UKHCDO Haemophilia Peer Review Audit Report

Nottingham Haemophilia Comprehensive Care Centre

Report Date: 16 May 2025

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1 Executive summary

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

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

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

The executive summary presents the key findings, while the full report details the assessments referenced against the quality standards. Peer review for the Nottingham Haemophilia Comprehensive Care Centre (the Service) was completed on 2nd October 2024.

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

Key Recommendations:

1. **Laboratory services:** The review team recommends that the specialist coagulation laboratory be sufficiently staffed with qualified personnel to ensure 24/7 access to specialised testing, a critical requirement of the national service specification.
2. **Centre facilities/environment:** The review team recommends that the Trust find a dedicated space for the centre where the entire team can be co-located to deliver services that are safe and well-integrated for this primarily ambulatory setting cohort.
3. **Medical staffing:** An assessment of medical staffing is necessary as the staffing levels fall below the standard of similar-sized centres for providing a bleeding disorder service.
4. **Psychological support:** Arrangements for dedicated psychological support for their patient cohort, particularly post-IBI, are urgently needed.

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 onsite review, each service conducts a thorough self-assessment against the standards, highlighting strengths and areas that require attention. During the onsite visit, the peer review team focuses on elements of care and support that have the potential to improve clinical outcomes and enhance patient experiences. Feedback is provided at the end of the day, particularly emphasising any areas of immediate clinical risk.

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

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

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

3 Service Description

The peer review for the Nottingham Haemophilia Comprehensive Care Centre was completed on 2 October 2024. A multidisciplinary team of haemophilia professionals, accompanied by patient representatives, conducted the review, which involved discussions with staff from the Service, reviewing documentation, and touring the facilities.

The Service provides care, support, treatment, and advice to both adults and children with bleeding disorders, with 997 registered patients. It is based at the Queen's Medical Centre Campus, Nottingham University Hospital NHS Trust.

The Service provides a comprehensive range of clinical and laboratory services for individuals with haemophilia and other bleeding disorders, as well as their families. The multidisciplinary team seeks to encourage self-management and independence for both adults and children with inherited and acquired bleeding disorders, enabling them to lead as normal a life as possible by addressing their medical, physical, and psychosocial needs effectively.

The Service is committed to providing specialist care for individuals of all ages. It offers adult and paediatric haemostasis clinics, nurse-led telephone clinics, transition clinics, and joint specialist clinics for obstetrics and adolescent gynaecology.

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	47	21	5	2	1	1	5	5
Moderate	7	2	2	2	180	74		
Mild	63	14	9	0				
Annual review in the last year	47	21	5	2	1	1	5	5
Inpatient admissions in the last year	Day cases and inpatient admissions were aggregated.							

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 mix of adult and paediatric-specific staff in both full-time and part-time roles. The service employs three consultants: one for adults, one for paediatrics, and one for both (2.75 WTE), with only 6.75 PAs per week supporting the bleeding disorder service. In addition, there are four nurses (3.4 WTE), one physiotherapist (0.58 WTE), one psychologist (vacant at the time of review), one social worker (0.25 WTE), one biomedical scientist, and two administrative staff.

Key staff include Consultant Haematologists and Joint Centre Directors, Dr Emily Millen and Dr Joannes Hermans, as well as Lead Nurse Helen Seymour.

Outpatient care: A wide variety of clinics for people with bleeding disorders are available, including new initiatives such as the adolescent gynaecology clinic, which has received commendation. Adult clinics are held in the outpatient area, while paediatric clinics take place in the children's outpatient department. Walk-in services operate in a single treatment bay, with no consulting room space designated for a social worker or psychologist.

Inpatient care: Admission to wards is per the presenting complaint.

Out of hours: There is 24/7 Haemostasis Consultant cover. Patients are seen in the Emergency Department out of hours with appropriate pathways in place.

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

Network arrangements: There are links with the Haemophilia Centres at Derby and Lincoln, with multidisciplinary meetings for complex cases.

