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

Alder Hey Children's NHS Foundation Trust

Visit Date: 27th November 2019

Report Date: March 2020

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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 Alder Hey Children's NHS Foundation Trust which took place on the 27th November 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:

- Alder Hey Children's NHS Foundation Trust
- NHS England Specialised Commissioning North West
- Welsh Health Specialised Service Committee (WHSSC)

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 at Alder Hey for all 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 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.

Alder Hey Comprehensive Care Centre

Alder Hey Children's NHS Foundation Trust (Alder Hey) combined with The Roald Dahl Centre, Liverpool University Hospitals NHS Foundation Trust, to form the Liverpool Haemophilia and inherited bleeding disorder (IBD) Comprehensive Care Centre (CCC). As the paediatric part of the service the team provided specialist multidisciplinary care to children and young people (CYP) affected by IBDs across Merseyside, Cheshire, Lancashire, Shropshire, North Wales and the Isle of Man.

The vision of the IBD team was to provide families with the knowledge, skills and understanding of their child's disorder to enable the child to live independently, confident that they had access to clinical, emotional and social support when needed. Children were admitted to hospital when necessary to provide high quality haematology advice and input.

The team worked in partnership with the families in their care, aiming to provide a service that was tailored to individual needs, was informed by current research and provided access to new and developing treatments. Their aim was to enable CYP to live well with their disorder by ensuring that all clinical and support teams within the Trust, the local hospitals, primary health care and the community that were, or that became, involved with the CYP were provided with relevant and up to date treatment and care information.

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

Condition		Number of patients	Number of patients who had an annual review in last year	Number of inpatient admissions in last year
Haemophilia A		Severe 34 Moderate 10 Mild 20	Severe 34 Moderate 8 Mild 16	1 x Severe had two admissions (port infection) 1 x Mild had one admission (knee bleed)
Haemophilia B		Severe 1 Moderate 2 Mild 1	Severe 1 Moderate 2 Mild 1	1 x Severe had three admissions (2 x infection related; 1 x # to heel)
Von Willebrand	Adults	3 (aged 18; 19; 21)	2	0
	Children	34	28	1 complex needs orthopaedic
Other	Adults	1	26	1 complex needs orthopaedic 1 cleft and palate bone grafting
	Children	36		

Emergency Care

For patients attending the Emergency Department (ED) at Alder Hey, their diagnosis was recorded in their electronic medical record. Treatment plans were updated at each clinic appointment and were located in the most recent Medisec[1] letter. On completion of an ED visit a referral was made and received on Meditech[2]. When the patient was outside the Liverpool area, families were advised to carry their bleeding disorder card, most

[1] Medisec is a commercial clinical correspondence system
[2] Meditech is a commercial electronic health record system

recent clinic letter and where, available, treatment with them to their local ED and for the clinicians to contact the haematology team at Alder Hey.

If carers were uncertain whether their visit to the ED was necessary, they could make use of the informal on-call service provided by the IBD nurse specialists. Carers were able to call and ask for advice, but they were advised to attend the ED for assessment if an immediate response was not received. This service was of particular benefit to those who were new to IBDs and who were uncertain as to what action to take.

When visits to the ED were necessary, carers were advised to attend, and, where possible, to bring with them the patients bleeding disorder card and any treatment that they had at home. They were advised that on arrival at reception, and again at triage, they should explain that their child had an IBD and to describe the acute problem that had bought them to the ED.

Ward Care

Acute admissions – patients with bleeding disorders could be admitted from the ED to the emergency decisions unit or to any ward within Alder Hey. Clinical responsibility remained with the admitting clinician unless the primary need for admission was related to the patient's IBD or their treatment, when a transfer to haematology care would be made, making the IBD consultant the lead clinician.

Planned admissions - when an overnight admission was anticipated, this would be to Ward 3B - the haematology oncology ward. Nurses on this ward had received training in IBD and were familiar with current treatments. Admission could also be to the ward that specialised in the primary reason for admission (e.g. surgical procedure). Patient-specific information, education and support were given by the IBD nurse specialist for the duration of the inpatient stay.

