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

Bradford Teaching Hospitals NHS Foundation Trust

Visit Date: 22nd January 2020

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 Bradford Teaching Hospitals NHS Foundation Trust that took place on the 22nd January 2020.

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:

- Bradford Teaching Hospitals NHS Foundation Trust
- NHS England & NHS Improvement (North)

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 at the Bradford Haemophilia Centre for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. We are grateful too to the patients and parents 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.

Bradford Teaching Hospitals Haemophilia Centre

Bradford Haemophilia Centre was a large haemophilia centre that formed part of the North and West Yorkshire Haemophilia Network (NWYHN) with the Leeds CCC as its hub. At the time of the review it had 1,045 registered patients. The Centre provided care for adult and paediatric patients. The Centre had a significant number of patients with rare bleeding disorders making up over half of the 86 patients with severe bleeding disorders. These disorders included FXIII deficiency, Bernard-Soulier Syndrome, Glanzmann's Thrombasthenia and severe von Willebrand.

The team were actively involved in the North and West Yorkshire Haemophilia Network (NWYHN) which was centred at the Leeds Comprehensive Care Centre (CCC) and care was delivered as part of the NWYHN which included a combined Multi-disciplinary Team, centralised specialist diagnostic service, a 24/7 on-call haemophilia consultant, clinical guidelines, network meetings and a patient support group. The centre director took part in the out of hours rota with the CCC consultants, there were weekly shared MDT telephone meetings, and the nurses felt well supported by their colleagues in the CCC.

At the time of the review, the paediatric haemophilia service cared for 188 patients, of whom 29 were categorised as severe. The adult haemophilia service cared for 527 patients of whom 57 were categorised as severe.

Bradford Haemophilia Centre was a tertiary centre for Airedale, Calderdale and Huddersfield with a population base of around 1 million. Some patients had chosen to have their care in Leeds because of transport facilities and place of work. All bleeding disorders, including acquired haemophilia and obstetrics, were treated at the hospital.

Condition		Number of patients	Number of patients who had an annual review in the last year	Number of inpatient admissions in the last year
Haemophilia A	Adults	Total – 67 Severe – 14 Moderate – 11 Mild - 42	*The Centre was not able to provide this information*	
	Children	Total - 21 Severe – 8 Moderate - 4 Mild - 9	*The Centre was not able to provide this information*	
Haemophilia B	Adults	Total – 6 Severe – 0 Moderate – 3 Mild – 3	*The Centre was not able to provide this information*	
	Children	Total - 3 Severe – 1 Moderate – 2 Mild - 0	*The Centre was not able to provide this information*	
Von Willebrand	Adults	Total - 259 Severe – 19 Moderate – 23 Mild - 170	*The Centre was not able to provide this information*	

Condition		Number of patients	Number of patients who had an annual review in the last year	Number of inpatient admissions in the last year
	Children	Total – 81 Severs – 10 Moderate – 10 Mild - 46 Unknown - 15	*The Centre was not able to provide this information*	
Other	Adults	Total – 195 Severe - 24	*The Centre was not able to provide this information*	
	Children	Total - 83 Severe - 10	*The Centre was not able to provide this information*	

Emergency Care

Adults

On normal working days, all adult patients with known bleeding disorders had direct access to Ward 16 (haematology day unit) at Bradford Royal Infirmary (BRI) between 9am and 5pm. Out of hours direct access for advice was via Ward 33 (haematology) where the call was triaged by a haematology SpR or consultant. The out-of-hours acute care pathway was followed with the options of being assessed in the treatment room for minor bleeds being directed to the Emergency Department (ED) for major bleeds or attending the day unit the following day. Ward 33 operated at near 100% bed occupancy, and direct admission to the ward out of hours was extremely unlikely.

Patients with mild bleeding disorders, could, after an acute injury, present directly to the ED. In such cases, ED staff were encouraged to call the haematology SpR or consultant for advice even if the problem did not seem to be associated with the patient's bleeding disorder.

Each patient had an emergency treatment plan written on their clinic letter which was accessible on the Bradford electronic patient record (EPR). It was expected that the haemophilia team would be contacted to notify them of the admission either at the time (if advice was required) or on the following working day to ensure appropriate review or follow up. Out of hours, the advice was to contact the on-call haemophilia consultant via the St James University Hospital (SJUH), in Leeds, switchboard.

