UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

UKHCDO Haemophilia Peer Review Audit Report

Birmingham Adult's Haemophilia Comprehensive Care Centre

HAEM-PSYCH ASSOCIATION UK & IRELAND

Haemophilia Nurses Association UK

HCPA Haemophilia Chartered Physiotherapist Association

HAEMOPHILIA SCOTLAND

The Haemophilia Society

HAEMOPHILIA WALES

Haemophilia NI
Supporting patients and families

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1 Executive summary

Haemophilia services undergo regular peer reviews to assess the quality of care provided to patients with bleeding disorders. 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 Birmingham Adult Haemophilia Comprehensive Care Centre (the Service) was completed on 12th September 2024.

The Service successfully met 22 of the 30 established standards, with eight standards partially met. The Centre's and the Trust's commitment to providing high-quality care was evident through various initiatives and pathways. 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 recommend that the Service increase its physiotherapy provision to ensure that the minimum HCPA standards are met. This is important because physiotherapy plays a crucial role in the care and recovery of patients.
2. **Centre facilities:** The review team recommends that the Trust collaborate with the Service to reconfigure the haemophilia centre, ensuring it provides sufficient space for both staff and patients.
3. **Consultant staffing:** The review team recommend that the Trust undertake a review of the consultant workforce covering non-malignant haematology services to support Service growth. The current provision of support for bleeding disorders is less than that seen in other centres.

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 for the Birmingham Adults Haemophilia Comprehensive Care Centre took place on 12th September 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 to patients aged 16 and above with bleeding disorders and currently has 1,400 registered patients. The service is based at the Queen Elizabeth Hospital in Birmingham. The Service works closely with the Children's Haemophilia CCC based at Birmingham Women's and Children's NHS Trust, which provides care to patients with bleeding disorders up to the age of 16. The Service also works with haemophilia treatment centres within the region, including University Hospital Coventry, Royal Stoke University Hospitals (Stoke-on-Trent), Princess Royal Hospital (up to the age of 18 and located in Telford) and New Cross Hospital (Wolverhampton).

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	116	0	12	0	418	0	655	0
Moderate	47	0	19	0				
Mild	112	0	21	0				
Annual review in the last year	159	0	38	0	201	0	198	0
Inpatient admissions in the last year	11	0	2	0	6	0	6	0

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 18 professionals, consisting of a blend of full-time and part-time roles. The team includes four consultant haematologists (3.5 WTE, with only 1.0 WTE designated for bleeding disorders across the four positions), four nurses (3.8 WTE) with a vacancy, one physiotherapist (1.0 WTE) currently unfilled, one psychologist (0.6 WTE), four biomedical scientists (4 WTE), and three administrative staff (2.5 WTE).

Key staff include consultant haematologists and Co-Centre Directors Dr Charles Percy and Dr Gillian Lowe, as well as lead nurses Helen Hupston and Malanie Waththegedara.

Outpatient Care: The haemophilia centre is open Monday to Friday, from 08:30 to 16:30. In addition to attending for acute assessments, patients are pre-booked for blood tests, intravenous iron infusions, post-procedure reviews, and treatment prior to planned procedures (e.g., platelet transfusions or factor injections). Two bleeding disorders clinics are held on Tuesday mornings and every other Wednesday morning. An obstetric haematology clinic is held at Birmingham Women's Hospital every Wednesday morning, and pre-pregnancy planning clinics are conducted on Thursday mornings as needed.

Physiotherapy reviews were previously held on Tuesday mornings when capacity permitted and subsequently scheduled at other times within the physiotherapy department. Psychology reviews occur on different days from the medical clinics and may take place at the haemophilia centre, the Centre for Clinical Haematology, or virtually.

There is a weekly laboratory MDT meeting on Monday afternoons to review investigation results and discuss planned procedures and inpatients, ensuring that the laboratory is informed of the necessary monitoring. Developments in laboratory services, EQA issues, and operational constraints are also addressed in this meeting.

