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

Guy's and St Thomas' NHS Foundation Trust

Visit Date: 4th December 2019

Report Date: March 2020

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Contents

Introduction

This report presents the findings of the peer review of services for people with Inherited and Acquired Haemophilia and other Bleeding Disorders at Guy's and St Thomas' NHS Foundation Trust which took place on the 4th December 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:

- Guy's and St Thomas' NHS Foundation Trust
- NHS England (London)

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

About the Quality Review Service

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

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

Acknowledgments

Quality Review Service would like to thank the staff of the Guy's and St Thomas' 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 and parents who took time to meet the review team. Thanks are also due to the visiting team (**Appendix 1**) and their employing organisations for the time and expertise they contributed to this review.

Guy's and St Thomas' Comprehensive Care Centre

The Haemophilia Service at Guy's and St Thomas'/Evelina NHS Trust (GSTT) was one of the largest services in the UK. The service managed the care of children and adults, and the Centre was the lead Comprehensive Care Centre for the South Thames Network. Most patients were based in London and Southern England but the Centre treated patients from all over the UK.

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

Condition		Number of patients	Number of patients who had an annual review in last year	Number of inpatient admissions in last year
Haemophilia A	Adults	Severe 125 Moderate 31 Mild 116	243	26
	Children	Severe 43 Moderate 4 Mild 36	81	19
Haemophilia B	Adults	Severe 18 Moderate 12 Mild 16	39	7
	Children	Severe 9 Moderate 2 Mild 0	11	7
Von Willebrand	Adults	Severe 10 Moderate 11 Mild 234 N/A 9	216	10
	Children	Severe 3 Moderate 7 Mild 44 N/A 1	54	12
Other	Adults	Severe 23 Moderate 15 Mild 254 N/A 196	397	8
	Children	Severe 4 Moderate 1 Mild 81 N/A 17	95	18

Emergency Care

There was a 24/7 service for haemophilia and other bleeding disorders. All patients had registration cards with emergency contact numbers. During office hours there was a dedicated telephone line and email contacts for the haemophilia nurses who triaged patients. Out of hours, all calls from patients were relayed to the on-call

Specialist Registrar (SpR) for haematology who provided advice to the patient. Operationally, most patients were directed to the Emergency Department (ED), where their key observations were done and where they were reviewed by the SpR who liaised with the on-call consultant for haemostasis and thrombosis. All patients presenting to the ED were directed to the haematology SpR.

Ward Care

If required, patients were admitted to the medical wards at St Thomas' or to the relevant ward at Guy's hospital e.g. ENT or orthopaedics.

Day Care

Day care was provided at the haemophilia unit at St Thomas' for adults and at the Evelina for children.

Outpatient Care

Outpatient care was provided at the haemophilia unit at St Thomas' for adults and at the Evelina for children.

Community Based Care

In the adult service, community visits were directed by the haemophilia nursing teams at GSTT in liaison with the community nursing teams. In the paediatrics service, home and school visits were undertaken by the paediatric haemophilia nursing team and the paediatric physiotherapist.

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Review Findings

Achievements

After a period of staffing challenges, the adult team had recently made two new consultant appointments and was providing a good service for its patients.

The paediatric team was well established but had also faced challenges with low staffing numbers. The team had been able to appoint two additional nurse specialists and was working well together in a fully multi-professional way.

Both the adult and the paediatric teams were well supported by clinical and non-clinical managers.

Patient feedback was overwhelmingly positive: patients felt they were getting a 'first rate service', and many were prepared to travel long distances to be managed by the Centre, by-passing more local treatment centres. All members of the paediatric team were greatly appreciated by the parents who met the review team, and in the adult service, the contribution made by the adult physiotherapist - who had been a constant over times of change - was also particularly noted by patients.

There was an active and broad research portfolio. The Centre was a gene therapy infusion site and there were currently nine studies open to recruitment with a further six being set up.

