UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

# UKHCDO Haemophilia Peer Review Audit Report

## Liverpool Adults Haemophilia Comprehensive Care Centre

Haemophilia Nurses Association UK

HAEM-PSYCH ASSOCIATION UK & IRELAND

HC PA Haemophilia Chartered Physiotherapist Association

HAEMOPHILIA SCOTLAND

The Haemophilia Society

HAEMOPHILIA WALES

Haemophilia NI
Supporting patients and families

**Report Date: 29 July 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 Liverpool Adults Haemophilia Comprehensive Care Centre (the Service) was completed on 26 November 2024.

**The Service successfully met 27 of the 30 established standards, with three 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. **Physiotherapy Provision:** The review team strongly recommends establishing a permanent physiotherapist within the current service. This is an essential component of service provision, as outlined in the service specification for bleeding disorders. The provision must be appropriate for the size of the service and capable of delivering both reactive and proactive services, including the management of joint bleeds, joint damage, and other musculoskeletal issues.
2. **Out-of-hours Laboratory Test Provision:** The review team recommends establishing a more robust out-of-hours service and expanding the laboratory's out-of-hours test repertoire

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 of the Comprehensive Care Centre was conducted on 26 November, 2024. A multidisciplinary team of haemophilia professionals, along with patient representatives, carried out the review, which involved interviewing staff from the Service, reviewing documentation, and touring the facilities.

The Service provides care to adults with bleeding disorders and has 1,036 registered patients. It is located at the Royal Liverpool University Hospital, which has been part of the NHS University Hospitals of Liverpool Group since its establishment on 1 November 2024. The Service serves a broad geographical area, including Merseyside, Cheshire, and parts of Lancashire.

The service operates across four main hospital sites: Royal Liverpool University Hospital, Aintree University Hospital, Broadgreen Hospital, and Liverpool Women’s Hospital. Inpatients, outpatients, daycare, and administrative services are all situated at the Royal Liverpool University Hospital.

The Service has strong connections with the Liverpool Paediatric Haemophilia Comprehensive Care Centre (CCC), situated at Alder Hey Children’s Hospital.

## 3.1 Patient numbers

| Number of patients | Inherited bleeding disorders | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Haemophilia A | | Haemophilia B | | Von Willebrand | | Other | |
| | Adults | Children | Adults | Children | Adults | Children | Adults | Children |
| **Severe** | 51 | 0 | 4 | 0 | 445 | 0 | 410 | 0 |
| **Moderate** | 9 | 0 | 5 | 0 | | 0 | | 0 |
| **Mild** | 100 | 0 | 12 | 0 | | 0 | | 0 |
| **Annual review in the last year** | No data provided | 0 | No data provided | 0 | No data provided | 0 | No data provided | 0 |
| **Inpatient admissions in last year** | No data provided | 0 | No data provided | 0 | No data provided | 0 | No data provided | 0 |

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 staff consists of a mix of full-time and part-time roles, including four consultant haematologists (4.0 WTE), three nurses (3.0 WTE), one physiotherapist (0.6 WTE), five biomedical scientists (4.5 WTE), and three psychologists (1.9 WTE). Additionally, there are 12 administrative staff in various roles, including an MDT coordinator and a data manager.

**Key staff** include Consultant Haematologist Dr Cathy Farrelly and Lead Nurse Jayne Keaney.

**Outpatient care**: Outpatient, daycare and administrative services are all based at the Royal Liverpool University Hospital

**Inpatient care**: Patients are admitted to the areas appropriate to their needs at the Royal Liverpool University Hospital

**Out of hours:** This is through the emergency department, where patient records are flagged, and pathways with ongoing education are in place.

**Transition:** The Service has close ties with the Liverpool Paediatric Haemophilia Comprehensive Care Centre (CCC), located at Alder Hey Children's Hospital**.**

**Network arrangements:** The Service is networked with the North Wales Haemophilia Service, which is nominally based at the Bangor (Ysbyty Gwynedd) Haemophilia Centre; however, patients are also seen at local hospitals in Glan Clwyd and Wrexham. Currently, the Service does not have any formal outreach clinics. Severe patients from the Network are seen either in person or remotely at the Service, in addition to their local follow-up. The Service has plans for outreach clinics in Wrexham due to imminent staffing issues, as well as virtual Severe Bleeding Disorders clinics in conjunction with the Welsh teams.