Every Thursday afternoon, a clinical MDT meeting is held, during which the following topics are discussed. All attendees at the haemophilia centre from the previous week are reviewed, and any clinic patients requiring specific actions are addressed. Additionally, any patients scheduled for planned procedures are considered. Physiotherapy patients were previously discussed but are not currently addressed due to a vacant position.

There is a monthly operational meeting on Tuesday afternoons with the group and operational managers, as well as the matron for the clinical haematology and haemophilia team.

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

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

Transition: The Ready Steady Go programme is initiated at the Children's Hospital and is subsequently followed by the Adult Service.

Network arrangements: The Service is, in theory, part of the West Midlands Bleeding Disorders Network; however, meetings ceased during the COVID-19 pandemic. They held a meeting in 2022, but the local commissioner was amalgamated with the East Midlands commissioner, and now this responsibility has been delegated to the integrated care boards in the region. The Service plans to restart meetings in autumn 2024, but these will focus on education rather than commissioning or service organisation.

4 Quality Standards

4.1 Overview

The table below outlines the status of each standard, categorised as met (green), partially met (yellow), or not met (red). Overall, the Service has met 22 out of the 30 standards, with eight partially met. The Service has outstanding findings from their previous peer review report in similar areas, which are provided in the appendix. The service is encouraged to review all descriptive assessments in addition to the key findings. This report, alongside local assessments, should steer discussions with the management team, highlighting areas of good practice while emphasising where further investment and improvement may be required.

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

4.2 Good Practice

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

1. There is excellent patient engagement, with patients noting that the staff are very caring, committed, and have good communication.

2. The team engaged openly and honestly during the Peer Review. It was noted that they provided excellent care, despite significant issues; for example, the nursing team worked creatively to cover staffing gaps.
3. The clinic documentation was very thorough and easy to see. Treatment plans were easily accessible on the system, and the orthopaedic and dental plans were particularly notable.

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 environment and facilities were suboptimal, contributing to issues of patient confidentiality. The review team acknowledges that space is a concern across the NHS; however, the team is worried about the physical space available within the haemophilia centre, particularly the lack of area for discussions with patients outside of consultations. There is insufficient desk space for a growing team and for MDT discussions, which are key components of Comprehensive Care. Patients attending the department can overhear telephone conversations with clinical staff and other patients. The admin desk is combined with the reception area, meaning patients enter the space where confidential information is displayed onscreen, and there is no barrier to shield the information from view. This arrangement prevents the maintenance of patient privacy and confidentiality. Furthermore, staff facilities are generally inadequate.

2. The nursing workload seems to be increasing, and the current nursing team includes some temporary or seconded staff members. We recommend conducting a comprehensive review of the nursing team's skill mix to ensure that experienced specialist nurses cover all aspects of the service, including the community visits.

3. Issues with emergency pathways were noted. The review team is concerned about the absence of an alert for ED staff and from the ED to the Haemophilia team. Patients understand the necessity of informing the out-of-hours doctor, and they frequently contact the haemophilia team when in the emergency department or en route there. Staff have acknowledged the alert issue and have made attempts to resolve it. However, the responsibility for notifying the haemophilia on-call should not rest solely with the patient or their family, who may be in pain or distress.

4. The specialist physiotherapy post is currently vacant. The review team is concerned about the amount of physiotherapy time available for the service. The postholder needs to meet the standards for joint surveillance and review post-bleed (HCPA standards). There is no representation from physiotherapy at MDT meetings. Physiotherapy is a key component of Comprehensive Care and should be present at all review clinics and all multi-disciplinary team meetings. It should be available to patients for acute treatment, rehabilitation, and guidance on musculoskeletal health, including exercise and sports activities.

5. The consultant workload was noted, with the haemostasis and thrombosis consultants covering numerous areas of general and laboratory haematology. This represents a significant workload, particularly during on-call shifts and differs from practices at other

haemophilia centres. Additional recruitment would help sustain the current model and increase the time commitment for the bleeding disorder service.

