UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

UKHCDO Haemophilia Peer Review Audit Report

Leeds Haemophilia Comprehensive Care Centre

Report Date: 29 August 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 Leeds Haemophilia Comprehensive Care Centre (the Service) was completed on 12 March 2024. The Children's Service is located within the Leeds General Infirmary, and the Adult Service is at St James' University Hospital.

The Centre successfully met 23 of the 30 established standards, with seven standards being 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. **Clinic Space:** The review team suggests that the Trust support the service in securing extra space in the outpatient area to boost capacity and flexibility for patients and carers to access all aspects of their multidisciplinary Comprehensive Care during each visit, especially their physiotherapy review.
2. **Admin and Data Support:** A single data manager or administrator appears to be multitasking and performing well, but lacks sufficient time to meet all national data reporting requirements. The peer review team suggests reviewing the job description and workload to ensure adequate support for the service.
3. **Physiotherapy Provision:** There is an urgent need to restore physiotherapy hours so that patients receive a proactive service for managing their bleeding-related joint complications.

This review has identified gaps in haemophilia services that should be addressed to improve patient care and ensure compliance with national service specifications. The peer review findings will be shared with the clinical team, the host organisation, local commissioners, and other relevant stakeholders. We extend our gratitude to the haemophilia centre and the peer reviewers for their invaluable contributions, and we hope this report 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 on-site review, each service conducts a thorough self-assessment against the standards, highlighting strengths and areas that require attention. During the on-site 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 was conducted on 12 March 2024, and both sites were visited. A multidisciplinary team of haemophilia professionals, accompanied by patient representatives, undertook the review, which involved discussions with staff from the Service, reviewing documentation, and touring the facilities.

The service has 1,035 registered patients with bleeding disorders across both adult and paediatric sites. The Leeds CCC is the hub of the North and West Yorkshire Haemophilia Network, with Bradford and York Haemophilia Centres, covering a population of 3.15 million.

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	73	34	4	5	97		61	
Moderate	20	11	0	1				
Mild	76	31	7	9				
Annual review in the last year	116		6		97		61	
Inpatient admissions in the last year								

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.

Adult Service: The Service employs four Consultants for Haemophilia & Thrombosis (2.0 WTE for Haemophilia), four nurses (3.6 WTE), two physiotherapists (0.9 WTE), one podiatrist (0.2 WTE), six biomedical scientists in the Coagulation Laboratory (4 WTE), a Data Manager (1.7 WTE), a Psychologist (0.3 WTE), and PA secretarial support to Consultants (1.4 WTE).

Paediatric Service: One consultant paediatric haematologist (0.2 WTE), three nurses (total 2.8 WTE), one social worker (0.5 WTE), along with physiotherapy, podiatry, laboratory, data management, and administration, all of which are shared with the adult service as described above.

Key staff include: Consultant Haematologists and Centre Directors, Dr Lishel Horne (Adults) and Dr Mike Richards (Paediatric), and Lead Nurse Sarah Garside.

Outpatient care: It is overseen by consultants and operates from 9 am to 5 pm, Monday through Friday.

The adult unit holds a weekly multidisciplinary (MDT) clinic, with allocated slots for individuals with severe and moderate haemophilia. This clinic is staffed by consultant haematologists, haemophilia clinical nurse specialists (CNS), and a specialised haemophilia physiotherapist.

The paediatric unit runs a weekly clinic every Monday morning, attended by a consultant paediatric haematologist, a specialist registrar when available, two clinical nurse specialists, a senior haemophilia physiotherapist, and a social worker dedicated to the service.

Inpatient care: On wards suitable for the patient's admission needs.

Out of hours: The adult patients are seen via the Emergency Department, and the children through direct access to the ward. Consultants provide 24-hour on-call advice.

Transition: A process of preparation for transition is undertaken with the young people in the paediatric service, and the Ready Steady Go documentation is completed after a succession of discussions with the young person. The rate of progress is tailored to the individual needs of each patient. Patients are prepared for transition at the nurse-led MDT clinic and the telephone transition clinic. A representative from the paediatric medical and nursing teams will attend the first review of the young person in the adult service.

