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

## University Hospitals of Derby and Burton NHS Foundation Trust

Visit Date: 26th March 2019

Report Date: July 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 Derby Haemophilia Centre which took place on 26th March 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:

- University Hospitals of Derby and Burton NHS Foundation Trust
- NHSE Specialised Commissioning

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 Derby 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 also grateful 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.wmqrs.nhs.uk

# Derby Haemophilia Centre

Derby Haemophilia Centre was part of the haematology department at University Hospitals of Derby and Burton NHS Foundation Trust. The haematology department was part of the Cancer Services Directorate, which belonged to the Cancer Services, Diagnostics and Support division. The Haemophilia Centre used the outpatient, day unit and inpatient facilities of the haematology department. The Centre was linked to the Comprehensive Care Centre at Nottingham but, given its relative size, it was agreed that the Derby Centre would undergo peer review as a standalone centre.

University Hospitals of Derby and Burton NHS Foundation Trust was formed on 1 July 2018 to bring together five hospitals in Derby, Burton, Lichfield and Tamworth to provide the highest quality of care to patients across Southern Derbyshire and South East Staffordshire. The Trust provided a wide range of services including general medical, surgical, maternity, and rehabilitation care, and Accident and Emergency services.

Derby Haemophilia Centre provided services to both children and adults. All aspects of diagnosis, treatment and care were provided at the Centre, with the exception of genetics (where the services were provided in Sheffield) and platelet function (where the services were provided in Birmingham). Management of inhibitor patients and high factor users, and difficult management problems, were discussed with the Comprehensive Care Centre at Nottingham and at the East Midlands Regional Haemophilia Committee.

There was a 24/7 UKAS accredited haemostasis laboratory, which offered all aspects of diagnosis and treatment monitoring with the exception of genetics and platelet function.

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

| Condition | | Number of patients | Number of patients who had an annual review in the last year | Number of inpatient admissions in the last year |
|---|---|---|---|---|
| Haemophilia A | Adults | Severe 12<br>Moderate 4<br>Mild 17 | 11<br>3<br>5 | 9<br>0<br>5 |
| | Children | Severe 5<br>Moderate 1<br>Mild 3 | 5<br>1<br>1 | 5<br>2<br>1 |
| Haemophilia B | Adults | Severe 2<br>Moderate 1<br>Mild 4 | 2<br>1<br>2 | 0<br>0<br>0 |
| | Children | 0 | | |
| von Willebrand | Adults | 42 | | |
| | Children | 26 | | |
| Other | Adults | 15 | | |
| | Children | 9 | | |

## Emergency Care

In hours, the Haemophilia Centre was open 9.00am to 5.00pm Monday to Friday, and contact details were provided for the haemophilia nurse specialist. Out of hours, at weekends and on bank holidays, patients were asked to contact the hospital switchboard and ask for the on-call haematology consultant.

In an emergency, children were asked to attend the Children's Emergency Department, with adults attending the main Emergency Department (ED).

## Ward Care

Eighteen haematology beds (including ten side rooms and one room specifically for teenagers and young adults) were available on Ward 301. Haematology/medical oncology beds were also available on Ward 302. Haemophilia inpatients were admitted to Wards 301 or 302. For paediatrics, there were forty-four inpatient and ten day case beds. There was also a four bedded ITU.

## Day Unit Care

There was a combined day unit for haematology and oncology, with three bays and seventeen treatment chairs between them. There were two bays for unwell patients, with nine chairs between them. There were two side rooms with two beds each. In addition, there were three treatment chairs in specialist outpatients. For paediatrics, there were ten day case beds.

## Outpatient Care

Haematology patients (including haemophilia patients) were seen in specialist outpatients, which hosted haematology, oncology and palliative medicine outpatients. Each specialty had its own section. Haematology had ten consulting rooms, all of which had adjacent examination rooms. For paediatrics, there were nineteen outpatient rooms available.

