UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

UKHCDO Haemophilia Peer Review Audit Report

St Thomas' Haemophilia Comprehensive Care Centre

Report Date: 29 August 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 St Thomas' Haemophilia Comprehensive Care Centre (the Service) was completed on 11th July 2024

The Service successfully met 21 of the 30 established standards, with 9 standards partially met. The commitment of both the Centre and the Trust to providing high-quality care was evident through various initiatives and clinical pathways. However, key recommendations have been made to help address the gaps that affect the ability to deliver comprehensive care.

Key Recommendations:

1. **Nursing Provision:** The review team suggests conducting a skill mix review to ensure the service has sufficient nursing staff for currently registered patients, including the potential appointment of a lead nurse at band 8 to support the development of the nursing service to meet all aspects of the service specifications.
2. **Laboratory Service Provision**: Any trust-wide review of laboratory services should take into account the National Service Specification for an on-site 24/7 specialist haemostasis and thrombosis laboratory service. This allows quick access to the specialist tests needed for the immediate management of emergencies.
3. **Facilities & Environment:** The review team would like to emphasise that the configuration and utilisation of the Space in the Centre needs to be reviewed. A suitable clinical space should be available for the multidisciplinary team to assess semi-urgent walk-ins.

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

2 Haemophilia and Bleeding Disorder Peer Review - Background

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

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

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

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

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

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

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

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

3 Service Description

The peer review was conducted on July 11, 2024. A multidisciplinary team of haemophilia professionals, together with patient representation, conducted the review, which involved discussions with staff from the Service, examining documentation, and touring the facilities.

The Service provides care to both adults and children with bleeding disorders and has 1592 registered patients from London and the Southeast of England. It is part of Guy's and St. Thomas' NHS Foundation Trust and is based on the St. Thomas' campus. For this cycle of peer review, Evelina and St. George's have made independent submissions for peer review. The assessment was conducted solely as an adult centre.

The service is one of the larger haemophilia centres in the UK. While most of its patients come from London and the Southeast, it also serves individuals across the UK. They provide a comprehensive 24-hour, seven-day-a-week clinical and laboratory service that acts as a reference centre for many hospitals in South London and the Southeast of England.

The Service offers all aspects of holistic, comprehensive care as described in the National Service Specifications with full-time Consultants in Haemostasis and Thrombosis supported by experienced, highly skilled specialist nurses, an allied health professional team, and healthcare scientists**.**

The Service is led by consultants and operates from 9:00 a.m. to 5:00 p.m. on weekdays, with consultant-led on-call advice available 24 hours a day.

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	159		20		261		644	
Moderate	32		13					
Mild	116		25					
Annual review in the last year	281		52		216		516	
Inpatient admissions in the last year	15		2		15		30	

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: There is a mix of staff in full-time and part-time roles, including nine consultant Haematologists (8.8 WTE), five of whom specialise in Haemostasis, five nurses (4.4 WTE), one physiotherapist (1 WTE), and 33 biomedical scientists, which include three clinical scientists, nine

senior BMS, and 16 BMS. Additionally, there is one psychotherapist (0.4 WTE). A total of 9.6 WTE administrative staff support both the thrombosis and anticoagulation services.

Key staff include Consultant Haematologist & Centre Director Dr Gerard Dolan and Lead Nurse Eduardo Lee.

Outpatient care: The Centre is open from 9:00 a.m. to 5:00 p.m., Monday through Friday, and all clinic appointments and treatments, including physiotherapy, are held within the Centre.

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

Out of hours: A 24/7 Haemostasis Consultant on-call rota is in place, and patients are seen in the Emergency Department outside of regular hours.

Transition: The Centre is closely linked to the children's Service at the Evelina Children's Hospital.

Network arrangements: The service is the lead for the South London Haemophilia Network, which includes the Evelina Children's Haemophilia Centre, St George's Haemophilia Centre and Lewisham Haemophilia Centre. These centres are invited to the weekly MDM meetings.

The service also works closely with other hospitals, including King's College Hospital in Brighton, Worthing, and Eastbourne, to share the care of patients residing in the vicinity of these hospitals. These are members of the wider haemophilia network meetings.

