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

Cambridge University Hospitals NHS Foundation Trust

Visit Date: 9th May 2019

Report Date: September 2019

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Introduction

This report presents the findings of the peer review of services for people with Inherited and Acquired Haemophilia and other Bleeding Disorders at the Cambridge Haemophilia Comprehensive Care Centre which took place on 9th May 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:

- Cambridge University Hospitals NHS Foundation Trust
- NHS England Specialised Commissioning

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

Acknowledgements

We would like to thank the team at the Cambridge Haemophilia Comprehensive Care Centre for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. We are grateful too to the patients, parents and carers who took time to meet the review team.

Thanks are also due to the visiting team (**Appendix 1**) and their employing organisations for the time and expertise they contributed to this review.

About the Quality Review Service

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

More detail about the work of QRS is available at www.qualityreviewservicewm.nhs.uk

Cambridge Haemophilia Comprehensive Care Centre

The Cambridge Haemophilia Comprehensive Care Centre (CCC) was based in a newly refurbished centre at Addenbrookes Hospital in Cambridge where it had moved at the beginning of 2013. The Centre was easily accessible from the main entrance of the hospital and there was a dedicated parking bay close to the entrance of the Centre for the use of patients with bleeding disorders.

The majority of the haemophilia team, including the consultants, haemophilia specialist nurses (both paediatric and adult), haemophilia trials manager, data manager, secretary and specialist haemostasis laboratory were based in the Haemophilia Centre. The paediatric haematology consultants were based in offices on the paediatric oncology ward, which was in a separate part of the main Addenbrookes building. The anticoagulation nursing team and the general haematology specialist nurse were also based within the Centre. There was a haemophilia physiotherapist, who had sixteen hours per week allocated to haemophilia and was based in the Haemophilia Centre on the designated outpatient clinic days, although working primarily from the physiotherapy department. Some of the physiotherapy hours included a weekly gym and hydrotherapy session that was open to all patients.

The haemophilia team treated both adult and paediatric patients from East Anglia including Cambridgeshire, Norfolk, Suffolk, Peterborough, and Bedfordshire and some patients from Essex and Hertfordshire, although the care of these patients had historically been based at the London centres. The majority of patients had their care from Cambridge, but some patients had shared care with their local treatment centre and the Cambridge CCC, depending on where they lived. All haemophilia outpatient clinics and emergency reviews were carried out in the Centre where there were three dedicated clinic rooms for haemophilia.

The haemophilia service was available between 8:30am and 4:30pm Monday to Friday and was consultant-led. Outside these hours there was an on-call consultant-led advice service available. Routine, consultant-led, adult outpatient clinics were held on two days each week. The consultant-led paediatric clinic was held on a Wednesday morning. If patients with a bleeding disorder had an appointment in another clinic (such as hepatology) on a different day of the week, the haemophilia team would try to see them on that same day. The team aimed to offer a holistic comprehensive care service with consultants being supported by experienced haemophilia specialist nurses. There was a dedicated clinical trials manager, who managed a large number of haemophilia clinical trials including a number of gene therapy trials. The clinical trials manager was supported by a trials data manager.

In the two to three years prior to the review, there had been a number of significant changes in leadership in the Haemophilia Centre, with the retirement of two well-established and well-respected consultants. The service had, however, continued to run smoothly as a result of the dedication of the wider team.

There was a twenty-four hours a day, seven days a week, specialist haemostasis laboratory service that had a team of dedicated and experienced biomedical scientists who ran an on-call rota for out of hours work, including laboratory monitoring for bleeding disorder patients post-operatively.