Good Practice

1. There were some very successful working partnerships with colleagues in other specialties, including:
    a. The paediatric physiotherapist and paediatric rheumatology consultant were working together to plan and promote exercise regimens for children who had suffered joint bleeds;
    b. An adult haematologist, together with a lead orthopaedic surgeon specialising in knee surgery, led monthly combined clinics reducing the waiting time for their patients to be seen and referred to the relevant orthopaedic MDT for spinal or other joint issues. There was a streamlined pathway for peri-operative care for elective surgery, which took place on the Guy's Hospital site;
    c. An adult dental consultant attended the MDT meetings to discuss referrals. They had jointly drawn up an 'order form' in which the dental surgeon stratified the risk of bleeding from a planned procedure in each patient, to guide the bleeding disorder team as to the degree of factor replacement necessary;
    d. In relation to antenatal care and delivery, the review team learned of a carefully planned and successful obstetric pathway; and
    e. In relation to Interventional Radiology for children, there were dedicated list spaces and a prompt and responsive service for intravenous device insertion.
2. Transition practice was excellent, with a consultant, nurse specialist and physiotherapist from both the paediatric and the adult teams jointly reviewing a young person from the age of approximately 14 years. The young person continued to attend this combined clinic until the age of approximately 18, when their care was taken over by the adult team.
3. Carers' needs for both services were supportively managed, and a psychologist worked particularly with parents of teenage children over the transition period.

4. Radioactive synovectomy1 was available on-site for adult patients.
5. Haemtrack compliance was high (80%). This had been achieved by a formalised process of encouragement and reminders.
6. The electronic patient record had a small 'alert' sign on its front page which, when clicked indicated that the patient had a bleeding disorder. The records system was accessible remotely for consultants on-call out-of-hours at home, and they could also input their comments and advice remotely, using 'e-noting'.
7. Several of the guidelines were noteworthy, including a Trust-wide 'quick guide to safeguarding', and a guideline on the management of girls and women with menorrhagia.
8. There was easy access to a gynaecology nurse consultant with an interest in bleeding disorders, and the care of this group of patients appeared to be excellent.
9. There was clear written guidance for some administrative processes underpinning the service, including a clear policy for the management of adult patients who did not attend clinics, giving specific actions at each stage.
10. There was an innovative approach to teaching teachers and nurses at the schools attended by the children, using 'Skype' sessions, saving travelling time for the professionals while still enabling them to give personal tuition to school staff.
11. Document control was systematic, with policies and guidelines indicating authorship and dates of approval and planned review.

Immediate Risks

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

Concerns

1. **Adult nursing team**

   There was a lack of clarity in the management structure for the adult nurse specialists. The review team heard that there was a vacant Band 7 'manager' post, but it was unclear how this role fitted within the specialist nursing team, and who provided senior nursing input to the team. Appraisal processes were not identifying specific training and educational needs, in line with the Haemophilia Nursing Association competency framework, and there was no follow through with opportunities to undertake relevant CPD. The Band 6 nurses were also undertaking some tasks that were not appropriate to their banding, such as taking routine height and weight measurements for patients in busy thrombosis clinics. They were additionally covering some sickness absence in the research nursing team. Their roles appeared task-orientated and their clinical potential was not being utilised in the more rewarding specialist roles such as undertaking nurse-led clinics or actively participating in multi-disciplinary care and decision making. The review team heard there was a sense of frustration in their work. While undertaking an advanced clinical assessment course is not necessary before taking on more autonomous practice, completion of that training might make the nurses feel more confident about taking on such work, and allow other members of the clinical team to recognise their abilities to do so.

[1] **Radioactive synovectomy** - is a very effective and gentle procedure, used for rapid and sustained pain relief of severe joint pain or arthritis, such as osteoarthritis. Through targeted sclerotisation of the synovial membrane with radioactive substances, lasting relief from pain and inflammation is achieved in most cases.

