UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

UKHCDO Haemophilia Peer Review Audit Report

Great Ormond Street Hospital for Sick Children Haemophilia Comprehensive Care Centre

Haem-Psych Association UK & Ireland
Haemophilia Nurses Association UK
HCPA Haemophilia Chartered Physiotherapist Association
Haemophilia Scotland
The Haemophilia Society
Haemophilia Wales
Haemophilia NI Supporting patients and families

Report Date: 20 June 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 Great Ormond Street Children's Haemophilia Comprehensive Care Centre (the Service) was completed on 19th April 2024. The centre is located within the Haematology service of Great Ormond Street Hospital for Sick Children.

The Service successfully met 26 of the 30 established standards, with three standards partially met and one remaining unmet. The commitment of both the Centre and the Trust to providing high-quality care was evident through various initiatives and clinical pathways. However, key recommendations have been made to help address the gaps that affect the ability to deliver comprehensive care.

Key Recommendations:

1. **Facilities management (Walk-in fridge):** The review team identified a significant concern related to the inoperability of the service's dedicated walk-in fridge, which has resulted in the storage of temperature-controlled medications across three locations, thereby increasing waiting times and clinical workload. The review team strongly recommends that repairs to the walk-in fridge be expedited, as this could have a detrimental impact on the treatment of patients.
2. **Psychology services**: The review team recommends examining the restricted psycho-social support available to children and families affected by a bleeding disorder. These are inherited, lifelong conditions that carry burdens both from the disease itself and its treatment regimens. Early interventions by psychologists experienced in this field can offer support that influences how the individual and their family approach and manage their condition.

This review has identified gaps in haemophilia services that 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 supports the Centre and the Trust in delivering high-quality haemophilia care.

2 Haemophilia and Bleeding Disorder Peer Review - Background

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

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

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

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

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

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

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

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

3 Service Description

The peer review took place on 19th April 2024 at the Haemophilia Centre, Level 5, The Royal London Hospital for Integrated Medicine, Great Ormond Street, London. A multidisciplinary team of haemophilia professionals, alongside patient representatives, conducted the review, which involved discussions with staff from the Service, reviewing documentation, and touring the facilities.

GOSH provides care to children with bleeding disorders and has 755 registered patients. The service is the largest children's bleeding disorder centre in the UK, serving a large and ethnically diverse population in north London, as well as south London and the South and East coasts. The service occupies the fifth floor of the Royal London Hospital for Integrated Medicine and is open daily from 08:30 to 17:00. It has strong links with the Royal London (where Dr Sibson holds a clinic once a month) and the Royal Free (where Dr Mathias runs an adolescent and young adult clinic weekly).

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		102		20		183		318
Moderate		17		5				
Mild		62		15				
Annual review in the last year		158		35		147		311
Inpatient admissions in the last year	29							

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

Staffing: The Service employs 14 healthcare professionals in a combination of full-time and part-time roles, including four medical consultants (4 WTE), three haemophilia nurses (3 WTE), two physiotherapists (1.6 WTE), two coagulation laboratory biomedical scientists (2 WTE), and three administrative staff (3 WTE).

Key staff include Consultant Haematologist and Centre Director Dr Mary Mathias, and lead Nurse Julia Spires.

Outpatient care: There is open access to the service from 08:30 to 17:00, Monday to Friday, with outpatient clinics running every day.

Inpatient care: Patients are admitted to the appropriate ward for the presenting cause for admission.

Out of hours: An on-call haematology registrar is supported by a Haemophilia Consultant to cover patients with bleeding disorders. There is no onsite Emergency Department; instead, families are triaged by telephone and, if necessary, advised to go to the nearest emergency department.

Transition: There are strong pathways and cross-service appointments in place with the Royal Free Hospital and the Royal London Hospital, allowing for a seamless transition through to young adulthood.

Network arrangements: There are currently no formal networks in place; however, a close working relationship exists with other London Centres.

