UKHCDO Peer Review Audit Report: Basingstoke and North Hampshire Haemophilia Comprehensive Care Centre

Report Date: 4 September 2024

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2 Executive summary

The United Kingdom Haemophilia Centre Doctors Organisation (UKHCDO) has systematically conducted peer reviews since 1998 to assess the quality of care provided to patients with bleeding disorders. In accordance with the latest National Service Specifications published in 2013, thirty quality standards have been defined, with new service specifications anticipated (2024/2025). These standards encompass the availability of suitable facilities, adequate staffing for a fully functional multidisciplinary team, appropriate guidelines, and round-the-clock expert clinical and laboratory cover. The most recent peer review cycle was conducted in 2019-20, prior to the onset of the COVID-19 pandemic. The 2024 peer review cycle marks the first such review since the pandemic began.

The peer review working party, which updated the review standard for this cycle had stakeholders from the Haemophilia Nurses Association (HNA), Haemophilia Chartered Physiotherapy Association (HCPA), Haemophilia Psychologist Association (HPA) as well as the Haemophilia Patient Societies of England, Scotland and Wales. A multidisciplinary team including a patient representative conducted the peer review. The findings from the peer review are disseminated to the team, the host organization, local commissioners, and service users and the UKHCDO peer review working party. Furthermore, on completion of the 2024 peer review cycle the data will be analysed to identify systemic issues within the service across the United Kingdom, and the report will be shared with all stakeholders' organisations including the Clinical Reference Group (CRG).

This report presents the outcomes of the peer review for the Basingstoke and North Hampshire Haemophilia Comprehensive Care Centre (The Service), conducted on 1 March 2024. Basingstoke serves as the hub for the Southern Haemophilia Network (SHN) in collaboration with Portsmouth, Bournemouth, Poole, and Salisbury. The service is appropriately staffed, with clear leadership, and able to provide comprehensive care to all patients. The centre employs a distinctive hub-and-spoke model unique within the United Kingdom. This model facilitates weekly virtual multidisciplinary team (MDT) meetings via Microsoft Teams and quarterly in-person meetings, thereby significantly enhancing patient care coordination.

The Basingstoke Centre successfully met 29 out of the 30 established standards, with one standard remaining unmet. The service is unable to use their excellent and dedicated haemophilia centre, which is popular with patients, due to an ongoing issue with the central heating system. The service had to vacate their centre over the winter months as it was too cold for staff and patients to use safely. The service has had to use clinic and office rooms across the hospital, as there is not enough space for the service to work altogether.

Key Recommendations:

1. The review team recommend that the gas pipe fault that is affecting Uplands House is rectified as soon as possible and certainly within 3 months of the review. If the situation cannot be resolved within this timeframe, then the Trust should find alternative accommodation where the Haemophilia team can be altogether in one place.
2. The review team advises that the service team continues to mitigate the possible clinical risks associated with the Centre's isolation within the hospital grounds, in order to protect their patients and themselves.

This report highlights The Services and Hampshire Hospitals Foundation Trust's commitment to providing high-quality care. It identifies specific areas for improvement, aiming to enhance quality of care for patients and achieve service excellence.

3 Introduction

The quality standards that underpin the outcomes of this peer review report are based on the current Haemophilia National Service Specifications 2013. The National Service Specifications set out the expectations of haemophilia comprehensive care in the UK. It acts as a blueprint for comprehensive care best practice.

A peer review is the process of evaluating professional work by others working in or associated with the same field. In other words, it is the assessment of people, processes and procedures against a set of agreed standards. Specifically in this context, a multi-disciplinary team of bleeding disorder professionals and patients assessed a Comprehensive Care Centre (CCC) against the quality standards for the Care of People with Inherited and Acquired Haemophilia and other Bleeding Disorders – v4.0.

In this 2024 round of peer reviews the UKHCDO has been focusing on the 31 CCCs across the UK. A CCC is a centre that typically provides a whole or comprehensive service, including multi-disciplinary team (MDT), access to specialist services, emergency department (ED) or links with a local ED, and transition procedures to or from their service. A CCC can provide care specifically to adult or paediatric patients, with some caring for both age groups. CCCs will generally have a mix of bleeding disorder specialist staff including consultants, clinical nurse specialists, physiotherapists and psychologist or social worker access.

