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

University Hospitals Coventry and Warwickshire NHS Trust

Visit Date: 5th November 2019

Report Date: January 2020

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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 University Hospitals Coventry and Warwickshire NHS Trust which took place on the 5th November 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:

- University Hospitals Coventry and Warwickshire NHS Trust
- NHS England Specialised Commissioning West 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, for monitoring their implementation and for 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

QRS would like to thank the staff of the Coventry Haemophilia Centre for all 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 and 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.

Coventry Haemophilia Centre

The Coventry Haemophilia Centre, based at the University Hospitals Coventry and Warwickshire (UHCW), provided care and treatment to patients in the Coventry, North Warwickshire and South Warwickshire areas and served a population of approximately 1 million people. The Centre cared for both adults and children with bleeding disorders, and the team worked with network partners in the regional Comprehensive Care Centres at University Hospitals Birmingham NHS Foundation Trust and the Birmingham Women's and Children's NHS Foundation Trust.

Support was also provided to George Eliot Hospital (Nuneaton) and South Warwickshire Hospital (Warwick). Referrals were made from these hospitals to the team at UHCW.

Although they were a relatively small team, the team aimed to deliver a high quality of care to a relatively large number of patients with inherited and acquired bleeding disorders

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 last year
Haemophilia A	Adults	113 14 Severe 86 Mild 13 Acquired	Consultant - 56 Nurse - 39	11 emergency 12 elective Acquired patients[1]: 17 emergency, 9 elective
	Children	21 10 Severe 2 Moderate 9 Mild	Consultant - 18 Nurse - 2	6 emergency 3 elective
Haemophilia B	Adults	23 3 Severe 2 Moderate 18 Mild	Consultant - 10 Nurse - 8	4 emergency 6 elective
	Children	9 Mild	Consultant - 3 Nurse - 2	3 emergency
Von Willebrand	Adults	84 4 Type III 75 Mild 5 Acquired	Consultant - 12 Nurse - 32	9 emergency 44 elective
	Children	21 1 Type III 20 Mild	Consultant - 8 Nurse - 11	2 emergency 0 elective
Other	Adults	108 Mild	Consultant - 8 Nurse - 45	3 emergency 12 elective

[1] **Acquired haemophilia** is a bleeding disorder that is not present at birth but develops suddenly. It occurs when the body's immune system attacks and disables a protein that helps the blood clot. About half the cases are associated with other conditions such as pregnancy, autoimmune disease, cancer, skin disease or allergic reactions to medication.

Condition		Number of patients	Number of patients who had an annual review in last year	Number of inpatient admissions in last year
	Children	18 2 Severe FVII 16 Mild	Consultant - 5 Nurse - 11	2 emergency 3 elective

Emergency Care

During working hours all patient referrals were triaged by the haemophilia specialist nurse and signposted appropriately for review in the Emergency Department (ED) or the haematology adult day unit or paediatric Medical Day Unit (MDU).

Out of hours, patients were advised to contact the on-call consultant. Calls were handled by the haematology ward nurses and forwarded to the on-call doctors.

An alert on the IT system at UHCW (CRRS) informed the haemophilia team of admissions and highlighted bleeding disorder patients to ED and on-call staff.

Ward Care

There was a 16-bed adult ward for all haematology inpatients including haemophilia patients. The paediatric wards were used for paediatric patients with bleeding disorders, if required. There were three wards available that catered for different age groups.

Day Care

There was a twelve-chair day unit at UHCW and a day unit, which was undergoing expansion at the time of the review, at Rugby St Cross hospital. The UHCW day unit was not specific to patients with bleeding disorders, but patients could be assessed in either the procedure room or the assessment areas, if needed.

The paediatric MDU was available on request for ad hoc or planned reviews of children.

Outpatient Care

Adult outpatient clinics took place in the haematology outpatient clinics which were located close to the day unit and inpatient ward. Children were reviewed in the paediatric outpatient clinic, which was located in the same building.

Community Based Care

This care was specific to bleeding disorder patients only and the activity level varied greatly. The team provided a wide range of support within the community setting, including: teaching venepuncture skills to parents and children; teaching vascuport[2] access to parents; taking blood samples; teaching for staff in schools and nurseries where children with bleeding disorders attend; and attending multidisciplinary team meetings with other specialities. Support for patients in residential/nursing homes was also provided, as required.

