UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

UKHCDO Haemophilia Peer Review Audit Report

Manchester Adult'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

Report Date: 30 April 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. The peer review of the Manchester Adult Haemophilia Comprehensive Care Centre (the Service) was completed on 17 May 2024. The Centre is located within the Department of Haematology at Manchester Royal Infirmary (MRI), part of Manchester University NHS Foundation Trust.

The Centre successfully met 25 of the 30 established standards, with five standards partially met. The Centre's and the Trust's commitment to providing high-quality care was evident through various initiatives and pathways. However, key recommendations have been made to address gaps that impact the ability to deliver comprehensive care.

Key Recommendations:

1. **Physiotherapy provision:** The current physiotherapy service provision is insufficient for the size of the Service, hindering the ability to offer proactive care in line with service specifications. The standards require physiotherapy advice and support to be available at all times, including appropriate cover for absences. To meet this standard, it is recommended that physiotherapy provision be increased proportionally to the size of the Service.
2. **Psychological service provision**: Similarly, the current provision of psychological services is inadequate for the size of the Service, with no cover for sickness or absence. It is understood that this may be addressed by the new funding from the Infected Blood Inquiry Psychology Service in the near future. The team urges support for early implementation and recruitment to the new Infected Blood Psychological Service.

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 took place on 17 May 2024 at the Department of Haematology, Manchester Royal Infirmary. A multidisciplinary team of haemophilia professionals, alongside patient representatives, conducted the review which involved speaking with staff from the Service, reviewing documentation, and touring the facilities.

The Service provides care for adults with bleeding disorders and has 2,406 registered patients. It serves Greater Manchester and the wider Northwest, including Cheshire and Cumbria. The Service operates within the Department of Haematology at Manchester Royal Infirmary (MRI). MRI is part of Manchester University NHS Foundation Trust (MFT), one of the largest acute trusts in the UK.

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	109	0	18	0	824	0	1171	0
Moderate	47	0	29	0				
Mild	181	0	27	0				
Annual review in the last year	237	0	59	0	407	0	508	0
Inpatient admissions in the last year	115	0	23	0	86	0	40	0

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

Staffing: The Service employs 27 professionals, including five consultants (4.2 WTE), a haematology specialist trainee (1.0 WTE), three nurses (3.0 WTE), three physiotherapists (0.6 WTE), one haematology social worker (0.2 WTE), one coagulation laboratory biomedical scientist, four genetic laboratory clinical scientists, and four administrative staff (including a centre administrator (1.0 WTE), a data manager (full-time), a data admin coordinator (0.5 WTE) and PA secretarial support to consultants (1.0 WTE)). The Service does not have a dedicated haemophilia specialist psychologist but has limited access to general hospital services. This mix of full and part-time roles ensures that most aspects of comprehensive patient care are addressed. However, the inadequate physiotherapy provision relative to the size of the Service is a significant concern.

Key staff include Consultant Haematologist and Centre Director Dr Martin Scott and lead nurse Hayley Dyos.

Outpatient care: Patients attending as outpatients for planned treatment are seen at the dedicated Haemophilia Centre situated within the haematology outpatient area (2nd floor, MRI). This includes office space for the specialist nurses, a treatment room with three treatment chairs, and a dedicated consultation room. The treatment room is equipped with two monitored fridges for the storage of routinely used clotting factor concentrates. There is a reception area adjacent to the Haemophilia Centre, which is staffed during normal working hours. The weekly haemophilia multidisciplinary team (MDT) clinic takes place within the main MRI outpatient area (clinic D) on the ground floor of MRI, where eight clinical rooms are available, including a separate room for physiotherapy assessment.

The main consultant-led multidisciplinary haemophilia clinic is held weekly on a Wednesday afternoon. Patients with clinically severe bleeding disorders are seen by a consultant or specialist trainee (with appropriate clinical supervision) and a haemophilia nurse specialist. During this appointment, a specialist physiotherapist reviews these patients and performs a full joint score. The full consultant team is in attendance at this clinic.

Inpatient care: If hospital admission is required, patients are assigned to a ward suitable for the admitting team. Patients admitted directly under Haematology are preferentially placed in Ward 44 (Haematology). This ward also serves patients in the regional malignant haematology, bone marrow transplant, and CAR-T service. If accommodation in Ward 44 is not feasible, patients will be admitted to an alternative acute medical ward.

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

Transition: The adult and paediatric haemophilia services maintain a close collaborative link. A joint adult/paediatric MDT meeting is held monthly, during which all transitioning patients for that period are discussed. Transition clinics involving both teams are also conducted monthly.

