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

Lewisham and Greenwich NHS Trust

Visit Date: 28th January 2020

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 Lewisham and Greenwich NHS Trust that took place on the 28th January 2020.

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

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

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

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

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

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

- Lewisham and Greenwich NHS Trust
- NHS England and NHS Improvement (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 at the Lewisham Haemophilia Centre for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. We are grateful too to the patients 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.

Lewisham Haemophilia Centre

Lewisham was a designated haemophilia centre that had, since the 1960's, been providing services for patients with inherited and acquired bleeding disorders. At the time of the review, Lewisham Haemophilia Centre was part of Lewisham and Greenwich NHS Trust, which served a population of 750,000. The team worked collaboratively as a spoke of the Guy's and St Thomas' Comprehensive Care Centre (CCC) to provide care to adult patients. The Centre was also linked with the Queen Elizabeth Hospital Woolwich, providing support and accepting referrals from there.

The team was small but aimed to deliver care that was tailored to individual patient's needs, enabling them to cope well with their bleeding disorders. The team aimed to deliver evidence-based care consistently to its patients, whilst building relationships with them, which is essential for the management of long-term disorders.

Condition	Number of patients	Number of patients who had an annual review in last year	Number of inpatient admissions in last year
Haemophilia A	Severe - 5 Moderate - 8 Mild - 24	Severe - 5 Moderate - 8 Mild - 24	Severe – 1 Moderate – 4 Mild - 2
Haemophilia B	Severe – 4 Moderate – 2 Mild - 7	Severe – 4 Moderate – 1 Mild - 6	Severe – 0 Moderate – 0 Mild - 0
Von Willebrand	Severe – 1 Moderate – 6 Mild - 45	Severe – 1 Moderate – 6 Mild - 30	Severe – 0 Moderate – 2 Mild – 0
Other	11	11	0

Emergency Care

During routine hours all patients were triaged by the haemophilia nurse specialist or the haematology Specialist Registrar (SpR), and patients were told to attend either the haemophilia day care unit or the Emergency Department (ED), depending on the severity of the presenting complaint.

Out-of-hours, at the weekends and on bank holidays, patients were told to contact the on-call haematologist via switchboard and to follow their advice.

Ward Care

All adults with bleeding disorders needing inpatient care were admitted to Laurel Ward. This was a 28-bedded ward shared between haematology and general medicine.

Day Care

There was a dedicated haemophilia day care unit located at the Haemophilia Centre where patients were assessed and all relevant blood tests and investigations were carried out.

Outpatient Care

Adult outpatient clinics took place in the clinic room located next to the day unit within the Haemophilia Centre. There was a waiting area with refreshments for patients available within the Centre.

Community Based Care

The Clinical Nurse Specialist (CNS) could take blood tests or administer treatment in patients' homes or in other hospitals, if required.

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Review Findings

Achievements

This small team was working hard, with a clear commitment to developing the service. This was evidenced by the (recently started) on-site clinics held jointly with the Guy's and St Thomas' (GSTT) CCC director and haemophilia physiotherapist; by local MDT meetings; by the production of guidelines and policies; and by a useful audit of patient management in the Emergency Department (ED). These developments, so long as they are sustained, will substantially improve the clinical service and give increased opportunity for shared audit and research, data sharing and benchmarking.

Patient feedback about the service was very positive; the patients appreciated the efforts made by the staff and the care they received from them. The clinical nurse specialist (CNS) had quite recently come into post but was already making a positive impact on practice and had a clear vision of what the team could achieve. The CNS and the data manager showed passion and determination to develop the service and were themselves undertaking some development activities in their own time.

Good Practice

1. Many of the written materials supporting the service were of a high quality. These included: the service guide for patients (a generic patient information leaflet outlining how their condition could affect them and how to manage it); the clinical guideline section about neuraxial anaesthesia (spinal or epidural blocks), and a comprehensive operational policy.
2. There was an alert on the electronic patient record indicating the patient's diagnosis, which, when opened, gave more detail including a specific plan for immediate management if the patient presented with a bleed or trauma, and who to contact. The clinical notes were mainly still in hard copy and these too had a 'front page' alert indicating that the person had a bleeding disorder.
3. The audit of management of patients coming through the ED, which had highlighted some delays in them receiving treatment, had led to an increase in the number of short focused training sessions given by the CNS to ED staff.

Immediate Risks

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

Concerns

1. **Service developments**

   The rapid pace of development of new treatment options for patients with these disorders requires staff in haemophilia centres of this size to be actively supported to maintain their knowledge and to be able to manage patients optimally. When, as at this centre, there is a single medical lead, this lead can lack the dialogue and challenge around clinical management decisions, that other specialist colleagues usefully offer. Clinics held jointly with visiting CCC staff, which had recently been reinstituted, were allowing for this discussion and knowledge sharing. Continued joint working is central to ensuring that patients have access to all suitable treatment options. Regular attendance by the Centre lead at the CCC MDT meetings was also essential. If patients from the Woolwich area currently attending GSTT are to be repatriated to have their care at University Hospital Lewisham, as planned, it will be important to ensure that they have an early shared review of their treatment with the CCC team.

