UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

# UKHCDO Haemophilia Peer Review Audit Report

## Southampton Haemophilia Comprehensive Care Centre

**Report Date: 21 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. Peer review for the Southampton Haemophilia Comprehensive Care Centre (the Service) was completed on 5th June 2024.

**The Service successfully met 26 of the 30 established standards, with 4 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 Recommendations:**

1. **Physiotherapy provision**: Physiotherapy is a key component of the comprehensive care, and the current provision is grossly inadequate and does not meet the service specification requirements. The review team recommends that the trust support an increased provision.
2. **Nursing provision:** The current nursing establishment is inadequate to deliver a full service at all times. We recommend that the trust increase nursing support to enable the development of specially trained nurses, ensuring sufficient cover across all aspects of the service.
3. **Environment & facilities:** The review team recommends that the Trust assist the service in finding additional space or in utilising the available space more effectively. This is important because inadequate space for working or treating patients adversely affects the well-being of both staff and patients. Moreover, limited space can also impact wheelchair users.

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 conducted on 5th June 2024. A multidisciplinary team of haemophilia professionals, along with patient representatives, carried out the review, which involved interviewing staff from the Service, reviewing documentation, and touring the facilities.

The Service offers care to both adults and children with bleeding disorders, supporting 647 registered patients. It is based at the University Hospitals Southampton NHS Foundation Trust and serves individuals from Hampshire, Dorset, and the Channel Islands.

The Service provides a comprehensive range of clinical, laboratory, support, and advisory services, including emergency treatment for bleeds, regular assessments and screenings, physiotherapy, genetic testing and counselling, investigation of bleeding disorders, patient and carer education, support and counselling, as well as professional advice for healthcare providers, employers, and schools. The Service is actively engaged in clinical research, contributing to significant advancements in patient care and treatment.

Haemophilia MDTs are conducted with a multifaceted agenda aimed at maintaining formal and robust communication with the Coagulation laboratory. Regular research meetings are held with research nurses to optimise engagement in research.

## 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** | 25 | 12 | 4 | 1 | 124 | 28 | 284 | 62 |
| **Moderate** | 6 | 6 | 5 | 0 | | | | |
| **Mild** | 57 | 17 | 12 | 4 | | | | |
| **Annual review in the last year** | 63 | 31 | 17 | 4 | 60 | 19 | 180 | 43 |
| **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 staff includes a mix of full-time and part-time roles, comprising three adult consultant haematologists and two paediatric haematology consultants. Two nurses (2 WTE) receive cross-cover from the thrombotic thrombocytopenic clinical nurse specialist. One adult physiotherapist (0.36 WTE) and one paediatric physiotherapist (0.1 WTE) are also present. The laboratory team consists of one lead biomedical scientist and seven specialist biomedical scientists, with training and cross-cover provided. Additionally, the service is supported by two administrative staff and one data manager (0.5 WTE). At the time of the review, there was no dedicated psychology or social work service; however, we are aware that since then, they have secured a contract with an external provider and will be recruiting.

**Key staff** include Consultant Haematologist & Centre Director Dr Rashid Kazmi and Lead Nurse Dawn Jenner.

**Outpatient care**: The outpatient facilities were completely refurbished in 2013, however space is limited for all team members to see patients.. Each patient is cared for by a named consultant haematologist with expertise in bleeding disorders. There are specialised Haemophilia Clinics for adult and paediatric patients.

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

**Out of hours:** The Service provides continuous care with a well-organised out-of-hours system, supported by one of three haemophilia consultants, and ensures seamless service through planned and cross-cover arrangements.

**Transition:** Transition clinics take place with the “Ready Steady Go” process in use

**Network arrangements:** The Service is not part of a formal network. However, it covers patients with bleeding disorders from the Isle of Wight and the Channel Islands. The Service also provides ad hoc support to colleagues for the management of their patients in satellite hospitals, including Chichester, Worthing, and Brighton. Staff from these hospitals join the weekly MDT to discuss their patients' management.

# 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 26 out of the 30 standards, with the remaining four partially met, and there are no outstanding findings from the previous peer review. The service is encouraged to review all descriptive assessments in addition to the key findings. This report, alongside local assessments, should steer discussions with the management team, highlighting areas of good practice while emphasising where further investment and improvement may be required.

| Standard | Title of standard | Rating |
|---|---|---|
| 1 | Service Information | 🟩 |
| 2 | Condition-Specific Information | 🟩 |
| 3 | Plan of Care | 🟩 |
| 4 | Outpatient Review of PwBD | 🟩 |
| 5 | Contact for Queries and Advice | 🟩 |
| 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 | 🟩 |

| Standard | Title of standard | Rating |
|---|---|---|
| 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. Patient access to electronic records and tailored electronic resources.
2. There is an excellent clinical trial portfolio with participation in phase 1, 2, and 3 clinical trials on extended Half-Life Concentrates, novel non-factor therapies, gene therapy, and cell therapy for haemophilia A and B. The Service is a leader in gene therapy, being one of only two sites in the country performing liver biopsies on gene therapy patients.
3. Patient-centred, multidisciplinary working with a peer support network for young people with bleeding disorders, and proactive signposting of carers to sources of support.
4. Multidisciplinary team meetings are open for other hospitals and clinicians in the region to join and discuss cases.

