UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

UKHCDO Haemophilia Peer Review Audit Report

Birmingham Children's Haemophilia Comprehensive Care Centre

HAEM-PSYCH ASSOCIATION UK & IRELAND

Haemophilia Nurses Association UK

HCPA Haemophilia Chartered Physiotherapist Association

HAEMOPHILIA SCOTLAND

The Haemophilia Society

HAEMOPHILIA WALES

Haemophilia NI
Supporting patients and families

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Table of Contents

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 Birmingham Children's Haemophilia Comprehensive Care Centre (the Service) was completed on 19 June 2024. The Service is located within the Birmingham Women's and Children's NHS Foundation Trust.

The Service successfully met 27 of the 30 established standards, with three standards partially met. The Centre's and the Trust's commitment to providing high-quality care was evident through various initiatives and pathways. However, key recommendations have been made to address gaps that impact the ability to deliver comprehensive care.

Key Recommendations:

1. **Haemophilia Specialist Physiotherapy**: The current provision is small in relation to the size of the service. Whilst annual joint score assessment and management of acute bleeding episodes are being done, there is no provision to promote and sustain good joint health.
2. **Provision of Psychosocial Services**: Priority should be given to establishing a dedicated psychology service for children and their families, as these are genetically inherited conditions that affect the mental health of both the children and their families. Similarly, access to dedicated social worker support is essential for families to receive appropriate assessment and support.
3. **Nursing skill-mix review:** A nursing skill mix should be undertaken with a view to converting the rotational post into a permanent role within the Haemophilia Centre Nursing Team, ensuring that the resources needed for training a nurse in the speciality are used effectively for the future.

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.

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

3 Service Description

The peer review took place on 19 June 2024 at the Haemophilia Centre, Outpatients 2, 1st Floor, Waterfall House. The service provides care for children with bleeding disorders and currently has 550 registered patients in the West Midlands. It is part of Birmingham Women's and Children's NHS Foundation Trust, one of the largest dedicated children's hospitals in the UK.

A multidisciplinary team of haemophilia professionals, along with patient representation, conducted a review that involved speaking to staff from the service, reviewing documentation, and touring the facilities. The Service offers comprehensive, holistic care as described in the National Service Specification B05/S/a, with full-time Consultants in Haemostasis & Thrombosis supported by experienced, highly skilled specialist nurses, an allied health professional team, and healthcare scientists.

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		69		10				
Moderate		7		4		121		128
Mild		20		5				
Annual review in the last year		96		18		98		88
Inpatient admissions in the last year		1		1		0		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 Service employs a number of professionals in full- and part-time roles, including three consultants (2.3 WTE), three nurses (2.4 WTE), one physiotherapist (0.4 WTE), and two administrative staff (1.1 WTE), a Data Manager (full-time), a Data Admin Co-ordinator, PA secretarial support for consultants. The service does not have a dedicated haemophilia specialist psychologist, with only limited access to general hospital services. This mix of full- and part-time roles ensures that key aspects of comprehensive patient care are delivered.

Key staff include Consultant Haematologist and Centre Director Dr Jayshree Motwani, and lead nurse Natalie Lawson

Outpatient care: Haemophilia services are integrated within the haematology/oncology department, which manages children with both malignant and non-malignant diagnoses. Outpatient and day-case care are provided in a large, purpose-built facility established in 2018 to expand the space and

improve upon previous facilities for patients. If admission is necessary, inpatient care is available on the Haematology-Oncology ward, Ward 18. Often, admission to another ward, such as Surgery or ENT is preferred.

A comprehensive diagnostic service is available to investigate children aged 0-16 years with potential bleeding disorders, with assays available 24/7 from the on-site haematology laboratory.

Children with bleeding disorders are under the care of three Consultants, one of whom is also the Centre Director. All carrier mothers are seen in a joint Haem–Obstetric clinic, and BCH also receives a copy of the birth plan. Any new neonate with a severe bleeding disorder is seen at BCH upon discharge from BWH.

All severely affected children are reviewed at least every six months in the Consultant-led clinic. Children with Severe and Moderate Haemophilia A & B are seen annually in a Multidisciplinary clinic by a haematologist, dentist, and physiotherapist. Haemophilia Joint Score assessment is performed during these clinics. Home delivery of factor concentrates is organised for those on prophylaxis. Comprehensive care is available for all patients, including those with inhibitors. Children with milder disorders are usually followed annually.

