UKHCDO Haemophilia Peer Review Audit Report

Cardiff Haemophilia Comprehensive Care Centre

Report Date: 29 July 2025

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1 Executive summary

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

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

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

The executive summary presents the key findings, while the full report details the assessments referenced against the quality standards. The peer review for the Cardiff Haemophilia Comprehensive Care Centre (the Service) was completed on 17 April 2024. The Centre is located in the outpatient department of the University Hospital of Wales. It supports the haemophilia centres in Swansea (the second-largest haemophilia centre in Wales) and Abergavenny in forming the Bleeding Disorders Network Wales (BDNW).

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

Key Recommendation:

1. **Providing a Suitable and Safe Environment:** The review team recommends that the Trust and Health Board assist the service in finding appropriate space or optimising current space utilisation for clinical care. In particular, conducting a risk assessment for adults and children sharing the same waiting area is advised. The persistent lack of sufficient space for a service serving the entirety of Wales remains an unresolved issue from the previous peer review and requires prompt attention.
2. **Patient survey:** The review team recommends implementing a bleeding disorder-specific survey to identify the needs of this patient group.

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

2 Haemophilia and Bleeding Disorder Peer Review - Background

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

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

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

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

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

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

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

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

3 Service Description

The peer review was undertaken on 17 April 2024 at the Cardiff Haemophilia Centre, University Hospital Wales. A multidisciplinary team of haemophilia professionals, along with patient representation, conducted the review, which involved speaking to staff from the service, reviewing documentation, and touring the facilities.

The Service functions as a comprehensive care centre, supporting the haemophilia centres in Swansea (the second largest haemophilia centre in Wales) and Abergavenny to form the Bleeding Disorders Network Wales (BDNW). The service offers lifelong support through separate paediatric and adult specialist nursing teams, while other team members cater to all age groups.

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	48	18	10	4	218	76	301	70
Moderate	28	8	14	9				
Mild	109	23	25	8				
Annual review in the last year	95	47	34	19	71	61	184	52
Inpatient admissions in the last year	57	7	21	7	41	9	78	4

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

Staffing: The service responsible for the Bleeding Disorders Network Wales employs 41 professionals (31 WTE), including four (3.2 WTE) consultants, 15 (13.6 WTE) nurses, three physiotherapists (2.85 WTE), five psychologists (1 WTE), a social worker (1 WTE), a play therapist (0.6 WTE), five laboratory technicians (4.6 WTE), and seven administrative staff (4.6 WTE). This combination of full-time and part-time roles ensures that comprehensive patient care is provided.

The service is Consultant led and well supported by adult and paediatric specialist nurses, an allied health professional team, and healthcare scientists. The registrar assigned to the Centre attends to calls between 9 am and 5 pm, and an on-call registrar will take over thereafter. All patients with bleeding disorders are discussed with a haemostasis consultant.

Key staff include Consultant Haematologists and Co-Centre Directors Dr Deepan Gosrani and Dr Samya Obaji.

Outpatient care: Patients attending as outpatients for planned appointments and treatment are seen in the dedicated Haemophilia Centre, which has one consultation room and two treatment rooms. The Centre was established when the number of patients and staff was significantly smaller, and the service has since expanded considerably to meet the needs of patients and their families. The available space in the Centre is now inadequate.

All paediatric clinics are based on a multidisciplinary team (MDT), which includes consultants, clinical nurse specialists (CNS), play therapists, physiotherapists, youth workers, and psychologists. Children on prophylaxis are seen at least three times a year in a joint clinic led by consultants and nurses.

A monthly paediatric outreach clinic has been established in four peripheral hospitals in West Wales. These are also MDT clinics with different members of the MDT based on the patient's needs. These clinics enable patients with bleeding disorders to be seen closer to home, thereby improving links with local hospitals and staff.

Inpatient care: If hospital admission is required, patients are admitted to a ward that is appropriate for the admitting team.

Out of hours: Consultant-led specialist care is available 24 hours a day, 7 days a week, along with access to specialist laboratory services. A consultant with a specialist interest in bleeding disorders is available 24/7 on a 1 in 4 rota.

Transition: The centre is a lifelong centre with a dedicated clinic for individuals aged 11 years and above, focusing on preparation for adult life. Since the last peer review, a youth worker has joined the team, which has facilitated this process.

