UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

UKHCDO Haemophilia Peer Review Audit Report

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

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

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

The executive summary presents the key findings, while the full report details the assessments referenced against the quality standards. Peer review for the Oxford Haemophilia Comprehensive Care Centre (the Service) was completed on 20 May 2024.

The Service 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. **Medical staffing:** The review team recommends that the trust facilitate the recruitment of medical staff, particularly in paediatric haemostasis, as the commissioned service covers a substantial network across the South West.
2. **Physiotherapy provision:** The review team recommends increasing physiotherapy provision, commensurate with the size of both the adult and paediatric services.
3. **Data Management:** The role of the Data Manager is vital in Haemophilia Management, and the review team recommends establishing this post in line with other services, as submission of key performance indicators have been missed for a considerable time.
4. **Network arrangements:** The review team recommend that the trust, centre leadership team and commissioners meet to discuss network arrangements, in particular for adult services in the context of the wide geographical area covered by Bristol CCC.

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 Bristol Haemophilia Comprehensive Care Centre took place on 20 May 2024. A multidisciplinary team of haemophilia specialists, accompanied by patient representatives, conducted the review, which included discussions with staff from the Service, reviewing documentation, and touring the facilities.

The Service supports both adults and children with bleeding disorders and currently cares for 863 registered patients. It is located at the Bristol site within the United Hospitals Bristol & Weston Trust and provides clinical care to individuals with bleeding disorders in South West England.

The service is divided between two sites; paediatrics is based in the Ocean Unit at Bristol Royal Hospital for Children (BRHC), while adult patients are treated at the Bristol Haematology and Oncology Centre (BHOC).

The regional specialist coagulation laboratory is located within the Bristol Royal Infirmary, offering 24/7 access to specialist testing for adults and paediatrics, including samples sent from centres within the region. Genetic samples are sent to Oxford, and results are discussed at the weekly laboratory team meeting.

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	95	28	6	7	217	46	247	28
Moderate	14	10	3	2				
Mild	113	32	25	9				
Annual review in the last year								
Inpatient admissions in the last year								

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 team comprises a mix of full-time and part-time roles, including four adult consultant haematologists (2.6 WTE), two paediatric haematologists (0.2 WTE), three adult nurses (2.43 WTE), one adult physiotherapist (0.4 WTE), one paediatric physiotherapist (0.6 WTE), one biomedical scientist (0.8 WTE), and two administrative staff (2.0 WTE). Notably, there is no dedicated psychology or social work service.

Key staff include Consultant Haematologist and Centre Director Dr Amanda Clark and Lead Nurse Emma Franklin.

Outpatient care: The service is divided across two locations, with paediatrics in the Ocean Unit at Bristol Royal Hospital for Children (BRHC) and adults in the Bristol Haematology and Oncology Centre (BHOC). Both paediatric and adult patients, along with their families, have direct access to nurses and support workers during working hours, which are from 08:00 to 17:00, Monday to Friday.

Paediatric patients may be booked onto the Ocean Unit for urgent review, treatment, or outpatient care. Adult patients can be scheduled in the treatment room or chairs for urgent review, treatment, or outpatient care, unless the clinical team recommends attending an emergency department instead. There are various multidisciplinary clinics in both the adult and paediatric services to cater to the specific needs of different groups, including telephone clinics.

Paediatric and adult nurses provide community support and visits as needed. The paediatric support worker delivers virtual support and education for schools. Face-to-face school visits are arranged if more complex needs are identified.

For paediatric patients, clinics run on the first and second Tuesday of every month in the afternoon. These clinics are multidisciplinary, featuring consultants, clinical nurse specialists, and physiotherapists, and they cover all paediatrics with bleeding disorders. Severe patients are seen in person, while all other patients are offered either face-to-face clinic appointments or telephone reviews.

For adults with severe haemophilia and von Willebrand's disease, clinics are held twice a month on Wednesday afternoons and are supported by a Consultant, Clinical Nurse Specialist, and Physiotherapist. Patients with moderate haemophilia are either seen in the Wednesday afternoon multidisciplinary clinic or at the Consultant and Specialist Registrar bleeding and thrombosis clinic, which takes place on Tuesday and Wednesday mornings. This clinic also reviews any new referrals, except for patients with severe disorders. All other adult patients with milder bleeding disorders are attended to in nurse-led telephone clinics, which are scheduled throughout the month. Patients are reviewed every one to three years, depending on the severity of their condition. Referrals to consultants can be made if necessary, or patients may be seen in person if deemed necessary or requested by the patient or carer.

