UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

UKHCDO Haemophilia Peer Review Audit Report

Hull Haemophilia Comprehensive Care Centre

HAEM-PSYCH ASSOCIATION UK & IRELAND

Haemophilia Nurses Association UK

HCPA Haemophilia Chartered Physiotherapist Association

HAEMOPHILIA SCOTLAND

The Haemophilia Society

HAEMOPHILIA WALES

Haemophilia NI
Supporting patients and families

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1 Executive summary

Haemophilia services undergo regular peer reviews to assess the quality of care provided to patients with bleeding disorders, and 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, with updated service specifications 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 constitute one of the twelve final recommendations of the Infected Blood Inquiry Report in 2024. This recommendation also requires trusts to consider peer review findings and prioritise the implementation of proposed improvements for comprehensive and safe care.

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

The executive summary provides the key findings, and the full report details the audit assessments referenced against these standards. Peer review for the Hull Haemophilia Comprehensive Care Centre (the Service) was completed on 7th October 2024. The service caters to adults and children and is located at Queens Centre, within Castle Hill Hospital in Cottingham.

The Service successfully met 23 of the 30 established standards, with seven standards partially met. The Centre's and the Trust's commitment to providing high-quality care was evident through various initiatives and pathways. However, key recommendations have been made to address gaps that impact the ability to deliver comprehensive care.

Key Recommendations:

1. **Nursing Staffing:** The review team recommends restoring nursing levels to those seen during the previous review, as diversion to non-haemophilia activities had an adverse impact.
2. **Physiotherapy Provision:** The physiotherapy services are limited, and the review team recommends increasing the amount of physiotherapy time allocated to the Service.
3. **Psychological Services:** There is no dedicated bleeding disorder specialist psychologist or social worker, and a business case for establishing these roles needs to be developed.

The UKHCDO advisory committee reviewed the final report on 9 October 2025 and endorsed the executive committee's recommendation to change the status from Interim to full CCC. This decision was based on the Service having the minimum number of registered severe patients and meeting 76% of both primary and secondary standards, with no standards unmet, demonstrating actions taken since receiving interim status. However, some gaps remain that need to be addressed to improve patient care and ensure compliance with national service standards.

The peer review findings will be shared with the clinical team, the host organisation, local commissioners, and other relevant stakeholders. We extend our gratitude to the haemophilia centre and the peer reviewers for their invaluable contributions, and we hope this report supports the Centre and the Trust in delivering high-quality haemophilia care.

2 Haemophilia and Bleeding Disorder Peer Review - Background

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

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

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

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

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

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

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

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

3 Service Description

The Service provides care to both adults and children with bleeding disorders and has 472 registered patients. It is based at the Queen's Centre, Castle Hill Hospital, which is part of Hull Teaching Hospitals NHS Trust. The Service serves the populations of the East Riding of Yorkshire, Hull, North Lincolnshire, and Northeast Lincolnshire. The Service participates in the regional haemostasis genomic multidisciplinary team meeting (MDT) but is not formally linked to any other haemophilia network.

The service offers care to adult and paediatric patients, including dedicated multidisciplinary clinics for severe haemophilia and an obstetric haematology service. There are also nurse-led clinics where haemostasis patients are supported, reviewed, and treated.

Within Hull, East Yorkshire, and North Lincolnshire, three acute hospitals provide emergency medicine services. Hull Royal Infirmary NHS Trust (HUTH) serves Hull and East Yorkshire, Diana Princess of Wales Hospital (DPOW) serves Grimsby and Northeast Lincolnshire, and Scunthorpe General Hospital (SGH) serves North Lincolnshire. HUTH delivers all haematology and haemostasis services, and no clinical haematology services are currently provided at DPOW or SGH. The Service thus functions as a standalone centre with no associated treatment centres.

