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

East Kent Hospitals University NHS Foundation Trust

Visit Date: 13th June 2019

Report Date: October 2019

8831

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Introduction

This report presents the findings of the peer review of services for people with Inherited and Acquired Haemophilia and other Bleeding Disorders at East Kent Hospitals University NHS Foundation Trust, which took place on 13th June 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:

- East Kent Hospitals University NHS Foundation Trust
- NHS England South Region

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.

Acknowledgements

We would like to thank the team at the East Kent Hospitals University NHS Foundation Trust for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. We are grateful, too, to the patients, parents and carers who took time to meet the review team.

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

About the Quality Review Service

QRS 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 QRS is available at www.qualityreviewservicewm.nhs.uk

East Kent Hospitals University NHS Foundation Trust

East Kent Hospitals University NHS Foundation Trust comprised three large acute hospitals: William Harvey Hospital, Ashford (WHH); Queen Elizabeth the Queen Mother Hospital, Margate (QEQMH); and Kent and Canterbury Hospital, Canterbury (KCH). Outpatient services were also held at Buckland Hospital, Dover, Estuary View Medical Centre, Whitstable, and the Royal Victoria Hospital, Folkestone. The Haemophilia Centre was based at KCH, where other specialist services (for example haematology, cancer, and renal services) were located. Elective orthopaedics had also recently moved to the KCH site. There was a paediatric day ward and assessment centre where haemophilia outpatient clinics and treatments were held. Adult patients were seen in the Haemophilia Centre for outpatient appointments, routine treatment and urgent appointments. Haemophilia clinics, with the consultant haematologist in attendance, were also held at the Medway Maritime Hospital. Patients were registered on the National Haemophilia Database (NHD) from Medway, and Medway patients were issued with bleeding disorder cards with the Canterbury contact numbers. As the Centre covered a large geographical area, patients with mild bleeding disorders were offered telephone consultations, if appropriate and if preferred.

There was a weekly multi-disciplinary team meeting at which patients requiring surgery, patients with acute bleeding problems and obstetric patients were discussed.

The haemostasis laboratory was situated within the Haemophilia Centre and had UKAS accreditation.

At the time of the visit the following numbers of patients were registered with the Centre:

Condition		Number of patients
Haemophilia A Total **130**	Adults	**94** Mild **58** Moderate **12** Severe **24**
	Children	**36** Mild **18** Moderate **2** Severe **16**
Haemophilia B Total **31**	Adults	**22** Mild **6** Moderate **11** Severe **5**
	Children	**9** Mild **3** Moderate **2** Severe **4**
Von Willebrand Total **201**	Adults	**156**
	Children	**45**
Other Total **364**	Adults	**303**
	Children	**61**

Emergency Care

There was no Emergency Department (ED) at KCH, but there was a minor injuries unit. Full ED services were provided at WHH and QEQMH. Patients could be seen and assessed at, and advice given by, the Haemophilia Centre. Patients could be admitted directly to Braebourne Ward, which was the haematology ward at KCH, depending on their clinical condition. Children were admitted to the paediatric wards at WHH or QEQMH and were under the care of a named paediatrician. Children requiring assessment could be seen on the Dolphin Ward at KCH by a paediatrician and the haemophilia team. Depending on the clinical scenario, children could also be admitted through the paediatric ED at WHH. Guidelines were in place for treatment out of hours. There was always a consultant on call for haemophilia who could be contacted 24/7.

Ward Care

Braebourne Ward was the seven-bedded adult haematology ward based at KCH, and adult patients with bleeding disorders were admitted there when it was possible and safe to do so. Children were admitted, by open access, to either Padua Ward or Rainbow Ward (which were general paediatric wards) under the care of a named paediatrician, and were jointly managed with the haemophilia team.

Day Unit Care

Adult patients were seen in the Haemophilia Centre for day case treatment. Children could also be seen in the paediatric assessment ward (Dolphin Ward at KCH) or one of the paediatric wards at WHH or QEQMH.

