QRS Quality Review Service

UKHCDO

NHS

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

Nottingham University Hospitals NHS Trust

Visit Date: 2nd October 2019

Report Date: December 2019

UKAS INSPECTION

8831

Contents

Introduction

This report presents the findings of the peer review of services for people with Inherited and Acquired Haemophilia and other Bleeding Disorders at Nottingham University Hospitals NHS Trust, which took place on 2nd October 2019.

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

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

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

The report reflects the situation at the time of the visit. The text of this report identifies the main issues raised during the course of the visit.

Appendix 1 lists the visiting team and **Appendix 2** gives details of compliance with each of the standards and the percentage of standards met.

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

- Nottingham University Hospitals NHS Trust
- NHS England Specialised Commissioning East Midlands

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 for monitoring their implementation, liaising, as appropriate, with other commissioners.

About the Quality Review Service

QRS is a collaborative venture between 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.

Expected outcomes are better quality, safety and clinical outcomes, better patient and carer experience, organisations with better information about the quality of clinical services, and organisations with more confidence and competence in reviewing the quality of clinical services. More detail about the work of QRS is available at www.qualityreviewservicewm.nhs.uk

Acknowledgments

Quality Review Service would like to thank the staff of the Nottingham Comprehensive Care Centre for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. We are grateful, too, to the patients, 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.

Nottingham Comprehensive Care Centre

Nottingham Comprehensive Care Centre (CCC) provided care and treatment for adults and children.

The adult service was within the Clinical Haematology (Cancer and Associated Specialities) Division, and the children's service within Child Health.

Nottingham University Hospitals NHS Trust (NUH) was a two-site Trust (Queens Medical Centre (QMC) and Nottingham City Hospital (NCH), which were four miles apart). QMC was the 'acute site', housing the Emergency Department (ED) and the trauma centre. Most elective surgery was carried out at NCH. The children's hospital was based at QMC. Obstetric services were provided on both sites.

Bleeding disorders were predominantly managed at QMC (complex pregnancy including haemophilia and other severe bleeding disorders) because of the availability of CCC staff and the paediatric haemophilia team, and the location of the specialist coagulation laboratory.

The adult malignant haematology service and all inpatient and outpatient facilities (except haemostasis and thrombosis) were based at NCH.

The haemophilia unit had always been based at QMC. Historically there had been inpatient facilities for both malignant and non-malignant haematology patients on both sites. The malignant service moved entirely to NCH (including for day cases and outpatient clinics) in 2006. The decision was made then to keep haemostasis and thrombosis at QMC because of the location of the children's hospital. Until four years ago the two adult haematology services were in different divisions, but at the time of the visit they were both in the Cancer and Associated Specialities (CAS) Division, which had led to improvement in the governance and administrative structure.

Nottingham CCC was part of the East Midlands Network. This was a non-commissioned informal network started by the clinicians to improve cooperation and learning to support patients. The network was set up and was managed and chaired by Nottingham CCC. It met three or four times per year.

Nottingham CCC shared patient care with Derby and Lincoln Haemophilia Treatment Centres. There were no formally commissioned pathways between the centres. Some Lincoln patients were referred to the Sheffield CCC, based on geographical considerations. Nottingham CCC also received referrals from Sherwood Forest Hospitals (King's Mill and Newark).

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

Condition		Number of patients		Number of patients who had an annual review in last year	Number of inpatient admissions in the last year
Haemophilia A	Adults	Severe	33	All	35
		Moderate	12	10 (1 DNA, 1 seen at another centre)	
		Mild	58	33 (10 DNA, remainder either not followed up as normal chromogenic F8 or lost to follow up following previous DNA)	
	Children	Severe	19	All	8

