UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

UKHCDO Haemophilia Peer Review Audit Report

Imperial College (Hammersmith) Adult 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

Report Date: 05 September 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 Imperial College Adult Haemophilia Comprehensive Care Centre (the Service) was completed on 23rd September 2024.

The Service successfully met 23 of the 30 established standards, with seven standards partially met. The commitment of both the Service 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. **Psychology Service Provision:** There needs to be a permanent arrangement for psychology provision within the service. This is a key component of Comprehensive Care and one of the recommendations of the Infected Blood Inquiry.
2. **Laboratory Service Provision:** There must be sufficient, properly trained specialist biomedical scientists to ensure the 24/7 availability of specialist testing.
3. **Signage:** The signage around the centre should be improved to help new patients find their way. The patient representatives, in particular, mentioned this.

The UKHCDO advisory committee reviewed the final report on 9 October 2025 and endorsed the executive committee's recommendation to change the status from Interim to full CCC. This decision was based on the Service having the minimum number of registered severe patients and meeting 76% of both primary and secondary standards, with no standards unmet, demonstrating actions taken since receiving interim status. However, some gaps remain that need to be addressed to improve patient care and ensure compliance with national service standards.

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 23rd September 2024. A multidisciplinary team of haemophilia experts, along with patient representatives, conducted the review, which involved interviewing staff from the Service, examining documentation, and touring the facilities.

The Service provides care for adults with bleeding disorders and has 746 registered patients. It is based at the Garry Weston Centre at Hammersmith Hospital. The Service is part of Imperial College Healthcare NHS Trust (ICHNT), which comprises five hospitals: Charing Cross, Hammersmith, St Mary's, Queen Charlotte's, and Chelsea and Westminster Eye Hospitals. The Haemophilia Centre serves an estimated population of 1.5 million in West London. However, due to historical referral patterns, some patients from West London attend larger hospitals in North and South London, such as the Royal Free Hospital and St Thomas' Hospital.

ICHT established one of the first Academic Health Science Centres in 2007, which now operates within Imperial College Health Partners, the Academic Health Science Network for Northwest London, and is among 11 National Institute for Health Research Biomedical Research Centres. In 2014, ICHT was designated by NHS England as a Genomic Medicine Centre. The vision to leverage research and education to improve disease prevention, detection, and diagnosis, as well as to develop more precise, targeted treatments, has resulted in patients treated at ICHNT enjoying some of the best outcomes in the UK.

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	30	0	11	0	185	0	454	0
Moderate	9	0	7	0				
Mild	46	0	4	0				
Annual review in the last year	37	0	22	0	Data not provided	0	Data not provided	0
Inpatient admissions in the last year	Data not provided	0	Data not provided	0	Data not provided	0	Data not 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 team comprises a mix of full and part-time staff, including five consultant haematologists (4.5 WTE), two CNS, one physiotherapist (0.6 WTE), two Biomedical scientists, and one social worker (0.5 WTE). They are supported by one administrative staff member and 0.5 WTE of a Data manager. Currently, there is no dedicated psychology service.

Key staff include Consultant Haematologist and Centre Director Dr Ferras Alwan.

Outpatient care: All registered patients with inherited and acquired bleeding disorders are reviewed in dedicated Haemostasis clinics overseen by specialist consultants. The service runs MDT outpatient clinics, staffed by medical professionals, specialist nurses, physiotherapists, and social workers.

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

Out of hours: Patients can access the Renal and Haematology Triage Unit. There are links to the Emergency Departments at Charing Cross and St Mary's Hospitals.

The Haematology Consultants and SpRs are responsible for all sites and visits to supervise care as appropriate. There is a 24-hour haemostasis consultant cover, with all consultants on the rota being specialists who work solely in bleeding disorders. The service has dedicated outpatient and clinical facilities and is conveniently located near other haematologist day care, outpatient, and inpatient areas.

Transition: A well-established transition program exists between the paediatric and adult haemophilia services within the North London Adult Haemophilia Network. This programme supports young people transitioning from Great Ormond Street Hospital (GOSH) to Hammersmith Hospital. The clinical nurse specialist, specialist physiotherapist, and/or consultant from Hammersmith Hospital will aim to attend the outpatient appointment at GOSH to meet the patient and their family, facilitating the handover. Additionally, there will be an opportunity for the young person to visit the haemophilia centre at Hammersmith before their first clinic appointment. Written information, including contact details, will be provided to young people and their families.

Network arrangements: The ICHNT Haemophilia service is part of the North London Adult Haemophilia Network, established in 2011 to share and develop staff expertise and experience, delivering high-quality specialist care and efficient services with the overall aim of improving patient experience.

