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

Liverpool University Hospitals NHS Foundation Trust

Visit Date: 26th November 2019

Report Date: March 2020

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Contents

Introduction

This report presents the findings of the peer review of services for people with Inherited and Acquired Haemophilia and other Bleeding Disorders at the Liverpool University Hospitals NHS Foundation Trust which took place on the 26th November 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:

- Liverpool University Hospitals NHS Foundation Trust
- NHS England Specialised Commissioning North West
- Welsh Health Specialised Service Committee (WHSSC)

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

About the Quality Review Service

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

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

Acknowledgments

Quality Review Service would like to thank the staff of the Liverpool Adults Comprehensive Care Centre for all 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.

Liverpool Comprehensive Care Centre

Bleeding disorders were managed through a dedicated non-malignant haematology centre (The Roald Dahl Centre for Haemostasis and Thrombosis). The Centre was networked with Bangor Hospital haemophilia centre (Ysbyty Gwynedd) to provide comprehensive care for patients in North Wales. Links were also in place with paediatric services at Alder Hey Children's Hospital, from where patients transition into the adult services.

At the time of the review, the team was undergoing a period of change within the service, with a newly appointed lead consultant / Centre director (commenced November 2019) and a newly appointed haematologist in Bangor with an interest in bleeding disorders (commenced August 2019). Additionally, the Royal Liverpool and Broadgreen University Hospitals NHS Trust had recently merged with Aintree University Hospitals NHS Foundation Trust to form Liverpool University Hospitals NHS Foundation Trust and consequently there was a phased implementation of a city-wide haematology service.

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

Condition	Number of patients	Number of patients who had an annual review in last year	Number of inpatient admissions in last year
Haemophilia A	Severe – 37 Moderate – 16 Mild – 83	Severe – 24 Moderate – 10 Mild - 52	Severe – 27 Moderate – 4 Mild - 18
Haemophilia B	Severe – 4 Moderate – 6 Mild – 12	Severe – 3 Moderate – 4 Mild - 9	Severe – 1 Moderate – 1 Mild - 1
Von Willebrand	418	89	51
Other	358	132	88

Emergency Care

During working hours, patients known to the service could present either acutely to the Roald Dahl Centre (the dedicated haemostasis/thrombosis centre) for review, or self-present to the Emergency Department (ED). All patients had contact details for the service and were advised to contact the service if planning to attend either area. During working hours, the haemophilia team supported the care of these patients in whatever area of the hospital they presented. There was access to admission on the haematology wards, rather than to another specialty ward, for patients who had been reviewed.

Out of working hours, patients were advised to attend the ED for acute care, with the haematology registrar being the first line of advice for patients or staff. The on-call haematology registrar provided advice and directed care, with the support of the on-call consultant, and would review patients as required.

Ward Care

Inpatient beds were located on the haematology ward (7Y) which was shared with haemato-oncology services (provided by The Clatterbridge Cancer Centre NHS Foundation Trust). The ward had 14 bay-beds, and six side rooms (including two designated for teenage / young adult patients).

Day Care

Day unit facilities (e.g. for platelet transfusions) were provided through the Medical Day Unit (Ward 9B), which was shared with biochemistry and endocrinology and respiratory and cardiology and renal medicine. The unit was open between 8am and 8pm (Monday to Friday). The unit had four bays and three side rooms available.

Other day case services (including DDAVP[1] administration, factor administration and tests) were provided in the Roald Dahl Centre.

Outpatient Care

Bleeding disorder outpatient clinics were provided in the Roald Dahl Centre. At the time of the review, there was a weekly clinic with two consultants, a registrar, and senior specialist nursing support, although this was due to change in 2020 with a new 'severe' clinic. The unit had three consulting rooms and a treatment room in addition to waiting areas, toilet facilities, clean utility and office accommodation. A telephone clinic had recently been started (building on a previous nurse-led face to face clinic), delivered from the Centre.

Community Based Care

At the time of the review, routine community services were not provided. However, patients were reviewed on occasion in their homes.

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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 Findings

Achievements

This was a dedicated team providing a very good service for their patients. Reviewers noted the contribution of some long standing members of the team who had developed the service and facilities into what they were as well as the contribution being made by newer members of the team who had been welcomed into the team and encouraged to develop into their new roles. The review team also noted the support that had been provided to the new Centre director (designate). The team was mutually supportive and was recognised by colleagues across the wider Trust. The team had recently won a leadership award, sponsored by NHS North West, for their work.