Network arrangements: The Leeds CCC serves as the centre for the North and West Yorkshire Haemophilia Network (NWYHN). NWYHN encompasses Bradford and York Haemophilia Centres, serving a population of 3.15 million. Its primary aim is to ensure equitable access to comprehensive care across the region. Out-of-hours consultant and specialist laboratory on-call services are initiatives within the network, provided on a regional basis. Multidisciplinary network meetings occur monthly, alternating between clinical MDT and business meetings, supported by an MDT coordinator (whose position is currently vacant). Network leadership is provided by a lead consultant and a lead nurse based at the service. The network engages in clinical governance and educational activities. Representatives maintain dialogue with regional NHSE commissioners, who have occasionally participated in network business meetings, and ad hoc meetings have also been arranged. A current challenge for our network is the fragility of staffing within the haemophilia treatment centres in the network.

There is an NWYHN Patient, Carer and Public Involvement (PCPI) Group, established by the lead nurse for the network, that is open to patients registered in all participant Centres.

4 Quality Standards

4.1 Overview

The table below outlines the status of each standard—met (green), partially met (yellow), or not met (red). Overall, the Service has met 23 out of the 30 standards, with the remaining seven partially met and no outstanding findings from the previous peer review. The service is encouraged to review all descriptive assessments in addition to the key findings. This report, alongside local assessments, should steer discussions with the management team, highlighting areas of good practice while emphasising where further investment and improvement may be required.

Standard	Title of standard	Rating
1	Service Information	
2	Condition-Specific Information	

Standard	Title of standard	Rating
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. There was excellent feedback from patients and carers across both sites, praising all members of the Multi-Disciplinary Team.
2. The Physiotherapy and Podiatry clinics are excellent, with the latter possibly being unique across the country.

3. There is a strong research portfolio, with staff actively involved in conducting research. Staff are encouraged to undertake research projects.
4. There is good social work support for the Paediatric site.

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 service faces significant challenges because all consultant clinics are currently scheduled on a Tuesday, creating pressure on available space, restricting patient choice, and limiting access to the full multidisciplinary team. Patients who are unable to attend on that day have no alternative clinic options, and the lack of space often requires physiotherapy reviews to be scheduled separately. In addition, with only one physiotherapist available on the clinic day, most patients are unable to receive their physiotherapy review at the same time and must return for a second appointment. This arrangement is inconsistent with the Comprehensive Care Model, which recommends that patients with bleeding disorders receive a full multidisciplinary review at least once a year, depending on the severity of their condition.
2. There has been a reduction in physiotherapy hours from 1.4 to 0.9 WTE, accompanied by a change in the type of service being offered. The service is now only reactive compared to the previously more proactive approach. Physiotherapy is a key aspect of Haemophilia Comprehensive Care, and all patients with haemophilia should have access to specialised physiotherapists for all their musculoskeletal needs.
3. There has been a rise in service demand due to a significant influx of patients from both York and Bradford Haemophilia centres during COVID, which has increased pressure on the entire team. The team is still experiencing this high demand.
4. The review team is quite concerned about the workload and job description of the data manager, who, alongside their significant data management role, also organises clinics. While the data manager is doing an excellent job, having responsibility for both data management and clinics does pose the risk of a single point of failure if they are absent for a prolonged period. Furthermore, this arrangement is quite unusual.
5. Access to HCIS is restricted to the data manager with limited access within the clinical team. Indeed, this is reflected in fewer adverse events reported from the centre.
6. The peer review team is also concerned about the lack of suitably experienced, dedicated psychology professionals to support the needs of this large cohort of complex patients.

4.5 Recommendations

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

1. **Provision of Clinic Space:** The review team recommend that the Trust assist the service in finding more space in outpatients so there can be more flexibility with clinic days and space for the multi-disciplinary team. This will provide greater flexibility for patients and carers to schedule clinic and physiotherapy sessions that fit their work and life commitments. All severe

patients should have a physiotherapy review during their annual or 6-monthly visit as part of the agreed standard for Haemophilia Care.

