UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

UKHCDO Haemophilia Peer Review Audit Report

Glasgow Children's Haemophilia Comprehensive Care Centre

Haemophilia Nurses Association UK

HAEM-PSYCH ASSOCIATION UK & IRELAND

HCPA Haemophilia Chartered Physiotherapist Association

HAEMOPHILIA SCOTLAND

The Haemophilia Society

HAEMOPHILIA WALES

Haemophilia NI
Supporting patients and families

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1 Executive summary

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

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

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

The executive summary presents the key findings, while the full report details the assessments referenced against the quality standards. Peer review for the Glasgow Children's Haemophilia Comprehensive Care Centre (the Service) was completed on 04 June 2024. The Service is located within the Royal Hospital for Children, Glasgow.

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

Key Recommendations:

1. **Nursing staff:** The review team recommends that the Trust work with the service to fill the two vacant nursing positions as soon as possible. The service should also consider distributing the workload more evenly among the existing nursing staff for consistency, continuity, and quality of care.
2. **Physiotherapy Provision:** The current physiotherapy provision is insufficient for the size of the service. More time is needed to effectively implement both reactive and proactive approaches, ensuring that more patients are reviewed in line with the National Service Specification Standards.
3. **Space Review**: The peer review team recommends a space review to ensure the implementation of one-stop clinics, as the current provision does not support a multidisciplinary review.

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

2 Haemophilia and Bleeding Disorder Peer Review - Background

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

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

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

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

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

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

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

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

3 Service Description

The peer review was carried out on 04 June 2024 at the Haemophilia Centre, Glasgow Children's Hospital. A multidisciplinary team of haemophilia professionals, including patient representatives, conducted the review, which involved speaking to staff from the Service, reviewing documentation, and touring the facilities.

The Service offers care to children and young people with bleeding disorders and has 321 registered patients. It is based at the Royal Hospital for Children in Glasgow, serving the population of west Scotland. It covers the greater Glasgow and Clyde area, Lanarkshire, Dumfries and Galloway, Ayrshire and Arran, the Western Isles, and parts of the Forth Valley and the Highlands.

The service is provided by a dedicated non-malignant team that covers Haemophilia, Bleeding Disorders, Thrombosis, Haemoglobinopathies, Bone Marrow Failure syndromes on transfusional support, Cytopenias, Laboratory Haematology and Consultative Medicine. The Service is affiliated with the Adult CCC but operates at different sites in the city. It has a specialist Haemostasis Laboratory on site and also collaborates closely with the one in the adult Haemophilia CCC.

The Service is part of the Scottish Inherited Bleeding Disorders Network (SIBDN – A National Managed Clinical Network commissioned by NSD).

3.1 Patient numbers

Inherited bleeding disorders								
Number of patients	**Haemophilia A**		**Haemophilia B**		**Von Willebrand**		**Other**	
	Adults	Children	Adults	Children	Adults	Children	Adults	Children
Severe	0	34	0	2	0	87	0	140
Moderate	0	6	0	5				
Mild	0	33	0	14				
Annual review in the last year	0	71	0	19	0	68	0	93
Inpatient admissions in the last year	0	14*	0	0	0	1	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. *Includes multiple admissions of a child with mild haem A post-transplant.

Staffing: The Service consists of two non-malignant Haematology Consultants (1.5 WTE), five nurses (5.0 WTE), but only one B7 and one B6 are dedicated to the Haemophilia/bleeding service and also have to provide cross-cover for the haemoglobinopathies service. There is support from physiotherapy (0.3 WTE) and psychology (0.1-0.2WTE). Admin includes one receptionist (1 WTE), one Data Manager (1.0 WTE), and one PA/ Secretarial support to Consultants (1.0 WTE).

Key staff include Consultant Haematologist and Centre Director Dr Fernando Pinto and Lead Nurse Katrina Adams

Outpatient care: Patients with a severe or moderately severe bleeding phenotype (and anyone with a mild phenotype, even if on prophylaxis) are seen every 3 months in the Haemophilia Clinic by a Consultant Haematologist, a Haemophilia Specialist Nurse, a Physiotherapist and a Psychologist. All other patients are reviewed every 6-12 months, or more frequently if necessary.

Inpatient care: Patients are admitted to the appropriate ward for clinical presentation

Out of hours: Patients are reviewed in the emergency department

Transition: The Service is linked with the Adult CCC but operates on separate sites within the city. Joint MDTs, meetings, and transition clinics are held regularly between these locations.

Network arrangements: The Service is part of the Scottish Inherited Bleeding Disorders Network (SIBDN – a National Managed Clinical Network commissioned by NSD). This network involves multidisciplinary team members, commissioners, governmental representatives, patient representatives (from Haemophilia Scotland and regional Haemophilia Society Groups), and members from many supporting service groups. 'The purpose of the SIBDN is to facilitate clinical and other improvements for individuals with inherited bleeding disorders. A key aim of the network is to enable timely and effective care for individuals with inherited bleeding disorders across Scotland.'

