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

The Newcastle upon Tyne Hospitals NHS Foundation Trust

Visit Date: 27th February 2019

Report Date: July 2019

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Introduction

This report presents the findings of the peer review of Services for People with Inherited and Acquired Haemophilia and other Bleeding Disorders at the Newcastle Haemophilia Comprehensive Care Centre on 27th February 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:

- The Newcastle upon Tyne Hospitals NHS Foundation Trust
- North of England Specialised Commissioning Team

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

Acknowledgements

We would like to thank the team at the Newcastle Haemophilia Comprehensive Care Centre for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. We are grateful, too, to the patients 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 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.wmqrs.nhs.uk

The Newcastle Haemophilia Comprehensive Care Centre

The Newcastle Haemophilia Comprehensive Care Centre (CCC) was based at the Royal Victoria Infirmary (RVI) in Newcastle upon Tyne and offered support, treatment and advice to both adult and paediatric patients and families affected by haemophilia and other related bleeding disorders. The CCC covered a wide geographical area, including Tyne and Wear, Cumbria, Co. Durham, Northumberland, North and South Tees and parts of North Yorkshire.

The RVI and the Freeman Hospital were the two hospital sites of the Newcastle upon Tyne Hospitals NHS Foundation Trust. Despite being on two sites, the Centre team regarded them as a single entity, and all patients with inherited and acquired bleeding disorders were managed by the haemophilia team, who travelled between the two sites as needed. The adult haematology ward was at the Freeman Hospital. Children were always seen at the RVI. The paediatric part of the RVI was called the Great North Children's Hospital (GNCH) and was effectively the specialist children's hospital within the RVI rather than being a separate children's hospital as is often the case.

The table below summarises the conditions and severity of patients managed by the Centre at the time of the review:

Diagnosis	Severity/Type	Age 18 & Over	Age 0-17	Total
Haemophilia A	Severe	53	28	**81**
	Moderate	19	7	**26**
	Mild	139	25	**164**
Haemophilia B	Severe	13	5	**18**
	Moderate	7	2	**9**
	Mild	17	11	**28**
von Willebrand Disease (vWD)	Type 1	164	24	**188**
	Type 2	16	7	**23**
	Type 2A	36	2	**38**
	Type 2B	7	2	**9**
	Type 2M	7	1	**8**
	Type 2N	13	1	**14**
	Type 3	6	0	**6**
	Unclassified	118	31	**149**
Factor V Deficiency		18	4	**22**
Factor VII Deficiency		30	7	**37**
Factor X Deficiency		1	1	**2**
Factor XI Deficiency		156	45	**201**
Factor XIII Deficiency		4	2	**6**
Combined V & VIII Deficiency		0	2	**2**
Combined VII & XI Deficiency		1	0	**1**
Acquired Haem A		34	0	**34**
Acquired vWD		10	0	**10**
Glanzmann's Thrombasthenia		1	1	**2**
Dysfibrinogenaemia		28	8	**36**

Diagnosis	Severity/Type	Age 18 & Over	Age 0-17	Total
Hypofibrinogenaemia		2	2	**4**
Platelet defects (miscellaneous)		71	21	**92**
Bernard Soulier		2	0	**2**

Emergency Care

On Mondays to Fridays (8.00am to 4.30pm), all patients had direct access to the Haemophilia Centre at the RVI. Patients were encouraged to phone for advice and then attend as necessary. If the clinical circumstances dictated that it would be better to review the patient elsewhere, then staff at the Haemophilia Centre would arrange urgent transport as required.

Out of hours (in the evenings, at weekends and on bank holidays), adult patients had direct access to Ward 33 (the haematology base ward at the Freeman Hospital). Patients were encouraged to phone the ward, and the phone call was triaged by the nursing staff. Patients were either reviewed on the ward or arrangements were made for assessment elsewhere according to the clinical circumstances. Children were asked to attend the Paediatric A&E at the RVI, and parents were asked to phone and then attend for review. The on-call haematology team was available 24/7 for advice and, if necessary, would review the child.

Because of the large geographical area covered by the Newcastle CCC, patients in parts of the region also had the option of direct access to their local Haemophilia Centre (at Middlesbrough, Sunderland, Whitehaven or Carlisle). Each of these locations had individual arrangements for the assessment of adults and children, and advice was always available from the Newcastle CCC.