This table shows the numbers of patients registered at the Centre at the time of the visit:

Condition		Number of patients	Number of patients who had an annual review in last year
Haemophilia A	Adults = 172	Severe = 42 Moderate = 17 Mild = 113	All patients with severe haemophilia, or moderately severe haemophilia on prophylaxis, were reviewed every six months in the haemophilia clinic. All patients with moderate haemophilia were seen at least annually and patients with mild haemophilia were seen every 1-2 years.
	Children = 60	Severe = 23 Moderate = 6 Mild = 31	All children with severe haemophilia, or moderately severe haemophilia on prophylaxis, were reviewed every six months in the haemophilia clinic. All children with moderate haemophilia were seen at least annually, and children with mild haemophilia were seen every year.
Haemophilia B	Adults = 37	Severe = 15 Moderate = 7 Mild = 15	All patients with severe haemophilia, or moderately severe haemophilia on prophylaxis, were reviewed every six months in the haemophilia clinic. All patients with moderate haemophilia were seen at least annually, and patients with mild haemophilia were seen every 1-2 years.
	Children = 12	Severe = 7 Moderate = 3 Mild = 2	All children with severe haemophilia, or moderately severe haemophilia on prophylaxis, were reviewed every six months in the haemophilia clinic. All children with moderate haemophilia were seen at least annually, and children with mild haemophilia were seen every year.
von Willebrand	Adults = 211		
	Children = 38		
Other	Adults = 447		
	Children = 44		

Emergency Care

Patients with bleeding disorders were advised to contact the on-call haematology Specialist Registrar (SpR) for advice out of hours via the Addenbrookes switchboard. There was a haematology SpR on site 24/7 at Addenbrookes who would inform Accident & Emergency (A&E) that the patient would be attending. The SpR, along with the specialist team, would review all bleeding disorder patients when they arrived, depending on presentation. This same system was in place for paediatric patients, when the haematology SpR would contact the on-call paediatric SpR and inform them that the patient was attending, to ensure a joint review. This was all done with the support of the on-call haematology consultant.

There was an agreed A&E guideline which was on Merlin (the hospital wide system for guidelines and policies). The guideline was also available in the A&E protocol folder. All bleeding disorder patients had an alert at the top of the Epic®[1] system which contained their diagnosis, baseline clotting factor levels (if appropriate) and the treatment plan.

If Addenbrookes was not the patient's local hospital and if it was safe for them to attend locally then the haematology SpR and consultant would liaise with that hospital and arrange transfer, if necessary.

Ward Care

If a patient was admitted under the care of haematology with a bleeding-related problem, were admitted to Ward D6 or Ward C10 (haematology wards). These wards were staffed with haematology nurses who primarily treat patients with malignant haematological conditions but were also familiar with the complex needs of bleeding disorders patients and the administration of clotting factor. All patients with bleeding disorders who had been admitted, were reviewed daily by the haemophilia consultant, or specialist coagulation SpR, along with one of the haemophilia Clinical Nurse Specialists (CNS).

If patients were admitted with a condition unrelated to their bleeding disorder, then they would be admitted to the appropriate ward for that speciality. Patients were regularly reviewed by the haemophilia consultant, SpR and CNS. The admitting team were fully supported by the haemophilia team.

Patients who were admitted for surgery were admitted under the surgical team to the appropriate ward. They were reviewed daily by the haemophilia consultant or SpR along with the haemophilia CNS, who co-ordinated clotting factor replacement and monitoring.

Paediatric patients were admitted under the care of the paediatric haematology consultants on Ward C2 (paediatric haematology and oncology ward). If a child had surgery, he or she might also be admitted to one of Wards D2 or F3 or Ward C3 (if the child was under 1 year old). This was where most surgical patients were cared for, and the haemophilia CNS team would ensure that the staff there had the appropriate education on the patient's condition and the treatment required.

Day Unit Care

The majority of day unit care was carried out in the Haemophilia Centre. In cases where patients required platelets, iron infusion or other treatment such as IVIg[2] or rituximab (for acquired bleeding disorder patients), the patients would go to the haematology day unit. The haemophilia team had a good working relationship with the nursing team there. If patients required planned clotting factor replacement over the weekend and were unable to administer this themselves, then they could go to the haematology day unit, which was open on Saturdays and Sundays. When patients telephoned the Centre with a problem the call was always triaged to ensure that they were reviewed in the best place. Where patients were asked to attend the Emergency Department (ED), the haemophilia team would notify the ED that the patient was on their way and would see them in the ED alongside the relevant teams required for the emergency presentation.

