UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

UKHCDO Haemophilia Peer Review Audit Report

Leicester 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

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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 Leicester Haemophilia Comprehensive Care Centre (the Service) was completed on 11th June 2024.

The Service successfully met 17 of the 30 established standards, with 13 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:

1. **Physiotherapy service:** The current allocation of 0.2 WTE for physiotherapy is wholly inadequate given the size of the service and necessitates an increase. An urgent review of this element is essential to ensure that all aspects of the National Standards are fulfilled.
2. **Psychology service:** There is currently no service available for children and their families dealing with this lifelong chronic condition, which imposes significant burdens related to both the disease and its treatment. The existing service for adults is dispersed across several services, and it remains unclear how easily and readily patients and their families can access it. The peer review team recommends dedicated psychological support to enable personalised and appropriate care for the lifelong condition.

This review has identified gaps in haemophilia services that were also highlighted in the 2019 peer review. Some of these appear to be potentially related to an erosion of organisational memory following retirements and leadership transitions. Enhancing support at both local and national levels could be beneficial to the service. These gaps should be addressed as soon as possible to improve patient care and ensure compliance with national service specifications. The peer review findings will be shared with the clinical team, the host organisation, local commissioners, and other relevant stakeholders. We extend our gratitude to the haemophilia centre and the peer reviewers for their invaluable contributions, and we hope this report assists the Centre and the Trust in delivering high-quality haemophilia care.

2 Haemophilia and Bleeding Disorder Peer Review - Background

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

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

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

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

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

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

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

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

3 Service Description

The peer review of the Leicester Haemophilia Centre was completed on 11 June 2024. A multidisciplinary team of haemophilia professionals, along with patient representatives, carried out the review, which involved interviewing staff from the Service, reviewing documentation, and touring the facilities.

The Service provides care for both adults and children with bleeding disorders and has 925 registered patients. It is based at Leicester Royal Infirmary and operates from 08:30 to 16:30, Monday to Friday. There is a separate children's hospital from adult services, utilised for cases of admission and day care facilities.

There are weekly Haemostasis multidisciplinary meetings, with an additional board round once a week (or more frequently as required). Once a month, there is a dedicated haemophilia/bleeding disorders multidisciplinary team (MDT) meeting with input from Haemophilia Clinicians, Haemophilia Adult and paediatric clinical nurse specialists, psychologists, Specialist haematology laboratory staff, and a data manager. There is no dedicated social worker, but patients are signposted to access social workers.

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	25	15	11	5	240	27	442	50
Moderate	12	6	5	1				
Mild	58	12	14	2				
Annual review in the last year	70	29	21	7	74	22	140	23
Inpatient admissions in the last year	16	5	3	0	9	0	11	0

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

Staffing: There is a blend of adult and paediatric-specific staff in both full-time and part-time roles. This includes two consultant haematologists (2 WTE), four nurses (2.6 WTE), physiotherapy (0.2 WTE), one psychologist covering the Haemophilia, bone marrow transplant, and TTP services, along with three administrative staff (3.0 WTE). The biomedical scientists include one senior BMS responsible for H&T and between one to three other staff members (Band 4-7) working in the section daily.

Key staff include Consultant Haematologist and Centre Director Dr Salta Styliani and Lead Nurse Sarah O'Connell.

Outpatient care: A weekly MDT bleeding disorder clinic is available for adults and children. An orthopaedic consultant holds a clinic within the unit alongside the bleeding disorder clinic on a monthly basis. Weekly joint haematology and obstetric clinics are held to review pregnant patients with bleeding disorders or carriers of bleeding disorders, while providing preconception counselling services.

Inpatient care: The Admission ward is suitable for presenting complaints, with good links to children's inpatient services.

Out of hours: Emergency care outside the centre's opening hours is provided by contacting an on-call haematology specialist trainee (contact details provided to patients and carers). If the patient needed to attend, they would attend the Osborne assessment unit or the emergency department, depending on the specific complaint for adults. Children are requested to attend the Children's Emergency Department (ED). There is 24/7 on-call consultant cover with a specialist interest in haemostasis and thrombosis.

Transition: The Centre provides lifelong care and follows the Ready Steady Go Transition programme.

