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

Manchester University NHS Foundation Trust

Visit Date: 22nd November 2019
Report Date: March 2020

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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 Manchester University NHS Foundation Trust which took place on the 22nd November 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:

- Manchester University NHS Foundation Trust
- NHS England Specialised Commissioning North 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 and for monitoring their implementation liaising, as appropriate, with other commissioners.

About the Quality Review Service

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

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

Acknowledgments

Quality Review Service would like to thank the staff of the Manchester Adults Comprehensive Care Centre for all 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.

Manchester Comprehensive Care Centre

The Manchester Comprehensive Care Haemophilia Centre (MCCC) was situated within the department of haematology at the Manchester Royal Infirmary (MRI). The MRI was situated on the Oxford Road Campus (ORC) of Manchester University NHS Foundation Trust (MFT). MFT consisted of eight other hospitals and is the largest Trust in the NHS.

Haemophilia services at the MRI were provided by the department of clinical haematology, which was part of the division of specialist inpatient medicine. The department provided a comprehensive secondary and regional tertiary referral service for haematological malignancy, stem cell transplantation and CAR-T therapy and thrombosis, haemostasis and haemoglobinopathies throughout the north west of England (excluding Merseyside), with a catchment area of about 4.6 million individuals. The department also provided general clinical haematology services for the local population of central Manchester.

MCCC provided a service to adults with inherited and acquired bleeding disorders within Greater Manchester and the wider north west region (Cheshire to Cumbria). Consultant-led specialist care was provided 24 hours a day, 7 days a week basis, as was access to specialist laboratory services. Over 2500 patients with heritable and acquired bleeding disorders were registered at Manchester CCC at the time of the visit, including 138 adult patients with severe haemophilia A or B. The centre managed patients with a very wide range of disorders, including a significant number of patients with rare bleeding disorders. The haemophilia service had close links with the Manchester paediatric CCC, located within the Royal Manchester Children's Hospital (also located on the ORC) and joint adult-paediatric MDT meetings and clinics were held on a regular basis.

Referrals for investigation and diagnosis of bleeding disorders were accepted from primary care and from secondary care organisations within the region. The team provided a full range of services to patients with heritable and acquired bleeding disorders, including open access to emergency care and specialist joint haematology clinics, including physiotherapy and orthopaedics; obstetrics and genitourinary medicine services. Links were also in place for referral within all specialist services at MFT, including an established pathway for referral to the Manchester Dental Hospital.

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

Condition	Number of patients	Number of patients who had an annual review in last year	Number of inpatient admissions in last year
Haemophilia A	Severe 110 Moderate 31 Mild 137	170	30
Haemophilia B	Severe 28 Moderate 16 Mild 24	43	7
Von Willebrand	Total 635 Type 3 27	268	35

Emergency Care

Within working hours (8.30am to 4.30pm Monday to Friday), all registered patients were encouraged to contact the Centre if they developed an acute medical problem related to their bleeding disorder. A contact telephone number was provided on their diagnosis card and in the Centre's information leaflet. Patients were triaged by the haemophilia nurse specialist and directed to the most appropriate service, according to their problem. Ambulant patients with acute musculoskeletal bleeds were requested to attend the Centre, where they were

assessed by the specialist trainee (with consultant supervision) and provided with appropriate treatment and follow-up advice. Patients with acute bleeds could be referred directly for physiotherapy assessment and treatment on the same day. More severe bleeds, or problems requiring urgent input from another specialty were directed to A&E, where they were managed according to a local A&E protocol. Patients who needed to attend an A&E department external to MRI were advised to inform their assessing team to contact the haemophilia team for advice. If attendance to an external A&E had been advised, the haematology specialist trainee would ring the department in advance to provide relevant information and advice.

Out of hours, patients were able to contact the on-call haematology specialist trainee for advice directly via the hospital switchboard. Consultant cover was provided 24/7 by all four haemostasis consultants on a rotational basis; this service did not require cross-cover from non-specialist haematology colleagues. Immediate advice was available to the haematology specialist registrar from the consultant on call.

