UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

UKHCDO Haemophilia Peer Review Audit Report

Sheffield Children's Haemophilia Comprehensive Care Centre

Report Date: 22 August 2025

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1 Executive summary

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

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

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

The executive summary presents the key findings, while the full report details the assessments referenced against the quality standards. Peer review for the Sheffield Children's Haemophilia Comprehensive Care Centre (the Service) was completed on 3rd May 2024.

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

Key Recommendations:

1. **Psychological Service:** The review team recommends establishing dedicated psychological support for patients and caregivers dealing with bleeding disorders, as current access is limited with long waiting times.
2. **Social Worker Support:** There is limited access to social workers, with no evidence of specific psychosocial resources, discussions with, or signposting for carers. .
3. **Physiotherapy Provision:** The review team suggests extending physiotherapy sessions for patients with bleeding disorders to support both proactive and reactive care.
4. **Consultant Medical Staff:** Reliance on a single consultant presents potential risks, and the review team suggests scoping the expansion of the non-malignant haematology service.

This review has identified gaps in haemophilia services that were also highlighted in the 2019 peer review. These gaps should be addressed to improve patient care and ensure compliance with national service specifications. The peer review findings will be shared with the clinical team, the host organisation, local commissioners, and other relevant stakeholders. We extend our gratitude to the haemophilia centre and the peer reviewers for their invaluable contributions, and we hope this report assists the Centre and the Trust in delivering high-quality haemophilia care.

2 Haemophilia and Bleeding Disorder Peer Review - Background

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

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

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

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

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

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

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

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

3 Service Description

The peer review was carried out on 3rd May 2024 at the Haemophilia Centre, Sheffield Children’s Hospital in Sheffield. A multidisciplinary team of haemophilia professionals, including patient representatives, conducted the review, which involved speaking to staff from the Service, reviewing documentation, and touring the facilities.

The Service offers care to children with bleeding disorders and has 349 registered patients. It is located within the Haematology and Oncology department of Sheffield Children’s NHS Foundation Trust, which caters to a population of 2.5 million children across South Yorkshire, Humberside, North Derbyshire, Nottinghamshire, and Northeast Lincolnshire.

The Service is not part of a network but does provide some shared care with Lincoln County Hospital for patients who live on the Sheffield side of Lincoln. In the past, the Service has provided comprehensive care for paediatric patients registered with Hull.

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	0	23	0	7	0	125	0	127
Moderate	0	2	0	1				
Mild	0	56	0	8				
Annual review in the last year	0	52	0	11	0	51	0	60
Inpatient admissions in the last year	0	10	0	4	0	10	0	25

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 23 professionals, including one consultant (1.0 WTE), three nurses (2.53 WTE), one physiotherapist (0.2 WTE), 13 biomedical scientists (12.76 WTE), and five administrative staff shared with Haematology and Oncology, which includes a 0.5 WTE dedicated Data Manager. The service does not have a dedicated haemophilia specialist psychologist with limited access to general hospital services.

Key staff include consultant Haematologist and Centre Director Dr Jeanette Payne and Lead Specialist Nurse Carly Bell.

Outpatient care: Outpatient and day case care is provided in a large, purpose-built facility established in 2018 to expand and improve upon the previously existing facilities. Parents and patients are given contact numbers for the haemophilia specialist nurses as the first point of contact for problems during routine working hours.

Inpatient care: If admission is necessary, inpatient facilities are available on the adjacent specialist haematology/oncology ward whenever possible.

Out of hours: All registered children have open access to the clinic and ward. Out of hours, the paediatric haematology consultant on-call is consulted and coordinates the care of any attendees and inquiries for children with bleeding disorders. Review is usually organised on the haematology ward rather than the Accident and Emergency to ensure children are managed promptly and effectively by the specialist service. For emergency problems out of hours, parents and patients are asked to call the haematology ward to speak with a staff nurse who completes a triage assessment and discusses the case with the consultant paediatric haematologist on call. When providing telephone advice, the haematology consultant will determine whether the patient is best directed to ED, for example, if immediate resuscitation is likely to be needed, or the patient is arriving via emergency ambulance, or has a suspected major head injury or fracture. If advising attendance at ED, the haematology consultant will liaise directly with the medical staff in ED to ensure that haemostatic aspects of management are appropriately addressed.

