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

Royal Cornwall Hospitals NHS Trust

Visit Date: 16th July 2019

Report Date: October 2019

8831

Contents

Introduction

This report presents the findings of the peer review of services for people with Inherited and Acquired Haemophilia and other Bleeding Disorders at the Royal Cornwall Hospitals NHS Trust (RCH) which took place on 16th July 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:

- Royal Cornwall Hospitals NHS Trust
- NHS England Specialised Commissioning South West

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

About the Quality Review Service

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

Expected outcomes are better quality, safety and clinical outcomes, better patient and carer experience, organisations with better information about the quality of clinical services, and organisations with more confidence and competence in reviewing the quality of clinical services. More detail about the work of QRS is available at www.qualityreviewservicewm.nhs.uk

Acknowledgments

Quality Review Service would like to thank the staff of the Truro Haemophilia Centre for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. We are grateful too to the patients and carers who took time to talk to 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.

Return to Index

Truro Haemophilia Centre

The Truro Haemophilia Centre was based in the haematology clinic of the Royal Cornwall Hospitals NHS Trust on the Treliske site in Truro, and was a designated haemophilia treatment centre. It served the population of Cornwall and the Isles of Scilly, with a resident population of just over 500,000 at the 2011 census, rising to nearly 900,000 in the summer months. Because of the location and the large rural population that the Centre served, both emergency and routine care was provided to patients with bleeding disorders.

As a treatment centre the team registered, managed and treated patients with a range of bleeding disorders, providing training and education for those on home treatment, prescribing, and monitoring home treatment. The team also supported and managed surgical procedures for patients with bleeding disorders locally.

There was an established network for paediatric care with the Bristol Comprehensive Care Centre (CCC), and joint clinics were held in Truro twice a year with the Bristol team. Although the local network for adults was not established at the time of the review, many adult patients with complex disorders were jointly managed with colleagues at the Bristol CCC. If a patient had previously been managed at another CCC, the Truro team liaised with that centre. At the time of the visit, the Truro Centre had patients jointly registered with the Royal Free (London), Cardiff, Oxford and Birmingham.

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

Condition		Number of patients	Number of patients who had an annual review in last year
Haemophilia A	Adults	Severe 12 Moderate 7 Mild 34	Severe 12 Moderate 7 Mild Data not available
	Children	Severe 2 Moderate 2 Mild 8	Severe 2 Moderate 2 Mild Data not available
Haemophilia B	Adults	Severe 1 Moderate 0 Mild 2	Severe 1 Moderate Not Applicable Mild 2
	Children	All severities 0	Not Applicable
Von Willebrand	Adults	Type 1 85 Type 2 (all sub types) 24 Type 3 1	Type 1 Data not available Type 2 Data not available Type3 1
	Children	Type 1 6 Type 2 (all subtypes) 7	
Other	Adults	68	
	Children	10	

Emergency Care

Adults: During working hours (8am to 4pm Monday to Friday), adults were encouraged to speak with the haemostasis Clinical nurse Specialist (CNS) for advice. The CNS would advise them to attend either the haematology clinic for assessment or the Emergency Department (ED) if that was more appropriate. Out of hours (OOH), adults were told to call the general OOH advice line and then attend the ED. The on-call consultant haematologist could be contacted by the nurse answering the advice line. Clinical management plans were in place for frequent attenders and for complex patients.

Children: During working hours (8am to 4pm Monday to Friday), parents and guardians were encouraged to speak with the haemostasis CNS for advice. The CNS would advise them to attend either the Paediatric Observation Unit (POU) or the paediatric ED, if that was more appropriate. Out of hours, parents and guardians were encouraged to contact the POU, where all children with bleeding disorders, including children who were on holiday in Cornwall, had open access.

Ward Care

Lowen Ward was the dedicated haematology ward, but beds on this ward were rarely available for patients with bleeding disorders. In general, patients with bleeding disorders were admitted to the Acute Medical Unit and managed by the medical teams there, but the haematology team regularly monitored and reviewed these patients.

Day Care

If a patient required treatment, this was usually managed by the CNS in the outpatient department. When the CNS was not available, the patient would either be managed by another CNS colleague or would attend the Headland day unit for treatment.