The Service holds a Network MDT Meeting once a month; however, the North Wales team can also attend the weekly MDT meetings in between, should urgent cases require discussion. The Consultant Haematologist, Haemophilia ANP, and Physiotherapist are all invited to this meeting.

Additionally, the Service has close links with Manchester Adults CCC, which will be hosting Gene Therapy and with whom the Service will share the regional navigator role for the IBPS.

The Service organises supra-regional educational and networking meetings several times a year, referred to as the Northwest Haemophilia Meeting. Initially, this was attended by representatives from North Wales, Alder Hey, MRI, and Manchester Children's; however, in more recent meetings, colleagues from further afield, including Leeds, Sheffield, Hull, and York, have also participated.

# 4 Quality Standards

## 4.1 Overview

The table below outlines the status of each standard, categorised as met (green), partially met (yellow), or not met (red). Overall, the Service has met 27 out of the 30 standards, with three 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 | 🟩 |

| Standard | Title of standard | Rating |
|---|---|---|
| 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 | 🟩 |
| 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. Overall, the review team was impressed by the excellent care provided by the Service.
2. The review team was extremely impressed with the physiotherapy documents, which included clinical guidelines, patient information leaflets, and Standard Operating Procedures on Synovitis/MSK health, among others. The overall level of service provided by the physiotherapy team was outstanding.
3. The information on how patients can access psychological support is excellent.

4. The service has a haematology pharmacist prescriber, which the review team regarded as fantastic.
5. Senior Biomedical Scientist support and the connections with the transfusion laboratory for the provision of clotting factor concentrates are very good.
6. The review team were impressed by the Emergency Department (ED) shared learning sessions

## 4.3 Immediate risks

There were no immediate risks identified.

## 4.4 Concerns

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

1. The review team is very concerned about the impending loss of the physiotherapist. The physiotherapist is on a fixed-term contract that is externally funded, and the Service was unsuccessful in securing the required full-time physiotherapy provision on a permanent basis. It has managed to extend the fixed-term contract on a 0.6 WTE basis by redirecting funds from other parts of the service. However, the post expires on 1 May 2025. If this occurs, the Service will lose all physiotherapy provision. This would be significantly detrimental to the treatment and recovery of patients, and the Service would no longer fulfil the requirements of a Comprehensive Care Centre. Physiotherapy is an essential part of the multidisciplinary team, as specified in the service specification, and commissioners for bleeding disorders services will expect funding to be allocated appropriately.
2. The review team is concerned that access to other specialist testing is restricted out of hours and at weekends due to a lack of robust cover. With the advent of new therapies, this has become increasingly important.
3. The review team is concerned about the impact of losing a consultant, a haematologist, and an advanced nurse practitioner from one of their linked centres in Wales, particularly on the consultant and nursing staff at the service.

## 4.5 Recommendations

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

1. **Physiotherapy Provision**: The review team strongly recommends that the Trust allocate the necessary funding to enable the Service to maintain its valuable physiotherapy provision. This is an essential aspect of service delivery, as specified by the National Service Specification for bleeding disorders, and it is a key component of the required multidisciplinary team. A specialist physiotherapist provides ongoing care and assessment of musculoskeletal health, including treatment and rehabilitation following bleeding episodes and surgery, as well as MSK health advice on how to exercise safely and improve joint health without triggering joint bleeds, all of which are crucial for haemophilia care. The Service should retain a minimum of one full-time band 7 substantive post for physiotherapy.
2. **Out of Hours Laboratory Testing**: The review team recommends expanding the out-of-hours laboratory test repertoire to include a broader range of tests that require support from

specialised lab staff, considering the ongoing changes in haemophilia treatment that necessitate updating the laboratory components of the National Service Specification.

