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

St George's University Hospitals NHS Foundation Trust

Visit Date: 18th December 2019

Report Date: March 2020

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Introduction

This report presents the findings of the peer review of services for people with Inherited and Acquired Haemophilia and other Bleeding Disorders at St George's University Hospital NHS Foundation Trust that took place on the 18th 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:

- St George's University Hospitals 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 at the St George's 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, parents and carers who took time to meet the review team. Thanks are also due to the visiting team (**Appendix 1**) and their employing organisations for the time and expertise they contributed to this review.

St George's University Hospital Haemophilia Centre

St George's Hospital was founded in 1733 and at the time of the review was one of the largest hospitals in Europe. It was run by the St George's University Hospitals NHS Foundation Trust. It shared the main hospital site in Tooting, in the London Borough of Wandsworth, with St George's University of London which offered degrees in all health sciences and carried out advanced medical research. St George's University Hospitals NHS Trust had approximately 1170 beds and treated approximately 80,000 inpatient and day cases and over 300,000 outpatients annually, serving a population of 1.3 million across southwest London. The Trust provided general acute services together with speciality services including haematology, neurosciences, cardiothoracic services, oncology and specialist children's services. In addition, St George's was one of the four major trauma centres in London, complete with a helipad for acute transfers. In addition to the main Tooting campus, specialist rehabilitation and other affiliated services were conducted from the Wolferson Hospital which was located in Wimbledon.

St George's Haemophilia Centre provided treatment and care to adult and paediatric patients with severe and mild bleeding disorders within the St George's Hospital campus. At the time of the review, it was the largest Haemophilia Centre in the UK. It was not recognised as a Comprehensive Care Centre (CCC) but had accredited CCC status with EUHASS[1] as a European Comprehensive Care Centre. There were over 650 registered patients with various inherited bleeding disorders, including 60 severely affected patients. Generally, patients were referred from Trusts across a wide geographical area, including the south west Thames area, Surrey, Sussex and North Hampshire.

Specialist diagnostic services were available on site. The hospital provided a 24-hour tertiary referral facility with specialist expert advice and offered a walk-in service for adults and children during office hours and a 24-hour telephone advice / information service both of which involved direct specialist haemostasis support. Specialist community care was managed from within the Haemophilia Centre. This encompassed supervision of home treatment programmes and the control and supply of factor concentrate. The Haemophilia Centre managed its own coagulation factor concentrate inventory, including ordering, storage within secure temperature-controlled refrigerators on site, and supply to patients.

All haemophilia services were primarily provided within the main hospital campus and comprised outpatient clinics, inpatient care and day unit facilities (for short treatments and tests). Telephone access to the haemophilia service was available Monday to Friday within working hours and out of hours there was a Specialist Registrar (SpR) available to give advice. All emergency patients were admitted via the Emergency Department (ED). Telephone consultations were available for patients with mild bleeding disorders, where appropriate. All new patients were seen by the Clinical Nurse Specialist (CNS) for consultation, family history and blood tests prior to meeting with the consultant.

Regular multi-disciplinary team (MDT) health reviews were offered for adults and paediatrics in established clinics. Specialist joint orthopaedic and hepatology MDT clinics were also available for patients. St George's had a large clinical infection unit (CIU) with a special academic and clinical involvement in HIV/HCV and related diseases. There was a maxillofacial unit on site for urgent and routine dental care for adults, and a paediatric dental service for routine and urgent dental care for children. All general surgery, orthopaedic, dental, obstetric and gynaecological procedures were expertly supported and co-ordinated on site. In addition, there were links with maternal medicine, anaesthetics and midwifery to provide care for obstetric issues.

[1] **EUHASS -** EUHASS is a pharmacovigilance programme to monitor the safety of treatments for people with inherited bleeding disorders in Europe. Haemophilia treatment centres report adverse events directly to the EUHASS website and regular surveillance reports are produced.