2. **Staffing shortfalls (Adult and paediatric teams)**

   a. Psychosocial care - There was a dedicated psychologist working with the team, and her input was highly valued by staff and patients, but she had only 0.2 WTE (one day per week) dedicated to the service, which was not sufficient for a service of this size. Her support for young people and parents over the transition period was important, but she only had time available to work with patients with the highest-level needs, and little time to undertake any support work within the professional team. There was no dedicated social worker affiliated to the paediatric or the adult team, and while patients could access the general hospital service, this meant that no individual worker had become acquainted with the conditions and the range of challenges that patients faced, in order to help them more efficiently.

   b. Senior paediatric medical staff - There was a single paediatric haematologist delivering the service, supported by two non-malignant haematologists on a 1:3 on call rota. However, if a patient presented with complex bleeding problems when the non-malignant haematologists were on-call, the paediatric haematologist was contacted, so that she was essentially working an informal 1:1 on call. Senior medical input to the service in general was dependent on this single individual, which was not sustainable.

3. **Network data**

   This centre was the hub of the South Thames Network, and was linked with haemophilia centres at St George's University Hospitals NHS Foundation Trust and University Hospital Lewisham. However, aspects of the network were not functioning (see general comment below), and there was a concern that the Centre team had no clear record of the numbers of patients with different disorders living over the wide geographical area from which they received referrals, and no oversight of factor usage and wastage, or clinical quality measures for patients attending the linked centres.

Further Consideration

1. In the adult service, there was a single 'patient information pack' for introduction to the service. This was not considered to be the most useful form for patients and carers. Although contact information was included, the document was lengthy and relevant information had to be looked for rather than being easily identifiable. The document included information about all bleeding disorders, whereas patients really want targeted information that deals with their own condition. The details in the document about HIV and hepatology clinics would not be necessary for most patients and could cause concern. Patients said that the adult service sometimes felt rather reactive, and that they sought information from other sources.

2. Reviewers saw some clinical audits and their outcomes for the adult and paediatric services, but these did not include some of the key areas such as audit against clinical guidelines, emergencies and out-of -hours care. Completion of these would enable the Centre to confirm and demonstrate its level of performance and consistency in treatment and practice.

3. In the adult multi-professional review clinics, patients typically saw a consultant individually, and then might additionally see the physiotherapist and/or nurse separately. More usual practice is for all patients to see the professionals simultaneously for a combined assessment, to which each professional brings their own different approach and expertise.

4. The laboratory was run independently by 'Viapath'. Efforts had been made to bridge the gap between the organisations in the interests of the service, and a biomedical scientist was a member of the MDT and attended meetings regularly. However, the facility for teaching haematologists in training in the laboratory was no longer available, which was a considerable loss to them.

5. The general hospital facilities were of a very high standard but it was noted that although there were seven consulting rooms in the adult centre, when large thrombosis clinics were taking place, it could be difficult to find a room to assess and treat any 'walk in' patients with bleeding problems. In paediatrics, the facilities were rather dispersed, with only two small clinic rooms; these were adjacent to a sleep laboratory so that attending children had to be asked to be quiet before and during their consultations.

6. There was no robust process in place to identify, and call up for testing and counselling, obligate or potential female carrier relatives before they reached reproductive age.

7. The guidelines referred in several places to 'blood product support', which was misleading as the majority of factor used was recombinant, and not derived from blood donations.

8. In the adult service, home visits were seldom undertaken. With an ageing population, the team might consider how they could offer these, and also identify an elderly medicine consultant colleague with whom they could work jointly when older patients develop co-morbidities.

9. One of the adult consultant haematologists had a joint appointment at GSTT and St George's University Hospitals NHS Foundation Trust. He had been advised that statutory and mandatory training undertaken at one site would not be honoured at the other, and so he was having to undertake two sets of identical training updates. For him, and other professionals in shared appointments, it may be possible to reach agreement that one Trust would accept evidence of training undertaken at the other.

10. Although orthopaedic surgery at Guy's Hospital worked well, reviewers heard from some adult patients that their experience of having surgical procedures undertaken at the Trust, and particularly the interface between the surgical teams and the haemophilia team, had not been positive. Consideration should be given to identifying actions that could be taken to ensure that communication is improved in order to enhance the patient experience.

11. Reviewers heard from patients and parents that they would find it useful to have a patient forum to discuss issues with the team and with each other.

