UKHCDO Haemophilia Peer Review Audit Report

Edinburgh Haemophilia Comprehensive Care Centre

Report Date: 29 August 2025

Table of Contents

1 EXECUTIVE SUMMARY 2

2 HAEMOPHILIA AND BLEEDING DISORDER PEER REVIEW - BACKGROUND 3

3 SERVICE DESCRIPTION 4

3.1 PATIENT NUMBERS 4

4 QUALITY STANDARDS 5

4.1 OVERVIEW 5
4.2 GOOD PRACTICE 6
4.3 IMMEDIATE RISKS 6
4.4 CONCERNS 6
4.5 RECOMMENDATIONS 7

5 QUALITY STANDARDS – DETAILED DESCRIPTION 7

6 ACKNOWLEDGEMENTS 21

7 APPENDICES 21

7.1 DEFINITIONS 21
7.2 PEER REVIEW TEAM 22
7.3 FINDINGS FROM PREVIOUS PEER REVIEW 22

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 Edinburgh Haemophilia Comprehensive Care Centre (the Service) was completed on 26 April 2024.

The Centre successfully met 28 of the 30 established standards, with one standard being partially met and one being unmet. 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. **Adult physiotherapy**: The review team recommends that the Trust supports the service in permanently establishing an adult physiotherapy post, as physiotherapy is a core part of comprehensive care for haemophilia. Inadequate physiotherapy risks prolonging treatment and delaying recovery, resulting in poorer outcomes.
2. **Medical Consultants:** The current medical consultant input into the bleeding disorder service, which is less than one full-time equivalent, is inadequate. The review team recommends increasing the medical consultant time to at least two whole-time equivalents. As treatment options expand, there is a rising need for personalised care with more discussions about treatment options, all of which improve outcomes.

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 of the Edinburgh Haemophilia Comprehensive Care Centre took place on site at the Haemophilia and Thrombosis Centre, Royal Infirmary of Edinburgh (RIE), and at the adjacent Royal Hospital for Children and Young People (RHCYP) on 26 April 2024. A multidisciplinary team of haemophilia professionals, accompanied by patient representatives, conducted the review, which included discussions with staff from the service, review of documentation, and a tour of the facilities.

The Edinburgh Haemophilia Centre is a Comprehensive Care Centre (CCC) based in the East of Scotland, providing care to both adults and children. It has 859 patients registered with its service.

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	41	14	1	3	145	26	437	68
Moderate	15	1	12	1				
Mild	64	13	13	5				
Annual review in the last year	96	27	18	9	89	21	434	48
Inpatient admissions in the last year	3	4	1	6	1	2	0	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 24 staff members, comprising 19 full-time staff and the equivalent of 5 part-time staff. The staffing includes five consultants (two in adult services and three in paediatrics), three nurses, two physiotherapists, one psychotherapist, seven laboratory technicians, and seven administrative and clerical staff (including 3 factor coordinators).

It should be noted that the time of the five consultants is not solely allocated to haemophilia work. Besides bleeding disorders, the two adult service consultants also handle all thrombosis cases and perform various other duties, including laboratory tasks. The three paediatric consultants oversee regional benign and malignant paediatric haematology services. Consequently, the haemophilia centre has a sessional commitment of four sessions per week (three for adults and one for children) plus administrative duties.

Key staff include Consultant Haematologist and Centre Director Dr Andrew Page, Chare Nurse Bindu Abraham and Paediatric Lead Dr Matthew Howard-Jones.

Outpatient care: The haemophilia centre acts as an outpatient clinic area for adult and paediatric patients, plus a day care centre for adult patients.

Inpatient care: This is based on wards appropriate to the indication for admission.

Out of hours: Patients have access to specialist clinical advice 24/7. Out of hours adult and paediatric patients can contact the on-call haematology registrar via the NHS Lothian switchboard for urgent advice. Out of hours for urgent review is via the Emergency Department in the RIE. For paediatric patients, urgent review is via the Lochranza ward day treatment area or RHCYP Emergency Department as appropriate.

Transition: Ready, steady, go process is used, and transition is supported by the adjacency of the services.

Network arrangements: Edinburgh CCC is part of the Scottish Inherited Bleeding Disorders Managed Clinical Network (SIBDN). Unlike the hub-and-spoke network model in the managed network, the Edinburgh Haemophilia Centre does not oversee patients under the care of the surrounding haemophilia centres but supports care by enabling improved standards. The network is more virtual in set-up to help enhance standards of patient care through the integration of services and collaboration.

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 28 out of the 30 standards, with one partially met and one unmet. The outstanding findings from the previous peer review are included in the appendix. The service is encouraged to review all descriptive assessments in addition to the key findings. This report, alongside local assessments, should steer discussions with the management team, highlighting areas of good practice while emphasising where further investment and improvement may be required.