2. **Governance issues**

   a. There was a clinical haematology governance meeting, held every two months but with a plan that the frequency be increased to monthly. However, only Serious Incidents were discussed there, and there was no forum to address other incidents or complaints or other feedback from users. The local MDT meetings that had recently started could include a governance section as a regular agenda item.

   b. The diagnostic and clinical guidelines and operational and other policies were in unapproved draft form. They were due for approval at a surgical and cancer services governance meeting to be held the month following the peer review, but until then were not available on the Trust intranet.

   c. The recent audit of ED practice and von Willebrand diagnosis and investigation have been noted above, but there was little evidence of other audit activity, and no evidence of audit against the other key practice areas recommended (Standard HP-702).

3. **Staffing**

   a. Physiotherapy - There was no on-site specialist physiotherapist, and it appeared that little use was made of the general hospital physiotherapy service. The CCC lead physiotherapist went with the CCC director to the monthly joint clinics, and the review team understood that there had been three of these by the time of the visit. As well as reviewing patients and undertaking joint scores, the CCC lead physiotherapist might also be asked during these sessions to start training up some members of the hospital physiotherapy team, so that they could see and manage patients presenting acutely at other times.

   b. Clinical Nurse Specialist - The previous CNS had had a full-time post, but this had been reduced to thirty hours per week for the current post-holder, and in these hours she had other responsibilities. This meant that she spent under twenty hours per week working in the IABD service. At other times the anticoagulant or haemoglobin disorders CNS's offered cover, but there was a lack of continuity. The CNS also had little time to undertake necessary teaching and service development work.

   c. Data manager - The current data manager had approximately ten hours per week allocated to the service, which was insufficient as within this time she had additional duties, such as arranging clinic appointments. She was working extra 'bank' hours, but this was not a long-term sustainable solution, as well as being more expensive for the Trust than increasing the substantive provision.

   d. Senior medical staff - The consultant lead had only four hours per week (one PA) allocated to work in the IABD service. This was insufficient to support new ways of working, including establishing local MDT meetings, attending the CCC MDT and undertaking necessary continued service development, governance and improvement work.

   e. Psychosocial care - There was no named psychologist as part of the MDT. In addition, there was no social worker attached to the team. Identifying a named individual, with dedicated hours, to work with the team would allow that professional to gain an understanding of the conditions and their challenges. With no named colleague to refer to locally, only patients with the highest-level needs were being referred to the psychologist at the CCC, and it is likely that lower-level needs were not being met.

4. **Laboratory**

   a. There was no robust mechanism in place to monitor the temperature of the fridge in which factor concentrates were stored, leading to the possibility of inappropriate storage conditions with deterioration in the products. It was unclear whose responsibility this issue was, but reviewers noted that it should be addressed as soon as possible to allow appropriate systematic monitoring.

b. When factor was required for a patient presenting out of hours, the on-duty Biomedical Scientist removed it from the fridge and dispensed it, recording this in a paper log. There was no evidence of training or competency records for these staff undertaking product issue.

Further Consideration

1. The Centre team will require the assistance of their clinical and non-clinical managers to maintain the progress they have made and to develop the service further, as required. A systematic review in approximately six months would be important to ensure that documentation has been formalised and is embedded in practice, and that the new ways of working are being sustained.
2. The visiting CCC staff coming to Lewisham to undertake joint clinics did not yet have honorary contracts, nor was a Service Level Agreement in place.
3. The reviewers felt that some aspects of the environment from which the service was delivered required attention:
    a. Signage to the Centre was very poor. It was understood that this was being addressed and that improved signs should be in place within a month of the visit.
    b. The clinic room was small and dark and there was insufficient space to accommodate all the staff attending the combined clinics. The CNS could not usually be included in the consultations; this was a loss both to her as a training opportunity and to the patients.
    c. Some of the materials displayed in the room were out of date.
    d. The unit was inaccessible, and did not have 'walk-in' access, so the CNS usually had to go down to meet patients as they arrived and escort them up to the Centre.
4. Transition from paediatric to adult services is an ongoing process that continues after the young person starts to attend the adult clinic. There was no transition information for patients, nor a written guideline, and although the lead consultant usually managed to attend the GSTT paediatric haematology consultant's outreach clinics at Lewisham, the process of transition should be formalised.
5. The CNS's work in identifying a link nurse on the ward and continuing to train and undertake competency assessments for staff on the ward, outpatients and the ED, as well as the other haematology CNSs who covered when she was absent, required active support.
6. Patients with moderate haemophilia A and B might usefully be offered a 'rescue dose' of their specific factor replacement to have at home, with instructions for use, so that they could self-treat if they had a bleed or trauma, before coming to hospital.
7. Clinic letters were not consistently being sent to patients. Patients and carers find clinic letters a valuable reminder of discussions and decisions made at consultations, as well as a record of their current care plan which they can use if they need to present to other centres or to ED.
8. There was little evidence that the views of, and suggestions from, patients and carers had been regularly sought. Their opinions should be canvassed, and opportunities made available to them to provide feedback whenever they wished to. Once reviewed, plans to respond to that feedback should be discussed amongst the MDT.
9. The Centre kept a single dose of NovoSeven, which they rotated with the CCC if it was nearing expiry. A small stock of other concentrates was also held, and given how relatively rarely these were needed, the team might consider requesting whether these stocks could be rotated with the CCC.
10. The service leads should ensure they have taken the necessary steps to consent patients for the research database component of the National Haemophilia Database.