It was acknowledged that at the time of the review, the haemophilia team were facing a period of change and uncertainty arising from the recent merger of the Royal Liverpool and Broadgreen University Hospitals NHS Trust and Aintree University Hospitals NHS Foundation Trust, the planned (but delayed) move to a new building, the separation of the malignant and non-malignant services, and recent staff changes. However, reviewers felt that the team were working well to manage this uncertainty and were well supported by clinical and non-clinical managers.

The haemophilia service was provided from a self-contained centre – the Roald Dahl Centre – which was based on the ground floor of the hospital. This was a dedicated and welcoming space for patients and their families.

Patient feedback was extremely positive, and patients expressed their gratitude to the team for the treatment and service that they received. The nursing team were specifically identified by patients for their care and hard work.

The service was well supported by a range of Trust and locally developed IT systems, which enabled the team to deliver timely care and make informed decisions at any time: patient records were available via remote access for all members of the medical team, and the medical team also had access to inpatient observations and NEWS[2] scores. An 'in house' SharePoint repository allowed for easier communication across the team.

Reviewers noted that there was a comprehensive research portfolio in place, with high recruitment to the NIHR Bio resource study and patients were also taking part in a range of other commercial and non-commercial studies.

Good Practice

1. There was a clear and informative patient information sheet available to provide background and answer specific queries for patients in relation to Emicizumab[3]
2. There was a comprehensive annual review proforma in place to ensure that detailed and structured discussions took place at clinic appointments. The completed proforma was included in patient notes and was also copied to patients.
3. The team reviewed and responded regularly to Haemtrack, but, in addition, there was a formal weekly review of the data by the team which ensured that all patient entries were reviewed and responded to in a timely manner.

[2] **NEWS** (National Early Warning Score) – is a guide used widely by clinicians to quickly determine the degree of illness of a patient. It is based on the patient's vital signs.

[3] **Emicizumab** (trade name Hemlibra) is a humanized bispecific antibody for the treatment of haemophilia A. It functions by bringing together other blood clotting factors to promote clotting and reduce bleeding, in the absence of factor VIII.

4. There was a nurse-led telephone clinic in place which was appreciated by patients. It was particularly valuable for those living some distance from the Centre.
5. MDT meetings were well attended with the Biomedical Scientist and pharmacist also attending. Discussions were structured and all outcomes were recorded in the patient record.
6. Patients reported that they were confident of receiving prompt and appropriate care when they were seen out of hours in the ED.
7. There were separate on-call rotas for staff treating malignant and non-malignant patients ensuring that at all times patients had access out of hours to staff who were competent to provide advice and treatment for patients with bleeding disorders.
8. Registrar training was comprehensive with doctors having two three-month blocks of training within the Centre, enabling them to gain a broader and more in-depth understanding of bleeding disorders.

Immediate Risks

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

Concerns

1. **Staffing**

    a. Physiotherapy: Provision was inadequate, with a specialist physiotherapist contracted to support just one clinic a month. At other times access was through the general physiotherapy service. Although she was able to attend monthly clinics, and clearly made every effort to be flexible to patient needs, there was no time available within the existing funded hours for the physiotherapist to offer any care to preserve joint health, so that even if joint scores were deteriorating there was no capacity for appropriate physiotherapy management to be offered. No outcome measures were being undertaken.

    b. Psychosocial care: Although the lead nurse had a counselling qualification and was using her skills to support patients, there was no psychologist working in the service, although this is an expected core team member for a Comprehensive Care Centre (as outlined in the Quality Standards). Patient needs were therefore not being met, and the support that a psychologist working as an integrated team member can give to colleagues was also lacking. In addition, there was no dedicated social work support for patients or families, although there was an acknowledged need for help for many of the families.

2. **Guidelines**

    Guidelines were incomplete, and in some cases were not available. Reviewers found that clinical guidelines were basic and were therefore not practical or operational. In addition, there was no guideline in place for the ED or surgery (though the reviewers heard from patients that in practice, their experience of both ED and surgery was excellent and seamless). There was a flowchart in place for ED but this was not supported by more detailed guidance covering, for example. the use of Intra Muscular Injections (IMIs) and Non-Steroidal Anti Inflammatory Drugs (NSAIDs).

3. **Audit**

    There was no evidence of any clinical audit activity taking place. This is an essential element of good governance within any clinical team as it allows the service to record formal measurements of the quality of the service that it is providing to its patients and also helps to identify where additional resources or changes to practice may be required.