Ward Care

Ward care was shared with malignant and other benign haematology.

Day Care

There were dedicated haemophilia facilities available with a joint haematology day unit.

Outpatient Care

Care was provided within a dedicated haematology outpatient area or shared area of the main MRI outpatients department.

Community Based Care

At the time of the review the Centre team was unable to provide home visits due to capacity.

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Review Findings

Achievements

This very well-established team, under long-serving leadership, was offering a good service for their patients. The contributions being made by some members, particularly the lead nurse, physiotherapists and social worker were outstanding.

Patient satisfaction was overwhelmingly positive, and there was great appreciation for the dedicated hard work which went into providing a good service. They felt very confident in the care they received and commented that the team were always approachable and made them 'feel at home'.

The Centre was a recognised training site of excellence, at national and international levels.

There was a very impressive research portfolio, with a dedicated research team supporting the clinical team, and over the last five years patients had been entered into 35 phase 1 to 3 clinical trials.

Good Practice

1. There was strong multidisciplinary team working, and meetings were held for the wider team including representatives from the laboratory and genetics service. There was a monthly joint MDT meeting with the children's service.
2. There had recently been a heightened focus on the transition process, with members of the adult and children's team taking part in an NHS improvement programme, and there was now a monthly transition clinic held at the adult centre, including members of the paediatric clinical team, for young people from the age of 14 upwards. The clinic was held on the same afternoon as the transition clinic for young people with haemoglobin disorders, so there was a comfortable age-appropriate waiting area. It was understood that the monthly clinic, an increase from the previous twice-yearly transfer clinic, was still in pilot form. The reviewers considered to be a priority that this should continue.
3. There was a nurse led telephone clinic, mostly for patients with milder bleeding disorders. Patients were seen in person every three years, and this prevented annual trips in person to the centre unless necessary.
4. Specialist haemostasis and thrombosis consultant cover was available out of hours, at all times.
5. Haematology midwives were supporting an excellent joint haematology and obstetric clinic. Women with complex pregnancies had open access to them for support and advice, and they provided a key interface with other hospitals in the region at which the women may have planned deliveries.
6. An arrangement had been made with the ambulance service so that all registered patients were brought to the Centre rather than their more local hospital, if they made a 999 call.
7. The electronic patient record system for local patients could be accessed remotely by consultants on call, and it was also possible to make investigation requests remotely.

Immediate Risks

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

Concerns

1. **Staffing**
    a. Nursing - There was substantial shortfall in the provision of specialist nursing staff for the size of this service. The pivotal role of the Band 7 lead nurse was evident, and the review team shared the host

team's concern about her plan to retire in around a year's time. In addition, the two Band 5 nurses were being trained up to undertake more specialist roles and it would be appropriate to assess whether the banding of all the nurses in respect to their expected duties was appropriate.

b. Data management - A data manager had been in post until a few months before the visit, but there had not been agreement to re-appoint. In the meantime, other members of the clinical team were picking up data entry duties; this was inappropriate, especially as they were already stretched to cover the clinical service. Some data submission was being undertaken by an administrative assistant outside the Centre, without the usual local ownership of data and regular checking and auditing by the core team.

c. Psychology - There was no psychologist working with the Centre team, and patients mentioned this as a gap in the service. A psychologist is expected to be part of the core team in caring for these conditions. Where there were high-level concerns, referrals were made through the patient's primary care team. However, the team were lacking in the support and guidance which a psychology member can bring to their practice, and it was inevitable that not all lower-level patient and family needs were being met.

d. Social work - A social worker worked within the team but only for 0.2 WTE (one day per week) which was insufficient for the numbers of patients and their complex social care needs. Other team members were, again, trying to offer this support, taking time away from their main clinical focus.

e. Physiotherapy - Three physiotherapists had a total of five sessions per week committed to the service, equivalent to one half-time post; this was a significant under-provision considering the size of this service. Because of the flexibility of the team, and their goodwill in working more than their contracted hours, they were managing to cover the essential parts of the service, but this was not sustainable.