Network arrangements: The Service operates as a comprehensive care centre and supports the haemophilia centres in Swansea (the second largest haemophilia centre in Wales) and Abergavenny to form the Bleeding Disorders Network Wales (BDNW). The BDNW leadership team includes the Centre co-directors (adult and paediatric leads newly appointed to these roles in September 2023), lead nurse, lead physiotherapist, network manager, and deputy network manager. BDNW is funded by the Welsh Health Specialised Services Committee (WHSCC), with the Cardiff Haemophilia Centre serving as the hub. The aim of the network is to manage individuals with inherited bleeding disorders across all age groups and to provide equitable care across South and West Wales. Some patients in England opt to be treated by the Cardiff HC, with shared care arrangements established with their local haemophilia centre.

4 Quality Standards

4.1 Overview

The table below provides an overview of the standards met (green), partially met (yellow) and not met (red). Overall, the Service has met 26 out of the 30 standards, with four standards being 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. Despite the difficulties posed by the lack of space, the review team was very impressed with the facilities available. The physiotherapy space, located in a separate area, is a spacious

facility with a dedicated hydrotherapy area. The teenage and paediatric areas, along with the play areas, were also excellent.

2. Patients entering clinical trials receive robust support from a research team with prior clinical training in Haemophilia. This research team is well-integrated with the clinical team, further enhancing support for patients.
3. The service boasts robust support, featuring a play therapist who attends clinics, the recent appointment of a pharmacist, a dedicated social worker, and an excellent psychology service.

4.3 Immediate risks

No immediate risks were identified.

4.4 Concerns

Overall, the service at Cardiff was excellent, but the review team wish to highlight three main concerns:

1. The review team is concerned about the general lack of space within the Haemophilia Centre, which is inadequate for the current patient and staff numbers, given the significant growth in recent years. The space for staff to operate presents a welfare risk due to a hot and cramped office environment. The general lack of space is exacerbated by the presence of a clinical trial refrigerator in the waiting area. The 2019 peer review also highlighted this issue.
2. There was no evidence that training had been provided to Emergency Department staff on caring for patients with bleeding disorders when they present at the ED. Additionally, there was no evidence of an audit of the emergency pathway or out-of-hours care.
3. Although there is an effective standard operating procedure for ‘Did Not Attend’ (DNAs), it does not provide information on managing repeat DNAs in children. This is particularly important from a safeguarding perspective.

4.5 Recommendations

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

1. **Providing a Suitable and Safe Environment:** The review team recommends that the Health Board support the service in identifying a suitable space or improving current space utilisation for clinical care. Specifically, a risk assessment is needed for adults and children sharing the same waiting room. This is an outstanding issue from the previous peer review report and must be addressed as a matter of priority.
2. **Training of Emergency Department Staff**: The review team advises establishing a regular training and audit program for the Emergency Department (ED) team. This initiative is crucial to ensure that emergency department (ED) personnel are fully equipped to respond appropriately when a patient with a bleeding disorder presents at the ED.
3. **Patient survey:** The review team recommends implementing a bleeding disorder-specific survey to identify the needs of this patient group.
4. **Updated DNA SOP for Children**: The review team recommends compliance with the trust's DNA standard operating procedure, which includes a process specifically designed for managing recurrent non-attendance in children.

5 Quality Standards – Detailed Description

A detailed description of the quality standards used in the assessment is provided, 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

Standard Met

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

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

How to:

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

How the Service meets or does not meet the standard

A leaflet is available that describes the haemophilia service, including contact details. There are plenty of leaflets available in the centre for patients, including in the Welsh language. Letters all have contact details for the service. There are links to national haemophilia organisations.

Quality Standard 2: Condition-Specific Information

Standard Met

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

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

k. Travel advice
l. Vaccination Advice
m. Health promotion to include smoking cessation, healthy eating, weight management, exercise, alcohol use, sexual and reproductive health, and mental and emotional health and well-being
n. Sources of further advice and information

Condition-specific information should be available covering:

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

How the Service meets or does not meet the standard

There was no local information on how to manage bleeding at home or vaccination advice.

In general, the Haemophilia Society patient information leaflets were used and displayed in the centre covering all the sections a-m, with the exception of dental services and the local approach to vaccinations. SOPs for dentistry and vaccination were seen, but no localised patient information.

