UKHCDO Haemophilia Peer Review Audit Report

The Royal London Hospital Haemophilia Comprehensive Care Centre

Report Date: 21 July 2025

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1 Executive summary

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

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

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

The executive summary presents the key findings, while the full report details the assessments referenced against the quality standards. Peer review for the Royal London Haemophilia Comprehensive Care Centre (the Service) was completed on March 19, 2024. The Centre, based at the Royal London Hospital, part of Barts Health NHS Trust, caters to both children and adults.

The Centre successfully met 21 of the 30 established standards, with eight standards partially met and one remaining unmet. The commitment of both the Centre and the Trust to providing high-quality care was evident through various initiatives and clinical pathways. However, key recommendations have been made to help address the gaps that affect the ability to deliver comprehensive care.

Key Recommendations:

1. **Medical Staffing:** The review team recommends reviewing medical staffing and facilitating the business cases to substantiate the current locum posts to substantive posts.
2. **Physiotherapy:** The team recommends that the hospital establish paediatric physiotherapy services to ensure appropriate care for both adults and children.
3. **Facilities Management (Fridges)**: The current refrigeration facilities for storing the large quantities of clotting factor supplies are insufficient, and the team strongly recommends expediting the installation of the fridges procured two years ago.
4. **Nursing:** There is a need for additional nursing support to facilitate appropriate community visits for children in the context of a new diagnosis and support through other milestones.

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

2 Haemophilia and Bleeding Disorder Peer Review - Background

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

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

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

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

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

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

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

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

3 Service Description

The peer review of the Royal London Haemophilia CCC took place on 19 March 2024, at the Royal London Hospital, Whitechapel, London. A multidisciplinary team of haemophilia professionals, along with patient representation, conducted the review, which included discussions with staff from the Service, examination of documentation, and a tour of the facilities.

The Service offers care to both adults and children with bleeding disorders and has 2208 registered patients from a population of over 2.5 million people across a large geographical area. Its catchment area in Northeast London is a recognised region of high social deprivation. Historically, the Service has had a disproportionate number of moderate and mild to severe haemophilia compared to other large London centres; however, recently, the number of patients with platelet disorders and other mild bleeding disorders has increased significantly. Given the ethnic diversity in the East London region, the centre has a large percentage of patients with rare, severe bleeding disorders, including severe factor VII and Glanzmann's thrombasthenia.

3.1 Patient numbers

	Inherited bleeding disorders							
Number of patients	**Haemophilia A**		**Haemophilia B**		**Von Willebrand**		**Other**	
	Adults	Children	Adults	Children	Adults	Children	Adults	Children
Severe	81	15	14	2	400	53	1144	217
Moderate	27	6	10	1				
Mild	175	29	27	7				
Annual review in the last year	332	67	53	11	227	34	1682	98
Inpatient admissions in the last year	48	17	32	2	57	5	148	43

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 14 healthcare professionals in a mix of full-time and part-time roles, including five consultant haematologists (2.8 WTE), six nurses (5.4 WTE), one physiotherapist (1.0 WTE), one consultant biomedical scientist (1 WTE), three coagulation laboratory biomedical scientists (3 WTE), five administrative staff (3.8 WTE), and one part-time psychologist (0.5 WTE).

Key staff include Consultant Haematologist and Centre Director Dr Priyanka Raheja and Lead Nurse Kate Forsyth.

Outpatient care: The Service is integrated within the Haematology Day Unit (HDU) of the Royal London Hospital (RLH). It provides care for all patients with inherited and acquired bleeding disorders, from cradle to grave. Due to redevelopment, the HDU and haemophilia offices were relocated to the second floor of the RLH. The current HDU offers shared clinical space, featuring one clinical or treatment room designated for the Haemophilia Centre's exclusive use, one clinical office, and one administrative office.

The Centre offers a comprehensive range of multi-disciplinary outpatient clinics and a walk-in service during opening hours. Four adult outpatient clinics operate weekly, providing a mix of face-to-face and telephone consultations. A face-to-face clinic is available on Monday afternoons with a haemostasis consultant, a physiotherapist, and a CNS for patients on prophylaxis or those with severe bleeding disorders. There is a consultant-led mixed clinic (telephone and in-person) on Wednesday mornings, staffed by 2-3 haemostasis consultants and a haematology specialist registrar. CNS and physiotherapy support is accessible if necessary. Additionally, a CNS-led telephone clinic is held on Tuesday afternoons for patients with mild bleeding disorders. A CNS-led in-person clinic is also available for new patients referred by GPs or urgent cases requiring a quick turnaround of blood tests before attending the consultant clinic.