2. **Audit**

There was very little evidence of audit of the practice, and no evidence of audit against the core standards including emergency care, inhibitor surveillance, and measurement of trough factor levels. Diagnostic and clinical guidelines were not in a form that would make it easy to carry out an audit against them, as they lacked specific measurables against which audit could be undertaken. There was no demonstration or confirmation that key aspects of care were in line with what was expected, or to highlight any areas requiring improvement.

3. **Fridge temperature alarms**

Three fridges held factor concentrate and other products; one held the stock for patients in research studies. Although there were local alarms which would be triggered if there were a temperature control failure, there was no system of communicating alerts to personnel who could act on them if no member of staff was in the storage area. Some products are temperature sensitive, and none can be refrigerated once they had been out of the recommended storage temperature range, so that an out-of-hours failure unnoticed for a prolonged period would result in the wastage of a large amount of stocks.

4. **ED Guideline**

The ED guideline should include an alert that patients on Emicizumab should not be given FEIBA if presenting with a bleed, due to the risk of thrombotic complications resulting from the two agents in combination

Further Consideration

1. Diagnostic and clinical guidelines were not in a form which would be useful in practice, lacking operational detail and guidance for local application within this Centre. Some guidelines, for example one for concentrate use and monitoring were not seen, and in a guideline on the management of joint bleeds had no reference to conditions other than haemophilia A and B, although there were many patients with severe von Willebrand Disease and other rarer bleeding conditions managed at the Centre.

2. There was no Emergency Department (ED) guideline. There was a flow chart, covering patients with haemophilia A and B and von Willebrand Disease, but it had no reference to the other bleeding disorders and it did not indicate that patients should not be given intramuscular injections or non-steroidal anti-inflammatory drugs.

3. There was no proforma or outline plan of care for patients' formal reviews, which meant that the content of these discussions could vary between clinicians. Putting in place a proforma, to ensure inclusion of all necessary elements of the review, against which a letter for the GP and patient could be dictated, would ensure consistency. The inclusion of the necessary information, such as what dose of factor replacement the patient used, the frequency of prophylaxis, and Haemtrack records of how many bleeds they had had since their last review would also be useful.

4. An operational policy was in place; it included no mention of home visits and the review team were told that none of the Centre's patients currently needed home visits. However, even if this were the case at the time of the review, once patients become older and acquire co-morbidities some will find visiting the Centre difficult and will benefit from home visits, and this would usefully be included in the operational policy. Also, the policy indicated that new patients should be discharged if they did not attend for their first appointment, which was at variance with the Trust policy indicating that they would not be discharged until they had not attended for a second new patient appointment.

5. The team reported that discussions about potential or obligate female relatives of patients, who should be recalled for testing and counselling before they reached reproductive age, was a regular part of clinic discussions; however no robust, fail safe system for identifying and recalling these young women was in place. A joint policy between the adult and paediatric comprehensive care centres would be useful to ensure that all identifiable young women carriers were tested or counselled before they became pregnant.

6. There was plentiful patient condition-specific information, but this material was not visible in all the clinical areas used by the patients as well as on Trust patient information websites. An otherwise helpful local service information leaflet did not mention how to apply for benefits, to receive immigration advice, to request interpreter services or to offer feedback about the service.

7. The facilities from which the services were offered were of a high standard, but were somewhat dispersed, with the outpatient and physiotherapy areas on the ground floor of the building, and the nurses' office and treatment room on the second floor. Signage to the haemophilia treatment centre areas was poor.

8. Patients reported that the waiting time to be seen in clinics could be very long. It may be valuable to undertake a timeline or pathway audit, to identify where blocks and delays are mostly occurring, to see if there were any remediable elements that could be improved.

