# Care of People with Inherited and Acquired Haemophilia and other Bleeding Disorders

## Oxford University Hospitals NHS Foundation Trust

Visit Date: 8th October 2019

Date: December 2019

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## Contents

# Introduction

This report presents the findings of the peer review of services for people with Inherited and Acquired Haemophilia and other Bleeding Disorders at Oxford University Hospitals NHS Foundation Trust, which took place on 8th October 2019.

The purpose of the visit was to review compliance with the Quality Standards for Inherited and Acquired Haemophilia and other Bleeding Disorders (V1 July 2018), which were developed by the UK Haemophilia Centres Doctors' Organisation (UKHCDO) Peer Review Working Group working with the Quality Review Service (QRS).

The peer review visit was organised by QRS on behalf of the UKHCDO.

The aim of the standards and the review programme is to help providers and commissioners of services to improve clinical outcomes and service users' and carers' experiences by improving the quality of services. The report also gives external assurance of the care, which can be used as part of organisations' Quality Accounts and Annual Governance Statement. For commissioners, the report gives assurance of the quality of services commissioned and identifies areas where developments may be needed.

The report reflects the situation at the time of the visit. The text of this report identifies the main issues raised during the course of the visit.

**Appendix 1** lists the visiting team and **Appendix 2** gives details of compliance with each of the standards and the percentage of standards met.

This report describes services provided or commissioned by the following organisations:

- Oxford University Hospitals NHS Foundation Trust
- Specialised Commissioning – NHS England South

Most of the issues identified by quality reviews can be resolved by providers' and commissioners' own governance arrangements. Individual organisations are responsible for taking action and monitoring this through their usual governance mechanisms. The lead commissioner for the service concerned is responsible for ensuring action plans are in place and for monitoring their implementation, liaising, as appropriate, with other commissioners.

## About the Quality Review Service

QRS is a collaborative venture between NHS organisations to help improve the quality of health services by developing evidence-based Quality Standards, carrying out developmental and supportive quality reviews (often through peer review visits), producing comparative information on the quality of services and providing development and learning for all involved.

Expected outcomes are better quality, safety and clinical outcomes, better patient and carer experience, organisations with better information about the quality of clinical services, and organisations with more confidence and competence in reviewing the quality of clinical services. More detail about the work of QRS is available at www.qualityreviewservicewm.nhs.uk

## Acknowledgments

Quality Review Service would like to thank the staff of the Oxford Comprehensive Care Centre for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. We are grateful too to the patients, parents and carers who took time to meet the review team.

Thanks are also due to the visiting team (**Appendix 1**) and their employing organisations for the time and expertise they contributed to this review.

## Oxford Comprehensive Care Centre

The Oxford Haemophilia Service provided care for adults and children. The adult and children's services worked closely together, with a shared data and a shared centre manager, a shared specialist haemostasis laboratory, a shared genetics service and mutual staff support, but they had separate clinical governance processes.

The adult service was based at the Oxford Haemophilia and Thrombosis Centre (OHTC) at the Churchill Hospital, and looked after patients over 16 years of age with inherited bleeding disorders. The children's haemophilia service was based within the Children's Hospital Oxford (CHOX) at the John Radcliffe Hospital and looked after patients up to the age of 18 years. Patients were generally transitioned from the children's haemophilia service to OHTC by the age of 18 years following a well-established 'Ready, Steady, Go' transition programme. In exceptional circumstances (complex care needs in the community) transition was delayed following multi-disciplinary / multi-speciality agreement.

Both the adult and the children's services had a nominated lead haemophilia consultant and specialist nurse. The medical and nursing leads, with support from the OHTC manager, had responsibility for staffing, training, guidelines and protocols, service organisation, governance and liaison with other services. They were registered healthcare professionals with appropriate specialist competences and undertook regular clinical work within the service as well as having specific time allocated for their leadership roles.

The services had effective multi-disciplinary teams with specialist haemostasis consultants, specialist haemophilia nurses who also performed research, specialist haemophilia physiotherapists, and essential support from an on-site UKAS accredited specialist haemostasis laboratory (within OHTC) and administrative staff including a data manager and the OHTC centre manager. The children's service had a named clinical psychologist (0.1 WTE), and the adult's service had had funding for 0.2 WTE clinical psychology support from April 2019, although at the time of the review this post was still vacant (awaiting recruitment). Consultants were responsible for training junior medical staff: the haematology specialist trainee and FY2 on rotation at OHTC, and also all the haematology specialist trainees who covered the on-call rota. Additionally, the specialist nurses and physiotherapists linked with ward, day unit, and Emergency Department (ED) staff when needed, to ensure competency in helping to manage patients with bleeding disorders. All staff completed relevant CPD, statutory and mandatory training, and there were policies and Standard Operating Procedures in place for cover for absences. The core multi-disciplinary team (MDT) was supported by close relationships with other specialities such as rheumatology, orthopaedics, infectious disease and obstetrics. There was good support from the hospital clinical directorate and division and a strong relationship with the specialist commissioners (biannual meetings were held with commissioners across the commissioning region – Oxford, Basingstoke and Southampton).

The standard clinic hours were 9am to 5pm Monday to Friday. There was a 24/7 specialist haemophilia consultant on-call service out of hours for both clinical services (separate adult/paediatric rotas) and the specialist haemostasis laboratory.

Both services had regular MDT and clinical governance meetings. The children's service held a weekly MDT every Tuesday morning to discuss patients (all inhibitor and central line patients discussed) and the procedures planned for that week. The adult service had an MDT meeting every afternoon to discuss inpatients, walk-ins, planned procedures and clinics. In addition, laboratory staff joined on a Friday to plan for the following week. There was a monthly meeting between adult and paediatric services, a monthly departmental OHTC meeting, a monthly specialist haemostasis laboratory meeting, bi-monthly clinical research meetings, and a quarterly OHTC clinical governance meeting. There were regular multi-disciplinary educational sessions, with a monthly lunch-time meeting (BLT) and fortnightly Specialist Registrar (SpR) haemostasis teaching (consultants and laboratory staff rotation).

The haemophilia services provided regional management advice and care for people with bleeding disorders over a wide area. The Oxford team were not part of a formal network as there was no other haemophilia treatment centre within the region, but the team worked closely with surrounding District General Hospitals (DGHs) to

provide safe emergency care across the region. These DGHs were Northampton General Hospital, Milton Keynes University Hospital, Royal Berkshire Hospital, Great Western Hospital, Wycombe Hospital, Stoke Mandeville Hospital, Wexham Park Hospital, Cheltenham General Hospital and Gloucestershire Royal Hospital. Each DGH had a named link consultant for the adult and children's services and clear pathways to coordinate and support emergency care and occasional minor invasive procedures (considered on an individual basis). The four DGHs with the highest concentrations of patients with known bleeding disorders had a stock of factor concentrate, which was managed by OHTC. Robust processes were in place to courier factor to surrounding DGHs, when required, and maintain stock control.