Network arrangements: There are no formal network arrangements in place. The East Midlands Regional Haemophilia Committee meets informally three times a year. These meetings are organised by the Nottingham HCC team and chaired by its centre director. They include members from the Leicester, Derby, Kettering, and Lincoln teams. The meetings provide a useful forum for data sharing, case discussions, and educational sessions.

4 Quality Standards

4.1 Overview

The table below outlines the status of each standard—met (green), partially met (yellow), or not met (red). Overall, the Service has met 17 out of the 30 standards, with 13 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	

Standard	Title of standard	Rating
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 work undertaken by the Adult and Paediatric Clinical Nurse Specialists (CNS) to ensure training and competence for cross-cover was excellent.
2. Patients provided overwhelmingly positive feedback about the service, in particular praising how accessible the team were and how safe they felt with the core team.
3. The review team specifically wished to highlight the great care being provided to patients despite difficulties. This was also reflected in patient feedback.

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. At the time of the review, the review team was very concerned about the lack of specialist physiotherapy provision at the Service. The physiotherapist had been on long-term sick leave and subsequently left their position, leaving the Service without any physiotherapy coverage. The Trust had not provided cover for this position. As a result, patients had not had access to physiotherapy for more than a year. Since the review, the Service has successfully employed a specialist physiotherapist; however, this is only at 0.2 WTE, and the review team believes this is a very low level of input for physiotherapy at a Comprehensive Care Centre. Physiotherapy is a key component of the multidisciplinary care team for haemophilia. It is necessary, not just for regular assessment, which the 0.2 WTE post will barely cover, but for the treatment and rehabilitation of acute joint bleeds, as well as ongoing support to improve pain, mobility, and function in those with chronic arthropathy.
2. While the Service has access to general psychology services, these are shared with two other services. The psychologists available to the Service are not directly employed by the trust, which means they do not have IT access to the past medical histories of haemophilia patients. The review team is also concerned that psychologists have only limited time for adult haemophilia patients, and there is no psychological support for paediatric patients and their families whatsoever.
3. The review team expressed concern regarding the low number of annual reviews in relation to the Standard. All individuals with severe bleeding disorders should be seen by the multidisciplinary team, including the Consultant, CNS, and Physiotherapist, at least twice a year. Those with less severe conditions should be reviewed annually. This can be accomplished through a combination of face-to-face and telephone clinics.
4. The letters observed did not encompass all the standards for a plan of care. There was no clear action plan for an emergency, nor a dose of Factor for those on Emicizumab experiencing a bleed or trauma.

4.5 Recommendations

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

1. **Physiotherapy service**: Since the review, the Service has appointed a replacement physiotherapist, but only at 0.2 WTE. However, the review team considers this allocation too low given the size of the service. The team recommends increasing the physiotherapy hours dedicated to haemophilia to align with the overall service needs. In addition, the physiotherapy provision should reflect the fact that this centre serves both children and adults.
2. **Psychology service**: The review team recommends employing a dedicated psychologist who specialises in bleeding disorders. In the short term, the Trust should identify a solution that allows psychologists working with haemophilia patients to access relevant past medical records, in line with a key recommendation of the Infected Blood Inquiry. A specialist bleeding disorder psychologist is vital for supporting both patients and carers who face the burden of a lifelong inherited condition, its treatment regimens, and any consequences of past

treatments. Experience in other services suggests that separating cancer and non-cancer pathways can help ensure appropriate care for those without an immediately fatal condition.

3. **Quality Management Group:** The review believes that establishing a quality management group within the team would be beneficial. This group would be responsible for reviewing standards, setting clear processes, and ensuring sufficient oversight, including regular audits.
4. **Increase annual reviews:** The number of reviews must be increased. For those with severe haemophilia receiving home treatment, this is a priority that requires the development of an action plan. Consideration should be given to improving the review of patients, including the use of nurse-led telephone clinics for those with mild disease. There should also be a detailed assessment of the impact of the PIFU (Patient-Initiated Follow-Up) system.
5. **Plan of care and patient information:** All patients should have a comprehensive written care plan that outlines their current treatment regime and provides guidance on what to do in the event of bleeding episodes. For those on prophylaxis, this plan should also consider lifestyle factors, personal treatment goals, and physiotherapy-led recommendations regarding physical activity, exercise, and joint health. This information can be included in their clinic letters.

