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

University Hospital of Wales

Ysbyty Athrofaol Cymru

Visit Date: 17th June 2019

Report Date: September 2019

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Introduction

This report presents the findings of the peer review of services for people with Inherited and Acquired Haemophilia and other Bleeding Disorders at University Hospital of Wales which took place on 17th June 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 Hospital of Wales
- Cardiff and Vale University Health Board

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.

Acknowledgements

We would like to thank the team at the Cardiff Haemophilia Comprehensive Care Centre for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. We are grateful too to the patients, parents and carers who took time to meet the review team.

Thanks are also due to the visiting team (**Appendix 1**) and their employing organisations for the time and expertise they contributed to this review.

About Quality Review Service

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

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

University Hospital of Wales – Cardiff Haemophilia Centre

The Cardiff Haemophilia Centre (CHC) was housed in a purpose-built facility on the ground floor of the main building of the University Hospital of Wales, Cardiff.

CHC was the only Comprehensive Care Centre in Wales and was responsible for the care of all people with inherited and acquired bleeding disorders who live in south, east and west Wales. There were a few patients who chose to attend from England, for whom shared care arrangements were in place with their local haemophilia centre.

The Centre provided outreach services to Swansea and Abergavenny. It worked closely with the haemophilia centre Multi-disciplinary Team (MDT) in Swansea, providing consultant advice for clinical attendances on a daily basis.

CHC managed all aspects of the diagnosis, treatment and care for children, adolescents and adults with inherited or acquired bleeding disorders.

The CHC MDT provided inpatient, outpatient and day case care as well as offering home visits and school visits by members of the MDT according to individual need.

Working alongside the clinical team was a clinical trials team who managed all aspects of commercial and investigator-led studies.

There was a UKAS accredited Haemostasis Laboratory with a team of senior Biomedical Scientists offering all aspects of diagnosis and treatment monitoring. This operated during routine office hours. Factor VIII and Factor IX assays were available 24 hours a day, 7 days a week. Ricof assays were available by prior arrangement on weekends.

The service offered all aspects of holistic comprehensive care as described in the National Service Specification.

At the time of the visit the following numbers of patients were registered with the Centre:

Condition		Number of patients	Number of patients who had an annual review in last year	Number of inpatient admissions in last year
Haemophilia A	Adults	Mild – 112	Mild - 44	Mild – 5
		Moderate – 12	Moderate – 8	Moderate – 1
		Severe – 47	Severe – 32	Severe - 7
	Children	Mild – 13	Mild – 9	Mild – 1
		Moderate – 7	Moderate – 6	Moderate – 1
		Severe – 21	Severe – 21	Severe – 1
Haemophilia B	Adults	Mild – 16	Mild – 8	Mild – 0
		Moderates – 13	Moderates – 5	Moderate – 3
		Severe – 9	Severe – 7	Severe – 2
	Children	Mild – 5	Mild – 5	Mild – 1
		Moderate – 5	Moderate – 4	Moderate – 0
		Severe – 2	Severe – 2	Severe – 0
Von Willebrand	Adults	Type 1&2 - 186	Type 1&2 - 122	Type 1&2 – 6

Condition		Number of patients	Number of patients who had an annual review in last year	Number of inpatient admissions in last year
		Type 3 - 5	Type 3 - 1	Type 3 – 0
	Children	Type 1&2 - 36	Type 1&2 - 15	Type 1&2 – 1
		Type 3 - 2	Type 3 - 1	Type 3 – 2
Other	Adults	252	240	13
	Children	47	24	2

Emergency Care

All patients were issued with a UKHCDO 'Bleeding disorder Information Card' that they were told to present to any healthcare practitioner with whom they come into contact. Patients were encouraged to contact the haemophilia centre or to call the on-call haematology Specialist Registrar (SpR) if they were attending any Emergency Department (ED), either inside or outside of Cardiff Vale hospitals.

There was an agreed pathway for patients registered with bleeding disorders attending the ED at Cardiff and Vale. This guideline was in line with the UKHCDO 'Standards of care for assessment and treatment 2009'. Information was available for all medical and nursing staff in the ED informing them of the pathway. The haemophilia Clinical Nurse Specialists provided teaching for junior medical staff and nursing staff about all aspects of bleeding disorders, as required.