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 26 out of the 30 standards, with three partially met and one unmet. There are no outstanding actions from the previous peer review. 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	🟩

Standard	Title of standard	Rating
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 facilities encompass a large area with ample rooms for the GOSH team and for reviewing patients. This has enabled a flexible service where daily clinics are conducted.
2. All staff, from administration to medical, nursing, and laboratory, are enthusiastic and highly motivated to support families. Multiple team members are engaged in both national and international projects.
3. Patient feedback from the brief survey and verbal reports was excellent, reflecting a strong rapport and trust between the patients and the GOSH team.
4. There is an extensive research portfolio, including clinical trials as well as investigator-led physiotherapy and nurse-led research projects.
5. The implementation of a transition tab ensures the delivery of appropriate knowledge during the transition to adult services. The model of cross-service appointments with the Royal Free and the Royal London hospitals facilitates a seamless transition for many patients and families.

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 lack of a dedicated walk-in fridge is due to delayed repair work, which has no definite timescale for completion and impacts the patient pathway. The service currently has stock stored in three locations; the majority is kept in a cooled room. This cooled room is not secured, allowing anyone in the Haemophilia unit to access it. However, since the review, the service has confirmed that repairs will be taking place imminently, though they will not be completed until the end of October.

2. While patients can obtain general psychology support from the main hospital, there is no specific psychology service for those with haemophilia. As a result, patients might face waits of 7 to 8 months for non-urgent psychological care, which is unacceptable. Providing psychological support is essential to comprehensive care for individuals with bleeding disorders. These inherited, lifelong conditions can affect multiple family members, and parents must manage complex treatment regimens. There's a recognised burden associated with both the disease and its treatment; thus, early intervention to address emerging issues can significantly enhance the quality of life for patients and their families, as well as improve engagement with services and adherence to lifelong treatment regimens.
3. There is no Emergency Department (ED) at GOSH. Patients must contact the service and attend their local District General Hospital (DGH) for out-of-hours or emergency care. Families who spoke to the review team reported poor experiences when accessing the ED at local DGHS. The review team believed that more could be done to provide information to families to support them in accessing these services.
4. The review team believed that there was insufficient evidence of a robust audit programme to support learning and service development.

4.5 Recommendations

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

1. **Facilities management (Walk-in fridge):** The review team identified a significant concern regarding the inoperability of the service’s dedicated walk-in fridge, which has resulted in the storage of temperature-controlled medications across three locations. The review team strongly recommends that the trust expedite repairs to the walk-in fridge, which has been raised as a risk by the service as this could have a detrimental impact on patient treatment.
2. **Psychology service provision:** There needs to be provision for dedicated psychological support for children and families affected by inherited bleeding disorders in the form of a part-time consultant.
3. **Emergency treatment pathways:** The current provision of patient-held information for attending DGHs should be reviewed to facilitate prompt and safe interventions at a local level in collaboration with the GOSH team whenever possible. Options for educating the various DGHs should also be explored.
4. **Audit:** The Service should consider implementing a more robust audit programme to provide opportunities for team learning and ongoing service improvement.

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

Standard Met

Written information should be offered to people with bleeding disorders (PwBD) and, where appropriate, their carers covering at least:

a. Brief description of the Service
b. Clinic times and how to change an appointment
c. Ward usually admitted to and its visiting times
d. Staff of the Service
e. How to access physiotherapy and psychology
f. Relevant national organisations and local support groups
g. Where to go in an emergency and how to access out of hours services
h. Information on delivery of products, including company contact details

How to:

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

How the Service meets or does not meet the standard

Service information is accessible onsite with the citizens' advice. Patients interviewed were uncertain about how to get involved, although there are instances of feedback from families and actions taken in response. There are no leaflets containing contact numbers for home care, despite verbal evidence indicating that this was provided during clinic visits.

Quality Standard 2: Condition-Specific Information

Standard Met

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

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

l. Vaccination Advice
m. Health promotion to include smoking cessation, healthy eating, weight management, exercise, alcohol use, sexual and reproductive health, and mental and emotional health and well-being
n. Sources of further advice and information

Condition-specific information should be available covering:

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

How the Service meets or does not meet the standard

Leaflets are available for most conditions, and a leaflet addressing women’s issues should be developed as part of transition care.

Quality Standard 3: Plan of Care

Standard Met

Each PwBD and, where appropriate, their carer should discuss and agree on their Plan of Care that is age-appropriate and should be offered a written record covering:

a. Agreed goals, including lifestyle goals
b. Self-management
c. Planned assessments, therapeutic and/or rehabilitation interventions
d. Early warning signs of problems, including acute exacerbations, and what to do if these occur
e. Agreed arrangements with the school or other education provider
f. Planned review date and how to access a review more quickly, if necessary
g. Who to contact with queries or for advice

The plan of care should be reviewed at each clinic appointment or at other times if clinically relevant.

