UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

UKHCDO Haemophilia Peer Review Audit Report

Oxford 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: 16 May 2025

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1 Executive summary

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

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

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

The executive summary presents the key findings, while the full report details the assessments referenced against the quality standards. Peer review for the Oxford Haemophilia Comprehensive Care Centre (the Service) was completed on 8th May 2024.

The Service successfully met 27 of the 30 established standards, with three standards partially met. The commitment of both the Centre and the Trust to providing high-quality care was evident through various initiatives and clinical pathways. However, key recommendations have been made to help address the gaps that affect the ability to deliver comprehensive care.

Key Recommendations:

1. **Physiotherapy provision:** The review team recommends that the service be provided with the resources to recruit a replacement adult bleeding disorder physiotherapist as soon as possible. In the short term, the team would like to see the agreement between the service and the OUH physiotherapy department reinstated until a permanent solution can be found.
2. **Paediatric Consultant Cover:** For a highly specialised service of this size, the Peer Review Team would expect to see more specialist medical cover to ensure the safety of all registered children, guaranteeing ready access to specialist advice. It urges the Trust to recruit additional consultants to provide adequate cover during daytime hours and outside of working hours, as out of hours cover is not available throughout the year.
3. **Facilities and environment:** The allocated space for reviewing and treating children with bleeding disorders appears insufficient and warrants additional space that is appropriate.

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

2 Haemophilia and Bleeding Disorder Peer Review - Background

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

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

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

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

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

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

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

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

3 Service Description

The Service provides care for both adults and children with bleeding disorders, serving 1,800 registered patients. The Adult Service operates at the Oxford Haemophilia and Thrombosis Centre (OHTC) located in the Nuffield Orthopaedic Centre and caters to patients over 16 years of age with inherited bleeding disorders. The Children's Haemophilia Service is situated within the Children's Hospital Oxford (OCH) at the John Radcliffe Hospital and attends to patients up to the age of 18 years.

Both the Adult and Children's Services have designated lead haemophilia consultants and specialist nurses. The medical and nursing leads, with support from the OHTC Manager, are responsible for staffing, training, guidelines and protocols, service organisation, governance, and liaison with other services. They are registered healthcare professionals with the appropriate specialist competencies and engage in regular clinical work within the service, while also having specific time allocated for their leadership role.

The Service has effective multidisciplinary teams with specialist haemostasis consultants, specialist haemophilia nurses, including research, specialist haemophilia physiotherapists, with essential support from an on-site UKAS accredited specialist haemostasis laboratory (within OHTC), administrative staff including a data manager and OHTC centre manager. All staff undertake relevant continuing professional development (CPD), statutory, and mandatory training. There are policies and standard operating procedures (SOPs) in place to cover absences.

The core MDT is supported by strong relationships with other specialities, including rheumatology, orthopaedics, infectious diseases, and obstetrics. Standard hours are from 9:00 a.m. to 5:00 p.m., Monday to Friday. Both services hold regular MDT and clinical governance meetings. The Children's Service conducts a weekly MDT meeting every Tuesday morning, while the adult service holds an MDT meeting every afternoon.

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	112	34	21	7	392	78	643	117
Moderate	30	11	18	3				
Mild	218	43	48	25				
Annual review in the last year	236	82	57	28	164	58	318	105

Inpatient admissions in the last year	16	6	4	4	14	5	10	5

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

Staffing: The staff consists of a mix of full-time and part-time roles, as outlined below. In the adult service, this includes four consultant haematologists (2.2 WTE), four nurse specialists (2.6 WTE), and one physiotherapist (0.8 WTE). In the paediatric service, there are two consultant haematologists (0.8 WTE), three nurse specialists (2.1 WTE), and one physiotherapist (0.6 WTE). Staff shared across paediatric and adult services include five biomedical scientists (4.5 WTE) and ten admin & clerical staff (8.61 WTE).

Key staff in the adult service include Consultant Haematologist and Centre Director, Dr. Dahlia Khan, and Lead Nurse, Amy Conquergood. In the paediatric service, the team comprises Consultant Haematologist, Dr. Sakit Badle, and Lead Nurses, Alice Wilkinson and Marie Eales.

Outpatient care: The service operates from 9 AM to 5 PM, Monday to Friday, at both locations.

