UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

UKHCDO Haemophilia Peer Review Audit Report

St George's Adult'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: 9 October 2025

TABLE OF CONTENTS

1 Executive summary

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

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

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

The executive summary presents the key findings, while the full report details the assessments referenced against the quality standards. Peer review for the St George's Haemophilia Centre (the Service) was completed on 30 October 2024. The Centre provides services for both children and adults, and is based within the St George's University Hospitals NHS Trust.

The Centre successfully met 23 of the 30 established standards, with six standards partially met and one remaining unmet. Although the centre is a combined facility, the peer review primarily focused on the Adult Service. Recognising the Trust's support and various initiatives, key recommendations have been made to help address the gaps that impact the ability to deliver comprehensive care.

Key Recommendations:

1. **Physiotherapy Provision**: The review team recommend an increase in physiotherapy provision to at least 0.6 to 0.8 WTE, taking into account the cohort size and complexity.
2. **Paediatric Consultant Support:** The children's service remains fragile, and delivery of comprehensive care requires additional consultant input for paediatric haemophilia. Further, there is limited evidence of joint working between the adult and paediatric services.

The UKHCDO advisory committee reviewed the final report on 9 October 2025 concerning an application for interim adult CCC status. The service was granted Adult CCC (Interim) designation, as it shows adequate governance and reasonable staffing to support this status. However, gaps exist that need investment to meet national service specifications. Progression to full adult CCC will require the appointment of additional physiotherapy support and clearer lines of accountability for the paediatric service.

The UKHCDO advisory committee also recommends conducting a full options appraisal of the paediatric service, given the small number of registered paediatric patients. This will help ensure the long-term, sustainable delivery of comprehensive care at St George's.

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 of the St George's Haemophilia Centre took place on October 30, 2024. The Service is based at St George's University Hospitals NHS Trust, located in the London Borough of Wandsworth. A multidisciplinary team of haemophilia professionals, along with patient representation, conducted the review, which included discussions with staff from the Service, examination of documentation, and a tour of the facilities.

The Service offers care to both adults and children with bleeding disorders and has 1,097 registered patients. It is based at the St George's University Hospitals NHS Trust, located in the London Borough of Wandsworth. As the largest Haemophilia Treatment Centre in the UK, it serves a broad catchment area in Southwest London, including the Thames area, Surrey, Sussex, and North Hampshire.

The Service does not currently hold a Comprehensive Care Centre (CCC) designation; however, it received a favourable review against the CCC standards in the 2019 peer review process. It was not awarded an interim CCC status due to staffing concerns. The Service has since been successful to some extent in increasing the staffing levels supporting the excellent care provided by the service.

3.1 Patient numbers

	Inherited bleeding disorders							
Number of patients	**Haemophilia A**		**Haemophilia B**		**Von Willebrand**		**Other**	
	Adults	Children	Adults	Children	Adults	Children	Adults	Children
Severe	49	14	6	2	196	39	643	
Moderate	6	8	9	2				
Mild	84	14	20	5				
Annual review in the last year	105	30	19	8	140	20	Data not provided	Data not provided
Inpatient admissions in the last year	5	2	1	0	30	2	Data not provided	Data not provided

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

Staffing: The service employs 18 professionals across adults and paediatrics, including six consultants (four adults, two paediatrics), six nurses (four adults, two paediatrics), one physiotherapist (0.2 WTE), three biomedical scientists, and three administrative staff (two adults, one paediatrics). The Service does not employ a psychologist. The proportion of medical time attributable to bleeding disorders is unclear.

Key staff include Consultant Haematologist and Centre Director Dr Steve Austin, and Lead Nurse Wandai Maposa.

Outpatient care: All haemophilia services are primarily provided within the main hospital campus and comprise outpatient clinics, inpatient care and day unit facilities (for short treatments and tests). Telephone access to the haemophilia service is available Monday to Friday within working hours. Out of hours, a Specialist Registrar (SpR) is available to provide advice, with consultant backup.

Telephone consultations are available for patients with mild bleeding disorders, where appropriate. All new patients are seen by the Clinical Nurse Specialist (CNS) for consultation, review of their family history, and blood tests prior to meeting with the consultant. Regular multi-disciplinary team (MDT) health reviews are offered for adults and paediatrics in established clinics. Specialist joint orthopaedic and hepatology MDT clinics are also available for patients when needed.

Specialist community care is managed from within the Haemophilia Centre. This encompasses supervision of home treatment programmes, and the control and supply of factor concentrate. The Haemophilia Centre manages its own coagulation factor concentrate inventory, including ordering, storage within secure temperature-controlled refrigerators on site, and supply to patients.

