UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

UKHCDO Haemophilia Peer Review Audit Report

Manchester Children's Haemophilia Comprehensive Care Centre

Haemophilia Nurses Association UK

HAEM-PSYCH ASSOCIATION UK & IRELAND

HCPA Haemophilia Chartered Physiotherapist Association

HAEMOPHILIA SCOTLAND

The Haemophilia Society

HAEMOPHILIA WALES

Haemophilia NI
Supporting patients and families

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1 Executive summary

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

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

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

The executive summary provides the key findings, and the full report details the audit assessments referenced against these standards. The peer review for the Manchester Children's Haemophilia Comprehensive Care Centre (the Service) was completed on 16th May 2024. The Centre is located within the Royal Manchester Children's Hospital, part of Manchester University NHS Foundation Trust.

The Centre successfully met 24 of the 30 established standards, with six standards partially met. The Centre's and the Trust's commitment to providing high-quality care was evident through various initiatives and pathways. However, key recommendations have been made to address gaps that impact the ability to deliver comprehensive care.

Key Recommendations:

Consultant staffing: The review team strongly suggests finding a sustainable solution to fill the gaps in consultant staffing. Current measures for covering long-term sickness or absence are unsustainable and could present future risks to patients.

Physiotherapy staffing: Support at 0.2 full-time equivalent is minimal, and the individual currently in post goes above and beyond to provide excellent care. There is an urgent need to increase physiotherapy staffing in line with the size of the service.

Psychology service provision: The review team is concerned about the absence of a dedicated haemophilia psychologist with specialised expertise. While access to general psychology services is available, these do not always meet the specific needs of patients.

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 was undertaken on 16th May 2024 at the Royal Manchester Children's Hospital. A multidisciplinary team of haemophilia professionals, along with patient representation, conducted the review, which involved speaking to staff from the service, reviewing documentation, and touring the facilities.

The Service provides care to children and young adults with bleeding disorders, with 616 registered patients. It is part of the Royal Manchester Children's Hospital and serves the populations of Greater Manchester, Lancashire, Cheshire, and Cumbria. Outreach clinics are provided in Blackburn, Burnley, Lancaster (virtual), and Crewe.

3.1 Patient numbers

Number of patients	**Inherited bleeding disorders**							
	Haemophilia A		**Haemophilia B**		**von Willebrand**		**Other**	
	Adults	Children	Adults	Children	Adults	Children	Adults	Children
Severe	0	60	0	8	0	209	0	276
Moderate	0	7	0	4				
Mild	0	48	0	4				
Annual review in the last year	449							
Inpatient admissions in the last year	20							

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 is provided by a dedicated non-malignant team that covers Inherited and acquired bleeding disorders, thrombosis, ITP, haemoglobinopathy, marrow failure and cytopenias, laboratory haematology and consultative haematology.

The Service employs four consultants (2.0 X WTE for bleeding disorders), seven non-malignant haematology nurses (2.85 WTE for bleeding disorders), one physiotherapist (0.2 WTE), one full-time laboratory lead supported by coagulation laboratory biomedical scientists, four administrative staff (including centre administrator, data manager (0.93 WTE), data admin co-ordinator (1.0 WTE) and 2 x PA secretarial support to the consultants (1.68 WTE)). The Service does not have a dedicated haemophilia specialist psychologist, and access to general hospital services is limited. This blend of full and part-time roles ensures most aspects of comprehensive patient care are provided.

Key staff include Consultant Haematologist and Centre Director Dr John Grainger and Nurses Rachel McDermott and Michelle Pelling.

Outpatient care: The Service has a total of 616 registered patients, demonstrating a 12% growth since the last peer review. Patients with a severe bleeding phenotype are seen 3-6 monthly by a consultant, specialist nurse, physiotherapist and dentist. All other patients are reviewed at least yearly, either face-to-face or by telephone. Outreach clinics are provided in Blackburn, Burnley, Lancaster (virtual), and Crewe.

Inpatient care: Patients are admitted to the appropriate ward for their needs.

Out-of-hours: The out-of-hours provision is made via telephone to the ward. The Service is based on the same hospital site as the adult service and shares the same specialist laboratory services.

Transition: The Service is based on the same hospital site as the adult service and shares the same specialist laboratory services. The Service holds joint monthly MDT and transition clinics with the adult team. In general, most patients are transferred to adult services in the summer after completing their GCSEs at 16-17 years of age.

Network arrangements: There is no formal network. The service works very closely with adult CCC, which is a distinct service. There are named local paediatricians at district general hospitals who provide local paediatric support when needed and run joint clinics as outlined above. Teaching sessions are held every 3 months in conjunction with the Liverpool Service.