2. **Clinic Appointments Review**: The review team recommends that the service consider reviewing the distribution of clinic appointments across the week in relation to space and commitments. By spreading out its clinics throughout the week, some of the space issues highlighted in this report would likely be resolved, whilst also providing greater choice to patients.
3. **Physiotherapy Service Restoration:** The review team recommends that physiotherapy resources be restored and the previous proactive service provision be reinstituted. With the current levels of physiotherapy, there is a risk of burnout, and consequently, the potential loss of valuable knowledge and experience. This could have a detrimental effect on patients.
4. **Data Management and Admin Support:** The review team recommends a review of the data manager's job description and current tasks with a view to providing additional support and reducing the risk of a single point of failure.
5. **Wider Access to HCIS:** Additional admin and clinical staff should be granted access and provided with training to use the system.
6. **Demand and Capacity Analysis:** The review team recommends conducting a formal demand and capacity analysis to provide the necessary resources to support the increased workload resulting from the larger volume of registered patients.
7. **Psychological Support Services:** The review team recommends assessing the needs of service users to establish permanent, dedicated psychology and social work services that are suitable for the complex group of patients registered with the service**.**

5 Quality Standards – Detailed Description

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

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

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 Leeds Teaching Hospital NHS Trust Website provides a clear description of the service. The NHS LTHT website covers all aspects of this standard, except for guidance on accessing psychology and social work services. Information is available in different formats, making it more accessible for people with speech or hearing impairments, language barriers, and learning difficulties.

There is clear evidence on the electronic patient record system (PPM Plus) that processes are in place to refer patients to psychology.

A leaflet in the centre explains how to access psychology, but currently, no referrals are being accepted for the service as it is overwhelmed.

On the NHS LTHT website, contact details are available for the dedicated haemophilia social worker. However, staff within the centre confirmed that this service is no longer available on-site, though staff can still refer to social work if necessary.

PWBD appointment letters clearly state the contact number if an appointment needs to be changed.

Quality Standard 2: Condition-Specific Information

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

Standard Met

4. Acquired haemophilia
5. Inherited platelet disorders
6. Bleeding Disorder of unknown cause (BDUC)
7. Other less common and rare bleeding disorders

How the Service meets or does not meet the standard

A well-organised selection of written patient information, including leaflets, booklets, and posters, was clearly visible and effectively distributed throughout clinical areas.

When specific information was not available within the clinical areas, staff confirmed they signposted patients and carers to online resources such as the UK Haemophilia Society and the LTHT Website.

All written and online information viewed was well written, up to date, and available in different formats. All points within this standard were met.

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

Clinical letters provided to the review team clearly showed evidence of goal setting, self-care plans, planned review dates, and dissemination of plans around the Multi-Disciplinary Team.

The centre documented that they partially met this standard, as not every patient currently had a care plan.The team felt this standard was still met, as patients do not always need care plans in place unless they have a procedure due or another reason to deviate from what is in the clinic letter.

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

Formal reviews of patients occur every 6 months for adults and paediatrics. The clinics involve the MDT; however, there are space issues with clinic accommodation. All consultants run their clinics on a Tuesday, with a total of 24 patients (8 patients each). Only one physiotherapist attends this clinic, and sometimes there is no available room for them to use, so they have to operate from the physiotherapy department, which is in a different location. As a result, not all patients are reviewed, and there is limited flexibility for those unable to attend on a Tuesday.

Access to other MDT members can be achieved through referral following a clinic review. Outcome measures are provided to patients upon attendance at the clinic.

Children and young people are assessed in the Children's Haematology and Oncology Day Unit. The bed bays and clinic rooms are shared with other haematology oncology clinics; however, there is only one medical-led haemophilia clinic or multidisciplinary team clinic at a time. There is sufficient space for medical reviews, as well as concurrent nursing and physiotherapy interventions.

Quality Standard 5: Contact for Queries and Advice

Standard Met

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

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

How the Service meets or does not meet the standard	
All PwBD and their carers have a clear point of contact. There is also plenty of information available online and in leaflet form. Evidence demonstrates that effective processes are in place to handle urgent problems clinically. Assessment is conducted by a Duty Nurse Practitioner using a triage tool, with contact made to the registrar on call. Patient feedback indicates that contact details for queries such as email addresses, centre contact numbers, emergency, and out-of-hours contact numbers are provided. It is also clear from patient responses that there is a quick reply turnaround for non-urgent enquiries. In the paediatric service, patient or parent contact is directed to the two clinical nurse specialists, whose mobile phone numbers are shared with families. If they are unavailable, calls are redirected to the paediatric haematology-oncology out-of-hours triage nurse, who will seek advice from the appropriate doctor or advise attendance at the hospital for clinical review.	
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	
The review team observed evidence of haemtrack usage documented in patient letters. Non-compliance with the haemtrack letter template was evident. Adherence to haemtrack is requested from all families whose patients are receiving regular factor concentrate prophylaxis during each paediatric clinical review, and the mobile phone app is reviewed. A note of adherence is recorded on the prophylaxis review proforma.	
Quality Standard 7: Environment, Facilities and Equipment	
The environment and facilities in outpatient clinics, wards and day units should be appropriate for the number of PwBD with inherited and acquired bleeding disorders and accessible by people with severe mobility problems. Facilities and equipment appropriate for the Service provided should be available, including: a. Fridges b. storage c. Clinical rooms for staff of all disciplines to see PwBD and carers with adequate space for physiotherapy assessment d. Room for multidisciplinary discussion e. Room for educational work with PwBD and carers f. Office space for staff g. Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all relevant clinical areas h. Access to adequate IT equipment with clinical systems i. All equipment should be appropriately checked and maintained.	**Partially Met**