Condition		Number of patients	Number of patients who had an annual review in last year	Number of inpatient admissions in the last year
		Mild 16	15 (1 DNA)	
Haemophilia B	Adults	Severe 6	All	3
		Moderate 2	All	
		Mild 8	4 (3 DNA, 1 seen at another centre)	
	Children	Severe 1	All	7
		Moderate 2	All	
Von Willebrand	Adults	227		43
	Children	67		1
Other	Adults	367		
	Children	113		

Emergency Care

During working hours, patients who were unlikely to require admission or other investigations were assessed and treated in the haemophilia treatment room (located within the anticoagulant clinic, D Floor, QMC). Children could sometimes be assessed in Ward E39 (day case) (paediatric haematology / oncology ward) depending on the reason for attendance. Any patient who might need admission was asked to attend the ED. The haemophilia team would notify the ED team of the patient's attendance and visit the patient as soon as they arrived.

Out of hours, patients were asked to attend the ED after calling the on-call haematologist. The on-call team then liaised with ED staff and the admitting team to ensure treatment was given appropriately.

When children required admission, the preferred ward was Ward E39, if a bed was available.

Adult clinical haematology patients were usually admitted to the Specialist Receiving Unit at NCH. It was rarely appropriate to transfer haemophilia patients across to NCH, but this might be required for another speciality e.g. burns, renal, urology. Admission was usually to the most appropriate ward for the presenting complaint e.g. orthopaedics, trauma, acute medicine (e.g. gastrointestinal bleeding), or Health Care for Older People (HCOP) for older patients. This facilitated timely review by the specialist haemophilia team, timely access to specialist laboratory support, and optimum nursing support for additional patient needs such as rehabilitation, surgical intervention, endoscopy etc.

Ward Care

For children, Ward E39 (paediatric haematology / oncology) was used. This also had day case facilities.

For adults, as described above, the Acute Medical Admission Ward (B3) was used. The ED also had a clinical decision unit (LJU) for patients who required a short stay for assessment. Other wards used were specific to the reason for admission.

Day Care

For paediatrics, day care was provided in the haemophilia treatment room (for routine treatment e.g. training, prophylaxis and assessment not requiring admission). Ward E39 (day case) could also be used in some cases if medical support was required. Children were sometimes admitted directly from day care, if needed.

For adults, routine treatment could be given in the haemophilia treatment room. The haematology day case unit, at NCH, was sometimes used if treatment was required prior to a day case procedure on that site and for procedures where more nursing support might be required (e.g. commencing a drug that might cause anaphylaxis).

Outpatient Care

Paediatric clinics were held in children's outpatients and adult clinics were held in Clinic 2 at QMC.

Community Based Care

School visits and home visits to housebound patients were provided by the haemophilia nursing team. Support for Central Venous Access Devices (CVADs) was provided by the haemophilia nursing team and / or the community nursing team, where required.

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Review Findings

Achievements

This specialist team was working very hard, and working extremely well together, particularly as there had been many staffing challenges over the preceding year. It was well led, and team members were mutually supportive and respectful. All were striving to achieve a high level of care for their patients and were working very effectively. The contributions of the data assistant, who was 'acting up' while the usual data manager was on sick leave and managing a wide range of responsible duties, as well as the physiotherapist, who was working well beyond her very limited contracted hours (including sometimes in her own time), were especially noted. There had recently been better support from the service's clinical managers. The extra time and efforts the team invested in running out of hours social events and outings for patients and families were also appreciated.

Patients, and parents of affected children, were overwhelmingly positive about the care they received, commenting on how often team members went above and beyond their expected duties to offer additional support.

The documentation supporting the service was excellent, including many strong diagnostic and clinical guidelines, and there was an outstanding guide to antenatal management for women with bleeding disorders or at risk of having an affected infant.

The team had made singular efforts to open a clinical trial for the benefit of one child under their care, for whom no other treatment was likely to be as effective as the trial agent.