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## Review Visit Findings

**Achievements**

The reviewers met a highly committed professional team who were offering outstanding patient-centred care, and at the time of the visit the service was judged to be safe in and out of hours. It was able to deliver this level of care as a result of the particular efforts of the lead medical and nursing team.

Patients and parents gave extremely positive feedback about the quality of care that they received and expressed their gratitude for their treatment. The major contributions by the dedicated Centre Director and the Clinical Nurse Specialist were particularly noted. Reviewers observed that these two team members were achieving a great deal within their working week. Patients welcomed the convenience of telephone clinics.

Diagnostic and clinical guidelines were of a very high quality: clear, in-depth, up-to-date, practical and user-friendly.

The clinical facilities for the paediatric service were especially good across outpatient areas, day care and inpatient wards. They were noted to be calming and welcoming, with special thought having gone into the provision for older children and young people.

**Good Practice**

1. There were very good pre-natal and neonatal services in place, with a joint obstetric clinic in which carrier women were seen pre-conceptually, and a plan put in place and recorded on the 'Lorenzo®' patient record system. This record was then immediately visible when a woman booked for pregnancy care. Genetic counselling was available on site, with a counsellor from the Nottingham Comprehensive Care Centre offering outreach appointments.
2. A specialist paediatric pain clinic was available on site.
3. The 'KITE' team (specialist nurses who care for children and young people with long-term conditions at home), who provided advice and education as well as being a link between the family and the hospital Multi-Disciplinary Team (MDT), was appreciated by families.
4. Transition between paediatric and adult services was flexible in its timing, depending on the maturity and needs of the young person, and could take place up to the age of 18 years.
5. Emergency Department practice was good. Patients were triaged at 'level 2' to hasten their assessment and treatment, and factor concentrates were kept in the department to facilitate early treatment. Following some negative patient feedback the service had recently improved, with new guidelines and additional staff training being put in place.
6. The pharmacy department had tight oversight of the ordering and dispensing of factor concentrate, and a 'Blood Bike' local home delivery system was reported to work well.
7. 'Medusa' (an injectable medicine guide available through the Royal College of Paediatrics and Child Health) was in regular use and accessed by nursing and medical staff.
8. Audits of service delivery and outcomes had recently been undertaken, covering most of the important aspects of care.
9. Patients' views on the services had been systematically canvassed, and changes to the service had been made in response to comments received.
10. Document control was good, with guidelines and operating procedures recording authorship, date of implementation and review date.

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

**Concerns**

1. **Multi-Disciplinary Team (MDT) working**

   Reviewers observed that there were no dedicated, minuted haemostasis team meetings providing an oversight of all newly diagnosed patients, review of patients on treatment, and discussion of those with pending invasive procedures or obstetric events. However, some of the MDT requirements were met through discussions in other meetings, such as a weekly department educational meeting in which audits and morbidity and mortality were discussed.

2. **Staffing**

   a. Current staffing levels appeared to be adequate, although stretched. However, reviewers felt that the levels were not resilient or sustainable, especially given the likelihood of increasing patient numbers following the merger with Burton Hospital.

   b. The current, excellent, service provision was noted to be heavily dependent on two hard-working individuals: the Centre Director and the Clinical Nurse Specialist (CNS). Both were working across paediatric and adult services, and the CNS was part-time (0.6 Whole Time Equivalent (WTE) hours).

      Consideration also needed to be given to succession planning for the Centre Director. More routine involvement of a recently appointed second haemostasis and thrombosis haematology consultant in this specialist service might allow for this. The CNS was being asked to take on broader roles across the haematology department, but it was felt that she did not have sufficient time for these.

   c. The work undertaken by the adult and paediatric physiotherapists and psychologists was acknowledged and valued. However, their role within haemophilia was not specified in their job plans, and they were therefore not usually able to be present at clinic reviews. Patients were therefore required to attend on a different occasion to see them. Patients who needed to see the adult psychologist had to travel to Nottingham, which may reduce uptake. Under current arrangements, the other core team members were therefore not able to work in the systematic and integrated manner recommended for this service.

