UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

UKHCDO Haemophilia Peer Review Audit Report

Sheffield Adults 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

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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, and 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, with updated service specifications 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 constitute one of the twelve final recommendations of the Infected Blood Inquiry Report in 2024. This recommendation also requires trusts to consider peer review findings and prioritise the implementation of proposed improvements for comprehensive and safe care.

The previous peer review cycle was completed in 2019–2020, and the 2024 cycle represents 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 provides the key findings, and the full report details the audit assessments referenced against these standards. Peer review for the Sheffield Adults Haemophilia Comprehensive Care Centre (the Service) was completed on 2 May 2024.

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

Key Recommendations:

1. **Environment and Facilities:** The review team recommend that the Trust provide the resources and support needed to increase the space and capacity of the haemophilia centre. This is important for the care and wellbeing of patients and carers, as it ensures they have easier access to the centre and facilities. Moreover, wheelchair access has been an ongoing issue.
2. **Medical Staffing:** The review team felt that the lack of recruitment to cover the consultant's maternity leave, alongside the vacant consultant post, has left the Service vulnerable and would urge the Trust to support the Service in recruiting for both posts permanently, (or as a locum in the first instance), as a matter of priority.

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.

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

3 Service Description

The peer review of the Sheffield Adult Haemophilia CCC was conducted on 2 May 2024. A multidisciplinary team of haemophilia professionals, along with patient representatives, carried out the review, which involved interviewing staff from the Service, reviewing documentation, and touring the facilities.

The Service provides care to adults and adolescents aged 16 and over with bleeding disorders, catering to 1,699 registered patients. Located at Royal Hallamshire Hospital in Sheffield, it serves patients across South Yorkshire, Derbyshire, and the Humber region, with some patients travelling from further afield, including Greater Manchester and West Yorkshire.

Patients with mild bleeding disorders are seen annually in nurse-led telephone clinics, though less frequently if they are deemed to be at low risk for bleeding concerns. If necessary, patients can be seen face to face in a timely manner (i.e. on the same day as an emergency if there are clinical concerns, or electively in the clinic). Additionally, these patients are provided with information on how to access the MDT and can do so as needed.

Counselling and genetic testing are provided by the department and the MDT. Support is provided by Sheffield Genetic Services, which is delivered from Sheffield Children's Hospital.

The Haemophilia Centre collaborates with Sheffield Children's Hospital, holding regular joint multidisciplinary meetings that encompass discussions on laboratory, genomic, transition, and pregnancy-related topics. There are shared guidelines for transition, management of transition documentation, and neonatal care.

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	85	0	13	0	580	0	864	0
Moderate	9	0	4	0				
Mild	131	0	13	0				
Annual review in the last year	164	0	24	0	281	0	415	0
Inpatient admissions in last year	15	0	1	0	16	0	20	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 mix consists of a combination of full-time and part-time roles, including seven consultant haematologists (one vacant post and one postholder on maternity leave at the time of review), six nurses (4.58 WTE), three physiotherapists (1.1 WTE), and one psychologist (0.4 WTE). Additionally, there is one social worker, 20 biomedical scientists, and administrative staff (5.45 WTE).

Key staff include Consultant Haematologist and Centre Director Dr Rhona Maclean, Advanced Nurse Practitioners Cathy Harrison and Caryl Lockley.

Outpatient care: Takes place in the Haemophilia Centre. There is a good mix of different types of clinics, including nurse-led telephone clinics for mild bleeding disorders, as well as close links with the Haematology Day Ward.

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

Out of hours: There is 24/7 Consultant cover for Haemostasis & Thrombosis. Patients are directed to attend the emergency department.

Lab services: Laboratory services are provided by the specialised Coagulation Laboratory at the RHH. All necessary specialist tests are available, with significant involvement from the biomedical scientists of the specialist coagulation laboratory. Diagnostic meetings have been established, including the departmental weekly Bleeding Disorders Diagnosis Meeting (BDDM). The coagulation laboratory is an international haemophilia training centre recognised by the World Federation of Haemophilia (WFH). The UK National External Quality Assurance Scheme (NEQAS) for blood coagulation and the WFH International External Quality Assurance Scheme (IEQAS) are organised by RHH.

Transition: Haemophilia care for paediatrics is provided at the Sheffield Children's Hospital (SCH) Comprehensive Care Centre. There is a clear transition pathway for individuals and families affected by bleeding disorders. The adult team attends clinics at SCH for patients aged 14 and above. Standard Operating Procedures (SOPs) and guidelines are in place to support the management of documentation related to transition, alongside quarterly MDT meetings involving both services to discuss transition issues and pregnancy/neonatal cases.