The UKAS/CPA accredited specialist haemostasis laboratory based at OHTC was an integral part of the service and enabled high-quality care 24/7. It was led by a senior clinical scientist. There were close links between the laboratory and the clinical team: the clinical team had easy access to, and direct discussions with, the laboratory many times a day (and vice versa), a member of the laboratory attended the weekly Friday adult MDT planning meeting, there was a monthly laboratory governance meeting at OHTC, and a member of the laboratory attended the monthly OHTC departmental meetings, the bi-monthly research meetings and the quarterly clinical governance meetings. The OHTC provided all coagulation factor assays and non-accidental injury panel (including basic platelet function), inhibitor screening and quantification 24/7; and, within hours, von Willebrand factor multimers and platelet function testing.

The Oxford University Hospitals (OUH) Molecular Genetics Laboratory service provided detection of causative mutations in patients with inherited bleeding disorders (including a gene panel for haemostasis/platelet disorders) and carrier detection. This service was supported by a lead consultant and there were monthly MDT genetic service meetings.

At the time of the review, the following numbers of patients were registered at the Centre:

| **Condition** | | **Number of patients** Severe / Moderate / Mild | **Number of patients who had an annual review in last year** | **Number of in-patient admissions in last year** |
|---|---|---|---|---|
| Haemophilia A | Adults | (244) – 105/22/117 | 229 | 42 total<br>(27 day cases) |
| | Children | (75) – 38/10/27 | 75 | 16<br>(8 day cases) |
| Haemophilia B | Adults | (56)-16/16/24 | 52 | 16 total<br>(9 day cases) |
| | Children | (18) - 8/5/5 | 18 | 0 |
| Von Willebrand | Adults | 240 - Adult<br>77 - Child | 176 - Adult<br>77 - Child | 50 total<br>(22 adult day cases)<br>(1 child day case) |
| | Children | | | |
| Other | Adults | 391 - Adult<br>78 - Child<br><br>'/' below indicates Adult/Child split<br>Glanzmann's Thrombasthenia – 6/3 | 167 – Adult<br>59 - Child | Total 37<br>Adult 33<br>Child 4 |
| | Children | | | |

| Condition | | Number of patients<br>Severe / Moderate / Mild | Number of patients who had an annual review in last year | Number of in-patient admissions in last year |
|---|---|---|---|---|
| | | Bernard Soulier – 2/1<br>Platelet Defects (all types) 43/24<br>Combined V+VIII Deficiency – 1/0<br>Combined von Willebrand's + XI deficiency – 2/0<br>F.V deficiency -2/0<br>F.VII deficiency – 23/5<br>F.X deficiency – 3/1<br>F.XI Deficiency – 79/12<br>F.XIII Deficiency – 2/2<br>FIX Leyden – 2/1<br>Afibrinogenemia – 1/0<br>Hypofibrinogenaemia – 1/0<br>Dysfibrinogenemia – 13/2<br>Hypodysfibrinogenemia – 0/2<br>Unclassified/Misc – 52/0<br>Acquired haemophilia/VWD – 14/0<br>Carriers with VIII deficiency – 49/16<br>Carriers with IX deficiency – 14/8<br>Confirmed carriers without FVIII/FIX deficiency – 83/0 | | |

## Emergency Care

During normal working hours, all patients had open access to either OHTC or CHOX. Patients/carers contacted the relevant haemophilia centre by telephone, and in case of emergency came to the haemophilia centre or ED, if required. There was an agreed pathway for patients with inherited bleeding disorders attending the ED in Oxford and the surrounding DGHs, and also pathways for emergency surgery.

Out of hours (evenings from 5pm to 9am, weekends and public holidays) there was 24/7 haemophilia consultant cover. There were separate on-call rotas for the adult and paediatric haemophilia consultants (and the paediatric rota included the Advanced Nurse Practitioner (ANP) who had additional support from the adult consultant on-call, if required). If a patient needed a review out of hours and was unstable, he/she was requested to attend the ED; in all other circumstances:

- If a child needed to be reviewed, he/she was asked to go to Kamran Ward at CHOX, John Radcliffe site.
- If an adult needed to be reviewed, he/she was reviewed in haematology-oncology triage or in the clinical haematology ward at the Churchill Hospital.

All patients with inherited bleeding disorders known to the service had a 'flag/alert' on their OUH Electronic Patient Record (EPR) (with contact details of the haemophilia team), and all clinic letters for OHTC/CHOX patients were available from the EPR. Haematology Specialist Registrars (SpRs), consultants and the haemophilia Associated Nurse Practitioners (ANPs) were able to access the full EPR from home when on-call. As an additional safety net, the haemophilia nursing teams also received an EPR alert when patients attended the ED or were admitted to any area within the Trust.

The clinical service was supported by the UKAS/CPA accredited specialist haemostasis laboratory at OHTC. Outside standard working hours (9am to 5pm Monday to Friday) there was a 24/7 on-call service for specialist testing if required for emergency care. This included all coagulation factor assays, inhibitor screen and quantification (human and porcine Bethesda) and a non-accidental injury panel including limited platelet function.

## Ward Care

**Adults**

Adult inpatients whose sole reason for admission was secondary to their inherited bleeding disorder (e.g. retroperitoneal bleed) were looked after on the clinical haematology ward at the Churchill Hospital. Otherwise, patients were looked after by the relevant speciality on the appropriate speciality ward (Nuffield Orthopaedic, John Radcliffe or Churchill) and reviewed at least daily by a member of the haemophilia team (haemophilia consultant, haematology specialist trainees, haemophilia nurse specialist, or physio as required). For example, if a patient was admitted under the orthopaedic team at the Nuffield Orthopaedic Centre (NOC) for elective orthopaedic surgery, the haemophilia team would liaise with the orthopaedic team before, during and after admission. Inpatients were handed over each evening to the haematology on-call SpR (also known as ST7).

**Children**

Children who were admitted with conditions related to their bleeding disorder (CVAD line insertions, epistaxis, bleeds) were cared for within the children's hospital. This was preferably on Kamran Ward (the paediatric haematology/oncology ward) or otherwise on one of the other wards within the Children's Hospital. Teaching had been conducted with all wards by the haemophilia team.

