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

Sheffield Children's NHS Foundation Trust

Visit Date: 3rd May 2019

Report Date: September 2019

8831

Index

Introduction

This report presents the findings of the peer review of services for people with Inherited and Acquired Haemophilia and other Bleeding Disorders at Sheffield Children's NHS Foundation Trust, which took place on 3rd 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:

- Sheffield Children's NHS Foundation Trust
- NHS England – North East and Yorkshire Region

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 Sheffield Children's NHS Foundation Trust 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 family who took time to meet the review team.

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

About Quality Review Service

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

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

Sheffield Children's NHS Foundation Trust

Situated in the north of England, Sheffield Children's NHS Foundation Trust (SCH) provided acute and tertiary specialist services for 2.5 million children in Yorkshire and Humberside. A comprehensive range of services relevant to children with bleeding disorders was available, including surgery, dental care, intensive care and clinical genetics.

Haemophilia services were integrated within the haematology/oncology department which treated children with both malignant and non-malignant diagnoses. Outpatient and day case care were provided in a large purpose-built facility created in 2018. If admission was required inpatient facilities were provided on the adjacent specialist haematology / oncology ward.

A comprehensive diagnostic service was available to investigate children with potential bleeding disorders aged between 0 and 16yrs, with assays available around the clock from the on-site haematology laboratory. The Centre director and the specialist haemophilia nurses co-ordinated diagnosis and management. Close to 200 children were registered with congenital bleeding disorders at the time of the visit between 35 and 40 of whom had severe haemophilia A or B. Severely affected children were reviewed every 3 months in the clinic led by a consultant or specialist nurse and annual joint reviews were provided by the haemophilia physiotherapist. Home delivery of factor concentrate was organised for those on prophylaxis. Comprehensive care was available for all patients including those with inhibitors. Children with milder disorders were followed up annually in a nurse-led telephone clinic.

All registered children had open access to the clinic and ward. Out of hours, the on-call paediatric haematology consultant was consulted, and this consultant co-ordinated the care of any attendances or enquiries for children with bleeding disorders. Reviews of patients were usually organised on the haematology ward rather than in the ED (See Emergency Department section below) to ensure that children were managed promptly and effectively by the specialist service.

Children remained under the SCH until they were aged between 16 and 18years, when they were transitioned to the neighbouring adult haemophilia centre at Sheffield Teaching Hospitals NHS Foundation Trust.

The adult and paediatric centres held regular joint MDTs to discuss families, including pregnant carriers and adolescent patients. This approach helped to ensure a co-ordinated approach and smooth transition between neonatal and paediatric care at SCH and between SCH and the adult haemophilia services. The MDT also served as a forum to create shared guidelines and to discuss common issues from NHS England, UKHCDO and local commissioners.

The table below summarises the conditions and severity of patients registered with the Centre at the time of the review:

Condition	No. patients	No. patients who had an annual review in last year	No. inpatient admissions in last year
Haemophilia A	63 in total: 30 severe, 1 moderate, 32 mild	61	8
Haemophilia B	12 in total: 7 severe, 5 mild	12	2
Von Willebrand	65 in total: 7 severe, 9 moderate, 49 mild	60	3
Other	36 in total: 9 severe, 1 moderate, 26 mild	36	16

Emergency Care

Parents and patients were given contact numbers for the haemophilia specialist nurses as the first point of contact for problems during routine working hours. If the nurse specialist was not available, they were asked to contact the on-call haematology consultant. For emergency problems out of hours, parents and patients were asked to call the hospital switchboard and to ask for the on-call haematology consultant. If an emergency review was required, the child was generally brought to the day care area or the haematology ward (out of hours) and reviewed by the specialist nurse or specialty doctor, with supervision provided by the haematology consultant, who directed all management decisions. All patients had direct access to the department for review, and for admission if required.

When giving telephone advice, the haematology consultant would make a judgement as to whether the patient was best directed to the ED. For example, if immediate resuscitation was likely to be needed, or the patient was arriving via emergency ambulance, or had a suspected major head injury or fracture they would be directed to the ED. In these circumstances, the haematology consultant would liaise directly with the medical staff in the ED to ensure that the haemostatic aspects of management were appropriately addressed.

It was rare for a patient to present directly to the ED with a bleeding disorder symptom without the prior knowledge of the haematology team. However, the ED had written guidance to contact the haematology consultant to discuss management whenever a patient with a bleeding disorder attended the department. This advice was also recorded as an alert on the patient's electronic record.