4.5 Recommendations

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

1. **Environment & Facilities:** The review team recommends that the Trust assist the Service in reconfiguring the haemophilia centre or identifying new space to ensure it provides adequate room for staff and patients, addressing the specific points raised in the concern above. The review team urges the Trust to consider how the current layout of the service's space fails to provide patients and their families with privacy and confidentiality, and to address this as a matter of urgency.
2. **Consultant staffing:** The review team recommends that the Trust conduct a review of the need for additional recruitment at the Consultant level in non-malignant haematology services to support service growth. The current provision of support for bleeding disorders is markedly less than what is observed in other centres.
3. **Nursing staffing:** The review team also recommends a comprehensive review of the nursing team's skill mix to ensure that experienced specialist nurses manage all aspects of the service, including community visits.
4. **ED Pathway:** The review team recommends that the service collaborate closely with the ED to implement an alert when a patient with a bleeding disorder presents at the ED. This is crucial because patients with bleeding disorders require specialist treatment to be administered promptly to prevent deterioration and the consequences of bleeding.
5. **Physiotherapy provision:** The review team recommends that the Trust collaborate with the Service to evaluate the physiotherapy provision, ensuring that the minimum HCPA standards are met. Physiotherapy is a vital aspect of the multidisciplinary management of bleeding disorders.

5 Quality Standards – Detailed Description

A detailed description of the quality standards used in the assessment is provided, along with a concise overview of how the Service has met these standards, with a particular focus on areas where the standards were 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	**Standard Met**

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

Patient information booklets were available. The nursing staff provides patients with additional information when they contact the centre. Additional signage on-site to help visitors locate the centre would be beneficial.

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

Evidence was seen and heard from patients as well as staff that this information is given to patients. Generic information is provided to patients regarding symptoms, behaviour, and emergency care. Further emergency care information, such as travel-specific advice, is provided to patients when they approach the centre for this purpose. Patients report that they feel that they have easy access to discuss these matters with staff.

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 provide this information, and additional details can be found on the portal. Consideration of making the plans easier to access would be helpful. Information is available for Emergency department staff, but there is no flag to alert them to PwBD specifically. Patients report that they or their relatives inform ED staff about their condition upon admission. Patients also report that they would routinely contact the haemophilia centre to advise them that they are about to attend the ED.

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

The lack of physiotherapy provision means that this standard is partially met. Awareness of the physiotherapy needs of PwBD and requirements surrounding standards of care among non-specialist physiotherapy staff is lacking, following the previous post holder's departure. Plans are in place to advertise for the role. This will help ensure that a physiotherapy service is provided in line with current guidelines rather than a reactive, emergency-only service.

Other members of the MDT meet to discuss patients, although space for these meetings is limited. There are two dedicated clinic rooms and two treatment rooms. Most of these rooms are small, and the number is insufficient to run multidisciplinary clinics. There is insufficient space to accommodate all required staff in one room for MDT meetings, and those attending online often struggle to hear properly due to the facilities not being designed for meetings.

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

Staff report that they field queries from patients and their relatives, both in person and by telephone. Patients echo this and report that the centre staff, including the administrative team, nursing and consultant teams, are very approachable and responsive. The space for managing these queries is lacking; given that there is no reception, there is limited confidential space for patients to raise queries and staff who are not engaged with resolving the matter report that their working environment is disrupted as a result.

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

Letters are provided with the above information, and patients and staff report encouragement of using Haemtrack.

Quality Standard 7: Environment, Facilities and Equipment

Partially Met

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

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

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

All equipment should be appropriately checked and maintained.

How the Service meets or does not meet the standard

There is limited space within the haemophilia centre, specifically in relation to the following points: the space for the MDT is small, does not allow for additional staff (once appointed), and is not conducive to in-depth discussions.

There is a lack of dedicated staff room, meaning that lunch and break facilities are spread between fridge room and desk space. Increased facilities are required for staff, including toilets.

There is a lack of confidential spaces for staff to discuss patients outside of face-to-face consultations. There was concern that patients attending the department could overhear phone discussions between clinical staff and patients. The admin desk is also the reception area, meaning patients enter the space where confidential information is displayed on screen, and there is no barrier in place to shield the information from view.

Whilst an additional band 5 member of staff is planned, it is unclear where there is space for them to work clinically.