Outpatient Care

Routine outpatient management for adults took place in the haematology clinic. Children were seen in the paediatric outpatient department, based on the Gwithian unit.

Community-based Care

There was a proactive and forward-thinking ‘acute care at home’ team for adults. This team was able to provide an intravenous (IV) service in people’s own homes. This allowed the haemophilia team to discharge patients home over the weekend, where appropriate, as they could continue to receive clotting factor concentrate at home up to twice daily. The paediatric community team were also able to assist with IV treatments where children had established IV access.

Review Findings

Achievements

The centre was staffed by a long-serving, highly experienced team who were offering a safe and very good service for a relatively small number of patients with inherited and acquired bleeding disorders. There was evidence of supportive and respectful working relationships within the team and with other hospital teams. The medical and nursing leads ensured that practice was up to date, with comprehensive continuing professional development activities. Within the limits of the small team (see Further Consideration 1), multi-disciplinary practice was strong, with fortnightly minuted multi-disciplinary team (MDT) meetings. The outcomes of these MDT meetings were filed in the patient record. The team were making good use of their specialist staff, even in those staff groups with limited time devoted to the service. They worked hard to ensure awareness about bleeding conditions among community healthcare colleagues. The data manager achieved a lot in her four hours per week, with a clearly defined job list and a work plan for the future. The laboratory team was excellent and worked closely with clinicians. The team was imaginative in planning for the future continuity of the service, with other consultants showing flexibility in their job plans and planning to pick up some bleeding disorder work as the Centre director was expected to reduce his working hours in the near future. Support from clinical and non-clinical managers was reported to be positive.

Patients were warmly appreciative of the service, which they valued highly, especially noting the care given by the specialist nurse. They said that they always felt listened to and had good access to team members who were responsive to their needs.

Although the South Western and Peninsula network was not well-developed, especially for adults, the team were working to ensure that their patients had access to aspects of care that were offered at larger Comprehensive Care Centres, including new medications such as Emicizumab[1], and access to research. There was an impressive portfolio, with good recruitment and effective support from the haematology research team.

Good Practice

1 There were strong governance processes within the wider haematology department, with quarterly meetings, including mortality reviews and discussion of incidents and complaints, and the possibility of extra meetings every month if any more urgent issues had arisen. The haemophilia team participated fully in these meetings.

2 Children known to the service had open access at all times to the POU, where they could be seen by staff trained in bleeding disorders if they required urgent assessment and care. Although children were managed jointly with the Bristol CCC team, who visited every six months, great effort was made locally to enhance care for children and their families. The skills of play therapists were fully utilised in assisting the haemophilia nurse specialist with distraction techniques when teaching home therapy or with difficult IV access.

3 The general electronic patient record system 'Maxims'®, and 'Oceana' (the system used in the ED) had an alert visible on opening a patient's record that prompted the user to read the care management plan which outlined the patient's diagnosis and treatment. When the care management plan had been updated, previous versions were clearly stamped to indicate they had been 'superseded'.

[1] **Emicizumab** (trade name Hemlibra) is a humanized bispecific antibody for the treatment of haemophilia A. It functions by bringing together other blood clotting factors to promote clotting and reduce bleeding, in the absence of factor Vlll.

4 There was a clear poster displayed in the ED outlining key management steps to take when a patient with a bleeding disorder presented there. The surgical proforma was also noted to be excellent.

5 Patients and families had e-mail access to the team for less urgent queries and advice.

6 Helpful support was available from an 'acute care at home' team working seven days each week, who could offer home visits to administer concentrate, if required. This supported early discharge, where appropriate, after an inpatient procedure for a patient with a bleeding disorder.

7 A list of patients (including their diagnosis and which factor concentrate they required for urgent care) was displayed on the storage fridge within the laboratory.

8 The electronic patient records were accessible remotely, for medical staff on call out of hours.

9 Patient feedback was actively sought, and there was evidence of changes to the service in response to patient and family comments.

10 Document control was good, with many policies held on Q Pulse®, a quality management system. Other guidelines also included details of authorship, approval and planned review dates.

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

Concerns: No concerns were identified at the time of the visit.