Paediatrics

All paediatric patients with known bleeding disorders had direct access to Ward 32 (the children's clinical decision unit) in BRI, which was open 24 hours per day, 7 days per week.

Patients were given the telephone number and asked to call before arrival in order to alert the paediatric team. If, when parents phoned, there was a clinical concern regarding significant ongoing bleeding or injury (for example if there had been a head injury), then the parent could be directed to attend the ED at BRI. In that case the ED team would be made aware and the child would be reviewed initially by the ED team (and then referred to the paediatric team) or seen initially by the paediatric team.

Patients with mild bleeding disorders, who did not normally need to attend Ward 32, could, after an acute injury, present directly to the ED. At that time, if there were concerns needing haematological advice, the paediatric team (or haematology registrar) could be contacted.

Each child's emergency treatment plan was written on their clinic letter which was accessible on the EPR. When there was uncertainty whether to give specific treatment or about the dosing schedule/follow up plans then,

during daytime hours the advice was to contact the haematology consultants. Out of hours and during leave, the advice was to contact the on-call haemophilia consultant via the SJUH switchboard.

Ward Care

Adults

Ward 33 at BRI was the principle haematology ward. Ward 24 was the combined haematology / oncology ward and generally had fewer acute haematology patients so that it could be used for haemophilia patients. Care was provided by nursing staff with variable experience in haemophilia care supported by the specialist haemophilia nursing staff and the haemophilia consultant on weekdays. There was a daily review by the haematology SpR including at weekends. The acute consultant of the week provided support during weekdays but at weekends there was no consultant ward round and advice was accessed through the network on-call haemophilia consultant. The haemophilia consultants all had honorary contracts at the hospital and were able to review patients out of hours if this was necessary. They could also arrange for transfer of the patient to SJUH if specific treatment was required.

Paediatrics

Ward 32 at BRI was the children's clinical decision area. This was open 24/7 and patients could attend if bleeding or unwell or for assessment or review. If an admission of up to 24 hours was needed, then patients could be admitted onto the observation area of this ward. Patients needing regular attendance, as ambulatory outpatients, (e.g. for daily factor concentrate or for treatment of a joint bleed) could attend Ward 32.

Inpatient stays of more than 24 hours were on Ward 30 (a 41-bedded ward for all paediatric inpatient stays).

Both Ward 32 and Ward 30 were used for paediatric assessment and admissions and included surgical and medical patients. For surgery requiring haematological monitoring longer than a day case, patients were admitted to Ward 30.

Day Care

Adults

Ward 16 was the haematology/ oncology day case unit where the Haemophilia Centre was located. The Haemophilia Centre had access to two specific rooms for the assessment and management of patients with bleeding disorders (shared with the haemoglobinopathy patients). In general, treatment was delivered by the specialist haemophilia nursing staff.

Paediatrics

Ward 2 at BRI was the day case unit for paediatric medical and surgical day case procedures including elective day case surgery and elective procedures. Patients with bleeding disorders had written peri-operative plans. Sometimes children with bleeding disorders attended Ward 2 for elective day case treatment, instead of Ward 32.

Outpatient Care

Adults

The adult haemophilia clinic was a designated clinic every two weeks and took place at St Luke's Hospital Bradford (about 2 miles from BRI) on a Monday afternoon, alternating with the paediatric clinic. In addition, there was a Monday morning immune thrombocytopenia purpura (ITP) /general haematology clinic and, because of capacity issues, some patients with bleeding disorders were seen in this clinic.

The obstetric haematology clinic took place on the first and third Friday of the month and was an MDT clinic with patients reviewed by the haemophilia consultant, an obstetrician with special interest and a specialist thrombosis nurse. This was a general obstetric haematology clinic reviewing all haematology problems in pregnancy.

Paediatrics

The paediatric outpatient department was located at St Luke's Hospital. A paediatric haematology clinic was held weekly on Monday afternoons and was attended by the consultant paediatrician. The consultant haematologist attended fortnightly. At least one of the paediatric clinical nurse specialists (CNSs) attended the clinic on weeks 1, 3 and 5 of the month. Every second and fourth week of the month, there was a paediatric CNS-led follow up clinic which ran alongside the medical clinic.

Community Based Care

Adults

At the time of the visit there was no specific out-reach from the Haemophilia Centre into the community.