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

Out of hours: Patients attend either the adult or paediatric Emergency Department, where protocols are in place. There is a 24/7 specialist haemophilia consultant on-call service available out of hours for both clinical services (separate adult and paediatric rotas) and the specialist haemostasis laboratory.

Transition: Patients are generally transitioned from the Children's Haemophilia Service to OHTC by the age of 18, following a well-established 'Ready, Steady, Go' transition programme. In exceptional circumstances, such as complex care needs in the community, a multidisciplinary or multispecialty agreement may delay the transition. One of the paediatric consultants holds a transition clinic at the adult centre.

Network arrangements: The Service is not part of a formal network, as there is no other haemophilia treatment centre within its region. However, it works closely with the surrounding District General Hospitals (DGH) to provide safe emergency care across the region. These DGHs include Northampton, Milton Keynes, Royal Berkshire Hospital, Great Western Hospital, Wycombe Hospital, Stoke Mandeville, Wexham Park, and Cheltenham and Gloucester Hospitals. Each DGH has a designated link consultant for both adult and children's services, with clear pathways to coordinate and support emergency care and, occasionally, minor invasive procedures (considered on an individual basis). The four DGHs with the highest concentration of patients with known bleeding disorders maintain a stock of factor concentrate, which OHTC manages. Robust processes are in place to courier factors to surrounding DGHs when required and to maintain stock control.

4 Quality Standards

4.1 Overview

The table below outlines the status of each standard, categorised as met (green), partially met (yellow), or not met (red). Overall, the Service has met 27 out of the 30 standards, with three partially met. The Service has outstanding findings from their previous peer review report in similar areas, which are provided in the appendix. The service is encouraged to review all descriptive assessments in addition to the key findings. This report, alongside local assessments, should steer discussions with the management team, highlighting areas of good practice while emphasising where further investment and improvement may be required.

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

4.2 Good Practice

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

1. The review team were very impressed with the state-of-the-art facilities and what is overall an excellent service.
2. The Service boasts a comprehensive research portfolio and research facilities that are unique to a haemophilia service. It is clear that research is important to the team.
3. The review team were impressed by the Service's rolling internal audit programme, which was excellent. This was supplemented by regular patient feedback questionnaires.
4. The review team wished to highlight the physiotherapist-led joint injection clinic as an example of good practice.

4.3 Immediate risks

There were no immediate risks identified.

4.4 Concerns

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

1. The review team were concerned about the potential loss of important experience and expertise due to a lack of succession planning for the adult physiotherapist. Since the review, however, the informal arrangement for additional physiotherapy support provided by the OUH physiotherapy department has come to an end. This has left the Service with very limited physiotherapy provision.
2. The paediatric team has limited consultant coverage. Indeed, their on-call staff are unable to provide adequate cross-cover for annual leave, with cover provided through goodwill, which is a potential clinical risk to the service.
3. Overall, the facilities available to the Service are excellent; however, the paediatric team has very limited space within the paediatric outpatient department. The review team feels that the paediatric team would benefit from access to an additional room during clinics, as there are occasions when children are being reviewed and undergoing phlebotomy in the same room.
4. Recruitment of a dedicated Haemophilia psychologist has been a challenge, one that was also highlighted in the previous peer review report of 2019.

4.5 Recommendations

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

1. **Physiotherapy provision**: Physiotherapy is a key component of Comprehensive Care for Bleeding Disorders, crucial not only for routine assessments but also for treatment, rehabilitation, and education of patients and their families to safeguard and enhance their musculoskeletal health. The Peer Review Team recommends the Trust prioritise increasing the number of permanent physiotherapy staff.

2. **Paediatric Consultant Cover:** For a highly specialised service of this size, the Peer Review Team would expect to see more specialist medical cover to ensure the safety of all children registered, with ready access to specialist advice. The peer review team recommends an urgent review of the out-of-hours cover and the recruitment of additional consultants to provide appropriate cover during daytime and outside working hours.

3. **Facilities and environment:** The space available for reviewing and treating children with bleeding disorders requires review and supplementation.
4. **Psychology provision:** Psychology is a key component of the multidisciplinary team and is a requirement of the National Service Specification and the findings of the Infected Blood Inquiry. The Peer Review Team recommends that the Trust work with the team to find a solution for the recruitment of a permanent psychologist.