How the Service meets or does not meet the standard

Pressure on outpatient clinic space at SJH limits options for changing clinic dates and times. Limited access to HCIS across the team, with clinical staff unable to access it, as access is restricted to only the data manager. A dashboard entry was missed partly due to issues with data collection and collation.

Outpatient clinics operate on Tuesdays due to space constraints on other days, allowing consultants and a physiotherapist to see 24 patients in one day. Physiotherapy staff report being unable to use rooms within the same area as outpatient clinics, resulting in more disjointed patient assessments. This lack of space forces the physiotherapist to work from the physiotherapy department, which is in a different part of the hospital. Access to disabled toilets and lifts is available.

Fridges in clinical areas storing blood products are adequately sized and securely locked. Factor concentrates are obtained from the Blood Bank, which the reviewers visited. These fridges are maintained and temperatures logged by the Blood Bank Department.

The office space for the data manager is suboptimal.

Children and young people are reviewed in the Children's Haematology and Oncology Day Unit. The bed bays and clinic rooms are shared with other haematology and oncology clinics, but only one medical-led haemophilia clinic or multidisciplinary team clinic occurs at a time. There is sufficient space for medical review and parallel nursing and physiotherapy interventions.

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

Standard Met

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

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

How the Service meets or does not meet the standard

A preparation process for transition takes place with young people in the paediatric service, and the Ready Steady Go documentation is completed after a series of discussions with the young person. The rate of progress is tailored to each patient’s individual needs. Patients are prepared for transition during the nurse-led

MDT clinic and telephone transition clinic. A representative from the paediatric medical and nursing teams attends the initial review of the young person in the adult service.

A standard operating procedure for the transition process is included in the Children's Hospital guidance for the management of patients with inherited bleeding disorders.

The review team examined a comprehensive leaflet titled ‘Mild and Moderate Haemophilia and the Transition to Adult Services’ intended for patients.

There is also a detailed checklist and SOP for transition requirements available on the adults’ site, which includes in-depth discussions with young people transitioning to adulthood.

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

This information is available online and in leaflets within the department, which people can access and are provided to patients and carers.

Carers are directed to the NHS Leeds Teaching Hospital Trust website, providing easy and clear access to online resources, including the NHS Information for Carers leaflet. Links are provided to organisations such as Carers Leeds, an organisation with which the Trust collaborates. These resources meet the requirements of this standard.

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

Excellent friends and family feedback.

Patient representative who attends relevant meetings with the team, providing evidence of feedback and actions taken.

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 a specific time allocated for their leadership role.

Standard Met

How the Service meets or does not meet the standard

Job planning involves the appropriate allocation of time. Clear job descriptions are in place for the Clinical Lead for the network and the Lead Nurse. Leeds CCC is the hub for the NWY haemophilia network, and there is evidence of strong leadership and liaison across the network.

The team, including both multidisciplinary clinical and support staff, maintain good working relationships with shared visions for the service.

The service is co-directed, with two consultant haematologists—one from the adult unit and one from the paediatric unit—forming the leadership team. Both job plans allocate time for managing the service, and the review team is satisfied that they provide an effective leadership team. The lead nurse, a paediatric nurse by training, offers nursing leadership and plays a key role in nursing development.

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

Partially Met

b. Specialist nursing staff:
    i. Bleeding disorders specialist nurses (5/7)
    ii. Ward, outpatient, and day unit staff with competences in the care of people with inherited and acquired bleeding disorders
c. Clinical specialist physiotherapist
d. Practitioner psychologist or appropriately trained psychotherapist with specialist knowledge in IBDs.
e. Access to specialist senior social worker
f. Data manager
g. Biomedical scientist and/or clinical scientist (further details on the requirements are included in QS 17)

How the Service meets or does not meet the standard

There is clear evidence of engagement with Continuous Professional Development, including trust-mandated training. Consultants at SJH are fully staffed, and there is an appropriate skill mix within the consultant teams. Although staffing has improved since the last review, long-term sickness of a consultant within the network increased pressures in 2023, leading to an increased workload and reduced capacity.

