UKHCDO Haemophilia Peer Review Audit Report

Alder Hey Children's Haemophilia Comprehensive Care Centre

Report Date: 22 August 2025

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1 Executive summary

Haemophilia services undergo regular peer reviews to assess the quality of care provided to patients with bleeding disorders. These reviews are conducted in line with existing service specifications. In accordance with the National Service Specifications published in 2013, thirty quality standards have been established, and updated service specifications are expected in the near future. These standards encompass key areas such as the availability of suitable facilities, sufficient staffing for a fully functional multidisciplinary team, adherence to clinical guidelines, and access to expert clinical and laboratory support.

Ongoing peer reviews represent one of the twelve final recommendations of the Infected Blood Inquiry Report from 2024. This recommendation also requires trusts to consider peer review findings and prioritise the implementation of proposed improvements for safe and comprehensive care.

The previous peer review cycle was completed in 2019–2020, and the 2024 cycle marks the first review since the COVID-19 pandemic. The multi-professional peer review team included representatives from the UK Haemophilia Centre Doctors Organisation (UKHCDO), Haemophilia Nurses Association (HNA), Haemophilia Chartered Physiotherapy Association (HCPA), Haemophilia Psychologist Association (HPA), and the Haemophilia Patient Societies of England, Scotland, Wales, and Northern Ireland.

The executive summary presents the key findings, while the full report details the assessments referenced against the quality standards. Peer review for the Alder Hey Haemophilia Comprehensive Care Centre (the Service) was completed on 27 November 2024.

The Service successfully met 22 of the 30 established standards, with eight standards partially met. The commitment of both the Centre and the Trust to providing high-quality care was evident through various initiatives and clinical pathways. However, key recommendations have been made to help address the gaps that affect the ability to deliver comprehensive care.

Key Recommendations:

1. **Laboratory Service:** The review team recommends establishing a robust out-of-hours service and expanding the laboratory's out-of-hours test repertoire. Appropriately trained staff should be available to ensure that these tests are available 24/7, either at the Alder Hey laboratory or through a service-level agreement with neighbouring hospitals.
2. **Medical staffing:** The review team recommends that the Trust support the service in addressing the gap in consultant input by increasing the time allocated for the Haemophilia service within consultant job plans, with cover provided by more than one consultant. The current staffing level does not provide sufficient time for haemophilia specific training or service development, such as incorporating clinical research, which is expected in a service of this size.
3. **Provision of Psychological Support:** Psychological services are vital for the well-being of patients and their carers, and this needs to be provided by staff with an understanding of bleeding disorders.

This review has identified gaps in haemophilia services that were also highlighted in the 2019 peer review. These gaps should be addressed to improve patient care and ensure compliance with national service specifications. The peer review findings will be shared with the clinical team, the host organisation, local commissioners, and other relevant stakeholders. We extend our gratitude to the haemophilia centre and the peer reviewers for their invaluable contributions, and we hope this report assists the Centre and the Trust in delivering high-quality haemophilia care.

2 Haemophilia and Bleeding Disorder Peer Review - Background

Since 1998, the UK Haemophilia Centre Doctors Organisation (UKHCDO), together with patient organisations and other stakeholders, has systematically carried out peer reviews to evaluate the quality of care provided to patients with bleeding disorders. Peer reviews involve the evaluation of services by professionals working within or associated with the same field, measured against a set of agreed-upon standards.

Established by the UKHCDO, the Peer Review Working Party provides guidance and direction for the peer review process. This group comprises bleeding disorder professionals and patients, including consultants, nurses, physiotherapists, and psychologists. Stakeholder input was received from professional associations, including the Haemophilia Nurses Association (HNA), the Haemophilia Chartered Physiotherapists Association (HCPA), and the Haemophilia Psychology Association (HPA). The Haemophilia Societies of England, Scotland, Wales and Northern Ireland provided patient and carer representation. In addition to developing quality standards, the Working Party has facilitated training through webinars and established peer review teams with the necessary expertise to conduct these reviews effectively.

Based on the Haemophilia National Service Specifications published in 2013 [1], the Peer Review Working Group developed the Quality Standards for the Care of People with Inherited and Acquired Haemophilia and Other Bleeding Disorders, Version 4.0. These national specifications outline the attributes necessary for comprehensive haemophilia care and ensure consistent assessments across all service specifications.

One of the twelve final recommendations from the 2024 Infected Blood Inquiry Report emphasised the critical importance of regular peer reviews and the need for NHS support. Furthermore, NHS trusts and health boards are expected to carefully assess the findings of peer reviews and give due consideration to implementing the identified changes to ensure comprehensive and safe care.

