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

Great Ormond Street Hospital for Children NHS Foundation Trust

Visit Date: 12th December 2018 Report Date: May 2019

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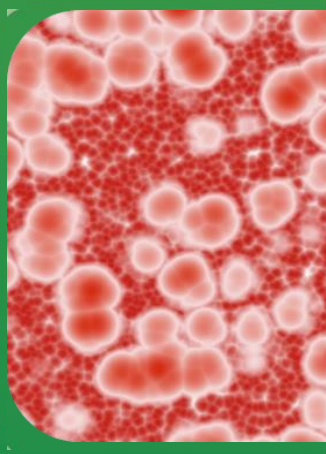

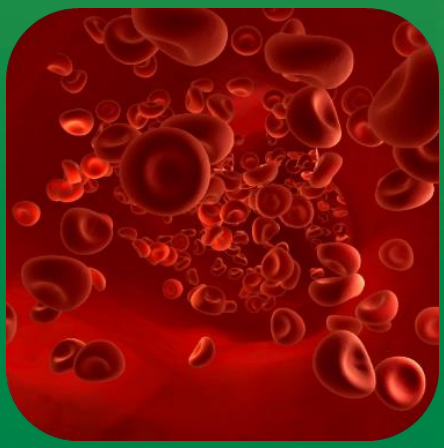

UKAS INSPECTION 8831

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INTRODUCTION

This report presents the findings of the peer review of services for people with Inherited and Acquired Haemophilia and other Bleeding Disorders at Great Ormond Street Hospital for Children NHS Foundation Trust on the 12th 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:

- Great Ormond Street Hospital for Children 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.

ACKNOWLEDGEMENTS

We would like to thank the team at the Great Ormond Street 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 parents and carers 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

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GREAT ORMOND STREET HOSPITAL FOR CHILDREN NHS FOUNDATION TRUST

The Haemophilia Comprehensive Care Centre at Great Ormond Street Hospital for Children NHS Trust (GOSH) is the largest Children's Centre in the UK. There was a dedicated outpatient facility with space for regular multi-disciplinary reviews, day cases, emergency attenders, new patient appointments and clinical trial visits. The Centre was open Monday to Friday 08:00 to 18:00 and the service was consultant-led on-site during those hours. The Centre also had office space for the whole team including: Consultants; Clinical Nurse Specialists (CNSs); Haematology Specialist Registrars (SpRs); Administrative team; the service manager and the research co-ordinator. A dedicated physiotherapy room for assessment and treatment and a walk-in fridge, for factor concentrates and trial stock, was also available.

Inpatient admissions were accommodated on one of the haematology/oncology wards when required - usually for portacath (a small implanted medical device that provides access to the central vein) insertions and removals.

The majority of patients who attended the Centre lived in the northern half of Greater London, but patients also travelled from South London and further afield across England. The Centre had a particular interest in children with complex haemophilia such as inhibitors and intracranial haemorrhage and in those with rare bleeding disorders such as severe platelet function defects.

The GOSH Centre staff work closely with colleagues at Barts Health NHS Trust and the Royal Free London NHS Foundation Trust. Medical consultants from this Centre provide clinics at these other Centres as well as University College London Hospitals. The team also worked closely with other Centres such as the Evelina London Childrens hospital and St Georges University Hospitals NHS Foundation Trust, who contacted the team when necessary and attend GOSH Multi-Disciplinary Team (MDT) meetings periodically for face-to-face catch-up sessions.

There were two MDT sessions every week: Mondays to handover from the weekend and plan the week ahead. This was attended by core staff – administrative, medical, nursing and physiotherapy as well as a laboratory representative; on Fridays the MDT focussed on discussion and treatment plans for patients with problems. The outcomes of discussions were uploaded onto the individual patient record. MDT discussions also include clinical trial updates and any other current relevant matters that require discussion. This meeting was attended by core staff, the laboratory (if required), psychology and colleagues from other London hospitals periodically.

A brief daily 'huddle' handover/update meeting occurred every Tuesday/Wednesday/Thursday. Each month there was a business meeting where the team discussed Trust updates, finance, operational issues, benchmarking, and any incidents or complaints etc. A quarterly Research & Development (R&D) / clinical trial update meeting was also held.