With the peer review process the UKHCDO has three core aims, which are to improve clinical outcomes for patients, to improve service user experiences and to highlight the good practice and hard work of those providing care to PwBD. These aims are not just for individual centres but also for a holistic UK-wide assessment of the care provided to PwBD.

3.1 Peer review process

The service was the first to be reviewed in this 2024 peer review cycle. The review was scheduled for 1st March 2024 and took place onsite at Basingstoke and North Hampshire NHS Foundation Trust, Aldermaston Road, Basingstoke. A multi-disciplinary team of haemophilia professionals along with patient representation conducted the review, which involved speaking to staff from the service, reviewing documentation and a tour of the facilities. The details of the review team can be found in 3.3, each member of the review team completed online training.

This report is the culmination of the review team's observations from that visit. The service has had the opportunity to provide clarification of the points made by the review team to ensure that both parties are satisfied with the findings of this report.

3.2 Acknowledgements

The UKHCDO and the review team would like to thank Basingstoke and North Hampshire CCC for being open and welcoming to the review team on the day, and for their hard work in preparing for the review. We would also like to thank the service users and carers who took time to meet the review team and for the feedback they provided.

The UKHCDO would also like to thank the review team and their employing organisations for granting the time to contribute to this review.

3.3 Peer review team

Name	Centre	Specialism
Dr Mary Mathias	Great Ormand Street Hospital	Consultant Haematologist
Trupti Bhandari	Evalina London Children’s Hospital	Paediatric Physiotherapist
Dr Emily Symington	Cambridge University Hospital	Consultant Haematologist
Kathleen Corcoran	University Hospital of Wales – Cardiff	Clinical Nurse Specialist
Nigel Millar	Haemophilia Society Wales	Patient Representative
Sarah Stevenson	University Hospital of Wales - Cardiff	Paediatric Clinical Nurse Specialist
Dr Priyanka Raheja	Royal London Hospital	Consultant Haematologist

4 Background

The Service provides care to both adults and children with bleeding disorders and has 1182 registered patients. It is based in Uplands House, a detached building on the edge of the Basingstoke and North Hampshire Hospital site. The ground floor consists of reception, waiting room and clinic rooms whilst upstairs houses office space for both haemophilia and thrombosis staff. Additional office space is available at Vickers House.

The Service offers all aspects of holistic comprehensive care as described in the National Service Specification B05/S/a with full time Consultants in Haemostasis & Thrombosis supported by very experienced, highly skilled specialist nurses, allied health professional team and healthcare scientists**.**

The service employs 18 professionals, including 3 consultants, 4 nurses, 2 physiotherapists, 2 psychologists, 2 biomedical scientists and 4.8 administrative staff. This blend of full and part-time roles ensures comprehensive patient care is provided. Key staff include Consultant Haematologist and Centre Director Dr Sarah Mangles and Lead Clinical Nurse Specialist Lara Oyesiku.

The Service is Consultant-led and operates from 9am-5pm on weekdays with consultant-led on-call advice available 24 hours a day as described below**.**

The Service is part of the Southern Haemophilia Network (SHN), which is a clinical network providing care for patients with Haemophilia and other inherited bleeding disorders in Basingstoke, Portsmouth, Bournemouth, Poole and Salisbury. It is funded as a network by specialist commissioners and North Hampshire Haemophilia CCC is the hub. SLAs were in place at the last peer review, and the service is in the process of updating these to reflect the changes to staffing, increased clinics and to give clarity on activity, funding, and responsibilities. The service's aim is to provide comprehensive care close to the patient's home where possible and centrally where necessary.

The SHN team has a network director, deputy director, lead nurse, lead physiotherapist, lead psychologist (shared role) and operational manager.

The service has shared clinical guidelines for investigation of possible bleeding disorders and management of those with inherited bleeding disorders. These have been adopted across all trusts. The service has the same on call rota across the network out of hours which is currently 1 in 4 with a plan to increase to 1 in 5 over the next year (dependent on successful recruitment to consultant job at UHD) with a further increase to 1 in 6 planned. Pathways are in place at each site for urgent access to treatment.

A weekly MDT using Microsoft teams happens every Monday. This includes review of all in-patients, complex out-patients, newly diagnosed patients for registration, management of planned surgery or obstetric deliveries and to review the psychosocial needs of patients as well reporting of Adverse events. On the 3rd Monday of the month this is a regional maternity medicine MDT led by obstetric medicine team at UHS.