[1] **Epic Systems** is a medical software corporation that develops electronic patient record systems.

[2] **IVIg** – stands for Intravenous immunoglobin which is a purified blood product containing antibody proteins from healthy blood plasma donors. IVIG infusion therapy is used for the treatment of a wide variety of neurological and autoimmune conditions.

Outpatient Care

All outpatient care (adults and paediatrics) for patients with bleeding disorders was based in the Haemophilia Centre. Clinical trials patients were also seen in the Haemophilia Centre for all of their trial visits.

Community-based Care

There was no formal community-based care in place at the time of the review. The paediatric haemophilia CNS did home visits and school visits on an ad hoc basis.

For elderly patients, or those who were unable to attend the Centre for post-operative factor replacement, the haemophilia CNS would go out on an ad hoc basis or arrange for the hospital at home team to visit. The Haemophilia Centre also liaised with the local District General Hospitals and patients could attend the haematology day units in those centres if they were closer to home.

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Review Visit Findings

Achievements

Following the departure of some senior clinical team members over the last two to three years, this young team was delivering a good, highly patient-focused service. Team members were going above and beyond their duty requirements in their efforts to support patients and their carers. The contribution of the lead nurse and her team was especially noted.

Patient feedback about the service was overwhelmingly positive, and patients appreciated the kind and personalised care they received from the haemophilia team.

There was an excellent laboratory service, offering the full range of specialist investigations when required, and all testing was UKAS[3] accredited.

The hospital had been an early adopter of Epic® software, and this supported the service well, with a detailed alert outlining diagnosis and treatment on the opening screen of records for all patients with bleeding disorders. This enabled senior clinicians to access results and to prescribe remotely when they were on-call out of hours. This record also included genetic tests results and a family tree. The 'MyChart' patient portal allowed patients to access results and have interactive online discussions with healthcare professionals regarding their results and treatment plans.

The dedicated facilities at the Centre were of a very high quality. This enabled the team to display a range of patient information suitable for patients of different ages. The Centre offered recliner chairs in the waiting room, and there was a plentiful supply of play equipment available for younger children. The laboratory was situated within the Centre allowing for close working between biomedical and clinical staff. The paediatric ward area was pleasant, and there were side rooms available for the use of teenagers. There were also excellent physiotherapy facilities, with a hydrotherapy pool and gym, for which there were some 'ring-fenced' sessions solely for the use of patients with bleeding disorders. There was a dedicated parking bay situated by the nearest entrance to the hospital block where the Centre was sited.

An active research programme was in place, and an impressive number of patients had been recruited into gene therapy studies.

Good Practice

1. Patient information leaflets were in plentiful supply and were easily accessible for patients and carers.
2. The quality of several of the guidelines was outstanding, including those for transition between paediatric and adult services, the emergency care guideline and the surgical pathway.
3. Patients had opportunities for maintenance and rehabilitation physiotherapy, with a tech-led gym class, and a tech-led hydrotherapy class each week.
4. A support group for parents of recently diagnosed babies, and children under the age of two, was appreciated. Parents who met the review team expressed their hope that this would continue to be offered to families of babies as soon as they were diagnosed with a significant bleeding disorder.
5. Play support on the paediatric inpatient ward was available every day for twelve hours, with flexibility to work with children in the Centre too when necessary.
6. Home visits had been undertaken by nursing and consultant staff, to assess frail elderly patients and teach families how to administer factor concentrate.

[3] **UKAS** is the UK's National Accreditation Body, responsible for determining, in the public interest, the technical competence and integrity of organisations such as those offering testing, calibration and certification services.

