UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

UKHCDO Haemophilia Peer Review Audit Report

Cambridge Haemophilia Comprehensive Care Centre

HAEM-PSYCH ASSOCIATION UK & IRELAND

Haemophilia Nurses Association UK

HCPA Haemophilia Chartered Physiotherapist Association

HAEMOPHILIA SCOTLAND

The Haemophilia Society

HAEMOPHILIA WALES

Haemophilia NI
Supporting patients and families

Report Date: 20 June 2025

Table of Contents

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 Addenbrookes Hospital (Cambridge) Haemophilia Comprehensive Care Centre (the Service) was completed on 22nd November 2024.

The Service successfully met 26 of the 30 established standards, with four standards partially met. The Centre's and the Trust's commitment to providing high-quality care was evident through various initiatives and pathways. However, key recommendations have been made to address gaps that impact the ability to deliver comprehensive care.

Key Recommendations:

1. **Physiotherapy provision:** The review team recommends that the Trust provide the Service with sufficient resources to increase its existing staffing levels for physiotherapy in line with the nationally recommended benchmarks for the size of this service. Physiotherapy is a key component of clinical care for people with bleeding disorders.
2. **Nursing staffing**: The paediatric and adult nursing teams feel quite stretched, particularly the adult nurse specialists, who are unable to take on roles aligned with advanced clinical practice. In addition to increasing the number of nurses, conducting a scoping exercise for cross-cover would enhance the robustness of the service.
3. **Psychology services:** The review team recommends that a dedicated psychologist specialising in bleeding disorders be appointed as soon as possible. This is an essential role that supports the well-being of patients and their caregivers.

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.

---

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

3 Service Description

The peer review for the Cambridge Haemophilia Comprehensive Care Centre took place on 22nd November 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 for both adults and children with bleeding disorders and has 1,604 registered patients. It is based at Addenbrooke's Hospital in Cambridge and serves as the comprehensive care centre for the East of England.

In 2013, the Service moved to a new purpose-built centre, which includes three clinic rooms, a reception area, offices, and a haemostasis laboratory. Following COVID and the loss of the haematology outpatient clinic in the main hospital, several other medical haematology clinics (including thrombophilia, TTP, and sickle cell) now operate from the centre. One of the clinic rooms is designed to be child-friendly, and the waiting area is equipped with toys.

The Service has a dedicated parking bay for haemophilia patients located just outside the centre. It is also conveniently close to the haematology day unit, where patients can receive treatment outside of the haemophilia centre's working hours (by prior arrangement).

3.1 Patient Numbers

	Inherited bleeding disorders							
Number of patients	**Haemophilia A**		**Haemophilia B**		**Von Willebrand**		**Other**	
	Adults	**Children**	**Adults**	**Children**	**Adults**	**Children**	**Adults**	**Children**
Severe	56	26	21	9	340	62	795	69
Moderate	22	7	10	2				
Mild	140	27	17	1				
Annual review in the last year	87							
Inpatient admissions in the last year								

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

Staffing: The service employs 27 professionals, including a mix of adult and paediatric staff in both full-time and part-time roles. Medical personnel comprise seven consultants, three adult haematology consultants (2.6 WTE), and four paediatric consultant haematologists (1 WTE). The nursing workforce consists of three adult nurses (2.66 WTE) and two paediatric nurses (1.4 WTE). The service does not employ a psychotherapist/psychologist. There is one adult physiotherapist (0.58), eight biomedical scientists (7.6 WTE), and four administrative staff (3.4 WTE).

Key staff include Consultant Haematologist and Centre Director Dr Emily Symington and Lead Nurses Jo Crowe (paediatrics) and Manju Aji (Adults).