Standard	Title of standard	Rating
1	Service Information	🟩
2	Condition-Specific Information	🟩
3	Plan of Care	🟩
4	Outpatient Review of PwBD	🟩
5	Contact for Queries and Advice	🟩
6	Haemtrack (PwBD on Home Therapy	🟩
7	Environment, Facilities and Equipment	🟩
8	Transition to Adult Services and Preparation for Adult Life	🟩
9	Carers' Needs	🟩
10	Involving PwBD and Carers	🟩
11	Leadership Team	🟩
12	Staffing Levels and Skill Mix	🟨

Standard	Title of standard	Rating
13	Service Competencies and Training Plan	🟩
14	Administrative, Clerical and Data Collection Support	🟩
15	Support Services	🟩
16	Emergency Department	🟩
17	Laboratory Service	🟩
18	Specialist Services	🟩
19	IT System	🟩
20	Diagnosis Guidelines for People with Suspected IABD	🟩
21	Guidelines: Treatment and Monitoring of IABD	🟩
22	Clinical Guidelines/ Pathways	🟩
23	Guidelines on Care of PwBD requiring Surgery	🟩
24	Service Organisation	🟩
25	Multidisciplinary Team Meetings	🟩
26	Multidisciplinary Clinics/ Liaison Services	🟩
27	Data Collection	🟩
28	Research	🟥
29	Multidisciplinary Review and Learning	🟩
30	Document Control	🟩

4.2 Good Practice

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

1. There is an on-site Psychologist, a demonstration of a true multidisciplinary team. It is also a valuable resource for patients and is not always available at other centres.
2. There is a dedicated orthopaedic haemophilia clinic and a close liaison with obstetrics and gynaecology.
3. The review team were impressed by the comprehensive and user-friendly patient leaflet.

4.3 Immediate risks

No immediate risk was identified during this review.

4.4 Concerns

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

1. The review team are particularly concerned about the vulnerability of the adult physiotherapy provision. This is because the current adult physiotherapy position is due to expire later this year, and no long-term funding has been agreed.

2. The review team are concerned about staffing pressures. The service only has two specialist haemophilia consultants, which results in a high workload for all consultants. Indeed, due to staff shortages, there has been no research within the department.
3. The rehabilitation gym at the Royal Hospital for Children and Young People (also located on the Royal Infirmary site) has been divided into two physiotherapy areas, one for adults and one for children. There is uncertainty about the long-term plans for adult physiotherapy rehabilitation facilities at the Royal Infirmary of Edinburgh site, which can impact the care provided to haemophilia patients.

4.5 Recommendations

1. **Adult physiotherapy**: The review team recommends that the Trust supports the service in permanently establishing an adult physiotherapy post, as physiotherapy is a core part of comprehensive care for haemophilia. Inadequate funding for physiotherapy risks prolonging the treatment and recovery of patients.
2. **Medical Consultants:** The current support from medical consultants at less than one full-time equivalent is inadequate, and the review team recommends increasing the time allocated to caring for patients with bleeding disorders to at least two full-time equivalents. As treatment options broaden, there is an increasing need for personalised care, which can significantly improve outcomes.
3. **Planning for Rehabilitation:** The review team recommends that an appropriate long-term solution be confirmed for the adult's physiotherapy rehabilitation facility. This is essential for the long-term treatment and recovery of patients.
4. **Research Participation:** While the review team acknowledges that staffing pressures have limited ongoing research, they would like to see more research being carried out once the pressure on staff has eased.

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 focus on areas where the standard was partially met or not met.

Quality Standard 1: Service Information	
Written information should be offered to people with bleeding disorders (PwBD) and, where appropriate, their carers covering at least: a. Brief description of the Service b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the Service e. How to access physiotherapy and psychology f. Relevant national organisations and local support groups g. Where to go in an emergency and how to access out of hours services h. Information on delivery of products, including company contact details	**Standard Met**

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

Almost all details are covered in written format and folders. Written details include clinic days covered. "How to" is well covered in written format.

Pamphlet covers all details thoroughly - very comprehensive and user-friendly.

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 information on how to contact and what to do in an emergency is excellent, but some reviewers felt there was a lack of clear, general information about which signs and symptoms would indicate an emergency. Clarity was higher regarding documentation of signs and symptoms found in individual patient letters. There were many leaflets available. Additionally, there was generic information on how to manage bleeding at home. It was noted that the contents of the Scottish Bleeding Disorder leaflet do not align with the page numbers in the contents.

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

There was a wide selection of clinic letters provided. A clear plan of care was included at the end of each clinic letter. Reviewers felt there was an excellent ability to quickly access all relevant clinic information.