Paediatrics

The paediatric CNS made home visits and also attended schools and nurseries to provide education for staff.

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Review Findings

Achievements

This large Haemophilia Treatment Centre was run by a hard-working team, who worked well together across the paediatric and adult services; the different professional groups within the team were cohesive. They were offering good core services. Their ability to offer the full range of care was prevented by staffing gaps (see Concern 1) but team members had clear visions of what they would be able to offer with a full team. The team were well recognised across the hospital, and their input and support to colleagues from other teams, when co-managing patients, was highly valued. Staff in the Emergency Department (ED) were very familiar with the team and were confident of receiving timely support for reviewing patients presenting there. After the two adult specialist nurses had left in 2018, the department had successfully recruited to the posts, and the new appointees were working very effectively. The team received valuable support from a member of the IT department, who helped the team data manager to extract data and produce reports.

Efforts to evaluate service quality and plan for service improvement were evident, with a comprehensive annual report and formal work plan for both the adult and the paediatric service.

The team were actively involved in the North and West Yorkshire Haemophilia Network (NWYHN) which was centred at the Leeds Comprehensive Care Centre (CCC). The Centre director took part in the out-of-hours rota with the CCC consultants, there were weekly shared MDT telephone meetings, and the nurses felt well supported by their colleagues in the CCC.

The review team met only one adult patient but met several parents of children using the paediatric service who were all extremely positive about the care they received, especially appreciating the contribution of the lead paediatric nurse specialist.

The facilities from which the services were offered were of a very high standard, being spacious and bright. The nurses' office and the adult treatment room were co-located, and the children's ward area was of a high standard, with children having been involved in the design. There was a welcoming play area and actively used school room.

Good Practice

1. Some of the documents in use were notable, including a school and nursery care plan, and 'traffic light' posters for parents of children with central lines, alerting them to the symptoms and signs of possible blockage or infection, and steps to be taken in response to these.
2. The electronic patient record supported the service well:
    a. An 'alert' had recently become possible, indicating the diagnosis, for immediate consideration if a patient presented acutely. The teams were working through these for all their patients, starting with those severely affected, and planning eventually to include those patients with mild conditions.
    b. It was possible for consultant staff to access the records remotely, when on call from home, and also to record their comments and advice directly onto the system.
    c. Clinical observations of inpatients could also be reviewed remotely from the ward.
    d. There was an alert for patients who were on clinical trials, so that the research team would be alerted if any attended.
3. Old clinical records were still available in 'hard copy', rather than attempts being made to scan them into bulky and often unusable legacy files.

4. Senior 'navigation nurses' worked from the front of the ED, triaging patients, and they were aware of the need to call the specialty team if any patients with bleeding disorders presented.
5. Samples for initial diagnosis and more complex testing had to be sent to the laboratory at the Leeds CCC. To reduce delays in transfer of samples, a dedicated taxi service arrangement had been established and this was working well.
6. Patients could get help from a benefits advice worker, funded by the haematology department charity.
7. Documentation and practice for transition of teenagers from the paediatric to adult services were good, and young people with co-morbidities and complex needs had additional support from a hospital 'disability transition team'.

Immediate Risks

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

Concerns

1. **Staffing**

   There were significant gaps in the specialist team, and under-provision of staff in other professional groups. The service could not therefore offer appropriate multi-disciplinary assessment or management of its patients.

   a. Physiotherapy - There was no specialist physiotherapist working in either the paediatric or the adult service. This had been the case for several months, and there was no immediate prospect of the situation improving as a business case was yet to be written. There was therefore no ongoing joint surveillance, and no joint scores being undertaken, with only about one third of patients having had a completed joint score within the preceding year. There was no consistent acute joint bleed service. Referrals could be made to the standard musculoskeletal service, but specialist support was not available. Physiotherapy is a key aspect of care for children and adults with bleeding disorders, and a specialist physiotherapist is an expected member of the core team, available to see patients at their regular assessments as well as when needed for acute complications.

   b. Nursing - At the current provision in both the adult and the paediatric teams, the nurses were restricted in what they could offer, and had very limited time for personal development and CPD activity. They were not able to offer ongoing training to staff in other departments, which is especially necessary in the ED. The adult nurses often could not attend the specialist clinics, held at St Luke's Hospital. They had started some ad-hoc telephone clinics which was important for making contact with some of the patients with milder disorders who did not attend in person, but this activity had then stopped because of capacity issues. In addition, it had not been possible to start a planned family counselling service which is key to testing and counselling potential haemophilia carriers.