Good Practice

1. Both the systems used in the ED and the main hospital system flashed a front screen 'alert' of the patient's diagnosis as soon as the record was open, so that it would not be possible to proceed without having seen it. It was also possible for consultants on-call out of hours to access the system remotely, and to input their comments and advice onto it.
2. Clinical governance activities were very well developed, with a comprehensive audit programme focusing on all the most important aspects of diagnosis and treatment. Multi-disciplinary team (MDT) meetings, and other meetings at which review and learning took place, were fully minuted. Individual patient discussions at MDT meetings were recorded on a proforma, which was then scanned into the permanent electronic health record.
3. Liaison between the specialist team and other clinical teams was good, with colleagues having been sent an e-questionnaire asking if co-operative working could in any way be improved; most were happy with the working arrangements in place.
4. Recent work undertaken by the data assistant included work on patients' genetic family trees, and the production of a database of relatives by age from which it was possible to identify, for recall, testing and counselling, potential or obligate carrier female relatives before they reached reproductive age.
5. In both the paediatric and adult EDs, a Band 7 nurse triaged patients arriving, to prioritise those that required the most urgent assessments.
6. A locally adapted version of the national haemophilia nurses' competencies template was in use.
7. The difficulties of managing patients having elective surgery on the NCH site, about four miles away from QMC, had been reduced by establishing a taxi service to collect pre- and post-operative specimens for factor level measurements and to bring them straight from the ward to the laboratory at QMC.

Immediate Risks

There were no immediate risks identified at the time of the visit.

Concerns

1. **Staffing**

   Some continued staffing shortfalls made it impossible for the team to offer the rounded multi-professional and holistic care expected for patients with these long-term conditions.

   a. Physiotherapy: Provision was grossly inadequate, with a specialist physiotherapist contracted to work for just 0.75 PA – three hours per week – for the service. Within this time, it was not even possible to undertake joint scores on all the patients, let alone to offer any care to preserve joint health, so that even if joint scores were deteriorating there was no capacity for appropriate physiotherapy management to be offered. No outcome measures were being undertaken. There were good physiotherapy/gym facilities on site, but very few patients had been given tailored programmes of exercise, meaning that they were unable to take advantage of these facilities.

   b. Psychosocial care: There was no psychologist working in the service, although this is an expected core team member. The highest-level patient or family needs had to be met through primary care, although it was uncertain how often or how promptly this led to appropriate support being offered. Lower-level patient needs were not being met, and the support that a psychologist working as an integrated team member can give to colleagues was also lacking. The lack of any available psychology session for these patients was inequitable, as there was availability for haemoglobin disorder and haematological malignancy patients being managed by the same department. There was no dedicated social work support for the patients or families, although there was an acknowledged need for help for many of the families.

2. **Electronic records**

   Although recent notes were being scanned and filed correctly, and were easy to access, legacy records of all previous activity were 'bulk filed' as a single unindexed document, which could run to many hundreds of pages. The quality of the scan was often poor, which made it difficult and time-consuming to locate any specific previous record, and it would be possible to miss a clinically relevant record from previous care episodes. Previous correspondence, however, was also kept in an older system called 'Notis'®, where documents were itemised and much easier to search. The team had been informed that, at some point, Notis would cease to be available; however, the Centre team, and review team, hoped that under these circumstances access to its contents can continue to be available in the long term.

Further Consideration

1. Despite clear guidelines provided by the specialty team, patients and carers of children reported inconsistent care in the ED, with, on occasion, delays in assessment and treatment. Further training sessions for ED staff were planned, and repeated input on a rolling programme was agreed to be necessary as the turnover of ED staff can be high.

2. Although this was not a regular occurrence, if children and adult patients presented at the same time needing non-elective assessment and treatment, they might need to wait together in the large waiting area used for the anticoagulant clinic, in which the haemophilia treatment room was sited. A small children's waiting/play area might be screened off from the main waiting room for the use of these children, and also for children attending anticoagulant clinics.

3. The single treatment room was usually adequate to assess and manage patients presenting acutely. However, it was noted that if the team expands to include, as it should, physiotherapy and psychology colleagues, then extra rooms would be required for them to see patients and families.

