CONFIDENTIAL: Final Report

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

Belfast City Hospital (Adult services)

Visit Date: 18th October 2019

Max WD		Date	QRS standard met? Y/N	Actual WD	Initials	Comments
0	On day recording of issues and compliance. Backed up.	18.10.19	Y	0	RB	
5	Compliance written and checked (N/A if lead also writing issues)	21.10.19	Y	1	RB	
10	Issues written	21.10.19	Y	1	AY	
10	Report sent to reviewers for comment	22.10.19	Y	2	RB	
20	Report revised and sent to Centre for comment	31.10.19	Y	9	RB	
35	Check Centre comments received and chase if required	20.11.19	Y	23	RB	
40	• Centre comments incorporated and additional information requested if necessary. • Response to Centre comments sent • Centre notified of QAG date.	29.11.19	Y	30	RB	
70 (max)*	Report revised and considered at QAG meeting	11.12.19	Y	38	RB	
75 (max)*	QAG comments incorporated and Centre notified of changes (if required)	12.12.19	Y	39	RB	
82*	Proof read					
83*	Formatted					
85*	Finalised and sent to Centre					
Not less than 6 wks from issue to HE	Published					
	Process completed satisfactorily (if not, recorded on learning log)					
	*If Centre response is within 35					

Quality assurance group reporting
Any problems during the review visit? If yes give details
No
Comments received from reviewers? If no give reasons
Yes
Comments received from Centre? If no give details
Yes
Has any external advice been sought? If yes give details
No
Compliance queries
No
Any other comments?
No

Contents

Introduction

This report presents the findings of the peer review of services for people with Inherited and Acquired Haemophilia and other Bleeding Disorders at the Belfast City Hospital, which took place on 18th 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 patient 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.

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Belfast (Adults) Comprehensive Care Centre

The Centre provided care for people with bleeding disorders across Northern Ireland and was based at the Belfast City Hospital. The team at the adult centre worked closely with colleagues at the Royal Belfast Hospital for Sick Children.

The adult haemophilia comprehensive care centre was established to ensure that the highest quality provision of care was available at all times for patients and their families affected by congenital and acquired bleeding disorders. The service was driven by the dedicated multi-professional team, which strove to provide a safe, equitable and accessible service to all.

The focus was to ensure that this goal was maintained through reflection, learning and feedback from both external meetings and also the patients and their families.

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 in-patient admissions in last year
Haemophilia A	Severe: 58 Moderate: 16 Mild: 109	Severe: 52 Moderate: 14 Mild: 79	Severe: 12 Moderate: 6 Mild: 1
Haemophilia B	Severe: 5 Moderate: 2 Mild: 10	Severe: 4 Moderate: 2 Mild: 7	
Von Willebrand	100	81	5
Other	60	69	4

Emergency Care

Patients were advised to contact the 24/7 help line which was operated by a haematology nurse specialist. The details of the call were taken and discussed directly with the on-call haematology specialty registrar. When required, patients were directed to the Emergency Department (ED) at the Royal Victoria Hospital or Altnagelvin hospital; the team would phone the ED in advance, alert them of the patient's condition, and pre-order necessary treatment to be available on arrival. On arrival, the patient would be assessed by the haematology specialist registrar, and a decision would be made to admit or to arrange an urgent outpatient review. On occasions, if the registrar was unavailable because of an emergency at another site, treatment was discussed with the emergency doctor.

During normal working hours, patients could call the haemophilia centre directly, and could be advised to attend, when they would be assessed by the team. If admission was required, this was facilitated through the haematology wards – predominantly patients were admitted to Ward 6 north.

Contact details were shared with patients regularly, and out of hours the Centre answering machine could direct the patient to the on-call number. Since the Centre was registered with UKHCDO and EUHANET, relevant numbers were accessible through their web sites.

Ward Care

Patients were, as required, admitted to either of the haematology inpatient facilities – 10 North or 6 North. These wards admitted all patients with known haematological disorders and complications of these disorders.

