WM QRS West Midlands Quality Review Service

UKHCDO UNITED KINGDOM HAEMOPHILIA CENTRES DOCTORS' ORGANISATION

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

Hampshire Hospitals NHS Foundation Trust

Visit Date: 7th March 2019 Report Date: May 2019

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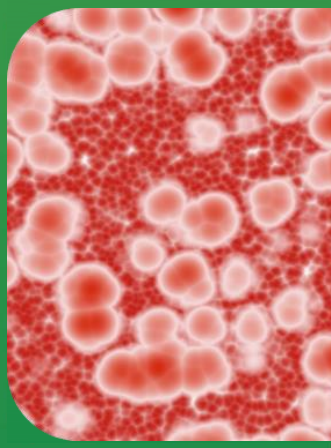

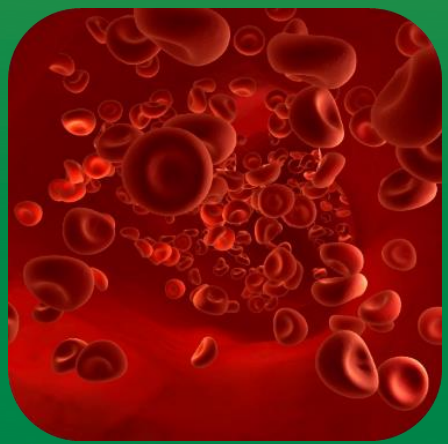

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INTRODUCTION

This report presents the findings of the peer review of services for people with Inherited and Acquired Haemophilia and other Bleeding Disorders at The North Hampshire Haemophilia Comprehensive Care Centre [CCC] which took place on 7th March 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 West Midlands Quality Review Service (WMQRS).

The peer review visit was organised by WMQRS 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:

- Hampshire 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 monitoring their implementation liaising, as appropriate, with other commissioners.

ACKNOWLEDGEMENTS

We would like to thank the team at the North Hampshire Haemophilia Comprehensive Care Centre for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks too to the patients and parents 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.

ABOUT WEST MIDLANDS QUALITY REVIEW SERVICE

WMQRS is a collaborative venture by 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.

More detail about the work of WMQRS is available at www.wmqrs.nhs.uk

The North Hampshire Haemophilia Comprehensive Care Centre and Southern Haemophilia Network

The Southern Haemophilia Network (SHN) was a clinical network providing care for patients with haemophilia and other inherited bleeding disorders in Basingstoke, Portsmouth, Bournemouth, Poole and Salisbury. The specialist commissioners funded the service as a network and the North Hampshire Haemophilia Comprehensive Care Centre (CCC) was the hub. When the SHN was set up Memorandums of Understanding were created between the Trusts and at the time of the review Service Level Agreements existed between Trusts at Basingstoke and Portsmouth, Bournemouth and Salisbury.

The SHN team had a network director, deputy director, lead nurse, lead physiotherapist and operational manager and provided comprehensive care close to the patient's home where possible. The set up at each hospital was slightly different to account for the number of patients, the existing experience of those working at the hospital and support provided from the hub at Basingstoke.

Over the previous two years the SHN had agreed shared pathways including emergency care, new diagnosis, routine care and obstetric pathways. Clinical guidelines had been written and adopted across all Trusts for the diagnosis and treatment of inherited bleeding disorders. The SHN had also implemented 'Ready Steady Go' for transition of patients from paediatric to adult services. A weekly Multi-Disciplinary Team (MDT) meeting using telephone and video conferencing had been established to include Mortality and Morbidity, governance, dashboards and reports to the National Haemophilia Database. As part of the SHN patients had access to clinical trials, early access Emicizumab and clinics close to home.

The network was a supportive environment with the Multi-Disciplinary Team happy to help colleagues and provide advice or training where needed. The network team met four times a year, two meetings in Basingstoke with the other two rotated around the network. These meetings allowed for service review and development, education e.g. recent teaching by the HIV consultant, peer support and feedback from conferences attended.

Basingstoke (Hampshire Hospitals NHS Foundation Trust)

The Haemophilia, Haemostasis and Thrombosis Centre was housed in Uplands House, a detached building on the edge of the Basingstoke and North Hampshire Hospital site. The service was consultant-led and operated from 9am-5pm on weekdays with consultant-led on-call advice available 24 hours a day.

There was a weekly network MDT meeting which included review of all in-patients and complex out-patients, newly diagnosed patients for registration, management of any planned surgery or obstetric deliveries and to review the psychosocial needs of patients who had been seen in clinics or at other times.