In 2024, peer reviews were scheduled across more than thirty Comprehensive Care Centres (CCCs) in the UK. The peer review team typically includes haematology consultants with expertise in bleeding disorders, clinical nurse specialists, a physiotherapist, and a patient, who systematically assess each centre against the quality standards. Before the onsite review, each service conducts a thorough self-assessment against the standards, highlighting strengths and areas that require attention. During the onsite visit, the peer review team focuses on elements of care and support that have the potential to improve clinical outcomes and enhance patient experiences. Feedback is provided at the end of the day, particularly emphasising any areas of immediate clinical risk.

The peer review report outlines each centre's level of compliance with the quality standards, as determined by the review team. Furthermore, the process involves revisiting findings from the previous peer review and assessing any outstanding actions. The final report highlights areas of good practice and risks to patient safety while offering recommendations for improvement. Services have the opportunity to clarify any points raised.

Following the completion of the peer review cycle, findings will be analysed to provide an overview of emerging trends, common challenges, and exemplary practices across the UK. This collective report will be shared with key stakeholders and discussed at the national level, including meetings of the Peer Review Working Party, the UKHCDO advisory group, and the Clinical Reference Group.

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[1] https://www.england.nhs.uk/wp-content/uploads/2013/06/b05-haemophilia.pdf

3 Service Description

The peer review was carried out on 27 November 2024 at the Haemophilia Centre, Alder Hey Children's Hospital in Liverpool. A multidisciplinary team of haemophilia professionals, including patient representatives, conducted the review, which involved speaking to staff from the Service, reviewing documentation, and touring the facilities.

The service serves the populations of Merseyside, Cheshire, North Wales, and the Isle of Man. The service provides care to children with bleeding disorders and has 284 registered patients. It offers a full range of services for patients with bleeding disorders from birth to the transition to adult services.

Although there is no dedicated psychology resource, referrals can be made to a general psychology service that supports the haematology/oncology children and young people's service. Patients can also be referred to the orthotics and podiatry service within the trust after a review by the specialist physiotherapist.

The laboratory service is provided by a specialist coagulation BMS in the main laboratory at Alder Hey Children's Hospital. The comprehensive portfolio of assays includes all coagulation factor assays, selected chromogenic assays, assays for inhibitor diagnosis and monitoring, and monitoring of emicizumab. Due to staffing and skill-mix pressures, the lab is unable to provide a 24/7 out-of-hours specialist testing service.

3.1 Patient numbers

Inherited bleeding disorders								
Number of patients	**Haemophilia A**		**Haemophilia B**		**Von Willebrand**		**Other**	
	Adults	Children	Adults	Children	Adults	Children	Adults	Children
Severe	0	39	0	2	0	87	0	121
Moderate	0	7	0	0				
Mild	0	22	0	3				
Annual review in the last year	0	73	0	5	0	87	0	121
Inpatient admissions in the last year	0	2	0	0	0	2	0	2

The table above shows the number of patients registered at the service and the severity of their bleeding disorder. It also shows the number of people who attended an annual review and inpatient admissions in the last year.

Staffing: The service includes one consultant, two nurses (one full-time and one 0.8 WTE), one physiotherapist (0.4 WTE), one quality manager (0.6 WTE), and three administrative staff (Admin 0.6 WTE, PCOs 1 and 0.8 WTE). The Service does not have a dedicated psychologist or social worker. This blend of full- and part-time roles ensures that partial, yet comprehensive, patient care is provided.

Key staff include Consultant Haematologist and Centre Director Dr Jessica Sandham and Lead Nurse Sharon Thind.

Outpatient care: Routine consultant-led multidisciplinary clinics are held every two weeks. The clinic provides a medical review and multidisciplinary team input, including nurse-specific interventions. Nurse reviews include monitoring prophylactic therapy. Annual joint reviews are also provided in this clinic.

Inpatient care: Patients are admitted to the areas appropriate to their needs

Out of hours: Out of hours regional specialist haemophilia consultant cover is on a 1 in 4 basis, with three substantive consultants and one locum. Patients and families are directed to the emergency department.

Transition: A transition clinic for those over 14 years is held twice a year and includes staff from the Liverpool Adults Service.

Network arrangements: There are no formal network arrangements, but the Service offers care to children and young people from North Wales, the Isle of Man, Merseyside and Cheshire.

4 Quality Standards

4.1 Overview

The table below outlines the status of each standard—met (green), partially met (yellow), or not met (red). Overall, the Service has met 22 out of the 30 standards, with eight partially met. The Service has outstanding findings from their previous peer review report in similar areas, which are provided in the appendix. The service is encouraged to review all descriptive assessments in addition to the key findings. This report, alongside local assessments, should steer discussions with the management team, highlighting areas of good practice while emphasising where further investment and improvement may be required.

