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

The Edinburgh Haemophilia and Thrombosis Comprehensive Care Centre

Visit Date: 22nd January 2019 Report Date: May 2019

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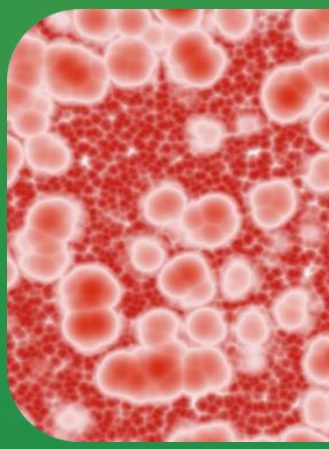

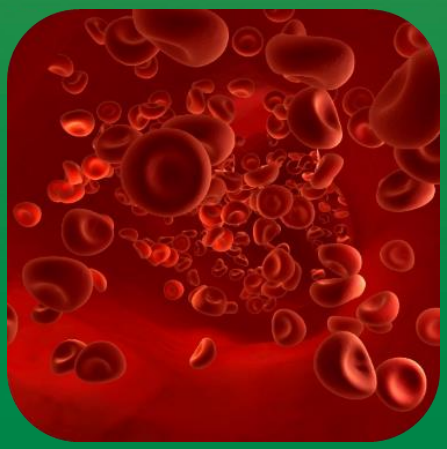

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INTRODUCTION

This report presents the findings of the peer review of services for people with Inherited and Acquired Haemophilia and other Bleeding Disorders at the Edinburgh Haemophilia and Thrombosis Comprehensive Care Centre on 22nd January 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.

Note: On this occasion the network and commissioning standards were not reviewed by the review team due to time constraints

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:

- Royal Infirmary of Edinburgh
- Royal Hospital for Sick Children
- NHS Lothian

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 Edinburgh Haemophilia and Thrombosis Comprehensive Care Centre for their work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks too to the patients and carers who took time to meet the review team.

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

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 EDINBURGH HAEMOPHILIA AND THROMBOSIS COMPREHENSIVE CARE CENTRE

The Edinburgh Haemophilia and Thrombosis Centre was the Comprehensive Care Centre for the East Coast and North of Scotland, with associated Haemophilia Centres in Aberdeen (Aberdeen Royal Infirmary), Dundee (Ninewells Hospital) and Inverness (Raigmore Hospital). The Centre provided support for adults and children with Inherited and Acquired Haemophilia and other Bleeding Disorders. The Centre was based in the Royal Infirmary of Edinburgh, where the adult Emergency Department (ED) was based. The Children's Emergency Department was located at the Royal Hospital for Sick Children at a city centre site, though a new hospital was due to open on the Royal Infirmary Site in late 2019.

The service provided care for a wide range of bleeding disorders and had close links with a number of specialties and healthcare professionals. The regional specialised coagulation laboratory was situated in the Royal Infirmary of Edinburgh and provided 24/7 access to specialist tests for both the adult and paediatric services but also other hospitals in the region. The Scottish Haemophilia Genetics Laboratory was also based at the Royal Infirmary, with whom the Centre had close links.

There were bi-monthly meetings between all Scottish Haemophilia Centres to facilitate clinical and managerial discussions, though there were good communication links at all other times. The data team in Edinburgh had oversight of the use of factor at the associated Haemophilia Centres.

In Scotland, funding for the Bleeding Disorder service was shared between the host health boards and the National Services Division (NSD).

Within the last 1-2 years there had been a large turnover of staff in the Edinburgh Centre, requiring the employment and education of new staff members.