Both the adult and paediatric services have access to physiotherapy and psychology support, and the paediatric service also has a support worker.

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

Out of hours: Patients are provided with a number to call for out-of-hours advice and are seen in the Emergency Departments, where clear pathways are established.

Transition: For the transfer to adult services, the paediatric team contacts the adult team to inform them of a patient transitioning to adult services and their appointment. An adult Clinical Nurse Specialist will attend the clinic appointment with the consultant and paediatric team to introduce the patient to the adult service.

Network arrangements: The service's network arrangements are divided between adults and paediatric units. The paediatric service is commissioned for the entire region within the Southwest, encompassing Taunton, Barnstaple, Exeter, Plymouth, and Truro. Patients from Gloucester are reviewed in Bristol, where they receive a multidisciplinary assessment involving a Bristol consultant,

a clinical nurse specialist, and a physiotherapist, alongside the local team, which typically includes a paediatrician and an adult haematologist.

Although the adult service is not formally commissioned to provide care for the entire region, it extends north to Gloucester, east to Bath, south to Taunton, and west to the Welsh border. When approached in 2019, the commissioners declined to allocate any funding for an adult network. All patients on emicizumab are registered with the service that prescribes and manages clinical oversight, and they are also dual registered with their local centre.

4 Quality Standards

4.1 Overview

The table below outlines the status of each standard—met (green), partially met (yellow), or not met (red). Overall, the Service has met 25 out of the 30 standards, with five 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	

Standard	Title of standard	Rating
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 department is clinically well-led by Dr Amanda Clark, is cohesive, and aims to deliver patient-centred care.
2. The service employs a support worker in paediatrics. This role appeared vital to both staff and patients, and the review team received outstanding feedback from both the team and patients regarding the support worker.
3. The patient experience is generally excellent, as supported by patient feedback.

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:

The review team are concerned that the Service is stretched in terms of staffing and workload, and the impact this has on different aspects of the Service, specifically:

1. The review team is concerned about the consultant staffing levels in the paediatric team. This is despite a newly created joint adult/paediatric haematology post contributing 0.2 whole-time equivalents to the Paediatric Haemophilia service. The loss of two paediatric consultants poses a risk to the ongoing viability of the paediatric provision for a service commissioned to lead the network in a large geographical area.
2. The service provided by the post holders in both the adult and paediatric services is excellent; however, the review team is concerned that, based on the number of patients, the staffing does not meet the recommendations of the Haemophilia Chartered Physiotherapists Association (HCPA).
3. The reviewers felt that the role of the admin lead with data management was too much for one position. Key performance indicators are being missed as a result, which will impact future commissioning decisions. A dedicated data manager would assist the service in reviewing clinics, patient numbers, and planning. This is important given the multiple smaller

haemophilia centres in the region and the need for accurate data. As the current post holder is moving on to another job, it would be sensible to review the job descriptions to ensure that both the admin lead and data manager positions have sufficient time allocated.

4. Both the adult and paediatric services have established network arrangements. The adult unit serves as a hub for an informal network, while the paediatric service is formally commissioned for the region. Both networks would greatly benefit from clearer treatment pathways and a more structured approach to multi-disciplinary team meetings. One of the main concerns highlighted in the previous peer review report pertained to the network arrangements for the care of adult patients across the southwest region. Please see section 7.0 for the full wording of the concern. Despite the clinical team's efforts to secure funding to formalise the adult network, this was rejected by the commissioners. The review team would like to see the adult network properly commissioned and funded to ensure that specialist professionals see all patients with severe bleeding disorders on an annual basis.
5. There is a lack of agreed-upon formalised pathways for referring patients to the MDT for discussion.

4.5 Recommendations

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

1. **Medical Staffing**: The review team recommends that the trust work with the service to fill the gaps in consultant staffing. This is important because an insufficient number of consultant staff will pose a risk to the treatment and recovery of patients.
2. **Physiotherapy provision**: The review team recommends that the trust allocate additional funding to increase physiotherapy hours in accordance with HCPA recommendations (for both adult and paediatric services), thereby ensuring dedicated time for each service.
3. **Data Management**: The review team suggests examining the current lead admin role with the aim of establishing a dedicated data manager. This is important, given the numerous smaller haemophilia centres in the region and the need for accurate data. As the current postholder is moving on to another job, it would be prudent to review the job descriptions and ensure that both the admin lead and data manager positions have adequate time allocated. The review team would also like to see enhanced oversight of data collection, national haemophilia database submission, and factor management at local hospitals that are part of the paediatric network.
4. **Network Provision:** The Bristol CCC is the only provider in Southwest England offering Comprehensive Care for individuals with bleeding disorders. We urge the Trust to collaborate with the commissioning teams to establish a formal network for adult services and to ensure appropriate funding for this, thus providing equitable care for all patients across the region.
5. **Network MDT processes**: We recommend that both adult and paediatric services ensure MDT coordination across both networks, enabling local hospitals within the region to participate in regular clinical decision-making. All stakeholders must agree upon a formal process, guidance, and a referral pathway to ensure the standards of clinical care are upheld throughout the region.