Day Care

As well as undertaking outpatient clinics, the Haemophilia Centre provided day care facility to manage patients who attended during the day either as an emergency or for an elective procedure within the hospital.

Outpatient Care

The majority of outpatient clinics were delivered through the Haemophilia Centre, with the exception of paediatrics, obstetrics and a bimonthly haemophilia clinic in Altnagelvin Hospital, Londonderry.

Community Based Care

Outreach services were available through the allied health care professionals and nursing staff, allowing patients to be seen at home or through local community health hubs.

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Review Findings

Achievements

This team, with strong non-hierarchical leadership, was offering a very good clinical service and exemplary multi-disciplinary team (MDT) working. In particular, the contributions made by the Occupational Therapist (OT), the physiotherapist, and the social worker – who were working in extended roles – were noted. The biomedical scientists were well integrated into the team. A specialty doctor with primary care experience brought a useful additional perspective to patient care. A psychologist had been appointed to support patients and families with issues raised by the Infected Blood Inquiry. The multi-professional team members were working extremely well together in a mutually supportive way.

There were good working relationships with, and evidence of valuable support from, other clinical teams, clinical and non-clinical managers, and commissioners.

There was active patient and public involvement, with a formal survey, '*What matters to you',* having been undertaken, and the team hosted a number of extra-curricular activities and events. Patients' feedback about the care they received was very positive, and they commented on the careful attention also given to families and carers.

The Centre facilities were spacious and pleasant, with plenty of patient information on display. There were integral OT assessment rooms, and the laboratory, inpatient wards and physiotherapy gym and hydrotherapy pool were conveniently co-located. The physiotherapist and service users had access to other gyms and rehabilitation in the Trust, including at Musgrave Park Hospital where elective orthopaedic surgery took place.

Team members had authored published guidelines and review articles, and the physiotherapist and nurses had presented posters at World Federation of Hemophilia meetings.

Good Practice

1 The team had made efforts to give patients and families easy access for advice and assessment, with a single urgent contact number. All team members additionally had work mobile phones which patients could phone or text, and the team could also be contacted by e-mail. An 'unscheduled contact' proforma recorded the details of the problem, and discussion outcomes, and was filed in the medical records.

2 An electronic patient record system held copy letters, and laboratory and imaging results, and could be accessed by healthcare professionals across Northern Ireland, including those in primary care. It could also be accessed remotely by doctors undertaking out of hours on-call duties.

3 Documentation supporting the service was generally good (although see Further Consideration 1 regarding guidelines). Reviewers especially commended a *Welcome to the adult service* pack for young people on transition from the paediatric service based at the Royal Belfast Hospital for Sick Children; a *Playing it safe* leaflet encouraging physical activities within safe limits; and a 'single assessment tool' which patients were asked to complete while waiting for their clinic consultations and in which they recorded any aspects of their physical or mental health that they wanted to discuss during their consultation. The social worker wrote excellent detailed guidance for each patient applying for Personal Independence Payments (PIP). A clear, colourful poster guided Emergency Department staff in the initial management of patients presenting acutely.

4 Transition practice for young people moving over to the adult service was good, with the adult haematologists going over to join the paediatric haematologists at the Royal Belfast Hospital for Sick Children in their twice-monthly bleeding disorder clinics. The time of transition was flexible, from the age of 14 up to 18 years, depending on the needs of the individual.

5 There was evidence of extensive in-service training for the team, which was subject to careful yearly evaluation.

6 Two ultra-sound devices were available in the Centre to enhance joint evaluation.

7 Family trees were reviewed and updated at each visit, and obligate or potential female carriers were invited to attend the Centre from around the age of menarche for factor testing, with genetic testing when needed, and discussion about the implications of the findings for their own reproductive and family health.

8 The whole team – medical, nursing, physiotherapy, social work and occupational therapy – travelled to Londonderry every two months to offer full multi-disciplinary clinic consultations for patients living in that area, who constituted the second largest group after those living in and around Belfast.