Outpatient Care

Consultant-led outpatient clinics for bleeding disorders were held three times a week for adults in the Haemophilia Centre. Multi-disciplinary physiotherapy and nurse-led clinics were held once a week, alternating with the consultant-led clinic appointments.

Consultant-led paediatric clinics were held in the paediatric day unit every two weeks. Multi-disciplinary physiotherapy and podiatry clinics were held once a month for children.

Nurse-led telephone clinics were held several times a week for patients with diagnosed mild bleeding disorders and to inform patients of their results following initial clinic appointments.

Clinics were held every three months at Medway Maritime Hospital, with medical, physiotherapy and nursing staff travelling from the Canterbury centre.

Community-based Care

The paediatric specialist nurses were able to visit children in their homes to administer treatment, train parents on venous access and perform blood tests. The adult nursing team visited adult patients who were unable to come to clinic appointments.

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Review Visit Findings

Achievements

This was an excellent service, provided by a team with strong medical, nursing and physiotherapy leads in which clinical and non-clinical members worked collaboratively and well together. The diagnostic laboratory was meticulously organised, with a strong focus on quality, and its staff were core team members. The clinical service was highly organised and compassionate, providing carefully individualised care. It was well supported by clinical and non-clinical managers at all levels of the organisation.

The potential difficulties of working across five hospital sites had been imaginatively addressed, and 'Careflow', a locally developed IT system, allowed clinical queries and referrals to be made to the team and their electronic responses to be included in a clearly visible trail. This system, as well as clinic letters (including care plans) and laboratory results, could be accessed remotely by clinical staff on call out of hours.

Parent and patient feedback about the Centre and its team was overwhelmingly positive, and parents and patients greatly appreciated the excellent and sensitive care they received. They commented that the needs of families and carers, not just of the individual patients, were well attended to.

The facilities for patients were of a very high standard. They were spacious and bright, and they included a well-equipped physiotherapy gym and hydrotherapy pool.

There was an active research programme, especially notable for its world-leading specialist physiotherapy elements.

Good Practice

1 Patient feedback on the service was regularly sought, and the findings were displayed in the clinic waiting area. There was evidence of several changes made in service delivery as a result of patient comments. Informal 'coffee mornings' were held so that patients could discuss any issues they had. These also served as a support group. Children were taken on a tour of the laboratory, so they could see what happened to their blood samples. This reflected unusual thoughtfulness about what they might find interesting and what could help de-mystify the process.

2 Governance arrangements were exemplary, with a comprehensive and active audit programme and a well-attended and minuted monthly 'Haemophilia business, clinical governance and audit' meeting. Every opportunity was being taken for review and learning, and for reflection on and improvement of the service.

3 The physiotherapy team were offering point of care ultrasound joint assessments in clinic, and they ran a clinic jointly with the podiatry team at which patients were proactively seen even if there were no symptomatic problems. The team also offered extended clinic appointments, together with the nurse specialist, alternating with consultant appointments.

4 The multi-disciplinary team (MDT) approach to patient management was excellent, with weekly meetings attended by all core team staff. Discussions and outcomes were recorded in an 'MDT Outcome Form' which was then filed as part of the permanent medical record and was accessible to staff at any of the five hospitals in the Trust.

5 There was plentiful patient information, with a comprehensive description of the service, and full condition-specific folders of information were prepared for each patient. A detailed and clear guideline and competency framework for the safe administration of clotting factors at home was also notable.

6 The clinical guidelines supporting the service were clear and comprehensive.

7 A Band 6 development programme for nurses was excellent, and reviewers noted that its application was a very good way of recruiting more junior nurses and then training them up as longer-term team members.

8 Patients with acute problems who needed to present for urgent daytime assessment used a dedicated emergency phone line to the Centre.

9 When patients were admitted to any of the five hospital sites, the Centre team received an automatic e-mail informing them of the episode.

10 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.

11 Women at risk of having a baby affected by a significant inherited bleeding disorder were seen at the Centre during pregnancy. An obstetric plan was drawn up and shared with the obstetric and midwifery teams, and they carried a request form and sample bottle to facilitate immediate correct testing of the neonate after delivery.