Network arrangements: Although there are no formal networking arrangements with the local district general hospitals (DGHs), close working arrangements are in place with clinicians and teams in Doncaster and Bassetlaw, Rotherham, Barnsley, and Chesterfield DGHs, with joint SOPs and joint learning following Morbidity and Mortality discussions.

4 Quality Standards

4.1 Overview

The table below outlines the status of each standard, categorised as met (green), partially met (yellow), or not met (red). Overall, the Service has met 27 out of the 30 standards, with three partially met. The Service has outstanding findings from their previous peer review report in similar areas, which are provided in the appendix. The service is encouraged to review all descriptive assessments in addition to the key findings. This report, alongside local assessments, should steer discussions with the management team, highlighting areas of good practice while emphasising where further investment and improvement may be required.

Standard	Title of standard	Rating
1	Service Information	
2	Condition-Specific Information	
3	Plan of Care	
4	Outpatient Review of PwBD	
5	Contact for Queries and Advice	
6	Haemtrack (PwBD on Home Therapy	
7	Environment, Facilities and Equipment	
8	Transition to Adult Services and Preparation for Adult Life	
9	Carers' Needs	
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 noted that the service functions as a cohesive unit, well integrated within the Haematology department, including its connections with the day care unit and inpatient

wards, as well as the laboratory and MSK department. The team also fosters excellent working relationships with all relevant support services.

2. The patient feedback provided to the review team was overwhelmingly positive.
3. The review team was very impressed with the level of detail in patient care plans, which were deemed excellent.

4.3 Immediate risks

There were no immediate risks identified.

4.4 Concerns

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

1. The review team is concerned that the Service has outgrown its centre, and therefore, the clinical space is insufficient for the size of the service. The lack of space does not only affect the clinic areas but also patient access, particularly for those in wheelchairs, who may find it difficult to access the centre. While the Service has attempted to address the lack of space by redesigning part of their estate for a new Haemophilia and Thrombosis centre, no funding is available to support the redesign. The 2019 peer review also highlighted the inadequate space within the haemophilia centre. Specifically, it was noted that the reception area and waiting room were small, with insufficient space for individuals in wheelchairs. As the same concerns have been raised in this report, the Trust should prioritise working with the Service to resolve these issues.
2. The review team is concerned about the consultant workforce, which, despite the apparent number of consultants on paper, is affected by the loss of two individuals: one on maternity leave and another due to a vacant post. Both are planned vacancies despite the efforts of the Services to address consultant shortages. The consequences of being understaffed are being felt across the service, particularly regarding the frequency of regular clinical reviews.
3. The review team is concerned that not all patients with severe and moderate bleeding disorders are being assessed every six months, in accordance with the National Service Specification.

4.5 Recommendations

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

1. **Centre facilities and wheelchair access:** The review team recommends that the Trust provide the resources and support needed to increase the space and capacity of the haemophilia centre. This is important for the care and wellbeing of patients and carers, as it allows easier access to the centre and facilities. A growing number of patients are ageing and experiencing mobility issues associated with their bleeding disorder, which necessitates the use of walking aids or wheelchairs. The current environment is very challenging for them and their carers to navigate safely.
2. **Consultant staffing:** The review team would like to see the Trust support the Service in recruiting for the vacant consultant posts. This will ensure that all patients with severe and moderate bleeding disorders are reviewed every six months, in accordance with the National

Service Specification. A robust system must be established to guarantee that this occurs, as these patients are most likely to receive the home treatment programme, which includes the home delivery of their clotting factor or other medicinal agents to manage their condition. Regular monitoring by all members of the MDT is essential for these treatments.

5 Quality Standards - Detailed Description

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

Quality Standard 1: Service Information

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)

Standard Met

How the Service meets or does not meet the standard

Patient information leaflets were well-developed, providing a good summary of the service, professions, and ways to meet needs. It may be beneficial to add some information about the ward for those new to the service. The team may wish to consider including headshots of the team members in the service so that patients are familiar with them.

However, there were a couple of aspects that could be improved. For instance, ward information was not included in the centre PIL (although it was available elsewhere in the transition PIL). While roles were mentioned in the centre PIL, there were no names of staff (and there was no photo board evident in the Haemophilia centre either).

Quality Standard 2: Condition-Specific Information

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

Standard Met

How the Service meets or does not meet the standard

Utilising a variety of resources from multiple sources provides patients with the best access to condition-specific information. All relevant information is available.

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

Standard Met

g. Who to contact with queries or for advice

The plan of care should be reviewed at each clinic appointment or at other times if clinically relevant.
The plan of care should be communicated to the PwBD GP and other relevant service providers involved in their care.