The service hosts formal meetings of the wider network and shares protocols, for example, the management of acquired haemophilia.

4 Quality Standards

4.1 Overview

The table below outlines the status of each standard, categorised as met (green), partially met (yellow), or not met (red). Overall, the Service has met 21 of the 30 standards, with 9 partially met. The Service has outstanding findings from their previous peer review report in similar areas, which are provided in the appendix. The service is encouraged to review all descriptive assessments in addition to the key findings. This report, alongside local assessments, should steer discussions with the management team, highlighting areas of good practice while emphasising where further investment and improvement may be required.

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

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

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

1. The service demonstrates true multi-disciplinary work both within the service and with other departments. Clinical, Laboratory, psychology, and physiotherapy can all provide input and work well together. Transition clinics show effective multi-disciplinary team working.
2. The review team received very positive feedback about the service from invited patients present on the day.
3. The service provides a schedule of regular training with various departments throughout the hospital.
4. The review team wish to highlight the excellent administrative, clerical and data support team.

4.3 Immediate risks

There were no immediate risks identified.

4.4 Concerns

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

1. The review team is concerned that the nursing provision is considerably understaffed, given the number and complexity of the registered patients. On the day, there seemed to be some confusion regarding the actual establishment numbers of posts, although 4.4 WTE are declared in the self-assessment. Current staffing levels have already limited several of the anticipated services, such as community visits and educational outreach to other hospitals. This will hinder further development of nurse-led initiatives within the service.
2. The Peer Review Team is concerned that the trust is considering a reorganisation of Laboratory Services. The Haemostasis and Thrombosis Laboratory at St Thomas's is a highly respected service, and on-site services are a requirement of the National Service Specification.
3. The review team was concerned to learn that there is not always a suitable clinical space for the examination and treatment of patients attending unbooked emergency attendances. They would like to highlight that the configuration and utilisation of the space in the Centre needs to be reviewed. There should always be a suitable clinical space available to see emergency patient attendees by the appropriate member of the MDT.
4. The provision of psychological services is very low, given the number and complexity of patients registered with the Service. A large cohort of individuals infected and affected by bloodborne viruses should have access to specialised psychological services in accordance with the recommendations of the Infected Blood Inquiry.
5. The review team found no evidence of a current audit plan, despite the plan for 2021-22 having been provided. There was no evidence of an audit of the Emergency Department pathway of care.
6. Despite excellent feedback from patients who were invited to attend peer review, the service is not proactive in seeking patient feedback. Furthermore, there is limited evidence of the service making changes in response to patient feedback.
7. The review team found that much of the patient information available was outdated. This included information about current treatments, which was very limited; this poses a risk to providing what is necessary for patient-centred care in shared decision-making about treatment and management of their condition.
8. The review team did not find sufficient information in patient letters that outlined their current treatment plans. The letters lacked a consistent format, including names and dosages of treatments, as well as plans for emergencies.

4.5 Recommendations

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

1. **Nursing provision:** Nurses are pivotal members of the Haemophilia MDT and serve as the primary point of contact for clinical advice and information. They also provide education and training to patients and families, including advanced clinical skills. The review team suggests conducting a skill mix review to ensure the service has sufficient nursing staff for currently

registered patients, including the potential appointment of a lead nurse at band 8 to support the development of the nursing service to meet all aspects of the service specifications.

2. **Laboratory Services Provision:** The Peer Review Team wishes to emphasise to the Trust that any reorganisation of laboratory services must include the National Service Specification requirement for on-site 24/7 provision of Haemostasis and Thrombosis Laboratory services. This is crucial to ensuring rapid access and turnaround times for specialist tests.
3. **Facilities and Environment:** The review team recommends that the trust support the Clinical Team regarding the configuration and utilisation of the space in the Centre, which requires examination. There should always be an appropriate clinical space available for the relevant member of the MDT to review emergency walk-ins.
4. **Psychology Provision:** This needs to be increased to meet the needs of patients and carers. The Trust should urgently support the Service in recruiting new staff members with the additional funding provided for the Infected Blood Psychology Service.
5. **Clinical Audit:** The review team recommends that the service establish a rolling audit plan that encompasses ongoing audits of the ED pathway and other key areas of concern.
6. **Seeking Patient Feedback:** The review team would like to see the service adopt a more proactive approach to gathering patient feedback and implementing changes accordingly. We suggest this could include a regular patient newsletter or a noticeboard in the reception area featuring "You said, we did" type feedback.
7. **Patient Information:** The review team recommends that the team conduct a comprehensive review of all patient information stored in both electronic and paper formats. Any outdated information should be eliminated.
8. **Plans of Care**: The review team recommends that a systematic approach is taken to develop written plans of care, encompassing all aspects required in the service specification.