The service offered 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**.**

There was a highly skilled clinical trials team who work closely with the Research and Development department of Hampshire Hospitals NHS Foundation Trust (HHFT). All clinical staff at Basingstoke were Good Clinical Practice (GCP) trained and participated in clinical trials. This enabled continuity of clinical care.

The diagnostic service was led by a Consultant Biomedical Scientist and Haemostasis Diagnostics Manager. The service was UKAS ISO15189 accredited and provided an extensive test repertoire to enable diagnosis and management of patients with haemophilia and other bleeding disorders. The service also provided diagnostic and scientific support to the SHN as a whole. Factor VIII/IX assays were available 24/7 performed by the

Haematology biomedical scientist on late or night shift. If support was required, they would contact an experienced Haemophilia biomedical scientist.

The core team was supplemented by close working relationships with other specialities. Orthopaedic clinic slots were available specifically for patients with haemophilia in one surgeon's clinic (ankle specialist), however with the on-going specialism of surgeons to individual joints patients could be referred to other orthopaedic consultants as well. A member of the haemophilia team attended the clinic appointment. Joint clinics were held in the Centre with the hepatitis and HIV consultant and a joint obstetric clinic in the antenatal department.

The routine dental needs of patients with bleeding disorders were mostly managed by General Dental Practitioners in the community, however specialist services for those with complex needs were arranged with the specialised dental services through referral to Solent specialised dental services, with patients seen at the surgery within Basingstoke or within the hospital.

Home delivery of factor concentrate was managed for all patients across the network by Basingstoke, with a local doctor or Non-Medical Prescriber (NMP) who knew the patients completing the prescription.

Portsmouth Hospitals NHS Trust

There was a clinical lead for haemostasis and thrombosis employed by Portsmouth, but the network supported a full time dual accredited (adult and paediatric) haemophilia Clinical Nurse Specialist (CNS) and administration support. The CNS was based at Portsmouth but also provided community visits and spent time at the hub in Basingstoke for peer support. In paediatrics, there was a paediatric consultant with an interest in haemostasis who liaised with the specialist team based at Basingstoke and the CNS at Portsmouth. Outpatient clinics took place monthly and team members from across the network attended. In the paediatric clinic, a haemophilia consultant from Basingstoke and the local paediatrician ran the clinic with paediatric nurse and paediatric physiotherapist present. For adult clinics a haemophilia consultant from Basingstoke, the adult physiotherapist, and psychologist attended routine bleeding disorders follow up clinics. Advice for all Portsmouth based consultants was available 24 hours a day.

All patients requiring operations or procedures were discussed in the network MDT.

Children had open access to the Children's Assessment Unit when they needed to be seen to assess/manage a bleed. If they sustained a head injury, they may initially be seen in the Emergency Department with appropriate paediatric staff support.

At the Queen Alexandra Hospital, the laboratory was UKAS accredited with complex investigations including platelet aggregation referred to Basingstoke.

Bournemouth/Poole (Royal Bournemouth and Christchurch Hospital NHS Foundation Trust)

There was a clinical lead for haemostasis and thrombosis employed by Bournemouth and the network supported a haemophilia Clinical Nurse Specialist (CNS), administration support, adult and paediatric physiotherapy and an additional two PAs of consultant time.

Haemostasis clinics for children were undertaken in Poole, with clinics for adults at the Royal Bournemouth, Poole and the Dorset County hospitals. The CNS was based at Bournemouth but also attended Poole clinics.

For paediatrics at Poole, there was a clinic every three months with a paediatric consultant who attended clinics with the local haemophilia consultant.

A paediatric physiotherapist was supported by the network for 0.1 WTE and attended MDT clinics as well as

having time to see patients outside of this. Patients had open access to the paediatric physiotherapist and often contacted her directly.

Children had open access to Elmwood ward (Poole) when they needed to be seen to assess / manage a bleed. If they sustained a head injury, they may initially be seen in the Emergency Department (ED) with appropriate paediatric staff support.

Adult patients were seen in the Jigsaw day case facility at the Royal Bournemouth Hospital between 0900 – 1700, but out of hours they were initially seen in the appropriate Emergency Department for the management of bleeds.

An adult physiotherapist was supported by the network for 0.2WTE and she attended MDT clinics as well as having time to see patients outside of this time. Patients had open access to the physiotherapist and often contacted her directly.