Further Consideration

1 Staffing in some groups was only just sufficient for the work of the service.

a. **Nursing** – At the time of the visit, there was a single Band 7 specialist nurse, working very effectively but without permanent specialist cover. She did not feel able to take more than a week's annual leave at a time, and regularly planned her holiday to avoid times at which patients had planned surgery etc. There was funding and approval to appoint to a 0.6 wte Band 6 support nursing post, which would alleviate the situation.

b. **Data management** – the data manager achieved a great deal in her four hours per week, but it was not always possible for her to cover all the expected work in the time allocated to this service. The lead nurse on occasion undertook some of the duties, and there was a backlog in getting MDT outcomes entered onto the patients' records.

c. **Physiotherapy** – There was an engaged and active physiotherapist with very little protected time for this service. In four clinic sessions per year she could attend for two adult and two paediatric clinics. She sometimes came to see patients in her lunch hour or after her working hours. There was insufficient time to undertake long-term joint health work, and inpatient work was delegated to colleagues. If the time allocated to the service were to be increased, she could take part in more development opportunities, which she was keen to do.

d. **Psychology and Social Work** – There was no psychologist or social worker associated with the team, although patients could be referred to the general hospital services if required. Patients with particular needs were therefore able to access some level of support. However, identifying a named psychologist and social worker, who would become familiar with the conditions and the problems faced by bleeding disorder patients, would be helpful, and it was acknowledged that some undeclared lower-level support needs were probably not being met within the current provision.

2 Some adult patients reported poor experiences within the ED, with long waits for treatment and a lack of confidence in the staff's understanding and knowledge of their conditions.

3 Elective orthopaedic surgery had moved to a hospital in Hayle, which was approximately fifteen miles from the Royal Cornwall Hospital site. High-risk surgery continued to take place at the RCH, but it had not been agreed formally that all patients with significant bleeding disorders fell into this category. The team were therefore frequently spending time persuading colleagues of the need for their patients to have surgery at the Treliske site. As there were no specialist clinical haematology staff, no factor concentrates stored, and no laboratory services for essential peri-operative factor level assays to be undertaken at the Hayle site, it is necessary to agree a formal protocol with the orthopaedic department under which these patients would have surgical procedures only at the Treliske site (where appropriate clinical and laboratory support is available).

4 Patient information in relation to the haemophilia service, and condition-specific information for bleeding disorders, was sparse, and no information was displayed in the clinical areas for patients' use.

5 There was no operational policy in place; this could usefully include guidance on the local implementation of the Bristol CCC diagnostic and clinical guidelines, and outline local referral pathways, as well as the other elements of the HP-601 standard.

6 Diagnostic guidelines, shared with the Bristol CCC, did not cover Von Willebrand Disease, acquired haemophilia or other platelet disorders.

7 Multiple IT systems supporting the services were complex, although functional. Different staff groups tended to include notes in different systems, and then had to remember to 'copy and paste' them into other sites to be sure they would be seen by all staff. It might be possible to allow automatic transfer of information between the systems, failing which the team might agree which system they would all prefer to use and refer to.

8 The care management pathway was adequate, although limited in detail. A haemophilia clinic proforma had previously been in use (and could be seen in some hard copy patient records), and this included many more elements of a plan of care (HP-103). The team might consider resuming the use of this proforma.

9 There was no robust system in place for recalling potential mildly affected or carrier female relatives for testing and counselling before reproductive age.

10 There was evidence of some audit activity, although not in a rolling programme against all the diagnostic and clinical guidelines. It was considered, in the light of some patient dissatisfaction, that an audit of the management of patients presenting to the ED would be useful. An audit against physiotherapy guidelines might also identify whether there is sufficient physiotherapy input to the service.

11 Parking for patients was limited, and there were no bays for the use of disabled badge holders in the haematology area.

Return to Index

General Comments

The services at the Centre were, in principle, part of a clinical network whose hub was at the Bristol Comprehensive Care Centre (University Hospitals Bristol NHS Foundation Trust), and the team at RCH reported being well supported by their colleagues in Bristol when they needed clinical advice.