How the Service meets or does not meet the standard

The service provides comprehensive and informative care plans that offer useful details and reassuring information for patients, as well as for other professionals.

The team should be commended for the excellent level of detail in their care plans.

Standard Met

Quality Standard 4: Outpatient review of PwBD

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

There is agreement that the standard is only partially met, but this is within the context of limited capacity. The content and approach are recognised as being thorough. There is good evidence of MDT working despite the limitations of space.

Excellent processes are in place, and the documentation is comprehensive, but patients with severe or moderate conditions are not seen twice a year, at least in part due to capacity issues.

Partially Met

Quality Standard 5: Contact for Queries and Advice

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.

Standard Met

How the Service meets or does not meet the standard	
Evidence from patient discussions indicates that they are content with the access to and choices for obtaining input. This is echoed by professionals in the ED.	

Quality Standard 6: Haemtrack (PwBD on Home Therapy)	
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.	Standard Met
How the Service meets or does not meet the standard	
Information leaflets and letters on Haemtrack are available.	

Quality Standard 7: Environment, Facilities and Equipment	
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.	Partially Met
How the Service meets or does not meet the standard	
There are clearly issues with clinical space. Although the available space is well utilised, it is insufficient to meet the service's needs. However, they do have access to suitable environments, and they are maximising this as much as possible. Additionally, they have access to excellent MSK facilities, which are conveniently located for patients with limited mobility. Patients raised concerns about access, particularly wheelchair access. They highlighted the lack of available space. The team has considered this and is making efforts to resolve the issue, but it will require input from the trust. As such, the standard was partially met, rather than failed completely.	

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

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.

Standard Met

How the Service meets or does not meet the standard

Joint appointments with the paediatric team are made during transition. There was good, positive feedback from patients about their experience.

Quality Standard 9: Carers' Needs

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

Standard Met

How the Service meets or does not meet the standard

There is clear evidence of carers being taken into account, but no evidence of a carer-specific booklet.

It was evident that the carers' needs were being considered; however, it was noted that there could be greater emphasis on this in the documentation, such as a PIL dedicated to carers of PwBD.

Quality Standard 10: Involving PwBD and Carers

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

Standard Met

How the Service meets or does not meet the standard	
Feedback from patients was overwhelmingly positive. The options for feedback are predominantly electronic, and it would be worthwhile to consider access for individuals with less electronic access. Comments from patients included: 'They are like a family; no one likes hospitals, but I enjoy seeing them'; 'Everyone is friendly and reliable', 'They go above and beyond'; 'They are a very knowledgeable team; they need more resources' and 'Services are all close together, which is brilliant'.	

Quality Standard 11: Leadership team	
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.	Standard Met

How the Service meets or does not meet the standard	
A supportive management structure is in place. Evidence of good communication has been observed. Patient feedback highlighted the success of succession planning, indicating that patients continue to feel safe and secure following changes to staff. Patient feedback was overwhelmingly positive regarding the change in medical personnel since the retirement of Mike Makris; there was a sense that this transition was well managed. Although staffing challenges persist, these are not apparent to the patient cohort.	

Quality Standard 12: Staffing levels and skill mix	
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:	Partially Met

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

All professionals are available, including support staff. However, there is insufficient consultant time to support the service. Psychologists have been recruited, with more joining later in the year.

All the standards were met, but the pressure regarding issues with the consultant workforce was evident.

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

CPD records and the bleeding disorder course were evidenced.

Quality Standard 14: Administrative, Clerical and Data Collection Support

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

Standard Met

How the Service meets or does not meet the standard

The review team agrees with the self-assessment regarding BDDM and Genomics meeting support. The terms of Reference for the BDDM and Genomics meetings were reviewed. The secretarial team supports meetings, including MDT, transition, and M&M. A dedicated reception team with defined roles and responsibilities includes operational policies, telephone and platelet SOPs, and a record of the education provided to the 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

There were positive examples of good practice.

Quality Standard 16: Emergency Department

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.

Standard Met

How the Service meets or does not meet the standard

There was positive feedback from the ED team. The alerts were demonstrated with clear ED guidelines.
Positive feedback from the ED consultant.

Quality Standard 17: Laboratory Service

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

Standard Met

How the Service meets or does not meet the standard

The laboratory is accredited by UKAS, as evidenced by the UKAS report.

Quality Standard 18: Specialist Services

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

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

Standard Met

How the Service meets or does not meet the standard	
Good relationships have been fostered with other teams, and there is clear evidence of effective collaboration.	