At the Royal Bournemouth Hospital there was a UKAS accredited Haemostasis Laboratory led by an experienced senior biomedical scientist providing comprehensive laboratory investigations for the diagnosis and management of patients with bleeding disorders.

SALISBURY NHS FOUNDATION TRUST

There was a clinical lead for haemostasis and thrombosis employed by Salisbury who worked with the support of consultant colleagues, a Specialist Registrar and a team of haematology Clinical Nurse Specialists. The numbers of patients with known inherited bleeding disorders was small and therefore the team from Basingstoke provided support for all haemophilia outpatient clinics with a haemophilia consultant, nurse (adult and paediatric) and physiotherapist (adult and paediatric) attending the clinics. For the paediatric clinics a local paediatrician with an interest in bleeding disorders was the lead and also attended the clinic.

New patients were seen and investigated locally and discussed at the MDT. Children had open access to Sarum ward / Sarum Day Unit.

Patients admitted to wards were directly managed by the paediatricians with support from the local clinical lead backed up by the haemophilia service wherever necessary.

The laboratory offered quality assured local testing in all first line bleeding disorder assays. Clotting factor assays were routinely available in working hours and by arrangement out of hours. A laboratory back up service could be activated for urgent testing of clotting assays where necessary.

The Table below summarises the conditions and severity of patients registered with the network at the time of the review:

Condition		**No. patients (show breakdown Severe, Moderate and Mild)**	**No. patients who had an annual review in last year**	**No. in-patient admissions in last year**
Haemophilia A	Adults	Total: 205 Severe: 64 Moderate: 11 Mild: 130	179	5
	Children	Total: 60 Severe: 24 Moderate: 6 Mild: 30	54	2

Condition		No. patients (show breakdown Severe, Moderate and Mild)	No. patients who had an annual review in last year	No. in-patient admissions in last year
Haemophilia B	Adults	Total: 29 Severe: 9 Moderate: 4 Mild: 16	25	2
	Children	Total: 5 Severe: 4 Moderate: 1 Mild: 0	5	0

Condition		No. patients	No. patients who had an annual review in last year	No. in-patient admissions in last year
Von Willebrand	Adults	246	138	5
	Children	66	48	2
Other	Adults	309	141	9
	Children	52	27	0

The following information relates to Basingstoke, as the hub of the network:

WARD CARE

Adult patients requiring admission due to bleeding complications were most frequently admitted to Wessex ward which was a mixed haematology/oncology ward. Nurses on Wessex ward had a good understanding of the complex needs of this patient group – they were most frequently looking after those with acquired haemophilia, although there were occasional admissions of those with other bleeding disorders. The haemophilia CNS team supported them, and training was provided as needed.

Paediatric patients were admitted to the day unit on G floor with a named paediatrician and support from the haemophilia team.

Most adult elective admissions were for orthopaedic surgery – the orthopaedic ward nursing staff were familiar with administration of clotting factor concentrates and had a good liaison with the specialist nursing team. The in-patient orthopaedic physiotherapists were trained by and liaised with the Haemophilia Clinical Specialist physiotherapist.

Planned admissions all had a Haemostasis treatment plan, which was written by the Haemophilia CNS or doctor and discussed at the weekly MDT. It was then distributed to appropriate members of the team involved with the surgery and to the patient. The Haemophilia CNS team usually treated patients having surgery pre-operatively and whenever measurement of clotting factor activity was required for treatment monitoring levels. Ward nurses also administered prescribed clotting factor after close liaison with the Haemophilia CNS team and after appropriate training. On the main elective orthopaedic ward, D1, there was a “red haemophilia box” which contained educational material, information about the different clotting factors and how to mix them. The ‘red haemophilia box’ was also available on Wessex ward, Acute Assessment Unit (AAU), Charlies Day Unit /G floor and ED.

DAY UNIT CARE

Most day unit care was provided within the Haemophilia Centre, although in some cases (e.g.: DDAVP[1] trial, Rituximab or Iron infusion) adult patients attended the Haematology or medical day unit (Lyford ward). There were arrangements with Wessex ward (Haematology) to treat patients at a weekend when planned. For children Charlie's Day Unit, on G floor, was used for DDAVP trials and all children had open access to the Unit where they could be assessed and treated.

OUTPATIENT CARE

All out-patient care for Haemophilia and inherited bleeding disorders took place in the Haemophilia Centre or for paediatric patients' clinics were held both on G-floor in the paediatric outpatients and the at Haemophilia Centre depending on clinic space, age and familiarity with the team. Patients who were referred to other services attended the relevant clinics/departments.