Standard	Title of standard	Rating
1	Service Information	🟩
2	Condition-Specific Information	🟩
3	Plan of Care	🟩
4	Outpatient Review of PwBD	🟩
5	Contact for Queries and Advice	🟨
6	Haemtrack (PwBD on Home Therapy	🟩
7	Environment, Facilities and Equipment	🟩
8	Transition to Adult Services and Preparation for Adult Life	🟩
9	Carers’ Needs	🟩
10	Involving PwBD and Carers	🟩
11	Leadership Team	🟩
12	Staffing Levels and Skill Mix	🟨
13	Service Competencies and Training Plan	🟨

Standard	Title of standard	Rating
14	Administrative, Clerical and Data Collection Support	🟩
15	Support Services	🟩
16	Emergency Department	🟩
17	Laboratory Service	🟨
18	Specialist Services	🟩
19	IT System	🟩
20	Diagnosis Guidelines for People with Suspected IABD	🟩
21	Guidelines: Treatment and Monitoring of IABD	🟨
22	Clinical Guidelines/ Pathways	🟨
23	Guidelines on Care of PwBD requiring Surgery	🟩
24	Service Organisation	🟩
25	Multidisciplinary Team Meetings	🟨
26	Multidisciplinary Clinics/ Liaison Services	🟩
27	Data Collection	🟩
28	Research	🟨
29	Multidisciplinary Review and Learning	🟩
30	Document Control	🟩

4.2 Good Practice

There were several areas of good practice, and the following are noteworthy:

1. Alder Hey Hospital has an amazing building and facilities for children
2. The review team was very impressed by the teeth brushing leaflet, travel information documents and immunisation factsheet.
3. The review team wishes to highlight the transitional summary letter and "My transfer" documents for patients as excellent.
4. The Bleeding Disorder newsletter and QR code questionnaire are both excellent.

4.3 Immediate risks

No Immediate risks noted.

4.4 Concerns

Overall, the service provides excellent care, but the review team wish to highlight these main concerns:

1. The review team has several concerns related to staffing, specifically that the medical consultant staffing is insufficient for the size of the Service, particularly that the time allocated for the lead consultant to manage bleeding disorders is inadequate to deliver the service safely.

2. The team is small, comprising only 1.5 CNSs, a data manager, and a 0.4 WTE physiotherapist. The review team considers that there is a real lack of resilience in this staffing structure for both planned and unplanned leave, as well as for continuing professional development and service development. Indeed, there is no bleeding disorder-specific CPD for some key members of the MDT, and attendance at MDT meetings is limited.
3. There is no dedicated psychology time allocated to the service to develop specialist skills and knowledge needed to support patients and their families. These are lifelong inherited disorders with a significant psychological impact that require specialist support.
4. Whilst some basic factor testing is available from the Laboratory out-of-hours, other testing is not always available out-of-hours or at weekends. There is a reliance on the goodwill and availability of staff for testing out-of-hours.
5. There were no guidelines covering the ordering/ stock control/ recording issue of factor concentrate to allow this to be done smoothly if members of the core team are not available.

4.5 Recommendations

This section outlines the recommendations made by the review team in response to the concerns raised above.

1. **Medical staffing:** The review team recommends that the Trust support the service in addressing this shortfall by increasing the time allocated for the Haemophilia service within consultant job plans. The current staffing level does not provide sufficient time for haemophilia specific training or service development, such as incorporating clinical research, which is expected in a service of this size.
2. **Laboratory Service**: The review team recommends expanding the out-of-hours factor testing performed by the laboratory service to include a broader range of tests. The service should not depend on goodwill to maintain the essential catalogue of haemostasis tests, and extra education and training should be implemented to ensure their availability at all times. This can also be supplemented with an SLA with neighbouring hospitals.
3. **Physiotherapy staffing:** Increasing the physiotherapy provision will enable both a reactive and a proactive approach and enable the patients to be seen across the week.
4. **Dedicated Psychology Service:** The review team requests the Trust to allocate dedicated time from a named psychologist to support the Service in developing the skills and knowledge necessary to meet the complex needs of this patient and family population.
5. **Haemophilia Specific CPD:** The service should be managed by experts in bleeding disorders who have adequate access to CPD to ensure safe and effective care at all times. Sufficient time should be allocated to both nurses and other allied health professionals to achieve this.
6. **Stock control and management guidelines:** There should be clear guidelines for both the ordering and issuing of stock within the Centre during normal working hours and elsewhere in the hospital. These guidelines must be accessible and reviewed by all stakeholders to prevent delays in accessing treatment or confusion when Core team members are not present.