Inpatient care: Children are admitted to the ward most appropriate for their needs

Out of hours: Out of hours and at weekends, patients attend the Emergency Department. Each child has an individualised treatment plan. A copy of which is available on the electronic patient record (PEPR) and to families. The family have a paper copy of this, and it is also available on the hospital patient correspondence system. These are updated at clinic visits or at least annually. The management is discussed with the Consultant Haematologist on call. All junior doctors in the hospital, including those in the ED, receive training in the management of children with bleeding disorders as part of their trust induction.

Transition: Children remain under BCH until the age of 16, when they are transitioned to the neighbouring adult haemophilia centre at University Hospital Birmingham (UHB). UHB conducts three monthly new patient clinics, specifically arranged for transitioned patients. All patients are offered a visit to UHB before transition. The Data team collaborates with the UHB team to ensure patients have been seen at UHB and that home delivery services from UHB are in place. They then cease home delivery from BCH and update NHD accordingly regarding the transition.

Network arrangements: Previously, all the Haemophilia Centre Directors from the West Midlands met 3-4 times annually with the Commissioners. These meetings were used to discuss appropriate factor concentrate use, complex patient management, expectant carrier mothers, and patients transitioning from BCH to UHB. Unfortunately, since COVID, these meetings have not been held regularly, and there is limited engagement with commissioners.

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 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	
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. The review team was very impressed by the 'Family Information Journal', which is shared with children and their families at diagnosis. It contains detailed information about bleeding

disorders in general, information about the service, including contact numbers, and information about the facilities and services available. This journal also includes space for families to record important details such as their child's diagnosis, date of diagnosis, and treatment protocol. A poem written by a patient, discussing their experience, is also included. The review team thought the addition of the poem, in particular, brought a human element to the journal, demonstrating the value the service places on patients' feedback and their individual experiences.

2. A youth worker is available by referral for wellbeing matters specific to young people with bleeding disorders. Opportunities are taken to discuss with patients and families whether they require support, education, or guidance to relevant topical resources.
3. The Service has 100% of its patients registered with Haemtrack.

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 has a general concern about staffing numbers within the service, which were highlighted in the 2019 Peer Review Report; some of these issues remain unaddressed.
2. There is no dedicated psychology provision specifically for haemophilia or other bleeding disorders. The service cares for over 550 children and families with genetically inherited, chronic, lifelong conditions. To help the children and their families adjust to the burden of their diagnosis and treatment, psychological support from a professional who understands the specific needs of the condition is a key component of Comprehensive Care.
3. While the specialist haemophilia physiotherapist is doing an excellent job, an allocation of only 0.4 WTE is insufficient for the size of the service. The current provision permits only annual monitoring and reactive treatment and management; however, haemophilia, in particular, is characterised by bleeding into joints, which may lead to long-term disability and chronic pain. Early intervention by a skilled physiotherapist trained in this disease area is crucial for promoting and maintaining good joint health. The advice from the specialist physiotherapist regarding physical exercise and sports activities is vital for protecting joint health.
4. The nursing team features a rotational Band 6 position. Given the service size, 3 WTE posts are essential to ensure the delivery of all aspects of Comprehensive care. This involves providing home visits and support within the child's community, which includes visits to the nursery and school. Teaching the staff who care for children with bleeding disorders is a key element in keeping the children safe and ensuring that each has an accurate and up-to-date Health Care Plan for emergencies. Due to the nature of rotational posts, these nurses often lack the time to develop the education, skills, and knowledge necessary to support the team fully. Furthermore, in the absence of a social worker, they are also being used to address the social needs of patients and caregivers beyond their clinical responsibilities.
5. There is currently no dedicated social worker, which results in some social support responsibilities for patients and their caregivers being placed on the nursing team, who are already stretched thin. Families with children facing lifelong chronic conditions experience

financial, physical, and emotional strain. They would greatly benefit from the assistance of a social worker knowledgeable about the specific needs related to their condition.

6. Concerns were raised by patients that phone conversations between nurses and patients could be overheard in the waiting area. Some patients were concerned that this posed a confidentiality issue.