Ward Care

For adults, Ward 33 at the Freeman Hospital was the haematology base ward for the Trust. There were also some haematology beds on Ward 34 (opposite Ward 33). There was a bed policy that prioritised patients with bleeding disorders if there were clinical reasons why inpatient care should be delivered on the haematology ward. If there was no bed available on Ward 33 (which was often the case), patients were admitted either to a medical or to a surgical bed, depending on the clinical circumstances. At the RVI there were close links with several departments. For example, a patient with a gastrointestinal bleed would most often be admitted to the gastroenterology ward, a patient with a musculo-skeletal problem would often be admitted to an orthopaedic ward, patients with infection-related issues as well as bleeding problems were often admitted to the infectious diseases ward, and patients undergoing elective surgery were managed on the appropriate surgical ward. All inpatients with bleeding disorders were reviewed daily by the haemophilia team.

Children were managed on the medical or surgical wards in the Great North Children's Hospital.

Day Unit Care

The Haemophilia Centre provided some day care facilities for both children and adults. There was also access to the Programmed Investigation Unit at the RVI; this was used by a number of specialties for day unit procedures, including blood transfusion and the administration of longer intravenous infusions (like intravenous immunoglobulin or Rituximab[1]).

[1] **Rituximab** (sold under the brand name Rituxan among others) is prescribed as a second line treatment in the eradication of inhibitors for patients with acquired haemophilia.

Outpatient Care

Outpatient clinics for patients with haemophilia and related bleeding disorders were carried out in the Haemophilia Centre at the RVI. There were facilities for both children and adults. At the time of the review there was a plan to move the children's clinics into paediatric facilities at the Great North Children's Hospital.

Community-based Care

When appropriate, care was delivered in the community. A number of members of the Multi-Disciplinary Team, including nurse specialists, physiotherapists, social workers and occasionally consultants, delivered care in the community.

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Review Visit Findings

Achievements

This was an excellent service: safe, innovative, and with plans in place to improve services further. The extended team worked in a very cohesive manner and constituted a committed and devoted workforce. There was evidence of strong management support. Patients were warmly appreciative of the personalised care that they received from the team.

Multi-disciplinary working was clearly well established, and the team psychologist, social worker and biomedical scientist were members of the core team, which also included medical and nursing staff, physiotherapists, and staff providing data and administrative support. The physiotherapists were undertaking some outstanding work, including: a fitness training and a weight loss programme; gait assessment; early detection of arthropathy using HEAD-US[2]; and a comprehensive pathway for managing target joints with radioactive synovectomy.[3] They also undertook visits to patients in the community. The psychologist provided important support to team members as well as to patients and carers. The dedicated social worker was a very active member of the team, whose work was recognised outside of the Newcastle Centre. The extended role of the medical secretary in completing detailed genetic 'family trees' for all patients was noted. There was a sense that the team felt responsibility for the well-being not just of individual patients, but of their families too.

There was a wide research portfolio in place, encompassing national and international studies and including children and adults. This was commendable given the demands of the clinical service and the levels of staffing.

Good Practice

1. Some of the documents supporting the service were of a particularly high standard, including a template for extended half-life product[4] switching, a patient contract for the home delivery service, and the operational policy.
2. The Paediatric Emergency Department worked well. Staff had access to the Haemophilia Clinical Information System (HCIS) and were clearly well versed in the care pathway. There was an easily accessible fridge for concentrate storage.
3. The laboratory support for the service was strong, with staffing retention issues being successfully addressed by a 'bonding' scheme. The senior biomedical scientist was an active member of the Multi-Disciplinary Team (MDT).
4. Stock control was well managed, with little wastage of concentrates. This was helped by input from a pharmacy technician who regularly checked stock and recorded usage.
5. Children were seen yearly in a nurse-led clinic, when they were also seen by the physiotherapist and social worker.

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[2] **HEAD-US** – Haemophilia Early Arthropathy Detection with Ultrasound [HEAD-US], a point-of-care ultrasound technique to detect abnormalities in joints without history of hemarthrosis and clinically asymptomatic joints.

[3] **Radioactive synovectomy** – a very effective and gentle procedure, used for rapid and sustained pain relief of severe joint pain or arthritis, such as osteoarthritis (in haemophilia the main indication for a radioactive synovectomy is to control bleeds rather than pain relief per se). Through targeted sclerotisation of the synovial membrane with radioactive substances, lasting relief from pain and inflammation is achieved in most cases.

[4] **Extended half-life products** – the recent development of new factor products with an extended half-life is able to stretch the time between infusions to once every week or two, with equal effectiveness.