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 – 40 Moderate – 10 Mild - 51	91	24
	Children	Severe – 12 Moderate – 7 Mild - 25	44	6
Haemophilia B	Adults	Severe – 4 Moderate - 2 Mild - 12	12	1
	Children	Severe – 1 Moderate – 2 Mild - 4	7	0
Von Willebrand	Adults	Type III – 5 Type II – 100 Type I - 91	89	42
	Children	Type III – 1 Type II – 11 Type I - 26	37	1
Other	Adults	414	150	66
	Children	78	74	1

Emergency Care

There was an ED at St Georges Hospital for bleeding disorder patients who required emergency intervention. Acute presentations in working hours were managed by the haemophilia team. Out of hours, haemophilia involvement was initially through the on-call registrar who provided advice for factor replacement where indicated and would subsequently assess the patient in person and discuss with the on-call haemostasis consultant. Following assessment and initial treatment, those requiring further care would be admitted to an inpatient ward via the bed management team. Patients did not have direct admission to the haematology wards (Ruth Myles Unit and Gordon Smith Ward) but were given priority for a bed once one was available. Paediatric patients were also seen via the ED or Jungle Ward (paediatric day care unit), and a similar pathway for admissions existed via the paediatric bed managers.

Ward Care

The Ruth Myles Unit was a 13-bedded haematology unit, that provided beds for all haematological conditions including malignant and non-malignant disorders and transplantation. The Gordon Smith Ward was a 12-bedded haematology / oncology ward. Patients were admitted to these wards whenever possible and when it was safe to do so.

Children were generally admitted to Pickney Ward or Frederick Hewitt Ward. These were general paediatric wards, and patient care was shared between the paediatricians and the paediatric haematologist.

Day Care

Adults were seen by the haemophilia CNS in the haematology day care unit. Paediatric patients were seen by the paediatric CNS on Jungle Ward.

Outpatient Care

Adult patients were reviewed in the haemostasis and thrombosis centre. The haemostasis clinic was held regularly on two or three Wednesday afternoons each month.

Paediatric patients were reviewed in the Dragon Centre in paediatric haematology clinics held on a Tuesday afternoon and a Wednesday (all day).

Community Based Care

Adult and paediatric CNS's often visited patients in the community in their own homes to train, educate, review and/or administer treatments, as required.

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Review Findings

Achievements

The team were dedicated and hard-working, and were offering good services. Some aspects of the paediatric service were very good, with improvements over the four years since the current paediatric haematology lead had come into post. There was strong joint working with the laboratory team, and biomedical scientists attended both the adult and the paediatric weekly MDT meetings.

The paediatric and adult physiotherapists were experienced, were well linked to the national physiotherapy group and, in the limited time they had allocated to the service (see Concern 1), were making important contributions to care, with close links with the musculoskeletal and joint-specific orthopaedic services. Play therapists on Jungle Ward were actively engaged with children attending for treatment. There were productive partnerships with other clinical teams in the Trust, who reported that they received excellent support when co-managing patients, for example during pregnancy or when patients required surgery. The Trusts' paediatric service was set in a department which had been rated 'outstanding' in a recent CQC visit.

Patients and parents who met the review team were overwhelmingly positive about the care they received. They felt well supported by 'amazing staff', and the work of the CNS's in both the paediatric and the adult services was especially noted.

The paediatric team, in particular, spent time in 'extra-curricular' activities with the children, organising zoo trips and an annual picnic. As part of the 'Harvey's Gang' initiative, children had visited the laboratory to help them understand what happened to their frequent blood samples. There was a large parent-led support group.

Good Practice

1. Some of the documents supporting the service were excellent. These included the information leaflets entitled 'How does physiotherapy help my haemophilia?' and 'Sports, exercise and activity in haemophilia'; a letter for adults and children explaining their diagnosis and the need to avoid intramuscular injections and non-steroidal anti-inflammatory drugs; a general letter to GP's entitled 'Caring for children with inherited bleeding disorders'; a comprehensive school care plan, and information transfer letters for patients visiting general dental practitioners, and for young people moving away from home to undertake higher education.
2. The diagnostic and clinical guidelines in the paediatric service were overall of a high quality.
3. The paediatric nurse specialists undertook frequent home visits, including a routine check on newly diagnosed infants after two to four weeks, and were able to visit children at home to take blood samples before they left for school in the morning.
4. Surgical management of patients was good, with appropriate clear guidelines and care plans. Patients reported positive experiences when they had required surgery.
5. A transition clinic was held monthly, where the young people were seen jointly by the consultants and nurse specialists from the paediatric and adult teams.
6. Physiotherapy facilities were excellent with a gym and hydrotherapy pool. Adult IABD patients were usually seen by the physiotherapists in the physiotherapy department, with access to facilities and equipment as required
7. The Trust electronic patient record displayed an alert indicating the person's diagnosis and giving a contact number for the specialist team. The records were accessible remotely for clinical staff on call out of hours.