5 Quality Standards – Detailed Description

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

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

How the Service meets or does not meet the standard

There is no information on how patients access Physiotherapy or Psychology services in the patient info booklet.

The Haemophilia Service leaflet is admirably concise but consider adding the Paediatric pathway and advice on Euhanet for European travel.

Quality Standard 2: Condition-Specific Information

Partially Met

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

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

Condition-specific information should be available covering:

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

How the Service meets or does not meet the standard

There are excellent Posters and Leaflets, and children’s leaflets are good.

Maternity patient information was not available to view on the day of the visit and was thought to be held on a separate computer system.

The example travel leaflet did not give condition-specific information, which is helpful for getting through Customs but not for medical input if necessary. Letters for patients on Hemlibra did not advise on emergency therapy for breakthrough bleeding.

Emergency treatment plans for patients are held centrally in the Haemophilia Office and are not easily available to non-Haemophilia Team staff in the hospital.

Quality Standard 3: Plan of Care

Partially Met

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

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

The plan of care should be reviewed at each clinic appointment or at other times if clinically relevant.
The plan of care should be communicated to the PwBD GP and other relevant service providers involved in their care.

How the Service meets or does not meet the standard

Letters were generally very informative but could be improved by addressing the following issues:

All aspects of care are not covered in the Clinic letters

No self-management plans are in letters.

No treatment goals are stated.

No rehabilitation plans have been stated (presumably due to no current access to Physiotherapy).

No Urgent care Plan for bleeding episodes is stated.
Children should have the main carer stated in the letter. Letters have a plan of care.

Quality Standard 4: Outpatient review of PwBD

Partially 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

An annual review rate of 70-80% for severe cases was deemed too low, and it is unclear whether there has been a loss of patients since the introduction of PIFU (Patient Initiated Follow-Up), which may not be suitable for severe patients. The Reviewers were advised that, under this system, the hospital's computer system should send a reminder to the patient at 12 months; however, it was unclear what safeguards are in place to ensure that Haemophilia patients are definitely seen. Patients who miss appointments are reminded by AccuRx, software that allows direct text messaging to patients' mobile phones.

There is an unavoidable deficiency in Physiotherapy follow-up reviews when there is no physiotherapy input.

Quality Standard 5: Contact for Queries and Advice

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

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

Standard Met

How the Service meets or does not meet the standard

No problems. Patients reported this works very well.

Quality Standard 6: Haemtrack (PwBD on Home Therapy)

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

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

Standard Met

How the Service meets or does not meet the standard

No problems. This is recorded centrally or on the patient's clinic letter.

Quality Standard 7: Environment, Facilities and Equipment

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

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

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

All equipment should be appropriately checked and maintained.

Partially Met

How the Service meets or does not meet the standard

There are no separate children's clinic rooms, and there are no changing facilities for babies in the Haemophilia Unit.

There is no specific children's treatment area, and there is clearly a good working relationship with the Paediatric OP clinic and the Play Therapy team.

The waiting area for children is open to more general adult patients in the Haemostasis and Thrombosis clinic waiting area.

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

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

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

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

Standard Met

How the Service meets or does not meet the standard	
The paediatric CNS is the lead for transition. The centre uses Ready Steady Go for Transitions. There is no documented UHL pathway or local SOP for transition, which would be a good addition to the current documents.	

Quality Standard 9: Carers' Needs

Carers should be offered information on the following: a. How to access an assessment of their own needs b. What to do in an emergency c. Services available to provide support	Standard Met
How the Service meets or does not meet the standard	
Note comments about patient letters above. However, there was excellent feedback from the patient groups on how well the Centre met their needs.	

Quality Standard 10: Involving PwBD and Carers

The Service should have: a. Mechanisms for receiving regular feedback from PwBD and carers about treatment and care they receive b. Mechanisms for involving PwBD and carers in decisions about the organisation of the Service c. Examples of how the Service has engaged PwBD / received feedback or made changes made as a result of feedback and involvement of PwBD and carers	Standard Met
How the Service meets or does not meet the standard	
The Review team heard excellent patient feedback about the service and care. The Service seeks feedback through the “Tell Matron” and “Friends and family test”, which work well, but there was no evidence of any changes made as a consequence of feedback received.	