The clinical paediatric network was relatively well organised, with the Bristol team offering six-monthly outreach clinics at the RCH as one of four linked hospitals. However, many aspects of a functioning managed network were not in place. The team at RCH had not been involved in any meetings with their specialist commissioners for several years. As reported at the peer review visit to the Bristol CCC, discussions between the clinical teams at the various sites, Trust managers and commissioners will be necessary to identify what additional support, resource and time will be required to develop the adult network and to allow a higher level of network activity for paediatric and adult services.

It is hoped that all the useful aspects of a fully functional managed network can be established, including staffing review, a joint education and training programme, shared audit, and network-wide review and learning opportunities.

Return to Index

APPENDIX 1 Membership of Visiting Team

Visiting Team		
Dr Ben Bailiff	Consultant Haematologist	University Hospitals Coventry and Warwickshire NHS Trust
Jemma Efford	Haemophilia Clinical Nurse Specialist	Great Ormond Street Hospital for Children NHS Foundation Trust
Vishal Patel	Physiotherapist	Barts Health NHS Trust
Nicola Sugg	Patient representative	Haemophilia Society
Jane Yeaman	Haemophilia Nurse Specialist	Hampshire Hospitals NHS Foundation Trust

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

Return to Index

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 takes no account of 'working towards' a particular Quality Standard. Reviewers often comment that it is better to have a 'No, but', where there is real commitment to achieving a particular standard, than a 'Yes, but', where a 'box has been ticked' but the commitment to implementation is lacking. With these caveats, table 1 summarises the percentage compliance for each of the services reviewed.

Table 1 - Percentage of Quality Standards met

Details of compliance with individual Quality Standards can be found below.

Service	Number of applicable QS	Number of QS met	% met
Comprehensive Care	37	31	84
Network	8	0	0
Commissioning	3	0	0
Total	48	31	65

Return to Index

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)	N	Although there was a welcome leaflet in place, this was not specific to haemophilia and did not include all the relevant requirements for this standard such as clinic times, ward details, community services, social services, interpreter services, etc.

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	N	Although there was some information in place, it was limited to national documentation rather than being localised. Reviewers could not see evidence for (f), (g), (j), (n), (o), (p), (r) or (s).

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	A care management plan was in place which covered the essential details of diagnosis and treatment. A fuller haemophilia clinic proforma had previously been in use. See Further Consideration section of main report regarding the possibility of resuming the use of this document.
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	
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	Clinical care management plans were in place and were reviewed and updated. They were also copied to patients. Reviewers saw evidence of responses to feedback from patient surveys.

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

Ref	Standard	Met?	Comments
HP-203	**Service Competences and Training Plan** The competences expected for each role in the service should be identified. A training and development plan for achieving and maintaining competences should be in place.	Y	
HP-204	**Competences – All Health and Social Care Professionals** All health and social care professionals working in the service should have competences appropriate to their role in: a. Safeguarding children and/or vulnerable adults b. Recognising and meeting the needs of vulnerable children and/or adults c. Dealing with challenging behaviour, violence and aggression d. Mental Capacity Act and Deprivation of Liberty Safeguards e. Resuscitation	Y	
HP-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be available.	Y	However, see Further Consideration 1 in the main report in relation to the limited time available to the data manager.
HP-301	**Support Services** Timely access to the following support services should be available: a. Play support (children's services only) including: i. Play and distraction during any painful or invasive procedures ii. Play support to enable the child's development and well-being b. Pharmacy c. Dietetics d. Occupational Therapy e. Orthotics	Y	
HP-302	**Emergency Department – Staff Competences** Medical and nursing staff working in the Emergency Department should have competences in urgent care of people with inherited and acquired bleeding disorders including awareness of: a. Guidelines on care of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) b. Who to contact for advice	Y	

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

Ref	Standard	Met?	Comments
HP-402	**Facilities and Equipment** Facilities and equipment appropriate for the service provided should be available including: a. Fridges b. Storage c. Clinical rooms for staff of all disciplines to see patients and carers d. Room for multi-disciplinary discussion e. Room for educational work with patients and carers f. Office space for staff g. Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all clinical areas All equipment should be appropriately checked and maintained.	Y	
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	N	Although there was access to the Bristol CCC guidelines, an assessment had been made that these did not meet the requirements of this standard ((c), (d) and (e)).