3. **Data management**

   a. The Derby Centre had no data manager in post. Data input was being undertaken by the CNS, which was an inappropriate use of her limited time.

   b. The IT structure of the National Haemophilia Service consists of four integrated parts: Haemtrack, Haemophilia Clinical Information System (HCIS), the National Haemophilia Database (NHD), and the National Haemophilia Information System (NHIS). Although the Derby centre was using Haemtrack and submitting data to the NHD, the team were not able to access HCIS, and the Centre Director had been informed that it was not possible to meet the cost of this. However, centres are expected to have access to HCIS as this would allow a centre and its patients to benefit from a higher level of data usage, including ready access to a broader range of recorded information about patients and their care; this is valuable not just to facilitate access to data for submission to the NHD but also allows comparative audit and benchmarking activities.

**Further Consideration**

1. Although the Centre Director led discussions in clinic about the need to counsel and test female potential carrier family members before they reached the age of planning their own families, it would be useful to formalise this process.
2. The CNS had applied for, but not yet undertaken, the nurse prescriber's course. Her early placement on the course would be beneficial, as she had to spend time finding members of the medical team to write concentrate prescriptions.
3. Laboratory tests
    a. The lead biomedical scientist was undertaking some scoping work with chromogenic factor Vlll assays; the service would benefit from making these available on a routine basis especially for new patients and, for those with discrepant results, on routine testing.
    b. Although there had been no instances in which extra investigations, over and above those the local laboratory could offer, had been required for immediate patient management out of hours, it would safeguard against future problems if arrangements were formalised with the nearest specialist centres to offer 'back up' for out-of-hours testing – for example for factor Xlll levels and inhibitor screening.
    c. Platelet aggregation studies had previously been run on site but were no longer happening. Patients needing these tests were therefore referred to more distant clinics, as samples for these tests do not travel well. Automated machines were available in the onsite laboratory to undertake these tests, and consideration should be given to re-instituting them to save patients' travelling time. These tests would be useful in initial screening for many patients referred with easy bruising.
4. In a time of transition between different electronic records systems, there was no longer a system whereby the Haemophilia Centre team was alerted when any of their known patients attended ED or any other clinic. This should form part of the new system when it is established.
5. A good ED guideline was in place and had improved patient flow and care there; however, it was noted that a maximum dose for desmopressin / DDAVP[1] per weight was not included, nor was a requirement for a 1L fluid allowance in the 24 hours following DDAVP administration.
6. There was usually only a single specialist haematology trainee involved in the service, and sometimes there were none. This would be a valuable training site, and specialist trainees could contribute usefully to the service. Discussions with the regional training programme director in this regard may be useful.
7. Some young people remained in the shared paediatric haematology clinic until the age of 18 years or above. It was noted that clinic letters even for these older users were still copied to their parents. The paediatric Administrative and Clerical team members could consider agreeing with children and their parents whether a teenager's letters should be copied directly to the teenager, where appropriate.
8. Some patients who met the review team were unsure about the accessibility of dental services. On discussion with the team, it was confirmed that there was a community dental facility available on site. It would be useful to ensure that all patients understand what dental services are available for them and to

[1] **Desmopressin,** sold under the trade name of DDAVP (among others), is a medication used to increase Factor VIII:C and Factor VIII:Ag in patients with mild to moderate haemophilia or von Willebrand disease undergoing surgery or following trauma.

that other community dental practices are educated about what procedures they may safely undertake without the need for factor concentrate or other specialist support.

9. Patient feedback regularly included dissatisfaction about parking arrangements: difficulty in finding a parking place and the need even for blue badge holders to pay for parking when attending. Any new parking plans should take account of the needs of this service's users.