Ward Care

Inpatients with an active bleeding problem, and those who had just undergone surgery, were seen on a consultant ward round at least daily. Surgical patients were seen by a consultant the day after surgery. Thereafter, clinical review was undertaken by the Consultant, Specialist Trainee or Clinical Nurse Specialist, as required. All inpatient care was discussed daily in the consultant led MDT board round, where decisions regarding treatment and monitoring were made.

Outpatient Care

Adults with haemophilia were generally seen on a Tuesday morning at the Haemophilia Centre. This allowed any patient infected with HIV to attend the infectious diseases clinic on the same day. It also allowed patients to meet with physiotherapists, nurses and psychologists during the same visit. Adults taking prophylaxis or with severe haemophilia were seen every six months.

Children were also seen at the Centre and were seen according to clinical need and at least every six months, when stable. Children needing urgent assessment and treatment had direct access at all times to a well-appointed Children's Ambulatory Unit.

Consultant-led clinics were also held regularly at Swansea Hospital and at Nevill Hall Hospital, Abergavenny.

Community-based Care

The MDT provided regular home visits to patients for blood tests, treatment, training, physiotherapy, social support, and psychological support. There were strong links in place with the community-based nursing teams to provide additional, holistic support for patients.

The MDT regularly visited schools and nurseries and provided education to teaching and support staff regarding support for children with bleeding disorders.

Review Visit Findings

Achievements

This was a very strong clinical service, with a well-led team of professionals who were working well together. All medical, nursing, physiotherapy, psychology, social work and laboratory staff were working to a very high standard. There was excellent multi-disciplinary team working in place. The team was providing individualised care, often close to home to save patients and families travelling. This included home visits by physiotherapists, psychologists, social workers and sometimes play therapists. Team members were described by community teams and the linked hospital staff as being highly approachable and supportive. They were well supported by their colleagues in all key clinical specialties, and in general by clinical and non-clinical managers.

Patients and parents were overwhelmingly positive about the service, especially welcoming the holistic approach to care. Patients said that their carers and families were also well supported by the team.

There was a wide-ranging active research portfolio, with high recruitment figures. Savings accrued from research activities had contributed to the Welsh Health Specialised Services Committee (WHSCC) approving funding for several new key posts in the team.

A Wales-wide achievement was the recent agreement with WHSCC to establish a formal managed network for the care of inherited and acquired bleeding disorders, with CHC as its centre. This covered all of Wales, with the exception of the Betsi Cadwaladr University Health Board region in the north. At the time of the review, the challenge facing the team and its managers was how to incorporate and accommodate the new team members and work jointly towards a fully functional network.

Good Practice

1. Children needing urgent assessment and treatment had direct access, at all times, to a well-appointed Children's Ambulatory Unit (CAU).
2. Adult patients reported that they were confident of receiving prompt and appropriate care when they were seen out of hours in ED.
3. The care of older children and young adults had been a focus of attention, with the establishment of a 'high school clinic' for those over 11 years. Inpatient beds for these patients were in a specific teenage and young adults ward area. Physiotherapists could also meet and treat teenagers and young people in their local gym.
4. The team were very active in obtaining patient feedback, including arranging regular focus groups. Patient events, attended by team members, were also arranged. An event with the Cardiff City football team had proved engaging and educational.
5. There were two hydrotherapy pools, one for children and one for adults. These were well used by the service, with a dedicated session for patients each week. For young children these sessions proved to be an opportunity to get to know the team and build confidence. For other patients, the sessions helped to promote good exercise habits.
6. There was a detailed staff training matrix in place.
7. Until approximately three years earlier, children needing line / port insertion had had to travel out of Cardiff, often to London, for this procedure. However, a paediatric intensivist anaesthetist had developed a service on-site and this was now offered in a weekly theatre session.
8. Play support was good, with therapists available for fifteen hours per week in the Centre, and access for urgent support outside those hours.

9. Many of the documents underpinning the service were excellent, these covered service information, the management of fever in children with indwelling venous devices, port training and assessment for patients and carers, a letter for patients to provide to the ambulance service regarding their condition, and school visits.