At the time of the visit the following numbers of patients were registered at this Centre:

Condition	**No. patients – all children (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	**181** 107 severe (17 current inhibitor) 16 moderate 44 mild 14 symptomatic carrier	**175** (all severe patients reviewed)	**39** 32 severe 7 mild

Condition	No. patients – all children (show breakdown Severe, Moderate and Mild)	No. patients who had an annual review in last year	No. in-patient admissions in last year
Haemophilia B	**57** 22 severe (1 current inhibitor) 6 haemophilia B Leyden 2 moderate 17 mild 10 symptomatic carrier	**54** (all severe patients reviewed)	**13** 8 severe 5 mild
Von Willebrand	**166** 7 severe 19 moderate 135 mild 5 'probable'	**166**	**30** 3 severe 9 moderate 18 mild
Other			
Afibrinogenemia	**2**	**2**	**1**
Hypo, hypodys and dysfibrinogenemia	**15**	**13**	**8**
Prothrombin deficiency	**3** severe	**3**	**0**
Factor V deficiency	**5** 3 severe 2 mild	**4**	**2**
Factor VII deficiency	**28** 2 severe 26 mild	**27**	**10**
Factor X deficiency	**14** 7 severe 7 mild	**14**	**5**
Factor XI deficiency	**75** 5 severe 70 mild (I also vWD)	**75**	**12**
Factor XIII deficiency	**1** severe	**1**	**5**
Bernard Soulier	**2**	**2**	**0**
Glanzmanns Thrombasthenia	**13**	**13**	**7**
Platelet defects (misc)	**49**	**46**	**10**
Unclassified	**28**	**27**	8

EMERGENCY CARE

GOSH had no Accident & Emergency (A&E) on site and therefore patients attended their local paediatric A&E when required with close liaison from the GOSH team. The pathway was that parents call the GOSH team for advice in the first instance and when it is advised that they attend their local paediatric A&E, the GOSH team called ahead to speak to the staff at the A&E or paediatric ward to give background information about the patient and ask them to call them back, after assessment. A joint decision was then made on whether the child could go home, should be admitted to the local paediatric ward (e.g. for portacath line infections) or whether the problem was severe enough to require transfer to a GOSH bed. The Centre had very good working relationships with many local paediatric teams as they also provided shared care services for all haematology and oncology children.

Where appropriate there was also a pathway for the child to attend one of the inpatient wards out-of-hours where they could be seen by the haematology or paediatric Specialist Registrar (SpR) on call and receive treatment and/or admission if required.

WARD BASED CARE

GOSH infants and children were usually looked after on one of the haematology/oncology wards although there were also intensive care facilities available, when required. Medical cover was provided by haemophilia consultants and SpRs. The ward nursing staff were fully supported by the Clinical Nurse Specialist team. There were, on average, 1-2 portacath procedures (insertion or removal or both) per month. In addition, patients were supported when having operations done under General Anaesthetic, by other specialities e.g. Ear Nose and Throat (ENT), General Surgery and Dental.

DAY CARE

Day cases were accommodated in the Haemophilia Centre and looked after solely by the Haemophilia team. There were between one and three day cases per week for platelet transfusions, rehabilitation after radioactive synovectomy, assessment of an acute bleed with imaging etc.

COMMUNITY BASED CARE

Practice at the Centre was to educate the parents to provide the care at home required for their children; this was for all severe and moderate patients and others who require regular treatment. In addition, the Clinical Nurse Specialist team completed home visits as required for the majority of our patients but there were a few patients who live more than 100 miles away and for these it was not always possible to do home and school visits. One of the physiotherapists did some home and school visits as well as liaison for a family with twins with long-standing inhibitors therapy (an inhibitor is a type of antibody that prevents factor replacement therapy from working).

Community Nursing teams were used occasionally, but they were rarely able to provide the specialist care required for patients.

REVIEW VISIT FINDINGS

Achievements

Reviewers felt that this was an outstanding service, provided by a cohesive, supportive team with excellent leadership. The team serve as a resource at a national and international level in the field of bleeding disorders. Communication between team members was clearly very effective, and there was strong mutual trust and respect. The nurse specialists were expert, flexible, and were able to work autonomously; all were non-medical prescribers. The physiotherapists were also highly experienced and contributed greatly to the team. The staff enjoyed working in the team, and this included relatively new members of the Administrative & Clerical staff who worked from an open office in reception and felt they were a valued part of the team. The quality of the service was reflected by overwhelmingly positive, appreciative feedback from parents and families.

The team worked from a dedicated clinical area which was welcoming, bright and spacious, with a dedicated room for older children and teenagers and a physiotherapy treatment room. Useful patient information leaflets and posters were prominently displayed. A refrigerated storage facility for concentrates and trial medication was situated within the facility.