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, particularly focusing attention on the 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

The website is fabulous and very thorough; it provides information on the service, as well as additional details on how to access other services and references to national and international support organisations. The service welcome pack is well thought through, although it mostly references haemophilia. It would be an added benefit if this could also reference other bleeding disorders. The newsletter and patient participation group are excellent initiatives that demonstrate good practice. All the written information referenced in this standard was available in the evidence supplied.

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

Patient Information Leaflets - Clear and concise. Website clearly laid out. However, I tried to find some information (primarily the Welcome to the Paediatric Services PIL) the following day and encountered some difficulty navigating and finding it. If not already considered, it will be worth undertaking some "User Assurance Testing" to ensure the website structure and navigation are as effective as possible - preferably by people with no or minimal knowledge and experience of bleeding disorders.

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

Templates for clinic letters, letters to schools, and plans of care were documented in clinic letters. Examples of these were in the centre's guideline document.

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

All information regarding the MDT clinic is communicated to the patient and GP in the clinic letters. They have a DNA policy and a PIFU policy, as outlined in the guideline document.

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

The website is in development, so there were points to add, but what was in place was good. The standard operating procedures are very good.

Contact details are provided in the welcome PIL, along with a clear pathway for triaging queries by reception staff. The paediatric team also has a backup plan for communication in the event of an unexpected staff absence.

Quality Standard 6: Haemtrack (PwBD on Home Therapy)

Standard Met

The review team saw evidence that patients on home therapy are encouraged to use Haemtrack in clinic letters and plan of care, which fulfils the requirements of this standard. However, this was not consistently documented across the service.

How the Service meets or does not meet the standard

Reference to Haemtrack seen in guideline document.

Quality Standard 7: Environment, Facilities and Equipment

Partially Met

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

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

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

How the Service meets or does not meet the standard

The adult Haemophilia and Thrombosis centre is a state-of-the-art facility. The paediatric team has a very limited space within the paediatric outpatient department and would benefit from access to an additional room during their clinics. There are occasions when children are being reviewed and undergoing phlebotomy within the same room.

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

The Centre should have a guideline/SOP covering this information.

How the Service meets or does not meet the standard

The Oxford team uses the Ready, Steady, Go, Hello Transition approach, with good information available on the hospital website and a clear Bleeding Disorders Transition Policy. We saw examples of transition letters to the adult team, and one of the Paediatric Consultants does a Transition clinic at the adult site at NOC.

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

Patient participation group has been set up to get feedback from patients/ carers. OUH carers website and Oxfordshire carers website.

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

Involvement with patients and caregivers was well-documented in the rolling audit programmes. Patient participation group is noted.

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

The Clinical Operating Policy for the centre provides clear documentation of the Leadership Team. There are dedicated bleeding disorders consultants, CNS/ANPs, adult and paediatric physiotherapy, and psychology support from the HBDCA team.

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

Excellent documentation in place. Adult on call is covered by haemostasis and thrombosis consultants only. The paediatric on-call is covered by a 1:3 rota with the two consultants and the ANP. The paediatric consultant cover is currently 0.8 WTE, resulting in incomplete cross-cover for leave. Consultants highlighted that registrar cover was patchy. The service is an excellent learning opportunity for registrars. Therefore, more time within this rotation is very beneficial and helps increase the number of registrars interested in this field.

The adult team is concerned that they have only one physiotherapist (0.8 WTE) and no succession plan in place, meaning expertise and exceptional service could be lost.

No dedicated haemophilia pharmacist. The adult nursing team cover a large geographical area, including care home visits, and only one is a nurse prescriber. An increase in the number of nurses is likely to be necessary due to the growing number of elderly patients. The communication between commissioners and the lead clinicians is inadequate.

Quality Standard 13: Service Competencies and Training Plan

Standard 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

All staff CPD, statutory, and mandatory training is up to date. Funding for nursing team members to attend meetings has become more challenging in recent years, and the team ensures that any available hospital study leave budget is applied for in a timely manner.

Quality Standard 14: Administrative, Clerical and Data Collection Support

Standard Met

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

How the Service meets or does not meet the standard

The team are happy with the administrative support within the adult service for both clinical and research practice. The paediatric nursing team felt that they needed to take on some administrative tasks because of a lack of administrative support.

