WM QRS West Midlands Quality Review Service

UKHCDO UNITED KINGDOM HAEMOPHILIA CENTRES DOCTORS' ORGANISATION

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

Hull and East Yorkshire NHS Trust

Visit Date: 20th November 2018 Report Date: May 2019

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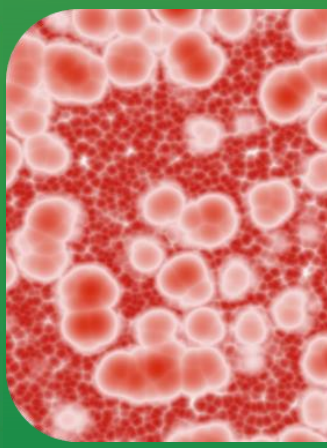

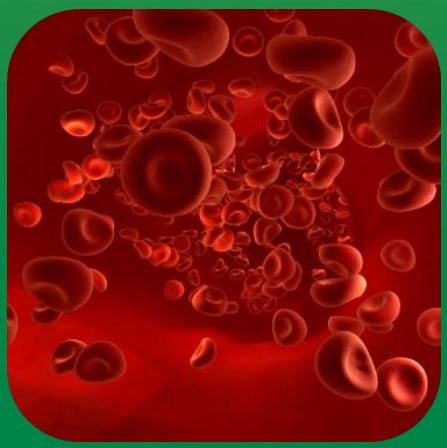

UKAS INSPECTION 8831

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INTRODUCTION

This report presents the findings of the peer review of services for people with Inherited and Acquired Haemophilia and other Bleeding Disorders at Hull and East Yorkshire NHS Trust on the 20th November 2018.

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

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

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

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

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

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

- Hull and East Yorkshire NHS Trust
- NHS England: Specialised Commissioning (Yorkshire and Humber)

Most of the issues identified by quality reviews can be resolved by providers' and commissioners' own governance arrangements. Individual organisations are responsible for taking action and monitoring this through their usual governance mechanisms. The lead commissioner for the service concerned is responsible for ensuring action plans are in place and monitoring their implementation liaising, as appropriate, with other commissioners.

ACKNOWLEDGEMENTS

We would like to thank the team at the Hull Haemophilia Centre for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks too to the users and carers who took time to come and meet the review team.

Thanks are also due to the visiting team (**Appendix 1**) and their employing organisations for the time and expertise they contributed to this review.

ABOUT WEST MIDLANDS QUALITY REVIEW SERVICE

WMQRS is a collaborative venture by NHS organisations to help improve the quality of health services by developing evidence-based Quality Standards, carrying out developmental and supportive quality reviews - often through peer review visits, producing comparative information on the quality of services and providing development and learning for all involved.

More detail about the work of WMQRS is available at www.wmqrs.nhs.uk

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HULL AND EAST YORKSHIRE NHS TRUST

The Hull Haemophilia Centre serves a population of approximately 927,000 derived from the East Riding of Yorkshire, Hull, North Lincolnshire and North East Lincolnshire Clinical Commissioning Groups. They treat patients with Inherited and Acquired Haemophilia and other disorders of haemostasis and provide a service to adult and paediatric patients which includes dedicated multidisciplinary clinics for adults and children with severe haemophilia as well as obstetric clinics. There were nurse-led clinics in which patients with mild bleeding disorders are supported and reviewed. The core membership of the MDT included two consultant haematologists and one paediatric trained haematologist, four haemostasis nurses (3WTE), two administrators, one coagulation biomedical scientist, one data manager, one haemophilia physiotherapist and one pharmacy technician. The team interacted closely with the regional Comprehensive Care Centre at Sheffield Teaching Hospitals Trust.