10. 'Progeny'®, a genetics information and family tree software system, was in use and could generate a worklist to prompt timely testing and counselling for potential carrier female relatives of patients.

11. A nurse-led clinic was in place, especially for patients with milder bleeding disorders. This was particularly valuable for those living some distance from the Centre.

12. Just outside the nearest entrance, there were a small number of dedicated parking bays for the use of patients attending the Centre, reducing the need for patients to walk too far.

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

Concerns

1. **Facilities**

   The space in the Centre from which the service was provided was inadequate for the size of the service being provided:

   a. The waiting area was too small and was poorly ventilated. Patients receiving intravenous infusions sat with other patients awaiting appointments. A fridge (locked) took up some space in the area as there was apparently no other place for it. On some occasions, children and adults shared the waiting area. Although there was a spacious and bright paediatric clinic area in the children's hospital, where clinics for these children had for a time been provided, parents had requested that the children's appointments should be back in the main Haemophilia Centre.

   b. There was a single consulting room. At the time of the visit, the team could use two adjacent treatment rooms to see patients. However, when the day unit refurbishment was complete one of these rooms (which was shared between the two units) would revert to previous arrangements according to which it was determined by clinical activity in the Centre. Staff explained that sometimes patients had long waiting times not because of staff availability, but because there was no room free for their consultation.

   c. Office space for team members was insufficient. The nurses, data managers and middle grade medical staff shared a small office and were 'hot-desking'.

   d. There were no rooms for psychologists or social workers to see patients and families. Unless the physiotherapist was seeing a patient in a joint consultation with the consultant, the patient had to go to a room some distance from the clinic for a physiotherapy assessment.

   It was noted that these constraints were already significant, and that new team members were shortly to be appointed without any available space for them to work from. Reviewers heard that the staff had repeatedly reported these issues, and the problems they caused for patients and staff, to their managers.

2. **Social work team**

   The social workers were Local Authority (LA) employees but had been informed about a year before the review that the LA did not intend to continue to employ them. Conversations about their being 'TUPE'd[1] over' to health service posts had not led to any conclusions and their future employment was therefore

[1] TUPE is The Transfer of Undertakings (Protection of Employment) Regulations, which preserve employees' terms and conditions when a business or undertaking, or part of one, is transferred to a new employer.

uncertain. In the meantime, they were lacking appropriate supervision, and as noted in Concern 1d (above) they had no physical space from which to work.

3. **Data**

   Data regarding the number of patients registered, concentrate usage etc were kept separately for the linked hospitals. This included Swansea which was an identified linked haemophilia centre. It was not clear whether data for all patients were being submitted, or whether there were double registrations for patients who had been seen at both Swansea and Cardiff. Establishing clear shared data collection arrangements for the sites, and accurately defining the patient base in the first instance, was noted to be a crucial initial step in progressing towards a functional network.

Further Consideration

1. No localised diagnostic guidelines were in place at the time of the visit. As the network becomes more established, some clear diagnostic pathways, drawing from national guidance but adapted for use between all the sites, will be required.
2. Clinical guidelines were available for many presentations. However, it was observed that these were largely operational and lacked in some expected clinical elements. Although there was no unifying operational policy (which will be required for the network) combining many of the guidelines already in place into one indexed policy would be a helpful starting point for compiling such a policy.
3. There was an informal 'back-up' arrangement for laboratory staff to be called in to undertake less commonly required specialist tests out of hours; it would be useful to formalise this process to ensure a fully robust system.
4. There was no automatic 'alert' on the electronic clinical portal record to ensure that any staff checking records before seeing a patient were aware of a patient's bleeding disorder; discussion with IT managers may make it possible to establish this valuable prompt.
5. The patient management plan was available for all patients on the clinical portal. However, as files were stored in date order, if several other documents had been saved since the file had last been reviewed and altered, the plan was not always immediately visible when opening the document list. Although it was also stored on the Welsh National Portal, it was stored under 'Other Correspondence' and so was not always prominent or easy to find. The plan was not always included in the patient's notes. An IT solution should be sought for ensuring that this key information is prominently displayed when records are opened on either system.
6. There were good written surgical plans in place however, it was noted only that the number to contact for any unexpected problems peri-operatively was not as prominent as would be useful in an urgent clinical situation.
7. Space at the centre was overcrowded (see Concern 1) and it was noted that, at times, children and adults waited in the same area to be seen. Consideration may be given to seeking input from families to better understand their concerns and to engage them in making the relocation to the spacious (and more child friendly) outpatients' area in the children's hospital. Although after the last attempt to do this, parents had expressed a preference to return to the Centre, this appeared to be partly due to staff having to return to the Centre for documents etc. during the clinic. With further preparation time and encouragement for families whilst they become more familiar with the new arrangement, another attempt to make the transfer may be successful, and preferable, in the long term.
8. Audit activity was plentiful, but there was no systematic audit plan to ensure care was in line with expected guidelines and standards. Findings were not always accessible in a form which would maximise their potential use in leading to improvement.