A comprehensive checklist was provided for new patients, covering all the required sections. These were available in printed format for staff in the centre.

There was excellent information and individual support for young patients regarding general health promotion, sexual health, and periods from the youth worker.

Quality Standard 3: Plan of Care

Standard Met

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

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

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

How the Service meets or does not meet the standard

Evidence in sample clinic letters demonstrated self-management. There were letters following physiotherapy reviews with planned assessments and discussions of activities and sports. In an emergency, patients were directed to nurses as appropriate during working office hours. At night, the phone was diverted to the switchboard, which then put the call through to the haematology registrar. There was clear evidence of school visits documented

Quality Standard 4: Outpatient review of PwBD

Partially Met

A formal review of PwBD should take place regularly:

a. For those with severe and moderate haemophilia, any PwBD on prophylaxis and other severe bleeding disorders at least twice a year. This may be more frequent in the paediatric setting based on clinical needs.
   The following multidisciplinary clinic arrangements for these PwBD should be in place:
    i. Involvement of medical, specialist nursing and physiotherapy staff in clinics
    ii. Availability or clear referral pathway for social work and psychology staff
b. For those with mild bleeding disorders, the Centre should have a documented follow-up pathway with a plan for managing DNA and PIFU if used. These PwBD should have access to the full MDT if clinically required but may not be seen in a combined clinic.

This review should involve the PwBD and, where appropriate, their carer.

The outcome of the review should be communicated in writing to the PwBD and their GP.

How the Service meets or does not meet the standard

Multidisciplinary clinics involving doctors, nurses, and physiotherapists were held. There were clear Standard Operating Procedures (SOPs) in place for referrals to psychology and social services. The psychologist and youth workers were usually present or accessible during clinics and had the opportunity, after the medical review, to see the patient separately.

It appears that adults on prophylaxis are booked into the clinic every six months, and all adults with moderate to severe bleeding disorders are offered an annual review. All paediatric patients on prophylaxis are scheduled for at least three clinics annually, including a consultant-led clinic, a joint paediatric clinic, and a nurse-led clinic. The review team observed that the figures provided suggested not all patients had undergone an annual review.

Adults and children with mild bleeding disorders are scheduled for follow-up based on clinical need and consultant judgment; clinic capacity is limited due to space constraints, with only a single consultation room within the haemophilia centre. Increasing numbers of clinical reviews are carried out in the community by CNS; however, this is poorly recorded in hospital clinic reporting systems.

A discussion was held regarding the potential use of PIFU. There was a Standard Operating Procedure (SOP) for DNAs, but it did not include guidance on managing repeat DNAs in children, particularly regarding referrals to safeguarding. A local adaptation of the hospital paediatric SOP for repeat DNAS is recommended. Sample letters to GPs are available. GPs receive a letter after each appointment, which is also copied to the patient.

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

The process of triaging patients was explained during the tour. There is a reliance on patients to contact the team for emergency or out-of-hours care. It was suggested that an electronic system to alert haemophilia staff if a patient is admitted elsewhere would be useful.

There is a direct phone line to the centre during office hours, as documented on clinic letters and the bleeding disorder card. Patients can choose from options, including those for urgent problems. The reception staff have received training in triaging calls and alerting the clinical team. The phone diverts to the switchboard out of hours, and the haematology registrar is contacted directly.

Quality Standard 6: Haemtrack (PwBD on Home Therapy)

Standard Met

All PwBD on home treatment should be encouraged to use the electronic recording of their treatment through Haemtrack.

Use should be documented in clinic letters/ plan of care.

How the Service meets or does not meet the standard

Haemtrack compliance isn't consistently recorded in letters—there is no audit evidence of Haemtrack compliance. Patients are encouraged to complete treatment records on Haemtrack. However, compliance has been lower than the team would wish.

Quality Standard 7: Environment, Facilities and Equipment

Partially Met

The environment and facilities in outpatient clinics, wards and day units should be appropriate for the number of PwBD with inherited and acquired bleeding disorders and accessible by people with severe mobility problems.

Facilities and equipment appropriate for the Service provided should be available, including:

a. Fridges
b. storage
c. Clinical rooms for staff of all disciplines to see PwBD and carers with adequate space for physiotherapy assessment
d. Room for multidisciplinary discussion

e. Room for educational work with PwBD and carers
f. Office space for staff
g. Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all relevant clinical areas
h. Access to adequate IT equipment with clinical systems
i. All equipment should be appropriately checked and maintained.

