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

University Hospitals Birmingham NHS Foundation Trust

Visit Date: 2nd July 2019

Report Date: October 2019

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Contents

Introduction

This report presents the findings of the peer review of services for people with Inherited and Acquired Haemophilia and other Bleeding Disorders at University Hospitals Birmingham NHS Foundation Trust, which took place on 2nd July 2019.

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

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

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

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

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

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

- University Hospitals Birmingham NHS Foundation Trust
- NHS England Specialised Commissioning West Midlands

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

About the Quality Review Service

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

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

Acknowledgments

Quality Review Service would like to thank the staff of the Haemophilia Centre at the Queen Elizabeth Hospital Birmingham 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.

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Queen Elizabeth Hospital, Birmingham

The Haemophilia Centre was located at the Queen Elizabeth Hospital Birmingham (QEHB). It was the regional Comprehensive Care Centre for patients over the age of 16 years. It covered the geographical area of Herefordshire, Worcestershire, Warwickshire, Shropshire, the West Midlands and most of Staffordshire. Referrals were accepted from primary and secondary care, and from outside the region when appropriate. Bleeding disorders clinics ran once a week on a Tuesday morning. An outreach clinic was also run at New Cross Hospital, Wolverhampton (and the frequency of these clinics had recently been increased to quarterly).

The Haemophilia Centre was located adjacent to the Cancer Centre at QEHB. It comprised a waiting area, two offices, two consulting rooms, two treatment rooms, a fridge and storage room and a counselling room (which was, at the time of the review, in the process of being converted into another office). The Centre was open from 8.30am to 4.30pm.

Patients requiring physiotherapy were seen either in the Haemophilia Centre (for acute bleeds) or in the main physiotherapy department (for rehabilitation); the physiotherapy department was located in the new hospital building.

There was a dedicated dental service for bleeding disorders patients. This provided routine dental check-ups as well as invasive dental procedures.

The specialist coagulation laboratory was co-located with other haematology laboratory services in the new hospital building. For assays not offered on site, referral arrangements were in place to send samples to Birmingham Children's Hospital or the Royal Hallamshire Hospital in Sheffield.

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 the last year	Number of in-patient admissions in the last year
Haemophilia A	Mild = 100 Moderate = 47 Severe = 88	Severe patients and moderate patients on prophylaxis were seen 6 monthly. All others were seen 12 monthly.	Mild = 4 Moderate = 2 Severe = 4
Haemophilia B	Mild = 17 Moderate = 13 Severe = 12	Severe patients and moderate patients on prophylaxis were seen 6 monthly. All others were seen 12 monthly.	Mild = 1 Moderate = 0 Severe = 3
Von Willebrand	350		4
Other	409		2

Emergency Care

During working hours, patients were advised to call the Centre if they had a bleed. The Clinical Nurse Specialists (CNSs) then triaged the call, liaised with the medical staff and advised on treatment. When it was deemed necessary to see a patient, the patient was seen either in the Haemophilia Centre or in the Emergency Department (ED), depending on the severity of their condition. Out of hours, patients were advised to speak to the on-call haematology registrar who would arrange a review in the Acute Oncology Assessment Unit or the ED, as appropriate. If admission was required, patients were admitted either under the haemophilia team to Ward 625 (with 622 and 623 as alternatives), or under the specialty and to a ward appropriate for the presenting complaint. The haemophilia team still reviewed these latter patients on a daily basis.

Ward Care

If an admission was related solely to a bleeding disorder, patients were usually admitted to Ward 625. If there was no capacity, they were admitted to Ward 622 (which also hosted the Acute Oncology Assessment Unit) or Ward 623 (Oncology). All staff on these wards had received training in the care of bleeding disorders patients from the haemophilia CNSs. Patients were seen daily by the haematology registrar and three times a week (or more often if required) by the haemophilia consultant who was on call for the week. The CNSs liaised with the wards on a daily basis and attended as required. Patients admitted under medical or surgical teams were reviewed with the same frequency. Patients undergoing elective surgery in the Royal Orthopaedic Hospital were reviewed daily or every other day by one of the haemophilia consultants or CNSs.