9. Some ‘out of hours’ clinic appointments would be appreciated by patients in full-time education or work.

10. Document control was incomplete, with some policies and guidelines lacking details of authorship, approval date and review date. Some patient information leaflets were not the most recent version.

11. There was a detailed staff training matrix in place. However, it was observed that staff members were listed by name, and that including their role titles would be helpful to ensure their training and competency requirements as listed were appropriate.

12. The notes from social worker consultations were not available as part of the main patient record as they were recorded on the LA system.

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APPENDIX 1 Membership of Visiting Team

Visiting Team		
Karen Gray	Social Worker	Newcastle upon Tyne NHS Foundation Trust
Sarah Johns	Clinical Nurse Specialist	Royal Cornwall Hospitals NHS Trust
Dr Sarah Mangles	Consultant Haematologist, Clinical Director Haemophilia and Thrombosis	Hampshire Hospitals NHS Foundation Trust
Victoria Morris	Physiotherapist	University Hospitals Birmingham NHS Foundation Trust
Caroline Roberts	Paediatric Clinical Nurse Specialist	University Hospitals Bristol NHS Foundation Trust
Paul Sartain	Patient representative	
Dr Alison Thomas	Consultant (Paediatrics)	St George's University Hospitals NHS Foundation Trust

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

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APPENDIX 2 Compliance with the Quality Standards

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

Table 1 - Percentage of Quality Standards met

	Number of Applicable QS	Number of QS Met	% met
Comprehensive Care	37	28	76%
Network	8	1	13%
Commissioning	3	1	33%
Total	48	30	63%

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Haemophilia Comprehensive Care Centres and Haemophilia Centres

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

Ref	Standard	Met?	Comments
HP-102	**Condition-Specific Information** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of their condition and how it might affect them b. How their condition is diagnosed c. Genetics of inherited bleeding disorders d. Testing for carrier status and the implications of being a carrier e. Problems, symptoms and signs for which emergency advice should be sought f. Out of hours services g. 'On demand' clotting factor treatment h. Prophylaxis i. Self infusion (or infusion by parent or carer) j. Home therapy and use of Haemtrack k. How to manage bleeding at home l. Ports, fistulae and in-dwelling access devices (if applicable) m. Possible complications, including inhibitors and long term joint damage n. Approach to elective and emergency surgery o. Women's health issues p. Health promotion, including smoking cessation, health eating, weight management, exercise, alcohol use, sexual and reproductive health, and mental and emotional health and well-being q. Dental care r. Travel advice s. Vaccination advice t. National Haemophilia Database, its purpose and benefits u. Sources of further advice and information Information should be available covering: 1. Haemophilia A 2. Haemophilia B 3. Von Willebrand Disease 4. Acquired haemophilia 5. Inherited platelet disorders 6. Other less common and rare bleeding disorders	Y	However, see comment in HP-799: not all of the documents were the latest versions.