4.1 Patient numbers

Number of patients	Condition							
	Haemophilia A		Haemophilia B		Von Willebrand		Other	
	Adults	Children	Adults	Children	Adults	Children	Adults	Children
Severe	62	25	7	3	298	56	446	70
Moderate	21	7	5	1				
Mild	132	25	20	4				
Annual review in the last year	171	57	19	8	236	48	250	53
In-patient admissions in the last year	11	5	0	0	12	3	8	1

The table above shows the number of patients registered at the service and the severity of their bleeding disorder. It also shows the number that have attended an annual review in the last year as well as in-patient admissions in the last year.

4.2 Staff numbers

Number of staff by role			
Role	WTE employed by HHFT *	Additional WTE funded at network sites	Total WTE funded by SHN
Consultants	2.7	0.4	3.1
Physiotherapists	1.1	0.4	1.5
Nurses	4.6	0.8	5.4
Biomedical Scientists	1.6	0	1.6
Clinical Psychologist	1.4	0	1.4
Admin/ Clerical staff	2.8	1.4	4.2

The information in this table shows the number of staff that are directly employed by the service, the number with a * denotes the staff who may work across the network. The networked staff may move around the network area or be based at different locations part time.

5 Findings

5.1 Good practice

The following is a breakdown of the good practice that is in evidence at Basingstoke:

- In the usual course of business (see main concern) the Haemophilia service is based at Uplands House, which is located on the wider hospital site. Uplands House is a positive space that offers PwBD a place to access their care, which is not a typical 'hospital' environment. Uplands House was highly praised by the patients who spoke to the review team.
- The Southern Haemophilia Network (SHN) provides a gold standard for availability of all members of the MDT but is particularly notable for its access to Psychology support for all Patients at hub and spokes. This is a huge achievement and is clearly highly valued both by the other team members and all the patients and families, underscoring the vital role of Psychology support for patient and families with Bleeding Disorders.
- Patient feedback has led to the introduction of QR codes in the clinic area, which is linked to an age-appropriate questionnaire, this is used pre-clinic to highlight any issues or questions the family would like to discuss.
- Transcripts of the answerphone messages were provided to the review team, which provide a clear and easy to follow message to patients and families. This helps them to understand which team member will be picking up the message. The on-call service gives patients and parents direct access to a consultant specialising in bleeding disorders.
- The review team saw that all clinic letters are written to the patients and families and copied to the GPs, rather than the converse. Feedback from families to the review team suggests that this is a positive change, allowing PwBD to feel more included in their care.
  - The data manager and team have done an outstanding job of coordinating data collection and prescribing for the whole network despite very significant current technical limitations.
  - The research portfolio of the SHN would be admirable at a CCC attached to a Tertiary hospital but is outstanding in the context of Basingstoke. The teams are commended for engaging in this high-level of research, which allows their patients to have early access to new treatments for bleeding disorders.

5.2 Immediate risks

There were no immediate risks identified.

5.3 Concerns

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

1. The Haemophilia service at Basingstoke is based in Uplands House, a standalone building in the grounds of the hospital. However, since January 2024 the service has had to move out of Uplands House due to a fault in the central heating system, and whilst efforts were made to keep the building warm using electrical heaters the service was not able to keep the building warm enough for patients and staff to use. There has been a significant delay in repairing the gas supply fault due to a legal dispute concerning the land ownership of where the damaged gas pipe is located. This is a critical finding, and the review team agrees that the situation needs to be resolved so that the service can move back into Uplands House by the end of May 2024. The review team would like to add that if the situation cannot be resolved before the end of May 2024, then the Trust should find alternative accommodation where the Haemophilia team can be altogether in one place.

2. Whilst the location of Uplands House is part of its appeal, that it does not feel like a typical hospital environment, and therefore a positive for patients and carers, the review team advise that the service team continues to mitigate the possible clinical risks associated with the Centre's isolation within the hospital grounds, in order to protect their patients and themselves.

Overall, the service has met 29 out of the 30 standards, with one standard remaining unmet. The service does not have any outstanding findings from their previous peer review report.