4 Quality Standards

4.1 Overview

The table below provides an overview of the standards met (green), partially met (yellow) and not met (red). Overall, the Service has met 24 out of the 30 standards, with six partially met. Some of the issues identified in this report have been outstanding from the last peer review and are listed in the appendix. Centres should ideally use this report to guide discussions with management, showcasing areas of good practice while highlighting those where further investment and improvement may be necessary.

Standard	Title of standard	Rating
1	Service Information	🟨
2	Condition-Specific Information	🟩
3	Plan of Care	🟩
4	Outpatient Review of PwBD	🟩
5	Contact for Queries and Advice	🟩
6	Haemtrack (PwBD on Home Therapy	🟩
7	Environment, Facilities and Equipment	🟨
8	Transition to Adult Services and Preparation for Adult Life	🟩
9	Carers' Needs	🟩
10	Involving PwBD and Carers	🟩
11	Leadership Team	🟩
12	Staffing Levels and Skill Mix	🟨

Standard	Title of standard	Rating
13	Service Competencies and Training Plan	🟨
14	Administrative, Clerical and Data Collection Support	🟩
15	Support Services	🟩
16	Emergency Department	🟨
17	Laboratory Service	🟩
18	Specialist Services	🟩
19	IT System	🟩
20	Diagnosis Guidelines for People with Suspected IABD	🟩
21	Guidelines: Treatment and Monitoring of IABD	🟩
22	Clinical Guidelines/ Pathways	🟩
23	Guidelines on Care of PwBD requiring Surgery	🟩
24	Service Organisation	🟩
25	Multidisciplinary Team Meetings	🟩
26	Multidisciplinary Clinics/ Liaison Services	🟩
27	Data Collection	🟩
28	Research	🟩
29	Multidisciplinary Review and Learning	🟩
30	Document Control	🟨

4.2 Good Practice

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

1. There was a high level of positive patient feedback, and the review team wanted to highlight the high level of trust that patients had in the clinical team.
2. The clinical nurse specialist provision is good, with the nursing team providing excellent care despite taking on the responsibilities of a Band 7 CNS without being recognised as such.
3. There is an excellent 'Did Not Attend' (DNS) policy in place.

4.3 Immediate risks

1. **Consultant Staffing: This issue was raised by the Peer Review Team in 2019 and remains unresolved.** The review team has serious concerns about the staffing levels of the consultants at the service. The service employs four consultants, one of whom is on long-term sick leave, and another is about to go on maternity leave. Neither of these posts has been filled at the time of review. If this situation continues, only two consultants (equivalent to 0.5 and 0.2 full-time positions) will be available to cover the service from July, which is not sustainable for meeting the needs of the children and families registered with the service. Such limited staffing presents a clinical risk and jeopardises ongoing service development. The issue of insufficient staffing was also raised by the Peer Review team in 2019.

4.4 Concerns

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

1. There seems to be some confusion regarding the out-of-hours pathway. The review team heard from one parent who stated that they would not phone the service out of hours, as they would not expect anyone to be available. This contradicts the standard operating procedure for out-of-hours care, which directs parents to call Ward 84. There appears to be a misunderstanding or a lack of awareness on the part of one or both parties.
2. A very limited physiotherapy provision has been observed. This concern was raised by the Peer Review Team in 2019 and remains unaddressed. The allocation of 0.2 whole-time equivalent physiotherapy cover means the team can only respond to patient needs rather than proactively addressing them.
3. There is no specialised haemophilia psychologist, meaning patients and their families only have access to general psychology services. This issue was raised during the Peer Review process in 2019 and remains unresolved.

4.5 Recommendations

This section outlines the recommendations provided by the review team in response to the concerns highlighted above.

1. **Consultant staffing:** The review team strongly recommends prioritising cover for the significant gaps in consultant staffing. The current level of consultant provision is unsustainable and presents a clinical risk to the service. It is recommended that a formal risk assessment be conducted, and the issue be added to the trust's risk register. An options appraisal should follow this to establish a robust strategy for the consultant workforce.
2. **Physiotherapy staffing:** Although the current physiotherapist delivers excellent care and goes above and beyond, the service remains reactive rather than proactive in meeting patient needs. Haemophilia is linked to joint bleeding, requiring comprehensive physiotherapy services to monitor joints effectively, manage acute bleeds, and provide ongoing support for physical activity and exercise. These interventions are vital to maintaining musculoskeletal health, protecting joints, and preventing long-term disability. The physiotherapy services need to be expanded to match the size and scope of the service, including sufficient cover for sickness and holidays.
3. **Psycho/Social service provision:** Access to general psychology services is limited, and the service lacks specialist support tailored to haemophilia patients. Since bleeding disorders are inherited, lifelong conditions with significant physical, emotional, and financial impacts on patients and their families, establishing dedicated haemophilia specialist psychologists and/or social workers is crucial. Appointing a psychologist with expertise in bleeding disorders is essential to address these specific needs.
4. **Out-of-hours service:** The review team recommends that the service review its out-of-hours procedure to ensure it accurately reflects current practices. This is important because parents and carers need to know what to do if they need to contact the centre outside of hours.