Patients were reviewed daily by a haemophilia consultant/nurse and plans were discussed with the team. Haemophilia nurses supported the ward throughout the day with factor administration etc., as needed. If children were admitted under other specialities for planned surgery or other care needs, the haemophilia team liaised with the main paediatric team each day. Paediatric inpatients were handed over each evening to the general paediatric on-call team (SHO/SpR/Consultant) as well as the haematology SpR. These staff were aware that they needed to liaise with the haematology SpR or on-call paediatric haemophilia consultant/ANP regarding any changes to the care.

## Day Care

**Monday – Friday, 9am-5pm**

**Adults**

Patients who required urgent review but who did not need to attend the ED were reviewed by the haemophilia team at OHTC. Whilst most day unit care was provided within OHTC, patients who required rituximab or blood transfusion attended the haematology day unit at the Churchill hospital. Patients who required day case procedure/surgery were admitted under the team performing the procedure, and the haemophilia team provided a haemostatic management plan, support and review as appropriate on the surgical day unit.

**Children**

Patients who required urgent review were seen in the Lion room (the designated haemophilia room) in the children's outpatient department. If they were unwell on presentation they were transferred to the ED, if they had

not already been directed there, following telephone assessment. If they needed a day case admission this would be coordinated on the Kamran day care unit (the paediatric haematology and oncology ward). Patients who required day case procedure/surgery were admitted under the team performing the procedure, and the haemophilia team provided a haemostatic management plan, support and review, as required.

## Outpatient Care

**Adults**

All bleeding disorder clinics took place at OHTC. Consultant-led MDT clinics (with a doctor, nurse, and physiotherapist) occurred every Tuesday and Wednesday morning. On a Thursday morning the three consultants ran parallel new patient clinics for patients with suspected bleeding disorders, and also for pregnant woman with inherited bleeding disorders and those who were carriers. In addition, there was a specialist nurse-led telephone clinic on Monday afternoons for the annual review of patients with mild bleeding disorders.

Patients who required additional physiotherapy were seen at either OHTC or NOC or in coordination with the local physiotherapy team.

**Children**

A regular follow-up clinic took place on Tuesday afternoons. This was a consultant-led MDT clinic (with a doctor, nurse and physiotherapist). Patients were booked to see the clinical psychologist during this time or just prior to clinic, as required.

New referrals for patients with suspected bleeding / thrombotic disorders or carriers were held on Wednesday mornings. These were generally consultant-led clinics but could instead be nurse or haematology SpR-led, depending on the patients who required review (with advice from the consultant).

Patients who required additional physiotherapy were seen at either CHOX or NOC, or in coordination with the local physiotherapy team.

## Community Based Care

**Adults**

Close links had been developed with DGHs in order to support safe care as close to home as possible. This facilitated occasional DDAVP/factor administration prior to minor local procedures such as dentistry, and also inpatient/outpatient care for patients with acquired haemophilia A. The specialist nursing team completed significant education with District Nursing teams, the OUH Acute Hospital at Home service, and care homes, when appropriate, to support patient care in these environments. A few patients, such as those with complex care needs, found it very difficult to attend OHTC, and the MDT (consultant/nurse/physiotherapist) visited these patients at home for clinical reviews.

Specialist physiotherapists liaised with local physiotherapy providers and visited gyms to encourage exercise or undertake home visits, as required.

Where appropriate, patients were signposted to ‘health promotion support’ networks and counselling, such as Oxfordshire Mind, and were also referred to their GPs to access local services.

**Children**

All DGHs had a named consultant who supported the care of patients when admitted to local hospitals, to ensure their care was safe and management of their bleeding disorder was appropriately considered (this often applied to patients with CVAD infections). The children’s team (nurses and physiotherapist) visited the shared care DGHs to ensure they were up to date with policies and procedures and to address any issues or questions.

The specialist nurses worked with the DGH community nursing teams to support the administration of treatment to patients with CVADs, or peripherally when the team were in the process of teaching parents who found it difficult to attend CHOX regularly.

The specialist nurses conducted a home visit as part of teaching parents/patients to self-administer treatment. School visits for all children with severe haemophilia or patients on prophylaxis were completed with every school change. Additionally, for some patients such as the service's regular inhibitor patients, the team attended the patients' homes for clinical reviews in order to reduce visits to hospital.

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# Review Findings

**Achievements**

This well-established and high-functioning team was offering an excellent service. Staff were highly committed professionals, working very well together and taking personal responsibility for the care they provided. Their flexibility in helping each other in covering absences was noted, and some members – especially the paediatric medical lead and the lead adult nurse specialist – were working extremely hard during a time of staffing shortfall. There was a focus on promoting staff development. One of the nurse specialists was an ANP, and three of the nurses were non-medical prescribers. There was a clear vision for the future service in general, as well as planning for medical staff cover for the following year as job plans were to change when two of the consultants taking up posts as Medical Research Council clinical academic research partners.

Several team members contributed to national work in the field of acquired and inherited bleeding disorders, being members of the Clinical Reference Group, Haemnet[1] management, and various working parties and guideline-writing groups. The Centre was one of a small number recognised as a World Federation of Hemophilia international training centre. In addition, there was evidence of a local focus and efforts to ensure the Centre's patients and families felt fully involved and supported, with regular social events, outings for adolescent patients, and a group especially for the parents of children under four years of age.

Patient feedback was very positive. All team members were appreciated, and the tireless contributions of the lead adult nurse and adult physiotherapist were especially mentioned. Families and carers, as well as patients, felt involved and supported.

There was a notable focus on the needs of older patients and others who could not attend the Centre for review: for a few patients, the consultant, nurse specialist and physiotherapist went together to the patient's home to allow a full multi-disciplinary clinic discussion there. The lead adult nurse had frequently visited care homes to teach nursing staff there about the condition, and about how to administer factor replacement.

There was a world-class, wide-ranging research portfolio, and the Centre had actively participated in gene therapy trials – including recruiting the first patient in the world into one of the trials. In addition, there were multi-disciplinary research activities, with high-level work being undertaken by the nursing staff and physiotherapists.