4. **Mandatory Training**

   No evidence was provided that demonstrated compliance with statutory and mandatory training for all members of the core team

Further Consideration

1. There was no robust system in place for identifying and recalling all potential carrier females which is usually expected at the age of 16. It was therefore possible for a carrier woman to become pregnant with an affected male baby without having been tested, so that appropriate care at delivery could not be planned. A system could be established in collaboration with the paediatric team at Alder Hey Children's hospital.
2. Transition arrangements were good. It was noted in patient feedback that this transition practice could be further embedded by trying to ensure that patients attending their first appointments within the adult centre were able to attend with some of those patients who they had known from the paediatric service.
3. Patients reported that waiting times in clinic for routine appointment were variable but that on occasions they could wait for over an hour for their appointment. An audit of waiting times may help to assess whether this is a regular occurrence so that changes can be made to improve the patient experience at routine appointments.
4. Written condition-specific information for patients was sparse and was not well displayed in the haemophilia centre.
5. Reviewers did not see an overarching training matrix for all members of the core MDT. This would be helpful in order to ensure that all relevant competencies are agreed and can be monitored to ensure that the team are up to date with relevant skills.
6. The role and contribution of the data manager was noted by reviewers. However, it may be helpful to ensure that at least some of the other members of the team are trained to be able to do some of the data collection and analysis when this key member of the team is not available.
7. There was a local database in use, but the team did not enter data onto the Haemophilia Centre Information System (HCIS) – as other CCCs do. It is essential that there are robust systems in place for accurately recording patients' numbers as well as recording their attendance and that their care plans have been reviewed in line with national guidance. Although some time would initially be required to set this up, once established it would save time and effort as data could be transferred across directly from HCIS to the national database.
8. Signage to the Centre within the hospital was not prominent or clear. Although many patients had been coming to the Centre for a number of years, someone attending the Centre for the first time would not find it easy to locate.
9. Document control was incomplete; some documents were in draft, and not all had details of authorship, date of approval or date of review. The operational policy included references to haemoglobin disorders, instead of bleeding disorders / haemophilia.

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General Comment

The adult centre at Liverpool was formally linked to the haemophilia centre at Ysbyty Gwynedd hospital in Bangor. Recently the team at Liverpool had provided invaluable clinical support to the team in Bangor in the absence of a consultant there (with a consultant from Liverpool providing outreach clinics in Bangor every six weeks).

However, it was still unclear how many patients with bleeding disorders were in the North Wales catchment area and therefore whether all were registered and receiving appropriate care and treatment. Although reviewers heard that work had commenced to address this, the team are encouraged to develop their systems so that patients are identified and followed up appropriately.

In addition to the formal link with Bangor, the team at Liverpool were also providing advice, via an informal network, to a number of District General Hospitals (DGHs) in the north west (including Wirral, Warrington, Chester, Southport, Ormskirk and the Isle of Man). It would be helpful for link haematologists from these sites to meet to progress joint working in the form of the sharing of guidelines and clinical audits (when they are available), and also for shared educational opportunities. The job plans of the consultants at the CCC will need to be reviewed if they are to undertake this development work.

The support of commissioners is vital to ensure that these network arrangements, and potential developments, are achievable, and it is recognised that the different commissioning arrangements in North Wales may make this more of a challenge.

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APPENDIX 1 Membership of Visiting Team

Visiting Team		
Andrew Clements	Physiotherapist	University Hospitals of Leicester NHS Trust
Alison Dawson-Meadows	Haemophilia Clinical Nurse Specialist	United Lincolnshire Hospitals NHS Trust
Emma Franklin	Haemophilia Centre Manager and Adult Clinical Nurse Specialist	University Hospitals Bristol NHS Foundation Trust
Dr Gill Gidley	Consultant Haematologist	Leeds Teaching Hospitals NHS Trust
Dr Joannes Hermans	Consultant Haematologist	Nottingham University Hospitals NHS Trust
Andy Martin	Patient representative	

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

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APPENDIX 2 Compliance with the Quality Standards

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

Table 1 - Percentage of Quality Standards met

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

Service	Number of applicable QS	Number of QS met	% met
Centre	37	24	65
Network	8	2	25
Commissioning	3	1	33
Total	**48**	**27**	**56**