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General Comment

The South Thames Network, which had this CCC at its centre and was linked with haemophilia centres at St George's University Hospitals NHS Foundation Trust and University Hospital Lewisham, was not currently fulfilling the requirements of the network standards. The paediatric team undertook regular outreach clinics at Lewisham, and the adult team had also recently started there, there was sharing of guidelines between the three sites, and patients at all the sites could be offered inclusion in research studies undertaken at the CCC, but other elements were not in place. There had been no recent network meetings, no data sharing (see Concern 3), no mechanisms for involving patients and carers in feedback about the services at the other centres, and no shared audits or recent educational events. It would be helpful to try to re-establish some meetings between the teams at the three sites, to work towards these network functions for the benefit of patients and staff at all of them, and the teams at the CCC would be keen to progress work in this way.

In addition, patients registered at the Centre lived across a wide area of Southern England and might be taken in an emergency to their local District General Hospital (DGH). Linked haematologists and paediatricians across this informal network of DGHs might usefully also be invited to some shared educational opportunities and review and learning sessions.

No direct engagement by specialist commissioners with the teams was evident at the time of the review. Their involvement and support would be necessary if the network is to be re-established and developed in this way.

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APPENDIX 1 Membership of Visiting Team

Visiting Team		
Dr Nicola Curry	Consultant Haematologist	Oxford University Hospitals NHS Foundation Trust
Charlene Dodd	Physiotherapist	East Kent Hospitals University NHS Foundation Trust
Anna Farrell	Paediatric Clinical Nurse Specialist	University Hospitals Bristol NHS Foundation Trust
Gemma Gardner	Patient representative	
Joanna Nightingale	Head Biomedical Scientist	East Kent Hospitals University NHS Foundation Trust
Dr Fernando Pinto	Consultant Paediatric Haematologist	NHS Greater Glasgow and Clyde
Debra Pollard	Lead Nurse, Haemophilia	Royal Free London NHS Foundation Trust
David Stephensen	Physiotherapist	East Kent Hospitals University NHS Foundation Trust

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

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APPENDIX 2 Compliance with the Quality Standards

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

Table 1 - Percentage of Quality Standards met

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

Service	Number of applicable QS	Number of QS met	% met
Comprehensive Care Centre	37	32	86
Network	8	2	25
Commissioning	3	1	33
Total	**48**	**35**	**73**

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Haemophilia Comprehensive Care 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, for the adult service, although an 'Introduction to the adult service' patient pack was seen, reviewers felt that this was lengthy, not in plain English, and was mainly a 'signposting document'. In addition, it did not cover all the aspects of this Standard.

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	N	Reviewers felt that this was limited, or in some cases missing, for the adult service: 'b' 'd', 'o' and 'r', limited information was available; 'g', 'l', 'q' and 's' was missing.

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.	N	This was in place for paediatrics. However, in the adult service not all clinics were taking place in a fully multi-disciplinary way.
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, see Further Consideration 7: It was noted that although there were seven consulting rooms in the adult centre, when large thrombosis clinics were taking place, it could be difficult to find a room to assess and treat any 'walk in' patients with bleeding problems. In paediatrics, the facilities were rather dispersed, with only two small clinic rooms that were adjacent to a sleep laboratory so that attending children had to be asked to be quiet before and during their consultations.
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	

Ref	Standard	Met?	Comments
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	
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	

Ref	Standard	Met?	Comments
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.
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 overall training matrix in place for either service.

Ref	Standard	Met?	Comments
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	This was a well-managed service and there was valuable input from the laboratory into the MDT. Work was collaborative, although there were often delays in getting results back from samples received from the Guys Hospital site.
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	There was limited information for ‘e’.

