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

Royal Belfast Hospital for Sick Children

Visit Date: 17th October 2019

Report Date: December 2019

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 the Royal Belfast Hospital for Sick Children, which took place on 17th 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:

- Belfast Health and Social Care Trust
- Health and Social Care Northern Ireland

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 Belfast 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 parents 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.

Belfast (Children's) Haemophilia Centre

The Belfast Children's Haemophilia Unit (CHU) was a regional haemophilia comprehensive care centre for all children living in the province of Northern Ireland. It was situated in the Royal Belfast Hospital for Sick Children (RBHSC) and managed all children with congenital bleeding disorders from birth until 16 years of age. A transition programme was in place for transfer to the adult services, which usually took place by the age of 16. The adult services were situated at the Belfast City Hospital, which was within one mile of RBHSC.

RBHSC was a tertiary referral paediatric hospital for Northern Ireland and, in addition, served as an acute paediatric centre for children in Belfast. There was a 24-hour dedicated paediatric emergency department within RBHSC.

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

Condition	Number patients	Number of patients who had an annual review in last year	Number of in-patient admissions in last year
Haemophilia A	Severe: 19 Moderate: 5 Mild: 25	19 4 24	12 (7 patients) 1 2
Haemophilia B	Severe: 3 Moderate: 2 Mild: 3	3 2 3	0 0 0
Von Willebrand	31	27	1
Other	19	19	0

Emergency Care

In the event of an emergency at any time of day, the advice to parents and patients was to call the 24-hour triage telephone number for the CHU. Each call was logged, and the details documented. The nurse would then contact the haemophilia nurse specialist during working hours, and/or the medical staff covering the CHU.

The patient would be assessed over the telephone, and advice would be given as to whether to attend the Emergency Department (ED) at RBHSC, the haematology day care centre or, in certain circumstances, the local emergency department.

Ward Care

Patients were admitted to the CHU. This was a ten-bedded unit in the RBHSC dedicated to paediatric haematology and oncology, with two isolation rooms and two teenager/young adult rooms. RBHSC had 85 beds. Occasionally, patients were admitted to other wards in RBHSC.

Day Care

Day care and outpatients were situated in RBHSC in the paediatric haematology oncology outpatient area. There were three consultation rooms. At the time of the review, the area was undergoing renovation to provide a three-bedded day care unit for paediatric haematology and oncology day cases and treatment.

Outpatient Care

Patients with bleeding disorders were seen in the paediatric haematology oncology unit, either as routine at clinic or as an emergency visit in working hours.

Community Based Care

The paediatric haemophilia nurse was hospital - and community-based. There was close liaison with the children's community nursing team in all regions of Northern Ireland. Outreach support was provided by the haemophilia social worker, physiotherapist and occupational therapist, who visited patients at home or school.

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Review Findings

Achievements

This team was working hard, and working extremely well together, to deliver high quality care for the children and young people using their service. It was fully multi-professional, with several members – the occupational therapist, the physiotherapist, the play specialists, the social worker and psychologist – working in extended roles, and some undertaking home and school visits. There was a focus on the whole family, and an emphasis on what the children could do, with encouragement and appropriate management, rather than on their limitations.

Patient feedback was overwhelmingly positive, acknowledging the important contributions made by all members of the team, and with special appreciation for the work of the nurse specialist.

The special effort made for one particular patient with learning difficulties, to train school transport staff so that they felt confident to allow him to use the school bus, was noted.

The facilities were excellent; although the Centre was housed in old hospital buildings, it was airy and light, with close proximity to the Emergency Department and imaging department. There was a separate quiet room used when sensitive family discussions were needed. The ward had individual rooms with a central play area, and separate age-appropriate rooms for teenagers. The physiotherapist could work with patients in a well-equipped gym and hydrotherapy pool in the same building, and could also use facilities on the Musgrave Park Hospital site.