6. The recently established Centre-based review and learning meetings, which then fed into larger Directorate-wide governance meetings, were effective and well-documented.
7. A network-wide teaching programme offered sessions 4 – 5 times a year, and this was appreciated by staff at the linked hospitals.
8. There was a well-established parents' group.
9. A 'twinning programme' organised with the World Federation of Haemophilia, which linked the Centre to a Haemophilia Treatment Centre in Aluwa in Kerala, India was providing highly valued support for the staff and patients there. It also provided interesting opportunities for the Newcastle staff to travel and work in a different healthcare setting.
10. There was an active local charity which was fundraising very effectively and also supporting activity and training weekends for young patients.
11. The dental service was using a computer assisted anaesthesia 'wand', avoiding the need for injections and allowing for pain free procedures.
12. The main hospital e-record system was clear and comprehensive, with a single system allowing access to clinic letters and pathology and radiology results.
13. Signposting to the Centre on the hospital site was excellent, enabling patients and visitors to find the Centre easily.

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

Concerns

1. **Environment**

   The limited space in the Centre posed problems. In the small waiting area, fixed chairs made it difficult for wheelchairs and pushchairs to be accommodated, and although paediatric and adult clinics were not scheduled at the same time, unplanned attendances by adults during paediatric clinics, or children during adult clinics, led to children and adults sometimes sharing the same waiting area. The day treatment area was open plan, with limited privacy for patients. Office space for staff was limited, and there was no 'rest area' in which they could take breaks.

2. **Staffing**

   The staffing numbers in all professional groups were low for the size of the service. Although they were currently managing, by co-operative and flexible working, it was anticipated that this would become more difficult when the service splits, as planned, with the paediatric service moving into specific paediatric facilities at the Great North Children's Hospital. It was noted that the nursing staff were undertaking additional work in the department, in addition to their specialist clinical roles, and devoting considerable time to stock management in the Centre and across the linked hospital sites. It was felt that this may not be sustainable after the service split.

3. **Guidelines**

   a. The adult guideline for care in the Emergency Department (ED) was limited, indicating only that the specialist team should be contacted. Delays in patients receiving factors when presenting with a bleed or trauma had also been documented.

b. There were several different versions of the guideline for care in the Paediatric Emergency Department, with some differing content, which might lead to confusion or delays in appropriate treatment.

4. **Northumbria Specialist Emergency Care Hospital**

   Northumbria Specialist Emergency Care Hospital (Cramlington) was a hospital specialising in the care of sick and injured patients; it had opened in 2015 and was situated about 8 miles north of Newcastle. There was a concern that if patients with inherited bleeding disorders presented there for one of a variety of clinical and non-clinical reasons, there may be delays in administering treatment as there was no stock of concentrates on site. Reviewers were concerned that necessary treatment could be delayed as a result, and felt that it was necessary to establish a stock of concentrates at the Cramlington site and to share clinical guidelines with the ED and haematology teams there, with the offer of telephone advice from the Newcastle team, where appropriate. This could be addressed within the network arrangements for haemophilia care (see below).

5. **Parking**

   There was no designated parking for patients using the Haemophilia Centre, and only a limited number of disabled parking bays; the multi-storey car park was reported to be frequently full. Patients found this a significant problem when trying to reach the Centre. The Centre should consider designating some parking spaces for the use of these patients.

Further Consideration

1. One of the guidelines for access to concentrates out of hours referred to 'fridge NCCC33' without indicating where that was, and a guide to Commissioning for Quality and Innovation (CQUIN) and data submission described what was to be done but did not specify whose responsibility this was. Some of the clinical guidelines were observed to be descriptive narratives rather than giving specific practical guidance.
2. Support from other disciplines was mostly very good, and there were several regular joint clinics. However, there was no identified care of the elderly link, which was felt to be important given the ageing population, and access to a specialist pain team for adult patients was reported to be lacking.
3. There was a competency framework in place. However, it was not populated and there was therefore no evidence seen regarding the competencies required by each staff member, nor assurance that all relevant training had been completed by individual staff members.
4. Statutory and mandatory training records for staff were not available for all core staff in the Centre.
5. Although some audit activity was evidenced, there did not appear to be a rolling programme of audits against clinical guidelines, initiation of prophylaxis in children, inhibitor surveillance and joint scores (HP-702) either in the Centre or across the network.
6. The social worker was a very effective team member, but it was felt that a 'gap analysis' of the work she was unable to cover within her hours may be useful in identifying whether any additional resource was necessary.
7. The clinical support for teams at the linked hospitals was greatly appreciated, and it was noted that the availability of shared guidelines, and copies of the out-of-hours rota of consultant staff to facilitate contact with the appropriate person, would be useful. In the meantime, although updated hard copies of individual patients' key data and care instructions were sent to the teams and kept available for ready access, access to the electronic system (HCIS) was also requested for linked hospital teams.
8. The home delivery service gave rise to patient dissatisfaction, with the service reported to be unreliable.