[2] **Vascuport** – an implanted venous access device

Review Findings

Achievements

This was a hardworking, dedicated, well organised and mutually supportive team who were committed to providing a very good service for their patients, their patients' carers and families. The team was well led by the Centre director in a non-hierarchical manner, and patients commented on how the care that they received reflected the effective teamwork. After many years without physiotherapy input, the team had recently secured dedicated physiotherapy input for their patients. The team also had access to dedicated psychology support, which was a particular achievement for a service of this size. There was evidence of strong working relationships with other specialties in the Trust to support the care of patients.

Patient, and parent, feedback about the team was overwhelmingly positive, and they greatly appreciated the compassionate care that they received. They also commented that the needs of the wider family, and not just those of the individual patients, were discussed and responded to by the team.

Although this was a small team, they were providing a significant amount of training to colleagues throughout the rest of the Trust, raising awareness with colleagues regarding the management of patients with bleeding disorders.

Care was provided in clinical areas that were welcoming, spacious and bright. Patient information was prominently displayed and therefore readily available to patients.

Good Practice

1. Locally produced written patient information was comprehensive, and reviewers saw some very good examples of patient information including the 'Looking after yourself and your bleeding disorder' leaflet, the short guide on 'Everything you need to know about ports' and the 'Guide for patients on administration of factor replacement'.
2. Other documentation supporting the service was also of a very high standard including the 'School Healthcare plan'; 'Guidance for nurses dealing with patients with bleeding disorders'; 'Referring on SOP'; the surgical guideline, the clinic attendance and telephone clinic templates, and the operational policy.
3. Governance arrangements were excellent, with a comprehensive and active audit programme and a well-attended and minuted multi-disciplinary (MDT) meeting, with a detailed action log (including the names of those assigned to specific actions). Opportunities were taken for review and learning, and for reflection on and improvement of the service.
4. The Trust IT system (CRRS) supported the service very well:
    a. There was an alert on the patient records informing the ED, and other staff, that a patient had a bleeding disorder and requesting them to contact the haemophilia team if advice was required.
    b. Patient records were accessible remotely by doctors covering out of hours.
    c. The haemophilia team were alerted, by email, of any ED attendances or hospital admissions for patients with bleeding disorders.
5. Patient engagement was evident; there had been various patient feedback questionnaires and a specific questionnaire relating to waiting times in ED.
6. There was a robust system for identifying, and recalling for testing and counselling, potential or obligate carrier females before they reached reproductive age.

7. There was a strong teaching programme in place, delivered by all the team members, for various hospital staff groups, as well as outreach to schools.

8. Time had been invested by the team in the development of a network of link nurses in adult clinical areas. This ensured that when the specialist team were not available, the staff caring for patients with bleeding disorders had a level of clinical knowledge to be able to provide timely treatment and interventions.

9. Reviewers saw that the paediatric waiting area in the ED was age appropriate and welcoming for younger patients.

10. Reviewers heard that there was a programme of school visits in place, and that each time a child started a new school, a member of the nursing team would attend to provide awareness training to teachers and other children. This was appreciated by parents, who specifically mentioned this at the patient feedback session during the review.

11. The lead nurse was able to prescribe factor for patients, enabling a timely and responsive service for patients.

12. The team had dedicated psychology support which was considered good practice for a service of this size.

13. Telephone nurse-led clinics were in place, mostly for patients with mild disorders, and these were especially useful for those who lived at a distance from the Centre.

14. Reviewers were shown a database that had been developed locally for monitoring factor usage. This ensured that accurate data was available on usage, and therefore enabled the team to manage stock effectively and reduce wastage.

Immediate Risks

No immediate risks were identified at the time of the visit.

Concerns

1. **Consultant staffing**

   Reviewers heard that the Centre director had only 1 PA[3] allocated within his job plan to cover his clinical and managerial responsibilities relating to patients with bleeding disorders as well as his operational responsibilities as Centre director. In addition, it was understood that with valuable support from the nurse specialists and consultant haematology colleagues, he also provided an informal 24/7 on-call response for other colleagues when they needed advice on treating patients with bleeding disorders. Reviewers considered that the number of PAs identified in the job plan to lead and manage a specialist service of this nature was inadequate.

   The fact the service functioned so well was a credit to the Centre director, and the wider MDT, but reviewers felt that this was not sustainable.

[3] **Programmed Activity** – a session of working completed by a Consultant. 1 PA = 4 hours of work.