**Good Practice**

1. Documentation supporting the service was strong. There was a lot of patient information available, especially for adult service users, including an excellent 'welcome to the adult service' leaflet and a useful paediatric inpatient booklet. Diagnostic and clinical guidelines were comprehensive, with hyper-links on the electronic version to facilitate searching. There was clear guidance for the initial management of children and adults attending the ED, and a series of very practical, locally written, one-page summaries of management for target joints, by individual joint type. There was a clear operational policy in place. A template was in use for clinic review letters, facilitating consistency and completeness of the reviews and their recording.
2. The emergency pathways appeared to work well. The Cerner® electronic patient record had a 'flag' tag on its front page once a patient's record was opened, and if any patient attended the ED, the Centre team received an e-mail alert. Families reported that they were happy with the care they received in the ED, and said that

[1] **Haemnet** is a community for allied care professionals who treat people with bleeding disorders. Haemnet supports health and social care professionals to ensure that excellent care becomes an everyday experience for people with bleeding disorders.

staff seemed competent and engaged. When patients or carers called the hospital out of hours for advice, they were put through to a specialist registrar doctor for initial discussion and advice.

3. Active patient and public involvement was evident and included various support groups, social outings, and a regular patient newsletter.

4. There were physiotherapist-led exercise classes, including a multi-condition group for children, and a core/balance class for adults.

5. Transition practice was good, with paediatric and adult teams in turn discussing issues with young people at around the time they moved from the paediatric to the adult services. An adult nurse specialist and physiotherapist attended the patient's last appointment in paediatrics, to meet the young person and become 'familiar faces' for when he/she first attended at the adult site.

6. There was written induction information and practical teaching for SpRs when they first joined the team, and they did not undertake on-call duties for the first month of their attachment, to ensure they were sufficiently knowledgeable to manage out of hours calls.

7. There was very good support from other specialist teams; paediatric interventional radiology was helpful and prompt when requested to insert intravenous access devices and performing urgent ultrasound scans and MSK radiology in undertaking musculo-skeletal ultrasounds for children at the John Radcliffe hospital. In the adult service, the management of synovitis was helped by a named specialist radiologist reporting all the MR joint scans, and there was a monthly joint clinic with rheumatology at which joint injections could be given if appropriate. Radioactive synovectomy was also available.

8. There was a robust local database system in place to flag up female obligate or potential carrier relatives of known patients, for testing and counselling, before they reached reproductive age.

9. Adults could access a local community venous access team if they were having difficulty in cannulation.

10. Clinical governance activities within the team were comprehensive, with minuted meetings covering mortality and morbidity case reviews and review and learning from incidents. There was an active audit programme in place, with evidence of changes made as a result of findings.

11. Consultants and specialist registrars could access, and input to, the electronic patient record remotely when on call out of hours.

**Immediate Risks**

No immediate risks were identified at the time of the visit.

**Concerns**

1. **Staffing**

   Some key staff members were not in place, or there was staffing under provision, so that the team could not offer the full multi-professional care and support expected for patients and families affected by these long-term conditions.

   a. Psychology - There was no psychologist in place supporting the adult service. Funding for 0.2 WTE had been agreed six months prior to the visit, as part of a shared post with the malignant haematology service, but the business case had not been finally approved and signed off[2] and it had therefore not

[2] The team confirmed that since the peer review visit, the Trust business planning group approved the business case on the 24th October and the Trust Management Executive gave final approval on the 14th November 2019.

been possible to recruit. Some high-level needs were being addressed by medical, nursing, and physiotherapy staff; this detracted from the specialist duties they could otherwise have been undertaking. Lower level patient needs were not being met, and the team lacked the guidance and support that a psychologist member usually offers.

A psychologist worked within the paediatric haemophilia service, but only for 1 session per week (0.1 WTE), which was insufficient; she attended the haemophilia clinic but did not have adequate time to offer consultations and support outside this time.

b. Adult nurse specialists - One of two Band 7 posts had been vacant for several months, putting the remaining Band 7 lead nurse under considerable pressure. Attempts had been made to recruit, but a suitable appointee had not yet been found. In the interim, the research nurses were undertaking clinical duties on occasions.

c. Social work - There was no named linked social worker involved in the service. Referrals could be made for inpatients to the general hospital social work team, and concerns about children were raised appropriately. However, this meant that nurse specialists, doctors and physiotherapists were spending time helping patients with issues and applications that a social worker would more appropriately have undertaken, which had a further impact on these professionals' specialist time.

2. **Paediatric facilities**

The paediatric service had moved from the Churchill Hospital to the John Radcliffe site in 2015, developing the service and increasing the number of staff, but there were several concerns about the facilities there.

a. There was a single dedicated clinic room (Lion room) for the use of this service. It was decorated to suit younger children, but if a child was being assessed and treated there, other children and their families frequently had to wait as there was no other open access clinic room for the paediatric haemophilia service. Whilst the latest volume of case notes were available (in Frog room, opposite the treatment room), earlier volumes were held a floor up (in Kamran room), so that nurses or secretarial staff had to take time to go and retrieve them when needed.

b. Lion room was also being used as the nurses' office, shared with Frog room which housed all the latest notes, trial files and patient information leaflets). The phone line in Lion room was used for families calling for advice; if calls came through at a time when a child was being treated, a nurse had to leave the room to take the call to avoid confidentiality issues. If the phone line was in use, for example if the nurse was calling to arrange investigations for the child being assessed, families could not get through. A review of the use of different telephone lines, and of nurses' office space, could usefully be undertaken.

c. There was no signposting indicating that this was the site of this large specialist haemophilia and inherited bleeding disorders service, and no patient information was seen displayed in the main paediatric outpatient area.

d. Car parking and access were extremely problematic. When children had painful joint bleeds, reaching the area presented a real struggle. Sometimes, when finding a parking space anywhere near the clinical area had proved impossible, team members had gone down to see a child in the car, bringing medication there. This was inappropriate, and the situation was distressing for children, families and staff. Car parking issues were also highlighted by the families who met with reviewers.

**Further Consideration**

1. There was usually a single senior registrar in haematology training working within the service. Given the excellent training opportunity of working in this large service, identified as an international training site for

haemophilia, the possibility of having two SpRs working with the team at any one time – at a junior and then a more senior level – should be investigated.

2. Some patient information leaflets were up to six years old. While the contents may not need to change significantly, patients and parents may be concerned that information appears to be out of date.

3. The current adult facilities in the OHTC at the east side of the Churchill Hospital site were appropriate. However, it was understood that the service will have to move from this site by April 2022. Discussions were underway as to where they might relocate, and service users were being brought into these discussions. It will be essential for the continuing service to be re-housed on one of the acute hospital sites, and for facilities to include at least the same number of clinical and treatment rooms as the current site. If, as hoped, the team grows to include a psychologist, an additional room may be required, and an additional four-bedded bay in which clinical trial patients could be observed and managed would enable the expansion of gene therapy and early phase clinical trial work

4. Electronic records contained patient demographics, clinic letters and results, but hard-copy notes were still in use within the Centre. If it is intended that these records will be scanned onto the electronic patient record, careful planning as to how this will be managed will be needed. In other centres, the scanning of legacy notes, often into a single large document, has made it extremely difficult to find and access relevant information within them.

