UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

UKHCDO Haemophilia Peer Review Audit Report

Glasgow Adult's 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 May 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 Glasgow Adults Haemophilia Comprehensive Care Centre (the Service) was completed on 03 June 2024. The Service is based at the Glasgow Royal Infirmary (GRI) and covers the West of Scotland from Dumfriesshire through to the Western Isles.

The Service successfully met 22 of the 30 established standards, with five standards partially met and three remaining unmet. 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**: The review team recommends increasing the provision of physiotherapy, as the current 0.15 WTE is inadequate for the size of the service, and the time allocated does not allow the service to meet national service specifications.
2. **Nursing staffing**: The review team recommends that the Trust work with the service to increase nursing staffing to a level appropriate for its size and the number of patients.
3. **Consultant medical staffing**: If the new consultant posts have not been advertised, the review team would like to see this addressed as a matter of priority.

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

2 Haemophilia and Bleeding Disorder Peer Review - Background

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

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

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

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

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

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

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

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

3 Service Description

The peer review was conducted on 03 June 2024 at the Haemophilia Centre, Glasgow Royal Infirmary. A multidisciplinary team of haemophilia professionals, along with patient representatives, carried out the review, which involved interviewing staff from the Service, reviewing documentation, and touring the facilities.

The Service provides care to adults with bleeding disorders and has 2,519 registered patients. It is based at the Glasgow Royal Infirmary (GRI) and covers the West of Scotland from Dumfrieshire through to the Western Isles. There are no associated Haemophilia Treatment Centres linked to the Service. Remote clinics based in NHS Ayrshire and NHS Dumfries had been held previously, but these have been stopped since the COVID-19 pandemic.

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	64	0	15	0	633	0	1629	0
Moderate	16	0	13	0				
Mild	115	0	34	0				
Annual review in the last year	80	0	26	0	Not provided	0	Not provided	0
Inpatient admissions in the last year	Not provided	0	Not provided	0	Not provided	0	Not provided	0

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

Staffing: The Service employs 14 healthcare professionals in a combination of full-time and part-time roles, including two medical consultants, four nurses (3.52 WTE), one physiotherapist (0.15 WTE), two (2 WTE) coagulation laboratory biomedical scientists, one psychologist, and four (3.5 WTE) administrative staff. The limited physiotherapy provision for the scale of the service is a concern.

Key staff members include Consultant Haematologist and co-Centre Directors Dr Catherine Bagot and Dr Ryan Rodgers, as well as Charge Nurse Pamela Wick.

Outpatient care: Currently, there is a weekly bleeding disorder clinic where the medical team reviews both new and routine patients. Additionally, there is a monthly carrier clinic. The service operates from 08:30 to 16:30, Monday to Friday, and has a walk-in, open access policy for patients with bleeding disorders. Within the centre, regular joint rheumatology clinics are held. There is also a joint haematology obstetric clinic every 2 to 3 weeks, where patients with bleeding disorders are

reviewed, including pre-pregnancy counselling. Specialised psychological support is located on the NHS Lothian site and is provided in person as a Scottish-wide service.

Inpatient care: There are no dedicated haematology beds or direct admitting rights in the GRI. Patients presenting to the Centre can be admitted through the local medical or surgical team as required. Acute admissions are managed by the local hospital teams with support from the Service. Elective surgical procedures are facilitated through GRI if possible, depending on the procedure or speciality, as well as the severity of the bleeding disorder.

Out of hours: Out of hours, an on-call haematology team covers patients with bleeding disorders for the West of Scotland.

Transition: Transition clinics are held with staff from the paediatric haemophilia centre.

Network arrangements: The Service is part of the Scottish Inherited Bleeding Disorders Network (SIBDN). SIBDN aims to ensure equal access to information and treatment across Scotland for patients with inherited bleeding disorders and their families at all stages of the patient pathway, from childhood to adulthood. It supports the provision of a high-quality service across Scotland, underpinned by evidence-based, professionally developed, and agreed clinical pathways and guidance. Additionally, it seeks to promote good practice in multidisciplinary and integrated working both within the network and its associated services.