Good Practice

1. There was a single mobile phone number used for parents to access advice, supported by a formal checklist triage tool which was completed and kept as a record of the consultation.
2. There was an ultrasound facility used by the physiotherapist for joint assessment in the Centre.
3. The dental service was excellent, with all children being seen routinely for preventative work; if dental extraction was needed, the team and clinic were already familiar to the child. Community dentists were also well supported by the hospital team.
4. Children and families attending for annual review were offered a 'one-stop' visit at which they could be seen by the whole range of professionals for a very thorough assessment and discussion of their care, which also meant that they did not have to make multiple trips to the hospital.
5. Transition practice for young people moving over to the adult service, based at Belfast City Hospital, was good, with the adult haematologists coming over to join the paediatric haematologists in the twice-monthly bleeding disorder clinics. The time of transition was flexible, from 14 up to 18, depending on the needs of the individual.
6. The bar code system on the hospital notes that allowed for easy tracking and retrieval was effective.
7. Urgent samples for processing in the laboratory on the City Hospital site were conveyed by 'pod', and a dedicated porter was available there to facilitate conveying factor concentrates back to RBHSC when needed urgently.
8. Full information packs, individualised by condition and severity, were available for children and families joining the service.
9. There was a strong teaching programme in place, delivered by all the team members, for various hospital staff groups and outreach to schools.

Immediate Risks

The guideline for the administration of factor IX did not include the risk of anaphylaxis due to inhibitor formation or the need for the first twenty doses to be administered in a suitable hospital setting and not at home.

Trust response - we are amending our RBHSC clinical guidelines to include the risk of anaphylaxis with Factor IX. Although we have in practice administered the first twenty doses in hospital, this was not written in our guidelines and we have made changes within the Unit since peer review to address this.

QRS response - we have reviewed the evidence you supplied with the clinician on the visit. I can confirm that once these changes are fully implemented as described in your letter, this will fully address the immediate risks identified.

Concerns

1. **Individualised data**

   There was a need for more individual data to be measured and recorded to guide the management of each child.

   a. More frequent checks of factor levels for children on prophylactic, or 'on-demand', treatment would allow for tailoring of on-demand or head injury doses to ensure levels were adequate, and to improve the efficacy of prophylaxis dosing.

   b. The 'pink sheet', held in the Centre and the Emergency Department for each child, gave only a general guide to factor dosing for use in an acute bleed. There was no indication of different dosing for different severities of presentation (on-demand or head injury), and complex dose calculation was left to the prescribing doctor, allowing for the possibility of error and incorrect dosing. A guide including the actual doses for each child, by severity of presentation, rather than a 'per kg' guide, would reduce this possibility.

   c. Some of the data on the pink sheets appeared to be out of date: for example indicating 'treatment – none' for children who were on regular prophylaxis. As the sheets were used as the summary of the child's condition and treatment, they need to be kept up to date. Additionally, recent trough or post-dose levels would be helpful to guide management, and if the number of on-demand factor doses was recorded, this could be used as a guide to inhibitor development risk.

2. **Factor use**

   Greater oversight of factor use and bleed frequency for each child was required. Haemtrack was not in place, and there was a reliance on 'paper returns' after treatment was given at home. However, families were bringing paper returns for fewer than 20% of treatments. Data submitted for factor use was therefore based on factor issue, not actual use. Factor use recorded in the Centre was low by national benchmarking, and there was the possibility of actual use being even lower than was currently being reported. It was not possible to establish annual bleed rate [ABR] without robust treatment records.

Further Consideration

1. There was a clear focus on delivering clinical care. A review of job plans may enable team members to identify more time for service update and development work, to ensure that patients can access the full range of newer treatments, and to allow more focus on audit and research, involving the whole multi-professional team.

2. Diagnostic and clinical guidelines were in place, but the reviewers felt that some could usefully be updated: for example, they still included the use of continuous intravenous infusion of factors; they suggested Monday, Wednesday and Friday prophylactic dosing rather than alternate days, and they did not specify the frequency for measuring factor levels in line with current best practice. Guidelines for the newer agents, including extended half-life products and Emicizumab, were needed.

3. A guide for parents administering home treatment through a central venous port device was in place but would usefully include a description of the signs of acute infection / sepsis after flushing, and the need for immediate hospital presentation should these signs appear. For children living outside Belfast, their local hospital should be requested to put an alert on their patient record indicating that the child had a central venous line and was therefore at risk of bacteraemic sepsis.

4. In advance of the introduction of Haemtrack (expected early in 2020), all staff will require training to ensure they are fully confident in using the system so that they can encourage every family to use it. This will improve oversight of bleed frequency and factor usage.

5. The adult haematologists worked with the paediatric haematology consultants in the twice-monthly bleeding disorders clinics, and there was a lack of clarity about whose was the primary responsibility for clinical decision making around treatment plans for children.