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

Concerns

1. **Staffing**

    a. There was no funded post for a psychologist to work as a member of the adult team. Patients requiring psychological support, including those transitioning from paediatric care to adult care, had to be referred to outside agencies whose staff were not familiar with their clinical history or background.

    b. There was a 0.4 WTE physiotherapist working across the paediatric and adult service. This was not a dedicated post but a rotational post, with different therapists working with the service every six months. This was not considered sufficient for the size of the Centre. Frequently rotating members of staff do not always have access to the necessary haemophilia-related training or CPD during their brief time in the Centre, and the care of patients was not therefore at the level that would be expected of a Comprehensive Care Centre. In addition, it was not possible to ascertain what proportion of patients had had formal 'joint scores' undertaken during the previous year.

    c. There was no identified social work support for the adult service. The absence of dedicated time from staff in these key roles meant that the team could not work in the fully multi-disciplinary way expected for this service.

    d. Consultant on-call rotas for the paediatric and adult services were worked at 1:6 frequency, with three of the consultants on each rota working routinely in the Inherited and Acquired Bleeding Disorder service. When other (non-specialist) consultants were on-call, this was through an informal arrangement that allowed one of the specialist consultants to be contacted. It was considered that this should be formalised.

2. **Data management**

    Not all the data requirements were being met. The team were not entering data to the NHS England Haemophilia Dashboard which serves as an important way of benchmarking aspects of the service. Reviewers learned that the Centre Director had contacted managers and commissioners asking how they might start submitting to the dashboard, but that there had been no response.

Further Consideration

1. The service had recently been moved into another management division of the hospital. Since the move, nursing supervision sessions for the Band 7 nurses had stopped. Continued supervision was necessary, especially to ensure that the lead nurse had time in her job plan to undertake all the tasks and responsibilities required of the role. Overall, however, the host team were optimistic that the new operational and management support would improve following this divisional change.

2. None of the centre's nurses were non-medical prescribers, and consideration might be given to encouraging this training for some, and also ensuring that as many as possible complete the 'Advanced Skills in Clinical Assessment' and 'Contemporary Care of People with Bleeding Disorders' courses, to ensure the team continues to be suitably qualified and skilled.

3. Direct access, for example to the inpatient ward areas, would be preferable for patients requiring out of hours assessment and management, to avoid them having to present through the Emergency Department.

4. Nurse-led clinics, especially for patients with milder bleeding disorders and those living greater distances from the Centre, would be very effective.

5. Care plan templates were seen in the evidence provided but were not routinely used in practice. Many but not all elements of care plans were included in clinic letters. It may be helpful to install a care plan and review template on Epic.

6. Patient feedback had recently been collected. However, more routine collection of patients' comments and suggestions would help guide service improvements. A box intended to display patient feedback cards in the waiting area was broken, and feedback forms were not therefore available for patients. The service would benefit from considering an interim arrangement while this box was being repaired.

7. Genetic testing was due to move from an on-site laboratory to Manchester. This will challenge the current close working between the genetics laboratory staff and the clinical team and may impact on assessing the significance of genetic mutations identified. This may also impede carrier detection. It will be important to ensure that new working relationships are established quickly to reduce any potential impact.

8. The detailed comprehensive care guideline presented in evidence included details of volume restriction required for adults, but not for children, receiving DDAVP[4]. On further discussion with the host team, it was understood that the guideline presented was a draft that was currently being updated, and the guideline in current use and available on the intranet did include this information. Authors will need to be sure that all the important information in the older guideline is transferred across into the new one.

9. There was no operational policy in place; however, the narrative included by the host team in self-assessment against the relevant standard (HP-600) included much of the information required in such a policy and could form a basis for this document.

10. Signage to the Centre within the hospital was not prominent or clear.

11. The 'Cambridge Haemophilia and Thrombosis Centre' had a rudimentary web page on the Cambridge University Hospitals website, without any service detail or links to informational material.

12. Document control was incomplete; some documents were in draft and not all had details of authorship, dates of approval or date of review.

13. A newsletter for patients updating current opportunities for participation in research would be valuable. A clinical trials meeting might also be established for the Centre, involving all the healthcare professionals working in the service, to plan the ongoing programme and broaden it as considered appropriate.

14. Although network commissioning arrangements were not clear at the time of the review (see comment below), outreach paediatric clinics were established at four linked hospitals: Peterborough, Norfolk and Norwich, Ipswich and Colchester. Offering outreach adult clinics would be beneficial so that there was a similar level of service for adults with bleeding disorders living nearer to these hospitals.