Please note that these findings are designed to support the centre in establishing areas where improvements can be made and should be used as the basis for ongoing improvement programs. Centres can use this report as part of discussions with management to show not only where good practices have been observed but also to highlight areas where investment and investment may be needed.

5.4 Recommendations

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

1. The review team recommend that the gas pipe fault that is affecting Uplands House is rectified as soon as possible and certainly within 3 months of the review. If the situation cannot be resolved within this timeframe, then the Trust should find alternative accommodation where the Haemophilia team can be altogether in one place.
2. The review team advises that the service team continues to mitigate the possible clinical risks associated with the Centre's isolation within the hospital grounds, in order to protect their patients and themselves.

6 Quality standards evaluation

The UKHCDO (UK Haemophilia Centre Doctors Organisation) Peer Review Working Group have developed the quality standards for the Care of People with Inherited and Acquired Haemophilia and Other Bleeding Disorders – v4.0. These standards are designed to ensure consistency and quality of care for patients and careful consideration has been made to provide a wide coverage of quality aspects.

The Peer Review Working Party is a group of bleeding disorder professionals and patients, whose objective is to provide guidance and direction to the peer review process. The group comprises consultants, nurses, physiotherapists and psychologists and stakeholder in put from the Haemophilia professionals' associations of Haemophilia Nurses Association (HNA), Haemophilia Chartered Physiotherapists Association (HCPA) and the Haemophilia Psychology Association (HPA). The working party also has patient and carer representation from the Haemophilia societies of England, Scotland and Wales.

A report is produced for each peer review audit and sets out how each centre has complied or not complied with each of the quality standards. The report will highlight good practice as well as any immediate risks to patients. It is then the responsibility of the centre to rectify, as best it can, any issues that have been identified. At the culmination of the 2024 peer review process, the data from all reports will be analysed and compiled into one overarching report that will identify the trends and key issues across the UK. This report will be shared with all stakeholders as well as the Clinical Reference Group (CGR).

6.1 Definitions

Reference	Reference number for quality standard
Quality Standard	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 documented or from auditors observing practices.
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 please state any good or best practice witnessed, this should be supported with evidence.

6.2 Overview of standards

See the below table for an overview of how many standards the service has met (green), partially met (yellow) and not met (red). In 6.3 each standard has been listed in full along with the notes from the review team.

Standard	Title of standard	Rating	Page number
1	Service Information	🟩	11
2	Condition-Specific Information	🟩	12
3	Plan of Care	🟩	13
4	Out-Patient Review of PwBD	🟩	14
5	Contact for Queries and Advice	🟩	15
6	Haemtrack (PwBD on Home Therapy	🟩	16
7	Environment, Facilities and Equipment	🟥	17
8	Transition to Adult Services and Preparation for Adult Life	🟩	18
9	Carers' Needs	🟩	19
10	Involving PwBD and Carers	🟩	20
11	Leadership Team	🟩	21
12	Staffing Levels and Skill Mix	🟩	22
13	Service Competencies and Training Plan	🟩	23
14	Administrative, Clerical and Data Collection Support	🟩	24
15	Support Services	🟩	25
16	Emergency Department	🟩	26
17	Laboratory Service	🟩	27
18	Specialist Services	🟩	28
19	IT System	🟩	29
20	Diagnosis Guidelines for People with Suspected IABD	🟩	30
21	Guidelines: Treatment and Monitoring of IABD	🟩	31
22	Clinical Guidelines/ Pathways	🟩	32
23	Guidelines on Care of PwBD requiring Surgery	🟩	33
24	Service Organisation	🟩	34
25	Multi-Disciplinary Team Meetings	🟩	35
26	Multi-Disciplinary Clinics/ Liaison Services	🟩	36
27	Data Collection	🟩	37
28	Research	🟩	38
29	Multi-Disciplinary Review and Learning	🟩	39
30	Document Control	🟩	40

6.3 Standards

Ref	**1**
Quality Standard	
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. i. 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	
The Centre have a patient information leaflet which signposts their service and all the points in this QS. It welcomes feedback and there is excellent evidence of 'You said, we did' responses to patient and family feedback.	