# 5 Quality Standards - Detailed Description

A detailed description of the quality standards used in the assessment is provided, along with a concise overview of how the Service has met these standards, particularly focusing on areas where the standards were either 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

Examples of all relevant service information have been provided, including details on accessing psychological support, and the availability of good physiotherapy support has been noted.

## 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

Relevant information was noted, and none was obviously missing.

## 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

Good examples of letters. The signed home delivery agreement is 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

Patient feedback noted that patients missed the centre as a base and the peer support that it provided. However, felt very supported by the team and know how to ask them.

## Quality Standard 5: Contact for Queries and Advice

**Standard 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

Positive patient feedback in this area; patients felt well supported by the team.

## 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

No concerns were noted.

## 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

Compared to the previous Roald Dahl Centre at the children's hospital, there is a lack of a dedicated haemophilia centre. Overall, the facilities are good. The only issue is the geographical location of the offices relative to the rest of the hospital, but the team has managed to make this work well for them. An ambulatory area on the base ward would be beneficial.

## 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 transition process was outlined, and the process map was shown.

## Quality Standard 9: Carers' Needs

**Partially 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 Trust Carer Passport is currently utilised. It encompasses a wide range of services but does not specifically refer to bleeding disorders or related support. It was suggested that steps be taken to request the addition of this information.

## 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

Feedback summaries were reviewed, and evidence was presented of a change in the home delivery service following patient feedback. Additionally, documents obtained from patients support the ongoing role of the physiotherapist. A suggestion was put forward to consider establishing an action plan for any issues and concerns raised during the annual survey.

## 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

Leadership meeting minutes were provided and included a lead consultant, a nurse, a physiotherapist, and a psychologist.

## 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 about the imminent loss of the physiotherapy service. There is no immediate plan to address this, and consequently, the Service will no longer meet the requirements of a Comprehensive Care Centre. The review team has noted the impact not only on patients but also on the increased pressure on the rest of the multidisciplinary team, and therefore, on the overall functioning of this Service if this is not promptly addressed.

The contemporary care document for people with bleeding disorders is in place. Job plans for Band 8, 7, and 6 nurses have been provided. The scope of work and roles are detailed, including outpatient clinical assessments and liaising with surgical teams. Information on nursing staffing, training, CPD, and appraisals has been supplied. Band 8 is an active member of HNA and serves as a nurse representative on the UKHCDO working party. Appropriate nursing staffing is in place. An additional consultant resource is needed (with an appointed colleague starting in January), but the loss of consultants and ANPs from Wales raises concerns.

Psychologist Michelle Kilmurray, appointed through IBPS/NHSE funding, has the capacity to see patients with other bleeding disorders. It is operational and seeing IBS patients as well as looking at transition.

## Quality Standard 13: Service Competencies and Training Plan

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

**Standard Met**

### How the Service meets or does not meet the standard

Mandatory training records are provided for the Physiotherapist, Nursing team, and Consultant. Information regarding HNA competencies for all nursing team members is included, along with evidence of attendance at meetings for all nurses.

A Band 6 nurse attended a contemporary care course. The Physiotherapy team has completed a comprehensive care course.

Nursing and medical appraisal, as well as CPD, have been provided.

## Quality Standard 14: Administrative, Clerical and Data Collection Support

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

**Standard Met**

### How the Service meets or does not meet the standard

Detailed in the operations policy, with one WTE data manager at band 5.

## Quality Standard 15: 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/podiatry

**Standard Met**

## How the Service meets or does not meet the standard

Dietetics, occupational therapy, and orthotics support are available within the wider hospital structure.

The peer review team noted the excellent contribution of the pharmacist prescriber.

## 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

Guidelines featuring a flow chart for patients presenting at the ED were created for the ED staff. Information on how patients can access the haemophilia centre staff for advice 24/7 was included. Evidence of teaching was provided by Cathy and the nursing team to the ED staff.

