UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

UKHCDO Haemophilia Peer Review Audit Report

Newcastle upon Tyne Haemophilia Comprehensive Care Centre

HAEM-PSYCH ASSOCIATION UK & IRELAND

Haemophilia Nurses Association UK

HCPA Haemophilia Chartered Physiotherapist Association

HAEMOPHILIA SCOTLAND

The Haemophilia Society

HAEMOPHILIA WALES

Haemophilia NI
Supporting patients and families

Report Date: 30 April 2025

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1 Executive summary

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

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

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

The executive summary presents the key findings, while the full report details the assessments referenced against the quality standards. Peer review for the Newcastle Haemophilia Comprehensive Care Centre (the Service) was completed on 21 March 2024. The Service is located within the Royal Victoria Infirmary site of the Newcastle upon Tyne Hospitals NHS Foundation Trust.

The Centre successfully met 23 of the 30 established standards, with seven standards being 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. **Centre environment and facilities:** The review team recommends that the Trust work with the service to find, create, or better utilise the space for the haemophilia team. This is essential to alleviate the issues posed by a lack of space.
2. **Psychology Service Provision:** The review team recommends increasing the dedicated haemophilia-specific psychology provision to provide timely support to patients and carers. A lack of timely psychological support can have a detrimental impact on the treatment and recovery of patients of all ages and the well-being of their carers.
3. **Data management and administration:** The review team also recommends reviewing the staffing within the data management team, as it appears very limited in comparison to other centres of similar size.

This review has identified gaps in haemophilia services that 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 for the Newcastle Haemophilia Comprehensive Care Centre took place on 21 March 2024. A multidisciplinary team of haemophilia professionals, accompanied by patient representatives, conducted the review, which involved discussions with staff from the Service, reviewing documentation, and touring the facilities.

The Service provides care to over 1900 patients, including both adults and children, throughout the Northeast and Cumbria. Newcastle upon Tyne Hospitals NHS Trust (NUTH) is one of the largest hospital trusts in the UK, offering a comprehensive range of medical and surgical specialities across two hospital sites: Royal Victoria Infirmary (RVI) and Freeman Hospital. This encompasses the regional trauma centre, the regional maternal medicine network hub, dedicated paediatric services at the Great North Children's Hospital (GNCH), and neurosurgery. Paediatric services are located at the Great North Children's Hospital, which is situated within the Royal Victoria Infirmary site.

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	58	31	13	5	406	69	904	173
Moderate	17	7	7	3				
Mild	152	32	25	12				
Annual review in the last year								
Inpatient admissions in the last year	30	71	4	2	15	3	43	6

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

Staffing: The service employs 14 professionals, including three consultants, seven (6.4 WTE) nurses, two (1.6 WTE) physiotherapists, one (0.2 WTE) psychologist, two specialist coagulation laboratory staff (1.5 WTE) and 3 (2.0 WTE) administrative staff.

Key staff include consultant haematologists and joint Centre Directors Dr Kate Talks and Dr Tina Biss, and Lead Nurse Julie Vowles.

Outpatient care: This is provided in the Haemophilia Centre, but the space is inadequate for the volume and needs of the complex patients seen. Multidisciplinary team meetings are attended by medical, nursing, physiotherapy, psychology specialists and social workers. Invasive dental procedures take place in the Newcastle Dental Hospital (based on the RVI site) if haemostatic cover and monitoring are required. The Newcastle MDT staff provides home and school visits for PwBD around the region.

Inpatient care: This is based on wards appropriate to the indication for admission.

Out of hours: Access and assessments are provided for children through the GNCH paediatric emergency department, with joint evaluations by the paediatric and haematology on-call teams. Adults are asked to contact the adult Haematology ward (ward 33 at the Freeman Hospital site) for advice out of hours, with assessment there or in the adult ED at the RVI, depending on the clinical need.

Transition: The transition process is facilitated by the adjacent facilities of the Great Northern Children's Hospital and the Royal Victoria Infirmary, together with staff engaged in both children's and adult care. Particular attention is given to progressing at a gradual pace throughout.

Network arrangements: The Newcastle Haemophilia Centre is part of a hub-and-spoke network that encompasses a broad geographical area, including not only Tyne and Wear but also North Yorkshire, Northumbria, and Cumbria. Newcastle oversees and maintains the stock of emergency haemostatic treatment for five regional hospitals: West Cumberland Infirmary (Whitehaven), Cumberland Infirmary (Carlisle), Sunderland Royal Hospital, James Cook University Hospital (Middlesbrough), and the Northumbria Specialist Emergency Care Hospital (Cramlington).