Day case admissions - planned admissions for minor surgical and dental procedures, such as dental extractions and port removal, were managed through the Surgical Day Case Unit, a collaborative process with prescribing and treatment managed by the IBD nurse specialists.

Day Care

The Haematology Treatment Room (HTR) was open between 8am and 5pm. It was run by the Bleeding disorder / Non-Malignant Haematology nurse specialists and was independent of the outpatient department.

The HTR was the identified space for IBD families to attend for support, advice, information, training and education sessions. Here, patients and their parents learned more about their diagnosis, how to recognise the signs and symptoms of a bleed and how to administer treatment. Appointments in the HTR could be booked in advance with the nurse specialists directly or through the office, but there were times when more urgent advice and treatment was needed and an in hours drop in service was provided for these unplanned attendances. Families were asked to contact the team on their way to the hospital. When the acute need was such that an ED visit was more appropriate, a patient review was arranged in the ED environment.

The HTR had storage for factor and other medication as well as the associated ancillaries.

Outpatient Care

The weekly IBD consultant new patient/diagnostic clinic was held in the outpatient clinic suite on Ward 3B. This area, which comprised of four clinical rooms, a waiting area, play facilities and a quiet room was part of the haematology-oncology department. Between eight and twelve patients attended this weekly clinic, with an approximate split 60:40 IBD/NMH. All other clinics were held in the outpatient area of the hospital.
Fortnightly annual review clinics and four monthly transition clinics were held for patients affected by IBDs only. Each clinic was attended by approximately five patients. Follow up clinics were led by the nurse specialist.

Community Based Care

Appointments in the home were provided by the IBD/NMH nurse specialist team. Home visits helped the IBD team to understand the opportunities and obstacles faced by a family unit that may enable or obstruct adherence to treatment plans or living well with an IBD. The team aimed to visit all patients with moderate or moderate to severe IBD at home at least once a year. Some families affected by mild IBDs need the same amount of community support as their more severely affected peers.

Initial training in becoming a clinical carer who was able to administer treatment was given in the HTR, providing an environment with treatment and ancillaries safely stored but easily accessible and with nurse specialists and emergency equipment available as needed.

Visits were made to those schools attended by patients with severe or moderately severe IBDs to provide training to teaching staff, lunch time/playground staff and first aiders. Visits were aimed at the transition points from infants to juniors and juniors to high school to discuss IBDs and day to day management and to provide written information which could be used by school nurses to draw up a care plan. Written information was also provided to the schools attended by patients with milder bleeding disorders.

Clinical school visits - patients were encouraged to learn self-infusion at some stage between the ages of 9 and 12 years. To minimise absenteeism most training took place on a weekly basis in school where the team engaged the support of school first aiders. Although the first aiders did not administer treatment, they provided support and encouragement when treatment was administered.

Out of school groups and holiday clubs - Where requested, information was provided or, where appropriate a meeting with the group leader or first aider was arranged using similar information to that provided for schools.

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Review Findings

Achievements

This team, working under very considerable staffing pressures, was offering a good and highly appreciated service to its patients and families. The three long-serving core team members were working remarkably hard and were clearly committed to the service and to trying to ensure their patient's best interests were met. They were well supported by colleagues in the laboratory, pharmacy and other clinical teams across the hospital, by whom they were held in high regard. The extra time and effort put into arranging extra activities for the children, including annual camping trips in Wales and Christmas parties and outings, was noted.

Patient and parent feedback was overwhelmingly positive, with the contributions of the two nurse specialists drawing special comment; there was also concern about the time when they would no longer be in post (see Concern 1). The team considered the needs of the whole family. Some parents had travelled from long distances to meet reviewers as they particularly wanted to record their gratitude for the care that they and their children had received.

The facilities from which the services were delivered were outstanding, within a beautifully designed new hospital; the ward area and physiotherapy areas were especially notable. Efforts had been made, in response to user comment, to separate the out-patient rooms from the haematology-oncology area.