The team's research portfolio was outstanding. Recent important contributions having been the HAVEN study, for which this Centre was the only UK site, and some physiotherapy research studies and publications including the iStep and association between potential developmental issues and haemophilia.

Good Practice

1. Multidisciplinary team functioning was strong and inclusive, at twice weekly team meetings and daily 'huddles'. Most scheduled patient visits were also multi-professional with children being seen by a nurse, physiotherapist and doctor at the same visit.
2. The team had autonomy to schedule their own appointments, which meant that they could often be fitted around appointments with other specialists such as dental or orthopaedics, which reviewers felt improved the overall patient experience.
3. Written information for patients was comprehensive; some was derived from national leaflets but adapted and badged for local use and some were novel, written by local team members. These included one regarding managing joint bleeds, and an information sheet about early detection and management of brain bleeds which had been adopted for use by other Centres.
4. Team members made every effort to be contactable. Reviewers saw small wallet-sized cards including phone numbers (in and out of hours) which are given to all families and are freely available on the reception desk. Contact phone numbers and e-mail addresses of all staff were also included on every clinic letter.
5. The management of delivery for pregnant carrier women was carefully planned, with mothers given a 'baby pack' before the birth, including a tube for cord blood to be collected into for immediate testing to see if the baby was affected, a dose of vitamin K and a small dose of the relevant factor concentrate.
6. The team reviewed affected new-borns immediately, if clinically needed, and otherwise for their heel prick test at ~ 6 days. They then attended again for their first immunisations, and one of the nurses undertook a home visit to administer the second immunisations. By the age of 12 weeks therefore there had already been a good deal of contact and communication with the child and their family.
7. Reviewers noted excellent transition practice, especially for children moving on to the Royal Free Hospital for ongoing treatment. This was led by one of the Centre's consultant medical staff undertaking joint clinics with the Haematologists there. Age at transition was specific to the child with the process starting

as early as 12 years, and the GOSH consultant staff continued to see young people at the Royal Free Hospital until they were comfortable to move wholly over to the adult team, which could be into their 20's.

Transition to the Bart's Health NHS Trust was facilitated by another member of the consultant team doing joint outreach clinics there. Transition of smaller numbers of other young people to different Centres was carefully thought through, as required, with one of the nurse specialists often accompanying them on their first visit. Physiotherapy transition reports were also sent to the physiotherapist at the adult Haemophilia Centre.

8. Comprehensive physiotherapy assessment and rehabilitation was provided post-procedures such as radioactive synovectomy and, as required, after joint and muscle bleeds. A physiotherapist was nearly always available in the Centre, and their protected research time had allowed for some important and innovative studies.

9. Team members took care to give full information about the child's condition and its impact on the family when referring to other providers such as social services and citizens advice bureau – which were available on site.

10. The establishment of a radioactive synovectomy1 service was an important advance for patients, and it was hoped that this would also be offered to patients from other Centres in the near future.

11. All children with moderate, as well as severe, factor deficiency had a 'save-a-life' dose of concentrate at home.

12. Use of a BloodTrack® system allowed for issue of blood components for children after a single venous sample had been received in the laboratory, without which two separate venous samples are often required.

13. When the IT systems migrate to the new patient record system (EPIC®) in April 2019, it was intended to purchase 'PhenoTips' ® software which has been reported to aid genetic diagnosis by allowing access to other, anonymised, patient and family results.

14. Reviewers commented that the design of their treatment /day case room was very good as it had a window adjoining the nursing office which enabled families learning intravenous infusion (via portacath/peripheral access) who were almost competent could perform the procedure on their own knowing that the staff were just next door if needed.

Immediate Risks: None

Concerns

1. **Electronic Patient Records**

   The current electronic patient record allowed for storage of material under approximately 10 different 'files' per patient, and the types of document stored in each was not systematic. For example, physiotherapy joint scores over successive visits could be found, for a single patient, either under 'Correspondence', or 'AHP records' or 'Investigations'. Using the records was difficult and time-consuming and reviewers were concerned that it could be possible to miss some documentation which had been scanned and stored into an inappropriate file.

[1] **Radioactive synovectomy** - 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.