Transition: Children remain under SCH until they are between 16 and 18 years old, at which point they are transitioned to the neighbouring adult haemophilia centre at Sheffield Teaching Hospitals. The adult and paediatric centres hold regular joint MDTs to discuss joint families, including pregnant carriers and adolescent patients. This approach helps ensure a coordinated approach and a smooth transition between neonatal paediatric care and Sheffield Children's Hospital, as well as between Sheffield Children's and adult haemophilia services. The MDT also acts as a platform to establish shared guidelines and discuss common issues raised by NHSE, UKHCDO, and local commissioners.

Network arrangements: The Service is not part of a network but offers some shared care with Lincoln County Hospital for patients living on the Sheffield side of Lincoln.

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 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	🟨

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

4.2 Good Practice

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

1. The team and management demonstrate clear dedication and passion for patient care and consistently provide excellent service.
2. The review team was very impressed by the quality of the patient review letters sent to GPs. These letters were suitable for the patient’s age, personal, and easy to read from both a patient's and a carer's perspective.
3. The feedback received indicated that the service is very accessible, which has been enhanced by the addition of staff headshot photos on the website. Patients who spoke to the review team knew who to contact and how to do so.

4. The review team would like to highlight the excellent child-friendly clinical environment and adolescent area. There was also easy access to play support for children attending the unit as inpatients or outpatients.

4.3 Immediate risks

There were no immediate risks identified.

4.4 Concerns

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

1. The review team is concerned about the lack of access to a dedicated bleeding disorder psychologist. While there is a referral pathway available for broader non-bleeding disorder psychologist support or to the Lucy Project, access to this service is limited due to long waiting times. This poses an issue for both patients and their carers, as a diagnosis of a lifelong condition in an infant has a significant impact on families and carries a psychological burden. The previous peer review report highlighted concerns about the psychologist and social worker provision, specifically, that the psychologist had no time allocated to review patients with bleeding disorders and, therefore, was not fully integrated into the service.
2. There is no dedicated resource providing social worker support for the very specific needs of children and families affected by bleeding disorders, including the financial burden of caring for a child with complex health needs. There is no evidence of specialised psychosocial resources, discussions with, or signposting for carers.
3. The physiotherapy time at 0.2 WTE is quite limited, given the number of patients seen, and only allows for basic joint assessments, with no capacity to provide care according to national service standards.
4. The service depends on a single consultant specialising in Haemostasis and thrombosis, making it vulnerable to absences and relying on goodwill for out-of-hours queries regarding complex patients.
5. While there is support from service management to upskill and train ward staff, the review team did not find evidence that this training has taken place, especially considering that this is where out-of-hours telephone triage, clinical assessment and treatment occur. Minimum clinical competencies for qualified nursing staff should be agreed upon, and appropriate training, such as the "Introduction to Bleeding Disorders Course", should be supported.

4.5 Recommendations

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

1. **Psychology Provision**: The review team recommends that the service be provided with the necessary resources to employ a dedicated bleeding disorders psychologist. Prompt access to psychological services is an essential part of the treatment and recovery of patients, and they are key members of the Haemophilia Comprehensive Care Multi-disciplinary team.
2. **Social worker:** The review team recommends that the service ensure there is appropriate access to social workers and signposting to meet the needs of carers.

3. **Physiotherapy Provision:** The review team recommends increasing the amount of physiotherapy time for patients with bleeding disorders to facilitate multidisciplinary care that is both proactive and reactive.
4. **Consultant Medical Staff:** Reliance on a single consultant poses potential risks, and there is a need to scope the potential for expanding the non-malignant haematology service to enhance the robustness of the service.
5. **Training of ward staff**: Given that the ward is where out-of-hours telephone triage, clinical assessment, and treatment take place, minimum clinical competencies for qualified nursing staff should be agreed upon. Appropriate training, such as the "Introduction to Bleeding Disorders Course," should be supported to ensure children with bleeding disorders are treated by trained staff at all times.

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, particularly focusing attention on the areas where the standard was partially met or not met.

Quality Standard 1: Service Information

Standard Met

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)

How the Service meets or does not meet the standard

Leaflets are available, containing all relevant information, staff details with photographs on the website, and patient awareness of the ward and access.

The physiotherapy leaflet is well-designed. There is no psychologist; this has been recognised as an issue, and it might be helpful to provide a signposting document if required.