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Comprehensive Care Centre

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

Ref	Standard	Met?	Comments
HP-102	**Condition-Specific Information** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of their condition and how it might affect them b. How their condition is diagnosed c. Genetics of inherited bleeding disorders d. Testing for carrier status and the implications of being a carrier e. Problems, symptoms and signs for which emergency advice should be sought f. Out of hours services g. 'On demand' clotting factor treatment h. Prophylaxis i. Self infusion (or infusion by parent or carer) j. Home therapy and use of Haemtrack k. How to manage bleeding at home l. Ports, fistulae and in-dwelling access devices (if applicable) m. Possible complications, including inhibitors and long term joint damage n. Approach to elective and emergency surgery o. Women's health issues p. Health promotion, including smoking cessation, health eating, weight management, exercise, alcohol use, sexual and reproductive health, and mental and emotional health and well-being q. Dental care r. Travel advice s. Vaccination advice t. National Haemophilia Database, its purpose and benefits u. Sources of further advice and information Information should be available covering: 1. Haemophilia A 2. Haemophilia B 3. Von Willebrand Disease 4. Acquired haemophilia 5. Inherited platelet disorders 6. Other less common and rare bleeding disorders	N	The team used the Haemophilia Society leaflets for Haemophilia and von Willebrand disease. However, there was no information for 'on demand' or prophylactic treatment, health promotion (except for sexual health), women's health or dental care.

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	This was in a comprehensive proforma on PENS (the Trust IT system) which was incorporated into a letter for the GP and copied to the patient.
HP-104	**Review of Plan of Care** A formal review of the patient's Plan of Care should take place at least six monthly for patients with severe or moderate haemophilia and at least annually for other patients. This review should involve the patient, where appropriate their carer, and appropriate members of the multi-disciplinary team. Haemtrack results should be reviewed (if applicable) and the outcome of the review should be communicated in writing to the patient and their GP.	N	Data provided did not give assurance that all patients had received their reviews of care in line with national recommendations (at least six monthly for patients with severe or moderate haemophilia and at least annually for other patients).
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	However, no audit of response times was seen.
HP-106	**Haemtrack (Patients on Home Therapy)** All patients on home treatment should be encouraged to use electronic recording of their treatment through Haemtrack.	Y	

Ref	Standard	Met?	Comments
HP-194	**Environment** The environment and facilities in out-patient clinics, wards and day units should be appropriate for the number of patients with inherited and acquired bleeding disorders and accessible by people with severe mobility problems. Services for children and young people should be provided in a child-friendly environment, including toys and books / magazines for children and young people of all ages.	Y	
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	There had been increased focus on transition recently, and the changes in place will meet the needs of the young person.
HP-198	**Carers' Needs** Carers should be offered information on: a. How to access an assessment of their own needs b. What to do in an emergency c. Services available to provide support	N	Written information only suggested carers contact the City Council in case of need, but patient feedback indicated the team did take account of carers' issues.
HP-199	**Involving Patients and Carers** The service should have: a. Mechanisms for receiving regular feedback from patients and carers about treatment and care they receive b. Mechanisms for involving patients and carers in decisions about the organisation of the service c. Examples of changes made as a result of feedback and involvement of patients and carers	N	A previous focus group had lapsed, although there were plans to reconvene it. The Friends and Family Test was apparently in use but no data or comments about results were made available to reviewers.

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 Concern 1 in main section of the 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	The nurse specialists had undertaken relevant training and continued to attend update courses, but very little evidence of training was offered for the wider team, and there was no matrix of training needs against completion.
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	Evidence was not provided showing that all members of the core team were up to date with relevant statutory and mandatory training. See Concern 4.
HP-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be available.	Y	
HP-301	**Support Services** Timely access to the following support services should be available: a. Play support (children's services only) including: i. Play and distraction during any painful or invasive procedures ii. Play support to enable the child's development and well-being b. Pharmacy c. Dietetics d. Occupational Therapy e. Orthotics	Y	
HP-302	**Emergency Department – Staff Competences** Medical and nursing staff working in the Emergency Department should have competences in urgent care of people with inherited and acquired bleeding disorders including awareness of: a. Guidelines on care of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) b. Who to contact for advice	Y	There was regular training of nurses and medical trainees in the ED, and a competency list.

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	
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.	Y	Factor concentrates were mostly held in the blood transfusion laboratory, with a small stock in the Centre. HCIS was not in use; there was a local database instead.
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	vCJD data was held on a database separate from the patient record. Family tree data was manual. There was not yet a system in place to alert the team when the patient attended the ED.
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	Although these were judged to be quite basic and could usefully be expanded. They did not mention genetic counselling.