5. Patients and families would appreciate some out of hours clinic appointments, to avoid children missing school time and patients and parents missing further education or work.

6. The Centre managed patients living over a wide geographical area, who may present acutely to a number of linked DGHs (see comment below). Depending on the presentation, the Centre may advise transfer of the patient to Oxford. However, at other times the Centre team may advise on management, and this may include giving advice on factor levels measured in the local laboratories. It would be useful for the Centre team to have sight of the local laboratories' quality assurance / NEQAS results for these investigations, to give assurance that they can be relied on.

7. The team might revisit the possibility of undertaking some outreach clinics at sites where there are a number of patients, both to save multiple patients and families the need to travel distances, and to offer useful training and learning opportunities for the clinical teams at these hospitals.

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## General Comment

The Centre was well supported by the regional specialist commissioning team. The commissioner was involved in the activities of the three CCCs across the region (Oxford, Basingstoke, and Southampton), and joined them in twice-yearly meetings. These meetings had all been held in Oxford, and the review team suggested it might be better to rotate them between the three sites, and to invite other team members – nurses, physiotherapists and psychologists – to attend, as well as medical leads and managers. The agenda could be expanded to include some difficult case discussions and reviews, as well as learning from incidents and mortality reviews.

There was no formal network in place; networks have traditionally been understood to include the work CCCs undertake in conjunction with linked haemophilia centres, and there are no identified haemophilia centres linked with the Oxford CCC. However, the Centre worked in an informal clinical network with nine DGHs in the areas in which its patients resided, stretching north to Northampton, west to Gloucester, east to Wexham Park, and south to Reading. Almost all the patients living in these areas attended the Oxford clinic for their specialist reviews, and some mildly affected patients were managed through nurse-led telephone consultations. Patients across the region were included in giving feedback on the service and in some of the audits run by the Centre and were offered inclusion in relevant research studies.

Factor concentrate stock was held at most of these sites, and the Centre managed rotation and safe delivery as required. The Centre also offered clinical and laboratory advice at all times, and the linked hospital colleagues commented that the Centre team were accessible and responsive. One colleague had asked for a list of the patients known to the Centre who lived in the area of that DGH, in order to put a flag onto the local electronic patient record; the same information could usefully be made available to the teams at all of the supported hospitals. A generic contact e-mail[3] was also requested for less urgent enquiries, together with copies of annual review appointment letters and other important correspondence.

Some elements of network functioning were therefore in place (see HY compliances below for detail). Further discussion and development would lead to an enhanced level of support and communication with the linked hospital teams.

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[3] The Centre confirmed that a generic email address is in place for paediatrics for less urgent enquiries. However, this may need to be publicised again, and consideration given to a similar system for adults.

# APPENDIX 1 Membership of Visiting Team

| Visiting Team | | |
|---|---|---|
| Dr Amanda Clark | Consultant Haematologist | University Hospitals Bristol NHS Foundation Trust |
| Helen Cook | Social Worker | Cardiff Council |
| Wandai Maposa | Haemophilia CNS | St George's Hospital NHS Trust |
| Dr Jayashree Motwani | Consultant Haematologist | Birmingham Women's and Children's NHS Foundation Trust |
| Anica Phillott | Haemophilia Nurse | Evelina Children's Hospital<br>Guy's and St Thomas' NHS Foundation Trust |
| Liz Rizzuto | Patient representative | |
| David Stephensen | Physiotherapist | East Kent Hospitals University NHS Foundation Trust |
| Caroline Webster | Physiotherapist | University Hospitals Southampton NHS Foundation Trust |

| QRS Team | | |
|---|---|---|
| Rachael Blackburn | Assistant Director | Quality Review Service |
| Dr Anne Yardumian | Consultant Haematologist | Programme Clinical Lead |

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# APPENDIX 2 Compliance with the Quality Standards

Analyses of percentage compliance with the Quality Standards should be viewed with caution as they give the same weight to each of the Quality Standards. Also, the number of Quality Standards applicable to each service varies depending on the nature of the service provided. Percentage compliance also takes no account of 'working towards' a particular Quality Standard. Reviewers often comment that it is better to have a 'No, but', where there is real commitment to achieving a particular standard, than a 'Yes, but', where a 'box has been ticked' but the commitment to implementation is lacking. With these caveats, table 1 summarises the percentage compliance for each of the services reviewed.

**Table 1 - Percentage of Quality Standards met**

Details of compliance with individual Quality Standards can be found below.

| | Number of applicable QS | Number of QS met | % met |
|---|---|---|---|
| Haemophilia Comprehensive Care Centre | 37 | 34 | 92 |
| Network | 8 | 7 | 88 |
| Commissioning | 3 | 3 | 100 |
| **Centre** | 48 | 44 | 92 |

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## Haemophilia Comprehensive Care Centre

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HP-101 | **Service Information**<br><br>Written information should be offered to patients and, where appropriate, their carers covering at least:<br>a. Brief description of the service<br>b. Clinic times and how to change an appointment<br>c. Ward usually admitted to and its visiting times<br>d. Staff of the service<br>e. Community services and their contact numbers<br>f. Relevant national organisations and local support groups<br>g. Where to go in an emergency<br>h. How to:<br>i. Contact the service for help and advice, including out of hours<br>ii. Access social services<br>iii. Access benefits and immigration advice<br>iv. Interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent)<br>v. Give feedback on the service, including how to make a complaint<br>vi. Get involved in improving services (QS HP-199) | Y | |

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HP-102 | **Condition-Specific Information**<br><br>Written information should be offered to patients and, where appropriate, their carers covering at least:<br>a. A description of their condition and how it might affect them<br>b. How their condition is diagnosed<br>c. Genetics of inherited bleeding disorders<br>d. Testing for carrier status and the implications of being a carrier<br>e. Problems, symptoms and signs for which emergency advice should be sought<br>f. Out of hours services<br>g. 'On demand' clotting factor treatment<br>h. Prophylaxis<br>i. Self infusion (or infusion by parent or carer)<br>j. Home therapy and use of Haemtrack<br>k. How to manage bleeding at home<br>l. Ports, fistulae and in-dwelling access devices (if applicable)<br>m. Possible complications, including inhibitors and long term joint damage<br>n. Approach to elective and emergency surgery<br>o. Women's health issues<br>p. Health promotion, including smoking cessation, health eating, weight management, exercise, alcohol use, sexual and reproductive health, and mental and emotional health and well-being<br>q. Dental care<br>r. Travel advice<br>s. Vaccination advice<br>t. National Haemophilia Database, its purpose and benefits<br>u. Sources of further advice and information<br><br>Information should be available covering:<br>1. Haemophilia A<br>2. Haemophilia B<br>3. Von Willebrand Disease<br>4. Acquired haemophilia<br>5. Inherited platelet disorders<br>6. Other less common and rare bleeding disorders | Y | |