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 24 out of the 30 standards, with six partially met. The service is encouraged to review all descriptive assessments in addition to the key findings. This report, alongside local assessments, should steer discussions with the management team, highlighting areas of good practice while emphasising where further investment and improvement may be required.

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

Standard	Title of standard	Rating
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 Service is easily accessible to patients and carers with a single point of contact during working hours—the “bat phone.” This system is highly effective, ensuring prompt triage and fostering confidence and trust among patients and their families.
2. The Service has built strong relationships with other care providers; in particular, we noted the pain team pathway, liaison with dental services and liaison with orthopaedic services.
3. The centre has recently expanded the services offered to its patients in several ways, such as an adolescent haemophilia/gynaecology clinic, a transition process, and nurse-led adult and paediatric telephone clinics.
4. There is ongoing community support, including support for schools and for patients in the home setting where relevant.
5. Since the last peer review, several new team members have joined: a physiotherapist, a social worker, and a psychologist (between April 2021 and October 2023).
6. The engagement with Haemtrack is impressive.
7. Documentation and record-keeping are generally very good, document control is managed appropriately, and patient letters are a good example.

8. During clinic reviews, there is good access to specialist physiotherapy. There is an excellent physiotherapy gym (including a treatment table) and a gait assessment area in a modern building separate from the main hospital. The specialist physiotherapist noted the benefit this has had, with many patients reporting their satisfaction.

4.3 Immediate risks

There were no immediate risks identified.

4.4 Concerns

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

1. The review team is concerned about the lack of dedicated space to provide the service. The current service operates across a large area within the trust, with staff moving between locations, which makes it challenging to deliver integrated care. This is evident in several ways, specifically (a) staff needing to move between different locations across the hospital site – patients reported that this makes them feel there is no foundation for their care; (b) there is no dedicated consulting or counselling room for social workers or psychologists; (c) office space for team members is widely dispersed across the hospital; and (d) desk space within the centre is limited, with no room for multi-disciplinary team meetings and education.
2. The review team is concerned about the centre's lack of a play therapy area for children. This concern is heightened by the relative isolation of the haemophilia treatment room.
3. The review team is concerned that the consultant staffing level appears to be very low for the scale of the service, and there is insufficient consultant SPA time allocated for service development and continuous professional development (CPD). While current nursing levels are adequate to manage the workload, there is no capacity to take on additional tasks. This is concerning because the retirement of a colleague in Derby may increase the Service's workload.
4. At the time of the peer review, the trust had withdrawn from the IBI psychological support services. Since the peer review, the service has appointed a clinical psychologist to its team, which addresses not only one of the initial findings from this review but also a concern from the previous peer review.
5. The review team was also concerned that the Service does not have access to specialist laboratory testing 24/7, as required by the Service Specification. This is due to a lack of suitably trained staff – in fact, the out-of-hours service is reliant on the goodwill of a single biomedical scientist. This is a major risk as a single point of failure in their absence.

4.5 Recommendations

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

1. **Laboratory services:** The review team recommends that the specialist coagulation laboratory be fully staffed with qualified personnel to guarantee 24/7 access to specialised testing. Relying solely on goodwill is inadequate. Furthermore, this is a requirement of the service specifications to ensure effective, clinically appropriate, and relevant care. The absence of such a provision has led to empirical management, which is neither clinical nor cost-effective.

2. **Facilities/Environment:** It is recommended that the Trust identify a dedicated space for the Service, enabling staff and patients to be co-located with a focus on the areas highlighted above. This is important because dispersing staff and patients across the hospital site makes delivering safe and effective integrated care challenging. The care of individuals with bleeding disorders requires a cohesive, multi-disciplinary team working collaboratively for the benefit of patients.
3. **Medical staffing:** The review team calls for an immediate reassessment of medical staffing, specifically focusing on the time allocated for the leadership and delivery of the inherited bleeding disorder service. Currently, staffing levels are below 1.0 WTE, significantly lower than the standard of similar centres. The new consultant team is managing remarkably well, with many activities carried out beyond the job plan. Having the appropriate staff size is crucial to ensure both patient safety and sustained staff engagement.
4. **Provision of psychological support:** The trust and the centre are urged to ensure the provision of psychological support for their patient cohort, funded locally as appropriate.
5. **Play therapy:** The review team recommends making access to play therapy available to children. This is important as it not only helps them cope with painful or invasive procedures but is also essential for their development and well-being.