Day Care

The majority of care was provided in the Haemophilia Centre. Patients requiring blood products, iron infusions and Rituximab were treated in the Haematology Day Unit. This facility was open from 8.30am to 6pm Monday-Friday and was shared with the rest of the clinical haematology department.

Outpatient Care

Bleeding disorder clinics were run in the Haemophilia Centre. They took place weekly on Tuesday mornings. The Centre director ran an additional ad- hoc clinic on Thursday mornings, when required. Outreach clinics were run every three months on a Wednesday afternoon at New Cross Hospital, Wolverhampton in the haematology / oncology outpatient centre.

Community-based Care

There was a 0.6 wte CNS in post whose role was to visit patients in the community.

(Note: see the Concerns section of the report regarding the ability of the team to provide this service at the time of the visit).

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Review Findings

Achievements

This team, under relatively new leadership, was working very hard and effectively to update practice. Despite being significantly under-resourced in most staff groups (see Concern below), they were providing a very good clinical service for a large number of patients and their families. All team members had a clear vision of what they could do if they had more time to work on service developments and improvements. The staff worked well with other hospital teams, and they were seen to have a respectful rapport with these teams.

Patient feedback was extremely positive, and patients felt that they received great personalised care. They had noted marked improvements over the last two years, with the service becoming more attuned and proactive to their needs. They valued the opportunities they were being offered for involvement in research studies.

There was an extensive research portfolio, with impressive recruitment numbers, supported by an enthusiastic research nurse, and there were plans to expand the team and research activity further.

Good Practice

1 Patient information was comprehensive, with an outstanding small laminated guide on 'caring for patients with a bleeding disorder', and good advice about dental care. Some of the patient information was marked by 'traffic lights' for clarity and ease of understanding. A guideline for patients self-treating at home, with a detailed competency assessment section, was excellent.

2 Information for healthcare professionals was also strong, with a notable 'haemophilia nursing tool' workbook. The guideline for patients undergoing surgery or other interventional procedures was also clear and thorough.

3 IT systems for medical records were complex, but there was a facility for remote access and input for clinical staff working on call out of hours.

4 There were excellent gym facilities, and patients were offered the opportunity to take part in several suitable classes held there.

5 The team received an e-mail alert if any of their patients had attended the ED for any purpose, so that they could provide appropriate follow up.

6 The Ambulance service held a list of all patients registered at the Centre, with instructions to bring them to QEHB for all but possibly time-critical injuries for which they needed to be taken to a more local ED.

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

Serious Concern

1. **Staffing**

The UKHCDO Quality Standards identify that '*sufficient staff with appropriate competences should be available for outpatient, day care, inpatient care and for supporting urgent care. Staffing levels should be appropriate to the number of patients cared for by the service and its role in the network'*. As has been previously highlighted in this report, the staff in post in the Birmingham CCC team were working extremely hard to provide a highly patient-focussed service, often going above and beyond what could reasonably be expected of them. Indeed, many examples of innovative good practice were being

delivered by this team. In addition, the team were providing support to other local hospitals in the network.

However, reviewers noted that all staff groups were substantially under-staffed for a service of this size, and some key professionals were not provided at all. Patients expressed their concerns directly about the number of nurses available to manage the large caseload, insufficient physiotherapy support, and the absence of a psychologist or social worker on the team. Reviewers were very concerned about the impact that this significant under-provision of staffing was having upon patient care and upon staff in the existing team.

