UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

UKHCDO Haemophilia Peer Review Audit Report

Evelina Children's Haemophilia Comprehensive Care Centre (Interim)

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: 09 October 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, and 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, with updated service specifications 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 constitute one of the twelve final recommendations of the Infected Blood Inquiry Report in 2024. This recommendation also requires trusts to consider peer review findings and prioritise the implementation of proposed improvements for comprehensive and safe care.

The previous peer review cycle was completed in 2019–2020, and the 2024 cycle represents 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 provides the key findings, and the full report details the audit assessments referenced against these standards. Peer review for the Evelina Haemophilia Centre (the Service), based at Evelina London Children's Hospital, part of Guy's and St Thomas' NHS Foundation Trust, was completed on 10 July 2024.

The Service successfully met 28 of the 30 established standards, with two standards partially met. The Centre's and the Trust's commitment to providing high-quality care was evident through various initiatives and pathways. However, key recommendations have been made to address gaps that hinder the delivery of comprehensive care.

1. **Medical Consultant Workforce**: The review team recommends recruiting a second paediatric haematology consultant, considering the size of the service; this issue was also raised in 2019.
2. **Psychology Service Provision:** The review team recommends that the trust offer dedicated psychological support as outlined in the National Service Specification.
3. **Facilities and Environment**: The review team recommends that the Trust allocate additional space to accommodate a large patient cohort, ensuring appropriate multidisciplinary care.

The UKHCDO advisory committee reviewed the final report on 9 October 2025 regarding an application for interim paediatric CCC status and confirmed that the children's service meets the relevant standards. The committee is therefore pleased to designate Evelina Haemophilia Service as a Paediatric CCC (Interim). However, important gaps remain that require investment to strengthen patient care and ensure full compliance with the national service specification. Progression to full CCC status will also require the appointment of a second paediatric consultant for a service of this size or an equivalent cross-cover from the adult service.

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 was conducted on 10 July 2024 at the Haemophilia Centre, based at Evelina London Children's Hospital, which is part of Guy's & St Thomas' NHS Foundation Trust. A multidisciplinary team of haemophilia specialists, along with patient representation, conducted the review, which involved speaking with staff from the Service, reviewing documentation, and touring the facilities.

The service was previously a combined centre with the Adult Centre, and this is the first time an application has been made to operate as a standalone paediatric comprehensive care centre. There is evidence of shared back-office functions with the Adult Centre, but no evidence of joint working in clinical areas, particularly medical consultant cross-cover. The Service provides care to children with bleeding disorders and has 322 registered patients. It offers care to children and young people up to the age of 18 across South London and Southeast England.

The Service is multidisciplinary, comprising a core team of doctors, nurses, and a physiotherapist. A specialist Haemostasis laboratory, including a molecular haemostasis laboratory, is located on-site. The team also manages a highly active paediatric thrombosis and anticoagulation service, in addition to general haematology patients. The Service actively participates in research and, as a team, is very involved with the UKHCDO working parties

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	0	49	0	9	0	66	0	135
Moderate	0	9	0	5				
Mild	0	49	0					
Annual review in the last year	0	99	0	14	0	60	0	122
Inpatient admissions in the last year	0	5	0	4	0	1	0	0

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

Staffing: The staff comprises a mixture of full-time and part-time professionals, totalling seven staff members, including two consultants (1.35 WTE), three nurses, one paediatric physiotherapist, and one administrative staff member, with additional shared staff supporting the adult team. The laboratory service shared with the Adult Haemophilia Centre and Thrombosis service has 33 Laboratory staff, including five senior scientists, three clinical scientists, and nine senior Biomedical Scientists (BMS). There is no dedicated psychology or social work service.

Key staff include Consultant Haematologist Dr Jayanthi Alamelu and Lead Nurse Clare James

Outpatient care: The service is provided from two small, dedicated haemophilia rooms, with one of them reserved each day for walk-in patients. Outpatient clinics are held weekly on Tuesday afternoons in three additional clinic rooms (allocated solely for haemophilia that afternoon) within the main outpatient department.

Inpatient care: Patients are admitted to the relevant ward and service depending on the primary complaint.

Out of hours: Via Emergency department – pathway in place

Transition: Ready Steady Go process in place with good links with St Thomas's Adult CCC and St George's Adult CCC (interim).

Network arrangements: The Service is the designated hub of the South London Paediatric Haemophilia Network, which includes St George's Hospital and University Hospital Lewisham. Previously, the Service operated an outreach clinic in Lewisham, but this has not been necessary recently, as patient numbers have decreased significantly. All patients with moderate to severe conditions are now registered and managed at Evelina.

The Service maintains a multidisciplinary team (MDT) that the St George's team joins on a monthly and ad hoc basis, as requested by the St George's nursing team. Patients treated at the Service by St George's have been offered clinical trials and non-factor therapy options. Formal network activities, such as audits, have not been conducted.