Immediate Risks

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

Concerns

1 **Factor use**

Greater oversight of factor use, and bleed frequency, for each patient was required. Haemtrack was not in place, and there was a reliance on 'paper returns' after treatment was given at home. However, patients 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 [per patient, per kg body weight] recorded by the Centre was low by national benchmarking, and there was the possibility of actual use being even lower than was currently being reported.

Further Consideration

1 Diagnostic and clinical guidelines were taken from nationally published guidelines but were not adapted for local application or use in practice. They were hard to navigate, with some confusion in titles, and they were all marked with the same document number. There were two versions of the *Management of acute bleeding* guideline, with closely similar content. Guidelines for management by other specialist teams, for example Emergency Department and surgery, were clearer and more complete.

2 Reviewers saw evidence of research taking place, but members of the MDT indicated that they would like to expand their research portfolio further.

3 The psychologist, currently working three days per week, was only seeing patients and families affected by the Infected Blood Inquiry issues. The review team heard that it was intended for her to continue working in the Centre once the Inquiry was over, and it will be important to consider ways in which her work can become embedded in the service, with availability to see patients attending clinics.

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 patients to use it. This will improve oversight of bleed frequency and factor usage.

5 The updated treatment plan following clinic review was included in a letter to the GP which was not routinely also being sent to the patient. Sending this additional copy would fulfil the need for the patient to have a written record of the care plan (see HP-103).

6 The electronic patient record did not include an 'alert' indicating that the patient had a bleeding disorder. It might be possible to scan the hard copy 'front page' (which had all the relevant information) onto the system, or onto a new system that the review team understood was soon to be implemented.

7 Patient feedback forms were seen, but they were not prominently displayed in the waiting area for ease of access and use.

8 There was no written operational policy in place that pulled together an outline of the service's functioning. This would be especially useful for newer team members.

9 The adult haematologists worked with the paediatric haematology consultants in the twice-monthly bleeding disorders clinics at the Royal Belfast Hospital for Sick Children, but there was a lack of clarity about whose was the primary responsibility for clinical decision making around treatment plans for children.

10 Document control was incomplete, with not all guidelines having details of authorship, approval date or planned review date.

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General Comment

There was no formal or commissioned network in place, although the Centre cared for people 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, patients sometimes attended healthcare facilities nearer to their homes, and so there was an informal network with haematology and Emergency Department colleagues in the other hospitals across the region, and there was an excellent fully multi-disciplinary outreach clinic offered six times a year in Londonderry. The team might consider inviting colleagues from the region's acute hospitals into the Centre for some educational, review and learning meetings, and ensuring that patients from all Trusts are involved in giving feedback about the service and are included in audit and research opportunities.

There was a strong constructive working relationship between the Centre director and the service's commissioners. Meetings and discussions could usefully include the paediatric centre director too, and consideration could be given to establishing a more formal joint network across the region. Although there was clear evidence of effective interaction with commissioners, there was little formal documentation about the process. Formal documented meetings, attended by the paediatric CCC team, 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		
Helen Cook	Social Worker	Cardiff Council
Howard Doupe	Patient representative	
Dr Will Lester	Consultant Haematologist	University Hospitals Birmingham NHS Foundation Trust
Paul McLaughlin	Clinical Specialist Physiotherapist in Haemophilia	Royal Free London NHS Foundation Trust
Clare Pateman	Clinical Nurse Specialist Haemophilia	University Hospitals Bristol 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			
Network			
Commissioning			
Total			

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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 used at the time of the review.

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	However, see Further Consideration regarding offering copies of clinic letters to patients.
HP-104	**Review of Plan of Care** A formal review of the patient's Plan of Care should take place at least six monthly for patients with severe or moderate haemophilia and at least annually for other patients. This review should involve the patient, where appropriate their carer, and appropriate members of the multi-disciplinary team. Haemtrack results should be reviewed (if applicable) and the outcome of the review should be communicated in writing to the patient and their GP.	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 place in Northern Ireland at the time of the review. However there were plans in place to introduce this in 2020.