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	Note: (c) is not applicable to this Centre.
HP-504	**Emergency Department Guidelines** Guidelines on management of patients with inherited and acquired bleeding disorders in the Emergency Department should be in use.	Y	

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

Ref	Standard	Met?	Comments
HP-601	**Service Organisation** The service should have an operational procedure covering at least: a. Ensuring all children who are in-patients have a named consultant paediatrician and a named haematologist with expertise in caring for patients with inherited and acquired bleeding disorders responsible for their care b. Ensuring all adults are under the care of a consultant haematologist with an interest in inherited and acquired bleeding disorders, either directly or through a shared care arrangement with a general haematologist c. Responsibility for giving information and education at each stage of the patient journey d. Arrangements for involving Haemophilia Centre staff in multi-disciplinary discussions relating to their patients (QS HP-602) e. Arrangements for follow up of patients who 'do not attend' f. Arrangements for transfer of patient information when patients move areas temporarily or permanently g. Ensuring patients' plans of care are reviewed at least six monthly for patients with severe haemophilia and at least annually for other patients (QS HP-104) h. Ensuring school visits for children with severe haemophilia at least at each change of school (children's services only) i. Ensuring patients are visited at home at least annually if they are unable to attend clinics, including those in nursing homes j. Lone working	N	There was no overarching operational policy supporting the service. However, policies covering (e) and (j) were in place.
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, there were no psychologist or social work members of the team (see Further Consideration 1 of main report).

Ref	Standard	Met?	Comments
HP-603	**Multi-Disciplinary Clinics** The following multi-disciplinary clinic arrangements for patients with inherited and acquired bleeding disorders should be in place: a. Involvement of medical, specialist nursing and physiotherapy staff in clinics b. Availability of social work and psychology staff in clinics c. Combined clinics or other arrangements for multi-disciplinary discussion with: i. orthopaedics ii. rheumatology iii. obstetrics and gynaecology iv. paediatrics v. dental vi. HIV / hepatology	Y	However, there were no psychologist or social work members of the team (see Further Consideration 1 of main report).
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 that there were no planned reviews with other services.
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	Some audits were in place, but not for all the requirements of this Quality Standard.
HP-706	**Research** The service should actively participate in research relating to the care of patients with bleeding disorders.	Y	

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

Return to Index

Network

Ref	Standard	Met?	Comments
HY-199	**Involving Patients and Carers** The network should have mechanisms for involving patients and their carers from all services in the work of the network.	N	Reviewers agreed with the Centre's self-assessment. The South West network was still under development at the time of the review.
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	Reviewers agreed with the Centre's self-assessment. The South West network was still under development at the time of the review.
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	Reviewers agreed with the Centre's self-assessment. The South West network was still under development at the time of the review.
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	Reviewers agreed with the Centre's self-assessment. The South West network was still under development at the time of the review.
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	Reviewers agreed with the Centre's self-assessment. The South West network was still under development at the time of the review.
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.	N	Reviewers agreed with the Centre's self-assessment. The South West network was still under development at the time of the review.
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	Reviewers agreed with the Centre's self-assessment. The South West network was still under development at the time of the review.

Ref	Standard	Met?	Comments
HY-798	**Network Review and Learning** Representatives of Comprehensive Care Centres and referring Haemophilia Centres should meet at least once a year to: a. Identify any changes needed to network-wide policies, procedures and guidelines b. Review results of audits undertaken and agree action plans c. Review and agree learning from positive feedback, complaints, critical incidents and 'near misses', including those involving liaison between teams d. Share good practice and potential service improvements	N	Reviewers agreed with the Centre's self-assessment. The South West network was still under development at the time of the review.

Return to Index

Commissioning

Ref	Standard	Met?	Comments
HZ-601	**Commissioning of Services** Commissioners should have agreed the configuration of clinical networks including: a. Designated Comprehensive Care Centres and Haemophilia Centres and the relationships between them b. Whether the service cares for children, adults or both c. Referral pattern to each service, taking into account the type of patients who will be treated by each team	N	Reviewers heard that discussions with commissioners had not taken place for some years.
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 that there had been limited engagement and discussions with 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 that there had been limited engagement and discussions with commissioners.

Return to Index