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 22 out of the 30 standards, with five partially met and three unmet. The Service has outstanding findings from their previous peer review report in similar areas, which are provided in the appendix. The service is encouraged to review all descriptive assessments in addition to the key findings. This report, alongside local assessments, should steer discussions with the management team, highlighting areas of good practice while emphasising where further investment and improvement may be required.

Standard	Title of standard	Rating
1	Service Information	
2	Condition-Specific Information	
3	Plan of Care	
4	Outpatient Review of PwBD	
5	Contact for Queries and Advice	
6	Haemtrack (PwBD on Home Therapy	
7	Environment, Facilities and Equipment	
8	Transition to Adult Services and Preparation for Adult Life	
9	Carers' Needs	
10	Involving PwBD and Carers	

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. The feedback from the specialist registrar provided at the meeting indicated an excellent training programme for haemophilia and bleeding disorders.
2. Participation in and leadership of the SIBDN affords opportunities for developing services not only in the West of Scotland but also nationally in Scotland.
3. ED praised the excellent working relationship between the ED and the Haemophilia Centre.
4. The laboratory service is well led by a knowledgeable clinical scientist and provides an excellent regional specialist service.
5. The joint haematology obstetric service is of very high quality. The consultant haematologist and the consultant obstetrician see all patients together.
6. Extensive relevant participation in key clinical trials has been noted. The experience of the centre in gene therapy trials has led to its designation as the gene therapy hub for Scotland.

4.3 Immediate risks

There were no immediate risks identified.

4.4 Concerns

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

1. The review team expressed concern regarding the inadequate physiotherapy provision currently offered by 0.15 WTE, which is completely insufficient for the service's size. This level of provision fails to allow even the most basic monitoring of all patients registered with severe haemophilia. Physiotherapy plays a vital role within any haemophilia service due to the musculoskeletal complications associated with the disease. The provision should be appropriate for the size of the service. This issue was highlighted during the last peer review in 2019 and has yet to be addressed.
2. The current nursing staffing for a centre of this size is inadequate. The pressure on the nursing team continues due to the recent retirement of the deputy charge nurse. Newly recruited nurses in specialist roles take considerable time to acquire the skills, knowledge, and confidence of their more experienced colleagues. During this period, the burden on the rest of the team is significant, leading to periods of risk when experienced staff are absent or on leave. It was noted that the nursing team does not comply with the expected National Standard for Haemophilia Nurse Education. They lack the necessary support to complete adequate continuing professional development, which is essential to their roles.
3. The current number of consultants and their contributions are also low relative to the size of the service. Two new consultant positions have been approved and will be advertised soon.
4. The review team noted that several documents and guidelines were either undated or outdated. Although these documents may have been reviewed, there was no evidence to support this claim, and it did not seem that any systematic document control system was in place to indicate the version number and last review date.
5. There was no evidence of any audit of local key performance indicators, although some were reportedly in development by the Network. It was unclear what local governance structures were established for the Service. No patient satisfaction surveys were available for review. All of this reflects the staffing shortages across the multidisciplinary team.

4.5 Recommendations

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

1. **Physiotherapy Provision:** The review team recommends that the physiotherapy provision be increased to support the existing physiotherapist as soon as possible. Physiotherapy is a key component of Comprehensive Care for Haemophilia due to the musculoskeletal complications associated with the disease. Enhancing physiotherapy provision should be made an immediate priority. The scale of this adult service and the complexity of the patient caseload of over 100 with Severe/Moderate haemophilia alone would suggest that at least 1 WTE physiotherapist, in the first instance, should address all of the acute and chronic care needs and develop the service.
2. **Nursing staffing:** The review team recommends an urgent assessment of the nursing skill mix to determine the appropriate staffing levels for a service of this size and complexity. Nursing plays a pivotal role in Bleeding Disorder Care and serves as the first clinical point of contact for patients and their families. The entire nursing team needs to be adequately

supported to achieve their CPD and the National Standard of Education for Haemophilia/Bleeding Disorders Nursing as a priority.