Three paediatric outpatient clinics are held each month: two on Thursday afternoons and one on Friday mornings. Each clinic is staffed by two consultants, a paediatric CNS, and a physiotherapist.

Inpatient care: Appropriate to the presenting condition

Out of hours: A 24/7 out-of-hours on-call rota is available with consultants specialised in haemostasis and thrombosis.

Transition: The service offers lifelong care for patients from birth to adulthood. There are arrangements in place for transition from other Centres where necessary.

Network arrangements: The centre is part of the North London Adult Haemophilia Network and North London Paediatric Haemophilia Network.

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 21 out of the 30 standards, with eight partially met and one unmet. The Service has outstanding findings from their previous peer review report in similar areas, which are provided in the appendix. The service is encouraged to review all descriptive assessments in addition to the key findings. This report, alongside local assessments, should steer discussions with the management team, highlighting areas of good practice while emphasising where further investment and improvement may be required.

Standard	Title of standard	Rating
1	Service Information	🟨
2	Condition-Specific Information	🟩
3	Plan of Care	🟩
4	Outpatient Review of PwBD	🟩

Standard	Title of standard	Rating
5	Contact for Queries and Advice	🟩
6	Haemtrack (PwBD on Home Therapy)	🟩
7	Environment, Facilities and Equipment	🟨
8	Transition to Adult Services and Preparation for Adult Life	🟨
9	Carers’ Needs	🟩
10	Involving PwBD and Carers	🟩
11	Leadership Team	🟨
12	Staffing Levels and Skill Mix	🟥
13	Service Competencies and Training Plan	🟩
14	Administrative, Clerical and Data Collection Support	🟨
15	Support Services	🟩
16	Emergency Department	🟩
17	Laboratory Service	🟩
18	Specialist Services	🟩
19	IT System	🟩
20	Diagnosis Guidelines for People with Suspected IABD	🟩
21	Guidelines: Treatment and Monitoring of IABD	🟩
22	Clinical Guidelines/ Pathways	🟩
23	Guidelines on Care of PwBD requiring Surgery	🟩
24	Service Organisation	🟨
25	Multidisciplinary Team Meetings	🟩
26	Multidisciplinary Clinics/ Liaison Services	🟩
27	Data Collection	🟩
28	Research	🟩
29	Multidisciplinary Review and Learning	🟨
30	Document Control	🟨

4.2 Good Practice

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

1. The new leadership of the centre, following all the recent changes, is keen and enthusiastic.
2. There is an updated clinical guideline and excellent information about what to do in an emergency, both in clinic letters and through the Haemophilia Centre app.

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. Despite the purchase of two new fridges for the Haemophilia department, there has been an unacceptable delay of two years in their installation. At the time of writing, the fridges remain unpacked in the reception area, thus unutilised, which not only wastes funds but also impacts the Service's ability to manage temperature-controlled medicines. This situation poses a risk to patients, due to the potential waste and unavailability of resources, as well as a financial risk to the Trust.
2. There have been significant and detrimental changes to staffing levels within the Service; despite the centre management's efforts, the business cases are still undergoing the approval process. Most notable is the loss of three experienced consultants: two have left the service, and a third has moved into a more senior departmental role. Two locum consultants have filled these posts, and although plans exist to make these positions substantive, they have not yet undergone the trust's approval processes.
3. The Service has also been unsuccessful in filling two nursing positions currently on maternity leave; this situation leaves the service critically understaffed and unable to carry out any community visits as outlined in the Service Specification.
4. There is one physiotherapist covering both adults and children, with no annual leave or additional cover. Consequently, this presents a single point of failure in the absence of the existing post-holder. Physiotherapy is a key aspect of comprehensive care for haemophilia, and it is unrealistic for one individual to specialise in both children’s and adult physiotherapy. Therefore, there is a pressing need to increase the number of physiotherapists available. Furthermore, there is no onsite orthotic support for the service, leading to delays for patients referred through their GPs.
5. The review team is concerned about the workload from the dental service at the Royal London Hospital and the impact this will have on haemophilia patients specifically. The dental service manages patients from across London and Cambridge, as well as its local patients. A lack of additional funding and administrative support exacerbates this issue.
6. There was no demonstrated programme for departmental clinical audit, teaching, or learning from clinical incidents, although the team attends the broader haematology department meetings. This is insufficient to ensure that all members of the MDT are engaged in service improvement plans.
7. Although the Service is part of the North London adult network in name, there is no evidence of collaborative efforts within the network. In this cycle of peer review, the networks have not been evaluated.

