UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

UKHCDO Haemophilia Peer Review Audit Report

Belfast Children's Haemophilia Comprehensive Care Centre

HAEM-PSYCH ASSOCIATION UK & IRELAND

Haemophilia Nurses Association UK

HCPA Haemophilia Chartered Physiotherapist Association

HAEMOPHILIA SCOTLAND

The Haemophilia Society

HAEMOPHILIA WALES

Haemophilia NI
Supporting patients and families

Report Date: 22 August 2025

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1 Executive summary

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

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

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

The executive summary presents the key findings, while the full report details the assessments referenced against the quality standards. This report presents the outcomes of the peer review for the Belfast Children's Haemophilia Comprehensive Care Centre (The Service), conducted on 30 April 2024, with a follow-up meeting on 27 January 2025.

The Service successfully met 17 of the 30 established standards, with ten standards partially met and three remaining unmet. The Service has close links with the Belfast Adults' Haemophilia Centre at Belfast City Hospital, sharing some resources. Key recommendations have been made to help address the gaps that affect the ability to deliver comprehensive care.

Key Recommendations:

1. **Environment & Facilities:** The review team recommends that the Trust supports the Service by identifying suitable space for the centre to operate effectively, as outlined in the national service specifications. This is crucial because limited space affects the service's ability to deliver high-quality care and support to patients and carers.
2. **Medical Staffing:** The review team recommends that the Trust provide the Service with the necessary medical cover to enable the Service to meet the national service specifications. Specifically, the service would benefit from more input from resident doctors, as well as assigning roles to non-consultant medical staff for managing the day unit.
3. **Nursing Staffing:** There is a severe dearth of clinical nurse specialists, and increasing the number would alleviate overall pressure on the clinical team.

Although the Service has no outstanding findings from the previous peer review, the clinical service appears to be stretched and merits additional management support. 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 Service offers care for children with bleeding disorders and has 170 registered patients. It is located at the Royal Belfast Hospital for Sick Children and is part of the Belfast Health and Social Care Trust.

The Service is not part of a haemophilia network, but as specified above, does have strong links with the Adult Haemophilia Centre.

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	0	22	0	6	0	31	0	57
Moderate	0	5	0	3				
Mild	0	43	0	3				
Annual review in the last year	0	68	0	36	0	34	0	
Inpatient admissions in the last year	0	3	0	1	0	3	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 staff comprises a mixture of full-time and part-time roles, including two consultant haematologists (1.9 WTE), one nurse (1.0 WTE), and two administrative staff. Posts shared with the adult service include one physiotherapist, one occupational therapist, a data manager, a social worker, and a clinical Psychologist.

Key staff include Paediatric Consultant Haematologist and Centre Director Dr Christine Macartney, Paediatric Consultant Haematologist Dr Bethany Mitchell, and Lead Nurse Fionnuala Diamond.

Outpatient care: The clinical review of PwBD occurs in a Day Care Unit shared with paediatric oncology, malignant haematology, bone marrow transplant, and other non-malignant haematology populations.

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

Out of hours: There is a dedicated telephone line staffed by appropriately trained nurses to triage incoming calls 24/7 on the haematology ward. An alert is also visible on the Electronic Record system in the emergency department.

Transition: A virtual transition clinic takes place every four months with the adult centre, during which all patients scheduled for transfer are discussed. Transition letters from the medical team at RBHSC are sent to BCH, summarising medical care from diagnosis up to the point of transition.

Network arrangements: The Service is not part of a haemophilia network, but as specified above, does have strong links with the Adult Haemophilia centre.

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 17 out of the 30 standards, with ten partially met and three unmet. The Service has no outstanding findings from its previous peer review. The service is encouraged to review all descriptive assessments in addition to the key findings. This report, alongside local assessments, should steer discussions with the management team, highlighting areas of good practice while emphasising where further investment and improvement may be required.

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

Standard	Title of standard	Rating
23	Guidelines on Care of PwBD requiring Surgery	🟥
24	Service Organisation	🟩
25	Multidisciplinary Team Meetings	🟨
26	Multidisciplinary Clinics/ Liaison Services	🟩
27	Data Collection	🟩
28	Research	🟩
29	Multidisciplinary Review and Learning	🟨
30	Document Control	🟥

4.2 Good Practice

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

1. The review team were very impressed with an animated video produced by the department about managing haemophilia as a young person, which included discussions of sports and activities.
2. The telephone triage system was effective and well-advertised in clinical areas and on relevant patient/carer-facing documentation.
3. An excellent guide by the Data Manager on how to use Haemtrack was available for patients and parents.
4. MDT clinics and post-clinic meetings appear to be well-attended by AHPs within the team. Regular virtual meetings with the adult bleeding disorders team to discuss children approaching transition age were seen as an effective way to manage the transition of care.
5. The peer review team was impressed by the play therapy support available, with the provision of play therapy in the home setting particularly commendable.