Good Practice

1. Some locally written information leaflets for patients, parents and carers were excellent. These included: condition-specific information; information for schools and first aiders, and a sign-off sheet for parents starting to administer treatment at home.
2. A range of approaches to encourage Haemtrack[3] compliance had resulted in substantial improvement.
3. Families had easy access to the nurse specialists who carried mobile phones and also gave e-mail contacts.
4. An annual review proforma was in use, and entries on the proforma could be transferred over for inclusion in letters to the GP and carers.
5. An audit of factor dispensed against factor actually used, undertaken as part of a CQUIN, was noted as this is an issue that some centres do not scrutinise.
6. The laboratory team were well integrated into the work of the Centre, sharing an 'Outlook' diary to indicate days on which more time-consuming investigations could best be requested.
7. Annual user satisfaction surveys had been undertaken over the last six years, with evidence of changes made as a result of comments received.
8. Efforts were made to introduce parents with newly diagnosed children to other affected families for support.

[3] **Haemtrack** - is a secure recording system connecting patients and clinicians through the Haemtrack phone apps and website. Haemtrack enables patients to record all therapies as they occur and allows clinicians to see up-to-date therapy information to help monitor, optimise and improve patient care.

Immediate Risk

1. In their efforts to provide support for children and families, the two nurses offered an informal out-of-hours service, receiving calls from families during evenings and weekends. This was the process outlined in the departmental operational policy. While this posed no risk to patients, it put them individually at risk as organisations may not support or indemnify professionals for advice given when not on duty. The hospital should formalise an on-call arrangement, or if it cannot be formally supported, the management team will need to inform patients of this, and of the alternative out-of-hours contact procedure.

   Trust response:

   The Division of Medicine Senior Leadership Team have met with the Haemophilia Specialist Nurses, and in response to the Immediate Serious Concerns highlighted following the QRS visit, have agreed the following plan:

   1. To formalise with immediate effect, the currently informal on call arrangements for the specialist nurses, with appropriate remuneration until the end of January 2020.
   2. To establish during January 2020 a working group to determine longer term solutions for providing safe and sustainable out of hours support to families of haemophilia patients.
   3. To implement this safe and sustainable service from beginning February 2020.
   4. To communicate with the families, the interim and immediate formalised arrangements for out of hours support and inform families of intentions to establish more sustainable support arrangements from February 2020, with further communication to follow.
   5. The Divisional Management Team will maintain close oversight, through meetings and audit, of the implementation of and adherence to the future formalised out of hours support arrangements and will report this through the Trust's governance meetings.

   QRS response:

   We have reviewed the actions that you have already implemented and the ones that are planned and I can confirm that once these changes are fully implemented as described in your letter, this will fully address the immediate risks identified.

Concerns

1. **Staffing**

   a. Senior medical staff - There were 1.6 WTE consultant vacancies in the team. Due to a combination of consultant sick leave, maternity leave, and a recent retirement and at the time of the visit there was 0.8 WTE consultant cover for the service. This was due to reduce to 0.3 WTE (one and a half days a week) two days after the visit as a locum appointment was coming to an end. As the remaining consultant was prepared to offer a 24/7 on call service until a colleague returned to work, possibly two to four weeks later, this did not constitute a clinical risk to patients, but was clearly unsustainable. In the limited number of senior medical sessions available, some aspects of the director's role such as managing a clinical audit programme and ensuring complete guidelines were in place, were not currently being performed.

   b. Nurse specialists - The complement of specialist nurses was 1.6 WTE, with current support from an additional whole time nurse whose secondment period was due to end in the near future. The nurses also worked across some other non-malignant haematology sub-specialties and were offering some aspects of psychosocial care as the team lacked some key members (see c below). In addition, they had also been undertaking some duties usually undertaken by senior medical staff – such as carrying out routine reviews of some moderately affected patients and writing guidelines for the department.