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	N	Concentrate therapy initiation, monitoring of prophylaxis, home therapy, and use of extended half -life products were not included. There was no distinction between arrangements for routine and those for emergency / out-of-hours access. The guidelines did not cover the recording of or use of concentrate by patients.
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	N	See Concern 2 in main section of the report.
HP-504	**Emergency Department Guidelines** Guidelines on management of patients with inherited and acquired bleeding disorders in the Emergency Department should be in use.	N	A basic flowchart was seen, directing ED staff to call the specialist team, but no other information was given and no indication that IMIs and NSAIDs should be avoided.

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	'Ready, steady, go' plus a generic Trust guideline was in place for transition.
HP-599	**Care of Vulnerable People** Guidelines for the care of vulnerable children, young people and adults should be in use including: a. Restraint and sedation b. Missing patients c. Mental Capacity Act and the Deprivation of Liberty Safeguards d. Safeguarding e. Information sharing f. Palliative care g. End of life care	Y	

Ref	Standard	Met?	Comments
HP-601	**Service Organisation** The service should have an operational procedure covering at least: a. Ensuring all children who are in-patients have a named consultant paediatrician and a named haematologist with expertise in caring for patients with inherited and acquired bleeding disorders responsible for their care b. Ensuring all adults are under the care of a consultant haematologist with an interest in inherited and acquired bleeding disorders, either directly or through a shared care arrangement with a general haematologist c. Responsibility for giving information and education at each stage of the patient journey d. Arrangements for involving Haemophilia Centre staff in multi-disciplinary discussions relating to their patients (QS HP-602) e. Arrangements for follow up of patients who 'do not attend' f. Arrangements for transfer of patient information when patients move areas temporarily or permanently g. Ensuring patients' plans of care are reviewed at least six monthly for patients with severe haemophilia and at least annually for other patients (QS HP-104) h. Ensuring school visits for children with severe haemophilia at least at each change of school (children's services only) i. Ensuring patients are visited at home at least annually if they are unable to attend clinics, including those in nursing homes j. Lone working	Y	However, there was no mention of home visits. In addition, there were some references to haemoglobin disorders instead of bleeding disorders / haemophilia – in the sections on transition and the joint obstetric haematology clinic. There was no authorship, approval or review date.
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	See HP-202 and Concern 1 - there was no psychologist, or social worker, and the physiotherapist could only attend clinics once a month.
HP-604	**Liaison with Other Services** Review meetings should be held at least annually with specialist services to consider liaison arrangements and address any problems identified.	N	
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	No clinical audit activity was evidenced. See Concern 3 of the main report.
HP-706	**Research** The service should actively participate in research relating to the care of patients with bleeding disorders.	Y	

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

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Network

Ref	Standard	Met?	Comments
HY-199	**Involving Patients and Carers** The network should have mechanisms for involving patients and their carers from all services in the work of the network.	N	See the General Comment section of the main report.
HY-203	**Inherited and Acquired Bleeding Disorders Network Leads** The network should have a nominated: a. Lead consultant and deputy b. Lead specialist nurse c. Lead physiotherapist d. Lead clinical or counselling psychologist e. Lead manager	Y	However, there was no psychologist in place to hold this role.
HY-204	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HP-203.	N	See the General Comment section of the main report.
HY-503	**Guidelines** Network guidelines should have been agreed covering: a. Diagnosis for patients with suspected inherited and acquired bleeding disorders (QS HP-501) b. Concentrate use and monitoring (QS HP-502) c. Clinical guidelines (QS HP-503) d. Management of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) e. Care of patients requiring surgery (QS HP-505) f. Transition and preparing for adult life (QS HP-595)	N	See the General Comment section of the main report.
HY-701	**Ongoing Monitoring** The network should monitor on a regular basis: a. Submission of data on all patients to the UK National Haemophilia Database (QS HP-701) b. Network-wide data on concentrate use and bleeds	N	See the General Comment section of the main report.
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.	N	See the General Comment section of the main report.
HY-703	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with inherited and acquired bleeding disorders b. A list of research trials available to all patients within the network.	N	See the General Comment section of the main report.

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

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Commissioning

Ref	Standard	Met?	Comments
HZ-601	**Commissioning of Services** Commissioners should have agreed the configuration of clinical networks including: a. Designated Comprehensive Care Centres and Haemophilia Centres and the relationships between them b. Whether the service cares for children, adults or both c. Referral pattern to each service, taking into account the type of patients who will be treated by each team	Y	However, the CCC did not hold a clear record of all the patients residing in North Wales.
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	See the General Comment section of the main report.
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	See the General Comment section of the main report.

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