Ref	Standard	Met?	Comments
HP-402	**Facilities and Equipment** Facilities and equipment appropriate for the service provided should be available including: a. Fridges b. Storage c. Clinical rooms for staff of all disciplines to see patients and carers d. Room for multi-disciplinary discussion e. Room for educational work with patients and carers f. Office space for staff g. Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all clinical areas All equipment should be appropriately checked and maintained.	Y	See HP-194.
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	However, there was no information in relation to home visits for the adult service.
HP-602	**Multi-Disciplinary Team Meetings** Multi-disciplinary team meetings to discuss patients' plans of care should take place regularly involving: a. All core members of the specialist team (HP-202) b. Senior biomedical scientist or clinical scientist with responsibility for the Coagulation Laboratory c. HC staff who are regularly involved in the patient's care as part of network arrangements	Y	

Ref	Standard	Met?	Comments
HP-603	**Multi-Disciplinary Clinics** The following multi-disciplinary clinic arrangements for patients with inherited and acquired bleeding disorders should be in place: a. Involvement of medical, specialist nursing and physiotherapy staff in clinics b. Availability of social work and psychology staff in clinics c. Combined clinics or other arrangements for multi-disciplinary discussion with: i. orthopaedics ii. rheumatology iii. obstetrics and gynaecology iv. paediatrics v. dental vi. HIV / hepatology	Y	
HP-604	**Liaison with Other Services** Review meetings should be held at least annually with specialist services to consider liaison arrangements and address any problems identified.	Y	
HP-701	**Data Collection** The following data should be collected: a. UK National Haemophilia Database data on all patients b. Data on concentrate use and bleeds, either through Haemtrack or an equivalent mechanism c. Data required to complete the UKHCDO National Haemophilia Dashboard or other national mechanisms	Y	
HP-702	**Audit** The services should have a rolling programme of audit covering at least: a. Clinical guidelines (QS HP-503) b. Emergency and out of hours care (QS HP-504) c. Initiation of prophylaxis in children d. Inhibitor surveillance and Immune Tolerance Induction (ITI) e. Clinical reviews including joint scores (QS HP-103 & 104) f. Concentrate use and wastage	N	Audit evidence was limited and did not cover all elements of this Quality Standard.
HP-706	**Research** The service should actively participate in research relating to the care of patients with bleeding disorders.	Y	See Achievements section of the main report.

Ref	Standard	Met?	Comments
HP-798	**Multi-disciplinary Review and Learning** The service should have multi-disciplinary arrangements for review of and implementing learning from: a. Positive feedback, complaints, outcomes, incidents and 'near misses' b. Morbidity and mortality c. Haemophilia Dashboard d. Review of UKHCDO Annual Report benchmarking information on concentrate use e. Ongoing reviews of service quality, safety and efficiency f. Published scientific research and guidance	Y	
HP-799	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	

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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	See the General Comment section of the main report.
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 General Comment section of the main report.
HY-204	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HP-203.	N	See the General Comment section of the main report.
HY-503	**Guidelines** Network guidelines should have been agreed covering: a. Diagnosis for patients with suspected inherited and acquired bleeding disorders (QS HP-501) b. Concentrate use and monitoring (QS HP-502) c. Clinical guidelines (QS HP-503) d. Management of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) e. Care of patients requiring surgery (QS HP-505) f. Transition and preparing for adult life (QS HP-595)	Y	
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	See the Concerns and General Comment section of the main report.
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.	N	See the General Comment section of the main report.
HY-703	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with inherited and acquired bleeding disorders b. A list of research trials available to all patients within the network.	Y	

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

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Commissioning

Ref	Standard	Met?	Comments
HZ-601	**Commissioning of Services** Commissioners should have agreed the configuration of clinical networks including: a. Designated Comprehensive Care Centres and Haemophilia Centres and the relationships between them b. Whether the service cares for children, adults or both c. Referral pattern to each service, taking into account the type of patients who will be treated by each team	Y	
HZ-701	**Clinical Quality Review Meetings** Commissioners should regularly review the quality of care provided by: a. Each service, including achievement of QS HP-701 b. Each network, including achievement of QS HY-701 and QS HY-798 c. Service and network achievement of relevant QSs	N	Reviewers heard that meetings with commissioners had not taken place for some time.
HZ-798	**Network Review and Learning** Commissioners should attend a Network Review and Learning meeting (HY-798) at least once a year for each network in their area.	N	Reviewers heard that meetings with commissioners had not taken place for some time.

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