Patients were reviewed according to need in routine outpatient clinics. All with severe haemophilia were seen in a multidisciplinary clinic at least twice yearly.

The CNS team operated a walk-in service every day for those with urgent clinical needs relating to their bleeding disorder. The CNS triaged patients and assessed whether they needed further assessment and management by the haemophilia specialist physiotherapist or the doctor on call. Patients could call the Haemophilia Centre for advice from the CNS or from the physiotherapist whenever the Centre is open.

COMMUNITY BASED CARE

Regular community visits including home treatment training for parents and children, supporting schools and home treatments for those with complex needs were performed by the CNS team.

[1] **DDAVP** - Desmopressin, sold under the trade name DDAVP among others, is a medication used to treat diabetes insipidus, bedwetting, hemophilia A, von Willebrand disease, and high blood urea levels. In hemophilia A and von Willebrand disease, it should only be used for mild to moderate cases.

REVIEW VISIT FINDINGS

Achievements

This Comprehensive Care Centre was providing a safe, excellent service. Led by a new Centre Director for the last two and a half years, the team were working in a cohesive, flexible, mutually respectful and supportive manner. They were highly patient-centred and forward looking. They were well supported by clinical and non-clinical managers and a responsive laboratory team. The haemophilia team had recently been voted the highest scoring team within the Trust's staff survey for their enjoyment and enthusiasm for their work. Patients were overwhelmingly positive in their comments about the team, and their appreciation for the work of all its members was evident. One of the senior nurses, and one physiotherapist, were singled out for special mention.

The Southern Haemophilia network, SHN, was geographically dispersed and linked with some hospitals which were nearer to another Comprehensive Care Centre. It was highly functioning, explicitly commissioned and worked very well for linked hospital teams and patients largely due to a great deal of time and energy invested by the Centre team in undertaking outreach work at the linked hospital sites and in the community. Some staff were both adult and paediatric trained; some were working in network-appointed posts and so could work flexibly across the different sites. This is an aspiration for other networks which had not been realised in many sites. It was noted that this was being achieved despite the fact that at the time of the review the team had a vacant 0.8 WTE consultant post, and a reduced nursing complement.

The excellent functioning of the service was particularly impressive. The Centre Director's leadership skills in managing the changes, brought about by a change in leadership, and the improvements to the service were outstanding. Communication had improved and collaborative working between the Centre team and other hospital teams was recognised. These improvements were specifically noted by the linked hospital teams with one haematologist commenting that the service had 'changed beyond recognition and was one of which he was proud to be a part'.

There was a broad research portfolio. The research lead was a key team member of the team and all members of the professional team were actively engaged in patient-centred research. The team had recruited the first patient, worldwide, to the Bioverativ 242HA201 study.

Good Practice

1. Patient information was comprehensive, locally produced, and was available on the network website by hospital. Condition specific information was especially good.
2. A new process for managing telephone calls from patients for advice was in place with a proforma recording the message, who had responded and when. This was implemented in response to patient feedback that responses were not timely. The outcome of telephone consultations was also included in the electronic record.
3. There was a rolling programme of audit in place at the Centre, with responsible team members named for each audit.
4. The Trust had a 'carer's hub' providing support as needed, and parents using the service noted that they had received excellent support from team members even if their concerns were unrelated to their child's condition.
5. There was a clearly visible 'red box' in the Emergency Department and other clinical areas, which included laminated copies of the pathways, contact details, full clinical guidelines and guidance on reconstituting and giving concentrates.

6. A ‘baton phone’ was held by the out of hours on-call consultant covering the service so that users had a single contact number and there was no confusion about rota changes etc.
7. A dedicated weekly clinic ‘slot’ for patients with bleeding disorders had been agreed with the Trust’s orthopaedic team specialising in ankle problems; this was at the start of the clinic so that members of the Haemophilia Centre team could attend with patients when they were seen.
8. A physiotherapist-led focus group had been successful and appreciated by patients. It had led to a number of recommendations and an action plan with clear deadlines for completion had been developed.
9. Radioactive synovectomy [2] was available [see also ‘Further Consideration’ 7]
10. Point of care ultrasound assessments, HEAD-US [3], was part of regular practice for adult patients [see also ‘Further Consideration’ 8]
11. Clear network pathway flowcharts were in place for patients with severe and milder disorders presenting acutely.
12. The network MDT process was clear and well-managed, with members of linked hospital teams joining by teleconference. Discussions were formally recorded at the Centre and returned for inclusion in the patients’ local records.
13. The setting up of Emicizumab monitoring assays was noted as a positive development by reviewers who also highlighted that the BMS and laboratory staff were responsive to the new/novel treatments.
14. The network website was clear, comprehensive and user-friendly.
15. A senior nurse provided enhanced peer support, with mentoring and supervision, to nurses across the network. Evening meetings were held, and staff were able to reclaim the time spent on this recognised professional development activity.
16. The IT system in place supported the service very well.
    a. There was a ‘red stick man’ alert attached to every patient’s record, and a ‘critical care plan’ detailing all key information of diagnosis, usual treatment and specific concentrate to be given at presentation for injury or bleed.
    b. It was possible to access records on patients across the network from the Centre, even if they had been seen in their local hospital at outreach clinics, and not at the North Hampshire Comprehensive Care Centre.
    c. Centre and network records were accessible from home by senior staff covering out of hours.
17. Document control was good, with authorship, dates of issue and dates for revision included.