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[4] **DDAVP** - Desmopressin (also known as DDAVP**,** which stands for 1-deamino-8-D-arginine vasopressin) is a synthetic medicine that boosts levels of factor VIII (FVIII) and von Willebrand factor (VWF) to prevent or control bleeding.

Commissioning and Network Arrangements

General Comment

The Cambridge team members were not aware of any formal network agreement, although they offered clinical advice and guidance as necessary to colleagues working in the region. Colleagues in linked hospitals reported no difficulty in accessing such support. Other aspects of network functioning, such as shared audits, or education and training for all staff groups, were not in place. There was a regional haemostasis meeting, held approximately once a year. Cambridge offered their care guidelines to others in the group, but colleagues in Ipswich indicated that they used their own local guidelines.

There had been no contact with commissioners, although it was acknowledged that their input would be valuable in shaping and agreeing service developments both within the Centre and across the region. Discussion with commissioners will be required to clarify their expectations around formalising a network in the region, with the Cambridge CCC at its hub, and what resource might be available to support this.

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APPENDIX 1 Membership of Visiting Team

Visiting Team		
Kate Forsyth	Haemophilia Clinical Nurse Specialist (Paediatrics)	Barts Health NHS Trust
Dr Georgina Hall	Consultant Paediatric & Adolescent Haematologist. Honorary senior lecturer – University of Oxford	Oxford University Hospitals NHS Foundation Trust
Dr Charles Percy	Consultant Haematologist	University Hospitals Birmingham NHS Foundation Trust
Debra Pollard	Lead Nurse, Haemophilia	Royal Free London NHS Foundation Trust
Clare Richards	MSK Physiotherapist Haemophilia	St George's University Hospitals NHS Foundation Trust
Nicola Sugg	Programmes and Events Manager	Haemophilia Society

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

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APPENDIX 2 Compliance with the Quality Standards

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

Table 1 - Percentage of Quality Standards met

	Number of Applicable QS	Number of QS Met	% met
Comprehensive Care	37	27	73%
Network	8	1	13%
Commissioning	3	0	0%
Total	48	28	58%

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Haemophilia Comprehensive Care Centres and Haemophilia Centres

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

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

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	Some elements were covered but not all. See Further Consideration section of main report.
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.	N	See QS HP-103.
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, reviewers commented that the signage to the Centre from the main hospital was not clear.
HP-195	**Transition to Adult Services and Preparation for Adult Life** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards f. Advice for young people going away from home to study, including: i. registering with a GP ii. how to access emergency and routine care iii. how to access support from their Comprehensive Care Centre iv. communication with their new GP	Y	
HP-198	**Carers' Needs** Carers should be offered information on: a. How to access an assessment of their own needs b. What to do in an emergency c. Services available to provide support	Y	
HP-199	**Involving Patients and Carers** The service should have: a. Mechanisms for receiving regular feedback from patients and carers about treatment and care they receive b. Mechanisms for involving patients and carers in decisions about the organisation of the service c. Examples of changes made as a result of feedback and involvement of patients and carers	N	Reviewers noted that the team had started to try and obtain patient feedback; however, this needed to become more routine and embedded. Reviewers did not see any evidence of changes to practice resulting from 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 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 training / competency matrix in place (see notes section of this Quality Standard for requirements).
HP-204	**Competences – All Health and Social Care Professionals** All health and social care professionals working in the service should have competences appropriate to their role in: a. Safeguarding children and/or vulnerable adults b. Recognising and meeting the needs of vulnerable children and/or adults c. Dealing with challenging behaviour, violence and aggression d. Mental Capacity Act and Deprivation of Liberty Safeguards e. Resuscitation	Y	
HP-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be available.	Y	
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	See Good Practice section of main report regarding play therapy provision.
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	See Good Practice section of main report regarding the clinical guideline.

