UKHCDO Haemophilia Peer Review Audit Report

Royal Free Haemophilia Comprehensive Care Centre

Report Date: 16 May 2025

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1 Executive summary

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

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

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

The executive summary presents the key findings, while the full report details the assessments referenced against the quality standards. Peer review for the Royal Free Haemophilia Comprehensive Care Centre (the Service) was completed on 14th March 2024. The Service is located within the Royal Free Hospital of the Royal Free London NHS Foundation Trust.

The Service successfully met 23 of the 30 established standards, with seven 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. **Physiotherapy provision:** Physiotherapy is a key component of the service specifications, and the organisation should substantiate the second physiotherapy post, which is currently a fixed-term role. The existing provision is relatively under-resourced compared to the service size.
2. **Nursing Workforce:** The review team recommends increasing the nursing workforce to meet the growing demand for services. The shortage is exacerbated by the loss of 0.5 WTE of the Lead Nurse. This has led to the loss of weekend cover and other nursing activities, with an emphasis on the immediate needs of the growing number of in- and outpatients.
3. **Facilities and environment:** There is a general lack of space for this large service, particularly for the physiotherapy team, who lack a dedicated area to conduct physiotherapy assessments and must instead utilise the corner of the main clinic room.

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

2 Haemophilia and Bleeding Disorder Peer Review - Background

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

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

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

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

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

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

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

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

3 Service Description

The peer review for the Royal Free Haemophilia Comprehensive Care Centre was completed on 14th March 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 primarily provides care for adults and children aged 12 and above, with 2,081 registered patients. It is located at the Royal Free Hospital, Pond Street, London NW3 2QG. The service offers comprehensive, holistic care as detailed in the National Service Specification, featuring full-time consultants in Haemostasis and Thrombosis, alongside a team of highly experienced specialist nurses, allied health professionals, and healthcare scientists. An on-site haemostasis laboratory is staffed by biomedical scientists who assist with all aspects of diagnosis and treatment monitoring.

The service's holistic approach incorporates inpatient, outpatient, and community-based care. It offers an outreach clinic at Luton and Dunstable University Hospital. The Centre also collaborates closely with the Great Ormond Street Hospital Haemophilia Comprehensive Care Centre, including a joint MDT transition clinic. A bi-weekly clinic is available for women and girls with bleeding disorders. Moreover, the centre serves as the Haemophilia Gene Therapy hub for the North Thames region.

Alongside the clinical team, the clinical trials team manages all aspects of haemophilia studies, including gene therapy. The team conducts several UCL-sponsored clinical studies.

3.1 Patient numbers

Number of patients	**Inherited bleeding disorders**							
	Haemophilia A		**Haemophilia B**		**Von Willebrand**		**Other**	
	Adults	Children (12 -18 yrs)	Adults	Children (12 -18 yrs)	Adults	Children (12 -18 yrs)	Adults	Children (12 -18 yrs)
Severe	162	1	37	3	95	4	1483	24
Moderate	36	0	21	0				
Mild	175	2	37	0				
Annual review in the last year								
Inpatient admissions in the last year	Not provided	Not provided	Not provided	Not provided	Not provided	Not provided	Not provided	Not provided

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

Staffing: The service employs 35 professionals, including four NHS consultants, one associate specialist, and two UCL academics, all of whom also cover haemophilia, haemostasis, thrombosis, and anticoagulation (2.0 WTE Medical cover).

The Haemophilia nursing staff comprises one lead nurse (0.5 WTE), three specialist nurses (3.0 WTE), and two junior nurses (2.0 WTE). The allied health professionals consist of one psychologist, one permanent physiotherapist (0.7 WTE), and one physiotherapist (1.0 WTE) on a fixed-term contract. Additionally, the team comprises nine administrative staff, including two full-time data managers, two reception staff, and three clinical pathway coordinators who also oversee Haemostasis, Thrombosis, and Anticoagulation Services, as well as one Band 5 office manager.

The service also has two research nurses, one clinical fellow, three data managers, and a gene therapy trial manager. This blend of full and part-time roles ensures that comprehensive patient care is provided.

Key staff include Consultant Haematologist and Centre Director, Prof. Pratima Chowdary, and Lead Nurse, Elsa Aradom.

Outpatient care: A weekly, consultant-led multidisciplinary clinic is available for patients with severe and moderate haemophilia. Additional weekly clinics cater to individuals with other bleeding disorders, alongside two weekly clinics specifically for newly referred patients undergoing diagnostic workup. Specialist nurses conduct telephone clinics for follow-up care of individuals with mild bleeding disorders, held twice a week. A specialist combined obstetrics and gynaecology clinic for women with bleeding disorders is held every two weeks, and bi-monthly combined orthopaedic clinics are also available.