Outpatient care: Adult and paediatric outpatient clinics are conducted at the centre. Adult clinics take place on Monday and Tuesday, while the paediatric clinic is held on Wednesday mornings. All patients with severe or moderate haemophilia are assessed in Cambridge at least once a year (with a six-monthly appointment at their local centre if they reside a significant distance away and cannot travel to Cambridge every six months). Before COVID, all clinic appointments were conducted in person. Since the pandemic, the Service has introduced hybrid clinics with telephone appointments for those with mild bleeding disorders, alongside a Trust PIFU policy for individuals who do not require regular follow-up. Patients experiencing bleeds that need treatment also visit the centre on a “drop-in” basis, unless there are concerns regarding the stability of their condition (such as a head injury), in which case they are referred to A&E, located a short walk from the centre, and the Service will review them upon arrival. The service now has a dedicated physiotherapist who conducts weekly gym and hydro sessions in the physiotherapy department.

Inpatient care: Good liaison with paediatric day surgery units and inpatient ward. All other admissions to the appropriate ward for the presenting condition.

Out of hours: 24/7 Haemostasis/Thrombosis consultant on call for both adults and paediatrics.

Transition: The Centre provides lifelong care, but it also follows the Ready Steady Go Transition programme.

Network arrangements: The Service has an informal network in the region, which includes registered haemophilia treatment centres in Norfolk, Norwich, Ipswich, and Peterborough. The service registers and assesses all patients with severe and moderate haemophilia A or B.

The Service holds a monthly multidisciplinary team meeting for bleeding disorders alongside other hospitals in the region to discuss complex cases. It is readily available for advice as needed. However, it does not have any outreach clinics.

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 26 out of the 30 standards, with four standards 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	🟩

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

4.2 Good Practice

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

1. The review team was very impressed by the patient welcome pack, which they found to be well considered and written in a patient-friendly manner. The inclusion of laminated cards with detailed, individualised emergency treatment plans was excellent.
2. The paediatric team has developed new posters covering the symptoms of a bleed and the care of ports, which are child-friendly and of an excellent standard. They are designed for use in schools and other departments.
3. Personalised paediatric care plans for schools are comprehensive and well thought out.

4. There is a clear pathway established for overseeing pregnancies where foetuses are anticipated to be affected by significant bleeding disorders, managed by the paediatric team. This supports expectant parents and ensures timely specialist follow-up from birth.
5. The haemostasis laboratory is located within the haemophilia centre. Laboratory staff members participate in several pre-clinic and procedure planning meetings daily and are actively engaged in MDT meetings. This facilitates excellent two-way communication between laboratory and clinical teams, ensuring safe patient care. Furthermore, a clinical scientist on the team oversees a new patient clinic, which effectively utilises expertise to alleviate service pressures.
6. The messaging feature within the MyChart system is employed for routine enquiries. A clear system ensures a prompt response from the appropriate member of the clinical team. This is very convenient for patients and families, with specific feedback from patient representatives confirming this on the day of the visit.

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. While there has been a clear increase in physiotherapy provision for both adults and paediatrics since the last peer review, the level of specialist physiotherapy staffing is below what would be expected for the size of the service. In both adults and paediatrics, staffing is inadequate to meet even minimum standards, and there is no provision for service development.
2. The feedback regarding the quality of care from the paediatric nurses was excellent; however, staffing levels are below expectations for a service of this size. Paediatric nursing constitutes 1.4 WTE roles, which means that there are times when there is no paediatric nursing presence within the centre, which also impacts the provision of home and school visits challenging. Assessing the development of adult nurses proved challenging due to two very recent appointments. The adult nursing team has lost significant experience, and there is no evidence of nurse-led clinics or other initiatives. Community visits are currently on hold because of staffing issues.
3. Although funding for a psychologist specialising in bleeding disorders was granted as part of the Infected Blood Inquiry (IBI), the Service is still awaiting the establishment of this role appointed.
4. There is no dedicated Social Worker provision for the Service.

4.5 Recommendations

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

1. **Physiotherapy provision:** The review team recommends that the Trust provides the Service with sufficient resources to increase its existing staffing levels for physiotherapy, in line with the nationally recommended benchmarks for the size of this service. Physiotherapy is a vital component of clinical care for individuals with bleeding disorders, and the service should be

adequately staffed to ensure all patients have access to specialist advice and support, not only for routine assessments but also for guidance regarding safe and appropriate physical exercise and rehabilitation following bleeding episodes and/or surgery.