Information on complaints and comments, interpreters, and spiritual support can all be found on their website.

The Trust already has a Youth Forum involving patients in service development. The team hopes to establish a patient group. Currently, there is no patient portal for the Trust.

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

Good information is provided in letters about conditions, with existing documents from the Haemophilia Society covering these conditions.

QR codes are also available in clinics, accompanied by clear and specific documents for the Trust.

Additionally, travel advice is included in letters, as well as information for children on understanding ports. However, there is limited information available for carers on managing ports and home care. Updated information provided after review with guidance for parents and carers on managing ports at home.

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

Reviewed detailed letters and care plans, which use patient-appropriate language and provide advice for families, along with information for schools and in-school training.

The management of bleed forms was positive and highly accessible for patients, carers, and other professionals.

Quality Standard 4: Outpatient review of PwBD

Partially Met

A formal review of PwBD should take place regularly:

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

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

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

How the Service meets or does not meet the standard

There is involvement of nurses and consultants, but there is a lack of a pathway for referral to a specialist psychologist or social worker.

There is referral pathway for wider psychologists or the Lucy project, but with long wait times, resulting in limited access.

Not clear that there is an adequate number of appointments available for review of patients in MDT clinics. All severe bleeding disorder patients have been seen twice in the last year, in line with the standard.

A commendable number of joint scores, given the very limited physio provision, should be noted.

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

Good information is available to patients from multiple sources, which is a positive development.

A clear triage pathway and good documentation are in place. Strong links with the ward for triage and training to upskill inpatient staff. Consultants cover clear.

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

Evidence of the use of Haemtrak and various options to make it as accessible and easy as possible was noted. Clear support for this is evidenced in letters.

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 storage of clotting factors was reviewed. Access to play specialists and resources was excellent and should be highlighted as a positive point, partly addressing the limited psychological support. Good access to clinical spaces, quiet areas for carers, meeting rooms, and MDT meeting rooms was observed.

There is a great waiting area for children and families to use.

Data manages HCIS, and nurses utilise other systems, including Haemtrak. Access to computers is available in each clinic area.

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

The team aims to further develop this to include a joint clinic with a consultant. Patients have a clear understanding of the process and feel involved. Documentation for 'Ready, Steady, Go' has been reviewed. Letters have been CC'd to Adult Services to update them about the transition process. An individualised approach to transition has been adopted, working flexibly to meet patient needs. A booklet is more widely available within the trust.

Quality Standard 9: Carers' Needs

Partially 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

There are no specific psychology resources available for carers, nor any evidence of discussions or signposting to psychology services for them. Although informal links to the cancer social worker are used, it would be helpful to have the social worker's input to support carer assessments and address their needs. The service provides information on what carers should do in an emergency.

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

Positive feedback from the patient survey was received, though response rates were low. Repeating the survey could be helpful in gathering more insights and guiding improvements.

There was a broad range of feedback from IBD patients. While there is no clear evidence of a 'you said, we did' approach, it was noted that feedback on actionable items was limited.

The hospital offers a Youth Forum for patients.

A QR code is available for inpatients to provide feedback, and it may be beneficial to invite outpatients to participate if this has not already been done.

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

A clear description of the structure available and accessible to patients using the online service, including a named deputy.

Quality Standard 12: Staffing levels and skill mix

Partially Met

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

Staffing should include:

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

How the Service meets or does not meet the standard

The team is dedicated, clearly passionate and competent, but the available time is insufficient to meet all standards.

Support to upskill and train ward staff is in place, but there is no evidence to suggest that it is being utilised. There is access to a Pharmacist.

Limited access to dedicated psychologists and social workers restricts the provision of multidisciplinary care.

Funding is also insufficient to expand CNS and physiotherapy services, with physiotherapy being particularly limited.

The service relies on a single consultant with an interest in Haemostasis and thrombosis, which makes it vulnerable to absences and depends on goodwill for any out-of-hours queries on complex patients. There is no need to assess the potential for a second consultant position, as this is a regional service.

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

Evidence of mandatory training includes the development of CNS competencies, such as the prescribing course, which was seen.

The physiotherapist completed ultrasound training. Cover physiotherapists have completed introductory IBD training and are working alongside an adult physiotherapist with a special interest in IBD.

There are opportunities for conferences, but none have been attended yet. Support from the wider trust facilitates access to these opportunities as a priority for development.