5 Quality Standards – Detailed Description

A detailed description of the quality standards used in the assessment is included, along with a concise overview of how the Service has met these standards, particularly focusing attention on the areas where the standard was partially met or not met.

Quality Standard 1: Service Information

Standard Met

Written information should be offered to people with bleeding disorders (PwBD) 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. How to access physiotherapy and psychology
f. Relevant national organisations and local support groups
g. Where to go in an emergency and how to access out of hours services
h. Information on delivery of products, including company contact details

How to:

i. Access social care and support services
ii. Access benefits and immigration advice
iii. Interpreter and advocacy services, PALS, spiritual support
iv. Give feedback on the Service, including how to make a complaint
v. Get involved in improving services (QS 10)

How the Service meets or does not meet the standard

No concerns, service information is clear.

Quality Standard 2: Condition-Specific Information

Standard Met

Written and or online information should be available and offered to PwBD and, where appropriate, their carers covering:

a. A description of their condition and how it might affect them
b. Problems, symptoms, and signs for which emergency advice should be sought
c. Genetics of Inherited Bleeding Disorders
d. Testing for carrier status and the implications of being a carrier
e. Treatment options including on-demand, prophylaxis, home therapy and the use of Haemtrack
f. How to manage bleeding at home
g. Ports, fistulae, and in-dwelling access devices (if applicable)
h. Approach to elective and emergency surgery

i. Women's health issues
j. Dental care
k. Travel advice
l. Vaccination Advice
m. Health promotion to include smoking cessation, healthy eating, weight management, exercise, alcohol use, sexual and reproductive health, and mental and emotional health and well-being
n. Sources of further advice and information

Condition-specific information should be available covering:

1. Haemophilia A
2. Haemophilia B
3. Von Willebrand Disease
4. Acquired haemophilia
5. Inherited platelet disorders
6. Bleeding Disorder of unknown cause (BDUC)
7. Other less common and rare bleeding disorders

How the Service meets or does not meet the standard

Use of haemophilia society patient information leaflets predominantly.

QR codes on patient information leaflets would be beneficial instead of web links. The trust information leaflet or port was used.

The review team appreciated the teeth brushing leaflet, travel information documents, and immunisation factsheet.

Quality Standard 3: Plan of Care

Standard Met

Each PwBD and, where appropriate, their carer should discuss and agree on their Plan of Care that is age-appropriate and should be offered a written record covering:

a. Agreed goals, including lifestyle 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 the school or other education provider
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 reviewed at each clinic appointment or at other times if clinically relevant.
The plan of care should be communicated to the PwBD GP and other relevant service providers involved in their care.

How the Service meets or does not meet the standard

Care plans were documented, and school letters were good.

Quality Standard 4: Outpatient review of PwBD

Standard Met

A formal review of PwBD should take place regularly:

a. For those with severe and moderate haemophilia, any PwBD on prophylaxis and other severe bleeding disorders at least twice a year. This may be more frequent in the paediatric setting based on clinical needs.
   The following multidisciplinary clinic arrangements for these PwBD should be in place:
   - i. Involvement of medical, specialist nursing and physiotherapy staff in clinics
   - ii. Availability or clear referral pathway for social work and psychology staff

b. For those with mild bleeding disorders, the Centre should have a documented follow-up pathway with a plan for managing DNA and PIFU if used. These PwBD should have access to the full MDT if clinically required but may not be seen in a combined clinic.

This review should involve the PwBD and, where appropriate, their carer.

The outcome of the review should be communicated in writing to the PwBD and their GP.

How the Service meets or does not meet the standard

The pathway for DNA is documented in the operational policy. PIFU is an option for some mild cases in the future. MDT clinics are established to coordinate nursing, medical review, and physiotherapy.

There was evidence of a referral pathway for social work, with Alder Hey currently having no social work services. Psychology input is non-specialised for haemophilia.

Quality Standard 5: Contact for Queries and Advice

Partially Met

Each PwBD 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 are not immediately available for non-urgent enquiries, then the timescales for a response should be clear.

How the Service meets or does not meet the standard

The information on how to contact the service for queries and advice is clear. Parents knew how to reach the service, but if the lead CNS was unavailable, it could take a long time for a query to be resolved. A parent raised a concern about accessing the service even during routine hours and being directed to the emergency department to obtain a supply of factor concentrates. The triage system for out-of-hours advice via the ward was not clear.