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

Standard Met

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

- a. Information and support on taking responsibility for their own care
- b. The opportunity to discuss the transfer of care with paediatric and adult services
- c. A named coordinator for the transfer of care
- d. A preparation period prior to the transfer

e. Written information about the transfer of care, including arrangements for monitoring during the time immediately afterwards
f. Advice for young people going away from home to study, including:
    i. Registering with a GP
    ii. How to access emergency and routine care
    iii. How to access support from their Comprehensive Care Centre
    iv. Communication with their new GP

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

How the Service meets or does not meet the standard

Ready steady go is started in the paediatric service and continues in the adult service. There is a leaflet that provides information to patients, although, with recent staff changes, some of the names require updating

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

The patient’s relatives reported feeling very well supported by the centre and its staff. Clear information, including contact details for the centre, are given to relatives. Relatives reported that they felt that their needs were considered in addition to those of the patients. They found the support from the centre's staff invaluable.

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

Service audits were presented. Staff have asked for these to be modified to give more service-specific information, as some are broad. A quarterly Friends and Family test report is available, along with informal feedback. Patients feel able to contact the centre and provide feedback readily.

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

The leadership team was clearly identified and knowledgeable about the service, its strengths, and its challenges. Training records were provided for all staff to show evidence of appropriate training in relevant competencies.

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 physiotherapy provision is limited for the size of the service, and it is unable to meet the standards for joint surveillance and review post-bleed (HCPA standards); there is no involvement in the MDT. Although there is now 1.0 WTE funding for physiotherapy, the cover is split between less than two full-time posts (0.7 WTE and 0.3 WTE, respectively). Currently, only the 0.3 WTE post is filled. This area only partially meets the standard.

Consultants cover haemostasis and thrombosis but are also noted to cover many areas of general and laboratory haematology. This represents a significant workload, especially on call and differs from practices in other haemophilia centres. Additional recruitment would help sustain the current model, where the input from consultant staff is less than in other centres, despite the provision of 24/7 cover.

The nursing staff is inadequate, with recruitment planned for band 5. It is important to note that the admin staff are currently undertaking some additional tasks to support the non-clinical service that nurses would normally do.

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

This is met for the staff in post, with the caveat that the physiotherapy specialist post can't contribute as it is vacant. Evidence of conference attendance and nursing training was presented.

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

Staff in this area are dedicated and provide invaluable support to the team. The team highlighted the need for increased data management resources. See Standard 27.

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 support services is available. The team has requested additional support from the pharmacy to help reduce product waste as it approaches its expiration date. This relates to the use of the off-site warehouse and variable requests that are made. There are some geographic challenges, and in some areas, access is provided through generic rather than specialist services.

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

No alert for ED staff. There is an email alert to inform the haemophilia team that someone has been admitted to the ED, but this does not include people who have arrived in the waiting room and have not yet been seen. There is a guideline in place for ED. However, patients are advised to contact the haemophilia staff during normal hours and the on-call haematology doctor outside of hours to ensure that the correct action is taken.

This is an ongoing national issue that has been recognised by staff, and they have attempted to rectify it locally.

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

Service meets laboratory standards with a 24-hour UKAS-accredited service. The laboratory offers a wide range of routine and specialist haemostasis assays onsite. The Genetics pathway includes regular regional genomic MDT.

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

Access to specialist services is available across the range required. Rheumatology services are available, although used infrequently, as patients are more often referred to orthopaedics. Dental services are provided via a private clinic off-site. HIV and hepatology services are provided via a separate liver clinic. Chronic pain service available.

Quality Standard 19: IT System

Partially Met

IT systems should be in use for:

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

How the Service meets or does not meet the standard

Increased data management is required, and current administrative staff are filling this gap. Plans can be difficult to locate on the current IT system. The ability to provide more detailed service audits would aid service review and development. Improved clinical alerts would highlight PwBD presenting in the ED.

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

Guidelines reviewed and in place. An additional section on the management of heavy menstrual bleeding would be of benefit within these documents.