There is one paediatric consultant haematologist specialising in haemophilia and bleeding disorders, who co-directs the service alongside their responsibilities for the paediatric haemoglobinopathy service. Other paediatric consultants, while competent in caring for children with bleeding disorders, primarily focus on other areas of haematology. The sole consultant for paediatric haemophilia has 2.0 PA in his job plan.

A shortfall in physiotherapy staffing makes the service vulnerable to further absences. Psychology service provision is limited, with no dedicated paediatric service. There is no substantial appointment of a practitioner psychologist or appropriately trained psychotherapist with specialist knowledge in IBDs. Social worker provision at St James' Hospital has recently been withdrawn.

The role of data manager also includes a significant clerical component. The specialist coagulation lab is properly staffed. Across the network, there is a need for more robust staffing, with only limited dedicated consultant expertise at Bradford Royal Infirmary and York.

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

Clear engagement with Continuous Professional Development, including attendance at conferences and meetings. Nursing staff supported to attend the 'Introduction to Bleeding Disorders' course. Consultant CPD and mandatory training records were documented, and appraisals were evidenced.

Quality Standard 14: Administrative, Clerical and Data Collection Support

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

Partially Met

How the Service meets or does not meet the standard

A dedicated Band 4 data manager is available and handles a heavy workload of administrative, clerical, and data collection duties for both adult and paediatric sites.

They organise clinics alongside their data duties. This arrangement creates a single point of failure risk, which could seriously disrupt clinic appointments if the data manager is absent for a considerable period.

The system is neither sustainable nor robust.

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

Pathways for referral to dietetics and occupational therapy as needed. Haematology pharmacist collaborates with the adult team.

Play support (children's services only) is available, including: (1) Play and distraction during any painful or invasive procedures and (2) Play support to promote the child’s development and well-being.

A dedicated pharmacist oversees prescriptions for haemophilia medications.

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.

Partially Met

How the Service meets or does not meet the standard

Training is provided to Emergency Department staff to support treatment pathways, demonstrating responsiveness to clinical incidents and understanding of pressures within the department. Liaison with senior clinical management is maintained to address time-critical elements of treatment pathways, aiming to reduce delays to treatment outside of standard hours. The audit was limited and highlighted the need to expand the programme. There is no standard link person in A&E, but effective alert systems and documentation are in place.

Children and Young People have direct, open access to the inpatient facility for emergency care. The Paediatric Emergency Department has clear guidance to stabilise an emergency admission and subsequently contact the on-call paediatric haematology teams for transfer. A specific link professional is designated for inherited bleeding disorders in the paediatric emergency department.

Quality Standard 17: Laboratory Service

Standard Met

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

How the Service meets or does not meet the standard

The specialist coagulation lab is UKAS accredited and led by an experienced senior Biomedical Scientist (Band 8a). The senior lab team demonstrates a clear vision and ambition for service development. The lab supports specialist coagulation services across Leeds Comprehensive Care Centre, Bradford, and York Haemophilia Centres as required. A 24/7 specialist out-of-hours rota operates for complex diagnostics and blood sciences. There is an excellent pathway for genomic testing, supported by a genomics MDT.

The two main challenges for the lab at present include relocating to new premises, which can pose a significant logistical challenge. Delays in receiving samples from different locations are an issue, but there are no problems once the samples are on-site.

Quality Standard 18: Specialist Services

Standard Met

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

a. Obstetrics, including reproductive counselling, information about pre-implantation genetic diagnosis and antenatal diagnosis
b. Foetal medicine
c. Vascular access (consultant surgeon or interventional radiologist with experience of venous access devices)
d. Orthopaedic surgery
e. Care of older people services
f. Dental services
g. HIV services
h. Hepatology
i. Medical genetics (Genetic Counselling Services)
j. Pain management services
k. Rheumatology
l. Specialist services should have an appropriate level of specialist expertise in the care of people with inherited and acquired bleeding disorders.