How the Service meets or does not meet the standard

The Cardiff Haemophilia Centre was built in 2000 and remains the same structural unit in use today. It consists of a single consulting room, two small treatment rooms, a waiting area shared by children and adults, a room for storing treatment supplies, a single office for nurses and registrars, and a reception area that holds patient records.

Across the corridor is an office shared by administrative staff, psychologists, and a social worker, as well as another room occupied by data coordinators and research staff. The physiotherapists reside in a separate building on the hospital site due to space constraints, but it is not a permanent location.

The Haemophilia multidisciplinary team consisted of six staff members when it was initially established 25 years ago. The establishment of Bleeding Disorder Network Wales has increased the staff to 40 WTE, with Cardiff CCC providing support to the peripheral haemophilia centres. Indeed, a 20% increase in activity was recorded in the last year. The increase in research activity further compounds this.

Essentially, the space in the haemophilia centre is insufficient for the service needs. There is inadequate clinic and office space for staff (except the physio area). Facilities were inadequate to support the growth in patient and staff numbers over recent years. The office space was cramped, and there were insufficient workstations for all staff, including those who worked in the office. Although there was access to IT systems in the clinical areas, there were insufficient desk spaces for staff to work, resulting in a lot of hot desking, and some staff were unable to find a place to sit. There is access to Haemtrack in clinical areas.

The waiting areas were small and in busy areas. There were trial fridges in the waiting areas. The fridges were locked, but this is an inappropriate location for storing medication. They also added to the heat in the area, and the entire atmosphere was very claustrophobic and hot. Furthermore, the Centre lacks adequate air conditioning facilities.

There was a very nice paediatric treatment room. The staff try to keep adult patients and paediatric patients separate; however, by necessity, there are times when adults and children are seen together.

It is the understanding of the review team that the centre has repeatedly approached the Clinical Board with suggestions regarding the acquisition of adequate space and working conditions to support the service. However, no additional space has been allocated with this, resulting in frequent delays in clinical activity and leading to staff and patient dissatisfaction and a negative impact on staff well-being and morale (staff frequently have to ‘hot-desk’ or share a workspace).

There have also been written patient complaints about waiting times and the cramped facilities.

The space issue is now on the risk register.

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

Standard Met

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

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

How the Service meets or does not meet the standard

An excellent transition checklist was used. "Ready, steady, go" was not employed, but the checklist met the standard.

The youth worker met with adolescents in the clinic, often doing so individually. a. She was able to advise on sexual health and had access to period packs to distribute. b. Patients received their care within the same centre.

Patients over the age of 11 were seen in separate clinics from younger children to facilitate transition.

Quality Standard 9: Carers' Needs

Standard Met

Carers should be offered information on the following:

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

How the Service meets or does not meet the standard

Leaflets were available for patients and carers on how to access services.

Quality Standard 10: Involving PwBD and Carers

Standard Met

The Service should have:

a. Mechanisms for receiving regular feedback from PwBD and carers about treatment and care they receive
b. Mechanisms for involving PwBD and carers in decisions about the organisation of the Service
c. Examples of how the Service has engaged PwBD / received feedback or made changes made as a result of feedback and involvement of PwBD and carers

How the Service meets or does not meet the standard

The review team suggests that the service conduct a broader survey of the service beyond the focus group. There was evidence of feedback from family and friends.
a. There were minutes of a focus group, walk, and talk and other support groups such as coffee mornings
b. However, there did not appear to have been a wider survey including more patients and specific to the service – a recommendation that this is carried out to get broader feedback on the service.

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 peer review team met the leadership team on the day. All were appropriately registered. A competency matrix was seen for all staff. Evidence of specialist competencies and CPD was provided in the file in the nurses’ office.

Quality Standard 12: Staffing levels and skill mix

Standard 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 are sufficient numbers of staff, and:
a. All undertake CPD.
b. A competency matrix was available.
c. The consultant staff specialise in bleeding disorders and are available on a 24/7 on-call rota. Patients presenting to other HC, such as Swansea, out of hours, are discussed with the Cardiff on-call consultant:
d. CNSs with the appropriate competency and training were planning to engage in nurse prescribing.
e. There was adequate physiotherapy provision with training in IBB.
f. Psychological input was available both directly to patients and their families and indirectly via the MDT. There are some vacancies to be filled to ensure the psychology service is operating at full scope.
g. There is a dedicated social worker.
h. There is a Whole Time Equivalent (WTE) data manager.
i. The lab was adequately staffed with qualified BMS.
j. The haematology registrars rotating through the centre received an induction.