## Network

Formal network arrangements were not in place, and the Centre team did not complete the self-assessment against the network standards HY-199 to HY-798. More information about network arrangements will be gathered at the visit to the Nottingham Comprehensive Care Centre (CCC) later in the review programme.

In the meantime, it was noted that all necessary clinical support from specialist teams at the CCC was readily accessed as and when needed, with the Centre Director and team contacting colleagues not just within the Sheffield or Nottingham CCCs but also further afield when it was felt that more experienced specialists were available there.

The East Midlands Regional Haemophilia Committee met three times a year and included members of the Derby, Nottingham and Leicester teams; this was a useful forum. However, it was acknowledged that some additional aspects of network functioning, including staff cover, shared audits, educational opportunities and offering all patients access to research studies would be valuable and that further work towards achieving this would be appropriate.

## Commissioning

The Centre did not complete the self-assessment against the commissioning standards HZ-601 to HZ-798.

Further discussion about commissioning arrangements will take place at the CCC (Nottingham) later in the programme.

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# APPENDIX 1 Membership of Visiting Team

| Visiting Team | | |
|---|---|---|
| Dr David Allsup | Senior Lecturer and Honorary Consultant | Hull York Medical School and Hull University Teaching Hospitals NHS Trust |
| Martin Beard | Patient representative | |
| Alexandra Butler | Clinical Nurse Specialist | Kettering General Hospital NHS Foundation Trust |
| Claire Forrester | Haemophilia Nurse Practitioner | University Hospitals North Midlands 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 varied depending on the nature of the service provided. Percentage compliance also takes no account of 'working towards' a particular Quality Standard. Reviewers often comment that it is better to have a 'No, but', where there is real commitment to achieving a particular standard, than a 'Yes, but' where a 'box has been ticked' but the commitment to implementation is lacking. With these caveats, table 1 summarises the percentage compliance for each of the services reviewed.

**Table 1 - Percentage of Quality Standards met**

| | Number of Applicable QS | Number of QS Met | % met |
|---|---|---|---|
| | | | |
| Comprehensive Care | 37 | 28 | 76% |
| Network * | 8 | 4 | 50% |
| Commissioning * | 3 | 0 | 0% |
| **Total** | 48 | 32 | 67% |

* The Centre did not complete the network and commissioning standards as they were a Haemophilia Centre. The compliances for these sections were therefore taken from Nottingham CCC, which was the Comprehensive Care Centre that this Centre was linked to.

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## Haemophilia Comprehensive Care Centres and Haemophilia Centres

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

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

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HP-103 | **Plan of Care**<br><br>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:<br>a. Agreed goals, including life-style goals<br>b. Self-management<br>c. Planned assessments, therapeutic and/or rehabilitation interventions<br>d. Early warning signs of problems, including acute exacerbations, and what to do if these occur<br>e. Agreed arrangements with school or other education provider and preparation for adult life (children and young people only)<br>f. Planned review date and how to access a review more quickly, if necessary<br>g. Who to contact with queries or for advice<br><br>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**<br><br>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**<br><br>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)**<br><br>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**<br><br>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.<br><br>Services for children and young people should be provided in a child-friendly environment, including toys and books / magazines for children and young people of all ages. | Y | See Achievements section of main report regarding the inclusion of a separate area for teenagers and young people in paediatrics. |
| HP-195 | **Transition to Adult Services and Preparation for Adult Life**<br><br>Young people approaching the time when their care will transfer to adult services should be offered:<br>a. Information and support on taking responsibility for their own care<br>b. The opportunity to discuss the transfer of care with paediatric and adult services<br>c. A named coordinator for the transfer of care<br>d. A preparation period prior to transfer<br>e. Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards<br>f. Advice for young people going away from home to study, including:<br>i. registering with a GP<br>ii. how to access emergency and routine care<br>iii. how to access support from their Comprehensive Care Centre<br>iv. communication with their new GP | Y | See Good Practice section of main report in relation to flexible transition age. |
| HP-198 | **Carers' Needs**<br><br>Carers should be offered information on:<br>a. How to access an assessment of their own needs<br>b. What to do in an emergency<br>c. Services available to provide support | N | There was no evidence available at the time of the visit to show compliance with this Quality Standard. |
| HP-199 | **Involving Patients and Carers**<br><br>The service should have:<br>a. Mechanisms for receiving regular feedback from patients and carers about treatment and care they receive<br>b. Mechanisms for involving patients and carers in decisions about the organisation of the service<br>c. Examples of changes made as a result of feedback and involvement of patients and carers | Y | |