The Centre is responsible for patients with a range of conditions, as follows:

Condition		**No. patients (show breakdown Severe, Moderate and Mild)**			**No. patients who had an annual review in last year**	**No. in-patient admissions in last year**
		Severe	**Moderate**	**Mild**		
Haemophilia A	Adults	20	2	52	74	14
	Children	5	1	9	15	1
Haemophilia B	Adults	7	2	1	10	3
	Children	3	1	1	5	0
Von Willebrand	Adults	92			92	12
	Children	37			37	1
Other	Adults	117			101	38
	Children	48			48	1

WARD CARE:

This facility was not specific to patients with bleeding disorders. Adult patients were managed at Queen's Centre for Oncology and Haematology, Castle Hill Hospital. Nurses with Acute oncology training managing acute haematology and oncology patients including administration of intensive chemotherapy and autologous stem cell transplant. Medical cover was provided by a Consultant Haematologist, Haematology specialist registrars and Foundation 2/Core Trainee 1 doctors. Paediatric patients were managed on the paediatric wards based at Hull Royal Infirmary.

DAY UNIT CARE:

This facility was not specific to patients with bleeding disorders. Nurse-led facility for adults was functioning to administer chemotherapy and supportive treatments for haematology and oncology patients. Medical cover was provided by Haematology Specialist Registrars with Consultant Haematologist cover as required. Any day care for paediatric patients is administered either at the paediatric out-patient clinic, Women and Children's hospital, or the Paediatric Assessment Unit, Hull Royal Infirmary.

OUTPATIENTS:

This facility was not specific to patients with bleeding disorders. Adult out-patient care was based at the Queen's Centre for Oncology and Haematology, Castle Hill Hospital whilst the paediatric out-patient care is based at the Women and Children's hospital, Hull Royal Infirmary.

COMMUNITY BASED CARE:

Haemostasis specialist nurses reviewed patients in their own home for administration of prophylaxis and treatment including education and training. They also attended schools and nurseries for appropriate staff training.

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REVIEW VISIT FINDINGS

General Comments and Achievements

Sited across two separate facilities, this large Haemophilia Centre had no specific or dedicated physical space, but it worked well as a coherent and functional Centre, largely due to the focus of its team members, and excellent communication between them. Efforts had been made within the Queen's Centre for this function to be visible, and the space was welcoming for its users. The physical environment at the Queen's Centre was excellent; that on the Hull Royal Infirmary site was pleasant and spacious.

Reviewers felt that this was a very strong service, although not well resourced especially in medical staffing (see concerns section below). This was reflected in the extremely warm and appreciative patient feedback. There was an excellent, flexible and responsive specialist nursing team. The efforts taken by the part time physiotherapist, the data manager's input to the work of the centre, and the involvement of the bio-medical scientist were noteworthy.

Patients with bleeding disorders could nearly always be managed at the dedicated Haematology Ward 33 (Castle Hill hospital). Children were seen in the Paediatric Assessment Unit (PAU) at Hull Royal Infirmary for treatment before being discharged home. Children who were admitted went to Acorn Ward at the Hull Royal Infirmary. Those of the relevant age group could be accommodated, and were welcomed, in the Teenage and Young Adult facility where they received excellent support from nursing staff working in inventive ways with all the patients in this age group.

Good Practice

1. Patients' feedback comments, and actions taken in response to them, were displayed and updated every month.
2. Families were invited to make direct contact, out of hours, with the Haematology medical team, via switchboard, if they had any concerns relating to their bleeding disorder or considered that they may require admission. Daytime contact with the specialist nurses, via a bleep and or mobile phone, similarly ensured quick access to appropriately knowledgeable staff
3. Transition practice, for teenagers moving from the paediatric to the adult service, was excellent. The change was made easier by the nursing team and physiotherapist working across the two services but it was nonetheless clear that effort and focus had been put into managing this potentially difficult time for young people.
4. The PATTI information system, which included both individual patient care plans and general clinical guidelines, was accessible to all staff and was felt by reviewers to be an excellent resource.
5. The Haemophilia Centre had a sophisticated and comprehensive website which ensured that information was easily accessible by patients and carers and this was reflected in the feedback from the patient forum which was held as part of the review.
6. The initial clinic consultation letter for each child was copied to the Comprehensive Care Centre in Sheffield, so that the team there were aware of them and had records on file in case of future contact being necessary.
7. The reviewers were impressed by the enormous efforts made by the team, involving other relevant teams within the Trust, to provide special care facilities for one patient with severe haemophilia and learning difficulties. This was provided in a carefully designed clinical room dedicated for his use.