Quality Standard 11: Leadership team

The leadership team will consist of a lead consultant, and other members agreed at a local level. This may include nurses, physiotherapists and psychologists, clinical scientists, or other members of the MDT. The lead consultant will be responsible for staff training, guidelines and protocols, service organisation, governance and liaison with other Services but may delegate some of these roles to others in the leadership team. The leadership team should all be registered healthcare professionals with appropriate specialist competences, undertake regular clinical work with the Service, and have specific time allocated for their leadership role.	Partially Met

How the Service meets or does not meet the standard	
There is a named consultant as Centre Director and a named Lead Nurse. There were no minutes for leadership meetings were seen. The evidence bundle includes two appraisals for the medical team. Individual job plans were not provided, but a team job plan was seen. The lead nurse is seen to be fulfilling all her responsibilities. The Haemophilia CNS team's cross-competency is excellent across Paediatric and Adult care. Networking with the Emergency Department and their CNS team seemed to work well. The day unit manager ensures that all Haemophilia patients are flagged in the hospital computer system. The data manager is excellent. No evidence of Paediatric Psychology input. There is some concern about the apparent lack of trained Paediatrician input to the Paediatric assessments.	
Quality Standard 12: Staffing levels and skill mix	
a. Sufficient staff with appropriate competences should be available for outpatient, day unit and in-patient care and support to urgent care services. Staffing levels should be appropriate for the number of PwBD cared for by the Service and its role in the network. b. All staff should undertake regular continuing professional development that is relevant to their work in the inherited and acquired bleeding disorders services. c. Staff working with children and young people should have competences in caring for children as well as in the care of people with bleeding disorders. Cover for absences should be available. d. In HCCCs, these staff should have sessional time allocated to their work with the IABD service. In HCs, the arrangements for accessing staff who do not have sessional time allocated to the IABD service should be clearly defined. Staffing should include: a. Medical staff: i. Consultant specialising in the care of people with inherited and acquired bleeding disorders available during normal working hours ii. On-call consultant specialising in the care of people with inherited and acquired bleeding disorders 24/7 in HCCC iii. On-call haematology consultant with arrangements for advice from a consultant specialising in the care of people with inherited and acquired bleeding disorders in HC b. Specialist nursing staff: i. Bleeding disorders specialist nurses (5/7) ii. Ward, outpatient, and day unit staff with competences in the care of people with inherited and acquired bleeding disorders c. Clinical specialist physiotherapist d. Practitioner psychologist or appropriately trained psychotherapist with specialist knowledge in IBDs.	**Partially Met**

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

A Service Manager has been appointed subsequent to the Peer Review, which is a strong indicator that the Trust is indeed supporting the Service.

Since the review, the Service has successfully employed a physiotherapist. However, this is only 0.2 WTE, which the review team considers to be very low for a CCC. Since the review, the Service has confirmed that they are in the process of recruiting a Social Worker, who will be shared with the regional navigator for the IBI.

The psychologists involved with the Haemophilia team are not employees of UHL Hospital Trust, so they do not have IT access to the past medical history of haemophilia patients. They have limited time for adult haemophilia input, and there is no paediatric psychology input. Haematology registrars typically undergo three-month rotations within the haemophilia unit during their training. The lead consultant for the haemophilia centre is relatively new to the post after the departure of more than one experienced consultant.

At the time of the review, a full-time consultant post was empty, but interviews for this post were due to be held. A full-time substantive consultant has now been appointed.

Quality Standard 13: Service Competencies and Training Plan

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

Standard Met

How the Service meets or does not meet the standard

Nurse competency and training records seen. Doctor's mandatory training records seen.

Quality Standard 14: Administrative, Clerical and Data Collection Support

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

Standard Met

How the Service meets or does not meet the standard

Data Manager was seen to be excellent.