## 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 three main concerns:

1. The current provision of physiotherapy time is entirely inadequate for the scale of the service. Physiotherapy for inherited bleeding disorders must be both reactive and proactive to treat and prevent the long-term sequelae of musculoskeletal bleeding. They should have sufficient time to participate in all MDT discussions and clinics, as well as providing their service to outpatients.
2. The peer review team is concerned that there is an insufficient number of nursing staff to meet the needs of this complex patient caseload and the wider service requirements overseen by the Lead Nurse. A specialist nurse should be available to patients at all times when the Centre is open. The nursing role in Bleeding Disorders Care as the first point of contact and triage is crucial to providing safe and effective care.
3. The review team is concerned about the general lack of space in the haemophilia centre. Specifically, there is insufficient space for all team members to see patients in the clinic, the waiting area is small, and there is limited room for the nursing team's expansion, as their office space is extremely restricted. The review team is also concerned about the physiotherapy gym and hydrotherapy suite being used simultaneously by both adults and children.

The Service has made commendable efforts to address the staffing concerns raised in the previous peer review, including the appointment of paediatric haematologists and, although not yet fully integrated, the establishment of a psychology service. However, staffing concerns persist, particularly regarding the inadequate provision of nursing and physiotherapy services in relation to the size of the service. The Service should prioritise resolving these outstanding issues. Staffing problems were also identified as a significant concern in the 2019 peer review report, particularly regarding the allocation of physiotherapy time. For more information on these concerns, please refer to Section 7 of this report.

## 4.5 Recommendations

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

1. **Physiotherapy provision:** The review team recommends that the Trust support the Service in increasing physiotherapy provision for patients with bleeding disorders immediately. This role is a core member of the multi-disciplinary team and is crucial for the delivery of Comprehensive Care.
2. **Nursing provision:** The review team recommends that the Trust work with the Service to conduct a skill mix review of the nursing team, ensuring that adequate specialist nurses are available at all times to support all aspects of their roles, including the broader service management responsibilities of the Lead Nurse. It is possible that a rotational training post with another service, such as a non-malignant Haematology service, could fulfil this need.
3. **Environment & facilities:** The review team recommends that the Trust assist the service in finding additional space or in utilising the available space more effectively. This is important because inadequate space for working or treating patients adversely affects the well-being

of both staff and patients. Moreover, limited space can also impact wheelchair users who access the service.

## 5 Quality Standards - Detailed Description

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

### 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

Clear information is available in both written and online formats, making it easy to understand.

### 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

**Standard Met**

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

Extensive resources. Information is accessible online, including via My Medical Record.

Patients noted that information is readily available and presented in a clear format.

## 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

Documented in all letters.

An excellent care plan for children that covers all aspects, including appropriate sporting activities, and so forth, was seen on the day.

## Quality Standard 4: Outpatient review of PwBD

**Standard Met**

A formal review of PwBD should take place regularly:

a. For those with severe and moderate haemophilia, any PwBD on prophylaxis and other severe bleeding disorders at least twice a year. This may be more frequent in the paediatric setting based on clinical needs.
   The following multidisciplinary clinic arrangements for these PwBD should be in place:
   i. Involvement of medical, specialist nursing and physiotherapy staff in clinics
   ii. Availability or clear referral pathway for social work and psychology staff

b. For those with mild bleeding disorders, the Centre should have a documented follow-up pathway with a plan for managing DNA and PIFU if used. These PwBD should have access to the full MDT if clinically required but may not be seen in a combined clinic.

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

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

### How the Service meets or does not meet the standard

Clear standard operating procedures. Clearly defined care pathways.

Established pathways for social workers and psychologists, although there is no dedicated service for adults.

## 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

Information is contained in care plans, on the website, in My Medical Record, and on the alert card.

## 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

The majority of patients are using Haemtrack.

There is good evidence of engagement, and Haemtrack is being actively used during clinic reviews.

## 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

There is insufficient space in the haemophilia centre for all team members to see patients in the clinic. The waiting area is small.

The nursing team is in a cramped office with extremely limited capacity for team expansion.

In the physiotherapy gym and hydrotherapy, the same space is used simultaneously for children and adults.

## 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

Transition clinics established. "Ready, steady, go" process in use. Access to youth workers.

## 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

Information provided in My Medical Records. Written and electronic information is also available. The nursing team guides and directs carers to additional sources of support.

## 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

Patient focus group meetings take place, with patient feedback being proactively collected via My Medical Record.

## 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

Time allocated in the job plan for the centre director. The lead CNS is highly motivated.

## 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 currently no dedicated social worker. The psychology service is being established.

The number of nursing staff is insufficient to meet the workload and remit.

There is inadequate provision of physiotherapy for both children (0.1 WTE) and adults (0.36 WTE).