The lead haemophilia consultant also conducts an outreach clinic at St Peter's Hospital, Chertsey, where patients with mild bleeding disorders are reviewed closer to home.

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 28 out of the 30 standards, with two standards being partially met. The previous peer review report of 2019 assessed the Service as one centre with Guys & St Thomas', but there were some concerns raised in the 2019 report that were attributable to the Service. Centres should ideally use this report to guide discussions with the management team, showcasing areas of good practice while highlighting those where further investment and improvement may be necessary.

Standard	Title of standard	Rating
1	Service Information	
2	Condition-Specific Information	
3	Plan of Care	
4	Outpatient Review of PwBD	
5	Contact for Queries and Advice	
6	Haemtrack (PwBD on Home Therapy	
7	Environment, Facilities and Equipment	
8	Transition to Adult Services and Preparation for Adult Life	

Standard	Title of standard	Rating
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

The following is a breakdown of the good practice that is in evidence at the service.

1. The Service is a cohesive and hardworking team that works well with the adult service at St Thomas' Hospital.
2. A strong transition process is in place that focuses on the emotional and mental needs of the patient, rather than their age. The process also assigns a paediatric nurse and an adult nurse to facilitate the transition. A psychologist is available to see all paediatric patients transitioning to adult services.
3. The review team was impressed by the research facilities available and that research is being undertaken despite the nurse staffing numbers. The feedback from patients who were seen on the day was excellent.
4. The review team wishes to highlight the ED pathway, surgical plans and home delivery service as examples of good practice.
5. The Service can provide excellent patient care while also supporting St George's CCC (interim).

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 service is potentially among the five largest in the UK, yet the medical consultant cover is insufficient, especially since there is no cross-cover with the adult clinical service. It depends on one consultant, with some cross-cover by another paediatric haematologist attending MDTs and providing out-of-hours support when the main consultant is absent. This effectively means that the Centre Director is on call for complex haemostasis/thrombosis queries on a 1:1 basis. While routine issues can be managed, the expertise available out of hours is less than expected for at least a fifth of the year, and managing neonates with newly diagnosed severe bleeding disorders can fall below expectations, risking adverse outcomes such as brain bleeds.
2. The review team is concerned that there is no dedicated psychologist specialising in bleeding disorders available to the service. This was raised as a concern in 2019 when 0.2 WTE was allocated to psychology; however, this has now been lost, and there is only a referral pathway with waiting times of up to a month. This does not meet the National Service Specification and is unsuitable for a service of this size and complexity.
3. The review team is concerned that the space within the haemophilia centre is inadequate for its purpose. Although there are two clinic rooms available, one must be converted into an office because it is not suitable as a clinic room. The physiotherapist is also not located in the same area as the Clinical Nurse Specialists (CNS). Haemophilia and Bleeding Disorders Care is a multidisciplinary service, and on-site access to all team members at each visit is the expected standard; however, the clinical space allocated to this large service is insufficient to support this.

4.5 Recommendations

This section outlines the review team's recommendations in response to the concerns raised above.

1. **Medical Consultant Workforce:** Since the last review in 2019, an additional 0.35 WTE has been identified, solely for cross-cover. The review team recommends recruiting a second consultant with an interest in thrombosis and haemostasis, due to the expanding service and the increasing complexity of haemostasis on-call.
2. **Psychology Service Provision:** The review team recommends that the Service prioritise recruiting a dedicated part-time psychologist specialising in bleeding disorders. This is essential because access to specialised psychological support improves the well-being of patients and caregivers and is a key component of Comprehensive Care for Bleeding Disorders, as outlined in the National Service Specification.
3. **Facilities and Environment:** The review team recommends that the Trust allocate additional space to the Haemophilia Centre to better accommodate the large and complex patient cohort attending for various interventions. At a minimum, the space in the Haemophilia Centre should be reviewed to determine how it can be utilised more efficiently, creating more

room for patients and staff. Specifically, the review team emphasises the need for sufficient clinical space to accommodate patients and enable staff to perform their roles effectively. The centre should also ensure adequate arrangements for storing clinical materials and equipment used in clinical trials.

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 particular focus on areas where the standards were partially 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

The centre information sheet is a large, comprehensive information document containing all relevant information.

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

Standard Met

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

Letters and personalised management plans are provided. They offer a detailed explanation of what is required or expected from the patient, along with clear information for clinical teams. The patient's passport is comprehensive, giving detailed explanations of the disorder and management strategies.

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

Letters and personalised management plans are provided. The patient passport provides an in-depth explanation of what is required or expected of them, as well as details of what is expected of the clinical team. The patient's passport is comprehensive, providing detailed explanations of the disorder and its management.