Ward Care

There were six beds in bays and nine cubicles shared with other haematology and oncology patients. There was access to beds on the general paediatric wards (with patients remaining under the care of the paediatric haematology team) if the haematology / oncology ward was full.

Day Care and Outpatient Care

Patients were seen in a purpose-built outpatient and day care department for the exclusive use of haematology and oncology patients. There was a large waiting area, with toys and activities available, and a waiting area for adolescents. There were four consulting rooms and a further clinic room for physiotherapy use as well as individual rooms for, phlebotomy, counselling, the administration of treatment and dental assessment, and there was a large day care area with reclining chairs.

Community Care

The specialist haemophilia nurses organised home visits as and when required. They also liaised with local community nurses from other hospitals who might be involved if the patient lived a long distance from SCH and who required portacath® access or venepuncture, for example.

Return to Index

Review Visit Findings

Achievements

This successful service was a tribute to its team members who worked hard, flexibly, and with a great deal of mutual support to deliver care for children and families, despite lacking sufficient time from some key team members (See Concern 1). Individual team members were ambitious, with good plans for how they might develop the service if they had time to provide more than core clinical care, although they were doing this to a very high standard. There was passionate medical and nursing leadership, and other noteworthy team members included an enthusiastic data manager, who was a key team member and undertook an extended role, excellent laboratory staff, and a named paediatric dentist who was often on site and who worked very closely with the team. The psychologist, with limited time to devote to this service, managed to undertake some consultation work with the nurse specialists to help promote psychological thinking.

Patients and families were warmly appreciative of the sensitive and personalised care they received.

Much of the service was offered from bright and spacious new facilities, including the day unit and clinic area, a dental room and an adjacent physiotherapy clinic room. On the ward, there was a play area and school room dedicated to the use of children with haematology and oncology conditions.

There was a good research portfolio including a wider range of studies, supported by an on-site clinical research facility and two research nurses.

Good Practice

1. There was direct access to the specialist team for emergency assessment and care at all times, with families phoning to talk to the on-call consultant out of hours. After this triage conversation, the patient could be directed to the ward or to the hospital's ED if he/she had suffered significant trauma. Families from out of the area might be directed to their local ED. If the child was to present at the ED on site or distantly, the on-call consultant would phone the ED directly to alert them of the child's imminent arrival and to guide the haematological care thereafter.
2. Families of children with moderate or milder disorders living distantly from the Centre, who might have needed to attend their district general hospital, held an 'emergency dose' of factor at home to take with them should they need urgent care.
3. Documentation supporting the service was of a very high standard, and included clear and succinct diagnostic and clinical guidelines, a surgical pathway, and an overall operational policy. Hard copies of the clinical guidelines were kept readily available on the ward for easy access.
4. There were policies guiding a systematic recall of children with mild, unconfirmed bleeding issues in their early teens, in order to establish a diagnosis before transition to adult services, or to discharge if no significant abnormality was found, and also policies for the testing of potential carrier female relatives of affected individuals before they reached child-bearing age, with counselling as necessary.
5. Transition practice was good, with nurses from the adult service at the Royal Hallamshire Hospital (RHH) coming to meet the young person and family together with the paediatric team before the transfer was made. A familiar paediatric nurse usually accompanied the young person on their first attendance at the adult clinic. The age of transition was flexible according to the needs of the young person, ranging from 16 to 18 years.
6. There was a comprehensive rolling audit programme, with many audits having been completed, presented, and actioned. There were specific plans for audits in the forthcoming year.
7. Medical records were electronic, and the system worked well for the most part (although see Further Consideration 5). Positive features included an alert to the patient's bleeding disorder diagnosis, for the

benefit of other healthcare teams, which appeared as the first screen when opening the record, so that it was impossible to proceed without seeing it. The next screen was an 'information record', which summarised diagnosis, factor levels, presence of inhibitors, and specifics of prophylactic and emergency treatments. Consultants on-call had remote access to the system to see clinic letters and results and could also access results for children in neighbouring district general hospitals about whom they could be contacted out of hours.

8. Children with severe and moderate bleeding disorders had frequent appointments, usually being seen every three months, alternately by the lead consultant and a nurse specialist.

9. Children with milder disorders were often reviewed by telephone appointment with a nurse specialist. This was popular with families, and especially convenient for families living some distance away from the Centre. However, if there were any concerns, they would be recalled for a face to face review.