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

Partially 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

On how to access out-of-hours services, the system, as described, is to call the phone held by the Nurse in Charge of Ward 86. This information was identified as not known to some parents/carers. The Centre should ensure this information is emphasised to all parents and carers and included in the patient information leaflet.

The information presented comprised a combination of specific Haemophilia Unit patient information leaflets and more generic hospital-wide ones; it was clear and concise.

Quality Standard 2: Condition-Specific Information

Standard Met

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

a. A description of their condition and how it might affect them
b. Problems, symptoms, and signs for which emergency advice should be sought
c. Genetics of Inherited Bleeding Disorders
d. Testing for carrier status and the implications of being a carrier
e. Treatment options including on-demand, prophylaxis, home therapy and the use of Haemtrack
f. How to manage bleeding at home

g. Ports, fistulae, and in-dwelling access devices (if applicable)
h. Approach to elective and emergency surgery
i. Women's health issues
j. Dental care
k. Travel advice
l. Vaccination Advice
m. Health promotion to include smoking cessation, healthy eating, weight management, exercise, alcohol use, sexual and reproductive health, and mental and emotional health and well-being
n. Sources of further advice and information

Condition-specific information should be available covering:

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

How the Service meets or does not meet the standard

A wide range of information was inspected, including leaflets produced by the Haemophilia Society and locally produced condition-specific information.

However, no leaflet display was observed on the facility's walk-around.

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

The requirements for this standard were all in evidence.

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 presented for all quality standards required.

Quality Standard 5: Contact for Queries and Advice

Standard Met

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

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

How the Service meets or does not meet the standard

All requirements met; this information is present in the patient letters also.

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

Hospital policy requires completion of treatment on Haemtrack for the continuation of home delivery. Follow-up letters for non-compliance are issued. The provided datasheets show that only eight patients were non-compliant.

Quality Standard 7: Environment, Facilities and Equipment

Partially Met

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

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

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

How the Service meets or does not meet the standard

Evidence was presented for factor ordering/storage/stock control, and fridge procedures. Clinical and office space for staff is a challenge. The waiting area for patients was limited and, at times, inadequate.

A review of these issues by management is encouraged.

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

Evidence presented to all quality standards required.

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

Information on (a) and (b) is available in the general information sheet for patients. Services available for support (c) include referral to social work, psychology (through the general hospital service), or a GP.

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

The Centre undertakes at least an annual survey of patients/carers. It intends to establish a patient consultative board to be run jointly with adult services.

The patients/carers we met were generally highly satisfied with the service and support they received from the Centre.

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 competencies, undertake regular clinical work with the Service, and have a specific time allocated for their leadership role.

How the Service meets or does not meet the standard

An appropriate leadership team and an extremely committed and competent lead consultant. However, the review team is concerned about the lead consultant's ability to continue carrying out all the lead roles described if the staffing shortage is not addressed urgently (see the next section). Good evidence of Leadership from the Lead Consultant, with dedicated time allocated for weekly teaching and monthly service development meetings. Lack of other Consultant cover with arduous on-call duties could compromise the time available for this program.

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

Although there are four consultants, there are only two WTE; one of the consultants (0.8 WTE) is on long-term sick leave, and another (0.5 WTE) is about to go on maternity leave. Neither of these posts has been covered yet. If this situation continues, only two consultants (0.5 and 0.2 WTE, respectively) will be left to cover the service starting in July. This is clearly unsustainable and puts the clinical service at risk.

In terms of nursing, a team of seven nurses covers non-malignant haematology. However, only two of these are specifically responsible for bleeding disorders patients, and only one is band 7 (when clearly others are doing 'band 7' work). There is only 0.2 WTE allocated to physiotherapy, so this service can still only be reactive and needs additional provision.

There is no dedicated psychologist aligned to the service, and families only have access to generalised psychology services at RMCH. This is likely to create a relatively high threshold for referral. A couple of the families expressed that they would have taken up the offer of psychological support had it been more obviously available.