12 Examination couches in the adult clinic rooms were covered with a novel soft wipeable 'topper' which made examinations more comfortable for patients with painful stiff joints.

Immediate Risks: No immediate risks were identified at the time of the visit.

Concerns

1 **Staffing**

a. A psychologist member of the team is expected in a Comprehensive Care Centre (CCC) multi-professional bleeding disorder team, but the Centre did not have one. It was noted that patients, families and other haemophilia team members were not therefore receiving the optimal help and support that can be offered by an integrated, familiar psychologist working as part of the Centre team. Reviewers did hear that the team could refer patients to Dover Counselling Services for support.

b. Adult nurse specialist provision was insufficient. One Band 7 nurse was working extra hours to try to meet the needs of the service, and this nurse was usually not able to attend the multi-disciplinary clinics with the Consultant. The nurse was not delivering some of the advanced practice elements of care expected in this role, but was undertaking some non-clinical duties such as stock management, which could be handled by members of the administrative and clerical team, with the nurse's supervision. Consideration should be given to reviewing the existing provision. A job description which supported work also in the community may be valuable.

Further Consideration

1 Patients and families reported problems when they attended the EDs at WHH or QEQMH. Not all patients were aware that they should call the specialist team before presentation, so that the ED staff would be forewarned of their attendance, and it may be useful to remind all users of this first step.

2 Parents and patients recounted that the helpfulness of the response they received when phoning the team for out of hours advice was inconsistent, depending on which senior doctor was on call.

3 Patients undergoing planned surgery had a detailed surgical care plan prepared by the Centre that was communicated to surgical and anaesthetic colleagues in advance. Patients and families did not receive a copy of this, but indicated they would find it helpful and reassuring to have it 'in hand' when being admitted for the procedure.

4 Children had, until recently, attended clinic appointments in the Centre. Families said that they had preferred this to the paediatric clinic area where they now attended, and that they missed the familiarity and support of the extended Centre team. Reviewers recognised that the move had been made for appropriate reasons, and considered that families should be encouraged to continue with the new arrangement, which would in time become equally comfortable and familiar. In the meantime, further discussion with parents about the intended benefits of the relocation may be useful.

5 Reviewers understood that children requiring some surgical procedures, for example Portacath® insertion, were referred to the Evelina Hospital at Guy's and St Thomas' Trust. The written surgical guideline could usefully include details of which children and for what procedures this is the pathway, and how the referral is made in practice.

6 Diagnostic guidelines were in the form of a flowchart. It would be helpful if the flowchart was backed up by some narrative describing local implementation and practice that covered, for example, the need for repeat testing for Von Willebrand Disease, when to recall the patient or family for discussion of results and which results should trigger urgent referral to the team.

7 The data manager had been appointed relatively recently and had not yet received specific training and guidance as to the use of the various data management systems, although a plan was in place for this individual to spend time at another large CCC to work with the data management lead there for training.

8 There was no social worker regularly working with the team, and patients reported that they would greatly value help with completing Disability Living Allowance and Personal Independent Payment application forms, etc. Referrals could be made to the general services; however, it was frustrating for patients to have to explain each time, to a social worker unacquainted with the condition, its nature and associated problems.

9 Although the centre was spacious, the office space allocated for nursing and physiotherapy staff was limited, and they were 'hot desking'. As they were offering telephone assessments and advice to patients, it would be beneficial if a space review could identify additional office space so that they could offer these services more privately and with less interruption.

10 Although patients had not specifically asked for this, generally those in full-time education or work appreciate the possibility of out of hours clinic appointments.

11 The consultants knew their patients and families well and were careful to discuss testing and counselling of potential carriers / mildly affected females in a timely way, before they reached the age of family planning. However, development of a prompt-system to discuss and recall these young adults at an appropriate time may be helpful to ensure a more robust process.

12 Document control was incomplete, with one document in draft, and a few Trust-wide policies beyond their 'review dates'.