How the Service meets or does not meet the standard

Comprehensive referral pathways to specialist services are in place. Joint clinics are held with obstetrics. There are close links with foetal medicine, vascular services, orthopaedics, elderly medicine, hepatology, and infectious diseases. Pathways for referrals to pain services, complex genetic counselling (including haemophilia team counselling as an initial step if needed), rheumatology, and dental services are available.

Joint paediatric haemophilia and rheumatology reviews are accessible with a dedicated paediatric rheumatologist. Recent improvements in joint health have reduced the demand for these clinics. Paediatric surgery or interventional radiology for the insertion of indwelling venous catheters is readily available. There is a very close liaison with the Leeds Dental Institute.

Quality Standard 19: IT System

Partially 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	
Only the data manager has access to HCIS due to issues with database access during the recent update; new passwords have not yet been sorted. All systems are integrated, and alerts are sent on PPM Plus. IT systems within the Trust, such as PPM Plus and PAS, are easily accessible electronically. It is evident that these systems allow appropriate management and sharing of PWBD data between health professionals. HCIS remains accessible but now only to the Data Manager; Trust-led IT upgrades have impacted the ability of all other staff to access the system HCIS.	

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

Standard Met

How the Service meets or does not meet the standard

Documents (guidelines) supporting the management of all conditions listed in this section were observed.

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
   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

Standard Met

How the Service meets or does not meet the standard	
Evidence of prescription charts, guidelines, and documents observed for all other points listed in this section.	

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	Standard Met
How the Service meets or does not meet the standard	
All guidelines and pathways very clear for all points listed in this section.	

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	
The standard proforma is sent via email and uploaded onto PPM+. It is a very clear process. Communication is also conducted face to face and documented afterwards.	

Quality Standard 24: Service Organisation

Standard Met

The Service should have an operational procedure covering at least:

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

How the Service meets or does not meet the standard

Very clear operational policies throughout.

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

MDT meetings are held regularly, with clear evidence of engagement from all team members. The MDT templates are concise and comprehensive. Additionally, a Genomics MDT is in place.

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

MDT discussions take place among specialist services, either as part of joint clinic MDTs, such as obstetrics, or as needed on a case-by-case basis for hepatology and HIV. The team review orthopaedic patients as required, and a team member attends the orthopaedic clinic if necessary. Before COVID, there was an orthopaedic MDT, which, unfortunately, has not been restarted; reinstating it would be beneficial for both patients and staff if resources allowed. Throughout the network, the BRI maintains its own specialist services with which it has very good working relationships. No joint clinics are held for HIV or Hepatology.

Quality Standard 27: Data Collection

Partially 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 NHS England National Haemophilia Dashboard entries for Adults and Paediatrics were missed, and the review team found no evidence of adverse events being reported to NHD. The service is aware of this and is considering potential tools to resolve the issue. The limited scope of the data manager role restricts data collection.

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 service has developed a clinical trials programme over the past 2 to 3 years, led by a consultant and a haemophilia CNS. The service is involved in five clinical trials. Administrative support has been recently allocated. Currently, there is no non-CTIMP research ongoing at the service, even though staff are fully capable of conducting such studies.

Dr Richard Wilkins, a podiatrist, has completed his Phd. Papers published by various members of the MDT.

Quality Standard 29: Multidisciplinary Review and Learning	
The Service should have multidisciplinary arrangements for review and implementation of learning from: a. Audit – the Service must have an audit plan, and it must include an audit of emergency and out of hours care (QS 23) b. Positive feedback, complaints, outcomes, incidents and 'near misses' c. Morbidity and mortality d. Haemophilia Dashboard (when relevant) e. Review of UKHCDO Annual Report benchmarking information on concentrate use f. Ongoing reviews of service quality, safety, and efficiency g. Published scientific research and guidance	Standard Met
How the Service meets or does not meet the standard	
Evidence of surveys and audits witnessed. Structured review of deaths document observed	
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	
Evidence of policies, procedures, and guidelines observed with version control numbers and review dates. All documents are stored on the EQMS system. Each document clearly states the author, document type, version control number, and review date.	

6 Acknowledgements

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

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

7 Appendices

7.1 Definitions

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

7.2 Peer Review Team

The Peer Review Team consisted of two consultant haematologists (one adult and one paediatric) four nurse specialists (one adult, two paediatric, and one paediatric research), one physiotherapist and a patient representative. UKHCDO holds details of the Peer Review Teams.