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

All staff undertake CPD in haemostasis.
a. Attendance at conferences is encouraged.
b. Some had attended EAHAD.
c. On the training plan, there was a clear plan for staff to attend the introduction and contemporary care courses.
d. Several new staff members have been in place, but a clear plan was in place to ensure that they all had a training plan and competency matrix.

Feedback and education were shared at departmental meetings. Clear processes for determining training and conference attendance were established, ensuring fairness among teams.

Quality Standard 14: Administrative, Clerical and Data Collection Support

Standard Met

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

How the Service meets or does not meet the standard

There was adequate administrative, clerical, and data collection staff as per the staffing list provided.

Quality Standard 15: Support Services

Standard Met

Timely access to the following support services should be available:

a. Play support (children's services only) including:
    i. Play and distraction during any painful or invasive procedures
    ii. Play support to enable the child's development and well-being
b. Pharmacy
c. Dietetics
d. Occupational Therapy
e. Orthotics/podiatry

How the Service meets or does not meet the standard

There is a 0.6 (WTE) play therapist available to attend paediatric clinic appointments and phlebotomy as required.
a. There was a nice paediatric room in the centre with good distraction available;
b. There has been a recently appointed pharmacist who has not yet commenced in post. There is an SOP for referral to Occupational Therapy, Dietetics and Podiatry.

Quality Standard 16: Emergency Department

Partially Met

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

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

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

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

How the Service meets or does not meet the standard

There is an electronic alert on the patient's electronic record, and patients know who to contact. However, there was no evidence of training for Emergency Department (ED) staff, with training appearing to be ad hoc.

No evidence of training presentations was provided.

There was no audit of the emergency pathway, except for the issue of the product being out of hours.

Quality Standard 17: Laboratory Service

Standard Met

a. A UKAS accredited laboratory service with satisfactory External Quality Assurance performance should be available 24/7
b. A laboratory representative (senior biomedical scientist or clinical scientist) should attend inherited and acquired bleeding disorder service multidisciplinary team meetings (QS 25) regularly
c. The following tests should be available in a timely manner for the diagnosis and management of inherited bleeding disorders:
    i. All coagulation factor assays
    ii. Inhibitor screening
    iii. FVIII inhibitor quantification
    iv. VWF antigen
    v. VWF activity
    vi. Platelet function testing
d. Pathway for referral to molecular Genetic Laboratory service for:
    i. Detection of causative mutations in PwBD
    ii. Carrier detection
    iii. Discussion of results in genomics MDT when needed

How the Service meets or does not meet the standard

The lab was visited, and the chief BMS was met.

There is 24/7 access to a UKAS accredited laboratory service on the same site as the haemophilia centre.

Range of UK and European EQA schemes undertaken for all assays performed by the specialist coagulation laboratory – satisfactory results.

A member of the laboratory team attends the daily morning handover to highlight any urgent samples.

There is a separate weekly lab MDT with medical staff and lab staff to discuss any laboratory issues, new diagnoses, interesting cases and EQA results. It was not felt appropriate for the lab to attend the main weekly clinical MDT, but it should be considered whether they could attend part of the MDT to discuss interesting patients, surgical planning, etc.

Platelet aggregometry and nucleotide testing are available. It is being developed to meet national standards. Genetic tests are sent to an external lab (Oxford), and results are discussed in Southwest Genomics MDT as required.

Out-of-hours one-stage clotting assays are available 24/7. For more specialist coagulation results (bovine chromogenic factor, VWF activity), the service relies on phoning staff to see if anyone is available to come in. This is not robust.

Consideration should be given to a formal rota or Service Level Agreement (SLA) with another lab offering 24/7 service to ensure specialised assays are available.

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

Access to specialist services is available across the range required. Rheumatology services are available, although used infrequently, as patients are more often referred to orthopaedics.

Dental services are provided via a private clinic off-site.

HIV and hepatology services are provided via a separate liver clinic.

Chronic pain service available.