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

Good information leaflets are available, with a key role provided by a support worker.

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

Standard Met

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

Information is available on all conditions. It was noted that the genetic consent version in the folder for review was outdated; however, the team confirmed that they use a more current one in clinical practice. A sample letter regarding vaccinations was provided.

Quality Standard 3: Plan of Care

Each PwBD and, where appropriate, their carer should discuss and agree on their Plan of Care that is age-appropriate and should be offered a written record covering:

a. Agreed goals, including lifestyle goals
b. Self-management
c. Planned assessments, therapeutic and/or rehabilitation interventions
d. Early warning signs of problems, including acute exacerbations, and what to do if these occur
e. Agreed arrangements with the school or other education provider
f. Planned review date and how to access a review more quickly, if necessary
g. Who to contact with queries or for advice

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

Standard Met

How the Service meets or does not meet the standard

Clear documentation in clinic letters. We recommend ensuring that contact details are included on all letters, not just the bleeding disorder card.

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.

Standard Met

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

Review of severe patients is clearly documented, and there is a clear pathway for referral to psychology. A family support worker in paediatrics will signpost to social services if needed.

All patients are recorded on a spreadsheet. All patients who are actively being followed up (i.e. all patients with bleeding disorders who have not been discharged from the clinic due to multiple DNA results will remain within a clinic).

All nurse-led and medic-led clinics are recorded within the electronic system. A spreadsheet indicates the expected date, and patients are booked into clinics based on their due dates. Once they have a clinic appointment, they will be scheduled for their next planned appointment.

Clear DNA procedure for mild patients. A robust process is in place to ensure that all non-severe bleeding disorder patients in the nurse-led review service are recalled appropriately. Currently, this is recorded on a spreadsheet that is reviewed manually.

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

Both adults and paediatrics have information leaflets that are distributed to patients (and parents/carers) to advise on the various ways to contact the team via phone, mobile, or email. Patients are provided with a number to call in case of an emergency outside of normal hours.

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

Haemtrack reports are generated, and a spreadsheet is completed and monitored by the administrative team. Patients who do not complete Haemtrack are called and sent a letter to encourage them to do so. The importance of Haemtrack is also discussed during clinic visits. Haemtrak usage is documented in clinic letters.

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.

Standard Met

How the Service meets or does not meet the standard

The review team toured the centre, observing all points relevant to this standard, including two fridges in the adults' unit and one in paediatrics, as well as the clinic rooms and office spaces for nurses. Physiotherapists and psychologists have their own office spaces within their respective departments.

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

Standard Met

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

How the Service meets or does not meet the standard

The use of "Ready steady Go" was demonstrated in notes and discussions with the team.

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

The review team observed the contact information provided to carers, which is identical to the information given to patients. It also included guidance on what they should do in case of an emergency.

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

The review team was shown feedback cards, which are available in treatment rooms. The service has made changes based on feedback, including more flexible appointment types: face-to-face, telephone, or video options available.

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

The leadership team is clearly defined with responsibilities, but there is no documentation of leadership minutes or operational meetings provided during the visit, although they were sent after the visit. There are Haemophilia meetings every two to three months with action logs that are stored and can be reviewed if needed.

Quality Standard 12: Staffing levels and skill mix

Partially Met

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

Staffing should include:

a. Medical staff:
    i. Consultant specialising in the care of people with inherited and acquired bleeding disorders available during normal working hours
    ii. On-call consultant specialising in the care of people with inherited and acquired bleeding disorders 24/7 in HCCC
    iii. On-call haematology consultant with arrangements for advice from a consultant specialising in the care of people with inherited and acquired bleeding disorders in HC
b. Specialist nursing staff:
    i. Bleeding disorders specialist nurses (5/7)
    ii. Ward, outpatient, and day unit staff with competences in the care of people with inherited and acquired bleeding disorders
c. Clinical specialist physiotherapist
d. Practitioner psychologist or appropriately trained psychotherapist with specialist knowledge in IBDs.
e. Access to specialist senior social worker
f. Data manager
g. Biomedical scientist and/or clinical scientist (further details on the requirements are included in QS 17)