Network arrangements: The Service is not part of a formal network but works closely with the Manchester Paediatric Haemophilia Comprehensive Care Centre, which is also part of MFT.

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 25 out of the 30 standards, with the remaining five partially met and with no outstanding findings from the 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	🟩

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

4.2 Good Practice

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

1. The review team was impressed by the centre staff, who are enthusiastic, knowledgeable, and eager to further develop the Service. In particular, the review team wished to highlight the lead nurse, whom they felt provided excellent leadership in building a new nursing team despite the constraints on resources.
2. The physiotherapy team was also recognised for going above and beyond their hours to provide reasonable Service.
3. The Service has a full complement of consultant posts, in contrast to many centres, which reflects the trust's commitment. This enables them to provide consultant-led multidisciplinary clinics.

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. While the physiotherapists are working hard and going above and beyond, the actual provision of services does not meet current quality standards. The service is highly reactive, meaning timely advice is not always available. Haemophilia is a disorder characterised by bleeding into major joints and muscles, significantly affecting musculoskeletal health, which is why physiotherapy is a crucial component of comprehensive care. The review team was also concerned that patients needing physiotherapy support had to be taken to the physiotherapy department even in acute situations, rather than being assessed at the centre, with no immediate plans to address this issue.
2. There are concerns about the robustness of the limited social worker provision. There is a real risk of a single point of failure due to the lack of cover for leave or illness.
3. The current provision of psychological services is entirely inadequate for the size of the Service, with no cover for sickness/absence. It is understood that this may be addressed by the bid for new funding from the Infected Blood Inquiry Psychology Service in the immediate future.
4. The clinic rooms in the outpatient department are very small, which not only affects the Service's multidisciplinary team approach but also restricts access for patients with mobility aids or those who need to attend with a family member or friend.
5. The waiting facilities in the centre are inadequate, and patients sometimes have to use an overspill area.
6. There is no pathway for patients with Acquired Haemophilia A for prioritised admission to the adult Haematology ward 44 in patients with life-threatening bleeds requiring haemostatic treatment.
7. The nursing team of 3.0 WTE appears inadequate for the size of the service. The B7 post holder has service-wide leadership and management responsibilities that require time away from the clinical setting. Consequently, the team is particularly vulnerable during any period of sickness or absence. It was also noted that the nursing team is expected to "backfill" for other disciplines, such as data management, which is an unacceptable use of valuable nursing resources.
8. The nursing team manages the stock control of the clotting factor.

4.5 Recommendations

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

1. **Increase in physiotherapy resource**: The review team recommends a suitable increase in the amount of physiotherapy WTE in line with the service size, enabling a proactive response to patients' needs rather than a reactive one. Enhancing the musculoskeletal health of

individuals with bleeding disorders is crucial for improving mobility, strength, pain management, and overall quality of life.

2. **Review of psychosocial service provision:** The review team recommends that additional provision of social workers and psychologists be sought, as the current arrangements are inadequate to meet the needs of such a large and complex patient group, many of whom have co-morbidities and disabilities, as well as the psychological impact of living with an inherited bleeding disorder and the well-publicised findings of the Infected Blood Inquiry. Due to the inherited nature of the diseases cared for in the service, provision is also required to support immediate family members. It is understood that the limited availability of psychological services may be addressed by the bid for new funding from the Infected Blood Inquiry Psychology Service in the immediate future. The review team suggests that this be implemented as soon as possible.
3. **Clinic Space:** The review team recommends that the Trust review the space allocated for multidisciplinary clinics and implement measures to mitigate the impact of the small clinic space on patients and carers.
4. **Waiting area space:** The waiting areas need to be reviewed to ensure safe and adequate space for patients and their carers. The particular needs of those with mobility issues need to be considered.
5. **Admission pathway for Acquired Haemophilia:** An explicit pathway for patients with Acquired Haemophilia A that prioritises admission to the adult Haematology ward 44 for those experiencing life-threatening bleeds requiring haemostatic treatment needs to be developed or agreed upon. These patients represent the most acutely unwell and vulnerable group within the bleeding disorders portfolio. They are admitted to the hospital with life-threatening bleeding and are at high risk of further bleeding due to interventions from inexperienced medical and nursing staff, a risk that is mitigated by admitting them to an area trained and experienced in appropriate care.
6. **Data Management:** Provision must be made for cross-cover for data management staff during periods of sickness or other absence to prevent the nursing team from being used to "backfill" this role. The data manager should receive training to liaise with the pharmacy in all aspects of clotting factor stock control, relieving the nurses of this responsibility.
7. **Managing IT Interfaces**: Access to HCIS for all clinicians should be reviewed.
8. **Emergency Pathway:** An electronic "alert" should be developed for the A&E pathway. A&E attendances and outcomes should be audited.