Ref	**2**

Quality Standard

Condition-Specific Information

Written and or online information should be available and offered to PwBD and, where appropriate, their carers covering:
a. A description of their condition and how it might affect them #
b. Problems, symptoms, and signs for which emergency advice should be sought.
c. Genetics of inherited bleeding disorders
d. Testing for carrier status and the implications of being a carrier.
e. Treatment options including on demand, prophylaxis, home therapy and 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 to 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

Standard Met

How the service meets or does not meet the standard

Good evidence for this information being available on the SHN website and in booklet form for families, both in the centre information booklet and in condition specific form.

Ref	3

Quality Standard

Plan of Care

Each PwBD and, where appropriate, their carer should discuss and agree 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 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 to relevant other services involved in their care.

Standard Met

How the service meets or does not meet the standard

The review team saw examples of anonymised patient letters covering all the elements with clear contact information and when the next clinic appointment was planned.

Ref	4

Quality Standard

Out-patient review of PwBD

A formal review of PwBD should take place regularly:

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 need.
The following multi-disciplinary clinic arrangements for these PwBD should be in place:
a. Involvement of medical, specialist nursing and physiotherapy staff in clinics
b. Availability or clear referral pathway for social work and psychology staff

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

Standard Met

How the service meets or does not meet the standard

Dr Mangles presented data including the proportion of severe patients who had been reviewed at least annually (100%). All MDT clinics involve, a physiotherapy, psychology, nursing, and medical review. The network has a pathway for follow-up depending on severity of the disorder. They have captured their DNA rates and have a template letter to send to patients who have not attended appointments. All the documents seen are shared throughout the network. In discussions with team members, the review team heard further information about school and home visiting (both for home training with children and for vulnerable adults).

Ref	**5**
Quality Standard	
Contact for Queries and Advice 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 is not immediately available for non-urgent enquiries, then the timescales for a response should be clear.	
Standard Met	
How the service meets or does not meet the standard	
Contact information for the centre teams are available on all the paperwork sent to families. The medical team hold a phone during working hours (usually with the SpR), which is then taken over by the on-call consultant out of hours. Families have direct access to this number.	

<table>
<tr><td>Ref</td><td>6</td></tr>
<tr><td colspan="2">Quality Standard</td></tr>
<tr><td colspan="2">Haemtrack (PwBD on Home Therapy)

All PwBD on home treatment should be encouraged to use electronic recording of their treatment through Haemtrack. Use should be documented in clinic letters/ plan of care.</td></tr>
<tr><td colspan="2">Standard Met</td></tr>
<tr><td colspan="2">How the service meets or does not meet the standard</td></tr>
<tr><td colspan="2">Haemtrack flyers are very visible within the centre. The nursing team check Haemtrack each week and it’s reviewed at regular clinic appointments. They sent everyone a letter outlining the new version of Haemtrack.</td></tr>
</table>

Ref	**7**

Quality Standard

Environment, Facilities and Equipment

The environment and facilities in out-patient 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 multi-disciplinary 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.

Not Met

How the service meets or does not meet the standard

Whilst the review team were able to visit the Haemophilia Centre (Uplands House), which is a standalone building in the grounds of the hospital site, the service had to move out of the building in January 2024 due to a fault with the central heating. Despite the best efforts of the team, they were not able to sufficiently heat the building and so the decision was made to move out on the grounds of patient and staff safety and wellbeing. There has been a very significant delay in repairing the broken gas supply fault due to a legal issue concerning the ownership of the land in position of the damaged gas pipe. This is a critical finding as the reviewers agree that the situation needs resolving so that the service can move back into Uplands House by the end of May 2024.

Or, if the situation cannot be resolved then then the Trust must find alternative accommodation where the Haemophilia team can be together in one place.

The review team would like to make a comment about the Haemophilia services returning to Uplands House. Namely that the service continues to mitigate the possible clinical risks associated with the service’s isolation within the hospital grounds. The service is very much aware of these risks and have appropriate resuscitation equipment onsite. They have also made arrangements to avoid situations of potential risk by giving first doses of factor concentrates or DDAVP in other parts of the hospital. The service also communicates to patients and parents that they should attend A&E with any clinical concerns which would not be appropriate to manage in the centre.