Quality Standard 19: IT System

IT systems should be in use for:

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

Standard Met

How the Service meets or does not meet the standard
The review team was shown the Electronic Patient Record (EPR) system. Example letters and care plans were also seen.

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

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

Standard Met

How the Service meets or does not meet the standard
The guidelines were excellent, clear, and of high quality, with detailed referencing.

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

There are daily safety huddles or handovers to discuss inpatients, ambulatory patients, and other patients admitted to DGHs, ensuring that everyone is informed.

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

Evidence of these standards was seen.

Quality Standard 23: Guidelines on Care of PwBD requiring Surgery

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

Standard Met

How the Service meets or does not meet the standard

Detailed surgical plans were observed, and all documents were reviewed and discussed that day.

Quality Standard 24: Service Organisation

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

Standard Met

How the Service meets or does not meet the standard

All policies have been reviewed and addressed. Patient engagement events were positive. All policies and SOPS are available and clearly demonstrated. Excellent opportunities for patient education.

Quality Standard 25: Multidisciplinary Team Meetings

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

Standard Met

How the Service meets or does not meet the standard

There were good examples of MDT meetings, both within and between teams. The team was commended for the excellent MDT held between the clinical and laboratory teams, which discussed cases and ensured that all relevant investigations had been completed.

Quality Standard 26: Multidisciplinary Clinics/Liaison Services

Combined clinics or other arrangements for multidisciplinary discussion with

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

Standard Met

How the Service meets or does not meet the standard

There is good evidence of strong communication between teams.

Quality Standard 27: Data Collection

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

Standard Met

How the Service meets or does not meet the standard

The team saw evidence that all relevant data had been submitted.

Quality Standard 28: Research

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.

Standard Met

How the Service meets or does not meet the standard

The team are involved in multiple research projects to enhance patient care and experience.

Quality Standard 29: Multidisciplinary Review and Learning

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

Standard Met

How the Service meets or does not meet the standard

Review and learning covered many areas and development of an audit plan is underway. The Sheffield team concluded that they only partially met this standard due to the lack of an audit plan, but they cover all the other sections of this standard so well that, overall, we felt they met the standard and that they were being too harsh on themselves.

Quality Standard 30: Document Control

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

Standard Met

How the Service meets or does not meet the standard

Although not all the documents had been reviewed recently, there is clearly a process in place for document 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 a consultant haematologist, two adult and one paediatric clinical nurse specialists, a specialist haemophilia psychologist, and a patient representative. UKHCDO holds details of the Peer Review Team.

7.3 Outstanding findings from the previous report

The table below provides details of relevant issues raised in the 2019 peer review report, some of which are also raised in this review. These have been highlighted here to reinforce the

recommendations in this report, as these issues should be addressed as a matter of priority. The Trust should ensure that appropriate resources are made available so these outstanding issues can be resolved.

Ref. number	Statement of original finding
2	Facilities
a	The Centre The facilities from which clinics were offered were inadequate for the needs of patients, carers, and staff. i. The reception area / waiting room was small, with insufficient space for people in wheelchairs, and the 'window' at the reception desk was so high that wheelchair users could not reach it to talk to reception staff. ii. There was a single clinic consultation room, so that only one patient at a time could be seen. Consequently, clinic consultations could only take place with the consultant and nurse in this room, and this had an impact on waiting times during clinics. Provision of at least one other adjacent consultation room at the time of clinics would also allow for separate assessment by the specialist nurses and / or haematology medical staff in training, which would increase clinic capacity and improve the opportunity for supervised training. iii. It was possible for people in the waiting area to over-hear conversations taking place in the clinic room, as the dividing door and wall were thin, so confidentiality could not be assured. iv. Disabled toilet access was not available, and those needing to use accessible facilities had to go into the ward area, next to the Centre, to access them. v. The office space used by the Centre staff was small, with no natural light, and review team members understood that it was difficult to hold telephone consultations with patients against the background noise of others working in the office. Reviewers heard that it may soon be possible for the service to move into new premises on the ground floor of the current block. These new facilities would be much more appropriate.
b	The hospital i. Lifts. The Centre was located on level P which was a number of floors up from ground level. There were lifts, but at the time of the visit - the review team learned that this was not unusual - only one lift was working. Staff, patients and visitors had to queue for a long time. Patients confirmed that this often resulted in delays with them reaching the Centre after their appointment times. They did, however, appreciate that Centre staff recognised the issue and were willing to see them later. ii. Parking. Patients and families highlighted that, for service users with joint problems and limited mobility, there was difficulty in finding parking close to the Centre for booked or urgent contact and they said that this was a significant problem for them.