5 Quality Standards – Detailed Description

A detailed description of the quality standards used in the assessment is provided below, 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)

Standard Met

How the Service meets or does not meet the standard

At the time of the review, the clinical psychology post was vacant, so there was no access to psychology through the service. The trust had opted to withdraw from negotiations with NHSE regarding the IBI psychology service—which is provided by Leicester. The lack of psychology provision is likely to have a negative impact on patients and team members who are having discussions with infected/affected individuals regarding IBI.

Quality Standard 2: Condition-Specific Information

Standard Met

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

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

Condition-specific information should be available covering:

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

How the Service meets or does not meet the standard

There is a good mix of internal, pharma and external leaflets/documents.

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

Evidence of plans of care was seen at the review, and comprehensive care plans for children in school were noted.

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

Evidence presented shows that the majority of those with severe/moderate haemophilia or requiring regular prophylaxis attend for regular review and engage well with the service. Selected patients with non-severe bleeding disorders have telephone clinic reviews (alternating with face-to-face visits) or PIFU.

There is a lack of access to psychological support, as indicated in Standard 1.

There are good care pathways for DNAs. During clinic reviews, there is good access to specialist physiotherapy (either alongside MDT or patients reviewed separately).

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

Daytime access to advice via CNS mobile telephone; Out-of-hours advice from haematology on-call doctors.

Quality Standard 6: Haemtrack (PwBD on Home Therapy)

Standard Met

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

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

How the Service meets or does not meet the standard

Patients have been successfully encouraged to engage with Haemtrack reporting (only one patient did not report via Haemtrack).

Quality Standard 7: Environment, Facilities and Equipment

Partially Met

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

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

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

All equipment should be appropriately checked and maintained.

How the Service meets or does not meet the standard

No dedicated haemostasis unit so lack of space- only able to provide treatment one patient at a time (in the haemophilia treatment room) leads to the need for careful scheduling. Lack of a separate paediatric waiting area. No dedicated consulting/counselling room for social worker or psychologist. Office space for team members is widely spread within the hospital and desk space in the haemophilia service office is limited. No MDT room so MDT/educational meetings are held as virtual meetings. The service is spread across a large area within the trust, with staff moving between areas, and cross site to cover surgical procedures at City Hospital. This makes it challenging to provide joined-up care. Clinics are held in shared outpatient areas for paeds and adults. There is adequate capacity in adult outpatients but clinic rooms are limited in paeds. Current fridge is monitored appropriately. Disabled parking is available at the adult clinic and treatment centre.

Temporary fridge facility for storage of factor concentrates currently due to broken fridge.

Excellent adaptation of the team to challenging circumstances in terms of the environment, physical separation of the service and lack of designated haemophilia centre.

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

Standard Met

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

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

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

How the Service meets or does not meet the standard

A clearer pathway to communicating with a new GP when a young adult leaves home is needed. Transition clinics have recently been set up. Transition paperwork that is bleeding disorder specific (rather than generic, e.g., Ready Steady Go) is used.

Quality Standard 9: Carers' Needs

Standard Met

Carers should be offered information on the following:

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

How the Service meets or does not meet the standard

Adequate information provided on support for carers.

Quality Standard 10: Involving PwBD and Carers

Standard Met

The Service should have:

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

How the Service meets or does not meet the standard

Evidence was provided that the quarterly patient survey was completed, with positive comments from patients/carers. However, there is no evidence that feedback is acted upon, and any changes made to the service are reported back to the users.

Children/family activities: Go-Ape, picnics, etc. Adult patients are invited to attend peer group meetings if they wish.

Quality Standard 11: Leadership team

Standard Met

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

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

How the Service meets or does not meet the standard

There is evidence of regular meetings held with the department head, directorate lead, matron, and others.