The number of patients registered to the Centre at the time of the visit is set out in the Table below:

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	Severe - 43 Moderate - 8 Mild - 52	Severe – 42 (97%) Moderate – 7 (87%) Mild – 30 (60%)	Severe – 14 Moderate – 7 Mild – 8
	Children	Severe - 11 Moderate - 1 Mild - 9	Severe – 10 (90%) Moderate – 1 (100%) Mild –9 (90%)	Severe – 3 Moderate – 0 Mild – 0
Haemophilia B	Adults	Severe - 1 Moderate - 13 Mild - 12	Severe – 1 (100%) Moderate – 11 (84%) Mild – 3 (25%)	Severe – 2 Moderate – 4 Mild – 0
	Children	Severe - 1 Moderate - 0 Mild - 2	Severe – 1 (100%) Moderate – 0 (N/A) Mild – 2 (100%)	Severe – 0 Moderate – 0 Mild – 0
Von Willebrand	Adults	Adults - 150 Children - 23	Adults – 58 (38%) Children – 14 (60%)	Adults - 3 Children - 0
	Children			

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
Other	Adults	Adults – 384	Adults – 97 (25%)	Adults - 26
	Children	Children – 69	Children – 24 (34%)	Children - 1

Emergency Care

Patients had 24-hour access to advice from the adult and paediatric teams. During working hours adults could contact the Haemophilia Centre and be reviewed in the centre or in the Emergency Department if required. Children and their carers could contact the Haemophilia Centre or the Haematology Day Care Unit at the Royal Hospital for Sick Children. Children could also be reviewed in the Day Case Unit or the Emergency Department.

Depending on the clinical problem both adults and children could be admitted directly to the appropriate ward. For adults, haematology had admitting rights to ward 206 (renal ward) where a number of nursing staff were trained in administering factor replacement therapy. Children could be admitted directly to the Haematology ward (ward 2).

Out of hours, after discussion with the on-call haematology Speciality Trainee (a doctor with at least four years post qualification training) or consultant, patients would attend the appropriate Emergency Department or ward 206 or ward 2 for review and/or treatment.

If an individual attended another hospital or Emergency Department there was a haematology Speciality Trainee (ST) and consultant on-call to assist with advice or transfer.

Ward Care

Adults – were admitted to the renal ward (ward 206) at the Royal Infirmary of Edinburgh. This was a 22-bed unit and the nursing staff had been trained by the Haemophilia nursing team regarding patient care and factor replacement therapy administration.

Paediatric patients with bleeding disorders requiring inpatient stay were predominantly admitted to ward 2 (11 beds) but could be seen on the other paediatric wards. Ward 2 nursing staff could administer factor replacement therapy and support this on other wards. Paediatric registrars were trained to administer factor replacement therapy.

Day Unit Care

For Adult patients, the haemophilia centre was open from 08.30 until 16.30, with 2 treatment rooms available for patient reviews (scheduled and unscheduled), education and for treatment assistance. There was access to the medical day case unit for platelet transfusions, iron infusions or rituximab infusions.

For Children, the paediatric day care was open 08:30 to 16:30 for acute attendance. All medical interventions could be performed here.

Outpatient Care

For adults, patients were reviewed within the Haemophilia centre in one of three consultation rooms, with clinics operating 5 days a week with medical staff including consultants, specialty doctors, or specialty trainees.

The paediatric haemophilia clinic was held on Fridays. New referrals were seen in general haematology clinic on Mondays.

COMMUNITY BASED CARE

At the time of the review there was no community-based care provided.

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REVIEW VISIT FINDINGS

Achievements

After a period of instability, with several senior staff retiring or leaving the service, a new enthusiastic and focussed leadership team was in place. They were hard-working and committed to moving the service forward. All members of the team reported that they were working together in a more integrated and co-operative manner. They felt more included and were supported to undertake training and development. Patients were warmly appreciative of the good care that they received. Reviewers noted that if the team were to be successful in achieving the operational improvements they had planned, that they would need greater support from clinical and non-clinical managers in the wider directorate and hospital. Once the team was more settled and the improvements identified had been achieved, the team intended to engage in research studies. All team members were keen to do this for the benefit of their patients.

A psychologist (0.8 Whole Time Equivalent), supported by a liaison psychiatrist, was in post; who additionally worked at the Glasgow Centre for one day each week. Patients reported that they helped them not only in managing their bleeding disorder, but with other challenges and difficulties too. They also undertook visits when necessary to the linked Centres at Dundee and Aberdeen.

The administrative and clerical and data management team were effective and were rising well to the challenges of managing the additional responsibilities that they had recently been given.

The laboratory team were managing to deliver a clinically responsive 24/7 service to meet the needs of patients, despite recent staffing shortages they continued to attend national meetings and keep up to date with any new or changing investigations.