Immediate Risks

No immediate risks were identified at the time of the visit.

Concerns

1. **Staffing**

    a. Senior medical staff

        i. Adult Haematologist - The Centre director worked for three days a week at the St George's Hospital site, the other two days was based at St Thomas' Hospital Comprehensive Care Centre at Guy's and St Thomas' NHS FT. Two other haematologists worked in the service but only for one PA each, giving eight PA's in total. A fourth post had been agreed and advertised, with an additional four PA's for the bleeding disorders service, but it had not yet been possible to appoint to this post. This meant that there were times when no adult consultant haematologist was working on site in this service.

        ii. Paediatric Haematologist – Although there was funding allocated for two WTE consultant posts, at the time of the review there was a single lead consultant in the service. She was covering all of the out-of-hours periods, except for periods of leave when the consultants at Great Ormond Street CCC covered for her. In practice, it had been demonstrated that work intensity was low, however this was not a feasible long term arrangement.

    There was concern about the sustainability of both the adult and paediatric services, which were each dependent on a single consultant. Reviewers also heard that sometimes there appeared to be insufficient time in the lead consultants' working weeks for communication within the adult team, and between the paediatric and adult teams.

    b. Physiotherapists

    In both the paediatric and the adult services, the physiotherapists' allocated time only allowed them to join the team for weekly multi-disciplinary clinics. In the paediatric service, there was no cover for leave, and if a child presented with a joint bleed, he or she was not always able to see the therapist until the next clinic session, which could be up to a week later. In the adult service, two therapists each offered one allocated session so there was cover, and some flexibility within the MSK team, but again there was insufficient time to work with patients presenting with acute bleeds between clinic sessions. Neither the adult nor the paediatric team had enough allocated physiotherapy time to provide a comprehensive service to the agreed UK standards as outlined by the Haemophilia Chartered Physiotherapists Association.

    c. Nursing

    Paediatric nurse specialists - within their allocated sessions, the two nurses between them covered nine out of ten working days each fortnight, with neither available on the tenth day; this allowed for some necessary overlap time for handover and team discussions. In addition, as they were helpfully undertaking frequent home visits, there were other times during the week when no nurse specialist was available on site to see any children presenting acutely with trauma or joint bleeds.

    d. Psychosocial care

        i. The adult service had no named psychologist working with the team; referrals could be made to the general hospital psychology service, but these were usually only for the highest level needs, and lower-level patient or carer needs were likely to be unmet. In addition, the team lacked the internal support which a psychologist member brings and were unable to work in the fully multi-professional way expected in the care of these long-term patients.

ii. The paediatric service had a named senior psychologist but the psychologist did not have dedicated time to offer these children and families. This was inequitable as there were dedicated sessions available for several other patient groups with long-term conditions, including asthma, haemoglobin disorders, and in the oncology service. Some very useful work had been undertaken with individual children with haemophilia, and there was frustration that valuable additional support could not be offered.

iii. There was no named social worker in either the adult or the paediatric team. In a geographical area where there are pockets of significant deprivation, patients and families would benefit greatly from the support of a knowledgeable, engaged social worker.

2. **Audit and clinical governance**

Clinical audit activity was very limited, and no audits were evidenced against the key areas of emergency and out-of-hours care, initiation of prophylaxis in children, and inhibitor surveillance. Such audits are essential for services to demonstrate their quality and performance, and consistency of treatment and practice. Early audit of emergency department care would be especially important given the issues that were highlighted by patients in terms of their experience of the ED.

There were some mortality and morbidity reviews, but no other evidence of reflective practice, such as discussion of clinical incidents and complaints or ongoing review of service quality, was provided for either the adult or the paediatric services. It was felt that an increased focus on formalising and evidencing governance activity was required.