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HP-103 | **Plan of Care**<br><br>Each patient and, where appropriate, their carer should discuss and agree their Plan of Care, and should be offered a written record covering at least:<br>a. Agreed goals, including life-style goals<br>b. Self-management<br>c. Planned assessments, therapeutic and/or rehabilitation interventions<br>d. Early warning signs of problems, including acute exacerbations, and what to do if these occur<br>e. Agreed arrangements with school or other education provider and preparation for adult life (children and young people only)<br>f. Planned review date and how to access a review more quickly, if necessary<br>g. Who to contact with queries or for advice<br><br>The Plan of Care should be communicated to the patient's GP and to relevant other services involved in their care. | Y | |
| HP-104 | **Review of Plan of Care**<br><br>A formal review of the patient's Plan of Care should take place at least six monthly for patients with severe or moderate haemophilia and at least annually for other patients. This review should involve the patient, where appropriate their carer, and appropriate members of the multi-disciplinary team. Haemtrack results should be reviewed (if applicable) and the outcome of the review should be communicated in writing to the patient and their GP. | Y | |
| HP-105 | **Contact for Queries and Advice**<br><br>Each patient 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. Response times should be no longer than the end of the next working day. All contacts for advice and a sample of actual response time should be documented. | Y | |
| HP-106 | **Haemtrack (Patients on Home Therapy)**<br><br>All patients on home treatment should be encouraged to use electronic recording of their treatment through Haemtrack. | Y | |

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HP-194 | **Environment**<br><br>The environment and facilities in out-patient clinics, wards and day units should be appropriate for the number of patients with inherited and acquired bleeding disorders and accessible by people with severe mobility problems.<br><br>Services for children and young people should be provided in a child-friendly environment, including toys and books / magazines for children and young people of all ages. | N | Adult facilities at the Churchill hospital were good. However, see Concerns section of the main report in relation to paediatric facilities. |
| HP-195 | **Transition to Adult Services and Preparation for Adult Life**<br><br>Young people approaching the time when their care will transfer to adult services should be offered:<br>a. Information and support on taking responsibility for their own care<br>b. The opportunity to discuss the transfer of care with paediatric and adult services<br>c. A named coordinator for the transfer of care<br>d. A preparation period prior to transfer<br>e. Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards<br>f. Advice for young people going away from home to study, including:<br>i. registering with a GP<br>ii. how to access emergency and routine care<br>iii. how to access support from their Comprehensive Care Centre<br>iv. communication with their new GP | Y | See Good Practice section of main report. |
| HP-198 | **Carers' Needs**<br><br>Carers should be offered information on:<br>a. How to access an assessment of their own needs<br>b. What to do in an emergency<br>c. Services available to provide support | Y | |
| HP-199 | **Involving Patients and Carers**<br><br>The service should have:<br>a. Mechanisms for receiving regular feedback from patients and carers about treatment and care they receive<br>b. Mechanisms for involving patients and carers in decisions about the organisation of the service<br>c. Examples of changes made as a result of feedback and involvement of patients and carers | Y | |

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HP-201 | **Lead Consultant and Lead Nurse**<br><br>A nominated lead consultant and lead nurse should have responsibility for staffing, training, guidelines and protocols, service organisation, governance and for liaison with other services. The lead consultant and lead nurse should be registered healthcare professionals with appropriate specialist competences and should undertake regular clinical work within the service and specific time allocated for their leadership role. | Y | |
| HP-202 | **Staffing Levels and Skill Mix**<br><br>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 patients cared for by the service and its role in the network. All staff should undertake regular Continuing Professional Development of relevance to their work in the inherited and acquired bleeding disorders services. 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. 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:<br>a. Medical staff:<br>i. Consultant specialising in the care of people with inherited and acquired bleeding disorders available during normal working hours<br>ii. On-call consultant haematologist (24/7)<br>iii. Arrangements for advice from a consultant specialising the care of people with inherited and acquired bleeding disorders (if not on call)<br>b. Specialist nursing staff:<br>i. Bleeding disorders specialist nurses (5/7)<br>ii. Ward, out-patient and day unit staff with competences in the care of people with inherited and acquired bleeding disorders.<br>c. Clinical specialist physiotherapist<br>d. Biomedical Scientist and Clinical Scientist (further detail on the requirements are included in HP-303)<br>e. Clinical or counselling specialist psychologist or appropriately trained psychotherapist<br>f. Specialist senior social worker<br>g. Data manager | N | See Concerns section of main report regarding access to psychologist and social worker support. |

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HP-203 | **Service Competences and Training Plan**<br><br>The competences expected for each role in the service should be identified. A training and development plan for achieving and maintaining competences should be in place. | Y | |
| HP-204 | **Competences – All Health and Social Care Professionals**<br><br>All health and social care professionals working in the service should have competences appropriate to their role in:<br>a. Safeguarding children and/or vulnerable adults<br>b. Recognising and meeting the needs of vulnerable children and/or adults<br>c. Dealing with challenging behaviour, violence and aggression<br>d. Mental Capacity Act and Deprivation of Liberty Safeguards<br>e. Resuscitation | Y | |
| HP-299 | **Administrative, Clerical and Data Collection Support**<br><br>Administrative, clerical and data collection support should be available. | Y | |
| HP-301 | **Support Services**<br><br>Timely access to the following support services should be available:<br>a. Play support (children's services only) including:<br>i. Play and distraction during any painful or invasive procedures<br>ii. Play support to enable the child's development and well-being<br>b. Pharmacy<br>c. Dietetics<br>d. Occupational Therapy<br>e. Orthotics | Y | |
| HP-302 | **Emergency Department – Staff Competences**<br><br>Medical and nursing staff working in the Emergency Department should have competences in urgent care of people with inherited and acquired bleeding disorders including awareness of:<br>a. Guidelines on care of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504)<br>b. Who to contact for advice | Y | ED guidelines were considered to be comprehensive and were easily accessible to clinicians.<br>However, reviewers were unable to assess levels of knowledge of ED staff because a major incident was taking place at the time of the review visit. |