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	Y	

Ref	Standard	Met?	Comments
HP-201	**Lead Consultant and Lead Nurse** A nominated lead consultant and lead nurse should have responsibility for staffing, training, guidelines and protocols, service organisation, governance and for liaison with other services. The lead consultant and lead nurse should be registered healthcare professionals with appropriate specialist competences and should undertake regular clinical work within the service and specific time allocated for their leadership role.	Y	
HP-202	**Staffing Levels and Skill Mix** Sufficient staff with appropriate competences should be available for out-patient, day unit and in-patient care and for support to urgent care services. Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network. All staff should undertake regular Continuing Professional Development of relevance to their work in the inherited and acquired bleeding disorders services. Staff working with children and young people should have competences in caring for children as well as in the care of people with bleeding disorders. Cover for absences should be available. In HCCCs these staff should have sessional time allocated to their work with the IABD service. In HCs the arrangements for accessing staff who do not have sessional time allocated to the IABD service should be clearly defined. Staffing should include: a. Medical staff: i. Consultant specialising in the care of people with inherited and acquired bleeding disorders available during normal working hours ii. On-call consultant haematologist (24/7) iii. Arrangements for advice from a consultant specialising the care of people with inherited and acquired bleeding disorders (if not on call) b. Specialist nursing staff: i. Bleeding disorders specialist nurses (5/7) ii. Ward, out-patient and day unit staff with competences in the care of people with inherited and acquired bleeding disorders. c. Clinical specialist physiotherapist d. Biomedical Scientist and Clinical Scientist (further detail on the requirements are included in HP-303) e. Clinical or counselling specialist psychologist or appropriately trained psychotherapist f. Specialist senior social worker g. Data manager	Y	

Ref	Standard	Met?	Comments
HP-203	**Service Competences and Training Plan** The competences expected for each role in the service should be identified. A training and development plan for achieving and maintaining competences should be in place.	Y	
HP-204	**Competences – All Health and Social Care Professionals** All health and social care professionals working in the service should have competences appropriate to their role in: a. Safeguarding children and/or vulnerable adults b. Recognising and meeting the needs of vulnerable children and/or adults c. Dealing with challenging behaviour, violence and aggression d. Mental Capacity Act and Deprivation of Liberty Safeguards e. Resuscitation	Y	
HP-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be available.	Y	
HP-301	**Support Services** Timely access to the following support services should be available: a. Play support (children's services only) including: i. Play and distraction during any painful or invasive procedures ii. Play support to enable the child's development and well-being b. Pharmacy c. Dietetics d. Occupational Therapy e. Orthotics	Y	
HP-302	**Emergency Department – Staff Competences** Medical and nursing staff working in the Emergency Department should have competences in urgent care of people with inherited and acquired bleeding disorders including awareness of: a. Guidelines on care of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) b. Who to contact for advice	Y	

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

Ref	Standard	Met?	Comments
HP-402	**Facilities and Equipment** Facilities and equipment appropriate for the service provided should be available including: a. Fridges b. Storage c. Clinical rooms for staff of all disciplines to see patients and carers d. Room for multi-disciplinary discussion e. Room for educational work with patients and carers f. Office space for staff g. Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all clinical areas All equipment should be appropriately checked and maintained.	Y	However, Haemtrack is not currently in use in Northern Ireland (see 'g').
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	Although the IT systems were very good (including integration across health and social care as well as primary care), see Concerns section of main report regarding lack of data for factor use. Haemtrack is not implemented (see HP-106), so reviewers felt that the Centre was not compliant with 'b'.
HP-501	**Diagnosis Guidelines for Patients with Suspected Inherited and Acquired Bleeding Disorders** Guidelines on diagnosis should be in use covering at least a. Haemophilia A b. Haemophilia B c. Von Willebrand Disease d. Acquired haemophilia e. Inherited platelet disorders f. Other less common and rare bleeding disorders	N	Diagnostic and clinical guidelines were taken from nationally published guidelines, but were not adapted for local application or use in practice. They were hard to navigate, with some confusion in titles, and they were all marked with the same document number.