4.3 Immediate risks

There were no immediate risks identified.

4.4 Concerns

Overall, the service provided was good, but the review team wishes to highlight several concerns, particularly regarding space and staffing.

1. The space within the Haemophilia Centre is insufficient to meet the service's needs. The review team is concerned about the severely limited space, which risks compromising the quality of care provided by the dedicated team. Additionally, the lack of space and facilities hampers service development and collaborative multi-disciplinary and cross-site working. Although two clinic rooms are allocated for Multi-Disciplinary Team (MDT) clinics, urgent assessment and treatment of children presenting at the centre often mean the MDT clinic cannot run efficiently or accommodate separate reviews by therapists, which are essential according to the service specification. The post-clinic MDT discussion takes place in a clinic room that lacks adequate space. The team reported that some aspects of clinical service

delivery are limited by the available clinical space within which to speak with patients and carers, e.g., engagement with Haemtrack reporting, transition planning.

2. A lack of space for clinical review in the Day Care Unit has led to reviews by physiotherapists and other MDT members being held in other areas, including the main physiotherapy department and Musgrove Park Hospital, which is located on a different hospital site. This can be inconvenient for patients and carers, particularly as it may need to take place on a different date – this is non-compliant with the standards for providing a multi-disciplinary review.
3. There is limited office space for MDT members who work cross-site between the adult and paediatric services. Desktops to work at are not always available when required.
4. Some patient feedback contained negative comments about the clinical space and waiting times to be seen by team members.
5. The review team considers that the current level of medical and nursing staffing is inadequate for the patient population. Additionally, at the time of review, the staffing levels would be unable to provide any resilience if a staff member were absent for a period. This is likely to significantly impact the Service's ability to deliver high-quality care and support to patients and carers.
6. The Service relies on national or UKHCDO guidelines rather than having its own localised guidelines, particularly for surgery, where there is no national guidance.
7. Policies, procedures, and guidelines provided to the review team lacked effective document controls. Most did not include details such as authorship, review date, or version control.

4.5 Recommendations

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

1. **Environment & Facilities:** The review team recommends that the Trust supports the Service by identifying suitable space for the centre to operate effectively, as outlined in the national service specifications. This is crucial because limited space affects the service's ability to deliver high-quality care and support to patients and carers.
2. **Medical Staffing:** The review team recommend that the Trust provide the Service with the necessary resources to increase staffing levels, not only to maintain current standards of care but also to build resilience in case of long-term absences. Specifically, the service would benefit from more input from resident doctors, as well as assigning roles to non-consultant medical staff for managing the day unit.
3. **Nursing Staffing:** A single clinical nurse specialist for a service is unusual and poses significant clinical risk. An increased nurse workforce can support the delivery of service very effectively, including the introduction of nurse-led clinics and other reviews.
4. **Guidelines & Document Control:** If the above two recommendations are followed, the team should be able to allocate time within their job plans to focus more on Service management and development, which is not feasible under the current circumstances and poses a risk to patient care. The review team would like to see the Service document its own local guidelines as outlined in section 4.4. They also wish to see document controls implemented to ensure that all policies, procedures, and guidelines are effectively managed.

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 patient and parent information booklet about Belfast Children's Hospital bleeding disorders service is excellent. It is well-presented and easy to read, with good use of diagrams and pictures.

The indexing supports quick access to relevant sections of the document. It covers sections 1a-h of the standards.

Quality Standard 2: Condition-Specific Information

Standard Met

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

a. A description of their condition and how it might affect them
b. Problems, symptoms, and signs for which emergency advice should be sought
c. Genetics of Inherited Bleeding Disorders
d. Testing for carrier status and the implications of being a carrier
e. Treatment options including on-demand, prophylaxis, home therapy and the use of Haemtrack
f. How to manage bleeding at home
g. Ports, fistulae, and in-dwelling access devices (if applicable)

h. Approach to elective and emergency surgery
i. Women's health issues
j. Dental care
k. Travel advice
l. Vaccination Advice
m. Health promotion to include smoking cessation, healthy eating, weight management, exercise, alcohol use, sexual and reproductive health, and mental and emotional health and well-being
n. Sources of further advice and information

Condition-specific information should be available covering:

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

How the Service meets or does not meet the standard

A substantial amount of documentation was provided to support this standard.