4. A guideline for the management of bleeding in patients with inhibitors suggested treatment with Feiba but did not differentiate between adults and children. For children, this would not be the usual first line treatment and it would be useful to clarify this.

5. A useful 'Prophylactic Home Treatment Regimen' proforma was seen for each patient, with individualised factor doses to be given for minor to more serious bleeds. It did not include details of recommended timing of repeat doses, nor alerts for bleeds which might require hospital assessment, which would be additionally useful.

6. Transition practice for teenagers and young adults coming across from the paediatric to adult service appeared to have lapsed a little in the time before the visit. It was understood this was due to an issue with clinical staffing capacity in the service in the preceding year, and that not many young people of transfer age were being managed at this time. Nonetheless, re-establishing a named co-ordinator for this process, and the previous twice-yearly transition clinics, to ensure that this is more formalised, would be valuable for the teenagers who next reach transition age.

7. Governance activities were noted to be strong (see Good Practice 2 above). A further level might be achieved if MDT actions, and audit recommendations, also included a note of which team member was to action them (and by when) in the form of a rolling 'action log'.

8. In regard to the significant shortage of specialist physiotherapy time currently contracted to the service, it may be useful to have a discussion around published evidence for reduction in factor concentrate usage – and therefore costs – in patients using high quantities who have appropriate physiotherapy support, to try to support the case for increased hours.

9. Research activity was low, although the team expressed an interest in increasing this and an intention to do so. It may be helpful to have discussions with service managers and commissioners before enrolling patients in trials, to ensure that savings accrued from reduced payments for factors for patients in clinical trials for whom concentrates are not charged can be directly invested in improvements such as increased physiotherapy and psychology support for the patients using this service.

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General Comment

The East Midlands inherited and acquired bleeding disorders network was informal, and not specifically commissioned. However, efforts had been made by the clinicians in the region to establish a network, and quarterly minuted meetings, chaired by the Centre director at Nottingham, had taken place over at least the last three years. None of these meetings had been attended by the service's specialist commissioners.

Until very recently, the Nottingham haemophilia team had been unaware of who their named specialist commissioner was. However, at these meetings there had been some useful shared discussion between staff at the two Comprehensive Care Centres at Nottingham and Leicester and the linked sites at Derby, Lincoln, and Kettering. During telephone discussion at the time of the review, haematologists at Derby and Lincoln confirmed that they felt well supported by the Centres if they made contact for clinical advice, in or out of hours. There had been some shared educational events, and the meetings included case presentations and discussion, and some data sharing between the Centres regarding factor use. Team members from all professional groups should be supported (and resourced) to attend these and other educational opportunities, including national meetings/conferences, to gain appropriate training updates.

Discussion between the service leads, NUH managers, and specialist commissioners will be required to identify and agree additional resource if this network is to be formalised and to function optimally, bringing opportunities for shared clinical guidelines, audits, benchmarking, research, recruitment, and the potential for shared staff appointments. This would be relevant across the East Midlands region, given the common shortfall in some key staffing including specialist physiotherapists and psychologists.

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APPENDIX 1 Membership of Visiting Team

Visiting Team		
Beverley Barnett	Senior Biomedical Scientist	Hull University Teaching Hospitals NHS Trust
Martin Beard	Patient representative	
Cathy Benfield	Haemophilia Nurse Specialist	Alder Hey Children's NHS Foundation Trust
Dr Pratima Chowdary	Haematology Consultant	Royal Free London NHS Foundation Trust
Claire Forrester	Haemophilia Nurse Practitioner	University Hospitals of North Midlands NHS Trust
Dr Mary Mathias	Haematology Consultant	Great Ormond Street Hospital for Children NHS Foundation Trust
Anne Penn	Haemophilia Physiotherapist	Leeds Teaching Hospitals NHS Trust

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

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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 varies 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

Details of compliance with individual Quality Standards can be found below.