9. Reviewers noted that document control required some attention. Many of the documents provided as evidence lacked a date of issue, date of intended review and authorship and ratification details.

Network

The team had self-assessed compliance with four of the eight network standards [HY-199 – 798]. Compliance was assessed by reviewers not to be complete in six of the eight.

Commissioning

The three commissioning standards were assessed as not being satisfactorily met, according to the evidence available at the time of the visit. The self-assessment had indicated non-compliance with two of the three.

Further discussion with commissioners will be required to clarify this situation and confirm whether working towards a more formal network is their expectation and, if so, what resource might be offered to support this.

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APPENDIX 1 Membership of Visiting Team

Visiting Team		
Dr Julia Anderson	Consultant Haematologist	Royal Infirmary of Edinburgh, NHS Lothian
Andy Cowe	Patient representative	
Shaun Emmitt	Benign Haematology Nurse Specialist	Sheffield Children's NHS Foundation Trust
Thuvia Flannery	Physiotherapist	Leeds Teaching Hospitals NHS Trust
Dr Simone Green	Paediatric Consultant Haematologist	Hull University Teaching Hospitals NHS Trust
Cathy Harrison	Haemophilia and Thrombosis Advanced Nurse Practitioner	Sheffield Teaching Hospitals NHS Foundation Trust
Nicola Hubert	Paediatric Physiotherapist	Great Ormond Street Hospital for Children 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 varied depending on the nature of the service provided. Percentage compliance also takes no account of 'working towards' a particular Quality Standard. Reviewers often comment that it is better to have a 'No, but', where there is real commitment to achieving a particular standard, than a 'Yes, but' where a 'box has been ticked' but the commitment to implementation is lacking. With these caveats, table 1 summarises the percentage compliance for each of the services reviewed.

Table 1 - Percentage of Quality Standards met

	Number of Applicable QS	Number of QS Met	% met
Comprehensive Care Centre	37	27	73%
Network	8	2	25%
Commissioning	3	0	0%
Total	48	29	60%

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Haemophilia Comprehensive Care Centres and Haemophilia Centres

Ref	Standard	Met?	Comments
HP-101	**Service Information** Written information should be offered to patients and, where appropriate, their carers covering at least: a. Brief description of the service b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the service e. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent) v. Give feedback on the service, including how to make a complaint vi. Get involved in improving services (QS HP-199)	Y	

Ref	Standard	Met?	Comments
HP-102	**Condition-Specific Information** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of their condition and how it might affect them b. How their condition is diagnosed c. Genetics of inherited bleeding disorders d. Testing for carrier status and the implications of being a carrier e. Problems, symptoms and signs for which emergency advice should be sought f. Out of hours services g. 'On demand' clotting factor treatment h. Prophylaxis i. Self infusion (or infusion by parent or carer) j. Home therapy and use of Haemtrack k. How to manage bleeding at home l. Ports, fistulae and in-dwelling access devices (if applicable) m. Possible complications, including inhibitors and long term joint damage n. Approach to elective and emergency surgery o. Women's health issues p. Health promotion, including smoking cessation, health eating, weight management, exercise, alcohol use, sexual and reproductive health, and mental and emotional health and well-being q. Dental care r. Travel advice s. Vaccination advice t. National Haemophilia Database, its purpose and benefits u. Sources of further advice and information Information should be available covering: 1. Haemophilia A 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	However, reviewers heard that there was a high turnover of reception staff so the Centre needs to ensure that handover and induction are robust. In addition, reviewers noted that there were times when the reception was not covered; there is a need to ensure that someone is available during the agreed opening hours.
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.	N	Reviewers noted that there was insufficient space for the size of the service being provided. This was particularly notable in the waiting area, where adult and paediatric patients waited together in the same area. The fixed chairs also made it difficult for wheelchair and pushchair access. Reviewers noted that there was no 'break out' space for staff.
HP-195	**Transition to Adult Services and Preparation for Adult Life** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards f. Advice for young people going away from home to study, including: i. registering with a GP ii. how to access emergency and routine care iii. how to access support from their Comprehensive Care Centre iv. communication with their new GP	Y	
HP-198	**Carers' Needs** Carers should be offered information on: a. How to access an assessment of their own needs b. What to do in an emergency c. Services available to provide support	Y	
HP-199	**Involving Patients and Carers** The service should have: a. Mechanisms for receiving regular feedback from patients and carers about treatment and care they receive b. Mechanisms for involving patients and carers in decisions about the organisation of the service c. Examples of changes made as a result of feedback and involvement of patients and carers	Y	

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

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	Although there was no named geriatrician or palliative care contact name provided, reviewers were assured that mechanisms were in place to access these services when required.