   c. Senior medical staff - The Centre director, who was the single adult haematologist working in the service, had four PAs allocated for this work, and the single paediatrician leading the children's service had less than two PAs. All of this time was consumed with direct patient care, leaving very little for activities required to underpin the service (see Concern 2) and to develop and improve it. The Centre director could cover the paediatric lead when on leave, but daytime emergency cover for the adult service was lacking if the director was on leave. Network support was being sought for these times.

   d. Psychosocial care - There was no dedicated psychology or social work time allocated to the service. Referrals could be made to general social services, or to hospital psychology for inpatients; however, all but the highest-level needs were likely to be unmet, and the team lacked the support and guidance

which a specialist psychology member can offer. The lack of psychosocial care was highlighted by the parents and patient who met the reviewers at the time of the visit.

e. Data management / administrative and clerical support - A single individual was undertaking these activities for the adult and paediatric teams, working 0.5 WTE as data manager and the remaining 0.5 WTE as secretary, managing clinic letters etc. She was struggling to keep up with the throughput, and working with a backlog of at least two weeks, which worsened if she had a period of leave. There were some important data update tasks which she had not been able to attend to, and without which the team could not be certain about some performance quality measures (see Further Consideration 1). In addition, some administrative tasks were being picked up by the already stretched nursing teams.

2. **Governance issues**

a. Consent for genetic testing - Verbal consent was usually still being requested for samples to be sent for genetic testing, whereas written consent is now expected practice.

b. Review and learning - For the adult team, some aspects of multi-disciplinary review and learning were no longer being discussed at local meetings, but instead were being taken to the NWYHN governance meetings. There was also a local haematology clinical governance meeting including mortality reviews where concerns could be raised. However, the review team observed that only high-level issues were likely to be discussed at that level, and that the best opportunity for reflection and learning would be to establish a local IABD governance meeting, or to include governance items on the agendas of other IABD MDT meetings.

c. Diagnostic and clinical guidelines - Some guidelines did not appear to be available, for example one describing concentrate use and monitoring. There was a lengthy guideline for each of the paediatric and adult services that was difficult to navigate and was judged to be hard to use in practice. Very few of the guidelines were available on the hospital intranet, as they had not yet been formally ratified.

d. Audit - Some review of practice had been undertaken and was included in the annual reports. However, none of the recommended core audits, checking for example emergency and out of hours care, initiation of prophylaxis in children, inhibitor surveillance and immune tolerance induction and review of joint scores (HP-702) were seen.

Further Consideration

1. Some revision and updating of data on the Haemophilia Centre Information System (HCIS) was necessary, including removal of patients who had died or were known to have transferred elsewhere. Figures recorded, for example for the number of patients screened for hepatitis C virus or HIV infection, were acknowledged to be out of date meaning that the figures presented were lower than the actual number of patients who had actually been screened.

2. The team understood that the hospital did not support their adult nurses in undertaking home visits, and nurses had therefore had not felt able to offer these. [1]

3. ED staff indicated that they would greatly value some short ongoing teaching sessions, when the nurse specialists have time to offer these.

4. Although the team were mostly made aware of patients attending ED out of hours (for example at the Monday morning MDT handover meeting). It may be beneficial to establish an e-mail system so that ED

[1] At the afternoon feedback session, a senior manager advised that this was a misunderstanding. Further discussions were therefore planned so that the adult nurses could once again offer home visits to patients where appropriate.

staff could alert the Centre of attendances overnight, or at the weekend when the registrars had not been called for advice, as staff may otherwise be unaware of these attendances.