The team conducted a tour of clinical areas with the ED staff, and the ED consultant was engaged and positive about interaction and support with the haemophilia service. Alerts are displayed on clinical records.

## 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

One-stage FVIII/IX/VWF assays are accessible outside of normal working hours. Continuous access to additional laboratory testing is important. Senior BMS support is good, but there does not appear to be a robust out-of-hours service for other specialist testing.

Connections with the transfusion lab regarding the provision of factor concentrates were also very good.

## 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

Some services are offered through the usual hospital referral pathways. The physiotherapist is present at the orthopaedic outpatient appointments with patients as availability permits. There is an excellent obstetric haematology service.

## 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

No concerns were noted.

## 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

Guidelines were all present with good use of flow charts.

## Quality Standard 21: Guidelines: Treatment and Monitoring of IABD

**Standard 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

The flowcharts and home treatment agreement are good, but the Roald Dahl Centre’s old name is still present on the emicizumab document.

## Quality Standard 22: Clinical Guidelines/Pathways

**Standard 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

The physiotherapy documents (clinical guideline, PIL, SoP on synovitis/MSK health, etc.) were excellent, as was the overall level of service provided by their haemophilia physiotherapy team.

## 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

A guideline is in place again with good use of flow charts.

## 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 seen of the above standards.

Good working relationships with the team at Chester.

## Quality Standard 25: Multidisciplinary Team Meetings

**Standard 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

There is only one consultant for bleeding disorders; however, please note the newly recruited post. Concerns have been raised regarding network arrangements with Wales, as well as upcoming staff changes. MDT meetings are in place with an online proforma which can be easily completed, and information is automatically integrated into the MDT. It comprises a multidisciplinary team that includes medical staff, nurses, trainees, physiotherapists, psychologists, and laboratory members; a social worker is expected to be employed soon. Regional and network MDTs have also been established.

## 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

Arrangements for HIV and Hepatitis C are detailed, as well as the joint obstetric clinic. The hepatology department manages patients with liver disease. Referrals to orthopaedics or rheumatology can be directed to specific clinicians or teams.

## 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

The data collection framework and SSQD submission have been provided. The data is excellent and sent to NHD; most entries have joint scores and physiotherapy assessments.

The blood bank conducts daily inventories and provides monthly updates on its stock.

A treatment calendar from the haemophilia centre lists all concentrates administered within the network.

The data manager is relatively new to the role, having been in the position for five months. They support all clinical teams, including TTP, ITP, and bleeding disorders. They document adverse events, send information to the NHD, register patients, and issue bleeding disorder cards.

## Quality Standard 28: Research

**Standard 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

Several studies are currently open, including the EHL outcome registry, VWD360, and vonicog alfa. Abstracts have been presented, but there is no documentation of the time allocated for research.

## 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<br>g. Published scientific research and guidance | |
| **How the Service meets or does not meet the standard** | |
| ED shared learning sessions are excellent. The physiotherapy audit was seen, and other audits included an audit of calls made to the centre. Patient feedback was provided and was all positive. The quality, safety, and effectiveness meeting notes, which include M&M and ED consultant, highlighted the shared learning that had occurred with haematology through M&M processes. | |
| **Quality Standard 30: Document Control** | |
| All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures. | **Standard Met** |
| **How the Service meets or does not meet the standard** | |
| Policies, guidelines, and documents are accessible on the trust intranet and comply with the trust document control policy. | |

# 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:<br>Met - Standard has been met fully.<br>Partially Met - Standard has been met in part.<br>Not Met - Standard has not been met at all.<br>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, a clinical nurse specialist, 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 |
|---|---|
| 1a | Staffing:<br>Physiotherapy: Provision was inadequate, with a specialist physiotherapist contracted to support just one clinic a month. At other times access was through the general physiotherapy service. Although she was able to attend monthly clinics and clearly made every effort to be flexible to patient needs, there was no time available within the existing funded hours for the physiotherapist to offer any care to preserve joint health, so that even if joint scores were deteriorating there was no capacity for appropriate physiotherapy management to be offered. No outcome measures were being undertaken. |