2. **Nursing staffing**: The paediatric nursing team is excellent and demonstrates great initiative, but it needs to expand in line with the large volume of children and families registered with the service. There should be no restrictions on school and home visits due to limited staffing, as this is a key component of the comprehensive care service specification. Similarly, with the adult service, once training for the new recruits has been completed, it is expected that there will be a transition to a more dynamic, advanced practice CNS role that includes nurse-led clinics and community visits.
3. **Psychology service**: The review team would like to see a dedicated psychologist specialising in bleeding disorders appointed as soon as possible, as this is a requirement following the Infected Blood Inquiry. This is an essential role that contributes to the well-being of patients and their carers. All service users will benefit from the introduction of this significant service enhancement, which is also a requirement of the National Service Specification.
4. **Social Work**: Consideration should be given to appointing a social worker to support the patients.

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 welcome pack is thoughtfully designed and presented in a patient-friendly format. The inclusion of laminated cards containing detailed, individualised emergency treatment plans is outstanding.

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

A wide range of condition-specific information is available to address all aspects of this standard. The paediatric team has developed new posters that cover the symptoms of a bleed and the care of ports, ensuring they are child-friendly and of excellent quality.

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

Clinic letters outline treatment goals. Care plans provide detailed information about emergency treatment, including signs of bleeding and the management of specific bleeds. Personalised paediatric care plans for schools are comprehensive and well-considered.

Quality Standard 4: Outpatient review of PwBD

Standard Met

A formal review of PwBD should take place regularly:

a. For those with severe and moderate haemophilia, any PwBD on prophylaxis and other severe bleeding disorders at least twice a year. This may be more frequent in the paediatric setting based on clinical needs.
   The following multidisciplinary clinic arrangements for these PwBD should be in place:
   i. Involvement of medical, specialist nursing and physiotherapy staff in clinics
   ii. Availability or clear referral pathway for social work and psychology staff
b. For those with mild bleeding disorders, the Centre should have a documented follow-up pathway with a plan for managing DNA and PIFU if used. These PwBD should have access to the full MDT if clinically required but may not be seen in a combined clinic.

This review should involve the PwBD and, where appropriate, their carer.

The outcome of the review should be communicated in writing to the PwBD and their GP.

How the Service meets or does not meet the standard

SOPs encompass all aspects of this standard. Relationships with neighbouring haemophilia centres, including provisions for the regular review of patients with severe haemophilia, are clearly defined.

Quality Standard 5: Contact for Queries and Advice

Standard Met

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

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

How the Service meets or does not meet the standard

The messaging facility within the MyChart system is utilised for routine enquiries. A clear system is in place to ensure prompt responses from the relevant members of the clinical team. This is very convenient for patients and families, with specific feedback from patient representatives to this effect on the day of the visit.

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

A clear process is in place regarding the use, including sending letters to patients who are behind in entering their treatments into the system.

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

Whilst facilities are of a high standard, clinic room space is at a premium following the relocation of other benign haematology services to the centre. There is a clinic room intended for use by the specialist physiotherapist, but it is often used for other purposes. Further, patients presenting with acute bleeds may need to await room availability (there is space to deliver treatment in a timely fashion, but the clinical review may be delayed owing to a lack of room availability).

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

Integrated adult and paediatric services within a single centre facilitate a smooth transition process, and clear guidelines are established.

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

Although the service lacks a dedicated social worker, there is clear signposting to available services.

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

Quarterly feedback exercises contribute to a clearly defined governance process. Specific examples of feedback resulting in change were provided.

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

Designated leads for each professional group are in place with evidence of regular meetings.

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

Since the last peer review, dedicated physiotherapy time has been established for both paediatric and adult services. However, the number of specialist physiotherapists is below what would typically be anticipated for the service's size. Specifically, the provision for paediatric services is restricted to half a day each week. In both adult and paediatric sectors, the staffing levels are inadequate for effective service development.