4.5 Recommendations

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

1. **Provision of Psychosocial Services**: Priority should be given to establishing a dedicated psychology service for children and their families, as these are genetically inherited conditions that affect the mental health of both the children and their families. Access to dedicated social worker support is essential for children and their families to receive appropriate assessment and support.
2. **Haemophilia Specialist Physiotherapy**: An evaluation of the current physiotherapy services is needed. The current post holder has been observed performing very well. However, the annual joint score assessment and management of acute bleeding episodes only represent part of the service that should be provided, and additional time is required to promote and sustain good joint health in children with bleeding disorders.
3. **Nursing skill-mix review:** A review of the nursing skill mix should be undertaken with the aim of converting the rotational post into a permanent role within the Haemophilia Centre Nursing Team, ensuring that the resources needed for training a nurse in the speciality are used effectively for the future.
4. **Optimisation of Office Space:** The area within the centre should be better arranged to ensure a division between the patient waiting area and the space where nurses receive and respond to calls on the patient helpline.

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, with a particular focus on areas where the standard was partially met or not met.

Quality Standard 1: Service Information	
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	Standard Met

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

The Family Information Journal v2.0 is highly comprehensive and includes all the necessary components of this standard. It was recently updated (April 2024) and is scheduled for another update in April 2027.

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

The Family Information Journal v2.0, mentioned in section 1, also addresses this effectively. Each family is provided with a copy of their consultation letter. The initial clinic letter includes more tailored and detailed information about the patient and their specific circumstances.

There are excellent signposting practices to various literature and websites, such as the Haemophilia Society, included through the letter, the Family Information Journal, and contacts with staff.

An example of one of these letters was shown to the review team, demonstrating that the standards were being met.

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

A robust care plan is agreed upon in the MDT Clinics, covering the necessary standards in this section.

An example (as referred to in section 2) was shown to the reviewing team. A copy is sent to the GP and uploaded to the Trust's electronic documentation system, allowing all professionals to access it.

The emergency department is informed of updates to the care plans, which can be accessed when a patient with a bleeding disorder presents at the Accident and Emergency department.

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

Evidence is available for most of this QS.

Standard Met

Quality Standard 5: Contact for Queries and Advice

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

Evidence was provided for this QS.

Standard Met

Quality Standard 6: Haemtrack (PwBD on Home Therapy)

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

Evidence was provided for this QS.

Standard Met

Quality Standard 7: Environment, Facilities and Equipment

Partially 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 office space is located in the same room as the clinical space for the nursing team. Some patients felt that this arrangement was not effective during their visits, for example, when the nurse was answering phone calls from other patients while they were present. Overall, however, the space is very good.

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

Ready, steady, go is implemented.

There is a trust policy on transition, but there is no localised policy for the haemophilia centre.

Quality Standard 9: Carers' Needs

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

Standard Met

How the Service meets or does not meet the standard

The service provides information about how carers can access an assessment of their needs, what to do in an emergency and the services available to provide support in their family information journal.

Quality Standard 10: Involving PwBD and Carers

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

Standard Met

How the Service meets or does not meet the standard

There is evidence of feedback (all good) as well as how this feedback has been used to bring about changes to the benefit of patients. An example of this was the procurement of a departmental mobile phone and email address

Quality Standard 11: Leadership team

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.

Standard Met

How the Service meets or does not meet the standard

A leadership team is in place, comprising a lead consultant and a lead nurse.

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 nursing team includes a rotational Band 6 post, which, while offering developmental benefits, presents challenges in maintaining continuity and developing specialist expertise in the field of bleeding disorders.

There is currently no dedicated social worker within the service, and much of the social support is provided by the nursing team, adding significantly to their overall workload.

The consultant on-call rota is shared with malignant haematology and oncology and operates on a 1:8 basis.

Of the eight consultants, only three are actively involved in the care of patients with bleeding disorders; the remaining five typically consult one of the three when calls relate to haemophilia.

Specialist physiotherapy support for haemophilia is limited to two days per week, with orthopaedic physiotherapists providing interim cover for acute musculoskeletal issues.

Psychology support is delivered through the general Trust service and is not haemophilia-specific, though the psychologist has some experience with inherited bleeding disorders.