The documents originated from various sources, including those produced locally and those obtained from pharmaceutical companies, other trusts, and bleeding disorders societies or charities.

All of the documents were relevant; however, it was noted that some were out of date and/or had been superseded by more recent versions but were still retained within the file.

Quality Standard 3: Plan of Care

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.

Standard Met

How the Service meets or does not meet the standard

Bleeding plans are in place and were shown post-review. At the time of review, plans were on paper in the ED and on ECR. Since the review, the Service has transitioned to digital plans, which were displayed in a very well-organised shared folder. Bleeding plans are not given to parents, but parents do receive a copy of the clinic letters that contain information about the care plan.

The 24-hour triage process and the pack given to parents at diagnosis, containing information about the bleeding disorder process, will change with the implementation of electronic notes after the 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

A formal review of all PwBD occurs at Belfast Children's Hospital. The review frequency aligns with team reports, typically 2-4 times a year for children with severe or moderate bleeding disorders on prophylaxis, and at least annually for those with mild bleeding disorders. However, there was no documentation confirming patient attendance at the clinic at the required frequency. Although data on clinic attendances was provided, it lacked the detail necessary to verify compliance with standards due to coding issues, which are expected to be addressed by the introduction of electronic care records (EPIC) in June 2024.

The review takes place in a dedicated clinic in the Haematology/Oncology Day Care Unit, held twice monthly on a Thursday. The clinic is attended by a doctor, physiotherapist, occupational therapist, and social worker. The psychologist is available by appointment and can attend on short notice if new concerns arise. The panel noted that the CNS did not routinely attend clinic reviews with the doctor, often being occupied with other duties in the Day Care Unit related to bleeding disorders or other patient groups. Nonetheless, the CNS would participate in consultations on an individual basis if needed. A clinic template for MDT review is completed and sent to parents and the GP. Team members (listed accordingly) meet following each clinic for an MDT meeting, which is minuted and discusses recent clinic reviews, attendances, inpatients, and adverse event reports for children with bleeding disorders. The minutes of these meetings were provided in the documentation.

The peer review team observed that no SOP or policy was presented for managing DNAs. The team verbally informed us that patients who did not attend a clinic are followed up via telephone by the CNS and notified to the hospital safeguarding team or local professionals if necessary.

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

A single contact telephone number is provided to patients and parents, answered 24/7 by nurses trained to triage calls for children with bleeding disorders. During working hours, this is based in the Day Care Unit, while outside normal hours, it is managed from the inpatient haematology ward. This setup is shared with the care of children with other non-malignant haematological disorders and those with malignancy.

Quality Standard 6: Haemtrack (PwBD on Home Therapy)

Partially 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

Although the clinical team encourages engagement with Haemtrack reporting, data shows that only a small proportion of those on home therapy actually use Haemtrack to report their product use.

The peer review team speculated that the team's ability to further promote Haemtrack reporting might be limited by the available time and clinic space to facilitate discussions with patients and carers.

Quality Standard 7: Environment, Facilities and Equipment

Standard Not 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 panel has significant concerns about the environment and facilities in relation to the following:

- The clinical review of PwBD takes place in a Day Care Unit shared with paediatric oncology, malignant haematology, bone marrow transplant, and other non-malignant haematology populations. Space is extremely limited, which risks negatively affecting the quality of care delivered by the dedicated team. For example, although two clinic rooms are provided for the MDT clinic—one for the doctor and one for other therapists—a clinic room may be required urgently to house a child needing urgent assessment or treatment. This often results in the MDT clinic being unable to operate efficiently or to conduct separate reviews by therapists.
- A lack of space for clinical review in the Day Care Unit has led to physiotherapists and other MDT members conducting reviews in other areas, including the main physiotherapy department and Musgrove Park Hospital, which is located on a different hospital site. This can be inconvenient for PwBD and their carers, especially as reviews may need to be scheduled on different dates.
- The post-clinic MDT discussion occurs in a clinic room that lacks sufficient space.
- There is limited office space for MDT members who work across both the adult and paediatric services. Desktops are not always available when needed.
- The team reported that some aspects of clinical service delivery are limited by the available space, especially when speaking with PwBD and their carers, such as in engagement with Haemtrack reporting and transition planning.
- Some patient feedback included negative comments regarding the clinical space and waiting times to be seen by team members.