Further Consideration

1. Although the team were inputting data into the Haemophilia Centre Information System (HCIS), they were not using the full functionality, including factor usage or joint scores. In order to get the full benefits from the system, it would be helpful to ensure that all relevant data is submitted.
2. Although reviewers saw a list of the training that staff had completed, there was no training matrix which outlined the expected competencies and training plan for how this would be achieved. The team should consider developing such a plan to ensure that there is an accurate record for all staff groups of the competencies required for their respective roles and whether this has been completed.
3. It would be helpful to share relevant guidelines with the clinical teams at other local hospitals e.g. George Eliot Hospital NHS Trust and South Warwickshire NHS Foundation Trust, who refer patients to the Coventry haemophilia team.
4. The operational policy contained guidance on dealing with patients who Did Not Attend appointments. However, this guidance should be extended to include a procedure for children who 'were not brought'.
5. The model for having trained link nurses in the adult service was highlighted as good practice. It may be useful for this model to be implemented in the paediatric service.
6. Whilst some of the locally produced documentation had clear authorship and review dates, document control was inconsistent, with some policies and guidelines lacking details of authorship, approval or planned review dates.
7. The diagnosis guideline should be amended to confirm that the first 20 exposures (rather than 10-20 doses, as was indicated at the time of the review) of FIX inhibitors for patients with severe haemophilia B should be given in hospital.[4]
8. A newly appointed band 6 physiotherapist did not have sufficient time allocated to the service to be available outside clinic sessions.
9. The recently appointed physiotherapist had not yet started attending the MDT's but was going to. The Biomedical Scientist seldom attended and might be encouraged to do so.
10. Patients reported dissatisfaction with the home delivery service. Some patients told the review team that it was unreliable.
11. Patients commented that the parking on site was very limited and this presented problems for patients, particularly those with mobility problems, when attending appointments.

[4] Diagnosis and treatment of Factor VIII and IX in congenital haemophilia 'British Journal of Haematology November 2012' – 'Factor IX inhibitors are associated with allergic reactions to FIX including life threatening anaphylaxis...the first 20 exposures (to factor replacement) in patients with severe haemophilia B should be given in hospital with access to paediatric resuscitation facilities'.

General Comment

Clinical support (including cover during periods of annual leave) was provided to the Coventry Haemophilia Centre by colleagues from the CCCs in University Hospitals Birmingham (adult service) and Birmingham Women's and Children's Hospital (paediatric service).

The Coventry haemophilia team were members of the Birmingham and West Midlands network and evidence was seen during the course of the review of regular attendance at those meetings.

Although the network was not well established, there had been progress towards making the network board (which had previously been attended only by doctors and commissioners) multi-professional and at the time of the review there was good nursing representation. However, the network meetings continued to focus mainly on concentrate usage and some business matters such as staffing.

It was acknowledged that some additional aspects of network functioning, including staff cover, shared guidelines, audits, review and learning, educational opportunities and offering all patients access to research studies would be valuable and that further work towards achieving this would be appropriate.

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APPENDIX 1 Membership of Visiting Team

Visiting Team		
Laura Beel	Haemophilia Nurse	United Lincolnshire Hospitals NHS Trust
Tracey Dandy	Physiotherapist	Nottingham University Hospitals NHS Trust
Jemma Efford	Haemophilia Clinical Nurse Specialist	Great Ormond Street Hospital for Children NHS Foundation Trust
Molly Musarara	Haemophilia Nurse	Royal Free London NHS Foundation Trust
Dr Bethan Myers	Consultant Haematologist	University Hospitals of Leicester NHS Trust
Dr Murugaiyan Thanigaikumar	Consultant Haematologist	Lewisham and Greenwich 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
Centre	37	33	89
Network	8	1	13
Commissioning	3	0	0
Total	**48**	**34**	**71**

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Haemophilia 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	Patient information was plentiful and of a high standard. Service and condition information were also well displayed in the clinic waiting area.

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	

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	Patients were actively encouraged to use Haemtrack.

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	See also 'Achievements' section of the main report.
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	There was a wide range of suitable information, and the process was supported with a Standard Operating Procedure.
HP-198	**Carers' Needs** Carers should be offered information on: a. How to access an assessment of their own needs b. What to do in an emergency c. Services available to provide support	Y	
HP-199	**Involving Patients and Carers** The service should have: a. Mechanisms for receiving regular feedback from patients and carers about treatment and care they receive b. Mechanisms for involving patients and carers in decisions about the organisation of the service c. Examples of changes made as a result of feedback and involvement of patients and carers	Y	Patients reported that the team encouraged informal comment on any aspect of the service, and that formal experience surveys had also been undertaken, which covered their experience when presenting to the Emergency Department.