General Comments

This Comprehensive Care Centre was unusual in that the majority of its patients received care at one of the five linked hospitals that constituted the East Kent Hospitals University NHS Foundation Trust, although they lived across a wide geographical area. Patients were therefore under the direct or indirect supervision of the Centre team. Most specialist clinic reviews took place in the Centre. The 'network standards', for example those on involving patients and carers, managing guidelines and policies, and monitoring and submitting data, covered functions that were fully controlled through the Centre. Audit, research recruitment, review and learning opportunities similarly included all service users. Reviewers therefore agreed that these standards were met.

In regard to commissioning, although the review team did not meet any of the specialist commissioning team, it was understood that the commissioners had agreed the configuration of services for adults and children, so that standard HZ-601 was met. As commissioners did not attend any of the clinical quality or review and learning meetings which took place, standards HZ-701 and HZ-798 were not met. The Centre team and managers might consider inviting commissioners to some of their comprehensive governance meetings.

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Appendix 1 Membership of Visiting Team

Visiting Team		
Dr Steve Austin	Consultant Haematologist	St George's University Hospitals NHS Foundation Trust
Melanie Bladen	Physiotherapist	Great Ormond Street Hospital for Children NHS Foundation Trust
Liz Carroll	Patient representative Chief Executive	The Haemophilia Society
Jemma Efford	Haemophilia Clinical Nurse Specialist	Great Ormond Street Hospital for Children NHS Foundation Trust
Debra Pollard	Lead Nurse, Haemophilia	Royal Free London NHS Foundation Trust
Jenny Rees	MSK Physiotherapist, Haemophilia	St George's University Hospitals NHS Foundation Trust

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

	Number of applicable QS	Number of QS met	% met
Comprehensive Care	36	31*	86
Network	8	8	100
Commissioning	3	1	33
Total	47	40	85

* One Quality Standard (HP-302) was not assessed as the ED was on a different site to the Haemophilia Centre (where the review was completed)

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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	

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

Ref	Standard	Met?	Comments
HP-194	**Environment** The environment and facilities in out-patient clinics, wards and day units should be appropriate for the number of patients with inherited and acquired bleeding disorders and accessible by people with severe mobility problems. Services for children and young people should be provided in a child-friendly environment, including toys and books / magazines for children and young people of all ages.	Y	However, reviewers noted that office space for staff was limited.
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	See Good Practice section of the main report.

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

Ref	Standard	Met?	Comments
HP-203	**Service Competences and Training Plan** The competences expected for each role in the service should be identified. A training and development plan for achieving and maintaining competences should be in place.	N	Reviewers saw lots of evidence of Continual Professional Development, but no matrix (as outlined in the requirements of this Quality Standard) was provided.
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	Not Assessed	There was no ED on the Kent and Canterbury site, and reviewers did not meet with or assess ED staff from the other sites in regard to their awareness of their responsibilities in relation to patients with bleeding disorders. Reviewers were therefore unable to assess compliance with this standard.

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

Ref	Standard	Met?	Comments
HP-402	**Facilities and Equipment** Facilities and equipment appropriate for the service provided should be available including: a. Fridges b. Storage c. Clinical rooms for staff of all disciplines to see patients and carers d. Room for multi-disciplinary discussion e. Room for educational work with patients and carers f. Office space for staff g. Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all clinical areas All equipment should be appropriately checked and maintained.	Y	
HP-499	**IT System** IT systems should be in use for: a. Storage, retrieval and transmission of patient information, including access to the latest vCJD status and family tree b. Patient administration, clinical records and outcome information c. Data to support service improvement, audit and revalidation d. Alerting the specialist team when patients attend the Emergency Department	Y	See the Good Practice section of the main report.
HP-501	**Diagnosis Guidelines for Patients with Suspected Inherited and Acquired Bleeding Disorders** Guidelines on diagnosis should be in use covering at least a. Haemophilia A b. Haemophilia B c. Von Willebrand Disease d. Acquired haemophilia e. Inherited platelet disorders f. Other less common and rare bleeding disorders	Y	See Further Consideration section of main report. The flowchart was functional but would benefit from some additional text that described local application e.g. repeat testing for Von Willebrand Disease was not included.