5. The paediatric team were using care plans to record clinic review outcomes, and clinic letters included all the necessary details including factor replacement dose for prophylaxis and acute bleeds. However, the adult team were yet to use the care plans routinely, and in the meantime should include additional details, including factor doses, in clinic letters.
6. The Centre director did not yet have remote access to the electronic patient record, for use when on call out of hours.
7. The weekly Monday morning handover MDT meeting was not minuted, and although important discussion outcomes were usually included on the patient record by a member of the team, there was no clearly understood system about who would always do this.
8. There was no robust system in place to identify, for testing and counselling, obligate or possible carrier females before they reached reproductive age.
9. There was a specialist joint haematology obstetric clinic, held twice a month. Reviewers learned that sometimes women were already in late pregnancy at the time of referral from the linked hospitals, for example Airedale General Hospital or Calderdale Royal Hospital. It would be valuable to ensure that the antenatal teams in all the peripheral hospitals are aware of this specialist clinic and the need for early referral where possible.
10. Although regular meetings including all the specialist teams who co-manage patients with the IABD service are not usually felt to be practicable, the review team suggested that it would be useful to increase the opportunity for informal meetings and discussion with colleagues in other specialties, who had suggestions to offer about improving the joint practice.
11. There was no clarity about whether the team took all new patient registrations to the network MDT meetings, or just the severe and moderate patients. Network agreement on this point would be valuable. It was observed that on this point, and other shared issues, the appointment of a network co-ordinator for the NWYHN would be beneficial.
12. Some policies were informally written and included explanations as to why some administrative processes that were meant to take place – for example, the management of repeated clinic non-attenders - did not, in practice, work well. Policies should state the intended practice.
13. Document control was inconsistent, with many guidelines and policies lacking details of authorship, approval date and intended review date.

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APPENDIX 1 Membership of Visiting Team

Visiting Team		
Martin Beard	Patient representative	
Caroline Clegg	Clinical Lead Rheumatology / Haematology Therapy Team	Manchester University NHS Foundation Trust
Katie Gladstone	Haemophilia Nurse	Hull University Teaching Hospitals NHS Trust
Dr Charlotte Grimley	Haematologist	Nottingham University Hospitals NHS Trust
Sharon Thind	Haemophilia Specialist Nurse (Paediatrics)	Manchester University 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 Centre	37	23	62
Network *	8	3	38
Commissioning *	3	3	100
Total	**48**	**29**	**60**

***** The Centre did not complete the network and commissioning standards, therefore these figures have been taken from Leeds, which is the CCC with which this Centre was linked.

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Bradford Haemophilia Centre

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

Ref	Standard	Met?	Comments
HP-102	**Condition-Specific Information** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of their condition and how it might affect them b. How their condition is diagnosed c. Genetics of inherited bleeding disorders d. Testing for carrier status and the implications of being a carrier e. Problems, symptoms and signs for which emergency advice should be sought f. Out of hours services g. 'On demand' clotting factor treatment h. Prophylaxis i. Self infusion (or infusion by parent or carer) j. Home therapy and use of Haemtrack k. How to manage bleeding at home l. Ports, fistulae and in-dwelling access devices (if applicable) m. Possible complications, including inhibitors and long term joint damage n. Approach to elective and emergency surgery o. Women's health issues p. Health promotion, including smoking cessation, health eating, weight management, exercise, alcohol use, sexual and reproductive health, and mental and emotional health and well-being q. Dental care r. Travel advice s. Vaccination advice t. National Haemophilia Database, its purpose and benefits u. Sources of further advice and information Information should be available covering: 1. Haemophilia A 2. Haemophilia B 3. Von Willebrand Disease 4. Acquired haemophilia 5. Inherited platelet disorders 6. Other less common and rare bleeding disorders	Y	

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

Ref	Standard	Met?	Comments
HP-194	**Environment** The environment and facilities in out-patient clinics, wards and day units should be appropriate for the number of patients with inherited and acquired bleeding disorders and accessible by people with severe mobility problems. Services for children and young people should be provided in a child-friendly environment, including toys and books / magazines for children and young people of all ages.	Y	
HP-195	**Transition to Adult Services and Preparation for Adult Life** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards f. Advice for young people going away from home to study, including: i. registering with a GP ii. how to access emergency and routine care iii. how to access support from their Comprehensive Care Centre iv. communication with their new GP	Y	
HP-198	**Carers' Needs** Carers should be offered information on: a. How to access an assessment of their own needs b. What to do in an emergency c. Services available to provide support	N	Although reviewers heard from parents that they were asked about their own welfare at regular clinic attendances, there were no structured mechanisms in place for assessing carers' needs and signposting them to other sources of help and support.
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	However, there was no evidence of actions that had been taken in response to patient feedback.