5 Quality Standards - Detailed Description

A detailed description of the quality standards used in the assessment is provided, along with a concise overview of how the Service has met these standards, with a particular focus on areas where the standard was partially met or not met.

Quality Standard 1: Service Information	
Written information should be offered to people with bleeding disorders (PwBD) and, where appropriate, their carers covering at least: a. Brief description of the Service b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the Service e. How to access physiotherapy and psychology f. Relevant national organisations and local support groups g. Where to go in an emergency and how to access out of hours services h. Information on delivery of products, including company contact details	Standard Met

How to:

i. Access social care and support services
ii. Access benefits and immigration advice
iii. Interpreter and advocacy services, PALS, spiritual support
iv. Give feedback on the Service, including how to make a complaint
v. Get involved in improving services (QS 10)

How the Service meets or does not meet the standard

There is a well-developed website that provides a comprehensive description of the services, which includes all clinics listed with their opening hours and contact information. It also features details about the clinical team, including contact information, links to patient resources, and genetic information. Additionally, there is a link to the National Haemophilia Society. Although no information about wards is included, this will vary depending on the specific location patients are sent.

Home delivery information is available, along with feedback forms, on the website. Details on how to obtain an interpreter for appointments are also provided, along with access to benefits within the Carers' Pack on the website.

Accessibility concerns: If English is not a native language, users may find it difficult to read the webpage. Furthermore, there are visual issues related to the colour and size of the text, particularly when printed. The website requires testing by patients, as navigation needs improvement.

Quality Standard 2: Condition-Specific Information

Written and or online information should be available and offered to PwBD and, where appropriate, their carers covering:

a. A description of their condition and how it might affect them
b. Problems, symptoms, and signs for which emergency advice should be sought
c. Genetics of Inherited Bleeding Disorders
d. Testing for carrier status and the implications of being a carrier
e. Treatment options including on-demand, prophylaxis, home therapy and the use of Haemtrack
f. How to manage bleeding at home
g. Ports, fistulae, and in-dwelling access devices (if applicable)
h. Approach to elective and emergency surgery
i. Women's health issues
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:

Partially Met

1. Haemophilia A
2. Haemophilia B
3. Von Willebrand Disease
4. Acquired haemophilia
5. Inherited platelet disorders
6. Bleeding Disorder of unknown cause (BDUC)
7. Other less common and rare bleeding disorders

How the Service meets or does not meet the standard

The generic website provides information on most disorders, although it offers minimal details on platelet and rare bleeding disorders. The only separate leaflets available are those from the NHS for Haemophilia A, B, and von Willebrand disease. The haemophilia leaflets are outdated, as they mention only one standard half-life product as a treatment option for both Haemophilia A and B. The website should feature a dedicated section for health promotion.

Quality Standard 3: Plan of Care

Partially 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

Five example letters are provided; however, some letters are missing essential details, including the type of product to be used in emergency treatment. Consequently, the treatment plan for an emergency bleed is ambiguous for any clinician. The care plan requires a thorough review and must be consistently applied across all patients.

Quality Standard 4: Outpatient review of PwBD

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.

Standard Met

How the Service meets or does not meet the standard

The evidence presented demonstrated the presence of relevant individuals at the appropriate times and explained how to access all services.

Quality Standard 5: Contact for Queries and Advice

Each PwBD and, where appropriate, their carer should have a contact point within the Service for queries and advice.

A clear system for triage of urgent clinical problems should be in place.
If advice and support are not immediately available for non-urgent enquiries, then the timescales for a response should be clear.

Standard Met

How the Service meets or does not meet the standard

Details were noted in the written information and on the website.