11. Document control was not yet in place, with most of the guidelines and policies not yet ratified or approved. Some patient information leaflets did not have details of authorship or date.

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APPENDIX 1 Membership of Visiting Team

Visiting Team		
Ralph Brown	Quality Manager	Imperial College Healthcare NHS Trust
Sandy Jeffery	Patient representative	
Lara Oyesiku	Haemophilia, Haemostasis and Thrombosis Network Clinical Nurse Manager	Hampshire Hospitals NHS Foundation Trust
Vishal Patel	Physiotherapist	Barts Health NHS Trust
Dr Charles Percy	Consultant Haematologist	University Hospitals Birmingham 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 below.

Service	Number of applicable QS	Number of QS met	% met
Comprehensive Care Centre	36 *	21	58
Network **	8	2	25
Commissioning **	3	1	33
Total	**47**	**24**	**51**

*HP-302 could not be assessed as ED was too busy on the day of the review.
** The Centre did not complete the network and commissioning standards, Therefore these figures have been taken from GSTT, which was the CCC with which this Centre was linked.

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Lewisham Haemophilia Centre

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

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

Ref	Standard	Met?	Comments
HP-103	**Plan of Care** Each patient and, where appropriate, their carer should discuss and agree their Plan of Care, and should be offered a written record covering at least: a. Agreed goals, including life-style goals b. Self-management c. Planned assessments, therapeutic and/or rehabilitation interventions d. Early warning signs of problems, including acute exacerbations, and what to do if these occur e. Agreed arrangements with school or other education provider and preparation for adult life (children and young people only) f. Planned review date and how to access a review more quickly, if necessary g. Who to contact with queries or for advice The Plan of Care should be communicated to the patient's GP and to relevant other services involved in their care.	N	Reviewers did not see evidence of populated care plans which covered all aspects of this Quality Standard.
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	Although there was no care plan in place which met the requirements of HP-103, reviewers did see evidence in clinic letters and heard from patients that their care was regularly reviewed in line with the requirements of this standard.
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.	N	The Centre was on the second floor and patients then had to walk from the lift area. See Further Consideration 3 in the main report.
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	N	Reviewers did not see any evidence of information for patients relating to transition.
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	There was no evidence of routine assessment of carers' needs, or provision of additional support, where required.
HP-199	**Involving Patients and Carers** The service should have: a. Mechanisms for receiving regular feedback from patients and carers about treatment and care they receive b. Mechanisms for involving patients and carers in decisions about the organisation of the service c. Examples of changes made as a result of feedback and involvement of patients and carers	N	Although a small number of questionnaires (from 2018 and January 2020) were seen by reviewers, this did not provide evidence of systematically involving patients and their families in the development of the service or changes that had been made based on feedback.

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

Ref	Standard	Met?	Comments
HP-203	**Service Competences and Training Plan** The competences expected for each role in the service should be identified. A training and development plan for achieving and maintaining competences should be in place.	Y	
HP-204	**Competences – All Health and Social Care Professionals** All health and social care professionals working in the service should have competences appropriate to their role in: a. Safeguarding children and/or vulnerable adults b. Recognising and meeting the needs of vulnerable children and/or adults c. Dealing with challenging behaviour, violence and aggression d. Mental Capacity Act and Deprivation of Liberty Safeguards e. Resuscitation	Y	
HP-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be available.	N	See the Concerns section of the main report.
HP-301	**Support Services** Timely access to the following support services should be available: a. Play support (children's services only) including: i. Play and distraction during any painful or invasive procedures ii. Play support to enable the child's development and well-being b. Pharmacy c. Dietetics d. Occupational Therapy e. Orthotics	Y	
HP-302	**Emergency Department – Staff Competences** Medical and nursing staff working in the Emergency Department should have competences in urgent care of people with inherited and acquired bleeding disorders including awareness of: a. Guidelines on care of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) b. Who to contact for advice	Not assessed	The review team were unable to assess this Quality Standard on the day of the review, as there was no one available in the ED to speak to, and the patients who the reviewers met with had not had any recent experience of attending the ED.