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

The CPD reviewed by the team was current, and mandatory training has been completed.

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

Data management team members have been trained and maintain compliance with their training. The training certificates evidence this.

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

All services are readily available for online referral within the Children's Hospital through the Trust's secure system (PEPR).

Quality Standard 16: Emergency Department

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.

Partially Met

How the Service meets or does not meet the standard

Evidence of the pathway was seen.

No specific audit was seen.

Quality Standard 17: Laboratory Service

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

Standard Met

How the Service meets or does not meet the standard

The laboratory is accredited for its current methodologies, and all verifications related to recent platform changes have been completed; the updated methods are pending inclusion in the UKAS extension to scope.

Post-infusion assay performance across various replacement therapies may warrant consideration, particularly to ensure assay reliability across different product-assay combinations. Laboratory results are discussed during multidisciplinary team (MDT) meetings held on Fridays, to which the laboratory lead attends. They participate in the results discussion segment but leave before the management and treatment planning components.

The laboratory participates in external quality assurance (EQA) schemes, with full coverage for all von Willebrand factor (VWF) and coagulation factor assays required for diagnosis.

Although the platelet lumiaggregometry (LTA) service was not formally registered for EQA in 2024/25, it is a newly introduced service. The laboratory has been performing LTA testing and submitting results as part of the pilot phase.

Assays are consistently available within clinically appropriate timeframes, supported by the haematology laboratory's out-of-hours provision.

Staffing has presented ongoing challenges due to recent retirements and internal staff movement. A Band 7 vacancy remains, although recruitment is underway. Once this position is filled, it is anticipated that workload pressures on the remaining staff will be significantly reduced.

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

A referral to an ENT specialist for a Type 3 vWD patient has been provided. The MDC clinics (evidence provided by evidence 26) demonstrate the effectiveness of the MDC approach.

Throughout the review, it was clear that cross-departmental collaborative working is central to the approach taken by the entire centre, as shown in the interactions between departments.

In particular, the availability of dental services as a routine part of patient care is commendable.

Quality Standard 19: IT System

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

Standard Met

How the Service meets or does not meet the standard

An NHD download was provided, demonstrating accessibility to comprehensive data for individuals with bleeding disorders (PwBD), including longitudinal records of concentrate usage.

A review of the Clinical Audit Registration and Management System (CARMS) confirmed both current and historical audit activity.

Recent audits have primarily focused on patient outcomes, clinic attendance, and the impact of the COVID-19 pandemic on the haemophilia service.

A regular rolling audit programme is in place for recurring audits, such as clinic attendance monitoring. The system also supports ad hoc audits for research and service improvement initiatives.

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

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

Standard Met

How the Service meets or does not meet the standard

Local guidelines have been reviewed and are available on the intranet.

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

Guidelines and SOPs that demonstrate compliance with the above standards were reviewed on the day.

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

Evidence for this QS was reviewed on the day.

Quality Standard 23: Guidelines on Care of PwBD requiring Surgery

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

Standard Met

How the Service meets or does not meet the standard

This standard is achieved, as is evidenced in Guideline 036, copies of surgical plans are agreed with the surgical staff and discussed with the anaesthetist.

Quality Standard 24: Service Organisation

The Service should have an operational procedure covering at least:

a. Ensuring all children who are in-patients have a named consultant paediatrician and a named haematologist with expertise in caring for 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

Standard Met

How the Service meets or does not meet the standard

Evidence was available for this QS.

Quality Standard 25: Multidisciplinary Team Meetings

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

Standard Met

How the Service meets or does not meet the standard

There is good evidence of this in the weekly MDT minutes. They should, however, include upcoming surgeries in this meeting.

The team was unsure of the network arrangements for MDT, but they had a good working relationship with their shared care HCs, as evidenced in the interviews.

Quality Standard 26: Multidisciplinary Clinics/Liaison Services

Combined clinics or other arrangements for multidisciplinary discussion with

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

Standard Met

How the Service meets or does not meet the standard

Combined monthly clinics are held, attended by physiotherapists, nurses, and dentists.

Quality Standard 27: Data Collection

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

Standard Met

How the Service meets or does not meet the standard

The Data Management Team has compiled and submitted the full dataset from the National Haemophilia Database (NHD) for the years 2022 and 2023.