4.5 Recommendations

This section outlines the recommendations made by the review team based on the concerns raised above.

1. **Facilities**: Immediate action is needed to install the new fridges bought two years ago, as this presents both a clinical risk to patients and a financial risk to the Trust, constituting an unacceptable delay.
2. **Medical Staffing**: We recommend that the Trust urgently review the medical staffing of the Centre, specifically, to support the business cases for establishing permanent posts currently

filled by two locum consultants, ensuring the availability of appropriately trained haemostasis/thrombosis specialists to meet the service specifications.

3. **Nursing Staffing**: We recommend that the Trust assist the nursing team in recruiting for vacancies.
4. **Physiotherapy Service**: The service is understaffed according to the national standards. A review of the service, benchmarked against similar national services, would provide an accurate assessment of the WTE physiotherapists required for this size and complexity of service. There is a need to establish dedicated paediatric physiotherapy services. Furthermore, the orthotics service pathway should be evaluated.
5. **Specialist Dental Services**: We recommend reviewing the service and engaging in discussions with commissioners to ensure adequate funding for the service to meet the needs of this patient group across North London.
6. **Departmental Service Development and Governance**: A robust, ongoing system of multi-disciplinary audit and teaching programmes should be implemented with sufficient support from the MDT team.

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)

Partially Met

How the Service meets or does not meet the standard

My haemophilia centre app is referenced regarding how this standard is met. The team was initially unable to access the app, but by the end of the visit, they were able to demonstrate the app to the peer review team. This app provided excellent information on what to do in an emergency, but it was noted that some sections, e.g., the "meet the team" section and the "doctors' section," were out of date.

There was ready access to hard-copy leaflets.

The PALS/complaint process is available on the main Barts Health website if searched for, but on the day, we could not find information about PALS/complaints in the centre. However, the Haemophilia Centre patient information leaflet contains this advice.

The "you said we did" notice board was empty.

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

A good set of information leaflets were available in the centre.

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

Clear plans in the clinic letters were shown to the review team

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

Patients are being reviewed at the appropriate frequency by the MDT team. While social work referral is a challenge as the client needs to be referred to the local team or through a GP, and the centre covers a large area, the team is aware of how to refer. There is a clear referral pathway into the HBDCA for accessing counselling services.

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

Contact details on the leaflet and letters.

There is clear information on the website about when to email and when to call.

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

Haemtrack checked in the clinic.

Good prescription compliance pathway.

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

Paediatric clinics: There is ample space and well-equipped day unit facilities. They are bright and well-maintained. They are located on a different floor from the main haemophilia centre, which means staff will occasionally be separated from the centre.

The main adult centre in a different area has inadequate fridge storage for products. The department ordered two new fridges, which have been in reception for two years due to issues with funding the installation. The warranty has been extended, and although the team informed us that work would commence by the end of this financial year, there was no indication that this would take place. These are intended to replace the current fridges, which cannot be locked and therefore do not meet the existing standards.

The haemophilia office is a reasonable size, but if all members are present (excluding those on maternity leave, annual leave, etc.), there is insufficient space, especially for face-to-face team meetings. HCIS is currently only available on a single computer located in the admin office. The team has plans for a new version that will then be accessible on multiple computers.

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

Partially 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

While the transition may be straightforward for many, as it is a paediatric and adult service, the SOP/guideline lacked clarity regarding the process for everyone. The review team found no evidence of ready steady go, although it was described in the self-assessment document.

Quality Standard 9: Carers' Needs

Standard Met

Carers should be offered information on the following:

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

How the Service meets or does not meet the standard

Standard met.

Quality Standard 10: Involving PwBD and Carers

Standard Met

The Service should have:

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

How the Service meets or does not meet the standard

Used the survey developed by the peer review working party. Overall results are not yet available, although answers from individual patients have been received.