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 provided evidence demonstrated letters of use and instructions on how to record, etc. A link to haemtrack on the website was provided.

Quality Standard 7: Environment, Facilities and Equipment

Partially Met

The environment and facilities in outpatient clinics, wards and day units should be appropriate for the number of PwBD with inherited and acquired bleeding disorders and accessible by people with severe mobility problems.

Facilities and equipment appropriate for the Service provided should be available, including:

a. Fridges
b. storage
c. Clinical rooms for staff of all disciplines to see PwBD and carers with adequate space for physiotherapy assessment
d. Room for multidisciplinary discussion
e. Room for educational work with PwBD and carers
f. Office space for staff
g. Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all relevant clinical areas
h. Access to adequate IT equipment with clinical systems
i. All equipment should be appropriately checked and maintained.

How the Service meets or does not meet the standard

The service operates from purpose-built facilities, featuring five clinic rooms, one physiotherapy room, and one treatment and phlebotomy room. Ad hoc face-to-face appointments can be challenging due to the shared use of the clinical space for haemophilia and thrombophilia. For a service of this size, there should be provision to see patients on the same day.

Office space is limited due to hot-desking and the restricted availability of individual PCs. There is insufficient space for psychology and MDT work. The waiting room serves its purpose, but there is potential to refresh the area with informational or staff picture boards, which would benefit patients. Additionally, there are no books or toys available for children who accompany their parents. However, there is access to language line facilities.

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

Standard Met

Young people approaching the time when their care will transfer to adult services should be offered:

a. Information and support on taking responsibility for their own care
b. The opportunity to discuss the transfer of care with paediatric and adult services
c. A named coordinator for the transfer of care
d. A preparation period prior to the transfer
e. Written information about the transfer of care, including arrangements for monitoring during the time immediately afterwards
f. Advice for young people going away from home to study, including:
    i. Registering with a GP
    ii. How to access emergency and routine care
    iii. How to access support from their Comprehensive Care Centre
    iv. Communication with their new GP
    v. The Centre should have a guideline/SOP covering this information.

How the Service meets or does not meet the standard	
There is no formal transition from GOSH to St. Thomas, and this pathway should be improved for the future. There is a patient focused pathway that enables a seamless transition from Evelina to GSTT. Patients are transferred to the service from the age of 18.	

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	
Lots of supporting evidence provided.	

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	
Paper feedback forms are accessible in the clinic, and the website includes a feedback form, along with text messages sent after the clinic visit. These provide evidence of basic feedback for the annual dashboard; however, they are not proactive in soliciting patient feedback and might consider implementing an annual survey. Evidence of changes made based on patient feedback is minimal (TV in waiting room, still to go up). Patient discussions on the day revealed very positive feedback regarding the service provided, with all patients expressing extreme satisfaction and feeling that a personal touch was evident. Patient response: "never on-boarded but receives text", i.e., receives text messages without being aware he gave permission.	

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

Minutes were made available.

Quality Standard 12: Staffing levels and skill mix

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)

Partially Met

How the Service meets or does not meet the standard	
Competencies for all staff were available, along with continuing professional development (CPD). There is a social worker at 0.8 WTE. Although nine consultants are listed, evidence was provided for only seven consultants. The psychologist primarily attended in-house CPD, as he did not have time to attend conferences. Additionally, staff are expected to be present with the new bespoke IBI service. Overdue mandatory training was noted for some staff. The nursing establishment is significantly low relative to the number and complexity of registered patients. On the day, there seemed to be some confusion regarding the actual establishment numbers of posts, despite 4.4 WTE being declared in the self-assessment. Current staffing levels have already restricted some of the anticipated services, such as community visits and educational outreach to other hospitals. They will impede the further professional development of the nurses in place and of nurse-led initiatives within the service. A skill mix review is needed to ensure that there are sufficient numbers of nurses to allow for ongoing professional development and support the current workload. An Advanced Nurse Practitioner / lead nurse is critical for a service of this size, and ideally, they should be a band 8 nurse as a minimum. The psychology provision is inadequate considering the number and complexity of patients registered at the service. There is a large cohort of individuals infected and affected by bloodborne viruses who should have access to specialised psychological services in accordance with the recommendations of the Infected Blood Inquiry.	
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	Partially Met
How the Service meets or does not meet the standard	
Appraisals are missing from the folders; evidence of conference attendance is noted, along with attendance at the contemporary care course.	
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 team is highly proactive and makes significant contributions to the care provided.	

