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

Sheffield Teaching Hospitals NHS Foundation Trust

Visit Date: 2nd May 2019

Report Date: September 2019

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Introduction

This report presents the findings of the peer review of services for people with Inherited and Acquired Haemophilia and other Bleeding Disorders at the Sheffield Haemophilia and Thrombosis Centre, which took place on 2nd May 2019.

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

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

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

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

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

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

- Sheffield Teaching Hospitals NHS Foundation Trust
- NHS England - North East and Yorkshire Region

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

Acknowledgements

We would like to thank the team at the Sheffield Teaching Hospitals NHS Foundation Trust for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. We are grateful too, to the 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.

About Quality Review Service

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

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

Sheffield Haemophilia Comprehensive Care Centre

The Sheffield Haemophilia and Thrombosis Comprehensive Care Centre (CCC) was situated in the Royal Hallamshire Hospital (RHH) in Sheffield. Sheffield Teaching Hospitals Trust was formed in 2001, merging the two major adult hospitals (the RHH and the Northern General Hospital (NGH)) and the Jessop Wing (the obstetric hospital), Charles Clifford Dental Hospital (CCDH), and Weston Park (the oncology hospital). In 2004 the Trust was granted Foundation Trust status, and it has since been known as Sheffield Teaching Hospitals NHS Foundation Trust (STHFT).

Haemophilia care for paediatrics was delivered from the Sheffield Children's Hospital (SCH) Comprehensive Care Centre. There was a clear transition pathway for individuals and families affected with bleeding disorders and the adult team attended clinics at SCH for patients aged 14 and above.

Clinical services within STHFT had evolved over the years, with services moving across sites (and in some cases back again). Haematology services were centralised at the RHH, which was part of the 'Central and the Jessop Wing, CCDH and Weston Park Hospitals were also located there.

Care for patients with bleeding disorders had been delivered from the RHH since the hospital opened in 1971, and the Haemophilia Centre had been in its current location since the 1990s.

The Haemophilia and Thrombosis Centre multidisciplinary team provided care to adult patients with Inherited and Acquired Bleeding Disorders living throughout South Yorkshire, Derbyshire and Lincolnshire, with some patients travelling from further afield including Greater Manchester and West Yorkshire. The Haemophilia centre team also cared for some patients with inherited and acquired thrombotic disorders and immune thrombocytopenia (ITP) and provided a thrombotic thrombocytopenic purpura (TTP) service to South Yorkshire and Derbyshire. The Centre was designated a European Comprehensive Care Haemophilia Centre, and the European Haemophilia Adverse Event Reporting System (EUHASS) was run from the Centre.

Laboratory services were provided by the specialised coagulation Laboratory at the RHH and all specialist tests were available. The coagulation laboratory was a World Federation of Haemophilia (WFH) international haemophilia training centre. The UK National External Quality Assurance Scheme (NEQAS) for blood coagulation and the WFH International External Quality Assurance Scheme (IEQAS) were organised from the RHH. Genetic services were provided from Sheffield Children's Hospital.

The Haemophilia centre worked as part of a formal network with Sheffield Children's Hospital, and regular joint multidisciplinary meetings (which included laboratory and genetic services) were undertaken.

While there were no formal networking arrangements with the local district general hospitals (DGHs), there were close working arrangements in place with Doncaster and Bassetlaw, Rotherham, Barnsley and Chesterfield DGHs. The Centre also had close links with Hull, and with Lincoln (for specific patients).

The Northern General Hospital (NGH) site (3 miles from the Central Campus) provided the majority of acute clinical services, including emergency care. Sheffield was the regional Major Trauma Centre. At the RHH, infectious diseases (including genito-urinary Medicine), elective orthopaedic surgery, and rheumatology services were provided. Hepatology, vascular surgery, interventional radiology and the acute Gastrointestinal (GI) bleeding pathway were delivered at the NGH, but 'elective' GI endoscopy was provided at the Clinical Investigation Unit (CIU) at the RHH. A number of national tertiary services (including national neurosurgery, spinal surgery and pulmonary hypertension services) were based within STHFT, and support for individuals affected by bleeding disorders from all over the country was provided by the Haemophilia Centre team.