Immediate Risks:

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

[2] **Radioactive synovectomy** - is a very effective and gentle procedure, used for rapid and sustained pain relief of severe joint pain or arthritis, such as osteoarthritis. Through targeted sclerotisation of the synovial membrane with radioactive substances, lasting relief from pain and inflammation is achieved in most cases.

[3] **HEAD-US** – Haemophilia Early Arthropathy Detection with Ultrasound [HEAD-US], a point-of-care ultrasound technique to detect abnormalities in joints without history of hemarthrosis and clinically asymptomatic joints.

Concerns

1. **Clinical Guideline**

   The only concern related to a clinical guideline for the management of children with inhibitors, in which it was not explicit that recombinant VIIa should be the first choice for bleed treatment over aPCC in plasma naïve patients; the guideline seemed to suggest aPCC as a suitable first choice.[4]

Further Consideration

1. As noted above, there was a vacant 0.8 WTE consultant post. In addition, there were only two Clinical Nurse Specialists (CNS) whereas there were previously three. Centre nurses also covered for colleagues sickness absence across the network. As well as the continued efforts to recruit to the vacant consultant post, the review team suggested that consideration should be given to reviewing the CNS resource, possibly a research nurse lead for which external funding may be available. It was recognised that other nurse team members would wish to continue with their research activity also, but the three nurses could share the clinical and research work between them.
2. The Centre team members had supported and educated the Emergency Department team. Patients and parents however reported that they did not feel confident that the staff there were fully aware for how they should be managed in the case of acute presentation and still preferred to be seen by a member of the haemophilia team.
3. Parents who had brought children to the Charlie Day Unit also described that although they had been told that they would be seen immediately that this did not always happen.
4. A large single clinical guideline that covered most areas required was in place but in some places, guidance was felt to be insubstantial or lacking, including:
   a. The guidance for long term joint health;
   b. There was no guidance about radioactive synovectomy;
   c. Details for practical local implementation of guidance for patients presenting to the Centre acutely were lacking; for example, if a patient needed to be transferred to the main hospital for imaging, at what point and by whom factor replacement should be administered.
   d. A training document for home care did not include any 'red flag' signs for which patients / parents should plan to seek immediate help; for example, signs suggestive of sepsis for those with indwelling intravenous devices.
5. Reviewers heard that when the paediatric clinic took place in the main hospital paediatric out-patient area, there was sometimes only a single room available and this could lead to long waiting times for families. Consideration should be given to making another clinic room available to the team or moving the clinic time to another session where more space was available.
6. The fact that the Haemophilia Clinical Information System (HCIS) was not networked or accessible remotely presented problems at the Basingstoke and other centres. At the Basingstoke centre, physiotherapy assessments taking place at outreach sessions were recorded manually, and subsequently transcribed onto HCIS by the specialist physiotherapist, using valuable professional time. It was suggested

[4] Following discussion with the clinical team it was clarified that in practice recombinant products would be the first line of treatment for a child with inhibitors however the guideline was not explicit].

that a member of the Centre's administrative team might be able to undertake this transcription onto HCIS.