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

There is adequate support from a pharmacy, with access to dieticians. Access to OT and orthotics evidenced with example referrals.

Quality Standard 16: Emergency Department

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

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

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

Partially Met

How the Service meets or does not meet the standard

a. Evidence of patient FYI on EPIC to alert other clinical staff.

b. A&E adult management policy observed. Alert card for patients noted.

Evidence of training sessions with various departments, including slides and calendar. There is no evidence of an audit of the ED pathway or PwBD survey.

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

Excellent laboratory facilities and UKAS certificate/scope provided, along with two EQA reports. There is evidence of MDT attendance from both Haemostasis and Molecular teams. The policies for Haemostasis/Molecular detail TAT and test availability, but there are no instructions on how to make contact if needed; it may be beneficial to include the pathway.

Given the scope for reorganisation of lab services, the centre needs to highlight to the organisation the absolute requirement for having onsite specialist H&T lab for rapid access and 24/7 cover.

Quality Standard 18: Specialist Services

Standard Met

Timely access to the following specialist staff and services should be available as part of an HCCC service where appropriate, depending on whether it is adult, paediatric or all-age service. HCs should be able to access these services through network arrangements:

a. Obstetrics, including reproductive counselling, information about pre-implantation genetic diagnosis and antenatal diagnosis
b. Foetal medicine
c. Vascular access (consultant surgeon or interventional radiologist with experience of venous access devices)
d. Orthopaedic surgery
e. Care of older people services
f. Dental services
g. HIV services
h. Hepatology
i. Medical genetics (Genetic Counselling Services)
j. Pain management services
k. Rheumatology
l. Specialist services should have an appropriate level of specialist expertise in the care of people with inherited and acquired bleeding disorders.

How the Service meets or does not meet the standard

a. Evidence provided for referral letters and genetics,
b. Foetal medicine email seen
c. Clinical notes provided
d. Policy provided and evidence of surgical

e. Webpage printout for the team. Fall telephone assessment - referral system in place. POPS team is available.
f. Dental services - pathway seen and appointment letter provided
g. joint HIV and Haemophilia clinic once a month
h. joint Hepatology and Haemophilia clinic once a month
i. Evidence of genetic counselling provided
j. Pain management was not evident. Evidence was provided of medical pain management but not self-pain management.
k. Rheumatology: department available, referral provided.

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

A new I.T. system is in place and seems suitable for purpose.

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

Evidence was provided for the above guidelines and pathways.

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

Various policies and SOPs were reviewed and met standards. The emicizumab policy outlines initial testing and subsequent testing procedures but does not address inhibitor testing after initiation, such as every 12 months for non-inhibitors and every 6 months for inhibitors.

Quality Standard 22: Clinical Guidelines/Pathways

Standard Met

The following clinical guidelines/pathways should be in use:

a. Management of acute bleeding episodes, including PwBD with inhibitors
b. Immune tolerance therapy
c. Dental care
d. Care of PwBD with hepatitis C
e. Care of PwBD with HIV
f. Antenatal care, delivery, and care of the neonate
g. Management of synovitis and target joints
h. Long-term surveillance of musculoskeletal health
i. "For public health purposes": care of PwBD at risk of vCJD who are undergoing surgery

How the Service meets or does not meet the standard

Evidence was provided for the above guidelines and pathways.

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

Partially Met

How the Service meets or does not meet the standard

Evidence of procedures in place; communication to teams has been demonstrated. Surgical plans do not include intraoperative management or escalations, nor do they specify actions to take in the event of bleeding during surgery.

Quality Standard 24: Service Organisation

The Service should have an operational procedure covering at least:

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

Standard Met

How the Service meets or does not meet the standard

Evidence was provided for all relevant standards, except for home visits and nursing home visits, which were not offered due to a lack of capacity within the nursing team.