Immediate Risks: None

Concerns

1. **Staffing**

    a. Paediatric support for the adult Haematologist leading the paediatric service was inadequate, and while the service functioned well, reviewers felt that this left her potentially vulnerable when managing specific paediatric issues. Senior managers were aware, but it had not yet proved possible to resource the service appropriately.

    b. The adult service lead had insufficient PA's identified in his job plan to manage a service of this size, and both he and the paediatric lead were also working across a range of other haematology sub-specialties. Consultant PA allocation across both sides of the service were not adequate for the demands of the leadership positions. The fact the service functions well is a credit to both of these individuals, but reviewers felt that this was not sustainable.

    c. There was no cover for the physiotherapist, who is in a part time post (0.6 WTE). Reviewers felt that this needed to be reviewed in order to ensure that this service was appropriately resourced both for patients and staff (see concern 3).

2. **Network Arrangements**

    This service was commissioned as part of a managed network, with Sheffield Comprehensive Care Centre being its linked specialist site. While clinical support from the Sheffield team was readily available, other expected network functions did not appear to be in place, including shared education and training, agreed guidelines, governance arrangements and review and learning. Meetings for teams across the network had not taken place for a long time. Communication with commissioners, which could have been through network meetings, was therefore also lacking. Reviewers noted that responsibility for improving this situation did not rest solely with the Hull team.

3. **Children being treated in adult sessions**

    Children were sometimes invited to attend to see the physiotherapist in the same clinic as adults, in an endeavour to offer prompt care to all patients who needed to be treated; and so adults and children shared the same waiting area. Reviewers saw that although staff made every attempt to preserve privacy and dignity, and children were always accompanied; ways should be sought to separate appointment times for adults and children wherever possible.

4. **Pathology services**

    Reviewers heard that it was not possible to perform simple coagulation screen tests, or factor assays, on the Castle Hill site despite analysers capable of running these tests being available and National External Quality Assessment Service (NEQAS) quality assurance checks were being submitted for them. There was concern about how patients could be optimally managed getting results back for these tests from the Hull Royal Infirmary laboratory, could often take two hours or more.

Further Consideration

1. There was some duplication of documents, with older and newer version both being in use. For example, the user's guide to the Queen's Centre was available as an older more generic guide with a section about the Haemophilia Centre and there was also a newer version with some different information but which did not seem to contain all of the relevant information in the previous version, and it was not clear if users were being given both versions. Also, a good guideline for the management of bleeding disorders in the Emergency Department had been updated, with clearer advice about numbers to call to access the specialist team, but both versions appeared in evidence in different sections.

2. Comprehensive care plan proformas were seen in evidence, and in some of the patients medical records presented, but this was inconsistent: not in all sets of notes and not for all annual reviews. It was not

therefore clear whether these were being consistently completed. If they were, and copies were sent systematically to patients, these would be a helpful and provide a sufficient record of the regular reviews.