3. **Consultant medical staffing:** The review team recommends that the Trust work with the service to increase staffing to a level appropriate for its size and the number of patients.
4. **Documentation:** The review team recommends that the service review and implement an appropriate document control process. This is important because, without effective document controls, there is a risk that an out-of-date guideline could be used, which may adversely affect patient treatment.
5. **Governance:** A rolling local clinical audit process needs to be developed. Local Key Performance Indicators should be identified, and a robust reporting system should be established to ensure learning alongside an appropriate action plan in response to critical incidents. Although it is suggested that the Network will undertake some of this work, it does not replace the necessity for a strong local system of clinical governance.

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	
Well-written, succinct information about the service was available. Although clinic times were not found, all other relevant information was available.	

Quality Standard 2: Condition-Specific Information

Standard Met

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

a. A description of their condition and how it might affect them
b. Problems, symptoms, and signs for which emergency advice should be sought
c. Genetics of Inherited Bleeding Disorders
d. Testing for carrier status and the implications of being a carrier
e. Treatment options including on-demand, prophylaxis, home therapy and the use of Haemtrack
f. How to manage bleeding at home
g. Ports, fistulae, and in-dwelling access devices (if applicable)
h. Approach to elective and emergency surgery
i. Women's health issues
j. Dental care
k. Travel advice
l. Vaccination Advice
m. Health promotion to include smoking cessation, healthy eating, weight management, exercise, alcohol use, sexual and reproductive health, and mental and emotional health and well-being
n. Sources of further advice and information

Condition-specific information should be available covering:

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

How the Service meets or does not meet the standard

The waiting area in the Haemophilia Centre featured a wide range of patient information leaflets, including the "blue leaflet" (SIBDN), which provided very good condition-specific information.

Quality Standard 3: Plan of Care

Partially 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

Partially met because patients do not routinely have a copy, and the plan did not cover all aspects a-g.

Quality Standard 4: Outpatient review of PwBD

Partially Met

A formal review of PwBD should take place regularly:

a. For those with severe and moderate haemophilia, any PwBD on prophylaxis and other severe bleeding disorders at least twice a year. This may be more frequent in the paediatric setting based on clinical needs.

   The following multidisciplinary clinic arrangements for these PwBD should be in place:
   i. Involvement of medical, specialist nursing and physiotherapy staff in clinics
   ii. Availability or clear referral pathway for social work and psychology staff

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

This review should involve the PwBD and, where appropriate, their carer.
The outcome of the review should be communicated in writing to the PwBD and their GP.

How the Service meets or does not meet the standard

MDT clinics were recently established, but there was no regular physiotherapy input to these clinics (see staffing and skill mix).

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

Patients have open access to the service through daytime contact numbers for centre staff, a walk-in service during the centre's normal working hours, and an out-of-hours service to the haematology doctor on call.

Quality Standard 6: Haemtrack (PwBD on Home Therapy)

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

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

Standard Met

How the Service meets or does not meet the standard

Haemtrack use is encouraged. An improvement graph on Haemtrack use was provided.

Quality Standard 7: Environment, Facilities and Equipment

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

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

a. Fridges
b. storage
c. Clinical rooms for staff of all disciplines to see PwBD and carers with adequate space for physiotherapy assessment
d. Room for multidisciplinary discussion
e. Room for educational work with PwBD and carers
f. Office space for staff
g. Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all relevant clinical areas
h. Access to adequate IT equipment with clinical systems

All equipment should be appropriately checked and maintained.

Standard Met

How the Service meets or does not meet the standard

The haemophilia centre is easily accessible as a ground-floor building near one of the main entrances of Glasgow Royal Infirmary.

The accommodation is spacious, with a pleasant waiting area, and the clinic rooms are well-equipped and of a good size. There is a large room for staff multidisciplinary meetings, and the centre has good IT facilities. Nursing staff and admin staff are based in the centre.

Consultant staff have offices in another hospital building some distance from the centre. Since the retirement of the associate specialist who was based in the centre, some issues at times regarding the immediate availability of medical staff have been addressed by establishing PGDs for nursing staff to administer coagulation factor products.

There are no dedicated in-patient beds or admitting rights. While this may seem suboptimal at first, the system works well due to good colleague relationships, and there are no difficulties obtaining in-patient beds for PwBD.

The factor storage facilities in the blood bank appear a little cramped.

