UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

UKHCDO Haemophilia Peer Review Audit Report

Belfast Adult's Haemophilia Comprehensive Care Centre

Haemophilia Nurses Association UK

HAEM-PSYCH ASSOCIATION UK & IRELAND

HC PA Haemophilia Chartered Physiotherapist Association

HAEMOPHILIA SCOTLAND

The Haemophilia Society

HAEMOPHILIA WALES

Haemophilia NI
Supporting patients and families

Report Date: 29 July 2025

Table of Contents

1 Executive summary

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

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

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

The executive summary presents the key findings, while the full report details the assessments referenced against the quality standards. Peer review for the Belfast Adult Haemophilia Comprehensive Care Centre (the Service) was completed on 23 October 2024. The Service is located within the Belfast City Hospital, which is part of Belfast Health and Social Care Trust.

The Service successfully met 27 of the 30 established standards, with three standards partially met. The Centre's and the Trust's commitment to providing high-quality care was evident through various initiatives and pathways. However, key recommendations have been made to address gaps that impact the ability to deliver comprehensive care.

Key Recommendations:

1. **Nursing staffing:** The review team recommends an assessment of nursing staffing with a view to incorporating the currently unfunded post into the existing staffing structure.
2. **Medical staffing:** A review of medical consultants' out-of-hours commitments should be conducted to ensure the safety of patients and staff, taking into account overall working hours. The review must also consider dedicated time to ensure access to clinical trials.
3. **Haemophilia Centre Information System:** It is recommended that the centre and Data Manager be provided with relevant support to facilitate implementation.

The service has no outstanding issues from the previous peer review and should be commended for its efforts to address the concerns raised in the 2019 peer review. However, this review has identified gaps in haemophilia services that need to be addressed to improve patient care and ensure compliance with national service specifications. The peer review findings will be shared with the clinical team, the host organisation, local commissioners, and other relevant stakeholders. We extend our gratitude to the haemophilia centre and the peer reviewers for their invaluable contributions, and we hope this report assists the Centre and the Trust in delivering high-quality haemophilia care.

2 Haemophilia and Bleeding Disorder Peer Review - Background

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

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

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

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

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

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

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

---

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

3 Service Description

The peer review for the Belfast Adult Haemophilia Comprehensive Care Centre took place on 23 October 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 adults with bleeding disorders and has 419 registered patients. It is based at the Belfast City Hospital campus, which is part of the Belfast Health and Social Care Trust.

3.1 Patient numbers

Number of patients	Inherited bleeding disorders							
	Haemophilia A		Haemophilia B		Von Willebrand		Other	
	Adults	Children	Adults	Children	Adults	Children	Adults	Children
Severe	58	0	5	0	24	0	186	0
Moderate	18	0	2	0				
Mild	115	0	11	0				
Annual review in the last year	Data not provided	0	Data not provided	0	Data not provided	0	Data not provided	0
Inpatient admissions in the last year	5	0	0	0	2	0	9	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 15 professionals, including three consultants, five nurses, one physiotherapist, one occupational therapist, one data manager, one social worker, one psychologist, three biomedical scientists, and two administrative staff. This combination of full-time and part-time roles ensures that comprehensive patient care is delivered.

Key staff include Consultant Haematologist and Centre Director Dr Gary Benson and Lead Nurse Helen Manson.

Outpatient care: The haemophilia centre serves as both an outpatient space and a treatment unit, covering blood transfusions, IVIG, monoclonal antibodies, iron and plasma infusions, among others.

Other sub-specialist clinics are based at different sites, such as fortnightly combined high-risk obstetrics clinics, the Royal Maternity Hospital campus. Some combined clinics, like the HIV and transition clinics, are based within the haemophilia centre.

The Service employs a multidisciplinary team approach across all areas of work, from a combined teams call on Monday morning to discuss all outpatients, inpatients, and planned work for the week, to the joint clinics for haemophilia and von Willebrand's disease.

Every other month, the whole team visit Altnagelvin Hospital to facilitate easier assessments for the patients within that area. The local hospital has no role other than providing the space for the team to operate.

Inpatient care: If hospital admission is required, patients are admitted to a ward that is appropriate for the admitting team**.**

Out of hours: Consultant-led specialist care is available 24 hours a day, 7 days a week, along with access to specialist laboratory services.