<table>
<tr><td>Ref</td><td>8</td></tr>
<tr><td colspan="2">Quality Standard</td></tr>
<tr><td colspan="2">Transition to Adult Services and Preparation for Adult Life

Young people approaching the time when their care will transfer to adult services should be offered:
a. Information and support on taking responsibility for their own care.
b. The opportunity to discuss the transfer of care with paediatric and adult services.
c. A named coordinator for the transfer of care.
d. A preparation period prior to 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</td></tr>
<tr><td colspan="2">Standard Met</td></tr>
<tr><td colspan="2">How the service meets or does not meet the standard</td></tr>
<tr><td colspan="2">The review team saw evidence of the hospital and SHN Transition pathways. Anonymised clinic letters demonstrated clinic discussion of transition. Teenagers are encouraged to use QR codes at clinic appointments which link to questionnaires giving them an opportunity to explore any questions or concerns they might have. This can also be completed on paper if they prefer and is a tool to aid discussion, rather than something to be stored in the patient record. The ‘Ready, Steady, Go.’ template is in use within the SHN and there are named Transition coordinators for each patient at the hub and spokes of the network.</td></tr>
</table>

Ref	**9**
Quality Standard	
Carers' Needs Carers should be offered information on: a. How to access an assessment of their own needs b. What to do in an emergency c. Services available to provide support.	
Standard Met	
How the service meets or does not meet the standard	
The SHN has an information leaflet specifically for carers and posters offering contact for support for all the centres, including access to psychology support.	

Ref	**10**
Quality Standard	
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	
All the SHN leaflets include requests for patient/family feedback. The review team saw evidence of 'You said, we did' communication, most notably including the introduction of QR codes in the clinic area, which is linked to an age-appropriate questionnaire. These questionnaires are used pre-clinic to highlight any issues or questions the family would like to discuss.	

Ref	**11**
Quality Standard	
Leadership team The leadership team will consist of a lead consultant and other members agreed at a local level. This may include nurse, physiotherapist and psychologist, clinical scientist, or other members of the MDT. The lead consultant will be responsible for staff training, guidelines and protocols, service organisation, governance and for liaison with other service but may delegate some of these roles to others in the leadership team. The leadership team should all be registered healthcare professional with appropriate specialist competences and should 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	
Review team saw minutes from Leadership meeting, which evidenced that an effective leadership team is in place. Leadership team includes a nurse who is appropriately banded at level 8a for their leadership duties.	

Ref	12

Quality Standard

Staffing levels and skill mix

a. Sufficient staff with appropriate competences should be available for out-patient, day unit and in-patient care and for 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 of relevance 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 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, out-patient, 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 detail on the requirements are included inQS 17)

Standard Met

How the service meets or does not meet the standard

The review team noted that the SHN provides a gold standard for the availability of all members of the MDT but is particularly notable for its access to Psychology support for all patients with bleeding disorders at hub and spokes.
Staffing levels are sufficient for the number of patients cared for by Basingstoke, with good levels of nursing, consultant, physiotherapist, and psychologist staff available. There is also a referral pathway to a social worker.
From conversations with staff on the day, Continuous Professional Development (CPD) is not only happening but is actively supported and encouraged.

Ref	**13**

Quality Standard

Service Competencies and training plan

a. All staff 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 opportunity to attend introduction to bleeding disorders course and the contemporary care course, provided by the Haemophilia Nurses Association
d. All specialist clinical staff to have opportunity to attend national and/or international conferences and to develop subspecialist interests.

Standard Met

How the service meets or does not meet the standard

The review team saw evidence of mandatory training at over 60 per cent. Conferences and courses attendance evidenced with a good mix of nursing, medic, and physiotherapist attendance. CPD is discussed in AHP meeting, physiotherapist is being given time to complete her PhD as well as time for research.
There is a clear culture of supporting and encouraging research and CPD.

Ref	**14**
Quality Standard	
Administrative, Clerical and Data Collection Support Dedicated administrative, clerical and data collection support should be available.	
Standard Met	
How the service meets or does not meet the standard	
There is dedicated administrative and data collection roles in place. The review team commend the data manager and their team for the outstanding work they do to coordinate data collection and the managing of home delivery and prescribing for the whole network, despite significant technical limitations. The introduction of HCIS V2 should help facilitate data collection and managing home delivery further.	