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

Transition clinics are held with staff from the paediatric haemophilia centre. A transition guideline was available. A possible improvement would be making this available through a shared portal that is in use.

A suggested addition is an SOP for the management of young people going to university.

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

This was comprehensive and considered very good.

Quality Standard 10: Involving PwBD and Carers

The Service should have:

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

Standard Met

How the Service meets or does not meet the standard

There is a Scottish-wide meeting between haemophilia professionals and patients. The SIBDN (Scottish Inherited Bleeding Disorders Network) has patient involvement. The review team felt it would be helpful to formalise the selection of a patient representative for the West of Scotland Haemophilia Centre.

Quality Standard 11: Leadership team

The leadership team will consist of a lead consultant, and other members agreed at a local level. This may include nurses, physiotherapists and psychologists, clinical scientists, or other members of the MDT. The lead consultant will be responsible for staff training, guidelines and protocols, service organisation, governance and liaison with other Services but may delegate some of these roles to others in the leadership team.

The leadership team should all be registered healthcare professionals with appropriate specialist competences, undertake regular clinical work with the Service, and have specific time allocated for their leadership role.

Standard Met

How the Service meets or does not meet the standard

There is a strong, hard-working leadership team.

Note that neither the co-directors nor the lead nurse have dedicated time to their job plans for their leadership roles. Dr Rodgers is the clinical lead for the SIBDN, and no dedicated time is available for this role.

It was also felt that the banding of the lead nurse might benefit from a review to reflect the considerable responsibilities in a large Comprehensive Care Haemophilia Centre covering the whole geographical area of the West of Scotland.

Quality Standard 12: Staffing levels and skill mix

a. Sufficient staff with appropriate competences should be available for outpatient, day unit and in-patient care and support to urgent care services. Staffing levels should be appropriate for the number of PwBD cared for by the Service and its role in the network.
b. All staff should undertake regular continuing professional development that is relevant to their work in the inherited and acquired bleeding disorders services.
c. Staff working with children and young people should have competences in caring for children as well as in the care of people with bleeding disorders. Cover for absences should be available.

Partially Met

d. In HCCCs, these staff should have sessional time allocated to their work with the IABD service. In HCs, the arrangements for accessing staff who do not have sessional time allocated to the IABD service should be clearly defined.

Staffing should include:

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

How the Service meets or does not meet the standard

There are several staffing gaps detailed below.

Physiotherapy coverage is not adequate, with only 0.15 WTE of physiotherapists available, which is grossly inadequate. An MSK physiotherapist based in rheumatology is available ad hoc, but they are not part of regular multidisciplinary teams.

The consultant establishment is currently lean, but two new posts have been approved, and they will go to the advert soon. The consultant on-call rota relies on two consultants whose regular duties outside of on-call do not include working in the haemophilia and bleeding disorders service.

Psychology service (Scotland-wide but provided in person and equitable across the patch) is considered excellent.

The nursing establishment is also relatively lean, and there are current pressures as the deputy charge nurse recently retired. There is access to a social worker, but this is not a dedicated role.

Quality Standard 13: Service Competencies and Training Plan

Partially 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

Two of the current nurses have only completed the introductory bleeding disorders course due to staffing pressures. The lead nurse has had limited opportunities for external CPD such as attendance at international conferences. Consultant appraisals and CPD were documented, but the last appraisal documented for a consultant who contributed only out of hours appeared to be out of date. Feedback from the specialist registrar who attended the review meeting indicated that excellent SpR training is in place.

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

3.5 WTE admin, data and clerical staff, including the Operational Manager. Data staff also contribute to clinic admin.

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 relevant to adults are available.

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

Alerts are in operation. Patient feedback on emergency care has taken place.

The ED consultant provided excellent feedback on the service provided to the ED by the haemophilia team.

Quality Standard 17: Laboratory Service

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

Standard Met

How the Service meets or does not meet the standard

The specialist coagulation laboratory service, led by a dedicated clinical scientist, is excellent, and the team clearly takes pride in this.

There is also evidence of integration with the clinical service.

Evidence of UKAS accreditation and participation in UKNEQAS for Coagulation was provided.