Quality Standard 13: Service Competencies and Training Plan

Partially Met

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

How the Service meets or does not meet the standard

Some staff members did not have evidence of mandatory training, regular appraisal, or relevant CPD at the time of the review.
(a) Yes (b) Could not see all the records (c) Yes, there is evidence of a Band 6 Nurse having attended the Introduction to Bleeding Disorders Course and the first part of the Contemporary Care Course (was unable to attend the next part of the course) (d) Yes for staff in post.

Quality Standard 14: Administrative, Clerical and Data Collection Support

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

How the Service meets or does not meet the standard

All requirements met.

Standard Met

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

How the Service meets or does not meet the standard

All requirements met.

Standard Met

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.

How the Service meets or does not meet the standard

Evidence for this standard was presented. The guideline is very clear, and training is in place. Just one caveat: a couple of the families mentioned that they weren't entirely clear on the pathway for who to contact out of hours, and for one family, there had been very long delays for treatment in ED on a couple of occasions, perhaps related to this.

Partially Met

This is partially met, as no electronic alert is visible in the ED at present; however, plans are in place to address this issue.

All patients have a care plan and who to contact out of hours. Patients are triaged by an onsite SPR and there is 24/7 consultant cover.

There is a training plan for ED staff. There is a clear pathway, but the review team did not see any audit information.

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

24/7 service for all coagulation tests (except platelet aggregation). All requirements met.

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 available, most with named leads.

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

Evidence of this standard is presented. IT systems are functional and fit for purpose.

The Electronic Patient Record System (HIVE) was introduced across the Trust in 2022. This brings together all patient records electronically from 10 hospitals within the Trust. MyMFT—a web-based portal—had some functionality enabled, but the full potential had not been implemented. When fully developed, the system will enable patients to access their test results and facilitate the integration of patient letters/care plans.

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 referenced guidelines are present and are very thorough.

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

Guidelines are in place and are detailed.

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 referenced. All guidelines were seen on the day except for vCJD for which a Trust guideline is available. The review team did not see the immune tolerance guideline but may have missed it on the day.

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

Evidence of this standard is presented.

All documentation seen. Clear and good.

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

Evidence of this standard is presented.

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

All requirements for this standard have been met, MDT documentation is excellent and very fit for purpose.

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

Requirements for this standard are all in place.

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

Some of these standards do not apply in a paediatric setting. Evidence of the requirements of this standard is in place and was seen on the tour of the facilities.

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

Evidence of this standard is presented. The service has a very active engagement in clinical trials, and evidence of this has been shown.

Quality Standard 29: Multidisciplinary Review and Learning

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

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

Standard Met

How the Service meets or does not meet the standard

Evidence of audits completed demonstrated and results reviewed regularly.

Morbidity, mortality, service quality, safety, efficiency in non-malignant MDTs, and info on benchmarking concentrate use are in the UKHCDO annual report.

Quality Standard 30: Document Control

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

Partially Met

How the Service meets or does not meet the standard

Evidence for the existence of relevant guidelines/policies/procedures presented but not for all.

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 Paediatric Haematologist, a Clinical Nurse Specialist, a Paediatric Research Nurse and a patient representative. Details of the Peer Review Team are held by UKHCDO.

7.3 Outstanding findings from previous peer review

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

Ref. Number	Statement of original finding
1.	Staffing:
a.	**Senior medical staff sessions:** Two consultant specialists had a total of 0.8 WTE devoted to this large regional specialist service, and there was no time in the Centre director's job plan for this particular role and no time to undertake management work underpinning the service (for example developing and refining clinical guidelines). There were also considerable time pressures within clinics, with long waiting times for patients and families.
b	**Physiotherapy:** Within the 0.2 WTE allocated to the service, a Band 7 physiotherapist could offer only a reactive service, with no time to work with families on early recognition of joint bleeds, other education, or advice about activities. Although she attended the monthly clinics for severely affected children (with the number of children attending being up to fifteen in a single morning) and all patients who attended were seen by a physiotherapist, there was often not time to undertake a full consultation. Children with mild and moderate disorders were seen only if there was a specific reason, so they did not benefit from any musculoskeletal education or advice.
c.	**Nursing:** Given the large number of patients, residing across a wide geographical area, specialist nursing provision was not adequate, and it had become impossible to offer school visits for many children. The situation was exacerbated by long-term sickness in the wider non-malignant haematology nursing team. The provision, and grading, of the specialist nurses should be reviewed.
d.	**Psychology:** There was no psychologist working within the team, although this is an expected core team member for patients with these conditions. Patients could be referred to the general hospital psychology service, but waiting times were long. Under these circumstances, only the highest-level patient and family needs were being met, and the team lacked the professional support that an integrated psychologist team member brings.