Ref	**15**
Quality Standard	
Support Services Timely access to the following support services should be available: a. Play support (children's services only) including: i. Play and distraction during any painful or invasive procedures ii. Play support to enable the child's development and well-being. b. Pharmacy c. Dietetics d. Occupational Therapy e. Orthotics/podiatry	
Standard Met	
How the service meets or does not meet the standard	
The network team have access to all support services mentioned in the quality standard when needed. After discussion with the review team, Pharmacy service across SHN does not have capacity to be involved in Haemophilia Homecare. Homecare is provided by Sciensis and Polar Speed but is organised by the data manager and team (see QS 14).	

Ref	**16**

Quality Standard

Emergency Department

Guidelines on 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 annual basis.

Standard Met

How the service meets or does not meet the standard

The SHN team have developed a 'Red box' system where all the hospital areas where their patients may have contact, including the Emergency Department (ED), have a box containing information about care of PwBD and all relevant contact numbers for the team. These boxes were clearly accessible and well known to the teams in the ED and were witnessed by the review team in person in different departments as well as the ED. Patient information leaflets also clearly signpost how to access emergency care in and out of hours. ED and Paediatric teaching slides were evidenced by the review team.

Evidence of audits in the ED having taken place (2019 and 2023), with Covid meaning an audit of the ED not being possible in the intervening period. The data from 2023 audit is awaiting analysis, the review team would recommend that 2023 audit data is processed as soon as possible so that outcomes can be taken forward in the 2024 audit.

Ref	17

Quality Standard

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 multi-disciplinary 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. 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 laboratory is UKAS accredited.
Genetics samples are sent to the regional genetics service at Oxford. Other than genetics testing only platelet nucleotide testing and platelet flow cytometry are sent away, but the laboratory team hope to provide this service in house soon.
The laboratory team are involved with the weekly SHN MDT meeting, with Biomedical Scientist attending more than 80 per cent of MDT meetings. There is also regular genomics MDT.

Ref	**18**

Quality Standard

Specialist Services

Timely access to the following specialist staff and services should be available as part of a HCCC service where appropriate depending on whether 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

Specialist services should have an appropriate level of specialist expertise in the care of people with inherited and acquired bleeding disorders.

Standard Met

How the service meets or does not meet the standard

The referral to specialist services, in particular to Orthopaedics, dental and ED were praised by the patients who the review team met. However, it was highlighted to the review team that out-of-hours care for bleeding disorder patients could be mixed, with patients having to advocate for themselves. For examples, one patient had a USB drive with all the contact details for the haemophilia centre.

There are joint clinics with obstetrics and HIV/Hep C clinicians. There are two named gynaecologists at Basingstoke to whom bleeding disorder patients can be referred and a gynaecologist at one of the spoke hospitals who has a special interest in adolescent gynaecology. As is the case with many other bleeding disorder services, genetic counselling is managed within the haemophilia service and genetics will pass on referrals to the team if the receive them.

Obstetrics have 2 joint clinics, foetal medicine in Southampton in maternity medicine unit, joint HIV, and hepatology clinics.

<table>
<tr><td>Ref</td><td>19</td></tr>
<tr><td colspan="2">Quality Standard</td></tr>
<tr><td colspan="2">IT System

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</td></tr>
<tr><td colspan="2">Standard Met</td></tr>
<tr><td colspan="2">How the service meets or does not meet the standard</td></tr>
<tr><td colspan="2">The reviewers saw evidence of appropriate use of IT systems for this QS. The bespoke EPR used at Basingstoke was developed by a member if the Haemophilia team and has a flagging system for both PwBD and vCJD status.</td></tr>
</table>

Ref	**20**
Quality Standard	
Diagnosis Guidelines for People with Suspected Inherited and Acquired Bleeding Disorders Guidelines on diagnosis should be in use covering the investigation and diagnosis of suspected bleeding disorders. The guidelines should cover. a. Haemophilia A b. Haemophilia B c. Von Willebrand Disease d. Acquired haemophilia. e. Inherited platelet disorders f. Bleeding disorder of unknown cause g. Other less common and rare bleeding disorders h. haematological investigation of menorrhagia i. haematological investigation in child suspected of inflicted injury. j. non-specific bleeding disorders	
Standard Met	
How the service meets or does not meet the standard	
The SHN has an excellent comprehensive guideline for investigation and management of PwBD. Their investigation of bruising/bleeding in the context of possible NAI is currently in draft awaiting sign-off from the whole network.	