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

Condition		Number of patients	Number of patients who had an annual review in last year	Number of in-patient admissions in last year
Haemophilia A	Adults	**Severe** 74 (incl. 12 shared care) **Moderate** 18 (incl. 2 shared care) **Mild** 135	62/62 (100%) 13/16 (81%) 71/135 (52.59%)	4 (5.33%) 0 7 (5.19%)
Haemophilia B	Adults	**Severe** 10 (incl. 2 shared care) **Moderate** 6 **Mild** 17	8/8 (100%) 5/6 (83.33%) 5/17 (29.41%)	0 0 0
Von Willebrand	Adults	**All types** 543	195/543 (35.91%)	7/543 (1.29%)
Other	Adults	656	233 (35.5%)	11/656 (0.02%)

Emergency Care

Patients had 24/7 access to haemophilia services within STHFT. There was an emergency care guideline in place outlining care arrangements. There was an 'attending' haemostasis and thrombosis consultant available 24/7via switchboard. There was a coagulation registrar attached to the haemophilia service during usual working hours (available by bleep) and a haematology registrar available via switchboard out of hours.

The Haemophilia Centre was open from 8am to 5pm. Patients were encouraged to phone the Centre if they had any concerns. The calls were triaged, and either arrangements were made to see the patient in the Haemophilia Centre (8am-5pm) or the patient was admitted to one of the haematology wards as appropriate. If it was felt that the patient would be best seen in the Emergency Department (ED) (if the injury was consistent with a possible fracture or internal organ damage) then the patient would be advised to attend ED. Patients with major trauma were taken by the ambulance service to the ED. Patients with a significant GI bleed were admitted under the care of the GI service at the NGH.

Out of hours patients were advised to phone the STHFT switchboard and ask for the haematology registrar on call; the registrar would advise the patient to attend the haematology ward (P3) for assessment, to go to the ED or to be admitted under the GI service as appropriate. The registrar would then make the appropriate referral.

The haemophilia service liaised proactively with the ED and acute services at the NGH to ensure the timely provision of haemostatic treatment should it be required. Coagulation factor treatment was made available via the blood bank at the NGH site.

Ward Care

The haemophilia service had access to beds on the haematology wards P3, P4 and O1 (43 beds in total). The majority of patients on the haematology wards were cared for by haemato-oncologists. The nursing team were educated by the haemophilia nursing team on elements of care for patients with bleeding disorders, and regarding administration of coagulation factor concentrate. Patients, where appropriate, were admitted under other teams (e.g. pregnant women at the Jessop Wing, patients for GI surgery at the NGH), and the haemophilia

team liaised actively with those teams. The haemophilia consultants did ward rounds twice weekly at the NGH site, when they saw patients admitted at that site.

Day Care

Where day case treatment was required (e.g. iron infusions, immunoglobulin infusions, rituximab), patients were cared for at the haematology day unit which was situated on O floor at the RHH. The haematology day unit provided care for all haematology patients (haemato-oncology, haemoglobinopathy, autoimmune haematology, and bleeding disorders), where required. The haemophilia nursing team educated the day unit nursing team on elements of care for bleeding disorder patients.

Outpatient Care

Outpatient care was delivered from the Haemophilia Centre on P floor at the RHH. All day attendances were seen in the Centre for DDAVP1 , trials, bloods and clinical review, whether emergency or planned.

Community Care

The haemophilia nursing team completed visits at home or nursing homes where required.