7. Patients referred for radioactive synovectomy had to be seen and assessed in a Rheumatology clinic, returning subsequently for the procedure. The review team suggested that it might be possible for referrals to be accepted directly from the Centre's specialist team members, cutting out the need for an additional attendance in Rheumatology.
8. Point of care HEAD-US, in regular practice for adults, could also be extended to the paediatric service.
9. The process for following up carriers of inherited bleeding disorders at 16 years, with further factor assays and advice, needed to be formalised.
10. There was no identified Care of Elderly team supporting the service, and with an aging patient population this would be beneficial.
11. Reviewers noted that the Haemophilia Centre was not well signposted from the main hospital. Improvements to signage could help to improve the overall patient experience.
12. The audit programme for the Centre is explicit and well managed, and some network-wide audits had taken place but there was no clear planned audit programme in place for the network.
13. Review and learning from incidents and complaints, and morbidity and mortality discussions, did not yet form part of the network-wide meetings, although this was planned.
14. There had been extensive patient and public involvement at the start of the service improvement project three years before, and it was felt that it would be useful to undertake a further Public and Patient Involvement exercise now that so many changes in service had occurred. The benefit of this would be improved if this was part of routine practice rather than for individual projects.

NETWORK

As described, the SHN was a very effective clinical network, and much effort had gone into improving the way in which teams at other sites in the network, and patients attending them, could be supported. The team had self-assessed compliance with the eight network standards [HY-199 – 798]; compliance was assessed by reviewers and standards were judged to be met for five of them.

Further detail is available on the compliance spreadsheet.

COMMISSIONING

Self-assessment against the three commissioning standards indicated all were met; on review it was felt that the network review and learning meetings did not yet include discussion of incidents, complaints, morbidity and mortality although it was planned that these be included in future agendas.

Further detail is available on the compliance spreadsheet.

The South-Central Specialised Commissioning group commissioned two other Comprehensive Care Centres, at Southampton and Oxford; paediatric tertiary services were available at these sites and there were referral pathways in place for children needing this level of care. Following the planned reviews at both of these sites, further discussion may be generated regarding the clinical pathways and working partnerships between the three Centres.

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APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Visiting Team		
Dr Jayanthi Alamelu	Consultant Paediatric Haematologist	Evelina London Children's Hospital Guys and St Thomas' NHS Foundation Trust
Trupti Bhandari	Paediatric Haemophilia Physiotherapist	Evelina London Children's Hospital Guys and St Thomas' NHS Foundation Trust
Dr Gillian Evans	Consultant Haematologist	East Kent Hospitals University NHS Foundation Trust
Simon Fletcher	Lead Research Nurse	Oxford University Hospitals NHS Foundation Trust
Sandy Jeffery	Patient representative	
Paul McLaughlin	Clinical Specialist Physiotherapist in Haemophilia	Royal Free London NHS Foundation Trust
Alice Wilkinson	Paediatric Haemophilia Nurse	Oxford University Hospitals NHS Foundation Trust

WMQRS Team		
Dr Anne Yardumian	Consultant Haematologist	Programme Clinical Lead
Rachael Blackburn	Assistant Director	West Midlands Quality Review Service

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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 varied 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

Adult Service	Number of Applicable QS	Number of QS Met	% met
Comprehensive Care	37	36	97
Networking	8	5	63
Commissioning	3	3	100
Total	48	44	92

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HAEMOPHILIA COMPREHENSIVE CARE CENTRES AND HAEMOPHILIA CENTRES

Ref	Standard	Met?	Comments
HP-101	**Service Information** Written information should be offered to patients 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. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent) v. Give feedback on the service, including how to make a complaint vi. Get involved in improving services (QS HP-199)	Y	

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

Ref	Standard	Met?	Comments
HP-103	**Plan of Care** 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: a. Agreed goals, including life-style 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 and preparation for adult life (children and young people only) 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 communicated to the patient's GP and to relevant other services involved in their care.	Y	
HP-104	**Review of Plan of Care** 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** 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)** 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** 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. 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.	Y	However, see Further Consideration regarding the requirement for more space in paediatric outpatients
HP-195	**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	Y	
HP-198	**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	Y	
HP-199	**Involving Patients and Carers** The service should have: a. Mechanisms for receiving regular feedback from patients and carers about treatment and care they receive b. Mechanisms for involving patients and carers in decisions about the organisation of the service 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** 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** 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: 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 haematologist (24/7) iii. Arrangements for advice from a consultant specialising the care of people with inherited and acquired bleeding disorders (if not on call) 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. Biomedical Scientist and Clinical Scientist (further detail on the requirements are included in HP-303) e. Clinical or counselling specialist psychologist or appropriately trained psychotherapist f. Specialist senior social worker g. Data manager	Y	