Further Consideration

1. The experience of using the Emergency Department was reported by patients and parents as not ideal. They did not feel listened to and said that waits for treatment could sometimes be long. Some training sessions for the ED team had recently been provided by the haemophilia team, but these need to be held regularly so as to reach a changing staff group.
2. The service information leaflets for families and patients joining the service were brief, they did not include any individual staff names or roles, and the emergency contact number was not prominent.
3. The adult diagnostic and clinical guidelines were numerous, and there was some overlap between the contents of specific ones and general haemophilia centre guidelines. The haemophilia centre guidelines were a mixture between an operational policy and a clinical guideline and did not cover all the requirements of a service operational policy (HP-601).
4. Some of the facilities from which the services were provided were not adequate. It had been an achievement to identify an area for the adult service, but this was shared with the large thrombosis service and there was usually no space for patients presenting acutely to be assessed and treated there. As a result, patients phoned the team before presentation, and could be directed to one of a number of different clinical areas for management. Children needing acute assessment could sometimes be seen on the Jungle Ward, but there was often no space there and they were directed elsewhere. Treatment rooms on the Jungle Ward were judged to be cramped. The office shared by all the nurse specialists was very small, and it was difficult for them to hold conversations with patients, and to concentrate fully, in this crowded space.
5. Although there were currently no patients managed by the Centre who were receiving Emicizumab, it was likely that some patients would start in the near future and there may be visiting patients who are on it. The ED guideline about management of an acute bleed should include a caution not to give FEIBA to anyone who is on this agent, because of the risk of thrombotic complications.

6. New adult patient referrals sometimes came through the nurse specialist, who triaged for urgency and made a clinic appointment. Not all the referrals were seen by a consultant, and a consultant's oversight would be advisable.

7. The adult team aimed to remember to discuss family members with patients at review, so as to identify potential or obligate carrier females in time to test and counsel them before they reach reproductive age; however, there was no failsafe mechanism in place to ensure none were missed. Family trees were recorded manually, but identified carriers were registered on the national database, which would give a mechanism to identify and recall carriers at an appropriate age. Further consideration was required to ensure that all relatives who had not yet been tested for carrier status were checked in a timely manner.

8. Evidence was seen of a local research portfolio and in addition, patients could also be registered for studies through Great Ormond Street Hospital and St Thomas' Hospital. However, nursing and physiotherapy members of the specialist teams would value the opportunity to be involved in some multi-professional research studies.

9. Document control was incomplete. Some Trust policies presented in evidence were considerably beyond their review dates, some by as much as five years. Some department documents lacked details of authorship, approval date and planned review date. Clinical guideline review frequency was different for the adult service (one year) and the paediatric service (three years).

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General Comment

St George's Hospital Haemophilia Centre was commissioned as part of the South London Network, with the Comprehensive Care Centre at Guys and St Thomas' NHS Foundation Trust (GSTT) as the 'hub' and University Hospital Lewisham as the other haemophilia centre. This network was not operating in practice. Some aspects were in place: for example the Centre director usually attended the weekly MDT at GSTT, the adult clinical guidelines were based on shared guidelines provided by GSTT, and some adult patients requiring complex orthopaedic surgery were usually managed through a clinic held jointly at GSTT by a specialist orthopaedic surgeon and the St George's Centre director during his sessions there. Patients could also be entered into research studies, for adults at GSTT and for children at Great Ormond Street Hospital (GOSH). However, these were the limits of the functioning of the South London Network between St Georges and GSTT at the time of the visit.

The paediatric service was linked with the CCC at GOSH (part of the North London network) and not with GSTT. The paediatric consultant lead attended the GOSH MDT every four to six weeks and referred more complex patients to that team. Arrangements were complex with some children being registered just at the St George's Centre, some dual registered at St Georges and GOSH, and others dual registered at St George's and GSTT. However, in practice, the clinical arrangements to provide the necessary tertiary level input for children were working.

It was observed that the links between the St George's team and the two CCC's with which they linked were overly dependent on the lead consultant haematologist for adults, and the paediatric haematologist for children, with no other members of the multi-professional team taking part in joint discussions.

There was also an 'informal network' of approximately eight district general hospitals across a wide geographical region, covering the areas where children and adults managed by the service lived and therefore where they might attend in an emergency. A named link paediatrician and haematologist had been identified in each, and it appeared that support for managing patients attending at these sites was readily available as needed. Formerly, there had been some educational and service review meetings including the linked consultants, and it would be helpful for continued partnership working if these could be restarted. It is acknowledged that, with the current staffing provision in both the adult and the paediatric services, resuming this additional work will not be possible, and a review of services and resources with Trust managers and specialist commissioners will be required if it is to progress.