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

Ref	Standard	Met?	Comments
HP-194	**Environment** The environment and facilities in outpatient clinics, wards and day units should be appropriate for the number of patients with inherited and acquired bleeding disorders and accessible by people with severe mobility problems. Services for children and young people should be provided in a child-friendly environment, including toys and books / magazines for children and young people of all ages.	N	See Concerns section of main report.
HP-195	**Transition to Adult Services and Preparation for Adult Life** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards f. Advice for young people going away from home to study, including: i. registering with a GP ii. how to access emergency and routine care iii. how to access support from their Comprehensive Care Centre iv. communication with their new GP	N	However, see Good Practice section of main report relating to the high school clinic and the Teenager and Young Adult Ward.
HP-198	**Carers' Needs** Carers should be offered information on: a. How to access an assessment of their own needs b. What to do in an emergency c. Services available to provide support	Y	
HP-199	**Involving Patients and Carers** The service should have: a. Mechanisms for receiving regular feedback from patients and carers about treatment and care they receive b. Mechanisms for involving patients and carers in decisions about the organisation of the service c. Examples of changes made as a result of feedback and involvement of patients and carers	Y	

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 outpatient, day unit and inpatient 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, outpatient 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	Y	

Ref	Standard	Met?	Comments
HP-203	**Service Competences and Training Plan** The competences expected for each role in the service should be identified. A training and development plan for achieving and maintaining competences should be in place.	Y	
HP-204	**Competences – All Health and Social Care Professionals** All health and social care professionals working in the service should have competences appropriate to their role in: a. Safeguarding children and/or vulnerable adults b. Recognising and meeting the needs of vulnerable children and/or adults c. Dealing with challenging behaviour, violence and aggression d. Mental Capacity Act and Deprivation of Liberty Safeguards e. Resuscitation	Y	
HP-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be available.	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	

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	However, see Further Consideration regarding the need to formalise out of hours arrangements for less commonly required specialist tests.
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	See Good Practice section of main report re *Progeny* system for identifying potential female carriers.

Ref	Standard	Met?	Comments
HP-402	**Facilities and Equipment** Facilities and equipment appropriate for the service provided should be available including: a. Fridges b. Storage c. Clinical rooms for staff of all disciplines to see patients and carers d. Room for multi-disciplinary discussion e. Room for educational work with patients and carers f. Office space for staff g. Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all clinical areas All equipment should be appropriately checked and maintained.	N	See Concerns section of main report.
HP-499	**IT System** IT systems should be in use for: a. Storage, retrieval and transmission of patient information, including access to the latest vCJD status and family tree b. Patient administration, clinical records and outcome information c. Data to support service improvement, audit and revalidation d. Alerting the specialist team when patients attend the Emergency Department	N	Reviewers could not see evidence for c or d.
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	N	Reviewers agreed with the Centre's self-assessment. The Centre follows UKHCDO guidelines, but these have not been localised. Reviewers suggested that this will be needed as the network becomes more established.

Ref	Standard	Met?	Comments
HP-502	**Guidelines: Concentrate Use and Monitoring** Guidelines should be in use covering: a. Concentrate therapy: i. Initiation and monitoring of prophylaxis ii. Home therapy b. Use of extended half life products, including inhibitor testing and PK assessment c. Management of concentrate supplies including: i. Ordering ii. Storage iii. Stock control to ensure all stock is up to date and waste is minimised iv. Prescription and delivery for patients on home treatment v. Arrangements for emergency 'out of hours' supply vi. Recording issue to patients vii. Recording use by patients, including on Haemtrack viii. Submission of data via NHD for national tenders coordinated by CMU	Y	
HP-503	**Clinical Guidelines** The following clinical guidelines should be in use: a. Management of acute bleeding episodes, including patients with inhibitors b. Inhibitor screening c. Immune tolerance therapy d. Dental care e. Care of patients with hepatitis C f. Care of patients with HIV g. Antenatal care, delivery and care of the neonate h. Management of synovitis and target joints i. Long term surveillance of musculoskeletal health j. "For public health purposes": care of patients at risk of vCJD who are undergoing surgery	N	Reviewers could not see any evidence for a, c, e, f or g and the only evidence for h was a copy of the national guidance that was not referenced in any other document.
HP-504	**Emergency Department Guidelines** Guidelines on management of patients with inherited and acquired bleeding disorders in the Emergency Department should be in use.	Y	However, the guideline for management was more in the form of a policy as to whom to call for immediate clinical advice rather than specifying direct management.