10. The hospital had recently established a 'Youth Forum', where 12 to 19 years old who had recently used the hospital and their siblings, were invited to give feedback and suggestions for improvements in services.

11. If children were requiring frequent appointments at the centre, for example for immune tolerance induction after having developed an inhibitor, families were offered free car parking for the duration.

12. Patients and families were invited to nominate any staff member for a Trust 'Star Award' and reviewers congratulated the senior nurse specialist who had won this award a number of times.

13. Document control was robust, with guidelines being on Q Pulse, but other documents also had record of authorship, approval and review dates.

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

Concerns

1. **Staffing**

   Some key team members had so little time allocated to the service that they could not work in the expected way as part of the core team, and children were not routinely receiving some important aspects of care.

   a. A physiotherapist was allocated to work with IABD patients for only four hours per month. This individual was therefore not able to work as part of the core team, was not able to be present at all clinic reviews for severe and moderately affected children and had managed to undertake joint scores on only approximately 50% of patients over the last year. The physiotherapist was not usually available to assess and help manage acute joint bleeds and had no effective cover. It was a concern that the physiotherapy service was not only minimal but also reactive, with no capacity to offer education about maintaining long term joint health.

   b. There had been a recent reduction in nurse specialist time from 1.6 to 1.4 WTE, and despite the fact that the two nurses also covered other non-malignant haematology services, including a growing haemoglobin disorder service, the team's request for an appointment to be made to cover these hours had not yet been granted.

   c. Although a psychologist was available to see these children and their families, the psychologist had no allocated time to do so and could not work in a fully integrated way in the service. Waiting times for routine appointments could be up to twelve weeks. Patients had reported that they would value more contact with a psychologist.

   d. There was no dedicated social worker available to work with younger children and families. The social worker from the adult team at RHH could sometimes help with young people at pre-transition age.

e. Although the Trust had approved the advertisement for a fourth consultant, it had not been possible yet to appoint into that post, so the remaining three consultants were working a 1:3 out of hours rota and were having to work intensively to manage the additional workload.

2. **Multi-disciplinary working**

   a. Given the lack of availability of key members, it was not possible for the team to undertake the expected regular multi-disciplinary meetings, which should be attended by a specialist physiotherapist, psychologist and social worker, to discuss the holistic needs and clinical management of children and any other service issues. Instead, the consultant, nurse specialists and physiotherapist met informally as and when needed.

   b. It is expected practice for clinic reviews routinely to include input from a specialist physiotherapist, and for a psychologist and social worker also to be available in clinics; this too was impossible at the current level of staffing provision.

Further Consideration

1. Although full multi-disciplinary meetings were not possible (See Concern 2a), it might be possible to establish a 'skeleton' multi-professional team meeting attended by the consultant, the nurse specialists, a biomedical scientist, and perhaps the data manager or other clerical staff. The other two consultants who undertook out of hours duties might usefully also attend when possible, both to familiarise themselves with children with active problems and to allow for discussion, challenge and / or support for clinical plans being made. This would be appropriate as an interim step until other staffing issues are resolved, when a fully functioning MDT meeting should be put in place

2. Although there was a good range of general and condition-specific information, the information was not available in age-appropriate versions for older children, and no information was seen in alternative formats or languages.

3. The school facilities were impressive. Other clinical facilities, although well set out, were mainly designed for younger children, with little provision for older children and teenagers.

4. Although the clinical areas catered for children with a range of haematological disorders, including bleeding disorders, it was not clear in the Centre signage or in posters or displays. The review team understood that a rack with information leaflets was put out at clinic times, but for families using the facilities at other times more specific signage and permanent information displays regarding haemophilia may be valuable and reassuring.

5. Although the electronic records system was serviceable for the most part, 'legacy' records from the time before the system was established had been scanned into a single file, which could run to hundreds of pages. This was cumbersome and time-wasting for staff needing to refer back to earlier records and search through these. The team saw that for the current records that were in clinical use, the filing was much clearer. Consideration could be given to ensuring that legacy records were better organised to enable easier access for clinicians.

6. Genetic test results were scanned into the system, as were hand drawn 'family trees' and the team may wish to explore some of the available software that can record this information.

7. The on-site dental service was excellent, although capacity was stretched. Trust-wide educational evenings for community dentists were run three or four times a year, and it may be valuable to include a session on bleeding disorders to educate and encourage community teams who might be able to offer some less specialist care in their surgeries.

8. Patient feedback had been sought and was mostly very positive. The team may want to revisit responses to see if there were any changes that could be effected to address some of the issues raised.