## Quality Standard 13: Service Competencies and Training Plan

**Standard Met**

a. All staff are to complete trust mandatory training, including regular appraisal.
b. All clinical staff to have CPD relevant to bleeding disorders
c. All new nurses/AHP/Psychologists to have the opportunity to attend an introduction to bleeding disorders course and the contemporary care course provided by the Haemophilia Nurses Association
d. All specialist clinical staff to have the opportunity to attend national and/or international conferences and to develop subspecialist interests

### How the Service meets or does not meet the standard

All staff are actively involved in CPD and up to date with mandatory training.

Funding is available for all team members to attend meetings and courses.

## 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

0.5 WTE data manager for haemophilia is in post.

## 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

All services are in place, including the youth/support worker programme.

## 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

Training is provided as needed. Guidelines and a clear pathway are in place.

There was no evidence of an ongoing audit.

## 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

All assays are available on site except for platelet nucleotides and glycoproteins.

Factor assays are available 24/7.

Genetic samples are sent to Oxford, with satisfactory turnaround times, and a regional MDT meeting is in place to discuss the results.

## 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

All services are in place.

## 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

Evidence provided for the above standards.

## 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

Comprehensive guidelines are in place, except for the explicit mention of bleeding disorders of unknown cause.

## 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

Excellent guidelines are in place, including information on target factor levels for different surgeries.

Evidence is also noted for the other quality standards.

## 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

Covered by a combination of local and trust-wide guidelines.

## 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

Well-structured management plans are in use.

## 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

A comprehensive standard operating procedure is in place addressing the above issues.

## Quality Standard 25: Multidisciplinary Team Meetings

**Partially Met**

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

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

### How the Service meets or does not meet the standard

Physiotherapists are unable to attend routinely due to insufficient physiotherapy time.

## 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

Access to appropriate clinics is in place. However, consideration should be given to establishing, in conjunction with gynaecology, a dedicated clinic for women and girls with bleeding disorders.

## 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

Relevant and appropriate processes are in place.

## 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

Excellent research portfolio. Extensive experience in gene therapy. The review team noted that, in light of this, it was very regrettable that Southampton was not successful in the tender process to become an NHS gene therapy hub, having had their bid excluded on a technicality.

## 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 an active audit programme that includes emergency and dental pathways. Involvement in Clinical Haematology governance and M&M meetings. Consistent review of incidents during MDT meetings. Regular formal feedback is obtained from patients.

| 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 is in place. | |

# 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:<br>Met - Standard has been met fully.<br>Partially Met - Standard has been met in part.<br>Not Met - Standard has not been met at all.<br>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 (one adult, one paediatric), two paediatric clinical nurse specialists, a youth worker, and a patient representative. UKHCDO holds details of the Peer Review Team.

## 7.3 Outstanding findings from previous peer review

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

| Ref. Number | Statement of original finding |
|---|---|
| 2 | Staffing<br>All staff in post were working very hard to try to ensure that their patients had appropriate care; however, staffing shortfalls were hindering the team's ability to deliver the expected, rounded multi-professional care. Patients especially noted the lack of psychology support and commented on how stretched the nurse specialists were. |
| a. | Paediatric senior medical staff: At the time of the visit, there was no paediatrician or paediatric haematologist working regularly with the team to deliver specialist care to children with bleeding disorders, and it was not possible for the review team to meet any paediatric medical staff to understand the workings of this service in context of the other paediatric clinical services. Reviewers were informed that a locum paediatric haematologist was due to start very soon, possibly within a month of the visit. However, there was uncertainty about how much time dedicated to this service the consultant was to have in their job plan |
| b. | Physiotherapy: There were adult and paediatric physiotherapists working within the service, but respectively with only one session per month and 3.5 hours per week. Within this time, they were not even able to attend all clinic appointments and were not able to see patients presenting with acute joint bleeds – sometimes for several days. The UKHCDO physiotherapy standards require physiotherapists to have sufficient time and flexibility in their work to see these patients promptly. Much of the physiotherapist's dedicated time was spent undertaking formal joint scoring rather than working to promote long term joint health. There were no clinical guidelines relating to managing synovitis, or target joints; it was noted that having guidelines in place would allow for audit of practice, to evidence gaps in service and to the need for additional dedicated time. |
| c. | Psychology: There was no psychologist working with either the paediatric or the adult team. A psychologist is expected to be part of the core team in caring for these conditions. Where there were high-level concerns, referrals were made through the patient's primary care team. However, the team were lacking in the support and guidance that a psychology member can bring to their practice, and it was inevitable that some lower-level patient or family needs were not being met. |
| d. | Social work: There was no named social worker available to support the patients and families, and it was unclear whether the haemophilia team had easy access to Trust-wide social care support. Social services support (e.g. for completing Personal Independence Payment (PIP) applications) is always greatly appreciated by people affected by long term conditions. |
| e. | Nursing: The lead clinical nurse specialist's work was central to the service and was greatly appreciated by her colleagues and patients. However, there was a concern about the impact on the service if she were off work for any reason or decided to retire. Reviewers heard that the nurses also had increasing demands on their time and that they now had insufficient time to fully support the service in the way they would wish, for example undertaking home visits. |