Ref	Standard	Met?	Comments
HP-203	**Service Competences and Training Plan** 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** All health and social care professionals working in the service should have competences appropriate to their role in: a. Safeguarding children and/or vulnerable adults b. Recognising and meeting the needs of vulnerable children and/or adults c. Dealing with challenging behaviour, violence and aggression d. Mental Capacity Act and Deprivation of Liberty Safeguards e. Resuscitation	Y	
HP-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be available.	Y	
HP-301	**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	Y	
HP-302	**Emergency Department – Staff Competences** 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: a. Guidelines on care of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) b. Who to contact for advice	Y	Reviewers saw that the team had undertaken a lot of work with ED colleagues in order to improve understanding of treatment and management of patients with bleeding disorders. However, based on feedback from patients they still preferred to contact the Haemophilia Centre staff direct on their way to hospital

Ref	Standard	Met?	Comments
HP-303	**Laboratory Service** a. A UKAS / CPA 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 HP-602) regularly c. The following tests should be available: i. All coagulation factor assays (24/7) ii. Inhibitor screening iii. FVIII inhibitor quantification iv. VWF antigen v. VWF activity vi. Platelet function testing d. Molecular Genetic Laboratory service for: i. detection of causative mutations in patients with inherited bleeding disorders ii. carrier detection	Y	
HP-304	**Specialist Services** 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: 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.	Y	However, reviewers did not see any evidence for e (care of older patients)

Ref	Standard	Met?	Comments
HP-402	**Facilities and Equipment** 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 patients and carers d. Room for multi-disciplinary discussion e. Room for educational work with patients and carers f. Office space for staff g. Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all clinical areas All equipment should be appropriately checked and maintained.	Y	However, see Further Consideration regarding the need for more space in paediatric outpatients
HP-499	**IT System** IT systems should be in use for: a. Storage, retrieval and transmission of patient information, including access to the latest vCJD status and family tree b. Patient administration, clinical records and outcome information c. Data to support service improvement, audit and revalidation 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** Guidelines on diagnosis should be in use covering at least a. Haemophilia A b. Haemophilia B c. Von Willebrand Disease d. Acquired haemophilia e. Inherited platelet disorders f. Other less common and rare bleeding disorders	Y	However, it was one very large document which may be unwieldy for staff. In addition, reviewers could not see any reference to training for staff in genetic counselling

Ref	Standard	Met?	Comments
HP-502	**Guidelines: Concentrate Use and Monitoring** Guidelines should be in use covering: a. Concentrate therapy: i. Initiation and monitoring of prophylaxis ii. Home therapy b. Use of extended half life products, including inhibitor testing and PK assessment c. Management of concentrate 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 patients on home treatment v. Arrangements for emergency 'out of hours' supply vi. Recording issue to patients vii. Recording use by patients, including on Haemtrack viii. Submission of data via NHD for national tenders coordinated by CMU	Y	
HP-503	**Clinical Guidelines** The following clinical guidelines should be in use: a. Management of acute bleeding episodes, including patients with inhibitors b. Inhibitor screening c. Immune tolerance therapy d. Dental care e. Care of patients with hepatitis C f. Care of patients with HIV g. Antenatal care, delivery and care of the neonate h. Management of synovitis and target joints i. Long term surveillance of musculoskeletal health j. “For public health purposes”: care of patients at risk of vCJD who are undergoing surgery	Y	
HP-504	**Emergency Department Guidelines** 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** Guidelines on the care of patients 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 patient's care prior to, during and post-surgery c. Documentation of care provided d. Arrangements for escalation in the event of unexpected problems	Y	
HP-595	**Guidelines on Transition and Preparing for Adult Life** Guidelines on transition of young people from paediatric to adult services should be in use covering at least: a. Taking responsibility for their own care b. Involvement of the young person and, where appropriate, their carer in planning the transfer of care c. Joint meeting between paediatric and adult services in order to plan the transfer d. Allocation of a named coordinator for the transfer of care e. A preparation period prior to transfer f. Arrangements for monitoring during the time immediately after transfer g. 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 the young person's new GP	Y	
HP-599	**Care of Vulnerable People** Guidelines for the care of vulnerable children, young people and adults should be in use including: a. Restraint and sedation b. Missing patients c. Mental Capacity Act and the Deprivation of Liberty Safeguards d. Safeguarding e. Information sharing f. Palliative care g. End of life care	Y	