Quality Standard 19: IT System

Partially Met

IT systems should be in use for:

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

How the Service meets or does not meet the standard

Increased data management is required, and the current administrative staff are filling this gap. Plans can be difficult to locate on the current IT system.

The ability to provide more detailed service audits would aid service review and development. Improved clinical alerts would highlight PwBD presenting in the ED.

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

Standard Met

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

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

How the Service meets or does not meet the standard

There was evidence of a guideline for the diagnosis of a bleeding disorder, but the guidelines did not define when and how to diagnose a BDUC. We would recommend that the SOP include when to diagnose BDUC and when patients should be discharged with normal investigations.

Quality Standard 21: Guidelines: Treatment and Monitoring of IABD

Standard Met

Guidelines should be in use covering:

a. Factors concentrate and non-factor replacement therapy
    i. Initiation and monitoring of prophylaxis
    ii. Home therapy
    iii. Use of extended half-life products, including inhibitor testing and PK assessment

   - iv. Use of non-factor replacement therapy
- b. Management of factor concentrate and non-factor replacement therapy supplies, including:
   - i. Ordering
   - ii. Storage
   - iii. Stock control to ensure all stock is up to date and waste is minimised
   - iv. Prescription and delivery for PwBD on home treatment
   - v. Arrangements for emergency 'out of hours' supply
   - vi. Recording issue to PwBD
   - vii. Recording use by PwBD, including on Haemtrack
   - viii. Submission of data via NHD for quarterly returns

How the Service meets or does not meet the standard

Guidelines available for these criteria also informed the use of SHL, EHL and non-replacement therapy.

The initiation of prophylaxis in children is typically with a Port-a-Cath, rather than veins, even if veins are present. Home visits to support proficiency.

Stock control is managed by the Admin team, which orders stock and reconciles usage outside of regular hours. Doctors/ Nurses record out-of-hours use on paper records. Products are stored in a temperature-controlled fridge.

Home care company used for patients on home treatment.

Nurses are undergoing prescribing courses; they have physio NMP; however, they are only prescribe for acute bleeding episodes. Emergency out of hours supply via Registrar on-call. Haemtrack not monitored adequately.

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

There was no specific pathway or guideline for synovitis.

Guidelines for hepatitis and HIV are not applicable, as other departments manage them.

Other guidelines covering the other standards were present.

Quality Standard 23: Guidelines on Care of PwBD requiring Surgery

Standard Met

Guidelines on the care of PwBD with inherited and acquired bleeding disorders who require surgery should be in use covering at least:

a. Involvement of surgical and inherited and acquired bleeding disorders service in agreement of a written plan of care prior to, during and post-surgery
b. Communication of the agreed plan of care to all staff involved in the PwBD 's care prior to, during and after post-surgery
c. documentation of care provided
d. Arrangements for escalation in the event of unexpected problems

How the Service meets or does not meet the standard

There were guidelines covering the surgical management of patients with bleeding disorders, and the evidence presented included the surgical plan document for individual patients.

Quality Standard 24: Service Organisation

Standard Met

The Service should have an operational procedure covering at least:

a. Ensuring all children who are in-patients have a named consultant paediatrician and a named haematologist with expertise in caring for PwBD with inherited and acquired bleeding disorders responsible for their care
b. Ensuring all adults are under the care of a consultant haematologist with an interest in inherited and acquired bleeding disorders, either directly or through a shared care arrangement with a general haematologist
c. Responsibility for giving information and education at each stage of the patient journey
d. Arrangements for involving Haemophilia Centre staff in multidisciplinary discussions relating to their PwBD
e. Arrangements for follow-up of PwBD who 'do not attend'
f. Arrangements for transfer of PwBD information when PwBD moves areas temporarily or permanently
g. Ensuring PwBD's plans of care are reviewed at least six monthly for those with severe haemophilia and at least annually for other PwBD (QS 3)
h. Ensuring school visits for children with severe haemophilia at least at each change of school (children's services only)
i. Ensuring PwBD are visited at home where clinically appropriate at least annually if they are unable to attend clinics, including those in nursing homes
j. Lone working

How the Service meets or does not meet the standard

Children who are admitted are managed jointly by staff from the haemophilia centre and the paediatric haematology department. All adults admitted are under the care of a consultant in the haemophilia department, and there are excellent checklists for new patients, transitions, and pregnant women. There is a weekly MDT.