Transition: The guideline is in place with named leads. Ready, steady, go process in use. There are quarterly transition meetings. There was a welcome book for new patients.

Network arrangements: The Service is not part of a network as it is the sole provider of care to adults with bleeding disorders in Northern Ireland.

4 Quality Standards

4.1 Overview

The table below outlines the status of each standard—met (green), partially met (yellow), or not met (red). Overall, the Service has met 27 out of the 30 standards, with three 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	🟩

Standard	Title of standard	Rating
17	Laboratory Service	🟩
18	Specialist Services	🟩
19	IT System	🟨
20	Diagnosis Guidelines for People with Suspected IABD	🟩
21	Guidelines: Treatment and Monitoring of IABD	🟩
22	Clinical Guidelines/ Pathways	🟩
23	Guidelines on Care of PwBD requiring Surgery	🟩
24	Service Organisation	🟩
25	Multidisciplinary Team Meetings	🟩
26	Multidisciplinary Clinics/ Liaison Services	🟩
27	Data Collection	🟩
28	Research	🟩
29	Multidisciplinary Review and Learning	🟩
30	Document Control	🟩

4.2 Good Practice

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

1. The patient information booklet was excellent, well-organised, and written in clear, easy-to-understand language.

2. Care plans are truly multidisciplinary. Clinic letters had sections for each part of the MDT.

3. Having an occupational therapist embedded within the team provides patients and caregivers with unique support. For instance, they collaborate closely and complementarily with the physiotherapist to address the broader needs of patients. They are heavily involved in the rehabilitation of patients and can liaise with local teams to support them in the community. Additionally, they assist with aspects of psychological wellbeing, such as advising on sleep hygiene. The facilities for physiotherapy and occupational therapy reviews are located outside the centre. Patients who do not wish to attend the centre can still access these services if they desire.

4. Letters sent to non-attenders highlighted the potential risks of not engaging with the Service. Nurse-led clinics provided comprehensive care, including ‘well man’ and ‘well woman’ checks, as well as significant health promotion.

5. 'Team Haem Go Green' was a project led by the OT and social worker to take patients into green spaces to address physical and psychological health. This has been successfully recognised as a unique and beneficial initiative nationally with AHP awards and locally as part of the Chairman's awards. This highly innovative approach of utilising horticulture as a means to improve general physical and psychological health deserves commendation.

6. There was a constructive and open dialogue with the commissioners, ensuring visibility of any challenges faced by the service.

4.3 Immediate risks

There were no immediate risks identified.

4.4 Concerns

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

1. The review team is concerned that one of the nursing posts is currently unfunded. This makes the post vulnerable and negatively impacts recruitment, retention, and staff morale. There is also no scope or capacity for the current postholders to include research activities.
2. There was concern that one of the consultants was effectively on call three weekends out of five due to the rota, which includes colleagues who were not specialists in bleeding disorders.
3. There is limited research capacity within the established staffing levels. As the only provider in Northern Ireland, patients should be provided with comparable access to studies occurring elsewhere in the UK.
4. The new Electronic Patient Record (EPR) will provide an alert when a patient with a bleeding disorder presents at the emergency department; however, this alert merely indicates that an emergency management plan is in place. It does not specify that the alert relates specifically to a bleeding disorder unless someone directly clicks on it.
5. The new EPR system encompasses a ‘break glass function’ that protects sensitive information recorded by the psychologist. However, there is no such functionality for equally sensitive information that the Social Worker may record. The review team recommends assessing whether the information recorded by the Social Worker should be treated similarly to that from the Clinical Psychologist.
6. There are concerns that although HCIS has been established, it is not currently in use, and training for the data manager is still pending. This effectively means that no data can be transferred to the National Haemophilia Database, which is a national requirement for all Haemophilia Centres, as it informs commissioning and other national benchmarking.

4.5 Recommendations

This section details the recommendations made by the review team based on the concerns raised above:

1. **Nursing Staffing:** The review team recommends that a review of nursing staffing levels be conducted as soon as possible. We advocate for the funding of the unfunded post so that it can be permanently included in the established nursing posts.
2. **Medical Staffing**: A similar review of consultant out-of-hours commitments should be conducted to ensure the safety of patients and staff, including consideration of overall working hours. A fourth consultant would facilitate a dedicated haemostasis rota with a more equitable distribution of work.
3. **Research:** A scoping exercise should be conducted to assess what may be required to enhance patient access to clinical trials and research.