Quality Standard 6: Haemtrack (PwBD on Home Therapy)

Standard Met

All PwBD on home treatment should be encouraged to use the electronic recording of their treatment through Haemtrack. Use should be documented in clinic letters/ plan of care.

How the Service meets or does not meet the standard

The team is engaged, and patients are using Haemtrack.

Quality Standard 7: Environment, Facilities and Equipment

Standard Met

The environment and facilities in outpatient clinics, wards and day units should be appropriate for the number of PwBD with inherited and acquired bleeding disorders and accessible by people with severe mobility problems.

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 PwBD and carers with adequate space for physiotherapy assessment
d. Room for multidisciplinary discussion
e. Room for educational work with PwBD and carers
f. Office space for staff
g. Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all relevant clinical areas
h. Access to adequate IT equipment with clinical systems
i. All equipment should be appropriately checked and maintained.

How the Service meets or does not meet the standard

The building and facilities for children are amazing, and the hospital is fantastic overall.

Some parents mentioned that they missed opportunities for networking and support because the clinics had been relocated to a separate area.

Rehab/physio zones are not currently suitable for all age groups. The physiotherapy area is insufficient for the number of patients and teams using it, though there is a wonderful hydro pool on site.

Quality Standard 8: Transition to Adult Services and Preparation for Adult Life

Standard Met

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 the 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
    v. The Centre should have a guideline/SOP covering this information.

How the Service meets or does not meet the standard

The paperwork and vision of the transition process are heading in the right direction, but in practice, it is not yet clear if this is happening smoothly. The team is aware that this remains a work in progress.

Clinics are running on paediatric and adult sites. The transitional summary letter is well done, and the "my transfer" document for patients is good.

Quality Standard 9: Carers' Needs

Standard Met

Carers should be offered information on the following:

a. How to access an assessment of their own needs
b. What to do in an emergency
c. Services available to provide support

How the Service meets or does not meet the standard

The information given to carers was seen and was good.

Quality Standard 10: Involving PwBD and Carers

Standard Met

The Service should have:

a. Mechanisms for receiving regular feedback from PwBD and carers about treatment and care they receive
b. Mechanisms for involving PwBD and carers in decisions about the organisation of the Service
c. Examples of how the Service has engaged PwBD / received feedback or made changes made as a result of feedback and involvement of PwBD and carers

How the Service meets or does not meet the standard

Patients would welcome the restart of patient events. The Bleeding Disorder newsletter (yearly) and the QR code questionnaire are both effective.

Quality Standard 11: Leadership team

Standard Met

The leadership team will consist of a lead consultant, and other members agreed at a local level. This may include nurses, physiotherapists and psychologists, clinical scientists, or other members of the MDT. The lead consultant will be responsible for staff training, guidelines and protocols, service organisation, governance and liaison with other Services but may delegate some of these roles to others in the leadership team.

The leadership team should all be registered healthcare professionals with appropriate specialist competences, undertake regular clinical work with the Service, and have specific time allocated for their leadership role.

How the Service meets or does not meet the standard

The centre director has time allocated in her job plan, and the leadership team includes nursing and biomedical scientists.

Quality Standard 12: Staffing levels and skill mix

Partially Met

a. Sufficient staff with appropriate competences should be available for outpatient, day unit and in-patient care and support to urgent care services. Staffing levels should be appropriate for the number of PwBD cared for by the Service and its role in the network.
b. All staff should undertake regular continuing professional development that is relevant to their work in the inherited and acquired bleeding disorders services.
c. 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.
d. 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 specialising in the care of people with inherited and acquired bleeding disorders 24/7 in HCCC
    iii. On-call haematology consultant with arrangements for advice from a consultant specialising in the care of people with inherited and acquired bleeding disorders in HC
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. Practitioner psychologist or appropriately trained psychotherapist with specialist knowledge in IBDs.
e. Access to specialist senior social worker
f. Data manager
g. Biomedical scientist and/or clinical scientist (further details on the requirements are included in QS 17)

How the Service meets or does not meet the standard

The review team is concerned that the service largely depends on one consultant, 1.8 CNS, a data manager, and a physiotherapist.

There is no specialist psychologist and no access to social workers outside of safeguarding pathways.

There is an on-call rota with haemostatic management plans discussed in non-malignant MDT meetings so that the other three consultants are familiar with new patients or upcoming surgeries.

While the number of medical staff is not specified in the standard, the peer review team felt that the time allocated for the lead consultant to deliver the service for bleeding disorders is inadequate for safe provision. Other medical staff are involved in general clinics and the out-of-hours rota, but there is insufficient time and expertise to oversee complex surgery in the absence of a lead consultant.