Quality Standard 25: Multidisciplinary Team Meetings

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

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

Standard Met

How the Service meets or does not meet the standard

There was evidence of scientific attendance at MDT, and minutes were seen.

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

Letters were seen as evidence of joint clinical arrangements and reviews.

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
e.

Standard Met

How the Service meets or does not meet the standard

Evidence of submission to the national database and other reports was also available.

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 clinical trials was reviewed. Two patients who were seen were involved in clinical trials. They felt very well-informed and happy about the trials available at GSTT.

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

Partially Met

How the Service meets or does not meet the standard

The current audit plan was not provided (the audit sheet was for the 2021-2022 period), and there was no evidence of rolling audits. Additionally, there was no audit for emergency and out-of-hours care, nor was there a discussion of UKHCDO benchmarking on concentrate use. The standing agenda for clinical governance does not consistently include morbidity/mortality and lacks patient feedback, apart from individual complaints.

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

The guidelines have not been consistently formatted with the relevant information. The ED Adult patient management was updated in May 2024, but no review date was provided. Similarly, the 'Ratified/authorised by' section is incomplete on several policies, creating uncertainty regarding whether the policy has been properly ratified and, if so, by which CG committee - for instance, the Clinical Operation Policy for Haemophilia and Bleeding Disorders and the Haemophilia DNA Policy. The version number is not always included in the footnotes of documents.

6 Acknowledgements

The UKHCDO and the Peer Review Team express their sincere gratitude to the Service for its openness, hospitality, and meticulous preparation. We are especially thankful to the service users and carers who generously contributed their time and offered invaluable insights during the review. Furthermore, we extend our appreciation to the members of the Peer Review Team and their employing organisations for facilitating their participation in this process. We are grateful to all involved for their commitment to enhancing patient care through this peer review process.

Finally, the peer review process would not have been possible without the dedicated efforts of several key individuals: Dr. Sarah Mangles, Chair of the Peer Review Working Party, provided continuous and strategic oversight; Debra Pollard, retired Advanced Nurse Practitioner at the Royal Free, ensured consistency across all peer review reports; Harry Evans, Peer Review Project Manager, coordinated and managed the process; and the UKHCDO Chair and Executive team for their contributions to the reports and their final review.

7 Appendices

7.1 Definitions

Reference	Reference number for quality standard
Quality Standard	The wording of the quality standard
Rating	The review team's opinion as to whether the standard has been: Met - Standard has been met fully. Partially Met - Standard has been met in part. Not Met - Standard has not been met at all. Not Applicable - Standard is not applicable for this specific centre.
How the service meets or does not meet the standard	What evaluations or conclusions can be drawn from the evidence. How does the evidence provided meet, partially meet, or not meet the standard. Evidence can be presented as a document or based on the observations of the peer review team.
Immediate risks	These are issues that pose an immediate risk to patients, carers, and or staff.
Good Practice (if applicable) (over and above the standard)	Where applicable, any good or best practice witnessed should be supported with evidence.

7.2 Peer Review Team

The Peer Review Team consisted of a consultant haematologist, a clinical nurse specialist, a clinical psychologist, a specialist haemophilia physiotherapist, a biomedical 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. 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	Adult nursing team There was a lack of clarity in the management structure for the adult nurse specialists. The review team heard that there was a vacant Band 7 'manager' post, but it was unclear how this role fitted within the specialist nursing team, and who provided senior nursing input to the team. Appraisal processes were not identifying specific training and educational needs, in line with the Haemophilia Nursing Association competency framework, and there was no follow through with opportunities to undertake relevant CPD. The Band 6 nurses were also undertaking some tasks that were not appropriate to their banding, such as taking routine height and weight measurements for patients in busy thrombosis clinics. They were additionally covering some sickness absence in the research nursing team. Their roles appeared task-orientated, and their clinical potential was not being utilised in the more rewarding specialist roles such as undertaking nurse-led clinics or actively participating in multi-disciplinary care and decision making. The review team heard there was a sense of frustration in their work. While undertaking an advanced clinical assessment course is not necessary before taking on more autonomous practice, completion of that training might make the nurses feel more confident about taking on such work and allow other members of the clinical team to recognise their abilities to do so.
2a	Staffing shortfalls 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.