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 guidance on handling DNAs/children's issues was not brought' issues. Nurse-led telephone clinics are running smoothly.

Quality Standard 5: Contact for Queries and Advice

Standard Met

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

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

How the Service meets or does not meet the standard

The review team agrees with the service self-assessment form that their updated pathway for patient calls meets this standard.

Quality Standard 6: Haemtrack (PwBD on Home Therapy)

Standard Met

All PwBD on home treatment should be encouraged to use the electronic recording of their treatment through Haemtrack.

Use should be documented in clinic letters/ plan of care.

How the Service meets or does not meet the standard

Mentioned in clinic letters/ plan of care.

Quality Standard 7: Environment, Facilities and Equipment

Standard Met

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

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

a. Fridges
b. storage
c. Clinical rooms for staff of all disciplines to see PwBD and carers with adequate space for physiotherapy assessment
d. Room for multidisciplinary discussion

- e. Room for educational work with PwBD and carers
- f. Office space for staff
- g. Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all relevant clinical areas
- h. Access to adequate IT equipment with clinical systems
- i. All equipment should be appropriately checked and maintained.

How the Service meets or does not meet the standard

The rehabilitation gym at the Royal Hospital for Children and Young People, which is also situated on the Royal Infirmary site, has been divided into two physiotherapy areas, one for adults and one for children.

The review team initially had concerns about this arrangement, but has since been reassured by the service.

However, there remains a lack of clarity regarding the long-term provision of adult physiotherapy facilities, as the current setup does not appear to be a permanent solution. Overall, though, the review team is satisfied that the service meets the requirements for this standard.

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

Standard Met

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

- a. Information and support on taking responsibility for their own care
- b. The opportunity to discuss the transfer of care with paediatric and adult services
- c. A named coordinator for the transfer of care
- d. A preparation period prior to the transfer
- e. Written information about the transfer of care, including arrangements for monitoring during the time immediately afterwards
- f. Advice for young people going away from home to study, including:
    - i. Registering with a GP
    - ii. How to access emergency and routine care
    - iii. How to access support from their Comprehensive Care Centre
    - iv. Communication with their new GP
    - v. The Centre should have a guideline/SOP covering this information.

How the Service meets or does not meet the standard

Followed the Ready Steady Go principles. Transition within the same clinic space appears to work very well, as it seems to be an organic process for paediatric patients moving into adult care, since patients are already familiar and therefore know what to expect.

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

Details included in pamphlet. Contact numbers for support/needs provided. There is ability to access social workers rather than a dedicated social worker.

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

The review team agrees with the service’s self-assessment that they have engaged with patients and carers to gather feedback. Changes have been implemented based on this feedback.

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

There is an effective leadership team in place that covers the standard.

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 is inadequate specialist consultant cover for on-call as reflected in the self-assessment: In adult services, there are two H&T specialists with one additional consultant working as part of the same team with twice-weekly joint ward rounds, handover meetings, and regular attendance at the MDT. There is also one general haematology consultant.

The rota is currently short due to staff changes at surrounding hospitals, with on-call shifts covered by internal locum cover. The adult rota should be 1 in 6, but has now been increased to 1 in 4 (for general or haemostasis duties). On-call duties include TTP, ITP, and haemoglobinopathy. "Support on informal basis" is provided to non-specialists. On-call queries originate from across the region. The medical consultant's cover is quite stretched and appears fragile.

Longer-term sick leave of the paediatric CNS (who has now returned to work) is covered by advanced nurse practitioners. Paediatric physiotherapy support is currently vulnerable due to cross-cover arrangements: it is only set at 0.4 of a post, and recruitment to this position has not been successful, so it is currently covered within the service.

There is a real vulnerability for the adult physio position, as long-term funding has not been agreed upon, and the current post is due to expire later this year.

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

Standards fulfilled.

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

Tight control of finance, stock take, and home delivery.

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

There is adequate provision of podiatry, orthotics, and hydrotherapy support.

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 clear, well-established relationship between the haemophilia centre and emergency department staff was observed during our tour, with ED evidently feeling supported.

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

Good documentation re accreditation: UKAS. All other criteria met, including the genetics pathway.

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

Excellent evidence for each speciality service previously utilised.

Port-a-caths provided by surgeons for children with severe haemophilia B (haemophilia A patients on emicizumab).

Dedicated obstetrics clinic with close liaison with gynaecology.

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

HCIS on multiple computers in the haemophilia centre. Alert for CJD status.

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

Concise guidelines for each item.

F and J combined are perfectly acceptable. Use genetic testing instead of multimer analysis.

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 review team agrees with the service self-assessment form.

The guidelines provided covered all aspects of this quality standard.

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

Management guidelines are in place and can be accessed through the intranet.

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

Guidelines for managing PwBD requiring surgery, available and accessible via the intranet.