The trust offers a walk-in service for adults and children during office hours.

Inpatient care: Appropriate to the presenting condition and access to inpatient haematology beds when required is uncomplicated.

Out of hours: A 24/7 out-of-hours telephone advice and information service is available with consultants specialised in haemostasis and thrombosis. All emergency patients are admitted via the Emergency Department (ED).

Transition: A dedicated 6-weekly Multidisciplinary Transition clinic is held in the Children's Outpatients. The Paediatric Haemophilia CNS acts as the key worker for transition, utilising the READY STEADY GO program through a telephone clinic to prepare adolescents for transition to the adult services. Where necessary, involvement from the learning disabilities team or other professional expertise is required to support young adults with additional needs.

Network arrangements: Whilst the Service is part of the South London Bleeding Disorders Network (for adults and children), the Service should have a more formalised link with a CCC, which includes regular lines of communication and formal network meetings. The Service is a designated spoke in a hub and spoke model, in which St Thomas' and The Evelina act as the hub.

The development of functional, integrated networks is important, and this is exemplified in the paediatric service, where regular expertise and shared care arrangements are in operation on a daily basis. Joint MDTs and multi-site assessments are commonplace. In the adult service, collaborative working within the network has allowed for the transition to non-factor therapy to be the mainstay in a large proportion of severe Haemophilia patients. Shared care arrangements remain in place. Inpatient transfers from GSTT to SGH have occurred in cases requiring tertiary referral obstetric care when unexpected IT service issues arose locally. Recent funding for dedicated social care across the region will further support an integrated service.

The current review did not seek evidence of the network's role or evidence of running a network.

4 Quality Standards

4.1 Overview

The table below outlines the status of each standard—met (green), partially met (yellow), or not met (red). Overall, the Service has met 23 out of the 30 standards, with six partially met and one unmet. The Service has outstanding findings from their previous peer review report in similar areas, which are provided in the appendix. The service is encouraged to review all descriptive assessments in addition to the key findings. This report, alongside local assessments, should steer discussions with the management team, highlighting areas of good practice while emphasising where further investment and improvement may be required.

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

Standard	Title of standard	Rating
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 whole team is motivated and committed, with evidence of going above and beyond what is expected in terms of service delivery and patient support for a Haemophilia Centre.
2. The feedback from patients seen on the day of the review was outstanding.
3. The review team were very impressed by the Service and felt that it could operate within the expectations of a CCC, if it had sufficient staffing to meet the requirements of a CCC.

4.3 Immediate risks

There were no immediate risks identified.

4.4 Concerns

Overall, the Service provides excellent care; however, the review team wishes to highlight some key concerns that were also raised in the 2019 peer review, specifically regarding consultant, physiotherapy, and psychology staffing. Substantial progress has been made in other areas.

1. Whilst the Service employs a physiotherapist, who has input into haemophilia patients through acute reviews and joint assessments, they are only employed 0.2 WTE Adults and 0.2 WTE Paediatrics, which is inadequate for the size of the patient cohort. Physiotherapy is required not just for joint assessments but also for rehabilitation and long-term care of joint health.
2. The Service does not have a psychologist specialising in bleeding disorders, which is a particular concern because St George's serves a large population affected by the findings of the Infected Blood Inquiry (IBI). Paediatric patients have access to the paediatric psychology service, and the Haematology dedicated psychologist attends the weekly paediatric MDTs. St George's has not received any infrastructure funding to support adult psychological services.
3. The peer review team is concerned about the fragility of the paediatric service. There is an insufficient amount of consultant paediatric Haemostasis time. Whilst currently there is one substantive and one locum consultant paediatric haematologist, there is a need for either increased time for paediatric haemophilia within existing job plans or another substantive paediatric consultant haematologist. There are two substantive Paediatric Haematology consultants, and a vacant post that requires recruitment. The proportion attributable to bleeding disorders is unclear.
4. One haemophilia / Obstetric clinic a month was deemed inadequate for a haemophilia centre linked with a maternal medicine centre, especially one that serves a large geographical area.

5. There was insufficient evidence of coordinated working between paediatric and adult services at the time of the review. Although the hospital offers a lifespan service, it is actually divided between two departments, and evidence of integrated working was not clearly visible.

4.5 Recommendations

This section presents the review team's recommendations and addresses the concerns detailed above.