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

Brilliant new patient pack given to patients with details of how to access the Service. A wider selection of paper documents would be useful for those who do not access the Internet.

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

Good selection of disease specific information. No patient information on IV access, which would be recommended. Individualised care plan for patients were noted.

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

Templates for a plan of care for both Haem A/B and vWD provided an example of the use of this within a patient letter. Note the specific brand of rFVIII is not provided, and this may be helpful, particularly for patients who may attend in an emergency at another hospital in the region. - explanation given that SHL FVIII used more generically.

HCIS is accessed by CNS but not available to wider medical team out of hours. Considering how information can be linked to HIVE.
No formal network arrangements are in place, but Manchester does provide advice for patients admitted with bleeding disorders to other hospitals and organises for treatment to be sent to blood banks in these hospitals on a named-patient basis.

MyMFT provides patients with electronic access to their clinic letters but cannot be accessed by medical teams at other hospitals and the opportunity to identify Haematologists in the regional DGH and cc them into correspondence could be explored particularly for patients with co-morbidities being seen by other medical/ surgical teams at these hospitals.

Quality Standard 4: Outpatient review of PwBD

Partially 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

All patients with severe bleeding disorders are offered a routine clinic review on a 6-monthly basis or more frequently, as required. For clinically stable individuals, these appointments may alternate between face-to-face and telephone appointments, according to the clinician's discretion. This system ensures that all patients are reviewed at least annually within the Haemophilia MDT clinic (consultant, registrar, specialist nurse, and physiotherapist), which includes a physiotherapy review and joint scoring. Patients with less severe bleeding disorders are reviewed less frequently (up to every 18 months, according to clinical need), either as a face-to-face consultation or telephone review, as appropriate. We encourage carers to attend appointments where possible.

Patients can be referred to the departmental social worker by any professional, self-refer, or family/carer can refer too. Referrals are currently made via email, telephone or on HIVE messages. The social worker also attends our weekly MDT meeting to discuss referrals.

There is a psychologist available in the wider department, however provision for haemophilia is limited. The Service has engaged with the National process of tendering for a psychologist, following the outcome of the IBI. The Trust has been awarded 0.6 WTE for Regional Navigator role. The Service has also expressed an interest in hosting a clinical psychologist/ therapist as part of this scheme and are awaiting the outcome. There are also developments within the wider department to address the gaps in psychological support services.

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

All registered patients and their careers are provided with the centre leaflet, which contains contact information (telephone and email) for routine and emergency use. Patients are encouraged to share this information with other members of their healthcare team (e.g. their dentist), to whom they will also provide direct advice. Patients are encouraged to sign up to MyMFT so that they can access their healthcare information and contact details of the Haemophilia secretary/appointments team are included in clinic letters should patients require.

For clinical problems, patients can contact the Haemophilia Centre, where a nurse is available to give advice. This Service is available Monday through Friday, 08:00 to 16:00. During weekends and out of hours, patients are advised to call the hospital switchboard and speak with the registrar on call, who will give advice. There is also an on-call Haemophilia consultant with whom the registrar can liaise.

From discussions with patients on the day of the review, there seemed to be uncertainty over the contact arrangements as described. It is suggested that the Centre check at outpatient review meetings that patients understand the arrangements in place.

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

Letters sent to encourage use. Patient contract. Leaflets given.

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

Very small Outpatient clinic rooms—minimal accommodation for people with mobility aids or who had to attend with a family member or friend.

The clinic rooms are small for an MDT approach. There is a long distance between the haemophilia centre and the physiotherapy department. One treatment chair is missing, patients mentioned that there are long waits for treatment. The fridges are monitored daily. Nurses manage the clotting factor, which is a time-consuming task that could be delegated to the data management team with pharmacy oversight.

Access to HCIS is restricted to a limited number of computers and users and is not used out of hours by SpRs. The Service should consider reviewing access rights to HCIS.

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

Standard Met

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

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

The Centre should have a guideline/SOP covering this information.