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

Partially 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 from paediatric to adult services is managed through the use of Ready Steady Go documentation in multidisciplinary team (MDT) clinics. This includes four monthly virtual discussions with the adult bleeding disorders team at Belfast City Hospital to review children approaching transition age. These meetings are minuted, and a clinic template was also presented. Attendance includes members of the medical and nursing teams, along with allied health professionals (AHPs) as needed.

Children and parents receive a copy of an information booklet about the Belfast City Hospital bleeding disorders service, which is well presented and comprehensive. Advice regarding point 8f is included within this document.

Some members of the multidisciplinary team, such as physiotherapists, occupational therapists, and social workers, work across both adult and paediatric bleeding disorders services.

The peer review team noted that no standard operating procedure (SOP) or policy for transition was presented and that there is no designated transition coordinator.

The team reported that the effective use of the Ready Steady Go documentation is limited by the lack of dedicated clinic space in MDT clinics, which results in pressured appointment times and limited opportunity for private discussion.

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

Documentation was presented of various support services for parents/carers and how to access them. This included services within each of the boroughs of NI.

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

A patient/parent feedback survey had been completed but it was not dated. There was excellent feedback about the care received from members of the team.

Prior to the appointment of an OT for adults/children with bleeding disorders, feedback was obtained about how this might improve the service.

Quality Standard 11: Leadership team

Partially Met

The leadership team will consist of a lead consultant, and other members agreed at a local level. This may include nurses, physiotherapists and psychologists, clinical scientists, or other members of the MDT. The lead consultant will be responsible for staff training, guidelines and protocols, service organisation, governance and liaison with other Services but may delegate some of these roles to others in the leadership team.

The leadership team should all be registered healthcare professionals with appropriate specialist competences, undertake regular clinical work with the Service, and have specific time allocated for their leadership role.

How the Service meets or does not meet the standard

The leadership team is established, but it was reported that there is no designated time for leadership within the job plans.

Quality Standard 12: Staffing levels and skill mix

Partially Met

a. Sufficient staff with appropriate competences should be available for outpatient, day unit and in-patient care and support to urgent care services. Staffing levels should be appropriate for the number of PwBD cared for by the Service and its role in the network.
b. All staff should undertake regular continuing professional development that is relevant to their work in the inherited and acquired bleeding disorders services.
c. Staff working with children and young people should have competences in caring for children as well as in the care of people with bleeding disorders. Cover for absences should be available.
d. In HCCCs, these staff should have sessional time allocated to their work with the IABD service. In HCs, the arrangements for accessing staff who do not have sessional time allocated to the IABD service should be clearly defined.

Staffing should include:

a. Medical staff:
    i. Consultant specialising in the care of people with inherited and acquired bleeding disorders available during normal working hours
    ii. On-call consultant specialising in the care of people with inherited and acquired bleeding disorders 24/7 in HCCC
    iii. On-call haematology consultant with arrangements for advice from a consultant specialising in the care of people with inherited and acquired bleeding disorders in HC
b. Specialist nursing staff:
    i. Bleeding disorders specialist nurses (5/7)

    ii. Ward, outpatient, and day unit staff with competences in the care of people with inherited and acquired bleeding disorders

c. Clinical specialist physiotherapist
d. Practitioner psychologist or appropriately trained psychotherapist with specialist knowledge in IBDs.
e. Access to specialist senior social worker
f. Data manager
g. Biomedical scientist and/or clinical scientist (further details on the requirements are included in QS 17)

How the Service meets or does not meet the standard

The peer review team felt that the current level of medical and nursing staffing was insufficient for the patient population. There was concern that staff numbers would not be able to provide any resilience if a staff member was absent for some time. This is likely to significantly affect their ability to provide education for other services, attend meetings for CPD, and develop or evaluate the service.

In terms of medical cover, the consultants are frequently interrupted due to the lack of junior medical team members. This often involves roles in the Day Unit that could be performed by non-consultant medical staff. Long working hours and the 1:4 on-call rota offer little time for recovery. The appointment of a specialty doctor, for which funding has been secured, would probably improve this. Nurse-led clinics are another option to reduce the burden on consultant medical staff, but current staffing levels prevent it from being developed.

Neither medical nor nursing staff have exclusive roles in caring for children with bleeding disorders, as external demands on their time are considerable. The peer review team was concerned that the increasing haemoglobinopathy patient population might impact their ability to provide high-quality care for Pwbd.

The physio is due to retire in June 2024 and remains in position at the time of the peer review. A new physio commenced post-review. The Data Manager shares responsibilities with adult services.