Feedback on the quality of care from paediatric nurses has been outstanding. However, staffing levels continue to fall short of expectations for a service of this magnitude. Currently, paediatric nursing comprises 1.4 WTE roles, which can result in periods without a paediatric nursing presence at the centre, complicating home and school visit provisions. For a service of this scale, staffing should be at least 2 WTE, and there is no evidence of competency training or assessment for adult service nurses to provide cross-cover (or vice versa).

Additionally, band 7 and 6 nurses share equivalent clinical responsibilities, and it is strongly recommended that a job evaluation be conducted.

The adult service nurse staffing consists of 2.66 WTE roles (0.8 WTE band 7 and 2 band 6 roles). There is no HCA within the service, so nurses are responsible for performing tasks that are better suited to less specialised staff, such as phlebotomy in clinics. Nursing staffing is below what is needed for the size of the service, which means that home visits cannot be easily performed and is likely to hinder service development (such as the establishment of nurse-led clinics, which should be a priority) and optimal use of current skills (the CNS has advanced practice and non-medical prescriber training but is currently unable to utilise these skills due to other commitments).

Furthermore, there has been significant staff turnover, with two new band 6s recently recruited. There is a lack of a clear pathway for career progression at all grades, which may limit retention. Although the band 7 role is crucial within the team, having only one person at this level represents a single point of failure.

Clinical psychology lacks dedicated support within the service. A funding proposal for a role aimed at assisting those affected by the IBI recommendations has been approved, but the service is still awaiting the establishment of this role. The participation of service management in advancing this initiative would be beneficial.

Regarding social work, there is currently no dedicated provision for the service.

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

New band 6 nurses have only just taken up their posts, but attendance at HNA courses is being arranged.

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

There is a high level of administrative support. Data management services, including those for clinical trials, are available to facilitate the service.

Quality Standard 15: Support Services

Standard 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

Access to play support had been limited, but dedicated time for the involvement of play specialists in the service has recently been assured.

Quality Standard 16: Emergency Department

Partially 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

Clear guidance is established. Evidence of training for ED staff was provided. Patient representatives expressed some frustrations with waiting times and the lack of detailed knowledge about bleeding disorders among clinical staff during certain episodes of ED care (specifically paediatric). However, others reported positive experiences and noted that ED staff were caring.

The presence of alerts in the EPIC system and comprehensive emergency treatment plans, including patient-held emergency treatment cards, should enhance ED care.

However, ED attendance currently lacks audit, so the effectiveness of these measures, or the necessity for alternative measures, has not been assessed.

Quality Standard 17: Laboratory Service

Standard Met

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

How the Service meets or does not meet the standard

UKAS accreditation is in place for the relevant assays in the hospital's haemostasis laboratory. Genetic testing is conducted by a genomics hub in another Trust, with MDT discussions available. The haemostasis laboratory is situated within the haemophilia centre.

Laboratory staff attend several pre-clinic and procedure planning meetings daily and are actively engaged in MDT meetings. This facilitates excellent two-way communication between laboratory and clinical teams, ensuring safe patient care. Moreover, a clinical scientist within the team oversees a new patient clinic, which effectively utilises expertise to alleviate service pressures.

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

Arrangements are in place for referral to appropriate specialist services. Genetic counselling is done by haematology consultants, but clinical genetics referral is readily available where necessary. Specialist services available on-site.

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 EPIC IT platform enhances communication across services, including referrals to other specialities, and provides a system for secure communication within teams. The Mychart patient portal allows secure communication with patients, thereby reducing administrative burdens. Systems are also available to facilitate audits. Although these are not currently in use, they are under development.

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

Detailed haemophilia centre guidelines address the majority of these topics. A Trust-wide NAI policy is established. Currently, the investigation of individuals presenting with heavy menstrual bleeding is included within more general guidance, and consideration should be given to developing more specific local guidance.