The Centre was in a self-contained area of the Out-Patient Department and the environment was welcoming with plentiful clinical and office space.

Good Practice

1. Senior and trainee medical staff had remote access to Trakcare®[1] through which they could access patients' clinic letters, details of concentrates used etc, when on call from home.
2. A printed clinical audit proforma accompanied each patient to their clinic appointment; this was returned to the Administrative & Clerical team and they submitted data centrally to inform regular assessments of the Centre's key performance indicators.
3. The use of Haemtrack [2] was rigorously encouraged.
4. All patients who were receiving Emicizumab[3] were listed in the laboratory, so that appropriate investigations were undertaken on their samples.

[1] **Trakcare** ® – an electronic medical record system for sharing patient records across different healthcare settings.

[2] **Haemtrack** - Haemtrack is a secure recording system developed 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.

[3] **Emicizumab–** is a monoclonal antibody used for the treatment of Haemophilia A complicated by inhibitors.

5. Materials used to guide emergency care of paediatric patients were comprehensive, including practical guidance as to how to make up concentrates, and the management of children with bleeding disorders was regularly included in the Emergency Department team's induction.
6. Children could be seen at weekends in the Day Care area at the Royal Hospital for Sick Children.
7. Dental and orthodontic services for children were readily available on the Hospital for Sick Children site.
8. Monthly transition clinics were held jointly by the adult and paediatric service lead consultants, and it was noted that the process of transition would be further improved once the paediatric service was re-located to the new premises on the Royal Infirmary of Edinburgh site.
9. At the linked Centre in Dundee, patients could access the ward directly for acute bleeds or trauma, bypassing the Emergency Department.
10. There was an active patient support group in Tayside, supported by the lead consultant from the Dundee Centre.

Immediate Risk [4]

At the time of the review, the review team heard that children were treated at the adult haemophilia centre at the Edinburgh Royal Infirmary. Children were treated by adult trained nurses who did not have any paediatric resuscitation and life support training and a paediatric doctor (who did have Advanced Paediatric Life Support training) was not always present at the time. In addition, although there was a paediatric team on site together with a paediatric cardiac arrest team who managed any emergencies at the neonatal unit, there was no agreed protocol in place for haemophilia centre staff to access the paediatric cardiac arrest team or for them to know who they should call in an emergency.

Reviewers observed that a child could need resuscitation while in the Centre, and that a member of staff with appropriate competences to lead the resuscitation would not always be immediately available on the team. As there was no clear guidance in place as to how the paediatric resuscitation team should be called in such an emergency there was therefore a risk that starting appropriate resuscitation efforts could be delayed.

Serious Concerns

1. **Physiotherapy.**
    a. Reviewers were very concerned that there was no dedicated physiotherapy member of the adult or paediatric team. Reviewers were told that this was due to a lack of funding, not an inability to recruit. One named physiotherapist tried to see patients who presented with acute joint bleeds but

[4] **Centre response to Immediate Risk** – The Centre confirmed that following discussion with the Royal Infirmary of Edinburgh Resuscitation Officer, confirmation was received that there was already a procedure in place for paediatric resuscitation in the Haemophilia Centre and throughout the hospital. In the event of such an emergency, an arrest call is made to switchboard providing details including the location of the patient and that a child / paediatric patient is involved. At this point the neonatal resuscitation team is informed in addition to a senior anaesthetist. These individuals are all trained in advanced paediatric life support and will attend. In order to ensure that all members of the Haemophilia Centre are aware of this protocol a poster has been created and placed beside the resuscitation trolley in the Haemophilia Centre. Paediatric resuscitation equipment has always been available on the resuscitation trolley in the Haemophilia Centre, together with visible paediatric life support algorithms. On further discussion with the resuscitation officer it was also confirmed that the nursing staff in the Centre undergo regular resuscitation training with an additional element on basic paediatric life support included. This had not been previously been separately noted on their certificates but will be in the future.