How the Service meets or does not meet the standard

Transition Policy in place (although document undated). Clear and informative leaflet for patient use made available. SoP dated August 2023 on general transfer/transition of children and young persons to adult services in place. As per visit to Manchester Paediatric Haemophilia Services there is good co-operation and commitment to smooth transition at an appropriate age over the period from 14 to 18. Flexibility provided for actual transition date based on individual circumstances.

Quality Standard 9: Carers' Needs

Standard Met

Carers should be offered information on the following:

a. How to access an assessment of their own needs
b. What to do in an emergency
c. Services available to provide support

How the Service meets or does not meet the standard

The supporting documents referenced do not cover carers. The information provided indicated that patients were invited to attend appointments with any carers. Carers were given contact details for the Haemophilia Centre in case of emergency. The Social Worker was also able to support carers and refer and signpost them to various teams and community organisations.

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

An introductory letter for new patients was issued, which encouraged feedback and signpost complaints/PAL service. System in place to encourage regular feedback from patients. Includes a variety of posters using QR codes to encourage responses. Limited evidence of active feedback. A short patient feedback survey was conducted in February 2024. It shows a response of 21 patients, which is low for the patient group and may not be representative. Most record excellent satisfaction. Plan to establish a local bleeding disorders forum with paediatrics, which would include representation from patients, parents or carers.

Patients spoken with during the review were generally satisfied with the Service provided and found the staff approachable and helpful. They were knowledgeable of the feedback systems. They identified some individual issues that they had not raised with the Service and were encouraged to communicate these to the nursing/medical staff.

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

Appropriate leadership team with evidence of lead consultant carrying out the appropriate roles described in the QS.

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 title "Clinical Nurse Specialist" is widely accepted as an advanced practice role. It was unclear to the review team what the roles and responsibilities of each nurse were and how this fit within the Agenda for Change pay band structure. It's not clear if there is a development framework to work towards B7. It seems to be a Trust issue that the specialist skills, knowledge and expertise of a CNS are not adequately recognised. Nursing staff are stretched, and any expansion in the Service would require additional staff.

Haemophilia and Thrombosis consultants provide 24/7 care.

Physiotherapy is only 0.5 WTE, which is insufficient to meet service needs.

There is no dedicated psychologist, and there is a long waiting list for hospital psychology. However, following the IBI, the Trust has been awarded 0.6 WTE for a Regional Navigator role and expressed interest in hosting a clinical psychologist/ therapist as part of this scheme.

There is good access to a social worker within the haematology department, but there is no cover for her leave, and the review team is concerned about the amount of work and responsibility they have.

A data admin coordinator (0.5 WTE) has recently started and is training to support the data administration previously carried out by the senior nursing staff.

Quality Standard 13: Service Competencies and Training Plan

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

Standard Met

How the Service meets or does not meet the standard

Evidence is seen for all of this.
Evidence that all staff have completed Trust mandatory training and have regular appraisals.
Staff have attended Haemophilia specialist courses.

Quality Standard 14: Administrative, Clerical and Data Collection Support

Dedicated administrative, clerical and data collection support should be available.

Standad Met

How the Service meets or does not meet the standard

CNS is currently temporarily responsible for inputting some data into HCIS and controlling stock.

A full evaluation should be conducted of what elements of data/admin work CNS is doing and what can be moved across (appropriately) to the data/admin/clerical team.

Quality Standard 15: Support Services

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

Standard Met

How the Service meets or does not meet the standard

The requirements of this standard were in evidence on the day of the review.

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

This is partially met as there is no electronic alert visible in ED at present, although there are plans to address this.

All patients have a care plan and who to contact out of hours.

There is a clear pathway, but no audit information available.

Patients are triaged by an onsite SPR and there is 24/7 consultant cover.

There is a training plan for ED staff.

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 laboratory service for the Manchester CCC is provided by a fully accredited specialist haemostasis laboratory, which is on the same site as MRI. The haemostasis lab is managed as part of the Division of Laboratory Medicine, MFT. Laboratory diagnostic services are provided 24/7 and all assays (other than platelet function aggregometry) are available out of hours. The laboratory lead is part of the leadership team and meets on a weekly basis as part of regular MDT meetings. The Service has access to all the tests within this standard - these are requested and reviewed in a timely manner via HIVE.

The haemophilia molecular genetics service at MFT is the designated Northwest/ East of England Hub for genomics in specialist haematology.

The laboratory provides a genomics service to these regions, including diagnostics and clinical interpretation. A regional MDT is held on a monthly basis, comprising diagnostic and clinical input.

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

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

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

The Team all acknowledges the difficulties they have had with adopting and working with the new EPR system HIVE.