6. The child's treatment plan was included in a letter to the GP which was not routinely copied to the parents / guardians. Sending an additional copy to families would also fulfil the need for them to have a written record of the updated care plan [see HP-103].

7. Some of the governance processes should be formalised, to include having minutes and an action log from the meetings at which the team discussed incidents, complaints, and morbidity and mortality reviews. Individual patient outcomes, following MDT discussion, could helpfully be included in their medical records.

8. The two consultants with a special interest in haemostasis constituted two of the five consultants in a 1:5 out of hours rota. If a child presented with a complex problem on the weeks when their colleagues were on call, they were contacted informally for guidance. Consideration might be given to a formal 'second on call' rota.

9. There was no alert on the electronic record used in the Emergency Department, to bring to immediate attention the bleeding disorder diagnosis of any child who presented, the need to contact the specialty team, and the instruction not to administer intramuscular (IM) injections or nonsteroidal anti-inflammatory drugs (NSAIDs).

10. The social worker and occupational therapist used a separate electronic system for recording their notes, and the physiotherapist used another system. A single integrated records system, so that all entries by different team members could be seen in one place, would be preferable. A planned move to 'Epic'® might enable this.

11. A data manager had been working with the team very effectively in the preceding months; he also worked in the adult team on the City Hospital site. It was understood that he had not always been able to come to the Children's Hospital for a full day per week as planned, and this should be encouraged.

12. A Band 6 nursing post to support the lead nurse specialist had been approved, and funding identified, but it had not been possible to appoint to it. Consideration might be given to part time or job share applicants in order to fill the post and give much needed support.

13. There was no operational policy in place to underpin the service; the narrative given in the self-assessment [HP-601] could form the basis of a useful short policy document.

14. A previous pre-school education day had been very successful, and much appreciated by parents. It would be very useful to make this an annual event.

15. Parents indicated that they would greatly appreciate the opportunity to meet together, and the formation of a parent support group could be considered.

16. Document control was incomplete, with some policies and guidelines lacking details of authorship, authorisation date, and planned review date.

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General Comment

There was no formal network in place, although the Centre cared for children from all over Northern Ireland who visited for their regular assessments and management review, and who were also encouraged to attend, where possible, for acute problems.

However, inevitably children sometimes attended local healthcare facilities, and so there was an informal network with paediatric and Emergency Department colleagues in the other Trusts across the region. The Centre team might consider offering some outreach support, for example clinic consultations by 'Skype', and invitations to colleagues from the other acute hospitals for education, review and learning meetings.

The leads at the paediatric centre had not had much direct communication with the commissioners of the services, and it was noted that increased dialogue about current provision and future developments would be helpful. It subsequently transpired that there was a strong and constructive working relationship between the Belfast adult CCC director and the service's commissioners. Meetings and discussions could usefully include the paediatric centre director, and consideration could also be given to establishing a more formal joint network across the region. Formal documented meetings with commissioners including the paediatric CCC leads, other members of the MDT, and service managers would help to develop the network, and increase transparency.

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APPENDIX 1 Membership of Visiting Team

Visiting Team		
Howard Doupe	Patient representative	
Dr Georgina Hall	Consultant Paediatric and Adolescent Haematologist and Honorary Senior Lecturer – Oxford University	Oxford University Hospitals NHS Foundation Trust
Paul McLaughlin	Clinical Specialist Physiotherapist in Haemophilia	Royal Free London NHS Foundation Trust
Julia Spires	Haemophilia Clinical Nurse Specialist	Great Ormond Street Hospital for Children NHS Foundation 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
Centre	37	25	68
Network	8	0	0
Commissioning	8	0	0
Total	53	25	47

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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, the Centre did not comply with 'j' as Haemtrack was not in use in Northern Ireland.

Ref	Standard	Met?	Comments
HP-103	**Plan of Care** Each patient and, where appropriate, their carer should discuss and agree their Plan of Care, and should be offered a written record covering at least: a. Agreed goals, including life-style goals b. Self-management c. Planned assessments, therapeutic and/or rehabilitation interventions d. Early warning signs of problems, including acute exacerbations, and what to do if these occur e. Agreed arrangements with school or other education provider and preparation for adult life (children and young people only) f. Planned review date and how to access a review more quickly, if necessary g. Who to contact with queries or for advice The Plan of Care should be communicated to the patient's GP and to relevant other services involved in their care.	N	Reviewers did not see evidence of a plan of care which covered all the elements of this standard.
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.	N	Haemtrack was not in use in Northern Ireland at the time of the review.