How the Service meets or does not meet the standard	
There is no data manager. The admin lead is covering both administrative and data responsibilities but lacks sufficient time to complete both tasks. Additionally, he is due to leave soon, and there is no succession planning in place. Due to challenges in recruiting paediatric consultant posts, there is currently a vacancy, and therefore no specialist paediatric haemostasis consultant. The on call for paediatrics is covered by benign haematology, not haemostasis specialists. They will call the adult haemostasis team if required. Currently, there is an adult haematologist with 0.2 WTE sessions in paediatrics, but the service is currently understaffed. Paediatric nurses are relatively new in their positions, and although they have the support of the medical team and adult CNS, the paediatric team is short of consultants. The nurses are still developing their competence and haven't attended the appropriate haemophilia courses. There is an excellent family support worker.	

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	
The review team reviewed the mandatory training records.	

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	
There is one WTE Service Coordinator, one Centre Coordinator, and a part-time admin clerk (0.2 WTE).	

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

A play specialist is available to all areas within paediatrics.

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 is an alert on EPR for all patients with bleeding disorders, and an audit is underway for the ED, but has not yet been completed.

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

Standard Met

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 meets standards and is UKAS accredited.

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

Useful information in clinic letters, with consultants from other teams consistently included.

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	
Due to the upcoming installation of a new HCIS, MDSAS has not been granted access to install HCIS on additional computers, as IT and governance issues have been identified.	

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	Partially Met
How the Service meets or does not meet the standard	
VWD guideline is not trust-specific and there are no guidelines for those with bleeding disorders of unknown cause.	

Quality Standard 21: Guidelines: Treatment and Monitoring of IABD	
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	Standard Met

How the Service meets or does not meet the standard	
Guidelines are in place for all aspects of this standard.	

Quality Standard 22: Clinical Guidelines/Pathways	
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	Standard Met
How the Service meets or does not meet the standard	
Guidelines are typically detailed and consistent across all areas.	

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	
Guidelines for each part of this standard were provided.	

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	Standard Met

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

Procedure in place and observed by the review team.

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

Partially Met

How the Service meets or does not meet the standard

There is no formal network MDT for either paediatric or adult services. Paedaitrics is commissioned as a network and therefore a regular MDT would be expected. The adult service constitutes an informal network with good relationships between clinical staff; however, there are no clear pathways for the haemophilia centres within the region to determine who should be discussed at MDT or other review pathways. It is vital that even without a formal network, clear pathways are developed for better oversight of the HCs in the region. Due to the wide geographical area covered, even an informal network is supportive of the HCs.

It was noted that the commissioners were approached in 2019 for additional funding to formalise the network, but this request was declined. We recommend that the CCC contact the commissioners again to discuss this urgently, particularly in light of the IBI report.

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	
Combined obstetrics clinics are held every second and fourth Friday. There are close working relationships with orthopaedic services; however, a reduction in patient numbers means that the service no longer operates combined orthopaedic or gynaecology clinics.	

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	Partially Met

How the Service meets or does not meet the standard	
No SSQD data from last year or for this year's submission was available on the day of review. Given the importance of data, the absence of a data manager complicates matters, although the admin lead and lead nurse do review the data. Following the review the team siad the data had been but was simply not accessible on the day.	

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	
Staff are encouraged to undertake research.	

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	Partially Met

How the Service meets or does not meet the standard	
There have been no audits in the last two years. There is no evidence of positive feedback or discussions regarding complaints. Additionally, there are no minutes, MDT lists, or records of operational/data meetings.	

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	
Document control was evidenced on all documents.	

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 two consultant haematologists, two clinical nurse specialists, a haemophilia contracts manager, a specialist paediatric haemophilia physiotherapist and a patient representative. Details of the Peer Review Team are held by UKHCDO.

7.3 Outstanding findings from previous peer review

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

Ref. Number	Statement of original finding
3	**Network arrangements** Robust network arrangements for the care of adult patients across the Southwest were not in place, and some patients had never been seen and assessed by the specialist team. Patients were offered appointments at the Comprehensive Care Centre by their local teams, but this could lead to some inequity of care as more mobile and more motivated patients could be seen, whereas those who might have more specialist needs may not be. The aim of the network should be that all patients – at least those with severe bleeding disorders – should be seen by specialist professionals on at least an annual basis.