9. Document control was not good, with many guidelines and policies lacking details of authorship, date of approval, or date for review. Some Trust policies seen were also beyond their review date.

10. It will be necessary to consider what additional senior medical time may be required to help interpret and assess the significance of the results reported from the newly centralised genomics laboratory service.

11. Given that patients attending the Centre come from a large geographical area, the team might consider providing some outreach clinics at the larger linked District General Hospitals (DGHs). This would be beneficial in providing educational opportunities for the local clinical staff, as well as helping patients and

families by reducing their travelling times for clinic reviews. It is acknowledged that a review of MDT job plans would be necessary before planning any additional clinical activity.

12. With a large number of working patients, out-of-hours clinic appointments are known to be greatly valued and the team might consider if it would be possible for them to offer an evening clinic service.

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General Comment

This Comprehensive Care Centre (CCC) had no linked haemophilia centres and had self-assessed the network standards (HY-199-798) as not applicable.

However, as in other regions where there is a CCC without linked HC's, the Centre was caring for patients from a wide geographical area that included several DGHs to which the patients might present for urgent care for any reason, and this constituted an informal clinical network. The specialists at the CCC offered a 24/7 clinical advice service for occasions on which patients attended their local DGH. All patients, wherever they lived, were included in patient feedback exercises, and offered entry into research studies. However, there were no specific named link haematologists, and reviewers heard that at least one of the DGH's there was currently no substantive haematologist in post. Moves towards identifying such link colleagues, with whom to share guidelines, offer educational opportunities, and share review and learning sessions may be useful in strengthening joint working to the benefit of patients having any treatment locally. In the meantime, clinical correspondence for patients living outside of Manchester could usefully be copied to the local haematology departments.

It was understood that some meetings were planned, together with the local specialist commissioners, between the Royal Manchester Children's Hospital CCC leads and their colleagues at the Alder Hey Children's Hospital NHS Foundation Trust in Liverpool, which was the CCC for Merseyside and parts of Cheshire, Lancashire, Shropshire, North Wales and the Isle of Man. However, it appeared that similar discussions had not been planned for the adult services. Engagement of the local specialist commissioning team had previously been strong, but it was said to have lapsed substantially over recent years and the adult CCC team leads no longer had any meetings or dialogue with them. If any progress is to be made with future plans for a network, and review of the work of the two CCCs, it will be necessary for the specialist commissioners to re-engage in discussions with the clinical teams.

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APPENDIX 1 Membership of Visiting Team

Visiting Team		
Beverley Barnett	Senior Biomedical Scientist	Hull University Teaching Hospitals NHS Trust
Dr Gary Benson	Haemophilia Centre Director	Belfast Health and Social Care Trust
Nancy Brodie	Operational Manager, Haemophilia and Thrombosis Centre	NHS Greater Glasgow and Clyde
Thuvia Flannery	Physiotherapist	Leeds Teaching Hospitals NHS Trust
Cathy Harrison	Haemophilia and Thrombosis Advanced Nurse Practitioner	Sheffield Teaching Hospitals NHS Foundation Trust
Clive Smith	Patient representative	Chair, Haemophilia Society

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

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APPENDIX 2 Compliance with the Quality Standards

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

Table 1 - Percentage of Quality Standards met

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

Service	Number of applicable QS	Number of QS met	% met
Comprehensive Care Centre	37	25	68
Network	8	3	38
Commissioning	3	0	0
Total	**48**	**28**	**58**

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Comprehensive Care Centre

Ref	Standard	Met?	Comments
HP-101	**Service Information** Written information should be offered to patients and, where appropriate, their carers covering at least: a. Brief description of the service b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the service e. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent) v. Give feedback on the service, including how to make a complaint vi. Get involved in improving services (QS HP-199)	Y	However, reviewers did not see any evidence for 'h' (ii) or (iii).