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	
HP-198	**Carers' Needs** Carers should be offered information on: a. How to access an assessment of their own needs b. What to do in an emergency c. Services available to provide support	Y	
HP-199	**Involving Patients and Carers** The service should have: a. Mechanisms for receiving regular feedback from patients and carers about treatment and care they receive b. Mechanisms for involving patients and carers in decisions about the organisation of the service c. Examples of changes made as a result of feedback and involvement of patients and carers	N	Although there was evidence of patient engagement (a survey completed six years ago), reviewers did not see any evidence of changes to practice that had occurred as a result of feedback.

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	However, there was limited time available to the lead consultant and nurse to undertake their leadership roles.
HP-202	**Staffing Levels and Skill Mix** Sufficient staff with appropriate competences should be available for out-patient, day unit and in-patient care and for support to urgent care services. Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network. All staff should undertake regular Continuing Professional Development of relevance to their work in the inherited and acquired bleeding disorders services. Staff working with children and young people should have competences in caring for children as well as in the care of people with bleeding disorders. Cover for absences should be available. In HCCCs these staff should have sessional time allocated to their work with the IABD service. In HCs the arrangements for accessing staff who do not have sessional time allocated to the IABD service should be clearly defined. Staffing should include: a. Medical staff: i. Consultant specialising in the care of people with inherited and acquired bleeding disorders available during normal working hours ii. On-call consultant haematologist (24/7) iii. Arrangements for advice from a consultant specialising the care of people with inherited and acquired bleeding disorders (if not on call) b. Specialist nursing staff: i. Bleeding disorders specialist nurses (5/7) ii. Ward, out-patient and day unit staff with competences in the care of people with inherited and acquired bleeding disorders. c. Clinical specialist physiotherapist d. Biomedical Scientist and Clinical Scientist (further detail on the requirements are included in HP-303) e. Clinical or counselling specialist psychologist or appropriately trained psychotherapist f. Specialist senior social worker g. Data manager	Y	

Ref	Standard	Met?	Comments
HP-203	**Service Competences and Training Plan** The competences expected for each role in the service should be identified. A training and development plan for achieving and maintaining competences should be in place.	N	Although reviewers saw a wealth of training evidence for the MDT, there was no matrix in place (as per the requirements in the notes for this standard).
HP-204	**Competences – All Health and Social Care Professionals** All health and social care professionals working in the service should have competences appropriate to their role in: a. Safeguarding children and/or vulnerable adults b. Recognising and meeting the needs of vulnerable children and/or adults c. Dealing with challenging behaviour, violence and aggression d. Mental Capacity Act and Deprivation of Liberty Safeguards e. Resuscitation	Y	
HP-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be available.	Y	
HP-301	**Support Services** Timely access to the following support services should be available: a. Play support (children's services only) including: i. Play and distraction during any painful or invasive procedures ii. Play support to enable the child's development and well-being b. Pharmacy c. Dietetics d. Occupational Therapy e. Orthotics	Y	
HP-302	**Emergency Department – Staff Competences** Medical and nursing staff working in the Emergency Department should have competences in urgent care of people with inherited and acquired bleeding disorders including awareness of: a. Guidelines on care of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) b. Who to contact for advice	Y	

Ref	Standard	Met?	Comments
HP-303	**Laboratory Service** a. A UKAS / CPA accredited laboratory service with satisfactory External Quality Assurance performance should be available 24/7 b. A laboratory representative (senior biomedical scientist or clinical scientist) should attend inherited and acquired bleeding disorder service multi-disciplinary team meetings (QS HP-602) regularly c. The following tests should be available: i. All coagulation factor assays (24/7) ii. Inhibitor screening iii. FVIII inhibitor quantification iv. VWF antigen v. VWF activity vi. Platelet function testing d. Molecular Genetic Laboratory service for: i. detection of causative mutations in patients with inherited bleeding disorders ii. carrier detection	Y	Compliance for this standard was fully assessed on Day 2 of the Belfast adult service peer review at Belfast City Hospital, where the main laboratory was based.
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	However, there was no evidence for 'g' (see HP-106).
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 in relation to 'c', and Further Consideration in relation to 'd'.
HP-501	**Diagnosis Guidelines for Patients with Suspected Inherited and Acquired Bleeding Disorders** Guidelines on diagnosis should be in use covering at least a. Haemophilia A b. Haemophilia B c. Von Willebrand Disease d. Acquired haemophilia e. Inherited platelet disorders f. Other less common and rare bleeding disorders	Y	