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HP-201 | **Lead Consultant and Lead Nurse**<br><br>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**<br><br>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:<br>a. Medical staff:<br>i. Consultant specialising in the care of people with inherited and acquired bleeding disorders available during normal working hours<br>ii. On-call consultant haematologist (24/7)<br>iii. Arrangements for advice from a consultant specialising the care of people with inherited and acquired bleeding disorders (if not on call)<br>b. Specialist nursing staff:<br>i. Bleeding disorders specialist nurses (5/7)<br>ii. Ward, out-patient and day unit staff with competences in the care of people with inherited and acquired bleeding disorders.<br>c. Clinical specialist physiotherapist<br>d. Biomedical Scientist and Clinical Scientist (further detail on the requirements are included in HP-303)<br>e. Clinical or counselling specialist psychologist or appropriately trained psychotherapist<br>f. Specialist senior social worker<br>g. Data manager | N | See Concerns section of main report. Reviewers agreed with the Centre's self-assessment and, in addition, noted that the haemophilia nurse resource was only available for 3 days per week and that the nurse had a range of other responsibilities. |

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HP-203 | **Service Competences and Training Plan**<br><br>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 a matrix (as required by this QS) but did see evidence of suitable training for all the staff in post. |
| HP-204 | **Competences – All Health and Social Care Professionals**<br><br>All health and social care professionals working in the service should have competences appropriate to their role in:<br>a. Safeguarding children and/or vulnerable adults<br>b. Recognising and meeting the needs of vulnerable children and/or adults<br>c. Dealing with challenging behaviour, violence and aggression<br>d. Mental Capacity Act and Deprivation of Liberty Safeguards<br>e. Resuscitation | Y | |
| HP-299 | **Administrative, Clerical and Data Collection Support**<br><br>Administrative, clerical and data collection support should be available. | N | Reviewers heard that the nurse specialist did many administrative tasks, including data collection and data entry, and therefore concluded that administrative support for the service was not adequate. |
| HP-301 | **Support Services**<br><br>Timely access to the following support services should be available:<br>a. Play support (children's services only) including:<br>i. Play and distraction during any painful or invasive procedures<br>ii. Play support to enable the child's development and well-being<br>b. Pharmacy<br>c. Dietetics<br>d. Occupational Therapy<br>e. Orthotics | Y | |

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HP-302 | **Emergency Department – Staff Competences**<br><br>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:<br>a. Guidelines on care of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504)<br>b. Who to contact for advice | Y | |
| HP-303 | **Laboratory Service**<br><br>a. A UKAS / CPA accredited laboratory service with satisfactory External Quality Assurance performance should be available 24/7<br>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<br>c. The following tests should be available:<br>i. All coagulation factor assays (24/7)<br>ii. Inhibitor screening<br>iii. FVIII inhibitor quantification<br>iv. VWF antigen<br>v. VWF activity<br>vi. Platelet function testing<br>d. Molecular Genetic Laboratory service for:<br>i. detection of causative mutations in patients with inherited bleeding disorders<br>ii. carrier detection | Y | However, see Further Consideration section of the main report regarding some laboratory tests. |