The genomic laboratory service is provided from Edinburgh. There are ad hoc MDTs with the genomics lab scientists.

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

There is an excellent joint haemostasis obstetric clinic, and arrangements for dental care and oral surgery are of a high standard with clear evidence of collaborative working.

There are also excellent and long-standing arrangements for joint care between rheumatology and haemophilia. There is good liaison with hepatology. There is not a dedicated pathway for older people, but there is access to older people's medicine service and access to HIV services

Both Dr Bagot and Dr Rodgers provide monthly carrier clinics.

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

Dr Bagot demonstrated the electronic patient record during the visit. There is access to HCIS and NHD.

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

Not 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

The guidelines made available to the reviewers for diagnosis were national UKHCDO guidelines.

There was no information provided as to how these are adopted and used within the Haemophilia Centre, so the review team considered that this standard was not met.

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

All of the listed guidelines (locally adapted) were available apart from a) iv: non-factor replacement therapy

Quality Standard 22: Clinical Guidelines/Pathways

The following clinical guidelines/pathways should be in use:

a. Management of acute bleeding episodes, including PwBD with inhibitors
b. Immune tolerance therapy
c. Dental care
d. Care of PwBD with hepatitis C
e. Care of PwBD with HIV
f. Antenatal care, delivery, and care of the neonate
g. Management of synovitis and target joints
h. Long-term surveillance of musculoskeletal health
i. "For public health purposes": care of PwBD at risk of vCJD who are undergoing surgery

Partially Met

How the Service meets or does not meet the standard

There are guidelines/pathways available on dental care, care of PwBD with hepatitis C, antenatal care, delivery, management of synovitis and target joints, and care of PwBD at risk of vCJD who are undergoing surgery. No guidelines were provided to the reviewers for the management of acute bleeding in people with inhibitors or immune tolerance therapy. No guidelines were provided on long-term surveillance of musculoskeletal health nor for care of PwBD with HIV.

Quality Standard 23: Guidelines on Care of PwBD requiring Surgery

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

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

Standard Met

How the Service meets or does not meet the standard

Guidance for the management of surgery and surgical plans was available. Noted that forthcoming surgical procedures were discussed at the weekly planning meeting.

Quality Standard 24: Service Organisation

The Service should have an operational procedure covering at least:

a. Ensuring all children who are in-patients have a named consultant paediatrician and a named haematologist with expertise in caring for PwBD with inherited and acquired bleeding disorders responsible for their care

Standard Met

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

All aspects of this standard that pertain to an adult service were met. This centre covers a vast geographical area, and telephone clinics are appropriately used to meet standards of care for follow-up, especially when patients live remotely.

There is a significant rate of non-attendance, and the policy covers the issuing of DNA letters.

Multidisciplinary planning meetings have been recently established as part of the service organisation.

Quality Standard 25: Multidisciplinary Team Meetings

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

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

Standard Met

How the Service meets or does not meet the standard

Multidisciplinary team "planning" meetings occur weekly. These are relatively recently established, and the review team felt this was very positive.

Quality Standard 26: Multidisciplinary Clinics/Liaison Services

Combined clinics or other arrangements for multidisciplinary discussion with

a. Orthopaedics and or rheumatology
b. Obstetrics and gynaecology
c. Paediatrics

Standard Met

d. HIV e. Hepatology	
How the Service meets or does not meet the standard	
Multidisciplinary clinics are held with rheumatology, obstetrics, and transition clinics with the children's haemophilia service. There are close links with hepatology. The arrangements for liaison with HIV are more ad hoc.	
Quality Standard 27: Data Collection	
The following data should be collected: a. UK National Haemophilia Database data on all PwBD b. Data on concentrate use and bleeds, either through Haemtrack or an equivalent mechanism c. Data required to complete the NHS E National Haemophilia Dashboard or other national mechanisms d. Adverse events reported to NHD	Standard Met
How the Service meets or does not meet the standard	
Note that the Haemophilia dashboard does not apply to Scottish Centres. The Glasgow CCC submits data to NSD when requested to do so.	
Quality Standard 28: Research	
The Service should actively participate in research relating to the care of PwBd with bleeding disorders. The Service should also offer links with other services to maximise research study opportunities. Staff members participating in research should be allocated appropriate time for this role.	Standard Met
How the Service meets or does not meet the standard	
This is an area of excellence. Evidence of participation in 7 clinical studies, including gene therapy studies, studies on Fitusiran, and Serpin C for haemophilia.	
Quality Standard 29: Multidisciplinary Review and Learning	
The Service should have multidisciplinary arrangements for review and implementation of learning from: a. Audit – the Service must have an audit plan, and it must include an audit of emergency and out of hours care (QS 23) b. Positive feedback, complaints, outcomes, incidents and 'near misses' c. Morbidity and mortality d. Haemophilia Dashboard (when relevant) e. Review of UKHCDO Annual Report benchmarking information on concentrate use f. Ongoing reviews of service quality, safety, and efficiency g. Published scientific research and guidance	Not Met