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 23 out of the 30 standards, with seven 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	
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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. Excellent physiotherapy service, which is developing well. Feedback from patients particularly highlighted the 'yoga for health' programme.
2. Positive improvements in the space for the haemophilia centre. Previously, some of the rooms were used by other teams one day per week, but they now have a dedicated space five days a week.
3. Patient feedback provided on the day was excellent.
4. Constructive working relationship with management.
5. The Service has a strong commitment to education, both its staff and those in other teams.

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 concerned that there is no permanent psychology provision, despite plans to commission this; no final decision has been made on who will deliver this service.
2. The review team felt that the current staffing levels in the laboratory were insufficient to meet the increasing demand for specialist coagulation testing.
3. The review team noted that some patient information was outdated, including leaflets from companies that no longer exist or no longer supply products under the national contract. The information was product-specific rather than disease-specific, as required by the service specification. Information for carers also needs to be updated.
4. The signage around the Centre was deemed to be poor - the patient supported this.
5. The review team noted that some of the SOPs relating to the treatment and monitoring of IABD were outdated and contained references to products no longer in use.
6. The review team noted that there is no alert on the electronic patient record and that there was no recent audit of Emergency department attendances and outcomes.

4.5 Recommendations

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

1. **Psychology Service Provision**: We recommend that the Trust support the service to find a permanent solution that provides adequate psychological support for patients. This is a key recommendation of the Infected Blood Inquiry.
2. **Laboratory Service Provision:** We advise that the Trust support increasing the number of permanent specialist laboratory positions to meet the rising demand for specialist coagulation tests, while also ensuring 24/7 cover, as outlined in the national service specifications.
3. **Environment & Facilities:** We suggest that the Trust support the Service to improve signage around the Centre to serve all patients and carers better. Feedback from patients should be collected to determine the most suitable solutions.
4. **Patient Information**: We advise the team to conduct an immediate review of patient information. All outdated data should be removed, and efforts should be made to find disease-specific alternatives as specified by the National Service Specification.
5. **Treatment and Monitoring of IABD**: We advise that all SOPs and guidelines related to the treatment and monitoring of IABDs be revised to solely include products that are currently available within the National Framework agreement.
6. **Emergency Department:** Although patients have direct access to a triage service outside of the ED, we recommend that the service works with the Trust to develop an alert on the

electronic patient record for patients who need to attend the ED. An annual audit of emergency attendances and outcomes should be carried out.

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 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)	Standard Met
How the Service meets or does not meet the standard	
There is no guidance on accessing Psychology services, but this is because Psychology provision has not yet been fully established.	
Quality Standard 2: Condition-Specific Information	
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	Partially Met

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 Peer Review team expressed concerns about providing product-specific rather than disease-specific information. Some of the information pertained to products that are no longer available in the UK. The reviewing team did not have access to the Centre App, and it was felt that not everyone would be able to access the online resource. Therefore, the leaflets available within the centre needed to be up to date.

Quality Standard 3: Plan of Care

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.

Standard Met

How the Service meets or does not meet the standard

Reviewed electronic notes and copies of letters, care plans, and surgical plans were made available to the team. Patients have access to 'patient knows best', although one of the patients interviewed was unaware of this resource.

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

Clear follow-up plan for severe and non-severe bleeding disorders. MDT clinics are aligned with the Trust policy for DNA. Currently, there is no provision for psychology, although discussions are ongoing to resolve this issue.

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

Patients carry a haemorrhagic disorder card along with a yellow alert card for emergency services. The review team visited the renal and haematology treatment unit, which functions as an ED avoidance strategy, and there were clear pathways for access 24/7.

Quality Standard 6: Haemtrack (PwBD on Home Therapy)

Standard Met

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

How the Service meets or does not meet the standard

The Haemtrack leaflet is given to patients and carers to encourage the use of electronic recording of their treatment through the database/app. Use of Haemtrack is discussed with patients during consultations and reviews.

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 patient waiting area was seen as very welcoming and non-clinical. Administrative and nursing staff share the space, which was positive for patients, but it means that if there are patients in the waiting room, staff must relocate to have confidential conversations. The measures in place include a mobile handset and space in the newly refurbished registrar's room.

Patients' feedback indicated that the signage was poor. There is no adequately designated confidential space for phone calls away from the patient waiting room.

The space near the waiting room could potentially be positioned closer to the front desk rather than the nursing workstation.

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 team are keen to strengthen links with GOSH further to support transition, but currently most of the patients are adult patients with no clear flow of adolescent patients.