Quality Standard 11: Leadership team

Partially Met

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

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

How the Service meets or does not meet the standard

There is a named centre director and lead nurse. The lead nurse currently lacks sufficient time for her leadership role due to the nursing team's staffing shortages.

The review team did not see minutes for any leadership meetings on the day, but they were provided after the review.

Quality Standard 12: Staffing levels and skill mix

Not 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

There has been a significant change in consultants since the last peer review. Three experienced consultants have left, and one has assumed a more senior departmental leadership role, resulting in a reduction in clinical time. Currently, there are two substantive consultants (one joint role with the university) and two locum consultants in place. While the plan is for locum posts to become substantive, this has yet to be confirmed, and the business case has not been finalised or approved. The recruitment needs to take into account the provision of the paediatric service.

There are insufficient nurses to provide care in both routine and urgent situations. Two nurses are on maternity leave, and positions remain unfilled or backfilled. This has resulted in a loss of community visits, which is important for supporting newborns with a diagnosis of a severe bleeding disorder.

A single physiotherapist is covering both adult and paediatric, with no annual leave or other cover. Although there is limited training in child development, there is excellent training in all haemophilia-related issues. Based on HCPA recommendations, the suggested physio provision should be 1.5–2.0 WTE physiotherapists. The review team recommends reviewing this and considering the creation of a paediatric physio post. Counselling is provided through HBDCA and is not integrated into the team. The service is primarily virtual, although it can also be conducted face-to-face if needed. Child psychology is currently accessed through referral to GOSH, but HBDCA may be able to provide this soon.

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

A log of meetings clearly highlighted opportunities to attend conferences and meetings, but it was unclear how they communicated feedback on learning to the rest of the department from these meetings.

It will be essential to ensure that the physio has clear clinical specialist support to identify training needs and to provide mentoring as the sole physio in the department. (HR, appraisal, etc., are managed well but not by a physio.)

Quality Standard 14: Administrative, Clerical and Data Collection Support

Partially Met

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

How the Service meets or does not meet the standard

The nurse is managing all the administration for dental services. This presents a significant concern that the trust must address. There is currently no backup for the Data Manager.

Quality Standard 15: Support Services

Standard Met

Timely access to the following support services should be available:

- a. Play support (children's services only) including:
  - i. Play and distraction during any painful or invasive procedures
  - ii. Play support to enable the child's development and well-being
- b. Pharmacy
- c. Dietetics
- d. Occupational Therapy
- e. Orthotics/podiatry

How the Service meets or does not meet the standard

There is excellent access to play support as needed.

Orthotics is done via GP, with significant delays or patients not even being able to access the service. The team/physio is not able to do direct referrals.

Quality Standard 16: Emergency Department

Standard Met

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

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

ED medical and nursing staff should have training on inherited and acquired bleeding disorders.
ED pathway should be audited +/- PwBD survey on emergency attendance on an annual basis.

How the Service meets or does not meet the standard

Electronic information is available on CERNER for all patients. An ED audit is underway. There are plans to restart teaching in ED.

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

The lab is UKAS accredited and part of the ESEL pathology partnership. The lead consultant biomedical scientist attends the MDT.

A full repertoire of tests is available in a timely manner, and genomics MDT is performed monthly.
There were some concerns regarding lab staffing based on recent benchmarking exercises with other haemophilia services of a similar size.

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

There has been no named rheumatology link since the lead professor who used to provide this service retired; however, there is still good access to services.

Evidence seen for other services.

Quality Standard 19: IT System

Standard Met

IT systems should be in use for:

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

How the Service meets or does not meet the standard

Cerner CRS is used for patient related information. HCIS is used to document batch numbers and submit data to NHD. Haemlive is used to extract useful data from Cerner.

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

Standard Met

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

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

How the Service meets or does not meet the standard

Good clinical guidelines, all recently updated.

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

Good clinical guidelines. There are SOPs in place for stock, storage, and submission of data.

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

Good clinical guidelines covering all areas.

Quality Standard 23: Guidelines on Care of PwBD requiring Surgery

Standard Met

Guidelines on the care of PwBD with inherited and acquired bleeding disorders who require surgery should be in use covering at least:

a. Involvement of surgical and inherited and acquired bleeding disorders service in agreement of a written plan of care prior to, during and post-surgery
b. Communication of the agreed plan of care to all staff involved in the PwBD 's care prior to, during and after post-surgery
c. documentation of care provided
d. Arrangements for escalation in the event of unexpected problems

How the Service meets or does not meet the standard

Good clinical guidelines covering all areas. There are good surgical plans with clear escalation and contact at the top of the plan.