Quality Standard 13: Service Competencies and Training Plan

Partially 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

Appraisal and Mandatory Training records are not available for all team members in the evidence folder. Only one CNS has completed the bleeding disorders course and the contemporary care course provided by HNA.

The peer review team noted that medical team members have had limited opportunities to attend national and international meetings (for CPD) due to clinical demands on their time.

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

Although shared with other aspects of the paediatric haematology/oncology service, there are two secretaries who support the paediatric bleeding disorders service. There is one data manager who works for both the adult and paediatric bleeding disorders services. He is present at the Children's Hospital site on one day per week and, if required, in addition to this. His ability to work on site is limited by a lack of desk space.

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 are play therapists who work with the team. They provide a service within the hospital and also offer home visits. Additionally, there is an OT specialised in adult and paediatric bleeding disorders services. Access to orthotics and podiatry services can be obtained through the team physios.

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

An electronic alert appears whenever a PwBD presents to any other hospital team or area. The paper hospital notes for each patient include a 'front sheet' summarising their bleeding disorder diagnosis, treatment, contact details for the team, and any other relevant information.

The peer review team visited the ED and spoke with two of the ED consultants. It was evident from these discussions that the teams work well together in caring for children with bleeding disorders. The CNS is available during working hours to administer treatment and access indwelling central venous access devices.

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

The coagulation laboratory is located at and shared with the Adult's service in Belfast City Hospital. Reviewed during the adult service review and was found to meet the standard; please refer to the adult's centre report for further details.

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

There was evidence presented regarding liaison with obstetric and dental services. The paediatric dental service is located on site at Belfast Children's Hospital, and there is a clear pathway for providing haemostatic treatment before invasive dental procedures. The team noted the increased burden of dental treatments on their service, as the number of procedures has risen significantly since the Covid pandemic. Dental reviews, once a routine part of clinic assessments, are no longer feasible due to the higher demand from the growing patient population.

For portacaths the surgical team plans to come to the ward for surgery. Genetics testing is conducted at the adult centre.

Quality Standard 19: IT System

Partially Met

IT systems should be in use for:

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

How the Service meets or does not meet the standard

The shared folder with bleeding plans was shown after review and demonstrates an effective IT system for storing, retrieving, and transmitting PwBD information.

The data manager is shared with the adult service and has access. No one else is designated as a backup, creating a single point of failure. Please refer to the adult's report for more details.

The team has access to Haemtrack, although only a few patients use it.

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

Partially Met

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

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

How the Service meets or does not meet the standard

Haemophilia guidelines are available, but not all areas were covered in the guidelines

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

All guidelines are available, and there is clear information about treatment and monitoring.

Quality Standard 22: Clinical Guidelines/Pathways

Partially 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

The team has no local guidelines, and they follow general UKHCDO guidelines. This does not allow for interpretation in the local context.

Quality Standard 23: Guidelines on Care of PwBD requiring Surgery

Standard Not 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

No local guidelines provided, but there is no national guidance available on this matter.

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 service sees all severe patients every 6 months and the rest every 12 months. The service has demonstrated the implementation of many of the above recommendations but there is no formal documentation of process or procedure.

Quality Standard 25: Multidisciplinary Team Meetings

Partially Met

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

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

How the Service meets or does not meet the standard

As noted above, MDT meetings occur fortnightly after each bleeding disorders clinic. These meetings include all members of the core team, and minutes are recorded.

The peer review team observed that there was no representation from the coagulation laboratory team, although the coagulation laboratory, located on the adult hospital site, presents a potential barrier to this.

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

Available where relevant/required.

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

The data manager is shared with the Adult Centre, and they update the National Haemophilia Database. The support for this comes from the adult service.

There is limited use of Haemtrack.

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

There was published research and guidance by physiotherapists, occupational therapists, and CNS. Research and service evaluations had been presented at relevant conferences and meetings, including regional, national, and European levels. Children were being recruited to the Dolphin Study by the physiotherapy team.

There had not been any engagement with clinical trials of existing or new products for the treatment of bleeding disorders, and the peer review team was concerned that this might reduce patients' access to these treatments.

Quality Standard 29: Multidisciplinary Review and Learning

Partially 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

No audit plan was presented, and the peer review team observed that little audit had been conducted. While presentations to the ED with head injuries had been audited, there was no audit of waiting times for assessment and treatment of emergency presentations to the ED.

Quality Standard 30: Document Control

Not 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

The policies, SOPs, and guidelines provided lacked evidence of document control. Most were missing authorship, review dates, and version control.

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 1 paediatric consultant haematologist, and three clinical nurse specialists. Details of the Peer Review Team are held by UKHCDO.