Further discussion with commissioners about the formal South London Network and its configuration will also be necessary.

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APPENDIX 1 Membership of Visiting Team

Visiting Team		
Ralph Brown	Quality Manager	Imperial College Healthcare NHS Trust
Alexandra Butler	Clinical Nurse Specialist	Kettering General Hospital NHS Foundation Trust
Gemma Gardner	Patient representative	
Dr Oliver Tunstall	Consultant Paediatric Haematologist	University Hospitals Bristol NHS Foundation Trust
Anna Wells	Physiotherapist	Hampshire Hospitals NHS Foundation Trust
Alice Wilkinson	Haemophilia Nurse (Paediatrics)	Oxford University Hospitals 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	24	65
Network	8	1	13
Commissioning	3	0	0
Total	**48**	**25**	**52**

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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	See Further Consideration section of main report regarding the need to include more detail.

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

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

Ref	Standard	Met?	Comments
HP-194	**Environment** The environment and facilities in out-patient clinics, wards and day units should be appropriate for the number of patients with inherited and acquired bleeding disorders and accessible by people with severe mobility problems. Services for children and young people should be provided in a child-friendly environment, including toys and books / magazines for children and young people of all ages.	N	Reviewers saw that the environment was fragmented, and patients also confirmed that they did not know from one appointment to the next where they would be seen.
HP-195	**Transition to Adult Services and Preparation for Adult Life** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards f. Advice for young people going away from home to study, including: i. registering with a GP ii. how to access emergency and routine care iii. how to access support from their Comprehensive Care Centre iv. communication with their new GP	Y	
HP-198	**Carers' Needs** Carers should be offered information on: a. How to access an assessment of their own needs b. What to do in an emergency c. Services available to provide support	N	Reviewers heard from patients and carers that support was good. However, there was no evidence of how carers' needs were assessed, or of the support services available to them.
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 were seen they were few in number and not specific to haemophilia patients. The only evidence relating specifically to haemophilia was a comprehensive physiotherapy service survey. No evidence was provided of changes that had been made in response to 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.	N	There were named people in post. However, see Concerns section of main report regarding the lack of time that the lead adult and paediatric haematologists had available in their job plans for these leadership roles.
HP-202	**Staffing Levels and Skill Mix** Sufficient staff with appropriate competences should be available for out-patient, day unit and in-patient care and for support to urgent care services. Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network. All staff should undertake regular Continuing Professional Development of relevance to their work in the inherited and acquired bleeding disorders services. Staff working with children and young people should have competences in caring for children as well as in the care of people with bleeding disorders. Cover for absences should be available. In HCCCs these staff should have sessional time allocated to their work with the IABD service. In HCs the arrangements for accessing staff who do not have sessional time allocated to the IABD service should be clearly defined. Staffing should include: a. Medical staff: i. Consultant specialising in the care of people with inherited and acquired bleeding disorders available during normal working hours ii. On-call consultant haematologist (24/7) iii. Arrangements for advice from a consultant specialising the care of people with inherited and acquired bleeding disorders (if not on call) b. Specialist nursing staff: i. Bleeding disorders specialist nurses (5/7) ii. Ward, out-patient and day unit staff with competences in the care of people with inherited and acquired bleeding disorders. c. Clinical specialist physiotherapist d. Biomedical Scientist and Clinical Scientist (further detail on the requirements are included in HP-303) e. Clinical or counselling specialist psychologist or appropriately trained psychotherapist f. Specialist senior social worker g. Data manager	N	See Concerns section of main report.

Ref	Standard	Met?	Comments
HP-203	**Service Competences and Training Plan** The competences expected for each role in the service should be identified. A training and development plan for achieving and maintaining competences should be in place.	N	Reviewers did not see evidence of a matrix as described in the requirements of this standard. Although some information was seen for the nurses and physiotherapists, this indicated the training that had been completed rather than the competencies that were required for the role. No information was seen for medical staff or other members of the MDT.
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	N	
HP-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be available.	Y	However, reviewers heard that nursing staff did not have administrative support.
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	

Ref	Standard	Met?	Comments
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	N	Reviewers did not see evidence of competencies for ED staff and patients reported that their experience of the ED was not positive and that sometimes ED staff did not listen to them.
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	

Ref	Standard	Met?	Comments
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	
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	However, it was noted by reviewers that office space for staff was limited and that the treatment rooms on Jungle Ward were cramped.