Quality Standard 15: Support Services

Partially Met

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

The paediatric team have no formal play support for children. Looking to charitable funds to provide a play therapist.

Quality Standard 16: Emergency Department

Standard 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

Excellent documentation of pathways for IBD patients in adult and paediatric A&E. We saw an example of a teaching presentation given to A&E staff by one of the Paediatric Consultants.

Quality Standard 17: Laboratory Service

a. A UKAS accredited laboratory service with satisfactory External Quality Assurance performance should be available 24/7

b. A laboratory representative (senior biomedical scientist or clinical scientist) should attend inherited and acquired bleeding disorder service multidisciplinary team meetings (QS 25) regularly

c. The following tests should be available in a timely manner for the diagnosis and management of inherited bleeding disorders:

    i. All coagulation factor assays
    ii. Inhibitor screening
    iii. FVIII inhibitor quantification
    iv. VWF antigen
    v. VWF activity
    vi. Platelet function testing

d. Pathway for referral to molecular Genetic Laboratory service for:

    i. Detection of causative mutations in PwBD
    ii. Carrier detection
    iii. Discussion of results in genomics MDT when needed

Standard Met

How the Service meets or does not meet the standard

The lab is UKAS accredited (2022) and offers all necessary tests, with urgent factor assays available out of hours. They have a genomics MDT that meets to discuss patient diagnosis and has representation from all the necessary areas. They have an example genomics MDT decision form and excellent minute-taking during the meetings. A member of the lab team attends the Friday clinical MDT to discuss cases. Their lab handbook is comprehensive, and diagnostics are also covered in their clinical guidelines. Staffing in the lab is adequate; however, an increase in capacity for platelet aggregation testing would be welcomed by the clinicians.

Quality Standard 18: Specialist Services

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

a. Obstetrics, including reproductive counselling, information about pre-implantation genetic diagnosis and antenatal diagnosis
b. Foetal medicine
c. Vascular access (consultant surgeon or interventional radiologist with experience of venous access devices)
d. Orthopaedic surgery
e. Care of older people services
f. Dental services
g. HIV services
h. Hepatology
i. Medical genetics (Genetic Counselling Services)
j. Pain management services

Standard Met

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

Access to specialist services is available across the range required. Rheumatology services are available, although used infrequently, as patients are more often referred to orthopaedics. Dental services are provided via a private clinic off-site. HIV and hepatology services are provided via a separate liver clinic. Chronic pain service available.

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

The hospital EPR (Cerner) has been effectively utilised to flag PWBD and vCJD status. Examples of plans of care were seen within the patient letters. The team maintains an active rolling audit program across various areas of the service.

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 aspects of this standard are met within the excellent departmental Guideline.

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

All aspects of this standard are met within the excellent departmental Guidelines.

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 aspects of this standard are met within the excellent departmental Guideline, including a pathway for ankle arthropathy and a separate paediatric physiotherapy protocol.

Quality Standard 23: Guidelines on Care of PwBD requiring Surgery

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

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

Standard Met

How the Service meets or does not meet the standard

Excellent documentation of the surgical pathway and proformas to share with the surgical teams with clear signposting of how to reach the team with any concerns during the admission.

Quality Standard 24: Service Organisation

The Service should have an operational procedure covering at least:

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

Standard Met

How the Service meets or does not meet the standard

All elements of this standard are covered within the Clinical Operations Policy or in separate documentation.

Quality Standard 25: Multidisciplinary Team Meetings

Standard Met

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

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

How the Service meets or does not meet the standard

Clear evidence was shown of MDT meetings, with discussions centred on plans of care for patients at high risk of developing an inhibitor or who have already developed inhibitors. They have two meetings per day, one in the morning and one just before the end of the day, which include the attending consultant, registrar, nursing team, and physiotherapist. The Friday MDT meeting includes members of the lab.

Quality Standard 26: Multidisciplinary Clinics/Liaison Services

Standard Met

Combined clinics or other arrangements for multidisciplinary discussion with

a. Orthopaedics and or rheumatology
b. Obstetrics and gynaecology
c. Paediatrics
d. HIV
e. Hepatology

How the Service meets or does not meet the standard

They do not have joint clinics with obstetrics, gynaecology, orthopaedics, HIV, and hepatology, but they have excellent liaison links with all these services, including a weekly high-risk obstetrics MDT meeting. Their joint injection clinic, led by their physiotherapist, is an example of best practice and has received positive patient feedback. The paediatrics service is staffed by paediatric haematologists and nurses.