3. Reviewers saw a wide range of condition specific information leaflets for patients. However, feedback suggested that these were not always being shared proactively with patients. The team should ensure that all team members are reminded to proactively share information with patients not just at diagnosis but on an ongoing basis, as new guidance material is developed.
4. Reviewers heard that funding for some laboratory work was reported to be limited, and staff felt they had to justify ordering even day to day reagents and other requirements, and ideas for development were difficult to progress. This needs to be investigated to ensure that staff have access to appropriate resources in order to provide appropriate diagnostics for care and treatment.
5. Consideration should be given to updating two of the routine laboratory tests: Von Willebrand Factor activity was being measured, rather than the now more frequently run RiCoF, and a urea solubility test for Factor Xlll activity has also now generally been superseded by a new methodology.
6. Reviewers heard from patients that they would always prefer to access care in the specialty areas, rather than the Emergency Department at Hull Royal Infirmary, where they reported that care can be inconsistent. They felt they needed to be assertive to get appropriate care there, and sometimes to guide clinicians as to what was required.
7. Reviewers felt that as all of the specialty nursing team were based at the Queen's Centre, this could lead to delays in them reaching acutely unwell patients at Hull Royal Infirmary; delays included not just distance but also difficulty finding parking at the hospital sites on arrival.
8. The self-assessment indicated that a recommended rolling programme of audit was not in place. It was noted however that several audits were in place, including; entry of compliances onto the Haemophilia Database; regular auditing of patient feedback; compliance and adherence to the national contract ensuring that patient treatment was in line with national guidelines. The MDT agenda also showed regular review / audit of patient management. However, consideration should be given to producing a programme of systematic audits including care elements against the Centre's clinical guidelines, initiation of prophylaxis and emergency and out of hours care.

NETWORK[1]

There was non-compliance with all of the Network standards.

At the time of the visit, although there were identified working relationships with the Comprehensive Care Centre at Sheffield Teaching Hospitals NHS Trust, this was not a formal network arrangement in place (see Concerns section above).

COMMISSIONING

There was non-compliance with all the commissioning standards. See reference to Network arrangements above.

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[1] This may be updated once the review has been completed for the Comprehensive Care Centre (Sheffield)

APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Visiting Team		
Cathy Benfield	Paediatric Clinical Nurse Specialist	Alder Hey Children's NHS Foundation Trust
Caroline Clegg	Acting Clinical Lead, Rheumatology/Haematology Therapy Team	Manchester University NHS Foundation Trust
Claire Forrester	Haemophilia Nurse Practitioner	University Hospitals of North Midlands NHS Trust
Dr John Hanley	Consultant Haematologist	Newcastle Upon Tyne Hospitals NHS Foundation Trust
Dr Jayashree Motwani	Consultant Paediatric Haematologist	Birmingham Women's and Children's NHS Foundation Trust
Paul Murphy	Healthcare Scientist	Newcastle Upon Tyne Hospitals NHS Foundation Trust

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

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APPENDIX 2 COMPLIANCE WITH THE QUALITY STANDARDS

Analyses of percentage compliance with the Quality Standards should be viewed with caution as they give the same weight to each of the Quality Standards. Also, the number of Quality Standards applicable to each service varied depending on the nature of the service provided. Percentage compliance also takes no account of 'working towards' a particular Quality Standard. Reviewers often comment that it is better to have a 'No, but', where there is real commitment to achieving a particular standard, than a 'Yes, but' – where a 'box has been ticked' but the commitment to implementation is lacking. With these caveats, table 1 summarises the percentage compliance for each of the services reviewed.

Table 1 - Percentage of Quality Standards met

Adult Service	Number of Applicable QS	Number of QS Met	% met
Comprehensive Care	37	27	73%
Networking	8	0	0%
Commissioning	3	0	0%
Total	48	27	56%

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HAEMOPHILIA COMPREHENSIVE CARE CENTRES AND HAEMOPHILIA CENTRES

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 a. Haemophilia B b. Von Willebrand Disease c. Acquired haemophilia d. Inherited platelet disorders e. 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.	N	See 'Further Consideration' section of main report. Although the review team saw examples of comprehensive care plans, they did not appear to be consistently applied in the Medical Notes that were made available to the review team. Some were not dated and not all sets of notes had the template care plans included.
HP-104	**Review of Plan of Care** A formal review of the patient's Plan of Care should take place at least six monthly for patients with severe or moderate haemophilia and at least annually for other patients. This review should involve the patient, where appropriate their carer, and appropriate members of the multi-disciplinary team. Haemtrack results should be reviewed (if applicable) and the outcome of the review should be communicated in writing to the patient and their GP.	Y	
HP-105	**Contact for Queries and Advice** Each patient and, where appropriate, their carer should have a contact point within the service for queries and advice. A clear system for triage of urgent clinical problems should be in place. If advice and support is not immediately available for non-urgent enquiries, then the timescales for a response should be clear. Response times should be no longer than the end of the next working day. All contacts for advice and a sample of actual response time should be documented.	Y	
HP-106	**Haemtrack (Patients on Home Therapy)** All patients on home treatment should be encouraged to use electronic recording of their treatment through Haemtrack.	Y	