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

Documentation reviewed and covered all areas, including management of factor concentrate, home treatment & out-of-hours treatment.

Quality Standard 22: Clinical Guidelines/Pathways

Standard Met

The following clinical guidelines/pathways should be in use:

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

How the Service meets or does not meet the standard

Clinical guidelines for the above conditions were seen. Some documents require updates.

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

Processes and guidelines are in place for managing surgical interventions.

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 above standards are met, with the exception of physiotherapy, which was missing from MDT discussions at the time of review.

Quality Standard 25: Multidisciplinary Team Meetings

Partially Met

Multidisciplinary team meetings to discuss PwBD's plans of care, including surgical procedures, should take place regularly involving:

a. All core members of the specialist team
b. Senior biomedical scientist or clinical scientist with responsibility for the Coagulation Laboratory
c. HC staff who are regularly involved in the PwBd care as part of network arrangements

How the Service meets or does not meet the standard

MDT meetings take place regularly; however, labs have separate meetings with clinical staff, which detracts from the MDT nature of the meetings. At the time of review, physiotherapy staff were unavailable, and this standard is therefore partially met.
The space available for MDT discussion does not facilitate full MDT involvement.

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

There are measures in place to provide all of the above MDT clinics/liaison services. There is a joint orthopaedic clinic at the Royal Orthopaedic Hospital. HIV and hepatology reviews are completed in separate clinics.

Quality Standard 27: Data Collection

Partially Met

The following data should be collected:

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

How the Service meets or does not meet the standard

HCIS data was, in places, incomplete and inaccurate. There is insufficient time/staff resources for the data manager to complete a data cleanse. The current resource for data management is 0.5 WTE.

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 an appropriate time for this role.

How the Service meets or does not meet the standard

The centre participates in a wide variety of research activities, and evidence was presented on review day.

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	
The reviews include all the required information, and consultant teams take the lead on service audits. There is evidence of involvement in the development of national guidance.	🟩

Quality Standard 30: Document Control	
All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	**Partially Met**
How the Service meets or does not meet the standard	
Some documents require the date updating.	

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, and specialist haemophilia physiotherapist. Details of the Peer Review Team are held by UKHCDO.

7.3 Outstanding findings from the previous peer review

The table below provides details of the issues that were raised in the previous peer review report of 2019 that have also been raised in this report, it does not include all findings. 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
1	Staffing
c	**Physiotherapy** At the time of the visit, a Band 7 physiotherapist was contracted to the service for only four hours per week. There was a plan to expand this back to the former provision of approximately seventeen hours per week. However, it was judged that this would still fall short of the requirement, given the patient numbers. Within this time allocation, the physiotherapist was able to offer an acute-only service and was not able to undertake the expected routine joint scoring or work with patients towards long-term joint health. The physiotherapist's interest and expertise in pain management could not be used within these hours, and patients particularly commented that they needed more help with joint pain. In addition, there were no clinical guidelines for the management of synovitis and target joints, or long-term joint health. It was understood that within the current physiotherapy provision it was not possible to undertake this work; however, establishing a guideline outlining expected levels of care would allow for an audit of compliance, highlighting the gap in the service. This may be powerful in supporting the case for increased specialist physiotherapy hours.
d	**Social worker** Following the retirement of a dedicated social worker over a year before, it had not been possible to get agreement to re-appoint to the post. Nurses were trying to undertake some of the duties that a social worker would usually undertake, in their already stretched working time, but patients were not getting the support they needed particularly in relation to applications for benefits.
Further consideration	
1	Space in the Centre was not adequate for the staff currently working there. At the time of the visit two consultants were seeing up to twenty-four patients in the haemophilia clinic. When the specialist haemophilia clinic was run on a Tuesday morning there was insufficient space for patients to wait, and they over-spilled into an oncology waiting area. When there was no available room for the physiotherapist to see patients in the Centre, they had to go instead to the physiotherapy department, which was a long distance across the large hospital site. A review of the consultants' job plans may be useful to see if the clinic could be split into separate sessions.
4	There was no 'alert' immediately visible on the electronic record that a patient had a bleeding disorder.