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	21	4	8	2	120	15	180	44
Moderate	8	1	1	1				
Mild	59	3	5	0				
Annual review in the last year	No data provided							
Inpatient admissions in the last year	No data provided							

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

Staffing: The staff comprises a mixture of full-time and part-time roles, including three consultant haematologists (6.3 dedicated PAs), four nurses (2.9 WTE), one physiotherapist (0.3 WTE), two biomedical scientists (24 on-call), and two administrative staff (1.4 WTE). There is no dedicated psychology or social work service.

Key staff include Consultant Haematologist Professor David Allsup and Lead Nurse Katie Gladstone.

Outpatient care: There is a monthly, dedicated consultant led clinic for severe and moderate haemophilia, and a weekly consultant led clinics for all other bleeding disorders. There is a nurse led telephone follow-up clinic every 2 weeks.

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

Out of hours: Patients attend the emergency department outside of the Centre's opening hours.

Transition: Ready Steady Go is in use to facilitate the transition between children's and adult services, supported by families through the encouragement of a 'buddying' scheme**.**

Network arrangements: The Centre is not part of any network for clinical care.

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 seven partially met. The Service has outstanding findings from their previous peer review report in similar areas, which are provided in the appendix. The service is encouraged to review all descriptive assessments in addition to the key findings. This report, alongside local assessments, should steer discussions with the management team, highlighting areas of good practice while emphasising where further investment and improvement may be required.

Standard	Title of standard	Rating
1	Service Information	
2	Condition-Specific Information	
3	Plan of Care	
4	Outpatient Review of PwBD	
5	Contact for Queries and Advice	
6	Haemtrack (PwBD on Home Therapy	
7	Environment, Facilities and Equipment	
8	Transition to Adult Services and Preparation for Adult Life	
9	Carers' Needs	
10	Involving PwBD and Carers	
11	Leadership Team	
12	Staffing Levels and Skill Mix	
13	Service Competencies and Training Plan	
14	Administrative, Clerical and Data Collection Support	
15	Support Services	
16	Emergency Department	
17	Laboratory Service	
18	Specialist Services	

Standard	Title of standard	Rating
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 transport system for blood samples between sites is well-organised and robust, particularly given the consolidation of laboratory services.
2. The transition process between children and adult services is supported between families through the encouragement of a ‘buddying’ scheme.

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 are concerned that the Service is stretched in terms of staffing and workload, impacting various aspects of the service.
2. The number and workload of the nursing team leave the service with no time to conduct audits or ongoing professional or service development. There has been a recent shift in their clinical responsibilities, resulting in significantly less dedicated specialist nursing time for patients with bleeding disorders, as reflected in the lack of audits. The nurses, in addition to covering non-malignant haematology, are also supporting immunology and allergy services.
3. Physiotherapy provision is also limited due to the absence of an agreed internal Service Level Agreement (SLA) or a designated time commitment between physiotherapy and haemophilia.
4. There is no specialised psychology or social worker support for bleeding disorders.
5. Despite developing a Standard Operating Procedure (SOP) for Accident & Emergency (A&E) and undertaking an audit, the review team could not find evidence of training being provided to junior and senior A&E staff.

6. The current process for surgery beyond tranexamic acid involves referring patients to Hull. While this is not unreasonable, it can result in unnecessary treatment delays and increased travel. The team has not yet investigated the possibility of supporting surgery at other sites to prevent these delays. However, this may not be feasible with the current staffing levels.
7. Patient feedback about the current service has been excellent. However, there have been no specific comments on involving patients in the organisation of care.
8. There was no evidence of consolidated diagnostic guidelines for local use in patients referred with suspected bleeding disorders.
9. The clinical team is unable to distinguish the workload from the haemophilia/bleeding disorder service from other non-malignant haematology services. No specific treatment function or appointment types are in use.