4 Quality Standards

4.1 Overview

The table below outlines the status of each standard—met (green), partially met (yellow), or not met (red). Overall, the Service has met 26 out of the 30 standards, with four partially met. The Service has outstanding findings from their previous peer review report in similar areas, which are provided in the appendix. The service is encouraged to review all descriptive assessments in addition to the key findings. This report, alongside local assessments, should steer discussions with the management team, highlighting areas of good practice while emphasising where further investment and improvement may be required.

Standard	Title of standard	Rating
1	Service Information	🟩
2	Condition-Specific Information	🟩
3	Plan of Care	🟩
4	Outpatient Review of PwBD	🟩
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	🟩

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

4.2 Good Practice

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

1. There was some very positive feedback from patients/families.
2. Excellent leadership demonstrated in the management and continuation of the service, especially following the retirement of a senior clinician.
3. Despite significant challenges with staffing, the CNS has shown commitment to the haemophilia role, having completed the relevant haemophilia courses and doing a prescriber's course.
4. The presence of the psychologist within the core team spanning paediatric and adult services is noted and appreciated by the reviewing team as an excellent model.
5. Despite being in this role for just 7 months, the data manager has made significant progress. They are mindful of patient needs, especially when drafting haemtrack reminder letters with sensitivity.
6. A separate research team manages the research portfolio, and this has meant research is delivered without additional burden to the short-staffed clinical nursing team

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. At the time of the review, there were 2 WTE vacant nursing positions within the service. The review team is concerned that the majority of the workload appears to rely on a single nurse, which could risk failing to deliver the same standard of care in her absence. Bleeding Disorders Care is a highly specialised and continually evolving field, and nurses play a crucial role as the first point of contact for clinical advice.
2. Due to the ongoing shortage of nursing staff, there are not enough resources to support children and their families at home or to provide educational assistance to nurseries, schools, and other community services. Without school visits from a specialist nurse, appropriate Education Health Care Plans may not be in place to ensure the safe management of all children with bleeding disorders.
3. The review team was concerned that the current physiotherapy provision is inadequate to meet patients' needs. Regular reviews of all children registered with the service are essential, including a Haemophilia Joint Health Score for all children with Haemophilia. Since Haemophilia manifests with joint bleeding, both reactive and proactive physiotherapy care must be available to ensure musculoskeletal health is optimised and the risk of lifelong joint damage is minimised.
4. There is not always a Haematology SpR covering the non-malignant service – this may have implications for both training and succession planning in the future.
5. The available space also seems limited, as patients appear to attend multiple times for reviews and assessments.

4.5 Recommendations

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

1. **Nursing Service**: The peer review team urges the trust to fill the two vacant nursing positions promptly. It also recommends reviewing potential challenges related to recruitment and retention. Additionally, distributing the workload more evenly among current nurses is crucial to reducing risks associated with one nurse handling most tasks. The service must ensure that enough nurses are available to perform Home, Nursery, and School visits by specialists who receive ongoing professional development and appropriate training, thereby ensuring that safety is not compromised. Nurses working in the bleeding disorders service should meet the minimum standards established by the HNA.
2. **Physiotherapy service**: The current provision is insufficient for the size of the service. A reactive and proactive approach will ensure that more patients are not only reviewed but also receive appropriate consultations related to musculoskeletal health and wellbeing, including advice on physical exercise and sporting activities. The present physiotherapist should have additional time and support from suitably trained cover to enable them to engage in more ongoing professional development without compromising the safety of the services.

3. **Space Review**: The peer review team recommends a space review to ensure the implementation of one-stop clinics, as the current provision does not support a multidisciplinary review.
4. **Specialist Trainee Medical Staff**: The review team recommends a review of the Haematology SpR rotation to ensure continuous presence of trainees in the non-malignant haematology service. This will support the Trust in meeting training needs and facilitate effective succession planning for the future.

5 Quality Standards – Detailed Description

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

Quality Standard 1: Service Information

Standard Met

Written information should be offered to people with bleeding disorders (PwBD) and, where appropriate, their carers covering at least:

a. Brief description of the Service
b. Clinic times and how to change an appointment
c. Ward usually admitted to and its visiting times
d. Staff of the Service
e. How to access physiotherapy and psychology
f. Relevant national organisations and local support groups
g. Where to go in an emergency and how to access out of hours services
h. Information on delivery of products, including company contact details

How to:

i. Access social care and support services
ii. Access benefits and immigration advice
iii. Interpreter and advocacy services, PALS, spiritual support
iv. Give feedback on the Service, including how to make a complaint
v. Get involved in improving services (QS 10)

How the Service meets or does not meet the standard

The service information is available to patients and carers through information leaflets that provide a basic introduction to the service.

Other leaflets cover the standards related to accessing different services.

The bleeding card issued has emergency contact details.

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 leaflets provide condition-specific information required for this standard.

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

The plan of care is documented in the clinic letters (a template is provided, and a redacted clinic letter was made available for reference during review).

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

MDT clinics are conducted monthly, with documented evidence of MDT meetings.

There is clear documentation of the plan, as evidenced by a clinic letter sent to the GP and patients.

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

Provided in the information leaflet and bleeding card.

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

Haemtrack review included as part of the clinic template.

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
i. All equipment should be appropriately checked and maintained.