There is a process for patients who are DNA, but regarding paediatric 'Did Not Attend' (DNA), the SOP should include a statement about a process for repeat DNAs and when to involve safeguarding.

There was evidence of school visits and care plans, and the patient received excellent community support, with nurses and physiotherapists visiting them at home. A lone working policy is also in place.

Quality Standard 25: Multidisciplinary Team Meetings

Standard Met

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

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

How the Service meets or does not meet the standard

The laboratory manager doesn't attend the weekly meetings of the multidisciplinary team (MDT). The review team recommends that a laboratory team representative attend at least part of the weekly MDT.

An attendance record is taken at the MDT. There is a weekly meeting of the MDT with the centre in Swansea.

Quality Standard 26: Multidisciplinary Clinics/Liaison Services

Standard Met

Combined clinics or other arrangements for multidisciplinary discussion with

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

How the Service meets or does not meet the standard

Orthopaedic and rheumatology referrals are made as required. There is a joint obstetrics and gynaecology and haematology clinic, and a paediatrician attends the paediatric clinics. There are separate HIV clinics as well as a joint hepatology clinic.

Quality Standard 27: Data Collection

Standard Met

The following data should be collected:

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

How the Service meets or does not meet the standard

All the requirements for this standard have been met. The data manager records on the National Haemophilia Database (NHD). Patients are encouraged to use Haemtrack, although compliance is lower than the team would wish. There is no national dashboard requirement; adverse events are reported to the NHD.

Quality Standard 28: Research

Standard Met

The Service should actively participate in research relating to the care of PwBd with bleeding disorders. The Service should also offer links with other services to maximise research study opportunities. Staff members participating in research should be allocated appropriate time for this role.

How the Service meets or does not meet the standard

There is a robust research portfolio with sufficient staffing.

Quality Standard 29: Multidisciplinary Review and Learning

Standard Met

The Service should have multidisciplinary arrangements for review and implementation of learning from:

a. Audit – the Service must have an audit plan, and it must include an audit of emergency and out of hours care (QS 23)
b. Positive feedback, complaints, outcomes, incidents and 'near misses'
c. Morbidity and mortality
d. Haemophilia Dashboard (when relevant)
e. Review of UKHCDO Annual Report benchmarking information on concentrate use
f. Ongoing reviews of service quality, safety, and efficiency
g. Published scientific research and guidance

How the Service meets or does not meet the standard

There is no audit of emergency pathways or out of hours care.

B and C are discussed at regular QSPE meetings. The haemophilia dashboard is not relevant in Wales.

Patient reported outcomes have been introduced recently. The QSPE meetings discuss quality, safety, and efficiency.

The audit team saw the agenda. There was evidence of several audits; however, no overarching audit plan was in place, and it is unclear how the audits are being implemented. Suggestion for a service-wide audit action plan encompassing all audit actions.

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

All SOPs were in trust format, and the date and version were controlled.

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 in Attendance comprised of a consultant haematologist, clinical specialist physiotherapist, two clinical nurse specialists (one paediatric and one adults) and clinical psychologist.

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 Health Board should ensure that appropriate resources are made available so these outstanding issues can be resolved.

Ref. Number	Statement of original finding
1	The space in the centre from which the service was provided was inadequate for the size of the service being provided:
a	The waiting area was too small and was poorly ventilated. Patients receiving intravenous infusions sat with other patients awaiting appointments. A fridge (locked) took up some space in the area as there was apparently no other place for it. On some occasions, children and adults shared the waiting area. Although there was a spacious and bright paediatric clinic area in the children’s hospital, where clinics

	for these children had for a time been provided, parents had requested that the children's appointments should be back in the main Haemophilia Centre.
b	There was a single consulting room. At the time of the visit, the team could use two adjacent treatment rooms to see patients. However, when the day unit refurbishment was complete one of these rooms (which was shared between the two units) would revert to previous arrangements according to which it was determined by clinical activity in the Centre. Staff explained that sometimes patients had long waiting times not because of staff availability, but because there was no room free for their consultation.
c	Office space for team members was insufficient. The nurses, data managers and middle grade medical staff shared a small office and were 'hot-desking'.
d	There were no rooms for psychologists or social workers to see patients and families. Unless the physiotherapist was seeing a patient in a joint consultation with the consultant, the patient had to go to a room some distance from the clinic for a physiotherapy assessment.