Service	Number of applicable QS	Number of QS met	% met
Haemophilia Comprehensive Care Centre	37	34	92
Network	8	4	50
Commissioning	3	0	0
Total	48	38	79

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Haemophilia Comprehensive Care Centre

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 2. Haemophilia B 3. Von Willebrand Disease 4. Acquired haemophilia 5. Inherited platelet disorders 6. Other less common and rare bleeding disorders	Y	However, this could be made more visible in clinical areas.

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

Ref	Standard	Met?	Comments
HP-194	**Environment** The environment and facilities in out-patient clinics, wards and day units should be appropriate for the number of patients with inherited and acquired bleeding disorders and accessible by people with severe mobility problems. Services for children and young people should be provided in a child-friendly environment, including toys and books / magazines for children and young people of all ages.	Y	
HP-195	**Transition to Adult Services and Preparation for Adult Life** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards f. Advice for young people going away from home to study, including: i. registering with a GP ii. how to access emergency and routine care iii. how to access support from their Comprehensive Care Centre iv. communication with their new GP	Y	However, there was no named coordinator in place, and transition work had lapsed because of recognised staffing issues.
HP-198	**Carers' Needs** Carers should be offered information on: a. How to access an assessment of their own needs b. What to do in an emergency c. Services available to provide support	N	Reviewers did not see any evidence of how carers' needs were assessed and managed.
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	N	See Concerns section of main report.

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.	Y	
HP-204	**Competences – All Health and Social Care Professionals** All health and social care professionals working in the service should have competences appropriate to their role in: a. Safeguarding children and/or vulnerable adults b. Recognising and meeting the needs of vulnerable children and/or adults c. Dealing with challenging behaviour, violence and aggression d. Mental Capacity Act and Deprivation of Liberty Safeguards e. Resuscitation	Y	
HP-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be available.	Y	
HP-301	**Support Services** Timely access to the following support services should be available: a. Play support (children's services only) including: i. Play and distraction during any painful or invasive procedures ii. Play support to enable the child's development and well-being b. Pharmacy c. Dietetics d. Occupational Therapy e. Orthotics	Y	
HP-302	**Emergency Department – Staff Competences** Medical and nursing staff working in the Emergency Department should have competences in urgent care of people with inherited and acquired bleeding disorders including awareness of: a. Guidelines on care of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) b. Who to contact for advice	Y	However, patients reported that their experience of the ED was not always consistent.

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

Ref	Standard	Met?	Comments
HP-402	**Facilities and Equipment** Facilities and equipment appropriate for the service provided should be available including: a. Fridges b. Storage c. Clinical rooms for staff of all disciplines to see patients and carers d. Room for multi-disciplinary discussion e. Room for educational work with patients and carers f. Office space for staff g. Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all clinical areas All equipment should be appropriately checked and maintained.	Y	
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	N	See Concerns section of main report.
HP-501	**Diagnosis Guidelines for Patients with Suspected Inherited and Acquired Bleeding Disorders** Guidelines on diagnosis should be in use covering at least a. Haemophilia A b. Haemophilia B c. Von Willebrand Disease d. Acquired haemophilia e. Inherited platelet disorders f. Other less common and rare bleeding disorders	Y	