They also worked across a wide geographical area, visiting schools and families as far away as North Wales. This provision was insufficient, and they were working well beyond their contracted hours. Furthermore, one of the two long-serving nurse specialists intended to retire less than a year after the review visit. It is hoped that planned interviews to appoint into an additional post will be successful in recruiting a substantive colleague.

c. Psychosocial care - There were no psychology sessions offered to the service, and social workers were only involved if there were safeguarding issues. Other team members, especially the nurse specialists, were undertaking some support work, and referral to the hospital psychology service could be made for high level needs. However, in the absence of a psychology member, the team were lacking the support that such a colleague can bring, and it was inevitable that some lower level child and family needs were not being met. Additionally, there was no dedicated play therapy available for children.

2. **Guidelines**

Some guidelines were lacking. Some guidelines had been written but were not comprehensive, and in many places they were at variance with current UKHCDO guidance. In two places, they were incorrect: inhibitor screening is expected to be undertaken after every three exposures to factor replacement, not after every five (as in the Trust guidelines); and the guidance for immune tolerance induction to offer all children a high dose initially is not what was recommended by national guidance. Neither of these would put children at clinical risk. The management of bleeding episodes did not contain specific information about treatment, doses or frequency. It was understood that the guidelines had not yet been distributed, and the review team recommended that they were revised as soon as senior medical time allowed and then made available for use. In the meantime, guidelines from other centres have been made available on the UKHCDO website and the team may wish to check whether these would be suitable to be adapted for local implementation.

Further Consideration

1. The evidence presented as audit was of factor usage and other data required for national submission. However, there was very little evidence of local clinical audit of practice, and no audits of emergency or out-of-hours care, initiation of prophylaxis in children or inhibitor surveillance and immune tolerance induction. This was recognised by the CCC team, who were planning to make audit an area for improvement once staffing numbers were re-established.
2. There was no 'alert' on the electronic patient record to bring a child's bleeding disorder to the attention of ED staff. There was no single clear guideline for the early management of a child presenting with a bleed or trauma. A practice educator had started work to establish regular training for ED staff in the management of children with these conditions, and this work should be supported and progressed as soon as possible.
3. Data management
    a. Some figures seen for the performance of the Centre benchmarked against national data appeared to have inconsistent patient numbers included in the submissions.
    b. There was a local database in use, but the team did not enter data onto the Haemophilia Centre Information System (HCIS) as most other CCCs do. Although initial time would be required to set this up, once established it may save time and effort as data can be transferred across directly from HCIS to the national database.
4. There was no robust system in place for identifying and recalling all potential carrier females for testing and counselling, usually expected by the age of 16. It was therefore possible for a carrier woman to become pregnant with an affected male baby without having been tested, so that appropriate care at delivery could

not be planned. This could be established in collaboration with the adult team at the Liverpool University Hospitals NHS Foundation Trust, Roald Dahl Centre.

5. Blood for factor level measurement was usually taken through peripheral venepuncture, even in children who had long-term intravenous devices / ports. As long as approximately the first 5 mls of blood removed are discarded before taking the sample for measurement, and any volume removed is replaced with an equal volume of saline, samples taken from central venous devices can be used, and this would reduce the discomfort of extra peripheral venepuncture.
6. The section in the operational policy that outlined the process to be followed for children who were not brought for appointments did not contain a step to involve social services after repeated failures of families to attend, although this was done in practice.
7. A newly established 'Inherited Bleeding Disorders Risk and Governance' monthly meeting included all the elements necessary for review and learning good practice, and efforts to protect staff time to continue and embed this meeting on a regular basis should be encouraged.
8. An appropriate level of document control was not in place, with many documents and guidelines lacking details of authorship, approval date and / or intended review date.
9. Signposting to the Haemophilia Centre was poor, so that patients and families new to the service might have difficulty locating it and families using the Centre would not see a demonstration of the ownership of the area by their specialist service.