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

The standard demonstrated in SOPs for Quarterly NHD returns and Dashboard completion, as well as an example of departmental MDT Minutes, which cover the reporting of any Adverse Events to the NHD.

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

The team has a large research portfolio with multiple IMP and investigator-led projects within the adult and paediatric departments.

Examples of multiple clinical trials, spanning from early to late phases, were shown in both adult and paediatric populations. Dr Shapiro and Dr Curry are both heavily involved in research and have NIHR-funded research time in their job plans. They have a wet lab within their centre that is unique and a testament to the importance of research for the team.

Quality Standard 29: Multidisciplinary Review and Learning

Standard 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

They conduct annual patient satisfaction surveys, including surveys for the emergency department, immunisation, and self-infusion services. They have an audit tracker to conduct yearly audits in various areas of care, including patient visits, DNA rates/appointment targets, joint scores, Haemtrack, prophylaxis, inhibitors, emergency department attendance, and satisfaction. The patients we met on that day were very happy with the exceptional care and service they received. Departmental monthly meetings include morbidity, mortality, and governance. Examples of study days with distinguished speakers were presented as evidence. This allowed clinicians within the network to gain CPD. The nursing team felt that they were able to attend conferences and learning opportunities, but these have decreased over the years as funding from the industry has declined. They are now planning to attend congresses in advance to gain access to trust funds.

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	
Published and review dates on documents.	

6 Acknowledgements

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

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

7 Appendices

7.1 Definitions

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

7.2 Peer Review Team

The Peer Review Team consisted of 2 consultant haematologists, a clinical nurse specialist, a specialist haemophilia physiotherapist 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 the issues that were raised in the previous peer review report of 2019 that have also been raised in this review. These have been highlighted here to reinforce the recommendations in this report, as these issues should be addressed as a matter of priority. The Service must be commended for the effort it has made to address these concerns. 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	**Psychology** – There was no psychologist in place supporting the adult service. Funding for 0.2 WTE had been agreed six months prior to the visit, as part of a shared post with the malignant haematology service, but the business case had not been fully approved and signed off and it had therefore not been possible to recruit. Some high-level needs were being addressed by medical, nursing, and physiotherapy staff; this detracted from the specialist duties they could otherwise have been undertaking. Lower-level patient needs were not being met, and the team lacked the guidance and support that psychologist member usually offers. A psychologist worked withing the paediatric haemophilia service, but only for 1 session per week (0.1 WTE), which was insufficient; she attended the haemophilia clinic but did not have adequate time to offer consultations and support outside this time.
2	**Paediatric facilities** The paediatric service had moved from the Churchill Hospital to the John Radcliffe site in 2015, developing the service and increasing the number of staff, but there were several concerns about the facilities there.
a	There was a single dedicated clinic room (Lion room) for the use of this service. It was decorated to suit younger children, but if a child was being assessed and treated there, other children and their families frequently had to wait as there was no other open access clinic room for the paediatric haemophilia service. Whilst the latest volume of case notes were available (in Frog room, opposite the treatment room), earlier volumes were held a floor up (in Kamran room), so that nurses or secretarial staff had to take time to go and retrieve them when needed.

b	Lion room was also being used as the nurses' office, shared with Frog room which housed all the latest notes, trial files and patient information leaflets). The phone line in Lion room was used for families calling for advice; if calls came through at a time when a child was being treated, a nurse had to leave the room to take the call to avoid confidentiality issues. If the phone line was in use, for example if the nurse was calling to arrange investigations for the child being assessed, families could not get through. A review of the use of different telephone lines, and of nurses' office space, could usefully be undertaken.
c	There was no signposting indicating that this was the site of this large specialist haemophilia and inherited bleeding disorders service, and no patient information was seen displayed in the main paediatric outpatient area.
d	Car parking and access were extremely problematic. When children had painful joint bleeds, reaching the area presented a real struggle. Sometimes, when finding a parking space anywhere near the clinical area had proved impossible, team members had gone down to see a child in the car, bringing medication there. This was inappropriate, and the situation was distressing for children, families and staff. Car parking issues were also highlighted by the families who met with reviewers.