heard that the transition process was very good and worked well for patients. A transition guideline was provided but it was still showing as 'Draft'.
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	Reviewers heard that the psychologist does provide good support to the wider family / carers
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	However, it was noted that there is no dedicated social worker input to the team

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	Reviewers heard that individual staff have their training needs assessments as part of their appraisal process. To date, no complaints or comments have been raised about the lack of opportunities or funding for attending conferences. All staff are expected to participate in a minimum of one haemophilia related meeting annually and attend the weekly seminars and the last two years time table are attached. Importantly the consultant staff and lead nurse and physiotherapist regularly lecture about haemophilia, submit abstracts to conferences and contribute to manuscripts. We believe it is the individual clinician's responsibility to maintain their CPD. There is funding available from Royal Free Charity, and the size of the team provides adequate cross cover. However there was no overarching training plan document that described requirements for each staff member / staff group and what had been achieved or was still to complete
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	

Ref	Standard	Met?	Comments
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	
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	

Ref	Standard	Met?	Comments
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	However there was no input from a rheumatologist - see comments in main report
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	

Ref	Standard	Met?	Comments
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, see Further Consideration in main report regarding speed of access
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	N	The Centre had implemented national guidelines and all workups were undertaken in consultant-led clinics. Registrars were regularly supervised on the evaluation of prolonged APTT and learn when to suspect a mild / moderate and severe bleeding disorder. There were regular Lab MDTs attended by senior lab staff and medical staff to review the results of bleeding state workups and abnormal test results for their clinical significance. Registrars participate in these meetings. The coagulation lab is one of three specialist labs in the country and is UKAS accredited. The Lab had all the relevent SOPs for the diagnosis and classification of bleeding disorders. The Centre had considered a local guideline but felt that it did not add value especially when the classification of mild bleeding disorders is regularly changing. Two of the consultants were members of the working party about rare bleeding disorders and Von Willebrand disease. Diagnostic SOPs and guidelines are held in the laboratory and a list was provided by the Centre.

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	However, this document has not been reviewed since 2012
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	N	Reviewers heard that the requirements of this standard were happening in practice and staff could articulate the process. However localised documentation was often not in place. See Further Consideration section of main report.
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	However the guideline was still in Draft
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	However, reviewers noted that this was still yet to be ratified
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	
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	N	Although evidence was provided on how the team works, there was no evidence (minutes of meetings etc) that all the elements as required by this standard were met
HP-799	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	Reviewers noted that a system had been implemented but that this was not yet embedded. Most documents reviewed were version 1 and in Draft

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	However see comments in main report regarding the functioning of the Network at the time of the review
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. *(There was a previously well attended pan-London audit/education programme which has been fallow for 2 years. There is an agreed plan to reconvene this with formal CPD programmes 3 times a year, where pan-London audit presentations will also take place).* However, reviewers did hear of some joint working across the Network in relation to Education and Training at the time of the review
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 did not see any evidence of Network guidelines as outlined in the requirements of this standard at the time of the review

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	Reviewers did not see evidence that this was routinely being monitored across the whole Network 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	There were plans in place to restart this work but it was not in place at the time 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	Reviewers did not see any evidence during the course of the review
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 did not see any evidence during the course of the review

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	
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. *(There has been a long period of changing personal in Commissioning both locally and regionally which has made it very difficult to achieve this - the pan-London NHSE(London) clinical advisory group for Haemophilia IBD was reinstated in 2017/18 with successful meetings addressing area of concern and service development, however there has since been yet another change and there is no date for a future meeting at the time of reporting).* This was not functioning as per the requirement of the standard at the time of the review.
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. *(Please see HZ-701 - MDT clinicians across the Network are keen to implement this).* Although there were plans in place to implement this was not in place at the time of the review

Return to *Index*