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	Test availability was appropriate for the size of the Centre.
HP-304	**Specialist Services** Timely access to the following specialist staff and services should be available as part of a HCCC service. HCs should be able to access these services through network arrangements: a. Obstetrics including reproductive counselling, information about pre-implantation genetic diagnosis and antenatal diagnosis b. Foetal medicine c. Vascular access (consultant surgeon or interventional radiologist with experience of venous access devices) d. Orthopaedic surgery e. Care of older people services f. Dental services g. HIV services h. Hepatology i. Medical genetics (Genetic Counselling Services) j. Pain management services k. Rheumatology Specialist services should have an appropriate level of specialist expertise in the care of people with inherited and acquired bleeding disorders.	Y	However, evidence was not seen 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.	N	See the Concerns section of the main report about fridge monitoring.
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	However, see the Concerns section of the main report. Most of the documents seen had not yet been ratified or included on the Trust intranet.

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	N	There was no evidence of a transition guideline.
HP-599	**Care of Vulnerable People** Guidelines for the care of vulnerable children, young people and adults should be in use including: a. Restraint and sedation b. Missing patients c. Mental Capacity Act and the Deprivation of Liberty Safeguards d. Safeguarding e. Information sharing f. Palliative care g. End of life care	Y	

Ref	Standard	Met?	Comments
HP-601	**Service Organisation** The service should have an operational procedure covering at least: a. Ensuring all children who are in-patients have a named consultant paediatrician and a named haematologist with expertise in caring for patients with inherited and acquired bleeding disorders responsible for their care b. Ensuring all adults are under the care of a consultant haematologist with an interest in inherited and acquired bleeding disorders, either directly or through a shared care arrangement with a general haematologist c. Responsibility for giving information and education at each stage of the patient journey d. Arrangements for involving Haemophilia Centre staff in multi-disciplinary discussions relating to their patients (QS HP-602) e. Arrangements for follow up of patients who 'do not attend' f. Arrangements for transfer of patient information when patients move areas temporarily or permanently g. Ensuring patients' plans of care are reviewed at least six monthly for patients with severe haemophilia and at least annually for other patients (QS HP-104) h. Ensuring school visits for children with severe haemophilia at least at each change of school (children's services only) i. Ensuring patients are visited at home at least annually if they are unable to attend clinics, including those in nursing homes j. Lone working	Y	
HP-602	**Multi-Disciplinary Team Meetings** Multi-disciplinary team meetings to discuss patients' plans of care should take place regularly involving: a. All core members of the specialist team (HP-202) b. Senior biomedical scientist or clinical scientist with responsibility for the Coagulation Laboratory c. HC staff who are regularly involved in the patient's care as part of network arrangements	Y	

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	There was no psychosocial or physiotherapy input (except in the recently commenced MDT clinics with GSTT) and reviewers heard that the CNS was not always included in the clinic.
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	Regular review meetings did not take place with other specialisms.
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	Only two audits were available to the review team (ED waiting times and von Willebrand diagnosis and investigation), and the remaining requirements of this standard were not evidenced. In addition, there was no audit programme in place.
HP-706	**Research** The service should actively participate in research relating to the care of patients with bleeding disorders.	N	Reviewers did not see evidence of research taking place within the Centre – which is appropriate, as most research would be completed at the CCC. However, reviewers did note that patients from the Centre had been included in network and national trials in recent years.

Ref	Standard	Met?	Comments
	Multi-disciplinary Review and Learning The service should have multi-disciplinary arrangements for review of and implementing learning from: a. Positive feedback, complaints, outcomes, incidents and 'near misses' b. Morbidity and mortality c. Haemophilia Dashboard d. Review of UKHCDO Annual Report benchmarking information on concentrate use e. Ongoing reviews of service quality, safety and efficiency f. Published scientific research and guidance	N	There was no evidence of routine learning from complaints and incidents etc apart from Serious Incidents that had occurred in the wider directorate.
HP-799	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	Many of the documents seen lacked dates or authorship and many were still in draft format awaiting ratification.

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Network

(Note: The compliances for the Network and Commissioning Quality Standards (below) have been replicated from the Guy's and St Thomas' (GSTT) peer review report, as GSTT is the CCC with which the Lewisham HC is linked).

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	
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	
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	
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	
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.	N	
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	

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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	
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	

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