Ref	Standard	Met?	Comments
HP-601	**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 patients 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 patients (QS HP-602) e. Arrangements for follow up of patients who 'do not attend' f. Arrangements for transfer of patient information when patients move areas temporarily or permanently 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) h. Ensuring school visits for children with severe haemophilia at least at each change of school (children's services only) i. Ensuring patients are visited at home at least annually if they are unable to attend clinics, including those in nursing homes j. Lone working	Y	
HP-602	**Multi-Disciplinary Team Meetings** Multi-disciplinary team meetings to discuss patients' plans of care should take place regularly involving: a. All core members of the specialist team (HP-202) b. Senior biomedical scientist or clinical scientist with responsibility for the Coagulation Laboratory 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** The following multi-disciplinary clinic arrangements for patients with inherited and acquired bleeding disorders should be in place: a. Involvement of medical, specialist nursing and physiotherapy staff in clinics b. Availability of social work and psychology staff in clinics c. Combined clinics or other arrangements for multi-disciplinary discussion with: i. orthopaedics ii. rheumatology iii. obstetrics and gynaecology iv. paediatrics v. dental vi. HIV / hepatology	Y	
HP-604	**Liaison with Other Services** Review meetings should be held at least annually with specialist services to consider liaison arrangements and address any problems identified.	N	Evidence was not provided that formal annual meetings take place as per the requirement of this standard.
HP-701	**Data Collection** The following data should be collected: a. UK National Haemophilia Database data on all patients b. Data on concentrate use and bleeds, either through Haemtrack or an equivalent mechanism c. Data required to complete the UKHCDO National Haemophilia Dashboard or other national mechanisms	Y	
HP-702	**Audit** The services should have a rolling programme of audit covering at least: a. Clinical guidelines (QS HP-503) b. Emergency and out of hours care (QS HP-504) c. Initiation of prophylaxis in children d. Inhibitor surveillance and Immune Tolerance Induction (ITI) e. Clinical reviews including joint scores (QS HP-103 & 104) f. Concentrate use and wastage	Y	
HP-706	**Research** The service should actively participate in research relating to the care of patients with bleeding disorders.	Y	See Further Consideration regarding potential to employ another nurse which may help increase the research portfolio

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

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NETWORK

Ref	Standard	Met?	Comments
HY-199	**Involving Patients and Carers** The network should have mechanisms for involving patients and their carers from all services in the work of the network.	Y	
HY-203	**Inherited and Acquired Bleeding Disorders Network Leads** The network should have a nominated: a. Lead consultant and deputy b. Lead specialist nurse c. Lead physiotherapist d. Lead clinical or counselling psychologist e. Lead manager	Y	
HY-204	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HP-203.	N	Reviewers agreed with the Centres own self assessment
HY-503	**Guidelines** Network guidelines should have been agreed covering: a. Diagnosis for patients with suspected inherited and acquired bleeding disorders (QS HP-501) b. Concentrate use and monitoring (QS HP-502) c. Clinical guidelines (QS HP-503) d. Management of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) e. Care of patients requiring surgery (QS HP-505) f. Transition and preparing for adult life (QS HP-595)	Y	
HY-701	**Ongoing Monitoring** The network should monitor on a regular basis: a. Submission of data on all patients to the UK National Haemophilia Database (QS HP-701) b. Network-wide data on concentrate use and bleeds	Y	
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.	N	Reviewers agreed with the Centres own Self Assessment. Although there are plans to implement this it was not in place at the time of the review

Ref	Standard	Met?	Comments
HY-703	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with inherited and acquired bleeding disorders b. A list of research trials available to all patients within the network.	Y	
HY-798	**Network Review and Learning** Representatives of Comprehensive Care Centres and referring Haemophilia Centres should meet at least once a year to: a. Identify any changes needed to network-wide policies, procedures and guidelines b. Review results of audits undertaken and agree action plans c. Review and agree learning from positive feedback, complaints, critical incidents and 'near misses', including those involving liaison between teams d. Share good practice and potential service improvements	N	Reviewers did see evidence (agendas and minutues) that these meetings were taking place regularly and were well attended. However, there was no evidence that all elements of this standard were regular items for discussion at the meetings or evidence that this resulted in sharing of good practice and changes to service delivery

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COMMISSIONING

Ref	Standard	Met?	Comments
HZ-601	**Commissioning of Services** Commissioners should have agreed the configuration of clinical networks including: a. Designated Comprehensive Care Centres and Haemophilia Centres and the relationships between them b. Whether the service cares for children, adults or both 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** Commissioners should regularly review the quality of care provided by: a. Each service, including achievement of QS HP-701 b. Each network, including achievement of QS HY-701 and QS HY-798 c. Service and network achievement of relevant QSs	Y	
HZ-798	**Network Review and Learning** 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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