a. **Nursing**

The nursing staff shortage was exacerbated at the time of the visit by the absence on long-term sickness of one of its members, but even when that nurse was working the provision was still insufficient for a centre of this size. There were just two specialist nurses in post, with 1.6 wte between them; an additional Band 6 nurse had been appointed, but a start date was yet to be confirmed. As a result, the nurses were working many additional hours over those contracted, to an extent that would not be sustainable. The problem was compounded by under-provision of other professionals in the team. Nursing (and medical) staff were sometimes working outside their scope (for example, they were counselling patients in distress), and while they were making appropriate onward referrals to outside mental health services this was placing a heavy personal demand on them. The nurse whose main remit it was to work with patients in the community had not been able to do home visits for a long time because of the work demands within the Centre. A nurse was not able to accompany the consultant in the quarterly outreach clinics at New Cross Hospital, Wolverhampton, although these are expected to be multi-disciplinary clinics. There was an impact on transition practice for young people moving over from the paediatric hospital, as nurses were not able to go across to meet the young people and families before transfer. One of the nurses had an interest in developing a family tree system to ensure any potentially affected or carrier relatives were tested but had not been able to progress this because of other work pressures.

b. **Psychology**

There was no psychologist working with the team. This is an expected core team member for patients with these long-term conditions. As a result, the team was not able to provide the required multi-disciplinary approach to care. Other team members were offering counselling and support, without supervision, and, as a consequence, the needs of some patients were not being met.

c. **Physiotherapy**

At the time of the visit, a Band 7 physiotherapist was contracted to the service for only four hours per week. There was a plan to expand this back to the former provision of approximately seventeen hours per week. However, it was judged that this would still fall short of the requirement, given the patient numbers. Within this time allocation, the physiotherapist was able to offer an acute-only service and was not able to undertake the expected routine joint scoring or work with patients towards long-term joint health. The physiotherapist's interest and expertise in pain management could not be used within these hours, and patients particularly commented that they needed more help with joint pain.

In addition, there were no clinical guidelines for the management of synovitis and target joints, or long-term joint health. It was understood that within the current physiotherapy provision it was not possible to undertake this work; however, establishing a guideline outlining expected levels of care would allow for an audit of compliance, highlighting the gap in the service. This may be powerful in supporting the case for increased specialist physiotherapy hours.

d. **Social worker**

Following the retirement of a dedicated social worker over a year before, it had not been possible to get agreement to re-appoint to the post. Nurses were trying to undertake some of the duties that a social worker would usually undertake, in their already stretched working time, but patients were not getting the support they needed particularly in relation to applications for benefits.

e. **Data management**

A data manager was in post, working approximately two days per week on this service and supporting the busy stem cell transplant practice. She was not always able to keep up with data requirements and, as a consequence, nurses were undertaking some of these tasks, such as registering patients on both the local database and the National Haemophilia Database.

f. **Administrative and clerical staff**

A long-serving secretary was a key team member, but within a 30 hour per week contract was supporting all three consultants, working on the Haemophilia Centre reception desk and also taking patient calls. There were no issues about her ability to undertake this work, as she escalated any concerns immediately to one of the clinical staff. However, her workload was heavy.

g. **Medical staff**

Although there were three consultants in post, they were also managing the broader haemostasis and thrombosis work, which was substantial in this large tertiary hospital. They were also undertaking some general haematology clinics, which left very little time for the service developments they hoped to progress. If the network is to develop as expected, it will not be possible for the Centre director to manage the demands of being the lead for services across the large geographical area within his current job plan.

Further Consideration

1 Space in the Centre was not adequate for the staff currently working there. At the time of the visit two consultants were seeing up to twenty-four patients in the haemophilia clinic. When the specialist haemophilia clinic was run on a Tuesday morning there was insufficient space for patients to wait, and they over-spilled into an oncology waiting area. When there was no available room for the physiotherapist to see patients in the Centre, they had to go instead to the physiotherapy department, which was a long distance across the large hospital site. A review of the consultants' job plans may be useful to see if the clinic could be split into separate sessions.