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

Ref	Standard	Met?	Comments
HP-203	**Service Competences and Training Plan** The competences expected for each role in the service should be identified. A training and development plan for achieving and maintaining competences should be in place.	N	There was no matrix in place (as outlined in the description of this Quality Standard) which outlined the core MDT roles and the competencies that were required (and had been completed) for each.
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 the main report. Reviewers also heard that nursing time was being diverted to undertake administrative tasks.
HP-301	**Support Services** Timely access to the following support services should be available: a. Play support (children's services only) including: i. Play and distraction during any painful or invasive procedures ii. Play support to enable the child's development and well-being b. Pharmacy c. Dietetics d. Occupational Therapy e. Orthotics	Y	
HP-302	**Emergency Department – Staff Competences** Medical and nursing staff working in the Emergency Department should have competences in urgent care of people with inherited and acquired bleeding disorders including awareness of: a. Guidelines on care of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) b. Who to contact for advice	Y	

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

Ref	Standard	Met?	Comments
HP-402	**Facilities and Equipment** Facilities and equipment appropriate for the service provided should be available including: a. Fridges b. Storage c. Clinical rooms for staff of all disciplines to see patients and carers d. Room for multi-disciplinary discussion e. Room for educational work with patients and carers f. Office space for staff g. Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all clinical areas All equipment should be appropriately checked and maintained.	Y	See the Achievements section of the main report.
HP-499	**IT System** IT systems should be in use for: a. Storage, retrieval and transmission of patient information, including access to the latest vCJD status and family tree b. Patient administration, clinical records and outcome information c. Data to support service improvement, audit and revalidation d. Alerting the specialist team when patients attend the Emergency Department	Y	
HP-501	**Diagnosis Guidelines for Patients with Suspected Inherited and Acquired Bleeding Disorders** Guidelines on diagnosis should be in use covering at least a. Haemophilia A b. Haemophilia B c. Von Willebrand Disease d. Acquired haemophilia e. Inherited platelet disorders f. Other less common and rare bleeding disorders	N	See the Concerns section of the main report regarding the need to review and revise the guidelines.

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	N	Reviewers did not see evidence of a guideline that met the requirements of this Quality Standard.
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 did not see any evidence for ‘e’, ‘f’ ‘h’, ‘i’ or ‘j’.
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	N	Reviewers saw a guideline for paediatrics but not for adults. There were templates for adult surgical care plans (and evidence of use in practice), but not the guidelines to support them.
HP-595	**Guidelines on Transition and Preparing for Adult Life** Guidelines on transition of young people from paediatric to adult services should be in use covering at least: a. Taking responsibility for their own care b. Involvement of the young person and, where appropriate, their carer in planning the transfer of care c. Joint meeting between paediatric and adult services in order to plan the transfer d. Allocation of a named coordinator for the transfer of care e. A preparation period prior to transfer f. Arrangements for monitoring during the time immediately after transfer g. Advice for young people going away from home to study, including: i. registering with a GP ii. how to access emergency and routine care iii. how to access support from their Comprehensive Care Centre iv. communication with the young person's new GP	Y	
HP-599	**Care of Vulnerable People** Guidelines for the care of vulnerable children, young people and adults should be in use including: a. Restraint and sedation b. Missing patients c. Mental Capacity Act and the Deprivation of Liberty Safeguards d. Safeguarding e. Information sharing f. Palliative care g. End of life care	Y	

Ref	Standard	Met?	Comments
HP-601	**Service Organisation** The service should have an operational procedure covering at least: a. Ensuring all children who are in-patients have a named consultant paediatrician and a named haematologist with expertise in caring for patients with inherited and acquired bleeding disorders responsible for their care b. Ensuring all adults are under the care of a consultant haematologist with an interest in inherited and acquired bleeding disorders, either directly or through a shared care arrangement with a general haematologist c. Responsibility for giving information and education at each stage of the patient journey d. Arrangements for involving Haemophilia Centre staff in multi-disciplinary discussions relating to their patients (QS HP-602) e. Arrangements for follow up of patients who 'do not attend' f. Arrangements for transfer of patient information when patients move areas temporarily or permanently g. Ensuring patients' plans of care are reviewed at least six monthly for patients with severe haemophilia and at least annually for other patients (QS HP-104) h. Ensuring school visits for children with severe haemophilia at least at each change of school (children's services only) i. Ensuring patients are visited at home at least annually if they are unable to attend clinics, including those in nursing homes j. Lone working	Y	
HP-602	**Multi-Disciplinary Team Meetings** Multi-disciplinary team meetings to discuss patients' plans of care should take place regularly involving: a. All core members of the specialist team (HP-202) b. Senior biomedical scientist or clinical scientist with responsibility for the Coagulation Laboratory c. HC staff who are regularly involved in the patient's care as part of network arrangements	Y	However, there was no adult MDT meetings to discuss, for example, new registrations and plans of care.