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: A joint Consultant appointment with Great Ormond Street Hospital enables a seamless transition for children and young people moving into adult services, and multidisciplinary clinics are held weekly.

Network arrangements: The North London Adult Haemophilia Network is under review. An outreach clinic is held at the Luton & Dunstable University Hospital to facilitate appointments closer to home for some patients with mild bleeding disorders and to support the Haemostasis Education of the team there.

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

Standard	Title of standard	Rating
1	Service Information	🟩
2	Condition-Specific Information	🟩
3	Plan of Care	🟨
4	Outpatient Review of PwBD	🟩
5	Contact for Queries and Advice	🟩
6	Haemtrack (PwBD on Home Therapy	🟩
7	Environment, Facilities and Equipment	🟨
8	Transition to Adult Services and Preparation for Adult Life	🟩
9	Carers’ Needs	🟩
10	Involving PwBD and Carers	🟨
11	Leadership Team	🟩
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. Excellent and universal praise from patients, with one comment in particular stating that the Haemophilia Centre is like an ‘extended family.’ Specific praise was also directed towards the

physiotherapy and nursing teams. Patients noted that it was great to see the same clinician at every review, as it demonstrated excellent continuity.

2. The current complement of physiotherapy staff provides a comprehensive service, available five days a week. The team also contributes to MDT clinics and offers flexible outpatient appointments for assessment and rehabilitation. Additionally, physiotherapy staff are encouraged to engage in research projects.

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. In particular, the review team is concerned that the Service is stretched in terms of staffing and workload, and the impact this has on different aspects of the Service, specifically:

1. The review team noted a general lack of space for patient assessment, which particularly affects the physiotherapy team, who do not have a dedicated physiotherapy area. Physiotherapy appointments are conducted in a corner of the main clinic room, often alongside patients receiving medication treatments.
2. It was also noted that the second physiotherapist was on a fixed-term contract. Given the size of the service, two physiotherapists are required; therefore, the current non-establishment of the Band 7 post poses an ongoing risk to this service.
3. The nursing team has lost 0.5 WTE since the Lead Nurse has been required to cover the Haematology Service as well. This has impacted already under-resourced services, resulting in a loss of time to attend community visits/outreach and the discontinuation of the weekend nursing service, which provided continuity for all in-patients and out-patients receiving treatment. A skills mix review is recommended to ensure adequate staffing is in place to continue developing all aspects of the nursing component of the national service specification and to facilitate CPD and service improvement.
4. Although there is daily temperature monitoring of the small fridge within the Centre, there is no out-of-hours monitoring or alarm. There is a risk that temperature-sensitive medicine could fall outside its operational window if the fridge fails late on a Friday, as this may not be noticed until the fridge is examined on Monday. This risk increases over a bank holiday weekend.

4.5 Recommendations

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

1. **Facilities & Environment**: The review team recommends that the Trust works with the Service to find, create, or better utilise space within the haemophilia centre. This will benefit the entire team, specifically the physiotherapy team, which currently lacks a dedicated physiotherapy space.
2. **Physiotherapy Service:** The Service and the Trust are urged to expedite the establishment of the second physiotherapy post as soon as possible, as there appears to be a deadline for the funding from R&D.

3. **Nursing Service:** The review team recommends that an urgent skill mix review be conducted for this large service to ensure there is sufficient specialist nursing time to cover all aspects of nursing care as outlined in the National Service Specification. Adequate staffing would enable the professional development and educational needs of the existing postholders to be met and would enhance and advance nursing practice within the service. Moreover, the amount of specialist nursing activity has decreased over the years, with fewer clinics and more focus on outpatient care.
4. **Refrigerated Medication Storage:** The review team recommends that the service assess its temperature monitoring procedures for the small fridge in the Centre to understand if changes are necessary to prevent the potential loss of temperature-controlled medicines in the event of a refrigerator failure. There is a risk that temperature-controlled medicines could be wasted if this fridge fails and the issue is not identified outside of hours.

5 Quality Standards - Detailed Description

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

Quality Standard 1: Service Information

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

All the information for this standard is available to patients; however, details about clinic times are only accessible on the website. The review team suggests that the service collates this information so it can be available to patients in one place.

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

The review team found evidence of information on the intranet that covered the points in this standard.

Quality Standard 3: Plan of Care

Partially 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

The review team noticed an inconsistency across patient letters regarding the bleed treatment plan. The template letter seen by the review team includes all points mentioned in this standard; the Centre needs to ensure that this information is included in all letters going forward.