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

Letters to the GP were reviewed. Pathways were identified for psychology, play, safeguarding, DNA, and PIFU. Access to social work is through the trust's safeguarding team and can be escalated from there. No issues were identified. The frequency of reviews is specified within the diagnosis and management protocols. A paediatric psychologist was unavailable—hence, a referral had to be made.

The psychologist is part of the NEST team, and the waiting time is no more than one month. MDT attendance is possible if required.

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

Flow sheets observed for ED and OOH.

Patient diagnosis cards and patient passports also had relevant information.

Quality Standard 6: Haemtrack (PwBD on Home Therapy)

All PwBD on home treatment should be encouraged to use the electronic recording of their treatment through Haemtrack.

Use should be documented in clinic letters/ plan of care.

Standard Met

How the Service meets or does not meet the standard

The data team arrange factor delivery, and reports are made for the clinical team. Urgent courier of factor can be done as needed.

Quality Standard 7: Environment, Facilities and Equipment

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.

Partially Met

How the Service meets or does not meet the standard

The space is insufficient for the care provided to individuals with haemophilia. There are two clinical rooms; however, one is not suitable for clinical use and is used as an office. Staff are dispersed—the physiotherapist is not in the same location as the CNS team. There is a CRF space designated for research specific to trials. A recent changeover of the IT system has occurred.

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

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.

Standard Met

How the Service meets or does not meet the standard

It is primarily for the St. Thomas Adult Centre. The ready, steady, go process is now in place. It is performed based on the patient's emotional and mental needs, rather than their age. A good transition process is established when all adolescents see an adult psychologist during the transition. Written information was noted.

Quality Standard 9: Carers' Needs

Carers should be offered information on the following:

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

Standard Met

How the Service meets or does not meet the standard

Parents/carers are kept informed of all treatment options for their child, but also to access services for themselves as required. Contact details are provided both through the website and via information leaflets.

Quality Standard 10: Involving PwBD and Carers

The Service should have:

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

Standard Met

How the Service meets or does not meet the standard	
The feedback from patients seen that day was very positive. The transition service was changed based on feedback.	

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	
The clinical operations policy indicates that all standards have been met.	

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

Currently, only one consultant manages the entire service, with a second covering only when the primary consultant is off. The primary consultant is often involved in managing complex cases, resulting in an on-call ratio of 1:1. Additionally, consultant time is required to cover thrombosis/anticoagulation, as well as management aspects such as UKHCDO responsibilities and research activities. Therefore, additional consultant time is necessary to ensure the smoother running of the services and to create a robust backup for consultant coverage. Of particular concern is that this consultant is also responsible for providing support for the service at Georges.

The nursing team requires more support. They are currently delivering care for bleeding disorders, managing thrombosis and anticoagulation, and conducting research activities. The current CNS team does not prescribe; a prescribing course will facilitate appropriate career progression and further support the team.

Additional nursing and administrative time is recommended to ensure the smooth operation of the service.

Currently, the physio role dedicated to haemophilia is essential and must be maintained.

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

All staff undertake relevant CPD, which is reviewed during annual appraisals, and staff have opportunities to attend conferences and courses specific to bleeding disorders.

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

The data team shared with the adult service arrange home deliveries of home treatment. Reports are sent to the clinical team.

An urgent courier of clotting factors can be arranged if necessary.

Quality Standard 15: Support Services

Timely access to the following support services should be available:

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

Standard Met

How the Service meets or does not meet the standard

Play therapy is available and accessible, and evidence provided for other QSs.

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.

Standard Met

How the Service meets or does not meet the standard

A pathway is in place with alerts on the HER visible to ED staff. Audit is ongoing and due for completion.

Quality Standard 17: Laboratory Service

a. A UKAS accredited laboratory service with satisfactory External Quality Assurance performance should be available 24/7
b. A laboratory representative (senior biomedical scientist or clinical scientist) should attend inherited and acquired bleeding disorder service multidisciplinary team meetings (QS 25) regularly
c. The following tests should be available in a timely manner for the diagnosis and management of inherited bleeding disorders:
   i. All coagulation factor assays
   ii. Inhibitor screening
   iii. FVIII inhibitor quantification
   iv. VWF antigen

Standard Met

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

UKAS accredited medical laboratory (No.8595) - scope to be reviewed 11/07/2024, but no major issues.

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

Evidence was provided regarding genetic counselling letters that contain adequate explanations and advice. Referrals to obstetrics are made in a timely manner, with sufficient details given for the referring clinician. Delivery plans address care for both the mother and baby. A gynaecology referral and interdisciplinary team collaboration were also noted.

Access to portocath insertions is available as needed, and provisions are in place for the escalation of clinically urgent cases.