Further Consideration

1. Reviewers looked at mandatory training records for staff and noted at the time of the visit that there were a few senior staff who were not up to date with all relevant elements including two who required renewed training in infection prevention and control, and one in resuscitation. The team should ensure that all members of the team are up to date with their appropriate mandatory training[2].
2. Psychology support for the service was good, but at the current level of provision it was not possible for the psychologist to be an integrated member of the team, meeting all children and families. Neurocognitive testing following brain bleeds often only occurred when a learning or behavioural problem was identified. Increased provision of psychology sessions would allow a higher level of input and support for children and their carers.
3. Dental services for children had been significantly reduced, due to staff shortages, and it was no longer possible for them to have routine 6-12 monthly dental reviews. This was noted as a problem by some families in written feedback.
4. At the time of the visit, reviewers did not see any evidence to establish that all staff were maintaining professional competence[3], for example CPD content, training records or a training plan for staff.
5. Reviewers heard that pathways and processes were in place and that staff could describe them consistently. However, they were not formalised in a written policy or Standard Operating Procedure. These included: accessing factor concentrates out of hours; a step-guide to managing out of hours emergency care for children attending their local Emergency Departments; guidelines on care for patients requiring surgery; management of children who were not brought for appointments; expected times for school visits and a lone working policy for staff working in this service. Documenting these guidelines would ensure that a new member of the team was clear about local processes and their roles and responsibilities within them.
6. Reviewers saw that Incidents, complaints and other patient feedback, were discussed at MDT's but it was not clear how any learning outcomes or actions were recorded or disseminated.
7. Clinical guidelines were mostly in the form of links to relevant national published guidance, but without any additional practical guide for staff applying them locally. The development of local guidelines would ensure new and existing team members were aware of 'how things are done' at GOSH and are therefore clear about their own roles and responsibilities.
8. Although care was taken to offer school holiday appointments, there was no provision of evening or weekend clinic appointments for older children and / or or those with working parents. This was noted to be a problem in some patient written feedback and the team may consider whether it is possible to provide more flexible appointments, in response to patient feedback.
9. Although washing facilities and hand gels were provided in the clinical rooms, there was none at the entrance to the Centre nor in the waiting area, and this should be considered by the Centre[4].

General Comments

1. **Network arrangements**

   The Centre had not completed self-assessment against the Network standards [HY-199 – 798] nor Commissioning standards [HZ- 601 – 798]. Great Ormond Street is commissioned as the 'hub' of the

[2] Evidence was subsequently received from the Centre that all staff were up to date with their mandatory training

[3] Evidence was subsequently received from the Trust regarding CPD for consultant staff.

[4] Evidence was provided that this was rectified soon after the visit

North London Network. On discussion, it was clarified that some elements of intended managed network responsibility, including review and learning, education, workforce planning, and governance were not functional. There were some good cross-London audits in place, however, and a great deal of collaborative clinical working across the north London Centres – and indeed some south London sites and beyond.

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. **Emergency Department Arrangements**

Great Ormond Street Hospital is unusual in being a Comprehensive Care Centre without an Emergency Department (ED), and initially this gave rise to some concern from the visiting team as to how children were managed when they needed urgent care out of hours. Although not formalised in a written guideline or protocol[5], team members all described that families were instructed that if their child needs urgent care, they should telephone the on-call consultant SpR at the time they were taking the child to their local hospital ED. The on-call doctor then telephoned the ED, often ahead of the child arriving, alerting staff there of his or her diagnosis and treatment, with instruction to assess and call back immediately after for further guidance. In this way, senior medical guidance for less experienced ED staff or Paediatricians was always accessible. If there were concerns about the child needing specific specialist input, transfer to GOSH for further assessment / admission would be recommended.

NETWORK

No self-assessment had been submitted against the Network standards

COMMISSIONING

No self-assessment had been submitted against the Commissioning standards

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[5] The Centre have confirmed that there was information included in the 'Information for families' leaflet and the Emergency section has since been updated. An Emergency Care Pathway SOP has also subsequently been developed to explain the process.

APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Visiting Team		
Charlene Dodd	Physiotherapist	East Kent Hospitals University NHS Foundation Trust
Dr John Grainger	Consultant Paediatric Haematologist	Manchester University NHS Foundation Trust
Lara Oyesiku	Haemophilia, Haemostasis and Thrombosis Clinical Nurse Manager	Hampshire Hospitals NHS Foundation Trust
Alice Wilkinson	Paediatric Haemophilia Nurse	Oxford University Hospitals NHS Foundation Trust
Heather Williams	Haemophilia Operational Services Manager	Barts Health NHS Trust

Please note: It is usual on peer reviews for a patient representative to be part of the team. Although a patient reviewer was due to attend this review, they had to cancel at the last minute due to illness

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

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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	35 *	28	80
Network	8	0 **	
Commissioning	3	0 **	
Total	46	28	80***