4. **Electronic Patient Record:** The review team recommends revising the EPR alert for the ED to clarify that it pertains to individuals with a bleeding disorder.
5. **Haemophilia Centre Information System:** It is recommended that the Data Manager receive immediate support with training and have the opportunity to shadow an experienced Data Manager who is familiar with the system.

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

Information leaflets were available covering all aspects of the service and the standard. The patient information booklet was excellent, well-organised, and written in language that was easy to understand.

Quality Standard 2: Condition-Specific Information

Standard Met

Written and or online information should be available and offered to PwBD and, where appropriate, their carers covering:

a. A description of their condition and how it might affect them
b. Problems, symptoms, and signs for which emergency advice should be sought
c. Genetics of Inherited Bleeding Disorders

d. Testing for carrier status and the implications of being a carrier
e. Treatment options including on-demand, prophylaxis, home therapy and the use of Haemtrack
f. How to manage bleeding at home
g. Ports, fistulae, and in-dwelling access devices (if applicable)
h. Approach to elective and emergency surgery
i. Women's health issues
j. Dental care
k. Travel advice
l. Vaccination Advice
m. Health promotion to include smoking cessation, healthy eating, weight management, exercise, alcohol use, sexual and reproductive health, and mental and emotional health and well-being
n. Sources of further advice and information

Condition-specific information should be available covering:

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

How the Service meets or does not meet the standard

A full range of information is available covering all conditions.

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

Very clear information and a copy were provided to all patients. The care plan was truly multidisciplinary. Clinic letters had sections for each part of the MDT.

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

Clear plans for follow-up and review were seen. There was evidence of nurse-led clinics. A proactive approach to managing non-attenders was evident.

A full MDT team was present in the clinic, comprising medical, nursing, physiotherapy, social work, and occupational therapy staff, which was impressive.

An outreach clinic was established to help reduce the distance people in the northwest needed to travel. This clinic involved the entire MDT, ensuring equity of access.

The facilities for physiotherapy and occupational therapy review were located outside the centre, and patients who did not wish to attend the centre could access these services if they chose to do so.

A dedicated occupational therapy support is rare to find, and the benefits are clearly evidenced through the innovative work being undertaken. 'Team Haem Go Green' was a project led by the OT and social worker to take patients into green spaces to address physical and psychological health. This initiative has been successfully recognised nationally with AHP awards and locally as part of the Chairman's awards. Indeed, this is a highly innovative approach that utilises horticulture as a means to address general physical and psychological health, and is to be commended. The incorporation of occupational therapy into the MDT provides patients and their carers with unique support.

Letters sent to non-attenders highlighted the potential risks of not engaging with the service. Nurse-led clinics cover the full breadth of care, including well-man and well-woman checks, as well as significant health promotion.

Quality Standard 5: Contact for Queries and Advice

Standard Met

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

Excellent helpline for out-of-hours queries.

Quality Standard 6: Haemtrack (PwBD on Home Therapy)

Standard Met

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

Excellent uptake since the last peer review.

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 office space for the clinical nurse specialist team.

HCIS has been set up but is not currently in use; training for the data manager is still pending. The data manager should receive support in obtaining this training, as fully implementing HCIS may alleviate their workload.

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

Guideline in place with named leads. Ready, steady, go process in use. There are quarterly transition meetings. There was a welcome book for new patients.

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

An excellent carer assessment tool was in place. There was detailed information for each area of Northern Ireland, so carers knew what local services were available to them.

The social worker provided excellent links to other services.

Quality Standard 10: Involving PwBD and Carers

Standard Met

The Service should have:

a. Mechanisms for receiving regular feedback from PwBD and carers about treatment and care they receive
b. Mechanisms for involving PwBD and carers in decisions about the organisation of the Service
c. Examples of how the Service has engaged PwBD / received feedback or made changes made as a result of feedback and involvement of PwBD and carers

How the Service meets or does not meet the standard

Members of the MDT regularly supported events organised by the Northern Ireland haemophilia patient association. Numerous pieces of patient feedback were included in the evidence. The DASH project, aimed at developing AHP services for individuals with haemophilia, demonstrated active patient involvement in shaping its development.