How the Service meets or does not meet the standard	
There was no evidence of any recent specific audits or QI projects. A rolling "audit sheet" is completed as a data collection exercise, originally designed for data submission to NSD, but to date, there has been no return of collated data from NSD for the unit to be then able to action. Formal patient feedback surveys were not available, although the patients who attended the peer review meeting provided very good verbal feedback about the service. A governance structure exists through a "Clinical Haematology Regional Services" meeting, but the senior haemophilia team rarely attend this meeting. Overall, the review team felt that governance structures were not well formalised. The review team felt that pressures of staffing had likely contributed to the difficulty in focussing on this area. KPIs for bleeding disorder services are being reformulated in the SIBDN, but there was no evidence at present of a robust reporting system in place for KPIs at present. Plans in place within SIBDN may help support governance in the future.	
Quality Standard 30: Document Control	
All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Not Met
How the Service meets or does not meet the standard	
Many of the guidelines and documents either were not dated or had dates from some time in the past. Whilst these documents may have been reviewed, there did not appear to be any systematic document control system in place that stated version number and last review date.	

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 2 consultant haematologists, a clinical nurse specialist, a haemophilia research nurse and a patient representative. Details of the Peer Review Team are held by UKHCDO.

7.3 Outstanding findings from previous peer review

The table below provides details of the 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

1a	Nursing: The two nurse specialists together constituted less than one Whole Time Equivalent (WTE), which was not sufficient for a service of this size. A business case had been submitted for an additional Band 6 nurse and if the business care was approved and a nurse was appointed this would bring the team to a more appropriate and sustainable level. Business cases had also been submitted for a number of other nursing posts within the Haematology-Oncology Directorate. A management plan to devolve the decisions to the clinical teams about which of these posts to support was considered unlikely to be productive.
b	Consultant staffing: The Centre director had four sessions for work on bleeding disorders, and the other consultant with a special interest in bleeding disorders had two sessions. This equated to six sessions (0.6 WTE) which was not sufficient. There were complex out-of-hours rotas, covering different sub-specialties, and the two consultants with a special interest in bleeding disorders offered an informal 'second on' back-up for colleagues with less experience in this field. It would be beneficial for some of the other consultant medical staff to consider undertaking some related CPD, to work alongside the haemophilia consultants in clinic and to join MDT discussions to gain the necessary clinical experience. (See also Concern 2 'Out-of-hours telephone advice').
c	Psychology: A clinical psychologist worked in this service one day per month. The contribution of this individual was highly valued, but the psychologist explained that she could only offer some initial intervention with subsequent signposting to other services. The importance of psychology support to children and families was not reflected in this allocation and did not enable fully integrated working with the wider MDT. The funding for this post was also temporary, lasting until the end of the financial year 2019/20 and at the time of the visit there was no plan in place to extend this.
e	Social Work: There was no named social worker to whom the team could make referrals. Although the review team heard that it was not possible to have social workers employed directly by the hospital teams, it would be beneficial to identify one or two named social workers within the existing hospital service who could develop an interest in and understanding of the problems for children and families with bleeding disorders.
f	Clerical support: Administrative and clerical time was insufficient for the requirements of the service. This resulted in nurses spending time making clinic appointments, generating travel letters, photocopying and scanning documents. This further detracted from their limited clinical time.