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

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

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

Ref	Standard	Met?	Comments
HP-603	**Multi-Disciplinary Clinics** The following multi-disciplinary clinic arrangements for patients with inherited and acquired bleeding disorders should be in place: a. Involvement of medical, specialist nursing and physiotherapy staff in clinics b. Availability of social work and psychology staff in clinics c. Combined clinics or other arrangements for multi-disciplinary discussion with: i. orthopaedics ii. rheumatology iii. obstetrics and gynaecology iv. paediatrics v. dental vi. HIV / hepatology	N	See HP202. As a result of the capacity or availability of some core team members, the requirements of this standard could not always be met.
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 agreed with the Centre's self-assessment, which confirmed that there was no formal process in place.
HP-701	**Data Collection** The following data should be collected: a. UK National Haemophilia Database data on all patients b. Data on concentrate use and bleeds, either through Haemtrack or an equivalent mechanism c. Data required to complete the UKHCDO National Haemophilia Dashboard or other national mechanisms	Y	
HP-702	**Audit** The services should have a rolling programme of audit covering at least: a. Clinical guidelines (QS HP-503) b. Emergency and out of hours care (QS HP-504) c. Initiation of prophylaxis in children d. Inhibitor surveillance and Immune Tolerance Induction (ITI) e. Clinical reviews including joint scores (QS HP-103 & 104) f. Concentrate use and wastage	Y	See the Good Practice section of the main report regarding the comprehensive clinical audit programme.
HP-706	**Research** The service should actively participate in research relating to the care of patients with bleeding disorders.	Y	

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

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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	This Comprehensive Care Centre was unusual in that the majority of its patients received care at one of the five linked hospitals which constituted the East Kent Hospitals University Foundation Trust, although they lived across a wide geographical area. Patients were therefore under the direct or indirect supervision of the Centre team. Most specialist clinic reviews took place in the Centre. The 'network standards', for example those on involving patients and carers, managing guidelines and policies, and monitoring and submitting data, were functions that were fully controlled through the Centre. Audit, research recruitment, review and learning opportunities similarly included all service users. Reviewers therefore agreed that these standards were met.
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	Y	See HY-199.
HY-204	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HP-203.	Y	See HY-199.

Ref	Standard	Met?	Comments
HY-503	**Guidelines** Network guidelines should have been agreed covering: a. Diagnosis for patients with suspected inherited and acquired bleeding disorders (QS HP-501) b. Concentrate use and monitoring (QS HP-502) c. Clinical guidelines (QS HP-503) d. Management of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) e. Care of patients requiring surgery (QS HP-505) f. Transition and preparing for adult life (QS HP-595)	Y	See HY-199.
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	See HY-199.
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.	Y	See HY-199.
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.	Y	See HY-199.
HY-798	**Network Review and Learning** Representatives of Comprehensive Care Centres and referring Haemophilia Centres should meet at least once a year to: a. Identify any changes needed to network-wide policies, procedures and guidelines b. Review results of audits undertaken and agree action plans c. Review and agree learning from positive feedback, complaints, critical incidents and 'near misses', including those involving liaison between teams d. Share good practice and potential service improvements	Y	See HY-199.

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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	
HZ-701	**Clinical Quality Review Meetings** Commissioners should regularly review the quality of care provided by: a. Each service, including achievement of QS HP-701 b. Each network, including achievement of QS HY-701 and QS HY-798 c. Service and network achievement of relevant QSs	N	Reviewers agreed with the Centre's self-assessment. Regular quality meetings had not been held with commissioners and there was therefore no formal review of the quality standards with the commissioners.
HZ-798	**Network Review and Learning** Commissioners should attend a Network Review and Learning meeting (HY-798) at least once a year for each network in their area.	N	Reviewers agreed with the Centre's self-assessment, which confirmed that no meetings had been held with commissioners since the lead commissioner had changed some years previously.

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