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

Partially Met

How the Service meets or does not meet the standard

There is a dedicated social worker, but there was no information on the day specific to carers.

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

Partially Met

How the Service meets or does not meet the standard

Although a patient experience survey was undertaken, no evidence of service development based on patient feedback was demonstrated.

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 strong leadership team supported by trust management and the quality team was evident that day.

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

Since the last peer review, staffing has increased significantly, including the addition of more consultants and a reorganisation of working patterns to ensure better coverage across all sites, nursing, and physiotherapy services.

The review team was concerned that staffing levels in the laboratory were too low to meet the growing demand for specialist coagulation testing. Pathology services are provided by NW London Pathology, not the Trust, so they are not entirely within the Trust's control.

Currently, there is no fixed Psychology service, although plans are underway to commission one; however, a final decision on the provider has not yet been made. The review team agreed with the Haemophilia Team that in-house provision for face-to-face consultations should be part of this service.

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

Strong support for staff development across all professions was evident. Haemophilia-specific training for the data manager is recommended if this has not already been completed (evidence not found on the day).

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

Dedicated administrative staff are present and highly valued by the team.

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/podiatrics

Standard Met

How the Service meets or does not meet the standard

Appropriate access to services is seen.

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	
The ongoing audit of ED attendances is part of the standard process and requires implementation. An electronic alert would also provide additional value.	

Quality Standard 17: Laboratory Service	Standard 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	
There are strong working relationships with the lab, with regular meetings to discuss cases and results.	

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

Appropriate access to services noted.

Standard Met

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

How the Service meets or does not meet the standard

Cerner acts as the primary patient record system, while HCIS is also utilised at the centre. Since the haemophilia service uses Cerner for patient records and tracking, it can request data from Imperial College Healthcare NHS Trust and the business information team for audits and demographic reviews.

Patients also complete Haemtrack, which helps the service collect data on treatments for audit and review purposes.

Additionally, the service submits annual data for the Specialised Services Quality Dashboard (SSQD) and discusses this information during the Quality Meeting.

Standard Met

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

How the Service meets or does not meet the standard	
Local guidelines are in place for all the above.	

Quality Standard 21: Guidelines: Treatment and Monitoring of IABD

Partially Met

Guidelines should be in use covering:

a. Factors concentrate and non-factor replacement therapy
   i. Initiation and monitoring of prophylaxis
   ii. Home therapy
   iii. Use of extended half-life products, including inhibitor testing and PK assessment
   iv. Use of non-factor replacement therapy
b. Management of factor concentrate and non-factor replacement therapy supplies, including:
   i. Ordering
   ii. Storage
   iii. Stock control to ensure all stock is up to date and waste is minimised
   iv. Prescription and delivery for PwBD on home treatment
   v. Arrangements for emergency 'out of hours' supply
   vi. Recording issue to PwBD
   vii. Recording use by PwBD, including on Haemtrack
   viii. Submission of data via NHD for quarterly returns

How the Service meets or does not meet the standard
SOPs have not been fully updated to reflect the current products used; i.e., some products included are no longer in use.

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
Relevant guidelines are in place, which show evidence of meeting the above standards.

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

Examples of surgical plans were provided.

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

Centre and hospital procedures that cover the above standards are in place.

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

An attendance log/minutes for lab MDT should be considered.

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

A newly introduced cross-site working policy to ensure that an attending consultant covers all hospitals. Access is available to all the above services.

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

Evidence for this has been provided in the operational policy.

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

Information regarding the research activity was provided. Clinical nurses are not engaged in research.

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	
Audit schedule and recent audits are presented at the Haemostasis Quality Meeting and reviewed monthly. Agendas and minutes are shared with the review team. Audits and service improvements are discussed at these meetings. The HC clinical team has published numerous papers. The Haemophilia service's documentation follows standard trust procedures, with a specific SOP on document control.	
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	
Document Control is overseen by the Quality Team. There is a specific SOP on document control.	

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 a consultant haematologist, a clinical nurse specialist, a specialist physiotherapist, a Senior Biomedical Scientist, and a patient representative. UKHCDO holds details of the Peer Review Team.

7.3 Outstanding findings from previous peer review

Ref. Number	Statement of original finding
1b	**Staffing** Provision of some key support staff was not sufficient. There was no psychologist on the team. Patients could be referred, if needed, to a network psychologist based at the Royal Free Hospital, but this did not happen frequently. In practice it was inconvenient for patients and did not meet the expectation that a psychologist us an integral part of the on-site team. Without this, reviewers observed that there was likely to be an unmet need for this support within the patient group.