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.	N	Clinical letters did not contain all the elements of this Standard and there was no plan of care template in place.
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	N	Although transition practice had significantly improved there was no evidence provided about the information given to patients and their families.
HP-198	**Carers' Needs** Carers should be offered information on: a. How to access an assessment of their own needs b. What to do in an emergency c. Services available to provide support	N	Reviewers did not see any evidence of support for carers to assess their own needs.
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	N	

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 the Concerns section of 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.	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.	N	See the Concerns section of main report.
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.	N	
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	However, there was no ED or email alert in place.
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	However, this was factual rather than practical and operational in detail.

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

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	N	Although transition practice was good, there was no guideline in place. See the Concerns section of main report.
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	However, there was nothing included in relation to home visits.
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 that these meetings were not in place.
HP-701	**Data Collection** The following data should be collected: a. UK National Haemophilia Database data on all patients b. Data on concentrate use and bleeds, either through Haemtrack or an equivalent mechanism c. Data required to complete the UKHCDO National Haemophilia Dashboard or other national mechanisms	Y	
HP-702	**Audit** The services should have a rolling programme of audit covering at least: a. Clinical guidelines (QS HP-503) b. Emergency and out of hours care (QS HP-504) c. Initiation of prophylaxis in children d. Inhibitor surveillance and Immune Tolerance Induction (ITI) e. Clinical reviews including joint scores (QS HP-103 & 104) f. Concentrate use and wastage	N	See the Concerns section of main report.
HP-706	**Research** The service should actively participate in research relating to the care of patients with bleeding disorders.	Y	See the Achievements section of main report.

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	Reviewers noted that some of the Trust policies were out of date.

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Network

Ref	Standard	Met?	Comments
HY-199	**Involving Patients and Carers** The network should have mechanisms for involving patients and their carers from all services in the work of the network.	Y	
HY-203	**Inherited and Acquired Bleeding Disorders Network Leads** The network should have a nominated: a. Lead consultant and deputy b. Lead specialist nurse c. Lead physiotherapist d. Lead clinical or counselling psychologist e. Lead manager	N	See General Comment in main report
HY-204	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HP-203.	N	See General Comment in main report.
HY-503	**Guidelines** Network guidelines should have been agreed covering: a. Diagnosis for patients with suspected inherited and acquired bleeding disorders (QS HP-501) b. Concentrate use and monitoring (QS HP-502) c. Clinical guidelines (QS HP-503) d. Management of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) e. Care of patients requiring surgery (QS HP-505) f. Transition and preparing for adult life (QS HP-595)	N	See General Comment in main report.
HY-701	**Ongoing Monitoring** The network should monitor on a regular basis: a. Submission of data on all patients to the UK National Haemophilia Database (QS HP-701) b. Network-wide data on concentrate use and bleeds	Y	See General Comment in main report.
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.	N	See General Comment in main report.
HY-703	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with inherited and acquired bleeding disorders b. A list of research trials available to all patients within the network.	Y	

Ref	Standard	Met?	Comments
HY-798	**Network Review and Learning** Representatives of Comprehensive Care Centres and referring Haemophilia Centres should meet at least once a year to: a. Identify any changes needed to network-wide policies, procedures and guidelines b. Review results of audits undertaken and agree action plans c. Review and agree learning from positive feedback, complaints, critical incidents and 'near misses', including those involving liaison between teams d. Share good practice and potential service improvements	N	See General Comment in main report.

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Commissioning

Ref	Standard	Met?	Comments
HZ-601	**Commissioning of Services** Commissioners should have agreed the configuration of clinical networks including: a. Designated Comprehensive Care Centres and Haemophilia Centres and the relationships between them b. Whether the service cares for children, adults or both c. Referral pattern to each service, taking into account the type of patients who will be treated by each team	N	Reviewers agreed with the Centres self-assessment.
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 were no specific haemophilia monitoring meetings 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 were no bespoke commissioner meetings with the haemophilia service.

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