WMQRS Response – We consider that the actions to address this issue have been noted and we consider the risk will be mitigated once all the actions have been implemented.

could not always do so and there was no cover for periods when she was away. There were no systematic joint health assessments. This led to poor management of joint health.

b. A file containing some guidelines seen by the review team held in the general Musculoskeletal physiotherapy area gave incorrect advice to treat all patients – except those with severe haemophilia – as normal. No specific guidance was noted for other groups such as those with inhibitors, acquired haemophilia or severe von Willebrand's disease. This file was also out of date.

Concerns

1. **Management of acute presentations in adult patients.**

   There were no Emergency Department (ED) guidelines in place for adult patients presenting with acute bleeds or trauma, and although ED staff were meant to inform the specialist team whenever a patient presented, in practice this did not always happen. A clear guideline and communication of this between the ED team and the haemophilia centre would ensure that ED colleagues were aware of their responsibilities regarding treatment of patients with bleeding disorders.

2. **Paediatric nursing, and service provision on the Royal Infirmary site.**

   a. There was no paediatric lead nurse in post.

   b. Although children were seen in the adult Centre for clinic appointments, there were no paediatric nurses on site, and no play support for interventions although venepunctures were undertaken there.

   c. Children were seen in clinics when adult patients were also attending.

3. **Clinical guidelines**

   Clinical guidelines were incomplete and out of date, some significantly [for example dated 2013] and required revision.

4. **Patient feedback**

   Although it was understood that some patient surveys had taken place no results were made available to the visiting team, and it was not clear whether the feedback had been analysed and appropriate actions taken.

5. **Fridge temperature control failure**

   Two fridges containing concentrates had recently erred outside the required temperature limits, no alarm was raised, and concentrates had been wasted. Once a new fridge is installed it will be imperative to be sure that controls and alarm systems are robust. Also, a fridge for concentrate storage on the in-patient ward was out of service at the time of the visit and required replacement. In the meantime factor was stored in the Blood Bank.

6. **Appropriate management support**

   Support for the Centre team from the wider organisation was not apparent. No clinical or non-clinical managers met the review team during the visit. They were based on another hospital site and were reported rarely to visit or engage with the team. Reviewers observed that if the Centre team were to achieve the operational improvements they planned to, they would need more active input and engagement from the hospital management teams.

Further Consideration

1. At the time of the visit, the nursing team did not access Haemtrack. The data management team did, on most days, but this was not a formalised daily task. Pending additional access by clinical staff, which

would be useful, the data team should ensure that daily checks are completed. Some patients reported that they found using Haemtrack difficult, and some 'coaching' in its use by Centre staff would be useful.

2. At the time of the visit, there was no community nursing activity by either team. This had previously been possible, by the adult team. Once the new team settle into all their duties, and once a paediatric nurse team is established, it should be possible to set up home and school visits.
3. There was a helpful 'yellow triangle' alert on Trakcare if an adult patient had visited the Emergency Department. However, especially as there was some uncertainty that the Centre team was informed every time a patient visited. It may be useful to explore if an automatic message or alert could be communicated to the centre team.
4. Children past their 16th birthday could continue to be seen in the Paediatric Clinic and Day Care area, but not be treated in the Hospital for Sick Children ED. Although it was noted that when paediatric services transfer to the Royal Infirmary site this would no longer be an issue (as the new paediatric ED will see young people up to the age of 18). It would be helpful, in the meantime, to clarify that the point of transition from paediatric to adult services, for any given patient, is the same for all elements of the service.
5. Paediatric diagnostic and clinical guidelines mostly referenced the national UKHCDO guidance, accessed via the internet, without any additional guidance as to how these should be implemented locally.
6. The social work office was located adjacent to the Adult Centre and it would therefore be beneficial to identify and develop a named social worker with an interest in the Inherited and Acquired Bleeding Disorders to provide a single point of contact and support for patients.
7. In order to meet the expectation that all patients with severe Inherited and Acquired Bleeding Disorders should be seen at least annually by members of a specialist team, an annual or twice-yearly outreach clinic by Edinburgh Centre staff to Inverness might be considered, as the haematology team at this site had less experience in managing the condition than at the Aberdeen and Dundee centres. This could additionally serve as a useful teaching opportunity for the local general haematology team.
8. Systematic recording of authorship, dates of development, and review dates was lacking for many documents. As they are revised and re-issued, further attention should be given to these aspects of document control.