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

Review Visit Findings

Achievements

This was an excellent service, with strong but non-hierarchical medical and nursing leadership of an enthusiastic and dedicated team, whose members worked flexibly and well together. Staff were well supported with time and resources for professional development, including service improvement sessions and team improvement meetings, demonstrating a commitment to enhancing service quality and staff progression. The laboratory was staffed by highly experienced bio-medical scientists who attended the multi-disciplinary team meetings, provided a comprehensive 24-hour services, and also co-ordinated national and international quality assurance schemes. The social worker was very much involved in the service and was particularly noted for supporting carers' needs. A recently appointed physiotherapist was very proactive; she had set herself a training schedule, visited other specialist centres, and had plans to establish joint orthotic and podiatry clinics. The clerical staff and data manager were committed and key team members. There was evidence of engaged and supportive operational and nursing managerial support. The Centre was offering excellent learning opportunities for haematologists in training, and regularly accommodated visiting trainees from other sites.

Patient feedback from surveys and from patients who met the review team, was overwhelmingly positive about the quality of the service. The patients stated that the service felt personal and caring and that they were offered opportunities for new treatments and participation in research studies. They explained that they felt well supported in whatever they chose to do, rather than feeling limited by their condition in what they could achieve.

There was a wide-ranging multi-professional research portfolio, encompassing national and international studies and with a notable laboratory research element.

Members of the team were additionally undertaking a great deal of work outside their Centre, including managing the laboratory quality assurance schemes, the European Haemophilia Safety Surveillance (EHASS) scheme (a Europe-wide safety surveillance scheme), and the internet global haemophilia centre locator service, which had been established by a previous centre director. The lead nurse specialist was the chair of the Haemophilia Nurses Association and active in Haemnet,[2] and the social worker chaired the Haemophilia Social Work Association (UK).

The quality of documentation supporting the service was outstanding. The documents included the diagnostic and clinical guidelines, and a comprehensive operational policy.

Good Practice

1. Multidisciplinary Team (MDT) working was exemplary, with good attendance at weekly meetings (although see Concern 1a), and formal minutes were available on the hospital 'shared drive'. MDT discussion outcomes were also included in individual patient record files.
2. Most urgent assessments and care were offered at the Centre. However, those patients with significant trauma, or those who were brought by ambulance, were taken to the Emergency Department [ED] at the Northern General Hospital. However, joint working between senior staff at the Haemophilia Centre and the ED was strong, with regular teaching and training of ED staff; the review team found the ED staff to be knowledgeable and confident about the emergency pathway for these patients.
3. A nurse-led telephone clinic was greatly appreciated by patients.

[2] **Haemnet** is a community for allied care professionals who treat people with bleeding disorders. Haemnet supports health and social care professionals to ensure that excellent care becomes an everyday experience for people with bleeding disorders.

4. Transition practice was good, with nurses from the adult service meeting the young person and his/her family together with the paediatric team before the transfer was made. The paediatric nurses usually accompanied the young person on his/her first attendance at the adult clinic. The age of transition was flexible according to the needs of the young person, from the age of 16 years. Once a person had been referred, their details and care plan were available on the electronic record so that if they presented for urgent care before their first clinic attendance, staff could access key clinical information about them.

5. Young patients with bleeding disorders were able to access ward facilities specially designed for the needs of people in this age group.

6. There was an easily visible 'alert' on the electronic patient record system that indicated that patients had a bleeding disorder. Consultants on-call could remotely access key records, including clinic letters and pathology and radiology results even for patients in local district general hospitals which was useful if teams needed clinical advice or patients were being transferred.

7. Patients who were undergoing surgery at NGH were jointly managed with the Centre team peri-operatively and then once stable from a surgical viewpoint, were transferred to the RHH for the remainder of their inpatient stay under the direct care of the bleeding disorders team.