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General Comment

The Alder Hey CCC supported a Haemophilia Centre (HC) in North Wales, where there was a named lead paediatrician and specialist nurse, and colleagues there reported feeling well supported by the specialist team when they needed clinical advice. However, a recently appointed adult haematologist and other local staff indicated that they would greatly appreciate some outreach sessions by the CCC team so that they could jointly review and manage children living locally. The CCC team are currently not sufficiently well staffed to offer this, but the plan to support the HC in this way should be reviewed once staffing numbers are restored. In the meantime, it was unclear how many children with bleeding disorders were in the North Wales catchment area and therefore whether all were registered and receiving appropriate care and treatment.

As well as the linked HC, the team at Alder Hey were also providing advice, via an informal network, to a number of District General Hospitals (DGHs) in the North West, including Wirral, Warrington, Chester, Southport, Ormskirk and the Isle of Man, several of which had Emergency Departments to which local children may present. It would be helpful for link paediatricians from these sites to meet with the CCC leads, to progress joint working in the form of sharing guidelines and clinical audits (when they are available), and to offer shared educational opportunities. This additional work will only become possible when the staffing levels at Alder Hey are re-established, and the job plans of the consultants will need to be reviewed if they are to undertake this development work.

The support of commissioners will be key to ensuring that these network arrangements and potential developments are achievable, and it is recognised that the different commissioning arrangements in North Wales may make this more of a challenge.

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APPENDIX 1 Membership of Visiting Team

Visiting Team		
Trupti Bhandari	Paediatric Haemophilia Physiotherapist	Guy's and St Thomas' NHS Foundation Trust
Shaun Emmitt	Benign Haematology Nurse Specialist	Sheffield Children's NHS Foundation Trust
Dr Jennifer Gardner	Clinical Psychologist	Great Ormond Street Hospital for Children NHS Foundation Trust
Andy Martin	Patient representative	
Dr Mary Mathias	Consultant	Great Ormond Street Hospital for Children NHS Foundation Trust
Sarah Updyke	Haemophilia Nurse	Lewisham and Greenwich NHS 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.

Service	Number of applicable QS	Number of QS met	% met
Centre	37	28	76
Network	8	1	13
Commissioning	3	1	33
Total	**48**	**30**	**63**

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Comprehensive Care Centre

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 2. Haemophilia B 3. Von Willebrand Disease 4. Acquired haemophilia 5. Inherited platelet disorders 6. Other less common and rare bleeding disorders	Y	See Good Practice section of main report regarding bespoke, localised condition-specific information. However, there was no evidence for 's' (vaccinations).

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	See Good Practice section of main report.

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	See Achievements section of main report.
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	However, see the Concerns section of main report regarding time allocated to these leadership roles.
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	N	See the Concerns section of main report.

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.	N	There was no evidence of a matrix which identified the competencies for each role in the core team and those competencies which had been completed.
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	However, play support was limited because there was no dedicated time for haemophilia patients.
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	N	However, this is in progress as reviewers heard that an ED practice educator had recently been appointed.

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	See Good Practice section of main report regarding diary management.
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	

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	
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	N	See the Concerns section of main report.

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	However, there was no guideline for extended half-life products.
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	N	There were some guidelines in place, but they were not comprehensive and were not all in line with UKHCDO guidance or available for medical use. The Immune Tolerance Therapy guideline was incorrect (though would not constitute a clinical risk).
HP-504	**Emergency Department Guidelines** Guidelines on management of patients with inherited and acquired bleeding disorders in the Emergency Department should be in use.	N	There was no ED guideline in place.

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	However, some required more detail.
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	Reviewers agreed with the Centre's self-assessment.
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	N	There was no evidence that the audits identified for this Quality Standard had been completed.
HP-706	**Research** The service should actively participate in research relating to the care of patients with bleeding disorders.	Y	

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.	N	An appropriate level of document control was not in place, with many documents and guidelines lacking details of authorship, approval date and / or intended review date.

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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	N	See General Comment section of main report.
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	See General Comment section of main report.
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)	N	See General Comment section of main report.
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	N	See General Comment section of main report.
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.	N	See General Comment section of main report.
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.	N	See General Comment section of main report.

Ref	Standard	Met?	Comments
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	See General Comment section of main report.

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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	N	See General Comment section of main report.
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.	N	See General Comment section of main report.

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