Quality Standard 4: Outpatient review of PwBD

Standard Met

A formal review of PwBD should take place regularly:

a. For those with severe and moderate haemophilia, any PwBD on prophylaxis and other severe bleeding disorders at least twice a year. This may be more frequent in the paediatric setting based on clinical needs.

The following multidisciplinary clinic arrangements for these PwBD should be in place:
  i. Involvement of medical, specialist nursing and physiotherapy staff in clinics
  ii. Availability or clear referral pathway for social work and psychology staff

b. For those with mild bleeding disorders, the Centre should have a documented follow-up pathway with a plan for managing DNA and PIFU if used. These PwBD should have access to the full MDT if clinically required but may not be seen in a combined clinic.

This review should involve the PwBD and, where appropriate, their carer.
The outcome of the review should be communicated in writing to the PwBD and their GP.

How the Service meets or does not meet the standard

The review team observed evidence of formal outpatient reviews being conducted regularly, including MDT reviews as mandated by the underlying condition. The review team is confident, based on the evidence provided, that patients are being reviewed as often as they should be by other members of the MDT, such as physio and psychology, when required.

Quality Standard 5: Contact for Queries and Advice

The website is in development, so there were points to add, but what was in place was good. The standard operating procedures are very good.

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.

Standard Met

Quality Standard 6: Haemtrack (PwBD on Home Therapy)

The review team saw evidence that patients on home therapy are encouraged to use Haemtrack in clinic letters and plan of care, which fulfils the requirements of this standard. However, this was not consistently documented across the service.

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.

Standard Met

Quality Standard 7: Environment, Facilities and Equipment

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 review team felt that the Centre is in danger of outgrowing its space, especially if it increases the number of staff as expected. The physio department lost space due to Covid reconfiguration; they do not have their own

Partially Met

space to conduct physiotherapy and must share clinic space with the rest of the haemophilia team. Physio appointments take place in the corner of the main treatment room, often at the same time as other non-physio appointments. Most nurses do not have access to HCIS.

WiFi and IT access are poor, which has an impact on patients who need to work while waiting for their appointments.

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

The review team observed evidence of a transition process, which is supported by a Paediatric Haematology consultant from Great Ormond Street Hospital, who also works at the Royal Free one day a week.

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 review team saw evidence of signposting to support hub.

Quality Standard 10: Involving PwBD and Carers

Partially 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

Whilst the feedback from the patients the review team spoke to was very positive about the service, there was little evidence that the service had a mechanism to collect feedback from patients and carers and act on the results.

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 very clear leadership structure was presented at the introductory meeting. A detailed clinical operational policy was in evidence

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 recent loss of experienced staff and the reduction in lead nurse time from 1.0 WTE to 0.5 WTE appear to have impacted the service, and existing temporary posts must be retained.

There has been a demonstrable increase in day-case activity, which has impacted the CNS's ability to provide long-term care. I am impressed that day-case activity includes Rituximab infusions for patients with acquired Haemophilia. Further, as activity continues to increase, additional staff members (e.g., clinical nurse specialists, physiotherapists) will be required, as well as more space.

No social worker is assigned to the service; however, there is a clear pathway for patients to be directed to the appropriate services.

It is also noted that one of the physiotherapists is on a fixed-term contract through R&D money. There is no suggestion of an imminent business case.

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

The self-assessment clearly described the CPD undertaken by the different team members, and evidence of compliance with mandatory training was provided at the time of the review.

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

Two full-time data managers are responsible for collating data. The service also has dedicated administrative and clerical staff, including those who manage the phone line and reception.

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

Pathways were in place to either signpost or refer directly to Occupational Therapy, Orthotics, and dietetics. Play and distraction support is not applicable as the service is an adult service.

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

A good pathway was documented for patients with bleeding disorders attending ED, but unfortunately, this was not easily accessible via Freenet at the time of review (the Centre advised of this at the end of the review).

Recent developments in alerts, which can be added to patients' electronic records with bleeding disorders, are being reviewed. Discussed some reticence from the Trust towards adding alerts on the electronic record, but the review team felt that this was an important addition to flag up patients with bleeding disorders in case they are unable to provide this information at the time of presentation and would fully support this implementation.

The self-assessment described training staff members in ED, but significant turnover has made this challenging. The review team has not seen any recent audit of the ED pathway or patient feedback on their experience of it.

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

Access to excellent UKAS accredited laboratory service in very close proximity to the Haemophilia centre, with all relevant testing available on site, including outside of normal working hours when required. Clear process for sending samples for genetic testing.