8. Work was in progress to allow couples at risk of having a baby affected by a significant inherited bleeding disorder, and who had opted for pre-implantation genetic diagnosis, to be managed in Sheffield. At the time of the visit, genetic counselling, ovarian stimulation and cycle monitoring were undertaken locally. The couples then attended Guys Hospital in London for egg collection, pre-implantation genetic diagnosis and embryo transfer, but plans were in place to start offering these aspects of the process in Sheffield too.

9. Transport of concentrates urgently required for patients presenting to local hospital ED's was facilitated by the use of 'bike angels' which reduced transport times.

10. The Centre team made active use of social media to communicate with their patients, carers, and other stakeholders.

11. Document control was excellent, with authorship, approval and review dates included on all important documents and guidelines.

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

Concerns

1. **Staffing**

    a. There was no clinical psychologist working with-in the Centre, and although patients could be referred to IAPT[3] in the community, this did not fulfil the expectation that the Centre had a specialist team, including a psychologist with dedicated sessions, working as an integrated member of the multi-disciplinary team.

    b. There had been a significant gap in physiotherapy input to the service and, although a new physiotherapist had recently joined the team so that the situation was expected to improve in the near future, at the time of the visit no patients had been thoroughly assessed by a specialist for joint health and no formal joint scores had been recorded for patients in the previous year.

[3] **IAPT** – Improving Access to Psychological Therapies - is a service providing evidence-based psychological therapies to people with anxiety disorders and depression.

2. **Facilities**

   a. The Centre

      The facilities from which clinics were offered were inadequate for the needs of patients, carers, and staff.

      i. The reception area / waiting room was small, with insufficient space for people in wheelchairs, and the 'window' at the reception desk was so high that wheelchair users could not reach it to talk to reception staff.

      ii. There was a single clinic consultation room, so that only one patient at a time could be seen. Consequently, clinic consultations could only take place with the consultant and nurse in this room, and this had an impact on waiting times during clinics. Provision of at least one other adjacent consultation room at the time of clinics would also allow for separate assessment by the specialist nurses and / or haematology medical staff in training, which would increase clinic capacity and improve the opportunity for supervised training.

      iii. It was possible for people in the waiting area to over-hear conversations taking place in the clinic room, as the dividing door and wall were thin, so confidentiality could not be assured.

      iv. Disabled toilet access was not available, and those needing to use accessible facilities had to go into the ward area, next to the Centre, to access them.

      v. The office space used by the Centre staff was small, with no natural light, and review team members understood that it was difficult to hold telephone consultations with patients against the background noise of others working in the office.

      Reviewers heard that it may soon be possible for the service to move into new premises on the ground floor of the current block. These new facilities would be much more appropriate.

   b. The hospital

      i. Lifts

         The Centre was located on level P which was a number of floors up from ground level. There were lifts, but at the time of the visit - the review team learned that this was not unusual - only one lift was working. Staff, patients and visitors had to queue for a long time. Patients confirmed that this often resulted in delays with them reaching the Centre after their appointment times. They did, however, appreciate that Centre staff recognised the issue and were willing to see them later.

      ii. Parking

         Patients and families highlighted that, for service users with joint problems and limited mobility, there was difficulty in finding parking close to the Centre for booked or urgent contact and they said that this was a significant problem for them.

Further Consideration

1. Evidence presented at the time of the visit indicated that some senior staff were overdue for refresher courses in some mandatory training, including infection control and resuscitation.

2. Nurse specialists were undertaking non-clinical duties, including some duties that would be undertaken by the social worker if the social worker was available for more of the working week, and others duties that could be undertaken by less senior clinical staff, including taking blood samples, completing forms, and taking samples to the laboratory. It was understood that a Band 2 or 3 support worker post had been agreed; appointment to this post as soon as possible would help alleviate the situation.

3. There did not appear to be a standardised care plan on the electronic record, although a laminated 'letter template' in the clinic room prompted the clinician to include all its elements in clinic letters.

4. The Centre may wish to consider implementing software (which is available) to ensure that genetic results and family tree information is inserted into the electronic record.