Quality Standard 13: Service Competencies and Training Plan

Partially Met

a. All staff are to complete trust mandatory training, including regular appraisal.
b. All clinical staff to have CPD relevant to bleeding disorders
c. All new nurses/AHP/Psychologists to have the opportunity to attend an introduction to bleeding disorders course and the contemporary care course provided by the Haemophilia Nurses Association
d. All specialist clinical staff to have the opportunity to attend national and/or international conferences and to develop subspecialist interests

How the Service meets or does not meet the standard

CPD specific to bleeding disorders was not evidenced for the wider MDT team and may reflect the inadequate staffing.

Quality Standard 14: Administrative, Clerical and Data Collection Support

Standard Met

Dedicated administrative, clerical and data collection support should be available.

How the Service meets or does not meet the standard

Appropriate and adequate with no concerns.

Quality Standard 15: Support Services

Standard Met

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/podiatry

How the Service meets or does not meet the standard

Support services within the wider hospital include a direct referral system.

The team would welcome the addition of a designated pharmacist with knowledge and interest in benign haematology to assist with processes such as safe prescribing, issuing, and stock management.

Quality Standard 16: Emergency Department

Standard Met

Guidelines on the management of PwBD in the Emergency Department should be in use:

- a. To include details of electronic alert visible in ED
- b. Who to contact for advice 24/7

ED medical and nursing staff should have training on inherited and acquired bleeding disorders.

ED pathway should be audited +/- PwBD survey on emergency attendance on an annual basis.

How the Service meets or does not meet the standard

No electronic alerts hospital wide. There is a 10-minute lunchtime huddle for teaching in the ED, which can include speciality sessions. The Haematology CNS provides this quarterly. There is no electronic alert on the ED system across the trust; a senior nurse in triage and supervising medical staff in the ED are familiar with the system.

The ED pathway is audited annually. Staff know how to contact haematologists. An emergency handbook is available for all to use.

Quality Standard 17: Laboratory Service

Partially Met

a. A UKAS 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 multidisciplinary team meetings (QS 25) regularly

c. The following tests should be available in a timely manner for the diagnosis and management of inherited bleeding disorders:
   i. All coagulation factor assays
   ii. Inhibitor screening
   iii. FVIII inhibitor quantification
   iv. VWF antigen
   v. VWF activity
   vi. Platelet function testing

d. Pathway for referral to molecular Genetic Laboratory service for:
   i. Detection of causative mutations in PwBD
   ii. Carrier detection
   iii. Discussion of results in genomics MDT when needed

How the Service meets or does not meet the standard

The service is not currently available 24/7, as it depends on staff availability and goodwill. Platelet aggregations are sent to Leeds, which incurs a delay in processing, potentially impacting the results. There is limited availability of specialist assays out of hours. Staffing problems are further compounded by sickness.

Quality Standard 18: Specialist Services

Standard Met

Timely access to the following specialist staff and services should be available as part of an HCCC service where appropriate, depending on whether it is adult, paediatric or all-age 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

l. Specialist services should have an appropriate level of specialist expertise in the care of people with inherited and acquired bleeding disorders.

How the Service meets or does not meet the standard

Swift vascular access support. Carrier clinics are in place. Adult genetics (e.g., for parents) will be referred to the Royal Liverpool. The dental service is excellent, and the dental leaflet on teeth brushing is fantastic. Good neonatal plans were observed.

Quality Standard 19: IT System

Standard Met

IT systems should be in use for:

- a. Storage, retrieval, and transmission of PwBD information, including access to the latest treatment plan and vCJD status
- b. PwBD administration, clinical records, and outcome information
- c. Data to support service improvement, audit, and revalidation

How the Service meets or does not meet the standard

Medisec and Meditech systems are used for clinical notes and letters. Theatre plans are electronic and circulated to relevant staff. The treatment plan appears at the bottom of each letter. Patient passports for patients in North Wales enable access to specialist care at local hospitals.

Quality Standard 20: Diagnosis Guidelines for People with Suspected Inherited and Acquired Bleeding Disorders

Standard Met

Guidelines on diagnosis should be in use covering the investigation and diagnosis of suspected bleeding disorders. The guidelines should cover.

- a. Haemophilia A
- b. Haemophilia B
- c. Von Willebrand Disease
- d. Acquired haemophilia
- e. Inherited platelet disorders
- f. Bleeding disorder of unknown cause
- g. Other less common and rare bleeding disorders
- h. Haematological investigation of menorrhagia
- i. Haematological investigation in child suspected of inflicted injury
- j. Non-specific bleeding disorders

How the Service meets or does not meet the standard

There are no specific guidelines for the investigation of menorrhagia or non-specific bleeding disorders.