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	See Further Consideration section of main report. Reviewers noted that the number to contact for "unexpected problems" peri-operatively was not as prominent as it could be.
HP-595	**Guidelines on Transition and Preparing for Adult Life** Guidelines on transition of young people from paediatric to adult services should be in use covering at least: a. Taking responsibility for their own care b. Involvement of the young person and, where appropriate, their carer in planning the transfer of care c. Joint meeting between paediatric and adult services in order to plan the transfer d. Allocation of a named coordinator for the transfer of care e. A preparation period prior to transfer f. Arrangements for monitoring during the time immediately after transfer g. Advice for young people going away from home to study, including: i. registering with a GP ii. how to access emergency and routine care iii. how to access support from their Comprehensive Care Centre iv. communication with the young person's new GP	N	Reviewers saw a range of information relating to transition, and commented that practice was good. However, this was not supported by specific written guidelines covering the requirements of this standard.
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 inpatients 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	All elements were covered. However, there was no overarching document in place. See Further Consideration section of main report.
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 Good Practice section of main report regarding joint MDT home visits. The team had also had to be creative in order to overcome issues of space in the Haemophilia Centre.
HP-604	**Liaison with Other Services** Review meetings should be held at least annually with specialist services to consider liaison arrangements and address any problems identified.	Y	
HP-701	**Data Collection** The following data should be collected: a. UK National Haemophilia Database data on all patients b. Data on concentrate use and bleeds, either through Haemtrack or an equivalent mechanism c. Data required to complete the UKHCDO National Haemophilia Dashboard or other national mechanisms	Y	Note: c is not applicable as Welsh haemophilia centres are not required to make dashboard submissions.
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	Reviewers saw a plentiful supply of audits, but these were not part of an overarching programme and did not cover all the elements of the Quality Standard. Findings from audits were not always accessible in a form that would maximise their potential use in leading improvements.
HP-706	**Research** The service should actively participate in research relating to the care of patients with bleeding disorders.	Y	See Good Practice section of the main report regarding the extensive research portfolio.

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

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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.	Y	
HY-203	**Inherited and Acquired Bleeding Disorders Network Leads** The network should have a nominated: a. Lead consultant and deputy b. Lead specialist nurse c. Lead physiotherapist d. Lead clinical or counselling psychologist e. Lead manager	N	Reviewers agreed with the Centre's self-assessment.
HY-204	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HP-203.	N	Reviewers agreed with the Centre's self-assessment.
HY-503	**Guidelines** Network guidelines should have been agreed covering: a. Diagnosis for patients with suspected inherited and acquired bleeding disorders (QS HP-501) b. Concentrate use and monitoring (QS HP-502) c. Clinical guidelines (QS HP-503) d. Management of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) e. Care of patients requiring surgery (QS HP-505) f. Transition and preparing for adult life (QS HP-595)	N	Reviewers agreed with the Centre's self-assessment.
HY-701	**Ongoing Monitoring** The network should monitor on a regular basis: a. Submission of data on all patients to the UK National Haemophilia Database (QS HP-701) b. Network-wide data on concentrate use and bleeds	N	Reviewers agreed with the Centre's self-assessment.
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.	N	Reviewers agreed with the Centre's self-assessment.
HY-703	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with inherited and acquired bleeding disorders b. A list of research trials available to all patients within the network.	N	Reviewers agreed with the Centre's self-assessment.

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

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Commissioning

Ref	Standard	Met?	Comments
HZ-601	**Commissioning of Services** Commissioners should have agreed the configuration of clinical networks including: a. Designated Comprehensive Care Centres and Haemophilia Centres and the relationships between them b. Whether the service cares for children, adults or both c. Referral pattern to each service, taking into account the type of patients who will be treated by each team	Y	
HZ-701	**Clinical Quality Review Meetings** Commissioners should regularly review the quality of care provided by: a. Each service, including achievement of QS HP-701 b. Each network, including achievement of QS HY-701 and QS HY-798 c. Service and network achievement of relevant QSs	N	Reviewers agreed that, although there were plans to develop this meeting for the newly commissioned network, it was not in place at the time of the review visit.
HZ-798	**Network Review and Learning** Commissioners should attend a Network Review and Learning meeting (HY-798) at least once a year for each network in their area.	N	Reviewers agreed that although there were plans to develop this for the newly commissioned network, it was not in place at the time of the review visit.

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