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 23 out of the 30 standards, with the remaining seven partially met and 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	🟩
11	Leadership Team	🟩
12	Staffing Levels and Skill Mix	🟨

Standard	Title of standard	Rating
13	Service Competencies and Training Plan	🟩
14	Administrative, Clerical and Data Collection Support	🟨
15	Support Services	🟩
16	Emergency Department	🟩
17	Laboratory Service	🟨
18	Specialist Services	🟩
19	IT System	🟩
20	Diagnosis Guidelines for People with Suspected IABD	🟩
21	Guidelines: Treatment and Monitoring of IABD	🟨
22	Clinical Guidelines/ Pathways	🟩
23	Guidelines on Care of PwBD requiring Surgery	🟩
24	Service Organisation	🟩
25	Multidisciplinary Team Meetings	🟩
26	Multidisciplinary Clinics/ Liaison Services	🟩
27	Data Collection	🟩
28	Research	🟩
29	Multidisciplinary Review and Learning	🟨
30	Document Control	🟩

4.2 Good Practice

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

1. The team has world-class physiotherapy expertise, including the use of point-of-care ultrasound to assess joint health. There is a highly experienced nursing team with innovative nurse-led clinics. Medical staff contribute to various regional and national organisations, including the UKHCDO executive and working parties and the NHSE Clinical Reference Group for Specialised Blood Disorders.
2. There is excellent engagement with patients, and a bespoke survey is sent out to them annually. It was evident during the review that there was extensive interaction between staff and patients. Recently, there was a workshop at a local museum for older children learning to self-infuse, taking the activity out of the clinical setting. The Centre has an excellent DNA and re-engagement policy.
3. There was evidence of various service developments, and a notable example is the development of a Q-risk score for adults to address cardiovascular health.

4.3 Immediate risks

There were no immediate risks identified.

4.4 Concerns

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

1. There appears to be insufficient space for the size of the service, creating significant challenges for the service, which has resulted in a cramped waiting area, competition for space with other clinics, and a shortage of consulting rooms. It should be noted that many people with haemophilia are using walking/mobility aids, including wheelchairs and may need to attend with carers. The waiting space is inadequate for their needs. Office space for staff, particularly nurses, is inadequate and shared with other services, which is inappropriate from a confidentiality perspective, considering they provide telephone triage and advice. The review team noted that due to insufficient space, patients sometimes need to attend more than once to receive all elements of their Comprehensive Care Review, such as a physiotherapy assessment, which is a crucial part of the required standards. Given the geographical area that this service covers, it is unacceptable that they cannot access a complete Haemophilia Review in a single visit.
2. The review team is concerned that it can often take up to six months for patients or parents to receive psychological support, particularly following a new diagnosis of a lifelong condition that imposes additional burdens on families. Psychology and social worker support is general rather than specific to bleeding disorders. A lack of timely psychological support can have a detrimental impact on the treatment and recovery of patients of all ages, as well as the well-being of their carers.
3. There seems to be insufficient secretarial and data management support. Although the secretarial and data management team is committed, considerable time pressures hinder the team from staying up to date with all aspects of the role. The team has been reduced from 1.6 WTE at the last review to 1.2 WTE now. These time pressures will impact reporting outcomes for gene therapy when this becomes available. There is a risk that the extensive knowledge and experience possessed by the secretary and data manager may be lost unless timely succession planning occurs to ensure their detailed understanding of the service can be transferred.

4.5 Recommendations

This section outlines the recommendations provided by the review team in response to the concerns highlighted above.

1. **Provision of adequate space:** The review team recommends that the Trust work with the service to identify, develop, or make better use of the space for the haemophilia service. This is necessary to address the clinical issues arising from a lack of space.
2. **Psychology & Social Work Provision:** The review team recommends increasing dedicated haemophilia-specific psychology provisions so that patients, children, and their carers can benefit from more timely support for bleeding disorders.
3. **Job planning for the Centre Director role:** The centre director role should be job planned, and appropriate PAs should be allocated.
4. **Data management:** The review team would like to see an increase in the staffing of the data management team to ensure adequate support for the clinical team. Furthermore, it will help

to alleviate some of the time pressure on the team and promote the sharing of knowledge and experience, as there will be capacity for succession planning.