4.5 Recommendations

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

1. **Nursing Staffing Increase:** The review team observed an erosion of nursing cover compared to the previous review, as a significant part of their time has been dedicated to non-haemophilia activities, particularly non-malignant haematology and immunology in recent years, following service reorganisation. There is a need to restore dedicated bleeding disorder nursing posts, which may also cover other non-malignant haematology, to enable a robust service. However, including immunology dilutes the expertise and hinders further professional and service development, such as establishing agreed-upon surgical pathways at other hospitals, which would help prevent delays and cancellations. Additionally, this will facilitate ongoing audit.
2. **Physiotherapy Provision**: The amount of physiotherapy is also limited due to a lack of dedicated funding. The review team recommends increasing the provision of physiotherapy time allocated to the Service. It should be noted that the service provides a combined care for both adults and children.
3. **Psychological Services:** There is also no dedicated psychologist or social worker specialising in bleeding disorders, and the service was unable to bid for psychological support due to its interim status. Support needs to be organised for this group, as the distance to the nearest service providing psychological support is considerable and could be a limiting factor.
4. **Emergency Pathway**: The review team recommends that the Service provide training to junior and senior A&E staff to ensure they understand the process when a bleeding disorder patient presents at A&E.
5. **Patient Involvement:** The review team would like to see patients more engaged in the organisation of care.
6. **Guidelines:** The review team would like to see the development of a consolidated diagnostic guideline for patients referred with suspected bleeding disorders and a schedule of audits.
7. **Audit:** The review team suggests that the service establish a continuous schedule of audits, recognising the constraints of time in job plans.
8. **Appointments:** The review team recommend implementation of specific appointment types and treatment functions as per national coding.

5 Quality Standards – Detailed Description

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

Quality Standard 1: Service Information

Written information should be offered to people with bleeding disorders (PwBD) and, where appropriate, their carers covering at least:

a. Brief description of the Service
b. Clinic times and how to change an appointment
c. Ward usually admitted to and its visiting times
d. Staff of the Service
e. How to access physiotherapy and psychology
f. Relevant national organisations and local support groups
g. Where to go in an emergency and how to access out of hours services
h. Information on delivery of products, including company contact details

How to:

i. Access social care and support services
ii. Access benefits and immigration advice
iii. Interpreter and advocacy services, PALS, spiritual support
iv. Give feedback on the Service, including how to make a complaint
v. Get involved in improving services (QS 10)

Standard Met

How the Service meets or does not meet the standard

The guidelines and polices demonstrate evidence of the above standards.

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

Standard Met

m. Health promotion to include smoking cessation, healthy eating, weight management, exercise, alcohol use, sexual and reproductive health, and mental and emotional health and well-being
n. Sources of further advice and information

Condition-specific information should be available covering:

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

How the Service meets or does not meet the standard

A variety of information booklets are used.

Quality Standard 3: Plan of Care

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.

Standard Met

How the Service meets or does not meet the standard

Letters have a Plan of Care.

Quality Standard 4: Outpatient review of PwBD

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

Partially Met

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

The haemophilia centre in Hull runs a dedicated monthly clinic for patients with severe and moderate haemophilia, as well as a weekly haemostasis clinic for those with ITP, thrombosis, and other bleeding disorders, both led by consultants. Nurses also manage a telephone clinic, which may be held on alternate weeks.

However, the current number of clinics and their follow-up capacity seem inadequate for the outpatient review needs of patients with bleeding disorders. To address this, a proposal has been introduced to introduce Patient-Initiated Follow-Up (PIFU) for a small group of patients, which is currently under review for approval.

Quality Standard 5: Contact for Queries and Advice

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

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

Standard Met

How the Service meets or does not meet the standard

One patient in the feedback mentioned occasional delays in responding to queries. However, most of the patients were very satisfied with the service provided.

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

A nurse checks Haemtrack almost daily and contacts patients as needed.

Quality Standard 7: Environment, Facilities and Equipment

Standard Met

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

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

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

How the Service meets or does not meet the standard

The facilities for the adult centre are world-class, housed within a dedicated haematology-oncology facility. Although the centre is signposted as the haemostasis unit, it is advisable to include clearer signage indicating it as a haemophilia centre as well.