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HP-303 | **Laboratory Service**<br><br>a. A UKAS / CPA accredited laboratory service with satisfactory External Quality Assurance performance should be available 24/7<br>b. A laboratory representative (senior biomedical scientist or clinical scientist) should attend inherited and acquired bleeding disorder service multi-disciplinary team meetings (QS HP-602) regularly<br>c. The following tests should be available:<br>i. All coagulation factor assays (24/7)<br>ii. Inhibitor screening<br>iii. FVIII inhibitor quantification<br>iv. VWF antigen<br>v. VWF activity<br>vi. Platelet function testing<br>d. Molecular Genetic Laboratory service for:<br>i. detection of causative mutations in patients with inherited bleeding disorders<br>ii. carrier detection | Y | |
| HP-304 | **Specialist Services**<br><br>Timely access to the following specialist staff and services should be available as part of a HCCC service. HCs should be able to access these services through network arrangements:<br>a. Obstetrics including reproductive counselling, information about pre-implantation genetic diagnosis and antenatal diagnosis<br>b. Foetal medicine<br>c. Vascular access (consultant surgeon or interventional radiologist with experience of venous access devices)<br>d. Orthopaedic surgery<br>e. Care of older people services<br>f. Dental services<br>g. HIV services<br>h. Hepatology<br>i. Medical genetics (Genetic Counselling Services)<br>j. Pain management services<br>k. Rheumatology<br><br>Specialist services should have an appropriate level of specialist expertise in the care of people with inherited and acquired bleeding disorders. | Y | |

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HP-402 | **Facilities and Equipment**<br><br>Facilities and equipment appropriate for the service provided should be available including:<br>a. Fridges<br>b. Storage<br>c. Clinical rooms for staff of all disciplines to see patients and carers<br>d. Room for multi-disciplinary discussion<br>e. Room for educational work with patients and carers<br>f. Office space for staff<br>g. Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all clinical areas<br><br>All equipment should be appropriately checked and maintained. | N | See HP-194. The facilities were adequate for adult patients but not for paediatrics (see Concerns section of main report). |
| HP-499 | **IT System**<br><br>IT systems should be in use for:<br>a. Storage, retrieval and transmission of patient information, including access to the latest vCJD status and family tree<br>b. Patient administration, clinical records and outcome information<br>c. Data to support service improvement, audit and revalidation<br>d. Alerting the specialist team when patients attend the Emergency Department | Y | |
| HP-501 | **Diagnosis Guidelines for Patients with Suspected Inherited and Acquired Bleeding Disorders**<br><br>Guidelines on diagnosis should be in use covering at least<br>a. Haemophilia A<br>b. Haemophilia B<br>c. Von Willebrand Disease<br>d. Acquired haemophilia<br>e. Inherited platelet disorders<br>f. Other less common and rare bleeding disorders | Y | |

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HP-502 | **Guidelines: Concentrate Use and Monitoring**<br><br>Guidelines should be in use covering:<br>a. Concentrate therapy:<br>i. Initiation and monitoring of prophylaxis<br>ii. Home therapy<br>b. Use of extended half life products, including inhibitor testing and PK assessment<br>c. Management of concentrate supplies including:<br>i. Ordering<br>ii. Storage<br>iii. Stock control to ensure all stock is up to date and waste is minimised<br>iv. Prescription and delivery for patients on home treatment<br>v. Arrangements for emergency 'out of hours' supply<br>vi. Recording issue to patients<br>vii. Recording use by patients, including on Haemtrack<br>viii. Submission of data via NHD for national tenders coordinated by CMU | Y | |
| HP-503 | **Clinical Guidelines**<br><br>The following clinical guidelines should be in use:<br>a. Management of acute bleeding episodes, including patients with inhibitors<br>b. Inhibitor screening<br>c. Immune tolerance therapy<br>d. Dental care<br>e. Care of patients with hepatitis C<br>f. Care of patients with HIV<br>g. Antenatal care, delivery and care of the neonate<br>h. Management of synovitis and target joints<br>i. Long term surveillance of musculoskeletal health<br>j. “For public health purposes”: care of patients at risk of vCJD who are undergoing surgery | Y | |
| HP-504 | **Emergency Department Guidelines**<br><br>Guidelines on management of patients with inherited and acquired bleeding disorders in the Emergency Department should be in use. | Y | |

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HP-505 | **Guidelines on Care of Patients requiring Surgery**<br><br>Guidelines on the care of patients with inherited and acquired bleeding disorders who require surgery should be in use covering at least:<br>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<br>b. Communication of the agreed plan of care to all staff involved in the patient's care prior to, during and post-surgery<br>c. Documentation of care provided<br>d. Arrangements for escalation in the event of unexpected problems | Y | |
| HP-595 | **Guidelines on Transition and Preparing for Adult Life**<br><br>Guidelines on transition of young people from paediatric to adult services should be in use covering at least:<br>a. Taking responsibility for their own care<br>b. Involvement of the young person and, where appropriate, their carer in planning the transfer of care<br>c. Joint meeting between paediatric and adult services in order to plan the transfer<br>d. Allocation of a named coordinator for the transfer of care<br>e. A preparation period prior to transfer<br>f. Arrangements for monitoring during the time immediately after transfer<br>g. Advice for young people going away from home to study, including:<br>i. registering with a GP<br>ii. how to access emergency and routine care<br>iii. how to access support from their Comprehensive Care Centre<br>iv. communication with the young person's new GP | Y | |
| HP-599 | **Care of Vulnerable People**<br><br>Guidelines for the care of vulnerable children, young people and adults should be in use including:<br>a. Restraint and sedation<br>b. Missing patients<br>c. Mental Capacity Act and the Deprivation of Liberty Safeguards<br>d. Safeguarding<br>e. Information sharing<br>f. Palliative care<br>g. End of life care | Y | |