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HP-304 | **Specialist Services**<br><br>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:<br>a. Obstetrics including reproductive counselling, information about pre-implantation genetic diagnosis and antenatal diagnosis<br>b. Foetal medicine<br>c. Vascular access (consultant surgeon or interventional radiologist with experience of venous access devices)<br>d. Orthopaedic surgery<br>e. Care of older people services<br>f. Dental services<br>g. HIV services<br>h. Hepatology<br>i. Medical genetics (Genetic Counselling Services)<br>j. Pain management services<br>k. Rheumatology<br><br>Specialist services should have an appropriate level of specialist expertise in the care of people with inherited and acquired bleeding disorders. | Y | However, patients commented on the lack of clarity regarding access to dental services. See Further Consideration section of the main report. |
| HP-402 | **Facilities and Equipment**<br><br>Facilities and equipment appropriate for the service provided should be available including:<br>a. Fridges<br>b. Storage<br>c. Clinical rooms for staff of all disciplines to see patients and carers<br>d. Room for multi-disciplinary discussion<br>e. Room for educational work with patients and carers<br>f. Office space for staff<br>g. Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all clinical areas<br><br>All equipment should be appropriately checked and maintained. | Y | |

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HP-499 | **IT System**<br><br>IT systems should be in use for:<br>a. Storage, retrieval and transmission of patient information, including access to the latest vCJD status and family tree<br>b. Patient administration, clinical records and outcome information<br>c. Data to support service improvement, audit and revalidation<br>d. Alerting the specialist team when patients attend the Emergency Department | N | Reviewers agreed with the Centre's self-assessment. See Further Consideration section of the main report regarding access to HCIS. |
| HP-501 | **Diagnosis Guidelines for Patients with Suspected Inherited and Acquired Bleeding Disorders**<br><br>Guidelines on diagnosis should be in use covering at least<br>a. Haemophilia A<br>b. Haemophilia B<br>c. Von Willebrand Disease<br>d. Acquired haemophilia<br>e. Inherited platelet disorders<br>f. Other less common and rare bleeding disorders | Y | See Good Practice section of the main report. There was good documentation control, and documents were detailed and practical. |
| HP-502 | **Guidelines: Concentrate Use and Monitoring**<br><br>Guidelines should be in use covering:<br>a. Concentrate therapy:<br>i. Initiation and monitoring of prophylaxis<br>ii. Home therapy<br>b. Use of extended half life products, including inhibitor testing and PK assessment<br>c. Management of concentrate supplies including:<br>i. Ordering<br>ii. Storage<br>iii. Stock control to ensure all stock is up to date and waste is minimised<br>iv. Prescription and delivery for patients on home treatment<br>v. Arrangements for emergency 'out of hours' supply<br>vi. Recording issue to patients<br>vii. Recording use by patients, including on Haemtrack<br>viii. Submission of data via NHD for national tenders coordinated by CMU | Y | |

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HP-503 | **Clinical Guidelines**<br><br>The following clinical guidelines should be in use:<br>a. Management of acute bleeding episodes, including patients with inhibitors<br>b. Inhibitor screening<br>c. Immune tolerance therapy<br>d. Dental care<br>e. Care of patients with hepatitis C<br>f. Care of patients with HIV<br>g. Antenatal care, delivery and care of the neonate<br>h. Management of synovitis and target joints<br>i. Long term surveillance of musculoskeletal health<br>j. "For public health purposes": care of patients at risk of vCJD who are undergoing surgery | Y | |
| HP-504 | **Emergency Department Guidelines**<br><br>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**<br><br>Guidelines on the care of patients with inherited and acquired bleeding disorders who require surgery should be in use covering at least:<br>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<br>b. Communication of the agreed plan of care to all staff involved in the patient's care prior to, during and post-surgery<br>c. Documentation of care provided<br>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**<br><br>Guidelines on transition of young people from paediatric to adult services should be in use covering at least:<br>a. Taking responsibility for their own care<br>b. Involvement of the young person and, where appropriate, their carer in planning the transfer of care<br>c. Joint meeting between paediatric and adult services in order to plan the transfer<br>d. Allocation of a named coordinator for the transfer of care<br>e. A preparation period prior to transfer<br>f. Arrangements for monitoring during the time immediately after transfer<br>g. Advice for young people going away from home to study, including:<br>i. registering with a GP<br>ii. how to access emergency and routine care<br>iii. how to access support from their Comprehensive Care Centre<br>iv. communication with the young person's new GP | Y | |
| HP-599 | **Care of Vulnerable People**<br><br>Guidelines for the care of vulnerable children, young people and adults should be in use including:<br>a. Restraint and sedation<br>b. Missing patients<br>c. Mental Capacity Act and the Deprivation of Liberty Safeguards<br>d. Safeguarding<br>e. Information sharing<br>f. Palliative care<br>g. End of life care | Y | |