The facility provides day-case treatment options and access to essential products, either through the pharmacy or directly from the ward, for immediate management.

In contrast, the facilities for children are less clear, as they appear to receive care mainly through outpatient services.

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 ready, steady, and go package of care is being implemented. Transition is supported between child and adult services, and school and home visits are arranged when appropriate. Support between families is encouraged through 'buddying' schemes.	

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	
A small number of staff and patients has led to a more personalised approach.	

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	Partially Met
How the Service meets or does not meet the standard	
Patient feedback about the current service has been excellent. There has been no evidence of involving patients in the organisation of care or incorporating their feedback, if any.	

Quality Standard 11: Leadership team

The leadership team will consist of a lead consultant, and other members agreed at a local level. This may include nurses, physiotherapists and psychologists, clinical scientists, or other members of the MDT. The lead consultant will be responsible for staff training, guidelines and protocols, service organisation, governance and liaison with other Services but may delegate some of these roles to others in the leadership team. The leadership team should all be registered healthcare professionals with appropriate specialist competences, undertake regular clinical work with the Service, and have specific time allocated for their leadership role.	Partially Met
How the Service meets or does not meet the standard	
The service is stretched, and there is no evidence of dedicated time in the nursing timetable for service development.	

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

Currently, there are three consultants specialising in non-malignant haematology; however, the exact time explicitly allocated to the bleeding disorder service remains unclear. The nursing team includes three full-time equivalent positions, one of whom is trained in paediatrics.

These nurses support the bleeding disorder service, paediatric allergy and immunology, and, more recently, ITP and complex thrombosis. The haemophilia nursing team is highly adaptable and motivated. However, there have been instances where surgeries have been postponed due to nursing capacity issues. In terms of time allocation, the bleeding disorder service requires considerably more input and is estimated to need at least 2 to 2.5 full-time equivalents to be adequately supported.

Furthermore, the need to travel between sites to review paediatric patients with acute bleeds can cause delays and disrupt other aspects of care. The journey between sites takes at least 30 minutes, and there is no designated parking. The need for cross-site working has not been factored into the workload assessment. The

nursing establishment for the haemophilia service does not need to take into account the cross-site nature of the service, i.e., the combined service for adults and children.

The concentrate is not stored within the paediatric outpatient area but is accessed by nurse specialists from the emergency cupboard elsewhere in the building.

Additionally, the service lacks dedicated psychological support or access to social workers. While patients can be referred to a psychologist within the adult service, the paediatric service has limited opportunities for background support. Nonetheless, the specialist nursing team, medical team, and physiotherapist strive to meet patient needs. A concern is the absence of dedicated psychology or social work services for people with bleeding disorders. The established and productive relationship with a general paediatrician helps mitigate this to some extent and provides a pathway to support families with safeguarding concerns.

Physiotherapy provision is also limited, with staff adjusting their schedules to support the service. There is no formal internal SLA or agreed time commitment between physiotherapy and haemophilia, resulting in episodic care that does not address long-term needs.

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

Opportunities for CPD development are seen.

Quality Standard 14: Administrative, Clerical and Data Collection Support

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

Standard Met

How the Service meets or does not meet the standard

Well supported with no gaps.

Quality Standard 15: Support Services

Timely access to the following support services should be available:

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

Standard Met

How the Service meets or does not meet the standard	
There is a very good working relationship with the pharmacy team, and all other services are available.	

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
An SOP for Accident and Emergency was provided, and an audit has been ongoing. There is no evidence of the training that is provided to staff in A&E, whether junior or senior.

Quality Standard 17: Laboratory Service

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

Standard Met

How the Service meets or does not meet the standard
UKAS accredited with access to all assays necessary for the diagnosis of bleeding disorders. The main coagulation lab is able to provide factor assays 24/7, and all BMSs on haematology rotation are trained to do so.