Quality Standard 19: IT System

IT systems should be in use for:

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

Standard Met

How the Service meets or does not meet the standard

There was a transition to a new IT system, with documentation now available on two systems. The new system includes features for electronic alerts. Going forward, notes, letters, etc., are accessible on EPIC. Lab results have been transferred.

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

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

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

Standard Met

How the Service meets or does not meet the standard

All guidelines are in accordance with BSH/UKHCDO guidelines.

Quality Standard 21: Guidelines: Treatment and Monitoring of IABD

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

Standard Met

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

Policies noted for topics related to paediatrics. The Data Management and Home Delivery team manages stocks, supplies, and invoicing for factor concentrates.

Quality Standard 22: Clinical Guidelines/Pathways

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

Guidelines and pathways are observed and used for designated areas. On enquiry, the HCPA guideline was followed for MSK issues.

Standard Met

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

Thorough documentation accompanies departmental protocols. Evidence of plans is recorded in the EPIC chart, and detailed surgical plans are provided. Contact details are supplied for escalation to CNS, Haematology SpR, or the consultant out of hours.

Quality Standard 24: Service Organisation

Standard Met

The Service should have an operational procedure covering at least:

a. Ensuring all children who are in-patients have a named consultant paediatrician and a named haematologist with expertise in caring for PwBD with inherited and acquired bleeding disorders responsible for their care
b. Ensuring all adults are under the care of a consultant haematologist with an interest in inherited and acquired bleeding disorders, either directly or through a shared care arrangement with a general haematologist
c. Responsibility for giving information and education at each stage of the patient journey
d. Arrangements for involving Haemophilia Centre staff in multidisciplinary discussions relating to their PwBD
e. Arrangements for follow-up of PwBD who 'do not attend'
f. Arrangements for transfer of PwBD information when PwBD moves areas temporarily or permanently
g. Ensuring PwBD's plans of care are reviewed at least six monthly for those with severe haemophilia and at least annually for other PwBD (QS 3)
h. Ensuring school visits for children with severe haemophilia at least at each change of school (children's services only)
i. Ensuring PwBD are visited at home where clinically appropriate at least annually if they are unable to attend clinics, including those in nursing homes
j. Lone working

How the Service meets or does not meet the standard

DNA policy provided and Lone working policy. Evidence noted for other QSs.

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	
All team members involved in the care of IBD patients attend the weekly MDM; psychologists join as needed. The SGH network team participates once a month.	

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	
Access is available to the relevant specialities.	

Quality Standard 27: Data Collection	
The following data should be collected: a. UK National Haemophilia Database data on all PwBD b. Data on concentrate use and bleeds, either through Haemtrack or an equivalent mechanism c. Data required to complete the NHS E National Haemophilia Dashboard or other national mechanisms d. Adverse events reported to NHD	Standard Met
How the Service meets or does not meet the standard	
The Service meets this standard, but it is encouraged to submit AEs more promptly.	

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	
Participation in research is demonstrated through documentation and authorship on various abstracts, posters, publications, and guidelines. CNSs and consultants carry out research activities, and while the standard is maintained, the service would benefit from additional nursing and administrative support for 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	
The team has governance meetings every two months. Audits, Data collection and other metrics inlcuing patient feedback are discussed here.	
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	
Policy for document control in place, with protocols having review dates. SOPS have a date of renewal/or expiry.	

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 paediatric consultant haematologist, a Paediatric clinical nurse specialist, a paediatric specialist haemophilia physiotherapist, senior clinical scientist and a patient representative. Details of the Peer Review Team are held by UKHCDO.

7.3 Outstanding findings from previous peer review

The table below provides details of relevant issues that were raised in the previous peer review report of 2019 some of which have also been raised in this review. It must be noted that St Thomas and Evelina Children's centres were reviewed as one centre in 2019, therefore the below findings were applicable to both St Thomas' and Evelina. 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
2	Staffing shortfalls (adult and paediatric teams)
a	Psychosocial care - There was a dedicated psychologist working with the team, and her input was highly valued by staff and patients, but she had only 0.2 WTE (one day per week) dedicated to the service, which was not sufficient for a service of this size. Her support for young people and parents over the transition period was important, but she only had time available to work with patients with the highest-level needs, and little time to undertake any support work within the professional team. There was no dedicated social worker affiliated to the paediatric or the adult team, and while patients could access the general hospital service, this meant that no individual worker had become acquainted with the conditions and the range of challenges that patients faced, in order to help them more efficiently.

b	Senior paediatric medical staff - A single paediatric haematologist was delivering the service, supported by two non-malignant haematologists on a 1:3 on-call rota. However, if a patient presented with complex bleeding problems when the non-malignant haematologists were on call, the paediatric haematologist was contacted, so that she was essentially working an informal 1:1 on-call arrangement. Senior medical input to the service in general was dependent on this single individual, which was not sustainable.