Quality Standard 24: Service Organisation

Partially Met

The Service should have an operational procedure covering at least:

a. Ensuring all children who are in-patients have a named consultant paediatrician and a named haematologist with expertise in caring for PwBD with inherited and acquired bleeding disorders responsible for their care
b. Ensuring all adults are under the care of a consultant haematologist with an interest in inherited and acquired bleeding disorders, either directly or through a shared care arrangement with a general haematologist
c. Responsibility for giving information and education at each stage of the patient journey

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

How the Service meets or does not meet the standard

Due to a shortage of nurses (resulting from maternity leave that has not been backfilled), nurses are unable to make any community visits. However, they do have a single post with community time within the job. There are also challenges of supporting children through school.

Quality Standard 25: Multidisciplinary Team Meetings

Standard Met

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

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

How the Service meets or does not meet the standard

Two MDTs a week and the lab team attend on Monday.

Quality Standard 26: Multidisciplinary Clinics/Liaison Services

Standard Met

Combined clinics or other arrangements for multidisciplinary discussion with

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

How the Service meets or does not meet the standard

Clear combined clinics, and there are appropriate arrangements for HIV and hepatology review.

Quality Standard 27: Data Collection

Standard Met

The following data should be collected:

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

How the Service meets or does not meet the standard

HCIS is only on one computer. Dashboard data annual 23/24 data not seen and 22/23 not compulsory, so not seen. There is an SOP for registration and EUHASS reporting.

Quality Standard 28: Research

Standard Met

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

How the Service meets or does not meet the standard

Excellent research portfolio and research team. The team has research as part of the job plan.

Quality Standard 29: Multidisciplinary Review and Learning

Partially Met

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

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

How the Service meets or does not meet the standard

There are haematology departmental audit meetings, which staff attend monthly. Haemostasis is the theme twice a year, but there are no haemophilia department audit meetings or plans. The audit is mentioned in the senior team meeting minutes.

There is no evidence of haemophilia department teaching, e.g. journal club or updates on guidelines. There are good examples of teaching slides (presumably for junior doctors). So far, there have been good responses to the patient survey.

Quality Standard 30: Document Control

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

Partially Met

How the Service meets or does not meet the standard

Guideline - good version control, but many documents did not have full version control with expiration date, date for review, or version number. Examples of no/incomplete version control - Lab investigation and ED SOP - no version 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 2 consultant haematologists, 2 clinical nurse specialists, a specialist haemophilia physiotherapist and a patient representative. Details of the Peer Review Team are held by UKHCDO.

7.3 Outstanding findings from previous peer review

The table below provides details of the issues that were raised in the previous peer review report of 2019 that 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	Facilities The facilities from which the service was provided were limited, with only a single clinic room available. This meant that sometimes staff had to ask other teams to vacate clinic rooms so they could see patients, which sometime caused delays. Reviewers also heard that sometimes up to ten team members could be sharing a cramped, dark office, where they may need to talk to patients, or take calls for clinical advice.
2a	Staffing Some of the clinical staff did not have enough time in their job-plans to manage this large clinical service. Nursing provision was felt be reviewers to be low and did not currently allow for adequate community work and home visits. Consultant Programmed Activity (PA) sessions (1.9 WTE)

	meant that they were often putting in extra unpaid time, and with growing patient numbers this is unlikely to be sustainable.
2b	The lack of any dedicated psychologist time, and of a social worker on the team, were cause for significant concern. Patients could be referred to see the psychologist at the Royal Free Hospital, but in practice this pathway was seldom used and would be very inconvenient for patients. Efforts to try novel ways to address the lack of psychology input, by holding funded ‘support group’ sessions, were noted but did not substitute for a psychologist as an integrated member of the core team. Reviewers also heard that the lack of social work support to work with families in this area of high social deprivation was a problem.
3	Homecare issues Reviewers saw patient feedback that highlighted that the current homecare delivery provider was not working well for a large number of patients. This was the main criticism of the service by patients in face to face and written feedback. The team had met the providers and were hopeful that some of the problems with communication and deliveries could be improved. Further patient satisfaction audits in the near future will be required to ensure the issues have been adequately addressed.