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 new physiotherapist was commencing following the retirement of the previous postholder. Otherwise, a full leadership team was in place, all possessing the requisite skills and qualifications.

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

There was one unfunded nursing post, which is essential for the development of the service; therefore, efforts should be made to secure permanent funding. The research capacity was limited; however, the team achieved very impressive outputs and participated in a variety of studies. Even more could be accomplished with additional nursing and data management time dedicated to research, which would relieve the strain on the rest of the team.

One of the coagulation consultants was available on-call for 3 out of 5 weekends, alongside colleagues who were not specialists in bleeding disorders. The cover for the other two weekends remains unclear. A fourth consultant would enable a dedicated haemostasis rota with a more equitable distribution of work.

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

Evidence provided covering all aspects of the standard and for all members of the MDT.

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

A proactive data manager, receptionist and secretary are in post.

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

All relevant services are in place, and there are strong links with local elective orthopaedic centres where hydrotherapy is also available.

Having an occupational therapist embedded within the team provides numerous benefits. For instance, they work closely and in a complementary manner with the physiotherapist to meet the broader needs of patients. They are heavily involved in the rehabilitation of patients and can liaise with local teams to support them in the community. Additionally, they assist with aspects of psychological well-being, such as advising on sleep hygiene.

Quality Standard 16: Emergency Department

Standard Met

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

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

ED medical and nursing staff should have training on inherited and acquired bleeding disorders.

ED pathway should be audited +/- PwBD survey on emergency attendance on an annual basis.

How the Service meets or does not meet the standard

A comprehensive guideline covering all eventualities is in place. The pathway was regularly audited.

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

An extensive repertoire of tests is available, including gene sequencing. Factor assays are available out of hours when needed.

Quality Standard 18: Specialist Services

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

The Service has access to all the services as specified in this standard.

Standard Met

Quality Standard 19: IT System

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

Partially Met

How the Service meets or does not meet the standard

HCIS is not currently in use but is being implemented once the data manager has received the necessary training.

The alert in the new EPR indicates the presence of an emergency management plan; however, it doesn’t specify that it relates to a bleeding disorder unless clicked on directly.

The new EPR includes a "break glass function" to protect sensitive information recorded by the psychologist. However, there is no such functionality for equally sensitive information that the social worker may record, and this merits a relook.

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

Comprehensive guidelines are in place.

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

Comprehensive guidelines are in place, providing clear definitions of roles and responsibilities for all processes.

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

Comprehensive guidelines are in place. The guidelines for factor VIII and IX inhibitors need updating to include emicizumab for haemophilia A (this is covered in separate treatment guidelines).

The guidelines have been well written to empower less experienced staff to support patients in self-managing episodes of bleeding where appropriate.

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

The management plan template was well constructed.

There was a written rota detailing who would review a patient following surgery and when. This ensured that surgical staff and patients knew what to expect.

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

Clear and comprehensive procedures are in place to cover all aspects of the standard.

Quality Standard 25: Multidisciplinary Team Meetings

Standard Met

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

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

How the Service meets or does not meet the standard

Meetings are held weekly. Minutes were taken, and actions were defined (including the owner).

Quality Standard 26: Multidisciplinary Clinics/Liaison Services

Standard Met

Combined clinics or other arrangements for multidisciplinary discussion with

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

How the Service meets or does not meet the standard

Joint obstetric and HIV clinics are in place.

Quality Standard 27: Data Collection

Standard Met

The following data should be collected:

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

How the Service meets or does not meet the standard

All required data collected.

Quality Standard 28: Research

Standard Met

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

How the Service meets or does not meet the standard

Excellent participation and outputs compared to similar-sized services.

More could be achieved with additional nursing and data management time dedicated to research.

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

There are extensive publications, conference posters, and oral presentations from across the MDT. Participation significantly exceeds that of many larger services. A regular audit programme is in place, along with a clearly defined governance structure. An annual "key themes" report reviews governance issues and incident trends from the previous 12 months.

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	
No concerns	

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 review team consisted of two Consultant Haematologists, a Bleeding Disorder Specialist Physiotherapist, a Haemophilia & Thrombosis Sister, a Centre Manager, and a Patient Representative. UKHCDO holds details of the Peer Review Team.