9. Operational management did not appear to have been contributing effectively to the running of the service, although a recently appointed manager was engaging more effectively. Some of the team members had been undertaking tasks that a well-functioning operational management team would usually be expected to support. Gaps in staffing, including those highlighted in previous service reviews, had not been addressed, and the management of the tasks of identifying and anticipating vacancies and recruiting in a timely manner had fallen to the clinical team.

General Comment

Neither the Centre team nor the medical managers who met the reviewing team were clear about which organisation(s) commissioned this service. There had been no meetings between clinicians and commissioners relating to this service for several years.

As far as the Centre team were aware, there was no formal network in place. Although there had been a meeting of clinicians and managers some time ago at which it had been agreed that the Sheffield Children's NHS Trust specialist team would provide cover the Hull centre when no coagulation consultant was available on-call, in practice this cover had seldom been required. The consultant leading the paediatric service at Hull did sometimes contact the Sheffield lead consultant for advice, which was freely given, and a previous visit to Hull by the review team had confirmed that the Hull team felt they could contact the Sheffield centre for any clinical issues. However, contacts between the two teams were limited to this ad hoc clinical support.

While networks are not fully established or functioning in all areas of the country, there are some networks in which specialist commissioner colleagues are actively engaged in all aspects of the service, including appointing flexible staffing across the different linked sites within the network, and supporting shared guidelines, shared clinical audits (allowing for benchmarking), educational activities, and review and learning meetings. The quality and equity of services for all the patients and families in the areas served can best be assured in these networks.

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

Return to Index

APPENDIX 1 Membership of Visiting Team

Visiting Team		
Catherine Benfield	Paediatric Clinical Nurse Specialist	Alder Hey Children's NHS Foundation Trust
Leah Denver	Data Manager, Haemophilia Unit	Birmingham Women's and Children's NHS Foundation Trust
Dr Jennifer Gardner	Clinical Psychologist	Great Ormond Street Hospital for Children NHS Foundation Trust
Jemma Leigh	Paediatric Physiotherapist	Manchester University NHS Foundation Trust
Andy Martin	Patient representative	
Dr Jayashree Motwani	Consultant Paediatric Haematologist	Birmingham Women's and Children's NHS Foundation Trust

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

Return to Index

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

	Number of Applicable QS	Number of QS Met	% met
Comprehensive Care	37	31	84%
Network	8	0	0%
Commissioning	3	0	0%
Total	48	31	65%

Return to Index

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	However, reviewers could not see evidence for h (ii) and h (iii). Reviewers also noted that they did not feel that the information was particularly child / adolescent friendly

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

Ref	Standard	Met?	Comments
HP-103	**Plan of Care** Each patient and, where appropriate, their carer should discuss and agree their Plan of Care, and should be offered a written record covering at least: a. Agreed goals, including life-style goals b. Self-management c. Planned assessments, therapeutic and/or rehabilitation interventions d. Early warning signs of problems, including acute exacerbations, and what to do if these occur e. Agreed arrangements with school or other education provider and preparation for adult life (children and young people only) f. Planned review date and how to access a review more quickly, if necessary g. Who to contact with queries or for advice The Plan of Care should be communicated to the patient's GP and to relevant other services involved in their care.	Y	
HP-104	**Review of Plan of Care** A formal review of the patient's Plan of Care should take place at least six monthly for patients with severe or moderate haemophilia and at least annually for other patients. This review should involve the patient, where appropriate their carer, and appropriate members of the multi-disciplinary team. Haemtrack results should be reviewed (if applicable) and the outcome of the review should be communicated in writing to the patient and their GP.	Y	
HP-105	**Contact for Queries and Advice** Each patient and, where appropriate, their carer should have a contact point within the service for queries and advice. A clear system for triage of urgent clinical problems should be in place. If advice and support is not immediately available for non-urgent enquiries, then the timescales for a response should be clear. Response times should be no longer than the end of the next working day. All contacts for advice and a sample of actual response time should be documented.	Y	
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	See Further Consideration section of main report regarding visibility of the service, signage etc. Reviewers also noted that the facilities were mostly targeted at younger children rather than adolescents.
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	Reviewers saw evidence of information relating to national societies etc., but could not see evidence of more localised support networks for carers.
HP-199	**Involving Patients and Carers** The service should have: a. Mechanisms for receiving regular feedback from patients and carers about treatment and care they receive b. Mechanisms for involving patients and carers in decisions about the organisation of the service c. Examples of changes made as a result of feedback and involvement of patients and carers	Y	