5. Clinic appointments for the review of patients with severe and moderate bleeding disorders took place at a fixed clinic on Wednesday afternoons; consideration could be given to offering some alternative and 'out of hours' appointments, and patients indicated they would appreciate this flexibility.

6. There was a good patient information leaflet but it did not specify that there was no ED on the RHH site, and the 'business card' given to service users with contact numbers for key staff might usefully also include details of the hours during which the various contact numbers could be used.

7. Not all patients were familiar with the available services, including dental services and social work support. For patients with milder disorders who did not see clinical staff very often, these services could be more actively promoted.

8. One of the team members commented that the pharmacy electronic system required concentrates to be prescribed using generic names. Although other team members confirmed that it was possible to prescribe using familiar concentrate names which they could then link to generic item names, consideration should be given to providing training to ensure that all team members are familiar with the process.

General Comments

The Centre team were uncertain about commissioning arrangements. They thought that the services were locally commissioned through CCG's, rather than through the specialist commissioners. There had been no meetings between clinicians and commissioners for several years.

As far as the team were aware, there was no formal network in place although the team at the other large haemophilia centre in the region. Hull had suggested that a managed network was supposed to be in place, with Sheffield Comprehensive Care Centre being the linked specialist site. A previous visit to the Hull centre had confirmed that the team there felt they could contact the Sheffield specialist team for any clinical issues, but that no other network activities took place. The Sheffield team indicated that they were not aware that they had any responsibilities for patients or services at Hull other than this freely offered clinical support. They explained that previous efforts to establish a joint MDT with Hull had not been successful.

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

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APPENDIX 1 Membership of Visiting Team

Visiting Team		
Tracey Dandy	Physiotherapist	Nottingham University Hospitals NHS Trust
Howard Doupe Dr Grainne O'Brien	Patient representative Clinical Psychologist	 NHS Lothian
Dr Ryan Rodgers Julie Vowles	Consultant Haematologist Team Lead / Haemophilia Nurse Specialist	NHS Lothian The Newcastle upon Tyne Hospitals NHS Foundation Trust
Heather Williams	Haemophilia Operational Services Manager	Bart Health NHS Trust

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

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APPENDIX 2 Compliance with the Quality Standards

Analyses of percentage compliance with the Quality Standards should be viewed with caution as they give the same weight to each of the Quality Standards. Also, the number of Quality Standards applicable to each service varies depending on the nature of the service provided. Percentage compliance 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

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

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Haemophilia Comprehensive Care Centres and Haemophilia Centres

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

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	See Concerns section of 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	Y	See Good Practice section of main report. Reviewers also noted that nurses were trained to level 3 safeguarding, and that there was a Trust transition evening in place at which the haemophilia team participated.
HP-198	**Carers' Needs** Carers should be offered information on: a. How to access an assessment of their own needs b. What to do in an emergency c. Services available to provide support	Y	See Good Practice section of main report regarding the involvement of the social worker with carers' needs.
HP-199	**Involving Patients and Carers** The service should have: a. Mechanisms for receiving regular feedback from patients and carers about treatment and care they receive b. Mechanisms for involving patients and carers in decisions about the organisation of the service c. Examples of changes made as a result of feedback and involvement of patients and carers	Y	Reviewers heard very positive feedback from patients.

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

Ref	Standard	Met?	Comments
HP-203	**Service Competences and Training Plan** The competences expected for each role in the service should be identified. A training and development plan for achieving and maintaining competences should be in place.	N	There was no training matrix in place as per the requirements of this standard (see notes section relating to the Quality Standard).
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	Some senior staff were not up to date in their mandatory training.
HP-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be available.	Y	
HP-301	**Support Services** Timely access to the following support services should be available: a. Play support (children's services only) including: i. Play and distraction during any painful or invasive procedures ii. Play support to enable the child's development and well-being b. Pharmacy c. Dietetics d. Occupational Therapy e. Orthotics	Y	However, OT was only available through the GP, and orthotics was only available at the NGH, although there were plans for the new physiotherapist to develop this service.
HP-302	**Emergency Department – Staff Competences** Medical and nursing staff working in the Emergency Department should have competences in urgent care of people with inherited and acquired bleeding disorders including awareness of: a. Guidelines on care of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) b. Who to contact for advice	Y	See Good Practice section of main report.