Ref	Standard	Met?	Comments
HP-502	**Guidelines: Concentrate Use and Monitoring** Guidelines should be in use covering: a. Concentrate therapy: i. Initiation and monitoring of prophylaxis ii. Home therapy b. Use of extended half life products, including inhibitor testing and PK assessment c. Management of concentrate supplies including: i. Ordering ii. Storage iii. Stock control to ensure all stock is up to date and waste is minimised iv. Prescription and delivery for patients on home treatment v. Arrangements for emergency 'out of hours' supply vi. Recording issue to patients vii. Recording use by patients, including on Haemtrack viii. Submission of data via NHD for national tenders coordinated by CMU	Y	
HP-503	**Clinical Guidelines** The following clinical guidelines should be in use: a. Management of acute bleeding episodes, including patients with inhibitors b. Inhibitor screening c. Immune tolerance therapy d. Dental care e. Care of patients with hepatitis C f. Care of patients with HIV g. Antenatal care, delivery and care of the neonate h. Management of synovitis and target joints i. Long term surveillance of musculoskeletal health j. “For public health purposes”: care of patients at risk of vCJD who are undergoing surgery	Y	
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	See HP-195 regarding transition practice.
HP-599	**Care of Vulnerable People** Guidelines for the care of vulnerable children, young people and adults should be in use including: a. Restraint and sedation b. Missing patients c. Mental Capacity Act and the Deprivation of Liberty Safeguards d. Safeguarding e. Information sharing f. Palliative care g. End of life care	Y	

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

Ref	Standard	Met?	Comments
HP-603	**Multi-Disciplinary Clinics** The following multi-disciplinary clinic arrangements for patients with inherited and acquired bleeding disorders should be in place: a. Involvement of medical, specialist nursing and physiotherapy staff in clinics b. Availability of social work and psychology staff in clinics c. Combined clinics or other arrangements for multi-disciplinary discussion with: i. orthopaedics ii. rheumatology iii. obstetrics and gynaecology iv. paediatrics v. dental vi. HIV / hepatology	Y	
HP-604	**Liaison with Other Services** Review meetings should be held at least annually with specialist services to consider liaison arrangements and address any problems identified.	Y	
HP-701	**Data Collection** The following data should be collected: a. UK National Haemophilia Database data on all patients b. Data on concentrate use and bleeds, either through Haemtrack or an equivalent mechanism c. Data required to complete the UKHCDO National Haemophilia Dashboard or other national mechanisms	Y	
HP-702	**Audit** The services should have a rolling programme of audit covering at least: a. Clinical guidelines (QS HP-503) b. Emergency and out of hours care (QS HP-504) c. Initiation of prophylaxis in children d. Inhibitor surveillance and Immune Tolerance Induction (ITI) e. Clinical reviews including joint scores (QS HP-103 & 104) f. Concentrate use and wastage	Y	
HP-706	**Research** The service should actively participate in research relating to the care of patients with bleeding disorders.	Y	

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

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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.	N	Reviewers agreed with the Centre's self-assessment. The East Midlands network is informal and not commissioned. Patient/carer involvement is the responsibility of individual centres.
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	N	The East Midlands network was informal and not commissioned. At the time of the review, the network was coordinated by Nottingham.
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.	Y	
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)	Y	The CCC had made their diagnostic and clinical guidelines available to linked centres via their internet page, although they had not been formally adopted for use elsewhere at the time of the peer review visit.
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	Y	
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.	N	A network-wide audit programme 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	A network-wide research policy was not in place.

Ref	Standard	Met?	Comments
HY-798	**Network Review and Learning** Representatives of Comprehensive Care Centres and referring Haemophilia Centres should meet at least once a year to: a. Identify any changes needed to network-wide policies, procedures and guidelines b. Review results of audits undertaken and agree action plans c. Review and agree learning from positive feedback, complaints, critical incidents and 'near misses', including those involving liaison between teams d. Share good practice and potential service improvements	Y	

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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	N	The CCC had only recently received confirmation of the commissioning contact. Although a meeting was planned with the commissioner, this was not in place at the time of the review.
HZ-701	**Clinical Quality Review Meetings** Commissioners should regularly review the quality of care provided by: a. Each service, including achievement of QS HP-701 b. Each network, including achievement of QS HY-701 and QS HY-798 c. Service and network achievement of relevant QSs	N	See HZ-601
HZ-798	**Network Review and Learning** Commissioners should attend a Network Review and Learning meeting (HY-798) at least once a year for each network in their area.	N	See HZ-601

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