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HP-601 | **Service Organisation**<br><br>The service should have an operational procedure covering at least:<br>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<br>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<br>c. Responsibility for giving information and education at each stage of the patient journey<br>d. Arrangements for involving Haemophilia Centre staff in multi-disciplinary discussions relating to their patients (QS HP-602)<br>e. Arrangements for follow up of patients who 'do not attend'<br>f. Arrangements for transfer of patient information when patients move areas temporarily or permanently<br>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)<br>h. Ensuring school visits for children with severe haemophilia at least at each change of school (children's services only)<br>i. Ensuring patients are visited at home at least annually if they are unable to attend clinics, including those in nursing homes<br>j. Lone working | Y | |
| HP-602 | **Multi-Disciplinary Team Meetings**<br><br>Multi-disciplinary team meetings to discuss patients' plans of care should take place regularly involving:<br>a. All core members of the specialist team (HP-202)<br>b. Senior biomedical scientist or clinical scientist with responsibility for the Coagulation Laboratory<br>c. HC staff who are regularly involved in the patient's care as part of network arrangements | N | See Concerns section of the main report. There was no dedicated minuted haemostasis MDT providing oversight of all patients undergoing surgery or obstetric events, new patients etc., although there were a range of other meetings where some of these topics were discussed. |

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HP-603 | **Multi-Disciplinary Clinics**<br><br>The following multi-disciplinary clinic arrangements for patients with inherited and acquired bleeding disorders should be in place:<br>a. Involvement of medical, specialist nursing and physiotherapy staff in clinics<br>b. Availability of social work and psychology staff in clinics<br>c. Combined clinics or other arrangements for multi-disciplinary discussion with:<br>i. orthopaedics<br>ii. rheumatology<br>iii. obstetrics and gynaecology<br>iv. paediatrics<br>v. dental<br>vi. HIV / hepatology | N | See Concerns section of the main report. |
| HP-604 | **Liaison with Other Services**<br><br>Review meetings should be held at least annually with specialist services to consider liaison arrangements and address any problems identified. | N | However, reviewers heard and saw that links with other services across the Trust were very good. |
| HP-701 | **Data Collection**<br><br>The following data should be collected:<br>a. UK National Haemophilia Database data on all patients<br>b. Data on concentrate use and bleeds, either through Haemtrack or an equivalent mechanism<br>c. Data required to complete the UKHCDO National Haemophilia Dashboard or other national mechanisms | Y | |
| HP-702 | **Audit**<br><br>The services should have a rolling programme of audit covering at least:<br>a. Clinical guidelines (QS HP-503)<br>b. Emergency and out of hours care (QS HP-504)<br>c. Initiation of prophylaxis in children<br>d. Inhibitor surveillance and Immune Tolerance Induction (ITI)<br>e. Clinical reviews including joint scores (QS HP-103 & 104)<br>f. Concentrate use and wastage | Y | See Good Practice section of the main report regarding the audit programme. |
| HP-706 | **Research**<br><br>The service should actively participate in research relating to the care of patients with bleeding disorders. | N | Reviewers agreed with the Centre's self-assessment. The current capacity demand on the existing team did not allow for the development of a research portfolio. |