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.	N	See comment for HP-194, and main report.
HP-499	**IT System** IT systems should be in use for: a. Storage, retrieval and transmission of patient information, including access to the latest vCJD status and family tree b. Patient administration, clinical records and outcome information c. Data to support service improvement, audit and revalidation d. Alerting the specialist team when patients attend the Emergency Department	Y	
HP-501	**Diagnosis Guidelines for Patients with Suspected Inherited and Acquired Bleeding Disorders** Guidelines on diagnosis should be in use covering at least a. Haemophilia A b. Haemophilia B c. Von Willebrand Disease d. Acquired haemophilia e. Inherited platelet disorders f. Other less common and rare bleeding disorders	Y	

Ref	Standard	Met?	Comments
HP-502	**Guidelines: Concentrate Use and Monitoring** Guidelines should be in use covering: a. Concentrate therapy: i. Initiation and monitoring of prophylaxis ii. Home therapy b. Use of extended half life products, including inhibitor testing and PK assessment c. Management of concentrate supplies including: i. Ordering ii. Storage iii. Stock control to ensure all stock is up to date and waste is minimised iv. Prescription and delivery for patients on home treatment v. Arrangements for emergency 'out of hours' supply vi. Recording issue to patients vii. Recording use by patients, including on Haemtrack viii. Submission of data via NHD for national tenders coordinated by CMU	Y	However, reviewers noted that the guidelines for out of hours arrangements, and responsibilities for stock control, needed more detail.
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	However, reviewers noted that more detail was required for dental care, and felt that the document was more of a narrative than a guideline.
HP-504	**Emergency Department Guidelines** Guidelines on management of patients with inherited and acquired bleeding disorders in the Emergency Department should be in use.	N	Reviewers saw documentary evidence for this standard. However, there were five documents in place, and there was a lack of clarity as to which was the final agreed document to which staff should adhere. The team subsequently confirmed that the guideline has been finalised and older versions removed.

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	Y	
HP-604	**Liaison with Other Services** Review meetings should be held at least annually with specialist services to consider liaison arrangements and address any problems identified.	N	Reviewers agreed with the Centre's self-assessment. These arrangements were not in place at the time of the review.
HP-701	**Data Collection** The following data should be collected: a. UK National Haemophilia Database data on all patients b. Data on concentrate use and bleeds, either through Haemtrack or an equivalent mechanism c. Data required to complete the UKHCDO National Haemophilia Dashboard or other national mechanisms	Y	
HP-702	**Audit** The services should have a rolling programme of audit covering at least: a. Clinical guidelines (QS HP-503) b. Emergency and out of hours care (QS HP-504) c. Initiation of prophylaxis in children d. Inhibitor surveillance and Immune Tolerance Induction (ITI) e. Clinical reviews including joint scores (QS HP-103 & 104) f. Concentrate use and wastage	N	Reviewers saw that some audits had been completed, but not those specified in the Quality Standard. In addition, there was no evidence of a rolling programme of audit.
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	Some documents reviewed by the team did not have robust document control.

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Network

Ref	Standard	Met?	Comments
HY-199	**Involving Patients and Carers** The network should have mechanisms for involving patients and their carers from all services in the work of the network.	N	Reviewers agreed with the Centre's self-assessment. This was not in place 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. This was not in place 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.	Y	
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. This was not in place 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	Y	
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.	N	Reviewers did not see any evidence relating to a programme of audit for the network.
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 did not see any evidence of a network policy relating to research activity.

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. This was not in place at the time of the review.

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Commissioning

Ref	Standard	Met?	Comments
HZ-601	**Commissioning of Services** Commissioners should have agreed the configuration of clinical networks including: a. Designated Comprehensive Care Centres and Haemophilia Centres and the relationships between them b. Whether the service cares for children, adults or both c. Referral pattern to each service, taking into account the type of patients who will be treated by each team	N	Reviewers did not see evidence of a written agreement that met the requirements of the Quality Standard.
HZ-701	**Clinical Quality Review Meetings** Commissioners should regularly review the quality of care provided by: a. Each service, including achievement of QS HP-701 b. Each network, including achievement of QS HY-701 and QS HY-798 c. Service and network achievement of relevant QSs	N	Reviewers agreed with the Centre's self-assessment. This was not in place at the time of the review.
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. This was not in place at the time of the review.

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