Ref	Standard	Met?	Comments
HP-194	**Environment** The environment and facilities in out-patient clinics, wards and day units should be appropriate for the number of patients with inherited and acquired bleeding disorders and accessible by people with severe mobility problems. Services for children and young people should be provided in a child-friendly environment, including toys and books / magazines for children and young people of all ages.	Y	
HP-195	**Transition to Adult Services and Preparation for Adult Life** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards f. Advice for young people going away from home to study, including: i. registering with a GP ii. how to access emergency and routine care iii. how to access support from their Comprehensive Care Centre iv. communication with their new GP	Y	See Good Practice. Reviewers heard from patients and carers regarding their positive experiences of transition.
HP-198	**Carers' Needs** Carers should be offered information on: a. How to access an assessment of their own needs b. What to do in an emergency c. Services available to provide support	N	Reviewers agreed with the Centres own self-assessment. However, the review team did meet with some carers as part of the review and they were very positive about the service that was provided for their relatives by the Hull team.
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.	N	The review team did note that there was a lead consultant and lead nurse in place for the service. However, see concerns section of the main report. Reviewers did not feel that the staffing levels or the support available to the lead clinicians was adequate for the size of the service.
HP-202	**Staffing Levels and Skill Mix** Sufficient staff with appropriate competences should be available for out-patient, day unit and in-patient care and for support to urgent care services. Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network. All staff should undertake regular Continuing Professional Development of relevance to their work in the inherited and acquired bleeding disorders services. Staff working with children and young people should have competences in caring for children as well as in the care of people with bleeding disorders. Cover for absences should be available. In HCCCs these staff should have sessional time allocated to their work with the IABD service. In HCs the arrangements for accessing staff who do not have sessional time allocated to the IABD service should be clearly defined. Staffing should include: a. Medical staff: i. Consultant specialising in the care of people with inherited and acquired bleeding disorders available during normal working hours ii. On-call consultant haematologist (24/7) iii. Arrangements for advice from a consultant specialising the care of people with inherited and acquired bleeding disorders (if not on call) b. Specialist nursing staff: i. Bleeding disorders specialist nurses (5/7) ii. Ward, out-patient and day unit staff with competences in the care of people with inherited and acquired bleeding disorders. c. Clinical specialist physiotherapist d. Biomedical Scientist and Clinical Scientist (further detail on the requirements are included in HP-303) e. Clinical or counselling specialist psychologist or appropriately trained psychotherapist f. Specialist senior social worker g. Data manager	N	See comments above for HP 201. In addition, reviewers noted that as per the requirements of this Quality Standard, there was no psychological or social worker support available to the team.

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	A training plan was not in place at the time of the review though reviewers did see an action plan which had been developed to ensure that one is developed
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	However, reviewers noted that the documentation describing this process was new and needs to be embedded
HP-302	**Emergency Department – Staff Competences** Medical and nursing staff working in the Emergency Department should have competences in urgent care of people with inherited and acquired bleeding disorders including awareness of: a. Guidelines on care of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) b. Who to contact for advice	Y	However, reviewers heard from patients that their experience of ED was not good

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	However, see Further Considerations section of main report regarding use of other assays and potential opportunities for some screening / testing to be undertaken at Castle Hill hospital
HP-304	**Specialist Services** Timely access to the following specialist staff and services should be available as part of a HCCC service. HCs should be able to access these services through network arrangements: a. Obstetrics including reproductive counselling, information about pre-implantation genetic diagnosis and antenatal diagnosis b. Foetal medicine c. Vascular access (consultant surgeon or interventional radiologist with experience of venous access devices) d. Orthopaedic surgery e. Care of older people services f. Dental services g. HIV services h. Hepatology i. Medical genetics (Genetic Counselling Services) j. Pain management services k. Rheumatology Specialist services should have an appropriate level of specialist expertise in the care of people with inherited and acquired bleeding disorders.	Y	