Quality Standard 12: Staffing levels and skill mix

Partially Met

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

Staffing should include:

a. Medical staff:
    i. Consultant specialising in the care of people with inherited and acquired bleeding disorders available during normal working hours
    ii. On-call consultant specialising in the care of people with inherited and acquired bleeding disorders 24/7 in HCCC
    iii. On-call haematology consultant with arrangements for advice from a consultant specialising in the care of people with inherited and acquired bleeding disorders in HC
b. Specialist nursing staff:
    i. Bleeding disorders specialist nurses (5/7)
    ii. Ward, outpatient, and day unit staff with competences in the care of people with inherited and acquired bleeding disorders
c. Clinical specialist physiotherapist
d. Practitioner psychologist or appropriately trained psychotherapist with specialist knowledge in IBDs.
e. Access to specialist senior social worker
f. Data manager
g. Biomedical scientist and/or clinical scientist (further details on the requirements are included in QS 17)

How the Service meets or does not meet the standard

The consultant staffing level appears very low for the size of the service (6.75 consultant PA). 3.4 WTE CNS are in post, managing the current workload, but there is no capacity within the team to take on more. The retirement of a highly experienced 0.4 WTE CNS currently in post will lead to a gap in the service. The lead CNS is a non-medical prescriber.

The team reports an increase in patient numbers over recent years. There is concern that the retirement of a colleague in Derby may increase the workload for the service.

Excellent social worker providing a good service despite space limitations. The appointment of a physiotherapist and social worker following the last peer review has had a positive effect on the team, in addition to patients/carers.

Quality Standard 13: Service Competencies and Training Plan

Standard Met

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

How the Service meets or does not meet the standard

Inadequate consultant SPA time for service development and self-led CPD, although able to attend national/international conferences.

Nurses report support to attend HNA meetings but have difficulty obtaining funding for larger meetings. Due to competing demands, training registrars in the haemostasis and thrombosis post is somewhat difficult, but the haematology fellow post is funded and due to start.

Quality Standard 14: Administrative, Clerical and Data Collection Support

Standard Met

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

How the Service meets or does not meet the standard

Data managers manage some of the data input for HCCs in addition to the Nottingham centre. There is a coordinated approach to family screening and carrier identification.

Quality Standard 15: Support Services

Partially Met

Timely access to the following support services should be available:

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

How the Service meets or does not meet the standard

There is a lack of access to play therapy, which is particularly important given the isolation of the haemophilia treatment room. A structured orthotics referral was noted. There is a good relationship between the high-cost pharmacy department and stock movement.

Quality Standard 16: Emergency Department

Standard Met

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

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

ED medical and nursing staff should have training on inherited and acquired bleeding disorders.

ED pathway should be audited +/- PwBD survey on emergency attendance on an annual basis.

How the Service meets or does not meet the standard

Guidelines, education, etc., are in place to support a positive experience in the ED, but patients/carers report problems—staff in the ED failing to listen to them or to understand their diagnosis and treatment and some delays in assessment and treatment. An audit of emergency attendances did not identify a significant problem with delay in time to treatment.

Poor patient experience might lead to delayed presentation with a bleed.

Quality Standard 17: Laboratory Service

Partially 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 lack of trained haemostasis BMSs has resulted in an inability to provide haemostasis testing reliably 24/7. There is reliance on the goodwill of senior laboratory staff member to attend out of hours if required. Treatment of PwBD is frequently modified in order to get around this problem, but with the concern that this may result in sub-optimal treatment.

Excellent planning and communication between clinical and lab teams to manage elective surgery on both hospital sites, as well as the monitoring required.

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

There is a specific pathway to access pain clinic review. Adolescent haem/gynae clinic commended. Good relationship with relevant orthopaedic consultants. A good relationship with dental hubs for managing dental procedures in PwBD.

Quality Standard 19: IT System

Standard Met

IT systems should be in use for:

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

How the Service meets or does not meet the standard

Email alerts every morning of new admissions/attendances overnight, picked up by CNSs.