How the Service meets or does not meet the standard

Haemophilia and IBD activity are situated within a children's hospital, between the outpatient and inpatient facilities.

Factor concentrates are stored in the laboratory areas.

Feedback indicates that the outpatient area can sometimes be busy, making it challenging to find space or a room for one-to-one sessions with wider team members, which may mean patients need to return on another day.

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

Standard Met

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

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

How the Service meets or does not meet the standard

The transition process follows the hospital policy and the 'Ready, Steady, Go' programme, but it needs to be documented in greater detail within the policy.

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

Ready access to psychological support is available for carers and is detailed in the information leaflet.

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

Feedback was shared through the feedback survey report and directly by parents.

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

Lead consultant responsible for the service with support from other team members. However, please see standard 12 regarding staffing concerns.

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

It was observed that the time allocated to haemophilia is insufficient for certain roles, particularly impacting nursing and physiotherapy. In nursing, most of the workload appears to be concentrated in the hands of a single nurse. A business plan is in place to increase haemophilia nursing, essential for a strong service.

The physiotherapist's hours are inadequate to meet the service's demands, which include reviewing children with severe bleeding disorders of all ages on both an elective and urgent basis, as well as allowing time for professional development and attending haemophilia/IBD-related courses. The nursing staff currently covering the team are also encouraged to participate in relevant training.

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

Completed and displayed.

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

Evidence provided for the standard.

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

Services available as needed.

Quality Standard 16: Emergency Department

Partially Met

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

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

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

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

How the Service meets or does not meet the standard

ED pathway reviewed. Some feedback from patients about out-of-hours presentation and waiting for specialist review. There is no evidence of ongoing audit, and this pathway may warrant a review by the team.

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

All required tests are either performed in-house or sent to the GRI/genetics labs.

Quality Standard 18: Specialist Services

Standard Met

Timely access to the following specialist staff and services should be available as part of an HCCC service where appropriate, depending on whether it is adult, paediatric or all-age service. HCs should be able to access these services through network arrangements:

- a. Obstetrics, including reproductive counselling, information about pre-implantation genetic diagnosis and antenatal diagnosis
- b. Foetal medicine
- c. Vascular access (consultant surgeon or interventional radiologist with experience of venous access devices)
- d. Orthopaedic surgery
- e. Care of older people services
- f. Dental services
- g. HIV services
- h. Hepatology
- i. Medical genetics (Genetic Counselling Services)
- j. Pain management services
- k. Rheumatology
- l. Specialist services should have an appropriate level of specialist expertise in the care of people with inherited and acquired bleeding disorders.

How the Service meets or does not meet the standard

Available as needed.

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

Combination of paper and electronic records. Awaiting HCIS to be integrated into the local IT system.

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

Standard Met

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

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

How the Service meets or does not meet the standard

Guidelines/policies present.

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

Guidelines are in place, but a more specific one detailing the initiation of prophylaxis would be helpful.

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

Relevant guidelines are in place.

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

Relevant guidelines in place.

Quality Standard 24: Service Organisation

Partially 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

While most of the activities are being completed, there is limited scope for community visits by the nurses.

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

Regular MDTMS held locally and as part of the National (Scottish) Peer Review for complex cases every 3 months.

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

Patients referred to clinics as appropriate.

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

Data collected and reported.

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

Research portfolio reviewed.

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

Feedback and governance meetings are in place to facilitate reflection and learning.

Quality Standard 30: Document Control

Standard Met

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

How the Service meets or does not meet the standard

Comply in general with standards, although occasional documents or versions require updated dates.

6 Acknowledgements

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

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

7 Appendices

7.1 Definitions

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

7.2 Peer Review Team

The peer review team consisted of a Consultant Paediatric Haematologist, a Clinical Nurse Specialist, a Paediatric Research Nurse and a patient representative. Details of the Peer Review Team are held by UKHCDO.

7.3 Outstanding findings from previous peer review

The table below provides details of relevant issues that were raised in the previous peer review report of 2019, some of which have also been raised in this review. These have been highlighted here to add strength to the recommendations in this report as these issues should be addressed as a matter of priority. The Trust should ensure that appropriate resources are made available so these outstanding issues can be resolved.

Ref. Number	Statement of original finding
1	Staffing
a.	**Nursing:** The two nurse specialists together constituted less than one Whole Time Equivalent (WTE), which was not sufficient for a service of this size. A business case had been submitted for an additional Band 6 nurse and if the business care was approved and a nurse was appointed this would bring the team to a more appropriate and sustainable level. Business cases had also been submitted for a number of other nursing posts within the Haematology-Oncology Directorate. A management plan to

	devolve the decisions to the clinical teams about which of these posts to support was considered unlikely to be productive.
d.	**Physiotherapy:** In the time allocated (two to three sessions per week), it was not possible for the physiotherapist to see all the severely and moderately affected children in clinic and to undertake their joint scores. Children were offered a separate appointment for this but often did not attend and the overall joint score completion rate was therefore only approximately 50%. Cover for the named physiotherapist was available, but the cover could be given by any of a number of colleagues, rather than a named deputy who could develop additional skills for working with this patient group.