Ref	Standard	Met?	Comments
HP-402	**Facilities and Equipment** Facilities and equipment appropriate for the service provided should be available including: a. Fridges b. Storage c. Clinical rooms for staff of all disciplines to see patients and carers d. Room for multi-disciplinary discussion e. Room for educational work with patients and carers f. Office space for staff g. Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all clinical areas All equipment should be appropriately checked and maintained.	Y	
HP-499	**IT System** IT systems should be in use for: a. Storage, retrieval and transmission of patient information, including access to the latest vCJD status and family tree b. Patient administration, clinical records and outcome information c. Data to support service improvement, audit and revalidation d. Alerting the specialist team when patients attend the Emergency Department	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	

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

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	However, reviewers could not see anything for (b) 'Missing patients'

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

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	N	Most elements are in place but reviewers could not see any evidence for (b)
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	Reviewers could not see any evidence of this in the folder
HP-701	**Data Collection** The following data should be collected: a. UK National Haemophilia Database data on all patients b. Data on concentrate use and bleeds, either through Haemtrack or an equivalent mechanism c. Data required to complete the UKHCDO National Haemophilia Dashboard or other national mechanisms	Y	
HP-702	**Audit** The services should have a rolling programme of audit covering at least: a. Clinical guidelines (QS HP-503) b. Emergency and out of hours care (QS HP-504) c. Initiation of prophylaxis in children d. Inhibitor surveillance and Immune Tolerance Induction (ITI) e. Clinical reviews including joint scores (QS HP-103 & 104) f. Concentrate use and wastage	N	Reviewers did see some good examples of audits but they did not cover all aspects of this Quality Standard and there was no evidence of an overarching plan or forward programme of audits
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	N	Reviewers heard and saw that Multi Disciplinary Team meetings did take place and that attendance was good. However, the evidence provided did not cover all aspects of this Quality Standard.
HP-799	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	See Further Considerations section of main report. Some evidence provided had different versions of the document and one still had tracked changes showing.

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NETWORK

Ref	Standard	Met?	Comments
HY-199	**Involving Patients and Carers** The network should have mechanisms for involving patients and their carers from all services in the work of the network.	N	See Concerns section of main report
HY-203	**Inherited and Acquired Bleeding Disorders Network Leads** The network should have a nominated: a. Lead consultant and deputy b. Lead specialist nurse c. Lead physiotherapist d. Lead clinical or counselling psychologist e. Lead manager	N	See Concerns section of main report
HY-204	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HP-203.	N	See Concerns section of 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 Concerns section of main report
HY-701	**Ongoing Monitoring** The network should monitor on a regular basis: a. Submission of data on all patients to the UK National Haemophilia Database (QS HP-701) b. Network-wide data on concentrate use and bleeds	N	See Concerns section of 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 Concerns section of main report

Ref	Standard	Met?	Comments
HY-703	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with inherited and acquired bleeding disorders b. A list of research trials available to all patients within the network.	N	See Concerns section of main report
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 Concerns section of main report

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COMMISSIONING

Ref	Standard	Met?	Comments
HZ-601	**Commissioning of Services** Commissioners should have agreed the configuration of clinical networks including: a. Designated Comprehensive Care Centres and Haemophilia Centres and the relationships between them b. Whether the service cares for children, adults or both c. Referral pattern to each service, taking into account the type of patients who will be treated by each team	N	See Concerns section of main report
HZ-701	**Clinical Quality Review Meetings** Commissioners should regularly review the quality of care provided by: a. Each service, including achievement of QS HP-701 b. Each network, including achievement of QS HY-701 and QS HY-798 c. Service and network achievement of relevant QSs	N	See 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	See Concerns section of main report

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