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HP-601 | **Service Organisation**<br><br>The service should have an operational procedure covering at least:<br>a. Ensuring all children who are in-patients have a named consultant paediatrician and a named haematologist with expertise in caring for patients with inherited and acquired bleeding disorders responsible for their care<br>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<br>c. Responsibility for giving information and education at each stage of the patient journey<br>d. Arrangements for involving Haemophilia Centre staff in multi-disciplinary discussions relating to their patients (QS HP-602)<br>e. Arrangements for follow up of patients who 'do not attend'<br>f. Arrangements for transfer of patient information when patients move areas temporarily or permanently<br>g. Ensuring patients' plans of care are reviewed at least six monthly for patients with severe haemophilia and at least annually for other patients (QS HP-104)<br>h. Ensuring school visits for children with severe haemophilia at least at each change of school (children's services only)<br>i. Ensuring patients are visited at home at least annually if they are unable to attend clinics, including those in nursing homes<br>j. Lone working | Y | |
| HP-602 | **Multi-Disciplinary Team Meetings**<br><br>Multi-disciplinary team meetings to discuss patients' plans of care should take place regularly involving:<br>a. All core members of the specialist team (HP-202)<br>b. Senior biomedical scientist or clinical scientist with responsibility for the Coagulation Laboratory<br>c. HC staff who are regularly involved in the patient's care as part of network arrangements | Y | |

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HP-603 | **Multi-Disciplinary Clinics**<br><br>The following multi-disciplinary clinic arrangements for patients with inherited and acquired bleeding disorders should be in place:<br>a. Involvement of medical, specialist nursing and physiotherapy staff in clinics<br>b. Availability of social work and psychology staff in clinics<br>c. Combined clinics or other arrangements for multi-disciplinary discussion with:<br>i. orthopaedics<br>ii. rheumatology<br>iii. obstetrics and gynaecology<br>iv. paediatrics<br>v. dental<br>vi. HIV / hepatology | Y | |
| HP-604 | **Liaison with Other Services**<br><br>Review meetings should be held at least annually with specialist services to consider liaison arrangements and address any problems identified. | Y | |
| HP-701 | **Data Collection**<br><br>The following data should be collected:<br>a. UK National Haemophilia Database data on all patients<br>b. Data on concentrate use and bleeds, either through Haemtrack or an equivalent mechanism<br>c. Data required to complete the UKHCDO National Haemophilia Dashboard or other national mechanisms | Y | |
| HP-702 | **Audit**<br><br>The services should have a rolling programme of audit covering at least:<br>a. Clinical guidelines (QS HP-503)<br>b. Emergency and out of hours care (QS HP-504)<br>c. Initiation of prophylaxis in children<br>d. Inhibitor surveillance and Immune Tolerance Induction (ITI)<br>e. Clinical reviews including joint scores (QS HP-103 & 104)<br>f. Concentrate use and wastage | Y | |
| HP-706 | **Research**<br><br>The service should actively participate in research relating to the care of patients with bleeding disorders. | Y | See Achievements section of main report. |

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HP-798 | **Multi-disciplinary Review and Learning**<br><br>The service should have multi-disciplinary arrangements for review of and implementing learning from:<br>a. Positive feedback, complaints, outcomes, incidents and 'near misses'<br>b. Morbidity and mortality<br>c. Haemophilia Dashboard<br>d. Review of UKHCDO Annual Report benchmarking information on concentrate use<br>e. Ongoing reviews of service quality, safety and efficiency<br>f. Published scientific research and guidance | Y | |
| HP-799 | **Document Control**<br><br>All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures. | Y | However, see Further Consideration section of main report, as some patient leaflets need updating. |

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## Network

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HY-199 | **Involving Patients and Carers**<br><br>The network should have mechanisms for involving patients and their carers from all services in the work of the network. | Y | Patient feedback included patients who came into Oxford for review, wherever in the region they lived. |
| HY-203 | **Inherited and Acquired Bleeding Disorders Network Leads**<br><br>The network should have a nominated:<br>a. Lead consultant and deputy<br>b. Lead specialist nurse<br>c. Lead physiotherapist<br>d. Lead clinical or counselling psychologist<br>e. Lead manager | Y | However, 'd' was not in place (see Concerns section of main report). |
| HY-204 | **Education and Training**<br><br>The network should have agreed a programme of education and training to help services achieve compliance with QSs HP-203. | Y | Some educational sessions had been started, although these need to be further developed, and to include doctors from across the region. |
| HY-503 | **Guidelines**<br><br>Network guidelines should have been agreed covering:<br>a. Diagnosis for patients with suspected inherited and acquired bleeding disorders (QS HP-501)<br>b. Concentrate use and monitoring (QS HP-502)<br>c. Clinical guidelines (QS HP-503)<br>d. Management of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504)<br>e. Care of patients requiring surgery (QS HP-505)<br>f. Transition and preparing for adult life (QS HP-595) | Y | The clinical guidelines that the CCC leads felt it was appropriate for DGH colleagues to access and use had been made available on the Network Site Specific Guidance website; they had not necessarily been agreed. |
| HY-701 | **Ongoing Monitoring**<br><br>The network should monitor on a regular basis:<br>a. Submission of data on all patients to the UK National Haemophilia Database (QS HP-701)<br>b. Network-wide data on concentrate use and bleeds | Y | |
| HY-702 | **Audit**<br><br>The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702. | Y | Patients attending Oxford CCC, wherever they lived, had been included in Centre audits. |
| HY-703 | **Research**<br><br>The network should have agreed:<br>a. A policy on access to research relating to the care of patients with inherited and acquired bleeding disorders<br>b. A list of research trials available to all patients within the network. | Y | Patients attending the Oxford CCC were all offered entry to relevant clinical studies, including those who lived distantly. |

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HY-798 | **Network Review and Learning**<br><br>Representatives of Comprehensive Care Centres and referring Haemophilia Centres should meet at least once a year to:<br>a. Identify any changes needed to network-wide policies, procedures and guidelines<br>b. Review results of audits undertaken and agree action plans<br>c. Review and agree learning from positive feedback, complaints, critical incidents and 'near misses', including those involving liaison between teams<br>d. Share good practice and potential service improvements | N | Meetings including these items were not in place. |

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## Commissioning

| Ref | Standard | Met? | Comments |
|---|---|---|---|
| HZ-601 | **Commissioning of Services**<br><br>Commissioners should have agreed the configuration of clinical networks including:<br>a. Designated Comprehensive Care Centres and Haemophilia Centres and the relationships between them<br>b. Whether the service cares for children, adults or both<br>c. Referral pattern to each service, taking into account the type of patients who will be treated by each team | Y | |
| HZ-701 | **Clinical Quality Review Meetings**<br><br>Commissioners should regularly review the quality of care provided by:<br>a. Each service, including achievement of QS HP-701<br>b. Each network, including achievement of QS HY-701 and QS HY-798<br>c. Service and network achievement of relevant QSs | Y | |
| HZ-798 | **Network Review and Learning**<br><br>Commissioners should attend a Network Review and Learning meeting (HY-798) at least once a year for each network in their area. | Y | |

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