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HP-798 | **Multi-disciplinary Review and Learning**<br><br>The service should have multi-disciplinary arrangements for review of and implementing learning from:<br>a. Positive feedback, complaints, outcomes, incidents and 'near misses'<br>b. Morbidity and mortality<br>c. Haemophilia Dashboard<br>d. Review of UKHCDO Annual Report benchmarking information on concentrate use<br>e. Ongoing reviews of service quality, safety and efficiency<br>f. Published scientific research and guidance | Y | |
| HP-799 | **Document Control**<br><br>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**<br><br>The network should have mechanisms for involving patients and their carers from all services in the work of the network. | N | Compliances for this section were taken from the Nottingham Centre, which was the Comprehensive Care Centre with which this Centre was linked |
| HY-203 | **Inherited and Acquired Bleeding Disorders Network Leads**<br><br>The network should have a nominated:<br>a. Lead consultant and deputy<br>b. Lead specialist nurse<br>c. Lead physiotherapist<br>d. Lead clinical or counselling psychologist<br>e. Lead manager | N | See HY-199 |
| HY-204 | **Education and Training**<br><br>The network should have agreed a programme of education and training to help services achieve compliance with QSs HP-203. | Y | See HY-199 |
| HY-503 | **Guidelines**<br><br>Network guidelines should have been agreed covering:<br>a. Diagnosis for patients with suspected inherited and acquired bleeding disorders (QS HP-501)<br>b. Concentrate use and monitoring (QS HP-502)<br>c. Clinical guidelines (QS HP-503)<br>d. Management of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504)<br>e. Care of patients requiring surgery (QS HP-505)<br>f. Transition and preparing for adult life (QS HP-595) | Y | See HY-199 |
| HY-701 | **Ongoing Monitoring**<br><br>The network should monitor on a regular basis:<br>a. Submission of data on all patients to the UK National Haemophilia Database (QS HP-701)<br>b. Network-wide data on concentrate use and bleeds | Y | See HY-199 |
| HY-702 | **Audit**<br><br>The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702. | N | See HY-199 |
| HY-703 | **Research**<br><br>The network should have agreed:<br>a. A policy on access to research relating to the care of patients with inherited and acquired bleeding disorders<br>b. A list of research trials available to all patients within the network. | N | See HY-199 |

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HY-798 | **Network Review and Learning**<br><br>Representatives of Comprehensive Care Centres and referring Haemophilia Centres should meet at least once a year to:<br>a. Identify any changes needed to network-wide policies, procedures and guidelines<br>b. Review results of audits undertaken and agree action plans<br>c. Review and agree learning from positive feedback, complaints, critical incidents and 'near misses', including those involving liaison between teams<br>d. Share good practice and potential service improvements | Y | See HY-199 |

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## Commissioning

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HZ-601 | **Commissioning of Services**<br><br>Commissioners should have agreed the configuration of clinical networks including:<br>a. Designated Comprehensive Care Centres and Haemophilia Centres and the relationships between them<br>b. Whether the service cares for children, adults or both<br>c. Referral pattern to each service, taking into account the type of patients who will be treated by each team | N | Compliances for this section were taken from the Nottingham Centre, which was the Comprehensive Care Centre with which this Centre was linked |
| HZ-701 | **Clinical Quality Review Meetings**<br><br>Commissioners should regularly review the quality of care provided by:<br>a. Each service, including achievement of QS HP-701<br>b. Each network, including achievement of QS HY-701 and QS HY-798<br>c. Service and network achievement of relevant QSs | N | See HZ-601 |
| HZ-798 | **Network Review and Learning**<br><br>Commissioners should attend a Network Review and Learning meeting (HY-798) at least once a year for each network in their area. | N | See HZ-601 |

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