Weekly meetings involving clinical and laboratory teams to discuss results.

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

Evidence was provided for access to all applicable specialist services, with a particularly good link for vascular access. Good Musculoskeletal guidelines are also in place.

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

A bespoke local database feeds into HCIS.
An electronic patient record was demonstrated to the review team during the visit. This system covers all of the relevant aspects of patient care, including administrative tasks and documentation.

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

Partially Met

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

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

How the Service meets or does not meet the standard

Local guidelines for the diagnosis of acquired Haemophilia and inherited platelet disorders, but no local guidelines are available for the other diagnoses or haematological investigation of heavy menstrual bleeding. That said, this is mitigated by clear documentation that national guidance from UKHCDO is followed for the diagnosis of all bleeding disorders and joint clinics with gynaecology addressing heavy menstrual bleeding.

NB: Adolescent/adult Centre, so haematological investigation of child suspected of inflicted injury is not applicable.

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

The clotting factor guideline and home treatment policy are very detailed and cover all aspects of this standard. However, the use of desmopressin is not covered in either of these documents, although it is referenced in the inherited platelet disorder guideline, and we were shown a dedicated PGD for its use.

It would be worth considering adding desmopressin to the clotting factor guideline, given that other non-factor treatments, such as Emicizumab, are already included in this document.

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

Clear documentation of the pathway for patients with hepatitis C or HIV and dental care.
Excellent guidelines for assessment and management of musculoskeletal bleeds and very detailed musculoskeletal service policy.

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

Excellent documentation of the surgical pathway and proformas to share with the surgical teams with clear The guidelines for perioperative management of patients with bleeding disorders and examples of perioperative treatment plans are provided.

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 review team observed evidence of operational procedures that cover the points in this standard applicable to an Adult's Centre.

Quality Standard 25: Multidisciplinary Team Meetings

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

Standard Met

How the Service meets or does not meet the standard

Detailed description of the MDT meetings in the self-assessment and introductory presentation. MDT outcome is documented on the electronic patient record for each case.

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

Combined clinics with orthopaedics and gynaecology are described in the self-assessment. Paediatric Haematologist working within the team.

Good links with Hepatology and Infectious Diseases as described in the self-assessment.

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

The service has two data managers who have developed a good process for collecting data and reporting adverse events.

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

The service has an extensive clinical research portfolio, including gene therapy. It also has dedicated clinical research staff members within the team.

Quality Standard 29: Multidisciplinary Review and Learning

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

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

Partially Met

How the Service meets or does not meet the standard

The review team saw no evidence of audits or annual feedback, but there was evidence demonstrating that other aspects of this standard were being done.

Quality Standard 30: Document Control

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

Standard Met

How the Service meets or does not meet the standard

Clear document management policy and evidence of adherence with this policy (including all guidelines being up to date).

6 Acknowledgements

The UKHCDO and the Peer Review Team express their sincere gratitude to the Service for its openness, hospitality, and meticulous preparation. We are especially thankful to the service users and carers who generously contributed their time and offered invaluable insights during the review. Furthermore, we extend our appreciation to the members of the Peer Review Team and their employing organisations for facilitating their participation in this process. We are grateful to all involved for their commitment to enhancing patient care through this peer review process.

Finally, the peer review process would not have been possible without the dedicated efforts of several key individuals: Dr Sarah Mangles, Chair of the Peer Review Working Party, provided continuous and strategic oversight; Debra Pollard, retired Advanced Nurse Practitioner at the Royal Free, ensured consistency across all peer review reports; Harry Evans, Peer Review Project Manager, coordinated and managed the process; and the UKHCDO Chair and Executive team for their contributions to the reports and their final review.

7 Appendices

7.1 Definitions

Reference	Reference number for quality standard
Quality Standard	The wording of the quality standard
Rating	The review team's opinion as to whether the standard has been: Met - Standard has been met fully. Partially Met - Standard has been met in part. Not Met - Standard has not been met at all. Not Applicable - Standard is not applicable for this specific centre.
How the service meets or does not meet the standard	What evaluations or conclusions can be drawn from the evidence. How does the evidence provided meet, partially meet, or not meet the standard. Evidence can be presented as a document or based on the observations of the peer review team.
Immediate risks	These are issues that pose an immediate risk to patients, carers, and or staff.
Good Practice (if applicable) (over and above the standard)	Where applicable, any good or best practice witnessed should be supported with evidence.

7.2 Peer Review Team

The Peer Review Team consisted of two consultant haematologists, two clinical nurse specialists, and a specialist haemophilia physiotherapist. UKHCDO holds details of the Peer Review Teams.