The plan of care should be communicated to the PwBD GP and other relevant service providers involved in their care.

How the Service meets or does not meet the standard

Clinic letters address all aspects effectively. There is good utilisation of smart phrases on EPIC. However, there is no evidence that lifestyle goals are addressed. The My GOSH app is available for electronic copies of letters.

Quality Standard 4: Outpatient review of PwBD

Standard Met

A formal review of PwBD should take place regularly:

a. For those with severe and moderate haemophilia, any PwBD on prophylaxis and other severe bleeding disorders at least twice a year. This may be more frequent in the paediatric setting based on clinical needs.
   The following multidisciplinary clinic arrangements for these PwBD should be in place:
   i. Involvement of medical, specialist nursing and physiotherapy staff in clinics
   ii. Availability or clear referral pathway for social work and psychology staff
b. For those with mild bleeding disorders, the Centre should have a documented follow-up pathway with a plan for managing DNA and PIFU if used. These PwBD should have access to the full MDT if clinically required but may not be seen in a combined clinic.

This review should involve the PwBD and, where appropriate, their carer.

The outcome of the review should be communicated in writing to the PwBD and their GP.

How the Service meets or does not meet the standard

Evidence of outstanding reviews from medical, nursing, and physiotherapy teams.

Quality Standard 5: Contact for Queries and Advice

Standard Met

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

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

How the Service meets or does not meet the standard

Contact information is clear in all correspondence. The uptake for MyGOSH (GOSH-specific patient portal) is not evident. Patients have open access to the service through daytime contact numbers for centre staff, a walk-in service during regular working hours, and an out-of-hours service to the on-call haematology doctor.

Quality Standard 6: Haemtrack (PwBD on Home Therapy)

Standard Met

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

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

How the Service meets or does not meet the standard

There is evidence that staff are encouraging patients to use Haemtrack. The uptake stands at 67%, which is below the target of 80%. Further encouragement may be beneficial.

Quality Standard 7: Environment, Facilities and Equipment

Not 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 purpose-built centre is spacious; however, the MDT room is relatively small, despite much of the work now being conducted online.

There is no walk-in secured fridge, with treatment distributed across three separate fridges; however, the most commonly used ones are stored within the haemophilia unit in a temperature-controlled room. This chilled room is unsecured, allowing anyone in the haemophilia unit to access it, as shown by the review team, who were able to walk in twice while it was left unattended. There is no definite timescale for the repairs.

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 a clear policy and joint clinics in place. There is no youth worker or evidence of support after the transition, but a note is made of the joint appointments, which allows for ongoing support.

Quality Standard 9: Carers' Needs

Standard Met

Carers should be offered information on the following:

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

How the Service meets or does not meet the standard

The review team agrees with GOSH's self-assessment that this standard is met based on the evidence reviewed.

Quality Standard 10: Involving PwBD and Carers

Standard Met

The Service should have:

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

How the Service meets or does not meet the standard

GOSH employs a concise local form, and the feedback has been outstanding.

Patients felt engaged in their care, with verbal evidence of how their input is valued.

However, there is no system in place for including carers in service organisations.

Quality Standard 11: Leadership team

Standard Met

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

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

How the Service meets or does not meet the standard

There is an active leadership team, and everyone felt they had ample time in their job plans to deliver and develop services.

Quality Standard 12: Staffing levels and skill mix

Partially Met

a. Sufficient staff with appropriate competences should be available for outpatient, day unit and in-patient care and support to urgent care services. Staffing levels should be appropriate for the number of PwBD cared for by the Service and its role in the network.
b. All staff should undertake regular continuing professional development that is relevant to their work in the inherited and acquired bleeding disorders services.
c. Staff working with children and young people should have competences in caring for children as well as in the care of people with bleeding disorders. Cover for absences should be available.
d. In HCCCs, these staff should have sessional time allocated to their work with the IABD service. In HCs, the arrangements for accessing staff who do not have sessional time allocated to the IABD service should be clearly defined.

Staffing should include:

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

f. Data manager
g. Biomedical scientist and/or clinical scientist (further details on the requirements are included in QS 17)

How the Service meets or does not meet the standard

There is excellent medical, nursing, and physiotherapy staffing. The service is consultant-led, and the haematology registrar could be more engaged in-service delivery for their education.