2 Patients who suffered an acute bleed at home attended the Centre and could be given a first dose of factor concentrate. However, for further doses and for any other medication such as tranexamic acid, analgesia and further supplies of concentrates, they had to go to the main hospital pharmacy, which was a considerable distance across the site, therefore creating an obvious problem when there was acute joint injury. Nurses sometimes took time to go to the pharmacy to collect products, or a porter was occasionally called. However, there was a smaller pharmacy very close to the Centre, which was currently dispensing only for in-patients. It might be possible to agree that this nearby pharmacy could hold stock of, and dispense, the items frequently needed for these patients.

3 A copy of the ED pathway was not visibly displayed in the department, and a couple of staff who spoke briefly to the team did not appear to be familiar with it, although patient feedback stated that their experience of attending the ED was positive.

4 There was no 'alert' immediately visible on the electronic record that a patient had a bleeding disorder.

5 Patients undergoing elective orthopaedic surgery were managed at the Royal Orthopaedic Hospital, approximately two miles from the QEHB. Blood samples were brought to the laboratory at the QEHB but there were apparently some delays in obtaining pre- and post-operative factor level assay results to guide replacement. An urgent courier service might help address this.

6 There was no robust system in place to ensure potential or obligate carrier women were tested and counselled before starting a family. Systems are available that generate a worklist to help ensure this happens in a timely way.

7 Out of hours arrangements for the laboratory to undertake less commonly requested specialist tests could usefully be formalised.

8 The monthly departmental quality meeting was entitled 'Haematology–Oncology and Stem Cell Transplant Quality Meeting', although this was apparently the meeting at which any incidents or complaints concerning the haemophilia service were discussed. The team might consider establishing a separate, shorter and more focussed review and learning meeting to consider issues relevant to the Centre.

9 The team had not been optimally supported by clinical and non-clinical managers; for example, the team had repeatedly highlighted their significant staffing deficiencies without success. However, they reported recent improvement in engagement, and it is hoped that this will lead to some necessary progress.

10 Document control was inconsistent, with some policies and guidelines lacking note of authorship, approval or planned review dates.

General Comments

The clinical network, in principle covering Herefordshire, Worcestershire, Warwickshire, Shropshire, the West Midlands and most of Staffordshire, was not well established. Outreach clinics took place only at New Cross Hospital, Wolverhampton, although these had recently been increased from two to four per year. There was no clarity about numbers of patients living across much of the area, with their diagnoses / severity, and it was not possible for the Centre team to take responsibility for the quality of care they received, with inequities likely to result. Expected elements of network functioning, such as shared clinical guidelines, audits, review and learning meetings, were not in place. A useful educational meeting targeting nurses and other health care professionals had been held in December 2018, and it was hoped that this could become a regular event. There had also been progress towards making the network board – which had previously been attended only by doctors and commissioners – multi-professional, and at the time of the review there was good nursing representation. However, the network meetings continued to focus mainly on concentrate usage and some business matters such as staffing.

The team at the Centre were keen to offer outreach clinics at other hospitals across the region, and to work on establishing a robust patient dataset, therefore progressing the other aspects of network functioning, if adequately resourced. However, there was no clarity about what commissioners were expecting from them in this regard, nor had it been made explicit what the current funding allocation was intended to cover. Discussions between the Centre team, Trust managers and commissioners will be necessary to work towards a network that assures the quality of care for all its patients, and to identify what additional support would be necessary to allow for this improvement.