Ref	Standard	Met?	Comments
HP-201	**Lead Consultant and Lead Nurse** A nominated lead consultant and lead nurse should have responsibility for staffing, training, guidelines and protocols, service organisation, governance and for liaison with other services. The lead consultant and lead nurse should be registered healthcare professionals with appropriate specialist competences and should undertake regular clinical work within the service and specific time allocated for their leadership role.	Y	
HP-202	**Staffing Levels and Skill Mix** Sufficient staff with appropriate competences should be available for out-patient, day unit and in-patient care and for support to urgent care services. Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network. All staff should undertake regular Continuing Professional Development of relevance to their work in the inherited and acquired bleeding disorders services. Staff working with children and young people should have competences in caring for children as well as in the care of people with bleeding disorders. Cover for absences should be available. In HCCCs these staff should have sessional time allocated to their work with the IABD service. In HCs the arrangements for accessing staff who do not have sessional time allocated to the IABD service should be clearly defined. Staffing should include: a. Medical staff: i. Consultant specialising in the care of people with inherited and acquired bleeding disorders available during normal working hours ii. On-call consultant haematologist (24/7) iii. Arrangements for advice from a consultant specialising the care of people with inherited and acquired bleeding disorders (if not on call) b. Specialist nursing staff: i. Bleeding disorders specialist nurses (5/7) ii. Ward, out-patient and day unit staff with competences in the care of people with inherited and acquired bleeding disorders. c. Clinical specialist physiotherapist d. Biomedical Scientist and Clinical Scientist (further detail on the requirements are included in HP-303) e. Clinical or counselling specialist psychologist or appropriately trained psychotherapist f. Specialist senior social worker g. Data manager	N	Reviewers heard that there was a shortage of nursing input and no social worker. There were insufficient hours available from the physiotherapy and psychology service.

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 overarching matrix or list (see notes section for this Quality Standard), although individual CPD was evident for some staff.
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	
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	
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	
HP-504	**Emergency Department Guidelines** Guidelines on management of patients with inherited and acquired bleeding disorders in the Emergency Department should be in use.	Y	

Ref	Standard	Met?	Comments
HP-505	**Guidelines on Care of Patients requiring Surgery** Guidelines on the care of patients with inherited and acquired bleeding disorders who require surgery should be in use covering at least: a. Involvement of surgical and inherited and acquired bleeding disorders service in agreement of a written plan of care prior to, during and post-surgery b. Communication of the agreed plan of care to all staff involved in the patient's care prior to, during and post-surgery c. Documentation of care provided d. Arrangements for escalation in the event of unexpected problems	Y	
HP-595	**Guidelines on Transition and Preparing for Adult Life** Guidelines on transition of young people from paediatric to adult services should be in use covering at least: a. Taking responsibility for their own care b. Involvement of the young person and, where appropriate, their carer in planning the transfer of care c. Joint meeting between paediatric and adult services in order to plan the transfer d. Allocation of a named coordinator for the transfer of care e. A preparation period prior to transfer f. Arrangements for monitoring during the time immediately after transfer g. Advice for young people going away from home to study, including: i. registering with a GP ii. how to access emergency and routine care iii. how to access support from their Comprehensive Care Centre iv. communication with the young person's new GP	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	N	See Concerns section of main report.

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 Quality Standard HP-202 regarding insufficient psychology and physiotherapy hours, resulting in these specialists not always being able to attend MDT clinics.
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	The reviewers agreed with the Centre's self-assessment.
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	Y	
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.	Y	

Return to Index

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	The reviewers agreed with the Centre's self-assessment
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	The reviewers agreed with the Centre's self-assessment
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 reviewers agreed with the Centre's self-assessment
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	The reviewers agreed with the Centre's self-assessment
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 reviewers agreed with the Centre's self-assessment
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.	N	The reviewers agreed with the Centre's self-assessment
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	The reviewers agreed with the Centre's self-assessment

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

Return to Index

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	The reviewers agreed with the centre's self-assessment.
HZ-701	**Clinical Quality Review Meetings** Commissioners should regularly review the quality of care provided by: a. Each service, including achievement of QS HP-701 b. Each network, including achievement of QS HY-701 and QS HY-798 c. Service and network achievement of relevant QSs	N	The reviewers agreed with the centre's self-assessment.
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	The reviewers agreed with the centres self-assessment.

Return to Index