NETWORK

The review team did not have the opportunity at the time of the visit to review compliance with the Network standards.

COMMISSIONING

The review team did not have the opportunity at the time of the visit to review compliance with the Network standards.

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APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Visiting Team		
Caroline Clegg	Acting clinical lead rheumatology / haematology therapy team	Manchester University NHS Foundation Trust
John Dearden	Patient Representative	
Anna Farrell	Paediatric Clinical Nurse Specialist	University Hospitals Bristol NHS Foundation Trust
David Hopper	Clinical Specialist Physiotherapist Haemophilia	The Newcastle upon Tyne Hospitals NHS Foundation Trust
Dr Rhona Maclean	Consultant Haematologist	Sheffield Teaching Hospitals NHS Foundation Trust
Dr Mary Mathias	Consultant Paediatric Haematologist	Great Ormond Street Hospital for Children NHS Trust
Pamela Wick	Sister	Glasgow Royal Infirmary

Observer

Dan Farthing-Sykes	Chief Executive Officer	Haemophilia Scotland

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	18	49
Network	8	4	50
Commissioning	3	3	100
Total	48	25	52

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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)	N	Reviewers did see some patient information but not for all the items in this standard. In addition, some information was out of date.

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.	N	Some elements were covered in clinical letters but not all. There was no plan in a single document. Information was included in different places - e.g. GP letters
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.	N	Although there was evidence that patients were being reviewed appropriately, this standard cannot be compliant due to a lack of a single plan of care - See HP103
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	
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	N	Although they were made aware of a joint transition clinic held monthly between the adult and paediatric lead haematologists, reviewers did not see any documentary evidence regarding the transition process.
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	N	Reviewers did not see any written evidence provided to carers. However, patients fed back that the psychologist did provide support to the wider family and carers which was appreciated by patients
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	N	Reviewers did not see any evidence of patient feedback results.

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, there was no paediatric trained nurse in place as a core member of the team
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	Arrangements for consultant cover out of hours, if neither of the two specialists were on call, were described but should be documented. This should include the process of how to contact the consultants at other sites in the network if needed, for clarity. There was no dedicated physiotherapy service There was limited social worker input There were no paediatric trained nurse specialists

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	Reviewers agreed with the Centres own self assessment. There was no evidence provided that competences were identified and recorded
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	N	Reviewers did not see any evidence of compliance with statutory and mandatory training
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	N	Reviewers did see guidelines for Paediatrics however there was no evidence for Adults. In addition, patients fed back regarding their particularly poor experiences of ED colleagues lack of knowledge relating to haemophilia (this included paediatrics)

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	Reviewers saw that this was a responsive service despite the high turnover of staff
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	However reviewers noted that although there was a system which flagged that patients had haemophilia or other bleeding disorders, it did not proactively alert the haemophilia team that a patient had been seen in ED
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 concerns section in main report. Reviewers noted that the guidelines were out of date, were not comprehensive and had not been revised to incorporate more recent developments in patient care. Paediatrics used national guidance but it was not localised

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	Network guidance was being used. However, it was out of date.
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	Dental guidance for paediatrics was in place. All other guidelines were national UKHCDO only and they had not been adapted for local use. Guidelines were not easily accessible on the Intranet All require revision and updating.
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	See also HP 302

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	There were no surgical guidelines for adults though there were guidelines in place for paediatric patients requiring the insertion of portacaths
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	N	See also HP 195. Reviewers did not see any guidelines relating to transition arrangements
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	N	There was no overarching operational policy or procedure in place which covered the relevant aspects of this standard
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	However, see comments in main report regarding the lack of dedicated physiotherapy service

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	However, see comments in main report regarding the lack of dedicated physiotherapy service
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 Centres own 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	Reviewers agreed with the Centres own self assessment
HP-706	**Research** The service should actively participate in research relating to the care of patients with bleeding disorders.	N	Reviewers agreed with the Centres own self assessment

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	Reviewers heard from staff that this was in place and that they were invited to attend. However, no documentary evidence - e.g. agendas and minutes were provided.
HP-799	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	Reviewers saw many documents which were out of 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	
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.	Y	
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	
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	

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.	N	
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	Y	

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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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