Quality Standard 21: Guidelines: Treatment and Monitoring of IABD

Partially Met

Guidelines should be in use covering:

a. Factors concentrate and non-factor replacement therapy
   i. Initiation and monitoring of prophylaxis
   ii. Home therapy
   iii. Use of extended half-life products, including inhibitor testing and PK assessment
   iv. Use of non-factor replacement therapy
b. Management of factor concentrate and non-factor replacement therapy 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 PwBD on home treatment
   v. Arrangements for emergency 'out of hours' supply
   vi. Recording issue to PwBD
   vii. Recording use by PwBD, including on Haemtrack
   viii. Submission of data via NHD for quarterly returns

How the Service meets or does not meet the standard

No Guideline or SOP is covering ordering, stock control, or recording the issue of factor concentrate to enable this to be done smoothly if members of the core team are unavailable.

Quality Standard 22: Clinical Guidelines/Pathways

Partially Met

The following clinical guidelines/pathways should be in use:

a. Management of acute bleeding episodes, including PwBD with inhibitors
b. Immune tolerance therapy
c. Dental care
d. Care of PwBD with hepatitis C
e. Care of PwBD with HIV
f. Antenatal care, delivery, and care of the neonate
g. Management of synovitis and target joints
h. Long-term surveillance of musculoskeletal health
i. "For public health purposes": care of PwBD at risk of vCJD who are undergoing surgery.

How the Service meets or does not meet the standard

There are no guidelines for ITI, management of synovitis, or MSK health.

Quality Standard 23: Guidelines on Care of PwBD requiring Surgery

Standard Met

Guidelines on the care of PwBD 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 PwBD 's care prior to, during and after post-surgery
c. documentation of care provided
d. Arrangements for escalation in the event of unexpected problems.

How the Service meets or does not meet the standard

Evidence for the above standards was provided.

Quality Standard 24: Service Organisation

Standard Met

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 PwBD 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 multidisciplinary discussions relating to their PwBD
e. Arrangements for follow-up of PwBD who 'do not attend'
f. Arrangements for transfer of PwBD information when PwBD moves areas temporarily or permanently
g. Ensuring PwBD's plans of care are reviewed at least six monthly for those with severe haemophilia and at least annually for other PwBD (QS 3)
h. Ensuring school visits for children with severe haemophilia at least at each change of school (children's services only)
i. Ensuring PwBD are visited at home where clinically appropriate at least annually if they are unable to attend clinics, including those in nursing homes
j. Lone working

How the Service meets or does not meet the standard

Evidence of the above was seen with no concerns raised.

Quality Standard 25: Multidisciplinary Team Meetings

Partially Met

Multidisciplinary team meetings to discuss PwBD's plans of care, including surgical procedures, should take place regularly involving:

a. All core members of the specialist team
b. Senior biomedical scientist or clinical scientist with responsibility for the Coagulation Laboratory
c. HC staff who are regularly involved in the PwBd care as part of network arrangements.

How the Service meets or does not meet the standard

Physio and BMS do not attend MDT meetings regularly, although alternative arrangements are made for discussions in clinics if needed.

Quality Standard 26: Multidisciplinary Clinics/Liaison Services

Standard Met

Combined clinics or other arrangements for multidisciplinary discussion with

a. Orthopaedics and or rheumatology
b. Obstetrics and gynaecology
c. Paediatrics
d. HIV
e. Hepatology

How the Service meets or does not meet the standard

The link gynaecologist was noted, and physio has good links with trauma &orthopaedics.

Quality Standard 27: Data Collection

Standard Met

The following data should be collected:

a. UK National Haemophilia Database data on all PwBD
b. Data on concentrate use and bleeds, either through Haemtrack or an equivalent mechanism
c. Data required to complete the NHS E National Haemophilia Dashboard or other national mechanisms
d. Adverse events reported to NHD

How the Service meets or does not meet the standard

This standard will be met when HCIS is installed (expected in the next 1-2 weeks).

Quality Standard 28: Research

Partially Met

The Service should actively participate in research relating to the care of PwBd with bleeding disorders. The Service should also offer links with other services to maximise research study opportunities. Staff members participating in research should be allocated appropriate time for this role.

How the Service meets or does not meet the standard

There was no evidence of participation in observational research or clinical trials. The lack of time has been cited as a major limitation. Opportunities for participation in research are part of the national service specifications.