5 Quality Standards – Detailed Description

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

Quality Standard 1: Service Information

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

Relevant information was identified as being available. One document (HA03 001) contained a lot of information but was lacking in some basics, such as emergency contacts and clinic times, which were provided in a separate card. There would be a benefit in reviewing the format of information on subspecialty access, including emergency access. Overall, the standard was met.

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

Standard Met

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 wellbeing
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

A variety of locally produced, web-based, and Haemophilia Society leaflets were available - some on display within the waiting area. These covered the majority of areas set out within the standard.

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

1. They have nurse-led Paediatric Health and Wellbeing clinics, allowing more time to focus on additional elements of care.
2. Home visits are available from very early on in the patient journey.
3. School visits/talks are carried out by nursing and physio staff.
4. There are examples of care plans using a standard format together with GP letters.
5. School plans are in place.
6. There is clear information/guidance on who to contact for advice.
7. Plans of care are shared with local hospitals in the region so that information is available if someone presents there directly.

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

There is evidence of regular reviews in clinic letters and from patient feedback and direct questioning of staff. Home visits are done at the establishment of prophylaxis. There is a nurse triage template for emergencies. An EPR alert is set up when patients are admitted to the trust. There is a re-engagement Policy adopted by the department.

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

There is a clear pathway for emergencies for adults and children. For children, there is a triage phone call via a single point of contact in the Paediatric ED.

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 who are on home therapy are registered to use Haemtrack. Discussions relating to Haemtrack are documented in letters.

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

All equipment should be appropriately checked and maintained.

How the Service meets or does not meet the standard

There is a clinical risk from an inability to deliver the service within the physical constraints of the department due to shared use. At times, it is very cramped in the waiting area in the Haemophilia Centre, with overflow patients having to wait in adjacent corridors.

There is competition for space with other regular clinics for patients with other haematology conditions. Sometimes, there is a shortage of consulting rooms.

The Physiotherapy team have had to re-arrange appointments, leading to patients having to attend on multiple occasions; this may be a particular problem given the distances many patients have to travel to the centre.

Office space for staff (notably nurses) is inadequate, as this is shared with other clinics.

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

Standard Met

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

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

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

How the Service meets or does not meet the standard

A transition document based on the "Ready Steady Go Transition Policy" can be seen. Longer transition appointments are offered in the Haemophilia Centre.

Patients are taken for visits to the Freeman Hospital to see the adult services.

Quality Standard 9: Carers' Needs

Partially 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

Whilst there is access to psychology and social worker support, these are general services rather than specific to bleeding disorders. The review team heard that it often took 6 months for psychology input to occur. This is a long time to wait for families who may be struggling with a new diagnosis in a child.

Children and their carers would, therefore, benefit from more timely support dedicated to bleeding disorders.

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 service shared a patient/carers survey from March 2024 covering 85 responses. There was a Trust process in place to consult service users where required. An earlier survey from December 2020 (during COVID-19) had also been undertaken to assess the impact of reduced face-to-face contact.

Two patients met with representatives of the peer review team and described a responsive service with which they were happy. Two carers also met the other members of the review team and gave very positive feedback about the service provided to their children.

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

There is an appropriate leadership structure. Consideration could be made to formal recognition of the joint director roles in terms of job plan PAs.

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 sufficient consultant staffing at present. The specialist nursing team cover other aspects of non-malignant haematology in addition to bleeding disorders. This poses a risk that time available for managing bleeding disorders may be eroded as other areas of the service expand unless there is appropriate planning. The haematology nursing teams on the wards at Freeman Hospital were all given relevant training, and those spoken to were knowledgeable about the essentials of managing bleeding disorders.

The physiotherapy provision is 1.6 WTE, and this, at times, is insufficient for the service being delivered, leading to pressure on those in post. Evidence of CPD was seen. Psychological and social work input is available to adults but not to children.

There is insufficient data management time (this has decreased from 1.6 WTE in 2022 to 1.2 WTE now) to meet data processing and reporting requirements, including reporting adverse events to the National Haemophilia Database in a timely manner.

Quality Standard 13: Service Competencies and Training Plan

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

Standard Met

How the Service meets or does not meet the standard

The department has a training matrix which demonstrates the requirements. There was evidence of mandatory training (94.07% complete).

All the nurses attend the HNA course. Staff are able to attend relevant conferences.

Quality Standard 14: Administrative, Clerical and Data Collection Support

Partially Met

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

How the Service meets or does not meet the standard

There is an excellent and dedicated secretarial and data management team with detailed documents around their roles. However, pressure on data management time results in this being insufficient to keep up to date with all aspects of the role. There is a risk of delay in Adverse Event reporting. This will also have a negative impact on reporting outcomes for gene therapy when this becomes available, with implications on income to the service and impact on national surveillance for any adverse events or lack of efficacy.