Ref	Standard	Met?	Comments
HP-502	**Guidelines: Concentrate Use and Monitoring** Guidelines should be in use covering: a. Concentrate therapy: i. Initiation and monitoring of prophylaxis ii. Home therapy b. Use of extended half life products, including inhibitor testing and PK assessment c. Management of concentrate supplies including: i. Ordering ii. Storage iii. Stock control to ensure all stock is up to date and waste is minimised iv. Prescription and delivery for patients on home treatment v. Arrangements for emergency 'out of hours' supply vi. Recording issue to patients vii. Recording use by patients, including on Haemtrack viii. Submission of data via NHD for national tenders coordinated by CMU	Y	
HP-503	**Clinical Guidelines** The following clinical guidelines should be in use: a. Management of acute bleeding episodes, including patients with inhibitors b. Inhibitor screening c. Immune tolerance therapy d. Dental care e. Care of patients with hepatitis C f. Care of patients with HIV g. Antenatal care, delivery and care of the neonate h. Management of synovitis and target joints i. Long term surveillance of musculoskeletal health j. “For public health purposes”: care of patients at risk of vCJD who are undergoing surgery	Y	
HP-504	**Emergency Department Guidelines** Guidelines on management of patients with inherited and acquired bleeding disorders in the Emergency Department should be in use.	Y	

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

Ref	Standard	Met?	Comments
HP-601	**Service Organisation** The service should have an operational procedure covering at least: a. Ensuring all children who are in-patients have a named consultant paediatrician and a named haematologist with expertise in caring for patients with inherited and acquired bleeding disorders responsible for their care b. Ensuring all adults are under the care of a consultant haematologist with an interest in inherited and acquired bleeding disorders, either directly or through a shared care arrangement with a general haematologist c. Responsibility for giving information and education at each stage of the patient journey d. Arrangements for involving Haemophilia Centre staff in multi-disciplinary discussions relating to their patients (QS HP-602) e. Arrangements for follow up of patients who 'do not attend' f. Arrangements for transfer of patient information when patients move areas temporarily or permanently g. Ensuring patients' plans of care are reviewed at least six monthly for patients with severe haemophilia and at least annually for other patients (QS HP-104) h. Ensuring school visits for children with severe haemophilia at least at each change of school (children's services only) i. Ensuring patients are visited at home at least annually if they are unable to attend clinics, including those in nursing homes j. Lone working	N	There was no operational policy in place. However, the description in the self-assessment would cover many of the elements needed in the operational policy.
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.	N	
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	N	See Concerns section of main report.
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	Evidence of audit activity was seen, but it did not cover all of the elements of this standard.
HP-706	**Research** The service should actively participate in research relating to the care of patients with bleeding disorders.	N	Reviewers did not see evidence of research activity.

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

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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	See the General Comment section of the main report.
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	See the General Comment section of the main report.
HY-204	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HP-203.	N	See the General Comment section of the main report.
HY-503	**Guidelines** Network guidelines should have been agreed covering: a. Diagnosis for patients with suspected inherited and acquired bleeding disorders (QS HP-501) b. Concentrate use and monitoring (QS HP-502) c. Clinical guidelines (QS HP-503) d. Management of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) e. Care of patients requiring surgery (QS HP-505) f. Transition and preparing for adult life (QS HP-595)	N	See the General Comment section of the main report.
HY-701	**Ongoing Monitoring** The network should monitor on a regular basis: a. Submission of data on all patients to the UK National Haemophilia Database (QS HP-701) b. Network-wide data on concentrate use and bleeds	N	See the General Comment section of the main report.
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.	N	See the General Comment section of the main report.
HY-703	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with inherited and acquired bleeding disorders b. A list of research trials available to all patients within the network.	N	See the General Comment section of the main report.

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

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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	Reviewers heard that there had been no discussion between the Centre and its commissioners in regard to this service. See the General Comment section of the main report.
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	Reviewers heard that there had been no discussion between the Centre and its commissioners in regard to this service. See the General Comment section of the main report.
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	Reviewers heard that there had been no discussion between the Centre and its commissioners in regard to this service. See the General Comment section of the main report.

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