1. **Physiotherapy Provision:** The review team recommend an increase in physiotherapy provision to at least 0.6 to 0.8 WTE, taking into account the complexity of the cohort overseen by the centre.
2. **Psychology & Social Work Provision:** The review team recommends increasing dedicated haemophilia-specific psychology provisions so that patients, children, and their carers can benefit from more timely support for bleeding disorders. The review team also recommend clarification of the provision of support for infected and affected patients within the service.
3. **Paediatric Consultant Support:** The children's service remains fragile, and delivery of comprehensive care requires additional consultant input for paediatric haemophilia. Further, there is limited evidence of joint working between the adult and paediatric services.

4.6 UKHCDO Advisory Committee Recommendation

1. The UKHCDO advisory committee also recommends conducting a full options appraisal of the paediatric service, as the number of registered paediatric patients is small. This will help ensure the long-term, sustainable delivery of comprehensive care. Progression to full CCC status will also require the appointment of additional physiotherapy support and clearer lines of accountability for the paediatric component of the service.

5 Quality Standards – Detailed Description

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

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

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

Evidence provided for the above QSs and information provided via the website. There are shared care arrangements for emicizumab with St Thomas' as the centre is HC.

Quality Standard 2: Condition-Specific Information

Partially Met

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

a. A description of their condition and how it might affect them
b. Problems, symptoms, and signs for which emergency advice should be sought
c. Genetics of Inherited Bleeding Disorders
d. Testing for carrier status and the implications of being a carrier
e. Treatment options including on-demand, prophylaxis, home therapy and the use of Haemtrack
f. How to manage bleeding at home
g. Ports, fistulae, and in-dwelling access devices (if applicable)
h. Approach to elective and emergency surgery
i. Women's health issues
j. Dental care
k. Travel advice
l. Vaccination Advice
m. Health promotion to include smoking cessation, healthy eating, weight management, exercise, alcohol use, sexual and reproductive health, and mental and emotional health and well-being
n. Sources of further advice and information

Condition-specific information should be available covering:

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

How the Service meets or does not meet the standard

Patient information booklets in use are either from the Haemophilia Society or industry partners, which are comprehensive and clear. There is no information on BDUC, nor any separate material on health promotion. More details about venous access devices would have been beneficial.

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

Clinic letters were provided, very clear and comprehensive, addressing the above QSs.

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

Documentation for nurse-led review of new patients. Evidence provided for the above standards.

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

Contact details for the centre are included on the bleeding disorder card, clinic letters, and are also available on the Trust website.

Evidence has been gathered from visits, presentations, patient interviews, and documents. There are clear pathways for patients to contact the service and for urgent review of those presenting acutely.

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

Evidence presented in relation to Haemtrak feedback and written information; no information was provided on the level of patient compliance.

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.

Standard Met

How the Service meets or does not meet the standard	
Evidence from the visit, tour of facilities, interview with staff and patients and the director's presentation.	

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	
The transition process is initiated and coordinated by the paediatric team using the Ready, Steady, Go transition programme, with a designated CNS coordinator. Evidence of documentation related to the transition was observed on the day. Additionally, evidence was gathered from interviews with staff and patients.	

Quality Standard 9: Carers' Needs

Carers should be offered information on the following: a. How to access an assessment of their own needs b. What to do in an emergency c. Services available to provide support	Standard Met
How the Service meets or does not meet the standard	
Evidence derived from written documentation, interviews with staff and service users.	

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

Evidence from friends and family, as well as internal feedback exercises. Evidence given of service improvement in response to patient 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.

Partially Met

How the Service meets or does not meet the standard

The lead consultant, Steve Austin, has dedicated PAs in his job plan, and the lead nurse is also in post, with dedicated time allocated for service management.

The paediatric lead for the service has also been identified; SA has leadership for both paediatric and adult services. Although there are designated roles, evidence of joint working was not presented during the peer review. Indeed, the presentation mainly focused on the adult service, as the children's service had staffing challenges at the time of the peer review.

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.

Partially Met

Staffing should include:

a. Medical staff:
    i. Consultant specialising in the care of people with inherited and acquired bleeding disorders available during normal working hours
    ii. On-call consultant specialising in the care of people with inherited and acquired bleeding disorders 24/7 in HCCC
    iii. On-call haematology consultant with arrangements for advice from a consultant specialising in the care of people with inherited and acquired bleeding disorders in HC
b. Specialist nursing staff:
    i. Bleeding disorders specialist nurses (5/7)
    ii. Ward, outpatient, and day unit staff with competences in the care of people with inherited and acquired bleeding disorders
c. Clinical specialist physiotherapist
d. Practitioner psychologist or appropriately trained psychotherapist with specialist knowledge in IBDs.
e. Access to specialist senior social worker
f. Data manager
g. Biomedical scientist and/or clinical scientist (further details on the requirements are included in QS 17)

How the Service meets or does not meet the standard

There is a 1-in-5 rota system in place for adult H&T consultants, with cross-cover between general haematology and H&T, ensuring 24/7 medical expertise (first-on/second-on system). This was clarified post-review and includes an internal hybrid rota of the paediatric consultants and the Haemophilia centre director, providing 24/7 provision initiated on July 25.