Ref	Standard	Met?	Comments
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	
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	

Ref	Standard	Met?	Comments
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	
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	

Ref	Standard	Met?	Comments
HP-595	**Guidelines on Transition and Preparing for Adult Life** Guidelines on transition of young people from paediatric to adult services should be in use covering at least: a. Taking responsibility for their own care b. Involvement of the young person and, where appropriate, their carer in planning the transfer of care c. Joint meeting between paediatric and adult services in order to plan the transfer d. Allocation of a named coordinator for the transfer of care e. A preparation period prior to transfer f. Arrangements for monitoring during the time immediately after transfer g. Advice for young people going away from home to study, including: i. registering with a GP ii. how to access emergency and routine care iii. how to access support from their Comprehensive Care Centre iv. communication with the young person's new GP	Y	
HP-599	**Care of Vulnerable People** Guidelines for the care of vulnerable children, young people and adults should be in use including: a. Restraint and sedation b. Missing patients c. Mental Capacity Act and the Deprivation of Liberty Safeguards d. Safeguarding e. Information sharing f. Palliative care g. End of life care	Y	

Ref	Standard	Met?	Comments
HP-601	**Service Organisation** The service should have an operational procedure covering at least: a. Ensuring all children who are in-patients have a named consultant paediatrician and a named haematologist with expertise in caring for patients with inherited and acquired bleeding disorders responsible for their care b. Ensuring all adults are under the care of a consultant haematologist with an interest in inherited and acquired bleeding disorders, either directly or through a shared care arrangement with a general haematologist c. Responsibility for giving information and education at each stage of the patient journey d. Arrangements for involving Haemophilia Centre staff in multi-disciplinary discussions relating to their patients (QS HP-602) e. Arrangements for follow up of patients who 'do not attend' f. Arrangements for transfer of patient information when patients move areas temporarily or permanently g. Ensuring patients' plans of care are reviewed at least six monthly for patients with severe haemophilia and at least annually for other patients (QS HP-104) h. Ensuring school visits for children with severe haemophilia at least at each change of school (children's services only) i. Ensuring patients are visited at home at least annually if they are unable to attend clinics, including those in nursing homes j. Lone working	N	There was a paediatric operational policy in place. However, it had not been approved / ratified at the time of the review. The adult service had a document entitled '*Haemophilia Centre Guidelines*', but this was part clinical and part operational and did not include evidence for 'e' or 'f'.
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	However, see other comments on the lack of psychosocial input.
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	Reviewers agreed with the Centre's self-assessment, that routine meetings did not take place.
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	See Concerns section of main report.
HP-706	**Research** The service should actively participate in research relating to the care of patients with bleeding disorders.	Y	

Ref	Standard	Met?	Comments
HP-798	**Multi-disciplinary Review and Learning** The service should have multi-disciplinary arrangements for review of and implementing learning from: a. Positive feedback, complaints, outcomes, incidents and 'near misses' b. Morbidity and mortality c. Haemophilia Dashboard d. Review of UKHCDO Annual Report benchmarking information on concentrate use e. Ongoing reviews of service quality, safety and efficiency f. Published scientific research and guidance	N	Reviewers only saw evidence for Morbidity & Mortality meetings. See Concerns section of main report regarding clinical governance arrangements.
HP-799	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	Reviewers noted that some documents did not have any document control, including dates of development, review dates and details of authorship.

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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 General Comment section of 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 General Comment section of 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 General Comment section of 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)	N	See General Comment section of main report.
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 General Comment section of 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 General Comment section of 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	Patients from this Centre were offered trials that were available across the network, and children could enter studies based at GOSH.

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 General Comment section of 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	N	Although there was a commissioner agreed pathway for services, reviewers heard that in practice the paediatric pathway referred to GOSH and not to Evelina at GSTT (the CCC).
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	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	Meetings with commissioners had not taken place for some time.

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