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APPENDIX 1 Membership of Visiting Team

Visiting Team		
Sarah Bowman	Haemophilia Social Worker	Sheffield Teaching Hospitals NHS Foundation Trust
Dr Keith Gomez	Consultant Haematologist	Royal Free London NHS Foundation Trust
Caryl Lockley	Haemophilia Nurse	Sheffield Teaching Hospitals NHS Foundation Trust
Lara Oyesiku	Haemophilia, Haemostasis and Thrombosis Network Clinical Nurse Manager	Hampshire Hospitals NHS Foundation Trust
Eileen Ross	Patient representative	
Ann Thomas	Senior Physiotherapist	University Hospitals Bristol NHS Foundation Trust

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	37	28	76
Network	8	0	0
Commissioning	3	0	0
Total	48	28	58

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Haemophilia Comprehensive Care Centre

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

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	There was a plan available on the portal, but it did not include all the elements outlined in the standard. However, a number of those elements were included in the clinical letter.
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	However, input to these records from the wider MDT was limited.
HP-105	**Contact for Queries and Advice** Each patient and, where appropriate, their carer should have a contact point within the service for queries and advice. A clear system for triage of urgent clinical problems should be in place. If advice and support is not immediately available for non-urgent enquiries, then the timescales for a response should be clear. Response times should be no longer than the end of the next working day. All contacts for advice and a sample of actual response time should be documented.	Y	
HP-106	**Haemtrack (Patients on Home Therapy)** All patients on home treatment should be encouraged to use electronic recording of their treatment through Haemtrack.	Y	

Ref	Standard	Met?	Comments
HP-194	**Environment** The environment and facilities in out-patient clinics, wards and day units should be appropriate for the number of patients with inherited and acquired bleeding disorders and accessible by people with severe mobility problems. Services for children and young people should be provided in a child-friendly environment, including toys and books / magazines for children and young people of all ages.	Y	However, on a Tuesday morning during clinic, space was limited and patients were often asked to wait in the main oncology waiting area.
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	Reviewers could not see anything for (f) – young people going away to university.
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	Reviewers saw that nursing staff and physiotherapy time was limited. There was no psychology or social worker input and there was limited data manager time. See the 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.	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 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	A copy of the ED pathway was not visible in the ED, and some ED staff who spoke to reviewers were unaware of it. However, there was lots of evidence that the team had made great efforts to train ED staff, and patient feedback of their ED experience was positive. See the Good Practice section of the main report regarding links with the ambulance service to identify patients with bleeding disorders.

Ref	Standard	Met?	Comments
HP-303	**Laboratory Service** a. A UKAS / CPA accredited laboratory service with satisfactory External Quality Assurance performance should be available 24/7 b. A laboratory representative (senior biomedical scientist or clinical scientist) should attend inherited and acquired bleeding disorder service multi-disciplinary team meetings (QS HP-602) regularly c. The following tests should be available: i. All coagulation factor assays (24/7) ii. Inhibitor screening iii. FVIII inhibitor quantification iv. VWF antigen v. VWF activity vi. Platelet function testing d. Molecular Genetic Laboratory service for: i. detection of causative mutations in patients with inherited bleeding disorders ii. carrier detection	Y	However, there was a need to formalise out of hours arrangements for less commonly requested specialist tests.
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	However, see the Further Consideration section of the main report regarding the lack of access to a robust pain management service.

Ref	Standard	Met?	Comments
HP-402	**Facilities and Equipment** Facilities and equipment appropriate for the service provided should be available including: a. Fridges b. Storage c. Clinical rooms for staff of all disciplines to see patients and carers d. Room for multi-disciplinary discussion e. Room for educational work with patients and carers f. Office space for staff g. Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all clinical areas All equipment should be appropriately checked and maintained.	Y	However, reviewers noted that there was no capacity to expand once new members of the team commence in post.
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	See the Good Practice section of the main report regarding the home therapy competency form.
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	N	Reviewers could not see any evidence for (h) or (i).
HP-504	**Emergency Department Guidelines** Guidelines on management of patients with inherited and acquired bleeding disorders in the Emergency Department should be in use.	Y	