Quality Standard 15: Support Services

Timely access to the following support services should be available:

a. Play support (children's services only) including:
   i. Play and distraction during any painful or invasive procedures
   ii. Play support to enable the child's development and well-being
b. Pharmacy
c. Dietetics
d. Occupational Therapy
e. Orthotics/podiatry

Standard Met

How the Service meets or does not meet the standard

There are excellent established pathways to additional supportive services. The paediatric CNS has very good links with the Play Team in the Children's Ward, who will support the adult CNS in her absence. There are clear pathways for patients with arthropathy.There is a very good working relationship with the pharmacy team.

Quality Standard 16: Emergency Department

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

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

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

Standard Met

How the Service meets or does not meet the standard

There is a relatively newly built Emergency Department with good facilities.

ED Physicians had a clear understanding that Haemophilia patients needed early liaison with the Specialist Team / on-call Haematology Registrar for optimum care. Paediatric ED has a separate entrance and a defined pathway for patients with bleeding disorders. Potential risk that emergency plans were held in a separate IT system that had limited access outside the Haemophilia team; the review team want to flag that it should be made clear to ED staff that an emergency care plan exists and that they need to contact the on-call haematologist to discover and enact it – patient care plans are not clear about this.

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:

Standard Met

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

There is a UKAS accredited haemostasis laboratory on site.

Quality Standard 18: Specialist Services

Partially 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

There was little evidence addressing this in the evidence bundle.

Obstetric and Foetal referrals may exist on a separate maternity IT system (not seen at the time of review). A pathway for vascular access referrals was present. There is a joint Orthopaedic / Haemophilia clinic with Mr Best every 8 weeks. There is no evidence of elderly care input, Dental arrangements, or an HIV care pathway.

Hepatology is dealt with in a hepatology specialist clinic, and genetics testing is sent to Manchester, but there does not appear to be any specialist genetic counselling locally. There is a clinical genetics team, and patients are referred to the services as appropriate.

There was no evidence for a pain referral pathway, and the rheumatology pathway was unclear.

Quality Standard 19: IT System

IT systems should be in use for:

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

Standard Met

How the Service meets or does not meet the standard

HCIS is used. The data manager was noted as an integral member of the team.

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

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

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

Partially Met

How the Service meets or does not meet the standard

There is an excellent protocol for diagnosis, although this had expired and was due for renewal in January 2024. There are no clear pathways for investigating menorrhagia. There are no pathways for investigation/diagnosis of non-specific Bleeding Disorders.

Quality Standard 21: Guidelines: Treatment and Monitoring of IABD

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

Standard Met

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

Excellent guidelines on factor usage are present, although the DDAVP guideline has been freshly updated and is awaiting approval. Factor fridge alarms to Ward 41. The data manager manages stock control. Quarterly returns are sent to NHD.

Standard Met

Quality Standard 22: Clinical Guidelines/Pathways

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

A very good general guideline exists for the management of bleeding, including inhibitors. However, there are no specific guidelines for immune tolerance, dental, Hep C, HIV, antenatal, or neonatal care. The overall protocol does include guidelines on treatment for target joints. Long-term surveillance of musculoskeletal health cannot occur without adequate physiotherapy input.

The surgery guideline for patients at risk of vCJD is from the BCSH, which has no trust-specific guideline. UKHCDO and local guidelines are in use.

Partially Met

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

Standard Met

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

Multiple condition-specific Surgical Proformas are used.

Quality Standard 24: Service Organisation

The Service should have an operational procedure covering at least:

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

Partially Met

How the Service meets or does not meet the standard

It is mostly covered in the "Bleeding Disorder Inherited and Acquired" UHL policy. Responsibility for Information and Education is not specified as a CNS responsibility. The evidence bundle included an excellent presentation for school staff. Paediatric reviews can be carried out at home if the patient is unable to attend the clinic, but this was not possible for adult services due to the pressure of work. There is an excellent trust-level lone working policy.

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

Evidence of an excellent Pathology MDT and Paediatric MDT. Evidence for Regional Haemophilia meetings, particularly with Nottingham.

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

There is a joint clinic with Mr Best in Orthopaedics, and a joint rheumatology/ haematology clinic runs every eight weeks in the haemophilia centre. Patients who require input from both specialities can be referred directly. The clinic is not specific to bleeding disorders.

O&G arrangements were not present in the initial evidence bundle; however, several anonymised examples of birthing plans were subsequently provided as evidence of good practice.