There are adequate CNSs in post, and most appear to have had specific induction.

The very limited physiotherapy provision of 0.2 WTE for adults and similarly for children, and the adult physiotherapist at the time of review was on secondment.

There is no specialist adult psychology service, but access to a dedicated paediatric psychology service is available. Local agreements with a non-profit organisation are in place, and referrals can be made to St Thomas' as necessary. Similarly, social work access is very limited. One full-time equivalent (1.0 WTE) of a data manager supports both adult and paediatric services. Additionally, three full-time Biomedical Scientists (BMS) are available to provide urgent FVIII and FIX assays, including an out-of-hours service.

Quality Standard 13: Service Competencies and Training Plan

a. All staff are to complete trust mandatory training, including regular appraisal.
b. All clinical staff to have CPD relevant to bleeding disorders
c. All new nurses/AHP/Psychologists to have the opportunity to attend an introduction to bleeding disorders course and the contemporary care course provided by the Haemophilia Nurses Association
d. All specialist clinical staff to have the opportunity to attend national and/or international conferences and to develop subspecialist interests

Standard Met

How the Service meets or does not meet the standard	
Evidence of mandatory training and CPD noted for relevant staff. Evidence of Haemnet HNA and contemporary care evidence for the CNSs was seen. There are opportunities to attend relevant conferences.	

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 manager provides cross-cover across adults and paediatrics, with a clear explanation in self-assessment regarding roles and responsibilities.	

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	
Written evidence and information from the site visit regarding play therapy and pharmacy. No information submitted in relation to dietetics and orthotics. There are paediatric and adult services for orthotics and dietetics, as well as a CEW (clinically excessive weight) service in paediatrics.	

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	
ED pathways for adults and paediatrics were reviewed through a recent audit of attendance and treatment times. As a result of the audit, additional educational sessions for ED staff were planned.	

Quality Standard 17: Laboratory Service

a. A UKAS accredited laboratory service with satisfactory External Quality Assurance performance should be available 24/7 b. A laboratory representative (senior biomedical scientist or clinical scientist) should attend inherited and acquired bleeding disorder service multidisciplinary team meetings (QS 25) regularly c. The following tests should be available in a timely manner for the diagnosis and management of inherited bleeding disorders: i. All coagulation factor assays ii. Inhibitor screening iii. FVIII inhibitor quantification iv. VWF antigen v. VWF activity vi. Platelet function testing d. Pathway for referral to molecular Genetic Laboratory service for: i. Detection of causative mutations in PwBD ii. Carrier detection iii. Discussion of results in genomics MDT when needed	Standard Met
How the Service meets or does not meet the standard	
The lab is UKAS-accredited and provides the relevant tests.	

Quality Standard 18: Specialist Services

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	Standard Met

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 in written form, through staff interviews, and via the director's presentation. No evidence was submitted regarding the care of older persons, pain management, or rheumatology. These services are available on an as-needed basis.

Standard Met

Quality Standard 19: IT System

IT systems should be in use for:

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

How the Service meets or does not meet the standard

There is an SOP for haemophilia data reporting and trust-wide for vCJD.

Standard Met

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

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

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

How the Service meets or does not meet the standard

Comprehensive guidelines for adults and paediatric patients, covering all specified areas and including some paediatric-specific guidance such as non-accidental injury.

Standard Met

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

Comprehensive guidance covering factor and non-factor concentrates, including a referral form to St Thomas' for emicizumab. Evidence provided includes details on stock control and Haemtrack returns.

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

All the above guidelines were seen.

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

A clear template for surgical procedures and pathways is documented in the central guideline document.

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

Partially Met

How the Service meets or does not meet the standard

MDT documentation and processes are clear, and clear policies are available for lone working and community care.