Ref	21

Quality Standard

Guidelines: Treatment and Monitoring of IABD

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

Standard Met

How the service meets or does not meet the standard

There is a clinical guideline in place that covers factor concentrate and non-factor replacement therapy.
The management of factor concentrate, and non-factor replacement therapy supplies is covered across separate documents.

<table>
<tr><td>Ref</td><td>22</td></tr>
<tr><td colspan="2">Quality Standard</td></tr>
<tr><td colspan="2">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.</td></tr>
<tr><td colspan="2">Standard Met</td></tr>
<tr><td colspan="2">How the service meets or does not meet the standard</td></tr>
<tr><td colspan="2">The review team saw evidence to support this standard, including clinical guidelines for the care of people with HIV and Hepatitis C.</td></tr>
</table>

Ref	**23**
Quality Standard	
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 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	
The team have a flow chart for management of surgeries in PwBD and proformas for individual patient plans that are then visible within the EPR. These include how to contact the team in the event of any concerns.	

Ref	**24**

Quality Standard

Service Organisation

The service should have an operational procedure covering at least:
a. Ensuring all children who are in-patients have a named consultant paediatrician and a named haematologist with expertise in caring for PwBD with inherited and acquired bleeding disorders responsible for their care.
b. Ensuring all adults are under the care of a consultant haematologist with an interest in inherited and acquired bleeding disorders, either directly or through a shared care arrangement with a general haematologist
c. Responsibility for giving information and education at each stage of the patient journey.
d. Arrangements for involving Haemophilia Centre staff in multi-disciplinary 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 move areas temporarily or permanently.
g. Ensuring PwBD ' 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

Standard Met

How the service meets or does not meet the standard

All these standards are met with clear documentary evidence and from discussion with members of the team.

Ref	**25**
Quality Standard	
Multi-Disciplinary Team Meetings Multi-disciplinary team meetings to discuss PwBD ' 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	
There are weekly network wide MDTs every Monday morning which also include members of the laboratory teams. These include discussion of difficult clinical situations and surgical planning. There is a separate network wide (and including Southampton) obstetric MDT monthly.	

<table>
<tr><th>Ref</th><th>26</th></tr>
<tr><td colspan="2">**Quality Standard**</td></tr>
<tr><td colspan="2">**Multi-Disciplinary Clinics/Liaison Services**

Combined clinics or other arrangements for multi-disciplinary discussion with
a. orthopaedics and or rheumatology
b. obstetrics and gynaecology
c. paediatrics
d. HIV
e. Hepatology</td></tr>
<tr><td colspan="2">**Standard Met**</td></tr>
<tr><td colspan="2">**How the service meets or does not meet the standard**</td></tr>
<tr><td colspan="2">The paediatric clinics are carried out in the hospital paediatric outpatient facility where the team have two rooms to enable access to physiotherapy and psychology alongside the medical review. The Nurse Consultant does a paediatric mild Bleeding disorder clinic face to face. As discussed above, there are MDT clinics for HIV/hepatology and obstetrics.</td></tr>
</table>

Ref	**27**

Quality Standard

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

This standard was evidenced by discussion with the Data Manager and documentary evidence of adverse event reporting. This is completed on paper by members of the clinical team and then reported to the NHD.

Ref	**28**
Quality Standard	
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 opportunity. 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	
The SHN has been in multiple interventional and non-interventional haemophilia CTIMP and investigator lead research projects since the last Peer Review with numerous publications demonstrated.	

<table>
<tr><th>Ref</th><th>29</th></tr>
<tr><td colspan="2">Quality Standard</td></tr>
<tr><td colspan="2">Multi-disciplinary Review and Learning

The service should have multi-disciplinary arrangements for review of and implementing learning from:
a. Audit – the service must have an audit plan and it must include 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.</td></tr>
<tr><td colspan="2">Standard Met</td></tr>
<tr><td colspan="2">How the service meets or does not meet the standard</td></tr>
<tr><td colspan="2">The reviewers saw examples of audit and QI, a patient feedback presentation, AE forms, dashboard data, minutes of operational meetings, the annual network report and patient network numbers. The SHN has established an ‘Education corner' which provides regular teaching sessions (with saved presentations).</td></tr>
</table>

Ref	**30**
Quality Standard	
Document Control All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	
Standard Met	
How the service meets or does not meet the standard	
Document control is exemplary.	