Adverse event reporting via the NHD was also provided; reported incidents remain low and do not exhibit any consistent pattern.

Data on inhibitor status is available; however, information on concentrate usage and bleeding episodes was not clearly delineated in the submitted dataset.

Haemtrack remains a mandatory requirement for all patients receiving treatment. The Advanced Nurse Practitioner (ANP) regularly monitors compliance.

If patients are found to be non-compliant, they are contacted, typically beginning with a phone call followed by formal written communication. In cases of persistent non-compliance, home delivery of treatment may be suspended until satisfactory data submission is resumed.

Quality Standard 28: Research

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.

Standard Met

How the Service meets or does not meet the standard

The opening presentation highlighted 14 recent clinical research activities undertaken by the team, with the full list submitted as part of Evidence 28. The service continues to be active in clinical research, currently managing a patient on efanesoctocog alfa (EFA), the latest extended half-life replacement therapy for patients with haemophilia (PwH). The laboratory has already evaluated and scoped assay solutions to support monitoring of this new product.

In terms of academic output, four posters were planned for the ISTH Congress in Bangkok (2024), in addition to a poster and an oral presentation delivered at the British Society for Haematology (BSH) Annual Scientific Meeting in April 2024.

There are also active discussions underway between the Advanced Nurse Practitioner (ANP) and physiotherapy team regarding the introduction of point-of-care ultrasound into routine practice. Although currently framed as a business case for service improvement, this initiative has clear research potential with meaningful implications for enhancing patient care in haemophilia and related musculoskeletal complications.

Quality Standard 29: Multidisciplinary Review and Learning	
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	Standard Met
How the Service meets or does not meet the standard	
Evidence reviewed and all in place.	
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	
All electronic documentation is saved and updated regularly using Q-Pulse software, which secures the document and sends alerts to the author if the document requires updating or reviewing.	

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, two clinical nurse specialists, a haemophilia contracts manager, a specialist paediatric haemophilia physiotherapist and a patient representative. Details of the Peer Review Team are held by UKHCDO.

7.3 Outstanding findings from the 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 provision in a number of professional groups was judged to be insufficient.
a.	Nursing. There had been a recent reduction from three to two specialist nurses. Based on the current complement, the nurses did not have capacity to undertake some of the expected duties, including attending the multi-disciplinary clinics for the review of moderately and severely affected children. Nurses were seldom able to undertake school or home visits. There were no nurse-led clinics, which are often in place to help manage children with milder disorders and reduce the need for clinic visits.

b.	Medical. The Centre director and a supporting consultant colleague each had two Programmed Activities (PAs) in their job plan for their work in the bleeding disorders service. This was a reduction from a total of 14 PAs and resulted from the retirement of a senior colleague approximately one year previously. A business plan for an additional colleague to contribute a further six PAs had been submitted and this, if the position was approved and appointed to, would help with the shortfall.
c.	Psychology. There was no named psychologist member of the team, and no psychologist was available to see children and families at multi-disciplinary team clinic visits. Reviewers heard that families and children with severe and moderate haemophilia were assessed, via a questionnaire, as to the possible need for a referral. Additionally, when there were concerns about an individual or a family, referrals could be made to the general hospital service. However, it was noted that some less pressing needs for psychological intervention and support could be unmet, and the team were not able to access clinical supervision or regular case consultation.
d.	Physiotherapy. At the time of the visit, two named physiotherapists were working in the service but were currently funded at 0.2 WTE (combined total) for this service, which limited the support that they could provide to patients. Although they provided support for multi-disciplinary reviews, and recorded Haemophilia Joint Health Scores (HJHS), any unplanned attendances at the haemophilia centre for joint bleeds were assessed instead by a physiotherapist from the inpatient orthopaedic team when bleeped. These physiotherapists were responsive and engaged but were not able to provide ongoing care for children with joint bleeds, and inpatient children were managed instead by the general ward physiotherapy team. There was no direct access for families to advice and guidance if they were concerned about joint symptoms. There was also insufficient time to provide education to patients and families. It was understood that approval had been granted to appoint to a total of 0.8 WTE dedicated to the service, which would be more appropriate for this size of centre.