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

Weekly MDTs review inpatients, planned surgeries, and other related issues. Evidence was gathered from directors' presentations, staff interviews, and a review of job plans. A Local Paediatric MDT meets weekly on Tuesday mornings, and a regional network MDT occurs monthly, or as needed, on the same day. There is a National Paediatric Haemophilia MDT that takes place quarterly. Additionally, there is a fortnightly paediatric meeting to discuss results and follow up on complex cases.

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

Partially Met

How the Service meets or does not meet the standard

Insufficient time in the obstetrician and haematologist's job plan for the formal delivery of haematology/obstetric care within a maternal medicine centre. For a maternal medicine centre, there should be more than one clinic a month to deliver the required work fully. We recommend increasing the number of clinics dedicated to haematology and obstetric services.

Quality Standard 27: Data Collection

The following data should be collected:

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

Standard Met

How the Service meets or does not meet the standard	
NHD outcomes are clearly visible, including examples of reporting to the dashboard and adverse event reporting to NHD.	

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	
Examples of research activities related to PwBd, including the PICC site for the Glanzmann study and EHL follow-up, with dedicated time in the centre director's job plan.	

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	
No evidence of an audit plan, need for more regular audits to be embedded in the department. We have plans for setting up a regular Haemostasis quality meeting to address other governance issues. No evidence of joint working across adult and paediatric services was provided at the time of the review.	

Quality Standard 30: Document Control	
All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Not Met
How the Service meets or does not meet the standard	
Need to align document control policy with trust guidance once this has been established.	

6 Acknowledgements

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

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

7 Appendices

7.1 Definitions

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

7.2 Peer Review Team

The Peer Review Team consisted of two consultant haematologists, a clinical nurse specialist, and a research nurse. Details of the Peer Review Team are held by UKHCDO.

7.3 Outstanding findings from previous peer review

The table below provides details of the issues that were raised in the previous peer review report of 2019 that have also been raised in this review. These have been highlighted here to add strength to the recommendations in this report as these issues should be addressed as a matter of priority. The Trust should ensure that appropriate resources are made available so these outstanding issues can be resolved.

Ref. Number	Statement of original finding
1	Staffing
a	Senior medical staff 1. Adult Haematologist - The Centre director worked for three days a week at the St George's Hospital site, the other two days was based at St Thomas' Hospital Comprehensive Care Centre at Guy's and St Thomas' NHS FT. Two other haematologists worked in the service but only for one PA each, giving eight PA's in total. A fourth post had been agreed and advertised, with an additional four PA's for the bleeding disorders service, but it had not yet been possible to appoint to this post. This meant that there were times when no adult consultant haematologist was working on site in this service. 2. Paediatric Haematologist – Although there was funding allocated for two WTE consultant posts, at the time of the review there was a single lead consultant in the service. She was covering all of the out-of-hours periods, except for periods of leave when the consultants at Great Ormond Street CCC covered for her. In practice, it had been demonstrated that work intensity was low, however this was not a feasible long-term arrangement. There was concern about the sustainability of both the adult and paediatric services, which were each dependent on a single consultant. Reviewers also heard that sometimes there appeared to be insufficient time in the lead consultants' working weeks for communication within the adult team, and between the paediatric and adult teams.
b	In both the paediatric and the adult services, the physiotherapists' allocated time only allowed them to join the team for weekly multi-disciplinary clinics. In the paediatric service, there was no cover for leave, and if a child presented with a joint bleed, he or she was not always able to see the therapist until the next clinic session, which could be up to a week later. In the adult service, two therapists each offered one allocated session so there was cover, and some flexibility within the MSK team, but again there was insufficient time to work with patients presenting with acute bleeds between clinic sessions. Neither the adult nor the paediatric team had enough allocated physiotherapy time to provide a comprehensive service to the agreed UK standards as outlined by the Haemophilia Chartered Physiotherapists Association.
d	Psychosocial care 1. The adult service had no named psychologist working with the team; referrals could be made to the general hospital psychology service, but these were usually only for the highest-level needs, and lower-level patient or carer needs were likely to be unmet. In addition, the team lacked the internal support which a psychologist member brings and were unable to work in the fully multiprofessional way expected in the care of these long-term patients. 2. The paediatric service had a named senior psychologist, but the psychologist did not have dedicated time to offer these children and families. This was inequitable as there were dedicated sessions available for several other patient groups with long-term conditions, including asthma, haemoglobin disorders, and in the oncology service. Some very useful work had been undertaken with individual children with haemophilia, and there was frustration that valuable additional support could not be offered.

	3. There was no named social worker in either the adult or the paediatric team. In a geographical area where there are pockets of significant deprivation, patients and families would benefit greatly from the support of a knowledgeable, engaged social worker.