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	Good range of long-serving, competent staff. A laboratory representative attended MDT meetings.
HP-304	**Specialist Services** Timely access to the following specialist staff and services should be available as part of a HCCC service. HCs should be able to access these services through network arrangements: a. Obstetrics including reproductive counselling, information about pre-implantation genetic diagnosis and antenatal diagnosis b. Foetal medicine c. Vascular access (consultant surgeon or interventional radiologist with experience of venous access devices) d. Orthopaedic surgery e. Care of older people services f. Dental services g. HIV services h. Hepatology i. Medical genetics (Genetic Counselling Services) j. Pain management services k. Rheumatology Specialist services should have an appropriate level of specialist expertise in the care of people with inherited and acquired bleeding disorders.	Y	

Ref	Standard	Met?	Comments
HP-402	**Facilities and Equipment** Facilities and equipment appropriate for the service provided should be available including: a. Fridges b. Storage c. Clinical rooms for staff of all disciplines to see patients and carers d. Room for multi-disciplinary discussion e. Room for educational work with patients and carers f. Office space for staff g. Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all clinical areas All equipment should be appropriately checked and maintained.	N	See Concerns section of main report.
HP-499	**IT System** IT systems should be in use for: a. Storage, retrieval and transmission of patient information, including access to the latest vCJD status and family tree b. Patient administration, clinical records and outcome information c. Data to support service improvement, audit and revalidation d. Alerting the specialist team when patients attend the Emergency Department	Y	
HP-501	**Diagnosis Guidelines for Patients with Suspected Inherited and Acquired Bleeding Disorders** Guidelines on diagnosis should be in use covering at least a. Haemophilia A b. Haemophilia B c. Von Willebrand Disease d. Acquired haemophilia e. Inherited platelet disorders f. Other less common and rare bleeding disorders	Y	

Ref	Standard	Met?	Comments
HP-502	**Guidelines: Concentrate Use and Monitoring** Guidelines should be in use covering: a. Concentrate therapy: i. Initiation and monitoring of prophylaxis ii. Home therapy b. Use of extended half life products, including inhibitor testing and PK assessment c. Management of concentrate supplies including: i. Ordering ii. Storage iii. Stock control to ensure all stock is up to date and waste is minimised iv. Prescription and delivery for patients on home treatment v. Arrangements for emergency 'out of hours' supply vi. Recording issue to patients vii. Recording use by patients, including on Haemtrack viii. Submission of data via NHD for national tenders coordinated by CMU	Y	
HP-503	**Clinical Guidelines** The following clinical guidelines should be in use: a. Management of acute bleeding episodes, including patients with inhibitors b. Inhibitor screening c. Immune tolerance therapy d. Dental care e. Care of patients with hepatitis C f. Care of patients with HIV g. Antenatal care, delivery and care of the neonate h. Management of synovitis and target joints i. Long term surveillance of musculoskeletal health j. “For public health purposes”: care of patients at risk of vCJD who are undergoing surgery	Y	
HP-504	**Emergency Department Guidelines** Guidelines on management of patients with inherited and acquired bleeding disorders in the Emergency Department should be in use.	Y	