Ref	Standard	Met?	Comments
HP-603	**Multi-Disciplinary Clinics** The following multi-disciplinary clinic arrangements for patients with inherited and acquired bleeding disorders should be in place: a. Involvement of medical, specialist nursing and physiotherapy staff in clinics b. Availability of social work and psychology staff in clinics c. Combined clinics or other arrangements for multi-disciplinary discussion with: i. orthopaedics ii. rheumatology iii. obstetrics and gynaecology iv. paediatrics v. dental vi. HIV / hepatology	N	See the Concerns section of the main report. There was no physiotherapist input or psychosocial support available in the service, meaning that full multi-disciplinary clinics could not be achieved.
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	Although colleagues in other specialisms spoke highly of the support that they received from the haemophilia team, there were no formal mechanisms in place to discuss issues.
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	There was no evidence that the audits outlined in this Quality Standard had been completed.
HP-706	**Research** The service should actively participate in research relating to the care of patients with bleeding disorders.	Y	

Ref	Standard	Met?	Comments
HP-798	**Multi-disciplinary Review and Learning** The service should have multi-disciplinary arrangements for review of and implementing learning from: a. Positive feedback, complaints, outcomes, incidents and 'near misses' b. Morbidity and mortality c. Haemophilia Dashboard d. Review of UKHCDO Annual Report benchmarking information on concentrate use e. Ongoing reviews of service quality, safety and efficiency f. Published scientific research and guidance	N	See Concern section of the main report.
HP-799	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	Many documents, including the operational policy, diagnostic guidelines and some Trust policies did not have clear documentation control.

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Network

[Note – the compliances for the network and commissioning Quality Standards have been replicated from the Leeds Comprehensive Care Centre report. The Leeds CCC is the hub for the Bradford Haemophilia Centre and the lead centre for the North West Yorkshire Haemophilia Network (NWYHN)

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	There was no named psychologist in place for the network.
HY-204	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HP-203.	Y	
HY-503	**Guidelines** Network guidelines should have been agreed covering: a. Diagnosis for patients with suspected inherited and acquired bleeding disorders (QS HP-501) b. Concentrate use and monitoring (QS HP-502) c. Clinical guidelines (QS HP-503) d. Management of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) e. Care of patients requiring surgery (QS HP-505) f. Transition and preparing for adult life (QS HP-595)	N	Paediatric guidelines were shared across the network, and some adult guidelines had been developed but not yet ratified ('e' and 'f').
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	Achievement of this Standard had not been possible because no data sharing agreement was in place across the network.
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.	N	Achievement of this Standard had not been possible as there was no data sharing agreement in place across the network.

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	Achievement of this Standard had not been possible because of staffing issues.
HY-798	**Network Review and Learning** Representatives of Comprehensive Care Centres and referring Haemophilia Centres should meet at least once a year to: a. Identify any changes needed to network-wide policies, procedures and guidelines b. Review results of audits undertaken and agree action plans c. Review and agree learning from positive feedback, complaints, critical incidents and 'near misses', including those involving liaison between teams d. Share good practice and potential service improvements	Y	

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Commissioning

Ref	Standard	Met?	Comments
HZ-601	**Commissioning of Services** Commissioners should have agreed the configuration of clinical networks including: a. Designated Comprehensive Care Centres and Haemophilia Centres and the relationships between them b. Whether the service cares for children, adults or both c. Referral pattern to each service, taking into account the type of patients who will be treated by each team	Y	
HZ-701	**Clinical Quality Review Meetings** Commissioners should regularly review the quality of care provided by: a. Each service, including achievement of QS HP-701 b. Each network, including achievement of QS HY-701 and QS HY-798 c. Service and network achievement of relevant QSs	Y	
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.	Y	

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