Ref	Standard	Met?	Comments
HP-505	**Guidelines on Care of Patients requiring Surgery** Guidelines on the care of patients with inherited and acquired bleeding disorders who require surgery should be in use covering at least: a. Involvement of surgical and inherited and acquired bleeding disorders service in agreement of a written plan of care prior to, during and post-surgery b. Communication of the agreed plan of care to all staff involved in the patient's care prior to, during and post-surgery c. Documentation of care provided d. Arrangements for escalation in the event of unexpected problems	Y	
HP-595	**Guidelines on Transition and Preparing for Adult Life** Guidelines on transition of young people from paediatric to adult services should be in use covering at least: a. Taking responsibility for their own care b. Involvement of the young person and, where appropriate, their carer in planning the transfer of care c. Joint meeting between paediatric and adult services in order to plan the transfer d. Allocation of a named coordinator for the transfer of care e. A preparation period prior to transfer f. Arrangements for monitoring during the time immediately after transfer g. Advice for young people going away from home to study, including: i. registering with a GP ii. how to access emergency and routine care iii. how to access support from their Comprehensive Care Centre iv. communication with the young person's new GP	N	Reviewers agreed with the Centre's self-assessment.
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	N	MDT clinics were taking place. However, they were not always attended by all members of the MDT due to staffing constraints (see HP-202).

Ref	Standard	Met?	Comments
HP-603	**Multi-Disciplinary Clinics** The following multi-disciplinary clinic arrangements for patients with inherited and acquired bleeding disorders should be in place: a. Involvement of medical, specialist nursing and physiotherapy staff in clinics b. Availability of social work and psychology staff in clinics c. Combined clinics or other arrangements for multi-disciplinary discussion with: i. orthopaedics ii. rheumatology iii. obstetrics and gynaecology iv. paediatrics v. dental vi. HIV / hepatology	N	Reviewers agreed with the Centre's self-assessment.
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.	Y	
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	Although there was some audit activity taking place, it did not cover all the requirements of this standard and there was no overarching forward audit plan in place.
HP-706	**Research** The service should actively participate in research relating to the care of patients with bleeding disorders.	Y	This was supported by an enthusiastic research nurse.

Ref	Standard	Met?	Comments
HP-798	**Multi-disciplinary Review and Learning** The service should have multi-disciplinary arrangements for review of and implementing learning from: a. Positive feedback, complaints, outcomes, incidents and 'near misses' b. Morbidity and mortality c. Haemophilia Dashboard d. Review of UKHCDO Annual Report benchmarking information on concentrate use e. Ongoing reviews of service quality, safety and efficiency f. Published scientific research and guidance	N	See Further Consideration section of main report regarding the potential for establishing a local clinical governance meeting.
HP-799	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	Policies followed Trust policy. However, good document control was not in evidence for other local documentation including clinical guidelines and SOPs.

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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 that this was not in place.
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 that there was a lead clinician and nurse but no nominated lead for other areas.
HY-204	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HP-203.	N	Reviewers agreed with the Centre's self-assessment that this was not in place.
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 that, although there were plans in place to harmonise guidelines, this had not been done at the time of the review.
HY-701	**Ongoing Monitoring** The network should monitor on a regular basis: a. Submission of data on all patients to the UK National Haemophilia Database (QS HP-701) b. Network-wide data on concentrate use and bleeds	N	Reviewers agreed with the Centre's self-assessment that, although discussions relating to data submission to the NHS (covering the lack of staff to make the submissions, new data initiatives, etc.) took place, they did not review the data submitted in any detail.
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.	N	Reviewers agreed with the Centre's self-assessment that this was not in place.

Ref	Standard	Met?	Comments
HY-703	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with inherited and acquired bleeding disorders b. A list of research trials available to all patients within the network.	N	Reviewers agreed with the Centre's self-assessment that there was no written policy in place, although network members were updated on trials that were open.
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	Although there were plans in place to start this it 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 clear and up to date commissioning agreement as outlined in the requirements of this 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	Although reviewers saw that regular meetings with commissioners did take place, they did not discuss the issues outlined in QS HP-701 or HY-798.
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	Although reviewers saw that regular meetings with commissioners did take place, they did not discuss reviews and learning.

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