Ref	Standard	Met?	Comments
HP-505	**Guidelines on Care of Patients requiring Surgery** Guidelines on the care of patients with inherited and acquired bleeding disorders who require surgery should be in use covering at least: a. Involvement of surgical and inherited and acquired bleeding disorders service in agreement of a written plan of care prior to, during and post-surgery b. Communication of the agreed plan of care to all staff involved in the patient's care prior to, during and post-surgery c. Documentation of care provided d. Arrangements for escalation in the event of unexpected problems	Y	
HP-595	**Guidelines on Transition and Preparing for Adult Life** Guidelines on transition of young people from paediatric to adult services should be in use covering at least: a. Taking responsibility for their own care b. Involvement of the young person and, where appropriate, their carer in planning the transfer of care c. Joint meeting between paediatric and adult services in order to plan the transfer d. Allocation of a named coordinator for the transfer of care e. A preparation period prior to transfer f. Arrangements for monitoring during the time immediately after transfer g. Advice for young people going away from home to study, including: i. registering with a GP ii. how to access emergency and routine care iii. how to access support from their Comprehensive Care Centre iv. communication with the young person's new GP	Y	
HP-599	**Care of Vulnerable People** Guidelines for the care of vulnerable children, young people and adults should be in use including: a. Restraint and sedation b. Missing patients c. Mental Capacity Act and the Deprivation of Liberty Safeguards d. Safeguarding e. Information sharing f. Palliative care g. End of life care	Y	

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

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

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

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Network

Ref	Standard	Met?	Comments
HY-199	**Involving Patients and Carers** The network should have mechanisms for involving patients and their carers from all services in the work of the network.	N	Reviewers agreed with the Centre's self-assessment. Some patients were shared across the informal network. Inhibitor patients were seen in Sheffield but were registered under local services too. This enabled access to emicizumab for individuals otherwise unable to access it, and orthopaedic access for individuals at centres otherwise they were unable to access it.
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	Reviewers agreed with the Centre's self-assessment.
HY-204	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HP-203.	N	Reviewers agreed with the Centre's self-assessment
HY-503	**Guidelines** Network guidelines should have been agreed covering: a. Diagnosis for patients with suspected inherited and acquired bleeding disorders (QS HP-501) b. Concentrate use and monitoring (QS HP-502) c. Clinical guidelines (QS HP-503) d. Management of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) e. Care of patients requiring surgery (QS HP-505) f. Transition and preparing for adult life (QS HP-595)	N	Reviewers agreed with the Centre's self-assessment. Support was provided to the nursing teams at both Hull and Lincoln with the provision of documents and advice from nurses at the Centre. The Centre also supported the provision of patient information, as required. An informal network was in place with local DGHs to whom the Centre provided a supply of coagulation factor concentrate for patients presenting to their units where required.

Ref	Standard	Met?	Comments
HY-701	**Ongoing Monitoring** The network should monitor on a regular basis: a. Submission of data on all patients to the UK National Haemophilia Database (QS HP-701) b. Network-wide data on concentrate use and bleeds	N	Reviewers agreed with the Centre's self-assessment
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.	N	Reviewers agreed with the Centre's self-assessment
HY-703	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with inherited and acquired bleeding disorders b. A list of research trials available to all patients within the network.	N	Reviewers agreed with the Centre's self-assessment
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	Reviewers agreed with the Centre's self-assessment

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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	Reviewers agreed with the Centre's self-assessment. No formal interaction with commissioners had taken place. A meeting was due to take place between the specialised commissioner, the Sheffield adults' and childrens' teams and the Hull team on 27 June 2019.
HZ-701	**Clinical Quality Review Meetings** Commissioners should regularly review the quality of care provided by: a. Each service, including achievement of QS HP-701 b. Each network, including achievement of QS HY-701 and QS HY-798 c. Service and network achievement of relevant QSs	N	Reviewers agreed with the Centre's self-assessment: No formal review of quality of care had taken place.
HZ-798	**Network Review and Learning** Commissioners should attend a Network Review and Learning meeting (HY-798) at least once a year for each network in their area.	N	Reviewers agreed with the Centre's self-assessment: No formal network review and learning meeting had taken place.

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