Although there is a designated psychologist, there is no dedicated time for bleeding disorders, and patients may see one of the psychologists without continuity. Patients may end up waiting 7–8 months for psychological support. A dedicated social worker is in post.

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

There is no written evidence for the haem registrar; however, after discussion, it became evident that this aspect is included in the lab's induction training. Opportunities to attend conferences are provided and are sufficient.

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 Band 6 manager operates in a unit with adequate time.

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 good access to all the services mentioned above. However, the dietitian leaflet is the one used for cystic fibrosis.

Quality Standard 16: Emergency Department

Partially Met

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

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

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

How the Service meets or does not meet the standard

There is no Emergency Department (ED) at GOSH. Patients contact the service and attend their local District General Hospital (DGH) for out-of-hours or emergency care. The families who spoke to the review team reported poor experiences when accessing the ED at their local DGH.

The review team believed that more could be done to provide information to families to assist them in navigating these services. Exploring various options, including more education and training that could be delivered locally, such as guidance on accessing local policies, videos demonstrating how to mix and administer treatments, improved handheld information, and liaising with adult services, may prove beneficial. Other options could even include the use of Haemtrack.

Quality Standard 17: Laboratory Service

Standard Met

a. A UKAS accredited laboratory service with satisfactory External Quality Assurance performance should be available 24/7
b. A laboratory representative (senior biomedical scientist or clinical scientist) should attend inherited and acquired bleeding disorder service multidisciplinary team meetings (QS 25) regularly
c. The following tests should be available in a timely manner for the diagnosis and management of inherited bleeding disorders:
    i. All coagulation factor assays
    ii. Inhibitor screening
    iii. FVIII inhibitor quantification
    iv. VWF antigen
    v. VWF activity
    vi. Platelet function testing
d. Pathway for referral to molecular Genetic Laboratory service for:
    i. Detection of causative mutations in PwBD
    ii. Carrier detection
    iii. Discussion of results in genomics MDT when needed

How the Service meets or does not meet the standard

The lab staff are very engaged and motivated.

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

All necessary services are readily available when needed. The service provides access to preventative dental care when it is not available within the community.

The service encourages families to have regular check-ups in the community, as a) it is more convenient, and b) the GOSH dental team must prioritise preventive care for children with complex, multisystem medical conditions. When the service requires a patient to be seen, they are attended to, but waiting times can be lengthy.

Quality Standard 19: IT System

Standard Met

IT systems should be in use for:

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

How the Service meets or does not meet the standard

Good use of EPIC with all documentation recorded clearly.

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

Standard Met

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

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

How the Service meets or does not meet the standard

All guidelines are available.

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

There are comprehensive local policies in place.

Quality Standard 22: Clinical Guidelines/Pathways

Standard Met

The following clinical guidelines/pathways should be in use:

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

How the Service meets or does not meet the standard

Relevant clinical pathways are in place.

Quality Standard 23: Guidelines on Care of PwBD requiring Surgery

Standard Met

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

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

How the Service meets or does not meet the standard

Standard operating procedures for managing surgery are in place.

Quality Standard 24: Service Organisation

Standard Met

The Service should have an operational procedure covering at least:

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

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

How the Service meets or does not meet the standard

Patients felt well-informed about their journey and the next steps in their care. Nurses provide community visits as required. Members from all areas of the multi-disciplinary team attend the MDT.

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

MDT records are created in patient notes and shared in the clinic or by nurses.

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

All are available but may not be on-site at GOSH.

Quality Standard 27: Data Collection

Standard Met

The following data should be collected:

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

How the Service meets or does not meet the standard

All standards were met.

Quality Standard 28: Research

Standard Met

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

How the Service meets or does not meet the standard

Good research portfolio with active recruitment.

Quality Standard 29: Multidisciplinary Review and Learning

Partially Met

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

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

How the Service meets or does not meet the standard

The audit portfolio is relatively small and old, and a more robust rolling programme is encouraged.

Quality Standard 30: Document Control	
All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Standard Met
How the Service meets or does not meet the standard	
All policies are signed off via trust procedures.	

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, 2 clinical nurse specialists, a clinical specialist physiotherapist and a patient representative. Details of the Peer Review Team are held by UKHCDO.