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

Protocols for stock control and issues are robust, providing excellent traceability for out-of-hours issues. Comprehensive local guidelines address the expected topics.

Quality Standard 22: Clinical Guidelines/Pathways

Partially 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

Local guidelines generally maintain an excellent standard. However, MSK guidelines are currently deficient. A plan is in place to address this. The inhibitor monitoring and ITI sections of the local bleeding disorders guidelines reference outdated material and require updating.

There is a very clear pathway established for overseeing pregnancies where foetuses are expected to be affected by significant bleeding disorders by the paediatric team. This supports expectant parents and ensures timely specialist follow-up from birth.

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

Clear, individualised plans are established. These are communicated effectively, with clear delineation of responsibilities for treatment both pre- and post-operatively.

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

The haemophilia service organisation document has passed its review date. Recent staffing pressures mean that the adult nursing team is currently unable to conduct 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

Two types of MDT meetings happen regularly: working MDTs on clinic days or surgery days, which involve the core MDT, including lab staff, and monthly MDTs for the wider network that focus on reviewing more 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

Joint clinics are established with the obstetric service and liaison arrangements are in place for other services. A named hepatologist is available. There are existing gynaecology liaison arrangements, and significant efforts were made to launch a joint clinic. However, the gynaecology clinical leadership did not believe this was necessary. This perspective is not aligned with national guidance and should be reconsidered.

Quality Standard 27: Data Collection

Standard Met

The following data should be collected:

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

How the Service meets or does not meet the standard

The EPIC system is the primary system in use. Data entry into other systems (including HCIS) is uploaded manually by the data manager. There was a hiatus in NHD data entry during the COVID pandemic, but this data entry has now resumed.

Quality Standard 28: Research

Standard Met

The Service should actively participate in research relating to the care of PwBd with bleeding disorders. The Service should also offer links with other services to maximise research study opportunities. Staff members participating in research should be allocated appropriate time for this role.

How the Service meets or does not meet the standard

The team has seen significant enrolment in gene therapy trials. Currently, no interventional paediatric studies are underway, but participation is available in observational studies. The recent recruitment of a third specialist adult consultant will enhance capacity. However, the team currently lacks trial nurses, which places an additional burden on the overstretched nursing team.

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

Currently, no regular clinical audit has been performed. Otherwise, robust clinical governance processes are in place, but greater use of DATIX to highlight staffing concerns may be beneficial.

Quality Standard 30: Document Control

Standard Met

All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.

How the Service meets or does not meet the standard

Clear Trust guidance is in place. Occasional documents are past the review date or have no review date documented.

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 a consultant haematologist, a clinical nurse specialist, a specialist haemophilia physiotherapist and a contracts manager. Details of the Peer Review Team are held by UKHCDO.

7.3 Outstanding Findings from Previous Peer Review

The table below provides details of the issues raised in the previous peer review report of 2019 that have also been mentioned in this review. These have been highlighted here to strengthen the recommendations in this report, as these issues should be addressed as a matter of priority. The Trust should ensure that appropriate resources are allocated so these outstanding issues can be resolved.

Ref. Number	Statement of original finding
1	Staffing:
a	There was no funded post for a psychologist to work as a member of the adult team. Patients requiring psychological support, including those transitioning from paediatric care to adult care, had to be referred to outside agencies whose staff were not familiar with their clinical history or background.

b	There was a 0.4 WTE physiotherapist working across the paediatric and adult services. This was not a dedicated post but a rotational post, with different therapists working with the service every six months. This was not considered sufficient for the size of the Centre. Frequently rotating members of staff do not always have access to the necessary haemophilia-related training or CPD during their brief time in the Centre, and the care of patients was not, therefore, at the level that would be expected of a Comprehensive Care Centre. In addition, it was not possible to ascertain what proportion of patients had had formal ‘joint scores’ undertaken during the previous year.
c	There was no identified social work support for the adult service. The absence of dedicated time from staff in these key roles meant that the team could not work in the fully multi-disciplinary way expected for this service.