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	This was an excellent service. However, see Further Consideration section of main report regarding the planned move of genetic testing to Manchester.
HP-304	**Specialist Services** Timely access to the following specialist staff and services should be available as part of a HCCC service. HCs should be able to access these services through network arrangements: a. Obstetrics including reproductive counselling, information about pre-implantation genetic diagnosis and antenatal diagnosis b. Foetal medicine c. Vascular access (consultant surgeon or interventional radiologist with experience of venous access devices) d. Orthopaedic surgery e. Care of older people services f. Dental services g. HIV services h. Hepatology i. Medical genetics (Genetic Counselling Services) j. Pain management services k. Rheumatology Specialist services should have an appropriate level of specialist expertise in the care of people with inherited and acquired bleeding disorders.	Y	

Ref	Standard	Met?	Comments
HP-402	**Facilities and Equipment** Facilities and equipment appropriate for the service provided should be available including: a. Fridges b. Storage c. Clinical rooms for staff of all disciplines to see patients and carers d. Room for multi-disciplinary discussion e. Room for educational work with patients and carers f. Office space for staff g. Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all clinical areas All equipment should be appropriately checked and maintained.	Y	
HP-499	**IT System** IT systems should be in use for: a. Storage, retrieval and transmission of patient information, including access to the latest vCJD status and family tree b. Patient administration, clinical records and outcome information c. Data to support service improvement, audit and revalidation d. Alerting the specialist team when patients attend the Emergency Department	Y	
HP-501	**Diagnosis Guidelines for Patients with Suspected Inherited and Acquired Bleeding Disorders** Guidelines on diagnosis should be in use covering at least a. Haemophilia A b. Haemophilia B c. Von Willebrand Disease d. Acquired haemophilia e. Inherited platelet disorders f. Other less common and rare bleeding disorders	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	
HP-503	**Clinical Guidelines** The following clinical guidelines should be in use: a. Management of acute bleeding episodes, including patients with inhibitors b. Inhibitor screening c. Immune tolerance therapy d. Dental care e. Care of patients with hepatitis C f. Care of patients with HIV g. Antenatal care, delivery and care of the neonate h. Management of synovitis and target joints i. Long term surveillance of musculoskeletal health j. "For public health purposes": care of patients at risk of vCJD who are undergoing surgery	Y	However, clarity for adolescent patients transitioning from other centres who have a late onset inhibitor is required, and reviewers noted that fluid restrictions for paediatric patients receiving DDAVP was not defined in the document presented to reviewers.
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	See Good Practice section of the main report regarding the surgical pathway.
HP-595	**Guidelines on Transition and Preparing for Adult Life** Guidelines on transition of young people from paediatric to adult services should be in use covering at least: a. Taking responsibility for their own care b. Involvement of the young person and, where appropriate, their carer in planning the transfer of care c. Joint meeting between paediatric and adult services in order to plan the transfer d. Allocation of a named coordinator for the transfer of care e. A preparation period prior to transfer f. Arrangements for monitoring during the time immediately after transfer g. Advice for young people going away from home to study, including: i. registering with a GP ii. how to access emergency and routine care iii. how to access support from their Comprehensive Care Centre iv. communication with the young person's new GP	Y	
HP-599	**Care of Vulnerable People** Guidelines for the care of vulnerable children, young people and adults should be in use including: a. Restraint and sedation b. Missing patients c. Mental Capacity Act and the Deprivation of Liberty Safeguards d. Safeguarding e. Information sharing f. Palliative care g. End of life care	Y	