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	N	Diagnostic and clinical guidelines were taken from nationally published guidelines, but were not adapted for local application or use in practice. They were hard to navigate, with some confusion in titles, and they were all marked with the same document number.
HP-503	**Clinical Guidelines** The following clinical guidelines should be in use: a. Management of acute bleeding episodes, including patients with inhibitors b. Inhibitor screening c. Immune tolerance therapy d. Dental care e. Care of patients with hepatitis C f. Care of patients with HIV g. Antenatal care, delivery and care of the neonate h. Management of synovitis and target joints i. Long term surveillance of musculoskeletal health j. "For public health purposes": care of patients at risk of vCJD who are undergoing surgery	N	Diagnostic and clinical guidelines were taken from nationally published guidelines, but were not adapted for local application or use in practice. They were hard to navigate, with some confusion in titles and they were all marked with the same document number.
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 at the time of the review.
HP-602	**Multi-Disciplinary Team Meetings** Multi-disciplinary team meetings to discuss patients' plans of care should take place regularly involving: a. All core members of the specialist team (HP-202) b. Senior biomedical scientist or clinical scientist with responsibility for the Coagulation Laboratory c. HC staff who are regularly involved in the patient's care as part of network arrangements	Y	

Ref	Standard	Met?	Comments
HP-603	**Multi-Disciplinary Clinics** The following multi-disciplinary clinic arrangements for patients with inherited and acquired bleeding disorders should be in place: a. Involvement of medical, specialist nursing and physiotherapy staff in clinics b. Availability of social work and psychology staff in clinics c. Combined clinics or other arrangements for multi-disciplinary discussion with: i. orthopaedics ii. rheumatology iii. obstetrics and gynaecology iv. paediatrics v. dental vi. HIV / hepatology	Y	
HP-604	**Liaison with Other Services** Review meetings should be held at least annually with specialist services to consider liaison arrangements and address any problems identified.	Y	
HP-701	**Data Collection** The following data should be collected: a. UK National Haemophilia Database data on all patients b. Data on concentrate use and bleeds, either through Haemtrack or an equivalent mechanism c. Data required to complete the UKHCDO National Haemophilia Dashboard or other national mechanisms	N	See the Concerns section of the 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	Although there was evidence of some audit activity taking place, it did not cover all the elements of this Quality Standard.
HP-706	**Research** The service should actively participate in research relating to the care of patients with bleeding disorders.	Y	

Ref	Standard	Met?	Comments
HP-798	**Multi-disciplinary Review and Learning** The service should have multi-disciplinary arrangements for review of and implementing learning from: a. Positive feedback, complaints, outcomes, incidents and 'near misses' b. Morbidity and mortality c. Haemophilia Dashboard d. Review of UKHCDO Annual Report benchmarking information on concentrate use e. Ongoing reviews of service quality, safety and efficiency f. Published scientific research and guidance	Y	Note: 'c' is not applicable in Northern Ireland.
HP-799	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	Document control was incomplete, with not all guidelines having details of authorship, approval date or 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.	Y	Mechanisms were in place for obtaining patient feedback across Northern Ireland.
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 General Comment section of the main report – there was no commissioned network in place, although the leads from the Centre would be able to fulfil these roles.
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 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 HP-503
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 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 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 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 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	Y	There was clear evidence of effective interaction with commissioners; however, there was little formal documentation about the process.
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	Whilst there was clear evidence of effective interaction with commissioners, there was no evidence of regular documented meetings with commissioners to discuss and review outcome data (see also Concerns section of 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	There was no evidence of regular meetings with commissioners to discuss clinical governance activities as outlined in HY-798.

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