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 saw procedures that covered this 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

The review team reviewed procedures covering this standard.

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

Point a. The orthopaedics joint clinic was well established, with planning in place to encourage new consultants to take on this role when the existing orthopaedic consultant retires.

Multi-disciplinary clinics are in place for the majority of the standard and good working relationships/ easy access to services, where a combined clinic is not 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

Points b and d were met. Dashboard not relevant - no evidence for other national mechanisms. No matched data collection for KPI.

Quality Standard 28: Research

Not 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

There is no ongoing research in the department, which was the main criticism of our review. This is clearly due to staffing shortages among consultants and the wider team. By working extremely hard to provide excellent care with an understaffed department, simply meeting clinical demands means that research has not been incorporated. This limits opportunities to deliver excellent care — not just affecting staff development and interest but actually restricting patient access to novel treatments. It also imposes both clinical and financial burdens, as investigational novel therapies are provided by Pharma.

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

M&M meeting recorded. No previous audits- excellent plan to now audit based on guidelines now implemented since last review. Small audits are included, which is useful to see. Nil seen for points e, f and g.

Information provided post review: MDM minutes from 01.12.2023 and 12.04.2024 show that points e, f, and g are discussed.

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	
All policies reviewed following last Peer Review. Matches NHS Lothian document control policy for adults and paediatrics.	

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 adult and paediatric consultant haematologists, a clinical nurse specialist, a physiotherapist, and a patient representative. Although a paediatric clinical nurse specialist had also been planned for the review, they were unable to attend on the day. UKHCDO holds details of the Peer Review Teams.

7.3 Findings from previous peer review

Ref. number	Statement of original finding
Immediate risk	At the time of the review, the review team heard that children were treated at the adult haemophilia centre at the Edinburgh Royal Infirmary. Children were treated by adult trained nurses who did not have any paediatric resuscitation and life support training and a paediatric doctor (who did have Advanced Paediatric Life Support training) was not always present at the time. In addition, although there was a paediatric team on site together with a paediatric cardiac arrest team who managed any emergencies at the neonatal unit, there was no agreed protocol in place for haemophilia centre staff to access the paediatric cardiac arrest team or for them to know who they should call in an emergency. Reviewers observed that a child could need resuscitation while in the Centre, and that a member of staff with appropriate competences to lead the resuscitation would not always be immediately available on the team. As there was no clear guidance in place as to how the paediatric resuscitation team should be called in such an emergency there was therefore a risk that starting appropriate resuscitation efforts could be delayed.
Physiotherapy Serious Concern 1	a. Reviewers were very concerned that there was no dedicated physiotherapy member of the adult or paediatric team. Reviewers were told that this was due to a lack of funding, not an inability to recruit. One named physiotherapist tried to see patients who presented with acute joint bleeds but could not always do so and there was no cover for periods when she was away. There were no systematic joint health assessments. This led to poor management of joint health. b. A file containing some guidelines seen by the review team held in the general Musculoskeletal physiotherapy area gave incorrect advice to treat all patients – except those with severe
Management of acute presentations in adult patients Concern 1	There were no Emergency Department (ED) guidelines in place for adult patients presenting with acute bleeds or trauma, and although ED staff were meant to inform the specialist team whenever a patient presented, in practice this did not always happen. A clear guideline and communication of this between the ED team and the haemophilia centre would ensure that ED colleagues were aware of their responsibilities regarding treatment of patients with bleeding disorders.

Paediatric nursing, and service provision on the Royal Infirmary site Concern 2	a. There was no paediatric lead nurse in post. b. Although children were seen in the adult Centre for clinic appointments, there were no paediatric nurses on site, and no play support for interventions although venepunctures were undertaken there. c. Children were seen in clinics when adult patients were also attending.
Clinical guidelines Concern 3	Clinical guidelines were incomplete and out of date, some significantly [for example dated 2013] and required revision.
Patient feedback Concern 4	Although it was understood that some patient surveys had taken place no results were made available to the visiting team, and it was not clear whether the feedback had been analysed, and appropriate actions taken.
Fridge temperature control failure Concern 5	Two fridges containing concentrates had recently erred outside the required temperature limits, no alarm was raised, and concentrates had been wasted. Once a new fridge is installed it will be imperative to be sure that controls and alarm systems are robust. Also, a fridge for concentrate storage on the in-patient ward was out of service at the time of the visit and required replacement despite alternative interim arrangements being in place.
Appropriate management support Concern 6	Support for the Centre team from the wider organisation was not apparent. No clinical or non-clinical managers met the review team during the visit. They were based on another hospital site and were reported rarely to visit or engage with the team. Reviewers observed that if the Centre team were to achieve the operational improvements they planned to, they would need more active input and engagement from the hospital management teams.