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

Ref	Standard	Met?	Comments
HP-603	**Multi-Disciplinary Clinics** The following multi-disciplinary clinic arrangements for patients with inherited and acquired bleeding disorders should be in place: a. Involvement of medical, specialist nursing and physiotherapy staff in clinics b. Availability of social work and psychology staff in clinics c. Combined clinics or other arrangements for multi-disciplinary discussion with: i. orthopaedics ii. rheumatology iii. obstetrics and gynaecology iv. paediatrics v. dental vi. HIV / hepatology	N	See Concerns section of the main report.
HP-604	**Liaison with Other Services** Review meetings should be held at least annually with specialist services to consider liaison arrangements and address any problems identified.	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	N	See the Concerns section of the main report.
HP-702	**Audit** The services should have a rolling programme of audit covering at least: a. Clinical guidelines (QS HP-503) b. Emergency and out of hours care (QS HP-504) c. Initiation of prophylaxis in children d. Inhibitor surveillance and Immune Tolerance Induction (ITI) e. Clinical reviews including joint scores (QS HP-103 & 104) f. Concentrate use and wastage	N	Reviewers did not see evidence of a formal audit programme, or completed audits relating to all the requirements specified in this Quality Standard.
HP-706	**Research** The service should actively participate in research relating to the care of patients with bleeding disorders.	Y	

Ref	Standard	Met?	Comments
HP-798	**Multi-disciplinary Review and Learning** The service should have multi-disciplinary arrangements for review of and implementing learning from: a. Positive feedback, complaints, outcomes, incidents and 'near misses' b. Morbidity and mortality c. Haemophilia Dashboard d. Review of UKHCDO Annual Report benchmarking information on concentrate use e. Ongoing reviews of service quality, safety and efficiency f. Published scientific research and guidance	Y	
HP-799	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	Reviewers saw that some documents were still in draft and did not have author details or 'developed on' or review dates

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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	It was not clear whether all patients were registered at Addenbrookes (moderate and mild) or that their care was monitored from the CCC.
HY-203	**Inherited and Acquired Bleeding Disorders Network Leads** The network should have a nominated: a. Lead consultant and deputy b. Lead specialist nurse c. Lead physiotherapist d. Lead clinical or counselling psychologist e. Lead manager	N	See the Concerns section of the main report regarding lack of psychology and physiotherapy input.
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	The host team members were not aware of any formal network agreement, although they offered clinical advice and guidance as necessary to colleagues working in the region, and colleagues in linked hospitals reported no difficulty in accessing such support. No other aspects of network functioning such as shared audits, or education and training for all staff groups were in place. There was a regional haemostasis meeting held approximately once a year.
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	However, reviewers heard that the Cambridge team had shared their guidelines with linked centres.

Ref	Standard	Met?	Comments
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	The host team members were not aware of any formal network agreement, although they offered clinical advice and guidance as necessary to colleagues working in the region, and colleagues in linked hospitals reported no difficulty in accessing such support. No other aspects of network functioning such as shared audits, or education and training for all staff groups were in place. There was a Regional Haemostasis meeting, held approximately once a year.
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.	N	The host team members were not aware of any formal network agreement, although they offered clinical advice and guidance as necessary to colleagues working in the region, and colleagues in linked hospitals reported no difficulty in accessing such support. No other aspects of network functioning such as shared audits, or education and training for all staff groups were in place. There was a regional haemostasis meeting, held approximately once a year.
HY-703	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with inherited and acquired bleeding disorders b. A list of research trials available to all patients within the network.	Y	
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	The host team members were not aware of any formal network agreement, although they offered clinical advice and guidance as necessary to colleagues working in the region, and colleagues in linked hospitals reported no difficulty in accessing such support. No other aspects of network functioning such as shared audits, or education and training for all staff groups were in place. There was a regional haemostasis meeting, held approximately once a year.

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	There had been no contact with commissioners, although it was acknowledged that their input would be valuable in shaping and agreeing service developments both within the Centre and across the region. Discussion with commissioners will be required to clarify their expectations around formalising a network in the region, with the Cambridge CCC at its hub, and what resource might be available to support this.
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	There had been no contact with commissioners, although it was acknowledged that their input would be valuable in shaping and agreeing service developments both within the Centre and across the region. Discussion with commissioners will be required to clarify their expectations around formalising a network in the region, with the Cambridge CCC at its hub, and what resource might be available to support this.
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	There had been no contact with commissioners, although it was acknowledged that their input would be valuable in shaping and agreeing service developments both within the Centre and across the region. Discussion with commissioners will be required to clarify their expectations around formalising a network in the region, with the Cambridge CCC at its hub, and what resource might be available to support this.

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