Given what we observed in the children's centre, we would suggest that the team liaise and work closely with colleagues in the paediatric Service on development and best use of HIVE functions (e.g. MDT meeting proforma).

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

Clear and thorough 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

Clear and thorough guidelines.

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

The lead physiotherapist works as an advanced practitioner in Rheumatology where they are responsible for independent Radiology requesting - however this is very constrained in haemophilia (due to local 'governance issues').

This represents a great way to enhance the patient experience and enables better overview of long-term management of MSK health in haemophilia (Physio taking responsibility as the advocate and lead on MSK health and wellbeing).

The peer review team acknowledge however that the 0.5 WTE for physio is not enough for this Service. This represents a significant element that if addressed by the hospital Trust would significantly improve care to and outcomes of patients.

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

All documentation seen. Clear and good.

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

Some of this was not relevant as pertained to children. Patients are not visited at home or in nursing homes. There were operational policies for the rest.

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

Terms of Reference for MDT have recently been developed but need to complete document control process for this. Attendance register maintained. Suggest the Service considers using proforma to document discussion and upload to HIVE (one demonstrated during peer review of children's hospital 16/5/24).

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

The Service has regular MDT clinics with obstetrics; Orthopaedics; GUM; Paediatrics. They have close links with the hepatology services at MRI which has 3 dedicated consultants and 4 clinical nurse specialists who can provide input when required and patients can be referred into this Service.

a. Joint haemophilia/orthopaedic clinic, every second month (Wednesday AM)
b. Joint haemophilia/obstetric clinic, weekly (Monday AM)
c. Transition clinic (with paediatric haematologists), monthly (Tues PM)

Quality Standard 27: Data Collection

Standard Met

The following data should be collected:

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

How the Service meets or does not meet the standard

All the requirements for this standard have been met.

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

Whilst this standard is met, it is done so with respect only to the medical team.

The physio team for example would be keen to participate in haemophilia related research if more time was available within the service provision.

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

Audit output had been limited until recently due to the introduction of the Trust EPR system and vacant data-manager post. Both issues have been recently resolved; audits completed in last month's include surgical care-plans; emergency department protocol; outpatient waiting times; outpatient DNA rate; inhibitor screening. All Positive feedback, complaints, outcomes, incidents and 'near misses'; Morbidity and mortality issues; review of UKHCDO Annual Report benchmarking information on concentrate use and ongoing reviews of service quality, safety, and efficiency are discussed at our weekly Haemophilia MDT, monthly clinical governance, monthly morbidity and mortality meeting or monthly consultant meetings, as appropriate. Note minutes MDT currently not taken but plan for this to start following the appointment of a data manager in the next few weeks.

Quality Standard 30: Document Control

Partially 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

Most of the documents had included a front document control page, and almost all had been updated very recently.
Was noted that the DNA policy was out of date.
Some of the documents / guidelines did not have a review date.

6 Acknowledgements

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

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

coordinated and managed the process; and the UKHCDO Chair and Executive team for their contributions to the reports and their final review.

7 Appendices

7.1 Definitions

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

7.2 Peer Review Team

The Peer Review Team consisted of one consultant Paediatric Haematologist, one adult haematologist, one clinical specialist physiotherapist, two clinical nurse specialists and one patient representative. Details of the Peer Review Teams are held by UKHCDO.

7.3 Outstanding findings from previous peer review

The table below provides details of the 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. No.	Statement of original finding

1a	**Staffing** Nursing - There was substantial shortfall in the provision of specialist nursing staff for the size of this service. The pivotal role of the Band 7 lead nurse was evident, and the review team shared the host team's concern about her plan to retire in around a year's time. In addition, the two Band 5 nurses were being trained up to undertake more specialist roles and it would be appropriate to assess whether the banding of all the nurses in respect to their expected duties was appropriate.
c	Psychology - There was no psychologist working with the Centre team, and patients mentioned this as a gap in the service. A psychologist is expected to be part of the core team in caring for these conditions. Where there were high-level concerns, referrals were made through the patient's primary care team. However, the team were lacking in the support and guidance which a psychology member can bring to their practice, and it was inevitable that not all lower-level patient and family needs were being met.
e	Physiotherapy - Three physiotherapists had a total of five sessions per week committed to the service, equivalent to one half-time post; this was a significant under-provision considering the size of this service. Because of the flexibility of the team, and their goodwill in working more than their contracted hours, they were managing to cover the essential parts of the service, but this was not sustainable.