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

The data manager is doing a thorough job.

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

Excellent access to play support services and prompt assistance tailored to individual requirements.

Good availability of broader development needs, including a school room.

Referral systems are in place to access services as needed.

Quality Standard 16: Emergency Department

Standard Met

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

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

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

How the Service meets or does not meet the standard

Patients do not routinely access ED. Alerts are in place for bleeding disorders on the system. An audit of attendance is underway.

It would be beneficial to develop a training package for ED. Information is available in their handbook. Caveat: met because ED is very rarely used due to the pathway with the ward.

Patient feedback indicated that when it was used, it was less effective than it could have been. This highlights the need for further training to prepare staff for this situation.

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-accredited labs and tests specify whether they are available in-house or if a process is in place to send samples elsewhere. There is a clear pathway for genomics.

The lab manager does not attend MDT meetings formally but is involved in frequent informal discussions due to staffing levels.

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

Available as necessary.

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

Access is available to letters and treatment plans, along with evidence of audits and summaries, as well as plans for improvement and audit strategies. A data manager is responsible for overseeing data management.

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

There is no specific guidance on menorrhagia from haemophilia, but it is discussed more broadly. It needs to be addressed specifically. NAI through safeguarding.

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

All areas are covered in SOPS, guidelines, and access on the intranet. Provides details on how to access and order products. Coordination with the adult team facilitates greater efficiency of use. Includes evidence of home treatment. Submission to NHD occurs regularly.

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

Lack of ITI guidelines made available for review. There is no HIV information, which is understandable. Following the review, diagnosis and management of congenital haemophilia with inhibitors have been provided.

No evidence of physiotherapy guidelines available for review—long-term surveillance of MSK health is not seen.

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
e.

How the Service meets or does not meet the standard

Good examples of surgical plans and details of working collaboratively with other teams for the safe delivery of care were provided. There are SOP guidelines that detail how to manage risk.

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

All named consultants and services engage with patients and carers, with regular reviews of care plans and school visits documented during transitions. A non-bought policy was not available (trust).

There is limited evidence of an annual review of care for mild patients, although all severe and moderate patients received reviews, most more than once a year.

After peer review, the updated information indicated that all mild patients were offered annual telephone clinic reviews with CNS, as described in the operational policy. Patients are on open access. There is scope to improve by increasing contact with VWD or milder bleeding cases to support long-term relationships with the bleeding disorder.

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

Clear attendance to MDT and a good summary document to guide discussion, including awareness of patient need (transition). Attendance at genomics MDT noted.

Quality Standard 26: Multidisciplinary Clinics/Liaison Services

Combined clinics or other arrangements for multidisciplinary discussion with

a. Orthopaedics and or rheumatology
b. Obstetrics and gynaecology
c. Paediatrics
d. HIV
e. Hepatology

Standard Met

How the Service meets or does not meet the standard

Evidence of communication and referral for lines and ports, and to obstetrics and surgery with adult services and referrals to the gynae clinic noted.

Quality Standard 27: Data Collection

The following data should be collected:

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

Standard Met

How the Service meets or does not meet the standard

Evidence of adverse event reporting, as well as dashboard reporting, was noted as expected.

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

Evidence of participating in research, no current active projects. Research support.

Quality Standard 29: Multidisciplinary Review and Learning

Standard 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

Audit presentation available.

Response to complaints evidenced by good feedback from patients in the survey.

MDT agenda items cover morbidity. Annual reports are reviewed. Audit reports, published research, and guidance are evidenced.

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

Document control was in evidence.

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 paediatric haematologist, two Clinical Nurse Specialists (one adult and one paediatrics) a Clinical Psychologist and a patient representative. Details of the Peer Review Team are held by UKHCDO.

7.3 Outstanding findings from previous peer review

The table below provides details of relevant issues that were raised in the previous peer review report of 2019, some of which 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 Trust should ensure that appropriate resources are made available so these outstanding issues can be resolved.

Ref. number	Statement of original finding
1c	Although a psychologist was available to see children and their families, the psychologist had no allocated time to do so and could not work in a fully integrated way in the service. Waiting times for routine appointments could be up to twelve weeks. Patients had reported that they would value more contact with a psychologist.
1d	There is no dedicated social worker available to work with younger children and families. The social worker from the adult team at RHH could sometimes help with young people at pre-transition age.