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, the Centre director had only 1 PA allocated to this role (see Concerns section of the main report).
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	Senior medical staff time was not judged to be sufficient for the role, and although there was an on-call haematologist 24/7, the director was contacted by colleagues for any complex issues, and so was effectively on-call at all times. A newly appointed band 6 physiotherapist did not have sufficient time allocated to the service to be available outside clinic sessions. There was no social worker working within the service.

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	Competencies expected for each member of the team, with training plans to achieve these, were not seen.
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	There was good access to play support for children in outpatients and on the ward, with prompt bleep access.
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	There was evidence of training sessions provided by the specialist team to ED staff, as well as to colleagues in other specialties. The patients reported that their experiences of care in the ED were mostly positive.

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	Platelet function testing was not available on site but was available from the linked CCCs in Birmingham; this was an acceptable level of provision for a Centre.
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	There was a very useful 'Referrals SOP' listing by name the specialists in other departments to whom patients may need to be referred, and contact details. Pain management services were not specifically mentioned in evidence provided, but there was a pain management clinic on site.

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	HCIS was available, but not all its functions were being used; alternative local databases were actively used instead.
HP-499	**IT System** IT systems should be in use for: a. Storage, retrieval and transmission of patient information, including access to the latest vCJD status and family tree b. Patient administration, clinical records and outcome information c. Data to support service improvement, audit and revalidation d. Alerting the specialist team when patients attend the Emergency Department	Y	
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	Network and local guidelines were seen.

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	There was a clear pathway for ordering and collecting factors, in- and out-of-hours. Records of use were meticulously recorded on a locally managed database.
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	(Note: ‘c’ does not apply – this was undertaken at the CCC in Birmingham).
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	A poster displayed in the ED summarised immediate management and alerted staff to the need for the specialist team to be contacted.

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	Trust policies covering these areas were seen by reviewers.

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	There was a good, clear operational policy in place. Arrangements for following up patients who did not attend were suitable for adults but did not include a section for children who were not brought – see Further Consideration section of the main report.
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	The recently appointed physiotherapist had not yet started attending the MDTs but was going to. The BMS seldom attended and might be encouraged to do so.

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	No social worker was available (see HP-202). Arrangements were in place for patients to be seen in all of these specialist clinics as needed.
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	Y	However, the use of HCIS was incomplete; local databases were used instead.
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	There was evidence of an active audit programme, with quality improvement projects arising from some e.g. an audit of Emergency Department presentations. Audits had been undertaken across a range of diagnostic and clinical management guidelines. 'c' and 'd' were not covered, but these aspects of care were undertaken at the CCC, so were not expected at the Coventry Haemophilia Centre.
HP-706	**Research** The service should actively participate in research relating to the care of patients with bleeding disorders.	Y	There was low level research activity, but evidence that patients were offered entry on to trials run at the CCCs.

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	The weekly MDT agenda covered many of these, and there was additionally a quarterly Clinical Haematology 'Quality Improvement and Patient Safety meeting' which was well attended. There was evidence of active review and learning from adverse incidents.
HP-799	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	Several documents lacked details of 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	Reviewers did not see any evidence of network mechanisms for involving patients and carers.
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	A lead consultant and specialist nurse were identified. However, nominated leads were not in place for 'c', 'd' or 'e'.
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	One educational event for nurses had taken place within the last year, but there was no regular programme.
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	Network guidelines had been shared by the CCCs, but had not been discussed, agreed or formally adopted.
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	These issues were discussed at quarterly network meetings.
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.	N	There was no network audit programme in place.
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	There was no policy guiding this, although network members were kept informed of open trials, and Centre patients could be referred for recruitment.

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	There had been discussions about extending network meetings to include these additional elements, but this had not happened yet in practice.

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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 did not see evidence of a clear and up to date commissioning agreement as outlined in the requirements of this standard.
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	Commissioners did attend the network meetings, but the agenda of this meeting had not yet been expanded to cover the elements described in this standard.
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	Commissioners did attend the network meetings, but the agenda of this meeting had not yet been expanded to cover the elements described in this standard.

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