Evidence was not presented for Paediatric joint working – there should be a named paediatrician.

All PWH infected by blood-borne viruses have access to specialist services. People infected with hepatitis or HIV are referred and seen by Infectious diseases. If liver damage is confirmed, they will be referred to a hepatologist.

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

An excellent Data Manager appropriately manages all data.

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 an appropriate time for this role.	Partially Met
How the Service meets or does not meet the standard	
There is evidence of a Haematology Department that is active in past and current research, but little of the evidence referred to is currently of relevance to bleeding disorders.	
Quality Standard 29: Multidisciplinary Review and Learning	
The Service should have multidisciplinary arrangements for review and implementation of learning from: a. Audit – the Service must have an audit plan, and it must include an audit of emergency and out of hours care (QS 23) b. Positive feedback, complaints, outcomes, incidents and 'near misses' c. Morbidity and mortality d. Haemophilia Dashboard (when relevant) e. Review of UKHCDO Annual Report benchmarking information on concentrate use f. Ongoing reviews of service quality, safety, and efficiency g. Published scientific research and guidance	Partially Met
How the Service meets or does not meet the standard	
No evidence of an audit plan was presented in the evidence bundle. There were audits on vWD and desmopressin use. There was no evidence for any Morbidity and mortality meetings given. There is no evidence of reviews of service quality. The Haemophilia Dashboard is under development. There is no evidence of benchmarking in the UKHCDO report. No published research was presented.	
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	
There is a Trust policy on document control.	

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 (one adults and one paediatric), 3 clinical nurse specialists, and 2 patient representatives (one shadowing the process). Details of the Peer Review Team are held by UKHCDO.

7.3 Outstanding findings from previous peer review

The table below provides details of the issues that were raised in the previous peer review report of 2019 that have also been raised in this review. These have been highlighted here to add strength to the recommendations in this report as these issues should be addressed as a matter of priority. The 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. There remained significant staffing shortages, and this impacted on the Team's ability to offer the mult-professional holistic care expected for children and adults with long-term conditions.
a	Paediatric medical staff: Senior paediatric medical support for the adult haematologist leading the paediatric service was lacking, and, while the service functioned well, reviewers felt that this potentially left him vulnerable when managing specific paediatric issues.
b	Physiotherapy: A very experienced physiotherapist was working in the service but was only contracted for 0.2 WTE (one day per week). Within this time, he could see patients in the adult and paediatric specialist clinics but could not offer ongoing management of synovitis or provide long term joint health surveillance and care. There was no cover for absence, so that in a period of sick leave earlier in the year no joint scores had been undertaken. He sometimes referred patients to the general physiotherapy service, but patients were not then having the advantage of specialist expertise. Patients often contacted him outside his contracted hours, but these discussions were not always fully documented. There was no guideline for long-term joint health; an audit against such guidance would be valuable in evidencing additional need.
c	Paediatric nursing staff: A 0.6 wte paediatric nurse lead was working very effectively, but there was no children specific cover for her at times of absence. Cover was provided by the haemophilia nursing team.
d	Psycho-social care: There was no psychologist working within the team, although this is an expected core team member for patients with these long-term conditions. Patients could be referred to the general hospital psychology service but could wait up to three months to be seen. Under these circumstances, only the highest-level patient and family needs were being met, and the team lacked the professional support that an integrated psychology member brings. Play therapy was usually not available at times when children were being treated; this had an impact on the work of the nurses, as two nurses were often required to manage children for cannulation etc.
e	Administrative and clerical support: This was insufficient, so the nurses and the data manager were undertaking clerical tasks such as recording and typing up minutes of meetings and answering phones. The review team learned that calls from patients and ED staff were not always answered promptly, and that this could result in delay for patients attending for urgent care.
f	Haematology medical staff: Although the PA provision was judged to be adequate, after a period of very severe under-provision, it was noted that the allocation for the Centre director to undertake this role had been reduced from 1 to 0.5 PA, and that he and his colleagues were having additional demands on their time, including a request to organise and run a regional Thrombotic Thrombocytopenic Purpura (TTP) service. If this team is to contribute, as would be expected for a Comprehensive Care Centre, to a functioning network in the East Midlands, additional resource will be required.