The secretary has extensive experience and knowledge of the service, ensuring family trees are updated, summary sheets are updated, patients awaiting surgery are tracked, and carriers who are pregnant are followed up during and after delivery. There is a work instruction in place to cover these extended roles, which describes how to do these tasks in the event that one of the post holders leaves their position, and the work would continue.

For both the secretary and the data managers, succession planning is essential to ensure their detailed knowledge of the service can be passed on.

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 wellbeing
- b. Pharmacy
- c. Dietetics
- d. Occupational Therapy
- e. Orthotics/podiatry

How the Service meets or does not meet the standard

There is play support via the paediatric outpatients.

The team have access to a pharmacy technician.

Referrals are made to other services as required.

Quality Standard 16: Emergency Department

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

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

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

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

Standard Met

How the Service meets or does not meet the standard

There is a flow chart for ED at the RVI (paediatrics) and for Freeman (adults). An audit has been done of time to factor/emergency management**.**

Quality Standard 17: Laboratory Service

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

Partially Met

How the Service meets or does not meet the standard

All relevant assays are offered at the onsite haemostasis lab, which is accredited by the UKAS. There is, however, an issue with genetic results, which are taking up to a year to be completed since the reorganisation of genetics services and movement of the work away from Newcastle (turnaround time should be 12 weeks).

Quality Standard 18: Specialist Services

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

- a. Obstetrics, including reproductive counselling, information about pre-implantation genetic diagnosis and antenatal diagnosis
- b. Foetal medicine

Standard Met

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

There are combined clinics in many services (e.g., orthopaedics, gynaecology). There is a CNS-led genetics clinic.

Referrals can be made to other specialities as needed. All the specialities outlined are available.

Quality Standard 19: IT System

Standard Met

IT systems should be in use for:

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

How the Service meets or does not meet the standard

The trust has an EPR in place. HCIS is used for treatment plans.

Factor treatment is recorded on a physical "green card" and then copied onto IT systems where Haemtrack is not used.

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 is a diagnosis guideline covering approaches to different patient groups, including inflicted injury.

Quality Standard 21: Guidelines: Treatment and Monitoring of IABD

Partially Met

Guidelines should be in use covering:

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

How the Service meets or does not meet the standard

There is no specific guideline for initiating and monitoring prophylaxis. However, appropriate guidelines cover all other aspects of the standard.

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

Local guidelines are in place for all aspects of the standards; these contain links to national guidelines/policies where appropriate.

Consideration should be given to adding information on target factor levels for managing certain types of bleeds so that less experienced or rotational staff members would have a framework to refer to if more senior advice was not immediately available; it would also have an educational benefit.

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 is a guideline covering the management of invasive procedures. A standardised proforma is used to document the care plan. An example of a care plan was seen. EPR alerts were in place to highlight admissions to the haemophilia team.

Consideration should be given to adding information on target factor levels for managing certain types of procedures so that less experienced or rotational members of staff would have a framework to refer to if more senior advice was not immediately available; it would also have an educational benefit.

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

Comprehensive procedures and arrangements are in place to cover all aspects of the standard.

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

There are joint adult and paediatric MDTs and daily handover meetings.

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

Either joint clinics or pathways to access all relevant services were in place.

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 relevant data is being collected, but as outlined earlier, the pressure on the data management team, with insufficient staff to cover the workload, was reported to be leading to reporting delays.

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

A list of research studies was supplied. A policy document outlines how patients are informed and approached about research opportunities.

Quality Standard 29: Multidisciplinary Review and Learning

Partially 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 are documented quality management processes encompassing reviews and escalation of adverse events. Audit results were presented for out-of-hours care. There was a verbal discussion of audit plans, but this was not documented.

Quality Standard 30: Document Control

Standard Met

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

How the Service meets or does not meet the standard

Documents are managed via Q pulse. A small number of documents require review dates to be added.

6 Acknowledgements

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

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

7 Appendices

7.1 Definitions

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

7.2 Peer Review Team

The Peer Review Team consisted of adult and paediatric consultant haematologists, a clinical nurse specialist, a physiotherapist, and a patient representative. Although a paediatric clinical nurse specialist had also been planned for the review, they were unable to attend on the day. UKHCDO holds details of the Peer Review Teams.