Quality Standard 29: Multidisciplinary Review and Learning

Standard Met

The Service should have multidisciplinary arrangements for review and implementation of learning from:

a. Audit – the Service must have an audit plan, and it must include an audit of emergency and out of hours care (QS 23)
b. Positive feedback, complaints, outcomes, incidents and 'near misses'
c. Morbidity and mortality
d. Haemophilia Dashboard (when relevant)
e. Review of UKHCDO Annual Report benchmarking information on concentrate use
f. Ongoing reviews of service quality, safety, and efficiency
g. Published scientific research and guidance

How the Service meets or does not meet the standard

Evidence provided for the standards.

Quality Standard 30: Document Control

Standard Met

All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.

How the Service meets or does not meet the standard

Evidence provided for the standard.

6 Acknowledgements

The UKHCDO and the Peer Review Team express their sincere gratitude to the Service for its openness, hospitality, and meticulous preparation. We are especially thankful to the service users and carers who generously contributed their time and offered invaluable insights during the review. Furthermore, we extend our appreciation to the members of the Peer Review Team and their employing organisations for facilitating their participation in this process. We are grateful to all involved for their commitment to enhancing patient care through this peer review process.

Finally, the peer review process would not have been possible without the dedicated efforts of several key individuals: Dr. Sarah Mangles, Chair of the Peer Review Working Party, provided continuous and strategic oversight; Debra Pollard, retired Advanced Nurse Practitioner at the Royal Free, ensured consistency across all peer review reports; Harry Evans, Peer Review Project Manager, coordinated and managed the process; and the UKHCDO Chair and Executive team for their contributions to the reports and their final review.

7 Appendices

7.1 Definitions

Reference	Reference number for quality standard
Quality Standard	The wording of the quality standard
Rating	The review team's opinion as to whether the standard has been: Met - Standard has been met fully. Partially Met - Standard has been met in part. Not Met - Standard has not been met at all. Not Applicable - Standard is not applicable for this specific centre.
How the service meets or does not meet the standard	What evaluations or conclusions can be drawn from the evidence. How does the evidence provided meet, partially meet, or not meet the standard. Evidence can be presented as a document or based on the observations of the peer review team.
Immediate risks	These are issues that pose an immediate risk to patients, carers, and or staff.
Good Practice (if applicable) (over and above the standard)	Where applicable, any good or best practice witnessed should be supported with evidence.

7.2 Peer Review Team

The Peer Review Team consisted of two consultant haematologists, three clinical nurse specialists, a specialist haemophilia physiotherapist and a patient representative. Details of the Peer Review Team are held by UKHCDO.

7.3 Outstanding findings from previous peer review

The table below provides details of relevant issues that were raised in the previous peer review report of 2019, some of which have also been raised in this review. These have been highlighted here to add strength to the recommendations in this report as these issues should be addressed as a matter of priority. The Trust should ensure that appropriate resources are made available so these outstanding issues can be resolved.

Ref. number	Statement of original finding
1	Staffing
a	Senior medical staff - There were 1.6 WTE consultant vacancies in the team. Due to a combination of consultant sick leave, maternity leave, and a recent retirement and at the time of the visit there was 0.8 WTE consultant cover for the service. This was due to reduce to 0.3 WTE (one and a half days a week) two days after the visit as a locum appointment was coming to an end. As the remaining consultant was prepared to offer a 24/7 on call service until a colleague returned to work, possibly two to four weeks later, this did not constitute a clinical risk to patients but was clearly unsustainable. In the limited number of senior medical sessions available, some aspects of the director's role such as managing a clinical audit programme and ensuring complete guidelines were in place, were not currently being performed.
b	Nurse specialists - The complement of specialist nurses was 1.6 WTE, with current support from an additional whole-time nurse whose secondment period was due to end in the near future. The nurses also worked across some other non-malignant haematology sub-specialties and were offering some aspects of psychosocial care as the team lacked some key members (see c below). In addition, they had also been undertaking some duties usually undertaken by senior medical staff – such as carrying out routine reviews of some moderately affected patients and writing guidelines for the department. They also worked across a wide geographical area, visiting schools and families as far away as North Wales. This provision was insufficient, and they were working well beyond their contracted hours. Furthermore, one of the two long-serving nurse specialists intended to retire less than a year after the review visit. It is hoped that planned interviews to appoint into an additional post will be successful in recruiting a substantive colleague.
c	Psychosocial care - There were no psychology sessions offered to the service, and social workers were only involved if there were safeguarding issues. Other team members, especially the nurse specialists, were undertaking some support work, and referral to the hospital psychology service could be made for high-level needs. However, in the absence of a psychology member, the team were lacking the support that such a colleague can bring, and it was inevitable that some lower-level child and family needs were not being met. Additionally, there was no dedicated play therapy available for children.