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

Standard Met

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

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

How the Service meets or does not meet the standard

Diagnostic guidelines are available to staff members via KOHA/intranet. They have been ratified by the haemophilia team/MDT. Document control is good; the governance lead has a spreadsheet to identify guidelines that are due to expire.

Quality Standard 21: Guidelines: Treatment and Monitoring of IABD

Standard Met

Guidelines should be in use covering:

a. Factors concentrate and non-factor replacement therapy
    i. Initiation and monitoring of prophylaxis
    ii. Home therapy
    iii. Use of extended half-life products, including inhibitor testing and PK assessment
    iv. Use of non-factor replacement therapy
b. Management of factor concentrate and non-factor replacement therapy supplies, including:
    i. Ordering
    ii. Storage
    iii. Stock control to ensure all stock is up to date and waste is minimised
    iv. Prescription and delivery for PwBD on home treatment
    v. Arrangements for emergency 'out of hours' supply
    vi. Recording issue to PwBD
    vii. Recording use by PwBD, including on Haemtrack
    viii. Submission of data via NHD for quarterly returns

How the Service meets or does not meet the standard

Treatment and monitoring guidelines are comprehensive and clear. Appropriate templates are provided within the documents, e.g., the home prophylaxis regime. Products are ordered by the pharmacy and stored in the blood bank at QMC.

Fridges are monitored for temperature change and alarmed. A small supply of factor concentrates is held at the City Hospital site and in the Haemophilia Treatment room. Intermittent problems with Haemophilia Treatment room fridge- product decanted intermittently, replacement fridge ordered.

The guidelines are very clear, and the tables are informative. Some of the documents have (recently) expired.

Quality Standard 22: Clinical Guidelines/Pathways

Standard Met

The following clinical guidelines/pathways should be in use:

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

How the Service meets or does not meet the standard

Clinical guidance and pathways are comprehensive and clear.

Quality Standard 23: Guidelines on Care of PwBD requiring Surgery

Standard Met

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

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

How the Service meets or does not meet the standard

Templates for surgical/dental care were provided and reviewed and meet the requirements.

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

Dr Simone Stokely & Dr Emily Millen- paediatric; Dr Joannes Hermans & Dr Emily Millen- adult. There is shared care for children with severe bleeding disorders or adults with severe Haemophilia A on Emicizumab; all other patients are managed independently in Derby or Lincoln but with support from regional MDT discussion where needed. Aimed to create resilience through two consultants to cover paeds/adults.

Pathway for DNAs followed, according to trust policy for paeds. Clinic attendance figures were presented at the welcome meeting. School visits are performed with home/community visits arranged as necessary. The team is rightly concerned about capacity within the team for additional work or any loss of staff. Template letters for the transfer of a patient to another centre are seen, and there are excellent nurse-led telephone clinics.

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

Virtual MDT meetings are held due to a lack of meeting room, less than ideal. Laboratory staff is not in attendance unless required to discuss complex cases.

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

Combined adolescent haematology/gynaecology clinic (3 monthly), hoping to set up a similar clinic for adult females. Combined haematology/obstetric clinic (twice weekly). There is no combined haematology/orthopaedic clinic, but there are good links with a foot/ankle surgeon, upper limb surgeon and knee surgeon. There are no patients requiring complex hepatology input.

Quality Standard 27: Data Collection

Standard Met

The following data should be collected:

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

How the Service meets or does not meet the standard

Evidence was provided that data were collected appropriately according to the standards set. Excellent engagement of patients with the Haemtrack reporting system (all but one patient involved).

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

HCCC is engaged in commercial and non-interventional haemophilia and bleeding disorders studies. The appropriate staff completed GCP training, and evidence was provided.

Quality Standard 29: Multidisciplinary Review and Learning

Partially Met

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

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

How the Service meets or does not meet the standard

The team were not able to demonstrate multidisciplinary review and learning in all areas.

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	
Use of KOHA for electronic distribution of documents. Documents are controlled and managed as per the trust policy.	

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), two clinical nurse specialists, and a specialist haemophilia physiotherapist. Details of the Peer Review Team are held by UKHCDO.