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

Designated staff are identified for specialist services, and a combined clinic with obstetrics is available. It is unclear if similar arrangements exist for gynaecology. Access is seen for all other services.

Quality Standard 19: IT System

Standard Met

IT systems should be in use for:

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

How the Service meets or does not meet the standard

The Centre uses HCIS and local systems.

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

Partially 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

There is no evidence of consolidated diagnostic guidelines for local use in patients referred with suspected bleeding disorders.

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

Evidence notes for all the above standards. The pharmacy is open to the idea of stocking products in other centres.

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

UKHCDO and local guidelines are in use.

Quality Standard 23: Guidelines on Care of PwBD requiring Surgery

Standard Met

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

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

How the Service meets or does not meet the standard

Evidence is seen for all standards. The current process for surgery beyond tranexamic acid is to refer patients to Hull. While this is understandable, it causes unnecessary delays in treatment and additional travel. The team has not yet considered the possibility of supporting surgeries at other locations to prevent delays. However, this may not be feasible given the current staffing levels.

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

Named consultants are present for all patients. Patients received sufficient information. There is evidence of school and home visits.

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

There is evidence of monthly meetings, which are also used for implementing new pathways.

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

Designated staff for these specialities were identified.

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	
HCIS is used.	

Quality Standard 28: Research	
The Service should actively participate in research relating to the care of PwBd with bleeding disorders. The Service should also offer links with other services to maximise research study opportunities. Staff members participating in research should be allocated appropriate time for this role.	Standard Met
How the Service meets or does not meet the standard	
Opportunities have been utilised. Clinical nurses contribute to research with minimal support from research data managers.	

Quality Standard 29: Multidisciplinary Review and Learning	
The Service should have multidisciplinary arrangements for review and implementation of learning from: a. Audit – the Service must have an audit plan, and it must include an audit of emergency and out of hours care (QS 23) b. Positive feedback, complaints, outcomes, incidents and 'near misses' c. Morbidity and mortality d. Haemophilia Dashboard (when relevant) e. Review of UKHCDO Annual Report benchmarking information on concentrate use f. Ongoing reviews of service quality, safety, and efficiency g. Published scientific research and guidance	Partially Met
How the Service meets or does not meet the standard	
There is evidence of MDT meetings, but no real evidence of audit or quality improvement projects. There is evidence of patient feedback. The ability of the nursing staff to meet all aspects of bleeding disorder care is limited by their need to cover other subspecialities, such as paediatric immunology and ITP. Essentially, this leaves them with minimal time available for audits or ongoing service development, as reflected by the lack of audits over recent years.	

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	
Trust policy is followed.	

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, a clinical nurse specialist, and a patient representative. UKHCDO holds details of the Peer Review Team.

7.3 Outstanding findings from previous peer review

The table below provides details of the issues that were raised in the previous peer review report of 2019 that have also been raised in this review. These have been highlighted here to add strength to the recommendations in this report as these issues should be addressed as a matter of priority. The

Service must be commended for the effort it has made to address the findings from the previous report, and the review team would like to see the progress continue. The Trust should ensure that appropriate resources are made available so these outstanding issues can be resolved.

Ref. Number	Statement of original finding
1	Staffing.
a	Paediatric support for the adult Haematologist leading the paediatric service was inadequate, and while the service functioned well, reviewers felt that this left her potentially vulnerable when managing specific paediatric issues. Senior managers were aware, but it had not yet proved possible to resource the service appropriately.
b	The adult service lead had insufficient PA's identified in his job plan to manage a service of this size, and both he and the paediatric lead were also working across a range of other haematology subspecialties. Consultant PA allocation across both sides of the service were not adequate for the demands of the leadership positions. The fact the service functions well is a credit to both of these individuals, but reviewers felt that this was not sustainable.
c	There was no cover for the physiotherapist, who is in a part time post (0.6 WTE). Reviewers felt that this needed to be reviewed in order to ensure that this service was appropriately resourced both for patients and staff.