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* GOSH did not have an ED and therefore QS 302 and 504 were not applicable

** Network and Commissioning standards were not completed by the Centre

*** This overall figure does not reflect that the network and commissioning standards were not completed

HAEMOPHILIA COMPREHENSIVE CARE CENTRES AND HAEMOPHILIA CENTRES

Ref	Standard		
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	Reviewers saw a wide range of electronic evidence that was also seen to be available in clinic areas and in a variety of languages

Ref	Standard		
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	Reviewers saw a wide range of electronic evidence that had also been localised for this particular centre and was in a variety of languages

Ref	Standard		
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	However, see concerns section of main report regarding document scanning
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		
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	See Achievements section of main report regarding the overall environment.
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
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	See Good Practice section of main report regarding staff at the Centre providing training to Citizens Advice Bureau and other staff regarding haemophilia
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		
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	See Further Consideration section of main report regarding psychology input

Ref	Standard		
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 Notes for this Quality Standard - for compliance with this QS the service should provide a matrix of all roles within the service, competences expected and the approach to maintaining competences. A training and development plan showing how competences are being achieved and maintained is also required
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	

Ref	Standard		
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	N/A	
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		
HP-304	**Specialist Services** Timely access to the following specialist staff and services should be available as part of a HCCC service. HCs should be able to access these services through network arrangements: a. Obstetrics including reproductive counselling, information about pre-implantation genetic diagnosis and antenatal diagnosis b. Foetal medicine c. Vascular access (consultant surgeon or interventional radiologist with experience of venous access devices) d. Orthopaedic surgery e. Care of older people services f. Dental services g. HIV services h. Hepatology i. Medical genetics (Genetic Counselling Services) j. Pain management services k. Rheumatology Specialist services should have an appropriate level of specialist expertise in the care of people with inherited and acquired bleeding disorders.	Y	See Further Consideration section of main report regarding dental services not being able to offer regular checks which would be better for patients. See also Good Practice regarding radioactive synovectomy
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		
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 were told that the stock control functionality of HSIS is not fit for purpose. This is not unique to this Centre and will be included as a general comment in the outputs of the overall review programme.
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	Reviewers noted that the Centre used relevant national guidance. However, they did not see any evidence that these guidelines had been localised (see notes section for this Quality Standard) at the time of the review. The Centre have confirmed post review that they will address this by updating the previous departmental guideline into one document that can be used alongside national guidelines
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	N	This was not all in place at the time of the review. However, a further document was received from the Centre as evidence (written February 2019)

Ref	Standard		
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.	N/A	Although reviewers noted that this is Not Applicable for this Centre as there is no Emergency Department (ED) at Great Ormond Street, reviewers agreed that documented procedures for children presenting at other EDs across London would be helpful
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	N	Although a surgical template was in place at the time of the review an associated guideline was not available. However, a surgical pathway SOP was received from the Centre post review as evidence (written February 2019)

Ref	Standard		
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		
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	N	At the time of the visit, reviewers did not see evidence of an overarching service procedure / policy in place. Individual evidence was not seen for E, G, H and I. The Centre has confirmed that 'e' is part of the hospital access policy and was one of the submitted documents at the time of the visit. For 'g' they plan to develop care plans as part of EPIC system which will go live in April 2019. This will then allow care plans to be generated which will be updated at 6 monthly reviews for severe patients and annually for mild patients. An SOP has now been provided by the Centre for 'h'. 'I' is not applicable to this centre
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		
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	N	Reviewers saw evidence of transition and joint scores audits. However, there were no audits available for the other items in this standard. Reviewers did not see evidence of an overall audit programme. The Centre has confirmed that a consultant has now been appointed as audit lead to develop a rolling programme to encompass all the elements of this standard

Ref	Standard		
HP-706	**Research** The service should actively participate in research relating to the care of patients with bleeding disorders.	Y	See Achievements section of main report - the Centre has an outstanding multi-disciplinary national and international research portfolio including physiotherapy (istep), autism and haemophilia and the HAVEN study
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 'developed on' and review dates. The Centre has confirmed that they will review departmental documents serially at monthly business meetings to ensure that document control is applied.

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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.	Not Assessed	Network standards not completed by the Centre
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	Not Assessed	
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.	Not Assessed	
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)	Not Assessed	
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	Not Assessed	
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.	Not Assessed	

Ref	Standard	Met?	Comments
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.	Not Assessed	
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	Not Assessed	

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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	Not Assessed	Commissioning standards not completed by the Centre
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	Not Assessed	
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.	Not Assessed	

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